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# THE EXPERIENCES OF TAIWANESE WOMEN CAREGIVING FOR

## PARENTS-IN-LAW

by

Shu-Yuan Chao

## A dissertation presented to the

## FACULTY OF THE PHILIP Y. HAHN SCHOOL OF NURSING

## **UNIVERSITY OF SAN DIEGO**

In partial fulfillment of the

## requirements for the degree

## **DOCTOR OF NURSING SCIENCE**

May 1997

## **Dissertation Committee**

Patricia Roth, EdD, RN, Chair Mary Jo Clark, PhD, RN Mary Ann Hautman, PhD, RN

#### ABSTRACT

Using grounded theory, a semi-structured in-depth interview was conducted to explore the experiences of Taiwanese women who were caregivers for their parents-inlaw. Thirty-one Taiwanese women aged 23 to 58 participated in this study. Just Doing was identified as the core category to indicate the caregivers' striving process once they committed to their in-laws' care. Recognizing Duty, Experiencing Trials, and Responding to Caregiving were subcategories and reflected how a caregiver perceived her role, how she was affected by caregiving tasks, and what's responses she had to the caregiving situation.

The findings also suggested that caregiving behaviors were influenced by cultural expectations when the parent-in-law was ill. Being Called, a condition in this study, indicated that caregiving tasks were started when the caregiver recognized providing care was her duty. Caring For reflected the context for providing daily comfort, keeping watch, as well as seeking assistance if needed.

The category of Holding Up involved the ability to persevere in providing care and was influenced by the depth of family relationships, their appreciation and degree of reinforcement. The extent of the difficulties and the resources for care also affected the ability to continue caring. Additionally, the strategy of Keeping Harmony, was adopted by caregivers to comfort themselves and cope with their caregiving difficulties. This category reflected Taiwanese women's fatalism and optimism in meeting the daily care needs of a parent-in-law. Maintaining Filial Pity was identified as a consequence of a caregiver's experience in fulfilling her duty. As a daughter-in-law, she was able to establish an inner

peace or serenity. If this was not possible, she continued to have inner conflict and perceived her life as one of sacrifice.

This story of Taiwanese women caregivers' experiences may be beneficial in facilitating the development of a comprehensive policy for long-term care. These women's voices will be helpful in forming the basis for nursing intervention strategies for individual and family care. Recommendations for future research focus on cultural determinants of caregiving roles and coping strategies.

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### DEDICATION

This dissertation is dedicated to my dad, who taught me to face challenge with perseverance. He always believed I would reach my life's goals, no matter how difficult the task. Although he passed away during the first year of my doctoral program, his belief continuously sustained me especially when I was frustrated. Dear dad, I wish you to know, I made it.

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بالمحاد والرابي والمحمد المحمد الدورامين

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### CHAPTER I

## FOCUS OF THE STUDY

The population of Taiwan is changing and there is an increasing older population. Predictions show that the proportion of the population over age 65 will be more than 10% by the year 2010 (Council of Economic Planning and Development, 1993). There is increasing incidence of chronic illness, along with an increasing aging population (Wu, Hu, & Yao, 1991).

It is estimated that around 12% of the elders over age sixty-five in Taiwan are frail and/or have cognitive impairments, such as senile dementia, and cannot provide self-care (Department of Accounting and Statistics, 1990). Most of them live at home and are taken care of by a family member. However, family members often lack enough resources, and research has found that these caregivers are facing great burdens when providing for elder care (Wu et al., 1991; Hu, 1994).

Although a government program for home care was started by health professionals in 1987, it is still in the early stages of development. Some private "geriatric home care" options exist, but are costly, and it is reported that clients have been abused (Lee, Wang, & Jou, 1990). In addition, inadequate medical insurance and a family's financial burdens often prevent patients from staying in hospitals for extended periods. Therefore, families may be the only providers for those who need extra care or rehabilitation after discharge from hospitals (Liu, 1991). In many cases, women family members are the primary caregivers (Wu & Chiang, 1995). The major reason might be cultural influences.

Traditionally, in this patriarchal society, women were subordinate to men. Females were taught to respect and obey male family members. They owed obedience to their fathers, to their husbands, and to their sons. Filial piety is the basis of all virtues, and is considered to enhance or maintain family harmony (Huang, 1989; Yang 1989). This virtue emphasized that a woman should devote herself to her husband's parents and extended family, and it especially emphasized taking care of parents-in-law (Yang & Yeb, 1991; Uba, 1994). In addition, this cultural emphasis on women being responsible for the care of parents-in-law is stronger than their responsibility for their own parents' care (Tsui, 1987). Too much involvement by a woman in her own parents' care is discouraged by the husband's family.

These cultural influences still exist in contemporary Taiwan (Hu & Chen, 1992; Hu, 1995, Chao, 1996). Although sons in Taiwan traditionally have the responsibility and obligation of taking care of their aging parents, more than half of their wives assume the responsibility of caregiving when the elder parents are frail (Hu, 1995). However, Taiwan is facing a transition. After 1945, when Taiwan was restored to China, Taiwanese women had the benefit of a Constitutional change in their legal status. Women began to enjoy equal rights and opportunities in various aspects of society such as education and employment, as well as participation in politics. By 1970, Taiwan had undergone a transformation from a traditional agricultural society to an industrial economy. Due to industrialization and urbanization, most women have joined the labor force (Tsui, 1987). Better opportunities for education and employment have helped women to gain more selfesteem (Yao, 1983). The result of this is an internal struggle among Taiwanese women with the pursuit of a career and its demands for more independence competing with the deeply imbedded cultural affinity for filial piety (Hu & Chen, 1992; Hu, 1995).

In addition, the family structure has been changing along with the changing society. Today, as the nuclear family becomes more prominent in this society, women are faced with the competing roles of worker and expanded family caregiver (Tsui, 1987). As the impact of providing elder care increases, its influence on the health of caregivers and care receivers is more apparent (Wu et al., 1991; Ton, Mao, Chou, Chen & Liu, 1992).

In Hu and Chen's study (1992), the findings reflected the difficulty of providing inhome care for in-laws in Taiwan's rapidly changing environment. The major social cause of role stress in this study was found to be facing the competing roles of worker, wife, mother, and daughter-in-law. In considering the sources of role stress, workload is not the only factor. The emotional and psychological burden of caregiving also has an impact. The burden women experience is related not only to the lack of support from family and colleagues, but from an outdated and rigid hierarchical status still operating in Taiwanese families. For example, in a dual career household, tradition dictates that working women should still carry out traditional roles such as handling household duties or providing service to parents-in-law. These women have been called "no voice caregivers" (Hu, 1995, p.85.)

Although caregiving issues related to the impact on the caregiver have been explored in Taiwan, there is still no theoretical model to interpret the phenomenon of caregiving. Currently, most studies conducted in Taiwan are approached from quantitative methodology based on the models and available instruments constructed in

the United Stated (Chiu, Lu, Shu, Ju Chen, & Liu, 1988 ; Die, Yui & Lien, 1990; Liu, 1991 ; Shern & Chang 1993 ; Ton et al., 1992; Tsai, 1995; Wu et al., 1991). These studies served an important role in identifying the needs of family caregivers. However, because of cultural limitations and lacking caregiver's subjective expression, there is not enough information to understand a Taiwan caregiver's inner thoughts, feelings and the family members' interaction during the process of caregiving. In addition, the caregiver's motivation is a subjective feeling, which was considered as an important factor affecting the caregiver's burden (Yang, 1989). However, few pieces of literature have been able to examine these subjective reactions, including the caregiver's relationship with her in-laws and her feelings of obligation and responsibility. In the literature review, both in Taiwan and the United States, it was found that the variables influencing caregivers' stress or burden are not all positive nor all negative, nor can they be fully understood through the use of carefully constructed quantitative studies on burden, benefit, and their mediating factors.

Therefore, another way to understand the situation is to truly enter the world of the caregiver, exploring the context and the caregiver's perception of the situation, identifying the inner conflict and coping strategies used in caregiving for the frail elderly.

## Purpose of the Study

The purpose of this study was to explore the caregiving experiences of daughtersin-law as they provide care for sick mothers- or fathers-in-law in order to generate data and develop a substantive theory based on the perceptions, beliefs, values, feelings and strategies regarding in-law's care among Taiwanese women. Thus, the study addressed the following questions:

1). What are the cultural factors which influence the caregiving experience?

2). How do perceptions of the caregiving role affect a caregiver's behaviors?

3). What is the impact of caregiving on daughters-in-law?

4). How do these daughters-in-law construct their daily lives and maintain balance?

## Assumptions

Since grounded theory research requires interpersonal interaction, one must become aware of personal perceptions, values, and beliefs in order to maintain the research's objectivity. Hutchinson (1993) emphasized that only through self-awareness of mind-set can the researcher begin to search out and understand others' worlds.

Thus, the researcher had certain assumptions about the experiences of women caregivers that must be stated in order to gain an understanding of an individual's experience of this phenomenon. The researcher's assumptions included:

1). People's experiences are based upon their personal histories, life experiences, and their own internal thought process.

2). Following Confucius thought, the belief of filial piety has been cultivated into Taiwanese people's minds regardless of age or education.

3). Taking care of parents-in-law is one's obligation and one's major virtue.

4). Filial piety, intertwined with religion has become the social norm, which will influence individual behaviors based on the heteronomous (being under the domination of an outside authority) or compulsory morality.

5). The belief in filial piety has been internalized by means of socialization. In other word, the perception of filial piety is the antecedent of filial behavior.

6). The nature and spirit of caregiving might be different between care for their own parents and those of parents-in-law. The former is based on biological feeling; the latter is based on obligation and responsibility.

7) Last, the process of caregiving brings tears, but also joy.

## Significance of the Study

As society changes, the needs of the elderly are increasing, and family members are considered the major resources for care. However, the phenomenon of care is still not understood completely, and institutional/governmental policies for care of the elderly are also in the initial stage of development. Therefore, it is important to obtain more information about the experiences of the primary caregiver and to specifically study three significant implications for women caregivers and their elder family members.

First, this study has explored the needs of both women caregivers and frail elders. Since there is a shortage of long term care institutions and insufficient health insurance, family care is considered the primary option. However, daughters-in-law, who are expected to provide elder care have been restricted by social norms from expressing their feelings about this role and have often tolerated stress without expressing feelings of dissatisfaction (Hu, 1995). This research may be an outlet for these women to voice their struggles, which might be derived from self-expectation and environmental expectations and demands. Furthermore, by identifying the complicated dynamics of roles, stresses, and issues in a different social and cultural context, the "voices" may help form the basis

for intervention strategies for individuals and also family care provided by health care professionals. Therefore, negative effects might be minimized, and shared positive experiences would be a valuable reference for empowering the caregiver to continue care.

Next, the findings could facilitate the establishment of a policy for long term care. Since there is a longer life expectancy and a lower birth rate, the result will be an increasing need for elderly care (Wu, 1994). As the burden on caregivers increases, the government has the responsibility to understand more about caregivers' challenges and difficulties during the process of parental care in order to provide better quality care for elders. Health policy initiatives may include instrumental support, financial aid, establishment of social welfare systems, and so on. In addition, the findings of this study may enhance the ability of decision makers to consider policy related to additional longterm care needs.

Finally, the findings of this study afford a direction for future research. As Leininger (1985) described "nursing has philosophical, historical, and epistemological beliefs that are deeply rooted in humanistic service to human kind, and these roots can best be discovered by qualitative methods" (p. 22). Since there is a lack of a complete model based on the cultural context for understanding women caregivers' constraints, this study is designed to gain a holistic perspective on the caregiving phenomenon in Taiwan. Hopefully, the findings will be helpful in facilitating formulation of a care model, which could be tested in subsequent research.

#### CHAPTER II

## **REVIEW OF THE LITERATURE**

This literature review focused on three aspects. The first aspect was the sociocultural context of Taiwan, which includes the ethno history of the Taiwanese people; women's roles and their past and current status; and family structure, values, and filial piety. It is important that these aspects of Taiwanese culture be reviewed, as they form the foundation for understanding the social context of caregiving behaviors and practices and the environmental changes which influence caregiving. The second aspect was current caregiving practices in Taiwan including needs, styles, and resources. The third aspect examined the impact of caregiving on families in terms of physical, psychosocial, financial, and other dimensions.

## Sociocultural Context

## Ethno History of the Taiwanese People

Taiwan is an island, located in the western Pacific Ocean, roughly 100 miles off the southeast coast of Mainland China, 200 miles from the Philippines, and approximately 700 miles south of Japan. The island, which is almost 394 kilometers in length and 144 kilometers in width at its widest point, is an area which is approximately 35,961 square kilometers; it is little larger than the Netherlands and a little smaller than Switzerland. Rugged foothills and mountains cover two-thirds of the island and forests cover over one-half of the island. Only a quarter of the total land area is arable, this area located in the

western coastal plain region and containing most of the area's population (Kuang Hwa, 1992).

Historically and culturally, Taiwan has been closely linked with the Chinese mainland. The island was settled by the Chinese in the Three Kingdoms Period (239 A.D.). Taiwan was first known to the West as Formosa, a name given by the 15th century Portuguese sailors who declared the island "beautiful island." The early Portuguese were not the only foreigners to be attracted to Formosa (Taiwan). During the 17th century, the island was subject to a variety of outside influences, who occupied it, in whole or in part. They included the Dutch, Spanish, and French. In 1661 A.D., Cheng Cheng-Kung took Taiwan from the Dutch and chose Anping as the capital. Chinese people soon came to Taiwan and became the majority of the island's population. For the next 200 years, the island was a destination for emigrants from the provinces of Fukien and Kwangtung. Culturally, economically and politically, Taiwan has remained predominately Chinese since it became a protectorate of the Chinese Empire in 1206. In 1684 it was made a prefecture of Fukien province, and in 1887 it attained provincial status. Governed by Japan as a colony from 1895 to 1945, Taiwan reverted to Chinese administration at the end of World War II (Kuang Hwa, 1992; Lieu, Jor-Lin & Song-Youn, 1993).

By December 1949, mainland China fell into the hands of the Communists. The National government of the Republic of China moved to Taiwan and many army officers and their families were transferred to the island, which increased the population. After 1949, approximately, one-eighth of the population were mainlanders from China, others were Hokkien and Hakka speakers, referred to as Taiwanese, a few minorities and

aborigines, most of whom still lived in the mountains (Kleinman, 1980; Chen, Chuang, & Huang, 1994; Kuang Hwa, 1992).

Many dialects are spoken in Taiwan. The main dialects are Taiwanese, Southern Fukienese, and Hakka. Mandarin was made the official language and is used for the language of instruction in the schools. Today, almost all of the younger generation is fluent in standard Mandarin, while dialects continue to be used in informal situations and in certain types of business (Kuang Hwa, 1992).

In the last forty years, tremendous progress has been made economically, politically, and socially. On the aspect of economy, Taiwan has changed from a basic agricultural society to a highly industrialized one; from labor-intensive to capital-intensive. With respect to politics, the government moved to carry out its program for local selfgovernment soon after it arrived in Taiwan. Dramatic reforms took place from 1986 to 1990. These included the lifting of martial law and the ban on strikes and demonstrations, the formulation of new political parties, freedom of speech, and publication. These moves reaffirmed the greater political maturity of both government and populace, which was enhanced by the direct election of the president by the people in 1996. On the social aspects, 99.9% of school-aged children are enrolled in elementary school and since 1950, the number of university students has increased more than 85 times. In addition, modernized and convenient transportation has crossed the island and improvements in science have improved the quality of life (Chiang & Ku, 1985 ; Kuang Hwa, 1992).

Since the post-war period, improvements have been made in public health, medical facilities, technological levels, sanitary habits, and the standard of living. Concurrent with demographic changes, improvements in social well-being have been indicated by other

statistics (Chiang & Ku, 1985). Life expectancy, for instance, has increased for males from 53.38 years in 1951 to 71.61 years in 1993, and from 56.33 to 77.52 years for females in the same period. The infant mortality rate has decreased from 44.71 per thousand live births in 1952 to 4.80 per thousand in 1993. Continuous increases in the population have resulted in Taiwan having one of the highest population densities in the world, with a population of over 21 million or 587 persons per square kilometer. In Taipei, the capital of Taiwan, there are 9,763 persons per square kilometer (Department of Health, 1995). As a result, new health issues have emerged including the need for more birth control programs. Chronic illness has replaced acute disease and has become the major cause of death. Consequently, more care is needed for elders. In addition, because more people have settled in Taipei, housing prices have become so expensive that most people live in small apartments. Because of this crowded environment and modern life style, many elderly people would like to stay in their own community in middle or south Taiwan, rather than move to Taipei to live with their younger generation.

Another important social aspect to consider is religion. The difficult pioneer environment of Taiwan for the past two centuries created a strong need for religion, and folk religion was the unanimous choice of Chinese immigrants. Taiwanese religious life is a combination of early folk tradition, native Taoism, and Buddhism, interwoven with Confucian philosophy. According to a survey, 65 % of the population in Taiwan can be considered believers in Chinese folk religions. Along with their beliefs, people brought the god images and rituals to which they were accustomed from the China mainland. However, they changed them functionally to fit into their new society, even creating new gods and rituals to meet their needs for security and survival. Because there is freedom of

religion in this country, Christian, Catholic, and Islamic religions are also practiced (Lieu, Jor-Lin & Song-Youn, 1993; Kuang Hwa, 1994; Kuang Hwa, 1992).

Traditionally, Chinese people have valued harmony and balance. The concept of harmony and balance is expressed on three planes: those of the individual, of nature, and of society (Li, 1989; Yang, 1989; Kuang Hwa, 1994).

On the individual level, Chinese people strive to maintain a balance between the forces of *Yin* and *Yang*, which have influenced the concepts of hot and cold in Chinese food and medicine. For example, the root of Chinese goldthread is considered cold and can relieve internal heat, while ginger duck is considered hot and a fortifying dish in the winter. In addition, many Chinese practice *ch'i-kung*, in order to regulate their respiration and stay healthy by balancing the forces of *Yin* and *Yang*. Both diet and Chinese medicine are related to an individual's inner balance. The external balance is how a person's name relates to the five elements of metal, wood, water, fire and earth. In popular belief, any imbalance among the five elements is dangerous. For example, an infant whose constitution is believed to be deficient in the water element would be given a name with the "water radical."

Balance in nature, the second plane of belief, can be explained in terms of time and space. The Chinese understand that time involves both public and personal time. Chinese people believe there is a public time in the universe that constantly flows forward and against which personal time can be oriented. The most crucial element in personal time, and the part that is fixed at birth, is a person's Pa-Tzu, or eight characters. The Chinese believe a person's Pa-Tzu determines his *ming*, or fate, which is fixed and immutable and determined at the point where personal and public time intersect. The so-called "fatalism"

of the Chinese people has evolved from this concept. However, a person's *Yun*, or fortune can be altered and changed. When the personal time of an individual is in proper accord with public time, good fortune is on its way. It is in order to seek such temporal balance that so many people have their fortunes told, even in today's scientific era. People also believe good virtue, which follows Confucius' norm, will affect their fortune.

The third plane of harmony and balance is social. It is believed that the highest principle is maintaining harmony among people in their interpersonal relationships, which can be divided into those involving the family, the community outside the family, and the supernatural. The supernatural refers to heaven, ghosts, spirits, and all things unknown. The Chinese have extended their desires to maintain harmonious relations within the family to deceased family members, thereby giving rise to ancestor worship. People maintain ancestral tablets in their homes.

Chinese culture, reflects Confucius's philosophy of "Benevolence" which is still the core belief of this country's people. This belief emphasizes harmonious interpersonal relationships, including those between husband and wife, father and son, older and younger brother, friend and friend, and ruler and subject. The foundation for each relationship should be built on sincerity, loyalty, and mutual respect. It is also based on the idea that desires must be controlled to avoid conflict. Self-cultivation and self-discipline are considered the mainstays of social identity and moral behavior (Tseng, 1981; Kuang Hwa, 1992).

Following these ideas, the Chinese reflect on aspects of the self. This includes, not boasting about one's accomplishments or expressing one's opinions; being humble and modest; being sensitive to subtle verbal and nonverbal cues, and hiding personal pain in

order to protect the feelings of the person who hurt them (Uba, 1994). Tseng (1981) also indicated that these beliefs influence the external relationships of people including respecting authority and emphasizing the reciprocity among people. These beliefs are reflected in the relationship among family members which emphasizes harmony. They are reflected in the interaction with cosmology which includes understanding that a person should adapt to the environment, not overcome the environment, and reflected in the attitude of time which includes keeping traditions and not making changes. Delayed gratification and perseverance are practiced when in unpleasant situations. Additionally, these beliefs are reflected in expression which emphasizes being patient, gentle, well mannered, cooperative; compromising instead of being against, and self-suppression instead self- expression. Traditionally, shame and guilt were used to control an individual's behavior. Chinese people tried to make people feel guilty especially when a person abandoned a family member. Communication style tends to be restrained and indirect. Verbal communication in a traditional Chinese family tends to be relatively restrained. In addition, emotions are communicated through actions rather than words, concern is revealed through care of others' physical needs (Kuo & Kavanagh, 1994; Uba, 1994).

#### Women's Role-- Past and Current Status

The mei blossom, in delicate colors of pink and white and light of fragrance, stands in the depth of winter, resisting the severe cold. It symbolizes the perseverance of the Chinese woman's character and also represents the hardiness of a woman who has passed through historical and societal restrictions. That is, although it is cold, the flower still blooms; the woman faces hardship and she still persists. This section reviews the historical

background of women's roles in China and the changes in the status of women over the past three decades.

The matrilineal clans were the basic social units prior to the Chou Dynasty (1100-120 B.C.) (Yao, 1983). However, the social status and rights of women had deteriorated rapidly since the Chou Dynasty with establishment of the patrilineal clan system (Chen, 1994; Lu, 1995). A feudal system was established to keep society in order. According to the system, only sons had privileges to succeed, not daughters. At the same time, the gap between the positions of men and women in the family widened (Lu, 1995, p. 62; Yao, 1983). During the East Han dynasty (25-208 A.D.), the standards for women's virtues were established. They became the social norms and were followed until the early part of this century.

