The aim of this study was to describe adult-child and spousal caregivers’ experiences of providing care for older family members with a tracheostomy during hospitalization. The findings indicated how adult-child and spousal caregivers coped, and how they needed to be supported during the care for older family members as they were hospitalized. Although providing care for older family members could be difficult, they were willing to participate in taking care of their loved ones. In other words, family participation in assisting older family members during hospitalization is a significant partnership between the health care team and family to enhance the quality of caregiving for older people.
FAMILY CAREGIVERS’ EXPERIENCES OF PROVIDING CARE FOR OLDER FAMILY MEMBERS WITH A TRACHEOSTOMY DURING HOSPITALIZATION: A PHENOMENOLOGICAL STUDY IN THAILAND
Watchara Tabootwong

FAMILY CAREGIVERS’ EXPERIENCES OF PROVIDING CARE FOR OLDER FAMILY MEMBERS WITH A TRACHEOSTOMY DURING HOSPITALIZATION: A PHENOMENOLOGICAL STUDY IN THAILAND

To be presented by permission of the Faculty of Health Sciences, University of Eastern Finland for public examination in MS 302 Auditorium, Kuopio on Friday, May 15th, 2020, at 12 o’clock noon

Publications of the University of Eastern Finland
Dissertations in Health Sciences
No 560

University of Eastern Finland
Kuopio
2020
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ABSTRACT

This descriptive phenomenological research was conducted to describe family caregivers’ experiences of providing care for older family members with a tracheostomy during hospitalization in Thailand. Data were collected in medical-surgical wards between January and June 2017. A purposive sample was used to recruit participants who were primary family caregivers, including adult children (n = 20) and spouses (n = 20). Data collection was conducted through face to face semi-structured interviews together with audio-recording at hospital. The descriptive phenomenological analysis method developed by Giorgi was used as a guideline for data analysis.

The findings revealed that adult-child caregivers described experiences of providing care for older parents with a tracheostomy that consisted of the meanings of providing care, ways to learn in providing care, caring activities, impacts of caregiving, and support needs. The meanings of providing care were described as filial responsibility, learning new things, and the end of life care for older parents with a tracheostomy. They learned to provide care for older parents by asking and observing about tracheostomy care from doctors and nurses together with sharing experiences with caregivers of other patients. Additionally, they performed various caring activities for older parents with a tracheostomy, including basic care, suction, massage and physical therapy, calling the nurse to ask for help, and encouragement. Regarding the impacts of caregiving, they felt tired, confused, and dizzy due to insufficient sleep, stress and worry about older parents’ symptoms, reduction in social interaction, and insufficient income due to the financial requirements of providing care for their loved ones. They also needed to be supported by meeting physicians frequently to update information about their older parent’s illness and any options for treatment in the future. Additionally, they needed assistance from their relatives when they felt tired from taking care of their older parents.
Spouses’ experiences of providing care for older partners with a tracheostomy during hospitalization included meanings of providing care, feelings of caregivers’ presence, caring activities, impacts of caregiving, support needs, and qualities of being a caregiver. Meanings of providing care were also described as spousal attachment, learning new things, and the end of life care for older partners with a tracheostomy. Meanwhile, they described their feelings in the role of caregivers, including pride, harder care, and being afraid. They performed various caring activities (e.g., daily routine care, calling the nurse to ask for help, decision making, and encouragement) for older partners with a tracheostomy. During the care for older partners, spousal caregivers experienced the impacts of caregiving, such as insufficient sleep, stress, worry, discouragement, reduction of a social friend group, and insufficient income. In addition, they also needed to be supported by their children with respect to financial support and by doctors and nurses involving knowledge that was fundamental for taking care of older partners. Although providing care for older partners was difficult, they were still proud of being a caregiver. Love, sincerity, and confidence were the qualities of being a caregiver.

In conclusion, either adult children or spouses were responsible for providing care to older family members with a tracheostomy during hospitalization. They learned to do procedures regarding tracheostomy care and how to take care of their older family members with a tracheostomy during hospitalization. In the act of providing care, they needed to be supported by relatives and healthcare professionals. The perspectives of adult children and spouses about providing care for elderly patients with a tracheostomy differed depending on the prior family relationship with older family members. Consequently, healthcare professionals should realize family relationships and family caregivers’ concerns when supporting them. Furthermore, healthcare professionals may negotiate for mutual understanding regarding tracheostomy care and promote family caregivers to maintain an older person’s health.

Keywords: aged; adult children; caregivers; family; hospitalization; parents; spouses; tracheostomy; Thailand
Tabootwong, Watchara
Omaishoitajien kokemuksia trakeostomian kanssa sairaalahoidossa olevien seniori-ikäisten perheenjäsentensä hoidosta: fenomenologinen tutkimus Thaimaassa
Kuopio: Itä-Suomen yliopisto
Publications of the University of Eastern Finland
Dissertations in Health Sciences 560. 2020, 121 s.
ISBN: 978-952-61-3356-0 (nid.)
ISSN: 1798-5706
ISSN: 1798-5706
ISBN: 978-952-61-3357-7 (PDF)
ISSN: 1798-5714 (PDF)

TIIVISTELMÄ


Puolisoiden kokemukset trakeostomoitujen sairaalahoidossa olevien seniori-ikäisten partnereidensa omaishoitamisesta käsittävät omaishoitamisen merkityksen, tunteutukset omaishoitajan länänäolosta, hoitavan toiminnan, omaishoitamisen vaikutukset, tuen tarpeen sekä omaishoitajana olemisen laadun. Omaishoitamisen


Avainsanat: ikääntyneet; aikuiset lapsi; omaishoitajat; perhe; sairaalahoito; vanhemmat; puolisot; trakeostomia; Thaimaa
ACKNOWLEDGMENTS

Doing a Ph.D. (Nursing Science) was a lesson of my life that it has to go through high and low situations that like happiness, stress, and obstacle while conducting research. I would like to sincerely acknowledge everyone who has assisted me throughout the conducting of this dissertation.

I would like to acknowledge my greatest gratitude to my first adviser, Professor Hannele Turunen, Ph.D., Department of Nursing, University of Eastern Finland, for her excellent guidance, kindness, and favor while conducting research. I am very appreciative to my second adviser, Professor Katri Vehviläinen-Julkunen, Ph.D., Department of Nursing, University of Eastern Finland, for her help, expertise, and kindness during the process of the study as well. They are my professors, colleagues, research team, and be the person who should respect and appreciate. Without their support, this study could not have been possible.

I warmly wish to manifest my thankfulness to Assistant Professor Pornchai Jullamate, Ph.D., who is my colleague at the Department of Gerontological Nursing, Burapha University, Thailand and he is a cooperator in this study. He has encouraged and helped me involving education and research. Second cooperator, Professor Edwin Rosenberg, Ph.D., who is my international amity at Appalachian State University, North Carolina, USA. He gave me the comments to improve the study.

I would like to manifest my appreciation to Elina Turunen, MNSc, RN, Ph.D., Department of Nursing Science, the University of Eastern Finland who helped with the evaluation quality of studies selected for literature review.

I wish to thank Maarit Putous, Information Specialist at the university library, the University of Eastern Finland who helped with the literature search. I also own my thanks to Usko Veikko Katto for his assistance in writing abstract in the Finnish.

I would like to thank Contact Nurses in medical and surgical wards, Thailand, who helped me to ask family caregivers for participation in this study. Meanwhile, I also appreciate the director of Buddhasothorn hospital who permitted me to get there for collecting the data.

I wish to thank my mother Phut Tabootwong, my sister Kulnipa Tabootwong, my cousin Pitthaya Joomprom and Kannika Muangmer, and my relatives who have always been encouraging and supporting everything to my education. I owe gratitude to my father Jinda Tabootwong, who provided my vitality and he passed away after I completed my master degree 7 years ago. From him, I got intention and tolerance to make my dreams as doctor’s degree come true.

I would like to thank participants, who consented to cooperate in this study. They devoted time to narrate his/her experiences in providing care for older family members with a tracheostomy. Without their narrative, this study could not have been possible.
I appreciate and respect them as my supporters. My special thanks go to my Thai and Finnish friends in Kuopio, Finland. Yupapron Nanthajak and her husband Markus Raatikainen as well as Wannisa Korhonen and her husband Ari Korhonen, I thank you for helping and sharing everyday life’s joys. Maratri Prichamrat, Panpen Sirapan, Dalika Buraphachon, and Juthathip Somboonnavakit thanks for your friendship and assistance. Everyone is supporters during my doctoral study programme at the University of Eastern Finland.

This study was funded by the Faculty of Nursing, Burapha University, Thailand and supported by the Department of Nursing Science, University of Eastern Finland, Finland. I want to acknowledge them for their support.

Kuopio, May, 2020

Watchara Tohootrong
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<th>Description</th>
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<tbody>
<tr>
<td>CCU</td>
<td>Cardiac Care Unit</td>
</tr>
<tr>
<td>CAMBS</td>
<td>Civil Servants Medical Benefits Scheme</td>
</tr>
<tr>
<td>COREQ</td>
<td>Consolidated Criteria for Reporting Qualitative Research</td>
</tr>
<tr>
<td>DOP</td>
<td>Department of Older Persons</td>
</tr>
<tr>
<td>DRG</td>
<td>Diagnosis-Related Group</td>
</tr>
<tr>
<td>ECTS</td>
<td>European Credit Transfer System</td>
</tr>
<tr>
<td>EU</td>
<td>European Union</td>
</tr>
<tr>
<td>FFC</td>
<td>Family-Centered Care</td>
</tr>
<tr>
<td>GDPR</td>
<td>General Data Protection Regulation</td>
</tr>
<tr>
<td>HHC</td>
<td>Home Health Care</td>
</tr>
<tr>
<td>HRQoL</td>
<td>Health-Related Quality of Life</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive Care Unit</td>
</tr>
<tr>
<td>IPFCC</td>
<td>Institute for Patient- and Family-Centered Care</td>
</tr>
<tr>
<td>LTC</td>
<td>Long-Term Care</td>
</tr>
<tr>
<td>MOPH</td>
<td>Ministry of Public Health</td>
</tr>
<tr>
<td>MSDHS</td>
<td>Ministry of Social Development and Human Security</td>
</tr>
<tr>
<td>NHSO</td>
<td>National Health Security Office</td>
</tr>
<tr>
<td>PHC</td>
<td>Primary Health Care</td>
</tr>
<tr>
<td>RCU</td>
<td>Respiratory Care Unit</td>
</tr>
<tr>
<td>SSS</td>
<td>Social Security Scheme</td>
</tr>
<tr>
<td>THPH</td>
<td>Tambon Health Promotion Hospital</td>
</tr>
<tr>
<td>TT</td>
<td>Tracheostomy Tube</td>
</tr>
<tr>
<td>UCS</td>
<td>Universal Coverage Scheme</td>
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1 INTRODUCTION

Tracheostomy involves making an incision in the windpipe in order to insert a tube and connect to mechanical ventilation in critically ill patients (Mehta & Mehta 2017). Critically ill patients usually require a tracheostomy due to prolonged endotracheal intubation (Voisin & Nseir 2017, Pelosi et al. 2018). Chronic illness and age-related changes in the respiratory system may cause respiratory failure, and thus, elderly patients need to be intubated for a long time (Woodrow 2012). Bergeron & Audet (2016) found that 112 elderly patients (average age: 79.3) required the insertion of a tracheostomy tube (TT) because of prolonged endotracheal intubation and respiratory distress. In Thailand, 53.39 % of prolonged weaning from mechanical ventilation is the most ordinary indication for tracheostomy (Saiphoklang & Auttajaroop 2018); 57.1% of performing tracheostomy for elderly patients are done at intensive care unit and 42.9 % are done at general ward (Disayabutr et al. 2013). Patients who received mechanical ventilation and underwent tracheotomy were in the oldest patient group (48.9 %), namely 75 or older, while 22.5 % of the patients were aged 65–74 (Chung et al. 2013). Therefore, the number of tracheostomies has been increasing in the elderly patient group (Schneider et al. 2009, Ehlenbach 2014).

The elderly patient is directed to undergo tracheotomy when they are diagnosed with other diseases. However, having a tracheostomy affects elderly patients’ wellbeing and body image. They are frustrated with their inability to effectively communicate and feelings of helplessness (Sherlock et al. 2009, Freeman-Sanderson et al. 2018). Additionally, elderly patients need care during their use of the tracheostomy, assistance in daily activities, and observing symptoms caused by the tracheostomy. Therefore, it is imperative that elderly patients with a tracheostomy are supervised by a doctor or a nurse. Moreover, they also need family caregivers such as spouses and children, who play an essential role because physical care and comfort are among the essential needs of such patients. Bathing, oral care, relief from pain, and even an encouraging touch are part of such physical care (Cypress 2011).

In Thai society, children are instructed to respect older people. Older people are recognized and valued (Choowattanapakorn et al. 2004). It is thus not surprising that over 60 % of children are the primary family caregiver for an older person; another 30 % of primary caregivers are spouses (Knodel & Teerawichitchainan 2017). Family caregivers at the hospital bedside are willing to provide caring activities for hospitalized older family members because of the family relationship (Happ et al. 2015). Family caregivers can provide an emotionally stabilizing influence on the hospitalized older family members by creating a sense of security, namely emotional support and ongoing decision making (Boltz 2012).

All caregiver groups who inhabit this role, sometimes quit other work when taking care of the older person and usually they do not have experiences and knowledge in caring for the older person with a tracheostomy (Im et al. 2004, Karaca et al. 2019). Furthermore, family caregivers report lifestyle change, poor physical and
psychological health, as well as insufficient income related to family participation in caring for elderly patients (Van Beusekom et al. 2016). Family caregivers who are responsible for caregiving to older family members for a long time find it affects their physical health; for instance, they might feel fatigued (Choi et al. 2014). Family caregivers perform a role in promoting well-being among older people with a tracheostomy. They need accurate information on issues concerning the patient’s conditions and any options of treatment (Boltz 2012).

Al-Mutair et al. (2014) described the experiences of family members in caring for critically ill patients. The findings demonstrated that family caregivers need assurance, proximity, information support, and participation in providing care. However, when family caregivers look after a seriously ill person with a tracheostomy, it may lead to family stress. Family caregivers have to adapt and cope with the situation in the hospital (Lin et al. 2016). These findings are consistent with those of Koukouli et al. (2018), who described family adaptation during critical care unit hospitalization. Their results showed that the family caregivers’ life was changing, and they had to seek strategies to cope with changes (Koukouli et al. 2018). To sum up, 41% of elderly patients with prolonged mechanical ventilation need to be treated and require a tracheostomy to assist them with breathing (Ehlenbach 2014). At the same time, family caregivers of prolonged mechanical ventilation patients are suffering from the heavy burdens of caregiving (Liu et al. 2017). Many previous studies aimed to investigate family caregivers of patients with Alzheimer’s disease (Cachioni et al. 2011, Valimaki et al. 2012, Pessotti et al. 2018), family caregivers of stroke patients (Caro et al. 2018, Lehto et al. 2019), family caregivers of emergent patients in the emergency department (Sak-Dankosky et al. 2015, Palonen et al. 2016, Leikkola et al. 2018), and family caregivers of critically ill patients (Choi et al. 2011, Jacob et al. 2016). Additionally, previous studies were conducted to find out the family functionality and social support for family members (Hautsalo et al. 2013, Cavonius-Rintahaka et al. 2019) as well as family participation in caring for hospitalized elderly patients (Khosravan et al. 2014, Nayeri et al. 2015, Palonen et al. 2016), but it is not focused on family caregivers of older people with a tracheostomy in general wards.

Previous studies about family caregivers who provide care for older people with a tracheostomy in general wards are few, and knowledge is insufficient. The researcher was interested in studying family caregivers’ experiences of providing care for older family members with a tracheostomy in the Thai context. Therefore, the phenomenological method was conducted to describe the experiences of providing care among adult children and spouses of older family members with a tracheostomy in medical-surgical wards in Thailand. Findings may be useful to improve the quality of care for older people and family caregivers by healthcare professionals. Meanwhile, qualitative data may be used for developing and testing the concept or theory related to this topic (Elo et al. 2013).
2 HEALTH CARE AND HEALTH CARE EDUCATION SYSTEMS IN THAILAND

2.1 LOCATION, LANGUAGE, RELIGION, AND POPULATION OF THAILAND

Thailand is located in South-East Asia. The capital city of Thailand is Bangkok. Thailand is divided into the northern, central, southern, and northeastern regions. These regions are divided into all 77 provinces. The map of Thailand is displayed in Figure 1.

Figure 1: The map of Thailand
Thailand’s native language is Thai. The major religion for the Thai people is Buddhism (Tangcharoensathien 2015). The population of Thailand increased from 62 million in 2000 to 66 million in 2019. Midyear 2019, the total population is 66,374,000, including male = 32,074,000 and female = 34,300,000. Population in the central, northeastern, northern, and southern regions is approximately 19, 18, 11, and 9 million respectively. Population by age group is the following: youth (under 15 years) and adult age (15–59 years) is 11,358,000 and 43,429,000, respectively. Meanwhile, the older population (60 years and over) is 11,587,000. (Institute for Population and Social Research 2019.) In 2019, the life expectancy of Thailand’s population is 75.9 years. The life expectancy of males and females is 73.0 and 80.1 years, respectively. (Institute for Population and Social Research 2019.) Additionally, the population of Thailand is estimated at 70 million in 2025 (World Population Statistic 2019). Between 2019 and 2030, the proportion of Thais of child and adult age will decrease, while the percent of the older population in 2019 was 12.4, and will extend to 19.6 in 2030 (United Nations 2019).

2.2 THAILAND’S HEALTH CARE SYSTEM

Thailand has the Ministry of Public Health (MOPH) as the national health authority. MOPH is responsible for formulating, implementing, and monitoring health policy (Tejativaddhana et al. 2018). National Health Security Office (NHSO) also operates with MOPH in order to organize health security. The administrative structure of the health system in Thailand is divided into central and provincial levels. At the central administration, there are three clusters of technical departments (e.g., Cluster of Medical Services Development, Cluster of Public Health Development, and Cluster of Public Health Service Support) and the Office of the Permanent Secretary. The regional health offices are committed functions from the Office of the Permanent Secretary. At the same time, provincial health offices will be assisted and supported by regional technical centers. Provincial public health offices are centers to support and monitor the work of general hospitals and district hospitals. (Tangcharoensathien 2015.) The administrative structure of the health system in Thailand is shown in Figure 2.
Regarding Thai health insurance, health insurance programs in Thailand consist of the Civil Servants Medical Benefits Scheme (CSMBS), the Social Security Scheme (SSS), and the Universal Coverage Scheme (UCS) (Paek et al. 2016). Characteristics of health insurance programs in Thailand are presented in Table 1.
Table 1. Characteristics of health insurance programs in Thailand
Source: Paek et al. (2016, p. 3)

<table>
<thead>
<tr>
<th>Health insurance programs</th>
<th>Target population</th>
<th>Financing source</th>
<th>Payment method</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSMBS</td>
<td>Government officers in the government sector, dependants as government officer’s parents, spouse and two children (age &lt; 20)</td>
<td>A general tax, the noncontributory scheme</td>
<td>Outpatient services and diagnosis-related group (DRG) for inpatient services is free.</td>
</tr>
<tr>
<td>SSS</td>
<td>Employees in the private sector, excluding dependants</td>
<td>Payroll tax-financed, tri-partite contribution 1.5% of salary, equally by the employer, employee and government</td>
<td>Employees can obtain capitation for outpatient and inpatient services.</td>
</tr>
<tr>
<td>UCS</td>
<td>All people can receive this health service without SSS and CSMBS</td>
<td>General tax</td>
<td>People can obtain capitation for outpatient services and global budget plus DRG for inpatient services.</td>
</tr>
</tbody>
</table>

Accessing health care services for Thai people, at the primary health care level, Tambon Health Promotion Hospital (THPH) is a health center service located in each sub-district, which is designed for primary health care (PHC) covering a population of about 5,000. At the secondary health care level, the district level, community hospitals play a role in detecting, preventing, and treating diseases and injuries. Community hospitals (30–120 beds) are designed to be the first referral centers covering a population of around 50,000. At the tertiary health care level, every province has either a general hospital or a regional hospital or both. General hospitals are designed to be the second referral centers covering a population of approximately 600,000. Therefore, provincial hospitals are also designed to be the third referral centers. (Tangcharoensathien 2015.) Additionally, the university and specialty hospitals provide specialized medical services, and they are the third referral centers as well. For the private hospital, there is no formal referral system within the sector, but patients from private hospitals may be referred to the general or regional hospital of the public sector (Tangcharoensathien 2015, World Health Organization 2017). In the whole country, there are healthcare professionals as doctors (35,388), registered nurses (160,932), dentists (9,760), and pharmacists (13,728) work for both government and private sectors (Strategy and Planning Division 2019). Healthcare professional density is greater at provincial and regional hospitals than at district hospitals (Witthayapipopsakul et al. 2019.)
2.3 HEALTH CARE SERVICES AND SOCIAL WELFARE FOR OLDER POPULATION

In Thailand, the Department of Older Persons (DOP) is the government sector that belongs to the Ministry of Social Development and Human Security (MSDHS). This department is responsible for supporting, developing, and protecting the rights of older people. Older people have been authorized to have access to free government medical services. If older people’s children or spouses work in the government sector as government employees, older people are authorized to somewhat superior advantages compared to older people who use the universal health coverage plan. (Knodel et al. 2015.) Furthermore, there are three types of the social welfare system in Thailand, consisting of:

1) the social insurance, which is the community savings fund for older persons.
2) the public assistance, which refers to a monthly allowance provided by the government. Older people have the right to receive a monthly allowance, which is allocated by age. Older people who are aged 60–69, 70–79, 80–89, and 90 or older are entitled to 600 Bath (~16.67 €), 700 Bath (~19.44 €), 800 Bath (~22.22 €), and 1,000 Bath (~27.78 €) per month respectively (Knodel et al. 2015).
3) the social services for supporting the social activities and recreation including the health care services, the lifelong learning as education, the home for the aged, and the multi-purpose center for older people (Jitramontree & Thayansin 2013).

Additionally, there are many forms of elderly care in Thailand. Informal care includes home health care for older people with disabilities, healthcare volunteers who, as members of elderly clubs, are trained to become healthcare volunteers and community-based integrated health care for older people. For formal care, family members may hire formal caregivers (e.g., registered nurses and practical nurses) when a family is unable to take care of the dependent older people, in particular, for family members who work primarily outside the home. Furthermore, home health care (HHC) is provided by healthcare professionals to assist older people. (Knodel et al. 2015.)

