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The Needs of Older Persons with Early Stage Dementia from their Perspectives: An Ethnographic Study in Northeast Thailand

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Doctor of

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by

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Dedication

I dedicate this thesis to my family, teachers, people with dementia and their families, relevant health professionals and colleagues. I hope this thesis is useful to everyone who works in the field of dementia to help to care and respect persons with dementia and better understand their personhood.

Acknowledgements

I am eternally grateful to my supervisors, Professor Fiona Cowdell, Birmingham City University, and Dr Moira Graham, University of Hull, for guiding, encouraging and providing great support to me from the first day of my PhD study up until my thesis was completed. Thank you for your patience, understanding and advice to me a Thai student who did not use English as a first language. I have been privileged to have worked with you. You have been role models and I have learned so much about being a professional, a good teacher and good researcher from you.

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Publications and Conferences

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Abstract

Background: Dementia is a progressive degenerative brain condition commonly affecting older people. The incidence is increasing worldwide. Dementia affects older people in many different ways, impacting on their physical, emotional, psychological and social well-being. In the early stages of dementia the person is able to express their wishes, feelings and needs. It is important to be able to identify needs early so that these can be addressed in order to provide appropriate care to maintain the persons' longer-term well-being. Research has been conducted on persons with early stage dementia, but less is known about their needs from their own perspective.

Objective: To explore the needs of older persons with early stage dementia living in Northeast, Thailand.

Method: Sixteen older persons with early stage dementia were interviewed using serial ethnographic interviews along with observations to capture the perspectives of older persons with dementia on their needs. Maslow's Hierarchy of Needs (1943) combined with Kitwood's (1997) concept of personhood underpin the study theoretically.

Findings: The route to a dementia diagnosis and receiving support illuminated four main themes relating to the needs of persons with early stage dementia: family is essential, companionship support is necessary, meaningful activities need to be maintained, and the nature of life needs to be accepted. The findings reflect the influence of family values and sociocultural background on participants.

Conclusion: The research showed that each person is unique. In Thailand, the family has a significant influence on the journey of people living with early stage dementia. Understanding the needs of people with early stage dementia is essential to help relevant people plan and provide positive support to older people with dementia to help them live well.

Keywords: needs; personhood; older people; early stage dementia; perspective; ethnographic interview

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Abbreviations

AA	Alzheimer's association
ADI	Alzheimer's Disease International
AS	Alzheimer's Society
CG	Caregiver
DOP	Department of Older Persons
ILO	International Labour Organization
IPSR	Institute for Population and Social Research
MoPH	Ministry of Public Health
MSHS	Ministry of Social and Human Security
NSO	National Statistical Office
OECD	Organisation for Economic Cooperation and Development
PNI	Prasat Neurological Institute
PwD	Person(s) with dementia
UN	United Nations
UNFPA	The United Nations Population Fund
WHO	World Health Organisation

Chapter 1 Background

1.1 Introduction

This chapter outlines the background to the study. It begins with an examination of global trends in ageing and, ageing in Thailand, in terms of culture and healthcare. Dementia, one of the most common illnesses in older people (World Health Organisation (WHO), 2019), is depicted. Next, a brief introduction to Thailand and the Thai healthcare system including health policy and long-term care for older people is given. The Thai cultural context on approaches to older people, dementia care and support available in the country is followed by Thai perspectives on this condition from the perspectives of PwD themselves, family caregivers and health professionals. Lastly, I discuss my background and motivation to conduct this study.

1.2 Worldwide ageing population

The world population continues to grow but the rate of growth is slowing with a steady decline in birth rate (United Nations (UN), 2017). Globally about 13% of the population were aged 60 years and over in 2017, which equates to 962 million people (UN, 2017). The world's population is ageing and almost every country is experiencing a rapid rise in the number of older people in their population (UN, 2015a). In 2017 the world population reached 7.6 billion and is projected to reach approximately 8.4 to 8.7 billion by 2030, rising further to approximately 9.4 to 10.2 billion by 2050, and it could rise to 9.6 to 13.2 in 2100 (UN, 2017). The inversion rate with declining of fertility and increasing life expectancy in recent years has affected the proportion of people in each age group of the world's population (UN, 2017).

The Asia Pacific countries have a similar rapidly increasing older population as the rest of the world and for the same reasons: the decline of birth rate, improvement in sanitation and advancement in medical technology (Krishnamoorthy et al., 2010).

1.2.1 Thai ageing population

Thailand is also experiencing a rapid growth in the older population (WHO, 2015a). The Thai population is about 69 million, with the number of people aged 60 and older being 10.7 million, comprising 15.8% of the total population (UN, 2017). With over 10% of the population aged over 60 years Thailand is classified as an 'Ageing Society' (National Statistical Office (NSO), 2014). The Thai population will increase to approximately 69.6

million by 2030, while the number of older people in the population will nearly double to about 20 million. Older people will therefore comprise 26.3% of the total population and this growth in proportion of older people is set to continue (UN, 2015a, b) (Table 1.1).

Table 1.1 World Population Prospects

Population	**2017**	**2030**	**2050**
	All age group (Thousands)		
In the World	7,550,262	8,551,199	9,771,823
Thailand	69,038	69,626	65,372
	Aged 60 years or over (Thousands)		
In the World	962,000	1,400,000	2,100,000
Thailand*	10,731 (in 2015)	18,355	23,153

Source: United Nations *(2017) World Population Prospects: The 2017 Revision*. New York: United Nations. (*) United Nations *(2015b) World Population Prospects: The 2015 Revision*. New York: United Nations.

The Thai population is ageing and along with this is a predicted rise in dementia in the population (WHO, 2015a). At the same time procreation is decreasing with resulting inversion of the traditional population pyramid. (Figure 1.1)

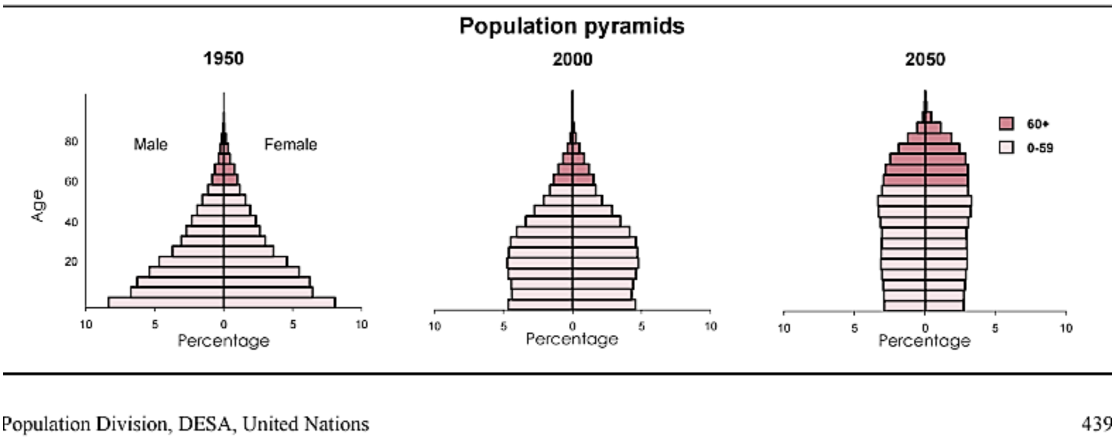


Figure 1.1 Thailand population pyramids

Source: UN, Department of Economic and Social Affairs, Population Division. (2002a) *World Population Ageing 1950-2050.*

1.3 Depiction of dementia

Dementia is a chronic, irreversible syndrome due to brain degeneration resulting from disease or injury, it predominantly effects older people (Barnett et al., 2012). There are many types of dementia, the most common of which is Alzheimer's disease which accounts for 60% of cases (WHO, 2019). Other common types include vascular dementia (20%), mixed Alzheimers / vascular disease (10%), dementia with Lewy Body/Parkinson's disease (6%) (Coope & Richards, 2014). Dementia has a direct effect on the brain and leads to memory impairment in the first stage, resulting in an inability to learn new things. As the dementia progresses memory impairment steadily increases. Other symptoms include problems in calculation, planning activity and naming persons or objects (Robert, 2009; Coope & Richards, 2014) and changes in self-perception, environment, language usage, initiative, temperament, behaviour, and personality.

Dementia is a progressive condition which each person experiences differently. Dementia is often categorised by severity as: early/mild stage, middle/moderate stage and late/severe stage (Alzheimer's Society (AS), 2017; WHO, 2019). The stages can overlap due to the symptoms appearing at different times for different people (AS, 2017).

In the early/mild stages, memory loss of recent events is the most common initial symptom. They may have difficulty in recalling daily events, lack of concentration and have a problem with planning or making decisions (AS, 2015a). However, the person may be able to lead an independent life (Waite, 2009; AS, 2015a). Most people will still be able to communicate in meaningful conversations and participate in social activities (Alzheimer's Association (AA), 2017a).

In the middle/moderate stage, symptoms progress with gradual cognitive decline. There are many problems in cognition such as calculation deficits, impairment in time and place orientation, inappropriate wearing of clothes or inappropriately acting in society, visuospatial and perceptual deficits, language errors in a complex sentence, difficulty in understanding logic and communication, and changes of behaviour and emotion (AS, 2015a, 2016a; WHO, 2019). Moreover, there may be increasing difficulty with activities of daily living such as washing, dressing and using the toilet (Waite, 2009). More assistance may be needed at this stage.

In the late/severe stage, PwD are likely to lose their ability to learn new things (Waite, 2009), become disorientated in time, place and person (WHO, 2019), become less able to use language and speech and eating and drinking will be more challenging (AS, 2016a; 2016b). Mobility will reduce and the person is likely to experience urinary and faecal incontinence. People may become confused and sometimes appear aggressive (Abley & Jackson, 2010). Hallucinations or delusions can also occur (Iliffe & Drennan, 2001; Krishnamoorthy et al., 2010; AS, 2015a). Socially, steady withdrawal from society may occur (AA, 2017b). The level of dependence on others to provide care at this stage is high (Adams & Manthorpe, 2003; AS, 2015a, b).

Dementia effects both people living with the condition and their family members and caregivers in four main areas: physical, psychological, social and economic (Alzhiemer's research UK, 2015; WHO, 2019). Caring for a PwD can be challenging impacting on physical and emotional health. Carers may experience stress, depression, sleep deprivation, poor nutrition and muscle pain (Tremont, 2011; Alzheimer's Research UK, 2015; Boots et al., 2015; WHO, 2019) and isolation from society. Family relationships and finances can change (Alzheimer's Research UK, 2015).

1.3.1 Prevalence of dementia

Worldwide, dementia affects approximately 50 million people with an estimated annual increase of 10 million cases (WHO, 2019); 60% of PwD are living in low and middle income countries.

Alzheimer's Disease International (ADI) (2014) estimates 23 million are living with dementia in Asia Pacific countries; rising to 70 million by 2050. Estimates for Thailand vary (Senanarong et al., 2013). The ADI predicted that 600,000 people would have dementia in Thailand by 2015, rising to 1.12 million in 2030, and more than 2 million people by 2050 (ADI, 2014) (Table 1.2). Estimated prevalence of dementia among Thai older people is around 3.4% with the age specific prevalence rate being 1% in the 60 – 64 years age group and 31.3 % in the 90 years and older age group (Jitapunkul et al. 2001).

Table 1.2 Projected number of PwD in the population compared to the World Population

Population	**2017**	**2030**	**2050**
	All age group (Thousands)		
In the World	7,550,262	8,551,199	9,771,823
Thailand	69,038	69,626	65,372
	Aged 60 years or over (Thousands)		
In the World	962,000	1,400,000	2,100,000
Thailand*	10,731 (in 2015)	18,355	23,153
	People with dementia (Thousands)		
In the World**	46,800	74,700	131,500
Thailand**	600	1,117	2,077

Source: United Nations (2017) *World Population Prospects: The 2017 Revision*. New York: United Nations, (*) United Nations (2015b) *World Population Prospects: The 2015 Revision*. New York: United Nations, (**) Alzheimer's Disease International (2014) *Dementia in the Asia Pacific Region*. Alzheimer's Disease International (ADI): London.

1.4 Introduction to Thailand

Thailand is located in Asia Pacific, it is surrounded by Myanmar, Laos, Vietnam, Cambodia and Malaysia. There are 77 provinces in five regions: North, Northeast, East, Central and South. Bangkok is the administrative capital city located in the Central region. Each region has major provinces where the infrastructures, economy, education, and healthcare facilities are situated. However, some services are not provided to the same quality or quantity as in the capital city. For example, there are differences between the numbers of special health institutions and expert health professionals between hospitals in urban and rural areas. Thai is the official language spoken and written by the entire Thai population, but people in each region may also have their own dialect. Buddhism is the main religion. People believe in recompense to their parents and adult children will normally take care of their parents as an obligation and/or because they wish to show gratitude to their parents for raising them.

Figure 1.2 Map of Thailand

Source: Maps of World (2015) Thailand Cities Map.

1.4.1 Population in Thailand

Northeast is the largest region consisting of 20 provinces and has the largest population. Apart from Bangkok, the majority of the ageing population are living in Northeast region. It underpins the fact that the higher the total population, the greater number of older people. Table 1.3 and 1.4 present the number of total population and ageing population in each region and the top 5 provinces having high populations in Thailand.

Table 1.3 The numbers of the total population and the ageing population in each region in Thailand.

Region	Total population			Older population aged 60 years		
Sex	Male	Female	Total	Male	Female	Total
Central	8,677,164	9,412,388	18,089,552	1,365,388	1,849,887	3,215,275
Bangkok	2,669,316	2,996,948	5,666,264	444,903	621,968	1,063,871
North East	10,932,109	11,082,139	22,014,248	1,600,641	1,931,474	3,532,115
Nakhon Ratchasima	1,303,944	1,344,983	2,648,927	202,231	251,157	435,388
North	5,938,482	6,181,090	12,119,572	1,032,601	1,254,869	2,287,470
Cheang Mai	861,692	917,562	1,779,254	149,919	183,773	333,692
South	4,667,592	4,819,165	9,493,757	606,548	755,607	1,382,155
Nakhon Si Thammarat	771,735	790,192	1,561,927	114,957	150,778	265,735
East	2,382,753	2,459,053	4,841,806	315,119	403,925	719,044
Chonburi	762,141	796,160	1,558,301	87,193	117,828	205,021

Source: Registration statistic system of Department of Provincial Administration (31st December 2019), Department of Older Persons (DOP) (2019a).

Table 1.4 Top 5 provinces having the highest older populations in Thailand.

Province	Population (person)
1. Bangkok	1,063,871
2. Nakhon Ratchasima	435,388
3. Cheang Mai	333,692
4. Khon Khan	312,933
5. Ubon Ratchathani	276,628

Source: Registration statistic system of Department of Provincial Administration (31st December 2019), DOP (2019a).

Due to dementia being commonly found in the ageing population, Nakhon Ratchasima was chosen to be a site for this study as it is the second province in the country with the largest total population and older population after Bangkok.

1.4.2 Educational and occupational background

There were no schools in Thailand in the last 19th century, people studied with Buddhist monks, in the temple (Eak-un, 1999 in Makkhakvun, 2014). The monks not only taught religion but also reading and writing. In ancient times, farming was more important than studying as people believed that subjects studied in school cannot be applied in everyday life (Inchan n.d. in Dachakupt et al., 1996). The Thai education system has developed over many years. Compulsory education for people up to grade 4 was introduced in 1932 (B.E. 2475). However, there were only schools in urban areas. If a person had the potential, opportunity and family support, they could get a higher level of education, whereas in rural areas, people tended not to study.

1.4.3 Spiritual belief and culture of people in Nakhon Ratchasima

Generally, many Buddhists attend the temple and continue practising religious activities. It is easily seen that people who do not have time to go to the temple would wait to give food and some personal things, like a toothbrush, toothpaste or soap, to the monks in front of their house or along the way that the monks pass every morning about 6 a.m. to 7 p.m. Some people do this every day while other people do this only on the Buddhist Holy Days (see Figure 1.3 – 1.4).

Figure 1.3 - 1.4 People give alms to Buddhist monks.

Buddhist monks have duties to preserve and transmit the teaching of the Buddha. From Figure 1.3 – 1.4, it can be seen that nobody wears shoes. Basically, the monks will not wear shoes or sandals as the strict rule in practice. Thus, people pay respect to the monk while giving food; they then go barefoot so as not to stand on a level higher than the monks.

Moreover, there is a famous holy place called "Thao Suranaree Monument". This monument became the symbol of Nakhon Ratchasima. People come to worship the bravest woman who fought against the enemy during the war to protect the area between Thailand and Laos. This monument is in the centre of the city, which is commonly known as "Ya Mo" (Ya = grandmother, and Mo = the name). Many locals and people from other provinces believe in praying to her to get their wish, and some people may also give offerings for her. Some people get sick and come to pray to her and wish to get better (see Figure 1.5).

Figure 1.5 Tao Suranaree Monument

1.4.4 Transportation in Nakhon Ratchasima

Figure 1.6 – 1.12 show varieties of transportation which people use to get around the province. However, the vehicles in Figure 1.10 – 1.12, are commonly found in the city. Also, the transportations are available to get access to some routes. There are still many routes that transportation does not access.

Figure 1.6 A bus transports people between districts around the province.

Figure 1.7 A train transports people around and between the province.

Figure 1.8 - 1.9 A minibus or ‘Songthaew’ has two benches inside; services in big districts.

Figure 1.10 Motor Tricycle taxi (tuk-tuk)

Figure 1.11 Cycle rickshaws taxi (samlor)

Figure 1.12 Motorcycle taxi

1.5 The public health services system in Thailand

Thailand has a Universal Health Insurance system which is funded through taxation. More than one-third of all health care units provide universal basic health care services under the Universal Coverage Scheme (UCS) to all. While the majority of health care services in Thailand are provided by the state, some are also provided by private organisations. Private healthcare is usually available in clinics and hospitals in metropolitan areas (Wibulpolprasert et al., 2011). It is mainly used by fee paying patients but some accept a basic 30 baht fee (approximately $1). The main public healthcare services have three levels: primary, secondary and tertiary, supervised by the Ministry of Public Health (MoPH).

There are primary, secondary and tertiary care units in all regions (Tangcharoensathien, 2015) (see Table 1.5 and Figure 1.13).

Table 1.5 Health care services in Thailand

Level of health care	**Primary**		**Secondary**		**Tertiary**
Area coverage	Sub-district	District		Provincial	
Approx. population coverage	1000-5,000	5,000 -10,000	30,000 – 50,000	80,000 – 200,000	600,000
Health care Unit	• Sub-district health promotion hospital • Community health centre	• Community hospital	• Community hospital	• General hospital	• Regional hospital • Centre hospital • Specific hospital • Medical school hospital
In-patient Bed	-	30, 60, 90	90-120	150-500	400-1,000

Additionally, there are private health facilities which are mostly located in urban areas for people who have good economic status and the ability to pay. There are a variety of services in the private sector such as drugstores, which provide modern or traditional medicine, medical premises with (hospital) or without inpatient beds (clinic), also some places provide spa, beauty or massage services for health. The private hospitals which provide health care services offer curative services for both outpatients and inpatients with 51-100 beds (Wibulpolprasert et al., 2011).

In theory, when people have minor health problems, they attend the primary health care unit, and where the primary care unit is not be able to provide treatment for them, they will then be referred to the next level which has a greater capacity and a higher efficiency treatment level. People who are living in the urban areas or those with high incomes often prefer to access the secondary care hospital services directly, because they often have greater confidence in these services. People in the rural areas are often obliged to access primary care services first, because of transport and income difficulties.

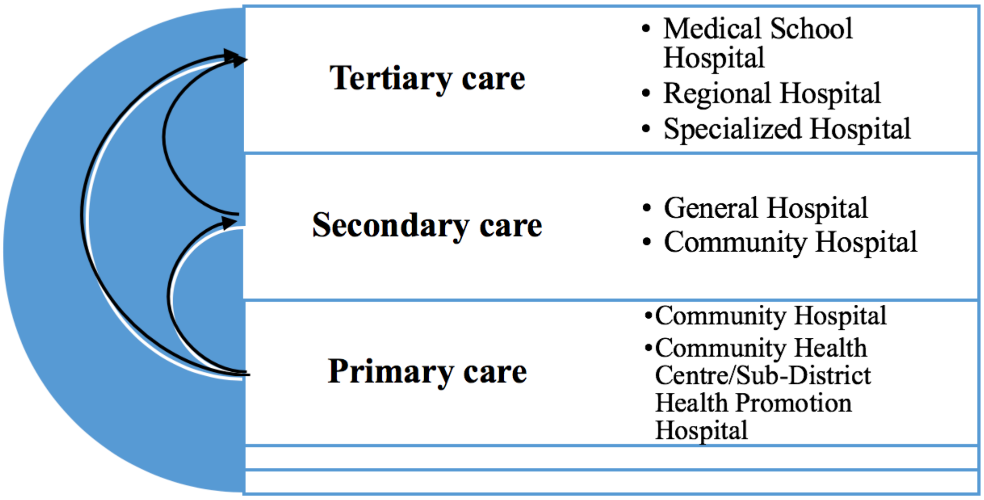


Figure 1.13 Health Care Levels of Service in Thailand

Note: → The arrows show the different patient referral routes.

In relation to healthcare services in Thailand, the specialist centres for all health care services are mostly concentrated in Bangkok and the larger urban cities. Persons living in rural areas experience greater difficulty accessing these specialist services than those living in larger conurbations.

The ratio between health personnel at all levels to the population is low which limits the delivery of health services in all areas (International Labour Organization (ILO), 2008; Wibulpolprasert et al., 2011; Aspalter et al., 2017). Currently, the Thai government are attempting to address this problem by offering training scholarships for nurses and doctors and trying get more health service personnel trained in the Non-Communicable Disease (NCD) specialisms (for example cancer, diabetes and coronary heart disease) (MoPH & MSHS, 2007). This is especially so for the rural areas. It will however take time for the outcomes of this to benefit health service delivery overall. Geriatrician and dementia experts are rare in Thailand especially at primary level and in rural areas (Wibulpolprasert et al., 2011); this impacts on quality of care.

1.5.1 Health policy for older persons

As the population ages, the Thai government and society are increasingly preparing for and planning ahead to assist older people to meet their needs holistically (Institute for Population and Social Research (IPSR), 2013; Ageing Asia, 2014); however, there is still much work to be done. This section addresses health policy for Thai older people, social welfare and also the situation as regards long-term care.

Internationally strategies for older person care depend to some extent on the stages of development of each country (Innes, 2009; Krishnamoorthy et al., 2010). In developing countries in which governments are still in the process of developing health care systems, societies and economies (UNFPA & HelpAge International, 2012), plans to care for the ageing population tend to be somewhat limited due to scarcity of resources as is the case in Thailand (Jitramontree & Thayansin, 2013). However, The First National Plan for Older Persons (1982-2001) was developed in 1981 as a guideline for treatment of older people and acknowledged the impact of the ageing population. The Second National Plan for Older Persons (2002-2021) focused more on social values, job creation, and development of knowledge about ageing and evaluation of implementation of the plan. Thai laws including in the Constitution (2017) and The Act on the Elderly 2546 B.E. (2003) support equal rights, liberties, the right to live a good quality of life, to be protected from violence and unfair treatment as well as to be provided with treatment, rehabilitation and access to health services in the long-term.

The social welfare system enhances self-reliance in older people to reduce the problems of being seen as a burden, and less entitled to a sense of worth or dignity (Yodpet, 2007). With respect to the quality of care, nurses will take care of older people as a part of the multidisciplinary team to enhance their quality of life. There are three categories of social welfare: social insurance, public assistance and social services with each contributing to ensuring that the basic human needs of Thai older people are met. The government allocates a budget of 600 baht (approximately £15, 40 THB = 1 pound in 2020) per month to older people. An average annual Thai household income is 26,018 baht per household (NSO, 2019). People aged 65 and over are tax exempt for income up to 190,000 baht (approximately £4,220). The government also attempts to preserve and enhance informal care by the family by offering tax relief to adults who are taking care of their parents. These carers will be entitled to a parental care allowance of 30,000 baht for taking care of an older parent, who must have an assessable income less than 30,000 baht per year after exempted income (Bureau of Legal Affairs, 2015).

While there are national policies to support older people, problems of accessing government welfare persist because there is a lack of information about the benefits and support that older people are entitled to claim. There is also a lack of integration of welfare policies and practices (Jitramontree & Thayansin, 2013; Khamngae et al., 2014).

1.5.2 Long-term care for older persons

According to the Organisation for Economic Cooperation and Development (OECD) (2005: 15)

> “Long-term care services are needed by individuals with long-standing physical or mental disability who have become dependent on assistance with basic activities of daily living, many of whom are in the highest age groups of the population”.

WHO (2015b: 127) referred the term Long-term care to:

> “the activities undertaken by others to ensure that people with or at risk of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity”.

In Thailand the most dependent older persons live at home, numbering approximately 140,000 in 2009, and expected to double by 2024 (Srithamrongsawat & Bundhamcharoen, 2010). Long-term care is most frequently provided by the family and alternatives include community-based care which involve informal caregivers like family members, community members and institutionalised long-term care facilities like residential homes, nursing homes, hospice care (Sasat et al., 2013). The need for long-term care for older persons is sharply increasing (Sasat & Bowers, 2013; Suwanrada et al., 2014; Tangcharoensathien, 2015; Knodel et al., 2018) and the Thai system needs to develop to meet population requirements.

Currently, there are two models of long-term care in Thailand: i) low care model for older people needing minimal care, ii) high care model for those needing continued nursing care (Sasat & Bowers, 2013). The aim is to support holistic care to maintain quality of life. There are older person clinics in the hospitals and some private hospitals have services such as long-term care, day care, and home care (Bundhamcharoen & Sasat, 2008).

The Thai Government is actively working towards increasing quality and availability of care for older people. The Sustainable Development Goals (SDGs) introduced a key measure into the National Agenda in the Twenty-Year National Strategic Plan for Public Health (2017-2036) (DOP, 2019b) to improve the quality of care for older people.

Care for older persons education is offered in short courses provided by the MoPH or educational institutions. However, specific training is not a requirement for working with older people in Thailand and while health personnel have professional level care standards, they do need to be trained specifically to care for older persons (Sasat & Pukdeeprom, 2010). Sasat et al. (2013), expert gerontological nurses, recommended improvement to the care of older people in Thailand. They suggest that long-term care should be established in order to support patients who have chronic illness or dependency and need a high level of care, and for the family caregivers who need assistance to help relieve the care burden. Despite the public and private healthcare segments in secondary health care units taking action on caring for older people in short and long-term care in communities and hospitals, the job description for these roles are unclear and need greater attention to be paid to them (Sasat et al., 2013). In other words, although there is specific education in caring for older people and those with dementia, clinicians with this expertise are more likely to be attended by clinicians in tertiary hospitals and in major provinces.

1.6 Dementia care and support in Thailand

This section will examine the care for PwD including strategies to support them and their family in the Thai context.

In Thailand dementia diagnosis can be slow, predominantly because there are barriers to early detection and access to specialist services. There is limited expertise in diagnosing and patients often cannot access required services (Prasat Neurological Institute (PNI), 2014).

The process of dementia assessment and diagnosis is summarised in Figure 1.14. It is important that patients and family are aware of the signs of behaviour change, or neurological or mental decline and seek expert advice. The examination processes will identify that the problem is dementia or otherwise something else, and refer for appropriate treatment and support.

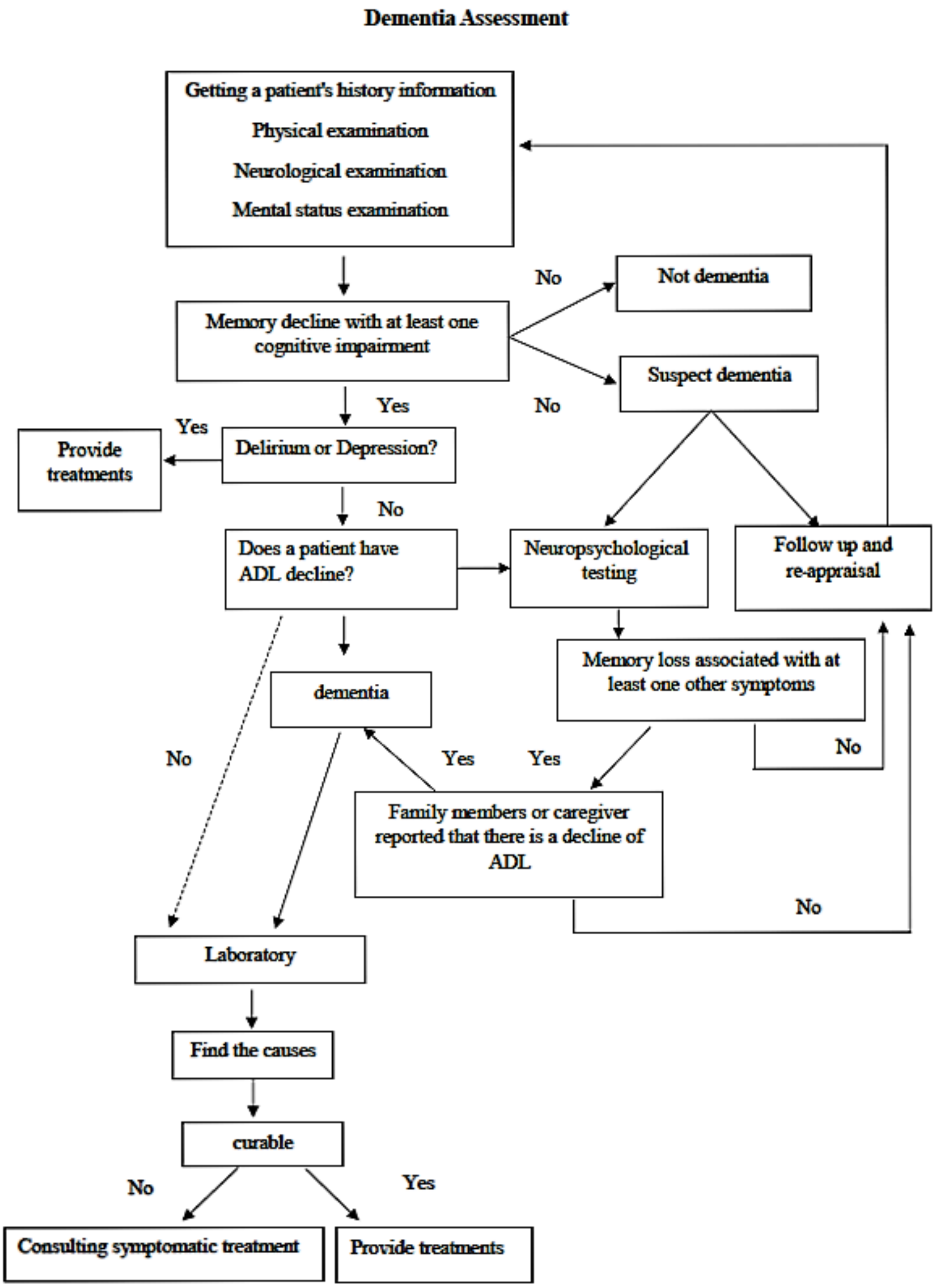


Figure 1.14 Dementia assessment

Source: The Manual for Establishing and Implementing the Elderly Clinic (2005) (Translated from the Institute of Geriatric Medicine): Bangkok: The Agricultural Cooperative Federation of Thailand Limited.

As seen in Figure 1.14, physicians will first assess history and perform a physical examination, followed by cognitive evaluation. They will consider differential diagnosis and undertake screening tests for dementia.

Dementia is incurable, however, progression can be slowed with drug treatment. Pharmacological management of dementia in Thailand using medicines such as donepezil, rivastigmine, galantamine, memantine, which help to delay the progression, and relieve the complications of dementia as long as possible, do exist. However, they are not yet registered in the National List of Essential Medicines (2012) (Tantiritisak, 2014) and health professionals need to consider their use on a case by case basis.

Thailand has limited services for PwD, especially in the rural areas (ILO, 2008). Those with greater knowledge living in urban areas are more likely to benefit from early diagnosis. They are more likely to be referred to secondary care to get a definitive diagnosis and management plan. Alternatively, they may be referred directly to a neurologist or specialist in the tertiary hospitals or specialist hospital to receive diagnosis and further treatments. It can be seen that this early referral step is dependent on individuals and family members knowledge of dementia, the area where they live, and also health professionals' awareness.

Due to increasing numbers of PwD, there are some tertiary hospitals and associations founded to help PwD and their caregivers. They are mainly Bangkok based. For example, there are the special care units at the Neurological Hospital as well as units in the University Hospital that provide support and have created manuals for caring for PwD. Also, some other organisations, across the country, in the major centres, from both government and private sectors, have established older people clubs or groups, long-term care centres and nursing homes to provide the care and treatment for older people including those with dementia. Moreover, there are organisations providing some services such as help and consultation hotlines, media online about dementia knowledge and support web board, articles on dementia knowledge and activities aimed at dementia caregiver group support, like the Alzheimer's Disease and Related Disorder Association (ARDA) (http://www.azthai.org), the Dementia Association of Thailand (http://thaidementia.org), the Foundation of Alzheimer's Disease (http://www.alz.or.th), and the Thai Society of Gerontology and Geriatric Medicine Association (http://www.thaigeron.or.th). Each of these networks work independently to provide support, information, education programmes and services to their local communities.

In summary, although there are guidelines for detecting and diagnosing dementia, a limitation of specialist support exists. People also have poor information about dementia and the care services available.

1.7 The Thai cultural context on approaches to older people

Differences in cultural context can influence the way older people are cared for. This section illustrates the Thai cultural context and overview of the Thai perspectives on dementia to provide an understanding of societal attitudes to ageing and the culture of family caring.

Thailand is a Buddhist country in which adult children are expected to value their parents and offer repayment to them by caring, this is especially so for daughters. It is ingrained in Thai culture that at least one child should live with their parents in order to provide care (Knodel & Chayovan, 2009; Sasat & Bowers, 2013). Long-term care is however becoming a serious concern as the population ages (Phillips & Chan, 2002; Bundhamcharoen & Sasat, 2008). The issue is exacerbated as the younger generation are breaking with tradition and moving to live and work in urban areas, with more women moving into the workforce and family size decreasing. These factors are all leading to decreased potential for family members to care for their elders.

1.7.1 Thai perspectives on Dementia

Dementia is not a normal part of ageing but rather becomes more common with advancing age. Currently, health professionals understand that dementia is a sensitive issue, more so than in the past and it is one of the long-term care problems commonly found in older people. At a multi-disciplinary conference, it was agreed that guidelines must be written to improve the model of dementia care for patients and carers in all contexts. Attendees recommended a campaign to increase awareness and knowledge about both prevention and treatment (Tantiritisak & Prajanatham, 2011).

Some private and public tertiary hospital board executives have shown an interest in improving dementia care services, for example, by establishing memory clinics and some general practitioners have received training, however, there is still much work to be done.

In Thailand, most PwD only meet their doctor once their symptoms have progressed, and treatment is less effective at this stage compared to when it is diagnosed at an earlier stage. Chansirikanchana (2011) highlights how it is important to enhancing the quality of care for PwD, and to delaying the severity of symptoms, that supportive health care be attentive and sensitive to the needs of both PwD and their caregivers.

In Thai culture, family members may feel disappointed and stressed by a dementia diagnosis and this may exacerbate challenges in providing care. Caregivers may feel disheartened and angry due to misunderstanding of the condition and the presenting symptoms. This can lead to relationship problems between them and the PwD (Sasat, 1998). Caring for PwD can be stressful and burn out is common, particularly when caregivers or family members do not understand what the person wants, and they cannot respond to their needs.

Thai caregivers can have misconceptions about the symptoms of dementia. Some caregivers misunderstand the confusion and forgetfulness that can accompany dementia as attention seeking of the older PwD and therefore the family member ignores them (Undara et al., 2016). Srinim (2015) found there was a lack of information given about dementia from health professionals. Additionally, relatives reported caring for someone with dementia impacts on a family’s financial status. Collectively these issues were reported to lead to caregiver burden and fatigue.

Conflict may occur as the PwD does not want to be a burden and needs to be independent as long as s/he can. Caregiving can be time consuming and a mental and physical burden, however caregivers may be reluctant to report this because of their sense of responsibility which children have to their senior family members (Muangpaisan et al., 2010). In terms of religion and culture, caregivers feel it is their responsibility to care for their relatives with dementia and this can cause caregiver suffering (Sethabouppha & Kane, 2005).

1.7.2 Perspectives from those living with Dementia

The sections above have outlined experiences and beliefs about dementia in Thai culture and presented the little available research about family carer experiences. However, the perspectives of PwD on their condition are very rarely shared or represented in the Thai literature. This may be because of late diagnosis, reluctance to tell others of their condition, or a perception that it is a normal part of ageing.

My Masters research focused on older persons living with early stage dementia. Using qualitative case study interviews I explored how they perceived life before and after receiving the dementia diagnosis and how they coped. The findings showed that participants felt confused when told their diagnosis and were unsure why their memory was failing. They were stressed when their ability to carry out certain activities declined. They were fearful that changes would worsen and some reported feeling depressed and hopeless about the future (Noysipoom & Sasat, 2014).

These perspectives of Thais on dementia illuminate that health professionals should attempt to improve the dementia care for supporting PwD. However, there is still misunderstanding about dementia and there are differences in views between older PwD and their caregivers. Therefore, there is growing interest about how healthcare support should be provided to older PwD and there is a recognition that older people should be included in research concerning their quality of life in relation to health and well-being.

1.8 Introduction to the study

Since graduating with a Bachelor's of Nursing Science, I have been working as a Nurse Instructor. My work is focused on the field of gerontology nursing, supporting students to improve and gain knowledge in the area of caring for older people. Nurse educators in Thailand are required to work with their nursing students in both the classroom and practice areas. I supervise students in various areas such as in the medical care unit in a hospital setting, nursing homes for seniors, and in the community. My other roles include working for Academic Services in the community, which aims to provide health promotion activities and knowledge for people in the community. This work is integrated with nursing lessons for nursing students. It is a privilege to train and hopefully inspire the next generation of carers.

I visit communities and private nursing homes for seniors where approximately half the older residents have a diagnosis of dementia. In one-to-one conversations with the residents, I discovered that many people thought dementia was a normal problem for older people. This inspired me to care for PwD. As a nurse, my intention with this study was to understand the views on care and support that people with early stage dementia need, so that we can better respond to these needs early, before their condition progresses so as to help them to maintain their health and wellbeing as best as possible.

There is a need for this study as the prevalence of dementia increases with age and as highlighted earlier, in common with other countries, the Thai population is ageing and along with this is a predicted rise in dementia in the population (WHO, 2015a). This ageing population influenced my choice to study for a Master's degree in Gerontology which I referred to earlier. A major part of this study involved research on living with early dementia in older persons. Five themes were generated from this study: physical perception about the signs and symptoms of dementia; mental perception before and after diagnosis; coping with dementia; management of the signs and symptoms; and planning for the future. The last theme, planning for the future, found that older persons with early stage dementia stated that they would like to receive their care from their family members and health care providers. This led me to become interested in seeking out the dementia care needs from the persons own perspective in order to contribute to an increased understanding of what is important to PwD themselves in order to improve their quality of life and well-being.

Moreover, levels of self-care in older persons diagnosed with dementia will vary according to their personal background such as economic, social participation and cultural contexts. In the early stages, dementia patients will lose some memory but retain the ability to think and express their feelings. People with early dementia have limited time to tell their story or to make their future needs and desires known as the condition will inevitably progress and make communication gradually more difficult. Therefore, there is a need to understand what kind of care patients would like to receive from a personal perspective because the findings will benefit older persons, family caregivers and healthcare providers to revise nursing care plans for the patients as they desire.

1.9 Summary of Chapter

This chapter has provided the background to this study of the care needs of older persons with early stage dementia in Thailand. It has presented data on the global ageing and the ageing population in Thailand. It has described dementia, including the worldwide and Thai prevalence of the condition. It has introduced the country of Thailand including the healthcare system as well as healthcare policy and long-term care for older persons in Thailand. The chapter has explained the cultural approaches to caring for older people in Thailand. It has further explained dementia care and approaches to caring for PwD in Thailand. It has highlighted the lack of literature on PwD’s perspectives on their condition, literature that discusses family perspectives on the condition as well as those of health care professionals in Thailand. Finally, the chapter has set out the background to my motivation for wanting to conduct this study including my gerontological nursing and teaching experience and my previous practice and research on the experiences of PwD. Further reasons for wanting to conduct this research including the lack of literature on older PwD’s perspectives of this condition and their care needs and the need to support PwD in the early stages of dementia are also explained in the chapter.

1.10 Overview of thesis

This thesis reports on a study to uncover: ‘What are the care needs of older persons with early stage dementia in Thailand from their own perspective?’ This first chapter has provided the background of the study focusing on the older population in Thailand, social perspectives on dementia in Thailand, my motivation to explore the perspectives of older persons with early stage dementia on their care needs to live well with dementia. Chapter 2 presents an integrative review of empirical literature regarding the care needs of older people with early stage dementia. Chapter 3 focuses on Maslow’s hierarchy of needs as a theoretical framework and is related to the concept of personhood and person-centred care to guide the study to answer the research question. Chapter 4 describes the philosophical perspective underpinning the study, it outlines the participants recruitment process, data collection methods and analysis processes used in this study. Chapter 5 presents experiences of Thai older persons with early stage dementia about the route to the dementia diagnosis. Chapter 6 presents findings about the perspectives of older persons with early stage dementia on their care needs and draws on their experiences of receiving support. Chapter 7 discusses the findings from this study with other existing knowledge about the needs to live well with dementia by concentrating on the theoretical framework and related concepts used in this study. Finally, chapter 8 concludes the thesis and provides recommendations to better support persons with early stage dementia to live well.

Chapter 2 Literature review

2.1 Introduction

This chapter presents a review of the literature regarding the care needs of people with early stage dementia from their own perspectives. The review was conducted using the integrative review methodology of Whittemore & Knafl (2005). This systematic method ensures the required rigour with respect to retrieving and appraising evidence. Although it is not a new method, it is a well-established approach for this review as it is allowed synthesis of different types of literature to identify relevant information about the care needs of PwD. The chapter comprises three sections. Firstly, the empirical literature on care needs of PwD from their own perspectives, this section will relate to the stages of Whittemore & Knafl's (2005) integrative review steps. Secondly, the grey literature, which focuses on an overview of dementia care needs research as a whole with PwD abroad and in Thailand. Thirdly, the chapter presents the learning from the included studies. All these sections of the review set the scene for my study.

2.2 The empirical literature on care needs of PwD from their own perspectives

In this section, I present the method and results of the systematic search conducted to explore the relevant empirical literature which consist of the five processes delineated by Whittemore & Knafl's (2005): i) problem identification, ii) literature search, iii) data evaluation, iv) data analysis and v) presentation.

2.2.1 Problem identification

The previous chapter set out the demographics of dementia worldwide and in Thailand and identified gaps in care provision in Thailand. One element that is often limited or absent in dementia policy development, research and care planning is the voice of PwD themselves. Therefore, the aim of this review is to synthesise existing literature concerning the care needs of older PwD, and emphasis on understanding the needs from their perspectives.

2.2.2 Literature search

The search strategy involved review of the electronic databases CINAHL Complete, Academic Search Premier, MEDLINE and PsycINFO using the search terms dementia OR "alzheimer*" with care OR caring OR service* OR support*, problem* OR issue*

OR need* OR demand* and Self OR Perspective* OR Experience* OR view* OR patient* (see Appendix 1 for full search strategy). Inclusion and exclusion criteria are summarised in Table 2.1.

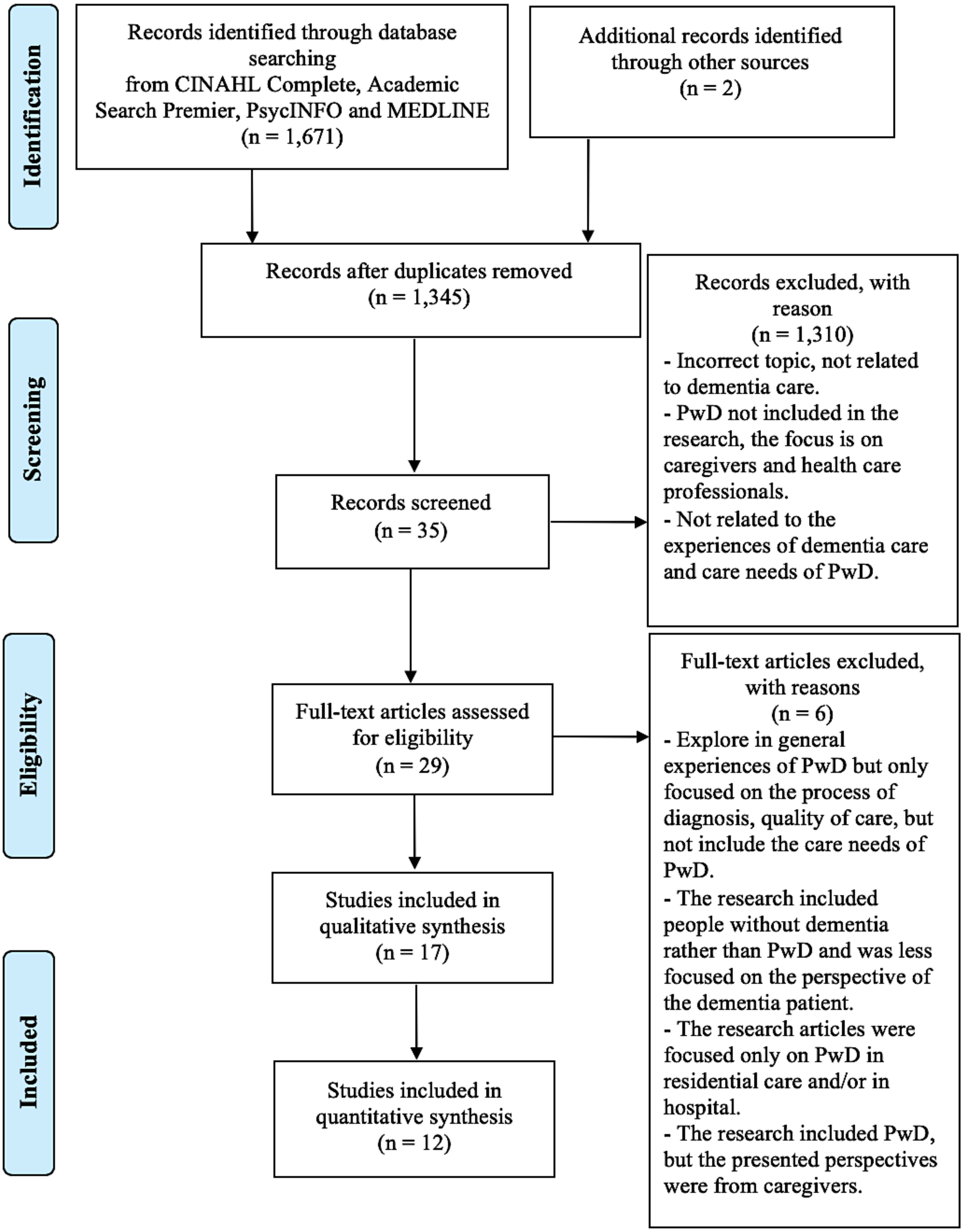
Table 2.1 Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
1) Focus is on the perspective of the person with dementia.	1) Not related to dementia care or care needs and experiences or perspectives of PwD, studies which approach other people without dementia.
2) Participants in the study are men or women who are aged 60 and above.	2) Research conducted with people without dementia.
3) The focus is on the person with dementia in the community, but participants from mixed institutional centres (day care centre, primary care unit, memory clinic etc.) will be accepted.	3) The research focus is on persons in residential or hospital care only as there may be different opinions between PwD who are still independent and those with dementia who rely on health or other providers.
4) Published in the English language.	4) Not published in the English language. (In the case of Thai publications relevant to the research topic, written in the Thai language these will be identified and included in a separate section)
5) Publication after 2000 in a peer-reviewed academic journals because PwD were tending to be included to participate in research since that year.	5) Published before 2000.

The search yielded 1,671 papers and two additional papers from reference lists. Deduplication reduced the number to 1,345 papers, the title, and if required abstract was reviewed for relevance leading to exclusion of 1,310 papers, predominantly because they focused on caregiver or healthcare provider perspectives.

The remaining papers (n=35) were read in full. At this stage, a further six papers were excluded as their primary focus was not the experiences of PwD. Finally, 29 papers were included, qualitative (n=17) and quantitative (n=12) (see Figure 2.1).

Figure 2.1 PRISMA 2009 Flow Diagram (Moher et al., 2009)



2.2.3 Data evaluation

Data from each included article were extracted using a bespoke spreadsheet. Details recorded included author, date of publication, location, title, study aims, participant characteristics, methods of data collection, main findings and quality appraisal.

Quality appraisal of quantitative articles was completed using guidance of Greenhalgh (2014) (ten questions to ask about a paper describing a questionnaire study) (Appendix 2). The Critical Appraisal Skills Programme (CASP, 2014) (Appendix 3) tool was used to quality appraise qualitative articles.

Quantitative and qualitative data are summarised in Tables 2.2 and 2.3 respectively.

Table 2.2 Data extraction and quality assessment of quantitative research

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
1. Meaney et al. (2005) Ireland	Needs assessment in dementia	To characterise the needs of community dwelling elderly patients with dementia who were referred to an old age psychiatry service between July 2002 and July 2003.	82 PwD currently living in the community. (mean age of PwD was 76 years old and the mean MMSE score of the group was 15.9)	82 PwD were interviewed at their home which could take up to an hour by the project nurse using The Care Needs Assessment Pack for Dementia (CareNap-D) (McWalter et al., 1998).	High levels of unmet need were identified in the domains of • Behaviour and mental state (84% of those with agitation); • Social interaction (79% of those with 'taking part in activities' need).	• The results from assessment were combined the opinion of PwD and their CG, thus the needs cannot be determined which were from PwD. • There was no description about what each need means. • Specific needs of people with early stage dementia cannot be disaggregated.
2. Chung (2006) Hong Kong	Care needs assessment of older Chinese individuals with dementia of Hong Kong	• To identify the met and unmet care needs of individuals with dementia • To examine the patterns of care	197 community-dwelling older adults with dementia aged 60 and above.	• The Care Needs Assessment Pack for Dementia (Carenap-D) (McWalter et	• Unmet care needs were identified mainly associated with social interaction (especially in item of 'taking part in activities'), thinking and memory (especially in item of 'repetitive	• The interviews included both PwD and family carers. In cases of PwD who could not participate, their carers were asked to provide the information.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
		needs presented in different stages of dementia.		al., 1996) was translated in Chinese language prior to use in this study by 8 trained assessors. • Semi-structured interviews were conducted at participants' home and discussed with both PwD and family carer.	questioning'), and mental state (especially in item of 'restlessness/agitation', and 'swings of mood'). • These care needs required the help to address social stimulation/ activity for PwD, carer strategies to handing maladaptive behaviours and skill of communication, and counselling for both PwD and their family carers. • The care needs of participants with increasing severity of cognitive impairment became diversified and evident in activities related to complex and instrumental daily living tasks, social interaction, thinking and memory, and behaviour and mental state.	Therefore, the needs of PwD cannot separated out from CG's opinion.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
3. Edelman et al. (2006) Illinois, USA	Information and service needs of persons with Alzheimer's disease and their family caregivers living in rural communities	• To identify the information and service needs of persons with Alzheimer's disease (AD) and their family caregivers living in rural communities • To compare each partner's perspective.	• 100 people with mild to moderate AD (mean age of 80 years) • 100 CGs	• This cross-sectional study started with interviews with CG of persons with early stage AD to determine the interest in the Checklist of CG topics of Interest in Services and Information (Kuhn, 1998) and identify their needs about services. • It then was listed as items checklist by slight adapting language in each version for	Both CGs and people with AD agreed interested in about the information of • Stage and symptoms of AD; • Approved drug treatment for memory loss; • Meaningful activities; • Coping with challenging symptoms; • Experimental drug for memory loss; and • Improving communication. • The results show that the CGs reported the interest of needs rather than the persons with AD. • The unique interest topics that were rated by only people with AD were the topics of support groups for people with memory loss and participation in research studies as the top choices.	• The needs were raised by CGs' discussion and then listed as items of needs for persons with AD rating which item they need. Thus, the entire needs of PwD may be scoped by CGs' perspective. • Specific of early stage dementia cannot be specific out from those in the later stages.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
				both CRs and CGs. - Persons with AD were interviewed to complete the checklist by clinic staff, while CGs complete their version.	- It different from their CGs which was found that the topics of genetic aspects of AD and dealing with family and friends were the unique interest topics.	
4. van der Roest et al. (2009) Netherlands	What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services	To assess the needs of community-dwelling people with dementia as reported by themselves and by their informal carers.	- 236 community-dwelling PwD (mean age of 79.8 years) - 322 informal carers	- Using a cross-sectional design - Participants were interviewed separately by using the Camberwell Assessment of Needs for the Elderly (CANE) (Dutch version).	- PwD reported fewer needs compared with their CGs and the professionals. - Most unmet needs were experienced in the domains of memory problems, information about dementia, available care and treatment, company, and psychological distress. - While CGs mentioned about memory and daytime activities.	- Specific needs of those with early stage dementia cannot be separated from those in the later stages.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
5. Miranda-Castillo et al. (2010a) UK	People with dementia living alone: what are their needs and what kind of support are they receiving	To identify the needs of PwD living alone and to compare the needs of PwD living alone versus those living with others.	• 152 PwD aged 60 years and over living at home • 128 informal CGs who was knowledgeable about the PwD and spent a minimum 4 hours a week in direct contact with PwD.	• Cross-sectional design Participants were interviewed separately using the Camberwell Assessment of Needs for the Elderly (CANE) (Reynolds et al., 2000; Orrell & Hancock, 2004). • PwD were interviewed about their cognitive status and quality of life. • CGs were interviewed about the	• PwD living alone have more unmet needs than those living with others, especially in the areas of looking after home, food, self-care and accidental self-harm. The most frequent unmet needs of PwD living alone and those living with others were similar, only have slightly different percentages as following: daytime activities (54.0%, 49%), company (52.0%, 33%), psychological distress (44%, 24.5%), eyesight/hearing (32.0%, 16.7%), and accidental self-harm (32.0%) only found more in PwD living alone. • However, no significant association between cognitive impairment and the number of unmet needs.	• The stages of dementia consisted of mild, moderate and severe. • The needs were rated by researcher based on their own views about the PwD's situation.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
				PwD's quality of life, social networks, behavioural and psychological symptoms, (BPSD), functional status and service used.		
6. Miranda-Castillo et al. (2010b) UK	Unmet needs, quality of life and support networks of people with dementia living at home	To identify the relationship between unmet needs, social networks and quality of life of PwD living at home.	• 152 PwD aged 60 and over living at home • 128 informal CGs who was knowledgeable about the PwD and spent a minimum 4 hours a week in direct contact with PwD.	• Cross-sectional study, interviews conducted by different assessors using The Camberwell Assessment of Need for the Elderly (CANE) (Reynolds et al., 2000; Orrell	• The most frequent unmet needs for PwD were daytime activities (50.7%), company (39.5%), help with psychological distress (30.9%), eyesight/hearing (22%) and accidental self-harm (15.1%). • Unmet need in PwD were predicted by a higher number of behavioural and psychological symptoms, low-community involvement social network, having a	• The stages of dementia consisted of mild, moderate and severe. • Different assessors may have different opinions when evaluating need. • Since the priorities of needs of PwD can be different from those of CGs and professionals, it is important to consider all

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
				& Hancock, 2004).	younger carer and higher carer's anxiety. • Social network, behavioural and psychological symptoms had and indirect effect on PwD's self-rated quality of life through unmet needs.	perspectives when making care plans.
7. Johnston et al. (2011) USA	Identification of community-residing individuals with dementia and their unmet needs for care	To evaluate a telephone screening approach to identify persons with memory problems who could be assessed for dementia in their homes and to develop a multidimensional needs assessment tool for determining the type and frequency of	• 13 PwD • 16 people with MCI • 14 people without cognitive impairment • All aged 70 and over. • Also, family member or friend was asked to participate in the home-assessment to serve as a proxy informant.	• A cross-sectional study • Using the Johns Hopkins Dementia Care Needs Assessment (JHDCNA) (Black et al., 2008) to identify unmet needs related to dementia.	The most frequent unmet needs being for a dementia workup, general medical care, environmental safety, assistance with ADL impairments, and access to meaningful activities.	• Some participants contributing the findings did not have dementia. • However, it was good that the authors separate the views of PwD from those with MCI.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
		unmet needs related to memory disorders in a community-based sample of elders aged 70 and older.				
8. Passos et al. (2012) Portugal	The needs of older people with mental health problems: A particular focus on dementia patients and their carers	To identify the met and unmet needs of the elderly and their carers and to analyse the relationship between those needs, psychopathology and functionality in order people with mental health problems.	• 75 people with the main diagnoses of depression (36%) and dementia (29.3%), aged 65 and over living at home • 52 CGs • 71 staff	• A Cross-sectional study The interviews were carried out by different assessors using The Camberwell Assessment of Need for the Elderly (CANE) (Reynolds et al., 2000; Orrell & Hancock, 2004).	• The main unmet needs found were daytime activities (40%), social benefit (13.3%), company (10.7%), psychological distress (9.3%), and continence (8%). • It different from their CGs which was found that psychological distress was the main unmet need.	• It was good that the authors separate the views of patients from their carers. • The care needs were rated by researchers and therefore, used of different assessors might have different opinions when evaluating needs. • Some participants contributing the findings did not have dementia. Thus, specific needs of those with early stage dementia cannot be

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
						separated from those without dementia.
9. Black et al. (2013) USA	Unmet needs of community-residing persons with dementia and their Informal caregivers: findings from the maximizing independence at home study	To determine the prevalence and correlates of unmet needs in a sample of community-residing PwD and their informal caregivers.	• 254 community-residing PwD aged 70 and over, who had informal CG • 246 informal CGs.	• A cross-sectional study • Using the Johns Hopkins Dementia Care Needs Assessment (JHDCNA) (Black et al., 2008; Johnston et al., 2011) to identify participant and CG dementia-related needs.	• 90% of PwD had unmet safety needs including fall risk management, home safety evaluation, wander risk management; • More than 50% had unmet needs for general health and medical care, and meaningful activities; and • Almost 33% had not received a prior evaluation or diagnosis, legal issues and advance care planning.	• The needs might not arise from entirely from the perspective of PwD as after assessment, the needs were judged by the assessors, although they were based on the interview with PwD and CG and observation.
10. Miranda-Castillo et al. (2013) UK	The needs of people with dementia living at home from user, caregiver and	To compare perceived needs according to user, their caregivers and professionals in a sample of	• 152 PwD aged 60 and over living at home • 128 informal CGs who were knowledgeable about	• Cross-sectional study • Interviews were carried out by different	• PwD reported fewer needs compared with their CGs and the professionals. • Most PwD rated psychological distress (21.6%), daytime activities	• Not specify about the stage of dementia. • Used of different assessors might have different opinions when evaluate the needs.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
	professional perspectives: a cross-sectional survey	people with dementia living at home.	the PwD and spent a minimum 4 hours a week in direct contact with PwD.	assessors using The Camberwell Assessment of Need for the Elderly (CANE) (Reynolds et al., 2000; Orrell & Hancock, 2004).	(14.5%) and company (12.8%) as the unmet need respectively. • Professionals rated higher needs in many areas of the CANE while PwD rated higher unmet needs for information. • Although the most frequent unmet needs reported by PwD, CGs and professionals were in the areas of daytime activities, company, and psychological distress, the needs of PwD from their opinion need to be concerned.	• Since the priorities of needs of PwD can be different from those of CGs and professionals, it is important to consider all perspectives when making care plans. • Specific needs of those with early stage dementia cannot be separated from those in the later stages.
11. Eichler et al. (2016) Germany	Unmet needs of community-dwelling primary care patients with dementia in	To describe the number and types of unmet needs of German primary care patients screened positive for dementia and	• 227 PwD aged 70 and over living at home; and • 128 informal CGs	• A Cross-sectional study • The “DelpHi-Standard” was developed based on the study DelpHi-	• More than 90% of PwD had three or more unmet needs. The majority of these were in the domains “nursing treatment and care” (38%), “social counselling and legal support” (20%), and	• Not specify about the stage of dementia. • Specific needs of those with early stage dementia cannot be separated from those in the later stages.

Authors, Date of publication, location	**Title**	**Study aim(s)**	**Participants characteristics**	**Method of data collection**	**Main findings**	**Critical Appraisal**
	Germany: prevalence and correlates	factors associated with the number of unmet needs.		MV (Dementia: life- and person-centred help in Mecklenburg-Western Pomerania) (Thyrian et al., 2012; Eichler et al., 2014)	"pharmacological treatment and care" (15%). • A higher number of unmet needs was significantly associated with the impairment of activities of daily living.	
12. Kerpershoek et al. (2018) Europe (Netherland, Germany, UK, Ireland, Sweden, Norway, Portugal and Italy)	Needs and quality of life of people with middle-stage dementia and their family carers from the European Actifcare study. When informal care alone may not suffice	• To describes the domains and level of needs in a group of people with middle stage dementia and their informal carers who do not yet use formal care. • To describes the relationship of needs and quality of life from different	• 451 people with mild to moderate dementia who do not use formal care at baseline. • Their informal CG who close contact with PwD at least once a week from 8 countries in Europe.	• Cross-sectional study • Interviews carried out by different assessors using The Camberwell Assessment of Need for the Elderly (CANE) (Reynolds et al., 2000; Orrell	• Needs were expressed in the domain of psychological distress, daytime activities, company and information. • PwD rated their unmet needs lower than their carers. • The level of needs reported was negatively associated with quality of life for both PwD and their carers.	• Used of different assessors might have different opinions when evaluate the needs. • Specific needs of those with early stage dementia cannot be separated from those in the later stages.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
		perspectives (i.e. self- and proxy-rated).		& Hancock, 2004) and Quality of life assessment (QOL-AD).		

Note: PwD = People with dementia, CG = Caregiver, AD = Alzheimer's disease, MCI = Mild Cognitive Impairment

Table 2.3 Data extraction and quality assessment of qualitative research

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
1. Aggarwal et al. (2003) UK	People with dementia and their relatives: personal experiences of Alzheimer’s and of the provision of care.	To elucidate the views and feelings of people with dementia in all stages and their relatives, and to find out how they perceive and receive care provision.	• 17 PwD and 18 relatives (from residential setting). • 10 PwD and 10 relatives (from day care centre).	• Qualitative study using semi-structured interviews. • 60 hours of videotape recorded the daily life of PwD in residential care. • 2 days of videotape recorded activities of PwD in day care (from the time they arrived at the centre until they left).	The PwD felt more satisfied in special day care than those in residential and nursing care due to the structure of the care services in each day in the residential care was limited. In particular, staff contact and activity, while there are two kinds of day care centre; a Community centre and Special Day Care Centres, which are more specifically for PwD. On the other hand, most of the relatives satisfied on the specific of the quality of care in the residential care and nursing care.	**Strength:** Both of PwD and relatives were interviewed separately, also, the findings. **Weakness:** • There is no explanation about inclusion and exclusion criteria for recruiting participants. • A videotape recorded perhaps contributed to participants being uncomfortable. • Specific needs of people with early stage dementia cannot be disaggregated. • The perspective of PwD from residential care setting and day care setting were combined.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
2. Innes et al. (2005) Scotland	Dementia care provision in rural Scotland: service users' and carers' experiences	To explore what service users perceive as the gaps and positive aspects of dementia service provision in rural Scotland.	• 15 PwD (aged 56-89 years) • 30 carers	• Semi-structured interviews were used to approach 15 PwD and 16 carers separately. • 14 carers were participated in focus groups.	• Information presented about the positive services and the gap in services. • As the study focused on the rural areas, the distance to services place which relate to a lack of transportation and the availability of care institutional were raised. • Also, activities in day care were needed more • However, the positive aspects of services were expressed as there was appropriate for their needs, loving care with genuine compassion from the staff, their service providers provided social life, stimulating by encouraging PwD to have activities and relationships	**Strength:** • PwD and CGs were interviewed separately. • Ongoing consent procedures. **Weakness:** • The entire views of both PwD and CGs were not presented separately. • PwD younger than 60 years old were included. • Specific needs of people with early stage dementia cannot be disaggregated. • One participant was not shown the agreement form since it used the term dementia and the service provider signed for her/him accompany with witness verbal consent. This can

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					with service provider was good.	be claimed that the information of the study was covered.
3. Gilmour & Huntington (2005) New Zealand	Finding the balance: Living with memory loss	To explore the experiences of living with memory loss and coping strategies of people with dementia.	• 9 PwD (aged 56-79 years).	• A qualitative study by using semi-structured interviews. • Interview lasting 30 minutes – 1.5 hour.	Regarding the experiences of people living with dementia there were three themes emerged: • Coming to terms with memory loss, this theme explained the process of coming to terms with a diagnosis of a progressive of illness was slow to present, the lack of meaningful information as what possible means for the future and what is helpful information. • Maintaining control, this theme highlights the strategies that the participants used to manage their abilities and	**Strength:** • Original perspective of PwD were presented. • Included only PwD. **Weakness:** • Authors did not state interview venue. Detail of interview process unclear. • Specific needs of people with early stage dementia cannot be disaggregated. • PwD who younger than 60 years old were included.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					the tensions between the need to maintain independence and control with the needing for support in everyday tasks. • Negotiating relationship, this theme focuses on the impact of illness on interaction with friends, families and health-care workers.	
4. Gill et al. (2011) Australia	Interaction in community-based aged healthcare: Perceptions of people with dementia	To understand how people with dementia perceive interaction in the context of their service experience	22 clients with mild to moderated stages of dementia (aged 80-92 years).	Semi-structured interview was conducted at participants' home with averaged 60 minutes.	• The need to be aware and encouraged to interact with their service providers were mentioned. • Participants appreciated both verbal and nonverbal communication that service providers approached. • Receiving support from the service providers and	**Strength:** • Perspectives of PwD directly presented. **Weakness:** • Focus is on the experience of using dementia service and most positive experiences were presented.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					rely on them as a dependent person were a positive experience since their needs were addressed. • PwD want to be heard and be offered the opportunity to be active participants in the service process. • They experienced the caring gentle as they need, however, many of them prefer not being treated as dependent. • The positive relation and interaction between care providers and PwD were raised, for example, they experienced the provider reliable, polite and respect them. • Several participants reported that they did not	

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					receive any service, only friendly relationship they were met.	
5. Lawrence et al. (2011) UK	Threat to valued elements of life: the experience of dementia across three ethnic groups	To examine the subjective reality of living with dementia from the perspective of people with dementia within 3 largest ethnic groups in the United Kingdom.	• 30 PwD (11 Black Caribbean, 9 South Asian, 10 White British). • Of these, there were 13 people with mild dementia, 9 people with moderate dementia, and 8 people with severe dementia. • Not all people had a formal diagnosis of dementia.	• A qualitative study by using semi-structured interviews. • Interview were spent lasted about 1 hour. • Together with using vignette related to the older PwD symptoms.	The PwD in different three ethnic groups have different perspectives of living with dementia. • Black Caribbean and White British worried about the symptoms and progression of dementia while South Asian perceived that it is normal for their aged. • Black Caribbean considered that family support was unavailable, as well as White British concern about they become a burden to their families. Unlike South Asian that confidence in family support.	**Strength:** • The original perspective of PwD were presented. • There was a variety sources of PwD. **Weakness:** • Specific needs of people with early stage dementia cannot be disaggregated. • Not all participants get a formal dementia diagnosis. Their perspectives might change if the know a diagnosis formally.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					Threat to valued element of life was a main theme. The participants concerned their valued roles, relationships and activities.	
6. Górska et al. (2013) Scotland	Service-related needs of older people with dementia: perspectives of service users and their unpaid carers	To develop a deeper understanding of the lived experience of people with dementia regarding their service-related needs.	• 12 PwD aged 77-93 years (median 84 years). • 19 unpaid carers.	• Narrative and individual semi-structured interviews. • Most interviews were conducted in the participants' home; two interviews were taken in the Queen Margaret University counselling room. • The average interview time with PwD was 40 minutes and 70 minutes with unpaid carers.	Although, participants satisfied with the service, there still the points of care need to be developed. Two themes of needs were identified: 1) Diagnostic services: the need for early diagnosis delivered through a comprehensive assessment package. Also, the gateway to service as a simple point of access information, service coordination and staff aware awareness especially in primary health care providers were mentioned.	**Strength:** • Both of PwD and relatives were interviewed separately. • Provide the option for persons who prefer interview together with a CG. **Weakness:** • The majority of participants were the CG and there was only one example of PwD perspective was presented.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					2) Post-diagnosis support: the needs were raised regarding for well-coordinate; greater continuity of care concerning the personal involved; enhance access to non-pharmacological interventions to support identity and social engagement.	
7. Innes et al. (2014) Scotland	Dementia diagnosis and post-diagnostic support in Scottish rural communities: Experiences of people with dementia and their families	To explore the reported difficulties and satisfactions with diagnostic processes and post-diagnostic support offered to people with dementia and their families living in the largest remote	• 6 PwD aged 58-82 years have been through the diagnostic process 6 months before interview; • 12 family members aged 45-80 years.	• Qualitative Interviews using semi-structured interviews and observation of participants' verbal and visual cues; • Each interview lasted between 60-90 minutes. • 2 interviews carried out at local NHS	The experiences of PwD and their carers were varied in the dementia pathway. Three points in the diagnostic process were explored and there were the themes emerged in each process: 1) Events and experiences pre-diagnosis; participants expressed their experiences about recognising the problem	**Strength:** • Paired interview offered to participants who need support or who had less potential to participate in the study. • Ongoing consent process used. **Weakness:** • Duration of interviews was long,

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
		and rural region in Scotland.		venue and 9 at participants' home.	of forgetfulness and confusion leading them to suspect memory problems, then they sought help; rationalization and denial were the experiences that CGs mentioned. 2) The experience of the diagnostic process; the explanation and information about available care and support were reported. 3) Post-diagnostic support; the services for support PwD were expressed satisfied but still need more services; CGs reported that group support for carers was appreciated, but the cost and transportation were challenged in the remote area. Additionally, a PwD	which can influence the concentration of PwD. • Interview PwD and CG together, PwD may find it harder to convey their views. • Specific needs of people with early stage dementia cannot be disaggregated. • PwD who younger than 60 years old were included.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					and one care reported family, friends, and neighbours can be other sources of support, while another carer felt reluctant to leave relative with someone; The direct approach in order to get information by asking questions from health professional and the appropriate format for information were raised by both PwD and CGs.	
8. Karlsson et al. (2014) 8 countries of Europe (England, Estonia, Finland, France, Germany, Netherlands,	Dementia care in European countries, from the perspective of PwD and their caregivers	To investigate PwD and their informal caregivers' views of inter-sectoral information, communication and collaboration throughout the trajectory of care,	• 25 PwD on average aged 66.11 years; • 112 informal CG.	• Qualitative research, conducting 20 focus-groups with an interview guide from 8 countries. • 17-18 participants per countries and 4-10 participants per focus group.	The relation to professional care was required were about establishing a trusting relationship between PwD and professional, tailor-made intervention and single person or organisation to contact. Professional knowledge and commitment,	**Strength:** • PwD and their CGs taking part in the study came from various settings. **Weakness:** • Balance between the number of PwD and CG not equal in each group. Therefore, the views or

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
Spain and Sweden)		in eight countries.		• The focus groups were carried out in the hospital, each group expected to spend about 90 minutes for discussion.	variation in service and care adapted to needs were also important.	the voices of PwD might be dominated by CG. • Not all groups included PwD. • There is only one example of PwD perspective presented.
9. Johansson et al. (2015) Sweden	Cognitive impairment and its consequences in everyday life: Experiences of people with mild cognitive impairment or mild dementia and their relatives	To explore experiences of cognitive impairment, its consequences in everyday life and need for support in people with mild cognitive impairment (MCI) or mild dementia and their relatives.	• 5 people with MCI • 8 people with mild dementia • 13 relatives.	• Grounded theory study with interviews • Interviews lasted between 40-95 minutes.	• People with MCI and dementia experienced cognitive changes that could be burdensome and changed activity patterns. • Both positive and negative experiences were expressed. Most people with MCI and PwD perceived the cognitive impairments affected their activity patterns included activities of daily living (ADL), instrumental activities of daily living (IADL) and social	**Strength:** • Original perspective of PwD presented. • Participants interviewed separately, also allowed the relative to be with as supporter if they prefer. **Weakness:** • People with MCI and PwD who younger than 60 years old were included. • Specific needs of people with early stage

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					interaction which were found it more difficult. • People with MCI and PwD dealt with impact using various strategies (e.g. taking notes, using a calendar, a dosage unit medication, use alarm watch, repetition, controlling). • People with MCI and PwD felt support in everyday life was natural, whereas some felt over-protected. • People with MCI or dementia wanted information about the disease and how cope with the symptoms. • Some people were satisfied with the day care services while others felt there was a lack of	dementia cannot be disaggregated. • Duration of interviews, which could influence concentration of PwD.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					interesting activities and participation. Transport was also an issue. • Most considered they were capable of coping on their own. Relatives noticed cognitive changes and activity disruptions to a greater extent and tried to be supportive in everyday life. Degree of awareness was varied and lack of awareness could lead to many problems in everyday life.	
10. Sutcliffe et al. (2015) UK	People with dementia and carers' experiences of dementia care and services: Outcomes of a focus group study	To present the views and opinions of people with dementia and carers on a range of topics including their positive and	• 11 PwD aged 54-94 years; • 16 CGs aged 58-87 years.	• Three focus groups using semi-structured guide. • Focus groups were carried out in the hospital, each group expected to spend	• There were both positive and negative experiences of using dementia care services. • They belief that it was a luck if they meet with good professionals.	**Strength:** • PwD and their CGs came from a variety setting. **Weakness:** • As focus groups included PwD and CGs,

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
		negative experiences of dementia care; access to information and its communication; and suggestions to improve dementia care and to discuss these in relation to the UK government and third sector agencies' objectives and strategies.		about one hour for discussion.	• It is a benefit to have group supports for carers or PwD. • However, at earlier stage they found that it was a long time for knowing the diagnosis was raised as well as the lack of resources for accomplishing the needed tasks in distant areas. • Moreover, the knowledge and information about dementia and the single point of contact & continuity of care from care providers were needed.	PwD may find it harder to convey their views. • There was no PwD in one group which all perspectives came from CGs. • PwD who have aged younger than 60 were included.
11. Svanström & Sundler (2015)	Gradually losing one's foothold – A fragmented existence when	To elucidate the phenomenon of living alone with dementia and having a	• 6 PwD aged 80-90 years living alone in their homes.	• Phenomenological • Fieldnotes from 32 visit participants at their home or healthcare facility	The findings revealed that PwD living alone had experienced with a feeling of loneliness, only a vague knowledge, longing	**Strength:** • Original perspective of PwD were presented. • Included only PwD.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
Sweden	living alone with dementia	manifest care need.		service varies about 10 minutes to 2 hours. - Individual interview 11 audiotape records approximately 35-65 minutes.	for other people and feeling of boredom.	- Findings were clearly presented - Recorded observations during the interviews also were explained. **Weakness:** - Stage of PwD not recorded.
12. Benbow & Kingston (2016) UK	'Talking about my experiences...at times disturbing yet positive': Producing narratives with people living with dementia	To build on previous work by investigating how narratives can be produced and used by families living with a dementia.	- 20 community-dwelling PwD (aged range 56-89) - 21 carers	- Participants were given the choice of preparing a written, audiotaped or videotaped narrative. - Process of speaking the narrative was started using a grand tour question. - Additional questions were not asked formally during the interview.	Four themes were identified - 'Relationships', PwD expressed positive about the support from their family. - 'Services', both positives and limitations of services were mentioned as the support and prompt referrals from staff, on the other hand, long time to get the investigate was raised.	**Strength:** - There were many options for participants providing data. - Original perspective of PwD were presented. **Weakness:** - Combination of older and younger adults who younger than 60 years old were included. - Stages of dementia were not specified.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					• ‘Prior experience of coping’, PwD and CGs expressed about the problem of cognitive impairment and • Having an ‘Explanation for the dementia’, this was various explanations from both PwD and CGs, for example, dementia is an act of God, or dementia can be explained as an illness of the brain. • Three themes were identified as possible additional stresses: ‘emotions’; ashamed, frustrated and hopeless were the feelings that PwD specified, • ‘Physical health’ was related to the underlying disease in PwD, and	• Findings not separated by perspective of PwD and CGs.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					• 'Identity' having an explanation for the dementia as they stressed about the continuity of self-identity.	
13. Powers et al. (2016) USA	'I wish they would remember that I forget:' The effects of memory loss on the lives of individuals with mild-to moderate dementia	To understanding specific areas and issues (e.g. perceived distress and dependency, family and role strain, self-esteem, social support) associated with the illness experience.	• 114 individuals with mild to moderate dementia (aged range 50-95), had family CG; • 131 dyads	• Interviews with participants with five open-ended questions. (It was a part of a larger randomized control trial of a dyadic Caregiving intervention.) • Interviews lasted between 45-60 minutes.	• About half of participants reported memory loss had no to minimum effect on their daily routine; around 20% of PwD felt embarrassed, frustrated and difficult with managing the cognitive and functional symptoms in their daily routine. • Cognitive and functional symptoms from memory loss was the most issue PwD concerned (i.e. forgetting name and appointment, losing one's independence, unable to	**Strength:** • Views of PwD were presented. **Weakness:** • It was a part of an intervention project of a dyadic Caregiving, which might influence the perspective of PwD at that time. • Using open-ended questions is good to provide participants' opportunity to answer but it might too limit only for these 5 questions. • Perspective of people with early stage

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					accomplish daily tasks and activities on their own.); the progression of this illness through loss of the personal dignity and do not want to be burden were concerned. • PwD reported that the memory loss decreased their interaction, involvement with friends and family as social withdrawal, while a small group of those with dementia reflected that they felt closer and stronger support from their family. • Some of the participants accepted the condition they had and not fear, while some of them worried about the cognitive and functional losses, fear of losing	dementia cannot be separated out. • Participants with dementia who had aged younger than 60 years old were included. • No explanation about the reason and conducting of including CGs.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					independence and sense of self. • PwD wished others understand the memory loss impact their cognitive and functional, understand their needs and feeling, and do not want to be careless or inattention.	
14. Risco et al. (2016) Spain	Perspectives About Health Care Provision in Dementia Care in Spain: A Qualitative Study Using Focus-Group Methodology	To identify the barriers and facilitators in dementia care with respect to information provision, communication, and collaboration from the perspectives of the PwD, family caregivers, and health professionals	• 7 PwD aged 63-81 years; • 11 family CGs aged 65-92 years; and • Healthcare providers.	• A focus-group by using interview guide; • Spent about 90 minutes for discussion in each group; and • Carried out in the hospital.	The findings were separated as the view of PwD and carer group and health professional group. There are three categories of the PwD and CGs: 1) Insufficient information provided by primary care physicians or outpatient clinic specialist was reported; 2) Specific dementia care needed for support PwD and their families as they will have the opportunity	**Strength:** • Focus group can gather a variety perspective and encourage participants to share their views. • PwD were at an early stage. **Weakness:** • As focus groups included PwD and CGs, PwD may find it harder to convey their views.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
		over the course of the illness.			to share care experiences with others; 3) Long-term care institutionalization was accepted as a positive service for PwD and family CGs, especially in advance stages of dementia. Three categories of healthcare professionals: 1) Insufficient communication between healthcare providers when PwD change from one provider to another; 2) Differential information according to disease stage must be related in order to better respond their needs at each stage; 3) Home care coordination between the primary health care team	• Perspective of PwD cannot separate out from CGs' views. • Duration of FG was long, which can influence concentration of PwD.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					and family CG is very important when a PwD is still cared at home.	
15. Stephan et al. (2018) 8 countries of European (Germany, Ireland, Italy, Netherlands, Norway, Portugal, Sweden and UK)	Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries	To explore the barriers and facilitators of access to and utilisation of formal care from the perspectives of PwD, their informal carers and health and social care professionals.	• 261 participants from 8 countries were conducted, involving - 51 PwD, - 96 informal carers - 114 professionals	• Focus groups were performed with PwD, informal carers and healthcare professionals separately. • Three –four PwD in the groups, only one group had two PwD. While, the groups of carers and healthcare professional consisted about five-eight people per group. • Interview guide was used. In the groups of PwD were interviewed lastly about 70	• There were three themes emerged related to 1) individual involved (characteristics of every individual involved), 2) the health and social care system, 3) overarching aspects. These themes consist of 16 categories describing barriers and facilitators. • PwD and their carers perceived as they often serve as barrier. Formal care was perceived as a threat to individual independence of PwD and was thus avoided as long as possible. • A healthcare professional serving as a	**Strength:** • Original perspective of PwD presented. • Included PwD from different countries. • PwD at an early stage were mainly included. **Weakness:** • Young PwD and PwD in later stages were included in some countries. • The stages of dementia were not specified and assessed prior to the focus groups. • Ability of people with later stages of dementia to discuss and express their perspectives

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
				minutes (26-120 minutes).	constant key person could be an essential facilitator to overcome these barriers. Contact should be initiated proactively, as early as possible, and a trusting and consistent relationship needs to be established. • Findings largely confirm previous research that barriers to accessing and using formal care still exit across Europe despite a number of national and European initiatives.	among the group of early stage dementia should be a concern. • Duration of discussion long which could influence the concentration of PwD. • Participants with dementia who had aged younger than 60 years old were included.
16. Portacolone et al. (2018) USA	The effects and meanings of receiving a diagnosis of mild cognitive impairment or Alzheimer's disease when one lives alone	To understand the effects and meanings of receiving a diagnosis of MCI or AD on the lived experience of older adults living alone.	• 13 older adults aged 65 years and above living alone and had a diagnosis of AD • 16 had a diagnosis with MCI	• Ethnographic interviews were used lasted approximately 1.5 hour and observed when visiting participants at home	There were three themes emerged • Relief, this theme explains the feeling of participants who received a diagnosis of AD. • Distress, this theme happened many times as	**Strength:** • Ethnographic interview is a good approach using to explore the experiences and perspective of participants. **Weakness:**

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
			6 members of their social circles	approximately 2.5 hours.	the news having an irreversible condition, the limits it caused, as well as the manner in which the diagnosis was given were often the sources of distress. • Ambiguous recollections, this explains the feeling of participants who had blurred recollections of their diagnosis, as well as blurred memories of the sequence of events leading up to it, making it difficult to gauge the effects and meanings of their diagnosis. • Not knowing what to do is the theme describes the long-term effect of receiving a diagnosis of MCI or AD that the participants did not know	• Not all participants had a formal dementia diagnosis. • There was a combination of perspectives of PwD and people with MCI. • Almost half of participants did not acknowledge that they have a diagnosis of AD or MCI, and this can affect to their perspective about the experience of living alone with cognitive impairment.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					what to do with regard to the treatment of their condition, and how to prepare for a likely worsening of their condition, which they would experience while living alone.	
17. Portacolone et al. (2019) USA	The precarity of older adults living alone with cognitive impairment	To examine the lived experience of older adults living alone with cognitive impairment to better understand their needs and concerns.	• 6 older adults aged 65 years and above living alone and had a diagnosis of AD • 6 had a diagnosis with MCI	• Ethnographic interviews were used lasted approximately 1.5 hours and observed when visiting participants at home approximately 2.5 hours.	There were three themes of lived experience of older adults living alone with cognitive impairment emerged • Awareness of cognitive impairment, this theme describes the distress stemming from the uncertainty of having cognitive impairment that has an unpredictable course. • Self-management of the challenges caused by the cognitive impairment;	**Strength:** • Ethnographic interview is a good approach using to explore the experiences and perspective of participants. **Weakness:** • Participants who had a diagnosis with MCI were included in the study. • There was a combination of perspectives of PwD and people with MCI.

