Chinese caregivers' experiences in the care of family members living with dementia: A systematic review and meta-synthesis

by

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Thesis

submitted to Flinders University

for the degree of

Graduate Diploma in Research Methods

(HLTH 7010F)

College of Nursing and Health Sciences

March 2021

Acknowledgements

There are many people and parties to whom I would like to send my appreciation.

I am extremely grateful to my supervisors, Professor Lily Dongxia Xiao at Flinders University and Associated Professor Jing Wang at Xi'an Jiaotong University, for their excellent supervision of my study and their critical feedback. They have provided constant encouragement, helped cultivate my ability to think critically, prompted me to develop my thoughts and ideas, and guided me throughout my research journey. This study might not have been completed without your great support. Both of you are wonderful, considerate, knowledgeable and insightful. It has been my honour to be supervised by you.

I am also deeply grateful to the Student Learning Center and Library at Flinders University for their help throughout my study journey. I would especially like to thank Leila Mohammadi for helping me complete my comprehensive searches. I am also grateful to Kung-Keat's encouragement and guidance.

I highly appreciate my workplace in China, Heilongjiang Nursing College. Without their continuous support and encouragement, I would not have had this opportunity to develop myself. I will use what I leaned at Flinders University in my practice in nursing education when I return to my work.

I also send my gratitude to my parents. Without your care and the influence of your spirituality, I could not have completed my overseas study. I would like to thank my extended family, especially my aunt, for their encouragement and support throughout my study.

I have been blessed with and cheered up by a friendly group of friends—specifically Francesco Provenzano, Chuan Ding, Fan Yang, Yandan Wang, Heng Li, Li Yang, Yumi Naito, Meew Kaewmanorom and Nancy Geregl. I could not have completed my study without your encouragement and help. I also thank my classmates and friends for all their understanding and support.

Summary

Background: Dementia is a leading cause of disability in people aged 65 years and older. China has the largest number of people with dementia, accounting for approximately 25 per cent of the total global population living with dementia. China also has a large diaspora living in developed countries. Chinese family caregivers, influenced by filial piety, are considered the cornerstone of caring for people with dementia at home. Understanding their experiences is vital for providing relevant support for them. However, systematic reviews on Chinese family caregivers' experiences in Greater China and developed countries are scarce.

Aim: The aim of this review is to understand Chinese family caregivers' experiences of caring for people with dementia.

Methods: This systematic review applied the Joanna Briggs Institute meta-aggregation approach. A comprehensive search was conducted using six English databases, four Chinese databases and manual searching. In total, 36 articles were included in the review. They were categorised into two study groups: studies from Greater China and studies from the Chinese diaspora in developed countries. The data were extracted, analysed and synthesised.

Results: Seven synthesised findings were identified from these two study groups: 1) multidimensional caregiver burdens; 2) barriers to dementia care; 3) positive coping strategies that caregivers use; 4) motivations for caregivers; 5) education and training; 6) family dynamics; and 7) expectations for dementia care services. The categories that supported these synthesised findings were slightly different between the two study groups. The lack of government-funded dementia care services was widely reported in the studies in Greater China, while barriers to accessing and using dementia care services were more widely reported in the studies in developed countries.

Discussion: Based on the comparison of findings between the two study groups, three issues were discussed. First, an insufficient level of social support for Chinese caregivers was found, and it must be addressed to improve caregivers' wellbeing and socialisation with others. Second, providing various care services is essential for reducing caregiver burden and improving quality of life. Third, the lack of culturally and linguistically appropriate dementia care services in developed countries must be carefully analysed and addressed.

Conclusion: The synthesised findings have informed recommendations for policymakers and dementia care service providers. They also have implications for further research that focuses on dementia care in Greater China and developed countries.

Keywords: family caregiver, experience, dementia, Chinese, systematic review

Statement of Original Authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the text.

Yujing Zhang

17/03/2021

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List of Abbreviations

Abbreviations	Expansion
ADI	Alzheimer’s Disease International
BPSD	Behavioural and psychological symptoms of dementia
JBI	Joanna Briggs Institute
JBI-QARI	JBI Qualitative Assessment and Review Instrument
PICo	Population, phenomenon of Interest, Context
PRISMA	Preferred Reporting Items for Systematic Review and Meta-analysis
WHO	World Health Organization

Chapter 1: Introduction

1.1 Introduction

This systematic review is based on searching, analysing and synthesising qualitative studies that focus on Chinese family caregivers' experiences of caring for family members who live with dementia. This study's research articles were obtained from Greater China (Mainland China, Hong Kong, Taiwan and Macau) and overseas countries. This chapter is organised into seven sections: the introduction, review context, terms and terminology, theoretical framework, review question and methodology methods, significance of the review, and summary. The outline of each thesis chapter will also be presented in this Introduction.

1.2 The review context

1.2.1 Prevalence and incidence of dementia

1.2.1.1 Prevalence of dementia

Dementia is a neurodegenerative disease that affects brain function. It has become a leading cause of disability in people aged 65 and older (Dementia Australia, 2020e). It has been reported that the worldwide population aged 60 or older in 2017 was 962 million, of which over two-thirds lived in low and middle-income countries (Prina, Mayston, Wu, & Prince, 2019). Therefore, it can be stated that the prevalence of dementia is high in low and middle-income countries (World Health Organization [WHO], 2020). Approximately 14 per cent of people with dementia live in low-income countries, 39 per cent in middle-income countries and 46 per cent in high-income countries (WHO, 2012). Currently, 50 million people worldwide are estimated to have dementia, and the number is expected to reach 152 million in 2050 (WHO, 2020). China has the largest population with dementia worldwide (Jia et al., 2020; The World Bank, 2020). In 2014, the Alzheimer's Disease International (ADI) 10/66 Dementia Research Group reported that 10,590,000 people with dementia were living in Mainland China and that this number will rise to 32,184,000 by 2050 (ADI, 2014). In 2018, the ADI group emphasised that approximately 25 per cent of the global population living with dementia live in China and that this number is expected to more than triple by 2050 (ADI, 2018). The group also stated that the number of people with dementia in Taiwan was 260,000 in 2015 and that this number will reach 840,000 by 2050 (ADI, 2014); that the number of people with dementia in Hong Kong was 115,000 in 2015, which is estimated to rise to 436,000 by 2050; and that the number of people with dementia in Macau was 4,000 in 2015, which is expected to rise to 26,000 by 2050 (ADI, 2014) (see Table 1). The prevalence of dementia in China will steeply increase as the aging population grows in the following years (ADI, 2018). Additionally, it was reported in 2018 that the prevalence of dementia was higher in Western China (7.2%) than in Northern China (5.5%) (Jia et al., 2020). However, a lower estimation of the prevalence of dementia was reported for Central China (5.2%) and Southern China (4.8%) than for Northern China (Jia et al., 2020). The prevalence of dementia could thus be influenced by geographical variation within China (Jia et al., 2020; Y.T. Wu et al., 2018). However, the prevalence of dementia is associated with dementia life expectancy after diagnosis (Jia et al., 2020). A Swedish study that focused on 50,076 individuals living with dementia to investigate the median survival time after a dementia diagnosis revealed that the average survival time is 4.3 years for men with dementia and 5.1 years for women (Haaksma et al., 2020). However, in China, the average survival time for people with dementia is approximately 5.9 years (Alzheimer's Disease Chinese, 2020). Further, Chinese caregivers are experiencing more burdens in their care of people living with dementia. In Australia, it is predicted that the number of people living with dementia—including younger onset dementia (dementia occurring before 65 years old)—will rise from 486,800 in 2020 to 1,117,250 by 2058 (Dementia Australia, 2020b). In the United States (US) in 2019, approximately 5.8 million people lived with dementia (including younger onset dementia) (Alzheimer's Association, 2019). With these high prevalence rates and future estimations, it can be stated that dementia is a global concern and that the high prevalence of dementia imposes a heavy burden on the public and health care system (Jia et al., 2020).

Table 1 Estimated number of people with dementia in Greater China

Regions	**Estimated number of people with dementia in year 2015**	**Estimated number of people with dementia in year 2050**
China Mainland	10,590,000	32,184,000
China Taiwan	260,000	840,000
China Hong Kong	115,000	436,000
China Macau	4,000	26,000

Data is resourced from ADI 10/66 Dementia Research Group (ADI, 2014, p. 4)

1.2.1.2 Incidence of dementia

The incidence of dementia is rising globally, and approximately 10 million new cases are reported every year (WHO, 2020). In China, few studies have examined the incidence of dementia (Jia et al., 2020). A review study by Chan et al. (2013) reported that between 1990 and 2010, the incidence of dementia in China was 9.87 per 1,000 person-years. Another review study in 2016 reported that the incidence of dementia was 12.1 per 1000 person-years in China (Yuan et al., 2016). The incidence of dementia presents a rising trend. Additionally, aging is the crucial potential risk factor that contributes to dementia (Yuan et al., 2016), and the age-specific incidence of dementia is increasing from 65 years (Jia et al., 2020). Currently, an estimated 119 million people aged 65 years or older live in China (Yuan et al., 2016). There is a possibility that the incidence rate of dementia will greatly increase in China (Yuan et al., 2016). Moreover, Yuan et al. (2016) revealed that this rapidly rising rate is similar to those in Western countries such the US and Europe; specifically, it was revealed that people aged 85 years or older have a higher incidence rate of dementia (Yuan et al., 2016). In Australia, 250 people were diagnosed with dementia every day in 2020, and the number of new cases is expected to rise to over 650 every day by 2056 (Dementia Australia, 2020c). In the US, the incidence rate of dementia was 0.4 per cent for people aged 65–74 years; 3.2 per cent for those aged 75–84 years; and 7.6 per cent for those aged 85 years or older (Alzheimer's Association, 2019). Additionally, for every 10-year increase in a person's age, the incidence of dementia was observed to double (Yuan et al., 2016). A study by Gao, Burney, Callahan, Purnell and Hendrie (2019) reported that, in non-Western countries, an 80 per cent reduction in the incidence of dementia correlated with a 10-year increase in birth year. This correlation is especially observed for individuals aged 65–74 years. However, the decreasing incidence rate crossed all age groups in Western countries. From this, an association can be identified between later birth years and a reduced incidence rate (Gao et al., 2019). Further, decreased dementia incidence rates are still linked to effectively reducing cardiovascular risks, recognising how to identify dementia and raising educational awareness of the disease (Gao et al., 2019).

1.2.2 Causes and risk factors of dementia

The causes of dementia are still unclear, though they are thought to be a combination of many risk factors (National Institute on Aging, 2020a). These risk factors can be divided into two categories: modifiable risk factors and non-modifiable risk factors (WHO, 2017).

1.2.2.1 Modifiable risk factors of dementia

There are 12 modifiable risk factors for dementia: a lack of education, lack of physical exercise, excessive alcohol consumption, smoking, hearing impairment, hypertension, obesity, depression, diabetes, traumatic brain injury, social inactivity and air pollution (Baumgart et al., 2015; Livingston et al., 2020; Norton, Matthews, Barnes, Yaffe, & Brayne, 2014; WHO, 2020). Across different life stages, the likelihood of developing dementia could be influenced by various modifiable risk factors. For example, in the early life stage (younger than 45 years old), a lack of education becomes the main modifiable risk factor for dementia; in the midlife stage (between 45 and 65 years), the modifiable factors of obesity, hypertension, excessive alcohol consumption, traumatic brain injury and hearing impairment increase the possibility of developing dementia; in the later life stage (older than 65 years), the factors of physical inactivity, depression, smoking, diabetes, social inactivity and air pollution are associated with dementia (Livingston et al., 2020). The prevalence of dementia can possibly be reduced if these factors are prevented through fundamental strategies (Baumgart et al., 2015; Livingston et al., 2020). In high-income countries, the incidence of dementia is decreasing due to changing lifestyles and developmental styles, as well as cardiovascular risk reduction (Prince et al., 2016). Studies have consistently revealed that reducing these modifiable risk factors is linked to dementia prevention strategies. For example, a study by Norton et al. (2014) reported that reducing risk factors for Alzheimer’s by 10 per cent per decade would result in an 8.3 per cent reduction in expected incidences of the disease; a 20 per cent reduction of risk factors would almost double this reduction figure and lead to a decrease of 15.3 per cent by 2050. It is assumed that if a 10 per cent reduction is achieved, then the prevalence of dementia would reduce by 8.7–9.1 per cent across the US, United Kingdom and Europe by 2050. If a 20 per cent reduction was achieved, then a reduced number of 16.2–16.9 per cent is assumed to occur in these countries by 2050 (Norton et al., 2014). WHO (2020) advocated that regular physical exercise, stimulating cognitive activities, reduced alcohol use and smoking, healthy blood pressure, cholesterol and glucose levels, a balanced diet and the effective management of diabetes can help reduce the risk of dementia or delay its progression.

1.2.2.2 Non-modifiable risk factors of dementia

The non-modifiable risk factors of dementia include age, family history and genetic inheritance, such as the Apolipoprotein E4 allele (APOE-4 allele) (Baumgart et al., 2015; Bookheimer & Burggren, 2009). Aging is the leading non-modifiable risk factor for developing dementia, though it is not a part of dementia (Alzheimer's Association, 2019; WHO, 2020). Further, even if dementia mainly affects people aged 65 and older, it can also develop in people aged between 40 and 50 (Dementia Australia, 2020e). For example, among the 5.8 million Americans who lived with dementia in 2019, three per cent were younger than 65 years old, 16 per cent were aged between 65 and 74 years old, 45 per cent were aged between 75 and 84 years old and 36 per cent were aged 85 years or older (Alzheimer's Association, 2019; Hebert, Weuve, Scherr & Evans, 2013). It is estimated that 13.8 million Americans who are 65 years or older might develop dementia by 2050 (Alzheimer's Association, 2019). Moreover, individuals who do not have a first-degree family member with dementia have a lower risk of developing dementia than those with dementia-related histories (Alzheimer's Association, 2019; Mayeux, Sano, Chen, Tatemichi & Stern, 1991).

1.2.3 Complications of dementia

Certain complications can appear as the disease progresses, such as swallowing disorders, immobility and malnutrition—which can result in acute health conditions and death (Alzheimer's Association, 2019). Older people living with dementia have a higher mortality rate (Prince et al., 2016). For example, in 2017, the mortality rate of dementia in the US was reported to be 37.3 per 100,000 people (Alzheimer's Association, 2019). Regarding the individuals diagnosed with dementia, the duration for surviving the disease is between four and 20 years (Alzheimer's Association, 2019). Due to worsening conditions, people with dementia often require care, as they lack abilities for daily activities (e.g., going to the toilet, showering and dressing). Consequently, care recipients have come to depend more on the assistance of caregivers. Therefore, the caregivers' burden is expected to increase over time.

1.2.4 Cost of dementia

This large population with dementia has resulted in a tremendous economic burden worldwide (WHO, 2017). It is estimated that US$2 trillion will be spent globally on dementia care services by 2030 (WHO, 2017). The cost is generally associated with three aspects of dementia care—medical treatments, social care support (i.e., non-medical costs like residential care) and informal care (ADI, 2014). The Chinese government spend approximately 1.2 trillion RMB on dementia services annually (Alzheimer's Disease Chinese, 2020). Data from the ADI 10/66 Dementia Research Group have revealed that the estimated total cost of dementia care was US$44,619 million in Mainland China in 2015 and US$6,990 million in Taiwan; the approximated aggregated cost of dementia care was US$3,227 million in Hong Kong and US$158 million in Macau (see Table 2) (ADI, 2014). A study by Jia et al. (2020) has similarly reported that the annual cost of dementia care will rise in China from $248.71 billion in 2020 to $1.89 trillion in 2050. However, in Australia, over $15 billion was spent on dementia care in 2018; it is predicted that this cost will rise to over $36.8 billion by 2056 (Dementia Australia, 2020c). This increasing trend of dementia will also negatively influence global economies (WHO, 2017). A Norwegian study found that the cost for institutional dementia care (which constituted the whole cost) rose from 11 per cent after receiving a recent diagnosis of dementia, or developing mild dementia, to 87 per cent on the third year of living with dementia (Vossius et al., 2014; Ydstebo et al., 2020). Consequently, some family caregivers choose home care for patients living with dementia, so they can save money by avoiding institutional care costs (Vossius et al., 2014).

Table 2 Costs of dementia in Greater China

Regions	Estimated cost of dementia in 2015
China Mainland	US$44,619 million
China Taiwan	US$6,990 million
China Hong Kong	US$3,227 million
China Macau	US$158 million

Data is resourced from ADI 10/66 Dementia Research Group (ADI, 2014, p. 4)

1.2.5 Social support

Social support plays a significant role in reducing the burden for families, caregivers and societies (Knight & Sayegh, 2009). This factor can be categorised into formal social support and informal social support (Lu, Wu, Mao, & Liang, 2020). Formal social support denotes support that formal institutions provide (e.g., governments, communities and organisations), and it is usually followed by related laws and policies (Lu et al., 2020). Regarding formal social support in dementia care, both governments and individuals who live with dementia in high-income countries share the cost of dementia care services, and 40 per cent of dementia care costs are covered by governments' social care schemes (WHO, 2017). Conversely, in low and middle-income countries, families usually cover most costs, and only 15 per cent of dementia costs are covered by governments' social care schemes (WHO, 2017). In China, social support focuses on supporting welfare systems, such as through pension insurance, basic medical insurance and social networks (Lu et al., 2020).

Informal social support includes assistance from informal institutions or individuals (e.g., family members, relatives, friends and neighbours) who usually take the role in caring (Lu et al., 2020). For the elderly population, informal support from family members or friends is the traditional source of assistance (Aranda & Knight, 1997). In China, informal support concentrates on emotional and instrumental support from family caregivers (Lu et al., 2020). Moreover, there is a link between high demand for informal support and the severity of the behaviours and psychological symptoms of people with dementia (Ydstebo et al., 2020). Both formal support and informal support significantly influence the health-related quality of life for older people who live with dementia. Consequently, sufficient supportive strategies are needed for family caregivers (ADI, 2014).

1.2.6 Caregivers in their care for people with dementia

As Asian societies are influenced by Confucianism, Taoism and Buddhism, family members become the primary caregivers of the aging and vulnerable population (S. W.-C. Chan, 2011). Filial piety plays an important role in Chinese culture, and family caregivers are the cornerstone for helping people with dementia at home (Wang, Xiao, He, Ullah, & De Bellis, 2014; X. B. Zhang, Clarke, & Rhynas, 2018). Family caregivers provide ‘day-to-day hands-on care’ for people with dementia by helping care recipients maintain activities of daily living (ADLs) and supporting them in their instrumental activities of daily living (IADLs) (Ames, Burns, & O’Brien, 2010, p. 138). For example, the caregiving tasks for recipients managing their ADLs include walking, dressing, grooming, bathing, feeding, toileting and managing incontinence (Alzheimer’s Association, 2019). Moreover, the caregiving tasks for supporting recipients’ IADLs include completing chores, shopping, preparing meals, arranging transportation, making health appointments and managing finances and legal affairs (Alzheimer’s Association, 2019). Consequently, undertaking multiple caregiver roles requires most of the caregivers' individual time. A Chinese study by J. Wang, Xiao, Li, De Bellis and Ullah (2015) revealed that the average caregiving hours of 152 caregivers who provided dementia care were up to 127.6 hours per week. A US study found that 25 per cent of 227 dementia caregivers spent 40 hours or more per week caring for dementia care recipients and that 32 per cent of the caregivers had maintained a caregiving status for five years or more (Ames et al., 2010). Similarly, an Australian study found that an estimated 65 per cent of 12,000 primary caregivers spent 40 hours or more per week caring for people living with dementia (Ames et al., 2010; Australian Institute of Health and Welfare, 2007).

Further, a Norwegian study of 395 people living with dementia found that the care recipients' family caregivers spent 141.9 hours per month (approximately 36 hours per week) caring for them (Ydstebo et al., 2020). Multiple dementia caregiving roles can negatively affect family caregivers, such as in the areas of psychological wellbeing, physical health and social and economic (WHO, 2020). Recognising the caregivers' emotions, care needs and individual expectations of dementia care is crucial for improving the quality of life of caregivers and those under their care (ADI, 2020).

1.2.7 Caregiver burden

Caregiver burden is described as a reaction that negatively influences the caregivers' quality of life, social status and occupational, psychological and individual roles due to caring for people with mental or chronic diseases and illnesses (S. W.-C. Chan, 2011; Wang, Xiao, He, Ullah, et al., 2014). Caregiver burden can be divided into objective burden and subjective burden (S. W.-C. Chan, 2011; Wang, Xiao, He, Ullah, et al., 2014). Objective burden emerges from the changed issues during the care process; it is linked to caregivers' physical health (i.e., physical symptoms and behaviours), sociodemographic characteristics (i.e., age, sex, ethnicity, education or finances) and caregiving activities (i.e., involvement in daily routines like feeding, dressing and toileting) (S. W.-C. Chan, 2011; Wang, Xiao, He, Ullah, et al., 2014). The level of dependency that people with dementia have on carers can be reflected by the objective burden (Ames et al., 2010). Subjective burden emphasises the evaluation of emotional reactions in terms of caring for recipients, and it is based on the effects of objective burden (Fekete, Tough, Siegrist, & Brinkhof, 2017; Wang, Xiao, He, Ullah, et al., 2014). Caregivers' burden can be evaluated by the 'Caregiver Burden Inventory (CBI)' questionnaire (Novak & Guest, 1989). The CBI was first constructed by Carol Guest in 1986, and then it was further developed by Mark Novak in 1989 (Guest, 1986; Novak & Guest, 1989). The CBI was then translated into Chinese and had its validity and reliability checked via 150 primary caregivers in Taiwan by Chou, Jiann-Chyun and Chu in 2002; these scholars found that the CBI is a comprehensive measurement for assessing the burden of Chinese caregivers in their care of people with dementia (Chou, Jiann-Chyun, & Chu, 2002). The CBI includes 24 items grouped into five dimensions: emotional burden, physical burden, developmental burden, time-dependence burden and social burden (Novak & Guest, 1989). Additionally, institutional care costs drive the financial burden of caregivers (Vossius et al., 2014).

The level of caregiver burden is influenced by various factors (van den Kieboom, Snaphaan, Mark, & Bongers, 2020). First, the extent of caregiver burden presents differently among the different types of caregivers (e.g., spouse, adult children, daughter-in-law, son-in-law or grandchild) (Novak & Guest, 1989). Among family caregivers, the level of caregiver burden is higher for spouse caregivers (Pinquart & Sörensen, 2011; van den Kieboom et al., 2020). The reason for this can be attributed to the close attachment between spouses, who become older together, experience physical issues together and live together during the time a spouse with dementia requires care

(Pinquart & Sörensen, 2011). Second, a higher risk of caregiver burden is linked to the dedicated time for caregiving (Kim, Chang, Rose, & Kim, 2011). One study revealed that in comparison to caregivers who spent fewer than eight hours performing caregiving activities, those who spent more than eight hours experienced higher caregiver burden (Park, Sung, Kim, Kim, & Lee, 2015). Specifically, the caregiver burden score increased from 44.36 to 52.14 (out of 88), as evidenced in Park et al.'s (2015) study. Third, a higher level of caregiver burden is associated with the care recipients' behavioural and psychological symptoms of dementia (BPSD) (van den Kieboom et al, 2020; Xiao, Habel, & De Bellis, 2015). J. Wang et al.'s (2015) study found that the level of caregivers' distress in the dementia care process is linked to the care recipients' BPSD severity. Family caregivers' higher level of caregiver burden is also associated with insufficient knowledge of how to manage care recipients' BPSD (J. Wang et al., 2015). Fourth, the sociodemographic characteristics of caregivers also influence the caregiver burden (van den Kieboom et al., 2020). For example, caregiver age is considered a concern that affects the level of caregiver burden (van den Kieboom et al., 2020). A Netherlands study identified that female or spouse caregivers aged between 50 and 70 years old exhibited a greater level of emotional distress in their care (Borsje et al., 2016). Compared to caregivers who care for people with diseases other than dementia, those who care for people with dementia experienced a higher level of care burden and more stress and mental issues (Brodaty & Donkin, 2009; Greenwood & Smith, 2019). The study by Papastavrou, Kalokerinou, Papacostas, Tsangari and Sourtzi (2007) in Cyprus found that 68.02 per cent of 172 caregivers who cared for family members with dementia experienced care burden, of which 65 per cent displayed depressive symptoms. Depression is one of the mental issues that most caregivers encounter (Zhong, Wang, & Nicholas, 2020). Additionally, residing family caregivers not only experience more anxiety and depressive symptoms but also exhibit higher levels of caregiver burden when compared to caregivers who do not reside with their care recipients (Magaña, Martínez, & Loyola, 2020; van den Kieboom et al., 2020). Consequently, caregiver burden can negatively influence the physical health and wellbeing of caregivers (S. W.-C. Chan, 2011).

1.2.8 Caregiver motivation

Motivation is defined as the reason for someone to participate in a given behaviour (Quinn, Clare, & Woods, 2010)—such as caring for people with dementia. The motivation for providing dementia care can be influenced by culture, spirituality, religious beliefs and kin relationships between caregivers and care recipients (Greenwood & Smith, 2019; Quinn et al., 2010). For example, while the motivation for caring is mainly influenced by religion in Western countries, it is mainly influenced by filial piety in Asian countries (Greenwood & Smith, 2019; Quinn et al., 2010). A better understanding of the motivations for caring can encourage society to understand and support caregivers. Two types of motivations are reported in dementia literature: the expectation of keeping an intimate and reciprocal relationship with a family member who lives with dementia at home and a perceived obligation and sense of responsibility for the care recipient (Alzheimer's Association, 2019; Brodaty & Donkin, 2009). For example, Ho, Friedland, Rappolt and Noh's (2003) study found that Chinese Canadian caregivers were unwilling to place their family members who lived with dementia into nursing homes because they felt that providing dementia care at home was an obligation. Other studies have also reported that caregivers' motivations were associated with their wellbeing and their care recipients' quality of life (Camden, Livingston, & Cooper, 2011; Greenwood & Smith, 2019). A lack of caregiver motivation will likely result in an unwillingness to care for those with dementia, poor quality of dementia care and abusive behaviour towards the care recipients (Camden et al., 2011). Caregivers' wellbeing and resilience could be guided by a healthy motivation to gain satisfaction from caregiving (Dombestein, Norheim, &

Lunde Husebø, 2020). Interventions that improve caregivers' self-efficacy (or their belief in their ability to care for people with dementia) could also stimulate their motivation.

1.2.9 Chinese culture

1.2.9.1 Chinese culture in Greater China

In the context of Chinese culture, xiàoshùn 孝顺（'filial piety') has been conceptualised by Confucius (W. Zhang, 2020). It is described as a relationship between parent and child, and it presents as an intergenerational relationship within a family (Yeh, Yi, Tsao, & Wan, 2013). Similarly, Sung's (1995) study found that filial piety included two dimensions: 'behaviourally oriented filial piety and emotionally oriented filial piety' (p. 240). The findings from X. B. Zhang et al.'s (2018) study demonstrated that if family caregivers integrate harmony, affection and satisfaction into their behaviour of caring for people with dementia rather than focus on meeting an obligation, then the quality of care will be improved (X. B. Zhang et al., 2018). Filial piety can be demonstrated in filial obligation and the belief of filial piety (X. B. Zhang et al., 2018). However, general issues can be observed regarding the implementation of filial piety and dementia care. First, it is difficult for family caregivers to fulfil their filial obligations when economic and social issues affect their lives (X.B. Zhang et al. 2018). Second, geographical issues are interlinked with economic and social issues. Where someone is located in China affects the level of filial obligation experienced by family caregivers (X.B. Zhang et al. 2018; W. Zhang, 2020). For example, a study by Chen, Bond and Tang (2007) revealed that participants in Hong Kong exhibited a lower level of filial behaviour even though they had the same level of filial attitude as participants in Beijing.

Since the Chinese government implemented the ‘one-child policy’ in the mid-1980s, the ‘4–2–1’ family structure—four grandparents, two parents and one child—is typical for most families, as well as a decreased family size (Mao, 2010; X. B. Zhang et al., 2018, p.2621). Due to the increasing size of the aging population and the subsequent increasing care needs within families, the number of family caregivers who can provide care has reduced (Mao, 2010). However, caring for family members who live with dementia is influenced by filial piety in the context of Chinese culture (Wang, Xiao, He, & De Bellis, 2014). Filial piety becomes accepted as it is reinforced in Chinese society, and people consider this acceptance a coping mechanism (X.B. Zhang et al. 2018). Therefore, family caregivers experience a higher level of caregiver burden (X. B. Zhang et al., 2018). Family caregivers also experience distress during their care, as they must readjust their care roles and lives (X. B. Zhang et al., 2018). In brief, there are both advantages and disadvantages to filial piety in dementia care. Every circumstance is different and has its own positive and negative aspects (X.B. Zhang et al. 2018).

1.2.9.2 Chinese culture in the Chinese diaspora

For the Chinese diaspora, cultural adaptation in the host country influences the use of social services and life satisfaction (Xiao, De Bellis, Habel, & Kyriazopoulos, 2013). Acculturation also plays a core role in cross-cultural psychology; it presents in the populations of international migrants and their immediate descendants, who are challenged by cultural adaptation in a host country (Berry, 2003; Schwartz, Unger, Zamboanga, & Szapocznik, 2010). Berry’s (2003) study characterised four levels of the acculturation process: assimilation, integration, separation and marginalisation. Assimilation presents in the migrant groups who discard their original culture and completely accept the host country’s culture. Integration includes migrants who can interact with other majority groups based on maintaining their original culture. However, those who retain their original culture and do not interact with individuals of the same cultural background are on the level of separation. Finally, marginalisation describes individuals who do not socialise with people of other cultures and who are unlikely to retain their own culture.

1.3 Terms and terminology

1.3.1 Greater China

The original term ‘Greater China’ stems from a historical distinction in Chinese history—specifically, that between ‘China Proper’ and ‘Outer China’ (Harding, 1993). According to Harding’s (1993) study, ‘China Proper’ denotes the government’s administration of Central China, which was governed in a strict and territorial way. Conversely, Outer China was governed loosely, and the emphasis was less territorial and more cultural (W. W. Zhang, 2005). From the late 1970s, the term ‘Greater China’ became modernised and adapted to fit the global landscape and context (W. W. Zhang, 2005). In a broad and modern context, Greater China refers to the commercial and cultural links with Mainland China, Taiwan, Hong Kong and Macau (Harding, 1993; W. W. Zhang, 2005). Three main definitions of Greater China exist: ‘economic, cultural and political’ (W. W. Zhang, 2005, p. 66). The economic definition of Greater China includes the regional trading bloc that comprises Mainland China, Hong Kong, Macau and Taiwan (W. W. Zhang, 2005). The cultural definition denotes the shared cultural ties that Mainland China, Hong Kong, Macau and Taiwan share (Wang, 1993; W. W. Zhang, 2005). The political definition denotes the need for the political unity of Mainland China, Hong Kong, Macau and Taiwan (W. W. Zhang, 2005). These three aspects are interlinked, but they compose the broad and modern definition of Greater China.

1.3.2 The Chinese diaspora

The term ‘diaspora’ originates from Greek and denotes ‘dispersion and scattering’ (Oxford, 2021). The Oxford English and Spanish Dictionary defined diaspora as ‘Jewish people living outside Israel’ or ‘the dispersion or spread of any people from their original homeland’ (Oxford, 2021, p. 1). Further, the *Merriam-Webster Dictionary* added extra meanings: ‘the movement, migration, or scattering of a people away from an established or ancestral homeland’ or ‘people settled far from their ancestral homelands’ (Merriam-Webster, 2021, p.1). China has large diasporas in many countries, such as in Australia, New Zealand, Canada, the US and UK (United States Census Bureau, 2019b). For example, the US Census Bureau reported in 2017 that approximately five million Chinese–Americans lived in the US (United States Census Bureau, 2019a). The emigration from China generally included three patterns (Liu & van Dongen, 2017). The first pattern of migration lasted from 1850s to 1950, and the migrating populations regarded themselves as *Huaqiao*. This population could be described as ‘Chinese sojourners or overseas Chinese’ emigrants who were still loyal to Chinese culture and politics (Liu & van Dongen, 2017). The second pattern of emigration was *Huaren*, which lasted from 1950 to 1980. This population could be described as ‘ethic Chinese or Chinese overseas’ emigrants who renounced their Chinese citizenship and pledged their allegiance to the host countries. The third pattern was known as *Xin yimin*, which occurred after 1980; this population can be described as new migrants existed. These large groups emigrated from different locations in China to overseas countries. In the 1990s, the term ‘Chinese diaspora’ was mentioned (Liu & van Dongen, 2017). This term encompasses all populations of Chinese descent who live outside Mainland China, Hong Kong, Taiwan and Macau; it also includes new migrants (Poston & Wong, 2016; Wong & Tan, 2018). The review in the current study uses the term ‘Chinese diaspora’ as a description throughout the whole study. After the Irish and German diasporas, the Chinese diaspora is considered the third-largest population worldwide (Poston & Wong, 2016). It is estimated that over 40.3 million Chinese people were living in 148 countries in 2011 (Poston & Wong, 2016). Further, in 2017, the figure increased; 46 million ethnic Chinese people were cited to live outside Mainland China, Taiwan, Hong Kong and Macau in 150 countries (Liu & van Dongen, 2017; Poston & Wong, 2016).

1.3.3 Dementia

Dementia is a complicated syndrome that is accompanied by cognitive impairment and progressively deteriorating brain function (ADI, 2014; Dementia Australia, 2020e). It is linked to reduced competency in thinking, memory, orientation, calculation, learning, decision-making and judgement (Dementia Australia, 2020c; WHO, 2020). As the symptoms worsen over time, people with dementia find it more difficult to maintain daily activities and dignity, which causes other complications (WHO, 2017). Disability and mortality are the final outcomes for people with dementia (ADI, 2014).

1.3.3.1 Types of dementia

There are seven types of dementia, including Alzheimer's disease, vascular dementia, Lewy body disease, frontotemporal dementia, alcohol-related dementia, down syndrome and HIV-associated dementia (Dementia Australia, 2020d). The first four types commonly occur (WHO, 2020). Alzheimer's disease is the most common type of dementia, and 70 per cent of all dementia cases are affected by Alzheimer's disease (Dementia Australia, 2020a). With Alzheimer's disease, small negative changes tend to occur 20 years or more before the noticeable symptoms appear (Alzheimer's Association, 2019). Alzheimer's disease includes abnormal plaques and tangles that build up in the brain and result in reduced brain function (ADI, 2014). Two categories of

Alzheimer’s disease include familial Alzheimer’s disease and sporadic Alzheimer’s disease (ADI, 2014). Familial Alzheimer’s disease occurs rarely, relates to gene mutations and normally develops at the age of 40 or 50 (ADI, 2014). Sporadic Alzheimer’s disease usually affects people aged older than 65 (ADI, 2014). No studies have found any specific genetic factors that cause this type of Alzheimer’s disease (William Rebeck, Reiter, Strickland, & Hyman, 1993). As the neurons in a part of the brain are damaged or destroyed over time, individual symptoms worsen; people with Alzheimer’s disease become ‘bed-bound and require around-the-clock care’ in the final stage (Alzheimer’s Association, 2019, p. 5). The average lifespan for people with Alzheimer’s disease is seven to 10 years (ADI, 2014). The second common type of dementia is vascular dementia, which accounts for 20–30 per cent of dementia cases (ADI, 2014). The lifespan for people after they develop vascular dementia is 3.5 to 4.2 years (WHO, 2012). People of any age can be affected by frontotemporal dementia, and approximately 5–10 per cent of dementia cases are caused by frontotemporal dementia (ADI, 2014). Lewy body dementia results from degenerated and dead nerve cells in the brain, with less than five per cent of dementia cases being attributed to Lewy body dementia (ADI, 2014).

1.3.3.2 Symptoms of dementia

Over time, the symptoms of dementia worsen, and people may act differently from their original personalities (WHO, 2020). According to WHO (2020), the progress of dementia can be divided into three stages: early stage, mild stage and late stage. In the early stage of dementia, forgetfulness and a loss of memory relating to familiar environments and time normally occur (WHO, 2020). As forgetfulness and memory loss are generally considered part of the normal aging process (National Institute on Aging, 2020b), the symptoms of early-stage dementia are always difficult to recognise and easy to neglect (WHO, 2020). In the mild stage of dementia, the symptoms become more prominent, and the people with dementia depend more on carers. For example, people with dementia can have trouble communicating, calculating and paying bills and making judgements of location or time (National Institute on Aging, 2020b). Some people with dementia can also experience changes in their behaviours—such as needing to repeat questions and wondering. In the late stage, people with dementia lose their ability to self-care and perform activities. They comprehensively depend on carers to maintain their daily living, and they may not recognise their family members (WHO, 2020). Aggressive behaviours also become more obvious in this stage of dementia.

1.3.4 Caregivers

Caregivers (also called care providers) assist others to meet their care needs (Johns Hopkins Medicine, 2020). There are two types of caregivers—formal caregivers and informal caregivers (Johns Hopkins Medicine, 2020). Formal caregivers are professionally trained and educated, and organisations or communities pay them to provide care services (Johns Hopkins Medicine, 2020). Informal caregivers do not have professional training experience and payment, and they normally comprise family members, relatives, neighbours and friends (Johns Hopkins Medicine, 2020). Eighty-three per cent of care assistance for elderly populations is received from informal caregivers (Friedman, Shih, Langa, & Hurd, 2015). For example, in the US, it is estimated that 16 million informal and unpaid caregivers (spouses, adult children or other family members, neighbours and friends) spend 18.5 billion hours providing dementia care (Gaugler, James, Johnson, Marin, & Weuve, 2019). Informal caregivers play a significant role in dementia care (Lopez Hartmann et al., 2019). A Belgian study found that among 13,229 elderly people with dementia, 85.9 per cent had at least one informal caregiver who played a primary role, and 42.3 per cent had two informal caregivers (Lopez Hartmann et al., 2019). Throughout dementia care processes in most countries, most caregiving tasks are provided by family caregivers (ADI, 2014). Normally, the spouses and adult children of people living with dementia are the main informal caregivers (Lopez Hartmann et al., 2019). In Lopez Hartmann et al.'s (2019) Belgian study, 56.5 per cent of the primary caregivers were adult children, and 29.3 per cent were spouses.

1.3.5 Behavioural and psychological symptoms of dementia

The BPSD are neuropsychiatric symptoms with clinical manifestations that are integrated into the psychological and behavioural symptoms of people with dementia (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; The Royal Australian College of General Practitioners, 2020). The BPSD are linked to functional and cognitive impairment, and they typically present in the late stages of dementia. Approximately 60–90 per cent of all types of dementia are affected by BPSD during the illness's progression (Cerejeira et al., 2012; The Royal Australian & New Zealand College of Psychiatrists, 2013). According to van der Linde, Dening, Matthews and Brayne (2014), BPSD symptoms are categorised into four groups: affective symptoms (i.e., anxiety and depression), psychosis (i.e., delusions and hallucinations), hyperactivity (i.e., irritability and physical aggression) and euphoria. Other behaviours are also linked to BPSD symptoms, including night-time behaviour disturbances, eating disturbances, apathy and aberrant motor behaviours (van der Linde et al., 2014). BPSD negatively influence the health outcomes of both individuals with dementia and their caregivers (e.g., distress, increased duration of hospitalisation, misuse of medication, increased healthcare costs, and decreased quality of life), and they are a source of caregiving burden (Cerejeira et al., 2012; van der Linde et al., 2014). For example, the care recipients' psychotic symptoms and disruptive behaviours (e.g., delusions, screaming or aggressive behaviours) severely burden the caregivers; therefore, BPSD are a leading cause of family caregivers choosing to place care recipients in nursing institutions (Cerejeira et al., 2012).

1.4 Theoretical framework

This review is based on a stress process model developed by Kim et al. (2011) that emphasises the multidimensional nature of caregivers. The predictors of caregiver burden in this model are categorised into three variables: contextual variables, primary stressors and secondary stressors (Kim et al., 2011). The model also explains that the caregiving burden negatively affects caregivers' physical health and wellbeing. The model is applied as a theoretical framework in this review so that the researcher can analyse the findings as reported in the reviewed articles. The framework is presented in Figure 1.

Image removed due to copyright restriction.

Figure 1 Theoretical framework (Retrieved from Kim et al., 2011, p. 848)

The contextual variables denote the context in which caregiving burdens occur (Kim et al., 2011). They include variables such as caregiving factors and the social demographic factors of care recipients and caregivers (Kim et al., 2011). Identifying the contextual variables associated with caregiver burdens is required for researchers to design interventions that alleviate caregiver burdens (Conde-Sala, Garre Olmo, Turró-Garriga, Vilalta Franch, & López Pousa, 2010).

The primary stressors are associated with the care recipients who live with dementia. They mainly focus on the care recipients' symptoms or disease progressions over time (Kim et al., 2011). For example, their cognitive status is an indicator of a primary stressor (Pearlin, Mullan, Semple, & Skaff, 1990). Without analysing the primary stressor, the need to help carers cope with stress might not be identified (Pearlin et al., 1990).

Secondary stressors are associated with other aspects that contribute to caregiving burdens (e.g., financial issues, family conflicts or difficulties at work) (Kim et al., 2011). These factors negatively affect caregivers' health and wellbeing (Conde-Sala et al., 2010). Therefore, identifying these stressors is also necessary for providing social support services and reducing caregiver burden (Kim et al., 2011).

1.5 The review question and methodology methods

1.5.1 The review question

The review question in this study is: what are the caregivers' experiences in their care of family members who live with dementia?

The aim of this systematic review is to understand the experiences of Chinese family caregivers who care for people with dementia.

The objectives of the review include:

1) determining the factors that enable Chinese family caregivers in their care of people with dementia
2) examining the factors that hinder Chinese family caregivers in their care of people with dementia
3) identifying the expectations of family caregivers regarding dementia care services.

