

The Association between Coping Strategies Utilized and Quality of Life among Thai Family Carers of Persons Living with Dementia Residing in Community

by

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Abstract

Background: Caring for persons living with dementia is complex, and there is a great cost associated with caregiving. Many family carers are at an increased risk of deteriorated physical and psychological outcomes. However, the numbers of Asian studies concerning the association between coping and quality of life (QOL) in family carers of persons living with dementia are limited. Less still is known about Thai family carers. Therefore, research is needed regarding the association between types of coping strategies utilized by carers and their QOL as a foundation to develop interventions that enhance carers coping skills and QOL.

Purpose: This dissertation aimed to identify the association between coping and QOL in Thai family carers of persons living with dementia. We hypothesized that, after adjusting for covariates including carer characteristics and carers' stress and social support, problem-focused coping and positive emotion-focused coping would have a strong, positive association with QOL; while, negative emotion- focused coping would have a strong, negative association with QOL.

Methods: The dissertation consists of four related papers: (1) a systematic literature review to identify factors that influence coping among Asian family carers of persons living with dementia, (2) a conceptual framework of stress and coping, which includes key variables that influence coping, distinguishing between positive and negative emotion-focused coping, (3) a methods paper that described the challenges and strategies used to recruit participants in this study, and (4) a cross-sectional, quantitative, correlational study to examine the association among problem-focused, positive emotion-focused, and negative emotion-focused coping strategies with QOL among Thai family carers of persons living with dementia. In the quantitative study, participants were recruited using a multi-pronged approach. The participants completed a demographic form

and measures of coping styles (Thai Brief COPE), quality of life (WHOQOL-BREF-Thai), perceives stress (ThaiPSS-10), and perceived social support (Thai-MPSS) either online, mail/paper or via telephone interview. Hierarchical multiple regression analysis was used to determine the association between types of coping strategies utilized and QOL scores, adjusting for carer characteristics and carers' stress and social support.

Findings: There were eighty-six participants (mean age 52.84 years), and the majority were female (87.2%). In bivariate analysis, total QOL scores were positively correlated with problem-focused coping ($r = .188, p < .05$), positive emotion-focused coping ($r = .390, p < .001$), and negatively correlated with negative emotion-focused coping ($r = -.216, p < .05$). After adjusting for covariates, hierarchical multiple regression revealed that only positive emotion-focused coping demonstrated a statistically significant association ($p < .1$) with total QOL scores ($\beta = 0.179, p = .08$). Problem-focused coping and negative emotion-focused coping were not significantly associated with total QOL scores of Thai family carers of persons living with dementia.

Conclusions: The findings of a significant association between positive emotion-focused coping and QOL have implications for the development of carer coping interventions to improve QOL. Nurses should encourage carers to use positive emotion-focused coping strategies (e.g., positive reframing, acceptance, and emotional support), as these strategies were found to be helpful in enhancing carers' QOL.

Preface

The quantitative study in Chapters 4 and 5 received ethics approval from the University of Alberta Research Ethics Board, Project Name “The Association between Coping Strategies Utilized and Quality of Life among Thai Family Caregivers of Persons Living with Dementia Residing in Community,” No. Pro00102422, July 28, 2020. Furthermore, ethics approval was obtained from the Ethical Review Committee for Human Research, Faculty of Public Health, Mahidol University, Thailand (MUPH 2020-123), October 14, 2020, and the Institutional Review Board of the Faculty of Medicine, Chulalongkorn University, Thailand (IRB 028/64) February 22, 2021.

Four manuscripts were prepared by Lalita Kaewwilai and the supervisory committee as co-authors. Four manuscripts are in various stages of publication. Chapter 2 of this dissertation was submitted to the International Journal of Older People and is currently under review. Chapter 3 of this dissertation was submitted to the International Journal of Care and Caring and is currently under review. Chapter 4 of this dissertation was submitted to the Journal of Advanced Nursing. Chapter 5 of this dissertation was submitted to the Dementia. In each manuscript, I was responsible for study conceptualization and design, data analysis, drafting, and revision of the manuscript. HM O’ Rourke, W Duggleby, and A Santos Salas contributed to study conceptualization and design and revision of manuscript drafts for important intellectual content.

Dedication

This dissertation is dedicated to the memory of my father, Somnuk Kaewwilai, who encouraged me to pursue my doctoral degree. He has been an inspiration for me to work on dementia and caregiving research. To my mother, Amporn Kaewwilai, you have provided me constant love, encouragement, and unwavering support. I am so grateful for all the values you have instilled in me. To my brother, Poomson Kaewwilai, thank you for taking care of Mom and Dad when I was away from home to pursue my doctoral degree; you kept me going on this work. To my husband, Mongkol Akko, you have allowed me the time to complete this work and reminded me to maintain healthy habits. I also dedicate this work and give special thanks to Thai family carers of persons living with dementia who took part in the study and enabled this work to be possible.

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Chapter 1. Introducing the Problem

Dementia is a major cause of disability and dependency among older persons, as it affects cognitive, social, and physical function (Alzheimer's Disease International, 2014). In 2017, there were approximately 11 million older persons in Thailand, or 16.7% of the total population (National Statistical Office of Thailand, 2018). As the proportion of older people in the population grew, so too has the number of persons living with dementia. To date, the health care system and social support from both the government and private sectors in Thailand have not yet sufficiently responded to the need for providing care for the older population (Phetsitong et al., 2019). In Thailand, family members (e.g., adult child or spouse) play a significant role in caring for persons living with dementia (Chuakhamfoo et al., 2020). Caring for persons living with dementia is complex, and there is a significant cost associated with caregiving (Schulz et al., 2020). Family carers of persons living with dementia have more anxiety, stress, and depression than non-carers (Farina et al., 2017). In addition, caring for persons living with dementia has more negative impacts than caring for people living with other disorders (Farina et al., 2017). One study in Thailand found that the quality of life (QOL) of Thai family carers of persons living with dementia was significantly lower than non-carers (Lamliangpon, 2015). Therefore, carers require coping skills to deal with the challenges of caregiving. As well, coping skills may mitigate the negative impact on their QOL. Most of the research on coping and QOL has been conducted in Western countries, and the numbers of Asian studies concerning the association between coping and QOL in family carers of persons living with dementia are limited, particularly in Thai family carers of persons living with dementia (Kaewwilai et al., submitted manuscript, 2021).

Therefore, research is needed regarding the association between types of coping strategies utilized by carers and their QOL as a foundation to develop interventions that enhance carers' coping skills and QOL. My dissertation aims to improve understanding of how carers could benefit from using specific coping strategies to improve their QOL.

This chapter provides a brief overview of my dissertation. I will describe gaps in our knowledge and my motivation to study coping and QOL. I will introduce the four dissertation papers and explain the linkage between each dissertation paper.

Key Terms

Dementia: An overall term to describe cognitive symptoms caused by any one of several diseases (e.g., Alzheimer's disease, Lewy Body dementia, Frontotemporal dementia, or Vascular dementia) that have slightly different manifestations and consequences depending on what parts of the brain are affected. Dementia is a chronic disease of the brain that results in impairment to short and long-term memory, abstract thinking, judgment, or personality changes. It interferes with one's ability to work and participate in social activities or relationships with others (Feldman et al., 2008).

Persons living with Dementia: Individuals living with the symptoms of dementia.

Family carers: Family members or friends of a person living with dementia who provide unpaid care for the person living with dementia. These carers may perform tasks such as assistance with bathing, dressing, meal preparation, housekeeping, transportation, and managing finances. In addition to these physical tasks, family caregiving can also include an emotional connection to the care receiver and the provision of psychosocial support (Peacock et al., 2013).

Coping: Behavioral and emotional strategies people use to manage stressful life situations (Lazarus & Folkman, 1984).

Problem-focused coping: Helpful strategies that directly address the stressful situation, including active coping, instrumental support, and planning (Lloyd et al., 2018).

Positive Emotion-focused coping: Helpful strategies that are used to manage emotional reactions and feelings of distress, including acceptance, emotional support, humor, positive reframing, and religion (Lloyd et al., 2018).

Negative Emotion-focused coping: Unhelpful strategies that are used to manage emotional reactions and feelings of distress, including behavioral disengagement, denial, self-distraction, self-blame, substance use and emotional venting (Lloyd et al., 2018).

Quality of Life (QOL): An individual's satisfaction with their own life, assessed in the context of one's culture, values, goals, expectations, standards, and concern (World Health Organization, 2020).

Filial piety: Asian cultural beliefs regarding respect and obligations to assist their parents (Kim et al., 2015). It has shaped intergenerational relations and family caregiving in Thailand.

Common theoretical frameworks in the study of coping among Asian Carers

As dementia advances, the person's ability to carry out activities of daily living will decline, eventually results in the person needing assistance to undertake even simple activities (Pot et al., 2013). Most of the care responsibility will fall on family members (e.g., spouses, adult children). In Thailand, most of persons living with dementia are being taken care at their own home by family members, particularly by children or a spouse (Pothiban et al., 2020). Filial piety is a social and moral obligation of Thai children to care for their parents. Therefore, to understand carer's stress and coping in Thai contexts of family caregiving, there is a need for a theoretical approach to guide research. However, none of the theories developed in Western countries have been used to explain the Thai unique caring culture. Kim et al. (2018) reviewed

studies on carers' caring for adult patients to identify the application of nursing theories to the Korean culture of caring. This review found that the application of nursing theory to the caregiving experience and carers' QOL has been lacking (Kim et al., 2018). Lazarus and Folkman's (1984) theory of stress, appraisal, and coping, and House and George (1980) theory of family caregiver stress coping was the most commonly used theory in Korean caregiving research (Kim et al., 2018). We examined 27 studies focusing on Thai carers of persons living with dementia. Of the 27 studies, only 13 studies utilized theory to guide their studies. Two studies utilized the Stress and Coping framework by Lazarus and Folkman (1984) (Hengudomsub et al., 2016) and Pearlin's Stress Process Model (Ondee et al., 2013) to guide stress and coping research in Thailand with carers of persons living with dementia. Therefore, in this dissertation, a conceptual framework of stress and coping, developed based on the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) and the Caregiver Stress Process Model (Pearlin et al., 1990) was used to examine stress and coping of Thai carers of persons living with dementia.

The Thai Setting

Asia is the largest of the world's continents, and included countries are determined by geographic definitions according to the United Nations Statistics Division. The regions of Asia include Central Asia (Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan, and Uzbekistan), East Asia (China, Hong Kong, Japan, Macau, Mongolia, North Korea, South Korea, and Taiwan), Northern Asia (Russia), Southern Asia (Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka), Southeastern Asia (Brunei, Cambodia, Indonesia, Laos, Malaysia, Myanmar, Philippines, Singapore, Thailand, Timor-Leste, and Vietnam), and Western Asia (Armenia, Azerbaijan, Bahrain, Cyprus, Georgia, Iran, Iraq, Israel, Jordan, Kuwait,

Lebanon, Oman, Palestine, Qatar, Saudi Arabia, Syria, Turkey, United Arab Emirates, and Yemen) (United Nations Statistics Division, 2013).

Asian peoples have a varied and diverse mix of cultures, values, and practices. Thailand is geographically located in Southeast Asia, and Thai people also share some common cultural values e.g., filial piety, as with some other groups from other Asian countries. However, Thailand also has unique characteristics such as the Thai language. Thais' social values also tend to be more collectivist and religious, as Thailand is the only country in Southeast Asia that has never been colonized by a Western country (Chunuan et al., 2007; von Feigenblatt, 2009). For example, cultural values of mutual dependence and reciprocity, moral indebtedness, and a sense of obligation are strong themes in Thai culture (Chunuan et al., 2007). However as there is limited scientific literature regarding Thai family carers of persons living with dementia, in this dissertation, we also explored research studies that were completed within other Asian countries. This helped to identify gaps in the broader literature and to contextualize this dissertation's findings and contributions.

The total population in Thailand was estimated at 66.2 million people in 2020 (National Statistical Office of Thailand, 2020). The majority of Thais are Buddhist (94.2%), followed by Muslims (4.6%) and other religions (National Statistical Office of Thailand, 2018). Beliefs and cultural values which come from Buddhism are social norms in Thai society. The concept of filial piety refers to cultural beliefs regarding respect and obligations to assist their parents (Kim et al., 2015), and it is a fundamental value in Thailand's culture and other Asian countries, substantially impacting people's lives and the parent-child relationship (Lai, 2009). Adult children have to respect and taking care of older parents (Knodel et al., 2018). Closely linked to this value of filial piety, in Asian cultures, caregiving is mostly a social obligation and also a

culturally appreciated practice (Miyawaki, 2015). For example, in Thai families, children have to show respect and take care of older persons. Children who neglect their parents are blamed by society (Knodel & Chayovan, 2011).

In Thailand, adult children, particularly daughters, provide care and practical assistance for older persons (Knodel & Chayovan, 2011). With increasing life expectancy, the number of persons living with dementia also increases. Currently, there are 11.3 million older adults living in Thailand (National Statistical Office of Thailand, 2020) and 600,000 people living with dementia, although dementia remains underdiagnosed in Thailand (Alzheimer's Disease International, 2014). However, a small number of hospitals have multidisciplinary programs to provide support for both persons living with dementia and carers. These hospitals are mainly located in big cities (Griffiths & Bunrayong, 2015). The majority of older persons in Thailand still live with their families, and increasing numbers of older persons combined with decreasing family size and increased out-migration of adult children raise concerns about the ability of family members to provide care for older persons (Knodel et al., 2018). Thus, it is important to ensure that family members can cope with caregiving challenges and maintain their QOL.

Thailand's setting provides an opportunity to study the association of coping and QOL. Based on our systematic literature review, no studies have examined the association of coping and QOL among Thai family carers of persons living with dementia (Kaewwilai et al., submitted manuscript, 2021). Most of the research on coping and QOL has been conducted in Western countries.

Researcher Motivation and Positioning

My research work originated from my own experience of being a daughter of a father with dementia. Being a family carer for ten years gave me insights into disease progression and

the challenges in caregiving. Carers are being burdened with the responsibility to deal with changing behaviors, increasing levels of dependency of persons living with dementia, as well as a sense of grief and loss, which leads to frustration and guilt. However, I observed that formal care for persons living with dementia was focused on the patient and did not support family carers. I had expected that individual consultation or other therapies that could help carers to cope with caregiving challenges would be provided. The literature also supported what I observed: Thai carers of persons living with dementia need dementia-related information, a broader range of services, e.g., training and consultation, and improved access to health professionals (Griffiths & Bunrayong, 2015; Muangpaisan et al., 2010). There is some evidence that the support needs identified by Thai carers are consistent with carers' needs identified in other countries. For example, the national dementia strategy in Canada has extended a broad scope to improve the QOL of persons living with dementia and carers. In addition, carer needs were identified, such as financial and educational support (Canadian Nurse Association, 2016; Public Health Agency of Canada, 2019). My career goal is to develop an online intervention to improve QOL for Thai family carers of persons living with dementia. However, there were insufficient numbers of studies to support the development of an intervention. From the literature review, I realized that there was a need to understand coping in this population first.

My motivation to study coping and QOL was strengthened by what was written in the literature, as it suggested that carers have to adapt to multiple caregiving challenges. In stressful situations, carers often use problem-focused coping strategies to solve problems or emotion-focused coping strategies to manage their emotional response (Lazarus & Folkman, 1984). For example, a meta-analysis of, which included studies from developed, English speaking countries (n=30), Taiwan (n=2), the Netherlands (n=1), Belgium (n=1), Taiwan (n=1), and China (n=1),

found that positive emotion-focused coping was associated with less anxiety and depression, and negative emotion-focused coping was associated with more anxiety and depression in carers of the persons living with dementia (Li et al., 2012). Problem-focused coping was not associated with carers' psychological health (Li et al., 2012). In contrast, two literature reviews of carers of persons living with dementia in non-Asian countries found that problem-focused coping had positive implications for carers' psychological health (Gilhooly et al., 2016; Kneebone & Martin, 2003). Findings from Asian countries have been completed in China, India, Iran, Japan, Singapore, and South Korea. In Asian countries, one study conducted in China reported a positive association between total coping scores and psychological health (Liu et al., 2012). Five studies reported that positive emotion-focused coping was associated with better psychological health (Jeong et al., 2018; Morimoto et al., 2019; Pattanayak et al., 2011; Saffari et al., 2018; Tay et al., 2016). Problem-focused coping was associated with better psychological health (Jeong et al., 2018; Pattanayak et al., 2011; Tay et al., 2016), while another study found that problem-focused coping was associated with lower psychological health (Morimoto et al., 2019). These findings reflect the results of just six studies, which have produced inconsistent findings, particularly in relation to the association between problem-focused coping and QOL. Two of the six studies examined the association between caregiving coping and QOL without adjusting for potential confounding variables.

There is, therefore, limited evidence that explores the different types of coping strategies and their association with QOL among Asian family carers, and no studies that explored the association between coping and QOL among Thai family carers of persons living with dementia. The findings from this study on influencing factors and the association between coping strategies utilized and QOL by Thai family carers will begin to fill this knowledge gap. Such knowledge is

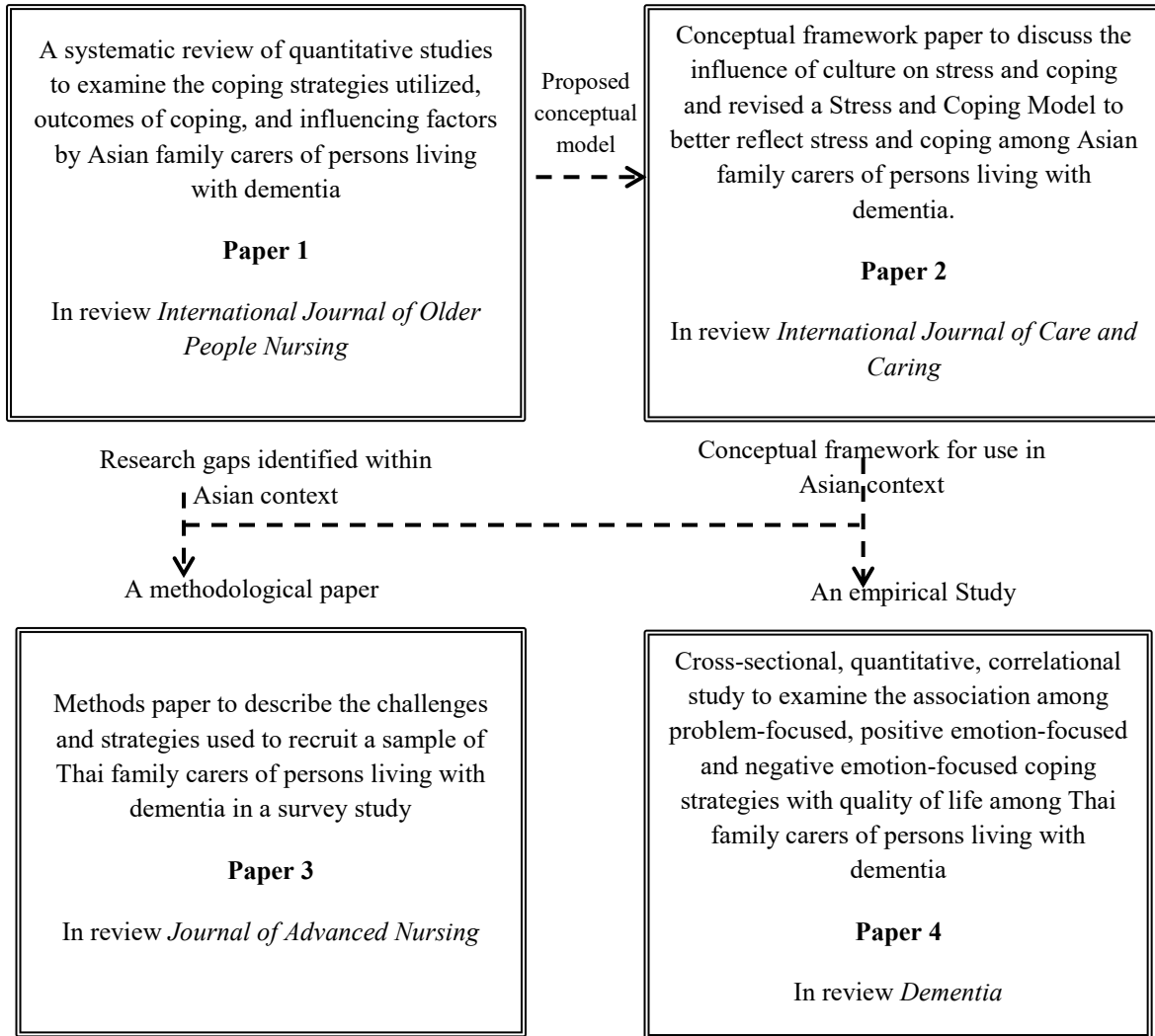
important for nurses to understand how Thai family carers cope with stress, factors that influence the choice of coping strategy, and which coping styles are helpful or unhelpful to assist carers to manage their stress and improve QOL. In addition, this study will be useful to support the development of a culturally appropriate coping intervention to strengthen coping skills and improve QOL of Thai family carers of persons living with dementia.

Dissertation Overview

My dissertation includes four related papers to address the research question “What is the association of problem-focused, positive emotion-focused, and negative emotion-focused coping strategies with the QOL of Thai family carers of persons living with dementia residing in the community?” Paper 1 is a systematic literature review of quantitative studies to examine the coping strategies utilized by Asian family carers of persons living with dementia, outcomes of coping, and influencing factors. Paper 2 is a conceptual framework of stress and coping that was developed based on the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) and the Caregiver Stress Process Model (Pearlin et al., 1990), to include key variables that influence coping. Factors that influence coping were taken from literature identified in a systematic review of quantitative studies as well as qualitative studies to assess coping strategies utilized among Asian family carers of persons living with dementia. In Paper 3, I describe the challenges and strategies used to recruit a sample of Thai family carers of persons living with dementia in a survey study during the COVID-19 pandemic. Paper 4 reports the findings of a cross-sectional, quantitative, correlational study to examine the association among problem-focused, positive emotion-focused, and negative emotion-focused coping strategies with QOL among Thai family carers of persons living with dementia. The hypotheses tested in this study

were derived from the conceptual stress and coping framework. The relationship between the four papers is also shown in Figure 1-1.

Figure 1-1 Diagram illustrating the linkage between four papers



Paper 1: Coping strategies utilized among Asian family carers of persons living with dementia: A systematic review

Objectives: To examine the coping strategies utilized by Asian family carers of persons living with dementia, outcomes of coping, and influencing factors.

Description: This study was a systematic review of quantitative evidence aimed to examine the: 1) types of coping strategies utilized by Asian family carers of persons living with dementia; 2) outcomes of coping that enhance physical and psychological health of Asian family carers of persons living with dementia; and 3) factors associated with coping strategies. A related aim was to identify research gaps and recommend future research directions. Research included English and Thai language articles published from 2010 to July 2020. Reference lists of included articles were reviewed. The databases searched included PUBMED/Medline, PsycINFO, CINAHL, Web of Science, Sociological Abstracts, Google scholar, Thai Journal online database, and Thai Citation Journal Index. The search yielded 185 studies, of which 16 quantitative studies were included in this review. Study quality was appraised using The Crowe Critical Appraisal Tool.

All studies were included, regardless of their quality scores. This systematic review revealed that Asian family carers of persons living with dementia used a variety of coping strategies, including problem-focused coping, positive and negative emotion-focused coping. Carer's demographic characteristics, the clinical symptoms of persons with dementia, familism beliefs as well as social support resources were found to have an influence on the choice of coping strategies. The greater use of problem-focused and positive emotion-focused coping was associated with better physical QOL, but use of problem-focused coping strategies inconsistently associated with outcomes. The greater use of positive emotion-focused coping was associated

with better psychological QOL. The review revealed methodological gaps related to differences in coping categorization and failure to adjust for potential confounders, which may explain inconsistent findings related to the associations between coping and QOL.

Linkage: Paper 1 demonstrated that a gap existed in our understanding of which type of coping strategy is associated with better QOL for Asian family carers of persons living with dementia because previous research showed an inconsistent association with outcomes. Further research using multivariable methods to examine the association between coping and QOL for Asian family carers of persons living with dementia is needed. This research gap supported the rationale for Paper 4.

Paper 2: Asian Family Carers of Persons Living with Dementia: Stress and Coping Model

Objective: The purpose of this article was to propose a conceptual model for understanding how Asian family carers of persons living with dementia cope with stress. To propose the model, I applied findings from a recent systematic review to build on the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) and the Caregiver Stress Process Model (Pearlin et al., 1990).

Description: The Asian Family Carers of Persons living with Dementia Stress and Coping Model was developed based on previous theory and qualitative and quantitative research findings specific to Asian populations. Key features of this adapted model include: specifying person and environment factors for the particular context of Asian family carers of persons living with dementia; highlighting the importance of perceived social support; describing a broader influence of culture on several aspects of the appraisal and coping process; differentiating between positive and negative emotion-focused coping strategies; and emphasizing QOL as an outcome of coping.

Linkage: The adapted Stress and Coping model from Paper 2 was used to guide the quantitative study described in paper 4. This conceptual model added to the literature on dementia caregiving by identifying specific related factors that influence the coping process of Asian family carers of persons living with dementia. Therefore, paper 2 will be useful as a conceptual framework to guide research to determine which factors influence coping strategies utilized and QOL outcomes among Asian family carers of persons living with dementia.

Paper 3: Lessons Learned: Challenges and Successful Strategies to Recruit Thai Family Carers of Persons Living with Dementia to Participate in Research During the COVID-19 Pandemic

Objectives: The purpose of this paper was to describe the participant recruitment processes and outcomes of Thai family carers of persons living with dementia in a survey study designed to examine the association between coping strategies utilized and QOL among these carers. As well, the main recruitment challenges and successful strategies to overcome the recruitment challenges are discussed.

Description: Recruiting participants during the COVID-19 pandemic was likely to present multiple difficulties. Specifically, carers of persons living with dementia have experienced a significant increase in their physical and psychological burden during the COVID-19 period. In this study, the recruitment of participants used a multi-pronged approach, which included social media, in-person recruitment, and word-of-mouth referrals. The main recruitment challenges included: (1) delays in securing site approvals; (2) challenges with social media, including lack of direct contact between the researcher and potential participants and a high proportion of incomplete surveys; (3) clinician's perceptions of the study inclusion criteria and length of time to complete questionnaires. Four strategies were employed to overcome the

recruitment challenges experienced. These included: (1) modification of the recruitment process; (2) working with organizations that have access to target participants; (3) using a multi-pronged recruitment strategy; and (4) tracking the number of participants regularly. Information on strategies to recruit family carers may be helpful to other researchers to improve their recruitment strategies.

Linkage: Paper 3 described the challenge of participant recruitment as well as discussed the successful strategies to overcome these challenges. It also described the successful participant recruitment strategies that we used in the survey study described in paper 4.

Paper 4: Coping Strategies Utilized and Quality of Life among Thai Family Carers of Persons Living with Dementia Residing in Community: A cross-sectional study

Objectives: The purpose of this study was to examine the association between coping strategies utilized and QOL among Thai family carers of persons living with dementia.

Description: The design was a descriptive, correlational, quantitative design. Data were collected between January 2021 and April 2021, inclusive. 97 Thai family carers of persons living with dementia residing in the community participated in the study. Hierarchical multiple regression analysis was used to determine the association between types of coping strategies utilized and QOL scores. Potential confounders were assessed and included carer characteristics (e.g., age, gender, education, financial status) and carers' stress and social support. The mean age of the sample was 52.84 years, and the majority were female (87.2%). In bivariate analysis, total QOL scores were positively correlated with problem-focused coping ($r = .188, p < .05$), positive emotion-focused coping ($r = .390, p < .001$), and negatively correlated with negative emotion-focused coping ($r = -.216, p < .05$). However, after adjusting for covariates, hierarchical multiple regression revealed that only positive emotion-focused coping was associated with total QOL

scores of Thai family carers of persons living with dementia ($\beta = 0.179$, $p = .08$). Problem-focused coping and negative emotion-focused coping were not significantly associated with total QOL scores of Thai family carers of persons living with dementia. These findings can help nurses, and health professionals develop interventions to enhance QOL by promoting the use of positive emotion-focused coping (e.g., positive reframing, acceptance, social support, humor, and religion).