Authors, Date of publication, location	Title	Study aim(s)	Participants characteristics	Method of data collection	Main findings	Critical Appraisal
					this theme focuses on the tendency of participants to feel responsible for managing their cognitive impairment. • Lacking tailored services, this theme describes the pressures stemming from the lack of appropriate services to independent living for persons with cognitive impairment.	

Note: PwD = People with dementia, CG = Caregiver, AD = Alzheimer's disease, MCI = Mild Cognitive Impairment

2.2.4 Data analysis

From table 2.3 and 2.4, this section aims to enhance more comprehensive understanding of the studies, know the strengths and weaknesses of those included studies and identify the gap in the knowledge base, make recommendations for future studies in order to encourage PwD to have an opportunity to share their perspectives and to contribute to society's understanding of their care needs. This phase focuses on findings categorised that were extracted from the all studies. Also, it discusses the quality/ advantages and limitation of the included studies that were evaluated under the quality appraisal tools to highlight gaps in current knowledge for the proposed study.

2.2.4.1 Data analysis of quantitative studies

I) Findings from the included quantitative studies

All included studies presented their findings by reporting the items from the assessment tool of each checklist divided into different domains. The results were analysed by descriptive statistics depending on the aims of each study.

As mentioned earlier that to improve the care for PwD, it is critical to understand their needs holistically. The findings can be categorised into the following holistic themes:

i) *Physiological needs*

   a. 'Safety needs': PwD and their CGs required environmental safety (Johnston et al., 2011; Black et al., 2013) in order to prevent and manage the risk of accident caused by physical and functional impairment. Examples include 'Assistance with Activity of Daily Living impairment' (Johnston et al., 2011), 'Fall risk management', 'Home safety evaluation', 'Wander risk management' (Black et al., 2013), 'eyesight/hearing' and 'accidental self-harm' (Miranda-Castillo et al., 2010a, b).
   b. 'General health and medical care' (Johnston et al., 2011; Black et al., 2013) including with 'stage and symptoms of dementia' (Edelman et al., 2006), 'information about dementia' (van der Roest et al., 2009), 'evaluation and diagnosis of dementia' (Black et al., 2013) were the information needs identified.
   c. 'Daytime activity' (Miranda-Castillo et al., 2010a, b, 2013; Passos et al., 2012; Kerpershoek et al., 2018) and the need for support groups for people

with memory loss. Also, the need to participate in research studies regarding memory loss was raised.

d. 'Nursing treatment and care' was the major unmet need detected in the study of Eichler et al. (2016) and it was followed by the need of pharmaceutical treatment and care.

ii) Psychological needs

This aspect can be divided into three main topics:

a. 'Meaningful activities' was the need commonly raised by PwD and their CGs (Edelman et al., 2006; Johnston et al., 2011; Black et al., 2013).

b. 'Coping and challenging symptoms' of dementia was reported as a need by PwD (Edelman et al., 2006) also people with early stage dementia mentioned especially 'restlessness/agitation' and 'swings of mood' (Chung, 2006). Three studies reported that PwD rated the item of 'psychological distresses' higher rather than CGs and professionals who rated the item of 'daytime activities' as more important (van der Roest et al., 2009; Miranda-Castillo et al., 2010a, 2013). In contrast, the study of Passos et al. (2012) reported that 'daytime activities' was the most unmet need and 'psychological distress' was lower rated whereas it was the main unmet need in CGs.

c. 'Making decisions and planning ahead' was also the need that PwD in the early stages most commonly reported (Chung, 2006).

iii) Social needs

Social needs were perceived differently by PwD and CGs. Two studies showed that the needs rated as the most unmet by PwD differed from the views of CGs and professionals (Edelman et al., 2006; Miranda-Castillo et al., 2013). For example, people with Alzheimer's disease were interested in information about support groups for people with memory loss and participation in research studies for memory loss while CGs were interested in the information about the stages and symptoms of Alzheimer's disease and approved drug treatments for memory loss (Edelman et al., 2006). The common needs raised in relation to this aspect was 'social interaction', in particular taking part in activities (Meaney et al., 2005; Chung, 2006) and company (van der Roest et al., 2009; Miranda-Castillo et al., 2010a, b; 2013; Passos et al., 2012) as well as the importance of communication (Edelman et al., 2006). It also included the need for 'social counselling and legal support' (Eichler et al., 2016) which focused on power of attorney and the right to get support.

The above themes show that care needs take on many dimensions; physical, psychological and social. Additionally, the care needs of PwD are diverse depending on the severity of the dementia and the different background contexts of each participant (Chung, 2006, Black et al., 2013). It is important to note however that the issues considered to be important by the CGs are different from those reported by PwD (Edelman et al., 2006; Miranda-Castillo et al., 2010b, 2013). Further, only the study of Miranda-Castillo et al. (2010b) reported that unmet needs in PwD were predicted by a higher number of behavioural and psychological symptoms, low-community involvement social network, having a younger carer and higher carer's anxiety. Meanwhile, the study of Eichler et al. (2016) found that the higher the number of unmet needs, independent of age, gender, living situation, presence of an informal caregiver, cognitive impairment, and depression, these were associated with greater impairment in activities of daily living. However, none of these studies explain the cause of the unmet need or how these needs could be addressed.

II) Learning from the included quantitative studies

The researchers all demonstrate appropriate links between the data, findings and conclusions.

i) Value of the research

The results showed that needs assessment would be beneficial to individuals with dementia to the delivery of patient centred health and social care and that they provided a good starting point for improving community care for PwD (Meaney et al., 2005). They also provided a good starting point for improving community care for PwD by collaborating with healthcare providers and social service agencies to regularly monitor and make a care plan to provide a high level support for PwD (van der Roest et al., 2009; Miranda-Castillo et al., 2010a, b, 2013; Black et al., 2013).

Several authors recommend further studies to confirm the preliminary findings and suggest that further research not only focus on the needs of PwD but also focus on the care they want (Meaney et al., 2005). Chung, (2006) and Edelman et al., (2006) suggest a need for a longitudinal approach to study more than needs but to use this method to gain an understanding of the pattern of how care needs are changed over the course of dementia.

ii) *Appropriateness of assessment tools and administration*

All assessment tools used to investigate the needs and unmet needs of PwD were good as they were categorised in different domains. PwD were asked to complete questions regarding their care needs which helps to answer the research purposes directly. Participants were interviewed face to face at their home to help them feel convenience and comfort. The assessors who were trained to use the assessment tools asked participants to answer the questionnaire. The assessors were multidisciplinary staff working with PwD, CGs, or in the gerontological field. Therefore, it was helpful that they had experience of approaching with PwD or older people.

Additionally, using the care needs checklist to assess the needs and unmet needs of PwD and their CGs was good since each assessment has been piloted before, and demonstrated good validity and reliability. The assessment tools were translated into their language in a country where people did not use English. This approach can help ensure the results were valid, reliable and can be generalisable to a larger population.

iii) *A large number and variety of participants*

Most studies had large sample size which can enhance accuracy, validity and reliability of results. Although studies were predominantly conducted in Western countries, there was one study conducted in Hong Kong (Chung, 2006). It was helpful to know that although there were different contexts, there was a similar unmet need from other countries in the West regarding social interaction.

Critical appraisal of these included quantitative studies led to the learning identified below.

i) *The limitation of care needs assessment*

In all included studies, there were commonalities in authorship and tools used to guide data collection. There might be a limitation in using an assessment where the needs were identified as items and are not interchangeable because it can be prone to preconceived ideas and limit people's opinions. Although the needs were divided into different domains, it can be seen that there might be overlap between items in different domains, for example, ‘not recognising face’ is a cognitive (‘thinking and memory’) need but also a social interaction need, recognising family and other people. Being ‘withdrawn behaviour’ is under ‘social interaction’ but it is also conceptual in the domain of ‘Behaviour and mental state’ needs (Meaney et al., 2005).

The Care Needs Assessment Pack for Dementia (CareNap-D) (McWalter et al., 1998) assessment combined the opinions of PwD and CGs, thus after analysis, both of their needs could not be disaggregated (Meaney et al., 2005). Assessments were conducted by assessors, who interviewed and observed the needs of PwD. Although they were trained in the judgement of needs, to avoid the inter-rater variability, one assessor was recommended (Meaney et al., 2005). Further to this, according to Meaney et al. (2005) the limitation of the use of the assessment was that the care needs assessments do not attempt to elucidate the causes of the needs, they rather just attempt to identify the needs. There is no description about what each item of the needs means or what its relevance is, also there is no explanation of what the cause of those needs is and how those PwD can be responded to in order to meet their needs.

ii) Participants taking part in research

Although the title and aims of all included studies mentioned that the studies focused on the needs of PwD, CGs also were involved in the research (Meaney et al., 2005; Chung, 2006; Edelman et al., 2006; Johnston et al., 2011; Miranda-Castillo et al., 2010a, b; Eichler et al., 2016). Five studies identified that the researchers would determine and compare the needs of PwD and their CGs (van der Roest et al., 2009; Miranda-Castillo et al., 2013; Passos et al., 2012; Black et al., 2013; Kerpershoek et al., 2018). Two studies also included people with MCI, depression (Passos et al., 2012) and persons who did not have cognitive impairment, or no dementia diagnosis (Johnston et al., 2011). Therefore, some participants contributing to the findings did not have dementia and were not therefore representative of PwD. Additionally, although there were many research participants in many studies and many areas, limitations are acknowledged in some studies, including small participant numbers, and research being in discreet locations and therefore not generalisable (Chung, 2006; Edelman et al., 2006).

All twelve studies involved caregivers in the assessment, whether as proxy informants, or as participants (Edelman et al., 2006; van der Roest et al., 2009; Miranda-Castillo et al., 2010a, b, 2013; Black et al., 2013). Four studies did not separate PwD and CG perspectives thus limiting value (Meaney et al., 2005; Chung, 2006; Johnston et al., 2011; Eichler et al., 2016). Further researchers state that as the CGs were included to the study, so the opinions of PwD and CGs cannot be distinguished since they were interviewed together and had the same instrument applied to both groups (Meaney et al., 2005).

It should be noted that when PwD find it difficult to express their views or who have a lack of capacity to understand questions due to the severity of dementia, that this can influence their participation and ability to express their views, so the CGs would be a proxy providing the opinions instead. For example, in the case of PwD in the severe stage who cannot engage and be interviewed, the needs were informed by only their CGs (Chung, 2006; Miranda-Castillo et al., 2013). Also, as the reports identified that there were some differences between the views of PwD and their CGs view (Edelman et al., 2006; van der Roest et al., 2009; Miranda-Castillo et al., 2013) this leads me to consider that the needs of PwD from their perspectives need to be carefully examined.

iii) Mixed stages of dementia

The stages of dementia were not specific for participants recruited in all of the included studies and PwD who participated in these studies were at different stages of dementia. This makes it difficult to identify the specific needs at each stage of dementia, and the needs of people with early stage dementia cannot be separated out from those in the later stages. Edelman et al's (2006) study included people with Alzheimer's disease having mild stage on average (mean Mini-Mental State Examination (MMSE) score was 20.4), and Chung (2006) and Black et al's (2013) studies also included PwD in the early stage of the condition. Only Chung's (2006) study separated out PwD and their carers identified needs in their reported results.

In the quantitative studies assessments may not be entirely from the perspective of PwD. Using an assessment which assesses for short time has limitations and reassessment as part of routine monitoring should be considered (McWalter et al., 1994). It may also be better if the needs of PwD are asked and taken into account at an early stage in the condition when they have capacity to express needs and plan for the future. Further, in order to explore the experiences of living with dementia including PwD needs should be assessed by using verbal and non-verbal means and time should be taken to hear and understand the voices of PwD.

To conclude, care needs of PwD identified by using assessment tools can be categorised holistically as physiological, psychological and social needs. These papers present these identified needs combining the views of PwD in all stages together with the views of people who did not get a formal diagnosis of dementia and also their CGs despite PwD prioritized differently from CGs in some domains. Therefore, as the specific needs of older people with early stage dementia cannot be separated from those in other stages of dementia and their CGs, we still cannot clarify causality of their needs and how to address them.

2.2.4.2 Data analysis of qualitative studies

I) Findings from the included qualitative studies

In relation to the findings presented, there were clearly stated results in all included studies. The findings were presented as themes/categories presenting participants' perspectives.

Results from the seventeen studies can be divided into two major finding categories firstly, the diagnostic process and secondly, post-diagnostic support. Findings from each study were related to the aim of explaining the experience and needs of PwD.

i) The diagnostic process

The findings discussed under this major theme all relate to the older persons experiences of going through the assessment process which led to their diagnosis of dementia and their needs can be explained by three issues.

a) Late diagnosis

In relation to this practice, the barrier to accessing services and delayed diagnosis were the issues pointed to in the included research studies (Górska et al., 2013; Karlsson et al., 2015; Sutcliffe et al., 2015). PwD felt the service providers were less aware of signs and symptoms and investigate the problem as they expressed that they were waiting long times for assessment and diagnosis (Gill et al., 2011; Górska et al., 2013; Sutcliffe et al., 2015; Benbow & Kingston, 2016).

b) Lack of explanation

It is not only a lack of general practitioners' awareness which PwD mentioned, but also a lack of clarity and poor explanation of the assessment and referral process (Innes et al., 2014; Johansson et al., 2015; Sutcliffe et al., 2015; Stephan et al., 2018). When PwD are confronted with a difficult situation, they need to be clear about the delivery of diagnosis and the comprehensive assessment which might assess the function of daily life and their environment (Górska et al., 2013) as well as the information about the disease (Johansson et al., 2015; Portacolone et al., 2018). Helpful information can lead to decreasing distress (Górska et al., 2013).

c) Awareness of cognitive changes is important

PwD suggest that cognitive changes which are related to dementia need to be taken seriously and that staff should know the signs to look for. They reported that the process of going to the hospital for assessment and diagnosis was time consuming (Sutcliffe et al., 2015) and sometimes distressing (Górska et al., 2013; Portacolone et al., 2018).

ii) Post-diagnostic support

PwD expressed positive experiences of receiving dementia care. They felt supported to address the care they need from healthcare providers (Benbow & Kingston, 2016; Stephen et al., 2018), staff (psychiatrist), family (Innes et al., 2014) and social (Sutcliffe et al., 2015). They also expressed that they received support with the good relationship (Gill et al., 2011) as well as staff encouraging them to have activities (Innes et al., 2005).

However, although the positive experiences were mentioned, negative experiences of the dementia journey were also expressed. After diagnosis, most thought that early support was crucial (Karlsson et al., 2015). The social contact and information about dementia care were needed to maintain their quality of life (Górska et al., 2013; Innes et al., 2014; Karlsson et al., 2015; Sutcliffe et al., 2015). Post-diagnostic support relates to the findings from the included studies on the experiences and needs of persons with a diagnosis of dementia and are examined as follows:

a) Insufficient information provided

PwD mentioned insufficient information provided (Aggarwal et al., 2003; Innes et al., 2014; Sutcliffe et al., 2015; Risco et al., 2016) and understanding of dementia was variable (Lawrence et al., 2011). Congruent with other studies, participants stated that there was less communication between the health professionals and them (Aggarwal et al., 2003; Sutcliffe et al., 2015; Risco et al., 2016), lack of meaningful information about dementia (Gilmour & Huntington, 2005), less explanation information about available care and support (Innes et al., 2014; Portacolone et al., 2018). These led them to realise the service response to reserve following a diagnosis was slow and attributed this to a lack of staff awareness (Sutcliffe et al., 2015).

Moreover, there was insufficient public information via social media and a lack of doctor awareness of the cause and treatment of dementia (Górska et al., 2013; Sutcliffe et al., 2015). In relation to information access, the point of access to information as a specific person and/or organisation to contact were required in order to provide well-defined pathways of dementia care (Górska et al., 2013; Karlsson et al., 2015).

According to Aggarwal et al's (2003) study, PwD felt more satisfied in special day care than residential and nursing care. Structure of care services in the residential setting was limited, in particular, the staff contact and activity. In this study there were two kinds of day care centre; a Community Centre and Special Day Care Centres, which were more specifically for PwD. Participants explained that there were many activities and staff to serve in the Special Day Care Centres. On the contrary, most of the relatives were satisfied about the quality of care in residential care and nursing care. The limitation of dementia care knowledge of the CGs and the provision of full-time care services were the reasons CGs were satisfied with the service. CGs were concerned to have services for when PwD lose the ability to communicate and when they have mental health problems.

b) Information and knowledge about dementia to support PwD and their family throughout the dementia trajectory

Information and knowledge about dementia is essential (Gilmour & Huntington, 2005; Górska et al., 2013; Innes et al., 2014; Johansson et al., 2015; Karlsson et al., 2015; Risco et al., 2016; Stephan et al., 2018; Portacolone et al., 2018). PwD and CGs need information that is easily accessed or obtained by directly approaching a single professional as an expert (Górska et al., 2013; Innes et al., 2014; Johansson et al., 2015; Karlsson et al., 2015; Risco et al., 2016).

c) Specific dementia care centre

Specific services for dementia in relation to activity in day care, social support, non-pharmacological or long-term care were needed (Innes et al., 2005; Aggarwal et al., 2003; Karlsson et al., 2015; Sutcliffe et al., 2015; Risco et al., 2016; Portacolone et al., 2019). Most participants valued the service they used and the relationship between them and staff, and the supportive care provided (Aggarwal et al., 2003; Innes et al., 2005; Gill et al., 2011; Innes et al., 2014: Benbow & Kingston, 2016; Stephan et al., 2018). Residential care was not a preference for south Asian people (Lawrence et al., 2011), there were different views of many people from various Western countries, Australia and New Zealand. They considered that moving from home to a care home was needed because family member may less possible and suitable source to support them when (Gilmore & Huntington, 2005; Lawrence et al., 2011). However, the need for a service to support PwD persists because there are a lack of dementia care services as well as a lack of transportation to travel to and from services, especially in the rural areas (Innes et al., 2005; Innes et al., 2014; Johansson et al., 2015).

d) Continuous visiting as a good collaboration

PwD desired good relationships and involvement in society, they need to be motivated to participate in social activity (Gilmour & Huntington, 2005). Although home care providers visited PwD at home, they need to consider duration of visiting and the importance of listening to the person, to PwD (Stephan et al., 2018). They need to pay attention to meaningful action to support PwD to decrease feelings of loneliness (Svanström & Sundler, 2015). Participants wanted ongoing support from health professionals post-diagnosis (Stephan et al., 2018; Portacolone et al., 2018), this can increase their sense of security and trust (Gill et al., 2011; Górska et al., 2013; Karlsson et al., 2015). Practitioners should be flexible and creative in providing care (Karlsson et al., 2015; Sutcliffe et al., 2015).

e) Need of understanding and valuing

PwD have to deal with the impacts of cognitive changes which influence their ability to manage activities of daily living, instrumental activity of daily living (ADL, IADL) and social interaction (Lawrence et al., 2011; Johansson et al., 2015; Powers et al., 2016; Portacolone et al., 2019). Cognitive changes lead to feelings of fear about the future, embarrassment, frustration, hopelessness, upset, distress, and stress about continuity of self-identity (Gilmour & Huntington, 2005; Benbow & Kingston, 2016; Powers et al., 2016; Portacolone et al., 2018, 2019). PwD expressed the need to be heard and offered opportunities to be an active participant in the service process (Gill et al., 2011). They wanted to be involved in decision making about their care (Stephan et al., 2018) and be socially active and have other people understand their illness and their needs and treat them with respect (Gilmore & Huntington, 2005). PwD did not want to be treated as dependents (Powers et al., 2016). They needed to maintain independence in everyday activities (Gilmore & Huntington, 2005) and did not want to be a burden to their family (Stephan et al., 2018).

f) Dementia care should be planned

Healthcare providers should plan care with PwD by focusing on their needs (information to get support, psycho-social support). The individual needs to be central in planning care that will provide emotional support, promote confidence (Aggarwal et al., 2003; Gill et al., 2011; Innes et al., 2014; Karlsson et al., 2015), offer a sense of security (Stephan et al., 2018) and reduce sense of loneliness (Svanström & Sundler, 2015).

PwD and their CG want information and knowledge about dementia (Aggarwal et al., 2003; Innes et al., 2014; Sutcliffe et al., 2015; Risco et al., 2016; Stephan et al., 2018; Portacolone et al., 2018). There is a need to improve communication between health professionals, PwD and CG. It is essential that health professionals understand the stages of dementia so they can tailor care accordingly (Aggarwal et al., 2003; Górska et al., 2013; Sutcliffe et al., 2015; Risco et al., 2016). At present PwD and CG suggest that care is a matter of “pot-luck” depending on the knowledge and skill of the care provider (Sutcliffe et al., 2015).

g) The PwD should be taken into account

There are many dementia recommendations and protocols which are not yet fully implemented (Sutcliffe et al., 2015). For example, the findings suggested that the services offered to help PwD should focus on tailored care and follow up as soon as people get a diagnosis, especially people living alone (Svanström & Sundler, 2015; Portacolone et al., 2018). Keeping people connected socially and offering opportunities to talk about their experiences and feelings can support social engagement as well as respond to their psychological and emotional needs (Gill et al., 2011; Górska et al., 2013; Svanström & Sundler, 2015; Benbow & Kingston, 2016; Powers et al., 2016). Comprehensive assessment should integrate functional and environmental aspects when assessing a person's ability in the diagnostic process rather than only cognitive assessment (Górska et al., 2013). It is important to understand about their needs to maintain independence (Gilmour & Huntington, 2005).

II) Learning from the included qualitative studies

This section will summarise the key lessons learnt from the critical appraisal of the included research studies. This learning will be used to develop the research question as well as plan and justify the research design for the proposed study.

i) Value of the research

Overall, the results of these included research articles are valuable for the information they provide on developing dementia care. In order to create new care models for PwD, the issues they expressed should be involved in the existing dementia care models/ policies by integrating their perspectives as holistically as possible.

Some studies suggest a new practice framework should be implemented in order to improve the quality of information provided in each dementia phase by addressing specific care needs (Innes et al., 2005; Risco et al., 2016; Stephan et al., 2018). Adoption of new communication and collaboration between healthcare providers and PwD and their CG is needed (Gill et al., 2011; Górska et al., 2013; Karlsson et al., 2015; Benbow & Kingston, 2016; Powers et al., 2016; Risco et al., 2016; Stephan et al., 2018), this brings tangible benefits to everyone involved in dementia care (Risco et al., 2016). Research on outcomes of new strategies is recommended (Karlsson et al., 2015).

Staff in residential care, should be trained in communication skills, person-centred approaches to achieve balance of power between staff and residents to value and to understand the residents' views (Aggarwal et al., 2003). Evidence from these studies can inform government and policy makers to target interventions and make information available in many ways. The researcher attempted to present the diagnostic process throughout post-diagnostic support (Górska et al., 2013; Innes et al., 2014; Karlsson et al., 2015; Benbow & Kingston, 2016; Risco et al., 2016) and also promote the client-centred service (Aggarwal et al., 2003; Gill et al., 2011) as a long-term supportive services (Portacolone et al., 2018, 2019).

ii) Best practice in researching with PwD using qualitative studies could be the way of approaching PwD

a) The participants in all included studies were recruited via gatekeepers from each setting

Participants were included from different health institutions such as residential settings, day care centres, primary care, memory clinics, specialist health care services, hospitals, counselling agencies, support group, community mental health groups, or known contact persons from other parts of project.

This approach to recruiting PwD by liaising with gatekeepers may be a good approach for the researchers because the gatekeepers might know and be familiar with the PwD. On the other hand, an important issue of concern is that some PwD may be excluded by the gatekeeper depending on how they understand the aim of study or what the relationship between the gatekeeper and potential participant might be (Bartlett & Martin, 2002).

b) The capacity of PwD to consent and to participate in research

With respect to the Mental Capacity Act (HMSO, 2005) it is important that the person consenting to take part understands the information, retains the information, has the ability to make a decision to participate in the study and is able to communicate. It is important that researchers are concerned about the capacity of the PwD since it can empower the potential participants to either take part or not and can ensure that the information collected is from a real representative of this group.

c) Appropriateness of qualitative approaches

In each case, a qualitative approach was appropriate as studies explored the views of people and required in-depth information. However, there is an issue of concern. Focus group studies including PwD and CGs offered differing information sources, however it is possible to lose the voice of PwD if CGs and PwD were in the same group because CGs might speak more than PwD. Aggarwal et al. (2003), Innes et al. (2005) and Gill et al. (2011) advocate direct communication with PwD as CG may not always have a complete understanding of how PwD feel, they may have diverse experiences in living with dementia and may not have accurate knowledge about services.

Total duration of interviews varied from 30-90 minutes. In the studies that included observation, the duration of visiting varied from 10-150 minutes. Focus groups lasted between 26 and 120 minutes. The duration of a research interview or focus group conducted with PwD is an important issue to be considered because the longer the duration for an interview perhaps impacts on the concentration of the PwD.

iii) PwD consent to participate in research is a concern

The process of gaining informed consent from PwD started with providing research information to potential participants. Information was shared by telephone or in person, at memory clinic or their house. Two studies clearly explained the process of gaining consent (Innes et al., 2005; Portacolone et al., 2018). In two cases researchers provided information a few weeks in advance so people had time to read and note any questions to decide if they were interested in taking part (Gill et al., 2011; Sutcliffe et al., 2015). Ongoing consent procedures were reported in five studies (Innes et al., 2005, 2014; Gilmour & Huntington, 2005; Svanström & Sundler, 2015; Portacolone et al., 2018). Some studies involved family members in the first meeting to discuss the research and consent (Gilmour & Huntington, 2005; Svanström & Sundler, 2015). Researchers were sensitive and attempted to avoid undermining by giving a chance to participants to decide to take part in the study. In other studies, the authors only stated that they gained consent from participants before conducting study.

iv) Good explanation of data analysis process

Overall, there were good explanations in all studies regarding the detail of data analysis processes to ensure the trustworthiness. Transcripts were read to get the sense of content (Risco et al., 2016), to check accuracy and missing information (Sutcliffe et al., 2015; Benbow et al., 2016), qualitative content analysis using open coding was performed in some studies constructed the initial coding and sub-coding (Lawrence et al., 2011; Górska et al., 2013; Górska et al., 2013; Sutcliffe et al., 2015; Innes et al., 2014; Stephan et al., 2018). This was followed by identifying themes and sub-themes (Gill et al., 2011; Górska et al., 2013; Innes et al., 2014; Johansson et al., 2015; Sutcliffe et al., 2015; Powers et al., 2016; Risco et al., 2016). In some studies data management tools were used, for example Nvivo (Innes et al., 2005; Benbow & Kingston, 2016), Atlas-Ti (Portacolone et al., 2018, 2019), and MAXQ-DAplus version 11 (VERBI GmbH, Berlin, Germany) (Stephan et al., 2018). In some studies, to improve trustworthiness, data were analysed by more than one researcher and analysis compared and adjusted. Studies did not report on non-verbal communication.

These studies highlight good practice in researching with PwD however, all have limitations.

i) Appropriateness and value of the appraised research

Overall, the assessed studies have contributed to an increased understanding of the experiences of PwD and those of their family CGs on living with this condition and using care services. They have provided important information for health professionals and governments to develop dementia care as well as plan services for people in this group in the future.

However, although the research appraised for this literature review has merit, the following discussion highlights some of the weaknesses/gaps in the included research articles. The learning from these limitations will be used to improve/inform the proposed research design in this study.

ii) Views of PwD

The main purpose of the seventeen research studies was to explore the experiences and perspectives of PwD/ CGs/ the professional on the dementia care. There are important issues regards the views of PwD to consider.

a) The sample in the seventeen studies is culturally homogeneous.

All included studies were conducted in developed countries with similar cultures. There remains a gap in knowledge about the needs of PwD in developing countries where culture and context will be different (Krishnamoorthy et al., 2010).

b) The experiences documented in the seventeen included studies are not representative of the voices of PwD.

Included studies do not all privilege the voices of PwD. Many have also drawn on the views and experiences of CGs. It is important to recognise that views may be entirely different (Tetley, 2013; Denning et al., 2013). CGs views may be dominant or less positive about the quality of life of PwD (Denning et al., 2013; Sheehan et al., 2012; Tetley, 2013). Whilst it is useful to involve CGs and healthcare providers to gain a variety views and experiences, it should be clear that views need to come directly from PwD.

iii) Potential participants

Even people with later stage dementia may have capacity to communicate, making the decision to take part in the study and express their views, given the right time and support (Tetley, 2013). However, the persons with early stage dementia have more possibility to be able to understand the aims of the study and decide to participate and capable to express their feelings rather than PwD at a later stage (Risco et al., 2016).

Included studies did not all separate the needs from PwD in early stage from those in later stage dementia. In my study, I would focus purely on the Thai older persons with early stage dementia. Information from them can be used to inform guidelines for caring to slowdown symptoms' severity and impacts from the beginning of the illness.

2.2.5 Presentation of key findings from the literature

Key points from qualitative and quantitative studies are summarised in Tables 2.4 and 2.5.

Table 2.4 Findings from quantitative studies

	Physiological needs	**Psychological needs**	**Social needs**
Needs identified using assessment tools (12 studies)	• Safety needs	• Meaningful activities	• Social interaction
	- Environment safety - Assistance with Activity of Daily Living impairment - Fall risk management - Home safety evaluation - Wander risk management - Eyesight/hearing - Accidental self-harm	• Coping and challenging symptoms - Restlessness/agitation - Swings of mood - Psychological distresses	- Taking part in activities - Company - The importance of communication
		• Daytime activities	• Social counselling and legal support
		• Making decisions and planning ahead	
	• General health and medical care		
	- Stage and symptoms of dementia - Information about dementia - Evaluation and diagnosis of dementia		
	• Daytime activity		
	- Support groups for people with memory loss		
	• Nursing treatment and care		
	- The need of pharmaceutical treatment and care		

Table 2.5 Findings from qualitative studies

Experiences	Diagnostic Process	Post- Diagnostic support
Problems/Barriers identified from the perspective of PwD (17 studies)	• Late diagnosis	• Insufficient information provided
	- Lack of accessing service - Delayed diagnosis - Inadequate awareness of the service providers - Inadequate awareness of the service providers	- Communication with professional - Lack of explanation information about available care and support - Timeliness of service response - Lack of public information - Lack of awareness from caregiver and professional
	• Lack of explanation	
	- a lack of clarity and less explanation of the assessment and referral process	
Needs identified from the perspective of PwD	• Awareness of cognitive changes is important	• Information, knowledge about dementia to support throughout the dementia trajectory
	- The cognitive changes relating to dementia signs need to be taken seriously by assessing to get the diagnosis.	• Specific dementia care centre
		• Continuous visiting as a good collaboration
		• Need of understanding and valuing
		• Dementia care plan should be concerned to address the people with dementia needs
		• The people with dementia should be taken into account

Learning from the seventeen included studies can provide the foundation for planning my research process. The next section explores the grey literature.

2.3 Grey literature

For completeness grey literature was searched, particularly for personal accounts of living with dementia using the search terms as before in Google, Google Scholar and dementia specific websites and journals (for example from the Alzheimer’s Society) and book sellers (for example Amazon). I found little information regarding the perspective of PwD themselves. There are few channels for PwD to convey and share their experiences and expressions of their life with dementia. Most information was contributed by people with early onset dementia. This section provides an overview of relevant literature. Included data is summarised in Table 2.6.

Table 2.6 Overviews of PwD on living with dementia and care needs from personal accounts and some public channels

Personal account, Date of publication, Location	Source	PwD's characteristics	Methods of data publication	Main views
Synder (1999) USA	Book	The author included people with Alzheimer's disease in various stages and ages.	Informants Interviewed	From experiences and perspective of older people with AD on their health condition, the needing for accompany is acknowledged, they noted that continuing meaningful activities as they used to do before getting a diagnosis is helpful to maintain their feeling of involvement.
Bandler (2012) USA	Newsletter	A 64 year old man was diagnosed by early onset dementia.	Organisation interviews	He has been working in the Foreign Service for about 27 years. He was diagnosed in 2008. There were two main clues related to his needs to live well with dementia: • He stated that "it is important to me to live my life and try to do everything I can and want to do now, as I am aware it is a progressive disease". • The improvement of diagnostic testing and roadmap for support patient and family is needed.
Bryden (1996, 1998, 2012, 2018) Australia	Book	A woman was diagnosed with early onset dementia when she started writing her book (aged 71 years).	Personal writing	She was diagnosed with early onset dementia when she was 46 years old, and she started writing her experience since then. She explained her experience as a PwD that PwD still has a meaningful and need to continue her sense of self.
Mitchell (2018) UK	Book/ Personal Blog	A woman was diagnosed with early onset dementia in 2014 (aged 64 years).	Personal writing	She was diagnosed with young onset dementia at 58 years old. She shared her experiences regarding her onset symptoms and when she was diagnosed with dementia. Her daughters visit her often to help in cases of she needs something. The main need

Personal account, Date of publication, Location	**Source**	**PwD's characteristics**	**Methods of data publication**	**Main views**
				focuses on preference to live independently and to not disturb the family.
Gladys (2019) UK	website of Alzheimer's society	82 years old woman	Informants Interviewed	The needs for being respected and company were raised. She stated that "We are the same people, just with a diagnosis of dementia, treat us like anyone else". "I need somebody to really talk to me, to interact with me. To want to be there".
John (2019) UK	website of Alzheimer's society	68 years old man	Informants Interviewed	Needing for being included was raised as he stated that "If you have dementia, you want to be included, you still want to feel part of things".

Grey literature confirms the ability of some PwD to write about their experiences, for example in books and Blog posts. Authors tend to be younger and early in the disease trajectory. Some suggest that the younger generation are more articulate and assertive (Whitman, 2016). It is important to remember that most PwD are older, experiences of these authors are personal and cannot and are not intended to be generalised.

Older people with Alzheimer's Disease living in the USA shared their experiences with professionals (Synder, 1999). The resulting book offers insights into the needs of PwD. Similarly, PwD expressed their perspectives on an Alzheimer's Society public blog. These writings suggest that PwD need to maintain their well-being and desire quality care from healthcare professionals and family members, understanding from others and holistic care.

Thai specific grey literature was absent. Although theoretically there are channels for sharing experiences, for example The Alzheimer Association of Thailand Facebook or web blogs there is no evidence that these are used by PwD.

2.4 Conclusion

This literature review addressed the question 'What do we know about the care needs of older people with early stage dementia from their own perspectives?' Both quantitative and qualitative studies demonstrate that researching *with*, rather than *on*, PwD is possible. Few studies focus wholly on PwD often relying on CG accounts. Quantitative studies used assessment tools and checklists to identify needs. Results can be categorised into three aspects: i) physiological, related to daytime activities, safety, help with daily activities and information about dementia, ii) psychological, learning to cope with dementia symptoms and manage psychological distress and iii) social, the need for social interaction and company.

Qualitative studies focus predominantly on pre-diagnosis and post-diagnosis support and report both positive and negative experiences. PwD identified the need for information and knowledge to increase their understanding and ability to cope. They wanted to be heard and to have the opportunity to discuss their feelings and experiences.

This review has identified a gap in knowledge about the needs of PwD from their own perspective. Although some evidence is available, it is Western focused and virtually no research of this nature has been conducted in the Thai context. Review of the literature and identification of the knowledge gap has led to development of the research question:

‘What are the care needs of older persons with early stage dementia in Thailand from their own perspective?’

The next chapter will explain the need for researching with PwD and present the theoretical framework for my study.

Chapter 3 Theoretical Framework Underpinning the Study

3.1 Introduction

The aim of this study is to explore the needs of older persons living with early stage dementia to maintain their well-being and enhance the quality of life. This chapter focuses on the theoretical framework and related concepts that underpin the thesis. The overarching theoretical framework is Maslow's hierarchy of needs, a theory of human motivation (Maslow, 1943), which is known worldwide as a hierarchy of needs. Additionally, to gain a better understanding of the unique experiences of PwD, I illuminate the related concept of personhood and person-centred care for PwD (Kitwood, 1997).

3.2 Theoretical framework

The value of using a theoretical framework in qualitative research is debated with some, for example Wolcott (1990), arguing it is not necessary. The benefits of using a framework in this study include provision of a:

- lens through which to interpret and describe data collection and analysis (Anfara & Mertz, 2006).
- broad explanation of conceptual knowledge (Reeves et al., 2008).
- structure and plan to develop an understanding of the topic (Grant & Osanloo, 2014).

Using a theoretical framework can be valuable in guiding a researcher. I selected Maslow's Hierarchy of Needs (Maslow, 1943) combined with the concept of personhood, which relates to person-centred care for PwD (Kitwood, 1997). This was done to enhance my thoughts about psychosocial care and how to address these to maintain personhood, which is somewhat limited in Maslow's Hierarchy of Needs. This was a study exploring a largely unexplored field regarding care needs of PwD from their perspectives, thus, a framework was useful for structuring the study. While using a framework in qualitative research allows the researcher to reveal existing preconceptions about the study, overreliance can lead to limiting the ability to see emergent findings (Collins & Stockton, 2018). Therefore, I was concerned about using these theoretical frameworks as they are Western focused and my study was conducted in an Eastern context. However, no culture specific frameworks were available and although my selected frameworks were useful in guiding my research process, they did not limit my data collection or analysis as evidenced by the cultural nuances uncovered in this study.

3.3 Maslow’s Hierarchy of Needs

At present knowledge about the needs of older Thai persons living with early stage dementia to maintain their well-being and enhance the quality of life is limited. Therefore, in contrast to much existing dementia research, such as drug trials that focus almost exclusively on physical and physiological parameters, or experience based studies examining psychosocial concerns, this study requires a framework that encompasses human needs holistically.

Maslow’s seminal hierarchy of human needs has been applied internationally and across disciplines (Maslow, 1943). Maslow’s work is derived from experience, including clinical, observational and experimental. It has been widely critiqued but has stood the test of time. This theory explains universal human motivation proposing types of human need considering the individual as a whole. Maslow classified the basic needs of humans into five categories as a hierarchy. The hierarchy moves from minimum to maximum as the Basic Needs of Persons as considered below. The most basic needs must be secured first, and then the others can follow. Figure 3.1 illustrates Maslow’s hierarchy, and Table 3.1 offers examples of the type of needs.

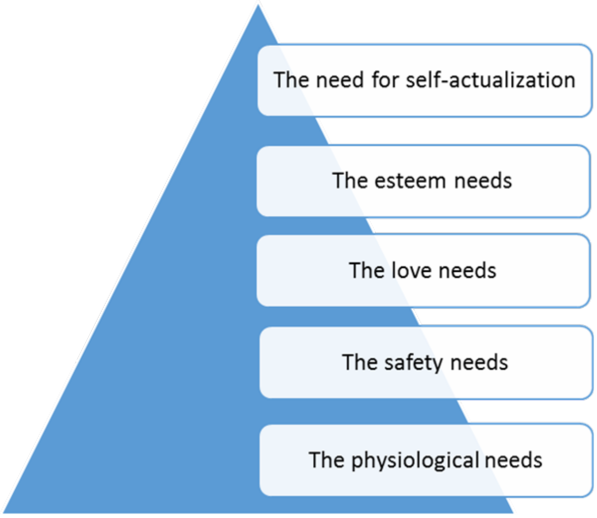
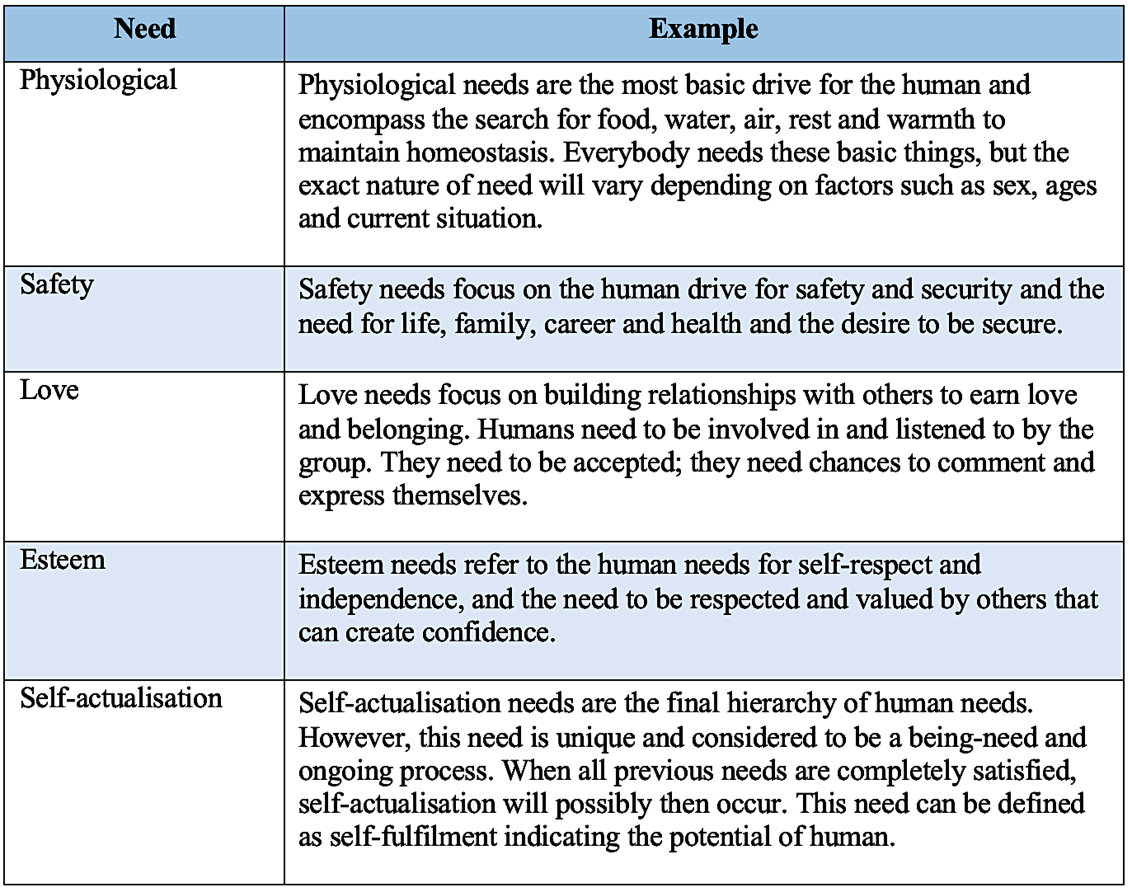


Figure 3.1 The Maslow’s Hierarchy of needs (adapted from Maslow, 1943)

Table 3.1 The examples of the type of need



Need	Example
Physiological	Physiological needs are the most basic drive for the human and encompass the search for food, water, air, rest and warmth to maintain homeostasis. Everybody needs these basic things, but the exact nature of need will vary depending on factors such as sex, ages and current situation.
Safety	Safety needs focus on the human drive for safety and security and the need for life, family, career and health and the desire to be secure.
Love	Love needs focus on building relationships with others to earn love and belonging. Humans need to be involved in and listened to by the group. They need to be accepted; they need chances to comment and express themselves.
Esteem	Esteem needs refer to the human needs for self-respect and independence, and the need to be respected and valued by others that can create confidence.
Self-actualisation	Self-actualisation needs are the final hierarchy of human needs. However, this need is unique and considered to be a being-need and ongoing process. When all previous needs are completely satisfied, self-actualisation will possibly then occur. This need can be defined as self-fulfilment indicating the potential of human.

From Table 3.1, Maslow’s theory concerning human motivation to achieve these five basic needs is infinite and fluctuating. This theory considers the needs of individuals for growth, fulfilment and development.

Maslow’s framework offers a universal and holistic starting point from which to understand the needs of older Thai persons living with early stage dementia. There are several examples of application in existing literature.

Horton-Deutsch et al. (2007) examined healthcare decision-making (HCDM) in people with mild to moderate dementia and their family caregivers. Firstly, these authors evaluated the decision-making capacity of both PwD and their family caregivers using a treatment vignette. They then interviewed PwD regarding their experiences of HCDM. The study showed that there were nine factors related to the HCDM of PwD: symptoms, resources, functions, trust in the healthcare systems, reliance on family, normality, safety, activity, and maintenance of identity. Horton-Deutsch et al. (2007) suggested that these factors could be collapsed into the fundamental framework of Maslow’s hierarchy of needs. They classified these factors into each element of the hierarchy of need: physiological needs (activity, function), safety (resources, reliance on family, trust in health care), love and belonging (reliance on family, function), and self-esteem (function, normality, identity), but this author did not address self-actualisation. This may be because the interview vignette relating to the physical health problem led PwD to think less about the need for self-actualisation.

Schölzel-Dorenbos et al. (2010) used Maslow's Hierarchy as a basis for designing the Hierarchy Model of Needs in Dementia (HMND). These authors reviewed instruments for assessing (unmet) needs of PwD and CGs to explore the interaction between unmet needs and health-related quality of life using Maslow's Hierarchy of Needs. They then presented the model of levels of needs in dementia and the consequences of unmet needs by using data from their previous studies (Dröes et al., 2006; Schölzel-Dorenbos et al., 2009). They related Maslow's hierarchy and general perspective of this theory to the needs and health-related quality of life (HRQoL) in dementia. The physiological needs consist of maintaining personal hygiene, housing and feeding. Safety needs are concerned about prevention of harm resulting from dementia signs and symptoms. Love and belonging needs included continuing social contact and receiving love and acceptance. Self-esteem needs deal with fear of loss of dependency, respect and social role. Self-actualisation needs focus on a being-need. However, the needs fitted in the model were derived from people with various stages of dementia and combined with opinions from CG. Also, it did not explain the reason for needs remaining unmet.

von Kutzleben et al. (2012) systematically reviewed the subjective experiences of PwD living at home to provide knowledge to develop an intervention for people with early stage dementia. The authors reported that the expressed needs mainly related to human emotions and feelings. PwD wanted social inclusion, positive sense of self and general well-being. They linked these needs with Maslow's Hierarchy of Needs. However, they did not discuss the relationship between the needs of PwD and each element of the hierarchy of need. They only discussed that self-expression regarding the needs of PwD is not different from those of people with any other chronic condition. This notion underpins the consideration of choosing Maslow's hierarchy of Needs as a framework for my current study.

Scerri et al. (2018) categorised the perceived and observed needs of PwD in acute medical wards in Malta using Maslow's Hierarchy of Needs as a framework and examined whether perceived needs had been addressed. Their study found that although the PwD were in hospital they still reported physiological needs. They report that the gap between met and unmet needs was a consequence of lack of observation and the declining ability to communicate. Self-esteem needs and the need for social contact is related to dignity and respect, which were often ignored and left patients feeling devalued. Also, patients felt useful when they were asked to do some activities. The researchers categorise this as a being need but did not link to the need for self-actualisation. Moreover, they found the spiritual/religious needs are important for PwD.

In summary, Maslow's Hierarchy of Needs has been employed as a framework to investigate the general needs of PwD (Schölzel-Dorenbos et al., 2010; Scerri et al., 2018). It is also referenced in the discussion sections of Horton-Deutsch et al. (2007) and von Kutzleben et al. (2012). However, only two studies included all dimensions of Maslow's Hierarchy of Needs: one study focused on unmet needs (Schölzel-Dorenbos et al., 2010), and another focused on the people admitted to an acute ward in the hospital (Scerri et al., 2018).

Although Maslow provides a useful overarching framework, there is also a need for a more nuanced, person-focused consideration of the needs of older PwD. For this reason, Kitwood's dementia-specific person-centred model will be used in combination with Maslow's Hierarchy.

3.4 Personhood of persons with dementia

Personhood can be considered as three components body, mind, and soul (Fowler, 2004). Personhood is a composite and includes factors such as gender, cultural practice, social background and other senses of identity, connectedness, self-awareness (Harrison, 1993; Fowler, 2004).

It is acknowledged that responding to the needs of a PwD and maintaining personhood is challenging (Moody, 2003) because cognitive impairment diminishes the ability to express needs and feelings (Alzheimer's Society, 2017; Downs & Bowers, 2014). PwD should not be viewed as having just cognitive or physical impairment but should be seen as a whole person in a particular context (Harrison, 1993). Personhood is also the valued basic concept of person-centred care in gerontological nursing, especially in dementia care (Dewing, 2008). The principal characteristics of this concept are focused on the relationship between PwD and service provider.

Rogers, a humanistic psychologist, wrote extensively about the “Person-Centred Approach” which focuses on the way to approach people to understand them regardless of kinds of role (i.e. client-centred therapy, student-centred teaching, nondirective counselling) (Rogers, 1961). The Person-Centred Approach has three characteristics, i) “genuineness” which focuses on the relationship between the client and therapist, ii) “unconditional positive regard” which describes the experiences of a therapist regardless of the client feeling the therapist is willing to care and iii) “empathic understanding” which focuses on the relationship that could be effective by active listening to understand the real feelings and personal meanings. Sometime service providers think they are listening to clients, but this may still be inadequate as they are not hearing the real feelings of the person and so lack understanding.

Later, Kitwood (1997), a social psychologist, influenced by the work of Rogers, coined the term personhood in relation to caring for PwD. Kitwood argued that PwD should be engaged in the care planning process and that we should listen to and value their perspectives to improve care. This approach allows health care providers to better understand PwD and can be more effective than merely following the guidelines (Brooker & Latham, 2015).

Kitwood described three issues for PwD as “those of transcendence, those of ethics and those of social psychology” (Kitwood, 1997:8). This focuses on the recognition that respect and trust are central, regardless of the severity of cognitive impairment (Mitchell & Agnelli, 2015). Kitwood (1997:8) defined the concept of personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust”. This concept will enhance the personhood of a person.

Approaches of caregivers impact significantly on the personhood of PwD (Mitchell & Agnelli, 2015). Kitwood delineates two main type of caregiver behaviour “malignant social psychology” and “positive person work”. The former, “malignant social psychology” refers to behaviours which can undermine personhood and wellbeing of PwD (Kitwood, 1997). This issue is important because PwD may lack the opportunity to express their opinions. Unawareness of staff or caregivers about personhood can lead to undermining both mental and physical potential of PwD and can lead to depersonalisation, disempowerment, imposition, or manipulate behaviour (Kitwood, 1997). The latter, positive person work, enhances personhood and well-being by for example, providing a feeling of security (Kitwood, 1997).

Kitwood (1997:81) argues that without addressing personhood “a human being cannot function, even minimally, as a person”. Kitwood (1997) delineates needs of PwD, for example comfort, attachment, inclusion, occupation and identity (see Table 3.2 for examples of each). These five needs are not a hierarchy. They overlap, and all needs connect to the need for love. They vary depending on personal background. If these needs are replenished, they result in feelings of safety, value, and self-esteem. Furthermore, these needs are also included in the concept of personhood to enhance the person’s well-being, regardless of the stage of dementia. Psychological needs are a crucial part of the person-centred approach and need to be understood to meet the real needs of PwD (Love & Pinkowitz, 2013). Needs of the PwD will change over time as the condition progresses (van Gennip et al., 2016).

Table 3.2 The examples of the type of need of PwD

Need	Example
Comfort	PwD experiencing a sense of loss need to feel secure in the company of someone who gives them tenderness, warmth which can soothe their feelings of pain, anxiety. Meeting this need can help them to feel safe.
Attachment	This need relates to a specific bond, which is a universal and natural feeling relevant to sense of security. When PwD recognise the presence of dementia is with them, as it can affect their memories, they would feel insecure and uncertainty attachment is needed.
Inclusion	Naturally, the human needs to be in a group to survive. In terms of social psychology, the PwD facing cognitive impairment seems to be punished and devalued if they are excluded from the group. Being a part of society can contribute the PwD to feel better.
Occupation	This need refers being involved in life activities which might relate to their life story. This need can link to the ability of a PwD to performing something by themselves.
Identity	This need refers to the sense of continuity to know who one is with the past to present an individual's life to other people. It would be helpful to the feeling of PwD if we know their background, whether they can tell or not, and provide empathy for the person as being.

From: Psychological needs of people with dementia (Kitwood, 1997)

The person-centred care concept aims to understand the perspectives of PwD regarding their needs by recognising personhood (Minghella & Schneider, 2012). Psychological needs and engagement with society to express their views are central factors (Kitwood, 1997). The strength of this framework is that it can contribute to illuminating the experiences of PwD because the way to approach the person encourages understanding of individual experiences and needs from their perspectives. Also, PwD can participate in a society which can maintain their relationship with others.

This section has provided a better understanding of being a person and how to maintain their personhood. The next section synthesises the relationship between Maslow's Hierarchy of Needs and the concept of person-centred care of Kitwood by linking existing research on the needs of PwD. The integrated framework for this study is then addressed.

3.5 A synthesis of Maslow's Hierarchy of Needs and Kitwood's Person Centred Care

Maslow's Hierarchy of Needs (1943) can provide a broad framework for this study but equally there is a need for a dementia specific approach to ensure a nuanced understanding of the needs and thoughts of PwD. This section describes the relationship between these two ways of thinking.

Firstly, in Table 3.3, I present the relationship between experiences or problems of PwD in receiving support that can influence their needs. With reference to the literature review, I selected relevant existing studies reporting experiences and the needs of PwD, and some related knowledge focused on problems in living with dementia or the need that should be addressed. In this section, I have linked information regarding PwD problems and the care they need to each element of Maslow's Hierarchy of Needs (1943).

Table 3.3 The relating of Maslow's Hierarchy of Needs to relevant existing research on the needs of PwD

Need	Example of problems	Example of care needs
Physiological	The physical changes might not present at the early stages of dementia. However, there are some decreases of individual ability such as short-term memory loss, reduced creativity, more difficulty in planning or solving complicated problems and lack of attention especially in people with vascular dementia. These can lead to difficulty in diagnosing dementia. Some PwD or their family members notice these problems and also behaviour changes (Noysipoom & Sasat, 2014; Alzheimer's Society, 2015b). PwD ability to meet their own physical needs declines. Psychological problem such as depression and anger may occur.	From these problems, remain physically active is one of the important ways to sustain well-being for PwD (Cedervall et al., 2015).
Safety	After receiving a diagnosis, PwD may feel sad and confused. Also, they may experience a lack of information about dementia care service including and difficulty in accessing these (Innes et al., 2014). They may find some health practitioners appear not to understand their needs (Aggarwal et al., 2003; Sutcliffe et al., 2015; Risco et al., 2016).	When confronted with this difficult situation, people need to be clear about the diagnosis and disease process (Johansson et al., 2015; Portacolone et al., 2018). Early diagnosis and continuity of support is important (Stephan et al., 2018; Portacolone et al., 2018). Coordinated services can support a sense of security and trust in the relationship between patients and health professionals (Gill et al., 2011; Risco et al., 2016; Górska

Need	Example of problems	Example of care needs
	There may be poor communication between professionals and patients as consequence of a lack of public information, a lack of awareness from professionals and caregivers, and limited time for effective communication (Sutcliffe et al., 2015; Górska et al., 2013; Karlsson et al., 2015).	et al., 2013; Karlsson et al., 2015). It is necessary to provide information regarding the progression of dementia and dementia care service, which they can consult (Risco et al., 2016). Healthcare providers should be trained in best practice for working with PwD and sufficient services should be available (Górska et al., 2013; Karlsson et al., 2015; Sutcliffe et al., 2015). PwD also need understanding and empathy from the family members and people around them. This reduces fear, confusion, and loneliness as it helps to fulfil the need for comfort and safety within their social environment (Kitwood, 1997; von Kutzleben et al., 2012).
Love	PwD are often socially excluded (Hubbard et al., 2003), they need to feel accepted and valued (Zimmermann, 2011). There can be a lack of a relationship between PwD and medical staff (Zimmermann, 2011).	PwD want to be connected with other people and participate in social life. They want equitable relationships with family members and care providers (van der Roest et al., 2007; Ablitt et al., 2009; Zimmermann, 2011; von Kutzleben et al., 2012; Noysipoom & Sasat, 2014). Meaningful activity can decrease feelings of loneliness

Need	Example of problems	Example of care needs
		(Svanström & Sundler, 2015) and can help to maintain well-being (Górska et al., 2013; Karlsson et al., 2015).
Esteem	Following diagnosis PwD can experience feelings of sadness, loss self-esteem, control and self-identity. They may feel they are becoming a burden to the family because they know they have decreasing physical ability (Steeman et al., 2006; de Boer et al., 2007; von Kutzleben et al., 2012; Noysipoom & Sasat, 2014).	PwD did not want to be a burden. They want maintain independence and slow disease progression (Steeman et al., 2006; von Kutzleben et al., 2012; Tetley, 2013; Noysipoom & Sasat, 2014). PwD need to be respected and understood about their illness and their needs (Gilmour & Huntington, 2005), but they do not want to be treated as a dependent (Powers et al., 2016). They strive to maintain normality and continue living in their own home and hold onto their identity (von Kutzleben et al., 2012).
Self-actualisation	Research has focussed on the need for safety and other levels on the Hierarchy of Needs but less is written about self-actualisation. It may be because this need seems to relate to the need of achieving full potential, acceptance of facts and creative activities, while patients after having received diagnosis realised that they have problem with cognitive decline or even physical changes. This thinking can affect the psychological problem; the need for safety and self-esteem are becoming more dominant.	PwD do not want to be stigmatised, they want to be treated as accountable adults (von Kutzleben et al., 2012) and gain encouragement to do activities as they are able (Scerri et al., 2018). They need help to cope with the problems of living with dementia to maintain a feeling of personhood, fulfilment, individual ability and well-being.

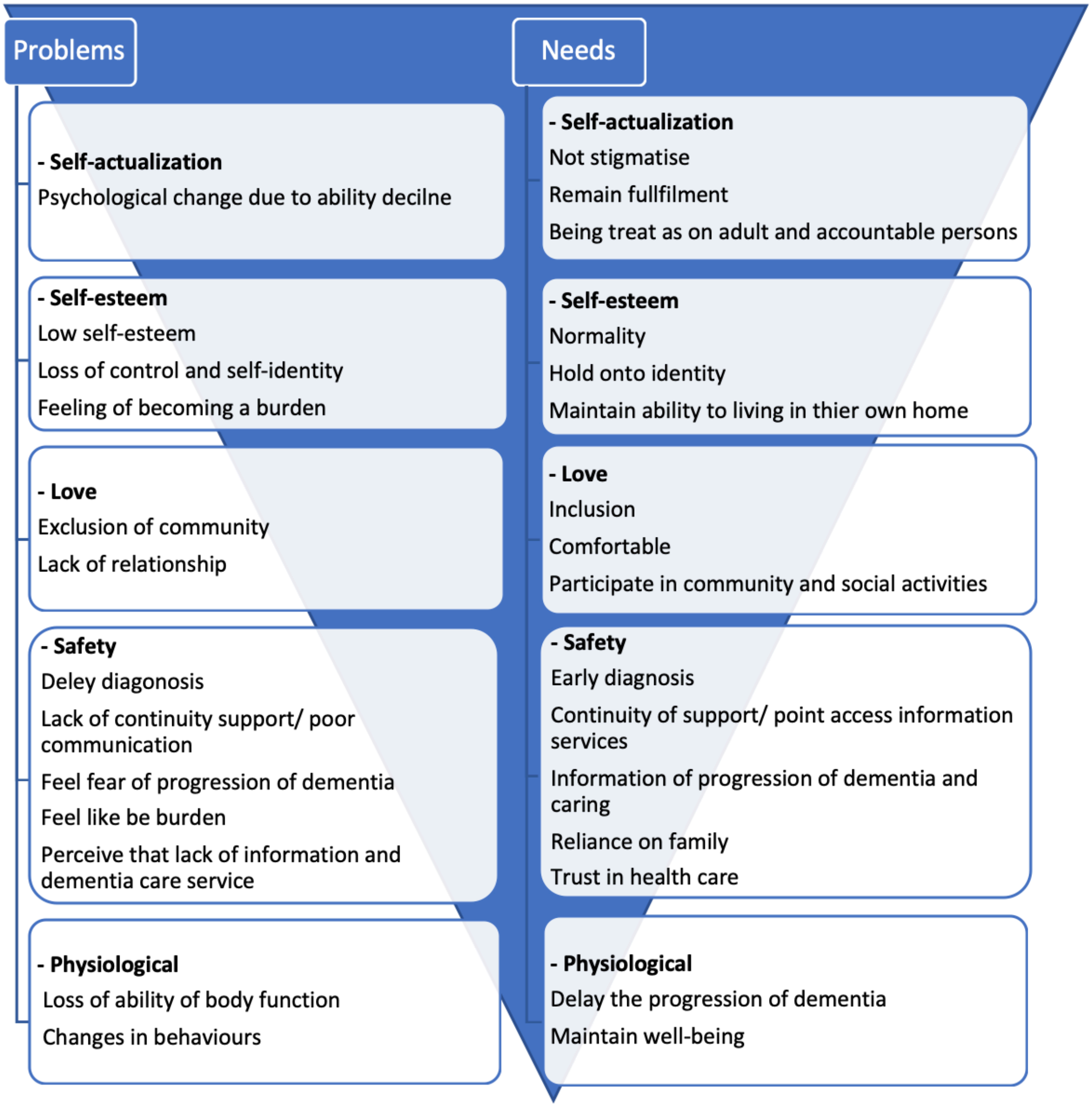


Figure 3.2 Generated framework for exploring the problems and care needs of PwD from existing literature.

This synthesis and generated framework will be used for guiding my investigation. It will support a deep and nuanced understanding of the motivations and needs of PwD. In order to respond to the needs of PwD to help them maintain their well-being, it is necessary to understand that each person is unique.

This generated framework is useful in addressing the research question. However, the framework should not block the idea to view the reality of PwD because the findings would be raised from the experiences and perspectives of older persons with early stage dementia along with the situations taking place in the setting during gathering data.

3.6 Summary of Chapter

This chapter has explained the value of using Maslow's Hierarchy of Needs combined with Kitwood's concept of personhood as the theoretical underpinning of this study. It has shown how, when synthesised, they provide a framework that addresses all levels of human need. This is essential for my study as to date there is minimal knowledge about the needs of Thai older people living with early stage dementia.

The next chapter will focus on methodology and research design to elicit experience and care needs of older persons living with early stage dementia from their own perspectives.

Chapter 4 Methodology and Methods

4.1 Introduction

The literature review has revealed a gap in knowledge about the experiences and needs of Thai older people living with dementia from their own perspective. Therefore, the research question I will address is ‘What are the needs of older persons with early stage dementia in Thailand from their own perspective?’ In this chapter, I justify my chosen ethnographic methodology and report the methods used. I address issues of ethics and rigour in the study.

4.2 Methodology

In order to understand philosophy for conducting this research, this section focuses on the research paradigm and theory of the ethnographic approach to answer the research question.

4.2.1 The qualitative paradigm

My research question belongs firmly in the qualitative paradigm as my aim is to deeply explore personal and nuanced experiences (Merriam & Tisdell, 2016) of multiple participants. Qualitative research is a broad approach to studying social phenomena (Marshall & Rossman, 2016) and focuses on people’s life experience in their natural setting (Holloway & Galvin, 2017). Qualitative ontology and epistemology are congruent with the research question and my own beliefs.

Ontology concerns what we believe about the nature of reality (Creswell, 2014) and aims to answer the question that ‘what is the nature of social reality?’ For this study, I want to understand the reality of older persons who have been diagnosed with early stage dementia and want to uncover their views about what they need to maintain well-being. Their views about how they live with early-stage dementia will depend on many subjective experiences of their reality. The perspective of each individual with dementia will differ depending on factors such as their socio-cultural context and individual experiences. I believe that understanding their experiences can help to meet care needs. To respond to the needs of older PwD and to create appropriate support for their holistic well-being, it would be helpful to increase understanding of the feelings and needs of people living with the condition.

Epistemology is concerned with ‘what’ and ‘how’ we know (Creswell, 2014). There is no possibility of ‘objective’ knowledge of the world as we all have different experiences. To know the needs of older persons with early stage dementia, therefore, I need to understand how they live and experience life. There are many qualitative research methodologies. For this study, I selected an ethnographic approach for the reasons set out below.

4.2.2 Ethnographic approaches

Ethnography originates from anthropology and sociology and investigates patterns of behaviour, language, actions of the culture, and nature of the group of participants (Creswell, 2014). Ethnography can be used to investigate and interpret the participants’ understandings and experiences in their cultural context (Roper & Shapira, 2000; Fetterman, 2010). Ethnographic research is the study of culture or subculture, which suggests the researchers immerse themselves in the culture by observing and spending time in the field (Spradley, 1979). This approach seeks to uncover the perspectives, behaviour, attitudes, beliefs and experiences of the life of individuals in their community (Parahoo, 2014; Glasper & Rees, 2017). Ethnographic research is characterised by the use of observation, interviews and field notes as sources of data and viewing experience of participants from emic and etic perspectives, which will be further explained in the following section. This combination of data sources can provide rich and detailed understanding of people in their natural setting (Guba & Lincoln, 1989; Creswell, 2014; Spradley, 1979).

There are several types of ethnography. Macro ethnography can be used to examine the context and culture of groups of people over time. Micro or focused ethnography has a sharper focus. Research questions tend to be more specific and data collection time shorter than in traditional ethnography. Questions emphasise what is happening with participants, and use various sources of information to gain a deep understanding of people and their experiences (Roper & Shapira, 2000). This approach aims to explore specific information in the natural context and enable participants to express their views (Cruz & Higginbottom, 2013).

Ethnography typically involves relatively small sample sizes studied in-depth (Atkinson & Hammersley, 1998). The number of participants can be judged by the researcher as the research progresses based on data saturation and whether there is sufficient, high quality data to answer the research question (Guest et al., 2006; Green & Thorogood, 2014).

4.2.3 Roles of the researcher

In any ethnographic study, the researcher is the instrument of data collection and the role they take needs to be considered before commencing data collection. This section offers an overview of the key aspects of ethnographer that help to gain sufficient data to answer the research question.

An ethnographic study is conducted in the field with the researcher becoming immersed in the culture of people in the group being studied (Richards & Morse, 2007). The researcher explores perspectives and patterns in everyday life of people in a natural setting.

The researcher should consider exploring and collecting two perspectives to gain sufficient data to answer the research question. Firstly, emic or insider's perspective, which refers to views of reality from members in a cultural group (Richards & Morse, 2007; Fetterman, 2010). Different views can help to understand multiple realities. Secondly, etic or outsider's perspective is a perspective from social scientific, or it can refer to the researcher reflections on what is captured during data collection (Fetterman, 2010).

Ethnography investigates what motivates people in the setting to behave as they do. Thus, collecting emic views from members living in a natural context and supporting with relevant etic views from the researcher's analysis provides robust data (Fetterman, 2010). There are four main phases in conducting an ethnographic study (Richards & Morse, 2007).

i) "Getting in" is a primary phrase. The researcher is new and a stranger in the setting. They need to find a role and begin to fit in, try to become familiar with people and learn about the context.

ii) Initial data collection involves non-participant observations and informal conversation. Potential participants could be identified in this phase.

iii) When early stage relationships with participants have been built the researcher can begin to collect more in-depth data and greater understanding of the culture and setting.

iv) Finally, researcher withdraws and focuses on data analysis but may collect some more data if gaps are identified.

Ethnographic data collection comprises observation, interviews and field notes. Using multiple methods can allow triangulation of data and offer deeper, richer understandings (Guba & Lincoln, 1989). Each method is examined in more detail below.

4.2.3.1 Observation

Observation is central in ethnographic research and may take several forms (Spradley, 1980; Fetterman, 2010). Everyday life and common behaviours of participants are observed in their natural settings (Roper & Shapira, 2000). Observation helps the researcher to understand the participant in their own context (Fetterman, 2010). Observation includes attention to non-verbal cues (Parahoo, 2014). Participant observation allows immersion in the real-world of participants and captures data that would not be forthcoming in interviews (Rashid et al., 2019).

In preparation for observation the researcher needs to invest time establishing relationships and gaining trust and acceptance. The researcher can approach observation on a continuum from complete observer to complete participant. ‘Complete observer’ focuses on only observing participants’ activities and interaction between participant and people and things that surround them (Richards & Morse, 2007). ‘Observer-as-participant’ is still focusing more on observing, and having a limitation on participating with the group, but the role of researcher is revealed (Gold, 1958; Spradley, 1980; Harrison, 2011). ‘Participant-as-observer’ is more engaged with participants in the group than the complete observer, but participants know that they are under observation by the researcher (Gold, 1958; Spradley, 1980; Kawulich, 2005). ‘Complete participation’ focuses on taking part in the participant’s activities (Richards & Morse, 2007).

There are advantages and disadvantages to covert and overt observation. The role of the ‘complete observer’ might be to observe what participants and people in the setting do without ‘going native’, but the researcher may not know the views of participants because the researcher remains an outsider (Gold, 1958). While ‘complete participant’ builds rapport with participants, and enables learning about aspects of behaviours in the setting, the researcher has to pretend about their role as a member, so a chance to ‘go native’ might occur when the researcher focuses too much on participating in participant activities (Gold, 1958). Therefore, there are concerns about bias as well as participant privacy. Regarding the hybrid roles, ‘observer-as-participant’, this might risk gaining less understanding of the what and how of participant behaviour (Gold, 1958), but this role may lead participants to feel more willing to talk to the researcher than the persons who they know well (Pearsall, 1970). With refer to the researcher, ‘participant-as-observer’ helps the researcher establish rapport and a relationship with participants, so it is possible to gain important data. However, the participants may become too much of an observer and the researcher may lose perspective by going native. Spradley (1980) suggests that it would be helpful to not only observe around the setting, but the researcher also needs to engage in the activities of people in the setting. To immerse the cultural context and understand views of PwD, therefore, ‘participant-as-observer’ was taken in this study.

The researcher can see what people do and what they say they do (Green & Thorogood, 2014). It offers deep and clear insights about the perspectives and experience of participants and access to their reality (Spradley, 1979; Creswell, 2014). During participation the researcher needs to record the events, take notes, and ask questions to uncover meaning behind participants’ behaviour to have enough experience and information to answer the research questions (Guest et al., 2017).

4.2.3.2 Interviews

In-depth interviews with key informants enable collection of further data (Northcote & Moore, 2010). Ethnographic interviews help the researcher to establish a participant’s cooperation in sharing their data because they can be conducted as series of informal conversations (Spradley, 1979). There are three major consideration in ethnographic interviewing (Spradley, 1979):

i) ‘explicit purpose’, the researcher needs to remind each participant of the purpose of the interview.

ii) ‘ethnographic explanations’, the researcher must gain rapport with participants, explain and justify data collection process, and then ask participants to explain their culture and knowledge.

iii) ‘ethnographic questions’, the researcher asks participants to describe their actions or things and ask structural questions about how they organised or identified their knowledge, and contrast questions to understand the meaning of participants actions.

In focused ethnography, interviews are extensively used accompanied by observation during interviews. Together, this allows the researcher to immerse themselves in the cultural context of participants (Spradley, 1979; Fetterman, 2010).

There are various types of in-depth interviews such as face-to-face, telephone or online methods. However, the face-to-face interview is the preferred method as it helps to establish a good rapport between the researcher and the participant (Ritchie et al., 2014), this is particularly so when working with PwD. Communication with PwD can be challenging work as cognitive impairment can impact on language usage, speech production and memory. Therefore, it is important to plan a study thoughtfully (Iliffe & Drennan, 2001). The researcher needs to listen attentively and observe non-verbal communication and ensure the environment is free from disturbance (Royan, 2003). Multiple shorter interviews can help to build rapport with participants (Hammersley & Atkinson, 2007) and particularly with PwD can reduce disruption of routine and fatigue (Pratt, 2002).

4.2.3.3 Field notes

Field notes are used to further understanding of participant's lives and experiences (Hammersley & Atkinson, 2007; Emerson et al., 2011). They also support making sense of and organising the information obtained during the interviews (Spradley, 1979).

Field notes record what the researcher observes, they can be written, audio-recorded and transcribed or use photographs (Richards & Morse, 2007). Key words, symbols, phrases may be used to prompt the researcher's memory (Fetterman, 2010; Northcote & Moore, 2010). The researcher may write or record field notes during or immediately after interviews and observations (Spradley, 1980; Fetterman, 2010).

Field notes may include the researcher's analysis offering an opportunity to make sense of the observation and interpret data (Emerson et al., 2011; Eriksson et al., 2012). Personal reflections can be recorded in a field work journal capturing the researcher's feelings, reflections and any issues encountered during field work (Spradley, 1997). The journal helps to retrace what happened during data collection and remind the researcher so they can mentally reconstruct events (Fetterman, 2010).

4.2.4 Ethnographic analysis

Data analysis in ethnographic research involves finding patterns and themes in the data which are relevant to the research question (Wolcott, 1994; Creswell, 2014). It focusses on the subject and context and has been described as particularly relevant for understanding an individual's experiences and reflections.

Ethnographic research requires constant feedback from the preliminary stage before collecting data through analysing data (Northcote & Moore, 2010). It begins with selecting a problem, collecting data, formulating ethnographic hypotheses, which arise from initial data, checking the suggested relationship by using it as a guide for going back to collect further data and then repeat it until no new relationship (Spradley, 1997).

