DEVELOPMENT OF
THE JAPANESE FAMILY CAREGIVING INVENTORY

by

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ABSTRACT

Title: Development of the Japanese Family Caregiving Inventory

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This dissertation reports findings from a methodological study to develop the Japanese version of the Family Caregiving Inventory. The questionnaire, Japanese Family Caregiving Inventory (JFCI), measures negative and positive aspects of family caregiving in Japan.

Most of the JFCI is a translation of Archbold and Stewart's Family Caregiving Inventory (FCI). Scales on the FCI have been found to be reliable and have evidence to support their validity, having been tested with caregivers of several different older populations in the United States. Caregiving concepts measured by scales in the FCI were verified within Japanese caregiving situations and two new measures for concepts important in caregiving in Japan but for which no measures currently exist were developed. The JFCI was constructed to combine the Japanese translation of the FCI and two new Japanese measures.

The content validity of the JFCI was reviewed by 10 Japanese nurses. All 10 reviewers agreed that most of items met the criteria for belonging to the label and definition of the concept and for fitting Japanese caregiving. Of the 212 items, there were only four items identified as problematic by three or more reviewers. Based on suggestions from the reviewers, a part of the definition of one item was reworded and the wording of three items was modified.

An invitation letter was sent to a total of 392 family caregivers and 354 of them agreed to participate in the study. Data were collected using a mailed questionnaire design. Of the 354 family caregivers who received a questionnaire, 238 returned their responses and 224 questionnaires were usable. The psychometric properties of data from these 224 questionnaires were evaluated.

Age of caregivers ranged from 34 to 87 years (M = 63.4), most were married and female, more than two-thirds were not employed, and nearly all caregivers lived with the care receiver. Age of care receivers ranged from 65 to 101 years (M = 80.8), about half were female and married. Stroke was the most common medical diagnosis followed by dementia, hypertension, and Parkinson's Disease.

In total, 22 scales on the JFCI measured caregiving concepts and 6 scales measured caregiver health. Internal consistency reliability (Cronbach's alpha) estimates for 28 scales ranged from .53 to .96. Evidence supporting construct validity of the scales was obtained through testing hypothesized relationships between measures. The findings of this study are consistent with findings in the United States. Caregivers received some rewards through providing care for the older person and such rewards can reduce some aspects of role strain that caregivers felt. The caregiver's perception of the high quality of a relationship between the caregiver and care receiver can also reduce some aspects of role strain that caregivers felt. Caregivers who perceived themselves as well prepared for caregiving and their caregiving situations as highly predictable also expressed less strain on some of the Caregiver Role Strain scales. Some unexpected but interesting findings were also obtained about correlations of the Role Strain from Interpersonal Relationships within *Miuchi* scale with the Mutuality scale and with the three Rewards scales.

TABLE OF CONTENTS

Introduction

This dissertation contains two main papers and several appendices describing a study designed to develop and evaluate the Japanese Family Caregiving Inventory (JFCI). The two papers were prepared for publication and the appendices include aspects of the work that are not in the papers. Following is a brief summary of each paper and appendix.

Paper 1: Development of the Japanese Family Caregiving Inventory: Concept Verification and Translation Results

Paper 1 describes the process of developing the Japanese Family Caregiving Inventory (JFCI). First, caregiving concepts identified in the United States were verified in Japanese caregiving situations, and concepts specific to Japanese caregiving situations were identified. Then, a draft of the JFCI was constructed through translation and back-translation processes and content validity of this draft was examined. Based on evidence from content validity evaluation, the final version of the JFCI was constructed.

Paper 2: Development of the Japanese Family Caregiving Inventory: Psychometric Evaluation

Paper 2 describes the psychometric evaluation of measures within the JFCI using data from 224 Japanese family caregivers. Reliability and construct validity of caregiving scales in the JFCI were examined. Results indicated that the internal consistency reliability of each scale was at an acceptable level and evidence of construct validity was obtained through testing of hypotheses. Implications of the findings and some recommendations for further research were discussed.

Appendix A: Support for Concept Verification in Japanese Data Bits

This section describes the results from content analysis of data in Japanese books written by caregivers. Examples of the data bits are presented to illustrate the existence of caregiving concepts identified in U. S. samples and new concepts found in the Japanese books but not previously identified in U. S. samples.

Appendix B: Content Validity Questionnaire

A copy of the content validity questionnaire is included in this section. The draft of the JFCI was systematically reviewed by 10 Japanese experts in the area of gerontological nursing, family nursing, and measurement. Each of them was asked to complete the questionnaire. The questionnaire contained questions to examine whether each measure fit the definition of the concept, how well the items covered the content of the concept, whether each measure fit Japanese caregiving situations, and how clear each item and explanation were. The questionnaire was translated into Japanese.

Appendix C: The Japanese Family Caregiving Inventory

The JFCI is 32-page self-administered questionnaire. Copies of both English and Japanese language versions of the JFCI are included in this section.

Appendix D: Protection of Human Subjects

No formal consent form was used for this study. Return of the questionnaire implied consent. A copy of the cover letter which accompanied the questionnaire is included in this section along with discussion of issues related to protection of human subjects. A copy of the form used by participants to request a summary of the study findings is also included. The cover letter and request form were translated into Japanese.

Appendix E: Review of the Research Literature

This section contains summary tables of some English and Japanese research literature related to family caregiving.

Paper 1

Development of the Japanese Family Caregiving Inventory: Concept Verification and Translation Results

Every developed country is dealing with issues related to care for older persons. Japan is no exception. As a matter of fact, Japanese society is the most rapidly aging population in the world. In 1965, 6.3% of the people in Japan were over age 65. The aged population doubled (12.6%) in 1991 and will double again (25.2%) by 2020 (Health and Welfare Statistics Association, 1992). Thus, care for older persons has been attracting considerable social attention in Japan.

The number of publications and media reports related to elder care has been increasing. Research on family caregiving for older persons, however, has just started in Japan. The majority of research publications in this area have been demographic surveys and case studies. Even though these studies have provided important information regarding the issues of family caregiving for older persons, there has been little research focused on identifying concepts central to family caregiving, or showing how the concepts are related. Developing measures to examine the relationships among the concepts central to the family caregiving is, therefore, essential to understanding the phenomenon related to family caregiving in Japan.

This is the first of two papers describing the development and evaluation of the Japanese Family Caregiving Inventory (JFCI). This paper summarizes Phase 1 of the study, which focused on four specific aims: 1) to verify that the concepts measured by scales in the English-language Family Caregiving Inventory (Archbold & Stewart, 1986; Archbold & Stewart, personal communication, 1994) are relevant concepts within Japanese caregiving situations, 2) to construct measures for concepts that are thought to be central to Japanese family caregiving by translating existing English-language measures, 3) to develop new measures for concepts important in caregiving in Japan but for which no measures currently exist, and 4) to examine the content validity of these Japanese measures. The second paper will report on the psychometric evaluation of scales within the JFCI.

The Theoretical Basis for the Study

Stress and coping theory (Lazarus & Folkman, 1984; Stephens, Crowther, Hobfoll, & Tennenbaum, 1990), exchange theory (Burgess & Huston, 1979; Cook, 1987; Gergen, Greenberg, & Willis, 1980), and role theory (Biddle & Thomas, 1966; Burr, Leigh, Day, & Constantine, 1979) have been the frameworks most commonly used to study family caregiving in the United States. In Japan, stress and coping theory has been used in research on family caregiving (Niina, Yatomi, Honma, & Sakata, 1989; Sugisawa, Nakamura, Nakano, & Sugisawa, 1992). From these theories, role theory was chosen as a framework for this study for several reasons. Stress and coping theory focuses on the individual, in contrast to role theory and exchange theory which focus on interactions between an individual and other persons. Caregiving situations are minimally dyadic and very complex; focusing only on the individual provides a limited perspective. In addition, stress and coping theory views caregiving as a stressful, and therefore negative experience in contrast to role theory and exchange theory, which views caregiving as both positive and negative experiences.

Exchange theory explains caregiving as activities that a person performs to pay back previous debts. This theory has been used to examine relationships between adult children caregivers and their impaired elderly parents in the United States (e.g., Ingersoll-

Dayton & Antonucci, 1988; Walker & Allen, 1991; Walker, Martin, & Jones, 1992). In Japan, daughters in-law, in particular the first son's wife, are still the main caregivers and their caregiving role is prescribed by cultural norms (Fujita & Kuroda, 1987; Nakajima, Abe, et al., 1982, Nakajima, Saito, & Tsukihashi, 1982; Noguchi, 1988; Saito, Ogino, & Kaneko, 1989; Sato, 1989; Takasaki, Nogawa, Sasaki, Yasuda, Uchida, & Ito, 1987; Waki et al., 1984). Exchange theory does not apply in the same way as it has been applied to caregiving by researchers in the United States. Even though exchange theory has been applied to examine general relationships among Japanese people, such as their custom of gift giving, the concept of exchange does not currently apply to most caregiving situations because the assumption of the caregiving role, first by the daughter-in-law if there is one and then by the daughter, is a cultural expectation.

In contrast, role theory is a useful framework for studying caregiving in Japanese culture. The Japanese culture is often described as a role dominated culture. Lebra (1976) referred to the individual as having the character of "a set of intra-individual overlaps occurring around a cluster of roles that he plays" (p. 250). She suggested that the individual is associated more with "role-cluster personality" than with "basic personality," and this is especially significant in Japan. In Japanese culture, it is very important to know what the appropriate role to be taken is, how to learn aspects of the role, how and when to play the role, and to have the ability to perform the role. For example, a daughter-in-law will take her position in the three-generation household when she marries the first son. She will also take on the role of caregiver for her mother-in-law because of the cultural norms.

Concepts for the Japanese Measures

The conceptualization of caregiving based on role theory used by Archbold (1982) and her colleagues (Archbold & Stewart, 1991; Archbold, Stewart, Greenlick, & Harvath, 1990; Archbold, Stewart, Harvath, & Lucas, 1986) was used to guide the study. Their concepts are mainly derived from role theory and focus on not only the negative consequences of caregiving but also the positive consequences of caregiving. Their measures have been found to be reliable and have evidence to support validity, having been tested with caregivers of several different older populations. Because concepts and items for their measures were derived largely from qualitative data gathered from caregivers, the possibility of clinical application of their measures is high.

The concepts selected from Archbold and colleagues' conceptual framework of family caregiving fall into three broad categories as shown in Figure 1: antecedents of caregiving, the nature of the caregiving role assumed, and responses to caregiving. Archbold and Stewart (1986) developed a questionnaire called the Family Caregiving Inventory (FCI) to measure these concepts. Caregiving studies conducted in the United States and Japan were reviewed based on the main caregiving concepts that were included in the FCI. Those concepts are the amount of care (the amount and type of direct and managed caregiving tasks done by the caregiver for the care receiver), mutuality (the positive quality of the relationship between a caregiver and a care receiver), predictability of the caregiving situation (regularity and routineness of caregiving activities), preparedness for caregiving (feeling prepared to provide care), rewards of caregiving (positive aspects of caregiving), caregiver role strain (felt difficulty in fulfilling the caregiving role), and amount of negative life style change (amount of change in the caregiver's daily life because of caregiving).

Amount of Care

The amount of care consists of all the caregiving activities which caregivers actually perform in helping their care receivers. Some researchers (Montgomery, Gonyea, & Hooyman, 1985; Moritz, Kasl, & Berkman, 1989) focus mainly on assistance with activities of daily living (ADL) and instrumental activities of daily living (IADL), in spite of results indicating that caregiving tasks usually go beyond ADL and IADL assistance. Others (Albert, 1991; Archbold, 1980; Archbold, et al., 1986; Bowers, 1987; Oberst, Thomas, Gass, & Ward, 1989) include not only ADL and IADL, but also other caregiving activities, such as medical/nursing treatments, monitoring and reporting, emotional support, behavior management, activities to meet possible needs of a care receiver, managed caregiving, and additional household tasks.

Archbold and colleagues (Archbold, et al., 1986) defined the nature of the caregiving role as "the amount and type of direct and managed caregiving tasks performed by the caregiver for the care receiver" (p. 6). Their measure is comprehensive and includes: 1) personal care; 2) protection; 3) management of behavior problems; 4) medically-related tasks; 5) housekeeping; 6) transportation; 7) financial, legal, and health decision making; and 8) little extras. Results of several survey studies in Japan indicated how much help care receivers needed (Department of Welfare, Tokyo Metropolitan Government, 1980; Matsumoto, Onakado, 1990; Matsumoto, Onakado, Inoue, & Yokoyama, 1985; Nakajima et al., 1982; National Organization of Local Welfare

Commissioners, 1987), but did not study how much help caregivers actually provided. Despite the lack of measures of help provided, the concept of amount of care does appear relevant to caregiving in Japan.

Mutuality

Several studies have indicated that the quality of the relationship between a caregiver and a care receiver is an important aspect of caregiving. Some studies (Archbold, et al., 1986; Hirschfeld, 1978) have used mutuality as a concept to describe the positive quality of the relationship and others have used different concepts such as affection (Horowitz & Shindelman, 1983), social ties (Okun, Melichar, & Hill, 1990), psychological attachment (Cantor & Hirshorn, 1989), marital closeness (Motenko, 1989), emotional investment in the relationship (Pruchno & Resch, 1989), and intimacy (Walker, et al., 1992).

Hirschfeld (1978) defined mutuality as the quality of the dyadic relationship. She considered mutuality as "the major parameter for families managing life with senile brain disease" (p. 77). She also described two important components of mutuality, "the caregiver's ability to find gratification in relationship with the impaired person and meaning from caregiving situation" and "the caregiver's ability to perceive the impaired person as reciprocating by virtue of his or her existence" (p. 77). Archbold and colleagues (Archbold, et al., 1986) also identified the concept of mutuality as representing the positive quality of the relationship between a caregiver and a care receiver.

Horowitz and Shindelman (1983) defined affection as "the quality of the caregiver-older relative relationship as perceived by the caregiver. It is the degree to which the latter has positive feelings towards the older person and experiences their relationship as close and enjoyable" (p. 9). The higher level of affection indicated caregivers felt close to, enjoyed spending time with, and had been able to confide in their care receivers. Okun and colleagues (1990) studied the concept of social ties, which referred to the amount of positive and negative social interactions and the degree of enjoyment with the interaction. Walker and colleagues (1992) used the concept of intimacy to examine good relationships between care receiving mothers and their caregiving daughters. Motenko (1989) used the concept of marital closeness, and Pruchno and Resch (1989) used the concept of emotional investment in the relationship in their studies of the relationships between wife caregivers and their care receiving husbands. In their theoretical and critique paper, Cantor and Hirshorn (1989) suggested that the psychological attachments which bond people to each other are the most elemental level of motivating factors for caregiving. They included concepts of love, hate, affection, intimacy, nurturance, and the positive and negative aspects of dependency in psychological attachment.

In Japan, Shimizu (1989) acknowledged the importance of studying relationships between caregivers and care receivers and other family members. However, he did not include the concept in his study because of a methodological difficulty that he did not explain in detail. Based on findings about help-seeking behavior in Japanese older persons, Inoue (1983) suggested that it is important to study relationships between caregivers and care receivers. The results indicated that older persons considered the quality of the past and present relationships with that person in deciding what kind of help they could seek from another person.

Oi and colleagues (Oi et al., 1984) were interested in the quality of relationships between caregivers and care receivers as a contextual factor for psychotic manifestations in bedfast elderly persons. Nakajima and colleagues (Nakajima et al., 1982) examined the relationship between a caregiver and a care receiver by asking whether caregivers thought their relationship with the care receivers were good. Even though researchers have acknowledged the importance of studying the quality of the relationship between caregivers and care receivers, this concept is not well developed in Japan.

Preparedness for Caregiving

The purpose of many interventions for caregivers is to increase their knowledge about diseases and caregiving situations, and skill in providing care and managing their own stress (Glosser & Wexler, 1985; Greene & Monahan, 1989; Haley, Brown, & Levine, 1987; Kahan, Kemp, Staples, & Brummel-Smith, 1985; Toseland, Rossiter, & Labrecque, 1989). An assumption underlying these interventions is that a person can better deal with a problem if he or she has enough knowledge about the situation and has skills in care provision and coping. The results from such intervention studies have been varied, but overall, receiving and sharing information and learning stress management skills have produced positive effects for caregivers.

Role theory emphasizes anticipatory socialization -- learning a role prior to entering it. It is assumed that learning about norms, values, and appropriate behavior in the new role before performing it makes the transition into that role easier (Burr, et al., 1979). This learning process is referred to as anticipatory socialization. Harvath and colleagues (Harvath, Archbold, Lucas, & Stewart, 1986), however, have questioned anticipatory socialization based on their findings that caregivers learned most parts of the caregiving role while in the role.

Instead of anticipatory socialization, Archbold, Stewart and colleagues "focused on caregivers' appraisal of how well-prepared they are, no matter when they learned the role" (Archbold, Stewart, Greenlick, & Harvath, 1992, p. 329). They (Stewart, Archbold, Harvath, Nkongho, 1993) used a concept of role acquisition that refers to "the way in which family caregivers learn about various aspects of the role of caregiver" (p. 219). Theoretically, even though family caregivers learn their caregiver role "both prior to and during role occupation" (p. 220), their study results suggested that "acquisition of the caregiver role occurs primarily after entering into the role" (p. 220). Thus, they defined the concept of preparedness as "how well prepared the caregiver believes he or she is for the tasks and stress of the caregiving role" (Archbold, et al., 1990, p. 328).

Based on their previous studies, Archbold and Stewart (1991) placed preparedness as a part of the nature of caregiving role assumed in their conceptual framework. However, their ongoing longitudinal study of spousal caregiving to people with early-stage Parkinson's Disease suggests that even though two-thirds of spouses did not yet view themselves in the role of caregiving, they could answer questions about their preparedness to provide care (Archbold and Stewart, personal communication, 1994). Based on these findings, they have moved the concept of preparedness to the category of antecedents of caregiving in their conceptual framework (Archbold and Stewart, personal communication, 1995).

In caregiving studies, concepts similar to preparedness have been used, including mastery, competence, and self-efficacy. Pearlin, Mullan, Semple, and Skaff (1990) defined mastery as "the control that individuals feel they are able to exercise over forces importantly affecting their lives" (p. 589) and competence as caregivers' self rating of "the adequacy of their performance as caregivers" (p. 589). Lawton, Kleban, Moss, Rovine, and Glicksman (1989) also used the concept of mastery. They defined caregiving mastery as "a positive view of one's ability and ongoing behavior during the caregiving process" (p. P62). Haley, Levine, Brown, and Bartolucci (1987) used the concept of self-efficacy as a part of caregivers' subjective appraisals of caregiving stressors. They defined self-efficacy as confidence regarding how well caregivers were managing caregiving problems. Even though these concepts are very similar to the concept of preparedness, slight differences exist. The definition of mastery by Pearlin and colleagues includes "control", but "well-prepared" does not encompass the notion of "control". Their definition of competency includes "adequacy", suggesting that external criteria must be met, whereas "feeling well-prepared" does not require meeting external criteria. The definition of mastery by Lawton and colleagues includes "positive view of ongoing behavior" that is not necessarily preparedness, but could be "self-approval." The concept of self-efficacy used by Haley and colleagues is most similar to the concept of preparedness. However, "managing caregiving problems" in their definition reflects a narrower view of the caregiving role than the definition of preparedness, which refers to the "tasks ... of the caregiving role."

Although there are some educational and training sessions for caregivers to prepare for caregiving in Japan, no Japanese research on the concept of preparedness for caregiving or related concepts was located.

Predictability of the Caregiving Situation

Archbold and Stewart (personal communication, 1993) defined predictability of caregiving situations as the caregiver's perception of regularity of activities or the establishment of routines within the caregiving experience. Other researchers have used concepts similar to predictability, including controllability (Dimond & Jones, 1983; Heckhausen & Baltes, 1991; Kuhl 1986; Rodin, 1986; Schulz, 1976) and uncertainty (Christman, 1990; Piper & Langer, 1986).

A difference between controllability and predictability is that having control over a situation also means that it is predictable. However, predictable situations are not necessarily controllable. If a situation is uncertain, it is also unpredictable and uncontrollable. Kuhl (1986) indicated that social norms related to aging encourage a more passive attitude toward life, and in some cultures or subcultures, this social pressure toward passivity may be strong enough to determine a person's behavior.

In the Japanese culture, one of the strongest factors determining a person's behavior is social expectation (Benedict, 1946). In a cross-cultural study comparing attitudes of women in the United States and Japan (Campbell & Brody, 1985), Japanese women were more likely than American women to feel that they have little control over the things that happen to them. At the same time, Japanese caregivers feel stress about unpredictability in their future (Takasaki et al., 1987). These data indicate that predictability, more than controllability, may be an important concept for research with Japanese caregivers.

Rewards of Caregiving

Even though most studies related to caregiving for elderly persons have focused on the negative aspects and consequences of caregiving, some researchers have documented its positive aspects (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Hinrichsen, Hernandez, & Pollack, 1992; Motenko, 1989; Walker, et al., 1992).

Archbold and Stewart (personal communication, 1993) studied the positive consequences or benefits of caregiving for the caregiver; they call this concept rewards of caregiving. They identified three dimensions of rewards of caregiving: 1) rewards of meaning, 2) rewards of learning, and 3) financial rewards.