Linkage: Paper 1 demonstrated that a gap existed in our understanding of which type of coping strategy is associated with better QOL among Asian family carers of persons living with dementia. At the same time, paper 2 described a conceptual framework that could be used to conduct research about coping within this population. Paper 4 addressed the research gap identified in paper 1 and applied the conceptual framework described in paper 2. Paper 4 reported on a study that tests three hypotheses derived from these findings to establish whether there is an association between each type of coping and QOL.

Summary of the Dissertation

To understand how carers could benefit from using specific coping strategies to improve their QOL, this dissertation examined types of coping strategies associated with QOL among Thai family carers of persons living with dementia. The findings from this study can be used to develop coping interventions to enhance QOL in future research. Chapters 2 to 5 will describe the detailed information of four related papers. In the final chapter, I will summarize the study findings, strengths, and limitations and propose implications for nursing research, policy, nursing practice and education.

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**Chapter 2. Paper 1- Coping strategies utilized among Asian family carers of persons living
with dementia: A systematic review**

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Introduction

Dementia is a disorder that causes a decline in intellectual functioning, affecting memory, physical functioning, and behavior (Lloyd et al., 2018; Segal, 2010). Persons living with dementia require increasing levels of care as their disease progresses, which may result in high levels of stress and burden, poorer quality of life (QOL), and increased risk of mortality for their family and friend carers (hereafter referred to as ‘carer’) (Choo et al., 2003; Fonareva & Oken, 2014). Coping strategies utilized by carers can influence how carers respond to stressors, and therefore, affect the QOL for both persons living with dementia and carers (Monteiro et al., 2018). Moreover, various socio-cultural factors in different countries may influence a family's commitment to care and their appraisal of stressors (Chan et al., 2010; Knight & Sayegh, 2010). For example, filial piety, defined as cultural beliefs regarding respect and obligations to assist their parents (Kim et al., 2015), is a fundamental value common among many Asian cultures (Lai, 2009). In addition, Asian family members are often responsible for the care of persons living with dementia (Choo et al., 2003). Previous studies and reviews examined the relationships between cultural values and coping (Knight & Sayegh, 2010; Liu et al., 2012; Sun et al., 2012). It was found that filial piety and familism, which is a group value that promotes respect for older adults, and it emphasizes how interpersonal relationships and sharing caregiving responsibility within a family impact care provision (Miyawaki, 2015), were associated with types of coping (Knight & Sayegh, 2010; Liu et al., 2012; Sun et al., 2012) and carer health (Knight & Sayegh, 2010; Liu et al., 2012). According to the Updated Sociocultural Stress and Coping Model by Knight and Sayegh (2010), cultural values directly influenced coping and social support. Coping and social support which, in turn, influenced carer health. Thus, cultural

values may strongly influence coping strategies utilized by Asian family carers, their subsequent social support, and resulting health outcomes.

Lazarus and Folkman (1984) categorized two broad categories of coping strategies: emotion-focused and problem-focused. Emotion-focused strategies seek to manage emotional distress by trying to change one's feelings about the problem (Lazarus & Folkman, 1984). Problem-focused coping strategies involve defining a problem, information gathering, planning, and generating alternative solutions (Lazarus & Folkman, 1984). The dichotomous categorization of problem and emotion-focused coping has been revised by Carver and colleagues (1989) to distinguish between helpful and unhelpful coping (Carver et al., 1989). Later a third category of dysfunctional coping was suggested (Carver, 1997; Li et al., 2012). Coping strategies were grouped into three categories: emotion-focused, problem-focused, and dysfunctional coping. Carers use dysfunctional coping strategies to avoid stressful situations such as mental and behavioral disengagement and substance use (Carver, 1997).

A recent meta-analysis of carers of persons living with dementia found that when emotion-focused coping strategies were frequently used and dysfunctional coping strategies were used less, there were improvements to the psychological health of carers of persons living with dementia (Li et al., 2012). However, problem-focused coping strategies showed an inconsistent association with outcomes (Kneebone & Martin, 2003; Li et al., 2012). Thus, there is no clear consensus regarding which type of coping strategy is most effective to improve carers' physical and psychological health. There has been no previous systematic review to assess the body of evidence related to the association of coping and QOL among Asian family carers, identify areas of consistent and inconsistent findings, and appraise study quality. Therefore, a systematic review was conducted to address this gap in knowledge and answer the following questions: 1)

what factors are associated with coping among Asian family carers of persons living with dementia? and 2) which type of coping strategy is associated with positive outcomes for Asian family carers of persons living with dementia?

Methods

This systematic review of quantitative evidence aimed to examine the: 1) types of coping strategies utilized by Asian family carers of persons living with dementia; 2) outcomes of coping that enhance physical and psychological health; and 3) factors associated with coping strategies. A related aim was to identify research gaps and recommend future research directions.

Search Strategy

Studies were identified by searching electronic databases and scanning reference lists of included articles to identify English and Thai language articles published from 2010 to July 2020. This date limit was applied to ensure that the review reflected current literature. The databases used in this systematic review included PUBMED/Medline, PsycINFO, CINAHL, Web of Science, Sociological Abstracts, Google scholar, and Thai Journal online database. An academic health sciences librarian collaborated with the first author (LK) to conduct controlled vocabulary and text-word searches in all key databases. Keywords used in searching included Asia, dementia or Alzheimer, carer, and coping.

Eligibility Criteria

The literature search was conducted to retrieve studies that focused on family carers of persons living with dementia who lived in Asian countries.

The inclusion criteria for the studies were (1) quantitative studies that test the association of coping and another variable among family carers of persons living with dementia who were

living in Asian countries, and (2) were published in English or Thai from 2010- July 2020. When included articles compared Asian family carers of persons living with dementia with other ethnic populations, we only extracted relevant results from the Asian subgroup. The exclusion criteria were (1) research that focused on coping of persons living with dementia and/or formal paid carers, (2) articles that were not specific to dementia but contained other neurological disorders or diseases, (3) studies designed to validate a coping instrument, (5) non-primary studies, including review articles, and (6) unpublished manuscripts or dissertations. Articles of Asian carers living in Western Countries were excluded, as their experiences may differ from Asian carers living in Asian countries due to the influence of Western cultural values.

Selection Process

First author (LK) screened the title and abstract of each research article in the electronic database to identify studies with potential to meet the inclusion criteria. Then, LK retrieved and screened the full texts of potentially eligible studies to determine the final set of included studies. The authors met as needed to discuss questions related to application of the screening criteria. Figure 1 outlines the study selection process as per PRISMA guidelines (Moher et al., 2009).

Search outcome

The search resulted in 185 records. Duplicates (n=62) were excluded. Based on the inclusion criteria, 123 abstracts were screened, and 21 full texts were reviewed. Of the 21 potentially suitable articles, five were excluded. Reasons for exclusion were as follows: coping strategies or coping outcomes were not measured (n=3), and studies were not conducted in the Asian region (n= 2).

Quality appraisal

LK assessed the quality of all included studies using The Crowe Critical Appraisal Tool (Crowe et al., 2012). This tool includes sections to assess the overall study design and data analysis, including preliminary overview, introduction, design, sampling, data collection, ethical matters, results, and discussion. Within each category, there are a number of items to be examined. Items are marked as being present, absent, or not applicable based on the research design used in the paper. Scoring of each category is on a scale from 0 (the lowest score) to 5 (the highest score); the maximum score was 40.

Data Extraction

One reviewer (LK) extracted the key information related to coping among Asian family carers of persons living with dementia. In order to enhance the rigor of the systematic review process, the first author reviewed each included article twice to verify data accuracy and discussed questions with a review team member. Data extraction included: study characteristics (author, publication year, country, study design, sample size, objective), coping measurement tool, type of coping strategies utilized and prevalence of their use (Table 2-1) and concepts tested as influencing factors and outcome of coping (Table 2-2 and Table 2-3). The results were including the p-value and measure of association demonstrating the direction and size of effect between influencing factors and coping and outcomes, were also extracted.

Data Synthesis

Our synthesis of findings from this review includes a description of the study characteristics (reported frequencies and ranges of results), identifying the coping strategies used, and assessing whether and how coping factors were associated with outcomes based on the findings. Types of coping strategies that were used and their prevalence were described by mean scores. There were a variety of coping assessment tools used. To facilitate a meaningful

synthesis, we have categorized coping strategies as problem-focused, positive emotion-focused, and negative emotion-focused coping using Carver's (1997) definitions of problem-focused, emotion-focused (which we refer to as positive emotion-focused), and dysfunctional coping (which we refer to as negative emotion-focused) strategies as a framework (Carver, 1997). Problem-focused strategies include active coping, instrumental support, and planning. Positive emotion-focused strategies include acceptance, emotional support, humor, positive reframing, and religion. Negative emotion-focused coping includes behavioral disengagement, denial, self-distraction, self-blame, substance use, and emotional venting. To assess the frequency of use of coping strategies, for studies that reported an average for each coping strategy utilized by carers, the top three most commonly used coping strategies reported in each study were extracted based on the mean scores reported in the study. The frequencies for the most commonly used coping strategies were calculated to synthesize this data across studies

For the findings related to the associations between coping and its influencing factors and outcomes, a statistical meta-analysis was deemed inappropriate due to heterogeneity in study designs and reported outcomes. For this reason, vote counting was used to identify the number of studies that tested and found a positive, negative, or no statistically significant association between each factor and coping (Ben Van Den, 2020).

The review has been reported using PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) (Moher et al., 2009).

Results

Description of included studies

A total of 16 quantitative studies were included. Table 2-1 shows the characteristics of the studies. Twelve studies were cross-sectional descriptive correlational design, two studies

were a longitudinal study design, and two studies were a randomized controlled trial. Studies were conducted in China (N=6), Singapore (N=3), Japan (N=2), Thailand (N=1), Malaysia (N=1), South Korea (N=1), India (N=1), and Iran (N=1). The sample size varied from 32 to 664 participants. Studies involved bivariate analysis (n=4), multivariate analysis (n=3), ANOVA (n=3), ANCOVA (n=2), multiple regression (n=4), and path analysis (n=5).

Methodological quality of the included studies.

Quality scores of the included studies are presented in Table 2-1. All sixteen included studies had quality scores ranging from 32 to 39 out of 40. In general, the quality of the studies was assessed as medium to high. The most common methodological weaknesses included lack of information regarding sampling, data collection and analysis. These limitations had an impact on transparency in data collection, analysis, and interpretation. None of the studies were excluded on the basis of their quality score.

Synthesis of the results

Coping Strategies Utilized

Several measurement tools were used to measure coping strategies (Table 2-1). Based on Carver's (1997) classification of coping strategies (Carver, 1997), studies reported that carers use a variety of problem-focused, positive emotion-focused, and negative emotion-focused coping strategies.

Problem-focused coping strategies: The problem-focused strategies most frequently used across all studies were: instrumental support (Au et al., 2010; Chen et al., 2015; Pattanayak et al., 2011; Tay et al., 2016); problem-solving (Au et al., 2010; Chen et al., 2015; Pattanayak et

al., 2011); active coping (Lau & Cheng, 2017; Lim et al., 2011; Yuan et al., 2020) and planning (Lim et al., 2011).

Positive emotion-focused coping strategies: The emotion-focused strategies most frequently used across all studies were: acceptance (Lau & Cheng, 2017; Lim et al., 2011; Pattanayak et al., 2011; Yuan et al., 2020); emotional support;(Au et al., 2010; Chen et al., 2015; Pattanayak et al., 2011; Tay et al., 2016; Yuan et al., 2020); positive reframing (Lim et al., 2011; Tay et al., 2016); and religious coping (Lim et al., 2011; Pattanayak et al., 2011).

Negative emotion-focused coping strategies: Negative emotion-focused coping strategies most frequently used across all studies were self-blame (Chen et al., 2015; Lau & Cheng, 2017; Lim et al., 2011); behavioral disengagement (Lau & Cheng, 2017; Lim et al., 2011; Yuan et al., 2020); self-distraction (Pattanayak et al., 2011; Yuan et al., 2020); passive appraisal (Tay et al., 2016); denial (Lau & Cheng, 2017); substance use (Yuan et al., 2020) and wishful thinking (Au et al., 2010).

Coping and outcomes

Table 2-2 shows the results of vote counting, which identified the association between coping and outcomes.

Quality of life (QOL): Studies that assessed the association between carer total coping scores identified a positive association with total QOL scores (Tay et al., 2016), psychological (Liu et al., 2012; Tay et al., 2016), or environmental domains of QOL (Tay et al., 2016). Studies reported that positive emotion-focused coping was associated with better psychological health (Jeong et al., 2018; Morimoto et al., 2019; Pattanayak et al., 2011; Saffari et al., 2018; Tay et al., 2016). Problem-focused coping was associated with better psychological health (Jeong et al.,

2018; Pattanayak et al., 2011; Tay et al., 2016), while another study found that problem-focused coping was associated with lower psychological health (Morimoto et al., 2019).

Several studies examined specific coping strategies and their relationship with QOL. Studies that assessed the association between instrumental support and emotional support consistently identified a positive association with the psychological, social, and environment domains of QOL (Pattanayak et al., 2011; Tay et al., 2016). There was a positive association between positive reframing and the psychological and environment domains of QOL (Tay et al., 2016). Studies that assessed religion coping mostly identified positive association with psychological domains of QOL (Saffari et al., 2018; Tay et al., 2016). On the other hand, there was a negative association between denial and self-blame with physical QOL (Pattanayak et al., 2011). Similarly, a negative association was found between active coping (Morimoto et al., 2019), denial (Pattanayak et al., 2011), and self-blame (Pattanayak et al., 2011) with psychological QOL.

Carer burden: Carer burden is defined as the caregiving challenges perceived by carers with respect to their physical, psychological, social, and financial situation (Pearlin et al., 1990; Zarit et al., 1985). The findings of the association between carer coping and carer burden were inconsistent. Studies reported both positive (Ondee et al., 2013) and negative associations (Liu et al., 2012) between carer coping and carer burden. For problem-focused coping, studies most often identified a positive association with carer burden (Chen et al., 2015; Nishio et al., 2017). There was a positive association between carer burden and problem-solving (Chen et al., 2015; Nishio et al., 2017), active coping (Baharudin et al., 2019; Lim et al., 2011; Yuan et al., 2020), instrumental support (Baharudin et al., 2019; Chen et al., 2015; Lim et al., 2011; Nishio et al., 2017), and planning (Baharudin et al., 2019; Lim et al., 2011), supporting that carers that were

more burdened used problem-focused coping more often. For positive emotion-focused coping, studies mostly identified no association between carer burden and acceptance (Lim et al., 2011; Yuan et al., 2020), or humor (Baharudin et al., 2019; Lim et al., 2011). However, there was a positive association between carer burden and emotional support (Chen et al., 2015; Nishio et al. 2017) and positive reframing (Baharudin et al., 2019; Nishio et al., 2017), also supporting that carers who have higher levels of burden use more emotional support and positive reframing. Moreover, a negative association between carer burden and religion coping was also found (Saffari et al., 2018), suggesting that religion coping is also used by carers with lower levels of burden. Regarding negative emotion-focused coping, a study that assessed the association between negative emotion-focused coping identified a positive relationship with carer burden (Lau & Cheng, 2017). Similarly, an association was consistently positive between carer burden and behavioral disengagement (Lim et al., 2011; Yuan et al., 2020), avoidance (Huang et al., 2015), denial (Baharudin et al., 2019), self-distraction (Baharudin et al., 2019; Lim et al., 2011), self-blame (Huang et al., 2015; Lim et al., 2011), substance use (Yuan et al., 2020) and emotion venting (Baharudin et al., 2019; Lim et al., 2011). This supports that carers who experience more burden also use more behavioral disengagement and negative emotion-focused coping.

Carer's depression and anxiety: An association between depression and negative emotion-focused coping has been found. There was a positive association between carers' depression and negative emotion-focused coping (Lau & Cheng, 2017); behavioral disengagement (Yuan et al., 2020); substance use (Yuan et al., 2020). Interestingly, there was a positive association between carers' depression and acceptance (Yuan et al., 2020), suggesting that these strategies may be used more by carers who are more anxious and depressed. On the other hand, there was a negative association between carers' depression and anxiety with religion

coping (Saffari et al., 2018), suggesting that religion coping may be used more by carers who are less depressed and anxious. No significant relationships between total coping score and carers' depression were found in another study (Ondee et al., 2013).

Other psychological outcomes: The association between carer coping, self-efficacy, positive aspects of caregiving (i.e., gain), and post-traumatic growth were identified. Studies that assessed self-efficacy identified a positive association with problem-solving (Au et al., 2010), positive reframing (Tay et al., 2016), and distancing (Au et al., 2010). In addition, positive aspects of caregiving (i.e. gain) had a positive association with active coping (Lim et al., 2011), instrumental support (Lim et al., 2011), planning (Lim et al., 2011), positive reframing (Lim et al., 2011) and a negative association with behavioral disengagement (Lim et al., 2011). Moreover, post-traumatic growth is positively associated with active coping (Li et al., 2020) and negatively associated with passive appraisal (Li et al., 2020).

Factors that influence coping

Coping and Demographic data: Demographic characteristics such as age, level of education, gender, carer relationship, and employment status are factors that could potentially influence carer coping.

Age: It is unclear whether carer age or the age of persons living with dementia influences carer coping. There was no relationship found between carer age and total coping scores (Pattanayak et al., 2011; Tay et al., 2016). However, there was a positive relationship between carer age, religion coping, and passive appraisal (Tay et al., 2016). In addition, increased age of persons living with dementia had a positive association with coping ability of carers (Tay et al., 2016).

Gender: The carers' use of coping strategies was related to carers' gender. Males were significantly more likely to use problem-solving (Pattanayak et al., 2011), behavior disengagement (Yuan et al., 2020), and substance use (Yuan et al., 2020). Females were more likely to use acceptance (Yuan et al., 2020) and emotional support than male carers (Yuan et al., 2020).

Level of education: The carers' use of coping strategies was related to the caregiver's level of education. Studies that assessed the association between levels of education mostly identified a positive association with total coping scores (Li et al., 2020; Pattanayak et al., 2011). Studies found a positive association between level of education and problem-solving (Pattanayak et al., 2011), active coping (Yuan et al., 2020), acceptance (Pattanayak et al., 2011), but also positively associated with behavior disengagement (Yuan et al., 2020), self-distraction (Pattanayak et al., 2011), and substance use (Yuan et al., 2020). In contrast, there was a negative association between level of education and religion coping (Pattanayak et al., 2011), denial (Pattanayak et al., 2011), and self-blame (Pattanayak et al., 2011).

Religion: The carers' use of coping strategies was related to carer's religion. One study identified a positive association between carer's religion with active coping (Lim et al., 2011), planning (Lim et al., 2011), and positive reframing (Lim et al., 2011).

Employment status: The carers' use of coping strategies was related to their employment status. Studies found that employment status was positively associated with problem-solving (Nishio et al., 2017), instrumental support (Nishio et al., 2017), emotional support (Nishio et al., 2017), positive reframing (Nishio et al., 2017), behavioral disengagement (Yuan et al., 2020), and substance use (Yuan et al., 2020). On the other hand, employment status was negatively associated with avoidance (Nishio et al., 2017).

Carer's relationship with the care recipient: The carers' use of coping strategies was related to carer's relationship to the person living with dementia. One study identified an association between carers' relationship with persons living with dementia and religion coping (Pattanayak et al., 2011). Spousal caregivers used more religious coping as compared to children (Pattanayak et al., 2011).

Coping and Clinical variables

Severity of disease: There was no relationship found between severity of disease and carer coping (Pattanayak et al., 2011).

Memory, Behavior, and depression: Behavior and depression of persons living with dementia influenced carer coping. Studies reported no association between memory problems and choice of coping strategies utilized (Huang et al., 2015; Pattanayak et al., 2011; Yuan et al., 2020) with the exception of acceptance (Yuan et al., 2020). Studies that assessed the association between behavior problems and total coping scores reported both positive (Ondee et al., 2013) and negative associations (Liu et al., 2012). There was a positive association between behavior problems and active coping (Baharudin et al., 2019), planning (Baharudin et al., 2019), acceptance (Baharudin et al., 2019; Yuan et al., 2020), avoidance (Huang et al., 2015), and self-distraction (Baharudin et al., 2019). In addition, studies found a positive association between depression and choice of coping strategies utilized. Depression was positively associated with active coping (Baharudin et al., 2019), planning (Baharudin et al., 2019), acceptance (Baharudin et al., 2019), avoidance (Huang et al., 2015), self-distraction (Baharudin et al., 2019), and wishful thinking (Huang et al., 2015).

Activities of Daily Living (ADL): It is unclear whether ADL influences carer coping. Studies that assessed the association between total coping scores identified a negative association

with ADL dependency (Ondee et al., 2013). However, carer religion coping was positively associated with the instrumental ADL scores of persons living with dementia (Saffari et al., 2018).

Coping and Familism/gratitude

Familism and gratitude influence the choice of coping strategies utilized. There was a positive association between familism and total coping scores (Liu et al., 2012). In addition, there was a positive association between gratitude and problem-focused coping, planning, emotion-focused coping, acceptance, emotional support, humor, positive reframing, and religion coping (Lau & Cheng, 2017).

Coping and social support resource

Social support resources influence the choice of coping strategies utilized. Studies that assessed the association mostly identified a positive association between social support resources and caregiver coping (Lau & Cheng, 2017; Liu et al., 2012; Nishio et al., 2017). A positive association was found between total coping scores (Liu et al., 2012), emotion-focused coping (Lau & Cheng, 2017), problem-solving (Nishio et al., 2017), instrumental support (Nishio et al., 2017), emotion support (Nishio et al., 2017), and avoidance (Nishio et al., 2017). In contrast, there was a negative association between social support resources and positive reframing (Nishio et al., 2017). Furthermore, a positive association was found between carer communication behavior (i.e., information seeking and information forwarding) and both problem-focused and positive emotion-focused coping (Jeong et al., 2018).

Coping and other psychological variables

Positive associations between carer coping and family functioning, carer competence, carer satisfaction, attention control, and inter-role conflict were identified. A study found a positive association between family functioning and active coping (Li et al., 2020). Similarly, a positive association was found between carer competence and positive emotion-focused coping (Lau & Cheng, 2017). Moreover, there was a positive association between carer satisfaction and total coping scores (Liu et al., 2012). Last, a positive association was found between attention control and inter-role conflict with instrumental support and emotional support (Morimoto et al., 2019).

Discussion

Through this systematic review of quantitative literature, types of coping strategies utilized, outcomes of coping, and factors associated with coping among Asian family carers of persons living with dementia were identified.

This review's findings suggested that Asian family carers of persons living with dementia frequently used problem-focused and positive emotion-focused coping and used negative emotion-focused coping less often. Furthermore, our review findings suggested that greater use of positive emotion-focused coping was associated with better physical and psychological QOL. Specifically, coping strategies based on instrumental support and emotional support, positive reframing, and spiritual coping were positively associated with better psychological QOL. In contrast, greater use of negative emotion-focused coping such as denial and self-blame were associated with lower physical and psychological QOL. Our findings on positive emotion-focused coping, negative emotion-focused coping, and QOL are consistent with previous studies of carers of older adults with dementia (Li et al., 2012; Riedijk et al., 2006) and dependent older adults relatives (Margarita et al., 2017). However, the findings of the studies we reviewed were

challenging to synthesize due to the small number of articles identified, which explored each association of interest, and the fact that some studies did not adjust for confounding variables. Therefore, additional research is needed to rigorously evaluate the association between coping and carer QOL, adjusting for the other factors that may affect the relationship between carer coping and QOL among Asian family carers of persons living with dementia.

A number of potential influencing factors on family carer coping were identified, including (1) carers' demographic characteristics (i.e., age, gender, education, religion, employment status, relationship with persons living with dementia); (2) clinical symptoms of persons living with dementia (i.e., behavioral and depression problems); (3) familism and gratitude; and (4) social support resources. Our findings are consistent with Lazarus and Folkman (1984) Stress and Coping Model that person factors, environment factors, and social support influenced the choice of coping strategies utilized. In addition, Knight and Sayegh (2010) also supported that familism had an influence on coping styles. As such, similarities may exist with Asian family carers and carers of other countries in regards to how familism may influence coping styles and affect the stress and coping process.

Methodological considerations and limitations of the review literature

This is the first review to synthesize studies of coping strategies utilized among Asian family carers of persons living with dementia using a coping classification for different coping measures to compare the results of each study with different measures. Numerous methodological considerations regarding the studies in this review were identified.

A variety of measurement tools used made it challenging to categorize coping strategies definitively. Few studies developed a measurement tool specifically to assess family carers' coping strategies. A more consistent use of measures would increase their comparative value and

enable meta-analyses to be conducted. Regarding outcome measures, only six studies assessed physical and psychological health outcomes, and only two of these six specifically examined the association between caregiving coping and carer QOL. Although we identified some consistent associations between coping and QOL, the findings of the studies we reviewed were challenging to synthesize due to the small number of articles identified for each association between coping and the selected factor or outcome. Further research should focus on examining the association between coping and QOL among Asian family carers of persons living with dementia.

Regarding cultural aspects of caregiving, a few studies used quantitative measurement to assess familism values and gratitude to care among Asian family carers. Culture has an important influence on the appraisal of stress and the use of certain coping strategies (Knight & Sayegh, 2010; Lazarus & Folkman, 1984). Further research should explore how Asian culture impacts several aspects of the appraisal and coping process, such as coping appraisal, coping strategies utilized, and coping resources.

The research team consists only of team members from Canada and Thailand. Due to language barriers, articles not written in English or Thai were excluded, and relevant studies written in other Asian languages may have been missed. Only one reviewer was available to complete screening and quality assessments; as such, it is possible that we introduced bias in these aspects of the review. In order to enhance the rigor of the systematic review process, the primary reviewer applied a structured approach to screening, extraction, and quality appraisal, reviewed each included article twice to verify accuracy during the data extraction phase, and had the opportunity to discuss questions with the review team on a regular basis.

Conclusion

Findings from our review suggest that carers' demographic characteristics, behavioral and depression problems of persons living with dementia, familism, and social support influenced the choice of coping strategies. However, knowledge concerning coping strategies and QOL among Asian family carers of persons living with dementia is very limited. Further research is needed to describe the type of coping strategy used in relation to the QOL among Asian family carers of persons living with dementia and whether the type affects the strength of these associations.

