The Importance of Reciprocity in Caring
for Older People with Dementia:
The Experiences of Female Family Carers in Thailand

Pornthip Netiparatanakul
พรทิพย์ เนติภารัตนกุล

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Department of Sociological Studies

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Abstract

This thesis explores the importance of reciprocity in caring for older people with dementia in Thailand, employing a feminist approach focusing on concepts of care, gender, reciprocity, family practice, and motivation. It draws on in-depth interviews (n19) which asked how female family carers make sense of repayment in caring, how they perceive the reciprocation given by their older relatives with dementia, and how their experiences of reciprocity relate to motivation to care.

The study reveals the notion of repayment to remain consistent as a significant social norm in Thailand, regardless of the reasons for caring. The carers explained the notion in ethical terms, reflecting the concept of connectedness. Previous research has highlighted the social value of 'katanyu' in caring for older relatives in Thailand. In this study, participants undertook care not simply to follow this value, but negotiated it within their caring circumstances, where an ethics of care frames their actions. While reciprocity in dementia care is typically understood to be limited, this research reveals how carers were the subjects of reciprocation from those for whom they cared, implying the agency of people with dementia. Expressed in various forms, verbal and non-verbal, such reciprocation was interpreted by carers using a mix of intimate and cultural knowledge, embedded meanings being understood as both positive and negative. Significantly, carers perceived reciprocation through the lens of connectedness with care recipients. Overall, participants' motives to care were derived from and negotiated through reciprocity occuring over the lifecourse of caring, but also based on Buddhism's wider timeframes influenced by the belief in karma and the cycle of birth and rebirth.

The study contributes to research knowledge in sociology, social psychology, cultural gerontology, and nursing, bearing policy and practice implications relating to family and dementia care in which aspects of caring, gender, and generational reciprocity intertwine.

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วิทยานิพนธ์เล่มนี้เป็นส่วนหนึ่งของการศึกษาระดับดุษฎีบัณฑิตโดยได้รับทุนสนับสนุนจากมหาวิทยาลัยธรรมศาสตร์ ประจำปี พ.ศ. 2558 ผู้วิจัยขอขอบคุณมหาวิทยาลัยมา ณ ที่นี้ และขอขอบคุณคณะสังคมวิทยาและมานุษยวิทยา ที่ให้โอกาสมาศึกษาต่อที่ต่างประเทศเพื่อพัฒนาความรู้และทักษะทางวิชาการ

ผู้วิจัยขอขอบพระคุณอาจารย์ที่ปรึกษา ดร. ลอร์นา วอร์เรน และ ดร. แอนเดรีย วิกฟีลด์ เป็นอย่างยิ่ง สำหรับคำปรึกษาและข้อท้วงติงทางวิชาการ ขอบพระคุณที่เอาใจใส่ดูแลและเข้าใจสภาวะการเรียนของนักศึกษาต่างชาติ สิ่งหนึ่งที่ผู้วิจัยไม่อาจลืมได้ ก็คือ ความใจกว้างของอาจารย์นั้นเป็นสิ่งที่ยืนยันได้ว่าท่านมีความเชี่ยวชาญและประสบการณ์สูงในเรื่องการดูแลทั้งในเชิงทฤษฎีและชีวิตจริง ขอขอบพระคุณกรรมการสอบวิทยานิพนธ์ ศาสตราจารย์โทนี ไรอัน และ ศาสตราจารย์เมอร์นา ดาวนส์ ที่ชี้แนะแง่มุมสำคัญเพิ่มเติมให้แก่ผู้วิจัย

ตลอดเส้นทางการเรียน ผู้วิจัยได้รับการสนับสนุนเต็มกำลังจากครอบครัวเนติภารัตนกุล ขอขอบพระคุณอย่างสุดใจแด่ ป๊า ม้า หลิน ซัน สำหรับความเข้าใจ ห่วงใย และเป็นลมใต้ปีกให้เสมอมา ขอบพระคุณอาม่าเป็นอย่างสูงที่สนับสนุนการเรียนทุกระดับและมอบประสบการณ์ชีวิตที่ต่อยอดมาถึงปริญญาเอก

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Chapter 1: Introduction

1.1 Introduction

This thesis explores Thai female family carers' experiences of reciprocity in caring for older relatives with dementia. Drawing attention to women's experiences, it has been conducted by using a feminist approach for it counts and values women's voices and their ways of knowing and brings gender relations into the study of women's social worlds (Ramazanoglu and Holland 2002, Oakley 2000). The study involves caring relationships within families, and therefore the researcher employs the concepts of caring, gender, reciprocity, motivations for caring, and family practice as the conceptual framework for the interpretation and analysis of findings. Intentionally, the researcher positions this thesis to contribute theoretical knowledge to researchers who are working in the areas of family relationships, care, gerontology, and dementia care, particularly from the sociological perspective.

Following this brief introduction, this chapter is divided into seven more sections. It begins with the background to the thesis (1.2), which talks about the researcher's interest in studying this topic along with the current social phenomena of caring for older parents and women's caring. The next section sets out an overview of Thailand's social and cultural context, covering health and social care policy for older people and Buddhist beliefs in relation to reciprocity and gender. The fourth section describes the characteristics of dementia, the contributions of sociology and social psychology to understandings of dementia, and the overlooked characteristics of dementia. The fifth section discusses the focus of the research on the notion of reciprocity in caring and women's care with an explanation of why the study of these notions is significant. The sixth section identifies the aims and objectives of the study, listing the main research questions along with supporting explanations of how they were developed and arguments for their importance. The seventh section outlines the research methodology used for this study. The last section (1.8) sets out the structure of the thesis, in which each chapter of this thesis is introduced and explained, as an overview.

1.2 Background of Study

Prior to this study, the researcher's interest started with personal and working experiences in the areas of the sociology of ageing and of health. A feminist approach suggests that the personal life experiences of a woman researcher have also influenced the ways of knowing things and understanding the subjective knowledge of the research participants, and also the ways of seeing the knowledge produced (Edwards and Ribbens 1998). In this thesis, reference is made to the researcher primarily as 'the researcher' though use is also made of the researcher's English nickname, 'Kim', where appropriate, i.e. when quoting the comments of research participants, in order to retain their original wording.

The researcher's personal interest was formed by her experiences as a carer for her paternal grandmother. Living under the same roof, the grandmother helped her sons to look after two grandsons (the researcher's cousins) and three granddaughters (the researcher and her two younger siblings). Her sons, the researcher's father and uncle lived nearby and visited her almost every day. Due to a declining health condition in her mid-70s, the researcher's grandmother needed someone to assist her in her daily activities, as they became more limited. The researcher, along with her two sisters, helped her parents to take care of her grandmother more closely. When providing care, the researcher, along with her two sisters, never referred to themselves as 'carers'. Being a granddaughter was a more salient identity than being a carer; to them, caring was like an everyday activity that family members normally did for each other. The researcher felt that generally it is women who recognise the significance of caring activities rather than men. Yet, caring done by women was valued differently, sometimes overlooked, and seen as unnecessary when compared with caring done by men. In terms of the researcher's experience, caring for her grandmother affected her own working life. After teaching class, the researcher went to the grocery store, shopped for fresh food, thought about preparing meals, and then went home to cook, and also to make sure that everything at home was in order. Caring involves many little things to think about. The researcher felt like her personal time was eaten into or sometimes replaced by family time, taken up by concern for others. The tensions of juggling time made the researcher think of all the different roles undertaken in caring for her grandmother. In addition to activities like preparing meals and cooking, the researcher shared time with her grandmother in chatting and watching television, since these activities helped support her emotionally. While she was keeping her grandmother company, the researcher spent time doing academic activities like preparing for the next day’s class, and reading academic journals. Both sets of tasks – care work and academic work – required attentiveness and concentration. Balancing them was stressful and, sometimes, this tension caused the researcher to treat the grandmother less tenderly than usual. Occasionally, this led to feelings of guilt. To the researcher, this was not due to the difficult circumstances of being a family carer or scholar, but rather because of being a woman and all the associated expectations concerning reciprocity and repayment associated with Thai culture. Actually, as a personal experience, caring for her grandmother not only inspired the researcher’s interest in studying this topic for her PhD, it also greatly influenced the process of data collection and data analysis. The personal experience of providing care is discussed further in Chapter 3, in which the researcher explains how caring for her grandmother following the diagnosis of end-stage cancer provided insights into data interpretation and helped her to reach the subjective understanding of the research participants.

Regarding work-related experiences in teaching and doing research, the researcher found there were some gaps in knowledge concerning caring for older people, family carers, and women’s roles in providing care, particularly in relation to dementia care. For example, the existing Thai literature lacks critical coverage of issues in relation to family carers, despite emphasis on the significance of filial norms. In her role as a lecturer, the researcher encountered difficulties in finding teaching materials charting the experiences of family carers’ in the context of Thailand, regardless of the fields of gerontology and family studies. Current knowledge in relation to family care seemed to accentuate the significance of reciprocity in family care but not critically. In addition, the body of knowledge about women’s experiences in relation to caring provision for older people remained limited in the fields of family relations, sociology of ageing, dementia care, and even feminist literature in Thailand, despite women constituting the majority of informal carers. Furthermore, whilst it addressed reciprocity, and specifically ‘katanyu’, defined in Section 1.3.2, as an important value in family relationships, the existing Thai literature appeared to explain the linkage of this value and women’s caring experiences in such a way as to suggest that it was a rule that should be followed. Critical perspectives on family care in Thailand therefore seem to be even more necessary. In the researcher’s view, women’s experiences in caring point to a variety of issues relating to care activities, challenges in providing care, women’s perceptions of social relationships, and wider gender relations, which need to be explored and unfolded. These issues have been absent in theoretical discussions but seem to be implicit in long-term care policy for Thailand’s older people, which is discussed as follows.

Recently, Thai social policy regarding the issue of caring for older people has been designed to deal with the prospective consequences of the rapid growth of the ageing population. The notion of family care has been positioned, in the second long-term care plan, published in 2009, as one of the major sources of support (Prachuabmoh 2015). Following this, in relation to both formal and informal care contexts, the issue of caring has been given greater recognition in policy (Khongboon and Pongpanich 2018). Given the growing demand for Carer in Thailand, family carers still play a significant role in supporting older people. In addition, institutional services such as nursing homes in Thailand remain limited, appearing to be the last choice to replace care provided by family members. In comparison to institutional care, paid or formal home carers seem to be more acceptable in the sense that they are helpers of family members (Knodel et al. 2015) since adult children are still expected to be the main actors in expressing repayment to parents. Thus, family is still the primary source of care for older people in Thailand.

Regarding the notion of repayment, researchers in western societies generally suggest that care provided by family involves the idea of returning care to the cared-for person as a response to benefits or support received (Smith 2001). In Thailand, the notion of repayment is also prevalent but more complicated, since it is greatly influenced by values of katanyu. In social policy, as well as in the media more broadly, katanyu is employed in promoting public awareness of the expectation that adult children recognise the significance of repayment along with contributions of older people. Buddhist Thai people are expected to follow katanyu and express it in the form of giving care and support for parents. While social policy is focused on care provided by family carers, women remain the majority of family carers (Limpawattana et al. 2013), since they are taken for granted as carers by nature, and they have less choice than men in fulfilling the duty of katanyu to older parents or older relatives. However, given that policies at the national level seem to target the idea of intergenerational reciprocity as a mechanism to deal with ageing population change, then several issues in relation to caring for older people are implicit, including family carers' needs and motives for caring, gender relations, significance of caring activities, family involvement in caring, and generational reciprocity.

For these reasons, the researcher wanted to map the existing theories relating to women's experiences of caring for older family members along with an investigation of women's understanding of reciprocity in order to bridge the gap in knowledge and inform new insights into family care, female family carers, and repayment in Thai social policy. This thesis explores these issues through the case of dementia care, chosen for a number of reasons, not least its impact as the most common form of mental deterioration in older people (McKeith and Fairbairn 2001). Indeed, dementia, and particularly Alzheimer's disease (Senanarong et al. 2013), in Thailand is commonly found in older people. In 2016, the number of older people with dementia was 617,000, and this number is projected to increase to 1,117,000 by 2030 (TGRI 2016), almost doubling in size over 14 years. Since most people with dementia continue to live in their own homes (van Zadelhoff et al. 2011, Parsons 2001), family carers are increasingly needed as they play a major role in providing support – spouses, middle-aged children or children-in-law being the initial providers of care (Davies et al. 2014). In Thailand, home-based care is the most common form of support for those with dementia (Karuncharernpanit et al. 2016), influenced by the social norms of family reciprocity.

Caring for people with dementia seems to be one of the hardest kinds of caring (Molyneaux et al. 2011 cited in Davies et al. 2014), since dementia, which is generally described as irreversible memory and cognitive decline, functional impairment, and challenging behaviour (Ruiz 1998, McKeith and Fairbairn 2001, van Zadelhoff et al. 2011), concerns the deterioration of the ability to manage functions that are key to everyday life (McKeith and Fairbairn 2001, Kitwood 1997) (See Section 1.4). In this respect, the irreversible characteristics of this illness not only bring about anxiety and depression for the people with dementia, but also cause pressures on family members. Given that, the degree of impact on family members' lives may lead to relatives with dementia being moved into caring homes (Gruetzner 2001). However, sending older relatives, particularly older parents, into institutional care has not been widely accepted in Thailand (Knodel et al. 2015); family care is still seen as repayment to parents, while the home is a fundamental place where adult children may express such repayment (Karuncharernpanit et al. 2016). With respect to repayment, research relating to family care in western societies shows that the provision for care by family members is the result of the idea of returning care to the cared-for people as a response to benefits previously received from them (Smith 2001). This notion is also prevalent in Thailand, though perhaps is even more complicated since the notion of caring and repayment is influenced by religious beliefs. Given that, three things – activities of caring, the norms of repayment, and katanyu, a social value influenced by Buddhist teaching – are understood as inextricably intertwined. At times, Thai people commonly perceive and use the three words – caring, repayment, and katanyu – interchangeably.

1.3 Thailand's Social and Cultural Context Related to Caring for Older People

As described earlier, the issues to be explored in this study, such as family carers, norms of reciprocity, katanyu, and gender relations in caring, are implied in Thailand's welfare policies related to caring and older people, but there appears to be a lack of critical review of such issues. This section thus provides information on how Thailand's current health and social care policy has taken into account family care so that the issues are better understood in terms of how they are relevant in policy implementation. The section then describes certain Buddhist beliefs relevant to reciprocity and gender as cultural context.

1.3.1 Health and Social Care Policy for Older People

Due to the perceived duty that adult children have towards caring, and their need to demonstrate a sense of gratitude to parents, Thai older people tend to live with their children (Prachuabmoh 2015, Ratanakul 2013). Adult children seem to be the major and primary source of assistance for older people in terms of material support, financial support, and personal assistance (Knodel et al. 2015, Prachuabmoh 2015). In a survey of older people in Thailand in 2014, 98 per cent of older people were supported by a family carer, where the carers included spouses, sons, daughters, adult children-in-law, grandchildren, and siblings. Only two per cent of older populations had professional carers and paid carers as their main care providers. Regarding family care, the proportion of households characterised by co-residence between older people and their family members decreased from 77 per cent in 1986 to 57 per cent in 2011 (Knodel et al. 2013), and to 54.7 per cent in 2014. According to the survey of older persons in Thailand in 2014, family transitions, for instance, expansion of nuclear families and increasing geographical distance of working adult children, caused the changes in co-residence of older people in the family. People aged over 60 are more likely to co-reside with their spouses while those 70 and above are likely to co-reside with their adult children. When compared to rural areas, older people living in urban areas are more likely to live alone or co-reside with one adult child. Generational co-residence – two generations, older people and their adult children, living together – slightly increased from 34.3 per cent in 2007 to 35.2 per cent in 2014. Meanwhile, three or more generations living under the same roof is still found but has decreased from 37.8 per cent in 2007 to 32.4 per cent in 2014. However, living with siblings is not commonly found in Thailand (Knodel et al. 2015). Despite the changes, co-residence still remains the common pattern of living for older people. Family care remains the primary resource of support and care for older people. Discussing family care in relation to the national long-term care plan, as will follow, contributes to understanding how family care is, and has been, influenced by the implementation of the social care policy.

Thailand’s government has implemented several social policies related to the health and wellbeing of older people, intended to deal with ageing population growth. Under the responsibility of Thailand’s Ministry of Labor and Social Welfare, the first national long-term care plan for older people was established in 1982. Before the year 2000, the term ‘long-term care’ and its definition seemed unfamiliar to the public in Thailand (Prachuabmoh 2015). It was often understood as the care provided by institutions such as nursing homes or residential homes (Kespichayawattana and Jitapankul 2008). The first plan implemented in 1982-2001 (Knodel et al. 2015, Regional Office for South-East Asia 2010) identified family care as major informal long-term care (Jitapunkul And Chayovan 2001). The second long-term care plan implemented in 2002-2021 placed emphasis on the issues of active ageing along with the promotion of family care and community care as major sources of support for older people (Prachuabmoh 2015). The definition of long-term care in Thailand was clarified when an amendment of the second National Plan for Older People was made in 2009. Classified by care institutions, long-term care in Thailand has two forms of provision. Firstly, it can be in the form of institutional care organised by the state or market providers. Institutional care includes residential homes, private nursing homes, and long-stay hospital wards (Prachuabmoh 2015, TGRI 2013). Secondly, it can be in the form of non-institutional care provided by the family or community. Regarding family care, the amendment in 2009 paid attention to the carer issue, which is a focus of the home-based care model along with integrated healthcare and social services (Khongboon and Pongpanich 2018, Prachuabmoh 2015). The policy implies a level of significance toward family as a central site for caring provision for older people in Thai society, in the sense that older people’s wellbeing should be sustained mainly by the family, at home, for as long as possible. Despite having been given more attention by the government, informal carers have not been supported practically as much as they should be (Khongboon and Pongpanich 2018, Regional Office for South-East Asia 2010). Family carers still lack professional advice and assistance and cannot access social and nursing care services provided by the community and the government. Ultimately, regardless of whether they are paid, unpaid, formal, or informal, demand for, outstrips availability of carers’ (Khongboon and Pongpanich 2018).

Despite higher demand for carers and appropriate sources of long-term care, institutional services such as state-managed nursing homes are still limited. As an alternative, new nursing homes run by the private sector are increasingly being built to serve the needs of some family members who require external assistance to relieve their caring burden. However, nursing homes are still considered to be the last resort for many (Khongboon and Pongpanich 2018, Regional Office for South-East Asia 2010). Compared to institutional care, paid home carers are more likely to be accepted and needed, particularly in urban areas. Nevertheless, it is uncommon for paid carers to be the main carers or full-time replacement for adult child carers. Paid carers are acceptable as temporary replacements whilst adult child carers are at work (Knodel et al. 2015). This indicates that family care is still the primary source of caregiving for older people. This appears to be due to the strength of social norms and beliefs towards parent-child relationships that are rooted in Buddhism (Yodpet 2002 cited in Regional Office for South-East Asia 2010). The social value of ‘katanyu’ is evoked in many campaigns for social policies supporting the care of older people, such as an older parent care credit and housing loans, to urge adult children to care for their older parents (TGRI 2018). The issue of Buddhist beliefs and katanyu is discussed in the next part.

1.3.2 Buddhist Beliefs in Relation to the Notion of Reciprocity and Gender

Approximately 94 per cent of Thai people are Theravada Buddhists (Ratanakul 2013, Tomalin 2006). Buddhist culture seems to configurate and influence the ways that Thai people behave and treat each other. To understand Thai cultural norms, such as the notion of reciprocity and gender relations, it is necessary to understand Buddhist teaching, as it is a religious context shaping the culture around gender and social relationships among Thai people (Keyes 1984). This section of the chapter explains certain Buddhist beliefs, providing the necessary cultural background in order to understand the notion of reciprocity and gender differences in making repayment. Firstly, the Buddhist concepts of karma, rebirth, and katanyu are introduced. The explanation paves the way to understanding their relationships with the notion of repayment. Next, the section describes how the repayments made by women and men are seen differently in the Thai context.

Karma, Rebirth, and Katanyu

The term 'katanyu' has been used commonly and interchangeably with that of 'repayment'. Before understanding katanyu, it is necessary to understand the core ideas of Buddhism, which are karma and rebirth, since they play a very significant role for Thai Buddhists.

Buddhists believe in a chain of rebirth. Occurrences in the present life and the next life depend on karma (the result of deeds/actions) generated in a past life. In this respect, karma is viewed as a principle of cause and effect (Ratanakul 2013, Choowattanapakorn 1999, Reichenbach 1989); Buddhist people believe that every event or circumstance exists because of those previously experienced. In other words, events depend on other events. A person's every act creates and accumulates 'boon' (merit, good deeds) or 'baab' (demerit, committing sin) (Reichenbach 1989, Choowattanapakorn 1999). Therefore, it can be said that the quality of the next life depends on what actions the individual performs in this life. Doing boon in the present life will be returned in the form of good things in the next life (Ratanakul 2013). Likewise, baab will cause a bad consequence in the next life (Choowattanapakorn 1999).

Buddhist Thai people are taught to realise the importance of receiving benefits from counterparts in a relationship, as well as the significance of reciprocity (Ratanakul 2013), particularly the idea of being indebted, and of spiritual and moral obligations by which children have to repay their parents by 'doing good in return'. Doing good is not only to show katanyu to them (Sethabouppha and Kane 2005, Gray et al. 2016), but also an opportunity to do boon, i.e. to earn merit that will be returned to them in the next life. Thus, the social value of katanyu shapes carers' understanding of caring roles and reminds them of the significance of caring for a parent (Gray et al. 2016). 'Katanyu' is explained as follows.

The value of katanyu involves a sense of obligation to repay a person for a favour or help received from them. More specifically, 'katanyu' is a term actually used along with the terms 'katavedhi' and 'kataweti', which refer to the act of caring for older parents in Thailand (Thanakwang et al. 2014). It can be said that the obligation to repay parents in Buddhist Thai society is based on those two concepts (Watana 2016, Sakyabhinand 2014). Some Thai scholars (Rabibhadana 1984 and Podhisita 1985 cited in Knodel et al. 2003) suggest that since those terms are inherited from and are deeply infused with Buddhist belief, there appear to be no exactly equivalent words in English. 'Katanyu' means a sense of gratitude towards parents

(Thanakwang et al. 2014) or a sense of awareness of the benefits received from other people (Knodel et al. 2003), whereas 'katavedhi'/'kataweti' refers to the obligatory actions of paying back to one's parents or doing something equivalent in return (Watana 2016, Thanakwang et al. 2014, Sakyabhinand 2014, Knodel et al. 2003). That is, 'katanyu' refers to the sense or feeling, whereas 'katavedhi'/ 'kataweti' refers to an action or expression of that feeling. Although both terms are separately described, they often come together when used. However, there are some associations and overlaps in their meaning. In some research, both terms are wrapped up as a single term, 'katanyu kataweti', referring to an act of filial piety to repay parents for their parental support (Nishizaki 2011). Despite that, when it comes to expressing repayment to older relatives or someone who used to provide benefits, the term 'katanyu' alone may also be used. In this respect, the meaning of 'katanyu' seems to also be perceived as a sense of awareness or appreciation of parents' kindness to the actions of repayment. Using solely 'katanyu' is widely found not only in daily conversation, but also in many studies in relation to caring for older parents. For example, a study by Gray et al. (2016) on strength and stress in caregiving for older adults in Thailand uses only the term 'katanyu', which is translated as 'gratitude'. According to Gray et al. (2016), katanyu is cited by the research participants as being filial piety in repayment for parents' kindness. In Upton (2010), 'katanyu' is translated into various terms including: *customary and dutiful kindness, gratitude, traits of respect, reciprocation towards elders, thoughtfulness and repayment, especially for elders* (italics in original).

Expression of Katanyu

Resting on Buddhist principles, the notion of reciprocity in terms of caring for older parents means that it is the duty of children to follow katanyu. It implies a sense of obligation to repay or express their feelings of gratitude to their parents for giving birth to them and raising them, reflecting mutual responsibilities in a relationship (Watana 2016, Sakyabhinand 2014, Choowattanapakorn 1999). For these reasons, parents are assumed to be deserving 'moral creditors' since they self-sacrificed to raise and take care of children. Given that most Thai Buddhist families still hold such beliefs, sons and daughters, in turn, are 'moral debtors' who are obliged to repay their parents (Yavaprabhas 2018, Watana 2016, Engelmajer and Izuhara 2010, Tantiwiramanond and Pandey 1987). However, there are various ways to repay parents when they become frail, i.e. supporting parents' bodies and souls (Watana 2016, Sakyabhinand 2014) through such things as feeding, bathing, pleasing them in gentle and patient ways, and putting aside negative thoughts and feelings. Anyone who disregards the duty will be called an 'akatanyu'; that is, a person who is believed to be bound for hell after death (Watana 2016, Sakyabhinand 2014). Thus, these duties must be done by everybody, even monks. Monks, who are usually bound to remain within or near to their live-in places of worship, are permitted to visit and take care of their parents in need. In Buddhism, male ordination is one of the traditional ways to repay parents, which is a duty of sons. Ordination is believed to be an avenue for repaying debt to parents; parents, particularly mothers who cannot be ordained, would obtain a huge boon, able to reach heaven by clinging onto the saffron robes worn by their ordained sons. It also pleases the parents' souls in the sense that sons will self-improve as a result of spiritual practices, according to Buddhist doctrine (Yavaprabhas 2018, Watana 2016)[1]. Moreover, the ordination helps to preserve Buddhism itself. In Thailand, monks have traditionally high status. Monkhood is seen as the 'field of merit', open only to men to enter, since women are seen as 'unclean' or a 'polluting agent' to the religion (Tantiwiramanond and Pandey 1987). There have been debates on women's ordination in Thailand for a long time. In 2009, some women were finally permitted to be ordained as female monks or fully ordained nuns. This tradition remains in an initiation phase (Seeger 2009) and female monks are still not able to obtain the same official status as male monks.

Thai Women's Positions and Their Roles in Family

According to Tantiwiramanond and Pandey (1987), while Thai Buddhism places great value on the reciprocal relationship between parent and child, it also creates gender bias and marginalised status for Thai women, as they are trapped in a religious patriarchal system that is disadvantageous to women and limits their opportunities. In the religious realm, while ordination is for men and considered as a way for men to accumulate merit for their parents, women are seen as supporters in preparing food for the monks (Keyes 1984). Thus, women are still expected to perform a nurturing role, both in the religious realm and in the domestic familial sphere. Since neither sphere allows women to make their own choices (Tantiwiramanond and Pandey 1987), women are destined to fulfil domestic roles, with the responsibilities and duties of a mother or daughter, which are forced upon them as moral obligations but not considered to be merit-reward activities in the way that ordination is (Mills 1997, Tantiwiramanond and Pandey 1987). Due to gender inequality, Thai women are expected to make repayments or express katanyu through other means, such as taking care of parents and serving their day-to-

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[1] Monks in Theravada Buddhism are constricted to keep the 227 precepts (Seeger 2009).

day needs within the family (Yavapraphas 2018, Seeger 2009). In addition, as dutiful daughters, some women are also expected to give financial assistance to their older parents. Due to the belief in katanyu in the parent-child relationship in Thailand, some Thai women are forced into or volunteer for prostitution to earn money to support their parents. Many studies (Nishizaki 2011, Engelmajer and Izuhara 2010, Cook 1998, Muecke 1992, Tantiwiramanond and Pandey 1987) explain that katanyu is mentioned as a reason supporting Thai women's entering into prostitution. Buddhist belief enables women to enter into prostitution, as it is not considered a sin in Buddhism (Engelmajer and Izuhara 2010, Tomalin 2006). In this respect, however, Buddhist belief appears to oppress women as inferior (Cook 1998, Keyes 1984).

In Thailand, the notion of caring for parents, repayment, and katanyu are closely related. Although a number of previous studies into Thai family carers mention the significance of katanyu, little is known about the experiences and voices of female family carers, despite the fact that the majority of family carers appear to be women. In relation to Thai women's roles, katanyu has been discussed in the context of prostitutions or sex workers more critically than the context of care. It might be because caring is taken for granted by the general public as an activity undertaken in domestic place in which it is understood as a common performance that Thai women show their katanyu to older parents. Regarding family care, Thai women are taught to begin their domestic responsibilities in early childhood, for instance, the servicing of other family members. Women are taught to give priority to seniors and men, whereas men or sons seem to be treated as superiors (Tantiwiramanond and Pandey 1987). Like in many countries, given that caring roles put pressure on Thai women in different ways, their family responsibilities are overloaded but not acknowledged (Suchila 1997 cited in Komolvadhin 2008). Women's extreme workload is a combination of their work outside the home, and domestic responsibilities, while men hardly share the housework. This causes tension and conflict for women, particularly for those living in urban areas. Thus, it appears that women need to balance their circumstances (Phananiramai 1996).

However, given that the caring roles within the family are allocated to women as a way to express katanyu (Yavapraphas 2018, Gray et al. 2016, Seeger 2009, Sethabouppha and Kane 2005), their ways of releasing stress from caring can be understood by the ideas of karma, rebirth, and katanyu. The idea of the 'polluting female sex', which means that women are considered inferior to men, seems to affect Thai women's self-perception and self-worth (Kabilsingh 1991, Tantiwiramanond and Pandey 1987). Thus, karma and related concepts of doing deeds play important roles in easing their stress when caring for parents, such as developing an acceptance of their caring roles (Sethabouppha and Kane 2005). Additionally, some studies (Muangpaisan et al. 2010, Limpanichkul and Magilvy 2004 cited in Limpawattana et al. 2013) point out that a sense of obligation in Thailand based on Buddhist belief may lead to a reluctance in adult carers to share caregiving problems and accept caring as a willing burden. As a result, at times, many Thai carers appear to feel guilty if they feel overwhelmed and would like to abandon caring tasks (Limpawattana et al. 2013).

To summarise this section, it can be said that while Thailand's social care policy has taken into account the issues of family carers, norms of reciprocity, and katanyu, the aspects of gender relations are also inevitably involved. The social care policy for older people implicitly invokes the maintenance of traditional gender relations, impacting on women who form the majority of family carers. Women's experiences, thus, need to be studied more critically. Yet, the existing studies in Thailand still lack explanation of how female family carers, in particular, make sense of repayment in the context for caring, where katanyu and other Buddhist beliefs are closely associated. Given that this study considers repayment and caring as negotiable, it attempts to bridge the gaps of knowledge in social care policy and research that involve the issues of family carers, reciprocity, and gender, and to inform some insights into caring for older people and intergenerational reciprocity which should be implemented in Thai policy.

1.4 Dementia

As discussed earlier, home-based care is the most commonly found form of care for those with dementia in Thailand (Karuncharernpanit et al. 2016). The social norms of family reciprocity and the social value of katanyu influence the provision of care at home in Thailand. As this thesis aims to study family carers' perceptions of reciprocity in dementia care, it necessarily includes the words and actions of people with dementia in care situations. It appears that this aspect should be understood through a sociocultural lens, as well as from a medical perspective. The following discussion provides the characteristics of dementia and the overlooked characteristics of people with dementia.

1.4.1 Characteristics of Dementia

The nature and characteristics of dementia are dominantly defined by a biomedical model (Innes 2009). Dementia is an umbrella term describing the symptoms caused by changes in the brain as a result of a range of diseases and conditions such as Alzheimer’s disease, alcohol abuse, and accidental brain injury (Morris and Morris 2010, Harding and Palfrey 1997). While dementia is defined by many risk factors such as age, family history and genetics, and lifestyle (Stephen and Brayne 2014), there has been a lack of consensus on what causes the condition of dementia (Stephen and Brayne 2014, Harding and Palfrey 1997). The prevalence of dementia seems to be greater in older people and increasing age seems to be a risk factor in terms of dementia progress. According to the World Health Organisation (2019), dementia is one of the major causes of dependency among older people worldwide. Nevertheless, dementia is not considered to be a part of the normal ageing process (McKeith and Fairbairn 2001).

There are a number of conditions under the umbrella term of dementia. The main sub-types of dementia include Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia, and Parkinson’s disease, for example (Stephen and Brayne 2014, McKeith and Fairbairn 2001). The most common cause of dementia in older people is Alzheimer’s disease (McKeith and Fairbairn 2001). In the medical explanation of dementia, the irreversible memory and cognitive decline result in increasingly worse behavioural changes, such as functional impairment and challenging behaviour (McKeith and Fairbairn 2001, van Zadelhoff et al. 2011, Ruiz 1998, Harding and Palfrey 1997). Various sub-types of dementia illustrate different pathological causes and affect people differently. The most common symptoms for dementia include: day-to-day memory loss; difficulties in recalling short term memory, concentrating and organising; difficulties in language usage; visual skills; being confused about place and chronological events; frustration; and mood changes (Alzheimer’s Society 2019). Dementia encompasses a deterioration of the individual’s social and personal performances (McKahnn et al. 1984 cited in Kitwood 1997), and influences the person’s ability to manage their activities and daily living (McKeith and Fairbairn 2001, World Health Organisation 2019) such as comprehension, competence of planning, and decision-making ability (Kitwood 1997).

Diagnosis of dementia is based on medical tests, but there is no single test to determine dementia. Generally, testing includes a physical exam, neurological exam, mental status test, and examination of background information. Some common tests are the mini-mental state examination (MMSE) and the mini-cog test. MMSE is a questionnaire with a 30-point scale designed to test memory, language use, comprehension, and motor skills, while the mini-cog test is a brief test to screen for dementia. These two tests are undertaken by primary care clinicians (McKeith and Fairbairn 2001, Alzheimer's Society 2019, Babu Sandilyan and Dening 2015, Nicholl 2009). Other laboratory tests, such as computed tomography (CT) and magnetic resonance imaging (MRI) might be used to investigate the causes of dementia. McKhann et al. (1984 cited in Kitwood 1997) suggest that even though the causes of dementia can be specified by various processes in a laboratory setting, dementia cannot be diagnosed by laboratory testing or brain scanning processes. Rather, it is determined by examination of behaviour.

There are many staging models of dementia (Grealy et al. 2005). A common staging model of dementia is the three stages model (Alzheimer's Society 2019, Grossman 2018, Reed-Guy 2016, Grealy et al. 2005), which describes early (mild), middle (moderate), and late (severe) stages. The three stages seem to be characterised by cognitive and functional impairment, and deterioration of different activities of daily living (Giebel et al. 2015, Babu Sandilyan and Dening 2015, Grealy et al. 2005) and are defined as a way to understand the changes (Alzheimer's Society 2019). In constrast, Kitwood (1997) explains dementia progression in terms of the person's state of independence and the need for support and assistance. In other words, he takes a person-centred approach that understands dementia in the context of relationships with others. Dementia is seen as 'mild' in cases where a person still has the capacity to live her/his own life without another's assistance. Dementia is considered 'moderate' when a person's ability to perform routine activities requires assistance. Lastly, dementia becomes 'severe' when support and assistance appear to be continuously needed.

It seems that many explanations of the symptoms, characteristics, and stages of dementia are derived from medical knowledge, which dominates the understandings of dementia, and has legitimised treatment of dementia for many decades, despite there being no known cure (Innes 2009). According to Lyman (1989), medical knowledge brings order to dementia care. However, extensive studies of dementia described by biomedical and psychological models might be partial, flawed, and inadequate (Innes 2009, Downs 2000). Commonly such models see what is expected to be seen and ignore other dimensions of dementia, particularly those living with dementia, and other aspects of their human condition (Harding and Palfrey 1997). The next section considers key contributions made by sociological and social psychological perspectives in providing broader insights into dementia.

1.4.2 Contributions of Sociology and Social Psychology to Understandings of Dementia

Despite a lack of concensus concerning the causes of dementia, dementia is medicalised and problematised as a disease, symptom, disorder, and syndrome which needs to be properly cured. Subsequent labelling of those with dementia and of their behaviours as requiring medical intervention may have multiple impacts on both their experiences and their well-being (Harding and Palfrey 1997, Innes 2009, Bond et al. 2004), as well as having implications for support for family carers in dementia care (Nolan et al. 2002). For these reasons, the study of dementia needs the contribution of a combination of other approaches, including historical, sociological and philosophical perspectives (Harding and Palfrey 1997) since it is a complex phenomenon for which science alone is not able to offer the definitive explanation.

Sociological perspectives have been used to explore dementia as a social construction (Harding and Palfrey 1997, Innes 2009), raising questions about how dementia is defined as problem, and how the authority of the medical profession operates in dealing with it through medical treatment. The studies described here not only illustrate the social construction of dementia but also highlight the experiences of people with dementia. For example, Gubrium (1986 cited in Innes 2009) argues that, contrary to popular understanding, dementia is not a normal part of ageing: rather, it is a distinct entity from ageing because people with dementia experience the condition differently from normal ageing. Gubrium and Lynott (1987) suggest that dementia is overgeneralised: once an individual is diagnosed, she or he is seen as being impaired as a whole person (Gubrium and Lynott 1987). Harding and Palfrey (1997) also posit that in Western societies dementia is typically linked to the ageing body and thereby to the accompanying fear of ageing, disease, and death.

Alongside sociology, social psychology has also contributed insightful perspectives to understanding people with dementia and their experiences in different ways. Social psychologist, Tom Kitwood (1990) highlighted the influence of interpersonal processes in caring and interaction upon the development and well-being of those living with dementia. With Bredin (1992), Kitwood mapped the different aspects of caring for people with dementia that might be expected and which could significantly enhance well-being. In so doing, Kitwood and Bredin

(1992) also flagged the link between cognitive abilities and aspects of ‘personhood’ of those with dementia. Kitwood notably used ‘personhood’ (1997) to indicate a broad conceptualisation of status and self in relation to people with dementia, locating personhood not as the individual’s property but it as given in social relationships by the presence of others in that relationship. The concept was developed further through the notion of ‘person-centered care’, which challenged the pathological view of dementia and provided an alternative view (Ryan et al. 2004, Reid et al. 2001) or a new culture of dementia care (Cowdell 2006). Additional studies by Sabat and Harré (1992) and Sabat (2005) have also focused on aspects of self. In the early 1990s, Sabat and Harré (1992) suggested that the self of those with Alzheimer’s Disease still persisted even when individuals were labelled as being in the terminal stage of dementia. More recently, Downs (2000) has highlighted empirical findings which suggest that the difficulties in the lives of those with dementia are the outcome of society’s ignorance and overlooking of their social and environment conditions. Putting the emphasis on socio-cultural conditions and the experiences of those with dementia, social research has thus helped to reveal new and different aspects to dementia studies, with potential to inform social policy and the improvement of care provision, and support for carers and caring relationships within dementia care (McKeown et al. 2010, Ryan et al. 2004).

Focusing on dementia care and the experiences of those with dementia, Innes (2009) has suggested that aspects of gender, culture, ethnicity and social class seem under-researched and need to be taken into account. The experience of dementia is not universal but shaped by social and cultural factors, which impact on how dementia is perceived and interpreted (Cipriani and Borin 2015, Innes (2009) and in turn result in different ways of seeking help (Cipriani and Borin 2015, Mukadam et al. 2011). Whereas Western societies seem to view dementia as a disease, other societies do not consider dementia as a medical condition. For example, in some Chinese communities in East Asia, dementia is viewed as fate; a retritbution for sins or family misdeeds, which cannot therefore be changed. However, in other Chinese communities such as Guangzhou, dementia is viewed as a normal part of ageing, for which, people therefore seek medical help as the dementia progressively develops (Cipriani and Borin 2015). In African American society, the cause of dementia is believed to be spiritual or God’s will, and so medicine is not seen as being an effective treatment (Cornnell et al. 2009 cited in Cipriani and Borin 2015).

From a socio-cultural perspective, dementia is significant not only as a set of symptoms but also as a focus of differentiation and discrimination. In some areas, people with dementia form minority groups stigmatized not only as a result of their age but also their ethnicity. The significance of ethnic identity is not always recognised, despite having a potentially considerable impact on levels of accessability to care services (Cipriani and Borin 2015, Bowes and Wilkinson 2002 cited in Innes 2009). Cooper et al. (2009 cited in Mukadam et al. 2011) have illustrated inequalities in access to professional services between ethnic minority versus ethnic majority populations. Barriers to healthcare among individuals from ethnic minority groups include language barriers, feeling discriminated against, limited knowledge of dementia, and lack of information concerning where and how to seek assistance. As a result, people with dementia from minority groups may delay looking for help until the illness is untreatable (Mukadam et al. 2011). Linked to this, the everyday experiences of those with dementia and their well-being, including feelings of depression, are inevitably affected by how their ethnicity is perceived (Pinquart and Sorensen 2005 cited in Kristani et al. 2018).

Social research on dementia has studied the experiences not only of those with dementia but also of those who care. The stresses and strains experienced by carers are an important topic of investigation because they affect quality of caring, the well-being of care recipients, and the continuation of care (Innes 2009). Indeed, empirical evidence suggests that interventions supporting family carers may be more ‘successful’ when a partnership approach is adopted (Nolan et al. 2002) and carers themselves play a significant role in determining ‘what works’ (Nolan et al. 2002). Despite the increasing prevalence of dementia, women still form the majority of carers, and it seems that the impact of caring falls on them more than on men. Yet in policy documents relating to dementia and caring experiences, the notion of gender appears to be lacking (Erol et al. 2015). While women’s experiences in caring may vary as a result of their ethnicity, education, relationship status, and health, they are typically marginalised. Women’s voices and needs are not recognised by supporting services. Also, women’s direct experience seems to be missing from research whether they are women diagnosed with dementia, paid or unpaid carers, or those who work as professional in supporting people with dementia (Savitch et al. 2015, Erol et al. 2015). Women living with dementia may find it difficult to accept changes to their role and identity as they are typically expected to be the family carer rather than a care recipient. For example, a mother who develop dementia does not want to be dependent on the family (Erol et al. 2015). As for female carers, dementia may impact on their physical and mental health, their financial and employment positions are challenged, and their activities and relationships with friends are challenged or even damaged (Erol et al. 2015, Savitch et al. 2015).

Sociological and social psychological perspectives help inform the analysis of the experiences of women in providing care for their relatives living with dementia in this study; women play a central role in the delivery of dementia care in families and therefore their experiences are key in unpacking perceptions of female family carers in Thailand. Concomitantly, sociological and social psychological perspectives also inform new insights, revealed by the study, into the behaviours and responses of people with dementia typically defined as problems or even overlooked in biomedical approaches. This issue is discussed next.

1.4.3 Overlooked Characteristics of People with Dementia

People with dementia form a heterogeneous group (Morris and Morris 2010, Innes 2009). This is not only because of the nature and characteristics of dementia and the different ways in which they are explained and perceived (Gove et al. 2016), but due to the varying backgrounds of those with dementia, based on factors including class, race, ethnicity, cultural group, age, gender, sexual orientation, religion, and the level of caring and support needed (Hulko 2004 cited in Innes 2009, Morris and Morris 2010). That said, those with dementia are still seen as different or deviant from healthier people because of their functional and cognitive impairment (Bond et al. 2004).

Through the medical perspective, particularly the lens of neuropathological, neurochemical, genetic study of the brain, and cognitive psychology (Bradbury et al. 2004, Davis 2004, Downs 1997), the dementia-related phenomena such as behavior of those with dementia are problematised in that they are defined as biomedical diseases (Innes 2009, Bond et al. 2004). That is, the behaviours of those with dementia, such as difficulties with communications – fragmented speech, repeating, and word choice – are viewed as being part of cognitive impairment which is interpreted in association with functional impairment (Boyle and Warren 2017), rather than as the person’s attempt to communicate. This perspective appears to devalue those with dementia, denying their personhood (Davis 2004, Kitwood and Bredin 1992) and overlooking their agency (Boyle and Warren 2017) to persevere in connecting with the world. Notably, such a medical perspective, despite offering the person treatment, may also create social exclusion (Bond et al. 2004).

Following this, the second research question of this thesis – in what ways do female family carers understand the reciprocation given by people with dementia? – implies an argument that not every person with dementia lacks the ability to reciprocate, since those with dementia are a heterogeneous group. Moreover, the implicit argument is that cognitive decline does not determine loss of expression, but rather that communication remains possible with the family carer's attentiveness, receptivity, and ability to interpret. This thesis considers that although verbal communication is likely to decline and later become absent, and it may be difficult for those with dementia to express themselves, their non-verbal mode of communication is still retained, which includes eye expressions, facial expressions, vocalisations, gestures, physical contact, imitation (Ellis and Astell 2017, Martin et al. 2013, Hyde'n 2013, Downs 2013), or even their silence, which they use to connect with the world and notably to signify their selfhood (Kontos 2005). The absence of verbal language in those with dementia might enable family carers and other people to view them as failing to engage emotionally (Ellis and Astell 2017). In fact, any emotional communication conveys, through words or actions, meanings intended to be shared in their external relationships. Although their emotions, whether manifested as anxiety, depression, or agitation, are assumed to be a pathological indicator of disease, they could indicate their reflexive ability (Boyle and Warren 2017). The literature previously cited suggests that although the communications of those with dementia are difficult to observe and understand, attentiveness to the person's expressions is necessary (Barnes 2012) so that their relational agency is recognised (Boyle and Warren 2017), and their preservation of expression along with their messages are not disregarded (Maciejewski 2011, Innes and Capstick 2001). Moreover, the carers' attentiveness to both verbal and non-verbal expression also urges carers to be more aware of the way they use their own words, gestures, and emotional expressions to communicate with those with dementia (Innes and Capstick 2001). Since this thesis draws attention to reciprocity, the expressions of people with dementia are described in relation to the concept of reciprocity, additionally in terms of the reciprocation given to the carer and the care provided.

In sum, ageing trends, the increase in rates of dementia, and patterns and understandings of informal care provide the background to an exploration of the issues of reciprocity in relation to dementia care in a Thai context. The researcher now sets out the research issues, explaining why the thesis draws attention to women's caring in relation to repayment in the context of Thailand, and the importance of reciprocity in caring for people with dementia.

1.5 Research Issues

In the context of caring, reciprocity is an important aspect since it refers to actions of giving and taking or exchanges of materials, services, and support in caring (Graham and Bassett 2006, Lewinter 2003, Gouldner 1960). There are several ways to express reciprocal support. Also, reciprocity can occur over a long period of time (Finch and Mason 1993). The term 'reciprocity' then has different usages according to different circumstances. In studying dementia care, this thesis looks at reciprocity in two different ways: reciprocity as *repayment* and reciprocity as *reciprocation.* Based on these two concepts of reciprocity, the research problems are now explained in two parts covering repayment relating to women's caring in Thailand, and reciprocation and dementia care. Repayment and reciprocation are defined respectively as follows.

The term *repayment* in this thesis is considered in the context of exchanges within family relationships. Here, repayment refers to the obligation of an individual to return something to parents or relatives for past favours done. However, in the family context, repayment is not necessarily made immediately but can be delayed, particularly in the case of repayment to older parents or relatives. In this respect, repayment or 'delayed reciprocity' (Funk 2012, Neufeld and Harrison 1995) leaves time for individuals, especially for those in younger generations, to accumulate resources to be used in repayments made to people in older generations.

With respect to *repayment,* caring for older people in Thailand has been consistent with a number of other Asian countries, in the sense that it has been influenced by Buddhist philosophy (Yen et al. 2010 cited in Wongsawang et al. 2013) which focuses on repayment to older adults. In Thai society, this repayment is captured by the term 'katanyu' (Gray et al. 2016, Wongsawang et al. 2013, Sethabouppha and Kane 2005). Although there have been a number of Thai-based studies (Knodel et al. 2018, Gray et al. 2016, Watana 2016, Sakyabhinand 2014, Taemeeyapradit et al. 2014, Meecharoen et al. 2013, Wongsawang et al. 2013, Sethabouppha and Kane 2005) discussing the notion of repayment in relation to caring for older relatives, particularly older parents, their findings seem to focus on the various ways of expressing katanyu and the ways that adult children follow the norms of repayment. In this sense, katanyu is presented as a significant social value to be respected. Following the social value of katanyu brings about a sense of obligation to repay older parents. Moreover, taking care of older people is recognised as the first priority within the family, to be honoured over personal goals (Sethabouppha and Kane 2005, Gray et al. 2016, Wongsawang et al. 2013). Thus, although economic and social changes such as family size and working migration may affect intimacy in a family relationship, filial obligation remains strong. There has to be at least one adult who stays at home to take care of older parents (Caffrey 1992). To abandon or neglect older parents indicates a lack of sense of filial obligation, and is considered to be a great sin (Klausner 1987 cited in Caffrey 1992). Moreover, according to the tenets of rebirth and karma, or the 'law of causation', such sins will have negative repercussions for the doer in the next life. Additionally, adult children feel pride in caring for their parents; it allows them to show katanyu to their parents, including the performance of good deeds (Gray et al. 2016, Sethabouppha and Kane 2005). In sum, many studies seemed to consider katanyu to be a norm of reciprocity that Thai people should follow to express repayment to older people.

Regarding repayment and Thai women, despite socioeconomic change and demographic changes in Thailand, Thai women still act as the main family carers rather than men (Limpawattana et al. 2013). In general, daughters are expected to provide a better quality of care, particularly personal and emotional care, compared with sons (Wongsith 1996 cited in Choowattanapakorn 1999, Knodel et al. 1995). Many studies indicate that typically the youngest daughters are expected to take care of older parents, because they are assumed to stay in the household longer than their siblings. In addition, divorced daughters and granddaughters are also assumed to be family carers for the same reasons (Caffrey 1992).

Caring may be a shared way to demonstrate repayment. However, it is understood both practically and theoretically that, compared with men, women more commonly express katanyu to their parents in this way. Women's choices concerning repayment to parents for favours previously received are more limited (Yavapraphas 2018, Seeger 2009). Compared with Thai women, Thai men have a greater range of options concerning how to achieve katanyu for older parents. For example, entering into Buddhist ordination is a way of embodying repayment that is open to men but not to women (Rittirong et al. 2014). In this sense, caring belongs to women as a domestic responsibility in meeting the norms of repayment and fulfilment of katanyu. Furthermore, in cultural terms, caring is understood as being done appropriately if it is carried out by women; the assumption is that they provide better care than men, particularly personal care, since women are assumed to be natural carers (Gray et al. 2016, Scambler 2008, Clarke

2001). Most studies on the issue of caring in Thailand have focused on the subject of the 'burden' of caring (Bastawrous 2013, Blom and Duijnstee 1997). Many studies mention the norms of repayment in relation to caring but simply in the sense of reporting adult children carers as following the duty to give care. Thus, repayment has not been viewed as negotiable. Furthermore, it seems that the issues of repayment and care have not been examined in depth in terms of gender relations, particularly from the women's point of view. The experiences and voices of Thai female family carers have not been given attention; there has been limited exploration of women's caring, along with notions of burden from within the framework of gender relations.

The aim of this thesis is to explore the extent to which, in fulfilling repayment in relation to caring, female family carers follow or surrender to, or alternatively negotiate, the circumstances. In other words, do they automatically care by simply following the norms of repayment or do they face difficulties and attempt to achieve balance when doing care or making decisions in providing care? The issue of negotiation in repayment or reciprocity helps reveal the gender inequality that positions female family carers as subordinated in the hierarchy of family obligation (Finch and Mason 1993) as well as exposing the ethics and value of women's care. Thus, it is interesting to study how Thai female family carers perceive or make sense of repayment in caring, particularly when reciprocity in the Thai context involves negotiation of the value of katanyu.

Another way to consider reciprocity is through the concept of *reciprocation*. This refers to those situations where care receivers reciprocate 'in the moment' or provide something for carers in exchange for assistance received (Gove et al. 2017, Guala 2012, Dwyer et al. 1994). Such reciprocation in caring helps reduce the carer's stress and engenders satisfaction from caring (Dwyer et al. 1994). Interestingly, much of the literature relating to reciprocity and dementia states that reciprocity or reciprocal relationships cannot be expected when dealing with people with cognitive problems, such as those with dementia. The loss of physical and cognitive skills resulting from the illness is thought to influence the cared-for person's ability to reciprocate, and influences the potential to create and maintain understanding between the carer and the person with dementia (Barnes 2012, Gouldner 1960). In situations where something is given back by people with dementia, such reciprocity can maintain the relationship but it is difficult to expect. Thus, it is assumed that the caring relationship in dementia care cannot be reciprocal (Killick and Allan 2001). This aspect implies that once people with dementia cannot give anything back to carers, relationships cannot exist. For this reason, lack of reciprocity in caring for people with dementia may lead to fragmentation in the caring relationship (Perrin and Hazel 2000 cited in Breheny and Stephens 2009), and mistreatment or violence (Pettersen and Hem 2011). This demonstrates that there is a link between lack of reciprocity and caring relationships in dementia care.

In general, it is taken for granted that people with dementia are unable to express themselves in the same way that other people do. In fact, the ability of expression possibly depends on the trajectory or stage of an individual's illness. Thus, not every person with dementia fails to reciprocate. Furthermore, some scholars claim that the communicative expressions made by those with dementia include not only the verbal mode, but the non-verbal mode of communication (Barnes 2012, Pettersen and Hem 2011, Innes and Capstick 2001). Both communicative modes exist but require the observation of others, particularly carers, since people may overlook non-verbal communication or take for granted that people with dementia fail to respond to human contact (Gove et al. 2016). Without attentive observation, the acts of reciprocation by those with dementia may not be perceived or affirmed as existing. In this sense, it is interesting to study how carers, especially female family carers, perceive and make sense of the reciprocation given by their relatives with dementia. Exploring family carers' perceptions of reciprocation is not only helpful in understanding the ability of people with dementia, but also in understanding carers' motives to carry on with care provision at home instead of admitting their relatives with dementia to institutional care, and to provide the quality of caring that helps prolong the wellbeing of those with dementia.

1.6 Research Aims and Objectives

This thesis aims to expand the sociological mapping of norms and practices associated with reciprocity, family care, and dementia care in Thailand. The research objective is therefore to explore female family carers' experiences of reciprocity in caring for older people with dementia in Thailand. In doing so, it is necessary to note that this thesis considers the characteristics of reciprocity, caring, and motivations for caring as culturally gendered but, in practice, as dynamic, flexible, changeable, and negotiable. Following this, the thesis has three main research questions, which are described along with their details and significance, as follows.

Research Question 1: How do female family carers make sense of repayment in caring for older people with dementia?

Although this question might be initially understood to explore female family carers' understanding of caring, in fact, this question puts the emphasis on the notion of repayment. As described earlier, the notion of repayment in Thailand seems complicated since it is considerably influenced by the values of katanyu and by religious beliefs. As explained earlier, the three concepts of caring, repayment, and katanyu are not understood separately but perceived as the same thing. In addition to the complexity of repayment, caring is seen to belong to women as their natural task (Barnes et al. 2015, Clarke 2001, Bowlby et al. 1997, Tronto 1993). In Thailand, women's caring is taken for granted as the way to repay older parents or older relatives, and also as an expression of katanyu (Yavapraphas 2018, Gray et al. 2016, Seeger 2009). However, by adopting a theoretical framework that emphasises relationality and negotiation in family practice, this question actually prioritises consideration of the negotiation of the understanding of repayment by family carers.

Research Question 2: In what ways do female family carers understand the reciprocation given by older people with dementia?

Reciprocity is generally unexpected in the context of dementia, as those with dementia are perceived to be incapable of reciprocating something to other people (Hooker et al. 2000 cited in Graham and Bassett 2006, Killick and Allan 2001, Neufeld and Harrison 1998). Here, the researcher's arguments are that not everybody with dementia loses the ability to reciprocate. Such ability depends on the different stages of dementia. Thus, reciprocation may exist and it may be possible to observe and facilitate reciprocation if carers pay adequate attention to it (Gove et al. 2016, Lewinter 2003) along with using their intimate knowledge of the cared-for person to access those reciprocations (Barnes 2012). Therefore, this question explores the reciprocations expressed by people with dementia based on the experiences of female family carers, focusing on whether or not carers notice what care receivers reciprocate and how family carers interpret the reciprocation received. Family carers' experiences are significant since they shape their motivations for caring. In this respect, the findings of this question are also related to the next research question, below.

Research Question 3: How do the family carers' experiences of reciprocity relate to their motivations to provide care?

This question links with the second research question, since how family carers' experience the reciprocation of people with dementia may play a role in their decisions to continue providing care at home. The motive to keep on providing care is significant for family carers as well as for care receivers because motives for caring can enhance the quality of care provision and the wellbeing of the cared-for person. Moreover, motives for caring can change and develop over time, depending on many factors such as the health conditions of the care receivers, the ability of family carers to cope with the care conditions, and the quality of the caring relationship (Kohli and Künemund 2003, Schulz et al. 1989 cited in Quinn et al. 2015). In this sense, reciprocity in the care relationship may also influence motivation for caring. Therefore, this question aims not only to identify what motivates carers in continuing to undertake care, but also to explore the relationship between reciprocity and motivation, which the family carers consider in making their decision to care for their relative at home instead of sending them into institutional care.

1.7 Research Methodology

This study was inspired by a feminist approach in exploring women's experiences based on in-depth interviews method with 19 Thai Buddhist female family carers. They all had at least one year's experience of caring for their relatives living with dementia. The research site of this thesis was a large city in the central region of Thailand along with its surrounding provinces. The researcher initially recruited and approached the participants by participating in the activities held by a health organisation, which is referred to in this thesis by a pseudonym, Diamond Dementia Care Center (DDCC). However, not all of the research participants were recruited through DDCC's activities, but through other public activities in relation to dementia. Additionally, some participants were approached via personal contacts of the researcher.

With respect to the notion of reciprocity and caring, the process of recruitment and data collection enabled the researcher to realise the challenges of undertaking research around these issues. The researcher found that being a female family carer is not easy but challenging. It is difficult to fix a time schedule for caregiving, therefore, it could not be expected that family carers would be available and willing to be interviewees. Furthermore, the researcher also found that caring and reciprocity seem to be quite sensitive issues for Thai people, particularly female family carers. It might be because the caring is likely to be allocated to women as a result of their limited choice of expression in the form of repayment and katanyu, which is connected to Buddhist beliefs and the public expectations put on women. As interviewees, the female family carers' stories disclosed their activities and a deep sense of the emotional aspects of caring. Their feelings of happiness, joy, and also sadness, for instance, were expressed in their stories. Their experiences were uncovered since the research methods suggested by a feminist approach emphasise the power relations between the researcher and research participants in doing research. These helped the two parties to develop trust during the course of interviews, and encouraged willingness in the research participants.

In the data analysis as part of this study, the theoretical framework is composed of five concepts: caring, gender, reciprocity, motivation, and family practice. Since the concept of family practice focuses on the aspect of relationality in doing family activities such as caring, this concept helps integrate the other four concepts.

1.8 Structure of Thesis

This section describes how this thesis is organised and written. The thesis is composed of eight chapters. The description below provides an overview of the content of each of the seven chapters that follow this first introductory chapter.

Chapter 2 identifies the theoretical framework. Five concepts are discussed and debated: caring, gender, reciprocity, motivation, and family practice. Firstly, each concept is described separately. Then, the relationship between the concepts is examined to explain how they are relevant and contribute to the research questions.

Chapter 3 is a discussion of the research methodology and the processes of this thesis' production. The feminist approach used in this thesis is thoroughly discussed in terms of its significance and implications for the research processes. The research sites, the criteria of selection and the recruitment of the research participants are described. A description of the ethical reviews of this thesis before undertaking data collection is provided. Following this, the process of data collection is detailed, demonstrating the way in which in-depth interviews as the main research approach was operated. This chapter also discusses reflexivity in relation to this research by explaining the status of the researcher when doing fieldwork, for the sake of transparency. Lastly, a section on data management describes how the researcher organised the collected data, including data transcription, the thematic approach, and the writing process.

The main body of research findings is presented in Chapters 4 to 7. Chapter 4 provides an overview of the caring experiences of the research participants, while Chapters 5 to 7 are organised in order of the research questions.

Chapter 4 discusses the caring experiences of the participating female family carers. This chapter effectively preludes the research findings in the sense that the female family carers and their circumstances surroundings the caring are made known. This chapter is intended to provide supporting information rather than any findings relevant to the main research questions. The discussion in this chapter includes the intimate knowledge of the carers, the consideration of their caring in terms of practice as well emotional labour, and the assistance that the female family carers received from friends and acquaintances. In this chapter, family involvement is also discussed to illustrate that dementia care is not only a matter of the relationship between people with dementia and their carers, but also a matter of the relationship between other family members in terms of their feelings of concern and conflict. Those relationships could affect the carers' perceptions toward caring responsibilities and their ways of providing care, for example.

Chapter 5 presents the findings of the first research question, which explores how female family carers make sense of repayment in caring for older people with dementia. This chapter identifies the facets of repayment that the female family carers perceived in their caring. Additionally, this part examines the complexity of the notion of repayment in the context of caring, in the sense of how it functions when Thai female family carers were undertaking care. This chapter also explores how the carers learned the concept of repayment within family, which shaped their perceptions towards the significance of ethics. Repayment is associated closely with katanyu and gender dimensions in Thailand, however this chapter also examines the ways that Thai female family carers negotiated repayment. It examines how female family carers consider the value of caring. Their negotiations also reflect that repayment in the form of caring can be done regardless of the gender of the carer. Lastly, this chapter discusses how katanyu is negotiated when associated with making repayment in the context of caring.

Chapter 6 addresses the second research question. It explores reciprocation by the people with dementia based on the experiences of the participating female family carers. This chapter then highlights how people with dementia have a variety of ways to express or communicate with others regardless of whether this is in the form of negative and positive expression. Thus, this chapter explores the presence and forms of reciprocation. It also examines in what way the female family carers perceived the reciprocation given to them, and how what was being reciprocated was meaningful to the carers and affected the care provision. This chapter explains the Thai cultural context, which plays a very important role in the carers' understanding of the meaning of reciprocation, particularly when it comes to bodily acts or embodied reciprocation of people with dementia in Thailand.

Chapter 7 addresses the third research question by focusing on the relationship between the female family carers' experiences of reciprocity and their motivation for caring. At the beginning of this chapter, the beliefs of karma and rebirth are discussed in relation to the carers' perceptions in terms of the cause of dementia and the destined relationships between carers and care receivers. Next, since the continuation of providing family care relates to the consideration of institutional care as an alternative, this chapter also discusses the female family carers' perceptions of sending their relatives with dementia into such care. However, since motivation for caring is a focus of this chapter, this chapter therefore explores the carers' motives which were developed and shaped in the duration of care provision. This chapter discusses the supporting conditions which were the consequences of the carers' experiences of reciprocation. The supporting conditions, therefore, help understand how a carer's motives for caring related to the reciprocation given and received. The last part of this chapter explains the motivation for caring as a negotiated process. That is, when considering the continuation of doing care because it is considered the proper thing to do, it requires the family carers to negotiate or balance their circumstances. Thus, this chapter illustrates the types of ethical accounts that the family carers used as part of their motives for caring. Lastly, this chapter highlights the significant aspect of timeframe and reciprocity in Buddhist beliefs towards the care provision for older people in Thailand. Thus, it helps to expand the understanding of intergenerational reciprocity and other aspects of its characteristics.

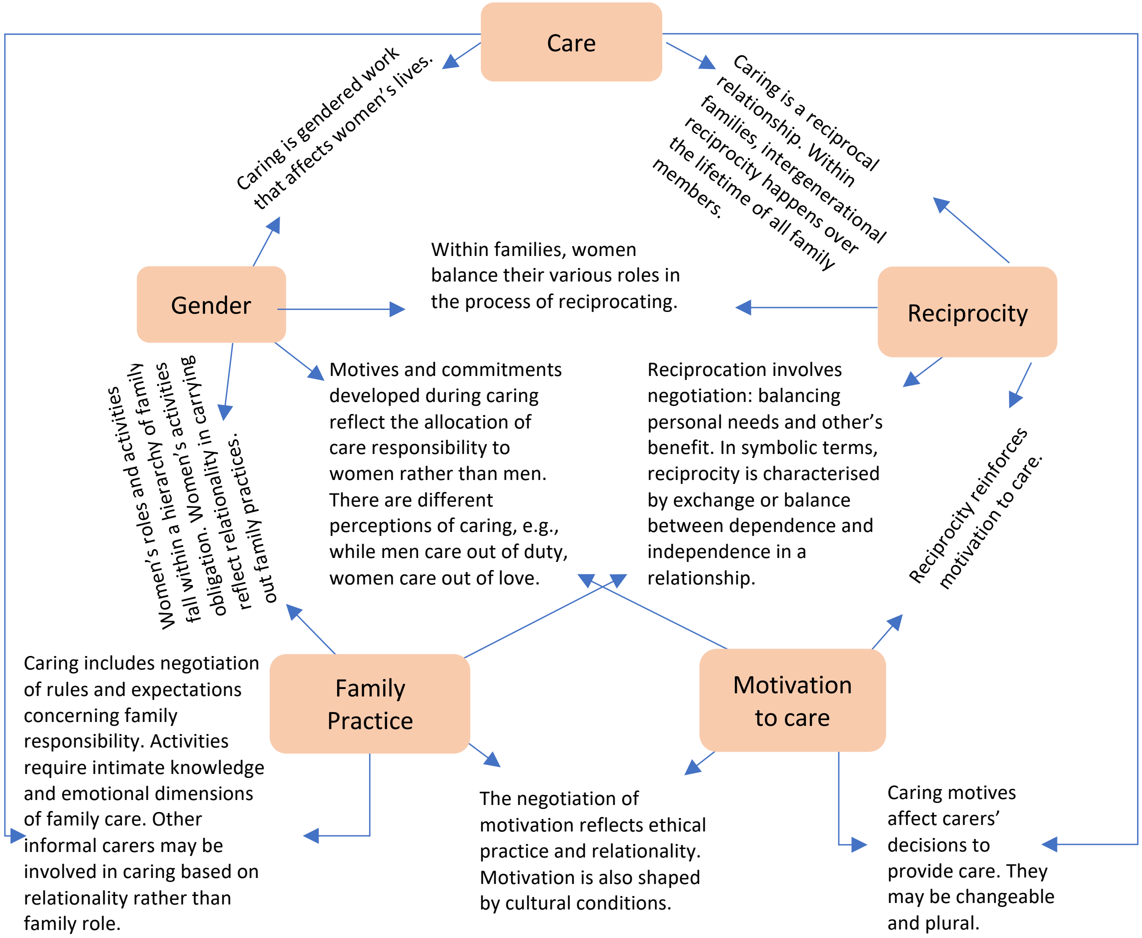
Chapter 8 is the conclusion, providing a synopsis of this thesis' findings. It also discusses what the findings contribute to the wider body of research, and its implications in terms of policy and practice in relation to family caring, gender-related reciprocity in providing family care, and generational reciprocity. As the study for this thesis was conducted in Thailand, it provides some additional insights into the significance of the socio-cultural context in shaping the understanding of reciprocity, for instance, the cultural acts of reciprocity, karmic reciprocity, and the timeframe of reciprocity. These research implications derived from this study might contribute to knowledge in the fields of sociology, social policy, social psychology, and related fields that look at family care, gender, culture, gerontology, and dementia care. The limitations of the thesis along with possible future research are discussed in this concluding chapter.

Chapter 2: Theorising Caring and Reciprocity in Caring for Older People with Dementia

2.1 Introduction

This chapter contributes to the aim of exploring the experiences of Thai female family carers in relation to caring and reciprocity in home-based dementia care by setting out the five concepts used in the theoretical framing of this thesis. The concepts comprise care, gender, reciprocity, motivation, and family practice. This conceptual framework is needed to understand reciprocity and caring in the Thai context, in which women are expected to be the carer within a family. Forming an overarching framework, these concepts relate to one other in the following ways: firstly, caring is a gender issue in which women have been positioned unequally under the patriarchal structure. Secondly, caring is a reciprocal relationship, in which people give and receive the others' assistance and support. Thirdly, the motivation for caring might be affected by reciprocity. This being so, this thesis aims to describe experiences of female family carers conforming to social norms, social values, or family responsibilities, but also their experiences of caring involving negotiation, which is a significant aspect of family practice. In this respect, the concept of family practice helps integrate the four concepts previously noted in order to explain how women conduct caring within their families. The following diagram is an overview showing how each concept relates to each other.

