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MASTER THESIS

Coping Strategies in Care Giving for Spouse with Dementia

A Comparative Social Study in Norway and Hong Kong

“How Do Different Cultural Contexts Affect Spousal Caregivers Coping Experiences?”

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ABSTRACT

People live longer and an increasing of prevalence rate of dementia takes place in most developed countries as a result. The responsibility of care giving for the people with dementia lies mostly on the family and then the government. Since there are a lot of studies about the impact of this disease on the people with dementia and their families done by health professionals mainly in Western countries, but there is not any comparative social study with a cross-cultural perspective done by international social work profession on this domain, therefore, in this study I have chosen to investigate and compare the coping experiences of spousal caregivers for people with dementia in Norway and Hong Kong. This study will try to provide an understanding of how the different social and cultural contexts may affect the coping experiences in response to care giving of spousal caregivers for people with dementia. The empirical data of the study is collected by applying semi-structured in-depth interviews with seven spousal caregivers, three in Norway and four in Hong Kong respectively. By applying interpersonal relation approach of system theory and strengths perspective in analysis, the findings of this study show that though both Norwegian and Chinese respondents have encountered a number of challenges of changes, the coping process is neutral and allows for positive aspects of caring to be considered along with grief and frustration. Couple relation, in spite of the difference between intimate level in the case of Norway and plain level in the case of Hong Kong, is the key driving strength of all the respondents in this study for taking up the role of caregiver for a spouse with dementia. Despite the challenges, coping with emotional support from family members and receiving the social services of day care center or institutional care, the adaption in their marital life has been slightly positive developed by the help of both informal and formal caring systems. As a result, the respondents have managed to maintain their quality of life as they can have a balance aging life with having time to take care of their own health and free time to do for their own well-being.

Key words: *Dementia, spousal caregivers, cultural context, couple relation & social support*

Chapter 1 Introduction

This study is about to explore and understand how different social and cultural contexts affecting the coping experiences in care giving for spouse with dementia in Norway and Hong Kong. By doing it, this study is to investigate and compare the similarities and differences in respect of their coping patterns and social support seeking behavior of the spousal caregivers of people with dementia concerning the systematic analysis of phenomena in two different social and cultural contexts, i.e. Norway and Hong Kong.

Because of a strong increase in life expectancy in the current demographic context, the epidemiological picture is characterized by a prevalence of chronic diseases and non-specific illness syndromes like dementia. Many people with dementia live with and/or are cared for, in part or entirely, by their families. Thousands of people find that they have to take care of their elderly relatives who can no longer remember where they are or what day it is, who has difficulty in speaking, and whose forgetfulness leads to the need for helping managing the activities of their daily living. (Almberg et al. 1997)

Schulz & Martire (2004) state that although no standard definition of family care giving exists, there is a general consensus that family care giving involves the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Care giving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable, and are psychologically stressful and physically exhausting.

In general, most of older people with dementia receive assistance from their spouse, but when the spouse is no longer alive or is unavailable to provide assistance; adult children usually step in to help. Adult daughters and daughter-in-law are more likely than sons and sons-in-law to provide routine assistance with household chores and personal care over long periods of time, and they also spend more hours per week in providing assistance. Family care giving for peoples with dementia is a stressful task. Although care giving tasks are sometimes divided among several family members or friends, the more typical scenario is that most care is provided by one individual (Schulz & Martire 2004). It is obviously that closer kinship between the caregiver and the person with dementia imposes a heavier burden. In America,

most of Alzheimer's disease caregivers stated that they frequently experienced high levels of stress and almost half reported that they suffered from depression.¹

1.1 What is Dementia or Alzheimer's Disease (AD)?

Dementia is a name from Latin, originally meaning "madness": de - "without" and ment -the root of mens - "mind". Dementia is commonly called "senility".² Dementia is not a necessary part of aging, but its prevalence increases with age. Dementia refers to a loss of mental functions in two or more areas, such as language, memory, visual and spatial abilities, and judgement, to the extent that the person's daily life is affected. Alzheimer's disease was first described by Dr. Alois Alzheimer, a German Psychiatrist and neuropathologist in 1906 and the disease was named after him since then. Alzheimer's disease is originally described as a pre-senile dementia, which can occur before the age of 65, caused by small strokes in the brain (Orford, 1987). The most common type has been termed "senile dementia of the Alzheimer's type which has the appearance of abnormal structures in the brain such as plaques and tangles. Peoples with dementia have significantly impaired intellectual functioning in solving problems and maintain emotional control. All these may cause them experience personality changes and behavioural problems such as agitation, delusion and hallucination which interferes their normal activities and relationships. Therefore, dementia is not a single disease, but rather a non-specific illness syndrome i.e., set of signs and symptoms which affect regions of short term memory, cognition, attention, language and problem solving and long term memory in the brain.

In the book (Ballenger, 2006), the author has explored the significance of dementia as a major health issue and the emergence of gerontology as a science to describe normal aging and distinguish it from disease. In addition, how psychiatry approaches the treatment of senility and following scientific attempting to understand the brain pathology of dementia is illustrated in the book. In short, dementia is a serious loss of cognitive ability in a person beyond what might be simply mistaken as an inevitable part of normal aging process.

(Saleebey, 2006) advocates us to be sensitive to our language use, particularly in our description of individual's perceived capacities and deficits. Based on this reason, the term of

¹ www.aboutalz.org

² From Wikipedia, the free encyclopaedia

‘people with dementia’ rather than ‘dementia patient’ will be used in this study to show our respect to the people who is suffered with this disease.

1.2 Double Role: Spouse and Caregiver

Family relationship basically starts between two persons and therefore marital relationship is a primary relationship for many adults. When a person is diagnosed with dementia, information on the symptoms and treatment of dementia may be provided by medical professionals to the family members. It can be realized that a tough road lies ahead in terms of the loss of mental and physical capacity of the patient with dementia. The early stages of dementia may present relatively few problems for caregivers. Progression of this disease through mild to moderate and then to severe stages can occur over a period of five to fifteen years.³ It may happen that the patients also suffer with other types of illness besides dementia, for example, heart disease, high blood pressure, lung problem, diabetes or other impairments. As the condition progresses, the challenges of care giving are likely to become more acute and demanding in terms of time and commitment from the caregivers.

Care giving responsibility causes a difficult adjustment period for what begins as a part-time role and could become “an unexpected career” of a spouse. The physical, psychological, financial, and social relational impact of care giving for patients with dementia have been explored in many studies (Thommessen et al., 2002), (Nordtug, 2003), (Adams & Sanders, 2004) and (Gruffydd & Randle 2006). A number of psychosocial consequences of care giving have been identified, i.e. isolation, loneliness, disappointment, anger, uncertainty and lacking of knowledge regarding dementia and its management. Furthermore, caregivers fail to utilize available services appropriately and thus gain little benefit from their presence with some psychological and practical reasons (Brodaty et al. 2005). Spouse has also been found to be less willing than children or siblings to consider institutional care for the people with dementia.

1.3 Motivation of the study

Direct personal experience is always a good starting point of a research. Fortunately, I do not have direct personal experience of this disease; but my uncle, my father’s younger brother, died of dementia eleven years ago. Being his wife, my aunt had been the main caregiver of

³ www.medicinenet.com/dementia/article.htm

him after he got diagnosis of this disease. Though I did not have chance to talk with her about her feelings and experiences, I could imagine that the death of my uncle was both her big lost and relief as she lost both her husband and her caregiver role at the same time.

Besides, working as a substitute personal-care worker in an elderly home for five and a half years at Bodø in Norway, I regard myself as a formal caregiver (paid worker) dealing with the care giving for residents with dementia. On job, I have also the chance to have direct contact with their spouses when they come to visit them. These contacts encourage me as a social work student to develop a learning interest in exploring their perceptions and experiences of being a spouse of people with dementia. In spite of having no medical educational background, I can understand that there is no clinical treatment can cure dementia so far. Therefore, a strong motivation for learning has been developed as I regard it is very meaningful to study how a spouse as an informal caregiver to cope with living as well as care giving for people with dementia at home.

Furthermore, research is critical in the area of dementia, and such research must not be restricted to the medical professions. Social work research is essential in order to further understand the variations in the experiences of both the individual with the illness and the caregiver. It is only through good research that effective interventions can be designed. Parallel to the bio-medical research being conducted on dementia, I regard social work research is essential to ensure the highest quality of life for those affected. Until both prevention and cures of this disease are found, all types of study and research are crucial.

1.4 Purpose of Comparative Study

Being a student of this program “*Master in Social Work - with a Comparative Perspective*” in the University of Nordland in Norway, I realize that it is challenging to do a comparative social study on one phenomenon in two different cultural contexts. I believe that I am capable to do this comparative social study in Norway and Hong Kong where I am familiar with in terms of social and cultural aspect rather than the other countries’. Though I was born and grew up in Hong Kong, after I had married with a Norwegian, I moved to live in Norway twelve years ago.

Learning by doing and practicing the skills of conducting a comparative social study is the main purpose for doing this study. Furthermore, I attempt to strengthen my master's thesis when I compare the findings of this study with those from relevant published research. Like the vast majority of students undertake their empirical thesis, I regard this study will enable me to explore and understand what families with dementia are facing by reading a lot of relevant literature and gain hands-on research and data analysis experience both in Norway and Hong Kong. Hopefully, the experience of doing this study will be helpful and useful for my future employment and career in social work field dealing with families with dementia especially working with the spousal caregivers.

1.5 Norway & Hong Kong

The following is some basic information about Norway and Hong Kong. Norway is a Scandinavian country with about five million inhabitants while Hong Kong is a city, with about seven million inhabitants, being a special administrative region situated at Canton province in the southern part of China. The area of Hong Kong is about 1, 100 square kilometer which is almost the same size as Bodø municipality in Norway actually. Therefore, Hong Kong is one of the most densely populated cities in the world.

About the cultural aspect, Norway is an individualistic society in which personal satisfaction and self-fulfillment are preferred while Hong Kong is a Chinese collectivistic society in which interpersonal harmony is highly emphasized comparatively. In Hong Kong, when a man gets married with a woman officially or in the church, then they become spouses to each other legally. On the other hand in Norway, instead of getting married legally, cohabitation is much more common in Norway than in Hong Kong. Furthermore, the rate of divorce or separation is higher in Norway than in Hong Kong. Most often when two individuals establish another new marriage or cohabitation, then they and their own children will enter into a step-family relationship as a result. Therefore, there are more step-families in Norway than in Hong Kong comparatively. The concepts of "family" and "family bonding" may be perceived and interpreted very differently in Norwegian culture and in Chinese culture.

About the social policy aspect, Norway is a welfare state which is a social democratic society and the provision of welfare is state based with universal citizenship right while Hong Kong is not a welfare society. Under the previous English colonial influence, the social policy of

Hong Kong is more or less like English system which is a liberal and the provision of social services is minimal and selective provision while the social security system is only for the weakest and poorest.

About the age of retirement in general case, it is 67 years old (earliest 62 years old) in Norway while it is 60 years old in Hong Kong. In Norway, after retirement the residents can have their pension from the state. But in Hong Kong, a central pension system is only in governmental sector for civil servants. Otherwise, there is a compulsory saving scheme for the retirement of the general residents, i.e. The Mandatory Provident Fund for the employees and their employers contributing monthly to the scheme according to their salaries and the period of employment. As one of the world's leading international financial centers, Hong Kong has a major capitalist service economy characterized by low taxation and free trade. The tax level of Norway is much higher than of Hong Kong comparatively.

From the data of statistics, it shows that there is a similarity of life expectancy between Norway and Hong Kong i.e. 78 years for male and 82 years for female. Surprisingly, there are almost about the same amount of 70,000 people are living with dementia both in Norway and in Hong Kong which make the prevalence rate of this disease be 1.4 % of total population in Norway and 1 % of the total population in Hong Kong respectively as a result. According to both Norwegian and Chinese culture, dementia may be associated with normal aging and disability, spouses often repeat part of their marriage vows by saying that they have promised to love and honour each other in sickness and in health.

About the public awareness of the knowledge about dementia, two incidents took place in 2009, one in Norway and one in Hong Kong might have effect on it. The one in Norway was about Mr. Jan Henry T. Olsen, a former Fishery Minister of Norway, got diagnosis of Alzheimer's disease. He and his wife travelled around Norway and shared their experiences with the public by holding seminars and wrote a book together: "Skynd Deg å Elske" (Lanes & Olsen, 2009). The one in Hong Kong was about Sir Charles Kuen Kao, a Hong Kong scientist, won The Nobel Prize in Physics in 2009 because the contribution of his study concerning the transmission of light in fibres for optical communication. He is suffered with dementia. He and his wife moved to live in American many years ago. After he had got the Nobel Prize, they visited Hong Kong for being interviewed by the mass media for sharing their story about how they had been living with dementia together. In order to advocate

enhancing knowledge about dementia, they donated a part of the money from the Nobel Prize to set up a Dementia Fund for helping the people with dementia and their families in Hong Kong.

Being famous figures, both Mr. Olsen and Sir Kao have given an important and clear message to the public that everybody has the possibility to suffer with dementia. Most of all, they have their spouse always be with them for supporting them and sharing with them both happiness and sadness whatever they have come across.

1.6 Research Question

Development, like social work helping individuals, is not a neutral activity when we have the insight and ability to step outside from our own point of view and to view international situations through a cultural lens and to approach them with humility (Gray 2005). Therefore, it is important to develop a critical understanding of the way in which international development works.

This study is about to explore, identify and compare the similarities and differences of coping experiences of spousal caregivers in care giving for people with dementia in relation to their own well being in Norway and Hong Kong. In fact, coping is a process in which how the spousal caregivers perceive the change in their role and self identity in their marital relationship when they have to take up the role of caregiver for their spouse with dementia. As Norway and Hong Kong are two different social and cultural societies, I suppose that ethnicity could be differentially associated with psychological outcomes as well as with care giving stressors, appraisals, coping patterns and coping resources. However, with a strong belief in the strength of interpersonal love which can enhance people to be an effective change agent in their living environment, a main research question of this study is set up like this:

“How Do Different Cultural Contexts Affect Spousal Caregivers Coping Experiences?”

Doing comparative study requires careful thought about sampling. In addressing the research question, the understanding of processes is more important than obtaining a representative sample of the respondent population. This can be best achieved by in-depth interviews of a small sample.

Therefore, the sample of this study was supposed to be eight respondents, four in Norway and four in Hong Kong respectively. They were recruited through local dementia association in Norway and Hong Kong. The study applied an in-depth interview method with a semi-structured interview guide including a set of open-ended questions to collect the empirical data of the coping experiences in care giving for spouse with dementia.

To sum up, this study intended to answer the research question through the perspectives of the spousal caregivers by plunging in depth into their inner worlds and exploring their marital life providing a means of understanding their coping experiences in care giving for spouse with dementia. By applying cross-cultural perspective, the analysis will focus on the similarities and differences of the coping patterns of spousal caregivers in relation to their perceived well-being in two different social and cultural contexts.

1.7 Organization of the Thesis

This study, about a comparison of coping experiences of care giving for spouse with dementia in Norway and Hong Kong, is structured in the six following chapters. Chapter 2 is a review of the relevant literature on the coping experiences in family care giving for people with dementia. A model of conceptual framework with six major concepts, i.e. knowledge about dementia, acceptance of caregiver role, pre-morbid couple intimacy, family functioning, social support and coping experiences will be presented in Chapter 3. Methodology issues about the research and the explanation how the study has been conducted is arranged presenting in Chapter 4 which also sheds light on how the research has been designed for data collecting and analysing. Ethic issues relating to validity, reliability of the study will be discussed in the chapter as well. The data collected in the field visits will be presented in Chapter 5. The analysis of empirical data collected from the interview conduction related to the respondents coping experiences will be presented in Chapter 6. It is a report on the findings of the study about a comparison on the relationship between their coping patterns and social support experiences in care giving for spouse with dementia and their perceived health conditions of spousal caregivers in two different social and cultural contexts; Norway and Hong Kong respectively. Conclusion and discussion will be presented in Chapter 7 which summarizes the main findings of this study and also provides suggestions to the helping professionals, especially social workers dealing with the families with dementia in general and further study on this topic.

Chapter 2 Literature Review

With the help by using electronic information technology, all kinds of the fact data materials of previous research can be located easily on the internet. There are hundreds of research study done by mainly Western countries in USA and Europe about the impact of dementia on the patients and their family life including marital relationship aspect. As long as this study is focused on the coping experiences in care giving for spouse with dementia, a review on the relevant literature and existing debates is a must. In order to find the data which is relevant and helpful to address the research question of this study, a careful searching as well as scanning process for the relevant literature is an important task to be done before the relevant data being located properly.

In this chapter, an understanding of how the spousal caregivers perceive the impact of dementia on the quality of their marital life and their perceived stress/burden in care giving for spouse with dementia will be presented. Relating to how the caregivers cope with care giving for spouse with dementia and some relevant aspects factors i.e. quality of life, family functioning and social support and coping patterns will be presented and discussed in follow. Moreover, a review of the literature related to the comparison between the coping experiences in family care giving for people with dementia among different races, ethnicities, religions and cultures, i.e. mainly in USA and Europe, will also be presented in this chapter.

2.1 Impact of Dementia on Quality of Life

As mentioned earlier that dementia is a serious loss of cognitive ability in a person beyond what might be simply mistaken as an inevitable part of normal aging process. When a person is suffered with dementia which means the loss of mental and physical capacity while the area of memory, cognition, attention, language and problem solving in the brain of that person are affected. In other words, the person with dementia is no longer as the same person as before. The influence of interpersonal and social factors on deficit identification is considered by Smyth et al. (2002) having impact on understanding quality of life (QoL) in dementia. They emphasise that the failure to identify deficits leads to conflict over maintaining former social roles and detrimental social interactions between the person with dementia and those in his/her environment. The loss of the ability of affected person will cause a big change in the quality of their marital life both for that person with dementia and the spouse problematically as a

result. Some more data materials of the previous studies, about how the family caregivers perceive their quality of life in care giving for persons with dementia have been located.

