FINDING A BALANCE POINT: A PROCESS CENTRAL TO UNDERSTANDING QUALITY OF FAMILY CAREGIVING IN TAIWANESE FAMILIES

by

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ABSTRACT

TITLE: **Finding a Balance Point: A Process Central to Understanding Quality of Family Caregiving in Taiwanese Families**

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The purpose of this study was to explore the attributes of variables related to the quality of family care to frail elders in Taiwan. The perspectives regarding quality of care of older Taiwanese care receivers, their family caregivers, and home health nurses were obtained in focused interviews. Interview data were subjected to constant comparative analysis (Glaser & Strauss, 1967) both within and across family care units (Miles & Huberman, 1994). The sample was obtained from home care agencies in Taipei Taiwan. Eight families including 15 caregivers, 8 frail elders, 4 hired aides and 5 home care nurses participated in the study. Thirty six face-to-face interviews including member checks were used to collect the data. A tentative theory of "Finding a balance point" derives primarily from data obtained from the 15 caregivers. Supporting data were also found in interviews with care receivers, aides and nurses.

"Finding a balance point" is used by caregivers to achieve or preserve interactive equilibrium in caregiving. For example, a caregiver described the process of "finding a balance point" in facing competing needs of doing housework and providing vigilance to the care receiver: "I have to cook and look out for her at the same time.... Sometimes I lock the door and tie a dead knot when I'm in the back to hang the washing; her hands are weak and couldn't untie the knot." The process of "Finding a balance point" includes three components: recognizing the competing needs or competing opinions about needs, weighing the competing needs or competing opinions about needs and taking balancing strategies. Concepts related to the process of "finding a balance point" include characteristics, caregiving factors and consequences.

Expert caregivers in "finding a balance point" recognized and anticipated competing needs or competing opinions about needs; experts knew ahead what the possible choices were and imagined the consequences of each choice when weighing competing needs or competing opinions about needs; and experts took a wide variety of different balancing strategies and predicted the consequences of the strategies accurately most of the time. Findings of this study add a new perspective to the caregiving process in Taiwan, and provide a basis for development of nursing interventions. Findings also provide a framework for future substantive theory development and related research conduct.

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CHAPTER 1

Introduction

The elderly population in Taiwan is projected to increase from 4.8% in 1984 to 7.7% by 1999 (Chen, Wang, & Chen, 1986). The number of older persons with disability in this aging population will also increase; currently 8.1% of the elderly have at least one dependency (i.e. 1 or more), and 6.1% have more than two (i.e. 3 or more) dependencies, in activities of daily living (ADL) and are cared for by family members (Wu, 1992).

A review of nursing and related journals in Taiwan found 10 articles that examine the activities family caregivers perform, the strain or burdens they feel, and the effect of health education programs on their attitudes and practices (Chiou, Lu, Hsu, Ju Chen & Liu, 1988; Dai, Yu, & Lian, 1990; Huang, Gwo, & Chang, 1993; Huang, Lee, & Mao, 1991; Liu, 1992; Liu, 1993; Shyu & Chang Yeh, 1992; Shyu, Chang Yeh, Yang, & Huang, 1992, Tiang, Mao, Chou, Chen, & Lin, 1992, Wu, Hu, Yao, 1991) (A table summarizing these studies is in Appendix A). These reports are based on models, concepts, or measures developed in the United States. Only 2 caregiving articles in Taiwan addressed quality of family care to frail elders (Chen, Dai, Yang, Wang, & Teng, 1995; Lin & Chiou, 1995). A review of nursing and related journals in the United States found only 6 articles that address quality of family care to frail elders (Cartwright, Inoue,& Levine, 1991; Kosberg, Cairl, & Keller, 1989; Phillips, Morrison, & Chae, 1990a; Phillips, Morrison, & Chae, 1990b; Phillips & Rempusheski, 1986; Phillips, Rempusheski, & Morrison, 1989). Studies of quality of family care to frail elders both in Taiwan and in the United States mostly focus on needs management for care receiver and caregiver competence (Appendix A). This paper reports findings from an exploratory study using a grounded theory approach to understand the quality of family care for frail elders in Taiwan.

"Finding a balance point" emerged as the core category of quality of family care in this study. "Finding a balance point" is the caregiving process by which caregivers maintain or achieve interactive equilibrium when faced with competing needs, or opinions related to competing needs, in providing care to their frail elders at home. By further understanding this process, nurses might assist families to "find a balance point" in caregiving to enhance the quality of family care. This paper presents a theoretical model describing the process through which families find or do not find a balance point in caregiving.

This paper represents the main analysis of a complex data set. The model of "finding a balance point" derives primarily from interview data from caregivers. Supporting data were also found in interviews with care receivers, aides and nurses. The researcher will complete and report the analysis regarding perspectives of care receiver, aides and nurses in a future study.

CHAPTER 2

Literature Review

There are no reports on "Finding a balance point" as a caregiving process central to quality of family care in the literature. Beach (1993) reported "balancing outside work and caregiving" as part of caregiving experiences. Using grounded theory, Beach (1993) conducted a study of family caregiving experiences in the United States using a sample of 10 family caregivers of elderly patients with terminal cancer or Alzheimer's disease. Three major categories of caregiving experiences emerged from the study: sense of self, role strain, and problem solving/coping. In this study, role strain is defined as the problematic features that result from balancing the primary caregiver role with other roles within the family network. However, the report did not provide examples or further information related to balancing the caregiver role with other roles. A subcategory of sense of self is "balancing outside work with caregiving." Beach found that over 67% of caregivers experienced significant work conflicts that resulted in disruptions in schedule and work performance. Changing work schedules or ceasing employment altogether seemed to be the most common strategies used by caregivers to deal with these conflicts. Based on the findings, Beach (1993) suggests the need for developing nursing interventions to assist caregivers in balancing outside workloads with caregiving responsibility.

Nkongho and Archbold (1993) conducted a study on caregiving experiences for older persons in African American families. "Working-out systems" in caregiving emerged as the core category from analysis of in-depth focused interviews with 17 African American caregivers. Working-out systems was defined as the process used by caregivers to make caregiving effective and efficient. She identified "balancing caregiving and other demands" as one of the five areas where working out systems are needed. Steps in working-out systems include identifying the need, developing plans, selecting and implementing one of the plans, evaluating the plan and refining the plan. They also identified related concepts to working-out-systems: reasons for caregiving, resources, caregiving activities, consequences and outcomes.

Several studies were found that focus on different aspects of the caregiving process. Most of the work in family caregiving process in Taiwan and in the United States describe types, frequencies and results of caregiving tasks; and by whom they are administered (Archbold, 1980; Bowers, 1987; Clark & Rakowski, 1983; Given, King, Collins, & Given, 1988; Lang & Brody, 1983; Shyu & Chang Yeh, 1992; Shyu, Chang Yeh, Yang, & Huang, 1992; Stetz, 1987; Stoller & Earl, 1983). These studies address direct assistance with the activities of daily living and the instrumental activities of daily living such as preparing meals, housework, transportation, and management of finances and treatment; and indirect care tasks such as planning, organization, monitoring, and supervising care receivers. Bowers

(1987) conceptualized the caregiving process from the perspective of care tasks into five dimensions: instrumental, anticipatory, preventive, supervisory, and protective care activities.

From the perspective of dynamics in family caregiving, Phillips and Rempusheski (1986) explored the differences between the caregiving of caregivers who self-identified as having "good" relationships with the elder and those who self-identified as having "abusive" relationships. Perceived personal identity of the elder, reconciliation of past with present, image of caregiving, and reconciliation of proscriptions with perceived reality of caregiving influence caregiver role beliefs and management strategies the caregiver chooses in everyday interactions with the elder. "Good caregivers" tend to have normalized images of the elder and "abusive" caregivers experienced divergence between their proscriptions and perceived realities. Nurturing-supporting role forms are exhibited in good quality caregiving and monitoring-controlling role forms are displayed in abusive caregiving.

Cartwright, Archbold, Stewart and Limandri (1994) developed a theory describing the process of enrichment that explains how families use pleasurable or meaningful experiences in their caregiving to frail elders. This study used interview and observational data collected from 20 dyads of caregivers and care receivers. The frailty trajectory and personal history of both caregiver and care receiver, the caregiving situation and the quality of the dyadic relationship are antecedents to the process of enrichment. The core elements of enrichment process are acquiring symbolic meaning, performing activity, and fine tuning. Consequences of enrichment process include relationship and identity sustenance for caregiver and care receiver, comfort for the care receiver, and rewards of meaning for the caregiver.

From a role perspective, Archbold, Stewart, Greenlick and Harvath (1990) examined how well prepared the caregivers believed they were for the stress and tasks of the caregiver role (preparedness); and how caregivers described the quality of their relationship with care receivers (mutuality). They used hierarchial multiple regression to analyze data from 78 older persons and their family and found that after controlling other variables commonly found to be predictors of caregiver role strain, mutuality and preparedness were associated with lower levels of some but not all aspects of caregiver role strain.

Four descriptive, qualitative studies focus on the caregiving process for persons with Alzheimer's disease (AD) (Lindgren, 1993; Willoughby & Keating, 1991; Wilson, 1989; Wuest, Ericson, & Stern, 1993). Lindgren (1993) used content analysis to examine the data from 10 spouse caregivers of persons with dementia. The role of family caregiver is characterized as a fatalistic career process with identifiable stages: in the encounter stage, caregivers confront the diagnosis and losses and acquire home nursing skills; in the enduring stage, caregivers manage extensive care routines and cope with their mental pain and social isolation; in the exit stage, the caregiving career is relinquished to a certain degree by death of the person with dementia or institutionalization.

Willoughby et al. (1991) used grounded theory approach to explore 10 family caregivers who had placed a relative in an institutional setting. A five-stage model of gaining and relinquishing control of caregiving emerged from the data: stage 1, emerging recognition; stage 2, taking control; stage 3, losing control; stage 4, adjusting to the psychiatric institution; and stage 5, moving on. Wilson (1989) conducted a grounded theory approach study on 20 family caregivers of relatives with AD. This study revealed that caregiving experiences consist of coping with negative choices. Three stages of Surviving on the Brink described the variation in behavior: first stage, take it on; second stage, going through it; and third stage, turning it over. Wuest et al (1994) conducted a grounded theory approach study on 15 caregivers of persons with AD. Findings revealed a reciprocal process of "becoming strangers" in which caregiver and persons with AD interact on a continuum from intimacy to alienation. There are three dimensions in the process of "becoming strangers": dawning, holding on and letting go.

These studies are all related to caregiving process and provide a wide variety of different perspectives to understand the nature of caregiving. Most of these studies (Archbold, 1980; Archbold et al., 1990, Beach, 1993; Bowers, 1987; Cartwright et al., 1994; Clark & Rakowski, 1983; Given et al., 1988; Nkongho et al., 1993; Lang & Brody, 1983; Phillips & Rempusheski, 1986; Shyu

& Chang Yeh, 1992; Shyu, Chang Yeh, Yang et al., 1992; Stetz, 1987; Stoller & Earl, 1983) described daily caregiving process without progressive and identifiable stages throughout care receiver's illness trajectory. In contrast, the four studies on caregiving to persons with AD (Lindgren, 1993; Willoughby & Keating, 1991; Wilson, 1989; Wuest et al., 1993) describe the caregiving process as progressive with identifiable stages throughout progression of the care receiver's illness. These models offer insights for individual care and health policy development, and also offer promise for substantive theory development for a basis of nursing interventions.

CHAPTER 3

Method

The original purpose of this study was to identify central variables for a model of the quality of family caregiving for frail elders in Taiwan from the perspectives of the caregiver, frail elder and home care nurse. Stern (1980) believes that one use of grounded theory is to gain a fresh perspective in a familiar situation and to study complex phenomena where salient variables have not been identified. Strauss and Corbin (1990) describe the purpose of grounded theory as building theory that illustrates the studied phenomena. Therefore, grounded theory methodology (Glaser & Strauss, 1967) was chosen for use in this study to develop a theory of the quality of family caregiving to frail elders in Taiwan. As the core category--"finding a balance point"--emerged, the research purpose was further specified to explore the nature and related factors of the core category. Strauss and Corbin (1990) believe that the original research question is a statement which identifies the phenomena to be studied and helps the researcher to start and stay focused. As the tentative theory emerged from the analysis, the research question was refined and further specified in order to build the density of the tentative theory. The proposed methodology was modified as the core category emerged. See Appendix B for a summary of, and rationale for, the modifications in the research method.

Setting

The sample was obtained through a free-standing home care nursing agency and a home care program at a local public health station in Taipei. These agencies primarily serve the Taipei area. Clients served by these agencies are mostly elderly persons with chronic or terminal illnesses, such as stroke, dementia, cancer, and heart disease, and who need skilled nursing care (see Appendix C for the letters of support from these agencies).

Participants

Families. A total of 8 families participated in this study. Among 8 care receivers, 2 were demented and unable to respond to the interview; data were obtained from the remaining 6 care receivers. A total of 15 caregivers was interviewed. Among them, 8 caregivers who shared the care responsibilities equally in one family were all interviewed. One caregiver from each family of the remaining 7 families was interviewed. A total of 4 aides was interviewed. Among them, 2 aides worked for one family. One aide from each of the other 2 families was interviewed. A total of 5 nurses was interviewed. Among them, one nurse cared for 3 families and a second nurse cared for 2 families. The other three families each had a different nurse for their care.

Care receivers. Care receivers' age ranged from 65 to 88, with an average of 75.8 (SD=8.9). Among them, 7 were males and 1 was female. According to clinical assessments done by nurses, 2 caregivers had severe cognitive impairment, 3 had mild to moderate cognitive impairment and 3 were cognitively intact. All participants.

Data collection consisted of three phases. In the initial stage, 2 caregivers, 2 care receivers and 1 nurse were interviewed to pilot test and refine the interview guides and study procedures, and to initially explore caregiving phenomena. In the second stage, 11 family caregivers, 4 care receivers, 4 hired aides and 2 nurses were interviewed to further explore the caregiving phenomena. In the last stage, 2 additional caregivers, 2 additional care receivers, 2 additional nurses, and 4 caregivers from previous interviews were interviewed in order to achieve theoretical saturation of the major categories and to conduct member checks (for a detailed sample summary in each phase, please see Appendix E). The researcher conducted data collection jointly with and guided by data analysis (Glaser,1978, 1992; Strauss & Corbin, 1990). This process ceased when no new properties of the core concept were found (Glaser, 1978). The length of the interviews ranged from 10 minutes (for a care receiver with cognitive impairment) to 3 hours, with most lasting 1 to 2 hours.

Interviews were transcribed verbatim for data analysis. The transcriptions were translated and entered in Wordperfect for audit trail and peer debriefing.

Data collection Strategies

The investigator used two data collection strategies: Face-to-face interviews using open-ended questions and participant observation.

Interviews. In the early stage of the study, interview guides were developed, one each for the elder, the caregiver, the hired aide and the home health nurse (Appendix F). The interviews for caregivers and frail elders began with a neutral question regarding activities done on a typical day for both caregiver and frail elders. Specific questions were used to explore their evaluation of the quality of caregiving. For caregivers the questions included: a) what were the things they paid more attention to in caregiving? b) what were the things they did that were good for frail elders? c) what were the things they did to make the care they provide to the care receiver as good as possible? and d) what were their priorities in caregiving? Frail elders were asked to identify the things the caregiver did that were good for them and things they would like to change. Interviews for nurses began with the question "If you had to tell another nurse about visiting this family, what would you tell them would be important for this family?" Nurses were asked about a) their assessment of the quality of family caregiving for a specific family; b) the determinants of quality caregiving; and c) their beliefs about prioritizing in family caregiving. Questions regarding nurses' ideas of good and problematic family caregiving then followed. Questions asked of the hired aide included: a) what do the family caregiver and the aide do to take care of the frail elder, and how do they do it? b) what things does the family caregiver ask the aide to pay attention to? and c) what are the important things for good family caregiving in this situation?

As the core category emerged, we developed an additional caregiver interview guide focused on the experiences of finding a balance point in caregiving (Appendix F). The conceptual process of "finding a balance point" with examples from previous interviews was described to the caregiver who was then asked about his/her opinions on "finding a balance point" in caregiving. Specific questions were developed and administered to the caregivers for the second interview and member check. These questions were: what things they need to balance within caregiving, how they recognize the need for balancing, how they set their priorities, what strategies they used to balance, what influences this process has on the consequences, how they feel about the process and what they think are the influencing factors for a successful process of "finding a balance point."

Participant observations. Field notes related to things observed by, and thoughts occurring to, the researcher during interviews were recorded in writing in the field notes. The investigator conducted participant observations as opportunities arose during the times of the scheduled interviews. These observations included morning care, meal preparation, caregiver supervision of aide's care, care receiver's drawing, friends' visits and family get togethers. The investigator conducted informal interviews during observations and recorded field notes after the observations. Notes about phone calls from a family caregiver during family crises were also recorded. The investigator used follow-up interviews with interview guides developed to elicit information about the emergent concepts to achieve theoretical saturation and validate findings through member checks.

Analysis

The analysis of this study is based primarily on data from interviews with caregivers with a focus on the core category. Data from interviews with care receivers, aides and nurses and data related to interactions among related concepts not the core category will be further analyzed in a future study. The constant comparative strategy (Glaser, 1978, 1992) was used to analyze the data. Open coding--which refers to constant comparison of incident with incident, and incident with concept, without preconceived codes, was used in the initial stage of analysis. Data analysis started at the within-case (nurse-caregiver-care receiver-aide) level and then moved to the cross-case comparison (Miles & Huberman, 1994), then within-case analysis and cross-case comparisons were done circularly to understand the complexity of the phenomenon. After the core category accounting for most of the variation in quality of family caregiving was identified, selective coding was used to delimit coding to only those incidents that related to the core category. Theoretical coding was used to identify the relationship between concepts. During the analysis process, memos were also used to record ideas related to formulation of the theory.

