Caring for Dementia in Thailand:

A study of family care for demented elderly relatives in Thai Buddhist society

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ABSTRACT

This study explores the nature of caring for elderly demented relatives living at home in Thailand. Structured and semi-structured interviews were carried out with 44 pairs of known cases of demented patients (subjects), who received treatment at out-patient departments (OPD) in three selected hospitals, and their principal carers. The Thai Mental State Examination (TMSE) and Behaviour Rating Scale (BRS) were applied to subjects, the Caregiver Strain Index (CSI) was applied to carers, and the Network Assessment tool was applied to both subjects and carers.

Significant correlations were found between levels of strain in carers and the cognitive impairment and physical dependence of subjects. Spouse carers experienced significantly less strain, but reported more stress and physical strain and a poorer current relationship than younger relative carers. The vast majority of subjects (94%) and more than half (57%) of carers had a small support network. Three-quarters of carers needed information about dementia illness and how to provide care at home and two-thirds felt the elderly relative should receive financial support. Despite difficulties in caring, three-quarters of carers were still willing to continue to provide care. The primary motivation to care was derived from a strong filial obligation based on Buddhist belief of *'reciprocity.'* The effects of the caring relationship and the quality of care need further investigation. Policy recommendations include providing health education, financial support, and carers support groups.

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ABBREVIATION

AD	Alzheimer's disease
AIDS	Acquired immune deficiency syndrome
BKK	Bangkok
BMN	Basic Minimum Needs
BP	Blood Pressure
BRS	Behaviour Rating Scale
CAPE	Clifton Assessment Procedures for the Elderly
CAS	The Cognitive Assessment Scale
CAT scan	Computerised Axial Tomography scan
CSI	Caregiver Strain Index
CT scan	Computerised Tomography scan
DSM-IV	The fourth edition of the Diagnostic and Statistical Manual of Mental Disorder
ER	Emergency Room
GDP	Gross Domestic Product
GHS	General Household Survey
HFA (2000)	Health For All by the Year 2000
HIV	Human immunodeficiency virus
HOMES	Household Model for Economic and Social Studies
ICD-10	The tenth revision of the International Statistical Classification of Diseases and Related Health Problems

MID	Multi-Infarct Dementia
MMSE	Mini Mental State Examination
MOPH	Ministry of Public Health
MRI	Magnetic Resonance Imaging
NESDB	National Economic and Social Development Board
NFT	Neurofibrillary tangles
NGO	Non-Government Organisation
NHS	National Health Service
NSO	National Statistical Office
OPCS	The Office of Population Censuses and Surveys
OPD	Out-Patient Department
PD	Parkinson's disease
PET	Positron Emission Tomography
PHC	Primary Health Care
SCA	Senior Citizen Association of Thailand
SCD	Subcortical dementia
SD	Standard Diviation
SEC	Socio-Economic Class
SECAPT	Socio-Economic Consequences of the Ageing Population in Thailand
SES	Socio-Economic Status
SOFT	Survey of Fertility in Thailand

TMSE	Thai Mental State Examination
UNICEF	United Nations Children's Fund
VHC	Village Health Communication
VHV	Village Health Volunteers
WHO	World Health Organization

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INTRODUCTION

Caring for elderly people varies among countries, depending upon the health and social services provided, religion, culture, normative belief, and, the socio-economic status of carers and cared-for persons. There has been a dramatic increase in the proportion of elderly people all over the world. In 1980, the percentage of elderly people over the age 65 in the total population of the world was 5.8 percent (Kinsella, 1988). Demographic projections between the years 1980 and 2000 show that three-quarters of the increase in the world's elderly population would take place in the developing world (Kalache, 1991), where half of the elderly population lives in Asia. By the year 2050, the proportion of the elderly population in Asia is likely to be trebled (Tabah, 1982; Centre for Policy on Ageing, 1989). The continued growth of population has become a major concern.

Although the present population in the developed countries has not changed much, because of the stabilisation of population growth as a result of low fertility rates and mortality rates over a long period, in contrast, population growth in developing countries is still increasing, even though fertility rates have reduced. There has been a decrease in mortality rates due to medical advances, better nutrition, clean water, and general improvement in the quality of life, causing people to live longer. We can predict that in the next decade, the world will face an ageing population, particularly in the Third World, where there are high birth rates. The question therefore arises, how can those countries cope with an ageing population, with limited resources?

Thailand is a developing country in South East Asia, where there was a high fertility rate in past decades. The success of family planning resulted in a decline in the total fertility rate. In 1960-65 it was 6.42 percent, while in 1985-90 it had dropped to 2.57 percent (Knodel, 1995). This has resulted in reduction in family size, and in the number of children who will be future carers. At the same time, the high fertility rates of the years before family planning had been introduced, combined with the benefits of economic growth and improved medical care, mean that, in the near future, Thailand will be faced by a proportionally large elderly population. This disproportion between numbers of elderly people and of carers is likely to be an increasing problem. Services and resources, particularly for elderly people who suffer ill health or chronic illness in later life, therefore need to be considered.

Dementia is a common condition of old age; 2%-4% of those between ages of 65 and 70, and 20% of those over 80 years of age, develop dementia (Forsythe, 1990; American Psychiatric Association, 1995). It is a condition involving the decline of memory and other cognitive functions in comparison with the patient's previous level of functioning. Despite this high incidence, dementia has not been intensively studied or investigated in Thailand. Whatever its cause, dementia is described in Thailand as senile dementia unless there are clear signs and symptoms of a particular disease such as Parkinson's disease (PD) or Alzheimer's disease (AD), or a clear history of illness. The reasons for not carrying out an investigation of the cause of dementia may be due to the cost of tests, insufficient medical technology and treatment resources, or the attitude towards dementia from the medical professionals themselves. At the same time, dementia is also accepted as a common result of ageing, because in Buddhist society, people believe that all human bodily functions will deteriorate with increasing age; thus, dementia is simply seen as part of the ageing process.

Although research into care of elderly people has been established and promoted in Thailand since 1960, it has still not received widespread study or attention. Currently, there are only five geriatricians, who qualified in the UK or USA, for approximately four million elderly Thai people (aged over 60). It is, therefore, not surprising that most elderly people receive treatment from general practitioners or neurologists where there is no geriatric medicine; frequently, if they show aggressive behaviour, demented people are treated in psychiatric hospitals. It may be argued that older people do not necessarily require medical care from geriatric medicine, but, as mentioned earlier, general care for older people has become stereotypical, while geriatric medicine in Thailand tries to promote quality of life and maintain independence in ways similar to these ideas advanced in the western world.

Since economic development has caused an increase in industrial and business growth in Thailand, this has led to a migration of the labour force from rural to urban areas and many elderly relatives have been left behind. Social structures have changed with the advent of modernisation. In contrast to the traditional extended family, there has been an increase in the nuclear family, with its values of individuality and privacy. Parsons (1949) concludes that the isolation of the nuclear family is an adaptive response to a technologically advanced industrial economy and is typical of modern societies. These changes are likely to lead to a lack of carers in the future, and result in smaller families, many of whom will be living in the cities, which will be a matter of serious concern. It is clear that the Thai government will have to prepare service strategies, including health social services, for elderly people who can not be cared for by their families.

In Thailand, health care is provided by both government and private sectors. In general, people are responsible for all medical costs, the exceptions being the families of government officials, and those who are on the poverty line, who are allowed free medical care from the government. There is not the same level of community support services that is available in industrial countries. Thus, there is a great burden on the family who bear the full responsibility for a relative with dementia .

Buddhism is the predominant religion of Thailand. Out of the estimated 55 million people in Thailand, about 95 percent are Buddhists, while about 4 per cent are Muslims, 0.5 per cent are Christians, and the remainder Brahmins, Hindus, Sikhs, Confucians and others (The Office of the Prime Minister, 1991). The Thai people have traditionally had a strong Buddhist based ideological system, which emphasises care and respect for the elderly. It is based on the cultural ideology of "parent repayment" in which children are expected to repay their parents for having given birth to them and raised them (Mulder, 1985; Klausner, 1987; Caffrey, 1992b). Thus, adult children become a care providing resource for elderly people in Thailand.

Little is known about the nature of family care in Thailand. In particular, the issue of care for elderly people who suffer from chronic illness, such as dementia, has been little considered. Regarding this concern, the present thesis aims to make a contribution to filling this gap. The aims of this study are first to identify the characteristics of those who are acting as carers by determining the relationship between the role of carer and age, gender, and level of education. Second, to study families in the caring situation, in order to explore how families are able to manage in caring; what factors influence carers to provide care for their demented relatives with the limited provisions available in Thailand; and what kind of responsibilities they bear and how severe are the problems they face. Included in the investigation are the problems of providing care for their demented relatives, such as financial problems from the cost of caring; the carers' own well- being; the degree of dementia of their demented relatives; and the relationship between carers and people with dementia, examining whether this relationship deteriorates according to the length of time in which care has been given, or the degree of dementia. A third aim is to assess the carers' emotional and psychological health by examining the levels of caregivers' emotional strain, using the Caregiver Strain Index (CSI). As Adams (1987) asserts, a common feature in studies of families with a chronically confused member is the experience of stress. When one member of a family is chronically confused, the family suffers from the effects. In addition, the ill health and functional disabilities of older persons and the resultant need for care may also strain informal care providers to the point that they can no longer offer continued support (Klein et al., 1967; Crossman et al., 1981). Using this index of strain provides an opportunity to ascertain the extent to which this western based instrument is applicable in the context of Thai culture. A fourth aim is to examine the effect of modernisation and demographic changes on traditional Thai family care, and more importantly, the effect of the Buddhist religion and Thai culture on this care. A fifth aim is to identify the needs of carers and identify primary assistance needed in providing care for people with dementia. The final aim is to contribute to policy and practice; particularly, to inform the policy makers of the problems of family care for elderly relatives who suffer from chronic illness, such as dementia, which may lead to development of an appropriate intervention plan to ease the carers' problems.

It is hoped that this study will contribute to a better understanding of how families care for a demented elderly relative in a developing country such as Thailand and help to establish the effects of culture and religious factors on the carers providing care to their demented relatives. It is also hoped that this study will assist in finding a way of helping carers to cope with a demented parent on limited resources. Thus, this study's findings will, it is hoped, support the Thai Government, through the Department of Health and Social Security, in its efforts to create for the future a suitable care package for dementia sufferers and their carers in Thailand.

This thesis contains eight chapters. Given the lack of literature about dementia and people who provide care for those with dementia, the first two chapters, dementia and carers, very much concentrate on the literature from the Western countries which is more extensive, in order to give an idea of what dementia is, and who are the principal carers, and what are their characteristics. Chapter 3 will focus on the available literature in Thailand about the ageing population, caring for elderly in the Thai culture, health and social welfare, and the impact of caring for elderly people. The research design and methodology will be described in chapter 4, the selection of assessment tools, how participants were found, and unforeseen circumstances. The research findings will be presented in three parts. The first two parts provide an analysis of quantitative data; chapter 5, describes the demographic characteristics of subjects, including their cognitive status and level of dependence, while the second part, chapter 6, is concerned with the demographic characteristics of carers, their support networks and their level of strain in caring. Chapter 7, the third part of the research findings, concentrates on the qualitative data from the open-ended questions. In this chapter, much use is made of direct quotation, and of simultaneous cross-reference to the quantitative data. Discussion of the present research is made in chapter 8, in which the findings, implications and recommendations for further research are considered along with the limitations of the research. Finally, a summary of the whole thesis is presented in the conclusion.

CHAPTER 1

Dementia

Introduction

The increased interest in the issue of ageing has focused on well being and quality of life in old age which needs to be emphasised within the clinical practice of medicine, geriatric care and provision of social support for both the elderly and their families. The dementia syndrome is a common disorder in later life, the commonest cause being Alzheimer's disease, followed by vascular disease, and then by multiple aetiologies. The prevalence of dementia is 2%-4% of the population over age 65 years and it is increased with age, particularly after age 75 years, with a prevalence of 20% or more over age 85 years (American Psychiatric Association, 1995).

The changing age structure in developing countries suggests they will have reached a situation comparable to that of Europe in 1950, by the year 2025 which means that an "epidemic" of dementia will occur in developing countries (Jones and Miesen, 1992) soon after the turn of the new century. If the proportion of elderly people who suffer from dementia is similar to that found in western countries, then the problems faced at this time will be immense. Unlike developed countries where national health services are available, in the developing world family members are the primary source of help and as a consequence may face more stress and burden in caring, as well as financial difficulties, in the long term care of their demented relatives. Dementia, therefore, has become a major public issue and there is a need for increased awareness on the part of health professionals and the public in view of its implications for the cost of long term care and lost earnings both of the demented person and of those who may stop work to provide care.

The aim of this chapter is to draw attention to the importance of developing greater understanding about dementia, to be aware of the increasing number of demented persons in the society, to provide a brief description of the different types of dementia and how to manage them and to provide the context for the present study.

1.1. Definition

The word dementia is derived from the Latin *'demens,'* which originally meant 'being out of mind,' and was a general term for insanity or madness (U'Ren, 1987). It also referred to any behaviour or state of mind considered irrational, unusual, abnormal or incomprehensible (Mahendra, 1984). The criteria for dementia syndrome were made more precise when the third edition of the Diagnostic and Statistical Manual of Mental Disorder (DSM-III) was published in 1980. Its classification represents an advance in conceptualisation, as the global term 'chronic organic brain syndrome,' which lumped together more specific brain syndromes and which connoted irreversibility, has been eliminated (Berrios, 1987). In DSM-III-R (American Psychiatric Association, 1987), this term was replaced by a section titled 'Organic Mental Syndrome and Disorders,' which referred to a constellation of psychological or behavioural signs and symptoms without reference to aetiology. However, the term *organic mental disorder* is no longer used in the recent DSM-IV (American Psychiatric Association, 1995) because it incorrectly implies that "non-organic" mental disorders do not have a biological basis. Thus, in DSM-IV, these types of disorders have been grouped into three sections: Delirium, Dementia, and Amnestic and other Cognitive Disorders; Mental Disorders Due to a General Medical Condition; and Substance-Related Disorders. Nowadays, perhaps the most widely accepted definition is that provided by the American Psychiatric Association (1995) in DSM-IV as follows:

> The essential feature of a dementia is the development of multiple cognitive deficits that include memory impairment and at least one of the following cognitive disturbances: aphasia, apraxia, agnosia, or a disturbance in executive functioning. The cognitive deficits must be sufficiently severe to cause impairment in occupational or social functioning and must represent a decline from a previously higher level of functioning.
>
> (American Psychiatric Association, 1995; p. 138)

The DSM-IV has mentioned that the diagnosis of a dementia cannot be made during the course of delirium.

The World Health Organization (WHO) provides the International Statistical Classification of Diseases and Related Health Problems (ICD). The tenth and latest revision of ICD, published in 1992, consisted of an official coding system and other related clinical and research documents and instruments. Although those preparing the ICD-10 and DSM-IV have worked together closely, resulting in much mutual influence (for example, the codes and terms provided in DSM-IV are fully compatible with both ICD-9 and ICD-10), however, the American Psychiatric Association (1995) have further pointed out that the ICD-10 Diagnostic Criteria for Research provides a narrower definition of dementia in several ways. For example:

> the minimum duration of the disturbance is 6 months, the additional deficits are restricted to a deterioration in judgement and thinking and in the general processing of information, and there must also be a "decline in emotional control or motivation or a change in social behaviour."
>
> (American Psychiatric Association, 1995; p. 143)

The difference in some of the criteria for diagnosis of dementia between these two systems may confuse those health professionals who apply these tools. Thus, there is a need to develop a single unique criterion for dementia diagnosis, to facilitate a consistent approach and compilation of more precise, accurate statistical data on the number of dementia sufferers all over the world.

According to Mayeux et al. (1993), more than 55 illnesses, some non-progressive, can cause dementia. At the present, there is a general agreement in defining dementia as a syndrome or a group of symptoms which can be manifested in variable combinations (Jones and Miesen, 1992). Each of these illnesses will have a clear underlying pathology, whether organic or psychological (Jacques, 1992). In all types of dementia, Holden and Woods (1995) point out, memory difficulties are usually prominent among the first indications that something is wrong. Typically, new learning ability will be particularly impaired.

1.2. Epidemiology

Epidemiological studies of dementia seem to show an apparent variation, "depending on the age of the subjects' sample; methods of determining the prevalence, severity, and type of cognition impairment; and the regions or countries studied" (American

Psychiatric Association, 1995; p. 141). For example, surveys carried out in Northern and Western European countries, in the United States, the Soviet Union, China, Japan, Australia, and New Zealand report a wide range in the average prevalence of dementia from about 1.5% to 14.0% of the general population and an ever wider range in the average of those who have a less severe form of dementia from 4% to 53%. However, these surveys failed to clarify the major geographic or ethnic differences in patterns of dementia (Jones and Miesen, 1992). In the United Kingdom, of a total 55 million population in the early 1990s, the number of definite dementia sufferers of all ages was estimated at 500,000-600,000 (5.5%-6.6%). Ineichen (1993) has reviewed studies of the epidemiology of dementia in East and Southeast Asia and compared prevalence rates with those found in European countries (Table 1.1). These findings, except Thailand, all point to the increasing prevalence of dementia with increasing age expectancy.

Table 1. 1. The prevalence of dementia in Asia and Europe (%)

Age groups	Singapore (1985) n=612	Korea (1896) n=549	China (1986) n=1,090	Japan (1987/88) n=3,754	Thailand (1989) n=500	Europe* (since 1971) n=9648
60-64	-	-	0.3	-	1.0	0.5
65-69	0.9	5.2	1.0	0.9	0.0	1.1
70-74	1.5	9.9	0.0	2.2	1.1	3.9
75-79	0.9	17.3	1.8	4.3	4.4	6.7
80-84	4.8	45.7	8.8	8.7	16.7	13.5
85 and over	12.0	45.7	16.7	15.2	7.6	30.3

*Note * 12 locations in Europe*
Source: Adapted from Ineichen (1993) p. 320.

1.3. Differential Diagnosis

The diagnosis of dementia depends on distinguishing whether the person has a normal cognitive deterioration with increasing age, delirium, or a mental disorder due to an other general medical condition and this issue is discussed in the following sections.

1.3.1. Dementia or Ageing Process ?

Dementia is still not recognised in many parts of the world, and the debate about dementia being part of the natural ageing process continues. There is a natural decrease in cell numbers in certain regions of the brain in later life. Brody (1970) pointed out, there is a significant decrease (approximately 40%) in cell numbers in the frontal lobe (affect awareness and personality); the superior portion of the temporal lobe (hearing, memory); the occipital lobe (vision) and the precentral gyrus (motor) (Brody, 1975). If dementia is part of the ageing process, all elderly people should show signs and symptoms of dementia. In fact, dementia is a minority condition. Jacques (1992) referred to a large number of community surveys on the prevalence of dementia, which indicated that approximately 0.7% of the 60-65 age group have definite dementia, but it increases in prevalence at later ages. Thus, age alone does not cause dementia. However, age has been reported as a strong risk factor for dementia (Katzman, 1986). Since both normal and demented persons have difficulty with recent memory, Copeland (1987) suggested the two groups can be distinguished by the more extreme amount of dysfunction on simple tests of new learning and recall of unfamiliar material, shown by the demented person. Dementia, therefore, should no longer be seen as an ageing process, but considered as a chronic illness. Demented persons need help to maintain their quality of life, as well as support for their families or those who provide care for them.

1.3.2. Dementia and Delirium

The former 'organic mental syndrome' in DSM-III-R has been grouped into three sections in the recent DSM-IV. One of these sections is Delirium, Dementia, and Amnestic and Other Cognitive Disorders (American Psychiatric Association, 1995). Since the delirium and dementia syndromes share the common characteristic of cognitive impairment, it is important that the signs and symptoms of delirium are recognised in order to make a differential diagnosis.

Although memory impairment is common to both dementia and delirium, the main difference is that the person with dementia alone is alert and does not have the disturbance in consciousness that is characteristic of delirium. Also, the typical clinical symptoms in delirium fluctuate while systems in dementia are relatively stable (American Psychiatric Association, 1995). However, the diagnosis cannot be made if there is no definite history of pre-existing dementia. The DSM-IV suggests that when there is uncertainty whether the symptoms in a given person are those of delirium or dementia, it is best to make a provisional diagnosis of delirium and observe the person carefully while continuing efforts to identify the nature of disturbance.

1.3.3. Depression and Dementia

Depression is the most common functional mental disorder affecting older people (Brayne and Ames, 1988), probably twice as common as dementia (Patterson and Crome, 1986). The DSM-IV suggests that major depressive disorder may be associated with complaints of memory impairment, difficulty thinking and concentrating, and an overall reduction in intellectual abilities. Thus, it is often difficult to determine whether cognitive symptoms can be accounted for dementia or a major depressive episode (American Psychiatric Association, 1995). Depression is generally reversible and treatable. Thus, it is important to differentiate depression from dementia. However, people with depression are likely to complain of their memory loss, while demented persons may try to conceal their memory problem. The onset of illness is also crucial. The duration of depression is often shorter, measured in weeks or a few months (Geldmacher and Whitehouse, 1996), while the demented person experiences gradual cognitive deterioration over a longer period of time. Although there may be symptoms and signs of dementia, in pseudodementia, there will usually be no evidence of damage to the brain. In a true dementia, there will be gradual brain damage (Jacques, 1992), although there is a considerable overlap between the two.

1.4. Classification of Dementia

As mentioned earlier, dementia is a syndrome which results from more than 55 illnesses. Although, in general, these illnesses share common signs and symptoms, the causes of illness, neuropathological or strategy of treatment are different. Dementia can be classified by using specific criteria, such as the age of onset of illness, its neuropathological characteristics, causes of illness, or the prospect of treatment as follows:

1.4.1. Pre-senile and Senile Dementia

The very first dementia classification was senile and pre-senile dementia, using the age of 65 as the dividing line between these subgroups. Jacques (1992) states that the benefit of this division is that it distinguishes the different effects on the family and social life of a person of working age and of an elderly, retired person. However, this may have caused those with pre-senile dementia to be referred to neurologists for expert diagnosis and possible treatment, while senile dementia was still seen as an ordinary problem of old age. Therefore, this type of classification is not popular nowadays.

1.4.2. Cortical and Subcortical Dementia

In most cases of dementia, there will be disturbance of memory and cortical functions (language deficits, apraxia, and agnosia). However, there are a number of dementia sufferers whose cortical functions and motor behaviour are unimpaired. This has led to speculation and attempts to differentiate dementia by pathological lesion and clinical symptoms. In recent years, these different types of symptoms has been proposed as a syndrome of "subcortical dementia" (SCD) (Jacques, 1992; Tolosa and Alvarez, 1992). The term subcortical refers to damage of the white matter, substantial nigra or other subcortical nuclei (Jacques, 1992, p. 38). SCD syndromes include Parkinson's disease, Huntington's disease, and Binswanger's disease. The classification of dementia syndrome by clinicopathology of cortical and subcortical pattern is shown in Table 1.2.

Table 1.2. Clinicopathological classification

Cortical pattern	Subcortical pattern
Alzheimer's disease	Wilson's disease
Pick's disease	Parkinson's disease
Creutzfeldt-Jakob disease	Huntington's disease
Dementia associated with large vessel stroke	Progressive supranuclear palsy

Source: Developed from Jones and Miesen (1992), Table 2.6, p. 16.

According to Tolosa and Alvarez (1992), the degree of cognitive loss is mild in SCD when compared with the cognitive abnormalities present in AD. Regarding the personality changes, people with cortical dementia are less concerned and show less insight into their problems. Another major feature distinguishing SCD from cortical dementia is psychomotor slowness, including the presence in cortical dementia of language deficits, apraxia, and agnosia, which are usually absent in people with SCD. Moreover, clinical differentiation is based on the neurological abnormalities in people with SCD, such as extrapyramidal syndrome, involving with movement disorders which include tremor, dystonia and abnormal gait, and a speech problem, characterised by slurring and hypophonia.

1.4.3. Aetiologic classification

Attempts have also been made to classify dementia syndromes by using aetiology or the cause of disease criteria. For example, the unknown cause of AD, dementia due to a central nervous system condition, dementia due to a systemic condition, the persisting effects of a substance, dementia due to multiple aetiologies and dementia not otherwise specified in which there is insufficient evidence to establish a specific aetiology (American Psychiatric Association, 1995) (see Table 1.3)

Table 1.3. Aetiological Classification

Aetiology	Illness
Unknown	Alzheimer's disease
Central nervous system condition	Cerebrovascular disease Parkinson's disease Huntington's disease
Systemic condition	Hypothyroidism Vitamin B12 deficiency HIV infection
Multiple aetiologies	Alzheimer's disease and Head Trauma The combined effects of a general medical condition (e.g., Parkinson's disease)
Substance-Induced Persisting Dementia	Alcohol-Induced Persisting Dementia Inhalant Persisting Dementia Unknown Substance-Induced Persisting Dementia
Dementia Not Otherwise Specified	Amnestic Disorders

Source: Adapted from DSM IV (American Psychiatric Association, 1995), pp. 144-160.

To identify the cause of dementia, it is necessary to obtain an adequate history and undertake careful examination, before a differential diagnosis can be made. However, a correct diagnosis cannot be guaranteed unless there is neuropathological confirmation. Nevertheless, even if the neuropathological confirmation is carried out, diagnostic error may still exist due to the differences in the histopathological diagnosis among several pathologists, for example, the lack of consensus concerning tissue dissection at autopsy; the use of different tissue-staining techniques; and distribution of the histopathological changes (Alafuzoff, 1992).

1.4.4. Treatable and Untreatable Classification

Dementia may be due to progressive damage of the brain. Thus, it is essential to identify patients whose dementia has a treatable cause and aim to remove that cause, in order to halt the progress of the dementia. It may be possible to provide effective treatment which may help the patient to recover well, if the damage is not too severe (Jacques, 1992). It is also important for the carers or relatives to know the prognosis of the disease, in order to help them understand the nature of dementia or the fact of progressive cognitive impairment and to be able to plan for the caring task. Therefore, classification of dementia according to whether it is reversible or irreversible seems reasonable and useful (see Table 1.4).

Table 1.4. Differential diagnosis of dementia

Treatable causes	Untreatable causes
1. Depressive illness	1. Alzheimer's disease
2. Cardiovascular disease	2. Ageing
3. Infective and inflammatory illness	3. Vascular dementia
Encephalitis	4. Parkinson's disease
Syphilis	5. Uncommon pathologies
4. Drug intoxication	Creutzfeldt Jakob disease
5. Normal pressure hydrocephalus	Huntington's chorea
6. Metabolic/endocrine condition	
Vitamin B12 deficiency	
Hypothyroidism	
Parathyroid disorder	
7. Subdural haematoma	
8. Neoplasia	
Brain tumour	

Source: developed from Whalley and Spratt (1992), figure 1, p. 301.

1.5. Types of Dementia

A number of illnesses can cause dementia, sharing a common symptom presentation. However, dementias are classified according to presumed aetiology: Dementia of the Alzheimer's Type, Vascular Dementia, Dementia Due to Other General Medical Conditions, Substance-Induced Persisting Dementia, Dementia Due to Multiple Aetiologies or Dementia Not Otherwise Specified. Only the most commonly found types of dementia will be presented in this section.

1.5.1. Alzheimer's Disease

Alzheimer's disease can be defined as a medical disease, characterised by loss of intellectual activity with impairment of short-term memory (Jones and Miesen, 1992). These degenerative neurological conditions were first described by Alois Alzheimer, a

German neurologist, in 1907 (Zec, 1993). Alzheimer's Disease (AD) is the most common type of dementia, affecting 2% to 4% of the population over age 65 years (American Psychiatric Association, 1995). The prevalence of AD has been found to increase with age, as many as 20% of population over the age of 75 (Davison, 1992) and 47.2 % for those over 85 years (Park et al., 1993) suffering from the disease. In most developed countries, in general, either AD alone or in combination with other illnesses accounts for 70% of all dementia (Copeland, 1991).

The pathological changes associated with Alzheimer's disease are brain shrinkage and weight loss. There is also enlargement of the ventricles (Jacques, 1992). Histologically, there are widespread plaques and filamentous tangles. The cause remains elusive. Five possible causes of AD include genetic factors, aluminium, environmental factors, a slow virus, and ageing. However, this list of possible causal factors is still inconclusive. Computerised Tomography (CT) scan appears to be helpful in distinguishing AD from dementia syndromes associated with intracranial tumour, subdural hematomas, brain abscesses, obstructive hydrocephalus, and stroke. Magnetic Resonance Imaging (MRI) which produces an image of the brain is particularly sensitive in determining pathological changes affecting the cerebral hemispheric white matter (Erkinjuntti et al., 1987). Positron Emission Tomography (PET) changes also appear early in the disease course, and as the illness progresses, there is diminished frontal lobe metabolism. To diagnose AD it is necessary to establish the presence of dementia by excluding other conditions that might produce a similar picture. AD can be identified by using the fourth edition of the Diagnostic and statistic Manual of Mental Disease (DSM IV) or other diagnostic criteria which was developed by the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) (McKhann et al., 1984).

1.5.2. Vascular Dementia (*formerly* Multi-Infarct Dementia or MID)

The second most common dementing disorder after Alzheimer's disease is vascular dementia (Metter and Wilson, 1993). It has been estimated that vascular causes account for about 10-30% of all cases of dementia (Jacques, 1992; Geldmacher and Whitehouse, 1996). Vascular dementia appears to be more common among men than women (American Psychiatric Association, 1995) and the prevalence increases with age (Metter and Wilson, 1993). It is also more common in Japan and China than in the West (Tatemichi, 1991). Vascular dementia was formerly called 'multi-infarct dementia' in the DSM-III-R (American Psychiatric Association, 1987). Since a substantial increase in research on diagnosis, it has been renamed 'vascular dementia' in the recent DSM-IV (American Psychiatric Association, 1995).

In general, vascular dementia results from pathological changes that occur in the circulatory system that supplies the brain and spinal cord leading to consequences within the nervous system (Metter and Wilson, 1993). At the present, multiple cerebral infarctions and haemorrhages are believed to be responsible for vascular dementia (Hachinski et al., 1974; Metter and Wilson, 1993). Almost every stroke will produce infarction to the brain. Cummings (1995) mentions that vessel occlusion is the most common cause of vascular dementia. Thus, the cognitive deficits depend on the site of the ischaemic damage or infarction of the brain. The infarction, or area of dead brain tissue (Jacques, 1992), is typically a result of occlusion of the blood vessel by either thrombosis or embolism which may be associated with the presence of arteriosclerosis with the narrowing of the artery. Cerebral infarction may also occur after cerebral haemorrhage as a result of either blood vessel disease or hypertension (Metter and Wilson, 1993). It has been found that the probability of developing dementia following stroke appears to increase with increasing age, prior stroke, and cerebral atrophy (Tatemichi, 1990).

1.5.3. Other causes of dementia

According to the DSM-IV (American Psychiatric Association, 1995), the causes of dementia, other than AD and vascular dementia, were Dementia Due to Other General Medical Conditions, Substance-Induced Persisting Dementia, Dementia Due to Multiple Aetiologies, and Dementia Not Otherwise Specified. In the category of Dementia Due to Other General Medical Condition, it is indicated that there must be evidence from history, physical examination, or laboratory findings that a general medical condition is etiologically related to the dementia; for example, infection with human immunodeficiency virus (HIV), traumatic brain injury, Parkinson's disease, Creutzfeldt-Jakob disease, Huntington's disease, Pick's disease, normal pressure hydrocephalus, hypothyroidism, brain tumour, or vitamin B12 deficiency. However, the dementia diagnosis cannot be made during delirium.

In the Substance-Induced Persisting Dementia category, there must be evidence from history, physical examination, or laboratory findings that the deficits are aetiologically related to the persisting effects of substance use, such as drug abuse, a medication, or toxin exposure. The Dementia Due to Multiple Aetiologies category includes more than one general medical condition which may be aetiologically related to the dementia, or dementia may be due to the combined effects of a general medical condition, and the long-term use of a substance, for example dementia of the Alzheimer's type and dementia due to Head Trauma, Parkinson's disease (PD), and Alcohol-Induced Persisting Dementia respectively. Finally, dementia which does not meet the criteria for any of the specific types, or where there is insufficient evidence to establish a specific aetiology, will be categorised as Dementia Not Otherwise Specified. Some types of dementia in these groups which frequently occur in old age will be presented below:

i) Dementia Due to Parkinson's disease

Parkinson's Disease (PD) was first described by James Parkinson, an English physician, in 1817. It is a disorder of a nucleus of nerve cells, deep in the centre of the brain, called the substantial nigra. Thus, there is a reduction in the neurotransmitter dopamine (Jacques, 1992), producing symptoms which affect movement and speech. It has been suggested that approximately 20%-60% of individuals with PD will develop dementia (American Psychiatric Association, 1995) and up to 70% have some degree of cognitive impairment (Mayeux et al., 1992). Dementia with PD is characterised by cognitive and motor slowing, executive dysfunction, and impairment in memory retrieval where depression is frequently exacerbated by declining cognitive performance (American Psychiatric Association, 1995).

ii) Dementia and Toxic Damage

There is evidence that dementia may be produced by any systematic illness that compromises cerebral blood flow, brain oxygenation, or neuronal metabolism (Cummings, 1995). Chronic excessive use of alcohol is one example of toxic damage which produces dementia, particularly recent memory loss. There will be progressive brain damage if the person continues to drink, but the damage becomes static when he or she stops drinking (Jacques, 1992). However, prolonged alcoholism and nutritional deficiency may produce severe neurological disorders which are likely to be related to irreversible cognitive impairment, including severe amnesia (Salmon, et al., 1993). Excessive use of prescribed medicine can also cause intellectual impairment (Cummings, 1995).

1.6. Dementia Management

Management of dementia focuses largely on psychological care and continuing care provision by the family rather than treatment per se, although there have been several advances recently in therapies which delay or slow the progress of dementia. Cumming (1992) offered a useful management plan for dementia sufferers which covers five aspects: treating the underlying disorder that is causing the cognitive decline; treating the cognitive deficit in selected patients with AD; improving associated behaviour disturbances; reducing the consequences of disability; and also addressing the needs of the care giver (Table 1.5).

Table 1.5. Management in Dementia

Treatment domain	**Intervention**
Underlying disorder	
Vascular dementia	Aspirin, ticlopidine, Lower BP?
Parkinson's disease (PD)	Selegiline, levadopa, bromocriptine, pergolide (Antiparkinsonian drugs do not help the dementia)
Depression	Antidepressants, electroconvulsive therapy
Brain tumour	Surgery, radiation therapy, chemotherapy
Hydrocephalus	Ventriculoperitoneal shunt
Infection (e.g., Syphilis, AIDS)	Antibiotic
Wilson's disease	Penicillamine
Alcohol abuse	Abstinence
Aluminium and other metals	Remove the poison
Vitamin deficiencies	Vitamin
Hypothyroid disorder	Thyroxin
Cognitive impairment	
Alzheimer's disease (AD)	Tacrine
Behavioural symptoms	
Depression	Antidepressants, electroconvulsive therapy
Psychosis	Antipsychotic agents
Agitation	Antipsychotic agents, trazodone, carbamazepine, anxiolytics, propranolol
Anxiety	Antixiolytics
Insomnia	Sedative hypnotics
Consequences of disability	
Seizures	Anticonvulsants
Pneumonia	Antibiotics
Urinary tract infection	Antibiotics
Pressure ulcers	Preventive measures
Family	
Psychological distress	Counselling, support groups, psychiatric care
Exhaustion	Assisted home care, day care, respite care, residential care
Financial planning, power of attorney	Legal consultation

Sources: Developed from Cumming (1995), table 2, p. 1482 and from Jacques (1992), Table 1.5, pp. 11-12.

Conclusion

Dementia is a common disorder in old age. It is characterised by multiple cognitive deficits that include memory impairment, cognitive disturbance and disturbance in executive functioning. Although dementia is not part of the ageing process, age itself has been reported as a strong risk factor for dementia. The incidence of dementia is 2%-4% amongst those aged over 65 years and increases to 20% amongst those aged over 80 years. The present situation of an increase in the proportion of elderly people, particularly in the developing countries, has raised awareness of the problem of dementia and it is become a major interest for the health professions concerned with the health and well-being of demented people.

The main difference between dementia and delirium is that the person with dementia is alert. People with depression are likely to complain of their memory loss while a demented person may try to conceal their memory problem. More than 55 illnesses can cause dementia. The most common causes of dementia syndrome are Alzheimer's disease (AD) and Vascular disease, accounting for 70% and 10-30% of all dementias respectively. Dementia has tended to be classified as reversible or irreversible, in order to be able to identify whether it is treatable or untreatable. Treatment of dementia is based on the elimination of the cause of the dementing process. However, in most dementing illness where the cause is not known, alleviating the symptoms is considered important.

The problem of diagnosing dementia is compounded in a country such as Thailand where access to experienced personnel and scanning equipment is limited. Confusion over diagnosis and lack of information about the cause of the individuals' illness may result from lack of adequate means for making a clear diagnosis. Dementia syndrome is a chronic illness and the vast majority of individuals with dementia are cared for by family members in the community (Tuokko, 1993). Caring for the confused elderly in the home environment may produce physical, psychological and financial strain to the carers. Therefore, caring by a carer at home and managing the caring task is a major issue, which will be discussed separately in Chapter 2.

CHAPTER 2

CARERS

A review of the literature

Introduction

Increasing life-expectancy is a universal phenomenon and has led to the increase in the very old age group (over the age of 75 or 85) (Thompson, 1987; Wilson, 1997) in the developed countries and the new phenomenon of a large proportion of elderly people in developing countries. Concern about the increasing incidence of chronic illness in old age, particularly dementia, has led to an increased awareness of the caring resources required in countries such as Thailand which have limited health resources.

Although Thailand and the UK have different health and social welfare systems, as Baggott (1994) has pointed out, it seems that different health care systems around the world are facing the same kinds of problems, such as a growing proportion of elderly people, the burden of chronic illness, and the need to control the cost of care which requires considering essential reform (Ham et al., 1990). In the UK, official 'community care provision,' in which caring for old and frail people has been shifted from institutions to the community has been developed over nearly 50 years (Walker, 1994), there have been extended studies of such systems of care (Finch, 1993; Henwood, 1995). In contrast, although care in the community or family care has always existed in Thailand, little is known about this care. It is possible that carers in the West and in the East may share some common problems and that Western studies may even help to identify or predict the future problems that Thai carers may face. Due to a lack of literature about carers in Thailand and in order to understand better the concept of carer, most of the definitions of carers in this chapter are based on literature from Western countries, particularly the UK, whilst a review of the literature on caring for elderly relatives in Thailand will be presented later, in Chapter 3.

2.1. Carers in general

The term 'carers' is in common usage nowadays, though it is not certain exactly when it first became current. Twigg et al. (1990) stated that the use of the term 'carer' has grown in the last decade. The word was itself developed within social care agencies and it bears the mark of that origin. In fact, there are many words which are frequently used and have the same meaning as carer, such as informal care or caregiver. The words carer and informal care are commonly used in the United Kingdom, while caregiver is more commonly used in the United States of America.

Arber and Ginn (1990, p. 430) defined carers as "a social group sharing a common problem and a common interest," and carers can experience similar problems, regardless of whether the dependant is a physically disabled child, a mentally handicapped adult or a frail elderly person (Twigg et al., 1990). Ungerson (1990) explained that, in Britain, the term 'caring' and the noun 'carer' have come to refer to a very specific kind of relationship between, usually, two people, one of whom is highly dependent and usually adult, and the other of whom looks after the dependent person and does it 'at home' and for no pay. The word 'caring' is used only to refer to caring for people who are dependent, not because they are infants, but because they have some distinguishable disability.

2.2. Differences between informal care and formal care

Bell and Gibbons (1989) suggested that the distinguishing characteristics of informal and formal care are that informal care or carer refer to people who, for a variety of different reasons, find themselves caring for an elderly dependent person - unpaid, untrained and for up to a full 24 hours each day. Formal carers, on the other hand, are people from the statutory and voluntary sector, both professional and others, who are paid and often highly trained to do a job of work which brings them in touch with elderly people and/or their carers. Ungerson (1990) asserted that 'informal' care is assumed to be restricted to one-to-one relationships on an apparently unchanging basis laid down by feelings of love and/or duty. In contrast 'formal' care, which takes place in the public domain, is provided by large numbers of substitutable social service personnel to even larger numbers of clients, on a basis of affordable cost, and competition between clients. Carers are usually kin relations, although they may extend to the bounds of friendship or neighbourliness where these have taken on the character of a primary relationship (Bell and Gibbons, 1989; Qureshi and Walker, 1989). In contrast, formal care is organised to be delivered to all members of the population in need and obligation to provide equal services for similar cases (Qureshi and Walker, 1989).

2.3. Categories of carers

In general, carers can be categorised, according to Twigg et al. (1990), in three main ways: first, in terms of features of themselves or demographic categories, such as male and female carers or elderly and child carers; second, in terms of features of their dependant, such as carers of elderly people or carers of head injury patients; finally, in terms of their relationship, for example, spouse carers or non-kin carers. However, Twigg (1990) further stated that there is a strong case to be made for regarding carers as a category in themselves, rather than subordinating them to the type of disability experienced by their dependant.

2.4. Gender and caring

The issue of gender has always been at the centre of debates on informal care (Finch and Groves, 1983; Ungerson, 1983,1987; Land and Rose 1985). In the UK, the 1985 General House Surveys (GHS) generated a large scale data set on carers for the first time (Green, 1988) and found that the largest contribution is made by women. This brought to public attention the major role of women in giving care to dependent people. In fact, the issue of informal care was first brought on to the policy agenda by feminists wishing to analyse the unequal burden being imposed on women and to reclaim the ways in which informal care was seen as oppressive to women (Twigg, 1992).

2.4.1. Female carers

In general, the concept of 'caring' was originally a gender concept, due to the idea of 'caring' being about the activities of women within their own families (Finch, 1993). Ungerson (1990) has asserted that 'carers' are generally regarded by feminists, just as much as by policy-makers, as very similar to mothers and housewives, working in their own homes and providing services for close kin. As the state withdraws more and more from the direct provision of care, particularly for elderly people, it now has an interest in ensuring that this apparently spontaneous caring by women is organised on a predictable and large scale. Moreover, there is a widespread belief that 'dependent' people are best cared for in their own homes, particularly by members of their own family (Dalley, 1993). Because of these circumstances, the focus was on carers as women, and caring for elderly people and other dependants was seen as another instance of women's unpaid domestic labour (Arber and Ginn, 1990). Feminists exposed the way in which social policy contained an implicit family policy in which the position of women was assumed and unchallenged. Particular concern was expressed at the growing emphasis in public policy on community care (Wilson, 1982).

As informal care is expected to be provided mainly by middle-aged women, parallel demographic and labour market changes, as more women enter the labour force, have called into question the future supply of carers, promoting a sense of crisis about the care of elderly people (Henwood et al., 1987).

2.4.2. The role of male carers

Although women carers are more likely to provide personal care than male carers, the gender difference is least among those caring for their spouse (Arber, 1995). For example, Green's (1988) study found that 40% of carers were male. Qureshi and Walker (1989), reporting on a small scale study of elderly people receiving help in Sheffield, found that 11% of elderly people receiving help had a son helping. In spouse carers, Arber and Gilbert (1989a and 1989b) found equal proportions of elderly men and women caring for a disabled spouse, while Bond (1992) found up to two-thirds of male carers who were identified as provided assistance for their spouse. The gender difference is least among elderly carers. Men and women over 75 years of age, provide equal amounts of co-resident care, reflecting gender equality in the care of elderly spouses (Arber and Ginn, 1990).

Parker and Lawton (1991) tried to distinguish between the caring roles of men and women by asking questions about the pattern of caring responsibility, the nature of caring responsibility, and the impact of caring on men compared to women. Their analysis has shown that men as a group are much less at 'risk' of becoming carers. However, younger single men and older men who have been married are as much at 'risk' as are their female peers. Co-residence is an important factor in men's caring responsibilities, suggesting that they sometimes become carers 'by default' because they have never left the parental home (Qureshi and Walker, 1989; Arber and Ginn, 1991; Glendinning, 1992). Male carers do have a different caring profile from women. For example, they look after their 'dependant' for fewer hours, but over longer periods. Women, however, generally carry out the most difficult and onerous caring tasks

(Nolan et al., 1994). Thus, the main difference which remains between men and women is the type of care that they provide.

2.5. Hierarchy among informal carers

Qureshi and Walker carried out a study of caring relationships in Sheffield, in 1982-83, and found a hierarchy of preference among informal sources of help from available informal network in older people in their study. In descending order, these were spouse, relative living in household, daughter, daughter-in-law, son, and other relative (Qureshi and Walker, 1989, p. 123). The rule of hierarchy, according to the traditional Western normative preference structure, is that the 'close relatives are preferred to more distant ones, any relative is preferred to a non-relative, and female relatives are preferred to male relatives' (Qureshi and Walker, 1989, p. 123). However, Qureshi and Walker (1989) mentioned that the hierarchy of preference findings may not be definitive for the whole of the UK due to their small sample size, so a large scale survey would be needed. Nevertheless, their findings provide a general indication of those who are the most common sources of help and are most likely to provide care for older people, given that the literature indicates that carers can be relatives, friends or neighbours. Finch and Mason (1990) carried out later a study on the hierarchy of obligations (i.e. what most people do) among network members in relation to decision-making about the provision of practical help to older people. Their findings indicated fairly strong support for the idea of filial obligations; nearly two-thirds (57%) of the sample agreed that children have a duty to look after their parents when they are old. This confirms Qureshi and Walker's findings that carers who were children felt that they were the right people to be helping (Qureshi and Walker, 1989). However, caution is needed as this study merged quantitative findings with the literature in establishing its generalised hierarchy.

2.6. Caring is a Public Concern

During the 1980s, in many countries, there was growing concern to contain spending on health and social services, which led to intensified policy debates about home care (Jamieson, 1993). In the UK, Arber and Ginn (1990) reviewed the literature and suggested that since the 1970s, the community and social consequences of demographic shifts in age structure have been areas of increasing policy interest. This concern has appeared in debates about the cost of pensions, the modification of the State Earning-Related Pension Scheme, and possible intergeneration conflict between pensioners and workers (Johnson et al., 1989). Another debate has been concern about the costs of health and welfare services for elderly people (Arber and Ginn, 1990).

Carers have entered the public domain of official statistics, demonstrating official concern and interest in this group after the first national survey of such carers conducted in the UK in 1985 by the Office of Population, Censuses and Surveys (OPCS) in UK as part of the GHS (Green, 1988; Arber and Ginn, 1990; Henwoods, 1995). It was found that there were an estimated six million informal carers (Arber and Ginn, 1990; Parker, 1992, Twigg, 1992) or one in seven adults. The survey identified 14 % of all adults over the age of 16 as being 'carers' and while the highest frequency age was 45-64 (20%), 13% of those age 65+ were also identified as carers (Green, 1988). However, Parker (1992) pointed out that those aged 56 and older were somewhat more likely than younger carers to be involved in helping with personal and physical tasks (35% and 27% respectively). That is to say, over a third of informal care to people over 65 is provided by other elderly people. The survey was repeated in 1990, and it was estimated that there were 6.8 million carers nationally (OPCS Monitor, 1992). There are also some other small scale studies about carers, data from which showed increasing numbers of spouses as carers. For example, in the case of dementia, Levin et al. (1989) found that 61% of carers were spouses and 10% siblings, i.e. 71% were same generation carers and therefore likely to be themselves elderly (Wenger, 1990).

2.7. Policy and Caring

In terms of welfare and policy for elderly people, a broad range of provision is found in Europe. Although the broad types of service offered are similar, such as pensions and financial and practical assistance in relation to transport and housing, these provisions vary in different countries; the levels of public provision are much higher in north and west Europe compared to the south and east (Hugman, 1994).

In the UK, the history of state welfare has been developed since the late 1950s and the idea of 'community care' increasingly became the centre of interest (Finch, 1993). During the post-war period, the principal services focused on people who were mentally handicapped or physically disabled and on children, whilst home services for older people were not regarded as a priority and were left largely to the voluntary sector (Means and Smith, 1994). Following growing concern about the demographic changes, with an increasing proportion of elderly people, increased interest in the cost of care of older people, changes in marital patterns and family formation, and an increase in the number of women participating in the labour force, the care of older people has drawn much research and policy attention and the idea of caring in the community been highlighted. The principal objective of community care is to guide the development of appropriate services to meet the needs of elderly people and their carers (Parker, 1993).

However, in relation to these concerns, Bebblington (1988) and Wells (1989) have argued that in each age group, the proportion of people with a given level of disability has decreased over time, with a corresponding increase in expectation of life without disability. The increased number of elderly people does not imply an equivalent increase in disability and need for carers (Arber and Ginn, 1990). Evidence suggests that the burden has been greatly exaggerated. Older people make the most use of health care and hence cost most in the last two years of their lives. As populations age, the last two years move up the age range, so that although the numbers of very old people increase, the number of high service users escalates much more slowly (Wilson, 1997).

2.8. Stress and Caring

The psychological well-being of carers has been a focus of interest since, although untrained, they provide continuing care for their elderly relatives who suffer from chronic illness, such as dementia. Literature shows that caring for someone at home can be stressful. Thus, many studies attempt to assess the well-being of the individual carer and stress related to care providing. Because there has been some confusion in the conceptualisation of stress and related terms, thus, in this section, the terminology of stress and other related concepts, the stress process, stress measurement, and individual and family stress will be discussed. The discussion of the concept of stress is limited to the stress that arises from providing care, particularly in the community, rather than in an institution.

2.8.1. The concept of stress

In studying stress in caring, it is important to know the terminology, for better understanding of the background theory. One may ask, what does stress really mean and how can it be measured? Although the term stress seems to be commonly used in everyday life, however, very few people are able to define when the precise concept is needed (Cox, 1978). The term stress also means different things to different people (Selye, 1976). Cox (1978) has further stated that because stress is poorly defined, the concept is somewhat elusive. To define stress has proved to be difficult, due to the confusion surrounding this term, as well as other terms used in connection with it (Pearlin and Schooler, 1978; Humphrey, 1984). Thus, Cox (1995) expressed concern that a lack of consensus on the definition 'would seriously hamper research into stress and the subsequent development of effective stress management strategies' (Cox, 1995, p.21-22).

In general, there are three different, but overlapping, approaches, to the definition and study of stress: as a stimulus (the engineering approach); as a response (the medicophysiological approach); and as an interaction (the psychological approach) (Cox, 1978 and 1995, and Charlton, 1992). Each of these approaches or basic concepts of stress, and the key researchers associated with each approach, are highlighted below.

i) Stress as Stimulus- Engineering approach

The concept of stress in this approach is derived from the field of engineering, according to which stress is said to produce a strain reaction (Cox, 1978 and 1995; Appley and Trumbull, 1986; Hingley and Cooper, 1986). Stress in this concept is described as 'the load or level of demand placed on the individual, or some aversive or noxious element of that environment' (Cox, 1995 p. 22). Thus, stress in this approach, will be treated as an independent variable and as a stressor or environmental stimulus. This is the most common definition of stress adopt by psychologists (Lazarus and Folkman, 1984).

However, certain limitations of the definition of stress applied in this approach have been pointed out. For example, Charlton (1992) argues that if the same stress is repeatedly applied, the effects wear off, as the organism adapts; thus, the stress is no longer a stress. In addition, although the same stress is applied, people may respond differently; therefore, stress cannot defined be solely in term of stimulus. Cox (1978) also points out the limitation of applying the engineering model to human beings, because 'men and their organisations are not machines'... and 'we have to accept some intervening psychological process which mediates the outcome of that relationship' (pp. 14-15). This approach does not allow for individual differences in the evaluation of events, as it assumes that certain situations are normatively stressful (Lazarus and Folkman, 1984). On the other hand, Kaplan (1996) admits the usefulness of the engineering model, in that it offers a clarification of relationship between the concepts of stress and strain.

ii) Stress as a Response- Medicophysiological approach

In this approach, stress has been defined in terms of response, i.e. the person's response to disturbing stimuli (Hingley and Cooper, 1986) and stress in this approach will be treated as a dependent variable. Response definitions have been widely used in biology and medicine. Thus, Cox (1995) called this approach the medicophysiological approach. The most influential theory of the stress process, although it has since been challenged, came from Hans Selye. Selye (1956,1976, p. 63) defined stress as 'the non-specific response of the body to any demand.' The non-specific response was composed of the 'general adaptation syndrome' (GAS) or biotic stress syndrome which is developed in three stages: the first, is the alarm reaction, the stage of the individual's defence mechanism towards any noxious agent. If individuals can survive, they will enter the second stage, the stage of resistance which provides maximum adaptation. After still more exposure to the noxious agent, the signs of alarm reaction reappear. People then enter the third stage, the stage of exhaustion, where the stress response is irreversible and the individual dies (Selye, 1976). However, later study found that not all noxious physical stimuli produce the GAS (Mason, 1971).

The model concentrates on the outcome or response, and is limited to the physiological level of analysis. It treats stress as the disturbance of homeostasis produced by environmental change (Lazarus and Folkman, 1984). It fails to acknowledge the role of psychological processes, though there are many psychological parallels. Although it is true that stress is found all in the most extreme and overwhelming situations, as in Selye's model (Appley and Trumbull, 1986), there are great variations in human response. For example, if the same stressor is applied, people may respond differently, depending upon individual perception and appraisal. Moreover, while any stimulus which produces a stress response is treated as a stressor, however, in the reality, not all such stimuli produce an unpleasant response; competitive sport is an example (Slater, 1996).

iii) Psychological approach

It has been suggested that stress cannot be described entirely according to stimulus-and response-based definitions, but need to be examined in a broader sense, which takes into account the person and the environment surrounded him by fusion of the stimulus-response approaches, to provide a reasonably comprehensive account of the stress system (Cox, 1978). Since the earlier two approaches provided inadequate explanation in stress process, thus, the psychological approach has been developed, in order to explore the stress process and be able to identify individual differences. According to Cox (1995, p. 24), stress refers to 'a dynamic interaction between the person and their environment.' Two distinct types of theory have been identified within this approach: the interactional and the transactional, as follows:

Interactional theories

The interactional theories focus on the structural characteristics of a person's interaction with their environment. There are two major interactional theories: person-environment fit and job demands/decision latitude. In the concept of person-environment fit, stress is seen as the result from the mis-fit between the individual and his environment (Hingley and Cooper, 1986). In job demand/decision latitude theory, stress is said to arise in the situation where workers perceive themselves to have low control over their tasks accompanied by high job demands. Such workers are said to be likely to report poor health and low satisfaction. However, these theories are mainly concerned to provide a structural model of work stress, particularly in organisations; thus, their details will not be included in this section.

Transactional theories

Transactional models are primarily concerned with the psychological process, cognitive appraisal and coping, the person's interaction with their environment (Cox, 1995). Thus, the psychological impact on the person, which is said to directly determine the psychological response rather than the actual presence of the stressors' agent, is become a centre of attention (Cox, 1978). Significant contribution to develop the transitional model came from the work of Lazarus (1966), with the recognition of cognitive appraisal. Thus, psychological stress was defined by Lazarus and Folkman (1984) as:

> 'a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being.' (p. 19)

Lazarus and Folkman (1984) also identified the causes of psychological stress in different persons by examining two processes that mediate the person-environment relationship: cognitive appraisal and coping. *Cognitive appraisal* is a process of evaluation and determination of why and to what extent a particular interaction between the person and the environment is stressful. It is comprised of primary appraisal, a function in which the person evaluates any potential risk or benefit to his or her well-being, and secondary appraisal, in which the person evaluates what can be done to overcome or prevent harm or improve the prospect of benefit. The *coping process* is 'the process through which the individual manages the demands of the person-environment relationship that are appraised as stressful and the emotions they generate' (Lazarus and Folkman, 1984, p. 19). In this theory, general appraisal influences coping and coping in turn influences encounter outcome. However, the direction of the relationship among appraisal, coping, and encounter outcome seems unclear. Folkman et al. (1986) found that the relationships among the variables were likely to be bi-directional. While appraisal influences coping, coping may influence the person's reappraisal; moreover, it is possible that certain forms of coping, such as positive reappraisal, may be influenced by the outcome. Although the concept of coping has become a centre of attention to find successful ways to solve or prevent problems, there is a need for further research, particularly longitudinal studies, to clarify the causal ordering in this model (Nolan et al., 1996), in order to complete the view of the stress process.

Although the psychological approach claims to offer more explanation of the stress process by including recognition of psychological processes, however, it has been criticised for not providing much more by the way of definition than the other two approaches. The definition is rather circular (Hobfoll, 1989; Charlton, 1992).

2.8.2. Stress process

Since the psychological approach to stress has been developed, the transactional theories have clearly moved forward in relation to the appraisal and coping processes, providing scope to explain why some people find a certain situation stressful, while others do not. This approach helps to assess individual differences in perceived stress and appears to provide a clearer picture of the stress process in human beings, despite some limitations. Thus, the majority of recent stress studies have focused on the transactional model of stress, which emphasises not only physiological and psychological, but also other variables, such as the individual's social and economic circumstances. These variations are brought into consideration and included in the stress-coping models, in order to achieve full understanding of individual differences in perceived stress.

Pearlin and colleagues (Pearlin et al., 1990) offer an extensive account of components of carer stress model which focuses on the relationships among the many conditions leading to personal stress and the ways these relationships develop and change over time (Pearlin et al., 1990). Thus, the stress process in this concept is comprised of four principal components: the background and context of stress; the stressors; the mediators of stress; and the outcomes or manifestations of stress. First, the background and context of stress, concern the carer's demographic and socio-economic characteristics, caregiving history, family and network and the available resources. Second, the stressors, refer to 'the conditions, experiences, and activities that are problematic for people; that is, that threaten them, thwart their efforts, fatigue them, and defeat their dreams' (Pearlin et al., 1990, p. 586). Stressors are divided into primary and secondary stressors. The primary stressor is conceived as the demands of caregiving which lead to other problems and hardships, which are referred to as the secondary stressors. The third element of the stress process is mediators, which consist of two principle dimensions: coping and social support. Coping is conceived as a response to life events, while social support helps to prevent or inhibit the development of secondary stressors. Finally, the outcomes involve the well-being of people, physical and mental health, and their ability to sustain themselves in their social roles.

According to Schulz (1990) and Giegel et al. (1991), based on their reviews of the theoretical framework of stress, the majority of conceptual stress-coping models are concerned with the relationship between stressors, mediators and outcome, to assess the well-being of individuals who provide care for their relatives (see Figure 2.1).

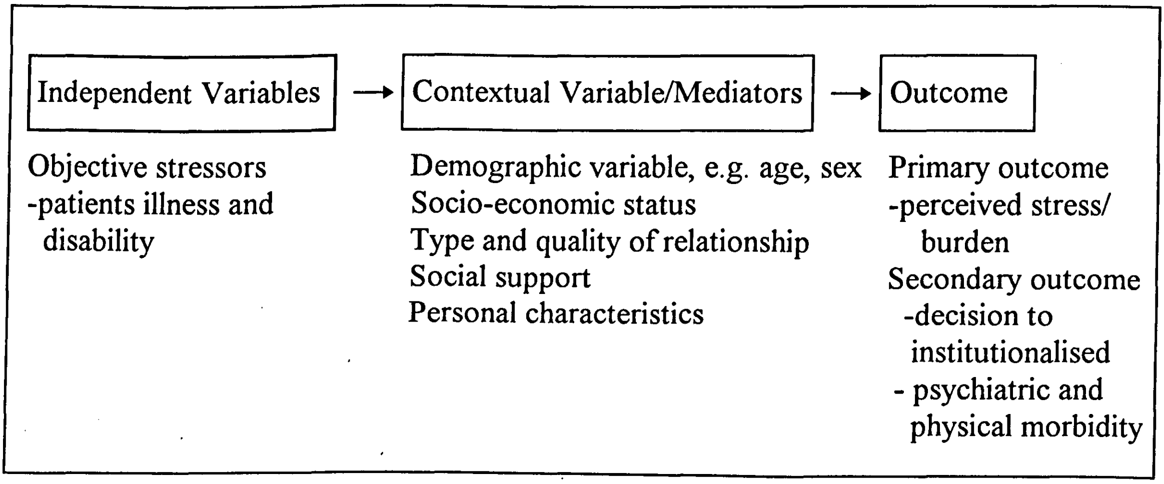

Figure 2.1. Composition of the general stress-coping model

i) The independent variables

The independent variables are antecedent events concerned with the objective stressors, the illness and disability, of cared-for person. The objective stressors include level of self-care, cognitive impairment, and behaviour problems. However, in this stage, in Pearlin et al.'s (1990) conceptual model of stress, the independent variables may include subjective variable which refer to subjective hardships experienced by carers. Pearlin and colleagues describe them as overload or burnout felt by carers.

ii) Contextual variables/ mediators

In this stage, cognitive appraisal and coping as critical mediators (Lazarus and Folkman, 1984) are taking place. Stressors will be appraised and a coping response will occur after the situation has been evaluated, facilitated by the resources. The resources include carer socio-economic status; type and quality of relationship; social support, and personal characteristics. However, it is still not clear whether appraisal occurs before coping or whether coping can occur before appraisal. There is a need for longitudinal studies to clarify this process. In addition, there is no clear relationship or interaction between individual carers and these resources variables, since a number of studies have produced inconsistent findings, as will be indicated in Sections 2.8.4 and 2.8.5.

iii) Outcome

The outcome of the stress process may depend on the individual's coping skill and resources and the coping strategy that produces a positive outcome in one person, may not in another (Lazarus, 1993). In persons who fail in the coping and adapting stage, the outcome will be assessed by the expression of their feeling of stress or burden. Thus, perceived stress and burden in this thesis will be used as synonyms. In caring related to burden, the term carer burden refers 'to the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults' (George and Gwyther, 1986, p. 253). Burden is often treated as the primary outcome or as a predictor of other outcomes such as depression or institutionalisation (Schulz, 1990; Giegel et al., 1991). For example, subjective burden (the relative feeling of carrying a burden) (Zarit et al., 1986) and failure to reduce carer's distress, have been found to be predictors of the breakdown of care and resulting institutionalisation (Gilleard, 1987).

2.8.3. Stress Measurement

The measurement of stress should be based on self-report, which is perhaps the most common proxy source of information. Since perceived stress is a subjective statement, thus, data need to be validated by Triangulation with other sources of information (Cox, 1995). A number of standardised instruments for measurement of perceived stress or burden also have been developed and refined, in order to assess stress in the individual as accurately as possible. Thus, Schulz (1990) and Biegel et al. (1991) point out that measures of burden have become more complex and more subjective and the burden scales available can vary from a narrow perspective to a broader view of the dimensions of conceptualisation of burden.

The earlier burden scales, such as the Burden Interview developed by Zarit et al. (1980) focus on the issues most frequently mentioned by carers, posing problems, such as feelings of health, psychological well-being, finances, social life, and relationship between carer and caring for. The Caregiver Strain Index (CSI) developed by Robinson (1983) also assesses the most common stressors in caring, in terms of the caring task, physical, emotional, work, and financial factors. Although these scales indicate the global burden which contributes to depression and other outcomes, however, they do not identifying which stressors contribute most to the outcome (Pearlin et al., 1990), so people cannot relate caregiving to its impact (George and Gwyther, 1986). The CSI scale was also criticised for making a number of simplistic and unwarranted assumptions, for example, that all the events provoke stress in the carer all the time and that the amount of stress provoked by differing events is equal, i.e. inconvenient and being overwhelmed (Nolan et al., 1994; Nolan et al., 1996).

The later caregiving burden scales take a broader view, assessing carer status in terms of general well-being or multiple dimensions. The multidimensional examinations include physical health, mental health, social participation, and financial resources (George and Gwyther, 1986; Novak and Guest, 1989). George and Gwyther (1986) suggested that carer well-being is an alternative measurement which is developed to overcome the limitation of the earlier carer burden scales. In particular, the specific dimensions of well-being can be measured separately. Carer burden has been classified into subjective and objective burden (Poulshock and Deimling, 1984; Zarit, 1986; Fadden, et al., 1987; Cafferata and Stone, 1989). Objective burden refers to the carer's behaviours while subjective burden refers to the carer's awareness and effective orientation (Cafferata and Stone, 1989). The advantage of this perspective is that it is able to highlight the specific importance of the carer's subjective burden (Poulshock and Deimling, 1984), which is later identified as an indicator of secondary outcome of placement decisions (Zarit, et al. ,1986). Burden can also be measured by focusing on the level of emotional distress experienced by carers (Gilleard et al., 1984; Gilleard, 1987).

According to Cox (1995, p. 27), measurement of stress is a measure of the process, 'antecedents through perceptions and experiences (and moderating factors) to immediate outcomes to health status' (also see Figure 2.1). However, these are complex to measure and single one-off measures of stress are inadequate. Poulshock and Deimling (1984) also suggested that perceived stress or burden, those subjectively interpreted by carer, should be treated as an intervening measure between impairment and other more objective indicators of caregiving effects. Therefore, 'global measure of psychological well-being, physical health, or depression should be viewed as being affected by burden, as well as many other factors, but should not be viewed as measures of burden' (Schulz, 1990, p. 38). There is no doubt that no satisfactory single completed stress measuring scale has yet been made available. Thus, there is still a need for further study.

2.8.4. Carer stress

In the literature on caring, individuals who provide support to ill relatives have received increasing attention since studies showed that carers frequently feel physically, psychologically, financially, and/or socially burdened as a result of the demands imposed by caregiving (George and Gwyther, 1986; Pearlin et al. 1990; Chappell and Penning, 1996) and the burden of caregiving often contributes to feelings of guilt, resentment, worry and grief (Biegel et al. 1994). Deimling and Bass (1986) identified four types of symptom of dementia: functional dependencies, cognitive impairment, impaired social interactions, and disruptive behaviour, of which Biegel et al. (1991) suggested that those with more severe symptoms cause greater stress. Levin (1985) also identified a number of factors which appear to be associated with strain when untrained care is being provided for an older relative, for example number of major problems; number of trying behaviours; severity of incontinence; absence of normal conversation; disturbance of carer during the night; and presence of dangerous behaviour. However, inconsistent research findings have also been reported. Zarit et al. (1980) reported that carers' feelings of burden are associated with the social support available, but not associated with the behaviour problems caused by the demented person's illness, and Biegel et al. (1994) also found little relationship between severity of illness and burden.

Level of stress has also been reported to vary among carers who provide care for different types of care receiver. It has been reported that caring for those suffering from dementia is more stressful, psychologically, than is caring for the physically frail (Eagles et al., 1987; Graftstrom et al., 1992), though the studies by Liptzen et al. (1988) and Conforti et al. (1991) found no significant difference. However, the greater stress on carers for people with dementia may result from the cognitive impairment which influences the psychological impact on the carer. Gilleard et al. (1984) indicated that the performance of physical tasks causes less stress than the 'loss of mutuality' and the destruction of the relationship between the carer and the dependant. Ungerson (1990) has included the association between loving and caring as another factor that brings emotional stress to carers. However, care has acquired such an overwhelming connotation of the feelings of affection and continuity that it turns out to be very difficult to provide care. Parker (1980) suggested that the word 'tending' might be more suitable, in order to convey the work involved as separate from the loving feelings.

Yeatman et al. (1993) found that physical proximity, such as cohabitation with the dementia sufferer or depressed old person, was an important determinant of psychological stress in primary care. Thus, this finding also supports a range of research findings in relation to the carers of elderly mentally infirm people. Twigg et al. (1990) stated that it is not simply the extent and repetitiveness of the caregiving task that can cause distress, but the limitations it places on life as a whole. Studies by Lovelock (1985) and Stephens and Christianson (1986) also suggest that restriction of life is one of the major sources of carer distress.

2.8.5. Family stress

For a better understanding of stress perspective in caring, not only is stress in individual carers explored, but family stress also has to be investigated. It is important to identify the problems which produce family stress, in order to help health professionals and social workers to develop and implement an intervention strategy (Adams and Barker, 1989). Adams (1987) asserted that a common feature in studies of families with a chronically confused member is the experience of stress. In general system theory, the family has been seen as a unit containing interacting components that function in a co-ordinated way to deal with the environment and family members are viewed as interacting elements (Biegel et al., 1991). Family stress is defined by Boss (1988, p. 12) as ‘a pressure or tension in the family system. It is disturbance in the steady state of the family,’ and it arises from the interaction of a number of factors.

Boss (1988) and Adams and Barker (1989) suggested that there are two main kinds of factors that give rise to family stress: internal and external factors. There are three factors comprising the internal conditions which families can change and control: psychological - the way in which families appraise and assess events they encounter; structural - the form and function of family boundaries, role assignments and rules about who can be included in the family; and philosophical- which includes the values and beliefs a family possesses which cause it to attribute particular meanings to events that happen to the family. The external factors are comprised of the components over which the family has no control: heredity - a history of physical disorder; history - factors that vary according to time; development - relating to the stage the family is at, including such factors as the length of time couples have been together, the number of children in the family and the splintering of families through divorce; economy such as unemployment and the system of state benefits; and finally, culture- the position and role of elderly people in society.

A stressor in the family stress context, is referred to ‘an event that marks a possible starting point of process of change and subsequent stress in the family’ and it is highly influenced by family’s external context (Boss, 1988, p. 38). In general, for family stress as for individual stress, we cannot assume a particular event is stressful, without asking the family how they define it. Thus, Boss (1988) has further stated that the degree of stress caused by the event depends not only on the actual magnitude of the event but, also, on the family's perception of that event.

Lewis and Meredith (1988) point out that frequently, additional stress is caused when the caring relationship affects carers' other social and family bonds, such as carers' marital relationships; their relationships with their children and the nuclear family as a whole, which suffer from conflicting demands and the family's lack of privacy and peace. Burden scores were found to be higher among co-resident carers and wives to have a higher level of burden than husbands (Harper and Lund, 1990). A longitudinal study of ageing by Clare Wenger (1992) found that most of those living with younger generation carers were in long-established households which had been set up originally for the benefit of the younger generation. Therefore, caring relationships were typically better and less stressful in this type of household.

In sum, stress has been described as 'a unifying concept which cannot be differentiated, in other words, there is no specific stress with this expression' (Charlton, 1992, p. 165). Thus, difficulty is created for researchers as to how to define stress and related terms, how to identify stressors and what type of theory and model should be used. The lack of consensus in conceptualisations of stress and little agreement on specific measure among studies (Biegel et al., 1994), results in inconsistent research findings and makes cross-study comparisons even more complex (Poulshock and Deimling, 1984; Nolan and Grant, 1992). They also lead to an increasingly confusing diversity among people and professionals who work or are interested in this field (Pearlin et al., 1990; Schulz, 1990; Biegel et al., 1991). In this situation, it would be useful to compare the research findings which derive from the same stress concept or theory-base and method. However, this solution appears difficult, because the majority of studies fail to apply a consistent theoretical approach (Nolan and Grant, 1992).

2.9. Why do carers continue providing care?

Research and instrument development in caring have focused on the effect of caring and there has been general agreement that informal carers face a great amount of burden in providing care for their frail elderly people, particularly from chronic illness. Despite the extensive studies, this approach has suffered from the lack of consensus on the conceptualisation of stress and related terms, resulting in inconsistent research findings and increasing confusion as to theoretical concepts. Meanwhile, a positive approach to caring has been developed, which aims to assess the other side of the same coin, to find a better explanation for the concept of caring. The question has been raised, why do a number of carers still continue to provide care (Grant and Nolan, 1993), despite the circumstances. What normative beliefs influence those who provide care (Qureshi and Walker, 1989), and how long will it last?

Although literature on satisfaction in caring is still limited, compared to that on stress in caring, however, there have been increasing reports of potential satisfaction or rewards in caring (Nolan et al., 1996). Grant and Nolan (1993) reported that 60% of carers identified rewards and satisfactions in their care providing role. A recent national retrospective survey of surviving carers who had cared for dying stroke patients showed that one-third of carers had found caring a rewarding experience (Addington-Hall, 1998).

The recent studies of family care, clearly, have moved forward to investigation of caring from a positive approach, in order to enhance understanding of family care. The aim in carrying out studies from the positive approach is to try to identify the sources and types of satisfaction, which may constitute a valuable coping resource (Summers et al., 1989) and may contribute to develop coping strategies for carers.

2.9.1. Sources of rewards and satisfactions

The earlier studies by Hirschfeld (1981, 1983) on carers of people with dementia found that mutuality was the main factor influencing a family to continue living with and caring for elderly demented people. Mutuality refers to 'the caregiver's ability to find gratification in the relationship with the impaired person and meaning from the caregiving situation' (Hirschfeld, 1981, p. 160). Findings indicated that the lower the mutuality, the more likely was the carer to consider institutionalising their elderly relative. These findings, certainly, have made a major contribution in assessment of the caring situation and ability to predict the secondary outcome as institutionalisation. Higher levels of mutuality have been reported to be associated with lower levels of carers' role strain, except for strain from economic burden or lack of resources (Archbold et al., 1990). Thus, early detection and appropriate intervention may help carers to regain their mutuality and so, perhaps, be able to continue caring in their own home. Carers may find the reactions of other people rewarding when they acknowledge what the carer has achieved (Beresford, 1994). Another important component of mutuality, Hirschfeld (1981, p. 160) indicated, was the 'the carer's ability to perceive the impaired person as reciprocating within the relationship by virtue of his/her existence.' Reciprocation for past services or for the things the cared-for person had done for carers in the past have been reported by Quresri and Walker (1989) and Grant and Nolan (1993).