The analysis process begins early during collecting data. It is intended to discover the parts and systems of organisation of cultural knowledge, meanings and their relationship from inside out (Spradley, 1997). As analytical field notes can be part of initial interpretation, they can lead the researcher to think about the data needed to understand participant's perspectives and behaviours (Northcote & Moore, 2010). Ethnographic analysis should offer a thick description of phenomenon under investigation (Holloway & Galvin, 2017). A detailed description is provided to enable the reader to understand the data and consider its applicability to other situations and populations (Shenton, 2004).

4.2.5 Reflexivity

In ethnography the researcher is the instrument of data collection (Marshall & Rossman, 2016). It is therefore crucial that the researcher reflects on their preconceived ideas and beliefs before and during the research process.

I am a nurse who has worked with older PwD and I am aware of how PwD should be supported to help them live well with their condition. I was aware that I was entering their lives and worlds with a knowledge gained from years of study and of working in the area of dementia. I had already begun to question the idea that those of us working with persons with dementia know best, but this research was to challenge me and push me to understand that PwD are the actual representatives of their lives, and that it is important if we are to increase our understanding of their experiences and perspectives, that I prioritise their viewpoints in this research, and not those of others speaking on their behalf.

I know that older PwD can find it hard to express their views and that it takes time and patience to gain the trust of anyone before they will share their lives and stories with you. I was prepared to do this. I was also aware that I was someone, a nurse, a nurse instructor from Bangkok, a person doing a doctoral degree at an overseas university, and that this made me an 'important' person and gave me a position that others might feel holds a certain amount of power. I held this in my consciousness particularly as I entered the field and began speaking to the doctors and nurses, and then the older persons and their families. I worked hard to build relationships with people and gain their trust. I was also aware that I might see things that troubled me but even though I was a visitor and a guest in the research site, that I was a nurse first and foremost and that I would have to respond to protect the older people I was seeing if I needed to, over and above doing my research.

On entering the field, I was prepared to listen and learn and participate in the activities that participants were doing. I thought this would be easy, but I had to slow down and sit and listen to the people I was meeting and spend time with them. I have kept extensive field notes of my observations and I have also tried to question myself about what I was seeing and hearing and I have taken my thoughts and ideas to my supervisions where I was challenged again.

Researching as participant-as-observer was useful as it allowed me to build rapport with PwD and their families. It also enabled me to more thoroughly understand contexts and culture in relation to each family and become immersed.

Being a Thai woman myself meant that I was comfortable with the environment and able to understand local dialect and social norms. It allowed me to behave in a culturally appropriate way. Many participants invited me to join their activities like when I was asked to drink some juice that the family member had made, eat a grass jelly dessert with them, have lunch with them, take offered fruits that they had grown themselves, or go to the 'senior school' with the participant. Although there were times when I was offered things I had not eaten before, I tried everything and this helped build rapport with participants and their families as I enjoyed and accepted their hospitality offers.

My pre-existing skills as a gerontological nurse gave me confidence to approach and talk with PwD and their families and gave them confidence in me as a researcher. They asked questions about the study but also about health problems, including dementia and how to access relevant services for better support. Offering some basic knowledge and advice allowed me to give something back to the participants.

Whilst familiarity with culture and context was useful, I was mindful of the need to keep an open mind throughout the study and ensure that my pre-conceived ideas and experience did not limit or overly influence the study process. To achieve this, I kept a reflexive journal throughout the study and regularly discussed data collection and analysis with my supervisors who were able to offer alternative understandings.

Concerning Thai culture, I thought that older PwD would be well supported in their families and I entered the field with this idea. I was shocked on a few occasions with the situations I encountered and to see what some of the older people in this research were having to cope with, on a few occasions, I had to take actions to help to protect them.

I have undertaken this research with older PwD because I view and value them highly. I have in the past been concerned about the lack of attention given to PwD and I know I want to make their lives better through my research. I understand now that do this I and all my colleagues working in the field of dementia need to stop and listen because if you take the time, in their own way, PwD will show the way forward.

4.3 Researching with PwD

In the past, the perspectives of older PwD have often been disregarded (Hubbard et al., 2003). As noted in the literature review most research is done “on” rather than “with” this group. More recently, researchers and health care professionals have increased efforts to include PwD in research to understand their perspectives (Kitwood, 1997; Adam & Manthorpe, 2003; Hubbard et al., 2003; Cowdell, 2008; Higgins, 2013). Ethics of researching with PwD have also been considered and some guidance on best practices and challenges provided (Dewing, 2008; Hellström et al., 2007; McKeown et al., 2010; Scottish Dementia Working Group, Research Sub-Group, UK, 2014; Lepore et al., 2017; Gove et al., 2018). In selecting the methodology and planning methods for this study, respect and meaningful inclusion of PwD was paramount.

4.3.1 Gaining consent from PwD

Being diagnosed with dementia does not mean that a person cannot give informed consent (Marson et al., 1994; Hegde & Ellajosyula, 2016). Ability to comprehend, make judgements, communicate, and remember may limit decision-making (Hubbard et al., 2003), but these factors need to be assessed and addressed to ensure that PwD are given time and support to ensure they are included where appropriate (Hegde & Ellajosyula, 2016; Higgins, 2013). There are two significant challenges in involving PwD in research i) recruitment and ii) ability to give meaningful consent (Mckeown et al., 2010). Capacity to consent is critical. Informed consent requires participants who have the capacity to understand the research information and research process to decide to take part in the study (Black et al., 2008b). Therefore, before giving informed consent, PwD should receive full and accessible information about the study and have time to consider and decide whether or not they choose to participate (Higgins, 2013; Alzheimer's Society, 2019a).

There are particular risks associated with researching with PwD, these include:

1) Capacity to consent may be difficult to judge and can change anytime throughout the study.
2) Participants may feel obliged to take part in the study as they have been invited by professionals involved in their medical care.
3) Participants may become distressed as they are talking about their conditions and having to face up to their diagnosis and its impact on their lives.
4) Tiredness during the interview.
5) In the case that participant prefers to have a friend or family members in the interview, there might be some impact on a discussion about the dissatisfaction with their care needs.
6) Confidentiality and anonymity, PwD may be concerned about how their data will be used and with whom it may be shared.

However, to respect the PwD, they will be free to withdraw from the study at any time.

4.3.2 Key points in researching with PwD

Good practice in researching with PwD includes:

1) Recruiting participants via a gatekeeper who knows and is familiar with the PwD and may help with assessment of capacity (Pratt, 2002). However, there is a risk that the gatekeeper may exclude potential participants (Bartlett & Martin, 2002) particularly if they do not fully understand the research purpose and process.

2) Assessing the capacity of PwD to give consent. Good practice advises that capacity should be presumed unless proved otherwise (HMSO, 2005). Research participation can support self-esteem, empowerment and a sense of being respected for PwD (Horton-Deutsch et al., 2007).

3) Full research information and explanation about the rights to withdraw from the study should be provided well in advance of gaining consent. Participants need time to read and ask questions before making a decision (Gill et al., 2011; Sutcliffe et al., 2015).

4) Researchers need to continually monitor the capacity of PwD and their willingness to participate in the study. Thus, ongoing consent procedures should be used (Innes et al., 2005, 2014; Gilmour & Huntington, 2005; Howe, 2012; Svanström & Sundler, 2015; Portacolone et al., 2018), written or verbal consent may be used to minimise tension and stress.

5) Involving family members in the first meeting may be helpful (Gilmour & Huntington, 2005; Svanström & Sundler, 2015) but it is important to avoid undermining the PwD and sensitivity should be used.

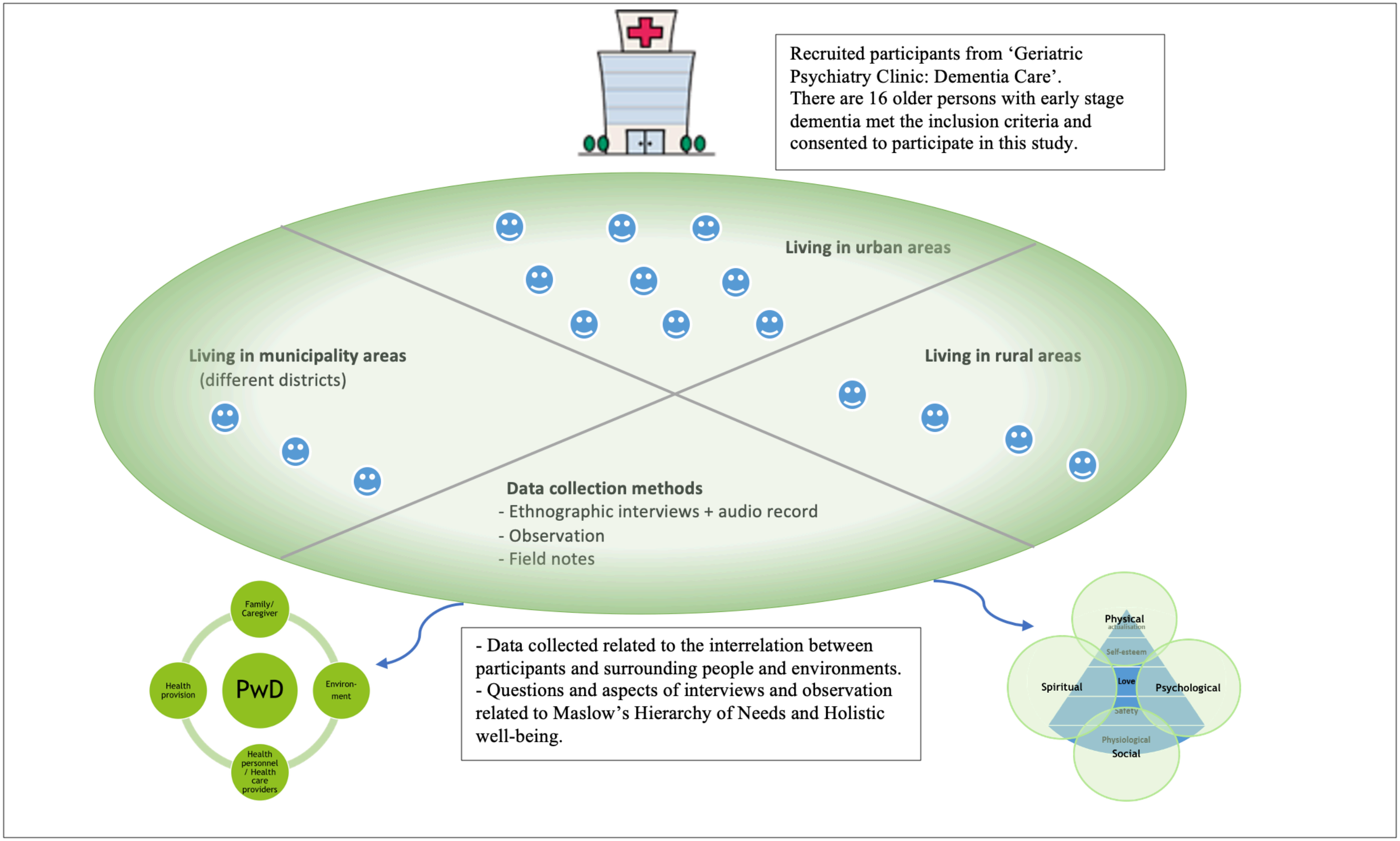
6) Involving family members in interviews may help the PwD to feel comfortable and safe. However, the researcher must be mindful that not all families and have good relationships (Pratt, 2002) and the PwD may be better able to express themselves unaccompanied.

7) Offering a relaxing, comfortable and convenient environment for PwD can encourage them to share their stories. Participant's homes can be a good setting (Innes et al., 2005; Gill et al., 2011: Lawrence et al., 2011; Górska et al., 2013; Innes et al., 2014; Johansson et al., 2015; Powers et al., 2016). This can allow some observation of daily routines (Portacolone et al., 2018, 2019). Sometimes interviews with PwD are conducted in hospitals or health facility (Lawrence et al., 2011; Górska et al., 2013; Innes et al., 2014) and day care centers or nursing homes (Aggarwal et al., 2003; Svanström & Sundler, 2015). All venues can offer deeper understanding of PwD's life. However, it depends on

the research design, the preference of participants and the need to attend to the suitability of the location for the participants.

4.4 Methods of data collection

This section set out the methods employed for my research. These are summarised in Figure 4.1.



Recruited participants from ‘Geriatric Psychiatry Clinic: Dementia Care’.
There are 16 older persons with early stage dementia met the inclusion criteria and consented to participate in this study.

Data collection methods

- Ethnographic interviews + audio record
- Observation
- Field notes

- Data collected related to the interrelation between participants and surrounding people and environments.
- Questions and aspects of interviews and observation related to Maslow’s Hierarchy of Needs and Holistic well-being.

Figure 4.1 Illustration of methods

4.4.1 Gaining ethical approval to conduct the study

Ethical considerations and approval to conduct this research study were gained from the Research Ethics Committee, Faculty of the Health Sciences University of Hull, United Kingdom (reference no FHS02), and Research Ethics Committee at Maharat Nakhon Ratchasima Hospital, Nakhon Ratchasima in Thailand (reference no 007/2018) (Appendix 4). After getting permission from both ethics committees, I contacted the head nurse at the dementia clinic to make an appointment to introduce myself and my research study in person.

4.4.2 Ethical considerations

It was essential that participants in the study would not be harmed in any way. One potential problem is inadvertent disclosure of diagnosis to people who have not been told of, or have forgotten, their diagnosis. I discussed awareness of accidental disclosure of dementia diagnosis with clinic staff. In this study, PwD had been informed of their diagnosis and were likely to remember as it was at an early stage, therefore I could refer to the condition when I invited them to participate in my study and during interviews.

4.4.2.1 Consent

I used a two stage process for consent. Firstly, gatekeepers broadly assessed the ability of potential participants to give their own consent, which happened at the recruitment process. Secondly, to protect and empower potential participants, I assessed their ability following the Mental Capacity Act (HMSO, 2005) which was developed to protect and restore power to persons who lack capacity. I assessed if the PwD could:

1) Understand the information relevant to the decision,
2) Retain that information,
3) Use or weigh that information as part of the process of making the decision, and
4) Communicate their decision (whether by talking, using sign language or any other means).

In this study, the gatekeepers and I worked closely with the older PwD to ensure that the meaningful informed consent (HMSO, 2005) was given. The gatekeeper had information about the patient's history which helped to make a judgement about their capacity, which was assessed by the gatekeeper before giving any study information. After that, the gatekeeper referred the potential participants to me. To obtain consent from the participants, I conducted following these steps;

1) I gave a participant information sheet (PIS) (Appendix 5) to the participants and explained my research, I answered questions and we reviewed of consent form (Appendix 6) together. I ensured that they were able to understand and retain knowledge through gentle questioning.
2) I invited participants to complete a consent form by signing in handwriting or fingerprint, if the person did not know how to write, on the two copies of informed consent, one of which was kept by the participant and one by me.

I was mindful that capacity can fluctuate. Therefore, I assessed capacity continuously following the suggestion of Howe (2012) even after the signature was obtained. This was to ensure the participant still had capacity and wanted to participate throughout the study. This assessment was conducted every time before interviewing following the guidelines of the Mental Capacity Act (HMSO, 2015).

I repeated the aim of the study at every interview and observation session and reminded participants that they have a right to decline to answer any question, to withdraw from the study at any time. Before each interview, I confirmed that the participant was willing to share their experiences and participate in the study. I reminded them about the purpose of the research at every visit. All participants listened to the research details, including the method of data collection with their family caregiver for the first interview. At the first meeting it was good to have family support and build rapport. At subsequent interviews PwD gave consent alone.

4.4.2.2 Risk limitation and management

During data collection I observed carefully for verbal and nonverbal communication which could indicate the participant was uncomfortable, tired or distressed. I prepared strategies to deal with this situation. To ensure that participants were comfortable in the setting they chose where data should be collected. Most preferred to be in their own home with only two choosing other places, the market and their daughter’s house. I arranged times that were convenient to meet participants.

I asked participants if they would like to have a friend or family caregiver with them during interviews. Also, I told the participant that their friend or family member could leave at any time during the interview if the participant would like to talk with me privately, especially when I asked about how he/she had been taken care of by friend or family.

For the first visit, all participants' caregivers were with them. For further interviews, many family caregivers did not sit with the participants during the interviews. They came to welcome me and returned when the interview finished. Few family members stayed with the participant at every interview. When present it was challenging for me to manage the interview because the CG tended to speak more than the PwD. Thus, I had to work hard to support the PwD to give their views. However, having the family member present gave me insights into interactions and relationships between participants and their family member(s). If a PwD became tired I talked with them and had a break or stopped the interview. I explained that this was not a problem and that we could meet again if they wished.

If participants became distressed or disclosed information about poor care or abuse, I asked their permission to consult and report to a relevant health care professional to help them get further support. All of them agreed to get support. I then reported the problem to the head nurse in the dementia clinic for safety reasons and for planning ahead to refer the person to get further help. As a nurse, I assessed the severity of their problem. Most problems concerned misunderstanding among the family about dementia symptoms. When PwD became distressed, I stopped asking them the questions; I encouraged them to see other positive situations and attempted to change to talk on different topics. However, they sometimes still wanted to share their negative experiences, so I continued to listen to them and observe non-verbal expression together with providing emotional support. I gave a list of supporting sources to them which I listed in the PIS (Appendix 5). Also, I gave the information about dementia symptoms and dementia progression to their family. For example, in the family having relationship problems due to the misunderstanding of dementia knowledge, I gave information about dementia knowledge, suggested they consult clinic staff or relevant professionals from a relevant organisation if they have any problem about this condition. Furthermore, I reported their issue to clinic staff to record and continue to monitor the problem. Two incidents are reported in detail in Chapter 6 regarding Nantana's and Pilaiwan's story.

4.4.2.3 Confidentiality and Data protection

I ensured that PwD knew that all data would be kept confidential on a password protected computer. I used an identity (ID) pseudonym instead of their real name in the interview transcripts and my field notes. This data was stored separately from contact and personal details.

Participant identification codes and consent forms were stored securely in a locked filing cabinet, in the office of my workplace in Thailand, which only I can access. Data will be securely stored in my office in Thailand for five years after the research is completed, then it will be securely deleted. The audio-files of interviews were deleted completely after the completion of the transcriptions. The consent form will be destroyed securely.

To summarise, ethnographic data collection with older PwD offers an effective way to directly understand them in their own context. When working with this group it is essential to consider the react to be inclusive but avoid harm and to be sensitive in approach.

4.5 Study setting

The study was conducted in Nakhon Ratchasima, also known as Korat, a province with a large older population which includes urban and rural areas. It is also my hometown so I was familiar with the cultural context and able to build rapport with participants. The research involved three main settings. Firstly, a large tertiary care level facility with approximately 1,280 beds for reserving in-patients. This hospital is big and provides specialist health care service for people living in Korat and also the provinces of Buriram, Surin, Chaiyaphumi and other provinces. Many people come to use services from this hospital as they believe in the quality of care and treatment provided.

This hospital is located in the central area of the city, parking is limited which can be difficult for patients. Public transport is available, but it can be busy and uncomfortable particularly for people who are older or unwell (see Figure 4.2). There is no transport timetable which can add to anxiety about arriving for appointments on time.

Figure 4.2 An example of minibuses service to access the hospital.

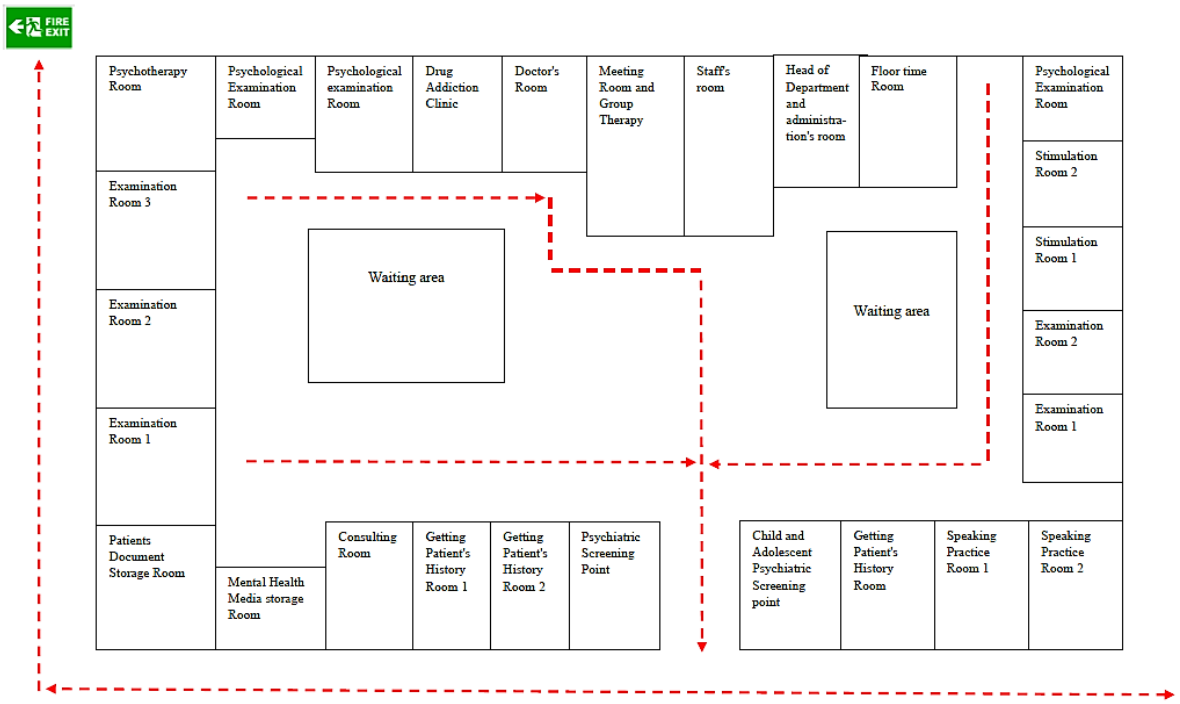
Patients have a long walk from the hospital entrance, where the bus drops people off to the outpatients' department. The hospital provides two shuttle buses to transport patients, relatives and staff from the parking area to the outpatient building for free (see Figure 4.3), but these tend to be busy.

Figure 4.3 A shuttle bus transporting people around the hospital.

People want to attend this hospital as it has a good reputation. Many travel great distances and plan to arrive at the hospital around 5 a.m. to join a queue for each element of their visit (Figure 4.4 – 4.5). This is tiring for the PwD and if a family member accompanies them, they are likely to have to take a day off work as one visit can take 5-8 hours.

Figure 4.4 - 4.5 Patients and relatives in hospital grounds and outpatient department.

The second setting was a Geriatric Psychiatry Clinic: Dementia Care or ‘dementia clinic’, in the tertiary hospital which is managed by three psychiatrists. Other staff include, four psychiatric nurses, of which only one has specialist dementia training, one patient assistant and one clerk. There is still a lack of dementia service support in Northeast region. As seen in this clinic dementia care is led by Psychiatry department. The dementia clinic runs each Monday. However, some PwD and their CG are allowed to meet a doctor on other working days if attendance on Monday is not possible. The doctors and the nurses rotate work at the outpatient department because they also care for and advise about inpatients. Figure 4.6 shows the map of the Department of Psychiatry that has many clinic rooms and caters for children and adults with psychological or brain function problems.



Map of the Psychiatric Clinic

Note: FIRE EXIT The picture shows the Fire exit (door)

←- - - - The arrows show the Fire exit

Figure 4.6 Map of the Psychiatric clinic

Figure 4.7 - 4.8 The counter of the Psychiatric clinic

Figures 4.7 – 4.8 show the workplace for the psychiatry clinic, which is including a dementia clinic. Once patients arrive, they have to:

i) Give their appointment ticket to staff at the counter.
ii) Get their blood pressure and weight checked.
iii) Wait to meet a nurse at a table near the counter to report current signs and symptoms.
iv) Wait to see a doctor.
v) Wait for the prescription and the next appointment ticket before going to collect medication from the pharmacy department.

The third setting, where most data was collected was the home of participants with dementia. In Thailand the word ‘city’ refers to a ‘municipality’. Each province has a capital city called ‘Amphoe Mueang’. Other districts in the province have their own centre called ‘town municipality’. Each district has a different name with the first word ‘Amphoe’ and followed by the name of the district. Each district is managed by different municipalities. Korat has 32 districts and 289 sub-districts (see Figure 4.9). Although these are the major cities in Thailand, many are quite rural.

Figure 4.9 Map of Nakhon Ratchasima province

Source: Detailed map of Nakhon Ratchasima Province, North-East (Isan) Region, Thailand (Web Sawadee Public Company Limited, 2018)

These three settings are known to some or all of the participants. I studied relevant settings as the participants are connected with these places. After planning about the settings for collecting data, I prepared for entering the field. I had concerns about ethics in research with older PwD which is explained in the next section.

4.6 Recruitment process

I recruited participants from one site, the Geriatric Psychiatry Clinic: Dementia Care. Observing daily life at the clinic enabled me to understand more about interactions between PwD and health professional and the context of the setting. It also gave me time to ensure that the gatekeepers understood my study.

The recruitment process is illustrated in Figure 4.10 and explained below.

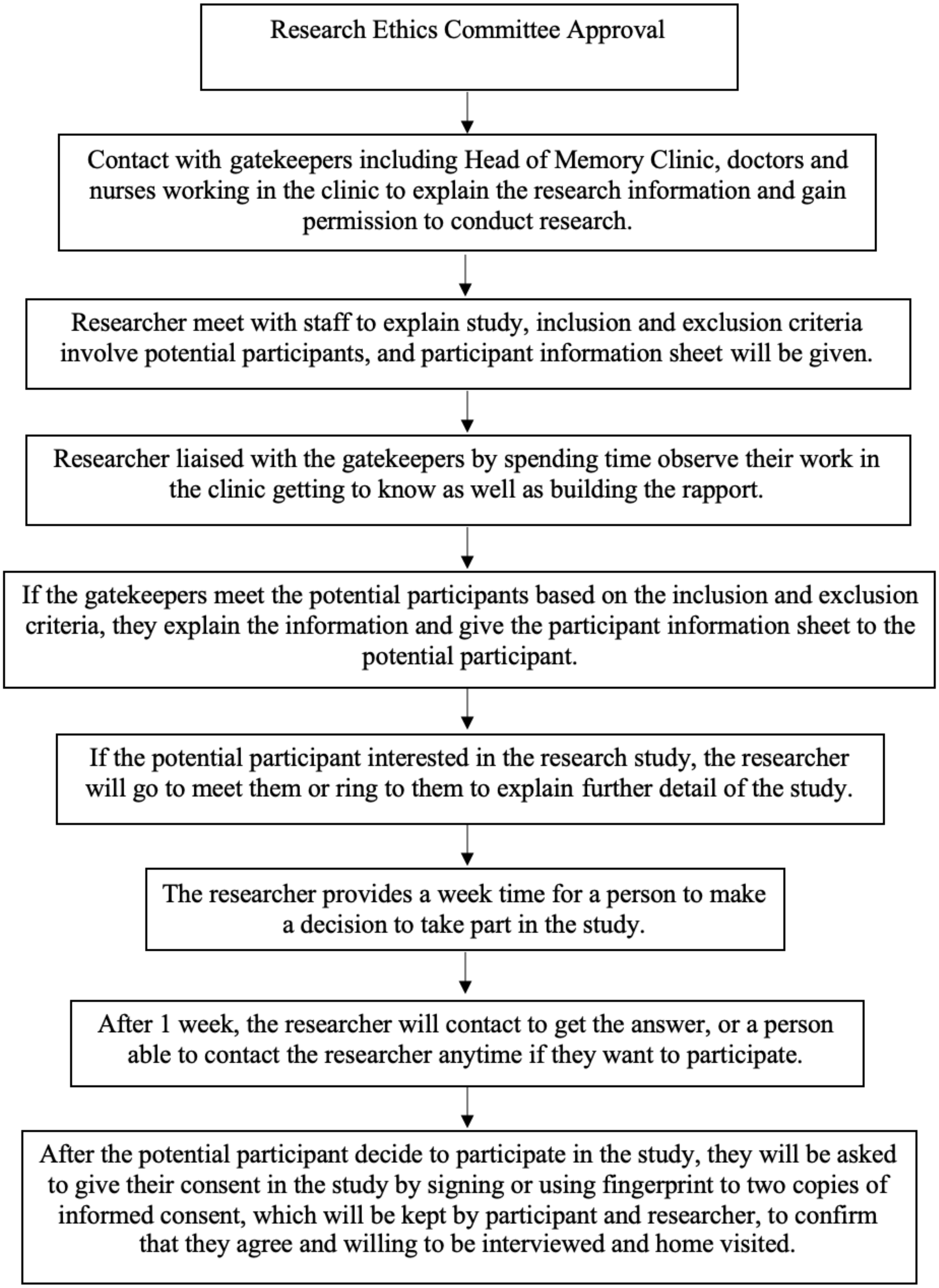


Figure 4.10 The process of participants' recruitment

Once I had ethical approval I contacted gatekeepers from the Geriatric Psychiatry Clinic: Dementia Care in the large tertiary hospital in the province via email and telephoned to explain my research and gain permission to access the clinics. I met the gatekeepers in person, fully explained my research and asked for their assistance in identifying potential participants who met the inclusion criteria. I explained to gatekeepers that participation was voluntary, and ensured they understood this before they spoke with potential participants. Before starting to recruit, I spent time attending the clinic to observe their work and building rapport and increase understanding of how they work with PwD and CG.

As the gatekeepers and I discussed the process of getting to know PwD attending the clinic, we decided that I should attend and observe 8.30 a.m. to 3 p.m. every working day for two weeks. After that, I attended the dementia clinic every Monday and on other days when potential participants were attending.

When the gatekeeper identified a potential participant or their CG (in some cases the PwD did not attend the clinic in person) they made an introduction. If they were interested in the study, I asked for their contact information. I then rang them to arrange an appointment to meet them to explain further details of my study. Majority of PwD meeting with me at the clinic first time decided to participate. Most of them agreed to be visited at their home as it was convenient for them. Their family member explained the address and the route to their house. However, there were some PwD, and their family decided not to take part in this research, details will be explained later in the chapter (see section 4.7).

At face-to-face meetings I gave potential participants further information about my study and answered questions. I then gave them a minimum of one week to decide whether they would like to participate. After a week, I contacted them again to see if they wanted to take part. I noticed that all PwD sought approval from their CG before agreeing to participate. Recruitment continued for a period of six months.

4.7 Participants

Purposive sampling and convenience sampling were used to recruit participants deliberately for a variety reasons (O’Reilly, 2009; Fetterman, 2010). These approaches supported my aim to gather data to illuminate dementia support needs from multiple perspectives (Creswell, 2013). Purposive sampling was used with the cooperation of the gatekeepers to ensure that potential participants met the relevant criteria for inclusion in the study. Convenience sampling was used to recruit from the clinic when unexpected participants who met the inclusion criteria were interested in participating in this study. Inclusion and exclusion criteria are summarised in Table 4.1. I liaised with the gatekeepers to purposefully sample for maximum variation. I informed the clinic staff when I had recruited enough participants for the study.

Table 4.1 Principle inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
1) Persons aged 60 years and over, both males and females who have been diagnosed with early stage dementia and living in Nakhon Ratchasima, Northeast Thailand. This includes early stage dementia as assessed by memory clinic staff. The Mini-Mental State Examination-Thai version 2002 (MMSE-Thai 2002) is commonly used as an assessment tool to measure cognitive impairment. As the level of education is one of factors affect to the MMSE score (Tombaugh & Mclntyre, 1992; Crum et al., 1993), in Thailand the cut-off scores to identify the PwD are adjusted by education as ≤ 14 for illiterates, ≤ 17 for elementary school, and ≤ 22 for over elementary school (Thai Cognitive Test Development Committee 1999, 2002; Shim et al., 2017). The person's communication and cognitive skills, the activities of daily living are also assessed by the health professional.	1) Older persons who are not willing to participate.
2) Older persons who are able to hear and communicate in Thai language.	2) Older persons who are unable to give consent to take part.
3) Older persons who have been diagnosed with dementia for a minimum of 12 weeks.	3) Older persons with low mood or depression.
4) Older persons who are willing and able to give informed consent to participate in this study and to share their experiences and knowledge.	4) Older persons who have Behavioural and Psychological Symptoms of Dementia (BPSD).
5) There are some criteria to gain a variety of cases. 5.1) The duration of receiving a diagnosis of dementia 5.2) The underlying diseases 5.3) The levels of education 5.4) The variety of occupational backgrounds	5) If there are lots of PwD in the clinic interested in taking part in the study, they will be excluded according to the criteria to gain a variety of cases, and the sample size expected in the study. The clinic staff will tell the people who are interested in taking part that the researcher already gained enough participants for the study.

In total twenty three potential participants were invited to take part by the gatekeeper, of these sixteen people were recruited. Four people were excluded because: one had moderate stage dementia; one had a hearing problem; one had BPSD and one lived in a different district over 100 kilometres from the city. The three other exclusions were one PwD and two CG who decided not to participate, no reason was given.

4.7.1 Participants demographics

Participant demographics are provided in Table 4.2 and summarised in Table 4.3. Detail is also given about participants' background to add contextual understanding, these will be described more in the findings chapters.

Table 4.2 Demographic of older persons with early stage dementia taking part in the research

No.	Pseudonym	Sex	Aged (year)	Education	Marital Status	Living with (number of family member)	Diagnosis	Underlying disease	Caregiver (name: occupation)	Health Insurance
PwD_01	Palapol	Male	80	Elementary school	Married	Dementia wife (1) = **1** (Son usually comes to take care every day)	Vascular dementia	Asthma	Son (Pongsak: Teacher)	Getting Civil servant medical benefit of son
PwD_02	Wannaporn	Female	85	Elementary school	Widowed	Son (1) = **1**	Alzheimer's	Hypertension, Hyperlipidemia, Chronic renal disease	Son (Puchong: Artist)	Older persons free service
PwD_03	Chompoo	Female	79	Elementary school	Widowed	Daughter (1), son-in-law (1), granddaughter (1) = **3**	Vascular dementia	Hypertension, Hyperlipidemia, Chronic renal disease	Daughter (Panthip: Seller)	Getting Civil servant medical benefit of son
PwD_04	Naree	Female	76	High school	Married	Husband (1) and daughter (1) = **2**	Alzheimer's	Hyperlipidemia	Daughter (Duang-jai: Seller)	Getting Civil servant medical benefit of daughter
PwD_05	Nantana	Female	83	Elementary school	Widowed	Nephew (1), granddaughter-in-law (1) and great-granddaughter (1) and great-grandson (1) = **4**	Vascular dementia	Diabetes Mellitus, Hypertension, renal disease	Grand daughter-in-law (Arunee: housewife)	Older persons free service
PwD_06	Rattana	Female	81	Elementary school	Widowed	Daughter (1), son-in-law (1), grandson (1) = **3**	Alzheimer's	Hypertension	Daughter (Rujira: Tailor)	Getting Civil servant medical benefit of son

No.	Pseudonym	Sex	Aged (year)	Education	Marital Status	Living with (number of family member)	Diagnosis	Underlying disease	Caregiver (name: occupation)	Health Insurance
PwD_07	Kanit	Male	70	Certificate	Married	Wife (1), son (1) and granddaughter (1) = **3**	Vascular dementia	Diabetes Mellitus, Hypertension, renal disease, Gout	Wife (Usa: Housewife)	Getting Civil servant medical benefit
PwD_08	Ngamta	Female	78	Elementary school	Divorced	Daughter (1) and son-in-law (2)	Vascular dementia	Diabetes Mellitus	Daughter (Tookta: Nurse)	Getting Civil servant medical benefit of daughter
PwD_09	Pilaiwan	Female	67	Elementary school	Single	Younger sister (1) and nephew (1) = **2**	Vascular dementia	Osteoarthritis	Sister (Siriporn: Cleaner staff)	Older persons free service
PwD_10	Dararat	Female	62	Elementary school	Married	Husband (1), sons (2) and daughter-in -aw (1) = 4 (Daughter live in dormitory, comes to visit once a week)	Alzheimer's	Parkinson	Daughter-in-law (Orawee: Seller)	Older persons free service
PwD_11	Pratumrat	Female	63	Elementary school	Divorced	Daughter (1) = **1**	Vascular dementia	none	Daughter (Prapasri: Seller)	Getting Civil servant medical benefit of daughter
PwD_12	Kannika	Female	77	Elementary school	Widowed	Son (1), daughter (1) and granddaughters (2) = **4**	Vascular dementia	none	Daughter (Paweena: Seller)	Getting Civil servant medical benefit of son

No.	Pseudonym	Sex	Aged (year)	Education	Marital Status	Living with (number of family member)	Diagnosis	Underlying disease	Caregiver (name: occupation)	Health Insurance
PwD_13	Aorasa	Female	82	Certificate	Widowed	Daughter (1) = **1**	Alzheimer's	Diabetes Mellitus, Hypertension, Osteoporosis, Osteoarthritis	Daughter (Kejmanee: Seller)	Getting Civil servant medical benefit
PwD_14	Tassanee	Female	77	Elementary school	Married	Husband (1), daughter (1), son-in-law (1) and grandsons (1) = **4**	Vascular dementia	Parkinson	Daughter (Tida: Officer in the company)	Getting Civil servant medical benefit of husband
PwD_15	Laiad	Male	77	Elementary school	Married	Wife (1), daughter (1), son-in-law (1), grandchildren (3), Grandson-in-law (1), greatgrandchildren (1) = **8**	Vascular dementia	Chronic renal disease, Osteoarthritis.	Daughter (Noi: Seller)	Older persons free service
PwD_16	Pimala	Female	90	Elementary school	Widowed	Daughter (1) and granddaughter (1) = **2**	Vascular dementia	none	Daughter (Malee: Embroiderer)	Older persons free service

All participants were diagnosed with dementia, including vascular dementia, Alzheimer's disease and frontotemporal dementia at an early stage. The average age was 76 years with the youngest being 62 and the oldest 90 years old. Most were female (n=13) and had graduated from primary school. One person graduated from upper secondary school, and two continued education to certificate degree level. Most were married and had children, some were divorced or were widowed. There was only one single woman.

All participants lived with their family. Although all could still do some activities independently, all needed some assistances. In most cases, CG were adult children with some relying on extended family. All PwD had some access to free medical treatment. Some also had access to the civil servant medical benefit scheme because they or their family member has worked in Thai government organisations.

Table 4.3 Participant characteristics

Characteristics	**Number of participants (person)** (*n=16*)
Sex	
Male	3
Female	13
Age	
60-70	3
70-80	7
80-90	6
Education level	
Primary school	13
Upper Secondary school	1
College	2
Marital status	
Single	1
Married	6
Widowed	7
Divorce	2
Place of living	
Urban	9
Other districts	3
Rural	4
Living with	
Couple and Child/children	5
Daughter and daughter's family	5
Daughter	2
Son	1
Wife (advanced stage dementia)	1
Relative	2
Underlying disease	
None	3
1 disease	7
2 diseases and over	6
Caregiver	
Daughter	10
Son	2
Couple	1
Sibling	1
Daughter/granddaughter-in-law	2
Health Insurance	
Older person free service	6
Civil servant medical benefit	10

4.7.2 Educational and occupational background of participants

Information regarding educational and occupational background of Thai people was stated in the background chapter, and it underpins this study. Most of my participants graduated from primary school level in grade 4. They left school at around 10 years of age to help their parents working in agricultural fields, growing rice and vegetables. Some took other employment. Once they got married, some started their own businesses. Women participants mostly worked as housewives looking after their husband and children. Relatively few participants had continued education and moved to higher level jobs such as government official.

4.7.3 Place of living

All participants were retired and lived close by, or with, family members. I visited people in city, town municipality and rural areas.

4.7.3.1 Living in the city (PwD_05,07,09,10,12,13,14,15,16)

It was easy to visit participants living in the city because their houses are not far from the hospital. The CG explained the route and some drew a map for me. Their houses were near to important places for example the temple, school, police station, market, restaurant or hotel. Many houses in the city look like commercial buildings. However, all participants lived in the residential area, so all of their homes are single houses, which are separated by a fence. Most families owned their house but three were rented. Often the PwD had had to move to a new and unfamiliar environment. It was notable that although people in the city areas know each other, they live separately, and they did not have the close relationship like in the rural area.

4.7.3.2 Living in town municipality (PwD_02,04,08)

The town municipalities have a combination atmosphere between the city and rural area. These areas are 30-70 kilometres from the city. The route to visit participants' house is not complicated because they are still in the municipal area. All participants living in municipality areas had their own house. Although their houses have a fence, their children and relatives live nearby. Therefore, the participants can get help if they need somebody to take care of them. Municipalities were friendlier than the city with people greeting each other, having conversations and feeling able to ask for help.

4.7.3.3 Living in rural area (PwD_01,03,06,11)

Four participants lived in small villages in the countryside surrounded by fields and farms. There are two different types of rural area: i) isolated houses set in large areas of land and ii) small villages where people’s houses are near to each other and separate from their fields. Normally, people living in the rural area know each other as families have often been there for generations. I found it complicated to get to the participants’ homes in rural areas because they are far from my home, GPS does not work in these areas and there are dirt roads which were difficult to drive on particularly following rain (see Figure 4.11 – 4.12).

Figure 4.11 - 4.12 The example of the road in the rural areas

4.7.4 Who do participants live with?

Figure 4.13 summarises who lives in the household with the PwD.

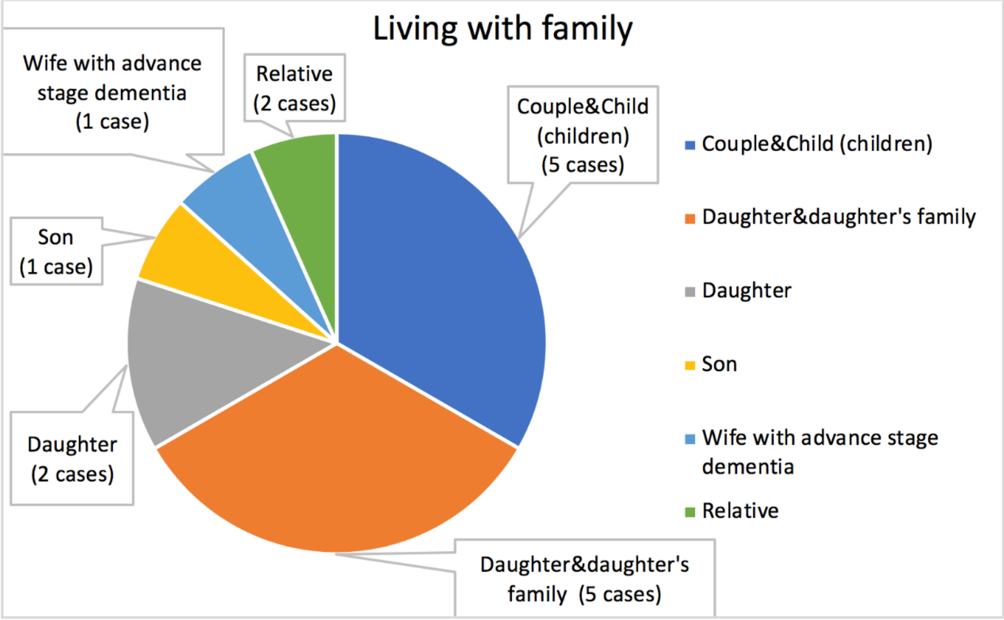


Figure 4.13 Person(s) living with the participants

There were both nuclear and extended family households of three types: one-generational, multi-generational and skipped generational. As mentioned previously there is a cultural expectation that the younger generation will care for relatives as they age. Although living with their family, almost half the participants were alone during the day as family members went out to work. Some were able to go out independently but others spent days alone. Only one participant went to work with a family member.

4.7.5 Health and underlying disease

In addition to early stage dementia, most participants have other long-term conditions. The top three were hypertension, chronic renal disease and diabetes mellitus, respectively. Others included hyperlipidemia, osteoarthritis, Parkinson’s disease, osteoporosis, gout and asthma. Most had had other long-term conditions diagnosed before the dementia. Even those without specific conditions experienced some health deterioration with symptoms like blurry eyes, leg pain, low back pain, but they did not consult with a health care provider about these.

4.7.6 Participants' caregiver

As mentioned above, all participants lived with one or more family members. Care was often shared but one person always had the main responsibility as illustrated in Figure 4.14. This was most often the daughter, or if there was no daughter the son took the principal carer role. In some cases care was seen as a duty, an obligation. This is discussed in more detail later in the thesis.

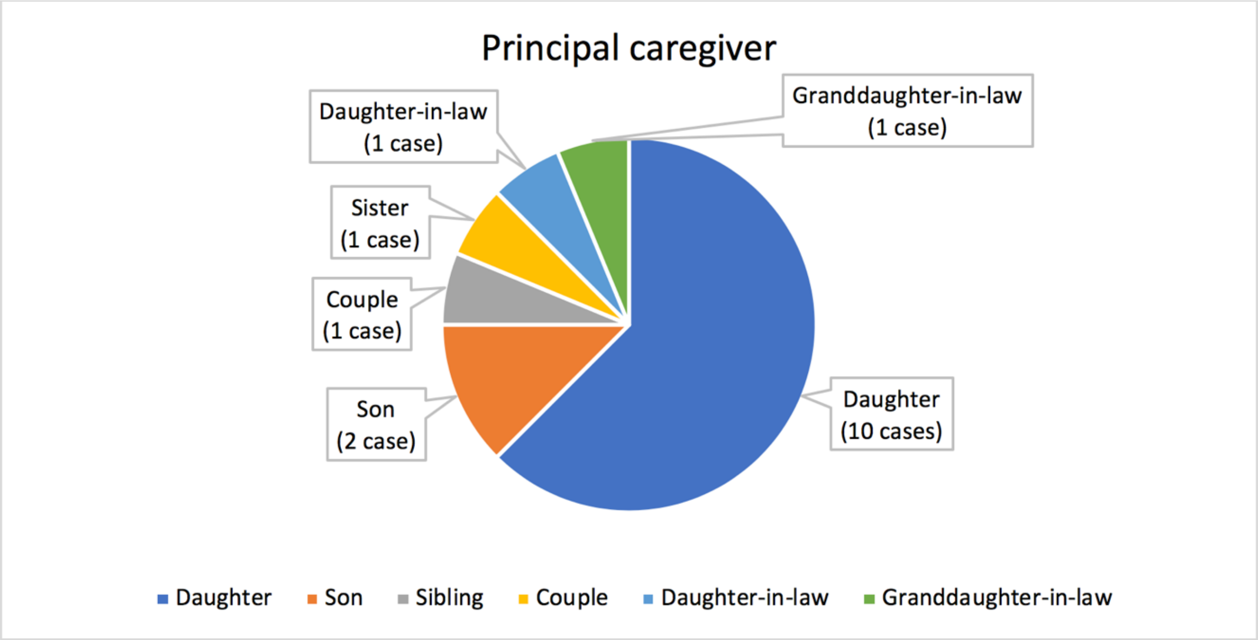


Figure 4.14 Principal caregivers who look after the participants

4.8 Methods of data collection

Data collection comprised a series of audio-taped interviews, ethnographic observation and field notes from March to August 2018. Through all data collection I was mindful of Maslow's Hierarchy of Needs (1943) and Kitwood's work (1997). I met with each participant between two and four times. A summary of data collection is provided in Table 4.4.

Table 4.4 Summary of data collection activity

No.	Recruit at	1			2			3			4			Total	
		Int	V	Pl.	Int	V	Pl.	Int	V	Pl.	Int	V	Pl.	Int	V
PwD_01		50 m.	11-13 =2 hr.	H	1.15 hr.	11.50-13.20 =1.30 hr.	H	-	12-13 =1	H	50 m.	13-14.30 =1.30	H	2.55 hr.	6 hr.
PwD_02	HP	-	10-11.30 =1.30 hr.	HP	1 hr.	10.30-12.30 =2 hr.	H	45 m.	11-12.45 =1.45 hr.	H	40 m.	10-11 =1 hr.	H	2.25 hr.	6.15 hr.
PwD_03		50 m.	11.30-1 =1.30 hr.	H	45 m.	11.45-13.45 =2 hr.	H	1.15 hr.	10-13 =3 hr.	H	-	-		2.50 hr.	6.30 hr.
PwD_04		40 m.	13-14.20 =1.20 hr.	H	45 m.	13-14.30 =1.30 hr.	H	1 hr.	13-15 2 hr.	H	-	-		2.25 hr.	4.50 hr.
PwD_05		1 hr.	14-16 =2 hr.	H	1.15 hr.	14-16 =2 hr.	H	1.20 hr.	15.20-17.30 =2.10 hr.	H	1 hr.	13-15 =2 hr.	H	4.35 hr.	8.10 hr.
PwD_06		1 hr.	10-11.30 =1.30 hr.	H	1 hr.	10.30-12.30 =2 hr.	H	1 hr.	10-12.00 =2 hr.	H	-	-		3 hr.	5.30 hr.
PwD_07	HP	50 m.	10-11.30 =1.30 hr.	H	40 m.	13-14.30 =1.30 hr.	H	1 hr.	13-15 =2 hr.	H	-	-		2.30 hr.	5 hr.
PwD_08	HP	50 m.	14-15.30 =1.30 hr.	H	1 hr.	13.30-15.30 =2 hr.	H	1.15 hr.	13-15 =2 hr.	H	-	-		3.05 hr.	5.30 hr.
PwD_09	HP	50 m.	11.30-13 =1.30 hr.	H	1 hr.	10.30-12.30 =2 hr.	H	40 m.	10-12 =2 hr.	H	1 hr.	10-12 =2 hr.	H	3.30 hr.	7.30 hr.
PwD_10	HP	1 hr.	13-14.30 =1.30 hr.	M	1 hr.	13-14.30 =1.30 hr.	M	1 hr.	13-15.30 =2.30 hr.	M	-	-		3 hr.	5.30 hr.
PwD_11	HP	40 m.	10.30-12 =1.30 hr.	H	45 m.	10.40-12.10 =1.30 hr.	H	50 m.	10.40-12.10 =1.30 hr.	H	-	-		2.15 hr.	4.30 hr.
PwD_12	HP	30 m.	10-11 =1 hr.	H	40 m.	14-15.30 =1.30 hr.	H	40 m.	10.30-12 =1.30 hr.	H	-	-		1.50 hr.	4 hr.
PwD_13	HP	40 m.	11.20-12.30 =1.10 hr.	H	40 m.	15.45-17 =1.15 hr.	H	-	8-10 =2 hr.	T	-	-		1.20 hr.	4.25 hr.
PwD_14	HP	50 m.	13-14.20 =1.20 hr.	H	1 hr.	12.45-14.20 =1.35 hr.	H	1 hr.	12.45-14.30 =1.45 hr.	H	-	-		2.50 hr.	4.40 hr.
PwD_15		40 m.	11-12.20 =1.20 hr.	H	1.10 hr.	11.45-13.30 =1.45 hr.	H	1 hr.	11.45-13.30 =1.45 hr.	H	-	-		2.50 hr.	4.50 hr.
PwD_16		40 m.	10.30-12 =1.30 hr.	H	1 hr.	15-17 =2 hr.	H	1 hr.	15-17 =2 hr.	H	-	-		2.40 hr.	5.30 hr.
Total														44	88.40

Note: Int = interview, V = visit, Pl. = place of interviews and visits, H = home, HP = hospital, T = temple, M = market (workplace), the duration of interviews and observation were reported by hour(s).

4.8.1 Observation

During the fieldwork, I observed interactions between participants and surrounding people, along with their environment and daily activity. Observational data were collected both at the recruitment clinic and in interview venues, mostly participant's homes. This approach allowed me to immerse myself in their culture, increase my understanding of their lifestyle also provided clarity when participants struggled to articulate particular issues. The details of observational data from each source are described in the following section and a summary of observation is provided in Table 4.5.

Table 4.5 A summary of observation

Fields	Areas of observation
1. Dementia clinic	- Health staff working - Interaction between health staff and patient - Environment and convenience to access to the service
2. Participant's home	- Personality - Lifestyle of participant - Activities at home, activities outside home - Relationship and interaction between participant with family members, neighbour, health staff - Environment
3. General lifestyle of people in the setting	- Culture and belief - Transportation - Interaction between general older people and other younger generations - Environment in each community

4.8.1.1 Dementia clinic

In total, I spent 152 hours observing how staff in the clinic worked and interactions between PwD, their CG and health practitioners. I also participated in activities with health staff in helping them doing basic tasks. I talked with staff about clinic processes. They told me that not many people attended the dementia clinic compared with other specialties. Staff tended to know all the patients. On one visit, I participated in a dementia seminar where there was an exchange of knowledge and perspectives between Japanese visitors and Thai staff (see Figure 4.15 – 4.16).

Figure 4.15- 4.16 A seminar on the network for dementia care

This event gave me more opportunity to understand clinic staff in this province. I learnt that dementia has become more important to people in this region due to collaboration among health professionals in the province and country. There is a growing interest in improving the quality of life of PwD and their CG. From my point of view, however, including voices of PwD would help staff to create tailored support plans to addressed to the needs of PwD.

4.8.1.2 Participant’s home

In total, I spent 88 hours and 40 minutes visiting participants and observing their everyday life. I limited duration of visits to avoid tiring or upsetting PwD. To build a good relationship and rapport with PwD and CG I took on the role of participant-as-observer. I was always mindful that I was a visitor to their home. I did not want participants to think that I was only visiting to get data, so I participated in activities that helped me understand each person more deeply. For example, after finishing the interview, I helped some participants to prepare lunch. I played with the cat or dogs with a PwD and their family members. I watched television and discussed with older PwD. I helped them to manage their medicines, watered gardens or played games. One participant and the family members also invited me to join the older people school where the participant was a member. It is a project that the government (DOP) collaborates with the provincial public health office and local administration organisation in conducting the school for older persons or senior society in the communities (see section 5.4.2.2). In some cases, participants introduced me to other relatives, neighbours or friends. I took a digital mobile sphygmomanometer to check their blood pressure if they wanted.

During visits I observed participants homes. Most were able to get around their home easily, go out for a walk and have a conversation with people in the community. For those with physical limitations this was more difficult. Being at home all day led to a mundane lifestyle. Many PwD spent hours watching television, talking with a family member, relative or neighbour, reading or listening to Dhamma, or simply doing nothing. Major forms of Dhamma are in books and audio records they offer thoughts about the nature of life, being a good person and living well and happy, which were taught by the Buddha and are distributed by many monks. Some PwD did religious practice from home while others went to Temple on every Buddhist Holy day. Few participants had activities outside the home. People living in the city tended to have less interaction outside the home than those living in familiar rural areas where they were already known in the local community. In some cases, the PwD had been moved to the home of the CG, this could be disorientating and also take people way from a familiar environment and network of friends.

4.8.1.3 Religion in daily life of PwD

Religion underpinned daily life for all participants. Most were Buddhist, and religion was an important element in achieving wellbeing. The local Temple was the spiritual anchor to support the mental and spiritual health.

During an observation on the Buddhist Holy Days, my participants who have physical limitation would be at home and gave water and flowers to the Buddha statue in their house. Some gave alms to the monks in front of their house, and some who were more independent went to the Temple and were picked up by their children. Additionally, I saw many older people, some children and teenagers attend the temple (see Figure 4.17). People chanted with the monks and listened to the sermon. Chanting is one of the fundamental practices in the Buddhist religion and is one of the spiritual anchors for Thai people. People believe that these religious practices can help them to get good merit. Cleaning the floor in the temple, washing the dishes, or helping people to do the good things, all the good things that they do will be good karma which accumulates throughout life.

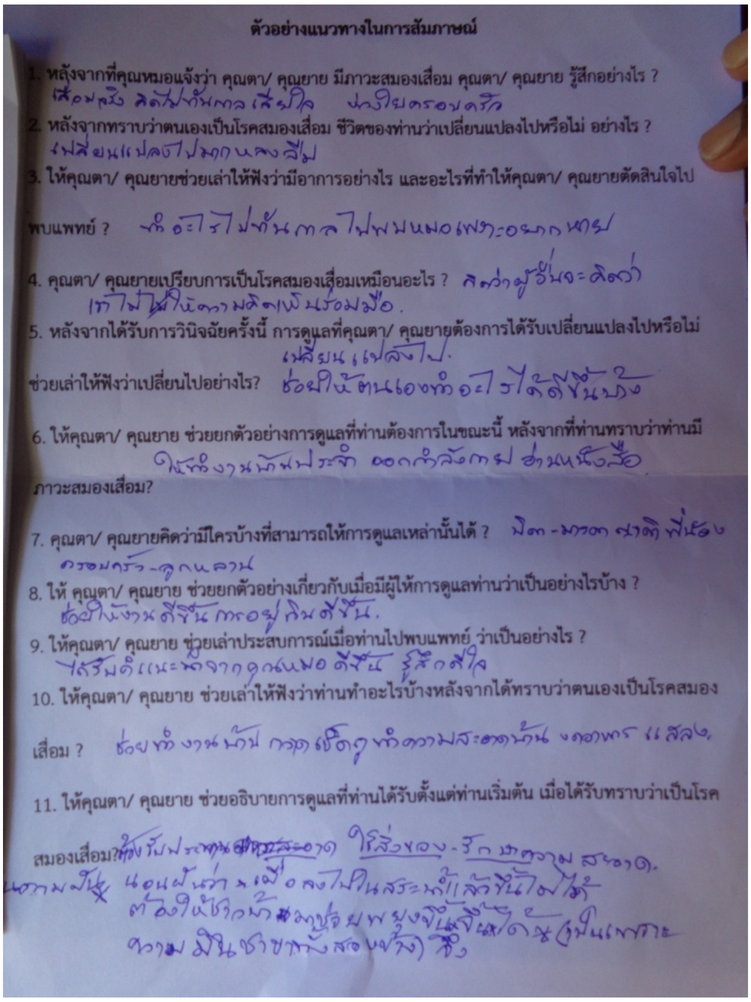
Figure 4.17 People attend the temple on a Buddhist Holy Days.

Theses religious practices have value for both the spiritual and social well-being of persons. My participants who attended the Temple talked with other people and seemed to experience spiritual well-being. The monks gave sermons about the teachings of Buddha to teach people about karma and remind them to do good things.

4.8.2 Ethnographic interviews

Interviews were carried out to understand the older person's background and experiences of receiving dementia care and to understand their perceived care needs. The ethnographic interview guide was developed in line with the approach of Spradley (1979). Each interview began with an informal conversation. Later, the formal interviews were continued to explore details about the PwD life. I started with grand tour questions about the participant's life and feelings after getting a dementia diagnosis. These were followed by mini-tour questions probing their perspectives on living with dementia and the care they need. In order to increase understanding of the perspective of the participants I asked them to clarify by telling their stories of living with dementia and receiving support as example and experience questions. These questions were also guided by Maslow's Hierarchy of Needs (Maslow, 1943) (Appendix 7). To prepare, I did an interview with my supervisor to practice, this helped me to find ways to adapt the conversation with participants.

Before interviews I gave each participant the interview guide to give them an opportunity to prepare. Not all participants prepared but it was an effective way of gaining rapport and starting the interviews. Figure 4.18 shows an example of how a participant prepared for an interview. At the beginning of each interview I confirmed consent verbally. The first interview question focused on the experience of living with dementia and the needs which would maintain their well-being. Then questions were adapted as the conversation progressed and for subsequent interviews.



ตัวอย่างแนวทางในการสัมภาษณ์

1. หลังจากที่คุณหมอแจ้งว่า คุณตา/ คุณยาย มีภาวะสมองเสื่อม คุณตา/ คุณยาย รู้สึกอย่างไร ?
[illegible] คิดไม่ทันกาล เสียใจ ห่วงใยครอบครัว
2. หลังจากทราบว่าตนเองเป็นโรคสมองเสื่อม ชีวิตของท่านว่าเปลี่ยนแปลงไปหรือไม่ อย่างไร ?
เปลี่ยนแปลงไปมากหลงลืม
3. ให้คุณตา/ คุณยายช่วยเล่าให้ฟังว่ามีอาการอย่างไร และอะไรที่ทำให้คุณตา/ คุณยายตัดสินใจไปพบแพทย์ ? ทำอะไรไม่ทันกาลไปพบหมอเพราะอยากหาย
4. คุณตา/ คุณยายเปรียบการเป็นโรคสมองเสื่อมเหมือนอะไร ? คิดว่าผู้อื่นจะคิดว่า เราไม่ ~~ไม่~~ ให้ความ[illegible].
5. หลังจากได้รับการวินิจฉัยครั้งนี้ การดูแลที่คุณตา/ คุณยายต้องการได้รับเปลี่ยนแปลงไปหรือไม่ เปลี่ยนแปลงไป.
ช่วยเล่าให้ฟังว่าเปลี่ยนไปอย่างไร? ช่วยให้ตนเองทำอะไรได้ดีขึ้นบ้าง
6. ให้คุณตา/ คุณยาย ช่วยยกตัวอย่างการดูแลที่ท่านต้องการในขณะนี้ หลังจากที่ท่านทราบว่าท่านมีภาวะสมองเสื่อม? ให้ทำงานบ้านประจำ ออกกำลังกาย อ่านหนังสือ.
7. คุณตา/ คุณยายคิดว่ามีใครบ้างที่สามารถให้การดูแลเหล่านั้นได้ ? บิดา-มารดา ญาติ พี่น้อง ครอบครัว-ลูกหลาน
8. ให้ คุณตา/ คุณยาย ช่วยยกตัวอย่างเกี่ยวกับเมื่อมีผู้ให้การดูแลท่านว่าเป็นอย่างไรบ้าง ?
ช่วยให้งานดีขึ้น การอยู่กินดีขึ้น.
9. ให้คุณตา/ คุณยาย ช่วยเล่าประสบการณ์เมื่อท่านไปพบแพทย์ ว่าเป็นอย่างไร ?
ได้รับคำแนะนำจากคุณหมอ ดีขึ้น รู้สึกดีใจ
10. ให้คุณตา/ คุณยาย ช่วยเล่าให้ฟังว่าท่านทำอะไรบ้างหลังจากได้ทราบว่าตนเองเป็นโรคสมองเสื่อม ? ช่วยทำงานบ้าน กวาด เช็ดถู ทำความสะอาดบ้าน ทำอาหาร [illegible]
11. ให้คุณตา/ คุณยาย ช่วยอธิบายการดูแลที่ท่านได้รับตั้งแต่ท่านเริ่มต้น เมื่อได้รับทราบว่าเป็นโรคสมองเสื่อม? [illegible] ใช้สิ่งของ-รักษาความสะอาด. [illegible] นอนฝันว่า เมื่อลงไปในสระน้ำแล้วขึ้นไม่ได้ ต้องให้ [illegible] พยุงขึ้น [illegible]

Figure 4.18 An example of the participant answered the interview guide

Data collection continued for six months. Most participants were interviewed on three occasions. Two who were particularly vulnerable were interviewed four times. Short interviews were used to avoid participant fatigue and stress, they lasted around 30 – 60 minutes depending on their condition. Before and after interviewing, I spent some time with participants and their family to observe everyday life and their interactions. Overall, I spent about 1 – 2.30 hours at each visit. Interviews were one-two weeks apart, so I had time to analyse data and consider further questions. In total I collected 44 hours of interview data.

Many participants prepared the place for an interview on every appointment date. I started the first interview with general questions regarding their dementia symptoms, how they got the diagnosis and how they felt about it. I asked them to tell me about their daily life and routines. We talked about wellbeing and what they needed to achieve a sense of wellbeing.

Interviewing older PwD requires particular skills, many of which I already have as a registered nurse who has worked with older people for many years. This notwithstanding, Murphy et al. (2015) cautions researchers to be aware of the unique challenges and opportunities presented in including PwD in qualitative research interviews. They highlight four important issues including; firstly, gaining consent, secondly maximising the participants responses by being attentive to participant comfort and building the researcher-participant relationship, thirdly enabling the participant to tell their story, and finally conveying the positivity of their participation in the research. I have considered and attended to all of these issues while conducting this research.

Some of the particular issues I encountered and needed to attend to included participants who did not remember me from one visit to the next. To aid memory, I dressed the same for each visit and reiterated the research information. Recognising that the readiness of PwD to communicate can vary from time to time is important (Digby et al., 2016). I gave people time in interviews and allowed long pauses so they could formulate answers without feeling pressurised or rushed. The stories the participants revealed were not necessarily coherent or logical but they were meaningful, and I took time to try to understand participants' meanings with gentle probing of their answers. I listened to repeated stories with patience, and was aware of nuanced changes in telling.

I did not force people to speak and answer my questions; sometimes I simply sat in silence for a while. It is important to have concern for each individual background, and to facilitate and prompt conversation and enhance the participants feelings of safety (Digby et al., 2016). I talked with participants wherever they were most comfortable, for example some preferred to lay on a hammock or sun lounge chair and others enjoyed me joining in their activities as we talked. On one occasion I visited a participant (Kanit), who had a problem with his speech; he paused and repeated himself many times during interviews, he invited me to have a dessert for him, so I sat with him and his wife while we were having our dessert we also conversed about his and his wife's health problems, we even discussed his family business. This was effective in building trust and removing any pressure on the participants. All approaches were concerned with enhancing the interviews with PwD; from before the study started through to the end of data collection (Cridland et al., 2016).

During the data collection, I sensed that participants felt free to talk with or without a family member being present. They seemed not to have any secrets from their family. Participants who spoke of family relationship problems were often ignored by family members. However, all families welcomed and willingly spoke with me. PwD reported that enjoyed interviews and having an opportunity to talk and be listened to.

There were some challenges in interviewing. As all participants lived with family, some people wanted to be interviewed together. This was helpful as I could observe interaction among the family, and on some occasions with wider family and friends.

Although this study focuses on the views of PwD, family members were present in some interviews and this can have both advantages and disadvantages. My researcher skills along with my nurse role, was helpful in establishing the relationship and creating trust between me and the PwD and their families. Including family in the interview helped increase my understanding of the holistic situation in each family, however their presence raises ethical dilemmas for a researcher in that, as Haahr at al. (2014) point out, the researcher needs to decide how to deal with others in the interviews. Sometimes having a family member present appeared to give participants the confidence to talk to me. Equally, it allowed me to observe interactions between people. The downside of including family members is that they can alter the dynamic of the interview, they can dominate conversation and reduce the PwD’s autonomy (Digby et al., 2016). This was evident in my study, sometimes family member talked more than the PwD. In these situations, I let the family member talk at the beginning, but I managed to steer the conversation back to the PwD. Some family members tried to correct what the PwD told me. They said that the PwD was confused and that what they said was wrong. In these situations, I did not comment and continued to listen to the PwD to understand their perspective. I also jotted these encounters in my field notes and reflected on them afterwards. In my study the family members of PwD participated in the first interview only, this helped build trust between us all. The family were then content for me to talk alone with the PwD in subsequent interviews where they only came to welcome me when I arrived and said farewell as I left the house at the end of each visit.

Throughout each interview I observed verbal and non-verbal communication which could indicate the participant was uncomfortable, tired or distressed. Using my nursing skills, I reassured the person that if they wished, I would stop the interview. Only one person felt upset while talking about her other children who lived far away. After that, she did not want to talk about her family again. In this case, I asked the person if I could visit her again another day and went to the Temple with her.

Although all participants had the ability to express and discuss their history and their feelings, many of them had problems sequencing the stories. Some were repetitive and had word finding problems and there were often long pauses in conversations. In these situations, I simply waited and gave participants more time to formulate and convey their thoughts. Where needed I reminded them of the topic of discussion.

4.8.3 Field notes

I recorded field notes about participants' non-verbal behaviours (facial expressions, e.g. happy, sad, worried, and body language, e.g. whether they used their hands to clarify their descriptions). In field notes I recorded observational data, where the interview took place (indoors and outdoors, which room), the environment while interviewing and also thoughts and feelings about each encounter with, and interactions between the PwD and their family member(s), relatives and friend(s). I jotted down key verbal and non-verbal expressions that the participants presented during my visits. I wrote in a personal notebook during and immediately after each interview and recorded my reflections on events.

Throughout the process I took photographs (as appropriate) to illustrate settings. For example, I took photographs while travelling to participants' homes (Figure 4.19 – 4.21). These reminded me that there is little public transport on the roads out into rural areas and of the difficulties facing participants attending the dementia clinic in the city.

Figure 4.19 The route to go to participants’ home (public transportation access)

Figure 4.20 - 4.21 The route to go to participants’ home (no public transportation access)

Additionally, I drew visual maps to report the layout of participant's homes (see Figure 4.22 – 4.23). This reminded me of where and how interviews took place and helped to deepen my understanding of the interview and the participant's lifestyle.

Figure 4.22 An example of visual maps during interviewing PwD_01

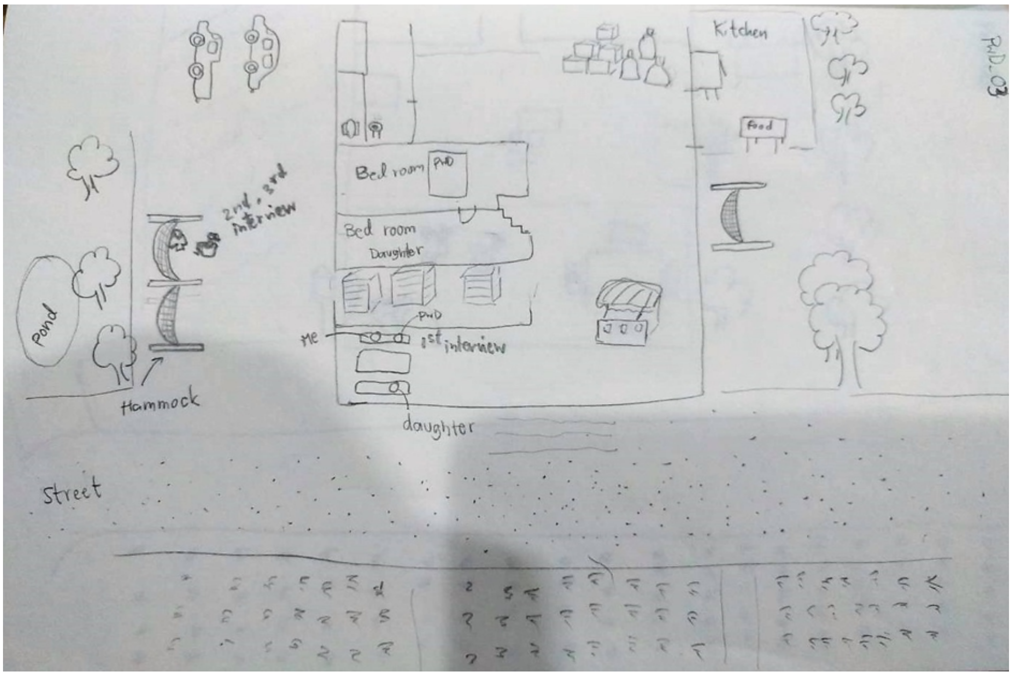


Figure 4.23 An example of visual maps during interviewing PwD_03

I also wrote my personal field work journal in my field notes to remind me of what occurred and what I learned and how I interpreted the event at the time when I was in the fieldwork. It was helpful to construct the pattern of participants' life and cultural meanings when I started analysing data and writing up a cultural description as describes in each story in the findings chapters.

4.9 Data analysis

As I started data analysis I considered the use of data management software. Using computer software for analysing data can help the researcher manage and organise the data set and can support coding and retrieving data from transcripts (Silver & Lewins, 2014; Richards, 2015). It can also provide evidence of rigour of the analysis process (Bryman & Burgess, 1994). However, using this software cannot help the researcher decide how or why to generate or apply codes or interpret data, so these skills remain required from the researcher (Silver & Lewins, 2014). Bryman (2012) highlighted that the temptation to quantify qualitative findings can potentially lead qualitative research being judged by the same validity and reliability criteria as quantitative research. The code and retrieve functions of computer packages can result in fragmentation of textual material (Graham, 2013). Coffey et al. (1996) suggest that most qualitative computer analysis software is rooted in methods of grounded theory and work less well with other qualitative methods, such as ethnographic data.

I attended study sessions on the use of NVivo software but when using it in practice I did not feel immersed in the data as a whole. Writing the case studies and identifying authentic codes and themes were helpful to get a sense of the data as a whole (Graham, 2013). Therefore, I decided to use a manual analysis. I read through the interview transcriptions which allowed me to make notes on the hard copies of the interview transcriptions and these, together with the written up case studies helped increase my understanding of the background and context of each participant.

Data collection and analysis were iterative processes informed by Maslow's Hierarchy of Needs (1943) along with concept of person-centred care of Kitwood (1997). Qualitative thematic analysis was used to analyse transcripts of interviews and field notes to identify the needs of older persons with early stage dementia. To analyse data, I used the six steps of Braun & Clarke (2006) as this provides a systematic approach to understanding large amounts of data. The six steps include: i) familiarising yourself with your data, ii) generating initial codes, iii) searching for themes, iv) reviewing themes, v) defining themes and vi) producing the report.

4.9.1 The process of analysing and interpreting data

In total, 49 audio recordings were transcribed, translated and analysed. After each interview, I listened to the recording, transcribed it verbatim and then translated it into English. Anonymised translated data were checked by a bilingual translator to ensure accuracy and no loss of nuanced meanings. English transcripts were then sent to my supervisors so they could advise on any developments needed in interview technique. For example, initially I asked about their 'needs for well-being' but my supervisors suggested I should ask 'what do you need to live happily and well'.

Data analysis was time consuming as I had large volumes of material. Using the six steps of data analysis (Braun & Clarke, 2006) gave me an opportunity to get truly immersed in the data. Below I present each step.

i) Familiarising yourself with your data

The first step was to transcribe the interview verbatim and then listen to the recording while reviewing the transcription to check for accuracy and increase familiarity. At this stage I also reviewed the field notes and reflections. I made notes and highlighted potential statements. This helped me to summarise the commonalities, similarities and differences across the data set. While reading transcriptions, I thought about messages PwD dementia were trying to convey as well as actual words recorded.

ii) Generating initial codes

In this second reading, I identified critical statements and keys quote relating to the experiences and needs of participants, thus beginning to address the research question. I also identified relationships between the data and Maslow's Hierarchy of Needs (1943) alongside a sense of personhood and concept of person-centred care of Kitwood (1997).

Relevant sections were manually highlighted and coded with descriptors such as 'dementia is a normal part of ageing', 'rely on family', 'family over supportive', 'still want to do something'. I reread the entire transcripts and reviewed coding continually looking for patterns and themes across the data.

iii) Searching for themes

In this step, I generated themes by grouping similar participants' expressions and experiences. I grouped codes into themes, for example the codes 'onset symptoms of dementia', 'entering the diagnosis process', 'perception of dementia' were components of the theme of the route to the diagnosis and codes ‘need for family understanding’, ‘need somebody to talk to’, ‘still want to do something by oneself’, ‘whatever will be will be’ were represented in the theme the need to live well with dementia.

Table 4.6 illustrates the transition from raw data to initial codes which were revised and refined over time as more data were collected. These revised codes were grouped inductively according to focus, to form sub-themes which ultimately formed the four overarching themes: ‘family is essential’, ‘companionship support is necessary’, ‘meaningful activities need to be maintained’, ‘the nature of life needs to be accepted’.