Farran and colleagues (1991) conducted a qualitative study to search for an explanation of how caregivers might grow and find meaning through the caregiving experience. They critiqued the stress and coping paradigm, the most commonly used theoretical framework in caregiving research, because outcomes of caregiving within this theory have been viewed as negative. Farran and colleagues used existentialism, which suggests that a person finds meaning through suffering, as a theoretical framework for their study. They found that four themes characterized caregivers' responses to caregiving: 1) valuing positive aspects of relationships and caregiving, 2) making personal choices about life and caregiving, 3) searching for provisional meaning, and 4) searching for ultimate meaning.

Hinrichsen and colleagues (1992) conducted a content analysis of responses to open-ended questions with family caregivers and found three categories of rewards. Their rewards categories were: 1) relationship with the patient -- includes improvement in the relationship with the patient, greater appreciation of the patient as a result of caregiving, and satisfaction in seeing the patient's improvement; 2) relationship with self -- includes the caregiver's satisfaction over having fulfilled an obligation, feelings of growing as a person as a result of caregiving, and general satisfaction from helping another person, and; 3) relationship with others -- includes improvement of relationships with other family members in the course of caregiving and satisfaction from interaction with the health care system.

Motenko (1989) examined the concept of gratification which they define as a caregiver's experience of moments of warmth, comfort, and pleasure through caregiving. She was specifically interested in the quality of the spousal relationship, such as whether a caregiver's marriage relationship is enjoyable, and whether a caregiver perceives any aspect of having the care receiver at home as pleasurable.

Walker and colleagues (1992) studied outcomes of caregiving for elderly mothers and their caregiving daughters based on exchange theory. They examined the data for both positive and negative outcomes of caregiving (i.e., benefits and costs) but found only negative outcomes in caregiving in daughters. As they stated, they might not have represented the domain of positive outcomes in their questions. They suggested a need for more work in conceptualizing and measuring benefits of caregiving.

In their questionnaire, Nakajima and colleagues (Nakajima et al., 1982) asked Japanese caregivers whether they had experiences in which they learned something from their care receivers. Their question is related to the concept of rewards of learning. However, it is a single item and does not capture the complexity of the concept of rewards of learning.

Sugisawa and colleagues (Sugisawa, et al., 1992) studied the relationships between the Japanese caregiver's life satisfaction and the care receiver's health status and characteristics of the caregiver (e.g., existence of a secondary caregiver, social support, economic status). They asked the caregiver whether he or she is happy in providing care for the elderly person. Their question is related to the concept of rewards of caregiving. However, it is an open-ended question and the findings from this question were not reported.

Caregiver Role Strain

Many researchers have studied the negative effects of caregiving on caregivers; however, they have used different names to describe it. Many of these researchers have used the term "burden" (Deimling & Bass, 1986; Fitting, Rabins, Lucas, & Eastham, 1986; George & Gwyther, 1986; Kosberg, Cairl, & Keller, 1990; Miller, McFall, & Montgomery, 1991; Montgomery, Gonyea, et al., 1985; Montgomery, Stull, & Borgatta, 1985; Morycz, Malloy, Bozich, & Martz, 1987; Pearson, Verma, & Nellett, 1988; Poulshock & Deimling, 1984; Pratt, Schmall, Wright, & Cleland, 1985; Vitaliano, Maiuro, Ochs, & Russo, 1989; Vitaliano, Russo, Young, Becker, & Maiuro, 1991; Zarit, Reever, & Bach-Peterson, 1980; Zarit, Todd, & Zarit, 1986; Zarit, Antony, & Boutselis, 1987), while others have used the term "strain" (Archbold, Stewart, Harvath, et al., 1986; Cantor, 1983; Mui, 1992; Robinson, 1983; Scharlach, 1987; Scharlach & Boyd, 1989), and "stress" (Deimling, Bass, Townsend, & Noelker, 1989; Green, Smith, Gardiner, & Timbury, 1982; Lieberman & Kramer, 1991; Stephens, Kinney, & Ogrrocki, 1991). Whatever these negative effects are called, they are often overlapping and usually include several factors such as physical and emotional responses, effects on family life, and difficulties in performing caregiving tasks. Clear definitions of each concept are needed because the similarity of meanings and difference of names can be confusing.

The concept of burden has been widely used in caregiving research especially after Zarit and his colleagues published their early work (1980). Zarit's framework is based on the stress and coping model of Lazarus and Folkman (1984). He developed the 29-item Burden Interview which measures discomfort caused by problematic caregiving situations (Zarit et al., 1980). He assumed that this discomfort placed burden upon the caregiver. Some researchers (Montgomery, Gonyea, et al., 1985, Poulshock & Deimling, 1984) criticize Zarit's measure because it did not distinguish between subjective and objective burden. They conceptually and instrumentally adapted parts of Zarit's work and studied both subjective and objective burden. George and Gwyther (1986) defined burden as the physical, psychological or emotional, social, and financial problems that can be experienced by caregivers. They conceptualized burden and well-being as two sides of the same coin and developed an instrument to measure well-being in order to examine caregiving burden. Even though Zarit (1990) acknowledges that researchers have operationalized burden differently, he stated that its common use is "the sense that care demands had overwhelmed the person's emotional, physical and financial resources for providing assistance" (p. 13).

Both stress and strain are sometimes used interchangeably or unclearly with burden (Vitaliano et al., 1989; Vitaliano, Young, & Russo, 1991), and stress and strain are also sometimes used interchangeably (Abel, 1990). Stress tends to be used more as a general term to describe the negative effect of caregiving. Using the stress process as a conceptualization, Zarit (1990) differentiated dimensions that various researchers had measured and assigned their measures to the categories of stressors, appraisal, coping, and outcome. His categorization has clarified the measurement of concepts of stress.

Sometimes strain is used as a general term in the same way as stress; sometimes it is used in a more specific way. It is important to clarify which way the concept of strain is being used based on its definition and underpinning theory. For example, Selye (1976) used "stressor" to refer to the cause of being worn out and "stress" to the effect of being worn out. Then he stated that "stressor" and "stress" in biology and medicine respectively correspond to "stress" and "strain" in physics. Knapp (1988) suggested that researchers use Selye's definition of stress and eliminate the use of strain in research on biological and psychological stress so that confusion would not occur.

In contrast to Selye's perspective, the concept of strain, as derived from role theory (i.e., role strain), is defined more specifically. The concept of role strain was developed and defined by Goode (1960) as the felt difficulty in fulfilling role obligations.

Burr and colleagues (1979) explained Goode's definition of role strain as "the stress generated within a person when he/she either cannot comply or has difficulty complying with the expectations of the caregiving role or his/her set of roles" (p. 57). They conceptualized role strain as a specific stress.

Archbold and Stewart conceptualized caregiver role strain based on Goode's work (Archbold, et al., 1986). They defined role strain as the caregiver's felt difficulty in performing the caregiver role (Archbold et al., 1990). They developed nine measures of Caregiver Role Strain and adapted two measures, Increased Tension and Feelings of Being Manipulated, from Montgomery and Borgatta's measures (Archbold, et al., 1986, 1990). Their measures are 1) Strain from Direct Care, 2) Strain from Managed Care, 3) Strain from Lack of Resources, 4) Strain from Worry, 5) Strain from Role Conflict, 6) Strain from Economic Burden, 7) Strain from Mismatched Expectation, 8) Strain from Increased Tension, 9) Strain from Feelings of Being Manipulated, 10) Strain from Communication Problems, and 11) Global Strain. Two measures, Strain from Direct Care and Strain from Managed Care, are associated with specific caregiving tasks and the others measure strain relate to the overall caregiving situation.

Several studies have been conducted to examine negative consequences of caregiving in Japan. However, their conceptual bases were not well described. Nakajima and colleagues (Nakajima et al., 1982) studied members of a Japanese support group for caregivers of demented older persons. They reported that the two most difficult problems for caregivers were 1) absence of a person who could help to provide care and 2) lack of sleep. Archbold and Stewart included these two problems in their measure of the caregiver role strain from lack of resources.

A series of survey studies with impaired elderly persons and their family caregivers have been conducted by sociologists, psychologists, and psychiatrists (Maeda & Shimizu, 1984; Shimizu, 1981; Shimizu & Honma, 1978; Shimizu et al., 1989) in a metropolitan area of Tokyo. The first study focused on objective difficulties of caregiving and the second one focused on subjective difficulties of caregiving. In the third, researchers developed a 10-item scale to measure subjective difficulties of caregiving and ran factor analysis. They found two factors -- a caregiver related factor (i.e., lack of manpower, conflict with a job, and economic burden) and a care receiver related factor (i.e., behavior problems and physical functional problems). Shimizu (1991) studied the concept of burnout among the Japanese family caregivers of older persons with dementia based on the stress-coping theory. He used the Maslach Burnout Inventory; however, further examination is needed before applying this measure with the concept to Japanese family caregivers because the investigators did not find evidence to support the reliability and validity of the instrument.

Nakatani and Tojo (1989) developed the Subjective Burden scale (SBS) which is a 12-item measure that examines subjective burden of caregiving for demented older persons. The SBS includes six dimensions: 1) anxiety, 2) fatigue, 3) relationships with other persons, 4) restrictions of social activities, 5) demand for freedom from caregiving, and 6) lack of caregiving will. Based on their study, the sixth dimension, lack of caregiving will, was separated from the SBS and became a 2-item scale of willingness to continue caregiving (Sakata, 1989).

Another study (Niina, et al., 1989) was conducted to explore factors which influenced subjective burden in caregivers of demented older persons and to examine the relationship between subjective burden in caregiving and the stress response. Based on the Burden Interview (Zarit, Orr, & Zarit, 1985) and the Caregiver Strain Index (Robinson, 1983), the researchers developed the Caregiving Burden Scale (CBS) to examine subjective burden in caregivers for demented older persons. The CBS includes nine dimensions: 1) burden from helping with activities of daily living (ADL), 2) managing dementia symptoms, 3) concern about the future, 4) caregiving related trouble with family and/or relatives, 5) restrictions in daily and/or social life, 6) physical health problems, 7) mental health problems, 8) financial burden, and 9) lack of social services. Later, they studied relationships between these dimension and social support, and suggested that emotional support could be a predictor of lower caregiving burden (Niina, Yatomi, & Honma, 1991). Niina and colleagues (Niina, Sakata, Yatomi, & Honma, 1990) developed a scale to examine psychological stress responses. However, applicability of the scale to older population is questionable because all participants in their study were college students and adults in middle age.

All of the dimensions identified by Japanese researchers are included in the concepts of caregiver role strain used by Archbold and Stewart, except burden from "relationships with other persons" and "caregiving related trouble with family and/or relatives." The investigator identified a similar concept, caregiver role strain from relationships with other family members through content analysis of books by Japanese caregivers that will be discussed later. This concept may be related to the Japanese culture.

Amount of Negative Life Style Change

Archbold and colleagues (Archbold, et al., 1986) defined amount of negative life style change as the amount of change in the caregiver's daily activities required by the caregiving role. They used a measure developed by Montgomery and Borgatta (undated) to measure objective burden.

In Japan, results of several studies (Nakajima et al., 1982; Niina et al., 1989; Noguchi, 1988; Takasaki et al., 1987) indicated that negative life style change is one of the important concepts related to family caregiving, and examined this concept as a part of difficulties in caregiving and/or caregiver burden. A limitation of these studies is that the definitions of the concepts are not clearly stated. Even though different researchers categorized their items under one concept, they used different terms to refer to the concept (e.g., difficulties of caregiving, subjective burden, caregiving influences on life). Further, a wide range of items (e.g., role conflict, economic burden, relationship difficulties, the negative life style change) were included under this one concept.

Archbold and Stewart conceptualized the concept of amount of negative life style change as one characteristic that accompanies assumption of the caregiving role. In contrast, Japanese researchers have conceptualized their concept as responses to caregiving. It can be argued either way -- the change occurs because of caregiving or the change occurs along with caregiving.

In summary, studies of caregiving reported in the United States and Japanese literature were reviewed. The review suggested that the caregiving concepts identified by Archbold and Stewart are important to study in both countries to expand understandings of family caregiving. However, using a concept cross-culturally requires concept verification in the target culture.

Concept Verification and Identification in Japanese Family Caregiving Situations

Using measures in cross-cultural research requires consideration of several issues. The first issue is whether the concepts of interest exist in the target culture. In order to proceed with the study, the concepts must be shared by the two cultures. Further, "when measuring a concept or construct across cultures, both cultural groups should agree on the properties and characteristics that encompass the concept. In addition, culture-specific differences need to be identified" (Munet-Vilaro, 1988, p. 113). Munet-Vilaro suggested "the use of an emic/etic approach" (p. 113) to obtain data from inside the culture (i.e., emic approach) as well as from outside the cultural system (i.e., etic approach). Thus, collaborative work by researchers from both cultures is essential.

A second issue pertains to the type of equivalency of measures that one desires as a result of translation of measures. Jones (1987) suggested that different translation procedures should be chosen based on the goal of the study. If the goal of a study is to demonstrate cultural differences or acculturation, "the translation from the original language into the second language should remain loyal to the source language" (p. 324), even though the target language version seems unnatural in its translation. On the other hand, "if the goal of a study is to reference a construct across cultures, that goal is comparative" (p. 324) and the translation should aim for equal familiarity in both languages and include items common to both cultures. An evaluation needs to be made about whether the measures can be translated adequately and whether the original and translated measures can provide comparable data. The most common and highly recommended strategy to verify the translation of a measure is back-translation (Brislin, 1970; Chapman & Carter, 1979).

The third issue is related to interpretation of study results. The results from the target culture must be interpreted based on that culture. Careful reviews by experts in the field and by the target population are required. To compare the results from Japanese samples to the results from U. S. samples requires that cultural differences should be carefully considered when interpreting the results.

In the study, an important question was whether the concepts that were identified in the United States also exist in Japan. In addition to the analysis of the research literature presented earlier, the investigator used Japanese books written by caregivers (Ikebe, 1992; Kuroda, 1987; Suzuki & Group WIFE, 1989; Takamizawa, 1988) or containing the caregivers' real voice (Okuni & Kawamura, 1982; Takasaki & Nogawa, 1988) as data, drawing out actual words of caregivers that explained their caregiving situations. These books represent the experiences of 44 family caregivers of impaired elderly persons. First, the data were analyzed using content analysis (Weber, 1985). Based on the definition of each concept from the FCI, corresponding data bits were classified to confirm which concepts identified in the United States also existed in

Japanese caregiving situations. Then, the data were carefully examined again to identify new concepts related to Japanese family caregiving.

The seven main concepts in the FCI -- amount of care, mutuality, preparedness for caregiving, predictability of the caregiving situation, rewards of caregiving, caregiver role strain, and amount of negative life style change -- were confirmed in the words of Japanese caregivers. In addition, two new concepts -- caregiver role strain from relationships with other family members and rewards from other people -- were identified (see Appendix A).

Measures based on these two new concepts were developed. Item wording for these new measures was generated from the words used by Japanese caregivers in the books reviewed because the words were in the language of the caregivers. The measure of Caregiver Role Strain from Relationships with Other Family Members has seven items and the measure of Rewards from Other People has four items (see Table 1).

Constructing the Japanese Family Caregiving Inventory

The back-translation technique is the most common and highly recommended strategy for translating measures from one language into another language (Chapman & Carter, 1979; Jones. 1987; Jones & Kay, 1992). Brislin, Lonner, and Thorndike (cited in Chapman & Carter, 1979) recommended that an instrument should be back translated at least three times and each time by a different translator. Brislin (1970) also suggested using one or more techniques of translation to minimize translation problems, and recommended the committee approach as an effective alternative method.

A combination of the back-translation technique and the committee approach was used for the study instead of back-translating three times because the repeated back-translation takes a longer time than using the committee approach. The committee approach requires a group of bilingual people to translate from the source language, English, to the target language, Japanese. Using this approach, the investigator expected that the mistakes of one translator would be caught by one of the other translators.

The Japanese Family Caregiving Inventory: Draft 1

First, the Family Caregiving Inventory (FCI) was translated into Japanese by five bilingual persons. One was a doctoral student in Psychology who was born in Japan and has lived in the United States for 17 years. The other four were nurses from Japan who had lived temporarily in the United States for at least 2 and up to 25 years, one has a doctoral degree and three have master's degrees in nursing. All five translators received their graduate degrees from universities in the United States.

One person translated the entire FCI, two persons independently translated two-thirds of the FCI, and two persons independently translated the remaining one-third. Thus each page of the FCI was translated into Japanese by three independent translators. Draft 1 of the Japanese Family Caregiving Inventory (JFCI) was formed by combining the three translations of the FCI and items that were generated for the new concepts (see Figure 2). Combining the three translations of the FCI required that the investigator make decisions when there were variations in how items were translated. The investigator discussed these situations with the dissertation committee, who developed the FCI, in order to clarify definitions of the concepts and to generate possible wording for items. The data from Japanese caregivers' books were also used by the investigator to obtain ideas for item wording for measures in Draft 1 of the JFCI.

The Japanese Family Caregiving Inventory: Draft 2

Draft 1 of the JFCI was back translated into English by a bilingual couple who were not members of the first group of translators. The husband is a Japanese native speaker and the wife is an English native speaker. They operate a translation business focused on translation of official papers, contracts, and letters between Japanese and English. They conducted the translation together and obtained one back-translated FCI.

Apparent discrepancies between the FCI and the back-translated FCI were examined by the investigator. Then, Draft 1 of the JFCI was revised based on this examination to obtain Draft 2. The process of this revision and modification of items also involved discussions with the dissertation committee (see Figure 2).

Finally, the two new measures -- Caregiver Role Strain from Relationships with Other Family Members (7 items) and Rewards from Other People (4 items) -- were added to Draft 2 of the JFCI. The 32-page Japanese questionnaire was formatted using Aldus PageMaker, a desktop publishing software, and TwinBridge Japanese System, an advanced multilingual interface software for Microsoft Windows. This questionnaire (Draft 2 of the JFCI) was used for content validity evaluation.

Evaluation of Content Validity

Content validity of Draft 2 of the JFCI was examined by Japanese experts. This section describes the expert panel, the evaluation procedure, and provides an overview of the results followed by details of the results for each caregiving concept.

Expert Panel

Content validity was checked by 10 Japanese nurses who are familiar with instrument development, gerontological nursing, and/or family nursing. These reviewers were identified through the investigator's personal network. The criteria for choosing the reviewers were that they had: 1) extensive experience in caring for elderly persons and working with family members of the elderly persons and/or 2) a strong background in family caregiving research and/or measurement. Of the 10 reviewers, 4 had a doctoral degree, 1 was a doctoral student, and 5 had a master's degree in nursing or health science.

Evaluation Procedure

The reviewers were asked to complete a content validity questionnaire that contained three to five questions about each caregiving or health concept to be measured (see Appendix B). The content validity questionnaire was developed drawing upon recommendations by Imle and Atwood (1988). The questionnaire was divided into three parts, Part A and Part B contained caregiving concepts and Part C contained demographic information.

Measures of all caregiving concepts (Part A and Part B) were reviewed both at the overall conceptual level and at the item level. However, the nine measures in Part A were reviewed more extensively at the item level than Part B which contained 10 measures because these nine measures either were newly developed for the JFCI (Rewards from Other People and Caregiver Role Strain from Relationships with Other Family Members), included new items (Role Strain from Lack of Resources), or measured concepts that had not been measured in Japanese samples (Mutuality, Preparedness, Predictability, Rewards of Meaning, Rewards of Learning, and Financial Rewards). The reviewers were asked the following questions for Part A: 1) how well does the label and definition of the concept fit the whole set of items, 2) whether each item belonged to the concept label and definition, 3) whether any item did not fit Japanese caregivers of elderly persons, 4) whether any item was unclear, and 5) whether anything was left off the list of items.

Part B included 10 additional caregiving concepts: 1) caregiver role strain from direct care, 2) caregiver role strain from economic burden, 3) caregiver role strain from worry, 4) caregiver role strain from communication problems, 5) caregiver role strain from role conflict, 6) caregiver role strain from mismatched expectations, 7) caregiver role strain from increased tension, 8) caregiver role strain from feelings of being manipulated, 9) global strain, and 10) negative life style change. The questions the reviewers answered for Part B were almost the same as for Part A except that question 2, whether any item did not fit the concept label and definition, were not answered separately for each item.

Part C included demographic information about the caregiver and care receiver: their age, gender, and relationship; amount of help the care receiver required; medical diagnoses the care receiver has; mental and behavioral conditions of the care receiver; help from other people; caregiver's health conditions; and caregiver-care receiver relationship before the care receiver required care. Part C also included open-ended questions about caregiver's additional thoughts related to their caregiving situations and about the JFCI itself, with directions on how to complete the JFCI. The questions the reviewers answered for Part C were: 1) whether any item did not fit Japanese caregivers of elderly persons, 2) whether any item was unclear, and 3) whether anything was left off the list of items. Lastly, the reviewers were also invited to give their comments and suggestions about concept labels, definitions, and items as well as their overall reactions to the JFCI.

Overview of Content Validity Results

Following is an overview of content validity results for the four main questions the reviewers answered. In order for a scale or item to be considered as meeting content validity criteria, eight or more of the 10 reviewers were required to give a favorable evaluation (Lynn, 1986). Of the 19 scales measuring the main caregiving concepts, no major changes were made based on the findings. The summary of the results is presented in Table 2, Table 3, and Table 4.