1.5.2 The review methodology methods

The researcher applied the Joanna Briggs Institute (JBI) meta-aggregative approach to synthesise the evidence from the included qualitative studies. This methodology addressed the review aims in three stages (Hannes & Lockwood, 2011; Lockwood et al., 2020). First, it extracted findings and themes from the original studies of primary researchers. Then, based on the similarities of these findings and themes, it assigned them into different categories. Finally, based on the categories, it conducted synthesised statements and recommendations. The detailed review methods will be explained in Chapter 2.

1.6 Significance of the review

Studies on Chinese caregivers' experiences have reported issues in dementia care worldwide. However, systematic reviews that have synthesised the research evidence are scarce. Therefore, this review aims to address this gap of synthesised research evidence regarding family caregivers who care for people with dementia. Systematic reviews are a rigorous and comprehensive approach to synthesising findings from numerous research articles on a topic without bias (Aromataris & Pearson, 2014). They can be used to answer a specific review question based on a carefully planned review protocol (Aromataris & Pearson, 2014). Findings from systematic reviews can help policymakers make informed decisions regarding health policies and recourse development, as well as support health professionals to improve their practice. Understanding the experiences and expectations of family caregivers is essential for developing culturally appropriate dementia care services.

1.7 Summary

This chapter has provided the context of the systematic review, as well as a foundational understanding of dementia-related knowledge. Caregiving for family members who live with dementia leads to multiple caregiver burdens that negatively affect caregivers' physical health outcomes. The prevalence of dementia has steeply increased worldwide; the literature has subsequently revealed that this disease not only negatively affects the caregivers and care recipients' quality of life and wellbeing, but it also causes multiple burdens for the recipients' families, communities and societies. Consequently, determining the experiences, challenges and expectations of family caregivers is necessary for improving the quality of life for both care recipients and caregivers. China has the largest population with dementia worldwide. Therefore, informing policymakers and assisting them in formulating dementia care support for family caregivers is essential. Introducing the theoretical framework will allow a clear understanding of what informs this review and how it was conducted. Thus, the methodology and methods of this review will be discussed in further detail in Chapter 2.

Chapter 2: Methodology and Methods

2.1 Introduction

This chapter will demonstrate the review methodology, review methods and transparent reporting approach that were undertaken in the study. Chapter 2 is divided into 12 sections, including the:

1) introduction
2) methodology and framework
3) review questions and objectives
4) inclusion and exclusion criteria
5) search strategy
6) critical appraisal process
7) data extraction
8) data synthesis
9) ConQual tool
10) recommendations
11) transparent reporting of the approach undertaken
12) summary.

Information regarding what methodology was chosen, as well as how and why it was chosen for this review, will be explained in each section.

2.2 Methodology and framework

2.2.1 Methodology design

The aim of this systematic review is to understand the experiences of Chinese family caregivers in their care of people with dementia. To address this aim, a meta-synthesis of qualitative studies was conducted. The experiences and meanings of individuals were identified through qualitative research (Porritt, Gomersall, & Lockwood, 2014).

Findings are typically synthesised as a meta-synthesis in the systematic reviews of qualitative research—with the two approaches of meta-synthesis, including meta-aggregation and meta-ethnography (Munn, Tufanaru, & Aromataris, 2014). To synthesise the qualitative evidence in this study, the review was conducted using the JBI meta-aggregative approach:

> Meta aggregation is a method that mirrors that accepted conventions for systematic review whilst holding to the traditions and requirements of qualitative research (it aggregates findings in to a combined whole that is more than the sum of the individual findings in a way that is analogous with meta-analysis). (Lockwood et al., 2020, p. 23).

The meta-aggregative approach is linked to the philosophy of pragmatism, and it is suitable for reviewers who want to examine a practical question (Munn, Tufanaru, et al., 2014). The critical feature of the meta-aggregative approach is that ‘it seeks to enable generalizable statements in the form of recommendations to guide practitioners and policymakers’ (Lockwood et al., 2020, p. 27). Further, this approach can guide practitioners and policymakers to take actions and move towards anticipated goals, develop a critical understanding of the phenomenon, ensure a transparent synthesised process and create synthesised statements that are useable and practical (Hannes & Lockwood, 2011; Lockwood et al., 2020). Additionally, the meta-aggregative approach seeks to provide reliability, practicality and useability; it intends to improve the transparency and auditability of the review rather than qualitatively synthesise and reinterpret the findings of primary authors (Hannes & Lockwood, 2011; Lockwood et al., 2020).

The meta-aggregative approach is divided into three phases (Hannes & Lockwood, 2011; Lockwood et al., 2020). The first phase involves extracting the findings, themes or metaphors that primary researchers have identified in original studies; the second phase involves sorting the synthesised findings into different categories based on the similarities of meanings; and the third phase involves synthesising statements or recommendations based on 'lines of actions' (Hannes & Lockwood, 2011; Lockwood et al., 2020). The meta-aggregative approach can help practitioners and policymakers understand what occurred during caregiver practices, how the participants felt, what the practitioners and policymakers can do in future cases and what kinds of goals can be followed and improved (Hannes & Lockwood, 2011). The current study's aims include synthesising the best evidence, as based on the experiences of family caregivers who care for people with dementia and producing high-quality recommendations for improving the quality of patient care; the meta-aggregative approach is thus the most suitable methodology for this review.

To avoid unnecessary duplication, the research title and protocol were developed and registered on the PROSPERO website (registration number: CRD42020205511), and the detailed information is presented in Appendix I. This review was conducted following the registered research protocol. The research protocol was published to increase the methodology's transparency in this review, improve the trustworthiness of the review findings, acknowledge that the review was performed and formulate the best available evidence for recommendations (Butler, Hall, & Copnell, 2016).

2.2.2 The PICo framework

This review was performed using the population, phenomenon of interest and context (PICo) framework, which is suitable for analysing human and social experiences (Stern, Jordan, & McArthur, 2014). The framework also helped the researcher identify the keywords for database searches, and it led to screen studies so that more relevant studies could be researched (Butler et al., 2016). The framework of this review is presented in Table 3.

Table 3 PICo framework

P (Population)	Chinese caregivers/relatives of people living with dementia, the spouse/partner of people with dementia; informal caregivers of people with dementia, or Alzheimer's disease
I (phenomenon of Interest)	Caregivers' experiences, emotions, expectation, feelings and perspectives
C (Context)	Chinese caregivers who provide care for people with dementia at home

2.3 Review question and objectives

Developing a specific and comprehensive research question is crucial, as it will help reviewers formulate the research protocol and develop search strategies (Bettany-Saltikov, 2012; Butler et al., 2016). The review question in this study is: what are the experiences of caregivers in their care of family members who live with dementia? Given the review question, the objectives of this review include exploring the enablers of family caregivers in their care of people with dementia; exploring the barriers to family caregivers in their care of people with dementia; and identifying the expectations of family caregivers regarding education, training programs and resources for dementia care and policy that can help them in their roles.

2.4 Inclusion and Exclusion criteria

2.4.1 Types of studies

The selected studies included primary research that had a qualitative design or that used a mixed-methods design with a qualitative component. Quantitative studies and secondary studies (e.g., narrative reviews, systematic reviews and scoping reviews) were not included. Primary studies that used a mixed-method design without retrievable qualitative data were also not included. All included studies were published in English and Simplified Chinese. No limited publication dates were used during the search for valid studies.

2.4.2 Types of participants

The participant selection criteria stipulated that the family caregivers had to care for people living with dementia, they were primary caregivers aged 18 years or older, and they spoke a Chinese language or held a Chinese culture. Paid caregivers or professional caregivers were excluded from this review, as well as non-primary family caregivers and family caregivers who cared for people who did not live with dementia.

2.4.3 Phenomena of interest

The phenomena of interest included the experiences, perceptions, feelings or emotions of Chinese family caregivers in their care of people living with dementia. Studies that did not focus on family caregivers' experiences, feelings, perceptions and emotions were excluded.

2.4.4 Study context

The context of the included studies was the home setting. The care recipients who lived in nursing homes or hospitals were excluded.

The inclusion and exclusion criteria are summarised in Table 4.

Table 4 Selection criteria

Inclusion criteria	Exclusion criteria
Primary study with a qualitative design	Quantitative studies; secondary studies such as narrative reviews, systematic reviews, scoping reviews
Primary study using a mixed-method design with a qualitative component	Primary study using a mixed-method design without retrievable qualitative data
Family caregivers care for people living with dementia	Family caregivers care for people not living with dementia
Family caregivers are primary caregivers	Family caregivers are not primary caregivers
Family caregivers age 18 years or over	Family caregivers are paid or professional caregivers
Family caregivers speak a Chinese language and hold a Chinese culture	Family caregivers do not speak a Chinese language and not hold a Chinese culture
Experiences/feelings/perceptions/emotions of family caregivers	Studies do not focus on family caregivers' experiences/feelings/perceptions/emotions
Home care setting	The care recipients are living in nursing homes or hospitals
Published in English and Chinese-Simplified language	Not published in English and Chinese-Simplified language

2.5 Search strategy

2.5.1 Identifying databases

Identifying appropriate databases was crucial for obtaining relevant studies, as inappropriate databases would have negatively influenced the quality of the review's findings (e.g., findings could have been invalid or unreliable) (Butler et al., 2016; Knudsen & Chalkley, 2011). This review's research process was performed for 10 databases, including six English databases and four Chinese databases. The English databases included Medical Literature Analysis and Retrieval System Online (MEDLINE), Scopus, ProQuest, Web of Science, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Emcare. The Chinese databases included China National Knowledge Infrastructure (CNKI), Wanfang Data, Weipu Data and China Biology Medicine (CBM). The descriptions of each database are presented in Table 5.

Table 5 Description of Databases

English Database	Description
CINAHL	CINAHL is the top and in-depth database for nursing research. More than 3000 journals, dissertations, books, and conference proceedings regarding the area of nursing and allied health are covered by this database. Also, the publication dates start from 1981 to the present (Polit & Beck, 2016).
Emcare	Emcare is a premium and ideal database for nursing and allied health searching. 3,500 international, peer-reviewed, and currently indexed journals are covered, and it assists researchers, educators or clinical practitioners in improving the research process (Wolters Kluwer, 2020).
MEDLINE	MEDLINE is a bibliographic database that comes from US National Library of Medicine. It focuses on the range of biomedicine and health that is needed by health professionals. More than 26 million references are included in MEDLINE, and the published literature start from 1966 to the

	present (Polit & Beck, 2016; U.S. Department of Health & Human Services, 2020).
ProQuest	ProQuest is a multidisciplinary database providing a single source for scholarly journals, reports, working papers, newspapers and datasets. It also provides digitized historical primary sources and sorts of ebooks (ProQuest, 2020).
Scopus	Scopus is the largest database of peer-reviewed literature with abstract and citation, and it covers the fields of medicine, technology, science, social sciences, and arts and humanities (Elsevier, 2020).
Web of Science	This database provides the access to world's leading scholarly journals covering the range of sciences, social sciences, humanities and arts (Harvard Library, 2018).
Chinese Database	**Description**
CBM	CBM is an in-depth Chinese medical database and covers the published literature starting from 1978 to the present. It focuses on the area of pharmacy, basic medicine, clinical medicine, preventive medicine, and traditional Chinese medicine (Baidu Baike, 2020a).
CNKI	CNKI is a comprehensive Chinese database, including full-text articles from over 4000 Chinese journals. It provides for subject areas regarding economics, management, medicine and health, agriculture and education (Baidu Baike, 2020b).
Wanfang Data	Wanfang Data is a Chinese database and includes 7,600 categories of scholar journals. The literature focus on the area of science, agriculture, medicine, industry, and humanities (Baidu Baike, 2020c)
Weipu Data	Weipu Data is the largest comprehensive database for searching Chinese literature and has a partnership with Google Scholar. It is widely used in Universities, public libraries and scientific research institutions (Baidu Baike, 2020d).

2.5.2 Developing keywords and search terms

After the PICo framework and review question were formulated, four keywords were identified: ‘family caregiver’, ‘experience’, ‘dementia’ and ‘Chinese’. Synonyms of each keyword were then analysed to create a logic grid (see Table 6) so that relevant studies could be comprehensively searched (Lockwood et al., 2020).

Table 6 Keywords and search terms

Family caregiver	Experience	Dementia	Chinese
home caregiver informal caregiver unpaid caregiver unprofessional caregiver caring	feeling perception emotion care need challenge care burden	Alzheimer’s disease cognitive impairment	China

2.5.3 Implementing the database search

The primary reviewer searched each database, and an expert librarian examined each search process. To ensure that all possibilities of words with similar spellings or endings were included, truncations (*) were used to find all relevant words (Butler et al., 2016). The same truncations were also used for all English databases. Each search term in the same column used the Boolean ‘OR’ to combine with each other item to create an individual group (Butler et al., 2016). The overall groups were combined with the Boolean ‘AND’ to search for final relevant studies. As the standards of Chinese databases are different to those of English databases, the Booleans 'OR' and 'AND' and MeSH headings were used to search for relevant studies (Butler et al., 2016). In total, 1,246 articles were searched. All were exported into EndNote (Version X9.3.3) and imported in 'xml' format into Covidence software for further screening. The search processes for each database are shown in Appendix II.

2.5.4 Data selection

Data selection is a crucial stage in the review process for ensuring that credible and useful results that inform healthcare policymaking are obtained. (Porritt et al., 2014). The data selection process included three stages, which the following subsections describe. Three independent reviewers participated in each stage of the selection. Two reviewers performed the stages of screening titles and abstracts and then reviewing full texts, and one reviewer resolved the conflictions. More than one reviewer undertook each stage of data collection so that personal bias could be avoided, potential errors could be minimised, and the validity of the review findings could be improved (Butler et al., 2016).

2.5.4.1 Stage 1: Excluding duplicated studies

Removing duplicated studies can reduce the workload involved in the screening stage, as well as decrease potential errors for the reviewers (Bramer, Giustini, de Jonge, Holland, & Bekhuis, 2016). In this review, all identified studies were exported into EndNote (Version X9.3.3) and then imported in xml format into Covidence software so that duplicated studies could be excluded. In total, 533 duplicated studies were removed, and the remaining studies were subsequently moved to the next stage for further screening.

2.5.4.2 Stage 2: Screening the titles and abstracts

Based on the inclusion and exclusion criteria, any irrelevant studies could be removed via screening the title and abstract (Butler et al., 2016). To minimise errors and bias in the later stage of data collection, the three reviewers collaborated in the screening (Butler et al., 2016). Two independent reviewers performed a first screening, which yielded 76 conflicts. The third reviewer resolved the conflicts. During the screening process, the outcomes were regularly discussed among the three reviewers, and 621 irrelevant studies were subsequently removed.

2.5.4.3 Stage 3: Screening the full-text reviews

Full articles were retrieved and screened for eligibility. The primary researcher uploaded the PDF versions of the potential full-text studies into Covidence software and reviewed each study one at a time. The second reviewer performed the same full-text review as the primary researcher, which yielded 43 conflicts. The third reviewer resolved the conflicts. After the screening, 37 articles were moved to the appraisal stage so that the qualities of each study could be assessed. Of the removed articles, seven were quantitative studies, nine were duplicated, 17 were not Chinese caregivers specific, 15 were not expected outcomes, seven were not primary research articles, two did not involve a home care setting, and two had patients that were not living with dementia. The primary reviewer then manually searched through the reference lists of the retrieved articles to critically appraise and search for additional related studies (Lockwood et al., 2020). Four articles were then generated through a manual search. In total, 36 articles were included in this review, which were moved to the appraisal stage. Regular meetings were conducted among the reviewers to ensure consistency in this stage. To reduce personal bias and improve the trustworthiness of included studies, two reviewers were included in the screening stage, and the third reviewer addressed the conflicts (Butler et al., 2016; Porritt et al., 2014). The reviewers in the group did not experience any disagreements, and the search process was completed on 27 September 2020. The search process was recorded and presented in the Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) flow chart (see Figure 2).

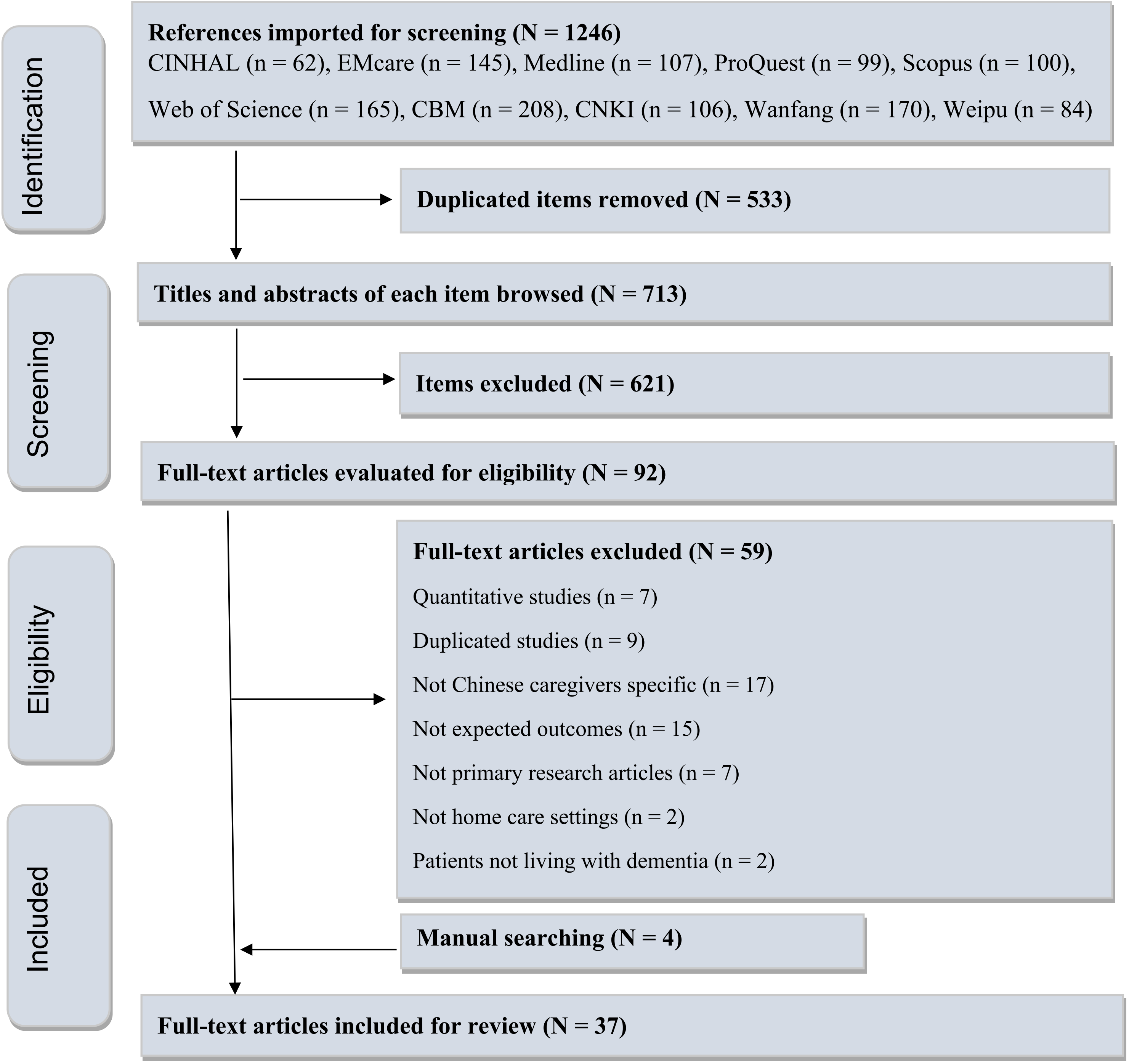

Figure 2 PRISMA chart: Searching and screening process

2.6 Critical appraisal process

2.6.1 Appraising selected studies

The aim of conducting a critical appraisal is to exclude studies with low-quality findings. This would increase the transferability of the research process, as well as the rigour of the review in terms of synthesising valid and transparent recommendations for policymakers (Porritt et al., 2014). Further, the appraisal process can help reviewers more deeply understand the phenomena and participants' perspectives, attitudes and experiences (Tong, Flemming, McInnes, Oliver, & Craig, 2012). The appraisal process also allowed the strengths and limitations of the selected studies to be identified (Porritt et al., 2014). This review adopted the JBI Qualitative Critical Appraisal Checklist (Version 2017) to assess the selected studies (JBI, 2017). Two independent reviews were conducted during this process, and any disagreements were discussed in the research group. After referring to the study by Chen, Xiao, Han, Meyer and Müller (2020), the cut-off point in the criteria regarding the appraisal tool increased from six out of 10 critical criteria to seven out of 10 critical criteria; one article was subsequently excluded after this appraisal (Mackenzie & Holroyd, 1996). The reasons for exclusion included the unclear congruity between the philosophical perspective and the research methodology; the absence of congruity between the research methodology and the data analysis; the researcher's unclear statement regarding their cultural and theoretical orientation; and not addressing the researcher's influence on the research and vice versa (Lockwood et al., 2020, p.67). The list of excluded studies is presented in Appendix III. Finally, 36 articles were included for this review. They were moved to the data stage after an agreement was made among the three reviewers. The detailed appraisal information is outlined in Table 7. However, the 36 included studies were divided into studies that focused on family caregivers from Greater China (G) and studies that focused on family caregivers from the Chinese diaspora (D). In this review, 21 G studies were derived from Mainland China, Taiwan and Hong Kong, while 15 D studies included Chinese American, Chinese Canadian, Chinese Australian and Chinese Singaporean caregivers. All included studies were numbered according to the population size and publication date.

2.6.2 Identifying strengths and weaknesses

The included studies had two strengths. First, this review's search process was conducted on 10 databases—both English and Chinese—so the study was comprehensive and widely searched for more relevant resources. Second, this review contained participants from various regions; Chinese family caregivers originated from Greater China (Mainland China, Taiwan and Hong Kong) and overseas (US, Canada, Australia and Singapore). Participants with different perspectives prompted the reviewers to gain a deeper understanding of the participants' attitudes and experiences, and they guided the reviewers to comprehensively explore the challenges that caregivers face in their care of people with dementia (Tong et al., 2012). However, four weaknesses were identified in these included studies. First, 17 out of 36 articles did not clearly state a congruity between the philosophical perspective and the methodological approach. Specifically, the 17 articles did not state a philosophical orientation. Second, three out of 36 articles did not state ethical approval, and two out of 36 articles unclearly stated ethical approval. Third, 13 out of 36 articles unclearly stated the researcher's cultural and theoretical orientations. Culturally and theoretically clarified research has a significant role in the research process. Finally, 12 out of 36 articles did not address the relationship between the research and the study participants, or they did not examine how the researcher's role influenced the data collection (Lockwood et al., 2020). Detailed information regarding each article is presented in Tables 7a and 7b.

Table 7a Critical appraisal for included studies (Greater China)

No.	Questions / Author /Year	Q1. Is there congruity between the stated philosophical perspective and the research methodology?	Q2. Is there congruity between the research methodology and the research question or objectives?	Q3. Is there congruity between the research methodology and the methods used to collect data?	Q4. Is there congruity between the research methodology and the representation and analysis of data?	Q5. Is there congruity between the research methodology and the interpretation of results?	Q6. Is there a statement locating the researcher culturally or theoretically?	Q7. Is the influence of the researcher on the research, and vice versa, addressed?	Q8. Are participants, and their voices are adequately represented ?	Q9. Is the research ethical according to current criteria or, for recent studies, and is their evidence of ethical approval by an appropriate body?	Q10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?
Greater China (Mainland)											
G1	Chen, Shen, Yang, Chen, & Sun. (2020)	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes
G2	Yang, et al. (2020)	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes

G3	Zhang, Zhang, & Hockley.（2020）	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
G4	Zhang, Clarke, & Rhynas. (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
G5	Zhang, Clarke, & Rhynas. (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
G6	Zhang, Clarke & Rhynas. (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
G7	Dai, Mao, Wu, Mei, Levkoff, & Wang. (2015)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes
G8	Sun, & Hu. (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes

G9	Sun. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes
G10	Wang, Xiao, He, & De Bellis. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
G11	Xiao, Wang, He, De Bellis, Verbeeck, & Kyriazopoulos. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
G12	Liu, Shang, & Yue. (2012)	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	Yes
G13	Zhang, Yang, Wang, & Li. (2008).	Unclear	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes
Greater China (Taiwan)											

G14	Yen, (2018)	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Greater China (Hong Kong)											
G15	Yiu, Zang, & Chau. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
G16	Yiu, Zang, Chew, & Chau. (2020)	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
G17	Pang, & Lee. (2019)	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
G18	Cheng, Mak, Lau, Ng, & Lam. (2016)	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes
G19	Au, Shardlo, Teng, Tsien, & Chan (2013)	Unclear	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes

G20	Chan, Ng, Mok, C. C. M., Wong, Pang, & Chiu. (2010)	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes
G21	Petrus, & Wing-Chung. (2008)	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes

Note: G= studies from Greater China

Table 7b Critical appraisal for included studies (the Chinese diaspora)

No.	Questions / Author /Year	Q1. Is there congruity between the stated philosophical perspective and the research methodology?	Q2. Is there congruity between the research methodology and the research question or objectives?	Q3. Is there congruity between the research methodology and the methods used to collect data?	Q4. Is there congruity between the research methodology and the representation and analysis of data?	Q5. Is there congruity between the research methodology and the interpretation of results?	Q6. Is there a statement locating the researcher culturally or theoretically?	Q7. Is the influence of the researcher on the research, and vice versa, addressed?	Q8. Are participants, and their voices are adequately represented?	Q9. Is the research ethical according to current criteria or, for recent studies, and is their evidence of ethical approval by an appropriate body?	Q10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?
Chinese diaspora (Chinese American)											
D1	Liu, Lou, Wu, & Mui. (2020)	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
D2	Lun (2019)	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

D3	Sun, Mutlu, & Coon. (2014)	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
D4	Zhan, (2004)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	No	Yes
Chinese diaspora (Chinese Canadian)											
D5	Koehn, McCleary, Garcia, Spence, Jarvis, & Drummon. (2012)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
D6	Ho, Friedland, Rappolt, & Noh. (2003)	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Chinese diaspora (Chinese Australian)											
D7	Caldwell, Low, & Brodaty. (2014)	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes

D8	Boughtwood, Adams, Shanley, Santalucia, & Kyriazopoulos. (2011)	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
D9	Tan, Fleming, & Ledwidge. (2001).	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Chinese diaspora (Chinese Singaporean)											
D10	Koo, Pusey, & Keady. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
D11	Tan, Ong, Ng, Ng, Wong, & Sim. (2020)	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes
D12	Chan, Phang, Glass, & Lim. (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes

D13	Tuomola, Soon, Fisher, & Yap. (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
D14	Vaingankar et al. (2013)	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
D15	Netto, Jenny, & Philip. (2009)	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes

Note: D= studies from the Chinese diaspora

2.7 Data extraction

Data were extracted according to the JBI meta-aggregation methodology (Lockwood et al., 2020). The JBI Qualitative Assessment and Review Instrument (JBI-QARI) instrument was specifically used to extract the data. This tool includes two phases for analysing data: study description (part A) and extraction of findings and illustrations (part B). The extracted results from all included studies are presented as studies from Greater China (a) and studies from the Chinese diaspora (b). The JBI-QARI part A study description extracted general information regarding 'the citation details, the populations, the phenomena of interest, and context as well as methodology, methods, settings and culture information, and geographical location' from each included study (Lockwood et al., 2020, p. 55). The results of the study description are presented in Appendix IV (a and b). Specific information regarding the findings and illustrations from selected studies were identified and extracted in the second phase of data extraction (Lockwood et al., 2020). In qualitative research, credibility can assess whether the represented finding is correct or not (Porritt et al., 2014). A level of 'credibility' should be identified for extracted illustrations based on the reviewers' perceptions of how the degree of support is related to each illustration (Lockwood et al., 2020). After the JBI systematic review, three levels of credibility were used to assess findings: 'unequivocal', 'credible' and 'not supported' (Lockwood et al., 2020). The unequivocal level signifies that 'the illustration is beyond reasonable doubt and therefore not open to challenge'; the credible level denotes that 'the findings accompanied by an illustration lacking clear association with it and therefore open to challenge'; and the not supported level denotes that 'the findings are not supported by the data' (Lockwood et al., 2020, p. 55). Phase B of the data extraction (extraction of findings) was also the first step of the data synthesis. (Lockwood et al., 2020). In this review, 100 findings and illustrations were extracted from the studies that focused on family caregivers from Greater China. Of those, 96 were ranked as unequivocal, and four were ranked as credible. Further, 86 findings and illustrations were extracted from the studies that focused on family caregivers from the Chinese diaspora. Of those, 85 were ranked as unequivocal, and one was ranked as credible. The types of family caregivers were also noted in the tables. The results of the extraction of findings (QARI-B) are presented in Appendix V (a and b). See Table 8 for the example of a QARI part A study description and Table 9 for the example of a QARI part B extraction of findings and illustrations. To ensure that the extracted findings and interpretations were consistent with the meanings of primary authors, the reviewers repeatedly read and checked the original studies, and they regularly discussed decisions with each other. Specifically, in the case of findings that were extracted from original articles in a Chinese language, the three reviewers discussed to ensure that the translation supported the primary authors' thoughts (with the translation based on the Google translation tool).

Table 8 Example of QARI part A study description

No.	Author (Year)	Methodology	Method	Phenomena of interest	Setting	Geographical	Cultural	Participants	Data analysis	Authors conclusion	Reviewers' Comments
Greater China (Mainland)											
G1	Chen, Shen, Yang, Chen, & Sun. (2020)	Qualitative study	Semi-structured face-to-face interview	To develop the sources of management burden of family caregivers living with dementia, and to seek solutions for supporting caregivers	Home care	China, Hang Zhou	Chinese cultural background	12 caregivers (3 daughters, 4 husbands, 3 sons and 2 wives)	Colaizzi's 7-step approach	After Identifying the source of management burden and seeking manage strategies can improve the quality of life for care recipients and their caregivers.	It demonstrates the sources of management burden of family caregivers' and raise awareness of taking steps for improving quality of life.

Table 9 Example of QARI part B extraction of findings and illustrations

G5. Zhang, X. B., Clarke, C. L., & Rhynas, S. J. (2019). A thematic analysis of Chinese people with dementia and family caregivers' experiences of home care in China. *Dementia-International Journal of Social Research and Practice*, 1-15. doi:10.1177/1471301219861466

Findings	Illustration from study	Evidence
Negative impacts of caregiver's role on physical health (Spouse caregiver)	'I rush to go shopping, rush for everything, this causes stress. I feel very tired since he got ill, my health is going down because of this ... This has resulted in a deterioration in my health.' (Liu, caring for her husband)' (p.8)	Unequivocal

G20. Chan, W. C., Ng, C., Mok, C. C. M., Wong, F. L. F., Pang, S. L., & Chiu, H. K. F. (2010). Lived experience of caregivers of persons with dementia in Hong Kong: A qualitative study. *East Asian Archives of Psychiatry, 20*(4), 163-168. Retrieved from http://ezproxy.flinders.edu.au/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=104978986&site=ehost-live

Findings	Illustration from study	Evidence
Caregiving strain resulted from lack of family support (Adult Children caregiver)	'It was extremely difficult at the very beginning. I always felt lonely, as no one in my family was willing to give me a hand. My husband scolded my mother … oh no, not only my husband … but also everybody at home. All of them hated her [A daughter caregiver].' (p.166)	Credible

G12. Liu, Q., Shang, S., & Yue, P. (2012). 基于 Lazarus 压力-应对模式的居家痴呆患者配偶的照顾体验研究 [Caring experiences of spousal caregivers of home dementia patients under Lazarus Stress-coping Model]. *中国全科医学 [Chinese General Practice], 15*(5). Retrieved from https://www.ixueshu.com/document/73db30d2f0e9cc0c318947a18e7f9386.html

Findings	Illustration from study	Evidence
Challenges in providing long-term care by family members （持久照顾的挑战） (Spouse caregiver)	‘The most difficult thing is to take care of the care recipient in patience continuously as it is a long-term condition. It is a great challenge for each family member to provide care [caregiver G].’ (p.499) (如 G 女士：’最难的就是对病人这么耐心地一直照顾下去。 我觉得，因为这个病是长期的，持久这样照顾下去对每个家属都是很大的挑战’)	Not support

2.8 Data synthesis

Based on the JBI meta-aggregated approach, a three-step process was conducted in the data synthesis: extracting the findings, grouping the findings into categories and developing synthesised findings based on those categories (Lockwood et al., 2020). However, the first step—extracting findings from included studies—had already been performed in phase B of the data extraction. Grouping two or more similar extracted findings into a category was the second step of the data synthesis. In this step, the primary reviewer created a brief description of each category. However, to ensure that the descriptions were consistent with the meanings of illustrations, the three reviewers reviewed and discussed the descriptions to achieve a consensus. In total, based on 100 extracted illustrations in the studies from Greater China, 22 categories were created; further, 21 categories were generated from 86 extracted illustrations in the studies from the Chinese diaspora. Developing synthesised findings based on the categories is the third step of the data synthesis. An overarching description was established in each synthesised finding, and at least two categories were created by one synthesised finding (Lockwood et al., 2020). Moreover, it should be highlighted that the synthesised findings have a crucial role in generating recommendations for practice or policy (Lockwood et al., 2020). Finally, seven synthesised findings were generated and then presented in two different groups of studies; of these synthesised findings, similar findings and different findings will be identified and discussed in Chapters 3 and 4. The data synthesis results are presented in Table 10. The three reviewers conducted regular meetings and multiple discussions throughout the whole process, and no disagreement was experienced. See Table 11 for examples of synthesised findings and Appendix VI for the detailed results of the meta-synthesis.

Table 10 Data Synthesis Results

Groups	Illustrations	Categories	Synthesis findings
Studies from Greater China	100 (96 Unequivocal; 4 Credible)	22	7
Studies from the Chinese diaspora	86 (85 Unequivocal; 1 Credible)	21	7

Table 11 Example of meta-synthesis (Greater China)

Findings	Categories	Synthesised findings
Loneliness and hopelessness due to the loss of communication ability in the care recipient (U)	Emotional burden	**Synthesised finding 1**: Multidimensional caregiver burdens
Tension and chaos in the family (delayed dementia diagnosis related) (U)		
Emotional burden (BPSD related) (U)		
Anxiety (BPSD related) (U)		
Feeling hopelessness (stress related) (U)		
Psychological stress related to caregiver obligation for spouse (U)		
Frustration (BPSD related) (U)		
Psychological burdens (long-term caregiver's role related) (U)		
Feeling hopelessness (dementia prognostics related) (U)		
Caregivers' worries and fears (U)		
Perceived losses (young-onset dementia related) (U)		
Worrying about care arrangement for the care recipient (U)		
Suicidal thoughts (financial burden related) (U)		
Emotional stress (caused by poor health in caregivers) (U)		
Inability to meet physical demands for caregivers (U)	Physical burden	
Decline in caregivers' physical conditions (U)		
Negative impacts of caregiver's role on physical health (U)		
Physical burden (U)		
Physical burden on caregivers (U)		

Physical burden (lack of sleep) (U)		
Like a prison at home for caregivers (U)	Time-dependence burden	
Lack of time for undertaking hobbies (U)		
Feeling of being isolated with little contact with friends and colleagues (U)		
Time-dependence burden (U)		
Caregiving around the clock (C)		
Time-consuming in social support for the person with dementia (U)		
A high cost on dementia-related treatment and care services (U)	Financial burden	
Caregivers’ financial strain in dementia treatment in hospital (U)		
Financial strain (U)		
The loss of paid work hours due to caregiver’s role sacrifices of jobs to caregiver’s role (U)		

2.9 The ConQual approach

The ConQual is an approach for establishing confidence for the synthesised findings of systematic reviews (Munn, Porritt, Lockwood, Aromataris, & Pearson, 2014). The aim of establishing confidence for the synthesised findings is to examine 'how practical and useful the findings are', as well as improve the qualitative systematic review usefulness in terms of helping health professionals and policymakers make informed decisions about healthcare (Munn, Porritt, et al., 2014, p. 3). The research type, dependability and credibility significantly influence how confidence is evaluated in the findings; moreover, dependability and credibility are the two main elements used to increase the believability and trustworthiness of synthesised findings (Munn, Porritt, et al., 2014).

In the ConQual approach, the initial ranking scale for qualitative studies extends from high, moderate, low to very low (Lockwood et al., 2020; Munn, Porritt, et al., 2014). The pre-ranking of qualitative studies is high, and low is for the expert opinion (Lockwood et al., 2020; Munn et al., 2014). The dependability score also affects whether the ranking of each article increases or decreases (Lockwood et al., 2020). The process of developing a dependability score is based on the responses from five critical appraisal questions (Munn, Porritt, et al., 2014, p. 4):

1) Is there congruity between the research methodology and the research question or objectives?
2) Is there congruity between the research methodology and the methods used to collect data?
3) Is there congruity between the research methodology and the representation and analysis of data?
4) Is there a statement that locates the researcher culturally or theoretically?

5) Is the researcher’s influence on the research, and vice versa, addressed?

Among these questions, if the response includes four to five ‘yes’ responses, then the ranking system remains unchanged. If the response includes two to three ‘yes’ responses, then the ranking system decreases one level. If the response incudes zero to one ‘yes’ response, then the ranking system decreases two levels (Munn et al., 2014). In this review, most articles reached the ‘high’ level of dependability due to four or five ‘yes’ responses in each article. However, four articles from Greater China (Au, Shardlow, Teng, Tsien, & Chan, 2013; Chan et al., 2010; Liu, Shang, & Yue, 2012; Zhang, Yang, Wang, & Li, 2008) and two articles from the Chinese diaspora (Netto, Jenny, & Philip, 2009; Tan et al., 2020) included three ‘yes’ responses, so the ranking score decreased one level. No articles decreased two levels. Based on the JBI meta-aggregated approach, the synthesised findings were generated from each article, and the ranking rates of all synthesised findings for this review retained a ‘high’ level.

The levels of credibility for each finding have been explained and analysed in Section 2.7. In terms of evaluating the level of credibility for each synthesis finding, if all aggregated findings are unequivocal, then the ranking remains unchanged; if the aggregated findings are a mix of unequivocal and credible, then the ranking decreases by one (–1); if the aggregated findings are credible or not supported, then the ranking decreases by three (–3); if the aggregated findings are not supported, then the ranking decreases by four (–4) (Lockwood et al., 2020; Munn, Porritt, et al., 2014, p.5). In this review, three synthesised findings remained unchanged, and four synthesis findings decreased by one (–1) in the studies from Greater China. Further, six synthesis findings remained unchanged, and one synthesised finding decreased by one (–1) in the studies from the Chinese diaspora. The example of the ConQual summary of findings can be observed in Table 12, and the detailed information can be found in Appendix VII.

2.10 Recommendations

Based on the results of the synthesised findings, the reviewers should provide meaningful and researchable recommendations to help policymakers make informed recommendations (Lockwood et al., 2020). The standard of JBI grades of recommendation was applied to make healthcare recommendations in this review. There are two grading levels for evaluating the recommendations: grade ‘A’ (strong recommendation) and grade ‘B’ (weak recommendation) (JBI, 2014). There are also four criteria for examining the extent of recommendations (JBI, 2014), including that 1) the desirable effects of strategies outweigh the undesirable effects of the recommendations; 2) the evidence for facilitating the use of recommendations is adequate and of good quality; 3) the recommendations can be used beneficially, or they do not negatively affect resource use; 4) and the recommendations should consider patients’ experiences and staff’s values and preferences (JBI, 2014, p.15). Based on these standards, five recommendations were generated from the synthesised findings from Greater China, and four recommendations were generated from the synthesised findings from the Chinese diaspora in this systematic review. All recommendations were grade A—that is, the recommendations were strong. To establish practicality and strong recommendations, the FAME scale was applied (JBI, 2014). The FAME scale includes feasibility, appropriateness, meaningfulness and effectiveness. An example of the process involved in constructing recommendations can be observed in Table 13.

Table 12 Example of ConQual summary of findings (studies on family caregivers from Greater China)

Systematic review title: Chinese caregivers’ experiences in the care of family members living with dementia: A systematic review and meta-synthesis
Population: Chinese caregivers/relatives of people living with dementia, the spouse/partner of people with dementia; informal caregivers of people with dementia, or Alzheimer’s disease
Phenomena of interest: Caregivers’ experiences, emotions, expectations, feelings and perspectives
Context: Chinese caregivers who provide care for people with dementia at home

Synthesised finding	Type of research	Dependability	Credibility	ConQual score
Synthesised finding 1: Multidimensional caregiver burdens	Qualitative	High	Downgrade 1 level (-1)	Moderate

The dependability score of primary studies is high due to the majority qualitative research studies remain unchanged (4 out of 21 studies downgrade 1 level). The credibility downgrade one level due to a mix of unequivocal and credible findings.

Table 13 Example of the process of constructing recommendations

Code	Comment	Recommendation
'I felt that it was difficult to take care of her at that time (when she was first diagnosed with dementia), I didn't know the disease very well, and I was reluctant to accept it. [caregiver A]' (Q.Liu et al., 2012, p.499)	Due to lack of dementia-related knowledge, family caregiver could not accept caregiver role.	Government should provide education and training in dementia care
'I wish that nurses from the Community Care Centre would offer training programs on dementia care [ChiP16].' (Xiao et al., 2014, p.10)	Family caregiver has an expectation of training program regarding dementia care.	
'I have taken some courses. I learned what dementia is … I have learned how to handle the missing of the dementia persons (Caregiver 4, Son, Age:30)' (Yiu, Zang, Chew, et al., 2020, p.4)	The positive effect of education in dementia care on family caregiver.	