Women were considered the property of the patrilineal family. In general, the traditional ideologies mandated that a woman should be chaste even when the husband had more than one wife or when the husband was dead. Footbinding was instituted in order to restrict a woman to the home. Woman were expected to be obedient to the male and the family. In addition, a young woman could not choose her own marriage; it was designated by her parents. A married woman belonged to her husband's family not her own, as she usually lost her own family after marriage (Tsui, 1987; Lu, 1995). Women were praised for being obedient, timid, and reserved rather than being assertive and independent, and women's activities were restricted to their homes, while men involved themselves in the world beyond the domestic sphere (Lu, 1995). In addition, economic or emotional investments were made in sons rather than daughters. Chinese parents did not consider educating their daughters beyond the needs of household management, even

though education had been praised in Chinese society. The inferior status of a female is especially pronounced during financial hardship (Tsui, 1987)

However, ideological changes in the social and economic environment and the influence from the West have offered alternatives to the lives of women. By the early 1800s, issues of footbinding, women's education, and women's rights became a great concern, along with other social and political changes in Chinese society. Foreign economic encroachment in China in the meantime compelled women to join the labor force (Tusi, 1987). Chinese women began to realize their potential and to take more control over their own lives. A number of women dedicated themselves to the overthrow of the Ching Dynasty. They not only played an important role in the revolution, but also accelerated the transition of the Chinese woman's life (Yao, 1983; Tsui, 1987). Working women's economic independence and their contributions to family incomes, as well as the modern ideological influence from the West, contributed to the change in women's position within the family. Women's continuing participation and effort in these major events demonstrated their capabilities. Consequently not only was their image altered, but also their social, legal and family status as reflected first in the Civil Laws (1936) and then the Constitution (1947) (Yao, 1983).

Unfortunately, since Taiwan was governed by the Japanese, the social, cultural, and political upheavals in Mainland China during this period of Japanese colonization did not have much influence on Taiwanese society, so it was not until the 1945 restoration of Taiwan to China that Taiwanese women had the benefit of Constitutional changes in their legal status (Yao, 1983, p.199). Under the Constitution of the Republic of China, which was enacted in 1945, women have enjoyed rights and opportunities for education and employment (Hsieh, 1994).

Up to the 1960s, a traditional value system was still followed in this agricultural society. Since there was a lack of opportunities to earn an independent livelihood, women were considered subordinate to men (Gallin, 1994). Since then, the demand for women's education has increased. However, parental attitudes and limited resources continue to be the main factors that affect providing educational opportunities to women. Some girls still quit study to work and help support their families by assisting their brothers to attend college. Women were employed as servants and laundresses, and some even become prostitutes. Some poor families had to send their female children to other families. Most women considered homemaking and childbearing as their primary responsibilities and did not seek formal higher education. People also believed that a woman's social class was defined by her husband's occupation.

During the 1970s, Taiwan was becoming industrialized, not only in the city, but in labor-intensive factories, service shops, retail stores, and construction companies which burgeoned in the rural areas (Gallin, 1994). In contemporary Taiwan, social stability, economic growth, and reductions in family size have enabled parents to change their attitudes towards education for girls. The government policy of providing free education for up to nine years, which started in 1969, gives better opportunities for the people who are financially less privileged, thus helping to reduce the discrepancy in educational opportunities between men and women (Chiang & Ku, 1985). As a newly industrialized country, the employment of women in the modern sector has increased tremendously to 72% of women born between 1950-1954 compared to 20 % of those born between 1930-

1934. Another major change, compared to 77% of the earlier cohort, only 26% of the later cohorts' marriages were decided by their parents (Chiang & Ku, 1985; Gallin, 1994). Despite these changes, the constraints of a patriarchal tradition and the conservative nature of the general public still place women in subordinate positions as reflected in the labor market, the media, the revisions of family law, and political participation (Hsieh, 1994; Chiang & Ku, 1985). However, patriarchal authority is decreasing, and women have gained more self-esteem and self-confidence through better education and employment. This has resulted in a series of changes in women's lives in Taiwan during the past few decades. Modern working women have achieved a higher position in the family than their mothers and grandmothers, and the relationship between a married daughter and her natural family is also in transition (Tsui, 1987; Chiang & Ku, 1985; Gallin, 1994). As to designated marriages, women have more opportunities and privileges to decide and choose their own mates (Gallin, 1994). Meanwhile, more women prefer raising a nuclear family (Tsui, 1987). Husbands are now expected to share household duties in order to decrease an employed wife's burdens (Hu, 1995).

#### Family Structure, Values and Filial Piety

In the traditional Chinese family, the father maintains an unapproachable authoritative relationship with the family. The maternal role is to monitor the emotional well-being of the family. The mother is the parent most involved in nurturing the children and communicating the children's needs, concerns, and desires to the father (Uba, 1994).

The family exerts a great deal of control over its members and individuals are expected to be devoted to and rely on the family. Parents stress the children's obligations to the family. Family solidarity is supported by the interdependence of the family

members, hierarchical relationships in the family, and an orientation to the family as a whole rather than to the individuals within the family (Kuo & Kavanagh, 1994; Uba, 1994). Thus, parents have obligations to raise their children, but children have obligations to honor and assist their parents as a reflection of filial piety. These obligations create large, extended families, and three or more generations living together is very common in traditional Chinese society.

Traditionally, an authoritarian hierarchy based on generation, age, and gender has dominated life within the family. The oldest male had the highest status, and a woman's status, although it increased with the birth of sons and age, was lower than that of any man (Gallin, 1994; Hu, 1995). The reason is because the male symbolically carries on the family line and is responsible for caring for his parents when they become old. The eldest son is considered to be the most important child because he has the primary responsibility for parental care. Since this son provides for the parents during old-age, he commonly receives better treatment than his siblings (Tsui, 1987). Thus, father has the highest rank, whereas the young daughter-in-law has the lowest rank (Hu, 1995).

Following traditional values of Chinese family form, the older generation's ideal was to maintain a stem or joint family. Therefore, most new couples lived with the husband's family until the family division (Hu, 1984). Family division usually happened when sons thought other family members were not contributing equally to the group's maintenance, while daughters-in-law believed that wealth and chores were distributed unjustly (Gallin, 1994). In such a division, the parents might join the conjugal family of one of the sons, thus forming a stem family. The parents receive a certain amount of

money from each son and, if they need medical care, it is their sons' responsibility to contribute equally to its cost (Hu, 1984; Gallin, 1994).

Many stories were found describing the conflicts which existed between a motherin-law and a daughter-in-law from ancient times until now. By the 1950s, in Taiwan villages, a young daughter-in-law would be immediately saddled with work under the close supervision and scrutiny of her mother-in-law upon marriage. Since respect for parents was the traditional norm, and there was a lack of the husband's support, a daughter-in-law, therefore, submitted to the will and whims of her mother in law and looked forward to the time when she could assume the role of wife of the head of the family, which occurred upon the retirement or death of a mother- in- law or upon family division.

Chinese family values really emphasize respect for the elderly. This respect not only includes an individual's respect for elderly people and the family's responsibility for aging parents, but also honor for society and country by giving preferential treatment to the elderly. Government sponsored media also advocate respect for the elders through billboards, signs and observance of a National Elder's Day. Additionally, schools provide courses which discipline children to respect all elders of the community.

The roots anchoring the hierarchy within the Chinese society were the mores of filial piety, which were derived from Confucius' thought. It was believed that filial piety was the basis of all moral behavior. Ancient literature suggested that filial piety was the first priority among virtues (Huang, 1989). From the perspective of cultural ecology, the purpose of filial piety was to enhance or maintain family harmony, solidarity, and continuity. Therefore, it was expected that children obey their parents and that sons carry

the family name and take care of their parents (Yang, 1989). A concept analysis of Chinese filial piety included the aspects of taking care of parents, waiting on parents, keeping parents free from worries and loneliness, and burying and offering sacrifice with courtesy when the parents passed away (Yang, 1989). Yang considered that children must have the belief in or awareness of the concept of filial piety and have an attitude of respect and love for their parents first, then they will have the intention of doing something for their parents and practicing filial piety in real life. From the perspective of interactions, Yang emphasized that filial behaviors were the result of interactions between the person and his or her environment, therefore, socialization was considered the necessary process for developing filial piety. As Chinese society has been changing, there have been changes in filial behaviors.

## Caregiving Practices in Taiwan

According to demographic statistics, each age stratum among the elderly, especially those over 80 years of age, has increased (Department of Health, 1994). Since most elderly people have more than one chronic disease (Wu et al., 1991) and as the prolonged life expectancy of the elderly increases, the number of chronic illnesses will likewise increase, creating a need for more care. It is estimated that 6.6% of elderly people in the community need assistance with at least one ADL (activity of daily living), and 10.8% of people in community need assistance with IADLs (instrumental activities of daily living ). The number will increase as the current population ages (Wu & Chiang, 1995). The demand for caregiving and assistance will dramatically increase and strategies must be developed to meet these increasing needs.

There are many approaches used to care for the elderly. They include home care, community care and institutional care (Yang, 1995). Only a few people reside in nursing homes. Community care provided by health professionals is very limited, because the care program is in the initial stages. Most elderly live at home with their sons/daughters-inlaw, while a few live alone (Hsu, 1989; Shei, 1993; Hu, 1995). There are two approaches to home care. They are referred to as "meal rotation" and a "federation family." Meal rotation, which involves sons taking turns in caring for their parents, is more popular in rural than in urban settings. The advantage of this approach is fairness in sharing the responsibility of taking care of parents. The disadvantage is that parents have to adapt to different living environments. In federation families, sons leave their family homes at marriage, but send money for their parents' life expenses, and return to see their parents during weekends or holidays (e.g., Chinese New Year). The advantage of this approach is a reduction in intergenerational conflict while maintaining family resources and support. The federation family approach may result in better adaptation for parents (Chu, 1989). However, when the elders become frail and dependent, the parents usually live with one son or their care is shared by all their sons (Hsu, 1989).

Most elderly people are unwilling to live in nursing homes. Because of traditional beliefs, they would feel discarded by their children if they had to live in such institutions (Chan, 1989). In Wu and Chiang's survey (1995), some elders had never heard about a "nursing home." As the matter of fact, most members of the younger generation also like to keep their elders at home, because the quality of nursing home care is still not trusted by them (Hu, 1994).

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However, as the nuclear family is becoming more prevalent in contemporary Taiwan, facing the competing demand between a worker and a caregiving role for parents, but lacking of enough resources, more children express their difficulties and the dilemma in living with their parents for an extended period of time (Hsu, 1989). These changes have occurred as a result of constraints for elderly care in this changing society (Hsu, 1989; Hu, 1994).

### The Impact of Caregiving

Literature suggests that the experiences of caregiving not only influence the primary caregiver, but also family functions. Overall, there are three major dimensions of stress associated with caregiving: physical, psychosocial, and financial.

Lack of sleep and rest while caring for family members affects a caregiver's health (Lin, 1987). Wu et al. (1991) and Ton et al. (1992) found that caregivers' health status became worse as they provided long lasting care. One out of every eight caregivers became ill in Ton et al.'s study (1992), while Wu et al. (1991) found that one of four became ill. In addition, because of patients' nocturnal disturbances and agitated behaviors, caregivers felt tired, exhausted, and powerless and developed related psychosomatic symptoms, such as headaches, weight change, and gastric disturbances (Ton et al., 1992).

The most prominent effect on the family was in the psychosocial dimension (Die et al., 1990). It was found that caregivers' social activities were restricted and isolation occurred (Die et al., 1990; Chiu et al., 1988). Some caregivers had to quit studies or work in order to care for family members (Yui, 1989). Their lifestyle had to be changed (Chiu et al., 1988). The familial atmosphere became stagnant and family members

experienced frustration, depression, fatigue, and impatience (Lin, 1987; Chiu et al., 1988). Most of the caregivers desired help, including emotional support, professional help, or guidance for resolving their problems with family members' care (Wu et al., 1991).

Yui (1989), studied hospitalized stroke patients and found that families still had to assume major responsibilities for their family members' care in the hospital. Yui indicated further that caregiving not only affected family activities, but also work, studies, and the interactions and relationships between family members. In addition, families also reported disagreement and arguments about parental care (Lin, 1987). Lin found that family relationships, both among siblings and between the spousal couple, changed, as did parenting for young children when care for relatives with dementia was needed.

Hu (1994) explored caregiving strain in the home care of 286 chronically ill elderly people. She found that the primary caregivers were women. Caregivers reported that the most embarrassing aspects of care were touching patients' sexual organs during the process of care. They reported a variety of negative experiences, including worries about changes in the patient's condition, feelings of helplessness, the restriction of social activities, absence of praise, or even receiving criticism from other family members or relatives. However, the most stressful aspects of caregiving occurred when elderly relatives lost their temper or did not cooperate with their care. Hu (1994) considered this phenomenon as a reflection of traditional family relationships in which women were subordinate in a traditional patriarchal lineal society. In interviews with the caregivers, Hu found that "home care" was considered symbolic of "filial piety." In contrast, if they were sent to nursing homes, frail parents might be considered discarded by their children and a lack of filial piety may be presumed. Therefore, women caregivers either tolerated the

stress of providing care and accepted it as fate, or reflected their distress in the quality of their caregiving by displaying indifference to the care of the elderly.

Children in Taiwan take the major responsibility for the living and health care expenses of the elderly. Pensions are so small that they offer little help (Shei, 1993) and government allowances for elderly people are not popular. Both Lin (1987) and Shern and Chang (1993) found evidence of financial burdens in their studies. Ton et al. (1992) discovered that caregivers experienced great stress if they were operating under economic constraints. Wu et al. (1991) contended that effective home health care would decrease the cost of hospitalization for caregivers. In Hu's study (1994), approximately 40% of elderly patients did not have health insurance and economic considerations were reported as barriers to choosing nursing home care for family members. The cost of caring is calculated not only in financial terms, but also in personal time devoted to caregiving services, especially when caregivers must stop working. In addition, since the cost of elderly care may be shared by children, it is difficult to determine the extent of the burdens on each family member (Hu, 1994).

Some factors were found related to the extent of stress in caregiving reported in Taiwanese literature in the last decade. They include the degree of patients' deterioration (Hu, 1994; Tsai, 1995); the relationship with the elderly before they require care (Wu et al., 1991; Hu, 1994; Hu, 1995); the available resources and support (Wu et al., 1991; Ton et al., 1992; Wu, 1995), and personal coping behaviors (Ton et al., 1992; Shern & Chang, 1993; Wu, 1995; Tsai, 1995).

Caregiver burden is significantly influenced by a patient's level of deterioration (Ton et al., 1992; Tsai, 1995; Hu, 1995). In Ton et al.'s study of dementia patient care,

patient dependency was one of the most important factors related to caregiver burden. Hsiao (1992) also studied families affected by parental dementia and found that families felt distressed and frustrated when their parents' deterioration was progressive, even when they did their best.

Hu (1994) found the degree of the patient's deterioration or disability is seen as the most important indicator for choosing an appropriate setting or pattern for frail parents' care. When the patient's condition became overwhelming, nursing home care or hired aid-in-home care were the primary choices.

The closer a caregiver's relationship with the elder and the more obligations for parental care they perceived, the larger the burden experienced (Wu et al., 1991; Hu, 1995). In Hu's study (1995), the relationship between elders and caregivers reflected the quality of care. From interviews, she found some caregivers' indifferent attitudes toward their elderly parents were a reflection of their resentment and prior conflicts with their relatives because they were ill-treated by an elderly parent, elderly parent-in-law, or husband.

In Ton et al.'s study (1992), available instrumental social support was found to be the most important predictor of a caregiver's burden. Instrumental social support was defined as help with cleaning, preparing food, offering care and companionship, providing economic support, and so on. In this study, good social support was negatively related to caregiver burden, and caregivers felt they lacked enough information and skills when taking care of their relatives with dementia. Wu et al. (1991) found that nurses were a major resource for caregivers, but that the assistance given was still not adequate. Caregivers wished the home care program could continue to provide more assistance or guidance in home care. In Hu's study (1994), caregivers complained that they were criticized by other family members because of knowledge deficiencies for care. In this study, only 8.3% of the caregivers had been taught the necessary skills to care for the frail elderly. Wu et al. (1991) suggested that increased home visits by nurses might reduce caregiver burden.

Since there is a lack of resources offered by professionals, caregivers often have to learn the skills and knowledge to resolve frail elderly parents' problems by themselves (Hu, 1994). Usually, relatives only offered minor assistance even when they lived together. The primary caregiver does not receive respite. They often resort to outside support (Hu, 1994). Some hired aides to help them but the family still took the major responsibility for care. Caregivers also reported that relatives' support most often included offering folk treatment or, unfortunately, criticism of the care giving, which did not relieve a caregiver's burden but created more stress. In Hu's study (1994), they expressed that they might be more willing to face the difficulties of care for their frail elderly if their families could praise or affirm what they did.

Emotional support had a relationship to stress similar to that of instrumental support (Ton et al., 1992; Hu, 1994). In Ton's study, more emotional support would lessen a caregiver's burden. Wu et al. (1991) also found family members' ability to support or take a turn in elderly patients' care was the most important factor related to the degree of a caregiver's burden.

From the perspective of social interaction, Hu (1994) found that role strain was not directly related to workload, but to the caregivers' perception of the work. Hu emphasized that role overload should be approached from multiple dimensions, including

personal perceptions of the role, the interaction between caregivers and care receivers, and the support by the environment. However, there is still a lack of understanding about these dimensions.

In addition to the factors stated above, different coping behaviors among caregivers were identified in Shern and Chang's study (1993). They included coping with stress by withdrawal, or isolation, or accepting their roles as fate, and so on. In this study, caregivers' health status was related to their coping behaviors and those with the worst health tended to be the most emotional. This was evidenced by worrying, crying, and so on. In addition, coping behaviors also affected the family's ability to adapt to the care of a relative with dementia (Hsiao, 1992). In this study, Hsiao advocated open communication and support as helpful in facing care crises in the family and in enhancing care for the frail elderly. Wang (1992) found the same conclusion in relation to family caregiving stress in chronic illness.

Research literature related to caregivers' experiences which were conducted in Taiwan have been summarized as Appendix A.

### Analysis and Critique

Overall, the research on parental care in Taiwan has been very limited. It has usually been a subcategory of studies in a field of specific disease care, which focused primarily on care of stroke patients and patients with dementia. The samples were usually generalized to include all family caregivers. There was very little information from a cultural perspective exploring the experiences of daughters-in-law, as primary caregivers. Most of the studies have been quantitative in nature with factor analysis used to identify the dimensions of a caregiver's stress and to predict the risk factors related to this stress.

In quantitative research, the investigator identifies the selected variables to be explored from the prior theoretical schema. Thus, the design would limit the research area and elicit responses that fit predetermined categories (Leninger, 1985). Therefore, there is insufficient information to draw a complete model in order to interpret this caregiving phenomenon. For example, there is limited information about the perceptions of caregiving roles; how these perceptions influence caregiving behaviors; varying attitudes of individuals and families when parental care becomes necessary; and how values might be influenced by personal, situational, and environmental factors. In addition, some research has indicated that women may be restricted by social normative beliefs from discussing the difficulties of caregiving without expressing dissatisfaction (Hu, 1994). There is little information to increase understanding of how they felt and in what way they work through the constraints of the situation.

The caregiving experience is not always negative nor always positive. Some research findings indicated that caregivers were satisfied with their caregiving because their status in the family was elevated when they cared for their parents-in-law and this brought peace of mind (Chao, 1996). In other words, the phenomenon of caregiving is a dynamic process, not a static state. The measurement of caregiving stress when approached by quantitative inquiry might have limitations in expressing a caregiver's subjective feelings. It may be difficult to assess a caregiver's psychological change during the caregiving process.

As noted previously, beliefs about parental care are a kind of cultural product. Exploration of caregiving behavior should consider the cultural background of the participants. Since there are a lot of issues which can not be clarified, it is hard to

establish a theoretical model for elder care in Taiwan. Thus, the research direction might need to shift to a qualitative approach, in order to discover and conceptualize the complex interactional process of in-laws' care in Taiwan.

# CHAPTER III

# METHODOLOGY

The purpose of this qualitative study, utilizing grounded theory, is to capture the experience of Taiwanese daughters-in-law who care for their sick in-laws. The inquiry of grounded theory is based on symbolic interactionism which emphasizes how people view their circumstances, how they interact, and how these processes change. The aim is to generate a theory about the social and psychological phenomenon which comprise the caregiving experience of the daughter-in-law (Chenitz & Swanson, 1986; Wilson & Hutchinson, 1991; Hutchinson, 1993; Bowers, 1988).

# Grounded Theory

Grounded theory is a research strategy--an inductive approach to the discovery of theory from data (Strauss & Corbin, 1990). It derives from the philosophy of symbolic interactionism which illuminates human behavior and the social world (Blumer, 1969).

Symbolic interactionists view behaviors as determined by the meaning of events to people in natural or everyday settings. They believe these meanings are created by people as a result of social interaction; nothing has inherent meaning or value in and of itself (Chenitz & Swanson, 1986). During the process of interaction, people engage in roletaking with others, grasping others' perspectives and create their own realities and meanings, which in turn, shape their actions (Wilson & Hutchinson, 1991). Thus, all meanings are subject to redefinition as a result of experience (Chenitz & Swanson, 1986), and the reality is dynamic rather than static (Baker, Wuest & Stern, 1992).

From the perspective of symbolic interactionism, grounded theorists believe that the meaning of the event must be understood from the perspective of the participants (Chenitz & Swanson, 1986). They believe that truth is subject-oriented rather than researcher-defined (Sandelowski, 1986). Therefore, to understand meaning, behaviors must be observed in context, since the context is what creates the meaning (Chenitz & Swanson, 1986; Bowers, 1988). Research methods must be able to capture the process and the change, because meanings are constantly evolving and do not remain static over time (Chenitz & Swanson, 1986; Bowers, 1988).

The essence of this qualitative method is induction, which uses a systematic set of techniques and procedures of analysis to discover a theory that is based on the substantive data of human experience. Grounded theory studies are done to identify abstract concepts and propositions and the relationship between them. The data are not established on a set of numbers, but on tightly-related themes of the participants' responses, the emerging concepts, and the relationships among these concepts. Grounded theory could initiate a new theory and reformulate and reclarify existing theory (Hutchinson, 1993). Therefore, grounded theory could contribute to the areas in which little research has been done and the variables relevant to the concepts have not yet been identified. It could also offer an existing new approach to an old problem (Stern, 1985; Chenitz & Swanson, 1986; Hutchinson, 1993).