Do the label and definition of the concept fit the items as a whole? On 14 of the 19 scales, all reviewers agreed that the label and definition of each concept fit the items as a whole. On five remaining scales -- role strain from lack of resources, role strain from relationships with other family members, role strain from role conflict, role strain from mismatched expectations, and role strain from increased tension -- only one or two of the 10 reviewers answered that the concept label and definition did not fit the whole set of items very well.

Does each item belong to the label and the definition of the concept? All of the reviewers agreed that each item belonged to the concept label and definition for more than 80% of the items (172 of 212) on the 19 scales. For 37 (17%) of the items, only one or two reviewers indicated that some items did not belong to the concept label and definition. The greatest disagreement occurred for three items, Item 6 of the Mutuality scale ("How much does he or she help you?"), Item 9 of the Rewards of Learning scale ("To what extent does caring for him or her help you show others the importance of caregiving?"), and Item 13 of the Caregiver Role Strain from Increased Tension scale ("Has assisting your family member increased your anxiety about things?"). Three reviewers answered that Item 6 on the Mutuality scale, and Item 13 on the Caregiver Role Strain from Increased Tension scale, did not belong with the concept label and definition and six reviewers answered that Item 9, Rewards of Learning scale, did not belong to the concept label and definition.

Does any item not fit Japanese caregiving? All reviewers agreed that 198 (93%) of the 212 items fit Japanese caregiving. Of the 19 scales measuring caregiving concepts, all of the reviewers evaluated all items of the 11 scales fitting Japanese caregiving. Only one or two reviewers indicated that 14 of the items from the remaining eight scales did not fit Japanese caregiving.

Is the wording of any item or direction unclear? All reviewers agreed that all directions and the wording of 162 (76%) of 212 items were clear. For 48 (23%) of the items, only one or two reviewers indicated that the wording was not clear. However, three reviewers rated two items -- Item 9 of the Rewards of Learning scale ("To what extent does caring for him or her help you show others the importance of caregiving?") and Item 4 of the Caregiver Role Strain from Feelings of Being Manipulated scale ("Has assisting your family member increased attempts by him/her to manipulate you?") -- as not being clear.

Results for each content validity question were discussed with several of the reviewers and the dissertation committee. Based on these discussions, modifications were made to Draft 2 of the JFCI and Draft 3 of the JFCI was created for the pretesting with Japanese caregivers. Details of the results for, and the decisions related to, each concept are described below.

Mutuality

In general, all of the reviewers agreed that the concept label and definition of mutuality fit well with the whole set of 15 items on the Mutuality scale. Some of the reviewers answered that two items (Items 6 and 15) did not belong to the label and definition. Three reviewers mentioned that Item 6 did not fit well with the definition and other items because the word "help" was too practical. One reviewer mentioned that the definition of Item 15 ("How often does he or she express feelings of warmth toward you?") was not clear because the phrase "feelings of warmth" was unclear. Two reviewers mentioned that the word "attachment" was not commonly used in Japan. Three reviewers also mentioned that distinctions among the words "attachment," "love," and "closeness" in Japanese were not clear. Another reviewer suggested taking out the words "to what extent," "how much," and "how often" to make the sentences clear.

These points had been previously discussed with the dissertation committee when the FCI, the first draft of the JFCI, and the back-translated FCI were compared. Even though the word "attachment" in Japanese is not as commonly used as other Japanese words such as "love" and "closeness," the word "attachment" was retained because there was no other Japanese word that was equivalent. Even though the meanings of the words "attachment," "love," and "closeness" overlapped somewhat, these words continued to be used because each word has a different flavor. Because only one reviewer said the phrase "feelings of warmth" was unclear, these words were retained. The words "to what extent," "how much," and "how often" were taken out of each item. The sentence structure of Item 6 was also changed from active to passive to soften the sound.

Preparedness for Caregiving

All of the reviewers agreed that the concept label and definition of preparedness for caregiving fit well with the whole set of eight items on the Preparedness for Caregiving scale. One reviewer answered that Item 5 ("How well prepared do you think you are to make caregiving activities pleasant for both you and him or her?") did not fit the label and definition because Japanese caregivers may not naturally view caregiving as including "making caregiving activities pleasant." Four reviewers pointed out the lack of distinction between Item 3 ("How well prepared do you think you are to find out about and set up services for your family member?") and Item 7 ("How well prepared do you think you are to get the help and information you need from the health care system?") and the potential difficulty of differentiating these two items in Japan. Three reviewers also mentioned that the Japanese word "*junbi*" for preparedness, which often refers to being physically ready, may not fit caregiving. They thought some caregivers might have difficulty understanding the meaning of "*junbi*" in relation to caregiving.

Because only one reviewer said that Japanese caregivers may not think of "making caregiving activities pleasant" as part of caregiving, Item 5 was retained. The wording of Item 3 and Item 7 was modified. Item 3 became a question about setting up help and Item 7 became a question about finding out information about services. The Japanese word "*kokoro-gamae*," which means a person's mental attitude was added to the Japanese label along with the definition of the concept. This Japanese word is commonly used in Japan to refer to being "ready to take on a new situation or information".

One reviewer suggested adding items about preparedness for setting up and modifying the physical environment (e.g., remodeling the house) and the interpersonal environment (e.g., sharing and restructuring roles in the family). The decision about adding these new items was postponed because the relevance of these items to Japanese culture needed to be examined more carefully.

Predictability of the Caregiving Situation

All of the reviewers agreed that the concept label and definition of predictability of the caregiving situation fit well with the whole set of six items on the Predictability of the Caregiving Situation scale. Only one reviewer answered that two items (Item 1 and Item 5) did not belong to the label and definition. She noted that Item 1 ("How predictable are your family member's needs?") asked about a care receiver's needs, but the other items asked about caregiving situations. In relation to Item 5 ("How much do you currently feel in control of your life?"), she thought that "feel in control" was different from "predictability." The decision about changes in these items was postponed because of the need for a more systematic analysis of the definition of Predictability in the Japanese culture. One reviewer pointed out that the time frame of predictability needed to be clarified. This point was also left for later consideration.

Rewards of Meaning

All of the reviewers agreed that the concept label and definition of rewards of meaning fit well with the whole set of 19 items on the Rewards of Meaning scale. Some reviewers indicated that five items (Item 6, 12, 13, 15, and 27) did not belong to the label and definition. Item 6 ("To what extent does caring for him or her help you feel good about yourself?") was thought to relate indirectly rather than directly to rewards of meaning. One reviewer also mentioned that the expression "feel good about yourself" may not be familiar for Japanese respondents. Item 12 ("To what extent does caring for him or her help your whole family feel closer to one another?") was thought to relate to interpersonal relationships rather than rewards of meaning. The word "accomplishment" in Item 13 ("To what extent does caring for him or her give you a sense of accomplishment?") was identified as not being commonly used in Japan and therefore not easy to understand. Item 15 ("To what extent does caring for your family member help you feel that you are giving back for all he or she has done for you?") and Item 27 ("To what extent has helping him or her brought the two of you closer together?") were viewed as belonging to the concept of mutuality rather than rewards. Four reviewers said that the words "rewarding" (Item 1, 16, 18, 24, 25, 26), "accomplishment" (Item 13), and "satisfying" (Item 21) were difficult to clearly differentiate in Japanese. Some suggestions were made regarding Japanese wordings. One reviewer suggested omitting some of these items.

Based on discussion with some of these reviewers and the dissertation adviser, Items 18, 21, 25, and 26 were omitted. The word "for myself" was added to the definition to make it clearer. Minor changes in the Japanese wording were also made to some items to make the items read more smoothly.

Rewards of Learning

All of the reviewers agreed that the concept label and definition of rewards of learning fit well with the whole set of five items on the Rewards of Learning scale. Six reviewers indicated that the Item 9 ("To what extent does caring for him or her help you show others the importance of caregiving?"), was different from the other four items. Some thought it belonged to Rewards of Meaning and others thought it belonged to Rewards from Others. One thought that this item was not meaningful for caregivers themselves but for other people. Some reviewers also said that the word "others" in the Item 9 was unclear.

A decision about the inclusion and final wording of Item 9 will be made after the psychometric analysis of the data from Japanese caregivers is completed. Based on discussion with some of these reviewers, minor modification of the Japanese wording in some items was made.

Financial Rewards

All of the reviewers agreed that the concept label and definition of financial rewards fit well with the whole set of three items on the Financial Rewards scale. Two reviewers strongly recommended omitting Item 4 ("To what extent does caring for him or her help you financially?") and Item 8 ("To what extent will caring for him or her help you financially in the future?") because of their feelings of resistance toward financial rewards. In addition, they pointed out that these items do not fit the Japanese culture. For example, it is very difficult to imagine future financial rewards because making out a will is not the custom for most Japanese persons. In addition, the division of inheritance is based on the percentage that is prescribed in the current law, not based on what the person's role was.

Based on discussion with some of these reviewers and the dissertation committee, Items 4 and 8 were omitted. The word "elderly hospital" -- a very popular place for older persons to move into when they have some health problems -- was added to Item 11 ("To what extent does caring for him or her help you to be more comfortable financially than if you put him or her in a nursing home?"). An open-ended question ("Do you think caring for your family member gives you any financial advantage or disadvantage? Would you describe your thoughts?) was added.

Rewards from Other People

All of the reviewers agreed that the concept label and definition of rewards from other people fit well with the whole set of four items on the Rewards from Other People scale. One reviewer mentioned that many Japanese may view a positive comment or approval from other people as just flattery or being polite. These comments are often used as strategies for being sociable or facilitating a smooth relationship in Japan. One reviewer suggested that Item 12 might belong to this concept rather than to rewards of meaning, and recommended adding an item to ask whether relationships among immediate family members improved. Decisions about these issues were postponed until the psychometric analysis of the data from Japanese caregivers was completed.

Caregiver Role Strain from Lack of Resources

All but one reviewer agreed that the concept label and definition of caregiver role strain from lack of resources fit well with the whole set of four items on the Caregiver Role Strain from Lack of Resources scale. One reviewer thought that the Japanese word "resources" seemed more like social resources than personal resources. She also identified Item 2 ("Your being too tired emotionally"), Item 3 ("Your being too tired physically"), Item 4 ("Not having enough time"), and Item 8 ("Decreased time you have for sleep") as not fitting the label and definition. Some reviewers indicated that the wording of Items 2, 3, 4, 5 ("Not having enough help from other people"), 6 ("Not having enough space in the home"), and 8 were unclear. They suggested minor changes in the Japanese wording. One of these reviewers also had a question about the word "time" in Item 4, in terms of "time for what."

Even though one reviewer mentioned that the Japanese word "resources" seemed to reflect social resources, the word "resources" was retained because the meaning of the word was included in the concept's definition. In some items, the Japanese wording was modified in minor ways to make these items clearer. The issue related to clarity of the word "time" in Item 4 was left for later consideration until the psychometric analysis of the data from Japanese caregivers was completed.

One reviewer suggested adding items about the caregiver's abilities (e.g., caregiving skills, knowledge about caregiving), caregiving equipment, and functional aspects of the house. The decision about adding these new items was postponed because these items may better fit under the concept of "Preparedness" and therefore needed to be examined carefully.

Caregiver Role Strain from Interpersonal Relationships within *Miuchi*

All but one reviewer agreed that the concept label and definition of caregiver role strain from relationships with other family members fit well with the whole set of seven items on the Caregiver Role Strain from Relationships with Other Family Members scale. One reviewer thought that the Japanese word "family" in the concept label did not include relatives other than immediate family, and suggested changing the label. Two reviewers indicated that five items did not belong to the label and definition. The five items were Item 6 on page 13 ("How much do you worry about what immediate family members think about you and your caregiving?"), Item 6 on page 21 ("How often do you feel that immediate family members do not understand what it is like for you to be a caregiver?"), Item 7 ("How often do you feel that other relatives do not understand what it is like for you to be a caregiver?"), Item 16 ("How much do you worry about what your relatives think about you and your caregiving?"), and Item 19 ("How much do you worry about whether your caregiving situation will have a negative impact on your relationships with other relatives?"). One reviewer thought these items did not ask about caregiver role strain from family relationships but asked about the relationship itself. The other reviewers thought these items asked about changes in family relationships because of caregiver role strain. Some other reviewers indicated that the wording of Item 4 ("How much stress do you feel because immediate family members do not accept the way you are providing care?"), Item 5 ("How much stress do you feel because other relatives do not accept the way you are providing care?"), and Item 19 were unclear. They suggested minor changes in the Japanese wording. One of these reviewers also questioned how popular the word "stress" is, particularly among older people.

The concept label was changed from "family relationships" to "interpersonal relationships within *Miuchi* (relatives)" to capture all items and to fit the definition more clearly. The issue related to question 2 (For each item, does the item belong to the label and definition?) was left for later psychometric analysis of the data from Japanese caregivers. In some items, the Japanese wording was modified in minor ways to make these items clear. The word "stress" was retained because it is commonly and widely used in everyday life and the mass media such as newspapers and TV.

Amount of and Caregiver Role Strain from Caregiving Tasks

There were two sets of caregiving activities, direct care (80 items) and managed care (6 items). Each set was used to measure two concepts -- amount of direct care and caregiver role strain from direct care and amount of managed care and caregiver role strain from managed care. All of the reviewers agreed that the concept labels and definitions of amount of direct care and managed care and caregiver role strain from direct care and managed care fit well with the whole set of 80 items on the Direct Care scale and 6 items on the Managed Care scale. One reviewer indicated that Item 24 ("Do you have discussions with him or her about the future, the meaning and purpose of life, or how he or she has lived his or her life?") on the Direct Care scale did not belong to the label and definition because it was not usually viewed as a caregiving activity. One reviewer indicated that Item 16 ("Do you do any of the driving for your family member?") and Item 40 ("Do you have to deal with his or her unsafe driving?") on the Direct Care scale did not fit Japanese culture because driving a car is not popular, particularly among older people in Japan. Two reviewers mentioned that Item 9 ("Do you try to keep him or her active and involved in activities that he or she enjoys?"), Item 17 ("Do you have to handle his or her paranoia or suspiciousness?"), and Item 40 ("Do you have to deal with his or her unsafe driving?") on the Direct Care scale were unclear because of the phrase "try to keep" and the word "handle". Another reviewer mentioned that the words "deal," "handle," "have to," "assist," and "help" were not clearly distinguished.

One reviewer indicated that Item 4 ("Have you had to make sure that people from these agencies continued to provide the needed service?") and Item 5 ("Have you had to check and make sure that they gave help in a skillful way?") on the Managed Care scale may not fit the Japanese caregiving situations because in the Japanese health care delivery system, services are often initiated and continued by health care professionals, not by families.

The issues related to driving a car were considered but these items were retained because driving has increased in Japan and only one reviewer questioned this point. The issue related to unclear phrases was left for later consideration and these items were retained as written because only two reviewers questioned the phrases and there was not enough evidence to make a decision at this point. Based on a suggestion from one reviewer, Items 4 and 5 on the Managed Care scale were omitted after discussion with the dissertation committee.

Caregiver Role Strain from Economic Burden

All of the reviewers agreed that the concept label and definition of caregiver role strain from economic burden fit well with the whole set of four items on the Caregiver Role Strain from Economic Burden scale. Furthermore, all agreed that all items fit Japanese caregivers. One reviewer indicated that Item 9 ("Do you pay other people out of your own pocket to take care of your family member?") was not clear and suggested a minor change in its wording. The Japanese wording of Item 9 was adjusted to make it clear.

Caregiver Role Strain from Worry

All of the reviewers agreed that the concept label and definition of caregiver role strain from worry fit well with the whole set of 16 items on the Caregiver Role Strain from Worry scale. One reviewer indicated that some items related to worry about a care receiver's condition (e.g., Item 1 "How much do you worry about your family member's health condition?") and others related to caregiving (e.g., Item 8 "How much do you worry about how you can go on if he or she gets worse?"). She suggested separating these items into two groups. This issue was left for later consideration and these items were retained because only one reviewer questioned this point.

Several reviewers suggested changes in item wording. Minor changes in the Japanese wording were made in some items to make the items read more smoothly.

Amount of Communication Problems and Caregiver Role Strain from These Problems

All of the reviewers agreed that the concept labels and definitions of two concepts, amount of communication problems and caregiver role strain from communication problems fit well with the whole set of four items on each of the two Communication Problems related scales. Further, all agreed that all items fit Japanese caregivers. One reviewer suggested dividing Item 3 ("To what extent does he or she have difficulty with remembering or understanding what is said?") into two items because "remembering" and "understanding" are two different things. Another reviewer suggested adding new items about eyesight and caregiver's ability to remember. These points were left for later consideration.

Caregiver Role Strain from Role Conflict

All but two reviewers agreed that the concept label and definition of caregiver role strain from role conflict fit well with the whole set of 14 items on the Caregiver Role Strain from Role Conflict scale. Two reviewers suggested changing the phrase "role expectations" in the definition to "roles a caregiver wants to achieve" to fit all items. Two other reviewers indicated that Item 11 ("To what extent does caring for your family member interfere with your ability to be active in your temple, church, or religious circle in the way you think you should be?") may not fit many Japanese people. They also indicated that Item 13 ("To what extent does caring for your family member interfere with your ability to be good to yourself?") was not clear. Another reviewer suggested adding the phrase "hobby groups" to Item 12 ("To what extent does caring for your family member interfere with your ability to be active in the community in the way you think you should be?").

The definition was changed to "conflict between the caregiver role and other roles the caregiver wants to achieve" based on discussion with the dissertation committee. The other points had been previously discussed with the dissertation committee when the FCI, Draft 1 of the JFCI, and the back-translated FCI were compared. The issues about Items 11 and 13 were left for later consideration and these items were retained as written since only two reviewers questioned these items and there was not enough evidence to make a decision at this point. "Hobby group" was added to Item 12.

Caregiver Role Strain from Mismatched Expectations

All but one of the reviewers agreed that the concept label and definition of caregiver role strain from mismatched expectations fit well with the whole set of five items on the Caregiver Role Strain from Mismatched Expectations scale. One reviewer suggested changing the phrase "expectations from a care receiver" in the definition to "expectations from a care receiver and caregiver's own expectation" in order to cover all items. The definition was changed to "expectations from care receiver, caregiver, or other people" based on discussion with the dissertation committee.

Caregiver Role Strain from Increased Tension

All but one of the reviewers agreed that the concept label and definition of caregiver role strain from increased tension fit well with the whole set of four items on the Caregiver Role Strain from Increased Tension scale. One reviewer stated that the label and the definition did not fit Item 7 ("Has assisting your family member added tension to your life?") and Item 13 ("Has assisting your family member increased your anxiety about things?") because these items asked about stress and anxiety in a caregiver's life but did not specify the caregiver and care receiver relationship. Four other reviewers indicated that "tension," "anxiety," "nervousness," or "depression" in Item 7, Item 9 ("Has assisting your family member increased the nervousness and depression you have concerning your relationship with him/her?"), and Item 13 did not necessarily occur in the relationship between the care receiver and the caregiver. They thought that these feelings might be caused by the relationships between a caregiver and other family members or a care receiver and other family members as well as a caregiver and a care receiver. Three of the five reviewers also suggested that these three items might need further consideration of wording to make them clearly fit the definition.

As a result of these findings, the definition was reexamined and found to be too narrow for the measure because of its emphasis on tension related to the caregiver-care receiver relationship. The definition was reworded to "the caregiver's felt difficulty in fulfilling the caregiver role because of tension, stress, depression, and anxiety in the caregiving situation" from "... because of tension, stress, depression, and anxiety in the caregiver-care receiver relationship."

Caregiver Role Strain from Feelings of Being Manipulated

All of the reviewers agreed that the concept label and definition of caregiver role strain from feelings of being manipulated fit well with the whole set of four items on the Caregiver Role Strain from Feelings of Being Manipulated scale. Two reviewers indicated that Item 6 ("Has assisting your family member increased the number of unreasonable requests made of you?") and Item 12 ("Has assisting your family member increased demands made by him/her that are over and above what he/she needs?") differed from "manipulation." One reviewer suggested changing the word "manipulate" to "making you move as he/she wants to" in Item 4 ("Has assisting your family member increased attempts by him/her to manipulate you?").

The issue in Items 6 and 12 was left for later consideration and these items were retained because only two reviewers questioned them. The other point, related to the word "manipulation," had been previously discussed with the dissertation committee when the FCI, Draft 1 of the JFCI, and the back-translated FCI were compared. At that time, the investigator and the dissertation committee agreed that this word might need to be changed and would discuss it after data related to the content validity were analyzed. Based on further discussion with the dissertation committee, the Japanese wording in Item 4 was changed as suggested.

Global Strain

All reviewers agreed that the concept label and definition of global strain fit well with the whole set of four items on the Global Strain scale. One reviewer indicated that the Japanese wording in Item 1 ("How confined do you feel because of all the caregiving things you do for your family member?") was not clear. Because it is difficult to translated the word "confined" into Japanese as one word, it was translated as "being restricted and locked up." The reviewer expressed concern about possible confusion between the words “restricted” and “locked up” (e.g., some caregivers may feel “restricted” but not “locked up”).

The investigator and the dissertation committee had previously discussed the translation of the word “confined” when the FCI, Draft 1 of the JFCI, and the back-translated FCI were compared, and agreed that the word “confined” included both feelings of “being restricted” and “being locked up.” Because only one reviewer expressed this concern, the original Japanese wording for this item was retained and was left for later consideration until psychometric analysis of data from Japanese caregivers was completed.