Grant and Nolan (1993) and Nolan et al. (1996) also reported three dimensions of overlapping sources of rewards and satisfactions in caring. First, satisfaction is derived from the interpersonal dynamic between carers and cared-for person. Thus, caring was perceived as a pleasure, giving a sense of reciprocity, appreciation, improving the relationship between carer and cared-for, or a way of honouring vows. Second, there are satisfactions deriving from the intrapersonal or intrapsychic orientation of the carers. Caring in this category gave rise to a more direct gain for carer, in terms of, for example, a personal challenge, altruism or religious beliefs. Finally, satisfaction can be derived from the desire to promote positive or reduce negative consequences, as when carers believed that they were the only person able to provide the best care, with their intimate knowledge. This can be seen in the case of carers who refuse to institutionalise their relatives unless they are happy with the institution (Nolan and Grant, 1992).

Other sources of satisfaction have also been reported. For example, satisfaction in caring can be identified when carers described their own emotional health in the positive terms (Grant and Nolan, 1993). Low levels of satisfaction with the care-related decision-making process has contributed to carer depression (Smerglia and Deimling, 1997). Although men were found having higher morale than women (Gilhooly, 1984), however, Grant and Nolan (1993) found that satisfaction was not significantly associated with the gender of the carer. Instead, satisfaction was found to be significantly related to the gender of the cared-for person, in favour of women. Spouses were found less likely to find caring rewarding (Addington-Hall, 1998), and were much less likely to consider long-term care than other relatives (Gilleard, 1984). However, among spouse carers, gender was found to be significant in relation to differences in the terms used to describe the motivation to care. Women tend to use the term 'duty' which reflects their feeling of obligation towards the person they cared-for,' while men tend to use the term 'love' which shows how they felt about the person they were caring for. These expressions may indicate that 'men would be unlikely to care for someone whom they could not legitimately claim to love on an intimate basis, while women would only be unlikely to care for someone who they felt could not make legitimate claims on their time based on kinship' (Ungerson, 1987, p. 99).

2.9.2. Benefit from caring

The positive aspect of caring has been paid less attention because the bulk of the literature emphasises the adverse affects on the carer's well-being. However, there have been some unpredictable results. Some carers have been found to have higher morale and mental health,. despite the long period of care provision (Gilhooly, 1984). Caring can involve a close relationship. This situation may bring carers and cared-for person close together, spending more time together than before. Thus, a feeling of closeness, which is often based on the satisfaction of being needed, may be found among carers of people with dementia and other mental impairment (Heron, 1998). Not only does closeness lead to an improved relationship between carer and cared-for (Grant and Nolan 1993), but carers who maintain their closeness also seem to be prepared to continue providing care (Gilleard, 1984). However, those carers who were not children were less likely to report feeling emotional close to the elderly person (Qureshi, 1986).

2.9.3. What does satisfaction tell about the caring situation?

Grant and Nolan (1993) indicated that satisfaction was associated with qualitative factors within or surrounding the carer and cared for person's relationship, rather than with personal dependency factors. The poor quality of the past relationship, in particular, was found strongly to be associated with the carer's distress (Gilleard, 1984). In other words, a good past relationship between carer and cared-for person may increase satisfaction in their current caring. Although, no intervention can improve their past relationship, the absence of satisfactions may serve as a risk indicator; thus, it may help to predict their current relationships and caring situation, increasing awareness not only of the risk of the poor emotional health of carer, but also of the 'risk of fragile and potentially abusive' carers (Nolan et al. 1996, p. 105). Then, appropriate intervention can be offered to ease their problems.

Where satisfactions in caring of individual carers can be identified, these could provide a powerful cognitive coping strategy. Improving the caring situation by strengthening satisfaction, as a coping strategy, may reduce stress as 'the stimulus is perceived as challenge, rather than as a threat or harm' (Nolan et al., 1996, p. 103). A study by Pound et al. (1993), which measured carer satisfaction after stroke, indicated that carers need a combination of practical and emotional support. Carers expressed dissatisfaction with the provision of information on allowances and other available services, but were satisfied with the receiving recognition of their difficulties and problems of caring from health professionals. Thus, satisfaction may also serve as a quality control related to the services that carers and cared-for receive (Nolan et al. 1996).

Satisfaction is an individual subjective perception. Perhaps, the first satisfaction measurement scale made available was the Carers' Assessment of Satisfactions Index (CASI) (Nolan and Grant, 1992). The CASI is comprised of 30 potential satisfactions of caring obtained deductively from study data. This scale allows individual carers to appraise whether each situation applied to them. If it does, then carers have to indicate their level of satisfaction: no real satisfaction; quite a lot of satisfaction; and a great deal of satisfaction. This scale would be useful for health professionals to detect the presence or absence of satisfaction in caring. However, this scale is limited in that it include only 30 potential satisfaction situations. In fact, there may be other variables that contribute to the individual perception. Thus, carers should be asked to indicate other sources of satisfaction which are not contained in the scale, in order to obtain a better concept of satisfaction. Most research on carers has been carried out by convenience sampling and with relatively small samples. Thus, further study may be needed with more representative samples and greater sample size, using the same method and measurement scale, in order to obtain more precise information and be able to make comparisons, to achieve a better conceptual and theoretical framework of satisfaction in caring.

2.10. Therapeutic Intervention

Many demented persons are cared for by family members in their own home. Some people who care for their elderly mentally ill relatives in this way suffer from physical and emotional strain (Hettiaratchy and Manthorpe, 1992) caused by multiple factors which occur during care provision, as discussed in the previous section. Thus, there is a need for interventions to help carers continue to care for their elderly demented spouse or relative to reduce stress and strain, as well as to improve the quality of life of both the demented person and the carer.

Intervention techniques which attempt to enhance carers' skill in coping include cognitive and behavioural approaches, training in problem solving and educational therapy, meditative relaxation, training in social skills, supportive counselling of individuals and groups or families, or both, and management of stress (Brodaty and Gresham, 1989). In this section, major caring problems will be discussed, including particular interventions and some successful carer support models which help carers to cope better in the caring situation.

2.10.1. Behavioural approach

In general, typical behaviours in dementia are often described as wandering, agitated, accusatory, or incontinent. However, the term 'problem behaviours,' was defined by

Mace (1990, p. 75) as 'those behaviours that endanger the person with dementia or others; that stress, frighten, or exhaust the carer; or that are perceived as socially unacceptable,' including lack of co-operation. As mentioned earlier, Deimling and Bass (1986) found disruptive behaviour in demented people to be one of the severe illness symptoms which directly affects carer stress.

The finding of Chappell and Penning (1996), in part of the Canadian Study on Health and Ageing (CSHA), a national study conducted in 1991-1992, revealed that the major behavioural factors related to carer distress (measured by using carer reports of carer depression and burden) were: a lack of interest or apathy; aimlessness; aggressiveness; forgetfulness; and restlessness or agitation. However, the lack of co-operation was related only to carers' depression, but not to a feeling of burden.

Mace (1990) suggested that the training of carers could reduce the difficulty that such behaviours create. The most frequently used approaches to behaviour management are summarised by Mace (1990) as follows. There are two types of behavioural intervention: those that attempt to change the patient and those that attempt to change behaviour by changing things external to the patient. Interventions that attempt to change patients, including medication, restraint, psychological intervention, or reduction of excess disability, may be appropriate to be carried out in the institution by those with professional skills. However, interventions that change the physical or psychological environment, for example concrete advice, general guidelines, problem solving, support of the carer, creation of a prosthetic environment (supports remaining function while avoiding or substituting for area of impaired function), and milieu or environmental therapy, would be appropriate to employ with carers and be carried out by carers in their own home. This type of intervention is described below.

i) Practical Advice: aims to provide concrete suggestions for changing the behaviour of the impaired person. For example, the practical advice for wandering behaviour includes fitting child-proof locks, using electronic devices to alert the carer, or hiding the person's coat. However, some possible causes of wandering may need to be investigated, such as whether restlessness was due to medication side effects, a search for something familiar, or the need to use the toilet.

ii) General Guidelines: offer guidelines for the carer that have been found to be successful in caring for people with dementia. For example, simple guidelines include understanding the person, knowing the person's limitations, keeping the person as healthy as possible, using a familiar routine, and making what one does as person-orientated as possible. Second, the management of catastrophic or negative reactions; it is suggested that carers need to recognise the early warning signs, remove the person or thing that upsets the patient, avoid arguing or restraining, or look for a way to avoid pushing the person to an extreme negative reaction.

Finally, there are guidelines for communication. Because people with dementia lose the ability to use and understand language, communication difficulties occur which result in frustration for people with dementia and their carer. General communication guidelines include, for example, making sure that the person has heard you; lowering the pitch of your voice as a raised pitch communicates stress; or using short words and simple sentences; remaining pleasant, calm and supportive. Holden and Woods (1995) also suggested that a slow approach from the front of the patient is less likely to be misinterpreted as aggressive than suddenly appearing at the patient's side from behind. As well as face-to-face contact, a warm smile expressing friendliness, and eye contact are useful in gaining and maintaining attention.

iii) Problem Solving: is an individualised intervention which requires more skill and support than other interventions. Psychiatrists or health professionals may help the carer to solve a specific problem by determining the probable cause of an individual behaviour at a specific place and time and with specific people, which offers a much greater chance of successful intervention. For example, carers may be asked what events led to the behaviour and whether it can be prevented in the future. However, behaviour management alone probably will not completely relieve the burden on carers, because behaviour is difficult to predict and interventions may only prevent the behaviour in some situations and when the intervention is withdrawn, the behaviour may resume (Mace, 1990).

2.10.2. Carer Support

Carer support is very important in terms of care by informal carers who are not paid or trained in caring. It not only helps carers to reduce their burden, but also helps their demented relative's condition and the caring situation. A study by Winogrond et al. (1987) showed that a therapeutic programme for patients and carers may slow behaviour deterioration in patients. In contrast, an exhausted caregiver or one who does not feel supported elicits more negative responses from the impaired person (Mace, 1990). Carer support interventions may include, for example;

i) Relative support group: According to the findings of Moniz et al. (1988), relatives know very little about the nature of dementia, nor are they aware of the help that is available through the statutory and voluntary agencies. The lack of knowledge itself, Russell et al. (1989) pointed out, can be a stressor as it causes anxiety, fear and uncertainty because the carer is not in control of the situation. An interesting study by Leng (1987) found that an adult education course for carers enabled them to feel more confident about caring for an elderly confused person, thereby reducing levels of stress. Such groups are operated by professionals, such as community nurses or social workers. The services which are offered include information about elderly illness, benefits and allowances, counselling, legal advice, financial planning, and other available practical help.

***ii) Carers' Group/Mutual Support Self-Help Groups*:** This type of intervention, Hettiaratchy and Manthorpe (1992) suggested, differs from the previous technique in that the carers are encouraged to meet together to draw strength from each other by sharing their problems and feelings within a group; the knowledge gained is personalised, nontechnical, and generally unavailable in libraries (Mace, 1990); the group facilitator or organiser did not set any agenda or direct discussion, and did not invite outside 'experts' to talk to the group. Thus, the role of the group leader was to act as a facilitator. The emotional or therapeutic function of the group allowed relatives to express their feelings. Thus, the benefits from this intervention were gained as individual members reported improvement in term of feeling under less stress, feeling less guilty or feeling less isolated.

iii) Training programme: The earlier studies by Hirschfeld (1981) and Gilleard (1987) suggested that there is a significant relationship between carers' distress levels and subsequent long-term institutionalisation of their dependant. This finding was confirmed by Brodaty and Gresham (1989), who conducted a dementia carers' group programme. The results from this study at 12 months' follow up showed that the carers' programme group had significantly lower psychological stress than carers in the memory retraining group, while the waiting list group's distress scores remained stable. The findings included the much lower rate of placement of patients with dementia in institutions when carers had been through the training programme. However, there has been an increasing awareness of the effect of intervention techniques delaying institutionalisation of the dementia patient by maintaining that person in the community but the question has been raised of the long-term effects on carers (Russell et al., 1989). Brodaty and Gresham's (1989) findings suggest that the dementia carers' programme had not delayed institutionalisation of the patients; instead, it reduced psychological stress on carers.

Conclusion

This review of the literature drawn from Western experience has shown that there are a number of issues which need to be considered in any study of carers. These include:

who undertakes care; why, what effect caring has on the carer and whether there are ways such problems could be alleviated.

The term 'carer' has been brought to public attention since caring for frail elderly people shifted from an institutional setting to the community. An informal carer is a caregiver who provides care for another person unpaid, untrained and up to 24 hours a day. Carers are usually relatives, friends, or neighbours. Women are always seen as having a major role in caring; a centre of debate is the issue of gender in care. However, gender difference in care is least among those caring for their spouse. The hierarchy of preference of carers from elderly people point of view in were descending order: spouse, relative living at home, daughter, daughter-in-law, son, and other relative. The 1990 OPCS survey in the UK found that up to 6.8 million were carers. On average, co-resident carers spent 52 hours per week providing care, almost six times greater than the average time spent by non co-resident carers, while children or spouses appeared to spend the greatest time in caring.

Understanding of stress related to caring is very confused, due to the lack of consensus in conceptualisation and inconsistent research findings. Definitions of stress are based on three different approaches: the engineering approach; the medicophysiological approach; and the psychological approach. The transactional model of stress in the psychological approach has received increasing attention, due to its ability to explain the interaction between person and environment and explore individual difference in appraisal and coping. Literature shows that there is little relationship between severity of illness and burden, but stress is related to the nature of the relationship between carer and cared-for person. However, there is an increasingly positive approach to carers which tries to identify source of rewards and satisfactions that carers may experience. It is believed that satisfaction may be a valuable coping resource, a quality control measure, and a risk indicator in informal care.

Therapeutic interventions aim to enhance the carer's skill in coping with the caring situation, as well to reduce stress in carers. Intervention techniques include behaviour approaches and carers' support groups. It has been suggested that training carers can reduce stress. Interventions that change the physical and psychological environment include practical advice, general guidelines and problem solving. In carer support, educating carers about dementia and caring skills, as well as encouraging carers to draw strength from each other by sharing problems and feelings within a group can significantly lower psychological stress among carers and help to maintain their dependants in the community.

CHAPTER 3

Thailand and its Background

3.1. Background

Thailand is situated on the mainland of Southeast Asia surrounded by Burma, Laos, Cambodia, and Malaysia (see Figure 3.1). The country is divided into four major regions: Northern, North-eastern, Central and Southern regions. Each of these four regions are quite different in term of physical conditions, cultural and socio-economic structures (Limanoda, 1995). The Thai population reached 60 million in 1996 within the area of 198,114 Sq. Miles, which is equivalent to France (The Office of Information, 1996). General information about Thailand is shown in Table 3.1. Thailand is the only country in Southeast Asia that has never been formally colonised by a Western country, although like the rest of the countries in this area, it has been gradually influenced by Western culture, particularly in the latter half of the 20th century. Despite this influence, much of the indigenous culture and customs of Thailand remain intact. For example, extended family homes containing three generations are very common and Buddhism remains the predominant religion in Thailand.

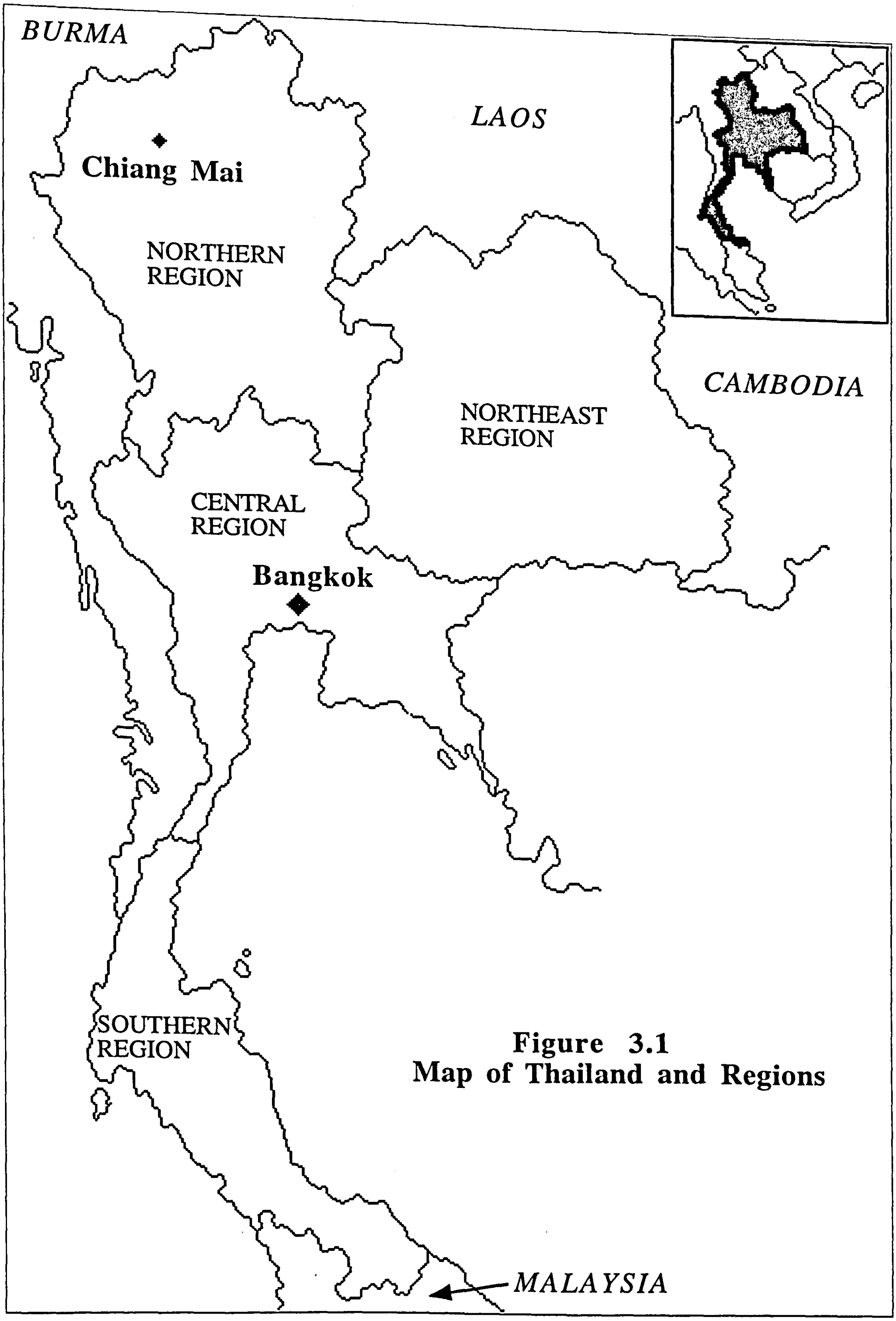

Figure 3.1
Map of Thailand and Regions

Table 3.1. Demographic Profile of Thailand

Population

Estimated total 1989	54,835,000
No. of over 65s	1,880,000
% over 65	3.7

Projected population 2025

Estimated total	85,929,000
No. of over 65s	7,799,000
% over 65	9.1

Life expectation

At birth 1985	M 60.7 ; F 64.8
2025	M 70.5 ; F 75.9
At 60; 1974-75	M 15.8 ; F 18.8

Over 65s as % of total population 1985

M 65-74	1.1
M 75+	0.4
F 65-74	1.3
F 75+	0.5

Urban/rural population

	Urban (%)	Rural (%)
Total population 1985	19.8	80.2
1980	17.0	83.0
Total over 65s 1980	16.1	83.9
M65+	15.5	84.5
F 65+	16.7	83.3

Socio-economic data

Gross domestic product	$ 38,570 m
National income per person	$ 661
Proportion of labour force in agriculture	66 %

Source: Developed from Centre for Policy on Ageing (1989) p. 147

3.2. Ageing Population

There has been a dramatic increase in number of elderly people all over the world. In 1980, the percentage of elderly people over the age 65 in the total population of the world was 5.8 percent (Kinsella, 1988). By the year 2050 that proportion in Asia is likely to be trebled (Centre for Policy on Ageing, 1989). Two thirds of the world population lives in developing countries especially in Asia.

3.2.1. The Increasing Ageing Population in the Developing Countries

The population structure of developed countries has not changed much in comparison with the countries in the Third World over the past 25-50 years. Most developed countries have had declining fertility rates since the beginning of this century, so there has been stabilisation of population growth. Although the fertility rates have reduced, the ageing population growth is still increasing as a result of decreasing mortality rates due to medical advances, better nutrition, clean water, and general improvement in the quality of life, leading people to live longer. Thus, we can predict that in the next decade, the world will face an increasingly ageing population, particularly in the Third World, where there has been a history of high birth rates in the past decade (Kalache, 1992).

3.2.2. The Increasing Ageing Population in Thailand

Thailand has celebrated achievements in fertility rate and mortality reduction which have resulted from the success in family planning and health promotion. However, this has brought a new problem, namely a change in age structure. Using the legal retirement age for government officials in Thailand of 60 years as the delimitation of elderly people. The National Population Survey in 1978 reported that elderly people aged 60 and over made up 4.99 percent of the entire Thai population. This ratio had increased to 6.6 percent by 1995 and it is expected to increase to 11 percent in 2015 (see Table 3.2). The age distribution of the Thai population is being transformed from a bottom-heavy one, dominated by children and young adults, to a mature distribution with greater representation from those who are middle-aged and elderly people (Mason et al., 1993). The number who are of working age (15-59) is increasing quite rapidly, from 60% in 1990 to 65% in 2000 (Campell et al., 1993).

Table 3.2. Projection of the Thai Ageing Population (60 and over) (1985-2015).

Year	Total population	60 and over	(%)
1985	51,682,600	2,885,100	5.6
1990	56,340,300	3,420,700	6.1
1995	60,505,600	4,007,600	6.6
2000	70,864,600	6,578,700	9.3
2015	73,207,300	8,038,100	11.0

Source : Developed from Institute of Geriatric Medicine (1995).

In 1977, the WHO called for health for all by the year 2000 which Dr. Eric Goon, Director General of WHO explained was an attempt to ensure that by the millennium, everybody would have equitable access to health care services (Little, 1992). The concept of primary health care has been developed all over the world, including Thailand, in order to achieve the goal of Health for All by the Year 2000. With the aim of improving individual health, quality of life, and well being, primary health care has been implemented in Thailand since 1977, and it was shown in the 4th Thai National Economic and Social Development Plan (1977-1981). Medical advances, as well as improved public health developed through health promotion to the community under the Primary Health Care Programme, are likely to lead to a reduction in the mortality rate and increase in life expectancy.

Table 3.3 shows the expectancy of life at birth during the last half century has dramatically increased. The projection of life expectancy at birth by the year 2000 to 2005 for males will be 66.8 years and for females will be 70.8 years. Comparatively, females' life expectancy at birth is higher than that of males, as is found elsewhere in the world.

Table 3.3 Thai Life Expectancy at Birth

Year	Life Expectancy at Birth (Sex) Male	 Female
1947	48.50	51.38
1959-1961	53.64	58.75
1964-1965	55.2	61.82
1969-1971	57.70	61.35
1974-1975	57.63	63.56
Life Expectancy Projected 1980-2015		
1980-1985	60.25	66.25
1985-1990	61.75	67.50
1990-1995	63.50	68.75
1995-2000	65.25	69.75
2000-2005	66.75	70.75

Source : Adapted from Health Statistics Division (1990), p. 255.

3.3. The context of caring for elderly people in Thailand

The word "caring" is a very common term for Thai people. Everybody has experience of being cared for by someone, in different situations, from when they were young though to their old age. In Thailand, the primary responsibility for elderly people has traditionally been with the family (Knodel et al., 1995). The question "why do I have to care for my parent?" is not usually asked. In addition, after marriage, many children prefer to stay with their parents in order to care for them until their parents die. At the same time, elderly people themselves generally prefer to live with their adult children, as well as grandchildren. Siripanich et al. (1988) reported that 73.2 percent of elderly people lived with children and that 84.2 percent of them never had any problems in living with their children, with only 8 percent preferring to stay in a residential home.

However, the rapid growth of the Thai economy towards becoming an industrialised country (Burnham et al., 1993) has led to a modern urban lifestyle, increasing migration of children away from the homes of their parents in search of work. Together with the demographic changes reported earlier, this has had a great impact on caring in Thailand.

In this section, the nature of elderly people and characteristics of caring for elderly people in Thailand will be explored. I will also describe the influences and impact on caring in this context, how religion and culture form the characteristics of caring, and how demographic change and economic transition need to inform policy making in the provision of services for this age group.

3.3.1. The Family and Family Structure in Thailand

The family, according to Melikian and Al-Easa (1993), is the primary institution for economic and social control as well as for the protection of the rights of its members. In term of provision of care, the family is also a major source of care for older people in the community, not only in the underdeveloped or developing countries, but also in the industrialised countries, such as the UK, since the emphasis in long-term care has shifted from institutional to community-based services (Robinson, 1983) (see Chapter 2). Thus, it is interesting to learn how family structure in different societies interact with the provision of care and what kinds of family structure enhance the provision of care in the community.

According to Ball (1974), the household refers to a group of persons (or a person) bound to a place, whereas families are groups of persons bound together by ties of blood and marriage. Although families may form households, they do not necessarily do so. Therefore, the family is more central to this study in terms of family relationship, social and moral obligation, or economic interdependence. The term, *'nuclear family'* is used to refer to a unit consisting of spouses and their dependent children (Elliot, 1986, p. 6); *'the conjugal family'* is then used to refer to a family system in which the nuclear family unit is more or less independent of kin and in which the main emphasis is on the marital relationship (Goode, 1963); and *'extended family'* is used to denote any grouping, related by descent, marriage or adoption, that is broader than the nuclear family (Bell and Vogel, 1968). The extended family is considered to exist in two distinct terms; the classical and modified extended family. Litwak (1960a and 1960b) describes the classical extended family as a family system based on the geographical propinquity of related nuclear families, economic interdependence, the authority of extended family groupings over the nuclear family and stress on extra-nuclear kin relationships while the modified extended family is a loose set of kin relationships in which nuclear families, though geographically dispersed and autonomous, value and maintain extra-nuclear kin relationships.

There are three major approaches in study of the evolution and direction of change in types of family: industrial revolution, sentiments, and household economics. First, the 'industrial revolution' approach. Sociologists view this event as a turning point, claiming that traditional families, peasant families and extended families have been changed to modern families, urban-industrial families and nuclear families after the industrial revolution (Morgan, 1985). However, earlier data accumulated from different parts of Europe reveal that the preindustrial household often included no more than two generations, like the present day household (Elliot, 1988). Thus, this finding suggested that nuclear families are not entirely the product of industrialsation. Nevertheless, Tepperman and Wilson (1993) asserted that there is still some connection between a number of changes in personal life and modernisation. For example, young people have greater opportunity to get paid employment; women tend to have higher education, and delay marriage and delay childbearing. These influencing factors, particularly, are found in Eastern Europe, Asia and Africa, where the nuclear family has not had the same historic prominence it has in Western Europe (pp. 24-26).

Second, the 'sentiments' approach which concerns the delineation of the processes of change which led to the growing separateness and distinctiveness of the conjugal-based family. However, Anderson (1980) criticised these studies as being loosely described. These studies do not demonstrate a shift from an extended family system to a nuclear family system, but rather, a shift in emphasis in patterns of control and in the relationships within the family and between the family and the wider society.

The third interesting approach is the 'household economics' approach, which seeks to explain change in family pattern in terms of the key notions of the resources that are available to households and individual household members, the strategies that household members individually, or in collaboration, adopt to deal with economic issues using these resources and the power relationships that arise out of and shape these strategies and use of resources (Anderson, 1980). This approach may have identified a key factor that leads to change in family patterns in many societies. Knodel et al. (1992) also stated that socio-economic changes were intertwined with fertility decline and were believed to reinforce the impact of the reduction of the availability of children who would be care providers for the elderly people in the future.

Mount (1982) asserts that the present family in the West is possibly unique and certainly of fairly recent origin. Categories which are popularly regarded as fixed and unchanging - love, childhood, parenthood and the nuclear family - are held to be 'socially constructed', the product of particular sets of historical experiences. In contrast, within an largely agrarian society, the extended family was very common in Thailand. It generally consisted of at least three generations: elderly persons, their adult children and spouses, and grandchildren, while the large extended family also included relatives such as aunts or uncles. Thailand has been until 1997 one of the fastest growing economies in Southeast Asia, and there is no doubt that modernisation and the ageing of populations will have a major impact on the traditional extended family, as many gerontologists have pointed out (Tout, 1995). A number of family studies undertaken by both sociologists and anthropologists have found that the predominant type of household in Thailand is now the nuclear family (Limanonda, 1995). For example, the 1989 Labour Force Survey found that 60.8% of households were nuclear, 23.3% were vertically extended, 9.0% were extended, 6.9% were one-person and primary individual households (Phananiramai, 1991). However, it is not clear what definitions of each family type were used in such studies.

Knodel et al. (1992b) and Siriboon and Knodel (1994) criticised the official definition of a household and co-residence in most surveys in Thailand and elsewhere as typically rather narrow. They cited as an example, a national survey called “Socio-economic Consequences of the Ageing Population in Thailand (SECAPT)” carried out in 1986. They claimed that this survey usually treated dwelling units with separate addresses as separate households. This might include elderly parents and children living in separate dwellings but within the same compound. Technically, these were regarded as separate households but the definition did not take the situation into account that such households were, in fact, interdependent to a substantial degree. Viewed in terms of Elliot’s (1988) definition, such families would be categorised as of the extended family type. Thus, this study probably failed to recognise the characteristics of one type of existing extended family which may also have led to an over estimate in the number of nuclear families, as well as an underestimate of extended families as a whole. In particular, it is likely to understate the extent to which the living arrangements of the elderly people and their families are intertwined (Knodel, et. al, 1992b).

3.3.2. Living arrangement for the Thai Elderly

The term 'family' in Thailand is ill defined and as a result family related information from independent institutions, and even from the national level, such as the 1986 SECAPT survey, must be treated with some caution. Despite the limitations of the SECAPT data, many researchers have tried to make the most of the available data to create a clearer picture of the nature of the family and caring for older people in Thailand. In the present study, SECAPT data were a crucial official source of information. Other research referred to included research findings from independent institutions, particularly from the Institute of Population Studies, Chulalongkorn University, Bangkok, and small studies concerning elderly people, carried out by postgraduate university students from Thailand and other countries.

i) Characteristics of the living arrangements of Thai elderly

The SECAPT survey included a total of 3,252 elderly people respondents aged 60 or more. Over three-quarters (77%) lived with at least one child, including step and adopted children (Knodel et al., 1992b; Siriboon and Knodel, 1994; Chayovan, 1995). No difference was found in this pattern between rural and urban or between male and female respondents (Siriboon and Knodel, 1994). This figure is very similar to findings from a comparative study on living arrangements for the elderly people in four

Asian countries, including Thailand, carried out between 1990-1991 (Asis et al., 1995). Just over half of non-co-resident elderly in the SECAPT survey, that is, elderly people who did not live with their own child and those who had no living child, lived only with their spouse. A substantial majority of both those who were co-resident with a child and those who were not (70% and 69 % respectively) had at least one non-coresident child living in the same locality and approximately a quarter of both groups had three or more children in their locality, though this was less common among urban elderly than rural elderly (Siriboon and Knodel, 1994).

The information from SECAPT reveals that just over half (54%) of the elderly people with non-coresident children saw at least one child daily and nearly three-quarters of those with a non-coresident child in the same locality had daily contact; this was almost twice as common among rural elderly as among urban elderly. Such daily contact, Siriboon and Knodel (1994) suggested, reflects a close proximity of residences and affords nearby adult children the opportunity to provide a variety of services to the elderly parent.

Since the SECAPT survey, the 1990 census, and a 1990 quasi-national survey have also shown that living with children is the most common form (77%) of living arrangement for the elderly people (Knodel and Debavalya, 1992). Taking into account those elderly people and adult children lived in separate dwellings, but within the same compound, or near enough to be in daily contact, this could mean that something approaching 90% (Knodel et al., 1992a) of the elderly people live in either classical or modified extended families.

ii) Family systems and living arrangements

In general, there are two family systems in Asian countries, the bilateral and patrilineal, which have influenced people's beliefs and the traditional preference for co-residence with an adult children. In the bilateral family system, kinship is traced on both the mother's and father's side and women when married, do not 'marry out' of their natal family, and kin networks but are part of the broader support system. This type of family system predominates in Southeast Asia, for example, in the Philippines, Thailand and amongst Singaporean Malays. In the patrilineal family, women are generally disadvantaged, in that they are only temporary members of their natal family while the vast majority of male members generally have control and ownership of property, as well as authority. Patrilineal societies are found in East and South Asia, for example, the Chinese in Taiwan and Singapore, and Singaporean Indians (Mason, 1992).

Data were obtained from a comparative study of four Asian countries, Taiwan, Philippines, Thailand, and Singapore, undertaken during the 1980s, based on focus group discussions with elderly people and adults with elderly parents, concerning their views towards the issue of living arrangements of the elderly. The findings of this study showed that among Taiwanese and Singaporean Chinese and Indians, who were under the patrilineal family system, gender was of more concern (Asis et al., 1995), with sons generally more valued than daughters. The majority of participants in these countries preferred to stay with a married son, while daughters were expected to care for their parents in-law instead. In contrast, in the bilateral family system, such as in the Philippines, there was little difference between coresidence with a married son compared to a married daughter. Although Thailand was characterised as having a bilateral family system, the data from the same study showed that a substantially higher proportion of all elderly aged 60 and over lived with a married daughter than with a married son (30% and 20% respectively) (Asis et al., 1995).

Birth order is also one of the crucial factors determining coresident child preference. The preference for the youngest child was suggested by most of the focus group discussions in both family systems, but there was a difference with regard to gender. For example, among the Singaporean Chinese, characterised by a patrilineal family system, there was some suggestion that the youngest son is replacing the eldest as the most common choice, whereas amongst Thais who were under a bilateral family system, the traditional choice of coresident child was the youngest daughter (Asis et al., 1995; Knodel et al., 1995). A similar finding was reported in an earlier study by Caffrey (1992a) of rural North-eastern Thai families, where youngest daughters were expected to remain in the household after their marriage, to bring their husbands into their family system and to continue to cultivate their parents' land, as well as to care for their parents until they die, while sons moved into the wife's family system. In the situation where there were no daughters in a family, the youngest son was expected to bring his wife into the household as the caregiver. Thus, the post marital residence pattern, as well as the custom of giving the house to the youngest daughter (or son) through inheritance, functioned to encourage her (or his) continued residence in the home and provision care for the elderly parent (de Young, 1955; Mizuno, 1968 and 1978; Foster, 1975; Cowgill, 1986).

It would be of interest to know why the youngest child was preferred as the coresident child. This preference may be associated with the marital pattern in which the older siblings progressively move out and set up their own family, while the youngest child remains in the parental home and may be the last one to marry. Thus, in this situation, he or she becomes coresident in the family household, as much 'by default as by design' (Asis et al., 1995)

iii) Living arrangements for the unmarried or childless elderly person

The question now arises as to the unmarried or childless persons' living arrangements. Who provides care for them when they grow old and to whom can they go for help, particularly in a society where social support and care of elderly people typically rests with the adult children (Siriboon and Knodel, 1994)? Data from SECAPT in 1986 reveal that 4% of the elderly respondents aged 60 and over had no living child (Knodel et al., 1992b; Wongsith, 1992 and Siriboon and Knodel, 1994). The childless elderly were described by Siriboon and Knodel (1994) as less likely to live in an established household and much less likely to live with a spouse, which may reflect the fact that a substantial proportion of them had never married or were divorced. They were likely to live with economically active relatives in the younger generation, such as: a grandchild, nephew or niece. Thus, Siriboon and Knodel (1994) stated that it is a norm for the family to be responsible, even for the childless elderly.

However, not all childless elderly live with younger relatives. Some of them may, of their own choice, turn to a Buddhist monastery or enter one of the government residential homes which are situated throughout Thailand. The results of the 1980 census indicated that only 1.7% of the Thai population aged 60 and over lived in temples, presumably as Buddhist monks or nuns (Chayovan et al., 1990). In Caffrey's (1992a) study of family care of the elderly in Northeast Thailand, it was found that a number of male elderly people became monks and lived in temples. They are supported by people in the community who respect them and offer them food.

Elderly people may also be able to live in the residential homes which are provided by the Department of Social Service, Ministry of Interior, if they meet the requirements. To meet the requirements for entering a government residential home: the person must be 60 or over; be homeless, and have no relative to live with, though special cases are made for elderly persons who are not happy to live with their own families. However, in general, people view living in these institutions negatively, as reflecting the failure of the family to fulfil their obligation to provide care for their elderly parents, which brings shame on the family members.

3.3.3. Family support for elderly people

In Thailand, where little social welfare is available, even from the government which has an almost exclusive role in providing health and social services (Campbell et al., 1993), a number of studies show that children are major sources of support to their parents, particularly when parents are too old to work or care for themselves (Kamnuansilpa, 1980; Xuto, 1982; Chayovan et al., 1990). Thus, family is the primary resource of help for elderly people in this society.

The support for elderly relatives comes not only from the coresident child, but also from non-coresident children. In general, children's responsibilities for elderly parents include the provision of food and clothes, social visits, help around the house, help with cooking, providing care during illness, and finance for medical services (Wongsith, 1992). Siriboon and Knodel (1994) raised the question whether non-coresident children provided more extensive support to their elderly parent than a coresident child, in order to compensate for their absence or inability to stay and provide care for their elderly parent at home. In terms of material support, the findings from the SECAPT show that coresident children and children who lived locally, typically provided food and/or clothes, while children who lived further away provided money for their elderly parent. The same survey also indicated that elderly parents who had no coresident children were more likely to receive material support from their children who lived elsewhere, than those elderly people who lived with children.

However, elderly people not only receive support from their adult children, they also pay an important role in the family. In the extended family, elderly people always carry out meaningful activities, such as taking care of grandchildren, cooking, or doing some housework, while their adult children or other economically active family members go out to work (Wongsith, 1992 and Knodel et al. 1995). Elderly people also provide advice, transmit their past experiences, and teach old traditions, culture and religious beliefs to the younger generation. Moreover, a reciprocal relationship is reflected in the custom, mentioned earlier, for elderly parents in the rural Northern area to allow coresident children to inherit their properties, for example, their house or farm, in order to encourage their children to continue residing at home and providing care for them.

3.4. Buddhism and Thai Culture related to the Care for Elderly People

The care of elderly people in Thailand may be characterised as family care in the community. This care also usually involves co- residence with the elderly relative and providing care for them. Thus, living with children is the most common form of living arrangement for elderly people. In a focus group survey of adult children, 96%

indicated that in general they believed elderly people should live with their children, while 87% said that they expected to live with a child when they grew old themselves (Knodel et al., 1995). This concept of caring seems to be agreed by both the person being cared for and the carers; adult children are expected to provide for their elderly relatives and, at the same time, they perceive themselves in the position of care providers, and this belief seems constant. What are the key factors that influence or promote this caring belief and how is this distinct caring characteristic formed in Thai society, though it may not be found in western countries? This question is essentially "why people do certain things." Mulder (1994) suggested that to understand this, it is necessary:

> to gain access to the basic criteria which people use to perceive, classify, and interpret their world and their experience, the concepts that give structure and regularity to their knowledge. Often the basic concepts are most pointedly expressed in mythology, theology, philosophy, and other forms of open-ended creative thinking that serve to elucidate the relationships between man, life, world, and cosmos. This 'philosophy of life' is expressed in symbolic representations that reveal the 'real' nature of things. It is no wonder that religious thinking and ritual may offer important clues in identifying basic conceptualisation (p. xv).

Buddhism is the national religion of Thailand, and the majority of the Thai population (96%) are professed Buddhists (Mulder, 1994). According to the history of the Buddhist religion, the Buddhist philosophy of life was first conceived 543 years before Christ (Jamsai, 1971). However, Theravada Buddhism first appeared in Southeast Asia in the 11th century and it was adopted by the Siamese (Thai) Kings as the national religion (Darlington, 1990). Since then, Buddhism has flourished in the Kingdom of Thailand. As Tambiah (1978) stated, Buddhism is more intact in Thailand today than any other Southeast Asian Buddhist country. It is also deeply rooted in the heart of Thai social and cultural life, profoundly influencing people's thinking and behaviour. Indeed, to most Thais, to be a Thai is equated with being a Buddhist (Mulder, 1994). It is quite common for people to use Buddhist teachings or *'dhamma'* to explain Thai social behaviour that they have observed (Komin, 1990). Thus, in this section, Buddhism is the focus of attention in the search for the basic concepts of family care for elderly people in Thai society.

3.4.1. Buddhist Philosophy in Caring for Elderly Parents

One of the fundamental principles of Buddhist philosophy is *'reciprocal identification,'* or more literally 'mutual' and 'regarding,' and could be defined as a mutual viewing from each other's perspective (Takakusu, 1975) or mutual interdependence. Phra Buddhadasa Bhikhu (1993), a leading Thai monk, stated that no one in this world can survive or succeed without receiving help from other people. Everyone who is raised, educated and successful, has received several sources of help from many people. For example, from birth they received help from their parents, then they were educated by teachers and then they succeeded with help from their employers and colleagues. Phra Buddhadasa Bhikhu further pointed out that if nobody recognised their reciprocal debt to each other, the world would be full of competition and desperation. Therefore, knowing and acknowledging one's debt to beneficiaries is very important to keep the peace in the world. Another respected Buddhist monk, Phra Dhammavisuthajahn (1995) also asserts that:

> Greatest of all is the recognition due to parents for having given birth to and raised their children. One way children can repay their enormous debt to their parents is to look after them in return, according to the teachings of Buddha: "since they have raised us, so we have to raise them in return"
>
> p. 18

Thus, this initial Buddhist principle has become a traditional Thai cultural ideology of *'parent repayment'* in which children are expected to repay their parents for having born and raised them (Klausner, 1987). The concept of repayment to parents by children, Asis et al. (1995) explain, is a symbol of appreciation, as well as payment of a debt of gratitude between two individuals. Parent repayment, in other words, in the Thai context, is *'kathanyu katawethi.'* *Katanyu* refers to a constant sense of awareness on the part of someone of the benefits which another person has bestowed on him and *Katawethi* refers to doing something in return for them. This also refers to the obligation to repay parents and is a value firmly ingrained in the Thai culture (Knodel et al., 1995).

3.4.2. How Buddhist belief translates into practice

The mutual obligation of parent repayment is widely accepted among Thai Buddhist believers. Although one of Buddha's teachings emphasises reciprocity and strongly suggests to people to practise parent repayment, however, the question arises: what makes people translate this belief into practice? In Buddhism, people are taught to believe in 'actions' or *'karm.'* *Karmic Buddhism* is largely concerned with existence in this world, that is, with worldly happiness and suffering, good and evil. This aspect deals with ethics and morality needed for a desirable existence here and now. *Karma* is also closely associated with the concept of merit *(bun)* and demerit *(bab)* (Chai, 1985). When one makes up one's mind to do something, one is responsible for it and is liable to retribution (Takakusu, 1975). In other words, one who does a good deed will receive merit, but doing an evil deed will also bring demerit.

In terms of care for elderly people in Thailand, if children do not take care of their parents, this would bring demerit. It would be considered immoral and not acceptable to people in the society. A person's *karma* may manifest itself immediately, or it may take a long time, not appearing until some future life (Darlington, 1990). Thus, in this respect, it may affect people's beliefs as to the uncertainly of their future when they grew old. The logical thinking is that if they do not provide care for their parents, their children will not provide care for them in the future either. On the other hand, if they provide care for their own parents, their children will see a good example and the value of Buddhist teaching, then they will follow that example and provide care for them, in turn, in their old age. Thus, Buddhist doctrine of *karma* seems to reinforce people's behaviour to preserve the traditional culture of providing care for their own parents.

Another Buddhist teaching which is associated with care for elderly people and which may encourage people to provide care for their parents is merit making. Merit making is important to people because it improves one's *karma*, which, it is believed, will ensure a prosperous rebirth and to enhance the possibility of a better life in the future (Tambiah, 1970; Chai, 1985). Merit can be made by doing good of any kind, for example religious activities: giving alms to the monks; supporting the Buddhist temple *(Wat)*; praying; following Buddhist precepts and practising meditation (Chai, 1985). Other types of meritorious activities, Darington (1990) indicated, include being generous to others, taking care of the poor and caring for one's parents. In this respect, it is clear that caring for one's parents is viewed not only as fulfilling filial obligation and cultural expectations, but also to accumulate good deeds for the carers, in order that they may themselves earn a better future life. As Caffrey (1992b) explained;

> The ideology of merit making in Buddhism is based on the concept of generalised reciprocity and, therefore, consistent with the cultural norm regarding appropriate filial behaviour. One not only collects merit for one's own future, but is also obligated to pay others who have accumulated merit and to whom one owes a debt for having been cared for. The accumulation of merit thus acts as a resource available to the elderly in exchange for care from others (p. 126).

Thus, it is clear that the continuing provision of care for elderly parents has a close relationship with the Buddhist doctrine of *'parent repayment'* and the belief in *'karma'* and *'merit making,'* giving rise to a tradition of family care for elderly people in Thailand. This raises the interesting question, what will happen in the event of a decline in Buddhist belief, associated with the transition to modernisation resulting from economic growth, bringing a greater inclination towards a secular culture, beliefs and lifestyle?

3.5. Health Care in Thailand

One of the most prominent characteristics of health care services in Thailand is the availability of both traditional and modern medicine for the patient. It is considered important that people have a choice. Practitioners from both type of institution have to obtain a legal license to practice from the Ministry of Health, Thailand. The characteristic and the roles in providing service and treatment of traditional and western medicine is described below.

3.5.1. Traditional Medicines and Traditional Healers

Traditional medicine is practised in most developing countries, particularly in Southeast Asian countries where, for the greater part of the population, it is the only resource available for those suffering ill health (Jaspan, 1969). In these countries, many people view illness as one of a number of misfortunes (Laderman and Esterik, 1988). Although today, western medicine is becoming more widely available, traditional medicine is still practised side by side with western medicine. However, it is important to ask why there has been so little improvement in attitudes towards western biomedicine. Why do people still believe in and practice folk medical systems? This is a feature not only in developing countries, but also of western countries where there is an increasing interest in so-called 'alternative' or 'complementary' medicine, even among some practitioners of modern biomedicine. For example, a survey in the Lancet reported that nearly half of Australians turned to alternative medicine in 1995, even though there is no proof the remedies work (Bangkok Post, 1996).

Traditional medicine was brought to health professionals attention when the World Health Organisation (WHO) launched the maternal, child health and health education programme (Jaspan, 1969). It has predominated in developing and underdeveloped countries for a long time, and is part of people's culture, which has influenced their beliefs and health behaviours. Therefore, the study of health in these countries will not succeed if traditional medicines are ignored. Thus, the WHO recommended the utilisation of indigenous practice to the underdeveloped and developing countries, with the co-operation of international health agencies, such as UNICEF (Jaspan, 1969). The recent health policies in several Southeast Asian countries, therefore, have stressed the need for culturally specific programmes, in addition to Western clinical practices based on biomedical models and standards (Laderman and Esterik, 1988).

i) Traditional Medical Theory

Little is known about traditional medical theory and pathology in Southeast Asia. Only a few studies and papers in this field are available, mainly from anthropological studies. One of the earliest studies was carried out by Jaspan between 1961 and 1963. Thus, the majority of information in this section will be based on Jaspan's findings. Jaspan (1969) explained that traditional medical theory in Southeast Asia is derived from deep religious, philosophical and sociological roots. Southeast Asian philosophy, religion and medicine were inspired by a later Indian import, that of Buddhism. As Misra (1968) pointed out:

> The most distinctive feature of Buddhist ethics is its freedom from theism, which leaves room for rationalism and rules out submission to some superhuman power controlling the world-process. (p. 54)

Although the Southeast Asian pathological theories are not the same, among many countries in the north, such as Burma, Laos, Khmer and Thailand, traditional medicine is reported to be powerfully influenced by an extra-sensory world of omnipresent, potentially nefarious spirits (Jaspan, 1969).

ii) Traditional Thai Medicine

Traditional medicine was described as an ancient art of healing indigenous to Thailand and received influences with various degrees of impact from surrounding medical traditions. Thus, it does not appear as one unified tradition (Brun and Schumacher, 1994) throughout the country. It is also influenced by other historical traditions and most significantly associated with Buddhism (Esterik, 1988). Thai traditional medicines usually come in liquid form, pill form, or as a salve or powder to pat on the body (Esterik, 1988).

Although the definition of traditional Thai medicine is 'medicines derived from the natural products of herbs or plants, animal, and minerals' (National Statistical Office, 1986, p. 3), more often it refers to herbal medicines which may reflect a greater popularity among users. Herbal medicine is well described as part of the total medical system in Southeast Asia, in terms of a health maintenance system, not simply treatment for a specific disease. In Thailand, herbal cures were more likely to be found in the rural areas where the western medicine was less available and more expensive (National Statistical Office, 1986; Esterik, 1988). However, since 1957, the value of traditional medicine has been recognised with the establishment of the School of Traditional Medicine in Bangkok and an increasing number of people in urban areas have become interested in and are seeking for traditional medicine.

Brun and Schumacher (1994) explain that there were two groups of traditional Thai practitioner; so called royal doctors or royal court (*mau luang*) and ordinary doctors. According to the contemporary point of view, it is also possible to classify traditional medicine into: the urban variant and rural or village variant. Basically, royal and urban are equivalent, and so are the terms common, rural and village. First, the urban variant, which is the direct heir of the royal tradition and taught at the various traditional medical schools. This type has earned its status, with its own printed textbooks and is officially recognised by the Thai Ministry of Public Health as the practice of healing based on traditional texts rather than science. The first Traditional

Medical School, which is located in Wat Pho, a Buddhist monastery in Bangkok, was founded in 1957 (Esterik, 1988) and later formed regional branches. A person who passes certain examinations based on the textbooks can obtain a licence to perform as a traditional doctor. The second type of traditional medicine was the rural or village variant. This was the traditional medicine which was practised in the countryside and consists of several regional subvariants. However, there was no clear-cut distinction between the urban and the rural traditions; they had many things in common and have influenced each other. This type of traditional medicine has no existing school and is not officially recognised by the Ministry of Health. This knowledge is normally transmitted individually from teacher to student, or from father to son, so it is rare to see female practice in the Thai traditional medicine.

iii) Classification of Traditional Healers

Few studies on traditional healers have been carried out in Thailand. Thus, the classification of traditional healers will be based on the available literature and the existing research findings. The term, 'traditional healers' refers not only to people who practise herbal therapy, but also includes a wide variety of therapeutic specialities which include magic and incantation, as follows:

Herbalists: Herbalists are one of several types of traditional healers in Thailand. Brun and Schumacher (1994) found that typically, herbalism was a male profession and the knowledge of the tradition was not passed on freely to people outside the tradition.

Since the School of Traditional Medicine was found in 1957, a person who has been trained and passed a government examination in traditional medicine will be granted a licence from the Ministry of Public Health to become a traditional Thai practitioner and can practice or open a drug store which sells only traditional Thai medicine (Esterik, 1988). However, Brun and Schumacher (1994) stated that this kind of herbalist from the traditional Thai medicine does not represent traditional practitioners as a whole, as many local herbalists did not train with the School of Traditional Medicine yet, but still practised in the countryside. They also mentioned that rural herbalists had non institutional dialectic instruction. Its medical knowledge was transmitted partly by word and partly by hand-written manuscripts and students acquired knowledge from many different teachers. Such treatment covered almost every kind of disease, using herbs and other natural substances, including incantation as an integral part of the tradition.

Supernaturalist Healers and Sorcery: Golomb (1988) pointed out that during a health crisis, traditional Thai and Malay villagers in north-eastern, central and southern Thailand have turned for assistance to the very Supernaturalist practitioners (*mau phii*) who are best equipped to undertake acts of sorcery. The task of supernaturalist healers is to expose, identify, and counter supernatural aggression which is inflicting physical or mental suffering on their patient. Many exorcists can perform sorcery, and most sorcerers can conduct exorcisms.

Basically, disease may be caused by 'amoral' spirits which are the many nameless and hungry spirits living anywhere in the immediate village, neighbourhood or in the forest. Similarly, disease may be caused by 'moral' spirits which means spirits which are normally good or protective, such as that of an ancestor, the village or the temple. Such spirits are thought to cause mild disease, like sudden attacks of fever, in retaliation for some disrespectful behaviour.

Golumb (1988) stated that in the rapidly modernised region of Thailand, particularly central region, supernaturalist practitioners have become somewhat marginal figures. Thus, the supernaturalists' status has only declined near the capital areas, but it still predominates in the isolated and technologically backward areas like north-eastern, southern, or even northern Thailand. Also, incurable or chronic illness which has initially been treated by the modern medical system may later be taken to a supernaturalist healer. In particular, psychological disorders and social problems are commonly referred to the attention of supernaturalist practitioners (Golumb, 1988). Alternatively, in the northern region, people may turn for advice to the mediums, part of a female tradition who find the cause of disease and may attempt to cure certain disease with "rubbing" ceremonies. They may also turn to the "sender," who performs a series of ceremonies by calling the spirit-essence of a person or by sending away bad luck (Brun and Schumacher, 1994).

Other traditional healers: The remaining traditional healers in the Brun and Schumacher's (1994) study were formed in the northern part of Thailand, and may be found in other parts of the country also. As they described it, the "blower" specialises in wounds and broken bones. The blower "blows" incantations and applies alcohol to the fracture without surgery, then supports the fracture area with sticks tied together. Traditional massage is practised in institutions such as the Traditional Thai Massage School and the Traditional Medical School in Bangkok, but in the northern region, aching muscles are often treated with massage which according to Brun and Schumacher (1994), most people seem to learn by personal experience. Finally, the traditional midwives who are predominately female and specialist in child delivery also use traditional healing methods in their practice. However, nowadays, most women prefer to give birth with Western-trained midwives or in hospital, thus, the traditional midwives are rapidly disappearing.

iv) The Impact on Traditional Thai Medicine

Although some people try to preserve traditional medicine as an aspect of the national heritage, others may want to use the traditional doctors to ensure better health services for the majority of people, or some may see traditional medicine as a source of new drugs from natural products, which are believed to be harmless and much cheaper than synthetic agents such as the imported western drugs. However, Brun and Schumacher (1994) claimed that few people are really interested in the tradition as a whole; most are concerned only with the pharmaceutical side.

Nevertheless, traditional medicine still exists as because of the long history of traditional medicine in Thailand, it has become a part of the people's culture, beliefs and health care behaviour. A survey of Health, Welfare and Use of Traditional Medicine 1986 by the National Statistical Office, Thailand, reported that of a population of 52 million population in 1896, 12.8 million (24.6%) had engaged in traditional or herbal medicine. The majority of them (84.8%) lived in the rural areas. The northern region had the highest (34.0%) and Bangkok the lowest (17.4%) proportion of people involved in traditional medicine. This finding suggests that traditional medicine is still practised side by side with western medicine. Should it be called an alternative medicine? Does it indicate the insufficient health education and health care provision in the rural areas? Or does it demonstrate a rich cultural knowledge of practices which have a beneficial affect on aspects of psychological as well as physical health?

3.5.2. Western Medicine

In Thailand, traditional medicine predominated until the late 19th and early 20th centuries. Western biomedicine was first brought to Thailand by Christian missionaries in the 1820s, and had little impact at the beginning. Then, Dr. Bradley, a Christian missionary physician, came to Thailand in 1835 during the reign of King Rama IV and became the King's personal physician and received a lot of support from the King. Bradley also introduced smallpox vaccination, started the programme of prevention against cholera, and performed new surgical and obstetric techniques (Esterik, 1988; Brun and Schumacher, 1994). Since then, western medicine has flourished, a number of western medical schools and nursing schools have been founded, and a lot of patients have been taken away from traditional medicine.

i) Health Care System and Insurance Schemes

Santerre and Neun (1996) explained that a health care system consists of the organisational arrangements and processes through which a society makes choices concerning the production, consumption and distribution of health care services. Thailand is a developing country and has a long history as an agricultural nation with low economic growth. There is no doubt that funding of health care is not the first priority from the Thai Government; the bulk of national funding goes on other developing projects. For example, the Thailand budget expenditures in fiscal year 1995 (from 1 October 1994 to 30 September 1995): 19.2% on education, 14% on national security, 9.8% on agriculture, 9.0% on transport and communication, 7.4% on public health, and 40.6% on other items (Alpha Research and Manager Information Services, 1995). Because the Public Health Department receives insufficient funding and support for developing better health care provision and the planning of an equitable system of health care distribution from the government, people, in general, have to be responsible for their own medical treatment.

In Thailand, national health care services are still not yet available. Previously, only two groups of people received medical care benefits from the government: first, government officers, state pensioners, and their immediate families, and second, those who worked with a semi-government firm or state enterprise, such as a tobacco factory or the state railway, and their immediate families. For the remainder of the population, out-of-pocket payments were common, unless people had private health insurance. Private insurance companies, however, function as third-party payers, the consumer has to pay a premium in exchange for some amount of medical insurance coverage. In addition, the consumer may be responsible for paying a deductible portion as well as a co-payment amount in which the consumer pays a fixed percentage of the cost each time he/she receives a medical service (Santerre and Neun, 1996).

Recently, there has been an increase in the range of sources of financing towards medical care in Thailand. These include employee health insurance, public health care insurance for low-income families and for vulnerable groups, and private agencies. Employee health insurance was started when the government introduced the Social Security Act in 1991 (Bennett and Tnagcharoensathien, 1994). The scheme is compulsory for companies with more than 20 employees; there is also the Workmen's Compensation Fund for work-related injuries and illness. The scheme mainly provides insurance coverage for employees of private corporations.

For the unemployed or self-employed, a 'health card' has been introduced by the Public Health Care Department. This type of insurance is financed by the people in the community. Basically, the households prepay health care cost as in the same way as an insurance premium, though the cost is lower than private health care insurance, in exchange for some amount of medical insurance coverage which functions as the third-party payer. However, there are some limitations to this type of insurance, coverage is for no more than eight illnesses per annum and 2,000 Bath (£50) per episode, and service must be sought only from the government sector (Nittayaramphong and Tangcharoensathien, 1994).

The Public Welfare Department also offers a 'welfare card' for free medical care to low-income families and vulnerable groups, such as elderly people who are on the poverty line, children and disabled persons. However, all of these insurance schemes still cover only two-thirds of the total population (Department of Medicine, 1996). Thus, there is a need to promote more health insurance to cover all the population, in order to ensure equality of opportunity to receive health service in all socio-economic classes (see Table 3.4 and 3.5).

Table 3.4. Financing in Health Care

Source of funds	Payment mechanism	Payment modality
Out-of-pocket	Fee-for-service	Pay at the point of service according to the fee schedule in public and private hospitals
Private insurance	Fee-for-service	Minimal co-payment if beyond the ceiling. Free access to health providers
Health card	Global budget-70% of premiums goes to compensate providers, with set formula for distribution between different levels of health care system	Maximum eight illness episodes per annum and 2000 Bath per episode. Care must be sought from government facilities following strict referral system.
Social security	700 Bath capita payment	System of main contractors with sub and supra contractors. Certain expensive procedures and emergencies covered by fee-for-service
Workmen's Compensation Fund	Fee-for-service, reimbursement with ceiling of 30,000 Bath	Free choice of health care provider.
Civil Servant Medical Benefit Scheme	Mixture of fee-for-service reimbursement with limits by item in the private sector and full direct payment in public sector	All out-patient service must be sought in public sector. In-patient service can be sought in public or private but only the expenses of public care will be fully met.

Source: Developed from Nittayaramphong and Tangcharoensathien (1994), p 39.
Note £1 = 40 Bath (prior 1997)

Table 3.5. Medical welfare and health insurance schemes

Schemes	Type of Insurance	Objectives	Target population	No. of persons covered* (million)
Social Security Scheme	Compulsory health insurance	Protection of workers for illness not related to work	Workers in firms with more than 20 employees	3.0
Workmen's Compensation Fund	Compulsory for work related injuries and illness	Protection of workers for work related illness	Workers in firms with more than 20 employees	3.0
Civil Servants' medical benefit	Public assistance	Fringe benefits in compensation for low salaries	Government officials and dependants	6.0-7.0
Health card	Community financing: prepayment, voluntary health insurance	Community development in PHC, promotion of rational use of services via a referral chain	Households	2.7
Welfare card	Public assistance	Promote equality in health care service for vulnerable person	Elderly, children, and disabled person	....
Private insurance	Voluntary insurance	Private personal insurance	The better off, private sector employees	0.2

Sources: Adapted from Bennett and Tnagcharoensathien (1994), p. 11, and Nittayaramphong and Tangcharoensathien (1994), p 33.

Note * *total population 56.1 million*

.... *no data available*

ii) Provision of Health Care in Thailand

Although the Thai Government is unable to provide free medical care for all people, such as is provided in developed countries (for example, the National Health Service (NHS) in Britain), the Ministry of Public Health (MOPH) is, in general, the main provider of health services. The exception is in the Bangkok metropolis and big cities where the private sector also plays a significant role (Ogawa et al., 1993). However, poverty is the most common problem which deters the use of health services in the private sector.

iii) Classification of Health Care Providers

Health care provision in Thailand can be classified by ownership, jurisdiction, region, type of administration, and type of patient treated (Alpha Research and Manager Information Services, 1995). In this section health care will be classified by type of ownership, particularly in hospitals and community health services. Three major ownership types can be identified: Government Ownership; Semi Government Ownership or State Enterprise; and Independent Sector. Thus, people in the community can make their own choice of where to get health services from the available health care providers (see Figure 3.2).

Government Ownership: Government Ownership is the dominant form of health care provision and the majority of health care services come from the MOPH which provides services throughout the country, such as community health care centres, district hospital, and provincial hospitals provides primary and secondary health care services. In addition the MOPH funds regional or central hospitals and specialised services hospitals, such as the Monks' hospital; Women's hospitals; Children's hospitals; Neurological hospitals; and Psychiatric hospitals, for providing tertiary care. The second type of health care services in this group is Teaching Hospitals, which are administered by the Ministry of University Affairs. These Teaching Hospitals are situated in Bangkok and in every region. They aim to provide health care services to patients who need a second opinion in case of complicated disease and treatment. They also serve patients who are transferred from the Public Health Hospitals. The last form of Government Ownership comprises mainly hospitals administered by the Ministry of Defence, such as Army hospitals; Navy hospitals; Air Force hospitals; and Veterans' hospital. Police hospitals, however, are administered by the Ministry of Interior.

Semi Government Ownership or State Enterprise: This type of hospital is operated by industrial corporations for their employees and by union members (Wilson and Neuhauser, 1974). There are only 5 State Enterprise hospitals providing 358 beds (Alpha Research and Manager Information Services, 1995) for health care services from the Tobacco Industry and the National Railroad. Although the primary objective of these hospitals is to serve corporations' own employees and members, their services are also open to other people.

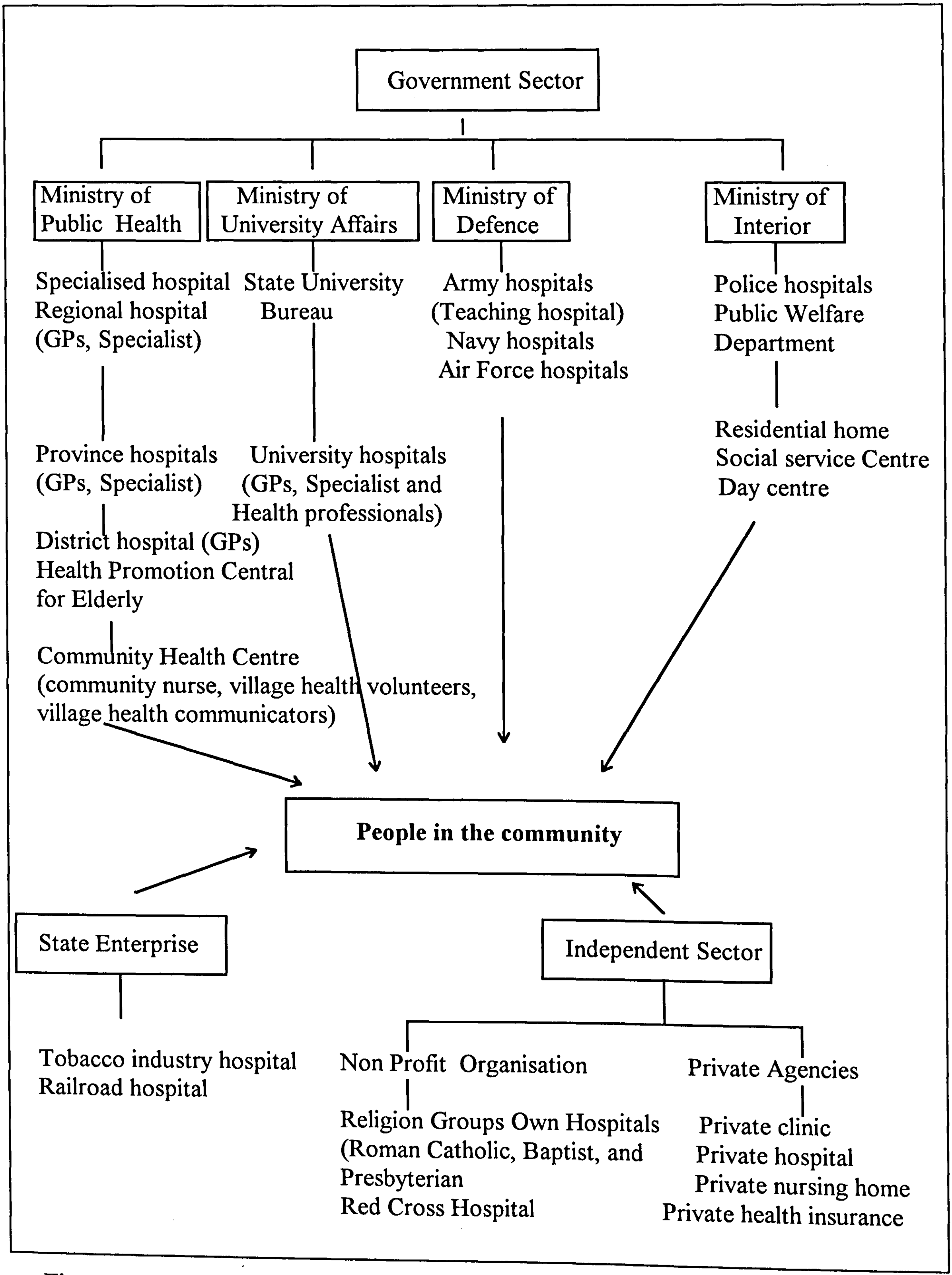

Fig 3.2. Structure and Administration in Health Care Services in Thailand.

Independent Sector: This group of hospitals consists of non-profit and profit health care providers. The non-profit hospitals are mostly operated by voluntary or charitable organisations. They include church affiliated and religious groups' own hospitals (Roman Catholic, Baptist, and Presbyterian), as well as the Red Cross Hospital in Bangkok. The second type of independent sector hospitals are operated by private agencies, such as private hospitals, private nursing homes, and private clinics which have private funding and provide care for their own profit. The number of private hospitals in Thailand has grown rapidly, particularly during the sixth national social economic development plan (1986-1991), when average GDP growth was almost 10% (Nittayaramphong and Tangcharoensathien, 1994).

iv) Administration in Public Health Care

The Minister of Public Health is responsible to Parliament for managing the provision of health care throughout the country. When health projects have been decided the Minister discharges them to the Director of Regional Public Health, Director of Provincial Public Health and Director of District Public Health respectively. All staff are appointed by the Minister and supervised within a hierarchy. Health care provision overall includes basic health care. The Federal Hospitals have the primary aim to care for army personnel and veterans, and secondarily, to provide care for army personnel dependants such as parents, wives/husbands and children, and finally, to provide care to other people who are not army personnel but need medical treatment. Social services are under the Public Welfare Department which is a division of the Ministry of

Interior. Teaching hospitals and central hospitals are major resources of tertiary care from specialists. They contain more modern medical equipment to provide treatment for complicated disease, as well as carrying out advance studies and research in health care. Tables 3.6 and 3.7 show the number of hospitals and hospital beds in the government and private sectors in Thailand.

Table 3.6. General services hospitals : by jurisdiction, 1991

Jurisdiction	No. of hospitals	No. of hospital beds
1. Office of the Permanent Secretary, Ministry of Public Health	681	45,587
2. Department of Medical Services, Ministry of Public Health	5	2,790
3. Ministry of Defence	56	7,979
4. Ministry of Interior	5	1,195
5. Other government agencies	1	30
6. Ministry of University Affairs	7	5,918
7. State Enterprise	5	358
8. Municipality	8	2,125
9. Independent organisation	6	1,820
Total Government Hospitals	774	67,802
10. Private Hospitals	209	11,354
Total	**983**	**79,156**

Source: Developed from Alpha Research and Manager Information services (1995), p. 81.

Table 3.7. Number of hospitals and Number of hospital beds : by region, 1991

Region	No. of hospitals	No. of hospital beds		
		Government hospital	Private hospital	Total
Bangkok	86	13,813	4,991	18,804
Vicinity of Bangkok	40	2,367	787	3,154
Central	60	4,467	449	4,916
Eastern	77	5,711	541	6,252
Western	80	4,862	608	5,470
North-eastern	280	14,529	1,139	15,668
Northern	200	12,968	1,819	14,787
Southern	160	9,085	1,020	10,105
Whole Kingdom	**983**	**67,802**	**11,354**	**79,156**

***Source:** Adapted from Alpha Research and Manager Information Services (1995), pp. 81, 85 and 86.*

3.6. Policy Context

In comparison to the western countries, there are significantly fewer services available for elderly people in Thailand. The responsibility for caring for elderly people in Thailand remains largely with the family, in accordance with the Thai tradition, and is influenced by the Buddhist philosophy, of caring for one's own elderly relatives (see Section 3.3). The Thai government also supports continuation of the traditional family role in providing support (Wongsith, 1992). It might be suggested that the Thai government has benefited from this traditional approach to care, which saves public expenditure on health care for elderly people. It may be asked is the Thai government interested in examining the needs of elderly people and their families and their problems in caring in the community? The following section describes government activity to identify and respond to the needs of older people.

In the course of Thailand's economic growth and transition to an industrialised country, the proportion of Thais engaged in agriculture is rapidly declining. In Thailand, as in other developing countries, a number of population studies have described a substantial migration of the labour force from rural to urban areas, women no longer confined to work at home, an increase in the number of nuclear families, and an increase in the number of homeless elderly who live on the street or in residential homes. These findings from a number of studies by both the government sector and private organisations have put pressure on the government to pay more attention to the existing problems and indicate that further problems can be expected in the future if insufficient services are provided. There has also been pressure from the United Nations, for example, at the Vienna International Plan of Action on Ageing World Assembly on Ageing, 1982, concerning humanity, development and education for elderly people (United Nation, 1983), and the WHO's campaign on Health Promotion in Ageing, which adopted the slogan, "Add life to years" (The Committee of the Benefit for Ageing and Social Development, 1991).

3.6.1. Policy Intervention

As a part of the Fourth Five Year National Development Plan (1977-1981), the Ministry of Public Health introduced an Advisory Committee for Planning Health Care Programmes for Ageing in 1979. Its main objectives were to train and educate health professionals in caring for elderly people and delivering health education to the public.

However, there has been little evidence of improvement in health and social benefit for elderly people. In 1982, when the Thai government faced pressure at the international level, for example from the United Nations and WHO, as well as from pressure groups in Thailand, legislation was passed to establish the "National Committee on Ageing of Thailand." The committee, chaired by the Minister of Interior, was composed of Thai intellectuals from government and private organisations. This committee emphasised the need to study the impact of demographic change.

3.6.2. Policy and Planning

Since the National Committee on Ageing was established in 1982, a number of sub-committees have been set up to address specific problems. The Long-Term Plan for Elderly People (1982-2002) was first introduced by the Ministry of Public Health, with the intention of bringing about improvements in five key areas: health care; education; secure income; social and culture's attitude; and social benefits with the co-operation of the Department of Medicine, Department of Continuing Studies, and Department of Social Welfare. In addition, seven national sub-committees on ageing were set up to cover all aspects related to social welfare, health and well being for elderly people. The remit for each sub-committee was to study their own specific area of concern, then plan programmes, set policy, and implement the agreed measure throughout the country (The Committee of the Benefit for Ageing and Social Development, 1991). In 1992, the first National Long-Term Plan for Elderly people (1982-2002) was revised to form a new National Long -Term Plan to be implemented from 1992 to 2011. The new plan's aims to meet the needs of elderly people are summarised in Table 3.8.

Table 3.8. The National Long-Term Plan for Elderly People

The National Long-Term Plan for Elderly People, 1992-2011

1. Health and diet: emphases health promotion and promote health care services both physical and psychological among elderly people, i.e. self health care, health prevention, exercises, and retirement preparation for well-being in later life.

2. Social Security: to increase the provision of social benefit and public welfare to meet the needs of elderly people, particularly, low-income groups and those who have no relative to depend on.

3. Employment and Income: encourage elderly people to continue working as well as to participate more in voluntary services. Including providing income support for elderly who are on poverty line.

4. Social and Culture: promote living in an extended family and encourage close relationships within the family as the traditional Thai family; emphasis believing in reciprocity and respect for the elderly; increase religious role by teaching Buddhist Dramma as well as providing psychological support to elderly people in the society; encourage people in the community and private organisations to provide more social services for the elderly; and enhance protection to ensure human dignity for the elderly group.

5. Research and Development: promote study and research on ageing as well as produce and train health professionals and social worker for providing service for elderly people.

Source: Adapted from Department of Medicine (1993), pp. 121-134.