According to the study of Coen et al. (2002), individual QoL can be suitably measured only by determining the opinions of the individuals concerned. The finding of their study regarding spousal caregivers' individual perceptions of those factors they considered to be the major determinants of their QoL are the level of satisfaction with marriage and the level of satisfaction with "time for self".

In order to enhance the quality of life of dementia caregivers from different ethnic or racial groups, Belle et al. (2006) state that family care giving for people with dementia is characterized by several challenges that seriously compromise the QoL for millions of family members in the United States. The caring for a family member with dementia is extremely stressful, contributes to psychiatric and physical illness among caregivers, and even increases the risk for caregiver death. In their study, the QoL of family caregivers is measured by the indicators of depression, burden, social support and self-care and problem behaviours of patient.

Furthermore, the study of Vellone et al. (2012) regards QoL as a principle outcome of health interventions and as a combination of physical functioning, work, socioeconomic status, support network, housing, income, self-esteem, life satisfaction, lack of stress and burden, happiness, meaning of life and health. In their study exploring the meaning of QoL for Sardinian caregivers of people with dementia in Italy, four themes of QoL are extracted from the respondents, i.e. unity and cooperation in the family; freedom, independence, having time for themselves, serenity/tranquillity (in peace with oneself and others); well-being and health. Besides, there are two themes emerged from factors that respondents of the study thought worsened their QoL, i.e. fear for the future – for the care needed and for the illness worsening; and continuous care of the patients – not having time for themselves.

To sum up the finding of their study, there are six themes regarded helping to improve their QoL by the respondents. First of all, despite of the awareness of illness progression, they hoped the illness would not worsen. Second was the help and support given by family as a factor improving their QoL. Third, the majority of caregivers said that their QoL would be improved if they received more help from formal services. Fourth, almost all respondents felt

satisfaction and reward from care giving, which they noted improved their QoL as they felt they were doing the best thing for the patient and were happy when seeing the patient serene because of the care they received. Fifth, more free time was a factor respondents identified as improving their QoL as they would like to dedicate time to do their favourable activities. Finally, the majority respondents noted that most people lack knowledge about dementia in general. Therefore, they felt not understood by others, isolated and abandoned.

2.2 Stress /Burden in Care Giving

Lazarus & Folkman (1984) state that there are always three existences when we talk about stress or burden in general sense, i.e. the stressor - the source of the stress; the person who is facing the stressor; and the stress or burden being perceived or felt by that person. In the case of care giving for spouse with dementia, there are many stressors from various sources or of different causes not under control to happen which are the events that cause the spousal caregiver feel stressed, e.g. the behavioural problems of spouse with dementia, lacking time for self, dissatisfaction with insufficient social support from other family members in care giving and economical problems etc. as mentioned earlier.

An American study, Pratt et al. (1985) found out that caregiver burden levels were significantly related to caregiver health status while all their respondents reported that care giving had a negative impact on their health status. Another American study, Deimling et al. (2001) examined the relationship between dementia and their effects on family caregivers found out that cognitive incapacity had a less important direct effect on care giving stress than disruptive behavior and impaired social functioning. However, it showed that cognitive incapacity having an important indirect effect through its influence on disruptive behavior and impaired social functioning. For example, it was not loss of memory that is problematic; it was the inability to remember to turn off the stove, and the hazard of consequence that in turn created was a problem (Orford, 1987).

Another American study, Kiecolt-Glaser et al. (1987) investigated possible health-related consequences of a long-term stressor; they took blood samples for immunologic and nutritional analyses and psychological data from family caregivers of people with dementia and socio-demographically matched comparison subjects. The result showed that family caregivers of patients with dementia were more distressed than comparison subjects without

similar responsibilities. Greater impairment in the patients with dementia was associated with greater distress and loneliness in caregivers. It showed that chronically stressed family caregivers of patients with dementia did not show immunologic or psychological adaptation to the level of their well-matched age peers.

According to the study of Chou (2000), burden is one of the most commonly variables being used in care giving research, both as a predictor and as an outcome. And the burden resulting from care giving can generate burden in several life domains of the caregiver: physical, psychological, social, spiritual and financial. Once the caregiver's resources are not adequate to meet the care giving demands, the caregiver may experience overload and it may result as a burden. However, the caregiver may not perceive all of the dimensions at one time.

In a Norwegian study of Thommessen et al. (2002), there are four most frequent problems are reported by elderly spousal caregivers, i.e. disorganization of household routines, difficulties with going away on holidays, constraints on social life and the disturbance of sleep. From the finding of their study, the psychosocial burden on elderly spousal caregivers can be categorised into three items: personal distress experienced by the caregivers in relation to their elderly spouse; life upset resulting from taking care of their elderly spouse, and negative feelings towards the elderly spouse with dementia.

Another study, Adams & Sanders (2004) found out that there are different emotional tasks with loss and grief reactions experienced by caregivers as the dementia progresses. Many care givers in the early stage are still hopeful and do not acknowledge grieving. Others who are grieving noted changes in communication with their loved one or losses of the activities they could enjoy together. Worries about future changes and the exchange of roles that occurs with increased dependency of the person with progressive dementia also marked responses of those in the early stage of care giving. It would appear that in the early and middle stages, caregivers undergo feelings of being burdened and overwhelmed, that may relate to their losses and stress levels. Some do not acknowledge feeling grief, perhaps because the worst problems have not come yet, and perhaps because they are feeling anger or self-pit that they are ashamed to discuss. Those in the middle stage focused on their own losses of freedom and mobility, loss of opportunities to socialize, independent activities, and threats to their health. Those in the late stage in their study have even higher levels of reported grief and depressive symptoms, but qualitatively their response are somewhat different as they are thinking about

the loss of the loved one whom they once knew more than about their personal stress. Their mood resembles bereavement with less ambivalence towards the dementia sufferer who by that time is often quite helpless.

The study of Gruffydd & Randle (2006) in England identifies a number of psychosocial consequences of caring including isolation, feelings of guilt, loneliness and uncertainty while those respondents have a distinct lack of knowledge regarding dementia and its management. All of respondents perceived their care giving experiences as “problematic” and they suffer negative psychosocial effects as a result. There are four themes emerged from the findings of their study: “Changes”, “not knowing”, “dealing with behavioural problem” and “fallout”. All respondents struggled to gain confirmation of their spouses’ diagnosis, and typically noted that they actively dismissed the changes that they had identified as being a consequence of old age. Family and friends also provided this rationale. After diagnosis, care givers perceived that healthcare professionals provided little support to them who regarded themselves were largely ill equipped with the knowledge and skills that could have helped their spouse and themselves. All found it difficult to cope with behavioural problems and many experienced negative physical and psychosocial effects, which were considered to the impact of the disease and their care giver role as well.

In the study of Campbell et al. (2008), caregiver burden is regarded as a key measure in caregiver research and is frequently used as a baseline measure in intervention studies. According to the findings of their study, the caregiver burden is accounted on the quality of relationship between carer and patient, the patient’s cognitive ability, behavioural and psychological symptoms displayed by the patient, adverse life events experience, caregiver gender, caregivers’ level of neuroticism, caregiver role captivity and the level of caregiver confidence.

About the characteristics of caregiver, the study of Eters et al. (2008) in American found out that wife experienced higher levels of caring burden compared to other family members. By their literature review, they coded some studies showing that female caregivers tend to report more health problems and depressive symptoms than male caregivers though some other studies have found no gender effect on global measures of caring burden. Gender has an influence on kinship roles, perceptions and experience of caring burden. Male caregivers were found to experience a lack of positive outlook and a need for social support while female

caregivers reported increased caring burden in their relationships with other family members as well as an increase in their own health problems.

About the review of study on burden experienced by caregiver of people with dementia, there are two others being located. The first one is the study of Chou et al. (2002). They regard the assessment of burden has become a challenging task for most researchers because cultural, ethical, religious, and other personal values may influence perceptions of the meaning and consequences of burden. From 1985 to 1990, most researchers conceptualized burden along two dimensions: subjective burden and objective burden. Later on, researchers have broadened their view of burden and see it as a multi-dimensional construct: physical, emotional/psychological, social and financial. The three main factors related to caregiver burden found in their study are the functional limitation and disturbing behaviour of patients with dementia, and care giving self-efficacy of care givers. Their study also listed out five sub-factors loading of the caregiver burden. First is time-dependence burden, e.g. the caregiver has to watch the care-receiver all the time. Second is developmental burden, e.g. the caregivers expected that things would be different at the point in their life. Third is physical burden, e.g. the caregivers feel physically tired. Fourth is social burden, e.g. the caregivers feel resentful of other relatives who could but do not help. Finally is the emotional burden, i.e. the caregivers feel angry at their care-receiver's behaviour. The study also found out that spousal caregivers showed higher time-dependence, physical and developmental burden scores than non-spousal caregivers.

The second one is the study of Torti et al. (2004). They made a multinational review of the literature focuses on the influence of ethnic, cultural, and geographic factors on the caregivers of patients with dementia among North America, Europe and Australia, and Asia. Their findings suggested that non-cognitive, behavioural disturbances of patients with dementia result in increasing caregiver burden. Female caregivers, particularly in Asian societies, bear a particularly heavy burden across cultures. Caregiver burden influences time to medical presentation of patients with dementia, patient condition at presentation, and patient institutionalization. Moreover, interventions designed to reduce caregiver burden have been unsuccessful except the pharmacological treatments for symptoms of dementia were found to be beneficial in reducing caregiver burden.

In the study of Hooker et al. (1994), personal characteristics of caregivers formulate models of the care giving coping process which influence their health outcomes. Five types of personality: neuroticism, extraversion, openness, agreeableness and conscientiousness, and three categories of coping strategies: problem-focused, emotional-focused and social support coping were listed out in their study. The evidence of the neuroticism type caregivers tended to use emotional-focused coping while the extraversion type caregivers tended to use social support coping showed in the finding of their study. The findings of their study show that it is important to study the relationship between personality and coping in order to identify who is most at risk for psychosocial problems and who may be most successfully helped by psychosocial interventions. However, since this study is in social work on the coping experiences of caregiver, interpersonal relationship will be the focus of this study. Besides, to study the personality characteristics of caregivers in psychological aspect is far beyond the capacity and scope of this study.

In short, caregiver burden is a negative impact of care giving for spouse with dementia that worsens their quality of life as a result. In the coping process of their care giving for spouse with dementia, there are some other factors playing important roles.

2.3 Family Functioning and Social Support

Rankin et al. (2001) state that for many elderly spouse caregivers, their marriage represents the single most influential and sustained relationship in their lives. A lifetime of shared experience between the spouses helps to define and maintain their individual sense of self. As the patient's cognitive decline continues to erode their capacity to maintain an intimate relationship, the ability of the marriage to contribute to and reinforce the care giving spouse's ongoing sense of self is also affected resulting not only in a loss of relationship but also a loss of self. Their study found out that spousal caregivers reporting low marital cohesion and satisfaction endorsed significantly more depressive symptoms.

In their study of Vellone et al. (2012), they found out that the family was particularly important for caregivers for patients with dementia. Within families, poor family functioning e.g. lack of communication and mutual support, has been found to have a direct effect on caregivers' level of distress and to negatively mediate the perceived impact of providing care.

Heru et al. (2004) emphasised that assessing a family functioning might be an important factor in the care of people with dementia and their families. In their study, caregivers who reported poor family functioning had higher rating of strain and burden. Family functioning in those caregivers in their study was poorest in the dimensions of affective responsiveness, problem solving and communication but it was also impaired in roles and affective involvement.

Social support seeking is another important approach to the reduction of one's stress. Evidence of social support as a protective, moderating factor yields implications for health care. For example, emotional support provided by family members has been found to have the strongest correlation both with enhanced life satisfaction and also decreased depressive symptoms among the caregivers for people with dementia. The quality of family functioning may be more salient to Chinese than to Western caregivers as traditional Chinese value is heavily influenced by Confucianism emphasizing the importance of interconnectedness and interpersonal harmony (Au et al. 2012).

2.4 Coping Strategies in Care Giving

There are several coping strategies used by family caregivers of dementia patient in relation to their subjective sense of care giving burden. The study of Sørensen & Pinquart (2005) showed that ethnic differences in care giving outcomes might have multiple explanations. Different racial and ethnic groups may vary in the intensity of typical care giving stressors, the availability of resources and the type of coping processes they use. Furthermore, previous research studies of Western caregiver populations have reported that the use of problem-focus coping, instrumental coping strategies were associated with lower levels of depressive symptoms among caregivers while emotion-focused coping strategies were associated with poorer caregiver health. A Chinese study (Meng et al. 2006) found that family caregivers of patients with dementia used both problem-focused coping and emotional coping, i.e. acceptance had lower perceived stress than those who only used problem-focused coping.

Perry & O'Connor (2002) mention that social constructionist perspective focusing on preserving the personhood of the spouse with dementia can promote more holistic, person-centred care. Four strategies that facilitate caregivers to preserve the personhood of spouse with dementia are identified, first is maintaining continuity, e.g. thinking what the person had

been like prior to the disease's onset. Second is sustaining existing competence, e.g. focusing on the spouse's strengths rather than weakness. Third is protecting the spouse from incompetence, e.g. ensuring that the spouse feels good about her/him-self and does not perceive her/him-self to be a problem. Fourth is strategizing public encounters, e.g. positioning the spouse with dementia within a broader societal context. Each of these strategies used to achieve the goal can present both challenges and opportunities for the spouse caregiver.

2.5 Contribution of this study

In modern society, there are two parties provide the regular and daily care i.e. the immediate family and paid personnel. The family caregiver is the main informal provider. This study is about to be a contribution to a social study literature on the coping experiences of spousal caregiver for people with dementia. This study is to explore the relationship between the coping patterns applied by spousal caregivers for people with dementia and the cultural contexts in Norway and Hong Kong. By doing so, the study brings forth in discussion on the general perception and knowledge about dementia, social and cultural factors affecting the impact of dementia on the quality of marital life and the coping methods in care giving for spouse with dementia. As long as there is not any social studies done on comparison of coping experiences in care giving for spouse with dementia in Norway and Hong Kong, this study therefore will contribute knowledge on this topic by discovering the similarities and differences of coping experiences of the spousal caregivers in two different social and cultural contexts – an area not ever represented in the social study before. Moreover, the study attempts to explore the relationship between the pushing and pulling cultural factors, e.g. marital relationship, family functioning, social support and the coping patterns which may contribute to social work practice in helping families with dementia. Most of all, this study may general knowledge on the importance of the interpersonal relations for the coping in care giving for spouse with dementia which may contribute to the students and researchers by providing additional information for social work intervention in helping spousal caregivers.

Chapter 3 Conceptual Framework

The best way to get into a theoretical way of thinking about what people do and how they do it is by asking the question ‘why’. We are curious and want to know what is going on tend to be interested in ideas, theories and explanations. In this study, we want to know how the respondents cope with care giving for spouse with dementia and why they do the things they do. And there are many other questions to be answered along the study.

By keeping ‘why’ question in mind is generally a good thing to do whenever this study is considered as thoughtful and justified. Intellectual curiosity is likely to keep us alive and alert. As we can see, theories or models are particularly good things to have if we want to address the research question. They help us to understand what might be going on. Moreover, the more we are aware of the many different ways we can understand about a person, a need or an action, the more humble and less dogmatic which is no bad thing for us as researcher or social worker likely to be (Howe, 2009).

3.1 Systems Theories

Among different social theories, I regard systems theories are very useful for helping to understand the situations of respondents being spouse of people with dementia. (Healy, 2005) states that systems perspectives have had considerable influence on the formal base of social work as they can provide ways of understanding problems and issues with ‘person-in-environment’ perspective.

In systems theories, interpersonal relationships are forever being shaped and re-shaped by mutual interactions. We affect and are affected by each other. When one thing is changed, other things are end up changed that might be totally unexpected. Lying behind this approach is the idea that everything is connected, everything can affect everything else. Complex systems are made up of many parts. It is not possible to understand the whole without recognized how the component parts interact, affect and change each other. As the parts interact, they create the character and function of the whole (Howe, 2009).

Systemic analyses focus on interactions within and across multiple ‘social’ systems, which can include the interpersonal system of family bonding and friendship ties, neighbourhood

system, organizational systems, social policy systems and social structural systems. The role of these systems is emphasized in contributing to individual and community well-being.

By drawing attention to the transactions between the respondents and their social environment, their well being can only be understood in relation to whether they have ‘an integrated framework consistent within the given cultural framework; in other words, from a general systems perspective psychological pathology is considered to be socially and culturally produced rather than primarily arising from their psyche (Healy 2005). By using a general systems approach, we can understand and identify states of steadiness or balance between respondents and their social system, especially their family system. When thinking about a family system, it is helpful to think of each part, each family member in dynamic relationship with every other part or family member. Rather than think about what is taking place at the individual level, consider what is happening between people and think interpersonally and interdependently (Howe, 2009).

3.2 Strengths Perspective

In order to challenge mind-sets that regarding the respondents being spouse of people with dementia as victims, strengths perspective helps me to realize and believe that they have strengths and capacities, and they can be resourceful when pursuing their own interests. Strengths perspective not only help us see the person behind the label or the situation, but that we also recognize that the respondents have potential and strengths. It is these potential and strengths that must be recognized, acknowledged and released. It emphasises people’s innate capacity to do something about their lives (Healy, 2005).