Amount of Negative Life Style Change

All reviewers agreed that the concept label and definition of amount of negative life style change fit well with the whole set of six items Amount of Negative Life Style Change scale. One reviewer indicated that the Japanese wording in Item 14 (“Has assisting your family member decreased the time you have for friends and other relatives?”) was not clear because the word “time” was too abstract. She suggested changing the word “time” to the phrase like “the chance to see your friend.” Another reviewer recommended adding an item about psychological energy, such as “Has assisting your family member decreased your psychological energy to be able to pay attention to your own self care such as your appearance?” Another reviewer expressed her concern that items in this concept asked about “time” to do something but did not ask about “energy” to do something.

The issue of "time" in Item 14 was left for later consideration because only one reviewer questioned this point. The recommended item related to "psychological energy" was also left for later consideration because the item suggested was included in other items such as Item 1 ("Has assisting your family member decreased the time you have to yourself?") and Item 5 ("Has assisting your family member decreased the time you have to spend in recreational activities?"). The final issue about "energy" was also left for later consideration because careful examination is needed regarding whether or not the concept "life style" includes "energy" and whether or not decreased "time" to do something and "energy" to do something are included in the concept of role strain from lack of resources. Based on some reviewers' suggestions, minor changes in the Japanese wording of some items were made to make items more clear.

Demographic Information, Open-ended Questions, and Directions to Fill in the JFCI

Some reviewers suggested changes in the Japanese wording of some directions to fill in the JFCI and some items in the sections on demographic information. Some of these suggestions were incorporated but others were not because most of these suggestions were made by only one reviewer. Following are some changes that were made based on these suggestions and discussion with the dissertation committee.

1. The following sentence was added to the directions on page 1: "If you are caring for more than one older persons, please answer about the one person whom you are caring for more."

2. The following response option was added to Item 8a ("How far away do you live from your family member?") on page 1: "_____ minutes by bus, car, or walk."

3. The response option was changed in Item 18a ("What are your family member's diagnoses, and when did each diagnosis occur?") on page 2 from "19 ____" to "____Year ____Month".

4. The Japanese word was changed in the directions to fill in Amount of Direct Care scale and Caregiver Role Strain from Direct Care scale on page 3 from "have to deal" to "need to deal".

5. The item "shoulder or neck" was added to questions about caregiver's health problems on page 25.

6. The word "hip" was added to Item 1 ("During the past 4 weeks, have you had a problem with your back?") on page 25. The Japanese word "hip" means lower back and "back" means upper back.

7. The word "arteriosclerosis" was added to Item 23 ("Do you have circulatory problems?") on page 25.

8. The response option "other" was added to Item 5 ("Are you currently employed?") on page 29.

9. The border design of each page was changed from a set of thick and thin lines to a set of two thin lines.

Minor changes in the Japanese wording in some items were also made to make the items more clear and read more smoothly.

Summary

Caregiving concepts measured by existing scales in the Family Caregiving Inventory (FCI) were verified within Japanese caregiving situations. New caregiving concepts important in Japan, but for which no measures currently existed were extracted from books by Japanese caregivers. Draft 1 of the Japanese Family Caregiving Inventory (JFCI) was constructed by translating the FCI. Then, Draft 1 of the JFCI was back translated into English. Draft 1 was revised based on examination of apparent discrepancies between the FCI and the back-translated FCI. Draft 2 of the JFCI was developed to combine the revised Draft 1 of the JFCI and new measures extracted from books by Japanese caregivers. The content validity of Draft 2 of the JFCI was reviewed by 10 Japanese nurses who are experts in gerontological nursing, family nursing, and/or instrument development (see Figure 2).

In their review of Draft 2 of the JFCI, all 10 reviewers agreed that the label and the definition of the concept fit the items as a whole for about three-fourths of the concepts. However, one reviewer indicated that the label and the definition of four concepts -- caregiver role strain from lack of resources, relationships with other family members, mismatched expectations, and increased tension -- did not fit the items as a whole well. In addition, two reviewers indicated that the label and the definition of one concept -- caregiver role strain from role conflict -- did not fit the items as a whole. Caregiver role strain from relationships with other family members was a new concept and the investigator expected changes in its label or definition. The label of this concept was changed to "caregiver role strain from interpersonal relationships within *Miuchi*." Problems with the other four concepts related to the lack of clarity of Japanese wording in their definitions. Based on suggestions from the reviewers, the definitions of those four concepts were reworded after discussion with the dissertation committee.

All 10 reviewers agreed that most of the items, 81% and 93%, met the criteria for belonging to the label and definition of the concept and for fitting Japanese caregiving, respectively. Eight or nine reviewers agreed that another 17% and 7% of items met these criteria, respectively.

Of the 212 items, there were only four items identified as problematic by three or more reviewers. These included Item 6 on the Mutuality scale, Item 9 on the Rewards of Learning scale, Item 4 on the Caregiver Role Strain from Feelings of Being Manipulated scale, and Item 13 on the Caregiver Role Strain from Increased Tension scale. The problem with Item 13 on the Caregiver Role Strain from Increased Tension scale was related to the definition of this concept and was resolved by rewording the definition. Based on suggestions from the reviewers, wording of the other three items were modified after discussion with the dissertation committee. However, the extent to which rewording these items was successful needs to be examined following the psychometric analysis of the data from Japanese caregivers.

Overall, Draft 2 of the JFCI met the four content validity criteria. The definition of each caregiving concept in the JFCI was finalized (see Table 1) and Draft 3 of the JFCI was constructed for pretesting with Japanese caregivers. The JFCI, in Japanese and English languages, can be found as Appendix C. Then, the JFCI was finalized and applied with Japanese caregivers. The results from the evaluation of the psychometric properties of this final draft of the JFCI are reported in Paper 2.

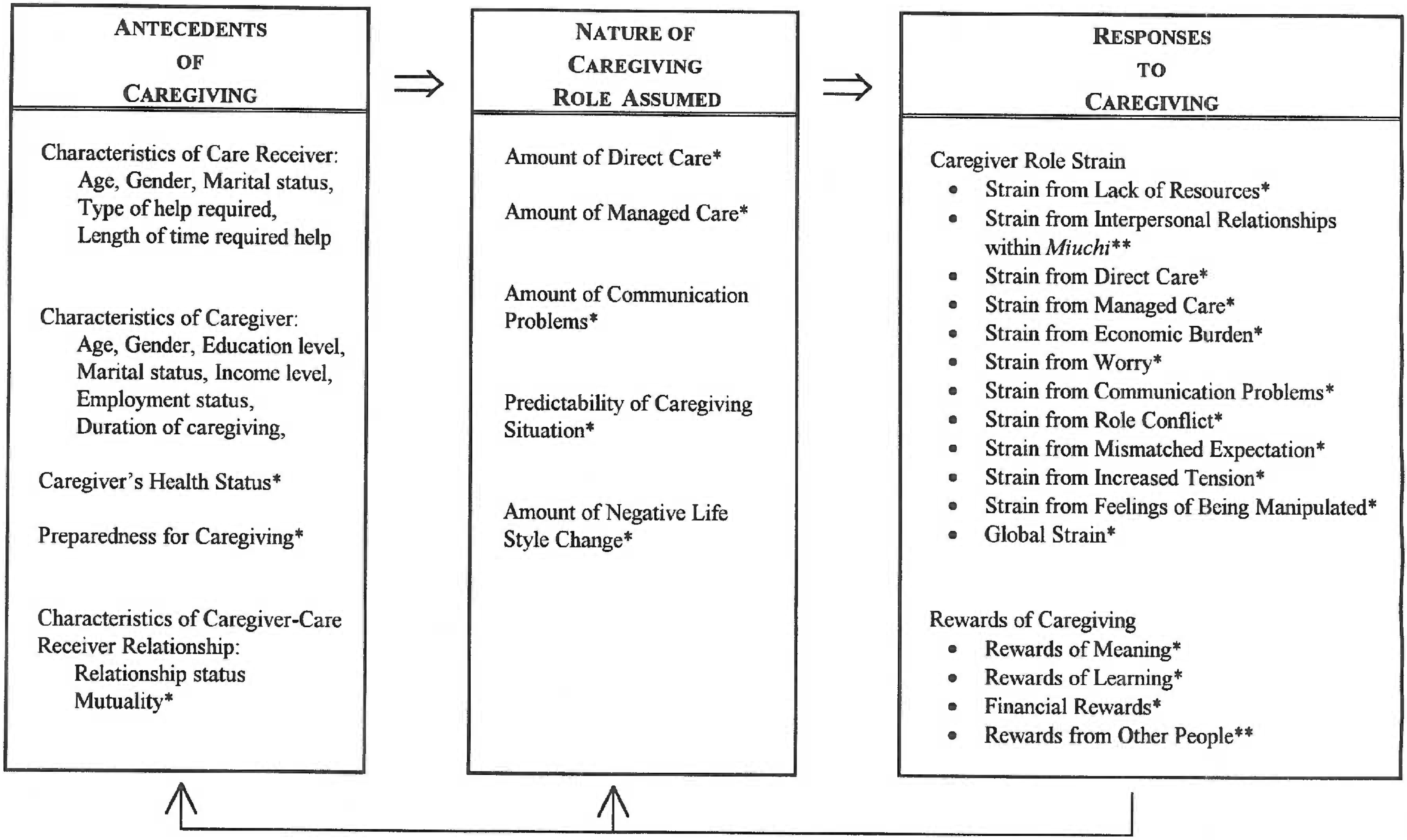

Figure 1. Conceptual framework of family caregiving: Relationships of caregiving concepts for which measures were translated or developed.

Caregiving concepts for which measures were translated are designated by an asterisk (*) and were developed are designated by two asterisks (**).

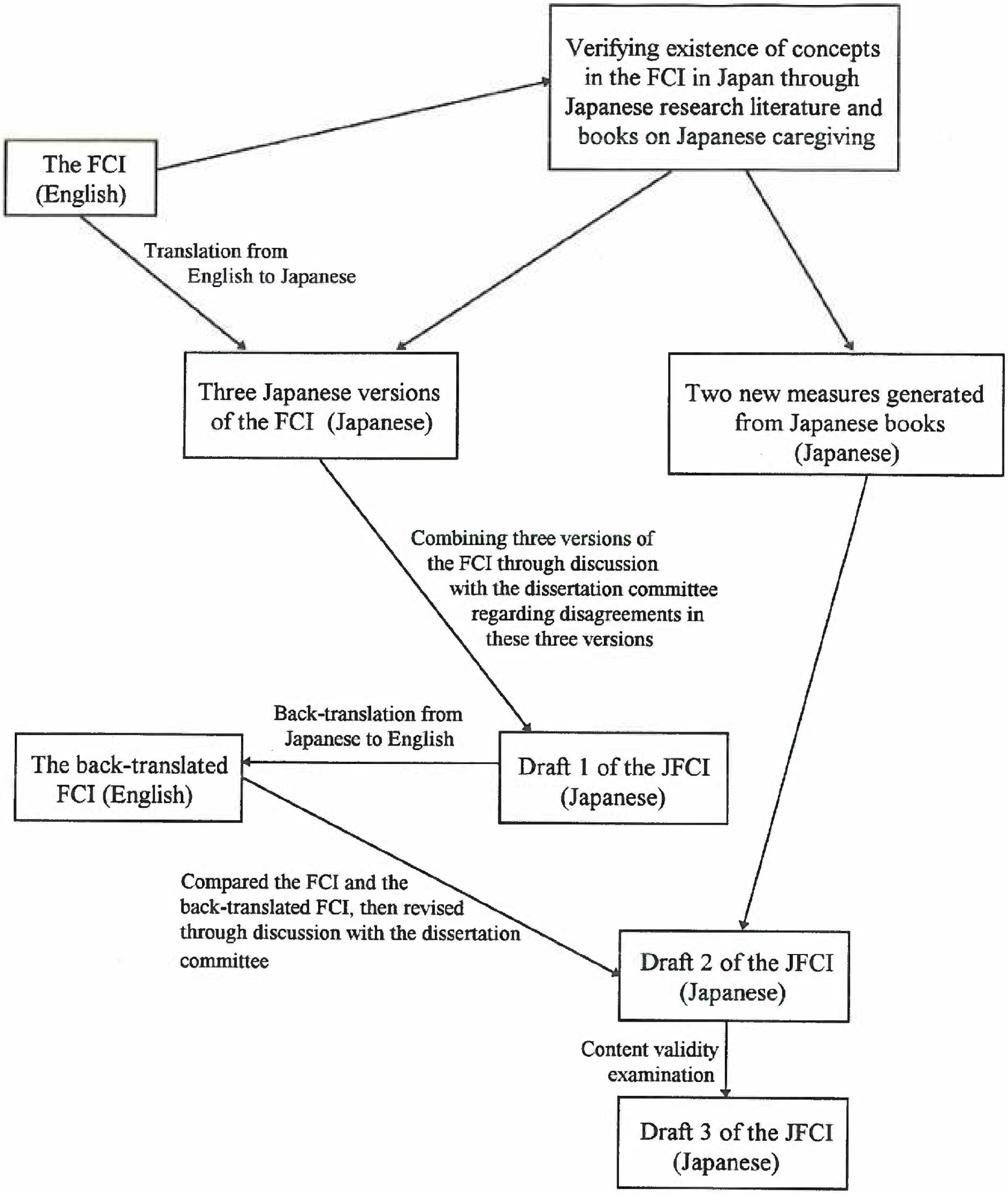

Figure 2. Procedure of Constructing the JFCI: Process of constricting the JFCI through translation, back-translation, and examination of content validity.

Table 1

Definition and Sample Items for Concepts Measured in the JFCI

Concept Name	Definition of the Concept	No. Items	Sample Item
Mutuality	Quality of relationship between the caregiver and the care receiver based on reciprocity, love, shared pleasurable activities, and shared values.	15	How close do you feel to him or her?
Preparedness for Caregiving[a]	The caregiver's perception of how well prepared he or she is for tasks and stress of caregiving role.	8	How well prepared do you think you are to take care of your family member's physical needs?
Predictability of the Caregiving Situation[b]	The caregiver's perception of how predictable his or her situation is and how much the caregiver feel in control of his or her life.	6	How predictable are your family member's needs?
Rewards of Meaning	The positive meaning the caregiver finds for him or herself in fulfilling the caregiver role.	4	To what extent does caring for him or her help you feel good about yourself?
Rewards of Learning	Beneficial learning that has occurred for the caregiver because he or she fulfills the caregiver role.	3	To what extent does caring for him or her help you understand your own aging?
Financial Rewards	Financial benefits that has occurred for the caregiver because he or she fulfills the caregiver role.	1	To what extent does caring for him or her help you live more comfortably financially than if you put him or her in a nursing home?

Table 1

Definition and Sample Items for Concepts Measured in the JFCI (cont.)

Concept Name	Definition of the Concept	No. Items	Sample Item
Rewards from Other People	The positive feelings and/or benefits that the caregiver receives because he or she fulfills the caregiver role, such as recognition and acceptance from other people and improvement of relationships with other people.	4	To what extent do you feel glad to be a caregiver because other relatives look at you as an important person?
Role Strain from Lack of Resources[c]	The caregiver's felt difficulty in fulfilling the caregiver role because of inadequate resources. The resources include emotional and physical energy, help from other people, time, space, and sleep.	7	Has this been a problem for you? "Your being too tired emotionally."
Role Strain from Interpersonal Relationships within *Miuchi*[d]	The caregiver's felt difficulty in fulfilling the caregiver role because of interpersonal relationships within *Miuchi* (relatives).	7	How often do you feel that immediate family members do not understand what it is like for you to be a caregiver?
Amount of and Role Strain from Caregiving Activities[ef]	The number of caregiving tasks performed by the caregiver for the care receiver and the caregiver's felt difficulty in performing specific caregiving tasks.	80	Do you do this type of help for your family member? "Do you have to help him or her with eating?" If yes, how hard it is for you to do that?
Role Strain from Economical Burden	The caregiver's felt difficulty in fulfilling the caregiver role because of its financial burden.	4	How much do you worry about financial problems related to his or her care?

Table 1

Definition and Sample Items for Concepts Measured in the JFCI (cont.)

Concept Name	Definition of the Concept	No. Items	Sample Item
Role Strain from Worry	The caregiver's felt difficulty in fulfilling the caregiver role because of worry about the care receiver, the caregiver him or herself, their future, and caregiving per se.	12	How much do you worry about your ability to continue taking care of him or her because of your own health?
Amount of Communication Problems and Role Strain from these Problems	How much problems in the communication or understandings between the caregiver and the care receiver and the caregiver's felt difficulty in fulfilling the caregiver role because of these problems.	4 + 4	To what extent does your family member have difficulty of hearing? To what extent does his or her hearing problem make it hard you to provide care to him or her?
Role Strain from Role Conflict	The caregiver's felt difficulty in fulfilling the caregiver role because of conflict between the caregiver role and other roles the caregiver wants to achieve.	14	To what extent does caring for your family member interfere with your ability to be the kind of spouse or partner you think you should be?
Role Strain from Mismatched Expectations[e]	The caregiver's felt difficulty in fulfilling the caregiver role because of conflict between the actual caregiver role and expectations of the role from the care receiver, the caregiver, or other people.	3	Are there things you do for your family member that, after you've done them, you think "It's not really my place to do that"?

Table 1

Definition and Sample Items for Concepts Measured in the JFCI (cont.)

Concept Name	Definition of the Concept	No. Items	Sample Item
Role Strain from Increased Tension	The caregiver's felt difficulty in fulfilling the caregiver role because of tension, stress, depression, and anxiety in the caregiving situation.	4	Has assisting your family member increased the stress in your relationship with him/her?
Role Strain from Feelings of Being Manipulated	The caregiver's felt difficulty in fulfilling the caregiver role because of feeling manipulated or taken advantage of as a caregiver.	4	Has assisting your family member increased attempts by him/her to manipulate you?
Global Strain[d]	The caregiver's felt difficulty in fulfilling the caregiver role as whole.	4	How often do you say that taking care of your family member is very difficult?
Amount of Negative Life Style Change	Negative changes in the caregiver's lifestyle because of taking the caregiver role.	6	Has assisting your family member restricted personal privacy?

Note. Unless indicated otherwise, response options for items on each scale are "Not at all" (0), "A little" (1), "Some" or "Moderately" (2), "Quite a bit" (3), and "A great deal" (4). [a] Response options for items on the scale are "Not at all" (0), "Not too well" (1), "Somewhat well" (2), "Pretty well" (3), and "Very well" (4). [b] Response options for items on the scale are "Not at all" or "Never" (0), "A little" or "Rarely" (1), "Somewhat" or "Sometimes" (2), "Pretty" or "Usually" (3), and "Very much" or "Always" (4). [c] Response options for items on the scale are "Not a problem" (0), "A small problem" (1), "A moderate problem" (2), "A big problem" (3), and "A very big problem" (4). [d] Response options for items on the scale are "Never" (0), "Rarely" (1), "Sometimes" (2), "Much of the time" (3), and "Always" (4). [e] Response options for items on the scale are "No" (0) and "Yes" (1). [f] Response options for items on the scale are "Easy" (1), "Not too hard" (2), "Somewhat hard" (3), "Pretty hard" (4), and "Very hard" (5).

Table 2

Summary of Content Validity Checked by 10 Japanese Nurses for Caregiving Concepts: Part A

Concept Name	Page	Q. 1: Label & definition fit items as a whole? (n)	Q. 2: Each item belong to label & definition? (n)		Q. 3: Any item not fit Japanese Caregiving? (n)	Q. 4: Wording of any item unclear? (n)
Mutuality	20	Very well (7)	Item #1-5, 7-14	Yes (10)	All fit (8)	All clear (6)
		Pretty well (3)		No (0)	Some not fit (2)	Some not (4)
		Not too well (0)	Item #6	Yes (7)		
		Not at all (0)		No (3)	**Item not fit:** #5 (2); #8 (1)	**Item not clear:** #2, 5 & 8 (2); #5 (1); #6 (1); #15 (1)
			Item #15	Yes (9)		
				No (1)		
Preparedness for Caregiving	15	Very well (8)	Item #1-4, 6-8	Yes (10)	All fit (7)	All clear (3)
		Pretty well (2)		No (0)	Some not fit (3)	Some not (7)
		Not too well (0)	Item #5	Yes (9)		
		Not at all (0)		No (1)	**Item not fit:** #2 (1); #3 & 7 (1); #5 (1)	**Item not clear:** #2, 4, & 5 (1); #3 (1); #3 & 7 (1); word "Preparedness" (1)
Predictability of the Caregiving Situation	16	Very well (7)	Item #2-4, 6	Yes (10)	All fit (9)	All clear (5)
		Pretty well (3)		No (0)	Some not fit (1)	Some not (5)
		Not too well (0)	Item #1, 5	Yes (9)		
		Not at all (0)		No (1)	**Item not fit:** ?	**Item not clear:** #4 (1); #5 (2); #6 (2)

Table 2

Summary of Content Validity Checked by 10 Japanese Nurses for Caregiving Concepts: Part A (cont.)