2.11 Transparency in reporting the approach undertaken

This systematic review applied the JBI meta-aggregative approach to synthesise the evidence obtained from the included qualitative studies. The undertaken approach was also reported through the ‘enhancing transparency in reporting the synthesis of qualitative research’ (ENTREQ) statement, which helps reviewers transparently report stages in correlation with the synthesis of qualitative health research (Tong et al., 2012). Twenty-one items are grouped into five main domains in the ENTREQ statement (Tong et al., 2012): the ‘introduction, methods and methodology, literature search and selection, appraisal, and synthesis of findings’ (Tong et al., 2012, p. 1). After this statement was completed, this review identified the research question and developed and introduced the research’s aim and objectives at the initial stage. The JBI meta-aggregation approach and the PICo framework were applied in this review. The inclusion and exclusion criteria were also established according to the types of studies, types of participants, phenomena of interest and study context so that more relevant literature could be selected. The detailed selection criteria are presented in Tables 3 and 4. Six English databases (CINAHL, Emcare, MEDLINE, Web of Science, Scopus and ProQuest) and four Chinese databases (CBM, CNKI, Wanfang Data and Weipu Data) were included to help the reviewers comprehensively search in this review, as well as a manual search through the reference lists of included studies. The searching and screening process was outlined in a PRISMA flow chart (see Figure 2). Further, a JBI Critical Appraisal Checklist was applied for the appraisal process in this review to ensure that the included studies exhibited strong credibility, dependability, transferability and confirmability (Tong et al., 2012). Moreover, to improve the quality of selected studies, the articles with fewer than seven out of 10 points of critical criteria were excluded. The JBI-QARI tool was used to extract data, and the following data synthesis was based on the JBI meta-aggregative approach in this review. The reviewers also undertook multiple interpretations, discussions and regular meetings to reduce bias, and no disagreements were experienced throughout the whole process. Additionally, the JBI ConQual tool was applied in this review to ensure the credibility and dependability of the synthesised findings. The JBI grades of recommendation were also used to assess the extent of each recommendation's practice suitability and effectiveness.

2.12 Summary

This review was conducted using JBI meta-aggregation methodology, and it was guided by the PICo framework to explore the enablers of and barriers to family caregivers in their dementia care, as well as identify their expectations. Based on the inclusion and exclusion criteria, comprehensive database and manual searches, and screening and critical appraisal processes, 36 articles were ultimately included in this review. The included articles were grouped into studies that focused on family caregivers from Greater China (21 articles) and studies that focused on family caregivers from the Chinese diaspora (16 articles). Based on the JBI meta-aggregative approach, the JBI-QARI tool was used to extract data. The extraction of findings, grouping of findings into categories and development of synthesised findings based on those categories was also conducted during the data synthesis. Finally, 100 extracted findings, 22 categories and seven synthesised findings were generated from the studies that focused on family caregivers from Greater China, and 86 extracted findings, 21 categories and seven synthesised findings were generated from the studies that focused on family caregivers from the Chinese diaspora. Further, the ConQual tool was used to assess the credibility and dependability of each synthesised finding. The JBI grade of recommendation and FAME scale were also used to assess how effective, meaningful, practical and useful the synthesised findings were. All recommendations were recorded as grade A.

Additionally, transparency was determined by reporting the chosen approach through the ENTREQ statement.

Chapter 3: Findings from Studies on Caregivers from Greater China

3.1 Introduction

Chapter 2 has discussed this systematic review's methodology and methods, as well as the synthesised findings that were aggregated. This chapter will focus on the findings that were extracted from the Greater Chinese studies. Chapter 3 is divided into four sections—the introduction, characteristics of the studies, synthesised findings and summary. The characteristics of the studies include demographics, geographical context, review methodology, total numbers of participants and characteristics of participants. The synthesised findings comprise these main themes: multidimensional caregiver burdens, barriers to dementia care, positive coping strategies that caregivers use, motivations for caregivers, education and training, family dynamics and expectations of dementia care services.

3.2 Characteristics of the studies

The characteristics of the included studies were discussed after the JBI systematic review methodology, and they cover the descriptive and demographic, geographical context, review methodology, total participants size and characteristics of participants.

In total, 21 research articles were obtained from Greater China (see Table 14). These 21 articles were generated from 16 studies, as some articles were obtained from the same studies (see Table 15). One study was conducted in both China and Australia (Xiao et al., 2014), but the data were extracted from the group that focused on Greater China. The other 15 studies were conducted in China. All studies were conducted in a home care setting in Greater China. Among the 16 studies, nine were conducted in Mainland China (Chen, Shen, Yang, Chen, & Sun, 2020; Dai et al., 2015; Q. Liu, Shang, & Yue, 2012; Fei Sun, 2014; Q. Sun & Hu, 2015; Wang, Xiao, He, & De Bellis, 2014; Xiao et al., 2014; Yang et al., 2020; R. Zhang, Yang, Wang, & Li, 2008; X. B. Zhang et al., 2018; X. B. Zhang, Clarke, & Rhynas, 2019; X. B. Zhang, C. L. Clarke, & S. J. Rhynas, 2020; X. X. Zhang, Zhang, & Hockley, 2020); one was conducted in Taiwan (Yen, 2018); and six were conducted in Hong Kong (Au, Shardlow, Teng, Tsien, & Chan, 2013; W. C. Chan et al., 2010; Cheng, Mak, Lau, Ng, & Lam, 2016; Pang & Lee, 2019; Petrus & Wing-Chung, 2008; Yiu, Zang, & Chau, 2020; Yiu, Zang, Chew, & Chau, 2020).

Out of the 16 studies, two applied a mix-method methodology, and 14 used qualitative methodologies (see Table 16). A total of 296 caregivers participated in these studies. Among these caregiver participants, 201 were female, and 95 were male. The participants' ages ranged from 30 to 93 years old, and the types of family caregivers included adult children, spouses, parents and other relatives (see Table 17 for caregiver details). However, the study G2 (Yang, et al., 2020) did not mention what type of caregivers participated in the study.

Table 14 Reviewed research articles from Greater China (n = 21)

Greater China	Lists of reviewed research articles
Mainland (13 articles)	G1. Chen, Shen, Yang, Chen, & Sun (2020); G2. Yang, et al. (2020); G3. Zhang, Zhang, & Hockley (2020); G4. Zhang, Clarke, & Rhynas. (2020); G5. Zhang, Clarke, & Rhynas. (2019); G6. Zhang, Clarke & Rhynas. (2018); G7. Dai, Mao, Wu, Mei, Levkoff, & Wang. (2015); G8. Sun, & Hu. (2015); G9. Sun. (2014); G10. Wang, Xiao, He, & De Bellis. (2014); G11. Xiao, Wang, He, De Bellis, Verbeeck, & Kyriazopoulos. (2014); G12. Liu, Shang, & Yue. (2012); G13. Zhang, Yang, Wang, & Li. (2008)
Taiwan (1 article)	G14. Yen, (2018)
Hong Kong (7 articles)	G15. Yiu, Zang, & Chau (2020); G16. Yiu, Zang, Chew, & Chau (2020); G17. Pang, & Lee. (2019); G18. Cheng, Mak, Lau, Ng, & Lam. (2016); G19. Au, Shardlo, Teng, Tsien, & Chan (2013); G20. Chan, Ng, Mok, C. C. M., Wong, Pang, & Chiu. (2010); G21. Petrus, & Wing-Chung. (2008)

Note: G = Greater China studies

Table 15 Articles from the same study

From the same studies	Reviewed articles
From the same study 1	G3. Zhang, Zhang, & Hockley (2020); G4. Zhang, Clarke, & Rhynas. (2020); G5. Zhang, Clarke, & Rhynas. (2019); G6. Zhang, Clarke & Rhynas. (2018)
From the same study 2	G10. Wang, Xiao, He, & De Bellis. (2014); G11. Xiao, Wang, He, De Bellis, Verbeeck, & Kyriazopoulos (2014)
From the same study 3	G15. Yiu, Zang, & Chau (2020); G16. Yiu, Zang, Chew, & Chau (2020);

Note: G= studies from Greater China

Table 16 Methodology from reviewed research studies

Methodology of studies	Lists of reviewed research articles
Mix-method methodology	G2. Yang, et al. (2020); G10. Wang, Xiao, He, & De Bellis. (2014); G11. Xiao, Wang, He, De Bellis, Verbeeck, & Kyriazopoulos, (2014)
Qualitative methodology	G1. Chen, Shen, Yang, Chen, & Sun (2020); G3. Zhang, Zhang, & Hockley (2020); G4. Zhang, Clarke, & Rhynas. (2020); G5. Zhang, Clarke, & Rhynas. (2019); G6. Zhang, Clarke & Rhynas. (2018); G7. Dai, Mao, Wu, Mei, Levkoff, & Wang. (2015); G8. Sun, & Hu. (2015); G9. Sun. (2014); G12. Liu, Shang, & Yue. (2012); G13. Zhang, Yang, Wang, & Li. (2008); G14. Yen, (2018) G15. Yiu, Zang, & Chau (2020); G16. Yiu, Zang, Chew, & Chau (2020);

	G17. Pang, & Lee. (2019); G18. Cheng, Mak, Lau, Ng, & Lam. (2016); G19. Au, Shardlo, Teng, Tsien, & Chan (2013); G20. Chan, Ng, Mok, C. C. M., Wong, Pang, & Chiu. (2010); G21. Petrus, & Wing-Chung. (2008)

Note: G = studies from Greater China

Table 17 Characteristics of the studies

Components	Findings
Total Participants	n=296
Gender	Female=201; Male=95;
Age range	30 to 93 years old
Caregiver categories	Adult children caregiver =130; Spouse caregiver =147; Parent caregiver = 1; Other relative caregiver =6; Study G2 (Yang, et al., 2020) not mention the caregiver categories
Geographic Context	Mainland China=11; Taiwan=1 Hong Kong=6;
Review Methodology	Mix-method methodology =2 Qualitative methodology=16

3.3 Synthesised findings

In total, 100 findings were extracted from the 21 included articles. Of those findings, 96 were ranked as unequivocal, and four were ranked as credible. These findings were grouped into categories based on their similarities. Twenty-two categories were identified and then further synthesised into seven synthesised findings, as aligned with the review's objectives. The seven synthesised findings and the categories under each synthesised finding are outlined in Table 18. The detailed synthesised findings and categories are also presented in the following subsections.

Table 18 Synthesised findings and categories (Greater China)

Synthesised findings	**Categories**
Synthesised finding 1: Multidimensional caregiver burdens	Emotional burden
	Physical burden
	Time-dependence burden
	Financial burden
Synthesised finding 2: Barriers to dementia care	Dementia stigma
	Lack of post-diagnosis support
	Difficulties in accessing dementia care services
	Insufficient social support
	Perceived poor care services
Synthesised finding 3: Positive coping strategies used by caregivers	Positive attitudes towards caregiving role
	Using various self-identified strategies
	Performing self-care
Synthesised finding 4: Motivations for caregivers	Filial piety as a motive
	Responsibilities for family members as a motive
	Other motives
Synthesised finding 5: Education and training	Lack of knowledge and skills in dementia care
	Participating in education and training
	Effects of education and training
Synthesised finding 6: Family dynamics	Support in the family
	Lack of family support
Synthesised finding 7: Expectations for dementia care services	Expectations for care services
	Other expectations

3.3.1 Synthesised finding 1: Multidimensional caregiver burdens

This synthesised finding included four categories: emotional burden, physical burden, time-dependence burden and financial burden. Caregivers perceived an association between multidimensional caregiver burdens and the deterioration of caregivers' physical health and wellbeing.

3.3.1.1 Emotional burden

This category indicated that performing a caregiver role negatively affected the caregivers' emotions. The specific factors that contribute to this emotional burden included care recipients losing the ability to communicate, the care recipient's untreated BPSD, the ensuing financial burden, concern for future care arrangements, dementia diagnoses and the caregiver's declining health conditions.

One spouse caregiver stated that he did not expect to lose his wife at a young age: '*I have never imagined that I would "lose" my wife at such a young age. I thought we would support each other for lifelong [Caregiver 003]*' (Pang & Lee, 2019, p. 1621). Additionally, the initial signs and symptoms of dementia were difficult to recognise at the early stage, and tension and chaos were present within some families. One caregiver described that *'initially, it was a disaster, filled with chaos. It was difficult to confirm his diagnosis a decade previously [B3, age, 40 years]'* (Yen, 2018, p. 197).

Caregivers were also worried and fearful about the care recipients' deteriorating memories: '*He just like a stranger to me. I'm afraid he will forget me eventually [caregiver F]*' (Q. Liu et al., 2012, p. 499). Even though one caregiver felt hopelessness for a future life, he could not express his feelings in front of his wife: *'I cried, but not in front of her, and I think she could no longer be cured, and what a life ahead of me ... [One caregiving husband in case 16]*' (Fei Sun, 2014, p. 808). Another caregiver displayed the same hopeless feelings, and she even wished that the care recipient would die: *'I sometimes cry during the night because of the stress, sometimes I wish he could die soon ... [Wan, caring for her husband]'* (X. Zhang, C. L. Clarke, & S. J. Rhynas, 2020, p. 5).

Dementia care is a long-term caring process that often results in caregivers experiencing mental and physical stresses. As one caregiver described: '*The stresses are both mental and physical. The past 10 years have been the hardest time of the entire caring process. He has been completely dependent on us [A3, age, 71 years]*' (Yen, 2018, p. 196). As care recipients might lose their ability to communicate, the caregivers often feel more frustrated and alone: *'She doesn't understand many things. There's no way to communicate. There's no discussion. It's very hard for you to explain clearly to her, so I feel (pause) very lonely, sometimes I just feel helpless [caregiver C]'* (Q. Liu et al., 2012, p. 499).

Further, the BPSD of care recipients also deteriorated. Caregivers felt even more challenged to care for the recipients. One caregiver felt frustrated and struggled to manage his care recipient's incontinence:

> *I feel very frustrated when he suddenly acts like this ... He sometimes behaves in a way that I cannot really understand. When he needs to go to the toilet, he cannot say so and doesn't know where to go. I need to pay more attention to him outside as he will urinate anywhere [Edmond's wife].* (Petrus & Wing-Chung, 2008, p. 7)

The BPSD of care recipients have driven the emotional burden of caregivers, as one daughter caregiver described: '*My mom is very mobile, and she often says she is going to die and does not want to live, which drives me crazy [A daughter caregiver in case 5]*' (Fei Sun, 2014, p. 808).

Moreover, one care recipient hid objects in unacceptable places, and the caregiver reacted negatively to the situation: '*It is irritable that she is worry about someone will take away her things, hide many stuffs in somewhere and could not find them. For example, she hided the kettle in the fridge and put the cookies inside of fridge. I am very upset [caregiver A]*' (Q. Liu et al., 2012, p. 499).

Caregivers becoming older and having increasingly insufficient energy to care for their recipients introduces more worries about the care arrangements for the recipients: *'Every day I stay with her and care for her ... There will be some day in the future when she completely depends on others' caregiving. When that day comes, perhaps my body also has some problems. What can we do then? [a caregiver and spouse of individuals with AD]'* (Dai et al., 2015, p. 192). Even though caregivers' physical health statuses declined, they could not stop their caregiving roles, which triggered emotional stress: *'My own health is very poor. He can't take care of me, but I have to take care of him. It's very uncomfortable, and I can't leave this role [caregiver B]'* (Q. Liu et al., 2012, p. 499).

Further, caregivers often experienced suicidal thoughts due to the difficulty of coping with the challenges of dementia care, as one parent caregiver described: '*I cannot let them [two sons with dementia] be starving once I am here. I am just thinking, I will kill them and myself together if one day I can do nothing ... I have no money to send them to hospital, we only can live like this, helpless [Gui, caring for her two sons with dementia]*' (X. B. Zhang et al., 2020, p. 6).

Placing care recipients in nursing homes made most caregivers feel guilty. One caregiver believed that caring for his wife at home was his obligation, which made him experience a psychological burden: *'I think it's too cruel to send my wife to a nursing home. I feel guilty towards her and blame myself for having such thoughts [A husband caregiver]'* (W. C. Chan et al., 2010, p. 165).

The examples in this subsection indicate that multiple factors negatively influence the emotional and psychological conditions of caregivers.

3.3.1.2 Physical burden

This category revealed that caregivers' felt physical exhaustion, which affected their performance in dementia care. The factors that contribute to physical burden include a lack of sleep, inability to meet caregivers' physical demands and caregivers' declining physical health conditions.

Caregivers who simultaneously undertook second jobs and caregiver roles would experience physical stress. One caregiver stated that insufficient sleep during the night was a serious concern: *'I feel very tired. I used to be able to work for long hours and sleep for 4 hours on average. However, now I feel sleepy at erratic hours [A2, age, 37 years]'* (Yen, 2018, p. 198). The same feeling was also voiced by another caregiver: *'The most obvious feeling is too tired. Tired all day but can't sleep well at night. It is exhausted [Caregiver Y]'* (R. Zhang et al., 2008, p. 590).

Moreover, the physical health conditions of caregivers are negatively influenced by intensive caregiving tasks: '*I rush to go shopping, rush for everything, this causes stress. I feel very tired since he got ill, my health is going down because of this ... This has resulted in a deterioration in my health [Liu, caring for her husband]*' (X. B. Zhang et al., 2019, p. 8).

Further, a feeling of strain could also be triggered by the caregivers' ages, health conditions and care recipients' level of deterioration. One caregiver stated, *'He has been bed-ridden since he suffered a hip fracture 2 years ago. I am too old to turn him on my own. He has large bedsores* *and I try my best to change the dressings for him. I am unable to clean him properly each time he has bowel movements; I have to wait for my daughter to come and help me. She has a job and family and is not available for most of the day [P6]'* (Wang, Xiao, et al., 2014, p. 1375).

Another caregiver revealed that she had experienced many physical health issues due to her caregiving activities: '*I am also old ... I have to bring him out everywhere; however, I do not have the energy to support him when walking ... After these years of caregiving, my shoulder and hands have become paralysed and are painful. My doctor told me that the problem is caused by the disorientation of joints of my neck as a result of supporting him ... I therefore have to see a specialist and receive physiotherapy [Benjamin's wife]*' (Petrus & Wing-Chung, 2008, p. 11).

Even though caregivers were experiencing their own physical issues, they could not stop undertaking their caregiver role: '*I myself have physical problems as well. I had surgery on my right kidney prostate. However, only two of us live at home, and I have to provide her everyday life care. I could not get any help from others even when I feel unwell [N3]*' (Chen et al., 2020, p. 2194).

These findings indicate that aging and a lack of sleep were the main factors that resulted in physical strain. Sleep disruption for the caregivers was evidently caused by their care recipients' untreated BPSD.

3.3.1.3 Time-dependence burden

This category described how caregivers performed daily care activities, even though they had little time for themselves. This care situation negatively affected their socialisation with others.

Since the care recipients in this review wholly depended on caregivers, the constant daily tasks of the caregiving restricted their time—to the extent that the caregivers lost their individual lives. One caregiver described her feelings in this way:

> *In the past, I would go for picnics or travel overseas with my friends quite often ... I would also attend meditation courses ... However, I cannot do these things anymore now ... I have to prepare meals [for my husband] and feed him every day and I am so busy with the housework ... How can I have time for my social activities? [Benjamin's wife].* (Petrus & Wing-Chung, 2008, p. 8)

Moreover, the caregiving process seemingly involved constant and unending work due to the care recipients' dependency: *'I always feel that my mother can't do without me. If I leave, I am afraid that she will be lost. If I couldn't find her, what should I do if she caught a cold in the cold season? Just never let go [Caregiver S]'* (R. Zhang et al., 2008, p. 590).

Caregivers also had to abandon their own hobbies so that they could accompany their care recipients: '*I was interested in playing, sing, and Peking Opera; however, I cannot join in any of them. Over time, I do not have time and energy to do my hobbies [caregiver C]*' (Q. Liu et al., 2012, p. 499). Caregivers also felt like they lost their social lives, as one caregiver explained: '*I have very little contact with friends and colleagues, and I don't have time. I think I am really isolated in the society [Caregiver Y]*' (R. Zhang et al., 2008, p. 590).

However, one caregiver recognised that the extensive time spent on care was linked to the quality of dementia care for the recipient: *'The more time and efforts you spend on the patient, the better life he(she) gets [FC04]'* (Yang et al., 2020, p. 600).

These findings revealed that caregivers had to discard their individual hobbies and sacrifice their personal lives to care for their recipients, who usually displayed a strong dependence during their ADLs.

3.3.1.4 Financial burden

This category indicated that caregivers encountered caregiving burdens relating to the financial cost of dementia care. Such caregiving burdens have negatively influenced the quality of life for care recipients.

As care recipients were frequently admitted to hospital for treatment, the high medical costs contributed to caregivers' financial strain. One caregiver said: *'Now he often visits the doctor or stays at the hospital, the money is not enough for us [Xue, caring for her father]'* (X. B. Zhang et al., 2020, p. 6).

People with dementia also experienced other health problems. The high cost for multiple treatments was a serious concern for caregivers. Often, caregivers can only choose the most crucial issue to treat, as they could not afford to treat all issues. One caregiver described this in the following way: *'During that time (when he was hospitalised), he took so many medications that I could not remember the names of all the medications. [After discharge] We couldn't afford all of the medications and decided to reduce to the essential ones to treat only his diabetes [P5]'* (Wang, Xiao, et al., 2014, p. 1375).

When undertaking caregiving activities, the cost for transportation or training programs also contributed to caregivers' financial strain:

> *As she needs to see the doctor very often, I have to spend extra money, usually several hundred dollars, for her medication. I also have to spend money to travel with her by taxi to see the psychiatrist every month ... The major expense is the fee for her day care program, which costs me eight hundred dollars per month [Alice's husband].* (Petrus & Wing-Chung, 2008, p. 10)

Further, caregivers spent most of their time caring for recipients; some had to reduce their work hours at other jobs because they did not receive sufficient payment to support their daily expenses. One caregiver said: *'As he always got lost, I have to cut my work hours, look for him and care for him [N9]'* (Chen et al., 2020, p. 2194).

These examples demonstrated that financial strain influences both care recipients' quality of dementia care and caregivers' wellbeing. The findings supported that multidimensional caregiver burdens existed in the caregiving process and that they contributed to caregivers' declining physical health, limited social activities and poor wellbeing.

3.3.2 Synthesised finding 2: Barriers to dementia care

This synthesised finding included five categories: dementia stigma, lack of post-diagnosis support, difficulties accessing dementia care services, insufficient social support and perceived poor care services. Caregivers perceived that dementia care at home was challenging due to having to cope with certain barriers.

3.3.2.1 Dementia stigma

Caregivers displayed feelings of shame and reluctance to tell others that they were caring for people with dementia. The negative public attitude towards dementia was described by a caregiver as *'a societal problem when dementia patients face discrimination [A caregiving wife in case 2]'* (Fei Sun, 2014, p. 810). Moreover, another caregiver feared to bring the care recipient to a public area due to the social stigma surrounding dementia: *'I wouldn't take her to the group support services [public place], because she would shout or speak nonsense [Yan, caring for her mother]'* (X. Zhang et al., 2020, p. 7).

In Chinese culture, ‘losing face’ signifies losing social standing, which generates feelings of embarrassment. One finding indicated that Chinese caregivers failed to seek help from others due to face-saving:

> *We [my husband and I] felt that we were being stigmatized by others [our friends and neighbours]. For example, one of our neighbours always asked him: ‘Who is she [caregiver]?’ My husband replied: ‘She is my mom.’ Then, he [the neighbour] laughed. I felt embarrassed ... It’s a ‘loss of face’ to have a husband with dementia, especially when he is so young. I will not seek help from others because they will look down on me. I felt inferior to others [Caregiver 006].* (Pang & Lee, 2019, p. 1620).

The findings in this category reveal how caregivers experienced both self-stigma and public stigma. Family caregivers have perceived these dementia stigmas as barriers to accessing social services.

3.3.2.2 Lack of post-diagnosis support

This category described how caregivers did not receive professional support after the dementia diagnosis as they had expected. Conversely, what they experienced during the caregiving process after the dementia diagnosis made them feel helpless.

After a diagnosis, caregivers hoped that doctors would offer more referral information for dementia care, as there was a lack of knowledge regarding dementia: *‘The doctors in the hospital do not tell you which organisation provides such services ... When we find out that our family members have dementia, we feel too upset ... We do not have resources and know nothing. [Someone] needs to tell us where to find the helpful organisations ... [Caregiver 7, Age 65, Wife]’* (Yiu, Zang, & Chau, 2020, p. 3).

Similarly, another caregiver also experienced unmet information needs in their dementia care: ‘*I heard about dementia from other people. It is a kind of loss of one’s ability to understand. It is* *abnormal and it is not treatable … We see doctors and nurses in the Community Care Centre but have not received any information about dementia [ChiP3]*' (Xiao et al., 2014, p. 8).

Moreover, some caregivers did not receive any helpful instructions for dementia treatment from doctors, as one caregiver described: '*It was impossible for me to get a doctor's appointment for my wife. Even though we had an appointment, the doctor was too busy to give us helpful instructions besides some lab tests and prescriptions [P7]*' (Wang, Xiao, et al., 2014, p. 1375).

These examples have demonstrated that post-diagnosis support services are strongly linked to the empowerment of both care recipients and caregivers, as well as to an improvement in their wellbeing. However, a lack of post-diagnosis support services from professionals is a barrier to accessing social services that support dementia care.

3.3.2.3 Difficulties in accessing dementia care services

This category demonstrated that caregivers encountered difficulties in terms of using dementia care services. Factors that contributed to these difficulties included environmental barriers, the distance of day care centres and the limited opening hours of day care centres.

For dementia care recipients who live at home, a friendly environment could encourage them to maintain their independence and reduce caregiver stress. One caregiver described how difficult it was to take a care recipient for outdoor activities when there was no lift: *'Most buildings (where her mother lives) have many stories but have no lift. It is difficult to go down and up. This problem is difficult to deal with [Mei, caring for her mother]'* (X. B. Zhang et al., 2019, p. 7).

Further, long distances were another factor that influenced the use of dementia care service: '*I bring my mother here. There is no centre in the district where I live. This one is so far [from home].*

It is quite hard and a big burden on me to get here. We cannot take the bus as it would take more than one hour. If my mother needs to suffer through more than an hour of transportation just to get here, how can she concentrate on the training afterward ... [Caregiver 11, Age 50, Daughter]' (Yiu, Zang, & Chau, 2020, p. 3).

Additionally, even though caregivers used respite care in their dementia care, the limited opening hours of day care centres still resulted in caregivers not relieving their stress of trying to balance work and their caregiver role. One daughter caregiver said: *'The day centre is a problem for me. The centre closes so early ... I am still at work so I cannot take her home. I need to find someone else to bring her home ... [Caregiver 3, Age 52, Daughter]'* (Yiu, Zang, & Chau, 2020, p. 3).

These examples revealed that various factors affect caregivers accessing in terms of accessing dementia care services. Family caregivers perceived that coping with the difficulties of accessing dementia care services as they cared for people with dementia at home was highly challenging.

3.3.2.4 Insufficient social support

This category demonstrated that caregivers performed care activities that were limited by inadequate social support. Caregivers perceived that an insufficient social support system was a barrier to performing the caregiver role and providing person-centred care for a family member living with dementia.

An uncoordinated medical insurance system negatively influenced the cost of dementia treatment in different cities. One caregiver stated that '*My husband's employment was not in Shanghai, which made it very complicated for us to get reimbursed for his medical cost [A caregiving wife in case 1]'* (Fei Sun, 2014, p. 810).

Moreover, one finding posited that the current governmental allowance was not enough to care for people living with dementia, as the cost for dementia treatment often supersedes caregivers' abilities: *'The price is out of my capability ... [We] need to have more allowance! We have a dementia caregivers association. We have meetings with the government every year. We have asked the government to give us more money many times ... but are still unsuccessful ... [Caregiver 6, Age 78, Husband]'* (Yiu, Zang, & Chau, 2020, p. 3).

Additionally, personalised support was required for caregivers to perform daily care activities for their care recipients: '*My mom [with dementia] became more and more reluctant to talk when she knew her situation ... suddenly showed to be unhappy or upsetting ... I don't know, what good coping strategies can take me to escape from this problem ... [FC05]*' (Yang et al., 2020, p. 601). Some caregivers recognised that continuously performing the caregiver role would be challenging without adequate social support: '*I can't give up my caregiver's role. It's hard to handle the care if I give up. I'm the only person she can rely on, it's really difficult [caregiver A]*' (Q. Liu et al., 2012, p. 499). However, one caregiver described how social care services for families were scarce: '*What community will help? There are staff (social worker) who work for the government, I have never heard them helping with these kinds of things [Xue, caring for her father]*' (X. B. Zhang et al., 2020, p. 5).

These examples demonstrated how insufficient social support services bar caregivers from providing optimised dementia care for their care recipients. They also demonstrated the possible link this lack of social support has to increased caregiving stress for the caregivers.

3.3.2.5 Perceived poor care services

This category described how caregivers' poor perceptions of nursing homes, insufficient appropriate facilities for dementia care and a lack of dementia-friendly outpatient clinics contributed to a decrease in the quality of dementia care and an increase in caregiver burden. One caregiver revealed that she was unwilling to use the institutional dementia care services for her father due to the poor environment quality in nursing homes: *'I have looked at a few private care homes; however, the conditions of these care institutions are too bad. Once I step inside, there is an extremely bad odour. There are also no facilities, along with other problems [Xue, caring for her father]'* (X. B. Zhang et al., 2020, p. 7).

In addition to consideration for the environment in nursing homes, the poor quality of dementia care services was another serious concern for caregivers who rejected institutional care services: *'care home is worse ... if we send her there, she would die soon. In care homes, there is nobody to look after her ... Therefore, I don't want to send her to a care home or psychiatric hospital (Yan, caring for her mother)'* (X. B. Zhang et al., 2019, p. 10).

Additionally, the long waiting list for specialist appointments in the hospital was another factor that influenced the quality of dementia care: *'It was impossible for me to get a doctor's appointment for my wife at that hospital due to the long waiting list [P7]'* (Wang, Xiao, et al., 2014, p. 1375).

These examples revealed a link between the quality of institutional facilities and dementia-friendly environments and caregivers' burdens. These findings support that caregiver access to effective dementia care faces various barriers.

3.3.3 Synthesised finding 3: Positive coping strategies used by caregivers

This synthesised finding included three categories: positive attitudes towards the caregiving role, use of various self-identified strategies, and self-care. Caregivers perceived that positive attitudes and coping strategies were associated with an enhanced quality of dementia care and a decrease in caregivers burdens.

3.3.3.1 Positive attitudes towards the caregiving role

This category demonstrated that positive attitudes towards the caregiving role helped caregivers by reducing caregiver burdens and promoting interactions with the care recipients. Caregivers encouraged themselves to stay positive, as one caregiver described: *'I used to be timid. However, I like to seek solutions when I encounter problems. I like asking for help and can find the resources. I encourage myself to stay active. Otherwise, I think I would remain a pessimist (A1, age, 55 years)'* (Yen, 2018, p. 200).

Additionally, the caregivers who sought better solutions to dementia care were more influenced by the positive attitudes towards the caregiving role. One caregiver described: *'My mother has this disease; you need to accept it. I need to try my best to care her and find social services to help her. She can meet more people when she comes to the centre [Family Caregiver 9, Daughter, Age: 60]'* (Yiu, Zang, Chew, et al., 2020, p. 5).

Moreover, another caregiver accepted the caregiver role by understanding the care recipient: *'She is sick, but we are healthy, so we should understand her, don't we? [N2]'* (Chen et al., 2020, p. 2194). Caregivers were convinced that maintaining positive thoughts towards the caregiver role would help their recipients in their spiritual and health conditions. One daughter caregiver described her experience in the following way: *'Why not think about it more positively then? As long as I can give mom some instant happiness, like letting her eat what she likes to and giving her compliments generously, we'll find happiness again! [Daughter caregiver]'* (Cheng et al., 2016, p. 456). Further, one caregiver's temperament was changed due to perceiving the caregiver role more positively: *'At the beginning, we felt anxiety and irritable, but now we changed our temperament as anxiety mood cannot solve problem [P1]'* (Q. Sun & Hu, 2015, p. 44).

Positive appraisals from others also increased caregivers' self-esteem and their confidence to cope with future challenges in dementia care. One caregiver stated his experience as so: *'To me, taking care of my wife is definitely meaningful because I can bring hope to her and build up her confidence to live with dementia ... Even my siblings appreciated what I have done to my wife. I'm confident to say that I have made a right decision [take up the caregiving role] (Caregiver 004)'* (Pang & Lee, 2019, p. 1622). Caregivers' self-appraisals could also support them in consistently performing their roles: *'My husband (CR) is doing better than other dementia patients in our neighbourhood. He looks clean and tidy. I did a very good job [A caregiving wife in case 1]'* (Fei Sun, 2014, p. 810).

These findings have revealed that maintaining a positive attitude towards the caregiving role is associated with caregivers' personalities positively changing, dementia caregiving becoming more sustaining, and emotional exhaustion becoming more reduced.

3.3.3.2 Using various self-identified strategies

Caregivers have identified various dementia care strategies for handling the challenges that they encounter—such as using technology to enhance care, tolerating care recipients' BPSD, using various strategies to handle difficulties in feeding, seeking assistance from friends and using day care services.

Downloading GPS technology has helped one caregiver find and return a lost care recipient: '*She always walks outside and can't come back. Then, I downloaded the GPS app on my smartphone and check her location regularly. If she goes far away from home, I will go find her back [N12]*' (Chen et al., 2020, p. 2195).

When handling the difficulties of feeding care recipients, one caregiver persuaded the care recipient like one would when feeding a toddler: *'I try to persuade her to eat more by using the same method to feed a toddler ... I use many ways to persuade her ... [FC6, Mei]'* (X. X. Zhang et al., 2020, p. 6).

Moreover, increased patience and tolerance was another method for coping with a care recipient's dementia-related symptoms, as described by one daughter caregiver: *'Just now, I chatted with mom on the phone. Aside from asking me the same questions over and over again, the sequence of her expressions or the sequence of happenings were all mixed up. I needed to have a lot of patience to guide her to describe the whole thing (Daughter caregiver)'* (Cheng et al., 2016, p. 455). Tolerating a recipient's BPSD could also encourage caregivers to better perform their caregiver roles: *'When he gets angry, you can't stand it, you can't stand it. The only way to deal with this situation is to tolerate him. You can't fight with him [N1]'* (Chen et al., 2020, p. 2195).

Social support from friends was considered another coping strategy during the caregiving process, especially when caregivers could not rely on their family members: *'I'm lucky to have some best friends who can help me at those most critical moments. They all understand, about one taking care of several ... [Shan]'* (Au et al., 2013, p. 1430). Additionally, caregivers used day care support services to enhance their dementia care processes: *'Basically, the people [service providers] know how to communicate with the people with dementia ... Also, they have clearly received good training in this [Caregiver 1, Age 46, Daughter]'* (Yiu, Zang, & Chau, 2020, p. 4).

These findings reveal that family caregivers have used various self-identified strategies to cope with the difficulties that they encountered during the dementia care process. These strategies have minimised caregiver burdens and promoted the quality of dementia care.

3.3.3.3 Performing self-care

This category described how caregivers performed self-care activities to gain more energy in their dementia care. This approach positively enhanced the wellbeing of both care recipients caregivers.

Self-care is essential for caregivers so that they can refresh themselves when they perform their caregiver roles and provide constant care. One finding indicated that caregivers could conduct self-care through enrolling in training courses: *'I enrolled in several training courses, such as a dancing course, fitness course and music course. I want to keep living a joyful life while I look after my mother ... [FC6, Mei]'* (X. X. Zhang et al., 2020, p. 6). Further, there are various self-care strategies that caregivers could perform at home for relaxation: *'I am staying at home playing computer games, reading books and newspapers, and sometimes we play cards [A daughter in case 18]'* (Fei Sun, 2014, p. 812).

These examples have demonstrated that caregivers' self-care methods positively influence physical health conditions of caregivers as they perform their caregiver roles. These findings supported the belief that positive coping strategies help caregivers cope with dementia care difficulties and improve the feeling of optimism regarding dementia care outcomes.

3.3.4 Synthesised finding 4: Motivations for caregivers

This synthesised finding included three categories: filial piety as a motive, responsibilities for family members as a motive and other motives (i.e., care goal as a motive, reciprocity as a motive and religion as a motive). Caregivers perceived that these motivations helped them adapt to their caregiver roles.

3.3.4.1 Filial piety as a motive

Filial piety is a traditional aspect of Chinese culture that influences Chinese caregivers' dementia care. Providing daily care for a parent living with dementia was considered a method of being filial. One caregiver stated: *'I think if someone can [physically] look after their parents, it would be Xiao [filial piety]. We can't value Xiao by money, it isn't Xiao if one only gives lots of money to parents. It is better to look after parents, take care of them in daily life. Err ... we must consider the situation of everybody. For my situation, I can look after my father which is Xiao [FC2, Xue]'* (X. B. Zhang et al., 2018, p. 2626).

Caregivers sacrificed their retirement lives to care for their parents and fulfil filial piety: '*We [she and her husband] could have had enjoyed our retirement life. We could travel around if not for my mother [One daughter who recently retired in case 18]*' (Fei Sun, 2014, p. 808). Moreover, caregivers sacrificed their social activities to perform their caregiver roles, which was influenced by Chinese culture: *'Because being filial is a priority in Chinese traditional culture ... The only thing is that I had to sacrifice many social activities and things which I am enjoying [FC 6, Mei]*' (X. B. Zhang et al., 2018, p. 2627). Similarly, another caregiver chose to leave their job so they could fulfil their filial piety: '*In fact, I have given up a lot ... I gave up my job as well [FC13, Yan]*' (X. B. Zhang et al., 2018, p. 2627). Similarly, another caregiver even left her marriage so she could perform her caregiver responsibility: '*In fact, I have given up a lot … I gave up marriage … [FC13, Yan]*' (X. B. Zhang et al., 2018, p. 2627).

Additionally, adult children caregivers have revealed that the caregiver role was not only motivated by filial piety, but also because they wanted to be role models for the next generation: *'I will get older later, looking after my mum is not only my responsibility, but I am also a role model for my son. If I am not filial to my mum, my son might not be filial to me [FC5, Ling]'* (X. X. Zhang et al., 2020, p. 9)

These findings have emphasised that filial piety is a motive for caregivers and that it influences how they perform the role. Further, setting a role model through filial piety also motivated caregivers to care for family members who lived with dementia.

3.3.4.2 Responsibilities for family members as a motive

Dementia care is not only influenced by filial piety but also by the traditional family values that have been established throughout thousands of years of Confucianism. Family caregivers believed that they were responsible for caring for family members with dementia, which was a significant motivation for them.

Even though caring for family members with dementia negatively affected caregivers' lives, they still performed the role to meet their family responsibility: *'It is a burden to us, and there is no quality for our life. However, I must take good care of her no matter how tired it is [P1]'* (Q. Sun & Hu, 2015, p. 43).

As previously mentioned, caring for a family member with dementia at home was motived by a kind of responsibility; however, this type of caring responsibility could not be transferred to others.

One caregiver stated: *'When my son came back from school, he saw my nurse assistance and me bathing my mother. He asked me, why don't you let the nurse assistance do this. I said, would you let an outsider bath you? I taught him not to shirk his responsibility first [P3]'* (Q. Sun & Hu, 2015, p. 44). Another example also emphasised this attitude: *'Erm ... I have to do it (looking after his mother), what can I do? She is my mother, who would look after [her] if I don't look after her? It is not possible to give the responsibility to others (Shou, caring for his mother)'* (X. B. Zhang et al., 2019, p. 9).

Further, one spouse caregiver sacrificed their retirement to fulfil their caregiver role: '*I originally planned to travel with my wife after retirement. However, I cannot go anywhere even though I have a healthy body, and the economy allows it. Our generation has been working hard when we were young. Now that the conditions are good, it's time to enjoy the happiness, but my wife has become like this [Caregiver X]*' (R. Zhang et al., 2008, p. 590).

These examples revealed that the caregiver role is influenced by family values and that responsibility for family members is a core aspect of the caregiving role in dementia home care.

3.3.4.3 Other motives

This category includes care goal as a motive, reciprocity as a motive and religion as a motive for caregivers to perform their roles. The caregiver role was motivated by a sense of purpose to enhance the care recipient's quality of life, as one a caregiver explained: *'After I understood that her behaviours were due to the disease, I would put more effort into finding ways to help her ... give her better quality of life. I won't be "pig-headed." [Daughter caregiver]'* (Cheng et al., 2016, p. 454).

The interdependence that can be observed between the caregiver and the care recipient has motivated the caregiver to effectively perform dementia care activities and maintain energy in the process. One adult caregiver said: *'My mother is my spiritual support. You see, I am always so nervous now, but I feel very energetic as my mother is supporting me. I think I will definitely get down if mum goes away one day [Caregiver L]'* (R. Zhang et al., 2008, p. 590).

Religion could help caregivers reduce their negative thoughts and feelings during the caregiving process: '*Religion provides me access to a place where I can talk about my feelings when I am depressed. "Empathy" is what I must learn and apply in the caregiving process. If I treat mom with empathy, I will not argue about little things with everyone or have negative thoughts [A1, age, 55 years]*' (Yen, 2018, p. 203). In long-term caregiving processes, certain beliefs and hopes have motivated caregivers to effectively perform their role: '*My belief is that if you give your best, there will be a return. As long as you take good care of it, you can extend his life [A wife caregiver G]*' (Q. Liu et al., 2012, p. 500).

These examples indicated that various caregiver motivations positively influenced caregivers' spiritual relaxation and the development of the caregiver role. Identifying caregiving motivations has positively affected the wellbeing of both care recipients and caregivers. Caregiving motivations were also influenced by cultural norms, care goals, reciprocity and kin relationships within a family.

3.3.5 Synthesised finding 5: Education and training

This synthesised finding included three categories: a lack of knowledge and skills in dementia care, a lack of participation in education and training and the effects of education and training. Caregivers believed that dementia education and training positively influenced dementia care by reducing dementia stigma, improving the quality of dementia care and minimising caregiver burdens.

3.3.5.1 The lack of knowledge and skills in dementia care

This category described the challenges that caregivers experienced in dementia care as related to a lack of knowledge and skills. These challenges included delayed diagnosis, frustration from managing incontinence and the inability to manage dementia-related symptoms.