In the later part of data analysis, in order to increase the theoretical sensitivity (Glaser, 1978, 1992; Strauss & Corbin, 1990), theoretical sampling of dictionaries, lay literature, related literature in nursing, psychology, anthropology, and sociology that pertained to balancing and were in Chinese or English was done. The theory of "finding a balance point" was shared with an anthropologist, two sociologists, and three nurses who work with caregivers. Literature on decision making models was also reviewed at the end of the data analysis to enrich, modify and support the emerging theory or further defining the stages of "finding a balance point." Concepts from the decision making models that are relevant to the emergent theory are presented in Table 1.

All the interviews were tape recorded and then transcribed verbatim in Chinese. Raw interview and observation data in Chinese were coded directly in both Chinese and English. Coding directly from Chinese data reduced the risk of losing or changing the meaning during translation into English. Due to the background of the researcher, both English and Chinese codes were used to enrich the range of ideas of codes. Theoretical coding and memos were also done in both Chinese and English to facilitate the development of theoretical ideas. Then all of the codes, memos, ideas, and example content were translated into English for peer debriefing and to create an audit trail.

Trustworthiness

This study used an audit trail and peer debriefing by experts in family caregiving and grounded theory in the United

Table 1
Key Aspects of Decision Making Models Which Have Concepts Similar to Present Substantive Theory of "Finding a Balance Point"

Model	Key aspect of model	Concept in substantive theory of "finding a balance point"
Noble (1993): Situation Assessment	A tentative interpretation of the situation is formed by concrete information on the situation and combined with context information and general knowledge retrieved from the decision maker's memory. This tentative interpretation is then tested, retained, refined, or rejected by additional information. People can decide what to do by observing that the current situation is similar to other previously observed situations. The actions that worked in those situations may also work in the new one.	Recognition of competing needs is context-dependent in present model. Caregivers could predict and recognize that current situation is similar to previously observed situation and can use previously learned strategies. Balancing strategies effective in previous similar situation will be used in the new one.

Klein (1993): Recognition-Primed Decisions	How proficient decision makers manage to be effective under high stress and time pressure a) Situation recognition: recognizes the situation as typical or novel. b) Serial option evaluation: evaluates alternatives one at a time until a satisfactory one is found c) Mental simulation	Time pressure interacts with influencing factors such as fewer resources, more task difficulty, less knowledge about care receiver tend to create the failure in maintaining balance and need for the getting back balance[a]. Situational recognition is related to recognition of competing needs in current theory. When situation is typical, plan-ahead recognition tends to take place. When situation is novel, the reactional recognition--which is not prepared by caregivers, but caregivers simply react to the competing needs--tends to take place. Simulation weighing is one kind of weighing competing needs.

Montgomery: Search for Dominance Structure (1993)	When several alternatives are available to decision maker: a) Pre-editing: selects attributes that are important b) Finding a promising alternative (option): picks most promising alternative c) Dominance testing: tests if the promising alternative is the best available option d) Dominance structuring: If promising alternative is not found to be dominant, the decision maker tries to make it one by reinterpreting its standing.	a) Pre-editing: care principle in current theory b) Finding a promising alternative: weighing competing needs d) Dominance structuring: Dominance structuring weighing competing needs[a].
Beach & Mitchell (1987): Image Theory	Images are cognitive structures that organize decision makers' values and knowledge and guide their decisions. Includes three types: a) value images--principles b) trajectory images--concrete goals c) strategic image: plans and tactics A candidate plan is adopted if it does not violate the decision maker's three images.	a) value images--care principles in current theory b) trajectory images--competing needs in current theory c) strategic image: choice of balancing strategies in current theory

Rasmussen (1993): The cognitive control of decision process	For familiar situation or expert: skilled-based behavior and rule-based behavior Skill-based behavior includes expert sensorimotor performance (e.g.bicycle riding), which runs smoothly without conscious attention. Rule-based behavior is controlled by rules and know-how that can be stated explicitly by the decision maker. For unfamiliar situation or novel: knowledge-based behavior This behavior is used to construct mental models representing causal and functional relationships in the environment.	Rule-based behavior: principle-oriented weighing of competing needs in current theory Knowledge-based behavior: Use simulation to weigh competing needs in current theory However, for expert caregiver, simulation weighing of competing needs was used often. This might be due to the retrospective perspective of the interviews.
Connolly & Wagner (1988): Decision Cycles	decision making process consisted of cyclical interplay between situation assessment, evaluation of alternatives and action.	Resembles the three stages of balancing process. It is a fluid and nonprogressive process.

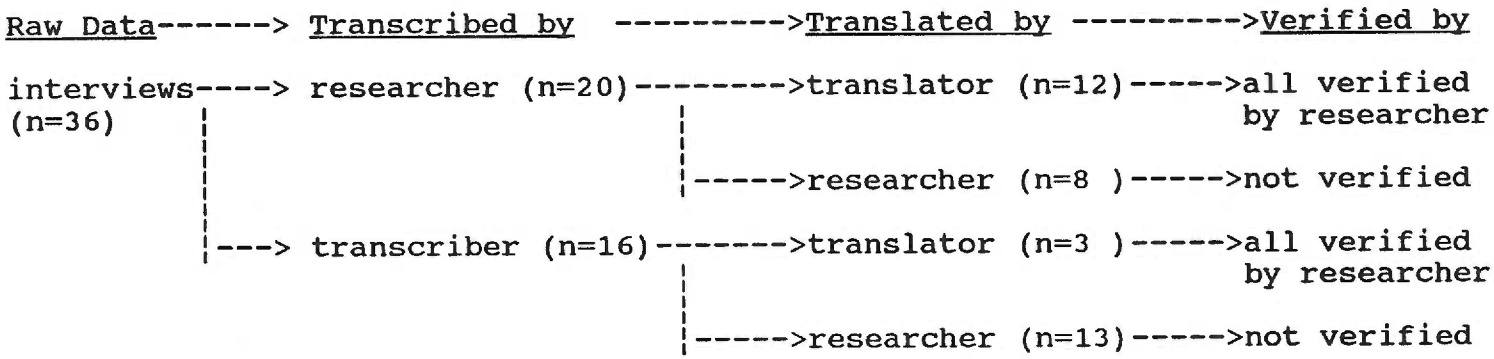
Lipshitz (1993): Decision Making as Argument-Driven Action	a) Consequential choice: forward-looking choices b) Matching: situation assessment c) reassessment after committed to a certain course of action	a) Consequential choice: simulation weighing in current theory b) Matching: plan-ahead recognition of competing needs in current theory c) reassessment after committed to a certain course of action: fluid and nonprogressive process and feedback loop from consequences to recognition of competing needs in current theory.

[a] concept in current theory was sensitized by the concept in decision making model

States and an anthropologist in Taiwan. All previously existing concepts related to family caregiving were generated in western society in order to minimize bias from familiarity with western research, a Taiwanese medical anthropologist, Dr. Mutsu Hsu, served as a consultant to verify the credibility of the coding paradigm, and to increase the theoretical sensitivity to the salient characteristics in the families in Taiwan.

All interviews and field notes were translated into English in order to create an audit trail and allow for peer debriefings by a panel of English-speaking experts in family caregiving and grounded theory. An expert translator who knows both Chinese and English well translated almost half (n=16) of the transcripts, which were then verified by the researcher; the researcher translated the other half. Figure 1 presents a summary of data translation and verification. The panel of experts reviewed all translated raw interview data, field notes, theoretical notes and memos to increase the credibility, dependability and confirmability of this study (Lincoln & Guba, 1985).

Triangulation of data collected from different data sources (nurse, caregiver, care receiver, and nurse aide), and triangulation of data from different methods (interview and observation) were used to increase the credibility of this study (Lincoln & Guba, 1985). Prolonged engagement in the Taiwanese caregiving experiences was accomplished through attending support group meetings of caregivers, conducting home visits, participating home health nursing staff meetings, and conducting



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Raw Data------> Transcribed by  --------->Translated by --------->Verified by

interviews----> researcher (n=20)-------->translator (n=12)----->all verified
(n=36)     |                       |                               by researcher
           |                       |
           |                       |----->researcher (n=8 )----->not verified
           |
           |---> transcriber (n=16)------->translator (n=3 )----->all verified
                                   |                               by researcher
                                   |
                                   |----->researcher (n=13)----->not verified
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Figure 1. Summary of data translation and verification.

family caregiving studies in Taiwan. Extended visits, thick data with theoretical sampling, and member checks with participants also helped to increase the trustworthiness of the study (Lincoln & Guba, 1985).

CHAPTER 4

Findings: Finding a Balance Point

"Finding a balance point" emerged as the core category of quality of family care for frail elders in Taiwan. "Finding a balance point" is a caregiving process that is central to the quality of family caregiving to frail elders in this Taiwanese sample. This process is used by caregivers to achieve or preserve interactive equilibrium in caregiving. To better understand this process, it is helpful to think about the analogy of "Tiao Biaan Dan" (Figure 2). "Biaan dan" is a flat carrying pole, usually made of bamboo, which Chinese laborers or farmers use to carry objects. "Tiao" is to carry things with a pole on one's shoulder, with two loads, one on each end of the pole. One can still see people "tiao biaan dan" in the countryside of Taiwan--such a person uses a shoulder carrying pole with two loads (weight) balanced on each end and walks forward. This person has to adjust the weights of the two loads and at the same time adjust the position of his shouldering point, to find the most efficient point. Efficiency in this sense, means finding the appropriate distance between the two loads. Like adjusting the shouldering point of a carrying pole according to the weight of the loads, caregivers adjust their priorities and efforts between competing needs, or competing opinions about needs, and also keep going on with daily life. A caregiver described the process of "finding a balance point" in facing competing needs of doing housework and providing vigilance to the care receiver:

<u>Figure 2.</u> The analogy of "Tia Biaan Dan." From <u>China</u> (p. 119), by K. Y. Fung, 1943, New York: Henry Holt and Company.

> I have to cook and look out for her at the same time.... Sometimes I lock the door and tie a dead knot when I'm in the back to hang the washing; her hands are weak and couldn't untie the knot.

Another caregiver who took care of her cognitively impaired mother-in-law described the process of "finding a balance point" in facing the competing needs of preserving the care receiver's self-esteem and yet giving the necessary help with activities of daily living:

> you don't want to ask her out loud whether she had a bowel movement or not, but ask her while whispering in her ear. The same applies to asking her if she wants to have a bath. It's a matter of pride. She'll think if I want to take a bath, then I'll take a bath. I don't need you to ask. You have to say, "you can take a bath by yourself, mother". You have to know her mood at any moment. She'll get upset even if her own daughter mentions to her that her daughter-in-law helped her to take a bath....

Nkongho and Archbold (1993) identified areas where caregiving systems were needed by caregivers to make caregiving effective and efficient are needed. They identified "balancing caregiving and other demands" as one of these areas. This finding supports the existence of the competing needs and implies the existence of the process of "finding a balance point" in caregiving.

Figure 3 displays different stages of the process of "finding a balance point." Figure 3 also displays the relationships among the concepts and core category and provides the framework for the following description to further understand "finding a balance point" in family caregiving. The description addresses different sources and types of "finding a balance point" and identifies and discusses differences between an expert

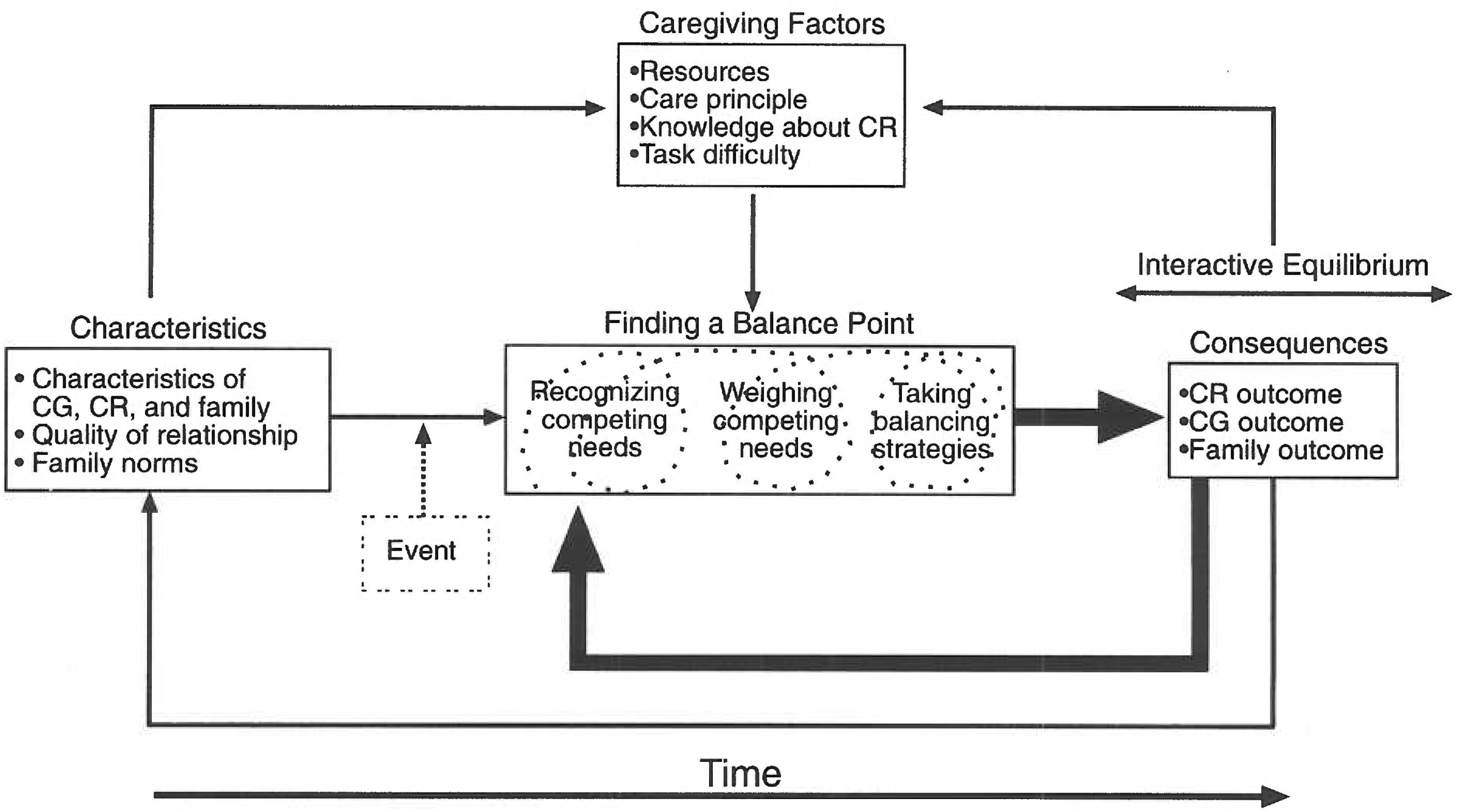


Figure 3. Finding a balance point : A process central to quality of family caregiving in Taiwanese families.

caregiver and a caregiver who failed in "finding a balance point."

Process of "Finding a Balance Point"

"Finding a balance point" involves three components (Figure 3): the first component is characterized by recognizing competing needs or competing opinions about needs, the second component by weighing competing needs or competing opinions about needs and making judgements about them, and the last component by taking balancing strategies which includes choosing and implementing balancing strategies. Both caregiver cognition and emotion are involved throughout the process of "finding a balance point." In the first example above, the caregiver recognized competing needs of doing housework and providing vigilance, weighed the two competing needs as both very important at that time, and then took balancing strategies of environmental arrangement to keep the care receiver from wandering out while she doing housework. In the second example, the caregiver recognized the needs of preserving the care receiver’s self-esteem and helping with activities of daily living. The caregiver weighed both needs equally important and took behavior management strategies of whispering, in order to meet both needs.

<u>Component 1: Recognizing competing needs or competing opinions about needs.</u> Two different types of recognizing competing needs or competing opinions about needs were plan-ahead recognition and reactional recognition (Figure 4). Sometimes the caregiver could foresee that needs would compete with each other.

Finding a Balance Point

Recognizing competing needs	**Weighing competing needs**	**Taking balancing strategies**
Reactional recognition Plan-ahead recognition	Simulation weighing Principle oriented weighing Dominance structuring weighing	Managing behavior/emotion problems Modifying environment Altering the schedule/activity Recruiting members to the work team Running the work team Innovating care task Engaging self-care activities Managing treatment

Figure 4. Components of “finding a balance point.”

Sometimes the caregiver was not aware ahead of time of the competing needs or competing opinions about needs. In this case, the caregiver reacted to the presence of competing needs or competing opinions about needs. The two kinds of recognition can be illustrated by the following examples:

> Reactional recognition: When I was cooking dinner, she (care receiver with dementia) complained that I took the place she was supposed to cook; I told her that I was cooking for her but it didn't help. She even went over to turn the gas stove on.... She started to get upset because I didn't let her cook, then she banged on the bowl and chopsticks and got mad at me....I can't predict the situation. Don't know what she's going to do next.
>
> Plan ahead recognition:...(A son-caregiver knew ahead that there will be competing needs between running business and providing care to mom on the day of his turn to take care of mom) I can not go to work today, I had to prepare and manage my business yesterday, or let people call me here. These things need to be dealt with in order.

Similar concepts can be found in several decision making models--Noble's Situation Assessment (Noble, 1993), Klein's Recognition-Primed Decisions (Klein, 1993), and Lipshitz's Decision Making as Argument-Driven Action (Lipshitz, 1993). These models suggest that in making decisions, individuals recognize the situation as typical (plan-ahead recognition) or novel (reactional recognition).