In recognition of the power of language to ‘elevate and inspire or demoralize and destroy’, strengths perspective also has some similarities with ego-psychology concepts. Both the strengths perspective and ego psychology emphasize the links between psychological strengths, such as ego strengths, and personal resilience and resourcefulness possessed by many people living in adversity (Saleebey, 2006). Resilience is the concept that psychologists use to describe people’s ability to deal competently with risk, to overcome hazards, to continue functioning well under pressure. One of the most valuable resilience is the ability to find, sustain and enjoy good quality relationships. In other words, although many resilience factors are characteristics of the individual, just as important is the quality of people’s social

supports and relationships where we enjoy love and care, esteem and recognition. Other people can be sources of information, advice and support. There is pleasure and comfort in friendship. If good relationships enhance resilience, and resilience allows people to play to their strengths. Problem-solving, healing and ‘self-righting’ nearly always take place in the context of supportive relationships.

Saleebey (2006) emphasises that every individual, group, family, and community have strengths. These can include what people have learned about themselves, their virtues, the world in which they live, their previous ways of coping, their past successes and their talents. Therefore in this study, the capabilities, assets, commitment, hopes and dreams of respondents have to be paid attention to.

To sum up, Healy (2005) states that the strengths perspective involves besides emphasizing people capacities, it refers to a distinct set of assumptions and principles. First of all, people have strengths, capacities and resources. Secondly, people have an inclination for healing. Thirdly, people have the capacity to determine what is best for them. Based on the above assumptions, there are two principles which can be applied in this study. Firstly is to adopt an optimistic attitude with belief in people having capacities to resolve their immediate problems and to achieve quality of life on their own terms. Secondly is to focus on eliciting the full range of assets of the individual, including their personal capacities as well as resources embedded in their social networks.

Living with spouse with dementia day in and day out, the respondents know what they are facing better than anyone else and they have ideas about how life could be better. Respondents may have a surprising amount of knowledge and expertise about their lives, their relationships and how to survive though in difficult circumstances. When facing a problem, they are instinctively driven to do something about it, to ‘self-heal’. They know what is in their interest and they know what their interests are. Even when respondents have struggled in caring for spouse with dementia, they may have shown some strength. However, we must be careful to be aware of and understand that they may sometimes be vulnerable and not being full of strength and resource.

3.3 Hypothetical Model

As the research question of this study is about how different cultural contexts affect the coping experiences in care giving for spouse with dementia in Norway and Hong Kong, a

hypothetical model has been set up to provide an overall conceptual framework for how the research question can be addressed. There is a good case for having an even more relaxed view of theories or models by simply calling them ‘*ways of knowing*’ (Fook 2002). If we can make sense of what is going on, then we are half way towards knowing what to do.

According to Silverman (2010), models provide an overall framework for how we can look at reality while concepts are clearly specified ideas deriving from a particular model. As long as research question is inevitably theoretically informed, therefore, we need social theories to help us to address even quite basic issues in social research. However, theories need to be distinguished from models and concept since theories arrange sets of concepts to define and explain some phenomenon. In contrast, Bell (2010) argues that model can sometimes be used instead of or even interchangeably with theory. As long as both theories and models may be seen as explanatory devices, the latter is often characterized by the use of analogies to give a more graphic or visual representation of a particular phenomenon. Providing they are accurate and do not misrepresent the facts, I regard models can be of great help in achieving clarity and focusing on key issues.

As mentioned earlier in the chapter of literature review, many previous studies have analysed care giving for spouse with dementia by using five main concepts, i.e. burden, quality of life, family functioning, social support and coping strategy. Burden is obviously the negative outcome of coping stress related in care giving while the quality of life of spousal caregivers being affected negatively by the impact of dementia.

As the focus of this study is put on the coping experiences in care giving for spouse with dementia, therefore all the relevant factors which may have effects on coping will be considered as useful for setting up the conceptual framework of the study. Besides, as there is no certain theory can be applied to address the research question directly about how different cultural contexts affect the coping experiences in care giving for spouse with dementia in Norway and Hong Kong, a hypothetical model in *Figure 1*. see p.28, has been set up in order to provide an overall conceptual framework as an explanatory device for how to address the research question of this study instead.

This model has been combined and modified from two models. The first model is from the study of DeLongis & Holtzman (2005) about the role of stress, social support and personality

in coping. The second model is a hypothetical model of factors affecting practitioners' use of theory in Muleya (2006), a comparative study of social work intervention in Zambia and England. Furthermore, Daatland (1983) suggests that care can be studied as care systems as the interplay of care as practical tasks and as ways of constructing and reconstructing social relations while the division of tasks in care reflects a social organisation.

DeLongis & Holtzman (2005) regard personality and social relationships play important roles in almost every aspect of stress and coping. They have examined the extent to which three important contextual factors, i.e. the nature of the stressful event, the social context in which coping occurs and the personality of the person involved; influence the likelihood of engaging in certain coping strategies, as well as the effectiveness and outcomes of these coping strategies. For example, they have compared the coping of individuals across a variety of stressful situations and have found that characteristics of the stressor appear to play a particularly important role in determining coping responses. Although these contextual factors may have a direct impact on well-being, their findings suggest that when an individual is coping with stress, contextual factors often exert an indirect effect on wellbeing, by influencing the choices and effectiveness of ways of coping.

As this study is a social work research, therefore social relationships, but not personality which is a psychological term, will be used as a variable which affects the coping experiences of spousal caregivers for people with dementia.

In the hypothetical model, there are two types of strength or resource, i.e. personal strength and interpersonal resource are regarded as variables of the coping experiences of spouse caregiver for people with dementia. Personal strengths are knowledge about dementia and acceptance of caregiver role while pre-morbid spousal intimacy, family functioning and social support are regarded as interpersonal resources in the care systems.

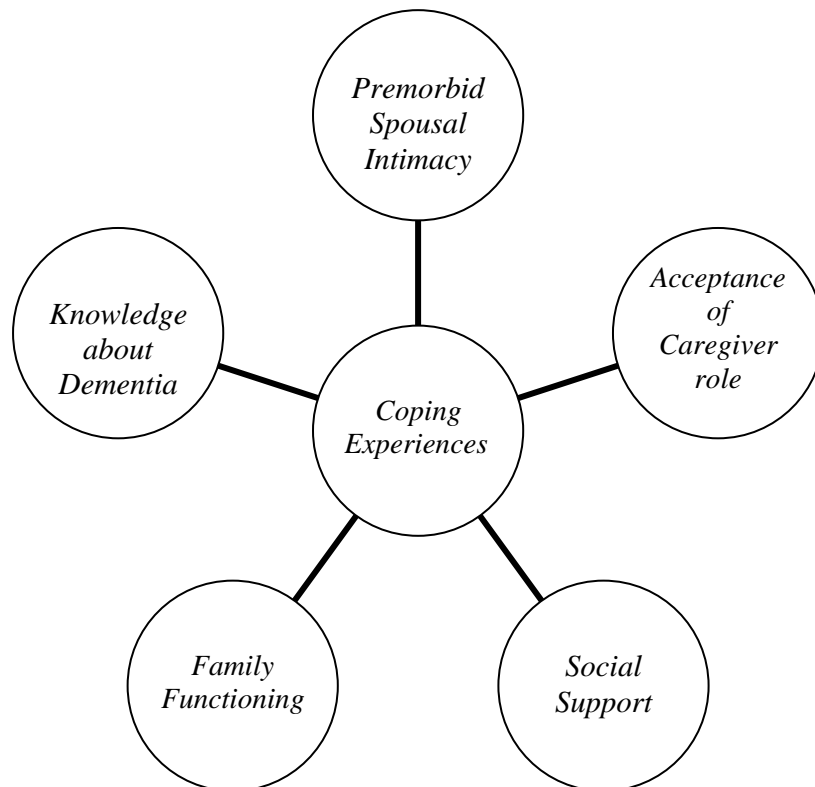


Figure 1: A hypothetical model of variables affecting coping experiences in care giving for spouse with dementia.

3.4 Knowledge and Roles

As the research question is about to explore the coping experiences of spousal caregivers for people with dementia, knowledge about dementia is a critical factor for the spousal caregiver in coping process. As the public education about dementia has not developed well in general yet, the public awareness of the early symptoms of dementia is therefore very limited.

The name of dementia may be heard by some people with an association of a normal aging process to have minor cognitive impairment. Besides being a spouse, to take up the caregiver role of a person with dementia is a question about a sense of values inherent in the rationality of caring (Waerness, 1984). Most of the care giving work still is performed on a family or private basis while most of us in our everyday life perceive as the essential values in a caring relationship.

In order to understand about roles which we are playing and taking in our daily life, some perspectives may offer us help. According to Berger & Luckmann (1967), there are two perspectives for analyzing the relationship between roles and knowledge. Firstly, the roles appear as institutional representations and mediations of the institutionally objectivised aggregates of knowledge from the perspective of the institutional order. Secondly, from the perspective of the several roles, each role carries with it a socially defined knowledge. Both perspectives, of course, point to the same global phenomenon, which is the essential dialectic of society.

The first perspective can be summed up in the proposition that society exists only as individuals are conscious of it, the second in the proposition that individual consciousness is socially determined. Narrowing this to the matter of roles, we can say that, on one hand, the institutional order is real only insofar as it is realized in performed roles and that, on the other hand, roles are representative of an institutional order that defines their character including knowledge and from which they derive their objective sense. Thus it is possible, for example, to analyze the manner in which this world view is manifested in the consciousness of an individual.

When we apply these two perspectives in this study, it is thus possible to understand the caregiver role of the respondents is taking represents the institutional order. This representation takes place on two levels. The first one is the performance of the role represents itself. For example, to engage in a marital relationship, a woman is to represent the role of a wife. The individual wife is not acting on her own, but as a spouse. Second, the role represents an entire institutional relation of conduct. The role of wife stands in relationship to other roles, e.g. mother and carer etc, the totality of which comprises the institution of a family. The wife acts as the representative of this family. Only through such representation in performed roles can the institution manifest itself in actual experience.

The institution, with its “programmed” actions, is like the unwritten words of a drama. The realization of the drama depends upon the reiterated performance of its prescribed roles by living actors. The actors embody the roles and actualize the drama by representing it on the given stage. Neither drama nor institution exists empirically apart from this recurrent realization. Roles represent institutions is to say that roles make it possible for institutions to exist, ever again, as a real presence in the experience of living individuals. In the traditional

family, caring and nurturing have been identified as the female spouse's role (Heru et al. 2004).

Furthermore, Berger & Luckmann (1967) state that roles may be reified in the same manner as institutions. The sector of self-consciousness that has been objectified in the role is then also apprehended as an inevitable fate, for which the individual may disclaim responsibility. The statement like: "*I have no choice and I have to act this way because of my position*" – as wife, mother is a paradigmatic formula for this kind of reification. This means that the reification of roles narrows the subjective distance that the individual may establish between herself and her role-playing. Identity itself (the total self, if one prefers) may be reified, both one's own and that of others. This consideration may be positively or negatively accented in terms of values or emotions. The analysis of reification is important because it serves as a standing corrective to the reifying propensities of theoretical thought in general and sociological of knowledge, because it prevents it from falling into an un-dialectical conception of the relationship between what people do and what they think. The historical and empirical application of the sociology of knowledge must take special note of the social circumstances that favour de-reification such as the overall collapse of institutional orders.

3.5 Social Relations

In the hypothetical model of this study, pre-morbid spousal intimacy, family functioning and social support are regarded as interpersonal resources in the care system as mentioned earlier. Kramer (1993) has suggested that the quality of the pre-morbid relationship impacts on how spousal caregivers experience their roles. According to Hellstrøm et al. (2007), the spousal caregiver's individual identity within the couplehood emerges as an important factor in their experience. The couple relationship in dementia is an intimate relationship that potentially faces major interpersonal and interpersonal issues (Baikie, 2002).

Hayes et al. (2009) regard pre-morbid spousal intimacy plays an important role in the foundation of the spousal relationship between the respondent and her spouse before the onset of dementia. Intimacy relation plays an important role in the active construction of self-identity. Intimacy contributes to the consensual validation of personal worth through the reciprocal expression involves openly communicating wants, desires, feelings, needs and preferences as well as trust and emotional closeness between each other.

Family functioning indicates the quality of the relationship among the family members, the respondent and her spouse with dementia. Social support from informal and formal sources can offer both emotional and practical help to the respondents in coping with the care giving task. Therefore, social relations can be regarded as the key concept of all these three variables affecting the coping experiences of the respondents in care giving for spouse with dementia.

Burkitt (2000) codes Marxist theory, the essential social relations and activities in which humans are engaged are those that transform the real world we live in. For Marx, this is the reason why we, humans are to be seen as social beings; it would be impossible for us to meet our needs and survive in the world where it is not for the power of transformation generated by social activity but, more specifically, by social labour. Burkitt (2000) further elaborates Marxist theory that social relations are essential in understanding social life and the capacities of individuals, because humans must enter into relations in order to transform the real world in which they live and satisfy their needs. The structure and organization of social relations, such as the division of labour, also shapes the labour activity of each individual – the activity humans must engage in so as to transform the real. Social relations are referred to as the human essence between people embody the productive power and, thus, the character of humanity.

3.6 Caring: Feelings & Labour

In the article “*The Rationality of Caring*” of (Waerness, 1984), caring is defined as a concept about that range of human experiences which has to do with feeling concern for and taking charge of the well-being of others. Both “feeling concern” and “taking charge” have practical and psychological implications. Caring is about relations between at least two people, i.e. the carer shows concern, consideration, affection, devotion towards the cared for. That is why we care for our parents, our lovers, our children, our friends and our neighbours etc. as “to care for” has a sense of the bonds which tie us to other people in a wide variety of social relationships. The one who needs care is invaluable to the one providing care, and when the former is suffering pain or discomfort, the latter shows empathy and offers help. We may feel that we have a right to *our need for care* being met. This means there must be others who feel that it is their duty or desire to honour this right. Person to whom we are attached through the ties of family, love or friendship, most often are the ones we expect to feel this obligation or desire. In principle, caring for healthy adults might be based on equal give-and-take

relationship between people who have personal ties to each other. This kind of informal care can be based on norms of balanced reciprocity in personal relations, i.e. help, support and favours can be exchanged between people in a symmetrical relation. However, when children, the ill, the disabled and the frail elderly are the care receivers, then they are the subordinate in relation to their caregivers as they are dependent on their families or some people who feel an obligation or desire to care for them (Waerness, 1984).

Chapter 4 Methodology

Silverman (2006) defines a methodology as the choices being made by a researcher about how a phenomenon is being studied. It includes the cases to study, ways of planning and undertaking research study, methods of data gathering and forms of data analysis. In social research, methodologies may be defined very broadly e.g. qualitative or quantitative or more narrowly e.g. grounded theory or conversation analysis. As I have decided on a topic, refined it and specified objectives, I am in a position to consider how to collect the data I require.

Silverman (2010) states that like theories, methodologies cannot be true or false, only more or less useful. Based on this, I regard methodology as a set of strategic methods which I can choose to gather, interpret and analyze the primary data from my respondents about their perceptions and experiences of care giving for spouse with dementia, and the secondary data by reading the relevant literature.

According to Nachmias & Nachmias (2009), social science research is not united by their subject matter but rather by their methodology which is defined as a system of explicit rules and procedures on which research is based and against which claims for knowledge are evaluated. Therefore, methodology serves as “rules of the game” to be followed for communication and reasoning in scientific research and analysis.

In this study, methodology enables me to share all the data of a social phenomenon about the coping experiences in the care giving for spouse with dementia in Norway and Hong Kong. Although collecting empirical data are fundamental to be the scientific approach, they do not “*speak for themselves*”. (Bell 2010). By using logic as the foundation of scientific thinking, methodology enhances the internal consistency of the scientific claims for knowledge. That logic, as the study of the foundations and principles of reasoning, is crucial to the scientific approach can be seen in the terms for many different areas of study, e.g. biology, sociology and geology etc. Therefore, a scientific methodology requires competence in logical reasoning and analysis (Nachmias & Nachmias, 2009).

In order to address the research question about how the different cultural contexts affect the coping methods used by spousal caregivers in care giving for people with dementia in Norway and Hong Kong, this chapter is about to present and explain the methodology of this study. It begins with the research design, the sample and continues by addressing the research

method, data collection and the role of researcher. The reliability, the validity and the ethical consideration related to the study will be elaborated and discussed at the final section of this chapter.

4.1 Research Design

As this study is to explore and understand how the spousal caregivers perceive the impact of dementia on their marital life and their coping experiences in care giving for spouse with dementia, it can therefore be considered as within the domain of interpretive paradigm. Interpretive studies attempt to demonstrate the expression of respondents and their actions in narrative or descriptive ways by presenting situations as closely as possible to their experiences. There are three main and interrelated problem areas about the research design have been considered. The first one concerns the management of research; the second one is availability of and access to comparable datasets and finally the definition of the research associated issues of equivalence of concepts and theories (Hantrais & Mangan, 1996).

As the research question of this study is about how the cultural contexts affect the coping methods in care giving for spouse with dementia in Norway and Hong Kong, it is exploratory and progressed through two stages. The stage one is the data collection of the coping experiences of spousal caregivers in Norway and Hong Kong respectively. The stage two is to make the comparison of the collected data in Norway and Hong Kong in order to identify the similarities and differences of their coping experiences in care giving for spouse with dementia in Norway and Hong Kong.

In the stage one, by applying the hypothetical model of coping methods in care giving for spouse with dementia, two assumptions have been made. First, the personal strengths, i.e. knowledge about dementia and acceptance of caregiver role play important roles affecting the respondents to apply different coping methods in care giving for spouse with dementia. Second, the interpersonal resources, i.e. pre-morbid spousal intimacy, family functioning and satisfaction with social support are also very important variables affecting the coping methods and experiences in care giving for spouse with dementia.

In the stage two, by using the comparative method, all parts of the collected data in the narrations of all the respondents during the interviews conducted in Norway and Hong Kong

in the stage one must be inspected and analyzed. It involves a repeated to and fro between different parts of the data and this is part of comprehensive data treatment in analyses (Silverman 2010). A comparison would be made to identify the similarities and differences of the relationship between the different cultural contexts the coping experiences of Norwegian respondents and Chinese respondents in care giving for spouse with dementia.