Most caregivers possessed insufficient knowledge regarding dementia. Therefore, cognitive decline was considered a normal part of aging. One finding posited that '*sometimes, his behaviours look funny ... We think it will be okay ... There is no need to seek health care or other kinds of help, it is a natural process, and nobody can help [a caregiver and son of an individual with AD]'* (Dai et al., 2015, p. 190). Another finding revealed how a daughter caregiver ignored dementia-related symptoms because she had insufficient dementia knowledge: *'I do not think my father is having a psychiatric problem. All he has is "善忘症" [shàn wàng zhèng, amnesia]. He does not beat up anybody. He is not aggressive at all. I believe persons with mental illnesses should be irritable and act aggressively [A daughter caregiver]'* (W. C. Chan et al., 2010, p. 165).

Moreover, one spouse caregiver realised that after his wife developed dementia, he could not accept the caregiver role because he barely knew enough about dementia: *'I felt that it was difficult to take care of her at that time (when she was first diagnosed with dementia), I didn't know the disease very well, and I was reluctant to accept it [caregiver A]'* (Q. Liu et al., 2012, p. 499).

Dementia-related symptoms deteriorated over time, and the BPSD were the main factor that contributed to increasing caregiver burdens. Managing a care recipient's dementia-related symptoms was difficult due to a lack of knowledge, as one caregiver described: *'I asked him not go outside, but he insisted in going out [N1]'* (Chen et al., 2020, p. 2193).

Incontinence was a serious concern for caregivers during the dementia care process. One caregiver explained how they struggled to cope with the care recipient's BPSD: *'He ate food from the garbage, cursed and hit others. We have no choice but to lock him at home. He urinated and defecated everywhere in the house: on the television, sofa, everywhere ... [P18]'* (Wang, Xiao, et al., 2014, p. 1373).

Caregivers experienced heavy caregiver burdens due to not being able to cope with dementia-related BPSD, as one wife caregiver described: '*My husband often scolded me fiercely with foul language. One morning, he suddenly sprinkled water at me for no reason [A wife caregiver]*' (W. C. Chan et al., 2010, p. 165).

These findings demonstrated that insufficient dementia-related knowledge and care skills have contributed to an ignorance of dementia, increasing caregiver burdens and a negative influence on dementia care practice.

3.3.5.2 Participation in education and training

Caregivers used various methods to improve their levels of knowledge, manage their care recipients' BPSD, reduce their caregiver burdens and meet the recipients' needs. These learning methods included using televised health education programs, seeking post-diagnosis information online and joining dementia training programs.

Caregivers enrolled in dementia-related courses to better understand dementia and the caregiver role: *'I have taken some courses. I learned what dementia is ... I have learned how to handle the* *missing of the dementia persons [Caregiver 4, Son, Age: 30]'* (Yiu, Zang, Chew, et al., 2020, p. 4).

After a recipient received a dementia diagnosis, seeking information online was a useful method for satisfying the learning needs of caregivers. One finding demonstrated that caregivers benefited from online learning: *'When the doctor first said that she [CR] had got dementia; we searched for information on the internet ... other people talking about their cases, those about caregivers – there are lot of information online (Hong)'* (Au et al., 2013, p. 1429).

Reading written materials to obtain dementia knowledge became more difficult for older caregivers. However, watching TV health education programs was an effective method for learning about dementia care. One caregiver stated: *'I learned a lot from TV programs, which is a good way for older people to learn as we can't see written materials clearly or don't have the ability to read [P3]'* (Wang, Xiao, et al., 2014, p. 1376).

Caregivers were also keen to participate in dementia training programs for improving learning skills, as one husband described: '*We come to here to have training every Saturday ... If the centre is very far from my home, I may also bring her there [Caregiver 6, Age 78, Husband]*' (Yiu, Zang, & Chau, 2020, p. 4).

These examples indicated that the experiences of caregivers using various approaches to develop dementia-related knowledge and skills have made them become more professional in their caring roles.

3.3.5.3 Effects of education and training

Dementia care education and training have positively influenced caregivers by helping them understand recipients' needs, provide advanced care support for both themselves and their care recipients and reduce caregiver burdens. These positive effects also included reducing dementia stigma and developing care skills.

Dementia-related education and training played a crucial role in reducing social stigma and improving dementia care. One caregiver gives an example of their experience with education:

> *Before I learned about the disease, I suffered a lot and could not adjust to [the caregiving role]. Now I feel less embarrassed and much more comfortable doing it. Initially, I wasn't used to the looks people gave me when I took mom out. Now, I feel more relaxed and less stressed [Daughter caring for her mother].* (Cheng et al., 2016, p. 453)

One finding indicated that caregivers gain dementia care skills after they receive dementia education and training: '*At the beginning, I could not understand her behaviours. Later, I learned about this disease so I could treat her patiently [Caregiver G]*' (R. Zhang et al., 2008, p. 590).

These examples indicated that dementia-related education and training have played a significant role in improving dementia care practice and managing care recipients' BPSD. These findings have revealed that participating in dementia care education and training programs enabled caregivers to adapt their roles and improve their care practice.

3.3.6 Synthesised finding 6: Family dynamics

This synthesised finding included two categories: support in the family and a lack of family support. Caregivers perceived that family, as a unit, both positively and negatively affected caregiving. Support in the family helped primary caregivers reduce caregiving burdens and interact with other family members. Conversely, a lack of family support increased primary caregivers' strains and challenges in their dementia care.

3.3.6.1 Support in the family

Sharing their role in their families has enabled primary caregivers to have better interactions with their family members, improve the quality of dementia care for their care recipients and minimise their social isolation. One primary caregiver described how her adult children were willing to share her caregiving activities to help reduce her caregiver burdens:

> *I am not doing these [care activities] as I am too old … My daughter and sons wash her if she is wet. She has faecal and urinary incontinence. My daughter has lived with us in order to care for her. My son also comes to help every day. His house is nearby [ChiP4].* (Xiao et al., 2014, p. 10)

Moreover, close relationships within a family have motivated caregivers to share their roles with each other and achieve healthy outcomes together. One finding demonstrated this in the following way: *'We brothers are very close to one another. Mom lives with me; we have regular family gatherings in my house. My brothers are medical doctors. They take care of mom as well. I think a family like ours is not common. I care for mom without any complaints. The five of us take care of her as much as we can [B2, 68 years]'* (Yen, 2018, p. 201).

Similarly, one caregiver stated that caring for her mother helped her connect with other family members much more effectively than before: '*Despite her not knowing anything, she is the connection among the big family. My sisters and my brother often come to visit her, we can see each other, and this is a connection between us [Yan, caring for her father]'* (X. B. Zhang et al., 2019, p. 10).

Another daughter caregiver also realised that her relationship with her care recipient had improved since she had provided dementia care at home: *'The gathering time of my mother and I become more and more. Both of us are changing. We can find a suitable way of communication. Our relationship is better and more harmony than before [Family Caregiver 11, Daughter, Age: 50]'* (Yiu, Zang, Chew, et al., 2020, p. 5).

These examples revealed that close and bonding relationships within families support primary caregivers, help them perform their caregiving activities and reduce their caregiver burdens in dementia care.

3.3.6.2 Lack of family support

This category revealed that insufficient family support resulted in caregivers experiencing strain, helpless feelings and negative outcomes of dementia care. Caregivers experienced strain while caring for family members due to a lack of family support: *'It was extremely difficult at the very beginning. I always felt lonely, as no one in my family was willing to give me a hand. My husband scolded my mother ... oh no, not only my husband ... but also everybody at home. All of them hated her [A daughter caregiver*]*'* (W. C. Chan et al., 2010, p. 166).

This lack of family support was also associated with caregivers' decision not to ask for help from family members: *'I can't tell anyone about my strain and burden. It is useless to tell other people, even my daughter, my relatives ... I am afraid they will look down on me [stereotyped as strong and tough] [Mr Ching]'* (Au et al., 2013, p. 1433).

These findings have demonstrated that the stereotype of dementia within family members, long-term dementia care conditions, and a family's unwillingness to care contributed to insufficient support within families. These findings also revealed that family dynamics influence caregivers' responsibilities and their quality of dementia care.

3.3.7 Synthesised finding 7: Expectations for dementia care services

This synthesised finding included two categories: expectations for care services and other expectations. Caregivers perceived that dementia care services helped them reduce their caregiver burdens, improve their acknowledgement of dementia care, perform optimistic care activities and protect both themselves and their care recipients from risks.

3.3.7.1 Expectations for care services

This category demonstrated that caregivers wanted to use social support services to monitor recipients' health conditions, reduce caregiver burdens and take breaks. Caregivers' expectations of dementia care included home visits, respite care, acceptable nursing facilities and support from community care services.

One caregiver expected to access home care services for people living with dementia: '*The Community Care Centre should provide homecare as an important part of aged care. Medical treatment for people with dementia should be an important part of homecare [P8]*' (Wang, Xiao, et al., 2014, p. 1376).

Caregivers also hoped to receive respite care from community care centres so that they could take breaks to manage individual issues: *'I wish that the Community Care Centre would provide a day care service for people with dementia, just like the child care centre in the community. This would allow me to leave the house to do the things I have to do [ChiP20]'* (Xiao et al., 2014, p. 10).

Moreover, another caregiver revealed an expectation that health professionals could provide home visits for people living with dementia: *'I hope there will be some staff (health professionals) who can do home visits ... However, there are no such services that exist now. I hope that we will have some social support in the future [Guang, caring for his mother]'* (X. Zhang et al., 2020, p. 5).

Additionally, although family caregivers considered future arrangements, they desired acceptable formal institutions to provide support service: *'I wish we can find an appropriate elderly home where we can live in together [a caregiver and spouse of individuals with AD]'* (Dai et al., 2015, p. 192).

These examples have revealed a need for home visits from health professionals, respite care and community care services to support caregivers and reduce caregiver burdens.

3.3.7.2 Other expectations

Family caregivers experienced difficulties in terms of managing recipients' BPSD and financial burdens. They wanted to receive education and training regarding dementia care, as well as governmental support in the welfare system.

One family caregiver expected to participate in dementia care training programs to learn care skills: *'I wish that nurses from the Community Care Centre would offer training programs on dementia care [ChiP16]'* (Xiao et al., 2014, p. 10).

Caregivers also expected that the welfare system of the government could support dementia care to reduce the caregivers' financial burdens: *'I hope dementia treatment can be covered by the medical insurance [ChiP16]'* (Xiao et al., 2014, p. 10).

These examples indicated that caregivers wanted to receive dementia care education from health professionals and financial support from the government. These findings also supported that an updated health care system is required to meet the caregivers' social care service needs, education and training requirements, and welfare system support demands.

3.4 Summary

Seven synthesised findings were aggregated from 100 findings, as based on the standards from the JBI synthesised review and this review's objectives. The findings revealed that the health conditions and wellbeing of caregivers were negatively affected due to multidimensional burdens. Caregivers reported that they experienced stigma towards dementia. Moreover, caregivers experienced a lack of post-diagnosis support, difficulties in using dementia care services, insufficient social support and poor care services. Caregivers also developed coping strategies to reduce caregiver burdens and improve the quality of dementia care (e.g., maintaining positive attitudes towards caregiving role, self-identifying care strategies and performing self-care). Additionally, the findings determined that caregivers were encouraged by various motivations to undertake the caregiver role (e.g., filial piety, family responsibilities, reciprocity, care goal and religion). Caregivers also reported that insufficient knowledge and skills in their dementia care resulted in delayed dementia diagnoses and an inability to cope with care recipients' BPSD. Additionally, education and training programs enabled caregivers to improve their care practice and avoid risks from caring. Further, support in the family helped caregivers effectively perform their care activities. However, a lack of family support was associated with caregiver burdens. Additionally, caregivers described their expectations of care services, education and governmental welfare system support.

Chapter 4: Findings from Studies on Chinese Diaspora Caregivers

4.1 Introduction

Chapter 4 will focus on the findings that were extracted from the overseas Chinese studies. The chapter is divided into four sections: the introduction, characteristics of the studies, synthesised findings and summary. The characteristics of the studies include demographics, geographical context, review methodology, the total numbers of participants and the characteristics of participants. The synthesised findings comprise the following main themes: multidimensional caregiver burdens, barriers to dementia care, positive coping strategies that caregivers use, motivations for caregivers, education and training, family dynamics and expectations for dementia care services.

4.2 Characteristics of the studies

In total, 15 research articles were obtained from studies that focused on Chinese diaspora caregivers (see Table 19). These findings were generated from 15 original studies. One study (D7: Caldwell, Low, & Brodaty, 2014) focused on both home care and a nursing home in Australia, but the data were extracted only from the home care setting. The other 14 studies were conducted in a home care setting.

Four studies included multiple ethnic groups of family caregivers, but data were only extracted from the Chinese ethnic group (Boughtwood, Adams, Shanley, Santalucia, & Kyriazopoulos, 2011; Caldwell et al., 2014; E. Y. Chan, Phang, Glass, & Lim, 2019; Vaingankar et al., 2013). The other 11 studies were conducted with Chinese ethnic groups. Among the 15 articles, four studied

Chinese American caregivers (J. Liu, Lou, Wu, & Mui, 2020; Lun, 2019; Fei Sun, Mutlu, & Coon, 2014; Zhan, 2004); two studied Chinese Canadian caregivers (Ho et al., 2003; Koehn et al., 2012); three studied Chinese Australian caregivers (Boughtwood et al., 2011; Caldwell et al., 2014; L. Tan, Fleming, & Ledwidge, 2001); and six studied Chinese Singaporean caregivers (E. Y. Chan et al., 2019; Koo, Pusey, & Keady, 2020; Netto, Jenny, & Philip, 2009; L. L. Tan et al., 2020; Tuomola, Soon, Fisher, & Yap, 2016; Vaingankar et al., 2013) (see Table 19).

These 15 studies used qualitative methodology. In total, 345 caregivers participated in these studies, of which 247 were female, and 98 were male. The age of participants ranged from 18 to 93 years. The family caregiver types included adult children, spouses, and other family relatives (e.g., sibling, niece or grandson). The caregiver details are presented in Table 20.

Table 19 Reviewed research articles from Chinese diaspora caregivers (n = 15)

Chinese diaspora	**Lists of reviewed research articles**
Chinese American (4 articles)	D1. Liu, Lou, Wu, & Mui. (2020); D2. Lun (2019); D3. Sun, Mutlu, & Coon. (2014); D4. Zhan, (2004);
Chinese Canadian (2 articles)	D5. Koehn, McCleary, Garcia, Spence, Jarvis, & Drummon. (2012); D6. Ho, Friedland, Rappolt, & Noh. (2003);
Chinese Australian (3 articles)	D7. Caldwell, Low, & Brodaty. (2014); D8. Boughtwood, Adams, Shanley, Santalucia, & Kyriazopoulos. (2011); D9. Tan, Fleming, & Ledwidge. (2001);
Chinese Singaporean (6 articles)	D10. Koo, Pusey, & Keady. (2020); D11. Tan, Ong, Ng, Ng, Wong, & Sim. (2020); D12. Chan, Phang, Glass, & Lim. (2019); D13. Tuomola, Soon, Fisher, & Yap. (2016); D14. Vaingankar et al. (2013); D15. Netto, Jenny, & Philip. (2009)

Note: D= studies from the Chinese diaspora

Table 20 Characteristics of the studies

Components	Findings
Total Participants	N = 345
Gender	Female= 247; Male= 98;
Age range	18 to 93 years old
Caregiver categories	Adult children caregivers = 237; Spouse caregivers = 84; Other family relative caregivers = 24
Geographic Context	Chinese American caregivers = 4; Chinese Canadian caregivers = 2; Chinese Australian caregivers = 3;

	Chinese Singaporean caregivers = 6

4.3 Synthesised findings

In total, 86 findings were extracted from the 15 included articles. Of those, 85 were ranked as unequivocal, and one was ranked as credible. These findings were grouped into categories based on their similarities. Twenty-one categories were identified and then further synthesised into seven synthesised findings, as based on this review's objectives. The seven synthesised findings and their subcategories are outlined in Table 21. The synthesised findings and categories are presented in further detail in the following sections.

Table 21 Synthesised findings and categories (the Chinese diaspora)

Synthesised findings	**Categories**
Synthesised finding 1: Multidimensional caregiver burdens	Emotional burden
	Physical burden
	Time-dependence burden
Synthesised finding 2: Barriers to dementia care	Dementia stigma
	Lack of culturally and linguistically appropriate dementia care services
	Lack of post-diagnosis support
	Perceived poor care services
Synthesised finding 3: Positive coping strategies used by caregivers	Positive attitudes towards caregiver role
	Using various self-identified strategies
	Using various care services
	Performing self-care
Synthesised finding 4: Motivations for caregivers	Reciprocity as a motive
	Filial piety as a motive

	Responsibilities for family members as a motive
	Other motives
Synthesised finding 5: Education and training	Lack of knowledge and skills in dementia care
	Participation in education and training
Synthesised finding 6: Family dynamics	Support in the family
	Lack of family support
Synthesised finding 7: Expectations for dementia care services	Expectations for education and training
	Expectations for care services

4.3.1 Synthesised finding 1: Multidimensional caregiver burdens

This synthesised finding included three categories: emotional burden, physical burden and time-dependence burden. The caregivers believed that their physical conditions and psychological health and wellbeing were linked to the level of multiple caregiver burdens.

4.3.1.1 Emotional burden

This category highlighted the negative feelings that caregivers experienced while they performed their roles. The factors that contributed to caregivers' emotional burden included the recipient's untreated BPSD, the caregivers' multiple care responsibilities in a family, the high cost for dementia care services and the caregiver's declining health conditions.

The caregivers felt a sense of hopelessness as they noticed their care recipients' cognition decline over time: '*Whatever I can tell him at night, I will talk [to] him, he is like before, he will [nods head]. But next morning it is gone. It is a complete wipe-out [P1]*' (Tuomola et al., 2016, p. 164). The care recipients' dementia-related symptoms also contributed to caregivers' anxiety and stress: '*The fear of someone very dear to you will one day not recognize who you are, things that caregiver* *will encounter, mainly in the first stage … at that time we do not know how to handle it because we fear [P5FE002]*' (Vaingankar et al., 2013, p. 1608).

Some caregivers recognised the care recipient's personality changes and reacted to the change emotionally: '*I noticed not only memory impairment, but also [his] personality changed. He became suspicious and [had] delusion[s], he told me our house has another person. Actually, only I and he lived here. Sometimes, he suspected I have a boyfriend and gossiped to his friends [Judy]*' (Koehn et al., 2012, p. 48).

Another example indicated that a caregiver experienced serious psychological stress due to a lack of knowledge and skills regarding how to manage the recipient's BPSD: '*She [mother-in-law] scolded me nearly every day, and I could not bear it anymore. At first, my husband could not understand and blamed it on me. I stayed away from home for a few weeks, and I hoped the situation would get better. When I returned home, my mother-in-law has not changed. She still scolded me [Daughter-in-law]'* (L. Tan et al., 2001, p. 13).

Even though some caregivers wanted to use social support services to relieve their caregiver burdens, they could not afford the care services, which resulted in an increase in their emotional burdens: *'I have to work. My wife is not working, I have two children, so the only solution I have for my dad right now is nursing home or long-term stay. But they are expensive [P6FE003]'* (Vaingankar et al., 2013, p. 1610).

One study demonstrated how a caregiver's worries and fears resulted from his poor health: '*Of course, I felt more irritated … blamed myself for not having enough strength to take care of my wife … If my health is better, I can take a better care of her. Whenever I feel weak, I feel more irritated and mad [A husband caregiver]*' (Lun, 2019, p. 754).

Further, another study explained how a spouse caregiver was worried about his recipient's future arrangements if he died earlier than her: '*What worries me most is that I may die before her. If that happens, who will take care of her? My children will have a huge burden [86 years old, husband who provided care for his wife]*' (J. Liu et al., 2020, p. 5).

Emotional burdens could also be generated from the caregivers' multiple care responsibilities in a family. One finding explained it in the following way: *'I have to take care of myself, home, and children when they come every week, got to think of what meals to give them. There are a lot of things; I am like a housekeeper [P6]'* (Tuomola et al., 2016, p. 163).

The examples above have highlighted that caregivers' emotional and psychological conditions are associated with their physical health and the care recipients' different levels of deterioration in terms of dementia.

4.3.1.2 Physical burden

This category revealed highlighted caregivers' feelings of physical exhaustion, tiredness and a lack of energy to undertake care activities. Such feelings also affected their performance in their dementia care. The factors that contributed to caregivers physical burdens included the recipient's strong dependency, night-time care and a lack of sleep. As one caregiver stated: *'Not enough sleep every night. Most of the time [feeling] tired [P6]*' (Tuomola et al., 2016, p. 164). Moreover, caregivers felt physical exhausted: '*Tired, very tired ... I can't sleep well ... Very stressful [58 years old, daughter who provided care for her father]*' (J. Liu et al., 2020, p. 5). The sleep patterns of caregivers' were also disturbed due to the recipient's BPSD: *'I now sleep in another room because he gets up so many times in the night [Wife]'* (L. Tan et al., 2001, p. 11).

Additionally, the physical strain that caregivers experience could also be triggered by lack of suitable care equipment at home: ‘*She is big and fat; I can’t lift her up. What I usually do is pull over all of the chairs we have. Then I gently put her onto the shortest chair, and from there, put her onto a higher chair, and then the highest chair to help get her up. My back becomes extremely sore after all that [Chinese family carer, husband]*’ (Boughtwood et al., 2011, p. 293).

These findings support that a lack of sleep was the main factor that contributed to physical strain. Further, the untreated BPSD, as displayed by the care recipients, were shown to contribute to caregivers’ sleep disruption.

4.3.1.3 Time-dependence burden

This category described how caregivers provided constant care activities and consequently had little time for themselves to engage in activities that they enjoy. This care situation negatively affected their socialisation with others. As care recipients strongly depend on caregivers, who had to perform various daily care activities, caregivers could not find time for a break: *‘Then after that when she [mother living with dementia] is resting, I have to run to the market come back and cook...school time I have to rush, send my son, then later fetch him. It's like a daily job [P4, daughter]’* (E. Y. Chan et al., 2019, p. 504). Moreover, caregivers also felt socially isolated: *‘I do not have time to socialize with others. I want to socialize with other people, but now I cannot. I cannot do that because I do not have the time [A daughter-in-law caregiver]*’ (Ho et al., 2003, p. 310). Additionally, caregivers almost lost their social lives: *‘I should expand my social life outside … after she [her mother] got Alzheimer’s disease, my life has been very limited. My life is limited to the home. I rarely interact with other people [A daughter caregiver]*’ (Ho et al., 2003, p. 311).

Caregivers expected to enjoy their retired lives with their partners; however, their hopes were destroyed by the harrowing truth that their spouses suffered from dementia: *'I used to think that my post-retirement life would be beautiful, such as travelling and volunteering. Now I can't do anything [80 years old, husband who provided care for his wife]'* (J. Liu et al., 2020, p. 5).

These findings revealed that caregivers had to sacrifice their personal lives so that they could care for the recipients, who usually exhibited a high dependence on ADLs. These findings support that caregivers experienced multiple types of burdens that contributed to their declined physical health, limited social activities and poor wellbeing.

4.3.2 Synthesised finding 2: Barriers to dementia care

This synthesised finding included four categories: dementia stigma, lack of culturally and linguistically appropriate dementia care services, lack of post-diagnostic support and perceived poor care services. Family caregivers believed that dementia care at home was challenging due to these barriers.

4.3.2.1 Dementia stigma

Caregivers often experienced prejudice and feelings of shame while they cared for family members who lived with dementia. Due to the negative public attitudes towards dementia, family caregivers often tried to hide that their family members suffered from dementia. Family caregivers were also reluctant to receive social services: *'Her children [caregiver's siblings-in-law] don't want to apply for any benefits for her [care receiver] because they don't want others to know their mom has dementia. They are concerned that no one will marry to their kids [care receivers' grandchildren]* *because the disease may be inherited [55 years old, daughter-in-law who provided care for her mother-in-law]'* (J. Liu et al., 2020, p. 5).

Further, caregivers experienced negative attitudes towards dementia in their communities: '*They [people in China town] made you feel so ashamed that you are afraid of telling others about you loved one's illness. It is just so hard*' (Zhan, 2004, p. 24). The stigmatisation of dementia could also be attributed to the family caregivers themselves, as their self-esteem and care motivation were lost over time: '*My daughter and son-in-law used to take us out to eat, but ever since my husband had dementia [at a very early stage], neither my husband nor I are willing to eat outside [A spouse caregiver]*' (Fei Sun et al., 2014, p. 130).

The findings in this category outlined caregivers' experiences in terms of both public stigma and self-stigma in relation to the stigma of dementia as a barrier to accessing social services for families who live with dementia.

4.3.2.2 Lack of culturally and linguistically appropriate dementia care services

As caregivers emigrated to overseas countries, the ensuing language barriers and cultural differences had become factors that affected caregivers' decision to use dementia care services to reduce caregiver burden. Difficulties in accessing dementia care services were widely reported, as well as a lack of assistance from bilingual professionals and ethno-specific care services; these were also factors that affected caregivers' choice to use care services.

The following example demonstrated how the caregiver found it difficult to seek bilingual professional service: '*It is very troublesome to take her to see a doctor, so I want to find a bilingual doctor who could make house calls. It is very difficult to find one [66 years old, daughter who* *provided care for her mother]*' (J. Liu et al., 2020, p. 5). Another similar example was expressed in this way: '*We wanted to look for a home taker [formal caregiver] for my mother, but we could not find bilingual and skilled formal caretakers [A daughter caregiver]*' (Fei Sun et al., 2014, p. 129).

Another caregiver described how care service providers refused to admit her mother to a nursing home because her mother could not speak English: *'I was looking for a long-term care facility for my mom. Staff at the facility told me that they would not take my mom because she did not speak English'* (Zhan, 2004, p. 25). Moreover, language barriers were considered a source of stress for caregivers: *'My English is not good. It is a huge burden for me to fill out forms or pay for bills [71 years old, wife who provided care for her husband]'* (J. Liu et al., 2020, p. 5). Caregivers also described how the lack of ethno-specific nursing homes affected their choice not to use care services: *'We wanted to look for a home taker [formal caregiver] for my mother, but there are few residential care facilities for Chinese patients [A daughter caregiver]'* (Fei Sun et al., 2014, p. 129).

The above examples have demonstrated how Chinese caregivers experienced several challenges in terms of culturally and linguistically appropriate care services for people with dementia, which increased the stress and burden that Chinese caregivers experienced.

4.3.2.3 Lack of post-diagnosis support

This category described how caregivers want to receive more post-diagnosis assistance—such as by obtaining dementia care information, supportive groups, approaches for managing BPSD and governmental policies; however, the actions of health professionals made them feel frustrated and helpless.

In one study, the caregiver complained that the health provider only supported limited and insufficient information regarding dementia care: *'I knew it was a bad diagnosis. I was very upset that they [health providers] did not provide more support and information. You cannot just tell the diagnosis and walk away'* (Zhan, 2004, p. 25). Further, even though the spouse caregiver wanted to use supportive services, the information regarding dementia care support services was scarce: *'I don't know whether there are any supportive services available in the community and nobody told us [A spousal caregiver]'* (Fei Sun et al., 2014, p. 129). Additionally, insufficient information about dementia care services resulted in caregivers' lives becoming more challenging: *'I am curious of what resources are out there ... any support groups, group programs, government programs that I can look into ... A lot of this we do not know much ... resources [A daughter caregiver]'* (Lun, 2019, p. 755). Another caregiver experienced the same issues: *'I did not know [about support services]. I don't know many people here. I did not come across these social services and their information before [Ping]'* (Koehn et al., 2012, p. 50).

Additionally, caregivers also searched for approaches to future care so that they could ensure the best care and wellbeing possible for their recipients: *'The problem lies with the doctor ... they can't tell you exactly what to do. When I asked the doctor, he said "you need to notice yourself." He said that my mother's condition would get worse after six to nine months, but he did not tell me how to deal with it either [P12SIC002]*' (Vaingankar et al., 2013, p. 1609).

The findings in this category revealed that the healthy life conditions of caregivers and recipients could be empowered by post-diagnosis support services; however, there are barriers to accessing these services due to insufficient information and support services.

4.3.2.4 Perceived poor care services

This category described how caregivers' negative thoughts about nursing homes, insufficient appropriate facilities for caring for people living with dementia, and a lack of dementia-friendly outpatient clinics contributed to increasing levels of caregiver burden and the decreasing quality of dementia care.

Due to a poor perception of nursing homes, caregivers were reluctant to use institutional care services. One caregiver believed that moving to a nursing home signified a loss of freedom and the imposition of restrictions: *'It's just too early stage to take her to the nursing home. Reason being that one, going to nursing home is just like going to jail … [CW14]'* (Caldwell et al., 2014, p. 418).

Moreover, another caregiver did not expect a nursing facility to expel their care recipient due to severe BPSD. This left negative thoughts in the caregiver's mind: *'I had admitted him to a nursing home three days ago; yesterday they called me and said that they had to throw him out, because he was caught with problems. And he even molested the staff there, so they threw him back [to the hospital] [P6FE003]'* (Vaingankar et al., 2013, p. 1610).

Additionally, one caregiver described a dilemma; they outlined how difficult it was to decide whether they should place the care recipient in a nursing home, as worse situations could occur: *'Late last year I decided to put my mum in the queue. But I actually don't want her to go even if a position is available … but end up you know we say "Ok we put her on the queue." Just in case … Because we understand she's already 86, things may drop at any time [CW2]'* (Caldwell et al., 2014, p. 417).

Staying in an unfamiliar environment could frighten people who live with dementia and prompt them to act with agitation and anxiety. Building a dementia-friendly environment deceases the recipients' agitation and anxiety and improves their wellbeing. One finding described one care recipient's experience in an outpatient clinic: *'It's always a very long waiting time, my dad cannot control his bowels, and he got angry very fast ... I tell them [clinic staff], please help me to let him go first ... Then my dad starts to get angry, very angry and that's when everybody starts to look at us ... when my dad finally threw a tantrum, then they let my dad go first [P10FT001]'* (Vaingankar et al., 2013, p. 1610).

These findings indicated that the quality of institutional facilities and dementia-friendly environments are associated with caregiver burdens. These findings also support that caregivers experience various barriers to accessing dementia care services during the caregiving process.

4.3.3 Synthesised finding 3: Positive coping strategies that caregivers use

This synthesised finding included four categories: positive attitudes towards the caregiver role, various self-identified strategies, various care strategies and self-care. Caregivers perceived that positive coping strategies for managing dementia care significantly improve both caregivers and recipients' health and wellbeing, as well as reduce caregiver burden.

4.3.3.1 Positive attitudes towards the caregiver role

This category demonstrated that positive attitudes towards caregiver role could help caregivers maintain a healthy mental status, reduce caregiver burden and promote connections with their care recipients.

One caregiver demonstrated that he had a better understanding of the recipient's needs due to his acceptance of the caregiver role: *'Just face it that he is like that, it does not affect me, I am ok. I understand that he is like that, not that he does it on purpose, that he cannot remember [P2]'* (Tuomola et al., 2016, p. 165). Moreover, in another example, even if the care recipient's health condition deteriorated, the caregiver still performed caregiving activities and positively coped with the challenges: *'If he deteriorates and has to go to nursing home, we will accept it as it we know this is inevitable ... When my father is still around, I show love to him. Even if he passes on the next day, I will not regret [P13, daughter]'* (E. Y. Chan et al., 2019, p. 506).

Another adult caregiver expressed the same opinion, indicating that performing the caregiver role with hope reduces their emotional stress and helps them gain happiness within their family: *'I often say that my mother is like my flower. If I cherish her well, I will be very happy. I have this feeling that I will be very happy if she is well because I have put in my effort. I do not mean that she has to give whatever back to me; the bottom line is that I did all that because I wanted her to be healthy [A daughter caregiver]'* (Ho et al., 2003, p. 312).

The above example indicated that when family caregivers expressed positive attitudes towards their caregiver role, they could avoid emotional exhaustion and maintain more energy in their provision of dementia care.

4.3.3.2 Various self-identified strategies

Caregivers identified various dementia care strategies to manage the challenges that they encountered (e.g., difficulty in feeding and a lack of information regarding dementia care).

In the early stage, most caregivers were confused about the dementia diagnosis. However, one caregiver researched dementia information online to recognise the symptoms, which significantly delayed the onset of dementia: *'I read Readers' Digest, it has a topic related with dementia and it provides the website. I kicked into their Internet and requested for further information. It sent me the information. It introduced ten signs and symptoms of dementia, I checked and my husband has eight [Judy]'* (Koehn et al., 2012, p. 48). Another caregiver believed that keeping the recipient informed of the dementia diagnosis could promote the cooperation between recipient and caregiver, even though acceptance was a tough stage: *'At least get her mentally prepared. At least she can face, we don't need to hide from her ... so she will accept. At least prepare and accept the facts that there will be some difficulty in handling her living style here and there [Caregiver 7]'* (L. L. Tan et al., 2020, p. 264).

In terms of difficulties in feeding, one caregiver pretended to 'cheat' the recipient and managed the issues: '*She [care recipient] said, "No, no, no. she (domestic helper) wants to poison me cannot." ... So, I take the same plate, I bring it to the kitchen. I don't let her see ... So I just turn one round, I come back and say, "I cook the rice for you ..." She said okay. Then she will finish her meal [P10, daughter]*' (E. Y. Chan et al., 2019, p. 505). Another caregiver locked all doors during the night to manage a recipient's BPSD and protect them from a dangerous environment: '*I have to make sure all the doors are locked and keep the keys on me or he would go out at night. [Wife]*' (L. Tan et al., 2001, p. 11).

The following example indicates that caregivers learned to be patient with their care recipients so that they could more effectively perform their caregiver roles: *'Because of her, I train myself to be more patient. Throughout the years, I think I have trained up myself to be more patient. But I think the patience level have to rise further in order to better deal with her [Mrs J]'* (Netto et al., 2009,

p. 250). Some caregivers also recognised that the closeness between caregivers and care recipients enhances dementia care: *'I'm drawn closer to him. There's that closeness causes I pay so much attention to him, I understand all his needs, so learning to love him would be better [Mrs L]'* (Netto et al., 2009, p. 254). Further, positive self-appraisal is associated with minimising caregivers' negative thoughts and helping them develop in their caregiver role: *'I have become more patient, [and] exercise more self-control, which I am still learning. I feel that [going] through a harder life tends to make you a better person. This is the hard way of learning about life [P5]'* (Tuomola et al., 2016, p. 163).

These findings have indicated that family caregivers use various self-identified strategies that helped them cope with the difficulties of providing daily care activities. These strategies protect care recipients from risks and improve the quality of dementia care.

4.3.3.3 Various care services

This category implied that caregivers use various types of social support services to improve dementia care and reduce caregiver burden. For example, caregivers used services provided by social workers, ethno-specific aged care providers and government-subsidised home care programs.

One caregiver described that gaining social support from social workers helped her overcome a tough stage in her life and minimise the psychological stress of caregiving: *'[The social workers] were supportive in a lot of things and have given me a lot of support. Although I was having a difficult time, having these people give me support for sure made me happier [A daughter caregiver]'* (Ho et al., 2003, p. 314).

Another finding indicated that a caregiver benefited from a referral support service after their care recipient received a dementia diagnostic: '*It was after referral that the social worker contacted us themselves and told me that they have these services and visits that could help me to see if they could provide me with some information or limited services to help me to see how to take care of my mother together … [Now] if I want to understand some information or to know certain things, at least there are people who could tell me because before I am totally blank with these concepts … [Ping]*' (Koehn et al., 2012, p. 50).

Further, ethno-specific dementia care services also played an important role in promoting social integration with other caregivers who possessed similar caregiving experiences, which decreased psychological stress: *'The home health agency in Chinatown really helped me a lot; otherwise, I did not know from whom, where, and how I could get help'* (Zhan, 2004, p. 25). Moreover, caregivers recognised that the government-subsidised home care service could share a heavy caregiving workload with them: *'I am so thankful for the government; it has helped me a lot. He [the home care worker] helps him with the shower, and also does the house cleaning for us, so my burden is not as heavy [One daughter caregiver]'* (Ho et al., 2003, p. 314).

The examples discussed above reveal that using social support services reduced caregiver burden, minimised social isolation, and promoted a sense of belonging in the family caregiver groups.

4.3.3.4 Self-care

This category described how caregivers performed self-care to gain more energy during their care of recipients living with dementia. This approach positively influenced both caregivers' and care recipients' health outcomes.

Self-care is essential for refreshing the caregiver role and providing more energy for the constant care. One caregiver performed self-care by taking a break: *'If I need a break, I will go out for a walk or go out with my friends. I need the break, away from him and I think that helps. That's how I find my way to get along [P3, son]'* (E. Y. Chan et al., 2019, p. 505). Another caregiver performed physical exercises before the care recipient awoke: *'I insist on exercising at home every day. Before he [care receiver] wakes up, I have some time to do it. If my health is poor, how can I take care of him? [71 years old, wife who provided care for her husband]'* (J. Liu et al., 2020, p. 5).

The findings discussed in this subsection have indicated that caregivers' self-care methods helped them maintain improved wellbeing when they performed their roles, which subsequently increased the recipients' quality of life. These findings highlight that maintaining positive attitudes towards dementia care, implementing various self-identified strategies, using social support care services and performing self-care activities positively affected both caregivers and care recipients.

4.3.4 Synthesised finding 4: Motivations for caregivers

This synthesised finding included four categories: reciprocity as a motive, filial piety as a motive, responsibility for family members as a motive and other motives (e.g., obligations and religious beliefs as a motive).

4.3.4.1 Reciprocity as a motive

Perceived reciprocal relationships among family members motivated caregivers to overcome challenges and decidualise in their caregiver role. Such relationships also helped caregivers maintain long-term care for the care recipient.

The reciprocity between husband and wife encouraged some caregivers to devote time and energy to caring for the recipient: *'Our relationship [giver and receiver] has been good ... Sometimes, he makes me very angry, but when I think he used to take care of me, I forgive him [71 years old, wife who provided care for her husband]'* (J. Liu et al., 2020, p. 5).

Moreover, this reciprocal relationship motivated a spouse caregiver to accept the caregiver role: *'So now, I have to do everything that he used to do for me, just like payback time [P1]'* (Tuomola et al., 2016, p. 166).

These findings indicate that reciprocal relationships between caregivers and care recipients encourages caregivers to optimise their dementia care for recipients.

4.3.4.2 Filial piety as a motive

Adult children performing the caregiver role was driven by filial piety—by beliefs that were influenced by Chinese traditional culture. One caregiver explained it in this way: *'I think the part of our Chinese culture, that one has to take care of and respect elderly people, is right. I think it really is culture ... being filial to our parents is right; take care of them is what we ought to do. We ought to live with them and hope that we can give even more than what they are getting now [A daughter caregiver]'* (Ho et al., 2003, p. 308). Similar findings were echoed in another study: *'It's an enriching experience and a sense of duty—you bring me up, I look after you. It's my chance to do a good deed for her [Mr E]'* (Netto et al., 2009, p. 255). Moreover, some adult child caregivers even made sacrifices for their parents: *'Even though I sacrificed my personal life, I had no regret for caring for my mom'* (Zhan, 2004, p. 26).

These findings highlighted that filial piety is a motive for adult children caregivers to overcome difficulties. Therefore, filial piety was a factor that sustained dementia care at home.

4.3.4.3 Responsibilities for family members as a motive

It was previously discussed that providing dementia care was considered a family responsibility. This category revealed that dementia caregivers were motivated by a sense of family duty: *'The responsibility is mine. I can take care of him like this only because I am his wife. The relationship between husband and wife is the most important. I am the closest to him; I ought to take care of him [A wife caregiver]'* (Ho et al., 2003, p. 307). Another caregiver expressed the same opinion: *'What to do, that is your husband, you must take care of him [P4]'* (Tuomola et al., 2016, p. 163). Further, the caregiver felt that he would lose his duty if he left the care recipient in the nursing facility. The following example explained the belief in this way: *'If I put my mum in the nursing home, I'm the bad guy … I fail my duty [CW5]'* (Caldwell et al., 2014, p. 419).

The examples discussed above indicated that the caregiver role is influenced by the perceived responsibilities for family members.

4.3.4.4 Other motives

Religious beliefs and spirituality are considered motives for caregiving, as they support caregivers by reducing emotional stress and help them seek spiritual solace. Caregivers perceived that they became more patient and powerful in their caregiver role due to their religious faith.

Caregivers believed that the situation would improve if it was entrusted to God. One caregiver stated that religious beliefs made her regard caregiving in a positive way: *'I always believe as I'm* *a Christian, I believe that God will never put me in a position or give me responsibilities that I can never handle [P8, niece]'* (E. Y. Chan et al., 2019, p. 505).

Moreover, caregivers are motivated in their roles by seeking spiritual solace and praying to positively cope with caregiving activities. One daughter caregiver stated*: 'Every day, when I have finished my tasks, I must have quiet time for myself … I will use the time to pray [P13, daughter]'* (E. Y. Chan et al., 2019, p. 506).

These examples revealed that religion and spirituality motivate caregivers in their roles and allow them to positively cope with the challenges of providing dementia care. These examples indicated that various caregiver motivations kept caregivers in a spiritually pleasurable condition and that it motivated the caregivers to develop their caregiver duty.

4.3.5 Synthesised finding 5: Education and training

This synthesised finding included two categories: a lack of knowledge and skills in dementia care, and participation in education and training. Caregivers perceived that the difficulties of communicating care recipients, managing their BPSD and experiencing caregiving anxiety and burnout were associated with insufficient dementia care knowledge and skills. Caregivers relieved caregiver burdens and improved their dementia skills by participating in education and training.

4.3.5.1 Lack of knowledge and care skills in dementia care

This category described how caregivers experienced delayed diagnoses, ineffective communications with their loved ones, frustration in managing incontinence and an inability to manage dementia-related symptoms—which are all attributed to insufficient knowledge and care skills in dementia care.