Policy and planning for elderly people have also been included in the Five Year National Development Plans. For example, the Fifth National Development Plan (1982-1986) included social welfare services, particularly for the elderly and people with disability, such as: non-institutional care; encouraged the private sector to participate in provision of such services; and emphasised the role of the family in taking care of elderly people (Wongsith 1992). The Sixth National Development Plan (1987-1991) focused on elderly people's needs and delivery of specific services for this age group. The Seventh National Economic and Social Development Plan (1992-1996) emphasised ensuring the opportunity of access to health care services and health promotion by introducing the 'welfare card' for the elderly who are on the poverty line, and other vulnerable groups, such as children and disabled persons (Department of Medicine, 1993).

The most recent five year plan is the Eighth National Economic and Social Development Plan (1997-2001). In this plan, the government has paid more attention to improving provision of health and social welfare for elderly people. Firstly, it plans to develop universal provisions for elderly people to be covered by social welfare benefits, including an increased living allowance, free health services, and discounted fares for all transportation services in both urban and rural areas. Secondly, it will encourage and assist families to understand and care for their aged members. Thirdly, private hospitals, non-government organisations (NGOs), religious institutions and communities will be encouraged to participate in caring for elderly people. Finally, it is planned to establish an effective focal point for the management of care for elderly people, including collection of data and co-ordination of activities for a comprehensive approach (National Economic and Social Development Board, 1997).

The policy and planning on health and social services for elderly people in Thailand, generally, are released with the co-operation of the Department of Public Welfare and Social Services, Ministry of Interior, Department of Medical Services, Ministry of Public Health, and Department of Informal Education, Ministry of Education (Wongsith, 1992). They are intended to be implemented not only by the government, but also the private sector. In addition, the Thai government has tried to raise public awareness of ageing and caring issues by designating 13th April as "National Senior Citizen Day" (Research and Development Group, 1993). On this day, the younger generation are encouraged to pay respect and recognise the contribution to the family and society of their elderly relatives and other elderly people, probably, in the hope that this will increase their sense of a need to repay debt by providing care for them.

3.7. Health and Social Welfare for Elderly People

Although health and social security provisions, particularly for elderly people in Thailand, have been introduced in the Fifth National Economic and Social Development Plan (1982-1986) and Long-Term Plan for Elderly people (1982-2002) since 1982 as discussed in Section 3.6, however, this provision is still developing. Health and social services available from the government are generally seen as basic help for daily living. The available services are described below.

3.7.1. Health Care Services for Elderly People

Formerly, health care services for elderly people in Thailand were not recognised as a special category; the elderly were simply categorised as adult patients. As health professionals became aware of the increase in the ageing population and their different health care needs, as compared with the middle-aged group, the first clinic for elderly people was opened in 1963 at the neurological hospital in Bangkok. Following this, most general hospitals in both government and private sectors, throughout the country, were encouraged to open geriatric clinics. The 1991 national hospital survey on health care services for elderly people reported that there were 225 geriatric clinics which provided services at least 1-2 times a week (The Committee of the Social Benefits for Elderly people and Social Development, 1991). However, it was found that the majority of geriatric clinics operated in the government sector, and only 4% were in private hospitals. Also, most of these clinics did not provide rehabilitation, health visitors or social services.

The Ministry of Public Health, the major health care provider in Thailand, currently delivers health care services for the elderly through two systems, the 'Primary Health Care System' and the 'Hospitalised Care System.' People in the community are encouraged to participate in giving primary health care to the elderly. Participants in this Community Voluntary Health Care, as it is called, are trained in first aid and screening for common diseases in elderly people, for example taking blood pressure (BP) to screen for hypertension (HT) and checking blood sugar in urine to screen diabetes mellitus (DM). At the same time, it is the policy of the Ministry of Public Health is to provide proactive health care services to elderly people in the community by sending health promotion teams to visit patients at home, to assess their needs for health care and provide help to meet their needs.

The second channel for delivery of health care services is the provision of free medical treatment to elderly patients who have a senior citizen card, at all hospitals and health care centres operated by the Ministry of Public Health (MOPH). However, the most recent information on funding in Public Health Care suggests that this project is under-funded. For example, in 1994, the MOPH received 44,335 million baths (1,108 million pounds) and it was increased to 52,596 million baths (1,315 million pounds) in 1995. Only 7.4% of the total budget expenditure in fiscal year 1995 was allocated to Public Health (Alpha Research and Manager Information, 1995). The lack of funding from the government raises doubts as to survival of the project, and hence the future well being of elderly people. Wongsith (1992) stated that the lack of funding from the government is due to the fact that its priorities lie elsewhere, e.g. socio-economic and educational improvement and that government policy tends to emphasise the traditional system of care within the family. These factors have led to limited provision of health and social welfare for the aged.

3.7.2. Social Welfare for Elderly People

Social services for elderly people provided by the Department of Social Welfare can be divided into two categories: institutional and non-institutional services (Department of Public Welfare, 1994b) as follows:

i) Residential Home

Bangkae Home for the Aged was established in Bangkok in 1953, and is administered by the Department of Public Welfare and Social Services, Ministry of Interior (The Committee of the Social Benefits for Elderly and Social Development, 1991). This was the first social service home available for elderly people. The recent information available from the Social Welfare Department (1994) shows that the number of residential homes has increased to 13 serving 2,200 residents throughout Thailand. An applicant for a place in one of these institutions must be aged 60 or over; have no communicable disease, have no physical disability or psychological problem; and meet one of the following criteria: be homeless and have no relatives; live alone and receive no help from their families or outside, or be unable to live happily with their own families. The majority of residents receive accommodation, food, clothing, and personal necessities, free of charge. Only 40 rooms, available in Bangkok, are operated like a hostel where residents have to pay a monthly rent which includes food; they bring their own clothes and personal belongings. Residents of both types of institution receive health and social services, for example, medical services, physiotherapy, recreational activities, religious rituals, and traditional festival activities (Wongsith, 1992).

ii) Residential compounds

Residential compounds provide for residents aged 60 and over, who have to build their own house in the given area, and can then live there throughout their lives (Department of Public Welfare, 1994a). However, on death, the resident's home is handed over to the institution, if the resident has no relative to be qualified to live there. This scheme is designed to meet the needs of elderly people in the medium to high income bracket. Health, and social services and social recreation are available in the compounds, as in residential homes, and a warden is available on-site. There are 4 residential compounds, of which two are situated outside Bangkok and the Metropolitan area. This type of service is likely to be expanded more in the near future, in order to provide services for elderly people in other parts of Thailand.

iii) Social Services Centre for the Elderly

The first social services centre was opened in 1979 in Bangkae residential home, to extend and expand the community's services to non-residents aged 60 and over, living nearby (Wongsith, 1992). Services available in the centre are: rehabilitation, recreation, family assistance and counselling service, including health promotion. The primary aim of providing this kind of service is to enable elderly people to live happily with their family in the community. At the moment, there are 10 social service centres in the major provincial areas (two centres are under construction) providing services to over 500 elderly people per month. Most centres are situated outside residential homes. Some centres also provide day care, respite care, and temporary accommodation, so called 'Emergency Homes,' where elderly people in urgent need can stay for not more than 15 days.

iv) Mobile Services

Mobile services for the elderly are provided by co-operation between the Department of Social Welfare and the Department of Public Health. These teams, which include social workers, and health professionals, generally visit rural communities where there is no other provision, either institutional or non-institutional. However, this type of service is likely to be able to address only immediate health and social problems; there is no continuity of care.

v) Other service projects

The Department of Public Welfare operates other projects to improve social security and quality of life for elderly people. One is the 'Spectacle Project,' first introduced in 1993, which aims to raise funds to provide spectacles for elderly people who are visually impaired, in order to improve their quality of life. The second project is the 'Funding Project' for elderly living in the community, which was introduced in 1993. To be qualified to receive this help, the aged need to prove that they are under the poverty line, have no relative to help out, or are not able to work and earn money by themselves, then they will receive income support of approximately 5 pounds a month until they die. The last project, introduced in 1994 was, 'Elderly Accommodation in Buddhist Monasteries.' It was initiated by the provincial public welfare departments, who carried out a survey to find out which Buddhist monasteries have elderly people resident, then provide funding support to those institutions, as well as providing income support for the elderly residents (Department of Public Welfare, 1994b).

3.7.3. Pension Schemes

In Thailand, the compulsory age of retirement is 60 years, however, not everyone is eligible to receive a pension when they retire from work, depending on the type of their occupation during their working life. Kiranandana (1989) classified the pension schemes into three groups: government, state enterprise, and private agencies employee. First, the government pension scheme, is applied only to those who were government officers. Although the compulsory age of retirement is 60 years, early retirement can be taken after age 50 or 25 years in service. Those who work for the government for 25 years or longer can obtain the benefits in the form of lifetime pension or a lump-sum payment as requested, whilst those who work continuously for 10 years or longer are only eligible to receive a lump sum of money. The amount of lump sum is calculated by multiplying the final monthly salary by the number of years in services, and the life time monthly benefit is equal to 2% of the final monthly salary times the number of years in service. Second, the state enterprise pension scheme, applies to all state enterprise employees. In this pension scheme, in general, the retirement age requirement or early retirement are the same as the government pension scheme. The state enterprises employers have to contribute a fixed percentage of the individual monthly salary to the pension fund. However, the benefits are available only in the form of lump sum.

The final group is the private employees pension scheme. Under the Royal decree on provident funds which has been effected since 1984, both employers and employees have to contribute the provident funds, each employee has to contribute not less than 3% of his/her salary, while each employer has to contribute not in excess of 15% of the paid salary. Benefits are paid to employees according to the terms specified in each employer's provident fund. However, only large private agencies provide retirement benefits to their employees while those who retired from small firms or were self-employed would not have had a pension or income support when they retired from work.

3.7.4. Organisations for Elderly People in Thailand

In Thailand, there are very few organisations working for elderly people. The majority of these organisations are run by non-government services or the private sector, either inside or outside Thailand. For example:

i) Senior Citizen Society

The senior citizen society, founded in 1963, aims to raise the awareness of the needs of health and social services for ageing population. Branches of the society have been formed in every part of Thailand and become a pressure group who call for the rights of elderly people and put pressure on the government to pass the legislation to improve their health and social security.

ii) Senior Citizens Association of Thailand

This association was founded in 1987 by a group of elderly people who were well educated and aimed to use their knowledge to help the society, such as by giving lectures to the public, providing counselling, and working with government bodies and international organisations to improve the quality of life for elderly people.

iii) HelpAge International

The international organisation for elderly people, Help the Aged International, was founded in the United Kingdom with the objective of improving the quality of life of the disadvantaged older people in the developing countries. Help the Aged International came to Thailand in 1988, since when it has provided funding for a number of projects related to elderly people, such as health promotion for elderly people, eye rehabilitation for elderly people with cataract, and provision of training centres to improve knowledge and skill at all levels, of those individuals and groups working in elderly care throughout the Asia Pacific Region (Help the Aged International, 1996).

3.8. Possible Factors Impacting on Caring for Elderly People in Thailand

In the past, the care of elderly people traditionally rested with their family members as the majority lived with an extended family and worked on the family farm. However, Thailand has gradually shifted from an agricultural to an industrialised economy. Moreover, the improvement in living standards and advances in medical treatment enable people to live longer, while at the same time, the success of family planning has lead to a decreasing fertility rate, resulting in older people forming a higher proportion of population (Kalache, 1992). These factors have raised awareness of the impact of changes which relate to the care of elderly people. This section, will focus on the causes of change and the consequences of these changes which lead to create problems and limitation on the caring for elderly people in Thailand at the present and in the near future.

3.8.1. Impact of Demographic Change

Sudden or rapid changes in birth and/or death rates have a fundamental impact on the age composition of the population. Changes in family size and the structure of households affect health costs, education, economic development, labour force participation, consumer demand, wages, and even a country's comparative advantage

(Burnham et al., 1993). Questions arise as to how these impacts have occurred, and how these changes have affected the quality of life, particularly for the ageing population, who are economically inactive and live in a country where health and social welfare provision are still insufficient.

i) Impact of demographic changes in Thailand

Thailand has recently experienced changes in the age structure of its population as has been experienced by other developing country (see Section 3.2.2). According to the growing size of the ageing population is always seen as a growing burden to family and society. For example: 'the growing number of oldest old has increased the need for social services and medical care in many countries during the last decade' (Thorslund and Parker, 1995: p. 199). Thus, the increasing proportion of elderly people in the population will no doubt have a powerful impact on public policy decisions influencing how resources will be distributed to care for this vulnerable population (Caffery, 1992a).

ii) Reduction in Household Size

According to the traditional family structure, care for older people in Thailand is a responsibility of the family, thus there is increasing concern the decline in extended family structure, which is able to accommodate elderly people. Although the findings from Mason et al. (1993) study on household size in Thailand suggested that family households predominated in both 1970 and 1980 and it was projected that four out of five of these would remain intact. Fewer than 5% of all households were one-person or primary-individual households and those consisting of unrelated individuals. However, household size has reduced dramatically since family planning was introduced as part of the 3rd National Economic and Social Development Plan during 1972-1976, to 5.2 in 1980 and 4.4 in 1990 (Limanonda, 1995), while the transition from an agricultural to an industrialised country, where there is no longer any advantage in having more children, has reduced household size still further. The latest findings obtained from the 1995 Statistical Yearbook of Thailand (NSO, 1995) indicate that the average household size has decreased from 3.9 in 1992 to 3.8 in 1994.

The household projection produced by Mason et al. (1993) suggested that households will average only 3.5 members by 2010 and the number of children living in households will decline by one-half between 1985 and 2005. Whereas, on average, intact households had two members under age 15 in 1985, this will decline to only one child by the year 2005. In contrast, the average number of adult members will decline only marginally during the same period, and the prevalence of elderly parents of the head of the household should increase markedly during the twenty-first century (Mason et al., 1995). In a country where health and social welfare services are not yet well developed, the family is a major source of help, particularly for the frail elderly who have no or low income. The impact of the demographic change and the continuing decline in family size raise concern as to the availability of future carers who will be able to provide care for frail elderly persons. It also calls for the government and policy makers to provide appropriate care for elderly people in terms of living arrangements, health care, and social and financial security (Chayavan et al., 1988).

3.8.2. Impact of Socio-Economic Change

Sustained economic growth in the Thai economy has been associated with the transition from an agricultural economy to one which is industry-based (Wongsith, 1992). There is no doubt that economic expansion and the widespread adoption of science and technology has moved Thailand into a period of modernisation which is characterised by an accelerated rate of change. What will be the impact of change that elderly people will have faced and how will these changes affect on the traditional family care system for elderly people in Thai society?

i) Modernisation

Korson (1978) points out that "modernisation" usually carries with it the implication of change for a culture and the movement of the society away from the traditional practices that it previously accepted. Traditionally, care providing is primary a role of women, especially in Thailand, where daughters, more than sons, are expected to provide care for their elderly parents when they grew old. Modernisation, Caffrey (1992b) explains, has resulted in a number of social changes which affect women, associated with the move from a kin-based to a cash-based economy. These changes include a breakdown in the traditional extended family system as children move to urban settings in search of work and women also move into the labour market. Thus, these factors would be expected to have a major impact on the availability of women to provide care for their elderly parents.

ii) Changes in Marriage Pattern

Today, divorce is becoming more common in Thailand. Social and economic changes have resulted in a greater frequency of conflict within the family which can lead to divorce (Wongsith, 1992). A report from the Administrative and Civil Registration Division (1994) shows that the divorce rate has increased from 8.3% in 1987 to 9.8% in 1993. Smith (1981) developed a life-table analysis of marriage using the 1975 Survey of Fertility in Thailand (SOFT) data. The results revealed that almost two-thirds of Thai women of reproductive age remarried within five years. These changes in marriage pattern might lead to complications in caring for parents-in-law. Moreover, children from previous marriages, may, due to loss of contact, be unwilling to provide care for their parents when they grow old.

iii) Changing in Elderly Status and Power

Age has traditionally been a basic determinant of status in Thailand (Cowgill, 1972). One of the Thai traditional values is respect for seniority, as mentioned earlier, elderly people are highly regarded and accorded a position of honour, both in public and at home (Wongsith, 1992). This respect includes the recognition of their experience of life and work, and also their roles in traditional and religious teaching (Asis et al., 1995). However, today, due to economic growth and technological advancement related to educational patterns, elderly people who have relatively low education, may find their knowledge and long experience no longer suitable for various new technologies. The power of age alone is no longer enough to keep them in a privileged position in society, which may affect their social-psychology, for example loss of dignity and experience of depression, in later life.

3.8.3. Insufficient health and social services for elderly people who suffer from chronic illness

From the literature presented above, of the limited health and social facilities available for elderly people, the majority of them, such as, residential homes, residential compounds, and other social clubs or societies focus on elderly who are in good health. Little attention has been paid to the elderly who are in poor health and are cared for at home. The available health services particularly for elderly people, such as geriatric clinics, have a limited role, providing services only in the hospital. As regards services in the community, mobile services are sometimes available in the rural areas, but, certainly, insufficient services are provided. No public nursing homes or respite care services are available. Most ill elderly people are treated and convalesce in hospital, and as there are no geriatric wards, elderly people are treated in the medical or surgical wards. There is an increasing awareness of 'bed-blocking' caused by long stay elderly patients. A study by Thamprechavai et al. (1992) found that of 119 medical patients surveyed at a teaching hospital in Bangkok, one-third were aged 60 and over. More elderly patients than younger patients were still in hospital for non-medical reasons (35% and 21%) and the duration of stay was also longer (median 11 and 8 days). In the situation of the increasing proportion of elderly people and lack of acute and long-term care services available, it is likely that hospitals will be faced with increasing problem of bed-blocking from elderly patients and long-term care for elderly people who have chronic illnesses will be shouldered by their families. However, with the gradual decline of the extended family, and the lower fertility rate leading to a reduction of family size and of the number of future carers, caring at home for chronically ill elderly people will be a serious problem in the near future.

Little is known about the nature of caring for elderly people who suffer from chronic illness at home. Therefore, it would be interesting to explore problems and the abilities of the families to cope with this caring situation. It would also interesting to explore how family structure and the relationship between carers and elderly relatives are affected by caring, who takes responsibility for caring, what health and social services are available, and what help carers need. The present research on family care for demented elderly relatives in Thailand was carried out in order to fill this gap.

Conclusion

Thailand is a Buddhist nation which is situated in Southeast Asia. Most developing countries, including Thailand, have recently experienced a change in ageing structure resulting from the success of family planning, added to improving living standards and medical technology. Thus, the ageing population has increased from 5.6% in 1985 and it is projected to be double that figure (11%) by the year 2015. This has given rise to concern about the quality of caring for elderly people.

In Thailand, in general, there is a tradition of family care for their own elderly relatives. The majority of elderly people (77%) live with at least one child. Over two-thirds of elderly people who are not co-resident with their children have daily contact with at least one child who lives locally, people who have no living child, live with their spouse, in a public residential home, or in some case become monks or nuns and live in the temple. The youngest daughter is the traditional choice of co-resident child, due to the bilateral family system in which a married son has to move into the wife's family while the youngest daughter who, normally, would be the last person in the family who get married, will remain at home to care for their elderly parents. However, support for elderly people also comes from children who are not co-resident. The Buddhist religion appears to be a major factor that influences people to provide care for elderly parents, under the concept of 'parent repayment'.

Health care services have to be paid for by users, unless the patient is covered by some kind of health insurance scheme. There are available both traditional and modern medicine. In traditional medicine, only practitioners who qualify from the Traditional Medical School or from Traditional Thai Massage School are recognised and granted a licence from the Ministry of Public Health. In western medicine, the government is the main health care provider at lower cost than the private sectors. However, health care is unequally distributed, with a greater number of doctors and medical facilities available in urban than in rural areas.

The Thai government has included a health and welfare plan for elderly people in the Long-Term Plan for Elderly People (1982-2002) and in each five year National Economic and Social Development Plan. Health and social welfare provision for the elderly includes geriatric clinics, free medical care schemes for elderly people who are on the poverty line, residential homes, social service centres for the elderly and mobile health and social services. Private agencies such as the Senior Citizens Society or Help the Aged International also provide services for elderly people. More information on organisations which help elderly people in Thailand is shown in Appendix III. However, demographic and socio-economic change, and the insufficiency of health and social services for elderly people who suffer from chronic illness, are possibly causing impact on caring for elderly people in Thailand.

CHAPTER 4

Research Design and Method

Introduction

The purpose of this chapter is to discuss the methodology of the present study on the nature of family care for elderly demented relatives in Thailand. This chapter is concerned with six main issues: aims of the study, research design, sample, instruments, methods, and data analysis. Each of these issues will be discussed in turn.

4.1. The Aim of the Study

As it was mentioned earlier, in the introduction, the aims of the present study are: to identify the characteristics of carers; to study families in the caring situation; to assess carers' psychological well-being; to examine the influence of the Buddhist religion and Thai culture on this care; to identify the needs of carers and to identify primary assistance needed. Moreover, this thesis is intended to contribute to policy and practice. These aims and the existing knowledge found in the literature have helped to shape the research design, to focus on the particular aspects of interest to the present study.

4.2. Research Design and Data Collection

One of the issues to be considered by researchers is the study's probable contribution to knowledge. Miller (1991) suggests, the question needs to be considered: what design would best ascertain any association among the variables under study? How that question is answered may well determine the future outcome of the study and it will most certainly determine the time and money required for the study. Thus, these questions help to shape and constrain the design of the study.

4.2.1. Types of research studies

Basically, research studies have been classified by Nieswiadomy (1993) into three types: exploratory, descriptive, and explanatory studies. Exploratory studies are carried out when little is known about the phenomenon of interest. Descriptive studies are carried out when there is more available information, to examine the relationships between variables, whilst explanatory studies are used to search for causal explanations and are usually experimental in nature. Because little is known about family care for chronically ill family members in Thailand, this study falls into the exploratory category. However, this category only indicates the type of study that has been conducted. There is also a need to specify a design for any research project, in order to clarify how a study has been carried out and why that particular research design was selected.

4.2.2. Design

Research design can be categorised into formal methods and informal methods (Nichols, 1991) or quantitative and qualitative studies or paradigms (Nieswiadomy, 1993; Creswell, 1994). In a formal or quantitative study, phenomena are ascribed numerical values, whilst an informal or qualitative study collects non-numerical data through methods such as unstructured interviews and participant observation. The aim of the qualitative approach is to provide in-depth descriptions of people or events, while the quantitative researcher aims for hard, replicable and reliable data (Porter, 1989). To distinguish qualitative from quantitative research, Hakim (1992) points out that qualitative research is concerned with individuals' own accounts of attitudes, motivation and behaviour. Qualitative research is often used for exploratory research in areas where relatively little is known. Merriam (1988) identified six characteristics of qualitative research: 1) the researcher is concerned primarily with process rather than outcome; 2) the researcher is interested in meaning; 3) the researcher is the primary instrument for data collection and analysis; 4) the research involves fieldwork; 5) is descriptive; and 6) is an inductive process. Table 4.1 shows the differences in assumptions about the research process, between qualitative and quantitative studies.

Nieswiadomy (1993) also described clearly the characteristics of quantitative and qualitative designs. For example, quantitative designs have been divided into experimental and non-experimental designs. Experimental studies involve manipulation of the experimental variables, whilst there is no manipulation in non-experimental studies, which include, for example survey studies, correlation studies, comparative studies, and methodological studies. A study can only show cause and effect if an underlying theory demands that an association should operate in a particular direction, or if the purported causal factor can be generally manipulated. In general, corresponding movements of observed variables can be described only as association. The qualitative design consists of five major approaches: phenomenological studies, ethnographic studies, grounded theory studies, historical studies and case studies. The most common method used is the depth interview (Hakim, 1992).

Table 4.1. Qualitative and Quantitative Studies Assumptions

Assumption	Process of Research	
	Qualitative	Quantitative
Methodological Assumption	Inductive process	Deductive process
	Mutual simultaneous shaping of factors	Cause and effect
	Emerging design - categories identified during research process	Static design - categories isolated before study
	Context-bound	Context-free
	Patterns, theories developed for understanding	Generalisation leading to prediction, explanation, and understanding
	Accurate and reliable through verification	Accurate and reliable through validity and reliability

Source: Developed from Creswell (1994), Table 1.1, p. 5.

Both qualitative and quantitative designs have their strengths and weaknesses that researchers have to bear in mind and justify before adopting any type of research design for their own work. In qualitative designs, the main strength is the validity of the data obtained. Since individuals are interviewed in sufficient detail, the result will be taken as true, correct, complete and believable reports of respondents' views and experiences. Qualitative research also offers substantially different and complementary information on the way attitudes and experiences cohere into meaningful patterns and perspectives (Hakim, 1992, p. 27-28). Matthew et al. (1994, p. 10) added that the confidence in qualitative data is stronger, because the data are collected in close proximity to a specific situation. In addition, qualitative research is claimed to be the best strategy for developing hypotheses, validate, explain, illuminate, or reinterpret quantitative data gathered from the same setting. The main weakness is that small numbers of respondents cannot be taken as representative (Hakim, 1992). In addition, the researcher who carries out research by observation may be seen as intrusive, while the researcher's presence during the interviews may cause bias response. Moreover, the information provided is indirectly filtered through the views of interviewers (Creswell, 1994). Thus, methods such as tape recording, verifying transcripts with respondents, etc., used to try to overcome this problem. In quantitative studies, the major strength is that the sample can be generalised to a population, in terms of some characteristic, attitude, or behaviour (Babbie, 1990). It is also claimed to have strong potential for testing hypotheses. Nevertheless, in all research attention needs to be paid to ethical issues (Marshall and Rossman, 1995).

4.2.3. A Combined Research Design

According to the aims of the present study, there were two explicit questions. First, what is it like for carers to look after their demented relative at home? This question was intended to explore carers' attitudes towards caring, their motivation to become a care provider, problems in caring and other possible influential factors, and carers' needs. Thus, it is clear that this is a qualitative question. In addition, much of the literature reviewed, suggests that stress is produced in related to care providing (Levin, 1985; Lewis and Meredith, 1988; Adams and Barker, 1989; Ungerson, 1990; Twigg, 1992) (see Chapter 2, Section 2.8), so in the present study carers were assumed to experience stress. Thus, the second question here is, what levels of stress do carers experience and what other influencing factors are associated with the level of stress? This question is a quantitative question, because exact numerical data need to be obtained and correlations among relevant variables need to be made.

Clearly, no single research design would be sufficient to answer both qualitative and quantitative questions. Therefore, a combination of methods or a mixed-methodological design was chosen in the present study. Thus, both qualitative and quantitative data were collected (Creswell, 1994). The purposes of combined methods generally are: uncovering findings, elaborating on results, using one method to inform another, discovering contradiction, and extending the scope of the enquiry (Greene et al., 1989). Thus, the advantages of combined designs are that they enable the researcher to understand better a concept being explored (Creswell, 1994) and they increase the researcher's ability to rule out rival explanations for phenomena (Hinds, 1989).

4.2.4. Interviews

Several types of data collection methods, such as self-report questionnaires, interviews, attitude scales, or observational methods (Nieswiadomy, 1993) are available. Interviews have a strong claim to being the most widely used method of research

(Fielding, 1993). The purpose of interviewing is generally to find out what is in and on someone else's mind (Patton, 1990). One of the major advantages of the interview is the presence of the interviewer, who can clarify questions that are not clear, and use additional prompting questions if the participants provide little information or seem hesitant (Williamson, 1981). Thus, interviews were chosen as the data collection method.

Interviews may be divided into three categories: unstructured, structured, and semi-structured. Unstructured interviews are particularly appropriate for exploratory or qualitative research where the researcher does not possess enough knowledge about the topic to structure questions in advance of data collection, whilst structured interviews are used when the researcher desires straightforward factual information and involve asking the same questions, in the same order, and in the same manner, of all respondents in a research study. In fact, the majority of interviews fall somewhere in between the unstructured and structured. In these so called "semi-structured interviews," interviewers are generally required to ask a certain number of specific questions, but additional probes are allowed or even encouraged (Nieswiadomy, 1993). Whilst most research about dementia and carers has been done in Western countries, studies of ageing Thai people have only recently been carried out. There is, thus, a lack of information about many aspects of the ageing process, dementia and caring. The need to construct an idea of the nature of caring, absent from the Thai literature, therefore dictated that semi-structured interviews were appropriate to use in this study.

4.3. Sample

The population of interest was defined as Thai elderly people with a hospital diagnosis of dementia (subjects) and their principal carer (carers) who were usually members of the subject's family (Taraborrelli, 1993). The further research criteria for selecting elderly demented persons were that the subject should have had at least primary school education and be resident in the community in the selected geographical area in Thailand. Carers were any family members who provided principal care for their elderly demented relatives. In addition, both carers and cared for persons were followers of the Buddhist religion. The details of how the participants were found sample size, and the place of field work will be discussed later in Sections 4.4, 4.5, and 4.6.

4.4. Preliminary Survey

The research fieldwork took place in Thailand, where I undertook preliminary location surveys during December 1994 in order to obtain up-to-date information and explore the possibility of conducting research in particular areas. My aim was to draw participants from all social classes and to compare the strain and cost of care in those who have free medical care and those who do not. In addition, availability of resources and co-operation from physicians had to be taken into account.

4.4.1. Seeking the key informants and their networks

The Neurological Hospital in Bangkok was the first hospital in Thailand which brought the need for elderly care to the attention of health professionals and the public. A geriatric clinic and Thai senior citizen society were initially introduced at this hospital (Theanprapart and Tunsiri, 1993) before such models of health care were adopted throughout the country. The Neurological Hospital, Bangkok, therefore, was approached to seek information about where I should recruit participants, and whether I could gain access to dementia patients and their carers from this hospital. Unfortunately, whilst there were general health services for elderly people, these were not specifically for dementia patients. However, I was informed about the 'Train the Brain Forum Group' which consisted of experts from neurology, psychiatry, geriatric medicine, psychiatric nursing and psychology, who were working and researching dementia in Thailand. I was then advised to contact Asso. Prof. Prasert Assantachai, a geriatric physician, who was one of the members of the Train the Brain Forum Group and currently researching into dementia. He was practising at Siriraj Hospital which is a general and teaching hospital in Bangkok.

4.4.2. Hospital survey and making personal contact with geriatrician

I was able to contact Asso. Prof. Assantachai who was interested in my research project and kindly agreed to let me recruit participants from the geriatric clinic where he worked, although he was unable to tell me the exact number of his dementia patients, since some of them had lost contact, some of them might have died, and there was neither a medical diagnosis classification on computer nor a specific dementia patients file available. He estimated, however, that there were around ten such patients. At this stage I had not yet decided which cognitive test instrument to use in my study, and he introduced me to the Thai Mental State Examination (TMSE), a brief test of cognitive mental state, which was developed from the Mini-Mental State Examination (MMSE) (Folstein et al., 1975) by the Train the Brain Forum. This test is written in Thai and has been used extensively throughout Thailand.

I had been told that there were only five geriatricians in Bangkok, and probably in the whole of Thailand, at that time. Asso. Prof. Assantachai suggested I should contact his geriatrician colleagues who practised in geriatric clinics at Pramongkutklao and Chulalongkorn hospitals, which were also teaching hospitals. Although Pramongkutklao hospital is a military hospital and aims primarily to serve military officials or their relatives who are entitled to receive free medical care, the 1994 statistics from the out-patient departments (OPD) showed that 63.9% of the patients were civilians (Division of Hospital Census and Statistic, 1995). There were two geriatricians and around ten demented patients in this hospital. This enabled me to examine the difference in caring situation between a group of patients who were able to get free medical care and those who were not. By contrast, Chulalongkorn is a general hospital managed by the Thai Red Cross Society, where the majority of patients were civilians. The geriatrician in this hospital told me he had only five demented patients in his geriatric clinic, but he knew there were some demented patients receiving health care in the out-patient psychiatric department, so he kindly introduced me to a leading psychiatrist who was interested in this field and was supervising a masters degree student involved in dementia research.

4.4.3. Seeking participants from a region

The second centre chosen for this research was Chiang Mai (see Figure 4.1), the biggest city in the northern region of Thailand. Chiang Mai was chosen because it is a historic town, which still preserves the traditional culture and way of life, in contrast to Bangkok which has been subjected to greater Westernisation. Chiang Mai is also the centre for medical care for the whole northern region, with many referrals from rural areas. It was also chosen because the 'Muang' dialect, the dominant language in the region, is my mother tongue; this avoided the problem of linguistic difference influencing the interpretation of interview responses (Proctor, 1993). Chiang Mai's medical facilities include a University hospital, Neurological hospital, Psychiatric hospital, Mother and Child hospital and so on. These hospitals provide advanced treatment for patients referred from all over the region. At the university hospital, the senior neurologist suggested that it might be preferable to confine the research to dementia from a particular disease, such as AD or PD, in order to have greater confidence in the research results. However, this was the first hospital in which I found dementia classified according to causes and there would have been only a small sample available if this suggestion had been followed. I, therefore, decided to draw a sample from the Neurological hospital, where there were more than twenty demented patients available who lived in close proximity to Chaing Mai. Co-operation was received not only from the medical director, but also from the neurologist himself. This was the only neurological hospital in the northern region, a region containing 17 provinces, covering 169,644.3 Sq.Kms with a total population of 11.8 million (Alpha Research and Manager Information Services, 1995). Therefore, the sample for this research drawn from the Neurological hospital in Chiang Mai was limited to those living in the neighbouring provinces of Chiang Mai, for example Chiang Rai, Phayao, and Lumpun (see Figure 4.1, also see Figure 3.1).

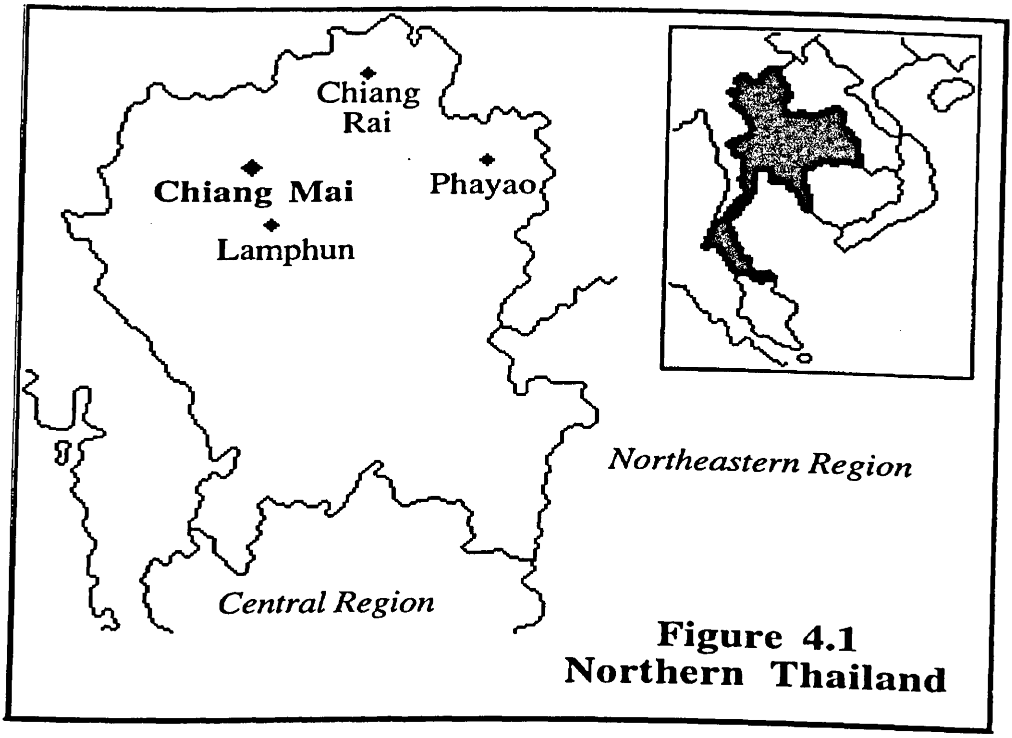

Figure 4.1 Northern Thailand

4.5. Preparation for research fieldwork

At this stage, all information from the preliminary survey were taken back to the UK, in order to consider future fieldwork in Thailand; the appropriate sample size; and ways to overcome anticipated difficulties in fieldwork. Preparation of the research instrument and contact in order to gain permission from organisations where research fieldwork would take place are discussed below.

4.5.1. Sample Size

The sample size was very difficult to determine and depended upon the number of dementia out-patients from each hospitals. After the preliminary survey, I decided to obtain the participants from the geriatric clinics in three general hospitals in Bangkok and the Chiang Mai Neurological hospital in the northern region where there were potential subjects available and good co-operation had been gained from the individual physicians. However, as there was no classification of patient diagnosis available, it was necessary to search for patients diagnosed with dementia from the entire OPD cards, either manually or by computer, when available. Waiting for subjects to see a doctor at the geriatric clinic was another option, but was later abandoned since this method proved to be too time consuming. Fortunately, most of the geriatricians whom I contacted offered to take a record of dementia patients' names and their hospital number for me, when such patients next visited the hospital.

The preliminary survey suggested that approximately fifty subjects and their carers would be available to participate in this study (Table 4.2). The question therefore arose whether this sample was large enough to be representative and how large a sample was required (Fox, 1982; Nieswiadomy, 1993). To obtain the right sample size is very important because the power of a statistical test is dependent on the sample size and the level of significance that is chosen. However, there is no clear-cut answer for the correct sample size depends on the purpose of the study and the nature of the population (Cohen and Manion, 1989). Generally, the larger the sample that is chosen, the more powerful the statistical test will be (Nieswiadomy, 1993).

However, the precision which is used in sample surveys in Western countries in many cases cannot be achieved in developing countries because of the limitation in resources (Zarkovich, 1993); for example, sampling frames are not readily available. The exact size of the population cannot be determined, nor can random sampling be undertaken. Therefore, it is even more difficult to determine the desired sample size for such studies. As Nieswiadomy (1993) has noted:

> Some factors to be considered are the homogeneity of the population, the degree of precision desired by the researcher, and the type of sampling procedure that will be used. If the population is very homogeneous or alike on all variables other than the one being measured, a small sample size may be sufficient.
>
> (p. 183)

One may ask: how small a sample size would be sufficient? It has been suggested that a sample size of 30 ensures the benefits of the central limit theorem (Roscoe, 1975), the phenomenon in which sample values tend to be normally distributed around the population (Nieswiadomy, 1993, p. 278). Thus, for most behavioural research, sample sizes as small as 30 are generally adequate to ensure that the sampling distribution of the mean will closely approximate the normal curve (Roscoe, 1975; Spatz and Johnston, 1984; Cohen and Manion, 1989; Shott, 1990).

However the issue of sample size is really more relevant to quantitative research where statistical tests are to be used or where it is hoped to make generalisations from the sample to the population as a whole; this issue is not as important in qualitative or exploratory types of research. The present research which was an exploratory study which combined quantitative and qualitative designs, with no attempt to generalise from the sample to the population as a whole. Given the purpose of the study and that the available sample group was very specific, as discussed above, fifty subjects and fifty of their carers available from four selected hospitals this sample was considered to be sufficient to participate in this study.

Table 4.2. Number of possible participants by hospital from preliminary survey

	Number of Subjects	Number of Carers
Bangkok		
Siriraj Hospital	10	10
Pramongkutklao Hospital	10	10
Chulalongkorn Hospital	10	10
Northern Region		
Chiang Mai Neurological Hospital	20	20
Total	**50**	**50**

4.5.2. Sampling Methods

In undertaking social research, there are two main sampling methods available: probability and non-probability. In probability sampling, elements in a population are chosen at random (each population element has a known probability of being selected for the sample) (Arber, 1993). When probability samples are chosen, inferential statistics can be used with greater confidence (Nieswiadomy, 1993). In non-probability methods, the sample element are chosen from population by non-random methods. This restricts the ability to generalise the findings of the study.

Despite this limitations, non-probability sampling methods are still more common than probability sampling in developing research in academic disciplines such as sociology, anthropology and political science, due to indefinite populations, unavailable sampling frames, small budgets, lack of time, inexperienced personal and pressure for results (Hursh-Ceasar and Roy, 1976). Arber (1993) suggested that;

> Where the researcher's aim is to generate theory and a wider understanding of social processes or social action, the representativeness of the sample may be of less importance and the best sampling strategy may be a focused or judgement sample.
>
> (p. 71)

Arber (1993) has also stated that using a probability sample is often unrealistic for small scale or qualitative research. As a result of the preliminary survey, it was found that there were no available sampling frames since in Thailand, for example, not everyone is registered with a GP, as in the UK. Patients can choose among several places of treatment, such as government hospitals, private hospitals, or private clinics. This leads to "shopping for treatment." In addition, as it was mentioned earlier, there are no available patient records which classify diagnosis. Thus, there was no possibility of undertaking random sampling for this study. Accordingly, non-probability, convenience sampling was chosen for this study, where the sample were drawn from available diagnosed demented people and their carers from OPD in the selected hospitals.

Just selecting people who have sought hospital treatment makes it difficult to make generalisations about the population as a whole from the study findings, as perhaps, only a minority of people with dementia have hospital care in Thailand. For example, Sommanawan (1994) carried out a cognitive screen test of 850 elderly people in fifteen communities in Bangkok and found that none of her demented elderly sample (n=29) were taken to see doctors. Given the time constraints and purpose of the study, a similar community survey to that undertaken by Sommanawan (1994) was not possible or necessary. It is of interest to ask why some proportion of people who have dementia get to a hospital in Thailand. In other words, what was it that made relatives decide to take their elderly demented relative to the hospital? Thus, it may be considered legitimate to focus on subjects and their carers who contacted the hospital, rather than focus on subjects who lived in the community and did not receive any treatment. One might speculate that subjects who were brought to the hospital presented more serious problems; they and/or their carers were sufficiently wealthy to pay for medical treatment; or that carer educational level influenced their decision. These findings may be generalised to the wider population of people with dementia who go to hospital. Therefore, in this study, it was decided to focus on subjects who had been examined and diagnosed as having dementia by a hospital based physician only. The study also aimed to explore the thinking and attitudes of carers toward their elderly relative, and how culture, religion (especially Buddhist values) and modernisation affected such carers in Thailand at the end of 20th century. The sample of carers were thus the carers of these people with dementia.

4.5.3. Interview Schedule

The most common interview instruments used in interviews are interview schedules, responses to which may be recorded by pen, audio or video tape recorders. An interview schedule is a set of questions to be asked by the interviewer usually in written form, with spaces to record the respondents' answers. Basically, there are two categories of questions: open-ended and closed questions. Open-ended questions are commonly used in unstructured interviews, to obtain information on participants' perceptions, beliefs, opinions, attitudes and feelings, and closed questions are generally used in structured interviews, to seek factual data from participants. Semi-structured interviews generally use both types of questions (Nieswiadomy, 1993).

In this present study, opened-ended questions and closed questions were designed for semi-structured interviews based on the literature and the aims of research. The interview schedule was divided into two sections (see Appendix II). The first section (Section A) contained questions about the carers. The demographic questions, such as age, sex, occupation, education, living arrangements, religion and financial status, were straightforward and were, therefore, presented as closed questions, whilst questions about the needs of carers, personal health, traditional medicine and the carers' attitude to their older relative were presented as open-ended questions. Two existing scales were adopted: the Caregiver Strain Scale (CSI), developed by Betsy C. Robinson (1983); and a assessment scale on carers' networks, the Network Assessment Instrument, developed by Clare Wenger (1994), to measure strain on the carers and support networks of the carer and the demented relative respectively.

The second section (Section B) concerned the elderly demented person. Similar demographic questions to those asked about carers were included and presented in closed questions. Individuals' cognitive function was assessed using the Thai Mental State Exam (TMSE). Carers were also asked to rate the ability of subjects regarding their independence in abilities of daily living by using the Behaviour Rating Scale (BRS). The overall methods of data collection exploring key themes in both subjects

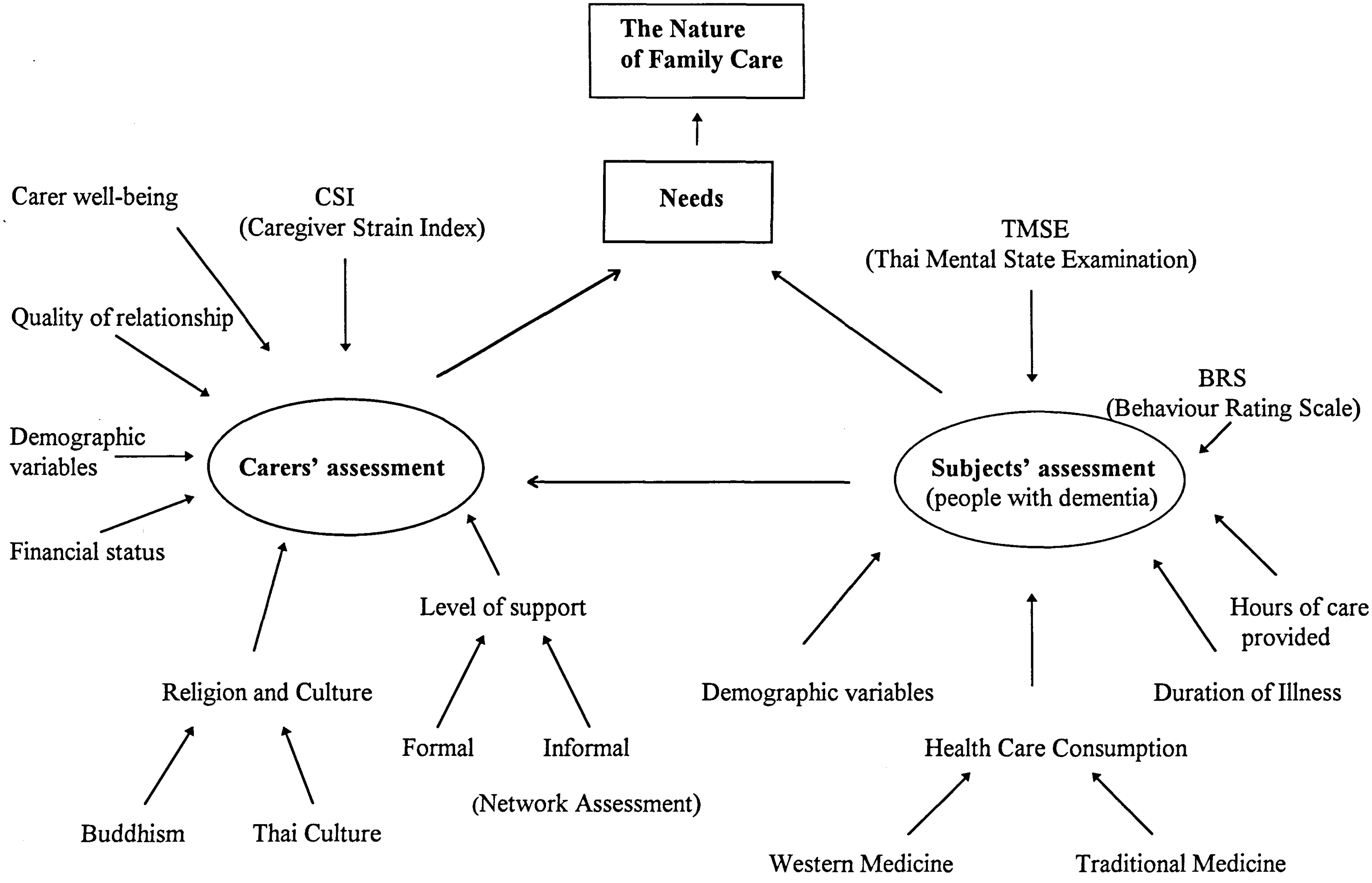

Figure 4.2. The nature of family care for demented elderly relatives in Thai Buddhist society

and their carers is shown in Figure 4.2 and the details about the standardised instruments will be discussed in Section 4.5.4.

4.5.4. Instruments

In general, most of the available instruments were developed in Western countries. Thus, to select an instrument to apply in Thailand where the culture, standard of living, and level of education are different from those in the West, instruments were needed which were highly sensitive, have been widely used and successfully used cross-culturally, were brief, convenient to apply, clear and simple (for translation), and not unduly costly to apply. The four main instruments which met these criteria and which were chosen to apply in the present study will be discussed below.

i) The Thai Mental State Exam (TMSE)

There are several instruments for detecting dementia, for example: Geriatric Mental State by the computer system (AGECAT; Copeland et al. 1986); Cognitive Assessment Scale (CAS) of the Clifton Assessment Procedure for the Elderly (CAPE) (Pattie and Gilleard, 1979); Information Memory Concentration (IMC; Blessed et al., 1986); Mini-Mental State Examination (MMSE; Folstein et al. 1975); Abbreviated Mental Test (AMT; Hodkinson, 1972); and Mental Status Questionnaire (MSQ; Pfeiffer, 1975). Although the AGECAT is claimed to provide differential diagnosis which can distinguish different types of dementia, particularly from depression and can be used by non-medical personnel (Copeland, 1990), it application would be costly, because it is delivered by a computer programme. Moreover, it has been criticised on the ground that 'it generates idiosyncratic diagnoses that do not correspond to standard criteria' (Henderson, 1992; p. 105). The CAP has been criticised for the low sensitivity (Black et al., 1990), but it is reported to work quite well in an institutional setting (Copeland, 1990).

Attention was therefore turned to scales which had already been tried out and validated in Thailand: IMC and MMSE. The IMC has been found to be influenced by level of education, with less educated subjects likely to have low IMC scores, and the IMC and MMSE scores have been found to be highly correlated (p<.001) (Kangsanarak, et al., 1992), whilst the Thai Mental State Examination (TMSE), which is derived from the MMSE has been found very successful in application (Poungvarin et al., 1995, 1996). Therefore, the TMSE/MMSE was chosen for assessing the mental state of the subjects in the present study. The TMSE, which was developed and translated into Thai from the MMSE in 1991 by the Train the Brain Forum Committee, has become the first standardised neuro-psychological test to be used in Thailand (Train the Brain Forum, 1993). It was hoped that this would provide an appropriate screening test for elderly people who had different socio-economic status, level of education and cultural backgrounds from Western society.

The original MMSE is believed to be a reliable, valid measure, easy to administer, useful for measuring cognitive decline into the later stages of dementia (Parks et al., 1993), and is probably the most popular brief scale (Bowling, 1995). Bowling (1995) has further stated that the MMSE has been used extensively in the USA and, increasingly, in the UK and Europe and been translated to many languages. The disadvantage of the MMSE is that it does not provide a definitive diagnosis of the cause of dementia (Copeland, 1990). However, a decline in cognitive function is an essential component of the diagnosis of dementia (DSM-III-R, 1987; Brayne and Calloway, 1990). Cohen et al. (1984) recommended that mental status tests be only one part of a comprehensive neuropsychological evaluation for dementia. Another limitation of the MMSE is the excessively high number of false-negative errors for patients with early dementia (Pfeffer et al., 1981; Wilson and Kaszniak, 1986) and false positives in persons who had less than 9 years of education also have been reported (Anthony et al., 1982).

Nevertheless, the MMSE has been found to produce significantly fewer false positives than the Abbreviated Mental Test (AMT) and MSQ when used to screen the over 75s (Mackenzie et al., 1996). It is also said to be a brief and sensitive instrument to measure the present cognitive impairment and TMSE has proved successful as a quick (less than 10 minutes), easy to administer, neuro-psychological test for Thai elderly, which has been applied throughout Thailand. The application of TMSE in this research was not intended to provide a definitive diagnosis, but it was used as a part of cognitive assessment with participants who had already been diagnosed by a physician as having dementia. Because the majority of elderly Thai people have little or no education (Kangsanarak, 1992; see also Chapter 5, Section 5.1.2), to minimise false positives related to level of education, subjects who had no formal education were excluded from this study.

Both MMSE and TMSE scales contains six sub-tests: orientation, registration, attention, calculation, language and recall. A score of zero is given when an individual refuses or is unable to attempt an item and the maximum total score is 30. The lower the score, the greater the degree of cognitive impairment. In the MMSE, those who score 23 or less out of 30 are considered to be intellectually impaired (Folstien and Folstien, 1990). Bowling (1995) stated that the cut-off score is 23-24, and most non-dementing elderly people rarely score below 24. However, in the TMSE, the agreed cut-off score was 23, so this was the cut-off selected for application in this research. The TMSE in English and Thai which is in the second part of the interview schedule is included in Appendix II (Part B).

ii) The Behaviour Rating Scale (BRS)

Significant impairment in a person's occupational and social functioning or relationships with others is another important factor which needs to be assessed alongside cognitive deficit, to establish a diagnosis of dementia (American Psychiatric Association, 1995). Two instruments related to this measurement have been applied in Thailand: the Dementia Scale (DS; Blessed et al., 1986) and the Barthel Activities of Daily Living (ADL) Index (Wade and Collin, 1988). However, neither of these scales appeared suitable for use with the elderly Thai sample; the former has been found to have low validity (Kangsanarak, et al., 1992) and the latter to produce false positives, because of the misinterpretation of behaviour and intellectual functioning due to cultural factors, which led to 90% of subjects being scored as disabled (Jitapunkul et al. 1994). Therefore, attention was turned to other available scales which have not been used in Thailand. The Behaviour Rating Scale (BRS) became the centre of attention because it provides measures of four principal areas of behavioural disabilities: physical disability, apathy, communication difficulties and social disturbance, the major areas that the DSM- IV recommends to be measured, as mentioned earlier (also see Chapter 1, Section 1.1).

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The BRS is one of two independent measures of the CAPE used to measure behavioural competence in elderly people and was developed and tested for validity by Pattie and Gilleard (1979). Although the CAPE has been criticised as being developed for use with elderly people living in institutions (Black et al., 1990; Copeland, 1990), the measure can provide useful information about the elderly in other settings (Pattie and Gilleard, 1979). The BRS is recommended as a tool for individual therapeutic assessment as well as for surveys of dependency by using it to determine the severity of disability and level of dependency (Wilkin and Catherine, 1989). It can also be used as a survey measure to describe and compare the characteristics of different populations and is able to discriminate between elderly people with different outcomes (Pattie and Gilleard; 1979). This scale is brief, simple, straight forward, and provides more detail about how frequently of each type of behavioural problem occurs (e.g. never, sometimes, and almost always) in the cared-for elderly person.

The BRS contains 18 items (see Appendix II, Part B) and provides an overall measurement of the individual's behavioural disability level, including mobility, continence, activities of daily living, and confused behaviour. Further items covering 'eyesight' and 'hearing' appear on the form but do not contribute to the scale scores. Each item has a range of score from 0, for no or few problems, to 2 for frequent or constant problems. Total scores range from 0 to 36 and are grouped into five dependency grades (see Table 4.3), which are also able to indicate the degree of support needed (Bowling, 1991). In general, the lower the score on the BRS, the more independent a person is in activities of daily living. For this reason I decided to use the BRS to measure the demented participants' dependency.

Table 4.3. CAPE Behaviour Rating Scale (BRS) Dependency Grade

Grade A (BRS scores 0-3)	**Independent**: no impairment - comparable to those living without support in the community.
Grade B (BRS scores 4-7)	**Low dependence**: mild impairment - likely to include those needing some support in the community, warden-supervised accommodation and better residents in residential accommodation.
Grade C (BRS scores 8-12)	**Medium dependency**: moderate impairment - people functioning at this level are likely to need residential care or considerable support and help if at home.
Grade D (BRS scores 13-17)	**High dependency**: marked impairment - it is within this category that there is the greatest overlap between those in social services accommodation and those in hospital care.
Grade E (BRS scores 18-36)	**Maximum dependency**: severe impairment - this level is seen most often in psychogeriatric wards and the ones who remain in community home/EMI hostels often present considerable problems to staff in terms of their demands on staff time.

Source: Pattie and Gilleard (1979), Table 2, p. 16

iii) The Network Assessment Instrument

The network perspective is concerned with the way in which individual people are linked into groups and society (Wenger, 1994). In studies of stress, networks are treated as resources which are important contextual elements of the stress process in carers. Networks (including family) refers to the number of people to whom people 'have attachments, the composition of the networks, and the frequency of contacts with their members' (Pearlin et al., 1990, p. 586). Pearlin et al. have further stated that networks are different from social support, in that 'network represents the totality of one's relationships, whereas support was treated as a mediator.' Therefore, one cannot have social support without having a network, but one may conceivably have a network without support. However, there is a close link between networks and social support where, in general, the majority of people who are in trouble may turn first to their own families for support, but under certain circumstances people may turn to wider kin, friends or neighbours (Bulmer, 1987). Thus, the support network refers to 'all those people involved with an elderly person in a significant way: as a member of the household, in providing companionship, emotional support, instrumental help, advice or personal care or receiving any of these from the old person' (Wenger, 1994; p. 2).

In studying the care of demented relatives in the community, therefore, the concept of the social network is particularly useful for the analysis and understanding of local level informal ties (Bulmer, 1987), which may help health professionals and social workers understand better the problems of caring in the community, such as stress or burden, and so provide services to meet their needs. Wenger (1997) pointed out that there are four main ways to measure social and support networks: measurement of total networks, proxy measures, measuring partial or purposive networks, and measurement of network structures. The measurement of network structures was developed based on the other types of measures to overcome their limitations and is able to describe the size, extent, composition or function of the network.

The leading network assessment tool for measuring network structure was developed by Clare Wenger from her longitudinal study of ageing conducted in North Wales since 1979. This work has led to the development of a typology of networks: Local family dependent support network; Locally integrated; Local self-contained; Wider community focused; and Private restricted (Table 4.4). This network typology has been claimed to have wide predictive reliability and has been used successfully and related to comparable factors in both urban and rural samples (Wenger and St.Leger, 1992), in Belfast, Cumbria, Liverpool, London and Netherlands, as well as being used to study support network distribution in Bangladesh and Beijing. Thus, it would be interesting to examine the distribution of the network types related to family care in Thailand where culture, religion and family structure are different, which may contribute to knowledge at the cross-cultural level.

Table 4.4. The Support Network Typology

(1) Local family dependent support network: This is mainly focused on close family ties, with nearly all support met by the family. These networks tend to be small and the elderly people are likely to be widowed, older and in less than good health than those with other types of networks.

(2) Locally integrated: This category includes close relationships with local family, friends and neighbours. This network is based on long-term residence and active involvement, and therefore, this network tends to be larger, on average, than others.

(3) Local self-contained: This type typically has arms-length relationships or infrequent contact with at least one relative living in the same or an adjacent community. Childlessness is common. Networks tend to be smaller than average.

(4) Wider community focused: There are, typically, active relationships with distant relatives, usually children, and high salience of friends and neighbours. Absence of local kin is typical. Networks are larger than average.

(5) Private restricted: This type is typically associated with absence of local kin. Contact with neighbours is minimal. Networks are smaller than average.

Source: Adapt from Wenger (1994), pp. 3-4.

While it was beyond the scope of the present study to examine network typologies throughout Thailand, the network instrument developed by Wenger (1991) was incorporated into my research project which aimed to look at the nature of caring for the demented person at home, in order to define the problems involved, explore what help is likely to be needed and, hopefully, to determine what type of intervention is likely to be most efficient in the light of limited health and social service resources.

Because the main carers constitute the primary support network for the dependent person, the help which carers receive in order to fulfil their responsibilities is also important. Therefore, it is interesting to know the carers' support network, which would be a secondary support network for the dependent person. The extensive study of dependent persons and their carers would help to give a clearer picture and better understanding of the real caring situation and provide a basis for planning suitable interventions to help with the continued provision of care in the elderly person's own home. Therefore, the support network instrument was applied to both subjects and their carers in this study.

The typology network assessment instrument consists of eight questions (see Appendix II, Part A) on the basis of which the support network type can be identified (Wenger 1991). In data collection, in general, questions should be asked directly and answered by the elderly people themselves, and their responses recorded. However, in the present study, the sample was of elderly demented persons, the majority of whom were not competent to answer because of their cognitive impairment and chronic confusion. In the case of severe incapacity, Wenger suggests that a close relative or friend may be used as a proxy, though it should be noted that responses will not be so reliable. Carers, therefore, were asked to answer the eight support network questions twice; once for themselves and the second time for their demented spouses or relatives.

iv) The Caregiver Strain Scale (CSI)

Although there has been extensive study on stress in carers in Western countries, however, little is known in Thailand. This is probably because no one questions care, which reflects a strong Buddhist ideology of reciprocity or parent repayment and the culture of family care in Thailand (see Chapter 3, Section 3.3). In general, when people accept their caring roles, for them to express satisfaction at fulfilling their obligation is not surprising, because it is fulfilling the culturally expected behaviour (Caffrey, 19992b). In contrast, people may be reluctant to express or discuss stress or burden in caring, even if they receive little or no support from outside, in order to avoid social condemnation. This has led to little being known about stress in caring. This study was designed to explore the stress experienced by carers who provide care for their elderly demented relatives in Thailand.

It is quite clear that, in this society, questions about stress in care providing for their own relatives are likely to be a sensitive issue. Thus, cultural factors need to be taken into account in seeking an appropriate stress measurement scale. Nevertheless, the only report that was found on stress in carers in Thailand was a small scale study (n=29) with a self-report on stress in carers who provided care for demented elderly relatives at home. It was found that 86% of carers agreed that they felt a burden in caring (Sommanawan, 1994). However, this self-report gives rise to a question of validity (Cox, 1995) and cultural domain, as people may answer in a way which is socially acceptable. In addition, little is known about what kind of difficulties carers faced and what level of stress they experience from caring. As discussed earlier in the Chapter 2 (Section 2.8), measuring stress by using a standardised scale was also found difficult, due to the confusion from the lack of consensus in conceptualisations of stress and related terms and to the development of measures of stress reflecting varies perspectives, resulting in inconsistent findings and making cross-study comparison difficult.

However, this is an exploratory study, which only aimed to begin to investigate the prevalence of stress in carers in Thailand and hopefully to be able to demonstrate ways of identifying who was at risk of high stress related to their well-being. The stress measure scale should be simple, brief, easy to apply for assessing stress, and the questions should not be too aggressive in finding out about stress without recognising the cultural context of the respondents. A review of stress measure scales is given in Chapter 2 (Section 2.8.3). The most simple and commonly used stress measure scales are the CSI, developed by Robinson (1983), and the Burden Interview, developed by Zarit et al. (1980). However, the Burden Interview was quite long (29 questions), and seems to be designed for assessing burden in spouse carers rather than carers in general (e.g. 'I wish that my spouse and I had a better relationship'). Some items also required carers to express their real feelings (e.g. 'I feel my spouse is dependent' or 'I feel that my spouse tries to manipulate me'), which may be difficult given the socially acceptability of caring in Thailand. In contrast, the CSI is brief (13 questions), straightforward, and seems to contain less intrusive questions than the Burden Interview. In addition, the CSI instrument had been validated and published in reputable journals and used in reputable studies, such as, Robinson (1983); Baldwin et al. (1989); Schumacher, et al. (1993); and O'Brien (1993), and was consistently included in the current studies, such as Marchi-Jones et al. (1996); Miaskowski et al. (1997); and Wilkinson et al. (1997). Given its wide use, it would be useful to be able to compare research findings derived from the same stress concept or theory-base and method with findings in the present study. Therefore, the CSI was included as part of the interviews I undertook with carers in the present study.

The CSI, a brief screening instrument for detecting strain, was produced by Robinson (1983). It consists of thirteen questions, the first ten of which were derived from the results of their earlier study (Robinson and Thurnher, 1979), in which ten stressors were identified: inconvenience, confinement, family adjustments, changes in personal plans, competing demands on time, emotional adjustments, upsetting behaviour, the parent seeming to be a different person, work adjustments, and a feeling of being completely overwhelmed. Another three questions came from the relevant literature which suggested that further potential stressors were: disturbed sleep, physical strain, and financial strain (see Appendix II). 'No' responses were assigned the score 0 and 'Yes' responses were scored 1, giving a scoring range for the CSI as a whole from 0-13. Cronbach's alpha was calculated to assess the internal consistency among items. The reliability coefficient alpha for the 13 items was 0.86. Validation of the CSI was carried out by Robinson (1983), who found that: CSI scores were related significantly to carers' perceptions that they were involved in helping; correlated negatively with carers' satisfaction with the understanding of their own problems; and also correlated positively with the anxiety, depression and hostility factors on the Profile of Mood States (POMS) (Robinson, 1983).

According to Robinson (1983), positive responses to seven or more items on the index would indicate a greater level of stress. This statement has given rise to a question about using the CSI as an outcome (stress) measure, as strain in this sense was defined as 'those enduring problems that have the potential for arousing threat, a meaning that establishes strain and stressor as interchangeable concepts' (Pearlin and Schooler, 1978; p. 3). Stressors or strain are antecedent events and precede appraisal and outcome. Thus, in this study, the CSI was treated as primarily measuring stressors or measuring strain. The relationship between the subject's cognitive abilities and their dependence level and carer strain was examined. Information about mediators and indicators of intervention from carers and their cared for needs was obtained from network assessment and other open-ended questions from qualitative data. Measuring the overall outcome was beyond the scope of the present study. The framework of measuring carers' stress is shown in Figure 4.3.

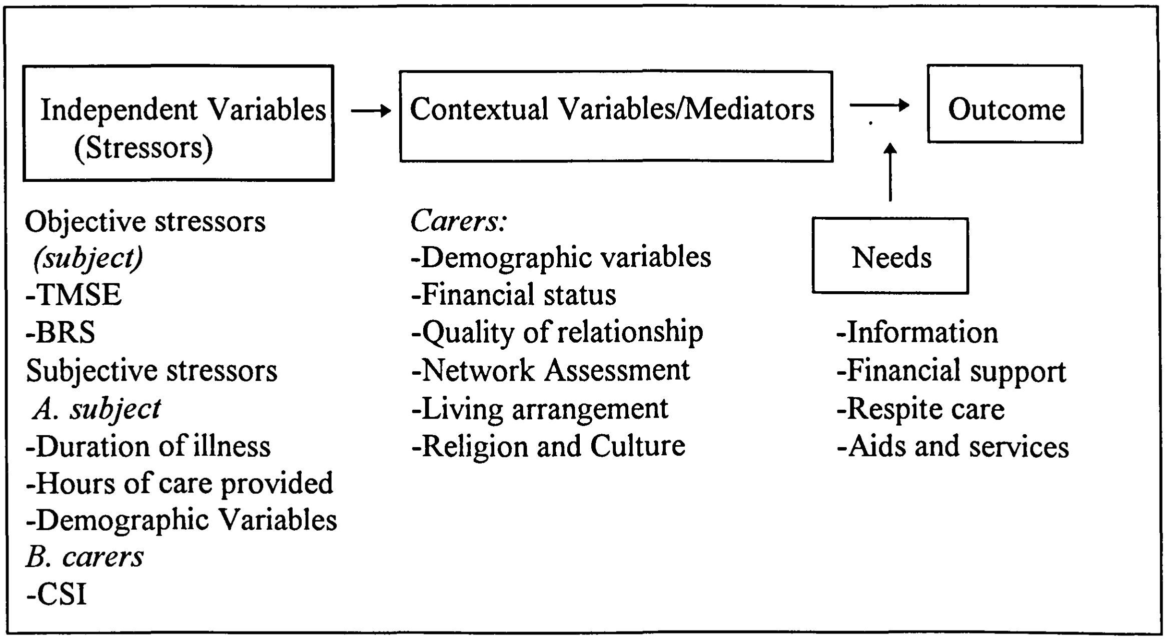


Figure 4.3. Stress process in Carers

4.5.5. Audiotape Recording

It is believed that the written recording of responses disrupts the flow of conversation, threatens the interview atmosphere and reduces the amount of eye contact that can be established between interviewer and the interviewee. In contrast, tape-recording can capture the total interview process, and the interviewer is free to observe the respondent (Nieswiadomy, 1993). In other words, this method of recording helps to ensure both the accuracy of the record of the verbal response and the affect with which it was given (Williamson, 1981). Nieswiadomy (1993) has further stated that if mechanical recording is permitted, subjects may respond differently than if answers are being written down by the interviewer and that the recorder may become familiar to the subject who then responds as if it was not present.

In this study, the audiotape recorder and a number of cassette tapes were prepared in order to record the open-ended questions with the consent of the individual respondents (see Appendix I). However, the length of time needed to analyse tape recorded data needs to be considered, since the entire tape has to be replayed and transcribed.

4.5.6. Interview Method

Semi-structured interviews were administered in this study, which involved using a check list of questions and issues, and encouraging the participant to respond (Pratt and Loizos, 1992). The interview process started in the selected hospital where the carers accompanying demented relatives to receive treatment from Geriatric clinics were approached to participate. A personal approached was made to each carer by the researcher. The carers were given verbal information about the study and were asked to read the introductory letter (see Appendix I) while the researcher was present. This provided an opportunity to clarify any questions they had. Loizos (1992) suggests that the researcher should give respondents certain basic information about a study before asking for their participation. The most important thing to do was to try to make it clear that the research might not lead to any action and thus avoid raising local expectations (Pratt and Loizos, 1992).

The introductory letter identified myself as the researcher and detailed my qualifications to conduct the research study. It also stated the purpose of the study, and described the potential benefits. Included were a number of questions aimed at selection of participants; those included seeking participants who were Buddhist and caring for an elderly relative with dementia at home. Finally it asked if the elderly relative was aged 60 or older and was educated to at least primary school level. If these inclusion criteria were met and the carers agreed to participate in this study, the letter explained that they would be interviewed at their own home and the interview tape-recorded. If relatives agreed, then, they were asked to sign a consent form (see Appendix I). All the interviews were carried out in the participants' own homes, both to see the real caring situation and to give respondents more time and freedom to talk in privacy, which they would not have had in the hospital.

4.5.7. Formal contact with the directors of selected hospital

After the preliminary survey which resulted in good co-operation from physicians who worked with dementia patients, formal contact was made by letter with the directors of the selected hospitals, in order to obtain their permission for research to be undertaken in that hospital. Also, a formal reminder letter was sent to individual physicians with whom I had formerly made personal contact. Only one hospital, Chulalongkorn Hospital, replied with permission to carry out research in that hospital before I returned to Thailand. At the other three hospitals, I had to find out if permission was granted after my return to Thailand. In the event, permission was granted by 3 out of the 4 hospitals. This issue will be discussed in more details later in this chapter.

4.5.8. Ethical Issues

Ethical issues are a prime concern in all forms of research involving human beings and animals. Protecting human rights requires the researcher to be sensitive and actively responsive to the rights of others (Williamson, 1981). The principal means for ensuring the rights of participants is through informed consent where their decision to participate is made with adequate knowledge of potential and real risks or benefits. The present research proposal was sent to the University of Hull Ethics Committee for ethical approval. Whenever possible, informed consent to participate in the study was obtained from subjects, although in many cases this was not possible because of the degree of their dementia. Therefore, approval and permission were sought not only from the individual carers but also from the individual demented person's physicians to protect the right of the person with dementia. A form consenting to participation was obtained from the participants (carers) before this research was carried out (see Section 4.3.5). Furthermore, the data were confidential and anonymity was guaranteed to participants, which is of the most importance to participants. The researcher was the only person who had access to lists which identified respondents.

4.6. Research Fieldwork

Research fieldwork challenges the ability of researchers to work in real-life situations where many variables can not be controlled. This is especially the case in social science research. Although a preliminary survey had been undertaken in order to develop a plan for the fieldwork, several unexpected problems and difficulties arose. To overcome these difficulties, some major changes had been made in the target group, sample size, and interview questions; and some other minor changes. These are discussed below.

4.6.1. Institutional permission

The research fieldwork was undertaken over a six month period between October 1995 until March 1996. It was necessary to follow up the request for permission I had originally made to the hospital directors who had not replied. My first contact was with physicians from whom I had received good co-operation, in order to gain access to patients through their geriatric clinics. Three hospitals were able to confirm that permission had been granted through these physicians. There was only one hospital where the physician did not know about the permission and, unfortunately, this permission was ultimately not forthcoming.

4.6.2. Recruitment of participants

Participants for the study were recruited through two processes. Firstly, I was introduced to carers by a physician while they accompanied their elderly relative to the hospital; secondly, I contacted carers using the limited information provided by physicians.

My preference was the first option, since Thai people have confidence in hospitals as organisations which people can trust and therefore trust people working within them. If I had undertaken the research on the street, stopping people and asking them to complete a quick questionnaire, there is no doubt that I would have met with a higher refusal rate than in a hospital where the physicians who introduced me commanded great respect as 'Someone who saves people's lives.' Since I was aware of the influence of the medical profession with patients and carers invited to participate in my research, I explained to all of my participants about their right not to participate in my study if they did not wish to do so. It was also important to meet participants before interviewing them at home, because such a home visit would be unusual for Thai people and I felt it was important to develop a relationship before seeing them at home. In this way I would not be a stranger by the time I made a home visit. In Bangkok, like many capital cities in the world, people often feel insecure about their personal safety and property, which leads to the common brief that 'one should never open the door for a stranger.' I therefore visited the Out Patient Departments (OPD) whenever physicians were seeing patients in a clinic. This posed something of a problem since there were four hospitals in two different regions. At this stage, time management therefore needed to be considered carefully and this is discussed in full detail later in this chapter.

Direct contact with participants at home, the second option, had the disadvantage that there was no opportunity to develop a relationship before making a home visit. The first contact was often made by telephone to arrange a date and visiting time, if those approached agreed to participate. Some of the physicians who co-operated in my research had started keeping a note of their dementia patients' names and hospital numbers since my first visit for the preliminary survey. Moreover, most physicians in Bangkok were able to present the names of only four or five demented patients. However, I later found this information very useful as achieving an adequate sample become more of a problem.