2.4 HEALTH CARE EDUCATION SYSTEMS IN THAILAND

The education system of Thailand is based on Western models; in particular, the U.S. system of education is modeled to perform in Thailand. Compulsory education in Thailand involve nine-years of education designed for students, comprising elementary school (Prathom 1–6 or grade 1–6) and lower secondary school (Mattayom 1–3 or grade 7–9). After that, students can consider studying at upper secondary education (Mattayom 4–6 or grade 10–12) in general academic or vocational schools. (Michael 2018.) In Thailand, students who graduate from high
school (grade 12) with major science-mathematics can apply to study the Bachelor of Nursing Science and Doctor of Medicine. There are two admission processes to recruit students for studying in universities, consisting of the direct university admission system and the Thai Central Admission System. (Michael 2018.)

Nursing education—the Bachelor of Nursing Science (Thai and English Programme)—requires four years of study. Nursing students are trained in public and private nursing institutions. The curriculum structure of the bachelor degree of nursing science program (120–150 credits) is comprised of general education courses (30 credits), nursing course (at least 84 credits), and elective courses (6 credits) (Liu et al. 2015). Generally, fifteen hours for theory is counted for one credit (~0.5 ECTS) and forty-five hours for training in the clinical setting are counted for one credit (~1.7 ECTS). Within the nursing course, at least forty-eight credits are required for studying about theories (e.g., basic human physiology for nursing, fundamental nursing, nursing theories, nursing administration, as well as nursing care for children, adults and elderly) and thirty-six credits are required for training in the clinical setting (Liu et al. 2015, Nursing Faculty of Burapha University 2019).

Graduate programs in nursing in Thailand—the master’s degree programs—require two years of study. A student who graduates from the Bachelor of Nursing Science at least one year can apply for studying. Meanwhile, he/ she has a nursing professional license. The student must pass the process of the graduate school selection process, including an interview and proof of English proficiency. (Nursing Faculty of Burapha University 2019.) Master’s degree programs are organized to include coursework (36 credits) and the master’s thesis (12 credits). The master’s program offers the opportunity for advanced study in specific fields of nursing science. (Liu et al. 2015.) For example, pediatric nursing, adult nursing, gerontological nursing, maternity nursing and midwifery, family nursing, and nursing administration.

Doctoral education in nursing has two types of doctoral curriculum: Type 1, which is dissertation only (48 credits), and conducted for students with a master’s degree; and Type 2, which is coursework (at least 12 credits) and a dissertation (36 credits), and conducted for students who graduate from a master’s degree or bachelor’s degree (Liu et al. 2015, Tilokskulchai & Srisuphan 2013). The selection process for studying includes an interview and proof of English proficiency. Applicants must submit a statement of professional goals, the reason for interest in the Doctor of Philosophy Program in Nursing Science, and a research proposal for consideration (Nursing Faculty of Burapha University 2019). The duration of the study must not be less than three years and not exceed six academic years. Doctoral students often conduct a research project which focuses on the management of chronic illness, health promotion, or health system (Tilokskulchai & Srisuphan 2013).

The demand for nurses in the hospital had increased since 2008 when the government implemented the Universal Health Coverage policy and with increasing of the older population (Resilient and Responsive Health Systems 2016). Many nurses also prefer to study in the program of nursing specialists such as nursing
management, cardiovascular nursing, nurses case management for chronic disease, gerontological nursing, oncology nursing, nurse practitioner (primary medical care), trauma nursing, nursing care of patients with infectious disease, and rehabilitation nursing. For example, the Faculty of Nursing, Burapha University is a center for nursing education with special courses (e.g., midwifery, newborn, renal replacement therapy, primary medical care, and rehabilitation practice workshop). Meanwhile, the Certificate Program for Practical Nurse is arranged for interested persons to work with the health care team in hospitals. This program has a minimum of 35 credits throughout one year of study (Nursing Faculty of Burapha University 2019).

The Doctor of Medicine six-year program (252 credits) is designed to teach medical students, including one year for general education and basic medical science in medical school, two years for pre-clinic, and three years for a clinic in affiliated hospitals that are the medical education centers (Faculty of Medicine Siriraj Hospital 2019). In the first year after graduation, they work in provincial hospitals under the supervision of senior doctors. For another two years, they work in either provincial or community hospitals. After that, they are free to continue their work in provincial or community hospitals, move to private hospitals, or apply for specialist training. (Yamwong 2006.)

Graduate medical education includes the Master of Science (36 credits) and Doctor of Philosophy degrees (48 credits) in various disciplines such as medical anatomy, medical physiology, medical microbiology, biochemistry, parasitology, pharmacology, immunology, and medical physic. Furthermore, the Medical Council of Thailand and the Royal Thai Colleges of Medical Specialties play a role in approving postgraduate residency/fellowship training programs. Higher Graduate Diploma Program in Clinical Sciences (at least 21 credits) is conducted by the Faculty of Medicine to teach physicians in various areas. (Faculty of Medicine Chiang Mai University 2019.)
3 FAMILY CAREGIVERS FOR OLDER PEOPLE WITH A TRACHEOSTOMY

3.1 THE OLDER PEOPLE WITH A TRACHEOSTOMY

Tracheostomy is a medical procedure to open into the windpipe to assist the patient with breathing as it is performed in patients requiring mechanical ventilation for a long time (Sherlock et al. 2009, Voisin & Nseir 2017). The purpose of inserting a tracheostomy tube is to prevent the obstruction of the upper respiratory tract, for patients who were using a ventilator for a long time, for tracheal suctioning to be better especially for patients who are unconscious, and for patients with an inability to cough and swallow (Russell 2005, Vargas et al. 2015). Additionally, they require ventilation by tracheostomy when weaning from mechanical ventilation (Baskin et al. 2004, Foster 2010). Benefits of tracheostomy are reducing laryngeal damage as well as enhancing comfort and daily self-care activities such as transferring, eating, and speech (Morris et al. 2013). At the same time, tracheostomy is performed for elderly patients with prolonged intubation of more than 7–15 days, and there may be serious complications with long-term laryngeal injury and stoma infection as well (Price 2004, Vargas et al. 2015). The placement of a tracheostomy tube is shown in Figure 3.

![Placement of a tracheostomy tube](Illustrated by Sirikan Tonthong, 2019)

Tracheostomy is a performed procedure for patients in ICU and other wards (Durbin 2010). Hospital discharge of elderly patients who undergo tracheostomy may be delayed as compared to younger patients (Bergeron & Audet 2016). Elderly patients may have a complication of tracheostomy, including hemorrhage, infection, tracheal stenosis, sore throat, and difficulties in speaking (Epstein 2005, Pelosi et al. 2018). Besides, the quality of life in elderly patients with a tracheostomy is often poor.
Therefore, healthcare professionals and family caregivers must observe the elderly’s symptoms to prevent the complication of tracheostomy. Elderly patients need to be supported and assisted by healthcare professionals and their families. However, family caregivers may experience the impacts of caregiving (Liu et al. 2017).

3.2 THE CARE OF OLDER PEOPLE WITH A TRACHEOSTOMY

Tracheostomy care is essential to prevent infection of the tracheostomy wound and respiratory tract (Bolsega & Sole 2018). The care of older people with a tracheostomy is not different from younger people. However, respiratory infection and airway obstruction may often occur in older people because of age-related physiological change, including decreased cough reflex, lung elasticity, mucociliary clearance, and immunity (Guidet et al. 2018, Esme et al. 2019). Tracheostomy care includes care of the tracheostomy wound, suctioning, changing inner cannular, and observing signs and symptoms of infection (Morris et al. 2013, Bolsega & Sole 2018). As part of the care of the tracheostomy wound, handwashing is important both before and after all procedures to prevent infection. The tracheostomy wound should be assessed and cleaned with 0.9% saline at least once in every 24 hours (St George’s Healthcare NHS Trust 2012, The Council of the Intensive Care Society 2018). Additionally, if a tube becomes soiled, it should be cleaned (St George’s Healthcare NHS Trust 2012). Suctioning is important in order to remove secretions from the tracheostomy tube and prevent the airway obstruction (The Council of the Intensive Care Society 2018). Tracheal suction should not be done as a routine procedure. The patient must be assessed for signs of sputum in the airways. If the patient can cough secretions independently into the top of the tracheostomy tube, secretions should be removed immediately (St George’s Healthcare NHS Trust 2012).

Changing the inner cannula is important. If a tracheostomy tube has an inner cannula, it should be removed and cleaned to prevent tube blockage with secretions. It should be done at least four hourly but this may be required more or less frequently depended on the quantity of secretions (St George’s Healthcare NHS Trust 2012). Tracheostomy tubes without an inner cannula should be changed approximately every 7–14 days (The Council of the Intensive Care Society 2018). At the same time, older people with a tracheostomy may experience a problem of swallowing food and liquid. Therefore, older people should be observed for aspiration (The Council of the Intensive Care Society 2018), whilst speech and language therapists may be involved in the assessment and management of older people with a tracheostomy who present with swallowing problem and communication difficulties (St George’s Healthcare NHS Trust 2012).
3.3 FAMILY CAREGIVERS AND THEORETICAL PERSPECTIVES

3.3.1 Definition of family caregivers

A family caregiver plays various responsibilities for assisting to his/ her family member during hospitalization and at home because of illness and dependency (Reinhard et al. 2008, EmblemHealth 2010). Family caregivers also provide care to family members who need to be assisted involving activities of daily living and how to care for a patient with mechanical ventilation (Reinhard et al. 2008). There are defining characteristics of informal and formal caregivers. The informal caregiver is a person who provides some unpaid care such as a family member, friend, and neighbor. They assist with activities of daily living to a person with illness or disability. (Roth et al. 2015.) Formal caregivers are responsible for assisting persons who have multiple diseases and complications, for instance, registered nurses and practical nurses (From et al. 2015). They are trained and paid for their professional services, but they may also be volunteers from a government (Roth et al. 2015).

When older people with prolonged mechanical ventilation or a tracheostomy are treated in hospitals, informal caregivers such as children or spouses always participate in caring for their older parents or partners during hospitalization (Maxwell et al. 2007, Van Pelt et al. 2007). In this study, a family caregiver is determined as an adult-child or spousal caregiver who participates in providing care for the hospitalized older family member (60 years and older) with a tracheostomy in Thailand.

3.3.2 Family-centered care

Many older people may live with multiple chronic illnesses or physical and psychological health problems (Boyd et al. 2014). Therefore, they delegate health care activities to healthcare professionals and family members as their family can decide health care for older people (Wolff & Boyd 2015). The family is an essential source of support for hospitalized older people for better recovery. Activities of the family caregivers to participate in assisting the hospitalized elderly patients include cleaning and rubbing the body dry, feeding the patient, repositioning the patient, massage of the body, encouragement, and protection from accidents or other dangers (Bhalla et al. 2014). Additionally, collaboration during the therapeutic process, including communicating with healthcare professionals, is the role of the family (Digby & Bloomer 2014).

Although it may be challenging to manage family participation in caring for patients (Nayeri et al. 2015), families and healthcare professionals believe that family participation is compulsory (Khosravan et al. 2014). Bahrami et al. (2019) indicated that nurses should have a competency of participation and empowerment of the patient and family. Family-centered care is a concept that emphasizes a partnership of healthcare professionals and families in planning and assisting older people.
The concept of family-centered care is shown in Table 2.

Table 2. The concept of family-centered care
Source: Institute for Patient- and Family-Centered Care (2017)

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dignity and respect</td>
<td>Healthcare professionals should respect the perspective of older people and families regarding the knowledge, beliefs, and cultural backgrounds of older people and families. Information and ideas from family caregivers may be essential for planning and assisting older people.</td>
</tr>
<tr>
<td>Information sharing</td>
<td>Information about older people should be shared between healthcare professionals and families. Information sharing is useful to cure older people and can make families obtain exact information from healthcare professionals as well.</td>
</tr>
<tr>
<td>Participation</td>
<td>Healthcare professionals should encourage family participation in caring for older people.</td>
</tr>
<tr>
<td>Collaboration</td>
<td>Family caregivers and healthcare professionals should collaborate in developing, implementing, and evaluating programme and policies about health care for older people.</td>
</tr>
</tbody>
</table>

The concept of family-centered care contributes a structure of family participation in providing care of older people, which is a crucial framework to improve the quality of care and safety for hospitalized older people (Institute for Patient- and Family-Centered Care 2017). Family participation can help the nursing team in providing care of the patient in the hospital, and it is a valuable opportunity for family caregivers to prepare themselves to assist older people after hospital discharge (Bhalla et al. 2014).

### 3.3.3 Theoretical frameworks used to view family caregiving

This study is phenomenological research to describe family caregivers’ experiences of providing care for older family members with a tracheostomy during hospitalization. Phenomenological research does not use theoretical frameworks or preconceived concepts because a phenomenologist needs to describe the reality from a participant’s direct experiences (Polit & Beck 2017). Therefore, prior theories or assumptions are suspended (Holloway & Galvin 2017). In this study, family caregiving theories are viewed to be a presumption of the researcher to understand family roles, but it is not used in the process of collecting and analyzing data (Polit & Beck 2017). Family is a significant supporter of patient care. The family has been considered as a social institution, that indicates a group of persons living under one roof as well as focusing on family relationships such as the marital couple or parent-child relationship (Friedman 1986, Whall 1991). Beyond the concept of family-centered care, theoretical frameworks from family social sciences, family therapy, and nursing are often used to view family function in providing care for a family member and coping with stressful situations (Kaakinen et al. 2014).
Family social science theory

Family social science theory is informative about family function, family interactions, changes in the family, and the family's reaction to health, illness, and stress (Kaakinen et al. 2014, Friedman 1986). In this study, family caregivers are playing a role in assisting and supporting their older people with tracheostomy during hospitalization. In other words, they interact with the new family functions. Meanwhile, they feel stressed with changes in the family. Therefore, to understand the perspective of family function and the family's reaction to stress, family system theory and family stress theory are reviewed.

Family system theory highlights the family interactions, which affect family function as functional or dysfunctional outcomes (Kaakinen et al. 2014). The Family Systems Theory is used to view the individual who is a member of the family (Haefner 2014). The principle of this theory is to indicate the emotional functioning of a person who is confronted with the ailment of the family member (The Center for Family Systems Theory of Western New York 2019). The emotional dysfunction of a person may disrupt the balance of the family system (Haefner 2014). Regarding family stress theory, it describes how family members respond and deal with stressful life events and crisis (Robinson 1997, Kaakinen et al. 2014). The crisis event has an impact on family life. It can make a family member feel stressed. Meanwhile, if there are sufficient social supports to assist them to manage stressful situations, they have to navigate through a stressful situation and prevent a crisis (Joseph et al. 2014).

Family therapy theory

Family therapy theory is developed for working with dysfunctional families and used to view what can be done to help individuals living in dysfunctional families (Kaakinen et al. 2014, Friedman 1986). Based on this study involving family caregivers of older family members with a tracheostomy, the family of older people can be viewed as dysfunctional. Family members are suffering because of an older person’s conditions, and they try to cope with various tasks while taking care of older people with a tracheostomy. To obtain knowledge concerning the family’s reaction in dealing with family changes, the Structural Family Therapy Theory developed by Minuchin (1974) could be used. A family is a system that performs through a personal relationship to manage family members’ behavior. When one family member becomes a patient who is suffering from illness, it affects the family system involving an expression of family dysfunction. A dysfunctional family is an outcome of family change, that family needs to react to demands for change. Demands for change have been adjusted by a reification of the family structure (Minuchin 1974). Therefore, family therapists should help patients and their families deal with problems (Minuchin 1974, Dallos & Draper 2010).
Nursing theories for family caregiving

Family caregivers of older family members with a tracheostomy bear the impact of caregiving, and they need to be supported by the nursing team. To seek for theories or conceptual frameworks related to family health care and how to assist family caregivers so as to get through this situation, nursing theories and models are selected for use in family health care (Kaakinen et al. 2014). For instance, King's conceptual system is seen in the context of humans as personal, interpersonal, and social systems (King 2007). King's conceptual system for nursing focuses on a human being as a person who is interacting with the situation related to a health issue (King 2007). With a situation of family member's illness, it affects the family through either psychological issues or financial situation, as well as family relationships (Golics et al. 2013). Sieloff et al. (2007) explained that the notion of King in family nursing can be used to assess the family’s perception of a family member’s illness, time since diagnosis of illness because time influences behavior in the family system, family coping, family stressors, communication among the healthcare professionals, individuals, and families.

Meanwhile, Orem's conceptual framework can be applied to family nursing (Dumas & de Montigny 1993). Orem & Taylor (2011) indicated that nursing care is a form of human assistance to help them meet their health care requirements. Regarding the self-care deficit of patients, patients require the assistance of physicians and nurses involving demands for self-care and daily living related to personal care and contact with family (Orem et al. 2003). Meanwhile, patients' deficits affect family members, so they always play a responsibility in the management of these deficits (Dumas & de Montigny 1993). Family members endeavor to grasp problems and deal with situations through relationships and the culture of each family (Kaakinen et al. 2014).

Roy's adaptation model is employed in family nursing to grasp family adaptation to the family situation, health issues, and burden of caregiving (Roy 2013). The family is viewed through a holistic adaptation system (Kaakinen et al. 2014). When families face life events, they have many coping strategies to help them handle and cope with the challenges. For instance, the family may adjust behaviors, attitudes, and expectations as well as move away from the stressors. The outcomes of adaptation are that families can reach a higher level of wellness and lead to family growth, survival, and coherence (Roy 2013). Additionally, Roy's adaptation model is utilized because the model is holistic and inclusive of family. The family is the main resource to achieving in adaptation and recovery of individual who has health problems (Weiland 2010).
Summary of theoretical perspectives for family caregiving

To view family phenomena, theoretical perspectives above can be preconceived ideas to use in guiding and thinking about family-focused care (Denham et al. 2016). The effect of illness influences family members’ life as families have stressful situations and changing family roles (Åstedt-Kurki 2010). The family system may vary in function as an expression of a dysfunctional family. Therefore, dysfunctional families as family phenomena can be investigated using family social science theories (Kaakinen et al. 2014). Based on family system theory, it provides the framework guiding with which to view family relationships (Eggenberger & Nelms 2007). To find out the family’s health, family changes, and stressful situation, family stress theory should be employed (Tomlinson 1986). Family therapy theory will be selected to use for working with dysfunctional families. To assist and support families, King’s perspective of the family is used to explain the family system in the part of the family’s perception, interaction, communication, transaction, time, and stress (Sieloff et al. 2007, Whall 1991). Furthermore, Roy’s adaptation model is also utilized in an understanding of the adaptive system in the life events of each family (Roy 2013). Orem’s perspective can be used to assess self-care deficit (Orem et al. 2003) and support the family (Dumas & de Montigny 1993, Whall 1991). The summary of theoretical perspectives for family caregiving is presented in Figure 4.

Phenomenological studies do not use philosophical or scientific theory because the phenomenologist attempts to grasp the essence of experience from participants (Neubauer et al. 2019). However, the construction of the theoretical perspectives would be the presumption of the researcher to guide the researchers on what issues are essential for this study (e.g., family function in caring for older people, changes in the family, and coping with changes in the family).
3.4 CAREGIVING FOR OLDER PEOPLE IN THAI FAMILIES

Thailand is an aged society. Caregiving for older people is met within the family. Therefore, the family is an important source for elder care in Thailand. Around 90% of older people receive daily care and assistance from children and spouses at home and hospitals. Over 60% of caregivers are adult-child daughters being the primary providers for older persons. (Knodel & Teerawichitchainan 2017.) Adult children supervise older people because they are instructed to respect older persons. Therefore, older people are recognized and valued by children (Choowattanapakorn et al. 2004). Even though their children get married, at least one child still stays in his/ her home with older people (Choowattanapakorn et al. 2004, Knodel & Teerawichitchainan 2017). Meanwhile, almost 30% of primary caregivers are spouses. Wives become caregivers for husbands because women live longer than men (Kaakinen et al. 2014). Female caregivers, from childhood, are instilled with the responsibility for caregiving to family members (Tavero et al. 2018).

Older people with multiple chronic illnesses are admitted to different wards of the hospital. Health issues affect everyday life and they become dependants. Thus, family caregivers always give informal care for hospitalized older family members (Dijkstra et al. 2015). Caregiving may be an expression of responsibility to older people based on Thai culture through both natural and dependent caregiving. When older people are observed that they should receive dependent care, dependent caregiving is performed through three crucial processes: mobilizing family members,
performing dependent care, and maintaining continuity of care. After performing dependent care and discovering unpredictable changes, the remobilizing of a family member will be conducted once again because the quality of care for older people is insufficient. (Wongsawang et al. 2013.) The conceptual model of family caregiving for older people in Thai families is presented in Figure 5.

Likewise, in a study by Li et al. (2000) about families and hospitalized elderly patients at one university hospital in the United States, they explained the typology of family care actions, consisting of providing care to elderly patients, working along with the healthcare professionals, and taking care of themselves as follows:

1) Providing care to elderly patients: Family caregivers perform various tasks in providing care of elderly patients as follows:
   (a) Being there, which is about staying with the elderly patient all day in the hospital.
   (b) Family caregivers maintain linkage, as family caregivers should tell the elderly patient what was happening at home, doing activities based on past experiences during hospitalization, providing reassurance that elderly patients are going to get help, and engaging in religious practices.

Figure 5. The conceptual model of family caregiving for older people in Thai families.
Source: Wongsawang et al. (2013)
(c) The pass way for providing care between home and hospital, family caregivers perform the task of keeping medications and belongings during hospitalization, transferring a patient and belongings to and from the hospital, as well as assisting the patients in adapting to stay in hospital.

(d) Attending to personal care, family caregivers participate in providing care about elderly patient’s daily activities and encouraging elderly patients.

2) Working along with healthcare professionals: Family caregivers exchange information about elderly patients with healthcare professionals, collaborate with healthcare professionals to provide care for elderly patients and participate in the therapeutic process.

3) Taking care of themselves: During family participation in providing care for hospitalized elderly patients, family caregivers may be confronted with various problems. Therefore, they have to find a way to cope with problems and take care of themselves as well.

From the principle of family caregiving for elderly patients, as mentioned above, caring for hospitalized older people is the role of family caregivers. Family caregivers provide care based on past experiences of natural caregiving. When older people are admitted to the hospital, they also participate in providing care for loved ones with care needs and functional limitations (Feinberg & Houser 2012). They work along with healthcare professionals to take better care of hospitalized older people. Choowattanapakorn et al. (2004) manifested that Thai family members are valuable persons in caregiving for hospitalized older people. Hospitalized older people were able to recover more quickly when family members were involved in taking care of them compared to elderly patients who were supervised by doctors or nurses only. Meanwhile, caregiving of a hospitalized older person was the intention of the family member who had a sense of filial responsibility. The nurses also believed that caring for the hospitalized older person was family responsibility.