4.2 The Sample

As mentioned before that doing comparative study requires careful thought about sampling. This can be best achieved by in-depth interviews of a small sample. Therefore, this study applied a convenience sample of eight respondents, i.e. four Norwegian and four Chinese for making an intercultural comparison between two ethnicities in Norway and Hong Kong. There were two ways to access the sample (potential respondents), i.e. by the help of the field workers in Norway and in Hong Kong, and through the local dementia association⁴ in Norway and Hong Kong Alzheimer's disease Association. The selection of the sample in this study would be the spouse/cohabitant of people with dementia, who had been the caregiver of the spouse/cohabitant for at least one year at home.

About the consideration of gender aspect of the sample of respondents, I could understand that it might be some differences between male and female spousal caregivers in their experiences and perceptions according to gender aspect in the social and culture context of Norway and Hong Kong respectively. Gender equality is emphasized in Norway where is a social democratic and individualistic society while Hong Kong is a Chinese collectivistic society where male is still dominating comparatively.

As I wanted to be open for both genders to be the potential respondent of this study, I did not set any gender in my research question at the first place. In case if both female and male potential respondents were available and reachable, then I had to take them as the sample of this study anyway. To make a comparison on the coping experiences of both female and male spousal caregivers of people with dementia of two different ethnicities was considerably more complicated and might beyond my ability. Therefore, it would be more favourable for me to do a cross-cultural analysis only focusing on one gender for making comparison on their coping experiences in care giving for spouse with dementia.

⁴ In Norwegian: Demensforeningene

4.3 Research Method

How to select a research method is based on the nature of the research problem. It is just like how to select a cooking method is depended on what kind of dish is going to be made. There are many research methods which can be used for social study. Among various research methods, qualitative research is aimed at gathering an in-depth understanding of human behaviour and the reason and meaning that govern such behaviour. Silverman (2006) defines qualitative research methods have the ability to investigate not only the questions of what, where and when, but also why and how that are fundamental to understand phenomena being studied. Numbers of qualitative method can be used such as observation, analyzing texts and document, interviews and focus groups etc. All these methods actually can be used in combination by qualitative researchers in practice. Therefore, this study can be referred to as qualitative research as it is meant to explore and understand how the spousal caregivers perceive the impact of dementia on their marital life and what their coping experiences in care giving for spouse with dementia are.

Semi-structured in-depth interview was chosen to employ as the research method by setting up a number of open-ended questions with an interview guide in this study. (see *Appendix 1*). Interviews were conducted by me as I could speak both Chinese (Cantonese) and Norwegian and I had intimate knowledge of both my home town, Hong Kong and Norway as well since I had been living in Norway for twelve years. The notion of listening to respondents and of activity encourages the participation of respondents in research process. Silverman (2006) states that in-depth interview with open-ended questions helps the respondents to be an intentional and self-directing actor to penetrate their experiential social worlds through the spoken word. Therefore, it is the respondents' own account that matters.

I had personal observation and the awareness of the differences of cultural knowledge and skill which I could apply in intercultural interactions when I was doing this research. Good relationship with trust between respondents and me was the basic platform for doing the research. I understood that culture was a flexible entity, molded and shaped by history, politics, religion, social change and economic systems. A dialogical approach was preferred wherein we had conversations about our cultures with similarities and differences. With an attitude of humility and curiosity and a mind of a learner rather than an expert was very important during the research. Through conversation and dialogue, and social interaction between the researcher and respondent, new cultures could emerge or, at least, we might learn to honour, value and learn from cultures other than our own (Handrais & Mangen 2006).

4.4 Field Visit in Norway

Before to identify potential respondents for conducting in-depth interview, field visit could be regarded a research method as well. The main purpose of field visit by semi-structure interview was primarily focus on comprehending the coverage of non-governmental organisations (NGO) and the municipality service for the patients with dementia and their families. Besides, the staff in the field dealing with social services for families with dementia was regarded as a door-opener for the recruitment of the potential respondents for the study as well. There were three primary contacts by e-mail message for making request for field visit being made in the August 2012. It was two gave positive reply for field visit and one did not reply, i.e. local dementia association in Bodø. However, two field visits might be enough and acceptable considerably.

In September 2012, the first field visit was paid in Bodø to the manager of Nordland county office of the National Association for Public Health ⁵ dealing with organizing activities for different local dementia associations in Nordland County. The second one was paid to an advisor of the Dementia Team, Health and Social Department in Bodø municipality ⁶ dealing with counseling service delivered by telephone, office and home visit for the patients with dementia and their families. As she was a front line worker, she was regarded as a door-opener to the potential respondents for the study in Norway. Therefore, she was requested by the researcher to refer the study to her clients' families. After two weeks time, she replied that there was no positive response to participate the study and she advised to consider another channel to recruit the potential respondents. Therefore, there were no potential respondents were identified at Bodø in Norway. However, there was a channel showed up unexpectedly.

4.5 Norwegian Respondents

Every year on 21st September, Alzheimer's disease Associations from across the globe unite to recognize the 'World Alzheimer's Day' in many ways. Because of this event, there was two activities took place in two neighbour municipalities, i.e. Fauske and Meløy in the Nordland County. One was a fund-raising campaign in Fauske and one was an open seminar in Meløy. By reading the report articles on newspapers⁷, I was very glad to find out some information, i.e. names of participants with photo were very useful for getting contact with the

⁵ In Norwegian: Daglig Leder, Fylkeskontoret for Nordland, Nasjonalforeningen for folkehelsen.

⁶ In Norwegian: Rådgiver, Demensteam, Tildelingskontoret, Helse- og sosialavdelingen, Bodø

⁷ In Norwegian: Avisa Nordland & Saltenposten

local dementia associations of Fauske and Meløy and potential respondents for the study. By using the information service ⁸ on the internet, the information of the telephone numbers and addresses of all the participants was located. Direct telephone contacts with brief information about the study were conducted with all of them successfully through several attempts. Unexpectedly, some of them claimed that they were only family members but not spousal caregivers of people with dementia while the others were only voluntary members of the local dementia associations.

Fortunately, they were very helpful and willing to offer their help to make contact and refer some potential respondents for the study. After several telephone contacts, four referrals of the potential respondents for the study were identified. All of these potential respondents were female caregivers for spouse with dementia living in two neighbour municipalities. In spite of the need for taking transport to access them, they were regarded as an acceptable sample of respondents though they lived in other neighbor municipalities rather than Bodø where I lived.

Four letters of *Request for the participation of the research project* (in Norwegian) were sent out to the potential respondents by post in October 2012 (see *Appendix 2*). Three of them gave positive reply by telephone or e-mail message. Interview appointments were arranged with them right away in the following weeks. All of three interviews were finished conducting by the end of October 2012. However, one had not given any answers of the request, therefore, telephone contact with the referrer was made and it was confirmed that the potential respondent was in the hospital and going to have operation. Due to this reason, the number of respondents became only three in Norway by the end of November 2012 when the first research period was finished in Norway. The second research period was arranged to take place in Hong Kong in the following month.

4.6 Field Visit in Hong Kong

During the month of December 2012, two field work visits were paid in Hong Kong. The first one was to a senior teaching fellow in social work of Hong Kong Polytechnic University, sharing some information about the social work training in elderly services in Hong Kong. The second one was to an assistant director of Hong Kong Alzheimer's Disease Association

⁸ Website: www.1881.no

(HKADA), providing some information about the scope of their services to the people with dementia and their families in Hong Kong. Besides as an information giver, the assistant director of HKADA was regarded as a door-opener for the access to the potential respondents in Hong Kong as well. Therefore, she was requested to refer the study to her clients' families. A letter of brief background information of the researcher and the purpose of the study (see *Appendix 3*) together with some copies of the interview guide of the study in Chinese (see *Appendix 4*) were delivered to the staff for passing the message of the study to the potential respondents. As expected, she was willing to offer her help with the assistance of her staff to make contact and identify the potential respondents for the study. Since the gender of the Norwegian respondents was only female, the gender of the respondents in Hong Kong was kept to the same gender as criteria for doing comparative study.

As it was during the research period in Hong Kong, the staff of HKADA was informed by the researcher that they had total free hand to arrange the time and place for the appointments of interview with the potential respondents while the researcher appreciated their effort and totally relied on their help. After about two weeks' time, four female respondents were identified and three of them were of one day care centre and one was of the other day care centre run by HKADA. To the extreme favourable circumstances, the staff had arranged two appointments on one day, i.e. one in the morning and one at the afternoon that saved the travel time of the researcher. Then the other two appointments were on the other two days in two different day care centres. After having all those four interviews arranged, the staff and the researcher confirmed that everything was fine with the arrangement of interview appointment.

4.7 The Role of Researcher

As mentioned previously that I have been working in an elderly home in Bodø more than five years. By the job nature as a personal-care worker, I have knowledge about the behavioural problems of patients with dementia. My prior involvement, working experience and knowledge on this topic was very useful for raising relevant and meaningful questions for the respondents to understand and answer in a mutual way easily. As I conducted the interviews myself, it was also an advantage in understanding the respondents' social and cultural contexts which helped the interview being run smoothly without the need for asking them to make many clarifications and elaborations. It can be imagined just like the necessity of knowing about the rules of football game for identifying and understanding the intentions of

all different behaviours of those two teams of football players who are chasing a football all the time during the match.

In general case, from the onset of dementia, obviously the focus had been put on the impact of the disease on their husband/cohabitant which caused the respondents had been taking double roles; i.e. being a spouse and caregiver at the same time. Moreover, the respondents might be regarded as the *caregiver* of their husband/cohabitant as their major role, stronger than as the partner or the *spouse* in their marital life. As the focus of this study was on the coping experiences of spousal caregiver, the researcher would help the respondents to express their perceptions, feelings and experiences about the impact of dementia on the quality of their life.

The interaction between the researcher and the respondent was a complex phenomenon as both parties attempt to influence the interactions. In light of this principle, attempts were therefore made to be sensitive, non judgmental and respectful to the respondents. Being a married woman myself, I could understand that it might not easy for the spousal caregivers to open up themselves to share their in-depth feelings about the impact of dementia on their marital life. However, the researcher was served as a medium for giving the respondents a chance to express their own feelings about themselves, not about their husband/cohabitant or anybody else.

Moreover, Healy (2005) emphasizes that through listening we would seek out strengths, not only within the individual, but also within their formal and informal networks. Listening to and being interested in people's stories is a very effective way of finding out what are people's strengths. As a social work student, I wanted to tease out and recognize what strengths, talents, experiences, skills, resources and supports the respondents were drawing on to cope with care giving for spouse with dementia. Being both a researcher and an interviewer, I regarded myself as a guide and an assistant to help the respondents to open up themselves to express their both positive and negative feelings out. However, I had to be open and aware of the interview setting where I was in a position of being a researcher rather than a counselor. Therefore, I had to prepare myself to tackle the negative emotions and even sad feelings of the respondents when they talked about their coping experiences in care giving for spouse with dementia. Most of all, I understood that I could share their feelings, but it might not easy for me not to be affected by their sad feelings.

4.8 In-depth interview

Silverman (2006) regards interviews, particularly “unstructured” or “open-ended”, have been the most commonly used data collecting method in qualitative research. I regard interviews are relatively economical in terms of time and resources compared with other methods for this study. In-depth interview can provide me the access to individuals’ attitudes, values, interpretation of events and understanding which cannot be obtained by using other methods such as a formal questionnaire or structured interview. As in-depth interview is defined semi-structure with interview guide, it is flexibility with interactive and generative in nature through the process of interview taking place.

In this study, being an interviewer, I had the opportunity to help the respondents to explore their feelings, opinions and beliefs in order to achieve a depth of information to address the research question. In-depth interviews were applied in order to gain an access to the inner world of the spouse caregivers and to explore their experiences and feelings in their marital life in response to the impact of dementia of their spouse. Altogether seven spousal caregivers (three in Norway and four in Hong Kong) had been interviewed for the purpose of the study. Interview guides were prepared and followed for the interview with the respondents.

Following the prepared interview guide, first of all, it was very important to build up a rapport between the researcher and respondent before the in-depth interview started. A brief presentation about the researcher and the study was given. The followed was to inform the respondent about their right to stop the interview whenever it was needed, even to withdraw from the study at any time without any responsibility or influence aiming to protect their voluntary participation. The confidentiality of information supplied by the respondents and the anonymity of them was treated respectably. The importance of tape recording for the security of data collection from interview was emphasised and got the acceptance of respondents with their informed consent.

Before the in-depth interview taking place and the conversation being recorded, a brief running down of the questions and areas listed on the interview guide was done in order to give respondents an overview about three main areas what the interview was going to cover i.e. pre-morbid spousal relationship, practical everyday life after the diagnosis and their coping methods in care giving for spouse with dementia. Moreover, it was also important for

the respondents to get warm-up before they started to talk about their own feelings and experiences. Therefore, it was beneficial to have some initial and easy questions for them to answer for presenting themselves and their spouse in terms of their basic social demographic characteristics, i.e. age, education level, past job nature, length of marriage/ cohabitation, number of children including step-children if any, religion if any and hobbies if any.

In-depth interview took place starting with some introductory questions relating to a number of area/issues including dementia-related information, pathways to obtaining a diagnosis, social care services and support for caregiver from community including knowledge about the cause of dementia and its management. Then the last part was key questions which focused on their coping experiences and social support seeking behaviour in being a spousal caregiver of people with dementia. There were questions about their own emotional and personal concerns related to how they redefined and interpreted marital relationship in response to their spouse's dementia, e.g. their experience of grief and loss, no time for self, anger feelings, worry about the future and deterioration in their own health condition etc. Besides, there were questions about how they tackled the duties of physical care and emotional care of spouse with dementia. Furthermore, there were questions about their perceptions on caregiver role, informal social support system in social network, i.e. family members, relatives, neighbours, colleague and friends etc, availability and usage of formal social support services including mutual help group activities which might reduce levels of depression, caregiver burnout, and might also help improve their overall health outcomes. As mentioned before in the hypothetical model, the main six concepts of the study were knowledge about dementia, pre-morbid spousal intimacy, acceptance of caregiver role, family functioning, social support and coping experiences which were operationally defined by constructing by semi-structured open-ended question items for each of the attributes or dimensions referred to by the concepts.

4.8.1 Interview in Norway

As mentioned previously that it was only three interviews were conducted in Norway successfully since one of the potential respondents had been in hospital. There were altogether three trips to the two neighbour municipalities where the respondents lived. All of three interviews were conducted at their homes and lasted from one and a half hours to three hours.

As Norwegian was not my mother language, I got the help of the interview guide which was well organized by listing out all the questions and areas for the respondents to answer. By following the interview guide, the interviews had been conducted smoothly while the respondents could keep their focus on answering the questions and areas about their perceptions and experiences being a spousal caregiver of people with dementia. They gave feedback that they found the coverage of the interview questions was quite complete. In spite of it, I had to admit that I was not totally confident in managing to understand everything they told me because of the language barrier. Therefore, it might happen that I missed some important chances to make proper reflections to what they talked about.

On the other hand, with the help of sound recording during the in-depth interview, it was very important for allowing me to pay all my attention to listen to the respondents except writing some important brief notes when needed. It did happen that when the respondents talked about their past experiences and became emotionally disturbed and even crying, one or two short breaks for a few minutes took place according to their wish as they could fetch something to drink or dry up their tears.

Brief social demographic characteristics of those three respondents and their spouses in Norway of this study: The range of the age of respondents was from 62 to 65 while the range of the age of their spouses with dementia was from 65 to 70. The education level of respondents and their spouse with dementia was from secondary school to high school level. Duration of illness before getting dementia diagnosis was from one year to three years. The range of the length of marriage/cohabitation before the diagnosis was from 3 years to 22 years. All of respondents lived in their own house and claimed that they had no financial strain.

4.8.2 Interview in Hong Kong

As it was mentioned at ***4.6 Field Visit in Hong Kong***, it was an extreme favourable circumstance that the staff of HKADA had arranged interview appointments with four potential respondents during the research period in Hong Kong. All of the first three interviews took place smoothly as all of the respondents showed up without any problems. But it was something happened with the last potential respondent who informed the staff of HKADA one day beforehand that she had to postpone the interview appointment for one

week. When the staff informed the researcher about it by telephone, the first and foremost reaction was that: “Oh no, please don’t happen the same as in Norway!” Anyway, there was nothing could be done except to wait for one week to see if she could show up for the interview or not. Hopefully, the last respondent showed up without any problems and the last interview was conducted. Finally, all of these four arranged interviews were conducted during January 2013 as planned before the Chinese New Year holidays.

Having the experience of conducting interview in Norway, it became easier to handle especially this time was in my mother language – Cantonese. Though it was still challenging for me, I felt more confident comparatively in interpreting everything they talked about. The procedure of interview following the interview guide with informed consent for sound recording lasted from one and a half hours to two hours. All the interviews were conducted at the meeting rooms in the two different day care centres of HKADA while their husbands were attending the activities in the day care centres.

Brief social demographic characteristics of those four respondents and their spouses in Hong Kong of this study: The range of age of respondents was from 60 to 77 while the range of their spouse with dementia was from 67 to 81. Both the education level of respondents and their spouse with dementia was from primary school to high school level. Duration of illness before getting dementia diagnosis was from one year to four years. The range of the length of marriage before the diagnosis was from 36 years to 47 years. Two respondents lived in public housing estate while the other two respondents lived in private housing estate. All of respondents claimed that they were satisfied with their economical conditions.

The semi-structured and open-ended interviews were tape-recorded and transcribed verbatim for analysis afterwards. The content of the transcripts was analysed using the framework approach to identify common themes and issues for making comparison. This process involved clustering, selecting and coding data on the basis of the thematic framework derived from the qualitative analysis and on issues raised by the respondents themselves during interviews.