Figure 1: Diagram Summarising the Five Conceptual Fields



Caring is gendered work that affects women's lives.

Caring is a reciprocal relationship. Within families, intergenerational reciprocity happens over the lifetime of all family members.

Within families, women balance their various roles in the process of reciprocating.

Women's roles and activities fall within a hierarchy of family obligation. Women's activities in carrying reflect relationality in carrying out family practices.

Motives and commitments developed during caring reflect the allocation of care responsibility to women rather than men. There are different perceptions of caring, e.g., while men care out of duty, women care out of love.

Reciprocation involves negotiation: balancing personal needs and other's benefit. In symbolic terms, reciprocity is characterised by exchange or balance between dependence and independence in a relationship.

Reciprocity reinforces motivation to care.

Caring includes negotiation of rules and expectations concerning family responsibility. Activities require intimate knowledge and emotional dimensions of family care. Other informal carers may be involved in caring based on relationality rather than family role.

The negotiation of motivation reflects ethical practice and relationality. Motivation is also shaped by cultural conditions.

Caring motives affect carers' decisions to provide care. They may be changeable and plural.

The chapter begins by introducing the concept of care, followed, in turn, by the concepts of gender, reciprocity, motivation, and family practice.

2.2 Concept of Care

Care is a well-known word that is often used in daily life but seems to be a complicated concept. Caring is defined broadly, and is still being discussed among scholars, even amongst those within the social sciences (Held 2006). On the definition of care, Held (2006) considers that although this term has been written and explained for over twenty years in order that it could be developed as a theory, it still needs a more precise definition. Scholars view that the conceptualisation of care is ‘elusive’ and ‘ambiguous’ (Rummery and Fine 2012), and that there is still no consensus on its definition (Webb 2001). The concept of care has been discussed not only in familial contexts, but also in the context of social policy, political activity, and the environment, such as global climate change and world hunger (Held 2006). Furthermore, the definition of care is considered through various lenses, such as those of values, activities, labour, work, emotion, and relationships.

Regarding the concept of care, the researcher has divided the discussion into three parts, one for each of the three dimensions of care covered by the study: the family carer as an informal carer; dementia care at home; and the challenges of care.

2.2.1 Characteristics of Care

There are several terms relating to care that have overlapping meanings, such as ‘care’, ‘caring’, ‘caring for’, and ‘care/caring about’. Fine (2007) suggests that none of these meanings have clear-cut definitions. The word ‘care’ as a noun refers to ‘a state of intention and support’, while ‘caring’ means the practice of giving care (Fine 2007). Caring is an ‘interactive process’ in which a person tries to meet the needs of another person (Phillips 1993). The caring process involves the management of various tasks, requires the carer to have certain skills, and is determined by the carer’s intentions (Webb 2001, Phillips 1993).

According to Rummery and Fine (2012), care can be distinguished by three aspects. First of all, care is seen as a feeling or emotion of concern for others, not only those sharing an intimate relationship, but also neighbours and strangers. Secondly, care can manifest in physical form as labour, which involves a cost of care, workload, stress, and rewards. Thirdly, care is considered as an aspect of social relationships. In this respect, the activities associated with care would be different from other forms of work due to the focus on emotion (Lloyd 2000 cited in Rummery and Fine 2012), including the power of control and dependency. Rummery and Fine (2012) note that many scholars attempt to downplay certain aspects in order to make a clear-cut definition of care, but they argue that these aspects should be understood interrelatedly instead.

Despite ambiguity in the definition of caring, the concept of caring can be grammatically divided into two sets of activities (Fine 2007): ‘caring for’ and ‘caring about’. ‘Caring for’ means to undertake activities of physical care and is a practical aspect, whereas ‘caring about’ is to do with emotional care and feelings (Fine 2007, Abbott and Meerabeau 1998, Ackers and Abbott

1996). In this respect, Scambler (2008) views that caring should not be seen as work of physical support, but emotional support, because emotion is a dimension that is essential to serve the needs of the person being cared for. Fine (2007) also suggests that, although the person being cared for needs physical care, emotional care is crucial in order to respond to their needs. However, these separated dimensions of caring seem to be only an artificial division that is used for the sake of analysis (Payne and Ellis-Hill 2001, Rose 2001). In fact, for carers, caring is to undertake both emotional and physical labour. Despite that, these dimensions can impact on one another and affect the carer's ability to care. That said, while 'caring for' involves bodily practices, clearly 'caring about' can be performed through bodily expression also, such as through eye contact, touching, hugging, or talking to them with a soft voice (Morgan 2011). However, since this thesis follows a feminist approach to study women's experiences in conducting family care, the emotional and physical labour as dimensions of care are also discussed in more detail in relation to a concept of gender.

Generally, when somebody cares about or cares for something – be it another person, an object, or even themselves – then they realise the worth of the object and would like to value it. The notion of care refers to 'otherness' whereby individuals try to associate with something beyond themselves (Held 2006, Tronto 1993). Hence, care is a central part of human life as it implies an engagement not only in the form of a human relationship, but also an engagement with things (Phillips et al. 2010, Tronto 1993). Care therefore links human beings to one another, not only within a family, but also among friends and communities (Phillips et al. 2010). Caring is viewed as a virtue that supports human life, but an ethics of care considers caring as more than simply a virtue that is a characteristic of the individual. Rather, it is also a virtue that is generated and embedded in the act of caring (Held 2006). According to Held (2006), the characteristics of an ethics of care are recapitulated as following. Firstly, an ethics of care draws attention to moral aspects of giving care for a person who is dependent and needs assistance. Secondly, within this field, care is considered to be comprised of relational activities associated with emotions. Emotional states such as sympathy, empathy, and sensitivity are recognised in the understanding of care. An ethics of care also emphasises moral aspects that are generated among caring relationships that are dependent and unequal. Thirdly, an ethics of care considers that moral aspects of care could be applied not only within the household, which is a private sphere, but also in public spheres.

In the context of social relationships, an ethics of care is formed by experiences that people share, such as mutual responsiveness, trust, and shared understanding, but people seem not to be aware that values of an ethics of care are embedded in such relations (Held 2006). In this thesis, an ethics of care is an important aspect of care that is analysed together with other concepts. A feminist ethics of care can make a contribution not only within the domestic sphere, like within a household family, but also provides potential for the public sphere. The issue of a feminist ethics of care is discussed further in more detail alongside the concept of gender in Section 2.3.3 where women's caring is explained as gendered work.

2.2.2 The Family Carer as an Informal Carer

Care can be considered to be the carrying out of certain activities, which can be undertaken in different ways depending on context (Held 2006). In a healthcare system, there may be differences in the provision of care between formal and informal sectors. A formal sector of care provision includes organisation agencies, voluntary groups, and private institutions that provide professional care services. The characteristics of a formal care sector include conforming to regulations and systematic training, including requiring registration for an individual before they can undertake caring work (Fine 2007). In addition, formal carers are understood to be those who possess a professional level of knowledge and are paid employees in organisations. On the other hand, the informal care sector refers to laypeople who provide care, for instance, family members, friends, and members of the neighbourhood (Clarke 2001), who care without being paid.

Regarding family carers, Fine (2007) attempts to describe this more clearly by breaking both formal and informal care into two separate categories, respectively. He proposes that a formal care service with unpaid carers refers to a care service that is given by the voluntary staff of a care service organisation, whereas a different type of formal care is that provided by professional paid caring staff. Informal care with unpaid care provision is family care based at home, whereas informal paid care refers to paid care service given within a private sphere. Bond (2011) considers that formal services are structured by bureaucratic organisations. A carer who works as staff in this sector, either as a member of unpaid voluntary staff or a paid employee, would be trained by someone with professional knowledge and would have to undertake caring work based on a technical approach to care practice, together with a formalised and bureaucratic process as well as accountability based on an occupational hierarchy (Fine 2007, Bond 2001). However, there seems to be a lack of good quality training for formal carers. Moreover, some formal carers are found to be untrained by formal care services (Meyer et al. 2007). Regarding family carers, Fine (2007) suggests that a family carer could be a paid carer as a private care staff-member employed by family relatives of the cared-for person. Nonetheless, most family carers still appear to take care of people at home on an unpaid basis (Fine 2007) or, at the best, in receipt of carer's allowance such as that available in the UK, a financial benefit for family carers who spend at least 35 hours a week caring for family members with severe illness or disabilities[2]. It has been suggested that the payments of such benefits are relatively rare, while the benefits themselves are so low that they have been described as an 'honorarium' rather than a payment for care (McLaughlin 1991 cited in Ungerson 1995). However, a recent study by Fry et al. (2011) found that a carer's allowance is an essential financial source for many carers who have difficulties or limited financial income, while some carers found that a carer's allowance is only one part of a variety of support from state.

In this thesis, whilst the family carers are family members who become responsible for taking care of older people with dementia, this informal care is characterised by a personal attachment between the carer and care receiver, rather than attachments based on tasks (Bond 2001). Meanwhile, a formal carer and the care receiver could be seen as being strangers to each other, because their care relation is established without a previous long-term relationship (Fine 2007). Ungerson (1995) states that domestic care called informal care is not called so because it is unpaid work, but because it involves norms and obligations developed from affection, kinship, and personal history between the carer and the care-for person. Likewise, Clarke (2001) states that emotional attachment might determine who tends to become the carer. Long-lasting relationships with affection and love may lead an individual to become a carer. Some carers may become so by being forced by circumstances, by being obliged due to familial duty, or as a form of repayment for a benefit previously received from the cared-for person (Rhodes and Shaw 1999 cited in Scambler 2008). There is no clear assumption as to which family member will assume the care. Rather, contextual situations shape the selection of the most appropriate carer. It could therefore be said that to become a carer is not entirely the individual's choice (Proctor et al. 2001 cited in Scambler 2008). However, some carers do not identify themselves as carers, particularly family carers, for they see their caring role as being associated with social

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[2] Carer's allowance in the UK (UK government 2014).

status in relation to the person being cared for. Arksey (2002 cited in Scambler 2008) views that a carer considers her/his caring role as partly obligation and duty, which varies with social status in relation to the cared-for person, while Rose and Bruce (1995 cited in Scambler 2008) point out that some carers might not consider caring to be a duty, but rather the ‘natural’ thing to do.

With respect to dementia care, a family carer often realises that she/he still cannot fulfil the caring role and might need professional advice on how to be a carer. Meanwhile, some family carers have the view that although they become carers, they still continue to do other roles the same as they had previously. Nonetheless, some family carers accept that they have to change their roles and statuses as a result of dementia (Gilliard 2001).

2.2.3 Dementia Care at Home and the Challenges Faced by Family Carers

At the turn of the last millennium, it was still the case that dementia was relatively overlooked, since it was perceived to be a disease without acute symptoms (King 1997). However, this has changed somewhat in recent years due to the considerable growth in numbers of people experiencing dementia. Subsequently, in 2015 the then-Prime Minister of the UK, David Cameron, proposed long-term strategies to raise people’s awareness of dementia. The strategies include investment schemes to fund and develop research on dementia, dementia care, and staff training to support people with dementia as well as their family carers at a local and national level (Prime Minister’s Office, UK 2015). Nevertheless, since dementia does not display acute symptoms, as King (1997) notes above, caring for older people with dementia by family members at home is still the expected appropriate care. Since dementia is an irreversible and incurable condition (King 1997), it inevitably has a huge impact on the carers of those suffering from it (Blom and Duijnstee 1997). The terms ‘hidden victims’ (Zarit et al. 1985) or ‘prisoners of love’ (Barnes et al. 1981 cited in Blom and Duijnstee 1997) are used to describe carers of people with dementia who face a number of challenges with which they must deal.

Before discussing challenges, it is helpful to note the tasks that family carers perform each day. Caring is also considered a career, which requires the skills of control, management, and expertise for caring activities (Aneshensel et al. 1995). The duration of caring varies according to the caring roles and the characteristics of the illness. A typical time schedule for caring would be difficult to outline. Nevertheless, caring tasks cannot be strictly organised (Martin et al. 1995 cited in Scambler 2008) and unexpected tasks are a frequent likelihood (Glendenning 1992 cited in Scambler 2008).

Moreover, Lancaster (1998) suggests that in relation to personal and physical care such as eating, bathing, and toileting, carers should assist the people cared-for in each step of an activity, rather than complete it for them. Carrying out some physical caring tasks might be difficult for carers because they may not have experience in performing those tasks. Also, some physical caring tasks may be difficult to manage or prepare for (Rose 2001). However, physical caring tasks seem to be intimate tasks, therefore, it could possibly create difficulties or embarrassment when carers try to assist with the physical needs of the person being cared for. It might be more awkward for carers if the cared-for person used to have authority in the family, for example, the relationship of a daughter-in-law to her father-in-law (Rose 2001). In some situations when undertaking physical care, carers are required to consider bodily safety and hygiene as much as self-esteem and the dignity of the cared-for person. Lancaster (1998) suggests that although bodily hygienic practices seem easy for most people, those tasks require the ability to make decisions, to make judgments, and to memorise each step of the task. The ill person should have those abilities as far as possible, but also the carers should also have those abilities, in order to guide the cared-for person in completing those tasks or at least help her/him remain bodily functioning and retain some self-esteem as long as possible (Lancaster 1998). In this respect, Barnes (2012) suggests that in so far as care practices are undertaken, ethical sensibilities and sympathetic skills are essential, as well as practical skills.

In Chapter 4, the researcher explores the activities of care so that women's activities are exposed. When considering care as a practice, care appears to involve a very broad range of activities (Tronto 1993) including feeding, washing, getting the cared-for person out of bed, bathing, teeth cleaning, (Gibson et al. 2019), toileting, dressing and undressing, helping to sit and stand up, assistance in using equipment, doing household tasks, giving medication, negotiation and communication with doctors and health and care staff, and financial management (Barnes 2006, Blom and Duijnstee 1997). The range of care is broad and sometimes overlaps with care activities provided by trained and professional carers (Transtadottir 2000 cited in Barnes 2006). The types of care are classified in different ways. In dementia care, according to Parsons (2001), care activities include three types of care. The first is helping the person with their basic needs such as eating, dressing and toileting. The second is help with instrumental activities such as medication, preparing meals, housework and financial management. The third is complex psychological care such as emotional support and self-esteem enhancement.

In dementia care, family carers' activities are associated with the progressing symptoms of people with dementia (Huang et al. 2015). Each stage of dementia needs different kinds of care, and also requires a different amount of time requirement for care. On average, the general path of dementia takes between three and nine years, with different characteristics in each stage (Wolfson et al. 2001 cited in Haung et al. 2015). Types of caring activities are given differently to people at different stages of dementia. Those in early dementia need carers' assistance with 'instrumental activities in daily living' (IADL) such as transportation (Huang et al. 2015), while those with more advanced dementia need assistance with 'activities in daily living' (ADL) (Huang et al. 2015, Wimo et al. 2002). Caring for people with severe dementia needs more time for supervision (Neubauer et al. 2008, Wimo et al. 2002). Regarding the amount of time spent on dementia care at home, it is difficult to be exactly examined due to various kinds of measurement necessary and other involved factors (Neubauer et al. 2008). Several studies found that primary family carers spent between 8 and 17.2 hours a day on ADL, IADL, and supervision/surveillance assistance (Wimo et al. 2000 cited in Neubauer et al. 2008, Clipp and Moore 1995). Carers for people with moderate to severe dementia spend at least 5.2 hours per day. The time burden on family carers seems to be greater for providing care for people with dementia. Many studies show that the carer spends more time caring if cognitive functioning is more severely declined (Neubauer et al. 2008).

Moreover, caring for people with dementia is not simple. It is a challenging task requiring carers' time and the skills to deal with many difficulties or disturbances. Thus, difficulties in day-to-day routines in social relationships, including those in doing activities, can lead to what some commentators have described as a 'burden' on carers (Dwyer et al. 1994, Chenowith and Spencer 1986). Compared with carers for people with other chronic illnesses, carers for those with dementia face a greater number of challenges, a higher level of stress, and are the most affected by health problems (Schultz et al. 1995 cited in Andrén and Elmståhl 2005). Furthermore, carers' burden is related to the irreversible symptoms of dementia. The more progressive the symptoms are, the higher the burden the carers have. The relation is also likely to become stronger over time (Berger et al. 2005 cited in Huang et al. 2015). The burden of a family carer for a person with dementia has been identified as being comprised of several components. The first aspect is carers' physical health problems, which will arise due to performing long-lasting tasks without a chance to rest and exercise. The second aspect is psychological health, which is affected as a result of pressures and difficulties in managing caring tasks. The third component is financial (Andrén and Elmståhl 2008, Dunkin and Anderson-Hanley 1998). Aside from the difficulties of accomplishing daily care tasks, Blom and Duijnstee (1997) indicate that lack of financial resources is seen as a matter of frustration to carers, and it can also directly influence the practicalities of care provision by family carers. During a long duration of care, carers may not be able to work to earn a salary to support caring expenses. Since carers find difficulty in financial limitation, their subjective burdens are increased (Blom and Duijnstee 1997). These burdens can affect and compound each other. Moreover, family carers can perceive the same situation differently. That is, some of them may find the financial problem to be the primary burden, while some may consider being the prime caregiver to be their major burden. In this sense, Blom and Duijnstee (1997) suggest that the differences in perceived burden depend on the differences in the individuals' ways of coping, acceptance, and motivation in relation to caring. (The perception of burden of care is also addressed in Section 7.5.2.1). However, the concept of burden has been criticised for its focus on the tasks that carers perform and the stress that they experience (Abel 1990); it is important to bear in mind the positive contributions made by family carers of people with dementia (Wigfield 2011). More immediately, although these studies have yielded useful practical and policy-related insights, they miss important elements of caregiving experiences that may be elicited by more qualitative approaches, especially those employing a feminist framework. As this thesis follows a feminist approach, the activities undertaken by female carers are described in order to help reveal women's experiences, including the use of time, difficulties, and burden of care, for example. In doing so, these concepts, as explained in Chapter 4, will reflect that performing caregiving tasks for people with dementia is not simple but challenging.

2.3 Concept of Gender

As this thesis focuses on women's caring within the family, the concept of gender must be considered, since the family is a site of gender relations (Morgan 2011). Also, the gender roles and identities of women are restricted in the domestic family setting, where their activities such as feeding babies, cleaning, cooking, caring for other family members, and other household tasks are done. These activities are seen as 'feminine activities' (Oakley 2005), and 'natural' (Bowley et al. 1997). In fact, the notion of women's activities is socially and culturally constructed.

In a feminist approach, gender relation is a key idea of analysis into women's lives and experiences (Walby 1997). The concept of gender has been used to argue about the differences of biological sex and gender; external and internal genitalia demonstrate someone's identity as male or female (Kessler and McKenna 1978 cited in Davis et al. 2006, Stoller 1968 cited in Oakley 2005). Thus, sexual differences are natural and cannot be deniable. 'Sex' is a biological term while 'gender' is a socially and culturally constructed idea based upon the biological differences (Oakley 2005, Pilcher and Whelehan 2004). Gender is a social aspect of sexual differences in which 'man' and 'woman' are social categories to which individuals are allocated according to their sexual differences (Delphy 1984 cited in Davis et al. 2006). Gender differences are expressed by dress, gestures, careers, personality, and gender roles (Oakley 2005). Women, then, are expected to exhibit feminine characteristics and activities, which are allocated to domestic spheres like home and family. In this sense, gender is not an isolated factor but related to other modes of social organisations, which produce and reproduce dimensions of social life including family, labour, class, and the state (Butler and Weed 2011). Gender is not understood as having a single meaning, but rather is engendered and organised differently over time, and relates to the concept of power. That is, gender and its mode of differentiation form part of the operation of power in which gender is, to use the words of Scott (2008 cited in Butler and Weed 2011, p. 3) 'a primary way to signify power'.

Following this, in this study, the concept of power is an important concept that it is explained within the analysis of gender. Taking a feminist approach which assumes the universal operation of power, gender is seen to be an ideological structure that demonstrates the hierarchical power relation where one group of people has more power than another one: men operate as a dominant group whereas women are subordinated and oppressed (Lazar 2005). Such gender division and relations bring about an inequality that impacts hugely on women and men's participation in social institutions. As subordinates, women in particular are affected by gender-power relations in different ways (Lazar 2005).

This study explores and discusses the concept of gender in relation to caring in terms of gender differences in caring, gender inequality in caring, gender and a feminist ethics of care. These issues are explored respectively.

2.3.1 Gender Differences in Caring

Sociological literature on kinship confirms that caring for older people is an obligation of the parent-child relationship (Finch and Mason 1991). Moreover, although family is a major centre of informal care provision, the issue of gender is inevitably involved, since it is an essential element of care provision (Clarke 2001). Regarding this, Graham (1983) suggests that caring is likely to be the activity of women. Although there has been the tendency that men become more involved and responsible with regards to the household, parenting, caring, and other activities in private places like homes, women are more often found as informal carers in both private and public spheres (Scambler 2008, McKeie et al. 2002). Regarding domestic care like family care, some scholars consider the familial obligation to be hierarchical, in which the obligation is decreasingly prioritised for spouse, parents, and children respectively (Qureshi 1986 cited in Finch and Mason 1991). Moreover, "the hierarchy of obligation" involves the issues of gender differences that are created under the patriarchal oppositions (Finch and Mason 1991, De Beauvoir 1972 cited in Pilcher and Whelehan 2004). Women's social lives and their experiences rested on gendered and power relations in which women are positioned as oppressed and subordinated (Ramazanoglu and Holland 2002, Gunew 1990). The hierarchy of obligation in domestic divisions of labour, therefore, is unequal in the sense that women are expected to be carers since their caring roles are seen as 'natural' (Bowlby et al. 1997).

In gender division of labour in private places like home and family, women's roles and activities are different from men's. That is, within close family structures, the women's roles involved proportionately more of the personal and everyday tasks than the men's, if not all. Men were responsible for installing and repairing home furniture and equipment. Men were more likely than women to provide occasional assistance (Scambler 2008). This unequal division seems to have implications for women's health and income throughout their lives (Mckie et al. 2004).

Regarding gender differences in caring, perceptions of the caring role among women and men appear to be different. Men perceive their caring role as work (Fisher 1994 cited in Cantley

2001). As a result, men are not likely to be afraid to request external support and may undertake caring tasks better than women do. In similar positions, a woman provides care for a husband because she would like to do so, whereas a daughter provides care for a parent because she perceives that she has to (Cahill and Shapiro 1998). For women, not only are their perceptions of caring different from those of men, but so are their gender roles, social identities, and self-identities. These could also be defined and redefined by undertaking informal care tasks in domestic places like the home (Morgan 1996, Graham 1983). That is, according to Graham (1983), although caring involves a transaction of materials and services, the relationship between carer and care receiver cannot be reduced. Thus, for Graham, caring requires not only labour, but also a loving relationship; she uses the term ‘labour of love’ to explain women’s caring. Although the word ‘love’ might not be used properly in certain circumstances, the term ‘care for’ can be used instead to express the sense of social ties between human beings, since it involves a sense of feeling and emotion. When care is given by women, love cannot be diminished to simply a labour process. By doing this with femininity and love, caring entails the capacity and sensitivity to watch out for the needs of the cared-for person, including the ability to wait, and adapt the way of caring to be more compatible to the other’s demands (Graham 1983). In this sense, caring might not be seen as merely an action that women do to fulfil a sense of self or create an identity for themselves. Rather, caring is an activity that women do in order to help the other person to survive (Tronto 1993, Graham 1983).

In gender differences, care provision from women and men may be recognised and valued differently. That said, whilst caring at home where ‘the hierarchy of obligation’ exists, reflecting the gender division of responsibility in which women are expected to act as carers rather than men, a ‘sense of responsibility’ in the family is likely to be allocated to women whereas it does not permeate to men (Finch and Mason 1991). In addition, caring is seen as creditable and notable if it is undertaken by men, while caring is perceived as a natural duty if it is undertaken by women (Barnes et al. 2015, Tronto 1993). Caring is then considered not limited to activities undertaken within the private sphere like at home but is also associated with ‘women’s work’ in general (Clarke 2001). Given that, although in informal care generally, men provide instrumental care whereas women provide more personal care (Scambler 2008), or caring tasks are not specifically identified, caring at home is clearly a gendered division of labour after all

(Fine 2007) as the responsibility for caring is taken for granted as a ‘natural’ endeavour which belongs to mother, daughter, daughter-in-law and wife, rather than men (Clarke 2001).

2.3.2 Devaluation of Women’s Caring and Their Difficulties in Life

Care as an activity has not received much attention from the public, and has even been devalued. Doing the ‘job’ of being a carer appears to be consuming but unrecognised (Gillard 2001). The value given to the activity of care seems to be determined by those who undertake these activities and where the activities are undertaken (Mckie et al. 2002, Tronto 1993, Graham 1983). According to Tronto (1993), in Western history, the activities in caregiving and receiving are allocated to powerless people such as working-class people, slaves, servants, people of colour and women. When it comes to women’s activities, caring seems invisible since such activities are taken for granted as a ‘natural’ quality of women (Barnes et al. 2015, Tronto 1993), and care activity seems to be disguised and embedded in normal activities in domestic life, since family is the source of the personal relationships that provides care to support individuals’ needs (Barnes et al. 2015, Barnes 2006, Graham 1983). Caring, therefore, appears to be seen as evidence of the nature of family responsibilities (Qureshi and Walker 1989) and be seen as ‘non-work’, not only because it is unpaid work but also because it is associated with the affection and love that often comes with family obligation (Mckie et al. 2004, Graham 1983). Moreover, whilst emotion and feeling are not valued in a society that esteems rationality (Tronto 1993), caring is then devalued because it is considered as unskilled labour although necessary to support people in need, such as children, ill people, and frail older people. However, feminist scholars argue that caring definitely is a form of labour, and more than a form of activity (Barnes et al. 2015, Held 2006, Sevenhuijsen 1998, Tronto 1993, Graham 1983), since it is undertaken to support others’ needs, to sustain and even to help them survive (Barnes et al. 2015, Held 2006).

In caregiving, some carers might devote themselves to the people for whom they are caring, i.e. they invest their emotions in what and whom they are caring for. In this respect, some scholars view this might be the romanticising of care and might reduce the significance of care activities as the instrument of care (Blustein 1991 cited in Tronto 1993), whereas some suggest that care can be seen as both a disposition and a practice. Otherwise, the needs of the cared-for person might be overlooked (Barnes 2006, Payne and Ellis-Hill 2001, Tronto 1993). Also, carers’ roles and skills (Ruddick 1990 cited in Tronto 1993), their abilities, and their willingness to ‘see’ and ‘hear’ the needs of the cared-for persons (Sevenhuijsen 1998) might not be given visibility. In this thesis, the issues of care activities that female family carers performed are discussed in Chapter 4 which aims to make not only the female carer's activities of care visible, but also reveal the effects of caring towards many aspects of their lives which are affected by gender relations.

In addition to the devaluation of women's caring, their activities in domestic places brought about many difficulties that they faced in life. Informal caring has implications regarding women's time, income, and health throughout their lives (Mckie et al 2004). Regarding time, women's time seems to be unavoidably influenced by gender relations. Understanding time in women's lives not only helps reveal how their time is spent, and for whom, but also helps expose gender relations that have a great effect on women's lives (Walby 1997). Women's activities, which involve a variety of life events such as marriage, caring for children and other family members, seem not to be carried out in line with clock time, but their own characteristics of each kind of life-event in particular (Walby 1997), thus, in comparison to men, women have a disproportionate level of family tasks to carry out (McKie et al. 2002). Consequently, women lack time for their own career opportunities. Having fewer opportunities has a huge effect on their earnings and financial conditions. In addition, women might have less potential for employment as they are seen as less reliable employees in comparison with men because women might need time off in case their family members such as children need their care. However, if women have more opportunities and spend more time in the labour market, their time in daily life for work and caring might be more overlapped (Mckie et al. 2002). Given that, women possibly spend some of their working time to plan their domestic activities, such as what to prepare and cook for each meal, and other caring activities. For these reasons, women have some difficulty with time management. Nonetheless, the time spent caring also affects women's health. The more time women spend caring, the more negative effects of caring increase, such as high levels of feeling of isolation, loneliness stress, and deterioration of physical health (Wigfield and Alden 2018). In this thesis, the issue of female family members' time spent caring is described in the methodology chapter (Chapter 3) which mentions the researcher's experience of the way some female carers negotiated the times of the appointment and interview. The issues of women's time in relation to caring are also shown in Chapter 4, where the women's use of time and the effects of the lack of time are reflected through the caring activities they undertook.

2.3.3 Gender and Ethics of Care

In describing the concept of care (see Section 2.2.1), it is discussed how women's care includes an ethics of care that supports people's lives. This part focuses on the association of gender and ethics of care in the sense that the morality actually implies the gender differences and gender inequality.

In moral philosophy, the notion of an 'ethics of care' is not a new understanding, especially in the development of a feminist interpretation of care (Bowden 1997). This notion needs to be mentioned since it helps liberate women, because to understand women's morality leads to an understanding of women's knowledge and their judgements in their lives, in which their experiences reveal the oppressed and subordinated positions in a patriarchal structure (Sevenhuijsen 1991, Bowden 1997). In comparison with men, women must be treated equally, and have equal duties to men. According to binary oppositions in Cartesian philosophy, women's morality is seen as impartial, since it involves emotion and attention to small and particular things. Women's morality is then seen as being below that of the abstract philosophy and neutrality that are seen as the highest level of moral virtue, and which belong to men's morality. Feminist scholars argue that some forms of care ethics, such as Confucian ethics and Christian ethics, are developed under patriarchal domination, which cannot provide an appropriate contribution to a wider context because women's thoughts and activities in relation to caring are concealed and generalised. Furthermore, the basis of morality puts value on rationality, whereas emotions such as empathy and concern are excluded, despite the fact that emotional dimensions help support human life and go beyond the self-interest of the person who is providing care for others (Held 2006).

Feminists propose that an ethics of care should be understood as relevant not only to women and within domestic places, but also to men and the public sphere (Held 2006). An ethics of care has been developed through women's experiences and practices in certain contexts such as caring (Tong 1998, Sevenhuijsen 1991). Women's experiences are more typically associated with caring for children and older people in domestic spaces than for strangers, and entail feeling as well as thinking. A feministic ethics of care subsequently reflects a way of operating, in which sensitivity and affection are required as 'moral guidance' to caring for and meeting the needs of the care receiver (Held 2006).

According to Tronto (1993), an ethics of care can be understood as being comprised of four elements, which also represent the four stages of the caring process. The four ethical elements are attentiveness, responsibility, competence, and responsiveness. Attentiveness is defined as recognition of what another person needs, which is opposite to ignoring them. In this respect, Weil (1988 cited in Tronto 1993) considers that the ability to be attentive is essential for a human relationship. The second ethical element is responsibility, which differs from obligation. Tronto points out that responsibility focuses on diverse cultural values involved with care, rather than on rules and regulations. That is, individuals actively consider whether they do or do not respond to another's need for care. Moreover, responsibility depends on various social and cultural factors such as gender, social class, and cultural differences. The third ethical element is competence. It refers to the potential to provide proper care for care recipients. The last ethical element is responsiveness, which means the capacity to meet the needs of others. This element also requires sensitivity, which is the ability to think about the inferior position and vulnerability of others and the skills to understand their needs, desires, and thoughts, including seeing situations from the cared-for person's point of view (Tronto 1993). Gender sensitivity in ethics of care includes receptivity, empathy (Bowden 1997), submissiveness (Ruddick 1980 cited in Bowden 1997), openness to the possibilities, trust, and concern (Held 2006). Sensitivity is not simply innate but a learned characteristic (Held 2006). Drawing attention to gender sensitivity in ethics of care thus helps the values of caring to be revealed and recognised. However, it is possible that the complexity of ethical concepts could be connected as well as conflicted. That is, feelings of concern or sensitivity to others' vulnerability probably are, at the same time, attempts to control the others' potential (Bowden 1997). In terms of ethical principles of care, Barnes (2012) suggests that an ethics of care provide some guidelines for the practice of care rather than to monitor, judge, and strictly indicate care, because there is diversity in the circumstances in which care activities occur. However, care should not be understood only in terms of ethical principles, but also in the form of particular daily activities of care (Barnes 2012, Tronto 1993). Thus, when considering care as a practice and as a political value, which are key arguments of an ethics of care, it is necessary to bring lived experience of caregiving and care receiving – in which social contexts, conflicts, and powers are embedded – into the consideration of how they influence difficulties in making decisions, together with the practicalities of caring (Barnes 2012).

In relation to an ethics of care and gender inequality, there is some debate about describing care activities. In one way, to mention women's care activities might enable their ethics of care to be visible and heard. In another way, it is also criticised as a way to romanticise or celebrate an ethics of care (Bowden 1997). Then, this does not seem to confront the patriarchal structure, since it still makes women to be treated unequally, remain suffering and oppressed as a result of their burden of care (Bowden 1997, Held 2006). In this sense, Bowden (1997) suggests that unless the activities of care are displayed, the ranges of moral possibilities in women's caring as well as their ethical agencies are reduced, simplified, and stereotyped. Therefore, an exploration of women's care activities is not merely a description of women's experiences and attitudes under the patriarchy.

In this study, the participating women's care activities are discussed so that the caring person and care activities are displayed as well as their care ethics. Accentuating the notion of a feminist ethics of care, this study assumes women's caring to be an ethical practice instead of exploring what the ethics of care are. This thesis views that ethical aspects of care emerge and are shaped by care activities. The ethical aspects of care are discussed throughout this thesis as they link with the family carers' perceptions of their caring, caring relationships, and their care receivers, including the decisions they made to continue caring for their relatives with dementia.

2.4 Concept of Reciprocity

In this part, the researcher talks about the concept of reciprocity, which is a significant concept in studying family relationships, gerontology, and caring. In social sciences, this concept is explained by many disciplines, for example, economics, anthropology, and sociology. In this thesis, the researcher draws attention to the sociological explanation of reciprocity by linking it with caring, particularly in the context of caring for people with dementia. The discussion here is divided into three parts: characteristics of reciprocity, reciprocity in caring, and reciprocity and people with dementia.

2.4.1 Characteristics of Reciprocity

The meaning of reciprocity is as complicated as finding a definition of care (Barnes 2012, Tarlow 1996). Reciprocity means the giving of benefits to another in return for benefits received (Molm et al. 2007). It is the idea of mutuality or social exchange (Molm et al. 2007, Lewinter 2003). Reciprocity is basically embedded in a social relationship (Gouldner 1960) as it implies the individual's position in terms of responding to another's needs while expecting a benefit in return. An individual commonly finds reciprocity to be the norm as a major form of obligation, and as part of a social contract (Drenovsky 2009, Mauss 1967 cited in Holroyd 2001, Gouldner 1960) in the sense that gaining assistance is associated with the social expectation of reciprocation, by which the assisted individual should give something to the other in return (Breheny and Stephens 2009). In other words, the individual has an obligation to repay her/his counterpart, since the individual has previously received some benefits from her/him that require a certain action or obligation to give back. The significance of reciprocity is that it helps to maintain support for an individual from others, sustain the person's cooperation, and prevent exploitation in either direction (Gove et al. 2016). The norm of reciprocity is also necessary to establish social cohesion (Drenovsky 2009) as it functions to sustain the existence of society (Antonucci et al. 1990 cited in Breheny and Stephens 2009). Thus, from a sociological perspective, the norm of reciprocity implies a mutual social tie, sense of obligation and sense of responsibility in that an individual should hold to the norms of reciprocity by pursuing an action of giving to others (Tarlow 1996, Malinowski 1932 cited in Gouldner 1960).

As a mutual action of giving to others, reciprocity occurs not only in terms of economic matters, but also in the non-economic realm. Given that, people can reciprocate as a response to the action of assistance, or because they have shared a previous social interaction (Tullberg 2004 cited in Graham and Bassett 2006, Malinowski 1932 cited in Gouldner 1960). However, when reciprocity is described as a mutual action in which people offer to give some of their resources in their exchange relationship, the quantity of exchanged things and time of giving in return are questioned. In terms of the quantity, the resources to be given should be similar and have an equal benefit to those received in return. It seems to be difficult to interpret the amount or value of things in a reciprocal relationship, but it is still quite important. Therefore, reciprocity in any particular relationship should be considered to be either 'roughly equivalent' (Gouldner 1960) or 'seldom' equivalent (Tullberg 2004 cited in Graham and Bassett 2006). In this respect, Tarlow (1996) argues that although reciprocity is sometimes recognised as being formed of equal exchanges, such equivalence cannot be required. Also, reciprocity can occur indirectly or even without anticipation of return (Tullberg 2004 cited in Graham and Bassett 2006). In terms of time, which is another characteristic of reciprocity, reciprocity could be immediate or deferred reciprocity (Lavoie et al. 2001 cited in Lewinter 2003). If reciprocity was seen as equal exchange, it would not be necessary that the expected repayment is given immediately. Instead, the exchange could be equal ‘in the long run’ (Malinowski 1932 cited in Gouldner 1960). The repayment would probably take a longer time than a simple mutual exchange. The time period allows the individual to earn and accumulate resources until they are sizable and suitable enough to be reciprocated to the giver (Gouldner 1960). Therefore, reciprocity should be equivalent but not necessarily immediate.

According the aspect of time, reciprocity could also be seen as direct or indirect payment (Molm et al. 2007, Chabal 1996 cited in Lewinter 2003, Finch and Mason 1993). In relation to reciprocity between family members, Finch and Mason (1993) suggest that direct repayment refers to the exchanges of financial resources or taking care of each other’s children or other kinds of help. The same assistance will be given return as repayment but at a different point in time. This kind of repayment involves a short timescale and normally creates a balanced reciprocation. Thus, this repayment does not develop the feeling of being in debt or dependent upon the counterpart. Indirect repayment has two types. The first type involves the exchange of differing kinds of assistance, perhaps in the form of goods or services. The second type involves more than two parties in a reciprocal relationship where the assistance is given by the first person to another one, but the prospective assistance is repaid to the third party. According to research by Finch and Mason (1993), most indirect repayments are intergenerational repayments, which occur with reciprocity between parents and children or grandparents and grandchildren. Moreover, an issue around the rate or value of what is to be repaid is brought into calculation by negotiation. The exchange might not be seemed to be balanced reciprocity as its timespan could last longer than a typical mutual exchange (Finch and Mason 1993, Neufeld and Harrison 1995).

The opposite of ‘balanced reciprocity’, which requires equal exchange immediately (Finch and Mason 1993), the concept of ‘generalised reciprocity’ is used to explain reciprocation within a family where more than two parties are involved in the reciprocal relationship. In generalised reciprocity, individuals realise their obligations to give the same kind of assistance as that which they obtained by providing to a third party (Finch and Mason 1993, Sahlins 1965 cited in Lewinter 2003). For instance, a woman gives financial support to her children, as her mother used to give the money to her in the past. Generalised reciprocity can take place in addition to giving the different kinds of assistance, but the repayment is made to the third party. The incentive to repay seems to be not explicitly mentioned since the mutual assistance seems to be a basic yet important element of kin relationship (Finch and Mason 1993). This reciprocity therefore seems to involve a state of indebtedness, which can be seen as a moral obligation (Gouldner 1973 cited in Finch and Mason 1993).

However, reciprocity can be either perceived or non-perceived, in that an action can be understood by one person as reciprocity whereas the action might not be sensed or even noticed by other persons as reciprocity for different reasons (Lewinter 2003). In addition, reciprocation can be either positive or negative. A positive reciprocation refers to a good response while a negative one means a harmful response (Adams and Sharp 2013 cited in Gove et al. 2016, Guala 2012). In the context of caring, if an expression of reciprocity is not perceived by carers, carers may feel resentment or dissatisfaction because they view that they provide more care for the care receivers than they are given in return (Blom and Duijnstee 1997). Gaining more knowledge of reciprocity between carers and care receivers will help enhance the quality of their relationships and help support the carers' wellbeing overall (Reid et al. 2005).

2.4.2 Repayment and Caring

Regarding caring, reciprocity is one of the fundamental elements of a caring relationship, for it reinforces shared meaning and a sense of belonging between the carer and care receiver (Graham and Bassett 2006, Lewinter 2003, Qureshi and Walker 1989). In gerontological literature, reciprocity is associated with parental caring, as it is an intergenerational reciprocity covering the lifetimes of several or all family members (Grundy 2005), there has been limited theoretical explanation of the concept of reciprocity (Lewinter 2003). Caring for parents in their later lives seems to be a part of the responsibility of adult children or the younger generation. This tradition is found in many countries in South East Asia and East Asia such as China, Hong Kong, Taiwan, Singapore (Holroyd 2001) and Thailand, where the reciprocity in parental caring remains strong. In Thailand, the gerontological literature still lacks a theoretical explanation of intergenerational reciprocity.

Caring in the parent-child relationship is rarely seen as equal by either generation (Holroyd 2001), because caring for older people in physical decline is likely to be one-directional (Gouldner 1960). In this sense, the perception of differences in debt and credit is more emphasised (Holroyd 2001). That said, reciprocity may be a significant factor in sustaining the independence of older people if they still reciprocate something to their adult children and other family members (Gibson 1985 cited in Lewinter 2003). Regarding reciprocity as a social tie between older parents and adult children, many studies on intergenerational reciprocity suggest that it can occur in the short-term or long-term once both sides have demands and resources to be exchanged. Then, familial norms towards caring might rest on generalised reciprocity, in which a family member can attain balance over a long period of time (Grundy 2005, Ingesoll-Dayton and Antonucci 1988).

Regarding reciprocity in family care, many scholars (Barnes 2012, Tulberg 2004 cited in Graham and Bassett 2006, Tarlow 1996) view that although reciprocity is a basis of care, reciprocity is not required, particularly in family care. That said, carers do not necessarily feel that providing care for somebody such as an older family member depends on either a previous or a prospective social relationship (Barnes 2012). Thus, care can happen indirectly or without the expectation of something being given back (Tullberg 2004 cited in Graham and Bassett 2006). A caring relationship then can count as successful if the definition of reciprocity is flexible and adaptable in accordance with varied situations (Tarlow 1996). Nonetheless, Tarlow (1996) believes that carers often feel appreciated most when the cared-for person can simply notice their caring and react to them positively. This aspect involves the motivation for caring in the sense that reciprocity from care receivers can decrease carers' burdens and feelings of stress (Reid et al. 2005, Dwyer et al. 1994). This relationship between reciprocity and motivation is discussed further in the section on motivation in which the context of caring for people with dementia is explored in more detail.

2.4.3 Reciprocation, Dementia Care, and People with Dementia

In caring, the balance of giving and taking between two parties can change over the course of the illness. Illness is a major cause of a changing balance in a relationship (Killick and Allan 2001). Dementia is also a challenging condition that impacts dependence and interdependence in a caring relationship. In dementia care, a reciprocal relationship seems to be difficult to accomplish when it involves caring for cognitively-declined people (Hooker et al. 2000 cited in Graham and Bassett 2006, Killick and Allan 2001, Neufeld and Harrison 1998), because their declined cognitive capacity influences their ability to understand and engage in shared meaning in the relationship, and particularly their ability to reciprocate (Perrin and Hazel 2000 cited in

Graham and Bassett 2006). Lack of reciprocity is a characteristic that people with dementia are perceived to have and which is stigmatised. However, their attributes are not stigmatised in itself but by other people's perceptions, which might lead to the dehumanisation of people with dementia (Gove et al. 2016). The stigma comes from the cared-for person's ability (or lack of ability) to respond to the other's contact, the absence of giving and building the relationship. Also, lack of reciprocity in caring for people with dementia possibly leads to fragmentation in the relationship (Perrin and Hazel 2000 cited in Graham and Bassett 2006), mistreatment or violence (Pettersen and Hem 2011). In this instance, the carer would possibly perceive the decline of attachment that the cared-for person has for the carer, or even towards their surroundings, as a lack of communication ability and understanding that may cause a breakdown in the relationship, because carers still expect the people with dementia to act based on past norms (Graham and Bassett 2006), and their 'old selves' (Gove et al. 2016). Thus, they might be seen as not a 'real' or 'whole' person, and their reciprocation might be overlooked (Gove et al. 2016).

Although it seems that reciprocity is difficult to be given by people with dementia, some scholars argue that reciprocity not only depends on 'well-articulated' communication but also non-verbal communication. People with dementia still have other modes of expression that are non-verbal (Barnes 2012, Pettersen and Hem 2011, Innes and Capstick 2001). Non-verbal communication is a form of dialogue that helps to maintain caring despite the absence of verbal communication (Pettersen and Hem 2011). Non-verbal communication could be expressed as a response embedded with gratitude, feelings of love, anger, or embarrassment towards the carer, because these emotional responses are parts of the caring process (Barnes 2012). Non-verbal communication also includes bodily actions such as facial expressions, gestures, eye contact, and touch (Ellis and Astell 2017, Martin et al. 2013, Hydén 2013, Kontos 2005). People with dementia may use such expressions as a form of acceptance, or even a form of refusal towards other people. Regarding this, the possibility that reciprocity is perceived or not perceived depends on the ability of other people to access and perceive the reciprocity of people with dementia (Gove et al. 2016, Lewinter 2003) despite the difficulty in doing so (Killick and Allen 2001). Thus, it is important for carers to have the skills to notice the many forms of non-verbal expression with which people with dementia attempt to communicate (Pettersen and Hem 2011, Innes and Capstick 2001).

The type of emotions that carers experience can help reduce carers' feelings of stress (Dwyer et al. 1994, Carruth et al. 1997 cited in Reid et al. 2005), enable carers to feel satisfaction, and lead to suitable caring (Barnes 2012). In this respect, an article written by Drenovsky (2009) illustrates her personal experience of visiting people with dementia. Drenovsky felt that she was receiving rewards in the form of being paid attention and having conversations in the final period of the lives of people with dementia. This example also reflects the notion of reciprocity as an aspect that people use to manage identity, which is at least in the form of being a giver and a receiver (Breheny and Stephens 2009). Moreover, whilst skills and the ability to notice the expression of care receiver's gratitude are needed, a carer's intimate knowledge about the care receiver is also required because it could help develop better caring practice (Barnes 2012), and reflects the way of respecting and maintaining the personhood and dignity of people with dementia (Frilund et al. 2014).

Regarding the reciprocity given by people with dementia, there is an argument that a caring relationship may exist if there is reciprocation from two parties (Gouldner 1960). In this sense, such reciprocations are difficult to be seen (Killick and Allen 2001), and the reciprocity may not be expected when caring for people with dementia (Barnes 2012). Despite lack of reciprocity, caring could be still given without any expectation of reciprocity, because not all carers need appreciation or even to be acknowledged by the other (Fox 1995 cited in Breheny and Stephens 2009). In this thesis, the notion of reciprocation from people with dementia is one of the arguments. The researcher assumes that those with dementia still have the ability to express and reciprocate something to their carers. These abilities are explored based on the participants' (carers') experiences of reciprocity, which are discussed in Chapter 6.

2.5 Motivation for caring

This part draws attention to the concept of motivation for caring. The researcher discusses this by dividing it into two parts. Firstly, characteristics of motivation and its relationship with reciprocity are explored and discussed. Secondly, caring motives are reviewed.

2.5.1 Motivations: Characteristics and Relationship with Reciprocity

Motivation is a notion that is paid little attention in the literature on caring (Quinn et al. 2015, Feeney and Collins 2003), despite its huge significance to the provision of care. Motivation has a great effect on caring, particularly the quality of care in the sense that it enables carers to accept the responsibility to give care, and to extend the time and resources for caring, including making the decision to continue caring or not. Without motivation, carers might not be able to provide the effective forms of support and the level of care that the care recipients need (Quinn et al. 2015, Oudijk et al. 2011). The more the carers have motivation, the more commitment they have to continue care (Quinn et al. 2015).

There are many factors that influence motivations for caring. One is the good quality of the previous relationship between carer and care receiver, which might sustain the carer's motivation to give and continue care (Quinn et al. 2015). The feeling of reciprocity within relationships and carers' self-esteem also affect the decision to give care. The higher self-esteem that carers have as a result of their care receiver's warmth, gratitude, and appreciation over the time of caring might help enhance the motivation for caring (Reid et al. 2005, Lewinter 2003, Feeney and Collins 2003), as might the carers' skills in coping with caring tasks. On the other hand, lack or absence of positive emotional support and skills might reduce the motivation to continue caring and increase the possibility of placement into institutionalised care (Buhr et al. 2006 cited in Quinn et al. 2015, Hirschfeld 2003).

To discuss the relationship between motivation and reciprocity, it is necessary to describe forms of reciprocity (Noddings 1996). Forms of care receivers' reciprocity that can be contributed to the relationship are the expression of love, gratitude, and warmth (Reid et al. 2005). Similarly, a study by Blom and Duijnstee (1997) suggests that a bunch of flowers or an expression of gratitude is considered to be appreciation for the carers' attempts. In addition, a study of parent-child relationships by Noddings (1996) explains that children respond to the caring relationship in two ways. First is their acknowledgement of their mother's caring. Second is the effort that children expend in order to meet their mother's expectations in terms of care, including their evaluation of the mother's care. As a result, these responsive expressions can empower mothers to care for children more easily. Similar forms of reciprocity can reinforce carers' motivation, help them to cope, and lessen their perceptions of subjective burden, though this is not to imply the infantilisation of older people with dementia in the receipt of their care. In caring circumstances, if an expression of reciprocity is not perceived by carers, they may feel unsatisfied because carers view that they provide more care for the care receiver than they are given in return (Blom and Duijnstee 1997).

2.5.2 Caring Motives

Regarding reciprocity, ‘repayment’ is a key motivational factor in the choice to continue care, since carers may want something in return from the care receiver for the favour done previously (Oudijk et al. 2011, Reid et al. 2005). Many studies, such as those by Cahill (1999), Feeney and Collins (2003), Feeney and Collins (2003) and Oudijk et al. (2011), suggest the different motives for caring. A carer could have more than one motive. Thus, motive for caring seems to be very complicated and cannot be definitely identified as a single motive (Kohli and Künemund 2003).

Love, affection, concern (Cahill 1999, Feeney and Collins 2003), and empathy (Batson et al. 1991 cited in Quinn et al. 2010) are factors encouraging carers to continue care; some studies suggest that these motives are altruistic (Oudijk et al. 2011, Kohli and Künemund 2003). Altruistic motivation, defined as a feeling of having derived pleasure and enjoyment from helping and caring (Feeney and Collins 2003, Oudijk et al. 2011), inspires carers to continue performing care. A sense of duty and of responsibility are also factors urging some carers to give care to their family members and may vary with cultural and relational conditions (Oudijk et al. 2011). In this respect, care-giving based on norms of duty and responsibility can have a relational aspect, though other carers may follow such norms out of affection (Feeney and Collins 2003). Additional studies have found that commitment to another person alone might underpin caring; that is, that moral obligation or moral commitment to care may drive caring despite the absence of love, affection and other relational aspects. In this respect, moral commitments may be influenced by external pressures including a lack of alternatives (Quinn et al. 2015), family pressures, and lack of ability to access institutional care (Blieszner and Shifflet 1989 cited in Quinn et al. 2010). Feelings such as guilt and avoidance of guilt seem to be strong motivational factors to continue care, despite carers’ lack of support and help from other family members (Quinn et al. 2010, 2015). The meanings attached to care, which are the positive effects of care and which rest on a sense of continuing relationships between carers and care receivers, seem to be significant motives (Quinn et al. 2012). Such meanings of care include, for instance, the appreciation received in return from care receivers, and self-esteem (Quinn et al. 2015). The search for reward in caring might also be a motive for caring, although this less likely to be found among carers of older parents compared with those who care for partners (Feeney and Collins 2003). Nevertheless, some motives are frequently overlooked, although it is possible to urge carers to continue providing care. Such motives might be control or power, the status of care receivers, and compliance with external norms (Kohli and Künemund 2003).

The differences, complications, and interrelation of motives for caring are not static but dynamic, because they can change during the duration of caring (Romero-Moreno et al. 2011, Schulz et al. 1989 cited in Quinn et al. 2015). Whilst a carer can have different motives for caring, it is difficult to assume or determine whether carers' behaviours continue as a result of the same motives over time; motives depend on certain circumstances in which carers interpret their situations and various motives differently (Kohli and Künemund 2003).

In this thesis, the concept of motivation and its relationship to reciprocity are used to explain female family carers' drivers for caring, which are set out in Chapter 7. Following that, Chapter 7 aims to explain the motivations by linking them with carers' experiences of reciprocity, particularly the reciprocations from their relatives with dementia.

2.6 Concept of Family Practice

This part discusses the concept of family practice. This concept helps frame the use of the four concepts previously described – care, gender, reciprocity, and motivation – in the sense that it provides insight into family activities, particularly the giving of care in which the aspects of gender, ethics of care, relationality, and negotiation are involved.

According to Morgan (2011), the concept of family practice views the definition of the term 'family' beyond the conventional model of family, which is fixed with individuals' positions, roles, and sets of relationships such as parenting and partnerships associated with family (Morgan 2011), or co-residence and marriage (Smart 2007). Instead, individuals are seen as 'doing family', which reflects a sense of fluidity, everyday and regular practice, rather than perfect practice (Morgan 2011). Finch (2007) suggests contemporary family to mean 'doing family' more than 'being a family'. This is to see 'family' in terms of qualities rather than a thing; as a facet of social life rather than a social institution (Morgan 1996).

This part begins by introducing relationality and emotional dimensions in family practice. It is followed by an examination of aspects of negotiation and ethical considerations in providing family care. Lastly, the discussion focuses on understanding caring and reciprocity as family practice.

2.6.1 Relationality and Significance of Emotional Dimension in Family Practice

Morgan (2011) has argued that affirming the existence of family seems to be beyond the fixed model of 'the family'. Traditional family-member functions may be fulfilled either by actual family members or by people outside the family who are intimately connected to the family (Morgan 2011), such as friends and neighbours or anyone who is a family-like person (Morgan 2011, Smart 2007). Instead, Morgan offers the concept of 'family practices'. Family practices maintain or reassert the existence of the family ties by reflecting the significance of relatedness of the persons involved in doing family practices; the individual constructs an identity in reference to other individuals involved in practices. Practices in families are established upon relational practices, in the sense that meeting a family obligation or duty is the result of how the individuals relate to each other rather than on their positions as blood relatives – on the basis of 'person', not 'position' (Finch and Mason 1993). The history of the relationship and related reciprocity, where individuals may have influence upon family practices, family obligations, and feelings about the ways that individuals have treated each other influence a person's decisions in their everyday life (Smart 2007, Finch and Mason 1993). Thus, practices or decisions are made as the result of an individual's thoughtful decisions and intentions, which are based on the relationship they have with another individual (Smart 2007, Mason 2004).

With respect to 'relationality', this thesis illustrates that caring for people with dementia may fall not only within the remit of family members but also that of friends and acquaintances. That said, most of the female family carers seemed to enact this role by default since they had been co-living with the person who developed dementia for much or all of their lives. Despite that, some carers regularly received assistance and support from their acquaintances rather than their own siblings who lived separately.

In family practice, the connectedness between individuals is associated with emotion, which is one of the major components of family practices (Morgan 2011). Taking emotion into consideration helps us to understand what individuals think about their intentions, decisions, and actions in undertaking family practices, and how they deal with certain circumstances or how they make sense of the actions they are to carry out (Smart 2007). Thus, according to Crossley (1998 cited in Smart 2007) emotion should not be seen as a mistake or failure in reasoning, since emotions make family living meaningful and valuable; they are not produced from one's self as an individual psychological property, but are generated out of the flow of social interaction and also help define the context of interactions and help individuals to interpret their actions. However, caring as family practice seems to be emotional work in which emotions are not only expressed but also controlled and managed. In ‘doing family’, individuals deal with family situations and relationships by expressing and managing their emotions, including using emotions as one aspect of their decision-making (Morgan 2011, Smart 2007).

Given that emotional work is established in daily family life, caring as family practice is embedded with a variety of emotions, which are constructed, shaped, controlled, and conveyed as part of care-based social interaction. As such, caring is as associated with emotion as it is with physical activity (Twigg and Atkin 1994, Tronto 1993). It requires both love and labour; those who provide care have caring experience, in that they have dealt with emotions; Graham (1983) calls caring a ‘labour of love’. Where feeling in caring is the basic thing for humans to do, emotions are associated with more than familial obligation. As a result, caring enacts itself as a form of emotional labour or emotional work (James 1989 cited in Twigg and Atkin 1994, Hochschild 1983), which is a concept intended to illustrate the management of emotion and feeling. In describing emotional work, Hochschild (1979, 1983) avoids using the term ‘manipulate’, but views manipulation as the individual’s act of attempting to evoke certain feelings in certain situations, whilst also needing to suppress some inappropriate feelings. Emotion management could be seen to be associated with the many professionals, for instance, doctors, flight attendants, clerks, funeral workers and care workers, since people working in these careers are the emotional labourers who respond to the need for care of their counterparts. However, emotional work could be considered as gendered as it typically involves the activities of women (Morgan 2011). Throughout this thesis, the significance of the emotional aspect of care is considered. For example, in Chapter 4, the emotional labour in women’s caring is revealed and discussed along with the activities of care. In other chapters, the discussions illustrate the significance of emotional aspects of care, not only in terms of the ways of performing care, but also in terms of negotiation or making ethical decisions about the continuation of care.

2.6.2 Negotiation and Ethical Consideration in Doing Family Care

Doing family practices appears not to be easy without consideration or without negotiations with someone else involved (Morgan 2011). Finch and Mason (1993) have suggested that family members who help each other are not doing so simply to follow the rules of family responsibility or family obligation, which are embedded in the public norm. Rather, the focal point is the negotiation regarding rules around what is to be done and how. In doing family practice, negotiation is operated with reference to relationship sets (i.e. parent-child, husband-wife), history of the family's inter-relationships, and significant other people involved. Thus, according to Finch and Mason (1993), family obligations, duties, and responsibilities are not rules but rather 'guidelines' which are fluid and can develop or change over time through the process of negotiation. In negotiation, the act of giving support between kin is seen not only as a material exchange, but also has a moral dimension (Morgan 2011, Finch and Mason 1993). The negotiation involves moral rationality, which Morgan (2011) suggests is not abstract morality but everyday ethics that support and help other people in practical ways. That is, the individual carries out the negotiating process with everyday ethics to keep things in balance and to do the right thing depending on the circumstances (Morgan 2011, Smart 2007).

According to Morgan's view of everyday ethics, the ethical family practices which are seen as the actions of reciprocity, obligations, fairness, etc. are not the actions of a lone individual that are done for his/her own sake. Rather, such ethical practices are directed towards other people for the other's benefit. A tangible practical example is a mother's care for her child, which reflects ethical practice as a result of maternal obligation and concerns necessary to support the child's life (Morgan 2011).

When it comes to caring relations, obligation, and dependence, etc. toward older family members, Morgan refers to 'moral economy', in which ethics such as obligation, fairness, and reciprocity are resources and services that are part of family practice. However, within a family, statements such as 'the mother's sickness' and 'the brother's debts' seem to show the feelings of clear concerns beyond a simple familial obligation because they indicate some decision needs to be made. This reveals the ethical considerations used in decision-making. In this respect, the term 'doing family' is used to explain how individuals deal with family matters among the dissonance or borderlines between distinguished norms, customs, circumstances, and in relation to the other people involved such as friends and other acquaintances, so that individuals can maintain their family configuration and affirm and reaffirm the family ties, as well as reproduce the individual's family-related identities.

2.6.3 Understanding Caring and Reciprocity as Family Practice

This part discusses caring and responsibility within a family, as suggested by the concept of family practice. Finch and Mason (1993) suggest that reciprocity is dynamic and can be understood as a product of negotiation, not as that of following the rules of family obligation. That said, some carers have to balance their personal needs and those of their care receivers, for example, people might need to quit their job in order to repay somebody for having done a favour for them in the past (Quinn et al. 2015, Finch and Mason 1993). This reflects how carers face pressure when they possibly need to make decisions when reciprocating. A study by Finch and Mason (1993) reported that there should be limits to repayment, while some of their respondents viewed that an individual who should be a carer should give up their job to take care of the person who had already assisted them. The respondents viewed that those expected to give up their jobs were mostly women with lower positions in the labour market or who have a low income.

In the process of negotiation, the commitment to family responsibilities emerges and develops gradually over time, demonstrating that responsibilities are accepted and have lasting consequences. Thus, in terms of family practices, commitment is too expensive for individuals to withdraw from as it involves relationality with relatives, friends, and public audiences (Morgan 2011, Finch and Mason 1993). Moreover, reciprocity as a negotiation means the exchanges of goods not only in terms of material value but also symbolic ones. Symbolic value includes the balance between dependence and independence in relationships. Thus, the balance in a relationship needs to be negotiated and renegotiated in accordance with the changing situation (Finch and Mason 1993).

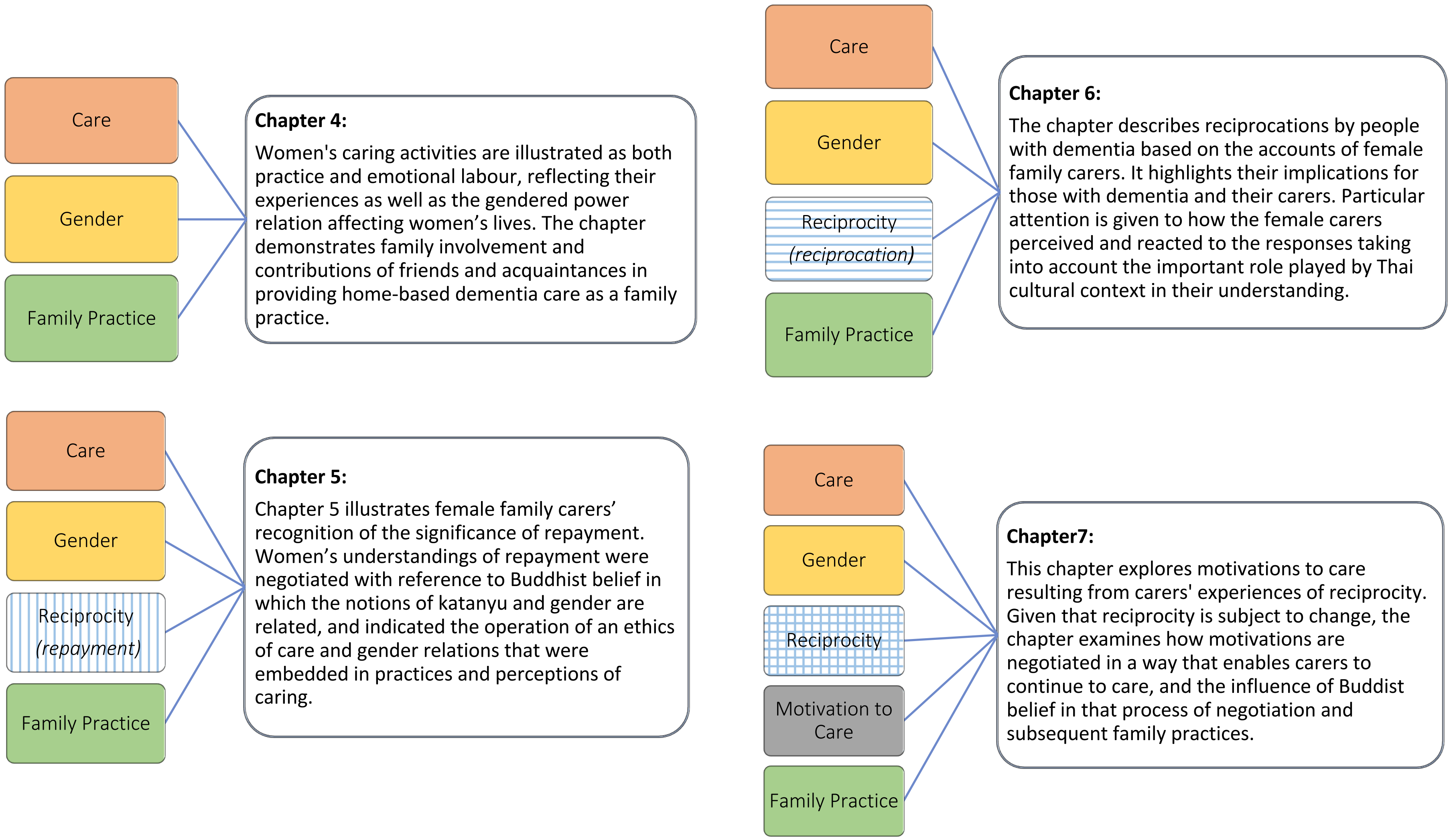
In this thesis, whilst reciprocity is seen as negotiation involving the aspects of commitment and relationality, these aspects and their relationships are explained not only in terms of involvement of kin relationships and public audiences, but also in terms of the way that commitment develops with family carers’ experiences of reciprocity involving care receivers with dementia. That said, reciprocity relating to longstanding commitments may also influence their motivations for caring. This issue is discussed in Chapters 6 and 7.

2.7 Conclusion

This chapter has explored the concepts key to the analysis of this study: concepts of care, gender, reciprocity, motivation, and family practice. The review of the literature reveals the foundations for the examination of the three research questions: 1) How do female family carers make sense of repayment for caring for older people with dementia? 2) In what ways do female family carers understand the reciprocation given by older people with dementia? and 3) How do the family carers' experiences of reciprocity relate to their motivations to provide care?

Framed by the concept of family practice, caring and reciprocity alongside motivation for caring are considered as negotiable. Female family carers are positioned as making sense of their repayments in caring not by following but by negotiating the norms of reciprocity (Finch and Mason 1993, Morgan 2011). When doing care, they have to manage their caring and family issues with the right balance. Similarly, motives for caring may be changeable over the duration of the care (Kohli and Künemund 2003). Furthermore, the thesis suggests that female family carers' ways of thinking about and caring for their relatives with dementia, including making decisions about caring, are informed by ethical and relational aspects.

Figure 2: Conceptual Maps of Chapters 4-7



Chapter 4:

Women's caring activities are illustrated as both practice and emotional labour, reflecting their experiences as well as the gendered power relation affecting women’s lives. The chapter demonstrates family involvement and contributions of friends and acquaintances in providing home-based dementia care as a family practice.

Chapter 5:

Chapter 5 illustrates female family carers’ recognition of the significance of repayment. Women’s understandings of repayment were negotiated with reference to Buddhist belief in which the notions of katanyu and gender are related, and indicated the operation of an ethics of care and gender relations that were embedded in practices and perceptions of caring.

Chapter 6:

The chapter describes reciprocations by people with dementia based on the accounts of female family carers. It highlights their implications for those with dementia and their carers. Particular attention is given to how the female carers perceived and reacted to the responses taking into account the important role played by Thai cultural context in their understanding.

Chapter7:

This chapter explores motivations to care resulting from carers' experiences of reciprocity. Given that reciprocity is subject to change, the chapter examines how motivations are negotiated in a way that enables carers to continue to care, and the influence of Buddist belief in that process of negotiation and subsequent family practices.

In Figure 2 above, *Conceptual Maps of Chapters 4-7,* provides a summary, in advance, of the way in which the five concepts to emerge from the literature review are employed in the data analysis according to the major themes of each findings chapter. Each of the 4 findings chapters starts with a reproduction of the relevant map set out here, moving on to apply and critique the respective concepts in more detail. The overall theoretical framework was developed as a result of taking a feminist approach, which is discussed next in Chapter 3 on research methodology.

Chapter 3: Research Methodology

3.1 Introduction

This qualitative research was undertaken to study female family carers' experiences of caring for older people with dementia in Thailand. The three main research questions, discussed in full in section 1.6, included how carers make sense of repayment for caring for older people with dementia; how they understand the reciprocation given by older people with dementia; and how family carers' experiences of reciprocity relate to their motivations to provide care. The study was informed by a feminist approach where in-depth interviews were used as the main research method.

This chapter encompasses a discussion of: feminist methodology as the methodological approach; the research sites; ethical considerations; research participants; data collection; the status of the researcher in the field; and data management.