Concept Name	Page	Q. 1: Label & definition fit items as a whole? (n)	Q. 2: Each item belong to label & definition? (n)	Q. 3: Any item not fit Japanese Caregiving? (n)	Q. 4: Wording of any item unclear? (n)
Rewards of Meaning	17-18	Very well (6) Pretty well (4) Not too well (0) Not at all (0)	Item #1, 3, 10, 16-21, 24-26, 28, 30 Yes (10) No (0) Item #6 Yes (8) No (2) Item #12, 13,15, 27 Yes (9) No (1)	All fit (9) Some not fit (1) **Item not fit:** #6 (1)	All clear (5) Some not (5) **Item not clear:** #6 (2); #13 (2); #16 (1); #21 (1); #24 (1); words “Reward”, “Satisfy”, “Accomplish” (1)
Rewards of Learning	17-18	Very well (6) Pretty well (4) Not too well (0) Not at all (0)	Item #2, 5,22, 31 Yes (10) No (0) Item #9 Yes (4) No (6)	All fit (10) Some not fit (0)	All clear (6) Some not (4) **Item not clear:** #5 (1); #9 (3)
Financial Rewards	17-18	Very well (9) Pretty well (1) Not too well (0) Not at all (0)	Item #4, 8,11 Yes (10) No (0)	All fit (8) Some not fit (2) **Item not fit:** #4 (1); #8 (1)	All clear (8) Some not (2) **Item not clear:** #4 (1); #8 (1)

Table 2

Summary of Content Validity Checked by 10 Japanese Nurses for Caregiving Concepts: Part A (cont.)

Concept Name	Page	Q. 1: Label & definition fit items as a whole? (n)	Q. 2: Each item belong to label & definition? (n)		Q. 3: Any item not fit Japanese Caregiving? (n)	Q. 4: Wording of any item unclear? (n)
Rewards from Other People	17 -18	Very well (6) Pretty well (4) Not too well (0) Not at all (0)	Item #7, 14, 23, 29	Yes (10) No (0)	All fit (9) Some not fit (1) **Item not fit:** "flattery"	All clear (9) Some not (1) **Item not clear:** #23 (1)
Role Strain from Lack of Resources	11	Very well (6) Pretty well (3) Not too well (1) Not at all (0)	Item #5-7 Item #2-4, 8	Yes (10) No (0) Yes (9) No (1)	All fit (10) Some not fit (0)	All clear (7) Some not (3) **Item not clear:** #4 (1); #8 (1) #2-6 (1)
Role Strain from Interpersonal Relationships within *Miuchi* (relatives)	13 21 23	Very well (6) Pretty well (3) Not too well (1) Not at all (0)	p.23: Item #4, 5 p.13: Item #19 Item #6, 16 p.21: Item #6, 7	Yes (10) No (0) Yes (8) No (2) Yes (9) No (1) Yes (9) No (1)	All fit (10) Some not fit (0)	All clear (7) Some not (3) **Item not clear:** p.13, #19 (1); p.23, #4 (1); p.23, #5 (1)

Table 3

Summary of Content Validity Checked by 10 Japanese Nurses for Caregiving Concepts: Part B

	Page	Q. 1: Label & definition fit items as a whole? (n)	Q. 2: Any item not fit label & definition? (n)	Q. 3: Any item not fit Japanese Caregiving? (n)	Q. 4: Wording of any item unclear? (n)
Amount of and Role Strain from Caregiving Activities	4-10	Very well (8) Pretty well (2) Not too well (0) Not at all (0)	All fit (8) Some not fit (2) **Item not fit:** #24 (1)	All fit (8) Some not fit (2) **Item not fit:** #16 (1); #40 (1) p.10: #4 (1); #5 (1)	All clear (8) Some not (2) **Item not clear:** #9 (1); #17 (1); #40 (1)
Role Strain from Economical Burden	11 13 22	Very well (10) Pretty well (0) Not too well (0) Not at all (0)	All fit (10) Some not fit (0)	All fit (10) Some not fit (0)	All clear (9) Some not (1) **Item not clear:** p.11, #9 (1)
Role Strain from Worry	13	Very well (8) Pretty well (2) Not too well (0) Not at all (0)	All fit (9) Some not fit (1) **Item not fit:** #1-3, 7, 9-11, 14-20 (1)	All fit (10) Some not fit (0)	All clear (6) Some not (4) **Item not clear:** #2 (2); #7 (1)

Table 3

Summary of Content Validity Checked by 10 Japanese Nurses for Caregiving Concepts: Part B (cont.)

Concept Name	Page	Q. 1: Label & definition fit items as a whole? (n)	Q. 2: Any item not fit label & definition? (n)	Q. 3: Any item not fit Japanese Caregiving? (n)	Q. 4: Wording of any item unclear? (n)
Amount of Communication Problems and Role Strain from these Problems	14	Very well (6) Pretty well (4) Not too well (0) Not at all (0)	All fit (10) Some not fit (0)	All fit (10) Some not fit (0)	All clear (8) Some not (2) **Item not clear:** #3 (2)
Role Strain from Role Conflict	19	Very well (7) Pretty well (1) Not too well (2) Not at all (0)	All fit (10) Some not fit (0)	All fit (8) Some not fit (2) **Item not fit:** #11 (2)	All clear (9) Some not (1) **Item not clear:** #13 (1)
Role Strain from Mismatched Expectations	21	Very well (6) Pretty well (3) Not too well (1) Not at all (0)	All fit (10) Some not fit (0)	All fit (10) Some not fit (0)	All clear (10) Some not (0)

Table 3

Summary of Content Validity Checked by 10 Japanese Nurses for Caregiving Concepts: Part B (cont.)

Concept Name	Page	Q. 1: Label & definition fit items as a whole? (n)	Q. 2: Any item not fit label & definition? (n)	Q. 3: Any item not fit Japanese Caregiving? (n)	Q. 4: Wording of any item unclear? (n)
Role Strain from Increased Tension	22	Very well (3) Pretty well (6) Not too well (1) Not at all (0)	All fit (5) Some not fit (5) **Item not fit:** #7 (2); #9 (2); #13 (3)	All fit (10) Some not fit (0)	All clear (7) Some not (3) **Item not clear:** #7 (2); #9 (2); #13 (2)
Role Strain from Feelings of Being Manipulated	22	Very well (7) Pretty well (3) Not too well (0) Not at all (0)	All fit (8) Some not fit (2) **Item not fit:** #6 (1); #12 (2)	All fit (10) Some not fit (0)	All clear (7) Some not (3) **Item not clear:** #4 (3)
Global Strain	23	Very well (9) Pretty well (1) Not too well (0) Not at all (0)	All fit (10) Some not fit (0)	All fit (10) Some not fit (0)	All clear (9) Some not (1) **Item not clear:** #1 (1)
Amount of Negative Life Style Change	22	Very well (7) Pretty well (3) Not too well (0) Not at all (0)	All fit (10) Some not fit (0)	All fit (10) Some not fit (0)	All clear (9) Some not (1) **Item not clear:** #14 (1)

Table 4

Summary of Content Validity Checked by 10 Japanese Nurses for Demographic Information Pages: Part C

Concept Name	Page	Q. 1: Wording of any item or direction unclear?	(n)	Q. 2: Any item not fit Japanese Caregiving?	(n)
Directions for Answering the Questionnaire	front cover	All clear	(7)	All fit	(9)
		Some not	(3)	Some not fit	(1)
		Item not clear: Line #3 (1); Line # 4 (2); Line #5-7 (1)		**Item not fit:** "caring for *friends*"	
You and Your Family Member	1	All clear	(8)	All fit	(10)
		Some not	(2)	Some not fit	(0)
		Item not clear: #1 (1); #4 (1); #7 (1); #8 (1)			
Care Receiver's Current Situation	2-3	All clear	(6)	All fit	(9)
		Some not	(4)	Some not fit	(1)
		Item not clear: p.2, #18 (1); p.3, #1-4 (2); #8 (1)		**Item not fit:** #1 (1)	
Extent of Help	11	All clear	(5)	All fit	(9)
		Some not	(5)	Some not fit	(1)
		Item not clear: #1 (2); #2 (1); #3 (1); #4 (1)		**Item not fit:** #4 (1)	
Help from Others in Caregiving	12	All clear	(9)	All fit	(9)
		Some not	(1)	Some not fit	(1)
		Item not clear: #10a (1)		**Item not fit: words** "Family" vs. "Relative"	

Table 4

Summary of Content Validity Checked by 10 Japanese Nurses for Demographic Information Pages: Part C (cont.)

Concept Name	Page	Q. 1: Wording of any item or direction unclear? (n)		Q. 2: Any item not fit Japanese Caregiving? (n)	
Caregiver's Health	24-27	All clear	(7)	All fit	(9)
		Some not	(3)	Some not fit	(1)
		Item not clear: p.24, #6 (1); p.25, #15 (1); #18 (1); #22 (1); p.26, #3-12 (1); #3 word "Vigorous" (1)		**Item not fit:** p.24, #3 & 4 (1)	
Mutuality before Caregiving	30	All clear	(8)	All fit	(10)
		Some not	(2)	Some not fit	(0)
		Item not clear: #2 (1); #3 (1)			
Caregiver's View about Caregiving	30-31	All clear	(7)	All fit	(9)
		Some not	(3)	Some not fit	(1)
		Item not clear: #6 (1); #7 (2)		**Item not fit:** #7	(1)
Opinions about the Questionnaire	32	All clear	(9)	All fit	(9)
		Some not	(1)	Some not fit	(1)
		Item not clear: #4 (1)		**Item not fit:** complete sentences	

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Paper 2

Development of the Japanese Family Caregiving Inventory: Psychometric Evaluation

This is the second of two papers describing the development and evaluation of the Japanese Family Caregiving Inventory (JFCI), a translation and modification of the Family Caregiving Inventory (Archbold & Stewart, 1986). Paper 1 described the development of the JFCI (Inoue, 1995). In Phase 1 of the study, the key caregiving concepts in Japanese caregiving were defined and evidence for the content validity of the scales in the JFCI was gathered.

The purpose of Phase 2 of the study was to evaluate the psychometric properties of the JFCI using data from 224 Japanese family caregivers. This paper summarizes the psychometric evaluation of measures within the JFCI.

Measures

Most of the JFCI is a translation of the Family Caregiving Inventory (FCI), measures developed in the United Status by Archbold and Stewart (Archbold, Stewart, Harvath, & Lucas, 1986). The FCI was developed and tested through several studies with different groups of caregivers in the United States (Archbold & Stewart, 1991; Archbold, et al., 1986; Archbold, Stewart, Greenlick, & Harvath, 1990, 1992). Evidence for content validity of measures in this instrument had been supported by ratings of experts in gerontological nursing and methodology; research findings in the United States consistently supported the construct validity of measures in the FCI (Archbold et al., 1990; Stewart & Archbold, personal communication, 1993). Measures from the FCI selected for translation were chosen because there was evidence that the concepts would be valid in the Japanese caregiving situations (Inoue, 1995).

The conceptual framework of family caregiving developed by Archbold and colleagues (Archbold, 1982; Archbold, et al., 1986, Archbold & Stewart, personal communication, 1995) was used to guide the psychometric evaluation of measures in the JFCI. The major categories of variables in the framework were Antecedents of Caregiving, the Nature of the Caregiving Role Assumed, and Responses to Caregiving. In Figure 1, caregiving concepts for which measures were translated are designated by an asterisk (*) and new measures developed for the JFCI are designated by two asterisks (**). Other variables listed in Figure 1 were used for descriptive purposes.

Details of the psychometric findings from previous studies conducted by Archbold and colleagues (Archbold & Stewart, 1991; Archbold, et al., 1986; 1990, 1992) for each measure in the FCI are reported below, and modification of the measure for the JFCI, if needed, is described. Summary tables of the psychometric findings from studies in the United States can be found on Table 1. Unless indicated otherwise, scales were computed by averaging a caregiver's responses to all items on the measure. This approach resulted in scores that corresponded to the metric of the response format in the original FCI. Average scores on multi-item scales were computed if the caregiver answered 75% or more of the items, allowing for up to 25% missing data on each scale.

Antecedents of Caregiving

Antecedents of Caregiving includes the three caregiving concepts measured by the scales of Mutuality, Preparedness for Caregiving, and Caregiver Health Status as well as selected demographic questions. The Mutuality and Preparedness for Caregiving scales were developed by Archbold and Stewart (1986). Mutuality is a 15-item scale with a 5-point response format ranging from 0 = not at all to 4 = a great deal. This scale is composed of four subscales --Affective Closeness, Shared Values, Shared Pleasurable Activities, and Reciprocity. Preparedness for Caregiving is an 8-item scale with a 5-point response format ranging from 0 = not at all prepared to 4 = very well prepared. The potential range for the both scales was 0.00 to 4.00, with higher scores reflecting higher mutuality and more preparedness. In a series of four studies conducted by Archbold and Stewart since 1986 (Archbold et al., 1990, 1992; Stewart, personal communication, 1993), internal consistency reliability (Cronbach's alpha) estimates of the scale ranged from .91 to .95 for the Mutuality scale and from .83 to .92 for the Preparedness scale. In a study with 99 caregivers of elderly persons with Alzheimer's Disease or other memory problems, the test-retest reliability over a 1-month interval was .92 (n = 95) for the Mutuality scale and .81 (n = 96) for the Preparedness scale (Stewart, et al., 1993).

Three different scales were included in the JFCI to measure Caregiver Health Status. The 23 items related to common health problems and general health developed by Archbold and Stewart (1986) were translated. Archbold and Stewart adapted nine of these 23 items from the measure developed by Montgomery and Borgatta (undated), then used a different response format. Archbold and Stewart developed two scales, the 12-item Medical Problems scale (e.g., arthritis, cancer, diabetes) and the 11-item System Problems scale (e.g., back, eyes, memory). The potential range for each scale was 0 to 12 for Medical Problems and 0 to 11 for System Problems, with higher scores reflecting more health problems. In previous studies conducted by Archbold and Stewart (personal communication, 1993), internal consistency reliability (Cronbach's alpha) estimates ranged from .54 to .61 for the Medical Problems scale and from .56 to .70 for the System Problems scale.

In addition, five subscales measuring general health (5 items), physical functioning (10 items), energy/fatigue (4 items), emotional well-being (5 items), and health change (1 item) from the RAND 36-item Health Survey (RAND, 1992) were translated. The remaining four RAND subscales, including role functioning-physical (4 items), role functioning-emotional (3 items), social functioning (2 items), and pain (2 items), were not used because components of these subscales were included in other parts of the FCI. For those components of the RAND that were used, a person's score on each item was recoded by values specified for the RAND, then averaged together to create each scale score. The potential range for the five subscales was 0 to 100, with higher scores reflecting better health. Internal consistency reliability estimates (Cronbach's alpha) of the four multi-item subscales ranged from .78 to .93 (RAND, 1992).

The questions about demographic characteristics of the care receiver included age, gender, and types of activities and length of time he or she had required help because of health and/or memory problems. The questions about demographic characteristics of a caregiver included age, gender, education level, marital status, employment status, household income, length of time he or she had provided care for the care receiver, and the relationship status with respect to the care receiver.

Nature of the Caregiving Role Assumed

Nature of the Caregiving Role Assumed was measured using five scales --1) Amount of Direct Care, 2) Amount of Managed Care, 3) Amount of Communication Problems, 4) Predictability of the Caregiving Situation, and 5) Amount of Negative Life Style Change. Amount of Direct Care is an 80-item scale that asks caregivers whether they do each of the listed caregiving activities. This scale includes the eight subscales: 1) personal care, 2) protection, 3) management of behavior problems, 4) medically-related tasks, 5) housekeeping, 6) transportation, 7) financial, legal, and health decision making, and 8) little extras. Amount of Managed Care is a 6-item scale that also asks caregivers whether they do each of the listed caregiving activities; it includes a list of different types of managed care tasks such as contacting health service agencies and getting help from outside the family. Both scales employ response options of yes (1) or no (0); the score is computed by summing the yes answers. Across the four studies examining psychometric properties of measures, the Amount of Direct Care scale ranged from 38 items in the study with 103 caregivers of post hospitalized elderly persons (the Caregiver Relief Study) to its current length of 80 items. Cronbach's alpha reliability estimates ranged from .79 to .91 (Stewart, personal communication, 1993).

Amount of Managed Care scale contained three items in the Caregiver Relief Study and currently contains six items. Cronbach's alpha reliability estimate of the 3-item scale was .87 (Stewart, personal communication, 1993). For the JFCI, the number of items for Amount of Managed Care scale was reduced from six to four, based on the content validity results. The potential range for the Amount of Direct Care scale was 0 to

80 and for the Amount of Managed Care was 0 to 4, with higher scores indicating that more care was provided.

Amount of Communication Problems is a 4-item scale with a 5-point response format ranging from 0 = not at all to 4 = a great deal. The potential range for the scale was 0.00 to 4.00 with, higher scores reflecting more communication problems. In a previous study, this scale contained three items and had reliability estimates (Cronbach's alpha) of .33 (Stewart, personal communication, 1993). This scale asked about different components of communication, such as hearing, speaking, and memory, that could occur independently. Therefore, high internal consistency was not expected for this scale. In the JFCI, a fourth item on hearing problems of the caregiver was used for the scale.

Predictability of the Caregiving Situation is a 6-item scale with a 5-point response format ranging from 0 = not at all or never to 4 = very or always. The potential range for the scale was 0.00 to 4.00, with higher scores reflecting more predictability. In previous studies, Archbold and Stewart used a 4-point response format for this scale (Archbold & Stewart, 1986). The scale with a 4-point response format had Cronbach's alpha reliability estimates that ranged from .82 to .88 (Stewart, personal communication, 1993).

Amount of Negative Life Style Change is a 6-item scale with a 5-point response format ranging from 0 = not at all to 4 = a great deal. The scale was originally developed by Montgomery and Borgatta (undated) to measure the concept of objective burden, but was used by Archbold and Stewart (1986) to measure the concept they refer to as Amount of Negative Life Style Change. The potential range for the scale was 0.00 to

4.00, with higher scores reflecting that more negative life style changes were made as a result of caregiving. This scale had reliability estimates (Cronbach's alpha) ranging from .84 to .90 in two studies of caregivers (Stewart, personal communication, 1993).

Responses to Caregiving

Responses to Caregiving were measured with 12 Caregiver Role Strain scales and four Rewards of Caregiving scales. Among 11 Caregiver Role Strain scales translated from the FCI, nine were developed by Archbold and Stewart (1986) (i.e., Global Strain and Caregiver Role Strain from Direct Care, Managed Care, Lack of Resources, Worry, Role Conflict, Economic Burden, Mismatched Expectations, and Communication Problems) and two were developed by Montgomery and Borgatta (undated) (i.e., Caregiver Role Strain from Increased Tension and Caregiver Role Strain from Feelings of Being Manipulated). One measure, Role Strain from Interpersonal Relationships within *Miuchi* (relatives), was newly developed and added to the JFCI. Three Rewards of Caregiving scales translated from the FCI were developed by Archbold and Stewart (1986) (i.e., Rewards of Meaning, Rewards of Learning, and Financial Rewards). One newly developed measure, Rewards from Other People, was added into the JFCI.

Items on the Caregiver Role Strain from Direct and Managed Care scales use a 5-point response format ranging from 1 = easy to 5 = very hard. The potential range for these two scales is 1.00 to 5.00, with higher scores reflecting more difficulty in providing care. Unless indicated otherwise, other Caregiver Role Strain scales and Rewards of Caregiving scales use a 5-point response format ranging from 0 = not at all to 4 = a great deal. The potential range for these scales is 0.00 to 4.00, with higher scores reflecting more strain or more rewards.

Caregiver Role Strain from Direct Care is an 80-item scale and Caregiver Role Strain from Managed Care is a 6-item scale. These scales ask caregivers how hard it is to provide each of the listed caregiving activities for which they answered yes on the Amount of Direct Care and Amount of Managed Care scales. Across the four studies examining psychometric properties of measures, the Caregiver Role Strain from Direct Care scale ranged from 38 items in the Caregiver Relief Study to its current length of 80. Cronbach's alpha reliability estimates of this scale ranged from .96 to .99 (Stewart, personal communication, 1993). The number of items on the Caregiver Role Strain from Managed Care scale increased from the original 3-item version to the current 6-item version. The 3-item version of this scale had reliability estimates (Cronbach's alpha) of .87 (Stewart, personal communication, 1993). As mentioned earlier, for this study, the number of items for Caregiver Role Strain from Managed Care scale was reduced from six in the FCI to four in the JFCI.

Caregiver Role Strain from Lack of Resources is a 5-item scale with a 5-point response format ranging from 0 = not a problem to 4 = a very big problem. In four previous studies, this scale had Cronbach's alpha reliability estimates ranging from .74 to .91 and test-retest reliability of .72 (n = 96) (Stewart, personal communication, 1993). For this study, two new items were added ("Not having enough space" and "Not having a separate room for him or her") in order to increase the scale's content validity for Japanese caregiving situations. Both the 5-item and 7-item scales were evaluated.

Caregiver Role Strain from Worry is a 12-item scale. Cronbach's alpha reliability estimates of this scale ranged from .86 to .90 (Stewart, personal communication, 1993).

Caregiver Role Strain from Role Conflict is a 14-item scale. This scale had Cronbach's alpha reliability estimates ranging from .84 to .93 (Stewart, personal communication, 1993).

Caregiver Role Strain from Economic Burden is a 4-item scale with a 5-point response format ranging from 0 = not at all or not a problem to 4 = a great deal or a very big problem. This scale had Cronbach's alpha reliability estimates ranging from .66 to .77 (Stewart, personal communication, 1993).

Caregiver Role Strain from Mismatched Expectations is a 3-item scale. Two items have a 2-point response format, 0 = no and 1 = yes, and one item has a 5-point response format ranging from 0 = never to 4 = always. This scale had Cronbach's alpha reliability estimates ranging from .28 to .60 (Stewart, personal communication, 1993).