#### Participant Inclusion Criteria

Participants in this study were women who were providing care for parents-in-law, either one or both. Originally, the study intended to recruit women from the home care agency of a comprehensive medical center, which is located in the north of Taiwan.

Patients with chronic or terminal illness are referred to the agency for follow-up care at home. However, the interview was usually interrupted when it was held in the home. Therefore, more participants who met the criteria in this study were recruited from the rehabilitation wards at the same hospital until data were saturated.

The participants and their parents-in-law's ages were not restricted in this study. Focusing on caregivers of different ages, a researcher will get more information about the similarities and differences faced by care providers. Based on Taiwanese social context, women over 50 who were born when Taiwan was occupied by Japan would have a different perception of a caregiving role and the views of their circumstances might be different from the younger generation. In addition, to understand the caregiving and care recipient relationship in context, one must consider a life span perspective which views this relationship not as an exceptional crisis, but as a part of normal lives that include dependencies, obligations, and entitlements. The second criterion considered the person who perceived herself as the major caregiver and who shared the home with an in-law in order to provide care. This reflects real situations when elders are sick as most of them are cared for by the younger generation even though they may not have lived together before. Either one son provides the care or he rotates with other brothers. The third

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criterion was that participants be giving care to disabled parents-in-law who may be particularly burdensome for the caregivers. Thus, the caregiver in this study was the person providing care for parents-in-law who require assistance with at least one activity of daily living (ADL) such as bathing, dressing or feeding, or who have been diagnosed as having cognitive impairment.

In total, there were thirty-one participants interviewed in this study.

### Entree

Permission from the home care agency was obtained during the pilot study conducted prior to this research (see Appendix B). In order to establish a trusting relationship between researcher and participant, a home health nurse introduced the researcher and the purpose by phone and asked potential participants for their agreement to be interviewed before visiting them. Then, the researcher initially accompanied the nurse when home care was provided to the patient. Taped interviews occurred in a place convenient to the caregiver. Similar procedures also were used when the interviews were conducted at the hospital ward, except the researcher was introduced by the head nurse.

At the beginning of each interview, participants were informed of the purpose of the study, potential risks and benefits, the time needed, and how confidentiality would be maintained during the study. Participants were informed that they could withdraw anytime during the study and they could turn off the tape recorder at any time during the interview.

The consent form (Appendix C) was verbally reviewed with each participant and all questions were answered before the consent form was signed. Some participants

preferred a verbal agreement, which was more in keeping with cultural norms. The consent was obtained verbally following the review of the project and response to questions.

### Data Collection

Data has been gathered through semi-structured interviews and observation of participants. Individual interviews lasted between one to one-and-a half hours in participants' homes or in the ward. All interviews were conducted in Mandarin or Taiwanese. Conversations were taped with the consent of those involved, and the researcher wrote field notes as well. Notes included descriptions of things observed and thoughts that occurred during the process of the interview. The interview allowed a free flow of information without forced replies or biased responses. Interview guides (see Appendix D), which had been refined based on information received during the pilot study (Chao, 1996), were used to elicit participants' experiences of in-laws' care. Participants' demographic data were recorded on a form by the participant after the first interview (see Appendix E). Interviews were continued until both the participant and researcher felt the experiences of an in-law's care had been adequately described. Each interview was concluded by asking the participant if there was anything else they wanted to say that was relevant to the experiences.

Observation was another information gathering technique which had been used. Observations have been recorded about the participants' home environments and the interactions of family members. These were beneficial when writing both operational

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notes and theoretical notes. In addition, noting non-verbal responses exhibited during the interview process also was useful in providing direction to the researcher for comparison and follow up interviews. Data collection continued until the data were saturated.

# Ethical Considerations

The Committee on the Protection of Human Subjects at the University of San Diego provided approval for the study proposal before data collection began ( see Appendix F). Potential risks were carefully evaluated, and it was determined that there was no risk in this study. The researcher paid attention to the participants' feelings, responses, and emotional discomforts. However, it was not necessary to discontinue any interview at the request of a participant.

All the data were kept confidential. Participant data had been coded with a number during transcription. All interview materials were locked in the researcher's desk. All the tapes, as well as the list of names of participants were destroyed when the study was completed.

# Data Analysis

The information obtained from audio-tapes and observations was transcribed by the researcher word by word first in Mandarin and then in English.

In grounded theory, data analysis begins simultaneously with data collection (Bowers, 1988; Strauss & Corbin, 1990). The constant comparative method (Strauss & Corbin, 1990; Hutchinson, 1993) has been applied in analyzing taped transcripts and field notes. The aim of this method is the generation of theoretical constructs that, along with substantive codes and the categories and their properties, form a theory that encompasses as much behavioral variation as possible (Hutchinson, 1993). The process has been conducted as follows: First, each transcript was analyzed line-by-line, coded and given an "in vivo" code where appropriate, using informants' own language, e.g. *Hsiang Kai, Ann-Shin, Wu-Nine*. Coded phenomena were then compared between texts for commonalties and clustered in similar categories. Then each category's properties and dimensions were described and illustrated with anecdotal excerpts. This method was continuous throughout the data collection process; data was analyzed for similarities and differences between categories. Then, the researcher linked the categories according to the relationships between causal conditions, context, interactional strategies, and consequences.

Memoing began with data analysis and after the first interview or observation in order to record the researcher's experience. During the analytic process, three different types of memos were written by the researcher according to the memoing process of Strauss and Corbin (1990). These three memos were code notes, theoretical notes and operational notes. The code notes were to discover and build the categories. After the code notes were written, the researcher used theoretical notes to link and identify core categories and to establish a conditional matrix. Finally, the operational notes guided the researcher in sampling, questions, possible comparisons, leads to follow up on, and other related issues. This process was conducted continuously until saturation occurred and the theory was generated.

#### Methodological Rigor

Analysis of data to determine methodological rigor or trustworthiness is important to determine the acceptability of this study. Lincoln and Guba (1985) identified four factors necessary for a study to be trustworthy: credibility, transferability, dependability, and confirmability. In this study, trustworthiness was established by utilizing this guideline.

Credibility is described as the degree of confidence in the truth of one's finding. It is similar to internal validity in a quantitative study, but credibility is a better term, since internal validity is based on the assumption that there is a single tangible reality to be measured (Krefting, 1991). In this study, credibility was established by utilizing openended questions and verifying whether the researcher "grabs" the accurate responses of the participants. Data were collected from multiple resources such as field notes, observation recordings (the interaction between caregiver and care recipient; and among the family members). Three participants were contacted a second time by phone to clarify components of the interview.

Transferability or the generalizability to other populations might be limited when using the qualitative method. However, the study also noted the great variation in the participants demographic characteristics which might support, elaborate, or illuminate the research in question (Lincoln & Guba, 1985). In addition the in-depth individual interviews also provide sufficient data to allow the reader to make judgments concerning possible applicability to other populations.

Dependability is concerned with stability and traceability, which is similar to reliability in the quantitative approach. Some strategies had been included to insure the

dependability of findings in this study, such as use of the "audit trail"--using external auditors to review the process by which the data was collected (Sandelowski, 1986). Four researcher's colleagues and three nurses in the health agency were invited to conduct peer review of interviews and analysis; the researcher also recoded the text after two weeks and compared it to the original in order to enhance dependability (Krefting, 1991). All interviews and field notes had been translated into English in order to evolve the audit trail. The dissertation committee reviewed transcripts, field notes and analysis and drew comparable conclusions. To prevent losing the participants' meaning when interviews were translated into English, two expert translators who know English, Mandarin and Taiwanese were invited to transcribe the same texts into English. Then the researcher discussed with them the differences between the transcriptions.

The last issue is confirmability, which emphasizes interpretation, objectivity and neutrality of this study. In this study, confirmability was established by bracketing or setting aside assumptions as they became evident to the researcher. Reflexive examination also is necessary to ascertain whether the analysis was affected by the researcher's personal background such as the theoretical perspectives about family care derived from research conducted in the United States. In addition, the method of auditability as stated above also contributed to confirmability.

### CHAPTER IV

# FINDINGS

The findings are included in three parts in this chapter. The first part discusses the characteristics of the caregiver and her in-laws. The second part presents a theoretical model of the experience of Taiwanese women caregivers for parents-in-law--Just doing. The relationships among the core category and other categories for reflecting these experiences will be described in this section. The third part discusses various categories which were derived from the daughters-in-laws' responses, including how women perceived their caregiving roles when their parents-in-law were sick, how they experienced their caregiving responsibilities what difficulties they met during the process of caregiving, what influences affected their caregiving experiences, and how they coped with these difficulties.

# Participants

# **Caregivers**

Data analysis was based on interviews with the thirty-one daughters-in-law who shared their caregiving experiences in this study. All of the women were approachable when they were invited to participate in this research. Most of them resided in the urban area of the county, which was located in the north of Taiwan. Some of them came from the middle of or south of Taiwan for advanced treatment for their relatives. Although most of the interviewees were currently residents in the north of Taiwan, they grew up in a

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farming family usually from a rural area in the middle or south of Taiwan. Some of them worked in Taipei as laborers after they graduated from primary school. Taiwanese was the common language spoken when the interviews were conducted. Most of women were housewives, some of them had to quit working when their parents-in-law became sick. All of the women were the major caregivers for their parents-in-law, some shared the care with another sister-in-law, or cared alone all day. Some of the daughters-in-law had just started their care, while some of them had been providing care for more than seven years.

Additional information about caregivers' demographics will give a better understanding about the character of the women in this study. Their ages were between 23 and 58. The youngest caregiver was a 23 year old woman, who had just gotten married ten months earlier. The eldest was a 58 year old woman who was married to her husband and his family for more than thirty years. Most participants were around forty, between the ages of 30 and 49; there were three participants who were over 50, and four were below 30. Most of them had been married for more than ten years with two to three children who were in school from primary to high school.

All of the women were married at the time of the interview, and were natives of Taiwan. Folk belief or combined Buddhism was the preferred religion of the participants, except for three participants who expressed they had no specific religious preference. One was Christian. Two of the participants were members of a Buddhism association.

With the exception of the eldest participant, all of the woman were educated, at least through the primary school level. There were 12 participants who were educated through high school level, 10 who had reached junior high level and 8 primary level. Most

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of them were housewives. One woman was still employed; 7 participants worked outside the home but had to quit due to their parents-in-law's illness.

Most of the caregivers' husbands were engaged in technical work. Since most of them shared the care with other family members, parents-in-law took turns living with them. There were 5 participants' families who were living in the same building with other married family members, in which the father-in-law was the dominate power. He dominated everyone's house affairs, and even assigned the family income and family tasks. There were two participants who lived beside the parents-in-law's home and served their relatives at the in-law's home. For example, one woman lived and worked downstairs, and her parent-in-law lived upstairs in the same building. While the years of living with in-laws ranged from 8 months to 37 years, the period of providing care was from 2 months to 7 years. Five women had taken care of their parents-in-law for more than five years, 13 women had provided care for one year (see Appendix G ).

# Care Receivers

Before describing participants' experiences, it is necessary to provide background for the care receivers.

Although thirty one parents-in-law had been cared for by their daughters-in-law, three of these families needed to provide care for both father-in-law and mother-in-law. More mothers-in-law were cared for than fathers-in-law in this study. Twenty-three of the care receivers were female, and just 8 were male. Half of them were widows or widowers. Their ages were between 44 and 90; most of them were around the age of 70. A majority of the in-laws had suffered a stroke which caused total paralysis or hemiplegia. Four of them suffered other kinds of diseases, such as brain tumor or spinal cord compression, which made them either totally or partly dependent for their activities of daily living. Most of the patients had suffered from chronic diseases such as hypertension or diabetes mellitus for a long time. Their physical conditions were deteriorating gradually and many patients suffered frequent strokes. However, there were a few patients who were very severely affected even after the first stroke. Half of care receivers were not conscious or were confused; half of them were fully conscious during the study. With regard to the degree of patients' disability, half of them were totally paralyzed and half them were partially paralyzed, including Hemiplegia or Semiplegia.( see Appendix G ).

The Experiences of Taiwanese Women Caregiving for Parents-in-Law

The discovery of a core category is the desired outcome of grounded theory. A core category is the main category that links to other categories in order to establish paradigmatic relationships with conditions, context, intervening conditions, strategies, and consequences of a phenomenon (Strauss and Corbin, 1990).

In this study, Just Doing emerged as the core category to represent the Taiwanese women caregivers' striving processes during their commitment to their parents-in-law's care. The categories surrounding the core category in the paradigm for this study include: Being Called, Caring For, Holding Up, Keeping Harmony, and Maintaining Filial Piety (see Figure 1).

To explain how the other categories relate to the core category of Just Doing, it is important to first examine the category of Being Called, which reflects the condition, or the reasons for becoming involved in care. Being called arises when an in-law becomes ill and due to cultural norms, a daughter-in-law recognizes her duty to care for her parentsin-law--Recognizing Duty. The second subcategory of Just Doing is Experiencing Trials, which includes emotional, physical and social aspects. Responding to Caregiving reflects the daughter-in-law's response toward providing care. Since each caregiver experienced various impacts during the process of providing care, it is possible that the caregiver will have different responses to the Caregiving situation.

Caring For provides the context or the background for the activities involved in providing daily comfort, keeping watch as well as seeking assistance if needed. Since the tasks of providing care are different, the trials of caregiving and responses toward the caregiving situation will also be different.

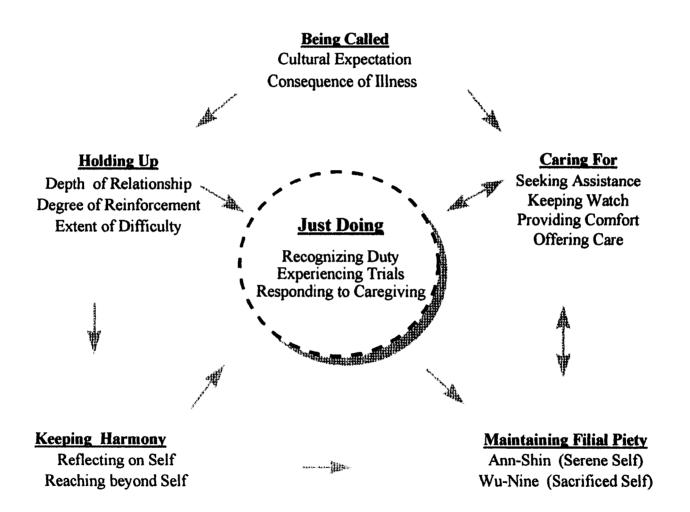
How a caregiver interprets her duty, the extent of trials a caregiver experiences, and how a caregiver responds are all influenced by the category of Holding Up. This includes the depth of her relationship with her in-laws, the degree of positive reinforcement she receives for providing care, and the extent of difficulties she encounters in the caregiving process. All of these subcategories are influenced by the consequence of the parent-in-law's illness and cultural expectation.

Another aspect is how the caregiver is influenced by her philosophy in interpreting her caregiving role, and her ability to ask for more resources to overcome any caregiving trials. These aspects are categorized in Keeping Harmony. That is, the strategies in Keeping Harmony help to enforce a caregiver's perception of her caregiving role and help to reduce her discomfort for the caregiving task.

The category of Maintaining Filial Piety is the consequence of the Just Doing theory. A daughter-in-law may feel that she is serene or at peace in fulfilling her duty, or she may believe that she has sacrificed herself and her life. Since providing care for an inlaw is the most important virtue for a daughter-in-law, it is expected that as a caregiver,

she will feel serene in what she does. Caregiving is considered the highest virtue, a caregiver must make sacrifices if the constraints of caregiving still exist and care must be continued. Regardless of her feelings, continuous care will be provided to maintain filial piety.

In addition, a relationship exists between the category of Holding Up and Keeping Harmony. That is, the strategy of Keeping Harmony is sometimes challenged by the difficulties a caregiver encounters. For example, if a caregiver did not feel she was appreciated by her family members, she would feel depressed. However, she would interpret this as "my fate" to comfort herself. Both Holding Up and Keeping Harmony influence the feeling of Serenity and Sacrifice as well. Therefore, the experience of Taiwanese women caring for their parents-in-law is very complex and influenced strongly by cultural expectation and family relationship. Figure 1. Just doing: A theoretical model of the experiences of Taiwanese women caregiving for parents-in-law



### Major Categories and Their Properties

# Just Doing

The data reflected the process of how a caregiver assumed her caregiving role, how she was influenced by the caregiving task, and how she reacted to the caregiving situation. Caregivers' responses to providing care were derived from the women caregivers' cognition and were affected by their experiences. Most of the women perceived caregiving as their responsibility. Then, they experienced the hardship of care, including both spiritual and physical torment, and the complicated interaction with the patient and family members, when the caregivers were involved in their care. Depending on different experiences and cognition, different responses were expressed about the caregiving situation. However, no matter how a caregiver felt about the caregiving situation, she provided continuous care.

# Recognizing Duty

Recognizing Duty, a subcategory of Just Doing, is used to describe a caregiver who recognized caregiving as "my duty." All the caregivers in this study believed they had responsibility for providing the care for their sick in-laws. When a woman caregiver is faced with a sick parent-in-law, this ideology is aroused. A caregiver's description about her caregiving role was derived from the culture, including the role expectation of serving the parents-in-law in order to perform filial piety and repayment for parents' benevolence toward her husband; an expectation of a woman's nurturing role, and carrying out human morality. <u>Obligation</u>. Regarding the role expectation of serving the parents-in-law, the women caregivers strongly revealed their perception that a married woman belonged to her husband's family and should be obedient to the man and devoted to the entire family, no matter how she was treated by the family. "I am a daughter-in-law" reflected a woman caregiver's inner perception for assuming the caregiving role. The belief was cultivated into a woman's mind and became her philosophy, which pushed a woman into the caregiving situation.

As a daughter-in-law, I have to accompany him (father-in-law) although I was so scared. His daughter accompanied him too, but it is not her responsibility. My only belief is this is my responsibility. I really appreciated her help. But, I have to take the major responsibilities even when she accompanied me.

A middle aged woman mentioned she had been abused by her mother-in-law and her husband for the last thirty years. However, she still considered the care of her motherin-law as her responsibility. She would like to provide care for her mother-in-law by herself although her children would occasionally help her. The thoughts of compulsory altruism were reflected in the following statement:

I have no complaints even though she treated me very bad before. I still consider I should do it by myself because it is my obligation. She is my elder. I belonged to my husband. And the obligation belonged to me. One generation follows one generation.

Similar beliefs were expressed by many women no matter how old they were. A

young woman mentioned:

I thought I should do that (take care of her mother-in-law) because I have married this family. I belonged to this family. I have an obligation to do it.

A daughter was considered a guest in her own family. Thus, a woman had the

obligation to her in-law, but not to her own family. Under this circumstance, the

daughter-in-law would become the only caregiver no matter how many daughters the

elders had. One woman succinctly described this:

Just me, day and night. In the night, I sleep with her. I am the only daughter-inlaw, although she has eight daughters.

Repayment. As a matter of fact, the woman also believed that she should share her

husband's fate. As a wife, she should repay her parents-in-law's benevolence toward her

husband. According to a Chinese proverb, "when one loves a house, one tends to love

even the crows perching on it." The respondents in this study expressed that they would

like to extend their love to the parent-in-law, i.e. "love him, love his parents."

I have married my husband. Although the day is very hard, he still gives me happiness. I should treat her as my own mother. I thought I should not differentiate because she is my husband's mother. It is said that "when one loves a house, one tends to love even the crows perching on it". So, "love him, love his parents."

Woman's Role. Concerning her role perception, a woman's character was

identified as being more tender, patient, and considerate than a man's. Thus, nurturing

and taking care of the patient should be her responsibility.

The following description explains why the caregiving role is better suited to the

female than to the male:

I felt the caregiving for a patient is better to be done by a woman, since a woman is more careful and sincere. It is because the woman has the experience of nurturing children.

In addition, although the society is changing, the inferior status of women still

exists in the work force and in the family. The women caregivers considered that their

husbands' work was more important than their own because their husbands made more

money. So it was important to support her husband's work.

He had assumed the responsibility for the family's finances. I made less money than him. Thus, I should assume the household affairs. . . . His work is important, the whole family depends on him.

In reality, most women did not work outside the home. The woman usually

perceived herself as the most available person to take care of the sick in-law.

All of the other family members went to work except me. So, it's natural for me to assume the caregiving task.

Humanity. The respondents' views also reflect the Confucian thought of

compassion to all human beings. One is taught to extend one's love to the surrounding

people, especially those who are sick, old, poor or frail, and not to ask for repayment.

The caregiver considered caregiving as the basic morality of being human, and believed

one should help a sick elder no matter what the relationship.

All of us are human. If we are capable of doing, we do our best. I help people even though they are not related to me. For my mother-in-law I should do more.

Taking care of my in-law is not only for filial piety but also because I feel that people should help each other. How could we see her suffering?

In summary, the woman caregiver's cognition was derived from four aspects: first, the daughter-in-law's obligation; second, repayment of parents' benevolence toward her husband; third, the traditional woman's role, and fourth, expression of a human being's benevolent spirit.

#### **Experiencing Trials**

Experiencing Trials is a second subcategory of "Just Doing." It represents the impact on the caregiver during the process of caregiving, including emotional, physical and social trial. A caregiver had to face the hardship of assisting the in-law in coping with his/her disability and suffering. Meanwhile, because of illness of the elder generation, the interaction among the family members changed. All of these would cause a caregiver to

suffer emotional distress and increase her physical burden, which could create a health risk.

<u>Emotional Trials.</u> Most of the caregivers experienced emotional distress, including worry, nervousness, and even fear about the in-law's changing physical condition. They suffered distress because they worried they would miss some warning signs about the in-law's changing condition, which would cause the in-law's death; then they would be criticized by people.

Her blood sugar changed dramatically. I became sensitive and suffered insomnia. The first thing I did in the morning when I opened my eyes was to see her. I was really scared... One night, I was called by my father-in-law. The first idea that flashed in my thought was something wrong had happened and I wondered if I hadn't taken care of her well. I was so nervous that I couldn't go downstairs.

Caregivers experienced the most frustration when they were misunderstood or the

parents-in-law were not satisfied with what they had done for them. A caregiver

mentioned she was very upset at being blamed by her father-in-law for preparing a light

diet for his wife, a diabetic patient. Her father-in-law misunderstood and thought she was

trying to abuse her mother-in-law.