3.2 Methodological Approach

3.2.1 Feminist Methodology

As this thesis concentrates on care and female family carers, a feminist methodology was viewed important. The study intended to examine the experiences of female family carers and how they make sense of caring and reciprocity in dementia care. It was therefore felt necessary to explore a feminist methodology to help understand the way in which feminist research ethics contributes to the study.

In social science, Bryman (1998 cited in Oakley 2000) has argued that it is the scholar's discontent with the outcome of using quantitative methodology that has led to the rise of qualitative methodology. Quantitative methodology, described as 'experimental ways of knowing', has been criticised in terms of ways of framing knowledge and ways of knowing, and in relation to the knower and the object of study (Oakley 2000). Based on experimental ways of knowing, the experiences and voices of those who take part in research have not been allowed to be heard openly. In this sense, Oakley (2000) states that women's voices are not necessarily absent in quantitative research, but qualitative research allows the voices of women research participants to be heard and represented. It can also provide a more equal status between researcher and research participants, a concern of a feminist approach.

3.2.2 Feminist Methodology and the Quantitative-Qualitative Dichotomy

In the academic world, feminist social science has contributed to debates on ways of knowing (Oakley 2000). The knowledge of social science, as well as research findings, particularly in traditional methods in sociology, have been derived by inherently sexist methods. They have been produced in a patriarchal world via men's ways of knowing and for the sake of men. Quantitative methodology has also been viewed as a mainstream method of understanding the social world, and particularly social science in general (Oakley 2000). For this reason, significant feminist critiques of the quantitative paradigm indicate that this paradigm supports 'sexist values' (Oakley 2000, Stanley and Wise 1993). Using quantitative methods, women's voices and experiences have not always been counted; women have not been included in research samples (Oakley 2000). Furthermore, women's interests and some areas of difficulty in the lives of women are not addressed by social science studies using quantitative methods. Women's experiences and their ways of knowing, therefore, are absent or positioned as unreliable voices that cannot be understood (Stanley and Wise 1983 cited in Oakley 2000).

For Oakley (2000), gender is a fundamental factor in determining which methodology is used and is to be valued. The dichotomy of quantitative-qualitative methodologies implies dualist thinking and the discussion around the dichotomy displays many gendered-bias notions. The quantitative and experimental methods are positioned as being 'hard, masculine, objective, and reliable and public'. In contrast, the qualitative method is said to be 'soft, feminine, private, subjective, and unreliable' (Oakley 2000), which cannot be suitable for providing reliable explanations. In this sense, Stanley and Wise (1993) suggest that women's 'sociological visibility' is low. Nevertheless, this dualistic thinking also implies the inequality of status among researchers and the people to be researched. The researcher is considered a 'knower' or 'expert' whereas the researched is treated as an object to be known. Therefore, this feminist critique notes how dualist characteristics are not only gender-biased, but also involve an inequality of power in society, because the nature of sex and gender are positioned differently in the social hierarchical structure (Ramazanoglu and Holland 2002).

3.2.3 A Feminist Approach as a Way of Knowing

Stanley and Wise (1993) suggest that the significant implication of gender could be considered in two ways. Firstly, considering gender helps us to understand that women's experiences have been subjugated and distorted by a patriarchal procedure of creating knowledge. Secondly, gender implies a hierarchy of thought and social relations. In this respect, there is no methodology that could be used and understood beyond the gender relationship (Stanley and Wise 1993). Non-sexist methods and feminist methodology are raised as the suggested solutions to deal with these.

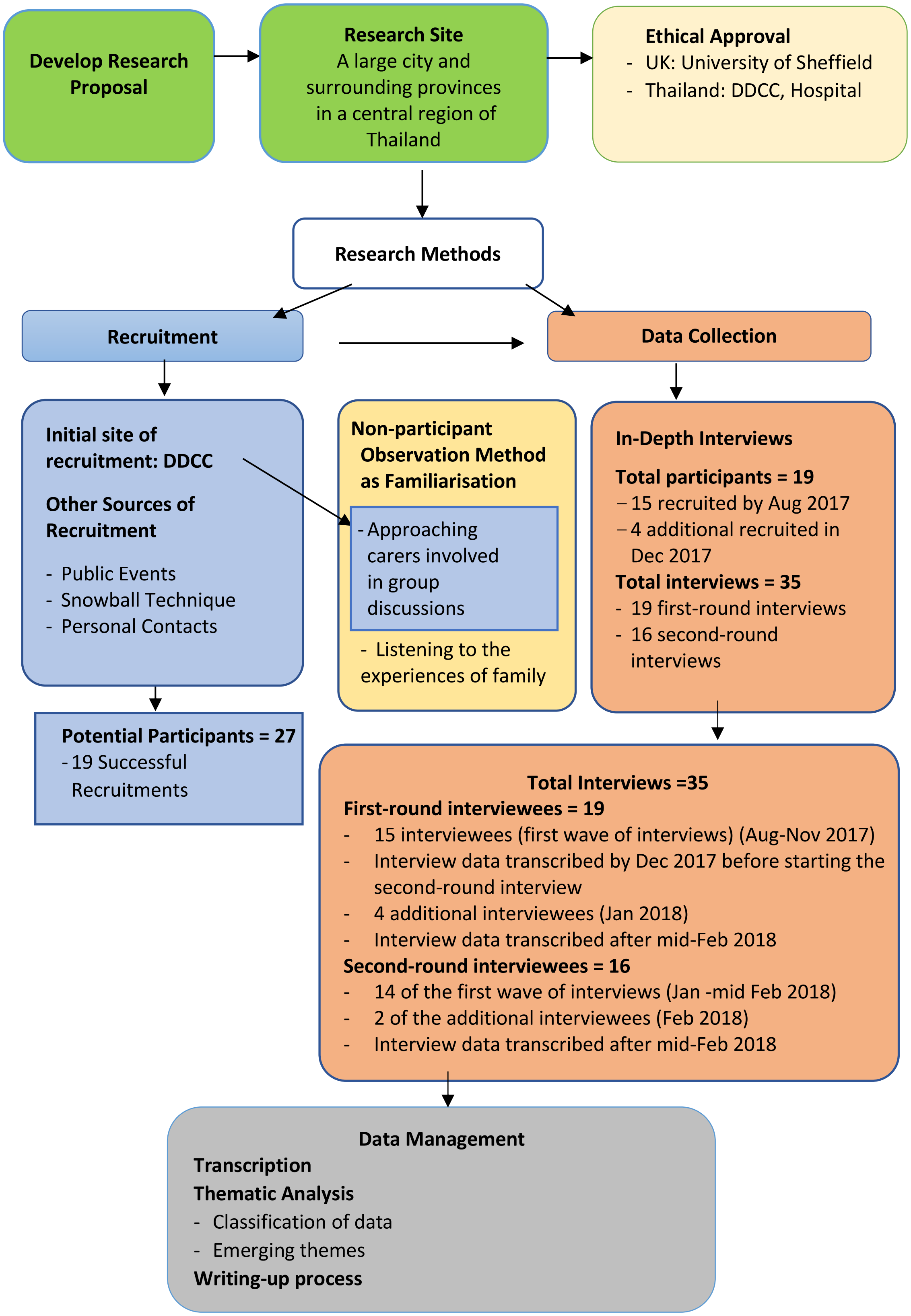
In this study, the researcher adopted a feminist methodology, which is an approach to deal with the problems of knowledge constructed within the context of gender relations. Feminists argue that using 'gender-blind theory' is not enough to understand people's life experiences, which are inevitably associated with gender relations (Ramazanoglu and Holland 2002). According to this, feminist criticism on gender and sexism should be undertaken *by* women, *on* women, and *for* women (Stanley and Wise 1993). Feminist research is also able to have a huge positive impact on women as it is a 'radical perspective' (Ehrlich 1976 cited in Stanley and Wise 1993).

For Stanley and Wise (1993), men cannot be feminist as they are not being treated as women. A feminist consciousness is embedded in the everyday life of being a woman. The marginalised position of women in society implies that women are able to perceive two different worlds. Namely, they know the thoughts of generalised people and the thoughts of those being excluded and subjugated. However, men realise only one (Stanley and Wise 1993). For this reason, using a feminist methodology helps correct the taken-for-granted understanding related to women's lives and thought. Feminist research, therefore, is not only a muckraking and corrective way of constructing knowledge, but also is likely to be a movement in itself (Ehrlich 1976 cited in Stanley and Wise 1993).

Although feminism seems to engage with values in a way that quantitative methods may not, it does not necessarily engage with those values that are seen to be specific to women's experience. The values should be human values in a broader context (Stanley and Wise 1993) which is democratic, since it views that all people are equal (Oakley 2000). Considering this with academic works, a feminist methodology can be used in research in which the researched people are not the objects of knowledge for researchers, and are not being judged or evaluated by researchers. Women being researched are able to be knowers by themselves. In this respect, Elshtain (1981 cited in Oakley 2000) suggests that feminist researchers need to avoid a ‘mode of explanation’ that seems to impose their own views onto those people being researched. Then, the power of the people being researched can be established. For this reason, they should be renamed research ‘participants’ (Oakley 2000, Reinharz 1992).

Before detailing how the research processes were undertaken, the following flowchart provides the overview of how this study was conducted.

Figure 3: Flow Chart of Conducting Research



3.3 Research Sites

In this study, the research site was a large city and surrounding provinces in a central region of Thailand where there was a variety of organisations working on the issues of older people and chronic illness, for instance, non-government health organisations, hospitals, universities, and research institutions. Among those organisations, the researcher chose one named Diamond Dementia Care Center (DDCC) as an initial research site for recruitment, and a site from which to increase knowledge of dementia care. The recruitment process is outlined in Section 3.5.2. Below is a description of how the researcher came to know of and gain access to DDCC.

3.3.1 Getting to Know Diamond Dementia Care Center as an Initial Research Site

In 2014, when the researcher was considering dementia care as a topic for postgraduate study, the researcher went to a lot of public activities held by organisations working on the issues of dementia including Alzheimer's disease. The researcher visited many public events including public talks, exhibitions and academic conferences in the hope that they would help develop the researcher's understanding of the context of dementia care in Thailand, so that the researcher could narrow the research questions and explore the possibilities of doing research on that topic.

In September 2015, a hospital set up public activities in acknowledgement of World Alzheimer's Day. On that day, the researcher asked for a brochure from the staff member of an organisation called Diamond Dementia Care Center (DDCC). The staff member handed the researcher a brochure and introduced a leading staff member of DDCC, Sansanee (pseudonym). A short discussion followed in which the researcher expressed an interest in dementia issues. After that, the researcher asked for Sansanee's contact details in case the researcher had some questions or needed advice. As a result of this conversation, the researcher learned that DDCC had regular activities in relation to dementia care issues. The conversation provided a possibility for the researcher to start doing research with DDCC as an initial site.

3.3.2 Gaining Access to Diamond Dementia Care Center

A few weeks later, the researcher sent an email to Sansanee to arrange an appointment with her. In this study, Sansanee was a gatekeeper and also a bridge upon which the researcher relied to access research participants (Miller and Bell 2012); Sansanee was a head of group discussions arranged monthly for family carers. The researcher met Sansanee at the hospital to ask for her advice about gaining access to DDCC, her working experiences in the organisation, and her views on the dementia care situation in Thai society. She said that there had been many researchers doing research in cooperation with DDCC recently. She also suggested that if the researcher wished to do research with DDCC corporation, an ethical review would need to be approved beforehand. (See Section 3.4 relating to the ethical consideration).

Prior to mailing the original copies of access letters to DDCC, the researcher sent the documents by e-mail along with the research proposal translated into Thai so that the DDCC team could know the research aims and research methods that may involve DDCC activities. The original copies of those documents were submitted a month later, once the researcher had a chance to visit Thailand. With respect to gaining access to DDCC's group discussion, Sansanee was in a position to allow the researcher to attend these activities, which normally were reserved for family carers of people with dementia only. By enacting a role as an observer of the activities, the researcher employed the non-participant observation method to recruit research participants, and to learn of the experiences of attending carers.

This approach to accessing research participants was chosen in preference to using a gatekeeper. The latter was considered as potentially problematic in two respects; research participants might be in a less powerful to negotiate their decision-making toward research participation, and the sample might show bias if participants were selected by the gatekeeper (Miller and Bell 2012). In this study, the researcher contacted Sansanee to ask for permission to attend the activities and access the family carers as an initial step. Acting as a gatekeeper, Sansanee introduced the researcher to all group discussants as a PhD student who was doing research on dementia. After observation of the group discussion, the researcher approached and recruited suitable research participants individually without the gatekeeper's suggestions. These elements of the research methods, group discussion and non-participant observation, are discussed in more detail in Section 3.5.2.3

3.4 Ethical Considerations

In line with all social science research involving humans as participants, the research needed to be ethically reviewed before the process of data collection started in order that the rights and safety of research participants were treated carefully, as well as those of researcher. Since this study aimed to undertake data collection with Thai people, the researcher was required to apply for two ethical reviews: one) Ethical Review of University of Sheffield, United Kingdom, and two) Ethical Review in Thailand.

3.4.1 Ethical Review of University of Sheffield

This ethical application was prepared three months prior to being submitted, along with the research proposal and other documents required for Confirmation Review.[3] The application was put together using the templated application and instructions provided by University of Sheffield's website, along with other guidelines from the ethics references and online ethics resources written by the British Sociological Association and the British Society of Gerontology. These were suggested by the researcher's supervisors. The major documents used in the ethical application included a consent form and the information sheet, which were submitted online along with the proposal and literature review. The researcher also enclosed an approval letter from DDCC, a not-for-profit organisation, as evidence that permission was obtained to undertake this research with DDCC's cooperation. The ethical approval was granted one month later.

In the researcher's point of view, although the process of ethical review was a requirement, it also enabled the researcher to more carefully reconsider the research design and research process in particular. The researcher learned that when doing research involving people's lives with the methods of non-participant observation and in-depth interview, the dignity and rights of research participants need to be respected, not only in the process of gathering data, but in all research processes.

3.4.2 Ethical Review in Thailand

After approaching DDCC, the researcher made informal contact with a DDCC staff member. Formal letters from the researcher and the research supervisors were then sent. DDCC granted permission to the researcher to attend to DDCC activities, which were held in Diamond Hospital. The researcher also needed to submit an ethical application to Diamond Hospital, due to the hospital's regulations relating to research activities undertaken inside the hospital. The

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[3] Confirmation Review is a University of Sheffield requirement whereby PhD students need to successfully defend their research proposal by the end of year one of full-time study and demonstrate that they are fit to commence their fieldwork studies (Department of Sociological Studies 2016).

researcher submitted the ethical application in Thailand after obtaining the ethical approval in the UK. The relevant documents, such as research proposal, consent forms and information sheet, were translated into Thai languages to be submitted for ethical review. Additionally, Diamond Hospital required certificates or evidence to confirm the researcher's experience of ethical training. The researcher then enclosed a statement of academic progress along with a letter of approval to conduct research at the Diamond Hospital. It took six weeks for ethical approval to be granted.

3.5 Research Participants

3.5.1 Selection of Research Participants

Participants in this research were selected by using a purposive approach as a guideline, which was the intent from the outset of research proposal development. After that, some criteria in selection had to be revised due to the researcher's fieldwork experience. In this section, the researcher explains the criteria used for the earlier selection, the reasons for revising the criteria, and the revised selection. These are described as follows:

The criteria in the earlier selection were that the research participants would be approximately 15-20 female family carers with Buddhist beliefs. They must be primary family carers who had at least one year or more of experience in taking care of older relatives with moderate or severe dementia. Other statuses such as age, education and socio-economic class were not the main factors in recruitment. The location of research was set to be a large province in a central region of Thailand.

Once the researcher entered the fieldwork and pursued the recruitment process, fieldwork data suggested some other criteria that were more significant and thoughtful considerations that could be used to better understand the family carers and their experiences. For example, some family carers did not identify themselves either as primary carers or as secondary ones. Instead, they looked after their parents with dementia with the assistance of other family members. As a result of learning this, the types of carers were reconsidered in the selection. Additionally, it was decided not to specify the level of symptoms manifested in people with dementia because the ongoing trajectory might help provide significant data in relation to perceived reciprocity in family carers' experiences. These considerations aside, the researcher found some uncertainty in the recruitment of sufficient numbers of family carers as research participants. The researcher was not able to recruit some of them as expected, even though they had relevant criteria. Those carers declined to participate or otherwise did not answer phone calls, for example. The details of challenges of recruitment are discussed further in Section 3.5.2.2.

Taking all these factors together, the revised criteria for selection of participants saw two major changes. First, while the gender and religious beliefs of the participants still remained major elements in recruitment, types of carers (i.e. primary) and level of symptoms in people with dementia were not specified. In other words, prospective research participants were female family carers with at least one year or more of experience in caring for their older relatives with any level of dementia. Second, the location of research was changed to be a large province and its surrounding provinces in a central region of Thailand.

By following the revised selection criteria of research participants, the researcher recruited a total of 19 female family carers with Buddhist beliefs. Their brief personal details along with details of their lives and caring situations are discussed separately in Chapter 4, with additional pen portraits provided in appendix 1 (pp303-310).

3.5.2 Recruitment

This section regarding recruitment is separated into two parts. In the first part, the researcher discusses how the recruitment efforts were arranged. The researcher explains each recruitment effort, whether that effort led to the researcher being able to collect data by in-depth interview successfully or whether it was a challenging recruitment. In the second part, the challenging recruitments are discussed.

3.5.2.1 Arranging Recruitment

First of all, the recruitment was planned to be undertaken through a group discussion activity hosted by the organisation known as DDCC. The researcher obtained an opportunity to join in the discussion in July 2017, which was before ethical approval in Thailand was granted. (Ethical consideration is described in Section 3.4.2.). Group discussion was an activity held for family carers only. It was similar to a self-help group in which family carers shared their experiences that they thought might be helpful for others. Additionally, some techniques in caring might also be suggested by healthcare professionals present. In this activity, the researcher employed the non-participant observation method to approach the potential research participants. Concomitantly, the researcher had the opportunity through the non-participant observation method to learn about the caring experiences shared primarily by family carers. However, non-participant observation is described in detail later in Section 3.5.2.3

At the beginning of the group discussion, every attendee introduced themselves. What they said about themselves helped the researcher to screen relevant research participants. Once the discussion was over, the researcher began approaching the attendees one-by-one and asked a set of basic questions which included: for whom they had been caring; symptoms recently manifested in their relatives with dementia; how the medical treatment was going; and whom they could ask for support if needed. Also, the researcher explained to them that the researcher had a special interest in dementia care and female family carers. At the end of conversation, the researcher asked them for permission to exchange phone numbers and email addresses in case the researcher needed to clarify any points in their understanding of dementia care based on the carer experience. At this time of recruitment, the researcher did not have information sheets and consent forms to show to potential participants, since ethical approval was still pending. Instead, the researcher openly told them that the researcher was interested in interviewing the female family carers but could not start any interviews at that time.

Although the DDCC organisation was the main channel through which the researcher was able to recruit research participants, the researcher did not ask any DDCC staff for assistance in approaching the family carers, nor in requesting carers' contact information. The researcher did not wish to disturb the DDCC working atmosphere. Also, it was felt appropriate to keep a suitably distant relationship between the researcher and the cooperating organisation, since it was assumed that this may influence the researcher's autonomy to carry out the research.

In the middle of August 2017, when ethical approval to collect research data was granted, the researcher phoned the first family carer to remind her of the earlier conversation and desire to conduct research. The researcher re-introduced herself and explained the research process and the rights of the interviewee. Verbal consent from the participant was gained and an appointment for the interview was made. Other participants whom the researcher met via the group discussion were also contacted in this way. Additional participants were approached and recruited via other sources, which included public events run for carers and related to dementia care such as workshops, exhibitions and conferences, the snowball technique, and personal contacts. These data are summarised in Table 1 as follows.

Table 1: Summary of Recruitment Data

	Total Number	**Source of Recruitment**		
		Group discussion / public events	Snowball technique	Personal contacts
Potential Participants Recruited	**27**	**21**	**3**	**3**
1. Interviewed	**19**	15	1	3
2. Not Interviewed	**8**	6	2	
Reasons not interviewed				
▪ Did not fit criteria: caring for people with other illnesses		1	1	
▪ Bored: previous experience of being interviewed		1		
▪ Not wanting to relive memories		1		
▪ No reason given / crying		1		
▪ Phone not answered / unable to reach		2	1	

Table 1 shows that the total number of potential participants identified thorough the various recruitment channels was 27. For the participants recruited via other public events, the researcher approached them on two occasions. Firstly, the researcher talked to them through face-to-face interaction and identifying herself as a PhD student. Then, the researcher started with a set of basic questions as per the previous recruitment efforts. Concomitantly, a copy of the information sheet and consent form, and the researcher's contact number were handed over to all individuals (See the appendix 3 (p312) for the example of information sheet and the appendix 4 (p316) for the consent form). Afterwards, the researcher left the potential participants some time to consider. The researcher contacted them via phone a few days later. While undertaking telephone recruitment, the researcher realised the challenges of building rapport and gauging willingness to participate without any visible bodily cues. During the calls, the researcher built up rapport by having a conversation with each potential participant about their caring experiences, the person for whom they cared, and recent medical treatments, for example. The phone conversation was a way of screening the relevant qualifications of the potential participants. The researcher checked if they read the documents provided, so that the researcher could gauge their level of interest and availability. Then, the researcher asked them for verbal consent and a convenient time to meet.

Through the snowball technique, some recruitment efforts were undertaken but only one person agreed to participate. The researcher later approached the snowballed participant by phone. Once the telephone conversation showed the possibility of collecting data, an appointment then was arranged. In attempting to employ the snowball technique, the researcher found that very few research participants had broad connections with other people caring for people with dementia. Although they had a number of friends or acquaintances who were caring for parents, the parents were living with other illnesses.

For recruitment opportunities gained through personal contacts, two participants were suggested by a relative of the researcher who was a nurse, while another one was a contact of the researcher's colleague. Once the contact numbers of the carers were received, the researcher phoned them to greet and identify as a PhD Student, including letting them know about the purpose of research.

Recruitment via the snowball technique and personal contacts was planned to be used only as alternatives in case there might be difficulties in recruiting research participants, such as the carer lacking time to participate. In fact, there were several unexpected reasons why people approached declined to participate. The challenges to recruitment efforts are discussed, as follows. Nevertheless, the snowball technique and personal contacts were helpful and effective complementary sources of recruitment.

In sum, among 27 potential participants, there were 19 that resulted in recruitment and interview, and 8 where recruitment did not go ahead to the interview stage. Challenges to recruitment are discussed in the next section. However, closing recruitment at 19 participants can be justified both in relation to the methodological principle of 'saturation' (Saunders et al. 2018) as well as on grounds of pragmatism. In qualitative studies, researchers continue with recruitment and data collection until they reach a point of data saturation. This is achieved when the data demonstrate the repetition of the same or similar comments, no new insights are being gained from participants (Gove et al. 2016, Grady 1998 cited in Saunders et al. 2018), and the collected data show clear potential for generalisation (Boddy 2016). In this study, recruitment ceased at 19 participants when data saturation was reached in the way that the data displayed similarities but also contrasts in the results. In other words, once the data showed a pattern of findings that could be analysed interactively with theoretical concepts, the recruitment then was stopped. In addition, this study limited the research sample to 19 participants for the reason of pragmatism: time for collecting data was running out as the researcher planned to return to the UK to continue the writing process.

3.5.2.2 Challenges in Recruitment Process

As shown in Table 1, among 27 potential participants, there were 19 that resulted in recruitment and interview, and 8 where recruitment faced challenges and interviews did not go ahead. The challenges highlighted the uncertainties and dynamics of the research process.

The first case of challenges to recruitment occurred after the researcher had already finished a few in-depth interviews. After that, the researcher encountered several reactions from potential participants and related reasons for non-participation. For instance, some family carers felt embarrassed and refused when approached. Some did not answer the phone call although the researcher's phone number was provided, and they had initially seemed to be willing to be interviewed. There was a carer that cried and refused to take part in the interviews without giving her reasons to the researcher. The researcher assumed that the terms 'caring for older parents' and 'katanyu', which was a social value in Thailand, might be sensitive terms for carers, since these words seemed to be associated with the public expectation and duty of children in Thai society. One carer, Metta, refused to be interviewed just a few minutes before the interview was about to start. Metta had agreed to undertake an interview after her Buddhist class at university. The class started at 9.00 a.m. and ended at noon. Once the class was over, the researcher walked over to greet her. The conversation covered general topics and the topic of the research. Metta asked why she had been chosen to be a research participant and whether the researcher was able to recruit somebody else. She seemed a bit reluctant to refuse directly. She explained that she did not want to recall her past experiences but would prefer to leave the events in the past. The researcher chose to respect her understandable decision. The researcher then thanked her for expressing initial interest and for having had a chance to meet. Other examples of challenging recruitment were caused by the failure of individuals, who were otherwise interested, to meet relevant criteria, such as being a carer for a family member with dementia.

The researcher came to realise that the dynamics of recruitment may be a challenge in conducting research on family carers, particularly those caring for people with dementia. However, dynamic characteristics are the nature of qualitative research and a researcher should be prepared to deal with uncertainty and unanticipated circumstances.

3.5.2.3 Non-Participant Observation in Recruitment and Familiarisation

In qualitative research related to human behaviours, observation has been used widely across disciplines including medical research, psychology, sociology, and anthropology (Salmon 2015, Cooper et al. 2004). Among different forms of observational approach, one of the major forms is non-participant observation (Bryman 2016). This study employed non-participant observation in two ways: as a route to approaching potential participants and as a means of learning about the experiences of family carers. Prior to discussion of how this technique was employed, the characteristics of this method and the reason why it was used are described.

Compared with participant observation, in which researchers spend a long period of time engaged with participants in a particular context by adopting the role of member to understand the participants' subjectivity (Salmon 2015, Guest et al. 2012), non-participant observation takes a shorter and more limited time approach to collecting data (Cooper et al. 2004). Researchers observe a situation but rarely participate or do not take part in what is going on in that setting (Bryman 2016). In this study, the researcher was permitted to attend the DDCC's group discussion. However, since it was only held once a month, the opportunity to develop membership of or become a volunteer for the organisation was difficult. Moreover, the researcher planned to use the group discussion primarily to approach the research participants rather than to study the pattern of behaviour within that setting, per se. For these reasons, in this study, non-participant observation was a more appropriate approach compared with participant observation. That said, not only did the group discussions hosted by DDCC prove to be a good place to start the recruitment process, they also allowed the researcher to become familiarised with existing information on dementia and with the experiences of Thai family carers.

Non-Participant Observation as a Route to Approaching Participants

In each group discussion that the researcher attended, attendees comprised an average of 10-12 family carers, both female and male, and three DDCC staff members. At the beginning of each discussion, the attendees introduced themselves. The researcher was looking for female carers of an older parent, which the researcher initially assumed would be the majority of attendees. In fact, it was surprising that the number of adult child carers was almost equalled by the number spousal carers. During this stage of introductions, the researcher made notes on what was said and considered each person based on whether or not their qualities were relevant to the research criteria. Another thing to consider was any indication of the participants' readiness to share their experiences or state of mind, which enhanced the possibility of approaching them.

Given that observation in qualitative research is conducted in naturalistic settings (Salmon 2015), researchers are able to use either covert or overt approaches, depending on the aims of their role in the observation. This study conducted non-participant observation in an overt approach in which the identity of the researcher was fully disclosed. In the group discussion, the researcher was introduced as a PhD student conducting research on dementia-related issues. The researcher's role was to listen to the attendees talking without any disturbance or initiating any questions to interrupt the discussion. Due to the naturalistic setting of observation, however, the researcher sometimes needed to answer questions from attendees, on issues such as social welfare in relation to family carers, in order to maintain the ongoing discussion. Group discussions lasted one-and-a-half hours and were followed by a short lecture by a DDCC staff member about dementia care. The researcher waited until all activities were finished, and then began approaching the attendees individually.

Non-Participant Observation – Listening to the Experiences of Family Carers

In addition to being a way to approach potential research participants, non-participant observation helped the researcher to understand carers' experiences prior to conducting the in-depth interviews. A study by Cooper et al. (2004) which explored the needs of hospital pharmacists' in their working environment similary suggests that non-participant observation provides a better understanding of behaviours and helps identify problems, in this case in the clinical setting. In this thesis, the observation helped the researcher to become familiarised with family carers' experiences as well as to learn of the conditions of dementia symptoms. The experiences raised by carers included difficulties communicating with their relatives with dementia, their physical and emotional stress, their ability to deal with spontaneous problems or unfamiliar situations, their ways of taking care of themselves, and the expectations put on them to provide care. Moreover, based on the principle of reciprocity, the researcher found that home-based care was a common form of care for people with dementia, but it was considered a normal act of "family care", an expectation by which every member of a household was expected to provide care and be cared for as required. As a result, some adult carers did not identify themselves clearly as a primary carer or a secondary carer; taking care of their relative with dementia could not be separated from family care. In other words, home-based dementia care was a family practice where, in some families, the responsibilities of caring were distributed equally. Such data, derived from the non-participant observation method, helped the researcher to identify what questions needed to be asked and ways to ask them using the in-depth interview method (Bernard 2006 cited in Guest et al. 2012, Cooper et al. 2004).

3.6 Data Collection

This section, relating to data collection, is divided into two parts. In the first part, the researcher describes the process prior to fieldwork, which includes developing interview questions, making appointments for interviews, and tools used for collecting data. Secondly, the researcher explains the research methods to be used when undertaking the fieldwork.

3.6.1 Prior to Fieldwork

3.6.1.1 Developing Interview Questions

In feminist research, the semi-structured or unstructured interview is a technique of data collection that allows researchers and participants to converse more openly (Reinharz 1992). Using semi-structured interviews, researchers can ask questions that they planned to ask, but are also open to allow the asking of other questions that might emerge during the conversation (Graham 1984 cited in Reinharz 1992).

After the Confirmation Review was approved, the researcher prepared each research question, and under the umbrella of these, developed sub-questions, making them understandable easily for the interviews. Along with this, the researcher looked again at the theoretical concepts and literature related to the topic to ensure that they guided the creation of the interview questions. In addition, the development of the interview questions was assessed by the research supervisors, who helped check the questions and suggested some other interesting avenues that could be explored during the interview.

3.6.1.2 Making Appointments for Interviews

When the interview questions were ready, the researcher phoned the first three participants to arrange one-to-one interviews with them. The researcher originally intended to conclude one interview before making a new appointment with the participant. The researcher understood that this might appear to unnecessarily extend the duration of the data collection period, but there were advantages to this. Firstly, it would allow the researcher to assess the first interview process and consider the ways that the interviewee responded. Secondly, it would allow the researcher to ascertain the practicality and suitability of the interview questions. Thirdly, it would allow for self-evaluation of the researcher’s performance when undertaking the interviews, so that the researcher could improve for further interviews. After pursuing this method for the first three participants, the researcher moved forward on arranging the interviews with the rest of the participants without waiting for each to conclude before arranging the next.

3.6.1.3 Tools of Data Collection

The researcher considered each of the necessary tools that were to be used during fieldwork. As a first step, the researcher prepared copies of the information sheet and consent form, which had already been translated into Thai. They all needed to be clearly printed or photocopied. A few pens were brought along with a booklet inside which a list of interview questions was folded. A sound recorder needed to be kept fully charged. Its storage space was also checked to be sure it was adequate. A fully charged portable battery was always brought too as a back-up. In addition, it was necessary to ensure that the researcher’s mobile phone had enough credit and that its battery was fully charged at the start of the day, since it would be used through the whole day for calls and internet access. These things needed to be prepared beforehand. Regarding getting to the meeting places, on many occasions the researcher used the various public transportation services which were available, including bus, motorcycle taxi, and sky train. Sometimes driving was more convenient. It depended on the time and place of the meeting.

3.6.2 Entering the Field: Research Methods in Data Collection

In this study, in-depth interviews were the main method of data collection. This section describes how in-depth interviews were conducted as part of the fieldwork.

3.6.2.1 In-Depth Interviews with Research Participants

In this study, in-depth interviews were chosen as the main method to understand female family carers' experiences. Employing a feminist approach, it was decided that the interview questions were to be semi-structured questions that were open-ended to allow the research participants' voices to be heard and their experiences to be disclosed. The in-depth interviews were conducted in two waves. The first wave of initial interviews contained 15 interviewees. The second wave supposedly of additional interviews actually contained four new interviewees. Across the 19 participants, the researcher therefore conducted a total of 35 in-depth interviews that encompassed 19 first round and 16 follow-up interviews. The first round interviews were undertaken between August 2017 and January 2018, while the follow-up interviews were undertaken during January 2018 and February 2018.

The data were collected by two modes of interviews, which were face-to-face and via telephone. In this section, the researcher describes: the characteristics of the in-depth interview using a feminist approach; the face-to-face and telephone interviews; and the two rounds of interviews, respectively.

Feminist In-Depth Interview as a Research Method

Oakley (1985 cited in Reinharz 1992) points out that feminist interviewing includes a commitment by researchers to build up a relationship with participants, who react with sincerity. Oakley (2000) suggests that the in-depth interview has been used by feminist researchers because it is a face-to-face method of conversation, and requires researchers to listen to the participants and vice versa. However, according to Oakley (2000), feminist qualitative research using in-depth interviews entails three distinctive features: the 'connected' knowing, breaking the binary of the knower and the known, and the grounding of knowledge in experiences and social context.

As feminist methodology breaks the hierarchical binary oppositions between researchers and research participants, James (1986 cited in Reinharz 1992) suggests that her interviewing was carried out by establishing a relationship with participants and avoiding the alienation of either party. Without the boundary, participants could be more actively involved in the interviews. This kind of interviewing also requires researchers to be careful listeners, which aids researchers in preparing their next questions. In this respect, Bart and O'Brien (1984 cited in Reinharz 1992) suggest that the process of interviewing seems to be oriented towards the research participants. This raises the question of whether the interview should be led by the researcher or the participant. Gilligan (1982 cited in Reinharz 1992) states that there does not seem to be any inconsistency between cases where the participants lead the interview and those in which they are asked the researcher's preset questions. Reinharz (1992) suggests that some feminist researchers initiate interviewing with standard questions, whereas some of them employ such questions near the end of interviewing. Some feminist researchers have attempted to combine these two approaches.

When participants are women, they will be better understood if their interviewers are also women (Reinharz 1992). DeVault (1987 cited in Reinharz 1992) considers that this helps women to reveal what they really think and feel, and helps enhance women's consciousness. Barrington and Gray (1981 cited in Reinharz 1992) point out that it enables researchers to see the essence of the interviewees' words, for instance the feelings or words representing hesitancies. These things may seem to be insignificant from a non-feminist researcher's points of view. Woman-to-woman interviews are also able to create a kind of trust that allows the interviewees to guide the interview. In this respect, trust is a component that researchers should obtain if they aim to gain valuable data from the participants (Bernard 1982 cited in Reinharz 1992).

With respect to the quality of received data in woman-woman interviews, Segura (1989 cited in Reinharz 1992) suggests that when the interviewer can develop familiarity with the participant, the interview can be more focused. On the other hand, Zimmerman (1977 cited in Reinharz 1992) points out that when the researchers are strangers, the participants are more likely to disclose their private data because researchers are not involved in the participants' lives.

Face-to-Face Mode and Telephone Mode of Interview

As mentioned above, the researcher actually used two modes of interview, which were face-to-face interviews and telephone interviews. The former were conducted as planned whereas the latter were set up as an alternative option. Below, the researcher describes how each mode of interview was conducted. Later sections explore the organisation of initial and follow-on interviews and the data subsequently generated.

Face-to-Face Mode of Interview

In qualitative research, the face-to-face interview is considered a standard tool of data collection widely used by researchers in conducting fieldwork (Novick 2008). The face-to-face interview is also viewed as an effective tool to help the researcher gain good quality data because the researcher will be able to observe the verbal and nonverbal reactions of interviewees and vice-versa. The presence of visual cues helps the interviewee and interviewer to create rapport, express empathetic feelings, and interpret each other's nonverbal reactions such as facial expressions and eye expressions, which creates rich research data. Among the 19 research participants in this study, face-to-face interviews were used for 18 participants. From doing fieldwork, the researcher agrees that this mode of interview was a useful tool of data collection since it enabled a deeper discovery of the female family carers' personal experiences. Their caring experiences were expressed through their words along with nonverbal expressions such as visible emotion, bodily expressions, and tears, which provided context and depth to their stories.

Telephone Mode of Interview

In addition to face-to-face interviews, the researcher also undertook a couple of telephone interviews. The telephone interview was not a method initially planned to be used: telephone interviews lack visible cues providing guidance and feedback for the researcher and participant (Novick 2008) and it was thought that having a chance to talk in person would provide richer data. Nevertheless, according to feminist approaches, research data can be collected using various methods and a telephone interview proved more convenient for one participant.

Before interviewing the participant on the phone, the researcher approached her in person at a dementia-related workshop, and then called her thereafter to make the appointment for a face-to-face interview. On the phone, this participant expressed that she would prefer to interview via phone at that time, since she had some difficulties going out. She could not leave her mother with dementia home alone, because her mother looked for her all the time. The researcher was not certain that a phone interview would serve the study well, being less well-prepared, but chose to meet the participant's request. At the outset of the telephone interview, the researcher informed the interviewee of the research aims, the interviewing processes, the interview questions, and the rights that an interviewee has over the course of the research processes. The researcher asked to arrange a time to call back for the interview, which might last approximately 30-45 minutes – pre-arranging the interview would allow the researcher more time to prepare. The researcher then asked the participant for permission to make an audio recording of the conversation using a digital recorder.

Mussselwhite et al. (2004) suggest that telephone interviews are effective in data collection provided researchers are able to prepare properly. The second-round interview with this participant was well-prepared for, in that the researcher managed the environment and devices of data collection to avoid technical problems and minimise distraction when conducting the interview. This also helped the researcher to focus on note-taking fully without the concern of maintaining eye contact with the interviewee (Jones 2017).

Due to the absence of visual cues, the telephone interview mode has been criticised since the collected data might have low quality, as the researcher lacks the opportunities to observe the research participant's nonverbal expressions, which include an emotional dimension of their verbal responses. In addition, researchers might not be able to establish rapport or to probe in the same way as they do during a face-to-face interview. It also probably leads to a misunderstanding of responses on both sides (Novick 2008). However, the telephone interview can be advantageous if researchers are aware of its usefulness as well as its limitations (Musselwhite et al. 2004). For instance, participants more feel at ease when talking about their personal data during a phone interview (Novick 2008, Musselwhite et al. 2004). Furthermore, interviewees may feel more comfortable when they were kept "physically confidential", as during a telephone interview, particularly in relation to sensitive research topics such as sexuality issues (Jones 2017). That said, it is also possible to develop rapport and trust via phone interview. Additionally, some scholars maintain that data collected by telephone interviews are not necessarily different from data gathered via in-person interviews. Despite the lack of visual cues in a telephone interview, participants may be franker in their discussions with researchers (Trier-Bieniek 2012, Sturges and Hanrahan 2004) and also provide deeper information if and when clarification is required (Novick 2008).

In this study, responses obtained via telephone interview were not different from those gained through face-to-face interviews. It was true that the researcher could not see the participant's facial expressions and other forms of nonverbal responses, but felt her voice and intonation reflected what the participant felt as she participant shared her caring experiences. From the researcher's perspective, the limitations of the telephone interview urged the participant to express her voice, thoughts, and feelings more intensely than if she were talking in a face-to-face interview. Such responses were able to replace the visual cues, the lack of which is seen as one of the disadvantages of the telephone interview mode.

First- and Second-Round Interviews

First-Round Interviews

The practicalities of first-round interview stage centered on places and times of interviews, obtaining the research participants' consent, and how the interviews were run.

The meeting places were set by each research participant. The places were varied and included her home, hospitals, coffee shops, universities, workplaces, local temples, and even in a car. The selection of the meeting place depended on the participants' availability, their day-to-day activities, and their concerns about the conversation's potential effect on their parent with dementia. Similarly, the meeting time varied to suit the participants' daily activities and employment. The majority of the first-round interviews lasted between 1h50m to 2h10m.

The researcher initiated the conversation with the interviewees by a set of greetings and questions related to their caring tasks and current symptoms experienced by their relatives with dementia. Once the interviewees were seated properly, the researcher offered the information sheet and consent form to them. Time was given to them to read and sign the form. In the meantime, the researcher answered any questions they had. The researcher also reassured them of the confidentiality of data and the rights of the interviewee throughout the research processes. In addition, the researcher told them the reasons that the researcher was interested in interviewing female family carers, including how it related to the researcher's personal experience of caring for the researcher's grandmother, and experience of doing research on ageing issues. This short dialogue formed a prelude to the interview, which helped research participants relax and helped to develop trust as part of the researched-researcher relationship.

After consent was obtained, and rapport was built to an extent, the researcher moved on to ask the interviewee more directly about dementia, starting with the questions: "Could you please tell me about the first signs that your [cared for person] had developed dementia? What did you do then?"

In the interview, semi-structured questions were used. The questions were categorised and written on a small piece of paper, which the researcher held in hand throughout the interview as a memory aid and to ensure that nothing was missed. The researcher considers that using a feminist approach with in-depth interview methods allowed the conversation to be conducted in a natural way. Therefore, the semi-structured questions might not need to be asked in order, and so often switched back and forth due to how the conversation, led by the interviewee, was flowing.

Although the in-depth interview method allowed the researcher to understand the experience of participants through their verbal explanations, it was felt necessary to also observe their gestures, which included facial expressions, eye expressions, smiling, crying, and tone of voice. When listening to the participants, the researcher took note of bodily cues. Bodily cues helped the researcher to interpret what the participant was saying at that moment. While interviewing, the researcher realised the need to maintain a high level of concentration to keep a balance between being a good listener and a good researcher. The researcher had to respond through physical reactions such as nodding to express understanding, saying some words to show understanding, and keeping eye contact with the participants. These gestures were signs of engagement with the participants and also inevitably shaped the on-going process of interview.

At the end of each interview, the researcher thanked the participant for sharing their deep and personal experiences and their time. The researcher also asked if it would be okay to contact them again in case the interview data might not be clear, and if so explained that the researcher might call them for further interviews. After each interview was over, fieldnotes were taken as soon as possible and then were saved to the researcher's personal computer. Sometimes, fieldnotes were taken by sound recording to be transferred to written form later.

Additional Interviewees

At the time of having almost finished undertaking the first-round interviews, which totalled 15 in number, the researcher reported to her supervisors concerns she had about approaching the participants again and the fear she might nor secure many second-round interviews (see the section on Second-Round Interviews below). The supervisors advised that the researcher should recruit at least a few additional participants if possible. During that time, there was a workshop about cooking and preparing a menu for people with dementia. The researcher attended that event and looked for additional interviewees. Four additional recruitments were made by approaching potential participants in person, followed by an introductory telephone call to each participant, before meeting at an appointed date. First interviews with these additional 4 participants took place alongside the start of the second-round interviews.

Second-Round Interviews

The researcher finished the transcription of the planned 15 first-round interviews in the middle of December 2017. The second-round of follow-on interviews began in January 2018, but the questions in this round were prepared alongside the transcription process. In other words, the questions in this round emerged from the first-round of collected data (the 4 additional interviews excepted), such as when a participant reflected on some aspects that were interesting to the researcher, or were derived from tentative extrapolation of themes from the first-round data by the researcher.

The time of approaching the interviewees was during the period of New Year 2018 celebrations. Due to this timing, the researcher felt a little anxious that the research participants might refuse the second-round interviews since they might have a trip planned during the long holiday. The researcher was also anxious because there was a necessity to finish undertaking all interviews within the five weeks left before leaving Thailand and heading back to the UK. As this feminist approach placed much value on data accuracy as well as power and knowledge of the research participants throughout the research processes, the researcher told the participants that the researcher wanted to make sure that the interview data was correct, and the researcher also would like to meet them again before leaving.

Using telephone and the LINE application, a freeware application for instant communication used widely among Asian Internet users, the researcher was able to approach sixteen of the 19 first-round participants. None of the remaining three was able to be interviewed: one participant had gone on a long holiday trip, whereas the other two participants lacked time because their relatives with dementia still needed their close assistance. As discussed before, the difficulty for carers in finding free time was still an issue to be aware of. Such situations certainly had an effect on the researcher's schedule to arrange the appointments with other participants. Thus, the schedule had to be managed very tightly in a way that allowed all remaining interviews to be conducted within five weeks as far as possible. The 16 second-round interviews were completed by the end of February 2018.

The aim of undertaking the second-round interviews was to ask additional items not included in the first round, and to check the data with the research participants to be sure that the researcher understood their responses correctly. Time spent on each second-round interview was between 40 minutes and 3 hours.

The researcher met each of the 16 participants at the same place they had met for the first interview. Some differences were evident; for example, the researcher felt that the participants spoke in a more relaxed fashion, which enabled the researcher to learn more confidential aspects of their personal lives and ways of thinking. For instance, they uncovered negative experiences relating to their childhood and their spousal relationships. The second-round interviews contributed by helping to fill any gaps of data from the first round, which some interviewees felt unclear about or uncertain in answering. Namely, some of them revealed that, after the first interview, they were still thinking of the questions that had been asked and had more to say on them. In the researcher's perspective, the follow-up interviews offered the opportunity for the researcher to allow data to be confirmed, as well as fill any gap of data, and really contributed to the gathering of very rich data for the study. However, the researcher reckoned that the extent of this varied depending on the level of trust and familiarity between the researcher and research participant.

Regarding the time spent on each interview, the researcher was quite surprised at how much longer some of these interviews were compared to the initial interviews. It may be because of the feeling of trust, allowed interviewees to feel they could speak more freely. Some interviewees said that they felt released when being interviewed because they needed someone to talk about what they faced during their caring experiences.

Lastly, due to time restrictions, transcriptions of the second-round interviews were undertaken after mid-February 2018, once all the interviews (first and second) held during the second-round period were completed.

3.7 Reflexivity

Feminist scholars put the emphasis on the knowledge production when undertaking research, in the sense that the research process deals with the power relations and exercise of power between the researcher and the research participants. In addition, the researcher's criticism and interpretation are limited by their personal experiences, feelings, cultural background, and political orientation (Pillow and Mayo 2014, Ramazanoglu and Holland 2002). Feminist research ethics therefore provide guidelines for conducting research in which an emphasis is placed on the issues of 'power and knowledge' which are embedded in the way of knowing, interaction with research participants as knowers, and the process of knowledge production. Therefore, in order to be honest and transparent with research participants, researchers should consider reflexivity when planning and undertaking their studies. In general, reflexivity refers to the researcher's effort to uncover the power relations and exercise of power between the researcher and the research participants (Ramazanoglu and Holland 2002). It helps reveal the position of the researcher, the research agenda and process, the knowledge produced by the research process, bias in interpretation and in knowledge production. Reflexivity also allows for renegotiation between the researcher and the research participants.

In line with feminist approaches, researchers are required to exercise reflexivity in every stage of the research process, although some processes might be lone work (Hesse-Biber 2011, Maynard 1994). Reflexivity here not only refers to honesty with research participants, their data, and their positions, but also refers to the transparency with which researchers communicate to those who read the research findings. A feminist approach suggests that the researcher describes what and how the researcher positioned themselves in their fieldwork.

This section describes what the researcher's statuses were in fieldwork and how the statuses were to be chosen to be presented during data collection. This section also explains the extent to which the researcher managed the insider-outsider status in fieldwork, and how that status influenced the data received. The researcher's reflections on the transcribing (see Section 3.8.1) and writing processes are discussed separately (see Section 3.8.3).

In this study, the researcher drew on several identities in non-participant observation and the interview method. Not only the identities of the researcher and research participants, but also their similarities and differences of backgrounds might influence or shape the situation in fieldwork, research data, and any stage of the research process (Hesse-Biber 2011). When undertaking fieldwork in the context of those differences, researchers need to develop an ‘insider’ status in order to share their similar social backgrounds with participants to build up rapport, to obtain cooperation and data. However, due to different backgrounds, researchers are inevitably ‘outsiders’ of the social world of participants. Some scholars suggest that these identities can be flexible and change over time. The appropriate time to change identities or time to reveal some information about the researcher might help to build rapport and gain useful data (Hesse-Biber 2011). In this study, the researcher inhabited several identities which included being a researcher, a PhD student doing research, a younger sister, and a female family carer. Generally, each identity will be selected and also changable over time in accordance with the research method being used, the present conversation, the approach of getting to know the participant, the trust gradually developed upon the interview, and the self-presentation of interviewees, for instance. Thus, the position of the researcher in the case of this study was not always fixed in the field. It depended on what the researcher encountered at that moment. The researcher needed to be flexible in accordance with surrounding conditions so that the researcher obtained the data required for the study and to enable an appropriate level of involvement in the conversation with the interviewee.

According to non-participant observation with overt approach (Salmon 2015), the researcher was aware that the appropriate statuses to be introduced to all participants in the group discussion from the outset should be the status of researcher and PhD student. The reason was that the group discussion was arranged for family carers and health practitioners only, and therefore usually not open for outsiders to join. In addition, some group participants might suspect or wonder about the position or involvement of the researcher and question the researcher’s presence. Thus, researcher and PhD student seemed the appropriate statuses to present, but these statuses alone were not enough to get to know the group discussants and develop trust with them. The researcher also gradually explained the interest of doing research on dementia care, and the personal experience of being a female carer. It was the researcher’s view that this social positionality helped the researcher be seen as an insider or a part of the family carers group. Ethnographers Villenas and Visweswaran claimed that, in the research process, the researcher can never exactly be an insider (Pillow and Mayo 2014). In this respect, the researcher considered that the identities of female carer might help reduce the doubtfulness of the other participants in group discussion and help the researcher to gradually build rapport and later approach the potential participants.

In this study, compared to the positions presented in the observation, some different identities were inhabited during the in-depth interview process. In most interviews, the researcher was presented as a PhD student when meeting the interviewees. After introductions and informing the interviewee of the research aims and methods, the researcher spoke to them as an experienced female carer. It was the researcher's view that disclosure of personal background and intentions little by little before starting the interview might help to establish rapport and enable the interview to flow. However, during the in-depth interview, there were some slight differences in the approach used during the observation. That is, some of the researcher's social identities, such as younger sister or friend of the research participant, were presented or developed during the interview stage. Social identities would be presented depending on whom the researcher was talking to and to what extent both parties could share their interests or social backgrounds, and how the interview situation progressed. This was the intended dynamic of the interview process, as some feminist scholars suggested researchers to be attentive to (DeVault and Gross 2006). This dynamic allowed expression and sharing of deep, personal data in the way that friends might talk. It might be true that, on the one hand, this was seen as a method for that researcher to obtain data. On the other hand, such a relationship occurred naturally with the flow of the situation. It can be said that after a certain duration the interviewee and the researcher were able to develop mutual trust, and some deep aspects of the interviewee's life were revealed to the researcher and, of course, vice versa.

An example of the flexible identities and developed trust during the interviewing could be illustrated by the case of Yuri. She said that nobody, even her close friends, could understand her current situation. Her friends' reactions could not help alleviate her troubles and sadness. She then did not want to let anybody know her stories anymore. When listening to her, the researcher shared the anxiety related to caring experience to Yuri, and also offered to be her listener if she would like. Yuri offered herself as a listener to the researcher in return. The extract below demonstrates the characteristics of friend-talk that emerged in the in-depth interview.

> The researcher: You can talk to me if you want someone to talk to. […] I used to feel like that too. My friends did not understand what I faced when caring for my grandmother at home.
> Yuri: You can talk to me, then.

The extract above seemed like talk between friends rather than that of an interview. It indicates that the identities of researcher and research participant were able to be changed to be closer like that of friends. When talking with Yuri, she showed photos of her parents and their living place, disclosing aspects of untidiness of the living place. This implies a friend-like status, in which there is the willingness to reveal ordinary life details, evidence that mutual trust and confidence between the researcher and research participant had grown.

Regarding the flexibility of the researcher's identities along with the established trust or developed intimacy in interviewing, some interviewees considered that the interviews offered them the opportunities to speak of some difficult feelings in relation to caring such as the anxiety, anger, and guilt, etc.. Although some of them did not speak frankly about the opportunities, their nonverbal reactions seemed to be signs of the releasing of suppressed feelings. Given that, the researcher considered the interviews to be therapeutic opportunities. Although an interview is often used as the typical approach in counselling fields such as family, marriage, and sexuality (Nelson et al. 2013), this study did not initially aim to use the interview as a therapeutic practice. Rather, it was intended to be used only as a research method that allowed space for the research participants to talk about their unhappiness and difficult life-events in their past experiences while the researcher acted as a good listener. Thus, the interview could be therapeutic practice in the sense that the telling of those stories helped research participants reveal and make sense of their ambiguous and fragmented feelings. In doing research with women participants, Bergen (1993 cited in Birch and Miller 2000) suggests that doing so allocated her the positions of 'counsellor researcher' and 'woman'. In addition, interviews and therapeutic practices share the common characteristics of self-disclosure and intimate relationships, whereby the thoughts of speakers are valued and voiced, not restrained when the researcher acts only as a listener (Birch and Miller 2000).

In this study, after the interviews were over, some research participants reflected to the researcher that they felt more comfortable when having the opportunities to speak rather than simply answering direct, closed questions. For example, Rungnapa (pseudonym) revealed to the researcher after finishing the second-round interview that she felt familiar with the researcher before they had even met, and had wanted to share her thoughts with the researcher.

> Rungnapa: I don't know why I feel like we've known each other before. I don't know why I want to let you know more and more what I faced and thought.

Rungnapa's comment could prove that the interview was able to provide space for the research participants to express their hidden thoughts and feelings as they would like, up until they felt relaxed. Similarly, Anchalee spoke about her feeling honestly to the researcher that, as an interviewee, she found the interview was also helpful to her.

> Anchalee: I decided to take part in your interview because I think it probably is a time to share our knowledge. I don't know if what I've been doing was right but I supposed that if the interviewer does research around caring issues they at least could understand what I've been doing. So, coming today [for an interview], it's like I have a chance to let out my pain.

From Anchalee's comment, she seemed to view the interview as a therapeutic event right from the start. She also affirmed at the end of the interview that the interview was therapeutic to her. In this respect, Anchalee's expectation toward the therapeutic aspect reflected that the researchers and research participants might have different perspectives on the revelation of personal data. That is, researchers might see it as a successful interview, while research participants might view it as a way of healing themselves (Birch and Miller 2000).

3.8 Data Management

Data management involved three parts, which encompassed transcription, emerging themes, and the writing process. They are discussed respectively.

3.8.1 Transcription

Transcription was carried out by the researcher manually as a process that enabled a form of preliminary analysis. Below are the descriptions of how the transcription was conducted, and of the importance of transcription for the research process.

The researcher commenced the transcription process after finishing some of the first-round interviews. The transcription was done little by little, beginning in the middle of August 2017, along with undertaking the rest of the first-round interviews. As the fieldwork of this study took place in a central region of Thailand, the language used in the interviews was the standard Thai language. The transcriptions were made in Thai prior to translation into English. Once the interview data were audio recorded, they were transferred to a computer, which made it more convenient for the researcher to listen to and transcribe the conversation. Most of the interviews lasted two hours, and the researcher spent two days transcribing each interview. The researcher views the process of transcription as being more than simply typing out the words.

The researcher considers there to be four important aspects to the transcription process. Firstly, self-transcription helped the researcher to review the collected data in overview. Subsequently, the researcher was able to draft tentative patterns of data in which the participants' stories revealed both similar and different aspects of their experiences. This tentative patterning of data helped structure the preliminary findings of the fieldwork. Secondly, regarding these similarities and differences in responses helped the researcher craft the second-round interview questions, which were aimed at exploring key aspects of participants' experiences in more depth. Thirdly, it was the researcher's view that the transcription process was also one of data analysis and recollection of theoretical concepts. Engaging the fieldwork data with theoretical frameworks initiated new reflections on findings that were helpful for writing the analysis. The researcher made notes or memos of these reflections along with the transcribed content so that the researcher could recall what needed to be written and analysed at the relevant stage. Lastly, self-transcription provided some opportunities for the researcher to learn and develop techniques for future interviews. For example, sometimes the researcher asked the interviewees questions in a formal way, namely, by using academic words. That often resulted in the participants asking for questions to be repeated. The researcher kept such lessons in mind so that the further interviews would be conducted more effectively.

3.8.2 Emerging Themes: Thematic Approach

As indicated in the previous section, the researcher found that the process of data analysis linked to the process of transcription closely, as the latter helped to form an early overview of findings. This section describes the thematic approach to the data analysis and the reason why this approach was chosen. It also explains how this approach was undertaken, step-by-step.

3.8.2.1 Thematic Approach Chosen as the Data Analysis

The process of identifying emerging themes is exciting because it requires the researcher to organise data so that it is presented in a way that is relevant to the research questions. Presenting this data in the form of academic writing is a challenge for the researcher. Thematic analysis was chosen as a realistic method of qualitative data analysis, as it helps to find repeated meaning, embedded in the data set and emergent as patterns and themes of data, and to explain that meaning by engaging with the theoretical concepts. Thus, the thematic approach is not only giving voice to the realities and experiences of the research participants, but also is presenting such data as themes along with the theoretical consideration in order to answer the research questions (Braun and Clarke 2006). In addition, it allows flexibility in the analysis and organisation of the data to be presented in a research report. Below, the researcher describes how the thematic analysis was run.

3.8.2.2 Running Thematic Analysis

Braun and Clarke (2006) suggest that the thematic approach illustrates the reality of what researchers have to understand, along with theoretical explanation. A theme resulting from thematic analysis represents patterns of data that are repeatedly exposed and can be developed to respond to research questions (Castleberry and Nolen 2018, Clarke and Braun 2017, Nowell et al. 2017, Vaismoradi et al. 2013). Themes can be derived from collected data or theoretical concepts. For this study, themes were developed based on the data collected. In developing the themes, the theoretical concepts were also employed, as they helped shape the themes into being more relevant to the research questions.

Braun and Clarke (2006) suggest six steps of thematic analysis. These steps include getting familiarised with collected data, coding data, searching for themes, reviewing themes, defining and naming themes, and producing the report. Regarding the first and the second steps, Braun and Clarke view that reading the whole data set at least once before coding can help figure out the rough pattern of data. In this study, the researcher read each of the transcribed interviews one-by-one and wrote short notes and keywords relating to early findings beside the content in the margins of the relevant page. The researcher also used coloured pens to categorise the data and then searched for the themes by considering initial coded data. In the process of searching for the themes of this study, the themes were identified at a latent or interpretative level (Braun and Clarke 2006); that is, the themes were not set up according to the explicit meaning of the empirical data but through the analytic process in which the data were interpreted along with the theoretical concepts. In this sense, the latent level in thematic analysis examines the underlying ideas that are implied or shaped by the surface meaning of the data. Therefore, latent analysis refers not just to the generation of descriptions but also involves the work done in relation to theories that need the researcher's interpretation. This process of latent analysis was complex and took time as it required considerable re-reading of the reviewed literature in order to set up the themes. The reading also meant switching back and forth to ensure that the themes presented were relevant to and answered the research questions properly. In this respect, thematic analysis at the latent level is an approach that demands reflexivity, thorough knowledge and understanding of theories, and transparency in data analysis (Braun and Clarke 2020).

Braun and Clarke (2006) suggest that themes are subject to change as tentative themes are revisited in the process of elaborating on them. The researcher followed this step by looking back to the research questions, since they framed the content and aims of this study. Research questions are the guidelines of how to organise the findings in accordance with the questions. However, themes can be reorganised; some are deleted, and some others are created, so that the themes are structured appropriately overall. In this sense, the data analysis process is not linear but may move back and forth between steps. Significantly, it requires frequent checking (Vaismoradi et al. 2013). The next steps are to review and name the themes. The researcher did these two steps together, since they both involved using relevant and concise words to present the findings in an informative and effective way. In refining the themes, for example, two sub-themes might be combined into one sub-theme.

As the last step of thematic analysis, Braun and Clarke (2006) suggest the production of a report. They point out that, in writing the thematic analysis, researchers need to present something beyond descriptive data. Researchers should instead present any valid, analysed data in a logical, coherent, and concise way. In addition, the write-up should also illustrate any reflective feedback from the researcher on their own research questions (Braun and Clarke 2006). The process of writing up is described in the next section.

3.8.3 The Writing of this Thesis

Writing a thesis is challenging not in terms of figuring out the complicated aspects of a studied phenomenon but in terms of how to illustrate and explain that complexity so that it is understandable. The writing process of a thesis itself can be complicated in that it is more than the act of writing; it involves other processes that require time management, such as reading a number of publications, thoughtful consideration, notetaking, and leaving more time for further thought and rework. This section explains three issues related to the writing of this thesis: the process of writing, the relationship between the researcher's personal experience and the thesis findings, and the difficulties of writing.

3.8.3.1 Process of Writing

Suggested by the researcher's supervisors, the researcher began to write Chapter 3, this methodology chapter, first whilst memory and reflections on the fieldwork were still fresh. Then, Chapters 4 to 7, the findings chapters, were written. It took approximately two and a half months to write each chapter. Each chapter has an introduction. The introduction was not the first part written, but was the last part to be checked. Prior to writing the introduction, the main body of each chapter, which contains extracts of the participants' comments, was written to illustrate the focal point of each chapter. The participants' comments remained in the Thai language and then were translated into English when being extracted and laid out in the chapters. In this thesis, the term 'the researcher' is used to represent the researcher in the third person (as noted in the Introduction), while the terms 'female family carer', 'interviewee', and 'participant' refer to the research participants. The participants' names shown in the thesis are all pseudonyms, to maintain anonymity, while the researcher's English nickname, 'Kim', is used in direct quotes from participants.

As said earlier, the writing process included a variety of activities. Therefore, the planning and writing process went back and forth between collected data and theories, to make sure that the findings were presented and discussed in line with theoretical concepts. The written findings were submitted as work-in-progress to supervisors around a week before a planned monthly supervision meeting. Supervisors provided feedback that helped to shape and gear the researcher's ideas in analysis, in that the supervisors as readers would reflect on whether the analysis made sense, and also suggested some recommended areas of further study. With respect to reflection on the thesis, the researcher found that taking a break from research for a couple of days was necessary. Afterward, the researcher reexamined the thesis so far as a reader, since introducing a little distance from the thesis could help provide further insights.

3.8.3.2 The Researcher’s Personal Experience and Thesis Findings

As described in Chapter 1, her personal experience of caring for her grandmother inspired the researcher to research this topic. In this section, the personal experience is explained to show the extent to which it was used in the writing process.

Whilst writing up the study findings in the UK, the researcher’s grandmother was diagnosed with last-stage gall bladder cancer. She wanted to have a family reunion as if she felt that it was her last chance to see all of the family together. The researcher also wanted to return to Thailand to take care of her, since prior to studying in the UK the researcher stayed with the grandmother and cared for her closely. Thus, whilst the researcher was in the UK, it was the researcher’s younger sisters’ turn to care for the grandmother more closely. This circumstance was a significant life-event for the grandmother, everyone at home, and also the researcher. This was a tough circumstance, but the researcher made the decision to visit her grandmother in Thailand without any hesitation. The researcher’s supervisors supported this decision and suggested that the researcher take a temporary leave of absence from the research to spend time providing care. However, in the researcher’s point of view, work on the PhD thesis might have continued alongside care provision.

The circumstances regarding caring for the grandmother provided many significant insights that could compare with the caring experiences of this study’s participating female family carers. To name a few, the following description highlights three issues relating to the researcher’s caring experience that contributed to the writing up of this thesis’ analysis: women’s time and caring, the awareness of the notion of reciprocity, and the carer as receiver in the context of care.

Firstly, when doing care, it seemed like there were a pile of activities that needed to be planned and completed. Although some activities might not be seen as caring activities by some, this was not the case. For example, based on personal experience, the researcher looked for online information about care such as how to deal with pressure sores and how to clean and heal wounds, and also to search for the necessary medical supplies for a bedridden person. In the researcher’s view, these activities were done for the grandmother’s sake, but they were hardly recognised by other family members, or were not even visible as caring activities despite the necessity. As a carer, the researcher felt like every minute was spent saving the grandmother’s life, or at least, easing her pain as much as possible. The necessity to keep on providing care every single day meant that the researcher had little time to reflect on and review the feelings deep inside of herself. The researcher was told by some family members that such altruistic caring might damage the researcher's health, due to the lack of any personal time to take care of herself. In providing care, the researcher felt as though she stood at a point in-between the positions of being a woman and a carer. Both positions are marginal statuses that are ways for a woman carer to understand the social world: women who provide care know well that caring is an ordinary thing that cannot be simply done, particularly when she tries to find a balance. Regardless of public or domestic circumstances, women and their experiences seem to be overlooked and taken for granted as personal issues. To the researcher, this represented a dilemma since the effects of caregiving seem to be more intense if women have to balance between their careers and domestic caring tasks. The researcher employed such personal experience in writing about caring activities, time, and the effect on female family carers, which are discussed in Chapter 4.

Secondly, while caring, the notion of reciprocity came to the researcher's mind more often. Providing routine assistance and care to her grandmother reminded the researcher of the support and love that her grandmother had given to everyone at home in the past. Since then, the researcher came to better understand and accept the term 'repayment' despite the implication of acts of exchange. It is true that the researcher was willing to care out of a desire to repay her grandmother, but not as a simple exchange. Rather, the grandmother was someone who used to give to others, and thus she deserved to be helped and cared for in return at this time of vulnerability and need. Moreover, to the researcher, the notion of repayment involved not only related to the relationship with her grandmother but with the researcher's parents and two younger sisters, since it was the researcher's view that caring for her grandmother was also to give something back to the other family members for their assistance and companionship (Leinonen 2011). This issue offered some insights that helped in interpreting the significance of repayment, which is discussed in Chapter 5. Moreover, the researcher found that providing care is to deal with public expectations that are implicit in the suggestions or reactions of relatives and neighbours. The researcher received a compliment: 'Kim, you are a katanyu granddaughter'. When providing care, the researcher had never thought of this term at all. But, if the researcher had said as such, then this would be frowned upon. This public view of repayment in relation to women carers is challenging. According to Edwards and Ribbens (1998), the status of a woman researcher is a source of insight to produce knowledge for the public. Following this, the researcher was standing in-between positions of undertaking research and undertaking care. For the researcher, a position of woman carer was a way to understand caring issues and to interpret other female family carers' subjective knowledge.

Thirdly, the researcher found that being a carer is to also be a receiver. It might be seen that the grandmother living with cancer could not do anything to help others, and then was a receiver more than a provider. In fact, the researcher received positive responses such as eye expression, smiling, and acceptance of the care given, as encouragement from her. In addition, the grandmother's severe illness granted the researcher a number of insights into life that the researcher was very grateful to experience. The grandmother helped create spiritual strength and expressed the meaning of giving and receiving to the researcher. It can be said that caring helps shape the way a person sees the social world. From the researcher's point of view, without such personal experience, the intersubjectivity towards the research participants' experiences might not be reached and interpreted clearly.

3.8.3.3 Difficulties in Writing: Challenges and Lessons Learned

The writing process was a pathway with challenges and difficulties, requiring the management of a number of pieces of related literature. Without management, it would take too long to search and re-read the relevant passages when needed. Using computer functions such as filing, words marking, and file tagging, helped. Tagging, in particular, is a helpful function to save time searching articles during the literature review and discussion, and when giving references or citation during the analysis. Following the management of a number of articles, the ideas gained from reading those articles needed to be taken note of in a booklet. In doing that, the space of the booklet was organised into eight chapters classified in line with the planned content of the thesis chapters.

Another challenge was how to explain the findings theoretically and how to critically apply existing literature to the arguments. The critical ideas seemed not always to come to mind at the moment of writing, but often when doing non-academic activities such as dishwashing, bathing, sitting on a bus, or walking in the garden, for example.