As caregivers possessed insufficient knowledge for recognising initial dementia signs, the disease was difficult to identify: *'I did not know why my mom could not find the place where we usually met for lunch'* (Zhan, 2004, p. 24). Another caregiver also stated that '*I did not know she had AD. We only knew when the doctor told us that my mom needed help'* (Zhan, 2004, p. 23). One finding indicated that the caregiver found communicating with his spouse difficult: '*When I didn't understand dementia, I didn't know how to communicate with her, especially in my first year of dementia care [89 years old, husband who provided care for his wife]'* (J. Liu et al., 2020, p. 5). The following example also indicated that the caregiver could not handle the care recipient's demands: *'I can only look after him for two or three hours because after that, my father starts to look for my mother. He would ask me where my mother has gone to and say that he wants her back. He is used to my mother [Chinese family carer, son]'* (Boughtwood et al., 2011, p. 294).

Additionally, one caregiver described the challenges that she encountered when she managed her husband's BPSD: '*He accuses me of stealing his things. But he hides them and forgets where he had put them. More and more challenges each day [Wife]*' (L. Tan et al., 2001, p. 13). A daughter-in-law caregiver explained how it became more difficult to manage incontinence due to lack of dementia care information: '*She started having urinary incontinence. It was getting harder in looking after her (Daughter-in-law)*' (L. Tan et al., 2001, p. 12). However, even though the one care recipient was not incontinent, the caregiver felt challenged to manage the accompanying issues. '*He went to the toilet at night-time all the time and wet the floor and the toilet bowl. He was not incontinent but when he went into the toilet, his pants were partly wet already [Daughter]*' (L. Tan et al., 2001, p. 12).

These findings support that the limitation of dementia-related knowledge and care skills results in delayed dementia diagnoses, a decreased quality of dementia care and increased caregiver burdens.

4.3.5.2 Participation in education and training

Caregivers have used various methods to improve the level of knowledge so that they can better manage their recipients' BPSD and meet their needs. The learning methods included using virtual caregiver support groups and peer support groups.

Peer support was a source of learning for one caregiver in terms of receiving more dementia-related information: '*I learnt a lot of information from the caregiver support group, and when I returned home, I see how to handle things better. Recently I saw my mother's dental problem, and I was able to know how to handle it from another caregiver [Sixth interview]*' (Koo et al., 2020, p. 13). Another finding demonstrated that a caregiver could learn about the caregiver role through an Alzheimer's disease support group: '*I joined the AD support group. I got information and learned about how to find resources, how to handle the patient but not feel frustrated and not to irritate patients because you are stressed or burned out, and how to take care of ourselves*' (Zhan, 2004, p. 25).

Additionally, virtual caregiver support groups were another effective approach for caregivers to gain pertinent knowledge. One caregiver used a WeChat group for support: *'We [Chinese American dementia caregivers] have a WeChat [a Chinese messaging and social media app] group and support each other [76 years old, wife who provided care for her husband]'* (J. Liu et al., 2020, p. 5).

The examples in this category highlighted how caregivers used various effective ways to gain dementia-related information and skills, which in turn enhanced their self-esteem. These findings revealed how participating in dementia care education and training programs enabled caregivers to be caregivers and gain information to improve their care practice.

4.3.6 Synthesised finding 6: Family dynamics

This synthesised finding covered two categories: support in the family and a lack of family support. The caregivers believed that family support provided emotional support for primary caregivers. However, the negative family dynamics influenced the care recipients' health outcomes.

4.3.6.1 Support in the family

Sharing a caregiver role with one's family has helped primary caregivers perform care activities, reduce caregiver burden and improve emotional support in long-term care. The positive family dynamic influenced the quality of care for care recipients.

As sharing the caregiver role with family was considered traditional in the family with a Chinese cultural background, one finding showed that family members shared caregiver burdens together within their family: *'For our Chinese culture, the children look after the parents when they are old. The brothers and sisters have very close relationship. We both love our dad very much and my sister and me ... share each other's burden ... [Daughter]'* (L. Tan et al., 2001, p. 14). Another caregiver described that all his adult children supported him in caring for his wife, which took him away from caregiving for a break: *'All my children pay for everything for their mother needs and they take turns to come here to look after her. They even pay for my holidays so that I can take a break. [Husband]' (L. Tan et al., 2001, p. 14).*

One caregiver indicated how close family relationships could be considered a source of dementia care that reduces caregiver burden: *'All of them do appreciate what my youngest sister and I do for my mother and I would say, we are still a very close-knit family. We care for one another and if there is any problem in our midst, we would help out in that sense. I think it has brought us* *closer [Sixth interview]'* (Koo et al., 2020, p. 17). Another caregiver also demonstrated the same opinion: *'I think because of this caregiving experience, we have become closer. We realize that we treasure our loved ones more and we understand that unity is very important in the family when things happen like that. The bonding of the family, united as well as be each other's support [Mrs H]'* (Netto et al., 2009, p. 254).

Moreover, the harmony within a family promoted family members to share care responsibilities: '*We like to keep everything within the family. We share our responsibilities and we do not like to "wash dirty linen in public". We must also keep our family honour and respect all elders [Daughter]*' (L. Tan et al., 2001, p. 12). One caregiver stated that she would place her care recipient in a nursing facility if there was no family support: '*If my family did not support me like this, I would not be able to hang in for so long, I would have placed him [her father] in a nursing home a long time ago [A daughter caregiver]*' (Ho et al., 2003, p. 313).

The examples discussed above indicate that strong familial bonding and the sharing of care responsibility within a family have contributed to a crucial component for long-term care at home.

4.3.6.2 Lack of family support

This category highlighted how family-related factors negatively affected primary caregivers and their care activities. The family dynamic was associated with a high level of caregiver burden that contributes to caregivers' health issues.

As family caregivers lived overseas and became influenced by Western culture, traditional family support for the second-generation recipient who lives with dementia was reduced: *'My son-in-law is an ABC [America-born Chinese]. He doesn't like living with older people, especially after my* *husband has dementia [76 years old, wife who provided care for her husband]'* (J. Liu et al., 2020, p. 5).

Performing the caregiver role has contributed to many conflicts with family, as one caregiver complained: *'As I had to stay with her all the time, my husband and me had a lot of arguments. I treated my children badly because my temper was bad too [Daughter-in-law]'* (L. Tan et al., 2001, p. 14).

Another caregiver recognised that she could not interact with her children due to her caregiver role: '*It has affected my relationship with my children to a certain extent because I cannot spend time with them. I cannot go anywhere. It is the same if they come home. He [her father] will get agitated [A daughter caregiver]*' (Ho et al., 2003, p. 310).

Additionally, a lack of family support has resulted in a recipient's untreated BPSD: '*He always threw his tantrum and scolded my stepmother and my cousin's family. He insisted to cook for himself and always made a big mess. His temper was even worse and kicked my cousin out of his house' [Daughter]*' (L. Tan et al., 2001, p. 13).

These findings have demonstrated that cultural adaptation, difficulties in managing the recipient's BPSD, and family conflicts contributed to insufficient support within families. These findings highlighted that family, as a unit, influences the quality of dementia care and the caregivers' health conditions.

4.3.7 Synthesised finding 7: Expectations for dementia care services

This synthesised finding included two categories: expectations for education and training, and expectations for care services. The caregivers believed that dementia-related education and training could encourage them in their provision of professional dementia care, while the dementia care support services could help them fulfil the caregiver role and reduce caregiver burdens.

4.3.7.1 Expectations for education and training

This category indicated that caregivers desired to receive education and training regarding dementia care. During a dementia diagnosis, caregivers should engage in dementia education to prepare themselves for the caregiver role: *'At the beginning, as soon as she is diagnosed with dementia, it's good to have a relatively good understanding of the condition as well as the kind of caregiving that is necessary [Caregiver 12]'* (L. L. Tan et al., 2020, p. 264).

Further, one caregiver suggested that dementia care education could be conducted in a Chinese community so that support could be provided for more people: *'We need to educate the Chinese community about AD so that people can try to help one another rather than walk away when we need support',* (Zhan, 2004, p. 26).

Additionally, caregivers expected that dementia education and training programs for caregivers could be provided in dementia care centres: *'I wish there are particular care centres, 24 hours, specialized, those that [can also] train [family] for taking care of dementia patient [P3FC003]'* (Vaingankar et al., 2013, p. 1611).

These examples revealed how caregivers possess a strong desire for dementia care education and training skills so that they can improve the recipients' satisfaction and enhance their care outcomes.

4.3.7.2 Expectations for care services

Family caregivers experienced physical and emotional stress. They needed to access and use social support. This category presented caregivers' needs for support from social care groups.

One caregiver suggested that support centres could help caregivers meet care needs: '*What type of services we need, like support centres for dementia or other types of care centres—who will be able to help us or give us counselling on how to handle this kind of emotional [problem] [P6FE002]*' (Vaingankar et al., 2013, p. 1609).

Moreover, one finding indicated a need for respite care services that can be used to temporarily care for the recipient: *'I think caregivers recognize there's a need for, what they call respite care. They [should] take leave to care for themselves, take a break, short holiday or just rest (P5FE002)'* (Vaingankar et al., 2013, p. 1609). Another caregiver wanted to use the respite care services for taking a break: *'We had to rely on my family members to take care of my mother when I had to go out of town. If there were respite care services that we could trust, I would definitely use them*' (Fei Sun et al., 2014, p. 129).

Caregivers also expected to receive dementia-friendly services in outpatient clinics: *'I want a hospital to be more understanding for the dementia patient, reduce our waiting time. [P10FT001]'* (Vaingankar et al., 2013, p. 1610).

These examples indicated a need for respite care services, dementia care centres and professional services that help caregivers minimise caregiver burden and achieve advanced caregiving quality. These findings highlight a need for the health care system to be updated so that it meets caregivers' education and training needs and dementia care services demands.

4.4 Summary

Based on JBI methodology that was used in this review, seven synthesised findings were aggregated from 85 findings. The findings indicated that the health conditions and wellbeing of caregivers could be negatively affected due to multidimensional burdens. Accessing dementia care was a barrier due to poor English proficiency in caregivers. Moreover, caregivers experienced stigmas towards dementia. They also reported insufficient culturally and linguistically appropriate dementia care services, a lack of post-diagnosis support and poor care services. Caregivers also developed coping strategies (e.g., showing positive attitudes towards the caregiver role, self-identified strategies, various care serviced and self-care). Additionally, performing the caregiver role was encouraged by various motivations in caregivers. Findings also revealed that caregivers exhibited insufficient dementia care knowledge and skills. Education and training enabled them to improve their care practice. Receiving care support within a family also positively affected the caregiving role. However, a lack of family support resulted in increased caregiver burdens that negatively influenced caregivers' health. Further, the findings indicated that caregivers had expectations of receiving social care services that reduced caregiver burdens.

Chapter 5: Discussion

5.1 Introduction

This chapter will discuss the findings that were obtained from the studies that focused on caregivers from Greater China and the Chinese diaspora. Chapter 5 is divided into five sections: the introduction, similar findings from studies that focused on caregivers from Greater China and the Chinese diaspora, different findings from studies that focused on caregivers from Greater China and the Chinese diaspora, strengths and limitations, and the summary. A comparison of the findings between Greater China caregivers and Chinese diaspora caregivers is based on the synthesised findings and categories that were presented in Chapters 3 and 4. The similar findings between the two groups include seven synthesised findings and 18 categories. The significant different findings between the two groups include three categories: insufficient social support, lack of culturally and linguistically appropriate dementia care services, and using various care services. The detailed explanations are outlined in each section.

5.2 Similar findings from studies on caregivers from Greater China and the Chinese diaspora

The similar findings from the two studies on caregivers from Greater China and the Chinese diaspora include seven synthesised findings and 18 categories. The detailed information is presented in Table 22.

Table 22 Similar findings from studies on caregivers from Greater China and the Chinese diaspora

Synthesised findings	Categories
Multidimensional caregiver burdens	Emotional burden
	Physical burden
	Time-dependence burden
Barriers to dementia care	Dementia stigma
	Lack of post-diagnosis support
	Perceived poor care services
Positive coping strategies used by caregivers	Positive attitudes towards caregiving role
	Using various self-identified strategies
	Performing self-care
Motivations for caregivers	Filial piety as a motive
	Responsibilities for family members as a motive
	Religion and spirituality as a motive
Education and training	Lack of knowledge and skills in dementia care
	Participation in education and training
Family dynamics	Support in the family
	Lack of family support
Expectations for dementia care service	Expectations for care services
	Expectations for education and training

5.2.1 Multidimensional caregiver burdens

Multidimensional caregiver burden is described as 'the extent to which caregivers perceived that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning' (Zarit, Todd, & Zarit, 1986, p. 261). This review supports the findings of previous studies indicating that family caregivers experience multidimensional caregiver burdens while they care for people who live with dementia in home care settings (Park et al., 2015; Queluz et al., 2020; J. Wang, Xiao, He, Ullah, et al., 2014; Xie et al., 2016). The perceived multidimensional burdens in dementia caregivers negatively affect the caregivers' health and wellbeing (Xie et al., 2016). The factors that contribute to multiple caregiver burdens can be grouped into three categories: care recipient factors, caregiver factors and social factors (Wang, Xiao, He, Ullah, et al., 2014). The care recipient factors include care recipients' functional statuses, BPSD and cognitive conditions (van den Kieboom et al., 2020; Wang, Xiao, He, Ullah, et al., 2014). Other studies have reported that caregiver burden scores are associated with advanced stages of cognitive impairment in Dementia, ADL dependency and behavioural problems (Park et al., 2015; van den Kieboom et al., 2020). Moreover, the caregiver factors include caregiver age, gender and level of education (van den Kieboom et al., 2020; Wang, Xiao, He, Ullah, et al., 2014). Females accounted for a large percentage of family caregivers, and they had a higher risk of experiencing care burden compared to male caregivers (Park et al., 2015; van den Kieboom et al., 2020). In Yıkılkan, Aypak and Görpelioğlu's (2014) Turkish study, 79.4 per cent of 63 family caregivers were females, and 47.6 per cent were the daughters of care recipients. Additionally, the social factors comprised social support, income status and the kinship between caregivers and care recipients (J. Wang, Xiao, He, Ullah, et al., 2014). Some studies have identified that a declining level of social support shown to caregivers results in emotional burden (J. Wang, Xiao, He, Ullah, et al., 2014).

Dementia stigma, as identified in the present review, was also supported by previous studies. Su and Chang's (2020) study found that caregivers feel ashamed and embarrassed about that their family members who live with dementia, with the negative feelings resulting in the emotional burden. The findings from this review are aligned with those of other studies that reported the presence of emotional burdens in family caregivers (Queluz et al., 2020; Su & Chang, 2020). A review study identified that 58 per cent of 31 studies reported that caregivers experienced emotional stress while caring for people with dementia (Queluz et al., 2020). Caregivers who resided with dementia care recipients possessed a higher level of emotional burden compared to those who did not reside with care recipients (Park et al., 2015; van den Kieboom et al., 2020).

Family caregivers may feel overwhelmed in their care of family members if they could not cope with the caregiver burden or deteriorating dementia symptoms (Park et al., 2015; van den Kieboom et al., 2020). The care recipients might have high care demands in the late stage due to the progression of the disease, so the constant dementia care could become more intensive (Alzheimer’s Association, 2021). Placing recipients in nursing homes is likely to be chosen by some caregivers (Alzheimer's Association, 2021). Although the care recipients are transferred to nursing homes, family caregivers still experience negative emotions and anxiety (Park et al., 2015; J. Wang et al., 2015). Therefore, emotional support is still needed for caregivers, even though they do not reside with their care recipients (J. Wang et al., 2015). An association can be observed between the high level of dependency in care recipients and a higher level of caregiver burden (Park et al., 2015). Older caregivers are more likely to experience higher levels of caregiver burden compared to younger caregivers (Borsje et al., 2016). Older caregivers could also experience declined physical function, which contributes to physical strain in dementia care (Xie et al., 2016). A study by Park et al. (2015) reported that deterioration in physical health is associated with higher scores of caregiver burden ($p < 0.001$). Time-dependence burden is described as ‘the restrictions on the caregivers’ time’ (Novak & Guest, 1989, p. 800), and it was identified in this review and in a study by Park et al. (2015). Park et al.’s (2015) study reported that in South Korea, 79.7 per cent of 1,133 primary caregivers resided with their care recipients and experienced a higher level of caregiver burden, as compared to those who did not live with their care recipients. Further, 18.7 per cent of caregivers spent at least 17 hours performing their caregiver activities each day. Performing constantly resulted in restricted socialising and limited engagement of caregivers’ personal hobbies (Bai, Liu, Baladon, & Rubio-Valera, 2018; Park et al., 2015).

Caregiver burden resulting from caring for family members who live with dementia not only occurred in developing countries but also in developed countries (WHO, 2017). It is documented in the WHO global action plan in its public health response to dementia in 2017–2025 that by 2025, 75 per cent of countries will need to provide dementia support for both recipients and their family caregivers (e.g., by updating national policies, developing strategies or integrating with other policies); this figure was cited to reduce caregiver burden and improve the quality of dementia and wellbeing (WHO, 2017).

5.2.2 Barriers to dementia care

Barries to dementia care are attributed to dementia stigma, a lack of post-diagnosis support and the perceived poor care of services, which resulted in choosing not to use social care services. These findings correlate with those of previous studies (Nguyen & Li, 2020; Yıkılkan et al., 2014). A review study by Nguyen and Li (2020) comprised 26 articles and identified that stigma towards dementia is associated with lower self-esteem, negative emotional reactions, poor understanding and a lack of using social care services in family caregivers.

5.2.2.1 Dementia stigma

Stigma can be divided into two types: public stigma and self-stigma (Nguyen & Li, 2020). Public stigma is described as ‘a combination of prejudice, stereotype and discrimination from the perspectives of general public’ (Nguyen & Li, 2020, p. 174). In a systematic review by Nguyen and Li (2020), 23 out of 26 studies reported that family caregivers had experienced public stigma. Moreover, the review reported that the public tries to avoid people with dementia, as dementia prompted disgust, fear and anxiety in them due to the stigma (Nguyen & Li, 2020). Self-stigma is described as ‘the process whereby an individual absorbs the stigma endorsed by the social groups surrounding him or her' (Nguyen & Li, 2020, p. 149). The care recipients and their caregivers are likely to experience frustration, a loss of esteem, depression and delayed help seeking due to internalised negative perceptions of dementia (Nguyen & Li, 2020; Walmsley & McCormack, 2016). The perceived stigma in caregivers contributes to the decision not to seek help from dementia care services, and it negatively affects both care recipients' and caregivers' quality of life and wellbeing (Nguyen & Li, 2020). Participation in dementia-related education is associated with decreased stigma and reduced caregiving burdens (Herrmann et al., 2018).

5.2.2.2 Lack of post-diagnosis support

The present review aligns with previous studies in its identification of the lack of post-diagnosis support as an issue. In a systematic review, nine out of 32 studies reported that caregivers did not know where to receive support or how to access dementia care support once their family members were diagnosed with dementia (Parker, Barlow, Hoe, & Aitken, 2020). Another review study by Queluz et al. (2020) reported that caregivers had high demands for receiving dementia-related information. Receiving post-diagnosis support is crucial for family caregivers to effectively perform their caregiver roles (Kelly & Innes, 2016). Post-diagnosis support positively affects information seeking, and it guides caregivers into setting a care plan and reducing social isolation for both care recipients and their family caregivers (Kelly & Innes, 2016). A Scottish study by Kelly and Innes (2016) identified that the gap between insufficient information and reduced clinical input could be addressed with post-diagnostic support services for both care recipients and their caregivers. This service can be implemented through peer support groups and one-on-one person-centred support to satisfy care needs, improve the level of confidence in caregiving and achieve care goals (Kelly & Innes, 2016).

5.2.2.3 Perceived poor care services

Constructing a dementia-friendly environment plays a significant role in improving dementia awareness and reducing the stigma associated with dementia (Lin & Lewis, 2015). Moreover, a dementia-friendly environment and communication with health professionals are associated with caregivers' accessibility to dementia care services (Lin & Lewis, 2015). Conversely, in the absence of a dementia-friendly physical environment in institutions, caregivers can experience difficulties in using dementia care services in their caregiving process—which is a barrier to dementia care (Lin & Lewis, 2015). To address these issues, decrease family caregiver burden and magnify the benefits for care recipients living with dementia, integrating a dementia-friendly environment with dementia care services is required (Kupeli et al., 2018; Lin & Lewis, 2015; S. M. Wu et al., 2019). This review's finding regarding the perceived poor care service supports the results from previous studies (S. M. Wu et al., 2019). A Taiwan study by S. M. Wu et al. (2019) identified that a third of 20 family caregivers mentioned that dementia-friendly hospitals were required because it was difficult to manage dementia care recipients due to the long waiting times when visiting doctors. A lack of dementia-friendly transportation during the caregiving process was also identified in this review study. Providing dementia-friendly services plays a significant role in improving the level of satisfaction regarding care needs and in ensuring a sense of safety for both care recipients and family caregivers (S. M. Wu et al., 2019).

5.2.3 Positive coping strategies that caregivers use

Caregiver burdens negatively influence a caregiver's quality of life during the long-term care (Rodríguez-Pérez, Abreu-Sánchez, Rojas-Ocaña, & Del-Pino-Casado, 2017). Effective coping strategies are required for managing difficulties while performing caregiving activities significantly influences the wellbeing of both care recipients and caregivers (Rodríguez-Pérez et al., 2017; Xie et al., 2016). This review's results support those of previous studies (Lloyd, Patterson, & Muers, 2016; Parker et al., 2020; Waligora, Bahouth, & Han, 2019; X.-R. Wang, Liu, Robinson, Shawler, & Zhou, 2019). For example, the study by Lloyd et al. (2016) demonstrated that maintaining positive attitudes towards dementia care, accepting the disease's progressive deterioration and promoting spiritual improvements in care are important. Family caregivers are likely to become stronger and more energetic in terms of coping with challenges if they maintain an optimistic attitude towards dementia care (Lloyd et al., 2016). Further, caregivers self-identified various strategies for coping with the difficulties of caring for recipients. For example, Parker et al.'s (2020) study found that caregivers chose to use TV and paper materials to learn dementia-related knowledge so that they could adapt to the caregiver role and seek help.

Performing self-care is one of many positive coping strategies that caregivers use, as evidenced in previous studies (Waligora et al., 2019; X.-R. Wang et al., 2019). Caregivers' health conditions are a serious concern. One study reported that 74 per cent of caregivers who care for people with dementia voiced a consideration of personal health (X.-R. Wang et al., 2019). As performing caregiving activities restricts caregivers' personal time, they have limited time to care for themselves (X.-R. Wang et al., 2019). Moreover, during long-term dementia care, physical inactivity, poor diet and a lack of sleep contribute to caregivers' physical health decline (X.-R. Wang et al., 2019). Waligora et al. (2019) investigated the need to conduct self-care activities for caregivers. The intervention of caregivers performing self-care is associated with the caregivers maintaining their physical and mental health, socialising with society and improving their quality of dementia care (X.-R. Wang et al., 2019). A review study by Waligora et al. (2019) identified various methods for caregivers to achieve self-care, such as by participating in social activities, taking a breaking from caregiving activities and engagement in religious activities. Self-care activities are associated with the reduction of caregiving stress (Waligora et al., 2019). In general, using respite care services and taking a breaking from caring for recipients' behaviours help caregivers reduce the caregiver burden and effectively maintain their wellbeing (Waligora et al., 2019). Rodríguez-Pérez et al. (2017) highlighted that to strengthen social assistance, one must concentrate on emotional support; they also noted that problem-focused coping is associated with a reduction in caregiver emotional burdens and an improvement in caregivers' quality of life.

5.2.4 Motivations for caregivers

This review supported the findings of previous studies regarding how caregivers who perform the caregiver role become motivated by various motivations (Agli, Bailly, & Ferrand, 2015; Eifert, 2017; Greenwood & Smith, 2019). Motivations for caregiving are described as 'why carers take on the role, whilst meaning related to how positive the experience of caring was for the carer' (Greenwood & Smith, 2019, p. 2). In terms of caring for people who live with dementia, motivations are influenced by the relationship between caregivers and care recipients (Greenwood & Smith, 2019; Quinn, Clare, & Woods, 2015). Conversely, motivations influence caregivers' spirituality, quality of life and outcomes in long-term care (Y. Kim, Carver, & Cannady, 2015; Quinn et al., 2015). Caregivers' motivations for performing a caregiver role are influenced by their social and cultural backgrounds (Greenwood & Smith, 2019; Xiao et al., 2015). The three main concepts of traditional Chinese philosophy include Confucianism, Taoism and Buddhism. Among them, Chinese families are predominantly influenced by Confucianism (Xiao et al., 2015; Yiu et al., 2020). The fundamental themes of Confucianism include filial piety, familism, the spouse relationship, the pursuit of restful and peace, and a willingness to learn (Yiu et al., 2020).

Filial piety is described as ‘emphasize honour and devotion to one’s parents … implies that adult children have a responsibility to sacrifice individual physical, financial and social interests for the benefit of their parents or family’ (Greenwood & Smith, 2019, p. 15). In Western society, the relationship between parents and children is based on love, and a limited number of obligations is designated (Yiu et al., 2020). When children mature, they are not obligated to provide resources to care for their parents (Yiu et al., 2020). Conversely, obeying the wills of parents’ and taking care of them when they become old are the core values of filial piety in Chinese families (Xiao et al., 2015; X.B. Zhang et al., 2018). Typically, it is the eldest son (assuming there is one) who takes responsibility for caring for his elderly parents (Yiu et al., 2020). Studies have reported that filial piety is a motive for caregivers to perform their role and caregiving activities (Greenwood & Smith, 2019). A systematic review study that comprised 26 studies reported that five studies mentioned filial piety as a motive for caregiving, while seven studies reported that caregivers cared for family members due to the caring responsibility of the culture (Greenwood & Smith, 2019). A perceived stronger level of filial belief correlates with lower caregiver burdens (Guo, Kinm, & Dong, 2019). Additionally, this review supported previous studies demonstrating that religion and spirituality are motives for caregivers too assume their caregiver roles (Agli et al., 2015; Eifert, 2017). A review study by Agli et al. (2015) identified that eight out of 11 articles demonstrated how religions or spirituality enabled caregivers to perform their roles, accept their roles, develop coping strategies and stay positive. Further, another study by Eifert (2017) emphasised that religion was a motive in the dementia caregiving process for helping family caregivers by providing care, relieving emotional stress and achieving better health outcomes.

5.2.5 Education and training

This synthesised finding from the review included two aspects: a lack of knowledge and skills in dementia care and participation in education and training. Both are aligned with other studies (Ding et al., 2020; Parker et al., 2020; Queluz et al., 2020). Parker et al.'s (2020) review study identified that 11 studies out of 32 reported delays in seeking help and in not recognising dementia's early symptoms—both of which were attributed to a lack of dementia-related knowledge for caregivers. Additionally, Ding et al.'s study (2020) proved that the increase in the prevalence of dementia and its incidence are associated with lower education, according to analysed findings. Similarly, another Chinese study evidenced that insufficient education is a main risk factor that contributes to the higher prevalence of dementia (Y. Liu et al., 2020). Factors that contribute to a low level of education might include low income, poor lifestyle, poor living environment and barriers to accessing medical health services (Ding et al., 2020). However, the dementia education program correlates with an improvement of dementia care knowledge and coping strategies (Jensen, Agbata, Canavan, & McCarthy, 2015). Conversely, as most people with dementia have dementia-related symptoms, other health conditions and complications, caregivers must be knowledgeable and skilful in terms of preventing and managing BPSD and other health conditions for those they care for (Queluz et al., 2020; J. Wang et al., 2015). In Queluz et al.'s (2020) study, 52 out of 33 per cent of studies demonstrated that caregivers possess a strong sense of education and training that is required in dementia care. For example, caregivers want to receive information regarding dementia progression, the coping strategies of managing BPSD, the available care support services and participation in dementia-related learning throughout the illness's trajectory (Queluz et al., 2020). Caregivers actively seek coping strategies to reduce caregiver burdens and manage challenges after they are educated (Yıkılkan et al., 2014). Further, higher education is associated with lower caregiver burdens, and caregivers improve dementia-related knowledge and skills through participating in education and training to achieve optimal dementia care (Yıkılkan et al., 2014).

5.2.6 Family dynamics

Family dynamics are associated with the quality of dementia care and the extent of informal support for caregivers (Panyavin et al., 2015). Studies have reported that support in the family significantly influences the caregiver role. Elnasseh et al.'s (2016) Argentinian study identified that greater communication and empathy within a family are associated with decreased family conflicts and improved caregiver resilience for coping with the challenges of dementia care. Another Argentinian study also found that primary caregivers who are supported by family members in dementia care would experience reduced caregiving burdens, increased emotional and social support and improved quality of life (Panyavin et al., 2015). Further, caregivers prefer to share their caregiving roles within their families, as the interaction with recipients can still be continued and their dignity can be maintained (Parker et al., 2020). In contrast, caregivers who lack family support have a higher time-dependence burden (Wang, Xiao, He, Ullah, et al., 2014). For example, the stigma within families can increase caregiver burdens and prevent family caregivers from using dementia care services (Xiao et al., 2015).

5.2.7 Expectations for dementia care service

The present review supports previous studies regarding the expectations for care services. In a systematic review study, eight out of 12 studies reported that caregivers did not have their formal support service needs met (McCabe, You, & Tatangelo, 2016). Additionally, the study by McCabe et al. (2016) identified that six out of 12 studies noted the requirement of caregivers to receive informal care support services (e.g., peer support groups). Further, Tretteteig, Vatne and Rokstad's (2016) review revealed that three out of 19 studies demonstrated the expectation of caregivers to seek information and use day care centres. However, inadequate information regarding dementia care resources is likely associated with a decreased use of social support services (Chang, Ming, Chang, Yen, & Lan, 2020). For example, a Chinese study from Taiwan found that 40 per cent of 97 caregivers did not use dementia care resources in long-term care due to their needs for information regarding care support services not being met (Chang et al., 2020).

Together with the findings of previous studies, this review found that an expectation of dementia education and training for caregivers is required (McCabe et al., 2016; Rathnayake, Jones, Calleja, & Moyle, 2019; W. Xu et al., 2016). Rathnayake et al. (2019) demonstrated that family caregivers have a strong desire for informational and educational needs. For example, caregivers are eager to receive resources regarding care skills so that they can provide functional care for their recipients (Rathnayake et al., 2019). However, the available resources are inadequate, either online or from training courses (Rathnayake et al., 2019). One review study indicated an association between education programs and a reduction in dementia risk, with the possibility of a 7 per cent reduction in dementia risk each year (W. Xu et al., 2016). A systematic review study by McCabe et al. (2016) identified that nine out of 12 studies further demonstrated caregivers' requirements for dementia-related knowledge and information. Generally, the caregivers expected to receive knowledge and information in three areas: dementia diagnosis and progression, coping strategies for managing recipients' BPSD, and using medications and social support services (McCabe et al., 2016). Dementia-related education and training enable caregivers to understand their care recipients' needs, construct dementia-friendly environments and perform their caregiver roles (Huang et al., 2019; McCabe et al., 2016).

5.3 Different findings from studies on caregivers from Greater China and the Chinese diaspora

Three significant findings between the Greater Chinese studies and the Chinese diaspora studies have been founded: insufficient social support, use of various care services and the lack of culturally and linguistically appropriate dementia care services (see Table 23). The detailed information will be discussed in the following sections.

Table 23 Different findings from studies on caregivers from Greater China and the Chinese diaspora

Synthesised findings and categories	Caregivers from Greater China	Caregivers from the Chinese diaspora
Insufficient social support	Yes	Nil
Using various care services	Nil	Yes
Lack of culturally and linguistically appropriate dementia care services	Nil	Yes

5.3.1 Insufficient social support/use of various care services

Positive social support correlates with higher life satisfaction, better psychological health and improved quality of life for caregivers (M. Wu et al., 2018; Zhong et al., 2020). However, a lack of social support is associated with caregivers' higher level of caregiving burdens, depression and declining quality of life (Magaña et al., 2020; Queluz et al., 2020). The unmet need for social support services is linked to caregivers' limitations in accessing and using various care services

(McCabe et al., 2016). The two findings are discussed in the same section, and the reasons for each different finding to exist in a focused group are explained in the following paragraphs.

One finding was that insufficient social support was identified in the Greater China studies for caregivers. This review supports previous studies in that insufficient social support is considered a barrier to dementia care (Queluz et al., 2020; Zhou & Walker, 2016). A review study by Queluz et al. (2020) reported that 55 per cent of 31 studies revealed that family caregivers required formal or informal support services, as inadequate support resulted in increased caregiver burden during caregiving activities. However, the finding that caregivers used various dementia care services for coping strategies was identified from the studies on caregivers from the Chinese diaspora. This review supports the findings of previous studies (Calvo-Perxas, Litwin, & O, 2018; Lethin et al., 2016).

5.3.1.1 Caregivers from Greater China

The dementia social support service system is undeveloped in China (Z. Chen et al., 2017). The reasons why this insufficient social support is a barrier to caregivers providing dementia care in Greater China are summarised in three aspects.

First, the Chinese commonwealth fund policy influences the limitation of social support services for dementia care (The Commonwealth Fund, 2020). In China, neither social support nor long-term care is covered by public health insurance (The Commonwealth Fund, 2020). However, dementia care is a long-term care process, and caregiving for people with dementia imposes a heavy financial burden on caregivers and families (Z. Chen et al., 2017). For example, a Guangzhou study comprising 5,747 dementia patients reported that the average hospitalisation cost for each dementia patient was RMB 9,169 for 24.2 days (average length of stay) (Approximate

AUD $1834) (H. Zhang, Zhang, Yin, Zhang, & Huang, 2019). Although public health insurance covers mental health services for inpatients and outpatients, 'The public insurance programs only reimburse patients up to a certain ceiling, above which residents must cover all out-of-pocket costs' (The Commonwealth Fund, 2020, p. 7). Additionally, another study from Shanghai, China, reported that the approximate direct economic cost for dementia care per person was RMB 8,432 and RMB 10568 for indirect costs (Z. Chen et al., 2017). Further, home care is usually performed by family members in long-term care processes, and family caregivers do not receive benefits from financial or tax assistance based on the Chinese public health care policy (The Commonwealth Fund, 2020). Such high costs for dementia care restrains caregivers from using social support services (Z. Chen et al., 2017). Second, community-based support services are in a developmental phase in China, so there are insufficient community-based dementia support services (e.g., respite care or day care centre for care recipients and caregivers) (Z. Chen et al., 2017; Zhou & Walker, 2016). Information regarding and experiences of social support services influence the caregivers' decision to use dementia-related support services (Tretteteig et al., 2016). For example, compared to non-users, family caregivers who used day care centre services displayed positive outcomes for caregiving motivations and coping behaviours for barriers to dementia care (Tretteteig et al., 2016). Consequently, limitations exist in terms of choosing and using dementia support services for Chinese family caregivers (Z. Chen et al., 2017; Tretteteig et al., 2016). The results from Zhou and Walker's (2016) study highlighted that community-based care is being urged to develop in China. Third, dementia caregivers receiving informal social support from family members will likely be influenced by Chinese traditional policy contexts (Z. Chen et al., 2017). For example, the Chinese one-child policy and 4–2–1 family structure is the most common family structure (M. Wu et al., 2018). This traditional family structure results in only one child in a family who could not share the caregiving responsibility and burdens for his or her elderly parents (Z. Chen et al., 2017). Additionally, although some adult children mature and emigrate to a different city in search of job opportunities and higher payment, the number of elderly people living with a spouse or alone at home is rising (M. Wu et al., 2018). This phenomenon is commonly called ‘empty nesters’ in China (Z. Chen et al., 2017). Some studies have demonstrated that compared with non–empty nesters, the empty nesters among the senior citizens have a higher risk of depression and loneliness, which negatively influences mental health outcomes (G. Wang, Hu, Xiao, & Zhou, 2017; H.-H. Zhang et al., 2020). Consequently, home care for senior citizens who live with dementia faces various challenges (Z. Chen et al., 2017). Further, inadequate social support from adult children, especially in rural China, is likely associated with a higher level of caregiver burdens and a decreased level of life satisfaction (Queluz et al., 2020; M. Wu et al., 2018).

The above three reasons reveal that the Chinese social support system is undeveloped for dementia care. This undeveloped system also results in caregivers from Greater China who are limited in their choice to use social support services in their caregiving activities (Z. Chen et al., 2017; Zhou & Walker, 2016). Further, insufficient awareness of dementia in the public negatively affects caregivers who seek help (Z. Chen et al., 2017; Nguyen & Li, 2020). As the discrimination and prejudice from the public prompt caregivers’ emotional stress, the family caregivers are unwilling to contact support groups (Z. Chen et al., 2017). Chinese people have a higher level of dementia stigma in comparison to African American and Latino populations (Z. Chen et al., 2017). Therefore, the finding regarding the use of various care services in coping strategies could not be found in the studies on caregivers from Greater China.

5.3.1.2 Caregivers from the Chinese Diaspora

To address and satisfy both care recipients' and caregivers' needs, the Australian Government facilitates many dementia-specific programs that encompass the national helpline and referral service (Commonwealth of Australia, 2018). Such programs include 'early intervention, carer education and training, counselling, community education and public awareness raising initiatives' (Commonwealth of Australia, 2018, p. 47). Further, the Australian Government accounts for caregivers' income status, as the caregiver role often results in a lack of paid working hours (Commonwealth of Australia, 2018). Therefore, the caregivers who constantly care for people with dementia can benefit from the financial support of the Australian Government (Commonwealth of Australia, 2018). For example, if the dementia care recipient displays a higher score of care needs, then his or her caregiver will receive a fortnightly supplement for carer allowance (Australia Government Services Australia, 2019).

Similarly, support services for caregivers are frequently provided and used in Europe (Calvo-Perxas et al., 2018). A study of 12 European countries (Austria, Spain, Germany, Sweden, France, Belgium, Czech Republic, Denmark, Netherlands, Switzerland, Luxembourg and Slovenia) demonstrated that many types of informal support were available to and used by caregivers to reduce caregiver burdens and avoid any negative influences on health outcomes (e.g., respite care, flexible work arrangements, unpaid leave, counselling or education and training) (Calvo-Perxas et al., 2018). Moreover, the results from another European study that focused on eight countries (France, Germany, Estonia, Finland, England, the Netherlands, Spain and Sweden) emphasised that dementia-related education, counselling and caregiver support were highly available for caregivers throughout their caregiving process (Lethin et al., 2016). Additionally, Lethin et al.'s (2016) French study found that the respite service for dementia care was used by all caregivers from the dementia diagnostic stage to the late-life stage. Consequently, it is more accessible for Chinese emigrants to use social support services for dementia care.

5.3.2 Lack of culturally and linguistically appropriate dementia care services

A lack of culturally and linguistically appropriate dementia care services was identified from the studies that focused on caregivers from the Chinese diaspora. This finding supports previous studies (Parker et al., 2020; Sagbakken, Spilker, & Ingebretsen, 2018; Xiao et al., 2015). Compared to emigrated caregivers, caregivers from host countries have fewer cultural and linguistic barriers (Handtke, Schilgen, & Mosko, 2019). However, the people who live in Greater China are native to that area. There is no barrier to the cultural adaptation of accessing dementia care (Handtke et al., 2019). Then, the people who live in Greater China speak Chinese, which is a mother language and easy to understand (J. Wang et al., 2019). In short, in Greater China, dementia care services are much easier to obtain due to cultural and linguistic advantages (J. Wang et al., 2019). Unlike the mainstream cultures, the caregivers with culturally and linguistically diverse backgrounds exhibit a strong sense of coping in terms of facing challenges and using dementia care services (Sagbakken et al., 2018; Xiao et al., 2015). First, the language barrier is a serious concern for ethnic minority groups (Parker et al., 2020). For people in the Chinese diaspora, as English is a second language for caregivers, the first generation of adult child caregivers somewhat relied on care coordinators when they used dementia services (Xiao et al., 2013). Similarly, a study that comprised six Vietnamese family caregivers who lived in South Australia also reported that the difficulties of accessing dementia care services result from low English proficiency (Xiao et al., 2015). Further, a cultural accordance between health professionals and care recipients is another concern when using dementia care services (Xiao et al., 2015). Xiao et al.'s (2013) study found that dementia education and training courses were not equally distributed among people from different ethical groups group; this is evidenced by the fact that caregivers from Chinese background along with other CALD groups did not present themselves in dementia education sessions provided in English without interpreters. Ethno-specific dementia care services are the main method on which Chinese diaspora caregivers rely (Xiao et al., 2015). Integrating bilingual and bicultural dementia care coordinators and professionals with dementia care services (e.g., through dementia education programs) will likely raise dementia care awareness, make caregivers more willing to use available dementia care services and reduce caregiver burdens (Xiao et al., 2015).

5.4 Strengths and limitations

This review showed a number of strengths. One was the use of six English databases and four Chinese databases to search for research articles. Using multiple databases enables reviewers to achieve optimal searches and reduce publication bias (Bramer, Rethlefsen, Kleijnen, & Franco, 2017). Second, there were no restrictions placed regarding the publication date; the researcher wanted to ensure that the comprehensive search retrieved more topic-related studies for data aggregation. Third, systematic reviews of Chinese family caregivers' experiences of caring for people with dementia were scarce; the findings of this review could thus inform policymakers and governments in their decision-making and updates of healthcare policies. However, this review also presented some limitations. First, the included studies were published in English and Chinese languages. There was a possibility of omitting publications in non-English journals. Second, a grey database search was not conducted in this review, as the comprehension of the searches could be affected.