In the hospital, nurses often spend most of their time in checking vital signs, administering medication, collecting medical documents while they give less precedence to other elements of care, for instance, personal hygiene and health education. To manage the gap, the family caregiver needs to participate in providing care for the patient about personal care activities. (Nayeri et al. 2015.) Caring for elderly patients by family members is essential; it can offer more adequate emotional support to elderly patients. Additionally, physicians and the nursing team also need to communicate regularly with family caregivers and provide them with appropriate information involving the condition of the elderly patient. (Bellou & Gerogianni 2014.) Therefore, family-centered care (FCC) is an essential method that involves partnerships between families and healthcare professionals in caring for hospitalized older people (Institute for Patient- and Family-Centered Care 2017).
3.5 PREVIOUS STUDIES OF FAMILY CAREGIVERS IN PROVIDING CARE FOR OLDER PEOPLE WITH A TRACHEOSTOMY

To explore how previous research findings (Prior to 2019) had described the experiences of family caregivers of older people with a tracheostomy, an integrative review was used to summarize, analyze, and arrive at an overall conclusion of the literature on all previous research (Whittemore & Knafl 2005).

Stages of the review

The scope of an integrative review was the broadest category of research review. Five steps of developing an integrative review developed by Whittemore & Knafl (2005) were used to review the literature, consisting of:

1) Problem identification: This stage involves clear identification of the problem and reviews purpose, which was necessary for determining the focus of an integrative review (Whittemore 2005). The purpose of this integrative review was to highlight the experiences of family caregivers of older people with a tracheostomy.

2) Literature search: The purpose of searching the literature was to identify as many studies as possible on the topic of interest to be included in an integrative review. The researcher used electronic databases such as CINAHL, PsycINFO, PubMed, Scopus, and Web of Science. The terms used included family, caregivers, older, elderly, seniors, geriatrics, tracheostomy, mechanical ventilation, ventilator, and critical care. These terms were combined with Boolean operators. In addition, the search term was performed with appropriate adjustments made to align the strategy to the requirements of each database. Electronic databases, the search terms and strategies, and years prior to 2019 are shown in Table 3.

Table 3. Electronic Databases, the Search terms and Strategies, Years prior to 2019

<table>
<thead>
<tr>
<th>Electronic Databases</th>
<th>Search terms and strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>CINAHL</td>
<td>(family or caregivers) AND (elderly or older or aged or geriatric) AND (tracheostomy or mechanical ventilation)</td>
</tr>
<tr>
<td>PsycINFO</td>
<td>(family or caregivers) AND (elderly or older or aged or geriatric) AND (tracheostomy or mechanical ventilation)</td>
</tr>
<tr>
<td>PubMed</td>
<td>(((family) OR caregivers) AND elderly) AND tracheostomy (((family) OR caregivers) AND elderly) AND mechanical ventilation) AND critical care</td>
</tr>
<tr>
<td>Scopus</td>
<td>Family OR Caregivers AND Elderly OR Older AND Tracheostomy OR Ventilator</td>
</tr>
<tr>
<td>Web of Science</td>
<td>Caregivers AND Tracheostomy</td>
</tr>
</tbody>
</table>
The process of selecting studies for an integrative review is shown in Appendix 1. The inclusion criteria in the search strategy included time (years prior to 2019), publication in the English language, term/keyword (use in the databases), and research articles published invalid peer-reviewed scientific journals. There were 823 studies discovered. Addressing the selecting of studies for this review, those accepted based on the title (n = 77) were concerned with 1) family caregivers of older people with a tracheostomy, 2) family caregivers of older people with mechanical ventilation, and 3) family caregivers of patients in the critical care unit. Studies accepted based on abstract (n = 25) included data about family caregivers who provide care for older people with a tracheostomy or prolonged mechanical ventilation. The inclusion criterion was the older people group (60 years of age or above) appearing in the abstract or full text. Finally, the studies accepted based on full texts (n = 10) were related to the aim of this review and met the selection criteria.

3) Data evaluation: Each study has to be assessed by the researcher and was either accepted or rejected for eligibility against inclusion criteria (Hemingway & Brereton 2009). The selection of studies was based on the quality of the primary source. In this review, the evaluation of each study was conducted by modifying the data evaluation process created by Hawker et al. (2002) to assess the studies. The researcher assessed each article based on the following aspects: abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability or generalization, and implications or usefulness. Each aspect was evaluated using a scale ranging from 1 to 4, where 1 = very poor, 2 = poor, 3 = fair, and 4 = good. Scales produced a score for each study of a minimum of 9 points and a maximum of 36 points. Studies with high quality were evaluated as 30–36 points, 24–29 indicated medium quality, and 9–23 points indicated low quality. Assessment form for appraising the quality of each article is presented in Appendix 2. The peer-research process was conducted to appraise the quality of the selected studies and comparison was made by the two researchers (WT, ET). After the evaluation, the score of the studies was compared and discussed based on each aspect of the quality appraisal checklist. Finally, the consensus of the score was determined for each study. The ten studies accepted for this review were evaluated as high and medium quality or with some limitations. Studies included in the review covering family caregivers’ experiences in providing care for older people with a tracheostomy (N = 10) are shown in Appendix 3.

4) Data analysis: This phase aimed to analyze data for combining the results. The results of the selected studies were analyzed by thematic analysis method. This method consists of familiarizing with data, generating initial codes, searching the themes, reviewing themes, defining and naming themes, and producing the reports (Vaismoradi et al. 2013). After reading several times to obtain the findings and ideas, the initial codes and potential themes were generated by collating relevant raw data. Reviewing themes was conducted to check the themes in relation to the code extracts and the whole data from the results of ten studies. Meanwhile, defining and naming themes were created, comprising of two themes (e.g., the impacts of caregiving and
support needs of family caregivers). Finally, the combined findings of this review were produced into the report of family caregivers’ experiences of providing care for older people with a tracheostomy at home and in hospital.

5) Presentation: After combining the data, the conclusions drawn from the integrative review are presented in the following paragraphs.

Characteristic of the study

The studies (n = 10) were published between 2001 and 2012. Most of the studies were from North America (n = 6), but others were conducted in Germany (1), Italy (n = 1), the Netherlands (n = 1), and Poland (n = 1). The studies were quantitative (n = 7), qualitative (n = 2), and mixed-method (n = 1). Five studies focused on family caregivers participation in providing care for older people with a tracheostomy at home, while five studies were to highlight family caregivers participation in providing care for older people with a tracheostomy in hospital, such as an intensive care unit (ICU), cardiac care unit (CCU), and respiratory care unit (RCU). In eight studies, most family caregivers of patients were the spouses. One study described family caregivers of patients were their children. One of these studies did not include information on whether the family caregivers were spouses or children. Moreover, nine out of the ten studies showed that family caregivers were female, while one study lacked information about family caregivers’ gender.

The impact of caregiving

Family caregivers experienced the impacts of caregiving. These experiences were different at home compared to the hospital as the following describes:

1) The impact of caregiving for an older person with a tracheostomy at home: Physical impact involved the family caregivers spending more time helping the older person with their daily activities at home. They performed bronchial suctioning for the elderly family members which caused the family caregivers to feel tied (Van Kesteren et al. 2001). Higher levels of dependency among older people with a tracheostomy and the age of the family caregiver were factors related to the caregiver’s health (Douglas & Daly 2003). Furthermore, family caregivers lacked sleep, making them tired, and reducing their capacity in assisting patients (Evans et al. 2012). The emotional impact meant that family caregivers felt anxious and depressed because their older family members might urgently require bronchial suctioning with little notice (Van Kesteren et al. 2001). The responsibility for caring for their older relatives left them feeling overloaded; together with the difficulty of communicating with tracheostomy patients, this caused the family caregivers to feel depressed (Douglas & Daly 2003, Douglas et al. 2010).

The social impact included the leisure time of family caregivers being reduced because they needed to take care of their older people. The constant care for older family members restricted their social relationships and limited their opportunities
to participate in outdoor leisure activities. They were usually unable to leave their older family members even for a short time, hardly ever saw friends, and never went to social meeting places (Evans et al. 2012). The financial impact came from the encroachment of family caregivers’ time, which reduced their ability to remain in paid employment (Evans et al. 2012), and the incomes were insufficient to cover the expenses of caring for older people with a tracheostomy (Van Kesteren et al. 2001).

2) The impact of caregiving for an older person with a tracheostomy in hospital: Physical impact meant that the family caregivers were overburdened, which affected their physical health, leading to symptoms such as fatigue and subsequently, general deterioration of health (Scott & Arslanian-Engoren 2002). Emotional impact included the family caregivers feeling stressed, depressed, and abandoned. They were responsible for providing care for older people (Scott & Arslanian-Engoren 2002). In addition, they felt depressed by their situation because of their reduced independence and perception that they had been abandoned by other members of their family (Scott & Arslanian-Engoren 2002, Van Pelt et al. 2007).

As for social impact, participation in society or family was reduced because they were usually unable to leave their older family members even for a short time (Scott & Arslanian-Engoren 2002, Van Pelt et al. 2007). Family caregivers had given up their working hours to provide care for their older relatives (Van Pelt et al. 2007, Scott & Arslanian-Engoren 2002), and therefore they faced difficulties with the financial strain associated with their responsibilities.

Support needs of family caregivers

Family caregivers needed to be supported by relatives and healthcare professionals. The support needs were different at home and hospital, consisting of:

1) Support needs of family caregivers at home: Family caregivers are responsible for caring for older people with a tracheostomy at home. They required information, and psychosocial and financial support. Family caregivers needed information regarding relative’s symptoms (Rossi Ferrario et al. 2001) and medical technical information about using a ventilator at home (Van Kesteren et al. 2001). Regarding psychosocial support, they had psychological problems such as anxiety associated with their older family members and technical medical care and needed professional home care to help them cope with their older family member’s suffering. Psychosocial support needs to be increased with the older family member’s level of infirmity and the need for providing care to them (Van Kesteren et al. 2001). With respect to financial support, the family caregivers required paid support from other family members and their social network because they lacked the financial resources to adequately care for their loved ones with a tracheostomy (Van Kesteren et al. 2001, Evans et al. 2012).

2) Support needs of family caregivers in the hospital: Although physicians and nurses supervised elderly patients in the hospital, they also needed to be supported by their family members. Additionally, family caregivers also required information
about their older family member’s condition when they took responsibility for providing care, for instance, the patient’s illness, their treatment and its effects, prognosis, and their expected care needs after hospitalization (Maxwell et al. 2007, Nelson et al. 2005). As for emotional support, family caregivers were worried and stressed about their older family members’ symptoms and illnesses. They required communicating directly with doctors to understand their relative’s treatment plans and provide proper care. In other words, they needed assurance (honest answers to their questions) and proximity to their loved ones (seeing the patient frequently, unrestricted visiting) (Maxwell et al. 2007).

As they had to take care of older peoples with a tracheostomy for a long time during hospitalization, they needed social support. They needed friends or other family members nearby for support to assist them in dealing with a stressful situation (Maxwell et al. 2007). Moreover, family caregivers needed to communicate with clinicians such as nurses, doctors, social workers, and respiratory therapists to better understand their older family member’s condition (Nelson et al. 2005). Besides, family caregivers required help from other family members to meet financial support for taking care of their older people with a tracheostomy (Scott & Arslanian-Engoren 2002).

**Summary of previous studies**

Older people undergo a tracheostomy resulting from respiratory failure and the rate of weaning failure from mechanical ventilation. They are treated and supervised by physicians, nurses, and other healthcare professionals. Although they receive the treatment and assistance from healthcare professionals, they also need to be supported by their family caregivers as spouses, children, and relatives.

Based on the integrative review, family caregivers perform a responsibility in assisting daily activities and decision making about treatment for older family members with a tracheostomy. Previous studies manifest that caregiving is burdensome for family caregivers. The burden of caregiving affects the physical, emotional, social, and financial situation both in hospital and at home by increasing tiredness, stress, and depression, as well as reducing social interaction and employment (Douglas & Daly 2003, Douglas et al. 2010, Evans et al. 2012, Scott & Arslanian-Engoren 2002). However, the family caregivers’ support needs are different in the hospital and the home. In the hospital, family caregivers need information about the patient’s symptoms and expected care needs after hospitalization, assurance, proximity, communication with clinicians, and support from other members in the family (Maxwell et al. 2007, Nelson et al. 2005, Scott & Arslanian-Engoren 2002). At home, they needed assistance with technical medical care, professional home care, and financial support (Van Kesteren et al. 2001, Evans et al. 2012).

Previous research highlighted family caregivers of patients with a tracheostomy and mechanical ventilation at home and in hospitals (e.g., ICU, RCU, and CCU), but
did not discuss the situation of family caregivers for older people with a tracheostomy in general wards such as medical-surgical. Additionally, most of the previous articles were studied using quantitative research in European countries and North America. Few studies were performed using qualitative research to describe family caregivers’ experiences of providing care for hospitalized older family members with a tracheostomy. However, the cultural care and healthcare systems of each country are different. Thailand as an Asian country also has its cultural care. Family caregivers of Thai older people with a tracheostomy were studied less. Therefore, the researcher is interested in studying family caregivers’ experiences of providing care for hospitalized older family members with a tracheostomy in the Thai context to enhance the quality of care for older people and families. Because family-centered care is a useful method, that indicates a partnership of healthcare professionals and families in maintaining older people’s health during hospitalization.
4  AIM OF THE STUDY AND RESEARCH QUESTIONS

Aim of the study

The aim of this study was to describe the experiences of providing care for older family members with a tracheostomy during hospitalization from the family caregivers’ perspective (adult children and spouses) in Thailand. The findings will be useful to healthcare professionals in assisting older people and family caregivers during hospitalization before an older person will be discharged to home.

Research questions

The research questions comprise the following:

1. What experiences do adult children have as family caregivers providing care for an older person with a tracheostomy?
2. What experiences do spouses have as family caregivers providing care for an older person with a tracheostomy?
5 METHODOLOGY

5.1 DESIGN OF THE PHENOMENOLOGICAL STUDY

To describe the experiences of providing care for older family members with a tracheostomy from the family caregivers' perspective, a phenomenological method was conducted to describe phenomena (Fain 2015, Holloway & Galvin 2017). According to the ontology of phenomenology, it concerns the nature of reality as a human being. There are multiple realities, and reality is described by participants (Bradshaw et al. 2017). If reality needs to be examined, the epistemological question is how we can know reality or knowledge and what can be known (Holloway & Galvin 2017). Phenomenological philosophy, rooted in a philosophical tradition, has been developed by two main phenomenologists: descriptive phenomenology of Edmund Husserl (1859–1938) and interpretive phenomenology of Martin Heidegger (1889–1976) (Polit & Beck 2017, Holloway & Galvin 2017). Both philosophies are a phenomenological study, but have different approaches. The philosophy of Heidegger involves interpreting the narrative of participants to obtain the meanings of the phenomenon in context (Holloway & Galvin 2017). On the other hand, the philosophy of Husserl does not interpret the narrative of participants because the purpose of this phenomenological approach is to involve remaining open how the meaning of a phenomenon appears (Giorgi 2017, Holloway & Galvin 2017). Therefore, phenomenologists who do research based on the descriptive phenomenological study have to suspend prior knowledge and belief in the process of data collection and analysis to generate possible truths, but interpretive phenomenological study can use prior knowledge of the researcher to interpret the narrative of participants (Giorgi 2017).

The philosophy of Husserlian Descriptive Phenomenology emphasized the description of the human experience (Polit & Beck 2017). It highlights the concept of intentionality, which is an expression of a person’s consciousness (Davidsen 2013, Holloway & Galvin 2017). Husserl believed that the human being is conscious; people perceive something by the individual’s consciousness as what appears in their consciousness (Holloway & Galvin 2017, Neubauer et al. 2019). Giorgi (1985) stated that phenomenology is an approach that is used to discover and describe for the presence of meanings based upon the consciousness of people. To gain the understanding of the existence of meaning or human experience, the descriptive phenomenological researcher has to use bracketing during data collection and analysis (Neubauer et al. 2019) as suspending or holding prior beliefs, attitudes, and knowledge of researcher to find out what is present (Holloway & Galvin 2017). In other words, the researcher does not think for other people who have direct experiences of everyday life or does not assume what other people think. Heidegger’s interpretive phenomenology is about the nature of being and time (Polit & Beck 2017). He regarded a person as having the person has the culture,
history, and language, which is valuable and significant. Persons are studied to comprehend the context of their lives. Persons can make interpretations of knowledge and is in time as awareness of now (being is temporal). This form of research explains the meaning of human being in the world. The phenomenological researcher attempts to interpret the meaning of the phenomenon to aid understanding. (Holloway & Galvin 2017.)

Other phenomenologists, Colaizzi, Giorgi, and Van Kaam developed a psychological phenomenological method that followed the philosophy of Husserl (De Chesnay 2014). For example, Giorgi (1985) developed a descriptive phenomenological method to use for data analysis about the experience of individuals from everyday life. It mentions the structure of the experience by discriminating, transforming, and synthesizing the phenomenon searched from informants’ experiences. Another interpretive phenomenological researcher Van Manen developed the Hermeneutic that followed the philosophy of Heidegger to identify the lived experience as the existence of persons, including lived time, lived space, lived body, and lived relationships (Rodriguez & Smith 2018).

This study was based on the descriptive phenomenological approach of Edmund Husserl and the analysis method developed by Giorgi (1985). This analysis method was used because Giorgi’s psychological phenomenological study was developed based on the notion of intentionality as Husserl explained it (De Chesnay 2014, Holloway & Galvin 2017). According to the philosophy of Husserl, bracketing as a process of suspending beliefs and prior knowledge was an important method to reduce the interpretation by the researcher (Holloway & Galvin 2017). Giorgi’s data analysis method is related to Husserl’s method as remaining within the bracketing was conducted in the phases of data analysis as well (Giorgi 2017). In other words, doing descriptive phenomenological research is a challenge for the researcher to describe family caregivers’ experiences during involvement in caregiving for older family members with a tracheostomy. The researcher’s prior knowledge and beliefs about family caregiving for older people with a tracheostomy were held during interviewing and analyzing data because the researcher needed to know what and how the meanings of phenomenon appear at present. The researcher did not attempt to interpret meanings or what a participant wants to describe his/her experiences to the researcher.

5.2 RECRUITMENT METHOD

A phenomenological study focused on participants’ everyday life experience, and it was to describe what participants had said and why participants had said it. Therefore, recruitment methods were chosen that enabled participants to express themselves openly. (Holloway & Galvin 2017.) To reach participants, permission was obtained from the director of one hospital in Thailand to recruit eligible participants. Participants were recruited from a list of family caregivers who had participated in
caregiving for elderly patients with tracheostomy. The following recruitment method was used:

1) The researcher made contact with the Contact Nurse in medical-surgical wards to illuminate the aim of this study and asked for co-operation to inform family caregivers about the study based on an information sheet for the Contact Nurse.

2) The Contact Nurse helped the researcher to ask family caregivers for participation in this study. The Contact Nurse illuminated the aim of this study to family caregivers based on an information sheet and provided a fact sheet to family caregivers for consideration.

3) The family caregiver did not have to make a decision at that time whether or not they would cooperate to be a participant in this study. Before the family caregiver decided, they could talk to any family member to help them feel comfortable to participate in this study.

4) The family caregiver had considered hearing more about the study. The family caregiver informed directly Contact Nurse about his/her wish. After that, the Contact Nurse made an appointment with the family caregiver and the researcher so that the researcher could establish initial contact with the family caregiver at the medical and surgical ward.

5) There were family caregivers who were willing to meet the researcher to hear more about the study; the Contact Nurse asked for permission to give the family caregiver’s name to the researcher. After that, the Contact Nurse informed only the family caregiver’s name and the appointed time to the researcher. The researcher visited the Contact Nurse at the medical and surgical ward or called the Contact Nurse to ask about the family caregivers’ interest in cooperating in this study.

6) The researcher visited the family caregiver who was willing to hear more about the study at the medical and surgical ward in a private room to discuss the study based on a fact sheet to the subjects. For literate family caregivers, the researcher provided a fact sheet to the subjects to read. For illiterate family caregivers, the researcher read aloud the text of a fact sheet to the subjects. Some family caregivers had questions about the study, which were discussed and asked to participate in this study. Examples of questions which were discussed included “Where are you from?”, “What the issue do you want to ask me?”, and “Why would you like to know my experiences in providing care for father/mother/ husband/wife?”. Therefore, the researcher had to explain and give more information based on his/her questions.

5.3 PARTICIPANT RECRUITMENT

The participants were family caregivers, including adult children (n = 20) and spouses (n = 20) of older people. Family caregivers had experiences in providing care for older family members (60 years of age or above) with a tracheostomy and had been admitted to medical-surgical wards of a provincial hospital as having surgeons who could perform a tracheostomy for patients. The recruitment of participants continued until data saturation, which meant that 20 adult children and 20 spouses
of older people with a tracheostomy from different families were interviewed and data from participants had redundancy. With regard to sample size and data saturation, twenty were enough for phenomenological study (Mason 2010). Adult-child and spousal caregivers were interviewed in the same hospital between January and June 2017. The researcher selected participants through purposive sampling because it was often used to select participants purposefully based on the information needs of the study (Fain 2015, Polit & Beck 2017). Inclusion criteria of participants was as follows:

1) A family caregiver who was the primary caregiver with experience in providing care for an older person with a tracheostomy for more than 1 month.
2) Family caregivers were persons who had attained the legal age according to the laws in Thailand, aged 18 and over.
3) Family caregivers were able to communicate and evaluate their own health status so that they had enough strength/ resources to participate in this study.
4) Family caregivers could speak the Thai language.
5) Willingness to cooperate in the study.

An exclusion criterion was if an older person underwent an emergency tracheostomy (performed when a person’s airway suddenly obstructs after having an accident or injury) to obtain an airway was not eligible for this study. Therefore, the family caregiver who took care of an older person with an emergency tracheostomy was excluded.

5.4 RESEARCH SETTING

This study was conducted at the medical-surgical wards of a provincial hospital, Thailand. Medical-surgical wards were the setting for family caregivers to look after hospitalized older family members either in regular visiting hours (11 a.m. to 8 p.m.) or during the night (after 8 p.m.). However, caregiving for hospitalized older people by family caregivers was in control of the nursing team. At the general wards, there are older people and family caregivers who work together with nurses to take care of older people with a tracheostomy. They worked hard with hospitalized older people living with an infirmity. Family caregivers’ participation in caregiving for hospitalized older people along with doctors and nurses consisted of decision making regarding treatment for older people and assistance about daily care (e.g., feeding, cleaning and rubbing the body dry, and providing encouragement to older people).