As an international student, the challenge of writing lies in effectively conveying ideas and understanding in English, since it is the researcher's second language. The difficulty of expression of ideas rested on both the researcher's English language efficiency and the difference of meaning or senses of English vocabulary compared to those in Thai. One process of writing is proofreading, for which the researcher looked to a native speaker of the English language to make grammatical corrections and check that the content was written understandably. The researcher read the proofread version to re-check the content before submission of the thesis.

Another important lesson learned from writing this thesis is the selection and avoidance of certain terms, since it is a sensitive topic. As far as reviewing the literature, some studies related to older people and dementia use negative-sounding words such as ‘patients’, ‘dementia sufferers’, ‘dementia victims’, ‘demented person’, or ‘the elderly’. These terms should not have been used as they negatively stereotype or generalise older people with dementia and define them as being in a different state (Gilliard 2001, Killick and Allan 2001). However, some literature uses more positive or neutral terminology. The changes in terminology used in dementia studies might be the result of a growing interest and research in this topic in the field of social sciences (Innes et al. 2004) and reflect that there is more attention on experiential perspectives of people with dementia and their families (Downs 1997). The researcher used positive terminology when writing this thesis an instrument to help raise public awareness of caring and dementia. At the beginning of writing a proposal for the thesis, the supervisors raised awareness of this issue and also encouraged the researcher to do so. For these reasons, there is careful use of neutral and positive terminology in this thesis. The words ‘person/people with dementia’, for example, are used instead of ‘patient’ or ‘demented person’. Also, references to cognitive ‘disabilities’ or ‘problems’ were avoided when writing. Rather, terms such as ‘cognitive changes’ or ‘difficulties’ are used instead as they sound more neutral and do not stigmatise those with dementia as ‘out of the ordinary’ (Dingwall 1976 cited in Bond et al. 2004). Selection of positive word helps reduce the stigmatisation of those with dementia and create public awareness of their dignity.

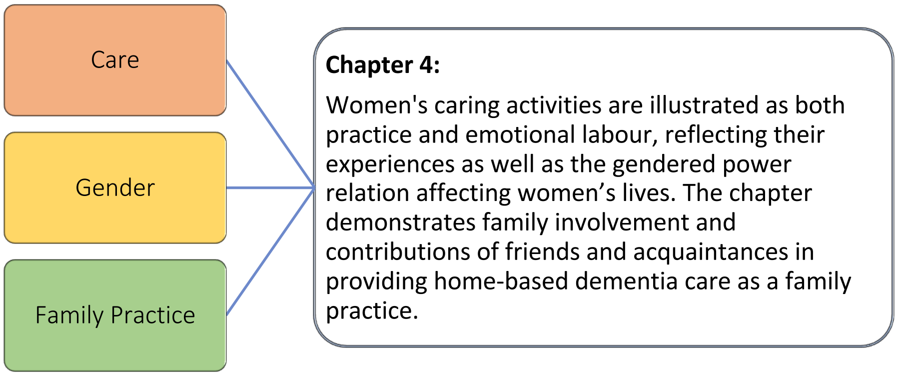
3.9 Conclusion

This chapter set out the research methodology and process of thesis production. A feminist approach was considered helpful in studying women’s experiences by allowing their voices to be heard and to reflect the ways they know and react to their social world. This approach encourages the equal status within power relations between researchers and research participants during research. In addition, this approach suggests that a researcher can show reflexivity and should be honest when showing research findings.

In this thesis, the research participants, selected using a purposive approach, included 19 Buddhist female family carers with at least one year's caring experience for their older relatives with dementia. Ethical considerations were approved by the University of Sheffield, the Diamond Dementia Care Centre (DDCC), and the Diamond Hospital as part of the process for permission to gain access to the field. The research methods included non-participant observation and in-depth interviews. Non-participant observation was used as a familiarisation to the fieldwork: a route to approaching participants, and to listening to their experiences. For in-depth interviews, the research participants were interviewed in two rounds by the face-to-face mode and telephone mode of interview. Due to the nature of qualitative research and the nature of caring, there were some obstacles and unexpected circumstances, and these are discussed in relation to interviews and work in the field. This chapter also set out the researcher's reflexivity when processing data collection. In this chapter, the researcher explained the statuses that were used acknowledged in line with the context of each conversation with the research participants. Those statuses helped develop mutual trust between researcher and research participants, which led to gaining deeper data. Trust also played an important role during interviews, making them therapeutic for some research participants. In data management, carrying out self-transcription provided the researcher time to review the collected data, which helped to plan the data analysis, which was guided by a thematic approach. In the last section of this chapter, the process of writing this thesis was described along with a description of how the researcher's personal experience offered insights to the thesis writing. Attention will now be turned to the details of that writing, starting with an overview of the experiences of female family carers in caring for people with dementia in Thailand.

Chapter 4: Female Family Carers and Experiences in Caring for People with Dementia

4.1 Introduction



Chapter 4:

Women's caring activities are illustrated as both practice and emotional labour, reflecting their experiences as well as the gendered power relation affecting women’s lives. The chapter demonstrates family involvement and contributions of friends and acquaintances in providing home-based dementia care as a family practice.

Figure 2a: Conceptual Map of Chapter 4

This chapter discusses the data obtained from research participants in relation to their caring experiences, which is divided into five parts. The first part is the participants’ data and how they become carers based on the notion of family obligation toward caring responsibilities. Second, it focuses on intimacy and the intimate knowledge that carers have of the cared-for persons, and how the knowledge influences their caring. The third part concerns the caring activities of female family carers. The fourth part features the contribution of carers’ friends and acquaintances towards the care. The last part discusses family involvement in caring for people with dementia at home highlighting concerns and conflicts within the family. This part illustrates that home-based dementia care is not only a matter of carers and care receivers, but rather a matter involving all members of the family.

Table 2: Researched Participants Data (Order Alphabetically by Name): 19 Female Family Carers Taking Care of Older People with Dementia

No.	Carer Name	Age	Marital Status	Education	Recent Job	Cared-for person	Type of Dementia	Years of Caring	No. of Siblings	No. of Paid Helpers
1	Anchalee	52	Married + 1 child	BA/BSc	Unemployed	Mother (77) w. father	Alzheimer's disease	2	2	0
2	Aurapa	60	Single	BA/BSc	Early- retired and unemployed	Mother (80)	Alzheimer's disease	1	2	0
3	Fenda	55	Single	High School	Unemployed	Mother (76)	Alzheimer's disease	2	3	0
4	Jan	53	Single	BA/BSc	Own business	Mother (85)	Alzheimer's disease	3	3	0
5	Koong	52	Single	Diploma	Unemployed	Sister (60)	Alzheimer's disease	3	3	0
6	Manee	58	Divorced + 2 children	BA/BSc	Early-retired and unemployed	Mother (79)	Alzheimer's disease	1	4	1
7	Neena	44	Single	MA/MSc	Unemployed	Mother (75) w. father	Parkinson's-plus	5	3	0
8	Noy	34	Married + 2 children	BA/BSc	Unemployed	Grandfather (92)	Alzheimer's disease	2	0	1
9	Paula	41	Single	MA/MSc	Part-time Psychologist	Father (80)	Frontotemporal dementia	7	3	0
10	Preeya	35	Single	MA/MSc	NGO	Mother (65) w. father	Alzheimer's disease	4	2	1
11	Ratchada	59	Single	BA/BSc	Manager	Mother (83)	Alzheimer's disease	3	1	1

12	Raywan	60	Married + 3 children	BA/BSc	Own business	Mother (76) w. father	Alzheimer’s disease	1	4	0
13	Rungnapa	49	Single	BA/BSc	Own business	Mother (88)	Alzheimer’s disease	4	6	0
14	Saipin	60	Single	BA/BSc	Early-retired and unemployed	Mother (88)	Alzheimer’s disease	2	5	1
15	Sasi	60	Single	BA/BSc	Accounting Manager	Mother (89)	Hydrocephalus	8	6	1
16	Sawalak	51	Single	MA/MSc	Freelance	Mother (78)	Alzheimer’s disease	6	3	0
17	Wipawee	57	Married + 2 children	BA/BSc	Own business	Mother (85) (died)	Alzheimer’s disease	9	2	0
18	Yuri	37	Single	MA/MSc	State enterprise employee	Mother (74) w. father	Alzheimer’s disease	2	1	0
19	Zin	45	Single	BA/BSc	Freelance	Mother (73) w. father	Alzheimer’s disease	2	1	1

Notes: Names of participants are pseudonyms; first-round interviews only were conducted with numbers 8, 14, and 16; w. = with another cared-for person

Summary

Age of carers: Age range 34-60 yrs, average age 51 yrs
Marital status: 14 single, 4 married, 1 divorced
Level of education: 5 Master’s degree, 12 Bachelor’s degree, 1 Diploma, 1 High School
Occupation: 5 unemployed, 3 early-retired and unemployed, 5 employed, 6 own business and freelance
The cared-for people: 16 mothers, 1 father, 1 grandfather, 1 sister
Age of cared-for people: Age range 60-92 yrs, average age 79 yrs
Type of dementia: 16 Alzheimer’s disease, 1 Parkinson’s-plus, 1 Frontotemporal dementia, 1 Normal Pressure Hydrocephalus

4.2 Getting to Know Female Family Carers and How They Come to Enact as Carers

The research participants in this study were 19 female family carers with at least one year's experience in caring for their relatives with dementia. All their names have been pseudonymised to protect their identities. Their personal data are presented case-by-case in the form of pen portraits (See the appendix 1 on pages 303-310). In this section, their personal data are summarily presented in Table 2.

Of the 19 participants, 17 female family carers were daughters caring for parents. One carer took care of her older sister, while another participant took care of her grandfather. The age range of female family carers was 34-60 years old. By marital status, 14 carers were single whereas four carers were married, and only one carer was divorced. By education, 12 carers graduated with Bachelor's degrees while five carers had completed their Master's degrees. Additionally, one carer graduated with a diploma and another carer had completed high school. By occupation, five carers were employed while six carers had their own businesses and worked as freelancers. Five carers were not employed, and three carers were early retired. All participants were family carers for relatives with different types of dementia. In terms of relationship to the carer, the care receivers included 16 mothers, one father, one grandfather, and one older sister. Sixteen of the care receivers were diagnosed with Alzheimer's disease. The other three people were diagnosed with Parkinson's plus[4], Frontotemporal dementia, and Normal Pressure Hydrocephalus[5], respectively. The age range of care receivers was 60-92 years with a mean of 79 years. In sum, the typical carer was a woman aged 51 years old, single, educated, employed, and providing care for a mother aged 79 living with with Alzheimer's disease.

The data above shows that most participants were single and lived with their parents. It is common in Thai families that adult children still live with their parents until they are married

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[4] Parkinson's-plus comprises a collection of conditions that cause symptoms like Parkinson's disease as well as other symptoms that may include dementia with Lewy bodies and progressive dementia (Downward 2017).

[5] Normal pressure hydrocephalus (NPH), involves a build-up of fluid in the brain, is uncommon, and typically affects people aged 60+. It can develop after an injury or a stroke and one of the main symptoms is dementia (NHS 2020).

or move out for work reasons. Respondents who were single included Fenda, Sasi, Jan, Rungnapa, Preeya, Zin, Sawalak, Paula, Neena, Yuri, Ratchada, and Saipin. When they were asked about how they came to bear their caring responsibilities, they said that it was because they were single and have lived with their cared-for persons right at the beginning. For example, Jan understood that her marital status brought her into the caring role. Jan said that if she married, she could not have time to care for the mother. Jan explained:

> Jan: Yes. [I am single.]
> The researcher: Do you think that you have come to be carer because you weren't responsible for a family of your own, like your siblings are?
> Jan: That's partly it. So, I have time to care. If I married, I could not have enough time for Mother.

Similarly, Neena told the researcher that she had been living with her parents and youngest brother while her eldest sister was married and lived abroad. Prior to being a carer, she was struggling with a thyroid condition. She needed to rest at home, according to medical advice. During that time, she also took care of her mother with Parkinson's-plus type of dementia, with the view that her mother needed to be assisted closely. That brought Neena into a caring role. Moreover, she understood that gender played an important role in becoming a family carer, too.

> Neena: When I saw my mother's symptoms, I thought she needed someone to take close care of her. So, I became a carer just by chance.
> The researcher: Apart from that, what do you think about your single status or gender? Do you think these things were involved with you becoming a carer?
> Neena: I think they're absolutely related. When people see we are women, they expect that we could be better carers. My single status was also relevant. My brothers were also single. But they might think I should carry out the care because I am a woman.

Except for Neena, no other respondent mentioned gender as a reason that they become carer. Instead, they mentioned their marital statuses, potential financial resources and time, their physical closeness, and their intimacy with their cared-for persons, which enabled them to become the carers. Those conditions seem not to be directly involved with gender. However, feminist scholars (Graham 1983, Chodorow 1978) suggest that caring is embedded and associated with patriarchy or a male-dominated society. The linkage between caring and femininity should not be considered as the simple outcome of sexual division of labour in a domestic sphere like the home (Graham 1983). That said, in gender-divided society, on the one hand, women are allocated the work undertaken within a domestic sphere like the home and family because it might be seen as a place of tenderness and warmth. On the other hand, family is also a place where women are oppressed and struggling under filial obligation as a result of their gender (Graham 1983). Thus, it appears that in order to understand the reasons for women becoming carers we should also consider the unequal distribution of caring responsibilities within the family (Barnes et al. 2015). To understand caring responsibilities, Finch and Mason (1993) suggest that family responsibilities in which family members give and help each other can be understood not as a notion of obligation but as a notion of negotiation. Negotiation is a mechanism by which family responsibilities are generated. It can be done via explicit and implicit discussion. There is a range of negotiation practices, which can be divided into three forms: open discussion, clear intention, and non-decision. In open discussion, family members have clear and direct consultation about what kind of support is to be given and by whom. The family responsibilities are then straightforwardly managed. In open discussion, there are some family members excluded from discussions while some are included. Also, there might be some issues unspoken while some things can be said openly. The second form is discussion with clear intention. In this category, some family members have the intention to provide support for care-receivers but they do not mention the topic directly, since they need to be aware of other relationships involved. This might be implicit rather than explicit negotiation. The third form is non-decision, a situation in which there is no negotiation about which family member would be responsible. By this, family members know implicitly who will provide support, or else the answer becomes obvious over time. However, non-decision might be different from the other two forms of discussion as it seems that women would be obviously taken for granted to take responsibility.

According to Finch and Mason (1993), in the process of negotiation, individuals are developing their commitment in responsibility by being willing to offer and to accept their responsibility and those of others. However, the strong sense of commitment could not be understood by the short period of time over which the needs of assistance arise but rather by the whole lifetime of individuals involved. Given that the commitment is built upon the history of family relationship, the negotiation is then understood in the same way. Within the home, there is an uneven distribution of power, which generates an unequal distribution of resources which could benefit men while women are oppressed (Morgan 1996). That said, gender seems to be a factor forcing women to develop their commitments, but Finch and Mason (1993) suggest that generally individuals do not commit themselves or follow the family obligation based solely on gender. Rather, we should consider social conditions that create the conditions for individuals to develop their commitments of family responsibilities. Following this, with respect to family obligation and caring responsibilities, this thesis is not arguing that men did not engage with caring activities or family responsibilities. Rather, it describes how female family carers came to be responsible for caring activities in a situation in which a negotiation within the family took place. A typical family negotiation about care has two parts. The first part is a negotiation before a decision is made about who should be responsible for the care. The second part is a renegotiation, which happens when the carer feels they need assistance from another family member, a sharing of the previously-negotiated responsibilities.

The participants of this study said that once the cared-for people were diagnosed with dementia, the family discussed medical treatment, but caring responsibilities were neither discussed nor distributed. For example, Sasi said that she consulted her siblings to help make a decision about her mother's brain operation according to the doctor's advice, but these conversations did not include the matter of distribution of caring responsibilities. Nor did her siblings offer her support in caring. Similarly, Neena said that her siblings never talked about division of caring responsibilities. She apparently became a carer by chance. A reflection by Neena is an example of how female family members become carer by chance, as described next.

> The researcher: When your mother got diagnosed, did your family members have a consultation about how and what kinds of things to do?

> Neena: No. We did not distribute our responsibilities. It’s like I gradually came to be the one to provide care.

After being in the role of carer for a while, some respondents felt that they needed some assistance from their siblings. Some of them reported that they used to ask their siblings to help bear the responsibility of care, but their requests were not taken seriously. Sawalak, Sasi and Jan talked with the researcher about their renegotiations.

Sawalak asked her siblings for assistance because she was not able to keep a balance between her own job and caring responsibilities.

> Sawalak: I talked to my siblings many times but the communications failed. Actually, I didn’t want to be a heroine caring for my mother alone. I asked them to help me because I was absent from work too often, and could not deal with my work well. […] They might think that I cared for mother at the beginning, so that it’s up to me to keep doing this.

Sasi had similar experience in filial negotiation.

> Sasi: I used to ask them [her siblings] to come to look after my mother once a week when convenient, but they didn’t make it.
>
> The researcher: So, attempts were made of negotiations, but failed.
>
> Sasi: Um … My eldest brother said he needed to take care of his own business and sometimes he had to pick up his kids. […] So I don’t know what to do. I asked other siblings instead. But again, it’s up to me to pick up the phone to ask them first, despite being very busy with caring. […] Sometimes, I phoned them to tell them about Mother’s symptoms. They listened but said nothing. It’s like I was only murmuring or over-chattering. And sometimes they did not even answer my call. So, it’s like I was disturbing them.

Sasi’s comment also indicated a feeling of dependence, which developed during the process of negotiation. She felt like she was bothering her siblings by asking for help. A similar sentiment was found in Jan's case. Jan used to try asking her younger brother for help looking after their mother, but she received a negative response from him.

> Jan: I asked my brother if he could help me sometimes when necessary. The way he answered me was very tough and rude. So, I did not want to ask him anymore. It would be best if kept quiet, I thought.

4.3 Female Family Carers and Their Intimate Knowledge of the Cared-for Persons

This section discusses the intimate relationships between the carers and care-receivers prior to the onset of dementia with a focus on the female family carers' intimate knowledge of their cared-for persons. Given that intimacy reflects the parent-child relationship that individuals have experienced in the past (Weisskirch 2018), the degree of intimacy appears to vary with gender differences of parent and child. The mother-daughter relationship is more intimate than the father-daughter one (LeCroy 1988) since mothers and daughters are able to talk and share personal things (Solomon et al 2002). Consistent with the gendered division of domestic labour allocated to women, mother's emotion work then involves interpersonal relationships with children to nurture and support children's lives (Barnes et al. 2015, Ungerson 1983) closer than a father does (Lynn 1999, LeCroy 1988). Parent-child closeness can help develop the more reciprocal companionship with parent, especially in same gender parent-child ties. In this sense, Jamieson (1999) suggests that, in many parent-child relationships, intimacy may not be close by talking with each other, but a few words or caring in which emotional connection such as a sense of love, trust, and acceptance could develop.

The degree of intimacy in terms of both physical presence and emotional connections can help understand how family carers provide care for care-receivers (Barnes et al. 2015, Barnes 2006). Okely (1999 cited in Barnes 2012), who cared for her mother with dementia, states that a long-term relationship with the cared-for person along with intimate knowledge is an essential part of providing good care. Similarly, intimate knowledge is considered a useful element of the provision of care, in the sense that such knowledge might be important to the cared-for person's sense of self, as it helps family carers and other family members recognise the previous, valued roles of their relatives with dementia (Purves 2011). Regarding the importance of intimate knowledge, Sabat (2010) suggests that, based on intimate knowledge, carers might also express their caring experiences and the symptoms of people with dementia to healthcare professionals (Sabat 2010). Additionally, intimate knowledge plays an important role in caring in the sense that it enhances care giving. That is, such knowledge enables the care-receivers to be treated more respectfully and gain proper care in accordance with their socio-cultural conditions (Barnes 2006). Regarding this, this study gives voices to the female family carers' stories of their long-term relationships with their relatives living with dementia prior to dementia care provision, so as to explore the intimate relationships and intimate knowledge that carers had.

In this study, the collected data shows that most research participants spoke of having a positive intimate relationship with the person being cared for. By positive relationships, they refer to 'the good old days' reflecting the happiness and memorable events that carers and their care-for persons had together prior to the onset of dementia, including the benefits they received from them. The experiences of Zin, Neena, Koong, and Manee are examples here. Zin spoke of her good memories of her mother and the intimacy developed from mother's emotional support. Her intimate knowledge gained from the felt intimacy was used as a tool to understand her mother's symptoms of dementia. From her understanding, the symptoms came from negative emotions that had not been released for years.

> Zin: We're close to each other. I remembered that my mother was so kind and gentle. To me, she was like an angel speaking with a soft voice. I can feel it.
> The researcher: Have you ever thought about what made your mother get dementia?
> Zin: She tried to keep her anger inside instead of confronting those who made her feel bad. […] So, I guess that it was because of her negative emotions that were never released.

Zin's comment suggested that intimate knowledge of her mother played an important role in making sense of the mother's dementia. Suggested by Jamieson (1999), intimacy in many parent-child relationships may be close by caring that helps create the emotional connection. Similar to Zin, the intimacy that Neena felt towards her mother rested on her mother's caring.

Neena knew about her mother’s common activities and valued role prior to having dementia. Then, her memory made her aware of and know how to give attentive care to her mother.

> Neena: Since my mother married, she hardly had any social activities of her own. Her time was devoted to the benefit of others. She didn’t have friends. Her closest friend was her sister. […] If I didn’t take her outside, she would never go anywhere.

Unlike the cases of Zin and Neena, Koong had intimate knowledge toward her sister living with dementia. Intimacy of sibling relationship can be characterised by closeness (Yeh and Lempers 2004) in which it can be sometimes higher than their parents. Their closeness and intimacy are learned from the activities such as playing and arguing (Edwards et al. 2006), and developed by emotional support and sharing their views alongside assistance to deal with problems (Cicirelli 1995 cited in Yeh and Lempers 2004). Moreover, the relationship of same-gender siblings seems to engender a higher sense of companionships than that of different-gendered sibling (Cole and Kerns 2001). In Koong’s case, her intimate knowledge seemed to be developed from having shared experiences of home violence. Koong understood that her sister’s dementia was developed because of volatile home life as a child, which affected her emotional state. Moreover, Koong used her intimate knowledge to provide emotional care to her sister skilfully. She explained how to deal with her sister’s behaviour by respecting the personhood of her sister below.

> Koong: I guess it’s because she experienced our parents’ quarrels since she was a child. She kept them in her mind since then. She thought that mother didn’t love her. My sister needed someone to be fond of her. […] I listened to what she wanted to say to me. But I won’t say something back, I’ll just listen. She liked to have someone listening to her. That made her confident.

Regarding the effects of intimate knowledge, the previous comments suggested that the presence of intimate knowledge was a resource used to understand their relatives with dementia. Conversely, some respondents reported that they had less intimacy with their parents, and thus they hardly had any knowledge of them. When asked about how their long-term relationships were in the past, some of them told the researcher of their poor relationships. Moreover, they revealed that they hardly had any ‘good old days’ with the cared-for person and could not recall any good memories. Manee is an example here. Manee had an unhealthy relationship since her childhood with her parents, who lived in a rural area for years, and so Manee did not have close physical connections with her parents. Physical distances influenced the feeling of intimacy and her intimate knowledge of her mother. So, when her mother moved to live with her after being diagnosed with dementia, Manee felt like there was a two-layered wall between her mother and herself. The first layer was how she felt unfamiliar with her mother (a child-parent relationship). The second one was the difficult nature of knowing someone with dementia. Manee did not use terms relating to ‘carer’ or ‘care-receiver’. She treated her mother by guessing what her mother needed in the absence of intimate knowledge. Manee reflected:

> Manee: We [Manee and her mother] have not lived together since I was a teenager. So, we are sort of strangers to each other. […] And my mum always made men the superiors. She valued her sons, and all men more than the women.
>
> The researcher: Then, is it hard to care for your mother?
>
> Manee: V…very hard. We started from zero to get to know each other. In our relationship, we learn to know each other in two types (two-layered wall). I would say I did not know her, or even understanding what she was trying to communicate to me or other people.

As described, the difference in degree of intimacy which was embedded in a good or bad emotional connection provided intimate knowledge, which the carers used as a resource to understand the behaviours of the cared-for persons, and find the appropriate ways to care for them. Intimate knowledge appears to influence female family carers’ understanding of repayment (see Chapter 5) and reciprocation from the cared-for person (see Chapter 6), and their motivations to care (see Chapter 7).

4.4 Female Family Carers and Their Caring Activities

Although this thesis focuses on the issue of reciprocity in dementia care, it is helpful to describe what the female family carers do in their caring tasks and what they have faced in their caring activities. Significantly, this is to uncover women's experiences, to make them visible and enable the voices of female family carers to be heard in wider society, which are things on which a feminist ethics of care and the feminist methodology put an emphasis. Particularly, when it comes to care and a feminist ethics of care, caring activities have been paid little attention by wider society and need to be addressed (Held 2006) since they are performed to sustain others' well-being and even their survival (Barnes et al. 2015). Moreover, since home is a site of the construction and reproduction of patriarchal relation, the demonstration of women's activities in domestic sphere helps reveal gendered power relations which impact women's identities and their lives (Bowlby 1997, Morgan 1985).

This study's exploration and exposure of the female family carers' experiences in relation to care activities are described in two parts. Firstly, their activities of care are discussed as being a practice. The activities are described along with the aspects of carers' lives that were affected as a result of their care giving, along with their knowledge relating to and gained from care activities. Secondly, their activities of care are discussed in association with their emotions, in the sense that care is emotion work in which carers manage the emotions of the cared-for persons and their own.

4.4.1 Care as Practice

Range of Caring Activities and Intensity of Tasks

As discussed in Chapter 2, the types of care activities provided to people with dementia (Parsons 2001) vary at different stages of the disease (Huang et al. 2015). When symptoms are developing and affecting daily activities and individuals therefore may need assistance, carers are likely to encounter many difficulties. Carers need to closely observe the behaviours of their relative with dementia, whilst providing assistance with their personal daily activities such as dressing and bathing. Thus, it appears to be difficult for carers to have time for themselves (Gruetzner 2001). Although the amount of time to assist the daily living activities of people with dementia varies in accordance with different stages of the disease (Huang et al. 2015), caring can be a 24/7 duty. Given caring is 'boundless' (Pickard and Glendinning 2002 cited in Barnes 2006) and non-stop in the sense that there may be spontaneous circumstances that must be dealt with at any time, carers may have few or no intervals between needing to go to help (Barnes 2006).

In Aurapa's case, she spent her days and nights caring closely for her mother with dementia. She confessed that, apart from her younger sister, she herself was the main carer doing almost all types of care activities. Aurapa described her caring activities as follows:

> Aurapa: I care for my mother from top to toe. Colouring her hair. Cooking for her meals. Her clothes. Managing the continence care. Bathing and then wiping her toes until they are all dry. In the night-time, I help her to wear an incontinence pad. I get everything done until half past midnight. I sleep around at 1 a.m.

Likewise, Fenda cared for her mother with dementia almost 24/7 since her mother could not manage her personal daily activities. Fenda was the only person whom her mother felt comfortable staying with and accepting help from with personal bodily activities such as toileting and cleaning.

> Fenda: Three meals. Having a shower. Toileting. Bringing her to bed and sleeping with her. All of these are what I do to assist her because she doesn't know how to do it for herself. She doesn't know how to go to the toilet. […] I can't stop keeping an eye on her because she might lose something. She used to put a coin into a glass. It's not safe.

The extracts by Aurapa and Fenda illustrate obviously that their provision of personal care inevitably involved touching parts of the body of care receivers, even the most private part like genital area. However, it could not be explained simply that the bodily care was possible due to same-gendered provision of care and intimate ties. Twigg (1999) suggests that since the human body has structured ordering of privacy, the different parts of body may be touched by different people due to the closeness or intimate relationship. And, it seems to be women's work since the women are taken-for-granted as naturally linked to bodily processes such as reproduction, menstrual cycle, and childbirth which bring them to stand for the body (Twigg 2006). In addition, according to Tronto (1993), in western histories, the activities of care giving belong to powerless and subordinated people such as working class, servant, slaves, and of course women since such activities involve dirtiness and waste that do not require skills to do. Given women are accepted to deal with bodywork and body waste, body care is then gendered (Twigg 2006). Following this, although the care activities as Aurapa and Fenda performed such as changing incontinence pad and helping the care recipient to toileting might be seen as the body intrusion, such activities are done to serve other's needs which are involved with other's privacy and cleanliness. In this thesis, it can be said that all of female family carers provided the body care. Additionally, they had to do other activities of care as described as follows.

Saipin, having two sisters to help with care, said that she cared for her mother in the daytime while her older sister stayed with mother for the night-time care. Her main activities of care included preparing meals, bathing, and driving to see the doctors. She also said that when her mother took a nap during the day, she did not have time to relax because she needed to keep the house clean. Keeping the house clean seems a simple activity but, to Saipin, it was very significant since it was associated with her mother's health and safety.

> Saipin: In the daytime, it's my turn to do all tasks thoroughly. Preparing the meals, for example. And, when my mother took a nap, I couldn't relax though. I need to keep the house clean and mop the floor. A dusty floor might mean she slips when walking. It's not safe when my mother was using her walker.

The previous cases showed that the care activities undertaken ranged from personal care to safety concerns related to the cared-for person. Actions to prevent accidents and health issues might be invisible tasks but are an important aspect that most of the female family carers recognised. In this respect, Seal (1996 cited in Payne and Ellis-Hill 2001) suggests that in providing care, family carers are involved with two kinds of activities. Namely, they need to reduce risks such as keeping an eye on their cared-for persons, while also needing to maintain their independence of them.

In relation to time spent on caring, Anchalee viewed herself as the main carer whose routine tasks consumed many hours of her day. In her view, her husband could not understand why such activities took so much time. Anchalee explained:

> Anchalee: I wake up to prepare breakfast for my parents and son. After that, I take care of my mother's medication. […] Also, I am the one bringing my mother to the hospital, and talking with the doctor too. I am not sure if I can manage all these things. My husband can't understand what I've been doing when I come back from caring. He asked me why I spent so much time caring.

During an interview with Anchalee, she told the researcher about her feelings of frustration and isolation which meant she sometimes needed somebody to talk to. On this subject, Payne and Ellis-Hill (2001) suggest that carers' feelings of frustration and unreleased pressures could lead to their negative emotions around family care. These psychological effects of caring are discussed later.

In the data presented as follows, the researcher aims to describe the care activities alongside the caregiving burden that female family carers faced so as to provide a broader understanding of female family carers' experiences. For family carers of people with dementia, the range and intensity of care activities alongside time-consuming tasks have a great effect on them (Gruetzner 2001, Twigg and Atkin 1994). Also, the number of hours spent in caring could be a huge burden for carers (Chappell and Reid 2002 cited in Bastawrous 2013). A lack of time for themselves to relax, to do their own daily activities, and to care for themselves leads to feelings of stress, exhaustion, and poorer health conditions. Conversely, carers who have time to take care of their health and well-being are likely to be able to cope with their caring responsibilities (Yeandle and Wigfield 2011). However, similar to caring in general, the term 'carer burden' (Bastawrous 2013, Blom and Duijnstee 1997) has been used to describe the effects of dementia on the carers. There is no consensus on its definition and the term also seems to be multi-dimensional and varies according to the types and intensity of care required (Bastawrous 2013). However, burden could be distinguished as either objective burden or subjective burden. The former refers to time spent caring, whereas the latter refers to the carers' physical and psychological wellbeing (van Der Lee et al. 2014, Montgomery et al 1985 cited in

Bastawrous 2013). However, due to providing care, many facets of burden that family carers experience include physical problems, psychological problems, emotional stress, social and financial stress (van Der Lee et al. 2014, Bastawrous 2013, Andrén and Elmståhl 2005). Each condition can influence another. For instance, inadequate sleep can impinge on physical health. It might also worsen psychological conditions such as more intense feelings of isolation (Yeandle and Wigfield 2011, Payne and Ellis-Hill 2001).

All the female family carers in this study experienced physical effects resulted from caring. A variety of physical manifestations were found in the cases of Aurapa, Neena, and Anchalee as examples. According to Aurapa, caring for her beloved mother was her dedication, but the only one thing she needed most was more time sleeping without interruption, because lack of sleep produced health problems in her.

> Aurapa: If I didn't get enough sleep, I get stressed and a headache. My lips get swollen too. What I need is just the time to sleep fully.

In Neena's case, she was almost wholly responsible for the caring tasks regardless of the degree of privacy in caring. That said, she had to do body care for her mother, not only because she had a very close relationship with the mother, but, as discussed earlier, because body care is perceived as gendered work (Twigg 2006). Whether care activities involve body care or not, the caring tasks for family members in a private sphere like home is still seen as gendered work as it is seen as women's responsibility. Then, provision of care has effects on female family carers. Neena is an example here. Her comment illustrated her lack of personal time. Moreover, spending all of her time on care activities caused the difficulties with her own personal physical activities, namely a problem with constipation. Neena said:

> Neena: After leaving the hospital in the last few months, my mother's health declined. She needed assistance with feeding. I have to help her with genital care, bathing, brushing teeth, dressing, driving and accompanying her to see the doctor, and preparing meals. I couldn't leave her alone even though I need to go to the toilet. So, my bowel got strained for many days.

It appears that caring could affect the health condition of female family carers. In this respect, Gruetzner (2001) suggests that if carers have age-related health concerns which are sensitive to stress such as hypertension, migraines and bowel problems then caring might worsen these conditions. In this thesis, some female family carers who had their own health problems reported that their health concerns increased when performing extensive care activities. For example, Anchalee, who was living with a stroke condition, explained that her own symptoms would flare up when she felt stressed from dealing with caring activities.

> Anchalee: When she [Anchalee's mother] resisted, I got stressed. My head was tight. If I didn't release the stress, I'll get a headache and neck pain. My doctor said my symptoms would occur when I felt strained.

Similarly, Neena talked about her experience of doing non-stop care activities, which aggravated her thyroid condition.

> Neena: There are times that I am so exhausted. I told my brother that I couldn't stand it anymore. I felt foggy and unfocused.

Some female family carers described their psychological and emotional health problems as the consequences of providing care, for example, feelings of stress, frustration, anxiety, depression, and emotional instability. Anchalee confessed that she felt so stressed that she screamed in front of her parents. For her, screaming was a way to help reduce the strain.

> Anchalee: There's a time that I slammed the door and screamed. And, they [Anchalee's mother and father] knew that I was burnt out. My father said to me, 'Do you have hysteria?' I wondered why he said it to me that way. I told him that I do know what I'm doing.

Anchalee explained that her screaming was a reaction to the accumulated and hard-to-release pressure. Similarly, Zin confessed that she could not find any way to relieve her pressure. Crying was the only way she could help herself find relief.

> Zin: There came a time that I realised that I was too depressed. I went to my car and screamed in there. Nothing could help me at that moment. The only thing I could do to help myself was to cry to let my pressure out. I wondered why it fell to me to care for other people. I would be alright if there was someone caring for me or to give me a hug. But there was nobody. I had to hug myself, then.

Likewise, Paula thought that she could endure her difficulties in caring. In fact, she did not realise that performing the care hugely affected her psychological health.

> Paula: The time that I came to realise that I was too exhausted was when my friend asked me a question: 'Are you doing okay?' I answered her, 'It's very tough but I think I am still able to do it all for my father.' But then, I cried.

A few carers found financial difficulties and limitations whilst undertaking care activities. They found it hard to work a full-time job or even to look for a part-time job. Some of them needed to change their careers to part-time jobs. Some of them did not have part-time jobs but they were paid or assisted financially by their siblings as compensation for caring for their older parents. However, the female family carers did not want to be financially dependent on anybody. They needed more time to earn by themselves. Having their own jobs was simply not possible because their time needed to be devoted to caring activities. Some comments by Neena, Anchalee, and Koong related to financial difficulties and job concerns.

In Neena's case, when asked about work, she said that there would be a job relevant to her qualification, but the problem seemed to be the time and concentration she would need to devote to that job. Thus, she stopped thinking about getting a job since she saw that her mother needed someone to care for her. Neena explained her difficulties in undertaking academic part-time work as follows.

> Neena: This kind of job needed consistency and a lot of time to concentrate. When it comes to deadline [of submission], I felt frustrated because I needed to take care of my mother as well. It's quite hard. So far, I couldn't have any job because I couldn't make a balance between work and care.

Anchalee was in a similar situation. She hoped to have an ice-cream café as a source of income after she had quit an earlier job because of her health concerns, but she found it difficult to do that due to the time she spent caring. She did not have as much time left for the café as she wished.

> Anchalee: When I am in this role [caring for her mother with dementia], I feel I couldn’t start doing something new for myself. […] I want to have my ice-cream café that opens from 11 a.m. to 3 p.m. But I couldn’t actually do that. Caring eats up my time.

This was a situation that Koong also faced. She would have liked to have her own job but recognised that she was the only one in the family caring for her older sister with dementia, because her eldest sister got married and also got dementia. Thus, she found it hard to start a job of her own. The expense of caring was paid for by her sister’s saving account, which her sister had funded from her salary. Koong did not dare to use that lump-sum for her own sake. However, regarding the difficulties of financial resources and job seeking, some family carers seemed to be forced into a financial dependent status. This issue is also described in Section 4.6.2 relating to conflict between carers in the family.

Knowledge and Skills in Care Activities

The previous section discussed the activities of care, which often involved very long hours of labour and influenced the female family carers in various ways. This section focuses on care activities in relation to female family carers’ use of their knowledge when providing care. Carers’ knowledge, which is also defined as local knowledge (Harvath et al. 1994 cited in Sheldon et al. 2001), refers to skills and understanding that carers gained from their experiences in managing caring situations. Therefore, areas of knowledge include knowledge of the cared-for persons, their needs, and caring activities (Sheldon et al. 2001). These areas of knowledge are developed as part of a family relationship. (A carer’s intimate knowledge as part of a family relationship is also discussed in Section 4.3.)

During interviews, the things the family carers told the researcher about what they did in caring indicated their various skills. In the case of Preeya, she realised that the trajectory of dementia is irreversible, therefore, she attempted to maintain her mother’s abilities as much as possible.

> Preeya: If there's something she could do by herself such as eating, I tried to let her do it herself little by little, and I kept watching over. I think this could help keep her ability as long as possible.

Based on her understanding of dementia, Preeya reckoned that her mother still retained certain abilities, so she considered how she could provide appropriate care for the mother. The way she cared implied a creative way of caring which helped sustain her mother's capacities longer and helped to avoid making her mother more dependent. In this respect, Gruetzner (2001) suggests that carers may attempt to provide everything they could to help the care-receivers remain functional. Seals (1996 cited in Payne and Ellis-Hill 2001) also suggests that carers appear to be in an ambiguous position. That is, on the one hand, carers' support might create dependency in the cared-for persons. On the other hand, carers need to maintain the independent status of those cared for at the same time. In such circumstances, carers need to have creativity and imagination when undertaking care activities so that the dignity and personhood of the cared-for persons are preserved.

With respect to retained ability, Yuri noticed that her mother still had the ability to feed herself. Yuri reflected that she did not agree with the way of care taking place at her mother's hospital, which seemed to overlook the abilities of her mother. Her mother was given liquid food despite having the ability to eat. Yuri viewed that this way of care did not help her mother to maintain the ability of bodily function. Thus, when leaving the hospital to home for recovery, Yuri supported her mother to exercise her eating ability for as long as possible.

> Yuri: My mother's hand muscles are still strong enough to use a spoon. And she can chew. So, she won't need liquid food.

Some carers applied their knowledge developed throughout their lives to their caring. Aurapa applied her cooking skills, which she had learned from a cooking course. In preparing meals for her mother, Aurapa was always aware of food nutrition. In the following comment, she proudly discussed her cooking techniques, which helped her mother's health to remain high.

> Aurapa: I never use oil if it's not necessary. My fried pork is cooked with water, not with oil. The pork is softer so my mother can chew. It's healthier also.

However, some activities of care are not obviously visible and are not performed straightforwardly. This type of activity is associated with support of the care receivers' living conditions and involve other forms of caring. Such activities include seeking additional information in relation to symptoms, medical treatment, and care. These kinds of information are the things that the family carers would like to know (Gruetzner 2001). Furthermore, Gillard and Rabins (1999 cited in Gillard 2001) have identified six areas of information needed by family carers: diagnosis-related information, prognosis-related information, information on effective tools to provide care well, information on social services who might be able to assist, information on financial matters, and information on legal matters. It can be said that these activities inevitably require carers' skills and knowledge. Carers need this information to plan their care giving and manage their coping strategies toward challenging situations (Yeandle and Wigfield 2011, Smith 2001).

Regarding carers' knowledge in relation to the six areas of information discussed previously, Neena and Ratchada spoke about the ways they looked for other information relating to their mothers' symptoms and the medical treatments with their side-effects. These activities required their accumulated experience derived from their past knowledge and caring experiences. In Neena's case, she reflected that she looked for a second opinion so that she could be sure of the most effective treatment for her mother. In this respect, looking for additional information via the Internet, such as medical treatments and medications, is considered to be a caring activity, which required Neena's skills to handle and prepare the care plans. Neena explained:

> Neena: A doctor prescribed some medicines for liver treatment. After taking those medicines, I noticed my mother's skin turned black and blue. After that, I looked for a second opinion. I do need more advice about using medication and the effects.

Likewise, Ratchada shared her experience relating to communication with doctors and seeking effective medical treatment. Her activities were important caring activities that required her skills of communication and management. In addition, Ratchada explained that she had some tactics for contacting the doctors that involved using an Internet application called 'LINE'.[6]

> Ratchada: Nobody dared to ask for the doctors' LINE accounts, but I did. When there's something wrong with my mother such as her insomnia, I can consult them through LINE. In doing so, I need to be well prepared, though. The prescriptions and appointment letter must be in my hand.

In Manee's case, she also looked for effective methods and other health information via the Internet to help boost her mother's cognitive capacities. She wanted to have a consultation with doctors. These activities also required her comprehensive competence.

> Manee: I tried to search for information about how to deal with the unusual behaviours of people with dementia. I also asked the doctor and told him I was so tired from my mother's unusual behaviours. Then, the doctor prescribed a new medicine for her, but the medicine didn't work. What I actually needed from him was information, but he didn't explain it in detail.

Some respondents also shared their activities in relation to financial accounts, which certainly needed their skills of management and planning. Financial planning in relation to caring is an important issue recognised by the family carers. An obvious example in this study is Koong's case. Koong was concerned that money to be spent on caring was running out. And, her sister, who had dementia, could not make the withdrawal herself. She realised that there could be any uncertainty in life. Thus, she hoped to manage everything properly beforehand as much as possible.

> Koong: I am planning to manage everything for my sister. I was looking at the process of being her power of attorney to manage her savings, which will be used for her survival.

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[6] 'LINE' is a messaging application offering its user a way to call and text. It is the most widely used in Thailand, and other countries in Asia. (https://en.wikipedia.org/wiki/Line_(software)).

Koong’s experience indicated that dementia care also involved financial and legal matter. While those with dementia may lack financial ability in some areas but may retain abilities in others, they need their family carers to support their decision-making and probably do the financial management on their behalf (Boyle 2013, Jacoby 2006). In this sense, Shrestha et al. (2011) also suggest that financial and legal services are needs of people with dementia and family carers. Notably, both those with dementia and their carers need to prepare power of attorney to take care of their financial needs, and also future health (Jacoby 2006, Shrestha et al. 2001). In this respect, managing well in financial matters could help the family carers undertake care with confidence (Yeandle and Wigfield 2011).

This section about care as practice shows that female family carers performed a broad range of care activities that were intense and very time-consuming. The care activities ranged from personal care to other kinds of care such as talking to the doctors or searching for necessary information. These activities illuminate the significance of their activities of care as well as their caring roles, during which the female family carers experienced physical, psychological, and financial problems resulting from performing those care activities. Additionally, the results of this study indicate that there are skills and certain knowledge that female family carers are investing in their care activities. Their knowledge could also help them feel confident in undertaking care (Yeandle and Wigfileld 2011). For this reason, caring is not a simple activity or to be taken for granted. Care is performed not only in terms of practice or labour. Rather, care also appears to involve emotional work. This is described as follows.

4.4.2 Caring as Skilled and Emotional Labour

In order to better understand female family carers’ experiences, we might consider the emotional aspect of care since caring is involved as much with emotion as it is with physical activity and they are present in caring together (Twigg and Atkin 1994, Tronto 1993, Graham 1983). Caring enacts itself as a form of emotional labour (Twigg and Atkin 1994, Hochschild 1983, Graham 1983). Moreover, the emotional element of care is similar to the physical element, in the sense that they both are hard work – carers devote themselves to labour in the form of provision of care that involves personal issues (James 1992). Caring appears to be understood as ‘unskilled’ work and women’s work since it deals with emotion in which it was underestimated and devalued according to dualism thoughts in Enlightenment (Burkitt 1994) where rationality is over the emotion. However, in feminist ethics of care, caring is a labour of love as women provided care for their family members distinct from ‘instrumental relationships’ (Graham 1983). Women invest and apply psychological qualities such as sensitivity, empathy, compassion (Miller 1976 cited in Graham 1983), sensitivity for the needs of others, the ability to watch over someone, waiting, and ability to adapt the way of providing care when any needs arise or any situations change (Parker 1981 cited in Graham 1983). Therefore, regarding the notion of caring as a labour of love, caring requires both love and labour in which women as family carers use psychological qualities and abilities of emotion management in their care activities and in dealing with difficulties in care giving.

In emotion management, according to Hochschild (1979), there are three different techniques that may go together to make help ease the individual’s feelings during their present situation. The first one is the cognitive technique, referring to changing thoughts or ideas along with the actions involved. The second one is bodily technique, such as trying to breathe more slowly. The last one is expressive technique, through which the individual tries to shape their inner feelings and express them in the proper manner, such as smiling towards the cared-for person (Hochschild 1979). In shaping or managing emotion, the individual’s skill in dealing with difficult circumstances, such as the inappropriate act of shouting at a baby to stop it crying, is essential for effective emotion management, since the outcomes of emotional labour might depend on how the skills are used to manage the situation. Likewise, to tell people with Alzheimer’s disease that there is something wrong with their cognitive capacities should not be done directly, but rather needs some skill to handle appropriately (James 1992). The experiences of Ratchada, Fenda, Paula, and Zin are the examples of care as emotion work.

Ratchada did not want her mother to feel depressed. When her mother asked about her father who had passed away, Ratchada told her that he was doing fine. For Ratchada, it could be worth telling a lie to help maintain her mother’s positivity. Ratchada’s technique reflected her skill of emotion management in caring in which she wished her mother to feel good.

> Ratchada: When she asked about him, I told her, ‘He’s 102 years old now and he’s doing fine. If you [the mother] get stronger, I’ll bring you to visit

> him.' I needed to tell a lie. I must keep the truth hidden, if necessary. And, I tried not to interrupt her good mood. I just follow her.

Regarding emotional work in relation to managing the mood of people with dementia, Ratchada managed her voice when talking to her mother. During the researcher's interview with Ratchada, Ratchada needed to take a phone call and talked to her mother on the phone with a very soft tone of voice. Ratchada told the researcher that when she needed to be outside for meetings with customers, for example, she often received a call from her mother. Ratchada also tried to keep in touch with her mother since she did not want her mother to feel abandoned.

> Ratchada: She clings to me very much. If I need to go outside to meet customer, for example, I need to speak with her on the phone, very often. Otherwise, she might think that I abandoned her. I need to be aware of her mood.

For Fenda, her mother needed to stay close with her almost all day. Fenda confessed that she has never had her own personal time, even time to enjoy a shower, which were limited to only ten minutes. Her mother often looked for her and knocked on the door of the bathroom. Fenda would attempt to make her mother calm down by shaping her own emotion first. She found it was not easy to keep a balance with her own feelings and her concerns of her mother.

> Fenda: When I have a shower, I need to do it in a hurry. My mother often calls my name, 'Fenda, where's Fenda?' I said, 'Hold on, mom. I'm in the shower. I'll be with you shortly.' She knocked the bathroom's door and tried to open to check if I was in there. Sometimes, I wondered why I couldn't have five minutes for myself. I know it was because of her symptoms. But sometimes, I'm trying to manage myself from getting in a bad tempered.

Paula shared the responsibilities of caring for her father with her older sister. Paula undertook all kinds of care. With respect to the emotional aspect of performing caring activities, she spoke about her techniques for changing her father's interest level and coaxing him into bathing.

> Paula: He refused to have a shower. He's just undressing and then getting dressed in fresh clothes. (*Laughing*). I need to notice what he likes. He liked playing with the body powder. So, I try to coax him to the bathroom by telling him that, 'Let me help you bathe, then you can have powder.' He's now like a kid.

Paula's comment indicated clearly that emotional aspects of care need to be performed alongside care as practice. By undertaking emotional work, she learned how to handle her father's emotions and behaviours by trial and error, which provided some techniques for caring. Paula accepted that emotion seemed to be a significant channel that her father was able to perceive the most. Then, she tried to manage her mood to be calm enough before caring for her father so that he would match her tone.

> Paula: It's like a mirror. If I tell him something in a rough way, he will get angry right away. So, if I treat him in the same way back, the situation will be getting worse.

In the case of Zin, she believed that her mother's unreleased emotions might be a cause of her dementia. Sometimes, when her mother displayed some aggressive behaviours such as clawing, Zin just let her mother do it. Zin learned that the angrier she acted toward her mother, the angrier her mother felt. Thus, Zin found that using logical thinking was not helpful in a caring situation. Zin's sympathetic reactions worked to help her mother feel calm. Moreover, acceptance and understanding of her mother's symptoms could help the situation ease.

> Zin: If I think logically, I get stressed. I used to cry, not because she hurt me, but because I don't want to see her suffer. I let her release what she felt inside. Have a look, Kim [the researcher's name]. Here I got 8-9 wounds when she clawed at my skin. [Zin showed her scars.]

The four cases of female family carers previously discussed are examples of care as emotional labour, and illustrate that family carers need to control their own emotions as well as needing to manage the emotions of others (Morgan 2011). In doing so, the feeling of love and concern of family carers alongside their skills and creativity were used to provide benefits for their cared-for persons and sustain their lives.

4.5 Contribution from Friends and Acquaintances

In view of the concept of family practice discussed in Chapter 2, family practices could be done by persons beyond blood relatives but having anyone who is family-like person and has intimate relationship (Morgan 2011, Smart 2007), the fieldwork data in this thesis showed that some respondents received regular support from their non-relatives, namely their friends and acquaintances.

In the case of Manee, she said that none of her siblings came to visit her mother with dementia, so Manee was the only adult child whom her mother could live with at that time. In her caring, however, Manee has a helper who used to work as her housemaid for more than 20 years. After having to take early retirement, and alongside the uncertainty of the financial cost of her mother's care, Manee could not pay for the housemaid's wage. Despite that, the housemaid was allowed to continue co-habiting with them. The housemaid, who found another job, still assisted Manee in caring for her mother with dementia, and also everyone else at home, without receiving any wage.

> Manee: I have my housemaid as my helper. She's not my relative but she's like a family member to me, actually. She helps me keep an eye on my mother and sometimes gives me suggestions about what to do. She knows me well.
> The researcher: You felt like you can count on her support.
> Manee: Yes. She has her own job, and still helps me take care of everyone at home. Every day, when she comes back from her job, she brings some food for everyone at home.

In the case of Koong, she was supported by her sister's close friend, Krit, who usually came to provide care for Koong's sister every Tuesday. Koong said that although Krit got married, he has been coming to see Koong's sister because they were both close friends for several years prior to the onset of her dementia. For Koong, he was also like a significant other whom she was able to consult or ask for any help whenever she needed.

> Koong: He's well educated, so he comes to read some books for my sister. And, he always lets her do what she wants. So, my sister has always been happy.

In the two cases above, the support given by non-relatives rested on the social relationship and intimacy developed over a long period of time. Their support was regularly performed in a family-like spirit, which meant that the identities of the non-relatives were blurred once they were involved with caring. In other words, the family-like activities performed by them could establish and develop identities of family members for them over a long period of time.

4.6 Family Involvement in Dementia Care: Concerns and Conflicts in Caring

Prior to data collection, the researcher understood dementia care at home to have a focus on the people with dementia, with an emphasis on the caring relationship between the carers and their cared-for persons with dementia. In fact, according the fieldwork data of this study, home-based dementia care, like other types of caring, is also family care. That is, as a family practice, caring is a practice that individuals appear to manage the emotions of family members, and also to prevent conflict in family (Morgan 2011). The fieldwork data findings revealed that in providing care for their relatives with dementia, the family carers also had to involve others in the family care. Having said, there were the concerns towards the other in family that involved. Meanwhile, they often encountered conflicts that emerged in the process of providing care (Zarit and Zarit 2010).

4.6.1 Concerns Towards the Others Involved in Family

The collected data indicated that dementia care at home does not only refer to the caring relationship between family carers and the cared-for person, but is also associated with other members of the family. In this study, the latter refers to the feeling of concern that emerges in some caring situations. Feelings of concern are explained alongside the situations that female family carers needed to handle when they cared for other members of the family, as described as follows.

Ratchada had a younger brother who could provide financial support for the provision of care for their mother. She said, her brother was very concerned that care work might affect her life in terms of income, her friends, and social activities. She was, in return, concerned about her brother's feelings and emotion because he seemed to be very sensitive. Sometimes, when he came to interact with their mother with dementia, he got stressed and felt unhappy. Therefore, Ratchada found it harder to deal with the brother's attitude and emotions than she did her mother's.

> Ratchada: After she got dementia, my mother used to curse my brother. 'You're a damn son!' She did it without knowing. But when he heard that, he was sad. He loved mum very much. I had to console him. 'Be calm, dear'.

Ratchada's brother thought that what the mother said was unreasonable. In Ratchada's view, her brother did not understand the behavioural changes of people with dementia well enough. She needed to give him suggestions on how to deal with their mother's behaviours and moods.

> Ratchada: I told him, 'Our mother got sick. Just say sorry to her. You can pretend that you're performing a play with her or telling a lie to her. It doesn't matter who's right or wrong. You won't lose anything if do that.' Then, when he did, my mother seemed to become calm.

Likewise, Sawalak was concerned about her niece, who helped her to care for Sawalak's mother with dementia. When alone with the mother, the niece had no idea how to cope with the challenging behaviour of the mother who often used a wooden cane to knock her own head. In this difficult situation, Sawalak saw signs of her niece's stress. Her niece would self-abuse by taking the cane to knock on her own head just as the ill mother did. Her niece's behaviour showed a degree of stress that resulted from dealing with the unusual behaviour of the person with dementia. For this reason, Sawalak suggested her niece to walk away from such a stressful situation.

> Sawalak: When I came back home, I saw my niece knocking her own head with a cane. I know she got stressed. So, I told her, 'Don't do it that way. If

> you are not alright with grandmum, you just walk out.' I don't want my niece getting mad.

Similarly, in Yuri's case, she was afraid that when she went to work, her father might be exhausted from taking care of her mother with dementia the whole day by himself. She thought that her father, at his age, should also be cared for, not a carer. Yuri shared her deep concerns with tears in her eyes and said that she wished to take better care of her parents. She was planning to gain some tools to help her and was looking for a paid helper to reduce her father's exhaustion, but she was not certain if she could afford to pay for the cost of a helper.

> Yuri: I am thinking of looking for some tools or someone to help so that my father will not be too tired and get weaker. For me, he's very old and should not need to deal with caring tasks that hard. For example, he helps my mother to toilet; I think it's hard for him. And, you know, my father does it every day.

4.6.2 Conflicts Between Carers and the Others Involved in Caring

In relation to family care, caring practices as family practices are associated with family disputes in which individuals attempt to manage their own emotions in order to manage the emotions of family members, and attempt to prevent conflict from rippling out (Morgan 2011). The researcher describes two conditions from which conflicts developed. The first condition is the differing ways of caring. The second condition is the power balance between carers.

Different Ways of Caring

Neena had some conflicts with her younger brother about providing care for mother. On one occasion, she had been up from midnight to 5 a.m. dealing with the consequences of having to give her mother a laxative. Afterwards, she asked the brother to wake her up in the morning to prepare the mother's breakfast according to strict nutrition advice from the doctor, but he did not. He prepared the food for their mother on his own. This situation created a misunderstanding and conflict between them. After their quarrel, her brother walked away to his flat while Neena was left to take care of their mother alone as usual.

> Neena: The doctor advised us to reduce her sodium intake. I reiterated to him that he should have woken me up so that I could make the meal for Mother on my own. We argued back and forth. Then, he packed his stuff and went to his flat. He's kind of waspish.

In Sasi's case, she talked about the conflicts she had with her brother about continence care. Sasi felt that his advice was not the proper care, since it might lead to an infection, but she did not argue with him about it.

> Sasi: My older brother visited my mother sometimes. When she sat and peed, he did not notice what she was doing, so he didn't come to help her. […] He told me she should wear an incontinence pad all the time. But you know, it's smelly and not good for air flow.

In the case of Koong, she had some conflicts with Krit, a close friend of her sister. One of their conflicts rested on their different opinions towards medications. He accused Koong of providing care in the wrong way. Koong used the medicine to help her sister to feel less depressed, but Krit considered it to possibly have a negative effect on brain cells. Koong felt accused of being unwilling to care for her sister, and drugged her sister so that she, Koong, could relax. Koong clarified that she knew well what the effects of the medicine were, but it helped ease her sister's headaches and depression. She pitied her sister, and therefore gave her the medication. Koong explained her conflict with Krit as follows:

> Koong: He often said things that hurt me. About the medicine, he told me that I was trying to perform a mercy killing on my sister. But actually, I didn't let her take that medicine everyday or throughout her life. My sister sometimes felt headaches and kind of confused, and the medicine could help ease her pain.

Also, on the matter of medication, Koong was also accused and misunderstood that she was greedy for her sister's money.

> Koong: He [Krit] said to me, 'If you cannot take good care of your sister, you'd better go and get a job to save your own money. Don't use her money.' [...] I've never thought like this. I've never even thought to send my sister to any care home either. I don't understand why he said that to me that way.

Collaborative Care: Dealing with Spousal Carers

In this study, the conflicts not only rested on the differing ways of caring, but were also influenced by the power balance within the family. In this section, power relation does not mean the gender relation, but refers to relations between spousal carers and adult child carers who have different degrees of intimacy with the cared-for person. In this study, some respondents were assisted by their co-resident fathers as helpers. The caring provided by spousal carers might be inconsistent to or incompatible with that of adult child carers. The inconsistency of expectation in relation to care might lead to feelings of stress in carers. This also makes them feel less committed to their caring responsibilities (Usita et al. 2004). Some respondents revealed that the inconsistency made them embarrassed and probably burnt out. Female family carers attempted to constrain themselves or manage their own emotions and behaviours in these situations. In other words, it appears that the adult child carers sometimes had to follow the spousal carers' ways.

In Zin's case, she was responsible for preparing meals for her mother with dementia. She said that she often felt stressed when she was not able to share her opinions with her father about the way to care for her mother with dementia, particularly in the matter of food and nutrition. She revealed that her parents were very closely intimate. Zin felt that her mother's life was likely manipulated by the father. Zin often argued with him about inconsistencies with her mother's care. At times, Zin attempted to manage her own emotions and let her father take care of the mother on his own without her intervention, in order to avoid further conflict.

> Zin: My father controlled almost everything about my mother. He often allowed my mother to have sweet desserts. I didn't want him to do that. But it's not easy to tell him, you know. When I started a conversation with him, it's like we were about to quarrel.

Similarly, Preeya also faced conflicts with her father when she helped him to care for her mother. For Preeya, her father was the primary carer. Sometimes, she was accused by him of having a less and inaccurate understanding and knowledge of caring. Preeya experienced the difficult situations resulting from misunderstandings with her father. Preeya considered that the intimacy of her parents led to the misunderstandings and made her feel very stressed. At times, she tried to deal with such circumstances by clarifying the occurrences with her father. But, sometimes, she could not help herself from arguing back to her father either. Despite that, she attempted to convince him that she was willing to provide care.

> Preeya: My mother wanted to stay close to my father. […] When my father came back home, mother told him that I hit her. He apparently believed what she said. I don’t understand why he thought that, because he knew well that she was not well. He never trusted me, but he trusted her and cared about her so much that sometimes he said some things that hurt me.

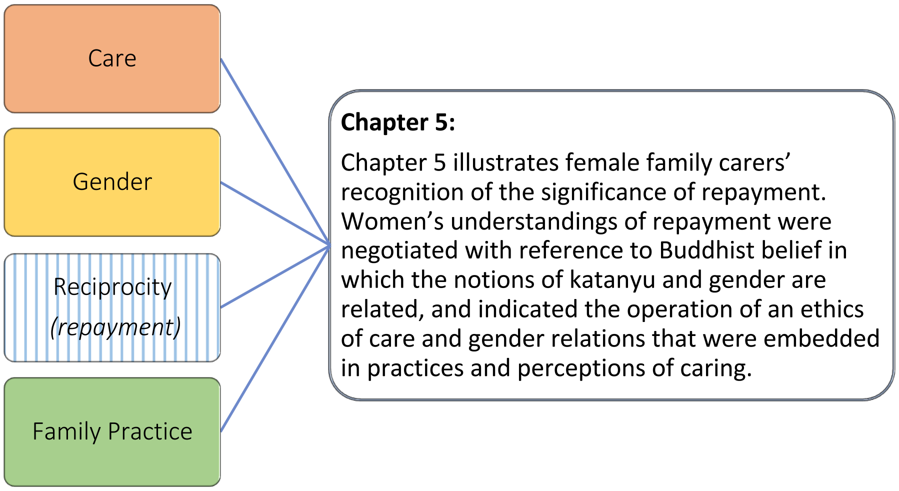
In this study, the degree of intimacy which spousal carers had with the individual with dementia was different to that of adult child carers. This difference could lead to difficult situations in dealing with family care. A high degree of intimacy illuminates a high level of power in managing caring situations, which adult child carers need to deal with in the proper way. In addition, spousal carers were adult carers’ parents who occupied higher family status. Thus, spousal carers had two statuses that influenced the adult carers. The first status was being a family carer, whereas the second status was being a parent. Thus, the conflicts between family carers were not only a matter of different ways of caring, but also a matter of family statuses in which carers needed to manage the power relation between each other so that they could move the caring practices forward properly. In this sense, Morgan (2011) suggests that when carers try to cope with the conflicts, they are following a sense of obligation to each member of the family.

4.7 Conclusion

This chapter has set out the caring experiences of female family carers as the supporting information or prelude to the findings chapters that follow. Given that caring is considered women’s work, which is hardly paid attention to by the public, this chapter has presented women’s caring activities in terms of care as practice and care as emotional labour. Since the nature of caring is considered implicit in common experience and everyday family practice (Finch and Mason 1993), it is seen banal and simple, or is even unrecognised (Morgan 2011). This chapter presents women’s caring activities in order to illustrate that caring is not simply a series of tasks. In fact, care entails a variety of tasks, some of which are not seen as activities of care, for example, seeking information (such as medical advice) or cleaning the floors whilst the care recipient is sleeping. In this chapter, activities of care have been discussed along with the time spent and skills that women used when providing family care. This is to show in what ways women are skillful to perform such activities. The findings also indicate that how caring activities were undertaken has an effect on the women’s lives. Moreover, suggested by the concept of family practice, this chapter has also presented how people who are family-like, such as friends and acquaintances, contributed to the family care (Morgan 2011, Smart 2007). Additionally, this chapter has discussed the family interactions surrounding dementia care, which inevitably involve concern and conflict between family members (Whitlatch 2010, Zarit and Zarit 2010). Family involvement has been described to demonstrate that dementia care within the family means care not just for the person with dementia, but for all family members, who should each be recognised and cared for by the others.

Chapter 5: Making Sense of Repayment in Caring as Family Practice

5.1 Introduction



Chapter 5:

Chapter 5 illustrates female family carers' recognition of the significance of repayment. Women's understandings of repayment were negotiated with reference to Buddhist belief in which the notions of katanyu and gender are related, and indicated the operation of an ethics of care and gender relations that were embedded in practices and perceptions of caring.

Figure 2b: Conceptual Map of Chapter 5

The focus of this thesis is reciprocity, which is a major element in caregiving and care receiving, even though, arguably, it is at least likely to be demonstrated in the lifetime or 'real time'. In this study, reciprocity is examined chiefly in relation to intergenerational support, where female carers provide care for their older relatives. One participant was providing care for her sibling, which is an example of reciprocity within the same generation.

This chapter sets out the findings of the first research question, which explores how female family carers make sense of repayment when caring for older people with dementia. This chapter is divided into three sections. First, it sets out the facets and extent of repayment in caring. This section describes the reasons for caring, but it also purposefully presents the notion of repayment to illustrate in what way it is significant and recognised when women provide care. Second, it talks about how the female family carers learn the significance of repayment within the family. Third, given that reciprocity is negotiated, it discusses how female family carers negotiate repayment in caring in which the notion of 'katanyu' and gender are significantly related.

5.2 Facets and Extent of Repayment in Caring

As described in Chapter 1, care provision for older relatives has been viewed as a way of making a repayment, and has been influenced by a prominent social value, 'katanyu'. Katanyu points to the sense of obligation in which adult children are duty-bound to repay their older relatives for their support in the past. In Thai society, the terms 'caring', 'repayment', and 'katanyu' seem to be inextricably associated. As such, they have often been used interchangeably in public understanding and in research related to family carers. Therefore, the idea of caring has still been taken for granted as an act of repayment. In addition, there seems to be few studies seriously exploring the female carers' understanding of repayment and caring. Thus, this section explains two facets of repayment in the context of care provided by female family members. The first facet illustrates that repayment is perceived as an intention to provide care. The second one is that repayment is hidden in other reasons for caring.

5.2.1 Repayment as an Intention to Care

The first dimension is that the caregiving is intentionally repayment to their relatives with dementia. A female family carer, Sasi, clearly spoke of the repayment for her relative's support as a reason to care. She recognised and accepted the importance of katanyu as a social value, but emphasised it less in her caring. Sasi explained that she cared because she intended to repay her mother. Sasi believed in expression of katanyu for parents but did not speak of it in terms of reason for repayment. Instead, she mentioned her mother's past care as her reason for caring. Her comment below shows that she not only knew but also understood the things her mother had done for her.

> Sasi: I just thought that I will repay her as much as I can.
> The researcher: Um…. You remembered what your mother had done for you.
> Sasi: Not just remembered, but I understood what she had done. When we [Sasi and her mother] moved in together, she would wake up at 4 a.m. to prepare breakfast for me.

Slightly differently, other female family carers considered their intention to repay their family member as being led by katanyu. The experiences of Wipawee, Raywan, and Manee are examples.

In Wipawee's case, she had a strong belief in Buddhist teaching. Wipawee mentioned that she followed katanyu as the reason she repaid her mother by providing care, although she had a poor relationship with her mother when she was young.

> Wipawee: Usually, I always hold on to the value of katanyu. As a human being, we need to repay those who do 'boon-koon' [give good things] for us even if that person is not our kin. Buddhism teaches us to do good things in return when we have the chance.

In repayments guided by katanyu, Raywan also commented that she was caring for her mother with dementia as she wanted to repay good things in the form of providing care to express katanyu. Her intention to repay seemed to be associated with her feeling of guilt. Given that, Raywan used to make her mother upset when she was young, thus, caring for her mother was also a form of compensation that helped reduce her guilt.

> The researcher: You've said you primarily care for your mother because you want to express katanyu. For what kinds of things?
> Raywan: Yes, to express katanyu. Erm ... I used to make her disappointed. I couldn't graduate school as she wished. So, I wanted to express katanyu by providing care for her since she was getting old.

In Manee's case, she had a poor relationship with her mother since the mother disliked daughters but loved sons. Despite that, once her mother was diagnosed with dementia, she started thinking about providing care without the expectation of any benefits. However, she was not sure about her genuine feeling of wanted to care and perform katanyu. She said that 50-60 years ago, people in her generation were taught of the significance of katanyu. She never had a problem with that until she needed to be responsible and care for her mother, whom she had a poor and less-than-intimate relationship with. Thus, to Manee, caring was to provide repayment framed by katanyu rather than her deep gratitude towards her mother.