Caregiver Role Strain from Communication Problems is a 4-item scale. This scale had Cronbach's alpha reliability estimate of .77 (Stewart, personal communication, 1993).

Global Strain is a 4-item scale with a 5-point response format ranging from 0 = not at all, never, no stress, or the positive outweighs the negative a lot to 4 = extremely, always, overwhelming, or the negative outweighs the positive a lot. This scale had Cronbach's alpha reliability estimates ranging from .72 to .84. Test-retest reliability estimates over a 1-month interval was .81 (n = 96) (Stewart, personal communication, 1993).

Caregiver Role Strain from Increased Tension is a 4-item scale. The scale, originally developed by Montgomery and Borgatta (undated) to measure subjective burden, was used by Archbold and Stewart (1986) to measure the concept of Caregiver Role Strain from Increased Tension. This scale had Cronbach's alpha reliability estimates ranging from .82 to .93 (Stewart, personal communication, 1993).

Caregiver Role Strain from Feelings of Being Manipulated is a 4-item scale. The scale, originally developed by Montgomery and Borgatta (undated) to measure subjective burden, was used by Archbold and Stewart (1986) to measure the concept of caregiver role strain from feelings of being manipulated. This scale had Cronbach's alpha reliability estimates ranging from .84 to .94 (Stewart, personal communication, 1993).

Three Rewards of Caregiving scales -- Rewards of Meaning, Rewards of Learning, and Financial Rewards -- have four, three, and three items respectively. In a series of four studies conducted by Archbold and Stewart since 1986 (personal communication, 1993), internal consistency reliability estimates (Cronbach's alpha) ranged from .76 to .94 and test-retest reliability estimates was .82 (n = 96) for the Rewards of Meaning scale, .20 to .66 and test-retest reliability estimates of .66 (n = 92) for the Rewards of Learning scale, and .47 to .82 and test-retest reliability estimates of .73 (n = 85) for Financial Rewards (Stewart, personal communication, 1993).

For the JFCI, the number of items for Financial Rewards scale was reduced from three to one, and one open-ended question ("Do you think caring for your family member gives you any financial advantage or disadvantage? Would you describe your thoughts?) was added based on content validity results. In addition to these scales, a 4-item

Japanese scale, Rewards from Other People, was developed for this study. Archbold and Stewart (personal communication, 1993) recently increased the number of items from 4 to 18 for the Rewards of Meaning scale and from 3 to 5 for Rewards of Learning scale. For the JFCI, the number of items for Rewards of Meaning scale was reduced from 18 to 14. Although additional items for the Rewards of Meaning and Rewards of Learning scales were included in the JFCI, only the original 4-item Rewards of Meaning and 3-item Rewards of Learning versions were evaluated.

Social Desirability

The Marlowe-Crowne Social Desirability Scale (M-C SDS) was used to examine the influence of response-set bias related to social desirability on scales in the JFCI. The original M-C SDS is a 33-item self-report scale that was developed to measure response-set bias and has been widely used since it was published (Crowne & Marlowe, 1960). For the M-C SDS in a sample of college students, reported internal consistency reliability estimate was .88 and the test-retest reliability estimate for a 1-month interval was .89.

The M-C SDS was translated into Japanese and its psychometric qualities evaluated by Nojima (1982). In a sample of 43 Japanese women, the internal consistency reliability (Kuder-Richarson Formula 20) of the Japanese version of the M-C SDS was .81 (Nojima, 1982). Even though this value was somewhat lower than internal consistency reliability estimates of the original M-C SDS, it was an acceptable level. Nojima noted that the mean was 13.1 (SD = 4.9) for the original M-C SDS and 12.8 (SD = 5.6) for the Japanese translated M-C SDS in a sample of English-Japanese bilingual persons (n = 11). The correlation between the original M-C SDS and the Japanese translated M-C SDS over a 3-week interval with this sample was .89. This value was the same level as the test-retest reliability estimates over a 1-month interval in the original M-C SDS. Nojima's Japanese version of the M-C SDS was used in a study of the construction and validation of a measure of *Amae* network with 482 Japanese female students (Minami, 1982).

In order to select a shorter version of the social desirability scale for the current study, a comparison of three M-C SDS short forms developed by Ballard (1992), Reynolds (1982), and Strahan and Gerbasi (1972) was made. The Reynolds 13-item form and the Strahan and Gerbasi 20-item form have adequately high reliability estimates (.76 for the 13-item form, .73 to .87 for the 20-item form) compared to the original 33-item form (.73 to .83) and high correlations with the original 33-item form (.93 for the 13-item form, .95 for the 20-item form). The 13-item form was chosen for the current study because it is psychometrically similar to these other forms and has fewer items. The Japanese version of the 13-item form was constructed from Nojima's Japanese translated M-C SDS. The potential range for the 13-item scale was 0 to 13, with higher scores reflecting more socially desirable responses.

Hypotheses

Based on the results from previous studies (Archbold & Stewart, 1991, Archbold, et al., 1986, 1990), the framework for this study posits that Antecedents of Caregiving will be associated with the Nature of the Caregiving Role Assumed, and the Nature of the Caregiving Role Assumed will be associated with the Responses to Caregiving (see Figure 1). The following hypotheses were generated based on the previous work of

Archbold and Stewart. These hypotheses were tested to examine the construct validity of the JFCI.

1. Mutuality will be negatively related to caregiver role strain, except for caregiver role strain from lack of resources, economic burden, and worry which will not be related to mutuality.

2. Mutuality will be positively related to rewards of meaning in caregiving.

3. Preparedness for caregiving will be negatively related to caregiver role strain.

4. Predictability of the caregiving situation will be negatively related to caregiver role strain.

5. Amount of direct care will be positively related to caregiver role strain.

6. Amount of negative life style change will be positively related to caregiver role strain.

7. Rewards of meaning will be negatively related to caregiver role strain.

8. Caregivers' health will be negatively related to caregiver role strain.

Some potential predictors of caregiver burden have been identified by Japanese researchers (Maeda & Shimizu, 1984; Nakatani & Tojo, 1989; Niina, Yatomi, & Honma, 1991; Niina, Yatomi, Honma, & Sakata, 1989; Shimizu, 1991; Shimizu & Honma, 1978; Sugisawa, Nakamura, Nakano, & Sugisawa, 1992). However, contradictory findings were reported regarding the relationships between caregiver burden and those variables including the care receiver's impairment level, the caregiver's age, employment status, type of household, other caregiving responsibilities, and social support. In addition, as some of the researchers (Nakatani & Tojo, 1989; Niina et al., 1989; Shimizu, 1991) indicated, the instruments used were not well established and needed further evaluation. Therefore, these variables were not included in the hypotheses for this study.

Method

Pretesting

After content validity was examined (Inoue, 1995), the JFCI was revised, the revised draft of the JFCI was pretested with 10 Japanese caregivers who were identified for the pretest through the investigator's personal network. Nine of them completed the questionnaire, one could not complete it by the deadline. The pretest sample included 2 men and 7 women, currently providing some care at home for elderly persons who were 65 years of age or older and who have one or more ADL and/or IADL impairments. Two men and 2 women were school teachers, 3 were nurses, 1 was a social worker, and 1 was a house wife.

These Japanese caregivers were asked to evaluate the clarity of each item and directions for each scale. None of these caregivers identified any unclear items or directions. The only comment some of them made was that the length of the questionnaire was too long.

Sample

Sampling Procedure

Family members who were known to provide care for their impaired elderly relatives were invited to participate in this study. These potential respondents were accessed through a local Japanese governmental office for elderly care. The sampling criteria were 1) the caregiver is currently providing care for his or her elderly family member, 2) the care receiver is 65 years of age or older, 3) the care receiver requires help in one or more ADL and/or IADL, 4) the caregiver is able to read to answer a self-administered questionnaire, and 5) both the caregiver and the care receiver live in the study area which is a middle size city in Japan.

Altogether, 392 caregivers were identified through the local governmental office for elderly care. A letter was sent to all these caregivers to invite them to participate in the study; potential participants were asked to contact the investigator if they could not or would not participate in this study.

Human Subjects

Before collecting data, the investigator sent the proposal of this study to the Institutional Review Board (IRB) of the Oregon Health Sciences University. The IRB gave the study "exempt" status, and indicated that the risk to participants in this study was minimal and the proposed study procedure was reasonable. Because responses could be anonymous, no consent was required. Return of questionnaire implied consent.

Response Rate

Of the 392 letters sent, 6 were returned because the forwarding address was unknown and 32 caregivers responded to the invitation letter stating they would not be able to participate in this study. Twenty-five of the 32 caregivers were not eligible: 9 care receivers had died, 10 care receivers were institutionalized, 5 caregivers were hospitalized, and 1 caregiver was not currently providing care. Four caregivers said they could not participate because of either the care receiver's health condition or their own, including 1 caregiver who was blind, 1 caregiver who had had a recent eye operation, 1 caregiver who was injured on her writing hand, and 1 care receiver was too sick. Three caregivers who did not want to participate gave no reason.

In total, 354 questionnaires were mailed to caregivers and 238 questionnaires were returned. Of these 238, 14 were incomplete because less than 75% of the questionnaire was answered and 224 were usable for analysis. The return rate was 67% and the usable rate was 63%. Of the 238 returned questionnaires, 70 (29%) caregivers were interested in receiving a summary of the study results.

Description of the Subjects

Age of caregivers ranged from 34 to 87 years (M = 63.4) and most were married (83%) and female (86%). Average length of education was 10.8 years and most caregivers had more than nine years education (81%). More than two-thirds were not employed (68%), including 17% who had quit a job because of caregiving. The majority (85%) felt their income was either "just enough" or "enough with a little extra sometimes." Their relationship with the care receiver was as follows: wife (39%), daughter (31%), daughter-in-law (16%), husband (7%), son (4%), and others (3%). Nearly all caregivers (95%) lived with the care receiver. Most caregivers (85%) spent 7 days a week (M = 6.9) and more than half of them (57%) spent more than 8 hours a day (M = 11.4) in helping the care receiver. The average length of time that they had been involved in caregiving was 7.7 years.

Age of care receivers ranged from 65 to 101 years (M = 80.8), and 53% were female. About half (53%) were married and 43% were widowed. About one-third (36%) lived only with their spouse and 4% lived alone. The fewest number of care receivers needed help in the ADL of eating (66%) and the greatest number needed help in the IADL of shopping and transportation (97%). About half (49%) were either totally bedridden or in a vegetative state or non responsive. About 92% of care receivers had received a medical diagnosis. Stroke was the most common medical diagnosis (60%) followed by dementia (16%), hypertension (8%), and Parkinson's Disease (7%). A summary of the characteristics of the caregivers and care receivers is presented in Table 2.

Data Collection Procedure

The data were collected using a mailed questionnaire design. The investigator prepared a questionnaire packet that included an explanatory letter about the study, the JFCI, and a stamped, self-addressed return envelope. Two weeks after the invitation letters to potential participants for the study were sent out, the questionnaire packet was sent to all caregivers except those who indicated that they would not be able to participate or whose address was unknown. The caregiver was asked to send back the questionnaire directly to the investigator by using the stamped, self-addressed return envelope that was enclosed in the questionnaire packet.

Results

Data were analyzed using the Statistical Package for Social Science (SPSS) for Windows, a statistical package for a personal computer (SPSS Inc., 1994). The JFCI contains some additional items translated from English-version measures that are newly developed by Archbold and Stewart. Because an evaluation of these items is currently in process with data from spousal caregivers for persons with Parkinson's Disease, the items were not included in the analysis of this study (Archbold & Stewart, personal communication, 1995).

Analysis of Reliability

After descriptive statistics (frequencies, means, and standard deviations) for each item were reviewed, Cronbach's alpha of each scale was calculated to determine the internal consistency reliability. In SPSS, Cronbach's alpha is computed using only those subjects who have answered all items on the scale. For the scales of the Caregiver Role Strain from Role Conflict, Direct Care, Managed Care, and Communication Problems, many caregivers answered "not applicable" if they did not have some of the listed roles or did not do some of the listed caregiving tasks. In order to estimate Cronbach's alpha using the maximum number of subjects, standardized alpha was estimated based on the pairwise correlation matrix among items in the scale. The summary of the psychometric findings of the JFCI can be found in Table 3, including the number of cases on which Cronbach's alpha is based.

Scale Construction and Descriptive Statistics for the Scales

Scale development proceeded in three stages: 1) examination of internal consistency, 2) scale construction, and 3) review of scale statistics. After the internal consistency reliability was examined, scales were constructed for each measure. The scores for most of the scales in the JFCI were computed by averaging a caregiver's responses to all items on the scale (Archbold, et al., 1986). Average scores were computed as long as the caregiver had answered 75% or more of the items. For three scales (Amount of Direct Care, Amount of Managed Care, and Caregiver Health Status), the computation procedure was different. Computation for these scales was based on a sum rather than on an average of the items. The investigator for this study followed the procedures recommended by Archbold and Stewart. After constructing the scale, descriptive statistics of each scale were reviewed.

For each scale, the possible range of scores, the actual range of scores, the mean, standard deviation, skewness, and kurtosis, are presented in Table 4. The actual range of score for all scales was the same or nearly the same as the possible range of scores

The frequency distributions for seven of the scales were significantly ($p < .01$) skewed: the Medical Problems in Caregiver Health Status scale (Skew. = 1.01), the System Problems in Caregiver Health Status scale (Skew. = .76), the RAND-Physical Function subscale in Caregiver Health Status scale (Skew. = -1.49), the Caregiver Role Strain from Direct Care scale (Skew. = .83), the Caregiver Role Strain from Managed Care scale (Skew. = .63), the Caregiver Role Strain from Interpersonal Relationships within *Miuchi* scale (Skew. = .91), and the Caregiver Role Strain from Feeling of Being Manipulated scale (Skew. = .73). Two scales were significantly ($p < .01$) leptokurtic, having peaked shape: the RAND-Physical Function subscale in Caregiver Health Status scale (Kurt. = 2.13) and the Caregiver Role Strain from Interpersonal Relationships within *Miuchi* scale (Kurt. = 1.44). The other eight scales were significantly ($p < .01$ or $p < .05$) platykurtic, having flat distributions throughout the possible range of scores: the Mutuality scale (Kurt. = -1.03), the Amount of Managed Care (Kurt. = -.93), the Caregiver Role Strain from Role Conflict scale (Kurt. = -1.05), the Caregiver Role Strain from Economic Burden scale (Kurt. = -.93), the Caregiver Role Strain from Mismatched

Expectations scale (Kurt. = -1.07), the Caregiver Role Strain from Increased Tension scale (Kurt. = -.93), the Rewards of Meaning scale (Kurt. = -.94), and the Rewards of Learning scale (Kurt. = -.90).

Missing data for each scale are presented in Table 3. Of 29 caregiving scales, 16 scales had low levels of missing data (0 to 9.4%). The remaining 14 scales had relatively high levels of missing data (10.3 to 29%). The percentages of missing data for four scales (the RAND Physical Function subscale, the RAND Emotional Well-being subscale, and the RAND Fatigue subscale, and the Caregiver Role Strain from Managed Care scale) were higher than 20%.

Analysis of Construct Validity

Initial evidence of construct validity was examined. Construct validity can be obtained using several different strategies (Messick, 1980). The most common strategy for obtaining evidence for construct validity is testing hypothesized relationships between variables (Stewart & Petersen, 1982). To obtained evidence for construct validity, the correlations between developed scales were reviewed based on the hypotheses listed earlier. Because response-set biases could interfere with accuracy of measures, the extent to which the measures were influenced by a respondent's tendency to respond in a direction which is socially desirable was examined.

Hypotheses Testing

The scales were separated into four groups to examine the relationships among the scales based on the conceptual framework. Group 1 contained 5 scales measuring the nature of caregiving role, including Amount of Direct Care, Managed Care, and

Communication Problems, Predictability of Caregiving Situation, and Amount of Negative Life Style Change scales. Group 2 contained 5 scales measuring positive aspects of caregiving, including Mutuality, Preparedness of Caregiving, Rewards of Meaning, Rewards of Learning, and Rewards from Other People scales. Group 3 contained 12 scales measuring caregiver role strain, including Global Strain and Caregiver Role Strain from: Direct Care, Managed Care, Lack of Resources, Worry, Role Conflict, Economic Burden, Mismatched Expectations, Communication Problems; Increased Tension, Feelings of Being Manipulated, and Interpersonal Relationships within *Miuchi* scales. Group 4 included six scales measuring caregiver's health status.

Relationships among scales within the same group and hypothesized relationships among scales were examined (see Table 5). All scales within Group 2 and 4 were significantly related to one other ($\underline{p} < .01$) in the expected direction. Most of scales within Group 3 were also intercorrelated as expected ($\underline{p} < .01$ or $\underline{p} < .05$). Only 3 out of 78 possible correlations were not significant at $\underline{p} < .10$ and 2 others had $\underline{p}$ values of $< .08$. Among 4 of 10 possible correlations in Group 1, 4 were significant ($\underline{p} < .01$ or $\underline{p} < .05$) and 2 had $\underline{p}$ values of $< .08$. Those weak or non-significant correlations were as expected. In Group 2, the correlations between the Rewards of Meaning scale and the Rewards of Learning and Rewards from Other People scales were higher than expected. The results from these correlations can be found in Tables 6 to 10. A summary of the hypothesized relationships among scales is presented in Table 11.

Hypothesis 1: Mutuality will be negatively related to caregiver role strain except for caregiver role strain from lack of resources, economic burden, and worry which are hypothesized not to be related to mutuality. As expected, the Mutuality scale related significantly ($p < .01$) and negatively with five out of nine Caregiver Role Strain scales and did not correlate with the Caregiver Role Strain from Lack of Resources, Economic Burden, and Worry scales. The Mutuality scale was not significantly related to Caregiver Role Strain from Role Conflict and Managed Care scales. The negative correlation between the Mutuality and the Caregiver Role Strain from Communication Problems scales was weak but in the expected direction ($p < .08$). The correlation between the Mutuality and the Interpersonal Relationships within *Miuchi* scales was weak but unexpectedly in the positive direction ($p < .07$).

Hypothesis 2: Mutuality will be positively related to rewards of meaning in caregiving. The Mutuality scale correlated significantly ($p < .01$) and positively with all three rewards scales (i.e., Rewards of Meaning, Rewards of Learning, and Rewards from Other People).

Hypothesis 3: Preparedness for caregiving will be negatively related to caregiver role strain. The Preparedness for Caregiving scale correlated significantly and negatively to 5 of 12 Caregiver Role Strain scales ($p < .01$). The correlation with the Caregiver Role Strain from Worry scale was not significant but in the expected direction ($p < .07$). The other six scales -- Caregiver Role Strain from Lack of Resources, Role Conflict, Communication Problems, Direct Care, Managed Care, and Interpersonal Relationships within *Miuchi* -- were not significantly correlated with Preparedness for Caregiving scale.

Hypothesis 4: Predictability of the caregiving situation will be negatively related to caregiver role strain. Predictability of the caregiving situation correlated significantly ($p < .01$ or $p < .05$) and negatively with 5 of 12 Caregiver Role Strain scales. The other 7 scales -- Caregiver Role Strain from Worry, Mismatched Expectations, Lack of Resources, Role Conflict, Direct Care, Managed Care, Interpersonal Relationships within *Miuchi*, and Global Strain -- were not significantly correlated with the Predictability of Caregiving Situation scale. However, the 7-item Caregiver Role Strain from Lack of Resources scale was correlated significantly ($p < .05$) and negatively to the Predictability of Caregiving Situation scale.

Hypothesis 5: Amount of direct care will be positively related to caregiver role strain. Amount of Direct Care scale correlated significantly ($p < .01$ or $p < .05$) and positively with all but two Caregiver Role Strain scales. Two scales -- Caregiver Role Strain from Economic Burden and Communication Problems -- were not significantly correlated with Amount of Direct Care scale.

Hypothesis 6: Amount of negative life style change will be positively related to caregiver role strain. Amount of negative life style change correlated significantly ($p < .01$ or $p < .05$) and positively with 11 of 12 Caregiver Role Strain scales. Only one scale -- Caregiver Role Strain from Managed Care -- was not significantly correlated with Amount of Negative Life Style Change scale, however, the correlation was in the expected direction ($p < .07$).

Hypothesis 7: Rewards of meaning will be negatively related to caregiver role strain. Rewards of meaning correlated significantly ($p < .01$ or $p < .05$) and negatively with 3 out of 12 Caregiver Role Strain scales --Global Strain and Caregiver Role Strain from Mismatched Expectations, Increased Tension. These correlations were very similar to the correlations between the Rewards of Learning scale and the Caregiver Role Strain scales except for one scale. Unexpectedly, the Rewards of Learning was significantly ($p < .05$) and positively correlated to the Caregiver Role Strain from Interpersonal Relationships within *Miuchi*.

Hypothesis 8: Caregivers' health status will be negatively related to caregiver role strain. All but eight relationships between six Caregiver Health scales and 12 Caregiver Role Strain scales were significantly correlated ($p < .01$ in 59 relationships and $p < .05$ in 5 relationships) in the expected direction. Among the 8 non-significant relationships, two were weak but nearly significant ($p < .06$). The other 6 were between the Medical Problems and the Caregiver Role Strain from Interpersonal Relationships within *Miuchi* scales; between the RAND Physical Function subscale and the Caregiver Role Strain from Role Conflict, Communication Problems, and Interpersonal Relationships within *Miuchi* scales; and between the RAND Emotional Problem subscale and General Health subscale and the Caregiver Role Strain from Managed Care scale.