I attended a course related to hypertension. But, it's hard for my father-in-law to accept it. He felt I abused my mother-in-law. He said "she can't eat this, can't eat that, what can she eat? All the food lacked nutrition. What did you cook for her?" I felt much sorrow during that time.

Actually, the caregiver felt this kind of feeling was hard to share with others. As a

daughter-in-law and a major caregiver, her feelings were different than any other person in

the family. Even her husband could not share her concern.

I was just nervous and worried, I don't know why. I knew how to manage an emergency, but I still worried something might happen. I knew my husband would help me, but I was still nervous. After all, I am a daughter-in-law.

<u>Physical Trials.</u> Lots of physical complaints were described by the caregivers, including tiredness, insomnia, dizziness, fainting, soreness and aches throughout the whole body. Some participants mentioned their physical condition became worse and they had to visit the doctor.

The most common difficulty in taking care of the in-laws was a woman's lack of physical strength because she was not able to move the patient.

My mother-in-law was so heavy. It was very hard to carry her to the bathroom by myself. My sister-in-law also had the same difficulty.

In coping with the caregiving workload, a lot of women mentioned lack of sleep. They often felt very tired. The caregiving task was a twenty-four hour a day job. The caregiver would be asked or would volunteer to sleep beside the patient in order to provide care. Due to a continuous feeling of nervousness, the caregiver suffered headaches, dizziness, back pain, insomnia, or irregular menstruation. Some caregivers mentioned they had to seek medical treatment for their own worsening physical conditions, or specific illnesses like hypertension.

One caregiver described her experience: since she stayed in the hospital to take care of her mother-in-law for more than three months, day and night, she felt very stressed about her mother-in-law's condition. And, she lacked sleep for a long time. She suffered from a lot of physical problems, and she finally had to visit the doctor in an emergency room.

I always worry about what I did not complete before bed. Because I worried too much, I had to visit the doctor. I suffered from dizziness, fainting, soreness and aches throughout my whole body. Yesterday, I went to the emergency room because I fainted too much, had a severe headache, and neck ache. I asked a family member of my mother-in-law's hospital roommate to go to the emergency room with me at midnight. I could not sleep, and my blood pressure had risen to one hundred seventy four. I worried I would have a stroke like my mother-in-law. I was without sleep for a long time. In addition, I felt very stressed about my mother-in-law's condition.

<u>Social Trials.</u> Since all of the patients in this study suffered chronic illnesses, the caregiving task lasted for a long time. When an elder's disabilities required ongoing care, the family members' interaction and family dynamics changed in order to cope with the demanding situation. Three aspects were identified. First, the personal social life was restricted; second, challenges arose during interactions with the patient; and third, the family's sense of balance was affected.

Social life was influenced in many ways: caregivers felt they had limited freedom, limited contact with their biological family or friends; their life style changed; and lack of privacy became an issue. Future plans had to be changed, and caregivers experienced role conflict between providing nurturing care for their young children as well as elder care.

It was common for the caregivers to mention that they had no recreation, no joy-only a feeling of being bound.

Our life changed greatly since my in-law was sick. We canceled our trip and did not travel again. Actually, we could not go anywhere. We worried that something would happened while we were gone. I did not go back to my home for a long time, not even when my mother was sick.

It was not only the family's sleep which was interrupted by the patient's disturbing behavior, but caregivers also faced personal issues. Some daughters-in-law were asked to sleep beside the sick in-law in order to serve the in-laws at all times.

My father-in-law asked me to sleep by my mother-in-law in order to provide care anytime.

Another informant described a conflicting situation when the caregiver had to take care of other family members, or her own children and, in addition, care for her in-law. Every time I went to the hospital to take care of my in-law, my daughter asked when I would come back. I felt so miserable.... (stop, the participant was too sad to speak. She cried....)

The second aspect addressed the challenges which occurred between caregivers and the care receivers. Role change was often a challenge the caregiver would encounter especially when the father-in-law suffered a stroke. The father was the authority in the family, while the daughter-in-law was usually a follower in the family. However, the roles changed when the father-in-law became a dependent and the daughter-in-law had to become a "controller," especially during the time of rehabilitation.

When my father-in-law suffered his first stroke, he lost his temper easily. My relatives told me I had to train him to use his left hand which was his healthy side. But, in the beginning, it was hard for me, he was the elder generation, he couldn't accept my explanations.

The third aspect relates to how the family's homeostasis was affected. The most

common occurrence was that the family atmosphere stagnated. Family members would

lose their tempers easily if the patient's condition became worse.

Everyday, when my husband returned home, the first concern was about his mother's condition. If it was not good, my husband's mood would become very depressed. The whole family atmosphere would become very bad.

Several women complained that their relationships with their husbands were

affected since their in-laws were sick. Their husbands would become argumentative or

apathetic; a caregiver did not perceive that she received respect from her husband. The

caregiver felt that discussion with her husband would not help or change her caregiving

reality. She felt that they were hurting each other.

Our arguments were always about my in-law, my husband felt that caregiving was my task. . . . he never treated me like this before.

We seldom talk. We exchanged less than ten words within three days. I felt we were becoming like strangers. Too many words would hurt each other.

In addition, sometimes the caregiving tasks were shared by the daughters-in-law, then the caregiving process became competitive and they were compared to one another. The relationships among the caregivers became so sensitive that blaming, criticizing, gossip, and conflict were easily aroused.

A caregiver mentioned her experience when she tried to tell her sister-in-law that their in-law seemed to have a lot of sputum when she took over. She mentioned she just wanted to discuss this with the sister-in-law. But, she was suspected of criticizing her sister-in-law.

My third sister-in-law was angry at my comment and talked to another sister-inlaw. Then sarcastic complaints spread through the whole family. I was comfortable to share the caring, but we had other kinds of problems. The gossip upset me more than the caregiving task.

Other criticism and blaming directly or indirectly also came from other relatives, such as married daughters or the in-law's relatives. Some of criticisms were "Why didn't you pay more attention to see whether she suffered a cold?" or "The reason for your mother-in-law's disease was because she helped you take care of your children. . . . You should be more responsible to her disease. . . ." The caregivers felt really upset by these comments.

In summary, regarding the caregiving impacts, emotional, physical and social suffering were all described by the caregivers. Several emotional burdens were related to her social role as a daughter-in-law, in which there were more worries about completing the caregiving role successfully. Some physical complaints were associated with the emotional distress, while some of the physical suffering came from the caregiving workload. Social suffering included the change in family roles, restriction of social activities and the changing interaction and relationship among the family members. The impact was felt not only on her in-law's family, but also her own family.

# Responding to Caregiving

Three types of caregiving attitudes were identified as the caregivers responded in the caregiving situation. They included numbness, or keeping a neutral attitude; reluctance, or a negative attitude, and going toward, or an optimistic attitude.

<u>Numbness.</u> Numbness was identified when the caregiver had neither a positive nor negative feeling for her care. The caregiving task was just done like a routine. Usually the caregiver had provided her care for a long time. The caregiver was capable of taking care of her in-law. Her anxieties and the worries for giving care were gradually lessened, although she felt tired. However, a numb response did not mean all of them had adapted to the caregiving situation. Conversely, it also was a state in which a caregiver hid her feelings to prevent herself from being hurt.

Now, I just live a "Numb" life, no feeling again. Everyday is like a circle. I follow a cycle.

I don't like to talk about my feelings because I don't like to touch my feelings. I just provide my care everyday, like a routine. It could be said that I am numb.

<u>Reluctance</u>. The subcategory of reluctance is used to indicate the caregiver who was not willing to provide care, even though she still assumed the responsibility. With no expectation for how long one would have to tolerate suffering in the caregiving situation, the caregivers expressed that they were tired of the caregiving task. The caregiver was struggling in her mind, and her making an excuse to explain her own behavior reflected this struggle. Hiring an aid may let my in-law experience a different person. She was not satisfied with our care. Why don't we let her experience an aid's care?

The caregiver might express her tiredness for caregiving tasks and feel frustrated.

I have no idea. I don't know what I can do. My husband said she would not live too long. I felt I could not tolerate it. I think I might collapse before she passes away.

Go Forward. Another minor category, "Go forward," is used to express the

caregiver who kept an optimistic attitude and encouraged herself to continuously do more

for her in-law. Although the family's economic status was not good, one woman

caregiver insisted that her mother-in-law, a ninety year old woman, would be treated the

best way.

I would pay all I have to treat her disease. She is my elder. For my elder, I should try to do my best.

One caregiver, facing a patient in a nonresponsive state and providing care for

more than six years, still kept an optimistic attitude about her care. She did not hold hope

that her mother-in-law could recover, but she still treated her like a living person. She

encouraged her children to speak to their grandmother as they did before her mother-in-

law was sick.

Although she cannot communicate with us, sometimes we get close to her ear and talk to her. In addition, everyday before my son goes to school or sleep, he always speaks close to her ear, telling her: "Grandma, I am going to school." or "Grandma, good night."

In summary, three subcategories were identified to form this core category Just

Doing. Recognizing Duty represented the theme of how a caregiver perceived her caregiving role; Experiencing Trial was used to describe the emotional, physical and social impacts during the process of providing care, which were interrelated. Mostly, the

psychosocial impacts were described. Responding to Caregiving is used to indicate the attitude toward her caregiving, including the feelings of positivism, negativism, and neutralism. This seemed to indicate the caregiving experience was individual.

#### Being Called

The category of Being called is conceptualized as the causal condition for engaging in care of a parent-in-law, which was the formulation of and reasons for the caregiving behaviors. In traditional Chinese society, a married woman was asked to assume the responsibility of caring for her husband's family, especially her parents-in-law. The caregiving task was not only based on caring for a patient, but also on respecting the older generation. In other words, if the parent-in-law was sick, a daughter-in-law would "be called" by the social norm to carry out her duty to take care of her sick in-law, either voluntarily or because she was asked by the family members. Thus, Being Called includes two parts, one is culturalized by the surrounding environment, which made a caregiver assume the caregiving task; the other is caused by the realistic need for in-law's care.

# Cultural Expectation

This subcategory, Cultural Expectation, represents the foundation of a woman's belief, which was derived from education, family background, religion and the whole society where they live. Taiwanese people believe that a woman belongs to the family she marries. Thus, a woman should have the responsibility to take care of her parents-in-law but not her own family because the daughter was considered "spoiled water." The woman would be praised for displaying good filial piety by taking care of her parents-in-law; if she did not, she would be criticized by the relatives or neighbors. Furthermore, a woman would be punished by god if she did not exhibit good filial duty.

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Women are raised to believe it is a daughter-in-law's duty, not a daughter's duty,

to assume the major care taking task. One woman mentioned this belief was taught by her

own parents since she was young:

I was taught that taking care of the parents-in-law is the first priority to a woman since I was young. My parents did not expect me to take care of them even though they were sick because they considered I had gotten married.

Some of the participants mentioned they were influenced by the neighbors,

especially the participants who lived in the rural area. It is because people were usually

getting together to discuss or criticize a woman's conduct.

In the rural area, the people often discuss and criticize what a daughter-in-law did for her parent-in-law. It is believed that a daughter-in-law should assume the responsibility for taking care of her parents-in-law when they are sick. Daughters have "married out," they have no responsibility to the family of origin. I also grew up in the country. I have the same belief. Parents-in-law's care is a daughter-in-law's responsibility.

The man still dominated the house in most of the families. The responsibility of a

daughter-in-law was just to provide care for her parent-in-law. A daughter-in-law was not

involved in making decisions about the management of her parent-in-law. They often

follow a man's opinion for in-law's care. For example, one woman said she must ask for

her brother-in-law's opinion if she had difficulty in taking care of her in-law or if her in-

law needed further management.

She (mother-in-law) rejected everything, including meals. I could not make any decision, because I am just a daughter-in-law. I had to call my brother-in-law to ask his opinion. I am just a daughter-in-law, my responsibility was to take care of her when she was sick.

Mostly, the elder generation expected that the daughter-in-law had the

responsibility to take care of the elders. And, a daughter-in-law was also often to follow

the in-law's will because she believed a daughter-in-law should respect her parents-in-law.

My in-law would be angry if I did not come here to take care of him even if we have hired an aide.

I was forced to provide care. My father-in-law disagreed with us about hiring an aide. He said that two daughters-in-law could take turns caring for my mother-in-law.

If one's father-in-law was dead, elder relatives would replace his position in the

family and ask the younger generation to assume the responsibility.

Each time, when my aunt (mother-in-law's sister) called me, she always said "Your mother-in-law helped you to take care of your children before.... You should treat your mother-in-law better....

Religion is another important part of the culture. Most of the caregivers in this

study were folk believers. Folk beliefs emphasize ethics and morality, with specific

concern about the ideology of cause and effect. These beliefs were found to be cultivated

into a woman's inner mind and influenced her caregiving behavior. The most common

belief mentioned by the participants was that heaven knows what they have done. A

Buddhist woman said:

I thought that the reason why I have to take care of my in-law was caused by something I did in my previous life. I owed them (parents-in-law) before. We have to treat them well to release the hate in this life, otherwise the hate will pass to the next life.

The influence of religion was sometimes invisible. Usually the house worshipped the Mercy goddess. On the wall of the living room hung words, such as "one has no worth if one does not perform filial piety for one's parent" or "Hsiao" (meaning filial piety) to remind each family member.

### Consequence of Illness

This subcategory represents the situations or the events which were caused by the patient's illness.

In this study, most of the patients suffered from a stroke, or related illness which caused symptoms similar to a stroke. Regardless of whether the illness happened suddenly or gradually, the family members found it hard to face this change.

First of all, the caregiving need would depend on the characteristic of the disability. The amount of caregiving needed depended on the period of the disease, the degree of the disease severity, and the degree of the patient's dependence.

The caregiver was most frightened when the in-law had the first stroke. During the beginning stage of the disease, caregivers usually suffered more because the patient's condition was critical and needed emergency care. Besides, the caregiver usually was shocked by the patient's changing condition, and they were not familiar with how to manage the patient's problems. When the caregivers described their experiences, this stage provoked the most frustration and anxiety. In the later stages, the caregiver adapted to the caregiving situation gradually by means of learning, observing, and seeking resources. The time needed to adapt was individual, from one month to one year.

There was a big difference between the beginning stage and how I feel now about the care. During the beginning stage, I lost much weight. But, I have recovered now. Now, the burden is much less than before.

I felt imbalance for about half a year. Then, it was like a routine. I just do it everyday.

The first year was really very hard. I have never cared for a patient like him. His mood was not good. He shouted. I did not know what I could do. I felt very sad.

The caregiving needs were also based on different degrees of the disease severity and dependence. A patient who was unconscious and needed to be totally cared for might be less troublesome than a patient who was suffering and struggling. One participant

described her experience:

In the beginning of his first stroke, we had to feed him because he was not used to using his left hand. During that time the biggest challenge was when he lost his temper. Now, his condition is more severe than before, but he cannot shout. He just lays on the bed. I just need to feed him on time. My stress is less than before.

In general, more caregiving functions would be required in the initial stage of a

patient's illness. However, the need is very individual, and could not be decided based only on the diagnosis.

Not only was the family shocked by their in-law's physical change, but the in-law was annoyed by his/her own physical disability such as being physically dependent or being unable to communicate. Since the parents-in-law had a hard time accepting the reality, most caregivers first described their experiences in coping with their parents-in-law's emotional reaction to physical disability, and about their suffering. The reaction to illness of in-laws' was different, most of them lost their temper, but some were overdemanding or were depressed.

In the beginning, when he suffered from a stroke, he shouted, because it was hard for him to communicate and move.

His character changed since his leg problem, especially in the last half year. He just makes demands: "I want to eat my meal." Everything has to be serviced for him.

My mother-in-law felt depressed. She blamed herself for making more trouble for us. . . .

In summary, the formulation of the caregiving role was based on the cultural

expectations of a woman when she becomes a daughter-in-law. The mechanism of

formulating this process is mixed with ethics, morality and religious thoughts. The

caregiving responsibility was especially aroused when the elders were sick.

### Caring For

Caring For is the context within which the caregiving task was implemented. This category manifested how a woman caregiver provided care for her in-law. Along with the consequence of illness, the caregiving tasks were a little different. In general, there were four kinds of tasks described by each participant, including Seeking Assistance, Keeping Watch, Providing Comfort and Offering Care.

# Seeking Assistance

Most of the patients in this study suffered from a stroke. In the beginning, all family members were anxious to send the patient to the hospital when the stroke occurred. Usually it was the man who moved the patient, and the woman usually accompanied the patient to visit the doctor for treatment. Also, the woman was asked to stay at the hospital if the patient was hospitalized. Usually, however, the woman was responsible for asking for medicine for her in-law. Since most of the patients suffered from chronic diseases, seeking treatment was not limited to one time.

Before the patient was hospitalized in a medical center, the patient might be sent to a local hospital and then transferred to the medical center. Care at the Emergency Room was the first management. Then they would be sent to the ward for further medical, surgical, or rehabilitation treatment.

After many kinds of treatment were tried in a western hospital, some traditional treatments also were adopted for the parents-in-law's therapy.

They (relatives) gave me some suggestions such as eating some herb or Chinese medicine, or ask "Shern," or whatever. My father-in-law also asked me to visit some traditional treatment, like "Chi-Kan", acupuncture or whatever. I also followed his will. I want to try everything. I thought there might be a chance for her there. Why don't we try that? Supernatural treatment like temple praying or asking a fortune teller also were

adopted for in-laws' treatment. This effort indicated that a daughter-in-law was sincere in wishing for her relatives to become better. She said:

My mother-in-law was so sick. I went to the temple to ask for an amulet for her.

# Keeping Watch

The daughters-in-law described that they had to keep an eye on their in-laws in

order to provide the care when it was needed. In addition, the women caregivers had to

closely monitor the patient's behavior to make sure she would not hurt herself.

A caregiver mentioned her experience in taking care of her mother-in-law, a senile dementia patient who was confused about the time, people, and places. Since the motherin-law could catch fire for burning "sheng," the daughter-in-law had to watch her all the time.

My mother-in-law was confused about time. She worshipped "shern" three or four or five times a day. I worried it would be dangerous for her. I hid the matchbox. I don't know where she got the lighter, not only one, but many. She took the candle and lighter to the road, to ask any pedestrian to help her light the candle. Then, she took the candle into the house. The holder for candle is so high that she had to step on a chair to set up the candle. It's very dangerous. I was so scared. So I had to keep her in my sight. We only relaxed when she sat on the sofa or she slept. If she went downstairs, we had to follow her to see where she went, to see if she went to the road or fell down.

In addition, when the patient's physical condition was not stable, the caregiver

mentioned they had to wait beside the in-law to serve her anytime, even when she slept.

After my mother-in-law choked, I took care of her day and night. My husband and I shared the same bedroom with my mother-in-law in order to observe her condition or to manage her when it was necessary.

Another participant had a similar situation, but worse, because she had to constantly run up and down three flights of stairs. The caregiver had to keep alert at all times for any change in her mother-in-law.

My mother-in-law had a lot of sputum. I had to clean the sputum in order to prevent suffocation. I could not go out. I had to observe her condition at all times. I had to keep alert. For example, when I am downstairs I had to go upstairs often to take a look. I had to get up to change her diaper, or when I hear her coughing. In order to provide care, I slept beside her for more than two years.

## Providing Comfort

This subcategory indicates how a caregiver managed her in-laws' emotional problems. A patient's mood was unstable when they first suffered a disease, especially after the first attack. It was usually mentioned by the caregivers that their relatives became agitated and easily lost their tempers. Coaxing, encouraging, and interpreting were provided for the patients in order to deal with their emotions, especially when the inlaw did the rehabilitation.

My mother-in-law was frustrated for the rehabilitation. She needed my continuous encouragement. So, I stayed at hospital to help her when she did the rehabilitation.

A lot of caregivers mentioned the patient's behavior was like that of a child. Thus,

the way they coped with the patient was to treat the patient like a child.

I often talked to him to make him feel better. The elderly person is like a child. I had to trick him. I often talked to him and comforted him.

Although the patient was unresponsive, the caregiver was also concerned with her

in-law's psychosocial needs. She mentioned "talking to her" was a way she did for the in-

law.

I thought she was just unresponsive. She heard what we said. So, we still talk to her to express our regards everyday.

# Offering Care

When taking care of totally dependent patients, the activities consisted of maintaining parents-in-law's daily activities and providing complete medical treatment. The tasks included changing the patient's positions regularly, feeding by nasal tube to supply nutrition and give medicine. They also managed personal care such as bathing while in bed, and changing their in-law's diapers if necessary. Additionally, the women provided other treatment, like sucking sputum, tracheotomy care, and performing exercises such as moving their arms and feet, giving a massage and changing their positions. The most troublesome situation was the dependent patient with bed sores from laying in bed for a long time.

She has lain on the bed for a long time. Changing positions was really important. We changed her position every two hours. We did it even in the night. We also used an air-cushioned bed. I was now used to it. I would wake up by myself every two hours and then turn her body once. When we were in XX hospital, two sides of her skin were slightly broken. We then applied medicine water over the broken-skin area once every 40 minutes. It took half a year for the skin to be fully healed. We paid more attention to this. In addition, we had to observe her condition closely, and suctioned the sputum if it was necessary. In order to prevent stiff joints, we moved his mother's arms and feet, massaged, and turned her body. I also cleaned the tracheotomy by myself.

According to the caregiver's description, professional knowledge for the long-term

care patients seemed to be required.

Another common caregiving task was to prepare the diabetic diet for parents-in-

law.

Since she suffered Diabetes Mellitus, I was concerned about her diet. I have to prepare a special diet for her.

In addition, helping to rehabilitation is also one part of the caregiving task.

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She had minor stroke many times. She could not do the rehabilitation herself. I had to do the massage for her everyday.

Furthermore, providing for a partially dependent patient was harder than it was for a totally dependent patient. Since the partly dependent patient was fully conscious, they would make more demands and be more resistant to care. For example, feeding a patient who was conscious might be harder than feeding by nasal gastric tube for a patient who had lost consciousness.

She did not open her mouth. Originally, she took soft rice. Now, we have to change to milk. We put the straw into her mouth. But she did not suck it, the milk flew out. So, we have to ask for her cooperation and give her advice, comfort her like a child.