5.5 Summary

Based on the synthesised findings from studies that focused on caregivers from Greater China and the Chinese diaspora, seven synthesised findings and 18 categories were found for similar findings, and three categories were found for different findings between the two groups of caregivers. All identified findings support previous studies. The similar synthesised findings from both groups included multidimensional caregiver burdens negatively affecting caregivers' quality of life and wellbeing. The review also revealed barriers to dementia care while the family caregivers performed their caregiving activities (e.g., dementia stigma, lack of post-diagnosis support and perceived poor care services). Family caregivers used positive strategies to cope with the challenges (e.g., positive attitudes towards the caregiving role, using various self-identified strategies and performing self-care). Performing the caregiving role were found to be mainly motivated by filial piety, responsibilities for family members, religion and spirituality. Family dynamics also influenced the caregiving role. Both family caregivers from Greater China and the Chinese diaspora possessed insufficient knowledge and skills regarding dementia care, and both caregiver groups expected dementia-related education and training. They also expected care services. The different findings from studies that focused on caregivers for the two groups included insufficient social support, which was identified from the studies in Greater China, using various care services and a lack of culturally and linguistically appropriate dementia care services, which were found in the studies from the Chinese diaspora. These findings have strong implications for developing recommendations for practice and research, which are presented in the next chapter.

Chapter 6: Conclusion

6.1 Introduction

This chapter will summarise the introduction, review methodology and methods, findings and discussion of this systematic review. Based on the synthesised findings from this review, recommendations and implications for practice and future research will also be summarised. Chapter 6 is thus divided into five sections: the introduction, summary of the review, recommendations, implications and conclusion.

6.2 Summary of the review

This systematic review aimed to understand the experiences of Chinese family caregivers in their care of people with dementia. The review applied a JBI meta-synthesis of qualitative study methodology. The PICo framework was also applied and used to identify keywords for searching and screening studies. After the search strategies were conducted, 38 articles were selected. Based on the JBI Qualitative Critical Appraisal Checklist for assessing selected studies, two articles were removed due to lower-quality findings and irrelevant information. Finally, 36 articles were included, and the data were extracted using the JBI-QARI tool. The included articles were categorised into studies that focused on family caregivers from Greater China and studies that focused on family caregivers from the Chinese diaspora.

In the Greater China group of studies, 100 findings were extracted from 21 primary studies. Based on these extracted findings, 22 categories were identified and then aggregated into seven synthesised findings: 1) multidimensional caregiver burdens, 2) barriers to dementia care, 3) positive coping strategies that caregivers use, 4) motivations for caregivers, 5) education and training, 6) family dynamics and 7) expectations for dementia care services.

In the Chinese diaspora group of studies, 86 findings were extracted from 15 primary studies. Based on these extracted findings, 21 categories were identified and then aggregated into seven synthesised findings: 1) multidimensional caregiver burdens, 2) barriers to dementia care, 3) positive coping strategies that caregivers use, 4) motivations for caregivers, 5) education and training, 6) family dynamics and 7) expectations for dementia care services.

6.3 Recommendations

Based on the synthesised findings in the review, six recommendations for practice were identified to inform policymakers in their development of evidence-based support for caregivers. The three recommendations for both governments from Greater China and from developed countries in which people from the Chinese diaspora live include the following: 1) the government should provide post-diagnosis support for Chinese family caregivers; 2) the government should develop dementia-friendly environments that enable Chinese family caregivers to practice; and 3) the government should provide education and training in dementia care to Chinese family caregivers (see Table 24). The recommendations specific to the governments from Greater China include the following: 1) the governments should provide appropriate financial support to sustain dementia care at home; and 2) the governments should develop community-based dementia care services (see Table 25). The recommendation specific to the governments in developed countries in which people from the Chinese diaspora live is that the governments should provide culturally and linguistically appropriate dementia care services for caregivers and the Chinese people in their care who live with dementia (see Table 25). After the JBI grade criteria were applied, the grade of each recommendation was A. This review also made implications for further practices and research. The lists of recommendations for each group are also presented in Appendix VIII.

Table 24 Similar recommendations for Greater China and the Chinese diaspora

Recommendations	**JBI Grade**
Government should support post-diagnostic service	A
Government should develop dementia-friendly community	A
Government should provide education and training in dementia care	A

Table 25 Different recommendations for Greater China and the Chinese diaspora

Synthesised findings and categories	Government from Greater China	Government from Chinese diaspora	**JBI Grade**
Government should provide appropriate financial support in dementia care	Yes	Nil	A
Government should develop community-based dementia care	Yes	Nil	A
Government should provide culturally and linguistically appropriate dementia care services	Nil	Yes	A

6.4 Implications

This review prompted certain implications for further theoretical research and practice. First, based on the above recommendations, specific approaches that implement these recommendations should be developed. Second, interventions that reduce multidimensional caregiver burdens for family caregivers in their care of people who live with dementia should be developed by community aged care organisations; this would reduce caregivers' mental and psychological stress, increase their life satisfaction and promote their quality of life. Third, the Chinese government's investment in dementia research is urgently required. Fourth, an investment is also required in terms of promoting formal support mechanisms (e.g., community centres, services and healthcare facilities). Finally, there is a need to integrate dementia courses with medical colleges and school learning in the future.

6.5 Conclusion

This chapter has summarised the whole systematic review. Based on the synthesised findings from Chapters 3 and 4, five recommendations were derived for the governments from Greater China, and four recommendations were derived for developed countries in which people from the Chinese diaspora live. Based on the synthesised findings, this review also noted the implications for further practice and research.

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Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist, 26*(3), 260-266. doi:10.1093/geront/26.3.260

Zhan, L. (2004). Caring for family members with Alzheimer's Disease: Perspectives from Chinese American caregivers. *Journal of gerontological nursing, 30*(8), 19-29. doi:10.3928/0098-9134-20040801-06

Zhang, R., Yang, Z., Wang, L., & Li, Z. (2008). 老年痴呆患者照顾者照顾感受的质性研究. [The qualitative research of caring experiences of caregivers of elderly dementia patients]. *Chinese Journal of Nursing [中华护理杂志], 43*(7).

Zhang, H.-H., Jiang, Y.-Y., Rao, W.-W., Zhang, Q.-E., Qin, M.-Z., Ng, C. H., . . . Xiang, Y.-T. (2020). Prevalence of depression among empty-nest elderly in China: A meta-analysis of observational studies. *Frontiers in psychiatry,* 11, 1-10. doi:10.3389/fpsyt.2020.00608

Zhang, H., Zhang, D., Yin, Y., Zhang, C., & Huang, Y. (2019). Costs of hospitalization for dementia in urban China: Estimates from two Urban Health Insurance Scheme claims data in Guangzhou city. *International Journal of Environmental Research and Public Health, 16*, 1-18. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6695624/pdf/ijerph-16-02781.pdf

Zhang, W. (2020). Perceptions and expectations of filial piety among older Chinese immigrants in Canada. *Ageing and Society*, 1-24. doi:10.1017/S0144686X20000902

Zhang, W. W. (2005). Overseas Chinese and the Concept of "Greater China". *Refugee survey quarterly, 24*(4), 65-73. doi:10.1093/rsq/hdi084

Zhang, X. B., Clarke, C. L., & Rhynas, S. J. (2018). What is the meaning of filial piety for people with dementia and their family caregivers in China under the current social transitions? An interpretative phenomenological analysis. *Dementia-International Journal of Social Research and Practice, 18*(7-8), 2620-2634. doi:10.1177/1471301217753775

Zhang, X. B., Clarke, C. L., & Rhynas, S. J. (2019). A thematic analysis of Chinese people with dementia and family caregivers' experiences of home care in China. *Dementia-International Journal of Social Research and Practice*, 1-15. doi:10.1177/1471301219861466

Zhang, X. B., Clarke, C. L., & Rhynas, S. J. (2020). Tensions in dementia care in China: An interpretative phenomenological study from Shandong province. *International Journal of Older People Nursing, 15*(1). doi:10.1111/opn.12291

Zhang, X. X., Zhang, X. B., & Hockley, J. (2020). A qualitative study of family caregivers' coping strategies of looking after people with dementia in China. *Journal of Research in Nursing*, 1-14. doi:10.1177/1744987120925128

Zhong, Y., Wang, J., & Nicholas, S. (2020). Social support and depressive symptoms among family caregivers of older people with disabilities in four provinces of urban China: the mediating role of caregiver burden. *BMC Geriatric, 20*(1), 1-3. doi:10.1186/s12877-019-1403-9

Zhou, J., & Walker, A. (2016). The need for community care among older people in China. *Ageing and Society, 36*(6), 1312-1332. doi:10.1017/S0144686X15000343

Appendices

Appendix I: Research Protocol

PROSPERO
International prospective register of systematic reviews

Systematic review

*Fields that have an **asterisk (*)** next to them means that they **must be answered. Word limits provide guidance** but do not actually limit the number of words that can be entered in each section. You are encouraged to follow maximum length. Registrant means the person filling out the form.*

1.* Review title.

Chinese caregivers' experiences in the care of family members living with dementia: a meta-synthesis protocol

2.Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

3.* Anticipated or actual start date.

Give the date the systematic review started or is expected to start.

27/09/2020

4.* Anticipated completion date.

Give the date by which the review is expected to be completed.

01/02/2021

5.* Stage of review at time of this submission.

Tick the boxes to show which review tasks have been started and which have been completed. Update this

field each time any amendments are made to a published record.
Reviews that have started data extraction (at the time of initial submission) are not eligible for inclusion in PROSPERO. If there is later evidence that incorrect status and/or completion date has been supplied, the published PROSPERO record will be marked as retracted.
This field uses answers to initial screening questions. It cannot be edited until after registration.

The review has not yet started: No

Review stage	**Started**	**Completed**
Preliminary searches	Yes	No
Piloting of the study selection process	No	
Formal screening of search results against eligibility criteria	No	
Data extraction	No	
Risk of bias (quality) assessment	No	
Data analysis	No	

Provide any other relevant information about the stage of the review here.

6.* Named contact.

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.

Lily Dongxia Xiao

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Professor Lily Dongxia Xiao

7.* Named contact email.

Give the electronic email address of the named contact.

lily.xiao@flinders.edu.au

8.Named contact address

Give the full institutional/organisational postal address for the named contact.

College of Nursing and Health Sciences Flinders University Sturt Road, Bedford Park, South Australia, 5042

GPO Box 2100, Adelaide SA 5001

9.Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

+61 8 82013419

10.* Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

Flinders University, Australia

Organisation web address:

https://www.flinders.edu.au/

* Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country now MUST be entered for each person unless you are amending a published record.**

Ms Yujing Zhang. Flinders University, Australia
Professor Lily Dongxia Xiao. Flinders University, Australia
Assistant/Associate Professor Jing Wang. Xi'an Jiaotong University, China
Mrs Leila Mohammadi. Flinders University, Australia

11.* Funding sources/sponsors.

Details of the individuals, organizations, groups, companies or other legal entities who have funded or sponsored the review.

Nil

Grant number(s) or award number and the date of award

12.* Conflicts of interest.

List actual or perceived conflicts of interest (financial or academic).

None

13.Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. **NOTE: email and country must be completed for each person, unless you are amending a published record.**

14.* Review question.

What are Chinese caregivers' experiences in the care of family members living with dementia?

15.* Searches.

State the sources that will be searched (e.g. MEDLINE). Give the search dates, and any restrictions (e.g. language or publication date). Do NOT enter the full search strategy (it may be provided as a link or attachment below.)

The following databases will be searched: six English databases including Medical Literature Analysis and

Retrieval System Online (MEDLINE), Scopus, ProQuest, Web of Science, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), EmCare, and four Chinese databases including China National Knowledge Infrastructure (CNKI), Wanfang Data, Weipu Data, China Biology Medicine (CBM).

Search dates: 27 August 2020 to 27 September 2020

Language: English and Chinese

Publication period: No limited publication date

P (Population): Chinese caregivers/relatives of people living with dementia, the spouse/partner of people with dementia; informal caregivers of people with dementia, or Alzheimer's disease.

phenomenon of Interest: Caregivers' experiences, emotions, expectation, feelings and perspectives

C (Context): Chinese caregivers who provide care for people with dementia at home

Reference:

Stern, C., Jordan, Z., & McArthur, A. (2014). Developing the Review Question and Inclusion Criteria. *AJN, American Journal of Nursing, 114*(4), 53-56. doi:10.1097/01.NAJ.0000445689.67800.86

16.URL to search strategy.

Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords) in pdf or word format. In doing so you are consenting to the file being made publicly accessible. Or provide a URL or link to the strategy. Do NOT provide links to your search **results**.

https://www.crd.york.ac.uk/PROSPEROFILES/205511_STRATEGY_20200907.pdf

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

17.* Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied in your systematic review.

China has the largest number of people with dementia, accounting for approximately 25% of global population living with dementia (Alzheimer's Disease International, 2018). China also has large diaspora in many countries. Most Chinese people with dementia are cared for by family members at home influenced by

Chinese filial piety (Wang, Xiao, He, & De Bellis, 2014). Understanding the experience and expectation of Chinese family caregivers is essential for the development of culturally appropriate education and social support for them. Studies on Chinese caregivers’ experiences have reported issues in dementia care across the globe. However, systematic reviews that synthesise the research evidence are scarce.

References

Alzheimer's Disease International. (2018). World Alzheimer Report 2018 The state of the art of dementia research: New frontiers Retrieved from https://www.alz.co.uk/research/WorldAlzheimerReport2018.pdf

Wang, J., Xiao, L.D., He, G., & De Bellis, A. (2014). Family caregiver challenges in dementia care in a country with undeveloped dementia services. Journal of Advanced Nursing 70(6), 1369–1380.doi:10.1111/jan.12299

18.* Participants/population.

Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and exclusion criteria.

Inclusion criteria

1) informal caregivers caring for people living with dementia in the home setting; 2) caregivers are primary caregivers aged 18 or over; 3) caregivers speak Chinese and hold a Chinese culture

Exclusion criteria

1) paid caregivers or professional caregivers; 2) care recipients are living in nursing homes

19.* Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The preferred format includes details of both inclusion and exclusion criteria.

Not applicable as this qualitative systematic review explores Chinese caregivers’ experiences in the care of family members living with dementia

20.* Comparator(s)/control.

Where relevant, give details of the alternatives against which the intervention/exposure will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

Not applicable

21.* Types of study to be included.

Give details of the study designs (e.g. RCT) that are eligible for inclusion in the review. The preferred format includes both inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be stated.

Inclusion criteria: 1) primary research with a qualitative design; 2) primary research using a mixed-method design with a qualitative component

Exclusion criteria: quantitative studies, secondary studies such as narrative reviews, scoping reviews, systematic reviews

22.Context.

Give summary details of the setting or other relevant characteristics, which help define the inclusion or exclusion criteria.

The context of studies is home care settings

23.* Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is

defined and measured and when these measurements are made, if these are part of the review inclusion criteria.

The main concerns of this systematic review include:

1) Chinese caregivers’ experiences and perspectives when caring for family members living with dementia

at home;

2) Chinese caregivers’ expectations of education, training programs, resources, care services and policy to assist them in their role.

* Measures of effect

Please specify the effect measure(s) for your main outcome(s) e.g. relative risks, odds ratios, risk difference,

and/or 'number needed to treat.

Not applicable

24.* Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state ‘None’ or ‘Not applicable’ as appropriate to the review

None

* Measures of effect

Please specify the effect measure(s) for you additional outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Not applicable

25.* Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

Data selection

Stage 1: Excluding duplicated studies

All identified literature will be exported into EndNote software and shared among three reviewers. Removing duplicated studies can reduce workload of the screening stage and decrease the errors for reviews (Bramer, Giustini, de Jonge, Holland, & Bekhuis, 2016).

Stage 2: Screening the title and abstract

The screening review process and outcomes will be regularly discussed among reviewers. The stage of screening the title and abstract is based on the inclusion and exclusion criteria (Butler et al., 2016).

Stage 3: Screening the full-text review

The stage of full-text reviewing only screen the articles which are moved from stage two. Full articles will be retrieved and screened for eligibility. In order to improve the trustworthiness of the included studies, two reviewers will review each full text independently (Butler et al., 2016).

Data extraction

Data extraction will be undertaken based on the Joanna Briggs Institute (JBI) meta-aggregation methodology (Lockwood et al., 2020). The extracted data will be presented in JBI-QARI tool for data analysis.

References

Bramer, W. M., Giustini, D., de Jonge, G. B., Holland, L., & Bekhuis, T. (2016). De-duplication of database search results for systematic reviews in EndNote. J Med Libr Assoc, 104(3), 240-243. doi:10.3163/1536-5050.104.3.014

Butler, A., Hall, H., & Copnell, B. (2016). A Guide to Writing a Qualitative Systematic Review Protocol to Enhance Evidence?Based Practice in Nursing and Health Care. Worldviews on Evidence Based Nursing, 13(3), 241-249. doi:10.1111/wvn.12134

Lockwood, C., Porrit, K., Munn, Z., Rittenmeyer, L., Salmond, S., Bjerrum, M., . . . Stannard, D. (2020). Chapter 2: Systematic reviews of qualitative evidence. JBI Manual for Evidence Synthesis. Retrieved from https://wiki.jbi.global/display/MANUAL/Chapter+2%3A+Systematic+reviews+of+qualitative+evidence

26.* Risk of bias (quality) assessment.

State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment tools that will be used.

The JBI Qualitative Critical Appraisal Checklist will be used for assessing the quality of included studies (Joanna Briggs Institute, 2017). The quality of included studies will be assessed by two reviewers independently. A third reviewer will be consulted when necessary.

Reference

Joanna Briggs Institute. (2017). The Joanna Briggs Institute Critical Appraisal tools for use in JBI Systematic Reviews Checklist for Qualitative Research. Retrieved from https://joannabriggs.org/sites/default/files/2019-05/JBI_Critical_Appraisal-Checklist_for_Qualitative_Research2017_0.pdf

27.* Strategy for data synthesis.

Describe the methods you plan to use to synthesise data. This **must not be generic text** but should be **specific to your review** and describe how the proposed approach will be applied to your data. If meta-analysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

The JBI ConQual tool will be used to evaluate the dependability and credibility of each finding to establish confidence in the synthesised findings (Munn, Porritt, Lockwood, Aromataris, & Pearson, 2014). The data synthesis will be achieved using the JBI aggregation approach in three steps as explained below (Lockwoodet al., 2020):

Step 1 Findings will be extracted from all included studies;

Step 2 Categories will be developed from findings of original studies reviewed, and each category should be consisted of at least two findings;

Step 3 The synthesised findings will be developed on the base of minimal two categories.

References

Munn, Z., Porritt, K., Lockwood, C., Aromataris, E., & Pearson, A. (2014). Establishing confidence in the output of qualitative research synthesis: The ConQual approach. Bmc Medical Research Methodology, 14(1), 108-115. doi: 10.1186/1471-2288-14-108

Lockwood C, Porrit K, Munn Z, Rittenmeyer L, Salmond S, Bjerrum M, Loveday H, Carrier J, Stannard D.(2020). Chapter 2: Systematic reviews of qualitative evidence. In: Aromataris E, Munn Z (Editors). JBI Manual for Evidence Synthesis. Retrieved from https://synthesismanual.jbi.global

28.* Analysis of subgroups or subsets.

State any planned investigation of ‘subgroups’. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

None planned

29.* Type and method of review.

Select the type of review, review method and health area from the lists below.

Type of review

Cost effectiveness
No

Diagnostic
No

Epidemiologic
No

Individual patient data (IPD) meta-analysis
No

Intervention
No

Meta-analysis
No

Methodology
No

Narrative synthesis
No

Network meta-analysis
No

Pre-clinical

No

Prevention

No

Prognostic

No

Prospective meta-analysis (PMA)

No

Review of reviews

No

Service delivery

No

Synthesis of qualitative studies

Yes

Systematic review

Yes

Other
No

Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system

No

Cancer

No

Cardiovascular

No

Care of the elderly

No

Child health

No

Complementary therapies

No

COVID-19

No

Crime and justice

No

Dental

No

Digestive system

No

Ear, nose and throat

No

Education

No

Endocrine and metabolic disorders

No

Eye disorders

No

General interest

No

Genetics

No

Health inequalities/health equity

No

Infections and infestations

No

International development

No

Mental health and behavioural conditions

No

Musculoskeletal

No

Neurological

No

Nursing

Yes

Obstetrics and gynaecology
No

Oral health

No

Palliative care

No

Perioperative care

No

Physiotherapy

No

Pregnancy and childbirth

No

Public health (including social determinants of health)

No

Rehabilitation

No

Respiratory disorders

No

Service delivery

No

Skin disorders

No

Social care

No

Surgery

No

Tropical Medicine

No

Urological

No

Wounds, injuries and accidents

No

Violence and abuse

No

30.Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.

Chinese-Simplified
English

There is an English language summary.

31.* Country.

Select the country in which the review is being carried out. For multi-national collaborations select all the countries involved.

Australia

32.Other registration details.

Name any other organisation where the systematic review title or protocol is registered (e.g. Campbell, or

The Joanna Briggs Institute) together with any unique identification number assigned by them. If extracted
data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

33.Reference and/or URL for published protocol.

If the protocol for this review is published provide details (authors, title and journal details, preferably in Vancouver format)

Add web link to the published protocol.

Or, upload your published protocol here in pdf format. Note that the upload will be publicly accessible.

No I do not make this file publicly available until the review is complete

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

34.Dissemination plans.

Do you intend to publish the review on completion?

Yes

Give brief details of plans for communicating review findings.?

35.Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords help PROSPERO users find your review (keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Family caregiver; informal caregiver; dementia; Alzheimer's disease; experience; feelings; perception; emotion; care needs; expectation; Chinese; China; qualitative systematic review

36.Details of any existing review of the same topic by the same authors.

If you are registering an update of an existing review give details of the earlier versions and include a full bibliographic reference, if available.

37.* Current review status.

Update review status when the review is completed and when it is published. New registrations must be ongoing.
Please provide anticipated publication date

Review_Ongoing

38.Any additional information.

Provide any other information relevant to the registration of this review.

39. Details of final report/publication(s) or preprints if available.

Leave empty until publication details are available OR you have a link to a preprint. List authors, title and journal details preferably in Vancouver format.

Appendix II: Searched databases

Following the search strategies, six English databases and four Chinese databases are used for searching qualitative studies or mixed-methods studies with qualitative content regarding Chinese caregivers' experiences in the care of family members living with dementia. The searched results of each database are presented in the column.

CINAHL

#	Search terms	Results
S1	MH "family caregiver*" OR MH "home caregiver*" OR MH "informal caregiver*" OR MH "unpaid caregiver*" OR MH "unprofessional caregiver*" OR MH caring*	8,599
S2	TI (("family caregiver*" OR "home caregiver*" OR "informal caregiver*" OR "unpaid caregiver*" OR "unprofessional caregiver*" OR caring*)) OR AB (("family caregiver*" OR "home caregiver*" OR "informal caregiver*" OR "unpaid caregiver*" OR "unprofessional caregiver*" OR caring*))	48,680
S3	S1 OR S2	53,048
S4	MH experience* OR MH feeling* OR MH perception* OR MH emotion* OR MH challenge* OR MH "care need*" OR MH "care burden*"	64,052
S5	TI ((experience* OR feeling* OR perception* OR emotion* OR challenge* OR "care need*" OR "care burden*")) OR AB ((experience* OR feeling* OR perception* OR emotion* OR challenge* OR "care need*" OR "care burden*"))	735,438
S6	S4 OR S5	756,901
S7	MH dementia OR MH Alzheimer* OR MH "cognitive impairment"	68,001

S8	TI ((dementia OR Alzheimer* OR “cognitive impairment”)) OR AB ((dementia OR Alzheimer* OR “cognitive impairment”))	86,052
S9	S7 OR S8	101,335
S10	MH Chinese OR MH China	51,910
S11	TI ((Chinese OR China)) OR AB ((Chinese OR China))	74,768
S12	S10 OR S11	90,476
S13	S3 AND S6 AND S9 AND S12	62

EMcare

Number	Search terms	Results
1	caregiver/	51112
2	"care and caring"/	322
3	("family caregiver*" or "home caregiver*" or "informal caregiver*" or "unpaid caregiver*" or "unprofessional caregiver*" or caring*).tw,kw.	38100
4	1 or 2 or 3	78326
5	experience/	8098
6	emotion/	38407
7	perception/	81040
8	health care need/	19326
9	caregiver burden/	5300
10	(experience* or feeling* or perception* or emotion* or challenge* or "care need*" or "care burden*").tw,kw.	882224
11	5 or 6 or 7 or 8 or 9 or 10	911475
12	dementia/	50477

13	Alzheimer disease/	51678
14	cognitive defect/	51776
15	(dementia or Alzheimer* or "cognitive impairment").tw,kw.	100971
16	12 or 13 or 14 or 15	141005
17	China/	49464
18	Chinese/	17706
19	(China or Chinese).tw,kw.	102870
20	17 or 18 or 19	113279
21	4 and 11 and 16 and 20	145

MEDLINE

Number	Search Terms	Results
1	Caregivers/	36940
2	("family caregiver*" or "home caregiver*" or "informal caregiver*" or "unpaid caregiver*" or "unprofessional caregiver*" or caring*).tw,kf.	50695
3	1 or 2	77333
4	Emotions/	67287
5	Perception/	34814
6	(experience* or feeling* or perception* or emotion* or challenge* or "care need*" or "care burden*").tw,kf.	2078704
7	4 or 5 or 6	2105722
8	Dementia/	51310
9	Alzheimer Disease/	94237
10	Cognitive Dysfunction/	17923
11	(dementia or Alzheimer* or "cognitive impairment").tw,kf.	251128

12	8 or 9 or 10 or 11	273251
13	China/	177883
14	(Chinese or China).tw,kf.	377360
15	13 or 14	417736
16	3 and 7 and 12 and 15	107

ProQuest

#	Search Terms	Results
S1	noft((“family caregiver*” OR “home caregiver*” OR “informal caregiver*” OR “unpaid caregiver*” OR “unprofessional caregiver*” OR caring*)) AND noft((experience* OR feeling* OR perception* OR emotion* OR challenge* OR “care need*” OR “care burden*”)) AND noft((dementia OR Alzheimer* OR “cognitive impairment”)) AND noft((Chinese OR China))	99

Web of Science

#	Search Terms	Results
S1	TOPIC: ((“family caregiver*” OR “home caregiver*” OR “informal caregiver*” OR “unpaid caregiver*” OR “unprofessional caregiver*” OR caring*)) AND TOPIC: ((experience* OR feeling* OR perception* OR emotion* OR challenge* OR “care need*” OR “care burden*”)) AND TOPIC: ((dementia OR Alzheimer* OR “cognitive impairment”)) AND TOPIC: ((Chinese OR China))	165

Scopus

#	Search Terms	Results
S1	(TITLE-ABS-KEY (("family caregiver*" OR "home caregiver*" OR "informal caregiver*" OR "unpaid caregiver*" OR "unprofessional caregiver*" OR caring*)) AND TITLE-ABS-KEY ((experience* OR feeling* OR perception* OR emotion* OR challenge* OR "care need*" OR "care burden*")) AND TITLE-ABS-KEY ((dementia OR alzheimer* OR "cognitive impairment")) AND TITLE-ABS-KEY ((chinese OR china)))	100

CBM

#	**Search terms**	**Results**
S1	family caregiver OR home caregiver OR informal caregiver OR unpaid caregiver OR unprofessional caregiver OR caring	117993
S2	experience OR feeling OR perception OR emotion OR challenge OR care need OR care burden	2043505
S3	dementia OR Alzheimer OR cognitive impairment	355940
S4	Chinese OR China	6194737
S5	(Chinese OR China) AND (dementia OR Alzheimer OR cognitive impairment) AND (experience OR feeling OR perception OR emotion OR challenge OR care need OR care burden) AND (family caregiver OR home	208

	caregiver OR informal caregiver OR unpaid caregiver OR unprofessional caregiver OR caring)	

Wanfang Data

#	Search Terms	Results
S1	TOPIC:(family caregiver or home caregiver or informal caregiver or unpaid caregiver or caring)*TOPIC:(experience or feeling or perception or emotion or challenge or care need or care burden)*TOPIC:(dementia or Alzheimer or cognitive impairment)*TOPIC:(Chinese or China)	170

CNKI

#	Search Terms	Results
S1	检索条件：（（（（旧版主题＝中英文扩展(family caregiver) 或者 keyword=family caregiver 或者 title=family caregiver 或者 abstract=family caregiver) 或者 （旧版主题＝中英文扩展(home caregiver) 或者 keyword=home caregiver 或者 title=home caregiver 或者 abstract=home caregiver)）或者（（旧版主题＝中英文扩展(informal caregiver) 或者 keyword=informal caregiver 或者 title=informal caregiver 或者 abstract=informal caregiver) 或者 （旧版主题＝中英文扩展(unpaid caregiver) 或者 keyword=unpaid caregiver 或者 title=unpaid caregiver 或者 abstract=unpaid caregiver)））或者 （（关键词＝中英文扩展	106

	(unprofessional caregiver) 或者 keyword=unprofessional caregiver) 或者 (关键词=中英文扩展(caring) 或者 keyword=caring))) 并且 (((((旧版主题=中英文扩展(experience) 或者 keyword=experience 或者 title=experience 或者 abstract=experience) 或者 (旧版主题=中英文扩展(feeling) 或者 keyword=feeling 或者 title=feeling 或者 abstract=feeling)) 或者 ((旧版主题=中英文扩展(perception) 或者 keyword=perception 或者 title=perception 或者 abstract=perception) 或者 (旧版主题=中英文扩展(emotion) 或者 keyword=emotion 或者 title=emotion 或者 abstract=emotion))) 或者 ((关键词=中英文扩展(challenge) 或者 keyword=challenge) 或者 (关键词=中英文扩展(care need) 或者 keyword=care need))) 或者 (旧版主题=中英文扩展(care burden) 或者 keyword=care burden 或者 title=care burden 或者 abstract=care burden)) 并且 (((旧版主题=中英文扩展(dementia) 或者 keyword=dementia 或者 title=dementia 或者 abstract=dementia) 或者 (旧版主题=中英文扩展(Alzheimer disease) 或者 keyword=Alzheimer disease 或者 title=Alzheimer disease 或者 abstract=Alzheimer disease)) 或者 (旧版主题=中英文扩展(cognitive impairment) 或者 keyword=cognitive impairment 或者 title=cognitive impairment 或者 abstract=cognitive impairment)) 并且 ((旧版主题=中英文扩展(Chinese) 或者 keyword=Chinese 或者 title=Chinese 或者 abstract=Chinese) 或者 (旧版主题=中英文扩展(China) 或者 keyword=China 或者 title=China 或者 abstract=China))	

Weipu

#	Search Terms	Results
S1	((((((((文摘=family caregiver OR 文摘=home caregiver) OR 文摘=informal caregiver) OR 文摘=unpaid caregiver) OR 文摘=unprofessional caregiver) OR 文摘=caring) AND ((((((文摘=experience OR 文摘=feeling) OR 文摘=perception) OR 文摘=emotion) OR 文摘=challenge) OR 文摘=care need) OR 文摘=care burden)) AND ((文摘=dementia OR 文摘=Alzheimer) OR 文摘=cognitive impairment)) AND (文摘=Chinese OR 文摘=China))	84

Appendix III List of excluded study

	Excluded studies	Reasons for exclusion
1	Mackenzie, A. E., & Holroyd, E. E. (1996). An exploration of the carers' perceptions of caregiving and caring responsibilities in Chinese families. International Journal of Nursing Studies, 33(1), 1-12. doi:10.1016/0020-7489(95)00066-6	1) the congruity between the philosophical perspective and the research methodology stated unclear, 2) not meet the congruity between the research methodology and the representation analysis of data; 3) the researcher's cultural and theoretical orientation stated not clear; 4) not meet the influence of the relationship between the researcher the study participants

Appendix IV QARI Data Extraction of Included Studies—Phase A Study Description

No.	Author (Year)	Methodology	Method	Phenomena of interest	Setting	Geographical	Cultural	Participants	Data analysis	Authors conclusion	Reviewers' Comments
Greater China (Mainland)											
G1	Chen, Shen, Yang, Chen, & Sun. (2020)	Qualitative study	Semi-structured face-to-face interview	To develop the sources of management burden of family caregivers living with dementia, and to seek solutions for supporting caregivers	Home care	China, Hang Zhou	Chinese cultural background	12 caregivers (3 daughters, 4 husbands, 3 sons and 2 wives)	Colaizzi's 7-step approach	After Identifying the source of management burden and seeking manage strategies can improve the quality of life for care recipients and their caregivers	It demonstrates the sources of management burden of family caregivers' and raise awareness of taking steps for improving quality of life
G2	Yang, et al. (2020)	Mix-methods study	semi-structured interview	To identify the influence of social support perceptions between cares and people with dementia	Home care, community	China, Chongqing	Chinese background	30 participants (12 family caregivers, 12 people with dementia and 6 community family physicians)	Content analysis	It is important to perform social support for people with mild dementia in China. Also, there is an urgent need of intervention and evaluations for meeting patients' and carers' needs	It shows that there is a need of perceived social support for people with dementia and their cares and imply that informing interventions for satisfising carers' needs are important

G3	Zhang, Zhang, & Hockley （2020）	Interpretative phenomenological analysis Qualitative study	Sei-structured interview	To explore the coping strategies for caregivers in care of family members living with dementia	Home care	China, Shandong	Chinese background	14 caregivers	Smith's six step of Interpretative phenomenological analysis	The filial piety has a significance effect on caring people living with dementia, and the coping strategies have been explored	It identified the coping strategies of caring people with dementia under the social context with Chinese culture
G4	Zhang, Clarke, & Rhynas. (2020)	Interpretative phenomenological analysis Qualitative study	In-depth semi-structured individual interview	To examine the challenges and tensions of taking care of people with dementia from family caregivers' perceptions	Home care	China, Shandong	Chinese background	24 participants (14 unrelated family caregivers, and 10 people living with dementia)	Smith's six step of Interpretative phenomenological analysis	There is a need of providing of public services, social support, and reducing stigma in order to improve the quality of long-term care for people living with dementia	The tensions and challenged of taking of people with dementia have been identified

G5	Zhang, Clarke, & Rhynas. (2019)	Thematic analysis Qualitative study	Semi-structured interview	To examine the experience of family caregivers in care of people with dementia from Chinese perceptions	Home care	China, Shandong	Chinese background	24 participants	Thematic analysis	The experiences of caring people with dementia including social isolation, care burden, and lacking support	It develops the experience of caring for family members living with dementia form caregivers' view, who hold Chinese culture background
G6	Zhang, Clarke & Rhynas. (2018)	Interpretative phenomenological analysis Qualitative study	semi-structured individual interview	To develop the understanding of filial piety of carers and their family members living with dementia	Home care	China, Shandong	Chinese background	24 participants (10 people living with dementia and 14 family caregivers)	Smith's six steps of Interpretative phenomenological analysis (IPA)	Different participants with different experiences have different viewpoints of understanding of filial piety, which have influence on caring people with dementia. Thus, there is a need of effective family care model	It presents participants' perceptions of filial piety and indication of developing family care model in the future

G7	Dai, Mao, Wu, Mei, Levkoff, & Wang. (2015)	Grounded theory Qualitative study	Semi-structured interview	To develop Chinese family caregivers' feelings and emotions of caring people with Alzheimer's disease	Home care	China, Wuhan Beijing	Chinese cultural background	46 family caregivers (7 adult children, 38 spouses, and 1 sibling)	Descriptive and thematic analyses	Improvement of supporting formal service is necessary for reducing family caregivers' burden. Also, reducing stigma of Alzheimer's disease can have positive effect on taking care of people with dementia	It shows that caregivers' care needs and implies that reducing stigma of dementia can promote both family caregivers and care recipients' quality of lives
G8	Sun, & Hu. (2015)	Phenomenological method Qualitative study	Semi-structured in-depth interview	To develop caregivers' positive experiences of post-traumatic growth	Home care Community	China, Wuhan	Chinese Culture background	6 caregivers (4 daughters, 1 spouse, and 1 sibling)	Colaizzi's 7-step approach	The positive experiences of caring for dementia people have been identified in this research and it has an implication of improving their quality of lives	It shows that there are positive experiences of caring people with dementia and it is worth to be explored among health professional's working
G9	Sun. (2014)	Lazarus and Folkman's stress process theory Qualitative study	Semi-structured face-to-face interview	Investigating family caregivers' caring stress and the strategies for coping	Home setting	China, Shanghai	Chinese Culture background	18 family caregivers (8 wives, 6 husbands, 3 daughters, and 1	Thematic analysis	Family caregivers' caring stress have been recognised, and it is necessary to reduce the stigma and enhance the public service	It presents family caregivers' stress and imply the coping strategy

								daughter-in-law)		for meeting their needs	
G 10	Wang, Xiao, He, & De Bellis. (2014)	Double hermeneutic approach informed by Giddens' Structuration Theory	Semi-structured in-depth interview	To develop the challenges and influenced factors of taking care of people with dementia for caregivers	Home care	China,	Chinese Culture background	23 caregivers	Based on Gidden's four levels of understanding of how social structures enable and inhibit people actions	Lacking public health service support has a negative influence on the qualities of caring people with dementia for family caregivers	It identifies the way of improving dementia care and explores family caregivers' challenge of taking care of people with dementia
G 11	Xiao, Wang, He, De Bellis, Verbeeck, & Kyriazopoulos. (2014)	Giddens' Structuration theory Mix-methods study	Semi-structured questions Face-to-face interview, and telephone interview	To explore barrier pertinent and constructed enablers from family caregivers' perceptions via comparison	Home setting	China, Australia	Chinese Culture background, and Australia	148 caregivers (91 Chinese caregivers, and 57 Australia caregivers)	Based on Gidden's four levels of understanding of how social structures enable and inhibit	From comparison, it is concluded that there is a need of developing dementia care service, decreasing family caregivers' burden, and	It presents the implications of improving dementia care in the future and reducing burdens for meeting family caregivers' needs

				between Australia and China					people actions for qualitative data, and descriptive statistics for quantitative data.	informing support for them	
G 12	Liu, Shang, & Yue. (2012)	Phenomenological research method Qualitative study	Interview	Following the theory of Lazarus stress-coping model, explore the caring experiences of caring people with dementia from spouses' viewpoint	Home care	China, Beijing	Chinese background	15 caregivers (8 females, and 7 males)	Phenomenological analysis	It is necessary to provide effective interventions for spouses whose family members living with dementia in order to enhance them health status	It explains the reasons of arising negative feelings, and decreasing physical health for caregivers and guide the strategies for releasing stress

G 13	Zhang, Yang, Wang, & Li. (2008)	Qualitative study	Semi-structured interview	To examine the family caregivers' feelings and emotions of taking care of people with dementia	Home care	China, Beijing	Chinese culture background	10 family caregivers (5 spouses, 3 daughters, and 2 sons)	Colaizzi's 7-step approach	The family caregivers have been influenced on filial piety with Chinese culture background, and changed social structure	The Chinese family caregivers' feelings have been identified
Greater China (Taiwan)											
G 14	Yen, (2018)	Qualitative study	In-depth interview	To develop how the models of transformative learning influence on family caregivers while taking care of people with dementia	Home setting	China, Taiwan	Chinese culture background	18 participants	Thematic analysis	Many positive changes have been investigated via this research while implementing the models of transformative learning	It assists family caregivers to transfer negative feelings to positive feelings, and guide policymakers and health professionals to consider their feelings comprehensively
Greater China (Hong Kong)											
G 15	Yiu, Zang, & Chau (2020)	The methodological framework proposed by Lincoln and Guba	Semi-structured face-to-face Interview	To examine the barriers and facilitators for family caregivers while use the service caring for	Communities	China, Hong Kong	Chinese culture background	15 family caregivers (8 adult children caregivers, 6 spouse caregivers; 1	Thematic analysis	There is a need of improving dementia care service from various directions in order to benefit people with	It identifies the barriers, and addresses family caregivers' needs while taking care of people with dementia

		Qualitative study		people with dementia				family relative)		dementia and their family caregivers	
G 16	Yiu, Zang, Chew, & Chau (2020)	The methodological framework proposed by Lincoln and Guba Qualitative study	Semi-structured interview	To investigate the influence of Confucianism on caregiving for people with dementia form family caregivers' perceptions	communities	China, Hong Kong	Chinese culture background	15 family caregivers	Thematic analysis	It implies that dementia care service for family caregivers should be improved in the future in order to improve family caregivers' conditions	It identifies how Confucianism influence on family caregivers in the care of people with dementia and make the implications for the area of clinical practical in the future
G 17	Pang, & Lee. (2019)	Qualitative descriptive approach	Face-to-face, in-depth interview	To explore the positive aspects of taking care of family members living with young-onset dementia for caregivers	Home Care, Community centre	China, Hong Kong	Chinese background	6 caregivers (3 husbands, and 3 wives)	Qualitative content analysis	The experiences of spouses of people with dementia have been investigated and the young-onset dementia can also have negative effects on family caregivers. Interventions should be taken step	It shows the experiences of spouses of people with young-onset dementia and provide information regarding enhancement of family-centred interventions