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Figure 2-1. Flow diagram adapted from Moher et al. (2009)

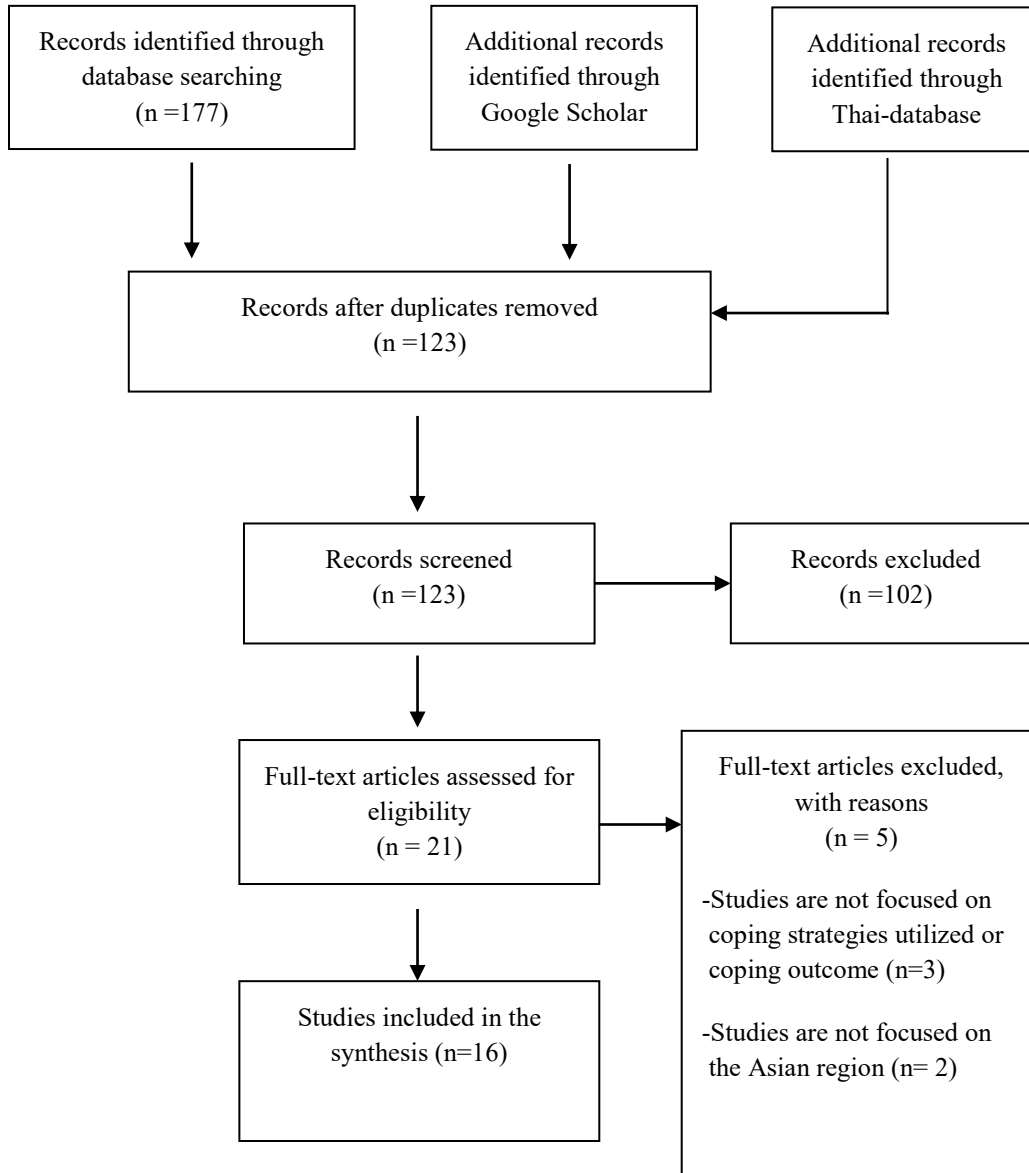


Table 2-1 Description of studies included, in chronological order, N=16

No	First author Publication year Country Journal	Primary Research Area	Study design/ data collection	Participants	Coping measurement tool	Type of coping strategies utilized and prevalence of their use.	Quality score (out of 40)
1.	Pattanayak, R.D. Publication year:2011 Country: India Journal: Dementia- International Journal of Social Research and Practice, 10(4), 499-508.	Assess coping strategies and QOL and the relationship between coping, QOL and severity of dementia.	A cross- sectional study design	32 Dyads of PLWD and carers those attending Memory clinic. Carers mean age =54 years.	Coping checklist	Coping strategies Most commonly used: (1) Acceptance, (2) Problem solving (3) Social support. (4) Positive distraction (5) Religion Least commonly used: (1) Negative distraction	32
2.	Lim, J. Publication year:2011 Country: Singapore Journal: Alzheimer Disease & Associated Disorders, 25(1), 34- 41.	Examine factors associated with negative and positive adjustment.	A cross- sectional descriptive correlational design	107 carers of PLWD Carers mean age=49 years	(1)The Brief COPE (2)The Systems of Belief Inventory- 15R) (3) The Dementia Management Strategies Scale	Coping strategies Most commonly used: (1) Acceptance (2) Active coping (3) Planning (4) Positive reframing Least commonly used: (1) Behavioral disengagement (2) Self-blame Carers also rated themselves as high level of religious and spiritual belief on The Systems of Belief Inventory Scale.	36

No	First author Publication year Country Journal	Primary Research Area	Study design/ data collection	Participants	Coping measurement tool	Type of coping strategies utilized and prevalence of their use.	Quality score (out of 40)
3.	Liu, Y. Publication year:2012 Country: China Journal: Nursing Research, 61(1), 39-50.	Test the proposed Dementia Caregiving Model.	A cross-sectional descriptive correlational design	96 carers of PLWD in moderate/ severe stage. Carers age between 25-83 years	The Simplified Coping Style Questionnaire		39
4.	Ondee, P. Publication year:2013 Country: Thailand Journal: Pacific Rim International Journal of Nursing Research, 17(2), 167-180.	Determine factors that predicted depression among carers of people with dementia.	A cross-sectional descriptive correlational design	226 carers of PLWD in moderate stage. Carers age between 20-83 years	The Thai version of the Jalowiec Coping Scale (JCS)	Carers tended to use problem-focused coping strategies more often than emotion- focused coping Strategies.	38
5.	Huang, M.F. Publication year:2015 Country: Taiwan Journal: American Journal of Alzheimer's Disease & Other Dementias, 30(7), 694-698.	Examine the association between specific dementia symptoms and burden with coping among carers of people with dementia.	A cross-sectional descriptive correlational design	57 carers of PLWD Carers mean age 52.46 year	The Revised Ways of Coping Checklist (WCCL-R).		33
6.	Jeong, J.S. Publication year:2016 Country: South Korea Journal: Health Communication, 33(1), 5-13.	Investigate the relationship between dementia carers' communication behaviors and coping outcomes.	A cross-sectional descriptive correlational design	104 carers of PLWD Carers mean age 44.21 years	Scale developed specifically for this study		32

No	First author Publication year Country Journal	Primary Research Area	Study design/ data collection	Participants	Coping measurement tool	Type of coping strategies utilized and prevalence of their use.	Quality score (out of 40)
7.	Tay, K.C.P. Publication year:2016 Country: Singapore Journal: Dementia: The International Journal of Social Research and Practice, 15(2), 204-220.	Examine the associations of burden, coping, self-efficacy with quality of life among family carers of people with dementia in Singapore.	A cross-sectional descriptive correlational design	84 carers of PLWD who attended outpatient clinic of a public hospital. Carers mean age 50.89 years	The Family Crisis Oriented Personal Evaluation Scales (F-COPES)	Coping strategies Most commonly used: (1) Reframing (2) Mobilizing family to acquire (3) accept help Least commonly used: (1) Passive appraisal (2) Seeking spiritual support	36
8.	Lau, B.H.P. Publication year:2017 Country: China Journal: Aging & Mental Health, 21(4), 445-453.	Examine the role of gratitude on relieving caregiving distress among familial carers of person living with dementia	A cross-sectional descriptive correlational design	101 carers of PLWD Carers mean age 57.6 years	The Brief COPE	Coping strategies Most commonly used: (1) Acceptance (2) Active coping (3) Positive reframing Least commonly used: (1) Denial (2) Behavioral disengagement (3) Self blame	35
9	Nishio, M. Publication year:2017 Country: Japan Journal: Journal of rural medicine : JRM, 10(1), 34-42	To clarify the association between emotional and instrumental support for male carers and their ability to cope with providing care	A cross-sectional descriptive correlational design	298 carers of PLWD Carers mean age 70.1	The Care Problems Coping Scale		33

No	First author Publication year Country Journal	Primary Research Area	Study design/ data collection	Participants	Coping measurement tool	Type of coping strategies utilized and prevalence of their use.	Quality score (out of 40)
10	Saffari, M. Publication year: 2018 Country: Iran Journal: Dementia (London, England), 1471301218798082.	To examined how spiritual coping and stigma-related family stress impacted the associations between the patient activities of daily living impairment and carer mental health.	A longitudinal study	664 carers of PLWD Carers mean age 54.39	Spiritual Coping Strategies (SCS) scale		35
11	Morimoto, H. Publication year:2019 Country: Japan Journal: Clinical Gerontologist: The Journal of Aging and Mental Health, 42(1), 34-46	To examine the stress-buffering effect of coping strategies on the adverse effects of interrole conflict on the mental health of employed family carers, and clarify the moderating role of attentional control on this stress-buffering effect	A longitudinal study design	379 carers of PLWD Carers mean age 51.54 years	Scale developed specifically for this study to assess family carer's coping strategies for interrole conflict.		30
12	Baharudin, A.D. Publication year:2019 Country: Malaysia Journal: BMC public health, 19(Suppl 4), 447.	To determine the association between Behavioral and Psychological Symptoms of Dementia (BPSD) and carer burden, and the mediating role of coping strategy and personality style of carers to patients with dementia	A cross-sectional descriptive correlational design	202 carers of PLWD Carers mean age 54.39	The Brief COPE		36

No	First author Publication year Country Journal	Primary Research Area	Study design/ data collection	Participants	Coping measurement tool	Type of coping strategies utilized and prevalence of their use.	Quality score (out of 40)
13	Li, Y. Publication year:2020 Country: China Journal: Aging & Mental Health, 1-8.	To examine the mediating effect of coping strategies on the relationship between family functioning and posttraumatic growth in family carers of PLWD	A cross-sectional descriptive correlational design	124 carers of PLWD Carers age range from 24-79	The Simplified Coping Style Questionnaire (SCSQ)		36
14	Yuan, Q. Publication year:2020 Country: Singapore Journal: The Gerontologist	To explore the coping patterns of primary informal dementia carers in Singapore, examine their significant correlates, and investigate whether different patterns would affect the depressive symptoms of carers.	A cross-sectional descriptive correlational design	281 carers of PLWD Carers mean age 55.6 years	The BRIEF-COPE	High coping group (36.3%)- carers frequently used active coping, self-distraction and emotional support Low coping group (26.0%) – carers frequently used acceptance Medium coping group (37.7%) – carers frequently used substance use and behavioral disengagement.	37

No	First author Publication year Country Journal	Primary Research Area	Study design/ data collection	Participants	Coping measurement tool	Type of coping strategies utilized and prevalence of their use.	Quality score (out of 40)
15	Au, A. Publication year:2010 Country: China Journal: Patient Education & Counseling, 78(2), 256-260.	1) To evaluate the effectiveness of Coping with Caregiving psychoeducation program for Chinese family carers of patients with Alzheimer's disease in Hong Kong	Randomized controlled trial	37 Carers of PLWD Intervention Group n= 13 Carers mean age 56.92 years Control Group n= 14 Carers mean age 51.57 years	Chinese Way Of Coping Questionnaire (CWOC)	Coping strategies Most commonly used: (1) Problem solving (2) Seeking support and Ventilation Less commonly used (1) Distancing (2) Wishful thinking	32
16	Chen, H. Publication year: 2015 Country: China Journal: Psychogeriatrics15 (1), 20-25.	To develop an intervention targeted towards improving coping strategies and to examine its effectiveness on reducing carer burden	Randomized controlled trial	46 carers of PLWD Carers mean age 54.9 years Intervention Group n= 24 Control Group n= 22	The Revised Ways of Coping Checklist (WCCL-R).	Coping strategies Most commonly used: (1) Problem solving (2) Wishful (3) Social support (4) Avoidance Less commonly used: (1) Blame self	36

PLWD: Persons living with dementia

Table 2-2 Overview of the outcome variables associated with coping in relation to the studies.

Coping strategies	Outcome										
	Total QOL scores	Physical QOL	Psychological QOL	Social QOL	Environment QOL	Carer's Anxiety	Carer's depression	Carer burden	Self-efficacy	Gain	Post-traumatic growth
Total Coping Scores	⊕ 7 ⊖ NS	⊕ ⊖ NS 1,7	⊕ 3,7 ⊖ NS 1	⊕ ⊖ NS 1	⊕ 7 ⊖ NS 1		⊕ ⊖ NS 4	⊕ 4 ⊖ 3 NS			
Problem-focused		⊕ 6 ⊖ NS	⊕ 6 ⊖ NS					⊕ ⊖ 5 NS			
Problem solving		⊕ ⊖ NS 1	⊕ 1 ⊖ NS	⊕ ⊖ NS 1	⊕ ⊖ NS 1			⊕ 9,16 ⊖ NS	⊕ 15 ⊖ NS		
Active coping			⊕ ⊖ 11 NS				⊕ ⊖ NS 14	⊕ 2,12,14 ⊖ NS		⊕ 2 ⊖ NS	⊕ 13 ⊖ NS
Instrumental support	⊕ 7 ⊖ NS	⊕ ⊖ NS 1,7	⊕ 1,7 ⊖ NS 11	⊕ 1,7 ⊖ NS	⊕ 1,7 ⊖ NS			⊕ 2,9,12,16 ⊖ NS 5	⊕ ⊖ NS 7,15	⊕ 2 ⊖ NS	
Planning								⊕ 2,12 ⊖ NS 1		⊕ 2 ⊖ NS	
Positive emotion-focused		⊕ 6 ⊖ NS	⊕ 6,11 ⊖ NS								

Coping strategies	Outcome										
	Total QOL scores	Physical QOL	Psychological QOL	Social QOL	Environment QOL	Carer's Anxiety	Carer's depression	Carer burden	Self-efficacy	Gain	Post-traumatic growth
Acceptance		⊕	⊕	⊕	⊕		⊕ 14	⊕ 12		⊕	
		⊖	⊖	⊖	⊖		⊖	⊖		⊖	
		NS 1	NS 1	NS 1	NS 1		NS	NS 14,2		NS 2	
Emotional support	⊕ 7	⊕	⊕ 1,7	⊕ 1	⊕ 1,7		⊕	⊕ 9,16	⊕	⊕	
	⊖	⊖	⊖	⊖	⊖		⊖	⊖	⊖	⊖	
	NS	NS 7	NS 11	NS 7	NS		NS 14	NS 2,5,12,14	NS 7,15	NS 2	
Humor								⊕		⊕	
								⊖		⊖	
								NS 2,12		NS 2	
Positive reframing	⊕ 7	⊕	⊕ 7		⊕ 7			⊕ 9,12	⊕ 7	⊕ 2	
	⊖	⊖	⊖		⊖			⊖	⊖	⊖	
	NS	NS 7	NS		NS			NS 2	NS	NS	
Religion/Spiritual	⊕	⊕	⊕ 7,10	⊕	⊕	⊕	⊕	⊕			
	⊖	⊖	⊖	⊖	⊖	⊖ 10	⊖ 10	⊖ 10			
	NS 7	NS 1,7	NS 1	NS 1,7	NS 1,7	NS	NS	NS 12			
Negative emotion-focused							⊕ 8	⊕ 8			
							⊖	⊖			
							NS	NS			
Behavioral disengage							⊕ 14	⊕ 2,14		⊕	
							⊖	⊖		⊖ 2	
							NS	NS 12		NS	

Coping strategies	Outcome										
	Total QOL scores	Physical QOL	Psychological QOL	Social QOL	Environment QOL	Carer's Anxiety	Carer's depression	Carer burden	Self-efficacy	Gain	Post-traumatic growth
Distancing									⊕ 15 ⊖ NS		
Avoidance								⊕ 5 ⊖ 9 NS 16			
Denial		⊕ ⊖ 1 NS	⊕ ⊖ 1 NS 12	⊕ ⊖ NS 1	⊕ ⊖ NS 1			⊕ 12 ⊖ NS			
Self-distraction		⊕ ⊖ NS 1	⊕ ⊖ NS 1	⊕ ⊖ NS 1	⊕ ⊖ NS 1		⊕ ⊖ NS 14	⊕ 2,12 ⊖ NS 14		⊕ ⊖ NS 2	
Self-blame		⊕ ⊖ 1 NS	⊕ ⊖ 1 NS	⊕ ⊖ NS 1	⊕ ⊖ NS 1			⊕ 2,5 ⊖ NS 12,16		⊕ ⊖ NS 2	
Substance use							⊕ 14 ⊖ NS	⊕ 14 ⊖ NS 12			
Emotional venting								⊕ 2,12 ⊖ NS	⊕ ⊖ NS 15	⊕ ⊖ NS 2	

Coping strategies	Outcome										
	Total QOL scores	Physical QOL	Psychological QOL	Social QOL	Environment QOL	Carer's Anxiety	Carer's depression	Carer burden	Self-efficacy	Gain	Post-traumatic growth
Wishful thinking								⊕ ⊖ NS 5,16	⊕ ⊖ NS 15		
Passive appraisal	⊕ ⊖ NS 7	⊕ ⊖ NS 7	⊕ ⊖ NS 7	⊕ ⊖ NS 7	⊕ ⊖ NS 7				⊕ ⊖ NS 7		⊕ ⊖ 13 NS

QOL: Quality of life ⊕ : Positive association ⊖ : Negative association NS: Not significant association

Table 2-3 Overview of the influencing factors associated with coping in relation to the studies.

Coping Strategies	Influencing factors										
	Demographics						PLWD clinical variables				
	Carer Age	PLWD Age	Gender	Education	Religion	Employment	Relationship with PLWD	Memory Problem	Behavior Problems	Depression Problems	ADL
Total Coping Scores	⊕	⊕ 7	⊕ 3	⊕ 1,13				⊕	⊕ 4		⊕
	⊖	⊖	⊖	⊖				⊖	⊖ 3		⊖ 4
	NS 1,7	NS	NS 7	NS 7				NS 1	NS		NS 13
Problem-focused								⊕	⊕	⊕	
								⊖	⊖	⊖	
								NS 1,5	NS 5	NS 5	
Problem solving	⊕		⊕ 1	⊕ 1		⊕ 9	⊕				
	⊖		⊖	⊖		⊖	⊖				
	NS 1		NS	NS		NS	NS 1				
Active coping			⊕	⊕ 14	⊕ 2	⊕		⊕	⊕ 12	⊕ 12	
			⊖	⊖	⊖	⊖		⊖	⊖	⊖	
			NS 3,14	NS 13	NS	NS 14		NS 14	NS 14	NS	
Instrument support	⊕	⊕	⊕	⊕	⊕	⊕ 9	⊕	⊕	⊕	⊕	
	⊖	⊖	⊖	⊖	⊖	⊖	⊖	⊖	⊖	⊖	
	NS 1,7	NS 7	NS 1,7	NS 1,7	NS 2	NS	NS 1	NS 1,5	NS 5,12	NS 5,12	
Planning					⊕ 2				⊕ 12	⊕ 12	
					⊖				⊖	⊖	
					NS				NS	NS	
Positive emotion-focused											
Acceptance	⊕		⊕ 14	⊕ 1		⊕	⊕	⊕ 14	⊕ 12,14	⊕ 12	
	⊖		⊖	⊖		⊖	⊖	⊖	⊖	⊖	
	NS 1		NS	NS 14		NS 14	NS 1	NS 1	NS	NS	

Coping Strategies	Influencing factors										
	Demographics						PLWD clinical variables				
	Carer Age	PLWD Age	Gender	Education	Religion	Employment	Relationship with PLWD	Memory Problem	Behavior Problems	Depression Problems	ADL
Emotional support	⊕ ⊖ NS 1,7	⊕ ⊖ NS 7	⊕ 14 ⊖ NS1,7	⊕ ⊖ NS 1,7,14		⊕ 9 ⊖ NS 14	⊕ ⊖ NS 1	⊕ ⊖ NS 1,5,14	⊕ ⊖ NS 5,12	⊕ ⊖ NS 5,12	
Humor									⊕ ⊖ NS 12	⊕ ⊖ NS 12	
Positive reframing	⊕ ⊖ NS 7	⊕ ⊖ NS 7	⊕ ⊖ NS 7	⊕ ⊖ NS 7	⊕ 2 ⊖ NS	⊕ 9 ⊖ NS			⊕ ⊖ NS 12	⊕ ⊖ NS 12	
Religion/spiritual	⊕ 7 ⊖ NS 1	⊕ ⊖ NS 7	⊕ ⊖ NS 1,7	⊕ ⊖ 1 NS 7			⊕ 1 ⊖ NS	⊕ ⊖ NS 1	⊕ ⊖ NS 12	⊕ ⊖ NS 12	⊕ 10 ⊖ NS
Negative emotion-focused											
Behavioral disengage			⊕ 14 ⊖ NS	⊕ 14 ⊖ NS	⊕ ⊖ NS 2	⊕ 14 ⊖ NS		⊕ ⊖ NS 14	⊕ ⊖ NS 12,14	⊕ ⊖ NS 12	
Avoidance						⊕ ⊖ 9 NS		⊕ ⊖ NS 5	⊕ 5 ⊖ NS	⊕ 5 ⊖ NS	
Denial	⊕ ⊖ NS 1		⊕ ⊖ NS 1	⊕ ⊖ 1 NS			⊕ ⊖ NS 1	⊕ ⊖ NS 1	⊕ ⊖ NS 12	⊕ ⊖ NS 12	

Coping Strategies	Influencing factors											
	Demographics						Demographics					ADL
	Carer Age	PLWD Age	Gender	Education	Religion	Employment	Relationship with PLWD	Memory Problem	Behavior Problems	Depression Problems		
Self-distraction	⊕ ⊖ NS 1		⊕ ⊖ NS 1,14	⊕ 1 ⊖ NS 14	⊕ ⊖ NS 2	⊕ ⊖ NS 14	⊕ ⊖ NS 1	⊕ ⊖ NS 1,14	⊕ 12 ⊖ NS 14	⊕ 12 ⊖ NS		
Self-blame	⊕ ⊖ NS 1		⊕ ⊖ NS 1	⊕ ⊖ 1 NS	⊕ ⊖ NS 2		⊕ ⊖ NS 1	⊕ ⊖ NS 1,5	⊕ ⊖ NS 5,12	⊕ ⊖ NS 5,12		
Substance use			⊕ 14 ⊖ NS	⊕ 14 ⊖ NS		⊕ 14 ⊖ NS		⊕ ⊖ NS 14	⊕ ⊖ NS 12,14	⊕ ⊖ NS 12		
Emotional Venting					⊕ ⊖ NS 2				⊕ ⊖ NS 12	⊕ ⊖ NS 12		
Wishful thinking								⊕ ⊖ NS 5	⊕ ⊖ NS 5	⊕ 5 ⊖ NS		
Passive appraisal	⊕ 7 ⊖ NS	⊕ ⊖ NS 7	⊕ ⊖ NS 3,7	⊕ ⊖ NS 7,13								

Coping Strategies	Influencing factors									
	Belief		Social support resources			Other psychological variables				
	Familism	Gratitude	Family stress stigma	Social support	Carer Communication behavior	Family functioning	Carer Competence	Carer satisfaction	Attention control	Inter role conflict
Total Coping Scores	⊕ 3 ⊖ NS			⊕ 3 ⊖ NS				⊕ 3 ⊖ NS		
Problem-focused		⊕ 8 ⊖ NS		⊕ ⊖ NS 8	⊕ 6 ⊖ NS		⊕ ⊖ NS 8			
Problem solving				⊕ 9 ⊖ NS						
Adjusting schedules								⊕ ⊖ NS 11		⊕ ⊖ NS 11
Reducing carer loads								⊕ ⊖ NS 11		⊕ ⊖ NS 11
Active coping,						⊕ 13 ⊖ NS				
Instrumental support				⊕ 9 ⊖ NS				⊕ 11 ⊖ NS		⊕ 11 ⊖ NS
Planning		⊕ 8 ⊖ NS								

Coping Strategies	Influencing factors									
	Belief		Social support resources				Other psychological variables			
	Familism	Gratitude	Family stress stigma	Social support	Carer Communication behavior	Family functioning	Carer Competence	Carer satisfaction	Attention control	Inter role conflict
Positive emotion-focused		⊕ 8 ⊖ NS		⊕ 8 ⊖ NS	⊕ 6 ⊖ NS		⊕ 8 ⊖ NS		⊕ ⊖ NS 11	⊕ ⊖ NS 11
Acceptance		⊕ 8 ⊖ NS								
Emotional support		⊕ 8 ⊖ NS		⊕ 9 ⊖ NS					⊕ 11 ⊖ NS	⊕ 11 ⊖ NS
Humor		⊕ 8 ⊖ NS								
Positive reframing		⊕ 8 ⊖ NS		⊕ ⊖ 9 NS						
Religion/spiritual		⊕ 8 ⊖ NS	⊕ ⊖ 10 NS							
Negative emotion-focused		⊕ ⊖ NS 8		⊕ ⊖ NS 8		⊕ ⊖ NS 13	⊕ ⊖ NS 8			
Behavioral disengagement										
Avoidance				⊕ 9 ⊖ NS						

**Chapter 3. Paper 2- Asian Family Carers of Persons Living with Dementia: Stress and
Coping Model**

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Introduction

The decline of physical, mental, and social functions of persons living with dementia may be challenging for their family carers (Farina et al., 2017). Family carers cope with the cognitive and behavioral decline of persons living with dementia, as well as a loss of relationships and changes to identity (Kneebone & Martin, 2003). Caring for persons living with dementia affects the daily lives of carers and can result in stress, poorer physical and mental health, and an increased risk of mortality (Fonareva & Oken, 2014). In Asia, many family carers accept the care of parents with dementia as their obligation (Chan, 2010). It is evident that Asian countries have a higher proportion of adult child carers and have more family members to share care, compared to Western countries (World Health Organization, 2012; Xiao et al., 2015). Carers in Asia who are unable to fulfill their social expectation and role may experience a higher level of stress than carers from other contexts. Carers utilize coping strategies to deal with the caregiving challenges they face, and the choice of coping strategy utilized is affected by various situational and intrapersonal factors (Lazarus & Folkman, 1984). These factors also include values and beliefs such as filial piety, which refers to cultural beliefs regarding respect and obligations to assist their parents (Kim et al., 2015). In particular, Asian family carers holding filial piety beliefs generally accept their duty and responsibility of caring for older persons (Chan, 2010). This value strongly influences the carers' attitudes towards dementia, their coping strategies, and help-seeking behaviors in dementia care (Chan, 2010; Xiao et al., 2015).

Research on carers' stress has mainly been guided by theoretical frameworks such as: (1) the Caregiver Stress Process Model (Pearlin et al., 1990), that emphasized the contribution of caregiving stressors to carers' distress and health outcomes; and (2) the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), that emphasized stress appraisal and coping.

Previous research also highlights that culture influences the coping strategies carers use (Janevic & Connell, 2001; Knight & Sayegh, 2010). Knight and Sayegh (2010) adapted the Transactional Model of Stress and Coping to incorporate the influence of culture on the use of coping strategies among European American and African American carers. Within this updated model, Knight and Sayegh (2010) proposed that cultural values influence a carer's coping style and social support, impacting a carer's well-being. However, there were a limited number of researchers that used this model as a foundation for their study, particularly to the unique population of Asian family carers of persons living with dementia.

The purpose of this article is to apply findings from a recent systematic review to build on the Caregiver Stress Process Model (Pearlin et al., 1990) and the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) to propose a conceptual model for understanding how Asian family carers of persons living with dementia cope with stress. This paper begins with a review of those models, which have been used to understand the experience of stress and coping of family carers of persons living with Alzheimer's disease. Similarities and incongruences of those models with the experience of family caregiving of Asian family carers of persons living with dementia are discussed, with reference to the literature. We then proposed a model to better reflect stress and coping among Asian family carers of persons living with dementia.