Seeking Assistance, Keeping Watch, Providing Comfort and Offering Care were identified as the caregiving tasks for the elders. According to the caregiver's description, the professional's knowledge for long-term care patients seemed to be required in order to help her providing care. Additionally, caregiving tasks could be said to be continuous work both day and night. It is not only a work of labor, but also of love.

## Holding Up

The category of Holding Up is used to describe the elements which influence the caregiver's cognition, experiences and behavior patterns. As they faced the caregiving situation, some difficulties would worsen the hardship. On the other hand, having enough resources and positive response would lessen the caregiver's burden and facilitate further caregiving. In addition, the caregiver was also influenced by the relationship which existed between the caregiver and her parent-in-law.

# Depth of Relationship

The relationship means the love between the caregiver and the care receiver. Love would be developed after the caregiver married her husband. A close relationship would enhance a caregiver's willingness for caregiving, but an alienated relationship would prevent the caregiver from becoming involved in the caregiving situation. A participant emphasized she had a deep feeling for her mother-in-law. That is the reason why she voluntarily assumed the caregiving task and continued for more than three months. It also indicated the importance of respect between the caregiver and care receiver, which made a caregiver satisfied and more likely to continue her care.

She is an easy going person. She let the daughter-in-law do what she wanted to do. We had love between us. . . . So, I shed tears when I heard her say "I called you when I fell down beside the river, but you did not hear me," which touched me. I would like to stay here to take care of her until she recovers.

Some participants cried when they mentioned their mothers'-in-law illness. Some were reminded of how nice their mother-in-law treated them before the illness, which made them feel sorry for their mother-in-law's suffering. Some were sorry that their inlaws could not enjoy their latter years. As a result, they would do their best to do rehabilitation for the mothers-in-law. In addition, caregivers mentioned that thinking about a parent-in-law's goodness, and about what the in-law had done for them, was a good way to decrease a caregiver's resistance to care. This subcategory also indicated the phenomenon of reciprocity between the caregiver and care receiver.

I have gotten along well with my in-law for a long time. We love each other. I treat him as my own parent. He also treats me as his daughter. He helped me when he saw I was busy. So, we have good relationship. He did not lose his temper easily before he was sick. I can understand how he feels. Seeing this, I can stand all of his bother. I felt uncomfortable when he lost his temper. But when I

think about his feeling, my uneasy feeling disappeared. If you care for a patient with such an attitude, you might feel better and it'll be easier.

Conversely, a daughter-in-law mentioned her experience of being abused by her mother-in-law. She mentioned her feeling about her role in this family as a "servant." The caregiver emphasized she would abandon the caregiving task if there was no religious support.

I cry when I think about how my mother-in-law abuses me. More than fifteen years have passed, my mother-in-law still dominates. She believes a daughter-inlaw should serve her parents-in-law. She was annoyed at me because my husband helped me to take care of my father-in-law. She believed a man should not do this

kind of thing. She said that my husband had been taught by me and belonged to me. I thought I would not provide my care for my in-law if there was no religious support.

This subcategory seemed to indicate the importance of respecting each other

between generations.

# Degree of Reinforcement

Sufficient reinforcements were found to be important for the caregiver for decreasing the degree of hardship of the care. Reinforcements were derived from three sources. First, medical resources provided by health professionals. Next was the family, including sharing of the workload and the family members' appreciative response. This was especially meaningful if appreciation was expressed by her husband or parents-in-law. Third was the financial support that came from health insurance or family member's support.

The major medical resources were provided by the nurses in hospital and a home care agency. Caregivers emphasized the nurses were good models for demonstrating how to manage their parent-in-law's problems. Actually, the influence the nurse provided was not only working skills, but also an invisible spiritual sustenance for a daughter-in-law in providing care.

When my father-in-law lived in the intensive care unit, nurses taught me how to manage it. In the beginning, I dared not to do it, because I was a woman, how could I touch a big man's... (private organ). Then, I thought, a nurse, who was not his relative, could do it, why couldn't I. In the beginning, it was difficult. Then, gradually, I knew how to do it.

Another aspect, the necessity of a home care agency, was confirmed by all of the

caregivers. Providing nursing care at home would not only resolve a caregiver's

difficulties in managing the in-law's physical problems, but also for preventing the frail

patients from more miseries by having to drive them to the hospital.

Family members seemed to be very anxious when they knew the home care agency

nurse could not visit the mother-in-law. One woman expressed this difficulty:

It's very hard to send her to go to XX hospital. She has too much sputum, she could choke easily. Last time, we were scared by the choking experience. So, we applied for home visit. We really appreciated your help. Would you (indicates health agency nurse) please come to visit us again.

In addition, if a positive response came from the parents-in-law, relatives, and

especially her husband, this proved to be important for a caregiver in performing her

caregiving. A pleasant smile appeared on one caregiver's face when she mentioned her

husband's expression of appreciation for her care, or when she mentioned that her parent-

in-law preferred her care to her sister-in-law's care. This response elevated the woman's

status in her family. The feelings of being needed or feeling worthy would cause some

women to continuing providing care.

Because of my behavior, their (family members') attitude toward me changed. In my family, a woman was not allowed the opportunity to express her opinion. Now, they always ask for my opinion because I know the most about my motherin-law. My husband said all of my family appreciate what you had done. I felt much better. So, I forgot about the hardship of the care.

Another caregiver mentioned the reason she was willing to tolerate the hardship of caregiving was because of her husband's support and understanding.

It's O.K. even though it was hard to provide care. The most that concerned me was my husband's understanding.

Another reinforcement is if the caregiver had somebody who could share her

workload. Opposite to a feeling of loneliness and more suffering, a caregiver felt more

comfortable if a family member could share the workload with her. Mostly, daughters-in-

law would take turns with their sisters-in-law. But sometimes other family members, like

the younger female generation, also provided a little assistance. One woman caregiver felt

much better since she hired an aide to assist with twenty-four hour care.

We are a big family. There are five brothers living in the vicinity. We take turns to take care of my in-law, every family once a week. One week passed easily. So, I did not feel the burden even though the caregiving task was hard.

All of the participants who hired a foreign aide felt the assistance was really a great

help. The aide did not assist with care in the day time, but replaced the caregiver beside

the sick in-law at night. The caregiver could not only share the care, but she could have a

good nights sleep. Additionally, foreign labor was much cheaper than the aid in the

hospital. It was not a big burden for this family.

The foreign labor policy established by the government is helpful for families. She (aide) was great help. Before she came to my home, I could not go to work, and I could not take care of my children because I had to take care of my mother-inlaw. Now, at least, I don't need to take care of her during the night. It felt much easier than before.

Financial support would be another important reinforcement because it would

relieve the economic burden of medical expenses for the patient's family. National health insurance provided financial relief for some families.

The medical expense was not a great burden because we have national health insurance. We could apply for insurance to sponsor the severely handicapped.

### Extent of Difficulty

This subcategory is used to indicate the difficulties a caregiver met during the process of caregiving, which made the caregiver feel more burdened. The difficulties a caregiver met were related to three aspects: medical resource shortage; the interaction barriers among the patient, husband, and other family members; and the patient's physical change.

The medical resources were insufficient in many situations. The data indicated that there seemed to be a gap existing between the health professionals' services and the family members' needs. This gap was revealed in many complaints expressed by the participants.

First, the participants felt there wasn't enough information for the family member to identify a patient's symptoms and manage a patient's problem in time, which they regretted.

We did not know she had suffered from a stroke. During that morning, nobody knew what happened, she vomited, complained of a headache. We just observed her until she lost consciousness. If we knew what happened, we could have sent her to the hospital earlier. Her condition would not be as bad as now.

Information about hypertension was not available for the family. Usually, the younger generation was taught by the health professionals at the hospital, but the key person, like a father-in-law was neglected. Thus, the cognition difference between what the caregiver knew and what the older generation knew would create another conflict,

which made a caregiver feel very distressed.

We had been taught the related knowledge since my mother-in-law suffered from the second stroke. We followed your (health professionals) instruction and did the exercises at home. But my father-in-law was against what the health professionals taught. For example, he considered that my mother-in-law must eat more fried fish to increase her physical strength. So, he considered that I abused my mother-in-law. Now, he regrets this, but it is too late. My mother-in-law had suffered from several strokes. I thought your health professionals should teach the whole family, not just one caregiver.

Since the required information was insufficient, the caregiver could not provide

appropriate care for the patient. This lack of information created a new physical problem.

Since my mother-in-law suffered from a stroke, she stayed in the emergency room for thirty hours. The next day, we found that there was a wound in her hip. So, I thought that the health professionals should teach the family to pay more attention to her skin, such as changing her position. We did not know the proper way to care. The wound was not cured until twenty days later.

Next, the delivery system for transporting the severe patient to the hospital was

not available when the relative was really in emergency. The caregiver considered that

was the cause of her parent-in-law becoming unresponsive.

During that time, my mother-in-law was choked by sputum in her throat. We called an ambulance. After half hour, they arrived and they asked us to move my mother-in-law downstairs by ourselves. This delayed, by one hour, my mother-in-law's arrival at the hospital. Her whole body became black because she lacked oxygen for so long, and she never awakened again. Sometimes it is faster to drive ourselves than calling for an ambulance.

The third difficulty mentioned by the participants was being anxious because they

were ignored by health professionals in an emergency unit.

The Emergency Room wait was the hardest time of taking care of my mother-inlaw. We were told that there was not an operating room for my mother-in-law. We could do nothing except wait. My mother-in-law was alert when she was not at the hospital, but then she became comatose. Although it was just three to four hours, it seemed to be very long for us. We felt we were ignored by the doctors. In general, it was found that insufficient management was provided for the patient

and family to help them continue the care after the patient was discharged from the

hospital. This caused the caregiver to become anxious.

Last week, the physician told us that my mother-in-law would be discharged from the hospital. I felt so scared. She seemed to be in such serious condition, such as a lot of sputum, stiff knees. I didn't know how to take care of her at home if she was discharged from the hospital.

Another caregiver mentioned her difficulties and proposed her needs for further

management for her in-law's care.

The doctor just pushed the patient out. And, they did not consider the difficulties of the family. They should do more for the family, such as coordinate which hospital we can transfer the patient to. They just ask us to do this ourselves. I really worry about what more we can do.

A lot of caregivers mentioned they had considered sending their relatives to a

nursing home. Unfortunately, due to the unavailability of a reputable nursing home, the

caregiver was forced to continue to provide further care.

I found I could not send her to a nursing home after I visited the nursing home. They just got very little attention by the care provider. Her physical condition would become worse if she stayed at a nursing home. So, I decided to take her back to my home.

The last difficulty expressed concerned unfair health insurance. While the national

health insurance had sponsored the patients who suffered from severe illness, it could not

benefit the family of a patient in an unresponsible state.

I applied before, but the "health insurance" department rejected us. They told us that people in nonresponsive states do not belong to the category of "serious illness." I feel that this is very unfair.

Caregivers also complained that the benefit provided by the government to old

people is inadequate, and the policy is rigid.

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The benefit provided by the government to old people is very little. There is essentially no financial assistance for my mother-in-law. I applied for the financial assistance for low income family. They told me my father-in-law is younger than 65 years old, and all of us can go out to work. They did not consider the fact that both my father-in-law and I cannot work because my mother-in-law needs our care.

Another aspect of Extent of Difficulty is Interaction Barrier. This minor category is used to reflect the barriers that existed among the patient, husband and family members during the process of providing care. These situations were found in three kinds of interactions: One is the barriers between the caregiver and the patient; next, is the caregiver and family members, the third, is between the caregiver and her husband.

The first situation concerns the barriers between the caregiver and the patient. A patient's restlessness, agitation, and lack of cooperation during the therapy process also were described to be troublesome for them. However, the most difficult situation occurred because of in-laws' overdemanding behaviors.

The biggest challenge was that she was so overdemanding. She bothered us even when she was O.K. At one moment she asked us to elevate the bed; the next moment she asked us to put it down. Sometimes she asked to sit, and then she asked to lie down a short time after that.

In addition, the more disturbing the behavior, the less patient the caregiver became. Continuous overdemanding behavior by the patient lead to a breakdown in trust and deterioration of the caring relationship. Often this would cause a caregiver to quit providing care.

I asked her to wear the diaper, but she said she could control it. When she urinated on the bed, she said she did not know when it happened. I thought she did it on purpose. She should have known when she needed to urinate. We always try to fulfill her requests. Now, I think I won't obey her will. . . . Maybe, I have to hire an aide to take care of her. This might make her experience better for us. There may have been a lack of trust between them. In addition, poor

communication would make their relationship worse. When something a caregiver did for her in-law was misunderstood, this made the caregiver feel most upset and distressed. The problem usually occurred when the care receiver did not communicate directly to the caregiver. Due to a lack of open communication, misunderstandings would negatively influence the desire to provide further care.

I bought one kind of fish (Shei) for my mother-in-law. It is very expensive. The reason is because I was told by a nutritionist that this fish is helpful for the patient after an operation. But, my mother-in-law misunderstood that it was another kind fish (Yui), which is for a fat reducing diet. She rejected it and complained to my sister-in-law, but did not tell me directly. I was told by my sister-in-law. My sister-in-law told me that my in-law disliked what I had done for her. I am lucky that I had a sister-in-law who I share with, otherwise I would have been misunderstood. The family may have thought that I abused my mother-in-law. I really did not expect that. So, now, I am really frustrated when taking care of her.

The elder generation would often compare which person provided better care and

then criticize the other. These comparisons often made a caregiver feel distressed and

discouraged.

My mother-in-law always said "your sister-in-law always fed me, why can't you?" I didn't know what I could do in the future. I had done my best.

In this study, it was found that the key caregiver was usually the one who was

praised by the parent-in-law. The other one who was criticized would often withdraw

from the caregiving situation or feel depressed.

A woman shared why her sister-in-law did not come to the hospital to give care.

She explained the following reason: "My mother-in-law told my sister-in-law that I made

her feel uncomfortable."

Another situation concerns the interaction barriers with other family members. The more blaming there was, the more frustration. A caregiver felt that "The good things never belonged to a daughter-in-law, but that bad things always follow her." The blaming would come from a healthy in-law or a married daughter. These relatives often became the stressors rather than resources at home. Additionally, the caregiver hoped they would leave her alone when she took care of her sick relative.

I am really tired of my mother-in-law. I just think I am willing to do anything if only they would leave me alone Actually, I would like to take care of my fatherin-law. My mother-in-law would increase my stress when she stayed with me.

Big families were an advantage as they shared the workload and/or medical expenses. However, there were many disadvantages too, such as conflict when there was unfair sharing or too many different opinions for treatment. These would delay medical treatment or make the member who made the decision for medical treatment suffer more stress. For example, a caregiver insisted that her mother-in-law should accept an operation in order to improve the in-law's condition. Since another family member disagreed, she had to pay the medical expenses and take care of her in-law alone. Furthermore, she was anxious because she felt she was then responsible for the result of the in-law's operation.

There are four people in this family. My father-in-law and my second brother-inlaw disagreed on proceeding with the operation for my mother-in-law. So, two agreed, and two disagreed. At last, the person who pays the most money signed the consent form for the operation. The other people did not pay because they disagreed. During the process of the operation and thirty- six hours after the operation, I stayed at the hospital and also hired an aide to assist me. I did not dare leave. I felt I had to assume all of the responsibilities. It was pretty scary.

Although a daughter-in-law believed she was obligated to provide caregiving tasks for a parent-in-law, as a primary caregiver, she would feel an imbalance if she felt there was unfair sharing of the workload. While family members criticize and compare each other about the quality of care, the results may be that nobody wants to assume the

caregiving tasks.

My brother-in-law criticized me and said that I was unwilling to take care of his mother because I am a daughter-in-law. I asked him "What's the quality of your care? My care is twenty-four hours a day, both me and my husband are involved. You always come home so late. We saw the elders cried when we visited them. They felt so lonely and scared when they stayed at his home.... I took care of my mother-in-law very well. She also praised me, but I dared not bring her back to my home again. More people, more gossip.

Another barrier was found to be the caregiver's interaction with her husband. A

husband's appreciation would encourage a woman to continue her care, whereas a

husband's lack of support would discourage a woman from continuing care.

Based on a stereotype about gender differences, a husband may insist that the

caregiving task should be assumed by his wife.

I asked him to accompany his mother overnight for care. He rejected my idea. I said "she is your mother, why couldn't you. . . . He said he thought it was a daughter-in-law's responsibility. He could not understand how tired a caregiver is (cry. . . .). I decide to hire an aide by myself; I didn't care what he would think.

When a woman was tired of giving care and felt her husband didn't appreciate her,

couples became apathetic. Poor communication would worsen the relationship between

the couple and make the woman feel more upset about her caregiving.

I told my husband "I would take care of his mother if our marriage relationship existed, but I would not if our relationship disappeared." That's all. I had no word to say to my husband.

Finally, the caregiver's mood would be greatly influenced by either dramatic or

very mild changes in the patient's physical condition. Most difficult for the caregiver was

when the physical condition changed unexpectedly and become very severe. One

caregiver described how scared she felt when her mother-in-law was suddenly choked by

sputum.

A couple days ago, I helped her to sit on the chair. It's hard to clean the sputum. Suddenly, she seemed to be choked by the sputum, I found her appearance had changed. It's pretty scary. I laid her down immediately, and removed her sputum. Then, she recovered gradually. It's pretty scary because I was cleaning her bed, and I didn't expect that.

Another situation which also made the caregiver feel stressed was when the in-

law's physical condition did not improve much or persisted for a long time

The only problem is that I could not achieve what I would like to do. Sometimes I think that it would be nice for her if she can pass away peacefully. Sometimes she was in pain and wrinkled her face. I asked her what was wrong and she could not answer. I felt very sad.

In summary, this category of Holding Up indicates the influences which affect the caregiver in giving care. Three subcategories were identified. They were the Depth of Relationship, which presented the importance of love between the caregiver and care receiver; Degree of Reinforcement, which emphasized the effects of various resources and spiritual support for a caregiver; Extent of Difficulty addressed how the lack of resources affected a caregiver, and how communication barriers hurt the caregiving of the woman.

### Keeping Harmony

Keeping harmony is a kind of strategy adopted by the caregiver to comfort herself over the difficulties associated with the caregiving.

Following Chinese culture, Taiwanese beliefs and living ways were strongly influenced by the philosophy of Confucianism, Taoism, and Buddhism. The teachings of Confucius, which are principles for social interactions, emphasized loyalty and benevolence. These behaviors were established by the rule of property (Li). It was expected a person should inhibit her emotions to attain a state of harmony with the surrounding environment. So, one reflects on everything one did everyday until the highest excellence is reached. The notion of benevolence is the belief that one should help others to acquire the same things as oneself or even to sacrifice the self. Confucian thought is that a person should accept one's destiny. In other words, one should optimistically carry out their duties ascribed by fate.

"Tao" or "way," is the major concept of Taoism, which is the Chinese people's philosophy for interpreting one's world view. Taoism teaches that a person should be in harmony with nature or conform with the nature. The so called "fatalism" also was formulated from this concept.

In Buddhist philosophy, "Inn" and "Ko" ( cause and effect) are the principles that encourage people to do "good" and "right" and to receive "good" in return. Actually, Taiwanese religious life is a combination of early folk tradition, native Taoism, and Buddhism, interwoven with Confucian philosophy. In general, this culture advocated affection among the people and emphasized negotiation with the cosmology, including heaven and other people.

In this study, it was found that these thoughts were cultivated into the minds of the women and was reflected in their strategies for interpreting and coping with the caregiving constraints. Women practiced inner self-reflection and reaching beyond the self.

# Reflecting on Self

As discussed above, Chinese culture seeks to maintain a person in a state of "integration with nature." As a caregiver, facing the challenge of the caregiving task, reflection of self is one way to search for the meaning and purpose of life in order to maintain a harmonious inner mind. The thoughts include the feelings of fatalism, optimism and religious thought.

Since taking care of the parents-in-law was considered as a good virtue in this society, Do Well and Get Well were the beliefs expressed by the religious caregivers.

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They also believe that heaven knows what they have done and heaven will repay them for their hardship. Mostly, the women wished the repayment could be passed on to their younger generation.

I am an honest person. I believe "causes and results," "Heaven will pay more love for the honest person." I wish heaven could see everything I have done, and reward the younger generation. Let them have a successful business and be healthy.

Conversely, the caregivers believed in the notion, "do not well, get not well." One

caregiver believed the reason why her mother-in-law suffered from this kind of disease

was because she had not lived by this idea.

Actually, I also felt my mother-in-law's disease was owing to what she did bad when she was young. She was mean to others. So, we had to do by our consciences. The care which I provide for my in-law was based on my conscience.

There were some caregivers who mentioned their good conduct in performing filial

piety would be a good model. They hoped their actions would provoke their children's

filial piety and would be repaid both for their good conduct and their good demonstration

to their sons.

Heaven sees what the person does. In addition, my son will see what I did for my father-in-law and so the same to me when I was old.

Another explanation for providing care was the notion of fatalism. "That's my

fate" was described by many women. The caregiver believed her situation was due to her

fate because of her role as "a daughter-in-law," rather than a daughter. The caregiver

believed the reason why she should provide caregiving for the in-laws was because she

owed it to them from a previous life. The caregiver considered she had to pay it off in this

life. And, she would like to provide the care until the in-law dies.

I ascribed it as my fate. I approached it from the perspective of cause-effect in the last life to interpret it for this life. I might owe her something from the last life time. So, I have to pay it off in this life time. I have until the time my in-law dies to pay it off. If I did not pay off what I owed, I would have to pay continuously until the following life time.

Hsiang Kai (Think through) is a common saying used to comfort one's self or others when one is in distress. It means that one should keep an optimistic attitude to make oneself become happier. This was mentioned by several woman who adopted it to comfort themselves. This phenomenon reflected the Chinese character of optimism and fatalism. So, when the woman mentioned her caregiving experience, most caregivers did not complain of their bad fate or blame others. They just silently accepted their fate, tolerated the suffering and comforted themselves.

I thought it would be better to see things "through." You have to look beyond the angle. It's not useful to think too much.