The study hospital was at tertiary health care level as the provincial hospital with 561 beds. One thousand five hundred and sixty-eight (1,568) healthcare professionals provide health care service to clients. This hospital is also designed to be the second referral center for district hospitals, the medical education center, and the clinical setting of training nursing students as well. Therefore, the researcher had considered selecting this hospital for collecting the data because older people who underwent
tracheostomy were treated and provided care by healthcare professionals here. By the way, family caregivers of older people with a tracheostomy also participate in supporting and assisting their older people together with the nursing team in the medical-surgical wards. In other words, this selected hospital was considered a diverse sample and the topic of interest (Martínez-Mesa et al. 2016).

### 5.5 DATA COLLECTION

A phenomenological interview involves conversation or obtaining a narrative of the participant’s experiences and gives deep comprehension into the phenomena between researcher and participants until data saturation (Stayt 2007, Fain 2015). The data were collected using semi-structured interviews at medical-surgical wards in private rooms between January and June 2017. The following steps were used:

1) The researcher gave an opportunity to the family caregiver to clarify any doubts before decision-making to participate in this study.

2) The literate family caregiver was asked when he/she would like to discuss the study based on a fact sheet for the subjects, as presented in Appendix 4. If the family caregiver liked to hear more details, the researcher explained the details to the family caregiver. For the illiterate family caregiver, the aim, processes, and benefits of this study were explained by the researcher based on a fact sheet for the subjects by reading it aloud. After that, the family caregiver was asked to sign a consent form before interviewing. Those who were literate signed a consent form by themselves. For those who were not literate, the consent form was read aloud to them and signed by fingerprinting. The researcher wrote the print name of a participant under the thumbprint of the participant after the family caregiver had fingerprinted.

3) After the participants had provided completely signed consent forms, the researcher collected data from the family caregiver at the beginning of the interview with the background questionnaire as the demographic data form concerned with the family caregiver. The demographic data form concerned with the family caregiver is shown in Appendix 5. The researcher followed the interview guide as a semi-structured interview which contained open-ended questions. Open-ended questions were defined from the literature review. Semi-structured interviews began with defined questions, but the researcher had considerable latitude to adapt questions based on what participants said to interview participants until the interviewer did not hear new information (Fain 2015, Polit & Beck 2017). The main interview questions which were used to collect the data are presented in Appendix 6.

The researcher visited participants one or two times in order to interview participants. Each interview took approximately 30 to 60 minutes in the Thai language. Some participants were interviewed twice because the first interview was interrupted by older people who needed assistance (e.g., toileting, turning the body, feeding) from family caregivers. During each interview, the researcher recorded data
by the audio recorder and made field notes about the family caregiver’s mood swings and specific behavior, such as gestures and facial expressions after interviewing.

5.6 DATA ANALYSIS

Experiences of family caregivers in providing care for hospitalized older family members with a tracheostomy in the Thai context were described using a descriptive phenomenological approach. Phenomenology was used because it was a method to find out what is the essence of a phenomenon from the perspective of participants who had experienced it (Neubauer et al. 2019). The obtained raw data from participants were analyzed to describe the essence of experiences that appeared (Giorgi 2017). The audio recorded data (Conversations between the researcher and participants in Thai) were transcribed word by word (Angsana new, front 16, line spacing 1). The raw data were divided into two parts, including a total of 75,880 words in 155 pages from 20 adult-child caregivers and 59,221 words in 126 pages from 20 spousal caregivers. The whole data as the Thai language was analyzed to protect meaning from being lost. Additionally, the data were translated from Thai into English for publishing.

A qualitative data analysis technique developed by Giorgi was conducted as a guideline for data analysis (Giorgi 1985) because this technique emphasized the scientific phenomenological reduction like Husserl’s descriptive phenomenological study (Giorgi 2017). Phases of analysis involved the following: 1) Reading all of the texts to grasp the language of the description and obtain a sense of the whole data; 2) Discriminating meaning units and focusing on the phenomenon that was explored. The discrimination of meaning units was noted directly in the description, upon rereading the text and gaining awareness of the change of meaning of the situation; 3) Transforming the discriminated meaning units of the participant’s everyday expression on the phenomenon that was investigated into language of discipline for possible category; 4) Synthesis of the transformed meaning unit into general structural description of the event as a participants’ experiences. The phases of descriptive phenomenological data analysis and how the method was applied in this study are displayed in Table 4.
Table 4. The phases of descriptive phenomenological data analysis

<table>
<thead>
<tr>
<th>Phase of analysis</th>
<th>In this study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phase 1: Reading all of the texts to grasp the language of the description</strong></td>
<td>• Listen to the audio recording to grasp and obtain a sense of the whole data</td>
</tr>
<tr>
<td>• Reading the transcription (Raw data) several times</td>
<td>• Reading whole data according to family caregivers’ narrative (from 20 adult children and 20 spouses)</td>
</tr>
<tr>
<td><strong>Phase 2. Discriminating meaning units</strong></td>
<td>• Asking the question from data: what is happening as phenomena? For example, impacts of caregiving, coping with problems, support needs, and family participation in providing care.</td>
</tr>
<tr>
<td>• Dividing the data</td>
<td>• Dividing data, the meaning units were discriminated from whole data to each aspect of phenomena (e.g., meaning of providing care, impacts of caregiving, support needs, learning of family caregivers to cope with problems, and family participation in providing care).</td>
</tr>
<tr>
<td><strong>Phase 3: Transforming meaning units</strong></td>
<td>• Transforming the discriminated meaning units into nursing language for possible categories</td>
</tr>
<tr>
<td>• Transforming the discriminated meaning units</td>
<td>• Transforming the discriminated meaning units into academic writing as a formal language. For example, resting is not enough (insufficient sleep) and I cannot go somewhere to meet friends (I have a reduction in social friend group).</td>
</tr>
<tr>
<td>into nursing language for possible categories</td>
<td>• Transformed meaning units which had similar meaning were summarized together as the transformed meaning unit expressions.</td>
</tr>
<tr>
<td><strong>Phase 4: Synthesis of transformed meaning units</strong></td>
<td>• Transformed meaning unit expressions were categorized in order to determine themes and sub-themes.</td>
</tr>
<tr>
<td>• Categorizing transformed meaning unit expressions into sub-themes and themes</td>
<td>• The transformed meaning unit expressions were synthesized into the general structural description involving experiences of providing care for older family members with a tracheostomy from family caregivers’ perception. For example, family caregivers had the impacts of caregiving, including physical impacts (insufficient sleep), psychological impact (stress and discouragement), social impact (reduction in social friend group), and financial impact (insufficient income).</td>
</tr>
<tr>
<td>• Synthesizing the transformed meaning unit expressions into the general structural description</td>
<td></td>
</tr>
</tbody>
</table>

In the process of data analysis, the researcher individually read the transcriptions while listening to the audio recording to grasp the language of participants. After receiving completed data from all participants, the researcher read the whole data (raw data) several times to obtain the sense of whole data and decide on the analysis of the situation that was the family caregivers’ narrative. After reading the whole
data several times to get a clear understanding of their findings and ideas, the researcher conducted to divide the data as discrimination of the meaning units and transform the discriminated meaning units into the nursing language for possible categories. Then, the researcher synthesized the transformed meaning unit expressions into subthemes and themes. In addition, the general structure of experiences of providing care for hospitalized older family members with a tracheostomy based on family caregivers’ perception was described. At that phase of data analysis, the researcher had to be alert to the possible incorrectness as the researcher analyzed the data based on descriptive phenomenological perspectives, the researcher would not interpret the received data from participants. An example of the data analysis concerning the impact of caregiving from the family caregiver’s perception is presented in Appendix 7.

5.7 ETHICAL CONSIDERATION

Ethical approval

The research proposal was submitted to the research ethics committee for consideration and obtaining ethical approval for the study (World Medical Association 2013). Ethical approval to collect the data was received from the University Committee on Research Ethics (STATEMENT 1/2017) and the Research Ethics Committee of one Hospital in Thailand (BSH-IRB 008/2560) for permission to carry out the research in the hospital. In addition, data protection was based on the EU’s General Data Protection Regulation (2016/679, GDPR) (The European Parliament and the Council of the European Union 2016)

Respecting the autonomy of participants

The researcher informed the participants about the aim of this study, the procedures, as well as risks and benefits of this study (National Advisory Board on Research Ethics 2009, World Medical Association 2013). Participants were informed that this study involved voluntary participation and they could refuse to cooperate in the study at any time (World Medical Association 2013). Before collecting data, a consent form was signed by the participant. The consent form to be signed by the subjects is presented in Appendix 8.

Avoiding harm

To avoid mental harm, mental issues (e.g., stress, dissatisfaction, soriness, and frustration) were observed during the interviews (National Advisory Board on Research Ethics 2009). During the interviews, three adult-child caregivers and one spousal caregiver cried while the researcher (WT) asked about the feelings of providing care for their older family members with a tracheostomy. They cried
because they were worried and stressed about this caregiving. Therefore, the researcher asked them if they wanted to skip questions or stop the interview. Meanwhile, the researcher, who is a nurse with experience in nursing care for elderly patients and their family caregivers, also provided emotional support to him/her (Holloway & Galvin 2017). After providing emotional support, the researcher asked to make an appointment for the next interviews, but they were willing to continue because they did not want to be interviewed again a second time.

Research data protection and confidentiality

Storing and backing up research data was conducted to protect the data (National Advisory Board on Research Ethics 2009, The European Parliament and the Council of the European Union 2016). Data files and all other files related to the research data was saved on the researcher’s computer. Folders and files were named in an uncomplicated and logical manner. A backup copy of the data was made and stored on the external hard drive. Accordingly, a password was created to access the research data by the researcher. Moreover, all participants’ answers and responses remained confidential and part of the dataset, so their identity was protected at all times. All responses were also stored securely and designated with a unique code, and no names were included in the questions for an in-depth interview. Any information inputted on the computer was securely protected with a password. This means that only the researcher could access the participants’ responses and nobody else (National Advisory Board on Research Ethics 2009).

To keep the textual dataset anonymous, background material containing identifiers was deleted, for example, contact details of participants and background information forms. The name of the participants and any third parties mentioned in the interview was removed or replaced by pseudonyms. The code was created to link other data with the informed consent, so the same data of participants were known, but the person’s identity remains unknown. A file linking participants’ names to pseudonyms was stored on a password-protected computer and separated from the transcripts, and only the researcher had access to this material (National Advisory Board on Research Ethics 2009, The European Parliament and the Council of the European Union 2016). The researcher had a code list of the participants and the code key in a separate protected place. Only the researcher heard audio recordings, and any transcripts were replaced by pseudonyms. In addition, a description of the scientific research data file, based on Personal Data Act (523/1999) Section 10, has been submitted to the Office of the Data Protection Ombudsman in Finland (Finlex Data Bank 1999), while the Ph.D. study was prepared in Finland. In Thailand, where the data were collected, the same kind of personal data act does not exist.
Storing and destroying research data

The researcher stored the documents for the trustworthiness of the data (Holloway & Galvin 2017). In Thailand, during the research period, the data collection sheet, transcript and other documents were kept in a locked cabinet with access only with a key, located in the researcher’s office, Faculty of Nursing, Burapha University. The external hard drive was used to save the data from audio-recording, and it was stored in a locked cabinet with access only with a key in the researcher’s office, Faculty of Nursing, Burapha University. After collecting data in Thailand, the researcher brought the documents and external hard drive to the University of Eastern Finland to store in a locked cabinet with access only with a key, located in the supervisor’s office at the Department of Nursing Sciences, University of Eastern Finland. Furthermore, after the research was completed, the original data will be stored in a locked cabinet and destroyed by the principal supervisor after three years have passed since the completion of the study. The processed data will be stored in a locked cabinet for ten years at the Department of Nursing Sciences, the University of Eastern Finland in order to protect personal data. After that, it will be destroyed by the principal supervisor (The European Parliament and the Council of the European Union 2016, Holloway & Galvin 2017).
6 FINDINGS

6.1 CHARACTERISTICS OF PARTICIPANTS

This study aims to describe family caregivers’ experiences of providing care for older family members with a tracheostomy during hospitalization. Either adult children (n=20) or spouses (n=20) as informal family caregivers were interviewed. The characteristics of family caregivers who cooperated in this study are as follows:

6.1.1 Characteristics of adult-child caregivers

Adult-child caregivers were sons (50%) and daughters (50%). Forty-five percent of adult-child caregivers were middle-aged (41–59 years). Three-fifths (60%) were married; the same percentage had secondary education. One-fourth (25%) were unemployed. About two-fourths (50%) had annual incomes of 100,000–200,000 Thai baht (about 2,778–5,555 €). Ninety percent of adult-child caregivers had no underlying disease. The length of providing care for older parents with a tracheostomy ranged from 1 to 6 months (Mean = 1.7; SD = 1.37). More information about the characteristics of adult-child caregivers who cooperated in this study are presented in Table 5.

Table 5. Characteristics of adult-child caregivers (N = 20)

<table>
<thead>
<tr>
<th>Demographic data</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship with an older family member</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Son</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>Daughter</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>Female</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–25</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>26–40</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>41–59</td>
<td>9</td>
<td>45</td>
</tr>
<tr>
<td>60–69</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>Couple</td>
<td>12</td>
<td>60</td>
</tr>
<tr>
<td>Divorce</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary</td>
<td>12</td>
<td>60</td>
</tr>
<tr>
<td>Vocational certificate</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>2</td>
<td>10</td>
</tr>
</tbody>
</table>
6.1.2 Characteristics of spousal caregivers

Ninety percent of spousal caregivers were female as wives participated in providing care for older husbands with a tracheostomy during hospitalization. Fifty-five percent of spousal caregivers were middle-aged (41–59 years). Ninety percent of spousal caregivers had an education while ten percent of spousal caregivers did not go to school. One-fourth (25%) was unemployed. Eighty-five percent of spousal caregivers had annual incomes of 100,000 Thai baht (about 2,777 €) or less. Forty-five percent of spousal caregivers themselves had at least one chronic disease such as diabetes mellitus, hypertension, or thyroid dysfunction. The length of providing care for older family members with a tracheostomy ranged from 1 to 3 months (Mean = 1.6; SD = 0.73). More information about the characteristics of spousal caregivers who cooperated in this study is presented in Table 6.
Table 6. Characteristics of spousal caregivers (N = 20)

<table>
<thead>
<tr>
<th>Demographic data</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship with an older family member</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wife</td>
<td>18</td>
<td>90</td>
</tr>
<tr>
<td>Husband</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Female</td>
<td>18</td>
<td>90</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>41–59</td>
<td>11</td>
<td>55</td>
</tr>
<tr>
<td>60–69</td>
<td>5</td>
<td>25</td>
</tr>
<tr>
<td>70–79</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Couple</td>
<td>20</td>
<td>100</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No education</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Elementary</td>
<td>13</td>
<td>65</td>
</tr>
<tr>
<td>Secondary</td>
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<td>25</td>
</tr>
<tr>
<td><strong>Vocation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employee</td>
<td>9</td>
<td>45</td>
</tr>
<tr>
<td>Agriculture</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Homemaker</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Grocer</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Unemployed</td>
<td>5</td>
<td>25</td>
</tr>
<tr>
<td><strong>Annual income (Thai baht and Euro equivalent)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 50,000 THB (&lt;1,388 €)</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>50,001–100,000 THB (1,389–2,777 €)</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>100,001–200,000 THB (2,778–5,555 €)</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td><strong>Spousal caregiver’s own underlying disease</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertension (HT)</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>Diabetes mellitus (DM)</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Thyroid disease</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>More than one disease (e.g., DM and HT)</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>No underlying disease</td>
<td>8</td>
<td>40</td>
</tr>
<tr>
<td><strong>Length of providing care for the older partners</strong></td>
<td>Ranged from 1 to 3 months (Mean = 1.6; SD = 0.73)</td>
<td></td>
</tr>
</tbody>
</table>
6.2 ADULT CHILDREN’S EXPERIENCES OF PROVIDING CARE FOR OLDER PARENTS WITH A TRACHEOSTOMY

After performing a tracheostomy, adult children played a role in caregiving to their older parents together with the nursing team. Adult-child caregivers as sons and daughters plentifully explained experiences in caregiving for older parents with a tracheostomy. Adult children’s experiences of providing care are illustrated in Table 7. Five themes emerged from the data, consisting of meanings of providing care, ways to learn in providing care for older parents, caring activities for older parents, impacts of caregiving, and support needs.

Table 7. Adult children’s experiences of providing care for hospitalized older parents with a tracheostomy.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
<th>The transformed meaning unit expressions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meanings of providing care</td>
<td>Filial responsibility</td>
<td>Adult children play a responsibility to take care of their older parents with a tracheostomy. Providing care was filial responsibility as a demonstration of gratefulness to an older parent who has been the child’s benefactor.</td>
</tr>
<tr>
<td>Learning new things</td>
<td></td>
<td>Providing care was learning new things to cope with older parents with a tracheostomy. They learned to do procedures related to tracheostomy care, which they had never done before.</td>
</tr>
<tr>
<td>End of life care for older parents</td>
<td></td>
<td>Providing care included the end of life care for older parents with a tracheostomy. Older parents would die eventually from tracheostomy.</td>
</tr>
<tr>
<td>Ways to learn in providing care for older parents</td>
<td>Asking for advice</td>
<td>They asked the physicians and nurses for advice about tracheostomy care.</td>
</tr>
<tr>
<td></td>
<td>Observing</td>
<td>They observed the nurses to learn how to suction and how to take care of older parents with a tracheostomy.</td>
</tr>
<tr>
<td></td>
<td>Sharing the experiences</td>
<td>They shared the experiences with family caregivers of other patients concerning the patient’s symptoms and how to take care of an older parent.</td>
</tr>
<tr>
<td>Caring activities for older parents</td>
<td>Basic care</td>
<td>They did the basic care that they had never done (e.g., rubbing the body dry, feeding, changing the diapers, and turning the body).</td>
</tr>
<tr>
<td></td>
<td>Tracheostomy wound cleaning and suctioning</td>
<td>They just wiped around the tube with cotton buds or tissue paper and sucked the phlegm by using the suction machine. They did not clean inside the tracheostomy tube.</td>
</tr>
<tr>
<td></td>
<td>Massage and physical therapy</td>
<td>When older parents had pains and aches, they gave a massage to older parents. Physical therapy was merely an exercise in lifting arms and legs.</td>
</tr>
<tr>
<td></td>
<td>Encouragement</td>
<td>Talking and holding hand was a way for encouragement.</td>
</tr>
<tr>
<td></td>
<td>Calling the nurse to ask for help</td>
<td>If the older parents could not breathe properly and there was much phlegm in the tube, they would call the nurses to ask for help.</td>
</tr>
</tbody>
</table>
6.2.1 Meanings of providing care

Adult-child caregivers participated in providing care for older parents with a tracheostomy during hospitalization. They described meanings of providing care that fell into three themes, including a filial responsibility, learning new things, and the end of life care for older parents.

Within parent-child relationships, providing care was filial responsibility as a demonstration of gratefulness to an older parent who has been the child’s benefactor. Adult-child caregivers had to take care of older parents, while their older parents were alive. They explained that duty and providing care for their loved one was not actually a duty, but it was rather a responsibility of children and within parent-child relationships in particular. Duty seemed like the duty of nurses to provide care for patients. Thus, the meaning of duty and responsibility was different. Family caregivers gave the following descriptions as examples:

1C: I would like to take care of her. She is very old. She is still alive with us not too long... It is my responsibility. I will do my best while she is alive.
4C: Because he is my dad, I will treat him well. I am saying it is not a duty. It is the responsibility of children. The duty of the nurse is working and doing because of their duties but between my dad and me, is the relation which I should do.

Meanwhile, they also explained a filial responsibility as providing care for older parents was a sign of gratefulness to benefactors as parents. Adult children had to provide care to their older parents with a tracheostomy. If they did not take care of them, it would be an abandonment and a sign of ungratefulness. For example, adult-child caregivers described it like this:

6C: I think that I never take care of my mom like this before when she has been like this, I want to do the good thing for her. I want to take good care of her...If I or even my family didn’t take care of her, it is not different from some older adults who are abandoned at the nursing home. If we don’t care, we are ungrateful to our parents.

14C: I do not think it is not the burden because it is my responsibility, descendants’ responsibility that must look after the benefactor.

In addition, providing care involved the learning of new things to cope with older parents with a tracheostomy. Adult-child caregivers learned to do procedures related to tracheostomy care (e.g., feeding, suctioning, rubbing the body dry, and exercising), which they had never done before. Family caregivers described:

15C: I do not think it is difficult caregiving for the patient. It is one way of learning for me to cope with the on-tube patient. I learned the new things about the patient on the tube for instance; feeding food and water, rubbing the body dry, and exercising by asking nurses.

18C: It is a responsibility that I have to do. If I can’t do it, I have to try to practice because I have to take care of him. It is the new things that I have to learn. Also, grandchildren go to school. But now this is school break duration, they come to help me.

Another important meaning described by adult-child caregivers was that providing care included the end of life care for older parents with a tracheostomy. Older parents would die eventually from tracheostomy. For example, adult-child caregivers described it like this:

3C: I only knew that it seemed the last way to cure the patient. I had found the patient who got tracheostomy would die eventually. After the doctor said, it was not the same as I had known. The patients could be treated and cured at home if they can breathe by themselves. He said, there is the case of a patient who got tracheostomy, and he has been being treated at home. Now I know what it is. I feel so relieved right now. Before that, I’m afraid of the word “tracheostomy.”

7C: I was confident that it would be as same as the treatment process….I thought she mightn’t survive and I have to take care of him.
6.2.2 Ways to learn in providing care for older parents

There were three ways of seeking information to gain knowledge from someone who had experience in providing care for older people with a tracheostomy, including asking for advice from doctors and nurses, observing nurses how to provide care for older parents, and sharing information with family caregivers of other patients. Firstly, adult-child caregivers had to learn about tracheostomy care by asking nurses and doctors for recommendations. They believed that if they gained knowledge and were advised by doctors and nurses about caring activities for older people with a tracheostomy, they could practice and assist their older parents at home after hospital discharge. Adult-child caregivers described:

8C: If it is about relatives, I believe it must be done. I think if I cannot do it, I can ask for advice from both nurses and doctors here. We get the knowledge from here, and then we can practice at home.

10C: When I feed my dad, he choked sometimes. He used to choke one time then I asked the nurse why he was like this. She taught me that I have to test before feeding him. I need to press the stomach to see there is anything inside the stomach or it is empty. After that, I follow her advice.

Secondly, adult-child caregivers still observed the nurses performing caring activities (e.g., rubbing the body dry, feeding, and doing exercise) for older parents with a tracheostomy. They recognized how nurses provided care to older people, and then they could assist their older parents with a tracheostomy as their observations. For example, adult-child caregivers described the following experiences:

3C: Most of the patients have the same symptoms. I noticed why some patients get well soon. Then I take care of my mom the same as they do.