Component 2: Weighing competing needs or competing opinions about needs. The data indicated three kinds of "weighing competing needs or competing opinions about needs" (Figure 4): simulation weighing, principle-oriented weighing, and dominance-structuring weighing. When weighing the competing needs or competing opinions about needs, caregivers sometimes use mental simulation--anticipating or imaging the consequences of possible choices, such as meeting one need instead of the other, or instead, meeting both needs. At other times, caregivers used principle-oriented weighing and made choices according to their care principle. Caregivers sometimes used mental simulation first, but found out that their preferred option was not the best option. Then they tried to rationalize their preferred option by reinterpreting it with care principle. This kind of weighing is "dominance-structuring weighing." These three kinds of weighing of competing needs or competing opinions about needs can be illustrated by the following examples:

> Simulation weighing: If the guests want to come in, it is impossible to drive them away. We live here too long. We were born here and grew up here, so, say the truth, it is really hard to shut people out. If we let the guests stay out and go out to talk to the guests, we have "one heart for two uses", we will be worried that she might need to go to the toilet, afraid that we can not keep sight on her and she might fall down. If she falls down on my shift, I would be seen as the sinner in the history
>
> Principle oriented weighing: When I balance my things and his things, taking care of him is most important... I take care of him whole heartedly, I do not do a lot of housework, only when he does not need me to do something, I would then do some house work...
>
> Dominance structuring weighing: One cognitive impaired care receiver always cried when people told her that her husband and parents died long time ago. Caregiver mental simulated that if they kept lying to her, she would loose her sense of reality and her dementia would get worse. They found out that "lying to her" was not the best choice but was their preferred choice. They rationalized their choice of "lying to her" by the care principle of "making care receiver happy". One of the caregivers of this care receiver said: "We lie to her... even a normal person who does not have dementia might be tricked into demented, if people keep lying to him, but we have no better way of doing this.....because she is already demented, her husband already died, but if we tell her that, she would cry, she

> would get really upset, so we have to lie to her... but she already demented, that we still lie to her may make her sense of reality worse, but we have no choice. She always talks about things in the past, always asks about her mom and dad, we cannot tell her that they already died for many many years, or else, she would cry. Not making her upset is very important.

Comparing related concepts in decision making models, Klein (1993) included mental simulation as part of his decision making model. Rasmussen (1993) suggests that people use rule-based behavior (principle oriented weighing) and skilled-based behavior for a familiar situation or by expert decision maker and use knowledge-based behavior (simulation weighing) for an unfamiliar or novel situation. In contrast to Rasmussen's model, skill-based behavior which is a reflexive type of behavior, was not found in the data from the caregiver in this sample. However, expert caregivers in this sample frequently used simulation weighing. The retrospective perspectives of the interviews might account for these differences.

Montgomery (1993) focused on the mental processes used when several alternatives are available to the decision maker. Montgomery's model suggests that finding a promising alternative (weighing competing needs or competing opinions about needs) is part of the decision making process. The literature of dominance structuring stage of decision making in Montgomery's model was used to sensitize the investigator to notice the dominance-structuring weighing of competing needs or competing opinions about needs.

<u>Component 3: Taking balancing strategies.</u> Common strategies

in "finding a balance point" (Figure 4) included managing behavior/emotion problems, modifying environment, altering the schedule/activity, recruiting members to the work team, running the work team, innovating care tasks, engaging in self-care activities, and managing treatment (see Table 2 for definitions and examples). When caregivers experienced the needs of their nuclear family competing with the needs of the care receiver, some of them viewed the needs of the nuclear family equal to or more important than the needs of care receiver. For example, a son-caregiver described that running business to support his family was equal or more important than taking care of his mother:

> CG: The economic situation of a family has to be good. If you have problems with support your family, how can you take care of mom. The kids needs money to go to different classes also. It takes a lot of money....If your family is not stable, unless you are exceptional optimistic, or else the caregiver might be sick also.

Caregivers took a wide variety of strategies to find the balance point, such as running work team, altering the schedule/activities and engaging in self-care activities. When housework competed with caregiving, caregivers often viewed the direct care for care receiver equal to or more important than other housework. Caregivers most often took altering schedule/activities to deal with these needs. When caregivers faced their own physical needs competing with the care receiver's needs, they often viewed both needs as equally important. Caregivers most often took engaging in self-care activities, running work team and recruiting members to the work as balancing

Table 2

Strategies Caregiver Used in "Finding a Balance Point" Process

Strategy	Definition	Example
Managing behavior/emotion problems	Caregiver's actions to deal with behavior/emotion problems of care receiver, in order to "find a balance point" when facing competing needs.	CG: I try to be with her in her world and lead her in a more relaxed way.......If she's in a state of panic over something, I always find that acting panic with her helps; then lead her back in a controlled way and solve the problem. A situation often happen: She would suddenly say, "Where's my money? Where's the gold I saved up? " and I would start out worrying with her then in a slow way remind the both of us where the gold is and slightly joke about how stupid we are to forget, and it's over!
Modifying environment	Caregiver's actions to deal with environment around care receiver, in order to "find a balance point" when facing competing needs.	CG: I have to cook and look out for her at the same time.... Sometimes I lock the door and tie a dead knot when I'm in the back to hang the washing; her hands are weak and couldn't untie the knot.
Altering the schedule/activity	Caregiver's actions to deal with timetable of caregiving tasks or care receiver's activities, in order to "find a balance point" when facing competing needs.	CG: I just have to do the grocery shopping in the morning, take my shift and do the cooking while she's still sleeping.

Recruiting members to the work team	Caregiver's actions to recruit new members for caregiving work team, in order to "find a balance point" when facing competing needs.	CG:.. since last year, we started to have Miss C (aide) to take care of him 24 hours a day...I am much relaxed to have her here.
Running the work team management	Caregiver's actions to run a group of people who work together in caregiving, in order to "find a balance point" when facing competing needs.	CG: There are eight of us to take turns, so we're able to do it despite of our work....someone took the lead and insist upon it ... and the others had to do it and got used to it eventually .....The basic rules and points were made; and within that, everyone takes up the work in different ways.
Engaging in self-care activities	Caregiver's actions to take care of her/himself, in order to "find a balance point" when facing competing needs.	CG: Recently, when I see the light is on downstairs before I go to bed, I know that he is still awake, but I force myself to let go and take a pill to go to sleep, just leave the care to the aide.
Innovating the care task	Caregiver's actions to invent and modify a care task, in order to "find a balance point" when facing competing needs.	CG: He needs to drink a lot of water, and I do not have enough strength to refill his glass so many times a day. I use this big milk bottle with this soft long tube to hold the water. He can easily crab the tube and drink as much as he want. I only have to refill this big bottle two to three times a day.

Managing treatment	Caregiver's actions to monitor and administer treatments for care receiver for maximum desired effect, in order to "find a balance point" when facing competing needs.	CG: I am afraid of too much medicine, and the time schedule for taking medicine is too busy.... One hour difference between the Chinese medicine and western medicine. Health food sometimes has 30 minutes difference, or can be the same time. Because Chinese medicine and western medicine might have some interaction, so they need to be given in different time. These are for treatment purpose. Health food does not have medicine components, so can be given with either Chinese or western medicine.

strategies.

Movement through components. In constantly changing caregiving conditions, caregivers need to readjust the "balance point." The process of "finding a balance point" does not necessarily occur in an orderly fashion from the first component to the second, then to the third component. For example, a caregiver might recognize competing needs or competing opinions about needs throughout the whole process; the caregiver might weigh the competing needs or competing opinions about needs while taking balancing strategies; and the balancing strategies might result in another condition that requires the caregiver to start a new process of "finding a balance point." For these reasons, the process of "finding a balance point" can be conceptualized as a fluid, nonprogressive movement (Strauss & Corbin, 1990) without clear and definite progressive stages.

Connolly's Decision Cycles model (Connolly & Wagner, 1988) supports the process of "finding a balance point". In this model, the decision making process consists of the cyclical interplay between situation assessment (recognizing competing needs or competing opinions about needs), evaluation of alternatives (weighing competing needs or competing opinions about needs) and action (taking balancing strategies).

Maintaining and Regaining the Balance Point

The process of "finding a balance point" is focused on "maintaining the balance point" or "regaining the balance point". The researcher will provide the definitions and examples of "maintaining the balance point" and "regaining the balance point" in the following descriptions.

Maintaining the balance point. Maintaining the balance point occurred when strategies were used to prevent a major problematic situations. For example, a caregiver said:

> If I am cooking and she does not want to stay in the kitchen with me, I have to keep the door open to watch her.

"Maintaining the balance point" occurred much more often than "regaining the balance point." In "maintaining the balance point", caregivers tended to use more global descriptions to describe the competing needs and the process of "finding a balance point" as patterns. The original event that caused the competing needs in "maintaining the balance point" was either not obvious or happened long ago. In this example, the care receiver became ill two years ago and gradually needed intensive supervision, and this situation created the competing needs of vigilance and cooking.

Caregivers took a wide variety of strategies more evenly in "maintaining the balance point" than "regaining the balance point". For example, altering the schedule/activity, running the work team (e.g., communication, shift changing, cooperation, supervising), modifying environment, managing behavior/emotional problems, engaging in self-care activities and managing treatment. Among these strategies, altering the schedule/activities and running the work team were used most often.

Regaining the balance point. "Regaining the balance point" took place in situations in which a major problematic situation had already happened and strategies were used to restore a more satisfactory situation. For example, a caregiver described:

> That day when my son left (to Europe), I was in a very bad mood, and he (care receiver) also got really confused. He would not let me make phone calls, he would not let me eat or do anything. I was in a bad mood because my son left. When he kept irritating me, we got into fights....... last time he hit me again, Miss C pull him away, I also called our previous aide and we tied him up, he then calmed down, then we release him in the evening.

In regaining the balance point, caregivers tend to use more situation-specific descriptions to provide the context for the competing needs. The event that caused the competing needs was usually more obvious and recent than in maintaining the balance point. In this example, the son's departure (event) created competing emotional needs between the caregiver and the care receiver. Time pressure interacted with fewer resources, and increased task difficulty to create the failure to maintain a balance point and the need to regain it.

Strategies taken in "regaining the balance point" were managing behavior/emotion problems, recruiting members to the work team recruiting management, engaging in self-care activities, altering the schedule/activities, managing treatment, and innovating care task. Among these, recruiting members to the work team was the strategy taken most often while other strategies were typically used once. Regaining balance point occurred most often when the needs of the caregiver competed with care receiver's needs.

Source of Competing Needs

Different sources gave rise to competing needs in the process of "finding a balance point": competing family needs and care receiver needs, competing caregiver needs and care receiver needs, and competing care receiver needs or competing opinions about care receiver needs.

Competing family needs and care receiver needs. The process of finding a balance point occurred when the needs of the care receiver competed with the needs of the family. For example, a caregiver described:

> My children came back from outside around 4pm and said that they were very hungry. Usually, if we are eating and did not give her (care receiver) any food, she got very angry. Maybe every one is like that. But this time, I thought she just had some thing, and my children were in a hurry, you know kids, they cannot wait. So I fried some eggs for the children and they started eating. I also fried eggs for mom, but did not give them to her right away, I just waited for the eggs to get colder. She saw my kids were eating and got really mad.

Competing caregiver needs and care receiver needs. The process of finding a balance point occurred when the needs of the care receiver and caregiver competed with each other, including other jobs competing with caregiving; the caregiver's physical, social, or emotional needs competing with the care receiver's needs; the caregiver's time table competing with care receiver's pace; and help from multiple caregiver competing with the need of the care receiver for consistency in care. For example, a caregiver described:

> my strength is not enough, it is hard for me to help him get up, but I have to push myself to the limit.... I have problems with my spinal cord. It is my weakest point. I am

> taking medicine for that, I also pay attention to my heart. Before you take care of other people, you have to take care of yourself.....

Competing care receiver needs or competing opinions about care receiver needs. The process of finding a balance point occurred when two of the care receiver's needs or opinions about care receiver's needs competed with each other. Competing opinions about care receiver's needs occurred when professional caregiving/treatment recommendations competed with a caregiver's ideas of how caregiving/treatment should be; giving western therapy competed with giving customary therapy to care receiver; protecting care receiver's self-esteem competed with giving the care receiver help due to functional decline; and going along with the care receiver competed with getting care receiver in control. Competing care receiver's needs include: the need for care receiver to exercise competed with the need for safety; the need for managing incontinence competed with the need to maintain skin integrity; and the need for enough nutrition competed with the need for not overeating. For example:

> take eating as an example, her son would have a good intention to encourage her to eat and maintain enough nutrition. On the other hand, if you keep doing this and accumulate all these calories and fat. Overweight is a torture for her when she needs to move around.

Related Concepts of the Process of "Finding a Balance Point"

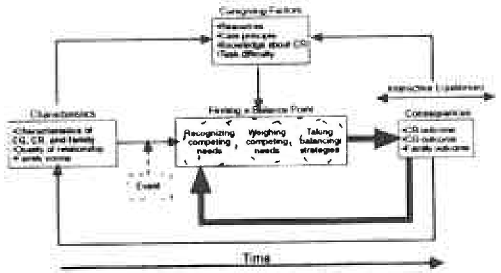
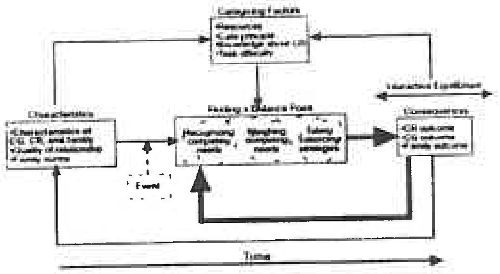
Characteristics. Several attributes influenced the process of "finding a balance point." These included characteristics each of the care receiver, caregiver and family; the quality of the relationship between caregiver and care receiver; and the family norms. The position in the model, definitions and examples of each characteristics are presented in Table 3.

Several observations were made related to how characteristics of caregivers influence the process of "finding a balance point." Children-caregivers are more often faced with competing needs of their own nuclear family along with the needs of care receiver, other jobs and caregiving, or multiple caregivers and the need for care consistency. Spouse-caregivers are more often faced their own physical needs competing with care receiver's needs.

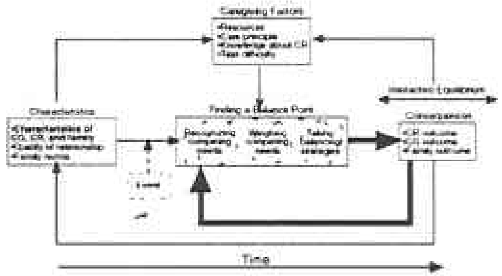
In terms of characteristics of care receiver, differences in "finding a balance point" occurred in families with cognitively intact care receivers and those with cognitively impaired care receivers. In families with cognitively intact care receivers, the caregivers and care receivers usually worked collaboratively in recognizing competing needs or competing opinions about needs, weighing them and discussing and evaluating balancing strategies. In facing competing needs, these caregivers and care receivers usually tried to negotiate and compromise with each other. In families with cognitively impaired care receivers, the care receivers' involvement in the process of "finding a balance point" depended on the degree of cognitive impairment: the more severe the impairment, the more likely that the caregiver worked independently in the process of "finding a balance point."

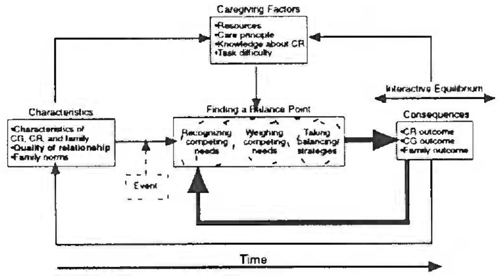
Characteristics of family also influence the process of "finding a balance point." For example, families with multiple

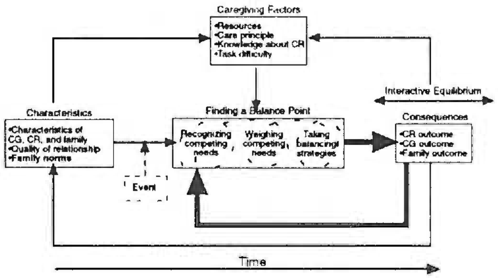
Table 3
Characteristics Affecting the Process of Finding a Balance Point, Their Definitions and Examples

Category & Position in Model	Definition	Example
Characteristics of the care receiver 	Care receiver's attributes which influence the present caregiving situation. These characteristics include care receiver's illness, functional level, degree and condition of impairment, physical condition, and circadian rhythm.	A caregiver described the competing needs between helping care receiver control the diet and yet providing enough nutrition. The characteristic of care receiver is over weight. The caregiver stated: "She is too heavy. It is hard to help her to move around."
Characteristics of the caregiver 	Caregiver's attributes which influence the present caregiving situation. These characteristics include caregiver's age, gender, role in family, physical condition, social condition, past experiences, and personality.	A caregiver described the competing needs of running the business and taking care of mom. Caregiver described: "I have my own business (more flexible schedule) and my wife is a teacher. For this reason, I am the one that takes care of mom."