4.6.3. Pilot Study

Interview schedules were developed in both English and Thai. An elderly British couple and an English speaking Dutch lady were asked to look through the English version of the interview schedule, while a Thai student, who had a first degree in English language and was studying for a masters degree at the same university, was asked to validate the translation from English to Thai. Interview questions occasionally needed to be changed several times and the purpose of a pilot study is to pave the way for the administration of an interview schedule that will obtain the desired data (Nieswiadomy, 1993). A pilot study, of course, should be conducted with a group of people and conditions should be similar to those that will be used in the actual research study.

The first pilot study was undertaken in England by interviewing a carer who was caring for her father who had suffered from dementia and chronic kidney failure for ten years.

Whilst her situation was not similar to that of my target group, she gave me an opportunity to experience an actual interview situation, develop interviewing skill, and practise and manage the tape recorder during the interview process. After I arrived to undertake fieldwork in Thailand, a pilot study was undertaken, in both Bangkok and Chiang Mai. The pilot study provided crucial information about the frequency and order of questions. I found that the carers seemed to prefer to begin with questions about the health of the person they cared for, rather than demographic questions. I also found they were uncomfortable if I started by asking about their own situation. However, when I started by asking questions about their caring problems, they tended to talk about these more readily and then the interview became smooth and flowed well. At the same time, I obtained responses about their elderly relative using the 'Behaviour Rating Scale,' and the 'Caregiver Strain Questions.' After that the remaining interview questions in part A, which were questions for carers, were rearranged in the sequence, beginning with 'Caring for questions', from the 3rd section, until the end of part A and then, finally, I came back to ask the demographic questions (see Appendix II).

4.6.4. Time management

Because participants were drawn from four hospitals from two geographical areas (the hospital in northern region was over 500 miles away from the three hospitals in Bangkok), I needed to plan my time very carefully. According to my plan, I would spend a few months getting to know participants at OPD, then I would spend the rest of the month interviewing participants in their own home. October (the start of the fieldwork) is the last month of the monsoon season before the onset of winter in

Thailand. There was flooding in some parts of Bangkok, including around one selected hospital situated by the river. It was therefore very difficult to travel around and few chronic patients came to see medical staff. I therefore decided to spend my first half month in the north, where I could go to the hospital, five days a week, to seek participants. I soon realised that few dementia patients came to see a doctor in any one day, since dementia is a chronic syndrome for which there is no need for frequent visits. Most patients were given a monthly appointment for their next visit. I was therefore concerned about how long I might have to wait to recruit a sufficient number of participants at each hospital.

After my first month in the hospital in the northern region of Thailand, I then spent alternate months at each of the two field sites, contacting participants. It was even harder to find participants in the Bangkok hospitals than in the northern region: some patients had lost contact or had moved to see a doctor in another hospital, since there were a number of hospitals, such as government, private hospitals and private clinics, available for treatment. In addition, some patients had died before I was able to interview them at home; and some were only temporary residents in Bangkok for a short duration of treatment and it was therefore very difficult to follow them to their own home. I also had a problem covering all three hospitals in the same week because some medical staff were working at the same time on the same day. Even when medical staff were working different times in the same day, I still found it very difficult to travel from one hospital to another, because of the traffic problems in Bangkok. Moreover, I found from my first session of fieldwork recruiting participants that I was totally reliant on these physicians' assistance for introduction. At the clinics, I spent most of the time waiting for their dementia patients. As they examined patients at OPD only in the morning, once or twice a week, I had nothing to do for the rest of the day.

4.6.5. Reduced number of selected hospitals in Bangkok

In one Bangkok hospital I found that my research application had not gained full approval. Although I had sent a formal application letter, together with a research proposal document to this institution nearly two months before I started my research fieldwork, I had been told that it would take at least three months to get a result from their Hospital Medical Ethics Committee. I tried to contact the person in charge of the approval process several times, but was unable to do so. This meant I lost 10 participants whom I expected to be able to recruit for my research. I therefore increased the number of participants from the remaining selected hospitals from 10 to 15 and recruited more participants, not only from geriatric OPDs, but also from psychiatric and neurological OPDs (Table 4.5). Table 4.6 shows that over half of subjects (56.8%, n=25) were recruited from neurological clinics.

Table 4.5. Number of expected and actual participants in selected hospitals

	Number of subjects expected	Number of subjects recruited
Bangkok		
Pramongkutklao Hospital		
Geriatric clinic	5	8
Psychiatric clinic	5	2
Neurological clinic	5	5
Total	15	15
Chulalongkorn Hospital		
Geriatric clinic	5	2
Psychiatric clinic	5	7
Neurological clinic	5	0
Total	15	9
Northern Region		
Chiang Mai Neurological Hospital		
Neurological clinic	20	20
Total	20	20
Total of participants	**50**	**44**

Table 4.6. Distribution of subjects in three different hospitals.

	Out patient Department			
	Neurological Clinic	Psychiatric Clinic	Geriatric Clinic	Total (%)
Northern Region				
Chiang Mai Neurological Hospital	20	0	0	20 (45.5)
Bangkok				
Pramongkutklao Hospital	5	2	8	15 (34.1)
Chulalongkorn Hospital	0	7	2	9 (20.5)
Total (%)	25 (56.8)	9 (20.5)	10 (22.7)	44 (100)

4.6.6. Interview schedule adaptation

Although in practice the sequence of the questions on the interview schedule shown in Appendix II did not work well during the pilot study, in theory, they were in a logical order for completion for the purpose of data collection. The sequence of the interview schedule, therefore, remained the same on the paper, although, in practice, I did not follow this order.

Additionally, the content of questions had to be changed as the sampling took place. The most influential factor which led to a major change in the interview questions was the change of population of interest. Initially, my population of interest was a group of adult children who cared for their elderly demented relative at home, in order to examine the practice of the ideology of 'parent repayment' in Buddhist followers. After spending some time in the OPD, I found that nearly half of carers were spouses. Their adult children were no longer able to provide care for them, as might have occurred in the past, because they had to work outside the house or because they had moved out to stay near the place of work. Moreover, I found that some carers were other relatives, or in-laws.

My sample size would have been very small, and little information gained, if I had only focused on adult child carers, so I decided to recruit participants from any group of carers. Therefore, the interview questions which were designed for this specific group needed to be changed for application to all groups of carers. For example, in the section 'Caring for' (see Appendix II), the question:

> "How did you and your brother/sister decide who should take care of your elderly relative?"

was changed to:

> "How did you and your....(family members)...... decide who should take care of your.............(could be any subject, such as husband, wife, father, mother, uncle, aunt and so on)........

4.6.7. Reduction in sample size

According to the initial selection criteria, participants in this study were to be individual cases who had had dementia diagnosed at the selected hospitals; aged 60 and over; co-resident with their carers; educated to at least elementary education; to believe in Buddhism; and to agree to participate in this study. However, the available number of individual demented persons lived over very broad area. For example, in Chiang Mai, the only neurological hospital in the northern region serves patients from 17 provinces, covering 169,644.3 Sq.Kms. In the case of the selected hospitals in Bangkok, some demented persons were resident only temporarily with their relatives in Bangkok and travelled back home to other regions, such as the eastern or southern region, after treatment. With concern for the limitations of time, safety, and the cost of travel, therefore, another criterion for selecting participants had to be added, namely, to choose only subjects resident in selected geographical areas. In the northern region, the participants were limited to the provinces adjacent to Chiang Mai province where the neurological hospital was situated, such as Chiang Rai, Lumphun and Phayao. In Bangkok, the participants were limited to residents of Bangkok and the metropolis. Even so, the progress of the research was impeded by the heavy traffic and the inadequate public transport, as well as safety concerns in travelling to isolated households in Bangkok.

After several months trying to recruit participants from OPD, very few subjects eligible to participate in the study had been found. I therefore decided to adopt an alternative approach, which was to consider the patient lists from the selected hospitals' physicians and obtain the necessary information for access, such as their current address and telephone number, from their OPD card. In Bangkok, it was impossible to visit patients without making an appointment by telephone, due to their safety concerns, living in the capital city. It was found that a number of prospective subjects had no current telephone number and a few of them had already passed away. Thus, the possibility to obtain more participants by this means was relatively low. In the northern region, where most of the target group had no telephone at home, I had no choice but to knock on their doors and ask for their co-operation. I had difficulties in travelling to the remote areas and finding their houses. I frequently got lost or could not find the participants' homes, due to lack of clear road signs. Policemen, postmen and village headmen proved helpful in providing directions. After I managed to find people's homes, I found everybody was very hospitable, co-operative and keen to participate in my study. Relatives were, in fact, very surprised by my visiting; none had any experience of being visited by somebody undertaking research or by a health professional before. They were very happy to see somebody with whom they could discuss their caring problems. At this stage, I had to make it clear that I was visiting in a researcher's capacity. However, as a health professional who is concerned to help people to gain knowledge about health and well-being and to play a give and take role with the participants, I included health education and provided information related to their caring problems at the end of the interview. This is consistent with the experience of Oakley (1979), who reported that the interview was not simply a conversation, researchers were part of human interaction, and those who were interviewed also appealed directly for advice. By the end of the research fieldwork, Oakley (1979, p. 312) found that people who were interviewed significantly mentioned 'interviewers' own contributions to the interview both as interviewers, and as people engaged in conversation with other people.'

There was no difficulty in obtaining 20 participants in the northern region. However, in Bangkok, where it was expected to obtain 30 participants from two hospitals, the situation was more difficult. I included all dementia patients and their carers from the geriatric clinic and recruited more participants from the psychiatric and neurological clinics, including some subjects who developed dementia before the age of 60. Even so, one hospital still did not provide as many participants as I expected (15 participants per hospital). There were only 9 participants from Chulalongkorn Hospital able to participate, 2 participants from the geriatric clinic, and the remainder from the psychiatric clinic. In view of all those circumstances, therefore, the sample size had to be reduced from 50 to 44 (see Table 4.2 and Chapter 5 for more details).

4.7. Data analysis

Data analyses in this study were carried out separately for quantitative and qualitative data. Then, the methodological triangulation was carried out by using data which were collected from both quantitative and qualitative methods, in the attempt to provide a complete picture of family care in Thailand.

4.7.1. Quantitative data analysis

In general, statistical analysis of quantitative data is carried out in two forms: descriptive and inferential statistics. As Foster (1993) and Donnan (1991a, 1991b) explain, descriptive statistics are used to describe and summarise sets of data, such as the distribution of the data or central tendency (mean, median, and mode). Data can be described in the form of tables, pie charts, bar charts/histograms, scatter diagrams and line graphics. Thus, in the present study, the demographic data (e.g. age, sex, marital status, living arrangement) of both carers and cared for person are presented by using descriptive statistics.

Inferential statistics are used in generalising the result from a sample to the larger population of interest. Inferential statistics are concerned with two main types of statistical tests: parametric and non-parametric tests (Greene and D'Oliveira, 1982; Donnan, 1991b) and it is necessary to choose an appropriate statistical test for each measurement scale. Parametric tests are often based on the assumption of normal distribution of data for the population of interest and the data subjected to such tests should use an interval scale (where the number represents the magnitude of the differences) or a ratio scale (where there is an absolute Zero and successive equal intervals), while non-parametric methods are based on an ordinal scale (the ranking of data) rather than the actual data.

In the present study, the sample was small and was not randomly selected, but all the available sample who conformed to the research criteria participated in the study. A convenience sample was used. Data from the Thai Mental State Exam (TMSE), the Behaviour Rating Scale (BRS) for subjects, and the Network Assessment and Caregiver Strain Index (CSI) for carers, formed an ordinal scale. Therefore, appropriate statistical data analysis techniques, such as *cross-tabulation,* were carried out. Non-parametric tests were also applied, for example, *Chi-square, Mann-Whitney, Kruskal Wallis, and Spearman Rank Correlation.* These non-parametric tests were carried out by using the SPSS for Windows version 6.0 computer program.

4.7.2. Qualitative data analysis

In qualitative data analysis, several simultaneous activities are carried out, differently from the quantitative data analysis: collecting information from the field, sorting the information into categories, formatting the information into a story, and actually writing the qualitative text (Creswell, 1994).

Initially, all tape-recorded interviews were transcribed in full, in Thai. Because the majority of questions were open-ended, it was left to the researcher to identify the answers which were relevant to each question. At this stage, a preliminary content analysis was carried out to identify relevant answers and exclude the information which was not helpful in establishing a new key theme and was not linked to other important issues. However, the remaining information was still keep intact for later use as needed. After that, all identified relevant answers were translated into English. Colour coding was found useful for secondary content analysis, in which those participants who answered in the same direction were categorised into groups by using the same colour pen. Then, the key themes of the answers to each question were identified, for example:

Question: What information do you need in caring for your..(elderly relative/spouse)...?

Answers: I'd like to know about his illness, whether it's a curable disease (son).
(need information about dementia)

I'd like to know how to stop him having obsessive toileting and he always says that he hasn't eaten when he has already had (son).
(need information about how to provide care)

I really need to have knowledge about his disease and how to treat it (wife).
(need information about dementia and treatment)

After the key themes were identified: the need for information about dementia, treatment, and how to provide care at home, the answers under the same key theme were counted and the theme mentioned most frequently was taken to reflect the information most needed by carers. Simple counting of qualitative data is suggested by Miles and Huberman (1996).

In translation, the participants' own words, which were minimally edited, were carefully translated from Thai to English. To minimise the error from translation, cross-checking was sought from two Thai lecturers in the Southeast Asian Studies Department, Hull University. A complete English transcription was randomly selected and a Thai-speaking lecturer who had been living in England for fifteen years was asked to translate it back into Thai. This aimed to validate the translation and identify whether it carried the same meaning as the original. In case of any doubt in transcribing, a consultation was held with an English-speaking lecturer who is fluent in the Thai language. The findings are also presented by using quotations and description in Chapter 7. These quotations are used to "validate research findings and to vitalise the research report, thereby contributing to both the scientific and artistic value of presentation" (Sandelowski, 1994, p. 482).

Although a number of software packages designed to aid the analysis of qualitative datasets are available, such as, askSam, InfoSelect, The Ethnograph, NUDIST, Ethno, Word for Windows (Stanley and Temple, 1993), TAP, TEXTBASE ALPHA, QUALPRO, and HyperQual (Tesch, 1990), they are quite expensive. In addition, to run a software package, the researcher needs to learn how to use it. This also involves detailed and time consuming work in creating and applying the indexing categories (Mason, 1996). Given the size of the sample and time restrictions, the qualitative data were analysed manually instead.

4.7.3. Triangulation

In the present study, two explicit questions needed to be answered: what is it like for carers to look after their demented relative at home? (a qualitative question); and what level of strain do carers experience and what influencing factors are associated with level of strain? (quantitative questions). It has been suggested that methodological triangulation or simultaneous triangulation occurs when the researcher answers qualitative and quantitative research questions at the same time, in the same study (Morse, 1991). Triangulation was defined by Cohen and Manion (1989, p. 269) as 'the use of two or more methods of data collection in the study of same aspect of human behaviour.' The advantage of using triangulation is to eliminate the personal bias that stems from single methodologies (Denzin, 1989). Moreover, it helps to explain more fully, the richness and complexity of human behaviour, and greater confidence will be achieved when the different methods of data collection yield substantially the same results (Cohen and Manion, 1989). Thus, in the present study, triangulation was carried out with the aim of gaining a complete understanding the whole picture of family care in Thailand. For example, after carers were identified as having a greater level of strain, the reasons why some carers experienced greater strain than others were examined by means of correlation with other quantitative data, such as the level of cognitive impairment and level of dependence in the cared-for person. In addition, an attempt was made to find links with the key themes of the qualitative findings, such as, the carer's religious belief and culture, the carer's attitude towards caring, the quality of relationship between the carer and cared for person, the financial situation, or the availability of social support.

Conclusion

A combined quantitative and qualitative design was chosen for the present research in order to understand better the concept being explored, to increase the ability to rule out rival explanations for phenomena, and to be able to use one method to inform another by cross-checking the findings from both research paradigms.

The research method was carried out in three phases: a preliminary survey; preparation for fieldwork; and research fieldwork. Although the first two phases were carried out in order to reduce problems in the fieldwork, there were still many unexpected problems and uncontrollable variables. Limitations encountered included the hierarchy in health care; difficulties in obtaining access to some institutions; safety concerns in the fieldwork, transportation problems; floods, and confusion as to the researcher's role, in that most participants saw me as a health visitor.

Semi-structured interview schedules were designed, containing a mixture of open-ended and closed questions. The interview schedule contained questions about demographic details; the needs of carers; personal health; traditional medicine; and the carers' attitude to their older relative. The Thai Mental State Exam (TMSE) and Behaviour Rating Scale (BRS) were completed by subjects to assess their present mental state; while the Network Assessment and Caregiver Strain Index were completed by carers. Interviews were carried out at participants' homes. The audiotape recorder was used to record the open-ended questions with the consent of the individual respondents. For the quantitative data, non-parametric tests were carried out, using the SPSS for Windows computer program, while for qualitative data, content analysis was carried out manually, using a colour-coding system. The research results will be presented in Chapters 5, 6 and 7.

CHAPTER 5

Research Findings (Part I)

Information on the Sample of Demented Persons

Introduction

Since both quantitative and qualitative data were collected, the research findings are presented both in terms of descriptive statistics and other descriptive information. The quantitative data, presented in Chapters 5 and 6, include demographic information about subjects' and their carers' age, sex, marital status, educational level, occupation, income and living status. In addition, a statistical analysis is presented of the research results from using specific assessment instruments, including the Thai Mental State Examination (TMSE) and the Behaviour Rating Scale (BRS) from the Clifton Assessment Procedures for the Elderly (CAPE) for subjects; and Network Assessment and Caregiver Strain Index for carers. The qualitative data presented concern the problems of caring experienced by carers as well as their financial situation and their relationship to subjects. These data, including the attitude of carers towards the subject; the effect of religion and culture on caring; personal health; carers' needs, including the need for information, financial support, respite, aids and services; and traditional medicine, are presented in Chapter 7. Further analysis of the relationship between persons with dementia and their carers and discussion of the main findings are presented in Chapter 8.

In this section the demographic characteristics of the subjects (people with dementia) are described in terms of gender, age, education, marital status, and current residential arrangements. Information is provided on the degree of dementia which was assessed using two standardised rating scales: the Thai Mental State Exam (TMSE; Train The Brain Forum Committee, 1993), which was developed from the Mini-Mental State Examination (MMSE) of Folstein et al. (1975) and the Behaviour Rating Scale (BRS; Pattie and Gilleard, 1979), one of the independent measures of the Clifton Assessment Procedures for the Elderly (CAPE).

5.1. Characteristics of Subjects

Subjects in this study were 44 people who had received a hospital diagnosis of dementia and were receiving treatment at Geriatric, Psychiatric and Neurological clinics from three hospitals: a Neurological hospital in the Northern Region and two General Hospitals in Bangkok between October 1995 and March 1996.

5.1.1. Age and Gender

There were 27 (61.4%) male and 17 (38.6%) female subjects with an age range of 51 to 93 years, mean 74, (SD=9.8) and median 75 years (Table 5.1). Amongst the more elderly group (above 70), the proportion of subjects who were male was higher. Relatively few subjects were aged 90 or more and there were 9 patients (20.5%) with pre-senile dementia (aged under 65).

Table 5.1. Age group by Sex

Age groups	Sex		Total (%)
	Male (%)	Female (%)	
below 60	1	2	3 (6.8)
60-69	6	4	10 (22.7)
70-79	13	5	18 (40.9)
80-89	6	5	11 (25.0)
90 and greater	1	1	2 (4.5)
Total (%)	27 (61.4)	17 (38.6)	44 (100)

5.1.2. Education

The Thai education system has changed considerably over the last 30 years and it was difficult to be exact about the number of years formal education that subjects had received. However, just over half (53%; n=23) of the subjects had 4 years or less of formal education (primary school level) only (see Figure 5.1). The remainder had had some kind of secondary education: 11% (n=5) in secondary school (around 9 years); 7% (n=3) in high school (around 12 years) and 31% (n=13) had had some form of higher education (college or university). The sample was not therefore representative of the Thai population as a whole, since subjects without formal education were excluded from this study. This exclusion was necessary since all participants undertook a test of cognitive mental state, the TMSE. For this test, participants needed to have a minimal level of literacy and numeracy. Without this level of education the test, in particular the calculation part, could have produced a false positive result. The test has been shown to yield false positive ratio of 39% for dementia and delirium where all of the false positives had less than 9 years of education (Anthony et al., 1982).

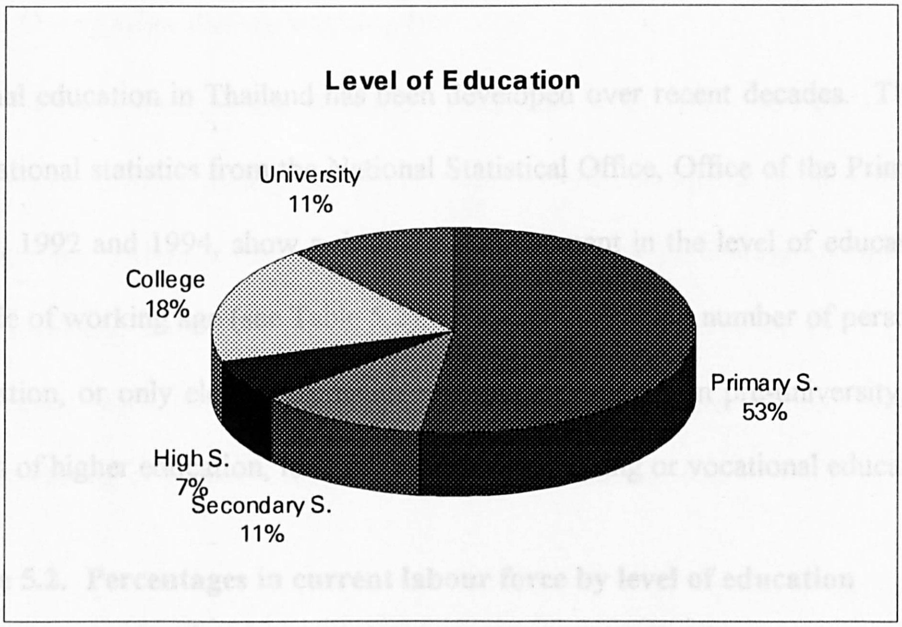


Figure 5.1. Educational level of Subjects.

Perhaps not surprisingly, there was a noticeable relationship between level of education and where participants lived; those living in the rural area had generally received fewer years of formal education than in urban areas (Figure 5.2).

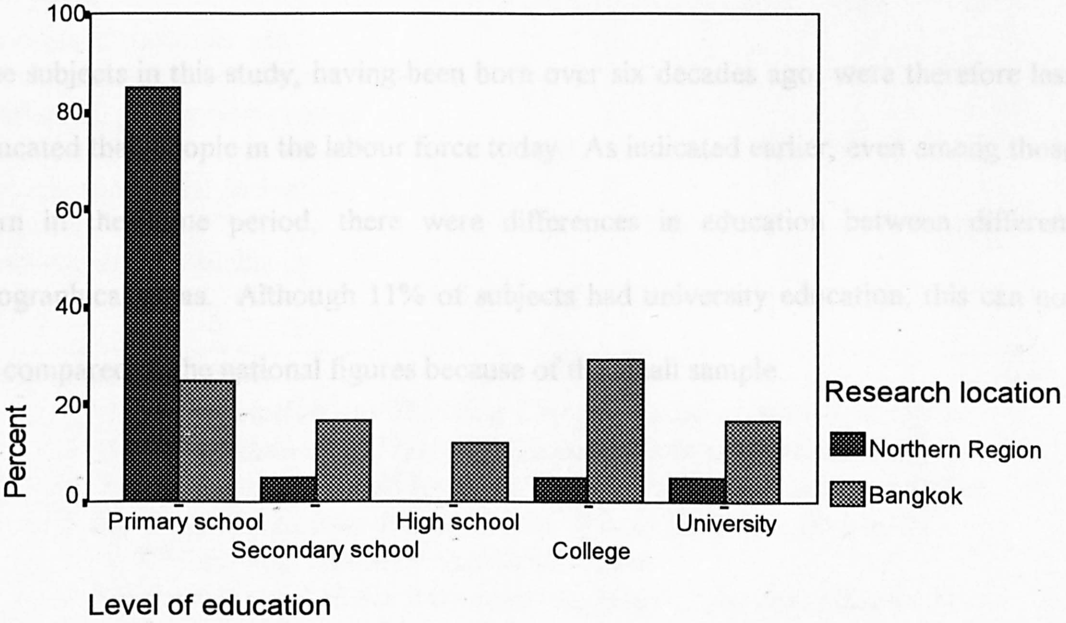


Figure 5.2. The Educational Level of Subjects by Location.

Formal education in Thailand has been developed over recent decades. The available educational statistics from the National Statistical Office, Office of the Prime Minister, 1988, 1992 and 1994, show a dramatic improvement in the level of education among people of working age (see Table 5.2). There is a declining number of persons with no education, or only elementary education, and an increase in pre-university, and other forms of higher education, for example, teacher training or vocational education.

Table 5.2. Percentages in current labour force by level of education

Level of Education	**Year**					
	1985*	**1986***	**1989****	**1990****	**1991*****	**1992*****
None	7.4	8.4	5.1	5.4	4.8	4.7
Primary/Elementary S.	80.0	75.8	79.1	78.2	78.0	77.3
Secondary-High S.	8.2	11.8	10.5	10.9	11.4	11.9
University	2.0	2.0	3.3	3.6	3.7	4.1
Others	2.1	1.8	1.9	1.9	2.0	2.0
Unknown	0.3	0.2	0.05	0.01	0.03	0.01

***Sources* * National Statistical Office, Office of the Prime Minister (1988)**
***** National Statistical Office, Office of the Prime Minister (1992)***
****** National Statistical Office, Office of the Prime Minister (1994)***

The subjects in this study, having been born over six decades ago, were therefore less educated than people in the labour force today. As indicated earlier, even among those born in the same period, there were differences in education between different geographical areas. Although 11% of subjects had university education, this can not be compared to the national figures because of the small sample.

5.1.3. Occupation during working life

The National Occupation Statistics (available from 1960 to 1993) show that agriculture, fishery, mining and other related work remain the main occupations for Thai people, although they now account for a smaller percentage of the work force than formerly, having declined from 82% in 1960 to 57% in 1993 (Table 5.3). Associated with increasing educational levels, more Thai people now work in manufacturing or skilled professional or technical occupations.

Table 5.3. Percentage of employed persons by occupation

Occupation	1970*	1980**	1990***	1992#	1994##	1996###
Professional, technical and related workers	1.4	3.0	4.2	3.8	4.6	4.7
Administrative, executive and managerial workers	1.5	1.9	1.8	2.0	2.1	3.5
Clerical workers	1.1	1.7	2.5	3.0	3.7	3.8
Sales workers	5.0	6.9	7.7	9.1	10.0	11.7
Farmers, fisherman, hunters, loggers and related workers, miners, quarrymen and related workers	80.0	72.3	67.4	60.8	56.1	50.2
Workers in transport and communication occupation	1.3	1.6	1.9	3.1	3.4	3.9
Craftsmen, production-process workers and labourers, etc.	10.8	9.6	11.2	14.3	16.1	18.9
Service, sports and recreation workers	2.7	2.9	2.9	3.8	4.1	4.4
Workers not classifiable by occupation	0.1	0.1	0.3	0.1	0.02	0.03

Sources: adapted from

**** 1970 Population and Housing Census, National Statistical Office***
***** 1980 Population and Housing Census, National Statistical Office***
****** 1990 Population and Housing Census, National Statistical Office***
 # Report of the Labour Force Survey, Whole Kingdom (Round 2) May 1992, National Statistical Office.
 # # Report of the Labour Force Survey, Whole Kingdom (Round 3) August 1994, National Statistical Office.
Report of the Labour Force Survey, Whole Kingdom (Round 3) August 1996, National Statistical Office.

In this study, the subjects' occupation during working life will be classified into four groups, based on the level of skill requirement: primary, secondary, tertiary, and quaternary. Primary occupations refer to farmers, fisherman, miners and related workers. Secondary occupations refer to craftsmen, production-process workers and labourers. Tertiary occupations include: sales workers; transport and communication; and service, sport and recreation. Finally, quaternary occupations are professional, technical and related occupations and administrative, executive and managerial.

The findings from the present study show that nearly half of the subject (43%; n=19) had been engaged in the primary occupations, as the majority of them were farmers and housewives. Over one-third of the subjects (36%; n=16) had worked in the quaternary occupations, such as medicine, engineering, the armed forces, law and education. The remainder had worked in the tertiary and secondary occupations (14%; n=6 and 7%; n= 3 respectively). There was a great difference in occupation related to location as the results from the present study revealed that the majority of those living in Bangkok and the metropolitan area (87.5%) had been engaged in tertiary and quaternary occupations, whereas the majority of those living in the rural Northern Region (79%) had been farmers during their working lives (see Figure 5.3)

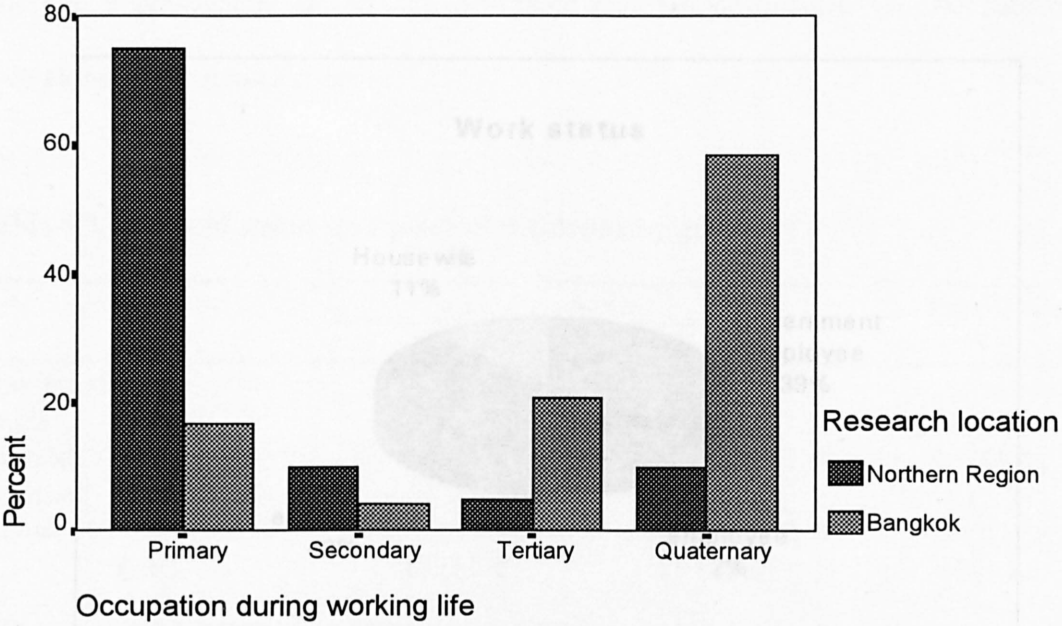


Figure 5.3. Occupation of subject by Location.

There is a clear relationship between level of education and job opportunities, in that less educated persons worked in unskilled occupations, whilst people with higher levels of education had better and more skilled occupations (see Table 5.4).

Table 5.4. Occupation during working life by level of education.

Occupations	Level of Education Primary S.	 Secondary and High S.	 College and University	Total (%)
Primary	17	1	1	19 (43.2)
Secondary	2	0	1	3 (6.8)
Tertiary	4	1	1	6 (13.6)
Quaternary	0	6	10	15 (34.1)
Total (%)	23 (52.3)	8 (18.2)	13 (29.6)	44 (100.0)

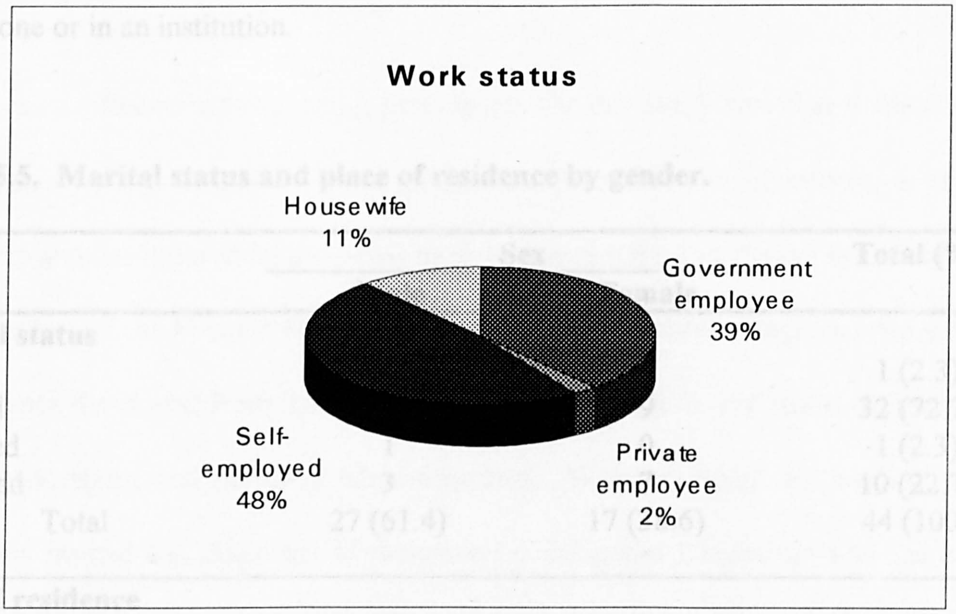


Figure 5.4. The working status of the Subjects

With regard to working status, almost half the subjects (n=21) had been self-employed, most of them engaged in primary occupations. The second largest category were government employees (n=17), while a small number were housewives (n=5) and one was a private employee (see Figure 5.4). Thus, slightly over a third of the sample, those in government service, had job security in terms of a guaranteed income, free medical care, pension and other benefits.

5.1.4. Marital Status and Place of Residence

All but one of the subjects had been married (Table 5.5). Half of them (50%, n=22) were living in an extended family with their spouse, children and/or grandchildren, 13.6% (n=6) subjects lived with their spouse only, while the divorced and all the widowed (25%) lived with their children and/or grandchildren (Table 5.6). There was only one single person, an old lady who lived with her close relatives. No subjects lived alone or in an institution.

Table 5.5. Marital status and place of residence by gender.

	Sex		Total (%)
	Male	Female	
Marital status			
Single	0	1	1 (2.3)
Married	23	9	32 (72.7)
Divorced	1	0	1 (2.3)
Widowed	3	7	10 (22.7)
Total	27 (61.4)	17 (38.6)	44 (100)
Type of residence			
With spouse	4	2	6 (13.6)
With children and/or grandchildren	5	10	15 (34.1)
With spouse, children, and grandchild	18	4	22 (50.0)
With other relative	0	1	1 (2.3)
Total	27 (61.4)	17 (38.6)	44 (100)

Table 5.6. Marital status by current living conditions

	Marital Status				Total
	Single	Married	Divorced	Widowed	(%)
Type of residence					
With spouse	0	6	0	0	6 (13.6)
With children and/or grandchildren	0	4	1	10	15 (34.1)
With spouse, children, and grandchild	0	22	0	0	22 (50.0)
With other relative	1	0	0	0	1 (2.3)
Total	1 (2.3)	32 (72.7)	1 (2.3)	10 (22.7)	44 (100)

5.2. Medical Diagnosis

The primary criterion when seeking participants for this study was that dementia had been diagnosed by a hospital-based physician. Dementia, is of course, a clinical syndrome and the differential diagnosis must be based upon the clinical syndrome only (see Chapter 1). As Folstein et al. (1975) comment, an accurate diagnosis depends on the evidence developed from the psychiatric history, the full mental status examination, the physical status and pertinent laboratory data. Without exception, hospital based physicians framed the diagnosis of dementia by using the Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R, American Psychiatric Association, 1987) together with, in some cases, a computerised tomography (CT) brain scan to support the diagnosis of dementia. There were neither brain biopsy nor unethical invasive techniques for routine diagnosis available in Thailand, which would involve an unnecessary risk to the patient in view of there being no available treatment for the disorder (Newens, 1994).

Confirmation of diagnosis of dementia is only by histopathological post-mortem examination (also see Chapter 1, Section 1.4.3.), which, as in the UK, is not routinely undertaken in Thailand. It is not within the remit of this thesis to discuss the problem associated with specific diagnosis or the accuracy of diagnosis. However, the likely causes of dementia among the subjects, and the duration of their illness, are discussed below.

5.2.1. Medical diagnosis classification

The medical diagnosis of dementia was based upon information extracted from subjects medical records (Figure 5.5). Alzheimer's Disease (AD) accounted only for 14% (n=6), with Vascular Disease, the largest number of classified cases (27%, n=12), and Parkinson's Disease (PD) accounting for 11% (n=5). Two patients (4.5%) were thought to have Mixed type of dementia, such as AD and PD or AD and Vascular Dementia. Remaining causes (13.5%) were thought to be due to: head injury (n=1); cancer metastasis (n=2); alcoholic dementia (n=1); and chemical substance toxication (n=2). However, almost a third of the sample (30%, n=13) of the subjects were left without a classification of the cause of their dementia.

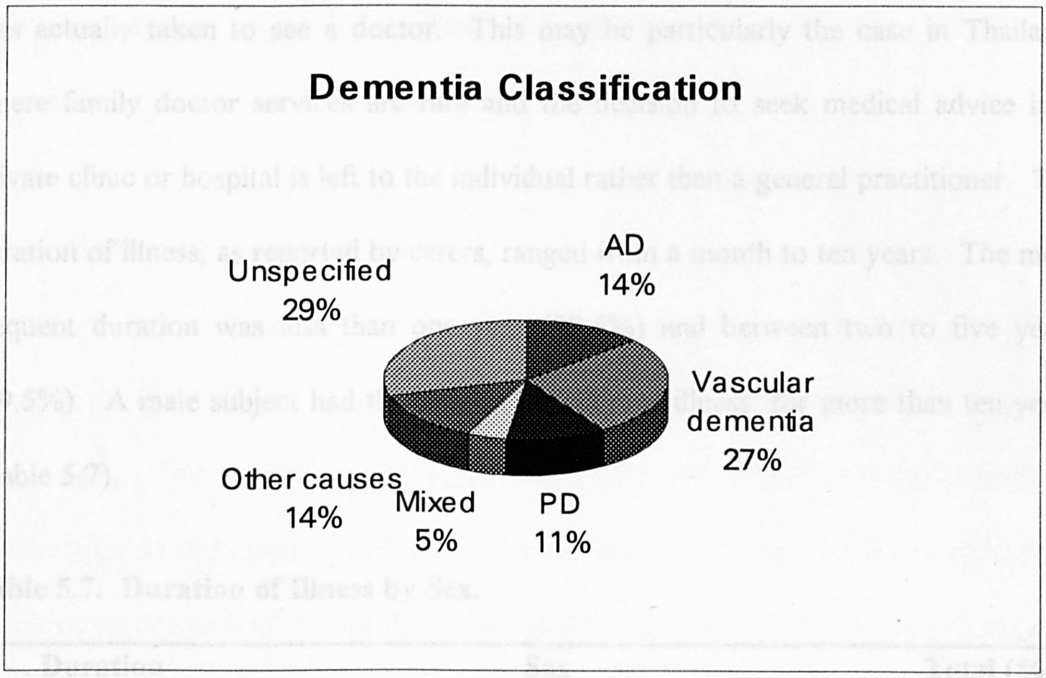


Figure 5.5. Dementia diagnosis classification by associated disease.

5.2.2. Duration of Illness

In many cases, the onset of the dementia syndrome is gradual and insidious. It is therefore difficult to determine with any accuracy the time and actual onset. Relatives were asked to recall the time that they first noticed the earliest signs associated with the dementia syndrome, such as memory loss, behavioural change or inability to perform activities of daily living.

The length of time that patients had been ill, therefore, was counted from when their carers first noticed their cognitive deterioration or change in behaviour, rather than from the day that they had been diagnosed by a medical professional. As discussed above, the dementia symptoms might be present for some period before the patient was actually taken to see a doctor. This may be particularly the case in Thailand, where family doctor services are rare and the decision to seek medical advice in a private clinic or hospital is left to the individual rather than a general practitioner. The duration of illness, as reported by carers, ranged from a month to ten years. The most frequent duration was less than one year (29.5%) and between two to five years (29.5%). A male subject had the longest duration of illness: for more than ten years (Table 5.7).

Table 5.7. Duration of Illness by Sex.

Duration	Sex		Total (%)
	Male	Female	
< 1 year	7	6	13 (29.5)
1 - < 2 years	8	2	10 (22.7)
2 - < 5 years	9	4	13 (29.5)
5 - < 10 years	2	5	7 (15.9)
> 10 years	1	0	1 (2.3)
Total	27 (61.4)	17 (38.6)	44 (100)

5.3. Thai Mental State Examination (TMSE)

The Thai Mental State Examination (TMSE), a standardised neuro-psychological test, developed from the Mini-Mental State Examination (Folstein et al., 1975) by the Train the Brain Forum Committee, Thailand, was used in order to provide an appropriate screening test for elderly people who had different socio-economic status, level of education and cultural backgrounds from Western society. The scale contains six sub-tests: orientation, registration, attention, calculation, language and recall (see Appendix II, Part B). These sub-tests are scored between 3 and 9, and the maximum total score is 30. The lower the score, the greater the degree of cognitive impairment. A score of zero is given when an individual refuses or is unable to attempt an item. The cut-off score for the TMSE is 23 (Train the Brain Forum, 1993).

5.3.1. TMSE and Medical diagnosis

Scores on the TMSE ranged from 0 to 28, with a mean of 14.8 (SD= 8.14). 38 of the 44 subjects (86.4%) had a score of 23 or less, the accepted cut off for cognitive impairment. Only 5 subjects (11.4%), who were suffering from other causes of dementia (n=1) and unspecified dementia (n=4), had sum scores 24 and over, and were classified as not suffering from dementia according to the TMSE criteria. There was one subject in the present study who could not be tested because of aphasia from a severe stroke, although she was able to communicate by using body language (Table 5.8).

Table 5.8. TMSE by Medical Diagnosis

Medical Diagnoses	TMSE having dementia	 not having dementia	 cannot test	Total (%)
Dementia in AD	6	0	0	6 (13.6)
Vascular dementia	11	0	1	12 (27.3)
Dementia in PD	5	0	0	5 (11.4)
Mixed type of dementia	3	0	0	3 (6.8)
Dementia in other causes	4	1	0	5 (11.4)
Unspecified dementia	9	4	0	13 (29.5)
Total (%)	38 (86.4)	5 (11.4)	1 (2.3)	44 (100)

Because the MMSE itself may yield with an excessively high number of false-negative errors for patients with early dementia (Pfeffer et al., 1981; Wilson and Kaszniak, 1986), it is recommended that mental status tests be only one part of a comprehensive neuropsychological evaluation for dementia (Cohen et al., 1984). As mentioned earlier that the confirmation of a clinical diagnosis of dementia is only achieved by histopathological post-mortem. Even in the case of histopathological diagnosis, differences may be found among several neuropathologists and among laboratories, due to a lack of attention to tissue dissection at autopsy; the use of different tissue-straining techniques; and the significance given to the number, type and distribution of the histopathological changes (Alafuzoff, 1992, p. 8). In addition, a recent study by Brakhus et al. (1995) looked at whether a low, "normal" sum score (24 or higher) on the MMSE near the cut off point usually employed for identifying persons with cognitive impairment predicts later development of dementia. It was found that persons with a sumscore of 24 or 25 are at high risk of developing dementia within 3 years. Therefore, all subjects were included in the present study, although the TMSE test indicated that 5 subjects, including one participant who could not be tested, might not have dementia.

5.3.2. TMSE distribution by Age Group, Sex, Educational level, and Work status.

In earlier studies by Brayne and Calloway (1990) with a group of women (n=410) aged 70-79 years from a rural area of Cambridgeshire, using the MMSE, it was found that lower scores on the MMSE were associated with increasing age, lower socio-economic status and less education.

The average TMSE score in each age group from the present study are shown in the form of boxplots (Figure 5.6). A boxplot is a type of graph that can be use to summarise the scores on a variable (Foster, 1993) and convey information about the distribution of a set of data points, including displaying the median (as the horizontal line in the box). The median, the indicator of the central value, divides the distribution of scores in half: 50% of the scores fall below the median and 50% fall above it. If the median is in the middle of the box, it means the data are symmetrically distributed. In contrast, if the median is not in the middle of the box, the distribution of scores is skewed. The figure skewness indicates how non-symmetric the distribution is. The lines which are drawn from the edge of the box indicate the largest and smallest values and all points outside this range are represented by circles (Pagano and Gauvreau, 1993). Figure 5.6, therefore, shows that the average TMSE score in each age group dramatically declined with increasing age, except that participants in the under 60 age group had lower average scores than those in the 60-69 age group. However, this could be a reflection of the small number of participants in this age group (n=3), and also of the severity of their dementia.

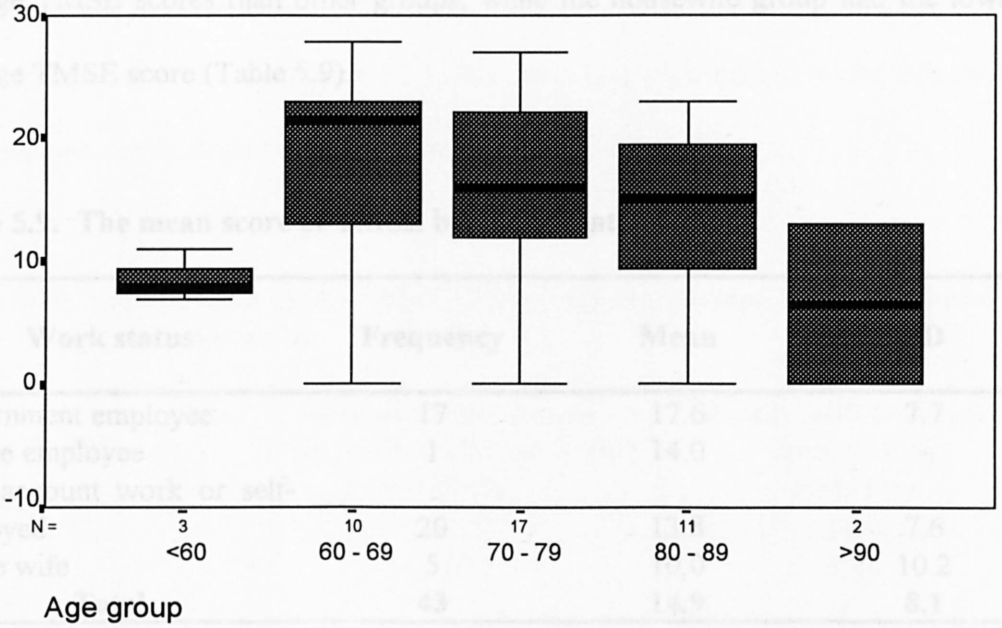


Figure 5.6. The mean score of TMSE by Age group.

There is, as yet, no clear socio-economic class classification (SEC) in Thailand, although a recent study on "Indications of socio-economic class in Thai society" by the Institute of Social Research, Thailand (Larkthananoon, 1995) identified seven factors: education, occupation, position in occupation, income, family background, intelligence level, and high profile, as contributing to indicate SEC among Thai people, especially in urban areas, which would be different from rural areas. Further study would be needed to confirm the reliability of these indicators for application throughout the country. Therefore, the subjects were classified in the present study according to work status, as an indicator of job security and income. People who work for the government have the most secure jobs in terms of security of long-term contact, guaranteed income and high social security (see Section 5.1.3). Although there is no significant difference in the TMSE scores among the subjects grouped according to working status, the participants who had worked as government employees had higher average TMSE scores than other groups, while the housewife group had the lowest average TMSE score (Table 5.9).

Table 5.9. The mean score of TMSE by Work Status

Work status	Frequency	Mean	SD
Government employee	17	17.6	7.7
Private employee	1	14.0	-
Own account work or self-employed	20	13.8	7.6
House wife	5	10.0	10.2
Total	**43**	**14.9**	**8.1**

There were no significant difference in the TMSE scores between the groups when classified according to their education level. However, the present study may contain insufficient subjects to attempt any comparison between the TMSE score and any other variables.

5.3.3. TMSE and Sub-test's Scores

The TMSE test contains six basic subtests: orientation, registration, attention, calculation, language and recall. In a study by the Train the Brain Forum (1993) in Thailand, the TMSE was applied to 180 normal healthy Thai elderly, aged between 60-70 years throughout the country. The mean total score in that study was 27.38 (SD=2.02). The major sub-tests which the normal Thai elderly failed were recall

(67%) and calculation (41%). Similarly, in the present study, it was also found that the highest proportion of demented subjects (79%) failed in the recall and over half (58%) failed in calculation. To compare the findings from these two studies, the main deterioration symptoms which can distinguish people with dementia from normal Thai elderly people are the greater decline in attention and registration, whilst orientation and language are likely to remain the same (Table 5.10 and Figure 5.7).

Table 5.10. Comparison of the TMSE scores between normal Thai elderly and people with dementia.

TMSE	**Normal elderly people** Train the Brain Forum (1993) n=180 (%)	**People with Dementia** Present study n=43 (%)
Mean	27.38	14.8
SD	2.02	8.14
Fail to score		
Recall	118 (67%)	34 (79%)
Calculation	72 (41%)	25 (58%)
Language	44 (25%)	5 (12%)
Orientation	42 (24%)	7 (16%)
Attention	8 (5%)	17 (40%)
Registration	5 (3%)	7 (16%)

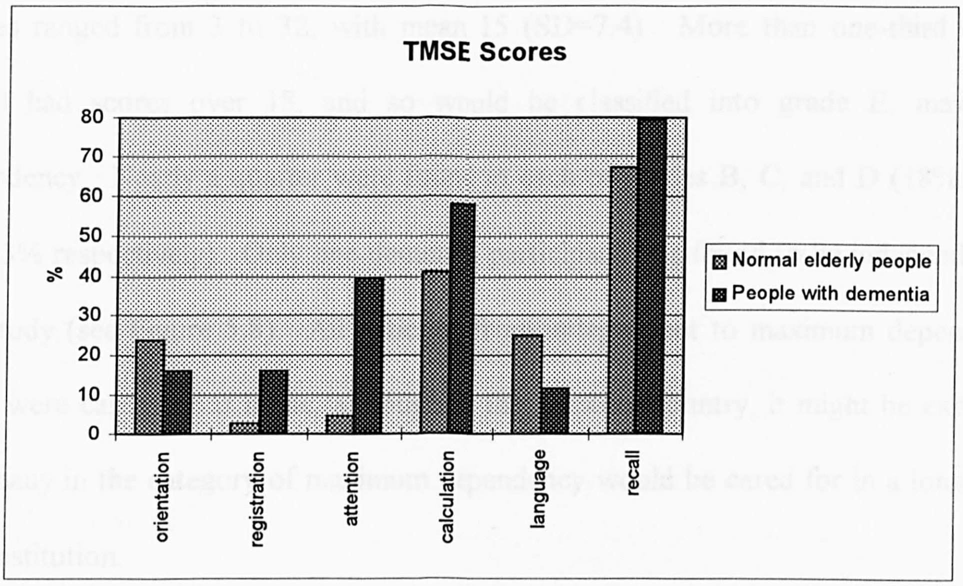


Figure 5.7. Percent of the sample who fail to score in the TMSE Sub-test.

5.4. Behaviour Rating Scale

The Behaviour Rating Scale (BRS) is an instrument being used to measure behavioural competence in elderly people. It contains 18 items (see Appendix II), which relate to mobility, continence, activities of daily living and confused behaviour. Further items covering 'eyesight' and 'hearing' appear on the form but do not contribute to the scale scores. Each item has a range of score from 0, for no or few problems, to 2 for frequent or constant problems. Total scores range from 0 to 36 and are grouped into five dependency grades: grade A (independent); grade B (low dependence); grade C (medium dependency); grade D (high dependency); and grade E (maximum dependency) (also see Table 4.3). In general, the lower the score in BRS, the more independent a person is in activities of daily living.

5.4.1 BRS distribution by Sex, Age Group, Educational level, and Work Status.

Scores ranged from 3 to 32, with mean 15 (SD=7.4). More than one-third (36%, n=16) had scores over 18, and so would be classified into grade E, maximum dependency. Nearly a quarter were found in each of grades B, C, and D (18%, 20% and 23% respectively). Only one dementia participant was found to be independent in this study (see Figure 5.8). All patients, from independent to maximum dependency level, were cared for at home, although in the Western country, it might be expected that many in the category of maximum dependency would be cared for in a long term care institution.

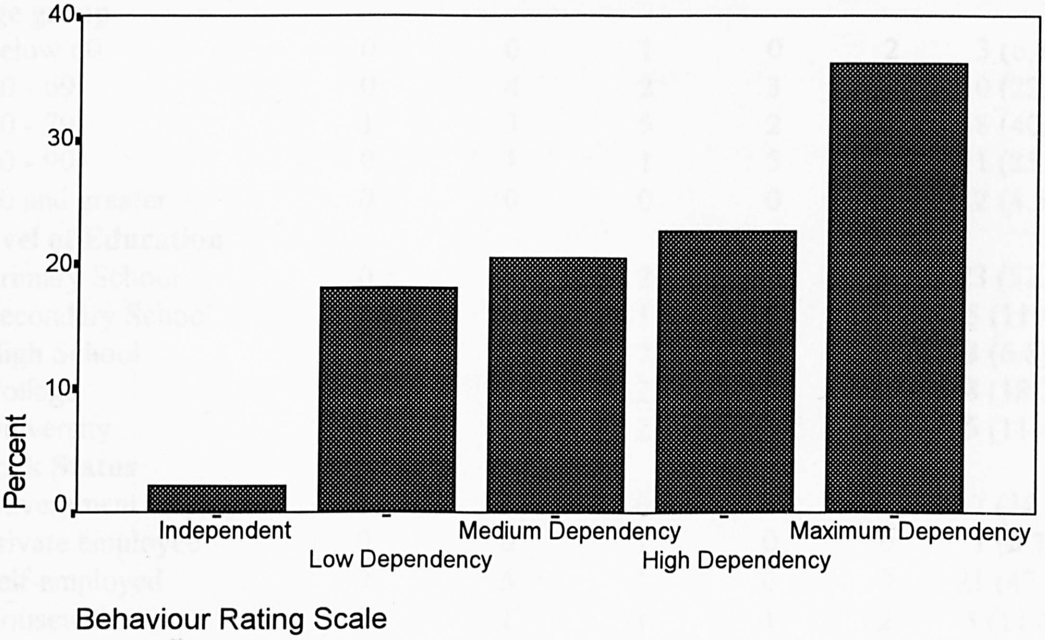


Figure 5.8. Distribution of dependency level among demented participants.

Table 5.11 shows the relationships between dependency and demographic characteristics. Although there were more male participants than female, more female subjects fell into grade E, maximum dependency, than male. In the present study, most subjects who were grade E were likely aged between 70 to 79 years, educated to primary school level only, and self-employed, while more male participants who had been in government service had medium dependency, grade C.

Table 5.11. Dependency level by Sex, Age group, Educational level, and Work status.

Variables	A n=1	B n=8	Grade C n=9	D n=10	E n=16	Total n=44 (100%)
Sex						
Male	1	5	6	8	7	27 (61.4)
Female	0	3	3	2	9	17 (38.6)
Age group						
below 60	0	0	1	0	2	3 (6.8)
60 - 69	0	4	2	3	1	10 (22.7)
70 - 79	1	3	5	2	7	18 (40.9)
80 - 90	0	1	1	5	4	11 (25.0)
90 and greater	0	0	0	0	2	2 (4.5)
Level of Education						
Primary School	0	6	2	6	9	23 (52.3)
Secondary School	1	0	1	1	2	5 (11.4)
High School	0	1	2	0	0	3 (6.8)
College	0	0	2	3	3	8 (18.2)
University	0	1	2	0	2	5 (11.4)
Work Status						
Government employee	1	2	6	3	5	17 (38.6)
Private employee	0	0	1	0	0	1 (2.3)
Self-employed	0	5	1	6	9	21 (47.7)
Housewife	0	1	1	1	2	5 (11.4)

Pattie and Gilleard (1977) found that there was a significant trend towards increasing disability with increasing age, whether reflected through behavioural ratings or cognitive test performance. In fact, these authors found that age accounted for only about 10 percent of the variance in level of disability. They later concluded that in an elderly disabled population age did not, by itself, account for much of the variance in behavioural competence (Gilleard and Pattie, 1977). When the effects of age are taken into account, no significant influence of sex on scores was observed. Similarly, in the present study, there were no statistically significant correlations between BRS scores and sex, age, educational level and work status.

Pattie and Gilleard (1979) suggested that the BRS also provided measures of four principal areas of behavioural disability: physical disability (Pd), apathy (Ap), communication difficulties (Cd) and social disturbance (Sd). However, Wilkin and Thomson (1989) argue that the evidence from the results of the BRS do not appear to provide support for grouping of the items into these four sub scales. The statistical analysis aspect of these four sub-scales was also carried out in the present study. There were neither significant differences nor correlations between BRS sub scales and sex, age, educational level and work status.

5.4.2. The relationship between BRS, TMSE, and Medical Diagnosis

Since the TMSE and BRS were developed to measure cognitive preference and behaviour competence in elderly, both scale should have a high correlation. Scatterplot is a type of graph that can be used to summarise a set of continuous observations (Pagano and Gauvreau, 1993). The scatterplot in Figure 5.9 shows the negative direction of the relationship between the BRS and the TMSE scores; the lower the BRS scores (indicating the more independence), the higher the TMSE scores (indicating the lesser cognitive impairment). In other words, the greater cognitive impairment in the subjects related to their lower levels of independence. *Spearman correlation* coefficients was used to examine the relationship between the subjects scores on the BRS and the TMSE. The correlation coefficient expresses the relationship between two variables as a number and can vary between -1 and +1 (Foster, 1993). A significantly negative correlation was found between the BRS and the TMSE scores ($r = -.78; p \leq .01$).

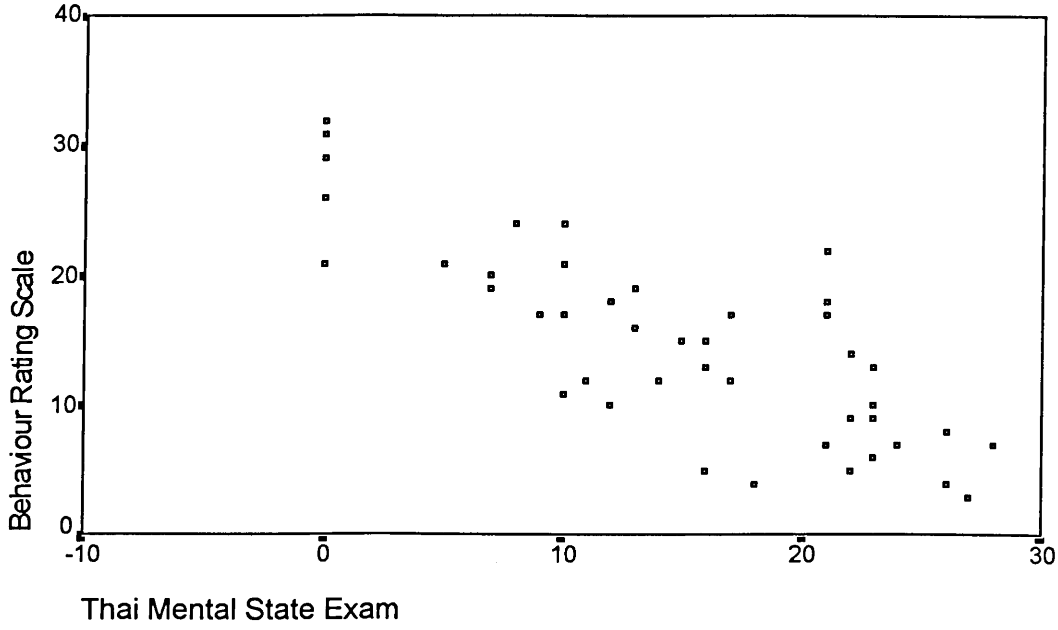


Figure 5.9. Distribution the BRS scores by the TMSE scores

Figure 5.10 shows the highest proportion (n=15, 40%) of those who had the TMSE sumscores 23 and lower (the cut off point to identify persons with cognitive impairment which might predict later development of dementia) had maximum dependence. Of those who had the TMSE sum scores 24 and over, a normal level of cognitive competence, one had independence and the remainder had low and medium dependency respectively (n=3, n=1). There were, however, some subjects who had a normal level of cognitive competence but had some level of dependency; this may be because they suffered from other concurrent chronic illness. In terms of relationship between BRS and medical diagnoses, the highest number of those who were maximally dependent (n=8) were subjects who had been diagnosed as having Vascular Dementia, followed by those with Dementia in AD (n=5).

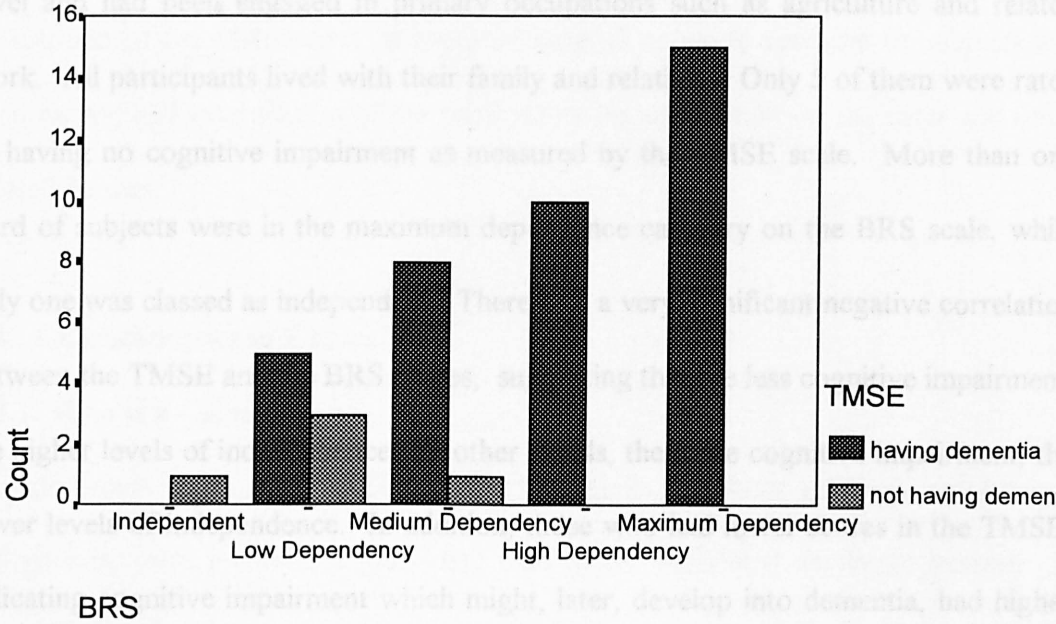


Figure 5.10. Thai Mental State Examination by Behaviour Rating Scale

Conclusion

Of the 44 subjects with a diagnosis of dementia, 27 (61%) were male and 17 (39%) were female. Their ages ranged from 51 to 93 years, mean 74 (SD=9.8). Over half (53%) of them were educated to primary school level only. Most of those who lived in the city areas were educated to a higher level, and had been engaged in tertiary and quaternary work (professional, technical, administrative, executive and related work), while most of those who lived in rural areas had been educated only to primary school level and had been engaged in primary occupations such as agriculture and related work. All participants lived with their family and relatives. Only 5 of them were rated as having no cognitive impairment as measured by the TMSE scale. More than one third of subjects were in the maximum dependence category on the BRS scale, while only one was classed as independent. There was a very significant negative correlation between the TMSE and the BRS scores, suggesting that the less cognitive impairment, the higher levels of independence. In other words, the more cognitive impairment, the lower levels of independence. In addition, those who had lower scores in the TMSE, indicating cognitive impairment which might, later, develop into dementia, had higher scores in BRS, which is related to a higher level of dependency.

CHAPTER 6

Research Findings (Part II)

Information on Carers

Introduction

This section describes the characteristics of carers in terms of their demographic variables, such as age, gender, education, and occupation. This is followed by a description of the distribution of types of support network available to subjects and their carers, and examination of the relationship between strain on the carer and other related factors.

6.1. Characteristics of Carers

6.1.1. Who is a Carer?

A wide range of people, including immediate family members, relatives, neighbours, and friends, were involved in providing care to the individual demented person. In more affluent families there were also paid helpers, in the form of care assistants, who were hired from private care institutions to assist in the caring task at home. Care was thus usually provided by a group of people, making it difficult to identify the main carer. According to Western literature, the terms carer or informal carer refer to those people who care for an elderly dependent person up to 24 hours each day, unpaid and untrained (Bell and Gibbon, 1989), and it is also assumed that such care is restricted to a one-to-one relationship (Ungerson, 1990) (see Chapter 2 for more details). In the present study, where the situation of co-caring occurred, the main carer was defined as the person who spent the longest hours in providing care for the demented person (referred to as the subject) each day. Although some family members had more responsibility in providing financial support, if they did not actually provide care themselves, they were not counted as the main carers. By identifying the main carer as the person who gave the most *time* to caring, it was possible to assess their strain from care providing by using the Caregiver Strain Index instrument. Moreover, only untrained, unpaid carers were included in the sample of main carers.

6.1.2. Types of Carer

Screening questions were undertaken with people who accompanied subjects to see the doctor at the selected Out Patient Departments (OPD), in order to identify the main carer (see Appendix I). Carers were classified into four groups: spouse, adult children, other relative, and in-laws. Out of 44 carers in this study, 20 from Northern Region and 24 from Central Bangkok, over half were spouses (55%, n=24), which is very close to the percentage of spouse carers in a study in Western countries where Sinclair and Gorbach (1989) found that 61% of carers were spouses. One-third were adult children (32%, n=14), 11% (n=5) were daughters-in-law, and only one person another relative (see Table 6.1).

Relationship to the subject, marital commitment and family membership were found to be crucial factors in being a carer, especially in a country where caring support in the community from health and social services has not been much developed (see Chapter 3). Being married to the demented person, being their child or being married to one of their adult children, gave a high possibility of becoming a carer. Table 6.1 also shows that the largest category of participant carers were wives (44%, n=19), nearly a quarter of carers (n=10) were daughters, while husbands or daughter-in-laws each accounted for 11% (n=5). Only 9% (n=4) were sons, and the remainder was a niece.

Table 6.1. Classification of carers and relationship of carers to the demented person

Carers	Frequency	(%)
Spouse		
Wife	19	44
Husband	5	11
Adult Children		
Daughter	10	23
Son	4	9
Relative		
Niece	1	2
In-law		
Daughter-in-law	5	11

6.1.3. Age and Gender

The 44 carers had an age range of 25 to 85 years, mean 56.2 (SD=16.5), median 55.5, and mode 50 years. The highest proportion of carers were found to be aged between 60-79 (n=16, 36%). The lowest frequency was found in age 80 and over (see Figure 6.1). Carers were then regrouped to spouse and non-spouse carers and these groups had an average age of 68.6 (SD=8.9) and 41.2 (SD=9.5) respectively. The non-spouse carers group, younger relative carers, included sons, daughters, daughters-in-laws and a niece. The 60-79 age group was the highest in the spouse carer group, whilst the majority of non-spouse carers were aged 40-59 (Table 6.2).

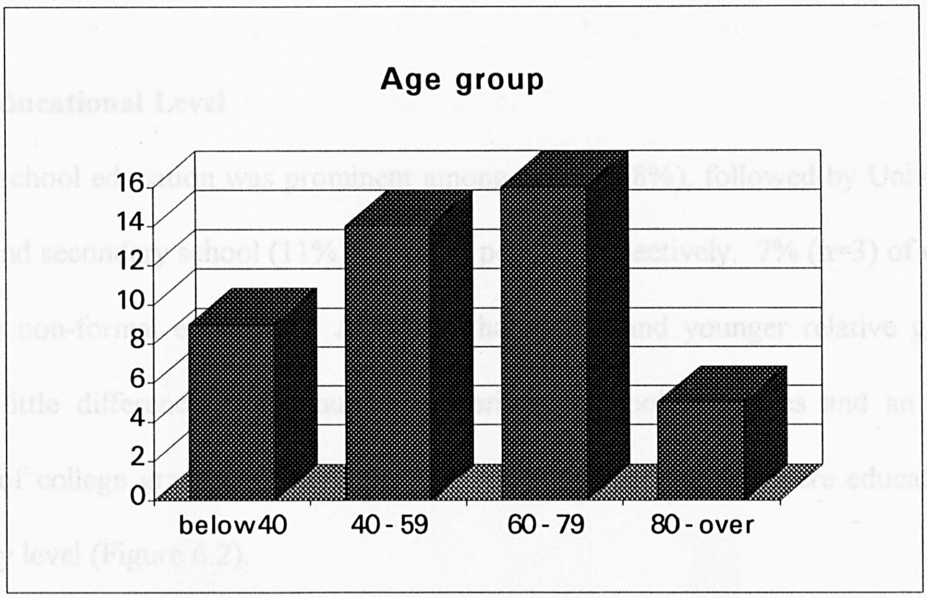


Figure 6.1. The distribution of carers by age groups.

There was a prominent gender difference among carers, with 80% (n=35) female and only 20% (n=9) male carers. Table 6.1 shows that four times as many wives as husbands were carers, and twice as many daughters as sons. Also there were niece and daughter-in-law carers, whilst no nephew or son-in-law carers were found in this study. Male carers were more likely to be the spouse than a non-spouse or younger relative (Table 6.2).

Table 6.2. The main Carer groups by Age and Sex.

	Spouse Carers (n=24, 54.5%)	**Younger Relative Carers** (n=20, 45.5%)	Total n=44 (100%)
Age group			
below 40	0	9	9 (20.5)
40 - 59	4	10	14 (31.8)
60 - 79	15	1	16 (26.4)
80 and over	5	0	5 (11.4)
Sex			
Male	5	4	9 (20.5)
Female	19	16	35 (79.5)

6.1.4. Educational Level

Primary school education was prominent among carers (48%), followed by University (20%), and secondary school (11%) educated people, respectively. 7% (n=3) of carers had only non-formal education. Although the spouse and younger relative groups showed little difference in the number of primary school graduates and an equal number of college graduates, more younger relatives than spouses were educated to university level (Figure 6.2).

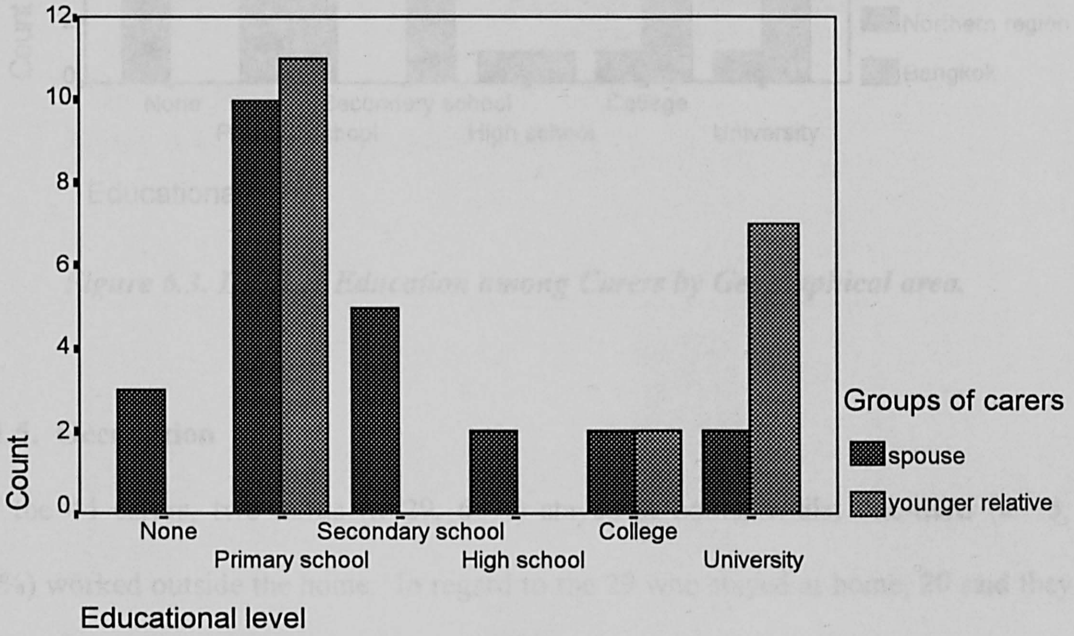


Figure 6.2. Educational level by Carer groups

There was a higher proportion of primary school educated carers in Northern region than in Bangkok. The three carers who had no formal education, two female and one male, also came from the Northern region. In contrast, carers with higher education, such as secondary school, college and university graduates were more frequent in Bangkok than in the Northern region (see Figure 6.3).