Caregiver Stress Process Model

This model developed through many studies on the effect of caregiving on stress process and carers' mental health in North America and an exploratory research study among spouses and adult children who care for persons living with Alzheimer's disease (Pearlin et al., 1990). It outlines four key domains to understand the experience of the stress of family carers of persons

living with Alzheimer's disease: (1) background and contextual factors; (2) stressors; (3) mediating factors; and (4) outcomes (Pearlin et al., 1990). Background and contextual factors are concerned with key characteristics of the carer (i.e., age, gender) and care-recipient (e.g., length of care). Stressors are divided into two categories: primary stressors, which are defined as the physical demands of the caregiving role (i.e., cognitive status, behavior problems, carer overload), and secondary stressors, which are the psychological strains associated with caregiving (i.e., family conflict, economic problems). Coping strategies and social support mediate the effects of stressors on outcomes and involve the mental and physical health of the carers as well as their ability to continue in their role. These domains interact together, forming a process that varies widely among carers (Lloyd et al., 2018). For example, stressors are influenced by a variety of background and contextual characteristics of the carers and persons living with Alzheimer's disease (i.e., sociodemographic factors), primary stressors, which may be objective or subjective (e.g., behavior problems and carer overload), and secondary role strains (e.g., economic strain). Stressors and contextual factors interact to affect caregiving stress and subsequent negative outcomes for carers. Even though the Caregiver Stress Process model considered coping as a factor mediating the impact of caregiving stress on health outcomes, this model appears to not effectively explain how carers appraise situations. How carers appraise situations in order to cope with stress is proposed in the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984).

Transactional Model of Stress and Coping

This model was developed in the United States of America, based on several studies on stress and coping (Lazarus & Folkman, 1984). It has been used in shaping stress and coping research over the past five decades (Biggs et al., 2017). The Transactional Model of Stress and

Coping posed that adaptation to stress is mediated by appraisal of stress and by the coping strategies that an individual utilized (Lazarus & Folkman, 1984). This model explains and predicts the variety of responses that carers may demonstrate when they encounter stressors. There are four domains in this model that explain this process: (1) The person and environment factors that affect the appraisal process; (2) A cognitive appraisal to determine whether the situation is a threat, a challenge, a harm or a loss; (3) An assessment of coping resources to select specific coping strategies to manage the problem; and (4) Outcomes that are produced by coping efforts and which are linked to somatic health, morale, and social functioning. Successful outcomes lead to positive emotions, while unsuccessful outcomes produce distress, which initiates reappraisal and additional coping attempts (Biggs et al., 2017; Lazarus & Folkman, 1984).

Lazarus and Folkman (1984)'s model emphasizes the two important phases of stress appraisals and coping. There are three stress appraisal steps. (1) The primary appraisal refers to evaluation of the stressor. It involves determination of whether the situation is a threat, a challenge, a harm or a loss. (2) The secondary appraisal refers to an evaluation of resources and ways to cope with a situation. A coping strategy is selected through secondary appraisal, and if the outcome produces distress, the individual engages in reappraisal. (3) Reappraisal accounts for changes based on new information received or experiences that lead to a reinterpretation of the situation.

In addition, Lazarus and Folkman (1984) suggested two broad categories of coping strategies: problem-focused and emotion-focused. Problem-focused coping strategies include actions that aim to manage the source of stress. These include active coping, planning, and problem-solving. Emotion-focused are aimed at lessening emotional distress, for example,

avoidance, minimization, and distancing. Which strategy is beneficial depends on how people appraise and cope with a situation, and this is influenced by person factors (e.g. an individual's values and beliefs) and environmental factors (e.g., demands and resources) (Lazarus & Folkman, 1984). As such, their model adds additional information on stress and coping and compliments the Caregiver Stress Process Model.

Combining the Caregivers Stress Process Model and the Transactional Model of Stress and Coping leads to a more complete understanding of stress and coping among Asian carers of persons living with dementia. Figure 3-1 represents the combination of the Caregiver Stress Process model (Pearlin et al., 1990) and the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). As shown in Figure 3-1, stressors are influenced by carer characteristics and how one forms an appraisal process and coping response to cope with stress. One's appraisal of a particular situation as harmful, threatening, or challenging is based on person and environment factors (Lazarus & Folkman, 1984). Person factors (i.e., cultural values and beliefs) work interdependently with environment factors to determine the degree to which the stressor will be experienced as harm, loss, threat, or challenge (Folkman & Lazarus, 1988). This experience moderates the stress process and coping. Coping is also influenced by cultural values and coping resources that impact outcomes, which are linked to somatic health, morale, and social functioning.

Previously, one study proposed a combination of the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) and the Caregivers Stress Process Model (Pearlin et al., 1990). This study focused on the stressors, joys, and parental coping among primary carers of children with Autism Spectrum Disorders in the United States (Corman, 2008). The findings from this study suggested that only focusing on the stress-coping process and the negative

outcomes associated with caregiving offers a limited lens for examining carers' lived experiences (Corman, 2008). The resulting framework was not specifically designed for caregiving, stress, and coping processes of Asian family carers of persons living with dementia.

While both Pearlin's (1990) Model and Lazarus and Folkman's (1984) model described cultural beliefs in terms of background factors that influence the stress appraisal process. However, Knight and Sayegh (2010) argued that cultural beliefs operate through influences on social support and choice of coping rather than directly influencing the stress appraisal process. Furthermore, carers from different cultures cope with caregiving challenges differently (Chun et al., 2006; Leong, 2007). For example, in cultures oriented toward individualism (e.g., United States) there is a strong emphasis on individual rights, a concern for oneself and immediate family, and personal autonomy and self-fulfillment (Chun et al., 2006). Conversely, in cultures oriented toward collectivism (e.g., China, Japan, Thailand), there is a focus on interpersonal harmony and fulfillment of social roles (Chun et al., 2006). Therefore, the role cultural beliefs play in stress and coping model tends to vary, depending upon the cultural group. To our knowledge, the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) and the Caregivers Stress Process Model (Pearlin et al., 1990) have not been adapted previously for use in studying the population of Asian family carers of persons living with dementia.

Developing a revised model

We developed a revised model to include key variables that influence coping identified in literature included in a systematic review of quantitative studies to assess coping strategies utilized among Asian family carers of persons living with dementia (Kaewwilai et al., submitted manuscript, 2021). In addition to quantitative studies, we reviewed qualitative studies conducted with Asian family carers to understand stress and coping. Further, we identified which variables

from the Caregiver Stress Process Model (Pearlin et al., 1990) and the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) required revision to better reflect the quantitative and qualitative literature related to coping among Asian family carers of persons living with dementia.

The main changes made to the model were: specifying person and environment factors for the particular context of Asian family carers of a person with dementia; highlighting the importance of perceived social support; describing a broader influence of culture on several aspects of the appraisal and coping process; differentiating between positive and negative emotion-focused coping strategies, and emphasizing quality of life (QOL) as an outcome of coping. The components of the revised model are explained below.

Asian Family Carers of Persons living with Dementia Stress and Coping Model

The revised interrelationships between the causal antecedent variables, stress appraisal process, coping strategies utilized, coping resources, and outcomes of coping are presented in Figure 3-2.

Antecedents

This revised model considers person factors of carer characteristics (i.e., age, gender, level of education, religion, employment status, and relationship to care recipient), environmental factors of care-recipient characteristics (i.e., cognitive status, problematic behavior, Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) dependencies of persons living with dementia), and perceived social support as antecedents for the three constructs: a) appraisal process, b) the stress appraisal associated with choice of coping strategies utilized and c) QOL outcomes. In addition, cultural beliefs appear to influence the

entire coping process, including the appraisal, choice of coping strategies utilized, coping resources, and outcomes of coping.

Person factors

In the revised model, we proposed to specify carer characteristics as person factors to be included in the model. Carer characteristics such as age, gender, level of education, religion, employment status, and relationship to care recipient were directly associated with the appraisal process and coping strategies utilized among Asian family carers of persons living with dementia (Kaewwilai et al., submitted manuscript, 2021). With regards to carer characteristics, passive appraisal and religion coping were associated with older family carers (Tayet al., 2016) and spousal carers (Pattanayak et al., 2011). Compared to female carers, male carers used more problem-solving coping (Pattanayak et al., 2011) and substance use and behavioral disengagement strategies (Yuan et al., 2020). Family carers who were more educated used coping strategies like problem-solving, positive distraction, and acceptance (Pattanayak et al., 2011).

On the other hand, less educated carers used more religion coping and denial (Pattanayak et al., 2011). Moreover, religion was positively associated with active coping, planning, and positive reframing (Lim et al., 2011). Further, employment status was positively associated with problem-solving, instrumental support, emotional support, positive reframing, behavioral disengagement, and substance use, and negatively associated with avoidance (Nishio et al., 2017; Yuan et al., 2020).

In the Pearlin (1990) Model, carer characteristics are factors that influence primary stressors, which influence appraisal and chose of coping strategies. Therefore, in the context of Asian family carers of persons living with dementia, age, gender, level of education, religion,

employment status, and relationship to care recipient were person factors that influenced both appraisal and choice of coping strategies.

Environment Factors

In the revised model, we proposed to specify cognitive status, problematic behavior, ADL, and IADL dependencies of persons living with dementia as the environment factors to be included in the model. According to our systematic review (Kaewwilai et al., submitted manuscript, 2021) cognitive status, problematic behavior, ADL, and IADL dependencies of persons living with dementia were associated with the coping strategies utilized. There was a positive association between cognitive status of persons living with dementia and acceptance (Yuan et al., 2020). Several studies found the association between behaviors and depression problems of persons living with dementia and which coping strategies were utilized (Kaewwilai et al., submitted manuscript, 2021). For example, there was a positive association between behaviors and depression problems with active coping, planning, acceptance, avoidance, and self-distraction (Baharudin et al., 2019; Huang et al., 2015; Yuan et al., 2020). Further, one study found that carer spiritual coping was positively associated with the instrumental activities of daily living of persons living with dementia (Saffari et al., 2018). Another study found a negative association between ADL dependency and total coping scores (Ondee et al., 2013).

In Pearlin's Model, cognitive status, problematic behavior, and ADL and IADL dependencies are considered primary stressors which influence appraisal and chose of coping strategies. Therefore, in the context of Asian family carers of persons living with dementia, cognitive status, problematic behavior, and ADL and IADL dependencies of persons living with dementia were environment factors that influenced both appraisal and choice of coping strategies.

Social support

Asian family carers of persons living with dementia sought support from other family members, friends, neighbors, the formal health care system, and the government to maintain their caregiving role. This support also helped them cope with caregiving responsibilities (Au et al., 2013; Balouch et al., 2020; Basnyat & Chang, 2017; Nguyen & Levkoff, 2020; Senchai et al., 2017; Srinim, 2015; Zhang et al., 2020). Studies revealed the positive association between social support and coping (Lau & Cheng, 2017; Liu et al., 2012; Nishio et al., 2017), particularly positive emotion-focused coping (Lau & Cheng, 2017). Another study found a positive association between social support resources and problem-solving, instrumental support, emotional support, and avoidance, but a negative association between social support resources and positive reframing was also found (Nishio et al., 2017). Thus, most studies identified a positive association between social support resources and coping strategies utilized among Asian family carers of persons living with dementia.

In addition, carers reported that sharing the caring responsibilities between family members helped them release burden and cope well with caregiving roles (Zhang et al., 2020). Moreover, one study also found a positive relationship between family functioning and active coping (Li et al., 2020). This positive relationship suggests that as family function increases, so does the family carers' coping.

In the revised model, we proposed to refer to social support specifically as perceived social support. Perceived social support is a stronger predictor of stress-related outcome than either the actual support received or one's network size (Liu et al., 2012; Roth et al., 2006; Williams & Dilworth-Anderson, 2002). del-Pino-Casado et al. (2018) suggested that the relationship between social support and health outcomes can vary according to whether it was

perceived or received social support that was measured (del-Pino-Casado et al., 2018).

Furthermore, a study among Asian family carers of persons living with dementia also reported the important influence of perceived social support on carers' appraisal and coping. For example, Liu et al. (2012) found an indirect effect of perceived social support on carers' psychological health mediated by caregiving satisfaction, caregiving subjective burden, and coping among Chinese family carers of persons living with dementia. Thus, it seems that perceived (rather than received) social support is an important factor that influences the caregiving appraisal, coping strategies utilized, and the outcomes of coping.

Cultural beliefs

Studies among Asian family carers of persons living with dementia suggested that cultural beliefs influenced not only the stress appraisal and choice of coping strategies, but also social support and outcomes of coping (Au et al., 2013; Balouch et al., 2020; Basnyat & Chang, 2017; Kaewwilai et al., submitted manuscript, 2021; Nguyen & Levkoff, 2020; Senchai et al., 2017; Srinim, 2015; Sun, 2014; Zhang et al., 2020). As a result, in the revised model, we considered cultural beliefs as one factor that influences appraisal, coping strategies utilized, quality of life, as well as social support. Studies found that carers held values of family responsibility and obligation in caregiving based on filial piety beliefs and social expectations. (Au et al., 2013; Balouch et al., 2020; Basnyat & Chang, 2017; Nguyen & Levkoff, 2020; Senchai et al., 2017; Srinim, 2015; Sun, 2014; Zhang et al., 2020). Within the Asian culture, it is the children's responsibility to take care of their parents to fulfill their social responsibility and expectations (Nguyen & Levkoff, 2020; Zhang et al., 2020). These values helped carers cope with their role and responsibilities (Zhang et al., 2020). In addition, a study found that higher levels of filial piety were associated with positive caregiving experience, which, in turn,

predicted lower levels of burden (Lai, 2009). However, carers may also feel obliged to care for their family, which can create conflicts resulting in carers having difficulty coping with their roles (Au et al., 2013; Balouch et al., 2020; Nguyen & Levkoff, 2020).

Familism is another cultural belief that has been found to be associated with stress appraisal and coping in family caregiving among Chinese family carers of persons living with dementia (Liu et al., 2012). Familism is a group value that promotes respect for elders, and it emphasizes how interpersonal relationships and sharing caregiving responsibility within a family impact care provision (Miyawaki, 2015). Carers who placed a higher value on familism were more likely to report higher caregiving satisfaction, more positive coping strategies, and better psychological health (Liu et al., 2012).

Finally, stigma and discrimination towards dementia does exist in Asian societies (Au et al., 2013; Balouch et al., 2020; Sun, 2014). For example, the stigma surrounding institutional care still persists. Studies reported that carers who would like to admit persons living with dementia to long-term care facilities feel frustrated from the judgment of their neighbors that they could not take care of their parents (Au et al., 2013; Balouch et al., 2020). In addition, because of stigma related to the dementia disease, carers felt uncomfortable acknowledging their relative's illness to other people who were not their family members, and this discouraged them from actively seeking support (Au et al., 2013; Balouch et al., 2020; Sun, 2014).

According to Lazarus and Folkman's (1984) model, the process of stress appraisal is influenced strongly by a person's beliefs, values, and attitudes about the stressor. Studies in Asian family carers of persons living with dementia found that cultural values and beliefs influenced other appraisal components in addition to the process of stress appraisal (i.e., social support and choice of coping strategies) that lead to different outcomes or further reappraisal.

Thus, it seems that cultural values are an important factor that influences the appraisal, choice of coping strategies, social support, and coping outcomes.

Stress Appraisal

Similar to Lazarus and Folkman's (1984) model, Asian family carers of persons living with dementia also described how carers' appraisal of the situational strain and their appraisal of personal/social resources influenced their ability to cope with strain. For example, if a carer appraises the caregiving situation negatively, then stress will occur in the form of a loss (e.g. identity loss of persons living with dementia), threat (e.g., threat to carer identification with the caregiving role), or challenge (e.g., difficulty coping with their new identity in caregiving). For example, carers who experience the identity loss of persons living with dementia also contributed to their own loss (Nguyen & Levkoff, 2020; Zhang et al., 2020). In addition, carers who were not able to cope with their new roles may experience negative emotions such as depression (Nguyen & Levkoff, 2020; Senchai et al., 2017; Srinim, 2015; Zhang et al., 2020).

Pearlin's (1990) Model considers inter-role conflict as a secondary stressor that links primary stressors (i.e., carer overload, ADL dependencies) and secondary intrapsychic strains (i.e., loss of self, role captivity) (Pearlin et al., 1990). In addition, one study found a positive association between inter-role conflict and social support seeking among Japanese family carers of persons living with dementia (Morimoto et al., 2019).

Finally, caregiving competence is defined as the psychological state associated with caregiving-related stressors and role strains (Pearlin et al., 1990). Pearlin's (1990) Model considers caregiving competence as a secondary intrapsychic strain that links secondary stressors and caregiving outcomes (Pearlin et al., 1990). Research findings have revealed a positive

association between caregiving competence and emotion-focused coping among Chinese family carers of persons living with dementia (Lau & Cheng, 2017).

Therefore, in the revised model, carer's appraisal is linked to problem- and/or emotion-focused coping strategies. Successful outcomes lead to positive emotions, while unsuccessful outcomes produce distress, which initiates reappraisal and coping attempts.

Coping Strategies

Lazarus and Folkman (1984) conceptualized coping as including both problem-focused and emotion-focused coping strategies. Asian family carers of persons living with dementia used problem-focused coping strategies as well as emotional-focused coping strategies. Kaewwilai et al.'s (submitted manuscript, 2021) systematic review found consistent evidence that greater use of problem-focused and positive emotion-focused coping was associated with better physical QOL. The greater use of positive emotion-focused coping was associated with better psychological QOL, while problem-focused coping strategies showed inconsistent associations with outcomes of psychological QOL. The greater use of denial or self-blame was associated with lower physical and psychological QOL (Kaewwilai et al., submitted manuscript, 2021).

In the revised model, we proposed to differentiate between positive and negative emotional coping strategies to help clarify the impacts of emotion-focused coping. This classification of positive and negative emotion-focused coping strategies differentiates between adaptive and maladaptive functions of emotion-focused coping strategies referred to as dysfunctional coping by Carver et al. (1989). Coping strategies will be grouped into three categories according to previous research evidence: (1) problem-focused strategies, including active coping, instrumental support, and planning; (2) positive emotion-focused strategies including acceptance, emotional support, humor, positive reframing, and religion; (3) negative

emotional coping strategies including behavioral disengagement, denial, self-distraction, self-blame, substance use and emotional venting (Coolidge et al., 2000).

The recent systematic review that assessed coping and adjustment in carers of all ages found that studies on coping and outcomes of coping in carers have been produced inconsistent findings (Hawken et al., 2018). For example, emotion-focused coping strategies were associated negatively with carer adjustment and linked to increased psychological and emotional distress in some studies (Figueiredo et al., 2014; Pakenham & Bursnall, 2006), while other emotion-focused coping strategies were found to be helpful by others (Azman et al., 2017; Figueiredo et al., 2014). Therefore, classifying coping strategies by differentiating between positive and negative emotion-focused coping strategies might be an alternative to the homogenous emotion-focused category to explain how Asian family carers of persons living with dementia benefit from different types of coping strategies.

Quality of Life as an Outcome of Coping

Consistent with Lazarus and Folkman's (1984) model, outcomes of coping (somatic health, morale, and social functioning) are influenced by the effectiveness of the coping strategy utilized. However, QOL is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to their environment (WHOQOL Group, 1993). The impact of coping strategies utilized and QOL among Asian family carers of persons living with dementia has been documented in the literature. In the domain of physical health, there is a positive relationship between problem-focused and emotion-focused coping strategies with the physical domain of QOL (Jeong et al., 2018). Conversely, negative emotion-focused coping strategies (i.e., denial and self-blame) were negatively associated with the physical domain of QOL (Pattanayak et al.,

2011). In the domain of psychological health, studies found a positive association between problem-focused and emotion-focused strategies with the psychological domain of QOL (Jeong et al., 2018; Morimoto et al., 2019; Pattanayak et al., 2011). Studies found that positive emotion-focused coping strategies (i.e., instrumental support, emotional support, positive reframing, and religion coping) had a positive relationship with psychological health (Pattanayak et al., 2011; Saffari et al., 2018; Tay et al., 2016). Conversely, denial and self-blame were negatively associated with physical QOL (Pattanayak et al., 2011). In the domain of social and environment relationships, studies found that instrumental support and emotional support had a positive relationship with the social relationship domain of QOL (Pattanayak et al., 2011; Tay et al., 2016). In addition, positive reframing was positively associated with the environment domain of QOL (Tay et al., 2016).

Thus, in the revised model, relevant research supported the inclusion of QOL as a key outcome of coping.

Nursing implications for research, theory, and practice

The Asian Family Carers of Persons Living with Dementia Stress and Coping Model has been developed based on previous theory and qualitative and quantitative research findings specific to the population. The Asian Family Carers of Persons Living with Dementia Stress and Coping Model can be used as a foundation for future research. For example, nurse researchers should examine the association between choice of coping strategies utilized and QOL as well as the potential person/environment factors, cultural beliefs, and social support that influence stress and coping process.

The model may also be helpful in developing an assessment tool to identify Asian carers who are at risk for poor QOL based on the specific coping strategies that they use. This

assessment tool would target the person and environment factors associated with type of coping strategies utilized and QOL outcomes. Assessing the person and environment factors by nurses may help identify carers who are at risk for stress and difficulty coping. Also, nurses could support carers to use positive coping strategies such as positive reframing and acceptance. This would allow nurses to help carers develop more effective coping strategies to reduce stress and enhance their QOL.

In addition, the model will guide the future development of interventions that incorporate cultural values of filial piety and familism and that target (1) carers and care-recipients, (2) social support, and (3) stress and coping processes to enhance Asian family carers' ability to cope with caregiving demands and achieve QOL.

This model was adapted to reflect the literature on dementia caregiving, and it may not be applicable to other populations of carers, such as those with other chronic diseases. It is also based on the literature of stress and coping in Asian family carers of persons living with dementia. As such, it may not be applicable to carers in different cultures.

Conclusion

Our conceptual model explains the interactions between stressors, appraisals, coping, and the various mediators that influence QOL. This conceptual model adds to the literature on dementia caregiving by identifying specifically related factors that influence coping process from Asian family carers of persons living with dementia. This model will be useful as a conceptual framework to guide research related to coping among Asian family carers of a person living with dementia, for example, by illustrating relationships to test and covariates to include in multivariable models. Future research is required to test and modify this conceptual model as

appropriate. Even so, this model describes how Asian family carers appraised dementia caregiving situations, coping strategies utilized, and outcomes.

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Figure 3-1 Stress and coping process of family caregiving. Adaptation from Lazarus and Folkman's (1984) and Pearlin et al.'s (1990) Models

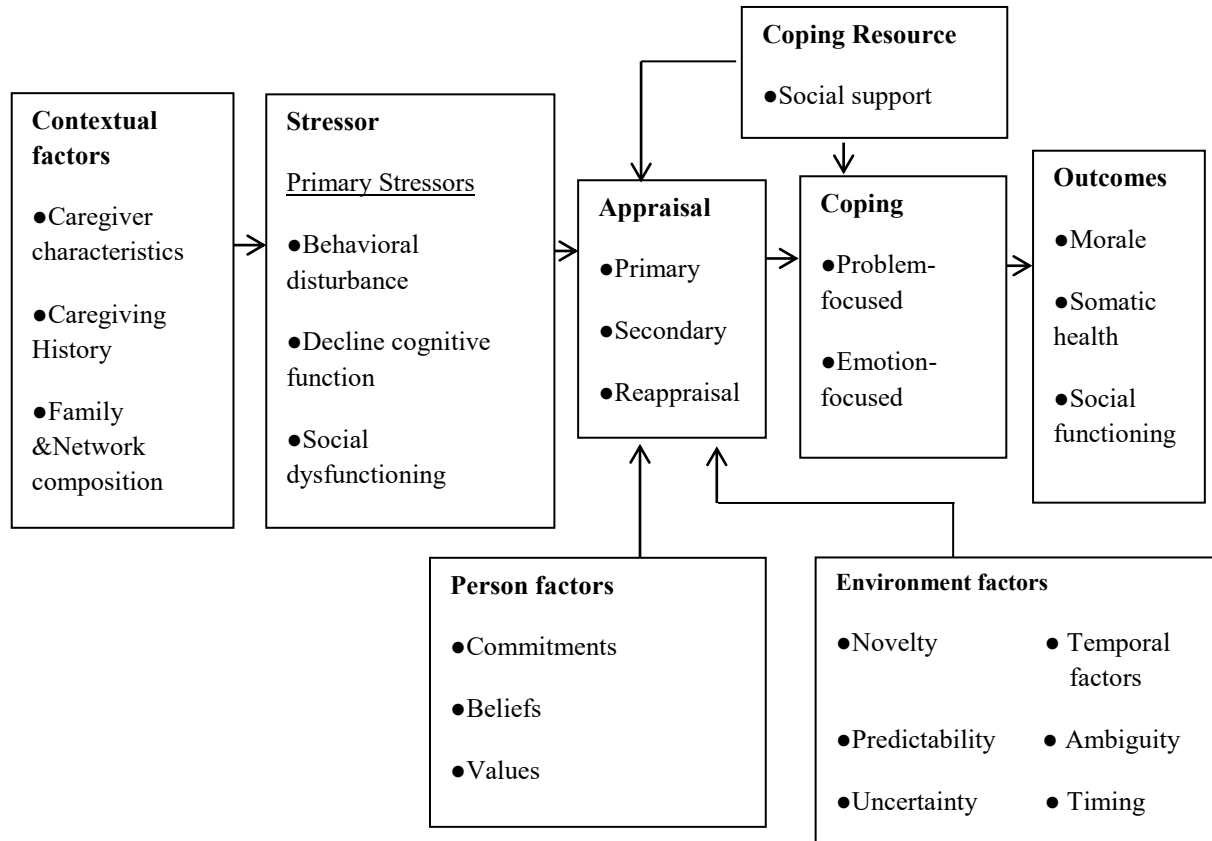
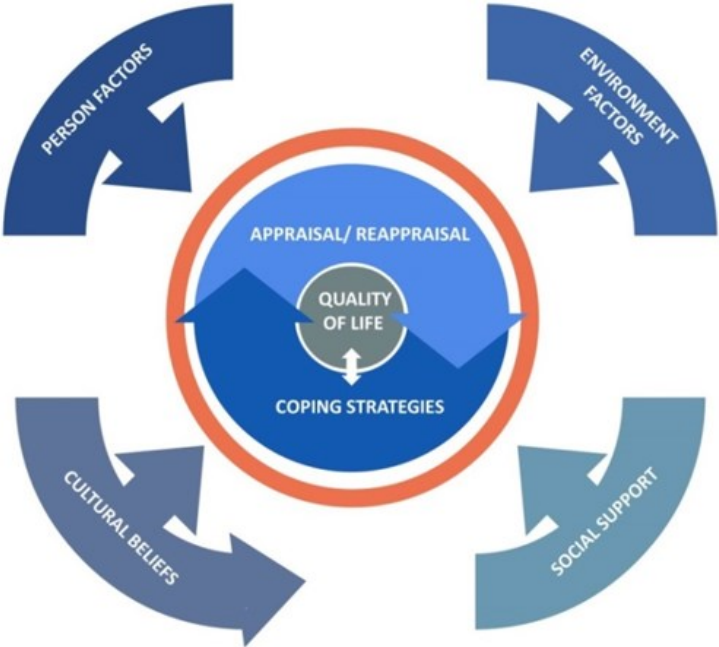


Figure 3-2 The Asian Family Carers of Persons Living with Dementia Stress and Coping Model



**Chapter 4. Paper 3-Lessons Learned: Challenges and Successful Strategies to Recruit Thai
Family Carers of Persons Living with Dementia to Participate in Research During the
COVID-19 Pandemic**

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Introduction

Recruitment of research participants in the area of dementia caregiving research can be very challenging. The challenges can surprise inexperienced researchers who tend to overestimate the number of potential participants and those willing to participate in their research (Gul & Ali, 2010). Recruitment challenges result in study re-design, delays in starting and consequently completing the study, or invalid findings (Williams et al., 2017). Recruiting participants during the COVID-19 pandemic is likely to create multiple further difficulties. Specifically, carers of persons living with dementia have experienced a significant increase in the physical and psychological burden of care during the COVID-19 period (Achraf et al., 2020; Budnick et al., 2021). Carers who were more concerned about the pandemic and received insufficient support from other family members were more likely to experience distress related to their role as carers (Savla et al., 2021). Research studies suggest that a common challenge for family carers' participation in research included being too busy to take time to participate in a study (Bull et al., 2014; Williams et al., 2017).