Bell (2010) emphasizes that data collected by means of questionnaires, interviews, diaries or any other methods mean very little until they are analyzed and evaluated. Along in this study, after the interviews being conducted and to be written in transcription, it came to the stage to

let the collected data to be presented, analyzed and interpreted in order to address the research question. In the written transcription, it was not the words themselves that matter, but their meaning. Before to find out the meaning, coding was a process helping to cluster the key issues among the collected data and made it possible to take steps towards to draw conclusions afterwards. Before the analysis chapter, there are some other issues of the methodology of the study should be mentioned.

4.9 Reliability and Validity of the Study

Whatever procedure for collecting data is selected, it should always be examined critically to assess to what extent it is likely to be reliable and valid (Silverman, 2010). Reliability stands for the extent to which a test or procedure produces similar results under constant conditions on all occasions. Like a train which shows up ten minutes slow some days and fast on the other days is unreliable. In a social study interview, a factual question which may produce one type of answer on one occasion but a different answer on another is equally unreliable. Moreover, questions which ask for opinions may produce different answers for a whole range of reasons. The respondent may just have seen a television program which affect opinions or may have had some experience which anger or please and so affect the response (Silverman, 2006).

The check for reliability will come at the stage of question wording and piloting of the instrument. It is useful by asking ‘*Would two interviewers using the same schedule or procedure get a similar result?*’ and ‘*Would an interviewer obtain a similar picture using the procedures on different occasions?*’ (Silverman, 2010) These two reasonable questions help me to check items on a question list and interview schedule.

Furthermore, with the help of my supervisor by going through all the questions in the interview guide, I was ensured that all those set questions were appropriate to be used for the purpose of the study. All concerns and queries on those set questions raised by my supervisor were being further discussed and clarified as well. Finally a revised interview guide was converged and accepted to be used for making sure of reliability of the study.

Validity is another word for truth. Usual definitions of validity are that it tells us whether an item or instrument measures or describes what it is supposed to measure or describe, but this

is rather vague and leaves many questions unanswered (Silverman, 2006). I argue whether data has to be interpreted not only by the way how I measure or characterize. Therefore, relevant narrations of the respondents from the interviews will be presented as much as possible which would be very helpful for allowing open formulation about the perspective of the respondents in order to ensure the validity of the study.

4.10 Ethical Consideration

Since this study is about to explore and understand the coping experiences of spousal caregiver of people with dementia, the first ethical consideration is that the researcher have to ensure voluntary participation with respect the right of the respondents to withdraw whenever they do not feel comfortable during being interviewed by getting the informed consent of the respondents before the interview take place. In the field of qualitative social study, the usual ethical procedure for protecting the respondents' private life and confidentiality is by anonymity. By doing this, I have applied pseudonyms for presenting their names. Besides maintaining ethical standards by informing the respondents about the study with their informed consent providing that they have full right to quit the study whenever they want, it is also very important to let the respondents know that the study is purely academic research aiming to get a deeper understanding of the impact of dementia on their marital life.

Chapter 5 Data Collected in Field Visit

This chapter is about to present the data collected in field visits in order to elaborate the two different care systems in Norway and Hong Kong. The purpose of field visit was to understand the scope of public services for the people with dementia and their families. There were four field visits being paid, i.e. two in Norway and two in Hong Kong respectively. Besides data collected by conducting the field visits, some information of relevant non-governmental organizations (NGO) or voluntary organizations were searched on the internet at their websites will also be presented in this chapter.

5.1 National Association for Public Health

National Association for Public Health is a voluntary humanitarian organization with 550 health clubs and 130 dementia associations in Norway. The main goal of the Association is to combat cardiovascular disease and dementia for having more people to enjoy a good and healthy life. Having a website⁹, they work with research, health policy, publications, information giving and prevention. Aiming to improve the situation for people with dementia and their caregivers, the Association runs a dementia hotline service (+47 815 33 032) from Monday to Friday from 9 a.m. to 3 p.m. for anyone with questions about dementia. All the operations of the Association are funded by donations and gifts.

In order to know about their service coverage, the first field visit was paid to the manager of Nordland county office of the National Association for Public Health. In Nordland county, there are 39 health clubs and 17 local dementia associations. The managing director works as a coordinator of those health clubs and dementia associations focusing on two major public health challenges from cardiovascular diseases and dementia.

Health clubs enhance public awareness about preventive health, such as diet and nutrition, cardiovascular questions, exercise and ageing issues. Local dementia associations in each municipality work specifically to spread knowledge and information about dementia, organize dementia course¹⁰ for family members or caregivers of people with dementia, discussion groups and social activities. Their aim is to make life better for the people with dementia and their families and enhance better care services in each municipality. When being asked about

⁹ Website: www.nationalforeningen.no

¹⁰ In Norwegian: Pårørendeskoler

the educational qualification requirement for working in his position in the Association, he shared that there was not a requirement of having either nursing or social work educational qualification background for his position. Besides, he could not give any comment on the role of social worker could play in helping the families with dementia as there was no social worker works in the Association.

5.2 Dementia Team

According to the report of Eek & Kirkevold (2011), a dementia team is set up in each municipality working with the patients with dementia and their families. Aiming to know their services, the second field visit was paid to the advisor of the Dementia Team in Bodø municipality. As an advisor and contact person for families with dementia, she provided counseling service delivered by telephone, office and home visit for the patients with dementia and their families. She stated that there were about 500 patients of about 50,000 inhabitants in the Bodø municipality, i.e. 1 % prevalence rate of the total population. Besides being a counselor, she arranged the course for patient with dementia and their relatives four times a year. The course was co-organized by members of local dementia association. It was six meetings of 2.5 hours arranged in the evening including information about dementia and caring methods and techniques delivered by medical care professionals, i.e. doctor and nurse, discussion groups and sharing sessions with relatives of patient with dementia.

Having nursing educational background, she shared her working experience with families with dementia that it was a shock for the whole family after a family member got diagnosis of dementia. She described it as SOS symptoms which took place in terms of five stages: denial, anger, bargaining, depression and acceptance. From her working experience, it would take at least two to three months to go through all these five different stages. But somebody might stay in the depression stage much longer than the others. Her helping tasks were also to refer the families with dementia to get the necessary services under social security system including the disabled allowance and care giving allowance, support contact person¹¹, and respite service¹² etc. When being asked about her opinion about the role of social worker could take in helping the patients with dementia and their families, she pointed out that it was a traditional practice that when a family member became a patient no matter which type of

¹¹ In Norwegian: Støttekontakter

¹² In Norwegian: Avlastning

diagnosis, the first helping intervention should be provided by medical care professionals but not a social worker.

The same data is also showed in the report about the national survey of service for people with dementia of (Eek & Kirkevold 2011, p.14), the main professionals working in the dementia team and coordinator positions are nurse (96 %), doctor (49 %) and ergoterapist (36 %) and other professional groups (7 %). Surprisingly, social worker ¹³ was classified in the other professional groups together with physiotherapist and occupational therapist which was only seven percent altogether.

5.3 Norwegian Women's Public Health Association

On their website¹⁴, it shows that the operation of Kloverasen Reporting and Resource Center for Dementia, Norwegian Women's Public Health Association¹⁵ is funded by an operating agreement with the Health Department of the government for the North Region in Norway. It is a reporting and resource center for dementia in Nordland County and it provides assessment and diagnosis by age psychiatric outpatient and inpatient in the municipalities of the Nordland County. Their other tasks are among teaching, counseling and testing new methods of "dementia-work". Besides, there is a hot line service at local telephone number: 7558 3333 providing advice and guidance to anyone affected by dementia. The aim of the hot line service is to make their expertise more accessible and making it easier for anyone to seek help in worry. They have confidentiality and the caller can remain anonymous. Hot line service is operated by healthcare professionals with extensive experience in dementia work. The service is open every Monday, Wednesday and Friday from 10 a.m. to 2 p.m.

Besides the services offered by the Dementia Team and the local dementia association to people with dementia and their families, there are support contact service, relief service, home-help service, day care center service and institutional care service run by municipality government for the people with dementia and others in need.

¹³ In Norwegian: Sosionom

¹⁴ Website: www.kloverasen.no

¹⁵ In Norwegian: N.K.S. Kløveråsen AS

5.4 Social Services for Families with Dementia in Hong Kong

The first field visit in Hong Kong was paid to a senior teaching fellow in Department of Applied Social Sciences, The Hong Kong Polytechnic University. Besides teaching elderly services in the course of “Bachelor in Social Work” in the university, she is a vice-chairman (external affair) of executive committee of Hong Kong Alzheimer’s Disease Association (HKADA) as voluntary work. She shared her opinion that to be aware of the symptoms of early dementia was very critical rather than regarding cognitive impairment as a normal aging process. As most people regarded minor cognitive impairment as a normal aging process, she emphasized that public education about dementia playing an important role to enhance the public awareness of this disease.

When being asked about her opinion about the role of social worker could take in helping the patients with dementia and their families besides medical help, she stressed that social work applied a holistic approach in helping people with dementia and their families. She had no doubt that a social worker could not give injection treatment to a patient but a nurse could offer counseling service to a patient. However, she emphasized that it was the best intervention model that social worker and medical and nursing professionals could work together as a team to help the people with dementia and their families. It was very important that to help the patient with dementia and the family as a whole to see the problem what they were facing and searching for the help and social services to meet their medical, emotional, interpersonal and psychosocial needs.

Comparatively in Hong Kong, there is not any local dementia team operating to provide service to the people with dementia in each municipality as the practice in Norway. However, there are many different kinds of social services for people with dementia mainly run by different non-governmental organizations. For example, home-help service, day-care centre service and institutional care service are operated by different NGOs in different districts in Hong Kong. The service users are not mainly people with dementia, but also can be elderly and people with other impairments. Among these NGOs, Hong Kong Alzheimer’s Disease Association is the only one which mainly serves people with dementia and their families.

5.5 Hong Kong Alzheimer's Disease Association

The second field visit was paid to the assistant director of Hong Kong Alzheimer's Disease Association (HKADA) in order to have some information about the scope of their services to the people with dementia and their families in Hong Kong. HKADA is a member of the *Alzheimer's Disease International*¹⁶. Besides running their website, the followings are the six service categories provided by HKADA for the people with dementia and their families in Hong Kong.

1. Five day care centers are located in five different districts providing two sessions (whole day) or one session (three hours) service. The staff of each center includes an occupational therapist, a social worker and a driver and assistants. Day care centers offer people with dementia a chance to socialize and take part in activities that stimulate their minds. The programs can also give spouses, children and other caregivers a break. Intuitively, that should ease some of caregivers' daily stress.
2. Home training team heading by an occupational therapist provides client-centered training program of individual daily self-care activities for the people with dementia and their immediate caregivers at home.
3. Resource center provides information and knowledge about dementia in terms of publications, library service, arranging monthly sharing group meetings and social activities.
4. Counseling service provided by a social worker helping people with dementia and their families on their personal, interpersonal or social affair problems.
5. Monthly free-of-charge public seminar about dementia is held in nineteen different districts for enhancing public awareness of the early symptoms of dementia in Hong Kong.
6. Free Hot Line Service (+852 2338 2277, +852 3553 3656) provides telephone counseling, information giving and referral. The service is available from Monday to Friday at 9 a.m. to 5:30 p.m.

Since the Association is self-financing without any economical support from the government, day care center service and home training are charged according to hour-basic. Besides, the Association receives donations from the public, the sponsors and supporters for running their services. Besides HKADA, there are some other day care centers running by Medical &

¹⁶ Website: www.alz.co.uk

Health Department of government under public hospitals or other NGOs providing services to people with dementia, elderly and people with disabilities. Medical referral is needed in applying for the day care center services run by public hospitals as the services charges are cheaper than the day care center services run by HKADA and other NGOs.

Having occupational therapy educational background and working as the assistant director of HKADA, she shared that they had a very good balance team work helping people with dementia and their families. She pointed out that the social worker in their team who worked as a case worker played an important coordinator role in order to meet the need of both the clients with dementia and their immediate caregivers. She emphasised the importance of holding seminar in different districts to enhance public awareness of the early symptoms of dementia as early diagnosis with proper medication and having client-centre training program provided by occupational therapist as well as family members could delay the deterioration of the cognitive ability of people with dementia.

5.6 Two Different Formal Care Systems

Care system involves two main actors, i.e. informal and formal. Informal actors are immediate family, kinship, friends, neighbours and social connections. Formal actors are paid workers employed by the government or NGOs. As mentioned in Chapter 1 that Norway is a welfare state, the provision of welfare is state based with universal citizenship right. When a person is suspected suffering with dementia, first of all, a primary medical assessment done by the family doctor¹⁷ is needed and then an appropriate referral to specialist in gerontology if necessary. According to the variety need of the people with dementia and their families, they may be eligible for the support contact person service, home-help service, relief service, day care centre service and institutional care service. All these services are run by the municipality providing for those inhabitants in need.

On the contrary, Hong Kong is not a welfare society and the provision of public services run by government is minimal and selective provision only for the weakest and poorest. When a person is suspected suffering with dementia, he or she can choose to visit a public or private medical practitioner for a primary medical assessment. But for the further gerontology specialist assessment, it is usually a long waiting time to have appointment in government

¹⁷ In Norwegian: Fastlegen

hospital. Therefore, private gerontology specialist is always an alternative for immediate appointment whenever the consultation charges are affordable without financial strain.

Moreover, there is no support contact person service or relief service as in Norway, but there are home-help service, day care centre service and institutional care service available in Hong Kong. All these social services are with charges mainly run by NGOs with or without governmental subvention. Again, it is a long waiting list for the public institutional care services. Therefore, private institutional care service is the only alternative to meet the need when it is necessary. Operation under commercial principle, there is a big variation range of the price and the quality of the private institutional care service.

People with moderate and advanced dementia typically need round-the-clock care and supervision to prevent them from harming themselves or others. They also may need assistance with daily activities such as eating, bathing and dressing. A typical home environment can present many dangers and obstacles to a person with dementia who may need institutional care. In Norway, public nursing homes for elders and people with impairments are driven by municipality government. On the other hand, most of public nursing homes in Hong Kong are run by non-governmental organisations (NGOs) with subvention from the government.

As the advisor of Dementia Team emphasised, it was a traditional practice applying medical and nursing intervention in helping patients and their families. The practice is also applied in the nursing home setting. First of all, the qualification requirement to take up the position of the centre in charge in a nursing home can only be with nursing educational background in Norway. On the contrary, the practice in Hong Kong is different; the centre in charge of nursing home can be a senior worker either with nursing or social work educational background. Besides, both in Norway and Hong Kong, care staffing of nursing home consists of nurses, personal-care workers and assistants. Most of the care staff members are trained with health care qualifications. But in Hong Kong, in addition to nursing and personal-care workers, there are at least one or even two social workers, depending on the capacity of the nursing home, working as case worker dealing with personal and social affairs of the residents and welfare workers deal with social activities in order to provide holistic care service for the residents.

In her book *“Social Work Theories in Context”*, Healy (2005) mentions that the dominant discourse influences who is regarded as an expert and who is considered to be a client, how client needs are constructed, and what types of intervention are seen as worthy. The practice of public care for older people, people with dementia and their families in Norway can be regarded as a good example of the traditional medical context while the biomedical discourse will strongly influence who is seen as the expert, i.e. a medical health care professional while the clients are old, sick and weak.

Having social work background, I have different perception from about expert knowledge, the nature of social work role and, most specifically, the kind of “help” or intervention that will best address the concerns and issues of service users. I would focus on the consumer rights discourse that underpins some contemporary service user advocacy services, particularly in vulnerable individuals, i.e. elderly and disability fields, repositions the clients as the expert and encourages the questioning of established “expert” opinion. As I see that different perspective as I have that enables me to view the biomedical dominant discourse not as “absolute truth”; but rather as one of many perspectives.

As long as there is biomedical discourse is dominant in determining the official practice of the care services for people with dementia and their families in Norway, I can see there is a lack of social work perspective; lacking a considerable different perspective of seeing the practice context, particularly in perceiving their social needs of service users. Under this circumstance, the importance of the role of social work element in helping the people with dementia and their families has not ever been recognized in the Norwegian case system yet. On the contrary in Hong Kong, the importance of social work with a holistic approach has been well developed in the education system of social work in the University for helping different kinds of service users, especially elderly and people with impairments.

Chapter 6 Comparison on Coping Experiences

In this chapter, it begins with presenting some brief background information of those seven respondents. Then it follows with the analysis of the narrations of their sharing about their perception and interpretation on the behavioural changes of their spouse and how they examined their support systems and their coping experiences in care giving. A comparison on how different cultural contexts affect their coping experiences following the conceptual framework of this study will cover in five aspects, i.e. knowledge about dementia, pre-morbid couple intimacy, acceptance of caregiver role, family functioning and social support. Besides, the aspects related to usage of social services, their own health status, time for self and need for institutional care will be covered in the comparison as well.

6.1 Knowing Respondents

Before presenting the respondents of this study, an explanation about how their names will be presented comes first. The way how to present a person in Norway is as usual as the most Western countries that a woman uses her first name in general case no matter what civil status she has. On the other hand in Hong Kong, it is more common for a woman will be named after her husband's family name after she has got married with him. Therefore, names of those seven respondents of this study besides presented in pseudonyms for protecting confidentiality and also in this way respectively, i.e. Karen, Joyce and Lisa for Norwegian respondents, and Mrs. Wong, Mrs. Woo, Mrs. Tse and Mrs. Yuen for Hong Kong respondents.

Brief information of those three Norwegian respondents as the following:

Karen: Her husband died some years ago. It was her recall memories about her experiences about the impact of dementia on their marital life. First time she had acknowledgement of dementia was when her father suffered with it. She felt completely different between being as a daughter and a wife of a person with dementia. She was angry with the disease which made her lose her husband whom she regarded as a good husband and a conversation partner. Because of she had a full time job and he became weak and she could not manage to take care of him at home, he was under institutional care as a result. She regarded it was very helpful for having emotional sharing with the members of the mutual support group.