This kind of thought also was expressed in many ways. Some caregivers said that a day passed no matter whether the caregiving was happy or unhappy. Thus, they would like to maintain a good mood instead of a bad mood. They said "Happy is one day, unhappy is also one day. I always keep a good mood to take care of him everyday." Some women felt they were more lucky than others when they compared themselves with another poor family in the hospital. The comparison gave them more balance and courage to do more. "Compared to others, I am not the poorest. Others could do, I also could do." Additionally, the caregiver's positive attitude suggested the reason she could provide care was because she was capable and healthy. A healthy person is much better than a sick one. "I think I am lucky because I am healthy, and I can do for a sick person." Some caregivers reflected on the thought of "conforming with nature." They felt life just is, one shouldn't think too much.

Life is just so so, one brings back nothing when one dies, why do we care about it. One should just do one's duty.

Furthermore, the optimistic caregiver would like to keep hope. Keeping hope would help a woman caregiver tolerate suffering. Because of such hope, it was perceived that the hardship was temporary. For example, a woman caregiver quit her job to take care of her mother-in-law. Although the family financial burden became more stressed, she comforted herself with the idea that the constraints were temporary, and the family status would improve in the future.

The hard time will pass. In the future, I could work outside of my home to earn money to help during this hard time.

### Reaching beyond Self

In addition to the feelings of optimism and fatalism stated above, the caregivers intellectually faced the caregiving reality and resolved the problems they encountered. Reaching beyond self reflected the ways a caregiver addressed the caregiving issues by asking for resources and negotiating with the surrounding people.

Because she was taught to respect the older generation, obedience was considered as a better way to react when her parent-in-law was angry, even though following the inlaw's will was not good for them. However, the caregivers had different interventions which they felt were the most effective way to cope with the in-laws' problems. The reality a caregiver would meet first was how to cope with her parent-in-law's disturbing situation, especially when the in-law lost their temper. The following table illustrates these strategies.

Intervention	Example	
Obedient	I just tried my best to follow my father-in-law's will. I just	
	hoped he was happy	
Leave him alone for a while	I leave temporarily and let him alone for a while	
Communicate openly	My mother-in-law resisted rehabilitation. I let her know	
	what my sincere hope is. Then my mother-in-law promised	
	me that she would try her best. We communicated openly.	
Communicate indirectly	Daughter-in-law is different with a daughter. Sometimes, I	
	would like to talk to his daughter, and ask her to talk to	
	him.	
Delaying	We have to delay his demands sometimes. Otherwise,	
	we'll fall down soon. I don't argue with him, I just say	
	"OK, OK" or "Why don't you take a nap first? After the	
	nap, I will take you to see a doctor." For awhile, he will	
	forget it.	
Trial and error	We got it, we had learned how to manage his disturbing	
	behavior	
Asking in-law's need	I asked him around one and half to two hours whether he	
voluntarily	needed to urinate. I wanted to let my in-law know I was	
	still concerned about his condition.	
Interpreting	I found that interpreting the purpose of each exercise was	
	important, such as for getting up the bed, for balancing the	
	bodyetc. She gradually accepted it.	
Encouraging	I stayed in the rehabilitation room with her to encourage	
	her to do the rehabilitation. Gradually, the aid also found	
	that my in-law would do more if I stayed there.	

Table 1. Caregiv	vers' Strategies fo	r Managing Sick In-laws
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Leaving the in-law alone for a while was suggested as a good way to let both the patient and the caregiver calm down. The ways of communicating were also different. Some caregivers like open communication, some believed the indirect communication by means of other family member's help would be more accepted by the father-in-law. Some caregivers proposed a flexible way, i.e. delaying patient's needs if the in-law was overdemanding. Actually, the so-called effective way was individual, and a process of trial

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and error. However, most of the caregivers confirmed they clearly interpreted treatment for patients and encouraged them to accept it. Many would ask about the in-law's needs first to allow her to express her concern. This would lessen the in-laws' demanding behavior.

Resources were needed when a caregiver felt burdened. The caregiver tried many ways for getting the resources to decrease her burdens, including both man power or institutions to share the workload. In addition, she also tried to search for emotional support from the surrounding people or she prayed.

Usually, the woman caregiver would share the workload with other sisters-in-law. However, during her turn or while she was the only caregiver, she would need her own family's support. The caregiver expected the husband to help mainly if it was an emergency situation. Next, it would be her own mother who usually took care of her children if she lived nearby. The younger generation, usually the participant's daughter, would be asked for help. This situation was especially true when the girl had a deep love for her grandma, for example if she was brought up by her grandma. In the rural area or in the country, the neighbors or relatives who resided around also were important resources.

However, if a family member was unavailable for care, other alternative ways were considered, such as paying for another sister-in-law to help or hiring an aide to share the workload. Lots of caregiver also searched for a nursing home, but most of them forgot the idea because of economic considerations or distrust of the quality of care.

The expense in a nursing home is higher than my salary. Can I put my mother-inlaw in a nursing home?

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After visiting the nursing home, I forget my idea of sending my mother-in-law there. I wouldn't stop worrying if I sent her there because the quality of care is not good.

While spiritual support was so important to help a person to overcome difficulties, just a few woman mentioned they shared their feelings with others. No caregiver mentioned sharing her feelings with health professionals. The only finding was that the caregiver prayed during the difficulties she met or went to church to search for inner power to encourage herself.

During the difficult time, I just whispered "Ya Mi To Fu" (Buddhism's word)." or I just prayed and depended on the God's will.

Probably, this phenomenon is owing to the Chinese character, i.e. hiding personal pain to prevent hurting others or a woman's persevering personality. It was also possible that the women believed that domestic scandals should not be publicized. Since most of the caregivers were religious believers, they pursued religious support to relieve their suffering. This phenomenon also reflects the woman's effort to keep harmonious with the surrounding people.

In order to share her workload, negotiating with other family members was considered necessary. This study found that the male was superior to a female in a family. A daughter-in-law usually was found behind her husband during the process of negotiation. The negotiation usually was held between the brothers except for a very few assertive women. Usually, the contents of the negotiation would include three aspects: how to assign the man power for the caregiving workload; the medical expense; and how to negotiate the medical treatment. The process of the negotiation included discussion, cooperation and compromising, and so on.

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First, the family members would have a meeting to discuss how to make arrangements for the parents. Such a family meeting was held. Even if the woman did not agree with the result of the discussion or felt it was an unfair division of the workload, she still compromised her belief. But she would search for some reason to comfort or humor herself again.

However, cooperation with other family members' decisions and following the contract were also common. Taiwanese people said "do what the most people did." In addition, since the women also worried about criticisms from neighbors or relatives, they believed it would be safer to cooperate with the strongest family member's decision.

In summary, the category of keeping Harmony includes both Reflecting on Self and Reaching beyond Self. These attitudes reflect the woman caregiver's optimism and fatalism to face her caregiving constraints, and to pursue harmony between the person and cosmology. Meanwhile, the harmonious way in which the woman faced and accepted the caregiving reality indicated the women's perseverant character.

#### Maintaining Filial Piety

The category of Maintaining Filial Piety represents the consequence of the entire striving process for in-law's care. After all, no matter what experience a woman encountered, filial piety still had to be maintained. Since the experience was different for each woman, diverse consequences were found.

### Ann-Shin (Serene Self)

Ann-Shin is one Taiwanese word which was used to describes a caregiver's feeling of serenity. It is an emotional experience of inner peace. Although the feeling of ann-shin

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is not always being happy, it is being able to have an inner calm. That is, although the caregiving task was hard, assuming the responsibility of providing care could prevent her from being criticized by people or struggling for her own morality. In nature, *Ann-Shin* evolved from the personal need to feel safe. However, it also represented that the caregiver was striving to keep the traditional culture norm and the harmonious relationship with the people and cosmology. Additionally, a woman who has experienced *ann-shin* also could be said to have reached a higher level of self actualization. Therefore, if a caregiver attained this level, she was actively working toward caregiving and she forgave the unpleasant experiences she encountered during the process of providing care.

A caregiver felt that assuming the caregiving responsibility would be wiser than avoiding it, because the need for care would not change. The caregiver explained that providing care would increase her peaceful inner mind and make her family harmonious. Conversely, avoiding the responsibility might endanger her marriage.

I have a peaceful mind for what I am doing. You might hurt your marriage relationship and be criticized by the relatives and by your mother-in-law if you resist it (indicated for caregiving). On the contrary, if I do my best to take care of my in-law. My sisters-in-law will (husband's sisters) appreciate my care. My whole families feel happy. Some things you have to do. Depend on yourself.

Another caregiver described the reason for feeling peaceful. She had followed traditional morality in caring for her in-law and this helped her reach her inner peace.

As a younger generation, I felt I could not go against my conscience. I feel peaceful in my mind, thus, I felt comfortable.

In addition, the woman might approach care from a religious perspective. In this case, she believed she would be paying off a debt from her previous life. So, she would

like to forgive the parent-in-law and continuously provide caregiving regardless of how

she was abused by her in-law.

Even though I was abused by my mother-in-law before, I did not hate her. I felt *ann-shin*, because of my care. I could pay off what I owed my in-law in a previous life. In Buddhism, it was said "happy to perceive one's suffering."

Furthermore, it could be said that the feeling of ann-shin was based on the

perception of being unconditional. The caregiver expressed that they did not expect to be

repaid for what they did for their in-laws.

I take care of my in-law not to be a model for my children. I just do what I should do. The caregiving just let me feel *ann-shin*. I do it whether or not my children will take care of me.

Besides, the feeling of ann-shin was found when the caregiver felt the caregiving

task was helpful for her relatives. So, she would also feel worthy for what she had done.

It's really a great reward and much more worth than others when you see her condition become better. My mood is much different when I found my care is helpful for her.

Additionally, a feeling of worth also was found when the caregiver was praised by

her husband, relatives or neighbors, with the most important praise coming from her

husband.

I don't care what others are saying. My husband was a silent man. He did not express to me, but he told his friend that he was lucky to be married to me. I felt everything I suffered was worthwhile.

Based on the feelings of being peaceful and feeling self-worth, a caregiver would

tolerate and forgive the distress she encountered during the process of her interaction with

the patient and the family members. Furthermore, she would appreciate herself for what

she had done.

When the caregiver experienced the feeling of *ann-shin*, this indicated she had worked through the struggling process.

This morning, I sat at the bed side. I was rethinking what I got during the time I took care of my in-law. I would like to say yes to myself. See, her blood pressure is normal, her spirit is cheering up. Right, I have gotten a lot. It let me stop worrying. I also think that my brother-in-law might have his difficulties for providing care. One can't just concentrate on people's negative aspect. I would not hate him. Nobody is perfect. I could not achieve perfection either.

Based on the statement above, under the circumstance of *ann-shin*, a caregiver's inner mind was calm and she could accept what she could not change, as well as actively work toward solutions for taking care of her parent-in-law.

### Wu-Nine (Sacrificed Self)

Another consequence of caregiving was sacrificing self. In Taiwanese *wu-nine* expresses a caregiver's sacrificing herself. The caregiving task was perceived as an obligation, but the caregiving experience was full of trials; the caregiver would like to escape from the caregiving situation, but she had to continuously commit.

*Wu-Nine* is also the feeling of being frustrated, unpleasant and depressed. Usually, the *wu-nine* was one feeling of struggling for long-term care, i.e. it's really hard to sustain the caregiving, but the caregiver perceived she should strive to carry out the caregiving obligation. It might be derived from many aspects, such as patient's disability showed no improvement despite her striving to provide care, no positive response or resource support from the family members and so on. However, the description of *wu-nine* would be the caregiver's emotional response and the feeling of being overwhelmed. The reflections of *wu-nine* might be expressed by verbal tiredness, or also physical distress.

Since most woman caregivers felt the daughter-in-law should assume service to her parents-in-law, the feeling of "no way out" was commonly expressed by the participants because the caregiving was inevitable and the complaints were of no use.

"Just tolerate. What can I do?" was another common reflection. Based on the belief of respect for the elder generation and rationales of caregiving obligation, to tolerate was considered a better way by the caregiver. However, the hidden emotion was one of sadness.

She is my elder. How could I ignore her? I have to tolerate this. This kind of family I have it, I have to face it (Crying. . . . ). Take it one day at time.

Escaping the caregiving situation was considered one way to be exempt from the

obligation. Taking care of parents-in-law was perceived as the younger generation's

obligation. So, getting a divorce was the only way to evade the caregiving duty.

I really wanted to give up. . . . (crying more), but I think my children are so young. . . . the kids are innocent.

Isolating one's feeling to prevent the idea of giving up the care was another

description. Some participants mentioned they would not like to share their experiences with others, including their husband, family member or any friend. Actually, talking was considered as hurtful for the surrounding people, especially their husbands. They felt there was nobody they could share with. The only way was just to freeze their feelings.

I just kept silent. I didn't talk much. Actually, complaints were no use. I knew my husband had no better way. So, complaints would increase his burden. In addition, I might hurt him if I did not control my emotion during the process of discussion. I don't want to talk to my parents either. They would worry. That would not help, but it would increase their burden. So I just isolated my feeling, and I don't like to think. Why am I a major caregiver? Exhaustion indicated a caregivers' feeling of wu-nine. Many woman expressed distress about the caregiving task and it was difficult enough to conjure up the energy and motivation to provide further care. Additionally, there was no hope that her situation would improve in the near future.

I am too tired. I thought I should hire an aid, otherwise I would fall down before her. . . . My mood is very low. I don't know how long the suffering will last.

The feeling of exhaustion followed long-term care, which had no obvious effect on

her in-law's physical condition. This type of woman felt frustrated and depressed.

A young caregiver mentioned her experience of providing for her father-in-law for more than one and half years, while he remained in a vegetative state. The caregiving task brought her very little sense of achievement, but a high level of distress.

I feel there is no hope. But I just do it. Everyday, I just cook and feed him by nasal tube. His abdomen always keep so flat that I don't know whether the feeding is helpful for him or not. It has lasted for one and half years. I really don't know what to do any more.

Although the caregivers expressed their tiredness or even intended to escape the caregiving situation, these caregivers also kept doing their caregiving tasks. It seemed that the perception of work was greater than the actual work load.

In summary, Ann-Shin and Wu-Nine are used to present the consequence of the caregiving experience. The former means the caregiver attained the feeling of serenity, while the wu-nine was a kind of frustrated and sacrificed feeling. However, the feelings of being serene or frustrated were not always kept in a static status. The caregiver's feeling changed with the influence and thoughts mentioned before.

### Summary

Culture was found to play an important role during the process of taking care of the in-laws. First, the caregiving role was formulated based on a feeling of the obligation and traditional assumptions of the nurturing task for a daughter-in-law and a woman. Obviously, this belief was based on the cultural expectation, not the affection factor. Although the perception of being a caregiver had many similarities, the caregiving experience was individual. As a matter of fact, the amount of the caregiving task was not the major load to the caregiver, but how a caregiver interpreted the caregiving role, which was dependent on the love between the caregiver and care receiver, and whether her work was affirmed and supported by the family members. After all, the caregiving task not only needed to involve physical labor, but it had to involve more caring to relieve the in-law's suffering. If the "obligation" of caregiving was in terms of love, the caregiver would be more satisfied with her care. And that might be an important reason to continue her caregiving.

In this study, in addition to the physical burden, more psychosomatic complaints were described by the caregivers, which were either aroused by the complicated interaction among a compound family or the role expectation of being a daughter-in-law taking care of an in-law. The evidence indicated, however, the resources from health professionals and the emotional support from her relatives were insufficient in facing this big burden.

Traditional woman's perseverant character and the belief about pursuing harmony between a person and heaven, and among the social interpersonal relationships, were

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disclosed as part of the strategies used to overcome difficulties in caregiving. Instead of being assertive or expressing personal needs, conforming to cultural expectations was considered the most common way to cope with problems. This phenomenon implies the Taiwanese women's health needs would be easily neglected, especially if the health resources were inadequate.

Furthermore, while the caregiver was striving for a peaceful mind during the whole process of caregiving, it was also found that she would sacrifice herself in order to maintain filial piety. The phenomenon not only reflected the caregiving behaviors, it was strongly subjected to cultural influence, such as the concept of Taiwanese woman's altruism. Based on these findings, another worthy area for further exploration would be whether hiding emotion affects a woman's health.

The following poem was written and chosen as a way to reflect the daughter-inlaw caregivers' inner voice.

------

## Where Is My Voice ? - Just Doing

by Shu-Yuan Chao

Do it ! Do it ! Just do it !

Do it under no voice,

Do it under no pay,

Where am I?

Sighing !

I am just doing on the way

What is my marriage,

What is my fate,

What is my conscience.

Ever !

I was scared for your hot temper,

I was helpless for your suffering,

I was conflicted between you and my child.

I know !

Everything is responsibility,

Everything is obligation,.

I just wonder why I am a daughter-in-law ....

Alone, at night, I cry.

As a matter of fact,

You couldn't understand

It's real !

I am willing,

I am really willing,

if, it is my voluntary choice.

And, If !

Your understanding,

His comforting

and, other resources are enough.

Then, I will feel,

Everything is worthy,

My heart will smile,

and, I will keep doing! doing! until. . . .

#### CHAPTER V

## **DISCUSSION OF FINDINGS**

The purpose of this study was to enter the world of the Taiwanese woman caregiver to understand her experiences in taking care of her frail parents-in-law. Through constant comparative analysis, the formulation of the caregiving role and impact on the caregiver's inner process and health were identified, and the categories related to the caregiver's coping strategies and its consequences were developed. Theoretical linkages were formulated between those categories in order to explore a substantive area for preventive care. Three parts will be included in this chapter which will contrast the findings of the daughters-in-law's caregiving experience in this study with the findings in related literature. The first involves about the contrast between a theoretical model, Just Doing, and related theories; the second part discusses major categories of the daughter-inlaw's caregiving experiences; and the third part is a comparison of in-laws' caregiving experiences between the United States and Taiwan.

#### The Grounded Theory of Just Doing

As a core category, Just Doing was tightly interrelated with other categories, Being Called, Caring For, Holding Up, Keeping Harmonious, and Maintaining Filial Piety.

Just Doing is a sophisticated dynamic process. It is the integration of personal cognition about a caregiving role and the interaction with the environment which enables

the daughter-in-law to care for her sick parent-in-law. The perception of the caregiving role was built upon the traditional belief of a woman's role. It also reflected the Chinese belief that displaying compassion and sacrificing self leads to harmony which is important in interpersonal relationships. All of these are shaped by the culture. Gormley (1996) described "altruism as caring for no obvious reward other than the belief that someone else will benefit or avoid harm." None of the participants were paid, and had no expectation of obvious repayment. The perception of caregiving and the responsibility were altruistic in nature. From this perspective, one can better understand how culture influences the formulation of a caregiving role in a family.

Through the caregiving task, the caregiver experienced different emotional, physical, and social trials,. The caregiver would have a different response to each experience, i.e. positivism, negativism and neutrality. However, no matter what the caregiver experienced, the work load was affected by subjective and objective factors, including the depth of the relationship between the caregiver and care receiver, the available resources, and the extent of difficulty a caregiver encountered during the caregiving situation. In other words, the workload was not the only factor related to role strain; the interaction with other family members also contributed. Additionally, how a caregiver perceived her responsibility also affected the caregiver's experience. As Klein (1989) stated, the burden is filtered through the moral and ethical belief system of each person. The caregiver's responsibility for and relationship with the care receiver determine the level of burden felt by the caregiver. This phenomenon reflected the complexities and interelatedness of the caregiving process.

A number of researchers have found emotional, physical, and social burdens as caregiving consequences in Taiwan (Lin, 1987; Chiu et al, 1988; Wu et al, 1991; Ton, et al., 1992). However, the caregiving process is not really in a static state. Although a caregiver experienced caregiving burden, the caregiver would try to balance herself in order to keep a harmonious state. The strategies included both adjusting her inner mind and taking actions to confront her problems. This phenomenon not only reflected the Chinese characteristics of "fatalism" and "optimism"; but also reflected a woman's perseverance in pursuing a harmonious relationship with the individual, nature, and the society (Li, 1989; Yang, 1989; Kuang Hwa, 1994). The result was that a lot of problemoriented methods evolved, including developing mastery to manage a patient's problem, keeping communication open, asking for resources from the family members or professionals, looking for an alternative way, and so on. As a matter of fact, the way of Keeping Harmony also interacted with the situation of caregiving difficulties stated above. For example, when the caregiver was blamed by the in-law for her care, the caregiver would at first feel distressed. Then she would decide that it was her fate and she owed this family. Then she felt better.

A caregiver's experience depended on whether a caregiver was serene herself or sacrificed herself for the care. Serenity was related to whether a caregiver had the ability to manage her caregiving problems, her own level of self-esteem and the level of being respected by the family members. However, the feeling of being serene or of sacrifice was not absolute, because the caregiving would continue and the caregiver would also interact with the environment and try to become harmonious again.

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In summary, the substantive theory of Just Doing focused on the continuous interaction between the individual and her surrounding environment. A caregiver's physical and psychosocial reaction to the caregiving situation was related to inner responses and the availability of outside resources. Corresponding to Lazarus and Folkman's notion (1984), the caregiving process would include the process of cognition, appraisal and reappraisal. While the caregiving task was challenging, the caregiving experience was very subjective, and it would depend on individual appraisal. Meanwhile, the caregiver also adjusted herself by means of regulating her cognition and adopting action in order to remain harmonious. Whether the feeling of serenity in this study could be an indicator of psychosocial well-being or be the consequence of coping strategies needs to be further evaluated.

Major Categories of the Experiences of Taiwanese Women

Caregiving for Parents-in-Law

### Just Doing

Just Doing included three subcategories: Recognizing Duty, Experiencing Trials, and Responding to Caregiving, which represented the caregiver's cognition, experience and response to the caregiving situation. The foundation of the cognition about a caregiving role followed the traditional belief of role expectation of being a woman and a daughter-in-law. It also reflected the Chinese characteristics of compassion and selfsacrifice for pursuing harmony in interpersonal relationships. In nature, the cognition of caregiving and responsibility was one concept of altruistic morality, which was mentioned by Chu (1993). According to Gormeley's (1996) analysis, the individual had some form

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of internal mechanism which was stimulated by the social circumstance and their simultaneous attunement with the individual. Therefore, the cognition is the process of individual attunement, which prompted the caregiver to provide care, while social circumstance is the social norm previously mentioned.

Experiencing Trials was the result of providing care. Experiencing Trials is similar to the caregiving burden which was found in Chiu et al.'s study (1988), including emotional, physical and social impacts. In addition, the finding revealed that physical problems tended to be psychosomatic in nature. This may reflect psychological trouble more than physical problems because Chinese people tend to express their physical problems instead of their psychological distress (Kleinman, 1980).