Previous studies have discussed the recruitment challenges found in dementia caregiving research and strategies to overcome these challenges (McPhillips et al., 2021; Morrison et al., 2016; Szabo et al., 2018). For example, Szabo et al. (2018) described barriers and challenges in recruiting early-stage dementia caregiving dyads into research studies. The following recruitment barriers were reported: (1) recruitment site population not appropriate for the study, (2) competing recruitment activities at referring organizations, and (3) rigid inclusion criteria that eliminated appropriate participants. Strategies used to address these barriers were telephone screenings for potential participants and staff is well trained to work with older adults and persons with cognitive loss.

Two studies examined the challenges in participant recruitment among Asian carers of persons living with dementia residing in Western countries (Fry et al., 2021; Hinton et al., 2000). Fry et al. (2021) reported a study that recruited British South Asian carers of persons living with dementia. Four barriers were reported, including (1) language barriers, (2) confusion over research, (3) feelings of shame/stigma, and (4) mistrust. A study regarding the barriers to the recruitment of Chinese–American family carers for dementia research reported four sociocultural barriers to recruitment, including 1) dementia was viewed as a normal part of aging, making it more challenging to identify dementia-affected older persons and to recruit families; 2) research participation was viewed as potentially harmful; 3) social stigma about dementia, leading families to ignore formal diagnosis and research participation; and 4) practitioners viewed research as having no direct benefit to participants (Hinton et al., 2000).

There are, however, no published studies that described recruitment challenges and strategies of family carers of persons living with dementia in Asia during the COVID-19 pandemic. Thus, there is a great need for additional information regarding recruitment efforts and strategies to overcome recruitment challenges in samples drawn from Asian countries. With this information, researchers can learn from previous research, and most importantly, researchers can estimate the time and resources required for successful recruitment. The purpose of the current article is to describe the participant recruitment processes and outcomes of Thai family carers of persons living with dementia in a survey study designed to examine the association between coping strategies utilized and quality of life (QOL) among these carers. As well, the main recruitment challenges and successful strategies to overcome the recruitment challenges are discussed.

Study Background

Recruitment challenges and strategies used to overcome these challenges were experienced when conducting a study to examine the association between coping strategies utilized and QOL among Thai family carers of persons living with dementia. A survey research design was used. Carers were sampled from Thai family carers of persons living with dementia residing in the community. We aimed to recruit a total of 100 Thai family carers of persons living with dementia, based on a sample size calculation. Inclusion criteria for the study were: (1) family or friend carer of a person living with dementia in the community; (2) providing any of physical, emotional, financial, or spiritual care for the person living with dementia; (3) over the age of 18; (4) have access to a telephone or a computer with the internet; and (5) English or Thai speaking. The exclusion criteria were: (1) carer of a person with dementia who had already died; (2) carer of a person with dementia residing in a long-term care facility or hospitalized; and (3) carer who had provided assistance to an individual with a neurological diagnosis other than dementia. Those who agreed to participate and met the inclusion criteria were invited to complete a 40-60 minute survey at a single point in time. Prior to participant recruitment and data collection, this study received ethics approval from (a) the University of Alberta Research Ethics Board, Canada (Pro00102422), (b) the Ethical Review Committee for Human Research, Faculty of Public Health, Mahidol University, Thailand (MUPH 2020-123), and (c) the Institutional Review Board of the Faculty of Medicine, Chulalongkorn University, Thailand (IRB 028/64).

Participant Recruitment

Recruitment of participants occurred between January and April 2021 using a multi-pronged approach, which included the use of social media and in-person recruitment.

Social Media

Initially, the research team planned to distribute a recruitment flyer through direct email contact to Thai family carers of persons living with dementia who were registered in the Thai Alzheimer's Disease and Related Disorders Association (ADRDA) database. The Thai-ADRDA organization did not agree to directly contact individuals with advertisements for research recruitment because their organization was formed to support persons living with dementia and their families, but not for research purposes. However, the Thai ADRDA offered an alternative option to post an advertisement of our study to their social media platform. The Thai ADRDA Facebook administrator posted a recruitment poster and survey link on behalf of the researcher on the Thai ADRDA Facebook group and page. At the time of posting, there were 730 members of Thai ADRDA Facebook group and 16,158 Facebook users following the Thai ADRDA Facebook page.

Thus, the research team adjusted the recruitment strategies to include the use of social media, not only through the Thai-ARDA, but also using Facebook groups and pages with content relevant to dementia or caregiving. Facebook groups and pages relevant to the population of interest were selected because these strategies demonstrated greater effectiveness in recruiting participants from former dementia carer populations in previous research (Corey et al., 2018). Furthermore, an integrative review of 18 studies of research participant recruitment through Facebook also supported that the use of social network sites can help in the recruitment of a hard-to-reach research population (Reagan et al., 2019). In addition, the number of Facebook

users in Thailand reached around 56.3 million users in January 2021, which accounted for 80.7% of the entire population (Napoleon Cat, 2021). Therefore, in this study, researchers used Facebook as a tool to facilitate recruitment in two ways.

First, the researcher posted the recruitment poster on her personal Facebook page. This strategy allowed the researcher to start recruitment while waiting for permission to post the recruitment poster on the online platforms of collaborating organizations. In the post, the researcher requested her friends to share the invitation to their own Facebook timelines to promote participant recruitment. The survey link was not posted with the invitation at this step because the researcher wanted to screen interested individuals for eligibility to participate in this study, as well as to explain the study information to potential participants. This strategy led to a small number of potential participants who met the inclusion criteria and participated in the study (n=8). In this step, one of the participants mentioned that a Facebook invitation with a survey link should be provided to facilitate recruitment because some interested individuals may prefer to not contact the researcher; the researcher noted this suggestion to discuss further with the team.

Second, the recruitment poster and the survey link were posted on the Facebook groups and pages of organizations related to carers and dementia, following review and approval from the organizations. The survey link included two screening questions to confirm eligibility to participate in the study, including: (1) Have you provided assistance to an individual with the confirmed diagnosis of dementia? (2) Does the person living with dementia reside in a community? If no was answered to any questions, the survey would end. Key organizations that helped with online participant recruitment included (1) Thai Alzheimer's Disease and Related Disorders Association, (2) Caregivers of Persons with Dementia Network, Siriraj Hospital, (3)

Cognitive Fitness Center support group, Chulalongkorn Hospital, and (4) The Nurses' Association of Thailand. The introductory letter, a summary of the study proposal, an ethics approval document from Human Research, Faculty of Public Health, Mahidol University, Thailand, and a recruitment poster were sent to the executive director or social media administrator for obtaining approval from the organizations to access the online community members who were likely to meet the study eligibility criteria. There were 76 individuals interested in participating in this study via Facebook recruitment. In total, 57 carers met the inclusion criteria and participated in the study. Nineteen carers were excluded from the study because (1) the carer had provided assistance to an individual without the confirmed diagnosis of dementia (n=11); (2) the person with dementia resided in a long-term care facility or was hospitalized (n=5); (3) the person living with dementia had died (n=1); or (4) both (1) and (2) (n=2).

In-person recruitment

Two months after online recruitment began, in-person recruitment was added to the study. In-person recruitment focused on recruiting participants who were attending appointments with their psychiatrist at the Memory Clinic at Chulalongkorn Hospital. The researcher provided information about the study to the psychiatrist at this clinic and asked for referrals of eligible participants who were interested in the study. In addition, the researcher was allowed to approach family carers who were in the waiting room of their psychiatrist before an appointment took place. The researcher identified eligible participants by asking whether they are family carers of persons living with dementia and explaining the study to the potential participants. If participants met the inclusion criteria and expressed interest in participating in the study, consent was obtained, and a paper questionnaire was provided. Some participants

completed the questionnaire on the spot (n=24). Others completed the questionnaire at a later time and returned it by mail (n=3). Only one participant requested to complete the questionnaire by telephone (n=1). In total, there were 28 participants recruited from the Memory Clinic, Chulalongkorn Hospital.

Six weeks after in-person recruitment began, the third wave of the COVID-19 outbreak occurred in Thailand; therefore, the participant recruitment activities at the Memory clinic were suspended because of hospital policy. Thus, the researcher resumed the Facebook recruitment strategy (n=1) and word-of-mouth referrals (n=3) to recruit the rest of the participants.

Recruitment Results

Of the total number of study participants who began the survey (N=97), 59.8% (n=58) of participants were recruited from organization Facebook pages and groups, 28.9% (n=28) of participants came from in-person recruitment at the Memory Clinic, Chulalongkorn Hospital, and 11.3% (n=11) of participants were referred from colleagues, friends, and neighbors. Of the 97 participants, 88.7% (n=86) of participants completed the entire questionnaire, and 11.3% (n=11) of participants answered only demographic information leaving all other variables unanswered. Table 4-1 demonstrates recruitment rates for the three recruitment strategies. Table 4-2 summarizes the socio-demographic characteristics of research participants.

Recruitment Challenges

Recruitment for a cross-sectional study is generally less difficult than that for cohort studies and randomized controlled trials because it involves single-time data collection with no commitment to follow-up (Patel et al., 2003). However, recruitment for this research study was challenging due to a number of reasons: 1) delays in securing site approvals, 2) challenges with

social media, and 3) clinicians' understanding of the study inclusion criteria and length of time to complete questionnaires.

1. Delays on authorization

The use of a multi-pronged approach required several levels of institutional approvals and constant communication with organizations. Recruiting during the COVID-19 pandemic also added barriers to recruitment resulting in delayed authorization of study recruitment and having to shift strategies. For example, because of COVID-19 pandemic restrictions, the Thai ADRDA moved all their in-person activities to online activities and was focused on the need to support family cares in different ways. As a result, supporting the study through recruitment was not a priority, which resulted in a delay of operational approval for the study recruitment.

2. Challenges with social media

One challenge encountered was the lack of direct contact between the researcher and potential participants as a result of posting advertisements on social media. A recruitment poster was posted on social media, and potential participants were asked to contact the researcher if they were interested. Following a suggestion made by a participant to post the weblink, the team discussed and received ethics approval to offer participants the option of completing the survey (without talking with the researcher) via a posted weblink. Most participants recruited through social media 59.8% (n=58) preferred to complete the survey link on their own without contacting the researcher, and 17.24% (10/ 58) of these surveys contained a large amount of missing data and could not be used in the analysis (e.g., only demographic information provided). A reminder email or letter was sent out to participants who did not complete the survey within two weeks.

Dillman et al. (2014) suggested that multiple contacts can improve the survey response rate (Dillman et al., 2014). Reminder emails were sent out to all participants who had not yet

completed the survey within two weeks (n=6), but only two of these participants responded and completed the survey after receiving a reminder. Unfortunately, we could not contact some participants because the contact information was not provided.

It is unclear why questionnaires were incomplete in our study. It is possible that because the researcher did not meet with study participants to verbally explain the study and answer questions, participants may not have understood the extent or nature of the survey and, once they started the questionnaire, may have decided they no longer wanted to or had the time to take part.

3. Ethical Review Committees' understanding of the study inclusion criteria and questionnaire length

The present study was recruiting family carers of a person living with dementia, and our definition of family carer, which was derived from previous literature, did not always fit with clinicians' understandings of this term. Family carers were defined as family members or friends of the person living with dementia who provide unpaid care for the person living with dementia. Care tasks may include assistance with bathing, dressing, meal preparation, housekeeping, transportation, and managing finances. In addition to these physical tasks, family caregiving can also include an emotional connection to the care receiver and providing psychosocial support (Peacock et al., 2013). The understanding of the study inclusion criteria resulted in recruitment challenges because the Ethical Review Committees from the organizations we collaborated with often asked us to be more specific with the inclusion criteria. The Ethical Review Committees often held the perception that variables such as being a primary family carer or the duration of care may influence stress, coping, and QOL among Thai family carers of persons living with dementia. We explained that our definition was broad, and our aim was to recruit any family carer or friend providing a broad range of assistance to persons living with dementia, not

necessarily primary carers. We did not make changes to the inclusion criteria as the Ethical Review Committee requested from two organizations because the study was descriptive/ exploratory in nature, so narrowing the inclusion criteria would have limited the type of participants. However, we added four questions in the demographic form: (1) How long have you been caring for a person living with dementia? (2) What is the average length of care per day? (3) Are you a primary carer? And (4) Do you have other family carers or other people to support the care for the person living with dementia? By adding these questions, the Ethical Review Committees approved our study.

In this study, participants completed the questionnaires in approximately 40-60 minutes. The Ethical Review Committees from the organizations we collaborated with often asked us to consider shortening the length of the survey. Additionally, some participants complained that the survey was too long. Nevertheless, we were unable to reduce the length of the questionnaires because we used formal standardized questionnaires to collect all related variables to address the research question. To address the challenge of the length of survey, the researcher provided motivational statements within the questionnaires that informed participants about the percentage of the questions that had been completed. For example, "You have completed 20% of the survey! There are three questionnaires to be completed." In addition, participants were offered the option to return to complete the questionnaires later if they could not complete it within one sitting.

Strategies to Support Successful Recruitment

Within a 4-month period, five key organizations assisted with participant recruitment, including: (1) Thai Alzheimer's Disease and Related Disorders Association, (2) Caregivers of Persons with Dementia Network, Siriraj Hospital, (3) Cognitive Fitness Center support group, Chulalongkorn Hospital, (4) Memory Clinic, Chulalongkorn Hospital, and (5) The Nurses'

Association of Thailand. A number of strategies were employed to address the challenge of achieving an adequate sample size, including (1) modification of the recruitment process; (2) working with organizations that have access to target participants; (3) using a multi-pronged recruitment strategy; and (4) tracking the number of participants regularly.

1. Modification of the recruitment process

Based on the delayed operational approval from the THAI-ADRDA, the research team met in December, 2020 to devise new recruitment strategies. This included (1) utilizing social media to recruit participants and (2) asking for referrals from colleagues, friends, and neighbors who know individuals interested in participating in the study. An amendment to the study protocol was submitted to (1) the University of Alberta Research Ethics Office, Canada, and (2) the Ethical Review Committee for Human Research, Faculty of Public Health, Mahidol University, Thailand. The amendment was approved from both institutions prior to beginning participant recruitment in January 2021.

At the same time, we sought opportunities for participant recruitment at the Memory Clinic, Chulalongkorn Hospital. Prior to recruitment and data collection, we had to obtain ethics approval from the Institutional Review Board of the Faculty of Medicine, Chulalongkorn University, Thailand. After obtaining ethics approval (February 2021), the introductory letter, the summary of study proposal, ethics approval document, and recruitment poster were sent to the executive director of Chulalongkorn Hospital to obtain permission for data collection at the Memory Clinic, Chulalongkorn Hospital. Recruitment at the Memory Clinic began on March 4, 2021.

2. Working with organizations that have access to target participants

The five organizations listed above were selected based upon the services provided that related to dementia and caregiving. The researcher established a trusting relationship with the organizations by a) introducing the researcher's background and b) explaining the research purpose, methodological approaches, and tools, as well as confidentiality and duty to report the results of the study.

For example, the researcher had initiated discussions with the nurse at Thai ADRDA a year before the study began to meet with the THAI-ARDA staff. Then, when the study was to begin, the researcher sent an email with an introductory letter, ethics approval documents, and a summary of the research protocol to the director of ADRDA. Next, the researcher held a phone conversation with the director of ADRDA about the research study and inquired about recruitment advertisements. The director of ADRDA authorized the researcher to advertise the study via the Thai ADRDA Facebook groups and pages.

For the Carers of Persons Living with Dementia Network, the researcher communicated with the Facebook administrator via Facebook messenger with a brief introduction of the researcher's background and the purpose of the research study, and the researcher requested a recruitment advertisement on their Facebook page. There were 8,639 Facebook users following the Carers of Persons Living with Dementia Network Facebook page. Similarly, the Facebook administrator of the Nurses' Association of Thailand was contacted through Facebook. The recruitment poster from the researcher's personal Facebook page was shared with the Nurses' Association of Thailand Facebook page. There were 12,705 Facebook users following the Nurses' Association of Thailand Facebook page.

For the Cognitive Fitness Center and the Memory Clinic, Chulalongkorn Hospital, the researcher met with key personnel to explain the study. For the Cognitive Fitness Center, the

researcher met with the nurse at the center who organized the support group for the older adults. At that time, the researcher introduced the research protocol and asked to advertise for recruitment among support group members. Next, the researcher contacted the psychiatrist at the Memory Clinic to help with the recruitment. After explaining the study's objectives and methods, the psychiatrist agreed to facilitate in-person recruitment at the Memory Clinic, Chulalongkorn Hospital.

3. Using a multi-pronged recruitment strategy

We used several recruitment strategies to reach the targeted sample size of Thai family carers of persons living with dementia. Recruitment on organizational Facebook pages and groups can be tailored to a targeted participant population who may have already been accustomed to receiving information related to dementia caregiving from other carers or healthcare providers. This strategy was specifically designed for people who met study inclusion criteria. In this study, we did not use a Facebook paid advertisement, which is common for online surveys but rather chose unpaid posts on organizations' Facebook pages and groups related to dementia and caregiving, which is a low-cost recruitment approach. One of the challenges with using an unpaid social media recruitment strategy was that we did not know how many people received the study information or from where participants received study information. Therefore, the response rate was unknown.

In this study, Facebook recruitment was used successfully, but not enough participants were recruited into the study using this single recruitment approach. Also, participants recruited through social media had higher rates of missing data than those recruited via in-person approaches. Thus, an in-person recruitment strategy was initiated.

4. Tracking number of participants regularly

Keeping track of the numbers of participants recruited through social media and in-person recruitment and reviewing these numbers monthly was helpful. This strategy helped the researcher determine which recruitment strategies were effective on an ongoing basis as well as to check for completeness of the questionnaires. In addition, the research team met every month to determine recruitment challenges and strategies and to make any required adjustments to ensure successful recruitment. For example, we decided to plan for a longer recruitment period because of delays in authorization (extending by three months) and used several recruitment strategies when we received low-response rates at the beginning of the study.

Discussion and Conclusion

Three participant recruitment strategies were compared: social media advertisements, in-person recruitment, and word-of-mouth referrals. Recruitment from organizations' Facebook pages and groups yielded the highest rates of actual study recruitment for Thai family carers of persons living with dementia. On the other hand, the in-person recruitment rate was highest for the short recruitment period (6 weeks). Word-of-mouth referrals were comparatively less effective than other strategies. Recruiting participants through Facebook groups and pages, particularly from Thai ADRDA and Carers of Persons Living with Dementia Network, resulted in the highest number of participants. Morrison et al. (2016) also found that those families who self-identify as caregiving and are connected to a social organization respond more frequently to a call for study participation, in comparison with families who encounter study information from other sources. In addition, previous research has found that relationships of trust between researchers and organizations were crucial (Shropshire et al., 2020).

Our findings suggested that using only Facebook for recruitment may not be the best strategy to recruit a large sample for a quantitative study on Thai family carers of persons living

with dementia. Key issues with this approach included lack of direct contact between the researcher and potential participants and a higher proportion of incomplete surveys when compared with in-person recruitment. Therefore, social media recruitment should be used in conjunction with other strategies. Nevertheless, online recruitment was needed to continue recruitment activities during the COVID-19 pandemic. Furthermore, studies using online research methodology are financially feasible, improving ease of participation, enhance the generalizability of findings, and have shortened recruitment periods while preventing potential viral transmissions to research participants or staff (Saber, 2020).

In-person recruitment was found to be effective because it occurred in a clinical setting where carers had a trusting relationship with healthcare providers and the institution. Guillemin et al. (2018) investigated how research participants and researchers understand trust in research. The study revealed that a trusting relationship is focused not only on the participant-researcher relationship but also on the institution and its research integrity (Guillemin et al., 2018). In contrast, word-of-mouth referrals generated the fewest participants in the present study, suggesting that this strategy did not work for this study. Word-of-mouth referrals yielding the lowest enrollment may be related to social stigma about dementia leading to difficulty in identifying dementia-affected older persons and their families. This outcome is consistent with previous research that recruited Chinese Americans for a dementia carer intervention (Gallagher-Thompson et al., 2006). Gallagher-Thompson et al. (2006) found that Chinese-American carers who were recruited by nonprofessional sources (i.e., community-based workshops or presentations, friends, neighbors, or word-of-mouth referrals) were less likely to participate in the studies than those who were recruited through media sources or professional referrals.

One of the reasons a multi-pronged strategy was particularly important in the present study was the occurrence of the third wave of the COVID-19 pandemic in Thailand, during which in-person recruitment activities were halted. Newlin-Lew et al. (2006) also supported the need for researchers to conduct a periodic review of recruitment goals to allow for modification of recruitment methods and an extension of the recruitment period to achieve the desired sample size, if necessary. Our experiences have implications for research planning and implementation for future survey studies. It appears that strategies employed to address the challenges in recruitment are beneficial to improve the participation rate. Our multi-pronged recruitment approach was also advantageous for the completion of doctoral requirements, given that graduate students usually face tight timelines.

Previous research indicates that a high involvement in caregiving appeared to be a burden for response a survey. Particularly, response rates were lower for a longer questionnaire (Galesic & Bosnjak, 2009; Rolstad et al., 2011). Conversely, in caregiving research, one study suggested that carers who were highly involved in their caregiving (i.e., high time investment, high burden) more often responded to an informal care questionnaire (Oldenkamp et al., 2016). McPhillips et al. (2021) also suggested that the decision to participate in a study by persons living with dementia and their carers is influenced by factors such as participants' attitudes, perceived norms, and perceived behavioral control. Previous studies among Asian family carers of persons living with dementia also found that sociocultural factors (e.g., stigma, mistrust) are significant barriers for research participation (Fry et al., 2021; Hinton et al., 2000).

The COVID-19 pandemic has presented multiple challenges not only on researchers' ability to recruit participants in-person but also on carers' ability to participate in the study. Carers of persons living with dementia reported an increase in the physical and psychological

burden during the COVID-19 period (Achraf et al., 2020; Budnick et al., 2021), which may increase respondent burden. In addition, carers may perceive participation in a survey as difficult, time-consuming, or emotionally stressful. Thus, future research may consider options to obtain additional information about carers' nonresponse and explore factors contributing to the decision to participate in the study by family carers of persons living with dementia to further inform recruitment strategies.

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Table 4-1 Recruitment rates for three recruitment strategies based on eligibility criteria

Recruitment strategy	Recruitment timeline	Total recruited	Completed demographic questionnaire only	Completed demographic and outcome questionnaires	Recruitment rate (participants/week)
Word-of-mouth referrals.	January-April 2021	11	1/11 (9%)	10/11 (91%)	0.69
Organization Facebook pages and groups	January-April 2021	58	10/58 (17%)	48/58 (83%)	3.69
In-person recruitment	March-April 2021	28	0/28 (0%)	28/28 (100%)	4.67
Total (N)		97	11/97 (11%)	86/97 (89%)	

Table4-2 Socio-demographic characteristics of research participants who completed and did not complete the outcome questionnaires

		Mean (%) participants who completed demographic questionnaire only N=11	Mean (%) participants who completed demographic and outcome questionnaires N=86
Carer	Female	n=10 (90.9%)	n=75 (87.2%)
	Age	M=47.33, SD=10.49	M= 52.84, SD=9.52
	Marital status		
	-Single	n=7 (63.6%)	n=48 (55.8%)
	-Married	n=2 (18.2%)	n=31(36.0%)
	Level of education		
	-Bachelor degree and above	n=10 (90.9%)	n=76(88.45)
	Employed	n=4 (36.4%)	n=44 (51.2%)
	Relationship with PLWD		
	-Adult children	n=7 (63.3%)	n=74 (86.0%)
	Hours spent caring	M=14.90, SD=9.17	M=15.04, SD=8.47
	Duration of care (years)	M=3.91, SD=2.21	M=4.94, SD=3.96
	Primary carers	n=9 (81.8%)	n=68 (79.1%)

PLWD: Person living with dementia

**Chapter 5. Paper 4- Coping Strategies and Quality of Life among Thai Family Carers of
Community-Dwelling Persons Living with Dementia: A cross-sectional study**

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Introduction

Caring for persons living with dementia is complex, and there is a great cost associated with caregiving (Schulz et al., 2020). For example, many family carers are at an increased risk of deteriorated physical and psychological outcomes (Schulz et al., 2020). As the numbers of carers increase worldwide, nurses need to understand the relationship between stress, coping, and quality of life (QOL) to assist carers to cope with caregiving challenges, minimize stress and maintain QOL. Dementia is a major cause of disability and dependency in older persons (Prince et al., 2013), and in countries such as Thailand, older persons comprise 20% of the population, making Thailand an aging society. The proportion of Thai people older than 60 years is anticipated to grow from 10% in 2000 to 38% by 2050 (Knodel et al., 2018). As the aging population increases, the number of persons living with dementia will also increase. In 2014, there were 600,000 persons living with dementia in Thailand, and this number is expected to increase to more than one million by 2030 and triple by 2050 (Alzheimer's Disease International, 2014). In Thailand, persons living with dementia mainly rely on their family and community for care (Phetsitong et al., 2019). One study in Thailand found that QOL scores of Thai family carers of persons living with dementia were lower than non-carers in all dimensions (Lamliangpon, 2015). The strategies individuals use to cope with stress may affect their physical and psychological health over time. Most of the research on coping and QOL has been conducted in Western countries, and the numbers of Asian studies concerning the association between coping and QOL in family carers of persons living with dementia are limited; even less is known about Thai family carers (Kaewwilai et al., submitted manuscript, 2021). Furthermore, literature from Asian contexts to date primarily tested associations between coping and QOL without adjusting for potential confounding variables (Pattanayak et al., 2011; Tay et al., 2016).

Background

Stress, Coping, and Quality of Life

The increasing dependency of persons living with dementia and the involuntary changes in relationships with family members are sources of carer stress (Pearlin et al., 1990). Lazarus and Folkman (1984) further suggested that adaptation to stress is a cognitive process which includes appraisal of stress followed by the use of coping strategies. Coping refers to a set of dynamic “cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). Lazarus and Folkman (1984) proposed two broad categories of coping strategies: emotion-focused (regulating emotion) and problem-focused (dealing with the problem). In this study, and in alignment with other research (Coolidge et al., 2000; Cooper et al., 2008; Li et al., 2012), emotion-focused coping was further categorized as positive emotion-focused coping and negative emotion-focused coping to distinguish between helpful and unhelpful coping (Carver, 1997; Li et al., 2012). Carers use problem-focused coping strategies to cope with stress by preparing themselves with information and actively managing the situation. Carers use positive emotion-focused coping strategies to cope with stress by managing their emotional response using strategies such as acceptance, positive reframing, and seeking emotional support. Carers use negative emotion-focused coping strategies such as denial, behavioral disengagement, and substance use to avoid stressful situations (Carver, 1997).

Stress and coping have been found to be associated with the mental health (e.g., anxiety, depression) and QOL of carers of persons living with dementia (Kneebone & Martin, 2003; Li et al., 2012). The World Health Organization Quality of Life (WHOQOL) Group defined QOL as "individuals' perceptions of their position in life in the context of the culture and value systems in

which they live and in relation to their goals, expectations, standards, and concerns" (p. 551). In previous research, positive emotion-focused coping was associated with less anxiety and depression among carers of persons living with dementia, and negative emotion-focused coping was associated with more anxiety and depression in carers of persons living with dementia (Gilhooly et al., 2016; Li et al., 2012), as well as, increased carer burden (Monteiro et al., 2018). However, problem-focused coping strategies showed an inconsistent association with outcomes. For instance, reviews of the literature on stress and coping of carers of persons living with dementia in non-Asian countries found that problem-focused coping had positive implications for carer psychological outcomes (Gilhooly et al., 2016; Kneebone & Martin, 2003). In contrast, a longitudinal study by Cooper et al. (2008) found that UK carers who used more problem-focused coping strategies tended to show more anxiety and depression. Meanwhile, a meta-analysis of, which included studies from developed, English speaking countries (n=30), Taiwan (n=2), the Netherlands (n=1), Belgium (n=1), and China (n=1), found that problem-focused coping was not associated with carer's psychological health (Li et al., 2012). Overall, findings regarding the relationships between carer coping and problem-focused coping strategies are inconsistent.