15C: Willingness for learning to assist the patient. Readiness for understanding the patient’s symptom. Recognize how the nurse rubs him dry and helps him to do physical therapy, doing exercise and feeding. I observed how to do it.

Lastly, adult-child caregivers shared the experiences with family caregivers of other patients concerning the patient’s symptoms and how to take care of an older parent with a tracheostomy. Learning from people who have direct experiences helped them get extensive information because doctors and nurses gave them narrow information. Adult-child caregivers described:

8C: We can ask other people besides our bed because they have more experiences than me. I talk about the general topic with them such as where are you from? How about your symptoms? After that, I will ask how they take care of the patient and then they share how they treat the patient to me. We share our experiences with each other. It helps me a lot because
sometimes either doctors or nurses give me narrow information. Learning from people who have direct experience is wider because they are with the patient all the time.

16C: I will worry about cleanliness and take care of the equipment. I used to talk with one caregiver who is next to our bed. He said we need to assist the patient concerning cleanliness. At our home, it is not suitable to be a convalescent home of the patient because there is too much dust. Our house is like a mansion that is not suitable for a patient to live.

6.2.3 Caring activities for older parents

With respect to caring activities for older parents, adult-child caregivers spent time interacting with parental caregiving together with nursing teams in medical-surgical wards. Caring activities were things that they had to perform for assisting their older parents because it was a filial responsibility. Caring activities consisted of basic care, tracheostomy wound cleaning and suctioning, massage and physical therapy, encouragement, and calling the nurse to ask for help. Basic care was about daily routine care to assist and support their older parents with a tracheostomy during hospitalization. They did the basic care that they had never done, such as rubbing the body dry, feeding, changing the diapers, and turning the body. Adult-child caregivers described:

2C: I rub her body and change her clothes. I help her when she passes urine and defecates. The doctor told me to feed her milk through the tube.

6C: I wipe and turn her body regularly because the patients with a tracheostomy cannot breathe by herself. If she does not breathe continuously for more than 1 hour, the brain will not work as it should be, right? That way I always turn her body every 2 hours to protect bedsore.

15C: I have learned things about the patient on the tube, for instance, feeding food and water, rubbing the body dry, and exercising.

Adult-child caregivers experienced cleaning a tracheostomy wound and suctioning phlegm. They wiped a wound around the tube with cotton wool in alcohol or cleaned the blood which seeped from the wound with tissue paper. They sucked the phlegm around the tube using the suction machine, did not suck the phlegm inside the tube. Adult-child caregivers described these experiences in the following quotations:

3C: She has a wound on her neck, and then the phlegm comes out through the wound, which makes the wound stained. I clean it with cotton wool in alcohol around the wound. There is a phlegm suction machine. I use it to suck the phlegm around the tube.

4C: At the beginning, I cleaned the blood when it seeped from the wound. There is the tube on his neck. He feels uncomfortable, and he tried to pull it out. I used the tissue paper to clean the blood around the tube.
17C: I take care of the phlegm suction. Sometimes, the phlegm comes out around the wound. I often use the suction machine to take it off...Suck at around the opened hole.

Adult-child caregivers gave their older parents a massage because older parents had pains and aches, owing to the prolonged bed rest. Meanwhile, they provided physical therapy to older people; it was merely an exercise in lifting arms and legs for older parents. Adult-child caregivers provided the following descriptions:

3C: I massaged her legs and shins. I offer her a bit of physical therapy. I lift and move her arms and legs.
10C: I give him a massage. Also, I do a basic physical therapy like lift his legs and arms up because I cannot lift up his body.

Regarding encouragement, adult-child caregivers stayed beside their older parents to encourage them by talking and holding their hands. They believed that encouragement was the most important for older parents with a tracheostomy because older parents would be comforted and not lonely. Furthermore, talking and holding hands made them and their older parents feel good. Adult-child caregivers gave these examples:

7C: I try to encourage and hold her hands. Unless she was unconscious, we held her hands then we could feel it. In my opinion, if we are here, her mind will come back. She would be comforted and not lonely. Therefore, I often did it.
15C: I encourage my father. When I feed him, I will talk to him or hold his hand to encourage him. I recommend love for taking care of the patients from our heart and encourage them every day. If we can do these things, it will be very good for them and our feeling.

Lastly, calling the nurse was a caring activity of adult children to ask for assistance from nurses. Nurses would be called straightaway when they noticed that older parents did not get breath efficiently, and there was much phlegm in the tube. Nurses would come to the bed to help older people who needed assistance. Adult-child caregivers described:

8C: If the phlegm is not ejected by vomiting, coughing or ejecting through the mouth, it will be around the tube. My dad will point at his neck when the phlegm flows out. I ask him, “too much?” If he says yes, I will call nurses that there is quite a lot of phlegm. However, nurses will come to suction every 2 hours. However, we can ask them to suck the phlegm if it is a lot.

16C: I keep my eyes that he has phlegm or has strange symptoms. Therefore, I can call the nurse straightaway...In case, he has too much phlegm. I used to ask nurses about this. They told me that if I hear the sound of water in the tube, I can call them all the time. If the patient can’t breathe properly, I can call them straight away.
6.2.4 The impacts of caregiving

The impacts of caregiving often resulted from the burden of caregiving, while adult-child caregivers played a responsibility in caregiving for older parents with tracheostomy in medical-surgical wards. Adult-child caregivers were involved in parental caregiving, such as rubbing the body dry, changing diapers, feeding, and turning the body. They had physical, psychological, social, and financial impacts of caregiving which were described as follows:

Regarding physical impacts, adult-child caregivers experience insufficient sleep because they played various caring activities to assist their older parents during hospitalization. They felt tired, confused, and dizzy because of insufficient sleep. However, they had to endure this in order to help their older parents to get well. Adult-child caregivers give examples of this problem in the following:

4C: We will do the best. We are all family. Even though it seems so hard, but it is not our difficulty to do for him. I do not have enough time for sleeping, but I do not mind. I only wish he gets well soon. I love him. I can endure it.

5C: I am tired because my sleeping is not enough. I need to sleep, however, I will be changed by children to take a rest in the afternoon, and I will continue to take care of him all night. I am better at sleeping. I have to see him because of concernment.

19C: Because I work in shift. As I said in the weekdays my shift end at midnight, I need to rest, right? But anyway, I can’t rest because I have to come here to replace my brother. Therefore, I have not enough time to sleep as before. It will be confused and dizzied sometimes.

With respect to psychological impacts, elderly patient’s symptoms affected the psychological aspect of adult-child caregivers who participated in parental caregiving during hospitalization. Elderly patient’s unstable symptoms made adult children stressed because they could not predict whether elderly patient’s symptoms would be better or worse. Adult-child caregivers described:

3C: I have stress about her symptoms. I concern that she would be better for the next day. However, we cannot predict her symptoms. As it ever happened, the previous day she was better but the next day she became worse. It made me stressed.

10C: When he was coughing, it seems he breathe to take the air go inside, but he cannot let it out. I’m so stressed about this. You know what I mean.

Adult-child caregivers were worried about the effect of the tracheostomy tube, suctioning, infection at the wound by a tracheostomy, and cleanliness of equipment if they must go back home. Adult-child caregivers provided the following descriptions:

2C: I worry about how to do phlegm suction if I must go back to home. If I am instructed to use that machine, I’m sure I can do it.
6C: I’m worried that he will be infected. Because of the tube inserted all the time, they can’t breathe by themselves. I’m worried some air pollution outside will get into her lung because it can probably get into the tube that gets through inside directly.

16C: I worry about what will happen after this. If he backs home, I will worry about cleanliness and take care of the equipment.

The social impacts were reflected in the fact that adult-child caregivers had no time to go anywhere and their time for visiting and talking with a friend was reduced. In other words, they had no time to go outside for buying foods and hanging out with friends because they worried about older parents’ symptoms and needed to look after this for their older parents. Therefore, they decided to reduce social activity, as described here:

3C: I worry that there will be any symptoms that occur with her and I don’t mind to hang out. I only go out for buying foods and rush to get home to prepare meals for her and my children. It becomes my routine. And I have no time left to go out.

19C: Like I have to cut down the activities that I used to hang out with friends. I told them that I can’t go because I have to think and do this.

Furthermore, a family problem occurred because the caregiver’s role was not understood. One adult-child caregiver who was a daughter of an older person with a tracheostomy narrated that she had a family problem. Her husband did not understand why she frequently went to the hospital and had to do caregiving so much. This adult-child caregiver described:

20C: It is discouraged. Sometimes, my husband will not understand because I have to get intensive care for my dad in the first period. I frequently go to the hospital. Thus, he will be annoyed and do not get why I have to do too much.

With respect to financial impacts, adult-child caregivers lost income and did not have enough money for caregiving older parents. Adult children’s income was insufficient to support the parental caregiving and themselves because they did not do an overtime job, and someone had to resign from their job to look after hospitalized older parents with a tracheostomy, as shown in the following examples:

15C: In the past, I finished my work at 5 pm and work overtime until 8 pm. I need to sacrifice the time a little bit like working 8 hours and don’t do the OT. I lost my overtime job and came to look after the patient. Working 8 hours a day from 8 am to 6 pm and over time from 5 am until 8 pm, so I lost this OT from 5-8 pm. I lost this part of my income.

16C: My life before I came to do this, I have the daily routine that I have to do my job. Now, everything was changed because I moved to stay at home. My personal life has changed definitely…I resigned from my job even it is not a permanent job. But anyway, I can’t do any job because I have to look after for my dad…I have no income.
6.2.5 Support needs

Adult children were responsible for parental caregiving during hospitalization. Adult-child caregivers needed information support from doctors and nurses and assistance from their relatives. They needed to know exact information from doctors and nurses, concerning older parent’s illness, symptom recovery, any options for treatment, and taking care of the elderly patient with a tracheostomy, as described in the following examples:

11C: I need to know about my mom’s illness. Does she get better or not? I should be okay if I can know my mom’s illness every day.
13C: I need to know if there are any options in the case, the patients do not want to be on a tracheostomy tube. And when they are on the tube, will they be normal?
14C: It is sure that I want to know if the symptom recovers or not, I just want to know.
19C: It’s quite hard such as the phlegm suction. If there is something wrong happened, I do not know how to handle it. I need to know how to take care of them. When we are here, the nurse does this for us. I will notice how they do.

Meanwhile, adult-child caregivers needed to be supported and assisted by relatives when they could not do caring activities by themselves because caring activities were complicated for them. In other words, they needed relatives to replace them for assisting the elderly patients when they felt tired and needed to rest. At the same time, they also needed assistance from relatives when they could not do some caring activities by themselves such as turning the body and cleaning after elderly patients defecated, as described in these examples.

3C: I need to be helped by others because I cannot do them all at the same time. For example, when she is defecating, there must be other assists me, to hold the tube that holding at her neck, then I can help her to stay on her side-lying. Moreover, if her head is lower than her neck, it makes she can’t breathe.
16C: I used to say with myself that why I am only one to do this. As I told you, I am willing to take care of my dad. He is my dad. But sometimes if I was tired and no one helps me here. Therefore, I think it should be okay if my relatives helped me to go back home to rest.

6.3 SPOUSES’ EXPERIENCES OF PROVIDING CARE FOR OLDER PARTNERS WITH A TRACHEOSTOMY

Spouses had various experiences during participation in caregiving for their older partners with a tracheostomy. Spouses’ experiences of providing care for older partners with a tracheostomy are summarized in Table 8. Six themes consisted of the meanings of providing care, feelings of caregivers’ presence, caring activity for older partners, the impact of caregiving, support needs of family caregivers, and the quality of being a good caregiver.
Table 8. Spouses’ experiences of providing care for older partners with a tracheostomy.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
<th>The transformed meaning unit expressions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meanings of providing care</td>
<td>Spousal attachment</td>
<td>Providing care for older partners with a tracheostomy was empirical evidence of spousal attachment as fondness and the quality of the relationship between husband and wife.</td>
</tr>
<tr>
<td></td>
<td>Learning new things</td>
<td>Providing care was the way of learning new things to cope with older partners with a tracheostomy. They had to learn caring activities related to tracheostomy care.</td>
</tr>
<tr>
<td></td>
<td>End of life care for older</td>
<td>Providing care for older partners with a tracheostomy seemed to involve end of life care for older partners. Older partners would die eventually due to tracheostomy performed.</td>
</tr>
<tr>
<td></td>
<td>partners.</td>
<td></td>
</tr>
<tr>
<td>Feelings of caregivers’ presence</td>
<td>Pride</td>
<td>Spouses were proud of caregiver role because they could do everything to help their older partners by themselves.</td>
</tr>
<tr>
<td></td>
<td>Harder care</td>
<td>Spouses though that providing care for an older partner was harder than taking care of the child because older people had a negative change in their health.</td>
</tr>
<tr>
<td></td>
<td>Being afraid</td>
<td>Spouses were afraid older partners would feel abandoned.</td>
</tr>
<tr>
<td>Caring activities for older partners</td>
<td>Daily routine care</td>
<td>They provided care for older partners, comprising of cleaning the body, changing diapers, changing the clothes, feeding, suctioning, and exercising.</td>
</tr>
<tr>
<td></td>
<td>Calling the nurse to ask</td>
<td>Nurses would be asked or called to help them regarding suctioning and managing any problems.</td>
</tr>
<tr>
<td></td>
<td>for help</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Decision making</td>
<td>They had consulted the children and relative when they needed to decide on the treatment for older partners with a tracheostomy because consultation would reduce the conflict in the family.</td>
</tr>
<tr>
<td></td>
<td>Encouragement</td>
<td>They would tell their older partners to keep fighting. Kissing and talking about positive things only was an encouragement to their older partners.</td>
</tr>
<tr>
<td>The impacts of caregiving</td>
<td>Physical impact</td>
<td>They felt tired and dizzy because of insufficient sleep.</td>
</tr>
<tr>
<td></td>
<td>Psychological impact</td>
<td>They were stressed about elderly patients’ severe symptoms</td>
</tr>
<tr>
<td></td>
<td></td>
<td>They were worried about the elderly patient’s illness/symptoms, providing care at home, and taking off a tracheostomy tube.</td>
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<td>They were afraid nurses would blame them for why the relative did not take care of older people.</td>
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<td>They became discouraged when older partners with a tracheostomy did not get better.</td>
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<td></td>
<td>Social impact</td>
<td>They had a reduction in the social friend group.</td>
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<tr>
<td></td>
<td>Financial impact</td>
<td>They had insufficient income to spend for the personal cost of living and caregiving for older partners with a tracheostomy.</td>
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</tbody>
</table>
6.3.1 Meanings of providing care

Spousal caregivers participated in providing care for older parents with a tracheostomy during hospitalization. They described the meanings of providing care, including spousal attachment, learning new things, and the end of life care for older parents.

Based on the strength of the relationship between husband and wife, spousal caregivers described the meaning of providing care for older partners with a tracheostomy as empirical evidence of spousal attachment as fondness and the quality of the relationship between husband and wife. This providing care was not a burden for family caregivers because they used to reside and share the troubles as well as happiness together. Spousal caregivers described:

3S: I think nothing. It is a duty. We live to share help; we live together. We will do the best for us.

12S: I do not know. Love, it is fondness since we were young. I have to take care of him because he looked after my children. My children have to work. If they have free time, the children will represent.

20S: Because of our relationship. By the way, we used to take care and live together as husband and wife... We used to share troubles and happiness. At this time, I have to take care of him.

Spousal caregivers also gave the meaning of providing care as the learning new things to cope with older partners with a tracheostomy. They had no experience involving tracheostomy care. Therefore, they had to learn how to provide care for their older partners with a tracheostomy. Spousal caregivers described:

Table 8. (Continue).

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
<th>The transformed meaning unit expressions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support needs</td>
<td>Knowledge</td>
<td>They needed to know how to assist and cure older partners with a tracheostomy from doctors and nurses.</td>
</tr>
<tr>
<td></td>
<td>Rotation in taking care</td>
<td>They needed to be helped by someone or children to rotate in taking care of the older people with a tracheostomy.</td>
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<tr>
<td></td>
<td>Financial support</td>
<td>Spouses needed financial support from children for expenses in providing care to their older partners.</td>
</tr>
<tr>
<td>Qualities of being a good caregiver</td>
<td>Love to provide care</td>
<td>If they would be a good caregiver for older people with a tracheostomy, they must love to provide care for older people.</td>
</tr>
<tr>
<td></td>
<td>Providing care with sincerity</td>
<td>A caregiver had to do everything about caring activities with sincerity.</td>
</tr>
<tr>
<td></td>
<td>Having self-confidence in providing care</td>
<td>They had to have self-confidence in caregiving for older people with a tracheostomy.</td>
</tr>
</tbody>
</table>
1S: I can do new things that I never do and never see before such as changing diapers and suctioning phlegm. I still cannot do many things right now. I still cannot do many things right now... I will ask nurses what this is and how to use the tube. Nurses always give me instructions and help. Caregiving is the way for learning by myself.

7S: I allow to insert the tube at his neck because it is easier for phlegm suction. It’s more comfortable, isn’t it? Therefore, I decided to go with this way...To be honestly, I don’t know. But the doctors had advised us we need to believe in what he said. Because I have no experience about this. It is my learning new things.

Furthermore, spousal caregivers described that providing care for older partners with a tracheostomy seemed to involve end of life care for older partners. Older partners would die eventually due to tracheostomy performed, as described in these examples.

17S: I thought that doing the tracheostomy is for the last stage for the patient, or something like that. A patient may die. So that is the only thing making me feel worried about caring as it will be last time for taking care of him too.

20S: I think it can continue to his survival, something like this...It does not have the other way to help him so that he can eat and breathe by himself, something like this.

6.3.2 Feelings of caregivers’ presence

When spouses became caregivers for their older partners with a tracheostomy, they described their feelings in the role of caregivers, including pride, harder care, and being afraid. Spousal caregivers were responsible for providing care to their older partners with a tracheostomy. They were proud of caregiver role because they could do everything to help their older partners with a tracheostomy by themselves, as described in these examples.

6S: I am proud to take care of him when he is sick. This is all of human life caring for each other when getting sick... I am proud that I can do everything to satisfy him.

11S: I proud of it that I can do something that some people do not brave to do such as some people are fearful of blood.

Regarding the family caregiver role, spousal caregivers also thought that providing care for an older partner was harder than taking care of the child because older people had a negative change in their health. Spousal caregivers described:

12S: I do not know why did I flatter? He looks like the baby. I have to hold his hand and blow his hand too...It is hard. If he is not obstinate, it is not difficult to take care of him. If he silently sleeps, I can also sleep.

16S: It’s harder than taking care of a child...Because it gets worse only, but for the children, they have positive changes and would like to talk with us every day. But for the
Because the family was everything, spouses should sympathize with older family members with a tracheostomy. Spousal caregivers could not abandon their older partners. Spousal caregivers were also afraid older partners would feel abandoned. Thus, they could not leave older partners with a tracheostomy. Spousal caregivers described:

5S: I sympathize with him and still worry about his though. I am afraid he would think that I am going to abandon him.

19S: It is about spirit. The human mind is different. Some people see the old people as a dead weight and abandon to take care of them. But that is not me. He is the father of my children, and all of them love him. We cannot leave him. We are a family that we have to love each other even though it is tough work.

6.3.3 Caring activities for older partners

Spousal caregivers performed caring activities to assist their older partners with a tracheostomy during hospitalization. They performed various caring activities in daily routine care, asking for help from nurses, decision making, and encouragement. Spousal caregivers participated in providing daily routine care for older partners with a tracheostomy. They assisted their older partners in such activities as taking a bath, wiping the body of the patient who had a high fever, changing the diapers, feeding, suctioning, doing exercise for older partners, and observing the elderly’s breathing, as in the following examples:

2S: I wipe his body, clean, feed food, and give him the medicines. I do every day. I have to take care of the patient by myself, but nurses are responsible for cleaning the tracheostomy wound.

4S: I help him with taking a bath, gently clean his body when getting fever and change diapers. I give him the basic caring the same as taking care of other patients.

14S: For example, inserting the tube for phlegm suction. At first, I’m really afraid when I saw the nurses did it. If we did not do, the patient would not get comfortable. The nurses also asked me “can you do this?” I said “of course” I do not want to wait for their help only, I have to practice and do it by myself.

17S: Feeding food to the patient. Wiping his body when he has a fever. There are other things such as keep my eyes on his breathing, and there is too much phlegm or not.

19S: I help him to do some exercise such as lift his arms and legs, move him to sleep on his’s side, clean up and take care of the wound.

Moreover, when older people had a problem breathing, and there was the phlegm in the tube, nurses would be asked and called by spousal caregivers to assist older partners. They also asked how to assist them, for instance, how to suck out the
phlegm in a tracheostomy tube. Nurses always instructed them in what they needed to know, as in the following examples:

1S: I always ask for help from a nurse when I have to do phlegm suction. When there is some liquid flow out, I will ask nurses what these are and how to use the tube. Nurses always give me instructions and help me do.

18S: I will take care of phlegm suction...If I see something wrong like she can't breathe properly, I will call the nurses straightway. She will get better after the phlegm suction.

In addition, spousal caregivers played a role to be a decision-maker to represent their older partners who could not decide about treatment by themselves. Therefore, spousal caregivers always consulted children or relatives regarding the treatment of older people with a tracheostomy. Decision making in the treatment had to be conducted within the family to find out the agreement and to protect the conflict of opinion.

7S: I consult my children if they agree. We make the decision together...Because we are a family. We have to share ideas together to find out the same agreement. I don’t want to see our conflict. We have to listen to what the doctor says because he knows well about the treatment. We don’t know anything about it, right?

20S: The husband’s sister helps me. We have decision making and think about how to treat him...I consulted a husband’s sister who lives in a foreign country. We had consulted about a tracheostomy.

In the meantime, spousal caregivers deemed older partners who underwent tracheostomy were feeling stressed and discouraged. Thus, they would tell their older partners to keep fighting. Spousal caregivers encouraged their older partners by kissing them and talking only about good things. They believed that encouragement would help their loved one feel comfortable. Spousal caregivers described:

10S: I have to talk with them gently and try to do whatever that does not make him stress. Do not pull him down and talk only the good thing to help him feel good.

18S: I see her look discouraged, then I pray for her and blow her head. I kiss her forehead as well when I back home. I tell her to keep fighting. We will be fighting together to let her know that I will leave her alone. To let her know our sincerity that can encourage her a lot.

### 6.3.4 The impacts of caregiving

The impacts of caregiving appeared on spousal caregivers who were primary family caregivers of older partners with a tracheostomy due to various responsibilities. The burden of caregiving affected their health. The negative impact of caregiving was composed of physical impacts. For example, spousal caregivers felt tired and dizzy because of insufficient sleep. They provided many hours of care for their older
partners with a tracheostomy during hospitalization. Besides, they got a feeling of tiredness and dizziness because of insufficient sleep. Spousal caregivers described:

    10S: Resting is not enough...My physical health is quite bad, honestly. I have a disease, and I have to look after the patient like this. I am quite to worry and think a lot about him. This affects my health quite a lot.