Table 4.6 An example of transition codes to themes

Statements (supported information about experiences and perspectives of older persons with early stage dementia)	Initial Codes	Revising Codes	Grouped codes	Subtheme relating to the needs of PwD	Theme
- *“Hmm…I think having somebody to talk to like when I go to senior school is good too. I can meet many people, practice using my brain, it is fun.” (PwD_03)* - “I just went to sit there (a small vegetable shop with some people) and talk to them. I find someone to talk to.*”, “*Sometimes they come to talk to me, sometimes I went to talk to them there*.” (PwD_04)* - “I didn’t do anything. After finishing breakfast, I would go to talk to some people. I would go to be with my sister-in-law.*” (PwD_06)* - “When I went to the temple, I can be a leader to do chant. If the temple has any event, the monks or people who attend in the temple will call me to help.” (PwD_08)	PwD able to participate in social events as normal	Continue participating in social as before getting the diagnosis	Being included	Being engaged in society	Companionship support is necessary
- “I think because I didn’t talk to them. I wanted to talk to them, but it was difficult for me to explain things to them.” (PwD_07) - “Sometimes, I don’t want to tell some story, and it difficult to answer. So, I don’t want to talk.” (PwD_13) - “They might not understand me. So, I don’t want to go to talk to others”. (PwD_14) - “Yes, I know them (neighbours). But we didn’t talk much. (silent) I only live in my house.” (PwD_15)	PwD faced with a feeling of social declines (but still has activities with family)	Lack of social engagement	Being excluded		
- “I always eat alone. They will take their food to eat on the high floor. I eat on the ground floor. If there is some food left, I will leave it in the fridge.” (PwD_09) - “Presently, she (cousin) knows I have a health problem. She said that she doesn’t want to invite me because she doesn’t want me to be her burden.” (PwD_10)	PwD are excluded from social or family				
- “Yes, we see each other every day (referring to her nieces living next door). When they go to the market, they always us if we wanted anything.” (PwD_02) - “It is good that my husband does not let me at home alone. He takes me to the work here with him, if the customer come I will call him. Also, at least, I can talk to them and some people around here.” (PwD_10) - “Sometimes, I speak wrong. I’m afraid that they will not understand me. I’m afraid they will blame me that I’m clueless. Therefore, I think I should be at home with my children. However, I still want to talk to them” (PwD_14)	Family member embraces PwD within the family	Being embraced by children and grandchildren or friends	Joyfulness	Somebody to talk to	
- “Yes, I feel lonely. I don’t know what I should do. I just live day by day, as normal. I have the television as my friend, if I were to feel lonely, I would just turn it on. Other than my wife, I don’t know who else I can talk to, and if I go out, my wife would have to be alone, but if I take her with me, she is clueless and could disturb others.” / “It’s good that you came to visit me and talk to me. I would like you or the doctors to come	PwD feels lonely	Being ignored	Loneliness		

Statements (supported information about experiences and perspectives of older persons with early stage dementia)	Initial Codes	Revising Codes	Grouped codes	Subtheme relating to the needs of PwD	Theme
whenever you want because I will have a friend to talk to. (laugh)" / "It's good to have friends." (PwD_01) - "I don't have somebody to share or talk to. I feel lonely." (PwD_11) - "I feel lonely because I only live with my daughter. You come here to talk to me is very good." (PwD_16)					
- "I did not talk with them (children and grandchildren) often because they normally have things to do. So, I just read my books." (PwD_12) - "They (grandchildren) are in their rooms. But I'm afraid they will blame me if I turn on the light. I'm afraid that I will see a ghost again, but they often remind me to not forget to turn off the light." (PwD_15)	PwD feels being ignored by their family or friends				
- "…My son wants me to live with him and his family in the city, but I don't want to because I would feel lonely. I prefer to live in my house even though it's in the rural area." / "If I live here (her hometown) I can give alms to the monks and it's easier to go to the temple." (PwD_03) - "There is a good environment. The neighbours living next to my house are very nice. They are very generous." / "Basically, I would meet them every morning on the Buddhist Holy Day because we will wait outside for giving alms to the monks." (PwD_10)	PwD prefers to live in their old place	Feel familiar with neighbour and place	Living in familiar environment	Living in a familiar environment	
- "I think there was good for me. Wherever I go, or whoever walk past my house, there would call me. They know who I am. Unlike here, I don't know them, and they don't know me. If you want to talk to somebody, you have to know each other first." / "Here (referring to her daughter's house) I don't have cousin. I don't know who they are. So, I don't know what I would talk to them. I sit here every day, I saw people walk past this way, but I don't know them. I only look at them." (PwD_16)	PwD moved from another city to live with their child	Moved to live with children	Moving to live in different places		
- "I'm bored. She is not my child (referring to her granddaughter-in-law). Also, this house is rented. If she goes away, where I can live. I can't walk. She doesn't allow me to speak anything. Moreover, my son neglects me." (PwD_05) - "I don't like to be there. I don't like if there will be somebody to look at me. I find difficult to get along with other people." (PwD_09)	PwD and family have a relationship problem	Family wanted the older PwD to live in a residential setting (or care setting)			
- "I don't want others (she misses her daughter who lives in abroad). I have a son, but he never looks at me. Even he drives pass my house he never looks here." / "I need a career. (Her daughter asked about information of residential setting)" / "I just said like that. I'm too afraid to leave from home." (PwD_05) - "I don't want to go there (his wife told him to live in the Psychiatry Hospital). I afraid of living there." (PwD_15)	Family thinks that PwD need to get better support				

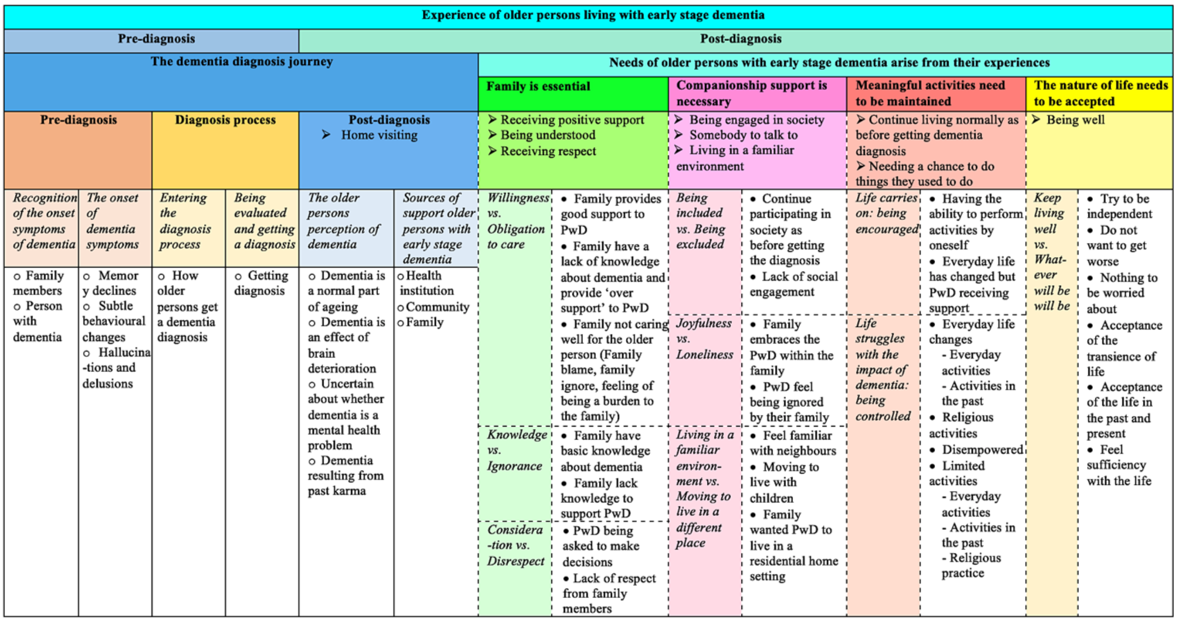
I drew maps to illustrate to life experiences of PwD to help increase my understanding of their life before diagnosis and throughout the time they have lived with the condition (see Figure 4.24).

Figure 4.24 Examples of thematic maps

Mapping helped me to coherently capture data which best answered the research question. This step explains the overall story of the data. It helped me see and recall the whole picture of participant's lives and situation to better understand and link their experiences and perspectives to their cultural context. At the end of this stage, I developed a table outlining all themes, which summarises data (see Table 4.7).

Table 4.7 offers an overview of the final themes and their component parts.

Table 4.7 Outlining all themes



<table>
<tr><th colspan="14">Experience of older persons living with early stage dementia</th></tr>
<tr><th colspan="4">Pre-diagnosis</th><th colspan="10">Post-diagnosis</th></tr>
<tr><th colspan="6" rowspan="2">The dementia diagnosis journey</th><th colspan="8">Needs of older persons with early stage dementia arise from their experiences</th></tr>
<tr><th colspan="2">Family is essential</th><th colspan="2">Companionship support is necessary</th><th colspan="2">Meaningful activities need to be maintained</th><th colspan="2">The nature of life needs to be accepted</th></tr>
<tr><th colspan="2">Pre-diagnosis</th><th colspan="2">Diagnosis process</th><th colspan="2">Post-diagnosis
➢ Home visiting</th><td colspan="2">➢ Receiving positive support
➢ Being understood
➢ Receiving respect</td><td colspan="2">➢ Being engaged in society
➢ Somebody to talk to
➢ Living in a familiar environment</td><td colspan="2">➢ Continue living normally as before getting dementia diagnosis
➢ Needing a chance to do things they used to do</td><td colspan="2">➢ Being well</td></tr>
<tr><td><i>Recognition of the onset symptoms of dementia</i></td><td><i>The onset of dementia symptoms</i></td><td><i>Entering the diagnosis process</i></td><td><i>Being evaluated and getting a diagnosis</i></td><td><i>The older persons perception of dementia</i></td><td><i>Sources of support older persons with early stage dementia</i></td><td rowspan="3"><i>Willingness vs. Obligation to care</i></td><td rowspan="3">• Family provides good support to PwD
• Family have a lack of knowledge about dementia and provide ‘over support’ to PwD
• Family not caring well for the older person (Family blame, family ignore, feeling of being a burden to the family)</td><td rowspan="2"><i>Being included vs. Being excluded</i></td><td rowspan="2">• Continue participating in society as before getting the diagnosis
• Lack of social engagement</td><td rowspan="2"><i>Life carries on: being encouraged</i></td><td rowspan="2">• Having the ability to perform activities by oneself
• Everyday life has changed but PwD receiving support</td><td rowspan="5"><i>Keep living well vs. What-ever will be will be</i></td><td rowspan="5">• Try to be independent
• Do not want to get worse
• Nothing to be worried about
• Acceptance of the transience of life
• Acceptance of the life in the past and present
• Feel sufficiency with the life</td></tr>
<tr><td rowspan="4">○ Family members
○ Person with dementia</td><td rowspan="4">○ Memory declines
○ Subtle behavioural changes
○ Hallucina-tions and delusions</td><td rowspan="4">○ How older persons get a dementia diagnosis</td><td rowspan="4">○ Getting diagnosis</td><td rowspan="4">○ Dementia is a normal part of ageing
○ Dementia is an effect of brain deterioration
○ Uncertain about whether dementia is a mental health problem
○ Dementia resulting from past karma</td><td rowspan="4">○ Health institution
○ Community
○ Family</td></tr>
<tr><td><i>Joyfulness vs. Loneliness</i></td><td>• Family embraces the PwD within the family
• PwD feel being ignored by their family</td><td rowspan="3"><i>Life struggles with the impact of dementia: being controlled</i></td><td rowspan="3">• Everyday life changes
- Everyday activities
- Activities in the past
• Religious activities
• Disempowered
• Limited activities
- Everyday activities
- Activities in the past
- Religious practice</td></tr>
<tr><td><i>Knowledge vs. Ignorance</i></td><td>• Family have basic knowledge about dementia
• Family lack knowledge to support PwD</td><td rowspan="2"><i>Living in a familiar environ-ment vs. Moving to live in a different place</i></td><td rowspan="2">• Feel familiar with neighbours
• Moving to live with children
• Family wanted PwD to live in a residential home setting</td></tr>
<tr><td><i>Considera-tion vs. Disrespect</i></td><td>• PwD being asked to make decisions
• Lack of respect from family members</td></tr>
</table>

iv) Reviewing themes

I reviewed the themes and read the data again to ensure each theme is meaningful and has sufficient supporting data and story. At this stage, I also prepared stories of participants to support the meaning of each theme which I discussed with supervisors. In this step, I considered Maslow’s Hierarchy of Need (1943), as a framework but I was careful not to overly limit other interpretations of the data. In this way, the themes authentically emerged from the participants expressions and experiences.

v) Defining themes

I named each theme and collated the supporting data. I considered what each theme contributed to answering my research question. Finally, there are four main themes identified: ‘family is essential’, ‘companionship support is necessary’, ‘meaningful activities need to be maintained’ and ‘the nature of life needs to be accepted’.

vi) Producing the report

In subsequent chapters I have reported findings by explaining the participants’ stories in relation to living with early stage dementia. In this step, I have combined stories and data from all three sources: observes, interviews and field notes. Importantly I have connected needs that emerged from the perspectives and experiences of participants with Maslow’s Hierarchy and a sense of personhood (Kitwood, 1997).

4.10 Summary of chapter

Chapter 4 has provided an outline of the philosophical underpinning of this ethnographic study. It has provided the rationale for the selection of research design. It has offered the theory of ethnography and the roles of the researcher in conducting ethnography. I have reviewed and implemented good practices in researching with PwD. Issues of ethics and reflexivity have been considered.

This chapter described the study setting and outlines the research process including selection and recruitment of participants. Participant details and data collection processes have been explained. Data analysis has been described.

Chapter 5 The Dementia Diagnosis Journey

5.1 Introduction

Chapter 5 is the first of the two findings chapters. It focuses on the route to dementia diagnosis and consists of three main sections: Firstly, the pre-diagnosis process which begins with recognition of the symptoms of the onset of dementia. The second section presents the older persons experiences of entering the diagnosis process, including being assessed and receiving a dementia diagnosis. Thirdly, the experiences of the post-diagnosis process which illuminates the older persons perceptions of dementia and their sources of support. The perspectives and experiences of older persons are foregrounded throughout the chapter.

Table 5.1 on the next page is an illustration of the overall experiences of older persons with early stage dementia. Chapter 5, the route to diagnosis, is represented in colour on the diagram. Chapter 6, which focusses on the needs of older persons is in grey in this illustration.

Table 5.1 An overview of the experiences of persons living with early stage dementia

Experience of older persons living with early stage dementia													
Pre-diagnosis				**Post-diagnosis**									
The dementia diagnosis journey						**Needs of older persons with early stage dementia arise from their experiences**							
						Family is essential		**Companionship support is necessary**		**Meaningful activities need to be maintained**		**The nature of life needs to be accepted**	
Pre-diagnosis		**Diagnosis process**		**Post-diagnosis** ➤ Home visiting		➤ Receiving positive support ➤ Being understood ➤ Receiving respect		➤ Being engaged in society ➤ Somebody to talk to ➤ Living in a familiar environment		➤ Continue living normally as before getting dementia diagnosis ➤ Needing a chance to do things they used to do		➤ Being well	
Recognition of the onset symptoms of dementia	*The onset of dementia symptoms*	*Entering the diagnosis process*	*Being evaluated and getting a diagnosis*	*The older persons perception of dementia*	*Sources of support older persons with early stage dementia*	*Willingness vs. Obligation to care*	• Family provides good support to PwD • Family have a lack of knowledge about dementia and provide 'over support' to PwD • Family not caring well for the older person (Family blame, family ignore, feeling of being a burden to the family)	*Being included vs. Being excluded*	• Continue participating in society as before getting the diagnosis • Lack of social engagement	*Life carries on: being encouraged*	• Having the ability to perform activities by oneself • Everyday life has changed but PwD receiving support	*Keep living well vs. Whatever will be will be*	• Try to be independent • Do not want to get worse • Nothing to be worried about • Acceptance of the transience of life • Acceptance of the life in the past and present • Feel sufficiency with the life
○ Family members ○ Person with dementia	○ Memory declines ○ Subtle behavioural changes ○ Hallucinations and delusions	○ How older persons get a dementia diagnosis	○ Getting diagnosis	○ Dementia is a normal part of ageing ○ Dementia is an effect of brain deterioration ○ Uncertain about whether dementia is a mental health problem ○ Dementia resulting from past karma	○ Health institution ○ Community ○ Family	*Knowledge vs. Ignorance*	• Family have basic knowledge about dementia • Family lack knowledge to support PwD	*Joyfulness vs. Loneliness*	• Family embraces the PwD within the family • PwD feel being ignored by their family	*Life struggles with the impact of dementia: being controlled*	• Everyday life changes - Everyday activities - Activities in the past • Religious activities • Disempowered • Limited activities - Everyday activities - Activities in the past - Religious practice		
						Consideration vs. Disrespect	• PwD being asked to make decisions • Lack of respect from family members	*Living in a familiar environment vs. Moving to live in a different place*	• Feel familiar with neighbours • Moving to live with children • Family wanted PwD to live in a residential home setting				

Note: -------- this border line refers to the links between the experiences

5.2 Pre-diagnosis

This section presents the findings on how dementia in Thai older people is first recognised. It then sets out the symptoms that the older people presented with before they were formally diagnosed.

5.2.1 Recognition of the onset symptoms of dementia

The signs and symptoms of the onset of dementia are often not noticed by older people themselves and sometimes even family may not be aware that their older family member has dementia, despite it being visible to others. In Thailand generally, many people believe that forgetfulness in older people is normal and may not be aware of the difference between general forgetfulness in older people and older PwD. Dementia is often difficult to identify in the early stages and symptoms can vary between people, even those at the same stage of the condition. During the early stages of dementia, older people will maintain their daily activities and continue to be able to communicate and express their feelings, although some might need a little help. Dementia causes gradual memory decline and at some point, begins to affect the older persons everyday life and triggers the family to realise that something has changed in their older family member. Some people put the change in the older person down to other underlying diseases that the older person has like stress, depression, or diabetes.

While family were less likely to notice small changes in older people as they see their older family member every day, there were some symptoms that caused concern and motivated the family to take the older person to see the doctor and these included mental health problems or psychotic disorder. These problems often impacted on the older persons daily life and led to impaired social interaction including with family members and other people in society. It is often at this point the family recognised they needed to get help from psychiatric services. Once they were on medication participants were reviewed regularly by the doctor for any changes in their symptoms. However, some participants did not go to see the doctor at every review appointment with reasons like they had difficulty walking or, it was inconvenient for the family caregiver to take them regularly. Thus, it was up to the family member to observe and report any changes in the older persons symptoms. If the doctor suspected that they needed an evaluation, their family member would be asked to take the older person to the hospital for the next appointment.

All participants initially went to see the doctor because their family members noticed that there was something wrong, and they were diagnosed with dementia (or Alzheimer's disease or vascular dementia or frontotemporal dementia). As a first detector, the family is important in the pre-diagnosis process helping to recognise the signs and symptoms of dementia. Most participants did not notice the changes themselves, but some participants were aware that something had changed. However, all participants were taken to see the doctor at the hospital by their family member.

5.2.2 The onset of dementia symptoms

There are a number of symptoms which trigger the family and the older person to go to see a doctor and get a diagnosis. To increase understanding of their illness backgrounds, which are different in each person, this section aims to present the three most common onset symptoms of dementia; memory decline, subtle behavioural changes and hallucinations and delusions.

5.2.2.1 Memory decline

This is the most common onset symptom of dementia. Most participants began with forgetful symptoms. Short-term memory gradually declined, and many participants also became confused. They were unable to remember what they did, or what had happened recently, as a result of their brain deterioration.

Pilaiwan, a 67 year old single woman was living with her younger sister, Siriporn and nephew Virut, Siriporn's son. They were living in a townhome, located in a small alley 20 meters off the main road in the city of Korat. Siriporn has 2 children and was widowed a long time ago. Her first daughter works and lives in another province approximately 200 kilometers away. She returns to visit her mother monthly. Virut is aged 40; he was unemployed at the time of the study.

Pilaiwan moved to live with her sister to help take care of their mother. After her mother died, 13 - 14 years ago, she decided to remain and live and work with her sister. Although Pilaiwan has 3 siblings, she had a close relationship with Siriporn. Another sister did not want to take care of Pilaiwan because she was married and did not want Pilaiwan to disturb her relationship with her husband. Pilaiwan had a boyfriend but she had not married him as her family did not accept him because he was an alcoholic. She told me;

> *"Sometimes when I got stressed, I would ring to talk to my boyfriend. He is always drunk. He goes to work in many provinces I can't remember where he went." [Pilaiwan, 1st interview]*

The family would not welcome him in the house on any visit to Pilaiwan. He was keeping his distance and Pilaiwan could only talk to him via mobile phone. This situation had led to Pilaiwan feeling uncomfortable because she felt she might be a problem and she felt left out of the family.

Pilaiwan recognised that she had become forgetful and was repeating questions. Before getting a dementia diagnosis, arguments in the family were increasing but nobody recognised what was going on. Pilaiwan was storing her belongings but forgetting where, and then thinking that household members or others were entering the house and stealing her possessions. This led to quarrels with her family members, especially Virut, and it made everybody in the family feel stressed.

> *"Oh! I forget easily. What they tell me, I forget in a moment. I forget where I placed my stuff. Right now, they think I am pretending to forget. I don't know how it feels. Sometimes I feel blurred too." [Pilaiwan, 1st interview]*

The excerpt above indicates Pilaiwan's feelings. She noticed that she had become forgetful while her family did not understand her. Pilaiwan's forgetfulness not only led to her misplacing things, but also to her sometimes being disoriented to place. One day, she went out to buy something at the grocery shop in front of the alley, which is not far from her home. She forgot the route back home. She also said she had vertigo and tinnitus and I asked her if she was still able to go to see the doctor or go outside alone as she used to do, and she said:

> *"I don't go anywhere like I used to do I'm too afraid to go alone because I'm afraid to get lost, I only walk out to buy something in front of the alley, I'm afraid to get lost. I do not have a good memory." [Pilaiwan, 1st interview]*

She was afraid and she walked into many alleys before she found her home.

Dararat is a 62 year old woman of Thai-Chinese heritage. She had graduated from primary school and then had helped her family to sell vegetables in the market. After her marriage, she continued working with her husband's family. They are also of Thai-Chinese heritage. Dararat had felt uncomfortable living with her husband's family so she and her husband decided to leave the family and build up their own family. Presently, they have a small business selling shallots and garlic in the fresh market in the city. She had been working in this business for more than 30 years. Dararat had occupational asthma.

At the first meeting Dararat was waiting for me in the ‘resting’ room. It was a small room inside her shop. The room was air conditioned and looked like a cashier’s room with a calculator, some documents regarding the business, notebooks, invoices, an arm chair sofa, some small chairs, packs of bottled water and kitchen equipment to use to eat lunch. Her husband had built this protective room for her after she had developed a severe asthma problem made worse by the dust from goods.

Dararat noticed that she was forgetful, lacked energy, and had functional brain decline. I asked her to explain the symptoms triggering her decision to consult the doctor. She said that becoming forgetful was problematic, leading her to feel stressed because she could not remember the prices of goods, and she was making inaccurate money calculations. As she explained:

> *Nittiya:* *Could you explain to me about how you felt at that time?*
>
> *Dararat:* *I felt confused and stressed. I sell goods, but I did the wrong calculation. When they (the customer) come to buy, I was fine, but I get stressed when I have to calculate the money. At that time, I felt like my brain was squeezed.*
>
> *Nittiya:* *Wow, has this affected your life?*
>
> *Dararat:* *Yes, it has.*
>
> *Nittiya:* *Could you tell me more about this?*
>
> *Dararat:* *I get stressed after I knew something was wrong with me. When I talked to the customers, I would repeat many times, and I could not remember the prices of the goods. Fortunately, I am still able to write, but I don’t want to write. I felt my brain doesn’t want to perceive anything. It looks like it doesn’t want to work, something like that. [Dararat, 3rd interview]*

Dararat and her family were concerned about these changes because in addition to her becoming forgetful she sometimes had delusions when she went to sleep. She also shared with me that she often forgot to take her medicines, but her children reminded her. I noticed that she was forgetful. During the interviews, she often asked me to repeat the questions and asked what she had talked about a few minutes ago. Her family were seemingly concerned about her health, they took good care of her and did not want her to work hard because of her asthma.

Pilaiwan and Dararat’s stories differ from Palapol’s because while Pilaiwan and Dararat knew they had cognitive decline Palapol thought his symptoms were ‘normal’ for his age. Palapol is an 80 year old friendly man who looked vigorous when he walked. This may have been because he was attempting to maintain his capacity to perform many activities and take care of his wife. Palapol had four sons but tragically two of them had died in a car accident years previously. Of his remaining two sons, Pongsak, his second son, was his parent’s principal caregiver. Palapol’s wife has advanced dementia. Their other son lives in Bangkok and comes to visit from time to time.

At the first visit, when I arrived at the house, Pongsak came to open the entry gate to welcome me, while Palapol was waiting on the terrace which Pongsak had prepared for our interview (see Figure 5.1). Pongsak offered fruit and refreshments. During the interview, Palapol, Pongsak, Pongsak’s friend, and I talked while Palapol’s wife walked nearby. I felt they were very friendly and joyful people. Everybody sat and listened to the conversation I was having with Palapol. Sometimes they talked together, and sometimes Pongsak helped Palapol to clarify the questions Palapol could not answer, or when he thought Palapol had given incorrect information. For example, Palapol said he went to the market alone almost every day, but there is no market in that area, it is a grocery shop. Pongsak corrected and said Palapol did not go out every day. At that time, I was unable to judge what I was hearing because Palapol was able to go outside when his son was at work. Meanwhile, Palapol smiled and insisted that he could go out alone. He said that he normally goes outside in the morning and sometimes in the afternoon, but his son does not know this. The son usually comes to take care of the parents in the morning before he goes to work, and in the evening after he has finished work. So, it was difficult to be sure what happened with the parents during the day.

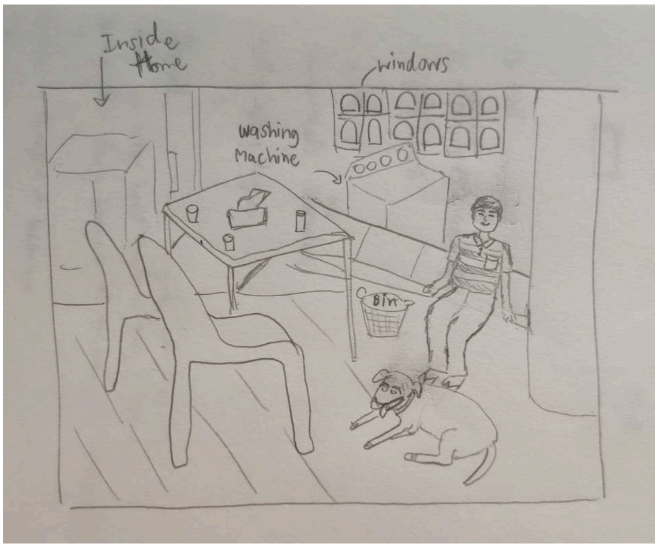


Figure 5.1 Palapol was waiting in the terrace where his son prepared for interview

When we first met at the hospital Pongsak told me that Palapol had become forgetful and tended to repeat some activities. One day Pongsak noticed that there were three bags of bananas on the kitchen table. He wondered why there were so many. He asked his father and thought that his father had forgotten he had already bought bananas. Consequently, he took his father to get evaluated at the Geriatric Psychiatry Clinic in the large tertiary hospital in the province (known as the dementia clinic in this study) as he suspected that his father had the same problem as his mother. Palapol was diagnosed with dementia at the Clinic, confirming Pongsok's suspicions. Palapol however sees himself as an older person. He lives day-by-day and does not see his forgetful symptoms as a problem. He needs to look after his wife and does the many house tasks as she is unable to do anything. He realises that he is becoming forgetful and that he is sometimes confused.

From the stories of these three persons with early stage dementia, it is clear that family is a key factor influencing the older person receiving a dementia diagnosis. Although people believe that dementia is a normal part of ageing, when they notice that there is something wrong with their loved one, affecting their daily life, they become concerned.

Kanit had an ischaemic stroke 13 years ago, long before getting a dementia diagnosis and like many older people, he had a number of comorbidities including diabetes mellitus, hypertension, gout, and osteoarthritis. His ischemic stroke may have been caused by his diabetes and hypertension. Kanit is aged 70 years and was being taken to the doctor regularly by his family for follow-up appointments for his multiple chronic illnesses. Kanit's physical changes that presented following his ischemic stroke affected his thinking and speaking skills. He had worked as a government official creating many projects to develop the rural areas, so he had worked with people in communities. He had enjoyed working. Kanit seemed proud of himself because he only shared his good moments when he was speaking to me. Following his stroke at age 56, Kanit was unable to work and retired early. He was diagnosed with dementia a year before taking part in this research. His family, especially his wife, Usa, looked after him by trying to empower and rehabilitate him to get better so that he could perform his daily activities as normally as he used to do.

Although Kanit and his family knew that he has physical changes as a consequence of his ischemic stroke, they did not recognise his cognitive changes as there is an overlap between the symptoms of ischemic stroke and early stage dementia. Kanit was seeing the doctor frequently, and Usa reported his symptoms at his appointments, so the doctor referred him for an assessment where he was then diagnosed as having dementia. Ever since his ischemic stroke, Kanit had recognised the huge negative impacts of this on his life. It was an unexpected situation for him. His dementia symptoms gradually worsened. Kanit expressed his feelings at the time as follows:

> *"I began with feeling like blank, I became torpid, confused, and forgetful, but I could remember and think of anything." [Kanit, 2nd interview]*

Although Kanit could still express his feelings, he found it difficult to speak and express his opinions. Also, he had to deal with the physical limitations resulting from the ischemic stroke. Kanit had language deficit. He found it difficult to speak, and sometimes his conversation was incoherent. He found it difficult to remember people's names, finding words to speak and naming common objects. He paused many times during the conversation and used word substitutions. I noticed a calendar and some papers with people's names and telephone numbers posted on the wall. Kanit was also losing his memory regarding his school and work-based knowledge.

The stories and excerpts from these older persons show that memory decline is the onset symptom that led their families to recognise that something in the person was changing. However, it was difficult to distinguish whether the symptoms were dementia onset symptoms, or just forgetfulness in the aged person and in Kanit's situation, to distinguish between his ischaemic stoke symptoms and dementia. The older persons and their families would normally become concerned about the symptoms when they became troublesome and affected the older persons daily life.

Nonetheless, as a result of insufficient knowledge of dementia and awareness of its onset signs and symptoms, along with the gradual changes of these signs and symptoms, it might be difficult for the family to identify that the onset symptoms are related to dementia. With respect to early stage dementia, older people can still perform their routine activities, so people might not see there are serious symptoms developing and diagnosis is therefor often delayed.

5.2.2.2 Subtle behavioural changes

Many participants have subtle behaviour changes like repeating actions, asking questions, doing something they had never done before, or changing in personality. Family members who live close to the older person are usually the first to suspect that they need to take the older person to see the doctor.

For example, Kannika, a 77 year old woman and mother of 4 adult children was living with her son, daughter and granddaughter. One of Kannika's children was living separately from her, while another child, a son, had died following a motorcycle accident. Kannika's husband had died after a stroke and shortly after these deaths in the family, she had developed depression.

Kannika knew that she had difficulty recalling details of conversations and some events. When I talked to her, she seemed to struggle with finding the words to express her feelings as she paused many times. She could not remember me on the first visit despite having met me at the hospital the week previously. Thus, on my second and third visits I went to see her wearing the same clothes as before and she then remembered me. Kannika liked reading and I took her some brochures about dementia and other health care topics and a chanting book. I wanted to be able to give her something helpful and not just take data from her. Chanting books are written with Pali texts that are translated into Thai and have been passed down through generations for over 2500 years. Many Buddhists believe that chanting and praying helps them escape from bad things.

Kannika's daughter explained about the trigger situation that made her decide to take her mother to see the doctor. Kannika had become forgetful, but nobody in the family recognised anything was wrong until she chose to wear her daughter's clothes. Her personality changed and she became silent, speaking less often than before. She also took a long time to express her thoughts. Kannika was initially not aware of these changes.

Although she knew that something was wrong with her, she did not think it a serious problem and she regarded the changes as a part of ageing.

Older persons with early stage dementia often have pauses and word substitutions when trying to find the words to speak. Although this symptom leads the family to suspect something is going on, they often put it down to ‘normal’ ageing, and do not do anything until the older person has more obvious behaviour changes.

5.2.2.3 Hallucinations and delusions

In addition to memory decline and other behavioural changes, both of which were common early symptoms, some older people also experienced hallucinations and delusions.

I met Tassanee, a 77 year old woman and her youngest daughter at the hospital during a follow up appointment with the doctor. Tassanee had been coping with memory loss before receiving a dementia diagnosis. Tassanee was small in body, with white hair and she had a strabismus in her left eye. She always wore a round-necked sleeveless top and sarong but covered this with a T-shirt on her visits to the hospital. She had dental damage from her enjoyment of chewing betel nuts. Tassanee lives with her family; her husband, her youngest daughter, son-in-law, and two grandsons. She has four adult daughters; two other daughters live close by and one daughter lives in a different province.

In the first interview, Tassanee said that she is forgetful and gets confused. She also repeated some of her daily activities, like preparing food for her children. Her hands were shaky, showing symptoms of her Parkinson’s disease. She told me:

Tassanee: *Sometimes, I have problems with forgetfulness and confusion. Sometimes, I forget that I had already cooked the rice and I cook it again.*

Nittiya: *Oh, what did you do then? Who eats it?*

Tassanee: *I then feed the dogs.*

Nittiya: *Did you repeat cooking rice?*

Tassanee: *Yes, I repeat.*

Nittiya: *How often do you have this symptom?*

Tassanee: *It is likely to happen around the evening. [Tassanee, 2nd interview]*

I had good opportunities to talk to her family members. They shared that one of the onset symptoms Tassanee had and which had led them to suspect that something was wrong was Tassanee had behaviour changes and hallucinations. Tassanee had suddenly recalled that her husband had in the past had a relationship with another woman, and she had become angry and hit him. The other relationship had happened, but a long time ago, when her children were very young. Tassanee also told me that sometimes she heard somebody calling her, and sometimes she 'saw' her adopted son, who was her husband's son from a former marriage. The family suspected that she had a mental health problem so they took her to the hospital where she was diagnosed with dementia. Although Tassanee knew that these symptoms were in her mind rather than real, her family realised that something was wrong. Although Tassanee had been experiencing memory decline, the family only became concerned when she started experiencing the psychological symptoms. This later recognition of a problem was common when family members did not know or have information about dementia.

Laiad is a 77 year old man who had worked as a rickshaw taxi rider for about 30 years. Around 2 years previously, before receiving his dementia diagnosis, he had a cardiac arrest and was resuscitated. He had a very low potassium level at that time and it was queried as to whether his arrest was due to the 1 to 2 energy drinks he drank daily and their possible effect on his blood electrolyte levels. After his discharge from hospital, he experienced hallucinations; seeing 'ghosts' and believing people would attack him. At first his family did not believe him, although they are superstitious. Laiad himself recognised that he often becomes confused and that he gets lost. He was presenting with aggressive behaviour and after hitting a glass window 'to protect himself' from something, his daughter took him to see the psychologist at the hospital. Laiad explained:

> *Laiad:* *I will tell you, I took my blanket and some of my stuff left from home I didn't know where I was. I got lost. I was confused and forgetful.*
>
> *Nittiya:* *Hmm, can you tell me why you left home that day?*
>
> *Laiad:* *I saw ghosts. I wanted to escape them. When I went out from home, I got lost, I didn't know where I was. I was confused. [Laiad, 2nd interview]*

Laiad lives with his family in a household with nine family members. The house is a single storey building with four bedrooms, a kitchen, and a shared toilet. The house has separate rooms for Laiad's daughter's family and grandchildren. Sometimes Laiad gets lost in the house and the surrounding area. Although Laiad was still able to do basic daily activities, he needed a little help because he had vision problems and osteoarthritis. I could see that he moved with difficulty.

At first, Laiad and his family were not concerned about his forgetful symptoms and thought this might be a result of his advanced age. Also, the family thought that his confusion and aggressive behaviour was due to his cardiac arrest, but once the hallucination symptoms appeared, his daughter decided to get help.

Some of the participants were experiencing delusion but family members found it difficult to distinguish between the delusions that can accompany depression and those associated with dementia.

Nantana was an 83 year old woman who had a gambling addiction throughout her adult life. This had led to her marriage break-up and divorce and also the loss of the care of her two daughters. Her first husband had subsequently died and also one of her two older daughters, from heart failure. She appeared not to have had a good relationship with her two daughters as they had never visited her.

Nantana's gambling was her main occupation and it overshadowed her adult life. She would leave her children from her second marriage with her mother and she would go out at night, travel with friends, and drink and gamble. Not long after the death of her second husband, she lost all her property because of her gambling and behaviour. After the loss of her properties, she had to rent accommodation. To add to Nantana's problems, her mother died at age 95 years, her friends and people around her began to keep their distance from her and one of her children went abroad to work. This situation stimulated her depressive disorder.

Nantana had been living with her third son for a long time. Although the relationship between her and her children was not good, they took care of her as well as they could. Her third son's death from renal disease was another stressful turning point in her life as he had been her principal caregiver. When I met Nantana she was living with her grandson's family, the son of her deceased son. Her granddaughter-in-law became her caregiver because she was at home bringing up her children.

Nantana's surviving adult children were living in the surrounding area and would visit her almost every day. Throughout the time I visited her, she remained living with her grandson and his family. Nantana told me about her family relationships and I could sense that these were strained and that she did not have a good relationship with her family. I thought this might be a consequence of her background. I met another of her sons on one occasion, he was a serious man who did not seem interested in Nantana and did not talk to her. Another daughter living nearby appeared closer to Nantana but they were always arguing with each other.

Nantana was still able to perform basic daily activities on her own. However, she sometimes needed help because of her other chronic diseases: diabetes mellitus, renal disease, and hypertension. These made her feel weak and she found it difficult to move. Nantana had become forgetful and she was repeating conversations and asking questions. These symptoms annoyed her family members and they ignored her.

Nantana also had sleep disturbances. One day she became confused when she saw herself in a mirror. She thought there was someone looking at her and accusing her. Another example of her delusions was when she saw a broom and thought that it was somebody looking at her. These situations made her children realise that she not only had depression, but that she might also have other health problems. Her grandson was regularly collecting her medications for her and on one of these visits he described Nantana's symptoms to the doctor who made an appointment to assess Nantana at the hospital.

To conclude this section, from the stories presented here about the onset symptoms of dementia, it is noticeable that there are key symptoms in early stage dementia which are triggers for the family to go for help. Brain deterioration results in cognitive decline and this affects a person's memory, thinking and speaking skills. The family often think that memory decline is a normal part of ageing and may fail to recognise this as an early symptom in the onset of dementia. It is often not until there are other visible symptoms, including changes in mood and personality and other subtle behavioural changes, or until the persons everyday life and that of their family is affected that they seek help. The most significant onset symptoms that provokes the family to take the older person to the doctor is confusion with time and place and hallucinations and delusions. Many participants did not recognise that they had these symptoms at first. Their family members are key in recognising the early symptoms and the impact of these on the older persons life and then taking their family member to hospital.

5.3 Diagnosis process

It is difficult to receive a dementia diagnosis but an early diagnosis can help the older person plan their life and maintain their well-being as well as possible. In this study, participants received an early diagnosis because somebody in their family recognised the onset symptoms. Regardless of whether older PwD have some basic knowledge about the condition, or the onset symptoms, it is important that they receive good support from health professionals.

This section presents the experiences of older persons of getting a dementia diagnosis. Participants were not able to remember all the processes, as many had been to see the doctor for follow up of other health conditions, not only their dementia. It was therefore slightly difficult for them to explain their experience of the dementia diagnosis process. What is clear is that there are different experiences of getting a diagnosis.

5.3.1 Entering the diagnosis process

As discussed in the previous section, the diagnosis process begins with the family taking the older person to hospital. Some of the older people in this research who first walked into the hospital with their onset symptoms were referred by the nurse at the reception screening point directly to the psychiatry department. I sensed that the reasons for this were because the older persons symptoms were not related to their physical problems. Some older persons with chronic illnesses, although they were seeing the doctor regularly, did not report their dementia onset symptoms to the doctor because they did not think their symptoms serious until it impacted on their daily life. Some people received a late diagnosis as they only went to see the doctor when they had severe symptoms. This might have been because of a lack of knowledge about dementia and the onset signs and symptoms of the condition. This might also be the reason why it is rare to see cases with early stage dementia in the province where the research has taken place. Older persons and their families think the symptoms they have are a normal part of ageing.

For example, Wannaporn, an 85 year old woman was born in Korat, but moved to live in Bangkok with her family after her marriage, many years previously. Wannaporn was a housewife who had stayed at home and looked after her husband and children. She has three sons; the oldest who is married and lives in Bangkok, her second son with whom she is living, and her youngest son who had died tragically in a car accident. Wannaporn's husband had died following a haemorrhagic stroke more than 20 years ago. It was after his death that she moved back to her hometown to live with her second son, Puchong, in a municipality town. Puchong works as a freelance artist and has the flexibility to move to live in different places. Wannaporn's nieces live next to her house within the same fenced boundary.

Wannaporn had a number of other chronic diseases; hyperlipidemia and chronic renal disease; she sometimes also has vertigo because of her hypertension; she has pain and finds it difficult to sit, stand and walk for a long time because of her lumbar spondylosis. One of Wannaporn's nieces has a psychological health problem and the family visit the hospital regularly to see the doctor and collect medication.

Wannaporn had become forgetful and had started to repeat herself. She was up at night and searching for items in the cabinet. When Puchong asked her why she was doing this she did not know. Puchong explained that he was suspicious of these behavioural changes because they were happening frequently, and he felt there was something wrong with his mother. He tried to consult the nurse at the community hospital when he went to collect Wannaporn's hypertension medication, but this nurse told him the symptoms he described were normal in older people. He was confused because he recognised that they were not. One day Puchong went to the large tertiary hospital in the province and he saw a poster promoting something about dementia. This made him decide to take Wannaporn to see the doctor.

It is difficult for doctors to detect dementia at an early stage, as discussed in the background chapter. This is especially so in persons who did not have clear symptoms and where the doctor is not an expert on dementia. Even health practitioners may think that forgetful symptoms in older persons is simply because they are getting older. Persons in early stage dementia who still have capacity to live normally and make decisions can confuse even professionals. Thus, if there are no clues to indicate that the person has changed in any way, it is hard to distinguish between dementia and forgetfulness in advanced age.

I also asked participants if they had been given a cognitive screen test when they visited the primary care unit. No one reported having been screened despite the fact that dementia is one of the health conditions that must be screened for in all older people. Also, none of the participants were referred on from primary or secondary health care level. All went directly to MNRH themselves because they believed in the potential of the health professionals in a tertiary hospital.

In theory, persons living outside the responsible area of the tertiary hospital should be referred from their primary health care unit, which is responsible for taking care of them if they need to get help from the tertiary hospital. Patients need to ask the local clinic to get a referral letter if they need to go to the tertiary hospital. Persons who live outside the boundary of the tertiary hospital area, even though they live in the city, must still get health support from the area where they live, as a first step. Patients will be referred on when their problem is beyond the scope of treatment that the primary care unit can provide. If this is the case then the health practitioner will refer to the next level of care unit giving the patient a referral letter. Usually one referral letter is effective for a year, but in some primary care units, a referral letter may only cover one visit. If patients do not have a referral letter on each visit to the tertiary hospital, they need to pay the service fees and/or medications themselves, except where they have medical health benefits from work as a civil servant. This shows the complicated access to the hospital. However, some people can afford to pay the services fees for private hospital care and do so because they prefer the convenience and comfort this offers.

For example, Dararat, the woman selling garlic and shallots in the market; she sees the doctor by appointment regularly, because her referral letter is renewed year-on-year. Dararat consults the doctor about her health problems in both the public and private hospital. The doctors at the private hospital also work full time at the tertiary hospital in the province. The interesting thing is she prefers to consult the specialist about her respiratory disease in the private hospital because she feels more comfortable with this doctor than other doctors. She has also been referred to the gerontology clinic in the public hospital, and the doctor at the clinic referred her to the dementia clinic to get support.

> *"Initially, I thought I didn't have any problem, but I felt something wrong. So, I decided to go to see the doctor. He said that he would refer me to the other department. He is a good doctor. I always go to see him. I never miss the appointments." [Dararat, 1st interview]*

Dararat usually goes to see the doctor with her daughter-in-law. After recognising that something was wrong with her, she talked to her family and searched for help by going to consult with the doctor with whom she felt comfortable to speak. She felt safe talking to this doctor and felt this doctor could help her solve the problem. Also, truthfulness can be a part of a good relationship between patient and doctor and this may be one of the factors that influenced Dararat to consult this doctor and enabled her to express her feelings.

Kanit with his many underlying diseases; diabetes mellitus, hypertension, gout, and renal disease, goes to see the doctor regularly with Usa, his wife and principal caregiver. He has a son, but his son gets busy with his work, and whenever he has to go to see the doctor his son drops the parents off at the hospital, and they take a Tuk-tuk back home afterwards. Kanit gets support from the hospital and taken is taken care of by his wife Usa who has accompanied him for every appointment for the last 14 years since his stroke.

Regarding Kanit's dementia onset symptoms, Usa recognised that he had changes in many of his behaviours. For example, he chose to wear a long-sleeved t-shirt which he usually wore when he was working, but that day he was only at home, and the weather was quite warm. He then began forgetting people's names, even his wife's sisters name who he meets every day. Usa therefore decided to consult the doctor, who was treating his diabetes mellitus. Usa shared with the doctor that Kanit was getting confused and he in turn referred Kanit for evaluation in the dementia clinic.

This situation is similar to that of many other participants who have underlying diseases and receive support from health professionals regularly. Approximately one-third of all the participants had depression before getting a dementia diagnosis. All of these participants were receiving ongoing support from a psychologist, consequently, even though the older person was not seeing the doctor at every appointment, the caregiver would report any changes in symptoms to the doctor. The doctor would then make the appropriate appointment to investigate the older persons other reported problems.

Slightly different to Kanit's situation, Chompoo's daughter Panthip noticed that there was something wrong with her mother, and she discussed with her stepbrothers whether Chompoo should go to see the doctor. Chompoo is a 79 year old woman with two sons from her first marriage and after her divorce, two further children from her second marriage. One of her children from her second marriage died as a baby following a high fever. Her remaining child from her second marriage, her daughter Panthip, is her principal caregiver.

Panthip sells grocery items and had taken over from her mother when she stopped work. Chompoo's two elder sons work as teachers in the city of Nakhon Ratchasima. Chompoo worked as a farmer and sold grocery items in her own business. She lived with her husband and children until they left home to build their own families. After her husband's death, Chompoo went to live with her brother and sister. Her brother is a retired teacher and her sister did not have her own home after her divorce, so she asked to live with her brother's family. Chompoo had been living with her brother and sister for about ten years before moving to live with her daughter.

This arrangement had come about after Chompoo noticed that her sister had memory decline. Panthip on her visits to her mother noticed that Chompoo had behavioural changes and that she was frequently forgetting things. She reported this to her stepbrothers, and they decided to take Chompoo for a check at the hospital. As Chompoo stated:

> *"At first, my children realised little changes about me, like being forgetful, something like that. Thus, my first child took me to the hospital to check and see what was wrong with me?" [Chompoo, 1st interview]*

After Chompoo's dementia diagnosis, her brother continued to take care of both his sisters. After a year Panthip became concerned for Chompoo's brother and also about the effect of her aunt's memory decline on her mother. After consultation with her stepbrothers, Chompoo came to live with Panthip so that she could support her mother appropriately and take better care of her.

The participants stories presented here show that it is family members who take their relatives for an evaluation of their symptoms. No-one went to see the doctor on their own. I noticed that older people seldom travel alone anywhere. This might be because of their older age. They usually go out with their children, as a couple, or with a relative, or friend. Some older people have physical limitations making it difficult for them to move. Some people live far away from the city, so it may be that they travel with someone to help them.

In short, the family are the ones to identify onset symptoms of dementia and then they help the older person to get a diagnosis. Health professionals in turn then evaluate the problem. None of the participants in this research were referred on by the primary care unit; all the participants went directly to see the doctor at the tertiary hospital, even though they needed to pay for the service themselves. Being detected at the primary care unit and then referred to get an early diagnosis are the important things that need to be considered to avoid late diagnosis in older people.

5.3.2 Being evaluated and getting a diagnosis

The diagnosis process is different in each case. Many participants cannot remember how they received their diagnosis. Some of them went to see the doctor for other reasons like depression, psychiatric disorder, or another illness and they could not recall the events from that time.

There is a general shortage of health professionals who are experts on dementia and gerontology, especially in the primary care units. Chompoo told me that because her sons live in an urban area and they are civil servants entitled to medical benefits they get free treatment from the public hospital. This free treatment also extends to the family so Chompoo also benefits from this. Therefore, when they recognised there was a problem, they decided to take their mother to see the doctor at the tertiary hospital.

> *Nittiya:* *Before receiving support from the [name of the hospital], have you ever visited any other hospitals?*
>
> *Chompoo:* *No, we went directly to the [name of the hospital].*
>
> *Nittiya:* *I see. Can you still remember what process you had to go through when you first visited the [name of the hospital]?*
>
> *Chompoo:* *Yes, I had to lay down and they put my head into something that's like tunnel.*
>
> *Nittiya:* *You mean, they had to scan your brain, right?*
>
> *Chompoo:* *Yes, scan (laughing)*
>
> *Nittiya:* *Ah, how did you feel then?*
>
> *Chompoo:* *Nothing (laughing)*
>
> *Nittiya:* *Did you know what they were doing to you?*
>
> *Chompoo:* *Yes, I knew because they informed me before they were going to scan my brain.*
>
> *Nittiya:* *Good, so how was the result after scanning?*
>
> *Chompoo:* *Nothing, the doctor did not say anything. [Chompoo, 1st interview]*

Chompoo's son took her for an assessment at the hospital. Her assessment included the Thai Mini-Mental State Examination (Thai-MMSE, 2002), and she had a brain scan. She reported that after the doctor had seen the result of the brain scan, she had been prescribed medication relevant to her brain atrophy, but the doctor had not explained in any detail about dementia. Chompoo recognises that she has dementia because she has memory decline, but her brain deterioration is not extreme.

In sharing their experiences of getting a diagnosis, the participants explained that they were assessed by the nurse who asked them many questions about their symptoms and lifestyle and the doctor also asked them about their everyday lives. Additionally, many participants also reported that they had a brain scan and that they were assessed with an assessment tool, but no one reported having any blood tests. Generally, the diagnosis process took approximately one month because the doctor needed to consider the older person's symptoms, history, and for those participants that needed a brain scan, the doctor made a follow up appointment to check the results of the scan.

Tassanee, who had delusions and repetitive action symptoms, stated that although the brain scan itself did not take long, the waiting time before getting the scan and the way that she had to lay down with the machine sliding over her, had scared her. She looked nervous and explained that she had been frightened with her scan. Tida, Tassanee's daughter, confirmed that her mother had cried after the MRI (Magnetic Resonance Imaging). The scan showed that Tassanee has Parkinson's and dementia. After getting a diagnosis, Tassanee said she felt sad; she realised that dementia would cause her to become forgetful and confused. Sometimes she complained and turned on her husband and daughters without any reason, but she did not know why this was happening to her. Generally, Tassanee did not know about dementia, the symptoms in the different stages and the progression of the condition.

Tassanee's family understood that she had her symptoms because of her illness. This contrasts with Pilaiwan's family who believed that she had a mental illness. Pilaiwan had complained of a headache and sometimes feeling blurred. Her sister Siriporn took her to see the doctor to be assessed and to find out what the problem with her was. Pilaiwan was diagnosed with cognitive impairment and it was six months before she received a dementia diagnosis. The result of her brain scan showed a small defect, and Pilaiwan said she had not thought it serious as she had no pain. She also doubted that she had dementia. Pilaiwan's family had been told that she had dementia, but they deemed that Pilaiwan had a mental health problem.

Ngamta, a 78 year old woman went to see the doctor because her daughter, a nurse, arranged this for her. Ngamta had worked hard during her adult life, doing many jobs to support her five children on her own, after she divorced her husband. All her children had married with only two of them remaining in the same area; the others were living in a different province. Ngamta lives in the same house as her daughter and son-in-law. Her son and his family live within the same fenced boundary. Her daughter recognised that something was changing in Ngamta. Normally, she could clean the dishes, but she started doing this less and less. She also sometimes seemed unable to settle and became forgetful and confused. Ngamta recognised this, but said this was normal in older people, it was not a very serious problem because she was still able to perform many activities by herself. Ngamta could remember the diagnosis process and the cognitive test, but while she was able to explain her experience of getting a diagnosis well, she repeated herself and kept combining this with the story of getting support from the diabetes clinic. Ngamta was diagnosed with diabetes mellitus many years ago. She explained:

> *Nittiya:* *Can you tell me what did the staff in the hospital did when you went to the hospital?*
>
> *Ngamta:* *When I arrived, the doctor asked me about my daily life. I can tell that, but I get diagnosed that I have a memory problem.*
>
> *Nittiya:* *How is it?*
>
> *Ngamta:* *I remember all. They asked me something like this. I just wondered and asked the doctor what is...zheimer…what does it mean because I didn't study about language. I studied only Thai. So, I don't know what ...zheimer…means?*
>
> *Nittiya:* *Did the doctor tell you about this?*
>
> *Ngamta:* *She asked me too that "do you want to know what it is" I said, "yes, I want to know what zheimer is?" The doctor said it is about memory decline including being confused and forgetful. About the memory, I think I still remember, but sometimes I have this problem. I forget where I left my stuff. So, do you think this can be the same? [Ngamta, 1st interview]*

Ngamta was aware that she has an Alzheimer's disease diagnosis; she is wondering if her sometimes forgetting where she leaves her things is this. She still wonders what it means as it is something in another language. She says she thinks she still remembers but sometimes this is a problem. Ngamta still remembered many things and many stories of her life in the past.

Other participants also wondered about their problem but were unaware of the progression of dementia and what might happen to them in the next stages of the condition. Many of the participants and their family members have a lack of information about dementia. There is a lack of support for older people and their families after they have received their diagnosis and both older people and their families need more details and knowledge about dementia. There is a definite need for more information about the condition to help the older person feel supported. This relates to a need for the older person to feel safe and secure.

5.4 Post-diagnosis

The participants expressed thoughts and feelings after hearing their diagnosis varied and were dependent upon their perception of dementia and how they received support from others. This section explores both these issues.

5.4.1 The older persons perception of dementia

The participants had multiple perceptions of dementia and these were related to their education, culture, beliefs, and experience of receiving health care.

5.4.1.1 Dementia is a normal part of ageing

After receiving a dementia diagnosis, although participants knew that they have this health condition, most participants believed that dementia is a normal part of ageing. While cognitive function will gradually decline, in the early stages of the condition, there are no clear changes. Many participants are still able to do their daily activities independently. Participants were aware that advanced age influences many chronic illnesses. Palapol expressed it like this:

> *"I think it is a normal part of ageing. Every old person will encounter this one day. I think it is better than being something worse than this." [Palapol, 2nd Interview]*

Palapol accepts he has dementia but for him it is a normal part of ageing and something all older persons will experience. He indicates that there are worse things than this condition, for Palapol being forgetful is preferable to suffering from other illnesses. Palapol was still largely able to carry out all his daily activities on his own. Palapol had no physical limitations and he was pain free. He did however indicate that he did not want his condition to worsen.

Naree is a 76 year old woman living with her husband and daughter. She appears to have a good quality life as she is still earning money from letting houses. Her husband also continues to work in construction at 80 years of age. She was still supporting her daughters in many ways. For example, she was helping another of her daughters in her grocery shop in the local area. Naree has five daughters and three of them live in the surrounding area.

Naree's first daughter is a nurse working in a community hospital. She recognised that something had changed in her mother and her sisters, who see Naree every day, started to observe this and agreed with her. Consequently, her daughter working as a nurse took her to be assessed. Meanwhile, Naree perceives that it is normal in older people to be forgetful. Although her daughters complained that she often repeats questions and forgets things, Naree resisted as she felt that this is normal in older persons. Naree did not think she had a serious problem as she still maintains a normal lifestyle. She continues to ride her motorcycle around her community, and she enjoys participating in social activities. Naree stated that her forgetfulness is due to her getting older:

> *Nittiya: Hmm, how do you feel when your daughters say that you are forgetful?*
>
> *Naree: It can happen as normal of older people. Even they (her children) also forget, then it can happen to me as I'm older than them.*
>
> *Nittiya: Hmm, so, you think it is a normal part of ageing, is it?*
>
> *Naree: That's it. [Naree, 1st interview]*

Naree's daughters attempted to explain and give her information about Alzheimer's disease, after she was diagnosed with the condition. When Naree spoke to me, she seemed not to worry about the diseases' progression. She was smiling and laughing in our interview and told me that she did not think her condition would worsen because she was still carrying out so many activities unaided. She was still independent, and she could fulfil her needs by herself. She was proud; she had her income, and she was contributing to her children. She felt that if her condition did worsen, that her children would look after her.

I gave Chompoo a notebook at my first visit to her home. I gave a notebook and pen to all the participants who were still able to write so that they could makes notes on anything they liked, whether this was to prepare to talk to me or to just note their thoughts or activities. When I visited her for the second interview, she showed me her notebook. She had written down some of her activities like the date she went to her sons' house, and when she went to the temple. She also wrote down a poem she had read in a book. It concerns older life. She said she did not know what she should be writing in the notebook but when she read the poem, she liked it because it had good meaning for her. The poem was composed as follows:

> *"When we get older, we feel lonely, thinking and searching for a place to live and rest. A place to rest our body and our mind. After so many years of work, a place to rest out body is not hard to find, but a place to rest our mind is hard due to all of the defilements that lie in our minds." [Chompoo, 2nd interview]*

I asked Chompoo why she had written this poem down and she explained that she liked to read Dhamma and chanting books. She had read the poem and thought it true and good to accept feelings of happiness and she wanted to share it.

Although Chompoo has experience of her sister who has dementia, she still believes that it is a part of the ageing process. She mentioned that being an older person usually comes along with other health problems. Thus, she believes that she is forgetful because she is getting old, and she may have dementia. She deals with her physical limitations like pain when she changes her position, and she also tires easily as many older people. She is aware when something affects her physically, rather than the dementia.

The participants believed that dementia is normal in older people. It is not serious as long as they still have their abilities to perform their many activities by themselves. Although the participants know that they have dementia because their brain is deteriorating, they seemed more concerned about their other health conditions. This is because their other diseases present more severe symptoms rather than the dementia. Some participants were stressed and sad after learning that they have dementia. For example, Dararat and Kanit felt sad that they had developed the condition because they were losing their ability to work and do many of the things they did previously. Others wondered why they have this particular problem, like Pratumrat and Nantana who were confused about what dementia is and why it was happening to them. Whereas some did not feel anything because they believed it was related to their old age.

5.4.1.2 Dementia is an effect of brain deterioration

Participants had multiple perceptions of dementia. Some participants believed dementia is a normal part of ageing while other participants realised that it was indeed caused by brain deterioration.

Rattana is an 81 year old woman who has had depression since her husband's death more than ten years ago. She has been on medication from the hospital for her depression for an extended time. Rattana started becoming forgetful and misplacing things. She shared her experience of getting her dementia diagnosis; she knows that her brain scan shows she has brain atrophy.

> *Nittiya:* *How about your symptoms presently?*
>
> *Rattana:* *I can only remember the old stories, but I can't remember the new things happened.*
>
> *Nittiya:* *Do you still remember something, don't you?*
>
> *Rattana:* *I can remember something. Presently, I couldn't remember what I had talked to people about. I might forget it. I'm getting older, it gradually deteriorates.*
>
> *Nittiya:* *Do you think it is happening by itself?*
>
> *Rattana:* *It's natural.*
>
> *Nittiya:* *Do you think it's natural? How do you feel when you know that you forget?*
>
> *Rattana:* *Sometimes I can figure it out. For example, I need to spend more time to think about people's name. Sometimes, I forget what I want to take. I couldn't figure out. Sometimes, when I back to sit, I remember. Then, I will back to take it again.*
>
> *Nittiya:* *Do you know what dementia is?*
>
> *Rattana:* *I don't know. It depends on what the doctor will tell.*
>
> *Nittiya:* *What did you tell the doctor about your symptoms?*
>
> *Rattana:* *Hmm, I sometimes have forgetful and confused symptoms.*
>
> *Nittiya:* *Can you tell me why you have to put this medicine patch on your arm?*
>
> *Rattana:* *The doctor said it is for treating brain atrophy. [Rattana, 2nd interview]*

Although Rattana did not understand what exactly dementia means, she knew that her dementia symptoms were relating to her brain atrophy because the doctor had told her.

Kanit clearly knew that his symptoms of dementia have occurred as a result of his ischemic stroke. I asked about how he learned about his condition and he told me that he had a brain scan and the doctor had then told him he had brain deterioration.

> *Nittiya:* *Did you known the result of your brain scan? What did the doctor tell you?*
>
> *Kanit:* *Yes, I did. He said my brain is defected. It is deteriorated. [Kanit, 1st interview]*

Kanit realised that his symptoms were related to brain deterioration. From my field notes and the many conversations I had with him, I noticed that he had accepted his condition. He seemed to be happy when sharing his story with me even though sometimes he felt sad when talking about losing abilities that he had before. This may be because he had already been forced to adjust to his long-standing stroke. He also told me that he hoped he would not get worse.

5.4.1.3 Uncertainty about whether dementia is a mental health problem

Some participants thought that they had a mental health problem. This view is derived from people around them, especially their family members and shows the misunderstanding of dementia in families. Families reasoned that because the older person was still able to perform their everyday activities and because they had still had the capacity to hold a conversation and make decisions, that the reason for their changed behaviour was a mental health issue.

The first time Pratumrat became confused, her family members and neighbours, none of whom understood what was happening, thought that she had a mental illness. I asked Pratumrat how she understands her diagnosis:

> *Nittiya:* *How do you feel when the doctor told that you have Alzheimer's disease?*
>
> *Pratumrat:* *I do not know this disease.*
>
> *Nittiya:* *Don't you know it? Then did you ask somebody for information?*
>
> *Pratumrat:* *People only think that I am mad.*
>
> *Nittiya:* *Did people say that?*
>
> *Pratumrat:* *Yes, they said that.*
>
> *Nittiya:* *In your opinion, what do you think dementia is?*
>
> *Pratumrat:* *I think it is madness.*
>
> *Nittiya:* *How do you feel then when people say that?*
>
> *Pratumrat:* *I do not know what's wrong with me. [Pratumrat, 1st interview]*

Pratumrat did not understand what was happening to her and why she had her problem. The opinions of others have confused her. She also told me later that she does not think she is 'mad'.

Nantana's family also believed that she had a mental health illness as she had been getting support for her depression for a few years before the onset of the symptoms of dementia. The family members believed that she was seeking attention from others. When I asked Nantana about her perception of dementia, she revealed her very negative feelings about her condition:

> *Nittiya:* *Well, what about your dementia symptoms? Do you know what dementia is?*
>
> *Nantana:* *Yes. I know.*
>
> *Nittiya:* *Could you tell me what about this disease?*
>
> *Nantana:* *Yes, I know. It is like a mad person.*
>
> *Nittiya:* *What do you mean a mad person?*
>
> *Nantana:* *I have forgetful. Do you think should I feel discouraged?*
>
> *Nittiya:* *Do you feel discouraged?*
>
> *Nantana:* *I do not think of what to say. Sometimes I think I want to die. I thought about suicidal, but I afraid to get a sin. I am too afraid to do that.*
>
> *Nittiya:* *Oh! No. You should be alive. I think your children do not want you to go away.*
>
> *Nantana:* *I only afraid that I could not walk.*
>
> *Nittiya:* *How would you do, if you can't walk?*
>
> *Nantana:* *I do not know. The doctor gave me a wheelchair. [Nantana, 4th interview]*

Nantana has had long-standing depression and depression can accompany dementia. Nantana says she understands that dementia is like being a 'mad' person. She says she has considered suicide but is afraid of committing a 'sin'. She is afraid that she will not be able to walk in the future. While I was interviewing Nantana I noted her non-verbal expression, she was crying for a moment when she said that she would rather die. In that moment I sensed that she was being treated badly by her family, they ignored her and neglected her and because of this she tended to live on her own.

Family members have an important impact on older PwD. Both Pratumrat and Nantana's families put their symptoms down to a mental health issue and this was picked up by both these participants. Family members' talk can deminish the feelings of the PwD. Pratumrat and Nantana felt stigmatized. After being judged that they had a mental health illness they began to lose their confidence. They felt socially excluded and felt like they received less respect from others. This impacted on their sense of self.

In summary, although the participants knew that they had received a dementia diagnosis, they can be confused by the opinions of others and their misunderstandings of what dementia is. Participants with hallucinations or delusions were judged by other people as having a mental health illness even if it only happened sometimes. Additionally, participants with a previous mental health issue or with behavioural changes, before getting a dementia diagnosis, were seen by others as having a mental health illness. While the older person may be negatively affected by being told they have a mental health illness, so too are the family. Once their loved was judged by people in the community to have a mental health illness they felt embarrassed and stressed. Although they tried explaining to others, this was often futile and added pressure on them. This situation in turn led to conflict in the family, and also to later family relationship problems.

5.4.1.4 Dementia resulting from past karma

Interestingly, spiritual belief is another factor related to the older persons perceptions of dementia. In addition to advanced age, the factor most participants relate to their dementia is past karma. Some participants also believe that they have dementia because of their past bad karma. This relates to their spiritual beliefs. This was an unexpected finding and one I had not previously thought about; the relationship between the participants culture and beliefs and their perception of dementia.

For example, Tassanee perceived that her dementia symptoms were related to her age. Tassanee realises that she has dementia because she is at the end of life and she accepts that the dementia is incurable. Her dominant view expressed is that she also thinks her symptoms have perhaps occurred because of her past karma. In the past, she had often killed fish for cooking; hitting them on the head many times. She believed this might have led to her problems with her brain. As she explained below:

Tassanee: *I sleep very well at night. I take medicine and sleep very well.*

Nittiya: *What kind of medicine do you take?*

Tassanee: *The doctor told me that it is a sedative medicine. Nobody makes me angry. I think it is a consequence of my karma.*

Nittiya: *Huh? Karma?*

Tassanee: *Yes. It is karma.*

Nittiya: *How is it? Why do you think it is karma?*

Tassanee: *I do not know what I did before?*

Nittiya: *Do you mean it is a result of your past life or present life?*

Tassanee: *Maybe past life. Regarding this present life, I did kill fish, you know? I did not hurt others.*

Nittiya: *Can you please tell me more how you kill fish?*

Tassanee: *I took the fish from the swamp. I hit on their head and scrape its skin and then clean them.*

Nittiya: *Hmm, do you think because of this?*

Tassanee: *It is a sin to do this, but I did it for food. [Tassanee, 3rd interview]*

These are spiritual beliefs. It is known by Buddhists and many others, interested in the teaching of Buddha, who believe that karma are the acts of an individual. There are both moral and immoral actions. Many Buddhists believe in what goes around, comes around. Humans cannot escape their karma. This has been ingrained in generations over a very long time. When people have to confront something they cannot solve, they tend to think about their bad karma.

Dararat, did not know why she has dementia, but she thinks that it might be because she has sinned and that this has led to her health condition. She expressed:

Dararat: *I feel much better. Before this, I felt a little bit sad. I was working hard and when I get older why I am like this. I think maybe I am a sinner.*

Nittiya: *Oh, could you tell me more why do you think like that? Why do you think you are a sinner?*

Dararat: *Sinner means a person who…hmm...(paused), how I can explain to you…joyless, you know?*

Nittiya: *Do you mean something like Karma?*

Dararat: *Yes yes, like that. I don't know what I have done in the past which make me be like this. I chant and pray every day. I was thinking so much. Right now, I feel better because my Husband and my children take good care of me. They encourage me, take me to the shopping mall sometimes. [Dararat, 3rd interview]*

She said that she is a good person as she was working hard. She hoped that she would have a good life in the future because she believed that she has done many good things, so she expected to get good things back. She did not expect to be unhealthy, so after developing her health conditions, she felt like she was living a joyless life.

Similarly, other participants accepted they had their health condition, it had already happened, so they had to continue living and keep confronting their karma. They did not know what would happen to them in the future. Some of them overlooked how they could cope with the dementia symptoms. They preferred to leave it and not to overthink it. I will discuss this further in the next chapter.

In summary, many participants perceived that they had developed dementia because of their old age. Although the participants knew that they had to live with dementia, many of them did not think it a serious problem because they still had the ability to perform in their everyday lives. However, many did recognise that dementia impacts their well-being in various ways after getting their dementia diagnosis. It can be claimed that perceptions of dementia influence how people manage their lives and cope with dementia. From the stories presented, I reflect that older persons with early stage dementia have different experiences, their perceptions of dementia were different, and each person has various ways to cope with dementia symptoms. However, I think their feelings need to be carefully considered as they still have their lives to live and they need to be in a relationship with others. Dementia impacts on an individual's personhood holistically, including their physical, psychological, social, and spiritual well-being. Importantly, each person is unique. Depending on the way they get support from others determines whether their well-being will be diminished or enhanced. Sources of support are presented next.

5.4.2 Sources of support older persons with early stage dementia

Each participant had different experiences of receiving support for living with dementia. The sources of support in early stage dementia, after getting a diagnosis, can be divided into three main sources: health institution, community, and family. This section presents the experiences of older persons with early stage dementia on how they get support from each source.

5.4.2.1 Health institution support

There are many ways that the participants received support after they were diagnosed with dementia or Alzheimer's disease by a health professional. All participants reported that they received good support from the health staff at the clinic including the doctors, nurses, and patient assistants, who all had a good manner with the patients and families. At every appointment, an older person with early stage dementia and their family would first meet the nurse to tell them about the older persons symptoms. The nurse would assess their symptoms and if there were any changes, these would be recorded on a nursing record. The nurse also provides the necessary advice to the older persons and their families. After this, the older person and their family would meet the doctor who would also discuss symptoms but would further focus on adjusting medication, especially in those persons needing control of their psychological symptoms.

When I first began collecting data, I found older people visiting the dementia clinic, but very few with early stage dementia. Compared to other clinics in the hospital, this clinic had fewer patients, so the health staff in the clinic got to know the patients and their caregiver or family member well. From my field notes after participating in this dementia clinic, I reflected that there is a lack of dementia knowledge that leads people to misunderstand the onset symptoms of dementia. Also, the clinic is a Geriatric Psychiatry Clinic, and I wondered if there were stigma issues in both older persons and families about attending. After conversations with people in the setting, I reflected that this might be one of the reasons why there are so few persons attending with early stage dementia. The name of the clinic, Geriatric Psychiatry Clinic, might also make people feel they are confronting mental illness. Some people might accept support from a psychologist but many think that getting support from a psychiatry clinic means they have a mental illness and other people, especially people who live around them, may think they are a mentally ill person. In my field notes after visits to Pilaiwan, Pratumrat and Nantana, I reflect that the perspectives of people around the PwD may also be a reason for them getting a late diagnosis.

After my conversation with the health professionals, I noticed that once the older person has received a dementia diagnosis, the doctor will see them every three months to review their medications. Many of the older persons needed to take antipsychotic drugs or anti depressives to treat depressive symptoms. Some needed to take medication commonly used to treat Alzheimer’s disease like Rivastigmine delivered as a transdermal patch. Some participants did not return to see the doctor for more than six months. There were a number of reasons for this including the older persons physical limitations like osteoarthritis, the inconvenience of travel to the hospital and the discomfort for the older person waiting around at each process in the hospital. Some families found it difficult to take the older patient to see the doctor because it took a full day. I learned in conversations with families that health professionals understood about these inconveniences and if the older person was stable they would take a history from the caregiver so that the older person did not need to travel to the hospital. The doctors would also adjust medication dosages if there were any changes reported by the caregiver. Sometimes the person going to the hospital to speak to the doctor about the patient's symptoms and collect medication was not the principal caregiver, but one of the family members able to go to the hospital. It depended on the doctor if they would ask to see the older person or if they were content to speak to the family member about the older persons symptoms.

Some participants living in the rural areas found it difficult to travel to the hospital and preferred to get someone to go for them. Although the older persons did not go to see the doctor regularly, they understood they were being supported by health professionals. For example, Rattana expressed that she gets good support and advice from the staff and that she talks to them about her health problems. However, it is inconvenient for Rattana to see the doctor for all her appointments because different doctors make her various appointments on different dates. She describes her experiences of being left with the staff while her son went to park in the following excerpt:

> *Nittiya:* *That is good. Hmm. Why didn't you go to see the doctor last time?*
>
> *Rattana:* *I did not go. I went before, and it was difficult.*
>
> *Nittiya:* *So, you do not want to go again, right?*
>
> *Rattana:* *Yes. Like now I said I would not go again. I would let my son go to tell my symptoms and take medicines for me.*
>
> *Nittiya:* *Please tell me why you do not want to see the doctor?*
>
> *Rattana:* *Oh! It made me tired. I do not want to go. He let me at the building. I have to sit in a wheelchair. Then somebody took me to the 2nd floor because he needed to park the car. I felt alone because other children go to work. Only me and my son go to the hospital. The staff are very good. They take care of me. They checked my weight and blood pressure. When my son parked the car, he came to me, and I only wait for the doctor. [Rattana, 1st interview]*

In the past, Rattana used to see the doctor regularly, but more recently, as she has become older and has felt that she was better, she has attended less. She lives with the youngest of her three children, a daughter who is her principal caregiver. Her son who lives in the city of Nakhon Ratchasima province has taken responsibility to take her for her medical appointments although she does not attend regularly because of the inconvenience of getting her to hospital. Instead her son sees the doctor and reports on his mothers' symptoms and collects her medication. Like some participants, Rattana takes medication relevant to her dementia symptoms. Rattana was not concerned about seeing the doctor; she found it difficult to go to hospital and she felt better, probably because of her medications, although she did not put her wellness down to this. She did not feel her dementia was anything serious at the moment, consequently she saw no need to go to the hospital. This may have been one of the reasons I had difficulty recruiting participants to the study at the clinic.

Like many participants Rattana still wondered about what the problem was with her brain, but she feels better after taking medication to support her symptoms.

> *Nittiya:* *Well, how do you feel when you know that you have dementia?*
>
> *Rattana:* *I was confused. I do not know what happened to me.*
>
> *Nittiya:* *When you know that you have this problem?*
>
> *Rattana:* *When the doctor told me, then I know.*
>
> *Nittiya:* *What did you do after that? Did the doctor tell you something?*
>
> *Rattana:* *I have to try to attend the hospital. I need to take medicine and also medicines for patching on my skin. I will stick it on my chest, or shoulder.*
>
> *Nittiya:* *After you know that you have dementia, do you feel something changes?*
>
> *Rattana:* *Hmm, I think I feel better.*
>
> *Nittiya:* *Huh? Do you feel better after you know you have this disease?*
>
> *Rattana:* *I do not think too much as I know what problem I have now.*
>
> *Nittiya:* *Can you tell me more what make you think like this?*
>
> *Rattana:* *It because the doctor prescribed the medicines for me, and I can sleep well, I can have some food. [Rattana, 1st interview]*

I asked Rattana to show me what medicine patch her applied to her skin. It was an Exelon patch, a thin transdermal patch containing rivastigmine which is in a group of acetylcholinesterase inhibitors. She also stated that:

> *"If I did not stick it about every 2-3 days, I felt like I forget something easy. However, if I stick this sticker medicine, I would not forget." [Rattana, 1st Interview]*

The medication was helping Rattana feel better. She was also taking Alprazolam which is used to treat anxiety and panic disorder symptoms by decreasing abnormal excitement in the brain. Ngamta and Wannaporn also reported feeling better after taking medication.

The majority of medications aim to adjust the chemicals in the brain but not all older PwD receive these. Some are given vitamin B supplements. Wannaporn expressed her experience:

> *Nittiya:* *Do you remember about the symptoms you started to have?*
>
> *Wannaporn:* *I did not know what I did. My son told me that I was searching things at night.*
>
> *Nittiya:* *Ah, don't you know what you did?*
>
> *Wannaporn:* *No. But I am better now. I did not be like before. I do not search things at night. I only feel pain at my waist.*
>
> *Nittiya:* *Oh! Really? Do you know why it is improved?*
>
> *Wannaporn:* *I am not sure. Maybe because I take medicines. I went to see the doctor and told them about my symptoms. So, the doctor prescribed medicines for me. After taking medicines I feel better and not confused.*
>
> *Nittiya:* *Have you been thinking that one day you will get worse?*
>
> *Wannaporn:* *No, I have not. I think it would not worse than this because I always take medicines (smile). I think the medicines that the doctor prescribed are effective.*
>
> *Nittiya:* *Hmm. You always take medicines from the hospital, so, you think relying on the doctor and the medicine would support you. Then you do not worry.*
>
> *Wannaporn:* *Yes.[Wannaporn, 3rd interview]*

The above excerpts show that the retention of the person's capacity in an early stage of dementia can create a misleading perception of dementia. Taking medicines can help older persons with early stage dementia to control their psychological symptoms. But the participants have a lack of knowledge about dementia and do not realise it is incurable. As long as they are still partly independent, look after themselves and have the ability to perform the basic activities of daily life, they tend to believe that they will not get worse and they are happy.

Kanit had a different understanding. He knew after his brain scan that he had brain atrophy. He was stressed and felt sad on learning this; it was unexpected and he recognised that he would lose the ability to do many things by himself. As he stated:

> *"I felt like all silent. All... I cannot do things I used to do. It has not happened in the appropriate time." [Kanit, 1st Interview]*

He knows that one day he might forget all, but he was attempting to maintain his abilities for as long as possible. He went to see the doctor with his wife at every appointment. He also explained that he gets good support from the health staff. The nurse also provided some occupational therapy. She assigned him homework like reading a newspaper that he was interested in and then he needed to make notes and show the nurse at the next appointment. I sensed that Kanit had a good understanding of his situation. He was preparing his future life for the short and long term. He already had experience of a physical limitation and was aware of how the loss of ability had impacted on his life.

In summary, the post-diagnosis phase is important because after getting a diagnosis of dementia, older persons and their family members have to live with dementia. It is not the final step of the diagnosis process, but it is a beginning step in supporting both the PwD and their family. Living well with dementia can lead the older person to fulfil their well-being and maintain their sense of personhood. Therefore, at the early stage of dementia, people need to understand basic dementia knowledge; they have to know what dementia is, how many stages there are, and the probable symptoms in each stage. They also need to know how they can retain their cognitive abilities to live well for as long as possible.

Further, regarding concern about supporting the older person and their family, perhaps it helps both feel more comfortable that the older person does not need to go to see the doctor at every appointment, especially if nothing is changing. However, this is not without problems since the doctor and nurse have not seen or talked to the PwD in person. At the very least if the PwD is seen they can be informed and asked about their opinion of the support plan and any other necessary information. In this case then the support offered, will be person centred.

5.4.2.2 Community support

Community can be an important source of support for older people. This section focuses on the support from people in the community and around the participants. It also highlights where a lack of knowledge about dementia in the general community can isolate the older PwD.

None of the participants in this study was entirely on their own. Some were living alone if they were still independent, but even these participants were surrounded by relatives. Those without relatives received help from others in the neighbourhood. If the older person was alone people around them would report to the head of the community or refer them for support if they needed it. As discussed in chapter 4, Nakhon Ratchasima is a mixed urban and rural area. People living in this province still have a sense of being related to one another and are willing to help each other, especially in the rural areas. Palapol is a good example of this; he had been living in his small town since he was a teenager and he knows many of the people in the local community. Also, his son is well-known as he is a teacher in a famous school in the district and as a teacher, he has a good relationship with people in the area. People in the area know the family and a neighbour offers to help when Pongsak is not able to be with his parents. Palapol shared an experience of when his wife had got lost, and people helped to get her back home. He said:

> *Palapol:* *When she (his wife was walking around while Palapol and I had our conversation) gets like this, she likes to walk around, and so I always have to lock the front door.*
>
> *Nittiya:* *Isn't it better for her to walk around, what do you think?*
>
> *Palapol:* *It is a good idea for her to walk around but sometimes she gets lost outside. Fortunately, everyone in this village knows us, so they always bring her back home to me.*
>
> *Nittiya:* *What about you? Do you like go to walk outside?*
>
> *Palapol:* *Oh! I like to walk everywhere.*
>
> *Nittiya:* *How often do you go for walks?*
>
> *Palapol:* *It depends, some days I think staying home is better.*
>
> *Nittiya:* *How frequent do you get out of the house?*
>
> *Palapol:* *I leave to go to the market almost every day to buy food.*
>
> *Nittiya:* *Who do you go with?*
>
> *Palapol:* *I go alone. [Papapol, 2nd interview]*

The community were aware of the older persons in the area who have memory loss and they help where they can. Palapol also expressed that he enjoys meeting people on his regular trips to the local grocery store but is careful to respect them and not to disturb others.