Among Asian family carers, five studies support that positive emotion-focused coping was associated with a better psychological health, a domain of QOL (Jeong et al., 2018; Morimoto et al., 2019; Pattanayak et al., 2011; Saffari et al., 2018; Tay et al., 2016). Specifically, coping strategies based on emotional social support (Pattanayak et al., 2011; Tay et al., 2016), positive reframing (Tay et al., 2016), and spiritual coping (Saffari et al., 2018) were positively associated with a better psychological health. In addition, Jeong et al. (2018) found that positive emotion-focused coping was associated with better physical health, another domain of QOL. In

contrast, Pattanayak et al. (2011) identified that greater use of negative emotion-focused coping such as denial and self-blame was associated with lower physical and psychological domains of QOL. Three studies found that problem-focused coping was associated with a better psychological health (Jeong et al., 2018; Pattanayak et al., 2011; Tay et al., 2016), while another study found that problem-focused coping was associated with a lower psychological health (Morimoto et al., 2019). Only one study supported that problem-focused coping was associated with a better physical health (Jeong et al., 2018). While findings for the positive impacts of emotion-focused coping are more consistent than those of problem-focused coping, each of these findings was only supported by, at most, five studies, and only three of these adjusted for covariates in their analysis.

Among these studies, Asian populations that have been studied include China, India, Iran, Japan, Singapore, and South Korea. Thus, there are very few published studies about the association between coping and QOL among Asian family carers of persons living with dementia, and even less is known specifically about Thai family carers. Further studies of coping and QOL among these groups of carers are needed. Such knowledge is of great interest to nurses as understanding which coping styles are helpful or unhelpful can assist carers to minimize stress and improve QOL.

Study Conceptual Framework

Overall, the study conceptual framework (Figure 5-1) illustrates the relationships between stressors, appraisals, coping, and QOL. The conceptual framework highlights this study's focus on the associations of positive emotion-focused coping, negative emotion-focused coping, and problem-focused coping with QOL. Carers' characteristics (e.g., age, gender, education, and financial status), carers' stress, and social support are factors that may also

influenced carers' appraisal and choice of coping strategies, and represent adjustment variables in this study.

The Transactional Model of Stress and Coping by Lazarus and Folkman (1984) and the Caregiver Stress Process Model by Pearlin and colleagues (1990) have been used to guide this research. We incorporated these two models with the findings from a literature review among Asian family carers of persons living with dementia to identify variables which influence coping, as illustrated in the study conceptual framework (Figure 5-1). The independent variables for this study are problem-focused coping, positive emotion-focused coping, and negative emotion-focused coping. Their associations with QOL are the focus of this study, and other variables from the framework are adjusted for as covariates in the analysis.

Given the theory grounding offered by the stress-coping model and the emerging literature, we selected adjustment variables that were important within the context of dementia caregiving and measureable in the Thai context. According to the stress-coping model, stress perceived by carers is partially mediated by coping and individual appraisal (Lazarus & Folkman, 1984). Social support has been shown to be associated with coping (Jeong et al., 2018; Lau & Cheng, 2017; Liu et al., 2012; Nishio et al., 2017). In addition, Pearlin et al. (1990) suggested that carer's characteristics such as age, gender, ethnicity, education, occupation, and economic status are expected to be threaded throughout the entire stress process. From the literature review by Kaewwilai et al. (submitted manuscript, 2021), a number of influencing factors on family carer coping were identified, which were supported by previous studies, including (1) carer's demographic characteristics such as age (2 studies), gender (3 studies), education (3 studies), and employment status (2 studies), and social support resources (4 studies). Therefore, in the conceptual framework of this study, we proposed that carers' demographic

characteristics (e.g., age, gender, education, financial needs), carers' stress, and social support are factors that influence coping, and adjusting for these factors will help us to determine whether types of coping strategy are associated with QOL among Asian family carers of persons living with dementia, and to accurately estimate the strength of these associations.

Methods

Aims

The aims of the study were to evaluate the association between problem-focused, positive emotion-focused, and negative emotion-focused coping strategies with QOL among Thai family carers of community-dwelling persons living with dementia while adjusting for covariates. We hypothesized that, after adjusting for carer characteristics (e.g., age, gender, education, financial status) and carers' stress and social support, problem-focused coping and positive emotion-focused coping would have a strong, positive association with QOL; while, negative emotion-focused coping would have a strong, negative association with QOL.

Design

A cross-sectional, descriptive correlational quantitative design was used to meet the study aims. This cross-sectional study has been reported using the STROBE guideline (Vandenbroucke et al., 2007).

Participants

Participants living in Thailand were recruited using a multi-pronged approach, which included the use of social media, in-person recruitment, and word-of-mouth referrals. An in-depth discussion of the recruitment strategies and their effectiveness has been described in chapter 4. Inclusion criteria were as follows: (1) family or friend carers of a person living with

dementia in the community; (2) providing any of physical, emotional, financial, or spiritual care for the person living with dementia; (3) over the age of 18; (4) have access to a telephone or a computer with internet; and (5) English or Thai speaking. Exclusion criteria were as follows: (1) carer of a person with dementia who had already died; (2) carer of a person with dementia residing in a long-term care facility or hospitalized; and (3) carer who had provided assistance to an individual with a neurological diagnosis other than dementia. A sample size estimation supported that 88 participants were needed to achieve 80% power to detect a statistically significant effect at $\alpha = .05$ and an effect size of 0.2 (Cohen, 1988). Anticipating missing data, we aimed to recruit 100 participants. The sample size calculation was completed for a linear multiple regression model with nine variables (stress, social support, age, gender, education, financial status, problem-focused coping, positive emotion-focused coping, negative emotion-focused coping) using G*Power 3.1.9.4. Among a sample of 97 participants, 86 participants completed the entire questionnaire (i.e., an 88.7% completion rate).

Measurements

1. The demographic questionnaire

Demographic data of carer participants were collected using a demographic questionnaire which has been used in previous research. Data collection included basic background information on carer characteristics, including age, gender, marital status, religion, level of education, employment status, income, comorbidity, relationship to the care recipient (i.e. persons living with dementia), hours of care per day, duration of caregiving, number of carers, and details of caregiving responsibility. Care recipient characteristics were collected from the carer participant, including age, gender, stage of disease, comorbidity, and behavior problems of a person living with dementia that impact the carer's QOL.

2. The Brief COPE Inventory

Coping strategies were assessed using the Brief COPE Inventory (Brief COPE), Thai version (Carver, 1997; Numsang & Tantrarungroj, 2018). The Cronbach alpha coefficient for the overall scale was .70, and the Pearson's correlation coefficient correlated in the same direction with the correlation coefficients ranged from .25 - .45 across coping subscales (Numsang & Tantrarungroj, 2018). The Brief COPE Inventory includes 28 items, scored from one to four, exploring 14 strategies: active coping, planning, use of instrumental support, positive reframing, acceptance, use of emotional support, denial, venting, self-blame, humor, religion, self-distraction, substance use, and behavioral disengagement. In this study, coping strategies were grouped into three categories according to Carver (1997)'s classification: (1) problem-focused strategies, including active coping, instrumental support, and planning; (2) positive emotion-focused strategies including acceptance, emotional support, humor, positive reframing, and religion; (3) negative emotional coping strategies including behavioral disengagement, denial, self-distraction, self-blame, substance use, and emotional venting. Each of 14 scales is comprised of two items, and total scores on each scale range from 2 to 8. Higher scores reflect a higher tendency to implement the corresponding coping strategies. According to the classification, the mean total scale is calculated by summing all subscale scores in each coping classification and dividing by the number of subscales; total scores on each classification range from 1 to 4.

3. World Health Organization Quality of Life Instrument (WHOQOL-BREF scale)

Quality of life was assessed using the brief version of the World Health Organization Quality of Life Instrument (WHOQOL-BREF), Thai version (Mahatnirunkul et al., 1998; WHOQOLGroup, 1998). A previous Thai study in HIV/AIDS patients showed that the internal

consistency reliability Cronbach's alpha ranged from .61 to .81 across four domains. The alpha value of the whole scale was .90 (Sakthong et al., 2007). A previous Thai study in cancer patients showed that the Cronbach's alpha for the scale was .85 and subscales ranged from .45 to .67 (Phungrassami et al., 2004). For convergent validity, the scores for the physical, psychological, social, and environmental domains correlated positively with general health satisfaction and overall quality of life questions of WHOQOL-BREF (Spearman's rho range: .22-.48 and .37-.44 across domains, respectively, all $p < .01$ with the lowest correlation between social domain & general health satisfaction, $p < .05$) (Sakthong et al., 2007).

The instrument comprises four domains- physical health (7 items), psychological health (6 items), social relationships (3 items), and environmental (8 items), with one additional item for general QOL and one item for health-related QOL (total 26 items). Each item is scored on a 5-point Likert scale. Four domains of QOL scores are calculated by summing up the scores of the corresponding items in each domain. The Total QOL score is the summation of all domain scores and two global item scores. The scores then are classified into three QOL groups by the criteria according to Mahatnirunkul et al. (1998). Table 5-1 presents domains of QOL and the total QOL scoring criteria of WHOQOL-BREF-THAI. This study uses both the total score and the scores for each domain as outcome variables in the analysis.

4. The Perceived Stress Scale (The PSS-10)

Perceived stress was assessed using the Perceived Stress Scale (The PSS-10), Thai version (Cohen et al., 1983; Wongpakaran & Wongpakaran, 2010). The test-retest reliability demonstrated a good reliability value with a Cronbach's Alpha of .84. The intraclass correlation coefficient (ICC) was .82 (95% CI= 0.72, 0.88) at 4 week-retest reliability. The internal consistency of the scale was high (Cronbach's alpha = .87 - .89) and the reported correlations

with measures of the State Trait Anxiety Inventory (STAI) ($r = .60, p < .001$), the Thai Depression Inventory (TDI) ($r = .55, p < .001$), and the Rosenberg Self-Esteem Scale (RSES) ($r = -.46, p < .001$) supported its construct validity (Wongpakaran & Wongpakaran, 2010).

The questions in the PSS-10 ask about feelings and thoughts during the last month. The ten items of PSS-10 were rated on a 5-point Likert scale based on the frequency of the stressful event experienced by the participant ranging from 0 (never) to 4 (very often). Individual scores on the PSS-10 range from 0 to 40, with higher scores indicating higher perceived stress.

5. The Multi-Dimensional Scale of Perceived Social Support (MPSS)

Perceived social support assessed by the Multi-Dimensional Scale of Perceived Social Support (MPSS), Thai version. (Wongpakaran & Wongpakaran, 2012; Zimet et al., 1988). The internal consistencies of the scale were good, with a Cronbach's alpha of .89 in the group overall, and with subscale scores of .89, .85, and .94 for family, friends, and significant others, respectively. The estimated reliability calculated based on the best fitted model demonstrated excellent reliability values (.90). The confirmatory factor analysis revealed an acceptable model fit: $\chi^2 = 147.44, df = 45, p < .001$; Tucker-Lewis Index .975; Comparative Fit Index .982; Good Fit Index .966; and root-mean-square error of approximation .056 which supported its construct validity (Wongpakaran & Wongpakaran, 2012).

The questions in the MPSS ask about perceptions of social support adequacy from three specific sources: family, friends, and significant others. A 7-point rating scale is used, ranging from 1 (very strongly disagree) to 7 (very strongly agree). The overall scale score ranges from 12 to 84. The mean total scale was calculated by summing across all 12 items and then dividing by 12 (Zimet et al., 1988).

Data collection

Data were collected between January 2021 to April 2021, inclusive. Five key organizations assisted with participant recruitment, including: (1) the Thai Alzheimer's Disease and Related Disorders Association, (2) the Caregivers of Persons with Dementia Network, Siriraj Hospital, (3) the Cognitive Fitness Center support group, Chulalongkorn Hospital, (4) the Memory Clinic, Chulalongkorn Hospital, and (5) The Nurses' Association of Thailand.

Figure 5-2 illustrates the data collection procedure. Instructions for study participation and the measures were in a secure website application called REDCap, which has been found to increase data security and quality (University of Alberta, 2020). Participants used a link to access the questionnaire website, study information, and instructions to complete the questionnaires.

Two screening questions were included to confirm eligibility to participate in the study. These questions were: (1) Have you provided assistance to an individual with the confirmed diagnosis of dementia? (2) Does the person living with dementia reside in a community? Participants were able to read the instructions and completed the questionnaire on their own time within a two-week time period. Participants completed the questionnaires in approximately 40 to 60 minutes. For in-person recruitment, the researcher identified eligible participants who were attending appointments with their psychiatrist at the Memory Clinic at Chulalongkorn Hospital. If participants met the inclusion criteria and expressed interest in participating in the study, consent was obtained, and a paper questionnaire was provided. Participants completed the questionnaire on the spot or completed the questionnaire at a later time and returned it by mail or telephone. Word of mouth referral was used in conjunction with other strategies to increase the participation rate. Eligible participants were able to complete the questionnaire on the website,

by mail, or by telephone. A reminder email or letter was sent out to participants who had started but who did not complete the survey within two weeks.

Ethical considerations

This study was approved by the research ethics committee from (a) the University of Alberta Research Ethics Board, Canada (Pro00102422), (b) the Ethical Review Committee for Human Research, Faculty of Public Health, Mahidol University, Thailand (MUPH 2020-123), and (c) the Institutional Review Board of the Faculty of Medicine, Chulalongkorn University, Thailand (IRB 028/64).

Data analysis

All data were downloaded from REDCap into SPSS version 24.0. Continuous descriptive data were reported as mean and standard deviation (SD), whereas categorical data were reported as percentages. Bivariate analyses using Pearson's correlation coefficients were conducted to examine the relationships among all variables.

The eight stage hierarchical multiple regression was conducted to examine the association between types of coping strategies utilized (independent variables, categorical data) and QOL scores (dependent variable, continuous data), adjusting for carer characteristics (i.e., age, gender, education, financial status) and carers' stress and social support. Because the purpose of this study was to determine the association between coping and QOL, rather than developing a model to explain or predict QOL, hierarchical multiple regression was used. In this approach, the researcher included those variables in the model that were important theoretically, and controlled which variables would be retained in the model (e.g., as opposed to a backward or forward stepwise procedure). As such, all covariates were kept in the model as identified in the

conceptual framework regardless of their statistical significance, or their contribution to model explained variance (i.e., R^2). Five models were completed, one for each QOL outcome (i.e., where total QOL was the outcome, and then for each of the subscales of physical health, psychological health, social relationship, and environmental domains of QOL). To answer the study hypotheses, the size of the association was indicated by the beta coefficient for each independent variable, and the statistical significance was indicated by the p-value associated with that beta coefficient. Although it does not refer to the study hypothesis, we also note the model R^2 in the results to describe the amount of model explained variance for each model.

To carry out the hierarchical multiple regression, the following steps were completed for each QOL outcome:

Step 1: QOL = Constant + stress + social support

Step 2 QOL = Constant + stress + social support + age

Step 3 QOL = Constant + stress + social support + age + sex

Step 4 QOL = Constant + stress + social support + age + sex + education

Step 5 QOL = Constant + stress + social support + age + sex + education + financial status

Step 6 QOL = Constant + stress + social support + age + sex + education + financial status
+ problem-focused coping

Step 7 QOL = Constant + stress + social support + age + sex + education + financial status
+ problem-focused coping + positive emotion-focused coping

Step 8 QOL = Constant + stress + social support + age + sex + education + financial status
+ problem-focused coping + positive emotion-focused coping + negative
emotion-focused coping

Empirical study supports an important variable to consider within the context of dementia caregiving is whether the carer is a spouse as compared to a non-spouse carer (Johansson et al., 2021). However, in the Thai context, the person who assumes a caregiving responsibility for persons living with dementia is typically the daughter or daughter-in-law and not the spouse (Chuakhamfoo et al., 2020), and we only had three (3.5 %) spouse carers in our sample, so it was not possible or meaningful to adjust for this variable within this study. We re-coded several categorical adjustment variables into dichotomous variables to address small numbers of respondents in some categories including gender, education level, and financial status. Gender was re-coded to Male (vs. female). Education level was re-coded to Bachelor degree (vs. less than a bachelor degree). Financial status was re-coded to financial adequate (vs. not adequate).

The following assumptions were verified for each model: (a) normality and homoscedasticity (residual plots), (b) linear relationship (partial regression plots), (c) independence of residuals (Durbin-Watson statistic), and (d) absence of collinearity (Tolerance and Variance Inflation Factor). The missing data in this study were less than approximately 5% missing per variable and were missing at random. In response to missing data, mean substitution for the same subscale and the same participant were used, in alignment with recommendations for how to handle missing data for these study scales (Dias et al., 2009; Hardt et al., 2013; Stewart et al., 2014; WHOQOLGroup, 1998; Xu et al., 2017).

Validity, reliability, and rigor

The instruments used in this study had been previously translated into the Thai language and had demonstrated good reliability and validity, as reported above. Potential confounding factors were considered based on the conceptual framework and included as covariates.

Results

Participant demographics

Table 5-2 and Table 5-3 present the family carer and care-recipient characteristics. Among the 86 participants included in the analysis, 75 (87.2%) were female, and 11 (12.8%) were male, with a mean age of 52.84 years (SD 9.52 years, range 32-81 years). Most of the carers were Buddhist (96.5%) Over half of the carers were single (55.8 %), held a Bachelor's degree or higher (88.4%), and reported meeting their financial needs adequately (54.7 %). Regarding comorbidity, 40 carers (46.5%) reported they had underlying diseases (46.5 %). The most common illness was hypertension, followed by hyperlipidemia and diabetes mellitus. Seventy-four (86.0%) were daughters/sons of persons living with dementia. Sixty-eight (79.1%) were primary carers. The mean caregiving hours per day were 15.04 hours (SD 8.47 hours). The mean duration of caregiving was 4.94 years (SD 3.96 years).

There were four participants who had two persons living with dementia in their family. Thus, 90 persons living with dementia were reported in this study, and the mean age was 82.10 years (SD 7.59, range= 54-97 years). Sixty-nine (77.5 %) were female and 20 (22.5%) were male. Most of the persons living with dementia were in the middle stage of the disease (40.7%), which is characterized by an increasing loss in cognitive and functional abilities as well as mood shifts (e.g., anxiety, depression) and behavioral changes (e.g., delusions and hallucinations) (Alzheimer Society of Canada, 2016). Sixty-seven (77.9%) had other underlying diseases. The most common illness was hypertension, followed by diabetes mellitus and hyperlipidemia. Sixty (70.6%) had behavioral problems that affected the carers reported affected their QOL.

Coping strategies, quality of life, perceived stress and perceived social support

Table 5-4 presents the descriptive statistics for the study variables. The mean score for problem-focused coping, positive emotion-focused coping and negative emotion-focused coping were 3.13 (SD 0.58), 2.99 (SD 0.48), and 1.85 (SD 0.30), respectively. The range of mean coping scores was 1 to 4. On average, carers in this sample most frequently used problem-focused coping and less frequently used negative emotion-focused coping. The mean score on each scale reveals that acceptance (mean 7.45, SD 0.90) was the most frequently used coping strategy on average, followed by positive reframing (mean 6.56, SD 1.48) and active coping (mean 6.53, SD 1.37). Less frequently used coping strategy included substance use (mean 2.23, SD 0.79).

The four domains of QOL scores were calculated by summing up the scores of the corresponding items in each subscale. The total QOL scores was the summation of all subscale scores and two global item scores. The scores then are classified into three QOL groups by the criteria according to Mahatnirunkul et al. (1998) (Table 5-1). The mean score of the participants' physical health domain of QOL was 24.50 (SD 3.12, range 17 to 32), which reflects moderate levels of the physical health domain of QOL (the moderate score range is 17-26). The mean score of the participants' psychological health domain of QOL was 22.15 (SD 3.56, range 11 to 30), which reflects moderate levels of the psychological health domain of QOL (moderate score range is 15-22). The mean score of the participants' social relationships domain of QOL was 10.84 (SD 2.10, range 5 to 15), which reflects moderate levels of the social relationships domain of QOL (moderate score range is 8-11). The mean score of the participants' environmental domain of QOL was 29.08 (SD 4.80, range 18 to 40), which reflects moderate levels of the environmental domain of QOL (moderate score range is 19-29). The range of Total

WHOQOL-BREF scores was 26 to 130. The mean score of total QOL was 96.15 (SD 13.14, range 62-130), which reflects good levels of quality of life, on average, among carers in this study. The mean score on the PSS-10 scale was 15.43 (SD 6.21). The mean score on the MPSS scale was 4.90 (SD 1.33), with support from friends being the lowest score (mean 4.72, SD 1.55).

Bivariate analysis

Relationships between coping and quality of life

Correlations between coping and QOL were analyzed using Pearson's correlation coefficients (Table 5-5). Problem-focused coping was positively correlated with total QOL ($r = .188, p < .05$), the psychological health QOL domain ($r = .200, p < .05$), the social QOL domain ($r = .197, p < .05$), and the environment QOL domain ($r = .178, p < .05$). Positive emotion-focused coping was positively correlated with total QOL ($r = .390, p < .001$), physical health QOL domain ($r = .208, p < .05$), psychological health QOL domain ($r = .405, p < .001$), social QOL domain ($r = .439, p < .001$), and environment QOL domain ($r = .272, p < .01$). Negative emotion focused coping was negatively correlated with total QOL ($r = -.216, p < .05$), physical health QOL domain ($r = -.244, p < .01$), and psychological health QOL domain ($r = -.283, p < .01$).

Hierarchical Multiple Regression

Five hierarchical multiple regression models were applied to test the association between coping and QOL, using the total QOL score and the domain scores as outcome variables. It was expected that problem focused-coping and positive emotion-focused coping would be positively associated with QOL, whereas negative emotion-focused coping would be negatively associated with QOL, after adjusting for covariates including carer characteristics (age, gender, education,

financial needs) and carers' stress and social support. The model as a whole explains 51.8 percent of variance in total quality of life. In support of our hypotheses, the regression of total QOL score revealed that positive emotion-focused coping was associated positively with total QOL score ($\beta = 0.18, p < .1$). This Beta coefficient was smaller and represented a weaker association with QOL, as compared to the association of positive emotion-focused coping with psychological health domain of QOL ($\beta = 0.25, < .05$) and social relationship domain of QOL ($\beta = 0.36, p < .01$). There were no significant associations found between positive emotion-focused coping and the physical health domain of QOL or the environmental domain of QOL. Contrary to our hypotheses, no significant associations were found between problem-focused coping or negative emotion-focused coping with total QOL scores, physical health domain of QOL, psychological health domain of QOL, social relationship QOL, or environmental domain of QOL. Table 5-6 presents the association between coping strategies and quality of life of Thai family carers of persons living with dementia.

Discussion

The present study examined the association between coping and QOL among Thai family carers of persons living with dementia. After adjusting for carer characteristics (e.g. age, gender, education, financial status) and carers' stress and social support, a significant positive association was found between positive emotion-focused coping with total QOL scores, and these associations were strongest in the psychological health QOL and social QOL domains. In contrast, there were no significant associations between problem-focused coping, negative emotion-focused coping, and total QOL scores or between these variables and other QOL domains.

Positive emotion-focused coping and quality of life

Our results support a positive association between positive emotion-focused coping and QOL, consistent with another previous study on the relationship between positive emotion-focused coping and QOL, after adjusting for potential confounders in carers of dependent older adults in Spain (Margarita et al., 2017). Studies of Asian family carers of persons living with dementia which did not adjust for potential confounding variables, also found that positive emotion-focused coping was positively associated with QOL (Pattanayak et al., 2011; Tay et al., 2016). Furthermore, various studies in Western countries also found that positive emotion-focused coping was associated with less anxiety and depression in carers of older persons with dementia (Cooper et al., 2008; Li et al., 2012), outcomes which are associated with poor QOL. Our findings contradict a previous review of carer studies that identified that emotion-focused coping was associated with negative outcomes (Hawken et al., 2018). A limitation of many studies on the relationship between emotion-focused coping and QOL is failure to differentiate between positive and negative emotion-focused coping as well as failure to adjust for potential confounders. A variety of coping measurement tools make it challenging to categorize coping strategies, resulting in an inconsistent association between coping and QOL. This present study addressed a gap in our knowledge by differentiating emotion-focused coping into positive and negative emotion-focused coping and using multi-variable analysis to adjust for confounding variables.

Our study also highlights that family carers in different cultures might have differing interpretation of the caring situation and consequently the utilization of coping strategies. In this study, acceptance was a coping strategy used frequently by Thai family carers of persons living with dementia. This is consistent with previous studies suggesting that Thai family carers

frequently used a specific coping strategy called “Thum-Jai” (Hamtanon et al., 2007; Senchai et al., 2017; Srinim, 2015). “Thum-jai is an emotion-focused coping strategy through which individuals cope with negative situations that they cannot change. It involved emotional regulation through cognitive reframing, accepting, and letting go of the negative situation” (Mills et al., 2017; pp 240-241).

Additionally, in Thailand, cultural values such as filial piety are a fundamental value that impacts peoples’ lives and the parent-child relationship (Lai, 2009). Thai family carers accept their caregiving responsibility of persons living with dementia as a normal course of life (Senchai et al., 2017; Srinim, 2015). Moreover, Buddhism, the major religion in Thailand, influences values and practices that suffering is considered part of life. The path to freedom from suffering is found through the absence of desire, not through active efforts to solve one's problems (Tweed et al., 2004). Rather than focusing on the external environment, Buddhist beliefs have an influence toward the use of positive emotion-focused coping when individuals focus on managing their internal emotional reaction when coping with stress.

Negative emotion-focused coping and quality of life

Our results do not support an association between negative emotion-focused coping and QOL, which is inconsistent with other studies (Li et al., 2012; Margarita et al., 2017; Pattanayak et al., 2011). This inconsistency may be explained by the reliance of previous studies on bivariate analysis. For example, Pattanayak et al. (2011) found that greater use of negative emotion-focused coping was associated with lower physical and psychological QOL in Asian family carers of persons living with dementia but did not adjust for any potential confounding variables. A relationship between negative emotion-focused coping and worse scores on the psychological dimension of QOL (adjusting for potential confounding variables) has been reported in carers of

dependent older adult relatives in Spain (Margarita et al., 2017) and carers of the older adults with dementia living in Asian and non-Asian countries (Li et al., 2012). Our bivariate analysis did support that negative emotion-focused coping was negatively associated with QOL; however, the multi-variable results did not support this finding. Another possible explanation is the Thai culture may influence the association between these variables. Culture may influence how Thai carers respond to stressful situations and their coping process. For example, in this study, substance use was infrequently reported among Thai family carers. Buddhists were found to be less likely to drink and had more negative values about alcohol consumption (Newman et al., 2006). Buddhism teaches to refrain from taking intoxicants (Newman et al., 2006), and this value may influence how carers choose their coping strategies. As well, other social factors may have an influence on the choice of coping. For example, Sequeira (2013) found that age, gender, marital status, educational level, employment level, and household situation are associated with coping and carer burden in Portuguese carers (Sequeira, 2013). Our study found that age, gender, and education level were not significantly associated with QOL. Future research should determine if these factors are significantly associated with coping and QOL.