    17S: I do not understand as well. I do not get enough sleeping... I feel dizzy. The blood pressure is up obviously when I ask the nurse to check my blood pressure.

    20S: I am sleepless... I am concerned about him because I have to look after my husband. I am tired, and I must take a nap and wake up to take care of him. It is my feeling.

Regarding psychological impacts, the older patient’s severe symptoms often made spousal caregivers stressed, and they could not leave older partners alone because of worry about the older patient’s symptoms. If spousal caregivers left their older partners and did not intimately provide care, they were afraid nurses would blame them for why family caregivers did not take care of older people. Furthermore, a feeling of discouragement on spousal caregivers had arisen as the result of deteriorating health in older partners with a tracheostomy. In other words, spousal caregivers felt discouraged when their older partners did not get better. Meanwhile, they also worried about tracheostomy care at home after hospital discharge as well, as shown in these examples:

    2S: His blood pressure was decreased severely yesterday. This makes me so stressed. His blood pressure was 54 and nurses told me that it was not good. It is not a good many times.

    5S: I just get out to buy some food sometimes and come back straight away...I am worried about him... I am afraid nurses will blame me for why patient’s relatives do not take good care of the patient. I’m also worried no one will take care of him when he’s hungry and thirsty.

    6S: Before I came to look after for husband, I am a farmer and work on the farm. When I come here, sometimes I feel discouraged. If he gets better, I will be so happy. But as you see, He doesn’t get better.

    9S: If I back home, which one do I have to take off and cleaned? How do I take care of him? This is the first time of my life though. I worry that he will not be cured. Some people used to tell me that it depends on the patient’s condition. The doctor also says, “we can close his hole and take the equipment off. However, it is depended on his physical health.” I’m still worried about how long he has to go with this tube. When will it be taken off?

The social impacts of caregiving on spousal caregivers for older partners with a tracheostomy included reduction in social friend interactions. For example, there were no children to take over for them to care for older partners with a tracheostomy and spousal caregivers had insufficient time to meet friends for doing activities together. Examples of what spousal caregivers described are as follows:
10S: I have to take care of the patient. Also, I have no many children. I have only one son; then there is no one to replace me.

17S: As I have friends and when we used to have a meeting or doing activities together. These activities are gone that I have to cut them out because I have not enough time to join with them.

Spousal caregivers were troubled financially. They had insufficient income to spend on the personal cost of living and caregiving for older partners with a tracheostomy. Expenditure for older partners with a tracheostomy was focused on consumer goods (e.g., diapers, shower cream, powder, and shampoo) and transportation fees while providing care for them. Spousal caregivers described:

1S: I worry more about him. If I had more money, I would like to spend on him. But I do not have enough money. I pay just only for his personal stuff such as diapers, shower cream, powder, and shampoo.

9S: I haven’t worked and have not enough rest. I was troubled financially. I have to pay for housing rent. At the end of this month, I have to pay for his room. Everything comes at the same time. He was sick. I have to pay for the transportation fee. My physical is so exhausted.

6.3.5 Support needs

Spousal caregivers assumed the responsibility to provide care of hospitalized older partners with a tracheostomy. They needed to be supported by doctors and nurses and their family members. Spousal caregivers needed knowledge from doctors and nurses regarding tracheostomy care. For instance, how to assist and cure older partners with a tracheostomy and how long does it take to recover from a tracheostomy. Spousal caregivers gave the following examples:

1S: I should have some knowledge about how to take care of the patient. It is necessary, but I do not know all of them. I still cannot do it perfectly because I am just starting to learn how people do. It just begins and because of my mind.

9S: Absolutely, I would like to know how long it takes, one year or 2 years. How long will it take or when will it be changed?

Some spousal caregivers were responsible for assisting their older partners with a tracheostomy around the clock. They demanded support from family members to rotate or replace them in providing care of hospitalized older people when they felt tired, as the following examples illustrate:

13S: I believe I can keep my eyes on him all the time, when I fell in sleep, I want a person whom I can believe in to replace me. Caregivers taking care of the patient 24 hours may be tired sometimes that they are unable to nurse 24 hours.
17S: The elderly caring needs to be 24 hours. For me, I need some people to rotate because we have to look after for him closer. I don’t want to let him alone.

Because of poverty and insufficient income, they needed to be supported by relatives or children with financial support for living expenses and caregiving for older partners during hospitalization, as these spousal caregivers described:

6S: I want all of the help because we’re from a poor family. I don’t have anything...I don’t know how to say. My relative often helps to take care of him...I bought diapers and everything. If it will be enough, it’s never enough. It’s the life of an employee.
12S: I do not plentifully need it. I need the money to buy the diaper. I called the children to deposit the money to me. My children do not have the money.

6.3.6 Qualities of being a caregiver

Spouses of hospitalized older people with a tracheostomy described the qualities of being a good caregiver as follows: a spousal caregiver had to (a) love to provide care for the elderly patient, (b) do everything about caring activities for their loved one with sincerity, and (c) have the self-confidence in caregiving for elderly patients. This is shown in the following:

1S: I think I can do it. It will be possible if we have more self-confidence. I believe that I can do it. I have the self-confidence to help him suctioning.
5S: I sympathize with him and still worry about his though. I am afraid he would think that I am going to abandon him. My duty is taking good care of my husband. We have to love to do and take care of him.
13S: If we do not think we can help him get better, we should not do it. I do everything with sincerity. I want to make sure everything is clean. I boil all equipment 10-15 minutes before use it. Some people just make it finished by ignoring how clean it is.

6.4 SUMMARY OF THE MAIN FINDINGS

The main findings of family caregivers’ experiences of providing care for hospitalized older family members with a tracheostomy in medical-surgical wards, Thailand are summarized in this paragraph. Adult-child and spousal caregivers participated in providing care along with the nursing team because they felt it was their responsibility. For adult-child caregivers, the meaning of providing care was a filial responsibility to show gratitude to benefactors as older parents with a tracheostomy. For spousal caregivers, providing care showed spousal attachment as the care of the older partner was a responsibility of a husband and a wife, which was a sign of fondness. Moreover, there was the similarity of meanings of providing care among adult children and spouses as family caregivers, providing care was learning new things to cope with older family members with a tracheostomy. Surprisingly, family caregivers also perceived that providing care seemed to involve end of life
care for older people with a tracheostomy. Older people would die eventually due to tracheostomy performed.

With family participation in providing care for older family members with a tracheostomy during hospitalization, family caregivers learned to assist their loved one who underwent tracheostomy by observing and asking for advice from healthcare professionals together with sharing information with caregivers of other patients. The care for older people with a tracheostomy involved activities, such as daily routine care (e.g., cleaning the body, changing diapers, changing the clothes, turning the body, and feeding), tracheostomy care (e.g., suctioning and cleaning the tracheostomy wound), massage and physical therapy, calling the nurses to ask for help, decision making about treatment for older people, and encouragement.

Family caregivers experienced impacts of caregiving, such as tiredness, confusion, and dizziness because of insufficient sleep, stress and worry about older people’s conditions, discouragement, reduction in social interaction, family problems, and insufficient income. They also needed to be supported by healthcare professionals and their relatives. They needed information from doctors and nurses; in particular, they needed to know about elderly patient’s symptoms, treatment, and caring. Assistance from relatives was required; they needed to be supported in assisting with financial support to spend on the personal cost of living and materials needed for caring for older family members with a tracheostomy during hospitalization. Meanwhile, family caregivers needed relatives to be on a roster to support them when they needed to rest when they felt tired from taking care of their older family members. Although providing care was difficult for them, they also felt pride at being a family caregiver for a loved one. Occasionally, they could not go somewhere because they were afraid that older people would feel abandoned to be alone. With being a family caregiver for an older person with a tracheostomy, family caregivers had to have a quality of being a good caregiver, including love to provide care and providing care with sincerity and confidence. The structure of experiences in providing care for hospitalized older family members with a tracheostomy among family caregivers in Thailand is illustrated in Figure 6.
Family caregivers’ experiences of providing care for older family members with a tracheostomy during hospitalization

Ways to learn in providing care
- Asking for advice
- Observing nurses
- Sharing experiences with family caregivers of other patients

Caring activities
- Daily routine care
- Tracheostomy wound cleaning
- Suctioning
- Massage and physical therapy
- Calling the nurse to ask for help
- Decision making
- Encouragement

Impacts of caregiving
- Physical impact (insufficient sleep)
- Psychological impact (stress, worry, fear, and discouragement)
- Social impact (reduction in the social friend group and family problem)
- Financial impact (Insufficient income)

Support needs
- Need to be supported from doctors and nurses (information or knowledge concerning older people and tracheostomy care)
- Need to be supported from relatives (rotation in taking care of older people and financial support)

Meanings of providing care
- Filial responsibility
- Spousal attachment
- Learning new things
- End of life care for older people with a tracheostomy

Feelings of caregiver’s presence
- Pride
- Harder care
- Being afraid

Qualities of being a caregiver
- Love to provide care
- Providing care with sincerity
- Having self-confidence in providing care

Figure 6. The structure of experiences in providing care for older family members with a tracheostomy during hospitalization among family caregivers in Thailand.
7 DISCUSSION

7.1 DISCUSSION OF THE FINDINGS

The aim of this phenomenological study was to describe family caregivers’ experiences of providing care for hospitalized older family members with a tracheostomy. Adult-child and spousal caregivers were responsible for caregiving for older family members with a tracheostomy at medical and surgical wards. Most of the primary family caregivers of older family members with a tracheostomy were informal female caregivers as wives and daughters. There are two reasons to explain this finding, including that family instills into women since they were little girls that they are responsible for caregiving to family members (Tavero et al. 2018), and wives become caregivers of the husband because women live longer than men (Kaakinen et al. 2014). In regard to female caregivers, Maxwell et al. (2007) indicated that seventy-five percent of the family caregivers were female. They looked after their older people who underwent mechanical ventilation in the hospital. According to a previous study by Karaca et al. (2019), the majority of family caregivers of older people with a tracheostomy were middle-aged and primary school graduates. They were adult-child and spousal caregivers and had the burden of caregiving.

7.1.1 Meanings of providing care for older family members with a tracheostomy

Adult-child and spousal caregivers of older family members with a tracheostomy described the meanings of providing care based on family relationship, including filial responsibility and spousal attachment. Providing care was a filial responsibility as a sign of gratitude for benefactors (older parents). Filial responsibility has been defined as a social norm involving an expression of children to assist older parents, including assistance with daily living activities as well as giving moral support and financial support (Chappell & Funk 2012, Aires et al. 2017). Meanwhile, the behaviors of children were determined as an expression of gratitude and a sense of appreciation or thankfulness to their parents who looked after them (Wood et al. 2010, Rothenberg et al. 2017). This finding corroborates the ideas of Mehta & Leng (2017), who explained that caregivers of older people had a powerful sense of filial responsibility that provoked them to continue to assist their older family members. In Thai culture, it is instilled in children to admire older people or persons of high status. Older people are admired and valued (Choowattanapakorn et al. 2004, Knodel & Teerawichitchainan 2017). It is thus not surprising that the meanings of providing care for older parents were filial responsibility and gratefulness to older parents.

On the question of the meanings of providing care for older partners with a tracheostomy among spousal caregivers, this study found that providing care was a part of spousal attachment and expressing fondness, as well as the relationship...
between husband and wife. This finding may be explained by the fact that it is a family relationship, which is performed through an emotional bond (Astedt-Kurki 2010). Spousal relationships involved bonding and were typically closer (Chan & Chui 2011) because older partners lived together and shared their life experiences for many years (Hoppmann & Gerstorf 2009). Furthermore, marital duty-bound roles and responsibilities were an emotional force for spouses to continue their caregiving roles for partners (Holroyd 2005). Likewise, Agard et al. (2015) explained that spousal caregivers committed themselves to care for their partners. They performed various caring activities for the recovery of their partners after critical illness.

Another finding was that providing care involved learning new things to cope with older family members with a tracheostomy. This finding of the current study can be explained by the fact that it was new experiences for informal caregivers. Family caregivers had to take on multiple new roles to take care of older people (Jacelon & Henneman 2014). Therefore, family caregivers attempted to learn skills necessary to assist and support their patients by communicating with the nursing team because medical and nursing knowledge was a crucial factor to increase their confidence in caring for older people (McKiernan & McCarthy 2010). This finding seems to be consistent with the study of Chen et al. (2017), which indicated that family caregivers expected the patient to be dependent on a mechanical ventilator by following the physician’s advice. Physicians and nurses were important persons for promoting family caregivers about decision making in selecting the method of treatment and assisting critically ill patients (LeClaire et al. 2005). However, a study by Stajduhar et al. (2013) explained that family caregivers learned and assisted their patients by applying knowledge and skills from previous experience as well as seeking needed information from books or websites.

Interestingly, adult-child and spousal caregivers perceived that providing care seemed to involve end of life care for older people with a tracheostomy. They thought an older family member who underwent tracheostomy would die eventually. Tracheostomy placement can be associated with significant morbidity and even mortality because of complications that may occur during and after performing tracheostomy (Cipriano et al. 2015). However, this finding does not support the study of Kojicic et al. (2011), which reported that forty-six elderly patients with a tracheostomy remained alive at one-year after hospital discharge. Therefore, it is recommended that health education for family caregivers should be performed by the nursing team to reconcile and increase knowledge about taking care of older people with a tracheostomy.

**7.1.2 Ways to learn in providing care for older family members with a tracheostomy**

Ways to learn in providing care for older people with a tracheostomy were described by adult-child caregivers. The current study found that family caregivers learned tracheostomy care to assist their older family members by observing and asking the physicians and nurses for advice about tracheostomy care, as well as sharing their
experiences with other patients’ caregivers. With learning by observing and asking for advice about caring activities, it was communication between healthcare professionals and family caregivers that enabled understanding and assurance in providing care (Al-Mutair et al. 2014). In accordance with the finding of the current study, Nelson et al. (2005) indicated that physicians and nurses were sources of information in suggesting the patient’s illness, treatments, and prognosis during the use of mechanical ventilation to the family caregivers. Nursing support helped family caregivers become more comfortable with caring for patients at home (Evans et al. 2012).

Sharing experiences with other patients’ caregivers might involve calling support group meetings to encourage the interaction between family members of different families. The benefits of support groups included reducing anxiety and obtaining exact information about medical treatment for their loved ones (Kirshbaum-Moriah et al. 2016). The finding of sharing experiences with other patients’ caregivers corroborates the study of Stajduhar et al. (2013), who described that family members attempted to look for information to gain knowledge for providing care for their patients by asking for advice from relatives and friends. It was a way of learning in seeking out information to help them deal with problems.

7.1.3 Caring activities for older family members with a tracheostomy

Either adult children or spouses were responsible for providing care for older family members with a tracheostomy. Adult-child and spousal caregivers performed various caring activities to assist and support their older family members with a tracheostomy, including daily routine care, tracheostomy wound care, suctioning, giving a massage and physical therapy, decision making, encouraging, and calling the nurse to ask for help. With regard to caring activity, it is the family that is involved in providing care to their patients (Al-Mutair et al. 2013) or caregiving tasks to assist their loved ones (Friedemann & Buckwalter 2014). Likewise, a study of Nayeri et al. (2015) explained that family caregivers needed to get involved in elderly patient care and assist the elderly patient with personal care activities. Family caregivers assisted elderly patients with caring activities such as managing challenges associated with daily routine, changing of position, assisting with mobility, bathing, and feeding (Faronbi et al. 2019). In addition, Karaca et al. (2019) reported that family caregivers of older people with a tracheostomy were trained by the nursing team to increase the knowledge level of caring to assist older people and decrease the burden of caregiving as well.

7.1.4 The impacts of caregiving

Adult-child and spousal caregivers experienced physical, psychological, social, and financial impacts of caregiving while older parents with a tracheostomy were treated in medical-surgical wards. They experience insufficient sleep, stress, worry, fear, discouragement, reduction in social friend interaction, family problems, and
insufficient income. This finding can be explained by the fact that it was a negative impact of caregiving. The burden of caregiving affected their health. Therefore, family caregivers were depressed, stressed, with worse health, social restriction, and more expenses (Vellone et al. 2011). Physical impact of caregiving was due to family caregivers spending many days and many nights in the hospital to look after their family members, so it was a common factor that related to sleep quality or sleep disturbance (Day et al. 2013).

Psychological impacts of caregiving often occurred in family caregivers due to severely ill patients with serious symptoms, so family caregivers explained that they were at high risk of psychological symptoms, such as anxiety and depression (Fumis et al. 2015a, Choi et al. 2016). Fumis et al. (2015b) also reported that family members' psychological symptoms might remain at three months. Discouragement can be a mental health problem in family caregivers, which was a sense of despondency (Schmidt & Azoulay 2012, Scott & Arslanian-Engoren 2002). Regarding the social and financial impact, family caregivers had a reduction in social interaction and insufficient income. These findings seem to be consistent with other studies; some authors have speculated that family caregivers could not abandon their loved one to be alone, so they had to be with their patients all the time. Besides, family caregivers had stopped working to assist their patients. Therefore, lifestyle disruption and employment reduction as insufficient income for expenses tended to be higher in family caregivers (Van Pelt et al. 2007, Evans et al. 2012).

With impacts of caregiving, previous studies have reported family caregivers of mechanically ventilated patients often had multiple physical and mental health issues such as poor sleep quality, fatigue, and stress (Day et al. 2013, Liu et al. 2017). A literature review of Van Beusekom et al. (2016) highlighted the burden of caregiving among informal caregivers of critically ill patients. The findings found that informal caregivers were at risk of anxiety and depression. Loss of financial income and reduced health-related quality of life (HRQoL) frequently occurred.

7.1.5 Support needs

The most important clinically relevant finding was the support needs. Adult-child and spousal caregivers needed to be supported by physicians, nurses, and relatives. They needed knowledge for caregiving older family members with a tracheostomy as well as more information about older parent’s illness/ symptoms recovery and any options for treatment in the future by talking to physicians or nurses every day. In other words, information support was considered to be essential in caregiving. Family caregivers might require information or education support by communicating information with doctors every day to know what was being done for their patients (Bandari et al. 2015). Likewise, Jacob et al. (2016) showed that family members of critically ill patients needed to communicate with a physician every day. The patient’s treatment and recovery were asked and discussed frequently (Czerwonka et al. 2015).
Meanwhile, family caregivers needed to be supported by relatives when they could not perform caring activities by themselves. A possible explanation for this finding may be that complicated caring activities involving a tracheostomy were challenging for family caregivers who were inexperienced in such care. They played the new roles (Frivold et al. 2016) and experienced the impacts of caregiving on their health status (Van Beusekom et al. 2016). Evans et al. (2012) showed that the factors related to family caregivers’ physical ailments included the length of time they cared for their family members, the level of the dependent care they provided, and the increasing age of caregivers. Ailments affected family caregivers’ capacity in their role in providing care for their loved ones. Therefore, it meant that difficulty of caregiving and family caregiver’s health was the cause of the need for support by relatives when they took care of their patients because family caregivers experienced a sense of turmoil and powerlessness associated with severe illness of their family members (Gibbons et al. 2014). Furthermore, family caregivers also needed financial support from relatives to spend for caregiving for older family members with a tracheostomy. It is probably because family caregivers were low-income group. The findings also accord with the study of Bandari et al. (2015), which explained about family caregivers needed to have friends in supporting and dealing with patients and financial problems (Bandari et al. 2015).

7.1.6 Feelings of caregivers’ presence

Pride, harder care, and being afraid were feelings of caregivers’ presence, which obtained from spousal caregivers’ experiences. Those feelings appeared while they participated in providing care for their older partners with a tracheostomy. Although providing care for older partners was laborious, they had a feeling of pride regarding their roles because they could do everything to help their older partners by themselves. These findings emphasize that providing care for older people with a tracheostomy was complex and difficult, as caregiving was not an easy task (Huang & Peng 2010). This finding may support the study of Zeng et al. (2014), which explained that the responsibility and burden for taking care of the elderly by family caregivers were so hard because the elderly had declining physical health status and needed to be supported. However, family caregivers were proud of their role. This feeling was a positive value of caregiving, that is caregiving for the elderly had a positive impact on family caregivers (Lopez et al. 2005, Meisner & Binnington 2017). This finding confirms the idea of Toljamo et al. (2012), which showed that a strong family relationship with the care of the patient was a factor that could predict the positive value of caregiving. Family members’ good relationships affects the capability in caregiving for older people, and it can make family caregivers have feelings of pride in providing care as a positive value of caregiving (Peacock et al. 2017).
7.1.7 Qualities of being a caregiver for an older family member with a tracheostomy

What is surprising is that love, sincerity, and confidence were the qualities of being a good caregiver. Family caregivers had to love in providing care for older partners with a tracheostomy, and they were sincere and confident in providing care for their older partners. These findings can be explained in that confidence refers to beliefs concerning a person’s ability as a caregiver and their own expression of confidence in providing care for older partners. If the family caregiver was confident in caregiving for his/her relative, the confidence might help them improve the capacity of caring more than the person who does not have the confidence (Li & McLaughlin 2012). Sincerity was important in supporting their loved one; it was the family caregivers’ awareness in caring for patients that they assisted them by respecting them. Therefore, family caregivers always performed multiple duties to support their relatives with sincerity as much as they could perform (Snellman et al. 2012).

Based on experiences of adult-child and spousal caregivers participation in caring for their older people with a tracheostomy in medical-surgical wards, Thailand, it is possible therefore that healthcare professionals such as physicians, nurses, and physical therapists should support family caregivers with what they need or are concerned about with respect to caregiving for older family members with a tracheostomy. Physicians and nurses were important persons, who were acknowledged as knowledgeable people or professionals. In nursing care, nurses should be aware of the prior family relationships and perspectives of family caregivers (Jacelon & Henneman 2014).

7.2 THE TRUSTWORTHINESS OF THE FINDINGS

Qualitative data were obtained from the narrative of participants. Therefore, trustworthiness could be enhanced by an application of a strategy concerning the approach and procedures used while conducting research (Chan et al. 2013). In addition, the details of the sampling method and participants’ descriptions were important to be verified for the trustworthiness of the findings from the participants’ narratives (Elo et al. 2014). Generally, there were four main methods—credibility, dependability, confirmability, and transferability—which were conducted to verify the qualitative data (Polit & Beck 2017).