G 18	Cheng, Mak, Lau, Ng, & Lam. (2016)	Qualitative study	Interview	To examine the positive aspects of taking care of family member living with dementia for their caregivers	Home care	China, Hong Kong	Chinese cultural background	57 caregivers (2 husbands, 2 sons, 8 wives, 42 daughters, 1 son-in-law, 1 daughter-in-law, and 1 nephew)	Thematic analyses	The identified positive emotions of family caregivers in care of people with dementia can increase their motivation for caring and reduce negative outcomes	It develops family caregivers' emotions from positive aspects and promotes advantage gaining
G 19	Au, Shardlo, Teng, Tsien, & Chan (2013)	Qualitative study	Semi-structured Interview design	To explore the coping strategies and help-seeking behaviours for caregivers in care of people with dementia	Home care	China, Hong Kong	Chinese cultural background	11 caregivers (2 wives, 2 husbands 2 daughters-in-law, 4 daughters, and 1 son)	Systematically analyses	Providing and integrating information, instrumental resources and primary care service regarding dementia care is crucial for caregivers living in community	Demonstrate the coping strategies and the helping behaviours that caregivers need
G 20	Chan, Ng, Mok, C. C. M., Wong, Pang, & Chiu. (2010)	Phenomenology approach Qualitative study	Focus group interview	To determine family caregivers' feelings, experiences and care needs in the care of	Home care	China, Hong Kong	Chinese cultural background	27 caregivers (10 care recipients' spouses, and 17 care recipients' children)	Colaizzi's 7-step approach	Family caregivers are lacking formal service regarding dementia care, and it is important to identify their difficulties and give them support	It identifies family caregivers' living experience with people with dementia and their care needs

				people with dementia							
G 21	Petrus, & Wing-Chung. (2008)	Exploratory, qualitative study	Semi-structured, in-depth interview	To develop caregivers' experience of coping with family member living with dementia and investigate the clinical trend	Home setting	China, Hong Kong	Chinese culture background	6 participants (3 husbands and 3 wives)	Unclear	Identify family caregivers' care needs of taking care of people with Alzheimer's disease, and there is a need of reducing care burdens for family caregivers	It develops family caregivers' care needs of taking care of people with Alzheimer's disease, and provides suggestion for policy maker
No.	**Author (Year)**	**Methodology**	**Method**	**Phenomena of interest**	**Setting**	**Geographical**	**Cultural**	**Participants**	**Data analysis**	**Authors conclusion**	**Reviewers' Comments**
Chinese diaspora (Chinese American)											
D1	Liu, Lou, Wu, & Mui. (2020)	Hybrid grounded theory model Qualitative study	Semi-structured face-to-face interview	Under the migration and sociocultural background, to explore the family caregivers' challenge and experiences of caring people living with dementia	Home care	United State, New York	Chinese American cross-cultural background Immigration from China (mainland, Hong Kong, and Taiwan)	27 caregivers (14 adult children caregivers; 12 spouse caregivers; 1 sibling)	Three-step hybrid model	The themes that found in the study demonstrate caregivers' care needs and experiences, and it has an implication of practice in the future	It shows caregivers' resilience and implicates the health professionals how to improve quality of health in the community

D2	Lun (2019)	Qualitative study	In-depth Interview	To develop Chinese American caregivers' perceptions and care needs of caring for family member with dementia	Home care	United States, New York	Chinese American cross-cultural background (Immigration from China)	4 caregivers (2 spouses, and 2 daughters)	Content analysis	Reflecting caregivers' feelings and increasing understanding on caregivers' stresses. Also, the results have a better implication for health workers and community nurses	It achieves the objectives of this study and demonstrates family caregivers' perceptions and give health professionals good implications
D3	Sun, Mutlu, & Coon. (2014)	Qualitative study	Focus group discussion	Identify the service barries from the Chinese American family caregivers' and professional' perspectives	Home care	United States, Phoenix	Chinese American background (Immigration from Mainland of China, Hongkong, and Taiwan)	6 professionals and 6 caregivers (2 wives, 1 husband, 2 daughters, and 1 daughter-in-law)	Content analysis	The service barriers have been identified from family caregivers' perceptions and there is a need for establishing effective services for meeting the group of people needs	It shows the service barriers existing in the group of population with dementia and their family caregivers

D4	Zhan, (2004)	Grounded theory method Qualitative study	In-depth interview	To develop Chinese-American caregivers' experiences of taking care of family member living with dementia	Home setting	United Stated,	Chinese American cross-cultural background (Immigration from China)	4 care recipients and 4 caregivers (3 adult children caregivers, and 1 family relative)	Content analysis	Chinese American caregivers' feelings regarding caring of family members living with dementia have been investigated, and it is important to reduce stigma to understand them well	It presents Chinese American family caregivers' emotions and care needs of caring people with dementia
Chinese diaspora (Chinese Canadian)											
D5	Koehn, McCleary, Garcia, Spence, Jarvis, & Drummond. (2012)	Critical-constructionist theory approach Qualitative study	Semi-structured interview	To develop what sorts of assistance for people with dementia to look for and how support them and caregivers in order to improve the quality of life	Home care	Canada, Greater Vancouver	Chinese Canadian cross-cultural background	10 people diagnosed Alzheimer's disease and related dementias (2 women and 8 men), and 11 caregivers (1 husband, 1 daughter, and 8 wives, and 1 son).	Thematic analyses	Exploring the Chinese Canadian family caregivers' care needs and imply that there is a need for exploring strategies in order to enhance the positive effects of non-pharmacological support	It explains the family caregivers', with Chinese Canadian cross-cultural background, experiences, and implies a future research regarding enhancement of their quality of life

D6	Ho, Friedland, Rappolt, & Noh. (2003)	Qualitative study	Semi-structured interview	To explore Chinese Canadian caregivers' stressed experiences regarding taking care of people with Alzheimer's disease	Home care	Canada, Toronto	Chinese Canadian cross-cultural background	12 Chinese-Canadian caregivers (8 daughters, 2 wives, 2 daughters-in-law)	Thematic analyses	It is crucial to provide formal and social service regarding dementia care for meeting family caregivers' needs with Chinese Canadian culture background	It demonstrates the psychological and social experiences of family caregivers with Chinese Canadian cultural background
Chinese diaspora (Chinese Australian)											
D7	Caldwell, Low, & Brodaty. (2014)	Qualitative study	Semi-structured interview design	To explore caregivers' experiences that make decision of placing family member living with dementia into nursing home	Home care and nursing home	Australia, Sydney	Chinese cultural background	27 family caregivers (20 Chinese, 7 English speaking background)	Thematic analyses	There is a need for providing home care service for caregivers in the care of people with dementia, and also the waiting time of placing people with dementia in nursing home should be decreased	Explore caregivers' emotions and experiences whenever transition of family members living with dementia from home to nursing residential

D8	Boughtwood, Adams, Shanley, Santalucia, & Kyriazopoulos. (2011)	Grounded theory Qualitative study	Focus group discussion	To identify caregivers' perceptions and experiences that take care of family members living with dementia	Home care	Australia	Culturally and linguistically diverse (CALD)	121 family carers (37 Chinese, 19 Arabic, 40 Italian, and 25 Spanish)	Thematic analyses	It is important to increase awareness for health professionals and clinicals in order to provide helping service for family caregivers of people with dementia	It identifies the Chinese family caregivers' experience of caring people with dementia in the CALD communities
D9	Tan, Fleming, & Ledwidge. (2001)	Qualitative study	Semi-structured telephone interview	To explore understanding and emotions of caregivers of taking care of family member living with dementia	Home care	Australia	Chinese-Australian culture background	20 caregivers (2 husbands, 1 son-in-law, 4 daughters-in-law, 9 daughters, and 4 wives)	Content analysis	The understanding and experiences of Chinese Australian family caregivers have been identified and synthesised recommendations for the future	It investigates Chinese Australian family caregivers' understanding and experiences regarding to take care of people with dementia
Chinese diaspora (Chinese Singaporean)											
D10	Koo, Pusey, & Keady. (2020)	Longitudinal qualitative study	Semi-structured biographical interview and digital photographs	To explore caregivers' experience of taking care of family member living with dementia	Home care	Singapore	Chinese Singaporean cross-cultural background	9 participants from 5 families (4 daughters, 2 sons, 2 grandsons, and 1 son-in-law)	Narrative analysis	The intergenerational family care of people with dementia can show a positive aspect in family bonding	Experiences of caring family members with dementia from different viewpoint have been explored

D 11	Tan, Ong, Ng, Ng, Wong, & Sim. (2020)	Thematic analysis Qualitative study	Interview	To explore the difficulties and barriers of making decision while caregivers taking care of people with dementia	Home care	Singapore	Chinese Singaporean cross-cultural background	14 participants (4 daughters, 7 sons, 2 spouses, and 1 family relative)	Thematic analysis	The family caregivers lack of knowledge and understanding of dementia and making decision, and there is a need of enhancing awareness of dementia in order to inform them making decision	It shows Chinese Singaporean family caregivers' barriers of making decision, the findings imply that raising awareness of dementia can help them to inform decision in the future
D 12	Chan, Phang, Glass, & Lim. (2019)	Descriptive phenomenological approach Qualitative study	Semi-structured face-to-face interview	To explore the Asian family caregivers' experiences of caring of people with dementia	Home care	Singapore	Chinese, Malay, Indian	16 family caregivers (2 wives, 9 daughters, 3 sons and 2 family relatives)	Colaizzi's 7-step approach	Family caregivers' feelings are different at each stage while taking care of people with dementia. Also, it is crucial to provide information regarding dementia for family caregivers	It shows family caregivers' emotions and care needs from different stages and provide a recommendation for health professionals

D 13	Tuomola, Soon, Fisher, & Yap. (2016)	Interpretative phenomenological analysis Qualitative study	Semi-structured interview	To examine caregivers' experience of taking care of people with dementia and sense of self	Home care	Singapore	Chinese Culture background	6 family caregivers (6 wives)	Interpretative phenomenological analysis	The family caregivers' sense of self will be influenced by different lived experiences regarding supporting dementia care, and the findings imply that it also be influenced by Confucian values	It shows Chinese family caregivers' lived experience of caring people with dementia and their sense of themselves
D 14	Vainganka ret al. (2013)	Thematic analysis Qualitative study	Focus group discussion, semi-structured interview	To develop the informal family caregivers' experiences, challenges and care needs of caring people with dementia	Home care	Singapore	Chinese, Malay, Indian	63 caregivers (37 children, 13 spouses, 13 siblings or grandchildren, or sister/daughter-in-law)	Thematic analysis	The family caregivers experience difficulties and challenges in the care of people with dementia, and there is high demand of supporting of dementia care service, emotion and education	It shows family caregivers' challenges that they are facing, and the findings guide that their care needs

D 15	Netto, Jenny, & Philip. (2009)	Grounded theory Qualitative study	Semi-structured, face-to-face, In-depth interview	To identify family caregivers' gained experiences and feelings in the care of people with dementia	Home care	Singapore	Chinese background	12 participants (8 daughters, 1 spouse, 2 sons, and 1 niece)	Coding paradigm and comparisons	Facilitating the gained experiences and designing dementia activities can be benefit for family caregivers in care of people with dementia	The family caregivers' gained experiences of caring people with dementia have been investigated

Note: G= studies from Greater China studies; D= studies from Chinese diaspora

Appendix V-a QARI-B Extraction of findings from included studies (Greater China)

Note: C= Children caregiver; S=Spouse caregiver; P=Parent caregiver

(Greater China: Mainland)

G1. Chen, Y., Shen, Q., Yang, L., Chen, C., & Sun, J. (2020). 阿尔茨海默病主要家庭照顾者管理负担来源及其管理策略的质性研究 [Sources of management burden and solutions among primary family caregivers of the Alzheimer's Disease patient: A qualitative study]. 中国全科医学 [Chinese General Practice], 23(17), 2192-2197.

Findings	Illustration from study	Evidence
Lack of knowledge about how to manage dementia-related symptoms (缺乏专业照顾知识) (C)	"I asked him not go outside, but he insisted in going out. [N1]" (p.2193)" (N1："我叫他不要出去，他一定要出去。)	Unequivocal
The loss of paid work hours due to caregiver's role (失去工作时间) (C)	"As he always got lost, I have to cut my work hours, look for him and care for him [N9]" (p.2194) (N9："我每天为了他赶回去，工作现在根本没办法干，没上班……没办法管的，因为他老是会丢失"。)	Unequivocal
Physical burden （身体性负担） (C)	"I myself have physical problems as well. I had surgery on my right kidney prostate. However, only two of us live at home and I have to provide her everyday life care. I could not get any help from others even when I feel unwell. [N3]" (p.2194) (N3："我呢，自己也有病，我刚刚做了一个手术，右肾给摘除了，前列腺也做了手术了。我自己身体也不好，但家里就是两个人，一天到晚地吃喝都是我的事。我自己有时候不舒服什么，得不到一点点帮助"。)	Unequivocal
Acceptance of caregiver's role （照顾者理性接受） (C)	"She is sick, but we are healthy, so we should understand her, don't we? [N2]" (p.2194) (N2："因为她病了，对不对啊，她病了，所以我们是健康人，我们要理解她，对不对"。)	Unequivocal

Tolerating care recipients’ BPSD （主动迁就） (C)	“When he gets angry, you can't stand it, you can't stand it. The only way to deal with this situation is to tolerate him. You can't fight with him. [N1]” (p.2195) (N1:“他发起脾气来的时候，你受不了，真受不了。只有……只有忍着，没办法，你不能和他争”。)	Unequivocal
Using technology to enhance care (downloaded GPS) （积极应对） (S)	“She always walks outside, and can’t come back. Then, I downloaded the GPS app on my smartphone and check her location regularly. If she goes far away from home, I will go find her back. [N12]” (p.2195) (N12:“她老是在外面走，完了又回不来，后来啊，我下了个定位APP，这样每天看看手机，看看她在哪里，走得远了，我就去把她找回来”。)	Unequivocal

G2. Yang, S., Zhang, Y., Xie, S., Chen, Y., Jiang, D., Luo, Y., . . . Yang, B. (2020). Predictors of perceived social support for patients with dementia: A mixed-methods study. *Clinical Interventions in Aging*, 15, 595-607. doi:10.2147/CIA.S249223

Findings	Illustration from study	Evidence
Time-consuming in social support for the person with dementia (not mention)	“The more time and efforts you spend on the patient, the better life he(she) gets [FC04]”. (p.600)	Unequivocal
Non-personalised support for caregivers (C)	“My mom [with dementia] became more and more reluctant to talk when she knew her situation … suddenly showed to be unhappy or upsetting … I don’t know, what good coping strategies can take me to escape from this problem [FC05]” (p.601)	Credible

G3. Zhang, X. X., Zhang, X. B., & Hockley, J. (2020). A qualitative study of family caregivers' coping strategies of looking after people with dementia in China. *Journal of Research in Nursing,* 1-14. doi:10.1177/1744987120925128

Findings	Illustration from study	Evidence
Caregiver’s self-care (C)	“.. . I enrolled in several training courses, such as a dancing course, fitness course and music course. I want to keep living a joyful life while I look after my mother ... [FC6, Mei]” (p.6)	Unequivocal
Using various strategies in feeding (C)	“I try to persuade her to eat more by using the same method to feed a toddler ... I use many ways to persuade her ... [FC6, Mei]” (P.6)	Unequivocal
Filial piety is a motive for the caregiver (C)	“.. . I will get older later, looking after my mum is not only my responsibility, but I am also a role model for my son. If I am not filial to my mum, my son might not be filial to me. [FC5, Ling]” (p.9)	Unequivocal

G4. Zhang, X. B., Clarke, C. L., & Rhynas, S. J. (2020). Tensions in dementia care in China: An interpretative phenomenological study from Shandong province. *International Journal of Older People Nursing*, 15(1). doi:10.1111/opn.12291

Findings	Illustration from study	Evidence
Expectations for home care services (C)	“I hope there will be some staff (health professionals) who can do home visits.… However, there are no such services that exist now. I hope that we will have some social support in the future. [Guang, caring for his mother]” (p.5)	Unequivocal
Lack of social care service for families (C)	“What community will help? There are staff (social worker) who work for the government, I have never heard them helping with these kinds of things. [Xue, caring for her father]” (p.5)	Unequivocal
Feeling hopelessness (stress related) (S)	“I sometimes cry during the night because of the stress, sometimes I wish he could die soon [Wan, caring for her husband]” (p.5)	Unequivocal
Suicidal thoughts (financial burden related) (P)	“I cannot let them [two sons with dementia] be starving once I am here. I am just thinking, I will kill them and myself together if one day I can do nothing … I have no money to send them to hospital, we only can live like this, helpless [Gui, caring for her two sons with dementia]” (p.6)	Unequivocal
Financial strain (C)	“Now he often visits the doctor or stays at the hospital, the money is not enough for us. [Xue, caring for her father]” (p.6)	Unequivocal

Lack of qualified nursing home care (C)	“I have looked at a few private care homes, however the conditions of these care institutions are too bad. Once I step inside, there is an extremely bad odour. There are also no facilities, along with other problems. [Xue, caring for her father]” (p.7)	Unequivocal
Public stigma towards dementia from the public (C)	“I wouldn't take her to the group support services (public place), because she would shout or speak nonsense. [Yan, caring for her mother]” (p.7)	Unequivocal

G5. Zhang, X. B., Clarke, C. L., & Rhynas, S. J. (2019). A thematic analysis of Chinese people with dementia and family caregivers' experiences of home care in China. *Dementia-International Journal of Social Research and Practice*, 1-15. doi:10.1177/1471301219861466

Findings	Illustration from study	Evidence
Environmental barriers in accessing dementia care services (no lifts) (C)	“Most buildings (where her mother lives) have many stories but have no lift. It is difficult to go down and up. This problem is difficult to deal with’ (Mei, caring for her mother)” (p.7)	Unequivocal
Like a prison at home for caregivers (C)	“I had to give it up, had to give it up. It is not possible for me to go out for a job. You know, I need to cook two meals or three meals, do this and do that for her [mother] . I cannot go anywhere; I can only stay at home. (Yu, caring for his mother)” (p.8)	Unequivocal
Negative impacts of caregiver’s role on physical health (S)	“I rush to go shopping, rush for everything, this causes stress. I feel very tired since he got ill, my health is going down because of this ... This has resulted in a deterioration in my health.’ (Liu, caring for her husband)” (p.8)	Unequivocal
Caring at home is a responsibility (C)	“erm ... I have to do it (looking after his mother), what can I do? She is my mother, who would look after if I don’t look after her? It is not possible to give the responsibility to others.’ (Shou, caring for his mother)” (p.9)	Unequivocal
Enhanced family relationships (C)	“Despite her not knowing anything, she is the connection among the big family. My sisters and my brother often come to visit her, we can	Unequivocal

	see each other, and this is a connection between us.' (Yan, caring for her father)" (p.10)	
Poor image of nursing homes (C)	"... care home is worse ... if we send her there, she would die soon. In care homes, there is nobody to look after her ... Therefore, I don't want to send her to a care home or psychiatric hospital...' (Yan, caring for her mother)" (p.10)	Unequivocal

G6. Zhang, X. B., Clarke, C. L., & Rhynas, S. J. (2018). What is the meaning of filial piety for people with dementia and their family caregivers in China under the current social transitions? An interpretative phenomenological analysis. *Dementia-International Journal of Social Research and Practice, 18*(7-8), 2620-2634. doi:10.1177/1471301217753775

Findings	Illustration from study	Evidence
Providing physical care is a way of paying filial piety (C)	"I think if someone can (physically) look after their parents it would be Xiao [filial piety]. We can't value Xiao by money, it isn't Xiao if one only gives lots of money to parents. It is better to look after parents, take care of them in daily life. Err... we must consider the situation of everybody. For my situation, I can look after my father which is Xiao. [FC2, Xue]" (p. 2626)	Unequivocal
Sacrificing social activities to fulfil filial piety (C)	"Because being filial is a priority in Chinese traditional culture. . . The only thing is that I had to sacrifice many social activities and things which I am enjoying. [FC 6, Mei]" (p.2627)	Unequivocal
Giving up job in order to fulfil caregiver's responsibility (C)	"In fact, I have given up a lot. . . I gave up my job as well. [FC13, Yan]" (p.2627)	Unequivocal
Giving up marriage in order to fulfil caregiver's responsibility (C)	"In fact, I have given up a lot. . . I gave up marriage ... [FC13, Yan]" (p.2627)	Unequivocal

G7. Dai, B., Mao, Z., Wu, B., Mei, Y. J., Levkoff, S., & Wang, H. (2015). Family caregiver's perception of Alzheimer's disease and caregiving in Chinese culture. *Social Work in Public Health, 30*(2), 185-196. doi:10.1080/19371918.2014.969858

Findings	Illustration from study	Evidence
Viewing cognitive decline as part of normal aging (C)	"Sometimes, his behaviours look funny .... We think it will be okay ... There is no need to seek health care or other kinds of help, it is a natural process and nobody can help. [a caregiver and son of an individual with AD]" (p.190)	Unequivocal
Worrying about care arrangement for the care recipient (S)	"Every day I stay with her and care for her .... There will be some day in the future when she completely depends on others' caregiving. When that day comes, perhaps my body also has some problems. What can we do then? [a caregiver and spouse of individuals with AD]" (p.192)	Unequivocal
Desire for formal services (S)	"I wish we can find an appropriate elderly home where we can live in together. [a caregiver and spouse of individuals with AD]" (p.192)	Unequivocal

G8. Sun, Q., & Hu, H. (2015). 老年痴呆患者照顾者创伤后成长的质性研究 [A qualitative study on the growth of caregivers in the care of people with dementia after trauma]. 现代临床护理[*Modern Clinical Nursing*] (8), 42-45,46. doi:10.3969/j.issn.1671-8283.2015.08.012

Findings	Illustration from study	Evidence
Perceived care responsibilities for family members （对赡养或照顾责任的认知） (C)	"It is a burden to us, and there is no quality for our life. However, I must take good care of her no matter how tired it is [P1]." (p.43) (Ｐ１：“这个病对我们确实是个负担，（生活）完全没质量，但是我肯定要照护好她，不管有多累”。)	Unequivocal
Positive temperament change during caregiving journey （对自己性格脾气的改变） (C)	"At the beginning, we felt anxious and irritable, but now we changed our temperament as anxiety or irritation mood cannot solve problem [P1]." (p.44)	Credible

	(Ｐ１：“疾病开始时，我们感觉焦虑与烦躁，现在我们脾气都变好了，焦虑与烦躁解决不了问题”。)	
Perceived responsibility for family members （对赡养或照顾责任的认知） (C) 39	“When my son came back from school, he saw my nurse assistance and me bathing my mother. He asked me, why don't you let the nurse assistance do this. I said, would you let an outsider bath you? I taught him not to shirk his responsibility first [P3].” (p.44) (Ｐ３：“那次儿子从学校回来，看到我和护工给母亲洗澡, 他问我，你为何不让护工洗，我说，你愿意让外人帮你洗澡吗？我教育他首先不能推卸自己应该承担的责任”。)	Unequivocal

G9. Sun, F. (2014). Caregiving stress and coping: A thematic analysis of Chinese family caregivers of persons with dementia. *Dementia, 13*(6), 803-818. doi:10.1177/1471301213485593

Findings	Illustration from study	Evidence
Feeling hopelessness (dementia prognostics related) (S)	“I cried, but not in front of her, and I think she could no longer be cured, and what a life ahead of me … [One caregiving husband in case 16]” (p.808)	Unequivocal
Emotional burden (BPSD related) (C)	“My mom is very mobile, and she often says she is going to die and does not want to live, which drives me crazy [A daughter caregiver in case 5]” (p.808)	Unequivocal
Sacrifices of retirement life to caregiver’s role for a parent (C)	“We [she and her husband] could have had enjoyed our retirement life. We could travel around if not for my mother [One daughter who recently retired in case 18].” (p.808)	Unequivocal
Discrimination towards dementia patients (S)	“… a societal problem when dementia patients face discrimination [A caregiving wife in case 2].” (p.810)	Unequivocal
Lack of supportive services related to the social welfare system (S)	“My husband’s employment was not in Shanghai, which made it very complicated for us to get reimbursed for his medical cost [A caregiving wife in case 1].” (p.810)	Unequivocal
Positive self-appraisal as a way to sustain care (S)	“My husband (CR) is doing better than other dementia patients in our neighbourhood. He looks clean and tidy. I did a very good job [A caregiving wife in case 1].” (p.810)	Unequivocal

Relaxation activities (C)	“I am staying at home playing computer games, reading books and newspapers, and sometimes we play cards [A daughter in case 18]” (p.812)	Unequivocal

G10. Wang, J., Xiao, L. D., He, G.-P., & De Bellis, A. (2014). Family caregiver challenges in dementia care in a country with undeveloped dementia services. *Journal of Advanced Nursing, 70*(6), 1369-1380. doi:10.1111/jan.12299

Findings	Illustration from study	Evidence
Lack of knowledge about how to manage care recipients’ BPSD at home (S)	“He ate food from the garbage, cursed and hit others. We have no choice but to lock him at home. He urinated and defecated everywhere in the house: on the television, sofa, everywhere [P18]” (p.1373)	Unequivocal
Physical burden on caregivers (S)	“He has been bed-ridden since he suffered a hip fracture 2 years ago. I am too old to turn him on my own. He has large bedsores and I try my best to change the dressings for him. I am unable to clean him properly each time he has bowel movements; I have to wait for my daughter to come and help me. She has a job and family and is not available for most of the day [P6].” (p.1375)	Unequivocal
Caregivers’ financial strain in dementia treatment in hospital (S)	“During that time (when he was hospitalised), he took so many medications that I could not remember the names of all the medications. [After discharge] We couldn’t afford all of the medications and decided to reduce to the essential ones to treat only his diabetes [P5].” (p.1375)	Unequivocal
Lack of helpful instructions for dementia treatment (S)	“It was impossible for me to get a doctor’s appointment for my wife. Even though we had an appointment, the doctor was too busy to give us helpful instructions besides some lab tests and prescriptions [P7].” (p.1375)	Unequivocal
Lack of dementia-friendly outpatient clinics services (S)	“It was impossible for me to get a doctor’s appointment for my wife at that hospital due to the long waiting list. [P7].” (p.1375)	Unequivocal

Expectations to support from Community Care Centre (S)	"The Community Care Centre should provide homecare as an important part of aged care. Medical treatment for people with dementia should be an important part of homecare [P8]." (p.1376)	Unequivocal
Televised health education programs as a learning resource (S)	"I learned a lot from TV programs, which is a good way for older people to learn as we can't see written materials clearly or don't have the ability to read [P3]." (p.1376)	Unequivocal

G11. Xiao, L. D., Wang, J., He, G. P., De Bellis, A., Verbeeck, J., & Kyriazopoulos, H. (2014). Family caregiver challenges in dementia care in Australia and China: a critical perspective. *BMC Geriatrics*, 14. doi:10.1186/1471-2318-14-6

Findings	Illustration from study	Evidence
Unmet information needs in dementia care (S)	"I heard about dementia from other people. It is a kind of loss of one's ability to understand. It is abnormal and it is not treatable … We see doctors and nurses in the Community Care Centre, but have not received any information about dementia [ChiP3]." (p.8)	Unequivocal
Shared care by family members (S)	"I am not doing these [care activities] as I am too old … My daughter and sons wash her if she is wet. She has faecal and urinary incontinence. My daughter has lived with us in order to care for her. My son also comes to help every day. His house is nearby [ChiP4]." (p.10)	Unequivocal
Expectations for training program in dementia care (S)	"I wish that nurses from the Community Care Centre would offer training programs on dementia care [ChiP16]." (p. 10)	Unequivocal
Expectations for welfare system support (S)	"I hope dementia treatment can be covered by the medical insurance [ChiP16]" (p.10)	Unequivocal
Expectations for respite care and community aged care (S)	"I wish that the Community Care Centre would provide a day care service for people with dementia, just like the child care centre in the community. This would allow me to leave the house to do the things I have to do [ChiP20]." (p.10)	Unequivocal

G12. Liu, Q., Shang, S., & Yue, P. (2012). 基于 Lazarus 压力-应对模式的居家痴呆患者配偶的照顾体验研究 [Caring experiences of spousal caregivers of home dementia patients under Lazarus Stress-coping Model]. 中国全科医学 [Chinese General Practice], 15(5). Retrieved from https://www.ixueshu.com/document/73db30d2f0e9cc0c318947a18e7f9386.html

Findings	Illustration from study	Evidence
Anxiety (BPSD related) （烦躁） (S)	"It is irritable that she is worrying about someone will take away her things. She hides many stuffs so that others could not find them. For example, she hided the kettle and cookies in the fridge. I am very upset [caregiver A]." (p.499) (如 A 先生: "有时候也很烦躁，怕别人拿她东西，她的东西都藏起来，哪也找不到。比如把暖壶放到冰箱里了，干的饼干也放冰箱里。我心里很烦躁。")	Unequivocal
Lack of time for undertaking own hobbies （没有时间从事自己爱好和活动） (S)	"I was interested in playing, singing, and Peking Opera; however, I cannot join in any of them now. Over time, I do not have time and energy to do my hobbies [caregiver C]." (P.499) (如 C 先生:"（过去）我非常爱玩，唱歌啊，唱京剧啊，现在任何事情都不能参与。慢慢心情发生了变化，没有时间、也没有精力去做其他的娱乐活动了。"	Unequivocal
Loneliness and hopelessness due to the loss of communication ability in the care recipient （孤独） (S)	"She doesn't understand many things. There's no way to communicate. There's no discussion. It's very hard for you to explain clearly to her, so I feel (pause) very lonely, sometimes I just feel helpless [caregiver C]." (p.499) (如 C 先生：" 很多事情她都不理解，没有方法交流，谈不上商量，你给她说清楚就很费劲，所以我感觉（ 停顿） 很孤独，有时候简直就是觉得孤立无援。")	Unequivocal
Emotional stress (caused by poor health in caregivers) （无助感） (S)	"My own health is very poor. He can't take care of me, but I have to take care of him. It's very uncomfortable, and I can't leave this role. [caregiver B]." (p. 499)	Unequivocal

	(如B女士:“ 我身体也是多病，他不能照顾我，我还得照顾他，特别难受，走也走不掉。)	
Caregivers’ worries and fears （担心、害怕） (S)	“He is just like a stranger to me. I’m afraid he will forget me eventually [caregiver F].” (p.499) (如 F 女士: “就跟个陌生人似得。真怕慢慢得就把我忘了。”)	Unequivocal
Lack of dementia care knowledge and skills （缺乏疾病知识和照顾技能） (S)	“It was difficult to take care of her at that time (when she was first diagnosed with dementia), I didn’t know the disease very well, and I was reluctant to accept it. [caregiver A] . ” (p.499) (如 A 先生：“感觉那个时候（ 刚诊断痴呆的时候）照顾比较困难，对这个病也不是很了解，不大愿意接受得这个病。”)	Unequivocal
Lack of support for caregivers (缺乏对照护者的支持) (S)	“I can’t give up my caregiver’s role. It’s hard to handle the care if I give up. I’m the only person she can rely on, it’s really difficult [caregiver A].” (p.499) (A 先生：“ 我不能垮了，我一垮了就不好办了，我是她惟一可以依靠的，真的很困难”。)	Unequivocal
Beliefs and hopes as motives in long-term caring （信念和希望也有助于照顾者坚持长期照顾） (S)	“My belief is that if you give your best, there will be a return. As long as you take good care of him, you can extend his life. [A wife caregiver G].” (p.500) (我的信念就是你全力付出，必有回报，你只要照顾的好，就能够延续他的生命)	Unequivocal

G13. Zhang, R., Yang, Z., Wang, L., & Li, Z. (2008). 老年痴呆患者照顾者照顾感受的质性研究. [The qualitative research of caring experiences of caregivers of elderly dementia patients]. Chinese Journal of Nursing [中华护理杂志], 43(7).

Findings	Illustration from study	Evidence
Decline in caregivers’ physical conditions （照顾事务繁重，身体受累） (C)	“The most obvious feeling is too tired. Tired all day, but can't sleep well at night. It is exhausted [Caregiver Y].” (p.590) (Y：“最突出的一个感受就是太累了， 身体上受不了。白天累了一天吧， 晚上还睡不好。特别累。”)	Unequivocal

Caregiving around the clock （个人时间受限） (C)	“I always feel that my mother can't do without me. If I leave, I am afraid that she will get lost. If I couldn't find her, what should I do if she caught a cold in the cold season? Just never let go [Caregiver S].” (p.590) （S：“我老是觉得我妈离不开我， 我要是一走了，也怕她丢了， 也不放心。 你说我要是找不到她了，大冷天的冻着她怎么办？就是没有一时能放下心来。”）	Credible
Feeling of being isolated with little contact with friends and colleagues （个人事业、家庭朋友的失去） (C)	“I have very little contact with friends and colleagues, and I don’t have time. I think I am really isolated in the society. [Caregiver Y].” (p.590) (Y: “我现在和朋友、同事什么的都很少来往，没有时间。我觉得我确实是跟社会有脱离”)	Unequivocal
Sacrifices of retirement life to caregiver’s role for a partner （美好生活计划的破灭） (S)	“I originally planned to travel with my wife after retirement. However, I cannot go anywhere even though I have a healthy body, and the economy allows it. Our generation has been working hard when we were young. Now that the conditions are good, it's time to enjoy the happiness, but my wife has become like this [Caregiver X].” (p.590) (X：“我本来计划着退休了和老伴一起出去旅游。现在身体允许，经济也允许，可是哪里都去不了了，有时候也是觉得挺遗憾的。我们这一辈人，年轻的时候一直艰苦过来了，现在条件好了，该享清福了，可是老伴又成了这样。”)	Unequivocal
Learning to improve dementia care （学习增进对痴呆相关行为的理解） (S)	“At the beginning I could not understand her behaviours. Later, I learned about this disease so I could treat her patiently. [Caregiver G].” (p.590) （G: “我刚开始真的想像不到这种病会是这个样子，她的行为我都不能理解。后来认识了这个病，才能耐着性子去对待她。”）	Unequivocal
Interdependence between the caregivers and the care recipients （相互依赖）	“My mother is my spiritual support. You see, I am always so nervous now, but I feel very energetic as my mother is supporting me. I think	Unequivocal

(C)	I will definitely get down if mum goes away one day. [Caregiver L].” (p.590) （L: “我妈妈就是我的精神支柱，你看我现在老是这么紧张，但我觉得特别有劲。是我妈妈在支持着我，要是有一天老妈妈没了，我想我肯定就趴下了。”）	

(Greater China: Taiwan)

G14. Yen, C.-M. (2018). Models of transformative learning among family caregivers of people with dementia: positive experience approaches. Jiaoyu Kexue Yanjiu Qikan, 63(2), 187-218. doi:10.6209/JORIES.201806_63(2).0008

Findings	Illustration from study	Evidence
Psychological burdens (long-term caregiver’s role related) (S)	“The stresses are both mental and physical. The past 10 years have been the hardest time of the entire caring process. He has been completely dependent on us. (A3, age, 71 years)” (p.196)	Unequivocal
Tension and chaos in the family (delayed dementia diagnosis related) (C)	“Initially, it was a disaster, filled with chaos. It was difficult to confirm his diagnosis a decade previously. (B3, age, 40 years)” (p.197)	Unequivocal
Physical burden (lack of sleep) (C)	“I feel very tired. I used to be able to work for long hours and sleep for 4 hours on average. However, now I feel sleepy at erratic hours. (A2, age 37 years)” (p.198)	Unequivocal
Being optimistic towards dementia care (C)	“I used to be timid. However, I like to seek solutions when I encounter problems. I like asking for help and can find the resources. I encourage myself to stay active. Otherwise, I think I would remain a pessimist. (A1, age, 55 years)” (p.200)	Unequivocal
Family support for the primary caregiver (C)	“We brothers are very close to one another. Mom lives with me; we have regular family gatherings in my house. My brothers are medical doctors. They take care of mom as well. I think a family like ours is not common. I care for mom without any complaints. The five of us take care of her as much as we can. (B2, 68 years)” (p.201)	Unequivocal

Religion as a motive for caregivers (C)	“Religion provides me access to a place where I can talk about my feelings when I am depressed. “Empathy” is what I must learn and apply in the caregiving process. If I treat mom with empathy, I will not argue about little things with everyone or have negative thoughts. (A1, age, 55 years)” (p.203)	Unequivocal

(Great China: Hong Kong)

G15. Yiu, H. C., Zang, Y., & Chau, J. P. C. (2020). Barriers and facilitators in the use of formal dementia care for dementia sufferers: A qualitative study with Chinese family caregivers in Hong Kong. Geriatric nursing, 1-6. doi:10.1016/j.gerinurse.2020.06.018

Findings	Illustration from study	Evidence
Insufficient governmental allowance for caregivers (S)	“The price is out of my capability... [We] need to have more allowance! We have a dementia caregivers association. We have meetings with the government every year. We have asked the government to give us more money many times … but are still unsuccessful... [Caregiver 6, Age 78, Husband]” (p.3)	Unequivocal
Distance of day care centre as a barrier (C)	“I bring my mother here. There is no centre in the district where I live. This one is so far [from home]. It is quite hard and a big burden on me to get here. We cannot take the bus as it would take more than one hour. If my mother needs to suffer through more than an hour of transportation just to get here, how can she concentrate on the training afterward [Caregiver 11, Age 50, Daughter]” (p.3)	Unequivocal
The limited opening hours of day care centre as a barrier (C)	“The day centre is a problem for me. The centre closes so early.. .I am still at work so I cannot take her home. I need to find someone else to bring her home [Caregiver 3, Age 52, Daughter]” (p.3)	Unequivocal
Lack of post-diagnosis support from health professionals (S)	“The doctors in the hospital do not tell you which organisation provides such services... When we find out that our family members have dementia, we feel too upset … We do not have resources and know nothing. [Someone] needs to tell us where to find the helpful organisations [Caregiver 7, Age 65, Wife]” (p.3)	Unequivocal

Participating in dementia training (S)	“We come here to have training every Saturday... If the centre is very far from my home, I may also bring her there. [Caregiver 6, Age 78, Husband]” (p.4)	Unequivocal
Utilization good day care services (C) 88	“Basically, the people [service providers] know how to communicate with the people with dementia.. .Also, they have clearly received good training in this [Caregiver 1, Age 46, Daughter]” (p.4)	Unequivocal

G16. Yiu, H. C., Zang, Y., Chew, J. H. S., & Chau, J. P. C. (2020). The influence of Confucianism on the perceptions and process of caring among family caregivers of persons with dementia: A qualitative study. Journal of transcultural nursing: official journal of the Transcultural Nursing Society. doi:10.1177/1043659620905891

Findings	Illustration from study	Evidence
Learning to be a caregiver via education and training (C)	“I have taken some courses. I learned what dementia is . . . I have learned how to handle the missing of the dementia persons” (Caregiver 4, Son, Age: 30). (p.4)	Unequivocal
Being positive to caregiver role (C)	“My mother has this disease; you need to accept it. I need to try my best to care her and find social services to help her. She can meet more people when she comes to the centre. ” (Family Caregiver 9, Daughter, Age: 60) (p.5)	Unequivocal
Improved relationship with the care recipients (C)	“The gathering time of my mother and I become more and more. Both of us are changing. We can find a suitable way of communication. Our relationship is better and more harmony than before.” (Family Caregiver 11, Daughter, Age: 50). (p.5)	Unequivocal

G17. Pang, R. C., & Lee, D. T. (2019). Finding positives in caregiving: The unique experiences of Chinese spousal caregivers of persons with young-onset dementia. Dementia, 18(5), 1615-1628. doi:10.1177/1471301217724026

Findings	Illustration from study	Evidence
Choosing not to seek help (face-saving related in young-onset dementia) (S)	"We [my husband and I] felt that we were being stigmatized by others [our friends and neighbours]. For example, one of our neighbours always asked him: 'Who is she [caregiver]?' My husband replied: 'She is my mom.' Then, he [the neighbour] laughed. I felt embarrassed...It's a 'loss of face' to have a husband with dementia, especially when he is so young. I will not seek help from others because they will look down on me. I felt inferior to others. (Caregiver 006)" (p.1620)	Unequivocal
Perceived losses (young-onset dementia related) (S)	"I have never imagined that I would "lose" my wife at such a young age. I thought we would support each other for lifelong (Caregiver 003)" (p.1621)	Unequivocal
Positive appraisal of caregiver role (S)	"To me, taking care of my wife is definitely meaningful because I can bring hope to her and build up her confidence to live with dementia.. .Even my siblings appreciated what I have done to my wife. I'm confident to say that I have made a right decision [take up the caregiving role]. (Caregiver 004)" (p.1622)	Unequivocal

G18. Cheng, S.-T., Mak, E. P. M., Lau, R. W. L., Ng, N. S. S., & Lam, L. C. W. (2016). Voices of Alzheimer caregivers on positive aspects of caregiving. The Gerontologist, 56(3), 451-460. doi:10.1093/geront/gnu118

Findings	Illustration from study	Evidence
Reduced self-stigma via education and training (C)	"Before I learned about the disease, I suffered a lot and could not adjust to [the caregiving role]. Now I feel less embarrassed and much more comfortable doing it. Initially, I wasn't used to the looks people gave me when I took mom out. Now, I feel more relaxed and less stressed. (Daughter caring for her mother)." (p.453)	Unequivocal

A sense of purpose impacts on caregiving motivation (C)	“After I understood that her behaviours were due to the disease, I would put more effort into finding ways to help her … give her better quality of life. I won’t be ‘pig-headed.’ (Daughter caregiver).” (p.454)	Unequivocal
Increased patience and tolerance towards dementia-related symptoms (C)	“Just now, I chatted with mom on the phone. Aside from asking me the same questions over and over again, the sequence of her expressions or the sequence of happenings were all mixed up. I needed to have a lot of patience to guide her to describe the whole thing. (Daughter caregiver).” (p.455)	Unequivocal
Positive thoughts on caregiver role (C)	“Why not think about it more positively then? As long as I can give mom some instant happiness, like letting her eat what she likes to and giving her compliments generously, we’ll find happiness again! (Daughter caregiver).” (p.456)	Unequivocal

G19. Au, A., Shardlow, S. M., Teng, Y. U. E., Tsien, T., & Chan, C. (2013). Coping strategies and social support-seeking behaviour among Chinese caring for older people with dementia. Ageing and Society, 33(8), 1422-1441. doi:10.1017/S0144686X12000724

Findings	Illustration from study	Evidence
Support from friends (C)	“I’m lucky to have some best friends who can help me at those most critical moments. They all understand, about one taking care of several... (Shan)” (p.1430)	Unequivocal
Post-diagnosis online information seeking (C)	“.. .when the doctor first said that she [CR] had got dementia; we searched for information on the internet. ... other people talking about their cases, those about caregivers – there are a lot of information online. (Hong)” (p.1429)	Unequivocal
Lack of family support (stereotyped as strong and tough) (S)	“I can’t tell anyone about my strain and burden. It is useless to tell other people, even my daughter, my relatives, . . . I am afraid they will look down on me [stereotyped as strong and tough]. (Mr Ching)” (p.1433)	Unequivocal