Whenever Pongsak was unable to visit his parents, he could ask the neighbour to check on them. Palapol in turn could ask the neighbour for help to ring to Pongsak if he needed to contact his son. On one occasion I visited Palapol without making an appointment because I was unable to contact Pongsak (I normally contacted the participant or the family caregiver before visiting, but Palapol does not have a telephone). Neighbours were sitting in their front yard. I asked them if Palapol was in the house as I had not been able to contact his son. An older woman, a neighbour, told me that Pongsak had lost his mobile phone at the hospital. Then she opened the front door and led me in to Palapol's house. She informed me that Pongsak had left 15 minutes before I arrived. Pongsak visits his parents almost every day and if he cannot come, he will ring this neighbour and ask her to give his parents their medicines and check if they had food. He used to leave some of his parents' medications with the neighbour. The neighbour gave me a new mobile number for Pongsak and I rang him to report that I had visited his parents. He was very happy that I had contacted him as he had forgotten where he had put my number.

While I was talking to the neighbour, Palapol sat silently watching television. He seemed not to want to disturb her. Although Palapol was grateful to his neighbour he did not want to be a burden to others. Once she had returned to her house, Palapol told me that they have known each other a very long time, but when I asked her name, he laughed and told me that he could not remember her name. This situation showed that there was good support in the community.

In terms of social interaction, people in the community still had conversations with the participants as normal, despite knowing that participants had a memory problem. Dararat told of her good experience with her neighbours. Although she sees them less because of her health problems, they still have a good relationship. She gave the following example:

> *Dararat:* *There is a good environment. The neighbours living next to my house are very nice. They are very generous. As I work in the market where food is cheap, sometimes I bring some vegetable or watermelon to them. Sometimes, they give me some rice. They are polite and helpful. For example, one day, one neighbour hired the gardeners to clean the wastes around her house, and there is no fence between our houses, so she asked them to do it at my house too.*
>
> *Nittiya:* *How often do you usually meet your neighbours?*
>
> *Dararat:* *I would meet them every morning on the Buddhist Holy Days because we will wait outside for giving food to the monks. Presently, I do not prepare the food because my daughter-in-law prepares it all for me, then sometimes I do not go out to give food to the monks. On a normal day, I have to come here to work. So, I did not meet them so much like before. [Dararat, 3rd interview]*

Dararat also had a good relationship with her friend in the market where she worked. Neither her neighbour nor her friend were concerned about her memory problem. She continues to live her life as usual, but this might be because Dararat does not yet have any symptoms or behaviours affecting other people.

However, people in the community do have different perceptions of dementia, and this influences how they behave towards older PwD. Aorasa's story is different to Palapol's and Dararat's. Aorasa, is an 82 year old woman who had lived in Bangkok since she was born. She had moved to live in Nakhon Ratchasima with her daughter, Kejmanee, about seven years ago. Aorasa has two children; her first son lives in Bangkok, but she did not talk much about him. I heard from her daughter that he has cerebrovascular disease, and his wife looks after him. Aorasa worked as a handicraft teacher. She developed depression after her husband died. She was seeing the doctor and taking her medication regularly and then she started to become forgetful and began misplacing things. Aorasa told me that other people in the area where she lives do not know that she has Alzheimer's disease because she does not think it important to tell them.

Dementia can affect persons' emotional state and PwD can experience mood changes at any time. During one conversation I observed Aorasa smiling, laughing and then just ten minutes later she became serious and moody. Aorasa was unaware that her unstable of emotions were happening because of the dementia. Her daughter shared with me that she found it difficult to cope with Aorasa because of her emotional instability. Sometimes they argued with each other. Also, when Aorasa attended the temple, she did not engage with other people as expected, sometimes she was silent and did not talk or answer people. People perceived that Aorasa had a mental health issue, and they in turn did not want to speak to her.

To my knowledge, in Thai culture, having a mental health problem can be stigmatising for the individual and also their family members. People are fearful of the behaviours exhibited by persons with mental health illness and are fearful they will be harmed by the person who is ill. Family members tended to keep persons with mental problems away from the community, so when the older person expressed similar behaviour to having a mental health illness, they excluded them. It can be seen that people have a lack of understanding about dementia which is often put down to having a mental health problem, especially in the later stages. Dementia is not a mental health problem (Knopf, 2019). However, as a brain condition, its progression can impact the person physically, cause behaviour changes and can lead to mental health issues like distress and depression. In some cases, people know that dementia is caused by brain deterioration, but the sigma still attaches to the PwD because of the presentation of the dementia symptoms. Some people do not want to talk to the PwD as they think they forget easily and do not understand things. These can be the reasons leading other people to withdraw from the PwD's life or think that the PwD is a mental health patient. From my point of view, therefore, many PwD do not want to disclose their diagnosis to others. I also found that the stigmatizing views of mental health problems are carried across many generations, not only in older people.

On my last visit to Aorasa I was told she was at the temple and I went to see her there. I sat a little way from her so as not to disturb her. I observed that she went to sit with a group of people dressed in white who had a special interest in Buddhist practices. Normally on a Buddhist Holy Day many people will attend the temple in the morning and then leave when the monks finish their chanting and blessing. The people in the white were going to stay all day and chant in the afternoon. Aorasa was interested in this activity but she did not talk to anyone throughout the morning activities, not even during the break.

Aorasa was sitting on the floor as is the practice in the temple but she found it difficult to get up because of her osteoarthritis and she needed some help. Another woman, an older person, but younger than Aorasa helped her to get up and walked with her to sit on a chair to have breakfast. Aorasa spoke to no-one and no-one spoke to her although others were eating and having conversations. While everyone else was eating I was helping people clean the floor and tidy up. After the meal Aorasa went to sit with some people but still she did not speak to them. I went up to her to say hello, she remembered me and she seemed happy to see me. No-one around her spoke to her while she and I had small talk and then she went to chant.

In a further conversation with Aorasa she expressed that she did not want to have conversations with other people because she disliked talking, and sometimes she did not want to listen to anyone. Even so Aorasa was excluded from the group and she seemed isolated. Kejmanee told me that she found it hard to speak to others about her mother. On two of my visits to interview Aorasa Kejmanee told me that sometimes she felt the need to tell people that her mother has Alzheimer's disease. She wanted people like the neighbours and some of the people who attend the temple regularly to know and understand why her mother did not speak to them, and why she sometimes got lost. Kejamanjee feared the stigma that Aorasa might experience but she was also concerned about the family being stigmatised. Dementia affects not only the individual who has the condition, but also the family who feel isolated and judged about the individual in the family having mental health problem.

Kejmanee, told me that she gets stressed looking after Aorasa and she dedicates all her time, and indeed her life, taking care of her mother. Caring for someone with dementia is a very demanding job. Kejmanee searched for strategies to maintain her mother's cognitive abilities and she encouraged her to do meaningful activities. For example, she prepared things daily for her mother to give alms to the monks, provided her mother with her favourite food when she sensed her mother was bored with her current food and she provided her mother with yarn to do her knitting, an activity she liked doing before she was diagnosed with dementia. Her efforts seemed to be helping as Aorasa had lived with early stage dementia symptoms for about seven years. Despite being stressed by her caring responsibilities, Kejmanee was careful before giving her mother any activities, she assessed whether Aorasa was ready to do them. Even so their relationship was very difficult at times.

Attending the temple is one of the ways that people engage in wider society. Many older people who were interested in religious practice attended the temple almost every Buddhist Holy Day, and they tended to know each other. This experience is one of the meaningful activities which is expanded on in the next chapter.

Palapol and Dararat had no symptoms which impacted on other people around them, so others were not negative towards them. This contrasts with Aorasa's experience where she was perceived to have a mental health illness and was isolated which in turn also affected her daughter who found it difficult to cope with this.

The Thai government has responded to the issue of supporting older PwD. The Department of Older Persons collaborates with the provincial public health office and the local administration to conduct health promotion sessions for older persons and seniors in communities (DOP, 2017). The aim of the project is to promote the development of older persons' quality of life and promote long-life learning in older persons. The programme delivers education on self-development, care, and on the protection of the rights of older persons. It also aims to support good physical and mental health. It is hoped that the programme will benefit communities and society and lead to the valuing of older people and their wisdom, and the continuation of local wisdom and culture. Although this initiative could potentially help older persons with early stage dementia to fulfil their needs for love and belonging, as they are included socially, the project focuses generally on older people and it does not focus specifically or address the needs of other

PwD. More generally there are inadequate social networks to support PwD in the area in which the research was conducted.

To conclude, in terms of community support, in the Thai cultural context, there is an interdependence of relationships, especially among people in rural areas, or in smaller cities. The stories presented in this section show that social support and social engagement can enhance the lives of older persons with early stage dementia and their sense of emotional and social well-being. To link this with the basic human needs, this kind of support can help fulfil the need for safety and love and belonging as the older people were helped to be safe and be attended by other people in the community. However, it does not mean that this support is everywhere in the community. Aorasa's story shows that people did not understand dementia symptoms and because of this her basic human needs for physical and psychological safety were not being fully met in her community. Many people perceive that older persons with early stage dementia have a mental health problem, and some behave negatively towards older PwD especially PwD who have family relationships problems. This in turn negotiating impacts the feelings of the older person.

5.4.2.3 Family support

The main and most important source of support for older PwD is their family. This is their primary social group in society. After older persons were diagnosed with early stage dementia, they continued to live as before they received their diagnosis. Many families were unsure about what exactly dementia or Alzheimer's disease was, what would happen to their family member who has dementia in the future, what the progression of the illness was, and how they could cope with it.

Chapter 6 expands on the older persons family but more generally, while some older persons with early stage dementia had positive experiences with being supported by their family some told of very unpleasant family experiences. Family support was spoken about by all persons with early stage dementia and these relate closely to all their experiences and needs. The family emerges as one important theme; it is the family that is the primary source of providing support to older people. Therefore, their experience on receiving support from their family leads to an understanding of the needs of older persons with early stage dementia.

5.5 Summary of chapter

This chapter has set out the experiences and perspectives of older persons on the dementia diagnosis journey. The stories of fifteen older persons with early stage dementia have illustrated in different parts the recognition of dementia onset symptoms, the experience of being evaluated, the impact of living with dementia, and the perceptions of dementia after the older person has received their dementia diagnosis. Each older person's story is different, and each has their own life story. The data presented in this chapter provides an understanding of the older participants personal backgrounds, their underlying health problems, family relationships, and how they are supported by family, the community and health institutions. The next chapter explores the different needs of older persons in order to enhance their well-being, which in turn can help slow the progression of the disease.

Chapter 6 Older Person's Experiences and Needs in Early Stage Dementia

6.1 Introduction

This chapter presents findings on the needs of older persons with early stage dementia. The data arises from discussions with the participants about their experiences, feelings, and perspectives on living with dementia. The findings are inextricably linked with Thai culture regarding family, social networks, religion, and beliefs. There are four themes and they all interlink with each other. The first theme, 'family is essential' is the primary theme, and relates to the importance of family to the older person (See also Table 6.2 which shows this theme in full). The second theme, 'companionship support is necessary' is about the older persons need for company, and feelings about being lonely (Table 6.3). The third, 'meaningful activities need to be maintained' describes the older persons experiences and perspectives regarding the need to continue performing their meaningful activities (Table 6.4). The fourth and final theme in this chapter, 'the nature of life needs to be accepted' presents findings on the older persons acceptance of the transience of life, and life satisfaction (Table 6.5).

Parts of the above themes connect to chapter 5 and further explain the relationship between the experiences and perspectives of older persons on the dementia diagnosis journey and their experiences of living with early stage dementia. In addition, the chapter links each of the needs presented to Maslow's (1943) basic human needs theoretical framework as well as Kitwood's (1997) concept of personhood. Table 6.1 on the next page, presents the second part on the experiences of older PwD, but in this illustration, the needs required to maintain the PwD's well-being are highlighted in colour. Table 6.1 encompasses Tables 6.2, 6.3, 6.4 and 6.5

Table 6.1 An overview of the experiences of persons living with early stage dementia highlighting the needs of older persons living with early stage dementia.

Experience of older persons living with early stage dementia													
Pre-diagnosis				**Post-diagnosis**									
The dementia diagnosis journey						**Needs of older persons with early stage dementia arise from their experiences**							
						Family is essential		**Companionship support is necessary**		**Meaningful activities need to be maintained**		**The nature of life needs to be accepted**	
Pre-diagnosis		**Diagnosis process**		**Post-diagnosis** ➢ Home visiting		➢ Receiving positive support ➢ Being understood ➢ Receiving respect		➢ Being engaged in society ➢ Somebody to talk to ➢ Living in a familiar environment		➢ Continue living normally as before getting dementia diagnosis ➢ Needing a chance to do things they used to do		➢ Being well	
Recognition of the onset symptoms of dementia	*The onset of dementia symptoms*	*Entering the diagnosis process*	*Being evaluated and getting a diagnosis*	*The older persons perception of dementia*	*Sources of support older persons with early stage dementia*	*Willingness vs. Obligation to care*	• Family provides good support to PwD • Family have a lack of knowledge about dementia and provide 'over support' to PwD • Family not caring well for the older person (Family blame, family ignore, feeling of being a burden to the family)	*Being included vs. Being excluded*	• Continue participating in society as before getting the diagnosis • Lack of social engagement	*Life carries on: being encouraged*	• Having the ability to perform activities by oneself • Everyday life has changed but PwD receiving support	*Keep living well vs. What-ever will be will be*	• Try to be independent • Do not want to get worse • Nothing to be worried about • Acceptance of the transience of life • Acceptance of the life in the past and present • Feel sufficiency with the life
○ Family members ○ Person with dementia	○ Memory declines ○ Subtle behavioural changes ○ Hallucinations and delusions	○ How older persons get a dementia diagnosis	○ Getting diagnosis	○ Dementia is a normal part of ageing ○ Dementia is an effect of brain deterioration ○ Uncertain about whether dementia is a mental health problem ○ Dementia resulting from past karma	○ Health institution ○ Community ○ Family	*Knowledge vs. Ignorance*	• Family have basic knowledge about dementia • Family lack knowledge to support PwD	*Joyfulness vs. Loneliness*	• Family embraces the PwD within the family • PwD feel being ignored by their family	*Life struggles with the impact of dementia: being controlled*	• Everyday life changes - Everyday activities - Activities in the past • Religious practice • Disempowered • Limited activities - Everyday activities - Activities in the past - Religious practice		
						Consideration vs. Disrespect	• PwD being asked to make decisions • Lack of respect from family members	*Living in a familiar environment vs. Moving to live in a different place*	• Feel familiar with neighbours • Moving to live with children • Family wanted PwD to live in a residential home setting				

Note: -------- this border line refers to the links between the experiences

6.2 Family is essential

The stories of older persons with early stage dementia illuminate their needs for living well with dementia and the family is essential in helping to achieve this. As explained earlier in this thesis, it is accepted in Thai society that older people will rely on their children or other family members for care and support. Most Thais believe that older people have valuable experiences to offer and contribute greatly to the family. When people get old, they may develop chronic illnesses leading to them becoming physically and psychologically frail and vulnerable. In Thai tradition, looking after parents when they are old or ill is the responsibility of adult children and there is shame if a family neglects their elders. Most families have at least one child that will look after the parents. In families where children live far away, and where children cannot be with their parents, there are often relatives nearby to help, especially in rural areas. In these families, children help in other ways; providing financial support or other facilities, and they usually visit their parents frequently. The overall needs and experiences of PwD relating to family are presented in Table 6.2.

Taking care of PwD can however lead to family strain. So, there are both positive and negative experiences related to receiving care from the family and this section on how the family is essential will present both on these, particularly in relation to family relationships, knowledge of dementia, and the awareness of the signs and symptoms, the progression and the impact of dementia on family members. It also presents findings on too little or too much family support. Older persons need to receive positive support, be understood, and receive respect from their family. This section expands on all these issues.

Table 6.2 Experiences and needs of PwD in relation to family

Family is essential

Experiences of PwD in receiving support from family	Code from experiences and perspectives of PwD	Needs for living well with early stage dementia
Family provides good support to PwD family • Family support well (physical, emotional) (PwD_01, 03, 04, 07, 08, 10, 11, 13, 16)	Willingness	Receiving positive support (Physiological) (Safety) (Love and belonging) *(Comfort)* *(Inclusion)*
Family have a lack of knowledge and provide 'over support' to PwD • Family wants PwD to relax and feels comfortable • Family helps and does everything (PwD_02, 06, 12, 14)		
Family not caring well for the older person • Family blames, ignores and neglects PwD (PwD_05, 09, 15)	Obligation	
Family have basic knowledge about dementia • They perceived that dementia is brain deterioration (PwD_01, 02, 03, 04, 06, 07, 08, 10, 11, 12, 13, 14, 16)	Knowledge	Being understood (Safety) (Love and belonging) *(Attachment)*
Family lack knowledge to support PwD (PwD_05, 09, 15)	Ignorance	
PwD being asked to make decisions (PwD_01, 02, 03, 04, 06, 07, 08, 10, 14, 16)	Consideration	Receiving Respect (Love and belonging) (Self-esteem) *(Attachment)*
Lack of respect from family members • Family members unintentional to behave negative behaviours (PwD_11, 12, 13, 15) • Family members do not pay respect as think that it is a duty to take care of PwD (PwD_05, 09, 11, 12, 13, 15)	Disrespect	

6.2.1 Receiving positive support

The participants expressed that sometimes they needed to rely on the family depending on the situation and this includes physical, psychological, social, and spiritual aspects. Although some participants can live alone during the day, they may still need help to do some of the more complicated activities like cooking or washing clothes because they have begun to lose the ability and the confidence to do daily life activities. Many participants are unable to travel outside the home alone as they fear getting lost. I noticed that no participant used assistive technology to help with living independently. Although some participants had a walking stick, walker, or wheelchair, they did seem familiar enough with the aids to use them.

PwD need to be supported to live well for as long as possible, to perform their daily activities, and to go out and make contact with other people. Family are the primary support helping the PwD to meet their basic human needs as set out by Maslow (1943), and also the psychological needs of PwD as delineated by Kitwood (1997). Getting positive support from family enhances the PwD's fulfilment of their holistic well-being.

The next section describes both positive and negative experiences and perspectives of PwD in relation to their need for support.

6.2.1.1 Willingness vs. Obligation to care

The stories from the participants on the care they have received from family show both positive and negative experiences. Each participant had a different experience of family support. Some participants perceived that their families were willing to take on the responsibility for supporting them. Others felt that they were a burden to the family, and controversially, some participants sensed that their families felt obliged to care for them.

a) Willingness: family provides good support to the older person with early stage dementia

Some participants like Tassanee were living in a multi generation household. She perceived that her family were willing to take care of her and this enhanced her sense of physical, emotional, and social well-being and supported her to live well with her dementia for as long as possible.

Tassanee had been living in her house since her marriage. All her children had grown up in the house and after their marriages had moved into separate houses, but all within the same fenced boundary. Although she is still able to perform some daily activities herself, she gets physical support from her children because they want her to feel comfortable and relaxed. For example, her daughter takes her to see the doctor for all her appointments, she prepares every meal for her parents and she washes their clothes and cleans the house. Tassanee is in a safe place, accompanied by the next generations as her children and grandchildren live around her. They meet each other daily and Tassanee is happy when her family members get together.

During my second interview visit to Tassanee, I noticed her sarong was falling from the clothesline. Tassanee got up from her hammock to pick it up and hang it again to dry. She did this slowly and clumsily, as she has Parkinson's disease, although she only understands that she sometimes has shaky hands. Tida her youngest daughter and principal caregiver, who is living with Tassanee, told her mother she would do it for her. Tassanee however attempted to do it herself, but she just put the sarong on the clothesline without using clothes pegs to fix it in position. I sensed that this was the reason why her family members preferred to help do her many activities for her.

Like many participants, the family is invaluable to Tassanee. However, while she gets good support from her family, Tassanee feels guilty and worries that she will become a burden to the family. She was concerned that she will annoy her children as she gets old and unhealthy. As she explained:

Nittiya: *Well, as you told me earlier, living with your family is an important thing for you; is that right?*

Tassanee: *Yes. I am just afraid that they will be annoyed with me because sometimes I speak cluelessly and something might be wrong. I am clumsy and stupid.*

Nittiya: *Hmm. I understand this makes you want to speak less. However, I think they are happy to listen to you.*

Tassanee: *They listen and talk to me. They are good children. They never blame me. I only sit and lie down like this. I have nothing much to do. They go out to work every weekday.*

Nittiya: *Do you feel lonely?*

Tassanee: *No, I sit and lie down here (on her hammock; See also Figure 6.1). I also have many grandchildren around here.*

Nittiya: *Are they come to visit you often?*

Tassanee: *They run around this area.*

Nittiya: *How do you feel when there are many children around you?*

Tassanee: *I'm glad when they come to visit me. Whatever I have, I give them. I don't have a money problem. My daughters give me some money. So, I leave them to my husband.*

Nittiya: *How long do you think you will be able to help yourself?*

Tassanee: *Oh! I don't like to live too long.*

Nittiya: *Aw! Why do you think that?*

Tassanee: *I don't want to be a burden to others. When I would die, I would accept it. It would not be a burden to others. [Tassanee, 3rd interview]*

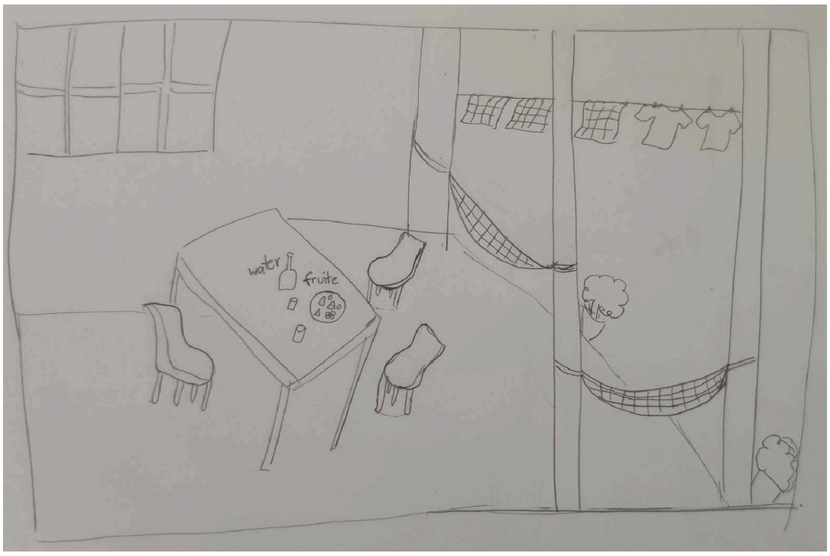


Figure 6.1 Location of Tassanee’s interview and an illustration of the hammock where she spends her days

Linking this situation with basic human needs shows how Tassanee would feel a sense of safety (Maslow, 1943) and comfort (Kitwood, 1997) because her family facilitates the support to help her feel comfortable, and she knows that she can rely on her family. Additionally, as the family members were always talking and listening to her, this could lead her to feel being attended to. Also, it could enhance her to fulfil the need for love and belonging (Maslow, 1943) and inclusion (Kitwood, 1997), which can improve her emotional well-being. However, Tassanee still worries about the dementia symptoms that might annoy her family; she does not want to make her family members feel sad with her words, and she does not want to be a burden to her family.

The data I obtained from the interviews, along with my observations, consolidated my understanding of Tassanee’s family relationship. They are an extended family, located in different houses around Tassanee and they often come to have lunch or dinner together. Every interview I conducted with Tassanee was on a weekend and I met her daughters and grandchildren who surrounded her. Her grandson aged six years, who did not know what dementia was, teased her and said that his grandmother likes to repeat the same phrases when she is speaking. They laughed at each other. Tassanee seemed to have a good and close relationship with her children and grandchildren.

I noticed that there was a link between the past and present relationships in families. Older persons who had looked after family or children in the past and have had a good relationship with their families received good support from their children in the present.

A willingness to take care of family members may relate to past relationships in a family. Good past family relationships mean that family members are more likely to take care of each other when their loved ones develop an illness. In terms of human dignity, being valued and feeling worthwhile can lead the person to a develop a sense of positive self-esteem. Thus, helping PwD to feel worthy and involved enhances the PwD to feel gratified and content with their lives.

Similarly, Kanit's story reveals he was the leader in his family and at work. He supported everyone in his family and attempted to ensure the family have everything they needed. His ischaemic stroke resulted in significant work and family support activities and he lost some ability to look after himself. Fortunately, he receives good support from his family. As I mentioned in the section of the perception of dementia (in chapter 5, section 5.2.2.1), in terms of family attention, Kanit and his wife Usa had more to focus on than just his dementia. Kanit has other diseases to cope with, including diabetes mellitus. Usa and Kanit's son must help manage his diabetes mellitus. Usa found ways to prepare his food as part of his dietary control. Usa prefers to cook herself and she also attempts to restrict some types of food. She understands however that sometimes Kanit wants to have delicious food, and if his symptoms are not too serious, she provides it for him. She buys hot soya milk for him and herself every morning from the morning market near their house. She also prepares some candy for him if he has hypoglycemia.

These stories show that families are willing to take care of their loved ones, and this occurs whether they understand dementia or not. They provided good support for PwD as good as was possible, with their perception of dementia. This influences PwD to feel touched by the love that their family has and provides to them. In addition to getting good support from family, PwD must be encouraged to maintain a sense of attachment. This can lead PwD to live enhanced by emotional well-being.

b) Willingness: family have a lack of knowledge about dementia and provide 'over support' to PwD

It is good for PwD to be attended to and receive support from family. Some families pay appropriate attention to support the person with early stage dementia to maintain their ability to live every day as well as they can. However, some families provided too much support for the older person simply because they wanted to protect their older parents. A good understanding of and knowledge about dementia is critical to support the PwD appropriately.

The first example of ‘over support’ is Rattana’s story. Rattana is a petite woman and she also has a kyphosis making it difficult for her to walk. This led to her family members not permitting her to do many things. She did not do any housework because her daughter and her son-in-law did it all for her. I asked her about how she prepares meals. Rattana explained:

> *“She (her daughter) doesn’t let me do the housework, like wash the dishes. They get back after work, I only want to help or do something, but they do not let me. Even cooking the rice, they don’t let me do it. Then, depending on what they want to do.” [Rattana, 2nd interview]*

Rattana understood that her children do not want her to work because they want her to relax and that it is the responsibility of children to do for their parents. However, she still wants to have some activities to do, because she feels like she has nothing to do and she gets bored. Rattana’s family members in the household do not know what dementia is, and they do not know how the dementia will progress in future. I was aware that the family do not understand that by acting in this way Rattana could lose the ability to perform daily activities by herself.

Tassanee’s family were willing to look after her. Like Rattana’s family, they were over supportive because they wanted to repay their mother for her care of them. As Tassanee has early stage dementia, she is still able to perform her daily activities. She can buy goods from the grocery shop near her house and she continues living as she used to live before getting a dementia diagnosis. However, she did not have many things to do in the day. She did no housework or kitchen tasks because her daughters did it all for her.

As Tassanee was not able to cook, she kept repeating that she feared using a gas stove, so her daughter cooks for her. Tassanee’s previous tasks like cooking food, washing dishes, laundering clothes, and cleaning the floor, were presently managed by her daughter. As her daughters live close by, they help each other look after their mother. Sometimes, Tassanee wanted to help her daughters clean the dishes and wash her clothes, but she did not do the tasks well. Therefore, her daughters prefer to take on the tasks as they wanted to look after their parents as much as they could.

Tassanee:	*I like to do housework like sweeping the floor, washing the clothes.*
Nittiya:	*Do you like to do that?*
Tassanee:	*Yes, I do.*

Nittiya: *Okay, do you mean that you like to help yourself and do things by yourself?*

Tassanee: *I think that, but my children do not want that I do that. I can do it only on the working days because they go to work. I only cook the rice (by using the rice cooker), but I don't use the gas stove. I'm fearful.*

Nittiya: *Do you know why they don't want you to do that?*

Tassanee: *They said that I don't need to do it. They will do it for me. They want me to get rest.*

Nittiya: *How do you feel about this?*

Tassanee: *It's fine. Whatever I can do, I will do, but whatever they don't want me to do, and I will not do it. [Tassanee, 2nd interview]*

Tassanee is at home all day where she relaxes in her hammock, chewing betel nuts. Sometimes, she sweeps the floor when her children are at work. She would prefer to clean the house to help her daughter. She likes to walk to each of her daughters' houses for exercise even though she knows that everyone is at work. These were her usual daily activities, simple activities, and much like older people without cognitive impairment do daily.

It is positive that the family pays attention to support her and are willing to take care of her, as she is their loved one. On the other hand, this is a double-edged sword as this can lead Tassanee to gradually lose her ability to do activities that she used to do by herself. This also risks disempowering the older person as families were not concerned about maintaining the ability of PwD to perform everyday life activities independently (Kitwood, 1997).

In both these cases the families had insufficient knowledge about dementia support. Sometimes when PwD wanted to help their children to do something, their children think it quicker and easier to do themselves. Families were unaware that they might be disempowering their parent and impairing their abilities to perform their everyday activities.

To link these stories to the theoretical framework, family providing physical support can address the PwD's needs for physiological care and promote physical well-being. However, the issue of concern is 'over support' from the family. Persons with early stage dementia still have the capacity to perform many activities and make decisions (AS, 2015a) and it would be beneficial for the older person if these abilities were maintained for as long as possible. It follows that knowledge about dementia is critical to help the family understand the PwD but also in promoting an awareness of maintaining the older persons ability to enjoy well-being for as long as possible.

c) Obligation: family not caring well for the older person

Some families perceive taking care of an older person with early stage dementia is an obligation. Caring for a PwD, as highlighted previously is demanding and can be stressful and sometimes this leads to poor care from the family. PwD present with unexpected and sometimes difficult and unpredictable behaviours and families need to be able to cope with these. In some situations, the family is abusive towards the older person and this can be both intentional and unintentional; this is particularly so in families where they do not understand what dementia is.

Pilaiwan for example experienced abuse from family members. Most of the violations were perpetrated by her nephew Virut who was unemployed at the time. The family were under financial pressure as only Siriporn and her daughter were employed. Financial stress together with Pilaiwan's behavioural changes triggered abuse towards her especially from Virut but also from her sister Siriporn. Virut's abuse took the form of criticism and he used impolite and disrespectful words towards her, as did her sister. This led to Pilaiwan feeling sad and feeling like she was a burden. Pilaiwan said she wanted to die because of the abusive behaviour towards her. As Pilaiwan and her sister discussed:

> *Siriporn:* *Sometimes I get angry at her, I have asked her when we will die. If I die before her, it would be good because I don't need to get trouble like these days. I feel stressed. Then, she thinks that I want her to die.*
>
> *Pilaiwan:* *I didn't mean that. I'd rather die too. I think I am like this. I am a burden to them. (Pilaiwan talked to me, she did not look at her sister) [Pilaiwan, 2nd Interview]*

This story highlights the family strain in caring for a PwD. Pilaiwan's family misunderstood her dementia symptoms and they felt caring for her was an obligation. Siriporn was concerned about the family relationships but she did not know how to solve the problem. Pilaiwan also has osteoarthritis in both knees and it was difficult for her to get a job because of her health problems to help with the family finances. Consequently, she lacked confidence feared going out and getting lost. As she expressed:

> *"I want to go out too, but I'm afraid that I will get lost and forget the way back home. I'm not mad. I still understand everything. I live here with my sister. I consider her. Sometimes she complains about me, and that makes me hurt. I want to help her by working, but nobody wants to employ me because I'm not healthy." [Pilaiwan, 1st Interview]*

Pilaiwan tried to help her sister by doing daily house tasks like tidying up, cleaning the kitchen, the kitchen items, and the gas stove. She also helps her sister by watering the plants and doing small gardening tasks. Pilaiwan feels less enthusiastic about doing the other day-to-day activities she used to do. The loss of her short-term memory impacted on her confidence. She needed to rely on her sister to take a day off to take her to the hospital or to do her other business matters. These physical and psychological capacity limitations lead her to feel dependent because she was unable to do many independently, as in the past.

Pilaiwan's caregiver was not primary kin, a child or husband, and it may be that this, she was her sister, and the lack of a strong relationship with her caregiver, that was the cause of the problem. With respect to the need for love and belonging and the need for self-esteem, the ways that family members behave and express themselves to the PwD can impact their feelings of being included and valued. Negative expressions can diminish their emotional well-being and lead them to feel devalued.

Nantana's granddaughter-in-law Arunee, was caring for her children at home and in this way became Nantana's main caregiver. Although Nantana's own children lived around her, they did not provide positive support to her. Nantana was at home with Arunee and her great-grandchildren but none of them talked to her, even when they were together. Sometimes when Nantana called her great-grandchildren, they ignored her. I sensed that the family did not have a good relationship with Nantana. Nantana misses her daughter who supports her financially. She said:

> *Nantana:* *There is no descendant interested in taking care of me. She (Arunee) is my granddaughter-in-law, she has to endure to take care of me. She annoys me, I can't do anything.*
>
> *Nittiya:* *Have things changed?*
>
> *Nantana:* *Only I would like to take something, I would fall. (sigh) I'm so frustrated. I don't want to live.*
>
> *Nittiya:* *Hmm. What do you think would help you to improve your well-being?*

Nantana: *Nothing. The person who can look after me, she has already gone to (name of country). She sends money to me, she supports me. People here have nothing, even the rental. You think about it. (Crying)*

Nittiya: *They are taking care of you too, aren't they?*

Nantana: *I have to get used to it. If that girl (the daughter working in abroad) doesn't come. I would not have the rental. I can speak to shameless. [Nantana, 4th interview]*

Nantana was aware of the difficulties with Arunee and also with her own children. She expressed that she needed someone who was willing to look after her. Sometimes when Arunee went back home to another province, Nantana had to stay alone at home. They would lock the door from the outside and leave her in the house. Her daughter, who lives in the area, would bring food for her in the morning. Nantana sits and lies down on the wooden sofa; she did not like to walk much because she fears falling. When I asked her, what could help her well-being, she seemed desperate, before telling me that she needed a care.

Nittiya: *Hmm. So, what do you think could help you to have well-being?*

Nantana: *Nothing. The only way that could help me be happy is returning to my old home (in Thai the meaning of this is to die).*

Nittiya: *Is that would make you happy?*

Nantana: *I don't know anything. What they blame me I have to stay still.*

Nittiya: *Have you consulted with the doctor or any healthcare professional about this problem?*

Nantana: *Never.*

Nittiya: *Do you want to consult them, or ask for their help?*

Nantana: *Yes, I want their help.*

Nittiya: *What kind of help do you need?*

Nantana: *I need them to take care of me.*

Nittiya: *How about the care you need?*

Nantana: *Hmm. I think the doctor couldn't help me. I need to have a care. [Nantana, 4th interview]*

Nantana is poorly supported in her family and she feels neglected by them. She was aware that she needed to get help as she was losing her abilities. She needed to be cared for by someone in a positive way.

After my interview with Nantana, I spent some time talking to her about her feelings and concerns. I also spoke to her about her not wanting to live. I took her for a little walk from her wooden sofa to the front yard with the help of her daughter. I obtained her permission to share her problem with a relevant professional and I reported her issues to the head nurse in the Dementia Care clinic. The head nurse told me that she would record my concerns on the patient information record and would refer Nantana to the home visit centre (a primary level care service which collaborates with the tertiary hospital). Additionally, as I had opportunities to talk with Arunee (her granddaughter-in-law) and Nantana's daughters, I give them information about dementia signs and symptoms and its progression and also encouraged them to be patient in taking care of Nantana.

In summary, to link these experiences and perspectives of the PwD with the basic human needs, receiving positive support from their family could help fulfil the physiological, safety, and love and belonging needs, and also fulfil the comfort need of PwD following Kitwood's (1997) concept of person-centred care. Conversely, if the family feels that taking care of a PwD is an obligation, along with a misconception of what dementia is, they may be stressed, burnout easily, not care well or even be abusive towards the PwD. PwD are vulnerable and poor or abusive care undermines their holistic well-being, including their emotional well-being. Families need to have sufficient knowledge about dementia to look after a PwD to help them maintain their abilities and enhance their well-being.

6.2.2 Being understood

Many participants stated that their family members did not understand them. Sometimes they worried about annoying or angering their families. This was because of their behaviours: their forgetfulness, repeated questions, speaking nonsensically and making mistakes, but also because of their dependence on their family in certain situations.

As all participants were living with their families, they needed their families to understand that they had health conditions. They hoped not to be judged as having a mental health illness even though they did not understand why they behaved as they did. Sometimes when the participants wanted to explain their feelings to their family member, the family member seemed not to understand and ignored them. It seemed that family were reluctant to have a conversation with them. I sensed that being understood by their family would be helpful to PwD to fulfil their love and belonging needs. Also, it could further enhance their emotional well-being. Once the family understands that they have brain deterioration, which affects their memory, causes behavioural changes, and some psychological symptoms like delusion or hallucinations, the family could open their minds to understand the PwD and accept what is happening to them. This need draws on the participants' experiences in receiving support from their families. The experiences vary and are relating to the participants' feelings of how their families behaved. The stories and perspectives of PwD led me to reflect that some families have a basic knowledge of dementia. When families have little knowledge, they can misunderstand dementia symptoms.

6.2.2.1 Knowledge vs. Ignorance

Having knowledge of dementia is important for both the older person and their family members. Knowledge promotes understanding of the condition and allows the family to offer positive support to their older family member. This in turn helps the older person maintain well-being and to live well. This section draws on the experiences and perspectives of PwD on receiving support from their families.

a) Knowledge: Family have basic knowledge about dementia

Generally, the principal caregiver in each family, either a spouse or a child, will support the PwD as well as they can, however, not all family members have basic knowledge about dementia. Some family members understand dementia is caused by brain atrophy, and that the aim is to slow down the disease progression and that the PwD should be encouraged and empowered to continue doing the activities of daily life to maintain ability and the capacity to live well as long as possible.

This is true in Dararat's family who support her well. Dararat lives with her husband, sons, daughter, and daughter-in-law, and she has a good relationship with them. Her daughter-in-law, Orawee, is her principal caregiver. The whole family are aware that Dararat is forgetful and has had a slight change in her cognitive abilities. When they first became aware of Darrarat's condition, the family preferred for her to stay at home, relax and to stop working. However, after regular contact with the doctor at the clinic the family gradually gained knowledge about dementia and its symptoms. Also, Orawee had experience of taking care of her grandmother with Alzheimer's disease, so she understood Dararat's symptoms and explained these to the other family members. This changed the family's support and they started taking Dararat to work with them in the market as she had done previously. Sometimes, when Dararat was forgetful or make incorrect money calculations, they might blame her, but they understood her and accepted that this could happen. Dararat expressed her feelings about the family:

> *"They speak well to me. I only hope they will understand me when I have problems. I do not want them to feel angry at me when I forget or do something wrong. Sometimes, they invite me to go to the shopping mall to do something different. For example, last week, I said I do not want to go because I felt lazy. My husband convinced me to go with my children, and my children said if I was lazy to walk, there are wheelchairs I can sit on, and they would push me. (laughs)" [Dararat, 2nd Interview]*

Family relationships are related to the background of each person. Dararat has a very good relationship with her family and she has contributed many things to the family over her life. She had worked hard to help her husband to build up the family and for them to have a strong economic foundation. She had looked after her children very well. Now that she is ill, they in turn provide excellent care and pay attention to her to make her feel comfortable and have holistic well-being.

Another example of a family who understands dementia symptoms and who was attempting to empower their older family member is Wannaporn's family. However, the situation was difficult as Wannaporn has physical limitations. Wannaporn's lumbar spondylosis makes it difficult for her to walk or stand for a long time. Therefore, she cannot do many of the activities she used to do. Sometimes, she also has vertigo from her hypertension. Although she is still able to look after herself and perform her basic daily activities, her son prefers to help her with almost all the activities she cannot do. As Wannaporn explained in the conversation below:

> *Wannaporn:* *I am still able to eat by myself. My son prepares the meals and I just eat (laughing). When I finish, he cleans up for me. He is good.*
>
> *Nittiya:* *That's good, he takes care of you. So, could you tell me about your daily activities?*
>
> *Wannaporn:* *I don't do anything, because of my lower back problem. I only get up to eat when my son calls me. (participant was sitting in a sun lounger/ folding bed in the living room).*
>
> *Nittiya:* *Where do you sleep at night?*
>
> *Wannaporn:* *I sleep in the bedroom.*
>
> *Nittiya:* *Hmm, could you please explain to me in step by step detail about your daily activities?*
>
> *Wannaporn:* *After I wake up, I clean my face, brush my teeth and lay down here (laughing) because of my lower back pain.*

Nittiya: *Do you do anything else after that?*

Wannaporn: *Nothing, only sleep and watch television, watch dramas.*

Nittiya: *Do you like watching dramas?*

Wannaporn: *Yes, I do. My son turns on the television and I don't know what I want to do, so watching dramas is fun.*

Nittiya: *Well what about cleaning the house, who takes care of that?*

Wannaporn: *My son does it all, he buys the food, washes the clothes, takes the clothes out to dry, after that he brings them into the house, and I will fold them to keep in the wardrobe. [Wannaporn, 1st interview]*

I had conversations with Puchong, Wannaporn's son, on every visit to them. He was aware that dementia is cognitive decline and he had sufficient information about dementia. He takes Wannaporn to all her appointments with the doctor and he was also providing cognitive training activities for her; like drawing and colouring pictures. However, sometimes Wannaporn was reluctant to do these and Puchong had to work very carefully with her on these occasions. Puchong understood Wannaporn's physical limitations and he was taking good care of her. Wannaporn in turn was happy with her son's care of her. Family members like Puchong need knowledge about dementia but they also need to know how to be able to support their older family member according to that persons' needs and their needs at different times. This requires much insight and knowledge from families.

In summary, a willingness to care for PwD needs to accompany knowledge about dementia, dementia symptoms, and how to be flexible and able to adjust care and support given to PwD. This can be challenging for families but is needed to help PwD fulfil their sense of personhood.

b) Ignorance: family lack knowledge to support PwD

When families regarded caring for older family members with early stage dementia as an obligation, they seemed not to want to know anything about dementia. These families were unconcerned about what was happening and what would happen to the older person; they did not understand the nature of dementia. Some thought that the older person was pretending to gain attention from the family with their symptoms. This situation led to negatively impacting on the emotional well-being of the PwD.

For example, Pilaiwan explained that her family ignored her and when she tried to explain her feelings and symptoms to them, they thought she was pretending with her symptoms.

This made her feel emotionally diminished. Her family did not understand her dementia symptoms or the progression of the condition. This was clear on my first visit to Pilaiwan; her nephew did not want to listen to anything I said, and he was angry towards Pilaiwan and wanted her to leave his mother's house. The family were ignorant about her dementia symptoms and there were relationship problems. Pilaiwan lacked confidence and she felt unsafe. She showed me her arm which was bruised. She told me that she and her nephew had argued and fought with each other; her nephew had held her arm and squeezed it. Siriporn, Pilaiwan's sister had witnessed the incident but she had not intervened. The stress in this family had led to the physical and emotional abuse of Pilaiwan.

This was a sensitive story for Pilaiwan and Siriporn to share with me. It may have been that they were wanting support from the relevant professionals or somebody else they could consult. I asked Pilaiwan for permission to report this issue to the nurse and the doctor in the Dementia Care clinic to find out ways to support them. Pilaiwan and Siriporn agreed and were willing to share their struggle with others. Siriporn was worried that her sister would be hurt, and her son sent to the jail if he harmed Pilaiwan again. I sensed that their relationship was a deep sibling bond, different from the relationship a person has with children or a partner. They were from the same family and could not neglect one another.

> *Pilaiwan:* *I am detached with all my physical problems. Legs are lamed, also my knees. Although I have had already surgery, they are still painful. I can't manage to do all my daily activities. Also, my memories began to deteriorate. I'm getting really forgetful. When I get to ask my sister, I always get told off; 'What? I have just told you that. You already forgot it?' Then, I replied 'yes, I did', and that made her think that I was pretending to be forgetful. And that hurt me. I insisted 'I forgot'. Why doesn't she understand me? The phrase "pretending to forget" was hurting to hear.*
>
> *Siriporn:* *Aw, I thought you pretend to forget because you chose to forget something. Also, you like to accuse somebody of stealing your things. This makes me angry too.*
>
> *Pilaiwan:* *I kept the house particulars in my pocket. Later, I couldn't find it. I said that I actually forgot where it is, and I couldn't find it when I wanted to use it.*
>
> *Siriporn:* *Why did you say what you said at that time? Why did you think somebody stole it? She thought that somebody took it to pawn. She knows herself that she has a memory decline, but she never thinks that she forgets. She often repeats, so I and my son, we get stressed and angry. [Pilaiwan, 3rd interview]*

The family had a clear lack of knowledge and understanding of dementia. They were stressed and Pilaiwan had been physically abused and could possibly be abused in the future. She was very vulnerable and misunderstood. She wanted her family to understand her at this difficult time. She repeated some of the stories she had shared in the previous interviews. The family believed that Pilaiwan had mental health problems, and that she was pretending to forget because she did not want to be involved in with anything or attend to their conversations. It made Pilaiwan feel hurt and she felt that nobody understood her, except for her niece. As she expressed:

> *"Only my niece understands me. She never blames me. I am never angry with her. She speaks with reasons, then I understand. You know, when my sister and my nephew blame me, I think about their words, I think am I like they said? I didn't blame others." [Pilaiwan, 3rd interview]*

Pilaiwan's niece understood her situation but she did not live with her. I had a chance to talk to her niece about Pilaiwan's dementia symptoms and the progression of the condition. She then explained this to Siriporn. Pilaiwan felt that Siriporn seemed to understand her more since I had started to visit her and had shared knowledge about dementia with the family. This seemed to be effective as after the conversation Siriporn appeared to change towards Pilaiwan. However, her nephew did not want to know anything and seemed closed to learning about dementia and Pilaiwan's symptoms. She said:

> *"Hmm...it seems my sister understands me increasingly. But my nephew... I feel like he annoys me. When I forget, or say something wrong, or have made him dissatisfied, he does like he does not respect me. Look at my arm, he squeezed my arm and hit my head. It's bruised here, but it's getting better." [Pilaiwan, 4th interview]*

Pilaiwan was the only participant who reported being physically abused. Her family was stressed but there were other participants families who were stressed and abuse towards PwD may occur more frequently than thought. For example, there was unintentional abuse directed at Laiad and Nantana by their families in the form of 'disrespect' I discuss this later in the chapter. Families need knowledge about dementia so that they can support the well-being of their family member and properly attend to their needs but families themselves may also need support from the doctors and nurses to help them care for their family member with dementia.

To conclude, the stories presented in this section on 'being understood' has showed that both the PwD and their families still have a lack of understanding about dementia. While the family realised that their loved one has dementia, they were sometimes confused about why their family member was acting as they were. Understanding refers to knowledge about dementia, the symptoms, and the progression of the disease. Neither the PwD nor their family understood what would happen to the PwD as the disease progressed. Both the older person and their family were unprepared for the future and both needed support to plan for this. If the family have a lack of dementia knowledge and feel obliged to care, this can lead to abusive acts or behaviour that destroys the PwD's well-being. Thus, the need to be understood can fulfil the need for safety, love and belonging and attachment to help the PwD feel safe and be more confident with the uncertainty in their lives.

6.2.3 Receiving respect

In Thai culture, it is expected that older people will be respected by the younger generation because of their advanced age and vast life experience. The need to receive respect from others was mentioned many times by the older participants. Receiving respect fulfils a sense of psychological well-being. In families where older people were being cared for because of a sense of obligation towards their elders, the older people were aware of this and felt that they were not being respected.

6.2.3.1 Consideration vs. Disrespect

There were two different perspectives derived from participants' experiences. This section illustrates firstly the experiences of PwD on receiving support from their family, which is relevant to the need to be respected. The next section on disrespect explores those experiences.

a) Consideration: older persons being asked to make decisions

Many participants were respected by their family. Two participants are examples of older persons being asked to make decisions by their families: Chompoo and Kanit. During one of my visits to Chompoo a mobile market truck arrived at her house selling a variety of foods like those sold in the market (see Figure 6.2). The driver was also the seller. Chompoo and her daughter were talking to the seller in a familiar way, as if they knew one another. Chompoo looked at the fresh products and searched for what she wanted to cook for the monks the following day. Her daughter allowed her to talk to the seller and helped her choose the food for cooking. The seller let Chompoo try a dessert to see how it tasted. They were all talking and her daughter bought some ingredients for cooking. Chompoo did not buy anything because she could not figure it out what she wanted to cook. Finally, only her daughter made the selections and bought the goods, Chompoo did not buy anything. Later we went back to sit and continued talking together.

Figure 6.2 Mobile food truck

I sensed that Chompoo was happy when she met and talked to people. During the interviews, customers came to buy goods in the family shop and Chompoo had conversations with them and they were all familiar with one another. Importantly Chompoo's daughter let her make her own decisions, she helped when needed and accepted what her mother wanted to do.

Kanit had come to rely on his family after his ischaemic stroke and his wife Usa had taken the lead family role because of his speech and physical limitations. Usa organised everything in the house in her role as a housewife and outside the house she was his assistant. They went everywhere together. She prepared his food and medicines, took him to see the doctor, and carried out several activities as his representative. Sometimes, she even helped him to prepare his clothes even though he was able to do this himself; Usa made sure his clothes were appropriate.

After my first visit, it was clear that Usa paid careful attention to Kanit's care. During my visit, a mobile dessert shop stopped in front of Usa's sister's house. The seller was selling a grass jelly dessert, which is served with ice and sugar syrup. The ringing shop bell letting people know the shop had arrived caused everyone to stop talking; both Kanit and Usa enjoyed this dessert as it is thirst quenching and refreshing. Kanit wanted a dessert; he smiled and asked Usa to buy the dessert for all of us.

Usa and other family members gave Kanit a chance to make decisions. They respected him as he is the accepted leader of the family: husband, father, and grandfather. This links to human dignity as their recognition of him and his full life is clear from the positive support he gets from his family.

These two examples of receiving respect from the family show how this helps the PwD achieve a sense of self-respect, which in turn leads the person to fulfil self-esteem needs. This enhances emotional and spiritual well-being and links to the positive care that Kitwood (1997) explains is the way to enhance the emotional well-being of PwD.

b) Disrespect: lack of respect from family members

This section presents stories from families where the older person was disrespected, not given a chance to decide what they wanted nor were they asked about their preferences. For example, not being asked what food they wanted to order, or eat. Some families did not respect the older person. There were often different generations in a family and sometimes young family members forgot to pay sufficient attention to the older person in a family. The phrase, 'what goes around, comes around', relates to when older persons look back on their lives and see their current situation as a pay-back for their past actions. Often the way the family behaved led the older persons to think about what they had done in the past was the cause of current disrespect. The examples in the families in this section are different from the families who gave the PwD the chance to make decisions.

Laiad's family paid little attention to him even though he was living with the extended family. In the morning, his daughter would prepare the material she was to sell in the afternoon and his grandchildren would be in their rooms. Sometimes, the family had breakfast and lunch together, but as the daughter needed to go to work, she would cook or buy the food from the market and leave it for her parents. Most of the family members went out to work in the early afternoon until late at night. Laiad and his wife would stay at home.

Laiad did many household jobs himself. He carried numerous buckets of water from the water tank to fill the big earthen jar. I asked him why he did it and he told me that he gets told off by his grandchildren if he asked them. He could not ask anyone, so he did it himself. In the second interview he said:

Laiad: *I do it all by myself. I have to look after myself. I don't want to ask them to do anything for me. I don't want to bother them. I'm afraid that they would blame me.*

Nittiya: *Have they ever blamed you?*

Laiad: *Yes. They blame me behind. Sometimes, they shout at me.*

Nittiya: *Did they shout at you too? Who did that?*

Laiad: *My granddaughters shouted at me. When I cannot do something by myself, I ask them to do it. They blamed and shouted at me, and then they go into their room.*

Nittiya: *Hmm, how do you feel after they did that?*

Laiad: *I felt sad that I cannot ask them to do something. So, I have to do it by myself.*

Nittiya: *Does this situation happen often?*

Laiad: *No, but when they did that, I felt sad because I cannot do something by myself. I only want their help. [Laiad, 2nd interview]*

Laiad had visual hallucinations, and aggressive behaviours as onset symptoms before getting a dementia diagnosis. Consequently, his family members did not believe him when he said anything because they did not understand about dementia symptoms and the progression of the condition. His daughter said that other family members would help him, but sometimes they were busy, and Laiad did not always want to wait, so he did things by himself. I observed his daughter leave home when I arrived because she had to do her business while his grandchildren remained in their rooms. So, during the last two visits, there was only his wife sitting with him.

Although the relationship between Laiad and his family seemed close-knit on the surface because they were all living in the same house, this was not the case. His children needed to go out to work and leave him at home, and his grandchildren left him alone. Laiad's family were unconcerned about his well-being, especially his emotional well-being. Their ignoring him and his needs was unintentional, but he felt emotionally diminished, nonetheless.

Another example is that of Nantana, who told me that she was very unhappy about her life. Although she was not living alone, she felt lonely. She found it difficult that no-one understood her. She was aware that she had not cared for her children when they were growing up as well as she should have. She acknowledged her gambling addiction and the loss of her properties and felt that her current troubles were possibly retribution for the way she had lived her life.

Laiad and Nantana’s past life stories and present situations were different but both felt they were not respected in their families and this impacted on their emotional well-being. Older PwD need to be respected; respect is related to their sense of self-esteem and their emotional well-being. Families play an important part in either enhancing or diminishing this need for respect in the PwD’s life.

To conclude, this theme has presented the stories and perspectives of PwD on the importance of the family and family support to the older person. To live well with dementia the older person needs the family. Three key elements connect the experiences of older persons, firstly, to help PwD, families need to be able to access information to understand what dementia is, to understand the onset signs and symptoms of the condition, and how to slow down its progression. Secondly, family relationships are important and good family relationships improve the well-being of older PwD. Conversely, difficult family relationships impact negatively on the well-being of the PwD. Thirdly, the difficult stories in this theme show that PwD and their families need support for the PwD to achieve well-being.

6.3 Companionship support is necessary

Humans need social support and, in this study, many of the participants had very few or no social activities, because of their dementia. They stayed at home all day and they were bored. Although all the participants were living with family, some of them reported feeling lonely because of a lack of activities and conversation, even with their family members. They had lost the sense of being a part of the family or society. This theme draws on the experiences and perspectives of the older persons need to be engaged in society, to have someone to talk to, and to live in a familiar environment. The need for companionship helps the PwD meet the basic human need for safety, love and belonging, and self-esteem. Moreover, it can enhance their emotional, psychological, social, and spiritual well-being. The overall needs and experiences of PwD relating to companionship support are presented in Figure 6.3.

Table 6.3 Experiences and needs of PwD relating to companionship

Companionship support is necessary				
Experiences of PwD in receiving support from family		**Code from experiences and perspectives of PwD**		**Needs for living well with early stage dementia**
Continue participating in society as before getting the diagnosis • PwD able to participate in social event as normal (physical, emotional, social) (PwD_01, 03, 04, 08, 13)	→	Being included	}	Being included in society (Love and belonging) (Self-esteem) (Self-actualisation) *(Attachment)* *(Occupation)* *(Inclusion)*
Lack of social engagement • PwD have face with a feeling of social declines but still has activities with family (PwD_02, 06, 07, 10, 11, 12, 14, 16) • PwD are excluded from social and family (PwD_05, 09,15)	→	Being excluded		
Family embraces PwD within the family (PwD_02, 04, 06, 07, 08, 10, 11, 14, 16)	→	Joyfulness	}	Somebody to talk to (Love and belonging) *(Attachment)* *(Occupation)* *(Inclusion)*
The PwD feels being ignored by their family (PwD_01, 03, 05, 09, 12, 13, 15)	→	Loneliness		
PwD feels familiar with the neighbours (PwD_01, 02, 03, 04, 06, 07, 08, 10, 11, 14)	→	Living in a familiar environment	}	Living in a familiar environment (Safety) (Love and belonging) *(Comfort)* *(Attachment)* *(Occupation)* *(Inclusion)*
Moving to live with children • PwD moved from another city to live with their child (PwD_12, 13, 16)		Moving to live in a different place		
Family wanted the PwD to live in a residential home setting • PwD and family have relationship problem (PwD_05, 09, 15) • Family thinks that PwD need to get better support (PwD_15)	→			

6.3.1 Being engaged in society

To fulfil their sense of emotional and social well-being, PwD need to engage in society. This need connects to both those participants able to participate in society and participants who are unable to because of the life changes brought about by dementia. This part of the chapter describes the perspectives and experiences of participants of being included and excluded from the family and society.

6.3.1.1 Being included vs. Being excluded

Although older persons with early stage dementia are still able to participate in society, they need to be supported and encouraged by others because of their cognitive decline. Once dementia impacts on the older persons physical and emotional abilities, they can lack confidence which in turn impacts negatively on their social engagement. This section presents participants' experiences and perspectives of being included as well as of being excluded from engaging in social activities. This influences their social well-being and is related to the need for love and belonging, and self-esteem and of being attached to others.

a) Being included: continue participating in society as before getting the diagnosis

Being engaged in a social group and joining activities can enhance the persons' sense of love and belonging, and self-esteem. It also gives the PwD an opportunity to train their cognitive skills, including speaking, thinking, and listening, all fundamental human social skills. Doing this allows the person to sense that they are still encompassed in the group. On the other hand, people may feel discouraged if they are socially excluded. Some participants believed that participating in social activities was important to help them to maintain their social well-being. There are various ways of participating in society, depending on the preference of each person as well as their background and past and current context.

For example, Chompoo said that she likes participating in social activities. Her opportunity to participate was in an older persons' 'school' run in the subdistrict as part of a national project for enhancing the ability of older people in long-life learning. I referred to this policy in chapter 5 (see section 5.4.2.2) and I had an opportunity to join Chompoo at the 'school' on one occasion (see Figure 6.3). I observed her speaking to many people, and no-one knew that she had dementia. She did not tell others because she thought it unnecessary. She did however believe that even if people knew she had dementia, they would still have a normal relationship with her. I saw that Chompoo was happy and enthusiastic as she participated in the event. As she said:

> *"Hmm…I think having somebody to talk to like when I go to senior school is good too. I can meet many people, practice using my brain, it is fun." [Chompoo, 3rd interview]*

Figure 6.3 An example of an activity in the older people’s school

Participation was helping Chompoo to maintain her emotional, social, and spiritual well-being which may help to slow the progression of dementia. Chompoo wanted to engage in activities as she had done previously, before getting diagnosed, because she believed that they would maintain her well-being. As well as participating in the senior school, Chompoo also attended the temple on all Buddhist Holy days and these gave her a chance to meet and talk to her friends and other people. This connects to the need for love and belonging, which could help Chompoo maintain her social and spiritual well-being.

b) Being excluded: lack of social engagement

Brain deterioration causes the persons cognitive decline; memory loss and behaviour changes. These can cause the PwD to be socially isolated, either through self-isolation or by being excluded by others. Some PwD find it challenging to interact with others and they might withdraw from their friends, family, and society.

Dararat for example finds it difficult to have a conversation with others. However, she still wants to be included socially and continues participating in activities that she engaged in before getting a dementia diagnosis. At the first interview, I sensed that Dararat lacked confidence when I asked her questions. She smiled and looked at her daughter-in-law to answer for her. I told her that she could relax, I could wait for her, I reassured her that she could take as long as she wanted to think before answering. At the second and third visits, Dararat was more confident talking about her life and expressing her feelings to me. She told me that since her memory decline, she had started to feel less confident and had fewer activities with other people.

Nittiya: *Could you please tell me about your social life after you received the diagnosis?*

Dararat: *I didn't talk much to other people. I'm not a talkative person. When I join with others, I only listen to them. Before, my cousin liked to invite me to travel. Presently, she knows I have a health problem. She said that she doesn't want to invite me because she doesn't want me to be her burden. (She smiles when she talks about this)*

Nittiya: *Do you want to travel with her?*

Dararat: *Hmm, if she invites me, I want to go. However, if she doesn't want me to go with her, I understand. She doesn't want to look after me because she wants to travel. I remembered that some time ago, we went to travel to Hong Kong. I got the wrong bus. Fortunately, my cousin saw me when I was taking a bus, and she called me very loudly because I was wrong (laugh). So, right now, I don't want to go anywhere with them because I don't want to be a burden. I will make them have more responsibility if I go. [Dararat, 2nd interview]*

After she had become forgetful and started to find it difficult to work, Dararat recognised that she was not the same. Although she still wants to participate in social activities, she understands that she can be a burden to others. She knows she is being excluded from some social events because of her cognitive decline. Nonetheless, PwD still need to be involved in society regardless of their ability to participate in social intercourse because it can help them to fulfil a sense of social well-being.

After his retirement following an ischaemic stroke, Kanit had been keeping in touch with his friends via the telephone. However, the onset of the dementia started to change his abilities to engage in social activities like this. Kanit revealed that he had many negative impacts from the dementia, including physical, psychological, and social aspects. He started to feel stressed when he began to forget the names of people or things, and to think and speak slower. These symptoms made it difficult for him to have conversations with people. He was taking a long time to think about what he wanted to say, and this caused him to stop contacting his friends. He also lacked enthusiasm for social activities. Kanit has a mobile phone, which he used to use previously, but he did not know how to use it now. As he expressed:

Nittiya: *Are there any changes in your life?*

Kanit: *Yes. My life is changed.*

Nittiya: *Could you tell me more about how your life is changed after you have known the diagnosis?*

> *Kanit:* *I could not work. I felt like I would do this, but I cannot. I don't know why I do things slowly, think slow. I miss my work.*
>
> *Nittiya:* *So, did your friends or other people know that you have dementia?*
>
> *Kanit:* *Yes, they know because they noticed that my behaviour was changed, when they asked something, I did not answer as I used to. Even somebody thought that I was haughty.*
>
> *Nittiya:* *Do you know why they had been thinking like that?*
>
> *Kanit:* *I think because I didn't talk to them. I wanted to talk to them, but it was difficult for me to explain things to them. [Kanit, 1st interview]*

Kanit found it difficult to recall his work knowledge from his days as a government officer working in a team creating and writing projects to develop the rural areas. He said:

> *"I started to forget people's names, things names, also the book and some of the knowledge I had." [Kanit, 1st interview]*

I sensed that it was not only the physical impact of what he was coping with but also the psychological impact which made him feel sad and stressed. He was aware that dementia had changed his abilities. He preferred to stay home all day because he was worried that one day, he might forget the route to a familiar place. His wife and son assisted if he needed anything. Although he still had the desire to go out and do activities he used to do, he found it challenging to engage in society. He stated:

> *"I could drive before. Now I cannot drive. In the past, I could drive a pickup truck, motorcycle. Right now, I cannot drive them anymore, I had already sold my pickup truck and gave my motorcycle to my cousin." [Kanit, 2nd interview]*

In this statement Kanit thinks back on his previous expertise. However, all is changed, and he has lost many of his abilities. Occasionally, his son would take him out somewhere, but they have little time to be together because his son is busy with his work.

Kanit revealed how difficult it is to live with his condition as he has lost almost all his capacity to live independently.

> *"I have to spend a long time to think. Sometimes I could not figure out. (He pointed to the post-it on the wall) Like these, I used to know them, I know their name, I know their work and their house. They taught me before. Now I forget all the content they taught me." [Kanit, 2nd interview]*

Kanit has to cope with his loss of cognitive ability, he thinks slowly, he has language deficiency. During the interview, he spoke slowly and sometimes had to pause to think about what he wanted to say. All this impacts on Kanit's social participation. He cannot go outside to join with his friends as in the past.

In summary, cognitive decline impacts on the PwD's ability to remain engaged in society. While older persons are still able to participate, they may need encouragement and support to do this. Being socially included enhances the persons sense of love and belonging and their self-esteem and it also provides opportunities to enhance the older persons cognitive skills. The participants in this study recognised that dementia impacted on their social well-being but nonetheless they still want to be included and engaged in society.

6.3.2 Somebody to talk to

PwD reported that they needed somebody willing to talk to them and listen to them patiently. This section presents the experiences of PwD on having company to fulfil their feelings of loneliness even though they might be living with their family. Having somebody to talk to enhanced their social and emotional well-being.

6.3.2.1 Joyfulness vs. Loneliness

The need to be engaged in society varied among the participants. Some were excluded from social interaction by others, but their family encompassed them. Whereas other participants were also excluded by their family. This section describes both these experiences. The stories told are helpful in increasing an understanding of why PwD need somebody to talk to.

> a) Joyfulness: Family embraces the older person with early stage dementia within the family

Being encompassed with children and grandchildren made many participants feel full of happiness. Tassanee and Wannaporn both had children and grandchildren living around them, and both families were willing to take care of them. So while dementia reduced their social interactions, they still had their family support.

After Tassanee became confused, she found it difficult to communicate with other people. Thus, her participation in society was reduced because she did not want to talk to others. She was afraid that other people would not understand her when she spoke.

Throughout my three visits to her, I observed that Tassanee was friendly, and she appeared happy to engage in conversations. However, she had realised that she was confused at times, that she had repetitive behaviour, and this made her feel afraid to talk to other people because she thought that her symptoms would annoy others. Sometimes she blamed her family members for her dissatisfaction with things and sometimes for the way they did things. Sometimes there was no reason at all. On occasions she used inaccurate words and sometimes she spoke nonsense. This made her reluctant to communicate. Although there were older people living next door to her house, she did not want to talk to anyone apart from her family because she was afraid of annoying others. She said:

Nittiya: *I feel you are chatty. Do you like to talk?*

Tassanee: *Yes, I like to talk.*

Nittiya: *So, do you talk to somebody, like the neighbour?*

Tassanee: *No, I don't go outside that much.*

Nittiya: *Why don't you go out and talk to somebody?*

Tassanee: *I feel that I would be confused when I speak.*

Nittiya: *Could you please explain more to me about the feeling of confusion?*

Tassanee: *Sometimes, I speak wrong. I'm afraid that they will not understand me. I'm afraid they will blame me that I'm clueless. Therefore, I think I should be at home with my children. However, I still want to talk to them.*

Nittiya: *Is there anybody who comes to talk to you?*

Tassanee: *No. There is nobody that comes to talk to me. They are living on their own. [Tassanee, 1st interview]*

Tassanee's dementia symptoms were affecting the relationship between her and the neighbours. She did not want to participate in society because she recognised that she sometimes speaks inaccurately. Although she is afraid to converse with others, she interacts with her family, which enhances her sense of inclusion in the family.

Similarly, Wannaporn, living with her son and two of her nieces within the same fenced boundary had good relationships with her family. One of her nieces has a mental health issue and was at home. The other niece had retired from her job to look after her sister. I saw Puchong and his cousin help one another to look after Wannaporn and her niece. Her niece would come round to talk to Wannaporn every time I visited. During my second visit, her nieces returned from hospital and Puchong ran to help his niece with her sister who was unable to walk. They helped her sit on a wheelchair and Puchong pushed her wheelchair into the house. Wannaporn also said that sometimes Puchong goes to the hospital to collect medication for her niece. If Puchong ever needed to travel for work to Bangkok, Wannaporn's niece would come to take care of her.

Although Wannaporn could not go out to participate in social activities because of her physical limitations, she still has her family to talk to and who listen to her. The family relationships were good and in the past Wannaporn had contributed to the family reinforcing the good relationships.

Being embraced by the family, as in Tassanee and Wannaporn's situations, can meet the need for love and belonging. The relationship in the family connects to the feeling of being safe. It also helps older persons be touched by family love.

b) Loneliness: PwD feel being ignored by their family

Although the participants were living with family, some of them felt lonely. This can happen when PwD is excluded or ignored. However, some families did not do this deliberately, it was just a fact of the demands of life.

For example, Palapol who lived with his wife who had advanced stage dementia. Although his son comes to care for his parents daily, Palapol was lonely as his wife was unable to engage in conversation. Palapol kept the television on for the company and watched it almost all day. Sometimes he turns it on and sits on the sofa with his wife. They watch it together and sometimes sleep in front of it. He said that he felt lonely.

> *Nittiya: Well, you told me previously that you feel lonely due to the fact that you don't have anybody to talk to, right?*
>
> *Palapol: Yes, I feel lonely. I don't know what I should do. I just live day by day, as normal. I have the television as my friend, if I were to feel lonely, I would just turn it on. Other than my wife, I don't know who else I can talk to, and if I go out, my wife would have to be alone, but if I take her with me, she is clueless and could disturb others. [Palapol, 3rd interview]*

He mentioned that when he feels lonely or gets bored, he goes to the grocery shop and he has a cup of coffee. In the past, he would go out with his wife, but these days he finds it difficult to take her with him as she wanders. Thus, he needs to be present with her and he just watches the television at home. If he wants to go to the grocery shop, he has his coffee and makes small talk with the shop owner and the people there, and he returns home. He said:

Palapol: *I do not go anywhere; I'm always at my home.*

Nittiya: *Hmm, don't you go out to talk with somebody around this area?*

Palapol: *I go out sometimes, when I feel annoyed, I would walk out to get a cup of black coffee.*

Nittiya: *Can you tell me more about your feeling of annoyance?*

Palapol: *I feel annoyed because sometimes I have nobody to talk to. I only watch television every day, and that makes me bored sometimes.*

Nittiya: *So, why don't you go out to talk with your neighbour?*

Palapol: *Oh, I do not talk with them every day, I don't know what to talk to them about. If I wanted to talk, I would go the shop where they have black coffee. I usually come back home when I finish my coffee. [Palapol, 3rd interview]*

Many participants said they felt lonely at home all day and they do not have many activities to keep them occupied. Palapol was frustrated because of this. He was at home because he was looking after his wife. Watching television did not solve his feelings of loneliness.

Older PwD needed someone to talk to, somebody they could share their feeling with and express their opinions. Palapol wanted someone to talk to him and he enjoyed my visits:

Nittiya: *How do you feel about the fact that I am here talking to you; do you feel annoyed by me?*

Palapol: *Oh, no. I don't feel annoyed. It's good that you came to visit me and talk to me. I would like you or the doctors to come whenever you want because I will have a friend to talk to. (laugh)*

Nittiya: *In terms doctors. Who would you like to come and talk to you? Would you want to include healthcare providers and other relevant medical staff or somebody else?*

Palapol: *Yes, I mean whoever can talk to me (laugh).*

Nittiya: *So, you do want somebody to visit you and to talk to you, do you?*

Palapol: *Yes, it's good to have friends. [Palapol, 2nd interview]*

Pilaiwan, with the difficult relationships with her family also needed somebody to talk to:

> *"Just talking to someone is good. It's good to have somebody to listen to me and understand me. I didn't pretend to be like this. I don't know whether they understand or not. I just try to get used to it because I live with them." [Pilaiwan, 3rd interview]*

Although Pilaiwan lives in the house with her sister and nephew, it was like she was living alone. Her sister leaves for work in the morning and returns at 8 in the evening. When Siriporn arrives home, she goes upstairs to her room and leaves Pilaiwan to watch television and eat her meal alone. Pilaiwan's family were deliberately avoiding her and she felt alone.

> *"I always eat alone. They will take their food to eat on the high floor. I eat on the ground floor. If there is some food left, I will leave it in the fridge. Sometimes my sister asks me if I want to warm the food. She will warm it for me as she has the microwave on the high floor. Sometimes I forget what food I have. Look! I am like this. I have no good memory. I accept that I have a memory decline, so that why I don't want to go out alone. I'm afraid to get lost." [Pilaiwan, 4th interview]*

PwD need someone to talk to and someone to listen to them. I reflect that this not only fulfils the need for love and belonging, but it also fulfils their self-esteem needs. In summary, being heard and attended to allows the older person to feel valued.

6.3.3 Living in a familiar environment

Living in a familiar place, surrounded by others they know, supports the PwD to feel secure. Some of the participants had to move from their homes to be supported by their children living in a different area. The need to live in a familiar environment is crucial in older people with early stage dementia because it links them to their past lives. This section presents the stories of older persons and their experiences of living in a familiar environment as well as those who have had to move to live in a new place.

6.3.3.1 Living in a familiar environment vs. Moving to live in a different place

a) Living in a familiar environment: feeling familiar with neighbours

Many of the participants living in the rural areas stated that their relationships with their neighbours was good. They felt people in rural areas were generous, exchanging food and conversations. For example, Chompoo's house is a grocery shop and customers come into the shop to buy goods and talk as if they know one another well. While we were talking during the first interview, a customer came into the shop to buy some goods. The customer greeted Chompoo and they exchanged small talk. Chompoo smiled and told the male customer that she was being interviewed. They spoke for about two minutes before Panthip told him not to disturb Chompoo because I had come from the hospital to interview her. The man understood and then left.

Chompoo lives with her daughter in her hometown while her sons live in the city. She misses her sons. They come to visit her occasionally because they are busy with their work. Her children understand that she wants to see and meet them often. Sometimes, Panthip drives her to stay with her sons in the city, or the sons come to see her to stay with them. They understand that Chompoo misses them and they try to attend to her need to see them. As she expressed:

> *Chompoo:* *They should allow me to enjoy my pleasure as I want. My son wants me to live with him and his family in the city, but I don't want to because I would feel lonely. I prefer to live in my house even though it's in the rural area.*
>
> *Nittiya:* *Could you please tell me more about why you would prefer to live here, but not with your son in the city?*
>
> *Chompoo:* *I feel uncomfortable, I don't know how to explain it. I don't like it there. My son is always busy, he has lots of work; he is a teacher in the city. [Chompoo, 1st interview]*

Although she misses her sons and wants to spend time with her children she prefers living in her hometown as she knows the area and the people whereas in the city she would not.

b) Moving to live in a different place: moving to live with children

Some participants had moved to a new place to live with their adult children to be supported. Although they were happy to live with their children, they missed life in their hometown because they did not have many friends in the new environment.

For example, Pimala had moved from the rural area where she had lived since her childhood to live with her daughter in the city. This had happened about a year after Pimala had received a dementia diagnosis. Before this, Pimala had lived with her daughter-in-law and grandson. However, Pimala's daughter decided that she should come to live with her because it is a child's responsibility to care for their parents. In addition, Pimala's daughter's house in the city was convenient to access the hospital.

The ambience of the rural areas is different from that in the city. There are small villages in the rural areas, and people living there know one another. Pimala remembered people calling out from the street to greet her as they passed by her house. Sometimes she would be given vegetables, and she said that sometimes she also exchanged food she had with others. However, now in the city she does not know her neighbours and they do not know her.

> *"I think there was good for me. Wherever I go, or whoever walk past my house, there would call me. They know who I am. Unlike here, I don't know them, and they don't know me. If you want to talk to somebody, you have to know each other first." [Pimala, 2nd Interview]*

Pimala is a friendly person. Every day she sits on a wooden sofa and looks outside. Although people come to talk to her daughter and to her sometimes, she does not feel familiar enough to speak to them, and she is also hard of hearing.

> *"Here I don't have a cousin. I don't know who they are. So, I don't know what I would talk to them. I sit here every day, I saw people walk past this way, but I don't know them. I only look at them." [Pimala, 2nd Interview]*

During my second visit a neighbour came to talk to her daughter, and she could have joined in the conversation, but she could not hear. On my third visit another neighbour on his bicycle stopped in front of her house, he was deaf-mute, and they greeted each other with a smile, as conversation was difficult.

Moving from their hometowns to live with children in a different place is meant to help the PwD feel safe because they will be with their family. However, in doing this the older person lost all their friends and familiar neighbours and it limited their activities because they were afraid to go out alone. Pimala moved to live with her daughter in the city and she is well supported by her daughter. However, the new environment is unfamiliar, she does not have friends and although the neighbours are good people, she does not feel close enough to them to talk to them.

C) Moving to live in a different place: the family wanted the older person to live in a residential home setting

Concerning Pimala, although she wanted to live in her hometown, moving to live with her daughter meant she had support. While some participants wanted to live with family, the family did not want them to live with them. They wanted the older person to live in a residential home setting which is rare in this this province and will be discussed in

Chapter 7. Living in a supported environment links to the PwD's sense of safety needs, as well as love and belonging and their need to be part of a supporting family.

Pilaiwan, a single woman, living with her sister Siriporn and nephew Virut was physically and verbally threatened by her nephew who did not want her living with him and his mother. Her sister was also not very welcoming. The situation was very unpleasant but Pilaiwan put up with it as she did not want to live elsewhere.

Pilaiwan's nephew and her sister would have preferred to send Pilaiwan to live in a residential home. The nephew threatened to evict her, and often repeats that he does not want her living with them as she stresses his mother, but she does not want to leave so they continue to argue when they meet. He has even said she should be in a psychiatric hospital. Pilaiwan is very hurt knowing her sister is stressed and that she is unwanted.

Siriporn and her daughter told me that they want Pilaiwan to move to a residential home to relieve the family stress and give Pilaiwan a new atmosphere to live in. Pilaiwan was afraid in her current situation and kept repeating that she was concerned about the family members hating her and wanting her out of the house. She was sad and said she felt like the third wheel in the family. She felt she a burden to her sister; they do not even take their meals together.

> *Siriporn and daughter:* *We want her to try to go there (residential home). She may get some new friends and see what other people do because I think they will have some activities for older people to do and relax. Just for changing the atmosphere.*
>
> *Nittiya:* *Yes. The relatives must sign the contract to ensure that they will not neglect and let the older person lives there. Moreover, it depends on Pilaiwan, whether she will go or not.*
>
> *Pilaiwan:* *(Pilaiwan shakes her head) I don't like to be there. I don't like if there will be somebody to look at me. I find difficult to get along with other people.*
>
> *Siriporn:* *We only want you to change the atmosphere, and to get some friends. Maybe other people will understand you more than people in the family. You might be happy. I know she will not go (Siriporn turned to say to me). [Pilaiwan, 2nd interview]*

At the time of the interview Pilaiwan had capacity to decide where she preferred to live and her sister was able to take care of her as she was still not fully dependent. I was concerned about Pilaiwan's future for when her dementia would progress. I also referred Pilaiwan to the head nurse in the Dementia care clinic for referral to the home visit centre.

Pilaiwan insisted that she would not go and live in a residential home because she does not like to live with others. She would feel uncomfortable to live in a place that was not her home. She acknowledges that she is a burden to her sister who must take care of her. Pilaiwan accepts that she must rely on her sister because she cannot do things on her own and she is grateful to her sister.