Credibility

Credibility was used to establish confidence involving accurate data. Credibility in qualitative studies was like the validity in quantitative studies. (Polit & Beck 2017.) There were various techniques for developing the credibility of qualitative data. For instance, the researcher used a long period to collect data, namely six months (January to June 2017). The data saturation was achieved by continuing to interview new participants who had direct experience in caring for older family members with
tracheostomy until the participants’ narratives were repetitive from the first interviews (Fain 2015). The prolonged engagement was an essential method to establish trust and find out participants’ experiences (Polit & Beck 2017). Additionally, the researcher was the data collecting instrument and originator of the research process; therefore, experiences of doing qualitative research and working in field of interest were crucial in establishing the trustworthiness of data (Polit & Beck 2017). Regarding the background and personal information of the researcher, the researcher had experiences in nursing care to the critically ill mechanically ventilated patients in a respiratory care unit, teaching nursing students in a hospital about caring for elderly patients with a tracheostomy, as well as using phenomenological methods in the research for the master’s degree about experiences of elderly patients during endotracheal intubation. Qualifications and experience were used for confirming researcher credibility.

**Dependability**

Dependability in qualitative studies was similar to the reliability in quantitative studies. Qualitative research also needs reliability as dependability (Polit & Beck 2017). In this study, the language issue is important, which was scrutinized by the research team for the accuracy of the data. Therefore, the data were translated from Thai to English by a specialist in English, and the data were checked after translation once again by the researcher to protect from loss of meaning (Van Nes et al. 2010). Meanwhile, the Thai and English vocabularies also were discussed in the research team to assure of meaning and ensure the dependability.

**Confirmability**

Inquiry audits were conducted to establish confirmability of the data. It was about a systematic collection of documentation (Polit & Beck 2017). The documents were collected for the trustworthiness of the data. The types of records were necessary for making an audit trail, including: 1) Field notes and interview transcripts—these documents were raw data from participants; 2) Document about data reduction and analysis products—it referred to documents about theoretical notes and documentation on working hypothesis; 3) Process notes—it was methodological notes; 4) Personal notes—it was materials relating to intention and depositing; 5) Instrument development information—it consisted of demographic data form concerning with the elderly and interview guideline; 6) Data reconstruction product—drafts of the final report were collected to assure the reported data. The audit trail or the detail of recorded documents for decisions in doing research were systematized before conducting research and during the research process to assure the quality of the research (Holloway & Galvin 2017).
Transferability

Transferability referred to the process of utilizing the findings of the research. The findings from the data could be transferred to other similar groups or settings (Polit & Beck 2017). For this research, the research methodology, findings, limitations of the study, and recommendations were written clearly to be useful to other researchers in studying other participants or settings. To ensure the transferability of studying, consolidated criteria for reporting qualitative research (COREQ) developed by Tong et al. (2007) was used to appraise the quality of this descriptive phenomenological research before publishing. COREQ checklist consists of 32—items in checking the quality of study about personal characteristics of the researcher(s), the relationship of researcher with participants, theoretical framework, participant recruitment, research setting, data collection, data analysis, and reporting research findings (Tong et al. 2007). The knowledge acquired in this study would be relevant in another and those who carry out the same research in another context (Holloway & Galvin 2017). This study was conducted in the Thai context as cultural care for older people with a tracheostomy appeared in Thailand, which is different from the cultural care of other countries. To grasp the phenomenon of providing care for older people from the family caregivers' perspective, this method of doing phenomenological research can be used as a guideline for studying in other cultures. The findings of this study may transfer to other cultures in utilizing an improvement of a partnership between families and healthcare professionals in providing care for older people with a tracheostomy during hospitalization and after hospital discharge.

7.3 LIMITATIONS OF STUDY

The aim of this study was to describe family caregivers’ experiences of providing care for hospitalized older family members with a tracheostomy. The findings can provide a contextualized understanding of participant experiences as the strengths of qualitative research. Participants coming from only one hospital in Thailand may have implications on the generalizability of the finding to family caregivers in other settings or contexts. Further study could improve the generalizability of findings via larger and representative samples.

In addition, the healthcare system and the cultural care of each country are different. Thai culture instills in Thai people respect for older people, gratefulness, and karma that may differ in other cultures. It is not surprising why Thai family caregivers can perform various tasks to assist older people either at home or in the hospital. In any case, performing caring activities for hospitalized older people by family caregivers was controlled by healthcare professionals to assure safety and quality of care. Therefore, researchers should develop research projects using replications in other cultures. Meanwhile, the perspective of family-centered geriatric care should be applied to enhance the quality of tracheostomy care in older people by the partnership of healthcare professionals and families.
The main points of adult-child and spousal caregivers’ experiences of providing care for hospitalized older family members with a tracheostomy in the Thai context were as follows:

1) Family caregivers participated in caregiving for their hospitalized older family members with a tracheostomy along with the nursing team because the family relationship includes a filial responsibility to be grateful to their older parents, and for the fondness between husband and wife to encourage spouses to provide care for older partner. Therefore, to enhance the quality of tracheostomy care in older people, healthcare professionals should consider the family relationship and how family caregivers perceive their responsibilities for providing care. If it is a weak relationship, it might affect the health care quality and safety of older people with a tracheostomy during hospitalization and at home after hospital discharge.

2) A perspective of the children and spouses as family caregivers was that the care for older people with a tracheostomy was a new experience for them, and they had to learn new things to cope with older people with a tracheostomy. Surprisingly, family caregivers also believed that an older person who underwent a tracheostomy would die eventually as if it was the end of life care of an older family member. Based on the knowledge and belief of family caregivers, it might be a misconception regarding tracheostomy. Therefore, healthcare professionals should negotiate for mutual understanding to family caregivers because knowledge about tracheostomy among family caregivers is insufficient.

3) Family caregivers had various experiences in supporting and caring for their older people who underwent a tracheostomy. They learned to perform caring activities for assisting and supporting their older family members. They observed and asked for advice from physicians and nurses about tracheostomy care, along with sharing his/her experiences with family caregivers of other patients. This situation indicates that the care for an older person by a family caregiver and nursing team is a partnership to enhance the quality of elderly care while obtaining the treatment by tracheostomy.

4) Family caregivers played multiple roles to assist their older people while obtaining treatment by tracheostomy. For instance, they were supporters concerning daily routine care and tracheostomy care, decision-makers about treatment, encouragers, and communicators to ask for help when their older people suffered problems from a tracheostomy. Regarding family caregiver roles, family caregivers indicated that if someone would like to be a good caregiver for an older person, they had to love to play a duty in caring for older people and provide care with sincerity. Moreover, they should have confidence in providing care.

5) There were both positive and negative impacts to caregivers. The positive included learning new things and the pride of caregiving. However, the negative impacts of caregiving often occur, such as poor sleep quality, fatigue, stress, worry,
discouragement, reduction in social interaction, family problems, and insufficient income. Therefore, family caregivers needed to be supported by healthcare professionals and relatives. To reduce the negative impact of caregiving, healthcare professionals should support and help them deal with problems. For instance, information support as health education about tracheostomy care and self-care of family caregivers if they have physical and mental health problems.

6) Family caregivers needed information about the older people’s condition and to gain knowledge regarding tracheostomy care from physicians and nurses. Additionally, they needed family members or relatives to rotate or help them with complicated caring activity. Interestingly, children who took care of their older parents with a tracheostomy received financial support by private funding and family support, so the financial impact was explained a little by children. However, the finding is interesting to note that spousal caregivers who were older adults needed financial support from children because they had low income and were not employed.

7) Based on findings of this descriptive phenomenological research, it manifests family participation in caregiving for hospitalized older people with a tracheostomy. The notion of family-centered care may be applied to elderly care in the hospital setting. Therefore, healthcare professionals (doctors and nurses) should respect to the family caregivers’ perspective, exchange or share information about the therapeutic process of older people, and collaborate in planning and developing the care for older people with a tracheostomy efficiently between the healthcare professionals and family caregiver.
9 RESEARCH IMPLICATIONS

Although the current study is based on a small group of participants, the findings suggest that further research is also needed to develop research projects in family nursing. Furthermore, basic information obtained from this research can be used to develop and improve the guidelines in caring for older people with a tracheostomy and their family caregivers. The following research implications for healthcare professionals, nursing administrators, nursing instructors, and researchers are presented:

1) Healthcare professionals who supervise care for hospitalized elderly patients with a tracheostomy can use the research knowledge for caring and responding to the needs of family caregivers. Caring for an elderly patient is difficult for a family member because the characteristic of an elderly patient differs from the younger patient, that is older age, illness severity, and length of receiving mechanical ventilation are associated with a higher caregiving burden in family caregivers of the elderly patient. Therefore, healthcare professionals should understand family caregivers’ concerns. In addition, in a digital society, healthcare professionals and programmers should originate website or communication technologies to boost social networking among family caregivers for older people. It can be a way to enable family caregivers’ learning about caring for older people with a tracheostomy.

2) Nursing administrators can apply the findings from this study for developing a care plan to guide caring for family caregivers of elderly patients who undergo a tracheostomy. For example: (a) providing information system and support for decision making about performing tracheostomy should be conducted by improving communication between healthcare professionals (e.g., physicians and nurses) and family caregiver; (b) family counseling management system should be conducted to encourage family caregivers who have psychological symptoms from caregiving.

3) Nursing instructors can apply this information to teaching nursing students about family participation in caring for older people, family-centered elderly care, and family nursing. When nursing students practice in gerontological nursing in the hospital, they can use the concept of family-centered geriatric care in assisting and supporting older people with tracheostomy and family caregivers. They should respect the perspective of family caregivers and share useful information between nursing students and family caregivers. Furthermore, they can collaborate with family caregivers to plan elderly care during hospitalization and hospital discharge.

4) Researchers can include this basic information when conducting further research relevant to this topic. Future studies can improve the generalizability of findings via larger and more representative samples, as well as replications because the generalizability of qualitative research is insufficient but rather to provide an understanding of family caregivers’ perspectives about elderly care. The findings of this study can be used to develop research in descriptive and mixed-method designs. For instance, adult-child and spousal caregivers’ perceptions about the burden of
caregiving and needs of the family as well as older caregivers’ health-related quality of life compared to younger caregivers. Additionally, experimental designs and action research should be conducted to enhance the quality of elderly care and families.
REFERENCES


Fain, J. A. 2015. Reading, understanding, and applying nursing research, F. A. Davis Company.


Holloway, I. & Galvin, K. 2017. Qualitative research in nursing and healthcare, West Sussex, Wiley.


## APPENDICES

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<tr>
<td>APPENDIX 8</td>
<td>A consent form to be signed by the subjects</td>
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</table>
Appendix 1

The process of selecting studies for inclusion in the integrative review

823 studies from electronic databases
Database: CINAHL = 197, PsycINFO = 69, PubMed = 266, Scopus = 200, Web of Science = 91
Key word: family, caregivers, elderly, older, aged, geriatric, tracheostomy, mechanical ventilation, ventilator, critical care.
Limits: English language and peer reviewed.

Accepted based on title
N = 77
(CINAHL = 22, PsycINFO = 7, PubMed = 21, Scopus = 18, Web of Science = 9)
Focused on family caregivers of a patient: 1) with a tracheostomy (n = 12); 2) with a mechanical ventilation (n = 39); and 3) in a critical care unit (n = 26).

Excluded based on title
N = 746
(CINAHL = 175, PsycINFO = 62, PubMed = 245, Scopus = 182, Web of Science = 82)
Focused on: 1) family caregivers of a patient with disease or disability (n = 43); 2) family caregivers for pediatric tracheostomy ventilation (n = 40); and 3) critically ill patients with mechanical ventilation or tracheostomy (n = 663).

Excluded duplicates
N = 16
(CINAHL = 4, PsycINFO = 2, PubMed = 5, Scopus = 4, Web of Science = 1)

Excluded based on abstract
N = 36
(CINAHL = 17, PsycINFO = 4, PubMed = 11, Scopus = 3, Web of Science = 1)
Abstract indicated that:
1) Study focused on children or adults with mechanical ventilation (n = 25).
2) Study examined family caregivers of patients with an endotracheal tube or non-invasive ventilation (n = 1).
3) Study aimed to describe family caregivers of patients in a critical care unit, and excluded patients receiving tracheostomy or mechanical ventilation (n = 10).

Accepted based on abstract
N = 25
(CINAHL = 1, PsycINFO = 1, PubMed = 5, Scopus = 11, Web of Science = 7)
Studies included data about family caregivers who provided care for older people with a tracheostomy or prolonged mechanical ventilation.

Excluded based on full text
N = 15
(PubMed = 1, Scopus = 9, Web of Science = 5)
The study was not related to the purpose of the present review or did not satisfy the quality criteria.

Accepted based on full text
N = 10
(CINAHL = 1, PsycINFO = 1, PubMed = 4, Scopus = 2, Web of Science = 2)
The study was related to the review’s purpose and satisfied the study criteria.
# Appendix 2

**Assessment form for appraising the quality of each article** *(Hawker et al. 2002)*

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Good (4)</th>
<th>Fair (3)</th>
<th>Poor (2)</th>
<th>Very poor (1)</th>
<th>Comment</th>
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<tbody>
<tr>
<td>1. Title and abstract</td>
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<td>2. Introduction and aims</td>
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<td>3. Method and data</td>
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<td>4. Sampling</td>
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<tr>
<td>5. Data analysis</td>
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<td>6. Ethics and bias</td>
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<td>7. Results</td>
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<td>8. Transferability or generalizability</td>
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<td>9. Implications and usefulness</td>
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<tr>
<td><strong>Total</strong></td>
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</table>

**Total score = ……………………….**  □ Acceptable □ Unacceptable

1. **Title and abstract:** Did they provide a clear description of the study
   - **Good** Structured abstract with full information and clear title
   - **Fair** Abstract with most of the information
   - **Poor** Inadequate abstract
   - **Very poor** No abstract.

2. **Introduction and aims:** Was there a good background and clear statement of the aims of the research?
   - **Good** Full but concise background to discussion/ study containing up-to-date literature review and highlighting gaps in knowledge. A clear statement of aims and objectives including the research question.
   - **Fair** Some background and literature review. Research questions outlined.
   - **Poor** Some background but no aim/ objectives/ questions or aims/ objectives but the inadequate background.
   - **Very poor** No mention of aims/ objectives. No background or literature review.

3. **Method and data:** Is the method appropriate and clearly explained?
   - **Good** Method is appropriate and described clearly. Clear details of the data collection and recording.
   - **Fair** Method appropriate, the description could be better. Data described.
Poor  Questionable whether the method is appropriate. 
The method described inadequately. 
A little description of the data.

Very poor  No mention of the method, and 
Method inappropriate, and/ or 
No detail of data.

4. Sampling: Was sampling strategy appropriate to address the aims?
Good  Detail (age/ gender/ race/ context) of who was studied and how they 
were recruited. 
Why this group was targeted? 
The sample size was justified for the study. 
Response rates are shown and explained.
Fair  Sample size justified. 
Poor  Most information is given, but some missing. 
Very poor  Sampling mentioned but a few descriptive details. 
No detail of sample.

5. Data analysis: Was the description of the data analysis sufficiently rigorous?
Good  Clear description of how the analysis was done. 
Qualitative studies: Description of how themes derived/ respondent 
validation or triangulation. 
Quantitative studies. Reasons for tests selected hypothesis driven/ 
numbers add up/statistical significant discussed.
Fair  Qualitative and quantitative: Descriptive discussion of analysis. 
Poor  Minimal details about analysis. 
Very poor  No discussion analysis.

6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval 
gained? Has the relationship between researchers and participants been adequately considered?
Good  Ethics: Where necessary issues of confidentiality, sensitivity, and 
consent were addressed. 
Bias: Researcher was reflective and/ or aware own bias.
Fair  Lip service was paid to above (i.e., these issues were acknowledged) 
Poor  Brief mention of issues. 
Very poor  No mention of issues.

7. Results: Is there a clear statement of the findings?
Good  Findings are explicit, easy to understand, and in a logical 
progression. 
Table, if present, are explained in the text. 
Results relate directly to aims. 
Sufficient data are presented to support findings.
Fair  Finding mentioned, but more explanation could be given. 
Data presented relate directly to results.
Poor  Finding presented haphazardly, not explained, and do not progress 
logically from results. 
Very poor  Finding not mentioned or do not relate to aims.
8. Transferability or generalizability: Are the findings of this study transferable to a wider population?

<table>
<thead>
<tr>
<th>Rating</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Good</td>
<td>Context and setting of the study are described sufficiently to allow comparison with other contexts and setting, plus high score in question 4 (sampling).</td>
</tr>
<tr>
<td>Fair</td>
<td>Some contexts and setting described, but more needed to replicate or compare the study with others, Plus fair score or higher in question 4.</td>
</tr>
<tr>
<td>Poor</td>
<td>Minimal description of context/setting.</td>
</tr>
<tr>
<td>Very poor</td>
<td>No description of context/setting.</td>
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</tbody>
</table>

9. Implications usefulness: How important are these findings to policy and practice?

<table>
<thead>
<tr>
<th>Rating</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>Contribute something new and/or different in term of understanding/insight or perspective.</td>
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<tr>
<td></td>
<td>Suggest ideas for future research.</td>
</tr>
<tr>
<td></td>
<td>Suggest implications for policy and/or practice.</td>
</tr>
<tr>
<td>Fair</td>
<td>Two of the above (state what is missing in comments).</td>
</tr>
<tr>
<td>Poor</td>
<td>Only one of the above.</td>
</tr>
<tr>
<td>Very poor</td>
<td>None of the above.</td>
</tr>
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Appendix 3: Studies included in the review covering family caregivers’ experiences in providing care for older people with a tracheostomy (N = 10).

<table>
<thead>
<tr>
<th>No</th>
<th>Reference, Country</th>
<th>Purpose</th>
<th>Participants, Methods, Sampling design, Materials, Data Analysis</th>
<th>Findings</th>
<th>Quality score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Van Kesteren, R. G., Vetvliet, B., &amp; Van Leyden, I. W. (2001). Psychosocial problems arising from home ventilation American Journal of Physical Medicine &amp; Rehabilitation, 80(6), 439-446. (Netherlands)</td>
<td>To study the psychosocial issues and problems of patients who are chronically dependent on artificial ventilation, and their families.</td>
<td>- A total of 38 patients and 43 family members.  - Qualitative (methodology not based on a previously described qualitative approach)  - Randomly selected  - Semi-structured interviews, the Visual Analog Scale was used to measure emotional strain  - Content analysis</td>
<td>Most included patients received respiratory support via a tracheostomy tube. Some of the patients were older people. Family caregivers were spouses providing care for the patients at home. The emotional stress of the family caregivers increased over time. The idea that the patients might urgently require bronchial suctioning at any moment made caregivers very anxious. More than half of the family caregivers (n = 27) reported feeling more tired because of the need to perform bronchial suctioning, accompanied by a feeling of increased isolation. The problems mentioned were medical-technical (n = 12) and psychosocial (n = 24).</td>
<td>24</td>
</tr>
<tr>
<td>2</td>
<td>Douglas, S. L., &amp; Daly, B. J. (2003). Caregivers of long-term ventilator patients: physical and psychological outcomes. Chest, 123(4), 1073-1081. (Ohio, USA)</td>
<td>To describe the characteristics of caregivers and evaluate their depression, burden, overload, and physical health.</td>
<td>- Caregivers of 135 patients receiving LTV admitted to an ICU  - Perspective longitudinal descriptive  - Purposive sampling  - Questionnaire; The Center for Epidemiologic Studies Depression Scale (CES-D)</td>
<td>The family caregivers of patients receiving long-term mechanical ventilation were often spouses (43.7%). 73.3% of the family caregivers were female with a mean age of 54.1. They provided care for patients at home after their discharge. The patients’ mean age was 62.4, and 76% were discharged with a tracheostomy. Family caregivers reported their health as poor. 36.1% of the family caregivers reported a negative change in their health. Mean overload scores were below the scale mean and fell within a range indicating feelings of overburden.</td>
<td>31</td>
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</table>
### Appendix 3 (Continued)

<table>
<thead>
<tr>
<th>No</th>
<th>Reference, Country</th>
<th>Purpose</th>
<th>Participants, Methods, Sampling design, Materials, Data Analysis</th>
<th>Findings</th>
<th>Quality score</th>
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</table>
| 3  | Kaub-Wittemer, D., von Steinbuchel, N., Wasner, M., Laier-Groeneveld, G., & Borasio, G. D. (2003). Quality of life and psychosocial issues in ventilated patients with amyotrophic lateral sclerosis (ALS) and caregivers. | To investigate the quality of life and psychosocial issues in ventilated patients with ALS and their caregivers | - 52 home ventilated amyotrophic lateral sclerosis patients and their caregivers  
- A cross-sectional approach.  
- Did not describe the sampling design  
- Questionnaire: the Profile of Mood States (POMS) and the Munich Quality of Life Dimensions List (MLDL) | All caregivers were spouses, and most were female. They took care of the ALS patients at home. The mean age of ALS patients with non-invasive ventilation (NIV) and tracheostomy ventilation (TV) was 60 and 61.1 respectively. The mean duration of ventilation was considerably higher for TV patients (34.6 months vs. 13.8 months for NIV, P = 0.01). The data showed a good overall quality of life for both NIV and TV patients, but TV caregivers were a very high burden of caregiving. As POMS data, the results revealed the low levels of self-reported depression, fatigue, and anger for both patients and caregivers. The burden of caregiving for the primary caregiver was significantly higher in the TV group than in the NIV group. | 30 |
Appendix 3 (Continued)

<table>
<thead>
<tr>
<th>No</th>
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<th>Participants, Methods, Sampling design, Materials, Data Analysis</th>
<th>Findings</th>
<th>Quality score</th>
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</thead>
</table>
| 4  | Douglas, S. L., Daly, B. J., O'Toole, E., & Hickman, R. L., Jr. (2010). Depression among white and nonwhite caregivers of the chronically critically ill. Journal of Critical Care, 25(2), 364-311-369. (Ohio, USA) | To describe the characteristics of the caregivers of chronically critically ill patients, describe key outcomes (depression, employment, physical health) and examine race as one of several predictors of post-hospital depression symptoms. | - 370 caregivers of survivors of prolonged mechanical ventilation (Nonwhite =118, White = 252)  
- Prospective study  
- Purposive sampling  
- Questionnaire: The Center for Epidemiologic Studies Depression Scale (CES-D), Caregiver health-related quality of life (HRQOL), The Charlson Weighted Index of Co-morbidity, Caregiver demographic - ANOVA, Mann-Whitney U test, Chi-square, and Multiple linear regression | caregivers of ventilated ALS patients, time spent on care of NIV and TV caregivers was 12.6 hours/day and 14.4 hours/day respectively. Both NIV and TV caregivers also had health problems. | 33 |