> Manee: Once my mother got ill and I need to care for her, I had no idea what my real feeling was.
> The researcher: You might be doing so because you’re following katanyu?
> Manee: It [katanyu] is what society tells us to do. […] I did it because of that [katanyu]. That, indeed.

In Manee’s explanation, the researcher found that although she said this value was a driver for her to repay and care for mother, her repayment was still influenced by what her mother had given her in the past, e.g. giving birth to her.

Interpersonal relationships in the past within family is considered to be ‘credit’ that can be cashed in later in exchange care (Barnes 2012, Morgan 2011, Antonucci and Jackson 1990 cited in Neufeld and Harrison 1995), for example, affectional support in early life. Following this, Neufeld and Harrison (1995) view that past conflicts in an interpersonal relationship might release the adult children from the expectation that they should give care. This thesis found that although poor interpersonal relationships with parents might influence the decision to provide care, it was not simple for adult children to abandon the sense of obligation. As described in the cases of Wipawee and Manee, their intention to repay their parents was not influenced solely by the quality of relationship, but by the katanyu that is associated with the sense of family obligation (Pierce et al. 2001, Neufeld and Harrison 1995).

Katanyu seems to have an influence in expressing repayment to older parents. In fact, it typically involves many people such as other relatives and siblings. In Koong’s case, the reason she gave for caring for her sister with dementia was that she intended to repay her sister for financial support she had given Koong. Koong realised that her sister earned money in a risky environment as a flight attendant, in the face of flight accidents and sexual harassment. Moreover, once her sister was diagnosed with Alzheimer’s disease, she was asked by the flight company to take a leave of absence without any guarantee that she would be able to return to work. Koong realised that this life event had a great effect not only on her sister’s health condition but also her financial resources. For these reasons, Koong mentioned that katanyu was her first reason for repaying her sister.

> Koong: I think, the first reason is katanyu. My sister had been very nice to me since I was young. […] She offered me the chance to study abroad, and I didn't ask her for this, either. […] I'd known her to be so tired from work. Sometimes, she was under pressure and didn't tell me what she faced.

In the context of caring in Thailand, expression of katanyu in repayment not only involves the carer and cared-for person but covers other people such as siblings whose assistance had an effect on making repayment. This study found that the repayment of one family carer, Rungnapa, was not only to her mother, but also to her older siblings, especially her fifth brother. He made significant sacrifices throughout his life to help pay Rungnapa's education fee. Rungnapa realised that her life was always supported by the others' devotions. Thus, she considered that it was her duty to give something back to them. Caring for the mother was one a duty that she saw as being repayment not only to her mother. In a way, she wanted to repay her brother by taking responsibility for taking care of their mother. This is consistent with a study by Funk (2012), which found that some carers feel happy that they have the opportunity to give back. The following comment illustrates how Rungnapa did not hesitate to speak of her duty.

> Rungnapa: It was my duty indeed. It's like I have a chance to repay.
> The researcher: Repay your mother?
> Rungnapa: Repay everyone in the family. As the youngest child, I felt like I was given many opportunities in life from them [her family members]. […] It was my opportunity to give back.

The comments discussed previously have shown that female family carers undertook care as an intentional repayment to their relatives. Intentional repayment was described as being an opportunity. Moreover, intentional repayment was explained in association with duty, katanyu, and feelings of gratitude towards past care. Following this, intentional repayment thus involves a sense of obligation or filial responsibility. However, although the female family carers interpreted the repayment as an intention, some of them reported they felt reluctance and constraints. From the researcher's point of view, repayment as an intention to care could be considered explicit repayment, which is discussed further in comparison with another facet of repayment.

5.2.2 Repayment Unpacked

This section uses the term ‘repayment unpacked’ to try to capture those situations where repayment existed but was not articulated as obviously and clearly as it was by respondents in the previous section. That is, some carers perceived that their caring was not done intentionally to repay something to their relatives. But they provided care because of a feeling of duty, deep connection, emotional closeness, and compassion. Given that, this part discusses how the notion of repayment was likely hidden or, in some cases, mixed with such reasons. In other words, acts of giving and receiving or the past care and support within the family were spoken of as being additional reasons why they provided care as a result of duty, love and concern.

Sawalak, Preeya, Paula, Fenda, Anchalee, and Yuri reported that they provided care because it was the duty of children to care for aged parents. In the family context, caring as a result of duty involves a sense of obligation (Pierce et al. 2001). Particularly, when parents become ill and are in need, the sense of family obligation seems to be higher than other duties (Selig et al. 1991).

In Sawalak’s case, she had a poor relationship with her mother, who treated her in an aggressive way and different from other adult children. To Sawalak, providing care for her mother was repayment out of a sense of duty. However, compared with the case of Rungnapa described above, Sawalak seemed to refer to duty more often. Because of the poor relationship with her mother, Sawalak admitted that she always desired to get herself out of the duty associated with being a child. Thus, she accentuated the term ‘duty’ during the interview to illustrate that it was the main reason for her to provide care. Sawalak felt like she was the only one of the adult children undertaking care. None of her siblings offered to help with the caregiving. By duty, she saw it was her responsibility to be a caregiver. Her comment reflects that she provided care as a result of duty in the same way that her mother did for her with the responsibility of being a mother. Sawalak said:

> Sawalak: Although she didn’t like me, she, as a mother, gave birth to me and didn’t abandon me. She supported my education. […] Although she did not

> please me with lovely dolls or such, she took me to buy the books I needed, took me to school on registration day. I can still remember that. [Smiling] So, that's why I'm caring for her now. I am doing my duty to repay her.

Likewise, Preeya's view was that her caring was her duty as a child. Whilst she performed this duty, she said she hardly saw her siblings doing the same, although they were closer to their mother. In her view, her caring was carried out for the reason of duty, not repayment. That is, by fulfilling her duty she did not intend to repay something to her mother. Nor was her caring because of emotional closeness, since her mother was not fond of her.

> Preeya: For me, the first reason might be the duty of a child. It's like, since I was a kid, I witnessed that my parents took care of my grandparents. So, caring for parents was like the duty that a child needs to do.
> The researcher: It's like your mother has done her duty by looking after you, so now it's your duty to repay her by caregiving?
> Preeya: No … I didn't think I needed to repay her. It's my duty and it's like I cannot leave her alone.

To make her explanation clearer, Preeya added that caring was her duty in the sense that she needed to care for the mother closely. She said, '*I used to run upstairs, just to flee from her. But I could stay there for only a few seconds, because the thought pops into my head what if she* [her mother] *opened the door and walk out, or what if she ran and fall down.'* Her account of duty seems to implicit attentiveness, since she monitored her mother's safety.

Comparing the cases of Sawalak and Preeya to Manee's, which have been discussed earlier, their poor interpersonal relationships with the care receivers in the past made them felt pressured and reluctant to care. In Manee's comment, katanyu was a salient reason to care, while in Sawalak and Preeya's accounts, the duty of adult children were their reasons to provide care. However, behind their different answers, they all spoke of what their care receivers did for them in the past. This is implicit of an awareness of giving and receiving within the family. This aspect is discussed in detail at the end of this part.

Paula, similar to Preeya, did not perceive that her caring for her father was to repay something to him. She rather saw that caring was an attempt to accomplish her duty as a child. Paula's comment shows that doing care as a result of duty also gave her self-respect, as she felt fulfilled with the family role, not as a daughter, but as an adult child. Paula said:

> Paula: I did it [caring] as it was a duty that a child should do. That is what being a good child was. At a deeper level, I would have self-respect for what I was doing for him. It might not be perfect, but I could fulfill my role and filial obligation.
> The researcher: What about to repay something to your father by caring for him?
> Paula: I feel it rather was the long-lasting relationship with him. Although we [Paula and her father] never became very close, I know that everything he did was to help our family to survive. It's not often that he would do something for himself. So, it's time for me now to care for him.

In Paula's case, doing care as a duty seems to be associated with the term 'good child'. Likewise, Fenda felt that it was her duty to care. To Fenda, being a good child was to provide care for parents in the same way that parents followed their duty to look after their children. Regarding the notion of repayment, Fenda accepted that it was valuable and may hold a different meaning in each family, but she did not mention it as the first thought.

> Fenda: I care for her [her mother] just because I feel it is what I need to do. It's like I have this duty. […] [Sighing] It's because my parents gave birth to me and looked after me.
> The researcher: Is repayment the reason for providing care?
> Fenda: It depends on the relationship in each family. My family usually had close relationships. Everyone always helps each other. I saw such relationships throughout my life.

Fenda's comment also showed that caring as a result of duty was not easy. Her sigh might imply the sense of commitment in fulfilling filial duty. In this respect, the family commitment in caring suggested by a study by Pierce et al. (2001) can be seen to come in two kinds. The first is enthusiastic commitment, which refers to care provided with happiness and joy. Here, caring is not seen as a burden. The second is a moral commitment, which stems from a sense of obligation toward other people. Following this, Fenda's case indicates that her duty to care might illustrate her moral commitment, since she felt it was her duty to do so. This aspect thus also reflects that making repayment within the family is not automatically done because family carers face difficulties that they need to negotiate. (The aspect of negotiation and repayment is discussed in Section 5.4).

Comparing with Fenda, Anchalee saw her caring for her mother was her duty and the result of her love for her mother. Caring seemed not to be a burden to her. When speaking of duty, Anchalee talked about the role and duty of her mother first, and then said that it was her turn to fulfil a duty to care for her parents in return.

> Anchalee: I see caring as a duty. It's not a burden. As a duty, I felt happier to do it. It's good to my mind and that of my parents. […] Previously, when I've got routine work, she did and looked after everything at home for me. It was her role and duty. So then, when she became ill, it was my turn to care for her in return.

Similar to Anchalee, caring with duty mixed with love was also found in the case of Yuri. Yuri regarded that her caring was done not to repay her mother. It was the duty of one of the adult children to care, which she carried out willingly. Thus, to her, caring was a combination of duty, a feeling of love, and a deep connection in the history of the family relationship. Yuri's comment shows that she linked duty with the past care and support that her parents gave to her, which she viewed as parental love.

> Yuri: I think caring is what a child needs to do for the parents, because when I was a kid, I saw her working so hard and devoted her life to me.

With respect to parent-child love, Selig et al. (1991) suggest that such love is beyond a role-based reciprocal relationship since parent sacrifices do not establish any obligation for children to love parents back. In this sense, Reid et al. (2005) also consider perception of love to be subjective and dependent on the carer’s perspective rather than that of the care receiver. Following this, for the carers Anchalee and Yuri, love was a reason for them to provide care since they witnessed their parents’ devotion.

Some of the female family carers did not mention duty at all, but spoke of love, deep connections, and emotional closeness as their reasons to care. Moreover, they recognised their older parents’ support but the notion of repayment was not a starting point to provide care.

Ratchada rejected the caring as duty and repayment. It might be because duty and repayment implied rules or principles to follow. When asked about caring, Ratchada apparently answered that it was care with love, not with duty. In taking care of her mother, it was like her mother was receiving what she used to give to her daughter.

> Ratchada: No … If I was supposed to do it for duty, then I wouldn’t do it. Each day I care just to make her feel comfortable. I’m aware that dementia is still with us. So, everything I do for her is to reduce her suffering. […] For me, caring is almost like you live with things you love. It’s not duty. The things my mother used to do for me were returning to her.

In doing care with love, Ratchada’s comment implied that her mother as the care receiver deserved to receive good care and love. That is, caring was returning the love to the former love-giver.

In the case of Saipin, when asked about repayment in caring, she rather reflected on feelings of love and the deep feelings between her and her mother since she was young.

> The researcher: You care for your mother because you want to repay her like everyone else?
> Saipin: No, I care with the love that I have for her. I love her so much. She never thrashed me, even I was very mischievous.

Although Saipin's comment indicated that love was major condition of caring, it implied that it was to give love back in return for the mother's love. Saipin interpreted that her mother's concern and the way mother treated her represented her love for her.

In studying the concept of repayment in relation to caring for older parents, it seemed complicated when love and deep connections were mentioned as the reasons to care. They could not be separated from the notion of reciprocity. In this sense, Noy seemed to reject the word 'repay'. She insisted that she never thought that she cared because she wished to repay him. Noy accounted that her love and emotional closeness enabled her to do so.

> Noy: To repay? [Thinking] It's *not* to repay [Emphasis]. To me, it was love and connection. I love him and feel very close to him. I couldn't leave him alone. I think this is more than just repayment.
> The researcher: So, it's not repayment?
> Noy: I would say that caring is both the love and repayment. How can you care for someone without love?

Among those whose reasons for caring were love and deep connection, the words 'duty' and 'repay' in particular were avoided in their answers. In this sense, if repayment would be used in the context of family care, it should not be considered in terms of an act of exchange, because care involves love, emotions, and deep connection. As Noy said, caring cannot be done without love. Ratchada, likewise, said that she was returning love to her mother. This is consistent with a study by Funk (2012) that said when some carers undertake care, they are giving love back to the care receiver.

The same sentiment about the love and notion of repayment in caring was also found in Zin's case. Zin saw that caring was not the same as repayment. They both were considered the same thing. For her, repayment was like an exchange. Repayment did not seem to be deep. Her view was that caring was more than and beyond repayment.

> Zin: Some said to me that our parents used to care for us so we should care for them. I said, 'I don't think so. I don't have a problem with that, either.' To me, I didn't care for my mother just because she used to care for me,

> not because I wanted to repay her. It was rather a matter of feeling, love, or even the emotional closeness, if you like. I didn't see caring as a responsibility, either. Caring was because of my desire to give something to her. I felt I needed to do it. I couldn't ignore it.

Zin explained further about repayment: If caring is to repay, it benefits the carer herself rather than the care receiver. In contrast to repayment, caring is paying attention for another's benefit.

> Zin: I felt like it would be a problem for her if I didn't do it. My feelings weren't about myself, but almost about her. So, if you see caring as a form of repayment, you'll be feeling good just for yourself.

From the comments previously discussed, it appears that the term 'repayment' was rejected as it implies the principle of transaction and lacks a sense of love and feeling, particularly when it is used in the context of care. It seems that caring should not be seen as following a mandatory rule or principle but following love and emotions.

Likewise, Neena indicated that it was clear to her that repayment was not her reason for providing care, or even her starting point. Despite that, she accepted that this notion often came to her thoughts, but she felt uncertain if her thought of repayment was associated with social expectation. For Neena, she began to provide care as a result of compassion. Her comment shows that she did care for her mother because she hoped to see her mother living well like everyone else.

> Neena: I think my caring started with the feeling that I want to see her happy and healthy. I want to see her having a normal life, like others have. I also want to be able to cope with the symptoms she's having. I never think so much about repaying her.

However, there were a few of female family carers considering that their reasons for caring were interrelated and equally played a role in the decision to provide care. They could not determine what their salient reasons for caring were. The comments made by Jan and Aurapa are examples.

Jan seemed to be unsure when answering what her salient reasons are. Her reasons included the duty of children, katanyu, and deep connection. That said, she also mentioned the past care and support received from her mother. Despite that, she avoided the words ‘repay’ and ‘debt’ in exchange for support within family, particularly when it was used in relation to the parent-child relationship.

> Jan: Katanyu is probably involved. Also, deep connection. And I’m her child, you know [Laughter]. I think I am lucky to have time to care for her. I’ve been doing the best I could do for her so that I won’t have regrets.
> The researcher: Because she used to care for you.
> Jan: [Pause] … She’s my mother. She used to look after me, used to do many things for me. […] I didn’t want to say the words, ‘repay the debt’, because she gave birth to me and breastfed me.

Likewise, Aurapa saw that emotional closeness, love, duty to repay, and katanyu were equally involved in her caring.

> The researcher: In general, people repay their parents by caring. How about you?
> Aurapa: I felt close to her. After my father died, I moved in with her. […] And, when I was a teenager and came back from school late in the evenings, she would go out to the street and wait for me almost every day, even on rainy days. I think in caring for parents, nobody can do it better than children.
> The researcher: Do you mean that you care because of katanyu?
> Aurapa: Yes. Katanyu is involved very much with what I am doing. I think that caring for anybody else is not the same as caring for one’s mother. To me, Mother is beyond everything [Trembling voice].

In the above comments, Jan and Aurapa could not determine their salient reasons for caring, but their comments have shown that the notion of repayment was recognised since they talked about the favours given by their parents' care over the course of their lives. Regarding the vagueness of reasons for care, the researcher assumes that it might be because caring is seen as a common thing done in a private sphere like family (Barnes et al. 2015, Finch and Mason 1993) and even as a banal family practice (Morgan 2011) in which family members' actions involve concerns, the needs of others and other emotional things as a natural part of caring (Barnes 2006, Held 2006, Tronto 1993). Moreover, family care as lay care, the mixture of love, duty, reciprocity, and other emotional content, is an essential dimension (Finch and Mason 1993, Guberman et al. 1992, Qureshi and Walker 1989, Ungerson 1987, Marshall et al. 1987 cited in Izuhara 2010,). Thus, it might not be easy for family carers to identify clearly the reasons why they cared. However, the issue of combination might be seen as ambiguity for researchers when searching for findings, but this issue suggests an insight for researchers, suggesting that there might be circumstances beyond researchers' expectations, or the collected data could not be clear enough or fit to the expectation of researcher. It might be the problem of conceptual thinking, which researchers are trained to do. Then, researchers are likely to expect the collected data to be explained theoretically. From the researcher's point of view, the individual's experience and perception of life sometimes are so complicated that they are explained by theories totally. A theory is like a tool or lens to see the social phenomenon and help understand human behaviours and perceptions, which are subjective.

Repayment seems not to be a major theme of caring or frankly mentioned by some family carers because they considered that their caring was done out of duty, obligation, love, deep connection or emotional closeness. Meanwhile, for some carers, repayment in caring was mentioned in relation to katanyu, a duty as a child, love, and closeness. In this facet of repayment, the researcher illustrates that upon the various reasons for caring, the notion of repayment seems to be embedded and plays a role in the female family carers' reasons for providing care, as illustrated by Figure 4.

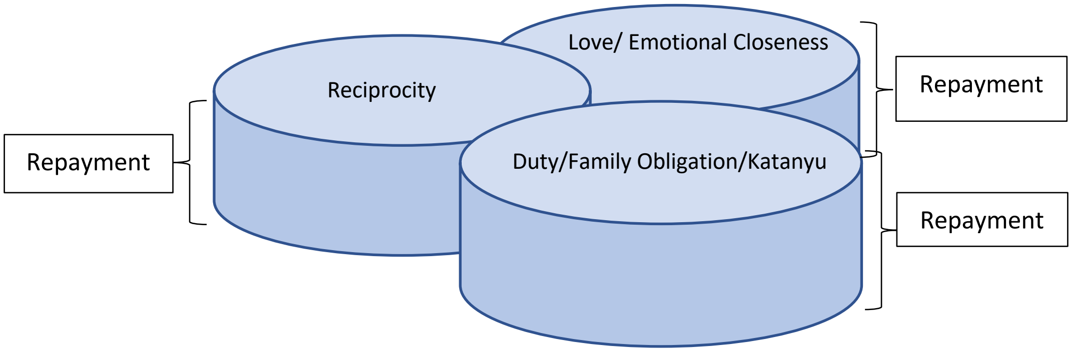


Figure 4: The Notion of Repayment Implicit in Reasons for Caring

Section 5.2 suggests the significance of repayment in two issues. First, the notion of repayment could be seen in two facets in which the repayment was perceived to have taken place, either overtly or in subtler ways. Second, female family carers perceived repayment to be beyond the sense of a material transaction but made sense of it in a relational and/or ethical way. These two issues are now discussed.

1) First, from the female family carers' understanding, there are two facets of repayment that imply different positions of repayment in the context of care: explicit and implicit.
Explicit repayment refers to repayment that is mentioned straightforwardly as an intention to care. The female family carers expressed repayment as the primary reason. Given that, some viewed that their repayment was led by katanyu, which was a frame of repayment expression. In doing so, their repayment was mixed with the sense of constraints and guilt. Some intended to repay as they viewed it as a duty, whereas some intended to repay out of gratitude for the past care received from their relatives. This study shows that repayment as an intention to care is clearly connected with a sense of obligation toward the family members. This is consistent with previous research, which explained that reciprocity in caring involves family obligations, which everyone should meet when there are the appropriate time and ability to repay them (Funk 2012, Neufeld and Harrison 1995). Thus, explicit repayment here is spoken clearly in relation to an opportunity to return support to their older relatives once they were in need. When mentioning opportunities to give back, the female family carers then openly

talked about the past acts and support exchanged within their families. The various kinds of assistance and help, such as parent raising and financial support were acknowledged as benefits to the carers. The acknowledgements of exchanged resources seem to be the supporting reasons given by female family carers for making repayment. However, the mention of exchanged resources and sense of obligation does not mean that the female family carers viewed their repayment as transactions of goods or services. Rather, they viewed the repayment as being ethical, which is discussed later in this part.

Implicit repayment does not seem to be a salient reason for care. In comments made by Anchalee and Yuri, the word 'repayment' was not mentioned, but 'duty' was given as a leading reason for care, whereas some female family carers emphasised love, deep connection, and emotional closeness as their reasons for care rather than repayment. In this sense, although the word 'repayment' seemed disregarded, the notion of repayment was always recognised by family carers. That is, when the carers gave their reasons for care, their reasons related to the acts of giving and receiving. Comments made by Paula, Anchalee, and Saipin are examples of this point. Paula said, *'I could fulfill my role […] I know that everything he did was to help our family to survive.'* Similarly, Anchalee said, *'She [her mother] did and looked after everything at home for me. It was her role and duty. […] it was my turn to care for her in return.'* Likewise, Saipin, who cared for her mother with love, said, *'No, [I didn't want to repay], I care with the love that I have for her. […] She never thrashed me.'* These examples indicated that repayment is implicit or embedded in other reasons since it is used to support other reasons for providing care. Additionally, some carers such as Zin and Neena who did not consider repayment as the starting point for their choosing to perform care, also mentioned the past care of their mothers along with their reasons for care. Thus, it can be said that the female family carers were aware of the significance of acts of giving and receiving, but they did not express it straightforwardly. It might be because the acts of family exchange of support such as caring are normal and simple in everyday life, or even a banal family practice (Morgan 2011) that an individual commonly experiences.

The findings of this thesis are consistent with Lewinter's work (2003) in which none of his respondents used the word 'reciprocity' itself but simply stated that they cared for parents because of the help received from parents in the past. The issue of avoidance or rejection of the word ‘repayment’ is also found in Funk’s work (2012). Funk suggests that the rejection might be a language problem. ‘Exchange’ and ‘paying back’ (Funk 2012) are interpreted in negative terms since they appear to exclude emotional aspects of a relationship and are interpreted as self-interested. In this study, the interpretation of the term ‘repayment’ or ‘paying back’ was also perceived negatively by some family carers, for example, some phrases from Jan’s extract: *‘I didn’t want to say the words, ‘repay the debt’, because she gave birth to me and breastfed me’*, or phrases in Noy’s comments: *‘It’s not to repay. To me, it was love and connection.’* These two examples illustrated that the word ‘repay’ could probably be understood to lack an emotional dimension. Meanwhile, the word may imply the sense of self-interest rather than benefit to another person, as Zin said, *‘If you see caring as a form of repayment, you’ll be feeling good just for yourself.’*

2) For the second issue, the female family carers made sense of repayment in relational and ethical ways. Given that the notion of reciprocity seems to be complex (Gouldner 1960), spoken, and experienced in different terms (Lewinter 2003), the understanding of the female family carers toward repayment has been spoken of in various terms, including the different usage of the word ‘repayment’. That is, as suggested by the concept of family practice, care, and reciprocity, repayment can be considered in ethical and relational terms. For some carers, their reasons to care were love and concern because they interpreted the parent’s assistance as such and returned care to them in the same way. Given that, parental support is not only in the form of material goods or services, but in the less tangible forms of the parent’s love and concern. Reciprocity then is symbolic rather than a literal quid pro quo or a transaction (Funk 2012, Lewinter 2003, Horwitz et al. 1996). Moreover, according to a feminist ethics of care, love and concern are forms of attention to be given from one person to another. Following this, the carers felt that their older relatives used to pay attention to them for their (the children’s) benefit. Thus, in turn, caring for a parent is to give love and concern back to their parents. Some phrases from Ratchada illustrate this point: *‘For me, caring is almost like you live with things you love. […] The things my mother used to do for me were returning to her.’* Repayment as a return of love is consistent with the existing research, which states that reciprocity within family caring is seen as an opportunity to give back. That is, giving back is returning love to the care receiver (Funk 2012, Peacock et al. 2010). Regarding love in caring, Reid et al. (2005) suggest that love is subjective and depends on the carer’s perspective rather

than that of the care receiver. Following this, having been a receiver of parents' support, the female family carers realised and interpreted parental love as kindness. Saipin's extract was an example reflecting this aspect: *"I care with the love that I have for her. […] She never thrashed me.'* Here, this phrase shows her interpretation of the mother's caregiving to be in the form of loving kindness, which was of benefit to Saipin, the child. This reflects the relational aspect of repayment in female family carers' understanding.

In addition to repayment by love and concern, reflecting the ethical aspect, repayment by duty or family obligation also illustrates this point. Pierce et al. (2001) state that a sense of obligation could create a moral commitment in which the individual feels obliged to do something. Moral commitment is thus associated with status (Pierce et al. 2001). However, this thesis argues that although some of the female family members may have felt obliged or duty-bound to repay their parents, they seemed to make sense of repayment by looking at what was behind the support or past care of their older relatives. Some female family carers considered the support to symbolise the cost of giving, for example, missed opportunities, risks, and tiredness, which were sacrifices in order to benefit the receivers. Suggested by the concept of family practice, this thesis argues that female family carers' repayment by duty is ethical as it stems from a family relationship in which the family's giving and receiving took place not only because of duty but because of concern for the other person. A phrase said by Rungnapa – "*I was given many opportunities in life from them [her family members]. […] It was my opportunity to give back."* – implied that her education was supported financially by her oldest brother, whose sacrifice was the opportunity to have and raise his own baby. Likewise, Koong's duty to repay her sister rested on awareness of her sister's sacrifice, a risky, difficult job, as Koong said, *"She offered me the chance to study abroad… […] I'd known her to be so tired from work. Sometimes, she was under pressure and didn't tell me what she faced."* Another example is the experience of Sawalak, who intended to repay her mother out of duty. Although mentioning the mother-child status, Sawalak made sense of her mother's support through their relationship, not their status. She interpreted that the support symbolised her mother's attentiveness: *"Although she didn't like me, she, as a mother, […] she took me to buy the books I needed, took me to school on registration day. […] So, that's why I'm caring for her now. I am doing my duty to repay her."* Following this, the carers' understanding towards repayment by duty implied the ethical sense of repayment, not only in terms of a family status-related obligation, but also in terms of an awareness of their relatives' concern and sacrifice, which were embedded in the relationship.

5.3 Learning Repayment

The previous part discussed the facets of repayment and the notion of repayment as an exchange of support and resources in the family, which the female family carers make sense of in ethical terms. Inspired by the concept of family practice, reciprocity, and care conducted by a feminist approach, this part looks at how female family carers learn the ethical aspects of repayment in the context of family. It shows that the reciprocity the carers experienced over their lifetimes are lessons and constitute their understanding of repayments. Their lessons here are rested on two types of practices: practices with ethics and practices without ethics. The concept of family practice puts an emphasis on the aspect of ethics in undertaking family activities. In this thesis, the word 'ethics' is used in the context of love and concern between family members and any others involved. In discussion of two types of practice, this part also discusses the ways that female family carers learn how the caring for the person should be done.

5.3.1 Practices with Ethics

When asked where their understanding of repayment came from, some female family carers spoke about the support and benefits received from their cared-for persons in the past. Saipin, Neena, Paula, and Raywan recalled receiving support.

In Saipin's case, she remembered her mother's love at a time when she had an accident at seven years old. Recklessly, she put her hand into boiling water. The mother instantly came to help her without reprimanding her, but spoke to her in her soft voice instead. Saipin mentioned that she always recognised her mother's love in terms of understanding and kindness. Thus, to Saipin, her mother's love was expressed in the forms of understanding, concern, and emotional consolation. Saipin recalled the following:

> Saipin: After she saw me being burnt, she apparently cured my wounds with coconut oil. Then, she taught me what I'd done wrong by speaking very softly to me. She didn't punish me, never scolded me, or even hurt me in

> any way. […] She brought me up without making me distressed. To me, this's important.

Besides the interpersonal relationship, the love and concern can also be interpreted by the way that the family members were fulfilling a duty. In Paula's case, she still remembered the way her father worked. In her view, he sacrificed his own happiness and interest in order to earn money and support the lives of his family.

> Paula: Since I was a kid, I saw him working very hard. Working as a television technician. He went out to work every day, so we hardly had a chance to meet and talk. But I know he was trying to build financial security for us [the family]. He always gave to us. So, now it's time for us to care for him.

Likewise, Raywan said that her impressive memory of her mother was in the financial support that the mother did her best to secure for her children.

> Raywan: My mother had a time finding the money to support all of us [Raywan and her siblings]. I was so impressed and felt the most grateful to her because she started looking for money from zero, so to speak, and worked hard along with our father so that they had enough money for us to go to school.

The practices with ethics illustrated the dimension of love and concern, which were not only visible through the interpersonal relationships within the family, but through the way that each member practiced supporting the family. Regarding love and care, Neena recalled her memories of her mother, who was always busy with housework and other things to support all family members. By devoting her time, her mother did not have personal time to do things for her own sake, including making friends and developing relationships with her neighbours. Living in an area like a small plantation was another reason why it was not easy for her mother to make friends. In Neena's memory, she recognised the time devoted to others and considered that it should be valued, as it was a significant aspect in supporting the lives of everyone within the family. Neena recalled her memories as follows:

> Neena: I remembered that before my mother was ill, she was strong enough to walk and get a bus to the fresh market herself. She came back home with the bunches of foods and things for all of us in the family. […] And she used to get up so early, around 3-4 a.m., to prepare the food, not just for our [immediate] family but also for our relatives. She did it so often and it took all day long.

Neena's comment also suggested an issue in feminist literature addressing how mothers or wives in the role of carer have less personal time, since they spend time on caring work that benefits others. In this sense, this issue mirrors the gender relations within a family, which have an effect on women's lives (Mckie et al. 2004, Walby 1997).

According to the concepts of intergenerational help and exchange, Robertson (1995 cited in Lewinter 2003) suggests that it is helpful to consider relationships not only with those members involved in the exchanges, but also with those who are more peripheral relatives. In addition, the past relationships are like deposits in the bank of intergenerational reciprocity. Fenda, Preeya, and Rungnapa's stories are examples here.

Fenda understood that caring was a normal thing, which her family members had always done for each other. She accredited the deep connections that everyone in her family had to this mutual help. For example, she needed to care for her grandmother who lived in another province while her sister needed to stay and care for her mother. However, in Fenda's view, her mother was not only a receiver of her children's care but also a giver who had helped raise the grandchildren.

> Fenda: Everyone in my family perceived the mutual assistance. We helped support each other. […] My mother, in her 40s and 50s, used to help look after the grandchildren. She did almost everything: cooking, washing clothes, and such.

Female family members were learning about mutual assistance from not only their older parents and carers, but also other family members. Likewise, Preeya learned the importance of repayment from her father's relationship with his grandfather. To Preeya, caring for her mother was a way to repay her father, rather than her mother. That said, she compared caring for her mother to the way her father cared for his family of origin.

> Preeya: I was so close to my father. So I perceived the many things he gave to my grandparents and also to my uncle. It's like he couldn't ignore the ways his relatives were living.

Similarly, Rungnapa said that she used to be a receiver of her siblings' support, which had significant and value for her, since they spent their lives supporting her education until she could have her own job. She was willing to be the only one responsible for caring for her mother. Her caring was to repay not only her mother, but also her siblings in the sense that they used to sacrifice their lives to benefit her. In following comment, Rungnapa gave an example of her older brother's sacrifice.

> Rungnapa: As the youngest child, I felt like I was given many opportunities in life from them [family]. Such as my fifth brother, he waited for my graduation before he decided to get married and had his baby. So, I think I'm now ready to help them. It was my opportunity to give back.

As described previously, the comments showed that female family carers learned and understood the importance of repayment from practices with ethics in which love, concerns, affection, and sacrifice were manifested. According to Morgan (2011), the ethical aspects of family practices might not be revealed simply in words such as 'sacrifice'. It is not the words, but the explanations that female family carers described to show how the notion of repayment was significant in the issue of caring. In female family carers' narratives, they learned ethical aspects by considering the way family members and other relatives supported and maintained members of the family.

5.3.2 Practices without Ethics

The previous part discussed the practices with ethics in which female family carers learned the importance of repayment in the family. However, according to McCarthy et al. (2000 cited in Morgan 2011), the ethical aspects appear not only in terms of what actions were done, but in terms of accounts that implied things not done, which may signify the expectation of things yet to be done. In this respect, this part considers how female family carers learned the importance of repayment from practices without ethics.

Wipawee, Sawalak, Jan, Sasi, and Manee are examples of people who had experiences where family members treated each other in inappropriate ways by traditional family standards. Their perceptions toward the absence of ethics in giving care and support reflected their expectations towards the significance of ethics when taking care of family members.

Wipawee said that she witnessed her older sister caring poorly for her mother. In her opinion, the way her sister undertook care should not be called good caring, and should not even be called repayment, since she did it without being respectful to her mother.

> Wipawee: I’ve seen my sister speaking to my mother with a disrespectful voice. I saw the tears in my mother’s eyes. I don’t know why this woman [her sister] treated my mother in this way. Why didn’t she improve her way of caring? I know my mother would forget it by the next day, but at that time she’s already hurt.

Similarly, in Sawalak’s case, she mentioned the way her sister responded to what the mother said. From her point of view, her sister was ignoring what happened to the mother’s life.

> Sawalak: When my sister came to visit my mother, my mother said that she wasn’t well and had pooped with blood. My sister didn’t listen to her symptoms but interrupted her by saying, ‘Mom, it’s late evening now. I should be going home.’ It’s like my mother wanted someone to listen to her suffering. […] When I heard that, I was disappointed in my sister.

Comments made by Sawalak and Wipawee showed that they learned the significance of attention and concern as essentials when caring for a parent. The same sentiment was also found in Jan’s case.

Jan reflected that at times her younger brother talked to her in a slightly aggressive way. Also, she was not happy with the way her brother cared for her mother.

> Jan: I asked him [Jan's brother] to take her for a walk for exercise. He said she walked too slow. So, I didn't want to say anything else. I thought I won't ask him anymore. [Her voice indicated stress.] I thought to myself, 'How can he think that way? Why didn't he think of when she used to teach him how to walk?

It seems that the ways that the female family carers learned the significance of repayment include observing, remembering, and comparing the circumstances of how their family members treated each other. Regarding comparing, some carers such as Sawalak and Jan compared the care that their mother gave to their siblings with the ways their siblings responded to their mother.

With respect to comparison as a way to know how to provide care, Manee also made sense of the significance of repayment by the difference between how her mother treated her and her brother. In her view, her mother spoiled her brother but disliked her. Their mother often asked Manee to help financially support Manee's brother. To Manee, this was not reasonable. It made her embarrassed, as she said:

> Manee: My brother often begged for my mother's money. If she didn't have any, she borrowed someone else's money to give to him. She also asked me to help him, although I had my own huge expenses to pay for my children. It happened so many times that I felt reluctant. My mother paid attention to him as a son too much, but she never cared about me as one of her children at all.

In sum, Section 5.3 illustrates that female family carers learned and established their understanding of repayment both by practices with ethics and without ethics. That said, they realised the significance of ethical aspects in the notion of repayment, such as the aspects of love, attention, and concern in the context of care. According to Neufeld and Harrison (1993), the reciprocity in a caring relationship is constructed through the carer's monitoring. Following this, this section illustrates that the ways the female family carers learned and established their understanding rest on observing, remembering, and comparing circumstances in relation to reciprocity in the past, which are the resources that they employed to make sense of and make decisions about making repayment. Furthermore, as suggested by the feminist view that women know things based on everyday life (Edwards and Ribbens 2011) this section illustrates that the female family carers' ways of knowing are incorporated with their respective status (Stanley and Wise 1993), not only as carers but also as women who are subjugated. This issue could be seen clearly in the case of Neena, who understood her mother's care, and in the case of Manee, who was overlooked by her mother and treated differently to her brothers. The female family carers' understanding of repayment therefore can be different from the public understanding of repayment.

5.4 Reciprocity in Caring: Negotiation, Katanyu, and Gender

As described in Chapter 1, the notion of repayment in Thailand closely involves katanyu, which is a social value based on Buddhist belief. Basically, Thai people believe that caring for parents is the adult children's duty, in order to make repayment for their parents' support. This is also seen as the act of earning merit or 'boon', which is accumulated and will return to the children in their next life. Traditionally, being ordained as a Buddhist monk is a way to repay parents, but only men are allowed to follow this path. Currently, women are not allowed to be ordained conventionally. (The relationship of ordination and repayment to parents was explained in Section 1.3.2). Thus, daughters are expected to repay their parents or express katanyu through other ways, such as taking care of parents and serving their day-to-day needs within the family (Yavapraphas 2018, Seeger 2009). Nevertheless, although these activities help women fulfill their duty as a child, their repayment seems not to be valued as much as the repayment made by men via ordination (Mills 1997).

Given that, the terms of repayment are not automatically set, but are negotiated by the carer internally, as a re-evaluated definition of "repayment" that is in resistance to the understanding of the term that is taken for granted within the family and wider society (Finch ,and Mason 1993). Thai female family carers negotiate repayment in relation to katanyu in three ways. First, they aim to establish the value of care provision and its position in comparison with ordination. Second, they argue that caring should be a gender-neutral practice. Third, katanyu itself is debated in the context of care.

5.4.1 Positioning of the Value of Caring in Relation to Repayment to Parents

There was disagreement between the participants as to the value of the care they were providing in relation to male ordination. Some saw it as being of lesser value, some as of equivalent value, some as of greater value.

Only one participant considered her caring less valuable than ordination. According to Fenda's belief, Buddhist teaching mentions that karma determined all things that happened in life and could not be changed, including her mother's illness and her being born a woman. In her comment, it seems that in one way, Fenda was likely to conform to the belief and public understanding of the value and significance of male ordination. In another way, her account reflects her negotiation, as she said that despite the lower value she attributed to caring, it could be considered as earning merit. The benefit her mother received from caring was real, visible, and could be given to her mother every day.

> Fenda: It might be true that women can't be ordained as men can, but we do many other things. Some people say that parents cling onto the saffron robes of their ordained sons; my mother used to say that parents get merit from their sons' ordination for only one day. The other days were their own days. But what I did was every day for ten years. So, my mother received what I did for her although it might not be equivalent to ordination. […] If men were ordained but never took care of their parents, their repayments would be worthless.

Ratchada, Saipin, Yuri, Aurapa, and Paula each considered their care to be of equal value to ordination.

Ratchada did not accept the idea that the beneficial result of ordination could be conveyed to the parent. She considered that ordination was only of worth to the person being ordained, because that person had the opportunity to learn and practice things that benefit his soul and consciousness. Moreover, she did not consider the gender bias in ordination as a disadvantage to women, because there were other ways that women were able to repay parents just as well as men could.

> The researcher: So, you don’t think the ways women repay are inferior to men’s ways?
>
> Ratchada: No, no, no…
>
> The researcher: Then, what do you think women can do as repayment?
>
> Ratchada: [Answering quickly] Caring for them [parents]. Doing whatever it takes for them to be happy and comfortable. Devotion. […] People have their own different ways of expressing repayment.

Saipin also considered ordination to be merely a religious ritual. She placed more value in the relations that people had with others, because they were connected with the law of karma. The acts of individual will certainly pay off. Saipin said:

> Saipin: Ordination is just a ritual. I don’t think it is a matter of advantage or disadvantage, either. I would say, whatever is done will be given in return to the doer. To me, caring is what I can do to repay my mother as much as I can. It will pay off, too.

Yuri felt that if she could do things to bring her parents happiness, then the value of those things was no different than that of ordination. Yuri said:

> Yuri: I don’t take ordination as a chance to repay seriously. If you do something good for them, that’s fine.

Regarding the importance of ordination compared to caring, Aurapa also viewed ordination as a traditional practice, and any good deeds/boon resulted from ordination would be shared with the female relatives such as the mother or wife. Nevertheless, it would be worth much more if ordination could be achieved in addition to caring for parents.

> Aurapa: It [ordination] is a traditional belief. But I think if they [men] are ordained and also took care for parents, it would be perfect.

According to the previous comments made by Ratchada, Saipin, Yuri, and Aurapa, they saw ordination as a ritual or practice in which only the person ordained received its value and benefit. This implies that the female family carers are likely to put emphasis on the acts of repayment that mirror the reciprocal relationships and are more obviously beneficial to the parents.

As shown in the following comments, Anchalee, Noy, Raywan, and Sasi explained that the value of repayment depended on the intention, rather than the form of expression. Thus, to them, the value of caring was no different to that of ordination if done with intention.

Anchalee's view was that the exclusion of women from ordination did not imply a disadvantage or inferiority to men. She seemed not to hold as it as the only way to reciprocate. Whatever women did was equivalent to ordination in value if done with good intentions.

> Anchalee: No. It's [what women do] not inferior [to ordination] at all, because women have many other strong points. […] It's true that men can repay that way but women don't need to do the same. Whatever women do can be substituted for the value of ordination because they are good deeds.

Noy considered that caring should not be absent in repaying to parents. She explained that her father said that repayment could be achieved only by a child's ordination, since the parents' wellbeing also needed attentive care.

> The researcher: Could the other things be equally replaced to ordination?
> Noy: Sure [Said in a high tone]. No one knows how much merit an ordination is worth to parents. That's a matter for the next life. And it depends on the intention of the actor. Men can be ordained, then women can care. It's fine. But to be ordained is not enough. […] I saw that my father was not ordained but he did everything for my grandfather. He [her father] used to say to me that my grandfather's life is of more value than everything, even our properties.

Sasi's view was that repayment can be expressed in many forms. As such, people can choose the ways that suit them and also choose whether they would make repayment or not.

> Sasi: Repayment has many forms. It depends on you and what’s a suitable method for you. It’s not to do with being women or men. We can do the same. […] I won’t blame my brother for not doing katanyu for Mother. I think it was his own intention and attention to care.

Likewise, Raywan said that repayment depends on the intention of the individual making it, not on the form of repayment. In her view, caring activities like she was doing were even more valuable than ordination.

> Raywan: I’ve never thought that I, as a woman, feel disadvantaged, because what I’ve been doing these days is [worth] much more than a male ordination. I don’t think about whether or not [a woman] can be ordained. It’s a matter of one’s intention to repay. I think what I did in caring will pay off more than ordination does.

It can be said that all of the female family carers put the value of caring not less than the value of ordination. Given that, they can describe the value in more detail to illustrate what it means and what it refers to.

It was Paula’s view that ordination was not the only way or the best way to repay parents. She added that the best thing that an adult child could do is everyday caring for parents, both physically and mentally.

> Paula: We [women] do many other things that make them [parents] happy, in both body and mind. In whichever ways that might work. To me, I just feel that what I’ve been doing every second whilst caring for him [her father] was to make him happy. So, I think every child can do whatever to repay their parents.

Likewise, Rungnapa said there were a variety of ways or forms of repayment, including doing good deeds, making them happy, ordination, not making them disappointed, conforming to their expectations, and caring for them both physically and emotionally. She gave examples to confirm that although men have more options in expressing their repayment than women, the things women do, particularly caring, had as much value as ordination and other forms of repayment.

> Rungnapa: There are many versions to choose from. Being a good person can also be counted as a way of repaying them. Ordination is not a must. A man might be ordained but when he leaves the monkhood he might rob someone's home, committing a crime. That would be 'baab' [bad deed] for making his parents upset. […] Women are not allowed to be ordained, but they care, cook, look after, do housework, and do more than men do, probably better. I manage everything in the house. I feed my mother and bathe her, massage her body and apply the medicine to her skin, for example.

In Rungnapa's comment, she gave several activities as examples of what caring refers to. Those activities reflect the connections that one individual has with another. The same sentiment was also found in Sawalak's case.

With respect to ordination as repayment, Sawalak said that once she used to desire to be ordained in order to accumulate the merit for her mother, and to prove her worth to her mother, who wanted a son to be born into the family. In the present, she attributed more value to caring than ordination. She also gave examples of the value of caring by illustrating the activities of care. Her examples reflected her awareness of connectivity, which is a significant aspect of repayment.

> Sawalak: I didn't pay attention to ordination anymore because I know what I've been doing [caring] is greater [strained voice] than ordination. […] My brother hasn't been ordained yet. I don't take this seriously with him, though. I just want him to care about Mother, have concern for her health, accompany her to hospital. Doing these things is more valuable than ordination. Ordination would be useless if he didn't treat our parents in a good way.

While almost all of the participating female family carers valued caring equally to or more than ordination, Manee, Neena, and Preeya did not place any value on ordination at all.

Manee told the researcher that she would not comment on this because she had a strong gender bias in the sense that she did not put any value on what men do. In this respect, the researcher considers that having no comment about ordination might be interpreted as ignorance of its value. The ignorance could be seen as a resistance towards or rejection of ordination. Nevertheless, Manee's short comment seemed to be consistent with the rejection of the value of ordination, because she commented that caring was neither an alternative to nor a substitute for ordination when it came to women providing repayment.

> The researcher: What do you think about the fact that women cannot be ordained? And how, because of that, they turn to caring instead?
> Manee: No, that's not the case. Caring and ordination have nothing to do with each other.

Similarly, Neena said that she used to think it was not fair that women did not have the opportunity to be ordained, but presently she had not valued ordination at all anymore, since it was no more significant than the things that women could do. For Neena, if ordination took place only to express repayment, it would be merely for appearances.

> Neena: I don't value ordination. […] If men who get ordained gave their attention to religious practices, that's of benefit in itself. And, if ordination was done to show that men are repaying to their parents, it's simply a social value that I don't need to put any value onto. Even if ordination couldn't help men learn or develop themselves, ordination is not profound, but just a shell.

Preeya was another carer who did not accredit ordination. For Preeya, ordination appeared to be a propagation or mission of religion. Therefore, she believed in the tangible consequences of caring rather than that of ordination.

> Preeya: I don't believe that people can do good things for parents through ordination. Where is the evidence? Would it be better if he [the man] took care of his parents? […] I don't feel disadvantaged by having no opportunity [to be ordained]. Sometimes I thought it was just a strategy to maintain and spread religious belief. No monks, no religion.

Almost all of the comments have demonstrated that in the experiences of female family carers, caring was a way of repayment which almost all of them valued at least equally to male ordination. That said, some carers valued their caring as equivalent to ordination, while some valued their caring higher than ordination. Moreover, a few carers commented that they did not value ordination at all or felt that it simply was not relevant. There was only one female family carer who, in one way, seemed to conform to the public understanding of the privilege or worth of male ordination. However, her account also implied her resistance to this traditional belief of repayment. This section illustrates that it can be said that the female family carers negotiated the notion of repayment by valuing the position of caring at least equally to ordination. The supporting reasons to value caring in this way were based on the daily practises of care and their tangible consequences, which reflect the aspect of connectedness or relationality in acts of repayment.

5.4.2 Caring Negotiated as a Gender-Neutral Practice

Another aspect that the participating female family carers negotiated is the view that care within the family is women's work. In response to the researcher's questions in relation to caring as women's work, all female family carers replied that caring could be done by anyone regardless of gender. That is, men are able to do care as well as women.

Ratchada's comment shows that caring can be expressed in various forms such as financial support, personal care, and emotional care. It depends on what kinds of support are available for each person to potentially do (Horwitz et al. 1996). Importantly, regardless of the different kinds of care, caring should not lack an emotional aspect, which men could do as well as women. Care should be undertaken as an ethical and emotional practice.

> The researcher: So, besides ordination, you think caring is a way that men can provide repayment to a parent?
>
> Ratchada: Absolutely [apparently in answer to the question]. I mean, although men mostly focus on their jobs rather than doing domestic chores, the money they earn could help cover the expenses of caring. That's true, but men also talk to parents on the phone to say hello or come to visit and see them. To me, if he's not as delicate as a woman, it's fine.

Likewise, Yuri agreed that men could also provide care – and probably better than women could. Yuri spoke of the way her father took care of her mother when Yuri went working. Yuri's view was that, as a male-spousal carer, her father paid attention to the mother's behaviours in everyday life.

> Yuri: I used to see the male family carer who took very good care of his parents. […] I saw the way my father did caring too. He paid a lot of attention to my mother, kept an eye on how she moved, and how her symptoms were going every single day, and also taught me how to notice her movements, such as a sign of wanting to go to the toilet.
>
> The researcher: So, the ability to be attentive is not only for women, is it?
>
> Yuri: I think anyone could also have it.

With respect to gender differences and attention in caring, Wipawee explained that men could provide good care. She gave the example of her husband taking care of his parents in a gentle way. She did not see a difference in the quality of care provided by a person based on gender.

> The researcher: What do you think of the idea that caring is the work of women only?
>
> Wipawee: No. My husband was a superb carer. Very delicate and attentive to what he cared about. […] Compared to my elder sister, she didn't give sufficient attention to her caring for my mother. Often, she wasn't careful enough in what she did.

For Wipawee, she appeared to consider the gender differences in terms of quality of care in general, but she saw some interesting aspects, such as knowledge of bodily care, if the genders of the carer and the care receiver were not the same.

> The researcher: So, why do you think caring is perceived as women's work?
> Wipawee: It might be because a woman carer knows better how to care for a woman. They aren't shy with each other when changing an incontinence pad.

In Noy's case, she viewed men as being able to provide care as well as women. She talked about her father who paid attention when caring for her grandfather. Similar to Ratchada and Wipawee, Noy also considered the ethical and emotional aspects of caring to play a very important role regardless of the different kinds of care being carried out.

> Noy: I think a man is able to care, but he might not be aware of how to prevent fungal infections and such. But for my father, he was strict in the matter of medication and cleanliness. He paid attention to these things. Often, he phoned me during his working hours to check about the medication and meals I gave to Grandfather.

Interestingly, Noy's comment suggested an aspect concerning the attention of care and gender, particularly when it comes to bodily care. In this study, several female family carers addressed that sanitisation in care must always be kept in mind. They viewed that women rather than men seemed to be aware of this when undertaking personal care for a care recipient. It might be because women are more likely to deal with bodily care since women are believed to be more involved in bodily activities such as reproduction and the menstrual cycle, which at the same time is perceived as unclean (See Section 4.4.1). Thus, it might be that bodily activities and events in relation to the body enable women to have more concern for bodily hygiene more than men.

Some of the female family carers viewed caring to be a gender-neutral practice. Given that, they still considered that women provided better care in terms of sensitivity when caring. Fenda, Jan, Anchalee, Raywan, and Paula are examples of this point.

Fenda said that men could care as well as women, but women could deal with it better in terms of attention and sacrifice.

> Fenda: As we know, women give care better. […] I used to see some men taking care of their mothers, but I think they might not be devoted to it 100 per cent as women can be.

Jan said that caring was not only the work of women, and that men could do care too. Given that, the significant point was the intention to care and attention when providing care.

> Jan: It doesn't matter what gender you are. It depends on each person. My brother [snorting] didn't have any responsibility. […] If men intend to care, they could do so. Like that man [an attendee in a workshop], he had a lot of experience and knew many tricks for good care. I guess if he had female siblings, he probably might not be a carer.
> The researcher: You mean that caring is women's work?
> Jan: No, but I think women have more sensitivity.

Anchalee also mentioned sensitivity, which she considered women to be more likely to have than men. By sensitivity, she meant emotional care when communicating with the care receiver, which she saw as important when providing care.

> Anchalee: I don't take sides with women. I think women have some aspects of sensitivity more than men. I saw my husband being not gentle when talking to his mother. Men don't consider the details and aren't thinking as thoroughly as women.

For Anchalee, sensitivity was to pay attention to the care receiver in a careful and delicate way, and to consider the effect of the care on the cared-for person. Some female family carers such as Raywan and Paula did not use the word 'sensitivity', but they explained in a simple way what sensitivity would be like in caregiving. Raywan said that attention in caring was to look at the details when giving care.

> Raywan: No. Women care better. Um … It's up to each person whether or not they [men] can do that [provide care]. But I don't think men would pay enough attention to detail when caring.

Likewise, Paula understood that caring could be gender-neutral, but women seemed to perform better as women were attentive to details when caring. Paula said:

> Paula: I think it's women who provide care better, isn't it? Because mostly women look at more details than men. But actually, there're some men taking good care, too. This is my personal view. I don't know what the facts are.

Regarding sensitivity, the participating female family carers did not consider it to be a qualification that men did not have. Rather, all human beings have this ability. That said, some of the female family carers suggested that it could be created through socialisation in the family.

Zin's view was that, in caring, attention and sensitivity were qualifications that could be established within a family; the individual could learn to know how to treat and care for another. Thus, attention and sensitivity were not qualities that only belong to women.

> Zin: It [caring] is about paying attention and sensitivity. Human beings should have this without judging them good or bad. But if it's helpful to others, let's use it.
> The researcher: Are these features only women have?
> Zin: All people. […] I'm not saying that men don't have such characteristics. I mean that they are things men should have. […] If men grew up warmly with these things, they could also give good care.

Likewise, Neena's view was that these qualifications involved a learning process relating to gender roles within the family. Neena said that when women were allocated caring tasks, they learned how to do things for others and how to be attentive in what they did. Thus, actually attention in caring was not innate but a learned skill for people regardless of gender.

> Neena: Um … I think they [caring and being women] relate, surely, because we [women] are trained to take care of others. It's like women's social role. If caring is seen as individual work, in some ways that's true, too. Because it involves paying attention to the cared-for person.

Some of the carers interpreted attention and sensitivity as relating to one's consciousness in meeting a family responsibility. In this sense, Sawalak's view was that when adult children provided care as a form repayment, consciousness was a major element and the primary factor. Consciousness manifested as attentiveness and responsibility in fulfilling a family duty, which the individual should have regardless of their gender.

> Sawalak: I think it depends on consciousness. […] It's like you need to pay attention to what you're doing in caring. By consciousness here I mean paying attention.

In this study, all of the female family carers viewed caring as a gender-neutral practice. Among those, they understood that women provide better care than men because they pay more attention and have more sensitivity, which they considered important in caring. However, there was one female family carer who interpreted this point in a different way. Koong also considered attention to be important but said that too much attention and focus on details in caring – in other words, being overly conscientious - might be a drawback because it might create a stressful unachievable expectation of the quality of care. Thus, for Koong, men might provide care better since they might not put too much emphasis on details, as she said as follows.

> Koong: I think men care better than women, because men are not too touchy and picky when caring. As far as I have experienced men organised their caring [for ill parents] very well. With women's caring, I see them [women carers] providing very good care as well, and they'll never leave the cared-for person alone.

It can be said that the female family carers internally negotiated their own definition of repayment in the context of care in the sense that they considered caring to be a gender-neutral practice, not a practice only for women. This is because there are various types of care which adult children are able to share in caring for parents, depending on the adult children's resources (Horwitz et al. 1996). Regardless of the different types of care, the focal point should be attention and sensitivity towards the parents as care receivers. The female family carers' comments on this point are consistent with a feminist ethics of care, which posits that attention is the first element of the caring process (Tronto 1993). The female family carers' view that women seemed to provide more attention in caring than men is neither to glorify the value of women nor accentuate that women make the most suitable carers. Rather, the female family carers were suggesting that attention is important in care provision regardless of the gender of the carer and that attention when caring is not a woman-only characteristic. Moreover, they accentuated that attention is not innate but a learned skill. Thus, men can learn how to be attentive when providing care.

5.4.3 Katanyu Negotiated in Undertaking Care

It seems uncommon for Thai people to share perspectives of katanyu that are different or opposed to public understanding. This may be because katanyu is based on religious belief and considered almost a doctrine of caring, as described in Section 1.3.2. Whilst katanyu is seen as such and intertwined with caring and repayment, the findings found that female family carers negotiated katanyu in two aspects. First, katanyu should be recognised in an emotional sense rather than in a rational sense. Second, katanyu should not be imposed as a measurement of caring, but should be flexible and adjusted to suit particular circumstances.

Katanyu in the Emotional Sense

Since katanyu is considered a rule for children to follow, almost all female family carers considered that katanyu should be considered in an emotional dimension. Comments made by some carers are examples to illustrate this point.

Manee said that katanyu should not be seen as something logical, but as something emotional, in the sense that it is expressed from feelings.

> Manee: Katanyu should be neither an idea nor a matter of logic. I think it should be a matter of emotion and feeling coming from your mind.

Ratchada expressed the same sentiment:

> Ratchada: Katanyu is talked and written about in a theoretical and logical context. It’s like an immutable frame of mind that is taught to people from childhood, otherwise it wouldn’t be recognised. It’s a good thing, anyway. […] To me, providing care as katanyu means that you must have heart in doing it.

Similarly, Saipin considered the expression of katanyu to not be simply the performing of an action or pretending to do something, without real feeling behind it. Saipin said:

> Saipin: Katanyu for me is very simple. It is just doing your best to care for your parents. […] Caring is not performing a drama. It must be practically done, with heart.

In addition to considering katanyu as an emotional practice, some of the female family carers suggested that katanyu requires that the person being cared for is understood by the carer.

To Sasi, understanding the cared-for person could help the carer understand how they could meet the cared-for person’s needs appropriately, without which the caring could not be called katanyu.

> The researcher: Is katanyu difficult to express?
> Sasi: The first thing you need to keep in mind is having heart so that you can love, and devote your life to it. Then, you need to understand the people you’re caring for, to know them and their needs.

Jan also commented that understanding the cared-for person could help katanyu be expressed in the proper way, since the understanding might calm the carer when facing challenging behaviours from the cared-for person.

> Jan: Caring will be seen as katanyu once you ‘have heart’ to care. Another thing is that you need to understand your cared-for person with dementia

> so that you won't be angry over what she did in a strange or aggressive way. If you get angry, you might react to them in a bad way.

In addition to understanding the condition of the cared-for person, some carers, such as Rungnapa, considered that katanyu in the context of care also involves patience and tolerance by the carer. In the following comment, Rungnapa explained that patience and tolerance could enable the caring to be done smoothly in order to meet the needs of the cared-for person.

> Rungnapa: To me, katanyu in caring means that you need to have patience and tolerance. And you might need to follow what they [the cared-for person] did, and what they need. Otherwise, they will be against your caring. Then you'll be stressed.

The previous comments suggested that katanyu should not be an idea or a rule that a person blindly follows in isolation but chooses to enact in relation to others. According to the female family carers who participated in this study, katanyu should instead involve an emotional aspect. Its expression in the form of care needs to be deliberately done with feeling, attentiveness, patience, and tolerance, which demonstrate the relational aspect of katanyu.

Katanyu As a Thing Not to Be Imposed

As described earlier in this chapter, it is not common to express different perspectives toward the notion of katanyu in public. One who does not follow this notion of repayment might be called 'akatanyu', which means 'a bad child' (Watana 2016). The importance of katanyu is reinforced by users of social media, where actions of katanyu and akatanyu are accentuated publicly, so much so that katanyu is sometimes used as a weapon to complain about something or somebody, or as an excuse for certain acts.

This study found that some of the female family carers accepted katanyu as a social value but did not hold katanyu at the heart of the matter of care provision. Neena, Preeya, and Zin are examples of this point. Neena said that her caring was not led by katanyu as much as ethics of care. To her, it seemed that caring should be based on its ethics rather than a social value:

> Neena: In my case, katanyu did not have a great influence on my caring. Caring should be judged by its own ethics, not by katanyu, I think.

The same sentiment was found in Preeya's comment. She seemed to consider that, in the context of care, there were other aspects to be aware of besides katanyu.

> Preeya: I didn't consider katanyu when caring for my mother, actually. I saw caring as my duty and I followed it. […] You need to have sympathy. Be willing to care, and to use your heart.

Similarly, Zin's view was that, despite recognition of its significance, katanyu was not at the heart of caring, as she said below.

> Zin: I don't have any idea of katanyu in mind at all [stressed voice]. I'm not saying that I don't believe in it. I keep it in mind though, and I also taught my niece about its importance. But I would say that I didn't have katanyu at the core of my caring. What I kept in mind when caring for Mother was my concern and attention to her.

The comments made by the female family carers illustrated that katanyu was recognised as a good social value, but it was not necessarily the central value of their provision of care. This shows that the female family carers were internally reconsidering the definition of katanyu in the context of care and considered that it did not play as significant a role as an ethics of care. This corresponds to a study by Finch and Mason (1990) in which their research participants considered that the principle of reciprocity is significant, but it should not dominate everything.

Koong and Ratchada stated that katanyu should not be used as a criterion to assess or judge the value of another's caring. Instead, it should be subjective and adapted in accordance with circumstances to suit the carer's way of providing care in each family.

Koong told of how she used to hear complaints about the quality of the care she was giving to her sister. She thought that the notion of katanyu was subjective, since it depended on experience in caring for people with dementia, which was more challenging than some people thought. Koong said:

> Koong: If we're talking about katanyu, I think everyone has it in mind. But some people, if they haven't experienced caring for someone, might not understand katanyu thoroughly. I used to be misunderstood and insulted by my sisters' friends, who thought that I was treating my sister like she was a fool. They said what I was doing wasn't giving good care.

Regarding the subjective characteristic of katanyu, Ratchada also thought that there was no need to strictly express katanyu in line with public expectation, because the worth and importance of katanyu in the context of care depended on the relationship between the carer and the care receiver in each family.

> Ratchada: If you stick on any frame or rule, be it duty or katanyu, you'll get stressed. Katanyu is a good value. […] But there is no need to fasten yourself to it. […] To me, the reason for care was not up to other people's judgement. To do it that way is like torturing yourself. If you do so, how can you know to what extent your caring was satisfying in the public eye? Why don't you look at how happy your cared-for person is [instead]?

Another account of negotiation is that there should be limits in the expression of katanyu. The following comments made by Aurapa and Manee demonstrate the flexibility of katanyu in the context of care.

In Aurapa's case, she recognised katanyu as a significant value encouraging her to make sacrifices in caring. However, her comment implied her negotiation that katanyu should be flexible to fit the situation. To her, having a break or personal time should be important to carers as well.

> Aurapa: Katanyu is involved very much. […] To me, Mother is beyond everything. I'm willing to care. It's alright for me if she wants me every hour to help her go to the toilet or change her incontinence pad. The only thing

> I beg is to let me sleep after 3 a.m. without waking me up 5:30-6:00 a.m. I couldn't get up.

Likewise, the flexibility and negotiability towards katanyu were directly explained in Manee's comments. By having terrible experiences and a poor relationship with her parents, Manee's perspectives toward katanyu in caring changed. To her, katanyu was something manageable and could conceivably become invalid in certain circumstances. Recently Manee has attempted to find a balance between her mother's benefit and her own.

> Manee: I've overcome my worst difficulties with katanyu. My mother and father cared for my brother only. My parents said they had a duty to care for their children [supporting them financially]. They took on a loan to support him [her brother], and asked me to pay the debt to the loaners instead. So, what about me? It took many years for me to think about how to handle katanyu and my own life. So, I put an end to katanyu by having no response to my parents' needs. But I felt guilty and very hurt, you know. I think katanyu should not have to be something to apply without limit.

The comments previously discussed indicated that the value of katanyu was acknowledged and appreciated, but that there were some limits to katanyu as an expression of repayment. This corresponds to the study by Finch and Mason (1990), in which their survey respondents suggested that despite the significance of reciprocity in kinship there might also be some limits to what could be expected as repayment. It can be said that such limits indicate that katanyu was negotiated as a flexible and alterable value, particularly in the context of caring.

However, in exploring the negotiation of katanyu, the findings suggest that the female family carers faced a dilemma. That is, on the one hand, caring could be seen as the expression of katanyu and a good thing. On the other hand, at times when caring tasks were challenging and required emotional management, carers might express aggressive behaviours to their cared-for parents. These behaviours could be seen as 'akatanyu' since they were disrespectful acts toward the parents. The comments made by Fenda, Sawalak, and Anchalee illustrate this.

In Fenda’s case, she was not sure whether her caring could be called katanyu because she used to lose her temper and shouted at her mother sometimes. Fenda explained:

> Fenda: Yes, we [family carers] need to be very patient and understand that those people are living with their illnesses. […] If they do something annoying, you should walk away from them. Otherwise, you might shout at them unconsciously. I used to be that way. So, sometimes I wondered if I was showing katanyu or not at all.

The same thought occurred to Sawalak, who had a poor relationship with her mother since she was a child. For Sawalak, caring was undertaken as part of the responsibilities and duties of a child. Her siblings ignored this duty, so it was up to only her to provide care for their mother. The constraints of the family relationship and the difficulties in managing care were likely to make her embarrassed and lead her to respond to her mother in an aggressive way.

> Sawalak: When caring, I might also have been doing bad deeds, because I got stressed. I didn’t have 100 per cent understanding of my mother and used to do some things angrily […] I used to say something to her like, if I could choose to resign from being her child, then I would. […] My mother insulted me by saying that I was ‘akatanyu’ child. Sometimes I wanted to say that if I was an ungrateful person, then what about the others [her siblings]? Were they good?

Likewise, Anchalee said that caring for parents was not similar to caring for children, since carers should be much more aware of showing dignity and respect to care receivers who are parents. She confessed that at times she spoke to her mother as if she had authority to take care of everything involved in the care, such as the expenses of medical treatment. In this respect, being an adult child carer sometimes cannot be consistent with the notion of katanyu. Anchalee explained:

> Anchalee: Katanyu should go with understanding and love. Actually, when I was caring for my mother, I didn’t recognise this value. But once I did something bad unconsciously, like treating her unkindly, I wasn’t sure

> whether I was showing katanyu or not. It’s like, I am trying to do my duty of care, but I wasn’t thinking of how she felt about what I did. I felt like I was standing in a dilemma.

The dilemma seems to evidence that katanyu might not always be a suitable and practical discipline in some circumstances. The notion of katanyu sometimes made the carers embarrassed or guilty in going about their provision of care.

It can be said that in negotiation, the female family carers challenged the taken-for-granted notion of katanyu and felt that it should be expressed with emotions and feelings, otherwise this concept is merely a rule or discipline that seems to be useless in giving care practically. In addition, the female family carers argued that katanyu should be changeable and more flexible in the sense that it should not be imposed and used as a measurement to judge or assess the care provided, since each family has their different ways of dealing with their circumstances.

5.5 Conclusion

This chapter explores how female family carers make sense of their repayment in caring for their relatives with dementia. Regarding the notion of repayment in the context of care, the findings suggest that it is expressed in two facets. The first facet is explicit repayment, where female family carers considered it as an intention to care. The second facet is implicit repayment, in which the notion of repayment was attached but somehow hidden amongst other reasons for caring. In fact, implicit repayment played an important role for the female family carers in caring since the giving and receiving of care and support in the past were recognised in their care provision. In addition to those two facets, the female family carers considered the notion of repayment not in terms of exchange of material goods or support or as a transaction, but in ethical terms. In this respect, the findings show that women’s understanding of repayment stems from the relationships they had with others, in the sense that they saw the value of support exchanged neither by the support itself nor by the statuses of the giver and the receiver. Instead, they valued the family support by the relational aspect, which is symbolised and embedded in the acts of giving and receiving between their cared-for person, other relatives involved, and themselves.