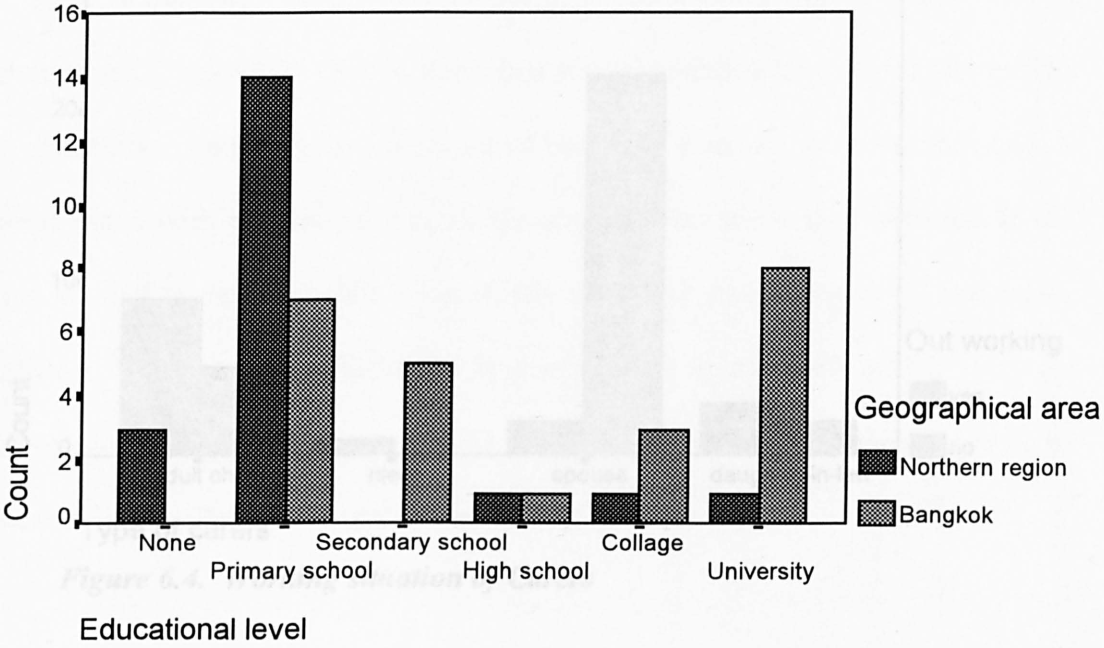


Figure 6.3. Level of Education among Carers by Geographical area.

6.1.5. Occupation

Of the 44 carers, two-thirds (n=29, 66%) stayed at home, whilst one-third (n=15, 34%) worked outside the home. In regard to the 29 who stayed at home, 20 said they did not work, the majority of these were housewives (n=14), and the remainder were retired from work. 5 worked full-time from home and 4 worked part-time. Of those working outside the home (n=15), 9 of them worked part-time, and only 6 worked full-time. Looking at working condition in relation to carer groups, it was found that almost all non-workers were spouses (19, compared with only one in the younger relative group), while younger relatives constituted a higher proportion of both full-time and part-time groups than spouses (4.5:1; 3.3:1) (Figures 6.4 and 6.5).

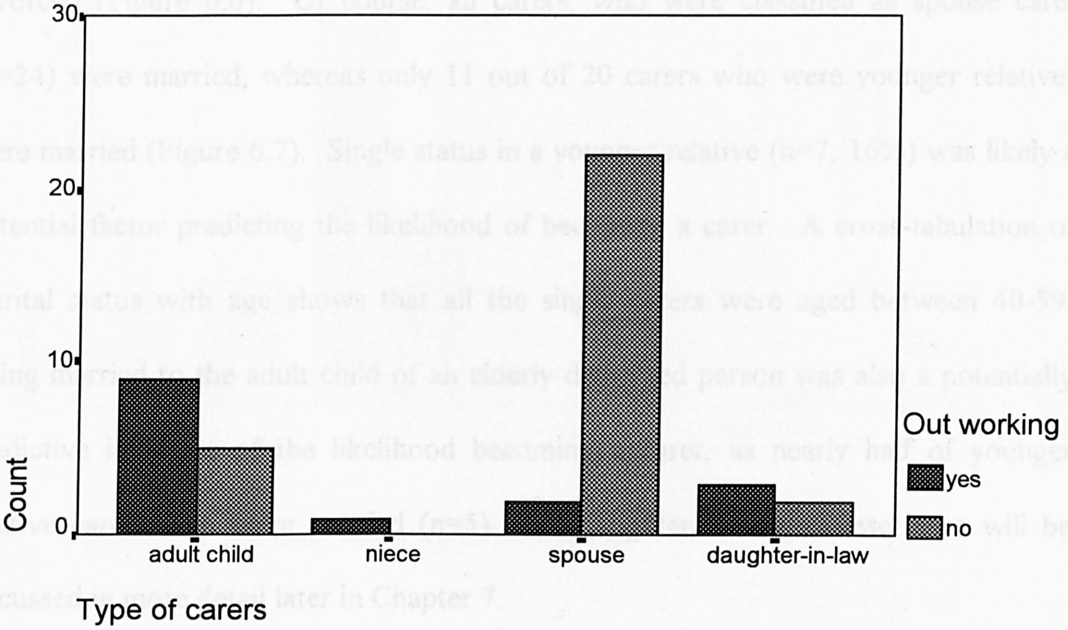


Figure 6.4. Working situation of Carers

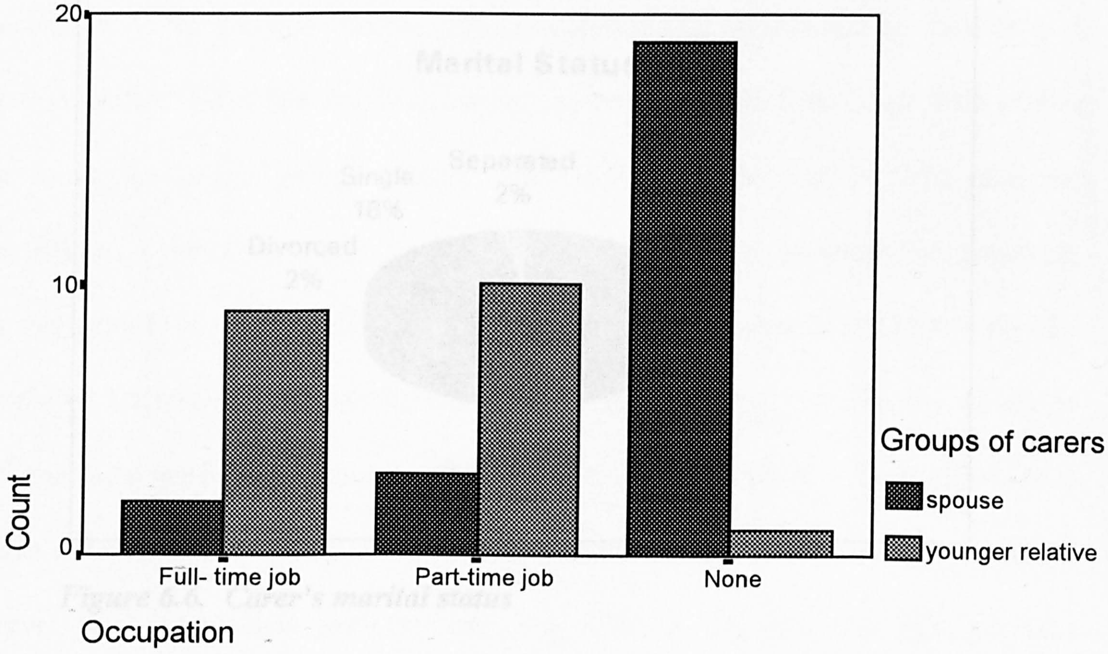


Figure 6.5. Characteristics of Carer's Occupation

6.1.6. Marital Status and Place of Residence

Of the 44 carers, most were married (n=35), 7 single, and only one separated and one divorced (Figure 6.6). Of course, all carers, who were classified as spouse carer (n=24) were married, whereas only 11 out of 20 carers who were younger relatives were married (Figure 6.7). Single status in a younger relative (n=7, 16%) was likely a potential factor predicting the likelihood of becoming a carer. A cross-tabulation of marital status with age shows that all the single carers were aged between 40-59. Being married to the adult child of an elderly demented person was also a potentially predictive indicator of the likelihood becoming a carer, as nearly half of younger relative carers who were married (n=5) were daughters-in-law. These issue will be discussed in more detail later in Chapter 7.

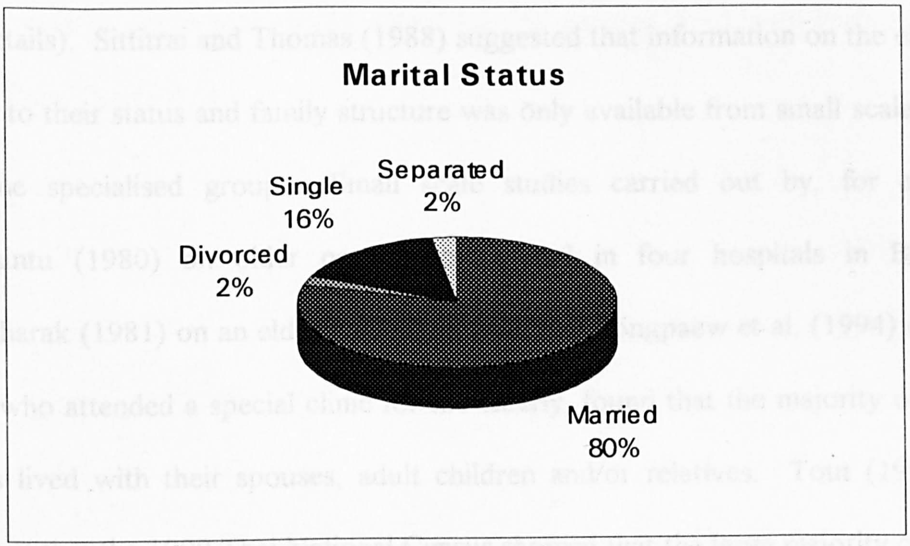


Figure 6.6. Carer's marital status

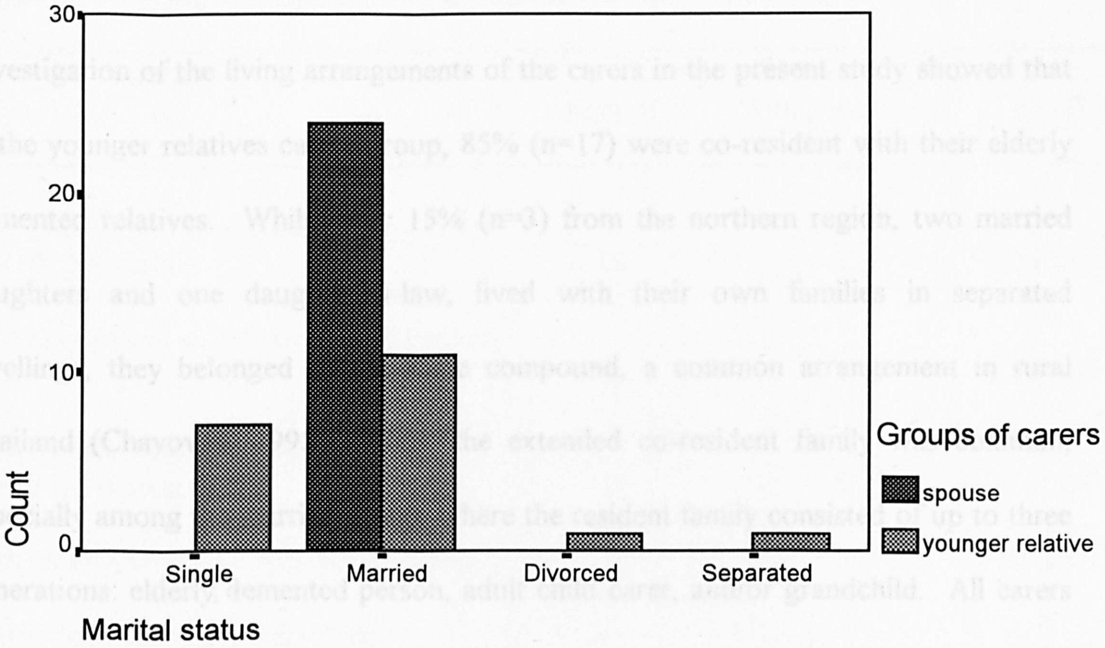


Figure 6.7. Marital status by Carers group

The traditional extended family, consisting of grandparent, adult children and their family, all living under the same roof, is still prevalent in Thailand (see Chapter 3 for more details). Sittitrai and Thomas (1988) suggested that information on the elderly in relation to their status and family structure was only available from small scale studies for some specialised group. Small scale studies carried out by, for example, Prasertsintu (1980) on older people hospitalised in four hospitals in Bangkok, Kandecharak (1981) on an elderly people's club, and Pongpaew et al. (1994) on older people who attended a special clinic for the elderly, found that the majority of elderly patients lived with their spouses, adult children and/or relatives. Tout (1995) also points out that the 1990 Thai National Census showed that the large majority of elderly parents were co-resident with at least one child, a situation that has remained unchanged since the 1980s. The results of the present study are consistent with the findings of the Thailand 1990 national census.

Investigation of the living arrangements of the carers in the present study showed that in the younger relatives carers group, 85% (n=17) were co-resident with their elderly demented relatives. Whilst only 15% (n=3) from the northern region, two married daughters and one daughter-in-law, lived with their own families in separated dwellings, they belonged to the same compound, a common arrangement in rural Thailand (Chayovan, 1995). Thus, the extended co-resident family was common, especially among the married group, where the resident family consisted of up to three generations: elderly demented person, adult child carer, and/or grandchild. All carers who were single, divorced, or separated were co-resident with the elderly demented relative and nearly half the carers who were single (n=3) tended to be co-resident not only with the elderly demented relative, but also with other relatives, such as an aunt or uncle. Amongst spouse carers, 80% (n=19) lived with their demented spouses, adult children, and/or grandchild, while only 20% (5) persons lived with their demented spouse alone (Table 6.3).

Table 6.3. Living arrangement by groups of carers

Living arrangement Groups of Carers	Groups of Carers Spouse	 Younger relative	 Total (%)
with (demented) spouse, children, and /or grandchild	19	3	22 (50.0)
with spouse and elderly demented person	0	3	3 (6.8)
with spouse, children, and elderly demented person	0	5	5 (11.4)
with elderly demented spouse or relative	5	5	10 (22.7)
with elderly demented person and other relative	0	4	4 (9.1)

6.1.7. Care providing hours per day

The period of time over which the carer provided care for the subject ranged from 2 to 24 hours per day, mean 8.4 (SD=5.7), median 8, and mode 4 hours. Nearly half of them (41%, n=18) provided care for less than 5 hours a day (less than 35 hours/ week). Less than one-fifth (18.2%, n= 8) provided care for 5-9 hours a day (between 35-63 hours/week). Over a quarter provided care for 10-14 hours a day (27.3%, n=12) (between 70-98 hours/week). The same distribution number of carers (7%, n=3) provided care between 15-19 and more than 20 hours a day, in other words 14% (n=6) cared for their relatives for over 100 hours a week. Figure 6.8 shows the hours of care provided by carers per week. Twigg (1992) stated that some 75% of those caring did so for between 50 and 99 hours and 85% of those caring for over 100 hours a week were helping with personal and/or physical care. In contrast, in the present study, only 41% (n=18) of carers were caring for between 50 and 99 hours a week.

Thus, carers in Thailand seem to spend less time on caring than carers in Western countries. As I mentioned earlier, in the present study, there were co-carers, helpers, and paid care assistants who participated and relieved the main carers of some caring responsibility. In such a situation, it is rather difficult to identify the precise hours of care in Thailand without collecting information about the care activities of all carers.

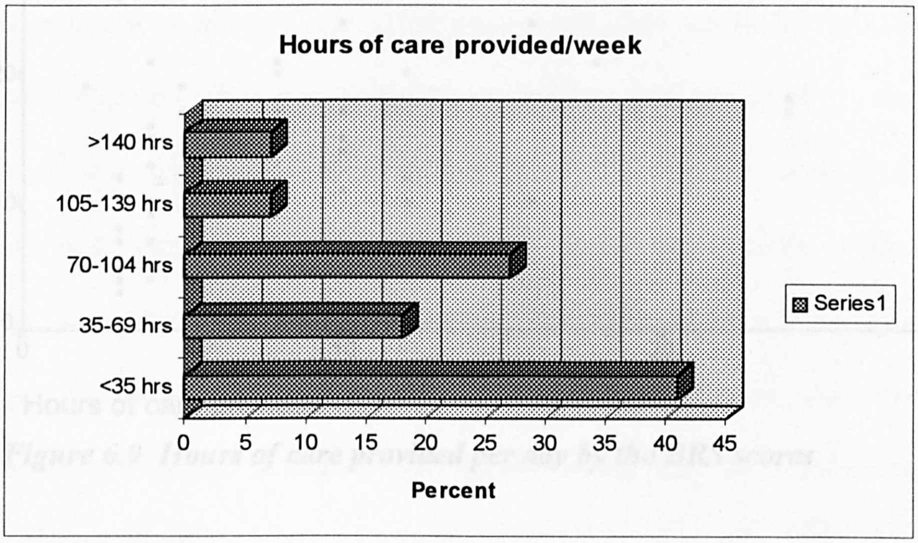


Figure 6.8 Hours of care provided per week by main carer

Spearman correlations were carried out and a significant positive correlation was found between the hours of care provided by carers and BRS scores of the subjects (r=.51; $p \leq .01$). This finding suggests that the higher the BRS scores, which indicates increasing levels of dependence, the longer the hours of care provided (see Figure 6.9). Moreover, a significant correlation was also found between hours of care provided and the level of strain on carers. This issue will be discussed later in this chapter. However, there were no statistical differences nor significant correlations between hours of care provided and other variables, such as sex, age, group of carers, and TMSE.

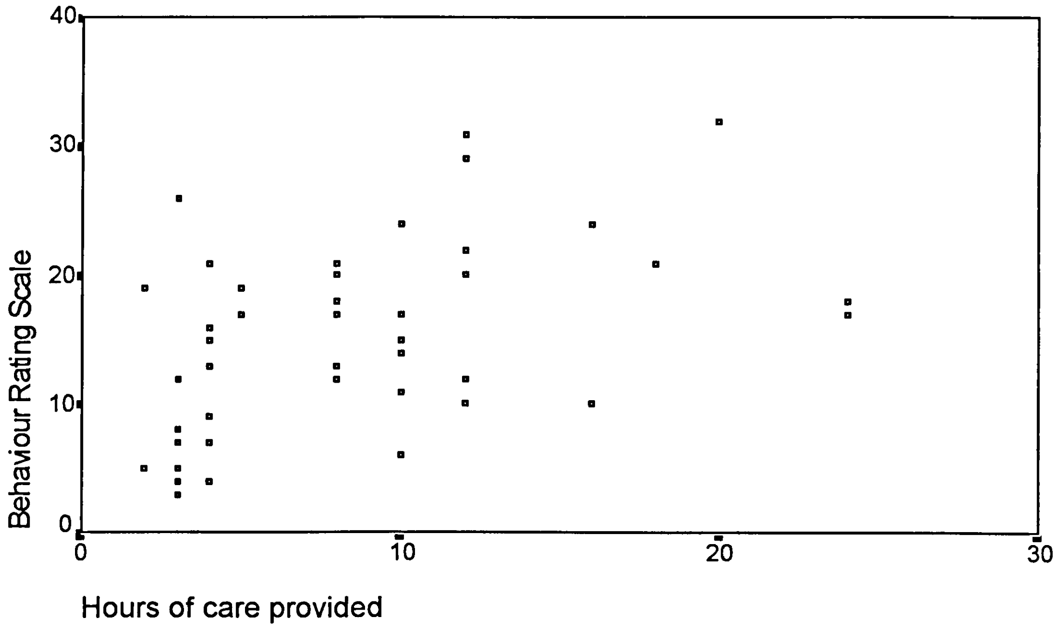


Figure 6.9 Hours of care provided per day by the BRS scores

6.2. Network Assessment

The network perspective is concerned with the way in which individual people are linked into groups and society and a core of people who are turned to for help, support and advice when these are needed (Wenger, 1994). Social networks, therefore, become a central issue of study for better understanding of the social ageing process (Wenger and Scott, 1995), to know their problems, and provide services to meet their needs. The Network Assessment Instrument was applied to both subjects and their carers in this study. It consists of eight questions (see Appendix II, Part A or see

Table 6.4) on the basis of which the support network type can be identified (Wenger 1991).

6.2.1. Proximity to and contact with relatives

The vast majority of subjects and carers had a nearest child or relatives living close by. As Table 6.4. shows, they were more likely to have a relative, including children, living in the same house or within a mile. However, carers were less likely than subjects to have a child close by. This may be because nearly one-fifth (16%) of the carers were either single or married with no children (see Figure 6.6). Nearly one-third of subjects had no siblings. This is likely to be related to the greater age of subjects compared to the carers, particularly younger relative carers. The subjects were more isolated, and were much less likely to socialise with their friends and neighbours, and participate in religious and community activities, than carers, which may be a reflection of the severity of their illness.

Table 6.4. Characteristics of Support Network (%)

	Subjects (n=44)	Carers (n=44)
Nearest child or other relative *(p<.0005)*		
<1 mile	96	86
1-5 miles	0	0
6-15 miles	4	7
More than 15 miles	0	5
No relatives	0	2
Nearest child *(p<.0004)*		
<1 mile	89	68
1-5 miles	2	2
6-15 miles	0	0
More than 15 miles	7	7
No children	2	23
Nearest sibling		
<1 mile	14	41
1-5 miles	7	7
6-15 miles	7	16
More than 15 miles	40	23
No sibling	32	13
Frequency see child/relative		
Daily	86	73
2-3 times/week	5	2
At least weekly	0	11
Less than weekly	9	14
Never	0	0
Frequency see/chat friend		
Daily	7	34
2-3 times/week	7	9
At least weekly	5	11
Less than weekly	20	32
Never	61	14
Frequency see/chat neighbour		
Daily	9	37
2-3 times/week	7	9
At least weekly	9	18
Less than weekly	20	27
Never	55	9
Attends religion meetings *(p<.04)*		
Regularly	5	20
Occasionally	20	39
Never	75	41
Attends community groups		
Regularly	2	13
Occasionally	11	39
Never	87	48

6.2.2. Distribution of support network typology by subjects and their carers

Of a total of 44 subjects, 32% (n=14) did not clearly belong to one type or another (see Chapter 4, Table 4.4), and 13 of them, having equal highest scores in two columns, were so-called 'borderline cases.' Also 18% (n=8) borderline cases were found among the 44 carers. In addition, 2.3% (n=1) of subjects and the same number of carers had the same highest figure occurring in more than three columns. In these cases, Wenger (1994) suggests that:

> Where a network is found to be borderline, it is necessary to weigh information in the context of both network types and to make decisions taking all factors into account. If the same highest figure occurs in more than two columns, then the network type is inconclusive.
>
> (p. 34)

After the borderline networks were weighed and the decisions on network types had been made, over half of the subjects and carers, 62% (n=27) and 57% (n=25) respectively, fell into the family dependent type of support network (Table 6.5). This suggests that both groups had turned to close local family ties for help and nearly all support was provided by the family. It also indicates that there was an extension of support from carers to their own network, who were also family members, which could be through integration between generations in an extended family.

Table 6.5. Distribution of support network type

Network Type	Subjects n (%)	Carers n (%)
Family Dependent	27 (62)	25 (57)
Locally Integrated	1 (2)	13 (30)
Locally Self-contained	0	4 (9)
Wider Community Focused	0	0
Private Restricted	15 (34.0)	1 (2)
Unclassified	1 (2)	1 (2)

Most borderline cases in the subjects group (n=12), were in the family dependent and private restricted types of network, while in the carers group, just half (n=4) of borderline cases had locally integrated and family dependent support networks. A few borderlines occurred between family dependent and private restricted; wider community focused and private restricted; and family dependent and local self-contained support networks. From these findings, it is possible to predict the direction of movement of support networks from wider to smaller networks, where most borderline subject cases had shifted from a family dependent to a private restricted support network and the majority of borderline carer cases had shifted from locally integrated to family dependent networks. This reflects the increasing family focus or household focus to which caring for a dementing person probably inevitably leads. This also may be an unpleasant indication of the continued decline in the support networks of carers in the near future.

Wenger and Scott (1995) state that private restricted and local self-contained networks appear to be more vulnerable in respect to ill-health or crisis. In this study, it was found that one-third of subjects (34%, n=15) had a private restricted network which showed a low level of community contact or involvement, because of their illness, rather than because of absence of local kin. Due to their illness, their networks were smaller than average. The local family dependent support network is the type that makes it easiest for impaired or frail elderly people to remain in the community (Wenger, 1995). Although a small number of subjects had the locally integrated type of network, nearly one-third of their carers (30%, n=13) manifested this healthy network that would help the subject to remain in their own home. The findings from the Bangor Longitudinal Study of Ageing, since 1979, suggest that differences between communities in the distribution of network types may result in different distributions of problems and different patterns of help-seeking behaviour. Also, different types of network have been shown to have different capacities to cope with the frailties of old age (Wenger, 1994).

6.2.3. Distribution of support network typology by geographical area.

It has been suggested that the distribution of network type is significantly related to a specific community or neighbourhood (Wenger and Shahtahmasebi, 1990; Wenger and St.Leger, 1992; and Thissen et al., 1992). Therefore, in this study, the distribution of network type was compared between samples from Bangkok, the capital city, and the Northern region, where 85% of the sample lived in a rural area.

Figures 6.10 and 6.11 show that the family dependent type of network dominated in both geographical areas, though it was slightly more common among subjects in the rural area than in the urban. Also there was little difference in the distribution of private restricted networks in both area. It is likely that these findings reflect the fact that the subjects were isolated and withdrawn from social involvement because of their illness. In contrast, it appeared that more carers in Bangkok had family dependent networks and fewer had social integration networks than carers in the rural areas. This reflects the individualism brought by urbanisation, where individuals have less local involvement and are increasingly cut off from social contact because of caring for their demented spouses or relatives. It also reveals the smaller support networks for carers who lived in Bangkok, which may have made it more difficult for them to continue providing care for the subject. Therefore, there may be a need for intervention from health and social authorities to address their problems before a family caring crisis occurs.

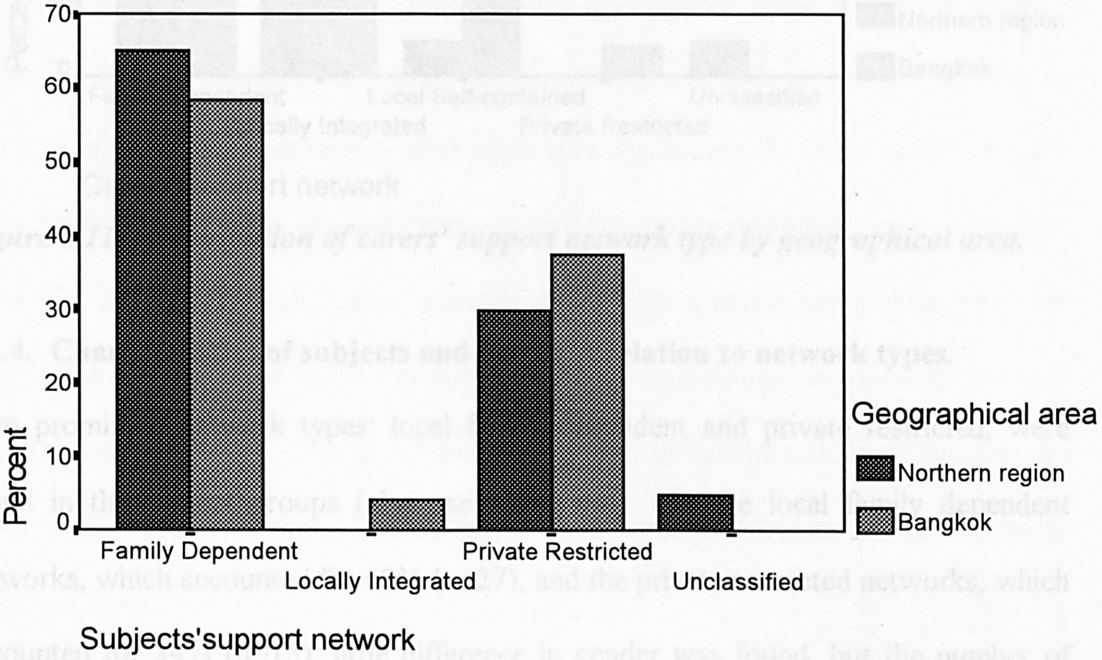


Figure 6.10. Distribution of subjects' support network type by geographical area

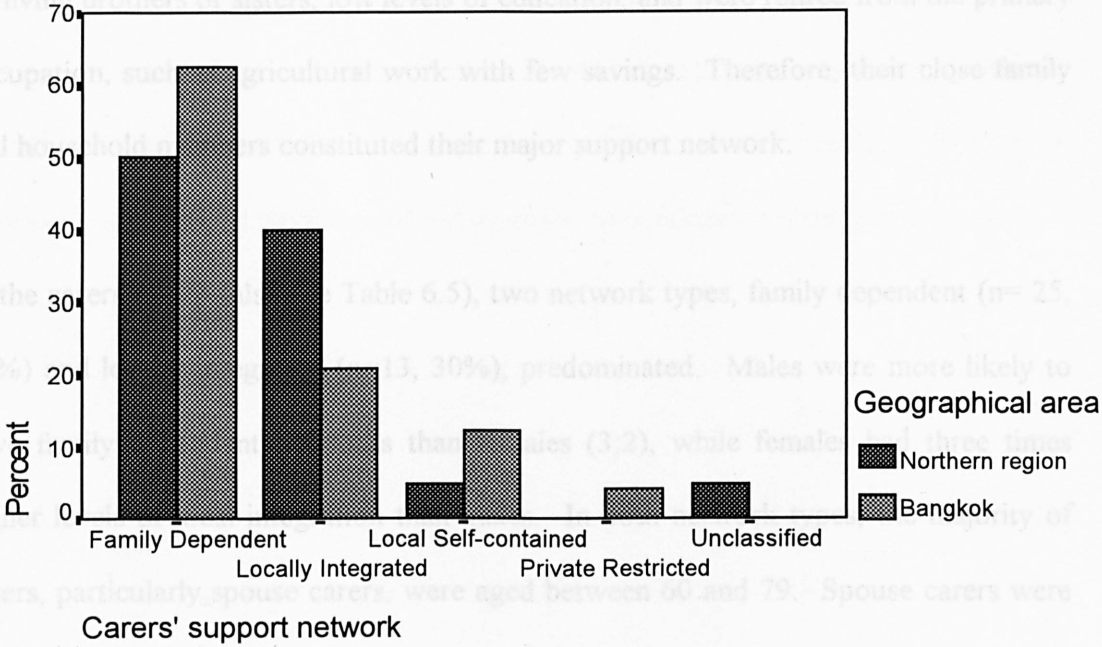


Figure 6.11 Distribution of carers' support network type by geographical area.

6.2.4. Characteristics of subjects and carers in relation to network types.

Two prominent network types: local family dependent and private restricted, were found in the subject groups (also see Table 6.4). In the local family dependent networks, which accounted for 62% (n=27), and the private restricted networks, which accounted for 34% (n=15), little difference in gender was found, but the number of family dependent networks appeared to increase with age, then dramatically dropped as fewer demented people survived to a very great age. The majority in both network types were aged between 60 and 89, with over one-third aged between 70 and 79. Most subjects (86%) lived with their spouse in an extended family consisting of their adult children and/or grandchildren, and other relatives; only 14% lived with their spouse alone. Although Wenger (1995) described the private restricted network as typically associated with absence of local kin, only 4 out of 15 subjects in this study lived with their spouse alone. Also, the majority of subjects in both network types had no living brothers or sisters, low levels of education, and were retired from the primary occupation, such as agricultural work with few savings. Therefore, their close family and household members constituted their major support network.

In the carers group (also see Table 6.5), two network types, family dependent (n= 25, 57%) and locally integrated (n=13, 30%), predominated. Males were more likely to have family dependent networks than females (3:2), while females had three times higher levels of local integration than males. In both network types, the majority of carers, particularly spouse carers, were aged between 60 and 79. Spouse carers were more likely than younger relative carers to be living in an extended family with their demented spouse, children and/or grandchild. It was common for spouse carers to have 3 to 4 adult children and it was common for younger relative carers to have 3 to 4 siblings, who provided support. The majority of carers did not work outside the house, 34% were housewives, while some worked either part-time or full-time at home (see Figures 6.5 and 6.7).

No subjects or carers fell into the wider community focused category, and only a few carers were categorised as local self-contained, which might be a reflection of the small sample size. On the other hand, those network types which were found in this study could be typically characteristic networks of demented persons and their carers in Thailand. Comparison of the distribution of network type between the subjects and their carers, indicates the direction of shift from a more independent network to a more dependent network type (also see Table 6.5). The most common shifts that have been identified are from locally integrated to family dependent support networks (Wenger,

1995) and from a family dependent network to a private restricted network. In addition, the decline of network size for both subject and carer is associated with the severity of the subject's illness and the level of demand for care from their carer. However, longitudinal studies need to be carried to confirm the change over time.

6.3. The Assessment of Strain on Carer

The Caregiver Strain Index (CSI) was used as a brief screening instrument for detecting strain in carers. It consists of thirteen questions about potential stressors: inconvenience; confinement; family adjustments; changes in personal plans; completing demands on time; emotional adjustments; upsetting behaviour; the parent seeming to be a different person; work adjustments; a feeling of being completely overwhelmed; disturbed sleep; physical strain; and financial strain (see Appendix II). 'No' responses were assigned the score 0 and 'Yes' responses were scored 1, giving a scoring range for the CSI as a whole from 0-13. Cronbach's alpha was calculated to assess internal consistency among items. Positive responses to seven or more items on the index probably indicate a greater level of strain (see Chapter 4, Section 4.5.4).

6.3.1. Distribution of carers' response to CSI

Although the present study was not specifically aimed at identifying high or low strain among carers, it was found that of 44 carers, nearly half (43%, n=19) responded positively to seven or more items on the index, and so were probably experiencing greater levels of strain, whilst 57% (n=25) responded to six or fewer items. The CSI scores obtained in the present study ranged from 2 to 12, median 6, and mode 6.

George and Gwyther (1986) and Novak and Guest (1989) have criticised the CSI instrument for being multidimensional. Thus, Marchi-Jones et al. (1996) suggested clustering the CSI items into 4 factors: physical and emotional strain; social strain, financial strain; and occupational strain of caregiving (Table 6.6). In the physical and emotional rather strains factor, the majority of carers appeared to experience considerable emotional than physical strain. For example 84% found changes in the cared-for person were upsetting, 66% had to make emotional adjustment, and 50% found the behaviour of the cared-for person upsetting. Nearly two-thirds (61%) of carers found family adjustment was related to the social strain of caregiving, including changes in personal plans and other demands on time. However, carers appeared to find less strain in caregiving, related to financial and work adjustments.

Table 6.6. Positive responses to CSI by factors

Items	"Yes"	
	Frequency (n=44)	%
Physical and emotional strains of caregiving		
Sleep disturbance	22	50
Inconvenient	11	25
Physical strain	12	27
Confining	14	32
Emotional adjustment	29	66
Behaviour of cared-for person upsetting	22	50
Change in cared-for person upsetting	37	84
Feeling overwhelmed	33	75
Social strains of caregiving		
Family adjustments	27	61
Changes in personal plan	24	55
Other demand on time	24	55
Financial strains of caregiving		
Financial strain	15	34
Occupational strains of caregiving		
Work adjustments	14	32

6.3.2. Distribution of CSI scores by carers' characteristics

Non- parametric tests are used to compare sets of scores when one can make certain assumptions about the data (Foster, 1993). The *Mann-Whitney U test* was used in this study to compare the median scores on a specified variable of two independent groups, such as, the CSI scores of carers by gender, carer group, care assistance, and geographical areas. Robinson (1983) suggests that women are not only usually the primary caregivers but also provide more extensive care than men and would perhaps experience more strain. The findings of the present study do not support that view, in that there was no significant difference (p >.05) between male and female respondents, the mean CSI scores being 6.2 and 7.1 for females and males respectively. However, there was a significant difference between the CSI scores of spouses and younger relative carers ($p<.05$), where spouses experienced lower levels of strain then younger relative carers. The younger relatives in this study included adult children, a niece, and daughters-in-law. The *Mann-Whitney* was also carried out to compare the two sets of CSI scores between geographical areas and groups of carers who did and who did not have care assistance at home. No significant differences were found between these two independent groups.

It might be assumed that the greater the number of living children or relatives, the more support will be available to the carer and the less strain they will experience. Spouse carers were asked the number of living children, whilst younger relative carers were asked the number of living siblings. The *Kruskal-Wallis* test can be used to compare the scores on a variable between more than two independent groups. It was found that there was no significant difference in the average CSI scores in carers who had different numbers of living children or relatives. There were also no significant differences between the CSI scores related to the carer's age, education, marital status, occupation, support network, and carers and cared-for relationship.

6.3.3. Distribution of CSI scores according to carer's well-being

Robinson (1983) found that carer health problems could exacerbate carer strain or, conversely, strain could adversely affect health. Carers, therefore, were asked to assess their health status as they themselves perceived it, by rating it from 1 (Excellent) to 5 (Poor) and comparing their present health to their health status one year previously, by rating it from 1 (Much better) to 5 (Much worse).

Carers who reported good and fair health represented equal proportions of the sample (45.5%, n=20), and no one reported poor health status (Figure 6.12). Half the carers said their health was somewhat worse than previously and nearly half (45.5%, n=20) reported that it was about the same, whilst only 4.5% (n=2) reported it was somewhat better (Figure 6.13). Cross-tabulation revealed that half the carers who reported good health said their health was about the same as it had been (50%, n=10) and nearly as many said it was somewhat worse (45%, n=9), whilst of carers who reported fair health status, the majority (60%, n=12) said their health was somewhat worse and about 35% (n=7) said it was the same.

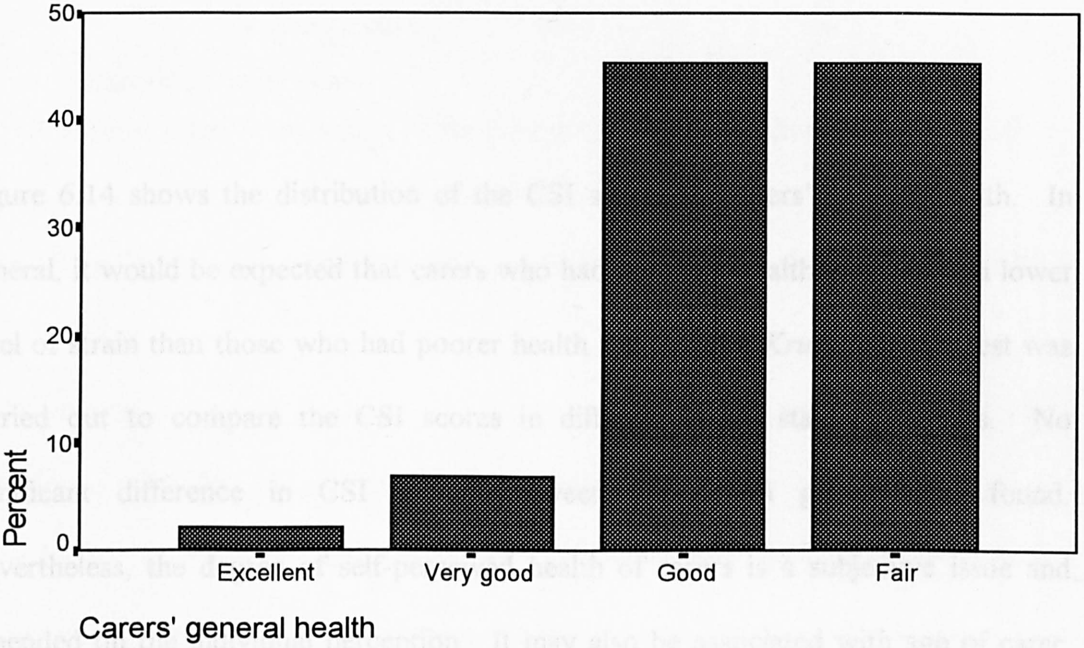


Figure 6.12. Carers' general health stage

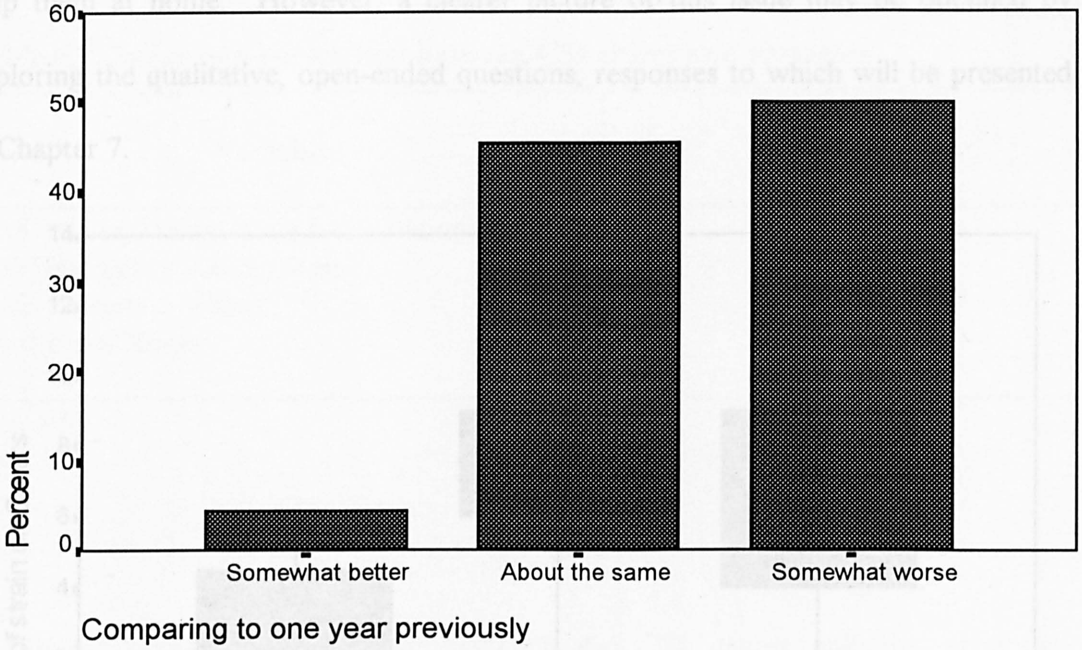


Figure 6.13 Carers' personal health status compared to one year previously

Figure 6.14 shows the distribution of the CSI scores by carers' general health. In general, it would be expected that carers who had excellent health might have a lower level of strain than those who had poorer health status. The *Kruskal-Wallis* test was carried out to compare the CSI scores in different health status of carers. No significant difference in CSI scores between the health groups was found. Nevertheless, the degree of self-perceived health of carers is a subjective issue and depended on the individual perception. It may also be associated with age of carer. For example, younger relative carers who perceived themselves as healthy but experienced a greater level of strain, probably did so, due to the disturbance to their regular work pattern, whilst spouse carers who saw themselves as having fair health status may have sought help from outside, such as a home help or care assistant, to help them at home. However, a clearer picture of this issue may be obtained by exploring the qualitative, open-ended questions, responses to which will be presented in Chapter 7.

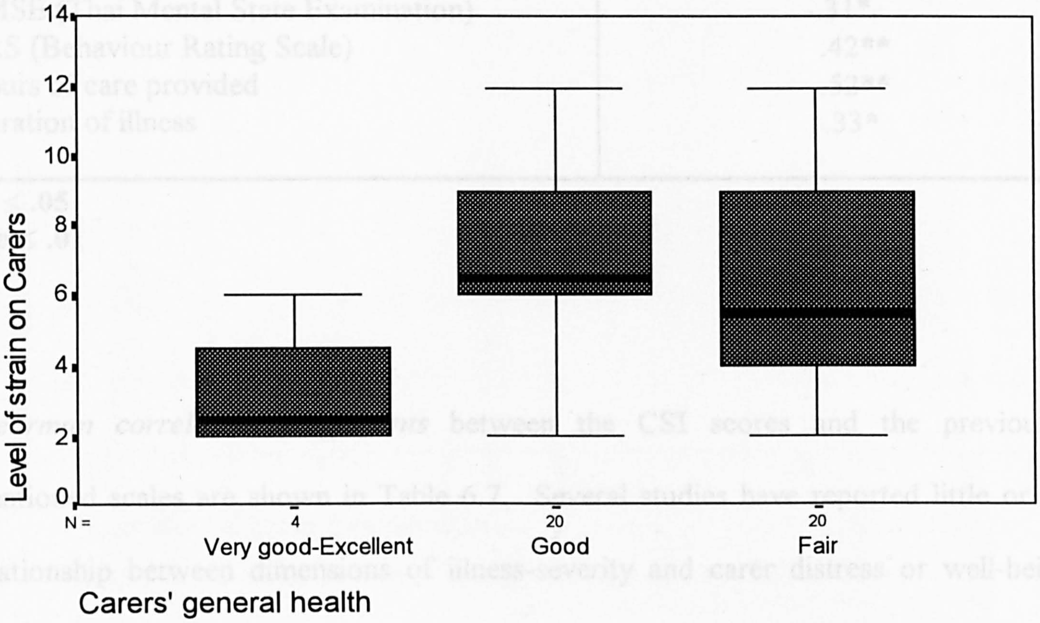


Figure 6.14. Distribution of the carers CSI scores by their general health

6.3.4. The Correlation between CSI score in the Carer and the Subject's health status.

The subjects' cognitive function was measured by using the Thai Mental State Examination (TMSE). In this scale, lower scores indicate more cognitive impairment. Behavioural competence was measured, to assess the level of the subjects' independence, by using the Behaviour Rating Scale (BRS), with higher scores indicative of more independence. These scales, together with the duration of illness and the length of time care was provided by the carers, were analysed in relation to CSI scores, using rank correlation, in order to examine whether these factors were related to the level of strain in the carers.

Table 6.7. Spearman correlation between CSI scores and variables

Variables	*r*
TMSE (Thai Mental State Examination)	-.31*
BRS (Behaviour Rating Scale)	.42**
Hours of care provided	.52**
Duration of illness	.33*

$*p \leq .05$
$**p \leq .01$

Spearman correlation coefficients between the CSI scores and the previously mentioned scales are shown in Table 6.7. Several studies have reported little or no relationship between dimensions of illness-severity and carer distress or well-being (Chappell and Penning, 1996). However, in the present study, there was a significant negative correlation between CSI scores and the TMSE ($p \leq .05$), which means there was a relationship between level of cognitive impairment and strain in carers. The scatterplot in Figure 6.15 shows a negative relationship between the CSI and the TMSE scores; the higher the CSI scores, the lower the TMSE scores. This suggests that higher levels of strain are associated with the higher levels of cognitive impairment.

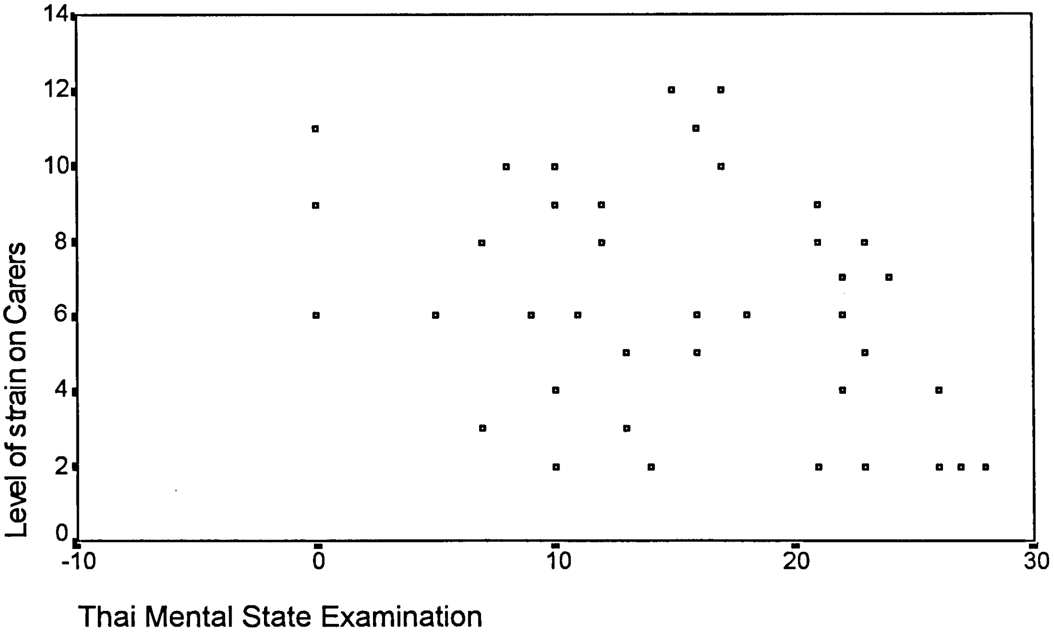


Figure 6.15. Distribution of the CSI scores by the TMSE scores

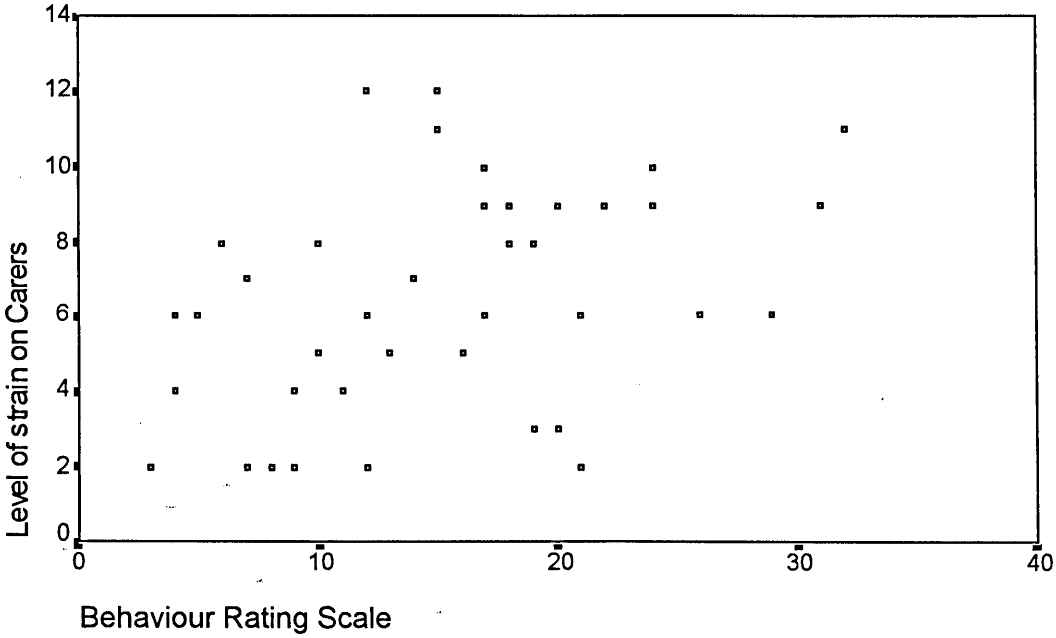


Figure 6.16. Distribution of the CSI scores by the BRS scores

There was a significant positive correlation between the CSI and the BRS scores ($p \leq .01$). One interpretation may be that lower levels of independence in the subjects influences the higher levels of strain in carers. The scatterplot in Figure 6.16 shows a positive relationship between the CSI and the BRS scores; the higher the CSI scores, the higher the BRS scores. This suggests that higher levels of strain are associated with higher levels of dependence.

The CSI scores were also related significantly to the duration of subjects' illness ($p \leq .05$) and the hours of care provided by the carer ($p \leq .01$). These findings suggest that the level of strain in carers is increased with the increasing hours of care provided and the duration of their elderly relative's illness. Figure 6.17 shows the distribution of the CSI scores, which gradually increased with the increasing hours of care provided. This correlation indicates that the longer the duration of the subject's illness (which might, perhaps, be associated with greater physical and cognitive deterioration) and the more care was provided, the greater the strain on the carers. This finding is similar to those of Deimling and Bass (1986) and Baumgarten (1989). These researchers found that the severity of dementia, such as functional dependencies and cognitive impairment symptoms, was related to carer strain, the more severe symptoms causing greater stress (Biegel, et al., 1991).

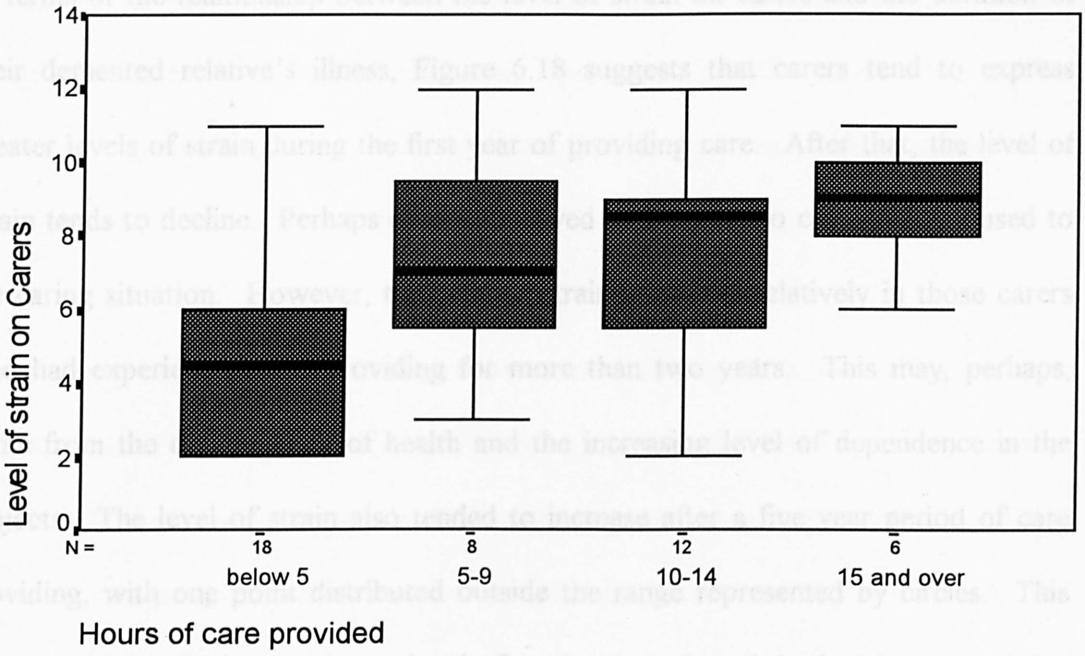


Figure 6.17. Distribution of the CSI scores on carer by hours of care provided per day

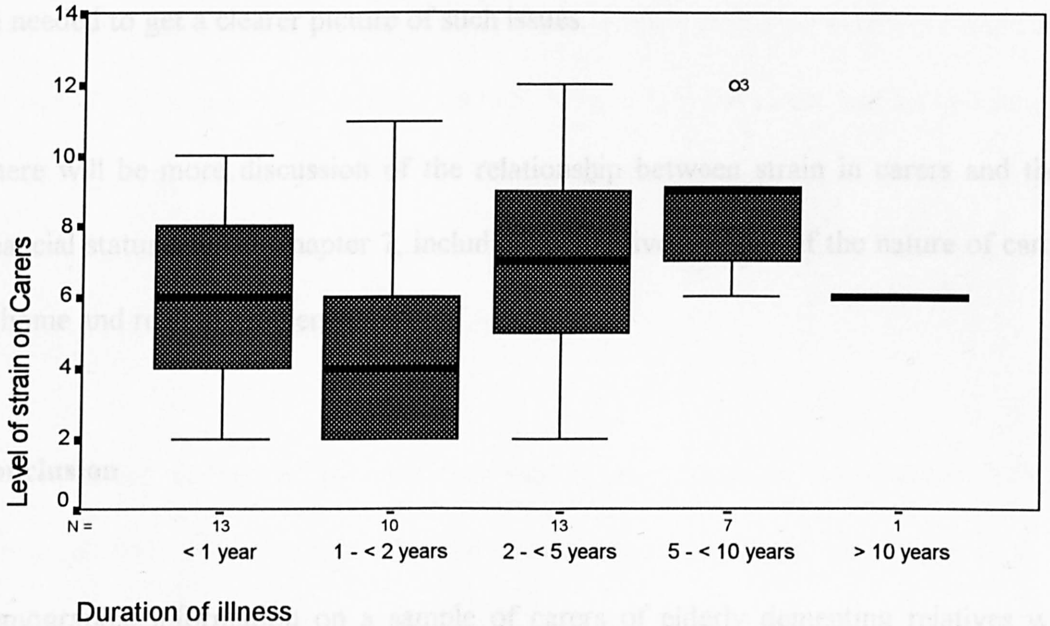


Figure 6.18. Distribution of the CSI scores by the duration of illness

In terms of the relationship between the level of strain on carers and the duration of their demented relative's illness, Figure 6.18 suggests that carers tend to express greater levels of strain during the first year of providing care. After that, the level of strain tends to decline. Perhaps carers improved their ability to cope and got used to the caring situation. However, the level of strain increased relatively in those carers who had experienced care providing for more than two years. This may, perhaps, come from the deterioration of health and the increasing level of dependence in the subjects. The level of strain also tended to increase after a five year period of care providing, with one point distributed outside the range represented by circles. This was a son who displayed a lower level of strain, even though he had been providing care for his alcoholic demented father for ten and a half years. This may indicate the individual ability to cope with the caring situation. However, a bigger sample would be needed to get a clearer picture of such issues.

There will be more discussion of the relationship between strain in carers and their financial status later in Chapter 7, including qualitative analysis of the nature of caring at home and related problems.

Conclusion

Demographic information on a sample of carers of elderly dementing relatives was presented in this chapter. The main carer was identified as the person who spent the longest hours in providing care. The 44 carers ranged in age from 25 to 85 years, mean 56 years, SD=16.5, and the most frequently found were aged between 60-70 (n=16, 36%). There was a prominent gender difference among carers, with 80% (n=35) female and only 20% (n=9) male. More than half the carers were spouses (55%, n=24), one-third were adult children (32%, n=14), and the remainder were daughters-in-law and other relatives.

The majority of carers in the rural northern areas were primary school educated, while carers in Bangkok and the metropolitan area had a relatively higher level of education. Two-thirds of carers did not work. The majority of these were spouse carers. Single status in younger relative carers was often found in this study. Only five spouses and five younger relative carers lived with the dementing person alone. There was a significant positive correlation between the hours of care provided by carers and level of dependence of the subjects ($p \leq .01$). 41% (n=18) of carers provided care for less than 5 hours a day or less than 35 hours a week, while 14% (n=6) carers provided care for over 100 hours a week. More than half (57%, n=25) the carers had a small support network, categorised as a local family dependent support network, in which nearly all support was met by the family. Carers in Bangkok and the metropolis had fewer social integration networks than carers in the rural areas.

Spouse carers were found to experience significantly less strain than younger relative carers ($p \leq .05$). The findings from the present study suggested that higher level of cognitive impairment and higher level of dependence in the dementing relatives related significantly to the greater levels of strain on carers. Moreover, the greater level of strain on carers was also found to be related significantly to the increase in hours of care provision, including the duration of the dementing illness.

CHAPTER 7

Research Findings (Part III)

The Nature of Caring for a Demented Relative in Thailand

Introduction

This chapter contains the final part of the research findings, namely qualitative data about carers. These data were based on in-depth interviews with individual carers, using open-ended questions. The answers were tape recorded and transcribed shortly afterwards. They were also translated from Thai into English; some responses will be quoted, in translation, later in this chapter. Qualitative data discussed includes the problems of caring; the financial situation; the relationship between carers and subjects, such as attitude toward subject; religion and culture; personal health; carers' needs, including needs for information, financial support, respite, aids and services; and finally, traditional medicine. Each aspect is discussed in turn below.

7.1. Caring situation

44 carers, comprising 24 spouse and 20 younger generation carers, were interviewed in their own homes. Most carers were living in the same house with the demented person, the subject, for whom they were caring. The interviews with carers explored how they came to provide care, how they coped with the problems they faced and the impact of caring.

7.1.1. How people became carers

The reasons people gave as to why they become carers varied, depending on their relationship to the demented person. In the case of spouse carers, marital commitment was the obvious reason; the most common answers were "I am his wife" or "I am her husband." The sense of duty and responsibility to care for one's spouse was expressed by some respondents, for example:

> C 12: "Of course husband and wife have to take care of each other whatever disease we suffer from, because we have been married more than 50 years."
>
> C 22: "If we don't take care of each other, who will care for us?"

Although some respondents mentioned 'living in the same house,' the meaning behind this reason also related to married commitment. The majority of them said, "we've lived together since we got married," reflecting on their loving caring and appreciation of a long and happy married life. In another sense it could mean they would care for anybody who became sick who lived in the same house.

Physical disability is also a potential force which led them to become a carer. An elderly lady, who had been blind for 22 years and could not go out to work, stayed at home all the time. When her husband developed cognitive impairment she became a carer because one of her adult children, who lived with her, had to work outside the home. She said, "we live in the same house and I can't go out because of blindness"

The reasons for becoming a carer in the younger relative group, including in-laws, varied, though again, family responsibility was a major factor. The majority of younger relative carers referred to their blood tie commitment to the subject, in such words as "I am his daughter" or " I am her son," reflecting their sense of filial duty to care for the subject. Traditionally, families cared for their elderly relatives, and this is still practised in Thailand. A study by Wongsith (1990), which surveyed rural adults in two different regions, found a general agreement that it was the children's responsibility to take care of their parents when the parents grow old. Also the further data analysis based on data from the national survey on the 'Socio-economic Consequences of the Ageing on the Thai Population' in 1986, with 2,113 younger generation sample aged between 15 to 44 years old, and found that most of this sample had frequently provided care and support to an elderly relative for more than 5 years and the majority of them intended to continue providing support until their elderly parents or they themselves passed away (Siriboon, 1993). Thus, most of the younger relative carers looked at me with wonder, in a way that made me feel uncomfortable, when I asked the question: how they became a carer. Knodel et al. (1995) found that 96% of the adult children respondent focus groups from both Bangkok and four rural villages from each of the major regions, held the view that the elderly should live with their children.

Marital status was also found to be a significant factor in becoming a carer. In Thailand, adult children tend to move out when they get married, while adult children who are not married will remain in the parental home. Both unmarried sons and daughters were found in this study, though five times more unmarried daughters than unmarried sons cared for their elderly demented parents at home. Since in Thailand marriages normally follow in sequence from the eldest child to the youngest child, the responsibility for care is most likely to fall on the youngest child, who would be the last to marry. However, this study included one eldest son and one eldest daughter who were single and remained at home and then became carers after their parents developed dementia.

Gender is another important factor in becoming a carer. As mentioned earlier, more unmarried daughters than unmarried sons became carers. In families where all the children are married, particularly in rural areas, daughters are expected to bring their husbands into their family system and continue to cultivate their parents' land, while sons move into the wife's family system. Thus, there is an expectation that the youngest daughter will remain in the household even after her marriage, to care for her parents until they die (Caffrey, 1992a). However, in the present study, care was not confined to the youngest daughter. The same number of only daughters as youngest daughters was found, and there was no difference, in this respect, between geographical areas.

According to cultural differences in Asia, there were two types of family systems which govern intergenerational relationships and living arrangements: the bilateral and patrilineal family systems (Asis, et al., 1995) (see Chapter 3, Section 3.3.2). In bilateral family system, mostly found in Southeast Asian populations, such as Filipinos, Thais, and Singaporean Malays, gender is less significant in the choice of co-resident child, whilst in the patrilineal family system, mostly found in East and South Asia populations, such as the Chinese in Taiwan and Singapore and Singaporean Indians, parents should live with a married son (Asis, et al., 1995).

In the present study, of the 10 subjects (22.7%) who were members of the Thai-Chinese ethnic minority, 8 subjects lived with their sons, although the person who provided care was their daughter-in-law or another co-resident daughter. In the case of carers who were daughters-in-law, most of them had moved into their husbands' families after they had married. In only one case had the son's mother moved into her son's house only after she developed dementia. Among the Thai-Chinese ethnic minority after marriage, the son, especially the eldest son, is expected to bring his wife into his family, in order to take care of his parents and his younger brothers and sisters. Four out of five daughter-in-law carers in this study were married to Thai-Chinese husbands who were born in Thailand, whilst only one was married to a Thai husband who was a youngest child and remained in the family. In contrast, the subjects who were Thai lived with their spouse and/or adult children, mostly a daughter rather than son. These findings also indicated that women, no matter whether they were daughters or daughters-in-law, were expected to provide care for their elderly relatives or in-laws.

7.1.2. How it was decided who should be a carer

Although marital commitment led spouses to become carers and blood ties led children to become carers, in the case of younger generation carers, how was it decided which sibling should take this role? When they were asked whether there had ever been any discussion about who should take care of the subject, the majority of carers said 'no' or 'never'. It is, therefore, interesting to know how the decision making took place, since the issue was, in most cases, never discussed.

The decision making as to who should take care of elderly relatives and living arrangements took place both before and after the elderly relative developed dementia. In Thailand, customarily, children do not wish to leave their parents alone (Caffrey, 1992b) and the traditional practice of one or more children remaining with the parent as they grew older is still common, especially in rural areas (Sittitrai and Thomas, 1988). Also, adult children who remain at home are expected to provide care when their parents become ill. We can call this situation, a 'primary caring arrangement,' where carers were selected to remain at home before their elderly relative became ill. The question then is 'who should remain at home' as well as 'who should be a carer.' Being the only child; being single; the expectation that a daughter will be a carer; being the last to get married, after siblings have married and moved out; and bringing a widowed parent into one's home or moving back to stay with parents after divorce, were all reasons which led to the pre-selection of a carer. The care situation after the onset of dementia was thus usually an extension of an existing arrangement.

Secondary caring arrangements were those that took place after the elderly relative became ill. It was found that individual responsibilities or difficulties determined who should take care of the elderly relative. Those adult children who realised that they had the least responsibilities, for example those who were single, or divorced with no dependent children, or worked at home; who had no financial difficulties; and were able to fit their care-providing with their other activities without difficulty (Caffrey, 1992b), tended to volunteer themselves to take care of their elderly relatives. Comments made by carers in this study included:

> C 14: "I have to take this responsibility , because my elder brother
> stays at his Army base." (son)

> C 17: "My husband decided to take care of his father, because we are better off than his brother and sister." (daughter-in-law)
>
> C 44: "No we haven't discussed it. I am the youngest daughter, divorced and have no children, so I decided to take care of my mother." (daughter)

In the present study, adult daughters often fell in with their parents' expectation that they would be the care provider, and some felt a female could provide better care than a male. Two younger relative carers, who were the only daughters in their respective families, volunteered to care for their demented mothers at home. In Thailand, daughters are trained from an early age to take on household responsibilities, and transition into the final phase of her parent's family life cycle as carer does not necessarily involve an assumption of an unexpected role (Caffrey, 1992b).

Co-residence with the subject and other members of the family was also associated with the care providing role in spouse carers. More than half (54%, n=24) the carers were spouse carers and the majority of them (79%, n=19) were co-resident with their adult children. Although five spouse carers (21%), four lived in Bangkok, lived alone with their demented spouse, over half of them had adult children living in the same area. Since the primary and secondary caring arrangements referred to earlier were not achieved, it was quite common for the spouse to become a carer automatically if their were no adult children or close relatives living nearby:

> C 8: "No we've never discussed it; my only son has moved out when he got married"
>
> C 22: "No,... all my children have moved out since they got married, as well as my single daughter"

In cases where the elderly couple were still co-resident with their adult children and the remaining adult children at home might be expected to provide care, the elderly spouse often provided care for their demented spouse themselves. This raised the question, why did spouses still become carers when they had adult children around? Again the process of deciding who should take the caring responsibility was not explicit. However, it was found that the working situations and the availability of time were central issues in determining who should become a carer. Where adult children were out at work there was a tacit agreement that the parent should take care of their demented spouse at home. Half the spouse carers who were co-resident with their adult children made comments such as:

> "No, we haven't discussed it. I have to do it myself, because my children have to work."

There were also two male spouse carers who had retired from work and so agreed to become carers because they had more free time than their adult children, who were still working:

> C 19: "I am retired from work while my married son and his wife are working outside the home, so I have to take care of my wife."
>
> C 36: " I am a pensioner husband."

Nevertheless, nearly half the spouse carers who were co-resident with their adult children mentioned receiving help in caring from their adult children, for example, "my daughter and my grandchild help me out" (C 2).

The decision as to who should take care of the elderly relative was also influenced by the elderly themselves, particularly in the case of a widow or widower. In the case of one elderly demented widow, her daughter said "it depends which children she wants to live with; everybody always welcomes her" (C 19). This shows the continued power of the elderly, in that whatever decision they made, their adult children appeared to accept it.

7.1.3. How happy are carers with the arrangement?

The present research focuses largely on the direct relationship between a number of variables and burden and strain on carers, to determine the level of help carers need. However, to understand informal care better in global terms, a positive approach question about their gratification in caring, i.e. how happy were they in providing care for their demented spouse or demented elderly relative and with the living arrangements, was included (see further discussion in Chapter 8, Section 8.3.2).

Nearly two-thirds (61%, n=27) expressed themselves as being happy and very happy, while only 16% (n=7) expressed themselves as being less happy and 7% (n=3) said they were doing fine. Including, 16% (n=7) considered caring for the elderly as their duty. Of 24 spouse carers, nearly half (n=11) said they were happy to provide care for their demented spouse with help from their adult children and/or from a paid care assistant:

> C 15: "Yes,... at least I have a son to help me out at home."
>
> C 23: "Yes, I am happy, because I still have my children around and I also have two helpers."

A quarter (n=6) claimed to be happy to be a carer because it was their duty as a wife or a husband of the subject. A few said they were very glad to be carers, because of their love for their spouse, while one simply said it was "all right." In the case of this last person, all her children worked abroad but they came to visit her regularly and hired a home help and a care assistant and provided financial support. In only two cases did the spouse carer claim to be unhappy with the arrangement. One was a housewife who had had a poor relationship with her husband before he became ill. Another housewife said that social pressure made her remain to provide care for her husband, in the face of the difficulties caused by his hallucinations, neglect of her instructions, and increasing aggression. She said she was fed-up of the difficulties of providing care for him, but she could not leave him because she was afraid his relatives and friends would blame her for not doing her wifely duty.

In an extensive study of family care in a rural area in Thailand, Caffrey (1992b) identified the primary motivations to care as, firstly, fulfilling the expected cultural norm of filial obligation; secondly, love or affection for the elder; and finally, a desire to reciprocate for past services and to build up future merit for themselves. The findings from this present study confirm Caffrey's (1992b) findings regarding the continuation of the family care culture in Thailand. Of 20 younger relative carers, nearly three quarters (n=14) expressed their gratefulness to have the opportunity to provide care, and their happiness with the caring arrangement was referred to as reciprocation for earlier parent care, so called *'parent repayment'*, and filial duty, for example:

C31: "Yes, it' s a good opportunity to repay him for raising me".

C 1: "Very glad, it's my duty".

A few of them said they were the only people available to provide care for the subject, but were also motivated by love and sympathy for the elderly person. Some indicated they felt an obligation to provide care since there were no other available carers. They made comments such as "He has nobody except me to care for him" (C 14) and one daughter said "It's a pity, she has nobody else who could provide care for her" (C 41). However, there was one case, where a daughter carer, although glad to be the carer, was not very happy with her brother's attitude towards the caring arrangement. She described how her brother had moved out after getting married and left his share of the responsibility for their mother to her. When she complained about the caring task, he said "It is your duty" (she was the only daughter) "and you have to accept this situation" (C 21). This reflects, again, the fact that the attitude to caring was associated with gender. Women, rather than men, are assumed to be the people with the caring responsibility. Strong traditional cultural values emphasise the role of women in providing care for their elderly parents (Caffrey, 1992b). This raises the question: what will happen in the near future as women are increasingly entering the labour market to overcome their economic difficulties?

7.2. Religion and Caring

The majority religion (95%) of Thailand is Buddhism (The Office of the Prime Minister, 1991). To most Thais, to be a Thai is equated with being a Buddhist

(Mulder, 1994) and Buddhism is deeply rooted in the hearts of Thai people (Suriyabongs, 1958). The Buddhist philosophy and its influences on the Thai culture and people's behaviour in everyday life were discussed in Chapter 3, Sections 3.4 and 3.5. The most important point for this study is the clear relationship throughout Thailand found between the Buddhist doctrine and caring for elderly relatives.

In the present study, the majority of adult children expressed their appreciation and satisfaction with caring arrangements and related this to the Buddhist doctrine of reciprocity. The sense of reciprocity or concept of parent repayment refers directly to the obligation to repay parents and is a value firmly ingrained in the culture which is equivalent to *'kathanyu katawethi'* in the Thai context (Asis et al., 1995). However, caring for demented people is very hard work. Carers have to devote most of their time to providing care, and this brings physical and psychological strain, especially when the elderly person is in the last stages of a dementing illness. In order better to understand the relationship between the Buddhist religion and the care of older people, particularly among carers who care for elderly demented relatives, the present study explored how individual belief in Buddhism was transformed into practice, whether there was any difference in care provision by religious, moderately religious, and non religious carers, and other influential factors which may have induced the carer to accept the care providing role.

7.2.1. Practising Buddhists

All the carer participants were Buddhist followers, and expressed their satisfaction in fulfilling the obligation imposed by Buddhist doctrine. As a result, the majority of carers were satisfied to adopt such a role and happy with the elderly relatives' living arrangement (see Section 7.1.3). It is still not clear from this how an individual carer's religion affected the motivation to become a carer and the quality of care provided. Do carers who are very religious follow the Buddhist doctrine more seriously and perform their duties with more satisfaction than carers who are not religious?

In order to explore individual religious belief, therefore, during the interviews, all carers were asked to rate how religious they considered themselves to be, from not at all, to strongly. Nearly two-thirds of carers said they were moderately religious, and only a few indicated they were not religious. Among spouse carers, most said they were moderately to strongly religious and none admitted to being non-religious. Among the younger relative group there were more who said they were non-religious (all of them were from Bangkok) or slightly religious. However, moderate religious belief was the most common in both carer groups. Age was also associated with differences in individual religious belief; no carer aged below 40 admitted to being strongly religious; the number strongly religious tended to increase with age (see Table 7.1).

Table 7.1. Correlation between religious belief and groups of carers, regions and age groups of carer, region, and age groups.