Problem-focused coping and quality of life

Our results found no association between problem-focused coping and QOL, which is consistent with the finding by Margarita et al. (2017) in carers of dependent older adults in Spain. In addition, the meta-analysis by Li et al. (2012) found no association between problem-focused coping and anxiety or depression in carers of persons living with dementia in both Asian and non-Asian countries. In contrast, our results contrast with findings from the review by Kneebone and Martin (2003) of carers of people with dementia in non-Asian countries and other carers literature that report problem-focused coping to be associated with positive outcomes such

as (Hawken et al., 2018). However, the bivariate analysis of our study found that problem-focused coping was positively associated with total QOL. Pattanayak et al. (2011)'s study also supported our finding that problem-focused coping was positively associated in bivariate analysis with psychological QOL in Indian family carers of persons living with dementia. This highlights the importance of adjusting for covariates in the analysis.

In Asian countries, two interventions were developed to help carers improve the use of problem-focused coping strategies, which effectively decreased carer burden (Chen et al., 2015) and increased their self-efficacy (Au et al., 2010). Quality of life was not measured. However, based on our findings, intervention aimed at improving the use of problem-focused coping strategies might not be helpful to enhance QOL of Asian family carers of persons living with dementia.

Nursing implications

Understanding whether specific coping strategies have the potential to improve QOL is important for identifying how best to support family carers of persons living with dementia. Our study supports that the use of positive emotion-focused coping strategies was associated with improved overall QOL. With the large population of family carers, improvement in QOL may have a significant impact on a population level. The development and evaluation of interventions for carers should encourage the use of positive emotion-focused coping strategies. An example of an intervention that enhanced positive emotion-focused coping strategies was mindfulness. Liu et al.'s (2018) meta-analysis found that mindfulness interventions reduced carer stress and depression, and improved mental health-related QOL among family carers of persons living with dementia.

In addition, in order to understand how best to support carers, nurses should determine how carers use positive emotion-focused coping, or when they find it challenging to use this strategy. For example, nurses may advise carers to practice “Thum-jai” which is a positive emotion-focused coping strategy involving emotional regulation through cognitive reframing and acceptance. Using "Thum-jai" carers can explore their own thoughts and beliefs that help them accept the reality of the situation. Studies reveal that practicing "Thum-jai" helps carers relieve stress and brings peace of mind (Mills et al., 2017; Mills et al., 2019).

Limitations

This study has some limitations that should be addressed in future research. Several variables were considered, but were not measured in this study to ensure that it was reflective of and would support a feasible study within the Thai context. Religion was not included in the conceptual framework, although three previous studies in Asian contexts did note that it was associated with coping because the majority of the Thai populations are Buddhist (94.2%; The National Statistical Office of Thailand, 2018). Behavioral and depression symptoms of persons living with dementia and familism beliefs were significant variables that influenced coping according 5 previous studies and 1 study, respectively; however, a validated assessment tool to assess disruptive behaviors and depression of persons living with dementia (Teri et al., 1992), and familism beliefs was not available in the Thai language. Thus, we did not include these variables in the study conceptual framework, and did not measure them in the study. Hence, future research is needed to examine the relationship between type of coping strategies utilized and care-recipient characteristics among Thai family carers of persons living with dementia.

Culture has an important influence on the appraisal of stress and the use of certain coping strategies (Lazarus and Folkman, 1984). Regarding the subjective nature of coping and QOL, it

is suggested that further studies on coping and QOL not only rely on quantitative measurements, but also incorporate qualitative methods to gain more comprehensive information to develop appropriate nursing interventions.

The study design was cross-sectional. Thus, it only captures coping and QOL at one point in time and does not consider changes in these variables over time. As well, rigorous testing of causal relationships is not possible from cross-sectional analysis, yet assessing these associations is an important pre-cursor to the design of future longitudinal or prospective studies aimed to explore causation. The correlation and regression analysis supported the hypotheses that positive emotion-focused coping was significantly associated with QOL, which generated evidence to support future prospective studies.

Conclusion

The study findings suggested that positive emotion-focused coping was associated with better QOL. Future research should focus on developing interventions to facilitate the use of positive emotion-focused coping (e.g., positive reframing, acceptance, emotional support, humor, and religion coping) and also evaluate the impact of these interventions on QOL of Thai family carers of persons living with dementia.

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Figure 5-1 Study Conceptual Framework

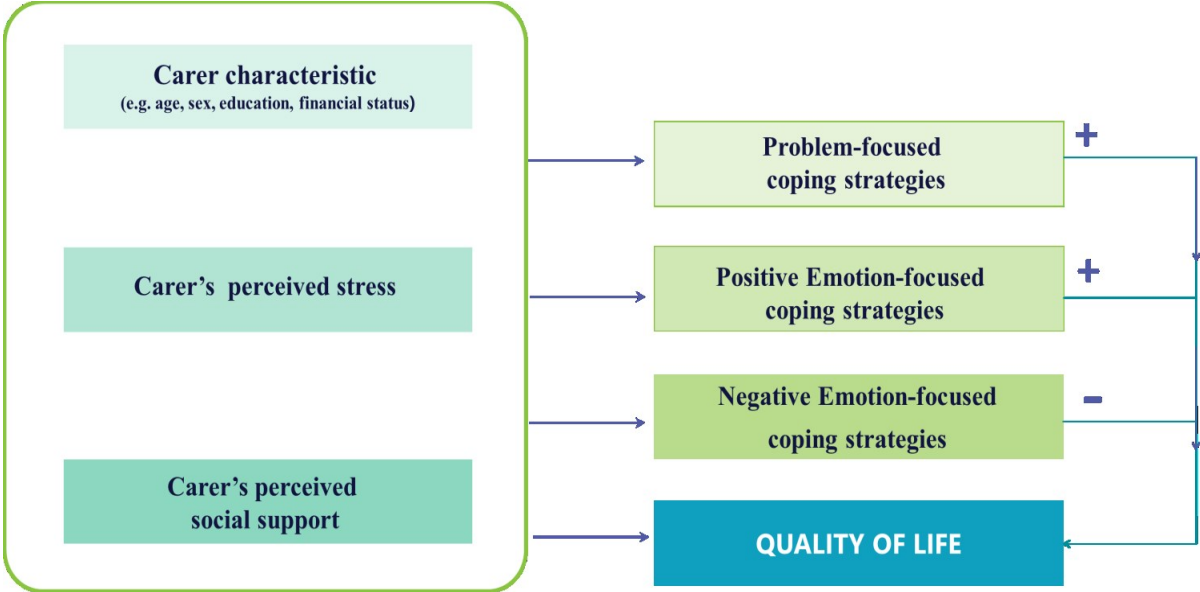


Figure 5-2 Data Collection Process

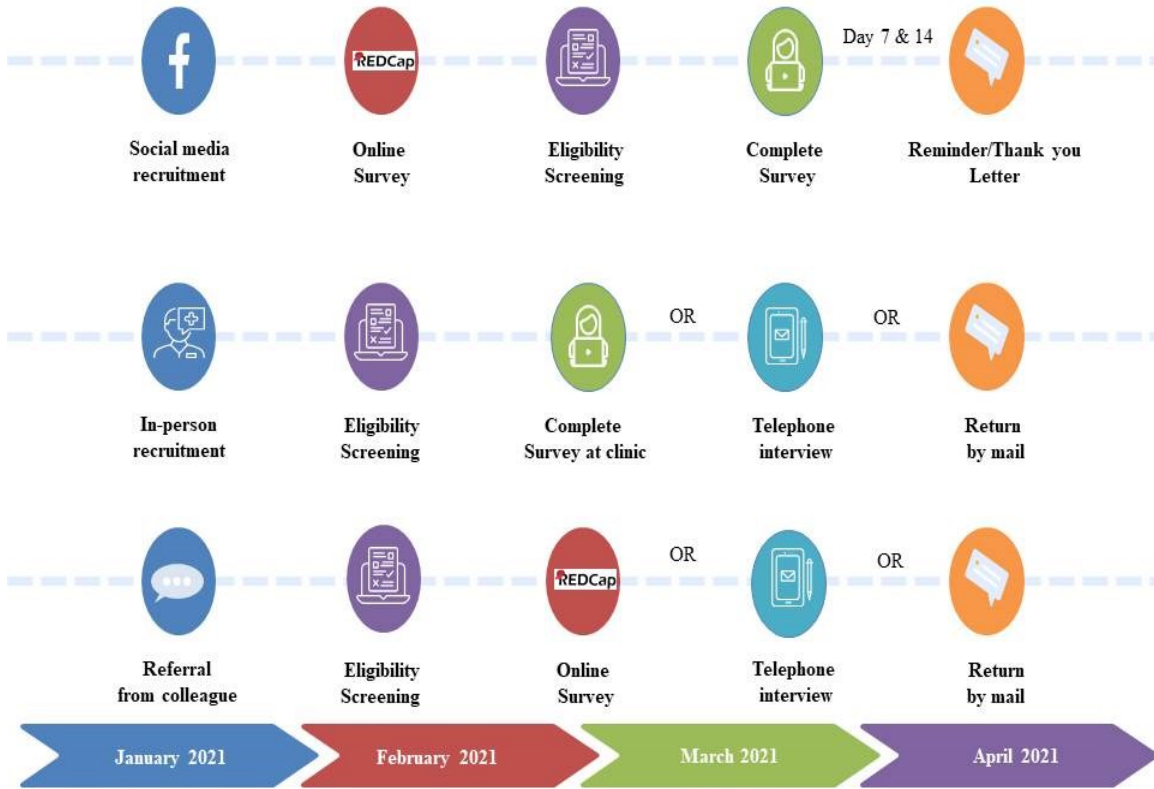


Table 5-1 Domains of QOL and total QOL scoring criteria of WHOQOL-BREF-THAI

Domains of QOL	Number of items	Poor QOL	Moderate QOL	Good QOL
Physical Health	7	7-16	17-26	27-35
Psychological Health	6	6-14	15-22	23-30
Social relationships	3	3-7	8-11	12-15
Environment	8	8-18	19-29	30-40
Total QOL*	26	26-60	61-95	96-130

*Total QOL is the summation of all domain scores and two global item scores. Range of scores for poor, moderate, and good QOL was developed by Mahatnirunkul et al. (1998).

Table 5-2 Family carer characteristics.

Carers	N	%	Mean	SD	Range
Age (years) (N=84)			52.84	9.52	32-81
Gender (N=86)					
Male	11	12.8			
Female	75	87.2			
Marital status (N=86)					
Single	48	55.8			
Married	31	36.0			
Widowed	1	1.2			
Divorced/Separated	6	7.0			
Religion (N=86)					
Buddhist	83	96.5			
Muslim	1	1.2			
Catholic / Protestant	2	3.8			
Educational level (N=86)					
Primary School	2	2.3			
Senior High School / Vocational Certificate	6	7.0			
Diploma	2	2.3			
Bachelor Degree	42	48.8			
Master Degree	28	32.6			
Doctoral Degree	6	7.0			
Average number of comorbidity			0.6	0.91	0-4
Employment Status (N=86)					
Yes	42	48.8			
No	44	51.2			
Relationship to Persons living with dementia (N=86)					
Husband/Wife/Life Partner	3	3.5			
Son/Daughter	74	86.0			
Son/Daughter-In-Law	2	2.6			
Sister/Brother	3	3.5			
Sister/Brother-In-Law	1	1.2			

Carers	N	%	Mean	SD	Range
Friend	1	1.2			
Nephew/Niece	2	2.3			
Financial needs (N=86)					
Adequately	63	73.3			
Not adequately	23	26.7			
Hours of care per day (Hours)			15.04	8.47	2-24
Duration of caregiving (years)			4.94	3.96	0.50- 20.00
Primary carer (yes)		68	79.1		
Other carers (yes)		63	73.3		
Number of carers					
1 person	29	46.0			
2 persons	14	22.2			
3 persons	14	22.2			
4 persons	3	4.8			
5 persons	2	3.2			
6 persons	1	1.6			

Table 5-3 Care-recipient characteristics.

Persons living with dementia	N	%	Mean	SD	Range
Age (years) (N=89)			82.10	7.59	54-97
Gender (N=90)					
Male	20	22.2			
Female	70	77.8			
Stage of Disease (N=90)					
Early Stage	27	30.0			
Middle Stage	38	42.2			
Late Stage	15	16.7			
End-of-life	1	1.1			
Don't know	9	10.0			
Average number of comorbidity			1.50	1.42	0-6
Behavior Problems (N=90)					
Yes	63	70.0			
No	27	30.0			
Behaviors that affect QOL of carers					
Sleep problem	17	18.9			
Agitation	15	16.7			
Repetitive action	14	15.6			
Forgetfulness/confusion	11	12.2			
Disinhibit	12	13.3			
Irritability	11	12.2			
Aberrant motor behavior	9	10.0			
Delusion	9	10.0			
Communication	8	8.9			
Hallucination	6	6.7			
Depression	6	6.7			
Anxiety	3	3.3			
Apathy	2	2.2			

Table 5-4 Descriptive statistics for coping strategies, quality of life, stress and social support

	Scale	Mean(SD)	Sample Range	Possible Scale Range
Coping strategies	Brief-COPE			
Problem focused coping				
Active coping		6.53 (1.37)	3-8	2-8
Use of instrument support		5.87 (1.69)	2-8	2-8
Planning		6.37 (1.50)	2-8	2-8
Positive emotion focused coping				
Use of emotional support		5.71 (1.53)	2-8	2-8
Positive reframing		6.56 (1.48)	2-8	2-8
Humor		5.15 (1.94)	2-8	2-8
Acceptance		7.45 (0.90)	2-8	2-8
Religion		5.06 (2.01)	2-8	2-8
Negative emotion focused coping				
Self-distraction		6.16 (1.46)	2-8	2-8
Self-blame		3.58 (1.45)	2-8	2-8
Venting		4.74 (1.49)	2-8	2-8
Denial		2.47 (1.10)	2-8	2-8
Substance use		2.23 (0.79)	2-6	2-8
Behavioral disengagement		3.01 (1.33)	2-7	2-8
Quality of life	WHOQOL-BREF			
Overall perception of quality of life		3.63 (0.77)	2-5	1-5
Overall perception of health.		3.36 (1.01)	1-5	1-5

	Scale	Mean(SD)	Sample Range	Possible Scale Range
Physical Health		24.50 (3.12)	17-32	7-35
Psychological Health		22.15 (3.56)	11-30	6-30
Social domain		10.84 (2.10)	5-15	3-15
Environmental domain		29.08 (4.80)	18-40	8-40
Total Quality of life score		96.15 (13.14)	62-130	26-130
Social support	MPSS			
From family		5.04 (1.74)	1-7	1-7
From friends		4.72 (1.55)	1-7	1-7
From significant other		4.93 (1.68)	1-7	1-7
Total scores		4.90 (1.33)	1.42-7.00	1-7
Stress	PSS			
Total scores		15.43 (6.21)	0-29	0-40

Table 5-5 Pearson’s correlations coefficient among all study variables

Carer	Total		Physical health		Psychological		Social		Environmental	
	quality of life		QOL		health QOL		relationship		QOL	
	r	Sig.	r	Sig.	r	Sig.	r	Sig.	r	Sig.
Problem-focused coping	.188*	.041	.113	.149	.200*	.033	.197*	.035	.178*	.051
Positive emotion-focused coping	.390***	.000	.208*	.028	.405***	.000	.439***	.000	.272**	.006
Negative emotion -focused coping	-.216*	.023	-.244**	.012	-.283**	.004	-.105	.168	-.092	.200
Perceived stress	-.653***	.000	-.552***	.000	-.601***	.000	1.000***	.000	-.528***	.000
Perceived social support	.417***	.000	.205**	.029	.319***	.001	-.383***	.001	.423***	.000
Age	.088	.210	.044	.344	.139	.100	.328	.379	.077	.242
Male (vs. female)	-.166	.063	-.140	.099	-.200**	.032	-.034	.154	-.154	.078
Bachelor degree (vs. less than a bachelor degree)	.060	.292	.094	.196	-.015	.445	-.111	.237	.128	.120
Financial adequate (vs. not adequate)	.303**	.002	.207**	.028	.144	.092	-.078	.074	.407***	.000

* p <.05; ** p < .01; *** p < .001

Table 5-6 Hierarchical multiple regression analysis

	Total quality of life			Physical health QOL			Psychological health QOL			Social relationship QOL			Environmental QOL		
	R ²	β	Sig.	R ²	β	Sig.	R ²	β	Sig.	R ²	β	Sig.	R ²	β	Sig.
Step 1															
Stress	.464	-.509***	.000	.305	-.496***	.000	.373	-.483***	.000	.188	-.266*	.025	.341	-3.427***	.001
Social Support		.133	.157		-.044	.690			.851		.072	.520		2.521**	.014
Step 2															
Age	.464	.000	.998	.306	-.058	.571	.377	.013	.885	.193	-.134	.204	.341	.799	.427
Step 3															
Male (vs. female)	.467	-.044	.606	.307	-.008	.936	.384	-.088	.326	.195	-.062	.541	.346	-.578	.565
Step 4															
Bachelor degree (vs. less than a bachelor degree)	.470	.047	.581	.311	.067	.498	.384	.005	.952	.204	-.090	.375	.366	1.033	.305
Step 5															
Financial adequate (vs. not adequate)	.482	.105	.224	.314	.060	.554	.385	-.030	.743	.207	.037	.721	.422	2.542**	.013

	Total quality of life			Physical health QOL			Psychological health QOL			Social relationship QOL			Environmental QOL		
	R ²	β	Sig.	R ²	β	R ²	β	Sig.	R ²	β	R ²	β	Sig.	R ²	β
Step 6															
Problem-focused coping	.497	.050	.602	.321	.081	.472	.411	.067	.513	.228	-.014	.901	.430	.754	.453
Step 7															
Positive emotion-focused coping	.517	.179 ⁺	.083	.324	.066	.579	.449	.253*	.022	.305	.357**	.005	.430	.124	.902
Step 8															
Negative emotion-focused coping	.518	-.039	.673	.337	-.128	.234	.458	-.111	.256	.306	-.022	.843	.433	.555	.580

⁺p < .1 * p < .05; ** p < .01; *** p < .001 β is standardized regression coefficient

Chapter 6. Summary, Conclusions, and Recommendations

My dissertation evaluated the association between coping and quality of life (QOL) in Thai family carers of persons living with dementia. This evaluation included an assessment of the coping strategies utilized, outcomes of coping that enhance physical and psychological health, and factors associated with coping strategies. My dissertation addressed knowledge gaps in understanding how carers could benefit from using specific coping strategies to improve their QOL. My literature review highlighted that there were inconsistent findings related to the associations between coping and QOL among Asian family carers of persons living with dementia. Moreover, there was a dearth of conceptual frameworks available to guide research among Asian family carers of persons living with dementia. To address these knowledge gaps, I proposed the “Asian Family Carers of Persons Living with Dementia: Stress and Coping Model” and designed a study to rigorously assess the associations between positive emotion-focused coping, negative emotion-focused coping, problem-focused coping, and QOL, adjusting for confounding variables. This study generated findings highlighting the significant association between positive emotion-focused coping and QOL among Thai family carers of persons living with dementia.

In this concluding chapter, I will summarize and discuss the main findings from my dissertation work. Strengths and limitations are also discussed, followed by discussing implications for research, policy, nursing, and education.

Coping and Quality of Life

To understand how Asian family carers of persons living with dementia cope with stress and how coping was associated with QOL, I focused on reviewing the literature that targeted

Asian family carers. In this review, I examined the type of coping strategies utilized, outcome of coping, and factors associated with coping strategies. The results of the systematic review are reported in paper 1. Carers' demographic characteristics, clinical symptoms of persons living with dementia, familism beliefs as well as social support resources were found to have an influence on choice of coping strategies. The review demonstrated that a gap existed in our understanding of which types of coping strategies were significantly associated with improved QOL for Asian family carers of persons living with dementia. Previous research showed inconsistent associations between coping and QOL outcomes. Key limitations of the literature that this review highlighted included (1) studies used a wide variety of coping measurement tools reflecting heterogeneity and (2) a small number of articles identified.

Studies used a variety of coping measurement tools. This made it challenging to categorize coping strategies, and I was not able to conduct meta-analyses due to this methodological and conceptual heterogeneity. The findings of the studies I reviewed were also challenging to synthesize due to the small number of articles identified for each association between coping and the selected factor or outcome. Only six studies identified in the review assessed physical and psychological health outcomes. Two studies specifically examined the association between coping and QOL and tested associations using bivariate approaches, not adjusting for important confounding variables. This resulted in many of the associations between coping and QOL being supported by only one study, and often this was a bivariate result.

The findings from the literature review were applied to build on the Caregiver Stress Process Model (Pearlin et al., 1990) and the Transactional Model of Stress and Coping (Lazarus and Folkman, 1984) to propose a conceptual model for understanding how Asian family carers of persons living with dementia cope with stress. The main changes made to the model were:

specifying person and environment factors for the particular context of Asian family carers of a person living with dementia; highlighting the importance of perceived social support; describing a broader influence of culture on several aspects of the appraisal and coping process; differentiating between positive and negative emotion-focused coping strategies, and emphasizing QOL as an outcome of coping. Linking previous stress and coping theory with qualitative and quantitative research findings specific to Asian Family Carers, I proposed a new “Asian Family Carers of Persons Living with Dementia: Stress and Coping Model.” The rationale for and the development of this new model is described in paper 2. This work thereby advanced understanding of stress, coping, and QOL in Asian family carers as a foundation for future research.

Based on papers 1 and 2, I developed the conceptual framework that differentiated between positive and negative emotion-focused coping and adjusted for relevant covariates that may influence the associations between coping and QOL among Asian family carers of a person living with dementia. This conceptual framework guided my quantitative study, described in papers 3 and 4. In paper 3, I described the participant recruitment processes and the main recruitment challenges, and successful strategies to recruit Thai family carers of persons living with dementia. The COVID-19 pandemic significantly impacted participant recruitment, including delaying authorization and temporarily halting in-person recruitment activities. Four strategies were employed to achieve successful recruitment. These included: (1) modification of the recruitment process; (2) working with organizations that have access to target participants; (3) using a multi-pronged recruitment strategy; and (4) tracking the number of participants regularly. It appears that these strategies were beneficial to improving the participation rate, and I was able to achieve the recruitment goal within the timeline.

The findings from the descriptive correlational study based on the adapted model are described in Paper 4. This study tested hypotheses which stated that, after adjusting for covariates including carer characteristics (e.g. age, gender, education, financial status) and carers' stress and social support, problem-focused coping and positive-emotion focused coping would have a strong, positive association with QOL; while, negative emotion-focused coping would have a strong, negative association with QOL. In contrast with the proposed hypotheses, multivariable analysis found no significant association between problem-focused and negative emotion-based coping and QOL after adjusting for covariates. However, the findings supported that positive emotion-focused coping was positively and significantly associated with total QOL of Thai family carers of persons living with dementia. Although statistically significant, the association between positive emotion-focused coping and total QOL was a weaker association, as compared to the association between positive emotion-focused coping and the psychological health and social relationship domains of QOL.

Pinijsuwan et al. (2018) study identified factors that were predicting QOL among carers of persons living with dementia. There were 158 carers who participated in the study. The majority of participants was female (77.85%), middle-aged (82.28%), adult children (67.10%), graduated bachelor degree (43.31%) and had financial adequately (81.01 %). The length of care per day was 17.78 hrs. and the total duration of care was 3.73 years. The sample characteristics in Pinijsuwan et al.'s (2018) study were similar to our study as most of them are adult daughter carers, educated, and have financial adequately. The mean total QOL scores in our study (mean 96.15, SD 13.14) was lower than Pinijsuwan et al. (2018)'s study (mean 102.38, SD 14.93). However, the total QOL scores in both studies reflect a good level of QOL among Thai family

carers of persons living with dementia, as determined by the criteria according to Mahatnirunkul et al. (1998); the range of total QOL 96-130 scores reflect a good level of QOL.

The study findings highlight the importance of applying a clear conceptual framework to identify the relevant variables in the study and map out the relationship among variables. It was also important to differentiate emotion-focused coping from positive and negative emotion-focused coping because they have different associations with QOL.

Strengths and Limitations

My dissertation aimed to identify the association between coping and QOL in Thai family carers of persons living with dementia. There are several key strengths of my dissertation, which include (1) a systematic literature review on coping strategies utilized by Asian family carers of persons living with dementia, (2) the development of a conceptual framework to guide the study, and the testing of hypotheses derived from the literature and framework, (3) utilization of a multi-pronged recruitment approach during the COVID-19 pandemic, and (4) a multi-variable approach to data analysis.

Paper 1, a systematic review of the coping strategies utilized among Asian family carers of persons living with dementia, identified four factors that influenced coping strategies. It was a systematic search of the literature published in either English or Thai languages. The review has been reported using PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis (Moher et al., 2009) and resulted in a comprehensive literature review on the topic. The systematic review in paper 1 included only quantitative studies. As qualitative methods have demonstrated their utility for exploring differences in carers' attitudes and beliefs (Chan et al., 2010; Nguyen & Levkoff, 2020), there was a need to further explore the qualitative literature exploring carer coping. Thus, paper 2 linked the quantitative systematic review with the

qualitative literature to derive an adaptation of the Stress and Coping Model applicable to Asian family carers of persons living with dementia that combined (1) the Caregiver Stress Process Model (Pearlin et al., 1990), and (2) the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984).

A strength of my empirical study (paper 3 and paper 4) is that it utilized a multi-pronged recruitment approach, leading to our success in participant recruitment. My empirical study was guided by the study conceptual framework derived from the Stress and Coping Models (Lazarus & Folkman, 1984; Pearlin et al., 1990), as well as the literature on stress and coping in Asian family carers of persons living with dementia. Participants were recruited through social media in combination with in-person recruitment and word-of-mouth referrals. Participants had various options to complete the survey either online, by paper/mail or by telephone. These strategies were beneficial to improving the participation and response rate. In addition, data were analyzed using a multi-variable approach because bivariate analysis may have limited the conclusions on the relationship between coping and QOL, as it did not adjust for potential confounders. The outcomes in this study demonstrated that positive emotion-focused coping was significantly associated with QOL. My findings highlighted that it is essential to differentiate between positive and negative emotion-focused coping in order to generate valid estimates of the association between coping and QOL and offer support for Carver et al.'s (1997) framework for understanding coping. This framework categorizes coping into emotion-focused strategies, including acceptance, emotional support, humor, positive reframing, and religion (which I refer to in my dissertation as positive emotion-focused coping). Dysfunctional coping includes behavioral disengagement, denial, self-distraction, self-blame, substance use, and emotional venting (which I refer to in my dissertation as negative emotion-focused coping).

There are also limitations to my dissertation. In paper 1, a variety of coping measurement tools made it challenging to categorize coping strategies. More consistent use of measures would increase their comparative value and enable meta-analyses to be conducted. The findings of the studies we reviewed were challenging to synthesize due to the small number of articles which assessed associations with each outcome. In paper 2, The Asian Family Carers of Persons living with Dementia Stress and Coping Model has been developed based on previous theory and qualitative and quantitative research findings specific to the population. This model can be used as a conceptual framework to guide research related to coping among Asian family carers of persons living with dementia, for example, by illustrating relationships to test and covariates to adjust for. However, given the limitations related to the primary studies that were synthesized in order to develop this model, future research is required to continue to test and modify the model as appropriate.

In paper 3, recruiting family carers of persons living with dementia was challenging, particularly during the COVID-19 pandemic. The impact of the pandemic was not only on researchers' ability to recruit participants but also on carers' ability to participate in the study and the availability of health care providers to facilitate recruitment. However, there are several factors that may have influenced research participation and carers' non-response, including the COVID-19 pandemic or sociocultural barriers to recruitment. For example, during the COVID-19 period, carers experienced a significant increase in the physical and psychological burden of care (Achraf et al., 2020; Budnick et al., 2021). On the other hand, social stigma about dementia and mistrust of researchers may lead carers to refuse research participation (Fry et al., 2021). Moreover, we found that the proportion of incomplete responses to online surveys was higher than for other data collection methods. Future research is needed to explore factors contributing

to the decision to participate and factors affecting item non-response in a survey conducted with Thai carers of persons living with dementia.