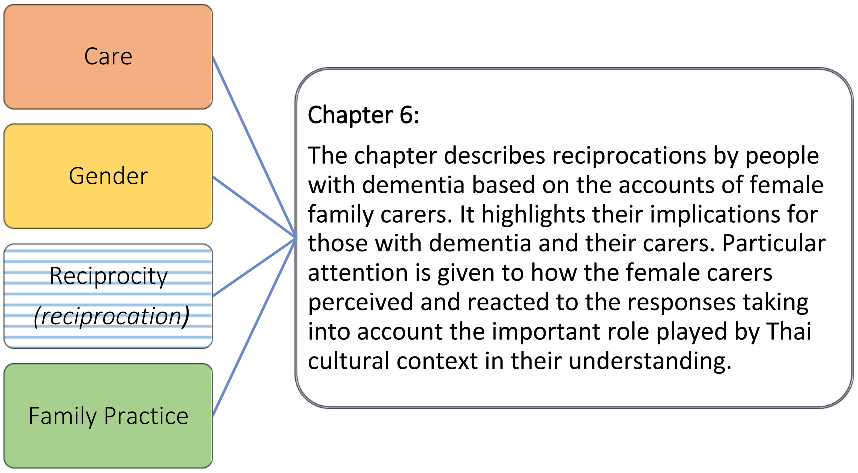
Suggested by a feminist approach, this chapter found that female family carers established and developed their understanding of repayment by learning from the ways their relatives acted towards each other. Upon learning these practices, which included both ethical practices within the family, and practices without love and concern, they realised the significance of repayment in several ways, for instance, in observing, remembering, and comparing the circumstances of reciprocity within the family. In this thesis, findings regarding how the female family carers learned and made sense of repayment suggest that the notion of repayment as an aspect of intergenerational reciprocity in Thailand is not only a matter between the parent and child, or the carer and care receiver. Rather, in the context of care, repayment also rested on the relationships of other relatives who might be more peripheral but involved and influenced the family carers' repayment and their ways of caring.

Inspired by a feminist approach and the concept of family practice, the notion of repayment within the family is not automatically enacted but negotiated. Participants identified three main ways of negotiating repayment and caring. First, they demonstrated how repayment could be performed in different ways. Then, they valued their caring as being, at the very least, equal to male ordination. This reflects that they were re-positioning the hierarchical order of women's ways of repayment. Second, they considered that caring could be a gender-neutral practice that should entail attentiveness and sensitivity with an emphasis on an ethics of care. Third, female family carers negotiated katanyu by arguing that katanyu should include an emotional aspect and should be flexible. Katanyu should not be imposed as a discipline or doctrine of caring, but rather be more flexible and have a limit. These aspects are consistent with the explanation of reciprocity and family practice put forward by Finch and Mason (1993) and Morgan (2011), which posits that reciprocity should be not a rule to follow but should be understood as a negotiation, which would provide insights into how the individuals are balancing when reciprocating. In this sense, the female family carers were proposing that katanyu should be just a guideline which carers are able to adjust in line with their caring circumstances. Moreover, the findings on negotiation and katanyu help reveal a dilemma that the carers faced which appears hardly acknowledged in public Thai society.

The findings in Chapter 5 offers insight into the dimensions of repayment, which are ‘routine acts of repayment’ and ‘significant acts of repayment’. They are discussed in Chapter 8 along with other dimensions of repayment.

Chapter 6: Reciprocation from People with Dementia

6.1 Introduction



Chapter 6:

The chapter describes reciprocations by people with dementia based on the accounts of female family carers. It highlights their implications for those with dementia and their carers. Particular attention is given to how the female carers perceived and reacted to the responses taking into account the important role played by Thai cultural context in their understanding.

Figure 2c: Conceptual Map of Chapter 6

The previous chapter focused on the family carers' repayment in the form of caring for older people with dementia. This chapter aims to explore the reciprocation given by care receivers according to the family carers' perspectives. Caring for those in physical decline, such as those with dementia, is likely to be one-directional (Gouldner 1960), where a reciprocal relationship might be difficult to achieve as the cared-for person's cognitive conditions influence their ability to communicate and engage with other people, including the ability to reciprocate (Graham and Bassett 2006, Killick and Allan 2001, Neufeld and Harrison 1998). However, reciprocation could be conveyed not only in verbal but also in non-verbal ways, meaning that reciprocation may not be wholly absent. The perception of reciprocation is possibly connected to the ability of carers and other people to notice or reach those with dementia (Gove et al. 2016, Barnes 2012). There are different types of reciprocation, for instance, positive reciprocation and negative reciprocation. The former is a good response while the latter refers to challenging behaviour or harmful responses (Adams and Sharp 2013 cited in Gove et al. 2016, Guala 2012).

In the study of how family carers understand reciprocation given by people with dementia, this chapter is divided into three sections. First, it discusses the negative reciprocation that the family carers received from people with dementia. Second, it describes the positive reciprocation. Regarding both negative and positive reciprocation, these were perceived to be such by the carers who participated in this study. Either form of reciprocation may be manifest in a way that was unintentional on the part of the care receiver. Both forms of reciprocation may come from people with or without dementia. In the discussion, the researcher addresses negative reciprocation prior to the positive form, as the former seemed close to the public perception of dementia; the researcher's intention in presenting the information in that order is purposeful in order to change such a taken-for-granted understanding of dementia. However, both negative and positive forms of reciprocation are presented on the basis of actions rather than on modes of expression, since some actions are composed of two modes and difficult to discuss separately. Also, it is the researcher's intention to uncover the acts of reciprocation to be obviously seen. The emotional responses of carers towards the things reciprocated are also discussed. Third, the chapter proposes that reciprocation is not solely an expressive action of behalf of an individual, but a site of connectedness between the family carer and the person with dementia.

6.2 Negative Reciprocation

This section describes the forms of negative reciprocation and also the female family carers' understanding of such reciprocation, as they perceived it.

6.2.1 Forms of Negative Reciprocation

The female family carers perceived that they received negative reciprocation from their relatives with dementia in two forms, which were refusal of the care provided, and blame or complaints towards carers.

Refusal of Care Provision

Some of the female family carers noticed responses from their care receivers that indicated some dissatisfaction regarding the care given.

Rungnapa talked about her mother's reaction when Rungnapa offered to help do something for her, but her mother insisted on doing it herself.

> Rungnapa: I gave her three oranges and peeled them for her. She insisted that she would peel them by herself. I said to her, ‘No’. Then she wasn’t interested in me or the oranges. She walked away and then lay down on the sofa [laughing].

Similarly, Neena reflected that sometimes her mother reciprocated by expressing dissatisfaction. She interpreted her mother’s reaction as a dislike or unappreciation of her caring. Neena said that she herself valued the act of giving and assistance. In this sense, to Neena, the dissatisfaction meant that the giver and the acts of giving were not acknowledged and valued.

> Neena: When I gave care to her, for example, I provided her with her medication, what I got was her stern face and unpleasant manner. She might think I interfered with her. But to me, what I did was about her. I spent my time totally for her benefit, not mine.

In the cases of Rungnapa and Neena, their relationships with their mothers with dementia had been good. The perceived negative expressions might have resulted from the cared-for people’s feelings of imposition because carers had intervened in their desires or their decisions to act. Regarding those with dementia, Boyle and Warren (2017) suggest that it is taken for granted that they lack the ability to make their own decisions. The decision-making could be indicative of excision of their agency. The perceived negative reciprocation from those with dementia might be manifested as a result of their agency being taken away.

Neither Rungnapa nor Neena reported the perceived negative reciprocation from those with dementia as having been expressed in an aggressive way. But, in other cases, negative reciprocation may be expressed aggressively. Whether the responses were aggressive or not, the responses of people with dementia contained some message to the carers, at least to show how they felt (Boyle and Warren 2017). The aspect of emotional response is discussed in relation to the agency of those with dementia in detail at the end of this section.

According to some of the female family carers, negative reciprocation was demonstrated when they provided personal care to their relatives with dementia, such as bodily care. As Twigg (2006) suggested, the subject of the human body is related to the matter of privacy, including allowing other people to access and touch one's body. Bodily care then is an intimate relationship, which may provide an opportunity for the carer to touch the cared-for person's body even though it is an undeniable invasion of privacy. In this sense, the aggressive reciprocation may be a reaction from those with dementia to their carer's invasion. Notably, the responses were not in response to actions initiated by those with dementia, but rather indicated dissatisfaction with the care performed. The experiences of Zin, Rungnapa, and Yuri are examples, as described as follows.

Zin said that when she changed an incontinence pad for her bedridden mother, she was scratched and clawed by her mother. Zin's view was that this reciprocation was her mother's release of tension, therefore, she did not try to stop her mother's reaction. Zin spoke of this situation while showing her wounds to the researcher.

> Zin: I often got her claw when I changed her incontinence pad in the night. She looked angry and unaware of everything at that moment. She might feel like my father and I were strangers because she looked at us very fiercely. I let her claw me until she stopped by herself.

Similarly, Rungnapa received many bruises from her mother when helping the mother bathe.

> Rungnapa: I helped her take a shower. When I wiped her body and poured the water, she scratched me [laughing].

In Yuri's case below, her view was that the aggressive reciprocation might make her neighbours misunderstand or wonder about her home situation. Yuri spoke of her mother's crying out when she helped her bathe, as follows.

> Yuri: When I poured the water on her body, she cried out and said loudly, 'No. No. Dirty.' So, I was afraid that my neighbors in the flats might wonder

> what's wrong with us or if we have some violence going on at our place. But actually, we were just taking a bath [laughing].

Blame and Complaint

Blame and complaint were the negative reactions that people with dementia reciprocated to their carers. Some of the family carers perceived such reactions to be intentional, while other carers thought that the reactions were the result of the symptoms of dementia. The following comments made by Preeya, Sasi, Sawalak, and Paula illustrate the blame and complaint they received from their relative in return for caring.

In Preeya's case, although she felt slightly hurt when being chastised by her mother, she understood that her mother's dissatisfaction might be caused by dementia.

> Preeya: If she doesn't like what I do for her, she gets angry and blames me, saying that I am an ungrateful child. Then I'll think about now it's only me taking care of her. My siblings are hardly interested in such stuff.

Some carers were complained to by their relatives with dementia on issues unrelated to the dementia care activities. For example, the family carers were expected to take care of everyone in the home, even though those people were not ill, because it was the expectation of them as women. The female family carers then were complained to by their parents with dementia if they failed to follow this expectation or seemed opposed to doing this family matter. In Sasi's case, she said that her mother with dementia urged her to welcome and take care of her brother, who came to visit the mother occasionally. Sasi felt very disappointed, because her mother treated her as if it was her duty to care for everyone in the family, while she was the only one to take care of the mother and was already exhausted in doing so. Sasi explained:

> Sasi: It's me who always takes care of her [her mother]. But when my brother came, she said to me, 'Why don't you serve some food for him?' I felt like I was seen as the 'other person' [who has never been familiar and close to her]. She said it as if I have lots of time to do everything. I always take care of her, but she complained at times. I felt so exhausted to the point of feeling very much neglected.

Sasi’s comment suggested that the negative reciprocation from her mother made her distressed. She attempted to cope with her emotional strain by accepting the situation little by little. Unlike Sasi, Anchalee said that her mother challenged her care so often that Anchalee got tired and then expressed her stress in front of her mother. But her mother only returned sarcastic words, which made Anchalee more disappointed.

> Anchalee: I used to feel stressed from caring for her. I touched my head and said something like, ‘Hurr … I have a headache’. She said back to me that she would move away from me, then. I was not feeling good at that moment.

In the cases of Sasi and Anchalee, the perceived reciprocation happened in different contexts, but the cared-for people’s reciprocation may illustrate their frustration of not being able to do the things they wanted or used to do.

For other family carers, the complaints received occurred when providing personal care. It can be said that the complaint or blame might be explained in relation to the nature of care rather than being judged as a symptom of dementia. Particularly bodily care where touching is inevitably involved, the complaint and blame indicated that those with dementia still have a sense of privacy and a sense of belonging. That is, the complaint and blame were the means to communicate how they felt and to inform the carer of their awareness of their bodies. Paula and Sawalak’s experiences are examples of this point.

Paula talked about her father’s complaint about her caregiving. Paula confessed that she was not happy at that moment. She was sad, but not because of her father’s demanding attitude. It was because the father’s complaint was a criticism, as though she did not know what proper care was. Paula explained:

> Paula: I was powdering his cheeks, and then he told me, ‘My back, you haven’t done my back yet.’ I told him, ‘Wait a minute. I am doing it on your face first, then on your back.’ I was not happy at all at the moment because his tone of voice was like he was criticising me as if I was a fool and didn’t know how to do it.

Sawalak experienced a similar sentiment when she helped clean her mother's body.

> Sawalak: When I was helping her clean her bottom, she ordered me, 'Wipe my bottom. Quickly, quickly.' She said it while I was holding the napkin and already doing it for her. What she did made me nervous, you know.

Generally speaking, the understanding of dementia is dominated by medical perspectives (Innes 2009), and the behaviour of people with dementia perceived as symptomatic of an illness. The forms of perceived negative reciprocation – refusal of care provision, and blame and complaint – were not seen that way. But neither were they necessarily seen simply as responses to the carers or the help offered. Instead, the findings also demonstrated people's ability to express, or even their perseverance in expressing emotions (Ellis and Astell 2017, Boyle and Warren 2017, Kontos 2003).

Hughes (2013) asserts that communicating with those with dementia is to do with feelings, not with words. Emotions are the way that individuals interrelate and connect to one another (Burkitt 2012) and therefore emotional reactions, regardless of the forms, seem to be indicative of the agency of those with dementia (Boyle and Warren 2017). Emotions in the form of aggression, anger, and dissatisfaction described in the findings were the ways that those with dementia were engaging and communicating with the carers. In other words, those with dementia appeared to inform their carers, through the negative reciprocation, that they were not satisfied, felt a lack of control and autonomy, felt anxious or uneasy, or even ignored as a result of the care provided. Following this, the negative reciprocation here could indicate the agency of people with dementia to express, to connect or attempt to connect with their carers.

6.2.2 Carers' Understanding of Negative Reciprocation

Carers' Emotional Responses

It is certain that the perceived negative reciprocation from people with dementia did not show their appreciation of the care given. Moreover, such reciprocation brought about negative feelings for the family carers. The comments made by the carers indicated that, after their negative feelings occurred, they then made sense of such reciprocation as being the result of dementia. Emotional responses are now discussed before looking at the way the carers later understood the reciprocation received from their cared-for people.

Family carers' emotional responses were manifested in various forms, which seemed to be not much different. Some of them felt disappointed, as can be seen in Anchalee's case, who said, *'I was not feeling good at that moment.'* Some carers felt terrible, such as Sasi, who said that, *'I felt so exhausted to the point of feeling very much neglected',* while some carers, Preeya for instance, felt slightly hurt: *'Then I'll think about now it's only me taking care of her. My siblings are hardly interested in such stuff.'* In addition to the feeling of disappointment, some family carers felt angry when receiving negative reciprocation, for example, Paula, who was angry when her father expressed his demand when she was giving him bodily care: *'...his tone of voice was like he was criticising me as if I was a fool and didn't know how to do it.'* Paula's case indicated that her anger was caused by her father's criticism of her caring. The feeling of anger also occurred with Neena, who said that her caring role was ignored. Neena responded that she was not pleased with the manner of ignorance or unappreciation that her cared-for person expressed toward the caregiving that they received. Neena reflected that*, 'I got angry easily when someone in the family didn't value what I did for them. With my mother, also. Sometimes I felt slightly dissatisfied.'* Similarly, Zin confessed that when she received bruises from her mother, she used to react to her mother in a moody way: *'I was angry back, but she didn't stop. The more I was angry, the more she was aggressive.'* Some carers suggested they did not feel angry, but rather nervous when the cared-for person seemed to be demanding about the caring which was being done. This kind of feeling was found in Sawalak's comments: *'What she did made me nervous.'*

Making Sense of Negative Reciprocity

It is not surprising that the female family carers had negative responses to the reciprocation given by their relatives with dementia. How they understood such reciprocation in order to deal with it and their own feelings more properly are more important. Given that, this study found that the family carers used their knowledge of dementia along with skills of emotional management in making sense of reciprocation.

In Preeya's case, her assumptions about the cause of her mother's negative phrase 'ungrateful child' were that it was a symptom of her dementia. It was her view that that dementia had an effect on the ability to control oneself in a person with dementia. The following comment indicated that the way Preeya made sense of the negative reciprocation expressed by her mother likely rested on her knowledge of dementia. Her comment indicates that she perceived the reciprocation as something resulted from dementia.

> Preeya: I think the time when she scolded me was after she got dementia. It's almost like when she got angry, she picked up everything around her to dispute. She kind of couldn't control herself.

Similarly, in Paula's case, although she was not happy about her father's negative reciprocation, and correspondingly had more awful moments than happy ones, she used her knowledge of dementia to understand that reciprocation was a manifested sign of dementia.

> Paula: What I have are not happy moments at all, but I dealt with it by thinking that it was a symptom of dementia, not his [pre-dementia] self. If he didn't have dementia, he wouldn't have done it that way.

However, Paula added that despite having knowledge of dementia, she could not automatically understand the negative reciprocation. Rather, she needed to control her emotions and learn to be careful with her own reactions so that the caring could be given to her father in a more measured way. Paula explained:

> Paula: At that moment, I couldn't help myself by instantly fine-tuning my emotions. It's hard to avoid responding suddenly to him. But at least, I realised that I was keeping my emotions inside and wouldn't let myself burn out.

Paula's comment suggested that emotion management also played an important role in the context of understanding reciprocation, particularly in dementia care. The aspect of emotional labour was brought into the discussion of the female family carers' understanding, as it can be found in other respondents' comments, for example, comments made by Zin, Koong, and Neena, as follows.

From her caring experience, Zin learnt that her untamed reactions neither helped her mother to stay calm nor she herself to stand the thing her mother was doing in reciprocating negatively to her caring. Her skill of emotional management was not an individual property, but an on-going process that she gradually learnt while providing dementia care.

> Zin: We need to know and accept that she's ill. It's true that I used to feel bad, but what else I can do with her, who wasn't fine? So, we shouldn't have given bad reactions to them [people with dementia] because they don't know. Using logical thinking towards them wouldn't help them or yourself. And we'd become stressed.

Zin's comment showed that making sense of negative reciprocation sometimes required the skill of emotional management. The acceptance was a skill for the controlling of emotion, which she attempted to do. The skill was not something enlightening, apparently, but was developed from reviewing the ways of dealing with her mother's earlier reactions.

Similar to Zin's technique of acceptance, Koong made sense of her sister's reciprocation by developing emotional management through a 'go with the flow' technique.

Koong perceived that the negative reciprocation came from her sister's cognitive condition, as part of which her sister needed time to concentrate on pressing the buttons of a phone and did not want to be interrupted. Thus, Koong made sense of the situation of negative reciprocation by a technique of letting the situation go. This technique was one way of managing her emotions in order to maintain a peaceful atmosphere. Koong added that the solution to a situation should be initially solved by the carers themselves, not those with dementia. In other words, carers were able to change themselves in order to deal with a situation.

> Koong: I needed to wait a little, until she asked me for help. I won't interrupt her. I know that I can't change her totally. I needed to do it [manage the situation] myself.

Likewise, along with having knowledge of dementia, Rungnapa made sense of negative reciprocation from her mother by managing the emotions of both her mother and herself. Her techniques were persuasion or diversion through the creation of some new situation. In addition, she emphasised that carers' understanding, tolerance, and attentiveness were necessary to understand the negative reciprocation from their relatives. Rungnapa explained:

> Rungnapa: As I've said, I needed to be attentive, patient, and understand her [the mother]. And, it's almost like I need to have persuasive skill when caring [laughing]. Doing everything to charm her.

The comments also indicated that carers' understanding of negative reciprocation by their relatives with dementia implied the notion of an ethics of care that put the emphasis on the benefits of the other person. Despite being regretful and unsatisfied with the negative reciprocation, the female family carers had the view that the care should be done for the sake of the care receivers rather than the carers themselves. In this respect, some carers, Neena for example, believed that spiritual growth was developed through the undertaking of care activities, particularly in the reciprocity in caring:

> Neena: After I often felt dissatisfied, I thought to myself more deeply and came to overcome this issue [the issue of being appreciated by the cared-for person]. If I still wanted something good to be reciprocated, it meant I was still self-centered. It shouldn't be that way. I think if I wish to learn to be free from my thoughts and self, I should not have been delighted or upset about anything.

In female family carers' experiences, negative reciprocation was described in the form of refusal of care, and blame and complaints expressed by those with dementia. Obviously, this reciprocation brought about negative emotional responses such as disappointment, anger, and neutral feelings toward the carers. The resources that family carers used to understand negative reciprocation were their knowledge of illness and their skills of emotional management. The carers had their own techniques for dealing with the situations calmly.

6.3 Positive Reciprocation

The previous section discussed the negative reciprocation of people with dementia. In one way, this reciprocation might be understood as the symptoms of dementia. In another way, the reciprocation held some meaning that the person was trying to communicate in response to the family carers and the care provided. This part describes the positive reciprocation, in order to increase public awareness and understanding of the presence and significance of positive reciprocation, as found in this study.

When considering positive aspects of reciprocation, people might think about words spoken, such as ‘thank you’, as it is a common and simple way to express appreciation for something given. However, carers may believe that people with dementia are likely to fail to give thanks or that they have nothing to give thanks for (Gove et al. 2016, Graham and Bassett 2006, Sweeting and Gilhooly 1997 cited in Ellis and Astell 2017). Many scholars suggest that the reciprocation given by people with dementia does not necessarily come in the form of ‘well-articulated’ communication, and that consideration must also be given to non-verbal modes of expression (Barnes 2012, Pettersen and Hem 2011, Innes and Capstick 2001), such as vocalisations, movements, facial expressions, eye gaze, and physical contact (Ellis and Astell 2017, Astell and Ellis 2006, Kontos 2004). This part then describes perceived positive reciprocation in a variety of both verbal and non-verbal modes experienced by the participating female family carers. Their emotional responses and understanding towards positive reciprocation are also discussed in this section.

6.3.1 Forms of Positive Reciprocation

This study found a variety of forms of positive reciprocation that people with dementia showed to their carers. They included smiling, laughing, lively reactions, eye expression, touching, expressing concern and care, recognising the carer’s importance and name, engaging with the carer, saying thanks, and making gestures of thankful expression. Participants reported the people for whom they cared reciprocating in either verbal or non-verbal modes of expression, and sometimes both, using their bodies as a communicative resource to engage with others

(Ellis and Astell 2017, Hydén 2013, Hughes 2013, Kontos 2004). Reciprocation was communicative; rather than isolated expressions unrelated to others, it was intended to express something (Kontos 2004) and responses were therefore meaningful to themselves and their carers.

Smiling, Laughing, Lively Reactions

Many participants confirmed that their relatives with dementia still responded to them with reactions such as smiling, laughing, and talking with them in a lively manner. For Neena, Noy, and Fenda, the smiling of their care receivers meant a positive state of mind, which supported the carers' emotions, too.

Neena said that she saw her mother smiling at her when receiving Neena's care. To her, smiling meant her mother's satisfaction.

> Neena: Yes, she used to smile at me. Actually, if only she looked happy and her face did not look sad or stressed, that's fine for me. She had no need to put anything into words.

Similarly, Noy said that it was worth receiving smiles from her grandfather because it was very difficult for him to smile. When asked this question, Noy answered enthusiastically.

> The researcher: After your grandfather became ill, did you get any smiles from him?
> Noy: Oh, yes [Answering quickly]. He smiled [Noy smiled when speaking], and called my father's name. […] I was so glad and hurried to phone my dad to let him know.
> The researcher: Is this [the smiling] better than saying something in words like 'thank you'?
> Noy: Definitely. It impressed me much more than those words. I was so happy.

This sentiment was also found in Fenda's comment.

> Fenda: Some days, she [her mother] smiled, looked very happy and fresh, and talked in a lively way with us. I was so happy. She was amused. That's everything for me. But this didn't happen every day. Other days, she may do things differently.

From these cases, smiling from their care receivers illustrated that they were mindful of the present situation, and their smiling was able to change the caring situation.

In addition to smiling, laughter was also an expression that those with dementia reciprocated to their carers. Zin and Fenda said it was not often that their mothers expressed positive emotions through smiling and laughing. Thus, their mothers' laughing could create moments of happiness for everyone in the family.

> Zin: My mum laughed. When she laughed, I was so happy. And you know, even my paid helper appreciated my mum's reaction. My helper said to my mum, 'If only you could be happy, everyone else would be happy, too.'

In this study, it was found that lively reactions were expressed accompanying verbal expressions. In Rungnapa's case, her mother sometimes both smiled and initiated a lively conversation. It was Rungnapa' view that these reactions were valuable and compared them with thankful words; she considered that the words 'thank you' were not necessary for her mother to say.

> Rungnapa: When my mum was laughing or responding to me, like asking me if she looked beautiful, that can make me smile. […] She had no need to say something thankful to me at all.

The lively reaction of Rungnapa's mother was also seen as an expression of humour. In this sense, Killick and Allan (2011) suggest that people with dementia can perceive and learn to encourage their moments of humour with other people. Following this, Rungnapa's case showed that a person with dementia was able to share the humour not only as a participant in the situation but also as an actor who contributes her/his feeling to create a lively situation.

Eye Expression

Some of the female family carers referred to the eye expression of their relatives with dementia. In the researcher's point of view, eye expression seems to be a non-verbal mode of communication that is very difficult to notice. In this study, carers noticed and confirmed that there were some messages embedded and expressed through the eyes of their relatives with dementia. They understood that their relatives were able to perceive the care they provided. Without words spoken, the carers could sense that their caregiving was satisfactory and recognised by their care receivers. Anchalee and Paula had experiences of eye expression, as described in the following comments.

Anchalee said that she noticed her mother's eyes, which showed satisfaction with the meal that Anchalee's husband cooked.

> Anchalee: When my husband cooked for her [Anchalee's mother], and she found it delicious, she smiled with her eyes. I would say that. It's like she still could make a good response to the care we gave.

Similarly, Paula noticed her father's eye expression when helping him to bathe, in which she could sense his satisfaction when receiving her care.

> Paula: In some moments, I can see … I noticed that if I was doing something for him [her father] in a gentle way or supporting him with tenderness, he could recognise my care. I saw this in his eyes when I helped him to bathe.

According to these examples, those with dementia expressed their emotions through their eyes, which was an unspoken language. If carers did not notice this form of expression and the only thing they recognised was silence, some of the messages that those with dementia wished to communicate, such as their feelings of appreciation or satisfaction, would not be perceived. However, the silent actions of those with dementia appeared to have meaning, as well. Here, silence accompanied with eye expression signifies not only the satisfaction of those with dementia, but their awareness of how others have treated them, and notably their acceptance of the care that the carers were providing. Therefore, their silence could be a way that those with dementia connected with their carers. In this respect, Kontos (2005) also suggests that bodily gestures accompanied with silence, or a silent exchange of expressive gestures, could be considered as one of their ways to engage with the world.

Before discussing other forms of reciprocation, the case of Paula suggests a final critical point which is that, alongside caring tasks which did not involve bodily touch (Section 6.2.1), bodily care, involving touching and privacy access, seems to give an opportunity to carers to receive positive reciprocation as well as negative reciprocation. Thus, the different sets of caring tasks are not necessarily the only factors that explain why and how the care recipient responds to the carer. The aspect of the care recipient's agency should also, then, be taken into account. Respecting the agency of the care recipient might relate to the expression of the care recipient, as the case of Paula suggested.

Touching and Expression of Concern and Care

Twigg (1999, 2006) suggests that touch is a form of human contact that spreads emotion and underwrites the engagement. Touching and expressions of concern and care were forms of reciprocation which tended to be reported by family carers who had a good relationship with their relatives prior to having dementia.

In this study, Saipin said that her mother's touch was an impressive action which made her love her mother more than before. Saipin added that although her mother was not able to communicate with her via the verbal mode, her mother was still able to encourage her by touching. During telling her story, Saipin also displayed her mother's touch and gesture as a demonstration for the researcher.

> Saipin: She [her mother] couldn't speak but she cheered up me. She touched my shoulder and gave me a thumbs up. It's almost like she wanted to say to me, 'Great, or good job [good caring]'.
> The researcher: Was that her thanks to you?
> Saipin: Yes, I think so. She's trying to say thanks for caring for her. That's her love given to me, also.

To Saipin, her mother’s touch and gesture were equal to acts of giving, in which the feeling of love was embedded. This respect was also found in the cases of Ratchada and Aurapa, whose mothers still had the ability to verbally communicate. They received bodily touches interwoven with other kinds of expressions in which their mothers attempted to convey feelings of concern and care.

Ratchada said she experienced her mother’s reciprocation through touching and holding her hands, smiling and eye expression. This reciprocation occurred when she provided a massage to her mother in the night.

> Ratchada: Yes, yes. I got her eye contact and smiles. And, sometimes when I massaged her arms, she would hold my hands and said to me, ‘I like it [massaging]. Are you tired? Are you sleepy? You’d better go to bed.’
> The researcher: How did you feel at that moment?
> Ratchada: My heart was full [laughing]. It’s much better than the word ‘thanks’.

In the cases of Saipin and Ratchada, touch and spoken words meant concern, love, and care. This corresponded with Kontos’s explanation that touch initiated by those with dementia could signify attention given to ease other’s anxiety (Kontos 2004). In Saipin and Ratchada’s cases, their mothers’ expressions indicated their awareness of the presence of the carers and conveyed their sensitivity towards them. In this sense, Kontos (2004) also suggests that the sensitivity could refer to a sense of compassion that those with dementia were able to give to others.

Likewise, Aurapa’s case demonstrates acts of embracing along with eye expression and spoken words from her mother delivering the feeling of concern, care, and attentiveness to her, particularly through eye contact. In this sense, eye expression or gaze could refer to a desire to communicate (Ellis and Astell 2017) as well as to the attention being paid to them; and care was expressed towards the carer through the gaze (Kontos 2004). Aurapa spoke of her mother’s concern:

> Aurapa: When I needed to go out on a personal matter, she said to me, 'Come back soon. Don't go too far.' Then, I gave her a hug, and she hugged me, also. I looked into her eyes and I sensed that she felt concerned and cared about me.

The previous cases showed that feelings of concern and care were reciprocation expressed through verbal language accompanied by different non-verbal language or bodily gestures such as touch, eye contact, and smiling. For people with dementia, the use of hands in gestures and touch helped to enhance the conveyed message in the sense that they used their hands to touch the other people's world (Killick and Allan 2001). The touch was a bodily movement that they held as their resource in creating interaction with others (Hydén 2013) and in providing comfort and gentleness for other people (Kontos 2004).

Recognising the Importance and the Name of the Carer

Some family carers considered the recognition of their names and caring roles as reciprocation given by their relatives with dementia.

In Sasi's case, her mother used to say that Sasi's care was an essential part of her life. In saying such a thing, those with dementia are making a verbal expression indicating their attention and awareness of something – in Sasi's case, she considered it to mean that her mother appreciated the care that she was providing.

> The researcher: Has your mother done or said something thankful to you?
> Sasi: Sometimes. Just on some occasions. For instance, when I helped her replace an incontinence pad, she said to me, 'Well, without you, it's more difficult for me.' Then, I said to her, 'No worries.' I did it because she was my mum and used to do things like this for me when I was a kid.

Similarly, Zin said that her mother was able to remember Zin's name. Remembering her name indicated that the mother was giving importance to her. In this sense, Zin felt she was the intended recipient of her mother's expression, and therefore she was needed by her mother.

> Zin: Sometimes she seemed not to be able to remember me. But during the night, she woke me up. She called my name, 'Zin, Zin…', to help her walk to the toilet. If she needs my support, she can remember what my name is [laughing].

The recognition of their carer's importance and name by those with dementia was a verbal expression reflecting the awareness they had of another's presence and support. The recognition in this sense was their attempt to connect to the other person. It also indicated their reflexivity in the way that they were showing what they desired, and how they felt towards their carers as well as recognised the need of their carers to be appreciated.

Engaging with the Carer

Some positive reciprocation by people with dementia was expressed in the form of engaging with their carers. The engaging response showed that those with dementia were aware of and collaborating with the care being provided. The experiences of Rungnapa and Saipin are examples.

Rungnapa recalled her mother's compliant response when she assisted her mother with walking upstairs. To Rungnapa, compliance with caring was more effective in demonstrating appreciation than spoken words.

> Rungnapa: When I was helping her go to bed upstairs, like teaching a child to walk, and she could walk, that's what she did for me without it being necessary to say anything appreciative to me. She was able to respond to what I was doing to support her.

Similarly, in Saipin's case, one of her mother's impressive ways to reciprocate was by being cooperative with her caring. The responses were considered actions that represented a 'thankful feeling' given back to her because these responses illustrated her mother's awareness of caring.

> Saipin: Sometimes when I helped her get dressed, she helped me by pulling up her own trousers. She made it easier to do.

Saying Thanks and Gestures of Thanks

In this study, saying 'thank you' is a form of reciprocation that most of the female family carers experienced in different ways. As noted earlier (p209), saying thanks is a normal expression of appreciation, which is widely understood as a thing reciprocated to a person who did a favor for another. In the Thai language, the word 'kob koon' means 'thank you', which people normally use when speaking to others in a public area rather than in a domestic area like with family, though occasionally it may be used in familial conversation.

In Anchalee's case, when asked whether she had experiences of receiving appreciative or positive reactions from her mother, she accepted that her mother still could remember her. Her mother said, 'Kob koon, loug'. The latter word, 'loug', means 'my child'.

> Anchalee: Yes, she's still able to say thank you. When I take care of her, she often says, 'Kob koon, loug' ['Thank you, my child' in English].

The researcher presents the term in the Thai language, since the language has cultural implications associated with family status and the relationships of family members. As described earlier, status and relationship influence the carers' understandings of reciprocation in the sense that they indicated that people with dementia still retain the cognitive ability to recognise other people and their statuses. Thus, in Anchalee's comment above, she felt that the reciprocation was given to her as a child rather than as a carer, because her mother spoke of Anchalee's status.

In this respect, there was a slight difference in Jan's case. Jan insisted that her mother often said thanks to her, but she was not certain that the word 'thank you' was given to her as a child or a carer.

> Jan: They [people with dementia] do have abilities. My mother, too. She often says 'thank you' to me. But prior to having dementia, she didn't say it that much. I was wondering if she thought that I was not her child.

Comments made by Anchalee and Jan suggested that the relationship between recognition of carers by the cared-for person and frequency of reciprocation was not straightforward. In Manee's case, although she often received the words 'thank you' from her mother, it was not easy for her to interpret reciprocation as she lacked closeness and intimacy with her mother. Manee explained:

> Manee: She said ‘thank you’ often. For example, when I did something for her such as giving her a meal and medication, she said thanks to me. But I was not sure if she knew who I was to her.

Paula commented that words of thanks from her father did not occur frequently, but he was able to give them. The following extract was her recent experience, in which she considered her father’s thanks as his ability to recognise the care being provided.

> Paula: Yes. He can say [thankful words]. He was just saying thanks to me yesterday. It’s not too often, though. […] I was glad that he knew what I did for him. It rarely happens, but it happens.

With respect to the presence of reciprocation expressed by people with dementia and the frequency of expression, Wipawee shared her comments that people with dementia have the ability to reciprocate and perceive the care given. Their abilities depended on their stages of dementia. Wipawee said:

> Wipawee: It’s up to which stage of dementia they are in. Not all of them express their gratitude to carers, but they are *conscious* of it [Said with emphasis]. In my mother’s case, she was aware of what I was doing for her sometimes. […] My mother said to me, ‘Thank you’. She felt and could react.

In Zin’s case, aside from the stages of dementia in relation to reciprocation, she believed that a person’s abilities were not a simple explanation, because not all parts of the brain declined or at the same rate.

> Zin: The brain does not decline 100 per cent. It just goes little by little. And it’s not fixed and predictable. For example, my mother often said ‘thank you’ to me. She said thank you along with doing a ‘wai’ gesture [a gesture

> of respect in Thai culture]. But some other days, she didn't. She scratched my skin instead.

In Zin's experiences, her mother's thankful expression was spoken along with a gesture, 'wai'. Wai is the most common non-verbal expression in Thailand (Powell et al. 2014, Cooper and Cooper 2005). It is a mark of paying respect, greeting, or recognition, performed by putting the palms together on the chest and bowing the head. Wai can be performed along with speech, while it is also performed solely without any verbal expression (Powell et al. 2014). Fenda and Rungnapa also experienced wai as a display of appreciation from their mothers with dementia.

Fenda said that her mother liked saying 'thank you' and gesturing wai to her and other family members, including nurses and other health practitioners at the hospital.

> Fenda: My mother liked to show wai to everyone who did something good for her. She also showed wai to me, my sisters, my niece, and the nurses.

Similarly, Rungnapa's mother often times that her gestured wai to her, especially when she prepared the meals for her mother. Rungnapa understood that her mother knew that there was someone giving her good things, but could not know who the giver was.

> The researcher: Some carers got the words 'thank you' from their cared-for people. What about your case? Did you get that sometimes?
> Rungnapa: My mother gave wai back to me when I gave meals to her. I will show you how she does it [Rungnapa acted as if she were her mother doing a posture]. I said, 'Mom, here's a meal for you.' She gave me wai and then I gave her wai back. She gave me wai more than ten times a day.

Reciprocation in the form of saying thanks and gestures of thankful expression were found in almost every case, at varying frequency. The frequency shaped the carers' understanding of the reciprocation. In addition, this study found that the wai gesture, which is a non-verbal mode of thankful expression, played a significant role in addition to thankful speech in interpreting the meaning of reciprocation that the carers received. Gestures in relation to cultural implications are discussed further in Section 6.3.2.2.

In sum, the positive forms of reciprocation shown by people with dementia were expressed in both verbal and non-verbal language. That is, their speech was exposed, and sometimes accompanied with bodily gestures and movement, and even sometimes replaced with silence. In other words, the findings showed that although the verbal communication ability of those with dementia may decline, their non-verbal communication remains a possible channel for them to supplement or substitute their spoken words (Hydén 2013) in order to reciprocate to carers. Then, their feelings, including gratitude, appreciation, and sympathy, are displayed in reciprocation. Thus, for those with dementia, the body seems to be their communicative resource to connect to others, when their verbal language is limited or absent. When they reciprocate, their bodily language or embodiment in reciprocation acknowledges their sense and abilities, which are central to their agency (Boyle and Warren 2017, Downs 2013, Kontos 2005). Taylor (1985 cited in Higgs and Gilleard 2016) suggests that not just the ability to do something is important, but also the ability to want to make choices, to be aware of choices, and to consider the choices that could be made in reaction to others. In this sense, the reciprocation of those with dementia could be considered not as individual expression but expressive responses in order to connect to the world. Embodied reciprocity is discussed further in Section 6.5, which underscores reciprocation as a site of connectedness.

6.3.2 Carers’ Understanding of Positive Reciprocation

The previous section showed that people with dementia still have the ability to contribute something back to others, and that reciprocation is not completely absent in those with dementia. Rather, reciprocation is manifested in a variety of forms in both verbal and non-verbal modes of expression. Not every reciprocation, however, is satisfying in the family carers’ views. This study found that the family carers perceived reciprocation to have two meanings in the context of caring. Firstly, reciprocation is perceived as a reward. Secondly, it is understood as only a symptom of dementia.

6.3.2.1 Reciprocation as Reward

The comments from carers in this study suggested that some reciprocation was equal to a reward, which brought about satisfaction for the carers. Before looking at the characteristics of rewarding reciprocation, the researcher presents satisfaction with caring as a positive dimension of care so that the discussion of reciprocity in this section is informative.

When caring is the act of giving and receiving, or a reciprocal relationship, satisfaction is a dimension that needs to be considered, since satisfaction represents the importance of reciprocity in terms of receiving some benefit of mutual exchange (Nolan et al. 1996). In addition, although reciprocal relationships are sometimes not of equal exchange, satisfaction as a product of a caring relationship helps maintain a sense of balance between dependence and independence of the two parties, and indicates the entire process of the reciprocal relationship (Tretteteig et al. 2017, Nolan et al. 1996). In the context of caring in Thailand, carer satisfaction is an aspect of caring that appeared to be less discussed in dementia care research compared to other aspects, such as carers' burdens and carers' difficulties. With respect to carers' experiences, the term 'satisfaction' is commonly used in explaining carers' pleasures and rewards in relation to caring, and feelings of joy and gladness (Tarlow et al.2004). Carers' satisfaction rests on numerous sources. For instance, the carers derive satisfaction from seeing their self-development, competence, and resilience through the act of care. Some carers might feel satisfied since caring helps reduce their feeling of guilt, while some want to feel loved and needed by their care receivers. Thus, satisfaction enables carers and caring to be meaningful (Tretteteig et al. 2017, Nolan et al. 1996). In this exploration of how family carers understand the reciprocation given by their relatives with dementia, satisfaction is a dimension brought into discussion alongside reciprocation.

According to the female family carers' perceptions, not every reciprocation was seen as reward. A reward here could be characterised by two aspects that are separate but interwoven. First is the ability of people with dementia. Second is the meaningfulness of caring.

Presence of Abilities of People with Dementia

The first characteristic is the abilities of people with dementia. The good signs of physical and psychological health conditions – which were manifested through a variety of forms of reciprocation such as remembering the carer's name, smiling, laughing, lively reactions, eye expression, touching, and engaging with the carers – are the capacities that those with dementia retained. From the family carers' points of view, those abilities are associated with the personhood of their cared-for people, since the reciprocation is the expression of their selves in different ways.

Zin was satisfied when her mother was able to remember her name occasionally, although she could not recognise who Zin was to her sometimes. Despite that, calling the carer's name indicates the ability to initiate a conversation, and respond relationally with other people. Therefore, her mother's ability not only showed retained cognitive ability but also reflected her mother's self. Zin's comment below shows her gladness when seeing her mother's ability of recognition.

> Zin: '…[D]uring the night, she woke me up. She called my name, 'Zin, Zin…', to help her walk to the toilet. If she needs my support, she can remember what my name is [laughing].

When it comes to non-verbal expression, the reciprocation expressed through the form of smiling, laughing, lively reactions, and eye contact indicate not only the wellbeing, but also the ability to communicate and express of those with dementia. For example, Noy, who cared for her grandfather with Alzheimer's disease, said that she was very satisfied when seeing him smiling at her, because his communicative skills used to come and go. It was Noy's view that her grandfather's smiling referred to the active state of his health and self.

> Noy: I was so happy, because I saw him stopping smiling and talking for a long period since we [the family] found there was something wrong with his behaviour. So, when he could talk and smile again, I was happy with that.'

Saipin also felt appreciated when her mother smiled and touched her during her care, including encouraging her with bodily reactions.

> Saipin: She wasn't completely silent or unaware. She was still able to react to me somehow.

It was Saipin's view that this reciprocation reflected the mother's retained abilities to engage and respond to the conversation. In addition, although the reciprocation was conveyed in a non-verbal mode of expression, Saipin believed that reciprocation was the mother's intended response. With respect to engaging in conversation, Sullivan (2012 cited in Boyle 2014) suggests that whilst lacking dialogical ability, people with dementia appear to be able to view themselves relationally.

In the extracts above, the abilities of people with dementia and the relation to their carers were expressed using words such as ‘can’, ‘still can’, and ‘able to’. Killick and Allan (2001) suggest that when talking about the ability to reciprocate, the notion of personhood is an issue to be considered. In a reciprocal relationship such as caring, carers might think about what they expect from those with dementia or at least the personhoods of two parties are recognised when caregiving. Personhood alludes to the fact that human beings have a relation to others (Kitwood and Bredin 1992). In this respect, a person then has a status and is to be respected by others. Thus, personhood is not the property of the individual, but it is socially constructed, as it is given by the presence of others. Moreover, upon the development of personhood, the sense of being a person emerges (Kitwood and Bredin 1992, Cassel 1982 cited in Dewing 2008).

There are a variety of studies researching the ability people of with dementia to invest in relationships with others (Sabat and Lee 2011, Kitwood and Bredin 1992). A study by Kitwood (1997) found that dementia is not an irreversible process. Rather, it is dialectic in the sense that there could be a possibility that a person with dementia’s reduced levels of ability and function – for instance, communication, feeling and learning – will return to their previous levels. This possibility is called ‘rementia’ (Kitwood 1997). There were attempts to explain the links between the cognitive abilities and the personhood of people with dementia through relative wellbeing indicators where the cognitive conditions were assessed to be wellbeing or ill-being (Kitwood and Bredin 1992) The indicators of wellbeing include the ability to experience and express a range of emotions, affectional warmth, humour, creativity and self-expression, relaxation, and showing pleasure. These indicators might be seen as simple actions. But, in the case of those with dementia, these indicators mark not only their relative wellbeing, but also their expressions, which reflect the sense of agency embedded in their state of wellbeing. This explanation helps mirror the dimension of personhood in reciprocation in this thesis.

In this study, the rewarding reciprocation shown by people with dementia expressed through smiling, laughing, lively reactions, eye expression, and touching, for example, illustrate not only the wellbeing of those with dementia but also their ability of expression, in which their intrinsic personhoods are also displayed. Some phrases by carers, for instance, *'…she can remember what my name is',* and *'she was still able to react to me'*, indicate that carers are satisfied not only by the witnessed abilities and personhood of their relatives, but also, based on concept of family practices, by feeling the connectedness within the reciprocal relationship in which the personhoods of two parties were recognised and maintained.

The abilities of people with dementia as the first characteristic of rewarding reciprocation were found in almost all of the carers' described experiences. The second characteristic of rewarding reciprocation is also now described.

Meaningfulness of Caring

The second characteristic of rewarding reciprocation refers to the meaningfulness of caring, which is interwoven with the abilities of people with dementia, as discussed previously. In this sense, the meaningfulness of caring includes the recognition of caring, the carers' feelings of being supported, and their perceptions of successful caring.

In terms of recognition of care, some family carers said that their parents could not remember who their children were, but the parents disclosed their ability to recognise the care provided. This aspect was found in the comments made by Saipin, Rungnapa, and Paula. Saipin acknowledged her mother's wai as her mother's ability to recognise her caring.

> The researcher: How did you feel when your mother said thanks and gave wai to you?
> Saipin: I'm glad that she still knew. […] She knew what I was doing for her but didn't who I was to her.

Likewise, Rungnapa spoke of her mother's cooperative attempt towards her assistance to walk. The reaction indicated that her mother was aware of and able to perceive Rungnapa's help. This means that her mother accepted her help and care, also. Rungnapa said:

> Rungnapa: That's what she did for me without it being necessary to say anything appreciative to me. She was able to respond to what I was doing in supporting her.

The awareness or recognition of the care provided was also found in Paula's experience. Paula was glad to witness her father's eye expression because it meant his ability to recognise her support.

> Paula: [I]f I was doing something for him in a gentle way or supporting him with tenderness, he could recognise my care. I saw this in his eyes when I helped him to bathe.

For carers, the reciprocation reflected the people with dementia's ability to recognise the care being given. The previous comments by Saipin, Rungnapa, and Paula showed that the recognition of care implied acceptance of care along with relationality from the cared-for people. These characteristics created reciprocation, which was rewarding and satisfying for the carers.

In addition to recognition of care, sometimes carers might feel satisfied since they were cared for by the person for whom they cared (Andrén & Elmståhl 2005). Aurapa said that her mother's encouraging words were meaningful to her. To her, the reciprocation indicated not only her mother's recognition but also the attention to and understanding of Aurapa's care. Aurapa felt that she received support from her mother in return.

> Aurapa: She used to say to me that, 'You'd better take a nap during the day.'
> This showed that she understood that I was tired and needed a rest.
> The researcher: How did you feel at that moment?
> Aurapa: Very delighted. It's like she was cheering me up. That's indescribable.

In addition to the recognition and support in caring, the perception that the caring is successful also influences the carers' understanding of reciprocation as reward. Some participants viewed that their cared-for person's abilities of expression and reaction were the result of the successful outcome of the care provided. Consequently, the carers found their roles meaningful and brought about pride and satisfaction as a form of reward (Quinn et al. 2015). The comments made by Saipin and Ratchada are examples of such perceptions. In Saipin's case, she appreciated her mother's reciprocation expressed in the forms of touching and encouraging her with bodily reactions, since they revealed the abilities that her mother still had. Such abilities were evidence of her success in caring, which in part was resisting the declining health of her mother.

> Saipin: I felt like I can do it [improving her mother's reactions]. She turned out better. […] I think I can help improve her health despite the fact that her symptoms might become worse.

Similarly, in Ratchada's case, her mother's smiling, touching, and talking were not only evidence of awareness of caring, but also illustrated the successful care that Ratchada provided. Her caring could make her mother happy and comfortable. To Ratchada, her mother's happiness was like positive energy flowing around both of them during care, especially when Ratchada massaged her mother's body.

> Ratchada: When I asked her if she liked my massage, she said, 'It's nice.' She's happy with what I did for her. So, if I could make her happy, I was happy too, because she gave the happiness back to me. It's like happy energy flowing between us.

Regarding considering reciprocation as the positive outcome or a reward to family carers, Qureshi et al. (2000 cited in Nolan et al. 2002) suggest four sets of valued outcomes in carers' views. Two of those are the quality of life of the cared-for people, and the recognition and support of the caring role (Qureshi et al. 2000 cited in Nolan et al. 2002). Following this, this study illustrates that family carers made sense of reciprocation as a reward when the reciprocation evidenced the ability of their relatives with dementia to reciprocate and express their personhoods. Additionally, family carers understood the reciprocation as a reward when such reciprocation reflected the meaningfulness of the care they gave. It can be said that, since the reciprocation occurred during the course of care provision, family carers were both receivers as well as givers, in a reciprocal relationship, because they felt the things they did were worthwhile.

6.3.2.2 Reciprocation as Illness

Among the various forms of reciprocation discussed earlier, saying thanks and gestures of thankful expression did not seem not to be rewarding or satisfying for the female family carers, despite being obviously seen as appreciation or gratification. In the family carers' perspectives, expressing thanks in words or gestures was not meaningful reciprocation. Rather, they seem to be indicators of the symptoms of dementia. Such perceptions were associated with intimate knowledge and cultural knowledge that family carers used to make sense of reciprocation they received**.**

Intimate Knowledge and Symptoms of Dementia

In this study, one of the sources to understand reciprocation as forming part of the person's illness was the intimate knowledge that family carers had of their cared-for people. The familiarity and intimacy prior to living with dementia provided them with accumulated knowledge and experience that they utilised in making sense of their relatives' symptoms of dementia. Family carers also used observations and comparisons of their relatives' behaviours as ways to understand the reciprocation that they received. For example, Yuri noticed that her mother's thankful words were given to her so frequently that she questioned it. In addition, she found that her mother's personality prior to having dementia was always kind. Kind words such as 'thanks' were normally said to everybody, but not to Yuri because there was no need for a mother to say 'thanks' to her child. Therefore, Yuri made sense of the thanks given by using her intimate knowledge as a source to identify her mother's developing symptoms of illness. Her extract illustrates that she understood that her mother's saying thanks was caused by dementia. Yuri said:

> Yuri: Yes, she also said thanks to me. […] After she became ill, she said it more often to me. […] She thanked me without knowing that I am her child. She thanked me for the things she got.

Preeya also made sense of reciprocation by recalling her past relationship with her mother. By comparing the situations in the past, she saw some differences in her mother's behaviours.

Preeya noticed that her mother's thankful words were never spoken to her until her mother became ill. Moreover, she was told 'Thank you, ma'am', a formal term that should not be used in family conversations where every member talked to each other casually.

> Preeya: She said to me, 'Thank you, ma'am'. This is not the way to say thank you to a daughter. […] I was upset. She knew my name was Preeya, but didn't know who Preeya was.

From Preeya's comment, it can be seen that Preeya's intimate knowledge was a source in interpreting her mother's reciprocation, including helping her keep an eye on her developing symptoms. Likewise, Saipin used her intimate knowledge of her mother to understand her use of the wai gesture. Saipin found wai in this context unsatisfying, because it indicated that her mother's symptoms of dementia were worsening. Saipin explained:

> Saipin: Previously, she never gave wai to me, because her brain and memory were still fine at that time. […] But now, she gave it [wai] to me and said, 'Thank you'. […] She didn't know I was her child, either. I was sad.

In addition to the issue of intimate knowledge in making sense of reciprocation, the comments above by Preeya and Saipin also had some interesting aspects in relation to cultural knowledge, which will be explained in the next part of this chapter.

Although intimate knowledge played an important role in making sense of reciprocation in some of the family carers, it seems to have been difficult for some, such as Manee. Manee confessed that she did not feel close or familiar with her mother because she had felt oppressed by her mother's gender-biased parenting since she was young. They were strangers to each other. It was more comfortable for Manee to learn to understand her mother and to guess her behaviours day by day. Thus, based on her knowledge of her mother, Manee was uncertain what was motivating her mother's reciprocation.

> Manee: I was not sure that it [saying thanks] was what she usually did or if it was her real appreciation. Because I didn't feel familiar with her. I mean I

> don’t know her at all. So, I have no idea if it [saying thanks] was given to me because I was her daughter, or if it was because of other reasons.

Cultural Knowledge and Symptoms of Dementia

In literature regarding illness and disease, including dementia, culture is explained as an influencing factor in understanding illness in many respects. With respect to dementia, cultural context and knowledge had an effect, for instance, on the interpretation of the meaning of dementia (Hillman and Latimer 2017), on clinical diagnosis and approaching dementia care service (Pachana and Gallagher-Thompson 2018, Elliott and Di Minno 2006), and on how family carers react to illness, their cared-for people, caregiving (Downs 2000), or even the recruitment of family carers for dementia research (Hinton et al. 2000).

Killick and Allan (2001) suggest that understanding non-verbal communication with people with dementia requires subtlety, as it holds cultural values that influence the ways people behave. Cultural values have an effect on assessing whether behaviours are right or wrong, or approved or not. It is possible that people from different cultural backgrounds misunderstand some non-verbal channels of communication as they do not know the norms (Killick and Allan 2001). When it comes to understanding reciprocation from people with dementia, this thesis found that cultural knowledge also played an important role in shaping the family carers’ perceptions of reciprocation, particularly saying thanks and the gesture of thankful expression called wai. Before looking at how cultural knowledge affects carers’ understanding, some background information relating to the wai gesture and styles of expressing thankful appreciation is provided.

The wai gesture was described earlier in this thesis as a form of reciprocation that the people with dementia expressed to their family carers. Thai people perform wai by putting the palms together on their chest. In Thailand, wai is a gesture commonly used for greetings or paying respect to other people. It is a form of body talk that can be expressed along with speech (Cooper and Cooper 2005) or without (Powell et al. 2014). Also, it can be done concomitantly with bowing the head or without, depending on the status of the counterparts. Wai is then a cultural practice designating the status of people in certain circumstances, since usually people of a younger age are expected to initiate wai with people with higher status, such as older people or monks. Thai people will not use the wai gesture with people with a lower social status than themselves, such as children, grandchildren, or servants (Powell et al. 2014, Cooper and Cooper 2005). However, wai is flexible and the gesture is sometimes given to people of the same age, such as colleagues, since it displays politeness and respect (William 2007 cited in Powell et al. 2014). According to some of the participants of this study, giving thanks and wai as a form of reciprocation from care receivers was seen as a problematic behavior, rather than an expression of appreciation. That said, the family carers considered that the reciprocation given by people with dementia was not expressed properly in accordance with Thai culture. Namely, wai is not a gesture usually used by parents with their children in Thai society.

When she received wai from her mother, Rungnapa interpreted this action by linking it to Thai cultural practice and the cognitive ability of her mother. Wai was perceived as the mother's failure to know the status of family members; the mother could not remember that Rungnapa was her child.

> Rungnapa: If she knew I was her child, she might have not shown wai to me.

Cultural knowledge was used by the female family carers to make sense of wai as reciprocation, and this interpretation led them to understand the self-perceptions of their cared-for parents with dementia. Following this, comments made by Fenda and Saipin suggest that, according to their assumptions, their mothers might perceive themselves as their children, or as simply unrelated younger people. Thus, wai was perceived as the manifestation of cognitive problems rather than thankful expression.

In Fenda's case, reciprocation expressed by wai urged Fenda to assume that her mother's ability was declining, evidenced by her mother's self-perception.

> Fenda: My mother liked to gesture wai to everyone who did something good to her. She also showed wai to me, my sister, my niece, and the nurses. I was wondering if she found herself as a younger person.
> The researcher: How did you feel about her expression?

> Fenda: Um… Not really happy. […] I know it is her way to express thanks, but it's not a way that a mother normally behaves toward her children. […] This is because of her illness.

Similar sentiment was also found in Saipin's comment below, in which she linked cultural knowledge and symptoms of dementia in her understanding. Based on her cultural knowledge of parent-child interaction in Thai society, Saipin interpreted the wai as the result of changes in brain function in her mother, because she viewed her mother as acting like a child. Saipin explained:

> Saipin: Previously, she never gestured wai to me, because her brain and memory were still fine at that time. […] But now, she shows it [wai] to me and said 'thank you'. She acted like she was a kid. She didn't know I was her child either.

In addition to wai, the changes in self-perception were also disclosed in the spoken term 'thank you'. Generally, this term is supposed to be used for expressing appreciation, both in public and personal areas like family. The way that the term is used depends on the extent of formality in a certain circumstance and on the statuses of actors. In this study, one participant, Preeya, reported that her mother with dementia knew this term was a way to express appreciation, but did not know to how use it properly. Her mother said, 'Thank you, ma'am'. In one way, it is a polite term that is acceptable to say to other people. It is also used in somewhat formal conversations. In another way, it is not normally used in personal relationships. In this respect, cultural knowledge of saying thanks and how it should be used enabled Preeya to perceive this reciprocation as a sign of dementia rather than as appreciation given to her.

> Preeya: I never got this ['thank you'] until she was ill. […] She said to me, 'Thank you, ma'am'. This is not the way to say thank you to a daughter. […] This proved that she was not able to remember me.

Regarding relationality in saying thanks and offering the wai gesture, the previous comments made by Rungnapa, Fenda, Saipin, and Preeya suggested that the relationship embedded in such reciprocation was misinterpreted. Their statuses and identities and those of their relatives were defined inaccurately and were irrelevant to their actual relationships. However, in this respect, some participants, Zin for example, had slightly different perceptions. Zin explained that although wai seemed to suggest her mother's failure of self-perception in relation to other family members, it showed her mother's ability of recognition, because she expressed gratitude to someone who helped her.

> Zin: No. She didn't [know that I am her daughter]. If she knew, she won't gesture wai to me. I think that although she probably didn't know that wai isn't normally shown to a younger person, it could be possible that she knew that people normally express gratitude or appreciation through wai, which can be perfomed to anyone.

As discussed, the family carers' comments suggested that cultural knowledge had a great effect in shaping the family carers' understanding of the reciprocation received from people with dementia. Family carers knew that the Thai gesture wai and saying thanks in the context of Thai culture were symbolic displays of relationships and relationality between people, however this reciprocation did not reflect their relationships in a practical everyday way. Instead, the irrelevant statuses and identities implied led some carers to perceive this reciprocation as the manifestation of the symptoms of dementia.

6.4 No Reciprocation Received

When asked about receiving something in return from the cared-for people, two participants reported that they never derived any reciprocation. The reason for their understanding rested on the feeling of being involved. The participants said they were not addressed by the cared-for person on the subject of the caring activities they did. Below are the experiences of Raywan and Sawalak.

Raywan answered the question by giving an example to the researcher. She explained that when someone asked her mother which person provided care, her mother never mentioned Raywan's name but spoke of her brother's and sister's names instead. To Raywan, mentioning the name of the carers seems to be a form of appreciation. Thus, she did not consider her mother's words to be reciprocation, but a failure of recognition that was caused by dementia.

> The researcher: Has your mother said thanks to you or given something back to you?
>
> Raywan: No. She failed to remember. I think she loves her son. One day, my aunt asked her who the carer was. My mother spoke of my siblings' names, not mine at all.
>
> The researcher: How did you feel then?
>
> Raywan: Well. She's sort of got memory problems. Her memory stuck with the son, whose children she helped look after.

A similar sentiment was expressed by Sawalak, who reported little reciprocation from her mother. She gave an example of her mother's reaction and recalled a childhood to describe how she regretted what her mother did. Sawalak compared her experience with her siblings', who received thankful words or appreciative feelings from their mother, but Sawalak rarely received any appreciation. Sawalak reflected that she felt slightly neglected.

> Sawalak: No. I never got any of that [reciprocation]. I felt a bit neglected, really. […] When I bought some food for her, I never got any thanks from her. This word never came out of her. She responded with complaints, instead. But, you know, when my siblings came to visit her and bought some low-quality food for her, she was glad and said she liked that food.

Although Raywan and Sawalak understood that reciprocation was hardly given to them, their comments implied that their parents still had the ability to reciprocate. That is, the carers witnessed that appreciative reactions existed, but the carers did not perceive them because their names or their roles were not paid attention to or straightforwardly addressed. Thus, in these two cases, not feeling involved led them to think that no reciprocation was paid to them. The issue of understanding of reciprocation is discussed in the next part.

6.5 Reciprocation as a Site of Connectedness

When considering reciprocation from people with dementia, it is not only an individual expressive phenomenon. Reciprocation itself is not a simple exchange as part of a reciprocal relationship. Also, it is not only the act of an individual giving their resources to another in return for things they previously received. Rather, reciprocation is also a site of connectedness for carers and care receivers. This connectedness can be understood in two ways. Firstly, the connectedness is established once reciprocation from people with dementia becomes known, read, and perceived by their family carers. Secondly, the connectedness happens once the family carers see themselves within the reciprocation received.

6.5.1 Reciprocation Expressed to Become Shared and Known

In this study, to deliberate the forms of reciprocation expressed by people with dementia, the aspect of embodiment of reciprocity is taken into account. Work on embodiment and dementia by Kontos et al. (2013) suggests the significant implication of bodily turn, which can build contributions toward both practices and theoretical works regarding dementia care and other healthcare issues. 'Embodiment' in the context of dementia refers to the consideration of the body as a source of opportunity in relations with and between people with dementia, in the sense that the body is a hub interconnecting history, culture, power, and discourse, which socially construct the notion and practices of dementia. 'Embodiment' also indicates and emphasises the bodily potential of people with dementia, their creativity, expression (Kontos et al. 2013), and sociability (Kontos 2004). It requires knowledge of the cared-for person with dementia, along with the psychological and cultural context, in the interpretation of non-verbal clues so that the meaning within bodily clues can be shared with other people (Hughes 2013, Kontos et al. 2013). There are a number of examples that illustrate the meaning embedded in bodily clues. For example, Downs (2013) suggests that the action of wandering is a bodily expression that indicates that people with dementia need to express themselves and to move. Kontos (2004) suggests that bodily movements of those with dementia convey their self-expression, including forms such as affection, love, dislike, sympathy, etc., which they use in inter-personal communications to other people. However, embodied reciprocation accompanied with verbal language together conveys the self of those with dementia, for instance, their words 'thank you', 'good morning', and 'bless you' (Kontos 2004). In this sense, the embodiment aspect helps the observer to understand the sense of self of people with dementia, including whether they are aware of their surroundings, define themselves as a person, and are able to interact with their counterpart as human beings in meaningful ways (Kontos 2004). Embodied reciprocation is therefore seen as informative and communicative to the others with whom those with dementia interact.

In this study, the embodied reciprocation by people with dementia – which included smiling, laughing, lively reactions, eye expression, touching, and the gesture wai, for instance – held messages that they communicated to their carers in a meaningful way. For example, the cases of Koong, Rungnapa, and Neena showed that the response to the carer's help by using speech and apparently walking away (in Koong's case), or avoiding walking without speaking (in Rungnapa's case), or a sullen expression (in Neena's case), carried the meaning that those with dementia wanted to express their emotions of dissatisfaction or anger. These examples of reciprocation were not merely physical responses but informative in the sense that the needs and emotions of those with dementia were conveyed and exposed to others. Lopez (2018) suggests that to give something back makes individuals related to one another. Kontos (2004) also suggests that the behaviours of people with dementia in order to engage with other people can be meaningful interactions rather than reflections. Those with dementia are more than passive recipients (Kontos 2004, Tronto 1993). Thus, family carers should be attentive and receptive (Barnes 2012, Tronto 1993), otherwise the meanings embedded in reciprocation will likely be lost. From the researcher's point of view, to understand embodied reciprocity more deeply, the notions of feminist ethics of care along with a concept of family practice might be used in the explanations accompanying the concept of reciprocity in order to explain the connectedness in family caring practices in more detail.

Following a feminist ethics of care (Tronto 1993), the researcher views that reciprocation might be considered as responsiveness on the part of the care receivers to the care provided. Understanding the responsiveness also requires attentiveness, since each element of care ethics is intertwined with the others. That said, when carers are attentive, and engage with the care receivers' needs according to the wishes of the care receivers rather than the carers' assumptions about how to care, the carers become recipients of the meaning embedded in reciprocation (Tronto 1993). In this study, the family carers noticed negative reciprocation, such as avoiding a walk and a sullen face, and understood that their care receivers wanted to change and direct a certain situation (Tronto 1993). Therefore, the connectedness between the family carers and the needs of the people with dementia emerged once the carers were attentive to the embedded meanings in reciprocation.

The following extracts by some carers are examples describing their attentiveness and their interpretations. The carers perceived that those with dementia wanted to communicate something back. In Paula's comment about negative reciprocation, her attention in reading the bodily clues in her father's reciprocation helped her to interpret her father's feelings and needs. She perceived that he wanted to blame her: *'…because his tone of voice was like he was criticising me…'*. Likewise, as shown by Koong's comment, her attentiveness enabled her to read and understand her sister's needs to achieve something on her own: *'I knew that she didn't want anyone to interrupt her. So, I needed to wait a little, until she asked me for help.'* In positive reciprocation, some carers were also attentive and interpreted the meaning embedded in the reciprocation. In Yuri's case, she realised that her mother wanted to thank her for her care: *'After she became ill, she said it more often to me. […] She thanked me without knowing that I am her child. She thanked me for the things she got.'* Similarly, Saipin perceived by being attentive and reading the embodied reciprocation that her mother wanted to encourage her: '*She [her mother] couldn't speak but she cheered up me. She touched my shoulder and gave me a thumbs up'.* As discussed, family carers' attentiveness involved their sensitivity to notice and read the meaning embedded in reciprocation. In understanding the reciprocation, carers' attentiveness thus plays an important role: to access and understand the subjectivity of people with dementia.

However, as discussed earlier, this study found that negative reciprocation and some forms of positive reciprocation were seen as illness. Once family carers witness reciprocation, it is possible that they might interpret or judge such reciprocation as a part of the illness initially but kept it in mind. In this respect, Sevenhuijsen (2018) suggests the term 'active attention', which emphasises the aspect of 'waiting' as a dimension of attention in caring interaction. The 'waiting' refers to holding back one's own suppositions and fixed ideas in order to better understand the otherness of the other. In this study, some of the participating family carers were still wondering if there might be other meanings hidden in the expression of reciprocation from their relatives with dementia. Some family carers had not judged the reciprocation instantly, but left judgement open for a time to see. In their understanding, the frequency of reciprocation along with their intimate knowledge and cultural knowledge were used in their interpretation. Comments made by Jan and Manee (see Section 6.3.1 for more of their comments regarding the use of thanks and thankful gestures) showed the aspect of waiting. Jan’s comment demonstrated her wonder and active attention when she observed her mother’s behaviour previously up to the present: *‘…prior to having dementia, she didn’t say [thanks] that much. I was wondering if she thought that I was not her child.’* To wonder is not to judge instantly what such reciprocation expresses. To Jan, she did not have a clear idea of whether her mother’s reciprocation was an appreciative feeling or a symptom of dementia. Similarly, Manee did not dare to judge her mother’s expression immediately, as she did not have enough intimate knowledge of her mother: *‘She said ‘thank you’ often. […] But I was not sure if she knew who I was to her.’* Comments made by Jan and Manee suggested that the family carers paid active attention to reciprocation because they were waiting for possible other meanings within the reciprocation. Thus, taking time to be aware of the other’s actions or their inner needs or whatever was hidden in their behaviour was necessary, otherwise projection and judgement might happen (Sevenhuijsen 2018). According to caring as a family practice, waiting in caring circumstances implies the notion of emotional labour, which is an important element when interacting with family members or family-like individuals (Morgan 2011). Whilst waiting is to hold back the carer’s supposition and to take time, emotional management then is needed to deal with difficulties or ambiguous situations, as suggested by the cases of Paula and Zina. Paula’s case illustrated her attempt to restrict her own negative response, and to make sense of the meaning of reciprocation and deal with it as if it was a symptom of dementia: ‘*If he didn’t have dementia, he wouldn’t have done it that way. […] It’s hard to respond suddenly to him. But at least, I realised that I was keeping my emotions inside and wouldn’t let myself burn out.’* Likewise, despite how often her mother would scratch her when changing her mother’s incontinence pad, Zin would let the mother scratch without stopping her. Zin said that she cried when her mother clawed her skin. Her crying was not due to pain, but due to her sympathy and understanding that this was her mother’s way of releasing inner painful feelings. Zin’s example showed that the family carers’ were waiting for some other possible meaning hidden in the reciprocation they had received, and that they were attempting to deal with it by controlling their emotions. In this respect, emotional management together with the aspect of sensitivity and waiting within the attentiveness (Sevenhuijsen 2018) allowed the family carers to reach the shared meaning and hidden desire of their cared-for person. Appropriate care could not be provided if family carers lack these aspects of attentiveness along with their skills of emotional management (Tronto 1993).