Demographic variables	Individual Religious Belief not at all n=3 (6.8%)	slightly n=7 (16%)	moderately n=26 (59%)	strongly n=8 (18.2%)	Total (%) n=44 (100%)
Carers' groups					
Spouse	0	2 (8.3)	16 (66.7)	6 (25.0)	24 (54.5)
Younger relative	3 (15)	5 (25.0)	10 (50.0)	2 (10.0)	20 (45.5)
Regions					
Northern region	0	3 (15.0)	14 (70.0)	3 (15.0)	20 (45.5)
Bangkok (Central)	3 (12.5)	4 (16.7)	12 (50.0)	5 (20.8)	24 (54.5)
Age groups					
below 40	2 (22.2)	1 (11.1)	6 (66.7)	0	9 (20.5)
40-59	1 (7.1)	4 (28.6)	7 (50.0)	2 (14.3)	14 (31.8)
60-79	0	2 (12.5)	10 (62.5)	4 (25.0)	16 (36.4)
80 and over	0	0	3 (60.0)	2 (40.0)	5 (11.4)

However individual rating of the strength of religious belief alone is not sufficient evidence of adherence to a religion. One way to address this issue was by cross-checking these ratings by asking respondents about their involvement in practising Buddhist doctrines. In general, a person who more often adheres to Buddhist ways may be assumed to be more religious. Again, measurement of practise of religion and moral belief is a complex issue. Mulder (1973) indicated that Thai religious behaviour is a syncretism of Hindu-Brahmanic, animist and Buddhist belief and ritual, with Brahmanic rituals often taking place in conjunction with Buddhist ceremonies in which the monks officiate. Buddhist ceremonies normally take place at the temple, although they are sometimes performed at home. To examine Buddhist activities among carers, therefore, they were asked how often they visited the temple per month. Nearly half the carers said they visited only infrequently and nearly one-third indicated never.

However, some of spouse carers explained that their own health, or their care duties, affected the frequency of their visits to the temple, as follows;

> C 4: "It depends on my children. If they have time, they can take me there, if they haven't, I can't go."
>
> C 35: "I visited the temple quite often previously, but now I rarely go there because I have to provide care."

Some younger relative carers commented that another family member represented them in carrying out Buddhist activities, as well as they were constrained by the time spent in care provision, for example:

> C 7: "Whenever, my father or mother go to the temple, it does represent to us, because we live in the same house."
>
> C 21: "I rarely go to the temple. I used to be able to go there, but now, I have a caring duty."

The Buddhist doctrine of *Karma* teaches that good deeds earn merit and evil deeds earn demerit or *baab* (Suriyabongs, 1958 and Wongsith, 1992), doing good things implies reciprocation, or kindness, or favours. This might be interpreted as reinforcing or contributing to a social manner involving selflessness, compassion, and altruistic qualities (Yablo, 1990). Buddhists seek to acquire merit, or in Thai the concept, *Tham bun,* through numerous religious rituals such as becoming a monk, building a temple or offering food to monks. The merit so gained is reflected in one's station in this life, resulting in feelings of security, consolation and well being, and in successive rebirths (Benedict, 1943, Mulder, 1973, and Basham, 1989). Carers were asked about a range of Buddhist activities, including temple attendance, practising meditation, and other activities. It may be suggested that those Buddhist carers who were very religious, might be found to have a positive attitude towards being a carer and provide a better quality of care and, whilst those who were not very religious, might be more likely to see their elderly demented relative as a burden and have negative attitudes towards caring.

Overall, the majority of carers in this study said they did not attend a temple, nor did they practise meditation, or perform other religious activities. Nevertheless, merit-making activities such as offering food to monks, and donating money or possessions to the temple or the poor were commonly found among carers. Out of eight carers who rated themselves as strongly religious, two admitted that they did not visit the temple, and seven admitted not attending ceremonies. Inability to participate in religious ceremonies may in some cases have been due to caring duties and health, as mentioned above, but this does not mean that respondents did not practise. They could offer food to monks who come to their door step every morning or follow the Buddhist teaching very strictly in their own home. Finally the possibility of error in the individuals' self rating needed be considered: strength of religious belief and practice could be under or over estimated by an individual.

7.2.2. Carers' views of 'reciprocity'

The Buddhist doctrine in relation to children's duty towards their parents is, since they raised you, you have to raise them back (Wantayun, 1973; Mulder, 1985; Klausner, 1987; Caffrey, 1992b), in other words *'parent repayment'* which is viewed as a continual obligation that starts when children are old enough to provide meaningful help and typically begins long before parents reach old age (Knodel, et al., 1995). This raises the question of what are younger relative carers' attitudes toward reciprocity to their elderly relatives.

In this study, the majority of younger relative carers (80%) mentioned a strong sense of obligation to repay their parents, and indicated how important it was. For example:

> C 6: "I think because they raised us, we have to repay them."
>
> C 7: "I will do everything I can to repay her for having borne and raised me."
>
> C 17: "It's very important. It's our duty to repay them."

Most younger relative carers appeared to appreciate their parents and described their desire to reciprocate. Only one participant mentioned explicitly that reciprocity is a tradition of this type of care.

There was also no difference in attitude toward reciprocity among spouse carers. The majority of spouses also had positive attitudes toward this term, saying things like "it is a good thing we have to do," and "it is very important to repay parents." There was also a sense of the need to be a good role model to their children and the expression of uncertainty as to whether parent repayment really exists in modern life, since all of them had to care for their demented spouses by themselves.

> C 4: "I think if I hadn't taken care of my parent, my child might not have cared for me too."
>
> C 20: "Really, children should take care of their parents, but nowadays they have to stay near their work place and set-up their own family."

Reciprocity or parent repayment in some instances means that children not only repay their parents by caring for them, but also stay in the same house with them. One spouse explained it by saying, "if a child who remained at home to care for their parent, that would be called parent repayment." These findings suggest that both spouse and younger relative carers had a positive attitude towards reciprocity which is associated with parent repayment. It was certainly clear that elderly parents who also acted as spouse carers preferred this kind of care, but their desire will not be met unless their adult children remain at home and care for them too.

In a comparative study of elderly living arrangements in four Asian countries, Thailand, Taiwan, Singapore and Philippines it was shown that Thailand had the second highest level of co-residence (77%), with at least one adult child. This comparative study concluded that co-residence appears to be stable in Thailand (Asis, et al., 1995). The findings from the present study also showed no decline in coresidence with adult children among elderly people with dementia, in that only 13.6% of demented person lived with their spouse alone. However, an adult child who is co-resident with an elderly parent is no longer assumed to be able to provide care, since three quarters of spouse carers were also co-resident with their adult children but they had to take the carer's role.

7.2.3. Expectation

The expectation of providing care for an elderly parent is very common not only in Thailand, but in Asian countries generally. In mainland China, there is an expectation that is similar to the idea of parent repayment and children are considered to owe elder care in return for child care and the gift of life that their parent provided (Sangkar, 1989). This expectation may also include co-residence with adult children which is associated with concerns regarding the need for health care was commonly found in Thailand, Singapore, Philippines and Taiwan (Asis et al., 1995).

Most younger relative carers seemed to know whether or not they were expected to provide care for their elderly relative. Nearly half said, "yes", or "I suppose so" and others said "no" or "I don't think so." Only a few of them said they did not know, for example, nearly half the younger relative carers who were either single or married with no children said, when asked, that they did not know whether they expected anybody to care for them. In contrast, the majority of spouse carers did not know whether they were expected to be a carer by their parent, however, most of them answered "yes", they expected one of their children to care for them.

It is quite clear that the majority of adult children or younger relative carers knew that they were expected to provide care for their parent, while spouse carers who were also parents, also expected their children to care for them. This evidence, thus, indicates a good prospect for the continuation of family care in Thailand, since both parties have the same expectation. Nevertheless, when this expectation is not met, disappointment is felt. Two old ladies who cared for their demented spouses expressed their disappointment with their children whom they had expected to care for them when they grew old. Comments were made such as, "I've never expected it. I'm afraid if I expect it, but it doesn't happen, I will feel unhappy." Further discussion revealed they were concealing their expectation, which had not been met.

When the question was raised, under what circumstance they would not expect their child to look after them when they grew old, over half the spouse carers and one-third of younger relative carers mentioned their own health, saying that if they remained in good health, they would not need their children to look after them. For example:

> C 8: "If I am still healthy and have no difficulties, I won't need any help from my child."
>
> C 38: "If I stay healthy, I won't bother her (daughter), because she is already busy with her work."

However, over one-third of spouse carers could not envisage any particular circumstance in which they would not be cared for by their children. Some of them added, "I think I need them all the time" or said they did not believe that any such circumstances would occur, because they did expect their children to care for them. This finding confirms the evidence that there is a strong expectation on adult children in Thailand that they will care for their parents. One younger relative carer expressed uncertainly as to whether she would be cared for by her son because she believed that males are more adventurous and less likely to stay at home than females, who tend to stay living with their parents.

7.2.4. Reciprocity and Mutuality in Caring

The perception of reciprocity in carers as synonymous with care providing and duty, was an important issue emerging from the present study. As mentioned earlier, the feeling of obligation or perception of reciprocity in this society is closely linked with the Buddhist doctrine, which is different from the West, where reciprocity is derived from normal family life (Frinch and Mason, 1993). Thus, the value of the term 'reciprocity' in the Thai context cannot be the same as that in the West. In the Thai context, although adult children are expected to provide care for their parent, however, satisfaction can be achieved when the care is delivered, arising out of a sense of fulfilling the expected cultural norm of filial obligation, fulfilling a desire to reciprocate for past services, and building up future merit for the carer (Caffrey, 1992b). If the 'mutuality' (the ability to find gratification and meaning in care providing) theory of Hirschfeld (1981) (see Chapter 2, Section 2.9.1) is applied to the present study, it will be likely to appear that most carers have high potential to develop mutuality, due to the potential the caring role gives them for reciprocity, rather than serving their elderly relative as a burden. With regard to these circumstances, the question arises whether carers in Thailand experience more rewards or satisfaction and experience less stress than carers in the Western countries. This issue will be discussed in Chapter 8 (Section 8.3).

7.3. Caring Problems

In the present study, carers were asked to explain the problems they faced in providing care at home and were also asked to mention the particular difficulties at the time of the interview. The caring problems are discussed below:

7.3.1. Particular Difficulties

The particular problems at the time of interview, which the majority of carers mentioned, were difficulty in dealing with the subject's psychological problems, carers' stress and physical strain, memory loss, and other problems, as follows:

i) Psychological problems: The subjects' psychological problems were a major difficulty that was mentioned by carers. Firstly, obsessive compulsive behaviour. For example: a few carers were concerned about their elderly relatives' obsessive eating; one son complained about his father who went to the toilet without passing any urine at all hours of the night; and a daughter said that her father washed his hands all day and came to check her very often at night when she was in bed. The second type of problem that carers mentioned was severe behavioural disturbance, such as risky behaviour, paranoia, and violence. In Chiang Mai an old man accused his wife of having an affair. In Bangkok a retired postman carried a gun, because he said he had seen a burglar trying to climb his fence. A retired teacher became more aggressive and had recently fought with his wife and hit her, breaking her arm. The third psychological problem which was found in the subjects was mood swings. One spouse carer said her husband easily lost his temper, and a daughter-in law talked about her mother-in-law saying "she always has a bad temper and shouts at people" (C 41).

Finally, carers were found to be upset at being unable to communicate with their elderly demented relative which led them to give poor co-operation, due to their confusion. In the case of early dementia, carers felt particularly frustrated about the subjects' lack of co-operation, for example:

C 4: " He never does anything that I ask him to do." (spouse carer)

C 6: " He always does what he wants to do. He never listens to us."
(younger relative carer)

Such unco-operative behaviour got worse when the subjects went through a very confused state which rendered them unable to communicate. An old lady said, "He's shouting and crying out all day all night." By the time the subjects get to the late state of dementia they become more quiet, and have no perception of anything, so one daughter said about her mother, "I can't communicate with her, so I don't know what she wants" (C 44)

ii) Stress and Physical Strain on carer: The majority of stress and physical strain complaints were found among spouse carers rather than younger relative carers. These complaints always related to the demands of caring for the subject with little or no help from either family members or outsiders. For example:

C 20: "I have to help her walking upstairs and downstairs everyday."

C 29: "I feel very stressed, because I have to look after her myself all
the time."

C39: "I feel so tired with taking care of her, especially as she always
struggles when I try to change her clothes."

A husband complained about stress, saying he had not been able to take time off for a holiday for two years. He said he should have more free time to relax himself after retiring from work, but he had to care for his demented wife who had rapidly deteriorated intellectually and could not perform everyday activities at all. In the present study, carers also were asked to explain about their own health problems during the interviewing, the findings are presented in chapter 6 (Section 6.3.2)

iii) Memory loss: Although only a few carers in this study found the memory loss in their elderly relative to be their particular difficulty at the time of interview, deterioration in memory was associated with the frequent report of psychological problems and behavioural disturbance. Memory problems described by carers included: “He is always forgetting where he keep his belongings and he’s searching for them all the time. He’s upset other family members by accusing them of stealing or moving his belongings” (C 43). A husband said his wife’s memory had deteriorated until she could not do many things that she used to do, for example she could not remember how to cook or how to wash clothes, and had become increasingly dependent on him. Thus memory loss was related to increasing dependence and demand for care.

iv) Other caring problems

The problem of finding help with care was mentioned quite frequently. Main carers who were no longer able to provide care by themselves because of the increasing demand for care due to the advanced illness of the subject said it was hard to find a good care assistant who was skilled in caring and loved looking after the elderly. They found it expensive to hire a personal health assistant from the private health service institution (there were no home helps nor care assistants available in the government sector). However, only one carer admitted that she had financial difficulty in providing care for her father since both of her parents were without a pension and totally relied on her family, and, in addition, she had two dependent children.

The final difficulty, which only a few carers mentioned, was difficulty in dealing with decisions on treatment. A son carer said his brothers and sisters had different ideas about seeking treatment for their mother. Some wanted to take their mother for Western medicine and others preferred to take her to see a traditional healer and have her treated with herbs or traditional medicine.

7.3.2. General problems

In general, the everyday problems that carers faced while providing care for their elderly demented relative were almost the same as the particular difficulties mentioned earlier, for example, the subject's psychological problems; memory loss; and co-operation problems. The exceptions were stress and physical strain in the carer and other problems such as difficulty in finding a good care assistant, which appeared only as an emerging problem. The caring problems in general included the subject's physical problems, lack of information about caring and the illness, and policy matters, as follows;

i) Psychological problems: Psychological problems were not only the particular difficulties that carers faced at the time of interview, but also the major everyday caring problems. Half the carers reported that their caring problems were associated with the subjects' behavioural problems. There was a broad range of psychological symptoms, the most common being confusion and depression, including hallucinations, mood swings, obsessive compulsive behaviour, paranoid delusions and anxiety. For example, an old lady who ran a small shop and cared for her husband who was in an early stage of dementia, complained that her husband was moody with customers and walked off without good reason; she worried it would affect their business.

ii) Physical problems: Most carers found it was difficult to handle the physical symptoms related to the subjects' deterioration, such as sleep disturbance, balance problems, incontinence, constipation, and dysphasia. There was also the increasing demand of close observation by the carer, in subjects who had additional physical functional problems, for example diabetes or paralysis.

iii) Lack of information: When the carers were asked what was wrong with their elderly relatives, over one-third replied they did not know. These included carers who knew the initial illness of their elderly demented relative, such as cardiovascular disease, brain tumour, or alcoholism, but did not know the subjects had developed dementia. One carer even said the doctor had refused to tell her. Although two-thirds of carers knew that the subjects had developed dementia, most of them had little idea of the pathology of this syndrome and how to provide appropriate care, except one spouse carer who was a former registered nurse and a daughter carer who had completed a short course in caring at home for the elderly. This lack of information also gave carers false hope, leading them to seek better treatment to cure the dementia symptoms in their elderly relative, while some carers turned to traditional medicine when they saw no sign of improvement.

iv) Policy matters: In Thailand people retire from work at the age of 60. Therefore, help schemes for the elderly, whether provided by the government or the private sector, normally only cater for people from the age of 60. One spouse carer appeared to worry about the cost of treatment for his wife who had developed early dementia from the age of 58; thus, she did not qualify to apply for the elderly welfare card, which would enable her to get free medical care from the government.

7.4. Managing caring at home

Most of the carers in this present study were either spouses or other family members living in the same house as the subjects. They were untrained and unpaid for this care. The nature of caring at home was explored to learn how the carers managed to provide care in their own home within the limited resources for help.

7.4.1. Sharing the burden

In the case of subjects who had many adult children living in the same house and nearby, this care would be shared among their children. The decision as to who would provide care, and when, depended on individual free time and it was possible to arrange to fill gaps, in order to provide care and supervision up to 24 hours a day. Thus, in the present study, the term "caring shift" is used to designate the period of care time provided by a carer.

There was no difference in the caring shift between rural and urban areas. In Chiang Mai, a widow who lived with her unmarried eldest son suffered from a severe recurrent stroke which left her with paralysis of both legs, aphasia, and intellectual deterioration. Since she needed 24 hour care, the burden of caring shifts was arranged among her children. Her daughter who lived in the same village came to see her and provided care during the day time, while her co-resident son and her nephew provided care at night. In Bangkok, an old man suffered from cerebrovascular dementia and had weakness on his right hand side. He had suffered rapid cognitive deterioration. He hardly remembered anybody and he could not perform everyday activities, such as dressing. He also had behaviour disturbance, with poor co-operation, agitation, obsessive eating and obsessive toileting at night. His wife and his daughter-in-law, who worked at home, took turns to care for him during the day, and his married daughter who lived elsewhere came to visit him very often and took responsibility to take him to see the doctor when necessary. His co-resident son who worked full time outside the home took responsibility to provide care at night. Sometimes, his son had to take alternate caring shifts with his nephew if the old man went to the toilet more often at night.

This caring shift approach was also adopted by families who had a helper or care assistant at home, where care was mainly provided by the personal health assistant who was hired from the institution, but the spouse or younger relative carers would relieve the personal health assistant as necessary and also provide a close supervision and helping role 24 hours a day. However, spouse carers who lived alone except for their demented spouse found it more difficult to manage their care provision. She said "I have no time to talk to him or stimulate his memory, because I have to do housework as well." Nevertheless, she was delighted when her niece came to visit her, because her niece was able to help her to do some housework and cooking, so she could take time off or go out by herself.

7.4.2. Managing disturbed behaviour

Strategies for coping with and managing behavioural disturbance in the subject varied among carers. In subjects who had mood swings and were very confused and uncooperative, most carers reported trying to control their temper and avoid confrontation by walking away and leaving the subject alone. A married daughter had to warn her guests about her father's strange behaviour. He easily got annoyed and moody when he saw somebody come to visit his daughter or when people tried to talk to him. He also walked away when I tried to interview him, but his daughter had already told me about it to prevent me feeling upset. The need to keep the subject company and give mental support was reported by the carers who cared for elderly people who had hallucinations. One carer said, "I will be with him and support him when he says he hears a strange voice or says somebody is trying to kill him" (C 7). When the subject appeared restless and agitated, some carers allowed them to go for a walk with supervision. Some carers would take them to bed and give a massage until they went to sleep, or some carers would give an extra sleeping pill to the subject if he/she was not able to sleep at night.

There were also other factors that impeded carers in their attempts to provide care. An old blind lady who cared for her confused husband in a rural area, lived on the poverty line with her husband and her divorced daughter who had to work outside the home. When interviewed she appeared tired and had a bruise and an old lesion on her forehead. She said her husband pushed her away when she tried to give him medicine and he always struggled against anybody who tried to do anything for him. Her husband remembered nobody and cried out all day and night. He tried to get out of his house and also pulled down everything that he could reach, so, her children agreed to restrain him.

7.4.3. Seeking a care assistant

Caring activities at home depended on the subject's condition. In the early stages of dementia, carers reported less demand in providing care for the subject; the caring activity was mainly supervision, because the subjects could still help themselves or perform their own everyday activities. When the subjects entered a very confused state the supervision increased to twenty-four hours a day to prevent risky behaviour. One spouse carer said, "He always leaves the gas on or leaves the refrigerator door open" (C 13). In this state, the supervision was extended to include neighbours and the close community, for example:

> C13: "When I want to go out, I will ask my neighbour or his niece who lives just a few yards from here to keep an eye on him. He always walks up and down the village and everybody knows him and helps keep an eye on him too, since he used to get lost if he walked further than the next village and couldn't find the way home." (Chaing Mai)
>
> C31: "I have to distribute my father's photograph to the motorcycle service who serve the passengers at the beginning of our Avenue and ask them to keep an eye on him and I offer a reward for anyone who recognises my father and brings him back home." (Bangkok)

In the next stage, when the subject becomes more confused and both intellectual and physical deterioration are severe, the demand of caring will be extreme and an assistant may be sought. Although only a quarter of carers were seeking help in caring, all of them were found among Bangkokian carers rather than in the northern region. Among carers who needed a home help or maid and personal health assistant in Bangkok, it was found that twice as many full-time rather than part-time home helps were hired by spouse carers than younger relative carers.

The decision as to whether to hire a home help or personal health assistant depended on the subject's condition, the availability of the carer's time, and the ability to afford this service. A home help may be needed when the subjects lose their ability to perform daily activities, such as bathing, cooking or dressing, or show risky behaviour which leads to increased dependence on their carer. Most of the home helps in the present study worked full-time and lived with their employers. They not only helped carers to do their housework, but also shared in providing care for the elderly demented patient, such as feeding, lifting, dressing or standing in for the carer when they needed to go out. Because of the extra work in providing care apart from housework, together with the behavioural disturbance of the demented person, many carers had experienced home helps walking out. They said it was increasingly difficult to find a long term home help or a new one. For example:

> C 21: "It's very difficult to find a good home help right now. If I found a good home help, I would try to keep her as long as possible. Even if she might request quite a high salary, I would have to pay, because I have a demented mother at home, so I need somebody whom I can trust and have quality of work as well".

When the elderly demented relative entered the late stage, such as being bed-ridden, or shortly after being discharged from hospital, needing more medical attention and close observation, most of the younger relative carers who worked outside the home would seek for a personal health assistant from the private health care service institution.

This type of care assistant has usually been trained in caring by the private care institution for at least three months. They have to move into their employer's house and provide care only to the demented person, 24 hours a day five to six days a week. The personal health assistant's duty is only to provide personal care for the demented person, and not to do housework. At this stage, therefore, the majority of carers complained about the additional burden of having a personal health assistant in the house because the carer had to prepare meals, provide accommodation, provide help in caring as needed and pay quite highly for this service. Moreover, carers complained about personal health assistants' lack of skill in caring and absence of a positive attitude toward the elderly.

7.5. Attitude towards Caring

The literature suggests that caring for a relative with dementia has the potential to affect mental health, for example contributing to; emotional distress and depression, chronic strain, and adversely affecting the health of family caregivers (Russell et al., 1989; Collins et al., 1994; Fink, 1995). In the present study these effects on health were consistently found. Nearly half of carers (n=19) experienced greater levels of strain and half the carers (n=22) said their health was somewhat worse than one year previously (see Chapter 6, Section 6.3.2). In general, it is assumed that a positive attitude toward the demented person is one of the most important factors that leads carers to be willing to continue providing care. In contrast, a negative attitude toward the subject could lead to family care breakdown. Levin et al.'s (1983) study of the correlation of 'willingness to care' and 'willingness to institutionalise' among the carers of the elderly mentally infirm, suggests that attitudes towards care-giving are instrumental in determining the breakdown of community care. This present study, therefore, examined the carers' attitude towards their demented relative at the time of interviewing by trying to compare their relationship before and after their relatives developed dementia. The carers were also asked about the prospects for future care providing: would they like to continue to provide care or prefer institutional care for their demented relatives?

7.5.1. Attitude towards the Subject

When carers were asked whether there had been any change in their feelings towards their demented relatives, half the carers expressed sympathy, a quarter said nothing had changed in their feeling, nearly a quarter said they felt bored and irritated with their demented relatives' behavioural disturbances, and a few of them found their demented relatives' childish behaviour funny. It was also found that nearly twice as many younger relative carers expressed sympathy toward the subject than spouse carers. While twice as many spouse carers as younger relative carers felt bored and irritated toward the subjects. It was generally the subjects' behavioural disturbance, such as ignoring the carer's instruction and not co-operating, constantly asking the same question or paranoia, which caused carers to feel bored and irritated. Those who found the subject uncontrollable and unmanageable, expressed their unhappiness and wished not to continue providing care to the subject:

> C11: "I hope it isn't too rude to ask you that when is he going to die? He's always shouting, crying out, and very unco-operative. I want him to go peacefully." (spouse carer)

> C33: "To be honest, I feel so fed-up with him, he never listens to me. All he wants to do is eat and sleep and he often says that he

> hasn't eaten where in fact that he already has. He also wakes up many times at night and I have to wake up with him too, so I don't get enough sleep and feel so tired because I have to work full-time outside the home." (younger relative carer)

7.5.2. Willingness to continue providing care

Despite the problems of providing care at home with limited resources, three-quarters of carers were still willing to continue providing care for their demented relatives at home. The majority of carers, when asked about the length of time that they would be able to provide care, showed a strong sense of commitment to continue to care until their elderly demented relative's death, or at least, as long as possible. Although, there were slight differences between spouse and younger relative carers in willingness to care at home; in the northern region, slightly more younger relative carers than spouse carers were found to be willing to continue care. By contrast, in Bangkok, spouse carers expressed more willingness to care than younger relative carers. Less than 10 % (n=4) of carers, found only in the northern region, said they did not really want to provide care, but did so because there was no other family member available to provide care, or because of the marital commitment. The remainder said they were uncertain.

When asked if there were any circumstances in which they would like to send their demented relatives to be cared for elsewhere, nearly three quarters of the carers insisted they would not send the subject to an institution. Only 14% (n=6) of carers from both regions said they would consider sending the subject to hospital if their condition deteriorated and they needed medical care. For example:

> C15: "No,.... but if he went mad I will send him to the psychiatric hospital." (wife)

> C31. "No, I won't...., not to a residential home. I will keep him to stay at home with me, unless his condition gets beyond my ability." (daughter)

In Gilleard's (1986) study in the UK, spouses were found to be much less likely than other relatives to consider giving up caring. Similarly to the present study, spouses were found to be less willing to consider an institution than younger relative carers and all of them lived in Bangkok. In the present study, only 7% of carers (one spouse and two younger relative carers) were prepared to consider a nursing home for their demented relative if their condition deteriorated. Nobody reported a desire to send the subject to residential home. Only one subject had experienced staying in the private nursing home in Bangkok. She lived with her elder sister and her niece who worked outside the home. She had a brain tumour and needed regular chemotherapy. Unfortunately, the tumour spread, she deteriorated physically and needed to be hospitalised several times. Moreover, she had severe depression and behavioural disturbance, crying out all the time, and her niece could not cope with her condition, so she was sent to stay in a private nursing home for one year. Because of the high cost of the nursing home service, after one year, she was brought back home and her niece hired a private care assistant for her.

Looking at the relationship between attitude towards people with dementia and willingness to care, in the present study, the majority of carers who felt sympathy with their demented relatives said that they would not send the subject to an institution and desired to continue providing care at home. However, the assumption of the correlation between a positive attitude towards the demented person and more willingness to continue providing care might not always be true. In the present study, nearly 90% of carers who felt bored or irritated with the subject were still willing to continue providing care at home. There may be other factors that influence carers' beliefs and caring behaviour.

7.5.3. Relationship between carers and subjects

Phillips and Rempusheski (1986) suggested that all of us have an implicit to explicit set of "rules" (belief and value system) which help to determine how we live our lives and what we see as acceptable. In the caring situation, these belief systems are the basis for comparison between the past and present behaviour of the person being cared for. Phillips and Rempusheski (1986) also believed that in the caring situation where a good past image of the person being cared for is maintained in the present, and where beliefs and behaviour are congruent, the caring situation will be a positive one. Conversely, where a good past image has been spoilt, and beliefs and behaviour are not congruent, then the caring situation is much more likely to be poor. This view is supported by other studies (Nolan et al., 1994). Therefore, in order to explore carers' beliefs and behaviour in caring associated with the quality of care, questions about the quality of the relationship between the carers and their demented relative were included. The findings are discussed below.

i) Past relationship between carers and cared for

Carers were asked to describe their previous relationship with their elderly relatives before they developed dementia, so called *'pre-relationship.'* Two-thirds of carers reported having a very good relationship and up to three-quarters had a positive relationship, from good to very good, towards their elderly relative (see Figure 7.1).

There was little difference in the number of carers who reported fair and poor relationships, amounting to one quarter. However, no younger relative carers reported having a poor relationship with their elderly relatives.

ii) Current relationship between carers and cared for

Carers were also asked to describe their relationship with their elderly relatives after they developed dementia, so called *'post-relationship.'* Nearly two-thirds reported that their relationship was worse. A greater number reported a poor relationship than a fair relationship with the person being cared for. While the number of poorer subject-carer relationships increased after the elderly relative developed dementia, at the same time, the number of very good relationships was reduced (also see Figure 7.1). Only one-third of carers thought that they had a good to very good relationship with the subject.

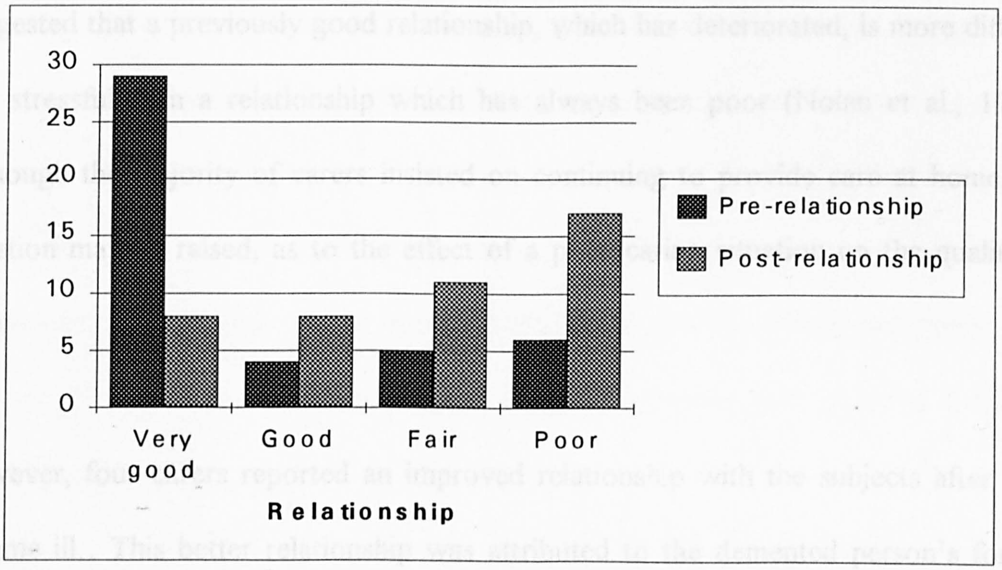


Figure 7.1. Pre and post relationships between carers and their demented relatives.

Spouses' carers, particularly those who lived in Bangkok and the metropolitan area, were found to have worse relationships than younger relative carers. Nearly 90% of spouse carers had moved from a positive to a negative relationship, whilst only half of younger relative carers reported a similar experience. Moreover, spouse carers who lived with their demented spouse alone were more likely to have a poor relationship than those one who were co-resident with their adult children.

The worst relationships were reported in the case of subjects with psychological problems, such as violent behaviour, unstable moods, lack of co-operation, and obsessive compulsive behaviour which made carers felt emotionally upset. Figure 7.1 shows the sharp decrease in very good relationships and increase in fair and poor relationships between carers and the people they care for. If Phillips and Rempusheski's (1986) theory is applied to this study, this would suggest that only a quarter of carers had a positive caring situation. Moreover, the literature clearly suggested that a previously good relationship, which has deteriorated, is more difficult and stressful than a relationship which has always been poor (Nolan et al., 1994). Although the majority of carers insisted on continuing to provide care at home, the question may be raised, as to the effect of a poor caring situation on the quality of care.

However, four carers reported an improved relationship with the subjects after they became ill. This better relationship was attributed to the demented person's former personality and beliefs. One subject, a retired army officer, was described by his wife and daughter as a strict disciplinarian. He was not only unhappy for his family members to question him, but also laid down strict rules for everybody in the house. His daughter also said he was only pleased with his younger son, who followed in his foot steps to become an army officer, not with her. Recurrent stroke had left him with difficulties in speaking, paralysis on his left hand side and cognitive impairment. Since then, he had become very quiet and co-operative and improved his relationship with his daughter who always came to visit and care for him. She said, "I like him better than before. He also say he loves me more than my brother. He has forgotten that he used to love my brother more than me."

7.6. Financial situation

The financial situation of families is a very sensitive issue for anyone to discuss. Moreover, in a developing country such as Thailand, it is perhaps an even more sensitive issue than in Western countries, because of the influence of culture on people's behaviour and interpretation. Although Thailand has achieved remarkable economic growth and is in the process of transition into a modern industrialised country, nonetheless, over half (57%) of the Thai population still work in agriculture (National Statistical Office, 1993) and have an unstable income. Moreover, Thai society has been characterised as hierarchical in term of social status, age, kinship, experience, and economic status (Hanks, 1975; Polter, 1976). The higher positions in the social hierarchy empower people with both formal and informal influence (Darlington, 1994).

Because of the hierarchy of power and prestige, there is a concern amongst people to present a favourable image of themselves in which self-presentation has a strong psychological value in regard to the individual's feelings of identity and acceptance (Mulder, 1994). Thus, most people probably will not admit that they are poor, though they may do so when they expect a positive outcome. In the present study, of 44 carers, only one carer mentioned financial problems when asked about her particular difficulties in care provision, and another two carers, in talking about general caring problems, mentioned concern about what their financial position would be in the future. However, a quarter of carers admitted that they had financial difficulties, when they were asked directly whether they had any financial difficulty in providing care. Taking into account the primary concern of the perception of hierarchy, the interview schedule included a question about the individual carers' income and their household income in an attempt to determine the possible extent of financial hardship. Additional questions about the expense of caring for the elderly demented person, in order to determine what extra expenses were incurred which affected their financial situation, were also included.

7.6.1. Income

Rapid economic growth and structural shifts in production and employment have had a significant impact on income distribution in Thailand, with the share of farm income falling as the agricultural sector has declined, while the trend in the share of income from professions and other unincorporated enterprises is increasing (Jansen, 1990). Although the incidence of poverty fell sharply from 57% in 1962-1963 to 24% in 1981 (Jansen, 1990), and reduced from 10.6% in 1995 to 10% in 1996, this still means that 6 million people out of total population of 60 million, were estimated to have an income below the poverty line. Moreover, the difference in income between the rich and the poor is getting wider. This difference of only 11.8 times in 1988 had increased to 16 times in 1996 (Matichun Weekly, 1997). The distribution of income also varies according to geographical area, as agriculture remains dominant in the rural areas. Therefore, the financial status of carers and their households in the rural and urban areas in the present study will be separately analysed.

Recent data on income are not available because it normally takes two years for the National Statistical Office (NSO) to process the Socio-Economical Survey (SES) data and publish the results (Kakwani and Krongkaew, 1996). In order to achieve a more accurate assessment of financial status and understanding of the existent financial situation in family care, the most recent statistics published by the government statistical office are used. Reference is made to data from the national statistical office and from independent research institutions. For example, Table 7.2 shows the average monthly income and the expenses in different geographical areas in Thailand, indicating the average monthly income differences between the Bangkok and the metropolitan area and the Northern Region.

Table 7.2. Average monthly income and expenditure by region : 1994

Region	Average household size	Average monthly income (Bath)		Average monthly expenditure (Bath)	
		Per household	Per person	Per household	Per person
Whole Kingdom	**3.8**	**8,262**	**2,191**	**7,567**	**2,114**
Bangkok and Metropolitan	3.3	16,418	5,013	13,667	4,241
Central Region	3.7	8,724	2,372	7,857	2,309
Northern Region	3.5	6,260	1,791	5,956	1,781
North-eastern Region	4.1	5,599	1,387	5,632	1,496
Southern Region	4.1	8,014	1,967	7,513	1,955

Source: Report of the 1994 Household Socio-Economic Survey, National Statistical Office, Thailand, cited by National Statistical Office (1996), p. 395.

Note Exchange Rate: approximately 40 Bath = 1 Pound (prior to 1997 devaluation)

i) Income and Poverty line

The present study sought to identify those carers who were on the poverty line. It is logical to assume that people who are poor and have to care for their relatives at home with few services and resources available would have more financial difficulty than other groups. Lapthananon (1995) studied socio-economic stratification in Thailand with a sample of 3,040 from 10 provinces, both urban and rural areas, covering every part of Thailand. This study suggested that the majority of the population who had low socio-economic status (SES), and were also classified as poor in the rural areas, had a monthly income of less than 63 pounds per person (2,500 bath) and less than 125 pounds per household (5,000 bath), whilst in the urban area, those classified as poor had a monthly income less than 86 pounds per person (3,500 bath) and less than 250 pounds per household (10,000 bath).

However, in the present study, using the individual carers' income to classify low SES or below the poverty line, the resulting figure would probably overestimate those in poverty, because the majority of the spouse carer group, who accounted for more than half, were housewives and had no income or pension of their own, but their husbands did, particularly in Bangkok. They may also have received support from their adult children. Similarly, younger relative carers, might receive financial support from their own family and from other siblings, an aspect of what is meant by family care. Therefore, household income would be more appropriate to show their actual financial status. Table 7.3 illustrates the carers' household income which includes other sources of financial income, either from their husband, adult children or siblings. It can be seen that over three-quarters of the subjects and their carers in the northern region, the majority of whom lived in the rural area, had low SES, while the majority of participants who lived in Bangkok and the metropolitan area had medium to high socio-economic status.

Table 7.3. Household income and Socio-Economic Status by geographical area.

Socio -Economic Status (SES)	Number of Households (Row %) (Column %)		Row Total (%)
	Northern Region	Bangkok and Metropolitan	
Low SES	15 (88.2) (75.0)	2 (11.8) (8.3)	17 (38.6)
Medium-High SES	5 (18.5) (25.0)	22 (81.5) (91.7)	27 (61.4)
Column Total (%)	20 (45.5)	24 (54.5)	44 (100)

Of 24 spouse carers, nearly two-thirds (n=15, 62.5%) said that they received financial support from their adult children, either from co-resident children or from the others who lived elsewhere. Only nine spouse carers (37.5%), mostly from Bangkok, who had their own savings or whose demented husbands had retired from the government sector and had state pensions, were less likely to receive financial help or preferred not to receive it from their adult children, for example:

> C 34: "They give me money sometimes, but actually, we have our own savings, so we don't need financial support from them." (Bangkok)
>
> C 43: "Not much.., because my husband has his own pension." (Bangkok))

Among younger relative carers (n=20), less than half (n=9, 45%) received financial support from their family or from their siblings who lived elsewhere. Among married carers it was found that their main income came from their own family. It was often found that carers who looked after a demented parent or parent-in-law at home, received their main financial support from their husbands, who worked outside the home. As one carer said, “my husband is my main financial resource.” However, nearly half of them (n=9) also received help from their siblings who lived elsewhere:

> C 6: “My sister who lives in Bangkok regularly sends money to my father at home.” (northern region)
>
> C 33: “All the medical expenses for my father are divided among my brother and sisters.” (Bangkok)

Some unmarried carers who had not received financial help had to spend their own savings or income to provide care, while some of them did not need help because their elderly demented relatives had savings or a pension. However, unmarried carers received slightly more financial help from their siblings than married carers.

ii) The loss of income

As an elderly demented person’s condition deteriorates physically and psychologically, so the demand for care increases. The need to spend more time in caring may not only affect the carers’ well being, but may also cause loss of earnings, which would make caring more difficult. The present research found that nearly one-third of carers reported loss of income or difficulties in working as a result of being carers. This trend was more noticeable in younger relative carers rather than in spouse carers, because the majority of spouse carers were housewives while, in the case of male spouse carers, most had retired from work.

Half the younger relative carers (n=10) reported losing income and disruption of their working pattern, such as having to stop working or to reduce hours spent working outside the home, in order to be able to provide care at home. Some carers had had to change their jobs from work outside the home to work at home with lower incomes. In other cases, their ability to work had been adversely affected by lack of sleep due to providing care at night. The loss of income was clearly a prominent problem among younger relatives who were still of working age and had to earn for their living too.

How long would they be able to provide this kind of care? The problem may be alleviated if they receive financial support from other family members, but what about carers who have no relatives to help them? This concern was expressed by a carer who had two dependent children and had to provide care for her elderly mother and demented father with support only from her husband.

7.6.2. Caring Expenses

In Thailand, the government plays an almost exclusive role in providing health services (see Chapter 3, Section 3.3.3). The main paid health services are provided by the Ministry of Health (MOH) though the private sector also plays a significant role in Bangkok and metropolis (Campbell et al., 1993). Studies of Thai household expenditure including expenditure on medical care have regularly been carried out by the National Statistical Office. For example, the expenses data of 1992 and 1994 shown in Table 7.4, indicates that expenditure on medical care was ranked in fifth place among consumption expenses for the kingdom as a whole. However, little is known about the average health costs for people who suffer from a chronic illness such as dementia. Therefore, the present study sought to explore the additional expenses involved in long term care provision at home, such as the cost of medical treatment and other facilities related to care for the subject.

Table 7.4 Average monthly expenditure per household by type of expenditure and region.

Expenditure group	Whole Kingdom 1992	Whole Kingdom 1994	Bangkok and Metropolitan 1992	Bangkok and Metropolitan 1994	Northern Region 1992	Northern Region 1994
Average household size	**3.9**	**3.8**	**3.4**	**3.3**	**3.7**	**3.5**
Total monthly expenditure	**6,529**	**7,567**	**13,479**	**13,667**	**5,028**	**5,956**
Consumption expenditure	**5,892**	**6,784**	**11,950**	**12,105**	**4,583**	**5,381**
Food and beverages	2,272	2,548	3,995	4,068	1,799	2,025
Alcoholic beverages	174	123	362	266	120	92
Tobacco products	112	93	176	169	84	58
Apparel	391	404	712	630	318	349
Housing	1,430	1,654	3,303	3,252	1,091	1,308
Medical care	226	262	434	441	194	257
Personal care	161	191	303	333	120	147
Transport and communication	802	1,122	1,873	2,118	651	886
Recreation and reading	153	169	399	382	106	119
Education	101	136	313	392	66	84
Miscellaneous	70	82	80	54	34	56
Non-consumption expenditure	**637**	**783**	**1,529**	**1,562**	**445**	**575**

Source: Report of the 1992 and 1994 Household Socio-Economic Survey, National Statistical Office, Thailand, cited by National Statistical Office (1996), pp. 389-399.

In this study, the health care consumers were simply divided into two groups, those who were eligible to claim health care benefit and those who were not. First, those eligible to claim health care benefit consisted of three sub-groups. The first sub-group were consumers who were able to claim health care services entirely free from charge, from the government sector. The majority of people in this sub-group were working for or retired from the government sector, together with their families. This sub-group also included people who are classified as poor. Since the Free Medical Care Project was introduced in the Fourth Five Year Plan, 1977-81, as part of the Government's proposals for helping those of low SES, those who are identified as poor, are also eligible to receive free health care services at the government facilities (Mills, 1991). The second sub-group was state enterprise employees or retirees and their families. This sub-group is able to claim over half of the cost of medical care for each visit; however, the exact benefits available vary from one organisation to another. The third sub-group was private sector employees. Since the labour law about basic health care insurance was introduced for everyone who works for a private company, they too can claim free basic medical treatment, though health care policies vary between companies.

The second health care consumer group was the private paying group, made up of the self-employed or agricultural workers, who are not eligible for any health care benefit. In general, paying for an elderly persons' health care is a constantly increasing financial strain (Polich et al., 1993). This problem will be increased in the case of chronic illness. However, the cost of health care would be less of a financial strain if the subject was eligible for some kind of health care benefit, as described above.

i) Medical treatment expenses

The costs of medical treatment, particularly out-patient expenses, include medicine, special tests, laboratory and doctors' fees. Although, 44 subjects participated in this study, only 24 subjects' carers were able to give an estimate of medical treatment expenses. The remaining subjects, were mostly eligible for free or subsidised medical care, so their carers seemed not to recognise or pay attention to the cost of care. The cost of medical treatment ranged from 3.0 to 1,316.0 pounds per month (120 - 52,640 Bath), the average being 169 pounds per month (SD=365.5) or 6,760 Bath per month. To set this in context, the national average spent on medical care in 1994 was only 6.6 pounds per month (262 Bath) (see Table 7.4), and the average cost of medical services in an elderly out-patient department, at Rajavithi Hospital, one of the major general government hospitals in Bangkok, was 12.7 pounds for each visit (Thanuvatana, 1994). However, data were not collected in this study to provide further details about how much carers had actually paid for medical services per month.

There was a statistically significant difference (t-values = -2.52, df = 11.7, $p<.05$) in the cost of caring facilities in different geographical areas. Although there was no statistically significant difference in the cost of medical treatment in different geographical areas, the average monthly expenditure for people with dementia in Bangkok and the metropolitan area was over ten times higher than in the northern region, where the majority of subjects lived in the rural area. There was also no statistically significant difference in medical care expenditure between subjects who were and were not eligible for health care benefit (Table 7.5).

Table 7.5. Monthly Medical Care Expenses (pounds) by Type of Health Care Consumer and Geographical Areas.

Medical Care Expenses	Average	SD	Minimum-Maximum
Total monthly medical care expenditure	**258.3**	**472.8**	**6.0 - 1,679.0**
Northern Region	**60.0**	**59.1**	**6.0 - 172.0**
Bangkok and metropolitan	**429.1**	**597.9**	**10.0 - 1,679.0**
Total monthly medical treatment expenditure (n=24)	**169.3**	**365.0**	**3.0 - 1,316.0**
Type of health carer consumer			
Eligible to get help	89.3	199.0	3.0 - 789.0
Private paying	302.7	531.6	3.0 - 1,316.0
Geographical area			
Northern Region	25.0	23.1	3.0 - 80.0
Bangkok and metropolitan	291.4	469.0	5.0 - 1,316.0
Total monthly facilities expenditure (n=20)	**89.0**	**107.8**	**3.0 - 363**
Type of health care consumer			
Eligible to get help	83.8	121.0	3.0 - 363
Private paying	99.7	82.7	8.0 - 211
Geographical area *			
Northern Region	35.0	36.0	3.0 - 92.0
Bangkok and metropolitan	137.7	128.9	5.0 - 363.0

*: *t-test* ($p < .05$)

ii) Expenses of other Caring Facilities

The cost of care does not include only medical treatment. Caring for a chronically ill person at home also brings extra expenditure on other facilities related to care. More than half the carers said that they had not paid for anything special or had spent little money on facilities for the subject. Only 20 carers were able to indicate the average cost of facilities. These were cases where the subjects had suffered physical deterioration. The most common extra expenses incurred in caring at home, that carers mentioned, were special food or food supplements, incontinence aids, the cost of hiring a home help or care assistant, and transportation. The average monthly expenditure on such items was 89 pounds (3,560.0 Bath), SD=107.8, and there was not much difference in expenditure between subjects who were eligible to get help for medical care and those who were not. However, there was a statistical significance (t-values = -2.52, df = 11.7, *p*<0.05) in the cost of facilities in different geographical areas, with subjects living in Bangkok and the metropolitan area spending almost four times as much as subjects who lived in the northern region (Table 7.5).

The cost of medical care, including medical treatment and other expenses, varied depending on the subject's health condition and what the family could afford. Although this study's findings suggest that the average total cost of medical care for an elderly demented person at home is 258 pounds per month (10,320 Bath), it was found that the subjects in Bangkok and the metropolitan had spent seven times as much on medical care as the subjects in the northern region. The minimum monthly cost of care is at least 6 pounds (240 Bath), while a wealthy family may spend up to 1,679 pounds per month (67,160 Bath). Subjects who were eligible for free or subsidised medical care spent less on medical treatment and less than half on other facilities, compared with those who met their own costs and on average spent more. Less medical care was paid for in the northern region than in Bangkok (also see Table 7.5), reflecting the fact that the majority of the subjects and their carers in the northern region were on the poverty line (see Table 7.3); in other words, the more money families had, the more they spent on caring. Siripanit et al. (1988) studied the way of life and behaviour among 1,574 healthy Thais aged between 70-74. It was found that the majority of sample (90.3%) had moderate to high income. This finding may be taken as an indication of a relationship between economic status and the well-being of the elderly, in a country where no national health service is as yet available.

7.6.3. Carers' attitude toward caring expenditure

The sensitive issue of carers' attitude towards caring expenditure was explored in order to gain a deeper understanding of the financial difficulties involved in caring and their likely impact on the continuation of care. Firstly, carers were asked whether they had ever thought that the cost of care was expensive. Just half of carers answered "No" and nearly half said it was quite high to very high, while the remainder said "Moderate." However, the SES of the subjects and their carers seemed not to be related to carers' attitude towards the cost of medical care. The cross-tabulations carried out indicated that among 17 participants (38.6%) who had low SES or were on the poverty line, mostly living in the rural area (n=15), more than half (n=9) said the cost of care was not expensive and only six of them said it was. Among 27 participants (61.4%) who had moderate to high SES, mostly living in Bangkok and metropolitan area (n=22), almost two out of three said the cost of care was expensive. Nor did the length of time the subject had been ill or the different causes of dementia appear to be significantly related to carers' attitude towards the cost of care. Nevertheless, it was found that a slightly higher number of carers who were caring for relatives with vascular dementia and unspecified dementia said the cost of care was expensive, than was the case for other causes of dementia.

A further question was asked about whether carers and their family members had ever thought that they would not be able to continue to provide care because of the cost of caring. The findings revealed that the majority of carers did not think so. Although some carers admitted that they had financial or caring difficulties, they were still willing to continue to provide care, particularly in the case of younger relative carers. For example:

> C 7: "No, I have to care for him whatever the circumstances."
>
> C 25: "No, I will try to provide care for her myself, because I cannot afford a care assistant any more."
>
> C 27: "We have a lot of financial difficulties at the moment, but we will try to continue providing care for her."

Among spouse carers, however, most said they had never thought about this issue, as their spouses had a pension, were eligible to get free medical treatment, had enough savings, or regularly received financial support from their adult children. However, spouse carers who heavily relied on their adult children for financial support seemed more concerned about the possibility of discontinuing care because of its high cost.

The last question about caring and financial difficulty asked who would be the next person to become a carer if the present carer could not continue to provide care because of financial difficulty or other circumstances. More spouse carers mentioned their daughter rather than son, as the next person to take on the responsibility, while younger relative carers, the majority of whom were female, nominated a brother rather than sister.

7.7. Traditional Medicine

Jaspan (1969) has suggested that traditional medical theory in South-East Asia is derived from deep religious, philosophical, and sociological roots, in which Buddhism has had a particular influence. Thailand is one of the countries in South-East Asia which continues to practice traditional medicine alongside western medicine (see Chapter 3, Section 3.5.1). In order to understand caring behaviour, respect individual beliefs, and find an efficient method to deliver health education to the patients and their families, it is important for health professionals to be aware of how ancient traditional beliefs influence Thai people's caring behaviour. What factors lead them to decide whether to go for traditional or Western medicine and how do they view these two systems?

7.7.1. Traditional healer

Of 44 subjects in the present study, nearly half (n=21, 47.7%) had sought help from traditional medicine where the majority of them lived in the rural area. In the following discussion, types of traditional healer will be defined mainly according to the work of Brun and Schumacher (1994, pp. 35-36) who spent some time studying traditional medicine in Northern Thailand. The types of traditional healer which were found in the present study were as follows:

i) Herbalists

The herbalist is one of several types of traditional healer in Thailand who use an arsenal of herbs and other natural substances as the basis for therapy. This may include the performance of incantations. The term herbalist also refers to rural traditional doctors who learnt from a popular traditional system which is part of an exclusively male tradition. Most carers reported that they had heard about herbalists or particular kinds of herbs, which could help the condition of their demented relative, from their neighbours and friends. At the time of prescribing, carers were told how to prepare the herbs before serving, for example, by steaming or boiling them, and given directions as to frequency, dosage and the duration of treatment. In Bangkok, this type of traditional healer was also influenced by Chinese medicine. One subject in Bangkok had received herbal treatment including a particular kind of Chinese mushroom which is believed to improve memory.

ii) Mediums

The mediums are part of a predominantly female tradition. They find the cause of disease, and may even attempt to cure certain diseases, with "rubbing" ceremonies. Brun and Schumacher (1994) suggest that people with psychological and social problems often turn to the mediums for help and advice. Darlington (1990), who studied Buddhism, morality and change in northern Thailand, found that people, mostly woman, went to ask for advice on personal problems and to solicit help in times of personal crisis, not only illness, but also when they had had a bad crop or lost an item. The findings from the present study confirmed that seeking advice about the cause of their elderly relative's illness from a medium was still a popular course of action among carers. There was a significant difference (chi-square = 11.7, df = 1, $p<.01$) in this respect, between carers who lived in different geographical areas. Of 11 carers who had sought advice from a medium, over 90% (n=10) lived in the rural northern region, rather than in the capital, Bangkok. — [illegible]

iii) Ritual

Many people in the rural area still believe in spirits, such as moral spirits which are basically protective, and amoral spirits which most frequently cause trouble to human beings. The type of diseases mainly considered to be caused by spirits are epidemic in nature (fever, swellings and aching joints or muscles); diseases with sudden onset; or those which are resistant to treatment, which can not be cured by normal herbal methods. If a disease is regarded as being caused by something being inserted into the body by spirits, magic becomes an essential part of the curing process. (Brun and Schumacher, 1994). The curing ceremonies for diseases caused by spirits in this study will be called 'ritual.' The ritual was normally carried out after the carer had been told by a medium about the cause of disease and what kind of ritual would help. The rituals which carers mentioned were candle worship, offering food to spirits and taking the subject to see a monk or spirit doctor to receive holy water, in order to drive away bad luck or a bad spirit.

iv) Traditional massage

In the present study, traditional massage appeared more popular among Bangkokian participants than those from the northern region, and four Bangkokian participants said they had never sought treatment using any other kind of traditional medicine, except traditional massage. This massage was either performed by family members, using a simple technique, or they hired a professional traditional massager who provided services at Wat Pho. It was reported to be helpful for the elderly demented who had problems with unstable mood, restlessness or insomnia. As one carer in Bangkok said, "When she starts having a bad mood, I will take her to bed and give her a good massage until she feels better and goes to sleep" (C 25).

7.7.2. The Carers' views toward Traditional and Western Medicine

Although nearly half the carers in this study stated that they had sought help from a traditional healer for their elderly demented relative, the majority of them lived in the rural northern region. Most Bangkokian participants had no interest in traditional medicine and only one-third preferred traditional massage and some kind of herbs alongside Western treatment. In view of the physical and mental incapacity of the subjects, the question was raised: who decided to take the subject for traditional medicine? It was found that usually carers had made the decision on this issue; only a few subjects had made the decision themselves. Therefore, the question was asked: why carers felt they needed help from traditional medicine? Juspan (1969) described the perception of how a person becomes ill in Southeast Asian countries as follows:

> Patient and his or her kinsmen want to know whether illness is a consequence of supernatural punishment for immoral or antisocial actions, or is a result of infection or contamination which could not be foreseen or prevented. Or is it result of someone's deliberate intent, by resort to witchcraft, sorcery or poisoning? Or was it brought about by the fickle, labile and malicious activities of spirits. (p. 12-13)

This was born out in the present study, the majority of carers in the northern region who preferred traditional medicine said that they needed to know the cause of the illness in their elderly demented relatives. They thought that the symptoms such as fever, sudden onset of personality change or failure to recognise family members must be associated with punishment from an angry spirit, or black magic. So, the mediums were seen as the only people who could tell what was wrong with the subject and how to deal with it.

Equal numbers of subjects had turned from traditional to Western medicine, and from Western to traditional medicine. They turned from one to another to seek better treatment, because their carers were not satisfied with the results of treatment or had seen no sign of improvement after the patient had undergone treatment for some time. Carers, thus, viewed both traditional and Western medicine as complementary or alternative treatments. Therefore, it is important to note that traditional medicine alone can not be called "alternative medicine," as it is in the West, where orthodox medicine is normally the first choice. The mediums also influenced carers' decision as to which system of medicine to choose. Two carers reported that they went to consult the mediums to find out the cause of their elderly relative's illness, and were advised to take the subject to see a Western-trained doctor, because the medium found no signs of a spirit agent, and no need for treatment by a traditional healer. Carers who believed in both systems preferred their elderly relative to undergo both traditional and Western treatment, in order to maximise the possibility of finding and treating the causes of illness.

The majority of participants who lived in Bangkok and the metropolitan area had an average higher SES (see Table 7.3), more education and more exposure to Western culture than participants who lived in the northern region (see Chapter 5 and Chapter

6). These factors may have given them a more positive attitude and preference for Western medicine, compared with traditional medicine. Most of the carers who preferred Western medicine said that they believed Western medicine was more established and offered a higher quality of care, than traditional medicine. Some carers preferred Western medicine as convenient, simple and safe. Another carer who turned to Western medicine said, "I used to boil the Chinese herbs and prepare for him, but I feel too lazy to continue" (C 30).

In the case of over 80% of subjects who received western treatment, carers reported that it had helped in decreasing subjects' psychological problems, resulting in fewer mood swings, decreased paranoia and improvement or stabilisation of the subjects' condition. In comparison, only one-third of carers whose elderly demented relatives had been given some kind of traditional treatment said they had seen signs of improvement in the subjects' condition.

7.8. Carers' Needs

In Thailand, the cultural view is that adult children and younger relatives have to take responsibility in caring for their elderly relative themselves, and therefore, the government seems to take it for granted that relatives will provide care and offers them little or no support. In the past, when the majority of people lived in extended families, the problem of caring may have been less since the caring role was shared among a large number of family members. However, today, there is a reduction in family size, economic hardship has forced women to work outside the home, and more adult children migrate from the rural areas to find jobs in the city, leaving the elderly behind. In order to prevent family care breakdown, the very first step and the most important is that carers' needs should be recognised, then caring intervention and caring support need to be offered. This research tried to explore the needs of carers looking after their elderly demented relatives at home. To assess carers' needs, it is important to ask questions about the extent to which carers face strain with regard to information, finances, respite, support, aids and services, and carers were also given the opportunity to indicate anything else that they wanted to mention.

7.8.1. Information Needs

An assessment of the information needs of the 44 carers was carried out during the interviews. It was found that there were four principal information needs among carers, though a number of carers wanted more than one type of information. These information needs, in order of the frequency with which they were mentioned by carers, were as follows.

The first need, expressed by nearly three-quarters of carers (72%, n=32), and by more younger relatives than spouse carers, was information about how to provide care for the subject, especially about caring techniques at home. For example:

> C 1: "It's very important, we really want to know how to communicate to my mother who has aphasia."
>
> C10: "How to divert his attention not to keep thinking about himself."
>
> C 33: "How to stop his obsessive toileting and what I should do when he keeps saying he hasn't had a meal, where in fact he already has."

This category of needs included what kind of food would be good for the subject, and how to administer medicine. Second, the need to know about the elderly person's illness was mentioned by 40% (n=18). Some carers had no idea what was wrong with their elderly relatives, and even though most knew that the subjects had developed dementia, they had little idea of the pathology of this syndrome (see Section 7.3.2).

The third common information need that carers mentioned was regarding the treatment of dementia. Most carers in this group wanted to know how to cure their relative's illness, thus this information need appeared to be associated with the lack of knowledge of the dementia syndrome. Examples of carers' comments were:

> C17: "The doctor isn't a good source of information. I know nothing about his illness, the pathology of the disease or how to care for him." (Northern Region)
>
> C31: "I don't know how his illness is going to be. I have just heard what people say, but I don't really know about it." (Bangkok)

Finally, there was a need for information about institutions, short and long term private nursing homes in particular, since state-run nursing homes have yet to be introduced in Thailand. Although only a few carers (n=3), especially those who lived in Bangkok, mentioned nursing homes, while the majority did not want to appear unable or unwilling to provide care themselves, the fact that this issue was raised at all, is evidence of a move towards consideration of alternative care options. However, government residential homes were low in carers' choice, because most carers had a negative attitude towards such institutions. These homes are seen as a last resort for the homeless or elderly people who have no relatives. A study of the living arrangements of the elderly in Thailand by Knodel et al. (1995) also found that cases in which the elderly are forced to rely on institutional care are seen as a reflection of the failure of the family to fulfil their obligation and thus cast shame on those who normally would take responsibility.

After the carers had indicated the information they needed, they were asked to say more about whether they had access to such information. More than half (n=24) the carers said they had not received any information and 18% (n=8) had received only some of the information they needed. Nearly one-quarter (n=10) said they had received some information either from the subject's doctor or from relatives who were health professionals. Thus, the majority of carers still had a great need for information about their elderly demented relative's illness. Carers who are not fully informed about the nature of the precipitating illness are likely to have a number of concerns and worries (Nolan et al., 1994).

7.8.2. The Need for Financial Support

In Thailand where there is no social welfare, not every elderly person is entitled to receive a state pension on retiring from work. Receipt of a pension depends on what kind of job the person has done during his or her working life. People who retire from the government sector can choose whether to take a lump sum or a monthly pension for the remainder of their lives, while those who retire from state enterprises can get only a lump sum; people who work outside the government scheme, if they retire from the private sector, may be able to receive a lump sum, depending on each company's policy, but people who were self-employed, will not be entitled to received any income support.

In the present study, of the 44 subjects, only 20% (n=9) were entitled to a state pension and all of them were cared for by their spouses. Just half the subjects were eligible for some form of financial help, and only three subjects had their own savings. Of the subjects who were being cared for by their spouses (n=24), two-thirds (n=16) received financial help. Nine of these, mostly male, had state pensions and also had additional financial help from their adult children, particularly daughters, and the remainder received financial help only from their adult children. Of those who did not receive financial help (n=8), only two said that they had their own savings and preferred not to get help from their children. Of the subjects who were being cared for by their adult children, most were not eligible for any pension or income support and relied heavily on their adult children; there was only one subject whose adult children used her mother savings to pay for her care. Nearly two-thirds of adult carers in this group reported that they had no financial help from other family members, while the remainder received some help from their brothers and sisters.

When the carers were asked whether they needed financial support while they were providing care, less than half (43%, n=19) replied that they did. However, looking at the responses by region (Table 7.6), spouse carers who lived in the northern region with their spouses, the majority of whom had no pension and relied on their adult children and income from farm produce, needed more financial support than those who lived in Bangkok and the metropolitan area. For example:

> C12: "Yes, I do. It would be nice if we could get it (financial support), because we have no income at all, our fruit plants gave us very poor produce this year."

> C16: "Yes,.....because I'm too old to work, so I have to rely on my children all the time."

By contrast, the majority of spouse carers in Bangkok and the metropolitan area made such comments as:

> C22: "He has enough pension for me to be able to care for him, so I don't need it."
>
> C37: "I don't need it, he's entitled to get free medical care from the government."

In contrast to the position with spouse carers, slightly more adult children who lived in Bangkok and the metropolitan area needed financial help than those who lived in the rural area.

Table 7.6 The need for financial support amongst spouse carers by region

Financial needs questions	Spouse Carers		Total (n=24)
	Northern region (n=12)	BKK and metropolis (n=12)	
Would you like to have income support?			
Yes	9 (75.0%)	1 (8.3%)	10 (41.6%)
No	2 (16.7%)	11 (91.7%)	13 (51.2%)
Don't know	1 (8.3%)	0.00	1 (4.2%)
Do you think elderly people should receive financial support?			
Yes	9 (75.0%)	2 (16.7%)	11 (45.8%)
No	2 (16.7%)	9 (75.0%)	11 (45.8%)
Don't know	1 (8.3%)	1 (8.3%)	2 (8.4%)

Carers were further asked whether they thought elderly people should receive financial support from the government. The findings revealed that of 12 spouse carers who lived in Bangkok and the metropolitan area, three-quarters (n=9) did not agree. This may be because the same proportion of their spouses had a pension and were entitled to free medical care, while the same proportion of spouse carers in the northern region (n=9, 75%), where fewer people had these benefits, said elderly people should have help (also see Table 7.6). The majority of younger relative carers in both regions agreed that the elderly should receive financial help. Some of them said the government should pay more attention to helping the elderly who are on the poverty line, have no income or who are not entitled to get free medical care. Another younger relative carer commented, "It would be very helpful, because I have to support my family as well" (C 3).

7.8.3. Respite Needs

Nearly half the carers (n=21) said that they could not go out and leave their elderly demented relative alone at home at all, unless there was somebody around. They often mentioned that the subjects needed supervision, due to their severe physical and psychological problems, such as being bed-ridden, wandering or having hallucinations. Although more than half the carers said they could go out, in fact only 20% (n=9) were able to leave the subject at home without supervision while 32% (n=14) admitted that they could leave only for a short period. A pensioner husband whose daughter worked outside the home said,

> C36 "I can go but I have to rush back. I have to lock her up in the room while I do some quick shopping...... I have to take a risk like this."

Nevertheless, carers said that other family members acknowledged the difficulties they faced caring for their elderly demented relatives, and they would be relieved sometimes when other family members came to visit them or returned home from work (in the case of co-residence). However, three daughter carers mentioned that they did not think their brothers understood their position, because they received no support from them, and one daughter-in-law complained about receiving little support from her brother-in-law and sister-in-law.

The next question was about the need for respite care. Carers were asked whether they would like to go out and stay somewhere else for a few days or weeks. It was found that 91% (n=40) carers would like to, but they could not, again because their elderly demented relatives needed so much care and supervision and there were no other family relatives available to take on their place while they were away. There were more spouse than younger relative carers (4 :1) who did not want to take holiday, but preferred to care for their spouse instead. One of them even said, "No I don't want it, we always go out or take holidays together" (C 29). This may be an indication of their loving and good relationship before her husband became ill which led her to wish not to leave him for a holiday or may reflect other concerns generated by the experience of being a carer.

7.8.4. Aids and Services

In the last part of the interview, carers were asked whether they needed any help and services in caring for their elderly relatives at home. Before help and services are delivered, it is important to know what sources of support carers already have, in order to know what level of help they have and what help and service they need to maintain their well being and provide a better quality of care. It was found that 84% of carers (n=37) mentioned their family members as their main source of help. Spouse carers mostly mentioned their adult children and grandchildren, while younger relative carers mentioned their siblings or their husband. Only a few carers mentioned that they had help from cousins, particularly those who worked as health professionals. The remainder sought help from other people from outside the family: friends or a doctor from the hospital or private clinic.

They were also asked whether it would be helpful if someone, particularly a health professional, came to visit them at home. It was found that all carers and their elderly demented relatives had no experience of being visited by health professionals. Most carers said they would be delighted and welcome a visitor with whom they could discuss their caring problems and who could give them information and suggestions about health care. For example:

> C17: "That would be very good, so I could discuss his illness and how to care for him."
>
> C31: "Very good, because sometimes I have a problem, but I don't know where to go for help."

The final question on carers' needs was the open-ended question which asked them to freely indicate what type of help they needed. This revealed that the need for information about health care was the main need among carers. They needed advice about caring from health professionals or a help-line service. One carer mentioned the need for an information centre. Secondly, carers wanted a better health care service, such as a respite care or day care centre, a health visitor, such as a community nurse, for those who had difficulty travelling to hospital, and shorter waiting at the OPD. Two daughter carers who had not been impressed by their experience of the health professionals who cared for their elderly demented parent in hospital said health professionals should have a positive attitude towards the demented person. One daughter carer said, "Doctor shouted at my father and treated him like he is stupid" (C 31), and another said, "I used to take my mother to the ER at night, I was asked whether I brought elderly patient, if I do please go to another hospital" (C 25). Carers' third need was for financial support from the government while they were taking care of their elderly demented relative at home. Finally, carers needed their elderly demented relative to obtain free medical care. This was particularly the case for carers who lived in the rural northern region rather than carers who lived in Bangkok and the metropolitan area.

Conclusion

The third part of the research findings mainly provided information about the caring situation, factors that affect caring, and the carers' needs. The majority of subjects were co-resident with carers. Most spouse carers were still co-resident with at least one of their adult children who had remained at home by reason of being unmarried or being the last person in the family to get married. This person would automatically become the carer when their adult relative became ill.

Although, the Buddhist religion and Thai culture emphasises that children should provide care for their elderly relatives, most adult children worked outside the home. Therefore, because of the of availability of time, spouses, the majority of whom were housewives, had to accept the caring role. The view of 'reciprocity,' however, was still very strong among younger relative carers. Although they had problems in caring, caused by subjects' psychological and physical problems and faced stress and physical strain on their own account, they were still willing to continue providing care at home.

Regarding help for carers, most help came from their family members. The burden of caring, including care providing and the cost of medical treatment, tended to be shared among family members, unless the subject was entitled to receive free medical care. Seeking for a care assistant to provide care at home has become popular among the Bangkokians who had to work outside the home or who were better off. Overall 66% of all carers felt the elderly relative should receive financial support, although there were regional differences as well as differences between spouse and younger relative carers. More carers who lived in the rural northern region than those who lived in Bangkok needed financial help, while the majority of carers who did not need additional financial support received financial support from their spouses' pension or from their own savings. In addition, a number of carers mentioned of a great for information about their elderly demented illness and how to provide a better care.

CHAPTER 8

Discussion

Introduction

This chapter commences with a discussion of the problems of the theory and literature on methodological developments which have led to some limitations in the present study as well as other limitations which affected the conduct of the research in practice. The chapter goes on to show how, nevertheless, given little is known about carers in Thailand, the findings from the present study contribute to knowledge by adding to the limited existing theory in cross-culture caring. The discussion will also consider the implications of the research for policy and practice.

8.1. Methodological Development

The present study was an attempt to explore the myth of family care in Thailand, where carers do not question their role or even admit they are carers, because caring for their own elderly relatives is part of their duty and has become traditional and socially accepted. This research would not have been considered interesting to carry out, if the researcher had studied only in Thailand, because the situation it explores is so much a part of everyday life. Since the researcher has spent some time in the UK, however, where the culture, normative belief, religion, and way of life are very different to those in Thailand, the researcher has detached herself and tried to view Thailand as an outsider, in order to be able to distinguish the differences and the similarities among developed and developing countries and raise a number of questions. She, therefore, become keen to find out what key factors influence these differences in caring for elderly people. Although research in Western countries has been extensively developed, which provide many constructive ideas, however, this advanced knowledge could not be totally applied or carried out at the same level, because the basics of research have yet to be developed in Thailand.

Nevertheless, the researcher tried to take advantage of Western theory by integrating, as far as possible, advanced concepts from the West to examine the caring situation within the limitations of information and resources. The available information about elderly people mostly comes from the sociological and anthropological points of view which, normally, concentrate only on elderly people in general and very little information has been found from health professionals, which is concerned more explicitly with caring for the elderly in institutions, such as hospitals and residential homes. As the majority of elderly people live in the community and are cared-for by their family, thus, to extend knowledge of caring in the community, there is a need for a multidimensional approach which combines medical knowledge with sociology, in order to achieve a full understanding of this type of care. Thus, the present study attempted to cover a wide scope of different dimensions of care, including physical, psychological, socio-economic, and the social network of both cared-for person and carers. Both quantitative and qualitative approaches were required to be able to address all of these aspects. Given the researcher's limited knowledge about sociology, she has not attempted to describe the participants in sociological terms nor assign specific social classifications to them, but has rather attempted to interpret the research findings in terms of what the participants actually said.

8.2. Limitations of the Research

The limitations of the present study fall into three categories: the limitations of the research design and its impact in the fieldwork, and the limitations of the application of the existing measuring tools in a different culture, the limitations of data analysis.

8.2.1. Limitations of the research in practice

Dementia syndrome is still not well recognised, and there has been little research about dementia carried out in Thailand. Searching for demented elderly in the community would need a medical practitioner to confirm the dementia diagnosis, and would be time consuming. Obtaining participants who had already been diagnosed from the hospital setting was the other choice. However, obtaining permission from hospitals was difficult. One of the selected hospitals had to be dropped due to problems with the management and their delay in giving approval. Although permission to carry out the research was granted by the remainder of the selected hospitals, the research process was impeded by the lack of clear records of dementia patients. Medical practitioners themselves, for example geriatricians, neurologists, and psychiatrists in these institutions, could not tell the precise number of dementia sufferers who had undergone treatment in their clinics. Even though illness classification records were available on the computer in one psychiatric department, however, lack of up-to-date information such as the patient's current address or contact telephone number made it difficult to contact patients. At this stage, it was impossible to establish a sampling frame from which to sample the participants. This circumstance led the researcher to spend over half of the field work period at the OPD, waiting for the dementia patients who visited for treatment. Because the number of dementia patients who visited the OPD each day was very small, and service hours very limited, all those who visited the OPD during this time were asked to participate in this research.

Then, the distance between participants' place of residence and the hospital had to be considered, due to the limitations of time and the cost of transportation. For example, the Chiang Mai Neurological Hospital in Chiang Mai province serves patients in 17 provinces in Thailand's northern region, covering 169,644.3 Sq.Kms. Thus, participants were limited to residents of the neighbouring provinces, such as Chiang Rai, Lumphun and Phayao. In Bangkok, some demented persons were resident only temporarily with their relatives in Bangkok and travelled back home to other regions, such as the eastern or southern region, after treatment. Thus, the participants were limited to residents of Bangkok and the metropolis, because of the difficulty of interviewing the others at home. In visiting people at home, it was easy to get lost, or be unable to find the participants' homes, due to lack of clear directions and the road signs, particularly in the rural area. Policemen, postmen, and village headmen were helpful in providing directions. Safety also had to be considered in travelling to remote areas as well as to isolated households in Bangkok. The progress of the research was also impeded by the heavy traffic and the inadequate public transport in Bangkok.