<table>
<tr>
<td>Characteristics of the family


</td>
<td>Family's attributes which influence the present caregiving situation. These characteristics include family structure, economic condition, relationship with neighbors, and family labor division.</td>
<td>A caregiver described the competing needs of maintaining relationship with neighbors and yet meeting care receiver's need for quietness at night. He stated the characteristics of the family: "If the guests want to come in... We live here too long. We were born here and grew up here, so, say the truth, it is really hard to shut people out."</td>
</tr>
<tr>
<td>Quality of the relationship between caregiver and care receiver


</td>
<td>The nature of the long-term interaction between caregiver and care receiver that influences the present caregiving situation.</td>
<td>A caregiver described the competing needs between having multiple helpers and maintaining consistency in caregiving. The caregiver: "Every one of us (caregivers) is involved differently. The feelings between mother-in-law (CG) and daughters-in-law are all different; some have been in the family for over twenty years and some only over two, of course it's different how every one does."</td>
</tr>
</table>

Family norms  	A set of family and caregiver beliefs and rules which guide, control, or regulate the present caregiving situation. These beliefs include beliefs about filial piety, custom and traditional medicine practice, husband-wife status difference, and difference in living and communication style caused by different background [a](Taiwanese vs Ha-Ga).	A child-caregiver described the competing needs to take care of mom and running his business. The caregiver described: "While we are taking care of our parents, our children are seeing it. If we treat our elders badly, our children will treat us badly in future."

[a] Taiwanese and Ha-Ga are two different groups of people living in Taiwan. Taiwanese and Ha-Ga people have different spoken language and different life style.

primary family caregivers took on a collaborative form of "finding a balance point"--they agreed on what the competing needs or competing opinions about needs were, which need or opinion weighed more, and usually took running the work team strategies, such as compensating and supporting each other. Families with a hired aide used a supervisory form of "finding a balance point"--the family caregiver supervised the aide in recognizing and weighing the competing needs or competing opinions about needs and supervised the aide in taking balancing strategies. Caregivers in families with hired aides also needed to balance the pros and cons of hiring an outside helper.

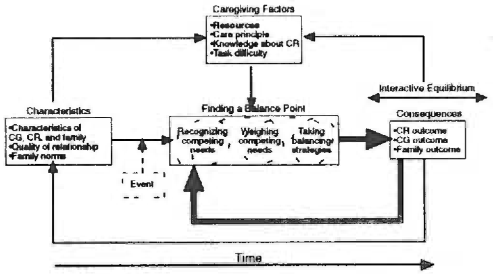
Event. The category labeled "event" in the model that identified as the cause of the competing needs or competing opinions about needs triggering the process of "finding a balance point" was not saturated in the data from this study. Caregivers identified an event in examples of "regaining the balance point", but not in examples of "maintaining the balance point". This might be due to the nature of the different types of "finding a balance point" as discussed before or might be due to the use of retrospective interviews with general interview guide. Using more situation specific interview guides and longitudinal study design in future might be helpful in saturating this concept.

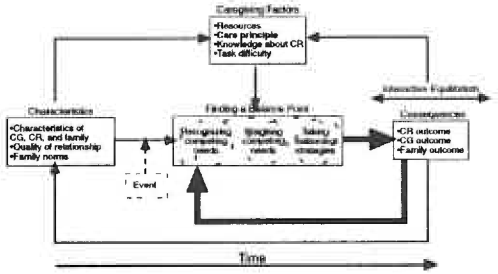
Caregiving Factors. Several caregiving factors were found to influence the overall process of "finding a balance point." These caregiving factors included resources, care principles, knowledge about care receiver, and task difficulty. At the same time, these caregiving factors were also affected by the characteristics described earlier (Figure 3). The position in the model, definition and examples of these factors are presented in Table 4.

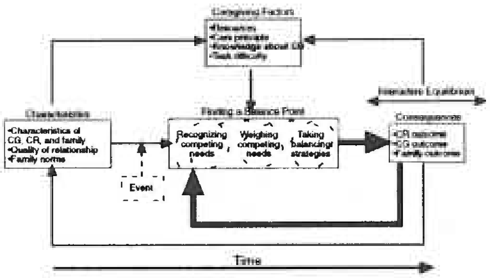
Using the analogy of "tiao biaan dan" again, a person has to adjust the position of his shouldering point of a "biaan dan" to find the most efficient point for balance between two loads. When one basket is heavier than the other, the person would carry the pole with a balance point closer to the heavier basket. Like adjusting the shouldering point of a carrying pole according to the weight of the baskets, caregivers adjust their priorities and efforts between competing needs according to their resources, care principles, the task difficulty and their knowledge about the care receiver. The more important the need is in meeting the care principle, the more difficult the task is; the less knowledge and fewer resources the caregiver has, the heavier the need (basket) for the caregiver. The caregiver would need to put a higher priority on and more effort into meeting the "heavier" needs than the "lighter" ones, in order to balance the competing needs and go on.

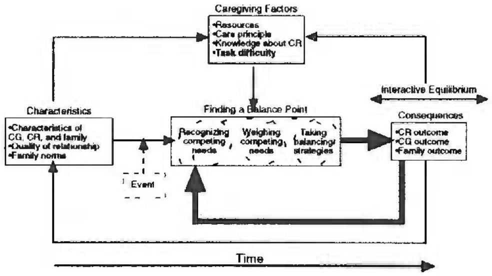
Interactions were found among these caregiving factors. For example, what caregivers believed (care principle) influenced their actual attitudes and competence (resources). At the same time, the influence of one factor on the process of "finding a balance point" might be different in the presence of one or more other factors. These interaction conditions will be explored in

Table 4
<u>Definitions, Dimensions and Examples of Caregiving factors</u>

Category definition & Position in Model	Dimension	Example
<u>Resources</u> The amount of support, abilities, skills, strengths which the caregiver has. Resources can come from family, friends, or personal strength.  	Family & friend resource-- The supports, supplies, person power and economic resources from family or friends that could be directed to the process of finding a balance point.	CG: "We have so many people, although we only have one on duty, but others always come over and check, we all live very close. For her, she can see a lot of her sons and daughters without changing her environment."
	Personal resource-- The strength, abilities, and skills which the individual caregiver has that could be directed to the process of finding a balance point. Personal resources include caregiver's competence and skills.	CG: He needs massage, but my strength is limited, I cannot do it myself.

<u>Care principle</u> The strength of influence on caregiving behavior from opinions, attitudes, or beliefs held by caregiver. Care principles include caregiver role values and care needs values. 	Caregiver role values--The caregiver's beliefs about what an caregiver's attitude, behavior, or standards of care should be for this care receiver.	CG: It's one's responsibility being the offspring. We're not wealthy but we should do what we can....
	Care needs values--Caregiver's general beliefs about all care receivers' needs and the priority of these needs.	CG: The main thing is to keep our elderly comfortable and happy; the others aren't so important.

<u>Knowledge about care receiver</u> The degree of familiarity caregiver has about care receiver, that is gained through experiences of contact or association with the care receiver as part of the caregiving situation.  		Demonstrating her knowledge about CR, one CG predicted: If he sleeps well and his spirit is better, he walks more stable and also easier for us to help. On the contrary, if he does not sleep well, it would be hard for him to walk and for us to help him to walk.

Task difficulty The degree of perceived hardness of the caregiving task for the caregiver.  		One caregiver said in handling care receiver's behavior problems: "Sometimes it's easy, sometimes it's hard. She is very unpredictable."

further analysis in a future study.

Variables found to facilitate a consequence with more interactive equilibrium included the caregiver’s ability to organize and recruit a work team (resource), the degree of flexibility in schedule management (resource), caregiver’s ability to self-care (resource), the sufficiency of family resources (resource), the ability to compromise and adjust the care principle, less task difficulty and having knowledge about care receiver.

Consequences. "Consequences" referred to the degree of interactive equilibrium that results from the process of "finding a balance point." The degree of interactive equilibrium can fall at any point on the continuum between balance and imbalance. A consequence with more interactive equilibrium occurred when competing needs or competing opinions about needs are both met more satisfactorily. For example, a caregiver said "his condition is not bad and our life is simple, very calm and stable, it is good to have a very stable life." A consequence with less interactive equilibrium occurred when one or both competing needs or competing opinions about needs were not met. For example, one caregiver said "I have to take care of him and am under so much stress that my mood swings with his condition. I was not able to take care of myself, that’s why I got colonitis."

Because caregivers, care receivers and families are all affected by the process of "finding a balance point", we categorized the consequences into caregiver outcomes, care receiver outcomes and family outcomes. Caregiver outcomes included a sense of reward, caregiver strain, a sense of powerlessness, and the degree of preparation for caregiving. One example of the sense of reward was described by a caregiver as "the feeling we're doing the right thing is rather satisfying." Care receiver outcomes included meeting basic needs, improvement in symptoms, functional improvement/maintenance and quality of life of care receiver. One example related to symptom improvement described by a caregiver is: "Now he doesn't have any more rashes. He used to have to lie flat on the bed and couldn't get up. Now before he sleeps I check his skin. It looks quite good--no more rashes."

Family outcomes that were identified included stability of family life and maintenance of family function. One child caregiver said "so far we brothers' families are doing well, our families are not affected by taking care of her." When children-caregivers faced competing needs between caregiving to parent and their own families, the functions of their own families were maintained through the process of "finding a balance point".

The degree of interactive equilibrium of the consequence had a direct feedback loop to the next cycle of "finding a balance point." After the cumulative effect of the process of "finding a balance" for a period of time, the consequences also influenced the characteristics including caregiver, care receiver and family characteristics such as the health of the caregiver and care receiver, the function of family, and the quality of relationship between caregiver and care receiver. These consequences also influenced the caregiving factors, for example, caregiver's knowledge about care receiver, caregiver's care principle, perceived difficulty of the task, and caregiver's resources--support from family, and caregiver's competence. Carrol and Johnson (1990) identified "feedback" as the last stage of decision making process. They believe that the outcomes of the decision making not only change the decision maker's knowledge (about the care receiver) and decision rules (care principle), but also influence the subsequent decision process.

Expertise in "Finding a Balance Point"

One of the caregivers in the sample seemed to be an expert in "finding a balance point" and another frequently failed in "finding a balance point". The different outcomes of these two processes of "finding a balance point" are illustrated in the following quotes:

> Expert caregiver who finds and maintains a balance point: Taking care of an elderly person is just like taking care of a kid "baby". When she is sleeping, it is easier to do housework, so you have to do it quickly, or else after she wakes up, especially if she is really confused, you can not do anything. When you want to cook and she is awake, I would let her participate the kitchen work, such as cleaning the vegetables. If she said that she is going home, I would tell her that she still has work to do, repeatedly saying these to keep her around.... Sometimes I would put away my work and enter her world or invite her to enter mine and then gradually lead her. She likes to fold the clothes. I just mess the clothes and she would take a long time to fold it. When she really wants to go home and folds very fast, I would mess them up again.... if you do not handle well, you would be very exhausted, very angry. This is like taking care of baby. When the baby is crying, you cannot do anything, because the baby cannot enter our world. It is the baby's nature to cry. But older people are still different from the baby. For a baby, you can not distract

> her/him......This is just self-awareness, a feeling. For example, if I am not comfortable myself and she is also very irritating, I also have other stuff to do at the same time, then I would think about how to deal with these and make both side balance. Or else, I would give up my work and totally spend time with mom, I would not give her up for the work, because she would get worse. She is a lively person that can move and make a mess. I cannot leave her alone, because she would get worse. The first priority is safety. When she insists on going home, if you leave her alone, she would just walk out and disappear. For this reason, when I need to cook, I take her to the kitchen with me, or pretend to ask her how to make certain dishes. She would teach you, then you can praise her.... When I feel odd, the thing I am doing is interrupted by her, when she becomes the obstacle, I try to resolve it. It is just like when there is a thing in your shoes that makes you uncomfortable, you try to take it out....Of course safety is the biggest consideration, because once she has an accident, she is the one that suffers, the caregiver would become really tired, more work to do, very troublesome. Like last time, she fell down badly, she was in a lot of pain, and we had to put ointment on for her, put ice bag on, and so on. Our work load also increased.

> Caregiver who failed to find a balance point: I went to the clinic because I did not feel good that day. After I came home. He (CR) got very angry and blamed me for not being home. I tried to be nice and explained to him, but he would not listen. I think I was too tired. I must have said something to irritate him. He started to hit me, and I hit back, he got more angry and hit me more. The aide came to help and he even hit her. I called the nursing home down on the street and they came and took him to the nursing home. That afternoon, one of our friends went to see him and said that he looked pitiful and kept saying "I did nothing wrong, why lock me up here." I feel bad too, so I took him home.

Caregivers who failed to find a balance point when facing competing needs or competing opinions about needs in caregiving differed in several ways from expert caregivers. In recognizing competing needs or competing opinions about needs, the caregiver who failed to find a balance point did not recognize either the competing needs, or competing opinions about needs, that needed to be balanced or the competing needs or competing opinions about needs that occurred unexpectedly. Even if the situation had happened before, the caregiver who failed to find a balance point did not link the situation to this past experience. In contrast, the expert caregiver not only recognized competing needs or competing opinions about needs, but linked the current situation to her past experiences. The expert caregiver also anticipated what kind of competing needs or competing opinions about needs would arise. In weighing competing needs or competing opinions about needs, the caregiver who failed to find a balance point did not know what the possible choices were, nor did she transfer knowledge from past experiences to the present condition. On the other hand, the expert caregiver knew ahead what the possible choices were and imagined what the consequences of each choice would be (simulation weighing). The expert caregiver transferred her knowledge from other experiences to reframe the situation, for example, using her experiences of taking care of a baby. In taking balancing strategies, the caregiver who failed to find a balance point took "engaging in self-care activities" strategies until things were out of balance, then she would take other strategies such as modifying environment or recruiting members to work team. The expert caregiver took a wide variety of different strategies including modifying the environment, running the work team, managing behavior/emotional problems, altering schedule/activities and engaging self-care activities; she predicted the consequences of the strategies accurately most of the time. This finding might be supported by the ideas of Means, Salas, Crandall, and Jacobs (1993) about the expert decision makers. They reviewed several studies on decision making and found that effective decision makers are distinguished by an ability to frame the questions, and use domain knowledge, such as pattern recognition and linking following action with that knowledge.

CHAPTER 5

Discussion and Conclusions

Contributions of Finding a Balance Point to the Caregiving Literature

The findings of this study represent a preliminary effort to understand the quality of family care. The process of "finding a balance point" in family caregiving when facing competing needs or competing opinions related to needs emerged as the central concept. Results of this study presented different sources and types of "finding a balance point." Results of this study also describe characteristics, caregiving factors and consequences related to "finding a balance point." The findings of this study contribute to the knowledge base about the nature of caregiving. This study adds a new perspective to the caregiving process that "finding a balance point" has not been reported as the caregiving process central to the quality of family care. The findings of this study also provide a framework for guiding research related to quality of family care, caregiving process and nursing actions to assist caregivers facing competing needs or competing opinions related to needs.

Contributions of finding a balance point to the literature about family caregiving in Taiwan. Most of the studies on family caregiving in Taiwan are based on measures, models and concepts developed in the western culture. This study contributes to the literature about Taiwanese families and caregiving by introducing a tentative theory of "finding a balance point". Only two previous studies of caregiving process in Taiwan reported findings on caregiving tasks (Shyu & Chang Yeh, 1992; Shyu, Chang Yeh, Yang, & Huang, 1992) and two studies reported on quality of family care (Chen, et al., 1995; Lin et al., 1995). The findings of this study contribute to the knowledge base of the caregiving processes central to quality of family care in Taiwan by identifying a previously unidentified process and by providing a framework for future studies related to the caregiving processes in Taiwanese families.

Limitations of the Study

A limitation of this study is that the process of "finding a balance point" was primarily understood retrospectively. Only one family was followed through the process of "regaining balance point" by two phone calls and two interviews at different points in time. This might explain why most of the data for "finding a balance point" reflected global descriptions rather than situational-specific descriptions. Only when a situation of "regaining balance point" had occurred, could situation specific descriptions be made. The nature of daily "events" which caused maintaining balance to occur was not saturated in this study and needs to further explored with situation-specific interview guides. Similarly, this study was not able to explore how different levels and different types of "finding a balance point" developed and changed longitudinally in caregiving. Also, the process of "finding a balance point" might exhibit different patterns in different phases of caregiving. For example, in addition to "maintaining the balance point" and "regaining the balance point", "establishing the balance point" may occur for caregivers who are just beginning to provide care for another family member.

Another limitation to this study is that although participant observations were conducted at the convenience of the family, interviewing was still the primary strategy for data collection. Without engaged and more structured observation, aspects of the process of "finding a balance point" that are performed but can not be described by participants may not be adequately captured by the described activities. For example, the skill-based behavior mentioned in Rasmussen's decision making model (1993) might not be captured by caregivers who are so familiar with it that they do it without thinking.

Findings a Balance Point Contrasted with Extant Theories

Decision theories. With concepts supported and sensitized by naturalistic models of decision making (Klein, 1993; Lipshitz, 1993; Means et al, 1993; Montgomery, 1993; Rasmussen, 1993), the process of "finding a balance point" can be viewed as a specific type of decision making process that focuses on decisions and actions related to balancing competing needs in caregiving. However, most of the decision making models do not deal with factors such as characteristics of caregiver, care receiver and family, quality of relationships between caregiver and care receiver and family culture. Most of the decision making models do not deal with the emotions of decision makers. In contrast, emotions and feelings played an important role throughout the process of "finding a balance point." These differences might be due to the fact that the process of "finding a balance point" emerged from family caregiving experiences that are interactive, emotionally-involved and rooted in family life history.

Family theories. Wright and Leahey (1984) described family dynamics from a systems theory perspective--families tend to maintain equilibrium and balance in a constant changing state. This observation supports the findings of the current study. In contrast to system theory, "finding a balance point" specifically focuses on the process of dealing with competing needs in the family caregiving process. Family caregivers made decisions and actively took strategies in this process.