Effects of Social Desirability on Responses

Because response-set biases can interfere with accurate measures of the target attribute, the extent to which the JFCI was influenced by the caregiver's tendency to respond in a socially desirable direction was of concern to the investigator. To estimate the influence of social desirability, a Japanese translation of the 13-item Marlowe-Crowne Social Desirability Scale (M-C SDS) (Nojima, 1982) was included in the questionnaire for this study.

Cronbach's alpha was calculated to determine the internal consistency reliability of the M-C SDS. The reliability estimate of the M-C SDS was lower than expected (α =.34). Based on examination of item level correlations, evidence for two subscales was found. Each subscale was computed separately and the reliability estimates of each subscale were at an acceptable level (α =.66 and .58). Even though the internal consistency reliability estimates of the 13-item M-C SDS was low, the investigator decided to use this 13-item scale instead of two subscales to examine the response-set biases because the Pearson correlation between these two subscales was relatively high ($r = .46$, $p < .001$). The Pearson correlation coefficients between the 13-item M-C SDS and each caregiving scale were computed to assess response-set biases.

Correlations between the 13-item M-C SDS and each caregiving scale are presented in Table 12. Seventeen of 29 caregiving scales of the JFCI were not significantly related to the 13-item M-C SDS ($p < .05$); these non-significant correlation coefficients ranged from -.13 to .14, with a median correlation coefficient of -.03. Even though 10 caregiving scales were significantly related to the 13-item M-C SDS, the magnitude of the correlations was low (absolute values ranging from .14 to .22). Two scales -- Preparedness for Caregiving ($r = .30$, $p < .01$) and Caregiver Health Status-RAND-Emotional subscale ($r = .25$, $p < .01$) -- exhibited significant correlations with social desirability that were of a low to moderate magnitude. However, even after controlling for social desirability, there was only one change in the significance of correlations between the Preparedness for Caregiving scale and the Caregiver Role Strain scales. The correlation with the Caregiver Role Strain from Feelings of Being Manipulated scale became non significant ($r = -.12$, $p < .09$).

Discussion

Characteristics of Subjects

Across studies of caregiving in Japan, 80 to 90% of caregivers were female, and the main caregivers of older persons were daughters-in-law (29 to 54%), daughters (10 to 31%), and wives (15 to 38%) (Fujita & Kuroda, 1987; Nakajima, Abe, et al., 1982, Nakajima, Saito, & Tsukihashi, 1982; Noguchi, 1988; Saito, Ogino, & Kaneko, 1989; Sato, 1989; Takasaki et al., 1987; Waki et al., 1984). The number of male caregivers in these studies was very small; 3 to 7% were husbands and 2 to 5% were sons. The number of female and male caregivers in this study is similar to those in other studies reported in the literature. However, the relationship between the caregivers and the care receivers in this study was different from the subjects of other studies -- in this sample there were more daughter caregivers (31%) than daughters-in-law (16%). There is no clear explanation for this difference but it may be a culture among people who live in the city where the study was conducted. One public health nurse told me, "Somehow, there are always more daughter caregivers in my city than other cities." In addition, even though daughters-in-law have been the largest group among family caregivers nationally in Japan, the number of daughter and spouse caregivers is increasing because of changing traditional values related to filial responsibility and increasing mobility. Therefore, the sample obtained for this study -- more daughters and fewer daughters-in-law -- may represent a current trend.

The degree to which subjects in this study represent a trait of the target population is an important issue in interpreting the study findings. Even though data about the population of caregivers in the city where this study was conducted are not available, some survey data about the elderly population in the city are reported (Matsumoto, & Onakado, 1990; Matsumoto, Onakado, Inoue, & Yokoyama, 1985). Based on these survey studies with a random sample of 1,869 persons from total population of 32,194 people 65 years or older (Matsumoto, et al., 1985) and a 5-year follow-up of these people (Matsumoto, & Onakado, 1990), the local governmental office for elderly care estimate about 450 older persons with health problems in need of help at home. The caregivers who were identified for the present study represent about 87% of those 450 impaired older people who include those without a family caregiver. Therefore, the caregivers who received an invitation letter for this study represent almost the entire target population. However, only 63% of those caregivers who received a letter could complete and return a questionnaire, and characteristics and caregiving situations of the remaining caregivers (37%) were unknown.

Evaluation of Psychometric Properties of Scales

Reliability

Cronbach's alphas for 24 of the 28 caregiving scales reached an acceptable level (α = .69 - .96) (Nunnally, 1978). For four scales -- Amount of Communication Problems (α = .53), Caregiver Role Strain from Mismatched Expectations (α = .55), Amount of Managed Care (α = .58), and Medical Problem subscale in the Caregiver Health Status (α = .63) -- the internal consistency level did not meet the .70 criterion recommended by Nunnally (1978) for research purposes; however, items in these four scales were not expected to be homogeneous. For example, in the Amount of Communication Problems scale, its four items asked about the extent of the care receiver's hearing, speaking, and understanding problems, and the caregiver's hearing problem. A care receiver who has a hearing problem does not necessarily have a speaking problem. Therefore, the internal consistency of the scale would not be expected to be high. In addition, three of these scales have a relatively small number of items (the Amount of Communication Problems scale, four items; the Caregiver Role Strain from Mismatched Expectations scale, five items; and the Amount of Managed Care scale, four items). Three of them (the Caregiver Role Strain from Mismatched Expectations scale, the Amount of Managed Care scale, and the Medical Problem subscale in the Caregiver Health Status scales) have dichotomous response options. Because Cronbach's alpha is related to the number of items in the scale and the range of response options, lower internal consistency for these three scales would be expected.

Response Rate

The overall response rate is one guide to the representativeness of the sample. Achieving a high response rate minimizes the chance of response bias. However, it is not clear how high a response rate should be in order to be acceptable. According to Babbie

(1990), "a response rate of at least 50 percent is generally considered adequate for analysis and reporting" (p. 182). The suggested response rate for a mailed survey by Dillman (1978) is 70% for general public and 77% for the specialized ones. Many of the procedures recommended by Dillman (1978) to increase response rate (e.g., reminder postcard, replacement questionnaire) could not be used in this study because names could not be matched to returned questionnaire. In light of these constraints, this study's return rate (67.2%) and usable rate (63.3%) were considered good.

Missing Data

It is also important that percentages of missing data on scales are at acceptable levels. Four scales -- the RAND Physical Function, Emotional Well-being, and Fatigue subscales of the Caregiver's Health Status scales and the Caregiver Role Strain from Managed Care scale -- had higher than 20% missing data and two others -- the RAND General Health subscales and the Caregiver Role Strain from Role Conflict scale -- had 16.5% missing data. The high percentage of missing data in these scales is of serious concern. The RAND scales contain four different response formats with five different response anchors within 25 items. This format may discourage people from completing the questions on the scale. Some older caregivers may not be able to answer the RAND Physical Function subscale because it contains activities that they may not do at all. For example, one item asks whether the person's health limits his or her ability to walk more than a mile. One caregiver commented that she does not know whether she can walk or not because she has not tried to walk that much recently. In this case, missing data would be high. The subjects of this study commented that the Caregiver Role Strain from Role

Conflict scale was the most confusing page. Clarification of the directions as well as item wording needs to be evaluated and additional instructional sentences may need to be added for this scale.

Construct Validity

For this study, the most important validity issue is whether or not the construct validity of the measure is supported by the findings. Evidence of construct validity for the scales was obtained through testing hypothesized relationships between measures (see Tables 10 and 11). Even though some correlations were not significant, most of the hypothesized relationships were supported.

Several unexpected but interesting findings were obtained. The correlation between the Caregiver Role Strain from Interpersonal Relationships within *Miuchi* scale and Mutuality scale was not significant ($r = .13$, $p < .07$), but it approached significance and its direction was positive. Examining the scatter plot of the correlation between these two scales, two outliers with scores higher than three standard deviations above the mean, were identified. After these two cases were taken out of analysis, the correlation between these two scales became significant ($r = .18$, $p < .05$). Mutuality was expected to correlate negatively with the Caregiver Role Strain scales except the scales of Strain from Lack of Resources, Worry, and Economic Burden. Among correlations of the Mutuality scale with the strain scales other than the Caregiver Role Strain from Interpersonal Relationships within *Miuchi* scale, five including those three scales were not significant, five were significant ($p < .01$ or $p < .05$) and negative, and one was not significant but in the negative direction ($p < .08$). The Caregiver Role Strain from

Interpersonal Relationships within *Miuchi* scale was significantly and positively correlated with all other strain scales (r = .15 to .47, p < .05). This scale was newly developed for Japanese family caregiving, thus, there are no previous data in the United States to use for comparison. However, the positive correlation between the Mutuality and the Caregiver Role Strain from Interpersonal Relationships within *Miuchi* scales can be interpreted. It is possible that, when the perspective of other family members is different from the perspective of the care receiver, the caregiver may have a very hard time standing with the care receiver even though the caregiver feels very close to the care receiver. In this case, the Mutuality scale would be positively correlated with the score of the Caregiver Role Strain from Interpersonal Relationships within *Miuchi* scale.

Caregiver Role Strain from Interpersonal Relationships within *Miuchi* was also significantly and positively correlated with the Rewards of Learning scale (r =.15, p < .05), and its correlations with other two Rewards of Caregiving scales were not significant: Rewards of Meaning (r = .10, p < .19) and Rewards from Other People (r = .05, p < .46). However, after removing one outlier with a score higher than three standard deviations above the mean, was taken out of the analysis, the correlation between the Caregiver Role Strain from Interpersonal Relationships within *Miuchi* and the Rewards of Meaning scales approached significance (r = .13, p < .08). After two outliers were taken out of the analysis, the correlation between the Caregiver Role Strain from Interpersonal Relationships within *Miuchi* and the Rewards from Other People scales also approached significance (r = .12, p < .10). These findings may be an indication that people can learn and find meaning through their hardships. The interpretation of these findings is not clear and further research is needed.

The correlation between scales of Rewards of Meaning and Rewards of Learning ($r = .79$, $p < .001$) was higher than expected. In addition, these two scales correlated with the Caregiver Role Strain scales in a similar way. This finding may indicate cultural difference between the United States and Japan. In the United States, the concept of rewards of meaning is distinctly different from the concept of rewards of learning. However, in Japanese culture, the concept of rewards of meaning and rewards of learning may both represent a gain for the caregiver as an individual.

Because the Rewards from Other people scale were newly developed for Japanese family caregiving, there are no previous data in the United States for comparison purpose. However, it is possible that caregivers who have rewards from other people may have more interactions with other family members, thus, they may have more chances to have strain from such interactions. As some studies about social support indicate (Coyne & DeLongis, 1986; Rook, 1984; Tilden, Nelson, & May, 1990) interpersonal relationships have both positive and negative aspects. This finding, that caregivers who had higher role strain from interpersonal relationships within *Miuchi* also had higher rewards from other people, may be an indication of positive and negative aspects of family relationships.

Review of Problematic Items Based on the Results of Content Validation

Some items were reworded based on analysis of the results from questionnaire for content validity. In addition, there were some items identified for later consideration with some questions from reviewers of content validity.

The results from the psychometric analysis of the data from Japanese caregivers indicated that most of those rewordings of the items were successful. Also, items in this questionnaire including those reworded items are clear enough to understand for Japanese caregivers because participants in this study commented that most of wording of this questionnaire was easy to understand.

Some reviewers of content validity suggested to add some items. Further qualitative study is needed to clarify the wording of items and confirm the conceptual coverage by items. Conceptual issues that were raised through translation and content validation processes are also needed to continue theoretical discussion as well as further studies.

Utility of Measures

The average length of time spent by caregivers in completing the JFCI was 133 minutes (range = 30 - 395 minutes). More than half (51%) of the caregivers completed it within 120 minutes and most caregivers (90%) completed it within 180 minutes. Some of the caregivers commented that they did not know about the length of time they spent completing the JFCI because they took several blocks of time to complete it as suggested. The length of time needed to complete the JFCI was somewhat longer than the investigator estimated. Even though only a few caregivers commented that the JFCI was too long, it should be shortened to reduce the burden for caregivers and to increase its utility. A shorter questionnaire may increases the response rate.

About two-thirds of the caregivers (67%) felt that the JFCI was clear and nearly all of them (97%) thought the print was large enough to read. Many of caregivers who answered that some questions of the JFCI were confusing commented that the Caregiver Role Strain from Role Conflict scale was most confusing. Some others commented that the list of caregiving tasks was hard to answer because some items were not applicable to their caregiving situations. Clarification of the directions for the Caregiver Role Strain from Role Conflict scale need to be considered. In addition, each item of the scale needs to be re-examined for content validity. The list of caregiving tasks needs to be shortened. Creation of several sets of caregiving tasks, such as generic caregiving tasks and special caregiving tasks for a care receiver's specific impairment or health problems may be needed.

The caregivers' reactions to the content of the JFCI were positive; most of them felt that the JFCI was interesting (88%), and not at all (80%) or only a little (15%) emotionally upsetting. Some caregivers commented that they were glad to answer the JFCI because they could have time to review what they were doing.

Limitations of the Study

This study has some limitations related to sample, methodology, and focus of the study. One of the issues in research on family caregiving for elderly persons is how to obtain representative samples (Barer & Johnson, 1990; Murphy & Stewart, 1985-86). It is also an issue for this study. Because the caregivers who participated in this study were self selected and not randomly selected, internal validity and generalizability are threatened. Because the caregivers who participated in this study were largely female and accessed through a local governmental office for elderly care services in a middle-size city in Japan, they were already connected to some public services. The findings from this study may not be applicable to caregivers who are male or who do not receive any public services. Even though the number of caregivers who responded to the initial invitation to participate in this study was close to the target population that the local government office in the city where this study was conducted estimated, the caregivers who did not return the JFCI may be in different caregiving situations. In addition, caregivers who live in a larger city or smaller town may have different perceptions about their caregiving situations. Further studies are needed with different samples.

All data for this study were obtained through a single method, involving a self-report, close-ended, mailed questionnaire. Some caregivers may not be able to express their thoughts and feelings through this method. The investigator actually received several phone calls and letters from caregivers who felt the questionnaire did not capture their caregiving situations and wanted to share more detail about them. To gain a better understanding of Japanese family caregiving, a multiple method approach may be necessary.

This study focused only on caregivers and the findings reflect only the caregivers' perceptions about their caregiving situations. However, caregiving situations are composed of at least a caregiver and a care receiver, and more people may be involved. Thus, a picture of Japanese family caregiving that was obtained through this study does not reflect all caregiving situations in Japan. Studies with care receivers and all family members who are involved in caregiving need to be done.

Implications of the Study and Recommendations

Implications of the Study

While further research is needed to clarify our understanding of caregiving in Japan, some implications can be made based on the findings of this study. Several caregiving concepts for Japanese family caregiving were examined in this study including the concepts of rewards of caregiving, mutuality, preparedness for caregiving, and predictability of the caregiving situations. Caregivers received some rewards through providing care for the older person and such rewards can reduce some aspects of role strain that caregivers felt. The caregiver's perception of the high quality of a relationship between the caregiver and care receiver can also reduce some aspects of role strain that caregivers felt. Caregivers who perceived themselves as well prepared for caregiving and their caregiving situations as highly predictable also expressed less strain on some of the Caregiver Role Strain scales. These findings are consistent with findings in the United States. Because caregiving studies conducted in Japan have focused mainly on negative aspects of caregiving such as caregiver burden and stress from caregiving, these findings provide new information for Japanese health professionals and add to our understanding of Japanese family caregiving phenomenon.

The findings of this study imply that the caregiving concepts identified in the United States also exist in Japan. The findings from this study have provided preliminary evidence of the universality of family caregiving phenomena. This will lead us to further cross-cultural research to gain a broader understanding of family caregiving phenomena.

Even though the total length of the JFCI may be too long for some clinical applications, the total and some parts of it can be used differently and separately. The total JFCI can be used as an initial assessment tool for relatively newer caregivers. It may help them to review their caregiving situations and learn about caregiving aspects because some caregivers in this study commented that it helped them this way. Each caregiving scale is short and easy to apply in clinical settings and could be used as an assessment tool as well as an evaluation tool. However, careful examination of each scale in relation to its sensitivity to interventions is needed before using these scales as an evaluation tool.

Recommendations

Because validation of measures is a continuous process, a series of additional studies are recommended. Further analysis of the data from this study could be useful to assess the construct validity of the JFCI including factor analysis of caregiving concepts and examinations of additional hypothesized relationships such as associations between the care receiver's impairment levels, amount of direct care, and caregiver role strain. Conducting multiple regression analysis may provide additional information about the adequacy of the conceptual framework of this study.

Further studies must be conducted with expanded samples, including more male caregivers and persons who do not receive public services and live in different parts of Japan. In addition, multiple-method studies are recommended including data collection through open-ended questionnaires, observations, and interviews to assess construct and concurrent validity. Use of multiple methods will reduce correlated error and increase validity of findings. A longitudinal study will provide additional information to validate the conceptual framework of Japanese family caregiving based on the framework developed by Archbold and colleagues (Archbold, 1982; Archbold, Stewart, Harvath, et al., 1986). Further research using structural modeling will provide information about cause and effect relationships among caregiving concepts in the conceptual framework for this study.

The findings from this study provide initial evidence of universality of the caregiving phenomena between the United States and Japan. Initial comparison between data from this study and previous studies conducted in the United States by Archbold and Stewart (1991, Archbold, et al., 1986, Archbold, et al., 1990, 1992) can be done. However, as suggested earlier, further validation is necessary prior to carrying out cross-cultural studies.

The long term goal of this program of research is to obtain efficient and usable measures for Japanese caregivers and to use them in clinical settings in order to improve nursing care services for older persons and their families in Japan. The findings from all of these studies, current and recommended studies, will lead to nursing interventions with Japanese family caregivers for older persons.

Table 1

Summary of the Psychometric Qualities of the Caregiving Scales on the FCI from Previous US Studies

Scale Name	Number of Items	Response Options	Missing Data (%)	Internal Consistency Reliability (Cronbach's α)	Test-retest Reliability
Mutuality	15	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	0.0-4.5	.91-.95 (n = 20-175)	.92 (n = 95)
Preparedness for Caregiving	8	0 = not at all 1 = not too well 2 = somewhat well 3 = pretty well 4 = very well	0.0-4.5	.83-.92 (n = 20-194)	.81 (n = 96)
Caregiver Health Status (Archbold): Medical (M) & System (S)	(M) 12 (S) 11	0 = no 1 = yes		(M) .54-.61 (n = 94-103) (S) .56-.70 (n = 94-103)	
Caregiver Health Status (RAND)	25	Vary from 3 to 6 response options		.78-.93 (n = 2471)	
Amount of Direct Care	80	0 = no 1 = yes	0.0-4.5	.79-.91 (n = 21-100)	
Amount of Managed Care	3	0 = no 1 = yes		.87 (n = 103)	
Amount of Communication Problems	3	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal		.33 (n = 45)	
Predictability of the Caregiving Situation	6	0 = never 1 = rarely 2 = sometimes 3 = usually 4 = always	0.0-4.5	.82-.88 (n = 21-41)	
Amount of Negative Life Style Change	6	0 = not a problem 1 = a small problem 2 = a moderaye problem 3 = a big problem 4 = a very big problem	0.0-4.7	.84-.90 (n = 21-102)	

Table 1

Summary of the Psychometric Qualities of the Caregiving Scales on the FCI from Previous US Studies (cont.)

Scale Name	Number of Items	Response Options	Missing Data (%)	Internal Consistency Reliability (Cronbach's α)	Test-retest Reliability
Role Strain from Direct Care	80	1 = easy 2 = not too hard 3 = somewhat hard 4 = pretty hard 5 = very hard	0.0-4.5		
Role Strain from Managed Care	6	1 = easy 2 = not too hard 3 = somewhat hard 4 = pretty hard 5 = very hard		.87 (n = 24)	
Role Strain from Lack of Resources	5	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	0.0-4.5	.74-.91 (n = 21-191)	.72 (n = 96)
Role Strain from Worry	12	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	0.0-4.5	.86-.90 (n = 19-37)	
Role Strain from Role Conflict	14	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	0.0-4.5	.84-.93 (n = 21-101)	
Role Strain from Economic Burden	4	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	0.0-4.7	.66-.85 (n = 21-103)	
Role Strain from Mismatched Expectations	3	0 = no 1 = yes	1.9-13.6	.28-.60 (n = 19-101)	
Role Strain from Communication Problems	3	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal		.77 (n = 45)	

Table 1

Summary of the Psychometric Qualities of the Caregiving Scales on the FCI from Previous US Studies (cont.)