Such problems could easily deter a researcher and not surprisingly, some have given up. However, on the other hand, it is a challenge to the ability of the researcher to overcome these problems. Thus, the identification of these limitations in the present research may be useful for other researchers who would like to carry out research not only in Thailand, but also in other developing countries; by being aware of these problems, they may be able to find ways to overcome them in their own research.

8.2.2. Limitations of the research tools

Four main research instruments were used in the present study: TMSE, CSI, BRS, and Network Assessment. In the case of the TMSE, CSI and Network Assessment instruments, some limitations were found in their application in the present study, which will be discussed in this section. Since these instruments were developed in Western countries with different socio-economic development, level of education, and cultural backgrounds, thus, these instruments need to be applied with caution.

i) The Thai Mental State Examination (TMSE)

The TMSE, the mental status test, is a tool developed from the Mini-Mental State Examination (MMSE) by a group of specialists in neurology, psychiatry, geriatrics, psychiatric nursing, and psychology in Thailand, who modified some questions to make the instrument compatible to the Thai culture and real life situation of Thai people. Because of this adaptation, the sensitivity of the original instruments may have been changed. These data from the TMSE test cannot be compared with MMSE results from another country. In addition, as it was mentioned earlier in Chapter 4

(Section 4.5.4), the MMSE test has an excessively high number of false-negative errors for patients with early dementia and false positives have been reported in persons who had less than 9 years of education (Anthony et al., 1982). These weaknesses seem to follow to the TMSE test. Also, a recent studied by Jitapunkul and Lilert (1997) suggested that using the MMSE for screening cognitive impairment in Thailand may be inappropriate because it is influenced by level of education and place of residence.

The present study found that among subjects who had already been diagnosed as having dementia, including early dementia, 12% (n=5) had normal levels of cognitive impairment. Even though the researcher is well aware of the false positive of the mental status test in people of low education, however, it was difficult to find a sufficient number of people who had 9 years of education, as the majority of Thai elderly people have little formal education. In order to minimise this type of error, the elderly demented persons who had no formal education or were not able to read and write were excluded from the present study. Nevertheless, over half of elderly demented participants in the present study were educated to only primary or elementary level (less than 9 years of education). The lower level of education would probably affect the abilities of recall and calculation in Thai elderly people. Results from the TMSE test with normal Thai elderly (Train The Brain Forum Committee, 1993) and with the demented elderly people in the present study, both revealed failure in recall and calculation (see Chapter 5, Section 5.3.3). Thus, there is still a need to modify the TMSE or search for a more appropriate cognitive test for Thai elderly people which provides fewer false positives in people who have little education.

ii) Caregiver Strain Index (CSI)

In the assessment of psychiatric illness using screening tests, Biegel et al. (1991, p. 58) suggested that "psychiatric screening instruments are limited in sensitivity and specificity," meaning that these instruments can only provide an estimation of emotional disturbance, but rarely provide information regarding frequency and duration of symptoms required for clinical diagnoses. Therefore, the results need to be interpreted cautiously. The CSI scale was initially chosen for using as a screen test for stress in carers, because it is brief, straight forward, easy to translate, and its questions appear less aggressive than other test, an important issue in a context where attitude towards caring for elderly relatives is likely to be a sensitive issue. Positive responses to seven or more items on the CSI index are said to indicate a greater level of stress (Robinson, 1983). The CSI has been criticised, however, for making a number of simplistic and unwarranted assumptions (Nolan et al., 1994; Nolan et al., 1996), lack of distinctions between the dimensions of burden (George and Gwyther, 1986), and lack of identifying the specific burdens which are most likely to result in the outcome of strain (Pearlin, 1990). In addition, the CSI defines strain synonymously with stressors, which are antecedent events and precede appraisal and outcome. Thus, the CSI would not be able to assess stress levels in carers, which is an outcome, but to assesses strain, as it primarily measures stressors and potential risk of stress, instead. Therefore, in this study, the CSI was treated as a test for measuring strain (see Chapter 3, Section 3.3 and Chapter 4, Section 4.5.4).

Since measuring stress as an outcome could not be achieved because of the limitation of the CSI scale, thus, this experience needs to be learned from in future research on stress. In addition, all researchers need to be aware of the literature about stress, which appears very confusing, due to the lack of consensus in conceptualisation and measurement, which have led to inconsistent research findings. Therefore, in the future research, caution must be exercised in selection of an appropriate scale as well as the interpretation of the findings. However, even if a more precise perceived stress or burden measurement scale is applied, 'burden should be treated as an intervening measure between impairment and other more objective indicators of caregiving affects' (Poulshock and Deimling, 1984, p. 238). Therefore, 'global measure of psychological well-being, physical health, or depression should be viewed as being affected by burden, as well as many other factors, but should not be viewed as measures of burden' (Schulz, 1990, p. 38). There is still a need for a single, complete stress measuring scale to be developed.

iii) Network assessment

The Network Assessment Scale was found to work quite well in Thailand. The network assessment scale provided a clear picture of relationships within the family and outside, including social activities of people who were assessed. It was also found easy to administer, as it does not need to be carried out by a person who has a background in sociology. The network assessment instrument was found to have only little limitation when compared to the TMSE and CSI. There was a need to modify just one question to make it more distinct and reflect the pattern of Thai living arrangements. This was the question, 'How far away, in distance, does your nearest child or other relative live?' and one of the available choices of response, 'same house/within 1 mile.' In Thailand, living arrangement among elderly people and their adult children, in general, can be simply categorised into three types: living in the same house, in the same compound, or at a substantial distance. Thus, this response needed to be redefined, in order to provide a clear picture of the family pattern in Thailand.

8.2.3. Data analysis

Quantitative data analysis has been limited to simple description, as the data collected were on nominal and ordinal scales. Because of the limitation of the CSI scale, the whole stress process could not be measured. Non-parametric correlation was carried out only on the CSI scale and other stressors, such as carers' demographic variables, socio-economical status, objective stressors (i.e. TMSE, BRS) and subjective stressors (i.e. duration of illness, hours of care provided) of carers. This relationship was not treated as a measure or predictor of stress, which is frequently treated as a primary outcome measure (Schulz, 1990; Biegel et al. 1991).

Although all the available sample agreed to participate in this study, nevertheless, the sample size was small (n=44). Not attempt is made, therefore, to generalise these findings to carers and their demented relatives in Thailand as a whole, but they are limited only to the group who participated in this study and, perhaps, provide some general ideas about the group of carers who decided to take their demented relative to receive treatment from the hospital. Therefore, interpretation of these research findings must be undertaken cautiously.

8.3. Contribution to theory

There has been an increasing awareness that caring for elderly people is not limited only to the ill health of the elderly, but that holistic care has to be extended to encompass socio-economic circumstances, the family, and help resources, which influence caring, particularly caring in the community. For a better understanding about caring for elderly demented people in Thailand, this study has moved forwards to examine how the religion, culture and normative beliefs influence people's perception and behaviour in taking a care-providing role in relation to its impact in the Thai society.

8.3.1. Religion, culture and normative belief in caring

The available literature suggests that the Buddhist religion sanctions and supports a vision of filial piety which imposes a heavy obligation upon children, as children owe a debt of obligation to their parents who gave them birth and provided care for them (Mulder, 1985; Klausner, 1987; Caffrey, 1992b), concerning their behaviour and responsibility toward their parents (Cowgill, 1986). Therefore, there is a clear normative belief (i.e. what people *think* is the right thing to do) that children should provide care for their elderly relatives (Wongsith, 1990). At the same time, elderly persons themselves appear to prefer to receive care from daughters and youngest children (Knodel, et al., 1995). From this normative belief, we might assume that daughters and youngest children predominate in taking up the care-providing role. However, the normative belief may remain, but in practice, things might have changed, corresponding to the present real life situation. This study shows that more than half of carers were spouse carers (54.5%), followed by younger relative carers (daughter, daughter-in-law, son, and a relative living in the household). This finding is similar to the findings in the Western studies where the majority of carers were spouse (Evandrou et al., 1986; Heron, 1998) and a hierarchy of people has been found to be involved in caring which were in descending order: spouse, relative living in household, daughter, daughter-in-law, son, and other relative (Qureshi and Walker, 1986). The findings from the present study may indicate some flexibility in selecting a carer whenever circumstance warrant it. Thus, in the situation that the expected person (i.e. daughter) cannot carry out the caring role, due to her working situation, another family member may need to be considered. It may also indicate that in situations where material conditions would appear to favour behaviour contrary to norms, the normative belief does not necessarily translate into the norms of behaviour (i.e. what most people *do*).

8.3.2. Impact on attitude towards traditional family care on *'parent repayment.'*

In Thailand and other Asian countries, the family has been the traditional social institution for care of the elderly (Knodel, 1992b). However, little is known about what family members really think about being expected to become future carers, and their attitudes towards traditional care in these societies. Do carers desire to provide care themselves, or have they just performed their caring role from the sense of duty and obligation, or have they behaved the way their society expects, while concealing frustration and pressure inside?

i) The influence of Buddhist doctrine

Filial obligation is central to the Buddhist and in Thai this is termed "parent repayment." This is one of the most respected and accepted Buddhist doctrines, which emphasises that children should provide care for their elderly parents. This may lead to the hypothesis that people who are more religious will show more signs of filial obligation and responsibility to their elderly parents. Religious belief might be measured by comparing how people rate their level of religious belief and their practice of religion. Those who claim to be strongly religious, would be expected to be much involved in several kinds of religious activity, which in the case of Buddhism includes temple attendance, merit-making and meditation. However, in the present study, this hypothesis could not be fully tested because a number of carers who rated themselves as very religious or moderately so, said that they had been unable to carry out their regular Buddhist activities since becoming carers, as they devoted most of their time to providing care for their demented relatives at home.

Since Buddhist activities could not be used as a measure of religious commitment, the positive perception of reciprocity towards elderly relatives within the meaning of the common term of parent repayment was used as a proxy measure. The majority of carers expressed positive attitudes towards reciprocity, including the sense of duty, obligation, and gratitude or appreciation that they were able to fulfil their responsibility, while only a few referred to a tradition of caring. Thus, it may be assumed that religion is one of the major factors which influences people's behaviour and creates a social norm of providing care for elderly relatives. However, it must be recognised that the social/religious obligation that they felt they should express may have prevented their expressing their true belief to the present researcher.

ii) Willingness to Care or Social Pressure

It is quite clear that Buddhism has influenced attitudes to family care for elderly parents or relatives in Thailand, and this eventually became a social and cultural tradition. Thus, there is evidence of public agreement on the mutual obligations between the elderly and their adult kin. However it is still not clear whether this belief has a role in pressuring adult children to become care providers by imposing the value of 'reciprocity' or parent repayment on them. It is also still not clear from the present study whether carers perceive their roles of caring for their elderly relatives as a duty, as something desirable, or as something done under social pressure. For example, some may see repaying their parents by providing care for them as their duty or obligation, without being happy to do so, while others may feel that it is something important that everyone should carry out and be happy to do so. Moreover, those who refer to reciprocity as a tradition of caring may reflect the influence of culture and social acceptance of caring. If they failed to follow the rules, carers might face heavy public condemnation. Therefore, carers in the present study were very cautious about indicating whether they might, in any circumstances, institutionalise their elderly demented relative. Thus, only a few carers, especially those who lived in Bangkok, mentioned nursing homes, while the majority seemed as if they did not want to appear unable or unwilling to provide care themselves. Because the concept of living in an institution is not very familiar and is generally viewed negatively, as a reflection of the failure of the family to fulfil their obligation (Knodel et al., 1995), it may be perceived as a sign of abandonment. The institution is seen as a place for elderly people who have no relatives to care for them.

8.3.3. Gender in carers

In general, the task of caring, perhaps in all cultures, is predominantly a female responsibility. The literature indicates that 'carers' are generally regarded by feminists as having a very similar role to mothers and housewives who work in their own home and care for their close kin (Ungerson, 1990). In Thailand, an earlier small scale study of the family burden of caring for elderly demented persons at home found that of a total of 29 carers, none of them were male (Sommanawan, 1994).

However, there has been growing evidence of the increasing number of male carers, such as in Qureshi and Walker's study (1989), where it was reported that over one-third of carers were male and of the 16% who were spouse carers, at least two-thirds were men. This trend is likely to be found in Thailand nowadays; in the present study, although it was found that female carers predominated (80%), however, 20% were male (see Chapter 6, Section 6.1.2). This indicates that males are involved in caring in Thailand. Nevertheless, when compared to the findings in the West, Thai males still appear on the evidence of this study to participate less in care provision.

The reasons why Thai women participate more in caring and factors which cause Thai men to participate less in caring can be obtained from the earlier sociology studies. Caring in Thailand is strongly associated with co-residence; the co-resident child is also expected to provide care for their elderly relative (see Chapter 6, Section 6.1).

Assis et al. (1995) pointed out that co-residence in Thailand appeared to be stable and that the preference is for co-residence with a daughter, which is reflected in the number of female carers reported in studies of living arrangements of elderly people in Thailand. For example, the youngest daughter was expected to remain in the household after her marriage, in order to care for her parents until their deaths (Caffrey, 1992a) and the large majority of this focus group study of the Thai elderly and their adult children indicated that they prefer to live with a daughter rather than a son (Knodel et al., 1995). Why is this? Assis et al. (1995) indicated that such preference with regard to co-resident children was found to be strongly influenced by relationship and tradition. In the bilateral family system, daughters have close ties with their elderly parents, as described in Chapter 7, and concern about possible conflict with a daughter-in-law which may arise from the day-to-day affairs of running the household, may have led elderly parents to prefer to live with a daughter rather than a son. Cultural influence is also crucial. The tradition that the co-resident child is the youngest daughter may be related to the fact that she is usually the last child to remain in the parental home and the last to marry. Moreover, Knodel et al. (1995) indicated that in Thai society, the role of daughters is better suited for providing personal care to parents than the role of sons, as daughters are conceived to be emotionally closer to parents, more dependable, and better care givers. In addition, after marriage, daughters are expected to bring husbands into their family system (Caffrey, 1992a). Thus, in this tradition, parents probably do not expect sons to remain at home and provide care for them, because they know that sons will move into the wife's family system after they get married. However, sons are still expected to support parents by contributing through economic activities, rather than helping in the household and attending to the personal needs of the elderly (Knodel et al., 1995)

In order to understand better the role of gender in caring in Thailand, particularly in the long-term care for elderly demented relative, questions on the gender of the carer and types of relationship between carer and demented elderly were asked. The results indicated that female carers predominated, as did spouse carers, who also had parental status. They expressed their preference for a daughter to be the next person to provide care if they were no longer able to do so. Thus, preferences for the gender of the carer remain unchanged.

However, in the vast majority of cases where the demented person and their spouse were co-resident with their children, closer examination of the relation between carer and demented person with regard to sex revealed that there were more spouse carers than younger relative carers among both sexes: male spouse carers outnumbered male younger relative carers by 5:4 and female spouse carers outnumbered female younger relative carers by 4:3. All the male spouse carers were retired from work, while most female spouses were housewives. This may indicate that the potential to be a carer depends on the time available to spend among the family members, rather than gender or birth order alone. This may also reflect the economic situation in modern times, resulting in an increasing number of women or other younger family members having to go out to work in order to earn enough money to support their family and elderly parents.

A particularly interesting finding was the increasing trend towards male carers, particularly spouse carers, compared with the study by Sommanawan (1994), mentioned earlier. In the past when their elderly parents were reasonably well and healthy, women may have accepted their caring role in the family. However, in a situation of long-term caring for someone with a chronic dementing illness, there was a call for males to participate more in providing care. One-third (n=7) of younger relative carers in the present study expressed their preference for their brother, rather than sister, to help in caring and to be the next person to become a carer. Why a brother? Three daughter carers in the present study mentioned that they received no support from their brothers, so they did not think their brothers knew about the caring situation. Thus, they seemed to show resentment at receiving insufficient help from their brothers. Since the majority of younger relative carers were female, perhaps this finding may indicate that female carers are beginning to ask for equality of responsibility in providing care.

8.3.4. Carers' experience of strain

Although carers in the present study felt happy to care for their elderly demented relatives, however under the condition of chronic and progressive impairment, their 'relationships become increasingly imbalanced, the reciprocities and give and take that had existed fade into the past'(Pearlin et al. 1990, p. 583-584), which can give rise to stress. According to findings from the present study, nearly half (43%, n=19) responded positively to seven or more items on the index, and so were probably experiencing greater levels of strain.

The first three most important areas related to strain were being upset that the cared-for person had changed so much, feeling overwhelmed, and emotional adjustment (see Chapter 6, Table 6.5). These areas are more related to emotional or psychological aspects of strain. This may result from the different pattern of living arrangement of demented person and their carers. The earlier studied by Yeatman et al. (1993) found that physical proximity, such as co-residence with the dementia sufferer, was the main determinant of psychological stress in the primary carer. The results of their study in Melbourne showed that carers of people with dementia who lived with the demented relative had General Health Questionnaire (GHQ-30) scores almost four times higher than those carers who lived apart from them. Since the majority of carers in this study (95.5%) were co-resident with elderly demented relatives, this would be a possible factor in rising strain in carers. In addition, the particular culture of caring, where carers in Thailand generally have carried a lot of expectation from their parents as well as the public as to their role as a future care provider, whatever the circumstances, as discussed above, would be another possible factor in raising strain in carers

When compared to the studies from the West, it was found that carers from the present study were more likely to express emotional upset at finding their parent has become a different person from the one they used to be, which was reported by 84% of the sample in the present study, compared to 65% in O'Brien' study (1993) and 58% in Wilkinson et al.'s study (1997). This may result from difference in the culture and attitude towards the elderly. In Thailand, age is a basic determinant of status and the elderly are treated to positions of honour both in public and at home (Cowgill, 1972), awarded the highest status within the family (Limanonda, 1995), and Thai children are trained to show respect for elders (Wongsith, 1992). Thus, seeing their most respected loved one having severe mental infirmity may have an effect more devastating in Thailand than in the West. A number of carers expressed their feelings towards their elderly demented relatives, for example: "It's a pity, she behaves likes a child to me" (C 17) or "I feel so sorry for him, he shouldn't be like this" (C 31).

Although this study is not able to predict or make a correlations between stressor, coping resources and the outcome, however, at the primary stressors level, the findings revealed that a higher level of cognitive impairment and lower level of independence in dementing relatives correlated significantly to a higher level of strain in carers. In addition, the level of strain was increased as the number of hours of care provided increased; the longer the duration of the dementing illness and the more care was provided, the greater the strain on carers. In the present study, strain has been treated as a stressor which may potentially serve as a risk factor leading to stress on carers. This assumption is supported by the qualitative data which showed that over two-thirds (68%) of carers reported particular difficulties in caring, related to the cared-for person's psychological and behavioural problems. Spouse carers, in particular, reported stress and physical strain from the caring tasks, which always related to the demands of caring for the subject with little or no help from either family members or outsiders (see Chapter 7, section 7.3).

A number of prior studies have also found relationships among these variables. For example, among co-resident carers, Twigg (1992) pointed out that there is very high level of stress among those heavily involved in helping; in addition, substantially more time is spent caring for the dependent as the carer's age increases, in response to an elderly person's increasing frailty or disability (Arber and Ginn, 1990; Finch and Mason, 1990). It has also been reported that the care receiver's illness is one of the major sources of stress for carers (Poulshock and Deimling, 1984; Bass et al., 1994) and several studies report a positive relationship between behavioural problems of the care receiver and the health and well-being of the carers (Chappell and Penning, 1996).

Financial strain could be one of the major causes of stress and strain on carers. Although from the interview, the vast majority of carers said they had no financial difficulties in caring, the finding from the CSI scale also shows that one-third admitted they had financial strain. Most of these came from the low socio-economic class (SES). There is no national health service in Thailand, only basic social services are available, and there are no home helps or health visitors for elderly people. It may be said that "you will get what you pay for" and those who have no money cannot get help from outside. Thus, the continuing expenditure on health services and treatment for the cared-for person suffering from chronic illness such as dementia syndrome may be producing greater stress on carers.

8.3.5. Do male carers experience less strain in caring than female carers?

Although the findings from the present study support Robinson's study (1993) in which there were no significant differences between CSI scores for men and women, however, it was shown that male carers have slightly higher CSI scores than female carers, the mean CSI scores being 6.2 and 7.1 for females and males respectively.

Since the positive responses to seven or more items on the CSI would indicate a greater level of strain, therefore, in this study, male carers likely experienced a greater level of strain than female carers. However, this finding is not in line with the existing Western literature, which suggests that women experience more strain than men because women are not only portrayed as primary caregivers but also as providing more extensive care than men (Robinson, 1983).

One may ask, why Thai men seem to experience higher levels of strain than women? Do Thai women have more of a sense of caring duty and do they more accept their caring role than men? In Thai culture, there is a clear gender division of responsibility and labour in the performance of domestic tasks. For example, daughters are more likely to be trained to do household and caring work for family members than sons. As was mentioned earlier, in Chapter 3, daughters are typically perceived to be emotionally closer to parents, more dependable, and better care givers. Sons are expected to help to support parents by contributing through economic activities rather than helping in the household and attending to the personal needs of the elderly (Knodel et al., 1995). Komin (1991) also described characteristic Thai women as having as their chief concern family happiness, security, a peaceful life without conflict, and with a low value for equality and freedom, while Thai men are characterised as being more socially oriented and concerned for broader issues, such as national issues, career development, security, power and politics. Thus, it seems clear that the lack of caring role experience may have caused men to have greater levels of stress than women. However, this was a small sample and male carers only constituted 21% (n=9) of the sample. Therefore this finding should be treated with caution and warrants further study.

8.3.6. Why do carers continue to provide care?

In the present study, the quantitative data have clearly identified that strain on carers was significantly correlated to the levels of cognitive impairment, the dependency levels, hours of care provided and duration of illness of the demented elderly relatives. The qualitative data from open-ended interview questions also indicated that carers expressed stress and physical strain and a deterioration in their relationship with their elderly demented relatives. Moreover, half the carers said their health was somewhat worse than in previous years. Despite these circumstances, the majority of carers still insisted that they would continue to provide care at home. Thus, it is still not clear what was the motivation to care.

Given the limitations of the information the standardised scales, much information was derived from the interviews. Figure 8.1 provides a simple diagram explaining the possible function of different factors in carer motivation to continue providing care in the present study. The motivation to care for an individual results from the strength of the influence of these four elements: caring problems; reciprocity/parent repayments; satisfaction; willingness to care or social pressure. Because care for elderly relatives in Thailand is limited to family members, spouses have to provide care for their own ill spouses and younger relatives have to provide care for their own elderly relatives as part of Thai culture, derived from the Buddhist religion; if they do so, then, certain rewards will be achieved. Moreover the majority of carers in the present study expressed a positive attitude towards the ideology of parent repayment (see Chapter 7, Section 7.2.2) and reported a sense of satisfaction in caring (see Chapter 7, Section 7.1.3). Carers in the present study, therefore, could have high levels of mutuality, since they expressed satisfaction at fulfilling a duty and fulfilling the role expected of them by society. Nearly three-quarters (70%) of younger relative carers expressed gratefulness and happiness in their living arrangement related to reciprocity and a sense of doing their duty, while nearly half the spouse carers were happy to undertake caring with help from their children or helper and only a quarter expressed happiness at fulfilling their duty. The presence of mutuality provides a potential satisfaction in care and the 'presence of satisfaction may serve as an important coping mechanism' and reduce the potential of an abusive relationship (Nolan et al. 1996, p. 3).

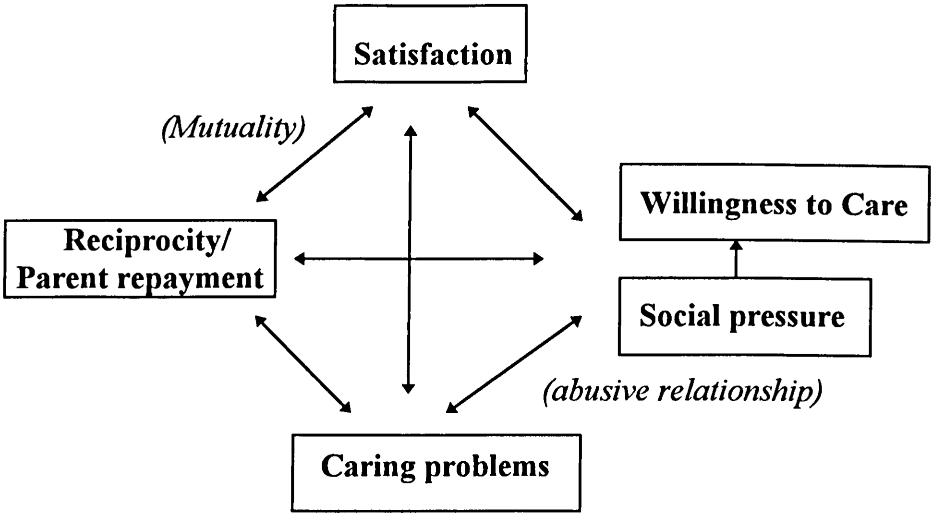


Figure 8.1. Motivation to care

Thus, it may be assumed that those carers who expressed positive feelings about care providing (i.e. happy, very happy or feeling a sense of duty) should experience no strain. A cross-tabulation revealed that of 19 carers (43%) with greater levels of strain, 13 (68%) expressed themselves as feeling satisfaction in caring. There were more younger relative than spouse carers experiencing greater levels of strain. These findings suggest that those who said they were happy to very happy or that it was their duty to provide care, were not free from strain. The finding from a study by Grant and Nolan (1993) also suggested that in caring, rewards and satisfactions can co-exist with strains in many informal carers.

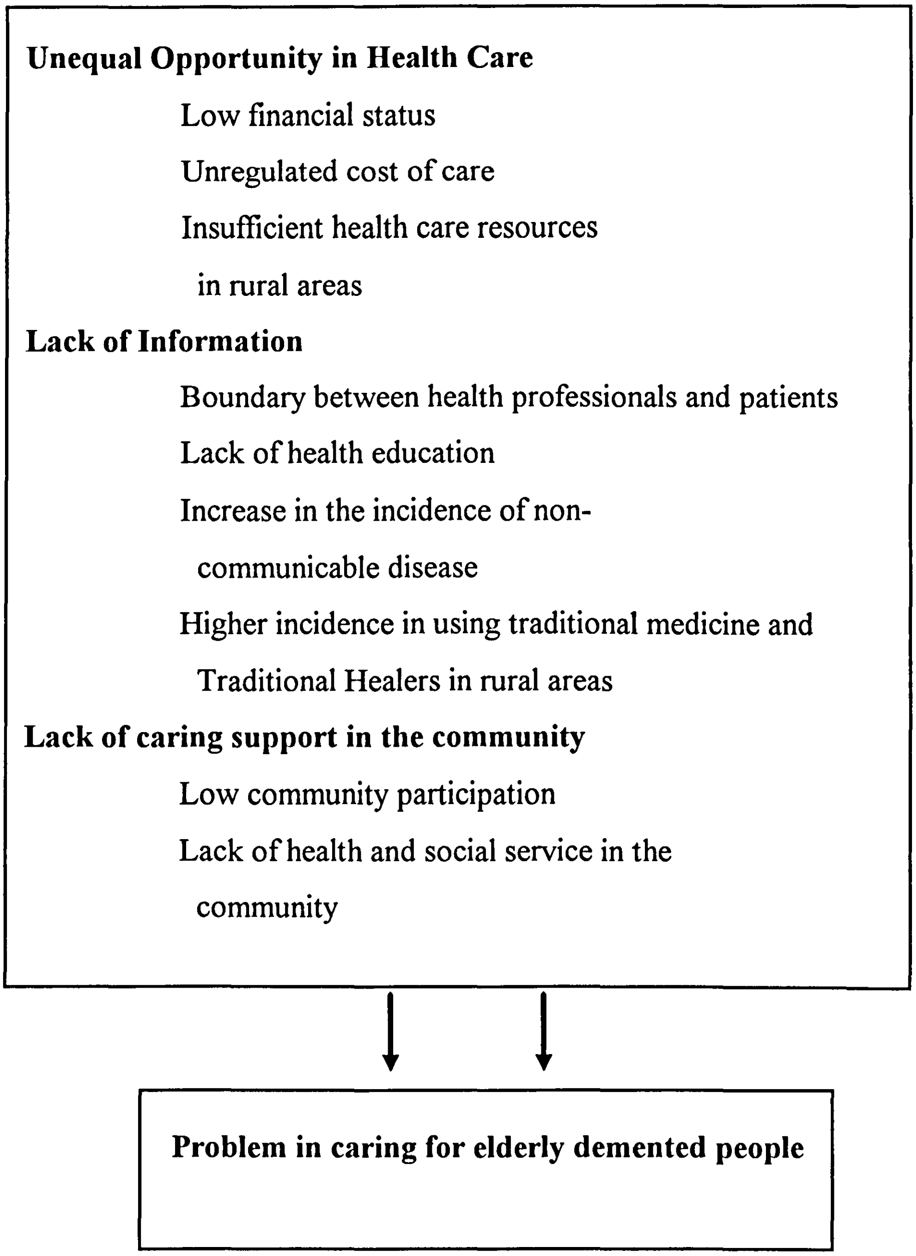
Despite the difficulties in caring, most carers still insisted they would continue to provide care (see Chapter 7, Section 7.5.2). This motivation may come directly from the a desire to reciprocate for the past service, which is very much influenced by Buddhist belief. It may also be influenced by mutuality and satisfaction at being able to fulfil the social expectation of taking responsibility for caring for their elderly relatives. Hirschfeld (1981, p. 163) suggested that 'the higher the mutuality, the more unlikely was the caregiver to (even) consider institutionalisation as a possible alternative to home care.' On the other hand, some carers who insist on continuing to provide care even when under strain and facing caring difficulties may do so out of a desire to avoid a negative reaction from people in the society, or because they are unable to support the cost of care an the institution rather than reasons of mutuality

However, family care can break down in a situation where there are severe difficulties in caring. As was mentioned earlier, when the relationships become increasingly imbalanced, reciprocities and give and take may be disappear (Pearlin et al. 1990) and satisfaction cannot be achieved. When the caring situation becomes stressful, and if people still insist on continuing to provide care, there is a danger of abuse in caring.

In the present study, attention was paid to this possibility, particularly among spouse carers. Although nearly half of them were happy to care with help from adult children or a care assistant, and a quarter expressed happiness to fulfil their duty, however, qualitative data showed that there were more spouse than younger relative carers who reported stress and physical strain and a poor current relationship. Nevertheless, the real motivation for continuing care could not be fully explored in the present study, due to the small sample size. Thus, there is a need for further study with a larger and more representative sample and using a more structured instrument with multi-dimentional measurement of the motivation to care.

8.4. Problems in the provision of Health and Social Services for Demented Elderly People

The present research findings and the relevant existing literature suggest that some of the major problems in caring for people with dementia concern the availability, the distribution and the effectiveness of the system of health and social resources for elderly people, particularly elderly who are frail or suffer from chronic illness, and their carers. The evidence of the present study indicates that the problems of caring for the elderly demented at home are as follows (see Figure 8.2):



Unequal Opportunity in Health Care

- Low financial status
- Unregulated cost of care
- Insufficient health care resources in rural areas

Lack of Information

- Boundary between health professionals and patients
- Lack of health education
- Increase in the incidence of non-communicable disease
- Higher incidence in using traditional medicine and Traditional Healers in rural areas

Lack of caring support in the community

- Low community participation
- Lack of health and social service in the community

Problem in caring for elderly demented people

Figure 8.2. Factors creating a problem in relation to health and social services for demented elderly people in the community

8.4.1. Unequal Opportunity in Health Care

In Thailand, as described earlier, in Chapter 3, there is no national health service as in the UK. However, the government is a major provider of cheaper health care throughout the country. In this system, almost everyone is responsible for meeting the costs of their own care. As Nittayarampong and Tangcharoensathein (1994) point out, household out-of-pocket payment is a major source of health care financing in Thailand, accounting for about two-thirds of total health expenditure. The medical welfare and health insurance schemes cover only those people who work or are retired from the government sector and entitled to receive free medical services from the government, employees or retired employees of private corporation which provide medical benefit, and people who buy private health care insurance. However, only approximately half of the population is covered by some form of insurance (Hongvivatana, 1990: Tangcharoensathin, 1990; Pannarunothai, 1992).

The findings from the present study suggest that unequal opportunities in health care for elderly Thai people are clearly initially associated with insufficiencies in the health care insurance system. With regard to long term care for chronic conditions such as severe dementia for those who have no health care insurance, the cost of medical treatment is a heavy burden on their carers, and the carers' financial status and cost of care would be key factors affecting carers' ability to pay for health care services. In addition, the insufficient distribution of health care services in various regions probably also exacerbates inequality of opportunities to access health care.

i) Financial status related to the cost of care

Over half of elderly people with dementia (53%, n=23) in the present study had only primary education and the majority had retired from agricultural occupations or self-employment. Therefore, they would not normally be eligible for any medical benefit, from either the government or through private insurance. In particular, elderly people who have no savings will rely on their children to meet costs of their health care, which may reflect the strong social value of parent repayment. Wongsith (1992) explains that parents expect and feel entitled to support from their adult children in both economic and non-economic respects. For example, during illness, elderly parents need physical care and psychological comfort as well as financial help in purchasing medicine or paying for medical service. The finding from the present study shows that there was a financial contribution among adult children to meet the cost of care for their elderly demented relative. Nearly two-thirds of spouse carers (n=15, 62.5%) said that they received financial support from their adult children, either from co-resident children or from others who lived elsewhere. Among younger relative carers (n=20), less than half (n=9, 45%) received financial support from their family or from their siblings who lived elsewhere.

With the mixture of public and private health care service in Thailand, the private sector is considered to provide consumer choice and competition with the public sector by offering a short waiting list, variety of specialists, highly sophisticated equipment such as MRI or CT scan, and better service. Although the cost of care in the private sector is greater than in the public sector, Bennett and Tangcharoensathien (1994) assert that rapid growth in income has produced an increasing demand for health care, including the public health service. The Health and Social Survey in 1986 showed that those in better paid occupations, such as professional and administrative staff and clerical and sales staff, tend to use private hospitals and clinical services more than those in poorer paid groups such as farmers and the unemployed (National Statistics Office, 1986).

Thus, it is quite clear that the quality of care for the elderly largely depends upon the financial situation of their adult children, whether coresident or not. If their adult children are affluent, they can afford to buy better health care for their elderly relatives. Thus, elderly people in this group have a better chance of early detection of their illness and more chance of appropriate treatment, as well as receiving better care from a well established hospital and being seen by the consultant. In contrast, in lower income families, the failure of public health service to meet their needs because of over crowding in the public hospitals, together with the rising cost of health care in the private sector, may lead them to turn to the non-formal health care sector, including drug counters, monks dispensing herbal remedies, and other types of folk healers. The Household Survey suggests that these non-formal health care providers are used mainly by poorer people (Nittayarampong and Tangcharoensathien, 1994). The data from the present study confirm that the majority of the elderly demented people who have low SES in the rural northern region had received traditional spiritual treatments.

The cost of care is relatively expensive, because it is not limited only to medical care. As the present study showed, it also extends to other caring facilities which were essential in providing care at home, such as supplementary food, incontinence aids, transportation, or home adaptation. In addition, a quarter of carers (n=11), all living in Bangkok, mentioned that they incurred extra expenses to pay for a care assistant at home. The average cost of care at home, excluding medical and hospital bills, was approximately £138 a month. Almost two-thirds of this cost was for the hire of a care assistant. It was found that most carers in Bangkok tended to hire a full-time home help to do housework as well as help them to look after their demented relatives, whilst carers who had relatively high SES tended to hire a personal care assistant, qualified to practice basic health care, through private care agencies. Although the cost of care is high, since having a personal care assistant is more expensive than hiring a home help, the advantage of having a care assistant is that the carer is relieved of some of the burden of caring, so carers will have more time for themselves. They may even be able to return to work outside the home. This caring situation may reflect the caring task in the capital city, where people with busy lives hardly know even their neighbours. Often care assistants to the main carer come from amongst their family members, or if not, it is necessary to seek help from outside. Wealthier carers clearly have more care options available to them, while for poorer families, particularly in the rural northern region, care has to be shared among family members, due to economic difficulties. Moreover, care assistants are still not recognised and available in the rural areas. Thus, these circumstance are likely to affect working patterns, and create physical and financial strain. As the evidence in this study shows, 80% of carers who work full-time in the northern region showed high levels of stress, compared to only one-third of those in Bangkok.

ii) The unregulated cost of care

Alternative health care services in Thailand can be obtained from the private sector. The majority are concentrated in Bangkok and some in the major provincial areas. This type of service tends to serve only the medium to high SES groups, due to its relatively high cost, but requires a shorter waiting time and offers better individual health care than the public hospitals. However, the private health care customers are also facing the escalating costs of care for modern medical technologies as a result of lack of competition in the cost of care between private hospitals (Bennett and Tangcharoensathien, 1994; Chitanondh, 1994; Nittayarampong and Tangcharoensathien, 1994). This circumstance may affect patient choice among the poorer people (The Lancet, 1992) and may lead people to shift from formal health care professionals to the non-formal health care sector (Nittayarampong and Tangcharoensathien, 1994), as mentioned earlier.

iii) Insufficient health care service in the rural area

In Thailand, most medical professionals view people with dementia syndrome as having an impairment of the nervous system. Thus, in the referral system, those suspected of dementia will be referred to the neurological department. The majority of hospitals in Bangkok are teaching hospitals which normally include all specialism, whereas most hospitals in the regions or rural areas are general hospitals and provide only general services. Complicated cases will be referred to the central or teaching hospital in the main region. Medical services specifically for demented persons are even rarer. For example, at the time of the research, there were only two neurological hospitals, one situated in Bangkok and another situated in Chiang Mai, in the northern region, comprising 240 beds (Alpha Research and Manager Information Services, 1995). The Bangkok hospital served only 1.5% of Thailand's 513.115 Sq.Kms while the Northern region, which contains 17 provinces, covers 33.1% of the country's total area. Thus, a number of demented participants in this study who lived in the northern part of Thailand had to travel over 100 miles just to receive out-patient assessment treatment from the neurological hospital in Chiang Mai, and had to stay overnight in order to be at the hospital early to queue to see the doctor the next morning.

8.4.2. Lack of Information

Carers were asked whether they had been told what was wrong with their demented relatives. One-third of carers gave negative answers. For example, some had been told nothing; some had been told about another symptom, but not the dementia illness; and one carer even said the physician had refused to tell her. Thus, many carers had no idea what was wrong with their elderly relatives, which caused confusion and distress to carers, some of whom lacked knowledge of how best to care for their elderly relatives. There is a need to consider why this happened. Part of the reason may be due to lack of access to hospitals and health personnel, including, as mentioned in the previous section, unequal distribution of health care throughout the country. However, other factors may also need to be considered, as follows:

i) Boundary between health professionals and patients

When the researcher made home visits, many questions were asked of her as to what exactly had happened to their elderly relatives, what was the prognosis, whether the disease was curable, what sources of treatment were available, how they should react, and how to provide care at home. The question arises as to why carers did not ask the doctor these questions during their consultation. What factors deterred them asking those questions and caused them to leave the medical professionals without the information they needed?

This section will discuss the relationship between medical professionals and patients. In dementing illness, of course, the patients have cognitive deterioration and confusion usually occurs; thus, their carers could be a useful intermediary to deal with doctors during consultations. There is a direct relationship between carers and the medical professions and the quality of this relationship seems to depend on the carers' perception, perspective and knowledge, as well as communication skills.

The term profession, can be applied to many occupations, such as the professions of medicine, law or architecture, which have a well established base of expert knowledge. Freidson (1986) suggests that central to a profession is the power to regulate its own affairs. Thus, an element of the professional-client relationship is the way in which professions create dependence on their skills and reduce the area of knowledge and experience they have in common with their clients (Williams, 1989). This is likely to promote *'social distance'* between themselves and their clients and so the professionals gain increasing autonomy (Johnson, 1989). This relationship, as Freire (1972) describes, is a one-way transmission of knowledge from expert to lay persons who are considered to know nothing. It is also a *'superior-subordinate relationship'*, which can be manifested in the doctor-patient relationship in the attitude of 'Don't question me, I am a doctor.' Therefore, it may be suggested that in some cases, the questions mentioned earlier were never asked by the carers.

Although some carers had tried to gain a better understanding of their elderly relative's illness, they still had not received the answers they wanted. Stimson and Webb (1975) suggest the use of strategies and negotiation during face-to-face consultation. Such strategies may be planned through the patients having anticipated problematic aspects of communication. They note that:

> the aim of the strategies used by both patient and doctor is to attempt to control and direct the consultation along their own desired lines, to persuade the other to recognise or accept a particular perspective on, and orientation to, the problem that has been brought.
>
> p. 37

Stimson and Webb (1975) have further explained that during the consultation, both patient and doctor use strategies to influence each other through a process of negotiation. However, there are several limits on the possibilities of action. In the UK, for example, limitations are imposed by the organisation of medical care; there is limited freedom to change doctor, so it is difficult for the patient to push disagreement with the doctor to the level of conflict; the patient is somewhat limited in his possibilities for action in that he perceives his knowledge, and the information available to him, to be of a different order from that of the professional; there are limitations imposed by the perception of what is possible, for example, patients may perceive that they are constrained by the amount of time available for the consultation; and finally limitations on strategic interaction arise from areas of implicit agreement in interaction.

The impediments to negotiation between doctor and patients in Thailand are somewhat different from those in the West. Although there is no clear explanation of this relationship, according to the Thai culture, Limanonda (1995) explains that there is an acceptance in Buddhist teaching of the principle of *'hierarchical order'*, so society is characterised by the prevalence of formalised superiordinate-subordinate relationships. This kind of relationship is called a *'respect pattern'*, because of age, wealth, power, knowledge, religious or government role, and the individual, regardless of his position in the hierarchy, deserves respect (Smith, 1979). Thus, there tends to be a barrier between doctor and patient during their interaction and the various forms of behaviour and conversation need to take into account the superior-inferior status or respect patterns (Smith, 1979). Therefore, in the present study, carers may have perceived themselves as inferior to the doctor and followed the respect patterns which deterred them from asking what they needed to know. However, those questions will be diverted towards friends and the family network, as Stimson and Webb (1975) found in the West. A number of carers mentioned they knew about the dementia syndrome from relatives or friends who worked as doctors, nurses and other health professionals, while carers who had no relative or friend in the health professional field, probably received no information at all.

ii) Lack of health education

There are three levels of health education: primary, secondary and tertiary health education. Ewles and Simnett (1995) describe primary health education as directed at healthy people and aims to prevent ill health arising in the first place. Secondary health education is involved when a person is already ill. At this stage it may be possible to prevent ill health moving to a chronic or irreversible stage by educating patients about their condition and what to do about it. Finally, tertiary health education is directed at patients whose ill health has not been, or could not be prevented or cannot be completely cured. Therefore, it is concerned with educating the patient and his/her relative about how to make the most of the remaining potential for healthy living and how to avoid unnecessary hardship, restrictions and complications.

Thus, the goals of health education are not only to improve knowledge about health, but also to raise health consciousness, increase self-awareness, induce attitude change, and encourage decision-making, behaviour change, and social change. People who suffer from dementia syndrome and their carers need to be provided with health education at the secondary and tertiary levels. This study shows that while carers lacked knowledge they would have liked a great deal more information about dementia. It is important to educate the dementia patients' relatives about dementia syndrome in general, the type of dementia the patient suffers from, whether it is reversible or irreversible, what signs and symptoms should be observed, and care management. Health education is clearly a useful health promotion strategy for helping carers to understand better the nature of dementia syndrome and to reduce distress in providing care at home.

As was mentioned earlier, dementing in old age was more likely to be viewed as a sign of the ageing process by spouse rather than by younger relative carers. More spouse carers tended to accept the deteriorated condition of their demented spouse as a normal condition of old age, without questioning, and said their relationship with the demented spouse remained the same. However, younger relative carers tended to express their disbelief or question why this had happened to an elderly relative. This was particularly the case among those whose elderly relatives developed dementia before the age of 60 or soon after they reached the age of 60. Younger relative carers in the rural area were likely to view these symptoms as a misfortune for their elderly demented relative, while those who lived in Bangkok tended to show more curiosity as to why it happened.

These findings may suggest that younger relative carers in the rural area, who had relatively lower education than those in the city, had received even less health education on dementia. Although those younger relative carers in the urban area appeared interested to ask questions, the boundary between carers and health professionals, discussed earlier, tended to block their communication and impeded them from gaining better understanding. However, overall, carers, including spouses and younger relative carers, from both rural and urban areas, expressed that their greatest need was to know how to provide care at home, followed by wanting knowledge about dementia syndrome, and its treatment respectively (see Chapter 7, Section 7.8). This may reflect the lack of health education, as there were no information centres or health professional bodies in the institutional setting or in the community, available to provide information about dementia syndrome. Whether carers had information depended on whether they were lucky enough to have a relative or friend who worked as a health professional or the doctor of their elderly demented relative had time and recognised their interest and the importance of giving information to them.

Although the national long-term plan for elderly people (1992-2011) includes health education, it is concerned only with primary health education to the healthy elderly population, such as self help care, health prevention, exercise, and retirement preparation for well-being in later-life (see Chapter 3, Table 3.8), There is no specific plan to intervene in the ill health experienced by elderly people. Clearly, not only is there a need to improve health education for the healthy elderly population, but also, policy makers should consider the health education needs of carers who provide continuing care for chronically ill elderly people at home.

iii) Increase in the incidence of non-communicable disease

A small scale study in a slum in Bangkok by Jithpunkul (1993) found that the major health problems of the elderly participants were non-communicable disease, disability and handicap. The most common problems of elderly out-patients were diseases of bone, joint and muscle (13%). Also, the Department of Health (1995) reports that during 1981-1991, there was an increase in the number of patients who suffered from non-communicable disease, for example diabetes mellitus (DM), bronchitis and bronchiectasis, asthma, nephritis, cardio-vascular disease and anaemia. In 1995 a Survey of the Welfare of the Elderly in Thailand was carried out with a sample of 7,708 persons throughout the country. 59% of respondents were aged 50-59 and 41% were aged 60 and over. This study found that the most common illnesses in the sample were back pain, arthritis, high blood pressure and others. However, types of illness differed by rural-urban areas. Hypertension, heart disease, diabetes and paralysis were more prevalent among urban elderly with relatively high income, whilst rural elderly were more likely to experience back pain, which may reflect their agricultural occupation (Chayovan and Knodel, 1997).

A research report by the independent organisation, Alpha Research and Manager Information Service (1995) shows that, in the general population, cardio-vascular disease ranked among the top five causes of death (Table 8.1). The death rate had increased from 49.5 per 100,000 population in 1989 to 78.9 per 100,000 population in 1995 (Epidemiology Division, 1995) and the report warned that all health professionals should be more aware of this preventable illness. The 1995, Survey of the Welfare of the Elderly showed that cardio-vascular disease remained among the top five illnesses in people of 50 and over year olds (Chayovan and Knodel, 1997).

Table 8.1. Top five causes of deaths, 1992

Cause group	No. of deaths/day	Rate per 100,000 population
1. Disease of pulmonary circulation and other forms of heart disease	84	53.6
2. Malignant neoplasm of other and unspecified sites	37	23.7
3. Disease of other parts of the digestive system	28	17.8
4. Other diseases of the respiratory system	23	14.4
5. Cerebrovascular disease	19	11.8
Others	516	358.5
Total	**752**	**479.8**

Source: Developed from Pocket Thailand Public Health 1995 (Alpha Research and Manager Information Service, 1995), p. 17.

The increasing number of non-communicable diseases among Thai people may be due to the insufficient and ineffective health education in Thailand. Clearly, there is a high incidence of cardio-vascular disease both in terms of illness and as a cause of death in the Thai population. There was a relatively high proportion of subjects in the present study who suffered from vascular dementia, which has risk factors which are treatable and some strokes are preventable (Hachinski, 1992). The present study shows that vascular dementia appeared to be the major cause of dementia (27%, n=12) followed by AD, accounting only for 14% (n=6) (see Chapter 5, Section 5.2). This finding seems to contrast to the world-wide picture of the prevalence of dementia in elderly people, in which Alzheimer's disease (AD) is the most common cause of dementia, followed by vascular dementia (see Chapter 1). Does this situation indicate the failure of health prevention? Insufficient health promotion, particularly in health education and health prevention, may be partly responsible for the increase in the number of preventable diseases and disabilities in later life, health problems which lead to a heavy burden on sufferers' families. No concrete study on the prevalence of dementia in Thailand is available. The present study was also carried out with a convenience sample of demented elderly people who received treatment at OPD from selected hospitals. Therefore, this finding may not represent the characteristics of people with dementia as a whole, or indicate the actual prevalence of dementia in elderly people in Thailand. Nevertheless, this finding may suggest that there is a group of people with dementia which is caused by vascular disease, and this group of patients may need particular help.

iv) Geographical difference in using traditional medicine

As indicated in the literature review on traditional medicine in Chapter 3 (Section 3.5.1) in Thailand, as in other developing countries, traditional medicine used to be the only health care resource available for those suffering ill health (Jaspan, 1969). It predominated in Thailand until the late 19th century. Since Western medicine was first introduced in the 1820s it has become more popular and is gaining trust from the Thai people. Nevertheless, Western medicine itself may be called the alternative medicine for Thai people. Thus, seeking help from traditional medicine, including herbal medicine, traditional Thai massage, spiritual mediums and ritual, was commonly found in the present study. Nearly half the subjects (47.7%, n=21), the majority of them living in the rural northern region (60%, n=12), had sought help from these remedies (see Chapter 7, Section 7.7).

When compared to the national figure, it was found that the figure in the present research was almost twice as high. The National Statistical Office, Thailand, reported the finding from a survey of Health, Welfare and Use of Traditional Medicine 1986, showed that 24.6% had engaged in traditional or herbal medicine, where the vast majority of them (84.8%) lived in the rural areas (the northern region had the highest and Bangkok the lowest usage). However, this finding might have been an under estimate, due to the limited definition of traditional Thai medicine in the study, which included only medicines derived from the natural products of herbs or plants, animals, and minerals (National Statistical Office, 1986), i.e. mainly herbal medicines. In contrast, in the present study the definition used included herbalists and other forms of traditional healers, for example, traditional Thai massage, spiritual mediums and ritual.

In addition, the higher percentage of elderly demented people who engaged in traditional medicine in the present study may reflect a greater than average preference for traditional medicine among this particular group of carers because of their belief in its effectiveness, or because Western medicine does not appear to help subjects' condition, or because of their concern to find some symptomatic relief.

Since Western medicine began to dominate the health care service, there has been concern about the rising cost of care, side-effects, and an increasing dependence on Western medicine and technology, as well as the high cost of imported products. Therefore, there is a trend to go back to studying traditional remedies, such as traditional herbal medicine. There is a variety of herbal remedies available throughout the country, many of them functioning similarly to Western medicine drugs. Thus, there is interest in using these herbal remedies to replace Western medicine, in order to reduce the cost of care and help to free people from the synthetic agents by using natural resources such as herbs instead. There has been increased use of herbal medicine in the modern health service setting recently. For example, treatment by a qualified practitioner of traditional Thai herbal medicine is available in 42 community hospitals in 30 provinces, while 65 primary community health centres throughout the country offer an over-the-counter herbal medicine service (Department of Medicine, 1996). Moreover, the latest public health plan in the 8th National Economic and Social Development plan (1997-2001) includes traditional Thai medicine, with the aim of offering people a choice in health care. Nevertheless, the decision on treatment choice should be based on knowledge of relevant information. In providing such information, health educators could help people to help themselves and work towards creating healthier conditions for everybody to make healthy choices more easily (Ewles and Simnett, 1995).

While herbal medicine is attracting increasing public attention, as is traditional Thai massage, the majority of practitioners are found in the urban area. Both types of traditional practitioners are accepted by the Ministry of Public Health. However, other types of traditional medicine or traditional healers, such as local herbalists, spiritual mediums and rituals, are still not officially accepted, but they are available in the rural areas. The finding from the present study was that the majority of demented people who went to some kind of traditional healer lived in the countryside. Many carers still believed in spirits and severe confusion and aggressive behaviour were perceived as being caused by spirits, as a punishment, and resulted in a request for a spirit ritual ceremony (see Chapter 7, Section 7.7). This evidence may indicate the inadequate provision of health education in this area as its shows that people lack knowledge of dementia syndrome and its management. However, the very act of participating in such a ceremony may have beneficial effects, at least for the carers.

Another sign of lack of health education were the group of carers, from both rural and urban areas, who decided to take their demented relative for both Western and traditional medicine. Of a total of 16 demented persons, 6 (37.5%) were taken for traditional medicine after the dementia symptoms did not disappear with Western treatment, the same figure left traditional treatment for Western medicine when they were not cured, and four people (25%) received treatment from both institutions at the same time, with the idea of covering all aspects of the cause of illnesses. This finding shows that most carers in this group thought that dementing illness is treatable and given the availability of both Western and traditional medicines, they were likely to go from one to another, if the first choice did not work. Clearly, this group of carers needed health education to understand better the nature of dementia syndrome and its management. This might help to prevent them wasting a lot of money on unnecessary treatment by shopping around for a cure for dementia and it might also help them to accept this illness and plan for future care.

8.4.3. Lack of caring support in the community

As the tradition is for care in the family in Thailand, as discussed earlier in section 8.1, family members are expected to provide care for their own family members. Government policies seem to take advantage of this tradition by encouraging people to provide care for their own relatives, but no clear information on how to manage caring at home or what caring support would be available was given to the carers, as indicated below.

i) Low community participation

The WHO policy on 'Health For All by the year 2000' (HFA 2000), first introduced in 1978, emphasises the need to encourage community participation in health, in order to reduce social inequalities in health and work for greater inter-agency co-operation for health at the local level (WHO, 1978). Thailand has included the WHO policy in a National Primary Health Care (PHC) programme since 1980 (Kachondham and Chunharas, 1993). At the same time, the basic minimum needs (BMN) approach was introduced (Meesapya, 1994). The BMN approach, as part of the nation's "Quality of

Life Programme", encourages a village to establish an information system whereby villagers can collect relevant data by using the essential components checklists to identify problems in attaining their basic minimum needs (Kachondham and Chunharas, 1993, p. 212). However, no relevant needs assessment for elderly people and people who provide care for their frail elderly relative at home was included in the provided checklists. Moreover, the Thai government policy on caring for elderly people still focuses more on individual family care rather than encouraging community participation. For example, the national long-term plan for elderly people (1992-2011) indicated in the plan for social care, education, culture and psychology the need:

> To encourage people to restore and be aware of the importance of the extended family; to promote good relationships within the family and mutual help among family members; and to preserve and promote the norms of parent repayment and respect for the elderly among the family and other people in the society.
>
> (Department of Medicine, 1993, pp. 121-134).

The latest (8th) national economic and social development plan (1997-2001) also mentioned helping the disadvantaged populations, including the isolated poor elderly, by encouraging and assisting their families to understand, and provide care for their elderly relatives and suggested that incentives may even be given to encourage effective carers (National Economic and Social Development Board, 1997).

To assess the level of participation of demented persons and their carers with people in the community, support network assessment was carried out. This aimed to identify the community relationships experienced by people, particularly those who were involved with an elderly person in a significant way, for example as a household member, in providing companionship, emotional support, instrumental help, advice or personal care or receiving any of these from the old person (Wenger, 1994). The research revealed that, of 44 individual demented elderly and their carers, the vast majority of demented persons (95%, n=42) and over two-thirds of carers (68.2%, n=30) had only a small support network. The majority of both types of participants were classified as local family dependent, i.e. nearly all support needs were met by the family and community involvement was generally low. Among the remainder, also, networks tended to be smaller than average. In addition, the demented persons themselves had even smaller support networks than carers. Over one-third of all demented participants (34%, n=15) were classified as having a private restricted support network, which is typically associated with absence of local kin, and contact with neighbours is minimal. Less than one-third of carers (29.5%, n=13) were classified as locally integrated, a type of network in which carers had close relationships with local family, friends and neighbours (see Chapter 6, Table 6.5).

The result of the culture or tradition in caring and the government policies on family care, is clearly pressure on carers, who are given a sense of responsibility by emphasis on the ideology of parent repayment, but not provided with support. This policy is also likely to encourage people to believe that caring for their own elderly relative is a personal or family matter and they have to cope with it by themselves. At the same time, it may affect people from outside, such as friends or neighbours, who may see caring as the family responsibility and decide not to get involved. This attitude may also affect the social relationships between elderly people and people outside the family. Tunsiri et al. (1996) studied the family relationships and social relationships among 132 elderly, nearly half of them (46.8%) suffering from some kind of chronic illness, who were members of the elderly health promotion centre at the Mahidol university hospital in Bangkok. This study found that the majority of elderly had good relationships with their family members, such as other elderly in their family and their children, 40% and 52.4% respectively. In contrast, the majority of elderly needed to improve their social relationships. For 62.7% and 50% respectively, there was a need to improve their relationships with the elderly and younger generation outside their family. Therefore, it is clear that there is a need to improve the policy on community participation in caring, which may also help to improve the caring situation at home, as well as help elderly people to improve their social relationships and improve their quality of life.

ii) Lack of health and social services in the community

According to the general referral system in health care, including the Health Card Scheme in Thailand, patients need to make the first contact at the village level or the nearest health centre, where they will be referred upwards (Kachondham and Chunharas, 1993), with a description of the illness on the referral form, to the district or community hospital. Then, if they have complicated disease, they will be transferred to the higher health facilities, for example, provincial hospitals, regional hospitals, specialised hospitals, or university hospitals (Sastravaha, 1985) (see Chapter 3, Figure 3.2). Patients are also transferred back to the community health centre by the same route after they have made progress.

However, not every patient will be under this referral system. The results of the present study showed that at PHC treatment level, private clinics were more convenient and popular among Bangkokians and those carers who lived in the city. Moreover, in the rural area, most carers complained of dissatisfaction with treatment, inadequate facilities and expertise, the complexity of the referral system itself, and the negative attitude towards dementia as an ageing process, among health professionals in health care centres and the community hospitals. These factors led carers to take their elderly demented relatives straight to the tertiary care level by themselves, without going through the referral system. In addition, those tertiary health care services are open to all patients, not only those who are under the referral system. This may be another reason why a number of patients do not follow the route and travel longer distances to get treatment. A problem arises, however, that where patients receive treatment outside the referral system, there would be no treatment record available at the community health centre. Thus, it would be difficult for the community nurse to make a home visit, even if one were available, after patients have been discharged and are being cared for at home.

In health care services at the local level, the PHC have introduced manpower recruitment and community organisation development since 1977, involving the training of village health volunteers (VHV), village health communicators (VHC), and villagers themselves in first aid. Screening for common diseases is also carried out in the villages. These measures aim to improve community and individual well-being (Kachondham and Chunharas, 1993). No guidelines had been issued to provide support for carers who look after relatives with chronic illness at home. This programme was later proved differentially effective depending on the community context, such as the ability of the leader, level of support and supervision at village and district. There were time constraints and participation on a voluntary basis was limited (Kachondham and Chunharas, 1993). In addition, the policies of the Ministry of Public Health in the 7th National Economic and Social Development Plan (1992-1996) included provision for proactive health care services for elderly people in the community by sending a health promotion team to visit patients at home to assess their needs for health care and provide help to meet their needs. However, in fact, none of those demented participants in the present study who were under the referral system had been visited or received support from the VHV, VHC, or community nurse. Also, since 1993, there has been an income support project for elderly people and their families who are on the poverty line (Research and Development Group, Beneficial and Welfare Division, 1993), but none of the demented elderly participants who were on the poverty line had received benefit from this project.

8.5. Policy and Practice Implications

Caring for elderly people in Thailand is traditionally family care by, particularly, adult children. Because of this long history of family care, it is essential to change people's attitude and awareness of their own problems, as well as to inform the policy makers of the difficulties in caring at home. Thus, the plan for implementation, perhaps, can be divided into two levels: short-term and long-term, as follows;

8.5.1. Short-term plan

This plan must be based on realistic and achievable aims at the individual level in the short term. In this primary stage, the researcher should be able to contribute the knowledge obtained from the research findings and seek to implement the results of the study through the informal channels, such as:

i) Publication of thesis

It has been said that research is not complete, unless it is published. Given that little is known about family care for chronic illness as such dementia in Thailand, publication of the thesis at the national level will, certainly, contribute knowledge and promote better understanding of the nature of family care, particularly on the issue of caring problems and carers' needs. The aim in doing this would be to reach multidisciplinary professionals who work with elderly people in a wide variety of settings, ranging from the elderly person's own home, to various types of institution, such as hospital, residential home, and nursing home. It is hoped that the insights gained from this research could be published in leading journals, for example: *Nursing Association Bulletin, Journal of Clinical Psychiatry, Journal of Medical Association,* and in the *Senior Citizen Association Newsletter*, in Thailand. At the international level, it is hoped that the findings might be published in a reputable international journal, which aims to contribute knowledge of cross-cultural family care for elderly people, for example, *Age and Ageing, Gerontologist*, and *Cross-Culture Gerontology*.

ii) Promote health education via the available media

The most common media which are able to reach people in the society are radio and newspaper. Knowledge about dementia and its treatment can be promoted through the available radio and leaflets should be made available in the hospitals or clinics where carers usually bring their elderly demented relatives for treatment. Articles about dementia could be sent to the radio presenter and to local and national newspapers, with the aim of raising awareness of this chronic illness and its impact on the family.

iii) Introduce support group

Not every demented person will be taken to see doctor and those principal carers who seek treatment for their elderly dementia relatives appear to have a higher level of strain compared to those reported in the West based on the same scale test. In particular, carers from the present study were more likely to admit to emotional or psychological strain (see Section 8.3.4). Carers also expressed the need for information about their elderly relative's illness. As it was mentioned earlier, in Chapter 2, a lack of knowledge itself can be a stressor (Russell et al. (1989). A support group would serve as a source of help for carers, in which they could draw strength from each other by sharing their problems and feelings within the group. Other services, such as information about dementia, counselling or other practical help, can be delivered to the group by health professionals and social workers. Thus, setting-up a support group would be an appropriate intervention to reduce the strain on carers over time.

8.5.2. Long-term plan

The long-term plan is more complicated and more difficult to achieve because it needs co-operation at national level to set out concrete goals and implementation throughout the country. This level very much depends on policy makers recognising and addressing carers' problems in their plans.

i) Provide Financial Support

The quality of care very much depends on the financial situation of the care provider, which leads to inequality in elderly health status. As Ewles and Simnett (1995) stated, people in the upper socio-economic classes have a greater chance of avoiding illness and staying healthy than those in the lower classes. The WHO goal of Health For All by the year 2000 will not be achieved if the Thai government continues to press people to care for their own relatives, with little support provided. Thus, there is a need for income support for families who care for chronic and deteriorating elderly at home, particularly elderly who have no pension and whose families are on the poverty line. Moreover, the existing income support project may need to be extended to include this group of people, in order to help them to improve the quality of care.

ii) Improved Health Education

The second great need is health education. The carers of the elderly or their family members need health education about the common illnesses in old age and how to provide care. Moreover, health promotion should be delivered to the well elderly, in order to keep them healthy and independent and improve their quality of life in later life. In this regard, there may be a need to train more health professionals to work with elderly people and home visits and respite care should be introduced for elderly who suffer from chronic illness. Health professionals should carry out the multi-dimensional assessment approach to frail elderly and their families, aware of the available services and refer them to an appropriate agency. Thus, there is also a need to increase funding of public health care and allocate more budget to health promotion programmes, rather than emphasise tertiary health care.

iii) Promote Community Health Care Insurance

There is a need to expand the existing 'Health Card' scheme, a form of community-financed health insurance, to cover older people who have low income or low SES and introduce a free medical care card for elderly people who are on the poverty line, in order to improve the equality of care in the society. Such a scheme would obviously promote equal opportunity for all socio-economic classes of elderly people in using health care services.

iv) Promote Community Participation

The role of primary caregiver is stressful, with the caring task largely unshared and little help received from neighbours, friends or relatives (Hettiaratchy and Manthorpe, 1992). Therefore, there is a need to raise the community's awareness of the problem of caring at home and the importance of support networks. This intervention may help to reduce strain and stress in carers and may lead to a successful caring in the community.

v) Make the full use of the available resource

The expansion of health service to elderly people in the community will no doubt be an additional cost to the Ministry of Public Welfare, for which a limited budget was allocated by the government. To minimise the cost of health care, the existing community health services and community nurses should be viewed as a resource for providing additional health services to the elderly group, because they are the only health professionals who provide primary health services for people in the community. Of course, they may need to gain knowledge and skill about caring for elderly people, so instruction and training should be carried out, for health professionals who have never been taught about elderly care from their nursing school.

vi) Others

It is not appropriate to encourage people to take care of their own elderly relatives by emphasising the ideology of parent repayment or reciprocity, without providing support, or to promote the extended family for responsibility for care of their elderly without acknowledging that today adult children have to go out to work or live where they can find a job, as mentioned in the current National Long-Term Plan for Elderly People, 1992-2011, in Thailand (see Chapter 3, Table 3.8). This plan may be seen as unrealistic and 'the sense of responsibility was open to abuse or exploitation by service providers' (Beresford, 1994, p. 70). To improve the quality of care and promote caring in the community, support must be made available, in order to reduce the burden on adult children.

8.6. The need for further research

Little is known about the life and family function in caring for frail elderly in the community in Thailand. Further research is recommended to focus on specific carer problems, such as stress in carer, the carer and cared-for relationship, the cost of care, or benefit and rewards from caring. There are a number of illnesses in old age and different types of illness have been found to present different caring problems. Thus, the findings from the present research alone can not represent all the problems in caring for elderly people with chronic conditions which may concern the policy maker. There is a need for further research on informal care for other chronic conditions affecting the frail elderly. There is also a need for a multi-disciplinary research approach, combining health and social research, to identify problems and to provide help and support to meet the needs of individual, in order to develop concrete evidence and better understanding of the caring situation given the limited resources in Thailand.

The unfortunate economic crisis has affected many countries in Southeast Asia, including Thailand, since the middle of 1997. There is no doubt that a number of health and development projects have been slowed down and funding for health and social services from the government have been cut. In the past, only those who were self-employed were not eligible for health benefit. However, in the near future, family members or parents of persons who work as government officials will no longer be eligible for health benefits. Thus, there will be an increasing number of carers facing not only physical and psychological burden, but also financial difficulty in caring for chronically ill people. Therefore, it would be interesting to carry out further family care research on how financial hardship affects the quality of care provision and how people are coping with this situation, the nation faces economic challenges.

Conclusion

This discussion chapter has contained six major components: methodological development; limitations of the research; contribution to theory; problems in the provision of health and social services for demented elderly people; policy and practice implications; and recommendations for further research. Methodological development of the present research was found difficult due to the lack of literature about family care for elderly who have ill health in Thailand. The advanced Western theories were also found confusing and not suitable to apply because of the differences in culture, religion, and normative belief. These circumstances led to several limitations in the present research, such as limitations of the research in practice, research tools, and data analysis. The most severe limitation was found with the CSI scale, in that, whereas the initial aim of using this scale was to screen stress on carers, the instrument turned out to be screening strain as a stressor, instead. Moreover, given the small sample of participants, data should be treated with caution.

Caring for elderly people in Thailand is very much influenced by Buddhist religion with the ideology of parent repayment. Although, traditionally, adult children are expected and they may also feel obliged to provide care for their own elderly relatives, however, more than half of carers were spouses. Negative attitudes toward care were less likely to be expressed because it is not socially acceptable. However, nearly half of carers were found to carry a greater level of strain, even though they expressed satisfaction in caring. Gender differences in this respect were found among younger relative carers, which may reflect the elderly preference for a daughter, rather than a son, to remain at home and care for them when they grow old.

Carers in Thailand admitted particular strain in the area of being upset that the cared-for person had changed so much, which may result from the culture and attitude of honour towards the elderly. Strain in carers was significantly related to the elderly person's cognitive status, level of dependence, hours of care provided and duration of illness. Three major problems in relation to health and social services for demented elderly people were: unequal opportunity in health care, lack of information and lack of caring support in the community.

As regards policy and practice implications, short-term and more achievable plans, such as publishing the research findings, promoting health education via the available media, and introducing a support group for carers, can be carried out in part by the researcher. A long-term plan should be carried out at the national level, and should include provision of financial support to those who fail the means test, improved health education, promote community health care insurance, promotion of community participation, and making the full use of the available resources.

Further research is recommended to be carried out by focusing on the specific carer problems, such as stress in carer, carer and cared-for relationship, the cost of care, or benefit and rewards from caring. The further research also should also be extended to the areas of caring for older people with other chronic illnesses, in order to develop concrete evidence and a better understanding of the caring situation with the limited resources in Thailand.

Conclusion

Dementia is one of the most common disorders in old age, characterised by multiple cognitive deficits that include memory impairment, cognitive disturbance and disturbance in executive functioning. The prevalence of dementia is 2-4% among those aged over 65 years and increases to 20% or more in those aged over 80 years. More than 55 illnesses can cause dementia. The most common causes of dementia syndrome are Alzheimer's disease (AD) and Vascular disease, accounting for 70% and 10-30% of all dementia, respectively. The present situation of the rapid increase in the ageing population, particularly in developing countries such as Thailand, has raised awareness of an increasing number of dementia cases and the available health and social service resources for them. Care for elderly people in Thailand rests mainly with their families, due to Buddhist religious and cultural influences. Regarding the concept of holistic care, health professionals and agencies who work with people with dementia should be aware of the health and well-being not only of demented people, but also of their carers who provide care at home, because the well-being of carers is a device in achieving the well-being of cared-for persons (Twigg and Atkin, 1994).

With regard to these concerns, thus, the aims of the present study were: to identify the characteristics of carers; to study families in the caring situation; to assess carers' psychological well-being; to examine the influence of the Buddhist religion and Thai culture on this care; to identify the needs of carers and to identify primary assistance needed. Moreover, this thesis is intended to contribute to policy and practice. However, methodological development of the present research was found difficult due to the lack of literature, and the advanced Western theories were also found confusing and not entirely suitable to apply, because of differences in culture, religion, and normative belief. These circumstances had led to several limitations in the present research, such as limitations of the research in practice, research tools, and data analysis.

The present research was conducted in Thailand between October 1995 - March 1996, among a sample of elderly demented people (subjects) who were receiving treatment from neurological, psychiatric and geriatric OPD in three selected hospitals in both urban and rural areas in Thailand. Subjects complied with other selection criteria: aged 60 and over, educated at least to primary school level, co-resident with carers, and either themselves or their carers were Buddhists. The available number of 44 subjects and 44 principal carers agreed to participate in the present study. Data were collected from structured and semi-structured interviews with subjects and carers in their own homes. Quantitative data giving demographic information, such as age, sex, educational level, or occupation, were collected in respect of both subjects and carers. In addition, the Thai Mental State Exam (TMSE) and Behaviour Rating Scale (BRS) were completed by subjects and their carers respectively, to assess subjects' present mental state and dependency level; while the Network Assessment and Caregiver Strain Index (CSI) were completed by carers. Correlations between scores on these assessment instruments were tested. Data were analysed by using non-parametric and appropriate statistics by using SPSS for Windows computer program for quantitative data in consultation with a statistician, while manual management was used for qualitative data analysis. However, the CSI scale was later found to have severe limitations as a measure of stress. Given the small sample of participants, the data should be treated with caution.

Of the 44 subjects, 27 (61%) were male and 17 (39%) were female; they ranged in age from 51 to 93 years, mean 74 (SD=9.8). The majority of subjects lived with their family, only 6 (13.6%) lived with their spouse alone, and over half (51%) were educated to primary school level only. Of the 44 carers, 35 (80%) were female and only 9 (20%) were male. Carers ranged in age from 25 to 85 years, mean 56 years (SD=16.5). More than half the carers were spouses (55%, n=24), one-third were adult children (32%, n=14), and the remainder were other relatives. 14% (n=6) of carers provided care for over 100 hours a week. A quarter of carers, more spouse than younger relative carers and all of these living in Bangkok, were seeking help in caring.

Spouse carers were found to experience significantly less strain than younger relative carers ($p \leq .05$). The significant findings confirmed that higher level of cognitive impairment and higher level of dependence in demented relatives related significantly to a higher levels of strain in carers ($p \leq .05$ and $p \leq .01$ respectively), including the increase in hours of care provision ($p \leq .01$) and the longer the duration of the dementing illness ($p \leq .05$). More than half (57%, n=25) of carers had a small support network. However, there was no significant correlation between support network or quality of relationship and strain on carer. Carers in Bangkok and the metropolis had fewer social integration networks than carers in the rural areas.

Younger relative carers were adult children who had remained at home by reason of being unmarried or being the last person in the family to get married. This person would automatically become the carer when their adult relative got ill. The view of '*reciprocity,*' however, was still very strong among younger relative carers. For example, although they had problems in caring, such as subjects' psychological and physical problems, and the present relationship with the subjects had been deteriorating, and faced increasing stress and physical strain on their own account. Nevertheless, they were still willing to continue providing care at home. How long can they cope with this situation? Clearly, a longitudinal study needs to be carried out. The Buddhist religion and Thai culture emphasise that children should provide care for their elderly relatives. However, nowadays, most adult children work outside the home. This was the case for many of the sample. Therefore, as they had more time available, spouses, the majority of whom were housewives, had to accept the caring role. The burden of caring, including care providing and the cost of medical treatment, tended to be shared among family members, unless the subject was entitled to receive free medical care.