On the aspect of Social Trials, it was found that a person's social life was affected; social activities were restricted or future plans changed. The family's harmony changed, including change among siblings, between spousal couples, and in the parenting of young children. Meanwhile, blaming and criticism created more stress for the woman. All of these findings were documented by previous research (Lin, 1987, Chiu et al 1988; Die et al, 1990; Hu, 1994).

No research was found on daughter-in-law caregivers' behavior patterns when providing care for their in-laws in Taiwan. A similar study was conducted in United States by Walker and Allen (1991), who found that three types of relationships were developed by the daughter caregiver in taking care of her mother: intrinsic, ambivalent and conflicted. There is some similarity between these types and the responses identified in this study. However, the difference that should be considered between Walker and Allen

and this study is the emotional factor, that is, the daughter-in-law's care was based on the marriage relationship, which was different than the relationship between a mother and a daughter. The classification of behavior patterns was approached from the participant's subjective feeling toward her caregiving experience. Since the caregiving experience is influenced by internalized beliefs and the interaction with the environment, the responses to the caregiving situation will be different. Again, it is noteworthy that although there were three patterns derived from this study, the patterns would be switched within an individual, because the feeling for care would change when a woman got more resources or she had a different interpretation of her caregiving situation.

### **Being Called**

The concept of Being Called was identified as the reasons a caregiver became dedicated in the caregiving situation. There were two major components encompassed in this category-- cultural expectation and consequence of the patient's illness. That is, cultural expectation is the foundation of the perception for the caregiving responsibility, especially when the in-law was sick.

Cultural norm was found to be the key factor in encouraging a daughter-in-law to assume the major caregiving role in a family, which included the traditional ideology and people's expectations. The evidence indicated that culture bestowed the caregiving responsibility on a son, however the daughter-in-law assumed the duty for her husband. This finding reflected the traditional role expectation for a daughter-in-law to assume the caregiving role. This finding was similar to Wen's study (1995) about the formulation of the caregiving role for disabled elders in a family. In Wen's study, social norm and gender identity were considered the major reasons why the woman became involved in a caregiving role. The traditional assumption has ascribed the caregiving role to a daughterin-law. In addition, the economic factor is another reason why a woman becomes a caregiver; that is, a woman would make less money than a man. This finding was also described by several participants in this study.

Although religion is one important part of the culture, few studies related how much religion influences a caregiver's devotion to the caregiving situation during the inlaw's illness. However, in Chu's (1993) study, the life philosophy of Taiwanese people was greatly influenced by folk belief, which reflected the benevolent behavior of Taiwanese people. Carrying out filial piety was emphasized as the highest priority of the benevolent behaviors in Chu's findings. Religious thought has been interwoven with Chinese philosophy, causing a woman to internalize and integrate this as part of her belief system. Based on their religious beliefs, good filial piety to parents-in-law was considered a virtue and a personal ethic by the woman caregiver. In Lawton, Kleban, Moss, Rovine, and Glicksman's study in the United States (1989), it was identified that religion was one major reason why a caregiver assumed responsibility for care. This might indicate that even though cultural differences exist between western and eastern society, the influence of religion on caregiving perception is similar.

The caregiving role became obvious when the elder family member was sick. Some individuals of the younger generation moved their elders to live with them to provide care. In exploring the relationship between the concept of altruism and providing care, Gormley (1996) mentioned the triggering mechanism for providing care. Gormley

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considered social responsibility as a motivating factor to stimulate acts of caring. While the caregiving task started from the time the elder became sick, the caregiving amount and caregiving needs would be dependent on the care recipient's physical condition and patient's response. The category of Consequence of Illness reflected the caregiving demands on a caregiver. Studies related to stroke patients' families mentioned all of the changes due to stroke were troublesome for the caregiver, including when the patient's physical condition became partial or total paralysis, cognition deterioration, or emotional symptoms (Die et al., 1990; Yui, 1989; Ou, 1992).

#### Caring For

Caring For was identified as the context within which the caregiving tasks were performed. It illuminated how a woman caregiver carried out her duty to her sick parentsin-law. Four major caregiving behaviors were performed, including seeking assistance, keeping watch, providing comfort and offering care. The findings presented the caregiving task as not only maintaining physical health, but also concern about the relative's psychosocial needs. It also indicated that the caregiving task was ongoing twenty-four hours day, both day and night. This category not only implied teaching the caregiver how to manage a stroke patient, but also predicting the caregivers' own health risk.

In addition, this study reflected that the patterns of seeking treatment were pluralistic, including western, traditional, and supernatural approaches. This is similar to Hu, Wang, and Kuo's statement (1995) that traditional folk medicine plays an important role in long-term care. In the beginning stage, western style was considered until the physical condition became stable. Then, temple praying or seeking a fortune teller was initiated.

## Holding Up

Holding Up was used to describe the intervening condition which influenced the caregiving burden during the process of caregiving. Depth of relationship, Degree of Reinforcement and Extent of Difficulties were the major influences. Similar to previous findings, it was found that the closer a caregiver's relationship was with the elder and the more obligation they perceived for parental care, the larger the burden they experienced (Wu et al, 1991; Hu, 1995). In Hu's study (1995), the relationship between elders and caregivers reflected the quality of their care. An indifferent attitude toward the elders was found to reflect resentment. This resentment occurred because the caregivers were previously ill-treated by the elders. In this study, participants emphasized that caregiving would continue no matter how ill-treated they were by the parent-in-law or husband. The participants explained further that they would like to forgive what they suffered before because of their religious belief and Chinese life philosophy. It seems that the mechanism influencing the caregiving experience was sophisticated and interrelated, not influenced by only one factor.

Degree of Reinforcement consisted of the medical resources, significant other's appreciation, sharing the workload with other family members, and enough financial support. All of them positively affected the caregiving experience. In other words, the more reinforcement a caregiver had, the less burden she suffered. A home care agency and aide's help were emphasized to be important to sustain her care, and the family

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members' encouragement was a required spiritual support. These findings have been documented by many studies both in Taiwan and in the United States (Wu et al, 1991; Ton et al., 1992; Wright et al, 1992; Ehrlich, 1992; Hu, 1994)

Conversely, Extent of Difficulties was considered to be the influences which increased the burden of providing care. In this category, shortage of resources and interaction barriers were identified among the caregiver and patient, husband, and family members. The findings in this study, that available health professionals' service could not meet the family's needs and that information and services for urgent care, long-term care and home care were insufficient, were similar to the findings of Wu et al (1991) and Hu (1994). In addition, this study, further presented the participant's difficulties in accessing the delivery system. National health insurance benefited the majority of patients, but did not provide a great help for the unconscious and their families.

Interaction Barriers indicated the participant's subjective difficulties with providing care. Corresponding to Hu's notion (1994), role strain was not only directly related to workload, but related to the interaction between the caregiver and care receiver. While most of the caregivers felt difficulty when patients lost their temper or resisted treatment, the more distressful time related to when goodwill toward an in-law was misunderstood, when in-laws compared the caregivers to each other, and when they made overdemands. At these times, the caregiver would become discouraged in her care. In addition, like Lawton et al.'s statement (1989), the expertise of the caregiver was identified as an important factor related to a caregiver's strain. Whether in the acute stage of the illness or in the recovery period, social support was considered to be the primary variable affecting

the caregiver's adjustment. In this study, uncertainty about the effects of care and the degree of difficulty in task accomplishment would cause anxiety in providing care. Although there were some studies found in which the caregiving needs were due to the patient's gradual deterioration (Ton et al., 1992; Hu, 1995), this study found it was when the patient's physical condition changed suddenly or there was more than one family member needing to be cared for. In other words, times of increased caregiving and the amount of the caregiving task should be considered in evaluating caregiving strain.

As Sanborn and Bould (1991) stated, the caregiving role would produce a change in the family system. Such family systems will experience stress in both their cohesion and adaptability, and family cohesion will be diluted. Since most of the participants in this study share the care with other family members, the changes in roles and relationships in the family system were explored. Blaming, criticizing or comparison among the family members were found to increase a caregiver's stress and make the family members become indifferent.

### Keeping Harmony

Keeping Harmony was identified as another intervening condition which was a strategy used by the caregiver to comfort herself and to facilitate her in providing further care. There were two major ways it was developed, Reflecting on Self and Reaching beyond Self. The Reflecting on Self indicated the woman caregiver in this study adopted the philosophy of fatalism, optimism and perseverant spirit to alleviate her psychological distress. Four minor categories consisted of Do Well and Get Well, My Fate, *Hsiang Kai* and Hope for the Future. In Ou's study (1992), eight factors were identified by means of

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factor analysis to interpret the coping mechanisms of the spouse caregiver for her husband following a stroke. Fatalism and Perseverance, Keeping Doing, and Alienation were considered the first three ways to cope. The Alienation in Ou's study was defined as the caregiver attempting to isolate herself from the pain of her situation. This might be similar to the subcategory of Reflecting on Self in this study. The phenomenon of Just Doing was also found by Ou. Ou interpreted that Just Doing was the reflection of the woman's perseverant and fatalistic character. Ou also found the woman caregiver was searching for a rational method to resolve the realistic difficulties. This is similar to the subcategory of Reaching beyond Self in this study. However, in opposition to Ou's study, this study found that a caregiver seldom expressed her emotion and tended to face the caregiving problem under the male family member's direction. The similarities not only reflected the Chinese woman's character, which tended to suppress her own emotions, but also reflect how she protected herself from hurt when she had to accept the "unchangeable" fact-showing filial piety. Personal relationship, whether it is husband to wife or parent-in-law to daughter-in-law will influence the caregiver's experience. In spousal caregiving relationships, the caregiver has more control in managing the caregiving tasks than in the intergenerational relationship.

### Maintaining Filial Piety

Maintaining Filial Piety was the consequence of striving to keep the filial responsibility. The focus of this category was on the caregiver's subjective feelings, *Ann-Shin* and *Wu-Nine*, which were derived from in vivo coding to represent being either serene or sacrificed. *Ann-Shin* was a kind of positive emotion indicating the feeling of

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serenity. In this study, the feeling was attained from providing care to ill parents-in-law, or from gaining respect or recognition from family members or others. Under this circumstance, a caregiver would feel peaceful in her deep inner mind. Conversely, the meaning of Wu-Nine, or sacrificing herself, was used to indicate the negative feeling in the caregiving situation, including frustration, being depressed, or being overwhelmed by the caregiving task, and being unable to express emotion. The negative feeling was due to lack of appreciation, support and struggling conflict between the traditional social norm and personal values. In the literature, less attention has been given to the serenity or sacrifice of caregiving than to the strain of caregiving, regardless of whether the study took place in Taiwan or in the United States. The concept of serenity was identified by Roberts and Fitzgerald (1991) as the spiritual experience of inner peace. Roberts and Fitzgerald further mentioned that peace of mind was the absence of mental conflict; peace of soul was the absence of moral conflict; and contentment was being satisfied with what we have. Roberts and Whall (1996) emphasized that serenity is not always being happy; rather it is being able to have an inner calm despite negative life circumstance. Those attributes correspond to the properties in the category of Ann-Shin in this study. In this study, if a caregiver accepted the filial responsibility for providing care for the elders, she would be free from moral conflict. Since she would get a spiritual reward for her caregiving, the caregiver would be satisfied with what she had. In other words, her inner mind was peaceful even though the caregiving task was hard.

A related study was found in Motenko's research (1989), in which frustration and gratification were considered to be associated with general well-being. Frustration

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reflected the caregiver's feeling for the caregiving task. Gratification was explored by asking the question "even though caregiving is difficult and exhausting, are there moments of warmth, comfort, and pleasure?" This would also reflect part of the caregiver's emotional responses in this study. Would the feelings of serenity or sacrifice be associated with the caregiver's health? This question needs further exploration. However, in this study it would appear that the feeling of serenity could create more energy to keep on giving care.

A Comparison of In-law's Caregiving Experience

between the United States and Taiwan

Since cultural norms were found to be important influences in formulating a caregiving role and a woman's caregiving experiences in this study, it is necessary to compare the findings to related experiences in the United Sates.

While most parent caregivers in America are women (Ehrlich 1992), daughters are usually the primary caregivers for the elder generation, not daughters-in-law (Merrill, 1993). The formulation of the caregiving role in the U.S. is based on the following premise: (1) women assume traditional nurturing tasks; (2) they have stronger emotional ties to their families, and (3) women are perceived to have more flexible free time in their role as homemakers than do male counterparts (Horowitz, 1985).

Although caregiver burden has been studied extensively in sons and daughters in the U.S., little is known about the daughter-in-law's caregiving experiences. In a rare qualitative study of 16 daughters- and sons-in-law conducted by Golberman (1996), the caregiving role of a daughter-in-law was characterized as a director, or initiator, or someone who took control and did the work that needed to be done without being asked. Daughters-in-law identified themselves as female and felt socialized into caring. In addition, they were typically involved in monitoring and supervising the care of their relatives, but not providing care directly. The caregiving role tended to be more of a manager function. Although the daughters-in-law expressed a feeling of obligation to giving care, they also were direct in expressing their sentiments that the caregiving was not done as an act of love for the in-law, but as an act of responsibility. In other words, affection for the sick in-law was not a strong motivator for involvement. The impact of caregiving involvement was related to lack of a social life, privacy, and control over decisions in their lives.

Although the findings in Globerman's study may not be generalized to all daughters-in-law, some similarities and differences between the caregiving experiences of the Americans and Taiwanese are worthy of consideration. The differences were that most of the Taiwanese daughters-in-law tended to be obedient and suppressed their personal feelings. They lived with the elders, providing care day and night. Their caregiving role tended to be one of a performer--they provided direct care, as well as managed the care. In addition, Taiwanese daughters-in-law seldom held the power of autonomy to control the environment. They were more subjected to the cultural norm and accepted cultural expectations of the caregiving role. Furthermore, the daughters-in-law in Taiwan provided care for the parents-in-law based on the idea of service of a younger generation to an elder generation. It was seldom seen as an act to bridge the relationship between their husbands and their husbands' parents, as was the case with American

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daughters-in-law. While the relationships between the daughters-in-law and the parentsin-law tend to be hierarchical in Taiwan, the relationships in the U.S. tend to be more equitable.

The similarities were the formulation of a caregiving role based on the traditional assumptions of a woman's caring role, which was considered a universal rule. Globerman's study showed that the social impact of being involved in the caregiving task was the same for American and Taiwanese women. Additional studies related to caregivers' burdens, were found to be similar in these two countries, addressing physical, psychological and social impacts (Stephens, Kinney, & Ogrocki, 1991; Ehrlich, 1992;. Wright, Clipp, & George, 1993;. Coleman, Piles, & Poggenpoel, 1994; Brenda, 1994).

Limited information was available about how an American daughter-in-law interpreted her caregiving role and how she overcame the caregiving constraints. In Taiwan, the women caregivers tend to approach caregiving from the perspective of religion and fatalism.

Until now, although a number of variables influencing the caregiver's burdens have been examined in the research in the United States, discrepancies in the results have been revealed. For example, population differences in terms of demographic characteristics (Coleman, et al. 1994; Marks, 1996); the status of caregiver's employment (Orodenker, 1990); whether caregiver and care recipient live together (Wright et al., 1993); the family's income (Orodenker, 1990; Ehrlich, 1992); characteristics of patients---patient's type of disease; duration of illness; severity of impairment, etc. all vary among studies (Wright, et al., 1993). However, although these studies differed in subjects'

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characteristics, they commonly explored the available resources and adaptive coping strategies as effective mediators to buffer caregiving strain (Whitlatch, Zarit & Eye, 1991; Wright et al, 1993). Probably, these findings could be further explored in Taiwan.

This study found considerable degree of conflict among family members, possibly related to the degree of caregiver's burden, cultural norms, or the fact that many families are larger and the potential for conflict increases with increasing number of members. However, in the United States, there is less attention given to this phenomenon in the research literature.

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### CHAPTER VI

# IMPLICATIONS AND RECOMMENDATIONS

As life expectancy increases, the percentage of elderly people living among us will continue to grow. This increase in the number of elderly persons will have a dramatic impact on those caregivers for the elderly. While Taiwan is changing, it still remains a patriarchal society with the daughter-in-law delegated the primary responsibility for care of the elderly. Daughters-in-law indicated their willingness to take responsibility for inlaws' care. The caregivers shared experiences of the process of recognizing duty, trials encountered and attempts to maintain balance in their lives have important implications for health policy, nursing practice, nursing education, and research for elders' care. This chapter includes a critique of the study, and discusses the implications and recommendations for the future.

## Critique of the Study

The research on parental care in Taiwan is very limited. Approached from the cultural perspective, this study will contribute and provide an opportunity for understanding a daughter-in-law's perception of the caregiving role, and it's influence on the caregiving experience and behavior. The respondents described their experiences from the beginning of caregiving to the time of interview. Their insights will contribute to further development of a data base for health professionals for intervention in stress related to the caregiving task.

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Since the population in this study ranged from the young adult to middle age or older, it included both women who were influenced by modern education and those who held traditional beliefs. Caregiving practice reflected the common phenomenon related to caregiving across the whole life span.

The caregivers were the individuals who were providing care for their in-laws. All of the patients have suffered from chronic disease for a long time. The caregiving experiences include both critical and stable stages of disease. The caregivers' descriptions will increase understanding, including the change of inner mind and the process of adaptation during this long-term period of providing care. Contrary to cross section research, this information will more richly benefit a practitioner in examining the differences during the period of the caregiving process, from initiation to termination, in order to predict the caregiving needs of caregivers.

Based on the guarantee of confidentiality, several caregivers cried when they mentioned their stories. This phenomenon might reflect that women are restricted by social normative beliefs from discussing the difficulties of caregiving. The caregivers expressed their appreciation for providing an opportunity to share their suffering. Some of them wished their voices could be understood and accepted by the bureaucratic representatives of the health policy institution.

In addition to the strengths of the study, there were also limitations. First, there was the cultural consideration--the daughter-in-law must become the major caregiver, a belief derived from traditional Chinese culture. Most of the participants were folk believers, which deeply influenced a caregiver's beliefs and behavior. Thus, the findings of

this investigation could not be generalized to another culture or population, such as spouse, daughter, son, or son-in-law. Second, most participants in this study were housewives or they recently quit work. Whether their substantive model could interpret the practice of the women who are still working needs further evaluation. Third, the participants in this study were major caregivers who were still providing the care. The daughter-in-law who withdrew from the caregiving situation might have had different experiences.

# Implications and Recommendations

### Health Policy

Cultural influence, morality and obligation were the major reasons for formulating a caregiving role. However, "obligation" in terms of "love" was found to empower a caregiver in this study. Therefore, it was suggested that the role expectation of a caregiver for providing elders care should be approached voluntarily and with respect for each other. That is, the caregiving behavior should be established by individual will, not marriage responsibility or forced altruism. Although children based their caregiving beliefs on the concept of filial piety, based on the "humanity" and "social justice," elders' care is also a social issue. Government should assume this responsibility.

Considering the realistic need for increasing elder care, and the limitations of resources, there is an urgent need to continue to develop a plan for quality long-term care and effective monitoring of the care provided. Currently, influenced by the traditional thought, institutional care is still ignored by the younger generation and by most elders and their families. However, the women expected a good quality of institutional care for themselves as they aged. It was also their subsequent choice if they were unable to provide their in-laws' care. In order to meet the different needs of elderly people, both now and in future, it is necessary to develop a continuum of care model and establish a complete care delivery system. To accomplish this, establishing a comprehensive case management system will be imperative.

Furthermore, the national health insurance system is in the initial stages. The report for the patient who needs long-term care such as the unresponsive patient, suggests the need for further evaluation and development of alternatives.

### Nursing practice

Anxiety, frustration, depression, feelings of helplessness, and lack of sleep can lead to both emotional and physical illness for caregivers. Nurses have to be sensitive to the characteristics of traditional Taiwanese women, which can include inhibition of emotions in order to maintain a harmonious relationship with others or the harmony of the family. In order to identify and recognize the overwhelming task of caregiving, a comprehensive assessment would include measures of how a woman experiences her caregiving trials, and her abilities to manage her caregiving situation. These issues could encompass the ways she adopted to comfort herself, mastery of situation and her perceived competence to deal with the caregiving tasks at hand. Caregivers must also be reassured that feelings of anger, resentment, and reluctance are neither uncommon nor bad. They should be cautioned that other people may offer an abundance of criticisms regarding the treatment of the older family member. Caregivers need a larger dose of empathy more than judgment from health care professionals. Support groups can allow caregivers to ventilate

feelings and provide available resources. But, they should be designed on a case-by-case basis so that it is perceived as helpful by the caregiver. Nurses in home care agencies can also assist caregivers by helping them define their role by teaching what to expect and how to deal with problems that might arise.

In addition, brief periods of emergency relief from the physical and emotional trial can re-energize a caregiver and renew her dedication to the role. As discharge care planning is developing currently, health care providers must help caregivers explore the range of options for relief. Whether the choice is in-home supportive services, day care, or a temporary overnight facility, such respite is vital to the caregiver's well-being. Since most aging people are unwilling to live in institutions, a concrete effort to build a more collaborative relationship between professional service providers and family caregivers is essential. The community health nurse may also involve other appropriate agencies to assist in meeting the demands of caregivers.

It is worthwhile to note that the family is the basic unit of community care. The health care team must get to know not only the older adult client, but also the caregiver and extended family, including the family's organization, coping strategies, and the impact of the illness or dependency on the system. The assessment should include the relationship between the family caregiver and the older adult to discover unresolved issues and negative feelings, as well as sources of strength and resilience. Plans can be made to offer support, provide information, mobilize resources, and strengthen family weaknesses.

Time is important to control the crisis of elderly care. The beginning stage was considered the most challenging time for caregivers and their families. Innovative

strategies are needed that help the caregiver to confront the event and to adjust to the changes that ensue.