Lisa: It was her second marriage and she and her spouse had an intimate marital relationship. They lived in a farm as he liked to spend his time with the animals and the outdoor activities while she liked to stay indoors to do her design and handicraft activities, e.g. knitting, sewing and painting. She painted a picture of a woman standing behind some bars for illustrating her feeling as a prisoner while she had to be together with him all the time. Because of suffering with health problem herself and her husband was so weak that he had to be under institutional care. She lived alone with two dogs since then.

Joyce: She had married once before and had been cohabited with her spouse for three years before the onset of dementia. He was a pensioner while she had a full time job, and it was him who took care of the household and prepared the dinner while she was at job. For her, dementia took away her dancing partner, trip partner and the housekeeper. After he had moved to live in elderly home, she visited him almost every day and kept on spending time together. She had made a log book recording all his activities in order to let them to have some topics to talk about with each other. Besides, she collected all his photos and put them in an album with information of date and names of people and places for reminding him of his happy life moments, e.g. running marathon and cycling trip etc. Furthermore, she arranged birthday parties in order to have celebrations with their relatives and friends for keeping him in touch with their common social network. They were once interviewed by the local newspaper and shared about the impact of dementia on their marital life.

Brief information of those four Chinese respondents in Hong Kong as the following:

Mrs. Wong: She was educated and had been working as a nurse in a public hospital for many years until she became a pensioner. Though they had been married for many years, she described their marital relationship rather distant because of her husband had paid all his attention to his company's business that caused him having no time together with her. In spite of having her own pension life plan, she had to sacrifice it and take up the role of caregiver for her husband with dementia. Because of suffering with stomach cancer, she had a big operation which caused her lose body weight and affected her health conditions.

Mrs. Tse: She was also educated as a nurse and had been working in a public hospital for many years until she became a pensioner. In spite of their distant marital relationship as she described because of their different points of view and personalities, she regarded herself had

been taking up the caregiver role for her husband since he had suffered with other diseases long before the onset of dementia. She could manage as long as her husband followed her instructions to take his medication. Because of having sleeping problem herself, she needed medication for it.

Mrs. Woo: She worked as a worker and got retirement when she was 60 years old. She described their marital relationship as normal couple as they spent time for doing things together sometimes besides they had their own interests and hobbies. She liked to spend time with her friends and being active in her social network. About her own health conditions, she had suffered with hypertension under medication for many years. She regarded herself manage to take up the caregiver role as long as her husband was not very weak and manage to stay at home alone while she could be out for many hours to be together with her friends.

Mrs. Yuen: She was a self-employed insurance agent and not retired yet. As her husband had been very kind, patient and concern about her during all those years in their marital life, she was very satisfied with their intimate marital relationship until the onset of dementia and he changed his personality. About her own health conditions, because of family genetic reason she had suffered with hypertension and diabetes under medication for many years. As she claimed that she could accept to take up the role of caregiver of her husband as a chance for her to “*pay him back*”. Her only worry was about the deterioration progress of his behavioural problems as she did not have any knowledge about dementia and its management.

6.2 Knowledge about Dementia

Something which we have never learned before are new to us. Knowledge about dementia is not a general knowledge which we have chance to come across generally in our daily life. Whether cognitive impairment is viewed as a normal part of aging will affect to recognize the onset and the willingness of families to seek assistance. Knowledge about dementia is very important for the awareness of the onset of symptoms. In addition, as initial symptoms, such as forgetfulness, may be more acceptable to certain cultures, they may not seek out services until a later stage of the illness.

Two respondents in Hong Kong, Mrs. Wong and Mrs. Tse, had nursing educational background and had been working as a nurse for many years until their retirement, but they

did not have opportunity to work with patients with dementia at job. They shared that they heard about it on the news report sometimes when elderly people were missing. Interestingly, all of four respondents mentioned about they had heard about the story of Mr. Koo, the Nobel Prize winner suffering with dementia. It showed that the public awareness of this disease, at least the name of it, has been enhanced by the propaganda with such famous figures of Mr. & Mrs. Koo since 2009.

On the other hand in Norway, Lisa had heard about dementia while she worked as a secretary in hospital. All she knew about this disease was that the patient with serious cognitive impairment could no longer live at home and needed institutional care in hospital or nursing home. Joyce had never heard about dementia and never thought of she would come across with this disease so close in her family. But it did happen with Karen as her father suffered with it when he was at his old age. Moreover, all of them had heard the story of Mr. Jan Henry T. Olsen, former Fishery Minister of Norway, suffered with Alzheimer's disease while he and his wife were interviewed on TV program for sharing their experiences.

6.2.1 There Was Something Wrong with Him

The belief that cognitive changes are a normal part of aging and normalization of memory loss symptoms has been reported to contribute to delays in diagnosis. When the respondents thought back, they reported that their spouse had some small behavioural changes even back to three years before getting the diagnosis. The followings were their recalled incidents which actually showed the cognitive impairment of their spouse.

He did not show up for the appointments with the family doctor and physiotherapist for several times, and it hurt me terribly when the staff told me because he was so unreliable that they could not give him any new appointments. It really struck me that I could not trust him any longer though he had been the most reliable person whom I had ever known. - Karen

Usually he liked to read newspapers and books but then it became very difficult for him as he took very long time to finish reading a newspaper. Besides, he had problem to write any greeting words except his own name when we wrote the Christmas greetings to our families and friends. - Joyce

First thing I noticed that he had problem when we stopped to have any sexual activities. He told me that he felt sorry for that, and it was ok for me as I did not keen on sex so much. The second thing was after we bought a new Television set, he could not manage to know how to use the remote control. - Lisa

It did happen several times that he went to a wrong place while I was waiting for him where we were supposed to meet. Besides, he did not complain or take any action for four months late rent payment. I found it very strange as it was not his usual way to handle things.

- Mrs. Yuen

Usually he was very careful in taking care of his belongings whenever he was out. It happened at least two times that the staff of the swimming pool announced his name and asked him to go to the office to pick up his wallet because they found it in the changing room. I could not understand why he became so careless, and the money in the wallet had not been stolen fortunately. - Mrs. Woo

It was when we visited our married daughter who lived in a big private housing estate with an activity club center, and he could not remember the way back to her apartment alone after being in the club center. Besides, he started to forget to take his medicine regularly and needed my reminders. Afterwards, I did talk with his doctor who claimed that it was only a normal aging process and refused to make any further referral. - Mrs. Tse

As all of their spouses with dementia were over sixty years old, i.e. old age group while all of the respondents were lack of knowledge about dementia and its symptoms which was an initial barrier for getting diagnosis. The respondents did realize there was something wrong with their spouse, but they did not associate those behavioural changes of their spouse were early symptoms of dementia.

6.2.2 Explanations for the Changes

The recognition that their spouse's behaviours were "not usual" served as a cue to action. However, there was only two of those seven respondents, one in Norway and one in Hong Kong, promptly sought medical evaluation for their spouse's behavioural change when it became obvious that something was wrong with their spouse. Unexpectedly, Mrs. Tse experienced with medical practitioner who was less well informed about dementia. Lack of

specialized knowledge on the part of medical practitioners interfered with initial diagnosis while they attributed cognitive changes to normal aging. But in the case of Karen, it was another explanation by the medical practitioner.

As my father was suffered with dementia, I wondered if my husband's lose of time concept might be a symptom of dementia. But when I told the family doctor about it, he just explained that my husband's problem was only because of lacking vitamin B12 and he would give him injection treatment to make him become a new man. For me, I did not want any new man but only my husband as healthy as before. - Karen

While Joyce and Lisa regarded the behavioural changes of their spouse might be the normal aging process, three of four Hong Kong respondents did not regard it in the same way comparatively. In their minds, they had some perceptions and interpretations on the behavioural changes of their spouse. The following are their explanations.

Once I saw him using his name card as the traffic card though they were at the same size but they were made of different stuffs and in different colours. I thought it might because of a minor stroke he got earlier that caused him become slower in physical motion and did not remember things well. - Mrs. Wong

He loved our two children very much and we often went to visit our son's family after they got a baby. But then they had to move to live in Shanghai because of our son got his job promotion there. Afterwards, our daughter got married and moved out from home. All these two events took place within one year might have big impacts on him and made him change. - Mrs. Yuen

He had always been very active in doing outdoor activities when he was young. Even after he retired, he still had some outdoor activities with his old friends or colleagues. But then they died one by one during only three, four years time and he was the only one still alive since then. As a result, he had no more activities to go to as before. - Mrs. Woo

According to the life developmental phases, the separation anxiety appears in the old age stage while the social network changes, e.g. children get married, move out and have their own family, and the number of friends will decrease because of death. From the above narrations of Mrs. Yuen and Mrs. Woo, it showed that their perceptions and explanations of

the behavioural changes were focused on the influences of the changes of their social life which was very important in Chinese collectivistic culture. However, it showed that initial denial and failure to recognize symptoms were the factors which caused the delay of finding out the actual reasons for the early cognitive problems.

6.2.3 Key Incident

Initial evaluation generally occurs when their symptoms are relatively advanced. In this study, all the respondents could recall a key incident in retrospect that they could not deny that their husband was really ill. All respondents did not hesitate in seeking for assistance when they perceived that their spouse had an actual cognitive impairment. The followings were their recalled key incidents.

He had been very keen on boat all the time, but then he suddenly changed completely. Whenever he was asked to have a boat trip, he refused it as he did not dare to get in on the boat. - Karen

It was easier for the people who were not living together with him to notice his changes. When his daughter came to visit us, she could recognize his changes immediately and emphasized that a doctor consultation was necessary. And she became very angry with me since then. - Joyce

It was when he went out and came back inside the house again and he was very nervous and became warm and sweating much. When he told me that he could not remember what he was supposed to fetch from the storage, then we realized that there was something very wrong with him and he had to visit the doctor right away. – Lisa

One evening later than 9 p.m. and he did not come home from job as usual. I called and reported it to the police. They called around to all the hospitals and they found out that he was sent to a hospital which was located far away from his working place. He could not remember what had happened and why he ended up in the hospital that evening. - Mrs. Wong

Once when he was suffered serious headache and was sent to emergency. As he could not manage to answer those basic informative questions being asked by the doctor who suspected

he had memory problem, therefore he was referred to consult gerontology for having a memory test afterwards. - Mrs. Tse

He was eager to share his ideas and opinions with me before, but suddenly he stopped to talk with me. Though I tried to talk with him, he just gave short answer or even no answer at all. Besides, I could not understand why he became very angry whenever our daughter came to visit us. - Mrs. Yuen

One midnight I was awake by some sounds. And I found him standing by the door and told me that he was going out to put some materials away. In fact, he retired long time ago and there was nothing for him to throw away that night. Then I told my daughter about it and we decided to take him to see the doctor. - Mrs. Woo (Mr. Woo worked as a construction worker)

From the above narrations, it showed that the Norwegian respondents having constant direct communication with their spouse that helped them to recognize the seriousness of the problem of their spouse mutually. Comparatively, all of Hong Kong respondents did not have good direct mutual communication with their spouse that made them being passively involved in coping with the influences of the behavioural changes of their spouse.

6.2.4 Way for Getting Diagnosis

When the situation of the spouse became critical and the respondents realized that their spouse suffered with cognitive impairment, they had to take some actions to deal with it eventually. Like Mrs. Woo did, Mrs. Yuen also talked with their children and shared her worries with them. The daughter of Mrs. Yuen had a friend whose father was suffered with dementia. After she had talked with her friend, she started to wonder that her father might have the same problem.

First of all, medical assessment is necessary for finding out what the problem is. In Hong Kong, it is a long waiting time to have appointment with the gerontology specialist of government hospital. Therefore, most people prefer to visit the private specialist though with high charges as long as they can afford it. Except Mrs. Tse, the other respondents arranged their spouse to consult even more than one private specialist searching for second opinion in

order to make sure of the diagnosis. Comparatively in relation to Norwegian respondents, all of spouses with dementia had been referred to central assessment centre (Kløveråsen) for dementia assessment by their family doctors. All of seven respondents shared that after their spouse got the memory test, it was confirmed that their spouse had short term memory problem while they got only around 12 points out of full points of 30 of the memory test.

6.3 Pre-morbid Couple Intimacy

For many elderly people, their marriage represents the single most influential and sustained relationship in their lives. A lifetime of shared experiences between spouses helps to define and maintain their individual sense of self. As the spouse's cognitive decline continues to erode their capacity to maintain an intimate relationship, the ability of the marriage to contribute to and reinforce the care giving spouse's ongoing sense of self is also affected resulting not only in a loss of relationship but also a loss of self (Rankin et al. 2001).

In this study, the perception on the quality of their marital relationship of the respondents, i.e. level of intimacy prior to the onset of dementia plays an important role on their coping experiences. In the Norwegian case, Karen was married only once while Joyce and Lisa had married once before. The range of the length of their marriage/cohabitation before the diagnosis was from three years to twenty two years before the onset of dementia of their spouse. The following narrations were their sharing about their intimate marital/cohabitant relationship.

We had been good conversation partners for sharing our ideas and opinions with each other. There were several times when I remembered that we had been very lucky and happy married and lived together in all those years with many nice and sweet memories before he became ill. That helped me a lot to keep on going. - Karen

I was very happy and satisfied with our marital relationship and I regarded it was the best period of my entire life after we got married and I moved to live with him here in this house. He was extremely kind to me and had good humor by using nice words about things around us all the time. - Lisa

As I had problem to sleep during the night sometimes, he suggested me to wake him up and then we could talk together. He had always been very considerate to me. - Joyce

Intimate pre-morbid couple relationship serves as a critical helping factor for the respondents to cope with the impact of the dementia with their spouse after getting the diagnosis. The followings are their sharing.

We did talk about it and he admitted that he was forgetful. Whenever he had to go to the hospital to see the doctor or for investigation, I would explain well to him about the purpose of the visit in order to make sure that he was prepared and willing to do it. For me, it was very important for him to make the decision for himself rather than I did it for him. As he trusted me, he accepted my explanation very well. - Karen

He and I did talk about his behavioural changes and he admitted that he forgot things. Actually, he had stopped driving long before he got diagnosis. By now I could understand that he had been very wise for asking me to overtake driving from him as he stated that he had no good sight any longer which made him have problem to drive any more. Besides, we went to attend the dementia course together to learn more about the disease. - Lisa

On the other hand in Hong Kong, though all of the respondents were in their only marriage and the average of the length of marriage before the diagnosis was over forty years, there was only one respondent had intimate marital relationship with her spouse before the onset of dementia.

We had a close and intimate marital relationship and doing things together all the time. He had been a good husband and being patient and supportive to me as I was an impulsive person. I was lucky and appreciated that he had been so good to me. But then he changed his personality and did not talk with me as before that made me feel terribly bad. - Mrs. Yuen.

Two other respondents did not have intimate but distant pre-morbid marital relationship and without good mutual communication with each other.

Like the most typical businessman, he worked very hard outside home and expected the wife to treat him very well, e.g. fetching him slippers when he came home. When we were out, he

usually walked in front of me, not like the modern couple walking hand in hand together.

- Mrs. Wong (felt her husband regarded himself was superior to her)

We had conflicts but we had never thought of getting divorced with each other since we had been married and having children together for over 40 years. - Mrs. Tse

He had never admitted that he had memory problem. He became angry and defensive whenever we said that he was forgetful. It was not easy to understand him. - Mrs. Woo

In both Norwegian and Chinese cultures, dementia like other diseases might be regarded as impairment. As the Norwegian respondents had good mutual communication with their spouse before the onset of dementia, it was much easier for them to share their feelings and worries about the diagnosis and they cope with it together. On the contrary, the Chinese respondents did not have good mutual communication with their spouse; therefore it might be difficult for them and their spouse to share their feelings and worries about the diagnosis openly like the Norwegian respondents did comparatively.

6.4 Preserving Personhood

In their study of Perry & O'Connor (2003) on preserving personhood in care giving for spouse with dementia, they state that it is important for the caregivers that others, particularly outsiders, developed a contextualized picture of their spouse. When spousal caregivers preserve the personhood of their partners, they also preserve their own identities as husband and wives. To insure this, the caregivers devote a great deal of time to "*telling the ways*" of their spouse.

In this study, though three Chinese respondents did not have intimate marital relationship with their spouse, they regarded that they had shared a long marital relationship and experiencing many things together. It was in common for all the respondents in this study to a certain extent inserted a description of their spouse about what the person they had been like prior to the onset of dementia. From the narrations of the Norwegian respondents, they focused on the personal characters and the contributions to the family of their spouse.

He had been an incredibly good husband, caring and clever in every sense and was the backbone of the family supporting and solving all the problems for me and our children. He was just a quiet person who never raised his voice. - Karen

He had been very active in participating outdoors activities, e.g. marathon running, cross-country skiing and long distant cycling, etc. Moreover, he had been a fantastic gentle person as a lamb as he had never talked in a high voice or used bad words about anybody. He did take good care of his own children and the children of his siblings. - Joyce

He had been unbelievable kind with my children (step children of him) and clever in teaching them about many outdoor activities, e.g. fishing and farming. He was used to go to the internet to search for information about everything. For me, he was just like a life lexicon because he knew and could do many things, i.e. food, farm, fish and mountain etc. - Lisa

Similarly, the Chinese respondents also gave the descriptions mainly focused on the personal characters and the contributions to the family of their spouse as well.