G20. Chan, W. C., Ng, C., Mok, C. C. M., Wong, F. L. F., Pang, S. L., & Chiu, H. K. F. (2010). Lived experience of caregivers of persons with dementia in Hong Kong: a qualitative study. East Asian Archives of Psychiatry, 20(4), 163-168. Retrieved from http://ezproxy.flinders.edu.au/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=104978986&site=ehost-live

Findings	Illustration from study	Evidence
Lack of knowledge about dementia-related symptoms (C)	"I do not think my father is having a psychiatric problem. All he has is '善忘症' [Jian Wang Zheng]. He does not beat up anybody. He is not aggressive at all. I believe persons with mental illnesses should be irritable and act aggressively [A daughter caregiver]." (p.165)	Unequivocal
Psychological stress related to caregivers' obligation for spouse (S)	"I think it's too cruel to send my wife to a nursing home. I feel guilty towards her and blame myself for having such thoughts. [A husband caregiver]." (p.165)	Unequivocal
Inability to cope with care recipient's BPSD (S)	"My husband often scolded me fiercely with foul language. One morning, he suddenly sprinkled water at me for no reason [A wife caregiver]." (p165)	Unequivocal
Caregiving strain resulted from lack of family support (C)	"It was extremely difficult at the very beginning. I always felt lonely, as no one in my family was willing to give me a hand. My husband scolded my mother … oh no, not only my husband … but also everybody at home. All of them hated her [A daughter caregiver]." (p.166)	Credible

G21. Petrus, N. G., & Wing-Chung, H. O. (2008). Experience in coping with Alzheimer's disease at home: a study of Chinese family caregivers. Journal of Social Work in Disability & Rehabilitation, 4(4), 1-14. doi:10.1300/J198v04n04_01

Findings	Illustration from study	Evidence
Frustration (BPSD related) (S)	"I feel very frustrated when he suddenly acts like this ...He sometimes behaves in a way that I cannot really understand. When he needs to go to the toilet, he cannot say so and doesn't know where to	Unequivocal

	go. I need to pay more attention to him outside as he will urinate anywhere. (Edmond's wife)" (p.7)	
Time-dependence burden (S)	"In the past, I would go for picnics or travel overseas with my friends quite often ...I would also attend meditation courses . . . However, I cannot do these things anymore now ...I have to prepare meals [for my husband] and feed him every day and I am so busy with the housework ... How can I have time for my social activities? (Benjamin's wife)" (p.8)	Unequivocal
A high cost on dementia-related treatment and care services (S)	"As she needs to see the doctor very often, I have to spend extra money, usually several hundred dollars, for her medication. I also have to spend money to travel with her by taxi to see the psychiatrist every month...The major expense is the fee for her day care program, which costs me eight hundred dollars per month. (Alice's husband)" (p.10)	Unequivocal
Inability to meet physical demands for caregivers (S)	"I am also old...I have to bring him out everywhere, however, I do not have the energy to support him when walking...After these years of caregiving, my shoulder and hands have become paralysed and are painful. My doctor told me that the problem is caused by the disorientation of joints of my neck as a result of supporting him ...I therefore have to see a specialist and receive physiotherapy. (Benjamin's wife)" (p.11)	Unequivocal

Appendix V-b QARI-B Extraction of findings from included studies (Chinese diaspora)

Note: C= Children caregiver; S=Spouse caregiver; R=family Relative caregiver

(Chinese American)

D1. Liu, J., Lou, Y., Wu, B., & Mui, A. C. Y. S. (2020). "I've been always strong to conquer any suffering:" challenges and resilience of Chinese American dementia caregivers in a life course perspective. Aging and Mental Health, 1-9. doi:10.1080/13607863.2020.1793900

Findings	Illustration from study	Evidence
Difficulty in identifying bilingual professionals (C)	"It is very troublesome to take her to see a doctor, so I want to find a bilingual doctor who could make house calls. It is very difficult to find one. (66 years old, daughter who provided care for her mother)" (p.5)	Unequivocal
Reluctance to gaining service due to dementia stigma (C)	"Her children [caregiver's siblings-in-law] don't want to apply for any benefits for her [care receiver] because they don't want others to know their mom has dementia. They are concerned that no one will marry to their kids [care receivers' grandchildren] because the disease may be inherited. (55 years old, daughter-in-law who provided care for her mother-in-law)" (P.5)	Unequivocal
Virtual caregiver support group as a source of learning (S)	"We [Chinese American dementia caregivers] have a WeChat [a Chinese messaging and social media app] group and support each other. (76 years old, wife who provided care for her husband)" (P.5)	Unequivocal
Language barrier in applying for services (S)	"My English is not good. It is a huge burden for me to fill out forms or pay for bills. (71 years old, wife who provided care for her husband)" (P.5)	Unequivocal
Sacrifice retirement life to caregiver role (S)	"I used to think that my post-retirement life would be beautiful, such as traveling and volunteering. Now I can't do anything. (80 years old, husband who provided care for his wife)" (P.5)	Unequivocal
Reduced traditional family support from children (caused by culture adaptation) (S)	"My son-in-law is an ABC [America-born Chinese]. He doesn't like living with older people, especially after my husband has dementia. (76 years old, wife who provided care for her husband)" (P.5)	Unequivocal

Reciprocity as a motive for caregiver (S)	“Our relationship [giver and receiver] has been good. … Sometimes he makes me very angry, but when I think he used to take care of me, I forgive him. (71 years old, wife who provided care for her husband)” (P.5)	Unequivocal
Lack of knowledge about communication with the care recipient (S)	“When I didn’t understand dementia, I didn’t know how to communicate with her, especially in my first year of dementia care. (89 years old, husband who provided care for his wife)” (P.5)	Unequivocal
Emotional stress (caused by care arrangement) (S)	“What worries me most is that I may die before her. If that happens, who will take care of her? My children will have a huge burden. (86 years old, husband who provided care for his wife)” (P.5)	Unequivocal
Physical exhaustion (C)	“Tired, very tired. … I can’t sleep well. … Very stressful. (58 years old, daughter who provided care for her father)” (p.5)	Unequivocal
Self-care by physical exercise (S)	“I insist on exercising at home every day. Before he [care receiver] wakes up, I have some time to do it. If my health is poor, how can I take care of him? (71 years old, wife who provided care for her husband)” (P.5)	Unequivocal

D2. Lun, M. W. A. (2019). Chinese American family caregivers' perception of program use and caregiver stress. Journal of Social Service Research, 45(5), 750-758. doi:10.1080/01488376.2018.1514679

Findings	Illustration from study	Evidence
Emotional burden attributed to caregiver’s poor health (S)	“Of course, I felt more irritated … blamed myself for not having enough strength to take care of my wife … If my health is better, I can take a better care of her. Whenever I feel weak, I feel more irritated and mad. (A husband caregiver)” (p.754)	Unequivocal
Insufficient information about dementia care service (C)	“I am curious of what resources are out there … any support groups, group programs, government programs that I can look into … A lot of this we do not know much … resources. (A daughter caregiver)” (p. 755)	Unequivocal

D3. Sun, F., Mutlu, A., & Coon, D. (2014). Service barriers faced by Chinese American families with a dementia relative: Perspectives from family caregivers and service professionals. Clinical Gerontologist, 37(2), 120-138. doi:10.1080/07317115.2013.868848

Findings	Illustration from study	Evidence
Lack of bilingual professional caregivers to relieve family caregivers (C)	"We wanted to look for a home taker [formal caregiver] for my mother, but we could not find bilingual and skilled formal caretakers (A daughter caregiver)" (p.129)	Unequivocal
Lack of ethno-specific nursing homes (Chinese culture related) (C)	"We wanted to look for a home taker [formal caregiver] for my mother, but there are few residential care facilities for Chinese patients. (A daughter caregiver)" (p.129)	Unequivocal
Lack of information about dementia care services (S)	"I don't know whether there are any supportive services available in the community and nobody told us. (A spousal caregiver)" (p.129)	Unequivocal
Desire for respite care service (C)	"We had to rely on my family members to take care of my mother when I had to go out of town. If there were respite care services that we could trust, I would definitely use them (A daughter caregiver)." (p.129)	Unequivocal
Self- stigma towards dementia (S)	"My daughter and son-in-law used to take us out to eat , but ever since my husband had dementia [at very early stage], neither my husband nor I are willing to eat outside (A spouse caregiver)." (130)	Unequivocal

D4. Zhan, L. (2004). Caring for family members with Alzheimer's Disease: Perspectives from Chinese American caregivers. Journal of gerontological nursing, 30(8), 19-29. doi:10.3928/0098-9134-20040801-06

Findings	Illustration from study	Evidence
Lack of knowledge about dementia (C)	"I did not know she had AD. We only knew when the doctor told us that my mom needed help." (p.23)	Unequivocal

Lack of knowledge about initial dementia signs (C)	"I did not know why my mom could not find the place where we usually met for lunch. " (p.24)	Unequivocal
Public stigma towards dementia (C)	"They [people in China town] made you feel so ashamed that you are afraid of telling others about you loved one's illness. It is just so hard ." (p.24)	Unequivocal
Lack of post-diagnosis support from health professionals (C)	"I knew it was a bad diagnosis. I was very upset that they [health providers] did not provide more support and information. You cannot just tell the diagnosis and walk away." (p.25)	Unequivocal
Inability to speak English as a barrier to accessing nursing home (C)	"I was looking for a long-term care facility for my mom. Staff at the facility told me that they would not take my mom because she did not speak English." (p.25)	Unequivocal
Using ethno-specific dementia care service (C)	"The home health agency in Chinatown really helped me a lot; otherwise, I did not know from whom, where, and how I could get help." (p. 25)	Unequivocal
Learning to be a caregiver via caregiver support group (C)	"I joined the AD support group. I got information and learned about how to find resources, how to handle the patient but not feel frustrated and not to irritate patients because you are stressed or burned out, and how to take care of ourselves. " (p.25)	Unequivocal
The need to provide dementia care education for the Chinese community (C)	"We need to educate the Chinese community about AD so that people can try to help one another rather than walk away when we need support." (p.26)	Unequivocal
Sacrificing personal life to caregiver role (C)	"Even though I sacrificed my personal life, I had no regret for caring for my mom." (p.26)	Unequivocal

(Chinese Canadian)

D5. Koehn, S., McCleary, L., Garcia, L., Spence, M., Jarvis, P., & Drummond, N. (2012). Understanding Chinese–Canadian pathways to a diagnosis of dementia through a critical-constructionist lens. Journal of Aging Studies, 26(1), 44-54. doi:10.1016/j.jaging.2011.07.002

Findings	Illustration from study	Evidence
Emotional burden attributed to untreated BPSD (S)	“I noticed not only memory impairment, but also [his] personality changed. He became suspicious and [had] delusion[s], he told me our house has another person. Actually, only I and he lived here. Sometime, he suspected I have a boyfriend and gossiped to his friends (Judy).” (p.48)	Unequivocal
Using online information about dementia online (S)	“I read Readers’ Digest, it has a topic related with dementia and it provides the website. I kicked into their Internet and requested for further information. It sent me the information. It introduced ten signs and symptoms of dementia, I checked and my husband has eight (Judy).” (p.48)	Unequivocal
Lack of information about social service (C)	“I did not know [about support services]. I don't know many people here. I did not come across these social services and their information before (Ping).” (p.50)	Unequivocal
Support from social workers (referral support service related) (C)	“It was after referral that the social worker contacted us themselves and told me that they have these services and visits that could help me to see if they could provide me with some information or limited services to help me to see how to take care of my mother together... [Now] there are people who could tell me because before I am totally blank with these concepts (Ping).” (p.50)	Unequivocal

D6. Ho, B., Friedland, J., Rappolt, S., & Noh, S. (2003). Caregiving for relatives with Alzheimer's disease: Feelings of Chinese-Canadian women. Journal of Aging Studies, 17(3), 301-321. doi:10.1016/S0890-4065%2803%2900028-8

Findings	Illustration from study	Evidence
Family relationship as a motive for caregivers (S)	“The responsibility is mine. I can take care of him like this only because I am his wife. The relationship between husband and wife is the most important. I am the closest to him; I ought to take care of him. (A wife caregiver)” (p.307)	Unequivocal

Filial piety as a motive for caregivers (C)	"I think the part of our Chinese culture, that one has to take care of and respect elderly people, is right. I think it really is culture... being filial to our parents is right; take care of them is what we ought to do. We ought to live with them and hope that we can give even more than what they are getting now. (A daughter caregiver)" (p.308)	Unequivocal
Lack of time to socialise with others (C)	"I do not have time to socialize with others. I want to socialize with other people, but now I cannot. I cannot do that because I do not have the time. (A daughter-in-law caregiver)" (p.310)	Unequivocal
Role conflict within a family (C)	"It has affected my relationship with my children to a certain extent, because I cannot spend time with them. It is the same if they come home. He [her father] will get agitated. (A daughter caregiver]" (p.310)	Unequivocal
Time-dependence burden (C)	"I should expand my social life outside … after she [her mother] got Alzheimer's disease, my life has been very limited. My life is limited to the home. I rarely interact with other people (A daughter caregiver)." (p. 311)	Unequivocal
Positive thoughts on caregiver's role (C)	"I often say that my mother is like my flower. If I cherish her well, I will be very happy. I have this feeling that I will be very happy if she is well because I have put in my effort. I do not mean that she has to give whatever back to me, the bottom line is that I did all that because I wanted her to be healthy. (A daughter caregiver)" (p.312)	Unequivocal
Family support for the primary caregiver (C)	"If my family did not support me like this, I would not be able to hang in for so long, I would have placed him [her father] in a nursing home a long time ago. (A daughter caregiver)" (p.313)	Unequivocal
Reduced burden by using government-subsidised home care programs (C)	"I am so thankful for the government; it has helped me a lot. He [the home care worker] helps him with the shower, and also does the house cleaning for us, so my burden is not as heavy. (One daughter caregiver)" (p.314)	Unequivocal
Supported from social workers (C)	"[The social workers] were supportive in a lot of things and have given me a lot of support. Although I was having a difficult time, having these people give me support for sure made me happier. (A daughter caregiver)" (p.314)	Unequivocal

(Chinese Australian)

D7. Caldwell, L., Low, L.-F., & Brodaty, H. (2014). Caregivers' experience of the decision-making process for placing a person with dementia into a nursing home: comparing caregivers from Chinese ethnic minority with those from English-speaking backgrounds. International Psychogeriatrics, 26(3), 413-424. doi:10.1017/S1041610213002020

Findings	Illustration from study	Evidence
Perceived dilemma when deciding to use nursing home (C)	“Late last year I decided to put my mum in the queue. But I actually don’t want her to go even if a position is available … but end up you know we say “Ok we put her on the queue.” Just in case … Because we understand she’s already 86, things may drop at any time. (CW2)” (p.417)	Unequivocal
Responsibility as a motive for home care (C)	“If I put my mum in the nursing home, I’m the bad guy … I fail my duty (CW5).” (P419)	Unequivocal
Negative thoughts about nursing home care (C)	“It’s just too early stage to take her to the nursing home. Reason being that one, going to nursing home is just like going to jail … (CW14)” (p.418)	Unequivocal

D8. Boughtwood, D. L., Adams, J., Shanley, C., Santalucia, Y., & Kyriazopoulos, H. (2011). Experiences and perceptions of culturally and linguistically diverse family carers of people with dementia. American Journal of Alzheimer's Disease and Other Dementias®, 26(4), 290-297. doi:10.1177/1533317511411908

Findings	Illustration from study	Evidence
Physical strain attributed to lack of suitable equipment at home (S)	“She is big and fat, I can’t lift her up. What I usually do is pull over all of the chairs we have. Then I gently put her onto the shortest chair, and from there, put her onto a higher chair, and then the highest chair to help get her up. My back becomes extremely sore after all that (Chinese family carer, husband)” (p.293)	Unequivocal
Inability to manage care recipient’s BPSD	“I can only look after him for two or three hours because after that, my father starts to look for my mother. He would ask me where my	Unequivocal

(C)	mother has gone to and say that he wants her back. He is used to my mother (Chinese family carer, son)" (p.294)	

D9. Tan, L., Fleming, A., & Ledwidge, H. (2001). The caregiving burden of relatives with dementia: experiences of Chinese-Australian families. Geriaction, 19(1), 10-16. Retrieved from https://search.informit.com.au/search;res=IELHEA;search=FTI=yes%20AND%20IS=1032-4410%20AND%20VRF=19%20AND%20IRF=1%20AND%20PY=2001%20AND%20PG=10

Findings	Illustration from study	Evidence
Disturbance in sleep due to BPSD (S)	"I now sleep in another room because he gets up so many times in the night. (Wife)" (p.11)	Unequivocal
Protective care for the care recipient with BPSD (S)	I have to make sure all the doors are locked and keep the keys on me or he would go out at night. (Wife)" (p.11)	Unequivocal
Shared caregiver responsibilities within the family (C)	"We like to keep everything within the family. We share our responsibilities and we do not like to "wash dirty linen in public." We must also keep our family honour and respect all elders. (Daughter)" (p.12)	Unequivocal
Inability to manage continence issues (C)	"He went to the toilet at night-time all the time and wet the floor and the toilet bowl. He was not incontinent but when he went into the toilet, his pants were partly wet already. (Daughter)" (p.12)	Unequivocal
Difficulty in managing care recipients' BPSD (C)	"She started having urinary incontinence. It was getting harder in looking after her. (Daughter-in-law)" (p.12)	Unequivocal
Inability to manage BPSD (S)	"He accuses me of stealing his things. But he hides them and forgets where he had put them. More and more challenges each day. (Wife)." (p.13)	Unequivocal
Family issues attributed to untreated BPSD (C)	"He always threw his tantrum and scolded my stepmother and my cousin's family. He insisted to cook for himself and always made a big mess. His temper was even worse and kicked my cousin out of his house. (Daughter)" (p.13)	Unequivocal

Family conflicts attributed to caregiver role (C)	"As I had to stay with her all the time, my husband and me had a lot of arguments. I treated my children badly because my temper was bad too. (Daughter-in-law)" (p.14)	Unequivocal
Psychological stress (BPSD related) (C)	"She [mother-in-law] scolded me nearly every day and I could not bear it any more. At first my husband could not understand and blamed it on me. I stayed away from home for a few weeks and I hoped the situation would get better. When I returned home, my mother-in-law has not changed. She still scolded me. (Daughter-in-law)" (p.13)	Unequivocal
Shared caregiver role with family members (C)	"For our Chinese culture, the children look after the parents when they are old. The brothers and sisters have very close relationship. We both love our dad very much and my sister and me ... share each other's burden..(Daughter)" (p.14)	Unequivocal
Support from children for the primary caregiver (S)	"All my children pay for everything their mother needs and they take turns to come here to look after her. They even pay for my holidays so that I can take a break. (Husband)" (p.14)	Unequivocal

(Chinese Singaporean)

D10. Koo, M. Y., Pusey, H., & Keady, J. (2020). 'I try my best ... I try to relieve the burden of my mum': a narrative analysis of the everyday care-giving experiences for five intergenerational Singapore-Chinese families where one member has dementia. Ageing and Society. doi:10.1017/S0144686X20000070

Findings	Illustration from study	Evidence
Peer support as a source of learning (C)	"I learnt a lot of information from the caregiver support group and when I returned home, I see how to handle things better. Recently I saw my mother's dental problem and I was able to know how to handle it from another caregiver. (Sixth interview)" (p.13)	Unequivocal
Family bond as a source of dementia care (C)	"All of them do appreciate what my youngest sister and I do for my mother and I would say, we are still a very close-knit family. We care for one another and if there is any problem in our midst, we would help	Unequivocal

	out in that sense. I think it has brought us closer. (Sixth interview)" (p.17)	

D11. Tan, L. L., Ong, P. S., Ng, L. L., Ng, W. F., Wong, H. K., & Sim, A. C. C. (2020). Decision-Making in dementia care: A qualitative study of Chinese family caregivers in Singapore. Annals Academy of Medicine Singapore, 49(4), 263-267. Retrieved from <Go to ISI>://WOS:000533623700011

Findings	Illustration from study	Evidence
Keeping the care recipients informed of dementia diagnosis (C)	"At least get her mentally prepared. At least she can face, we don't need to hide from her … so she will accept. At least prepare and accept the facts that there will be some difficulty in handling her living style here and there. (Caregiver 7)" (p.264)	Unequivocal
The need for dementia education for caregivers at the point of diagnosis (C)	"At the beginning, as soon as she is diagnosed with dementia, it's good to have a relatively good understanding of the condition as well as the kind of care giving that is necessary. (Caregiver 12)" (p.264)	Credible

D12. Chan, E. Y., Phang, K. N., Glass, G. F., & Lim, W. S. (2019). Crossing, trudging and settling: A phenomenological inquiry into lived experience of Asian family caregivers of older persons with dementia. Geriatric nursing 40(5). doi:10.1016/j.gerinurse.2019.03.015

Findings	Illustration from study	Evidence
Caregiving around the clock (C)	"Then after that when she [mother living with dementia]is resting, I have to run to the market come back and cook...school time I have to rush, send my son, then later fetch him.. It's like a daily job. (P4, daughter)" (p.504)	Unequivocal
Coping strategy for feeding (C)	"She (care recipient) said, 'No, no, no. she (domestic helper) wants to poison me cannot.' ...So, I take the same plate, I bring it to the kitchen. I don't let her see...So I just turn one round, I come back and	Unequivocal

	say, ‘I cook the rice for you...’ She said okay. Then she will finish her meal. (P10, daughter)” (p.505)	
Self-care by taking a break (C)	“If I need a break, I will go out for a walk or go out with my friends. I need the break, away from him and I think that helps. That's how I find my way to get along. (P3, son)” (p.505)	Unequivocal
Religious beliefs as motives for caregiving (R)	“I always believe as I'm a Christian, I believe that God will never put me in a position or give me responsibilities that I can never handle. (P8, niece)” (p.505)	Unequivocal
Positive attitude towards caregiver role (C)	“If he deteriorates and has to go to nursing home, we will accept it as it we know this is inevitable.. .When my father is still around, I show love to him. Even if he passes on the next day, I will not regret. (P13, daughter)” (p.506)	Unequivocal
Spirituality as a motive for caregiving (S)	“Every day, when I have finished my tasks, I must have quiet time for myself...I will use the time to pray. (P13, daughter)” (p.506)	Unequivocal

D13. Tuomola, J., Soon, J., Fisher, P., & Yap, P. (2016). Lived experience of caregivers of persons with dementia and the impact on their sense of self: A qualitative study in Singapore. Journal of Cross-Cultural Gerontology, 31(2), 157-172. doi:10.1007/s10823-016-9287-z

Findings	Illustration from study	Evidence
Emotional burden (multiple care responsibilities related) (S)	“I have to take care of myself, home, and children when they come every week, got to think of what meals to give them. There are a lot of things; I am like a house keeper. (P6).” (p.163)	Unequivocal
Physical burden (lack of sleep) (S)	“Not enough sleep every night. Most of the time [feeling] tired (P6).” (p.164)	Unequivocal
Emotional burden attributed to care recipients’ memory loss (S)	“Whatever I can tell him at night, I will talk [to] him, he is like before, he will [nods head]. But next morning it is gone. It is a complete wipe-out (P1).” (p.164)	Unequivocal

Acceptance of caregiver role (S)	"Just face it that he is like that, it does not affect me, I am ok. I understand that he is like that, not that he does it on purpose, that he cannot remember (P2)." (p.165)	Unequivocal
Obligation for the care recipient (S)	"What to do, that is your husband, you must take care of him (P4)" (p.163)	Unequivocal
Reciprocity as a motive for the caregiver role (S)	"So now, I have to do everything that he used to do for me, just like payback time (P1)" (p.166)	Unequivocal
Improved care through learning and positive self-appraisal (S)	"I have become more patient, [and] exercise more self-control, which I am still learning. I feel that [going] through a harder life tends to make you a better person. This is the hard way of learning about life (P5)" (p.163)	Unequivocal

D14. Vaingankar, J., Subramaniam, M., Picco, L., Eng, G., Shafie, S., Sambasivam, R., . . . Chong, S. (2013). Perceived unmet needs of informal caregivers of people with dementia in Singapore. International Psychogeriatrics, 25(10), 1605-1619. doi:10.1017/S1041610213001051

Findings	Illustration from study	Evidence
Need for respite care (C)	"I think caregivers recognize there's a need for, what they call respite care. They (should) take leave to care for themselves, take a break, short holiday or just rest. (P5FE002)" (p.1609)	Unequivocal
Emotional stress due to memory loss of care recipients (C)	"The fear of someone very dear to you will one day not recognize who you are, things that caregiver will encounter, mainly in the first stage . . . at that time we do not know how to handle it because we fear, we keep thinking, one day if my mom not recognize (us), how are we going to handle that part? (P5FE002)" (p.1608)	Unequivocal
Lack of post-diagnosis support from medical doctors (C)	"The problem lies with the doctor . . . they can't tell you exactly what to do. When I asked the doctor, he said "you need to notice yourself." He said that my mother's condition would get worse after six to nine months, but he did not tell me how to deal with it either. (P12SIC002)" (p.1609)	Unequivocal

The need for social support service (C)	"What type of services we need, like support centres for dementia or other types of care centres – who will be able to help us or give us counselling on how to handle this kind of emotional (problem). (P6FE002)" (p.1609)	Unequivocal
Emotional burden attributed to cost on dementia care (C)	"I have to work. My wife is not working, I have two children, so the only solution I have for my dad right now is nursing home or long-term stay. But they are expensive. (P6FE003)" (p.1610)	Unequivocal
Lack of appropriate facilities to care for people with sever BPSD (C)	"I had admitted him to a nursing home three days ago; yesterday they called me and said that they had to throw him out, because he was caught with problems. And he even molested the staff there, so they threw him back (to the hospital). (P6FE003)" (p.1610)	Unequivocal
Lack of dementia-friendly outpatient clinics services (C)	"It's always a very long waiting time, my dad cannot control his bowels and he got angry very fast . . . I tell them (clinic staff), please help me to let him go first . . . Then my dad starts to get angry, very angry and that's when everybody starts to look at us . . . when my dad finally threw a tantrum, then they let my dad go first.(P10FT001)" (p. 1610)	Unequivocal
Expectation for outpatient clinics to provide dementia-friendly services (C)	"I want a hospital to be more understanding for the dementia patient, reduce our waiting time. (P10FT001)"(p. 1610)	
Expectation of dementia care centre that includes education and training for caregivers (C)	"I wish there are particular care centres, 24 hours, specialized, those that (can also) train (family) for taking care of dementia patient. (P3FC003)" (p.1611)	Unequivocal

D15. Netto, N. R., Jenny, G. Y. N., & Philip, Y. L. K. (2009). Growing and gaining through caring for a loved one with dementia. Dementia, 8(2), 245-261. doi:10.1177/1471301209103269

Findings	Illustration from study	Evidence
Learning to be patient with the care recipient (C)	"Because of her, I train myself to be more patient. throughout the years, I think I have trained up myself to be more patient. But I think the patience level have to rise further in order to better deal with her. (Mrs J)" (p.250)	Unequivocal
Closeness between caregiver and care recipient enhanced dementia care (S)	"I'm drawn closer to him. There's that closeness causes I pay so much attention to him, I understand all his needs, so learning to love him would be better. (Mrs L)" (p.254)	Unequivocal
Improved family relationship via caregiver role (C)	"I think because of this caregiving experience, we have become closer. We realize that we treasure our loved ones more and we understand that unity is very important in the family when things happen like that. The bonding of the family, united as well as be each other's support. (Mrs H)" (p.254)	Unequivocal
Filial piety as a motive for caregivers (C)	"It's an enriching experience and a sense of duty – you bring me up, I look after you. It's my chance to do a good deed for her. (Mr E)" (p.255)	Unequivocal

Appendix VI-a Results of meta-synthesis (Greater China)

Findings	Categories	Synthesised findings
Loneliness and hopelessness due to the loss of communication ability in the care recipient (U)	Emotional burden	**Synthesised finding 1**: Multidimensional caregiver burdens
Tension and chaos in the family (delayed dementia diagnosis related) (U)		
Emotional burden (BPSD related) (U)		
Anxiety (BPSD related) (U)		
Feeling hopelessness (stress related) (U)		
Psychological stress related to caregiver obligation for spouse (U)		
Frustration (BPSD related) (U)		
Psychological burdens (long-term caregiver's role related) (U)		
Feeling hopelessness (dementia prognostics related) (U)		
Caregivers' worries and fears (U)		
Perceived losses (young-onset dementia related) (U)		
Worrying about care arrangement for the care recipient (U)		
Suicidal thoughts (financial burden related) (U)		
Emotional stress (caused by poor health in caregivers) (U)		
Inability to meet physical demands for caregivers (U)	Physical burden	
Decline in caregivers' physical conditions (U)		
Negative impacts of caregiver's role on physical health (U)		
Physical burden (U)		

Physical burden on caregivers (U)		
Physical burden (lack of sleep) (U)		
Like a prison at home for caregivers (U)	Time-dependence burden	
Lack of time for undertaking hobbies (U)		
Feeling of being isolated with little contact with friends and colleagues (U)		
Time-dependence burden (U)		
Caregiving around the clock (C)		
Time-consuming in social support for the person with dementia (U)		
A high cost on dementia-related treatment and care services (U)	Financial burden	
Caregivers' financial strain in dementia treatment in hospital (U)		
Financial strain (U)		
The loss of paid work hours due to caregiver's role sacrifices of jobs to caregiver's role (U)		
Discrimination towards dementia patients (U)	Dementia stigma	**Synthesised finding 2:** Barriers to dementia care
Public stigma towards dementia from the public (U)		
Choosing not to seek help (face-saving related in young-onset dementia) (U)		
Lack of post-diagnosis support from health professionals (U)	Lack of post-diagnosis support	
Lack of helpful instructions for dementia treatment (U)		
Unmet information needs in dementia care (U)		
Environmental barriers in accessing dementia care service (no lifts) (U)	Difficulties in accessing dementia care services	
Distance of day care centre as a barrier (U)		
The limited opening hours of day care centre as a barrier (U)		

Insufficient governmental allowance for caregivers (U)	Insufficient social support	
Lack of social care service for families (U)		
Lack of supportive services related to the social welfare system (U)		
Lack of support for caregivers (U)		
Non-personalised support for caregivers (C)		
Lack of qualified nursing home care (U)	Perceived poor care services	
Poor image of nursing homes (U)		
Lack of dementia-friendly outpatient clinics services (U)		
Acceptance of caregiver’s role (U)	Positive attitudes towards caregiving role	**Synthesised finding 3**: Positive coping strategies used by caregivers
Being optimistic towards dementia care (U)		
Being positive to caregiver role (U)		
Positive temperament change during caregiving journey (C)		
Positive thoughts on caregiver role (U)		
Positive appraisal of caregiver role (U)		
Positive self-appraisal as a way to sustain dementia caregiving (U)		
Using technology to enhance care (downloaded GPS) (U)	Using various self-identified strategies	
Tolerating care recipients’ BPSD (U)		
Increased patience and tolerance towards dementia-related symptoms (U)		
Using various strategies in feeding (U)		
Support from friends (U)		
Utilization of day care services (U)		
Relaxation activities (U)	Performing self-care	
Caregiver’s self-care (U)		

Filial piety is a motive for the caregiver (U)	Filial piety as a motive	**Synthesised finding 4:** Motivations for caregivers
Sacrifices of retirement life to caregiver's role for a parent (U)		
Sacrificing social activities to fulfil filial piety (U)		
Giving up marriage in order to fulfil caregiver's responsibility (U)		
Giving up job to fulfil filial piety (U)		
Providing physical care is a way of paying filial piety (U)		
Perceived care responsibilities for family members (U)	Responsibilities for family members as a motive	
Sacrifices of retirement life to caregiver's role for a partner (U)		
Caring at home is a responsibility (U)		
Perceived responsibility for family members (U)		
A sense of purpose impacts on caregiving motivation (U)	Other motives	
Interdependence between the caregivers and the care recipients (U)		
Religion as a motive for caregivers (U)		
Beliefs and hopes as motives in long-term caring (U)		
Viewing cognitive declined as part of normal aging (U)	Lack of knowledge and skills in dementia care	**Synthesised findings 5:** Education and training
Lack of knowledge about dementia-related symptoms (U)		
Lack of knowledge about how to manage care recipients' BPSD at home (U)		
Inability to cope with care recipient's BPSD (U)		

Lack of knowledge about how to manage dementia-related symptoms (U)		
Lack of dementia care knowledge and skills (U)		
Participating in dementia training (U)	Participation in education and training	
Learning to be a caregiver via education and training (U)		
Televised health education programs as a learning resource (U)		
Post-diagnosis online information seeking (U)		
Reduced self-stigma via education and training (U)	Effects of education and training	
Learning to improve dementia care (U)		
Shared care by family members (U)	Support in the family	**Synthesised 6:** Family dynamics
Improved relationship with the care recipients (U)		
Enhanced family relationship (U)		
Family support for the primary caregiver (U)		
Caregiving strain resulted from lack of family support (C)	Lack of family support	
Lack of family support (stereotyped as strong and tough) (U)		
Expectations to support from Community Care Centre (U)	Expectations for care services	**Synthesised finding 7**: Expectations for dementia care services
Expectations for respite care and community aged care (U)		
Expectations for home care services (U)		
Desire for formal services (U)		
Expectations for training program in dementia care (U)	Other expectations	
Expectations for welfare system support (U)		

Appendix VI-b Results of meta-synthesis (Chinese diaspora)

Findings	Categories	Synthesised findings
Emotional burden attributed to untreated BPSD (U)	Emotional burden	**Synthesised finding 1:** Multidimensional caregiver burdens
Emotional burden attributed to care recipients' memory loss (U)		
Emotional burden attributed to caregiver's poor health (U)		
Emotional burden (multiple care responsibilities related) (U)		
Psychological stress (BPSD related) (U)		
Emotional stress due to memory loss of care recipients (U)		
Emotional burden attributed to cost on dementia care (U)		
Emotional stress (caused by care arrangement) (U)		
Physical exhaustion (U)	Physical burden	
Physical burden (lack of sleep) (U)		
Disturbance in sleep due to BPSD (U)		
Physical strain attributed to lack of suitable equipment at home (U)		
Caregiving around the clock (U)	Time-dependence burden	
Lack of time to socialise with others (U)		
Time-dependence burden (U)		
Sacrifice retirement life to caregiver role (U)		

Reluctance to gaining service due to dementia stigma (U)	Dementia stigma	**Synthesised finding 2:** Barriers to dementia care
Public stigma towards dementia (U)		
Self-stigma towards dementia (U)		
Inability to speak English as a barrier to accessing nursing home (U)	Lack of culturally and linguistically appropriate dementia care services	
Lack of bilingual professional caregivers to relieve family caregivers (U)		
Language barrier in applying for services (U)		
Difficulty in identifying bilingual professionals (U)		
Lack of ethno-specific nursing homes (Chinese culture related) (U)		
Lack of information about dementia care services (U)	Lack of post-diagnosis support	
Insufficient information about dementia care service (U)		
Lack of information about social service (U)		
Lack of post-diagnosis support from medical doctors (U)		
Lack of post-diagnosis support from health professionals (U)		
Lack of dementia-friendly outpatient clinics services (U)	Perceived poor care services	
Negative thoughts about nursing home care (U)		
Lack of appropriate facilities to care for people with sever BPSD (U)		
Perceived dilemma when deciding to use nursing home (U)		
Positive attitude towards caregiver role (U)	Being optimistic	**Synthesised finding 3:** Positive coping strategies used by caregivers
Positive thoughts on caregiver's role (U)		

Acceptance of caregiver role (U)		
Keeping the care recipients informed of dementia diagnosis (U)	Using various self-identified strategies	
Coping strategy for feeding (U)		
Protective care for the care recipient with BPSD (U)		
Using online information about dementia online (U)		
Learning to be patient with the care recipient (U)		
Improved care through learning and positive self-appraisal (U)		
Closeness between caregiver and care recipient enhanced dementia care (U)		
Supported from social workers (U)	Using various care services	
Support from social workers (referral support service related) (U)		
Reduced burden by using government-subsidised home care programs (U)		
Using ethno-specific dementia care service (U)		
Self-care by taking a break (U)	Performing self-care	
Self-care by physical exercise (U)		
Reciprocity as a motive for the caregiver role (U)	Reciprocity as a motive	**Synthesised finding 4:** Motivations for caregivers
Reciprocity as a motive for a spouse caregiver (U)		
Filial piety as a motive for caregivers (U)	Filial piety as a motive	
Filial piety as a motive for caregivers (U)		
Sacrificing personal life to caregiver role (U)		
Responsibility as a motive for home care (U)	Responsibilities for family members as a motive	

Obligation for the care recipient (U)		
Family relationship as a motive for caregivers (U)		
Religious beliefs as motives for caregiving (U)	Other motives	
Spirituality as a motive for caregiving (U)		
Lack of knowledge about initial dementia signs (U)	Lack of knowledge and care skills in dementia care	**Synthesised finding 5:** Education and training
Lack of knowledge about dementia (U)		
Lack of knowledge about communication with the care recipient (U)		
Inability to manage BPSD (U)		
Difficulty in managing care recipients' BPSD (U)		
Inability to manage care recipient's BPSD (U)		
Inability to manage continence issues (U)		
Learning to be a caregiver via caregiver support group (U)	Participation in education and training	
Peer support as a source of learning (U)		
Virtual caregiver support group as a source of learning (U)		
Family support for the primary caregiver (U)	Support in the family	**Synthesised finding 6:** Family dynamics
Support from children for the primary caregiver (U)		
Shared caregiver role with family members (U)		
Shared caregiver responsibilities within the family (U)		
Improved family relationship via caregiver role (U)		
Family bond as a source of dementia care (U)		
Reduced traditional family support from children (caused by cultural adaptation)	Lack of family support	

(U)		
Family issues attributed to untreated BPSD (U)		
Family conflicts attributed to caregiver role (U)		
Role conflict within a family (U)		
The need to provide dementia care education for the Chinese community (U)	Expectations for education and training	**Synthesised finding 7:** Expectations for dementia care services
The need for dementia education for caregivers at the point of diagnosis (C)		
Expectation of dementia care centre that includes education and training for caregivers (U)		
Expectation for outpatient clinics to provide dementia-friendly services (U)	Expectations for care services	
Need for respite care (U)		
Desire for respite care service (U)		
The need for social support service (U)		

Appendix VII-a ConQual Summary of Findings (studies on family caregivers from Greater China)

Systematic review title: Chinese caregivers' experiences in the care of family members living with dementia: A systematic review and meta-synthesis
Population: Chinese caregivers/relatives of people living with dementia, the spouse/partner of people with dementia; informal caregivers of people with dementia, or Alzheimer's disease
Phenomena of interest: Caregivers' experiences, emotions, expectations, feelings and perspectives
Context: Chinese caregivers who provide care for people with dementia at home

Synthesised finding	Type of research	Dependability	Credibility	ConQual score
Synthesised finding 1: Multidimensional caregiver burdens	Qualitative	High	Downgrade 1 level (-1)	Moderate
Synthesised finding 2: Barriers to dementia care	Qualitative	High	Downgrade 1 level (-1)	Moderate
Synthesised finding 3: Positive coping strategies used by caregivers	Qualitative	High	Downgrade 1 level (-1)	Moderate
Synthesised finding 4: Motivations for caregivers	Qualitative	High	Remains unchanged	Moderate
Synthesised finding 5: Education and training	Qualitative	High	Remains unchanged	Moderate
Synthesised finding 6: Family dynamics	Qualitative	High	Downgrade 1 level (-1)	Moderate
Synthesised finding 7: Expectations for dementia care services	Qualitative	High	Remains unchanged	Moderate

The dependability score of primary studies is high due to the majority qualitative research studies remain unchanged (4 out of 21 studies downgrade 1 level). The credibility remains unchanged due to all unequivocal findings, the credibility downgrade one level due to a mix of unequivocal and credible findings.

Appendix VII-b ConQual Summary of Findings (studies on caregivers from Chinese diaspora)

Systematic review title: Chinese caregivers' experiences in the care of family members living with dementia: A systematic review and meta-synthesis
Population: Chinese caregivers/relatives of people living with dementia, the spouse/partner of people with dementia; informal caregivers of people with dementia, or Alzheimer's disease
Phenomena of interest: Caregivers' experiences, emotions, expectations, feelings and perspectives
Context: Chinese caregivers who provide care for people with dementia at home

Synthesised finding	Type of research	Dependability	Credibility	ConQual score
Synthesised finding 1: Multidimensional caregiver burdens	Qualitative	High	Remains unchanged	Moderate
Synthesised finding 2: Barriers to dementia care	Qualitative	High	Remains unchanged	Moderate
Synthesised finding 3: Positive coping strategies used by caregivers	Qualitative	High	Remains unchanged	Moderate
Synthesised finding 4: Motivations for caregivers	Qualitative	High	Remains unchanged	Moderate
Synthesised finding 5: Education and training	Qualitative	High	Remains unchanged	Moderate
Synthesised finding 6: Family dynamics	Qualitative	High	Remains unchanged	Moderate
Synthesised finding 7: Expectations for dementia care services	Qualitative	High	Downgrade 1 level**	Moderate

The dependability score of primary studies is high due to the majority qualitative research studies remain unchanged (2 out of 15 studies downgrade 1 level). The credibility remains unchanged due to all unequivocal findings, the credibility downgrade one level due to a mix of unequivocal and credible findings.

Appendix VIII-a Recommendations for practice (Greater China)

Recommendations	JBI Grade
Government should support post-diagnostic service	A
Government should develop dementia-friendly community	A
Government should provide education and training in dementia care	A
Government should provide appropriate financial support in dementia care	A
Government should develop community-based dementia care	A

Appendix III-b Recommendations for practice (Chinese diaspora)

Recommendations	JBI Grade
Government should support post-diagnostic service	A
Government should develop dementia-friendly community	A
Government should provide education and training in dementia care	A
Government should provide culturally and linguistically appropriate dementia care services	A