Psychosocial homeostasis theory. "Finding a balance point" is also different from the concept of "psychosocial homeostasis" (Hsu, 1973, 1978), although psychosocial homeostasis might be able to provide some explanations for a family's balancing strategies. Psychosocial homeostasis refers to the state of harmony of a individual's affective involvement. To maintain the sense of intimacy, individuals search for and establish links with other persons. "Finding a balance point" specifically describes the interactive process between a dyad or within a family and involves not only the sense of harmony of the "actors'" affective involvement, but also the care receiver and family's outcomes that result from the process.

Roy's adaptation theory. Similar to Roy's adaptation model

(Roy & Andrews, 1991), "finding a balance point" focuses on responses of a adaptive system (caregiver) to a constantly changing environment which is full of stimuli (constantly changing competing needs or competing opinions related to needs) and adaptation as a dynamic state of equilibrium (interactive equilibrium) involving responses brought by autonomic and cognitive processes (Roy & Roberts, 1981). In contrast to Roy's model, the consequences of "finding a balance point" are not limited to equilibrium on the individual level, but also the dyadic and family levels; and the process of "finding a balance point" might occur as a collaborative process between and among multiple caregivers or between caregiver and care receiver. In contrast to Roy's adaptation model, the "finding a balance point" model includes caregiving factors and related characteristics because "finding a balance point" occurs in a caregiving context.

Finding a Balance Point Contrasted to Findings from Caregiving Research

Caregiving literature related to caregiving process. Similar to studies on caregiving tasks (Archbold, 1980; Bowers, 1987; Clark & Rakowski, 1983; Given et al., 1988; Lang & Brody, 1983; Shyu & Chang Yeh, 1992; Shyu, Chang Yeh, Yang et al., 1992; Stetz, 1987; Stoller & Earl, 1983), on dynamics in family caregiving (Phillips & Rempusheski, 1986), on enrichment process in caregiving (Cartwright et al., 1994), on mutuality and preparedness (Archbold et al., 1990) and on working-out systems (Nkongho & Archbold, 1993), the findings of this study describe what and how caregivers engage in daily caregiving processes, the results of the caregiving process and related factors. A care receiver's illness trajectory and caregiver's characteristics are usually considered. The model that emerged from this study provides another perspective to look at caregiving process with concerns of quality of family care.

Four descriptive qualitative studies on caregiving to persons with AD describe the caregiving process (Lindgren, 1993; Willoughby & Keating, 1991; Wilson, 1989; Wuest et al., 1993) as progressive with identifiable stages throughout progression of the care receiver's illness. In contrast, the process of finding a balance point does not have progressive, identifiable stages, but is circular in daily caregiving situation.

<u>Caregiving literature related to balance.</u> "Finding a balance point" as a central variable for quality of family care has not been reported in literature. However, "balancing outside work with caregiving" as part of "sense of self," which influence the degree of caregiver role strain, was reported in a study of family caregiving experiences using grounded theory methodology (Beach, 1993). In Beach's study, most caregivers reported having difficulties in balancing caregiving with full-time employment and disruptions in work performance or work schedule. The results of Beach's study support the findings of this study: "having difficulties" can support the stage of "recognizing competing needs or competing opinions about needs"; "changes in work performance or alteration of work schedule" can be viewed as the

actions of "taking balancing strategies"; and role strain can be seen as one of the caregiver consequences.

In contrast to this study, none of the participants of Beach's study considered the option of hiring outside care in order to remain employed and they also rarely received assistance from family members. This difference might due to the different family kinship system between Chinese and western families. According to Hsu (1973, 1978), the Chinese family is a father-son dominated kinship system that appears to have the characteristics of continuity and inclusiveness. Individuals tend to establish kinship or kinship-like ties. This might explain why caregivers in the current study tended to involve their families in the caregiving work team. At the same time, most of the hired aides in the current study lived with the families for years and were also seen as part of the families. In contrast, the western family is a husband-wife dominated kinship system that appears to have the characteristics of discontinuity and exclusiveness, which leads them to discard their kinship system (Hsu, 1973, 1978).

Caregiving literature related to balancing strategies. Work team recruiting/running management and schedule management were found to be taken most often to "find a balance point" when facing competing needs in caregiving. Involving family and outside help in the caregiving team is recommended in a caregiver's guide book for lay people in Taiwan (Ko, 1994). Schedule management in balancing competing needs, or competing opinions about needs, can increase predictability for the caregiver. Predictability is a dimension of quality of family care (Cartwright et al., 1991) and is defined as the regularity of care activities or the establishment of routines within the caregiving experience.

Implications for Nursing Practice

The findings of this study might contribute to nursing practice in the following area: taking the perspective of "finding a balance point" when dealing with families might increase the sensitivity of home care nurses to a family's conditions and actions. Nurses might be more alert to different sources of competing needs or competing opinions about needs that caregivers face. When working with families of children-caregivers, nurses can focus more attention on the competing needs of the caregiver's nuclear family and his/her parent. When working with families of spouse caregivers, nurses can be more conscious about the competing needs of the care receiver and the caregiver's own physical, emotional and social needs. In families with multiple caregivers, nurses can focus on finding a balance point between multiple sources of help and consistency in care.

Based on the findings of differences between expert caregivers and caregivers who fail to maintain balance, nursing interventions can be developed in the following areas: helping family caregivers to recognize the competing needs or competing opinions about needs ahead of time by linking past experiences with present conditions; helping family caregivers to simulate possible choices and following outcomes in weighing competing needs or competing opinions about needs; helping family caregivers to become familiar with a wide variety of balancing strategies and choosing/implementing effective strategies that will balance competing needs or competing opinions about needs. To further facilitate the process of finding a balance point between competing needs or competing opinions about needs, nurses can work on increasing a caregiver's resources and caregiver's knowledge about the care receiver, decrease task difficulty, and helping caregivers to establish a realistic care principle. Since characteristics influence both caregiving factors and the balancing process, nurses can activate some existing family and caregiver characteristics to become resources that can contribute to the balancing process. The assessment of characteristics might also enable nurses to predict some of the potential competing needs or competing opinions about needs and prepare a family for them.

Implications for Nursing Research

Further research is needed to answer the following questions: How does "finding a balance point" develop over time in family caregiving? What are the specific daily events that facilitate "maintaining" balance? What are the nurse's roles longitudinally in helping families to find a balance point when facing competing needs or competing opinions about needs? What kinds of symbols and behaviors related to the process of "finding a balance point" might be used for engaged participant observation? We will further analyze and report the data on interviews with care receivers, aides and nurses in this study related to "finding a balance point", comparison between different perspectives, and the data on interactions among related concepts of "finding a balance point".

Summary

This paper represents the main analysis of a complex data set from a descriptive qualitative study of quality of family caregiving for frail elders in Taiwan. The model of "finding a balance point" derives primarily from interviews with caregivers. Caregivers used the process of "finding a balance point" to deal with competing needs or competing opinions about needs, in order to achieve or preserve interactive equilibrium in caregiving.

The process of "finding a balance point" includes three components: recognizing the competing needs or competing opinions about needs, weighing them and taking balancing strategies to deal with them. Caregivers used "maintaining the balance point" to prevent major problematic situations, and used "regaining the balance point" to restore a more satisfactory situation after a major problematic situation already happened. Different sources giving rise to competing needs in the process of "finding a balance point" were: competing family needs and CR needs, competing CG needs and CR needs, and competing CR needs or competing opinions about CR needs. Concepts related to "finding a balance point" include characteristics, caregiving factor, event, and consequences.

Expert caregivers in "finding a balance point" were able to recognize and anticipate competing needs or competing opinions about needs; know ahead what the possible choices and consequences were when weighing competing needs or competing opinions about needs; and take a wide variety of different balancing strategies. Findings of this study increase the knowledge base of caregiving process and quality of family care in Taiwan. Findings of this study also provide suggestions for practical nursing interventions and a framework for future substantive theory development.

REFERENCES

Archbold, P. G. (1980). Impact of parent caring on middle-aged offering. Journal of Gerontological Nursing, 6(2), 78-85.

Archbold, P. G., Stewart, B., Greenlick, M., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. Research in Nursing & Health, 13, 375-384.

Beach, D. (1993). Gerontological caregiving: Analysis of family experience. Journal of Gerontological Nursing, 19(12), 35-41.

Beach, L. R., & Mitchell,T. R. (1987). Image theory: Principles, goals, and plans. Acta Psychologica, 66, 201-220.

Bowers, B. J. (1987). Intergenrational caregiving: Adult caregivers and their aging parents. Advances in Nursing Sciences, 9(2), 20-31.

Carrol, J. & Johnson, E. J. (1990). A primer on decision making. In J. Carrol & E. J. Johnson (Eds.), Decision Research (pp.19-30). Newbury Park, CA: Sage publications, inc.

Cartwright, J., Archbold, P. G., Stewart, B. J., & Limandri, B. (1994). Enrichment processes in family caregiving to frail elders. Advances in Nursing Sciences, 17 (1), 31-43.

Cartwright, J., Inoue, I., & Levine, B. (1991, June). Development of a quality of family caregiving instrument. Unpublished manuscript, Oregon Health Sciences University, School of Nursing, Portland.

Chen, Y. J., Dai, Y. Z., Yang, C. T., Wang T. C., & Teng, Y. S. (1995). A review and proposal on patient classification in long-term care system. Department of Health, Republic of China. (in Chinese)

Chen, K., Wang, T., & Chen, W. (1986). Causes and consequences of population change in Taiwan. Journal of Population Studies in Republic of China, 9, 1-23. (in Chinese)

Chiou, C. J., Lu, S. Y., Hsu, Y. Y., Ju Chen, Y. J., & Liu, L. I.(1988). The primary caregivers' burden of stroke patients at home and its related factors. The Journal of Nursing in Republic of China, 35(1), 69-83. (in Chinese)

Clark, N. W., & Rakowski, W. (1983). Family caregivers of older adults: Improving helping skills. The Gerontologist, 23, 637-642.

Connolly, T., & Wagner, W. G. (1988). Decision cycles. In R. L. Cardy, S. M. Puffer, & M. M. Newman (Eds.), Advances in information processing in organizations (Vol.3, pp.183-205). Greenwich, CT: JAI Press.

Dai, Y. Z., Chao (Yu), Y. M., & Lian, I. N. (1990). The impact of stroke on family. Public Health in Republic of China, 17(2), 171-180. (in Chinese)

Glaser, B. G. (1978). Theoretical sensitivity. Mill Valley, CA: Sociology Press.

Glaser, B. G. (1992). Basics of grounded theory analysis. Mill Valley, CA: Sociology Press.

Glaser, B. G., & Strauss, A. (1967). The discovery of grounded theory. Chicago: Aldine.

Given, B., King, S., Collins, C., & Given, C. W. (1988).

Family caregivers of the elderly: Involvement and reactions to care. Archives of Psychiatric Nursing, 11, 281-288.

Hsu, F. L. K. (1973). Psychosocial homeostasis and Jen: Conceptual tools for advancing psychological anthropology. American Anthropologist, 73(1), 23-44.

Hsu, F. L. K. (1978). Passage to understanding. In G. Spindler (Ed.), The making of psychological anthropology (pp.140-173). Berkeley: University of California Press.

Huang, T. T., Gwo, M. Y., & Chang, C. F. (1993). The influence of the health education programs on the primary caregivers of demented patients: A K.A.P. study. Nursing Research in Republic of China, 1(1), 60-70. (in Chinese)

Huang, P. L., Lee, Y. Y., & Mao, C. L. (1991). An investigation of the family burden experience of ex-schizophrenic patients during home care period. The Journal of Nursing in Republic of China, 38(4), 77-87. (in Chinese)

Klein, G. A. (1993). A recognition-primed decision (RPD) model of rapid decision making. In G. A. Klein, I. Orasanu, R. Calderwood, & C. E. Zsambok (Eds.), Decision making in action: Models and methods (pp.138-147). Norwood, New Jersey: Ablex Publishing Company.

Ko, S. H. (1994). Guidebook for taking care of elderly people. Taipei: Da-Jan. (in Chinese)

Kosberg, J. I., Cairl, R. E., & Keller, D. M. (1989). Caregiver competence: Conceptual and methodological issues. Paper presented at the meeting of 42nd Annual Scientific Meeting of

Gerontological Society of America. The Gerontologist, 29 (Special Issue), 212A.

Lang, A. M., & Brody, E. M. (1983). Characteristics of middle-aged daughters and help to their elderly mothers. Journal of Marriage and the Family, 45, 193-202.

Lin, M. N., & Chiou, C. J., (1995). The quality of family care for the elderly homebound stroke victim. Nursing Research in Republic of China, 2(3), 138-148. (in Chinese)

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry (pp. 289-331). Newbury Park, CA: SAGE publications, Inc.

Lindgren, C. L. (1993). The caregiver career. Image: Journal of Nursing Scholarship, 25(3), 214-219.

Lipshitz, R. (1993). Covering themes in the study of decision making in realistic settings. In G. A. Klein, I. Orasanu, R. Calderwood, & C. E. Zsambok (Eds.), Decision making in action: Models and methods (pp.103-137). Norwood, New Jersey: Ablex Publishing Company.

Liu, H. E. (1992). Factor related to the caregiving Appraisal. The Journal of Nursing in Republic of China, 39(4), 65-76. (In Chinese)

Liu, H. E. (1993). An exploration of the psychometrics of the Quality of Life Index of Chinese Family. Nursing Research in Republic of China, 1(2), 127-136. (in Chinese)

Means, B., Salas, E., Crandall, B., & Jacobs, T. O. (1993). Training decision makers for the real world. In G. A. Klein, I. Orasanu, R. Calderwood, & C. E. Zsambok (Eds.), Decision making in action: Models and methods (pp.306-326). Norwood, New Jersey: Ablex Publishing Company.

Miles, M. B. & Huberman, A. M. (1994). Qualitative data analysis (2nd Eds.). CA: Thousand Oaks, CA: Sage Publication, Inc.

Montgomery, H. (1993). The search for a dominance structure in decision making: Examining the evidence. In G. A. Klein, I. Orasanu, R. Calderwood, & C. E. Zsambok (Eds.), Decision making in action: Models and methods (pp.182-187). Norwood, New Jersey: Ablex Publishing Company.

Nkongho, N. O., & Archbold, P. G. (1993). Caregiving model for older persons in African American families. In press.

Noble, D. (1993). A model to support development of situation assessment aides. In G. A. Klein, I. Orasanu, R. Calderwood, & C. E. Zsambok (Eds.), Decision making in action: Models and methods (pp.287-305). Norwood, New Jersey: Ablex Publishing Company.

Phillips, L. R., Morrison, E. F., & Chae, Y. M. (1990a). The QUALCARE scale: Developing an instrument to measure quality of home care. International Journal of Nursing Studies, 27(1), 61-75.

Phillips, L. R., Morrison, E. F., & Chae, Y. M. (1990b). The QUALCARE scale: Testing of a measurement instrument for clinical practice. International Journal of Nursing Studies, 27(1), 77-91.

Phillips, L. R., & Rempusheski, V. F. (1986). Caring for the frail elderly at home: Toward a theoretical explanation of the dynamics of poor quality family caregiving. Advances in Nursing Sciences, 8(4), 62-84.

Phillips, L. R., Rempusheski, V. F. & Morrison, E. (1989). Developing and testing the beliefs about caregiving scale. Research in Nursing and Health, 12(4), 207-220.

Rasmussen, J. (1993). Deciding and doing: Decision making in natural contexts. In G. A. Klein, I. Orasanu, R. Calderwood, & C. E. Zsambok (Eds.), Decision making in action: Models and methods (pp.158-171). Norwood, New Jersey: Ablex Publishing Company.

Roy,C., & Andrews, H. A. (1991). The Roy adaptation model: The definitive statement. Norwalk, CT: Appleton & Lange.

Roy, C., & Roberts, S. L. (1981). Theory construction in nursing: An adaptation model. Englewood Cliffs, NJ: Prentice-Hall

Shyu, Y. I., Chang Yeh, M., Yang W. W. & Huang, J. M. (1992). Family Caregiver's Burden and Related Factors of Dependent Elderly Persons in Urban and Rural Communities. The Journal of Nursing in Republic of China, 39(3), 99-106. (in Chinese)

Shyu, Y. I., & Chang Yeh, M. (1992). Caregiver tasks of families of disabled middle aged and aged persons in urban and rural communities and the consequent strain. The Journal of Nursing in Republic of China, 39(4), 57-64. (in Chinese)

Stern, P. N. (1980). Grounded theory methodology: Its uses and processes. Image, 12(1), 20-23.

Stetz, K. M. (1987). Caregiving demands during advanced cancer. Cancer Nursing, 10, 260-268.

Stoller, E. P., & Earl, L. L. (1983). Help with activities of everyday life: Sources of support for the non-institutionalized elderly. The Gerontologist, 23, 64-70.

Strauss, A., & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park, CA: SAGE publications, Inc.

Tiang, L. Y. Mao C. L., Chou, C. F., Chen, R. C., & Lin, H. C. (1992). Caregiver burden of demented elderly and related factors: An exploratory study. The Journal of Nursing in Republic of China, 39, 89-98. (in Chinese)

Willoughby, J. & Keating, N. (1991). Being in control: The process of caring for a relative with Alzheimer's disease. Qualitative Health Research, 1(1), 27-50.

Wilson, H. S. (1989). Family caregiving for a relative with Alzheimer's dementia: Coping with negative choices. Nursing Research, 38(2), 94-98.

Wright, L. M., & Leahey, M. (1984). Nurses and families: A guide to family assessment and intervention. Philadelphia: F.A. Davis.