41% of the caregivers were the sons or daughters and 29% the spouses of the patient. The family caregivers were predominantly female. More than half (57.2%) of all patients were discharged with a tracheostomy. During the two-month post-hospital discharge period, 57 patients (15.4%) who had been alive upon hospital discharge had died. Nonwhite caregivers of patients residing in an institution showed the least improvement in depression over time. Predictors of depression during the two-month post-discharge period were depression during hospitalization (P = .001), sex (P = .019), health status (P = .009), and residence of the patient (P = .001), with no differences based on race. Almost 50% of the employed caregivers had reduced their volume of paid work. There was a significant reduction in physical health status over time (P = .001), with no difference based on race.
### Appendix 3 (Continued)

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<tr>
<th>No</th>
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<tbody>
<tr>
<td>5</td>
<td>Evans, R., Catapano, M. A., Brooks, D., Goldstein, R. S., &amp; Avendano, M. (2012).</td>
<td>To explore the impact of caring for a ventilator-assisted individual on informal caregivers.</td>
<td>- 21 caregivers had provided informal care at home for an invasively ventilated family member with progressive neuromuscular disease.</td>
<td>Informal caregivers had provided care at home for an invasively ventilated family member with a progressive neuromuscular disease for at least 6 months. The family caregivers’ mean age was 45 (range: 30-65). The majority of the primary caregivers were wives of the patient. The impacts included: 1) A sense of duty: the caregiver did not regret their decision to care for their loved one. 2) Restriction of day-to-day life: caregivers felt chained to their house because they were often unable to leave their loved ones and the encroachment on caregiver’s time impacted their employment, equipment and paid care were expensive; and the caregiver role greatly restricted their ability to advance professionally or maintain a job. 3) Physical and emotional burden: increasing levels of patient dependency and increasing caregiver age were mentioned as factors contributing to the physical stress leading to aggravating ailment. Caregivers did not always get enough sleep and were tired. Emotionally, they were unable to speak fluently with their loved one and felt extremely depressed by the situation due to their lack of an independent life. 4) The need for more paid support: the caregivers did not have enough support to give adequate care to their loved one. Caregiver Burden Inventory scores indicated a high level of burden, with a median 49 (interquartile range 39.5 to 53.0) on a scale with a maximum score of 96.</td>
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### Appendix 3 (Continued)

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</table>
- Type of hospital rehabilitation facility  
- Quantitative  
- Purposive sampling  
- The characteristics of both patients and caregivers, Family Strain Questionnaire (FSQ)  
- Descriptive statistics, frequency distributions, Pearson’s correlation coefficient, and analysis of variance for repeated measure | This study involved family caregivers who provided care for patients with a tracheostomy in a hospital. The majority of the family caregivers were female. Family caregivers were spouses, varying in age from 25 to 80 years. Patients’ mean age was 65 ± 9.1 years (range 34 - 86). There were no significant differences in levels of family strain after 3 months and 1 year; the test – retest correlation was 0.69 (p < .01). All family caregivers showed a moderate level of strain, which tended to persist at the same level 1 year later. Knowledge of the disease was also not different between the 3 months and 1-year points; the test – retest correlation of 0.38 (p < .05) showed that the family caregivers continued to need more information about their relative’s disease. The family caregiver’s leisure time appeared to be characterized by restricted social relationships (77.5% never saw friends, and 85.5 % never went to social meetings) and restricted outdoor leisure activities (75% never went to the cinema, walking, or cycling). 94.7 % of the family caregivers said that they felt better when they were caring for the patients. | 25 |
<p>| 7  | Scott, L. D., &amp; Arslanian-Engoren, C. (2002). Caring for survivors of prolonged | This study investigated family caregiver’s perceptions of | - 65 family caregivers derived from a population of patients in tertiary care who underwent a tracheostomy | Most of the family caregivers were wives providing care for their husbands with a tracheostomy at a university-affiliated medical center. The family caregivers were female (93.3%), varying in age from 37 to 70 years. | 24 |</p>
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</table>
|    | mechanical ventilation. Home Health Care Management & Practice, 14(2), 122-128. (Michigan, USA) | caring for individuals who survived tracheostomy for prolonged mechanical ventilation. | - Type of hospital not specified  
- Quantitative  
- Purposive sampling  
- Demographic questionnaire, Caregiver preparation appraisal, the Caregiver Reaction Assessment (CRA), the Mental Health Inventory-5 (MHI-5)  
- Descriptive statistics | The family caregivers reported feelings of enjoyment and gratification from the caregiving role. 60% reported interruptions in their activities. Almost half of the caregivers reduced their participation in family and social interactions and found it difficult to relax due to constant caregiving demands. 27% of the family caregivers reported feeling abandoned by other family members. Financial impact: 60% denied any monetary burden or difficulty paying for caregiving expenses. Physical health: more than half (53%) of caregivers described feeling constantly fatigued. 33% of caregivers reported deterioration in their health status since assuming caregiving duties. Mental health: more than 53% of the caregivers felt anxious, 40% reported experiencing feelings of depression, and 73% reported periods of despondency. | |
| 8  | Nelson, J. E., Kinjo, K., Meier, D. E., Ahmad, K., & Morrison, R. S. (2005). When critical illness becomes chronic: informational needs of patients and | To investigate what information is relevant and important for clinician – patient/family communication when critical illness becomes chronic | - 25 subjects participated (4 survivors, 7 survivors’ surrogates, 4 non-survivors’ surrogates, 10 clinicians)  
- Type of hospital: RCU  
- Grounded theory  
- Purposive sampling  
- Focus groups and structure interviews | The study focused on patients with chronic critical illness being treated in a Respiratory Care Unit. Patients’ mean age was 65 (range: 39-77 years). Family caregivers were spouses, and most were female. The six domains of information for communication and decision-making about chronic critical illness included (1) the nature of the patient’s illness and treatment, (2) prognosis for outcomes including ventilator independence, functional status, and life quality, (3) impact of treatment on patient experience including symptom burden; (4) potential | 31 |
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<tr>
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<td>9</td>
<td>Van Pelt, D. C., Milbrandt, E. B., Qin, L., Weissfeld, L. A., Rotondi, A. J., Schulz, R., . . . Pinsky, M. R. (2007). Informal caregiver burden among survivors of prolonged mechanical ventilation. American Journal of Respiratory and Critical Care Medicine, 175(2), 167-173. (Pennsylvania, USA)</td>
<td>To describe 1-year longitudinal outcome for caregivers of patients who survived Critical illness, and to compare depression risk between caregivers of patients with and without pre-intensive care unit and functional dependency.</td>
<td>- 169 caregivers of patients were divided into two cohorts on the basis of whether the patients were functionally independent (N = 99) or dependent (N = 70) before admission. - Type of hospital; ICU - Cohort study - Purposive sampling - 1) Patient data collection; Acute Physiology and Chronic Health Evaluation (APACHE), Short From -36 Physical Function (SF-36 PF), the Charlson Comorbidity Index score, the Activities of Daily Living (ADL) scale, the Instrumental Activities of Daily Living (IADL) scale,</td>
<td>The majority of patients were male. 41.4% had pre-ICU functional dependency and used a tracheostomy. The patients’ mean age was 64.4. The majority of the family caregivers were female, 53% of them spouses. One third of the caregivers were at risk of depression at 2 months. 28% of the caregivers were employed and 13% indicated that they had stopped working to provide care. Lifestyle disruption was high, with a mean (SD) Activity Restriction Scale (ARS) score of 22.1 (8.5) and moderate or high scores for reported restriction in lifestyle activities (mean 3.5, SD 3.4). Caregivers spent more time helping patients with their IADLs than with their own ADLs. Assistance was provided most often for problem-solving, shopping, laundry, housekeeping, and managing finance. Multiple models identified only the patient’s age (p = 0.005) and paid help (p = 0.049) as significant predictors of caregiver depression risk, indicating that caregivers of older patients and those using paid help had an increased risk of depression.</td>
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<td>10</td>
<td>Maxwell, K. E., Stuenkel, D., &amp; Saylor, C. (2007). Needs of family members of critically ill patients: a comparison of nurse and family perceptions. Heart &amp; Lung, 36(5), 367-376. (Poland)</td>
<td>To explore the difference in the perception of the needs of a family member of a critically ill patient and the perception of nurses and the extent to which these needs were met.</td>
<td>30 critical care nurses and 20 family members of critically ill patients. - Type of hospital; CCU - Descriptive (exploratory design) - Purposive sampling - A demographic questionnaire for the family members, the CCU nurses' demographic tool, the Critical Care Family Needs Inventory (CCFNI), and open-ended questions - Descriptive and inferential statistics.</td>
<td>The mean age of patients related to family members was 60.2 years. Some patients underwent mechanical ventilation in CCU. Family members' mean age was 48 (range: 33–78 years). Seventy-five per cent of the family members (15) were female. Statistically significant differences (p ≤ .05) were demonstrated for nine items of the critical care family need inventory and for 22 items on the needs met inventory. Family members rated all items as being of greater importance than the nurses. Family members’ needs were categorized according to Lek’s dimensions of assurance, proximity, information, comfort, and support. Family members’ needs included getting honest answers to their questions, being assured that the best possible care was given to the patients, getting explanations in understandable terms, feeling that there is hope, and speaking with the patient’s doctor every day.</td>
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Appendix 4

A Fact sheet to the Subjects

Family caregivers’ Experiences of Providing Care for Older Family Members with a Tracheostomy

You are invited to participate in a study conducted by Mr. Watchara Tabootwong, Ph.D. Candidate, Department of Nursing Science, Faculty of Health Sciences, University of Eastern Finland. I am conducting research on family caregivers for older people with a tracheostomy. I am going to give you the information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. There may be some words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. You will be given a copy of this form.

Purpose of the research: There is a growing number of older people with a chronic illness with age-related changes leading to respiratory failure and the utilization of an intubated endotracheal tube with long-term mechanical ventilation. Due to this condition, elderly patients require a tracheostomy tube to assist them with breathing. Family caregivers are providing care for their older family members with a tracheostomy. This research aims to describe the experiences of family caregivers who provide care for older people with a tracheostomy.

The method of collecting data: The data in this research will be collected by interviewing the participants one or two times. Each interview will take approximately 30 to 60 minutes. The interviews will be carried out in a private room at the hospital. If it is better for you, the location will be determined according to your preference. You will be asked to discuss with the researcher about your experiences as a family caregiver providing care for an elderly person with a tracheostomy. If you do not wish to discuss some of the questions during the interview, you may say so and the interview will move on to the next question. The entire interview will be audio-recorded, but no one will be identified by name on the audio recording and no one except the principal researcher will listen to the audio tapes.

The right of the subjects: Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate, all the services you receive at this hospital will continue and nothing will change. If you accept to participate, you will be asked to provide information about the experiences of family caregivers who provide care for an older person with a tracheostomy. Moreover, if you volunteer to be in this study, you may withdraw at any time without consequences of any kind. In that kind of situation, the previously collected data will be used.
Confidentiality: All the information that is obtained in connection with this study and where you could be identified will be proceeding confidentially and the study findings will be reported so that your anonymity is guaranteed. The original data will be stored in a locked cabinet and destroyed after 3 years have passed since the completion of the study. The processed data will be stored in a locked cabinet for 10 years at the Department of Nursing Sciences, University of Eastern Finland.

Payment for participation: the participants will not receive any payment for their participation in this research study.

Contact information: If you have any questions, you can ask them from me now or later. If you wish to ask questions later, you may contact any of the following:

1) Mr. Watchara Tabootwong, Ph.D. Candidate, Department of Nursing Science, Faculty of Health Sciences, University of Eastern Finland, P.O. Box 1627, 70211, Kuopio, Finland, Tel. +358456647757, +66877192391, E-mail: tabootwong@buu.ac.th

2) Main supervisor, Hannele Turunen, Ph.D., Professor, Department of Nursing Science, Faculty of Health Sciences, University of Eastern Finland, P.O. Box 1627, 70211, Kuopio, Finland, E-mail: hannele.turunen@uef.fi

3) A second supervisor, Katri Vehviläinen-Julkunen, Ph.D., Professor, Department of Nursing Science, Faculty of Health Sciences, University of Eastern Finland, P.O. Box 1627, 70211, Kuopio, Finland, E-mail: katri.vehvilainenjulkunen@uef.fi.

4) Collaborators, 1) Pornchai Jullamate, Ph.D., Assist. Professor, Department of Gerontological Nursing, Faculty of Nursing, Burapha University, 169, Long-Hard Bangsaen Road, Tambon Saenook, Amphur Muang, Chonburi, 20131, Thailand, E-mail: pornchait@buu.ac.th and 2) Edwin Rosenberg, Ph.D., Professor, Department of Sociology and Social Work, Appalachian State University, Boone, NC 28608, Email: Rosenberge@appstate.edu
 Appendix 5

The demographic data form concerning the family caregiver

Relationship with the elderly patient  □ Son  □ Daughter
□ Wife  □ Husband

Gender  □ Male  □ Female

Age  ............ years

Marital status  □ Single
□ Couple
□ Divorce

Education  □ Elementary education
□ Secondary education
□ Certificate
□ Diploma
□ Bachelor degree
□ Master degree
□ Doctoral degree
□ Other .................

Vocation  □ Leadership  □ Employee
□ Entrepreneur  □ Agriculture
□ Student  □ Retirement
□ Homemaker  □ Unemployed
□ Other .................

Annual income  □ < 50,000  Bath  □ < 100,000  Bath
□ < 200,000  Bath  □ < 300,000  Bath
□ < 400,000  Bath  □ < 500,000  Bath
□ ≥ 500,000  Bath

Family caregiver's own underlying disease  □ HT  □ DM
□ Hyperlipidemia  □ COPD
□ Osteoarthritis  □ Other........

Length of providing care for the elderly patient  ...........month........day
Appendix 6

Interview guide/ open-ended questions

Would you please, describe
- What kind of everyday experiences you have about providing care for your family member?
- What does it mean to be a family caregiver providing care for a family member who has tracheostomy?
- Why do you provide care for your family member?
- What kind of feelings you have concerning providing care for a family member?
- Have there been some changes in your life whilst being a family caregiver, for example in relation to health, financial situation, social life, hobbies?
- Do you need support for your role as a family caregiver? What kind of support you would prefer?
Appendix 7

Example of data analysis of family caregivers’ experiences of providing care for older family members with a tracheostomy concerning the impact of caregiving.

<table>
<thead>
<tr>
<th>Phases of data analysis</th>
<th>Example</th>
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</table>
| 1) The researcher read the whole data (raw data) several times to obtain a sense of whole data. | **Raw data:**
I do everything such as wipe his body. I have no time to rest or even sleep. I have to wipe his body frequently because he feels so hot inside. Sometimes I haven’t slept at night because I have to do this. Resting is not enough. My physical health is quite bad, honestly. I have a disease and I have to take care of the patient like this. I do not sleep at all. If I feel dizzy, I will shortly take a rest. After that, I will continue to take care of him and take a rest again after everything is completely done. I’m quite to worry and think a lot about him. This affects my health quite a lot. I’m worried he is going to be normal or not. If it does not, I want him to get better. So that would be our burden. If he just sits or sleeps without using the tube anymore. It will comfortable for me to wipe and clean his body. It would be better. I worry just only this. His blood pressure was decreased seriously yesterday. This makes me so stressed. His blood pressure was 54 and nurses told me that it was not good. It’s not a good many time. I feel discouraged sometimes. I have looked at him. I think he is suffering but we can do nicely. We try to do everything as finding the best doctors to treat him and he would get better. I haven’t worked and have not enough rest. I was troubled financially. I have to pay for house renting. At the end of this month, I have to pay for his room. Everything comes at the same time. He was sick and I have to pay for the transportation fee. I have to pay for the diaper. At least 2 night, the diaper is clear. My children deposited some money at 400 – 500 Bath for buying the diaper. I do not dare to buy some foods for eating because I have to keep the money. All of my time, I give it to him. I have to tell him all the time where I am going. He always looks at me when I am going to leave. This is the reason that I cannot leave him alone. As I have friends and when we used to have a meeting or doing activities together. These activities are gone that I have to cut them out because I have not enough time to join with them. |
<table>
<thead>
<tr>
<th>Phases of data analysis</th>
<th>Example</th>
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<tr>
<td>2) The researcher discriminated the meaning units.</td>
<td>Raw data were divided into the meaning units (MU):</td>
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<tr>
<td>MU1:</td>
<td>I do everything, such as wipe his body. I have no time to rest or even sleep. I have to wipe his body frequently because he feels so hot inside. Sometimes I have not slept at night because I have to do this.</td>
</tr>
<tr>
<td>MU2:</td>
<td>Resting is not enough. My physical health is quite bad, honestly. I have a disease and I have to take care of the patient like this.</td>
</tr>
<tr>
<td>MU3:</td>
<td>I do not sleep at all. If I feel dizzy, I will shortly take a rest. After that, I will continue to take care of him and take a rest again after everything is completely done.</td>
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<tr>
<td>MU4:</td>
<td>I’m quite to worry and think a lot about him. This affects my health quite a lot.</td>
</tr>
<tr>
<td>MU5:</td>
<td>I’m worried he is going to be normal or not. If it does not, I want him to get better. So that would be our burden. If he just sits or sleeps without using the tube anymore. It will be comfortable for me to wipe and clean his body. It would be better. I worry just only this.</td>
</tr>
<tr>
<td>MU6:</td>
<td>His blood pressure was decreased seriously yesterday. This makes me so stressed. His blood pressure was 54 and nurses told me that it was not good. It’s not a good many time.</td>
</tr>
<tr>
<td>MU7:</td>
<td>I feel discouraged sometimes. I have looked at him. I think he is suffering but we can do nicely. We try to do everything as finding the best doctors to treat him and he would get better. I haven’t worked and have not enough rest.</td>
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<tr>
<td>MU8:</td>
<td>I was troubled financially. I have to pay for house renting. At the end of this month, I have to pay for his room. Everything comes at the same time. He was sick and I have to pay for the transportation fee.</td>
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<td>Phases of data analysis</td>
<td>Example</td>
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<tr>
<td>MU9: I have to pay for the diaper. At least 2 night, the diaper is clear. My children deposited some money at 400 – 500 Bath for buying the diaper. I do not dare to buy some foods for eating because I have to keep the money.</td>
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<tr>
<td>MU10: All of my time, I give it to him. I have to tell him all the time where I am going. He always looks at me when I am going to leave. This is the reason that I cannot leave him alone.</td>
<td></td>
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<tr>
<td>MU11: As I have friends and when we used to have a meeting or doing activities together. These activities are gone that I have to cut them out because I have not enough time to join with them.</td>
<td></td>
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<tr>
<td>3) The researcher transformed the discriminated meaning units into the nursing language for possible categories.</td>
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<tr>
<td>Transforming the discriminated mining units into the language of nursing discipline:</td>
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<tr>
<td>TU1: I provide care for my older partner. For example, I wipe his body frequently when he has a high fever at night. It makes me insufficient sleep.</td>
<td></td>
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<tr>
<td>TU2: I have to take care of the patient. Insufficient sleep affects physical health.</td>
<td></td>
</tr>
<tr>
<td>MU3: I have an insufficient sleep. If I feel dizzy, I will shortly take a rest. After that, I will continue to take care of him and take a rest again after the caring activity is completely done.</td>
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</tr>
<tr>
<td>TU 4: I have the psychological impact of caregiving. I am worried about him.</td>
<td></td>
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<tr>
<td>TU5: I am worried about his symptoms as it will be stable or unstable. If it is unstable, it would be our burden. I want him to get better. If he can sit and without the use of the tracheostomy tube. It will be comfortable for me to wipe and clean his body. It would be better. I worry only this.</td>
<td></td>
</tr>
<tr>
<td>Phases of data analysis</td>
<td>Example</td>
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<tr>
<td><strong>TU 6</strong>: His blood pressure was decreased seriously yesterday. Nurses told me it was not better. His symptom makes me stressed.</td>
<td></td>
</tr>
<tr>
<td><strong>TU7</strong>: I feel discouraged when he suffers from his symptoms. I attempt to do everything as seeking for the best doctors to treat him. He would get better. I resigned from my job and I am not getting enough rest.</td>
<td></td>
</tr>
<tr>
<td><strong>TU8</strong>: I have the financial impact of caregiving. I must pay for a rental house and for the transportation fee when he was sick and treated in hospital.</td>
<td></td>
</tr>
<tr>
<td><strong>TU9</strong>: My children made a deposit of 400 – 500 Bath to me for buying the diaper. At least 2 night, the diaper is clear. I do not need to buy some foods for eating because I need to save money.</td>
<td></td>
</tr>
<tr>
<td><strong>TU10</strong>: I spend the time to provide care for him. I cannot leave him alone.</td>
<td></td>
</tr>
<tr>
<td><strong>TU11</strong>: I used to meet friends to do activities together. Nowadays, social interaction is reduced because I am responsible for providing care for my partner in the hospital.</td>
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4) The researcher synthesized the transformed meaning units into general structural descriptions.

Family caregivers experience the physical, psychological, social, and financial impact of caregiving. The physical impact of caregiving included insufficient sleep. Insufficient sleep made them dizzy. The psychological impact of caregiving, spousal caregivers were worried and stressed about older people’s symptoms. In addition, they felt discouraged when their older people with a tracheostomy suffered from their own symptoms, and older people did not get better. The social impact of caregiving, they spent all the time to provide care for hospitalized older people. Therefore, they could not meet friends as a reduction in social interaction. The financial impact of caregiving, they resigned from a job to provide care for older people. The income was insufficient. Thus, they needed to save the money for spending on stuff in the care of older people with a tracheostomy.
A consent form to be signed by the subjects

Family caregivers’ Experiences of Providing Care for Older Family Members with a Tracheostomy

I have been invited to participate in research about the experiences of family caregivers in providing care for older family members with a tracheostomy.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions. I have been asked, have been answered to my satisfaction. I understand that participation in the study is voluntary and that I have the right not to participate and the right to withdraw my consent at any given time without giving a reason. In that kind of situation, the previously collected data will be used. I also understand that all information given will be confidential.

Print Name of participant __________________

Signature of participant __________________
Date __________________
	Day/month/year

If illiterate

The information has been read to me by researcher and the individual has had the opportunity to ask questions. I understand that participation in the study is voluntary and that I have the right not to participate and the right to withdraw my consent at any given time without giving a reason. In that kind of situation, the previously collected data will be used. I also understand that all information given will be confidential.

Thumbprint of participant

Print Name of participant
Date __________________
	Day/month/year
The aim of this study was to describe adult-child and spousal caregivers’ experiences of providing care for older family members with a tracheostomy during hospitalization. The findings indicated how adult-child and spousal caregivers coped, and how they needed to be supported during the care for older family members as they were hospitalized. Although providing care for older family members could be difficult, they were willing to participate in taking care of their loved ones. In other words, family participation in assisting older family members during hospitalization is a significant partnership between the health care team and family to enhance the quality of caregiving for older people.