This study has been able to identify three major problems in caring for an elderly demented person at home: unequal opportunities in health care, lack of information, and lack of caring support in the community. Firstly, the findings from the present study suggest that unequal opportunities in health care for demented elderly people are clearly initially associated with the financial status of carers and cared-for persons, insufficiencies in the health care insurance system and insufficient distribution of health care service in the rural areas. Secondly, nearly three-quarters of carers (72%, n=32) need information about how to provide care for their elderly demented relatives, especially on caring techniques at home, followed by a need to know about the dementia syndrome (40%, n=18). Finally, lack of caring support in the community was commonly reported; none of subjects were visited by health professionals and no financial support had been received by those who were on the poverty line. It was felt by 66% of all carers that the elderly relative should receive financial support.

The findings have implications for policy and practice on two levels. A realistic short-term plan at the individual and local level would be to publish the research findings to raise the awareness of problems in family care, encourage health professionals using multi-dimensional approaches with patients, promote health education via the available media, and establish a support group for carers. There is also a need for a long-term action plan at the national level. Although the WHO goal of Health For All by the year 2000 will not be achieved, as it is only two years away, there is a need to promote health education, including training more health professionals to work with elderly people and setting up carers' support groups. Home visits and respite care should be introduced for elderly people who suffer from chronic illness. Income support should be provided for families who are caring for chronic and deteriorating elderly at home, particularly the elderly who have no pension and whose families are on the poverty line. There is a need to increase funding of public health care and allocate more budget to health promotion programmes, rather than emphasise tertiary health care. One approach could be to expand the existing 'Health Card' scheme, a form of community-financed health insurance, in order to promote equal opportunity for all socio-economic classes of elderly people in using health care services. There is also a need to raise the community's awareness of the importance of care in the community and encourage them to participate in this care in order to improve the equality of care in the society. The effects of the caring relationship and the quality of care need further investigation. It is recommended that research be carried out using carefully selected instruments and extended to the areas of caring for other chronic illness in older people, in order to develop concrete evidence and a better understanding of the caring situation with the limited resources in Thailand.

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GLOSSARY

Agnosia:	cannot interpret sensations correctly
Amnesia:	total or partial loss of memory
Aphasia (dysphasia):	a disorder of language affecting the generation of speech
Apraxia (dyspraxia):	inability to make skilled movements with accuracy
Baab	demerit, evil, sin, or bad deed
Bhikkhu	Monk
Bun	merit or good deed
Dhamma:	as used by the Buddhist, refers both to teaching, the doctrine of Buddha (where it naturally comes to mean "truth") and to the phenomena or elements of experience (Narada Maha Thera, 1973)
Focal cortical symptoms:	e.g. aphasia, apraxia, and agnosia
Idiotism:	an obliteration of the intellectual faculty
Karma or Kamma	Destiny, lot or deeds. The law of Kamma states that every deed, verbal, physical or mental, created Kamma. Therefore a man is born according to his past Kamma, and together with his present Kamma, will determine his future existence (Mulder, 1973, p. 50).
Mau luang	royal court
Mau phii	supernaturalist practitioners
Phra	Monk; prefix meaning "holy," "venerable" (Mulder, 1973, p. 50).
Reciprocity	parent repayment
Traditional healers	people who practise herbal therapy, includes magic and incantation
Wat	Buddhist temple

Appendix I.

A. Introductory letter and Questions for screening participants' criteria (in English)

Questions for screening participants' criteria

Date of interview............................
Place of interview...........................
Time from..............to.................

Background information to be completed before interview (see medical records)
Patient name ....
Sex..
Name of hospital.................................
Out patient department number.............................

Introduction

Hello, may I speak to you. My name is Siriphun Sasat and I am a PhD. student in Gerontology from the University of Hull in England. You may remember being informed by the doctor at the hospital that a research student would come to ask you to participate in an interview, about how you provide care for your ......(e.g. mother, father)..... I am interested in finding out what is it like to be a carer. What is your view in coping with this situation, and what are your problems and needs in giving care, so I can understand and contribute to improve the methods of formal and informal care, and carers' support in the future. I would be grateful if you could spare me some time for this interview. Everything that you tell me today will be treated with confidence. First of all,

I would like to ask you some general information about yourself and your older relative.

1. Are you Buddhist?
   - A. Yes
   - B. No.

2. What is your............religion?

A. Buddhist
B. Islam
C. Christain
D. Other (please specify).......

3. What is your relationship to person you care for?

A. Husband
B. Wife
C. Son
D. Daughter
E. Nephew
F. Niece
G. Other...Who........

4. When did you leave school?

A. None
B. Primary school
C. Secondary school
D. High School
E. Vocational education
F. University

5. How old is your ....?

A. under 60
B. 60 and over

6. Does your..............live with you?

A. Yes
B. No

7. Who pay for his/her treatment?

A. Government (enable to get free medical treatment)
B. Private firms
C. Self-paid

8. How much money do you earn per month?

A. Less than 75 pounds
B. 75 - 125 pounds
C. 126 - 175 pounds
D. 176 - 250 pounds
E. more than 250 pounds

Do you mind if I ask you to participate in my research and make arrangements to do interview in your own home? This interview will take about an hour, and about a half-hour for assessing your..(e.g. mother, father)....mental state. Also, I would like to make tape- records during the interview processes.

If you agree to participate in my research, could you please sign your name in the given space and give me your address?

Name of carer ....

Sex ( ) Male ( ) Female

Address ....

.... Tel..........................

Time and date will be convenient ....

A. Introductory letter and Questions for screening participants' criteria (in Thai).

ลำดับที่............

คำถามสำหรับคัดเลือกกลุ่มเป้าหมาย

วันที่สัมภาษณ์ ....

สถานที่สัมภาษณ์ ....

เริ่มจาก เวลา..................................น. จนถึงเวลา ....น.

<u>**เติมข้อมูลเบื้องต้นก่อนเริ่ม สัมภาษณ์**</u> **(ดูจากบัตรผู้ป่วยนอก)**

ชื่อผู้ป่วย ....

เพศ ....

เลขที่ผู้ป่วยนอก ....

ชื่อโรงพยาบาล ....

<u>แนะนำตัวก่อนเริ่มสัมภาษณ์</u>

สวัสดีค่ะ คุณ..(ลุง ป้า น้า อา)...ดิฉันขอพูดคุยด้วยสักครู่ จะได้ไหมคะ......ดิฉันชื่อ ศิริพันธุ์ สาสัตย์ นักศึกษาระดับปริญญาเอกทางด้านผู้สูงอายุ จากมหาวิทยาลัย HULL ณ ประเทศอังกฤษ คุณหมออาจจะเคยบอกท่านแล้วว่าจะมีนักศึกษามาขอความร่วมมือจากท่านเข้าร่วมในการทำวิจัยเกี่ยวกับการให้การดูแลญาติของท่านที่ป่วยด้วยโรคสมองเสื่อมที่บ้าน ดิฉันมีความสนใจที่จะศึกษาว่าชีวิตของคนที่ดูแลคนป่วยที่บ้านนั้นเป็นอย่างไร คุณมีความคิดเห็นอย่างไรในสถานการณ์เช่นนี้ คุณประสบกับปัญหาอะไรบ้างในการให้การดูแลและคุณต้องการความช่วยเหลือทางด้านใดบ้าง การศึกษาในเรื่องนี้มีจุดประสงค์เพื่อเพิ่มพูนความรู้และความเข้าใจในสถานการณ์สภาพปัญหาและความต้องการของบุคคลที่ให้การดูแลญาติที่ป่วยด้วยโรคสมองเสื่อมที่บ้านและหวังเป็นอย่างยิ่งว่าผลของการวิจัยชิ้นนี้จะเป็นข้อมูลพื้นฐานให้กับทั้งทางภาครัฐและเอกชนในการปรับปรุงและวางแผนการให้การช่วยเหลือทั้งทางตรงและทางอ้อมต่อไปในอนาคต จะเป็นพระคุณมากถ้าคุณจะกรุณาสละเวลาสักครู่เพื่อให้ดิฉันสัมภาษณ์ในครั้งนี้ซึ่งทุกสิ่งทุกอย่างที่คุณบอกมาวันนี้ดิฉันจะเก็บไว้เป็นความลับ

ดิฉันจะขอเริ่มต้นถามคุณด้วยคำถามทั่วๆไปเกี่ยวกับตัวคุณและญาติตนที่คุณกำลังดูแลอยู่

1. คุณนับถือศาสนาพุทธหรือเปล่าคะ?
    1. ใช่ 2. ไม่ใช่
2. แล้วญาติของคุณ.... (ผู้สูงอายุ)....นับถือศาสนาอะไร?
    1. พุทธ 2. อิสลาม
    3. คริสต์ 4. อื่นๆ (โปรดระบุ)

3. คุณมีความเกี่ยวพันอย่างไรกับผู้สูงอายุ

   1. สามี
   2. ภรรยา
   3. ลูกชาย
   4. ลูกสาว
   5. หลานชาย
   6. หลานสาว
   7. อื่นๆ (โปรดระบุ)........................

4. ตอนนี้ผู้สูงอายุอายุเท่าไหร่?

   1. น้อยกว่า 60 ปี
   2. 60 ปี หรือมากกว่า

5. คุณและผู้สูงอายุอาศัยอยู่บ้านเดียวกันหรือเปล่า?

   1. อยู่บ้านเดียวกัน
   2. ไม่ได้อยู่บ้านเดียวกัน

6. ใครเป็นคนจ่ายค่ารักษาพยาบาลให้ผู้สูงอายุ?

   1. มีสิทธิ์เบิกได้จากรัฐบาล
   2. มีสิทธิ์เบิกได้จากภาคเอกชน
   3. จ่ายเอง

7. คุณมีรายได้ประมาณเดือนละเท่าไหร่?

   1. น้อยกว่า 3,000 บาท
   2. 3,000 - 5,000 บาท
   3. 5,001 - 7,000 บาท
   4. 7,001 - 10,000 บาท
   5. มากกว่า 10,000 บาท

คุณจะรังเกียจไหมถ้าดิฉันจะขอความร่วมมือจากคุณเข้าร่วมในการทำวิจัยซึ่งได้กล่าวมาแล้วตั้งแต่ต้นโดยที่ดิฉันจะขอนัดเวลาและติดตามไปสัมภาษณ์ที่บ้านด้วย การสัมภาษณ์ช่วงแรกจะสัมภาษณ์คุณก่อนโดยใช้เวลาประมาณ 1 ชั่วโมง ต่อจากนั้นจะเป็นการสัมภาษณ์ผู้สูงอายุและทำการทดสอบสภาพสมองโดยใช้แบบทดสอบซึ่งจะใช้เวลาประมาณครึ่งชั่วโมง และดิฉันขออนุญาติอัดเทปในระหว่างการสัมภาษณ์นี้ด้วย ถ้าคุณยินยอมที่จะเข้าร่วมในการทำวิจัยครั้งนี้แล้วดิฉันขอให้คุณกรุณาเซ็นต์ชื่อตรงช่องว่างที่เตรียมไว้และดิฉันขอเรียนถามที่อยู่ของคุณด้วยค่ะ

ลงชื่อ.. เพศ ( ) ชาย ( ) หญิง

ที่อยู่ ....

.... โทรศัพท์ ....

วันและเวลาที่สะดวก ....

Appendix II.

A. Example of Questionnaire (in English)

No________

INTERVIEW QUESTIONS

Date of interview...........................
Place of interview...........................
Time from..............to................

Introduction

Hello, may I speak to you. My name is Siriphun Sasat and I am a PhD. student in Gerontology from the University of Hull in England. You may remember that I have met you at the hospital, and you were asked to participate in an interview, about how you provide care for your ....(e.g. mother, father). I am interested in finding out what is it like to be a carer. What is your view in coping with this situation, and what are your problems and needs in giving care, so I can understand and contribute to improve the methods of formal and informal care, and carers' support in the future. I would be grateful if you could spare me some time for this interview. Everything that you tell me today will be treated with confidence. First of all,

Part A. Questions for Carer

1. Demographic Questions

I would like to ask some questions about yourself.

Note * completed before interview (see screening questions)

*1.1 Gender

A. Male B. Female

1.2. Could you tell me what year were you born? ....

1.3. Where were you born?

A. Bangkok and Metropolis

B. Large Urban

C. Small Urban

D. Rural

Where were you raised?

A. Metropolis

B. Large Urban

C. Small Urban

D. Rural

1.4. Have you had any brothers or sisters?

Number	Sex	Age	Education	Status	Occupation	Income/ month
1						
2						
3						
4						
5						
6						
7						

1.5. Education, when do you leave school?

A. None
B. Primary school
C. Secondary school
D. High school
E. Vocational education
F. University

1.6 Are you married?

A. Single
B. Married
C. Divorced
D. Separated
E. Widowed

*1.7. Current living condition

A. With demented spouse and children/grandchildren or partner

B. With spouse and elderly demented relative

C With spouse, children and elderly demented relative

E. With demented spouse/relative

F. With elderly demented relative and other relative (please specify)

1.8. Are you working outside the home? If yes, what are you doing?

A. Full-time job

B. Part-time job

C. None

*1.9. What is your relationship to elderly person you care for?

A. Husband

B. Wife

C. Son

D. Daughter

E. Niece

F. Nephew

G. Other...(please specify)

2. **Network Assessment** (from G. Clair Wenger, 1994)

I am interested to find out how close you are with your relatives and friends.

2.1. How far away, in distance, does your nearest child or other relative live?

Do not include spouse

A. No relatives

B. Same house/within 1 mile

C. 1-5 miles

D. 6-15 miles

E. 16-50 miles

F. 50+ miles

2.2. If you have any children, where does your nearest child live?

A. No children

B. Same house/within 1 mile

C. 1-5 miles

D. 6-15 miles

E. 16-50 miles

F. 50+ miles

2.3. If you have living sisters or brother, where does your nearest sister or brother live?

A. No sisters or brothers
B. Same house/within 1 mile
C. 1-5 miles
D. 6-15 miles
E. 16-50 miles
F. 50+ miles

2.4. How often do you see any of your children or other relatives to speak to?

A. Never/no relative
B. Daily
C. 2-3 times a week
D. At least weekly
E. At least monthly
F. Less often

2.5. If you have friends in this community/neighbourhood, how often do you have a chat or do something with one of your friends?

A. Never/no friends
B. Daily
C. 2-3 times a week
D. At least weekly
E. At least monthly
F. Less often

2.6. How often do you see any of your neighbours to have a chat with or do something with?

A. No contact with neighbours
B. Daily
C. 2-3 times a week
D. At least weekly
E. At least monthly
F. Less often

2.7. Do you attend any religious meetings?

A. Yes, regularly
B. Yes, occasionally
C. No

2.8. Do you attend meetings of any community/neighbourhood or social groups, such as old people's club, lectures or anything like that?

A. Yes, regularly
B. Yes, occasionally
C. No

3. Caring for

3.1. Have you been told what is wrong with your elderly relative?

....

....

3.2. How did you come to be looking after your elderly relative?

....

....

3.3. How did you and your and your brother/sisterdecide who should take care of your elderly spouse/relative?

....

....

3.4. How are you happy for the arrangement?

....

....

4. Financial situation

Now, I would like to ask you about your financial status.

*4.1. How much money do you earn per month?

A. less than 75 pounds
B. 75 - 125 pounds
C. 126 - 175 pounds
D. 176 - 250 pounds
E. more than 250 pounds

4.2. Do you support any family members living elsewhere? Who?

....

4.3. Do you have any financial difficulties supporting your ....?

....

4.4. Do you think that caring for your older relative is (will be) too expensive?

....

....

4.5. Have you any idea for how long you will be able to provide care ?

....

4.6. Who is the next person who will be able to provide care if you cannot?

....

4.7. Do you receive additional support from others family members?

....

*4.8. Who pay for his/her treatment?

A. Government (enable to get free medical treatment)
B. State Enterprise
C. Private firms
D. Self-paid

4.9. How much do you actually pay per month for medical treatment for your elderly relative?

....

4.10. How much do you actually pay per month for other facilities for your elderly relative?

....

4.11. What income have you lost for caring your older relative?

....

4.12. Do you think your family and yourself cannot (will not be able to) afford these extras cost because of the expense of caring for your elderly relative?

....

5. Relationship between carers and demented person

Can I ask you about your relationship with your..........

5.1. Could you describe your relationship with your older relative? How is it now?

....

....

5.2. Did you have a good relationship with your elderly relative before he/she became ill?

....

Attitude

5.3. Have your feelings towards your older relative changed? In what way?

....

....

5.4. Do you have any particular difficulties at the moment?

....

....

5.5. Do you have any problems in providing care? What? If no, go to 6.

....

....

5.6. How do you manage with his/her strange behaviour, such as being aggressive, wandering or undressing?

....

....

6. Religion and Culture

*6.1. What is your religion?

A. Buddhist
B. Islam
C. Christian
D. Other (please specify).........

6.2. Would you describe yourself as religious ?

A. Not at all
B. Slightly
C. Moderately
D. Strongly

6.3. How often do you visit the temple each month? ....

6.4. What religious activities do you regularly take part in?

A. Temple attendance
B. Merit-making
C. Practice meditation
D. Other (please specify)

6.5. Would you describe your .... as religious ?

1. not at all
2. slightly
3. moderately
4. strongly

6.6. What is your view of reciprocity or parent repayment? Is it important to you?

....

....

6.7. Did your parents expect you to look after them in their old age?

....

6.8. Do you expect your children to look after you when you get old? Why?

....

6.9. What circumstance would you (not live with or) not expect your child look after you when you get old?

....

....

6.10. Can you conceive any circumstances where you would be sending your parent to stay in any institutions?

....

....

6.11. Do you feel there is any social pressure to care for your older relative? If yes, in what way?

....

....

....

7. **Personal Health**

May we talk about your personal health in general.

7.1. In general, would you say your health is:

A. Excellent B.Very good

C. Good D. Fair

E. Poor

7.2. Compared to one year ago, how would you rate your health in general now?

A. Much better	B. Somewhat better
C. About the same	D. Somewhat worse
E. Much worse	

7.3. If you have any health problems, please tell me about it?

....

....

8. <u>The needs of carers.</u>

This part are questions about your needs

Information need

8.1. What information do you need in caring for your older relative?

....

8.2. Do you think you have all information you need?

....

8.3. Do you know what help is available?

....

....

8.4. Where to go for it?

....

....

8.5. Who can you contact?

....

8.5. Is there anything you would like to know?

....

....

Financial needs

8.6. Are you entitled to any financial help?

....

8.7. Would you like to have income support whilst you are providing care to your elderly relative? Why?

....

....

8.8. Do you think older people should receive financial support from the government? Why?

....

....

Respite needs

8.9. Are you able to go out and leave your older relative at home?

....

8.10. Do you and your family acknowledge the difficulties of your older relative?

....

8.11. Would you like to go and stay some where else for a few days or weeks?

....

8.12. Would it be helpful if someone came to your home? How?

....

9. Aids and Services

9.1. Is there anything that you have found particular difficult caring for your elderly relative?

....

....

9.2. How long does he/she need care from you per day?

.... hours.

9.3. What sources of help do you need?

....

10. Traditional Medicine

10.1. Have you ever sought help from traditional medicines? If yes, could you tell me about it?

....

....

10.2. What was it that you most needed help for?

....

10.3. Was traditional medicine helpful? If no, go to question 10.7.

....

....

10.4. How does it help? Could you tell me about it?

....

....

10.5. Did you seek help from traditional healer before or after you have seen Western medicine?

....

10.6. Could you describe what kind of traditional medicine your elderly relative has received?

....

....

10.7. Who decided to go to traditional healers?

....

10.8. What was it make you decided to take your elderly relative to see a doctor?

....

....

10.9. Does it help? If no, go to question 10.11 .

....

....

10.10. How does it help? Could you tell me about it?

....

....

10.11. What was it that your ....need to see western doctor?

....

....

11. Caregiver Strain Questions

I am now going to read a list of things which other people have found to be difficult in helping out. Would you tell me whether any of these apply to you. (GIVE EXAMPLES)

Yes=1 No=0

11.1. Sleep is disturbed (e.g., because___ is in and out of bed, wants help throughout the night) ____ ____

11.2. It is inconvenient (eg because helping takes so much time or it's a long journey over to help) ____ ____

11.3. It is a physical strain (eg because of lifting in and out of chair, effort or concentration is required) ____ ____

11.4. It is confining (eg helping restricts free time or cannot go visiting) ____ ____

11.5. There have been family adjustments (eg because helping has disrupted routine, no privacy) ____ ____

11.6. There have been changes in personal plans (eg had to turn down job, could not go on vacation) ____ ____

11.7. There have been other demands on my time (eg from other family members) ____ ____

11.8. There have been emotional adjustments (eg because of severe arguments) ____ ____

11.9. Some behaviour is upsetting (eg because of incontinence, she/he has trouble remembering things) ____ ____

11.10. It is upsetting to find she/he has changed so much from her/his former self. ____ ____

11.11. There have been work adjustments (eg because of having to take time off) ____ ____

11.12. It is a financial strain ____ ____

11.13. Feeling completely overwhelmed (eg because of worrying about her/him, concerns about how you will manage) ____ ____

Total Score (count yes responses) _____

12. Is there anything else you would like to say to me?

....

....

Thank you very much for your time

Part B. Questions for Demented person

Introduction

Hello, may I speak to you. My name is Siriphun Sasat and I am a PhD. student in Gerontology from the University of Hull, England. You may remember being informed by the doctor at the hospital that a research student would come to ask you to participate in an interview about family care. I am interested in finding out about the family care situation, so I can understand and contribute to improve the methods of formal and informal care, and carers' support in the future. I would be grateful if you could spare me some time for this interview. Everything that you tell me today will be treated with confidence. First of all,

Note **** means completed before interview (see screening questions)***
 # means completed by carers

1 Demographic Questions

I would to ask you about yourself

*1.1 Gender

A. Male B. female

1.2. Could you tell me what year were you born?

....

1.3. Where were you born?

A. Metropolis
B. Large Urban
C. Small Urban
D. Rural

Where were you raised?

A. Metropolis

B. Large Urban

C. Small Urban

D. Rural

1.4. Number of your brothers and sisters

Number	Sex	Education	Status	Occupation	Income /month
1					
2					
3					
4					
5					
6					
7					

1.5. Education

A. None	B. Primary school
C. Secondary school	D. High school
E. College	F. University

1.6 Are you married?

A. Single	B. Married
C. Divorced	D. Separated
E. Widowed	

1.7. Current living condition

A. With spouse or partner	B. With children
C. With spouse or partner and with children	D. With other relative (please specify) ....

1.8. Occupation during your working life ? ....

2. How long have you been ill?.......................... years.

3. Thai Mental State Exam (TMSE)

3.1. ORIENTATION (Score 6)

Score

- (1) What day is it? (Monday, Tuesday, Thursday, etc.) ___
- (1) What date is it? ___
- (1) What month is it? ___
- (1) What period of today is it? (morning, noon, afternoon, and evening ___
- (1) Where are we now? ___
- (1) What is her occupation? (show picture on overleaf) ___

3.2. REGISTRATION (Score 3)

"I shall say three words for you to remember. Repeat them after I have said all three words....."

(Score only for the first presentation)

- (1) TREE ___
- (1) CAR ___
- (1) HAND ___

Note, after the score is given, repeat those three words until he/she remember. Then tell him/her that he/she will be asked again later.

3.3. ATTENTION (Score 5)

Could you tell me BACKWARDS the days in one week. (allowed to repeat only one time)

- (1) Friday ___
- (1) Thursday ___
- (1) Wednesday ___
- (1) Tuesday ___
- (1) Monday ___

3.4. CALCULATION (Score 3)

Ask him/her to calculate 100-7, 3 times (give 1 score for each correct answer and allow one minute for thinking before each question).

If he/she can not answer the first question, ask him/her to calculate in the next step: 93-7, and finally, 86-7 repectively.

(1) 100-7 ___
(1) -7 ___
(1) -7 ___

3.5. LANGUAGE (Score 10)

(1) Ask him/her to name: Watch ___
(1) Clothes ___

(1) Say "repeat what I say, 'Grandma takes her grandchildren to buy sweets at the market' ". ___

Obey 3 stage command. Score 1 point for each correct part.
(1) "Take this paper in your right hand" ___
(1) "Fold it in half" ___
(1) "Hand it back to me" ___

(1) Read and obey the command "CLOSE YOUR EYES"
Score 1 point if correct ___
(2) Ask him/her to copy the pentagon figure as similarly as he/she can ___
(1) "Banana and orange are both fruit"

Ask "IN WHAT WAY ARE CAT AND DOG ALIKE?" ___
............................(animals, living things)

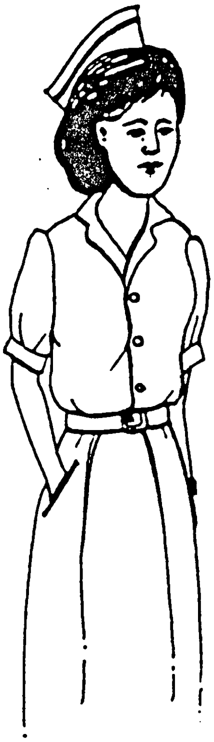
3.6. RECALL (Score 3)

"What are the three words that I asked you to remember?"
Score 1 point for each correct word. No hints
(1) Tree ___
(1) Car ___
(1) Hand ___

Total ___

(Total possible score = 30)

CLOSE YOUR EYES



#4. CLIFTON ASSESSMENT PROCEDURES FOR THE ELDERLY (CAPE)

Behaviour Rating Scale (BRS)

Please ring the appropriate **number** for each item

1. When bathing or dressing, he/she requries:

- no assistance	0
- some assistance	1
- maximum assistance	2

2. With regard to walking, he/she:

- shows no signs of weakness	0
- walks slowly without aid, or uses a stick	1
- is unable to walk, or if able to walk, needs frame, crutches or someone by his/her side	2

3. He /she is incontinent of urine and/or faeces (day or night):

- never	0
- sometimes (once or twice per week)	1
- frequently (3 times per week or more)	2

4. He/she is in bed during the day (bed does **not** include couch, settee, etc):

- never	0
- sometimes	1
- almost always	2

5. He/she is confused (unable to find way around, loses possessions, etc):

- almost never confused	0
- sometimes confused	1
- almost always confused	2

6. When left to his/her own devices, his/her appearance (clothes and/or hair) is:

- almost never disorderly	0
- sometimes disorderly	1
- almost always disorderly	2

7. If allowed outside, he/she would:

- never need supervision	0
- sometimes need supervision	1
- always need supervision	2

8. He/she helps out in the home/ward:

- often helps out	0
- sometimes helps out	1
- never helps out	2

9. He/she keeps him/herself occupied in a constructive or useful activity (works, reads, plays games, has hobbies, etc):

- almost always occupied	0
- sometimes occupied	1
- almost never occupied	2

10. He/she socialises with others:
- does establish a good relationship with others 0
- has some difficulty establishing good relationships 1
- has a great deal of difficulty establishing good relationships 2

11. He/she is willing to do things suggested or asked of him/her:
- often goes along 0
- sometimes goes along 1
- almost never goes along 2

12. He/she understands what you communicate to him/her (you may use speaking, writing, or gesturing):
- understands almost everything you communicate 0
- understands some of what you communicate 1
- understands almost nothing of what you communicate 2

13. He/she communicates in any manner (by speaking, writing or gesturing):
- well enough to make him/herself easily understood at all times 0
- can be understood sometimes or with some difficulty 1
- can rarely or never be understood for whatever reason 2

14. He/she is objectionable to others **during the day** (loud constant talking, pilfering, soiling furniture, interfering with affairs of others):
- rarely or never 0
- sometimes 1
- frequently 2

15. He/she is objectionable to others **during the night** (loud or constant talking, pilfering, soiling furniture, interfering in affairs of others, wandering about, etc,):
- rarely or never 0
- sometimes 1
- frequently 2

16. He/she accuses others of doing him/her bodily harm or stealing his/her personal possessions - if you are sure the accusations are true, rate Zero, otherwise rate one or two:
- never 0
- sometimes 1
- frequently 2

17. He/she hoards apparently meaningless items(wads of paper, string, scraps of food, etc):	- never	0
	- sometimes	1
	- frequently	2
18. His/her sleep pattern at night is:	- almost never awake	0
	- sometimes awake	1
	- often awake	2

Eyesight:	- can see (or can see with glasses)
	- partially blind
	- totally blind
Hearing:	- no hearing difficulties, without hearing aid
	- no hearing difficulties, through requires hearing aid
	- no hearing difficulties which interfere with communication
	- is very deaf

Rated by:...Date..

B. Example of Questionnaire (inThai)

ลำดับที่...........

แบบสอบสัมภาษณ์

ตอนที่ 1 คำถามสำหรับผู้ให้การดูแลผู้สูงอายุ

แนะนำตัวก่อนเริ่มสัมภาษณ์

สวัสดีค่ะ คุณ..(ลุง ป้า น้า อา)...ดิฉันขอพูดคุยด้วยสักประเดี๋ยวจะได้ไหมคะ...ดิฉันชื่อ ศิริพันธุ์ สาสัตย์ นักศึกษาระดับปริญญาเอกทางด้านผู้สูงอายุ จากมหาวิทยาลัย HULL ณ ประเทศอังกฤษ คุณอาจจะจำได้ว่าดิฉันเคยพบคุณที่โรงพยาบาลและขอความร่วมมือในการสัมภาษณ์จากคุณในการให้การดูแลผู้สูงอายุที่บ้าน ดิฉันมีความสนใจที่จะศึกษาสภาพและลักษณะการดูแลผู้สูงอายุที่บ้าน นั้นเป็นอย่างไร การศึกษาในเรื่องนี้มีจุดประสงค์เพื่อเพิ่มพูนความรู้และความเข้าใจในสภาพปัญหาและความต้องการของบุคคลที่ให้การดูแลผู้สูงอายุที่บ้านและหวังเป็นอย่างยิ่งว่าผลของการวิจัยชิ้นนี้จะเป็นข้อมูลพื้นฐานให้กับทั้งทางภาครัฐและเอกชนในการปรับปรุงและวางแผนการให้การช่วยเหลือทั้งทางตรงและทางอ้อมต่อไปในอนาคต จะเป็นพระคุณมากถ้าคุณจะกรุณาสละเวลาสักครู่เพื่อให้ดิฉันสัมภาษณ์ในครั้งนี้ซึ่งทุกสิ่งทุกอย่างที่คุณบอกมาวันนี้ดิฉันจะเก็บไว้เป็นความลับ

ดิฉันจะขอเริ่มต้นถามคุณด้วยคำถามทั่วๆไปเกี่ยวกับตัวคุณดังต่อไปนี้

* เติมคำตอบก่อนสัมภาษณ์ (ดูคำถามสำหรับคัดเลือกกลุ่มเป้าหมาย)

1. คำถามเกี่ยวกับข้อมูลพื้นฐาน

*1.1. เพศ

1. ผู้ชาย 2. ผู้หญิง

1.2. ดิฉันขอทราบวัน เดือน ปีเกิด ....

1.3. คุณเกิดที่ไหน ?

1. นครหลวง (กรุงเทพฯ และเขตปริมณฑล)
2. เมืองใหญ่ (เมืองใหญ่ตามภาคต่าง ๆ)
3. เมืองเล็ก (จังหวัดเล็ก ๆ)
4. ชนบท (ระดับอำเภอ หรือ เล็กกว่า)

คุณโตที่ไหน ?

1. นครหลวง (กรุงเทพฯ และเขตปริมณฑล)
2. เมืองใหญ่ (เมืองใหญ่ตามภาคต่าง ๆ)
3. เมืองเล็ก (จังหวัดเล็ก ๆ)
4. ชนบท (ระดับอำเภอ หรือ เล็กกว่า)

1.4. คุณมีพี่น้องร่วมบิดาและมารดาหรือเปล่า? ถ้ามีดิฉันขอทราบรายระเอียดดังต่อไปนี้

คนที่	เพศ	อายุ	การศึกษา	สถานภาพสมรส	อาชีพ	รายได้(บาท/เดือน)
1						
2						
3						
4						
5						
6						
7						

1.5. การศึกษา

1. ไม่รู้หนังสือ
2. ประถมศึกษา
3. มัธยมศึกษาตอนต้น
4. มัธยมศึกษา
5. วิทยาลัย
6. มหาวิทยาลัย

1.6. สถานภาพสมรส

1. โสด
2. แต่งงาน
3. หย่า
4. แยกกันอยู่
5. ม่าย

1.7. สถานที่อยู่อาศัย

1. อยู่อาศัยร่วมกับสามีหรือภรรยา
2. อยู่อาศัยร่วมกับลูกหลาน
3. อยู่อาศัยร่วมกับสามีหรือภรรยาและลูกหลาน
4. อยู่อาศัยร่วมกับญาติพี่น้องคนอื่น ๆ (โปรดระบุ)...

1.8. คุณทำงานนอกบ้านหรือเปล่า ? ถ้าใช่ คุณทำงานอะไร และลักษณะการทำงานเป็นอย่างไร?

....

1. ทำงานเต็มเวลา
2. ทำงานไม่เต็มเวลา

*1.9. คุณมีความเกี่ยวพันอย่างไรกับผู้สูงอายุ

1. สามี
2. ภรรยา
3. ลูกชาย
4. ลูกสาว
5. หลานสาว
6. หลานชาย
7. อื่น ๆ (โปรดระบุ)..............................

2. แบบประเมินการติดต่อสื่อสารกับบุคคลใกล้ชิด เช่น ลูกหลาน ญาติ เพื่อน และเพื่อนบ้าน

ดิฉันสนใจที่จะทราบถึงการติดต่อและความใกล้ชิดระหว่างคุณกับญาติและเพื่อน ๆ

2.1. ลูกหรือญาติที่อยู่ใกล้ที่สุดอยู่ห่างจากคุณประมาณเท่าไร ?(ไม่นับสามีหรือภรรยา)

1. ไม่มีญาติ 2. อยู่บ้านเดียวกัน/ไม่เกิน 1.5 ก.ม.
3. 1.5 - 8 ก.ม. 4. 9 - 23 ก.ม.
5. 24 - 75 ก.ม. 6. มากกว่า 75 ก.ม.

2.2. ถ้าคุณมีลูก ลูกคนที่อยู่ใกล้ที่สุดอยู่ห่างจากคุณประมาณเท่าไร ?

1. ไม่มีลูก 2. อยู่บ้านเดียวกัน/ไม่เกิน 1.5 ก.ม.
3. 1.5 - 8 ก.ม. 4. 9 - 23 ก.ม.
5. 24 - 75 ก.ม. 6. มากกว่า 75 ก.ม.

2.3. ถ้าคุณมีพี่น้องที่ยังมีชีวิตอยู่ พี่น้องที่อาศัยอยู่ใกล้ที่สุดอยู่ห่างจากคุณประมาณเท่าไร ?

1. ไม่มีพี่น้อง 2. อยู่บ้านเดียวกัน/ไม่เกิน 1.5 ก.ม.
3. 1.5 - 8 ก.ม. 4. 9 - 23 ก.ม.
5. 24 - 75 ก.ม. 6. มากกว่า 75 ก.ม.

2.4. คุณพบปะพูดคุยกับลูกหรือญาติบ่อยแค่ไหน ?

1. ไม่เคย/ไม่มีญาติ 2. วันละครั้ง
3. 2 - 3 ครั้งต่ออาทิตย์ 4. อย่างน้อยอาทิตย์ละครั้ง
5. อย่างน้อยเดือนละครั้ง 6. นาน ๆ ครั้ง

2.5. ถ้าคุณมีเพื่อนในย่านนี้ เพื่อนบ้านคุณพูดคุยหรือทำกิจกรรมร่วมกันบ่อยแค่ไหน ?

1. ไม่เคย/ไม่มีเพื่อน 2. วันละครั้ง
3. 2 - 3 ครั้งต่ออาทิตย์ 4. อย่างน้อยอาทิตย์ละครั้ง
5. อย่างน้อยเดือนละครั้ง 6. นาน ๆ ครั้ง

2.6. คุณพบปะพูดคุยกับเพื่อนบ้านหรือทำกิจกรรมร่วมกันบ่อยแค่ไหน ?

1. ไม่เคยพบปะพูดคุย 2. วันละครั้ง
3. 2 - 3 ครั้งต่ออาทิตย์ 4. อย่างน้อยอาทิตย์ละครั้ง
5. อย่างน้อยเดือนละครั้ง 6. นาน ๆ ครั้ง

2.7. คุณเข้าร่วมประชุมทางศาสนาหรือเปล่า

1. เข้าร่วมเป็นประจำ 2. เข้าร่วมเป็นบางครั้งบางคราว
3. ไม่เข้าร่วม

2.8. คุณเข้าร่วมประชุมของชุมชน/เพื่อนบ้าน หรือสมาคมต่าง ๆ เช่น สมาคมผู้สูงอายุ การเข้าฟังการบรรยายหรือเปล่า ?

1. เข้าร่วมเป็นประชำ 2. เข้าร่วมเป็นบางครั้งบางคราว
3. ไม่เข้าร่วม

3. การให้การดูแล

3.1. เคยมีคนบอกคุณหรือไม่ว่า.......(ผู้สูงอายุ).......... ป่วยเป็นอะไร ?

....

....

3.2. เรื่องราวเป็นมาอย่างไรคุณถึงได้มาเป็นผู้ให้การดูแล.......(ผู้สูงอายุ)..........

....

....

3.3. คุณและพี่น้องของคุณตกลงกันอย่างไรว่าใครจะเป็นผู้ให้การดูแล......(ผู้สูงอายุ)..........

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3.4. คุณพอใจกับการตกลงในเรื่องนี้หรือไม่ อย่างไร?

....

....

4. สถานภาพทางด้านการเงิน

ดิฉันอยากจะขอเรียนถามคุณเรื่องสถานภาพทางด้านการเงินของคุณ

*4.1. คุณมีรายได้ประมาณเดือนละเท่าไหร่?

1. น้อยกว่า 3,000 บาท
2. 3,000 - 5,000 บาท
3. 5,001 - 7,000 บาท
4. 7,001 - 10,000 บาท
5. มากกว่า 10,000 บาท

4.2. คุณมีภาระที่จะต้องส่งเสียคนในครอบครัวที่อยู่อาศัยที่อื่นหรือเปล่า ? ใครบ้าง ?

....

....

4.3. คุณมีปัญหาทางด้านการเงินในการดูแล........(ผู้สูงอายุ)............ หรือเปล่า ?

....

....

4.4. คุณคิดว่าค่าใช้จ่ายในการดูแล.........(ผู้สูงอายุ)......ค่อนข้างสูงมากหรือไม่ อย่างไร ?

....

....

4.5. คุณคิดว่าคุณจะสามารถให้การดูแลอย่างนี้ไปอีกนานเท่าไหร่ ?

....

....

4.6. ใครเป็นคนต่อไปที่จะสามารถให้การดูแลถ้าคุณไม่สามารถให้การดูแลได้อีกต่อไป

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....

4.7. มีพี่น้องคนอื่นๆได้ให้การช่วยเหลือในด้านค่าใช้จ่ายในการดูแลบ้างหรือไม่ ?

....

....

*4.8. ใครเป็นคนจ่ายค่ารักษาพยาบาลให้ผู้สูงอายุ?

1. มีสิทธิ์เบิกได้จากรัฐบาล 2. มีสิทธิ์เบิกได้จากภาคเอกชน
3. จ่ายเอง

4.9. คุณเสียค่าใช้จ่ายในด้านค่ารักษาพยาบาลผู้สูงอายุประมาณเดือนละเท่าไหร่ ?

....

....

4.10. คุณเสียค่าใช้จ่ายในการดูแลและอุปกรณ์ต่าง ๆ ประมาณเดือนละเท่าไหร่ ?

....

....

4.11. รายได้อะไรบ้างที่คุณสูญเสียไปเนื่องจากต้องทำหน้าที่ดูแลผู้สูงอายุ?

....

....

4.12. คุณและครอบครัวคิดว่าจะไม่สามารถรับภาระในการดูแลผู้สูงอายุได้ เนื่องจากเหตุผลด้านค่าใช้จ่ายหรือเปล่า ?

....

....

5. สัมพันธภาพระหว่างผู้ให้การดูแลและผู้สูงอายุที่มีอาการความจำเสื่อม

5.1. คุณจะอธิบายสัมพันธภาพระหว่างคุณและผู้สูงอายุว่าเป็นอย่างไรบ้างในตอนนี้

....

....

5.2. คุณมีสัมพันธภาพที่ดีกับผู้สูงอายุก่อนที่จะป่วยเป็นโรคความจำเสื่อมหรือเปล่า อย่างไร ?

....

....

ทัศนคติต่อผู้สูงอายุ

5.3. ความรู้สึกของคุณ ต่อผู้สูงอายุเปลี่ยนไปบ้างหรือเปล่า เปลี่ยนไปในทางใด ?

....

....

5.4. คุณประสบกับปัญหาหรือ ความยากลำบากอะไรเป็นพิเศษในช่วงนี้หรือไม่ ?

....

....

5.5. คุณมีปัญหาในการให้การดูแลผู้สูงอายุหรือไม่ ? อะไรบ้าง? (ถ้าไม่มีข้ามไปข้อ 6)

....

....

5.6. คุณมีวิธีควบคุมพฤติกรรมแปลกๆของผู้สูงอายุ เช่น อารมณ์ก้าวร้าว, ละเมอเดินไปมาหรือไม่ยอมใส่เสื้อผ้าอย่างไร ?

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6. ศาสนาและวัฒนธรรม

*6.1. คุณนับถือศาสนาอะไร ?

1. พุทธ
2. อิสลาม
3. คริสต์
4. อื่น ๆ (โปรดระบุ).......................

6.2. คุณเป็นคนเคร่งศาสนามากน้อยแค่ไหน ?

1. ไม่เลย
2. เล็กน้อย
3. ปานกลาง
4. เคร่งศาสนามาก

6.3. คุณไปวัดประมาณกี่ครั้งต่อเดือน .... ครั้ง

6.4. คุณเข้าร่วมกิจกรรมอะไรทางศาสนาบ้างเป็นประจำ

1. ไปฟังเทศน์ที่วัด
2. ทำบุญต่าง ๆ
3. ฝึกนั่งสมาธิหรือกรรมฐาน 4
4. อื่น ๆ (โปรดระบุ)........................

6.5. ....(ผู้สูงอายุ)......... เป็นคนที่เคร่งศาสนามากน้อยแค่ไหน ?

1. ไม่เลย
2. เล็กน้อย
3. ปานกลาง
4. เคร่งศาสนา

6.6. คุณมีความคิดเห็นอย่างไรกับคำว่า ทดแทนบุญคุณหรือการตอบแทนบุญคุณพ่อแม่ สิ่งเหล่านี้สำคัญต่อคุณอย่างไร ?

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....

6.7. บิดามารดาของคุณคาดหวังว่าคุณจะต้องดูแลท่านเมื่อท่านสูงอายุหรือไม่ ?

....

....

6.8. คุณคาดหวังว่าลูก ๆ คุณจะดูแลคุณเมื่อคุณเข้าสู่วัยสูงอายุหรือไม่ ? เพราะอะไรทำให้คุณถึงคิดอย่างนั้น?

....

....

6.9. ด้วยภาวะการณ์และสภาพแวดล้อมประการใดบ้างที่คุณไม่คาดหวังจะให้ลูก ๆ คุณดูแลเมื่อคุณ เข้าสู่วัยสูงอายุ?

....

....

6.10. ถ้าหากคุณจะต้องส่งผู้สูงอายุไปอยู่ที่สถานดูแลผู้สูงอายุ ที่ไหนที่คุณต้องการจะส่ง ท่านไปอยู่อาศัย?

....

....

6.11. คุณมีความรู้สึกว่าคุณได้รับแรงกดดันจากสังคมแวดล้อมที่จะต้องให้การดูแลผู้สูงอายุหรือไม่

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7. สุขภาพส่วนบุคคล

ต่อไปดิฉันจะขอถามเรื่องสุขภาพของคุณโดยทั่วไปนะคะ

7.1. โดยทั่ว ๆ ไป คุณบอกได้หรือไม่ว่าสุขภาพของคุณอยู่ในระดับไหน ?

1. ยอดเยี่ยม
2. ดีมาก
3. ดี
4. ดีพอใช้
5. ไม่ดีเลย

7.2. ถ้าเปรียบเทียบกับปีที่ผ่านมา คุณจะบอกได้ไหมว่าสุขภาพของคุณปัจจุบันเป็นอย่างไร ?

1. ดีขึ้นมาก
2. ค่อนข้างดีขึ้น
3. เหมือนเดิม
4. ค่อนข้างเลวลง
5. เลวลง

7.3. ถ้าคุณมีปัญหาทางด้านสุขภาพ กรุณาบอกดิฉันด้วยคะว่าคุณมีปัญหาในด้านใดบ้าง ?

....

8. ความต้องการของผู้ให้การดูแล

ส่วนนี้จะเป็นคำถามเกี่ยวกับความต้องการของคุณในฐานะผู้ให้การดูแลในด้านต่าง ๆ

ความต้องการทางด้านความรู้และคำแนะนำ

8.1. คุณต้องการความรู้และคำแนะนำอะไรบ้างในการให้การดูแลผู้สูงอายุ?

....

....

8.2. คุณคิดว่าคุณได้รับความรู้และคำแนะนำที่คุณต้องการหรือเปล่า ?

....

....

8.3. คุณทราบหรือไม่ว่ามีแหล่งที่ให้ความรู้และคำแนะนำทางด้านนี้ที่ไหนบ้าง ?

....

....

8.4. ใครบ้างที่คุณสามารถจะติดต่อขอความช่วยเหลือได้ ?

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8.5. มีเรื่องอื่น ๆ อีกบ้างไหมที่คุณ ต้องการจะทราบ ?

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ความต้องการทางด้านการเงิน

8.6. คุณได้รับการช่วยเหลือทางการเงินบ้างหรือไม่ ? จากที่ใดบ้าง?

....

....

8.7. คุณต้องการเงินช่วยเหลือในระหว่างที่คุณให้การดูแลผู้สูงอายุหรือไม่ ? ทำไม ?

....

....

8.9. คุณคิดว่าผู้สูงอายุควรจะได้รับเงินช่วยเหลือจากรัฐบาลหรือไม่ ทำไม ?

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ความต้องการทางด้านการหยุดพักผ่อนหรือมีเวลาเป็นส่วนตัว

คุณต้องการความช่วยเหลือด้านใดบ้าง ดังต่อไปนี้

8.10. คุณสามารถออกไปข้างนอกโดยปล่อยให้ผู้สูงอายุอยู่ที่บ้านคนเดียวได้หรือไม่ ?

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8.11. คุณและครอบครัวรับทราบถึงอาการผิดปกติที่ผู้สูงอายุกำลังประสบอยู่หรือไม่ ?

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....

8.12. คุณต้องการที่จะออกไปข้างนอกหรือไปพักผ่อนในบางสถานที่สัก 2 - 3 วันหรือประมาณอาทิตย์หนึ่งหรือไม่ ?

....

....

8.13. คุณคิดว่าจะเป็นการช่วยแบ่งเบาภาระคุณได้หรือไม่ถ้ามีคนไปเยี่ยมให้การช่วยเหลือที่บ้านอย่างไร?

....

....

9. การให้การช่วยเหลือและการให้บริการ

9.1. คุณประสบกับปัญหาหรือความยากลำบากอะไรเป็นพิเศษในการให้การดูแลผู้สูงอายุ ?

....

....

9.2. คุณใช้เวลาให้การดูแลประมาณวันละกี่ชั่วโมง/วัน..

10. การรักษาตามแผนโบราณ

10.1. คุณเคยหาความช่วยเหลือจากผู้ที่ให้การรักษาตามแผนโบราณ (เช่น หมอพื้นบ้าน, เจ้าเข้าทรง, หมอผี, พระ ฯลฯ) ถ้าเคย กรุณาเล่าให้ดิฉันฟังว่าเป็นมาอย่างไร ?

....

....

10.2. อะไรที่ทำให้คุณคิดว่าคุณต้องการความช่วยเหลือมากที่สุด ?

....

....

10.3. การรับการรักษาตามแผนโบราณช่วยผู้สูงอายุดีขึ้นหรือไม่ ? ถ้าไม่ช่วยเลยข้ามไป 10.7

....

....

10.4. การรักษาตามแผนโบราณช่วยเหลืออย่างไร? คุณพอจะบอกดิฉันได้ไหม ?

....

....

10.5. คุณพาผู้สูงอายุไปรักษาตามแผนโบราณก่อนหรือหลังจากการไปรับการรักษาทางการแพทย์สมัยใหม่?

....

....

10.6. คุณช่วยอธิบายว่า ผู้สูงอายุได้รับการรักษาทางแผนโบราณอะไรบ้าง ?

....

....

10.7. ใครเป็นคนตัดสินใจที่จะรับการรักษาตามแผนโบราณ ?

....

....

10.8. อะไรทำให้คุณตัดสินใจพาผู้สูงอายุมารับการรักษากับคุณหมอที่นี่ ?

....

....

10.9. การรับการรักษาแบบนี้ช่วยให้ผู้สูงอายุดีขึ้นหรือไม่ ? ถ้าไม่ช่วยข้ามไปข้อ 10.11

....

....

10.10. การรักษาทางการแพทย์สมัยใหม่ช่วยเหลืออย่างไร? คุณพอจะบอกได้หรือไม่ ?

....

....

10.11. อะไรที่ทำให้คุณหรือผู้สูงอายุต้องการรับการรักษาทางการแพทย์สมัยใหม่ ?

....

....

11. คำถามเกี่ยวกับความเครียดในผู้ให้การดูแล

ดิฉันจะอ่านรายการต่าง ๆ ที่มีผู้พบว่าเป็นปัญหาในการให้การดูแล คุณช่วยระบุได้หรือไม่ว่าข้อไหนที่คุณก็ประสบปัญหาเช่นเดียวกัน (ยกตัวอย่าง)

	ใช่=1	ไม่ใช่=0
11.1. ถูกปลุกหรือรบกวนขณะนอนหลับ (เช่น ผู้สูงอายุต้องการความช่วยเหลือในการลุกจากเตียงและขึ้นเตียงตลอดคืน)	----------	----------
11.2. เรื่องของความไม่สะดวกสบาย เช่น ต้องใช้เวลานานมากในการช่วยเหลือหรือใช้เวลานานในการเดินทางมาเพื่อให้การช่วยเหลือ	----------	---------
11.3. ใช้กำลังมากเกินไป เช่น ต้องช่วยพยุงหรือดึงขึ้นจากเก้าอี้, ต้องใช้ความพยายามหรือต้องการการเอาใจใส่อย่างมาก	----------	----------
11.4. รู้สึกเหมือนถูกกักตัว เช่น การดูแลทำให้ไม่มีเวลาว่างที่จะไปข้างนอกหรือไปเที่ยว	----------	----------
11.5. มีการปรับปรุงกิจวัตรประจำวันของบุคคลในครอบครัว เช่น การให้การดูแลทำให้ไม่มีความเป็นส่วนตัวกระทบกับกิจวัตรประจำวัน	----------	----------
11.6. มีการเปลี่ยนแปลงแผนการของแต่ละคน เช่น ปฏิเสธงาน, ไม่มีเวลาพักร้อน	----------	-----------
11.7. เวลาส่วนตัวของฉันยังต้องใช้ในด้านอื่น ๆ อีก เช่น จากคนอื่น ๆ ในครอบครัว	----------	----------
11.8. มีการปรับระดับอารมณ์ เช่น เพราะว่ามีการทะเลาะกันรุนแรง	----------	----------
11.9. มีพฤติกรรมบางอย่างของผู้สูงอายุทำให้รู้สึกอารมณ์เสีย เช่น มีปัสสาวะกลั้นไม่อยู่, มีปัญหาในเรื่องความจำในสิ่งต่าง ๆ	----------	----------
11.10. ดิฉันรู้สึกเสียใจที่พบว่าผู้สูงอายุเปลี่ยนไปมากจากเมื่อก่อน	----------	-----------
11.11. มีการเปลี่ยนแปลงในเรื่องงาน เช่น จะต้องหาเวลาหยุด	----------	----------
11.12. เป็นเรื่องความตึงเครียดทางด้านการเงิน	----------	----------
11.13. มีความรู้สึกว่าเรื่องต่าง ๆ ประดังเข้ามา เช่น กังวลเกี่ยวกับผู้สูงอายุเป็นห่วงว่าดิฉันจะดูแลจัดการได้อย่างไร	----------	----------

รวมคะแนน (นับเฉพาะที่ตอบใช่) ------------

12 คุณมีสิ่งอื่น ๆ ที่ต้องการจะบอกดิฉันอีกหรือไม่ ?

....

....

ขอบคุณมากสำหรับเวลาอันมีค่าของคุณ

ตอนที่ 2. คำถามสำหรับผู้สูงอายุ

แนะนำตัวก่อนเริ่มสัมภาษณ์

สวัสดีค่ะ คุณ..(ลุง ป้า น้า อา)...ดิฉันขอพูดคุยด้วยสักประเดี๋ยวจะได้ไหมคะ...ดิฉันชื่อ ศิริพันธุ์ สาสัตย์ นักศึกษาระดับปริญญาเอกทางด้านผู้สูงอายุ จากมหาวิทยาลัย HULL ณ ประเทศอังกฤษ คุณหมออาจจะเคยบอกคุณแล้วว่าจะมีนักศึกษามาขอความร่วมมือจากท่านเข้าร่วมในการทำวิจัยเกี่ยวกับการให้การดูแลผู้สูงอายุที่บ้าน ดิฉันมีความสนใจที่จะศึกษาสภาพและสถานการณ์การดูแลผู้สูงอายุที่บ้าน นั้นเป็นอย่างไร การศึกษาในเรื่องนี้มีจุดประสงค์เพื่อเพิ่มพูนความรู้และความเข้าใจในสถานการณ์สภาพปัญหาและความต้องการของบุคคลที่ให้การดูแลผู้สูงอายุที่บ้านและหวังเป็นอย่างยิ่งว่าผลของการวิจัยชิ้นนี้จะเป็นข้อมูลพื้นฐานให้กับทั้งทางภาครัฐและเอกชนในการปรับปรุงและวางแผนการให้การช่วยเหลือทั้งทางตรงและทางอ้อมต่อไปในอนาคต จะเป็นพระคุณมากถ้าคุณจะกรุณาสละเวลาสักครู่เพื่อให้ดิฉันสัมภาษณ์ในครั้งนี้ซึ่งทุกสิ่งทุกอย่างที่คุณบอกมาวันนี้ดิฉันจะเก็บไว้เป็นความลับ

หมายเหตุ *** หมายถึงให้เติมคำตอบก่อนเริ่มสัมภาษณ์**
 # หมายถึงผู้ให้การดูแลเป็นผู้ตอบคำถามหรือกรอกคำตอบ

ดิฉันจะขอเริ่มต้นถามคุณด้วยคำถามทั่วๆไปเกี่ยวกับตัวคุณ

1. คำถามเกี่ยวกับข้อมูลพื้นฐาน

*1.1. เพศ

1. ชาย 2. หญิง

1.2. ดิฉันขอทราบวัน เดือน ปีเกิด

....

1.3. คุณเกิดที่ไหน ?

1. นครหลวง (กรุงเทพฯ และเขตปริมณฑล)
2. เมืองใหญ่ (เมืองใหญ่ตามภาคต่าง ๆ)
3. เมืองเล็ก (จังหวัดเล็ก ๆ)
4. ชนบท (ระดับอำเภอ หรือ เล็กกว่า)

คุณโตที่ไหน ?

1. นครหลวง (กรุงเทพฯ และเขตปริมณฑล)
2. เมืองใหญ่ (เมืองใหญ่ตามภาคต่าง ๆ)
3. เมืองเล็ก (จังหวัดเล็ก ๆ)
4. ชนบท (ระดับอำเภอ หรือ เล็กกว่า)

1.4. คุณมีพี่น้องร่วมบิดาและมารดาหรือเปล่า?

คนที่	เพศ	อายุ	การศึกษา	สถานภาพสมรส	อาชีพ	รายได้(บาท/เดือน)
1						
2						
3						
4						
5						
6						
7						

1.5. การศึกษา

1. ไม่รู้หนังสือ
2. ประถมศึกษา
3. มัธยมศึกษาตอนต้น
4. มัธยมศึกษา
5. วิทยาลัย
6. มหาวิทยาลัย

1.6. สถานภาพสมรส

1. โสด
2. แต่งงาน
3. หย่า
4. แยกกันอยู่
5. ม่าย

1.7. สถานที่อยู่อาศัย

1. อยู่อาศัยร่วมกับสามีหรือภรรยา
2. อยู่อาศัยร่วมกับลูกหลาน
3. อยู่อาศัยร่วมกับสามีหรือภรรยาและลูกหลาน
4. อยู่อาศัยร่วมกับญาติพี่น้องคนอื่น ๆ (โปรดระบุ)..

1.8. ช่วงที่คุณทำงาน คุณมีอาชีพอะไร? ....

2. <u>คุณรู้ตัวว่ามีความจำเสื่อมมานานกี่ปี</u>? .... ปี

3. แบบทดสอบสภาพสมองของไทย (THAI MENTAL STATE EXAMINATION)

3.1. ORIENTATION (6 คะแนน) คะแนนที่ได้

(1) วันนี้ วันอะไรของสัปดาห์ (จันทร์ อังคาร พุธ พฤหัส ฯลฯ) ....

(1) วันนี้ วันที่เท่าไร ....

(1) เดือนนี้ เดือนอะไร ....

(1) ขณะนี้เป็นช่วง (ตอน) ไหนของวัน (เช้า เที่ยง บ่าย เย็น) ....

(1) ที่นี่ที่ไหน ....

(1) คนที่เห็นในภาพนี้มีอาชีพอะไร (ภาพอยู่ด้านหลัง) ....

3.2. REGISTRATION (3 คะแนน)

(3) ผู้ทดสอบบอกชื่อของ 3 อย่าง โดยพูดห่างกัน ครั้งละ 1 วินาที (ต้นไม้ ....

รถยนต์ มือ) เพียงครั้งเดียว แล้วจึงให้ผู้ทดสอบบอกในครั้งแรกให้ 1 คะแนน ใน ....

แต่ละคำตอบที่ถูก ....

*หมายเหตุ หลังจากให้คะแนนแล้วให้บอกซ้ำจนผู้ถูกทดสอบจำได้ทั้ง 3 อย่าง และบอกให้ผู้ถูกทดสอบทราบว่าสักครู่จะกลับมาถามใหม่

3.3 ATTENTION (5 คะแนน)

ให้บอกวันอาทิตย์ - วันเสาร์ ย้อนหลัง ให้ครบสัปดาห์ (ให้ตอบซ้ำได้ 1 ครั้ง)

(1) ศุกร์ ....

(1) พฤหัสบดี ....

(1) พุธ ....

(1) อังคาร ....

(1)จันทร์ ....

3.4. CALCULATION (3 คะแนน)

ให้คำนวณ 100 - 7 ไปเรื่อยๆ 3 ครั้ง (ให้ 1 คะแนน ในแต่ละครั้งที่ตอบถูก ใช้เวลาคิดในแต่ละช่วงคำตอบไม่เกิน 1 นาที หลังจากจบคำถาม)

ถ้าผู้ถูกทดสอบไม่ตอบคำถามที่ 1 ให้ตั้งเลข 93 - 7 ลองทำในการคำนวณครั้งต่อไป และ 86 - 7 ในครั้งสุดท้ายตามลำดับ

(1) 100 - 7 ....

(1) - 7 ....

(1) - 7 ....

3.5. LANGUAGE (10 คะแนน)

(1) ผู้ทดสอบชี้ไปที่นาฬิกาข้อมือ แล้วถามผู้ถูกทดสอบว่าโดยทั่วไป
"เราเรียกสิ่งนี้ว่าอะไร" (นาฬิกา)) ....

(1) ผู้ทดสอบบอกผู้ถูกทดสอบว่า จงฟังประโยคต่อไปนี้ให้ดี แล้วจำไว้
จากนั้นให้พูดตาม
"ยายพาหลานไปซื้อขนมที่ตลาด" ....

จงทำตามคำสั่งต่อไปนี้ (มี 3 ขั้นตอน) ให้ผู้ทดสอบพูดต่อกันไปให้ครบประโยค ทั้ง 3 ขั้นตอน ให้คะแนนขั้นตอนละ 1 คะแนน

(1) หยิบกระดาษด้วยมือขวา ....

(1) พับกระดาษเป็นครึ่งแผ่น ....

(1) แล้วส่งกระดาษให้ผู้ตรวจ ....

(1) ให้ผู้ทดสอบอ่านแล้วทำตาม "หลับตา" (ข้อความอยู่ด้านหลัง) ....

(2) จงวาดภาพต่อไปนี้ให้เหมือนตัวอย่างมากที่สุด เท่าที่ท่านจะ
สามารถทำได้
(ภาพอยู่ด้านหลังและให้ผู้ถูกทดสอบดูตัวอย่างตลอดเวลาที่วาด) ....

(1) กล้วยกับส้มเหมือนกันคือผลไม้
แมวกับสุนัขเหมือนกันคือ...................... ....
(เป็นสัตว์, เป็นสิ่งมีชีวิต)

3.6. RECALL (3 คะแนน)

สิ่งของ 3 อย่างที่บอกให้จำเมื่อสักครู่ มีอะไรบ้าง

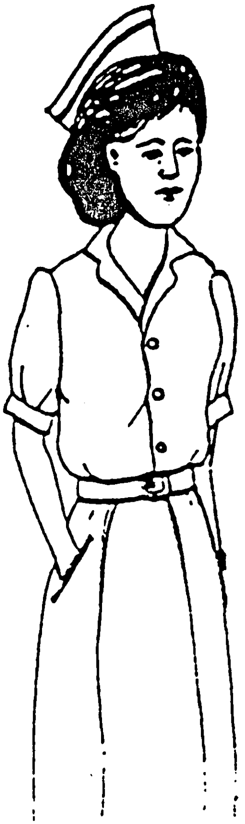
(1) ต้นไม้ ....

(1) รถยนต์ ....

(1) มือ ....

รวม ....

"หลับตา"



4. แบบทดสอบพฤติกรรม (BEHAVIOUR RATING SCALE) จากแบบทดสอบ CLIFTON สำหรับ ผู้สูงอายุ (CAPE)

กรุณาวงกลมรอบตัวเลขในแต่ละข้อที่ท่านเห็นว่าเหมาะสม

4.1. ขณะที่อาบน้ำหรือ แต่งตัว ผู้สูงอายุต้องการ:

- ไม่ต้องการความช่วยเหลือเลย	0
- ต้องการความช่วยเหลือบ้าง	1
- ต้องการความช่วยเหลือมากที่สุด	2

4.2. ขณะเดิน ผู้สูงอายุ:

- ไม่แสดงอาการอ่อนเพลีย	0
- เดินช้า แต่ไม่ต้องการความช่วยเหลือหรือใช้ไม้เท้าช่วยเ	1
- ไม่สามารถเดิน ถ้าต้องการเดินต้องใช้ไม้เท้าหรือไม้ค้ำยันหรือต้องมีคนคอยพยุงอยู่ข้างๆ	2

4.3. ผู้สูงอายุมีอาการกลั้นปัสสาวะและ/หรืออุจจาระไม่อยู่ (กลางวันหรือกลางคืน):

- ไม่เคย	0
- บางครั้ง	1
- เกือบเป็นประจำ	2

4.4. ผู้สูงอายุจะนอนอยู่บนเตียงในช่วงกลางวัน (คำว่า 'เตียง' ไม่รวมถึง เก้าอี้นอน หรือ เก้าอี้นวม และอื่นๆ

- ไม่เคย	0
- บางครั้ง	1
- เกือบเป็นประจำ	2

4.5. ผู้สูงอายุมีอาการสับสน (หลงทิศไม่สามารถหาทางเดินไปที่ต่างๆได้ สูญเสียความรู้สึกเกี่ยวกับการเป็นเจ้าของหรือการหวงแหน

- แทบจะไม่มีอาการสับสนเลย	0
- สับสนเป็นบางครั้ง	1
- แทบจะมีอาการสับสนตลอดเวลา	2

4.6. ถ้าปล่อยให้ผู้สูงอายุแต่งตัวเอง ผลปรากฏว่า (เสื้อผ้า และ/หรือ ทรงผม):

- เป็นระเบียบเรียบร้อยดี	0
- ไม่เป็นระเบียบเรียบร้อยเป็นบางครั้ง	1
- แทบจะไม่เป็นระเบียบเรียบร้อยอยู่ตลอดเวลา	2

4.7. ถ้าปล่อยให้ออกไปข้างนอก ท่านผู้สูงอายุจะ:

- ไม่ต้องการคนดูแล	0
- ต้องการคนดูแลเป็นบางครั้ง	1
- ต้องการคนดูแลตลอดเวลา	2

4.8. ท่านผู้สูงอายุช่วยทำงานในบ้านบ้างหรือเปล่า?

- ช่วยอยู่เสมอ	0
- ช่วยเป็นบางครั้ง	1
- ไม่เคยช่วยเลย	2

4.9. ท่านผู้สูงอายุมักจะไม่อยู่เฉยๆ จะสร้างหรือทำกิจกรรมที่เป็นประโยชน์ (ทำงาน อ่านหนังสือ เล่นเกมส์ มีงานอดิเรก และอื่นๆ):

- ส่วนมากจะไม่อยู่เฉยๆ	0
- อยู่เฉยๆเป็นบางครั้ง	1
- ส่วนมากจะไม่ทำอะไรเลย	2

4.10. ผู้สูงอายุคบหาสมาคมกับผู้อื่น:

- สร้างความสัมพันธ์ที่ดีกับผู้อื่น	0
- มีความยากลำบากบ้างในการสร้างความสัมพันธ์ที่ดีกับผู้อื่น	1
- มีความยากลำบากมากในการสร้างความสัมพันธ์ที่ดีกับผู้อื่น	2

4.11. ผู้สูงอายุเต็มใจที่จะทำตามคำแนะนำหรือทำตามคำขอร้อง:

- จะทำตามเป็นประจำ	0
- ทำตามเป็นบางครั้ง	1
- ส่วนมากจะไม่ทำตาม	2

4.12. ผู้สูงอายุเข้าใจในสิ่งที่คุณสื่อสารกับท่าน (คุณอาจจะพูด เขียน หรือแสดงท่าทาง):

- เข้าใจเกือบทุกอย่างที่ท่านสื่อสาร	0
- มีความไม่เข้าใจเป็นบางครั้ง หรือมีความยากแก่การเข้าใจบ้าง	1
- เกือบจะไม่เข้าใจเลย	2

4.13. ผู้สูงอายุใช้การสื่อสารด้วยกริยาท่าทางต่างๆ (โดยการพูด เขียน หรือแสดงท่าทาง):

-เป็นการช่วยให้ผู้สูงอายุเข้าใจดีขึ้นตลอดเวลา	0
-สามารถทำให้เข้าใจได้บางครั้งหรือมีความยากแก่การเข้าใจบ้าง	1
- ไม่ค่อยเข้าใจหรือไม่เข้าใจเลยไม่ว่าอะไรก็ตาม	2

4.14. ผู้สูงอายุคัดค้านหรือต่อต้านผู้อื่นในช่วงตอนกลางวัน (ส่งเสียงดังตลอดเวลา ฉีกดึงเครื่องเฟอร์นิเจอร์ ยุ่งกับเรื่องของคนอื่นๆ):

- น้อยมากหรือไม่เคยเลย	0
- เป็นบางครั้ง	1
- บ่อยๆ	2

4.15. ผู้สูงอายุคัดค้านหรือต่อต้านผู้อื่นในช่วงตอนกลางคืน (ส่งเสียงดังตลอดเวลา ฉีกดึงเครื่องเฟอร์นิเจอร์ ยุ่งกับเรื่องของคนอื่นๆ):

- น้อยมากหรือไม่เคยเลย	0
- เป็นบางครั้ง	1
- เป็นประจำ	2

4.16. ผู้สูงอายุกล่าวหาว่ามีคนจะมาทำร้ายหรือจะขโมยทรัพย์สมบัติส่วนตัว ถ้าคุณแน่ใจว่าการกล่าวหานั้นมีมูลความจริงให้คะแนนเท่ากับ 0 และ 1, 2 ตามลำดับ :

- ไม่เคยเลย	0
- เป็นบางครั้ง	1
- เป็นประจำ	2

4.17. ผู้สูงอายุสะสมสิ่งต่างๆที่ไม่มีค่าหรือความหมาย (เศษกระดาษ เหล็กหรือโลหะ เศษอาหาร และอื่นๆ):

- ไม่เคยเลย	0
- เป็นบางครั้ง	1
- เป็นประจำ	2

4.18. ลักษณะการนอนของผู้สูงอายุในช่วงตอนกลางคืน:

- แทบจะไม่ตื่นเลยตลอดทั้งคืน	0
- ตื่นในช่วงตอนกลางคืนเป็นบางครั้ง	1
- ตื่นในช่วงตอนกลางคืนบ่อย ๆ	2

สายตา	- มองเห็น (หรือสามารถมองเห็นโดยสวมแว่นสายตา) - มองไม่ค่อยเห็น - มองไม่เห็นเลยหรือตาบอด
การได้ยิน	- ได้ยินชัดเจนโดยไม่ต้องใช้เครื่องช่วยฟัง - ได้ยินชัดเจนโดยใช้เครื่องช่วยฟัง - ได้ยินแม้ว่ามีปัญหารบกวนในการสนทนาบ้าง (หูตึง) - หูหนวก

ให้คะแนน โดย...

วันที่...

Appendix III. Public Welfare and Social Services for Elderly people in Thailand

A. Public Welfare for Elderly People *

	Region
1. Bangkae Home for the Aged 81 Petkasem Road, Moo. 15, Bangwai, Bangkok, 10160 Tel: (02) 413-1140-1 Fax: (02) 4131140	Central
2. Din-Deang Social Service Centre for the Elderly 4641 Mitrmaitree Road, Din-Deang, Huay Kwang, Bangkok, 10400 Tel. (02) 246-1942 Fax: (02) 2455191	Central
3. Nakhon Pathom Home for the Aged Moo 5, Tumbon Samamchan, Muang, Nakhon Pathom, 73000 Tel: (034) 255102	Central
4. Thammapakorn Home for the Aged 1 Moonmuang Road, Muang, Chiang Mai, 50000 Tel : (053) 278573	Northern
5. Bao Kaew Home for the Aged 92 Moo 3, Tumbon Nicom Kaobaokaew, Payukhkiri, Nakhon Sawan, 60130 Tel: (056) 221503 Ext. 529	Northern
6. Thammapakorn Poeklang Home for the Aged 583 Poeklang Road, Muang, Nakhon Ratchasima, 30000 Tel: (044) 242521 Fax: (044) 244300	North-eastern

7. Maha Sarakham Home for the Aged — North-eastern
   277, Moo 8,
   Maha Sarakham-Vapeepratum Road,
   Tumbon Nongwangnang, Muang,
   Maha Sarakham, 44000
   Tel: (043) 721524

8. Banglamung Home for the Aged — Eastern
   Tumbon Rongpo, Banglamung,
   Chon Buri, 20150
   Tel: (038) 241121
   Fax: (038) 241759

9. Chanthaburi Home for the Aged — Eastern
   54/5 Moo 4,
   Tumbon Tungbenja, Ta Mai,
   Chanthaburi, 22170
   Tel: (039) 321601, 321959, 321630 Ext. 009

10. Tuxsin Home for the Aged — Southern
    62 Sukyang Road,
    Tumbon Satang, Muang,
    Yala, 95000
    Tel: (073) 212904

11. Aoutong-Panangtuk Home for the Aged — Southern
    44/1 Moo 4,
    Tumbon Nachaung, Muang,
    Chumphon, 86000
    Tel: (077) 503464

B. Non Government Organisation for help for elderly people *

1. Senior Citizen Association of Thailand
   4641 Mitrmaitree Road,
   Din-Deang, Huay Kwang,
   Bangkok, 10400
   Tel. (02) 246-3246

2. Society of St. Vincent DePoul in Thailand
   57 Trok Orientent, Bangruk,
   Bangkok,
   Tel: (02) 2332976

3. Jong Hua Foundation for Destitute Elderly People
   184 Nipatutit 3 Road,
   Hat Yai District,
   Songkhla, 90110

4. HelpAge International
   Asia Training Centre on Ageing (ATCOA),
   Faculty of Nursing,
   Chiang Mai University,
   Chiang Mai, 50200,
   Tel. (053) 221-294, 221-122 Ext. 5045
   Fax: (053) 221-294, 217-145

5. Prachanukul Foundation
   327 Voradeth Road,
   Tumbon Narmuang, Muang,
   Ratchaburi, 70000
   Tel: 337037, 337057

6. Northern Social Welfare for Elderly People Foundation
   Northern Social Welfare for Elderly People,
   Chiang Mai, 50000
   Tel: (053) 214573

C. Health care services for elderly people from the private sector

1. Golden Years Nursing Home,
   55/3 Suitthisan Road, Huay Kwang,
   Bangkok, 10310
   Tel: (02) 693-0733-40
   Fax: (02) 2755295.

2. Care West Health Services
   Care West Home Support Division,
   758/4 Soi Sukhumvit 30/1,
   Sukhumvit Road,
   Bangkok, 10110
   Tel: (02) 258-9385, 258-5383, 259-2460-1

3. Klaoynumthai Hospital 2 (Gerontological Hospital)
   27 Sukhumvit 68,
   Bangna, Phakakhong,
   Bangkok, 10260
   Tel: (02) 393-0883, 393-3418, 399-4259-63

*** Source: Department of Public Welfare, Ministry of Interior (1994)**