As he was a director of a big company, he worked very hard all the time just as a typical Hong Kong businessman. Though he did not have much time to spend together with me and our four sons, he supported the whole family very well. Besides, he was always a calm and quiet person who had never attempted to make any violence, e.g. attack people. - Mrs. Wong

Despite he did not have university educational level; he had been keen on self-study learning all the time, i.e. reading different kinds of English literature. He had been working as a secretary in a big international company for many years until he got retirement. Moreover, he was cleverer in English than his two brothers, and therefore they asked him often for his help with assisting them in writing their jobs related documents. - Mrs. Tse

Both of us worked very hard for supporting our family of five children. He had been a good father who contributed almost all his income to support the family. He just kept a little amount of money for his own expenses for food, transportation and activities etc. Though he and I did not have high education, we managed to support our five children to finish university educational level that made us very pride of. - Mrs. Woo

As all of my six siblings were very worried about the handover of Hong Kong back to China, they immigrated to other countries long before 1997. But my husband regarded that Hong Kong was our home town and no other places were better than here to live in. And the fact showed that he was right as our two children had been studied abroad and finished their university education. Now they had good job in high position with bright prosperity. He emphasized that the most important thing was our whole family still live in Hong Kong without any problem after the handover. - Mrs. Yuen

It was a similarity between both Norwegian and Chinese respondents as they regarded they had shared and experienced many things together with their spouse during their marital life, it was very important for them to preserve the personhood of their spouse in order to preserve their own identities as well.

6.5 Acceptance of Caregiver Role

Appraisal processes are especially important in understanding coping because they offer an explanation about the process of adaptation. The individual's appraisals of their own self-efficacy and degree of control over the caregiving situation, for example, may alter their response. Ethnicity may play a role in one's appraisal of the caregiving situation (Adams 2002). Cognitive appraisal is generally defined as the process the person uses to evaluate whether a particular event is relevant to his or her well-being, and whether anything can be done to modify it.

As the condition progresses, the challenges of care giving are likely to become more acute and demanding in terms of time and commitment from the caregivers. Besides, an unbearable feeling of loss was experienced gradually by those respondents who have intimate pre-morbid couple relationship with their spouse. To take up the role of caregiver, a sense of compassion and nonjudgmental love were critical factors in helping the respondents with not taking the behavioural problems of their spouse personally, but seeing the pain and suffering of their spouse caused by their cognitive impairment. The experience of Karen is an example.

For me, he had been a lover, a husband, a tour companion and everything before. After he got dementia, then all of his roles to me seemed to be disappeared when I became only a caregiver to him. I still could talk with our children, my siblings and friends etc., but he could

not. It was him who had lost the chance to have contact with our children, others in family and friends. It became easier for me to deal with the situation after all when I was able to focus on that it was him who was the real unlucky one being a victim of this disease.

- Karen

On the other hand, as Au et al. (2012) mention that in Chinese culture, a certain degree of cognitive decline at older ages is tolerated and a return to a child-like state is deemed a natural part of aging. It means that the family has to take care of the old and weak as well as small children. Mrs. Woo is an example of it.

When I asked him to pass something to me and he was just standing there and could not manage to do what I told him. Sometimes, I found him like a small child. Our grandchild who is seven years old can do even much more things than him. We are used to say that when people get older and become weaker, then they will behave like a child. - Mrs. Woo

The level of acceptance of taking up the role of caregiver for the spouse with dementia among both the Norwegian and Chinese respondents is more or less about the same. To take care of their spouse most of all because he is their spouse, and by taking care of him the respondents confirm their couple relationship and the way they see their relation.

After he became sick, I had to prepare the food for him before I went to job as he was alone at home during the day. Since we still liked to take a trip together after dinner, therefore, when I came home after job, we made the dinner together and then after dinner we packed the things and went for trip. - Joyce

As I was injured in a car accident some years ago that made me become disabled, and I only stayed at home as a housewife since then. But I developed my interest in painting and knitting. I painted a picture showing that I was like a prisoner when I had to be together with him all the time without having time for myself to do what I liked. - Lisa

That time I had a full time job with four small children, I did not have much time to do the things which I would like to do, e.g. travelling, meeting friends and learning how to use high technology devices, e.g. computer and iPad-phone etc. And all these things were in my

retirement plan. But now it seemed that I had very little time for myself as I had to take care of him with everything. - Mrs. Wong

Pre-morbid relationship might be a key factor affecting how the respondents performing care giving role. Emotional involvement in delivering care with concern and love has been identified in the narration of Karen.

I told myself several times I should not be angry with him even though he did ask me the same things several times, never manage to find the way to the toilet and did the wrong things again and again. Fortunately I was glad that I managed to distinguish these two things: he was a victim of the disease and therefore I had never been angry with him, but the disease who took my husband away from me. - Karen

On the other hand, from the narrations of those three Chinese respondents, they regarded that as long as they had the control over what the caregiving task was that they could manage to perform it. Therefore, it showed that they were rather more task-oriented than the Norwegian respondents in caregiving for their spouse with dementia comparatively.

Having nursing education and working experiences, I regarded it was not difficult for me to take care of my husband. I understood that he could not manage to take the medicine himself and needed my supervision and assistance. There was no problem as long as he could do what I told him to, e.g. he could fetch a glass of water himself when I was taking the tablets from the medicine box for him. - Mrs. Tse

As a matter of fact, I was a patient rather than him. I had been suffered from diabetes and hypertension and under medication for over ten years while he had been physical active and enjoyed rather good health before. It seemed that it was I who needed to be taken care of rather than him. But now every morning I had to help him to put on his hearing aid and teeth prosthetics. And I found it was not easy sometimes when he was not cooperative to do what I told him to. - Mrs. Woo

As he attended day care centre five days a week, I had to go to the centre to help him with food taking and medicine during the lunch time. Because of taking blood-thinner medicine, it could be very dangerous for him in case he got injury with bleeding. And I understood it was

not possible for the staff to take care of all the clients at the same time, therefore, I regarded it would be the best that I went to help him during the lunch time for making sure everything was fine with him. - Mrs. Wong

Besides, Mrs. Wong employed a domestic helper for taking care of the house works and giving personal-care assistance to Mr. Wong, e.g. after toileting. As she explained that she regarded the domestic helper could not make good food, therefore, she preferred to do the food-cooking herself and let the domestic helper to take care of the personal-care of her husband.

As care involves concern feelings and labour activities, from their narrations, it showed that Norwegian respondents had been coping with both concern feelings and labour activities well in caregiving for their spouse with dementia while the Chinese respondents mostly focused more on the labour activities than the concern feelings in their caregiving.

6.6 Family Functioning

When a family member has problem and needs help, it is expected that the whole family is responsible to offer their help to that family member in need. An example from Daatland (1983 p. 4) of an elder Norwegian spousal caregiver's statement: "*My sister would have been here every day, had she been alive. That's the kind of person she was.*" The expectation for getting help from siblings or adult children is found very natural in most families traditionally both in Norway and Hong Kong. When the siblings or adult children show their concern in term of making regular telephone call or even visit is probably just as important for the caregiver as for the care giving event. Their concerns indicating their involvement and participation as siblings and children contribute to the maintenance of the family ties and obligations which support caregiver take care of their spouse at home. The followings are some examples identified in this study.

His sister was a nurse who felt sad for him and commented that the worst was he himself could realize what the changes he experienced. Besides, my daughter was very supportive and concerned about us. They called me very often and came to visit us sometimes too. - Lisa

Our sons were very concern about him and me and they understood our situations as they called us and showed their support often. Though they were married and lived far away, they visited us whenever they had time. They reminded me that I should take care of myself besides taking care of him. - Karen

Our children showed their concerns about us, especially those two who were not married and they live on their own. They came home for dinner and visiting us once a week. Just like last evening our son came home and insisted to do the dishes after dinner before he left. I did talk about the behavioural problems of my husband with them, e.g. he refused to take a shower every day. It was really hard for me and he made me mad. It was our daughter who encouraged me to be patient with him, so I put my arm around his shoulder and told him that after taking a warm shower, he could go to bed and would have a nice sleep afterwards. And it worked. Most of all, our children were glad that their father got my help with his daily life activities. - Mrs. Woo

My husband and his younger sister had a very good sibling-relation. Though she lived in England with her own family, she came to Hong Kong for visiting us once a year. It was when I had an operation; she stayed with my husband at home while I was in hospital. Besides, our four sons were very concern about us and they drove us home after we had taken part in some social events in the late evening. But if they were not available, then we had to take a taxi home. Furthermore, they took turn to have tea gathering ¹⁸ with us almost every Sunday.
- Mrs. Wong

As I was the only child in my family, I thought it might be good if I had an elder sister who could help me whenever I need it like the other sisters did in helping each other within a family. For example, it was possible to ask a sister to help with preparing a meal rather than asking a friend to do it. On the other hand, though he had two brothers but only the younger brother who did keep on calling him sometimes as before, but not the elder brother.
- Mrs. Tse

¹⁸ Tea gathering is the most popular social activity for family members or friends to meet each other to have a meal together in a Chinese restaurant.

The expectation for getting help from siblings is natural in a family. However, it may not happen as it is expected. It could be a social burden which makes the caregiver feel resentful of other relatives who could but do not help. Joyce is an example.

Actually, I could drive and take Peter to his siblings and just let them to take care of him while I was at job. I could say to them: "Here is your brother!" But I did not want to do that. As I had a full time job, I expected his siblings could offer their help initially and I had told them that only with their help could make it possible for Peter continued to live here together with me. On the other hand, my siblings and my children showed their concern about me and they gave me telephone call often which I appreciated very much. - Joyce

First of all, as Peter had cognitive impairment and lost the ability to communicate, his siblings withdrew to have contact with him since then. Secondly, even when his brother promised to be a support contact person of Peter assisting him with some outdoor activities, e.g. swimming, Joyce reported that his brother did not manage to fulfill his promise to do the helping task properly. About the help from adult children, on the contrary, the anger reaction of the daughter of Peter towards Joyce caused the helplessness and disappointment among them. As Joyce regarded that it was not easy for the people who did not have any knowledge about dementia though they were his siblings and knew him very well before, patience and consideration were the basic requirements in helping the people with dementia. She coded an example that a support contact person walked in front of Peter with a short distance when they were out for a trip. For her, the best way to show Peter respect was to walk together with him side by side instead of letting him walking behind as a follower. Furthermore, she also pointed out it was important not to make him feel being ignored and excluded in a social contact setting, therefore, she usually arranged Peter sitting at the middle position between her and the other people during a conversation.

6.7 Social Support

Daatland (1983) regards the role which friends can play as a case of almost purely symbolic interchange while friendship in modern society is recognized by a positive will, but a limited responsibility. For example, friends very seldom take on heavy care burdens. However, in some cases, the help from the social network besides family members can be critical strength for supporting the caregiver in coping.

As Hong Kong is a densely populated city, people live closely to each other and it is easier to have social contacts among family members, friends and even neighbours than in Norway comparatively. Therefore, the Chinese respondents could have more constant social contacts and activities with their social networks than the Norwegian respondents did. The followings are some examples of the respondents' experiences of practical and emotional support from, i.e. colleague and supervisor at work, friends and even neighbours in their social network.

I became panic when they lost my husband in the hospital after giving him treatment for his heart problem while I was at job. My colleague comforted me and helped me by making some telephone calls and the staff found my husband without any harm at last. Moreover, my supervisor who was a social worker understood our situations and even accompanied me to attend the meeting with the nursing home. - Karen

One of my friends had same situation as me. Her husband was sick and she had to take care of him at home. Because of time collision, I could not meet her often but we talked on the phone sometimes for sharing and supporting each other. - Mrs. Wong

We had known some good neighbours and took part in many different kinds of activities together for many years. They were very supportive and understood our situations, e.g. they invited us to join day tour together, including meal and direct corresponding transport that was convenient for us. - Mrs. Woo

Because of the onset of dementia of their spouse, the respondents came across to have contact with the medical practitioner besides their social network who might have influence on their coping experiences, especially when the experience was not a positive one.

The doctor was very arrogant and irritated that put us in a very vulnerable situation. I told the doctor directly that we were finished with him as there was no good chemical working relationship between him and us. Therefore, I wanted Peter to see a local doctor in order to let him being treated well and feel safe and comfortable. - Joyce

The private specialist did not pay attention to us and just wonder if my husband might suffer with depression and just prescribed him some medicine to see if it could help. For me, the

most important was not medicine, but finding out what his problem was. Moreover, I was very disappointed with the staff who did not talk with me about the result of his memory test. They explained that it was not their normal routine to talk with the family except by advance arrangement. - Mrs. Yuen

6.8 Usage of Social Services

Daatland (1983) points out that family obligation and the ways they are expressed vary both by families and by cultural settings. What we do maintain that a family, like any social organization, needs to reproduce itself as a family, and that family members are actively engaged in this process during their interaction with others and each other, among other things through what they do, or do not do, in a care event. How they define their roles will in turn affect the care event in a care system.

Among those three Norwegian respondents' experiences, all of them had attended local informative and training course for the family members of people with dementia after their spouse got the diagnosis. Both Karen and Joyce had a full time job while Lisa was a housewife. Though it was only for a short while, Joyce received support contact person service while Karen received day care center and respite service and Lisa did not receive any social services. Besides, it was only Karen who had constant contact with the mutual support group members after attending the course.

Comparatively, the spouses of all of four respondents in Hong Kong received only day care center service. Besides, only two of respondents had been attended dementia seminar organized by HKADA and took part in monthly sharing meeting with the other family members of people with dementia. Mrs. Tse arranged her husband having a safety bell¹⁹ for ensuring his location in order to get rid of losing him for letting him to go to public facilities on his own. Mrs. Yuen had not arranged her husband having a safety bell yet, but she had heard about this service and she planned to receive the service in future though she was together with him almost all the time.

¹⁹ Safety Bell is a special device connecting to an operation central in 24- hour with monthly service charges.

6.9 Own Health Status & Time for Self

In fact, all of the Chinese respondents had their own health problems. Two of them were suffered with the most prevalent diseases, i.e. hypertension and diabetes and under medication for many years themselves before their spouse got diagnosis of dementia. Besides, Mrs. Wong suffered with cancer and had operated and got recovery after treatment. Mrs. Tse had to use a mild sleeping medicine while she suffered with sleeping disturbance disease because she had unconscious leg movement during sleeping in the night.

On the other hand with Norwegian respondents, except Lisa who got injury after a car accident, the other two respondents did not suffer with any serious diseases before their spouse got diagnosis of dementia. But they became to have psychological burden after their spouse got dementia, and Joyce had to take her early retirement as a result.

About the aspect of time for self, in the case of Hong Kong, while their spouse attending the day care centre, it provided Mrs. Wong to have a little break and have time to take care of daily chores and house work, most of all for some personal pleasures as she emphasised. The following are some other examples.

I did not go to elderly activity centre as the others did, but I liked to play mah-jong²⁰. Actually, it was possible for him to attend day centre everyday with payment. But it would be a time constraint for me as I had to escort him to and from between day centre and home. Therefore he stayed at home alone for some hours once a week while I could play mah-jong with my friends. It's good for me and I enjoyed it very much; otherwise, I might also suffer with dementia. - Mrs. Woo

I had been very satisfied with our happy marriage as our children had got married and having their own families. When he got retired some years ago, I had considered getting my retirement soon so that we could enjoy our retired life together. But after he became sick, and I realized that I did not want to retire yet because I had been working in my job over twenty years which was very important to me for giving me satisfaction in my life.

- Mrs. Yuen

²⁰ Mah-jong is a game played by four players. Similar to the Western card game playing by gambling, mah-jong is a game of skill, strategy and calculation and involves a certain degree of chance. It is one of the most popular social activities in Hong Kong.

6.10 Need for Institutional Care

When the deterioration becomes in advance stage, institutional care comes into consideration. The responsibility of caring will be too great; it is not the work involved that tired the caregiver most, but rather the worry about what might happen, and the fear that their spouse might be in danger without the benefit of nursing care aid. The co-operation between formal and informal care is thus not only a question of dividing task, but also a question of establishing and reconstructing role relations (Daatland, 1983).

In the case of Norway, one of the spouses died some years ago while he was under institutional care. The other two spouses became weak and had to be under institutional care. As Norway is a welfare state, it is a social right for people to get the public service when it is necessary.

On the other hand in Hong Kong, it is not a social right for everybody to get the public service except for the poorest and weakest. Since all of the spouses of the Chinese respondents were in the early stage of dementia, the need for institutional care had not come yet at the present moment. However, worries about the future care arrangement were identified among two of them who did not have intimacy couple relation with their spouse.

It was hard to say who would live longer. But I wished I would live as long as I could manage to take care of him. And I could not imagine who would take care of him in case I passed away first. - Mrs. Wong

It was only me who had pension but not him, and it was just enough for our daily expenses. I had considered about in the future when he became weaker then he needed institutional care. It had been a long waiting time for the public nursing home and the private ones were very expensive, i.e. about six to seven thousands per month. Therefore, I had started to save money for the future use. - Mrs. Tse

However, as the family bonding is so strong in Chinese culture that it is not usual to send the older people under institutional care unless there are not any other alternatives for caring arrangement within family. Mrs. Yuen and Mrs. Woo did not mention anything about the plan for an institutional care arrangement for their spouse with dementia.

Chapter 7 Conclusion and Discussion

By applying ‘person in environment’ approach, this study has explored how different cultural contexts affect the coping experiences in care giving for spouse with dementia of three respondents in Norway and four respondents in Hong Kong respectively. From the findings of this study, based on the strength of interpersonal relations between the respondents and their spouse with dementia as well as with other systems, three main affecting factors were assessed and identified, i.e. couple relation prior to the onset of dementia, functional family relationship and satisfaction with social support.

From the findings among those three Norwegian respondents of this study, it showed that an intimate couple relation was a key factor for the respondents in coping with the caregiving for their spouse with dementia. As Norway is an individualistic society where personal satisfaction and self-fulfillment are preferred, a couple stay together in their relationship either in marriage or cohabitation whenever they have emotional and interpersonal intimacy, otherwise, most people may choose to separate from each other rather than staying in a non-functional couple relationship.

The respondents and their spouses coped together by having good mutual communication when there was shared recognition of the impact of dementia and help was sought jointly. Besides being occupied with a full time job, Karen and Joyce had a plan or a view of what they could manage on the good days in order to maintain their spouse’s presence was the major coping component. All of three respondents spent most of their time together with their spouse as before the onset of dementia though Lisa found it so tough that she regarded herself like a prisoner. However, the pattern of their coping experience might be referred as ‘*working together*’ as the best case scenario by Keady & Nolan (2003).