In paper 4, some variables (e.g., relationship to care-recipient, behavioral and depression symptoms of care-recipients) may be difficult to adjust for within the Thai context because of issues with translation of measures or because of differences between Thai and Western samples, so we did not include these variable as confounding variables in this study. For example, empirical study supports that the relationship to the care-recipient, particularly spouse as compared to non-spouse carers, is an important variable to consider within the context of dementia caregiving (Johansson et al., 2021). However, in this study, my sample was predominantly adult children (e.g., son/daughter) of the care-recipient (86%, n=74). Only 3 participants were a spouse of a person living with dementia, so this variable may be difficult to adjust for within the Thai context. In addition, behavioral symptoms and depression of persons living with dementia and familism beliefs were significant variables that influenced coping according to the stress model. However, a validated assessment tool to assess disruptive behaviors and depression of persons living with dementia (Teri et al., 1992) and familism beliefs were not available in the Thai language. Thus, we did not include these variables in the study. Further study may consider including these variables as valid and reliable measures are available in Thai.

In particular, future studies concerning familism are needed. We located only one study in our systematic review that used quantitative measurement to assess familism values among Asian family carers. Liu et al. (2012) examined how caregiving appraisal, coping, perceived social support, and familism influenced the impact of caregiving stressors on the psychological health of Chinese carers. Familism was measured by the Attitudinal Familism Scale (Steidel &

Contreras, 2003). Study findings suggested that the increased value of familism was linked to more caregiving satisfaction, more positive coping strategies, and better psychological health among Chinese carers of persons living with dementia (Liu et al., 2012). In order to conduct future studies related to familism in Thailand, a tool is needed which has been translated and validated for use within that context.

Implications for Future Research

With the increase in the prevalence of dementia, the number of family and friends providing informal care to persons living with dementia has also increased (Richardson et al., 2013). Thus, research is needed to identify the type of help that may be effective for carers of persons living with dementia to maintain their QOL. When caregiving is long-term, many carers experience coping difficulties (Shim et al., 2013). Thus, we need to learn more about the perceptions of the caregiving and coping experiences, which can lead to a better understanding of the potential challenges carers face. My dissertation findings have implications for future research. First, my conceptual framework can be used as the foundation for future studies on factors that are associated with coping strategies, which influence carer QOL among Asian family carers of persons living with dementia. The categorization of positive and negative emotion-focused coping generated valid estimates of association between coping and QOL. Second, my study tested the association between problem-focused, positive emotion-focused, and negative emotion-focused coping and QOL as an example of how the conceptual framework can be used. My findings supported that positive emotion-focused coping is positively associated with total QOL, particularly the psychological health and social domains of QOL. No association was found between problem-focused coping and total QOL and other QOL domains. In previous literature, differences in coping categorization and failure to adjust for potential confounders

resulted in findings of inconsistent associations between coping and QOL. My dissertation addressed gaps in our knowledge by identifying various factors that have been associated with coping, differentiating emotion-focused coping into positive and negative emotion-focused coping, and using multi-variable analysis to adjust for confounding variables. In my study, females were the predominant family carers of persons living with dementia. Because my sample was predominantly (87.2%, n=75) female, this may be the reason why I found that emotion-focused coping was the most common strategy used. Literature reviews explored sex and gender differences in carer QOL (Pinquart & Sörensen, 2007; Sharma et al., 2016). A previous review found that females more frequently used emotion-focused coping, while males used problem-focused coping (Sharma et al., 2016). In addition, a previous meta-analysis found that female carers reported higher levels of burden and lower levels of subjective well-being and physical health compared with males (Pinquart & Sörensen, 2007). Thus, future research is needed to understand how caregiving experiences may differ between men, women, and others in order to enhance the planning and development of gender-specific carer interventions and social policy recommendations to improve QOL. Moreover, other social factors may have an influence on carer stress and coping. For example, Sequeira (2013) found that age, sex, marital status, educational level, employment level, and household situation are associated with coping and carer burden in Portuguese carers (Sequeira, 2013). Our study found that age, sex, and education level were not significantly associated with QOL. Future research should determine if these factors are significantly associated with coping and QOL.

Implications for Nursing Practice

The study results help inform practical implications for family carers in dementia care in Thailand and other Asian countries with similar sociocultural contexts. First, Asian Family

Carers of Persons Living with Dementia: Stress and Coping Model can be used in nursing practice. For example, nurses can use this model to identify carers who may be at risk for poor QOL based on their characteristics or specific coping strategies. Second, the quantitative study findings supported the development and evaluation of interventions for carers that encourage the use of positive emotion-focused coping strategies (e.g., positive reframing, acceptance, and emotional support), as these strategies were found to be helpful. This would help carers develop more effective use of coping strategies, which have been found to be helpful to Thai carers, to reduce stress and enhance their QOL.

Implications for Nursing Education

The detailed information on recruitment challenges and strategies for successful recruitment will be an important source of information for both researchers and nursing students, which can help them in research planning and implementation for future survey studies. Several factors influence carers' decision to participate in a study, such as participants' attitudes, perceived norms, and perceived behavioral control (McPhillips et al., 2021). Thus, further studies should identify factors that contribute to the decision to participate in research by Thai family carers of persons living with dementia to further inform recruitment strategies. In this study, the recruitment of participants through Facebook and social media alone did not result in sufficient sample size, and we needed to use a multi-pronged recruitment strategy to achieve the recruitment goal. Nevertheless, online recruitment was needed to continue recruitment activities during the COVID-19 pandemic to maintain research activities while preventing potential viral transmissions to research participants or staff.

In addition, my dissertation addressed the knowledge gap related to inconsistent association between coping and QOL among Asian family carers of persons living with dementia

identified in previous literature. The study findings supported the strength of the association between positive emotion-focused coping and QOL, which has implications for the development of carer coping interventions to improve QOL.

Building on this Work

In the beginning of my doctoral study, my goal was to develop an online intervention for use in Thailand to improve QOL for Thai family carers of persons living with dementia. I conducted a systematic review of online interventions for Asian family carers of persons living with dementia. Only one online intervention was previously developed. This online intervention provided information related to dementia and psychological support through e-mail communication (Chiu et al., 2009; Chiu & Eysenbach, 2010, 2011; Chiu et al., 2010). To develop an intervention, Medical Research Council (MRC) provides guidelines to help researchers adopt appropriate methods that highlight the importance of conducting phase one conceptual work to develop and understand the problem as laying the groundwork for intervention development (Medical Research Council, 2019). Thus, I conducted a literature review about Thai family carers of persons living with dementia to gain a better understanding of carer needs. I found a limited number of studies related to Thai family carers, which was insufficient to support the development of an intervention. The next steps were the completion of this dissertation. During my Ph.D. study, I have learned to conduct comprehensive literature searches to identify research gaps, form a valid research question and develop a clear conceptual framework that maps out the relationships among variables, conduct a study to test hypotheses, analyses the results, and discuss the study findings, and link study findings to the broader carer research. These skills are helpful, and I can apply them in my academic career.

Future studies that I will aim to conduct to build on this work will include: (1) a literature review to identify positive emotion-focused coping interventions used in Asian populations and the effectiveness of interventions in improving QOL of family carers of persons living with dementia; (2) conduct qualitative research to explore how carers use positive emotion-focused coping, or when they find it challenging to use this strategy, to identify problems and needs of the target population; (3) development of a carer coping intervention based on the evidence-based and theory; (4) feasibility testing and adaptations to ensure that the intervention can be delivered and is acceptable to use with Thai family carers of persons living with dementia; and (5) evaluating the intervention in a large scale study to determine whether it will be effective to improve QOL.

Conclusion

My dissertation enhances the understanding of how Asian family carers of persons living with dementia cope with stress, factors associated with coping strategies utilized, and the association between coping and QOL. A systematic process was used to first identify factors associated with stress and coping in Asian family carers, then develop a model and hypotheses to guide my study. The study findings support the association between positive emotion-focused coping and QOL. This knowledge can help nurses to support carers to develop more effective coping strategies to reduce stress and enhance their QOL. Furthermore, based on the coping strategies used by carers, this finding may help nurses to identify carers who are at risk for decreased QOL. In addition, this finding may guide the development of carer coping interventions to support carers to use positive emotion-focused coping more frequently or apply positive emotion-focused coping in different situations.

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Appendix 1. Ethics Approval

1.1 The University of Alberta Research Ethics Board

Notification of Approval

Date: July 28, 2020
Study ID: Pro00102422
Principal Investigator: [Lalita Kaewwilai](#)
Study Supervisor: [Wendy Duggleby](#)
Study Title: The Association between Coping Strategies Utilized and Quality of Life among Thai Family Caregivers of Persons Living with Dementia Residing in Community
Approval Expiry Date: Tuesday, July 27, 2021
Approved Consent Form: Approval Date 7/28/2020 Approved Document ICF version 1,2 Date July28

Thank you for submitting the above study to the Research Ethics Board 2. Your application has been reviewed and approved on behalf of the committee.

Any proposed changes to the study must be submitted to the REB for approval prior to implementation. A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Approval by the Research Ethics Board does not encompass authorization to recruit and/or interact with human participants at this time. Researchers still require operational approval as applicable (e.g. AHS, Covenant Health, ECSD etc.) and where in-person interactions are proposed, institutional and operational requirements outlined in the [Resumption of Human Participant Research - June 24, 2020](#) must be met.

Sincerely,

Ubaka Obogogu, LLB, BL, LLM, SJD
Chair, Research Ethics Board 2

Note: This correspondence includes an electronic signature (validation and approval via an online system).

1.2 The Ethical Review Committee for Human Research, Faculty of Public Health, Mahidol University, Thailand



Certificate of Approval Ethical Review Committee for Human Research Faculty of Public Health, Mahidol University

COA. No. MUPH 2020-123

Protocol Title : THE ASSOCIATION BETWEEN COPING STRATEGIES UTILIZED AND QUALITY OF LIFE AMONG THAI FAMILY CAREGIVERS OF PERSONS LIVING WITH DEMENTIA RESIDING IN COMMUNITY

Protocol No. : 131/2563

Principal Investigator : Miss Lalita Kaewwilai

Co-Investigator(s) : Dr. Wendy Duggleby
Dr. Hannah O'Rourke

Affiliation : Department of Public Health Nursing
Faculty of Public Health, Mahidol University

Approval Includes :

1. Project proposal
2. Information sheet
3. Informed consent form
4. Data collection form/Program or Activity plan

Date of Approval : 14 October 2020

Date of Expiration : 13 October 2021

The aforementioned project have been reviewed and approved according to the Declaration of Helsinki by Ethical Review Committee for Human Research, Faculty of Public Health, Mahidol University.

S. Nanthamongkolchai

(Assoc. Prof. Dr. Sutham Nanthamongkolchai)

Chairperson of Ethical Review Committee for Human Research

C. Tanasugarn


(Assoc. Prof. Dr. Chanuantong Tanasugarn)

Dean of Faculty of Public Health

420/1 Rajvithi Road, Bangkok, Thailand 10400

Tel. +66 2354 8543-9 ext. 1412, 1127 Fax. +66 2640 9854

1.3 The Institutional Review Board of the Faculty of Medicine, Chulalongkorn University, Thailand



COA No. 279/2021
IRB No. 028/64

INSTITUTIONAL REVIEW BOARD
Faculty of Medicine, Chulalongkorn University
1873 Rama 4 Road, Pathumwan, Bangkok 10330, Thailand, Tel 662-256-4493

Certificate of Approval

The Institutional Review Board of the Faculty of Medicine, Chulalongkorn University, Bangkok, Thailand, has approved the following study which is to be carried out in compliance with the international guidelines for human research protection as Declaration of Helsinki, The Belmont Report, CIOMS Guideline and International Conference on Harmonization in Good Clinical Practice (ICH-GCP)

Study Title : The Association between Coping Strategies Utilized and Quality of Life among Thai Family Caregivers of Persons Living with Dementia Residing in Community

Study Code : -

Principal Investigator : Miss Lalita Kaewwilai

Affiliation of PI : Department of Public Health Nursing, Faculty of Public Health, Mahidol University.

Review Method : Expedited

Continuing Report : At least once annually or submit the final report if finished.

Document Reviewed :

1. Research Proposal Version 2.0, December 21, 2020
2. Protocol Synopsis Version 2.0 Date February 16, 2021
3. Information sheet for research participant Version 2.0, February 16, 2021
4. Informed Consent Form Version 1.0, January 11, 2021
5. Personal information questionnaire of dementia caregivers Version 2.0, February 16, 2021
6. Online Questionnaire



7. Short Stress Management Assessment (Brief COPE) Version 1.1, October 14, 2020
8. WHOQOL – BREF Version 1.1, October 14, 2020
9. Thai version of 10-item Perceived Stress Scale-10 (T-PSS-10) Version 1.1, October 14, 2020
10. Revised-Thai version of the Multi-dimensional Scale of Perceived Social Support (r-T-MSPSS) Version 1.1, October 14, 2020
11. Poster Version 2.0, February 16, 2021
12. Curriculum Vitae and GCP Training
 - Miss Lalita Kaewwilai
 - Dr. Wendy Duggleby
 - Dr. Hannah O'Rourke

Signature Tada Sueblinwong
(Emeritus Professor Tada Sueblinwong MD)
Chairperson
The Institutional Review Board

Signature Onanong Kulaputana
(Associate Professor Onanong Kulaputana MD, PhD)
Member and Assistant Secretary, Acting Secretary
The Institutional Review Board

Date of Approval : February 22, 2021
Approval Expire Date : February 21, 2022

Appendix 2. Carer Demographic Form

1. What is your age? _____(years)
2. What is your gender? Man Woman Prefer not to say
3. Marital Status: Single Married Widowed Divorced/separated
4. Address, including postal code:

5. Religious Preference
 Buddhist Muslim Catholic / Protestant Others _____
6. What is the highest level of school you have completed?
 No schooling completed
 Some high school, no diploma
 High school graduate, diploma or the equivalent
 Some college credit, no degree
 Trade/technical/vocational training
 Bachelor's degree
 Master's degree
 Doctorate degree
7. Are you employed? Yes No
8. If employed do you work: Full-time Part-time Casual
9. What is your relationship to care receiver:
 Husband/wife/life partner
 Parent
 Parent-in-law

- Son/daughter
- Son/daughter-in-law
- Sister/brother
- Sister/brother-in-law
- Friend
- Other (specify) _____

10. Do you have any medical conditions? Yes No

a. If yes what are they? _____

11. What is your estimated monthly household income:

- Less than 5,000 THB
- 5,000-9,999 THB
- 10,000-14,999 THB
- 15,000-19,999 THB
- 20,000-24,999 THB
- 25,000-29,999 THB
- 30,000-34,999 THB
- 35,000 -39,999 THB
- 40,000-44,999 THB
- More than 50,000 THB / month
- Prefer not to answer

12. Your finances meet your needs:

- Completely
- Very well

- Adequately
- With some difficulty
- Not very well
- Totally inadequately

13. How long have you been caring for a person living with dementia ? _____ (years)

14. What is the average length of care per day? _____ (hours)

15. Are you a primary carer Yes No

16. Do you have other family carers or other person to support the care for person living with dementia? Yes No

If yes, please specify the total number of carers _____

17. What is your carer's role and responsibilities?

About the person you are caring for:

18. What is their age? _____

19. What is their gender? Male Female

20. What is their medical diagnosis?

21. What is their stage of disease? *Please find below information for the staging criteria.

- Early stage of life
- Middle stage
- Late stage

End of Life

Don't know

22. Thinking about the person that you care for, do they have any behaviors caused by their dementia that affect your quality of life?

No

If yes, please provide briefly state of what there are

Stages of Alzheimer's disease

Alzheimer's disease is a brain disease where brain cells progressively degenerate. Alzheimer's disease typically follows certain stages which will bring about changes in the lives of the person and their family. Because the disease affects each individual differently, the symptoms, the order in which they appear, and the duration of each stage vary from person to person. In most cases, the disease progresses slowly, and the symptoms of each stage may overlap, often making the move from one stage to another quite subtle. There is currently no cure for Alzheimer's disease nor can its progression be reversed. Present treatment options and lifestyle choices, however, can often significantly slow the progression of the disease.

Early stage

The term "early stage" refers to individuals of any age who have mild cognitive impairment due to advancements of Alzheimer's disease. Common symptoms include forgetfulness, communication difficulties, and changes in mood and behaviour. People in this stage retain many of their functional capabilities and require minimal assistance or adjustments. They may have insight into their changing abilities, and, therefore, can inform others of their experience of living with the disease and help to plan and direct their future care.

Middle stage

The middle stage is also referred to as “moderate Alzheimer’s disease”. This stage brings a greater decline in the person’s cognitive and functional abilities. Memory and other cognitive abilities will continue to deteriorate although people at this stage may still have some awareness of their condition. For instance, the person can have difficulty remembering recent events or names of family, but still recognize familiar faces. Mood shifts may include anxiety, suspiciousness, depression, anger and agitation. Behavioral changes may include passiveness, restlessness, repetitive questioning or actions, delusions and hallucinations. Assistance with many daily tasks, such as shopping, housekeeping, dressing, bathing and toileting will eventually become necessary. At this stage, the person may move to a long-term care home. With increasing need to provide care, everyone involved will need help and support.

Late stage

The late stage of Alzheimer’s disease may also be called “severe” or “advanced” stage. In this stage, the person eventually becomes unable to communicate verbally or look after themselves. Care is required 24 hours a day. Persons can experience severe impairment in memory, ability to process information and orientation to time and place. Individuals experience physical and physiological deterioration, such as impaired swallowing, walking, controlling head or facial expressions. Because the person with late stage Alzheimer’s disease cannot initiate activity alone, family and carer involvement is necessary, and in many cases, the person will need to live in a long term care home, or, if at home, with added support. The goal of care at this stage is to continue to support the person to ensure the highest quality of life possible. Activities should be tailored to remaining strengths

and abilities, taking into consideration the person's life history and personal preferences.

End of life

People in the final months of dementia will experience progress in symptoms and physical pain or discomfort. Physical changes include poor blood circulation, challenges in breathing, breakdown of skin, dry mouth, etc. Persons with dementia at this stage also experience changes in senses such as impaired vision and increased sensitivity to noise or lights. Thus, close observation for signs of physical pain or emotional change is needed and adjustments of sensory stimuli should be provided in order to avoid distressing the individuals. When the person nears death, comfort measures become the focus.

Aggressive interventions that produce fear or discomfort may not be in the person's best interest and may do more harm than good. As in the care of any person living with a terminal illness, physical as well as emotional and spiritual needs must be carefully considered and attended to, focusing on quality of life and comfort.

*Resource: <https://alzheimer.ca/en/Home/About-dementia/Alzheimer-s-disease/Stages-of-Alzheimer-s-disease>

Appendix 3. The Brief COPE Inventory

Brief-COPE (Brief-COPE)

Instructions:

The following questions ask how you have sought to cope with a hardship in your life. Read the statements and indicate how much you have been using each coping style.

		I haven't been doing this at all	A little bit	A medium amount	I've been doing this a lot
1	I've been turning to work or other activities to take my mind off things.	1	2	3	4
2	I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3	I've been saying to myself "this isn't real".	1	2	3	4
4	I've been using alcohol or other drugs to make myself feel better	1	2	3	4
5	I've been getting emotional support from others.	1	2	3	4
6	I've been giving up trying to deal with it.	1	2	3	4
7	I've been taking action to try to make the situation better.	1	2	3	4
8	I've been refusing to believe that it has happened.	1	2	3	4
9	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10	I've been getting help and advice from other people.	1	2	3	4
11	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13	I've been criticizing myself.	1	2	3	4
14	I've been trying to come up with a strategy about what to do.	1	2	3	4
15	I've been getting comfort and understanding from someone.	1	2	3	4
16	I've been giving up the attempt to cope.	1	2	3	4

		I haven't been doing this at all	A little bit	A medium amount	I've been doing this a lot
17	I've been looking for something good in what is happening.	1	2	3	4
18	I've been making jokes about it.	1	2	3	4
19	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20	I've been accepting the reality of the fact that it has happened.	1	2	3	4
21	I've been expressing my negative feelings.	1	2	3	4
22	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23	I've been trying to get advice or help from other people about what	1	2	3	4
24	I've been learning to live with it.	1	2	3	4
25	I've been thinking hard about what steps to take.	1	2	3	4
26	I've been blaming myself for things that happened	1	2	3	4
27	I've been praying or meditating	1	2	3	4
28	I've been making fun of the situation.	1	2	3	4

SAMPLE

Appendix 4. WHO Quality of Life-BREF

WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Appendix 5. Perceived Stress Scale

PERCEIVED STRESS SCALE

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.

Name _____ Date _____

Age _____ Gender (Circle): **M** **F** Other _____

0 = Never 1 = Almost Never 2 = Sometimes 3 = Fairly Often 4 = Very Often

- | | | | | | |
|--|---|---|---|---|---|
| 1. In the last month, how often have you been upset because of something that happened unexpectedly? | 0 | 1 | 2 | 3 | 4 |
| 2. In the last month, how often have you felt that you were unable to control the important things in your life? | 0 | 1 | 2 | 3 | 4 |
| 3. In the last month, how often have you felt nervous and "stressed"? | 0 | 1 | 2 | 3 | 4 |
| 4. In the last month, how often have you felt confident about your ability to handle your personal problems? | 0 | 1 | 2 | 3 | 4 |
| 5. In the last month, how often have you felt that things were going your way? | 0 | 1 | 2 | 3 | 4 |
| 6. In the last month, how often have you found that you could not cope with all the things that you had to do? | 0 | 1 | 2 | 3 | 4 |
| 7. In the last month, how often have you been able to control irritations in your life? | 0 | 1 | 2 | 3 | 4 |
| 8. In the last month, how often have you felt that you were on top of things? | 0 | 1 | 2 | 3 | 4 |
| 9. In the last month, how often have you been angered because of things that were outside of your control? | 0 | 1 | 2 | 3 | 4 |
| 10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them? | 0 | 1 | 2 | 3 | 4 |

SAMPLE

Appendix 6. Multidimensional Scale of Perceived Social Support

Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988)

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
 Circle the "2" if you **Strongly Disagree**
 Circle the "3" if you **Mildly Disagree**
 Circle the "4" if you are **Neutral**
 Circle the "5" if you **Mildly Agree**
 Circle the "6" if you **Strongly Agree**
 Circle the "7" if you **Very Strongly Agree**

1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7	SO
2.	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	SO
3.	My family really tries to help me.	1	2	3	4	5	6	7	Fam
4.	I get the emotional help and support I need from my family.	1	2	3	4	5	6	7	Fam
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7	SO
6.	My friends really try to help me.	1	2	3	4	5	6	7	Fri
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7	Fri
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7	Fam
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	Fri
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7	SO
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7	Fam
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7	Fri

The items tended to divide into factor groups relating to the source of the social support, namely family (Fam), friends (Fri) or significant other (SO).

Appendix 7. Information Letter and Consent Form

You are invited to participate in a study entitled “The Association between Coping Strategies Utilized and Quality of Life among Thai Family Carers of Persons Living with Dementia”

This study is being undertaken as part of the doctoral study of Miss Lalita Kaewwilai.

Please read this form carefully and feel free to ask any questions you may have.

Research Investigator:

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Background

You are being asked to take part in this study because you have a family member or friend who has dementia. This Information & Consent Form is part of the process of informed consent. It explains this research study and what will happen to you if you choose to be in this study. If you would like to know more about anything you read here, or have any questions at any time regarding this research study, please be sure to ask the researcher. Read this form carefully to make sure you understand all the information provided. You will get a copy of this form to keep. You do not have to take part in this study if you don't want to. Your family member's care does not depend on whether or not you take part.

Purpose of the Research

The purpose of this study is to describe the coping strategies utilized among Thai family carers of persons living with dementia and its relationship with the quality of life. Understanding specific coping strategies utilized may help to support family carers to cope with stress and help nurses and other health care professionals to develop coping intervention to strengthen the coping skills among Thai family carers of persons living with dementia.

Procedures

Approximately 100 Thai family carers of persons living with dementia will take part in this study. If you agree to participate, you will be asked to answer questions about yourself (age, gender, etc.) and your care recipient. Your perceived stress, perceived social support, type of coping strategies utilized, and quality of life will also be assessed. You can answer these questions via an online system. If you are not able to respond to an online system because a computer or internet is not available, you can answer these questions via a telephone interview if you wish. Completing the questions will take about one hour. You do not have to answer the questions all at the same time, but can answer them as you have time over a two-week time period.

In recognition of your time for this study, you will be given a hand sanitizer (50ml). Even though you are receiving this gift, you do not need to answer any questions you don't want to.

Below is a table of the questionnaires that you will be asked to complete:

Questionnaires	Duration
Demographic	5 minutes
Perceived stress	10 minutes
Perceived social support	10 minutes
Coping strategies utilized	10 minutes
Quality of Life	15 minutes

Potential Risks

There are minimal risks to taking part in this study. Your participation in this study will not affect the care of your family member with dementia in any way. Answering the questions may be tiring for you. You do not have to answer any questions you don't want to answer. You can stop being in the study any time you want. If you get tired, don't feel well, or become upset, you can take a break at any time. There is no cost to you associated with taking part in the study other than your time to complete the questionnaires.

Potential Benefits

There is no direct benefits to you for participate in this study. Sharing your experience of to cope with stress may help others in the future, as the information will be used by health care professionals to provide better support for Thai family carers of persons living with dementia.

Confidentiality

Every effort will be made to keep confidential any information that is obtained during this research study. The information collected will not have your name on it. All reporting will be done in a group format, so you will not be able to be identified. Anything that we find out about you that could identify you will not be published or told to anyone. Your identity will remain protected in any publications or presentations of the study results.

The findings will be published in scholarly journals as well as presented at various conferences related to caregiving. If you desire, you may receive a summary of the results.

Participation and Withdrawal:

Your participation in this study is voluntary. If you decide to take part in the study, you are free to stop at any time, even after signing the consent form or part-way through the study. If you decide to stop taking part in the study, there will be no penalty to yourself. Just let the researcher know. If you do not want to answer some of the questions you do not have to but you can still be in the study. If you would like your data to be destroyed, just let us know before April 30, 2021.

Rights of Research Participants:

You may withdraw your consent at any time during the study without consequence. If you have any questions or concerns about the research study, please feel free to contact Lalita Kaewwilai at 780-709-2868 or by email at kaewwila@ualberta.ca. This study has been reviewed and received ethics clearance through the University of Alberta Research Ethics Board. If you have any questions or concerns regarding your rights as a participant, or how this study is being conducted, you may contact the University of Alberta's Research Ethics Office at 780-492-2615. This office has no affiliation with the study investigators.

Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

Printed Participant's Name

Date

Printed name of Person Obtaining Consent

Date

Appendix 8. Recruitment Material



Are You:

- (1) family or friend caregiver who is providing any support for a person living with dementia
- (2) age over than 18
- (3) have access to a telephone or a computer with internet
- (4) speak Thai language

If you answered **yes** to the above questions

You are invited to participate in a study to describe the coping strategies used by Thai family caregivers of persons living with dementia and its relationship with the quality of life.

- You will be asked to answer questions about yourself and your care recipient.
 - You can answer these questions via online system or a telephone interview if you wish. Completing the questions will take about one hour.
 - In appreciation of your time, you will receive a hand sanitizer (50ml).
- If you are interested in participating in this study or for more information please contact:

Lalita Kaewwilai, a PhD Nursing Student, University of Alberta

Telephone: 780-709-2868 Email: kaewwila@ualberta.ca

This research study has been reviewed and approved by the University of Alberta Research Ethics Board (Pro00102422 Approval Date July 28, 2020).