The family situation was also difficult for Nantana whose family did not pay her much attention. On one of my visits to the family home Nantana's daughter asked me about the information on placing her mother in a residential care setting. She spoke to me in front of Nantana and appeared to be having difficulty taking care of Nantana. Nantana said that she felt she was a burden to the family and was being neglected by her children. Her daughter who was listening stated that Nantana always thinks that nobody loves her. Sometimes, Nantana thought that it might be better for her if she moved to live in a residential setting because she needed somebody to look after her. I was not sure if she was saying this because she really meant it or if she wanted to provoke a reaction from her daughter. I asked Nantana about going to live in a residential home setting.

> *Nittiya:* *So, have you ever thought about living in the residential care home?*
>
> *Nantana:* *Yes, I want to live there too.*
>
> *Nittiya:* *Could you please tell me why you want to live there?*
>
> *Nantana:* *Living at home makes me feel hurt. I have many diseases. (crying) Look! My teeth are almost gone through. I don't have them for chewing. Can you help me?*
>
> *Nittiya:* *How could I help you?*
>
> *Nantana:* *Help me about the place to live, care and money. I don't have money.*
>
> *Nittiya:* *Could you please tell me more about why you want to live in the residential care home?*
>
> *Nantana:* *I'm bored. She (Arunee) is not my child (referring to her granddaughter-in-law). Also, this house is rented. If she goes away, where I can live. I can't walk. She doesn't allow me to speak anything. Moreover, my son neglects me.*
>
> *Nittiya:* *Hmm. Do you know how people will be taken care of in the residential care home?*
>
> *Nantana:* *I don't know.*

Nittiya: *Then, why you want to be there?*
Nantana: *I don't want to be at home.*
Nittiya: *Can you live with others?*
Nantana: *Do they provide good care of me?*
Nittiya: *Hmm, how do you think about this?*
Nantana: *I just said like that. I'm too afraid to leave home. [Nantana, 4th interview]*

From my many visits and interviews with Nantana, I reflected that although she was living with her family, she was not receiving good support. She was having to deal with very difficult family relationships. Once Nantana expressed about she did not want to be at home, I went to find out about her being able to move to a residential care home. There were two public residential care homes in the area where she lives. However, both settings would only agree to accept older persons who were without a family and living alone, or, those with a severe problem with family members like Nantana, but the older person would need to be assessed to confirm that they are independent and have no mental health issues. They would be referred to other organisations for support if they did not meet these criteria. After I had reported Nantana and Pilaiwan's issues to the head nurse at the Dementia Care Clinic, I also consulted with the social care staff working in the municipality and referred Nantana, Pilaiwan and their families for help from this service.

Different reasons for moving to live in another place can affect different feelings of persons. Some participants were told by their family member that they should move out to live in the residential home or the psychiatry hospital. This can make them feel that they are a burden or a problem for their family. This negative action can impact psychological symptoms.

From the stories and excerpts relevant to the impacts of dementia presented above, it can link to how people perceive dementia. The participants who have a feeling of being a burden have to confront the difficult situation in the family. Although they live with their family, sometimes the family members can cause the participants to feel that they are a burden for the family. They might have a combination of good and difficult moments during living in the family. However, they prefer to be with their family, although they might feel lonely even though they are with the family. To maintain personhood, 'companionship support is necessary' to enhance the PwD to fulfil the need for comfort, attachment, inclusion and occupation.

6.4 Meaningful activities need to be maintained

Although older persons with early stage dementia need positive support, to be understood and respected by their families, they still need independence and to be able carry on with their lives. Further, they do not want to be a burden to their families. The participants were proud that they were still doing their routine daily activities, they did not perceive the dementia as a serious condition and many were more concerned about their other health conditions like diabetes mellitus, osteoarthritis, or spondylosis as these had a more immediate effect on their lives than dementia or Alzheimer's disease.

Although dementia does impact on their life in various ways, they regarded dementia as only a part of their lives. They dealt with their decreasing mental and social capacity much like they dealt with their physical limitations. Maintaining meaningful activities are important to all older persons including those with early stage dementia as they enhance a sense of self-worth and self-esteem and to retain their identity.

Meaningful activities in this study include physical, social, and spiritual activities, which PwD need and choose to engage in. They can be divided into three main activities, everyday activities; activities that they used to do in the past; and religious activities. This theme presents the different experiences of PwD in performing their activities while acknowledging that they had been diagnosed with early stage dementia.

Some PwD continued living normally and did not notice any changes in their lives, whereas others stated that their everyday lives had changed, but they still needed and wanted to do the activities they had done before. The overall needs and experiences of PwD related to meaningful activities is presented in Table 6.4.

Table 6.4 Experiences and needs of PwD related to meaningful activities

Meaningful activities need to be maintained				
Experiences of PwD in receiving support from family		**Code from experiences and perspectives of PwD**		**Needs for living well with early stage dementia**
Life carries on - Having the ability to perform activities by oneself (everyday activities, activities in the past, religious activities) (PwD_01, 03, 04) - Everyday life has changed but PwD receiving support (PwD_07, 13, 10, 15, 16)	→	Being encouraged	}	Continue living normally as before getting dementia diagnosis (Physiological) (Self-esteem) (Self-actualisation) *(Comfort)* *(Inclusion)* *(Occupation)* *(Identity)*
Life struggles with the impact of dementia - Everyday life changes and family disempowered PwD (limited activities) (PwD_02, 05, 06, 08, 09, 11, 12, 13, 14)	→	Being controlled	}	Needing a chance to do things they used to do (Physiological) (Self-esteem) (Self-actualisation) *(Comfort)* *(Occupation)* *(Identity)*

6.4.1 Continue living normally as before getting dementia diagnosis vs. Needing a chance to do things they used to do

The need to continue living normally is related to the older persons perception of dementia and how the dementia impacts on them. This section illustrates the different experiences of PwD; the experiences of those for whom life carries on and the experiences of persons who are struggling with the impact of dementia.

6.4.1.1 Continue living normally as before getting a dementia diagnosis

Persons with early stage dementia who do not have any severe physical limitations are able to carry out their everyday lives independently.

a) Life carries on: being encouraged

Most of the participants carried on their lives as usual after receiving their dementia diagnosis, even those participants whose cognitive decline had already resulted in some changes in their lives. Most participants stayed at home all day preferring to do their activities in places where they can rest when they needed to and where they felt comfortable. Most are still able to maintain basic daily activities as older people generally do. Some participants connected to friends and other family using technology like a mobile phone.

Everyone has their routine. Those able to do the housework continued their activities while other participants' children managed this for them. Some gave food to the monks in the early morning while others started the day drinking coffee, soya milk, or chewing betel nuts. During the day, many of the participants watched television. Some participants went outside and spent time with family and friends. Those participants went out to talk to others while those that had no-one sat and looked outside.

Some participants who were unable or struggling to do their everyday activities were sometimes encouraged by their family to do more things, but with their supervision. This helped the PwD feel partly independent because although they had cognitive decline, they still had physical well-being. If they can perform physical activities and carry out social interactions, this improves emotional well-being. Those participants who had physical health conditions which limited their physical functioning sometimes looked for other activities to do and sometimes family were helpful in assisting them finding meaningful activities.

In the Thai cultural context, religious belief was something that the participants referred to as being an important aspect in their lives. The temple or religious community is an important source of social support apart from family and neighbours.

Aorasa gives alms to the monks every morning and attends the temple on all the Holy days. Her daughter prepares food and flowers for her to give to the monks early every morning and takes her by motorcycle to the temple on all the Holy days. Aorasa was a handicraft teacher and her long-term hobby is knitting so her daughter buys colourful yarn and accessories for her hobby. Aorasa was very happy knitting, doing it every day. Sometimes her daughter had to remind her to stop and rest or do other activities. Her daughter supported her but also tried to balance her activities. I had a chance to talk to her daughter who said that she had to confront and accept her mother's illness a long time ago and has tried to understand her dementia symptoms and how to cope with them. However, she still finds it difficult because her mother is sometimes emotionally unstable and for example would sometimes insist on knitting all day and not do anything else.

Aorasa said something leading me to understand why attending the temple had meaning for her; it was essential that she continued as she had been going since she was a child.

> *"Oh! I cannot miss this. I have been doing this since I was young. I went to the temple with my parents. Originally, I was always accompanying them. Later, they were too old to go to attend the temple, so I went alone, and I like this." [Aorasa, 2nd interview]*

Although she did not talk to other people, she seemed not to worry. This activity positively influenced her emotional and spiritual well-being. She prefers to continue doing the activities which have much more meaning for her. Many Buddhists practice and live according to the teachings of the religion. However, while some participants were interested in religious activity and they wanted to practice, they could not attend because of their physical limitations. Each participant is different in terms of managing their life to practice what they believe.

Dararat, she worried about her symptoms because she was still working as a seller in the market and she realised that her symptoms were affecting her ability to work. She was struggling with the calculations and remembering the cost of goods. She also worried that the customers and her family would blame her for getting things wrong.

> *"I am still faced with it. For example, there was a customer came to buy garlic, and I could not return a change to him. I called my employee to help me calculate the money. She told me I did wrong. You know, in the past I did not need to use a calculator, but right now even though I have a calculator, I still get confused. Sometimes, when I have a conversation, I forgot what I have to say next and what I have talked about." [Dararat, 2nd interview]*

It is good for Dararat that her family understands and supports her. She still goes to work at the market with her family, but she no longer sells the goods. She only looks after the shop but at least she can maintain her social activity by having conversations with her family, employees, customers and some of the sellers near her shop. When her husband and son go out to deliver the goods, Dararat remains in the shop with the employees. She is able to talk to the customers and she does attempt to sell the goods. Dararat told me that she was *'not fluent as before'*. She said that on one occasion one time when she gave an inaccurate price and the customers questioned it, her employees helped her and told the customer that she has a problem with her brain, and the customers appeared to understand this.

Usually persons with early stage dementia are not affected physically. They tend to lose their physical abilities at a later stage, as the brain deteriorates. Regarding the stories many participants shared about the impact of living with dementia, they reported that they can still perform everyday activities, although some of them must rely on their family members to engage in other outside activities. Other than this, they mostly live as usual.

For example, Naree, still rides her motorcycle as she did before getting a dementia diagnosis. She said that she had been riding it for a long time, it feels familiar, and as she still able to do it, she prefers to do it for as long as she can. Naree keeps up all her daily living skills, even the more complicated ones like riding her motorcycle. She said:

> *Nittiya: Well. How do you feel that you still help yourself?*
>
> *Naree: I can look after myself. I can go everywhere by myself.*
>
> *Nittiya: How do you feel that you still go to many places by yourself?*
>
> *Naree: I am proud that I still do many things by myself. While some people with a similar age to me cannot do. [Naree, 3rd interview]*

To link Aorasa, Dararat and Naree's situations to the basic needs, their keeping up of activities with the support of family, helps these older PwD to meet the sense of self-esteem because they are still able to perform activities independently. Also, some activities fulfil their sense of love and belonging because they can engage in society. However, the family needs to balance encouraging PwD to maintain their abilities with supervision while still being concerned about their safety in some activities.

6.4.1.2 Needing a chance to do things they used to do

Some participants spoke about being discouraged from doing activities by their families. If the family over supports the older person, this limits their ability to do many activities themselves. This can happen if the family lacks knowledge and understanding of their older family members dementia symptoms. The family then becomes stressed and this can lead them to control and limit some activities that might have a meaning for the PwD.

If a family only thinks about their own pressures and do not validate the feelings of the PwD, this can undermine the PwD's ability to be independent. To attend to the needs of the PwD families need to be willing and know how to take care of their older family member. Lack of understanding about dementia can lead families to act in ways that negatively affect the PwD's feelings.

This section presents the experiences of PwD who are controlled by their families and do not get the chance to maintain their meaningful activities.

a) Life struggles with the impact of dementia: being controlled

Many of the participants think back to the time when they worked throughout their adult lives and how much a part of them this was to them. Like, Rattana, who grew up in an agricultural family and who herself worked as a farmer to provide for her children. Her son-in-law work is also as a farmer. Rattana and the family have rice and fish farms and they grow other produce in the agricultural fields. Although Rattana has early stage dementia, it has not affected her ability to work. She is however old, she has a kyphosis and her children are worried about her, so they have stopped allowing her to walk to the farm even though it is not far from her home. She has found it difficult to stop working.

Rattana's children want her to relax and be comfortable as they think she is old, and they believe that she does not have to do anything because they want to do it for her. Although Rattana wants to go for a walk outside to look around her vegetable garden where she had planted in the past, her children were concerned for her safety as they are afraid that she could fall when she is out walking. As she expressed:

Rattana:	*I want to go out to see my vegetable garden, but they don't let me go.*
Nittiya:	*Do you want to go there? How you can go there?*
Rattana:	*I can walk there by using a walking stick.*
Nittiya:	*Can you go there, where is it?*
Rattana:	*Here, it is near.*
Nittiya:	*Ah, but why they don't let you go.*
Rattana:	*There is a pond. They are afraid that I will fall into it.*
Nittiya:	*I see. Did you go before?*
Rattana:	*Yes.*
Nittiya:	*What did you go for?*
Rattana:	*Oh! I was there. I walked there with my walking stick to look for what I can pick for cooking. Presently, they don't let me go, I think perhaps for about 2 years.*
Nittiya:	*Hmm, they would worry about you. [Rattana, 2nd interview]*

I was aware from our conversation that visiting the place where she used to spend her life was meaningful to Rattana as it was a part of her life. I noted that it would not be too difficult for the family to take her with them because the son-in-law goes to the farm every day. She remembered the route to the farm and her agricultural skills. The possible reason the family limited where Rattana could go was because while the family knew she wanted to go out they were too concerned for her safety. They were ignoring her wishes. Some older people like Rattana were disempowered because they are prevented from doing the things they like to do. The consequence of this is that this undermines the PwD's feelings of well-being.

Some participants were prevented from doing religious activities as they had done in the past. For some it was because of their dementia and for others their dementia and their other health conditions. Pilaiwan's family limited her religious practices. She said:

> *"I chant every day, but when he comes back, I'm too afraid to chant upstairs because my sister complains that they don't want me to light up the incense sticks and the candles. She said that she worries if I will forget to blow out the candles. She worries a fire will burn the house. I then think too much that hmm… maybe my nephew told her this. He came to live here about 2-3 months ago, so I only chant before going to sleep." [Pilaiwan, 3rd Interview]*

Pilaiwan said that she was not allowed to chant as before. Chanting is however her preferred religious practice and she does this every day. Presently she must chant without lighting up candles and incense sticks because Siriporn worries she may forget to put out the candles and set fire to the house. So she chants in her room where she sleeps on the ground floor of the house, but the Buddha statues are on a shelf on the upstairs floor, near the nephew's room, and he does not want her to walk up there.

> *"Right now, I stop to light up the incenses and candles anymore because they do not allow me to. So, I only chant in front of the Buddha statue without the incenses and candles." [Pilaiwan, 3rd Interview]*

Pilaiwan was sad however she had to accept the restrictions because she needed to live with her family in their house. Religious practice is a necessary practice for her. She had adapted her activity and chants without lighting up. Pilaiwan's situation was difficult and it was hard for her and the family to reach a compromise to allow her to continue chanting and maintain her spiritual well-being. The final solution was not completely satisfactory, Pilaiwan was still able to chant but it is different, and this impacted her emotionally.

Participants had their own individual meaningful activities, but it is important to encourage them to participate in activities that they enjoy and maintain their abilities. Where participants were limited from engaging in activities, they experienced negative emotions. This most often happened in families who lacked knowledge about dementia symptoms and their progression but also more often in families who were caring because they felt obliged to do so.

Sometimes families unintentionally criticised the work done by the older PwD. For example, when the older PwD was unable to do the housework as well as they had done it previously, family members criticised them, and did not want them to do it again. Although the family member might not think anything of their criticism it often affected the older person's emotional well-being and they felt they had less value in the eyes of others.

While Ngamta's daughter encouraged her to participate in social activities to maintain her social well-being, her daughter does not want her to do kitchen activities because she does not do it to her daughter's satisfaction.

> *Nittiya:* *What do you do after doing exercise?*
>
> *Ngamta:* *I would go back to do chanting. If it is the Buddhist Holy Day, I will attend the temple. I don't like to stay still. I would have lunch in the late morning and take a nap. I don't sleep for a long time because I cannot sleep long during the day.*
>
> *Nittiya:* *Hmm. What would you do after you wake up from taking a nap?*
>
> *Ngamta:* *There is nothing to do. I might sweep the leaves from the floor sometimes. I don't like to sit without doing anything.*
>
> *Nittiya:* *Hmm, but there is nothing to do so, right?*
>
> *Ngamta:* *Yes. I only search for something to do. My daughter doesn't want me to wash the dishes. She said I do not clean them properly. I don't know because I didn't see clearly.*
>
> *Nittiya:* *How did you feel when she said that?*
>
> *Ngamta:* *Oh! I don't know how to do it because I didn't see clear. Then, I let her clean all.*
>
> *Nittiya:* *Do you still want to do it?*
>
> *Ngamta:* *I want to do it, but she said it isn't clean when I wash. Also, my hands don't work like before. In the past, I could hold and carry heavy things, unlike now I cannot carry things for a long time because they will fall from my hands. [Ngamta, 3rd interview]*

At the time of the interviews Ngamta was not doing any housework or kitchen tasks. Because her daughter was concerned about her safety. She was either doing it herself or employing someone to do these tasks for her mother. Ngamata was still capable of doing some of the tasks and she felt undervalued. In addition to this, over time, she will become less capable as she will lose confidence in undertaking the tasks.

The family influenced all parts of the PwD's life. Before the older person could undertake an activity, they needed to ask their children's permission, whether they had capacity or not. Older people in these situations do not have the freedom to make their own decisions.

To conclude, this theme explores the perspectives of PwD in relation to maintaining their meaningful activities for as long as possible. This theme also links to the theme on the need for companionship because some meaningful activities involve PwD participating in society. If the family empowers PwD to continue doing their daily life activities, as far as is possible, it will enhance their self-esteem. Once the person with early stage dementia has enhanced self-esteem, this impacts on their emotional well-being. They are still able to perform activities independently and they are not fully a burden to their family. This could be the way of providing PwD with a sense of being valued.

All meaningful activities need to be practiced if they are to be maintained. This does require support from families because some activities need to be supported and supervised for the safety of the person and those around them and these include kitchen tasks, driving, managing medication and financial matters. In terms of personhood, this support can enhance the PwD to fulfil their need for comfort, inclusion, occupation and identity, once the PwD is able to fulfil their need for love and belonging and self-esteem, this will enhance holistic well-being.

6.5 The nature of life needs to be accepted

The PwD are from different backgrounds and situations and this influenced their perspectives on how to live well with dementia. Regarding the ways they received support from their families, some PwD were satisfied with their lives, while others were disappointed. However, whatever their experiences, in keeping with Thai religious teaching, all participants accepted that they cannot escape the nature of human life. Thai Buddhists believe in the circle of human life. You are born, you will get old, you may have illnesses and you cannot escape death. These steps are the life cycle. Nothing is forever, so people should not attach to things, people or feelings that cause suffering. Older people admit and accept that one day they have to die.

This theme presents the perspectives of the Thai older persons living with early stage dementia on the needs for 'being well', related to their experiences in keeping on living well, with the aim of maintaining and enhancing physical, psychological and social well-being, and with an acceptance of whatever will be will be. The overall needs and experiences of PwD relating to the belief in the nature of life is presented in Table 6.5.

Table 6.5 Experiences and needs of PwD relating to the belief in the nature of life

The nature of life needs to be accepted				
Experiences of PwD in receiving support from family		**Code from experiences and perspectives of PwD**		**Needs for living well with early stage dementia**
Keep living well • Try to be independent (do not want to get worse) (PwD_01, 03, 04, 07, 08, 09, 10, 15, 16) • Nothing to worried about (PwD_01, 02, 03, 04, 06, 07, 08, 10, 13, 14, 16)	➡	Keep living well	}	Being well (Self-actualisation) *(Identity)*
Acceptance of the transience of life • Acceptance of the transience of life in the past and present (PwD_01-16) • Feel sufficiency with life (PwD_01, 02, 03, 04, 06, 08, 09, 11, 12, 13, 14)	➡	Whatever will be will be		

6.5.1 Being well

The need for being well links to the PwD's perspectives on coping and searching for ways to reach self-actualisation. Although dementia impacts the PwD, they need a positive approach and accept that they are still alive and what is happening to them is related to the transience of life. Something has happened in their lives, they cannot change it, they attempt to accept it and live with it as well as they can.

6.5.1.1 Keep living well vs. Whatever will be will be

During my fieldwork, I found that all participants were still able to perform their basic everyday activities. Although the dementia was impacting on their lives, some older persons view dementia as a chronic condition that has happened to them at their advanced age and is a part of their life. They expressed that keeping physically, psychologically, socially and spiritually well would empower them to be valued and to live fully every day.

Some PwD were not empowered to live and continue an independent life as they had before getting a diagnosis but still they attempted to view life positively. Something had happened in their lives, they were unable to change it, they accepted it and lived with it as best they could. This section presents the PwD's experiences on how they 'keep living well' and the perspectives of PwD on acceptance of the transience of life as 'whatever will be will be'.

a) Keep living well

This perspective is related to the need for the PwD to maintain meaningful activities, but it does not only focus on the need to do physical and social activities. This perspective seemed to connect with the spiritual and philosophical beliefs which can enhance the PwD to feel content with their life whether they still had, or were losing their sense of self.

PwD normally live in the early stage of the disease for about 1-3 years. Some PwD taking part in my study had lived in early stage dementia for approximately 3-5 years before I met them. They were still living normally. They did not know what would happen to them in the future, or when their condition might worsen. They did not overthink their problem, and this might have helped them not to stress and live as normal a life as they always had. I sensed that the way they accepted their dementia may have helped them cope with it.

Chompoo attempted to search ways to maintain her early stage disease for as long as possible. She knew that she had dementia, and she understands that one day dementia will reduce her ability to live normally like her sister, who was living with advanced stage dementia. She accepted what has happened to her; she did not stress herself because she did not know what would happen to her in the future. At the time I interviewed her, she was still able to look after herself and participate in the social activities normally. She reported that she was forgetful, that she was aware something was different, but it was not a big change for her.

She practiced her religious activities, prayed every day to keep calm and she felt satisfied. She attempted to understand but did not think too much about her problems. As she stated:

Nittiya:	*How did you feel when the doctor told you that you have dementia?*
Chompoo:	*Nothing. I do not think about it too much. I accept it, then I would pray Budto, Budto. I pray every day except for that one time when I was sick, I would complain about it, because I could not pray.*
Nittiya:	*Hmm...Could you please tell me the reason for praying?*
Chompoo:	*I pray for happiness and it is a way to make merit. [Chompoo, 1st interview]*

As time has passed, I have begun to increase my understanding of how Chompoo and other participants maintained their capacity for living with dementia, as Chompoo expresses in the extract above. Her way to cope is to accept it, keep doing daily activities, and not to think too much about the problem. This may affect her ability to maintain well-being while living with early stage dementia. Although she fears the dementia progressing, she is still living well and believes that overthinking it may make her condition worsen. For Chompoo, spiritual care as a religious practice is needed to help her to face her worry and stress. Additionally, religious practice or spirituality beliefs can show the PwD's attitude to life because it helps the person cope with their life problems and illness. It can enhance their sense of psychological and spiritual well-being.

b) Whatever will be will be

According to the acceptance of the nature of life, many participants perceived that they are old and had their health conditions, so at this advanced age, they do not think that they can do anything more. Although older persons attempted to keep living well with early stage dementia, they thought that whatever was going to happen that they would accept and let it be. This view relates to their acceptance of the transience of life, they accept what has happened in their lives in the past as well as the present. The most important thing is that they feel their life is sufficient, they are still living and able to do things. Some people have nothing to worry about; they perceived that nothing is out of control.

As older persons had passed through many things in their life, their advanced age was a time to review their lives, look back on things that had happened and then look forward to what can happen in the future. PwD expressed that it is essential to think about the need for acceptance of the nature of life to enhance emotional and spiritual well-being.

Palapol had done many things to build his family up from nothing and now he has land and a house. He has also brought up his children to have a good life. Whenever Palapol spoke about his sons, I sensed that he was satisfied with them and also the way he had brought them up. Although only Pongsak takes care of his parents, it is clear that Palapol has a very tight-knit family. During the conversation, he clearly expressed his contentment with his life, and that he is happy with the rest of his life. As he responded:

Nittiya: *Hmm, are you happy now?*

Palapol: *Yes, I am. I can watch television. If I feel tired, I can rest, no need to do anything. I'm at the end of my life. I eat whatever I have and just live like any normal old people would live. [Palapol, 3rd interview]*

This excerpt leads me to reflect that if a person fulfills their life aspirations as well as possible, they might feel content, together with my conversations during in the field that many people said, 'to do the best today'. I sense that it is because if they do their best, whatever happens, they have done the best they could. Some people might feel sad if they cannot accomplish their goals while others are not, because they have already achieved it when they had the chance. It is relevant to the philosophical belief about fate.

Palapol is one of the older persons believing in this philosophical belief. Although he needs his son to support him, he lets everything happen as it would be, because he thinks that he is old, and is at the end of his life. Therefore, he accepts whatever will be will be, so he will not worry about anything. One reason that he does not worry about what will happen is that because he has his children to look after him and his wife.

Nittiya: *I've realised that your son takes care of you nowadays, but as an elderly PwD do you feel that you may need something more to maintain your well-being as long as possible, do you think there is anything else which is more important to you rather than what you are receiving now?*

Palapol: *Nothing, except if I were to be bedridden or completely dependent, then I would need for my children to look after me more than now. However, if they don't want to take care of me, I would just let it be, whatever will happen will happen and just let it be and soon the life would just end on its own.*

Nittiya: *Hmm, that means you accept whatever may happen to you right? Then could you tell me more on how you could be happy before you would ever become dependent?*

Palapol: *It would just be like any other normal old people's lives. Do not expect you to be happy all the time when you're old. We are deteriorating, whether it's the brain or our lives. Do not over think. This is what I think, I am not suffering so there is no need to be too serious with life. If you think negatively you will not be happy, if you think positively you will be happy. I accept everything as the way it is, because everyone will face old age or sickness one day. No need to want or request anything. If you think too much, it can lead to psychological problem. If I get bored, I just watch television. If you want too much or if you want to have many things, you might suffer. We should be happy that we are still able to eat, to walk, and we can still do everything by ourselves. [Palapol, 3rd interview]*

The above excerpt underpins Palapol's perspective on accepting the nature of life. Although Palapol has realised that he has dementia and he is experiencing his wife's advanced stage of dementia, he still perceives that dementia is normal for many older people as they can get it and that it is inevitable. He receives care from his son and finds it a little difficult living with dementia. He knows that his wife is in the advanced stages of dementia, but he does not imagine that one day he will be at the same stage as her. He believes in a life cycle that when he was born, he would get older, one day he would get sick, and then, at the end, he will die. Nobody can escape this cycle. Therefore, he lets it happen as whatever will be will be. Concerning the past, he has contributed generously to his family, he does not worry because he believes that his son will not neglect him and his wife.

Although older persons accept that this is a situation that they have to deal with, under the feeling of accepting this principle, some people found it difficult and questioned why this had happened to them or why it had happened at an inappropriate time. Although Kanit and Dararat felt sad after learning of their diagnosis, they knew they needed to accept it and to continue living as well as they could. However, Pilaiwan and Nantana had to cope with not only their dementia and their other chronic diseases but they also had family relationship problems; they felt sad about their situations, but they accept it because they perceive that they cannot do anything about it. They only let it be and face the illness.

The participants believed that acceptance of the nature of life is important. Once they had accepted this principle, they should prepare their life for the future as nobody knows when an event will happen. Several participants had already separated and given their treasured possessions to their children. Whist, many others had not planned, and others still had not thought about it. Normally, the child who looks after their parents and lives closer to them will receive more treasured possessions than other children living further away. However, this depends on the parents' preference. Some PwD like Chompoo, Ratana, Ngamta, Laiad, Pimala and Palapol had already divided their land and rice farms to their children as they preferred to manage this before anything happened to them. Palapol for example did not worry that after doing this his son would neglect him. He was also unconcerned about what his son did with his inheritance.

I sensed his feeling of letting it go. He had already done many things in his life and he felt content. So, he had nothing to worry about. He also believed in 'what goes around, comes around’. He believes that he has brought up his son very well and so in return he would be getting the good care back. This perspective also connects to their belief of ‘karma’ which was mentioned about perceptions dementia in chapter 5 (see section 5.4.1.4). Thai Buddhist belief is that there are good karma and bad karma, referring to the previous actions of the person; the person would receive those actions in their future, sooner or later in life. Therefore, from conversations with PwD, their family and also others, I sensed that when something happened that was out of their control and unable to be changed, the individual tends to accept it.

However, each person has a different history, some persons have fulfilled their lives in the past and they were satisfied with their lives and accept the nature of life with well-being. While others still feel guilty about their pasts, like Nantana, who had neglected her children, so the term ‘acceptance of the transience of life’ can relate to the feeling of hopelessness at the end of life.

To conclude, noticeably, many PwD realised and accepted that dementia happens to them as it is the ‘nature of life’. What happens is that they accept it and live well with their long-term illness and the essential thing is to continue living as independently as they can. This can help them to maintain their well-being to live well with their illness. This theme is relevant to philosophical belief. It links to the self-actualisation need as it is relevant to the feeling of life satisfaction well-being that older persons need to fulfil for their lives to be as good as possible.

6.6 Summary of chapter

This chapter has presented the perspectives and life experiences of older persons living with early stage dementia. The stories of these older persons have illuminated their different backgrounds and experiences. Each person has reflected on their needs to enhance their well-being, regardless of whether those needs have already been responded to or not. Different persons have different journeys. Four themes on the needs of persons to live well with dementia have been presented. These arise from the experiences and perspectives of the older persons with early stage dementia.

‘Family is essential’ is the first and foremost theme. Family connects to ‘physiological’, ‘safety’, ‘love and belonging’, and ‘self-esteem’ needs in Maslow’s hierarchy because the PwD needs to receive positive support from family, be understood by family, and receive respect from family. Family is essential because they play a role from the beginning of the dementia journey and continue providing support to the PwD after they have received the diagnosis. PwD live with their family, the family members usually support the older person to maintain their physical needs. However, the family might not respond to the needs of a PwD because they have a lack of knowledge about dementia and how to support PwD. Therefore, the family also needs support to help them care for the PwD.

The theme of 'companionship support is necessary' is related to the need for love and belonging, and self-esteem. It is not only related to the people in the community but also the connection to the environment and spirituality. The PwD's decline in cognition impacts their ability to engage in society and can diminish their emotional and social well-being. Although all the PwD in the study lived with family, they can still feel lonely. Therefore, it is necessary to keep the PwD engaged in society to maintain their sense of love and belonging. To be included in family and community activity encourages the PwD to maintain their cognitive function in communicating. Living in a familiar environment, regardless of whether they are living with their children, can help the PwD maintain contact with somebody they know, help avoid the feeling of loneliness and may encourage them to feel safe. However, although living with family is important to PwD and they prefer to live with family to fulfil their physiological, safety, love and belonging, needs, in some cases, living with family may not be a safe place.

The theme of 'meaningful activities need to be maintained' is critical to help the PwD fulfil a sense of self-esteem and retain their capacity to live less dependently. This chapter has presented that although PwD still have their abilities to perform basic daily activities as they did before receiving a dementia diagnosis, many of them were not able to do things they did previously. Losing the ability to do activities can lead the PwD to lose a sense of safety and self-esteem. PwD were sometimes prevented from carrying out their usual activities to prevent accidents or other harm. However, the PwD needs to continue doing their everyday activities as much as they can to maintain their ability. Some activities have a meaning for the PwD as it allows them to connect with other people and it can fulfil the sense of love and belonging. This need also can link to self-actualisation particularly when the PwD still has the potential to engage in activities.

With reference to Thai Buddhist culture, the PwD believed that 'the nature of life needed to be accepted'. This theme connects to the philosophical belief and their life in the past, which is relevant to the sense satisfaction and dissatisfaction with their lives. To keep living well also can fulfil the need for self-actualisation and identity. It presents the perspectives of the PwD that although their life has changed after getting the diagnosis, they accept it and let it go as they accept whatever will be will be. They were satisfied with their life, so they keep living well and accept this condition regardless of what will happen. This theme also relates to the belief of karma and it leads the PwD to accept what has happened in their life.

The needs of older persons with early stage dementia are related to the basic human needs, which can connect to the sense of holistic support to have well-being. Each person is unique. Therefore, it is critical to consider every PwD’s background and experiences for maintaining their well-being by enhancing their sense of personhood.

Chapter 7 discusses the findings in this study.

Chapter 7 Discussion

7.1 Introduction

This thesis has revealed the needs of older persons living with early stage dementia. To answer the research question: “what are the perspectives of older persons with early stage dementia on their needs”, this study conducted ethnographic interviews with Thai older people living with dementia as well as observations. The findings are pertinent to the experiences, beliefs, and socio-cultural context within which persons with early stage dementia live. The thesis makes a unique contribution to knowledge and practice on how to support older persons living with early stage dementia in Thailand to live well.

The thesis has used Maslow’s (1943) hierarchy of needs as an overarching framework to guide data collection, analysis, interpretation, and presentation of the findings. Kitwood’s (1997) concept of personhood was also adopted as an approach to increase understanding of how to enhance well-being in older persons with early stage dementia. The findings demonstrate a holistic understanding of the needs of Thai older persons with early stage dementia. The needs of PwD are consistent with Maslow’s (1943) framework and each person had their own journey, which was dependent on their background and personal beliefs.

This chapter discusses the findings and compares these with relevant existing knowledge. The needs of persons with early stage dementia are then related to Maslow’s (1943) hierarchy of needs and linked to Kitwood’s (1997) concept of personhood.

Table 7.1 on the next page gives an overview of the experiences of persons living with early stage dementia highlighting both the dementia diagnosis journey and the needs of older persons living with early stage dementia.

Table 7.1 An overview of the experiences and needs of older persons living with early stage dementia

<table>
<tr><th colspan="14">Experience of older persons living with early stage dementia</th></tr>
<tr><th colspan="4">Pre-diagnosis</th><th colspan="10">Post-diagnosis</th></tr>
<tr><th colspan="6" rowspan="2">The dementia diagnosis journey</th><th colspan="8">Needs of older persons with early stage dementia arise from their experiences</th></tr>
<tr><th colspan="2">Family is essential</th><th colspan="2">Companionship support is necessary</th><th colspan="2">Meaningful activities need to be maintained</th><th colspan="2">The nature of life needs to be accepted</th></tr>
<tr><th colspan="2">Pre-diagnosis</th><th colspan="2">Diagnosis process</th><th colspan="2">Post-diagnosis
➢ Home visiting</th><td colspan="2">➢ Receiving positive support
➢ Being understood
➢ Receiving respect</td><td colspan="2">➢ Being engaged in society
➢ Somebody to talk to
➢ Living in a familiar environment</td><td colspan="2">➢ Continue living normally as before getting dementia diagnosis
➢ Needing a chance to do things they used to do</td><td colspan="2">➢ Being well</td></tr>
<tr><td>*Recognition of the onset symptoms of dementia*</td><td>*The onset of dementia symptoms*</td><td>*Entering the diagnosis process*</td><td>*Being evaluated and getting a diagnosis*</td><td>*The older persons perception of dementia*</td><td>*Sources of support older persons with early stage dementia*</td><td rowspan="3">*Willingness vs. Obligation to care*</td><td rowspan="3">• Family provides good support to PwD
• Family have a lack of knowledge about dementia and provide ‘over support’ to PwD
• Family not caring well for the older person (Family blame, family ignore, feeling of being a burden to the family)</td><td rowspan="2">*Being included vs. Being excluded*</td><td rowspan="2">• Continue participating in society as before getting the diagnosis
• Lack of social engagement</td><td rowspan="2">*Life carries on: being encouraged*</td><td rowspan="2">• Having the ability to perform activities by oneself
• Everyday life has changed but PwD receiving support</td><td rowspan="5">*Keep living well vs. Whatever will be will be*</td><td rowspan="5">• Try to be independent
• Do not want to get worse
• Nothing to be worried about
• Acceptance of the transience of life
• Acceptance of the life in the past and present
• Feel sufficiency with the life</td></tr>
<tr><td rowspan="4">○ Family members
○ Person with dementia</td><td rowspan="4">○ Memory declines
○ Subtle behavioural changes
○ Hallucinations and delusions</td><td rowspan="4">○ How older persons get a dementia diagnosis</td><td rowspan="4">○ Getting diagnosis</td><td rowspan="4">○ Dementia is a normal part of ageing
○ Dementia is an effect of brain deterioration
○ Uncertain about whether dementia is a mental health problem
○ Dementia resulting from past karma</td><td rowspan="4">○ Health institution
○ Community
○ Family</td></tr>
<tr><td>*Joyfulness vs. Loneliness*</td><td>• Family embraces the PwD within the family
• PwD feel being ignored by their family</td><td rowspan="3">*Life struggles with the impact of dementia: being controlled*</td><td rowspan="3">• Everyday life changes
- Everyday activities
- Activities in the past
• Religious activities
• Disempowered
• Limited activities
- Everyday activities
- Activities in the past
- Religious practice</td></tr>
<tr><td>*Knowledge vs. Ignorance*</td><td>• Family have basic knowledge about dementia
• Family lack knowledge to support PwD</td><td rowspan="2">*Living in a familiar environment vs. Moving to live in a different place*</td><td rowspan="2">• Feel familiar with neighbours
• Moving to live with children
• Family wanted PwD to live in a residential home setting</td></tr>
<tr><td>*Consideration vs. Disrespect*</td><td>• PwD being asked to make decisions
• Lack of respect from family members</td></tr>
</table>

Note: -------- this border line refers to the links between the experiences

7.2 The dementia diagnosis journey

The first findings reveal the experiences of older persons on being diagnosed with early stage dementia (or Alzheimer's disease, vascular dementia, or frontotemporal dementia). The diagnosis journey involves the experiences of PwD from a recognition of the dementia onset symptoms right up to getting a diagnosis of dementia. Family members have many roles in supporting PwD (Small et al., 2007) and findings in chapters 5 and 6 show that family members were the key people supporting older PwD. Family are also important in meeting the needs of older persons with early stage dementia and I discuss this further in section 7.3 of this chapter.

In relation to the beginning of the journey, the findings revealed that memory decline was the main initial symptom affecting the daily life of the older person in the early stages of dementia and this is consistent with studies by Krull (2005) and Leung et al. (2011). All participants in this study were taken to hospital by their family. This differs from research in Western countries and other regions where persons diagnosed with early stage dementia were more independent (Leung et al., 2011); they noticed their symptoms and sought help themselves.

With reference to the study of Leung et al. (2011) which explored the experiences of Anglo-Canadians with dementia and their carers in getting a dementia diagnosis, the persons with early stage dementia and their carers had problems recognising the onset signs and symptoms of dementia, which led to a delay in receiving a diagnosis. This is similar to findings in this research which discovered older persons and their families had a lack of dementia knowledge and awaited clear visible symptoms where those symptoms impacted their life.

After knowing the diagnosis, older persons in this present study felt sad and stressed with their symptoms, but they focused more on their other chronic diseases. There were some aspects different from people in other studies who had been diagnosed with dementia for the first time (Derksen et al., 2006; Vernooij-Dassen et al., 2006). People diagnosed with dementia in the other studies felt sad and distressed that they had to live with dementia because they knew that their condition would deteriorate, and they will lose memory and autonomy. Due to a lack of dementia knowledge in older people in this present study, older people have doubts as to why this has happened to them, they did not know what the illness is, how it will progress and what will happen to them in the future.

Concerning dementia knowledge, previous studies revealed that PwD and their caregivers indicated receiving insufficient information about dementia from professionals (Aggarwal et al., 2003; Innes et al., 2014; Sutcliffe et al., 2015; Risco et al., 2016). The previous research noted that the need for dementia knowledge and information to get support for persons living with dementia begins with the diagnosis process (Innes et al., 2014; Johansson et al., 2015; Sutcliffe et al., 2015). In addition to this, awareness of and timeliness to detect dementia (Górska et al., 2013; Karlsson et al., 2015; Sutcliffe et al., 2015; Gill et al., 2011; Sutcliffe et al., 2015; Benbow & Kingston, 2016) and the need to know where people could access information on dementia were also raised (Górska et al., 2013; Karlsson et al., 2015).

PwD needed to know the result of their dementia evaluation as early as possible to plan for their future and search for ways to maintain their well-being in living with dementia. In contrast to those studies, this current research study found that Thai older people with a dementia diagnosis did not discuss the pre-diagnosis or diagnosis process. They depended on their family and health practitioners, and their families were involved in every step of getting a dementia diagnosis. It is clear from this that the perspectives of Thai older people with early stage dementia are different from those in Western cultures. Thai people perceived that dementia is not a serious problem as it is a normal part of ageing. Many of them with other health conditions were also more concerned with their other chronic diseases than early stage dementia. Thai older PwD have a more philosophical attitude and focus on Buddhist religious beliefs. They accept the illness while they have a lack of information about dementia. Unlike Western people being more likely to need more information to plan for their future.

The findings from this study revealed that perceptions of dementia are varied, including that dementia is age-related, brain deterioration, mental illness, and related to karma. These views are similar to those found in a study by Mazaheri et al. (2013) which explored the experiences of Iranian immigrants living with dementia in Sweden. They found that PwD realised that being a PwD means living with forgetfulness, it is age-related, some of them thought about mental illness, and that it was God’s punishment. These views can indicate that although people believe in different religions, backgrounds and education, philosophical beliefs are important in influencing perceptions. Regarding the faith in karma as one of the findings from this present study, it is one of the Buddhist teachings relating to the concept of cause and effect (Ratanakul, 2004). This belief encourages people’s attitudes to perform good acts to gain good results. It also shaped their perception of many things together with their health conditions. Consequently, some participants also perceived that their dementia is caused by their bad karma which led to a more acceptance attitude.

In the post-diagnosis process, this study revealed that after older people knew they had to live with dementia for the rest of their lives, most of them continue to live normally and think that whatever will be will be. Although some older persons with early stage dementia considered the future, they did this because they knew they were getting older, rather than because of their dementia. Nobody made any advanced directives because of their dementia. Meanwhile, PwD in the West tend to discuss things in advance regarding power of attorney or written living wills, which is advisable in early stage dementia. Also, it is one of the responsibilities of the health professional to take any action to help older PwD and their families in designing appropriate plans (Porteri, 2018; Cotter et al., 2018). It can be reflected that PwD did not think about it because they perceived that they were not in a serious situation, and also, they have their family to take care of them. Older persons who received a dementia diagnosis lived at home with their family in the present study.

This study found three principal sources of support that older persons with early stage dementia rely on; health institution, community and family. To begin, the health institution support, although all participants revealed that they got good support from health professionals when they went to visit the hospital, no participants were screened for cognitive function by the health personnel until the initial symptoms emerged. It might reflect a lack of awareness and recognition of onset signs and symptoms of dementia, which is similar to previous research that mentioned about service providers unawareness of dementia signs and symptoms (Gill et al., 2011; Górska et al., 2013). It can indicate that primary health practitioners are important persons in the screening process to analyse onset of disease symptoms and to refer older persons to get further support (Panegyres et al., 2016). Besides, in the pre-diagnosis process, the family member is also a dominant person helping older persons to get early support.

Based on the findings from similar studies (Gill et al., 2011; Sutcliffe et al., 2015; Risco et al., 2016), being visited and receiving support from health professional led older PwD to feel happy and safe. In this study, health professionals did not visit participants at home as they were not bedridden. With regard to the limitation of visiting the hospital for all their appointments, the findings from this study confirmed that to be visited and interviewed for this research study, the older persons felt glad and very delighted. They thought that they were privileged to be visited, and they could have a chance to consult about their health problems. Therefore, they might be very grateful if the health professional could visit them at home because it enhanced them to feel they matter, they are important and are not alone. Moreover, as with taking part in this research, it could boost their sense of value and self-esteem (Barnett, 2000).

In the past, dementia might have been overlooked by health personnel and the public because of misconception about dementia until it manifests and has a wider impact on families and the health system. This study discovered that there was still a lack of multidisciplinary and health organisation relevant to support PwD, especially outside Bangkok. In terms of health institutions support, there may be some nursing home or long-term care setting looking after PwD, but they are likely to be more established in Bangkok and the outskirts of the city. Although there were home health care services, primary health care nurses or community health volunteers only visit patients who are bedridden at home. Meanwhile, older persons with early stage dementia, as a person dealing with chronic health condition, also needs to be visited by nurses or health professionals. However, as the participants were still able to be supported to undertake activities, they had to go to see the doctor at the hospital.

This corresponds with a previous study conducted in the UK that examined PwD and carer preferences for home support in early stage dementia (Chester et al., 2018). The researchers found that participants preferred to receive home support to support their feelings and concerns, for information for coping with dementia, and also the chance to participate in society. Therefore, it was validated by experiences and perspectives of PwD that the home visit could be one effective strategy for supporting older PwD in the post-diagnosis process, which will be utilised by the nurses working in the primary care unit. As primary care nurses work closely to the people living in the area for which they are responsible, this could help them discover exactly the problems that PwD and their family had to confront. The nurses will increase their understanding of the problems of older PwD and their families by learning from their background.

The community was raised as one source of support. This current study revealed that neighbourhood support was especially prevalent in the rural areas. This is congruent with the findings from a study by Herron and Rosenberg (2017), who interviewed forty six PwD living in the community and forty three of their care partners in rural Ontario, Canada. PwD in their study expressed that sometimes they got support from their neighbour if their family asked for it but PwD preferred to have some space and refrained from sharing their diagnosis with other people. There was still a lack of community support for PwD in their area, so PwD in their study needed the appropriate care services for their earlier stage of dementia. Fukui et al. (2019) interviewed seven PwD and their eight family carers regarding their perspectives on their need and use of a dementia café service. Nine staff members were also interviewed about their role in supporting PwD and their caregivers. They found that PwD enjoyed the entertainment in the service and it was good for them to keep in touch with other people. The family carers expressed their anxiety and problems in caring for PwD and that the dementia café was useful for them to exchange their experiences in caring for PwD with others. This current study has revealed that there was no dementia service support run by the community or other organisations, but there is community support for older people that PwD can participate in, like the 'older people school' which is managed by the government and municipality. However, whether the support was from a neighbour or the municipality they were coordinated by the family of the older PwD but some families may need support to use these services.

To summarise, the findings of the journey of getting a dementia diagnosis have shown the experiences of older persons with early stage dementia. In terms of the perception of dementia, it is related to the belief in fate, which is established in Buddhism. In terms of getting support, family plays an important role to support older people with early stage dementia in each process. Additionally, participants have a lack of information about dementia and what it is. Therefore, dementia knowledge and relevant information are needed as well as establishing the awareness of being diagnosed and planning for the future by cooperation among PwD, family and primary health professionals.

It is difficult for participants to say what they need or what is important to them for the future to maintain their well-being and slow down the severity of dementia. This is because they did not know how dementia will impact their lives in the future, and they did not think about how to slow down the severity. However, they can still express their feelings at present.

7.3 Four main themes of the needs of older persons with early stage dementia

The stories of older persons with early stage dementia underpinned that the needs of older PwD vary depending on the cultural context (Chung, 2006; Black et al., 2013). With reference to the included studies in chapter 2, those studies were conducted in Western countries, so they present the views of the needs of people living with dementia in Western circumstances. This study maintains that different cultural contexts influence different perspectives. The findings revealed the uniqueness of the experience and the views on the needs required to live well with dementia of older persons with early stage dementia in Northeast Thailand. As this study was conducted in Thailand, so there are some different sociocultural backgrounds and beliefs between Thai and Western cultures. This includes the lifestyle, education and religious beliefs which were reflected in peoples' behaviours and perspectives. The next sections discuss the PwD's experiences on being supported and their need to live well with dementia.

7.3.1 Family is essential

Obviously, the family is a dominant theme for this thesis because it connects to other themes. This theme consisted of the need for 'receiving positive support', 'being understood' and 'receiving respect'. All participants live with their family, whether the family is willing to care for them or not. The Thai cultural context influences the family to care for older people. The findings reinforce Thai culture about family support, which is perhaps different from other regions in some details. Although older persons with early stage dementia did not need the family to take care of them as if they were a dependent person, it is common to see older people live with family and their family take care of them.

Thais consider that older people are persons who have valued experiences and can offer the younger generations much about family matters and other topics (Limanonda, 1995). The families also teach children in the family to pay respect to older people. Thus, younger generations would normally treat older people with deference. Pinyuchon and Grey (1997) described that Thai families were influenced by six cultural influences: religious beliefs, rural and urban considerations, family relationships, societal values, masculine and feminine roles, and sexuality.

In this study, the dominant theme about family relates to topics like religious beliefs, the consideration on which area the older persons live, the relationships in the family, and societal values. Thai people believe that their parents are the gods in their house, who gave them birth and brought them up. Therefore, they have to respect and obey their parents. Once their parents become old, the children need to take care of them and support them as well as they can. This point also reflects the Thai Buddhist culture that children can look after their parents in return to repay their parents for raising them (Sasat, 1998).

These have been cultural changes are the past decades. It is acknowledged that many Thais have embraced some of the Western cultures (Burnard & Gill, 2008) as seen in the findings which revealed that there were different experiences on receiving support from their family and different perspectives on living with dementia. However, the family values evident in the findings are still being preserved by Thai people. The findings are consistent with Burnard and Naiyapatana (2004), who highlighted that children looking after their parents is common in the Thai context which also indicated that it differs from Western people who are considered to be more independent.

Many Thai older people request to live with their families at the end of their life, whether they are healthy or not. This current study discovered that older people commonly live with the family and are being supported by their younger generation regardless of the older persons' health status. It strengthens Thai culture. Although some families thought that looking after older PwD is a burden for them, they are still responsible as it is their duty. This is consistent with Knodel et al. (2018) who found that the need for long-term care increases with age, and in Thailand, family members become the main caregiver. In terms of Thai culture and the feeling of the touch of love from the family, although older people do not want to be a burden to others, at the same time, they are satisfied being supported by their family (Manasatchakun et al., 2016). It is also a positive way for the family to show their gratitude and build good karma when they take care of their parents (Gray et al., 2016).

Older PwD in this study reported that they would rely on their family in their old age. The family provided them with basic physical support, which can fulfil their physiological needs. It can be considered that facilitating PwD to be more comfortable could influence their physical and emotional well-being as they would feel that they were attended and valued by their family. Additionally, once the family includes them in family activities, it can enhance their sense of being a part of society and also improve their social well-being which can link to the need for love and belonging. In terms of family support, it is necessary to meet the holistic approach including physical, psychological, social, and spiritual support because it can influence them to reach a sense of well-being. The family is important in supporting the PwD to continue religious practices which I discuss in a section 6.4.1, these practices enhance the spiritual well-being of older PwD. These could be provided to older persons with early stage dementia once the families open their mind and understand the situation and needs of older PwD.

It is clear that taking care of older parents in the family is the norm in Thailand. Also, there is a lack of relevant public institutions for taking care of older persons, especially older PwD. There are very few private care home settings outside Bangkok, even in a major city like Nakhon Ratchasima where there is still a lack of external support for older people. Although there are some private services which provide care for older people, they are expensive, and the quality of services can be of concern. Therefore, this can be one of the reasons underpinning why older people live with their family. Additionally, at early stage dementia, as older people do not have a severe problem and they still have the ability to perform their everyday activities, people perceive that they do not need full physical support. Meanwhile, in Western countries, there are many long-term care settings to support people with a long-term health condition, and people are more independent from their children.

In the Western context, although some older people live with their children, there are a lot of older people living alone, including PwD. For example, there was a report that the number of PwD living alone in the UK is about 120,000 people, and this number is predicted to double by 2039 (Alzheimer’s Society, 2019b). However, to praise the family is essential for PwD, and this is congruent with the study of Cahill and Diaz-Ponce (2011), who explored the perceptions of quality of life of people with cognitive impairment living in a nursing home in Dublin, Republic of Ireland. Their study revealed that people with cognitive impairment mentioned the need for social contact, including from family, residents and staff. The people with mild to moderate cognitive impairment appeared to express that their family is important to them. Also, PwD need to receive positive support from their family (Benbow & Kingston, 2016). Based on the findings of similar studies, there is agreement with the findings from this study that family support is highlighted and valued as part of the cultural context. Whereas the family in the West is more nuclear and independent, regardless of family types, in later life, the family is essential.

The findings from this study indicate the distinction from other existing knowledge about the importance of the family. It became more and more apparent that the family is essential for PwD interviewed in this study. I reflect that a strong bond in the family and good relationships in the family are crucial to enhance the well-being of family members. However, as they are vulnerable, some PwD had faced abusive action from family. Sometimes, they had to confront insecure situations, but older persons preferred to live with their family even when they were unhappy. It seems that living with family could make older PwD feel secure as they would be supported, at least they could feel close, and familiar with their family members.

However, as there were differences in perceptions between PwD and family members, it is then possible that they will not understand each other (Denning et al., 2013; Giebel et al., 2019). PwD and their caregivers had different perspectives on their needs (Edelman et al., 2006; Harmer & Orrell, 2008; Miranda-Castillo et al., 2013; Fukui et al., 2019). I suggest that because PwD and their family members did not always understand each other, that this can cause family relationship problems to occur. Many older persons with early stage dementia in this study expressed that they were blamed by their family members when they made errors, misjudgments or mistakes, and the family members then took over and did the work instead of them. This could be a consequence of the family's perception of health and that they had a lack of dementia knowledge and did not understand that the errors made by the older person happened because they were affected by their dementia. Therefore, understanding from the family is needed as it can connect to the emotional well-being of PwD.

Other relevant factors like a family relationship and the declining ability of the older person with early stage dementia could be reasons for the family taking over from the older person. However, concerning the experiences of receiving support from family, some participants faced abusive behaviours from the family because of misunderstanding about dementia. The abuse consisted of blaming, accusing, controlling, neglecting, limiting some activities, ignoring what the older person expressed, not listening to the older person and in one situation, actual physical abuse. Most of these behaviours relate to psychological and emotional abuse which were the most common type of elder abuse in Thailand (Chompunud et al., 2010; Kulachai, 2018). The findings from this thesis are supported by research from Chompunud et al. (2010) which examined the prevalence, associated factors and predictors of elder abuse in Thailand. The results from their study revealed that gender; adequacy of income; perceptions of health; personal health compared to the health of other elders; and family member's mental health, dependency and relationship issues were the factors associated with elder abuse.

A recent review of the literature by Kulachai (2018) demonstrated the prevalence rate, causes, and consequence of elder abuse. The study showed that abuse has increased since Thailand has become an ageing society. This corresponds with my findings in terms of the Thai culture in taking care of older people, as some families perceive that taking care of older persons was an obligation, so family conflict led to the problem of family relationships. As the family members' dependency and family relationship are the predictor factors of the elder abuse, it can be referred to the findings of this current study that family relationships and the dependency level of PwD could lead them to be at risk of abuse. Although these previous studies on abuse did not focus on older persons living with dementia, they could have an applicability to the older persons with early stage dementia in my study since they had experienced a health condition and had a family relationship problem.

In research in the West, Cooper et al. (2009) examined the prevalence of abusive behaviours by 220 family carers of PwD in Essex and London, UK. They found that psychological abuse occurred most often, and in the form of verbal abuse. Most participants reported that it happened sometimes, only one carer stated that abusive behaviours were taking place most of the time, and only three carers reported that sometimes actual physical abuse also occurred. However, Cooper et al. (2009) did not explore the views of PwD, and some family carers may not have reported abusive behaviours. Abusive behaviour by the carer can be related to the stress of caring for a person with behavioural symptoms day in and day out (Fang & Yan, 2018; Pickering et al., 2019). However, the perspectives of abuse between Western and Asian cultures might be different (Yan et al., 2015) as identification of abuse from Asian perspectives tend to be culturally specific forms like a lack of paying respect to older people (Tam & Neysmith, 2006), blaming older persons (Arai, 2006), paying less attention to their older relative, or arguing with them.

Findings relating to the need to be understood were presented in the literature review (Gill et al., 2011; Johansson et al., 2015; Power et al., 2016). The findings from this study showed that the understanding of the family on the symptoms that older PwD presented related to behaviours that the family member expressed to older PwD. Some family members had undermined the older PwD with verbal, non-verbal or actual abuse.

Understanding of dementia is needed to protect against abusive behaviours (Watson, 2019). Therefore, I strongly suggest that to increase family understanding of the older persons with early stage dementia, both older persons and the family have to understand what dementia is, including its symptoms, progression, and how to deal with it to live well with dementia. Caring for a PwD in the family can be very stressful and this present study shows that while the family need knowledge of the condition they also need support to help the older person live well with dementia.

Some older persons represented a pressing problem regarding family relationships. Older PwD were not properly respected by the younger family members; younger family members had impolite behaviours including verbal and nonverbal, and less concern for older persons' feelings. I reflect that it might be because the PwD did not make an immeasurable contribution to the family in the past. However, some family members did not behave that way intentionally. It could be argued that this issue links to the sense of low self-esteem as a person who is respected by others, could fulfil their self-esteem. It was consistent with the findings of Lethin et al. (2019), who explored the needs and expectations of support within everyday life among community-dwelling people living with early stage dementia and their informal carers in four countries: Greece, Italy, Portugal, and Sweden. Their study revealed that it was important for PwD to be supported emotionally and be respected by both formal and informal carers (the informal carers in this research, including a family member or significant others). Family relationships are an area of concern because the behaviours of the family can affect the feelings of the PwD and can sometimes lead to serious harm.

To summarise, regarding the treatment of older persons in Thai culture, Thais perceive that older people tend to be frail, so they need to rest and be supported. Older persons have a high status in the house, and the younger family members should pay respect to them. With time, social factors have influenced Thai culture regarding family values. This has had an impact on the family, which is smaller, but it has also changed the close-knit relationship between the generations. Therefore, older persons with early stage dementia might perceive themselves as a burden of the family because they tended to need support as they are frail people. However, it also depends on how the older persons behaved in the past to their family. Older persons who had been neglectful of their children and families had difficult relationships with their adult children. Regarding the feelings of older people, these often seemed to be overlooked. Some families might respond to caring for their older family member as it is a duty and they had less awareness of the older persons feelings who was living with them. This led the older person to feel devalued as they did not get respect from the younger generation. This issue also impacts the dignity of older persons with early stage dementia. Thus, older PwD should be taken care of, especially their feelings.

7.3.2 Companionship support is necessary

Dementia affects a person's well-being. In terms of social interaction, older persons with early stage dementia discussed the need for companionship. It encompasses three relevant needs for living well with dementia: 'being engaged in society', 'somebody to talk to', and 'living in a familiar environment'.

This study has revealed that older persons with early stage dementia need to retain their social relationship by engaging in social activities. This is consistent with previous research (Miranda-Castillo et al., 2010; 2013) which found that companionship was the major unmet need for PwD. Studies by Aggarwal et al. (2003); Meaney et al. (2005) and Chung (2006), reported that PwD needed to engage in social activities, along with having social interaction (Gill et al., 2011; Passos et al., 2012; Górska et al., 2013; Johansson et al., 2015). This need connects to social support, which assists the PwD to maintain their social and emotional well-being.

The findings from my research found that there were some older PwD who withdrew from participating socially because they could not keep up with the conversation. They also worried that others would not understand what they had talked about. This is congruent with the study of Holst and Hallberg (2003) who explored the meaning of everyday life of people living with dementia in Sweden. They interviewed eleven people with early stage dementia. The findings in their study indicate that many PwD felt shame, sorrow, and sadness with their life with dementia. Dementia affected their lives and relationship to others as they lost the ability to remember people and events, and they lost the ability to reach out to others because of their restricted ability to communicate and manage their daily activities.

Concerning the need for engaging in social activities, findings in this present study are congruent with the study of Caddell and Clare (2013) who found that people with early stage dementia had changed in their social abilities. They found it difficult to find the right words, which led them to feel embarrassed, angry at themselves and worried about making other people upset. However, they still maintain their identity regarding their attitudes and values. Meanwhile, Mattos et al. (2019) found that connecting with neighbours and community and relying on children coordinated with social integration and support. Therefore, I argue that being engaged in society also can help older persons with early stage dementia to meet the need for love and belonging. Once they receive appropriate support, they could search for adaptation to maintain their psycho-social well-being to fulfil their sense of personhood (Pratt & Wilkinson, 2003). Besides, if they are still able to participate in social activities as they used to do, this could improve their self-esteem and perhaps also, self-actualisation.

Additionally, Passos et al. (2012) presented the results of their pilot study to identify the met and unmet needs of older people with mental illness and their carers in Northern Portugal. Most older patients in their study have dementia, but many of them have depression and anxiety. They found that most PwD living in a rural area were of a low-level socioeconomic class compared to persons living in an urban or suburban area. Their findings revealed that although the persons living in the rural areas lived alone or lived with their partner who responded as a caregiver, most of them reported a lack of company. This is congruent with this current study in that older persons need companionship regardless of where they live. However, older persons with early stage dementia who lived in the rural area tended to have more social contact rather than some in urban areas because they have relatives and neighbour surrounding them. On the other hand, some older persons living in the city with many family members still felt lonely and needed somebody to talk to them.

This current study revealed that although PwD live with their family, they can still feel lonely. This concords with the literature that PwD were at risk of loneliness (Moyle et al., 2011). Social isolation and loneliness were found in persons who experience Alzheimer's disease rather than healthy older people (El Haj et al., 2016). I reflect that further to connectedness to the society, needing somebody to talk to can enhance the feeling of joyfulness in older persons. Some older persons with early stage dementia were faced with coping with other physical health conditions which impacted their ability to move, so it could affect their preference to participate in society. On the other hand, if the family limit their activities outside, it could also affect their ability to maintain social activities. This situation also could lead to older PwD being lonely. Therefore, they need somebody to talk to them and listen to them. However, this can be a problem when there is poor communication among the family members, either verbal or non-verbal communication, which is a key to the PwD expressing their feelings to others.

From the stories and the participants' expressions regarding loneliness, it could suggest that a greater the level of loneliness could lead to worse cognitive function (O'Luanaigh et al., 2012; Shankar et al., 2013; DiNapoli et al., 2014). This is consistent with Holwerda et al. (2014), who examined the association between social isolation, feelings of loneliness, and incident dementia in a cohort of older people without dementia in a longitudinal study (3 years follow-up). They collected data with 2,173 non-dementia affected community-living older persons in Amsterdam, Netherlands, and they found that feeling lonely is associated with an increased risk of dementia rather than being alone. Although the previous research studied older people without dementia, it can be related to the situation of older people with early stage dementia in my study who experienced a feeling of loneliness despite living with their family and so being prone to cognitive function decline.

In terms of being in a familiar place, older persons with early stage dementia feel comfortable when they are with their family and friends or even acquaintances in a pleasant environment who can support them. Not only did they know the area very well as it was their home but the area that they lived in encompassed their memories. I reflect that it can enhance PwD to fulfil the needs for safety and love and belonging. This study revealed that even when older PwD had a serious relationship problem with their family member, they did not want to go to live in a nursing home or residential setting and leave their home. There is research which has studied PwD in residential settings and nursing homes. One study reported that sending PwD to live in a health care setting threatened the feelings of the PwD, especially those persons who valued being independent and living at home (Han et al., 2016). However, some PwD might agree to being in a residential care home or nursing home because they preferred to have activities with others (Phinney et al., 2007).

Some families perceived that placing older PwD in a long-term care setting like a residential or home care setting might be one of the ways to provide support for PwD and help deal with the feelings of loneliness. Concerning the findings from this present study, I reflect that the families who wanted to send the PwD to live in other places may not have known how to cope with their particular difficult situation or they did not want to have the burden of taking care of a PwD.

On the other hand, there were some families who preferred to look after the older PwD by taking them to live with them to facilitate the older person feeling comfortable. That means the older person had to move to live in another place, where their children lived. In this situation, they might feel unfamiliar with the new circumstances. Older persons with early stage dementia discussed the need to live in a place where they used to live with their familiar neighbours and people around the area. It can be explained that although the familiar human relationships could reduce the feelings of loneliness in PwD, placing PwD in an unfamiliar environment and with people they do not know may not improve their situation regarding loneliness (Moyle et al., 2011). However, in the person who did not have relatives or somebody to live with them, they agreed to move from their familiar area to live with their family.

In the sense of societal values, I respond that being in an unfamiliar environment might affect persons to feel a lack of people around them who they can trust. This is concordant with Pratomthong & Baker (1983), and Burnard & Gill (2008) who explain that the majority of Thais did not want other people to know about any problems in their family because they can be stigmatised, and it can undermine the persons' well-being. Therefore, telling others about the health and family problem might bring great shame to their families as they cannot confide in others, especially about mental health illness. The findings from this study revealed that many people still perceive that dementia is related to mental health problems, so most persons did not tell other people outside the family about their dementia. The notion about psychological stigmas has been studied across regions. Recently, Pitakchinnapong and Rhein (2019) did an ethnographic study exploring the perception of the causation of stigmatisation of mental illness in Thailand. They did two focus groups with students from a Social Science faculty. Although the findings from both groups indicated that they did not stigmatise patients with mental health illness, they argued that most Thai people still have negative perceptions of mental health illness. Based on my study, I argue that having negative perceptions of a mental health illness is stigmatising and can lead to diminishing the sense of personhood of a person who has, or who is judged to have, a mental health problem.

In summary, the need for companionship not only provided a sense of social contact but also enabled PwD to meet the psychosocial well-being needs. I sense that older persons with early stage dementia, who had experienced psychological problems or behaviour change, tended to be concerned about what others will think about them. It might be difficult for older PwD to have somebody that they can trust, somebody who understands them and has the willingness to talk and listen to them. Therefore, for the PwD, the family member was identified as the most significant and safe source of support which they can rely on. However, this depends on the family relationships, if the family cannot address this need of older PwD, they would seek somebody outside the family, which perhaps will be other relatives or their neighbours who can respond to them. Some older PwD who had physical conditions would find it difficult to go outside. Therefore, if they still have their family to talk to them, helping to support their emotional well-being, this could influence the person to fulfil the love and belonging needs. Unlike, some older persons who had nobody who they could rely on, who would feel very depressed and lonely.

7.3.3 Meaningful activities need to be maintained

Generally, older persons with early stage dementia who did not have other health conditions were able to live as usual. Older persons with early stage dementia in this study were able to live partially independently. They were able to perform essential activities in their everyday life. Some older persons were still able to manage complicated activities, whereas some struggled to do it. Although their ability to perform activities changes, they still need to 'continue living normally as before getting a dementia diagnosis. Also, persons who were confronted with dementia impacts were still 'needing a chance to do things they used to do' to keep maintaining some fundamental activities in their everyday life for as long as possible.

This study revealed that PwD are still able to perform daily activities and have some activities that they are interested in and prefer to do. It could be implied that a meaningful activity fulfils their sense of physical well-being if they were to continue living less independently. Also, when persons can do some of the preferred activities they did in the past, their emotional well-being would be improved as well as their social and spiritual well-being. I reflect that it is the quality of the experience that is important rather than specific activities. This is consistent with the study of Harmer and Orrell (2008), who explored the concepts of meaningful activity, which were defined by older PwD living in care homes, staff, and family caregivers. They found that PwD defined meaningful activity as the activities that addressed their psychological and social needs, whereas caregivers and staff defined that it was the activities for maintaining the physical capacity of PwD. This present study affirmed that older persons have their own activities which connected to their personal characters, backgrounds, and depended on their physical abilities. Similarly, Phinney et al. (2013) identified that although daily activities of each person were different, the patterns of everyday activity are meaningful for them.

Living with dementia means struggling to preserve a sense of self to maintain one's values (Harmer & Orrell, 2008). This current study found the older persons with early stage dementia need to keep engaging in their usual activities. They need to be independent as much as they can to avoid the feeling of being a burden to their families. This need was consistent with some research studies in the literature review chapter, which presented that PwD need to maintain their meaningful activities as much as they could (Edelman et al., 2006). Also, they need to remain doing their daytime activities (Miranda-Castillo et al., 2010; 2013) to maintain their well-being and to slowdown the progression to the disease (Steeman et al., 2007; von Kutzleben et al., 2012; Tetley, 2013; Noysipoom & Sasat, 2014).

Concerning the perspective of older persons with early stage dementia in needing to maintain their meaningful activities, I suggest that practising everyday activities was valuable for the PwD to retain the ability to be partly independent. Additionally, if they are still able to continue doing their meaningful activities, it could improve their well-being and encourage them to fulfil their self-esteem need because they would not be a full burden to their family and still be able to have the activities that mean something for them.

Remaining physically active was one of the important ways to sustain well-being and a sense of self for PwD (Cedervall et al., 2015). It not only helps older PwD to maintain their performance in doing activities but also retains their sense of self if they can refer to their routines from their adult years. This is consistent with the study by Pearce et al. (2002) who explored the assessment and coping processes of men with early stage Alzheimer's disease living in London. They suggested that to maintain the sense of self PwD should be encouraged to continue to live and do their usual daily activities as long as they could. This can help older PwD fulfil the sense of continuity with the past as they can retain their feelings and memory, which is compatible with identity needs (Kitwood, 1997).

Harmer and Orrell (2008) found that the main factors making activities more meaningful appeared to be based on values and beliefs that related to their past roles, interests, and routines. Their study has some resonance to my findings in that PwD withdraw from activities because of the loss of the ability that they used to have, like the ability to communicate, despite their need to have their usual activities.

Regarding this view, the other chronic diseases that older persons had, including diabetes, osteoarthritis, spondylosis, blurred eyes, dry and itching skin, and also cognitive decline, can impact their ability to manage some activities relating to physical needs. It needs to be considered how to help PwD to live well in the future when they lose the ability to express and look after themselves. This present study found that some older persons with early stage dementia preferred to be at home doing things, like watching television, chewing betel nuts or doing nothing, and that also had meaning for them and helped them to fulfil well-being. It was congruent with the study by Phinney et al. (2007) that some older PwD needed to continue doing activity as much as they possible could including passive and active activity like doing household chores and engaging socially. I reflect that performing meaningful activities is helpful to lead the PwD to fulfil a sense of continuity regardless of where they are involved in doing activities.

This study revealed that some older PwD were indulged and pampered by their children, despite them being able to perform their daily activities. This could be because they had become forgetful and had cognitive decline together with some physical health conditions. While some PwD perform their activities as normally as they used to do, some were supported by the family. On the other hand, some families attempted to limit the activities of the PwD because of the risks associated with it, but some older persons still insist on doing their activities although they were not always successful. There is an issue around the safety of some of the activities that older persons wanted to continue doing. These situations present an imbalance between security and the risk of disempowering and discouraging the PwD which relates to the sense of infantilisation (Kitwood, 1997).

I argue that enhancing older persons with early stage dementia to maintain their favourite activities would help them keep reminiscences about their lives and improve their emotional well-being. However, it is critical to think about what activities should be tailored to PwD. Also, their ability to do activities needs to be considered, which is related to the progression of dementia as this can affect their sense of safety. Therefore, the family needs to consider and balance the safety and satisfaction needs of their loved ones. I reflect that this can be difficult for families to do on their own without support from others like health services because it requires insight by the family into the person, their needs, their dementia condition and their good relationship and communication skills with the PwD.

This present study has also revealed that older persons with early stage dementia need to continue practising their religious activities. Religious practice is related to spiritual needs and enhancing this will allow emotional and spiritual well-being to flourish. As spiritual practices or religion was used to cope with memory problems (Giebel et al., 2019), I advocate that attending the temple or giving alms to the monks, which were a part of the morning activities for some people, can encourage their social and spiritual interaction. It can also help the PwD to maintain their social contact as they will meet with other people. Even chanting or reading the Dhamma book, these are also part of the PwD's meaningful activities. These religious practices should enable the PwD to satisfy their emotional, social, and spiritual well-being, which will also help them to maintain their social interaction. In terms of personhood, McCarthy (2011) described that connecting to others or even participation in religious activities is part of fulfilling a person's sense of personhood.

It is acknowledged that religion is one of the spiritual anchors that people can rely on, so it could help them to cope with their problems, and stress (Beuscher & Beck, 2008). Although people believe in different religions, religious practices can be meaningful activities which help to enhance the emotional well-being of PwD, as well as praying or going to church (Beuscher & Grando, 2009). This is consistent with the research of Agli et al. (2015), who examined relevant literature on the effects of religion and spirituality on health outcomes in PwD. The research highlighted the benefit of spirituality and religion on health outcomes, which relates to using spirituality or faith in everyday life to help people cope with their situation, maintain their relationships, maintain hope, find the meaning of their lives, and improve their quality of life.

To summarise, concerning the meaningful activities, these relate to a sense of continuity and a sense of social contact, once individuals with dementia achieve this need, they could fulfil their physiological, love and belonging, self-esteem and also self-actualisation needs. The family plays a role in supporting PwD to maintain the sense of being included in doing the activities that they are still able to do (Phinney et al., 2013; Eriksen et al., 2016) to support the personhood of the PwD.

7.3.4 The nature of life needs to be accepted

In general, once persons had been diagnosed with dementia, they and their families experienced negative feelings and were troubled. Previous research indicates they might be worried, sad, distressed, shocked and not understand what changes were happening to them and they did not know how long they will be able to be independent (Pratt & Wilkinson, 2003; Derksen et al., 2006; Vernooij-Dassen et al., 2006).

This theme relates to the perception of dementia; the majority of older persons with early stage dementia appraised their memory problem as a normal part of ageing. All participants accepted that they must live with dementia. The findings of this study revealed that older persons accepted what was happening in their life, especially when they are old. They accept it and continue living as well as they could as the need for 'being well'. This perspective corresponds well with the terms of "keep living and keep living well", which were described in the study of Wolverson et al. (2010). This theme could be referred to the sense of hope, which health status and social circumstance (including family, others, and society) are important in maintaining hope. Concerning the context of this current study, it also related to spiritual need.

Concerning the view that they need to accept the nature of life, to link with the basic human needs, I reflect that as they were still able to live as usual and are less dependent, they seemed to satisfy the need for self-actualisation. In the setting of the Thai cultural context, and Buddhism as a religion, people believe in the teaching of Buddha, which explains that humans are born, they get older, develop illness, and then they die. They think that these are inevitable; they accept it. At the end of life, they did not fear dying, these are the truths of rising and falling. However, they do not want to be a burden to their family. Although this perception is different from the perception of PwD in Western countries, who perceive dementia as an illness which needs help (Clare et al., 2006), some PwD in Western countries also perceive that dementia is not too serious compared to the other health illnesses as it was aged-related (Pearce et al., 2002; Perry-Young et al., 2018).

This perception is congruent with the study of Steeman et al. (2007), which was conducted in Belgium. They revealed a positive story from people with mild dementia and found that older PwD perceived that memory loss was a small issue. I reflect that older people might see the positive in a negative situation. In a difficult position, there was good, as some persons stated that at least they were still alive and not bedridden, they still live with their family and get support from their children.

In terms of chronic illness, the perspective of having dementia is better than having other chronic diseases emerged because dementia did not cause pain, and the persons did not know about dementia and what would happen to them. Some PwD are quite sure that their dementia symptoms had improved because they took medication. This is consistent with Pearce et al.'s (2002) research where half of their participants took acetylcholinesterase-inhibiting medication, which had been used for supporting the symptoms and behaviours from the imbalance of a chemical in the brain. They believed that the medication is needed to maintain their well-being.

This present research revealed that although some older persons with early stage dementia got more stressed because they had become forgetful, they accept it and continue living as usual as before getting the diagnosis. I advocate that this correlated with their religious belief. It might be the method that they use for coping with their feelings. This was congruent with my previous research on a master's degree (Noysipoom & Sasat, 2014) which explored the life experiences of older persons with early stage dementia living in Bangkok. Those older persons with early stage dementia coped with negative feelings when they knew that they had to live with dementia by using religious practices to help them accept the problems. Also, it was consistent with the study carried out by Giebel et al., (2019), which revealed that older people with memory problems are more concerned with their adaptation to an acceptance of their situation 'waiting for things to come back to memory' and 'accepting and dealing with fate'. It seemed related to philosophical belief. Similar to PwD in Taiwan, they accepted that dementia was happening to them naturally and consequently they decided to continue retaining their life as long as they could (Chen et al., 2019).

As all needs intertwine, concerning the perspective of needing to continue to practise religious activities is also meaningful for older persons with early stage dementia. It can influence people to accept what has happened in their life. They believed that doing good acts, avoiding doing bad things, and purifying their mind could help them to get good things, especially at the end of life, keeping on doing religious practice could help them to die peacefully. Similarly, Dalby et al. (2011), explored the lived experience of spirituality and dementia in older people living with mild to moderate dementia. Their study found that PwD experience having dementia as a spiritual challenge which left them uncertain and distressed, but they remained connected to God or the Divine Force. They reported that their spiritual life was related to their life.

In summary, although there were differences in cultural contexts and perspectives between Thai older persons with early stage dementia and those living in other regions, there were similarities, particularly psycho-social needs. The needs of older PwD were related to their cultural context and their self-retrospect. Their background and past experiences built their needs up. This thesis focused on the needs which are important to older persons with early stage dementia regardless of met or unmet needs. This is because their needs maintain their well-being and are also able to fulfil their sense of personhood.

7.4 The relationship between the needs of older PwD, the Maslow's hierarchy of needs and Kitwood's concept of personhood

Concerning the theoretical framework underlying this study (Maslow, 1943), the basic human needs have given significance to the needs of older persons with early stage dementia. It can be understood that the needs of older persons with early stage dementia presented in this thesis are all linked together and connect to all levels of the hierarchy of the basic human needs. While Maslow created a hierarchy of needs that represents the drive of the individual's actions to meet the next need in the hierarchy, the needs of older persons with early stage dementia from this study all seem to correlate with the improvement of well-being to maintain their sense of personhood. Hence the findings in this study show that the needs of older PwD are not hierarchical. Also, the necessity of each need might be different in each person, which is variable in each situation, depending on the PwD's background and experience in receiving support, and how well they were.