Wu, S. C. (1992). Long-term care for the elderly. Department of Health, Republic of China. (in Chinese)

Wu, S. L., Hu, H. C., Yao, K. M. (1991). A study on the burdens and needs of primary caregiver of frail elderly in home care program. Public Health in Republic of China, 18(3), 237-248. (in Chinese)

Wuest, J., Ericson, P. K., Stern, P. N. (1994). Becoming strangers: The changing family caregiving relationship in Alzheimer's disease. Journal of Advanced Nursing, 20, 437-443.

LIST OF APPENDICES

Appendix A

Summarized Review of Research Literature Related to Quality of Family Caregiving and Research Literature Related to Family Caregiving in Taiwan

Summarized Review of Research Literature Related to Quality of Family Caregiving

Author/Purpose	Design/Method	Sample/Data Collection	Perspective	Findings
Cartwright, Inoue, & Levine, 1991. The purpose of this study was to develop a measure of quality of family caregiving.	A descriptive study using structured interview guide and qualitative analysis.	A convenience sample consisting of 10 caregivers was interviewed. A structured interview guide was developed to obtain detailed narrative description from family caregivers about how they conduct specific caregiving activities.	Quality of family caregiving was based on pre-existing constructs to analyze caregivers' responses.	The results of the qualitative analysis confirmed the dimensions of quality of family caregiving-competence, enrichment, and predictability. After quantifying the results, inter-rater reliability ranged from .71 to .92. Enrichment was positively associated with rewards of meaning. More enrichment and greater predictability were associated with more ease over time. Predictability was associated with caregivers' confidence of ability to continue caregiving.

Kosberg, Cairl, & Keller, 1989. The purpose of this study was to explore the relationship between caregiver burden and competence as experienced by caregivers of Alzheimer's disease patients.	A descriptive correlational design using structured interviews and team-based assessments for determination of competence of caregivers.	A convenience sample consisted of 96 caregivers were selected. Kosberg's Cost of Care Index (CCI) was used to measure caregiver burden. The level of caregiver competence was determined by an instrument developed by the multidisciplinary team of professionals and team-based assessments.	Caregiver competence was determined by the assessment by health professionals.	A low and insignificant correlation ($r= .19$, $p= .47$) between burden and competence was found: burdened caregiver is not an incompetent caregiver. Caregiver competence being predictive of quality of care for a frail and vulnerable person in both the present and future was also suggested by the study.

Lin, & Chiou, 1995. The purpose of this study was to explore the quality of family care and related factors of elderly persons with strokes.	A descriptive correlational study design with structured interview was used.	A purposive sample of 70 stroke patients discharged from two hospitals and their caregivers. Quality of Family Care Scale which was modified from Phillips et al (1990 a b), O'Malley, & Minshull's (1986) scales and Chiou et al's (1988) Caregiver Burden scale were used. Quality of family care measured included assessment of the satisfaction of stroke patient's physiological and safety needs.	From nurses' perspective to assess the degree to which the caregiver meets the needs of the elder.	The quality of family care for these stroke patients was above average. Four factors which explained 42.99% of the variance of quality of family care were identified. The stroke patients who received better quality of family care were those who had medical insurance, a good relationship with the caregiver, a shorter period after suffering stroke, and primary caregiver with lower psychological burden.

Phillips, Morrison & Chae, 1990a. The purpose of this study was to describe the development of QUALCARE instrument and theoretical issues associated with developing observational measures for nursing.	A pilot exploratory descriptive study was used to test the instrument. QUALCARE scale including 53 items in environmental, physical, medical maintenance psychosocial, human rights and financial subscales was examined.	A convenience sample of 29 elder-caregiver dyads was interviewed by 8 data collectors at joint and separate visits. Development of the protocol for using the instrument and rater training were described. The QUALCARE scale was completed by professional nurses after the nursing assessment. Data were collected by using observation and structured interviews.	From nurses' perspective to assess the degree to which the caregiver meets the needs of the elder.	Inter-rater reliability in the pilot study of 6 subscales ranged from 52% to 77% in a five-point scale and ranged from 73% to 97% in a three-point scale. Item analysis and individual feedback from data collectors were used to examined the items. A false assumption that a positive outcome was attributable to good quality caregiving was identified in the Physical Assessment Subscale. The items of low inter-rater reliability were rewritten and the Physical Subscale was revised to focus on the behaviors of the caregiver rather than on the outcome of caregiving. Higher inter-rater reliability of the post-test on revised QUALCARE scale was reported.

Phillips, Morrison & Chae, 1990b. The purpose of this study was to examine the validity and reliability of QUALCARE scale.	A descriptive correlational design using structured interviews and observations was used.	A convenience sample of 249 caregiver-elder dyads participated in this study. Inter-rater reliability, internal consistency, and conceptual clarity were examined. Several measures were used to test the criterion validity and construct validity.	From nurses' perspective to assess the degree to which the caregiver meets the needs of the elder.	**Inter-rater reliability:** percentage agreement remained above .70, and x/x mas did not remain above the criterion. **Internal consistency:** Cronbach's alpha in subscales ranged from .81 to .95. Eight items failed to achieve Nunnally's criterion for item-to-total scale correlations. A majority of intersubscale correlations between .50 to .70 indicated subscales were related but not redundant. **Conceptual structure:** Six factor structure, accounting for 64.4% of variance, was found in confirmatory factor analysis. Revisions were made on items failing to meet the statistical criteria for internal consistency and factor analysis. **Criterion validity:** Correlations of 8 criterion variables and revised QUALCARE scale and subscales were in the predicted direction

Phillips & Rempuskeski, 1986. The purpose of this study was to generate a theory of caregiving dynamics.	This exploratory descriptive study used intensive interview guided by grounded theory methodology.	A theoretical sample of 39 caregivers-14 having the "good" and 25 having "abusive" relationships-was recruited through advertisements in three communities. Interview questions were guided by the theoretical sampling and interviews continued until theoretical saturation of the evolving theory occurred.	Caregivers identified themselves as having good or abusive relationship with the elder	Multiple factors influencing the quality of family caregiving were identified. Perceived personal identity of elder, reconciliation of past with present, image of caregiving, and reconciliation of proscriptions with perceived reality of caregiving influence, caregiver role beliefs and on management strategies the caregiver chooses in everyday interactions with the elder. "Good caregivers" tend to have normalized images of the elder and "abusive" caregivers experienced divergence between their proscriptions and perceived realities. Nurturing-supporting role forms are exhibited in good quality caregiving and monitoring-controlling role forms are displayed in abusive caregiving.

Phillips, Rempuskeski, & Morrison, 1989. Four studies were conducted to test Beliefs About Caregiving Scales (BACS) which was designed to identify caregivers who are at high risk for providing poor-quality care to a dependent elder in the home.	A descriptive correlational design using structured interviews and observation was used.	Four independent convenience samples (N=54, 19, 100, 249) were used for these four studies. BACS was tested in all four studies while different measures were administered in different study to test the internal consistency, stability, and construct validity of BACS.	Caregiver's standards and values regarding the performance of the caregiving role	Following initial revisions, internal consistency ranged from .66 to .92 in different subscales and the test-retest reliabilities were .72 and .86. Following final revisions, alpha ranged from .85 to .90 in subscales and .82 to .89 in the whole scale. Test-retest reliability was .82. Monomethod-multitrait correlation matrix constructed to test for convergent and divergent validity. Bivariate correlations demonstrating acceptable convergent and divergent validity were reported. Predictive modeling by examining the correlations between two quality of care outcome measures and BACS was also used to test the construct validity of the instrument. The evidence of BACS total scale and Monitoring Subscale is more convincing than the evidence for the

Summarized Review of Research Literature Related to Family Caregiving in Taiwan

Author/Purpose	Design/Method	Sample/Data Collection	Findings
Chiou, Lu, Hsu, Ju Chen &Liu, 1988. The purpose of this study was to understand the family caregiver burden and related factors in families with stroke patients.	An exploratory descriptive study design with structured interviews was used.	A convenience sample of 70 stroke patients and their primary caregivers was interviewed. Caregiver Burden Scale was developed to measure the caregiver burden. One time face-to-face interviews were used to collect data.	Although the burdens experienced by these caregivers were not severe, emotional and social burdens were greater than physical burden. Lower functional level of care receiver, worse subjective health status of caregiver, and higher "caregiver's agreement to institutional care as the best caregiving way" were found to be predictors of more caregiver burden.

Dai, Yu, & Lian, 1990. The purpose of this study was to understand the impact of stroke on families.	A descriptive correlational design using structured interviews and observation was used.	Ninety-seven families of stroke patients before and after discharge from the hospital were interviewed.	Caregiver's social participation was impacted most prominently both before and three months after patients were discharged 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. Most of the families did not suffer severe functional or structural changes before and three months after patients were discharged. Lower functional status of patient, more severe families who perceived the cognitive impairment of patients as more severe, and families with less expectations that the patient will recover predicted a higher level of impact on families three months postdischarge.

Huang, Gwo, & Chang, 1993. The purpose of this study was to understand the influence of the health education program on the knowledge, attitude and practice of primary caregivers of demented patients.	A pre-experimental study design was used.	A convenient sample of 19 primary caregivers of demented patients at a medical center was used. Caregiver Knowledge Attitude and Practice scale was developed based on the literature review and researcher's clinical practice experiences.	The health education program had significant, influence on the caregivers knowledge and practice. There was no significant improvement in the attitude.
Huang, Lee & Mao, 1991. The purpose of this study was to explore the family burden experience related factors, and the coping behavior of the discharged schizophrenic patients' relatives.	A descriptive correlational study design with structured interview was used.	A convenience sample of 47 relatives of patients with schizophrenia was selected. Family burden experience scale, and family coping behavior scale were developed to collect the data.	The more frequency of admission and episode, the less satisfaction in life and on degree of treatment outcome, and lower appraisal of recovery degree were reported, the more burden experience appeared.

Lin, & Chiou, 1995. The purpose of this study was to explore the quality of family care and related factors of elderly persons with strokes.	A descriptive correlational study design with structured interview was used.	A purposive sample of 70 stroke patients discharged from two hospitals and their caregivers. Quality of Family Care Scale which was modified from Phillips et al (1990 a b), O'Malley, & Minshull's (1986) scales and Chiou et al's (1988) Caregiver Burden scale were used. Quality of family care measured included assessment of the satisfactory of stroke patient's physiological and safety needs.	The quality of family care for these stroke patients was above average. Four factors which explained 42.99% of the variance of quality of family care were identified. The stroke patients who received better quality of family care were those who had medical insurance, a good relationship with the caregiver, a shorter period after suffering stroke, and primary caregiver with lower psychological burden.
Liu, 1992. The purpose of this study was to investigate factors related to caregiving appraisal for family caregivers while they take care of the home-bound or hospitalized patients.	A descriptive correlational study design with self-reported questionnaire was used.	A convenient sample of 484 caregivers was used in this study. OMFAQ Activities of Daily Living (Fillenbaum, 1988) and Caregiving Reactions Inventory, CRI (Given, Given, Collins, &King, 1988b) were translated and administered.	The significant predictors of caregiving appraisal were caregivers' perceived health status, patient's ADL and co-residence.

Liu, 1993. The purpose of this study was to validate the Quality of Life Index (QLI) in Chinese caregivers.	A descriptive correlational study design with self-reported questionnaire was used.	A convenient sample of 437 effective questionnaires from caregivers of chronically ill elders was collected. Quality of Life Index (Ferrans & Powers, 1985) was translated and tested. Content validity, criterion-related validity and factor analysis were used to test the validity of this measure. Internal consistency and test-retest reliability was used to test the reliability of this study.	Cronbach's alpha=.93; test-retest reliability=.87; criterion-related validity with a overall life satisfactory item .77 were reported. Psychosocial, health, environmental, intimacy and family factors were found from the factor analysis. Among these factors, the Chinese caregivers reported highest satisfaction in the intimacy factor and lowest satisfaction in the environmental factor.

Shyu, Chang Yeh, Yang, Huang, 1992. The purpose of this study was to understand the family caregiver's burden of dependent elderly persons in urban and rural communities.	This exploratory descriptive study used structured interviews to collect data.	A convenient sample of 91 disabled elders and their primary caregivers participated in this study. One time face-to-face interviews were administered. Caregiver Burden scale modified from Zarit, Reeber and Bach-Peterson (1980) and Chiou et al's (1988) measures, Archbold and Stewart's (1986) Caregiving Tasks measures, and Chiou and Wong's (1987) self-care measure were used to collect data.	Both urban and rural caregivers presented slight physical burden, moderate emotional and social burdens. It was also found that the worse the caregiver felt his or her own health was, the more difficult the caregiving tasks were perceived to be, and the greater the caregiver burden was.

Shyu & Chang Yeh, 1992. The purpose of this study was to understand and compare the caregiving tasks, feelings toward these tasks, and help from others of families with disabled middle age and aged persons in rural and urban communities.	A descriptive correlational design using structured interviews was conducted.	A convenient sample of 91 families caregivers was one time face-to-face interviewed. Archbold and Stewart's (1986) Caregiving Tasks measures were used in this study.	In general, protection and personal care tasks were the most tiring/upsetting caregiving tasks, but received least help from others. Caregivers in rural community provided less financial, legal and health decisions and emotional support tasks than the caregivers in urban communities. Caregivers in rural community reported feeling more difficult and tired/upset about personal care and medically related tasks than the caregivers in urban community. Caregivers in rural community also received more help from others at financial, legal and health decisions tasks than the caregivers in urban community.

Tiang, Mao, Chou, Chen, & Lin, 1992. The purpose of this study was to investigate the caregiver burden and related factors for caregivers of the demented elderly.	A descriptive correlational design using structured interviews was conducted.	A convenience sample consisted of 85 demented patients and their caregivers from three medical centers in Taipei participated in this study. Novak, Guest's (1989) Caregiver Burden Scale, and Knowledge of Dementia, Attitudes toward Dementia, Social Support measures, and Dementia Behavior Disturbance Scale and Modified Barthel Index were used to collect data.	Quantitative measures of patient behavior disturbance, the response of caregivers toward patient behavior disturbance and caregiver need for social support had significant positive correlation with measures of caregiving burden. The most predictive variables in descending order for caregiver burden were caregiver adequacy of instrumental social support, caregiver need for emotional social support, caregiver attitude toward dementia and patient function of self-care. These variables could explain 62% of variance of caregiver burden.
Wu, Hu, & Yao, 1991. The purposes of this study were to understand the burdens, needs and related factors of primary family caregivers to frail elders in home care programs.	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 programs. Questions related to demographic background, quality of relationship, burden scales (Chiou et al., 1988), and support system scale (Yang, 1990) were used to collect data.	Majority caregivers were female caregivers, mostly spouses and daughters-in-law. Caregivers experienced mild caregiver burden. Factors influencing caregiver burden included caregiver 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.

Appendix B

Summary of and Rationale for Modifications in the Research Method

	Proposed	Actual implementation	Explanation of modification
<u>Aims</u>	A. identifying attributes of the phenomenon of quality of family care to frail elders in Taiwan; B. describing the relationships between and among the attributes of quality of family care; C.identifying antecedent and concurrent variables which influence the quality of care in families and the consequences that are associate with the quality of family care; D. describing the perspectives of the frail elder, caregiver and home care nurse regarding the quality of family care and comparing the differences among three different perspectives within a family unit.	"Finding a balance point" emerged as the core category of quality of family care to frail elders in Taiwan. The aims of this study then focused on a) identifying components and types of "finding a balance point"; and b) identifying antecedent and concurrent variables which influence the process of "finding a balance point," and consequences that were associated with "finding a balance point" or not. However, the analysis of data from frail elders and home care nurses did not complete.	The original research question is a statement which identifies the phenomena to be studied and helps the researcher to start and stay focused. As the tentative theory emerged with the data collection and analysis further along, the research question was refined and specified in order to build the density of the tentative theory (Strauss & Corbin, 1990). Researcher will complete and report the analysis of data from frail elders and home care nurses and comparison between different perspectives in future.
<u>Methods</u> design	Grounded theory methodology (Glaser & Strauss, 1967) will be chosen for use in this study.	Proceeded as proposed.	

setting	The sample was proposed to be obtained through the Taipei Home Care Nursing Agency and several home care programs at local public health stations. These agencies primarily serve the Taipei area. Clients served by these agencies are adults, mostly elderly persons with chronic or terminal illnesses such as stroke, dementia, cancer, and heart disease and need skilled nursing care. The number of monthly visits of the Taipei Home Care Nursing Agency is approximately 180 visits.	Besides Taipei Home Care Nursing Agency, the home health care program in public health station of Da-On was asked and agreed to participate in the study. Clients served by this agencies are adults, mostly elderly persons with chronic or terminal illnesses such as stroke, dementia, cancer, and heart disease and need skilled nursing care. The number of monthly visits of this home care program ranged from 10 to 30 visits.	Many of the clients served by Taipei Home Care Nursing Agency paid for the services themselves. The care for most clients in the home health care program of public health station is reimbursed by government. The social economic situation of clients from these two agencies might be very different. For this reason, the Da-On public health station was added in order to enhance the social economic diversity of the sample. Among all the home care programs in public health stations, Da-On was the most well established and suggested by the supervisors in Long-Term Care Association of Taiwan.

sampling--	Two phases of sampling were proposed: purposive sampling of frail elders, caregivers, their home care nurses and hired aides, and theoretical sampling of concepts relevant to the emerging theory.	As proposed.	
sampling--purposive sampling	The proposed purposive sampling of initial participants includes 10 to 20 families (frail elder and caregiver), their hired aide(s), if any, and their home care nurse. Inclusion criteria for frail elders were: 1) age 65 years or older, and 2) receiving home health care. Inclusion criteria for family caregivers are 1) age 18 years or older, and 2) taking responsibility for the care of the frail elder. For families in which several family caregivers share the same caregiving responsibility and a primary caregiver cannot be identified, multiple family caregivers will be interviewed. In families with hired aides, the family member who supervises the aides and the aides will be interviewed.	A total of 8 families including frail elder, caregiver, hired aide, if any and home care nurse was interviewed. The inclusion criteria for caregivers and frail elders were the same as proposed. Eight caregivers from one family that shared the same caregiving responsibility were all interviewed. Family members who supervise aides and the aides were interviewed.	The core category was saturated by the interviews with 8 families (30 individuals). There were no new concepts found after the interviews with 6 families. For this reason, there was no need to recruit 10 to 20 families in the sample.