6.5.2 Reciprocation Received When the Carer Perceived

Reciprocity is considered a mutual action, by which two parties are connected in the act of exchange, or that of giving and receiving resources within the relationship. However, the connectedness to be discussed in this study was considered not only to be the interactions that people with dementia have with carers, but also to be the involvement of carers within the process of reciprocation from people with dementia, i.e. that connectedness occurred when the family carers saw themselves being involved with the expressed reciprocation.

The notion of connectedness here can be seen through positive reciprocation, because the meaningfulness of caring is evidence of such connectedness. In considering reciprocation as a reward, the meaningfulness of caring meant that the family carers felt their caring had been recognised, was successful, and that they themselves felt supported. An extract by Paula suggested connectedness in terms of recognition of care. Her feeling of connectedness emerged through her father's reciprocation, which showed his recognition of her care: *'He could recognise my care. I saw this in his eyes when I helped him to bathe.'* Connectedness was also found when the family carers perceived that their caring was successful. For example, Saipin's comment showed that connectedness occurred when she witnessed her mother's bodily reciprocation, where she saw herself as having a part in improving her mother's ability to express: *'I felt like I can do it [improving her mother's reaction]… despite that her symptoms might become worse.'* Connectedness also took place when each of the family carers felt supported emotionally by their cared-for person, through positive reciprocation. A comment made by Aurapa was an example of this. Aurapa said that she felt supported emotionally when her mother told her to take a rest: *'…she understood that I was tired and needed a rest. […] It's like she was cheering me up.'* Aurapa's case suggested that the family carers could feel connected to the care receivers and their caring because their dedication to care was acknowledged.

By the three examples above, it can be seen that the participating family carers connected themselves to their cared-for people through reciprocation. They realised that what they did was worthwhile and they themselves were a part of supporting the others' lives. The connectedness accentuates that care is an activity that links the carer to the care receiver and vice versa. In this respect, the findings show that over the course of caring, the carer was not only the giver, but also the recipient, because their caring roles were valued, validated, and acknowledged by the care receivers. The connectedness that emerged through reciprocation will enable the next phase of care to be provided appropriately, since reciprocation as responsiveness allowed the care to be assessed and reviewed, in the sense that the activities of care were done to meet the needs of the care receivers (Brannelly 2016, Tronto 1993).

However, the findings of this study suggest that some of the carers did not feel engaged with the reciprocation expressed by their care receivers. According to comments made by Raywan and Sawalak, as discussed earlier, the words ‘no reciprocation received’ did not mean that their cared-for people with dementia did not reciprocate something to the carers. In fact, they did, but the meaning within the reciprocation in the carers’ views did not show the involvement of carers and their caregiving. In this sense, it can be said that connectedness might be not possible unless family carers feel engaged with the reciprocation that those with dementia expressed. In other words, the carers did not see themselves being valued through the reciprocation.

6.6 Conclusion

This chapter discusses how female family carers understand the reciprocation given by their relatives with dementia. Given that it is taken for granted that those with dementia lack the ability to respond or reciprocate, and that their reciprocation might be difficult to observe, this chapter argues that their reciprocation was present and manifested via verbal and non-verbal modes of expression. This chapter does not aim to examine whether or not their expressed reciprocation resulted from dementia, but it rather demonstrates that those with dementia have different ways to communicate, and their ability of expression reflects their agency to connect to the world. In addition to this, in an ideal scenario, the carers would arrive at the ‘true’ understanding of the response. That this has been achieved cannot necessarily be proven. Ultimately, the analysis is to show the carers’ reaction to and reading/understanding of the response.

From the experiences of the participating family carers, there were both perceived negative and positive responses received from their relatives. This chapter does not examine if such responses resulted from symptoms of dementia. Rather, it underscores those with dementia's abilities to express and connect with the world, and also considers how the carers perceived those responses. Regarding the perceived negative reciprocation, it was certain that they brought about negative feelings in the carers initially, for instance, feeling neglected, disappointed, angry, and nervous. Suggested by a feminist approach along with the concepts of care and family practice, the findings show that the family carers used their knowledge of dementia and their emotional management skills to make sense of negative reciprocation and to also deal with the circumstances they faced. According to the perceived positive reciprocation, which manifested in interesting different forms, the carers perceived this as reward and as illness by using intimate knowledge and cultural knowledge to interpret. The finding suggests that cultural understanding played a very important role in the perception of reciprocation, whether or not the responses were verbal or non-verbal such as gestures. To wrap up the findings, the researcher highlights reciprocation as a site of connectedness for carers and care receivers. Connectedness can be understood in two ways. Firstly, it is created once reciprocation becomes known, read, and perceived by family carers. Secondly, it happens once family carers see themselves in reciprocation. Having said that, some of the participating female family carers reported that they did not receive any reciprocation from their care receivers. It was not because there were no responses, or because those with dementia lacked the ability to reciprocate. But, it was because the carers did not see themselves as being engaged with those responses. It can be said that although family carers observed and noticed the responses, they might not perceive the responses as reciprocation paid to them unless they could see themselves involved with such responses.

The findings in Chapter 6 provide some insight into the dimensions of reciprocity called 'in-the-moment acts of reciprocity' and 'cultural acts of reciprocity', which are discussed in Chapter 8.

Chapter 7: Motivations for Caring and Reciprocity

7.1 Introduction

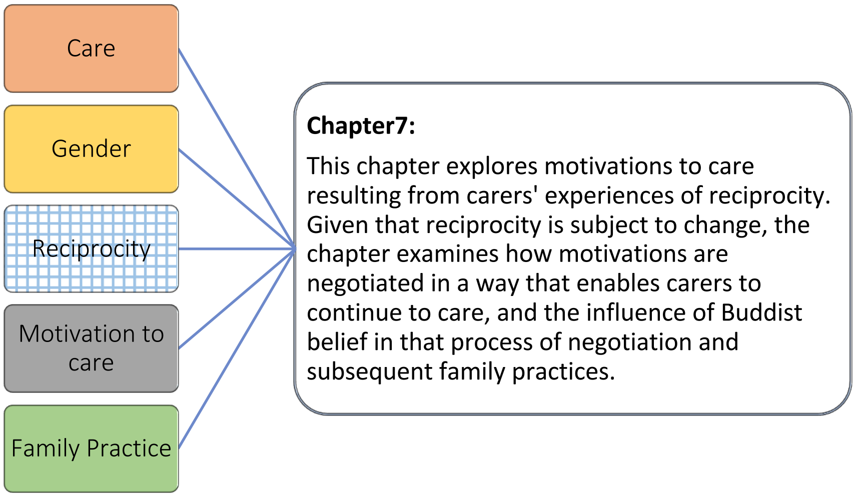


Figure 2d: Conceptual Map of Chapter 7

In the previous chapter, the family carer's experiences of reciprocation were discussed in terms of the various forms of reciprocation and how the family carers made sense of the reciprocation they received. This chapter explores how the family carers' motivations for caring relate to reciprocity. Initially, the study intended to explain how the carers' motivations relate to the reciprocation that they received from their care recipients over the course of caring. With respect to reciprocation, a lot of research suggests that the motivations for caring are linked to reciprocity (Reid et al. 2005, Kohli and Künemund 2003). The need for reciprocity can motivate a person to give care (Reid et al. 2005, Blom and Duijnstee 1997). Given that, some form of reciprocity, such as expressions of love, gratitude, appreciation, and warmth, can drive carers' motivations. These suggestions are understandable since positive reciprocity can prompt family carers to continue caring. Framed by concepts of care, reciprocity, and family practice, this study considered motivation as a result of a negotiated process of doing family practice, rather than merely as a part of giving and receiving, or as being automatically driven by love and duty. Given that the motives for caring are changeable and flexible, this chapter illustrates that the motivations for caring are negotiated upon more than the current responses of their care recipients or upon 'real time' reciprocity; the carers' perceptions of reciprocity over different timeframes are also associated with the their motives for caring.

This chapter is comprised of four sections. Firstly, Buddhist beliefs are explained in association with motivation of care. As discussed in Chapter 2, Buddhist beliefs influence Thai people's perceptions of life. The first section describes its influences on carers' perceptions of dementia and their relationships between their care receivers and themselves. The first section provides the background to understand the motivation for caring, to be discussed in the third and fourth sections. Secondly, it discusses the idea of institutional care in relation to motivation for caring and whether it might be an option for family carers. Thirdly, it sets out motives for caring along with their supporting conditions. As motives of care are dynamic and changeable over the course of caring (Romero-Moreno et al. 2011, Kohli and Künemund 2003, Schulz et al. 1989 cited in Quinn et al. 2015), the motives to be presented here are those derived from having experiences in caring, in which the reciprocity between carers and care receivers had already taken place. Lastly, the fourth section discusses the negotiation in motivation for caring and how it is a product that the family carers attempted to negotiate in their caring as a family practice. The fourth section discusses motivation for caring as a negotiation in which the cultural conditions in Thailand influence the negotiated process.

7.2 Influence of the Belief in 'Karma' and 'Cycle of Rebirth' Towards Motivations

As discussed in Chapter 1, the belief in 'karma' and 'cycle of rebirth' influences Thai people's behaviours and their understanding of life. In this chapter, the concepts of 'karma' and 'cycle of rebirth' are brought into the understanding of how family carers perceived their caring, since caring for them means the undertaking of good actions, and also the understanding of their expectation of reciprocation. The previous research on caring in the context of Thailand (Gray et al. 2016, Ratanakul 2013, Sethabouppha and Kane 2005) found that family carers believed in making 'boon', which refers to the accumulation of good karma as a result of good deeds. This boon in the present life could return to the person in the next life once they are reborn. In this study, most of the participating family carers believed in karma and the cycle of rebirth, but they expected to reap the benefits of any of their good deeds in their present lifetimes, rather than in their next lives. The expected benefit in the present life was not the reciprocation given to them by their cared-for person. Instead, it was a benefit that would happen to the care receivers.

This section describes the relevant Buddhist beliefs that the family carers had, which influenced their perceptions of caring and motivations of care. Most of the family carers believed in the law of karma. A few of the family carers overlooked these beliefs, whereas some carers were uncertain as to whether karma and the cycle of rebirth were true. However, among the differences in the carers' beliefs, a common perception was that all of the family carers expected to witness the result in the health of their relatives in present. This section is divided into three parts. Each related to the law of karma and the cycle of rebirth. The first part discusses the cultural explanation of illness. The second part discusses destined relationships. The third part discusses the result of karma in the present life.

7.2.1 Karma and Dementia: A Cultural Explanation of Cause of Illness

Most of the family carers believed in the law of karma. With respect to the cause of illness, some of them believed karma to be a cause of dementia, whereas some did not. Their belief played a role in shaping their motivations for caring along with their experience of reciprocity. Before going through how this belief related to their motivations, the following comments describe the relationship between karma and the cause of dementia according to the family carers' perspectives.

Sasi believed that everyone had their own karma, which would influence their lives at any time. Following this, the dementia that her mother was still facing was the result of karma: some thing or things she had done in her past life:

> Sasi: I've read about Buddhist teachings and the Dharma, which address how everyone has their own karma. Someone also said to me that my mother was sick because of her own karma. And, I think that's true.

Saipin also believed that the sickness of each person was the result of karma. This suggests that if people cannot find a clear explanation of the cause of illness scientifically, the karma is often considered to be the explanation.

> Saipin: I believe in karma. My brother-in-law was sick because of his karma. My mother too. She was sick without knowing why it happened, exactly. I couldn't find the cause. Unexplainable.

In using the belief in karma to interpret the unexplainable origin of dementia, some family carers believed that dementia was caused by bad karma, the result of acts that people with dementia had done in their past lives. Jan, for example, compared dementia to a disability.

> Jan: I think it's partly involved with karma. It's like we believe that people with disabilities might have tortured some animals or killed them. Their karma then paid off to them afterwards.

With respect to the unexplainable cause of dementia, some family carers believed that dementia, like other illnesses, was destined as a result of karma. According to her belief, it was derived from a preachment by a respected monk.

> Fenda: A monk that I respected said that everything that happens on the pathway of our lives is predestined, including illness and death. It's like we cannot find the reason why someone got cancer while some didn't, despite eating meat. Then, it's not totally a coincidence, but destined. It's the truth that none of us can change it, but need to accept it. It's no one's fault. There is nothing to blame except karma. Blaming karma makes us feel better.

In the comments above, it can be seen that some carers used the law of karma to understand the cause of many illnesses including dementia because sometimes the cause of illness cannot be understandable scientifically for them, while some carers believed in karma alongside scientific explanations of illness. However, when comparing with other illnesses, some carers viewed dementia as a result of karma while the other illnesses might not be seen as such. For example, Paula said that dementia might be her father's karma because he had no other illnesses, such as diabetes or hypertension. The past life karma of her father caused him to live with dementia, which he could not control and which had symptoms that he could not deal with. Then, dementia was like a barrier to his enjoyment of life, as people with dementia might lose their consciousness while those with other illnesses would not. Based on religious belief, dementia seemed to be destined by karma, so Paula did not address the reason why her father deserved karma in the form of dementia. However, according to her account, she recognised that her father's dementia was caused by his bad karma. Paula discussed her belief as follows:

> Paula: I think it's his own karma that made him have this illness. He had no other illnesses. No hypertension. No heart disease or kidney disease at all, but dementia. So, it [dementia] makes him unable to enjoy his life and his time with his family. People with other illnesses can still mostly do as they wish, but for those with dementia, their lives seem to end. So, I think dementia came from karma. If he could choose, he wouldn't want to be like this.

Paula's comment suggested that she considered dementia to be related to karma since life with dementia seemed to have no hope or no way out so that people can live happily. Similarly, Sawalak compared dementia to 'karmic illness' since dementia symptoms are irreversible and incurable:

> Sawalak: Kim [the researcher's name], I hope your relatives won't face this illness. It's hurtful. It's like karmic illness. A doctor said to me that other illnesses can be cured but not dementia. A person with dementia only gets worse.

By the family carers' comments above, it can be seen that their interpretations of the relationship between dementia and karma suggest implications in relation to their motivations for caring. This aspect is discussed further in the section on motivations.

7.2.2 Karma and Destined Relationships

Following the law of karma and the cycle of rebirth, almost every one of the family carers viewed that karma determined their relationships and statuses with their care receivers in at least one way, for instance, the mother-child relationship, or the caregiver-care receiver relationship. As these relationships were believed to be destined, they are linked to the understanding of 'being in debt' in relation to the cycle of rebirth (Watana 2016). Each individual needs to exchange something, such as caring, in order to compensate for or return something to another who had given them something in the past. When it comes to the term 'debt', the relationship would be considered in the economic sense. If it is used in the parent-child relationship, where affections and warmth are involved, the term 'being in debt' is replaced by 'boon koon' which implies the notion of 'katanyu' involving a sense of gratitude and obligation of adult children toward their parents in exchange for their parents' self-sacrifice (Engelmajer and Izuhara 2010, Knodel et al. 2003). However, while the destined relationship relates to the notion of debt, such relationships are sometimes viewed as opportunities to collect 'boon' or 'good deeds', which are benefits for the carers themselves.

Neena reflected that, prior to caring for her mother, she viewed religious belief as an ideological instrument of upper-class people. Once she became a full-time carer for her mother, she began to believe in the cycle of rebirth and karma because her acquaintances convinced her of this belief at times. Despite holding this belief, Neena accepted that she never thought that caring was a way to accumulate merit for herself through good deeds, even in the next life. Neena explained:

> Neena: Previously, I never thought about karma and our relationship in the present life. But now, sometimes I think we are destined to be mother and child and matched well in this life.
> The researcher: So, when it comes to caring, do you think you continue to care for your mother to collect your boon for the next life?
> Neena: No, no. I never really think that way. But my friends used to say that I'm making boon. As you know, parents are like 'the gods of home'. But I never think that I'm making boon to the gods at all. Actually, I was just caring for her.

Likewise, Paula believed that karma meant that her and her father's lives were predestined. She took care of him without expecting any benefit for herself in the next life. Caring was rather something she needed to do, and she felt that she should focus on the outcomes for her father in the present.

> Paula: I believe that what we [people] have done in the past life brought us to live together in this life, like father and child. […] I believe in the next life, but I don't expect that what I do [in caring] in this life will pay off to me. I never think that way [undertaking care to accumulate good deeds in the next life].

Saipin's view was that she did her best in caring for her mother. Despite that, her care could not be compared to her mother's care in any way. With a strong belief in Buddhist teaching, Saipin believed that she was indebted to her mother in the past life and also present life. However, caring was not a way to collect good deeds, but might be a way to avoid the debt in the next life.

> Saipin: I believe in karma and the next life, but I did not care for Mother just to collect something good for myself in the next life. I just did my best so that at least we'll not be in debt to each other.

It was described earlier that the idea of caring for an older parent in Thailand is sometimes likened to a debt, since older parents were the givers and the source of support for their children prior to a more settled adult life. The notion of debt here seems consistent with the notion of credit and debit within the family, which is a characteristic of the intergenerational contract. That is, parents' support given to children serves as the parents' credit, to be cashed in when the parents become older and need support from their children (Izuhara 2004). But, in Thailand, the term 'in debt' seems to have negative definitions when used in the family context, and thus it is replaced with the term 'boon koon' or a 'debt of merit' (Engelmajer and Izuhara 2010) which sounds positive as it links with katanyu and carries spiritual and emotional connotations. In this sense, the term 'boon koon' is more acceptable for both adult children and parents when speaking about parental support and the care given to their children. Thus, ‘being in debt’ refers to being owed parental ‘boon koon’, which sounds in spiritual rather than economical. Following this, some family carers then avoided saying the term ‘debt’. Thus, in Saipin’s case above, although she spoke of her anxiety of being in debt to her mother in the next life, she still avoided saying it in the context of caring for parents. Likewise, Anchalee believed in the cycle of rebirth but did not believe in karma in the context of care. For her, karma was not a cause of becoming a carer for her mother, and also sounded negative, as though adult children are oppressed in caring for their parents.

> Anchalee: Yes, I believe in the next life, but I don’t think that karma brought me to be a carer. It [karma] has a much more negative meaning than the word ‘burden’. It would be like you were being punished and reimbursed for what you did to your parent in a past life.

It was Anchalee’s view that she continued to care because it was her duty as a child, which was her goal or expectation in her current life. This issue is discussed in the section on motives for caring.

In slight contrast to Anchalee and Saipin, comments made by Fenda, Preeya, and Sawalak suggest that they would have liked to do their best in caring for their parents because they wanted to re-accrue merit to make up for their bad karma and cancel out the debt by caring, whether or not karma really exists. Fenda said that there were many times that this idea was in her thoughts, especially when she got stressed from caring.

> Fenda: Yes, I believe that everyone has their own karma. We can’t know what we did to someone in the past. We can’t change what we’ve done. […] You know, this idea often pops up when I get stressed [laughing] and so badly tired. I said to myself, ‘Why do I have so much karma?’

Preeya said that she was not sure about rebirth and the next life, but she often thought about ‘old karma’ or karma created in her past life that determined her relationship with mother, at the times she could not find any clear explanation for her hardship in the caring context. In her view, if her bad ‘old karma’ brought her to face the life challenges with her mother in the present, she should do good things with her so that they might pay off and cancel out the debt.

> Preeya: Given that I can’t find the answer to what’s wrong with us [Preeya and her mother], and that we stayed close but not felt very close, I would say it’s because of my old karma. […] If we believe that we face such difficulties because of our past karma, we shouldn’t make it worse. Otherwise, our debt will not come to an end. Could it be better if we take good care of each other?

Likewise, Sawalak said that she was told that the cause of becoming a carer was her past karma, but she did not take this belief seriously. Despite that, Sawalak used to say the word ‘karma’ when talking with her mother in stressful situations.

> Sawalak: I never thought about it [the belief] until someone told me. It’s probably true. But I don’t take it seriously. I sort of think that perhaps I used to treat her badly in a past life. If my thinking was right, I then want to get off my past karma right away in this life. There were many hurtful things that I said to my mother. I knew I was saying something terrible, but I couldn’t help myself. I said, ‘Let our karma come to an end in this life.’ Once I said it, I felt very guilty.

In the cases of Fenda, Sawalak, and Preeya discussed above, the so-called ‘debt’ in relation to caring did not refer to previous acts in the present life, but debt that covered all acts made and their effects over the entire cycle of rebirth. This notion has some association with how family carers deal with their caring in the sense that it helps heal the carers’ stress.

Regarding the uncertain verifiability of the belief, Ratchada preferred to consider it in a scientific way. That is, karma and the cycle of rebirth were replaced by ‘energy’ and ‘time’, but the fundamental idea of karma as a cause of things still remained the same. However, Ratchada never expected any benefits in her next life. She explained:

> Ratchada: About the reasons why we are related to our parents, siblings, and even husband, I think it was our old karma that we've done together in past life. I used to think about karma. It may cause what I am experiencing now. But, to me, karma is like a force or energy that is invisible and movable. It travels across time and affects our lives. Our karmas influence each other. When the energy runs out, we'll be apart […] When it comes to caring, I never expect that I'll get anything in the next life.

The belief in karma and the cycle of rebirth seems to be complicated. Given that, a few carers, for example, Aurapa and Koong, seemed not to believe in the next life, but had different beliefs.

Aurapa believed that karma determines the cause and effect of human actions including her destined relationship with her mother in the present life, but that the next life was something unknown and unforeseeable. Despite that, she did good deeds for the good outcomes in her present life, instead. Aurapa explained:

> Aurapa: I can't see the next life, so I just do my best in the present. Make it better every day. I would say I'd rather believe in the present life in the sense that we'll get something from what we do in the present life, because we don't know about the next life. […] So, I don't believe in the next life, but I just think about the way I can do my best in the present.

Koong said that she never kept the belief in rebirth and karma in mind, therefore, she did not believe in destined relationships. Koong spent much of her lifetime caring for her sister with dementia. In doing that, her acquaintances said that she was making boon. She said that she did not take the belief seriously. She focused on visible things involved with caring matters, instead.

> Koong: I never think about it [rebirth and karma]. The only thing I always think is that [caring] is what I must do. Many people have said that caring offers the chance to do boon. Some said that I was making boon every day. But what I think about is how to keep my sister's conditions stable…'

Koong's comment seemed to indicate that her disregard for the belief was replaced by the responsibility. This is discussed further in the section on motivations for caring.

Regarding the belief in karma and destined relationships, it appears that the family carers believed in the present life whether or not the next life truly exists. Based on the attitude towards the present, the family carers' motivations for caring were also affected, which is discussed in Section 7.5.2.

7.2.3 Result of Karma in the Present Life: Experiences of Benefits from Caring

With respect to the belief that good karma will pay off in the same way, either in the present life or the next life, some family carers reported the benefits that they already received. In general, the results of karma were mostly benefits, such as a better situation, good luck, and financial benefits. The latter is mentioned the most. However, such benefits were neither their wishes nor expectations as a result of caregiving.

Financial benefits were mentioned the most often. They came in the form of business profits, and a lottery win, for instance. Rungnapa explained that the benefit she received was unexpected income. The windfall was otherwise unexplainable to her since she did not have enough time to look after her business. She explained:

> Rungnapa: I believe in the next life, but I only think of what happens in the present life.
> The researcher: Some say that if we care for a parent, we'll get some good things back in our lifetime. What do you think?
> Rungnapa: Yes. The first thing is my happiness, which I can feel it at the present. And another thing is my income. It's an unbelievable story. I didn't have time to fully take care of my shrimp farm, but I got more benefit than I expected. […] And you know, one day I was home taking care of my mother as usual. A woman visited me and gave me a lotto ticket. And I won it. That's unexplainable to me. I couldn't say that this belief is true but at least I had these experiences.

The financial benefit seemed to be a tangible benefit that some of the family carers believed was the outcome of caring for parents. Also, Raywan spoke of an increase in orders from her customers, which helped her maintain her financial status.

> Raywan: I never think of the next life's benefit. But I believe that if I do good things for my parents, my next life might not be bad. But you know, I witnessed the benefit already. In my present life. At times, when I'm close to having financial problems, there're a lot of customers' orders coming in. It happens even though I do nothing. Unexplainable, but that helped save my life.

Aurapa also mentioned that although she did not have enough time to manage her money fully, as she spent time caring, she still received financial benefits. Aurapa kept the financial sources hidden to the researcher, but she confirmed that the benefit came to her unexpectedly, which helped her support her personal expenses. Aurapa believed that it was the result of having always taken care of her mother.

> Aurapa: I have no debt at present, but I used to worry about how to earn more money to support myself. But unexpectedly, how did the money [that she needed] come to me? It wasn't that much, but I've never lacked for it. I think it's because I do the good things for my mother, and take care of her. For example, I cook for her and sometimes persuade her to offer food to the monks almost every morning [a Thai religious practice] at a time when she was stronger.

Financial benefit was also mentioned by Ratchada, who believed in karma in scientific terms. She said that there seemed to be an invisible force that magnetically attracted good occasions that supported her life when needed. Her following comment is an example of a good benefit that she received without her making any effort to look for it.

> Ratchada: Right. When we do something good, the force will bring good things to you, but it maybe takes time. […] I would say when I didn't have time to find some new customers, because I was very busy with my mother

> and hospital matters, people who wanted to apply for their insurance contacted me on their own. Another thing was one of my customers offered me a second-hand electric patient bed for my mother as soon as he knew that I was always busy with caregiving.

Zin had a different understanding of karma and its effect in the present. She believed that a good outcome that carers received might have come from the caring circumstances itself, in the sense that caring helped shape the way of thinking about life and illness and also the way an individual treated another. Zin gave an example of her belief:

> Zin: It might not be simply that the caring for the parent pays off with a good thing. It might rather be that we develop our spiritual side, because caring for an ill parent teaches us compassion and mercy. Once we learn how to be merciful, it attracts good things to us. […] Previously, I faced some problems with my business partners. I was misunderstood and cheated. Once I came to care for my mother, there were nicer people coming into my life and offering me a bunch of work, and of course the money.

Benefits that come in the present life might not only be financial, but also come in the form of life security and good luck which might occur to other members of the family. This can be found in comments made by Jan and Wipawee. Jan spoke of a lucky situation that she felt lessened the hardship in her life and make it more manageable. Jan believed that her good luck resulted from her caring for her parents.

> Jan: I believe that we all have a next life, though. So, I just do good things so that they pay off, although the result may not instantly happen. […] Good things will return to you if you care for your parents, ummm … I have experienced this at times. It's like if there are some difficulties or problems happening to me, their effects didn't turn out that badly for me.

Good outcomes happened not only directly to the carers, but also to other family members involved. Following this, Wipawee spoke of some good luck that came to her and her daughter. Wipawee felt as if she and her daughter have been protected by a sacred spirit. She said that her daughter aimed to study in a medical school, but, on the day of the exam, the daughter did not follow the instructions correctly on her answer sheet. Despite that, her daughter passed the examination unexpectedly. Wipawee believed that it was what she gained from doing good things for her parents.

> Wipawee: It's unbelievable, Kim [the researcher's name]. How could she pass her exam, despite failing to tick some answers in the answer sheet? This [lucky situation] proves that the thing I did for my mother already pay off to me and my daughter, although I never expect or beg anything for myself at all.

The family carers' beliefs and experiences of unexpected benefits that they received in the present relate to their motivation for caring. Despite the received benefit, most of the family carers still focused on outcomes in their present lives rather than their next lives. There was only one family carer who stated personal benefit as one of her motives for caring. This is discussed in detail in the section on motives for caring.

To conclude this section, it can be said that among the different perceptions of the law of karma and the cycle of rebirth, there are two aspects that all of the participating family carers had in common, which are: 1) they wished to experience the outcomes of their caring in their present lifetimes, which they considered visible and witnessed, and 2) they expressed that they cared for their relatives with dementia for the sake of the cared-for people, not for their own sakes. Under their commonality, there are still some slight differences in their beliefs that shaped their caring motives, which are discussed in the section on motives for caring.

7.3 Carer Motivation and Institutional Care as an Option

To explore family carers' motivations to care for people with dementia, the perspectives of family carers towards institutional care seems to be another important aspect to consider, since the incurable and irreversible characteristics of dementia may influence the tendency to place the people with dementia in institutions instead of allowing them to remain in informal family care (Quinn et al. 2015, Hirschfeld 2003). Quinn et al. (2015) suggest that family carers have concerns about their ability to continue their caring when their care receivers' symptoms later become more severe. The decision to place an ill family member into full-time care has various other influences (Buhr et al. 2006, Yamamoto-Mitani et al. 2003) such as the family carers' health problems, and pressure from other relatives in the family.

Sending older people into institutional care appears not to be widely accepted in Thailand, as described in Section 1.3.1.. In this study, some of the participating female family carers conformed to this apparent norm, and did not consider institutional care for their relatives with dementia. However, some carers viewed institutional care as an option. These two views are discussed as follows.

There were 12 family carers who did not consider institutional care as an option, since they felt that their home-based care was still effective and important to the care receivers. Comments made by Rungnapa, Fenda, Raywan, Anchalee, Neena, Wipawee, Manee, and Sawalak are examples here.

When asked about institutional care as an option, Rungnapa said that she was still able to take care of her mother. Also, she viewed the warmth and place of the home was an important aspect of the end-of-life relationship between her and her mother.

> Rungnapa: No, I don't [consider sending her mother to institutional care]. I can still take care of her on my own. She might be bedridden one day, [so] I will think about it, if it becomes an appropriate option. To be honest, I don't want her to be restricted in such a place. I'd rather that she stayed in this house because she bought it herself. She should have her later life here, whatever that will be like.

Fenda also had the view that she and her other family members could still provide care for her mother. For Fenda, caring at home meant connectedness within her family, which could provide emotional support to her mother. In the home the mother could feel connected with other family members and vice versa. Fenda stated:

> Fenda: No, no. All of my family take care of each other. […] Although sometimes we don't please her [the mother] so much, it's better than to let her stay with other people, because she never knew them. Imagine that if she stays home, she still can see her children and grandchildren. At times, she felt frustrated and looked for me when I didn't stay with her for just a few hours. So, if I leave her in institutional care, how can she live? So, sending her to such a place of care is never in my mind.

In the context of dementia care and institutional care, some of the family carers previously discussed felt that the emotional aspect of caring is necessary, particularly if people with dementia retain their cognitive ability. Their emotional reaction indicates the necessity of emotional caring. According to carers, institutional care might not be able to provide such emotional caring, but family care can.

Likewise, Raywan considered that institutional care will never be an option for as her mother retain her cognitive ability. Also, her view was that institutional care might not provide tender enough care to her mother. Raywan explained:

> Raywan: Institutional care may be good if she [her mother] can't remember me anymore. But if she still can, I'd never do that. I think she will miss home. And yes, I'd miss her too. I have renovated a room in my house specially for her. So, I will take care of her on my own. […] I don't think that institutional care would take care of my mother as well as I do. I won't let her be abused, either.

Regarding abuse, Anchalee expressed that it could happen, since the caring could be so stressful that even the family carers sometimes could not bear it. She said that sometimes she also carelessly said some abusive words to her mother. Such circumstances could occur in a care institution, too.

> Anchalee: I think that caring in [places of] institutional care is done just by duty. Carers might not pay attention so much. I would say, even when I took

> care of my parents, sometimes I used to feel moody and care for them in a bad manner. So, what about institutional care? I couldn't rely on this.

Some family carers felt that care institutions were places where people with dementia might receive professional care. However, they seemed to be good for physical care, not emotional care. In this respect, it was Neena's view that a care institution was not an alternative for her mother's care. Neena said:

> Neena: I used to visit a nursing home and see its environment. It's good for caring for the residents physically, but not good for their feelings. I didn't see any clues of happiness in their eyes at all. I don't think it's a place to send my mother.

The same sentiment was also found in Wipawee's case. She confessed that she used to think about sending her mother into institutional care as she also had to deal with her responsibilities in her own family by marriage. However, she viewed that emotional care provided by family members was a very important aspect that her mother might need. She felt guilty thinking that way, since she recognised the value of reciprocity for the help and support her mother had given.

> Wipawee: I used to think about it [institutional care] because I have to take care of my own family. I can't balance it. I can't fully take care of both my father and mother. My mother was bedridden at that time. But then, I asked myself how I dared to think like that. If she was in there, who would care for her? If she still stays home with me, she still sees me and everyone at home and is happy. That's all.

The above comments suggested that the family carers saw the house as a place that encompasses the relationship, intimacy, and warmth given by family members. These things cannot be replicated in institutional care.

When considering institutional care, some family carers also thought about the expense. To place a relative in institutional care would carry a considerable cost (Winter et al. 2011). Manee knew that the full-time care needed would be expensive, but she said that she was already focused on the payment of her child’s education fee. Moreover, she had lost a chance to begin a new job after retirement due to being responsible for her mother. She chose to follow medical advice that said institutional care might reduce the abilities of people with dementia, while family care might help sustain them for longer. Therefore, institutional care was not Manee’s choice, as she addressed as follows.

> Manee: I know that there’s a lot of money needed to pay for such care [institutional care]. Now I don’t have a permanent job and I need to pay for the cost of my youngest child’s school. But I think institutional care isn’t a thing that I worry about. It’s not my problem now. And I think, in the end, I will take care of her until one of us dies, anyway. Another thing is that a doctor suggested that I not send her there unless it was necessary because it might worsen her symptoms more rapidly.

With respect to the cost of institutional care, Sawalak said that she could afford this form of care, but she preferred to continue to care for her mother on her own because she was concerned about the formal carers’ level of understanding and attention towards the care receivers. Sawalak said:

> Sawalak: I can pay for that [institutional care], but I don’t want to use this service for I believe that nobody can care as well as the family. To be honest, I can’t trust other people. They can’t understand my mother. Even me, I can’t understand her, either. Looking for someone to help is not easy, though. There’re a lot of problems, such as stealing and abuse. So, I don’t think the other options are helpful for me so far.

With respect to the cost of institutional care, hardly any of the family carers cited it as a primary issue for them. It might be because the family carers were able to deal with their home-based care. In addition, the closeness and emotional aspects of the caring relationship were still significant to them, as these things can affirm the sense of family relationships. Regarding this, looking for paid carers might be a more feasible alternative to family care. Many of the family carers favoured family care more than they did institutional care. For example, Aurapa said institutional care was never on her mind. It might be the last resort. Even though she might need some assistance in caring, the house was still the main place to provide care, rather than another place like an institution.

> Aurapa: I haven’t thought about it that far. I only think that if I need some help, the place of care should be here [home]. A new room in my house has been renovated just for hiring someone to care for my mother. Despite having a helper, I still need to stay with my mother, and keep an eye on what the help does as well, anyway.

The comments previously discussed indicated that instead of institutions, the home was considered a place of support and warmth in which it is family members who provide the assistance, particularly emotional support for each other. The notion of home might be associated with katanyu, which emphasises the parent-child relationship, and the ‘boon koon’ of the parent, and the adult children’s duty, as described in Section 1.3.2. Moreover, parent abandonment seems to be forbidden. Additionally, sending older parents or relatives into institutional care might be perceived as parent abandonment. For this reason, a nursing home is still seen as the last resort (Khongboon and Pongpanich 2018, Regional Office for South-East Asia 2010). Thus, the relationship between the notion of home, katanyu, and institutional care might explain the low prevalence of placement in caring institutions such as nursing homes in Thailand (See Section 1.3.1). As said earlier, given that home was perceived as a place of support and warmth, the family carers felt that the emotional aspect of care was very important for caring which also helped maintain the sense of family relationship. The family carers asserted that they were still able to provide emotional support to their relatives of dementia. Thus, institutional care was not an alternative for them. The carer’s competence in caring was associated with their sense of connectedness, as mentioned in Chapter 6. Given that, for as long as the family carers found their caring to be still helpful in supporting the lives of their relatives with dementia, they still continued to care. Moreover, where the family carers found that a sense of family in the connectedness was still significant to their relatives’ lives, institutional care will not be their choice.

Although some of the participating family carers refused institutional care, other family carers planned to use it as an alternative. Their view was that institutional care provides professional care undertaken by trained carers, which may be better than family care in certain ways. This seemed to be considered only as a last resort, should the circumstances of caring change, for instance, if the symptoms of the illness changed, or if the family carers' felt or became less competent in caring, or both. The following comments by some family carers indicate that institutional care could be the proper thing to do if the circumstances of caring changed.

Preeya said that institutional case was one of her alternatives for the care of her mother, because it provides more systematic and professional care. However, this option should only be considered on the condition that the family was no longer competent enough to care.

> Preeya: I used to think about it [institutional care], but my father didn't agree with me. So, we looked for a helper to care for her at home instead. But I don't think it's working. She [the helper] is exhausted from caring for my mother […] Institutional care might be more helpful because there are professional carers to provide care throughout the night and day, by schedule. But for now, we still can cope with it on our own.

Paula also considered institutional care in the case that she and her sisters could not cope with caring for her father at a more advanced stage. Given that, the cognitive condition of her father with dementia was another important thing to consider along.

> Paula: Yes, I used to think about that. If I couldn't deal with the caring, for example, if his health condition needed some advanced care, then institutional care might be better. But I'm saying that this is just in case his ability of recognition goes totally, so to speak. […] I don't care if anyone says anything, because I think institutional care can provide better care than me.

The lack of someone else willing to care might lead the institutionalization of the people with dementia (Quinn et al. 2015). In Sasi's case, when asked about institutional care, she accepted the need for day care when she goes to work. Despite accepting this form of institutional care, she did not find it easy to look for information about it, since she was busy with her own work. She was the only one dealing with caring issues.

> Sasi: I often think about day care, where I can take my mother to be cared for during the day and pick up her home in the evening when I get off. I used to talk about this with my younger brother, but he didn't help me find any information about it. The contact and information were all on me, as ever. It takes time to do that, but I'm so busy with work. I'm concerned about the quality of institutional care, too. I'm afraid they couldn't provide good care for my mother, either. There are a lot of things to think about.

The previous comments suggested that some family carers had institutional care in mind as an alternative because they focused on their relatives' benefit. This issue still reflects ethical family practice in the sense that the family carers viewed the care provided by institutions as better than their own, particularly in terms of physical care. Their consideration of institutional care as an option does not mean a loss of the connectedness and/or emotional dimension of care they had with their relatives. In fact, the carers' assessment of their competence in providing appropriate care indicates ethical issues in family caring practice, in the sense that the carers were making an effort to provide more suitable care for their relatives as much as possible. This indicates the connectedness embedded in the carers' views.

7.4 Motives for Caring and their Supporting Conditions

As described in the Introduction, the motives found in this study were derived from the conditions relating to the family carers' caring experiences. This section begins with a description of those conditions, which supported and shaped the motives for caring. Then, the motives for caring are also described. The supporting conditions help in understanding the characteristics of motives for caring, in that it appears to be socially developed upon carers' experiences, and is changeable over the course of caring, rather than only being an intrinsic psychological property of the carers (Romero-Moreno et al. 2011).

7.4.1 Experiences of Reciprocation as Supporting Conditions of Motives for Caring

Regarding reciprocity and motivations for caring, Lewinter (2003) suggests that the decision to provide care can be influenced by a feeling of reciprocity. Thus, this part explores the conditions which were derived from the experiences of reciprocation and which then shaped the carer's motive for caring. Motives for caring are not static but dynamic, in the sense that they seem to be changeable and shaped by the circumstances of care (Romero-Moreno et al. 2011).

This study found that the experiences of reciprocation during the course of caring generated conditions to support and shape the motives for caring of the participating family carers. The emerged conditions found in this study are classified into five types: acceptance of circumstances; the attachment between the carers and their relatives with dementia; the enjoyment of caring; a sense of competence; and spiritual growth. Many previous studies on this topic were conducted with a view of the meaning of caring and a positive dimension of caring (Tretteteig et al. 2017, Lloyd et al. 2016, Shim et al. 2013, Zarit 2012, Robertson et al. 2007, Noonan and Tennstedt 1997), meaning that the bright side of caring must be promoted as well as the burden of caring, the latter of which is a major theme in the topic of caring. However, this thesis considers the five conditions to be influencing conditions that shape motives for caring, since motives for caring can vary according to context (Kohli and Künemund 2003). Given that, by their understanding of reciprocation as both illness and reward, the family carers developed these five conditions, some of which emerged concomitantly and were interrelated. They are described as follows.

Acceptance of circumstances

As discussed in Chapter 6, the family carers considered reciprocations as rewards and illnesses, both of which were associated with their motives for caring. The acceptance of expressive reciprocation from people with dementia seems to be important for the family carers, as it helped encourage them to continue caring. Whether it was that the family carers felt happy, appreciated, and glad of positive reciprocation, or whether it was that they felt unsatisfied or sad as they witnessed the illness within the thankful expressions of their relatives, all family carers seemed to develop their acceptance during the course of receiving reciprocation. A study by Shim et al. (2013), which looked at the meaning in caring for a spouse with dementia, discuss the acceptance of the situation as an early strategy for carers to find meaning in caring.

Accepting the situation refers to accepting the illness and coping with unpredictable changes in their lives. However, the developed acceptance seemed to stem from the connectedness between carers and care receivers, as described in Section 6.5. In addition, the acceptance of the caring circumstances allows the carers to make the decision to give care, and enables them to develop positive attitudes despite facing caring difficulties and loss. Types of positive attitudes include optimistic thinking, feeling blessed, taking joy during caregiving, and finding humour (Shim et al. 2013).

Attachment

Upon satisfaction and acceptance of caring circumstances, attachment was developed. The following comments made by Preeya and Wipawee indicate their attachment in relation to their motives for caring.

Preeya said that it was her duty to become a carer. But, when asked about her motive to continue caring, she added that it was not only the sense of duty, but also her attachment to her mother that enabled her to continue the care provision. For her, duty and attachment were involved with feelings of guilt and regret. Preeya said:

> Preeya: I love my father the most. At first, I used to think that when he's gone, I might leave my mother and not continue caring for her anymore, but actually I can't. […] We were not that close. […] Um … It may be that I'm afraid to feel regret and guilt if I don't do that [care for her mother].

In Preeya's experience of reciprocation, she was likely to accept her mother's dependency and symptoms of dementia, as she has said that despite her mother's disturbing and aggressive reactions, Preeya could not leave her mother alone.

Likewise, the attachment gained alongside acceptance of dependency and illness in caring was also found in Wipawee's case. With hope for her mother's good health as her motive, Wipawee said that it was her feeling of attachment that encouraged her to carry on the caring, although she was always aware that dementia is incurable. Despite that, she accepted the illness and still wished to stay close to her mother:

> Wipawee: I know this is an incurable illness, but I'm trying to find every way to keep her with me as long as possible, because I feel attached. It is the attachment of a mother and child. Although she's lying in bed and doesn't know the things around her, I'm still happy.

The comment made by Wipawee indicated an interesting aspect of attachment and no reciprocation. The relationship between the family carer and the cared-for person can be gained simply by accompanying the cared-for person despite there no longer being reciprocation (Ribeiro and Paul 2008).

Enjoyment in Caring

In addition to attachment, enjoyment was also developed upon the experience of reciprocation in the context of care. Some studies consider enjoyment as a caring motive (Reid et al. 2005, Feeney and Collins 2003, Farran 1997). However, this study views that enjoyment is also a developed condition during the course of caring. Thus, in this thesis, enjoyment is referred to in two places: as a supporting condition and as a motive of care, which is mentioned in the next section.

As a supporting condition, enjoyment was derived from positive reciprocations from their care receivers. This could be seen by the comments made by Fenda, Sasi and Aurapa, as follows.

> Fenda: If I give care and see that she's fine and interacts with me actively, I am happy. But if she's challenging or cursing me, I lose my encouragement.

Likewise, Sasi talked about the happiness that she derived from giving her mother the opportunities to do some easy Buddhist practices. Sasi's comment illustrated that her happiness was from offering some good things to her mother.

> Sasi: Yes. I am happy even though I won't get anything back from her. I'm really happy because of what I do routinely for her, such as taking her to pray and offering food to monks [Buddhist practices].

Aurapa also developed happiness from her mother's physical abilities, which was understood to be a result of her care. She said:

> Aurapa: I feel satisfied and happy when I take care of her. I'm happy to see her eating up the food I cook. […] I feel like what I do for her is successful at those times.

However, Aurapa's case also suggested that her confidence was developed in the act of giving. This sentiment was also found in comments from some of the other family carers, as follows.

Sense of Competence

The family carers were also able to establish and strengthen a sense of confidence from caring, even though some of them experienced negative reciprocation from their care receivers. Some family carers looked at the bright side of the caring, despite its difficulties. Paula, for example, gained self-respect from the things she did for her father. She said:

> Paula: The difficult thing is that, sometimes, he does something challenging, so it's hard for me to keep going, but anyway it's my duty. […] And what I get from doing that is I can respect myself. I can say to myself that I've done my best to do the duty of a good child.

Some carers felt that they were proud that they were able to fulfil the duty of care. Regarding duty as a motive for caring, the feeling of pride then helps enhance the motive to care. This sentiment can be found in Sawalak's comment.

> Sawalak: No [I do not feel guilty]. I rather feel like I'm proud that I've been the only one to care for her. If I didn't do that, it would be like I failed to complete my duty.

Likewise, Yuri felt herself lucky that she had a chance to complete the duty of a child. She followed this duty not because of a fear of public complaint, but because she felt that it should be done.

> Yuri: I would say I'm lucky. It's like I can do my duty as a child completely. I did provide care not because I fear what people say, but because it's the right thing to do.

Spiritual Growth

Insightful knowledge was developed during the course of caring, which family carers learned to overcome their own egos and benefits. The process of developing such knowledge was gradual. The knowledge came out of reciprocation and the acceptance of the illness gradually over the course of caring until the insight helped enhance and push forward the family carers' motive. The following extracts from Neena and Zin are examples here. In Neena's case, as discussed above, she used to expect appreciation from her mother in the form of compliance with the care, and despaired at the negative reciprocation given instead. Through such experience, she learned about her own needs, emotions, and egolessness until she was able to abandon her self-interest and then highlight the needs and interests of her mother instead.

> Neena: I used to be sad and unsatisfied, but I got over it. I understood that if I have expectations [of appreciation], or need to be valued, it's like I was seeing myself as a centre. I should truly abandon my own self, I shouldn't be too sensitive to it [herself]. If I always think about what I'll get, my mother's conditions and other situations may be worse. Her illness couldn't wait.

Regarding spiritual insight in relation to encouraging motives for caring, Zin talked about her insight into self-mercy, which helped drive her motive for caring. This insight was generated from the stress of caring, and from the negative reciprocation, which was one of the difficulties in caring. Her insight, in turn, encouraged her to continue and deal with the caring tasks despite the difficulties in caring and the negative reciprocation she received from her mother. Zin said:

> Zin: It's like I can't ignore it [caring]. I need to do it anyway. And, as I've said, care is not something to do in order to get something back. But I really get something back. It enlightened my spiritual views. I've learned to let go.

> But, in doing so, I need to learn how to give compassion and mercy to myself. I find ways to relax. Leave all things behinds and let go. It may be like selfishness, but it isn't. That's the way to heal yourself in order to be strong enough to care for others.

It was both Zin's and Neena's view that the things they did allowed them to be not only the givers, but also the receivers, in the sense that they gained spiritual growth from caring for their mothers.

7.4.2 Motives for Caring

This study divides motives for caring into three categories: the family carers' hopes for the wellbeing of the people with dementia; the happiness gained from providing care; and the norms and values of family obligations. The researcher found that the motives for caring could not be identified and classified simply. Also, there seemed to be more than a single motive for caring being addressed by each of the participating family carers. Additionally, some motives were interrelated. Kohli and Künemund (2003) suggest that it is unrealistic to assume that each person has a single well-defined motive. In fact, one person may have several motives that overlap and sometimes contrast to each other. The three categories of motives for caring are discussed as follows.

Hope for Wellbeing of People with Dementia

Considering this motive in relation to the supporting conditions, it seems to be shaped by an acceptance of circumstances, enjoyment of caring, and spiritual growth. For most of the family carers in this study, their hopes for the wellbeing of their care receivers appeared to be the first motive they addressed. This motive implies a sense of concern, love and desire in the family carers. However, some carers stated that they loved their relatives and wished them good health, while some did not address this straightforwardly. Whereas caring is seen as a labour of love (Graham 1983), love is subjective and depends on the perspectives of the carers (Reid et al. 2005). Graham (1983) suggests that although caring relates to emotions, the term 'love' might not be appropriate. Other words could be chosen to convey a sense of bond. The carers used different terms to refer to their love and sense of concern and connectedness. For this reason, the researcher intends to present this motive literally as 'hope for the wellbeing of people with dementia' without conceptualising the motive into love. This motive, not different from love, implies a sense of connectedness, intention, and attention that the carers had for their relatives, as described below.

Koong, without any expectation of reciprocation from her sister, said that about her motive for caring was that she wished to maintain her sister's health for as long as she could.

> Koong: Some say that I am making boon every day. But all I think about is how to keep my sister's condition stable, and not let it get worse. I have no idea about that, though.

Based on spiritual growth and the acceptance of circumstances as supporting conditions, Zin reflected that she had no expectation that something would be given to her from her mother in return for her care. For Zin, a religious belief related to making good deeds was not the point, either. Rather, she viewed that caring without any expectations helped sharpen her spiritual mind. With respect to her motive for caring, Zin said that the ability of her mother was a goal for her to achieve. Zin did not mean straightforward physical and cognitive abilities, but communicative abilities that her mother could share with her. Given that communication was important to Zin, she felt that the period of time that her mother was able to remain active was about to end. She felt herself having not enough time to provide care for her mother. Zin said:

> Zin: What motivated me to care? It's like I want to do whatever allows her ability to remain for as long as possible. The ability for her to communicate with me. I don't want the time to pass so quickly that it's the point that we [Zin and her mother] can no longer connect. I feel like I don't have enough time to care for her.

In some cases, it seems that the cultural explanation of the causes of dementia shaped their motive for caring. That is, family carers' understandings of dementia as a karmic illness linked with their hopes to see the health of relatives with dementia remain good. The family carers saw the characteristics of dementia and saw some limits to their caring, and so the wellbeing of their relatives seemed to be the maximum that the carers hoped for.

Jan reflected with tears on her motive for caring. Although there seemed to be little reciprocation that her mother could give to her, Jan still kept taking care of her. With her acceptance that the illness was irreversible, she still kept caring in the hope to see her mother remain active for as long as possible. Jan explained:

> Jan: I didn't think about it at all [reciprocation], and never expected her to appreciate my caring. I just wanted to see that she could eat, still be strong, and be able to help herself. Actually, I don't want to see her getting worse, but it's impossible, I know [said with tears].

In some family carers, the hope for better health for their care receivers as a caring motive was mentioned along with their happiness in caring. These carers include Noy, Sasi, and Ratchada. In Noy's comment below, it can be seen that her hope was accompanied by her love and concern for her grandfather with dementia.

> Noy: Um … What made me keep on caring for him [despite there being no appreciation received] is that I feel concerned for him. I love him. I want him to stay longer, as long as he can.

Sasi was the one who spoke of her happiness along with her hope. Whether reciprocation was positive or not, or even if no reciprocation was given to her, Sasi wished to see the health of her mother remain good, though she understood that her mother's dementia was a karmic illness that was incurable.

> Sasi: Yes. I am happy, even though I won't get anything back from her. […] Although what I do can't make her better, I just want to keep her present condition for as long as possible. That's the most important thing I'd like to achieve. I know that, of course, her health will worsen more and more. The doctor said that it's up to how the care is given. It can also help sustain each stage for longer.

Likewise, Ratchada said that although no reciprocation was given from her mother with dementia, she kept undertaking care so that her mother would be happy by being given good care. This motive also enabled her to feel comfortable.

> Ratchada: If I don't get reciprocation, I'm not sad because I never expect anything from her. And I accept that because I know what each stage of this illness will be like. So, I just focus on how to make her feel comfortable for as long as possible until she is no longer breathing.

Fenda, who believed that dementia is a karmic illness, said that her motives were hope for her mother's good health mixed with katanyu and the wish to cancel out the debt or her past karma, which she believed caused the hardship in caring in her present lifetime. In the following extract, Fenda talked about the hardship of caring in relation to her motive for caring and her encouragement in caring.

> Fenda: Actually, if she [her mother] stays calm, I'm fine with her and do my best for her. If I give care and see that she's fine and interacts with me actively, I am happy. But if she's challenging or cursing me, I lose my encouragement, usually when I'm having some conflict with her and with caring.

As a caring motive, hope for the care receivers' wellbeing implied that there was urgent assistance to be given to care receivers. For example, Neena, with spiritual growth as a supporting condition, said that although she used to experience unappreciation from her mother, which made her desperate, her leading motive of care was her mother's urgent need for assistance. Therefore, when comparing with the mother's urgent needs, her wish for appreciation was apparently less important. Neena explained:

> Neena: I accepted that I would despair, but just for a short time. […] I think that if I won't do for her, then how will she live by herself? She needs help. […] I have a hope to see her get better. I think my care can help make this happen, or at least make her feel more comfortable.

Happiness from Undertaking Care

In previous research on caring, happiness from caring was described as enjoyment from undertaking care, which was explained either as a positive effect or a motive for caring. Happiness and enjoyment from undertaking care were discussed previously in Section 7.4.1 as supporting conditions. Here, the researcher intends to discuss the happiness and enjoyment as a motive for caring.

Suggested by reflexivity according to a feminist approach, the voices of female family carers should be heard literally. As described earlier, although some carers addressed their happiness along with their hopes to see continued good wellbeing of their relatives, some carers considered their happiness as a leading motive for caring. Extracts from Yuri, Aurapa, and Wipawee indicate this notion, as follows.

When Yuri was asked what motivated her to keep caring despite the negative or no reciprocation, she spoke of her happiness but did not say it directly. This could be because there might be many conditions that shaped the motivation which were not easy to define.

> Yuri: I have no idea about motivation. I think I don't have any. I'm just willing to do care. I'm happy to do that, even though I might not get any appreciation or there's no hope to see her get better. It's not the same as taking care of kids who you'll see grow up. But my mother gets worse. I would say I'll keep caring, because I'm happy when I see my mother happy [smiling].

Similarly, Wipawee mentioned happiness as a motive. She explained that this was because caring gave her the opportunity for her and her mother to spend some time together despite terrible experiences with her mother previously, and the rare reciprocation received. Wipawee said that she derived happiness from caring even though she had to care for a mother who lived in a bedridden state and who could no longer communicate with her.

> Wipawee: What made me carry on the care was the happiness that my mother and I can share when we stay close. I don't want to lose her. I know

> this is an incurable illness […] Although she's lying in bed and doesn't know the things around her, I'm still happy.

Some carers, such as Aurapa, linked happiness to the successful outcome of care. Successful care was very meaningful as it motivated Aurapa to carry on caring. Aurapa said that caring had great value to her despite there being no reciprocation, because at least she felt good and happy in supporting her mother's daily life, such as preparing meals and medication.

> Aurapa: I feel satisfied and happy when I take care of her. I'm happy to see her eating up the food I cook [smiling]. You know, the result of a medical check-up turned out very good. Her cholesterol level had become lower. Her heart condition was better. Her kidney problem was gone. I feel like what I do for her is successful at those times. I'm happy to see her get better, not worse.

There is a link between happiness or satisfaction from providing care and a good pre-caring relationship (Yu et al. 2018, Quinn et al. 2012). The experiences of Wipawee and Aurapa provided some additional insight about it. Wipawee and Aurapa had different types of pre-caring relationships with their cared-for relatives. Aurapa felt warm and close with her mother, whereas Wipawee seemed to have had a poor relationship with her mother; however, both identified happiness as their motive for caring. This aspect indicates that a good pre-caring relationship might help in creating happiness from care to some degree. Given that, the findings here offers an insight that happiness from care is also derived from experience of reciprocity.

Norms and Values of Family Obligations

In this study, some family carers reported the norms and values in the family as their motive for caring, which include duty, katanyu, and norms of repayment. These motives are presented altogether under one topic to make the research findings easily understandable, since they are cultural and structural elements of family obligations. Duty, katanyu, and norms as motives are discussed respectively below.

Regarding duty, the following comments show that the family carers still carried on their caring as it was seen as the duty that an adult child has to do to parents. For some carers, the explanation on duty as a caring motive was accompanied by a notion of care as a work while some carers spoke of duty mixed with emotional aspects such as the attachment, guilty, pride, and self-respect. These aspects are discussed in the section in relation to experience of reciprocation as supporting conditions of caring motives.

In Anchalee's case, her motive was a sense of duty, which she also considered to be work. Responsibility was a third motive to care, which together were reinforced by the positive behaviours of her mother.

> Anchalee: I see it [caring] as a duty, and a little like it's work, although often I'm wondering why it's only me who's fulfilling this duty. I never expect anything from caring, though. […] If she said, 'thank you', it would be OK. It would mean she knew and understood the things I did for her. If she's not challenging, I'm happy. If she doesn't follow what I want her to do, I'm sad.

Preeya, who felt that attachment with her mother had been developed, explained that her motive was duty mixed with attachment that emerged during the course of caring, when she experienced reciprocation. Preeya confessed that, prior to this, she used to think that she cared for her mother because she wanted to help her father. But now, even if she lost her father, she would not consider abandoning her mother. To Preeya, following her duty to care for her parents seemed to be a way to avoid feelings of guilt or regret. Preeya stated:

> The researcher: What made you continue to care even though you hardly got anything from her and she got worse?
> Preeya: Probably, I've never expected happiness from caring for her, or expected her to give something in return. […] I feel like it's both a duty and an attachment, although we [Preeya and her mother] were not that close. […] Um … It's rather a duty, because I don't want to regret it later if I didn't do that.

In contrast to feelings of guilt, Sawalak stated that her duty involved a sense of pride for her, rather than guilt. Her pride was resulted from and supported by a sense of competence, as she said that her pride also encouraged her to achieve her duty as a child.

> Sawalak: I just think that I'll take it [caring] to the limit. I think that to be born as a child is not just to use her womb to be born, but that I have a duty to take care of Mother. If it wasn't duty, I'd go away. But I can't. My siblings never cared about her. There's only me to do it. […] No. I'm not guilty. No. I rather feel like I'm proud that I've been the only one to care for her. If I didn't do that, it's like I'd have failed to complete my duty.

This sentiment was also found in Paula's experiences. Duty as her motive of care was supported by the sense of competence that gave her self-respect, which enabled her to fulfil her duty of care.

> Paula: It's fine with me that I continue caring, even though I didn't get anything back. I still take care of him because, for a child, this is the right thing to do. The difficult thing is that, sometimes, he does something challenging, so it's hard for me to keep going, but anyway it's my duty. […] I'll try to give everything to him as much as I can, because he spent his own lifetime for me. […] And what I get from doing that is I can respect myself. I can say to myself that I've done my best to do the duty of a good child.

In addition to duty, another motive for caring was the norm of repayment. The balance of reciprocity seems to influence the provision of care and support within the family. The reciprocity is then reflected in family solidarity, in which people of different generations exchange their provision of support within their social relations. Family reciprocity then is a central characteristic of a generational contract (Izuhara 2010, Walker 1996). Therefore, reciprocity plays a significant role in the ideological construction of a caring relationship, and also in quality of care (Walker 1996). Considering repayment as a normative motive for caring, this study found that some family carers did not simply follow the norms as a rule, but rather followed them with based on intentions and feelings. In this respect, Walker (1996) suggests that feelings of affection and reciprocity mutually reinforce motivation to provide intergenerational care for family relations. Comments made by Rungnapa, Saipin, and Raywan describe their motivations, as follows.

Rungnapa stated that a person who gives care should not expect anything from the receiver, particularly a parent who used to support and care for the child. Thus, she never seriously expected reciprocation. Supported by enjoyment in caring, Rungnapa said that her motive was to repay good things to her mother.

> Rungnapa: I didn't take it [reciprocation] seriously. Don't expect anything from a receiver if you are a giver. I don't expect any thanks from Mother because she gave us everything throughout her life. […] I need to repay her, anyway. And, I'll do my best, as much as a child could do for a mother, until we're apart.

Similarly, Saipin's motive was to repay her mother. Supported by a sense of competence, she intended to continue doing her best in caring. Also, she would like her mother to stay active for as long as possible. Saipin said:

> Saipin: In one way, I would like to repay her as much as I can. In another way, I always keep in mind to do my best in caring for her so that hopefully she can talk with me one day.

Raywan said that despite rare acknowledgement from her mother, her motive was to repay her mother. However, it was remarkable that her experience of receiving unexpected benefits (as discussed in Section 7.2.4) was connected to her intention to repay. In speaking of those benefits, Raywan seemed hesitant to say directly that it was another motive for caring. Her benefits, such as the business profit she received, was mentioned concomitantly with the repayment motive for caring, but downplayed. Raywan said:

> Raywan: I believe that if I do good things for my parent, my next life won't be bad. […] It's unbelievable, I get more and more orders from customers. All the things I got were totally good. The reason I take care of her is … ummm … I want to repay her, also, because I want to correct what I've done [being disobedient as a child] […] For me, it is katanyu. I want to care, I really want to do so, because she brought up me.

The business benefit seemed to be mentioned under the shadow of repayment based on katanyu, which may be because the care was seen as an activity done for the care receiver's benefit rather than that of the family carer. Thus, Raywan's comment reflected that although the family care was an act of exchange of giving and receiving, it should not be done in terms of financial benefit.

Regarding katanyu, it was discussed in Chapter 5 that it was negotiated in the context of care. The findings of Chapter 5 showed that women's perceptions differ from the taken-for-granted understanding of katanyu. However, in Chapter 7, katanyu was reported as a motive for caring, addressed under the umbrella of norms and family obligations.

Katanyu is associated with the duty of a child to repay their parents for giving birth and providing care, however these three things – katanyu, duty, and repayment – are not the same. There were some carers who viewed duty or repayment as their motives without mentioning katanyu, while some mentioned all three. Manee, for example, accentuated katanyu as her motive for caring. Manee said that she cared for her mother without expectation of reciprocation, therefore, she felt neither good nor disappointed when she did or not receive reciprocation from her mother. Because of her less intimate relationship with her mother, Manee had no idea of the emotional feelings associated with her caring. Her motive was katanyu, and she was not sure whether or not this contained her emotions. Given that katanyu is based on Buddhist belief, and involves the notion of karma and is emphasised in policy and everyday life, Manee did not perceive or treat katanyu in religious and karmic terms. Instead, she considered it like a social value, that it was like a simple frame or rule to force her to take care of her mother. Otherwise, she felt guilty and regretful. Manee explained:

> Manee: I wasn't upset [at any lack of reciprocation] because I let her live with me and care for her without any expectations, right from the beginning. […] I couldn't say that I keep doing it as I feel good about it. I would say that I provide care because of katanyu, which we've been taught from society. If we, as adult children, are able to care for them [parents], then just follow this rule so that we might not feel regretful and guilty because we didn't spend time with them.

In exploring the motive for caring, the findings show that the motives seemed to vary according to the type of past relationships the carers had with those they were caring for. Those who had a poor relationship and did not feel emotional closeness to their relatives, such as Manee, Sawalak, and Preeya, cited the norms and family obligation as their motives, while those with emotional closeness to their care receivers identified the wellbeing of their care receivers and happiness from care as their motives. There was the only female family carer, Wipawee, who had a poor relationship with her care receiver who said that her motive was happiness from care. Wipawee's motive may be explained by her experiences of providing care and the reciprocation received from her mother, the care receiver.

7.5 Negotiation in Motivations for Caring

Providing care for relatives is a family practice in which any decisions involve morality (Morgan 2011). In dementia care, the relationship between family members and those with dementia seem to be very affected by the characteristics of this illness. To continue caring for them is the act of 'doing family' in the sense that the family carers and other family members try to maintain their relationships and sense of family as much as possible. In considering care as a practice of doing family, it is helpful to explain the motives behind the decisions to keep undertaking care using the notion of negotiation, as did Finch and Mason (1993) in their analysis of family responsibilities.

This section thus discusses how motives for caring appear to be the results of a negotiation process. This section is comprised of two parts. Firstly, it talks about types of accounts from carers, including simple but hidden ethical aspects to negotiation. Secondly, it talks about how the motive to care is not negotiated only upon reciprocity in 'real time', but also upon reciprocity over time according to Buddhist beliefs.

7.5.1 Types of Ethical Account in Negotiated Process

This section explains that motives for caring are ethical decisions in which family carers are negotiating and balancing with other related issues to legitimate their decisions to continue caring as the proper thing to do. In their decision-making, there are three types of interrelated accounts: 'Never give up despite there being no hope'; 'to care is just to do it', and 'fulfilling one's duty'. Each carer used more than one of these accounts in making decisions. These ethical accounts were influenced by cultural conditions in that they rested on an understanding of illness and destined relationships, and a notion of time influenced by belief in karma and the cycle of rebirth. This is discussed in the next section. However, inspired by the concept of family practice, the family carers' motives for caring were made according to ethical decisions, evidenced by their accounts, which showed that they were focusing on the everyday concerns of their relatives with dementia rather than family responsibilities (Morgan 2011). The three types of accounts are discussed, as follows.

Never give up despite there being no hope

The more general caregiving notion of 'never give up', or 'keep undertaking care' seem to be slightly different when it comes to caring for people with dementia. The notion is influenced by the characteristics of the incurable symptoms of dementia, which the family carers were aware of. Even under this condition, the family carers never gave up their provision of care. Their accounts indicated this: Zin said: '…*do whatever to allow her abilities to remain for as long as possible*.' Sasi said: '… *I just want to keep her present condition for as long as possible.*' Ratchada said: '…*make her feel comfortable for as long as possible*…'. Also, phrases such as 'do my best' were found in many comments, such as one of Saipin's: '…*do my best in caring for her so that hopefully she can talk with me one day.'* These accounts were mostly found in comments regarding the care receiver's wellbeing as a caring motive, which implies an ethical decision in the sense that the carers did not surrender to the illness. These phrases reflect that the decisions to continue caring were made under limited conditions, i.e. that the family carers understood that caregiving could not cure their relatives' symptoms. This indicated a negotiated process by which family carers weighed up the choices among difficult conditions in order to save the lives of their relatives with dementia to the best of their abilities.

To care is just to do it

'To care is just to do it' is a simple phrase that is used in everyday language in Thailand. It might be seen as an ordinary and pointless phrase. In fact, despite some of the simple phrases found in the participating family carers' accounts, some moral aspects are evidenced. The simple but moral phrases by family carers can be seen, for example, in comments made by Yuri: '*I have no idea about motivation. I think I don't have any. I'm just willing to do care'*, and by Jan: *'I didn't think about it at all [reciprocation], and never expected her to appreciate my caring.'* In the phrases used by Yuri and Jan, the family carers considered their care provision to be uncalculated or the result of less rational decisions. It may be because of the nature of care, the activities of which are so simple and ordinary that they do not warrant any use of logic or rational consideration, but rather a moral reasoning that prioritises the other's survival of life. Moreover, some phrases showed that, in dementia care, moral decisions might be made without any expectation of reciprocation. Phrases that indicate this point can be found in comments made by Paula, Sasi, and Rungnapa. Paula said, *'It's fine with me that I continue caring even though I didn't get anything back.'* Also, Sasi's comments showed that she had no expectation of reciprocation: *'I am happy even though I won't get anything back from her*.' Similarly, Rungnapa stated: *'I didn't take it [reciprocations] seriously. Don't expect anything from a receiver if you are a giver.'* Caring without expectation therefore showed that the family carers focused on the benefit of others rather than that of themselves.