From the stories and perspectives of older persons with early stage dementia, it is noticeable that although PwD might not meet the lower level, the next levels of needs were still needed in order to live with well-being to fulfil their sense of personhood (Kitwood, 1997) as much as they could. There are some needs the PwD cannot fulfil by themselves, they need their family, or other people to support them to reach their needs. The person needs to be connected to self, others, society and nature, to fulfil the sense of holistic well-being. If the person meets all their needs, they will have a sense of physical, psychological, emotional, social, and spiritual well-being, and also life satisfaction, implying that they fulfil their sense of personhood. According to Kitwood (1997) who exclusively highlighted psychological needs, which are related to the basic love needs, and created the concept of person-centred care for PwD, caregivers and people working with PwD need to be concerned about these issues to increase understanding of PwD and integrate them into a support plan for PwD to enhance their sense of personhood. In Thailand, no existing research study on the needs of older persons with early stage dementia have related these to Maslow's hierarchy of needs (Maslow, 1943) or the psychological needs of PwD (Kitwood, 1997). Hence, increasing understanding of the relationship between these two concepts and the needs of Thai older persons with early stage dementia, is useful for developing dementia care plans to address the needs of PwD and enhance them to live well with dementia.

The next section presents the relationship between the needs of older persons with early stage dementia to each of Maslow’s (1943) basic human needs as well as to Kitwood’s (1997) psychological needs of PwD to increase an understanding of how to preserve personhood; each need overlaps with others. Figure 7.1 on the next page is an illustration of this interlinked process.

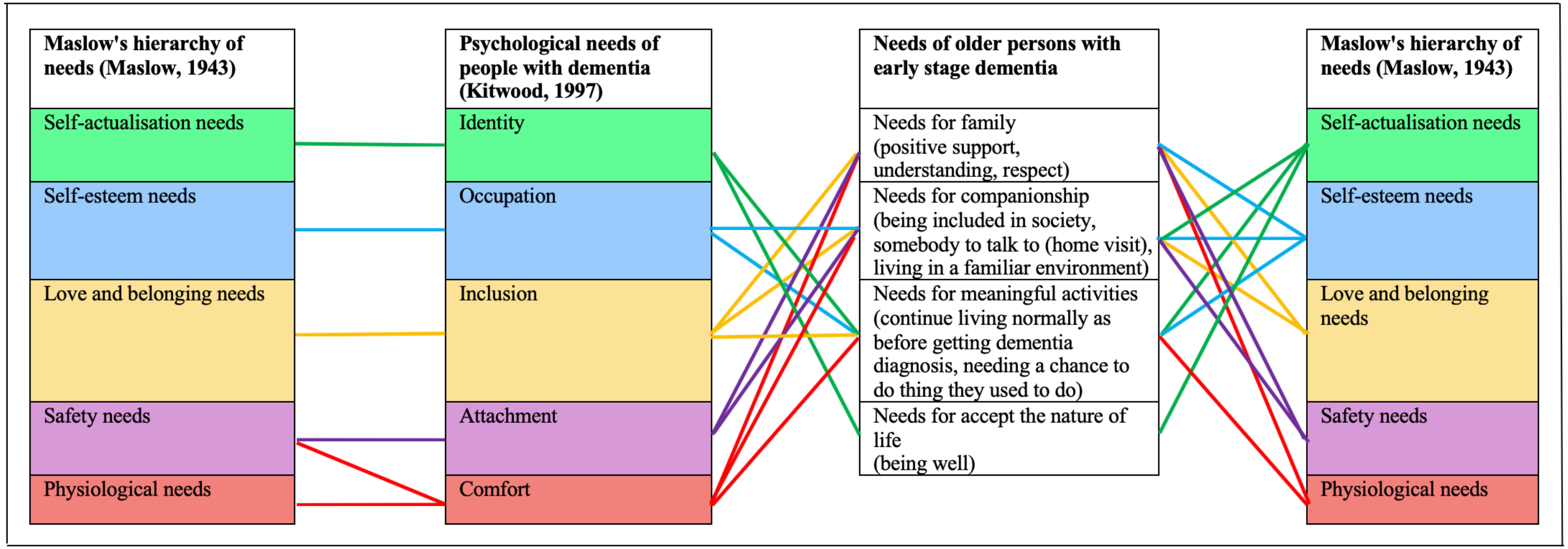


Figure 7.1 Relationship between Maslow’s hierarchy of needs, Kitwood’s psychological needs of PwD and the needs of older persons with early stage dementia

7.4.1 Physiological needs

The physiological needs are at the fundamental level of need and relate to the need to maintain the biological body (Maslow, 1943). In this thesis, physiological needs refer to the essential things maintaining the PwD’s feeding, mobility, sleep, personal hygiene, dressing, and a place to live. This need is necessary to help persons continue living and maintain a functioning body. It focuses on the individual and not the need to connect to others. Although older persons with early stage dementia were still able to do most things to fulfil the physiological needs by themselves, they sometimes needed to rely on others to help them meet this need. This need corresponds to both physical and psychological need, and relates to the feelings of persons when they were helped or supported by others.

Previous studies by Vittoria (1998), Hancock et al. (2006) and Scerri et al. (2018) indicated that PwD had their physical needs met in hospital or dementia care services. This thesis focused on older persons with early stage dementia living at home and found that the physiological needs were provided by the PwD’s family, even though some participants still had the ability to do many of the daily activities themselves. However, while some families provided physical support, they might overlook the feelings of older PwD.

Feeding and drinking are at the basic level of human need to maintain body functioning. Although the PwD might have lost the ability to cook or prepare food by themselves, their family member does this for them. In this situation, there were some PwD who could request what kind of food they wanted for their meal. Some PwD were never asked, while others let their children decide for them because they did not want to think about what they wanted to eat and ate whatever their children prepared for them.

This is consistent with Scerri et al.’s (2018) study which explored the needs of PwD in an acute medical ward in Malta. Their study found that while the PwD had their physiological needs met, they felt the ward staff rarely asked about whether their needs were met or not. Older PwD also felt reluctant to express their needs to the staff in the ward, and sometimes they were ignored. Some of the older people in my research reported similar feelings, even though they were at home. This situation could be related to the gradual decline of the PwD’s ability to communicate to express their needs, the relationship between older PwD and their family members, together with the PwD’s feelings about being reluctant to ask other people for anything.

In terms of sleeping, some older persons with early stage dementia had nocturnal problems. These might be because of the dementia, the other chronic illnesses like diabetes leading them to need to go to the toilet at night, or relationship problems with family, so they needed to search for a solution in their own way. Many of them slept during the day. This is congruent with the study of Suvanchot & Pensuksan (2020) who found that most PwD had poor sleep. The researchers conducted a cross-sectional study of the factors affecting sleep quality among 80 Thai PwD using the Pittsburgh Sleep Quality Index. The results showed that mental health problems, night-time cough, urinary frequency, pain, and fever during at night, sleep environment, and stimulant use were factors affecting their sleep. Interestingly, those experiencing family relationship problems were at higher risk for poor sleep than those experiencing good family relationships.

Based on the concept of personhood described earlier in this thesis (Kitwood, 1997), maintaining the well-being of the PwD is necessary to fulfil the sense of personhood. I argue that physiological needs can be related to both physical and psychological aspects, this need can also link to the need for comfort in Kitwood’s (1997) psychological needs model, which is a need for tenderness and soothing. Being supported to fulfil the physiological needs can help the PwD feel that the need for comfort is addressed which in turn can enhance their physical and psychological well-being.

The findings from this present study revealed that older persons with early stage dementia can perform their fundamental everyday activities for maintaining their daily lives. However, as they had cognitive decline, and sometimes additional physical limitation affecting their ability to manage things, this could affect their fulfilling their physiological needs. Although older persons did not identify the importance of physiological needs directly, this does not mean that it is trivial for them.

Noticeably, the families provided physical support for older persons with early stage dementia to help them meet their basic physical needs. This situation reinforced the Thai culture relevant to the family responsible for taking care of older parents. However, older persons might discount this need because they had already met it as they tended to fulfil this need by themselves. On the other hand, perhaps they did not think forward to a time when they might need it because they did not know what would happen to them as their dementia progressed.

Additionally, the findings showed that the families are responsible for the older persons in the family and if they have good family relationships, older persons with early stage dementia are likely to receive positive support and be able to express their needs to their family members. Unlike older persons who had family relationship problems, they were reluctant to communicate their needs. However, as in Thai culture, where older persons have high status as an old parent in the family, they would be taken care of by the younger generation. Therefore, the physical needs were addressed regardless of family relationships.

Moreover, this present study found that some families provided 'too much' support to their parent. This contrasts with some families who provided too little support or took care of parents as a duty without being concerned about the feelings of the older PwD. In terms of needing positive support from family, I advocate that although the physiological needs were addressed, how appropriate support should be provided is a matter of concern. Regarding disempowerment, the way that families limited older persons to do activities, or treated them as an object, led them to feel being excluded and can undermine personhood and the sense of well-being of the PwD (Kitwood, 1997).

7.4.2 Safety needs

Safety needs are different in each person and can even be different in the same person depending on the situation. This need is relevant to the sense of being secure and safe from harm, which could be a consequence of dementia symptoms, and also any other sources of harm which may affect the PwD physically and psychologically.

Older persons with early stage dementia live with uncertainty due to the progression of ongoing loss, and the impact of the dementia symptoms resulting from cognitive decline (Dalby et al., 2011; Alzheimer's Society, 2019c). This is a tragedy because it affects their physical, emotional, and social well-being (van Wijngaarden et al., 2018). Thus, the need for safety emerged to maintain the PwD's psychological well-being. Concerning the findings on perceptions of dementia, when people knew that they had to live with dementia, many of them had doubted what it was. As many of the participants had other chronic diseases to cope with, some of them experienced a sense of insecurity. They continued getting health support from the family and the health practitioners. This showed that some older PwD and their families coped with the impact of dementia and other chronic illnesses by continuing to live as normal. Meanwhile, some of the others lost their sense of well-being because they faced up to the impact of dementia.

In terms of physical safety, the findings showed that older persons with early stage dementia were supported by their family, even though they could still look after themselves. For example, the family taking them to meet with health professionals, as they had other chronic illnesses, the family helping to prepare medication, turning the light on in the night so that they could walk safely to the toilet. This support was aimed to protect older PwD and make them feel safe. Unlike, the study of Black et al. (2013), who conducted a cross-sectional study to determine the prevalence and correlates of unmet needs in PwD and their caregivers. They found that personal and home safety was the most common unmet in PwD, in particular, for fall risk management and home safety evaluation. Their study did not explain the context within which PwD were living, alone or with family, and neither do they discuss what stage of dementia the PwD were. Concerning addressing the needs for safety to PwD, I argue that it is good that the caregiver supports the PwD to avoid accidents or unpleasant events, but assessing the ability to do activities and balancing between physical and psychological needs is necessary to maintain personhood of the PwD.

PwD in this study trust in institutional health care, receiving support from health professional leads the PwD to feel safe. Some PwD were taking psychological medicines, while some used medication to help with memory retention. Based on literature, dementia is incurable, I respond that although there is no medication that can cure dementia, medication is still necessary to PwD as it helps to control the behavioural and psychological symptoms of dementia (BPSD). Some PwD were satisfied with medical treatment because they felt better, consonant with previous research (Pearce et al., 2002; Zimmermann, 2011; Johannessen & Möller, 2013).

As they had lost the ability to manage their medication, their family members helped them to manage the medication. However, they had to see their doctors at the hospital about every 1-3 months depending on their illness. This study has revealed that some of the older people did not go to see the doctor on the appointment date, sometimes this was for a period of more than nine months because of their physical limitations and because it was inconvenient. Therefore, a home visit is crucial as the PwD needs to be regularly supported by health professionals. It could be considered that PwD are neglected by health care providers in terms of the availability of long-term care settings compared with persons living in other long-term care settings. However, as previously mentioned there is a shortage of long-term care settings in Thailand, especially in some provinces, and there is insufficient support for older people in some areas. Importantly, health care professionals tend to focus on other chronic diseases rather than dementia. Although primary health care professionals did not visit the PwD at home, they would get good support from the health staff who are experts on dementia if they go directly to get help from the dementia clinics. However, some limitations made them not go to the hospital.

The findings from this present study discovered that visiting and asking older persons with early stage dementia to express their feelings about their health condition or personal matters could enhance them to feel more secure. They felt privileged to be attended by me, a health professional researcher, as they could consult me about their health problems. I enhanced the participants sense of love and belonging in that they felt supported. This demonstrates that it is important for older persons with early stage dementia and their family to be given information about dementia and how to cope with it on an ongoing basis.

The need for being secure and being in a familiar environment, which are contained in Kitwood's (1997) need for comfort, attachment, occupation and inclusion link to Maslow's (1943) safety and belonging needs. Living with family or in a familiar environment where there were many memories for the PwD enhanced their feeling of safety (Kitwood, 1997; von Kutzleben et al., 2012). The need for family support and living in a familiar environment, which connects to the need for being secure, is important to maintain well-being. This is consonant with the study of Mazaheri et al. (2013), which revealed that the safe environment enhances the feeling of being secure and PwD felt confident to live in the environment.

Nevertheless, some older persons with early stage dementia could not meet this need because they were in complicated situations. For example, persons living in a safe place but having to cope with a physical limitation from other chronic illnesses could not perform many activities as they used to do. In the worst situation some older persons were living with family but because of relationship problems, were exposed to abusive actions from their family. It is known that as PwD are vulnerable persons, they may be hurt by the family (Cooper et al., 2009; Chompunud et al., 2010). In this present study some older persons were physically or/and emotionally abused by family and this destroys well-being. However, these persons still preferred to live with their family. Although the family might not be a safe enough place for them to maintain their well-being, they felt better to live in their own place than to live with others, somewhere else.

In summary, being physically secure as well as feeling safe in terms of family relationships, connects to psychological well-being. Older persons with early stage dementia need the family to understand them and they need to get appropriate attention from the family. If they are assessed and encouraged to live well with dementia, this helps the PwD fulfil their safety needs and also their self-esteem needs, which can enhance well-being (Kitwood, 1997). Family is always a predominant factor in the lives of older PwD. They believe that even when the family members were unwilling to take care of them, they would feel safe when they are with their family, at least the strong bond of relationship would help them to not live alone. Older PwD need to be secure in their home and when family prefer them to be elsewhere, like in a residential home, they feel sad and insecure.

7.4.3 Love and belonging needs

The next level of these needs are the love and belonging needs, which in PwD is met by interacting with others, being attended to and engaging in social activities.

Having a good relationship with other people is necessary for older PwD because this ensures they have somebody to talk to and listen to them. It also includes getting sufficient attention and understanding from family. This is consistent with findings from previous studies (van der Roest et al., 2007; Ablitt et al., 2009; Zimmermann, 2011; von Kutzleben et al., 2012; Noysipoom & Sasat, 2014). When PwD feel free to talk to someone, they can share their feelings and express their needs to those who are willing to listen and understand them, including health professionals.

This present study reported that most older persons with early stage dementia commonly lived at home all day. Many of them did nothing, and some of them felt lonely. There were only some persons still able to leave to go outside to do their activities on their own. Although older persons with early stage dementia wanted to be included in social events and family activities, some older persons, who had physical limitations because of their other health conditions, realised that it was difficult to engage socially as they had done previously. However, they noticed that participating in society is needed to maintain social contact. I argue that being a part of the family is not only connected to the sense of being secure but it also meets the PwD's need for love and belonging. To link the needs for love and belonging with Kitwood's (1997) psychological needs, once older PwD interact socially, it fulfills the need for inclusion. Additionally, fulfilling these needs can also improve their psychosocial well-being to continue living well with dementia (Kitwood, 1997).

On the other hand, if the family ignores the older PwD, it undermines their psychosocial well-being because they feel devalued. This was underpinned by the malignant social psychology of dementia (Kitwood, 1997), which was discussed in chapter 3 (see section 3.4), this is relevant to the act of ignoring, which can impact the sense of personhood because of the behaviour of the caregiver. Further to this, it would affect the individuals self-esteem if they were still able to maintain their social interaction as usual. If they were still getting support in positive actions, it could help them to have emotional and social well-being.

In conclude, the need for love and belonging in PwD refers to the feeling of being included and listened to. To link this need to the psychological needs of PwD (Kitwood, 1997), the need for inclusion would occur once the PwD is accepted and understood by their family and friends and this influences their emotional and social well-being to fulfil their sense of personhood.

7.4.4 Self-esteem needs

This need deals with the sense of self-awareness regarding the ability to live independently and keep maintaining meaningful activities. Having the ability to manage their daily activities and making decisions by themselves, even though they need some help could lead older persons to feel less of a burden to others. Also, being dependent as little as possible can enhance the sense of self-esteem.

Engaging in social activities not only fulfils the PwD's sense of love and belonging but also their sense of self-esteem as they remain connected to others and able to participate in social activities (Han et al., 2016). The findings in this study revealed that some older persons were disrespected in their families and treated in an undignified manner by their family members. This impacted on the PwD's sense of sense esteem. The family members ignored and overlooked their older family member because they thought that older PwD had no knowledge, understanding or ability. This behaviour undermined the PwD's emotional well-being (Kitwood, 1997). Being taken care of and respected by their families and the younger generations, or even other people, like neighbours, can enhance the older PwD's sense of self-esteem.

In terms of being respected, most older persons diagnosed with dementia or Alzheimer's disease did not understand the illness and what would happen to them next. Health staff might give this information to the caregiver or the older PwD, but as their cognition declined, they needed information which was clearly delivered and explained in a way which could be easily understood. This is congruent with a study of Scerri et al. (2018), who suggested that the staff in the clinic providing the relevant information to PwD presented it in a way that respected the dignity of older PwD.

Feeling as if they were a burden to their families impacts on the older PwD's sense of self-esteem. As older persons with early stage dementia began losing the ability to live independently, and perform complicated activities like cooking food, driving, fixing household devices or engage in activities they used to do before, they needed to rely on their family members. In this situation, to fulfil their psychological well-being, it is still important for PwD to carry out some activities. It might be difficult for families to help the PwD find a suitable activity that is meaningful for them and allows them to feel they are of value, but it is a way of encouraging the person to fulfill their sense of personhood (Kitwood, 1997).

The need to maintain their self-esteem may relate to life-satisfaction and the last stage of Erikson's theory of psychological development regarding integrity and despair (Erikson, 1982 in Erikson, 1998; McLeod, 2018). Most of the PwD think about their good contributions in their lives and in their present situation that they did to their families and others. Although they need help from family member, they may perceive themselves as independent or less of a burden to their family because they are still able to do some basic activities by themselves. This can influence their feeling of being valued and fulfil their sense of self-esteem. Two participants however did feel they were dependent and a burden to their family. From these views, I reflect that the level of self-esteem of older persons with early stage dementia is related to the feeling of being a burden to the others. In addition, the way that family behaved towards the older PwD, positively or negatively, also influenced their sense of self-esteem. Sometimes just small talk, asking the older person how they were feeling, or what they wanted, would help them feel valued and enhance self-esteem.

7.4.5 Self-actualisation needs

Self-actualisation is the final need on the hierarchy and it relates to the need in a person to achieve their potential (Maslow, 1943). Older persons with early stage dementia could lose the drive to fulfil their potential because they were losing their ability to live independently and their contact with society. Hence, this need, from the perspective of older persons with early stage dementia, seems to differ from other people who do not have cognitive decline.

I advocate that the self-actualisation needs are related to Kitwood's (1997) Identity need which focuses on what makes the person unique. This notion is underpinned by the perspectives and experiences of older persons with early stage dementia that they still need to preserve their memories. Also, participants expressed that they hoped not to get worse than they currently were so they could keep doing their meaningful activities. Although some participants were not allowed to do certain activities, they searched for other activities they could do. This implies that they still needed to maintain their ability to look after themselves and be as independent as possible to avoid being a burden to the family.

There are also other self-actualisation needs and these are spiritual and religious needs. Religion was key in helping older PwD have emotional and spiritual well-being. In this study, older persons with early stage dementia believe in Buddhist teaching and accept the core content of the instruction. According to the nature of human life, being old, ill, and dying are inevitable, and as they believe that they cannot escape this way of nature, so they accepted what has happening to them. They need to understand and accept these philosophical beliefs because they help the PwD to not overthink their problems, which could help to not worsen their condition. This philosophical belief connects to spiritual well-being. It can be assumed that the more they fulfil this spiritual need, the more they can accept their illness, which can help them live well with their health condition for as long as they possibly can.

To link the findings from this study to the theoretical framework (Maslow, 1943), and the concept of psychological needs for fulfilling the spiritual well-being of PwD (Kitwood, 1997), the findings revealed that Thai older persons with early stage dementia accept what they have to confront even though the dementia changes their life, their family relationships and involves losing ability. It can be implied that they felt satisfied with the ability to live as usual and still have the potential and capacity to live normally, compared to people who were bedridden and alone.

To conclude, regarding the basic human needs, from the findings in this thesis, the family is essential to enable older persons with early stage dementia to achieve the physical, safety, love and belonging and also, self-esteem needs. If family are able to do this, then older PwD will experience well-being because they are safe and supported. In this study, while PwD had their physical needs responded to, this was not always true with regards to their feelings. PwD need positive support when they are feeling uncertain. To link with the concept of personhood, in relation to Kitwood's (1997) psychological needs, the need for comfort and attachment are important to enhance the physical and emotional well-being of PwD. Thus, older persons with early stage dementia should be attended to and asked to make the decisions about their current and future lives.

7.5 Summary of chapter

This chapter has discussed the experiences of persons living with early stage dementia including the route to getting a dementia diagnosis followed by the four themes related to the needs of older persons with early stage dementia; the essentialness of family, the need for companionship support, the need to maintain meaningful activities and how the 'nature of life' needs to be accepted. The chapter has also linked the needs of persons with early stage dementia to Maslow's hierarchy of needs (1943) and the psychological needs of PwD which are related to the concept of personhood (Kitwood, 1997). I have argued that when the needs of older persons with early stage dementia are addressed, it helps them to fulfil their well-being, which will in turn preserve their sense of personhood. The findings discussed in this chapter have provided some insights into how to enhance the well-being of older persons with early stage dementia. The final chapter suggests some useful actions to improve the supportive model for persons with early stage dementia, makes recommendations and brings the thesis to a conclusion.

Chapter 8 Conclusion and Recommendations

8.1 Introduction

This research study is the first ethnographic study in Thailand to focus on the experiences of older persons with early stage dementia from their perspective. It aimed to explore PwD's holistic perspectives on their needs to live with well-being with a dementia diagnosis. The literature review undertaken for this research showed that there was little research conducted with persons with early stage dementia, and there was no research located on the individual needs of older persons living with early stage dementia undertaken in Thailand. There was a lack of information about holistic approaches to support PwD focusing specifically on their needs to maintain their well-being in the Thai context. This chapter consists of four sections: The first is a summary and brings the findings in this research study to a conclusion; next is a discussion of the strengths and limitations of this research study; this is followed by recommendations which are aimed to improve dementia support in Thailand; finally I end this chapter with my concluding reflections on this research.

8.2 Drawing conclusions and answering the research question in this study

The research question that has guided this study is: 'what are the care needs of older persons with early stage dementia from their perspectives?' Drawing on forty nine ethnographic interviews with sixteen participants, observations and extensive fieldnotes, this study has gained an understanding of what older people in the early stages of dementia need to help them have well-being and live well with dementia. This section draws conclusions from the findings in the study.

The findings show that each person is unique. Cultural values influence the experiences and perspectives of persons with early stage dementia as well as their needs to live with well-being (see Figure 8.1).

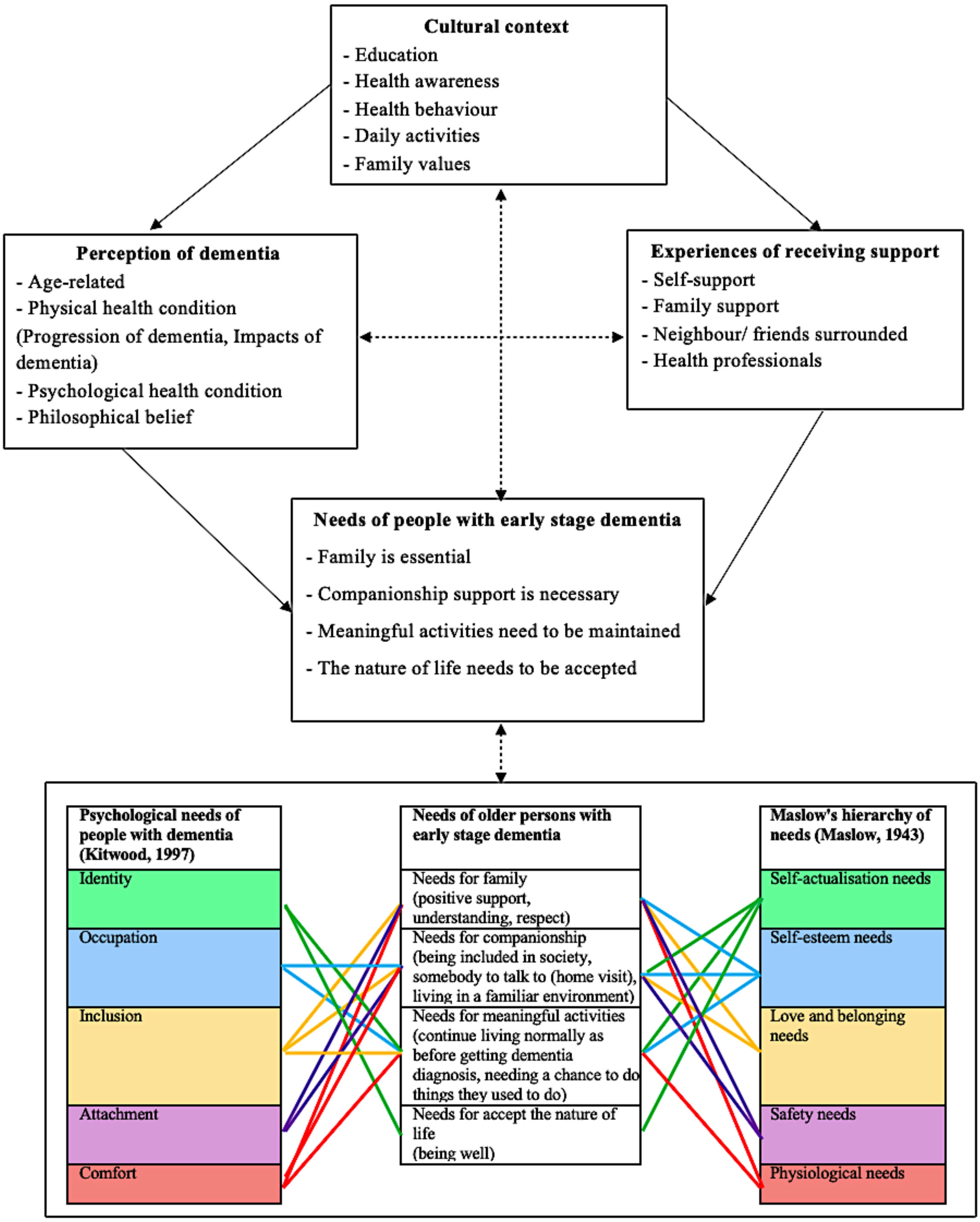


Figure 8.1 Model of the relationships between cultural context and the needs of people with early stage dementia

This exploration of the needs of older persons with early stage dementia from their own perspectives illuminated their background, cultural context, beliefs, life experiences and their experiences of living with dementia. It all links together. It is acknowledged that persons with early stage dementia are still able to communicate and express their feelings and needs. Additionally, the needs correlated to the overarching theoretical framework used to underpin the thesis (Maslow, 1943) and are connected to the concept of personhood (Kitwood, 1997) to preserve their well-being.

The study shows that the value of family is fundamental in Thai culture and makes this study different from other studies. As all participants lived with their family, this reinforces the importance of family care in Thai culture. Importantly, it is noticeable that the family is essential for older people interviewed in this study with early stage dementia as they can influence their well-being and personhood. So, they need a family to maintain their well-being and fulfil their sense of personhood. The family was responsible for supporting older persons with early stage dementia and this is common in Thai culture regardless of the family's willingness to look after the older person. This study concludes that the family was significant to older PwD as they travel with the older person along the diagnosis journey. Family members are the essential factor to help the older person get a dementia diagnosis as they are usually the persons recognising the onset symptoms of dementia and they take the older person to be evaluated.

Although older persons with early stage dementia perceived that dementia is a part of ageing, they did not want their condition to worsen. They continued to receive regular support from the hospital, they took their medications and they believed this would influence their health for the better. However, many of the older PwD did not go to see the doctor at every appointment because of their physical limitations and their family member would go instead, see the doctor, and collect their medications. There could be long intervals between seeing the doctor in person in some situations. Some older PwD lost their appointment notification. This points to a need for PwD to be visited at home by a healthcare practitioner.

This study has also illuminated that there are both positive and negative influences from being supported by the family. Further to the need for receiving positive support, older PwD need the family to understand about their symptoms and that they were not pretending or lying, they need to receive appropriate attention from family, and they need to be respected by their family. Some families provided 'over' support to older PwD, whereas some families ignored them. If older persons with early stage dementia get positive support from their family, they could meet their physiological and safety needs. Family members knowledge and understanding about dementia is related to how they behave to the PwD, and this affects the PwD's emotional well-being which links to the basic needs of love and self-esteem. If they are beloved by their family and receive affection from the family, this helps them feel valued, which satisfies the self-esteem needs.

In terms of the need for love, older persons with early stage dementia need to have social relationships because having companionship leads to psycho-social well-being. The primary social group is the family, so the family is essential for maintaining social contact. However, there were some older persons with early stage dementia living with family, but they felt lonely because they felt excluded. This could be because of family relationship problems and the PwD being perceived as a burden to the family. Therefore, it is important to have somebody willing to talk and listen to the PwD. Health and Social Care practitioners also have a role to play in helping the PwD and their family maintain social relationships and gain knowledge and understanding about dementia. Support from these sources could enhance the PwD to meet their needs for safety, love and belonging and also self-esteem because they may feel they are being attended to and they can consult these practitioners about their health and other issues.

Almost all the older PwD in this study were able to perform the fundamental activities of daily living in the same way as many older people can. Most of them stayed at home all day while some of them went out to participate in social activities. There were several participants who kept up their religious practices. Some were able to do their preferred activities. Performing activities helped the older PwD to retain their physical, psychological, social, and also spiritual well-being. Each activity has meaning for the older person in different ways. Therefore, to preserve holistic well-being, it is necessary to empower older persons with early stage dementia to continue doing their meaningful activities for as long as possible. Support for this leads the PwD to fulfil their physiological needs if they are still able to look after themselves, through to fulfilling the needs for self-esteem and self-actualisation, which will enhance them to have well-being.

Finally, older persons with early stage dementia need to accept the nature of life. As they believe in the teaching of Buddha, so they understood about karma, and attempt to accept the nature of life that what is happening with them is normal and inevitable. At the end of their lives they think back about their past and accept ‘whatever will be’. This also relates to the feeling of life-satisfaction. If they are not in pain and are still able to be independent, they continue living and do not overthink their illness because they still have their family to support them, even though they may need some help. Therefore, they have to keep living as usual with the hope that they could live as long as possible without additional help because they do not want to be a burden to their family. Moreover, being well could lead them to meet the needs of self-actualisation.

To conclude, this study represented the Thai context and revealed information derived from Thai older persons with early stage dementia. Each person has their own experiences, which influence their needs to live well with dementia. Each of their needs is required to maintain their well-being, and all needs link to each other. In turn, each need connects to Maslow's (1943) basic human needs. Therefore, to enhance the well-being of the individual with early stage dementia, the initial significant concern is understanding their background, which includes cultural context, sense of self, belief, perspectives, family relationships, the surrounding environment along with assessing their needs, to provide appropriate attention for enhancing positive care and avoid undermining their personhood. Once they are able to fulfil their needs, they can live with holistic well-being.

This study has revealed that older persons with early stage dementia were still very able to express their feelings and experiences in conversation. To link with the positive personhood work of Kitwood (1997), this reflects that asking older persons with early stage dementia to express their experiences and needs can improve the ways to care for PwD. As they still have the ability to engage in interactions, encouragement and empowerment PwD to maintain this ability should be a concern in dementia care because it could help us to increase understanding of their life and address their needs. This can enhance their emotional well-being and fulfil their needs for safety, love and belonging, self-esteem and self-actualisation and they can contribute usefully to others.

8.3 Strengths and limitations of the study

This section acknowledges the strengths and limitations of this research. It is critical to determine the strengths and weaknesses to be able to appraise the quality of the study and to prepare for developing further research.

8.3.1 Strengths

Firstly, there was very little research in Thailand exploring the experience of older persons with early stage dementia. This research is the first study investigating the perspectives of older persons with early stage dementia on their needs. A strength of this study is that it has included only older persons with early stage dementia to share their life stories and their experiences of living with dementia. Other relevant studies that have aimed to explore the needs of PwD have included PwD at various stages of the disease and have included their families or caregivers in the research. Also, other studies have focused on the viewpoints of family caregivers rather than on the perspectives of individuals with dementia. In addition, there is more information obtained from persons living in nursing homes and health institutions than those living at home. The data exhibited were analysed from the experiences and perspectives of older PwD who were the real representatives. Therefore, this study presents new and valuable knowledge, which would benefit PwD, their families, relevant health and social care practitioners, and others working with PwD.

Secondly, this study was guided by the generated theoretical framework, which has not been done before in Thailand. It was synthesised from the Maslow's hierarchy of Needs (Maslow, 1943), the universal theory using across disciplines along with the concept of personhood of PwD (Kitwood, 1997) focusing on person-centred care.

Thirdly, this research study was conducted using ethnographic interviews, along with observations to capture the perspectives of older persons with early stage dementia. Revisiting older PwD to talk to them in serial interviews was needed because it was helpful to establish rapport and confidence in the participants before asking them to share their histories. Also, it was a good way to provide opportunities for the older participants to think and confirm what they had spoken. Therefore, this qualitative research study has been able to provide rich and in-depth data of the journeys of older persons with early stage dementia, especially their experiences of living with dementia and their personal perspectives on their needs to maintain their well-being.

Finally, a strength of this study is that it has been carried out with rigour. Guba and Lincoln (1989) describe four criteria to judge rigour in a qualitative study; 'credibility', 'transferability', 'dependability' and 'confirmability' and I use these to show the rigour of this study. Credibility relates to the trustworthiness of the researcher's interpretation of the data and is similar to internal validity in quantitative research. To achieve credibility the researcher must show long engagement in the field, careful observation, case comparisons, and supervision of the study to monitor data collection, analysis and interpretation. Transferability is comparable to external validity or generalisability and in qualitative research it is about being able to apply the findings from one context to another and it allows readers of the research to decide whether they can apply the findings to other situations. Dependability is about providing a clear description of the research so that others can make a judgement about how carefully and rigorously the researchers have carried out the study, from the start to the end of the research. Finally, confirmability is about making sure that the data, analysis, interpretation, and the outcomes of the research truly come from the research context and are not just made up by the researcher.

With respect to credibility, I have already described that I spent 6 months in the research site and I got to know it very well. Throughout my stay I kept extensive field notes where I recorded my observations and reflections of the site, as well as the people I met and the interactions I observed. I conducted interviews to collect data from the older PwD but I added to this data by my observations of the environment and the interactions among the participants, their family members and the people around them.

With respect to transferability, I have presented a clear explanation of every step of the research process including from participant recruitment, to data collection and data analysis. I have provided a lot of in-depth detail to allow the reader to make a judgement about how I got from one step to the next so that they can make a decision about applying my findings to other settings.

In terms of supporting dependability, as stated above, I have provided a detailed description of every aspect of this study, including the methodology, data collection and analysis. I transcribed the interviews verbatim and then translated them into English, the anonymised translated data were checked by a bilingual translator to ensure accuracy and no loss of nuanced meaning. I reviewed these again in case they needed amending. This thesis records all the steps in the research.

Regarding confirmability, throughout my studies I have had very regular supervision and I have discussed every step of the research with my advisors who are experienced nurse researchers and supervisors in dementia and qualitative research and they have asked questions and monitored the progress of the research very carefully, including data collection, data analysis, data interpretation and the writing up of the findings.

8.3.2 Limitations

This research has provided a large amount of useful information and because of this has been able to answer the research question. However, it is critical to point out the limitations of this research study for other studies and to suggest how to improve further research and develop dementia support to address the needs of PwD to maintain their sense of personhood. The limitations discussed relate to the recruitment process and the sample in this study and these need to be attended to in future studies.

Firstly, as some older persons with early stage dementia did not see the doctor for all their follow up appointments, I often only met their caregivers. Therefore, I had no chance to explain the study and meet other possible participants. If the caregiver did not inform the PwD about the research, they had no opportunity to decide to participate in the study. So older people who may have wanted to take part in the research, had they been given the information, were excluded.

Secondly, as the majority of older persons in Thailand live with the family, they get their support from their family. Similarly, all older persons with early stage dementia who participated in this study also lived with and were supported by their family. Meanwhile, there might be some older people living alone, who did not know whether they have dementia or not. I was not able to speak to anyone living alone. Also, there were some older PwD living in residential homes who did attend the hospital and they have not been asked to express their needs. This is an issue other researchers need to think about.

8.4 Recommendations

After knowing what Thai older persons with early stage dementia need to live well with dementia, it is useful to think about how to improve the quality of their lives. There are things that can be done, and this includes by PwD themselves, their family members, and as well as the health professionals working in this field.

This section provides recommendations in four areas: Recommendations for policy, practice, education, and further research. The recommendations are made to enhance the quality of practice for practitioners who work with PwD, including health professionals, general practitioners, primary health care nurses, family care professionals, social workers, nursing teachers, nursing students and certified nursing assistants. They are also made to improve multidisciplinary working in the field of dementia.

8.4.1 Recommendations for policy

1) Ministry of Public Health (MoPH) and relevant health institutions, including non-profit organisations and private health institutions, should pay more attention to the current and future impacts of dementia. It is necessary for the government to survey the number of

PwD in each region and assess the perceptions of dementia in health and social care practitioners and in the general population to understand how to plan further support.

2) The research findings have identified a serious issue about the lack of health professionals, including geriatricians and health professionals in the field of gerontology and those who are dementia experts. To improve the quality of health services, the government should focus on increasing the number of health and social care professionals and also community health volunteers and to educate them about dementia and dementia care through the country.

3) Developing resources regarding dementia support is necessary. For example, the government and relevant organisations should promote taking a proactive approach to provide knowledge about dementia, how to get a diagnosis, sources of support for PwD and their families, and how to approach PwD. This is especially important in primary care units outside Bangkok as it would support earlier diagnosis. There is also a need to enhance education and awareness of the public about the onset signs and symptoms, the impacts of dementia and how to maintain well-being in PwD.

4) This research study recommends that both local and national policymakers should include persons with early stage dementia in some critical processes for developing dementia support, including taking part in research and being asked for their opinions.

5) The findings from this research study indicate that it would be worthwhile to increase the number of nursing homes in communities, including day care centres, which can support PwD holistically. As there is a lack of healthcare practitioners, the MoPH should collaborate with private organisations to develop these centres to improve the well-being of PwD, and to help their families to decrease the burden and stress in taking care of PwD.

8.4.2 Recommendations for practice

1) The findings from this research show that there is a need to enhance family relationships by providing dementia knowledge to PwD and their families at an early stage. Therefore, involving family members in a counsellor support group or any activities together with PwD need to be established to encourage the family to improve their understanding of the PwD. Further, they can exchange their experiences with other families about supporting PwD, which can help them to build their network.

2) Concerning the older persons limitations in being able to go to see the doctor at every appointment; the perspectives of older persons with early stage dementia indicate that they would be grateful for healthcare practitioners to visit them regularly to assess their problems and provide advice as necessary. Therefore, it would be helpful to develop the referral system between the hospitals and primary care units. The health professionals in dementia clinics or neuro-medical departments in the hospitals need to collaborate with the primary health care nurses to support PwD and the family holistically.

3) The findings from this research show that PwD need to be included and given opportunities to express how they feel, and what they want, to preserve their well-being. Hence, to address and improve the sense of personhood, it is necessary to understand the needs of PwD and support them by creating or enhancing tailored activities which have meaning for them.

8.4.3 Recommendations for education

1) This research study has shown that the lack of dementia knowledge was problematic to improve dementia support. So, it is necessary to increase the understanding of dementia and an awareness of the need to support PwD. It would be helpful to disseminate dementia information to health professionals and social care practitioners, including gerontologists, general practitioners, gerontology nurses, psychologists, primary health nurses, training nurses because they need to know, understand and be able to advise PwD, the families of PwD, and also communities.

Further to this, it is important that education programmes for students in nursing, social care and allied health ingrain theoretical knowledge and practical skills training on dementia so that these future practitioners identify PwD earlier and know how to approach them and their families.

2) In terms of approaching PwD, it would be useful for health and social care practitioners, especially primary health care nurses, and also caregivers, to improve their skills in approaching PwD and evaluating their problems, this includes improving their communication and listening skills and building up rapport with PwD.

3) There are a number of universal dementia care plans developed by experts for caring for PwD. However, what this research has shown is that there is a need to understand the personal background, culture, experiences and needs of the PwD and to critically consider what is necessary for the person to maintain their well-being. Dementia care plans provide

a useful guide, but what this research has shown is that there is a need for more personalised approaches to caring for PwD. Thus, it would be helpful to educate health and social care practitioners on the concept of personhood and person-centred care for PwD so that they can apply this knowledge to support PwD.

8.4.4 Recommendations for further research

1) The findings in this study show that there is a need to evaluate new ways of caring for older persons with early stage dementia in Thailand. A study which implements and evaluates the effect of person-centred, needs based ways of caring would build on this doctoral research and help improve PwD ability to live with well-being, especially in areas outside Bangkok.

2) This research has shown that older PwD in early stage dementia and their families had little knowledge about dementia and how it progresses. This shows that there is a need to research the needs of PwD as their disease progresses and how to prepare and support their families to care for them.

3) This research has been conducted in one province in Thailand. Given the lack of research on dementia in Thailand it would be helpful to know what is happening in other regions and research more on the needs of PwD living in other contexts.

4) It would be valuable to study the relationship between meaningful activities and the quality of life in PwD to prepare tailored activities for PwD.

5) Regarding the findings about spirituality in older persons with early stage dementia, it would be interesting to explore how religion and spirituality relate to coping with dementia. This would potentially help the relevant experts plan for the improvement of dementia support.

8.5 Personal reflections

This section presents my experiences of conducting this research, together with what knowledge and experience I have developed and gained from this doctoral study. Concerning my practical nursing and instructional experience in Thailand, I explained in the introduction to the study that working with older people in the community and with residents living in a nursing home inspired me to follow my desired career. I have carried with me thoughts about what older persons with early stage dementia need to maintain their well-being, and this became the research question for my study.

With respect to my personal purpose, I travelled from Thailand to the United Kingdom for my doctoral degree. I have achieved my four main personal goals from doctoral study and they are as follows: firstly, I have worked with expert faculty members in nursing research science who have enabled me to think about providing the highest level of care in my practice. I have also learned about rigorously conducting research and also about the ethical considerations in researching dementia. Secondly, after travelling back to Thailand to collect data, I worked with the health professionals in the research setting. I was welcomed and had good collaboration from the health and social care staff as they knew my purpose in conducting this research study. They were prepared to invite the potential participants for me and to have conversations with the PwD and their caregivers. They also provided other relevant information that was beneficial for my thesis. Thirdly, all the participants and their families engaged with me closely in taking part in this research study. Thai culture, especially in the countryside, was for people to make me feel welcome. The older people were glad when they were visited and had somebody listen to their history. Additionally, they knew I worked as a nursing teacher, and now I was studying for a doctoral degree. Older persons and their families were willing to share their experiences and as they felt more and more confident, they shared more deeply, they consulted about their health problems, and they also told me about the difficulty of caring. Fourthly, throughout the period of conducting my research I have been fortunate to exchange knowledge and experiences within a collaborative and intellectually stimulating environment made up of a diverse faculty and supervisory team, I have increased understanding of what PwD need. I have gained valuable information to develop a model of practice that will facilitate nursing care for older PwD within a Thai cultural context.

A qualitative study using ethnography interview underpins the selection of research method and led to the findings that cultural context, personal beliefs and experiences contribute to the PwD's perspectives on their lives and needs. The findings from this research study combined with the theory of human motivation related to the basic human needs (Maslow, 1943) along with the concept of personhood (Kitwood (1997) are critical to the understanding of the needs of PwD as well as their personal backgrounds and experiences. This study discovered that the needs of older persons with early stage dementia connect to all of the hierarchy of Maslow's (1943) basic human needs and the psychological needs of Kitwood (1997). However, in terms of personhood, to see the older person with early stage dementia in a holistic way, all the needs of older persons with early stage dementia in this study need to be seen as intertwined rather than in a hierarchy. The necessity of each need for the PwD might be different for each person, which is variable in each situation and is dependent on their background and their experience of coping with the impact of dementia, and on receiving support.

The significant contribution of this research is that it has provided a way to support persons with early stage dementia to enhance their well-being. It is important that the voices of PwD are taken into account while they are still able to tell and discuss their needs to live well with dementia and to plan early for their future. However, people need to understand and be aware of the impacts of dementia, they need to consider their futures after learning that they have dementia. The findings from this research differ from other research exploring the needs of PwD in that the PwD lacked knowledge of the progression of the disease. Knowledge is crucial as the basis for enhancing people's awareness of dementia. Health care professionals are an essential factor to distribute dementia knowledge to the public. Particularly, health professional working in the primary care units need to understand dementia because they have easy access to the community. So, they should be aware of the early signs and symptoms of dementia and be the representative to disseminate this knowledge to people.

During data collection, I noticed that many relevant meetings and seminars regarding dementia and dementia care for the public, caregivers, and health professionals, tended to occur in Bangkok. Also, the speakers all seemed to be working as professionals in hospitals in Bangkok. This puts limits on people living in other provinces because they could not easily travel to Bangkok to participate in these sorts of meeting. This is something I will raise when disseminating my research.

During my research I was able to give information about dementia and relevant health care to the older participants and their families. Most of these people had an increased understanding of dementia because of this, especially family members who did not realise the behaviour of their family member was due to dementia. They were able to understand and begin to accept what was happening to their loved one. Further to this, I have a further reflection from one of the nurses who reported that after I had seen the older person and their family, a family who misunderstood dementia and who had relationship problems, they began to understand the condition and were more willing to support the older PwD.

I reflect that knowledge I was able to give them during my visit had made a difference. Thus, with my background, knowledge and experience in practical nursing, my nursing education career and now with my research skills, I can continue to contribute to this area of healthcare.

Older persons with early stage dementia are still able to participate in society and contribute many benefits to others. They need to be included in the process of dementia service development. I intend to use the knowledge and skills I have gained through my doctoral studies to enhance nursing education for others, including nursing students, give relevant training to healthcare staff, give information to patients and the general public. The findings from this research can be used to exchange ideas about cultural beliefs and mores as well as bring new ideas and approaches to my chosen field and develop new ways to better integrate the areas of nursing theory and real life situations. It will be beneficial to PwD and their families because they can make use of these findings to care for PwD by responding to their actual needs and their problems.

Having completed my research and written my thesis I have taken some time to reflect on my own personal journey as a researcher. I arrived at the University of Hull on the 24th September 2015 as an experienced nurse and educator and a novice researcher. I quickly had to adapt to this new culture and work on my English language skills.

As part of my PhD programme I completed the Post-graduate training scheme which enhanced my theoretical knowledge of research methods and research methodology. This, alongside working with my supervisors and other academics in an academic environment has supported me in developing a range of research skills. Learning by doing has been the most effective way of using my new skills in practice. I now feel more confident to share and discuss my perspectives in academic conversation as an expert in gerontological nursing, a provider of care and as a researcher with people living with dementia. As a researcher, I have learned that I can plan, manage and organise a study.

My research journey has not always been smooth but I realise how resilient I have become and how I have met obstacles head on and overcome them. The process has taught me to be strong and to not give up. All things are possible if I have the intention to succeed. I have learned to improve my critical skills and reflect to improve myself and my work at every supervision with my supervisors; it is helpful to learn from the professionals.

In this doctorate I have generated new knowledge that has the potential to improve future care for Thai people living with dementia. Equally importantly I have developed knowledge, skills and confidence in dementia research that I can take back to Thailand and share with policy makers, researchers, clinicians, students and wider society. Completing the PhD has been another major step on my research journey. My intention now is to disseminate this work and plan my next career and research steps.

8.6 Concluding comments

It was hard for the older persons with early stage dementia to answer and tell me exactly what they needed to maintain their well-being. It was also very challenging for me to extract the data from what they shared of their experiences. Some information was clearly expressed by the participants, whereas some needed to be interpreted from their storytelling and from what I have observed in my fieldwork.

This research using an ethnographic approach has generated in-depth information from the interviews and observations. I have immersed myself in the data and increased my understanding of what participants have said, what they did, what they felt, and what they need to enhance their well-being to fulfil their personhood. Additionally, the use of Maslow's hierarchy of needs as a framework guided me to understand the basic human needs we all hold in common. In addition, the concept of personhood in relation to person-centred care, which was adopted to help me increase the understanding of how to approach PwD, supported me to establish their confidence to provide valued information by enabling the participants to express their feelings and share their histories with me.

I reflect that it was completely worthwhile to undertake this study with older PwD. The participants were very happy and felt privileged to be included in the research and to be asked to express their perspectives. The voices of PwD are crucial to be a representative to develop a dementia care model. Giving opportunities to PwD to express their perspectives is needed to improve dementia care. To address their needs, we need to know what they need and what is necessary to them to help them live with well-being. Thus, we need to listen to them while they have the capacity to tell us.

References

Alzheimer's association (AA) (2017a) Communication and Alzheimer's. Available online: https://www.alz.org/help-support/caregiving/daily-care/communications [Accessed 12/6/2017].

AA (2017b) Communication and Alzheimer's. Available online: https://www.alz.org/help-support/caregiving/caregiver-health/relationship-changes [Accessed 12/10/2017].

Abley, C. & Jackson, J. (2010) Practice question...Why should people with dementia be included in research and how can the barriers to their involvement be addressed? *Nursing older people,* 22 (3), 14-14.

Ablitt, A., Jones, G. V. & Muers, J. (2009) Living with dementia: a systematic review of the influence of relationship factors. *Aging & mental health,* 13 (4), 497-511.

Adams, T. & Manthorpe, J. (2003) *Dementia care.* London: Arnold.

Alzheimer's Disease International (ADI) (2014) *Dementia in the Asia Pacific Region.* London: Alzheimer's Disease International. Available online: https://www.alz.co.uk/adi/pdf/Dementia-Asia-Pacific-2014.pdf [Accessed 10/9/2016].

Ageing Asia (2014) *Ageing population in Thailand*. Available online: https://ageingasia.org/ageing-population-thailand/ [Accessed 10/9/2016].

Aggarwal, N., Vass, A. A., Minardi, H. A., Ward, R., Garfield, C. & Cybyk, B. (2003) People with dementia and their relatives: personal experiences of Alzheimer's and of the provision of care. *Journal of psychiatric and mental health nursing,* 10 (2), 187-197.

Agli, O., Bailly, N., & Ferrand, C. (2015) Spirituality and religion in older adults with dementia: A systematic review. *International Psychogeriatrics,* 27 (5), 715–725.

Alzheimer's Research UK (2015) *Dementia in the Family: The impact on carers*. Alzheimer's Research UK: Cambridge. Available online: https://www.alzheimersresearchuk.org/wp-content/uploads/2019/09/Dementia-in-the-Family-The-impact-on-carers1.pdf [Accessed 15/2/2017].

Anfara, V. A. & Mertz, N. T. (2006) *Theoretical frameworks in qualitative research*. Thousand Oaks, Calif.; London: Sage.

Arai, M. (2006) Elder abuse in Japan. *Educational Gerontology,* 32 (1), 13-23.

Alzheimer's Society (AS) (2015a) *The progression of Alzheimer's disease and other dementias.* Available online: https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses?documentID=133 [Accessed 14/11/2016].

AS (2015b) *The later stages of dementia.* Available online: https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/later-stages [Accessed 15/2/2017].

AS (2016a) Communicating. Available online: https://www.alzheimers.org.uk/sites/default/files/2019-09/500lp-communicating-190521.pdf [Accessed 15/2/2017].

AS (2016b) *Advance decisions and advance statements.* Alzheimer's Society: London. Available online: https://www.alzheimers.org.uk/sites/default/files/pdf/factsheet_the_later_stages_of_dementia.pdf [Accessed 15/2/2017].

AS (2017) *What is dementia?* Available online: https://www.alzheimers.org.uk/about-dementia/types-dementia/dementia-causes [Accessed 15/2/2017].

AS (2019a) *Consent and capacity of people with dementia*. Available online: https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/how-recruit-people-dementia/consent-and-capacity [Accessed 15/4/2020].

AS (2019b) A lonely future: 120,000 people with dementia living alone, set to double in the next 20 years. Available online: https://www.alzheimers.org.uk/news/2019-05-15/lonely-future-120000-people-dementia-living-alone-set-double-next-20-years [Accessed 04/10/2019].

AS (2019c) *Memory loss and dementia*. Available online: https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/memory-loss-dementia [Accessed on 13/6/2019].

Aspalter, C., Pribadi, K. T. & Gauld, R. (2017) *Health Care Systems in Developing Countries in Asia*. New York: Routledge.

Atkinson, P. & Hammersley, M. (1998) Ethnography and Participant Observation. In Denzin, N.K. & Lincoln, Y.S. (ed) *Strategies of Qualitative Inquiry*. London: Sage, 110-136.

Bandler, D. (2012). Living with dementia A person-centered experience. *Global Perspective, 22* (1): 6.

Barnett, E. (2000) *Including the person with Dementia in Designing and Delivering Care*. London: Jessica Kingsley.

Barnett, K., Mercer, S. W., Norbury, M., Watt, G., Wyke, S., Guthrie, B., Barnett, K., Mercer, S. W., Norbury, M., Watt, G., Wyke, S. & Guthrie, B. (2012) Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *The Lancet,* 380 (9836), 37-43.

Bartlett, H., & Martin, W. (2002). Ethical issues in dementia care research. In Wilkinson, H. (ed), *The perspectives of people with dementia: Research methods and motivations*. London, UK: Jessica Kingsley, 47-62.

Benbow, S. M. & Kingston, P. (2016) 'Talking about my experiences … at times disturbing yet positive': Producing narratives with people living with dementia. *Dementia,* 15 (5), 1034-1052.

Beuscher, L., & Beck, C. (2008) A literature review of spirituality in coping with early-stage Alzheimer's disease. *Journal of Nursing & Healthcare of Chronic Illnesses*, 17 (1), 88–97.

Beuscher, L. & Grando, V. T. (2009) Using spirituality to cope with early-stage alzheimer's disease. *Western Journal of Nursing Research,* 31 (5), 583-598.

Black, B. S., Brandt, J., Rabins, P. V., Samus, Q. M., Steele, C. D., Lyketsos, C. G. & Rosenblatt, A. (2008b) Predictors of providing informed consent or assent for research participation in assisted living residents. *The American Journal of Geriatric Psychiatry,* 16 (1), 83-91.

Black, B. S., Johnston, D., Handel, S., et al. (2008a) *Manual for the Johns Hopkins Dementia Care Needs Assessment (JHDCNA)*. Baltimore, MD.

Black, B. S., Johnston, D., Rabins, P. V., Morrison, A., Lyketsos, C. & Samus, Q. M. (2013) Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. *Journal of the American Geriatrics Society,* 61 (12), 2087-2095.

Boots, L. M. M., Wolfs, C. A. G., Verhey, F. R. J., Kempen, G. I. J. M. & de Vugt, M., E. (2015) Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. *International psychogeriatrics,* 27 (6), 927-936.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3 (2), 77–101.

Brooker, D. & Latham, I. (2015) *Person-centred dementia care,* 2nd edition. London: Jessica Kingsley.

Bryden, C. (1998) *Who will I be when I die?* London: Jessica Kingsley.

Bryden, C. (2012) *Will I still be me?* London: Jessica Kingsley.

Bryden, C. (2018) *Dancing with dementia.* London: Jessica Kingsley.

Bryman, A. & Burgess, R. G. (1994) Reflections on Qualitative Data Analysis. In Bryman, A. & Burgess, R. G. (Eds.) *Analysing Qualitative Data.* London: Routledge. 129-145.

Bryman, A. (2012) *Social Research Methods*. 4th edition. New York: Oxford University Press.

Bundhamcharoen, K. & Sasat, S. (2008) Long-term care: Comparative analysis for policy recommendation. *Ramathibodi Nursing Journal*, 14, 385–399. (in Thai)

Bureau of Legal Affairs (2015) Guide to personal income tax return 2015. Bangkok: Revenue Department. Available online:

http://www.rd.go.th/publish/fileadmin/download/english_form/Guide91_090359_eng.pdf [Accessed 14/7/2017].

Burnard, P. & Gill, P. (2008) *Culture, communication, and nursing*. Harlow; New York: Pearson Education.

Burnard, P. & Naiyapatana, W. (2004) Culture and communication in Thai nursing: A report of an ethnographic study. *International journal of nursing studies*, 41 (7), 755-765.

Caddell, L. S. & Clare, L. (2013) How does identity relate to cognition and functional abilities in early-stage dementia. *Aging, Neuropsychology & Cognition*, 20 (1), 1-21.

Cahill, S. & Diaz-Ponce, A. (2011) 'I hate having nobody here. I'd like to know where they all are': Can qualitative research detect differences in quality of life among nursing home residents with different levels of cognitive impairment? *Aging & Mental Health,* 15 (5), 562-572.

Cedervall, Y., Torres, S. & Åberg, A. C. (2015) Maintaining well-being and selfhood through physical activity: experiences of people with mild Alzheimer's disease. *Aging & mental health,* 19 (8), 679-688.

Chansirikanchana, S. (2011) *Brainstorming summaries to develop policies for prevention, treatment and care for people with dementia in Thailand: Dementia's problems and situation*. Thailand: Health Intervention and Technology Assessment Program (HITAP) & Alzheimer's Disease and Related Disorders Association in Thailand (ARDA). Available online: http://www.hitap.net/wp-content/uploads/2014/09/completed_dementia.pdf [Accessed 14/6/2017]. (in Thai)

Chen, H., Chan, S. W., Yeh, T., Huang, Y., Chien, I. & Ma, W. (2019) The spiritual needs of community-dwelling older people living with early-stage Dementia—A qualitative study. *Journal of Nursing Scholarship,* 51 (2), 157-167.

Chester, H., Clarkson, P., Davies, L., Sutcliffe, C., Davies, S., Feast, A., Hughes, J. & Challis, D. (2018) People with dementia and carer preferences for home support services in early-stage dementia. *Aging & Mental Health,* 22 (2), 270-279.

Chompunud, M. S., Charoenyooth, C., Palmer, M. H., Pongthavornkamol, K., Vorapongsathorn, T. & Jitapunkul, S. (2010) Prevalence, associated factors and predictors of elder abuse in Thailand. *Pacific Rim International Journal of Nursing Research,* 14 (4), 283-296.

Chung, J. C. C. (2006) Care needs assessment of older Chinese individuals with dementia of Hong Kong. *Aging & mental health,* 10 (6), 631-637.

Clare, L., Goater, T., & Woods, B. (2006) Illness representations in early stage dementia: A preliminary investigation. International Journal of Geriatric Psychiatry, 21, 761–767.

Coffey, A., Holbrook, B. & Atkinson, P. (1996). Qualitative Data Analysis: Technologies and Representations. *Sociological Research Online*, 1 (1), 1–12.

Collins, C. S. & Stockton, C. M. (2018) The central role of theory in qualitative research. *International Journal of Qualitative Methods*, 17 (1), 1609406918797475.

Constitution of The Kingdom of Thailand (2017) Chapter 3. Thailand: Government Gazette.

Coope, B. & Richards, F. A. (2014) *ABC of dementia* Chichester, West Sussex: Wiley-Blackwell.

Cooper, C., Selwood, A., Blanchard, M., Walker, Z., Blizard, R. & Livingston, G. (2009) Abuse of people with dementia by family carers: Representative cross sectional survey. *BMJ,* 338, b155-b155.

Cotter, V. T., Spriggs, M. & Razzak, R. (2018) Advance care planning in early stage dementia. *Journal for Nurse Practitioners*, 14 (3), 142-147.

Cowdell, F. (2008) Engaging older people with dementia in research: Myth or possibility. *International Journal of Older People Nursing,* 3 (1), 29-34.

Creswell, J. W. (2013) Qualitative inquiry & research design: Choosing among five approaches. Los Angeles: Sage.

Creswell, J. W. (2014) *Research design: Qualitative, Quantitative, and Mixed methods approaches*, 4th edition. Thousand Oaks, Calif.; London: Sage.

Cridland, E. K., Phillipson, L., Brennan-Horley, C. & Swaffer, K. (2016) Reflections and recommendations for conducting in-depth interviews with people with dementia. *Qualitative Health Research*, 26 (13), 1774-86.

Critical Appraisal Skills Programme (CASP) (2014). *CASP Checklists (URL used).* Oxford. CASP Available online: http://www.casp-uk.net/appraising-the-evidence [Accessed 10/10/2016].

Crum, R. M., Anthony, J. C., Bassett, S. S. & Folstein, M. F. (1993) Population-based norms for the Mini-Mental State Examination by age and educational level. *Jama*, 269 (18), 2386-2391.

Cruz, E. V. & Higginbottom, G. (2013) The use of focused ethnography in nursing research. *Nurse Researcher*, 20 (4), 36-43.

Dachakupt, P., Utairat, S., Sirisomboonwet, P. and Sakolrak, S. (1996) *Development of Thai education during Rama IX era: Secondary education During the year 1946-1995*. Kanchanaphisek Research On the occasion of the King Reigning 50th throne. Chulalongkorn University. Available online: http://cuir.car.chula.ac.th/handle/123456789/6650 [Accessed 5/3/2020]. (in Thai)

Dalby, P., Sperlinger, D. J. & Boddington, S. (2011) The lived experience of spirituality and dementia in older people living with mild to moderate dementia. *Dementia*, 11 (1), 75-94.

De Boer, M. E., Hertogh, C. M. P. M., Dröbes, R., Riphagen, I. I., Jonker, C., Eefsting, J. A. & Dröes, R. (2007) Suffering from dementia - the patient's perspective: a review of the literature. *International psychogeriatrics,* 19 (6), 1021-1039.

Denning, K.H., Jones, L & Sampson, E.L. (2013) Preferences for end-of-life care: a nominal group study of people with dementia and their family carers. *Palliative Medicine,* 27 (5), 409-417.

Derksen, E., Vernooij-Dassen, M., Scheltens, P. & Olde-Rikkert, M. (2006) A model for disclosure of the diagnosis of dementia. *Dementia,* 5 (3), 462-468.

Dewing, J. (2008) Personhood and dementia: Revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing*, 3 (1), 3-13.

Digby, R., Lee, S. & Williams, A. (2016) Interviewing people with dementia in hospital: recommendations for researchers. *Journal of Clinical Nursing*, 25 (7-8), 1156-65.

DiNapoli, E. A., Wu, B. & Scogin, F. (2014) Social isolation and cognitive function in appalachian older adults. *Research on Aging,* 36 (2), 161-179.

Department of Older Persons (DOP) (2017) Handbook of school for older people. Bangkok: Division of Older Person Potential Promotion. Available online: http://www.dop.go.th/download/knowledge/th1561096758-197_0.pdf [Accessed on 21/7/20]. (in Thai)

DOP (2019a) Ageing population statistics. Available online: http://www.dop.go.th/download/knowledge/th1580099938-275_1.pdf [Accessed 9/5/2020]. (in Thai)

DOP (2019b) *Driving measures National agenda About Ageing Society 6 Sustainable 4 Change (Revised Version),* 2nd edition. Bangkok: Amarin Printing and Publishing Public Co. Ltd. Available online: http://www.dop.go.th/download/knowledge/th1551432930-155_0.pdf [Accessed 6/5/2020]. (in Thai)

Downs, M. & Bowers, B. J. (2008) *Excellence in dementia care*. Maidenhead: Open University Press.

Dröes, R. M., Boelens-Van Der Knoop, E. C. C., Bos, J., Meihuizen, L., Ettema, T. P., Gerritsen, D. L., Hoogeveen, F., De Lange, J. and SchöLzel-Dorenbos, C. J. M. (2006) Quality of life in dementia in perspective: An explorative study of variations in opinions among people with dementia and their professional caregivers, and in literature. *Dementia,* 5 (4), 533–558.

Edelman, P., Kuhn, D., Fulton, B. R. & Kyrouac, G. A. (2006) Information and service needs of persons with Alzheimer's disease and their family caregivers living in rural communities. *American journal of Alzheimer's disease and other dementias,* 21 (4), 226-233.

Eichler, T., Thyrian, J. R., Dreier, A., Wucherer, D., Köhler, L., Fiß, T., Böing, G., Michalowsky, B. & Hoffmann, W. (2014) Dementia care management: going new ways in ambulant dementia care within a GP-based randomized controlled intervention trial. *International Psychogeriatrics*, 26 (2), 247–256.

Eichler, T., Thyrian, J. R., Hertel, J., Richter, S., Wucherer, D., Michalowsky, B., Teipel, S., Kilimann, I., Dreier, A. & Hoffmann, W. (2016) Unmet needs of community-dwelling primary care patients with dementia in Germany: Prevalence and correlates. *Journal of Alzheimer's Disease,* 51 (3), 847-855.

El Haj, M., Jardri, R., Larøi, F. & Antoine, P. (2016) Hallucinations, loneliness, and social isolation in Alzheimer's disease. *Cognitive Neuropsychiatry,* 21 (1), 1-13.

Emerson, R. M., Fretz, R. I. and Shaw, L. L. (2011) *Writing Ethnographic Fieldnotes*, 2nd edition. Chicago: University of Chicago Press.

Eriksen, S., Helvik, a., Juvet, L. K., Skovdahl, K., Førsund, L. H. & Grov, E. K. (2016) The experience of Relations in Persons with Dementia: A systematic meta-synthesis. *Dementia and Geriatric Cognitive Disorders,* 42, 342-368.

Erikson, E. H. & Erikson, J. M. (1998) *The life cycle completed: a review/ Erik H. Erikson. – Extended version with new chapters on the ninth stage of the development.* London: Norton & Compamy, Inc.

Eriksson, P., Henttonen, E. & Meriläinen, S. (2012) Ethnographic Field Notes and Reflexivity. In Naidoo, L. (ed) *An Ethnography of Global Landscapes and Corridors*. IntechOpen, DOI: 10.5772/36039, 9-22.

Fang, B. & Yan, E. (2018) Abuse of older persons with dementia: A review of the literature. *Trauma, Violence & Abuse,* 19 (2), 127-147.

Fetterman, D. M. (2010) *Ethnography: Step-by-step*, 3rd edition. Los Angeles, Calif.: Sage.

Fowler, C. (2004) *The archaeology of personhood: An anthropological approach*. London: Routledge.

Fukui, C., Fujisaki-Sueda-Sakai, M., Yokouchi, N., Sumikawa, Y., Horinuki, F., Baba, A., Suto, M., Okada, H., Ogino, R., Park, H. & Okata, J. (2019) Needs of persons with dementia and their family caregivers in dementia cafés. *Aging clinical and experimental research,* 31(12), 1807-1816.

Giebel, C. M., Worden, A., Challis, D., Jolley, D., Bhui, K. S., Lambat, A., Kampanellou, E. & Purandare, N. (2019) Age, memory loss and perceptions of dementia in south asian ethnic minorities. *Aging & Mental Health,* 23 (2), 173-182.

Gill, L., White, L. & Cameron, I. D. (2011) Interaction in community-based aged healthcare: Perceptions of people with dementia. *Dementia,* 10 (4), 539-554.

Gilmour, J. A. & Huntington, A. D. (2005) Finding the balance: Living with memory loss. *International Journal of Nursing Practice,* 11 (3), 118-124.

Gladys. (2019) Real stories. *Glady's story: 'We are the same people, just with a diagnosis of dementia, treat us like anyone else' Blog.* 21 May. Available online: https://www.alzheimers.org.uk/blog/gladys-story [Accessed 9/4/2020].

Glasper, E. A. & Rees, C. (2017) *Nursing and healthcare research at a glance*. Chichester, West Sussex: Wiley Blackwell.

Gold, R. L. (1958) Roles in Sociological Field Observations. *Social Forces,* 36 (3), 217–223.

Górska, S., Forsyth, K., Irvine, L., Maciver, D., Prior, S., Whitehead, J., Flockhart, J., Fairnie, J. & Reid, J. (2013) Service-related needs of older people with dementia: perspectives of service users and their unpaid carers. *International psychogeriatrics,* 25 (7), 1107-1114.

Gove, D., Diaz-Ponce, A., Georges, J., Moniz-Cook, E., Mountain, G., Chattat, R. & Øksnebjerg, L. (2018) Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging & Mental Health,* 22 (6), 723-729.

Graham, M. E. (2013) *"It's about family innit?": Towards an understanding of the lives and experiences of teenage mothers and fathers as they make the transition to parenthood*. PhD thesis. City University London. Available online: https://openaccess.city.ac.uk/id/eprint/3018/ [Accessed 18/9/2020].

Grant, C. & Osanloo, A. (2014) Understanding, selecting, and integrating a theoretical framework in dissertation research: Creating the blueprint for your "house". *Administrative Issues Journal: Connecting Education, Practice, and Research*, 4 (2), 12-26.

Gray, R. S., Hahn, L., Thapsuwan, S. & Thongcharoenchupong, N. (2016) Strength and stress: Positive and negative impacts on caregivers for older adults in Thailand. *Australasian Journal on Ageing,* 35 (2), E7-E12.

Green, J. & Thorogood, N. (2014) *Qualitative methods for health research*, 3rd edition. Los Angeles: Sage.

Greenhalgh, T. (2014) *How to read a paper: The basics of evidence-based medicine.* Chichester, West Sussex: John Wiley & Sons Inc.

Guba, E. G. & Lincoln, Y. S. (1989) *Fourth Generation Evaluation*. Newbury Park, Calif.; London: Sage.

Guest, G., Bunce, A. & Johnson, L. (2006) How many interviews are enough?: An experiment with data saturation and variability. *Field Methods,* 18 (1), 59-82.

Guest, G., Namey, E. & Mitchell, M. (2013). Participant observation. In Guest, G., Namey, E., & Mitchell, M. *Collecting qualitative data*. London: Sage, 75-112.

Haahr, A., Norlyk, A. & Hall, E. O. (2014) Ethical challenges embedded in qualitative research interviews with close relatives. *Nursing Ethics*, 21 (1), 6-15.

Hammersley, M. & Atkinson, P. (2007) *Ethnography*. London: Routledge.

Han, A., Radel, J., McDowd, J. M. & Sabata, D. (2016) Perspectives of people with dementia about meaningful activities. *American Journal of Alzheimer's Disease & Other Dementias,* 31 (2), 115-123.

Hancock, G. A., Woods, B., Challis, D. & Orrell, M. (2006) The needs of older people with dementia in residential care. *International journal of geriatric psychiatry,* 21 (1), 43-49.

Harmer, B. J. & Orrell, M. (2008) What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. *Aging & Mental Health,* 12 (5), 548-558.

Harrison, A. (2011) Using “observations of care” in nursing research: a discussion of methodological issues. *Journal of Research in Nursing,* 16 (4), 377–387.

Harrison, C. (1993) Personhood, dementia and the integrity of a life. *Canadian Journal on Aging*, 12 (4), 428-440.

Hegde, S. & Ellajosyula, R. (2016) Capacity issues and decision-making in dementia. *Annals of Indian Academy of Neurology*, 19, S34-S39.

Hellström, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007) Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14 (5), 608–619.

Herron, R. V., & Rosenberg, M. W. (2017) “Not there yet”: Examining community support from the perspective of people with dementia and their partners in care. *Social Science & Medicine,* 173, 81–87.

Higgins, P. (2013) Involving people with dementia in research. *Nursing times,* 109 (28), 20-23.

Holloway, I. & Galvin, K. (2017) *Qualitative research in nursing and healthcare*, 4th edition. Chichester, West Sussex: Wiley Blackwell.

Holst, G. & Hallberg, I. R. (2003) Exploring the meaning of everyday life, for those suffering from dementia. *American Journal of Alzheimer’s Disease & Other Dementias,* 18 (6), 359-365.

Holwerda, T. J., Deeg, D. J. H., Beekman, A. T. F., van Tilburg, T. G., Stek, M. L., Jonker, C. & Schoevers, R. A. (2014) Feelings of loneliness, but not social isolation, predict dementia onset: Results from the Amsterdam study of the elderly (AMSTEL). *Journal of Neurology, Neurosurgery & Psychiatry,* 85 (2), 135-142.

Horton-Deutsch, S., Twigg, P. & Evans, R. (2007) Health care decision-making of persons with dementia. *Dementia,* 6 (1), 105-120.

Howe, E. (2012) Informed consent, participation in research, and the Alzheimer's patient. *Innovations in clinical neuroscience*, 9 (5-6), 47–51.

Hubbard, G., Downs, M. G. & Tester, S. (2003) Including older people with dementia in research: challenges and strategies. *Aging & mental health,* 7 (5), 351-362.

Iliffe, S. & Drennan, V. (2001) *Primary care and dementia.* London: Jessica Kingsley.

Innes, A. (2009) *Dementia studies: A social science perspective.* Los Angeles, Calif.; London: Sage.

Innes, A., Blackstock, K., Mason, A., Smith, A. & Cox, S. (2005) Dementia care provision in rural Scotland: service users' and carers' experiences. *Health & social care in the community,* 13 (4), 354-365.

Innes, A., Szymczynska, P. & Stark, C. (2014) Dementia diagnosis and post-diagnostic support in Scottish rural communities: Experiences of people with dementia and their families. *Dementia,* 13 (2), 233-247.

Institute of Geriatric Medicine (2005) *The Manual for establishing and implementing the Elderly Clinic.* Bangkok: The Agricultural Cooperative Federation of Thailand Limited. (in Thai)

International Labour Organization (ILO) (2008) Thailand: Universal health care coverage through pluralistic approaches. Available online: http://www.ilo.org/wcmsp5/groups/public/---ed_protect/---soc_sec/documents/publication/wcms_secsoc_6612.pdf [Accessed 15/2/2016].

Institute for Population and Social Research (IPSR) (2013) *Population Ageing.* Available online: http://www.ipsr.mahidol.ac.th/ipsrbeta/en/ResearchClusters.aspx?ArticleId=46 [Accessed 10/9/2016].

Jitapunkul, S., Kunanusont, C., Phoolcharoen, W. & Suriyawongpaisal, P. (2001) Prevalence estimation of dementia among Thai elderly: a national survey. *Journal of the medical association of thailand = chotmaihet thangphaet,* 84 (4), 461-467.

Jitramontree, N. & Thayansin, S. (2013) Social welfare for older persons in Thailand: policy and recommendation. *Journal of public health and development,* 11 (3), 39-47.

Johannessen, A. & Möller, A. (2013) Experiences of persons with early-onset dementia in everyday life: A qualitative study. *Dementia,* 12 (4), 410-424.

Johansson, M. M., Marcusson, J. & Wressle, E. (2015) Cognitive impairment and its consequences in everyday life: experiences of people with mild cognitive impairment or mild dementia and their relatives. *International psychogeriatrics,* 27 (6), 949-958.

John (2019) Real stories. *John's story: 'If you have dementia you want to be included, you still want to feel part of things' Blog*. 23 May. Available online: https://www.alzheimers.org.uk/blog/johns-story [Accessed 9/4/2020].

Johnston, D., Samus, Q. M., Morrison, A., Leoutsakos, J. S., Hicks, K., Handel, S., Rye, R., Robbins, B., Rabins, P. V., Lyketsos, C. G. & Black, B. S. (2011) Identification of community-residing individuals with dementia and their unmet needs for care. *International journal of geriatric psychiatry,* 26 (3), 292-298.

Karlsson, S., Bleijlevens, M., Roe, B., Saks, K., Martin, M. S., Stephan, A., Suhonen, R., Zabalegui, A. & Hallberg, I. R. (2015) Dementia care in European countries, from the perspective of people with dementia and their caregivers. *Journal of advanced nursing,* 71 (6), 1405-1416.

Kawulich, B. B. (2005) May. Participant observation as a data collection method. In *Forum: Qualitative Social Research,* 6(2). Available online: http://www.qualitative-research.net/index.php/fqs/article/view/466/996 [Accessed 10/7/20].

Kerpershoek, L., de Vugt, M., Wolfs, C., Woods, B., Jelley, H., Orrell, M., Stephan, A., Bieber, A., Meyer, G., Selbaek, G., Handels, R., Wimo, A., Hopper, L., Irving, K., Marques, M., Gonçalves-Pereira, M., Portolani, E., Zanetti, O. & Verhey, F. (2018) Needs and quality of life of people with middle-stage dementia and their family carers from the european actifcare study. When informal care alone may not suffice. *Aging & Mental Health,* 22 (7), 897-902.

Khamngae, S., Boonleaing, S., Bungchan, N. & Na Sokolnakorn, T, P. (2014) Social welfare needs and policies for elderly people in Thailand: a case study in Pitsanulok community. *Asian Social Science,* 10 (12), 142-148.

Kitwood, T. (1997) Dementia reconsidered: the person comes first. New York: Open University Press.

Knodel, J. & Chayovan, N. (2009) Older Persons in Thailand: A Demographic, Social and Economic Profile. *Ageing international,* 33 (1-4), 3-14.

Knodel, J., Teerawichitchainan, B. & Pothisiri, W. (2018) Caring for Thai older persons with long-term care needs. *Journal of Aging & Health,* 30 (10), 1516-1535.

Knopf, A. (2019) Dementia: Not a mental illness, but boundaries frequently blurred. *Mental Health Weekly*, 29(36), 1–7.

Krishnamoorthy, E. S., Prince, M. & Cummings, J. L. (2010) *Dementia: A global approach.* Cambridge: Cambridge University Press.

Krull, A. C. (2005) First signs and normalizations: Caregiver routes to the diagnosis of alzheimer's disease. *Journal of Aging Studies*, 19 (4), 407-417.

Kuhn, D. R. (1998) Caring for relatives with early stage Alzheimer's disease: An exploratory study. *American Journal of Alzheimer's Disease,* 13 (4), 189–196.

Kulachai, W. (2018) Elder abuse in Thailand: Prevalence, causes, consequences, and public supports. *International Journal of Management and Applied Science,* 4 (10), 52-56.

Lawrence, V., Samsi, K., Banerjee, S., Morgan, C. & Murray, J. (2011) Threat to valued elements of life: The experience of dementia across three ethnic groups. *The Gerontologist,* 51 (1), 39-50.