sampling--theoretical sampling	The researcher will code and analyze the data immediately after each interview. The results of the data analysis drove decisions about what data will be sought next in order to generate the emergent theory. Decisions about whom to sample are guided by the emergent theory, such that the sample will be chosen for its ability to contribute to the emerging concepts. Theoretical sampling will cease when the concepts and incidents indicate the same pattern and no new properties of it are found. At the same time, theoretical sampling of the empirical based related literature, lay literature, movies, newspapers, documentation, and other people who are knowledgeable in the area of the emergent concepts will be used to enrich and support the emerging theory.	"Finding the balance point" emerged as the core category in the mid of data collection and data analysis. Caregivers who were expressive and described experiences of "finding a balance point" in caregiving in the first interview were interviewed for theoretical sampling. Two additional families were also interviewed with the focus on "finding a balance point" to look for new concepts. Theoretical sampling ceased when new properties of the core concept were not found. Theoretical sampling of dictionaries, lay literature, related literature in nursing, psychology, anthropology, and sociology which were related to balancing and "Tiao Biaan Dan" and were in Chinese or English was done. The theory of "finding a balance point" was shared with an anthropologist, 2 sociologists, and some nurses who work with caregivers.	Caregivers who were expressive and described experiences of "finding a balance point" in the first interview were interviewed to enrich the emerging theory. The additional families were interviewed for saturation of the core concept. Theoretical sampling on movies, news papers and novels in Taiwan found very little information related to balancing. However, related literature in lay articles for caregiving, dictionaries, and works in nursing, psychology, sociology and anthropology were found. Theory of "finding a balance point" was shared with anthropological theorist and grounded theorists in sociology in Taiwan to enrich, modify and support the emerging theory.

instrument	Face-to-face interviews using open-ended questions (Appendix F) will be used to collect the data. Five interview guides will be developed, one each for the elder, the caregiver, the combined caregiver and care receiver, the hired aide and the home health nurse. A second interview will be done as needed for clarification of data obtained on the 1st interview, for expanding previous information, or obtaining member checks as needed.	Interview guides were administered as proposed. An additional interview guide focused on the experiences of finding a balance point in caregiving was developed for theoretical sampling (Appendix F). The concept of "finding a balance point" and examples from previous interviews were described to the caregiver who was then asked about his/her opinions on "finding a balance point" in caregiving. Specific questions included: what things they need to balance within caregiving, how they realize the need for balancing, how they set their priorities, what strategies they used to balance, what influences of this balancing process are on the consequences, how they feel about the process and what they think the influencing factors are for a successful process of "finding a balance point" were developed and administered to the caregivers for second interview and member check.	Additional interview guide with the focus of "finding a balance point" was developed to enrich the emerging theory. Because this concept primarily (around 90%) emerged from interviews with caregivers, the focused interview guide was developed specifically for the caregivers to clarify and expand related information.

procedure--sample access	Home care nurses will be asked by the investigator to participate. Nurses who are interested in participating will first sign a consent, then will be asked to identify families who meet the sample criteria. Because the pilot families refused to sign consent form, only taped verbal consent will be obtained from families including hired aides.	Proceeded as proposed.	

procedure--consent	The researcher will explain the study to the nurses, review the consent form with them, and answer all questions they have about the study. Nurses who agree to participate will approach potential families first by phone to assess their willingness to participate. Families who express interest will be contacted by the researcher by phone to set up the time for face-to-face explanation of the study. The researcher will explain the goals and methods of the study, the potential risks to participants, their right to withdraw from the study at any time and to refuse to answer questions, and the strategies used to protect their confidentiality. Participants will then be asked if they have questions or comments and these will be answered. Finally, the participants will be asked if they agree to participate in the study and their responses will be recorded. For cognitively impaired elders, proxy verbal permission will be obtained from the caregiver. After participants have given taped verbal permission, interviews will proceed. The researcher will ask to interview the caregiver and frail elder	For the additional site, explanations of the study were given to the head nurse and home health care nurses individually. As proposed, taped verbal permissions were given by the families. Proxy verbal consents were obtained from the caregiver. Only one family was interviewed jointly. Some	Available time of individual nurses and head nurse were all different. Both caregiver and care receiver were cognitively intact and could interact with each other during the joint interview. Caregivers or aides were present during

procedure--interviews	Before the interview, participants will be asked to sit comfortablely and told that there are no right and wrong answers to the questions in the interviews. During the interview, signs of discomfortable and stress will be monitored, and if they are detected, the researcher will provide the chance for withdrawing or postponing the interview. At the end of the interview, the purpose of an additional interview or phone call to clarify data or member checks will be explained. The family's agreement for possible second interviews will be asked. If a second interview is needed, the researcher will contact the family by phone and set up time for the second interview.	Two interviews were postponed due to caregiver's time conflict with other activities. One interview with the caregiver was cut short because of caregiver fatigue and discomfort. One interview with a care receiver was stopped and rescheduled because of signs of stress. Second interviews were prepared and scheduled as proposed. All of the caregivers who were asked to participate in the second interview agreed to.	

procedure--participant observation	This part is missing in the proposal, but verbal agreement related to participant observation was obtained. Meaningful caregiving activities will be identified in the first interview. Observation of these activities will be arranged with the family. Questions related to why and how the caregiver performs the activities and how well they think they are doing will be asked during or after the observation for clarification. Field notes will be used to document the observations.	Participant observations were conducted spontaneously. These observations included morning care, meal preparation, watching TV together, caregiver supervision of aide's care, care receiver's drawing, friends' visits, and family get togethers. These activities occurred at different times of the day, ranging from morning, noon, to the afternoon. Informal interviews focused on why and how caregivers performed the activities and their feelings about the activities during these observations.	From the interviews, caregivers reported a wide variety of different caregiving activities related to family care quality and "finding a balance point." During the family visits, caregiving activities occurred spontaneously. It was more natural and easy to conduct participant observation and related interviews.
procedure--data management	All the interviews will be tape recorded and then transcribed verbatim in Chinese. Transcriptions will be translated by professional translator, entered in Wordperfect and verified by the researcher.	Half of the transcripts were translated by people who have both Chinese and English as their mother language. These translations were entered in Wordperfect and verified by the researcher. The other half of the transcripts were translated by researcher.	The modification was due to the lack of availability of the translators.

<u>Data Analysis</u>	Constant comparative strategy will be used to analyze the data. Open coding, which refers to constant comparison of incident with incident, and incident with concept, without preconceived codes to develop more categories, will be used in the initial stage of analysis. Data analysis will start at the within-case (nurse-caregiver-care receiver-aide) level, then move to the cross-case comparison (Miles & Huberman, 1994) to handle the complexity of the phenomenon. After the core categories accounting for most of the variation in quality of family caregiving are identified, selective coding will be used to delimit coding to only those incidents that relate to the core categories. Theoretical coding will be used to identify the relationship between concepts. During the analysis process, memos will also be used to record ideas related to formulation of theory. Raw data in Chinese will be coded directly in both Chinese or English. Theoretical coding and memos will also be done in both Chinese and English to facilitate the development of theoretical ideas. Then all of the codes, memos, ideas, and example content will be	Constant comparative strategy was used to analyze the data. Open coding was used in the initial stage of analysis. Data analysis started at the within-case (nurse-caregiver-care receiver for one family) level. However, within-case analysis and cross-case comparisons were done circularly to understand the complexity of the phenomenon. "Finding a balance point" emerged as the core category accounting for most of the variation in quality of family caregiving, selective coding related to "finding a balance point" was used to delimit coding to only those incidents that relate to the core categories. Theoretical coding was used to identify the relationship between concepts. Memos were also used to record ideas related to formulation of theory. Raw data in Chinese were coded directly in both Chinese or English. Theoretical coding and memos were done in both Chinese and English to facilitate the development of theoretical ideas. Then all of the codes, memos, ideas,	Due to the complexity of the phenomena, it was more manageable to start the analysis from within-case analysis. After the initial within-case analysis, within-case analysis and cross-case comparison were done circularly. This "circular" analysis is a way of administering the constant comparative strategy and helpful in grounding the emerging theory in the empirical data.

Reliability and validity--related to translation	The interviews will be conducted in two different dialects of Chinese-Mandrin and Taiwanese. These two dialects are both the researcher's mother languages and share the same written characters. Interviews in both dialects should be able to be transcribed correctly. This study will be conducted in Taiwan but will be written up in English. On the other hand, all the existing concepts related to family caregiving were generated in western society and might influence researcher's interpretation and analysis of the data. For these reasons, an Taiwanese medical anthropologist -Dr. Mutsu Hsu-will serve as a consultant to verify the credibility of the coding paradigm, and to increase the theoretical sensitivity to the salient characteristics in the families in Taiwan. Translation will be done by an expert translator who knows both Chinese and English well, and will then be verified by the researcher.	Implemented as proposed. Quality of data related to transcribing and translating process: please see figure 1.	Translations done by the translators and verified by the researcher occurred in the earlier stage of the data collection. High consistency (over 90%) was found when the researcher verified the translations done by the translators. Most of the inconsistency occurred when respondents repeated the content and the translators did not translate word for word. Due to the high consistency between translators and researcher, the later interviews translated by researcher did not need to be verified word by word.

Reliability and validity--related to methodology	Monitoring of audit trails and peer debriefing by committee members at OHSU and an anthropologist in Taiwan will be done. All original and translated raw data, field notes, theoretical notes and memos will be reviewed by committee members, thus increasing the credibility, dependability and confirmability of this study (Lincoln & Guba, 1985). Triangulation data collected from different data sources (nurse, caregiver, care receiver, and nurse aide) will also be used to increase the credibility of this study (Lincoln & Guba, 1985). Prolonged engagement with extended visits, thick data with theoretical sampling, and member checks with participants will help to increase the trustworthiness of the study.	Audit trails were monitored and peer debriefings were conducted by committee members at OHSU and an anthropologist in Taiwan were done. All original and translated raw data, field notes, theoretical notes and memos were reviewed by committee members to increase the credibility, dependability and confirmability of this study. Triangulation data collected from different data sources (nurse, caregiver, care receiver, and nurse aide) were also used to increase the credibility of this study. Prolonged engagement with extended visits, for example, multiple visits to some families and participant observations; thick data with theoretical sampling; and member checks with participants were done to increase the trustworthiness of the study.	

Abuse/Neglect	There are no laws in Taiwan regarding elder abuse. If abuse is detected, the researcher will report it to the home care agency for further assessment and intervention. The management of elder abuse, if detected, will be included in the informed consent.	A suspected elder abuse in a previous hospitalization was described by a caregiver. The situation was reported to the home health care agency. A interview with a cognitively impaired care receiver was postponed due to the presence of signs of being stressed by the questions. Emotional and environmental supports by praising the care receiver and changing to topics which she liked were used to reduce the stress. One neglect case due to caregiver physical limitation and another cognitively impaired elder who hit and was hit by the caregiver were reported to the home health care agency after the interviews. Nursing interventions were given to deal with the situations.	Because this incidence happened two years ago, nothing was done about it. Praising and changing to topics which the care receiver likes were often used and effective strategies were used by her family members to handle her emotional problems. There is no related law pertaining to neglect. For this reason, only nursing interventions can be provided.

Appendix C

The Letters of Support from Home Care Agencies

Novemver 20, 1994

Yea-Ing Lotus Shyu, RN, MS
3F., No.8-1, Ln., 16,
Wen-Chou Street, Tapei

Dear Ms. Shyu,

Your research project "Quality of Family Caregiving to Frail Elders in Taiwan" is an important study to the community health nursing in Taiwan and our nursing department is willing to support you. As a head nurse of this department, I would welcome the opportunity to participate in this research project.

Sincerely yours,

Yu Huei Chen

Yu Huei Chen
Head Nurse of Health Station of Ta-An District

February 20, 1993
1F., No 4-1, Ln 16, Wen Chou Street
Taipei, Taiwan, R. O. C.

Yea-Ing Lotus Shyu, RN, MS
S.W., Campus Dr., Rm 618
Oregon, OR, 97201
U. S. A.

Dear Ms. Shyu,

Your proposed research pilot project "Quality of Family Caregiving to Frail Elders in Taiwan" is a valuable study that our agency supports whole heartily. Our mission at Taipei Home Health Care Nursing Agency is to provide comprehensive quality care to our clients. As an administrator of this agency, I would welcome the opportunity to participate in this pilot study and the following larger study.

I look forward to assist you in collecting data for your study.

Sincerely,

Huey Jane Lee

Huey Jane Lee
Administrator of Taipei Home Care Nursing Agency

Appendix D

Consent Forms for participation

Oregon Health Sciences University

Consent Narrative to be Read to: Family Caregivers

Quality of Family Caregiving to Frail Elders

PRINCIPAL INVESTIGATOR:	Yea-Ing Lotus Shyu, RN, MS, Doctoral student, School of Nursing, Oregon Health Sciences University.
ADVISOR:	Patricia G. Archbold, RN, DNSc, FAAN Professor, School of Nursing, Oregon Health Sciences University.
CONSENT NARRATIVE:	To be used with caregivers who provide care to a frail elder person receiving home health care.

Study Purpose

The purpose of this study is to learn about what people involved in family caregiving think about the quality of family care. Ms. Shyu will be interviewing and observing frail elders, their caregivers, their home health nurses regarding their caregiving experiences.

Procedures

If you agree to participate you will be interviewed, at least once, in your home. The interview will last approximately 1 to 2 hours. You will be asked questions about your caregiving day, the things you do to make the care you provide to [CR] as good as possible, the things you think can be improved, and what you think are the important things for family caregiving.

Confidentiality

The interview will be audio-tape recorded and written notes will be kept. The tapes will be transcribed in Chinese, with all personally identifying information deleted in the transcription process. The audio tapes will be destroyed after the transcription is complete. The transcripts will then be translated into English. The information you share with Ms. Shyu will be handled in a manner to ensure confidentiality. Neither your name nor your identity will be used for publication purposes. Only Ms. Shyu and her faculty dissertation advisors will have access to your responses. In the event, that Ms. Shyu should discover elder abuse, she will report it to the home care agency.

Risks and Benefits

Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which are uncomfortable to you. Participating in this interview may provide some benefits for you. For example, some

caregivers report that talking to someone about their situation is helpful.

Cost of Participation

There is no charge for participating in this study. No reimbursement or compensation will be given to you as the result of your participation in this study.

Your Rights as a Participant

Participation in this research project is completely voluntary. You may refuse to participate and may withdraw from this study at any time without affecting the care you received from Taipei Home Care Agency.

If you have questions about this research, or your rights and responsibilities as a research participant, you should contact Yea-Ing Lotus Shyu at 363-1184.

Name of Participant ______________________________

Narrative read to subject	Yes	No	
Did participant have questions	Yes	No	
Subject questions answered	Yes	No	N/A

Signature of investigator ______________________
Date

Oregon Health Sciences University

Consent Narrative to be Read to: Care Receivers

Quality of Family Caregiving to Frail Elders

PRINCIPAL INVESTIGATOR:	Yea-Ing Lotus Shyu, RN, MS, Doctoral student, School of Nursing, Oregon Health Sciences University.
ADVISOR:	Patricia G. Archbold, RN, DNSc, FAAN Professor, School of Nursing, Oregon Health Sciences University.
CONSENT NARRATIVE:	To be used with elders who receive care from a family member and a home care nurse.

Study Purpose
The purpose of this study is to learn about what people involved in family caregiving think about the quality of family care. Ms. Shyu will be interviewing and observing frail elders and their caregivers regarding their caregiving experiences.

Procedures
If you agree to participate you will be interviewed, at least once, in your home. The interview will last approximately 1 hour. You will be asked questions about your day, the things [CG] does that are good for you, the things you would like to change about your care, and what you think are the important things for family caregiving.

Confidentiality
The interview will be audio-tape recorded and written notes will be kept. The tapes will be transcribed in Chinese, with all personally identifying information deleted in the transcription process. The audio tapes will be destroyed after the transcription is complete. The transcript will then be translated into English. The information you share with Ms. Shyu will be handled in a manner to ensure confidentiality. Neither your name nor your identity will be used for publication or publicity purposes. Only Ms. Shyu and her faculty dissertation advisors will have access to your responses. In the event, that Ms. Shyu should discover elder abuse, she will report it to the home care agency.

Risks and Benefits
Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which are uncomfortable to you. Participating in this interview may provide some benefits for you. For example, some care receivers report that talking to someone about their

situation is helpful.

Cost of Participation

There is no charge for participating in this study. No reimbursement or compensation will be given to you as the result of your participation in this study.

Your Rights as a Participant

Participation in this research project is completely voluntary. You may refuse to participate and may withdraw from this study at any time without affecting the care you received from Taipei Home Care Agency.

If you have questions about this research, or your rights and responsibilities as a research participant, you should contact Yea-Ing Lotus Shyu at 363-1184.

Name of Participant ____________________________________

Narrative read to subject	Yes	No	
Did participant have questions	Yes	No	
Subject questions answered	Yes	No	N/A

Signature of investigator ________________________________

Date

Oregon Health Sciences University

Consent Form: Home Care Nurses

Quality of Family Caregiving to Frail Elders

PRINCIPAL INVESTIGATOR:	Yea-Ing Lotus Shyu, RN, MS, Doctoral student, School of Nursing, Oregon Health Sciences University.
ADVISOR:	Patricia G. Archbold, RN, DNSc, FAAN Professor, School of Nursing, Oregon Health Sciences University.
CONSENT FORM:	To be used with home care nurses who provide home care to the families in the study.