### Nursing Education

Facing the increasing demand for a quality of care for elders, the development of an educational program to create or maintain quality long-term care environments and establish an effective nursing care system is needed. Since the long-term care program is in the initial stage, more qualified manpower will be needed in the near future. The educational program would included three aspects: school educational curriculum design, in-service education, and leadership training for managing the long-term care system. The contents of an educational program would cover home care, day care, discharge care planning, institutional care, and health care delivery. Cultural considerations would be emphasized in designing these education programs in order to match Taiwanese families' needs. For example, when developing the discharge care plan one should make a comprehensive assessment of family and care receiver's expectations. The educational program would also foster health providers' abilities to utilize community resources effectively and cooperate with other health professionals in the development of a multidisciplinary approach to health care problems.

## Nursing research

Several implications and recommendations for research can be drawn from the study. First, it is different from previous studies which focused on the caregiving burden. The feeling of being serene for caregiving was found to be the caregiving consequence, which facilitated a caregiver continuing her care. This phenomenon suggested the

importance of the meaning of caregiving to the caregiver. The feeling of being serene self implied the caregiver obtained more value, self-respect, and identity from the caregiving, which would keep a caregiver's mind at peace. Conversely, the woman who sacrificed herself was struggling for her own care. In other word, it is possible that serenity or sacrifice of self are predictors of the caregiver's health. That is, this assumption could be tested by exploring if the woman who is more serene and at peace with herself is also more healthy, and the woman who feels she has sacrificed herself is at a higher health risk. Second, this study suggested that the perceived social support network of caregivers could intervene to decrease the caregiver's suffering. Support from a spouse was described as the strongest influence. However, the degree of influence on the marriage and man's perception of his wife's duty to assume a caregiving role is not yet clear. Third, communication barriers between the caregiver and the care receiver were considered the most difficult for continuing to provide care. Studies are needed to investigate the elders' care expectations and their experiences in receiving care from their daughters-in-law. Fourth, the reasons why many daughters-in-law withdraw from the caregiving situation would be important information to understand the constraints of providing in-law's care. Differences in perceptions and experiences between women who continue and who quit care should be investigated. Lastly, and most important, is the question of whether the core category Just Doing, and its conditions and consequence describe the process of taking care of parents-in-law in different types of illness or disabilities, or in other

caregiver populations. These questions could be answered and verified through the design of larger studies.

# Conclusion

In order to effectively intervene with caregivers, this study entered the world of the caregiver, attempting to understand the context and the caregiver's perception of her situation, identifying the caregiver's inner conflict and the coping strategies used in the caregiving process. The findings suggest that the caregiving experience is not absolutely positive or negative, it depends on the meaning of the caregiving to the caregiver and the perceived available support network. The use of available resources and appreciation of her caregiving activities encouraged the daughter-in-law to provide care, while blaming and criticizing discouraged her. Taiwanese women caregivers continuously provide caregiving for their sick in-laws with perseverance, like the mei blossom, in the delicate light of fragrance, stands in the depth of winter, resisting the severe cold. That is, although it is cold, the flower still blossoms; woman faces the hardship and she still persists.

Compared to the western society such as the United States, neither the role expectation nor the caregiving task of a daughter-in-law providing care for the parents-inlaws is the same. The greatest difference is that women in western society have more power of choice. Based on cultural expectations, women caregivers in Taiwan expressed their will to assume the caregiving role for the sick in-laws. However, as the society is

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changing with more women entering the work force; the increased pace of modern life, increasing life expectancy and fewer children to take care of more elders, the cultural expectation of responsibility for an in-law's care may change. Is it possible to extend the caregiving net for the elders to any available family member, regardless of their relationship to the elders? Perhaps, but cultural expectations change slowly.

Additionally, elder care is obviously not only the family's issue, it is a social issue. Policies developed for long-term care should be an urgent task, giving priority to the evaluation of the health care delivery system, particularly for long-term care. The facilities and services designed must give greater attention to the care of elders and their families. Curricula require both redesign and expansion for training related health professionals. Clearly, related research to evaluate the caregiving constraints and caregiving needs should be the basis of developing health policies for elder care.

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Author/Durness	Design/	Sample/ Data	Finding
Author/Purpose	Design/ Method	Sample/ Data Collection	Finding
Chiu, Lu, Hsu, Ju	An exploratory	There were 70	Although the burdens
Chen & Liu (1988)/	descriptive	stroke patients and	experienced by these
The purpose of this	study design	their primary	caregivers were not
study was to	with structure	caregivers were	severe, emotional and
understand the		interviewed.	social burdens were
	questionnaire interview.		
family caregiver's burden and related	interview.	Caregiver Burden Scale was	greater than physical
factors in families			burden. Lower functional
		developed to	level of care receiver,
with stroke patient		measure the	worse subjective health
		caregiver burden.	status of caregiver, and
			higher caregiver's
			agreement to institutional
			care were identified as the
			major factors related to
			caregiver's burden.
Die, Yui & Lien	A descriptive	Ninety-seven	Caregivers' social
(1990)/	correctional	families of stroke	participation were
The purpose of this	design using	patients before and	impacted most
study was to	structured	after discharged	prominently both before
understand the	interviews and	from the hospital	and three months after
impacts of stroke on	observation	were interviewed.	patients were discharged
families	were used.		from the hospital. The
			lower socioeconomic
			status of families and
			patients who did not have
			a living spouse predicted a
			higher level of impact on
			the families before patients
			were discharged. Lower
			functional status of
			patients, more severe
			families who perceived
			patient's cognition was
			impaired, and families with
			less expectations that
			patient will recover,
			predicted a higher level of
			impact on families three
			months post discharged.

	17	Case method	<b>T</b>
Hsiao (1992)/ This is	Home visiting	Case method	This study provided a sample
a case study for	and interviewing		of applying Otto's family
dementia family's care			assessment and nursing
1			interventions for a dementia
			family's care. Providing care
			for a dementia father-in-law
			was found to be
			powerlessness.
Hu (1994)/	Semi-structure	Two hundred and	Family care was lacking of
The purpose was to	interview	sixty two families	one-hand care support from
examine the cultural		caregivers were	formal and informal network.
constraints and their		interviewed.	The caregivers experienced
effects on the			various form and degrees of
caregivers'			psychosocial burdens which
psychosocial burdens.			is also related to their
pojonoboona ouracite.			unsuccessful efforts in
			looking for care alternatives.
Hu, Wang & Kuo	Semi-structure	Two steps:	(1). 78% of the disabled
(1995)/	interview	(1). Preliminary	elderly are cared by the
	TITEL AIGM	•••	family members in their
The purpose was to		screen by phone for	-
assess community		262 caregivers	homes, and most of them
long-term care need		(2). Deep interview	need constant care; (2). Most
from caregivers'		with 20 caregivers	of the caregivers are women.
perspective.		who were screed by	The difficulties in caring are
		the phone.	less related to the severity of
			their disability, but rather
		• •	than to non-medical tasks and
			interpersonal problems; (3).
			Very few of the caregivers
			had ever received formal
			training or support of home
			care services, and many of
			them had difficulties with
			doctors. In some cases,
			traditional healing methods
			play an important role;(4)
			Family members and
			neighbors can play a
			supplementary role on care.
			and Home-health and nursing
			home services are the only
			alternatives caregivers can
			expect to replace them and
			there exist serious cultural
			and financial barriers.
L		L	www.initiation.comments.

	1		
Lin (1987)/The	Psychiatric	A systematic	1.7% prevalence rate of
purpose of this	diagnostic	sampling was	dementia was found.
study were to	examination	conducted. There	The family caregivers were
explore the	was conducted	were 27 dementia	found: 1). increase of
prevalence rate of	at home	were identified	economic pressure in care-
dementia and to	visiting by	among a sample of	taking, 2). difficult
understand the	using a	1586 elderly	handling the deviant
caregivers' stress for	structured	persons. A	behaviors of patient, 3).
taking care of their	questionnaire	demented screen	difficulty in performing
dementia relatives	first. And	scale and family's	ordinary family tasks, 4)
	reexamined by	crisis measures	long term sleep
	the	were performed. In	disturbance, and 5)
	psychiatrist.	addition, added the	deprivation of free-time,
		65 dementia's from	and these stressors
		clinical studies, 92	positively related to the
		family caregivers	length of the dementia
		were interviewed.	illness. needs of the family
			members for medical
			treatment were found to
			be high.
Liu (1991)/	A descriptive	474 family	The significant predictors
This study was to	correlational	caregivers were	of caregiving strain were
explore the impact	study design	recruited by	health status of caregivers,
of caregiving	with self self-	snowball sampling	patients' level of disability,
situation and	administered		family hardiness, reason
caregiving strain on	questionnaire		for quitting job,
the quality of life of	1		employment status, and a
Chinese caregivers			satisfying relationship with
of elderly family			the patients. Meanwhile, it
members with			was found that the
chronic disease			significant predictors of
omonio usouse			the caregivers were family
			satisfaction, health status
			of caregivers, family
			hardiness, caregiver's
			strain, whether the patient
			was insured, and the
			satisfaction with
			relationship with the
			patient.
L	L		Paucin.

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Ou (1992)/ This study was to describe the related factors and relationships among stress appraisal, coping style, and mental health status in female spouse of home-stay stroke patients.	Retrospective and cross- sectional study with a structured questionnaires interview at home visiting.	35 females spouses of stroke patients discharged from hospital for one to two months.	<ol> <li>(1). The most stressful factors were appraised as couples' relationship and personal physical status, then was the patient's signs and symptoms, prognosis and deficiency of caring knowledge or skills.</li> <li>(2). Three more frequent coping styles were "let fate go and forbear it" " Rely on self, do what can do" and " distancing". The more the spouse adopted " let fate go and forbear it" the worse their mental health status.</li> <li>(3). The scores of the female spouse on Chinese Health Questionnaire was not very high.</li> </ol>
Shern & Chang (1993)/ The purpose of this study was approached in terms of time series and frequency of the disease attacked to investigate the family caregiver's stressors, coping strategies and caregiver's health status for taking care of the psychotic patients.	A descriptive correlatonal study design with a structured questionnaire was used to interview.	A purposive sampling consisted 128 first attack patient and 129 more than one times attack patients' families were recruited from Medical centers in Taiwan. Caregivers' stressors scale was developed, Coping Scale modified by Jalowiec (1979), and Chinese Health Questionnaire were conducted.	Four types of stressors were identified as: psychotic symptoms, social stigma, financial burden and stress for medical treatment. Three patterns of coping strategies were identified as: facing reality, conforming nature and emotional-focus problem solving. Stressors and emotional-focus problem solving were negatively related to caregivers' health status. Conforming nature was more adopted by the caregivers whose relatives were suffered from more than one times. But, the influence of disease frequency on caregivers' health was not certain.

Ton, Mao, Chou, Chen & Liu (1992)/ The purpose was to explore caregiver's burden of demented elderly and related factors for taking care of the demented	An exploratory descriptive study design with structure questionnaire interview	A convenient sample consisted 85 demented patients and their primary caregivers from three medical centers in Taipei were recruited in this study. Caregiver Burden Scale, and knowledge of Dementia, Social Support measures, Dementia Behavior Disturbance Scale were applied to collect data.	Most of the caregivers were women. Caregivers' health status became worse since they provided care for the demented elderly. The adequacy of instrumental social support, the needs for emotional support, caregiver's attitude toward dementia and patient's activities of daily life were considered the major predictors for caregiver's burden. These variables could explain 62% of variance of caregiver burden.
Tsai (1995)/ The study was to investigate the caregiver's burdens of the patients with major depression and related factors	An exploratory descriptive study design with structure questionnaire interview	There were 60 patients and their caregivers were interviewed. Depression scale was used to measure patient's depressive status. Caregiver Burden Scale, caregiver's attitude scale toward depression and caregivers' need for social support scale were developed to measure the caregiver burden and correlation.	The needs for health professionals help were identified after one to six months discharged from the hospital. The characters of patient's disease, caregiver's attitude toward depression and the needs for being supported by the health professionals were considered the major predictors for caregiving burden

Wen (1995)/ The purpose of this study was to exploring the formulation of caregiving role, caregiver's experiences, family dynamic process for providing care and caregiver's opinions for alternative ways.	Qualitative methodology narrative analysis	There were 12 caregivers, whose relatives were the patients with Barthel Index scores lower than sixty, were deeply interviewed by the open questions.	Cultural norm, gender expectation, lower status at work force and the love for providing care were identified as the major reasons to become a caregiver. The caregiving experiences was sophisticated, including upset for patient's disturbing behaviors, being misunderstood, regret, emotional stress, social bounded, relatives' stress and so on. Family members' interaction process include negotiation, communication, cooperation and compromising. The alternative opinion were explored in order to provide for reference of related health welfare policy.
Wu (1995)/ This study was a cross-cultural and cross-national study of family caregiver burden imposed by the serious and chronically mental ill	An exploratory study design using structured questionnaire was conducted.	In total, 122 caregivers were interviewed in Taipei and Los Angels. 52 were Chinese living in Taipei; 35 were Chinese living in Los Angles; 35 were Caucasians living in Los angles. Eight bio- psycho-social variables were measured and administered to each subject and the findings along with demographics were analyzed.	The total caregiver burden was the same among three caregiver groups but there were considerable difference in the path of bio-psycho- social variables contributing to burden. This differences indicated that perception, stressor, and resource variables play unique and apparently culturally- determined roles in caregiver burden and this in-turn points to the importance of cultural issues in formulating treatment and support services for the mentally ill and their caregivers

collected.	Wu, Hu & Yao (1991)/ The purpose of this study was to understand the burdens, needs and related factors of primary family caregivers to frail elders in home care program	A descriptive correlational design using structured interviews was conducted	A random sample consisted of 192 primary caregivers of frail elders from 36 hospital based, government insurance contracted home care agencies. Questionnaire including caregiver's and care receiver's demographic background, quality of relationship, burden scales, and support system scale were used to	Major caregivers were female caregivers, mostly spouse and daughter-in- law. Caregivers experienced mild caregiving burden. Factors influencing caregiver's burden included caregiver's subjective health, help from others and quality of relationship between caregiver and care receiver. Home care services and respite help were higher priority in caregivers' needs.
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## APPENDIX B

## LETTER OF PERMISSION

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Ms. Shu-Yuan Chao 2F.203, Chang-Gung Community Kweishan Linko Taoyuan 333. Taiwan, R.O.C

December 26, 1995

Dear Ms. Chao:

I am glad to inform you that your research project entitled "The Experience of Tatwanese Women Caregivers for Their Frail Parents-inlaw" has been accepted by the research committee in Chang-Gung Memorial Hospital. As the Director of Nursing Department in the hospital and President of Chang-Gung Institute of Nursing. I would welcome this research project to be conducted in Chang-Gung, and look forward to your findings contributing to the caregivers and benefiting the nursing professionals.

Sincerely,

Mrs. Jenny C. Liao M.A. Director of Nursing Department Chang-Gung Memorial Hospital. President of Chang-Gung Institute of Nursing

# APPENDIX C

### CONSENT TO PARTICIPATE IN THE STUDY

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#### University of San Diego Consent to Act as a Research Subject

Shu-Yuan Chao, a Lecturer in the Chang-Gung Institution of Nursing, and a doctoral candidate in the Philip Y. Hahn School of Nursing, University of San Diego, USA. is conducting a study to explore the experience of Taiwanese women caregivers of frail parents-in-law.

If I agree to be in the study, I will be interviewed for about one to one and half hours concerning my experiences in taking care of my father/ mother- in- law. My responses will be recorded and transcribed.

I understand that my name will be kept separately from the interview and tapes will be kept in a locked filing casing and erased at the conclusion of the study. The confidentiality will be maintained.

I understand that I will derive no direct benefit from being in the study but Shu-Yuan Chao hopes to learn more about the experience of the daughter- in- law who provides care for her husband's parents.

I have talked with Shu-Yuan Chao about this study and have had my questions answered. I may reach her at (03) 328-3147, if I have more questions at a later time.

I understand that participation in this research is voluntary and that I have the right to refuse to participate and the right to withdraw at any time without jeopardy. There is no agreement written or verbal beyond that expressed on this consent form.

I, the undersigned, understand the above explanations and on that basis, I give consent to my voluntary participation in this research study.

Signature of subject	date
Location	
Signature of principal investigator	date

## APPENDIX D

# INTERVIEW GUIDES

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#### **Interview Guides**

1. Tell me about your parents-in-law?

(Probe: age, gender, diagnosis, severity and duration of the disease, how long has suffered this disease)

2. What are your caregiving responsibilities?

(Probe: How long have you provided care? How much time do you spend on a daily basis? What type of care do you provide? e.g. cooking, shopping, feeding, personal hygiene, walking, moving, dressing, toileting, or incontinence )

3. What are the difficulties or challenges of caring for your parent- in-law?

(Probe: How do caregiving responsibilities impact you and your ability to do your own work and daily chores? How do you spend your free time? How does the caregiving impact on your care for your children? Do you feel nervous or stressed during the process of caregiving? What type of stress? In what situations? Explain. ? Could you describe your in-law's temperamental behaviors? Do you ever feel depressed? explain. Has your health changed since taking care of your parent-in-law? explain. Do you have difficulty with financial obligations?)

4. How do you deal with all of this?

(Probe: How do you schedule your daily activities? How do your maintain balance in your life? What do you do if you feel stressed or uncomfortable when providing care?)

5. Does anyone help on support you?

(Probe: Who provided it? How is it provided? What kind support? If it is in emergency, who helps you?)

6. How do your family members treat one another?

(Probe: Is there difference between before and after your parent-in-law became sick? Do you all shared the responsibilities of caregivings ?)

7. What benefits do you receive in caregiving?

(Probe: Money? Spiritual? What kind spiritual? Explain. How do benefits affect your caregiving?. How do your feel about the consequences of your caregiving? How does the caregiving affect your relationship with your husband / children?)

8. How did you come to care for your mother/father-in-law? Does the Chinese value of filial piety influence how you think or feel in this situation? In what way?

(Probe: Did you think you would care for your parents-in-law? Why?

Did you have the experience of caregiving for your own parent? Explain.

Do you anticipate that you would be cared for by your daughter-in-law? Explain.

Society is changing, do you have any ideas for the elders' care in Taiwan?

What would you do if your parents-in-law and your own parents need your care at the same time?).

9. Is there anything else you would like to tell me related to your experience of caregiving?

# APPENDIX E

# DEMOGRAPHIC INFORMATION FORM

#### **Demographic Information Form**

Tell me about your self:

 Age \_\_\_\_\_\_ Year of birth \_\_\_\_\_\_

 Education \_\_\_\_\_\_\_

 Religious preference \_\_\_\_\_\_\_

 Your Occupation \_\_\_\_\_\_\_

 Marital status \_\_\_\_\_\_\_

 Marital status \_\_\_\_\_\_\_

 How many years have you been married

 Your husband's occupation \_\_\_\_\_\_\_

 Number of children \_\_\_\_\_\_\_

 Children's age \_\_\_\_\_\_\_\_

 Other family members living with you \_\_\_\_\_\_\_

 How long you have been living with your in-law \_\_\_\_\_\_\_(Year)

APPENDIX G CARE RECEIVERS AND CAREGIVERS' DEMOGRAPHIC DATA

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#### Demographic Data

### **Care receivers**

Age: 44-90 years, most of them around seventy

Sex: Eight were male, twenty three were female. Three families had two patients needing care. ( both father and mother-in-law are patients)

	Married	widow/widowers	Total
Male	5	3	8
Female	11	12	23
Total	16	15	31

Marriage: 16 of them are married, other's spouse were dead.

**Diagnosis**: Most of the patients had a diagnosis of Cerebra Vascular Accident. There were four patients with other diagnoses owing to other diseases, including: Lung cancer with brain tumor, spinal cord compression, and amputation. The degree of disability is identified on the following table.

Degree of Disability	Total	Hemiplegia/	Total
	paralysis	Semiplegia	
Unconsciousness or confuse	14	2	16
Consciousness clear	2	13	15
Total	16	15	31

### Caregivers

Age	23, 25, 28, 29,31,31,33,33 Range : 23-58 years 35, 36,37,37, 38,38, 38,38
	39, 40,40, 40, 41, 42, 44,45,
	45, 47,48, 49,50, 50 ,58,
Native	Taiwanese 31

Primary 8 Junior 10	
Junior 10	
High 12	
Buddhist 8	
Christian 1	
Folk religion 19	
none 3	
Housewife 23	*********
Labor 2	
Assembler 4	
Peddler1	
Accounting Clerk 1	
All of them are married	
10m, 3, 4, 4, 7, 7, 8, 11, 12,	Range: 10m-37 years
12, 13, 13, 13, 13, 13, 13, 13,	
14, 15, 15, 16, 17, 17, 18,	
21, 22, 23, 25, 25, 25, 25,	
37.	
Government Employee 4,	Peddler 2,
Business owner 8	Technician 5,
Chauffeur 4,	Safety guard 1
Farmer 2,	Car salesman 1,
Labor 4,	
0,0,1,2,2,2,2,2,2,2,2,2,2,2,2,2,2,2,2,2,	Range: 0-6
3,3,3,3,3,3,3,3,3,3,3,3,4,4,4,5,	
6,6,	
	Buddhist 8         Christian 1         Folk religion 19         none 3         Housewife 23         Labor 2         Assembler 4         Peddler1         Accounting Clerk 1         All of them are married         10m, 3, 4, 4, 7, 7, 8, 11, 12, 12, 13, 13, 13, 13, 13, 13, 13, 13, 13, 13

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Children's' age	6-12,8-12,13-14,3-10,15-22	Range: 8m- 36 years
	11-14,20-36,6-13,8m-2yrs,	
	15-20,18-27,12-14,9-12,	
	2-12,18-24, 1.5-6,13-15,	
	10-17,13-17,6-7,6-16,15-23,	
	20-23,4,15-21, 21-24,	
	10-11, 10-17, 13-20, 3-7.	
Family type	Compound family 5	
	Stem family 24	
	Nuclear/ beside in-law 2	
Years of living with in-law	8m,10m,1,1,1,2,2,3,4,4,5,6,	Area: 8m-37 years
	6,6,6,7,7,7,8,10,10,13,13,14	
	15,16,17,20, 22,25,28,37	
periods of providing care	2m, 2m,2m, 3m, 4m, 6m	Area: 2m7years
	8m, 8m, 1/2,1, 1,1, 1, 1+, 2,	
	2, 2, 2, 2, 2, 2, 3, 3+, 4, 4,	
	5, 6 ,6, 6, 7, 7	

\*Stem family: Couple, children, and parents- in-law live together.

\*Compound family: Parents-in-law, caregiver's family, and brother-in-law's family live together.