However, ethical decisions are not made by an individual alone, but involve other people in their social circles (Morgan 2011). In this respect, although the willingness to care is an ethical account as there was no hesitation in continuing care, the accounts were based on the notion of repayment by which the relationalities between family carers and their care receivers were inevitably brought into their decision-making. This issue is discussed more in the next section, which wraps up the relationships between reciprocity and motivation.

Fulfilling one's duty

Regarding duty as a motive for caring, the concepts of family practice and the notion of negotiation suggest that an individual does not provide care by following the rules according to family duty, family obligation, or family responsibilities. These things are not fixed rules but are fluid and negotiable. Therefore, they are negotiated in that responsibilities were developed over time, commitment within the kin relationship in which mutual aid or assistance, such as giving care, contained a moral dimension (Finch and Mason 1993). At the same time, family is understood to be the first resource of help, thus when seeing any relatives are in need, giving help might not mean to fulfil a duty but rather fulfil a moral commitment. The motive of continuing care therefore is an ethical decision which the family carer negotiates based on their commitment, developed over the course of caring. In this study, the words and phrases indicating a negotiated process and commitment were 'regret', 'guilt', and 'can't leave'. These can be found in a comment from Preeya: *'Um … It's rather a duty, because I don't want to regret it later if I didn't do that.'* Preeya added that she could not leave her mother with dementia alone. This reflected the dimension of morality to the commitment that developed over the course of caring. Likewise, a comment made by Sawalak illustrated that the duty of a child seems to be a commitment that is built upon morality: *"…Duty binds us* [Sawalak and her parents]. *It's not like a job, I can't resign from this duty [being a child]. Otherwise, how could they [parents] live without us?'*

According to duty as a motive for caring, the notions of commitment and its moral dimension are also linked with the notion of reciprocity. In this study, findings suggest that repayment was a significant factor in the provision of care, although it might be hidden amongst duty, love, or katanyu (See the repayment in caring section in Chapter 5). The linkage between the notions of reciprocity and commitment is discussed in the next section, where cultural conditions in the context of Thailand are brought into the analysis of motivations for caring and intergenerational reciprocity.

These three types of account indicate that the family carers' motives for caring were linked with ethical decisions, since these accounts showed that they were focusing on the everyday concerns of their relatives with dementia rather than family responsibilities (Morgan 2011).

7.5.2 Different Timeframes of Reciprocity

This section discusses how motivations for caring are negotiated upon the understanding of reciprocity in different timeframes, i.e. reciprocity given during a single lifetime, or reciprocity over more than one lifetime according to belief in the cycle of rebirth and the law of karma. This appears to have an influence on the negotiation that takes place in relation to the decision to continue care provision.

7.5.2.1 Reciprocity over the Life-Course and Negotiation in Motivation

Reciprocity over the life-course was discussed in Chapter 5. In this chapter, reciprocity over the life-course is explained in relation to how motivations for caring were negotiated upon the understanding of reciprocity.

It was common that when talking about reciprocity for the family carers to address past assistance and support received from their care receivers over their life-course. They called the past assistance 'boon koon', which was a condition of their continued caring. Suggested by Finch and Mason (1993), the exchange of family support is indirect repayment by which two people exchange materials or services, but of different kinds of help to each other. It may take many years for individuals to maintain the balance of giving and receiving. How they count the balance or equivalence of the exchanges is important because sometimes there are no obvious means to measure (Finch and Mason 1993). In this study, the family carers expressed that they did not attempt to maintain the balance of reciprocity. Instead, they accepted and realised its imbalance because, in their view, the past support or boon koon cannot be comparable. However, this study found that upon the imbalanced reciprocity they perceived, they were negotiating to continue to care by using a rate of exchange calculated in ethical terms. Shown as follows, comments made by some carers illustrate this point.

By considering care as a form of mutual exchange in relation to the notion of repayment, this study found that although the family carers spoke of the materials and services given by their relatives of dementia, they valued those favours not in material or quantitative terms. Rather, they calculated those favours in ethical terms. The extracts from some family carers, Sasi and Rungnapa, are examples of considering ethics as part of the rate of exchange. Sasi said:

> Sasi: 'She's my mother. How many kids did she give birth to, breastfeed, and care for? When we can't do things on our own, she did everything for us.'

Although Sasi mentioned her mother's acts of care and support, which seemed to form a visible and taken-for-granted duty of mothering, Sasi perceived those acts of giving in an ethical sense which was embedded in the visible exchange of materials. With respect to ethics, Sasi's comment shows her concern over the issue of dependence, in that she used to need care from her mother. Rungnapa also expressed this:

> Rungnapa: '…because she gave everything to us throughout our lifetime, ever since we were born.'

The two examples above illustrate that the carers negotiated the rate of exchange in ethical terms so that they could achieve the proper balance of return, stated in ethical terms. With respect to the ethical aspect of care, Anchalee linked her mother's financial assistance with the support she gave to her own child. The comparison enabled the family carers to recognise the aspect of ethics, which was bound to but hidden within the goods, services, and assistance given. Anchalee said:

> Anchalee: I never think of the balance of favours that she's done for me and I've done for her. Just in some moments, where I just think of what she gave to me [education fee] when she's in financial trouble. So, I felt like she did that with a high level of dedication**.**

Negotiating the rate of exchange in ethical terms was also done through the comparison of time spent in the course of giving and receiving support. The family carers viewed that the time their parents spent taking care of them was much more than the time they gave them in return. The value of giving was not simply the time spent, since the time spent also implied the dedication that their parents had in supporting the lives of their children. Comments made by Preeya, Sasi, Rungnapa, and Aurapa are examples.

Preeya spoke of the time left for her to care for her mother. In doing so, she calculated the time along with her desire to perform care for her mother's benefit, regardless of whether it was called the duty of a child. She said:

> Preeya: From now on, I have roughly ten years to do everything I want to do for her. No matter whether it's the duty of a child or not.

In Sasi's calculation of proper balance, she recognised the time left that she had with her mother by connecting with the dependent condition of her mother.

> Sasi: Now she's in need […] I don't know how long she can live with me. Life is not a certain thing.

In some cases, the time spent in giving care linked with the idea of burden of care (See Section 2.2.3 on dementia care and the challenges faced by family carers). To keep giving care despite the burden or difficulties of care was seen as having high dedication. Some carers compared the time that their parents were devoted to their children, and their time that the carers gave in return. This comparison indicated that the parents had held the burden of care for a much longer time than the children did. Rungnapa, for example, saw this matter as an aspect of the ethical sense of care.

> Rungnapa: Some might say that caring is a burden […] but if you think in reverse, weren't you once her burden? She carried you in her body for nine months, and brought up you, also. […] She might be annoying to you, but for how many years from now will she be able to live with you? […] So, I'll do my best.

Some sentiment was also found in Ratchada's comment, in which she talked about the time spent caregiving and the tiredness that came from it. By comparing her time caring with the time her mother spent dedicated to her as a child, Ratchada saw her mother's tiredness and dedications. Ratchada stated:

> Ratchada: Some asked me if I'm weary. No, I'm not. She cared for me for decades, but how many years from now do I have to do care for her?

It can be said that, in their motivations for caring, the family carers brought the reciprocity between the care receivers and themselves over their life courses into their consideration of and decision to continue caring. In doing so, the family carers viewed reciprocity or mutual support in ethical terms as well as in material terms, and negotiated the rate of that exchange in ethical terms so that they were able to calculate the proper balance of exchange and then repay their parents for the favours done, or boon koon, at the same rate. In this sense, the family carers seemed to position themselves as the receivers of boon koon. They felt that they were receiving more than giving, since they valued the caring as an ethical practice. Therefore, it could be considered that ethics can influence the motivation for caring in that the children were repaying some ethical thing to their older relatives, and/or doing something ethical in return.

7.5.2.2 Negotiation Upon Reciprocity Based on Belief in the Cycle of Rebirth and Karma

The notion of reciprocity involves credit and debit – often within a family, in the sense that parents' support serves as credit to later be cashed in as support from their children. Since reciprocity in Thailand is influenced by Buddhist belief, the perceptions of generational reciprocity within the family appear to be in a different sense. That is, belief in the cycle of rebirth and karma, as discussed in Section 7.2, form the carers' perceptions of destined relationships and their insights into time. In such perspectives, the terms 'boon koon' and 'being in debt' were used to interpret the hardship of caring and a way of lessening the burden of care. The former means a debt of merit (Engelmajer and Izuhara 2010), which sounds more positive, while the latter links to bad karma as the result of past negative actions, which individuals need to compensate for. These perspectives played an important role in shaping the participating carers' motivations for caring, in that they enabled the family carers to make a decision as to whether they continued to care or not. However, if continuation of care was possible, the care would not be undertaken merely as an act. Instead, the care would be provided with good intention so that the past life's debt would be cleared, and also as a means to prevent negative circumstances in the next life. Extracts from some of the participating family carers, Saipin, Preeya, Raywan, and Ratchada, express their perspectives on providing good quality care, and the link between such perspectives and motivations for caring, as follows. Saipin said, '*…I just did my best so that at least we'll not be in debt to each other',* and Preeya said: '…*If we believe that we face such difficulties because of our past karma, we shouldn't make it worse. Otherwise, our debt will not come to an end. Could it be better if we take good care of each other?'* These extracts illustrate that belief in the cycle of rebirth and karma enabled them to provide good care, thereby avoiding karmic debt within the cycle of rebirth. Similarly, Raywan believed that doing good things will pay off: *'I believe that if I do good things for my parent, my next life won't be bad.'* Although there is no tangible proof, it was believed that doing good deeds may lead to good results in the next life.

This is not to say that the carers provided good care intentionally for their own benefit in the next life, nor that carers without such beliefs overlook the good quality of care or have less motivation to provide care. Rather, cultural beliefs could be a supporting factor in the decision to continue caring. Moreover, as discussed earlier, the findings suggest clearly that the family carers provided good care mainly to benefit their care receivers, in the present life in particular.

7.6 Conclusion

This chapter answers the third research question, which explores how female family carers' experiences of reciprocity relate to their motivations for caring. This chapter then not only searches for motives for caring, but also their relationships with reciprocity. In this thesis, it is shown that there are three motives for caring that interrelate: hope for the wellbeing of their relatives with dementia; carers' happiness in providing care; and norms and values of family obligations.

Exploring the relationships between motivation for caring and experience of reciprocity, this chapter found that three motives were developed and shaped by carers' perceptions of their relatives' reciprocation through five supporting conditions that were generated from experiences of reciprocation. The five conditions are: the acceptance of circumstances; the attachment between carers and care receivers; enjoyment of caring; sense of competence; and spiritual growth. Although some of these supporting conditions are not new to the understanding of caring issues, this thesis illuminates different aspects to them for consideration; the existing literature considers them to be positive effects of care, while some literature describes some of these conditions as motives for caring. The findings in this chapter do not refute those aspects but discusses them as a linkage between reciprocity and motivation. Thus, motives for caring were developed by these conditions, which emerged from the experiences of reciprocation.

The findings also suggest that these motives for caring were associated with the carers' perceptions towards institutional care, in that they do not consider it to be an alternative to family care. As long as the family carers still have the competence to care, and particularly a sense of connectedness, which they viewed as a significant to the lives of those with dementia, they would still provide care for their relatives at home. However, these motives were also influenced by the belief in karma and the cycle of rebirth, which shaped their understanding of dementia as a karmic illness, and the understanding that the relationships between parent and child and between carer and care receiver are predestined relationships.

Given that the motivations for caring involve negotiation, this chapter found that the female family carers offered three types of ethical accounts in their explanations: ‘never give up despite there being no hope’; ‘to care is just to do it’; and ‘fulfilling one’s duty’. These accounts illustrate that the motivations for caring were made upon ethical decisions focusing on the everyday concerns of their relatives with dementia, rather than following the rules of family responsibilities (Morgan 2011). Behind these accounts, the female family carers took into account their perceptions of reciprocity in making the decision to continue caring. Such perceptions of reciprocity are classified into different timeframes: reciprocity occurring over the life-course, and reciprocity based on the belief in the cycle of rebirth and karma.

The different timeframes of reciprocity found in this thesis suggest some new aspects to the concept of reciprocity within the family in terms of intergenerational and intragenerational reciprocity. In addition, the findings in this chapter illustrate a kind of reciprocity called ‘karmic reciprocity’. These aspects are discussed in Chapter 8.

Chapter 8: Conclusion

8.1 Introduction

This thesis is based on a qualitative study exploring the importance of reciprocity and caring for older people with dementia in Thailand. Inspired by a feminist approach, the central findings rest on the experiences of women who care for their older relatives with dementia. Five concepts covering: care; gender; reciprocity; motivation; and family practice were used in developing the theoretical framework. Through the process of analysis, the researcher found that the concept of family practice was the most helpful as it provided a way to consider family caring as a set of practices that brought together issues of care, gender, reciprocity, and motivations for caring. Moreover, the concept of family practice in turn suggested other notions that have contributed to family studies in understanding how individuals 'do family' (Morgan 2011); these include activity, fluidity, everyday life, and individual life history. The notion of negotiation in family practice was notably helpful in discussions of repayment, caring, and motivations for caring in this thesis. Summarised in relation to the three research questions, the key findings are as follows:

Research question 1: How do female family carers make sense of repayment in caring?

- Findings: Repayment remains a dominant social norm in caring in Thailand, although how it is expressed may vary from carer to carer. Repayment is negotiated in ways that reflect relationality and an ethics of care.

Research question 2: How do female family carers understand reciprocations by their relatives with dementia?

- Findings: Carers experience both negative and positive reciprocations in the course of caring. A site of connectedness, the reciprocations require the carers' skills and knowledge to understand the embedded meaning shared in the responses of people with dementia.

Research question 3: How carers’ experiences of reciprocity relate to their motivations for caring?

- Findings: Carers’ motivations are developed and negotiated within different timeframes of reciprocity, which are influenced by Buddhist beliefs in karma and rebirth.

In terms of the first research question, the findings indicated that the notion of repayment could not be separated from reasons for caring, no matter the nature of those reasons. This is because the notion of repayment remains a dominant social norm, at a deep and fundamental level of the carers’ consciousness, although carers were not necessarily able to express this straightforwardly. In addition, the female family carers understood repayment in ethical terms because they saw the value of family support. That is, their understanding stemmed from their relationships with others. The ways in which female family carers learnt the significance of repayment included observing, remembering, and comparing relationships within their own families and broader relatives. Drawing on the concept of family practices and feminist work focusing on the aspect of negotiation (Morgan 2011, Finch and Mason 1993), the analysis of findings in Chapter 5 shows how the female family carers negotiated the expectations of repayment and ‘katanyu’. Their negotiation reflected their recognition of relationality. Moreover, the notion of negotiation also helped reveal the degree of dilemma that the female family carers faced in the context of care provision. On one hand, caring is seen as an opportunity to perform katanyu and subsequently carers might be complimented publicly as good children for caring for their parents. On the other hand, caring is comprised of challenging tasks that require carers to be skilled in managing their own emotions. It was possible for carers to feel guilty or embarrassed about whether they were doing good things and ‘showing katanyu’ to their parents, especially if they could not control their emotions properly when providing care.

Second, the research explored how female family carers understand reciprocations by their relatives with dementia. As discussed in Chapter 6, by reciprocations the participating female family carers meant the acts that people with dementia gave in response to their care, through both verbal and non-verbal expression. The forms of perceived reciprocation included a refusal of the care provided, blame and complaint, smiling, laughing, lively reactions, saying thanks and gestures of thanks. Such expressions were perceived reciprocation, sometimes negative and sometimes positive based on the carers' perceptions, rather than the behaviours of people with dementia per se. Moreover, the discussion of findings indicates that the female family carers presented the reciprocations they received as either rewards for caring or signs of illness, depending on their cultural understanding along with the intimate knowledge that they used to interpret the actions and behaviour of their relative. However, how the female family carers made sense of reciprocation was further influenced by the connectedness that was established once they perceived themselves to be the subject of such reciprocations.

Third, the study questioned how carers' experiences of reciprocity relate to their motivations for caring. The findings suggest that the carer's motivations were developed and shaped significantly by their experiences of reciprocity over the course of the care provision. Motivation was negotiated in relation to reciprocity, which in turn was dependent upon different timeframes of reciprocity. Reciprocity was played out over the life-course and also over more than one lifetime according to beliefs in rebirth and karma. Both of these timeframes of reciprocity played important roles in the family carers' decisions to continue the provision of care.

8.2 Research Implications

This thesis contributes to knowledge in the areas of family care, caring for people with dementia, and generational reciprocity both in the context of Thailand and in the wider international context. The specific contributions, as well as the implications of the research findings, are discussed as follows.

8.2.1 Conceptualisation of Reciprocity

In terms of the conceptualisation of reciprocity, this study has highlighted the complexity of the notion of repayment. Its findings identify five dimensions of reciprocity, as described below.

The Complexity of Repayment

Focusing on reciprocity, this thesis sheds light on the notion of repayment in the context of care. Suggested by a feminist approach working with concepts of family practice and reciprocity, the findings derived from the women's voices illustrated the complexity of repayment. On the complexity of repayment, the female family carers' experiences suggested that they considered the notion of repayment not in terms of material or support transaction, but in ethical terms. Inspired by the concept of family practice, which puts an emphasis on relationality, the findings showed that the female family carers' perceptions of repayment were generated from the relationships that women had with other people. Below, the complexity of repayment, as a research implication for the existing body of knowledge on the notion of repayment, is described.

This study was conducted in Thailand, where there are differences in culture and beliefs compared with western countries. That is, in western studies, while the repayment, or reciprocity, has been widely discussed in terms of a reason or a motive for caring in the same way that duty and love are, the findings of this study proposed that repayment could not be separated from those factors, as discussed in Chapter 5. And, while some researchers consider reciprocity not to be a necessary condition of providing care (Qureshi and Walker 1989), this study, which was undertaken in a different cultural context, shows repayment as a dominant social norm that remains constant, if sometimes implicit or not clearly articulated, in carers' rationalisations for caring. This is not to suggest that the notions of repayment in the existing literature should be replaced. Rather, by studying in a different cultural context, the findings offer another angle from which to consider the position and significance of repayment.

Five Dimensions of the Reciprocity

Regarding the significance of reciprocity, this study's research findings identify five dimensions of reciprocity that are interrelated and overlapping. These dimensions cover: 1) routine acts of repayment, 2) significant acts of repayment, 3) in-the-moment acts of reciprocity, 4) cultural acts of reciprocity, and 5) karmic reciprocity. Below, the explanation of these dimensions of reciprocity is shown to be guided by the theoretical framework of this study along with a feminist approach in which gender is a central idea of the issue of caring. Women are typically positioned as subordinate in the hierarchy of family obligation, where women's activities such as caring seem devalued, overlooked, and even invisible (Bowley et al. 1997, Finch and Mason 1991, Tronto 1993, Graham 1983). In this study, the five dimensions of reciprocity were then generated and explained according to the perceptions and positions of women within the hierarchy. Moreover, according to a feminist ethics of care (Barnes 2012, Morgan 2011, Tronto 1993), aspects of cultural differences should be taken into account in understanding the women's caring. The five dimensions of reciprocity are discussed below, in which the aspect of gender, relationality, and cultural implications are emphasised.

First, *'routine acts of repayment'* refers to repayment made through activities of care within the family. It is discussed mainly in Chapter 5. A routine act of repayment in the context of family care is, in theory, a gender-neutral practice, the significant characteristic of which is ethical practice. That is, love and concerns play very important roles in routine caring as emotional labour (Morgan 2011, Hochschild 1983) or labours of love (Graham 1983) to benefit the care receiver to repay them for past help and care. Routine acts of repayment therefore are defined in ethical terms as they are made on the basis of concern rather than as an exchange of material support or service.

Second, '*significant acts of repayment'*, as discussed mainly in Chapter 5, describe the repayments made to persons who used to be givers in the history of family relationships. In this sense, a carer is repaying not only the cared-for person, but also a third person or third party who used to give significant support through a specific role in the family. There were some cases illustrating this kind of repayment. For example, Preeya helped her father care for her mother because she wished to repay her father's love and care toward her (Preeya). However, a significant act of repayment is done through caring, which is at the same time a routine act of repayment, as discussed above.

Third, *'in-the-moment acts of reciprocity',* as described in Chapter 6, refer to the current responses of care recipients in the moment of care-receipt. In-the-moment acts of reciprocity could convey messages to the carers through verbal and non-verbal modes of communication. The two modes might be seen as ordinary ways of communicating that people use in everyday life. However, given that this thesis shines a light on dementia care, the current responses of those with dementia need to be notably addressed, especially their gestures and tones of voice as non-verbal responses. This thesis shows that in-the-moment acts of reciprocity are both verbal reciprocity and embodied reciprocity, which require attentiveness from others to interpret. That is, as discussed in Chapter 6, the findings suggest that the interpretation of in-the-moment acts of reciprocity in the context of dementia care might need an ethics of care to be understood: aspects of attentiveness, patience, or holding back suppositions (Sevenhuijsen

2018) are needed in order to perceive the meaning of the acts of reciprocity from people with dementia. Moreover, guided by the concept of family practice along with a feminist approach, intimate knowledge as well as gender and cultural differences as sociocultural factors play a role in shaping the carer’s understanding (Barnes 2012, Morgan 2011, Tronto 1993). The interpretation of in-the-moment acts of reciprocity regardless of the mode of expression has to take into account intimate knowledge and cultural knowledge. Such combined knowledge seems to be a resource that female family carers use to understand in-the-moment acts of reciprocity in caring, whether this reciprocity is perceived as a reward or not.

Fourth, *‘cultural acts of reciprocity’* are discussed in Chapter 6. The findings reveal how the interpretation of gestures may vary according to cultural meaning and context. ‘Wai’, for example, is a positive gesture commonly used in paying respect to others, however this gesture could be interpreted as an illness indicator in the context of caring for older relatives with dementia. In this respect, it is interesting that positive meaning in a cultural context might not always be consistent depending on the circumstances. Cultural acts of reciprocity interrelate and overlap with in-the-moment acts of reciprocity in the sense that they both require a knowledge of cultural norms and values to understand the meaning behind every mode of expression.

Fifth, ‘*karmic reciprocity’* refers to the reciprocity occurring on the basis of a belief in karma and the cycle of rebirth according to Buddhist beliefs, as discussed mainly in Chapter 7. Karma and the cycle of rebirth were found in relation to the notion of destined relationships and clearing of debt. Although these beliefs are inevitably associated with caring in Thailand, where Buddhist teachings strongly influence the way people think and behave (Ratanakul 2013, Keyes 1984), this thesis found that karma and the cycle of rebirth had an implicit rather than explicit influence on family carers’ decisions regarding the provision and continuation of caring. The implicit influence of karma on reciprocity might be associated with the notion of good deeds and returning benefit. These notions, as well as the clearing of debt, seem to be spoken of only indirectly, especially when providing care for older parents. The influence of a belief in karma and the cycle of rebirth illustrates the interrelation between karmic reciprocity and routine acts of reciprocity in the sense that the former enables some carers to provide a good quality of routine care. In this study, every family carer perceived that providing good care was undertaken for the sake of the care recipients in the present. Meanwhile, some family carers provided good quality of care to cancel out debt accrued in their believed past lives and also to prevent bad deeds from occurring as a result of karma in the future.

Regarding the five dimensions of reciprocity, the research findings grounded in this thesis suggest other research implications concerning the timeframe and gendered nature of generational reciprocity in Thailand and other societies, where applicable. Such implications are now described.

8.2.2 Timeframes of Reciprocity in the Context of Care

The research implications of timeframes of reciprocity in the context of care in Thailand were derived from working with the concepts of reciprocity, care, motivation, gender, and family practice, the latter of which helps emphasise the aspects of gender and negotiation in relation to reciprocity and caring. Recognising that the motive for caring is flexible, Chapter 7 shows the female family carers' motives for caring to be negotiated based on the reciprocity from their cared-for people, which was understood in relation to their perception of time. According to Buddhism, perceptions of time are influenced by the cycle of rebirth and the law of karma. How perceptions of time shaped the ways that the female family carers thought about reciprocity and motivated their provision of care, is discussed as follows.

The notion of reciprocity is explained in terms of mutual exchange, in which the aspect of time is involved. When it comes to the family context, reciprocity involves different periods and lengths of time (Neufeld and Harrison 1995, Finch and Mason 1993) regardless of whether repayment is direct or indirect. Considering different periods of time is useful to understand the repayment in family context: a long period of time is considered an opportunity to accumulate resources with which to repay parents or other givers for their assistance in the past. Different periods of time are helpful as they suggest the carer's consciousness of time in reciprocity. The findings suggest that the consciousness of time could be varied depending on cultural beliefs. As described in Chapter 7, carers' consciousness of time in reciprocity is beyond the lifetime or present time or 'real time'. In this sense, whilst reciprocity could be understood as a moral matter of debt within a lifetime (Gouldner 1973 cited in Finch and Mason 1993), reciprocity based on Buddhist beliefs could be seen as debt within the cycle of rebirth. Thus, this thesis suggests that an understanding of the consciousness of time in each cultural context might provide some insight into how individuals engage with reciprocity.

8.2.3 Generational Reciprocity

As a social norm, family reciprocity is a characteristic of the generational contract (Izuhara 2010), and is also a motivation to develop a social contract between generations in social policy (Walker 1996) in the sense that reciprocity enables people to accept and give support within the family, including credit and debt within the family. In this sense, given that parents raise their children and provide various kinds of resources and support, such support serves as credit that parents can 'cash in' to receive care from their children later (Izuhara 2010). As described previously, it might seem that intergenerational reciprocity is a characteristic of a generational contract as it helps enhance family solidarity. However, intergenerational reciprocity is suggested by the concepts of reciprocity and family practice, which provide a broader definition of family and insights into reciprocation (Robertson 1995 cited in Lewinter 2003). Having said that, intergenerational reciprocation, such as caring for older parents, could be reinforced by intergenerational and intragenerational reciprocity within the family, as discussed in Chapter 5. The findings illustrate that, in some cases, caring for older relatives as a form of intergeneration reciprocity could be operated and reinforced by reciprocity with a third party regardless of the generations of the people involved. Some cases in this thesis, such as those of Rungnapa, Preeya, and Noy, demonstrate this point. For instance, Rungnapa took her responsibility for being the main carer of her mother instead of her siblings since she intended to repay her siblings for past assistance. Her significant acts of repayment for her mother were magnified by this intragenerational reciprocity. It can be said intergenerational reciprocity is enhanced and interrelated with intragenerational reciprocity when understanding the characteristics of a general contract within the family.

Regarding family reciprocity, the findings suggest that the benefit receivers in family repayment are not only the cared-for people, but also any involved third person or people, despite not being involved fully in the care provision. The benefits might be invisible and intangible, such as time for working, opportunities to earn money or to achieve their own family plans, for instance.

8.2.4 Meaning and Significance of Katanyu, Women, and the Context of Care

In many Thai studies, katanyu is a significant social value that explains the parent-child relationship, in which adult children are considered to have a duty to care for parents. It is, of course, gendered and has an effect on women’s lives. In relation to Thai Buddhist women, it was found that the notion of katanyu and/or the ‘dutiful daughter’ has been given attention in previous studies of women’s prostitution (Nishizaki 2011, Engelmajer and Izuhara 2010, Cook 1998, Muecke 1992, Tantiwiramanond and Pandey 1987), rather than women carers within the family. Inspired by a feminist approach which puts an emphasis on gender, the variety of women’s experience, knowledge, and ways of knowing, this thesis then expands the understanding of katanyu, locating it in the context of women’s caring through in-depth interviews and the concept of family practices.

The findings in Chapter 5 highlight that the female family carers constructed their understanding and negotiation of katanyu from their caring roles and the gendered nature of care. The significance and meaning of katanyu were negotiated in the sense that, against public understanding, participants did not consider katanyu as a fixed doctrine in their caring. Although katanyu is undeniably positive for a parent-child relationship, it should not be imposed as a fixed idea in a context of care in which each family’s caring circumstances are different. In other words, katanyu should not be used as a measure by which to judge or criticise the value of care. In addition to this, katanyu was negotiated by the female family carers in the sense that it was a form of emotional labour. In this respect, katanyu reflected the connectedness between family members rather than being a rigid social value that should be followed unquestionably. The findings regarding the policy implications of katanyu are described in Section 8.3.1.

8.2.5 Theorising the Relationship Between Reciprocity and Motivations for Caring

The importance of reciprocity and good quality relationships to motivations for caring is mentioned in the literature (Quinn et al. 2009, Kohli and Künemund 2003, Lewinter 2003). However, little is known about how motivations relate to reciprocity. The findings in Chapter 7 highlight five supporting conditions that develop and shape carers’ motivations: acceptance of circumstances, attachment between carers and their relatives with dementia, enjoyment in caring, a sense of competence, and spiritual growth. These conditions were not new discoveries since they have been described in previous research as the positive effects of caring (Zarit 2012, Robertson et al. 2007, Reid et al. 2005) which are helpful for adaptive coping and instilling a sense of mastery in carers. Also, they are explained as sources of meaning, which some carers found during the course of caring (Quinn et al. 2009). In this thesis, the findings suggest that these conditions bridge the relationship between motivations for caring and reciprocity. Furthermore, they reflect the aspect of connectedness, on which a feminist ethics of care and the concept of family practice put an emphasis.

8.2.6 Culture and Dementia care

The implications of culture in relation to dementia care is derived from analysis working with the concept of care and a feminist approach which puts the emphasis on women's knowledge, their ways of knowing, caring, gender, feminist ethics of care, and cultural differences (Barnes 2012, Tronto 1993). The findings show how the female family carers constructed their knowledge of reciprocation from their relatives with dementia. Their insight was generated through not only their cultural knowledge and accumulated intimate knowledge but through the articulation of both. This is discussed as follows.

Recent trends in dementia studies have been drawing attention to body and self, agency, embodied experiences of people with dementia, and also the socio-cultural context in studying dementia in order to improve quality of care for those with dementia and their living (Downs 2013). This being so, the findings in Chapter 6 underscored the embodied dimensions of the expressions of those with dementia. They also took into account the influence of culture, illustrating that cultural context alone could not provide an understanding of dementia. Rather, consideration needed to be given to the articulation between cultural context and the carers' intimate knowledge of their relatives and of dementia. Positive reciprocation, particularly the wai gesture and the words 'thank you, ma'am' are useful examples here. These two reciprocations are typically culturally perceived as expressions of appreciation like the way people with dementia normally say 'thank you' or 'bless you' (Kontos 2004). In this respect, the Thai cultural expressions of wai and 'thank you, ma'am' are initially offered by a person of lower social status to another of higher status, for example by a child to parent. These actions are understood generally as gestures of appreciation, but seem not to be as such if they occur in the context of family care for older people with dementia. In some family carers' perceptions, these actions were a symptom of illness as well as signs of appreciation. This illustrated that the carers' perceptions rested on the articulation of cultural meaning in embodied reciprocation and the context of illness, and also their knowledge of their relatives with dementia.

8.3 Policy and Practice Implications

8.3.1 Katanyu Readdressed and Significance of An Ethics of Care in Family Care

The research findings contribute to the understanding of carers' interpretation of katanyu, which is highlighted in Thailand healthcare policy as being of major value in family care for older people. The findings show that the female family carers accept that katanyu is of worth in family relationships, particularly parent-child relationships, but that katanyu should not be an overriding rule or used as a measurement to justify the quality of care provision that suggests one size fits all. That said, the findings indicate that the female family carers seemed to value an ethics of care above katanyu. To the female family carers, care ethics seemed to be more practical and effective. Moreover, katanyu sometimes made the family carers feel troubled despite their attempts to do their best (see Section 5.4.3). For these reasons, based on the findings, this thesis considers that an ethics of care should be addressed and promoted with a greater emphasis than previously in social care policy, alongside katanyu. That is, the care should be undertaken effectively according to an ethics of care, not solely and foremost by katanyu. In addition, the findings in Chapter 5 (Section 5.4.2) suggest that caring should be a gender-neutral practice, meaning that men could take on this role to express katanyu equally as well as women do. In this sense, while Thailand's government has launched a long-term care plan for older people emphasising 'family care' as the main form of care, the notion of equal participation in caring across genders/family members/family roles should be promoted, unpacking the full meaning and broader potential of family care.

8.3.2 Positive Images of People with Dementia

The research findings in Chapter 6 show the various kinds of expressions that can be made by people with dementia, which accentuate their ability to reciprocate, react, and connect with others. This creates a more positive image of those with dementia, which should be promoted to family carers, healthcare professionals, and practitioners working with people with dementia. Given that those with dementia are likely to be assessed as isolated and lonely people (Wigfield and Alden 2018), the promotion of their communication abilities with various modes of expression may help create a better understanding of dementia, and may help reduce the feelings of social isolation in people with dementia. Moreover, the findings indicate that not all people with dementia lack reflexive abilities. Observation and recognition of these abilities will help people with dementia connect with those around them and the wider public. It will highlight the notion of personhood and agency of those with dementia in the sense that although their abilities are limited, they are still able to demonstrate their own needs, and demonstrate emotional reflexivity (Boyle and Warren 2017). Public awareness of the agency of those with dementia can help enhance their positive image as a whole. Moreover, it could reduce the mistreatment and abuse of people with dementia (Pettersen and Hem 2011).

8.3.3 Support for Family Carers for People with Dementia

Although the findings in this thesis focus on reciprocity in the context of caring, the interview data also revealed difficulties in caring, reflecting carers' need for support. In the course of interviewing, the researcher found that Thai family carers needed techniques to deal with bodily care and other difficulties in caring. The tasks that they needed techniques to help with include toothbrushing, bathing, and personal care for those with dementia, such as helping them to swallow. Given that these difficulties related to types of care provided routinely, the carers continued to face these difficulties whilst care demands grew more frequent. One solution might be increased access to relevant information in Thai language. Some of the carers were able to look for information in English but others could neither access the information nor understand it. In this respect, healthcare professionals should not simply be the providers of professional healthcare knowledge but also the facilitators or coordinators of self-help groups of family carers. Given that lay carer's knowledge is generated by their varying caring experiences, sharing that lay knowledge could offer helpful, practical techniques for caregiving. The carers' perceptions of negative reciprocations as well as carers' emotional management skills for coping with the challenging behaviours of those with dementia could have policy implications worldwide. That is, these issues could be shared among family carers to support each other. In doing so, the carer organisations could be facilitators to arrange supporting activities for family carers to reinforce their confidence to care (Wigfield and Yeandle 2011).

Difficulties in caring lead to concerns over carers' psychological wellbeing. Caring responsibilities can result in feelings of isolation and loneliness (Wigfield and Alden 2018). Consistent with other feminist research, this study found that domestic activities such as caring had a great effect on women's time, income, and physical and emotional health across their lives (Mckie et al 2004). This information was found by working with the concept of care along with a feminist approach – which makes women's voices heard and takes gender inequality as a major idea of analysis – and in-depth interviews as the main research method, which helped unfold female family carers' difficulties and the support that they needed, particularly the need for a consultant or someone to talk to or who could listen to their troubles. In addition to enabling women's voices to be heard and valued, the in-depth interview could also be a therapeutic practice to soothe women's troubles. The interviews helped release women's fragmented feelings and stories. In this sense, interviews can be helpful in social science research or other studies on people who need counselling (Nelson et al. 2013, Birch and Miller 2000), for example, people with anxiety or those grieving after bereavement or loss.

As this thesis was undertaken in a large city and surrounding area, the characteristics of urban households and social relationships may affect the development of close relationships and trust for family carers. Therefore, the findings of this thesis imply that the supporting system for carers must be improved and reinforced to assist family carers living in urban areas in particular. Ways to do this might include promoting dementia helplines more widely, and creating home visiting teams in primary healthcare units or in local state hospitals.

8.4 Limitations

Fieldwork can be affected by several factors: geographical location and associated cultural and social conditions (Newington and Metcalfe 2014), the nature of the research, infrastructural issues, recruiters, and participant characteristics such as well-being and socioeconomic group (Daly et al. 2019, Hanratty et al. 2012). Such factors may have implications for recruitment, generalisability, representation, participant inclusion, and quality of research findings (Daly et al. 2019, Beattie et al. 2018).

This study was conducted in a large city and its surrounding provinces in the middle region of Thailand. Family carers were recruited mostly through public networks and associated events, suggesting that participants were literate and had more opportunities to take part in social activities compared with other groups of carers such as those of a lower educational status or with limited access to social participation due to their caring responsibilities, emotional burden, health problems, lack of resources, or general isolation (Beattie et al. 2018). Moreover, the sample size of participants was small. The researcher was aware that the nature of care affects the recruitment of research participants, and therefore recruitment of participants in health studies, including research on dementia, can be challenging (Beattie et al. 2018), as discussed in Chapter 3. Carers for people with dementia seem to be a time-poor group, and their daily schedules are busy with caring and other obligations (Leocadie et al. 2018, Beattie et al. 2018, Whitebird et al. 2011, Schulz and Martire 2004) and therefore lack of time is identified as a barrier to recruitment. This challenge applied to this study. Additionally, the small sample size was affected by the trust of the prospective participants; since the notion of caring along with repayment and katanyu relates to family issues, personal lives, and family conflicts, the consent and trust of some family carers might not be gained easily. In sum, the findings of this study might not cover the voices of hard-to-reach family carers and certainly could not claim to represent practices of reciprocity and caring experienced by the full range of female family carers in Thailand.

Regarding research methods, the researcher considered using a diary method in data collection. Diary methods are helpful in doing health-related research such as that relating to family carers (Bartlett and Milligan 2015). However, a study by Walker and Warren (1996) suggests that using diaries to gather data from carers might be stressful for them. In that study, some carers found that recording their activities of care in diaries was too time-consuming, difficult, and stressful. The researcher also considered that this method might be extra work for research participants who already had limited personal time due to caregiving. Thus, requesting the research participants to write a diary might affect their consent to participate in the research.

As such, the study was mainly conducted using in-depth interviews with the female family carers. The researcher would have liked to talk with some of their siblings, since the researcher thought that it might uncover some aspects relating to the distribution of family responsibilities. However, this might affect the trust, willingness, and personal data of the main participants, which would be informative to findings. From the researcher's points of view, the distribution of family responsibilities is a sensitive issue since it engages with negotiation within the family. It was decided by the researcher that it would be most appropriate for data to be provided by female family carers only.

8.5 Future Research

The findings of this thesis suggest some new aspects for future research regarding the reciprocity, caring, dementia care in Thailand, as follows.

First, as discussed earlier, this thesis cannot be claimed to be representative of Thai Buddhist female family carers in general, because it was conducted in the middle region of Thailand only. Future research on family carers living in other regions of Thailand might help broaden the understanding of the notion of reciprocity and katanyu in Thailand. Although caring within the family is based on balancing reciprocity, normative values appear to reinforce reciprocity and vice versa (Walker 1996). Following this, exploring normative ethnic values besides katanyu in different regions will help to gain insights into reciprocity in relation to caring for older people in Thailand. Additionally, more insight into dialectic and various modes of living might have implications for the cultural impact on care provision. For example, ethnic culture might play a role in carer's interpretation of the languages and gestures of those with dementia. In this sense, paying attention to aspects of different cultures is helpful not only for research conducted in Thailand, but also elsewhere. Future research in different ethnic groups of carers might be useful for health practitioners who work with local ethnic people, as knowledge of cultural beliefs may help reduce misconceptions when providing interventions and communicating with those with dementia and their family carers. Moreover, an understanding of one cultural group might be useful for practitioners to apply to other groups or in other settings (Panchana and Gallagher-Thompson 2018).

Second, future research should take into account the notion of repayment and katanyu from men's perspectives. According to this thesis, caring is, in theory, a gender-neutral practice, therefore, it would be interesting to explore the meaning of repayment in the form of caring from Buddhist Thai men's perspectives. In addition, the context of family care seems to be changing. That is, although there has been no official survey of numbers of family carers by gender, there seems to be an increasing number of men caring for their older parents. The transformation seems to be inconsistent with the public images of Thai men since, compared to women, they have more options by which to express katanyu to their parents. These conditions are interesting and attractive for study in the future, as they might be able to contribute a better understanding of gender relations implicit in the notions of repayment, katanyu, and caring. However, future research should be comparative among different genders, if possible.

Finally, this thesis was not designed to distinguish between intergenerational or intragenerational reciprocity, but the findings illustrate their linkage and also some distinguished aspects of repayment that could be examined in future research. Since the population of older people living alone and single older people is increasing in number, particularly the population of female older people (Tasingh and Chuanwan 2018), it would be worth researching how intragenerational reciprocity plays a role in care provision. That is, the intragenerational reciprocity such as spousal caring or sibling caring does not imply a connection with obligation related to giving birth or being raised, which are seen as significant and incomparable in parental caring. Thus, it would be of interest to explore how intragenerational reciprocity is significant in care provision in the later life of members of a population living without children.

Appendix 1: Pen Portraits

Carer Name with Age: Anchalee (52)
Marital status: married and 1 child
Recent Job: unemployed
Cared for person with Age: mother (77) living with father
Type of dementia: Alzheimer's disease
Years of caring experience: 2 years
Brief details: When approaching Anchalee, she said she was willing to participate in the interview since she hoped her caring experience might contribute to research regarding dementia. Anchalee was the middle child out of three daughters who was now taking care of both her older parents. When they started to become frail, her parents moved into the house where Anchalee was living with her husband and child. Anchalee said that neither of her siblings was able to provide care. According to Anchalee's account, her eldest sister had her own financial problems while the youngest sister seemed to have insufficient patience to deal with activities of care. At first, Anchalee invited the researcher to her house for the interview. After learning about the interview questions in more detail, she moved the venue to a coffee shop near her home instead since she was afraid that her mother, who had mild dementia, would understand what Anchalee was saying about her in the interview. Anchalee had her own health problems resulting from a hysterectomy and also poor memory. She said that occasionally she felt stressed from carrying out care tasks and from lack of time to sleep, thus her health sometimes grew worse. She said to the researcher at the end of the interview that she was really delighted when she was invited to take part in the research, as she wanted somebody to talk to.

Carer Name with Age: Aurapa (60)
Marital status: single
Recent Job: early-retired
Cared for person with Age: mother (80)
Type of dementia: Alzheimer's disease
Years of caring experience: 1 year
Brief details: Aurapa started caring for her mother with Alzheimer's disease just a few months after her early retirement. She invited me to interview her at her sister's home into which she had recently moved in order to look after her mother as a main carer. Since her younger sister had to go out to work from Monday to Friday, the only free time that Aurapa had to manage her own essential affairs was Sunday. Aurapa reflected that social activities with friends had decreased due to spending all her time on care provision. Despite that, she said that she was willing to do everything for her mother. Nothing was as important as her mother. The only thing she needed was the time to sleep without disturbance from her mother. If her mother simply called out for no reason during the night, Aurapa would feel annoyed. But for other reasons such as continence management, she was willing to get up to do whatever was necessary. She claimed that her sister never took on the responsibilities that she did, so her sister could not imagine the extent of the impact of caring.

Carer Name with Age: Fenda (55)
Marital status: Single
Recent Job: Unemployed
Cared for person with Age: mother (76)
Type of dementia: Alzheimer's disease
Years of caring experience: 2 years
Brief details: The researcher met Fenda at a university seminar. Fenda was the only participant who had to be interviewed by telephone because she needed to stay home to accompany her mother 24/7. Fenda was unemployed. She was able to devote most of her time to caring for her mother as a result of being supported financially by her older sister and adult niece who were also living in the same house. Fenda reported that to stop thoughts of feeling depressed, she called to mind an idea in Buddhist teaching called 'karma', a belief about causation of action, in order to make more accountable the experience of becoming a carer. Having strong religious belief, Fenda practised meditation to relieve her own stress from caring.

Carer Name with Age: Jan (53)
Marital status: single
Recent Job: own business
Cared for person with Age: mother (85)
Type of dementia: Alzheimer's disease
Years of caring experience: 3 years
Brief details: The researcher met Jan in a hospital-run seminar about dementia care. Jan was friendly but said very little in conversation. Being alumni of the same university, Jan welcomed the researcher's approach. Jan had her own business, a plastics manufacturing factory, which was a family asset shared with her brother. Thus, her daily activities covered both the public and the domestic sphere: she worked as a business woman alongside providing care for her mother. Regarding the notion of repayment, she said her single status offered the time to care fully for her mother. During the interview, she became tearful when she talked about the support and care her mother gave. The researcher felt that Jan was pressured by the responsibility of caring for her mother. Jan said she sometimes felt she need to take time out and go for a week's meditation but she did not have the available time.

Carer Name with Age: Koong (52)
Marital status: single
Recent Job: unemployed
Cared for person with Age: the second older sister (60)
Type of dementia: Alzheimer's disease
Years of caring experience: 3 years
Brief details: The researcher met Koong for the first interview at a hospital where she had a medical appointment to pick up a prescription for her sister. Koong had only ever lived with her older sister. It seemed like she had devoted her lifetime to take care of her sister, who used to provide financial support for Koong when she was studying abroad. Koong stayed with her sister almost 24 hours a day without any help from her oldest sister who had recently begun to experience symptoms of the early onset of dementia. Instead, if Koong need some help, she asked Krit who was a close friend of her sister. He regularly came to visit Koong's sister, keeping

her company, particularly when Koong needed to leave the house for financial or medical reasons. Koong was a very cautious to everything in relation to her sister's safety and well-being.

Carer Name with Age: Manee (58)
Marital status: divorced with 2 children
Recent Job: early-retired
Cared for person with Age: mother (79)
Type of dementia: Alzheimer's disease
Years of caring experience: 1 year
Brief details: Since she was a child, Manee's relationship with her mother had been poor. In Manee's view, the mother loved and admired sons, so daughters were treated oppressively. Prior to her early-retirement, Manee worked as a manager in a private sector company. A few months after retirement, her mother needed to move in Manee's house since none of her siblings wanted to take care of their mother. Despite living under the same roof, Manee felt that she and her mother were like strangers since they lacked any shared good experiences. In caring for her mother, Manee was assisted by her teenage daughters and a housemaid who had been living with her more than ten years.

Carer Name with Age: Neena (44)
Marital status: single
Recent Job: unemployed
Cared for person with Age: mother (75) living with father
Type of dementia: Parkinson's Plus
Years of caring experience: 5 years
Brief details: When approaching Neena to be a participant, the researcher felt uncertain about whether or not she was willing to be interviewed since she seemed to be hesitant. One week after the information sheet was provided to her, Neena phoned the researcher to ask for further details of the study including the interview questions and the purpose of the research, as well as the personal background of the researcher. Neena was the middle child and the only daughter among three siblings. She took up responsibility for the care of her mother, who had Parkinson's Plus, during a period of sick leave while she was recovering from a thyroid problem. Her mother was in-and-out of hospital so often that it was not easy for Neena to find time for devote to her own matters. Prior to taking care of her mother, she worked as NGO and then freelance. Although ideally she wanted to continue working, even part-time, as a freelance writer, she accepted that she could not do it. She had balanced caring and part-time work for a while, but then found that she could no longer submit her work on time since her mother now required close personal care. Neena did not need to worry about the financial costs of care as they were paid by her father who was an entrepreneur. Neena was well-educated, so she could seek information from the internet as supporting knowledge in consultation with her mother's doctors.

Carer Name with Age: Noy (34)
Marital status: married and two children
Recent Job: unemployed
Cared for person with Age: grandfather (92)
Type of dementia: Alzheimer's disease
Years of caring experience: 2 years
Brief details: The researcher met Noy at a workshop about nutrition for people with dementia. In approaching her, the researcher was uncertain if she would be willing to be interviewed because she gave no clues of her interest. In addition, when calling her to arrange the interview appointments, she seemed to be busy with her schedule for the New Year when she planned to visit her child and husband who lived in the South. Noy went back and forth between her hometown in a southern province and her grandfather's house, which was located in the middle region of Thailand. Noy had come to care for her grandfather since there was nobody else to do it. She was the lone daughter of her father who was similarly a lone child. To her, caring for her grandfather was repayment to her father at the same time. Noy had resigned from her career as nurse to care fully for not just her grandfather but also her grandmother who lived in a separate house within same area of the city. Thus, Noy had two paid helpers to assist her: one to help care for her grandfather, the other for her grandmother.

Carer Name with Age: Paula (41)
Marital status: single
Recent Job: part-time psychologist
Cared for person with Age: father (80)
Type of dementia: Frontotemporal dementia
Years of caring experience: 7 years
Brief details: The researcher met Paula in a hospital. She was the middle child of three sisters. Before taking on his care, her father had been looked after by Paula's older sister together with their mother. However, her father had clung to her mother so much that her mother became stressed and needed to stay in another place. Since then, Paula had assumed responsibility for his care instead. Paula was unable to work full-time since she assisted her sister in providing care. She said she was fine with this arrangement because the caring responsibilities were distributed equally between her sister and herself. Thus, Paula held down a part-time job as a clinical psychologist, working for two days a week. Potentially as the result of her training in the field of psychology, Paula observed that at times she noticed that emotion was a channel that her father could communicate to her; his reactions mirrored her caring. Therefore, sometimes she tried to manage her emotion to make her father calm down although the circumstances were challenging.

Carer Name with Age: Preeya (35)
Marital status: Single
Recent Job: NGO
Cared for person with Age: mother (65) living with father
Type of dementia: Alzheimer's disease
Years of caring experience: 4 years
Brief details: In the interview, Preeya talked to the researcher as friend as they were the same age. Preeya identified herself as a secondary carer helping her father, the primary carer, to look after his wife, her mother, with dementia. She was responsible for providing four full days

of care a week. Preeya had a younger sister, who was married, and a younger brother, but viewed herself as the only one providing significant parental care for their mother in relation to her dementia. Preeya accepted she was not her mother's beloved child. At the time of interview, she still faced negative reactions from her mother while caring. Preeya felt closer to her father than her mother. Despite that, she was willing to care for her mother since this was a way to lessen her father's exhaustion. However, disagreements sometimes arose over ways of providing care that led to her father and Preeya hurting each other's feelings.

Carer Name with Age: Ratchada (59)
Marital status: single
Recent Job: manager
Cared for person with Age: mother (83)
Type of dementia: Alzheimer's disease
Years of caring experience: 3 years
Brief details: Ratchada was caring for her mother. Employing a paid carer enabled Ratchada to hold down her part-time job, which regularly involved meeting with customers. Her younger brother worked full-time and was responsible for the financial care of their mother. During the interview, there was no sign indicating that Ratchada felt any anxiety about caring for their mother, who had dementia. Ratchada said that it might be because once her mother was diagnosed with dementia, she searched for information on how her mother's dementia would develop so that she could plan her mother's life and hers as well. Ratchada was optimistic, considerate, and had good skills in management. In caring, Ratchada seemed to do a good job of providing emotional support to her mother. In addition, she had to support her brother emotionally. Ratchada said that her challenge was not about providing care but about how to deal with her brother's feelings. He often felt depressed by what their mother said and by her reactions since he did not know much about the behaviour of people with dementia.

Carer Name with Age: Raywan (60)
Marital status: married with 3 children
Recent Job: own business
Cared for person with Age: mother (76) living with father
Type of dementia: Alzheimer's disease
Years of caring experience: 1 year
Brief details: Raywan lived with her husband, her daughter, and her one-year grandson in a house that was also Raywan's shop. Raywan took care of mother, with Alzheimer's disease, who lived together with her father. She checked her mother's activity regularly through a CCTV camera set up in her parents' house. Everyday, Raywan drove to pick up her mother, bringing her to stay with her at the shop in the late morning or to observe religious practice at a temple nearby. Alongside this, Raywan helped to look after her grandson on a daily basis while her daughter was out at work. With respect to caring for her mother, Raywan accepted that her younger sister and brother offered very little support. Instead, her husband was the one who stayed with her mother when Raywan had to attend appointments with customers.

Carer Name with Age: Rungnapa (49)
Marital status: Single
Recent Job: Own business
Cared for person with Age: mother (88)
Type of dementia: Alzheimer's disease
Years of caring experience: 4 years
Brief details: Rungnapa was the youngest of six children who had lived with with her mother ever since she was born. Rungnapa said that of the six siblings, she had been the one to access the highest educational opportunity; her other siblings had left school to work for the financial support of the family and also to support her education. After quitting her secretarial job, Rungnapa established her own farm. Compared with other more routine jobs, she believed that working in farming could give her more flexible time to care for her mother, who had dementia. Rungnapa's belief in Buddhist teaching was very strong. At home, she had a sister to help her look after mother.

Carer Name with Age: Saipin (60)
Marital status: single
Recent Job: unemployed (early-retired)
Cared for person with Age: mother (88)
Type of dementia: Alzheimer's disease
Years of caring experience: 2
Brief details: The researcher met Saipin in a hospital where she gave her the information sheet about the project. Saipin seemed very willing to be interviewed but with little available time. The appointment for the interview was made but rearranged several times. Eventually, the interview took place early in the morning in a hospital where Saipin had applied to attend a workshop. In the interview, it seemed like Saipin welcomed the opportunity to have somebody with whom to share her story of caring and of her relationship with her mother. Saipin was looking after her mother with the assistance of her sister though she repeatedly said that she cared for her mother more than her other siblings. This was because she was able to do some caring activities that her sister could not, for example, driving and cooking. Saipin had retired early and so far had not found any part-time work.

Carer Name with Age: Sasi (60)
Marital status: single
Recent Job: accounting manager
Cared for person with Age: mother (89)
Type of dementia: Hydrocephalus
Years of caring experience: 8 years
Brief details: The researcher approached Sasi at the end of a workshop. She shared her experience of caring for her mother at that first meeting. Sasi had a soft voice and spoke to the researcher in a very gentle way, always holding Buddhist teaching at the forefront of her mind. At the start of the interview, Sasi explained that she was the fifth of seven children and was the youngest daughter. After her siblings got married and moved out to raise their own families, she had been living alone with her mother. Since her mother's diagnosis of Hydrocephalus 8 years ago, Sasi had been the only one providing care with barely any support

from her siblings. Her mum loved and prioritised her sons over her daughters. Sasi felt that she loved her mother the most but at times her mother neglected her, particularly, when her brothers visited home and her mother expected Sasi to prepare meals to welcome them. With her interest in Buddhism, Sasi believed that 'karma' might be the reason for her caring circumstances. At the time of interview, Sasi carried sole responsibility for a number of different aspects of caring which included care expenses, domestic costs, transporting her mother to hospital, and seeking out and paying for a formal care worker.

Carer Name with Age: Sawalak (51)
Marital status: single
Recent Job: freelance
Cared for person with Age: mother (78)
Type of dementia: Alzheimer's disease
Years of caring experience: 6 years
Brief details: According to Sawalak's narrative, her poor relationship with her mother was the result of mother's disappointment that she had born a daughter and not a son, as she had desired. In Sawalak's view, it was a duty of children to care for their parent, but she was left with sole responsibility for the care of her mother while her siblings rarely visited or assisted her. One person that helped her to provide care was her niece, who was living under the same roof. During interview, the researcher could sense Sawalak's emotional distress. Sawalak explained that her niece was affected emotionally by the demands of care, as she was. Sawalak used to have a full-time academic career, and was able to do a number of part-time jobs. She was the main breadwinner in the family and never received assistance with the expenses of caring for her mother.

Carer Name with Age: Wipawee (57)
Marital status: Married and two children
Recent Job: Own Business
Cared for person with Age: mother (85) died
Type of dementia: Alzheimer's disease
Years of caring experience: 9 years
Brief details: The researcher met Wipawee at a dementia-related exhibition. In her 50s, Wipawee had spent 9 years taking care of her mother, who had recently passed away. Despite her bereavement, Wipawee was willing to participate in this research because she wanted her own caring experiences to be useful for other carers and wider society. Wipawee told the researcher that she did not know that her mother's aggressive behaviours were the signs of dementia because she often treated her that way. Her mother preferred her sons to her daughters consistently. Wipawee had deep belief in Buddhism. She often recalled Buddhist teaching to calm her mind when facing difficulties in relation to caring for her mother and conflict within her own family.

Carer Name with Age: Yuri (37)
Marital status: single
Recent Job: state enterprise employee
Cared for person with Age: mother (74) living with father
Type of dementia: Alzheimer's disease
Years of caring experience: 2 years
Brief details: The researcher arranged to interview Yuri in a coffee shop near her flat where she and her parents lived together. Yuri had an older sister but she lived in another province with her husband and their baby. Yuri said that normally her father was the primary carer for her mother, who had dementia, while she saw herself as his assistant as she needed to go out to work. In reality, Yuri regularly provided care for both of her parents. Every evening after work, Yuri prepared their meals. She also helped her father provide personal care for mother such as bathing, as she knew her father already felt tired from spending all day undertaking caring tasks. Yuri did not have any problems with the distribution of caring responsibilities, since her older sister always came and helped when necessary. For example, when their parents had medical appointments on the same day, Yuri's sister assumed responsibility for taking one of their parents to see the doctor. Prior to taking over the role, her older sister used to be the main carer for their parents because Yuri was away living and studying at a university in another province.

Carer Name with Age: Zin (45)
Marital status: single
Recent Job: freelance
Cared for person with Age: mother (73) living with father
Type of dementia: Alzheimer's disease
Years of caring experience: 2 years
Brief details: Zin had been told about this research by a colleague. As soon as the researcher received Zin's phone number, she contacted her to introduce herself. As a writer, Zin regularly shared her story of caring for mother in a blog. Nevertheless, she did not hesitate in responding to the researcher's request to interview her: she hoped that her experience might be informative and helpful to other family carers. Zin said that her father and her niece assisted with the caring tasks involved in looking after her mother. Zin was responsible for various caring tasks ranging from cooking, medications, and consultation with doctors, to more mundane caring activities. Zin claimed that working as freelance writer offered her the flexible time to care for her mother at night. Typically, she stayed up until 4:00 a.m. to take care of her mother. Zin wanted to try her best in providing care despite feeling very pressured.

Appendix 2: Interview Questions for Research Participants

Personal Information:

age, occupation, income, education, religion, siblings, marital status, number of children

Providing care and the relationship with the cared-for person:

1. Could you please tell me for whom you have been caring? Do you live with the person or separately?
2. Could you explain what the symptoms of your relatives with dementia are, and what medical advice you have been following?
3. How and why have you come to take up your caring role?
4. Is the care shared with other people? If not, why not?
5. What activities of care do you do daily? How do you balance caring with other commitments?
6. Are there any caring tasks or other matters related to care that you find difficult or impossible to handle? How have you dealt with such things?
7. What skills are required for caring?

Caring and repayment:

8. What prior experience of dementia do you have?
9. What do you think about dementia? What does it look like?
10. In your view, why did this illness happen to your cared-for person?
11. How long have you been taking care of your relative with dementia?
12. What have you done to take care of each other in the past?
13. Have you ever thought that your caring is counted as a repayment to the person you are caring for? Repayment for what?
14. I am interested in the concept of 'katanyu' and its relationship to caring. How do you understand 'katanyu'? In what way might it be expressed?
15. Do you think that caring can be collected as 'boon' (good deeds) that pays benefits in the next life?
16. What differences are there in the nature/quality/importance of care provided by men and women, respectively?
17. What role do you think men have in expressing repayment to older parents?

Motivation and caring:

18. What did you receive from your relatives with dementia when providing care for them, e.g. appreciation? How?
19. How do you determine the needs of the person for whom you care? Could you provide an example of this process?
20. What would you think if someone said that caring is a sort of burden?
21. Do you think that institutional care could be an alternative to provide care for your relatives? Why/why not?

Appendix 3: Information Sheet for Research Participants

1. **Research Project Title:** The Importance of Reciprocity in Caring for Older People with Dementia: The Experiences of Female Family Carers in Thailand

   You are invited to participate in this research project. Before you make a decision on whether or not to participate, it is important that you are aware of why the research is being done and what it will involve. Please take time to read the following information carefully, and discuss it with others if you wish. Feel free to talk to Pornthip, the researcher, if there is anything that is not clear or if you would like more information. You can take time to decide whether or not you would like to take part. Thank you for reading this.

2. **What is the project's purpose?**

   This research is a postgraduate study in social science. The overall objective of the research is to explore the meaning of reciprocity and caring, in the context of caring for older people with dementia, from the point of view of Thai family carers. Dementia is a severe chronic illness that can have many effects not only on the daily lives of people with dementia, but also on their family. Family carers play a very important role in supporting people with dementia. In Thailand, caring for older people is seen as a repayment that Thai people should make for the purpose of showing respect for them or to thank them for benefits received. However, caring for those with dementia at home is not easy, since it requires family carers to possess various kinds of skills and experience, including a good understanding of the nature of the illness and the associated caring tasks. This research, therefore, aims to study what reciprocity, repayment, and caring for older people with dementia mean to family carers. The research also aims to study what motivates family carers to continue to provide care for older people with dementia.

   This duration of this research is three years. Data collection will be carried out in Thailand for six months through in-depth interviews with family carers and observation. The researcher's activities will include observing the activities and interviewing family carers.

3. **Why have I been chosen?**

   You are invited to take part because you have been identified as a family carer. The project aims to interview 12-15 Buddhist women who have at least one year's experience in caring for people with moderate to severe dementia. Your experience could help to improve understanding of family carers' needs and in turn to improve social policy relating to dementia care and quality of life of carers.

   Participation in this research is entirely voluntary. It is up to you to decide whether or not to take part. If you do take part, you do not have to answer interview questions and can withdraw from the project at any time. You do not have to give a reason.

4. **What type of information will be sought from me and why is the collection of this information relevant for achieving the research project's objectives?**

The information that will be sought from you includes:

1. Personal characteristics (age, education, previous or current jobs, marital status, type of family status with care receiver, duration of relationship, and the likes),
2. Details of caring (amount of time for caring each day, type of caring work, period of time for caring),
3. Caring relationship with care receiver,
4. Religious belief and your understanding towards repayment for older people,
5. Experiences of caring.

To meet the research objectives, the collected data will be analysed in order to better understand carers' everyday experiences of caring, their thoughts on reciprocity and repayment, and the ways in which caring experiences shape the provision of care for older people with dementia.

5. **What will happen to me if take part?**

As an interviewee, you will be asked open-ended questions inviting you to discuss what is important to you or to raise any questions you may have with the interviewer. Interviews will last for approximately an hour to an hour and a half. You can decide the place and time that is most convenient for the interview. You can also be given GBP 5.00 (300 Baht in Thai currency) per day towards your travel costs.

Audio recording will be used only with your permission. You may request that recording be stopped at any point during the interview. Please let the researcher know. Throughout the research process, your personal data will be kept confidential and your anonymity will be guaranteed. This means that you will be renamed in the process of writing the research report.

6. **What are the possible benefits of taking part?**

Whilst there may be no immediate benefits for those people participating in the research, the hope is that you will find it personally interesting to be involved, and that the information you share will have benefits in the long run by raising the profile of family carers as one of primary importance to the policy agenda in contemporary ageing society in Thailand. By working together and exploring many different perspectives, the findings should provide a reliable body of knowledge to expand understanding and make practice better informed about the role of family carers as valuable and cooperative partners in the Thai healthcare system.

7. **What are the possible disadvantages and risks of taking part?**

There are no foreseeable risks from taking part in the research. However, given the research topic is related to dementia care, it is possible that, as an interviewee, you may refer to some previous sensitive experiences, problems in caring, or feelings of embarrassment. If this should happen and you would like to stop the discussion, the interviewing process can be paused or ended immediately to reduce your discomfort. In case you need particular support, the researcher is willing to help inform relevant organisations such as Alzheimer's Disease and Related Order, The Alzheimer Foundation of Thailand, hospitals and other related health care bodies to help solve your problems or alleviate your distress.

8. Will my taking part in this project be kept confidential?

As noted above, any information you provide as part of the research will be kept confidential to the research team. However, if anything were to be disclosed that related to an offence of a criminal nature or the restriction of someone's rights, the researcher would need to bring this to the attention of her supervisors.

Your personal data will be kept securely in a locked cabinet. You will not be identified in any reports or publications. In the process of writing the research report and any accompanying documents and/or materials based on the project interviews, you will be renamed so that your personal data cannot be identifiable. Information will be kept for a period of up to six months after the research has completed in case any further reports are to be written and published. After that the information will be destroyed.

9. What will happen to the results of the research project?

This project is a part of a postgraduate research study that will be submitted to the University of Sheffield. A summary of the final research thesis can be made available on request. It is also possible that some parts of the research will be published as specific journal articles or best practice publications. You will not be identified in any report or publication. Participants will be provided with a copy of any subsequent publication, as required.

10. Who is organizing and funding the research?

This project is a part of a postgraduate research study, sponsored by Thammasat University, the researcher's work organisation.

11. Who has ethically reviewed the project?

This research has been approved via the Department of Sociological Studies ethics review procedure, which is monitored by the University of Sheffield's Research Ethics Committee.

12. Contact for further information

The research has been carefully and sensitively planned, but if at any time you should you have any questions or concerns about the research process, you can contact:

Researcher

Ms. Pornthip Netiparatanakul
275 Petkasem Road, Bangkae District
Bangkok 10160
Thailand
Telephone: +66 (0) 81 490 0705

Postgraduate Research Student
Department of Sociological Studies
The University of Sheffield
Elmfield, Northumberland Road
Sheffield S10 2TU, The United Kingdom
Telephone: +44 (0) 749 011 1204
Email Address: pnetiparatanakul1@sheffield.ac.uk

If you feel that your concerns have not been dealt with satisfactorily, you can contact my research supervisors Dr. Lorna Warren <l.warren@sheffield.ac.uk> or Dr. Andrea Wigfield <wigfield@sheffield.ac.uk>. Dr. Warren is also Director of Postgraduate Research Studies in the Department of Sociological Studies, University of Sheffield and, if necessary, can escalate any complaint you may have through the University complaints procedures.

Doctoral Research Supervisors

Dr. Lorna Warren
Director of Postgraduate Research Studies
Department of Sociological Studies
The University of Sheffield
Elmfield,
Northumberland Road
Sheffield S10 2TU
Email: l.warren@sheffield.ac.uk

Dr. Andrea Wigfield
Director and Research Specialist, CIRCLE
Department of Sociological Studies
The University of Sheffield
Elmfield
Northumberland Road
Sheffield S10 2TU
Email: wigfield@sheffield.ac.uk

Thank you for reading this information sheet and considering whether to take part in the research. If you agree to take part, you will be given a copy of this sheet to keep and will be asked to sign a consent form.

Pornthip Netiparatanakul, Doctoral Researcher.

Appendix 4: Consent Form

Title of Research Project: The Importance of Reciprocity in Caring for Older People with Dementia: The Experiences of Female Family Carers in Thailand

Name of Researcher: Ms Pornthip Netiparatanakul

Date:……………………………………

Participant Identification Number for this project: **Please initial box**

1. I confirm that I have read and understand the information sheet dated …………………… explaining the above research project and I have had the opportunity to ask questions about the project. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐
3. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. ☐
4. I understand that I will have an opportunity to comment on the report that results from the research to ensure that the information that I provided is clear and my confidentiality is well protected. ☐
5. I give permission for appropriately anonymised data collected from me to be used in future research. ☐
6. I agree to take part in the above research project. ☐
7. I agree to my interview being audio-recorded. ☐

________________________	________________	____________________
Name of Participant	**Date**	**Signature**

(*or legal representative in case of participant's illiteracy*)

________________________	________________	____________________
Name of researcher	**Date**	**Signature**

To be signed and dated in presence of the participant

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