Study Purpose

The purpose of this study is to learn about how persons involved in family caregiving think about the quality of family care. Ms. Shyu will be interviewing and observing frail elders, their caregivers and their home care nurses regarding their caregiving experiences.

Procedures

If you agree to participate you will be interviewed, at least once. The interview will last approximately 1 hour. You will be asked questions about what aspects of the family you are taking care of reflect high quality or problems of family care, and how you know when a caregiving situation is good or problematic.

Confidentiality

The interview will be audio-tape recorded and written notes will be kept. The tapes will be transcribed in Chinese, with all personally identifying information deleted in the transcription process. The audio tapes will be destroyed after transcription is complete. The transcript will then be translated into English. The information you share with Ms. Shyu will be handled in a manner to ensure confidentiality. Neither your name nor your identity will be used for publication or publicity purposes. Only Ms. Shyu and her faculty dissertation advisors will have access to your responses.

Risks and Benefits

Participating in this study will require some of your time. You are free to decline to participate at anytime. Participating in this interview may provide some benefits for you. For example, having the chance to organize and gain insight about how you view the quality of family caregiving may be helpful to you in providing home health care.

Cost of Participation

There is no charge for participating in this study. No reimbursement or compensation will be given to you as the result of your participation in this study.

Your Rights as a Participant

Participation in this research project is completely voluntary. You may refuse to participate and may withdraw from this study at any time without affecting your job at Taipei Home Care Agency.

If you have questions about this research, or your rights and responsibilities as a research participant, you should contact Yea-Ing Lotus Shyu at 363-1184.

Signature ______________________

Date ______________________

Oregon Health Sciences University

Narrative to be Read to: Hired Aides

Quality of Family Caregiving to Frail Elders

PRINCIPAL INVESTIGATOR:	Yea-Ing Lotus Shyu, RN, MS, Doctoral student, School of Nursing, Oregon Health Sciences University.
ADVISOR:	Patricia G. Archbold, RN, DNSc, FAAN Professor, School of Nursing, Oregon Health Sciences University.
CONSENT NARRATIVE:	To be used with caregivers who provide care to a frail elder person receiving home health care.

Study Purpose

The purpose of this study is to learn about what people involved in family caregiving think about the quality of family care. Ms. Shyu will be interviewing and observing frail elders, their caregivers, their home health nurses and hired aide regarding their caregiving experiences.

Procedures

If you agree to participate you will be interviewed, at least once, in the home you are hired. The interview will last approximately 1 hour. You will be asked questions about your caregiving day, how do you work with the family caregiver to take care of the care receiver and the things you think you are important for family caregiving.

Confidentiality

The interview will be audio-tape recorded and written notes will be kept. The tapes will be transcribed in Chinese, with all personally identifying information deleted in the transcription process. The audio tapes will be destroyed after the transcription is complete. The transcript will then be translated into English. The information you share with Ms. Shyu will be handled in a manner to ensure confidentiality. Neither your name nor your identity will be used for publication or publicity purposes. Only Ms. Shyu and her faculty dissertation advisors will have access to your responses. In the event, that Ms. Shyu should discover elder abuse, she will report it to the home care agency.

Risks and Benefits

Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which are uncomfortable to you. Participating in this interview may provide some benefits for you. For example, some

caregivers report that talking to someone about their situation is helpful.

Cost of Participation

There is no charge for participating in this study. No reimbursement or compensation will be given to you as the result of your participation in this study.

Your Rights as a Participant

Participation in this research project is completely voluntary. You may refuse to participate and may withdraw from this study at any time without affecting the care you received from Taipei Home Care Agency.

If you have questions about this research, or your rights and responsibilities as a research participant, you should contact Yea-Ing Lotus Shyu at 363-1184.

Name of Participant ______________________________

Narrative read to subject	Yes	No	
Did participant have questions	Yes	No	
Subject questions answered	Yes	No	N/A

Signature of investigator ______________________________

Date

Oregon Health Sciences University

Consent Narrative to be Read to: Care Receivers & Caregivers

Quality of Family Caregiving to Frail Elders

PRINCIPAL INVESTIGATOR:	Yea-Ing Lotus Shyu, RN, MS, Doctoral student, School of Nursing, Oregon Health Sciences University.
ADVISOR:	Patricia G. Archbold, RN, DNSc, FAAN Professor, School of Nursing, Oregon Health Sciences University.
CONSENT NARRATIVE:	To be used with elders who receive care from a family member and a home care nurse.

Study Purpose

The purpose of this study is to learn about what people involved in family caregiving think about the quality of family care. Ms. Shyu will be interviewing and observing frail elders and their caregivers regarding their caregiving experiences.

Procedures

If you agree to participate you will be interviewed, at least once, in your home. The interview will last approximately 1 to 2 hour for both of you together. You will be asked questions about your day, the things [CG] does that are good for [CR], and the things that can be improved or you would like to change about the caregiving, and what you think are the important things for family caregiving.

Confidentiality

The interview will be audio-tape recorded and written notes will be kept. The tapes will be transcribed in Chinese, with all personally identifying information deleted in the transcription process. The audio tapes will be destroyed after the transcription is complete. The transcript will then be translated into English. The information you share with Ms. Shyu will be handled in a manner to ensure confidentiality. Neither your name nor your identity will be used for publication or publicity purposes. Only Ms. Shyu and her faculty dissertation advisors will have access to your responses. In the event, that Ms. Shyu should discover elder abuse, she will report it to the home care agency.

Risks and Benefits

Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which are uncomfortable to you. Participating in this interview may provide some benefits for you. For example, some

care receivers report that talking to someone about their situation is helpful.

Cost of Participation

There is no charge for participating in this study. No reimbursement or compensation will be given to you as the result of your participation in this study.

Your Rights as a Participant

Participation in this research project is completely voluntary. You may refuse to participate and may withdraw from this study at any time without affecting the care you received from Taipei Home Care Agency.

If you have questions about this research, or your rights and responsibilities as a research participant, you should contact Yea-Ing Lotus Shyu at 363-1184.

Name of Participant ____________________________________

Narrative read to subject	Yes	No	
Did participant have questions	Yes	No	
Subject questions answered	Yes	No	N/A

Signature of investigator ________________________________
Date

Appendix E

Detailed Sample Summary in Each Phase

Study Families, Respondents, Gender & Age, and Date of Interview

Family	Respondent	Gender	Age	Interview 1	Interview 2	Member Check
			Phase 1--Pilot			
Pilot F 1	Care receiver (immobility)[a]	male	77	3/15/94		
	Caregiver	female	77	3/15/94		
	Aide					
	Nurse A	female	34	3/18/94		
Pilot F 2	Care receiver (stroke)[a]	male	65	3/16/94		
	Caregiver	female	65	3/16/94		
	Aide					
	Nurse A	female	34	3/18/94		
			Phase 2--Purposive & Theoretical Sampling			
Family 1	Care receiver (dementia)[a]	male	88	7/24/94	--	--
	Caregiver	female	82	7/24/94	4/15/95	4/15/95
	Aide A	female	52	7/24/94	--	--
	Nurse B	female	32	7/26/94	--	--
Family 2	Care receiver (dementia)[a]	female	80	7/28/94	--	--
	Caregiver 1	female	57	8/17/94	--	--
	Caregiver 2	female	47	7/28/94	--	--
	Caregiver 3	female	44	8/01/94	--	--

Family	Respondent	Gender	Age	Interview 1	Interview 2	Member Check
	Caregiver 4	female	42	7/28/94	--	--
	Caregiver 5	female	38	8/03/94	1/17/95	1/17/95
	Caregiver 6	male	40	8/02/94	2/20/95	2/20/95
	Caregiver 7	female	35	7/28/94	--	--
	Caregiver 8	male	38	8/02/94	--	--
	Aide	--	--	--	--	--
	Nurse A	female	34	8/19/94	--	--
Family 3	Care receiver (dementia)[a]	male	66	10/04/94[b]	--	--
	Caregiver	female	58	10/04/94	2/15/95	2/15/95
	Aide B	female	38	10/04/94	--	--
	Nurse C	female	30	10/24/94	--	--
Family 4	Care receiver (dementia)[a]	male	87	10/08/94[b]	--	--
	Caregiver	female	82	10/08/94	--	--
	Aide C	female	54	10/08/94	--	--
	Aide D	female	35	10/08/94	--	--
	Nurse C	female	30	10/24/94	--	--

Family	Respondent	Gender	Age	Interview 1	Interview 2	Member Check
Family 5[c]	Care receiver (difficulty in swallowing)[a]	male	74	1/20/95	--	--
	Caregiver	female	73	1/20/95	--	1/20/95
	Aide	--	--	--	--	--
	Nurse D	female	42	2/08/95	--	--
Family 6[c]	Care receiver (dementia)[a]	male	69	2/09/95	--	--
	Caregiver	female	68	2/09/95	--	2/09/95
	Aide	--	--	--	--	--
	Nurse E	female	40	2/08/95	--	--

[a] Reason for home health referral. [b] This respondent was unable to respond to interview.

[c] This family was interviewed once for both basic data and theoretical sampling.

Sample Summary

8 Families total

<u>Data from</u>:

CR	6	(2 demented and unable to respond to interview)
CG	15	(8 from one family)
Aide*	4	(2 from one family)
Nurse	5	(one nurse cares for 3 families, a second nurse cares for 2 families)

30 individuals (21 family members, 5 nurses, 4 aides)

<u>Interviews with families</u>

Interview 1	N=8 families
Interview 2	N=3 families (2 caregivers in family 2)
Member check	N=5 families (2 caregivers in family 2)

* Some aides are within family (although paid), others are service providers only.

Appendix F

Interview Guide

Caregiver

I would like to ask you some questions about your experiences in taking care of [CR]. There are no right or wrong answers:

1. I am interested in how your day goes in caring for [CR]. Could you describe a typical day (perhaps yesterday)?

2. When you take care of [CR], what are the things you pay more attention to? What are the things that are most important for you? for the [CR]?

> If you have to leave home to go to some place for a couple days, and someone come to take care of [CR] for you, what would you tell him/her, so that they could do a good job in taking care of [CR] ?

3. When you have limited energy and time, what are the things you will do first and what are the things you will let go? How do you decide? What things do you consider when you make those decisions?

4. Can you identify what things you do for [CR] that are good for [CR]? or the things you do that are effective and the results turn out to be good? What do you think about that? What do you like about the outcome?

5. What are the things you do to make the care you provide to [CR] as good as possible? Why?

6. Can you identify the things you do for [CR] that can be improved or you would like to be changed? Why is that? How would you wish it to be different?

7. I would like to know what you think are the important things for family caregiving? What would you say about a good caregiving? and what things might indicate problematic caregiving?

Do you have anything else you would like to talk about? or other questions that you would like to ask me?

If I have some more questions later, can I call you and come visit you again?

Many thanks for your participation!

Care Receiver

I will ask you some questions about your experiences of being taken cared for by [CG]. There are no right or wrong answers:

1. I am interested in how your day goes in receiving care from [CG]. Could you describe a typical day (perhaps yesterday)?

    I'd like to hear as much as possible about the beginning of the day, when you wake up-to the end of the day, before you fall asleep, for both of you.

2. When you being taken care by [CG], What are the things that [CG] does to take care of you that are most important to you? what things does [CG] pay more attention to? How do you decide?

3. Can you identify the things that [CG] does for you that are good for you or that you like the most? Why is that? How are they good?

4. Can you identify the things [CG] does for you that you would like to change? Why is that? How?

5. What do you think are the important things for family caregiving? What would you say about good caregiving? and what things might indicate problematic caregiving?

Do you have anything else you would like to talk about? or other questions that you would like to ask me?

If I have some more questions later, can I call you and come visit you again?

Many thanks for your participation!

Nurses

I will ask you some questions about how you view the quality of family care. There are not right or wrong answers.

1. If you had to tell another nurse about visiting this family, what would you tell them would be important to know for this family?

2. I am interested to know what aspects of this family situation reflect a high quality of family care?

3. I am interested to know what you think it is about this family that makes the caregiving problematic?

4. How do you decide what is important to look for in terms of the family care quality in this family?

5. In this family, if the caregiver has limited time and energy, what are the caregiving things you think should be viewed as first priority, what are the things you think could be let go, why is that?"

6. In general, when you visit families, what are things you pay most attention to? Why?

7. How do you know when a caregiving situation is a good one? What characteristics does it have?

8. How do you know when a caregiving situation is a problematic one? What characteristics does it have?

Do you have anything else you would like to talk about? or other questions that you would like to ask me?

If I have some more questions later, can I call you and come visit you again?

Many thanks for your participation!

Hired Aide

I would like to ask you some questions about your experiences in taking care of [CR] with [CG]. There are no right or wrong answers:

1. I am interested in how your day goes in caring for [CR]. Could you describe a typical day (perhaps yesterday)?

2. How do you and [CG] work together to take care of [CR]? How do you divide the labor? How much is [CG] involved in the direct caregiving? What else beside these things does [CG] do for [CR]?

3. When you take care of [CR], what are the things [CG] asks you to pay more attention to? What are the caregiving things that concern [CG]?

4. I would like to know what you think are the important things for family caregiving? What would you say about a good caregiving? and what things might indicate problematic caregiving?

Do you have anything else you would like to talk about? or other questions that you would like to ask me?

If I have some more questions later, can I call you and come visit you again?

Many thanks for your participation!

Joint Interview Guide For Caregiver and Care Receiver

I will ask you some questions about your experiences of taking care of [CR] and being taken cared for by [CG]. There are no right or wrong answers:

1. I am interested in the day goes for both of you. Could you describe a typical day (perhaps yesterday)?

> I'd like to hear as much as possible about the beginning of the day, when you wake up-to the end of the day, before you fall asleep, for both of you.

2.
CG. When you take care of [CR], what are the things you pay more attention to? What are the things that are most important for you?

> If you have to go to some place for a couple days, and someone come to take care of [CR] for you, what would you tell them to be careful about in caregiving?

CR. When you being taken care by [CG], What are the things that are most important for you? what are the things you think [CG] pay more attention to?

3.
CG. Can you identify what things you do for [CR] that are good for [CR]? or the changes you made are effective and results turn out to be good? What do you think about that? why?

What are the things you do to make the care you provide to [CR] as good as possible? Why?

CR. Can you identify the things that [CG] does for you that are good for you or you like the most? Why is that?

4.
CG. Can you identify the things you do for [CR] that can be improved or you would like to be changed? Why is that? How would you wish it to be different?

CR. Can you identify the things [CG] does for you that you would like to change? Why is that?

5. I would like to know what both of you think are the important things for family caregiving? What would you say about a good caregiving? and what things might indicate problematic caregiving?

Do you have anything else you would like to talk about? or other questions that you would like to ask me?

If I have some more questions later, can I call you and come visit you again?
Many thanks for your participation!

Focus Interview on "Finding a Balance Point"

From our previous interview, it seemed to me that when you take care of [CR], you often found yourself facing competing needs and needing to find a balance point between meeting these competing needs, For example: [Insert Example]. I would like to talk to you about these caregiving experiences.

1) How do you see "finding a balance point" between competing needs in relation to caregiving?

2) What are the things you need to balance with in caregiving?

3) How do you realize the need for balancing?

4) How do you set your priorities between the competing needs?

5) What are the strategies you used to balance these competing needs?

6) What are the influences of this balancing process on the care you provide?

7) How do you feel about this balancing process?

8) What might be the influencing factors for a successful process of "finding a balance point"?

Do you have anything else you would like to talk about? or other questions that you would like to ask me?

If I have some more questions later, can I call you and come visit you again?

Many thanks for your participation!

Quality of Family Caregiving to Frail Elders

Telephone Recruitment of Potential Subjects

Sample Script

Hello, I am calling to speak to (CAREGIVER). My name is Shyu, Yea-Ing. Ms. (home care nurse) talked with you about me? I am a PhD nursing student working on my research project about family care. Is this a convenient time for you to talk?

(If it is not convenient, ask when you might be able to call them back)

I am interested in family caregiving situations for disabled elderly persons at home. I would like to talk to you about how you take care of [Care Receiver] and your opinions about family caregiving. I would also like to talk to [Care Receiver] about his/her daily activities and his/her experience of being taking care of. I would like to interview you and [Care Receiver] separately if possible. The interview will be about 1 hour for each of you.

A lot of families are taking care of disabled elderly members at home like your family. The findings of this study may help home care nurses to better understand family caregiving situations and provide appropriate services.

Do you have any questions about the study? Does this sound like something you would like to participate in?

> (If the caregiver declines to participate, try to determine her reason for refusing. Then thank her for her time and wish her well.)

I would like to be able to interview at a time that is convenient for you, and for [Care Receiver]. I can come twice to interview you and [Care receiver] separately, if it is more convenient for you. What would be a convenient time for me to come?

Date: ________________________________

Time: ________________________________

Quality of Family Caregiving to Frail Elders

Follow-up Telephone Contact for Further Information

Sample Script

Hello, I am calling to speak to (CAREGIVER). I am Shyu, Yea-Ing. I interviewed you about _____ months or weeks ago about family caregiving, do you remember?

At our last interview, you said that I could call you or visit you again if I have some more questions to ask you. Are you still willing to meet with me? I have a few questions that I would like to talk with you more about.

> (If the caregiver declines to participate, try to determine her reasons for refusing. Then thank her for her time and wish her well.)

What would be a convenient time for me to come?

Date: ______________________________

Time: ______________________________