Comparatively, among those two Chinese respondents showed that though they and their husband had been living and having children together for many years, it was not of course that they might have an intimate couple relation. Since Hong Kong is a Chinese collectivistic society in which interpersonal harmony is highly emphasized, the only reason why most people still stay as a couple in a marriage is to keep themselves as a family together. A divorced couple means not only a broken marriage but also makes a family being broken, especially if they have second generation and it may be hard for their children. One finding in

this study is worth to pay attention to: long marriage, in the case of Hong Kong, might not be a good indicator of couple intimacy, but comparatively it could be in the case of Norway.

Lacking of knowledge about dementia of its symptoms and management was a common feature of all of respondents in this study. Therefore, the awareness of the symptoms was low and caused the delay of getting diagnosis. However, after getting the diagnosis, most of respondents got the information actively by attending course and reading books that helped them to understand that it was because of the cognitive impairment which caused the behavioural change of their spouse. At least they got the name of the problem and accepted it. By acknowledging that their spouse would not recover, they had no other option but they and their spouse had to cope with it.

The reaction and attitude toward obtaining a diagnosis of dementia was quite different among the Norwegian respondents and the Chinese respondents since the level of intimacy of their couple relation were different. Feelings of loss and grief were common among the Norwegian respondents as they struggled with a diagnosis that suggested an ongoing cognitive decline and increasing impairment of their loved one, i.e. an important person in their life. When *he* became sick, Karen referred that '*Dementia took him away from me*'.

Comparatively, except Mrs. Yuen, the other three Chinese respondents did not have a feeling of loss while they regarded the problem was 'he became *sick*'. When Mr. Wong did not come home as usual that evening, Mrs. Wong called the police for help rather than calling to her husband directly, it might because she did not have good mutual communication with her husband. After getting the diagnosis, the focus of the problem was on how to cope with the dementia rather than their feelings towards to their spouse.

All of seven respondents redefined themselves within the context of caring for and responding to their spouse. The role of caregiver became part of their new identity besides being a spouse. In spite of the level of intimacy of their couple relation were different, all of the respondents knew their spouse very well since they had been living with their spouse for many years. Their special knowledge and skill served as a kind of strength for them being a caregiver for their spouse. From their descriptions, almost all of the respondents claimed that they managed quite well to look after their spouse in their daily life activities as well as they could while they knew their spouse better than anyone else did.

The history of their couple relation had a powerful impact on their identities, as did the commitment the respondents felt both to their spouse and to their couple relationship. It could be understood that all of the respondents were in their generation keeping their relationship for better or for worse, and that they were not the divorcing generation especially for the Chinese respondents.

The findings suggested there was a couple-or family-oriented aspect to the care giving of the respondents while they saw themselves and their spouse as a couple (in Norwegian case) or as a family (in Chinese case), and that perspective did not disappear for them after their spouse got dementia. Although the dependency of the spouse with dementia was problematic and had an impact on roles and identities, the presence of their spouse was powerful enough to be part of how the respondents constructed their daily lives. Caring for a lifelong partner was simply part of the marital bond for the respondents as many older adults. It showed that there was an association between their cultural belief and caregiver reward, i.e. a common cultural norm of obligation served as a motivating force for the respondents to provide care for their spouse with dementia both in Norway and Hong Kong.

About family relation and functioning aspect, as Daatland (1983) points out that it is not implied that closer relation is necessarily the better in Norwegian society. Furthermore, he refers Bengton and Kuypers conclude that there is surprisingly little evidence that close family interaction improves the morale and psychological well-being of the aged. Most of all, they regard the ambivalence of family relations is probably the explanation for what Rosenmary and Kjøckeis term '*intimacy but at a distance.*'

In the Norwegian case, Karen and Lisa got some extent of emotional support and concern from their adult children and siblings. However, Karen emphasized that she found it was very helpful for joining the support group where she could get social support from the other spouses who had the same situations as her. On the other hand, Joyce felt frustrated and helpless while his siblings withdrew back and her step-daughter's anger on her that made no supportive family functioning in her case.

Inside a family, couple relation comes first, and then the parent-child relation. Filial obligation is a Chinese cultural norm that children have to '*pay back*' to parents for their rearing and upbringing. Although not all of the respondents who did enjoy an intimate couple

relation with their husband, as a mother, they had a close parent-child relationship with their adult children. Constant concern and emotional support from their adult children were key factors of strength for the respondents to cope with the care giving for the spouse with dementia whom they regarded as '*the father of their children*' in a family as a whole.

Comparatively, since the family bonding was much stronger in Chinese culture, the family functioning was much better among the families of the respondents in Hong Kong. In spite of whether the presence of the expressions of gratitude or appreciation direct from the spouse, the acknowledgments from other family members, i.e. children, siblings and in-laws etc. whether perceived as praise and recognition were found to be important factors that made the respondents feel rewarded and less burdened in coping with caregiving for the spouse with dementia. Moreover, the respondents also got social and informal support from friends or even neighbours in promoting their psychological adjustment in coping with the caregiving as well.

Spousal caregivers are usually seniors themselves, so they often have to face the most difficult challenge of their life while experiencing their own age-related health problems. Moreover, women are an important group of caregivers who may be particularly vulnerable because of their won advanced age and concomitant health difficulties in most cultural contexts. As a result, caregiver burden and health deterioration are reasons for their discontinuing home care. It is emphasised that social and health care services for caregivers, particularly elderly frail spouses, need to be developed which promote health and quality of life.

There are three limitations of this study. First of all, the sample is small, only seven respondents that the results could not be generalized to all female spousal caregivers for people with dementia. Secondly, the sample is only spousal caregivers of one gender, i.e. female and of two ethnic, i.e. Norwegian and Chinese. Besides the issue of gender and ethnicity, there are many other aspects, e.g. age, educational level, working experience, social class, economical situation and religion etc. have not been discussed in this study. Thirdly, the results are an interpretation of their recollections and reconstructions of their coping experiences in care giving for spouse with dementia. It can be understood that relying on data coming from people's retrospective perceptions runs the risk that memories become distorted in the light of subsequent experiences.

Willingness to take part of this study could be regarded as a good sign that for showing that the respondents had been coping satisfactory with their situations. However, there are many silent and passive spousal caregivers who might not receive any attention about their needs from their family members, their social network or even the society where they live in. Because of limited or inadequate personal and interpersonal resources to meet the caregiving demands might put them in vulnerable situations in coping with the caregiving for spouse with dementia.

As this study only used interpersonal relation approach of systems theories and strengths perspective in the data analysis, it is suggested to apply other social work theories may be useful to explore different experiences in care giving for spousal with dementia in different ethnic groups. Intervention needs vary, in part, among different ethnic groups of caregiver in different social and cultural contexts.

Being a Chinese, I regard older people are respectable since they have made a lot of valuable contributions both material and non-material to the society through their families, occupations and social participations, and younger generations benefit from their experiences. Most of all, social and economic policies, services and research are needed to enhance the well-being of older people and to eliminate the ageism that prevents older people from living with dignity, realizing their full potential and accessing resources.

Finally, according to The International Federation of Social Workers (IFSW), many countries report that Alzheimer's disease is one of the costliest illnesses, yet research and investment are at a significantly lower level compared to other major illnesses. IFSW advocates joining around the world who are involved in focusing on the need for governments and the general public to take any action they can to raise awareness of dementia and improve service provision for people with dementia and their caregivers. Most of all, social workers are well positioned to collaborate with older individuals in creating and advocating for ageing-friendly policies and programmes, and to provide culturally competent services to older individuals.

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Intervjuguide

”Mestringsstrategier i Omsorg for Ektefelle/Samboer med Demens”

A. Innledning

- a. Presentere meg selv
- b. Informere om **Forespørsel om deltakelse i forskningsprosjektet**
- c. Informere om informantens rett til å avbryte intervjuet når som helst
- d. Antyde hva intervjuet vil vare tre områder:
 1. samlivsforhold før fikk diagnosen
 2. praktiske dagligliv etter fikk diagnosen
 3. mestring i å gi omsorg

B. Intervjuespørsmål

1. Faktaspørsmål

Fortell litt om deg og din familie

Alder: _____ Utdannelse: _____ Jobb: _____,

Sivil status: gift/samboer Barn: _____, hvor gamle: _____ år _____ år

Økonomiske situasjon: _____ Pensjon, omsorgslønn

Religion: _____

2. Introduksjonsspørsmål

- 2.1 Hvilke tanker hadde du om demens?
- 2.2 Hvordan og når hadde du merket at det var noe er galt, endring med din ektefelle/samboer (lider av hukommelsessvikt)?
- 2.3 Når fikk din ektefelle / samboer diagnosen? Hva hadde hindret eller hjulpet evalueringsprosessen?
- 2.4 Hvordan ble diagnosen mottatt i din familie?

3. Nøkkelspørsmål

- 3.1 Hva tenkte du på da din ektefelle / samboer fikk diagnosen?
- 3.2 Beskriv din opplevelse av å være hovedomsorg person for din ektefelle / samboer?
Hva betydde deres samliv for deg?

- 3.3 Hva var *forskjell* på hvordan deres samliv arter seg da - og tidligere?
- 3.4 Hva var praktiske utfordringer i hverdagen?
- 3.5 Hvordan løste du dem? Hvem hjalp du med?
- 3.6 Hvor ofte hadde du kontakt med dine barn / slektninger / venner?
- 3.7 Hvor ofte fikk du råd og informasjon om medisinske, økonomiske eller familieproblemer av dine barn / slektninger / venner?
- 3.8 Hva kjente du til av noen kommunetjenester? Hva hjelp hadde du?
- 3.9 Hvilken hjelp ønskte du få, savnet du noen hjelp?
- 3.10 Hva gjorde du dersom du hadde fritid?
- 3.11 Hvordan beskrev du helsen din?
- 3.12 Savnet du noe i forhold til deg selv?
- 3.13 Hva synes du er det viktigste i livet?

4. Avslutning:

- Har du noe du vil legge til?
- Er det noe du lurer på om intervjuet?

Da takker jeg for din tid.

Paulina Leung Rønvik
Kanalveien 17, 8030 Bodø.

Navn av mottaker

Adresse

05.10.2012

Hei!

Forespørsel om deltakelse i forskningsprosjektet

Bakgrunn og hensikt

Mitt navn er Paulina Leung Rønvik. Jeg er student i sosialt arbeid ved Universitetet i Nordland og holder nå på med en avsluttende masteroppgave. Professor Agnete Wiborg er min veileder. I denne anledningen skal jeg skrive prosjekt oppave om demensomsorg. Jeg vil undersøke hvordan samlivsforholdet mellom personer med demens og deres ektefeller/samboere fungerer. For å finne ut av dette, ønsker jeg å intervju fire personer som er hovedperson i å gi omsorg for ektefelle/samboer med demens.

Hva innebærer undersøkelsen?

I studien vil jeg bruke intervju som metode for å samle inn relevant informasjon. Undersøkelsen er frivillig, og informasjonen vil bli behandlet anonymt. Spørsmålene vil dreie seg om hva demensomsorg betyr for deg, hvordan du oppfatter og opplever å gi omsorg for din ektefelle/samboer med demens hjemme. Jeg vil ta lydopptak og notater mens vi snakker sammen. Intervjuet vil ta omtrent en time, og vi blir sammen enige om tid og sted.

Hva skjer med informasjonen om deg som informant?

Informasjon om deg som informant vil ikke bli registrert verken i notater eller i oppgaven. Alle opplysningene vil bli behandlet uten navn eller andre direkte gjenkjenkende opplysninger. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å være med, og du har muligheten til å trekke deg når som helst underveis, uten å måtte begrunne dette nærmere. Dersom du trekker deg, vil alle innsamlede data om deg bli slettet. Opplysningene vil bli behandlet konfidensielt, og ingen enkeltpersoner vil kunne kjenne seg igjen i den ferdige oppgaven. Opplysningene anonymiseres, og notatene vil bli makulert når oppgaven er ferdig midt i mai 2013.

Hvis det er noe du lurer på, kan du ringe meg på mobiltelefon: 452 64 451, eller e-post: paulina.leung@hotmail.com

Jeg håper å få positivt svar av deg. Takk på forhånd.

Med vennlig hilsen

Paulina Leung Rønvik

“Coping Strategies in Care Giving for Spouse with Dementia”

A Comparative Social Study in Hong Kong and Norway

Hi, my name is Paulina Leung. I was born and grew up in Hong Kong. In 1986 I got a Diploma in Social Work at the City Polytechnic of Hong Kong. Later on I had been working as a Senior Social Work Assistant for many years in Hong Kong until I got married with a Norwegian man and moved to live in Norway in December, 2000. I finished a Bachelor in Social Work here in Norway last year. Being a student of ***Master in Social Work with a Comparative Perspective*** program 2011- 2013, I am doing my master’s thesis at the present moment. As I think about the usefulness of comparative analysis, I aim to practice the skills of doing comparative social study by comparing the findings of this study with those from relevant published research, survey and census analysis. Most of all, like the vast majority of students undertake their empirical thesis, I regard this study will enable me to explore and understand what dementia families are facing by reading a lot of relevant literature and gain hands-on research and data analysis experience both in Hong Kong and Norway. Hopefully, the experience of doing this study will be helpful and useful for my future career and employment in social work field dealing with dementia families.

Furthermore, there are a lot of studies about the impact of dementia on the patients and their families done by health professionals mainly in Western countries, but there are a few comparative social studies with a cross-cultural perspective done by international social work profession on this domain. Therefore, my research project will employ in-depth interviews as research method to explore and understand the relationship between the perceived well-being of the spousal caregivers and their coping strategies and social support seeking behaviour in care giving for people with dementia in Hong Kong and Norway in response. The study findings will hopefully be used as a reflection of social work interventions including identifying the pull and push factors that contribute successful or unsuccessful service delivery.

I understand that doing comparative study requires careful thought about sampling. As this study will use cross-cultural perspective to analysis both the similarities and differences, and the strength and limitation of the coping strategies of spousal caregivers in relation to their

perceived well-being, I believe that I am capable to do this comparative social study in Hong Kong and Norway where I am familiar with in terms of social and cultural aspect rather than the other countries'. Norway is a Scandinavian country with about five million populations. The data of statistics shows that the life expectancy in Hong Kong and Norway is almost the same, i.e. around 78 years for men and 82 years for women. Surprisingly, there is also almost the same amount, i.e. 70,000 people are living with dementia both in Hong Kong and Norway. As a result, the prevalence rate of this disease is 1 % of the total population in Hong Kong while 1.4 % of total population in Norway respectively. Norway is a welfare state which is a social democratic society and the provision of welfare is state based with universal citizenship right while Hong Kong is not a welfare society comparatively. Interpersonal harmony is highly emphasized in Hong Kong Chinese collectivistic society while personal satisfaction is highly preferred in Norwegian individualistic society.

I know my research project is going to study only eight respondents, four in Hong Kong and four in Norway, i.e. a relatively small database, but I believe that the finding will indicate far larger phenomena. In order to deal with growing aging population with dementia, I hope via the findings of this comparative social study on coping strategies of spousal caregiver of people with dementia will hopefully have significant implications for social work professions to have better understanding when they deal with dementia families in Hong Kong and Norway. There is an increasing need to provide interventions which offer opportunities for spousal caregivers to decrease their loneliness, to increase their self-esteem and to enhance their quality of life.

Professor Steven M Shardlow has been very supportive for my research project and I am very grateful for his help. In order to collect data in Hong Kong, I am going to take a trip to Hong Kong in December and stay until February in 2013 to do the interview. I am writing here and asking for your help with recruiting the four respondents in Hong Kong for my research project. Besides, I want to get some information about relevant published research or survey and census analysis in Hong Kong. All kinds of help and information related to my research project are welcome and highly appreciated.

Best regards,

Paulina Leung

paulina.leung@hotmail.com

面試指南

“照顧癡呆患者配偶因應策略”

A. 導言

- 介紹自己
- 通知要求參與的研究項目
- 通知參與者的權利, 任何時候終止訪問
- 面試將持續三個方面：
 - 被確診前的婚姻關係
 - 實用的日常生活
 - 照顧服務的應對

B. 面試問題

1. 事實問題: 告訴我一些有關你自己和你的家人

年齡:____ 教育:_____ 職業:_____

婚姻狀況: _____ 兒童: _____, _____歲

經濟狀況: _____ 宗教: _____

2. 簡介問題

2.1 你如何認為老年癡呆症呢？

2.2 你何時注意到你的配偶患有記憶力減退, 有什麼不對的變化？

2.3 什麼阻礙了或幫助評估過程？

2.4 你的家人如何收到你的配偶診斷？

3. 關鍵問題

3.1 你的配偶/伴侶被診斷, 你覺得如何？

3.2 你是主要照顧你的配偶/伴侶的人, 描述你的經驗, 你們的關係意味著什麼嗎？

3.3 早前的時候有什麼不同, 你如何體現你們的關係呢？

- 3.4 日常生活中面臨的實際挑戰是什麼？
- 3.5 有沒有關心你的人？有誰幫到你嗎？你的孩子 / 親戚 / 朋友？
- 3.6 什麼樣的幫助？你是怎麼得到他們呢？
- 3.7 什麼建議和有關信息，醫療和家庭問題嗎？
- 3.8 你得到了什麼社會服務嗎？什麼樣的幫助？
- 3.9 你想要得到的什麼樣的幫助，但沒有得到？
- 3.10 如果你有自己的時間，你想做什麼？
- 3.11 你如何描述你的健康？
- 3.12 你想給自己什麼東西嗎？
- 3.13 你認為什麼是生命中最重要？

C. 結論：

- 是否有任何有關採訪的問題嗎？
- 你有什麼要補充的嗎？

非常感謝您的寶貴時間