Lepore, M., Ferrell, A. & Wiener, J. M. (2017) Living arrangements of people with Alzheimer's Disease and related dementias: Implications for services and supports. *Issue Brief: Research Summit on Dementia Care: Building Evidence for Services and Supports.* Available online: https://aspe.hhs.gov/system/files/pdf/257966/LivingArran.pdf [Accessed 12/4/2020].

Lethin, C., Hanson, E., Margioti, E., Chiatti, C., Gagliardi, C., Vaz de Carvalho, C. & Fänge, A. M. (2019) Support Needs and Expectations of people living with dementia and their informal carers in everyday life: A European study. *Social Sciences.* 8, 203, Leung, K. K., Finlay, J., Silvius, J. L., Koehn, S., McCleary, L., Cohen, C. A., Hum, S., Garcia, L., Dalziel, W., Emerson, V. F., Pimlott, N. J. G., Persaud, M., Kozak, J. & Drummond, N. (2011) Pathways to diagnosis: Exploring the experiences of problem recognition and obtaining a dementia diagnosis among anglo-canadians. *Health & Social Care in the Community,* 19 (4), 372-381.

Limanonda, B. (1995) Families in Thailand: Beliefs and Realities. *Journal of comparative family studies,* 26 (1), 67-82.

Love, K. & Pinkowitz, J. (2013) Person-Centered Care for People with Dementia: A Theoretical and Conceptual Framework. *Generations,* 37 (3), 23-29.

Makkhakvun, C. (2014) Looking backwards and forwards on the Thai education reform, is it better or still at the same place? *Sisaket Rajabhut University Journal*, 6 (2), 26-39. (in Thai)

Manasatchakun, P., Chotiga, P., Roxberg, Å & Asp, M. (2016) Healthy ageing in Isan-Thai culture--A p he no me no graphic study based on older persons' lived experiences. *International Journal of Qualitative Studies on Health & Well-Being*, 11 (1), 29463.

Maps of World (2015) *Thailand Cities Map*. Available online: https://www.mapsofworld.com/thailand/cities-map.html [Accessed 15/2/2017].

Marshall, C. & Rossman, B. G. (2016) *Designing qualitative research.* Thousand Oaks, California: Sage.

Marson, D. C., Schmitt, F. A., Ingram, K. K. & Harrell, L. E. (1994) Determining the competency of alzheimer patients to consent to treatment and research. *Alzheimer Disease and Associated Disorders*, 8, 5-18.

Maslow, A. H. (1943) A theory of human motivation. *Psychological review,* 50(4), 370-396.

Mattos, M. K., Burke, L. E., Baernholdt, M., Hu, L., Nilsen, M. L. & Lingler, J. H. (2019) Perceived social determinants of health among older, rural-dwelling adults with early-stage cognitive impairment. *Dementia,* 18 (3), 920-935.

Mazaheri, M., Eriksson, L. E., Heikkilä, K., Nasrabadi, A. N., Ekman, S. & Sunvisson, H. (2013) Experiences of living with dementia: Qualitative content analysis of semi-structured interviews. *Journal of Clinical Nursing,* 22 (21-22), 3032-3041.

McCarthy, B. (2011) *Hearing the person with dementia: Person-centred approaches to communication for families and caregivers.* London: Jessica Kingsley.

McKeown, J., Clarke, A., Ingleton, C. & Repper, J. (2010) Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19 (13-14), 1935-1943.

McLeod, S. A. (2018) *Erik Erikson's Stages of Psychosocial Development*. Simply Psychology. Available online: https://www.simplypsychology.org/Erik-Erikson.html [Accessed 04/10/2019].

McWalter, G., Toner, H., & Corser, A. (1994) Needs and needs assessment: their components and definitions with reference to dementia. *Health Social Care.* 2 (4). 213-219.

McWalter, G., Toner, H., Eastwood, J., Corser, A., Marshall, M., Turvey, A. & Howie, C. (1996) *CarenapD-Manual User Manual for the Care Needs Assessment Pack for Dementia (CarenapD)*. Stirling: University of Stirling.

McWalter, G., Toner, H., McWalter, A., Eastwood, J., Marshall, M. & Turvey, T. (1998) A community needs assessment: the care needs assessment pack for dementia (CarenapD)--its development, reliability and validity. *International journal of geriatric psychiatry,* 13 (1), 16-22.

Meaney, A. M., Croke, M. & Kirby, M. (2005) Needs assessment in dementia. *International journal of geriatric psychiatry,* 20 (4), 322-329.

Merriam, S. B. & Tisdell, E. J. (2016) Qualitative research. San Francisco, CA: Jossey-Bass.

Minghella, E. & Schneider, K. (2012) Rethinking a framework for dementia 1: a journey. *Working with older people: Community care policy & practice,* 16 (3), 122-131.

Miranda-Castillo, C., Woods, B. & Orrell, M. (2010a) People with dementia living alone: What are their needs and what kind of support are they receiving. *International psychogeriatrics,* 22 (4), 607-617.

Miranda-Castillo, C., Woods, B. & Orrell, M. (2013) The needs of people with dementia living at home from user, caregiver and professional perspectives: a cross-sectional survey. *BMC health services research,* 13, 43.

Miranda-Castillo, C., Woods, B., Galboda, K., Oomman, S., Olojugba, C., & Orrell, M. (2010b) Unmet needs, quality of life and support networks of people with dementia living at home. *Health and quality of life outcomes*, 8, 132.

Mitchell, G. & Agnelli, J. (2015) Person-centred care for people with dementia: Kitwood reconsidered. *Nursing standard,* 30 (7), 46-50.

Mitchell, W. (2018) *Somebody I used to know.* London: Bloomsbury.

Moher D, Liberati A, Tetzlaff J, Altman DG & The PRISMA Group. (2009) Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med*, 6(7): e1000097.

Moody, J. (2003) Dementia and personhood: Implications for advance directives. *Nursing Older People*, 15 (4), 18-21.

Ministry of Public Health (MoPH) & Ministry of Social and Human Security (MSHS), Thailand (2007) *Thailand: country report on social welfare and health care services for elderly*. Tokyo, Japan. Available online: https://www.mhlw.go.jp/bunya/kokusaigyomu/asean/asean/kokusai/siryou/dl/h19_thailand.pdf [Accessed 5/6/2017].

Moyle, W., Kellett, U., Ballantyne, A. & Gracia, N. (2011) Dementia and loneliness: An australian perspective. *Journal of Clinical Nursing,* 20 (9-10), 1445-1453.

Muangpaisan, W., Praditsuwan, R., Assanasen, J., Srinonprasert, V., Assantachai, P., Intalapaporn, S., Chatthanawaree, W., Dajpratham, P., Kuptniratsaikul V. and Pisansalakij, D. (2010) Caregiver burden and needs of dementia caregivers in Thailand: a cross-sectional study. *Journal of the Medical Association of Thailand*, 93 (5), 601-607.

Murphy, K., Jordan, F., Hunter, A., Cooney, A. & Casey, D. (2015) Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies. *Dementia*, 14 (6), 800-24.

Northcote, J. & Moore, D. (2010) Understanding Contexts: Methods and Analysis in Ethnographic Research on Drugs. In Miller, P. G., Strang, J. & Miller, P. M. (eds) *Addiction Research Methods*. Oxford: Blackwell Publishing Ltd, 287-298.

Noysipoom, N. & Sasat, S. (2014) Living with Early-stage Dementia of Older Persons: A Qualitative Case Study. *Journal of nursing science Chulalongkorn University,* 26 (2), 99-110. (in Thai)

National Statistical Office (NSO) (2014) *The 2014 Survey of The Older Persons in Thailand*. Bangkok; Text and Journal Publication Company. (in Thai)

NSO (2019) *Executive summary Household socioeconomic survey 2019 (B.E. 2562)*. Available online: http: www.nso.go.th/sites/2014/DocLib13/ด้านสังคม/สาขารายได้/เศรษฐกิจสังคมครัวเรือน/62/Exclusive_62.pdf [Accessed 05/01/2020]. (in Thai)

O'Luanaigh, C., O'Connell, H., Chin, A., Hamilton, F., Coen, R., Walsh, C., Walsh, J. B., Caokley, D., Cunningham, C. & Lawlor, B. A. (2012) Loneliness and cognition in older people: The Dublin healthy ageing study. *Aging & Mental Health,* 16 (3), 347-352.

O'Reilly, K. (2012) Sampling. In O'Reilly, K. (ed), *Key Concepts in Ethnography*. London: Sage, 194-201.

Organisation for Economic Cooperation and Development (OECD) (2005) Long-term care for older people. Paris: OECD.

Orrell, M. & Hancock, G. (2004) *CANE: Camberwell Assessment of Need for the Elderly.* London: Gaskell.

Panegyres, P. K., Berry, R. & Burchell, J. (2016) Early dementia screening. *Diagnostics*, 6 (1), 1-6.

Parahoo, K. (2014) Nursing research: Principles, process and issues Basingstoke, Hampshire: Palgrave Macmillan.

Passos, J., Sequeira, C. & Fernandes, L. (2012) The needs of older people with mental health problems: A particular focus on dementia patients and their carers. *International Journal of Alzheimer's Disease,* 1-7.

Pearce, A., Clare, L. & Pistrang, N. (2002) Managing sense of self: Coping in the early stages of Alzheimer's disease. *Dementia,* 1 (2), 173-192.

Pearsall, M. (1970). Participant observation as role and method in behavioral research. In W. J. Filstead (ed), *Qualitative methodology: Firsthand involvement with the social world*. Chicago: Markham, 340–352.

Perry-Young, L., Owen, G., Kelly, S. & Owens, C. (2018) How people come to recognise a problem and seek medical help for a person showing early signs of dementia: a systematic review and meta-ethnography. *Dementia*, 17 (1), 34-60.

Phillips, D. R. & Chan, A. C. M. (2002) *Ageing and long-term care: national policies in the Asia-Pacific.* Singapore: Bestprint Printing.

Phinney, A., Chaudhury, H. & O'connor, D. L. (2007) Doing as much as I can do: The meaning of activity for people with dementia. *Aging & Mental Health,* 11 (4), 384-393.

Phinney, A., Dahlke, S. & Purves, B. (2013) Shifting patterns of everyday activity in early dementia: Experiences of men and their families. *Journal of Family Nursing,* 19 (3), 348-374.

Pickering, C. E. Z., Yefimova, M., Maxwell, C., Puga, F. & Sullivan, T. (2019) Daily context for abusive and neglectful behavior in family caregiving for dementia. *The Gerontologist,* 60 (3), 483-493.

Pinyuchon, M & Gray, L. A. (1997) Understanding Thai families: A cultural context for therapists using a structural approach. *Contemporary Family Therapy*, 19 (2), 209-228, 1997.

Pitakchinnapong, N. & Rhein, D. (2019) Exploration of the Causation of Stigmatization of Mental Illness in Thailand: Perceptions of Thai University Students. *Human Behavior, Development and Society,* 22 (2), 7-19.

PNI (2014) *Clinical Practice Guideline: Dementia.* Bangkok: Tanapress. (in Thai)

Portacolone, E., Johnson, J. K., Covinsky, K. E., Halpern, J. & Rubinstein, R. L. (2018) The effects and meanings of receiving a diagnosis of mild cognitive impairment or alzheimer's disease when one lives alone. *Journal of Alzheimer's Disease,* 61 (4), 1517-1529.

Portacolone, E., Rubinstein, R. L., Covinsky, K. E., Halpern, J. & Johnson, J. K. (2019) The precarity of older adults living alone with cognitive impairment. *Gerontologist,* 59 (2), 271-280.

Porteri, C. (2018) Advance directives as a tool to respect patients' values and preferences: Discussion on the case of alzheimer's disease. *BMC Medical Ethics,* 19 (1).

Powers, S. M., Dawson, N. T., Krestar, M. L., Yarry, S. J. & Judge, K. S. (2016) 'I wish they would remember that I forget:' The effects of memory loss on the lives of individuals with mild-to-moderate dementia. *Dementia,* 15 (5), 1053-1067.

Pratomthong, S. J., & Baker, S. B. (1983) Overcoming obstacles to the growth and development of guidance and counseling in Thailand. *Personnel and Guidance Journal,* 61*,* 466-469.

Pratt, R. (2002) 'Nobody's ever asked how I felt'. In Wilkinson, H. (ed) *The Perspectives of People with Dementia: Research Method and Motivation.* London: Jessica Kingsley, 165-182.

Pratt, R. & Wilkinson, H. (2003) A psychosocial model of understanding the experience of receiving a diagnosis of dementia. *Dementia,* 2 (2), 181-199.

Rashid, M., Hodgson, C. S., & Luig, T. (2019) Ten tips for conducting focused ethnography in medical education research. *Medical education online*, 24 (1), 1624133. https://doi.org/10.1080/10872981.2019.1624133 [Accessed 27/5/2020].

Ratanakul, P. (2004) The Buddhist concept of life, suffering and death, and related bioethical issues. *Eubios Journal of Asian and International Bioethical*, 14, 141-146. Available online: https://www.eubios.info/EJ144/ej144f.htm [Accessed 17/7/ 2019].

Reeves, S., Kuper, A. & Hodges, B. D. (2008) Qualitative research methodologies: Ethnography. *BMJ*, 337, a1020.

Reynolds, T., Thornicraft, G., Abas, M., Woods, B., Hoe, J., Leese, M. & Orrell, M. (2000) Camberwell Assessment of Needs for the Elderly (CANE): Development, Validity and Reliability. *British journal of psychiatry*, 176 (5), 444-452.

Richards, L. (2015) *Handling Qualitative Data: A Practical Guide*. 3rd edition. London: Sage Publications Ltd.

Richards, L. & Morse, J.M. (2007) *Readme First for a User's Guide to Qualitative Methods*, 3rd edition. Thousand Oaks: Sage.

Risco, E., Cabrera, E., Farré, M., Alvira, C., Miguel, S. & Zabalegui, A. (2016) Perspectives about health care provision in dementia care in Spain: A qualitative study using focus-group methodology. *American Journal of Alzheimer's Disease and Other Dementias,* 31 (3), 223-230.

Ritchie, J., Lewis, J., Nicholls, C. Mc. & Ormston, R. (2014) *Qualitative research practice: A guide for social science students and researchers*. London: Sage.

Robert, H. (2009). Now that I live with dementia. *Global Perspective.* 19 (1): 3.

Rogers, C. R. (1961) *On becoming a person: A therapist's view of psychotherapy* London: Constable.

Roper, J. M. & Shapira, J. (2000) *Ethnography in nursing research*. Thousand Oaks, California: Sage.

Royan, L. (2003) Working with people in the early stages of dementia. In Adams, T. & Manthorpe, J. (eds) *Dementia Care.* London: Arnold, 51-68.

Sasat, S. (1998) *Caring for dementia in Thailand: A study of family care for dementia elderly relatives in Thai Buddhist society***.** Unpublished Ph.D. Thesis, University of Hull, UK.

Sasat, S. & Bowers, B. J. (2013) Spotlight Thailand. *Gerontologist,* 53 (5), 711-717.

Sasat, S. & Pukdeeprom, T. (2010) Elderly care assistant. *Journal of Health Science,* 19 (1), 103-119.

Sasat, S., Choowattanapakorm, T., Pukdeeprom, T., Lertrat, P., & Arunsaeng, P. (2013) Long-term care institutions in Thailand. *Journal of Health Research,* 27 (6), 413-418.

Scerri, A., Scerri, C. & Innes, A. (2018) The perceived and observed needs of patients with dementia admitted to acute medical wards. *Dementia*, 1471301218814383, Available online: https://doi.org/10.1177/1471301218814383 [Accessed 2/8/2019].

Schölzel-Dorenbos, C. J. M., Draskovic, I., Vernooij-Dassen, M. J., & Olde Rikkert, M. G. M. (2009) Quality of Life and Burden of Spouses of Alzheimer Disease Patients. *Alzheimer Disease & Associated Disorders,* 23 (2), 171–177.

Schölzel-Dorenbos, C. J. M., Meeuwsen, E. J. & Olde Rikkert, M., G.M. (2010) Integrating unmet needs into dementia health-related quality of life research and care: Introduction of the Hierarchy Model of Needs in Dementia. *Aging & mental health,* 14 (1), 113-119.

Scottish Dementia Working Group, Research Sub-Group, United Kingdom. (2014) Core principles for involving people with dementia in research: Innovative practice. *Dementia,* 13 (5), 680-685.

Senanarong, V., Harnphadungkit, K., Poungvarin, N., Vannasaeng, S., Chongwisal, S., Chakorn, T., Jamjumrus, P., Raksthaput, A., Chaichanettee, S., Aoonkaew, N., Udompunthurak, S., Doody, R. S. & Cummings, J. L. (2013) The dementia and disability project in Thai elderly: rational, design, methodology and early results. *BMC neurology,* 13 (1), 3-3.

Sethabouppha, H. & Kane, C. (2005) Caring for the seriously mentally ill in Thailand: Buddhist family caregiving. *Psychiatric Nursing,* 19 (2), 44-57.

Shankar, A., Hamer, M., McMunn, A. & Steptoe, A. (2013) Social isolation and loneliness: Relationships with cognitive function during 4 years of follow-up in the English longitudinal study of ageing. *Psychosomatic Medicine,* 75 (2), 161-170.

Sheehan, B. D., Lall, R., Stinton, C., Mitchell, K., Gage, H., Holland, C. and Katz, J. (2012) Patient and proxy measurement of quality of life among general hospital in-patients with dementia. *Aging and Mental Health,* 16 (5), 603-607.

Shenton, A. K. (2004) Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, 22 (2), 63-75.

Shim, Y. S., Dong, W. Y., Hee-Jin Kim, Park, Y. H., Kim, S., Yang, D. W., Kim, H., Park, Y. H. & Kim, S. (2017) Characteristic differences in the mini-mental state examination used in Asian countries. *BMC neurology*, 17 1-9.

Silver, C. & Lewins, A. (2014) *Using Software in Qualitative Research: A Step-by-Step Guide*. 2nd edition. London: Sage Publications Ltd.

Small, N., Froggatt, K. & Downs, M. (2007) *Living and dying with dementia*. Oxford; New York: Oxford University Press.

Snyder, L. (1999) *Speaking Our Minds, Personal Reflections from Individuals with Alzheimer's*. New York: W.H. Freeman and Company.

Spradley, J. P. (1979) *The ethnographic interview.* Belmont, Calif.: Warsworth Cengage Learning.

Spradley, J. P. (1980) *Participant observation.* Belmont, Calif.: Warsworth Cengage Learning.

Srinim, N. (2015) Preliminary report: Problems and coping experience of caregivers who provided care for dementia patients at home. *Journal of Mental Health of Thailand*, 23 (1), 61-71. (in Thai)

Srithamrongsawat, S. & Bundhamcharoen, K. (2010) *Synthesis of Long-term Care System for the Elderly in Thailand.* Bangkok: Foundation of Thai Gerontology Research and Development institute. (in Thai)

Steeman, E., De Casterlé, B. D., Godderis, J. & Grypdonck, M. (2006) Living with early-stage dementia: a review of qualitative studies. *Journal of advanced nursing,* 54 (6), 722-738.

Steeman, E., Godderis, J., Grypdonck, M., Bal, N. D., & De Casterlé, B. D. (2007). Living with dementia from the perspective of older people: Is it a positive story?. *Aging & Mental Health*. 11 (2). 119-130.

Stephan, A., Bieber, A., Hopper, L., Joyce, R., Irving, K., Zanetti, O., Portolani, E., Kerpershoek, L., Verhey, F., de Vugt, M., Wolfs, C., Eriksen, S., Røsvik, J., Marques, M. J., Gonçalves-Pereira, M., Sjölund, B., Jelley, H., Woods, B., Meyer, G. & on behalf of the, Actifcare Consortium (2018) Barriers and facilitators to the access to and use of formal dementia care: Findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight european countries. *BMC Geriatrics,* 18 (1), 1-16.

Sutcliffe, C.L., Roe, B., Jasper, R., Jolley, D. & Challis, D.J. (2015) People with dementia and carers' experiences of dementia care and services: Outcomes of a focus group study. *Dementia,* 14 (6), 769-787.

Suvanchot, K. S. & Pensuksan, W. C. (2020) Factors affecting sleep among Thai people with dementia attending an outpatient psychiatric department. *Dementia,* 19 (2), 135-147.

Suwanrada, W., Pothisiri, W., Prachuabmoh, V., Siriboon, S., Bangkaew, B. & Milintangul, C. (2014) *Community-Based Integrated Approach for Older Persons' Long-Term Care in Thailand*. Chulalongkorn University. (College of Population Studies). Available online: https://www.toyotafound.or.jp/international/2014/publications/data/2015-0430-1012.pdf [Accessed 7/1/2017].

Svanström, R. & Sundler, A. J. (2015) Gradually losing one's foothold: A fragmented existence when living alone with dementia. *Dementia,* 14 (2), 145-163.

Tam, S. & Neysmith, S. (2006) Disrespect and isolation: Elder abuse in Chinese communities. *Canadian Journal on Aging,* 25 (2), 141-152.

Tangcharoensathien, V. (Ed) (2015) *The Kingdom of Thailand Health System Review*. Manila: WHO, Reginal Office for the Western Pacific. Available online: https://apps.who.int/iris/bitstream/handle/10665/208216/9789290617136_eng.pdf?sequence=1&isAllowed=y [Accessed 7/5/2020].

Tantiritisak, T. (ed) (2014) *Clinical Practice Guideline: Dementia.* Bangkok: PNI. (in Thai)

Tantiritisak, T. & Prajanatham, A. (2011) *Brainstorming summaries to develop policies for prevention, treatment and care for people with dementia in Thailand: Diagnosis and treatment of dementia*. Thailand: Health Intervention and Technology Assessment Program (HITAP) & Alzheimer's Disease and Related Disorders Association in Thailand (ARDA). Available online: http://www.hitap.net/wp-content/uploads/2014/09/completed_dementia.pdf [Accessed 14/06/2017]. (in Thai)

Tetley, J. (2013) Articulation, service use, managing and coping: understanding the needs of older people and carers living with dementia. *International Practice Development Journal,* 3 (2), 1-14.

Thai Cognitive test Development Committee 1999. (2002) Mini-mental state examination-Thai 2002. Bangkok: Institute of Geriatric Medicine, Department of Medical Services, MoPH, Thailand. (in Thai)

The Act on Older Persons B.E. 2546 (2003). Thailand: Government Gazette.

The Mental Capacity Act (2005) London: HMSO Government.

Thyrian, J. R., Fiß, T., Dreier, A., Böwing, G., Angelow, A., Lueke, S., Teipel, S., Grabe, H. J., Freyberger, H. J. & Hoffmann, W. (2012) Life- and person-centred help in Mecklenburg-Western Pomerania, Germany (DelpHi): study protocol for a randomised controlled trial. *Trials,* 13 (1).

Tombaugh, T. N. & McIntyre, N. J. (1992) The mini-mental state examination: a comprehensive review. *Journal of the American Geriatrics Society*, 40 (9), 922-935.

Tremont, G (2011) Family Caregiving in Dementia. *Medical and Health, Rhode Island*, 94 (2), 36-38.

United Nations (UN) (2002a) *World Population Ageing 1950-2050.* New York: UN. Available online: http://globalag.igc.org/ruralaging/world/ageingo.htm [Accessed 10/09/2016].

UN (2015a) *World Population Ageing 2015.* New York: UN. Available online: https://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2015_Report.pdf [Accessed 10/9/2016].

UN (2015b) *World Population Prospects: The 2015 Revision.* New York: UN. Available online: https://population.un.org/wpp/publications/files/key_findings_wpp_2015.pdf [Accessed 10/9/2016].

UN (2017) *World Population Prospects: The 2017 Revision*. New York: UN. Available online: https://population.un.org/wpp/Publications/Files/WPP2017_DataBooklet.pdf [Accessed 12/11/2019].

Undara, W., Singhasenee, U. & Wongnitikul, P. (2016) The study of dementia knowledge and prevention of dementia and the demographic data in the elderly association of Royal Thai Air Force nursing college. *Journal of The Police Nurses*, 8 (1), 23-33. (in Thai)

United Nations Population Fund (UNFPA) & HelpAge International (2012) *Executive summary Ageing in Twenty-First Century: A Celebration and A Challenge.* London: UNFPA & HelpAge International.

van der Roest, H. G., Meiland, F. J. M., Comijs, H. C., Derksen, E., Jansen, A. P. D., van Hout, Hein P. J., Jonker, C. & Dröes, R. (2009) What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services. *International psychogeriatrics,* 21 (5), 949-965.

van der Roest, H. G., Meiland, F. J. M., Maroccini, R., Comijs, H. C., Jonker, C. & Dröes, R. (2007) Subjective needs of people with dementia: a review of the literature. *International psychogeriatrics,* 19 (3), 559-592.

van Gennip, I. E., Pasman, H. R., Oosterveld-Vlug, M., Willems, D. L. & Onwuteaka-Philipsen, B. (2016) How Dementia Affects Personal Dignity: A Qualitative Study on the Perspective of Individuals with Mild to Moderate Dementia. *Journals of gerontology series B: Psychological sciences & social sciences,* 71 (3), 491-501.

van Wijngaarden, E., van der Wedden, H., Henning, Z., Komen, R. & The, A-M. (2018) Entangled in uncertainty: The experience of living with dementia from the perspective of family caregivers. *PLoS ONE,* 13 (6), 1-21.

Vernooij-Dassen, M., Derksen, E., Scheltens, P. & Moniz-Cook, E. (2006) Receiving a diagnosis of dementia: The experience over time. *Dementia,* 5 (3), 397-410.

Vittoria, A. K. (1998) Preserving selves. *Research on Aging*, 20 (1), 91-137.

von Kutzleben, M., Schmid, W., Halek, M., Holle, B. & Bartholomeyczik, S. (2012) Community-dwelling persons with dementia: what do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia. *Aging & mental health,* 16 (3), 378-390.

Waite, J. (2009) *Dementia care.* Oxford: Oxford University Press.

Watson, J. (2019) *Joy's story: 'The restaurant has given a voice to those of us affected by dementia' blog* 12 June. Available online: https://www.alzheimers.org.uk/blog/joy-story-restaurant-makes-mistakes?utm_campaign=GenNewsletter&utm_content=010519&utm_medium=email&utm_source=SmartFocus [Accessed 13/6/2019].

Web Sawadee Public Company Limited (2018) *Detailed map of Nakhon Ratchasima Province, North-East (Isan) Region, Thailand.* Available online: http://isan.sawadee.com/nakhonratchasima/map.html [Accessed on 11/03/2019]. (in Thai)

Whitman, L. (2016) *People with dementia speak out.* London: Jessica Kingsley.

Whittemore, R. & Knafl, K. (2005) The integrative review: updated methodology. *Journal of advanced nursing,* 52(5), 546-553.

World Health Organisation (WHO) (2015a) *Thailand: WHO statistical profile.* Available online: https://www.who.int/gho/countries/tha.pdf?ua=1 [Accessed 17/8/2016].

WHO (2015b) Chapter 5 Long-tern-care systems in World Report on Ageing and Health. WHO, Geneva. Available online: https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf;jsessionid=16A539B273A45A17A3BCA97230B8434B?sequence=1 [Accessed 7/1/2017].

WHO (2019) *Dementia*. Available online: https://www.who.int/news-room/fact-sheets/detail/dementia [Accessed 7/2/2020].

Wibulpolprasert, S., Sirilak, S., Ekachampaka, P. & Wattanamano, N. (eds) (2011) *Thailand Health Profile 2008-2010.* Thailand: The War Veterans Organization of Thailand. Available online: http://bps.moph.go.th/new_bps/thailand_health_profile/Thailand%20Health%20Profile%20Report%202008-2010.pdf [Accessed 18/5/2016].

Wolcott, H. F. (1990) On seeking — and rejecting — validity in qualitative research. In Eisner, E. W. & Peshkin, A. (Eds.), *Qualitative inquiry in education: Continuing the debate.* New York: Teachers College Press, 121-152.

Wolcott, H. F. (1994) Transforming qualitative data: Description, analysis, and interpretation Thousand Oaks, Calif.; London: Sage.

Wolverson, E. L., Clarke, C., & Moniz-Cook, E. (2010) Remaining hopeful in early stage dementia: A qualitative study. *Ageing and Mental Health*, 14 (4), 450-460.

Yan, E., Chan, K. & Tiwari, A. (2015) A systematic review of prevalence and risk factors for elder abuse in Asia. *Trauma, Violence & Abuse,* 16 (2), 199-219.

Yodpet, S. (2007) The development of long term care in family for older persons. *Paper presented at the Thai Society of Gerontology and Geriatric Medicine annual conference. Proceeding of the Continuing Care and Long Term Care for Thai Older Persons*. Bangkok, Thailand, 21-23 Nov 2007, 20-17.

Zimmermann, M. (2011) Dementia in life writing: our health care system in the words of the sufferer. *Neurological Sciences,* 32 (6), 1233-1238.

Appendix 1: Search strategy

After the research question was identified, the search terms and keywords were created to locate relevant research articles. The databases selected were **CINAHL Complete**, **Academic Search Premier**, **MEDLINE** and **PsycINFO** as collectively they include literature from a broad range of relevant fields such as nursing care, health and social care, psychological or biomedical, which is multidisciplinary.

With regard to the research subject, three major categories of search terms were identified. The search terms were used are shown in table A1.

1. Category I consists of "dementia" and included terms covering all forms of **dementia OR "alzheimer*"**. The truncation symbol * was used to pick up different word endings and put in double quotation marks to find this exact phrase.

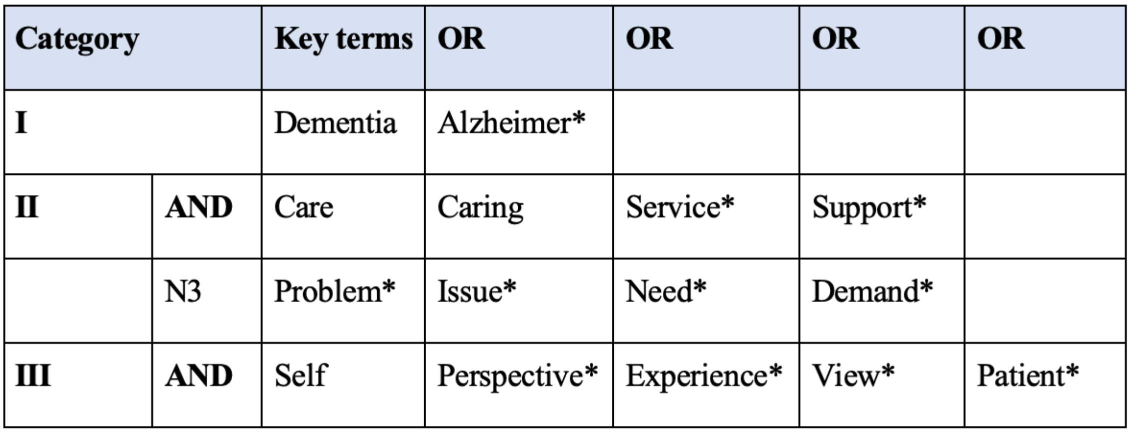
2. Category II, I involved all terms related to aspects of health care problem* OR problem* OR health care need* OR care need* OR need* OR demand*. Using "AND" between category I and II to narrow the search did limit results rather than using OR because it is used for synonyms or similar words and can expand a search. Thus, this category was looked at as problem* OR impact* OR health care need* OR need* OR demand* However, from these search terms I found that there were many research articles published but few were relevant to my topic. Therefore, I refined my search terms by removing health care needs but to find more relevant studies but retained all terms related to aspects of **care OR caring OR service* OR support***, together with put the related term which can be near to the word **problem* OR issue* OR need* OR demand***.

3. Category III as the research question was identified regarding the PwD perspectives, the key terms were related to the **Self OR Perspective* OR Experience* OR view* OR patient***.

As this review focuses on the participants' perspectives, the terms such as self-perspective OR self-report* OR self-expression* OR experience* or perspective* were set to include different types of research, adding more about these search terms because it is expected that more relevant research publications may be found. The result had found the different articles and more relevant studies than using only the two categories of keywords. Therefore, the second set of keywords was devised (Table A1). I set the key terms to search as **dementia OR alzheimer* AND (care OR caring OR service* OR support*)**

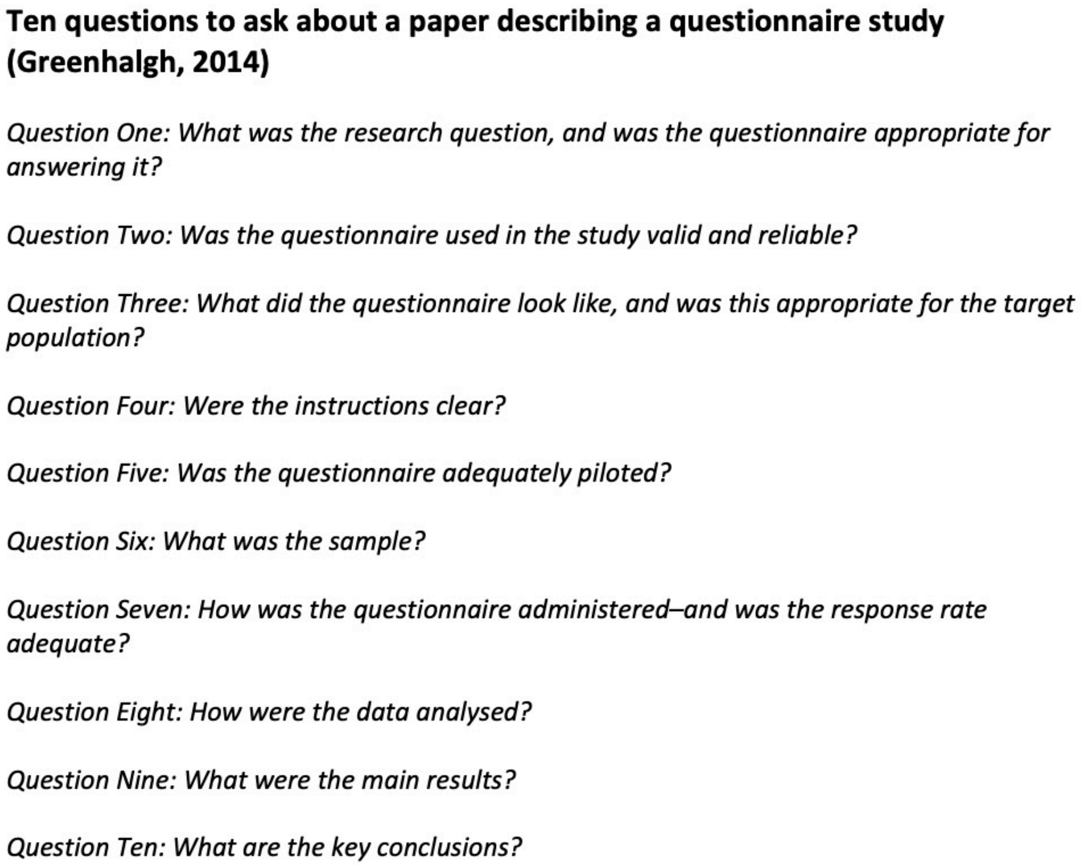
N3 (problem* OR issue* OR need* OR demand*) AND Self OR Perspective* OR Experience* OR view* OR patient*. Although there were some relevant papers the topic, many reported from the perspective of caregivers and healthcare professionals.

Table A1



Category		**Key terms**	**OR**	**OR**	**OR**	**OR**
I		Dementia	Alzheimer*			
II	**AND**	Care	Caring	Service*	Support*	
	N3	Problem*	Issue*	Need*	Demand*	
III	**AND**	Self	Perspective*	Experience*	View*	Patient*

Appendix 2: Ten Questions to ask about a paper describing a questionnaire study



Ten questions to ask about a paper describing a questionnaire study (Greenhalgh, 2014)

Question One: What was the research question, and was the questionnaire appropriate for answering it?

Question Two: Was the questionnaire used in the study valid and reliable?

Question Three: What did the questionnaire look like, and was this appropriate for the target population?

Question Four: Were the instructions clear?

Question Five: Was the questionnaire adequately piloted?

Question Six: What was the sample?

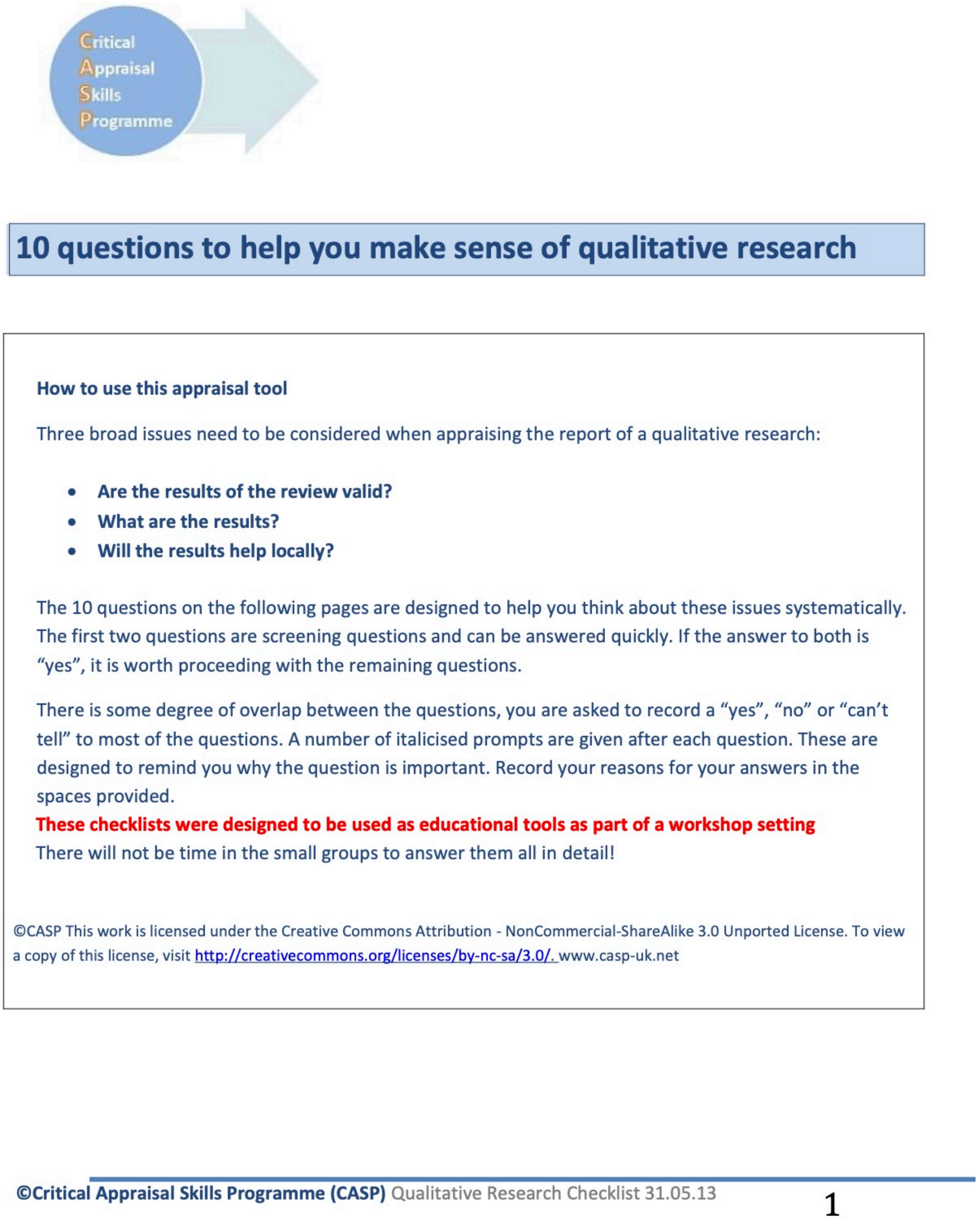
Question Seven: How was the questionnaire administered–and was the response rate adequate?

Question Eight: How were the data analysed?

Question Nine: What were the main results?

Question Ten: What are the key conclusions?

Appendix 3: The Critical Apprasial Skills Programme (CASP, 2014)



Critical
Appraisal
Skills
Programme

10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

- **Are the results of the review valid?**
- **What are the results?**
- **Will the results help locally?**

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

These checklists were designed to be used as educational tools as part of a workshop setting

There will not be time in the small groups to answer them all in detail!

Screening Questions

1. Was there a clear statement of the aims of the research? ☐Yes ☐Can't tell ☐No

HINT: Consider
- What was the goal of the research?
- Why it was thought important?
- Its relevance

2. Is a qualitative methodology appropriate? ☐Yes ☐Can't tell ☐No

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

Is it worth continuing?

Detailed questions

3. Was the research design appropriate to address the aims of the research? ☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

---

4. Was the recruitment strategy appropriate to the aims of the research? ☐ Yes ☐ Can't tell ☐ No

HINT:Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Was the data collected in a way that addressed the research issue? ☐Yes ☐Can't tell ☐No

HINT: Consider
- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

---

6. Has the relationship between researcher and participants been adequately considered? ☐Yes ☐Can't tell ☐No

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during
  (a) Formulation of the research questions
  (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration? ☐**Yes** ☐**Can't tell** ☐**No**

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous? ☐**Yes** ☐**Can't tell** ☐**No**

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings? ☐Yes ☐Can't tell ☐No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix 4: Ethics approval

Ethical approval from the Research Ethics Committee, Faculty of the Health Sciences

UNIVERSITY OF HULL

University of Hull
Hull, HU6 7RX
United Kingdom
T: +44 (0)1482 464030 | **E:**T.Alexander@hull.ac.uk
w: www.hull.ac.uk

PRIVATE AND CONFIDENTIAL
Nittiya Noysipoom
Faculty of Health Sciences
University of Hull
Via email

6th November, 2017

Dear Nittiya

REF FHS02 - The perspectives of older persons with early stage dementia of their care needs: a study in Northeast Thailand

Thank you for your responses to the points raised by the Faculty of Health Sciences Ethics Research Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of subsequent amendments to your study.

I wish you every success with your study.

Yours sincerely

Dr Tim Alexander
Deputy Chair, FHS Research Ethics Committee

UNIVERSITY OF HULL

Tim Alexander | Research co-ordinator| Doctorate Course in Clinical Psychology
University of Hull
Hull, HU6 7RX, UK
www.hull.ac.uk
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@UniOfHull /UniversityOfHull universityofhull

คณะกรรมการพิจารณาจริยธรรมการวิจัยในคน โรงพยาบาลมหาราชนครราชสีมา
สำนักงานสนับสนุนการศึกษาวิจัยทางคลินิก: ศูนย์แพทยศาสตรศึกษาชั้นคลินิก โรงพยาบาลมหาราชนครราชสีมา 49 ถ.ช้างเผือก ต.ในเมือง อ.เมือง จ.นครราชสีมา 30000
Maharat Nakhon Ratchasima Hospital Institution Review Board (MNRH IRB)
Clinical Research Support Office: Medical Education. Maharat Nakhon Ratchasima Hospital, 49 Chang Phueak Rd.,
Mueang District, Nakhon Ratchasima Province, 30000, THAILAND Tel. & Fax. +66 44 295614-5 Email irb@mnrh.in.th

Number 007/2018

Certificate of Approval

Protocol title : The perspectives of older persons with early stage dementia of their care needs: a study in Nakhon Ratchasima, North East Thailand

Protocol no. : -

Document of approval/acceptance:

1. Self assessment form for PI
2. MNRH IRB Submission Form
3. Research Proposal English version
4. Questionnaire
5. Participation Information Sheet
6. Inform Consent Form
7. Investigator's Curriculum Vitae
8. Budget

Principal investigator: Ms. Nittiya Noysipoom

Research site: Maharat Nakhon Ratchasima Hospital

Date of meeting: 21 December 2017

Date of approval: 21 December 2017

This is to certify that Institutional Review Board, Maharat Nakhon Ratchasima Hospital Ethics Committee is in full compliance with Declaration of Helsinki and the International Conference on Harmonization in Good Clinical Practice (ICH-GCP), and approved the study above.

Expired date: 20 December 2018

(If available)

Signature: Nipat Sim.
(Nipat Simakachorn, MD)
Chairman of Institutional Review Board

Signature: ______________________
(Somchai Asawasudsakorn, MD)
Director of Maharat Nakhon Ratchasima Hospital

Appendix 5: Participant Information Sheet

UNIVERSITY OF Hull

SCHOOL OF HEALTH AND SOCIAL WORK, UNIVERSITY OF HULL
PARTICIPANT INFORMATION SHEET

Title of Project: The Perspectives of Older Persons with Early Stage Dementia of Their Care Needs: A Study in Northeast Thailand.

Name of Researcher: Nittiya Noysipoom

This project under supervision of advisor and co-adviser as follows:

Supervisor I: Prof. Fiona Cowdell, DProf, MA, PGCE, BA (Hons), RN
Supervisor II: Dr Moira Graham, PhD, MSc, BMedSci (Hons), Diploma in Nursing and Midwifery (S.A), Diploma in Community Nursing Science (S.A), RN (Adult), SCPHN (Health Visitor).

I am a PhD student at the University of Hull, England. I want to find out more about the experiences of care and the care that older people with early stage dementia need. You are being invited to take part in a research project because you are aged 60 years or above and have a diagnosis of early stage dementia. Before you decide to participate it is important for you to understand why the research is being done and what it will involve. Please take a time to read the following information carefully and do not hesitate to contact me directly via the contact detail provided on page 3 of this form if anything is unclear or if you would like more information.

Part 1 tells you about purpose of the study and what will happen if you take part.
Part 2 gives you more information about the conduct of the study.

PART 1

The purpose of this study…

I would like to ask about the care you need now after you have been diagnosed with dementia. This information will help us when planning care for people with dementia in the future.

The benefit of this study…

Although there is no direct benefit to you of taking part in the study, your participation may help other people with dementia in the future by helping us to better understand the care that people with dementia needs.

The permission for the study to take place…

This study has been approved by Research Ethics Committee of the School of Health and Social Work, University of Hull, England and the Ethics Review Committee for Research Involving Human Research Subjects, Maharat Nakhon Ratchasima Hospital, Thailand.

If you decide to participate in this study...

If you decide to take part in the study I will invite you to sign two copies of a consent form, one for you to keep and one I will keep for my records. We will arrange a time and place to meet which is convenient for you. I can come to your home or we can meet at the hospital or another place that is convenient for you. I will invite you to take part in up to three interviews which I would like to audio-record. These will take between 30 – 60 minutes each and we can stop at any time for a break. Subsequent meetings will be 1-2 weeks later at a time and place that is convenient to you. There are no right or wrong answers, I am interested in hearing your thoughts about your experiences of care and the care you need.

You can have a family member or friend or caregiver to be with you during the interview if you would like to and you can ask them to leave when you want to talk privately with me.

Part 2

Confidentiality and Data protection...

The results of this study will be used as part of my PhD and in publications and conference presentations. You will not be identifiable in any of these as all anonymized (your name will not be on it). It will be stored safely and only myself and my academic supervisors will be able to see it.

Further to this, you can share and request the help that related to poor care or abuse issue. The researcher will share this with a relevant health care professional for support you with your permission. If you do not want to share this with your health care professionals, you can directly contact to the relevant organisations or foundations as the list of "Sources of support" below or ask me to liaise with them on your behalf if you prefer. However, if there is seriously harmful to yourself or others, the researcher needs to report this issue to the relevant professionals without your permission for safety reasons and to refer you to get further support.

If you do not want to participate in this study...

You are free to withdraw from the study at any time. The study will not change your medical care in any way. However, if you have taken part in interview(s) the researcher will ask permission to use this data. Once data analysis has begun, it will not be possible to withdraw data.

Any questions or queries...

If you have any questions you are welcome to contact me: Nittiya Noysipoom, PhD student (Researcher), School of Health and Social Work, University of Hull, England. Phone: +66 909711555, Email: Nittiya.Noysipoom@2015.hull.ac.uk

Complaints and Concerns…

If you have any comments or complaints, please contact my supervisors:
Dr Moira Graham, Second supervisor, School of Health and Social Work,
University of Hull, Cottingham Road, Hull, HU6 7RX
Phone: +44 (0) 1482 464514, Email: M.Graham2@hull.ac.uk

Professor Fiona Cowdell, Supervisor, Faculty of Health, Education and Life Sciences,
Birmingham City University, Birmingham, UK
Phone: +44 (0) 121 300 4345, Email: Fiona.cowdell@bcu.ac.uk

A list of "Sources of support"

If you would like further support about your problem of receiving care you can speak to your nurse or your doctor at the clinic or contact to the relevant organisations or foundations:

Office of Social Development and Human Security, Nakhon Ratchasima,
Nakhon Ratchasima Town Hall, 2nd Floor, Petchakasem Road, Muang District, Muang District, Nakhon Ratchasima 30000.
Phone: +66 (0) 4424-1079, +66 (0) 4424-3000, +66 (0) 4425-1777, Fax: +66 (0) 4425-5732

Alzheimer's Association in Thailand,
114 Pinnacorn 4 Boromratchachonnani Road, Talingchan Bangkok 10170 Thailand
Phone: +66 (0) 8-6990-4207, Fax: +66 (0) 2201-2588

The Alzheimer Foundation of Thailand,
22 Floor, CMMU Building, Vibhavadi Rangsit Road, Samsennai, Phayathai, Bangkok 10400. Phone: +66 (0) 2644-5499 ext. 138, Fax: +66 (0) 2644-9538.

Thank you for reading this information.

เอกสารชี้แจงสำหรับอาสาสมัคร

ชื่อโครงการวิจัย : มุมมองของผู้สูงอายุที่มีภาวะสมองเสื่อมระยะเริ่มต้น เกี่ยวกับการดูแลที่ต้องการได้รับ: การศึกษาในจังหวัดนครราชสีมา ภาคตะวันออกเฉียงเหนือของประเทศไทย

ผู้วิจัยหลัก : นางสาวนิตติยา น้อยสีภูมิ **ตำแหน่ง** นักศึกษาปริญญาเอก

สถานที่ปฏิบัติงาน : วิทยาลัยพยาบาลบรมราชชนนี นพรัตน์วชิระ **หมายเลขโทรศัพท์** 090-971-1555

- **เหตุผลและความจำเป็นที่ต้องทำการศึกษาวิจัย** การศึกษานี้เป็นส่วนหนึ่งของการเรียนปริญญาเอก ซึ่งต้องการศึกษามุมมองและประสบการณ์ของผู้สูงอายุที่มีภาวะสมองเสื่อมระยะเริ่มต้นเพื่อทราบถึงการดูแลที่ท่านต้องการได้รับ หลังจากท่านได้รับการวินิจฉัยว่ามีภาวะสมองเสื่อมระยะเริ่มต้น
- **เหตุผลที่อาสาสมัครถูกเชิญให้เข้าร่วมการวิจัย** ท่านได้รับการคัดเลือกเข้าร่วมการวิจัย เนื่องด้วยมีคุณสมบัติตรงตามเกณฑ์ที่ผู้วิจัยกำหนดขึ้นจากการศึกษาแนวคิดต่างๆ การเป็นผู้สูงอายุที่ได้รับการวินิจฉัยว่าเป็นผู้ที่มีภาวะสมองเสื่อมระยะเริ่มต้น จะเป็นบุคคลที่สามารถให้ข้อมูลได้ตรงตามวัตถุประสงค์ของการวิจัย ซึ่งถือเป็นตัวแทนของประชากรที่ต้องการศึกษาอย่างแท้จริง
- **วัตถุประสงค์ของการศึกษาวิจัย** การวิจัยครั้งนี้มีวัตถุประสงค์เพื่อศึกษามุมมองความคิดเห็นของผู้สูงอายุที่มีภาวะสมองเสื่อมระยะเริ่มต้น เกี่ยวกับการดูแลที่ต้องการได้รับ และเพื่อให้ผู้สูงอายุมีส่วนร่วมในการเสนอแนวคิดเพื่อที่จะนำไปพัฒนาแนวทาง ในการวางแผนการดูแลผู้ที่มีภาวะสมองเสื่อมต่อไป
- **การเข้าร่วมโครงการวิจัยของท่านเป็นไปด้วยความสมัครใจ** หากท่านไม่ยินดีเข้าร่วมการวิจัย จะไม่มีผลกระทบใดๆ ทั้งในปัจจุบันและอนาคตด้านการรักษาพยาบาล และท่านอาจถอนตัวออกจากโครงการได้ทุกเวลาโดยไม่มีผลกระทบเช่นกัน อย่างไรก็ตาม หากท่านได้ให้การสัมภาษณ์แล้ว ผู้วิจัยจะขออนุญาตใช้ข้อมูลที่ท่านให้สัมภาษณ์ไว้ โดยข้อมูลดังกล่าวจะไม่สามารถระบุถึงตัวท่านได้
- **จำนวนอาสาสมัคร** ในโครงการวิจัยนี้ต้องการอาสาสมัครในการให้ข้อมูลประมาณ 20-30 ราย
- **ขั้นตอนการปฏิบัติตัวของอาสาสมัคร**

  1) หลังจากที่ท่านตัดสินใจเข้าร่วมเป็นอาสาสมัครในโครงการวิจัยนี้ ท่านจะถูกขอให้เซ็นชื่อเพื่อเป็นหลักฐานในการเข้าร่วมเป็นอาสาสมัครในงานวิจัยลงในใบยินยอม เป็นจำนวน 2 ฉบับ โดยท่านเก็บไว้ 1 ฉบับและสำหรับผู้วิจัย 1 ฉบับ

  2) ผู้วิจัยจะทำการนัดหมายวัน เวลาและสถานที่ ที่ท่านสะดวก เพื่อทำการสัมภาษณ์เกี่ยวกับประสบการณ์การได้รับการดูแล และการดูแลที่ท่านต้องการได้รับ ทั้งนี้ผู้วิจัยจะขออนุญาตเยี่ยมบ้านท่านเพื่อสัมผัสและเข้าถึงการดำเนินชีวิตของท่าน อันจะนำมาซึ่งความสมบูรณ์ ถูกต้องของเนื้อหา หลังจากนั้นผู้วิจัยจะทำการสรุปเนื้อหาและให้ท่านได้ตรวจสอบ ยืนยันความถูกต้อง และให้ข้อเสนอแนะ

  3) ขณะทำการสัมภาษณ์ท่านสามารถหยุดพักได้ ข้อมูลที่ได้จากการสัมภาษณ์นั้นไม่มีถูกหรือผิด ผู้วิจัยยินดีที่จะรับฟังประสบการณ์ และความคิดเห็นของท่านเกี่ยวกับความต้องการในการได้รับการดูแลหลังจากที่ท่านได้รับการวินิจฉัยว่ามีภาวะสมองเสื่อม

  4) ท่านจะได้รับสมุดบันทึกและปากกาจำนวน 1 ชุด เพื่อไว้บันทึกสิ่งที่ท่านต้องการ หรือนึกขึ้นได้และต้องการบอกเล่าแก่ผู้วิจัย ในระหว่างการนัดพบครั้งถัดไป ซึ่งไม่ต้องส่งคืนผู้วิจัยหลังการวิจัยสิ้นสุด

  5) ท่านสามารถให้ญาติหรือผู้ดูแลหรือบุคคลที่ท่านไว้วางใจอยู่ด้วยขณะทำการสัมภาษณ์ แต่ผู้วิจัยจะทำการสัมภาษณ์ข้อมูลจากท่านเท่านั้น และท่านสามารถขอให้ญาติหรือผู้ดูแลหรือเพื่อนของท่านออกจากการสัมภาษณ์ไปก่อนได้ หากท่านต้องการให้สัมภาษณ์เป็นการส่วนตัวกับผู้วิจัย
- **ระยะเวลาที่อาสาสมัครต้องเกี่ยวข้องในการศึกษาวิจัย**

  ผู้วิจัยจะทำการเยี่ยมบ้านเพื่อทำความรู้จัก สร้างความคุ้นเคย และศึกษาการดำเนินชีวิตและความเป็นอยู่ของท่าน หลังจากนั้นท่านจะได้รับการสัมภาษณ์ 3 ครั้ง หรืออาจมากกว่านั้นขึ้นอยู่กับข้อมูลที่ได้จากการเยี่ยมบ้านและการสัมภาษณ์ในแต่ละครั้ง โดยผู้วิจัยจะสัมภาษณ์ท่านครั้งละประมาณ 30-60 นาที การสัมภาษณ์ในครั้งต่อไปจะห่างจากครั้งก่อน

หน้าประมาณ 1-2 สัปดาห์ ซึ่งผู้วิจัยจะทำการนัดหมายวัน เวลาและสถานที่ ที่ท่านสะดวกสำหรับการให้สัมภาษณ์ รวมระยะเวลาที่ท่านต้องเกี่ยวข้องในการศึกษาวิจัยประมาณ 2 เดือน

- **ประโยชน์ที่คาดว่าจะเกิดขึ้นทั้งต่ออาสาสมัครและต่อผู้อื่น**

  การวิจัยครั้งนี้อาจไม่ได้มีผลประโยชน์โดยตรงต่ออาสาสมัครที่เข้าร่วมการวิจัย แต่ข้อมูลและความรู้ที่ได้จากการศึกษาเพื่อทำความเข้าใจเกี่ยวกับประสบการณ์การได้รับการดูแล และการดูแลที่ท่านต้องการได้รับครั้งนี้ จะช่วยให้ผู้ดูแล และบุคลากรที่เกี่ยวข้องเข้าใจและรับรู้ถึงความรู้สึก และความต้องการที่แท้จริงของผู้ที่มีภาวะสมองเสื่อมระยะเริ่มต้น ซึ่งข้อมูลนี้จะเป็นประโยชน์ในการนำไปสู่การวางแผนในการให้การดูแลผู้ที่มีภาวะสมองเสื่อมในระยะยาวต่อไป

- **ค่าชดเชยการเดินทาง/ค่าเสียเวลา/ของที่ระลึก ที่อาสาสมัครจะได้รับ (ถ้ามี)**

  ในการเข้าร่วมโครงการวิจัยครั้งนี้ผู้วิจัยไม่ได้มีการจ่ายค่าชดเชยการเสียเวลาให้กับอาสาสมัคร

- **ความเสี่ยงหรือความไม่สบายทุกประการที่คาดว่าจะเกิดขึ้นกับอาสาสมัคร**

  ในระหว่างการสัมภาษณ์หากคำถามใดก่อให้เกิดความรู้สึกไม่สบายใจ หรือทำให้ท่านเกิดความลำบากใจในการตอบ เช่น ไม่สบาย ร้องไห้ เศร้าโศก เสียใจ ท่านสามารถหยุดหรือปฏิเสธที่จะตอบหรือพูดคุยในเรื่องนั้นๆ ที่ก่อให้เกิดความไม่สบายใจได้ ผู้วิจัยจะยุติการสัมภาษณ์ชั่วคราว และเปิดโอกาสให้ท่านได้ระบายหรือแสดงออกถึงความรู้สึกอย่างเต็มที่ หลังจากท่านได้ระบาย ความรู้สึกแล้ว ผู้วิจัยจะถามความพร้อมของท่านก่อนว่าต้องการจะสนทนากับผู้วิจัยต่อหรือไม่ หากท่านไม่พร้อม ท่านสามารถนัดผู้วิจัยให้มาสัมภาษณ์ในวันถัดไปได้ตามที่ท่านสะดวก

- **การรักษาความลับ**

  ข้อมูลที่เกี่ยวข้องกับท่านจะถูกเก็บเป็นความลับ และเมื่อเสร็จสิ้นการวิจัยแล้วผู้วิจัยจะทำลายแถบบันทึกเสียงทันที หากมีการเสนอผลการวิจัยจะเสนอเป็นภาพรวม ข้อมูลใดที่สามารถระบุถึงตัวท่านได้จะไม่ปรากฏในรายงาน นอกจากนี้ท่านสามารถขอความช่วยเหลือหรือบอกเล่าเกี่ยวกับการได้รับการดูแลที่ไม่เหมาะสมหรือประเด็นของการได้รับการดูแลที่ไม่พึงประสงค์ได้ โดยผู้วิจัยจะส่งต่อปัญหาของท่านไปยังผู้เชี่ยวชาญที่เกี่ยวข้องหลังจากได้รับการยินยอมจากท่านเท่านั้น แต่หากท่านไม่ต้องการเล่าปัญหาเหล่านี้ให้ผู้เชี่ยวชาญที่เกี่ยวข้อง ท่านสามารถติดต่อหน่วยงานที่เกี่ยวข้องด้วยตนเองตามรายชื่อหน่วยงานที่ให้ไว้ในหน้าสุดท้ายของเอกสารนี้ หรือขอให้ผู้วิจัยประสานหน่วยงานดังกล่าวให้ได้ อย่างไรก็ตาม หากผู้วิจัยพบว่ามีปัญหาที่อาจส่งผลอันตรายต่อชีวิตของท่านหรือผู้อื่น ผู้วิจัยจำเป็นต้องรายงานปัญหานี้ให้ผู้เชี่ยวชาญที่เกี่ยวข้องโดยไม่ขอความยินยอมจากท่าน ทั้งนี้เพื่อความปลอดภัยของท่านและจะได้ให้การช่วยเหลือต่อไป

- **ชื่อ ที่อยู่ เบอร์โทรศัพท์ของผู้วิจัย**

  หากท่านมีข้อสงสัยหรือคำถามเกี่ยวกับโครงการวิจัยนี้ ท่านสามารถติดต่อผู้วิจัยได้ที่ นางสาวนิตติยา น้อยสีภูมิ วิทยาลัยพยาบาลบรมราชชนนี นพรัตน์วชิระ 681 ถ.รามอินทรา แขวง/เขต คันนายาว กรุงเทพมหานคร โทรศัพท์ 090-971-1555 หรือ E-mail: nittiya.n@gmail.com และ/หรือ กลุ่มงานจิตเวช โรงพยาบาลมหาราชนครราชสีมา ชั้น 5 ตึกผู้ป่วยนอกและอำนวยการ โทรศัพท์ 044-232022 และ 045-232025 ซึ่งเป็นผู้ประสานงานสำหรับโครงการวิจัยนี้

- **แหล่งให้ข้อมูลหากมีข้อสงสัยเกี่ยวกับสิทธิอาสาสมัคร**

  ในกรณีที่มีการปฏิบัติที่ไม่เป็นไปตามข้อมูลในเอกสาร ท่านสามารถซักถามข้อสงสัย หรือร้องเรียนได้ที่ “สำนักงานคณะกรรมการพิจารณาจริยธรรมการวิจัยในคน โรงพยาบาลมหาราชนครราชสีมา อาคารศูนย์แพทยศาสตรศึกษาชั้นคลินิก โรงพยาบาลมหาราชนครราชสีมา ชั้น 2 โทร. 044 – 235226”) หรือท่านสามารถติดต่ออาจารย์ที่ปรึกษาของผู้วิจัยได้ที่

  Dr Moira Graham (ดร. มอยร่า เกรแฮม), School of Health and Social Work (สำนักวิชาสาธารณสุขและสังคมสงเคราะห์), University of Hull (มหาวิทยาลัยฮัลล์), Hull (เมืองฮัลล์), ประเทศอังกฤษ

  โทรศัพท์: +44 (0) 1482 464514, Email: M.Graham2@hull.ac.uk

  Professor Fiona Cowdell (ศาสตราจารย์ ฟีโอน่า คาวเดล), Faculty of Health, Education and Life Sciences (คณะสาธารณสุขศาสตร์ การศึกษาและวิทยาศาสตร์เพื่อชีวิต), Birmingham City University (มหาวิทยาลัยเบอร์มิ่งแฮมซิตี้), Birmingham (เมืองเบอร์มิ่งแฮม), ประเทศอังกฤษ โทรศัพท์: +44 (0) 1213 004345, Email: Fiona.cowdell@bcu.ac.uk

- **รายชื่อหน่วยงานที่เกี่ยวข้องกับการให้ความช่วยเหลือ**

  หากท่านต้องการความช่วยเหลือเกี่ยวกับปัญหาการได้รับการดูแลที่ไม่เหมาะสม ท่านสามารถปรึกษาแพทย์หรือพยาบาลประจำคลินิกได้ หรือสามารถติดต่อหน่วยงานที่เกี่ยวข้องดังต่อไปนี้

  สำนักงานพัฒนาสังคมและความมั่นคงของมนุษย์ จังหวัดนครราชสีมา
  ศาลากลางจังหวัด ชั้น 2 ถนน มหาไทย ตำบลในเมือง อำเภอเมือง จังหวัดนครราชสีมา 30000
  โทรศัพท์ 044-243-000 โทรสาร 044-255-732

  สมาคมผู้ดูแลผู้ป่วยสมองเสื่อมแห่งประเทศไทย
  114 ปิ่นนคร 4 ถนนบรมราชชนนี ตลิ่งชัน กรุงเทพมหานคร 10170
  โทรศัพท์ 086-990-4270 โทรสาร 02-201-2588

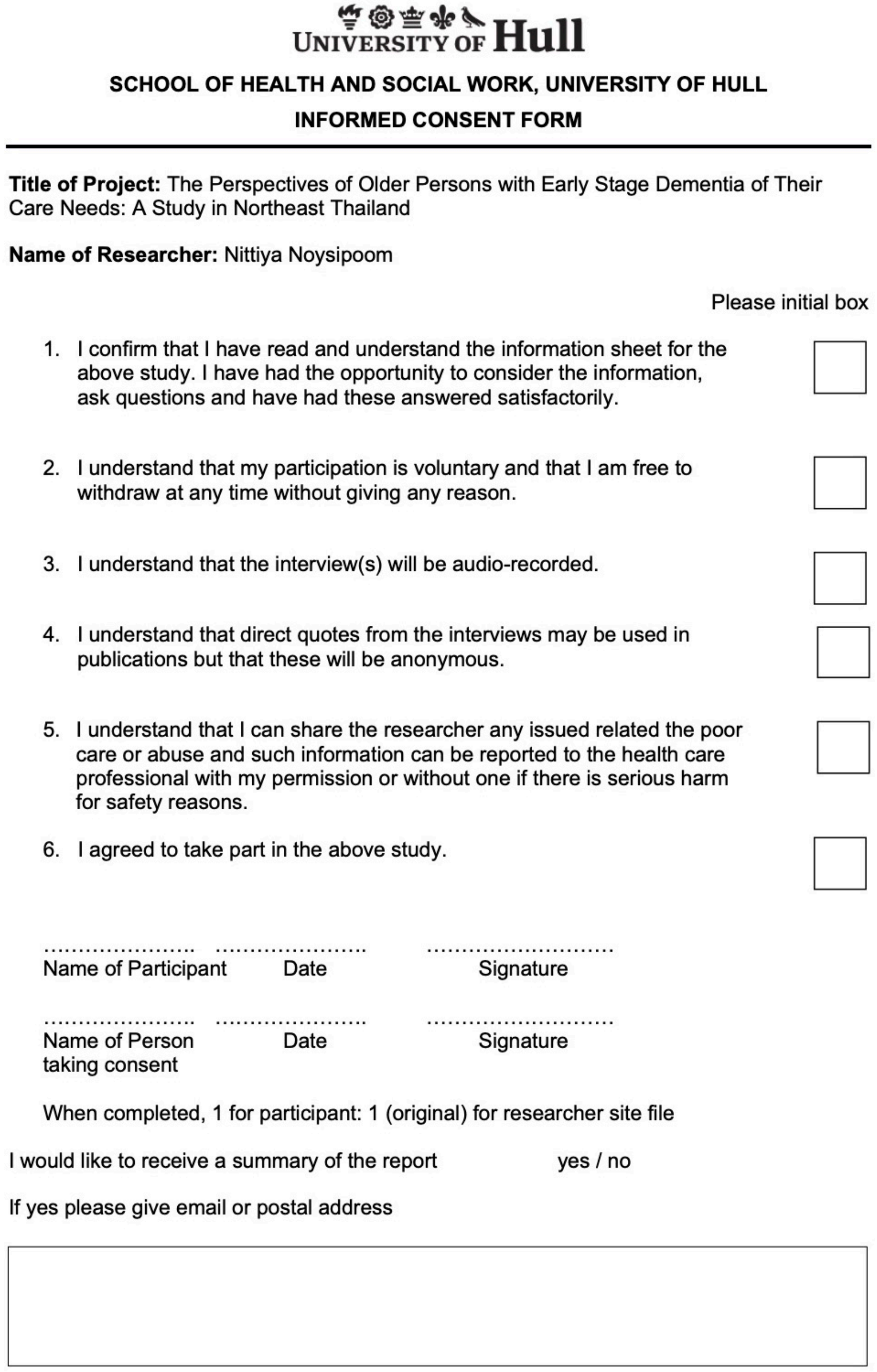
  มูลนิธิโรคอัลไซเมอร์ห่งประเทศไทย
  ชั้น 22 อาคาร ซีเอ็มเอ็มยู (CMMU) ถนนวิภาวดีรังสิต สามเสนใน พญาไท กรุงเทพมหานคร 10400
  โทรศัพท์ 02-644-5499 ต่อ 138 โทรสาร 02-644-9538

หมายเหตุ: ผู้วิจัยต้องมอบสำเนาแบบยินยอมอาสาสมัคร พร้อมแบบคำชี้แจงอาสาสมัคร อย่างละ 1 ชุด ให้อาสาสมัครหรือผู้ปกครองด้วย

"ท่านจะได้รับสำเนาของเอกสารฉบับนี้และใบยินยอมด้วยความสมัครใจเก็บไว้ 1 ชุด"

โครงการวิจัยนี้ได้ผ่านการรับรองการพิจารณาจริยธรรมการวิจัยในคนจาก สำนักงานคณะกรรมการพิจารณาจริยธรรมการวิจัย คณะวิทยาศาสตร์สุขภาพ, มหาวิทยาลัยฮัลล์ ประเทศอังกฤษ (Research Ethics Committee Faculty of Health Science, The University of Hull, England) และ สำนักงานคณะกรรมการพิจารณาจริยธรรมการวิจัยในคน โรงพยาบาลมหาราชนครราชสีมา

Appendix 6: Informed Consent Form



UNIVERSITY OF Hull

SCHOOL OF HEALTH AND SOCIAL WORK, UNIVERSITY OF HULL

INFORMED CONSENT FORM

Title of Project: The Perspectives of Older Persons with Early Stage Dementia of Their Care Needs: A Study in Northeast Thailand

Name of Researcher: Nittiya Noysipoom

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
3. I understand that the interview(s) will be audio-recorded. ☐
4. I understand that direct quotes from the interviews may be used in publications but that these will be anonymous. ☐
5. I understand that I can share the researcher any issued related the poor care or abuse and such information can be reported to the health care professional with my permission or without one if there is serious harm for safety reasons. ☐
6. I agreed to take part in the above study. ☐

………………….. ………………….. ………………………
Name of Participant Date Signature

………………….. ………………….. ………………………
Name of Person taking consent Date Signature

When completed, 1 for participant: 1 (original) for researcher site file

I would like to receive a summary of the report yes / no

If yes please give email or postal address

☐

ใบยินยอมด้วยความสมัครใจ

ชื่อโครงการวิจัย ภาษาไทย/ภาษาอังกฤษ “**มุมมองของผู้สูงอายุที่มีภาวะสมองเสื่อมระยะเริ่มต้น เกี่ยวกับการดูแลที่ต้องการได้รับ: การศึกษาในจังหวัดนครราชสีมา ภาคตะวันออกเฉียงเหนือของประเทศไทย/ The Perspectives of Older Persons with Early Stage Dementia of their Care Needs: A Study in Nakhon Ratchasima, North East Thailand”**

ข้าพเจ้า (นาย, นาง, นางสาว)……………............นามสกุล……………….........อายุ…………ปี ผู้เข้าร่วมโครงการ

ก่อนที่จะลงนามในใบยินยอมให้ทำการวิจัยนี้ ข้าพเจ้าได้รับการอธิบายจาก ผู้ให้ข้อมูล ถึงวัตถุประสงค์ของการวิจัย ระยะเวลาที่ทำการวิจัย ขั้นตอนและวิธีการปฏิบัติตัวที่ข้าพเจ้าต้องปฏิบัติ ผลประโยชน์ที่ข้าพเจ้าจะได้รับ รวมทั้งผลข้างเคียงหรืออันตรายที่อาจเกิดขึ้นจากการเข้าร่วมโครงการวิจัย อย่างละเอียด และมีความเข้าใจดีแล้ว

ผู้วิจัยรับรองว่าจะตอบคำถามต่างๆ ที่ข้าพเจ้าสงสัยด้วยความเต็มใจ ไม่ปิดบัง ซ่อนเร้นจนข้าพเจ้าพอใจ

และข้าพเจ้าสามารถถอนตัวจากการศึกษานี้เมื่อใดก็ได้ถ้าข้าพเจ้าปรารถนา โดยไม่เสียสิทธิ์ใดๆ ในการรับการรักษาพยาบาลที่จะเกิดขึ้นตามมาในโอกาสต่อไปทั้งในปัจจุบันและอนาคต ณ สถานพยาบาลแห่งนี้ หรือสถานพยาบาลอื่น

ผู้วิจัยรับรองว่าจะเก็บข้อมูลเฉพาะเกี่ยวกับตัวข้าพเจ้าเป็นความลับและจะเปิดเผยได้เฉพาะสรุปผลการวิจัย หรือการเปิดเผยข้อมูลต่อผู้มีหน้าที่ที่เกี่ยวข้องกับการสนับสนุนและกำกับดูแลการวิจัยเท่านั้น

หากเกิดกรณีฉุกเฉินขึ้นกับข้าพเจ้าอันเกี่ยวข้องกับการเข้าร่วมการวิจัย ข้าพเจ้าสามารถติดต่อผู้วิจัยได้ที่ นางสาวนิตติยา น้อยสีภูมิ วิทยาลัยพยาบาลบรมราชชนนี นพรัตน์วชิระ 681 ถ.รามอินทรา แขวง/เขต คันนายาว กรุงเทพมหานคร E-mail: nittiya.n@gmail.com โทรศัพท์: 090-971-1555 ซึ่งเป็นบุคคลที่รับผิดชอบโครงการวิจัยนี้ และ/หรือ กลุ่มงานจิตเวช โรงพยาบาลมหาราชนครราชสีมา ชั้น 5 ตึกผู้ป่วยนอกและอำนวยการ โทรศัพท์ 044-232022 หรือ 045-232025 ซึ่งเป็นแหล่งประสานงานสำหรับโครงการวิจัยนี้

ข้าพเจ้าได้อ่านข้อความข้างต้น และมีความเข้าใจดีทุกประการ และได้ลงนามในใบยินยอมนี้ด้วยความเต็มใจ และหลังจากลงนามแล้ว ข้าพเจ้าจะได้รับสำเนาของเอกสารฉบับนี้เก็บไว้ 1 ชุด

ลงนาม ....ผู้ยินยอม
(...)
(วันที่ ..... เดือน .... พ.ศ. ....)

ลงนาม .... ผู้ให้ข้อมูล
(...)
(วันที่ ..... เดือน .... พ.ศ. ....)

ในฐานะของพยาน ข้าพเจ้าขอยืนยันว่า

- ผู้เข้าร่วมโครงการ ได้รับการอธิบายถึงข้อมูลในเอกสารชี้แจงและเอกสารใบยินยอมอย่างชัดเจน
- ผู้เข้าร่วมโครงการมีโอกาสได้ถามผู้วิจัย เกี่ยวกับโครงการวิจัย
- ผู้เข้าร่วมโครงการ ได้ยินยอมเข้าร่วมโครงการ โดยสมัครใจ

ลงนาม .... พยาน	ลงนาม .... พยาน
(..)	(..)
(วันที่ ..... เดือน .... พ.ศ. ......)	(วันที่ ..... เดือน .... พ.ศ. ....)

หมายเหตุ: (1) พยานต้องไม่ใช่แพทย์ ผู้วิจัย หรือผู้ให้ข้อมูล
(2) ผู้ให้ข้อมูล/คำอธิบายชัดเจนต้องไม่เป็นแพทย์ผู้รักษาเพื่อป้องกันการเข้าร่วมโครงการด้วยความเกรงใจ
(3) ในกรณีที่อาสาสมัครไม่สามารถลงลายมือชื่อ ได้ ให้ใช้การประทับลายมือแทนดังนี้:

ข้าพเจ้าไม่สามารถลงลายมือชื่อได้ แต่ผู้วิจัยได้อ่านข้อความในแบบยินยอมนี้ให้แก่ข้าพเจ้าฟังจนเข้าใจดี ข้าพเจ้าจึงประทับตราลายนิ้วมือขวาของข้าพเจ้าในแบบยินยอมนี้ด้วยความเต็มใจ

ลายมือชื่อผู้อธิบาย ……………………………….
(………………………………..)

“ขอรับรองว่าเป็นลายนิ้วแม่มือของ ………………………………………………… จริง”

ลงชื่อ ………………………………… พยาน
( )
วันที่………เดือน………..….พ.ศ………

ประทับลายนิ้วมือขวา

ลงชื่อ ……………………………………พยาน
( )
วันที่………เดือน………..….พ.ศ………

Appendix 7: Ethnographic questions guide

Ethnographic topic guide (based on the work of Spradley (1979))

This is an interview guide will be used to contribute the researcher to approach participants.

Preparation before interview:

Getting to know participant before starting the first interview, the researcher will establish the rapport with a participant to develop the sense of trust which encourages a participant feels free to express the information, the research starts with a general conversation and overview questioning.

Interview process:

After establishing rapport with the participant, the interviews will be conducted following these below questions guide. The participants will be interviewed up to three times by:

1) First interview, the researcher will use Grand Tour Questions, listen to the participants and respond to what participants tell.

2) Second interview will be conducted when the first interviews already reflected in order to inquire more about previous questions asked and observed.

3) The next interviews will be conducted to clarify the answers until gain the sense of information.

Ethnographic questions guide:

1. Grand Tour Questions: Asking broad opening questions

- Could you tell me a bit about how your life has changed since getting your diagnosis of dementia?
- How did you feel when you were told you had dementia?

2. Mini-Tour Questions: Asking to follow up questions about an act, event or category.

- Could you tell me about what made you go to the doctor?
- What was it like getting a diagnosis of dementia?

- In what ways have your care needs changed since diagnosis?
- Is there anyone who can help with these needs?

3. Example Questions: Asking to lead to the interesting stories of actual happenings.

- Could you give me some examples of when someone take care of you?
- Could you give me some examples of your care needs?

4. Experience Questions: Asking about experiences.

- Could you tell me a bit more about the experiences of when you go to meet the doctor?
- Could you tell me what did you do since getting your diagnosis?
- Could you describe the care you have received since your diagnosis?