Scale Name	Number of Items	Response Options	Missing Data (%)	Internal Consistency Reliability (Cronbach's α)	Test-retest Reliability
Global Strain	4	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	0.0-9.1	.72-.84 (n = 19-198)	.81 (n = 96)
Role Strain from Increased Tension	4	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	0.0-4.7	.82-.93 (n =21-103)	
Role Strain from Feeling of Being Manipulated	4	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	0.0-4.7	.84-.94 (n =20-103)	
Rewards of Meaning	4	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	0.0-2.6	.76-.94 (n =21-173)	.82 (n =96)
Rewards of Learning	3	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	0.0-6.9	.20-.64 (n =21-173)	.66 (n =92)
Financial Rewards	3	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	1.9-8.1	.47-.82 (n =21-173)	.73 (n =85)
Social Desirability (English)	13	0 = no 1 = yes		.76 (n =85)	.73 (n =85)
Social Desirability (Japanese)	33	0 = no 1 = yes		.81 (n =43)	

Table 2

Characteristics of the Caregivers and the Care Receivers (N = 224)

Caregiver Characteristics		
Age	M = 63.4	SD = 10.0
	Range: 34-87	
Gender	Male:	14 %
	Female:	86 %
Marital Status	Married:	83 %
	Widowed:	5 %
	Divorced:	6 %
	Never Married:	6 %
Education	<6:	1 %
	6:	5 %
	7- 9:	26 %
	10-12:	50 %
	13-14:	13 %
	15-16:	4 %
	≥17:	1 %
Employment Status	No:	68 %
	Yes:	32 %
Income Adequacy	Can't ends meet:	7 %
	Just enough:	52 %
	Enough + a little:	33 %
	Always left over:	9 %
Relationship with Care Receiver	Wife:	39 %
	Husband:	7 %
	Daughter:	31 %
	Son:	4 %
	Daughter-in-law:	16 %
Days Providing Care per Week	M = 6.9	SD = 0.7
	Range: 1-7	
Hours Providing Care per Day	M = 11.4	SD = 7.8
	Range: 1-24	
Years of Caregiving	M = 7.7	SD = 6.3
	Range: 0.5-40.0	

Care Receiver Characteristics		
Age	M = 80.8	SD = 9.0
	Range: 65-101	
Gender	Male:	47 %
	Female:	53 %
Marital States	Married:	53 %
	Widowed:	43 %
	Divorced:	3 %
	Never Married:	1 %
Needs Help Most	Shopping:	97 %
	Transportation:	97 %
	Heavy Housework:	97 %
	Prepare Meals:	96 %
	Manage Money:	93 %
	Light Housework:	91 %
	Bathing:	89 %
	Around Outside:	89 %
	Dressing:	83 %
	Use Phone:	81 %
	Walking:	80 %
	Totally Bedridden:	33 %
	Vegetative State/Non Responsive:	8 %
Major Medical Diagnoses (Duplicated)	Stroke:	53 %
	Dementia:	14 %
	Hypertension:	7 %
	Parkinson's:	6 %
	Others	19 %
	No Diagnoses	8 %
Living with Who	Alone:	4 %
	Spouse only:	36 %
	Spouse+Child:	6 %
	Children only:	27 %
	Three generations:	25 %
Living with Caregiver	Yes:	95 %
	No:	5 %

Note. Not all percentages total to 100% due to rounding error.

Table 3

Summary of the Psychometric Qualities of the Caregiving Scales on the JFCI

Scale Name	Number of Items	Response Options	Missing Data (%)	Internal Consistency Reliability (Cronbach's α)
Mutuality	15	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	8.9	.96 (n = 173)
Preparedness for Caregiving	8	0 = not at all 1 = not too well 2 = somewhat well 3 = pretty well 4 = very well	2.2	.85 (n = 190)
Caregiver Health Status Medical	12	2 (0-1)	0.0	.63 (n = 204)
System	11	2 (0-1)	0.0	.75 (n = 199)
RAND-physical	10	3 (1-3)	26.3	.87 (n = 165)
RAND-emotion	5	6 (1-6)	21.0	.76 (n = 177)
RAND-fatigue	4	6 (1-6)	20.9	.72 (n = 177)
RAND-general	5	5 (1-5)	16.6	.81 (n = 197)
Amount of Direct Care	80	0 = no 1 = yes	0.0	.93 (n = 107)
Amount of Managed Care	4	0 = no 1 = yes	0.0	.58 (n = 195)
Amount of Communication Problems	4	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	3.6	.53 (n = 203)
Predictability of the Caregiving Situation	6	0 = never 1 = rarely 2 = sometimes 3 = usually 4 = always	2.7	.71 (n = 210)
Amount of Negative Life Style Change	6	0 = not a problem 1 = a small problem 2 = a moderaye problem 3 = a big problem 4 = a very big problem	5.8	.84 (n = 191)

Table 3
Summary of the Psychometric Qualities of Caregiving Scales on the JFCI (cont.)

Scale Name	Number of Items	Response Options	Missing Data (%)	Internal Consistency Reliability (Cronbach's α)
Role Strain from Direct Care	80	1 = easy 2 = not too hard 3 = somewhat hard 4 = pretty hard 5 = very hard	3.6	
Role Strain from Managed Care	4	1 = easy 2 = not too hard 3 = somewhat hard 4 = pretty hard 5 = very hard	29.0	.73 (n = 45)
Role Strain from Lack of Resources	7 5	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	7.1 8.5	.83 (n = 188) .85 (n = 193)
Role Strain from Worry	12	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	11.2	.87 (n = 139)
Role Strain from Role Conflict	14	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	16.5	.94 (n = 55)
Role Strain from Economic Burden	4	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	13.4	.86 (n = 71)
Role Strain from Mismatched Expectations	3	0 = no 1 = yes	4.9	.55 (n = 196)
Role Strain from *Miuchi* Relationships	7	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	12.9	.69 (n = 180)

Table 3

Summary of the Psychometric Qualities of Caregiving Scales on the JFCI (cont.)

Concept Name	Number of Items	Number of Response Options	Missing Data (%)	Internal Consistency Reliability (Cronbach's α)
Role Strain from Communication Problems	4	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	10.3	.74 (n = 60)
Global Strain	4	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	5.8	.77 (n = 206)
Role Strain from Increased Tension	4	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	4.9	.84 (n = 202)
Role Strain from Feeling of Being Manipulated	4	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	5.8	.86 (n = 195)
Rewards of Meaning	4	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	11.6	.88 (n = 187)
Rewards of Learning	3	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	9.4	.83 (n = 203)
Rewards from Other People	5	0 = not at all 1 = a little 2 = some 3 = quite a bit 4 = a great deal	11.2	.92 (n = 190)
Social Desirability	13	0 = no 1 = yes	0.0	.71 (n = 195)

Table 4

Summary of the Descriptive Statistics of the Scales in the JFCI

Scale Name		Possible Range of Score	Acutual Range of Score	Mean	SD	Skew	Kurt
Mutuality		0.00-4.00	0.00-4.00	2.09	1.13	-.01	-1.03*
Preparedness for Caregiving		0.00-4.00	0.00-4.00	1.94	.65	.18	.19
Caregiver Health Status	(Medical Problems)	0-12	0-10	2.24	1.98	1.01**	.83
	(System Problems)	0-12	0-11	3.50	2.54	.76**	.36
	(RAND-Physical)	0-100	5-100	79.36	19.41	-1.49**	2.13**
	(RAND-Emotion)	0-100	12-100	62.96	19.48	-.29	-.33
	(RAND-Fatigue)	0-100	0-95	51.75	21.35	-.31	-.24
	(RAND-General)	0-100	0-95	46.74	20.88	.11	-.28
Amount of Direct Care		0-80	1-71	42.59	12.98	-.36	-.01
Amount of Managed Care		0-4	0-4	1.78	1.23	.06	-.93*
Amount of Communication Problems		0.00-4.00	0.00-3.00	1.18	.83	.42	.17
Predictability of the Caregiving Situation		0.00-4.00	0.33-3.33	2.02	.56	-.28	.02
Amount of Negative Life Style Change		0.00-4.00	0.00-4.00	2.08	.96	-.20	-.55
Role Strain from Direct Care		1.00-5.00	1.00-5.00	2.46	.83	.83**	.70
Role Strain from Managed Care		1.00-5.00	1.00-5.00	2.41	.94	.68**	.38
Role Strain from Lack of Resources	(7 items)	0.00-4.00	0.00-4.00	1.64	.94	.19	-.45
	(5 items)		0.00-4.00	2.00	1.07	-.10	-.86
Role Strain from Worry		0.00-4.00	0.00-4.00	2.20	.87	-.27	-.36
Role Strain from Role Conflict		0.00-4.00	0.00-4.00	1.51	1.07	.20	-1.05*
Role Strain from Economic Burden		0.00-4.00	0.00-4.00	1.28	1.10	.45	-.93*
Role Strain from Mismatched Expectations		0.00-1.00	0.00-1.00	.45	.33	.06	-1.07**
Role Strain from *Miuchi* Relationships		0.00-4.00	0.00-3.29	1.03	.60	.91**	1.44**
Role Strain from Communication Problems		0.00-4.00	0.00-4.00	1.72	1.16	.24	-.82
Global Strain		0.00-4.00	0.00-4.00	1.97	.86	-.15	-.36
Role Strain from Increased Tension		0.00-4.00	0.00-4.00	1.95	1.08	-.01	-.93*
Role Strain from Feeling of Being Manipulated		0.00-4.00	0.00-4.00	1.11	1.05	.73**	-.50
Rewards of Meaning	(4 items)	0.00-4.00	0.00-4.00	2.06	1.07	.05	-.94*
Rewards of Learning	(3 items)	0.00-4.00	0.00-4.00	2.44	1.06	-.31	-.90*
Rewards from Other People		0.00-4.00	0.00-4.00	1.42	1.16	.57	-.86
Social Desirability		0-13	0.00-13.00	8.02	3.08	-.54	-.13

* $p < .01$. ** $p < .001$.

Table 5

Organization of Tables for Scale Correlations

	Nature of Caregiving Role (N): 3 scales	Positive Aspects of Caregiving (P): 5 scales	Caregiver Role Strain (S): 12 scales	Caregiver's Health Status (H): 6 scales
Nature of Caregiving Role (N): 3 scales	N x N (Table 6)	N x P (Table 10)	N x S (Table 10)	N x H (Table 10)
Positive Aspects of Caregiving (P): 5 scales		P x P (Table 7)	P x S (Table 10)	P x H (Table 10)
Caregiver Role Strain (S): 12 scales			S x S (Table 8)	S x H (Table 10)
Caregiver's Health Status (H): 6 scales				H x H (Table 9)

Table 6

Summary of Correlations among Scales Measuring Nature of Caregiving Role

	Amount of Direct Care	Amount of Managed Care	Amount of Communication Problems	Predictability of the Caregiving Stituation
Amount of Managed Care	.18**			
Amount of Communication Problems	.03	.14*		
Predictability of the Caregiving Stituation	.08	.12[a]	.06	
Amount of Negative Life Style Change	.27**	.12[b]	.14	-.02

* $p < .05$. ** $p < .01$. [a] $p < .078$. [b] $p < .074$.

Table 7

Summary of Correlations among Scales Measuring Positive Aspects of Caregiving

	Mutuality	Preparedness for Caregiving	Rewards of Meaning	Rewards of Learning
Preparedness for Caregiving	.33**			
Rewards of Meaning	.56**	.53**		
Rewards of Learning	.48**	.49**	.79**	
Rewards from Other People	.35**	.34**	.79**	.66**

** $p < .01$.

Table 8

Summary of Correlations among Scales Measuring Caregiver Role Strain

Caregiver Role Strain from ...	Worry	Economic Burden	Lack of Resourcese (5 items)	Lack of Resourcese (7 items)	Direct Care	Managed Care	Communication Problems
Economic Burden	.52**						
Lack of Resourcese							
(5 items)	.68**	.48**					
(7 items)	.63**	.53**					
Direct Care	.32**	.35**	.41**	.40**			
Managed Care	.24**	.28**	.35**	.33**	.58**		
Communication Problems	.41**	.20**	.41**	.41**	.34**	.17*	
Role Conflict	.37**	.28**	.36**	.31**	.27**	.15[a]	.23**

* $p < .05$. ** $p < .01$. [a] $p < .075$. [b] $p < .073$.

Table 8

Summary of Correlations among Scales Measuring Caregiver Role Strain (cont.)

Caregiver Role Strain from ...	Worry	Economic Burden	Lack of Resourcese		Direct Care	Managed Care	Communication Problems
			(5 items)	(7 items)			
Mismatched Expectation	.25**	.17*	.18*	.13^{b}	.22**	.20**	.02
Incresed Tension	.59**	.34**	.64**	.58**	.37**	.21**	.40**
Feelings to Being Manipulated	.36**	.32**	.31**	.29**	.25**	.19*	.02
Interpersonal Relationships within *Miuchi*	.46**	.28**	.46**	.43**	.16*	.24**	.15*
Global Strain	.53**	.36**	.54**	.50**	.33**	.11	.32**

* $p < .05$. ** $p < .01$. ^{a} $p < .075$. ^{b} $p < .073$.

Table 8

Summary of Correlations among Scales Measuring Caregiver Role Strain (cont.)

Caregiver Role Strain from ...	Role Conflict	Mismatched Expectation	Incresed Tension	Feelings to Being Manipulated	Interpersonal Relationships within *Miuchi*
Mismatched Expectation	.20**				
Incresed Tension	.48**	.41**			
Feelings to Being Manipulated	.30**	.50**	.55**		
Interpersonal Relationships within *Miuchi*	.30**	.19**	.38**	.32**	
Global Strain	.44**	.34**	.68**	.46**	.39**

* $\underline{p} < .05$. ** $\underline{p} < .01$. ^{a} $\underline{p} < .075$. ^{b} $\underline{p} < .073$.

Table 9

Summary of Correlations among Scales Measuring Caregivers' Health Status

	Caregiver Health Medical Problem	Caregiver Health Syatem Problem	RAND Physical Function	RAND Fatifue	RAND Emotional Well-being
Caregiver Health Syatem Problem	.62**				
RAND Physical Function	-.33**	-.36**			
RAND Fatifue	-.43**	-.44**	.47**		
RAND Emotional Well-being	-.39**	-.41**	.31**	.77**	
RAND General Health	-.50**	-.45**	.53**	.64**	.55**

** $p < .01$.

Table 10

<u>Summary of Correlation Coefficients in Hypothesized Relationships</u>

Caregiver Role Strain from ...	Mutuality	Preparedness for Caregiving	Predictability of the Caregiving Stituation	Amount of Direct Care	Amount of Negative Life Style Change	Rewards of Meaning
Worry	-.04	-.13^{a}	-.02	.39**	.42**	.01
Economic Burden	-.02	-.21**	-.18*	.10	.26**	-.06
Lack of Resourcese						
(5 items)	-.06	-.04	-.11	.31**	.56**	-.02
(7 items)	-.04	-.07	-.15*	.22**	.49**	-.02
Direct Care	-.19**	-.05	-.24**	.14*	.24**	-.01
Managed Care	.13	-.01	-.09	.20*	.15^{c}	.10
Communication Problems	-.13^{b}	-.01	-.18*	.11	.37**	-.08

* $\underline{p} < .05$. ** $\underline{p} < .01$. ^{a} $\underline{p} < .070$. ^{b} $\underline{p} < .076$. ^{c} $\underline{p} < .061$.

Table 10

Summary of Correlation Coefficients in Hypothesized Relationships (cont.)

Caregiver Role Strain from ...	Mutuality	Preparedness for Caregiving	Predictability of the Caregiving Stituation	Amount of Direct Care	Amount of Negative Life Style Change	Rewards of Meaning
Role Conflict	-.10	-.08	-.01	.29**	.46**	-.10
Mismatched Expectation	-.23**	-.19**	-.02	.20**	.20**	-.20**
Incresed Tension	-.21**	-.20**	-.16*	.31**	.65**	-.15*
Feelings to Being Manipulated	-.18*	-.15*	-.05	.37**	.35**	-.04
Interpersonal Relationships within *Miuchi*	.13^{c}	-.04	-.01	.32**	.32**	-.10
Global Strain	-.29**	-.21**	-.09	.26**	.58**	-.25**

* $\underline{p} < .05$. ** $\underline{p} < .01$. ^{a} $\underline{p} < .070$. ^{b} $\underline{p} < .076$. ^{c} $\underline{p} < .061$.

Table 10

Summary of Correlation Coefficients in Hypothesized Relationships (cont.)

Caregiver Role Strain from ...	Caregiver Health Medical Problem	Caregiver Health Syatem Problem	RAND Physical Function	RAND Fatifue	RAND Emotional Well-being	RAND General Health
Worry	.27**	.37**	-.29**	-.42**	-.40**	-.47**
Economic Burden	.32**	.31**	-.19*	-.28**	-.27**	-.34**
Lack of Resourcese						
(5 items)	.29**	.38**	-.22**	-.40**	-.41**	-.39**
(7 items)	.29**	.36**	-.23**	-.36**	-.37**	-.37**
Direct Care	.24**	.30**	-.27**	-.29**	-.30**	-.31**
Managed Care	.16*	.26**	-.22**	-.24**	-.11	-.13
Communication Problems	.20**	.14^a	-.12	-.15^b	-.22**	-.26**

* $p < .05$. ** $p < .01$. ^{a} $p < .052$. ^{b} $p < .060$.

Table 10

Summary of Correlation Coefficients in Hypothesized Relationships(cont.)

Caregiver Role Strain from ...	Caregiver Health Medical Problem	Caregiver Health Syatem Problem	RAND Physical Function	RAND Fatifue	RAND Emotional Well-being	RAND General Health
Role Conflict	.21**	.26**	-.02	-.34**	-.35**	-.24**
Mismatched Expectation	.18**	.22**	-.17*	-.22**	-.29**	-.21**
Incresed Tension	.35**	.38**	-.21**	-.43**	-.55**	-.41**
Feelings to Being Manipulated	.26**	.32**	-.30**	-.29**	-.36**	-.38**
Interpersonal Relationships within *Miuchi*	.12	.18*	-.12	-.28**	-.33**	-.34**
Global Strain	.30**	.36**	-.16*	-.48**	-.56**	-.41**

* $p < .05$. ** $p < .01$. [a] $p < .052$. [b] $p < .060$.

Table 10

Summary of Correlation Coefficients in Hypothesized Relationships (cont.)

	Rewards of Meaning	Rewards of Learning	Rewards from Other People
Mutuality	.56**	.48**	.35**

** $p < .01$.

Table 11

Summary of the Number of Significant Correlations per Hypothesized Relationships

Hypothesized Concepts	# of Significant Correlations / # of Hypothesized Relationships		# of Non Significant Correlations / # of Hypothesized Zero Relationships	
Mutuality and Caregiver Role Strain	5 / 9	Range = -.29 to .13 Median r = -.18	4 / 4	Range = -.06 to -.02 Median r = -.04
Mutuality and Rewards of Caregiving	3 / 3	Range = .35 to .56 Median r = .48	0 / 0	
Preparedness and Caregiver Role Strain	6 / 12	Range = -.21 to -.01 Median r = -.08	0 / 0	
Predictability and Caregiver Role Strain	5 / 12	Range = -.24 to -.01 Median r = -.09	0 / 0	
Amount of Direct Care and Caregiver Role Strain	10 / 12	Range = .39 to .10 Median r = .26	0 / 0	
Amount of Negative Life Style Change and Caregiver Role Strain	11 / 12	Range = .65 to .15 Median r = .37	0 / 0	
Rewards of Meaning and Caregiver Role Strain	4 / 12	Range = -.25 to .10 Median r = -.06	0 / 0	
Caregiver's Health Problems and Caregiver Role Strain	24 / 26	Range = .38 to .12 Median r = .29	0 / 0	
RAND Health Scales and Caregiver Role Strain	46 / 52	Range = -.56 to -.02 Median r = -.29	0 / 0	

Table 12

Summary of Correlations between the Caregiving Scales and the Social Desirability Scale

	Social Desirability
Amount of Direct Care	.05
Amount of Managed Care	-.02
Amount of Communication Problems	-.03
Predictability of the Caregiving Stituation	.04
Amount of Negative Life Style Change	-.17*
Mutuality	.07
Preparedness for Caregiving	.30**
Rewards of Meaning	.18
Rewards of Learning	.16
Rewards from Other People	.09
Caregiver Health - Medical Problem	-.19**
Caregiver Health - System Problem	-.15*
RAND Physical Function	.03
RAND Fatigue	.19*
RAND Emotional Well-being	.25**
RAND General Health	.14

* $p < .05$. ** $p < .01$.

Table 12

Summary of Correlations between the Caregiving Scales and the Social Desirability Scale (cont.)

		Social Desirability
Worry		-.07
Economic Burden		-.11
Lack of Resourcese	(5 items)	-.14
	(7 items)	-.15*
Direct Care		-.12
Managed Care		-.07
Communication Problems		-.02
Role Conflict		-.03
Mismatched Expectation		
Incresed Tension		-.22**
Feelings to Being Manipulated		-.11*
Interpersonal Relationships within *Miuchi*		-.08
Global Strain		-.21**

* $p < .05$. ** $p < .01$.

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Appendix A

Support for the Content Verification in Japanese Data Bits

Concepts Identified in the Unite States

Concepts	Examples of Data Bits
Mutuality	
Affective Closeness	"I try to watch my mother-in-law's face and listen. She does not open her heart yet but I can understand more about her feelings." (N-33) "My mother-in-law became off her guard." (P-45) "I think things like close touch of heart to heart can get through to my mother-in-law if I talk repeatedly." (B-49) "Because there are problems of in-law relationship with my mother-in-law and emotional conflict with relatives, I decide to be just a hired caregiver." (M-40) (*Luck of Mutuality*)
Shared Value	"My father likes the fine art very much and it make him happy. He said the fine art make people feel warmth. I think so too." (T-181)
Shared Pleasurable Activities	"My dear wife, you must be very tired. --- When she likes a dishes she pleased and said good. --- We sing together. Her voice is pretty. I praise it. She looks like happy. It is pleasurable moment for us." (Q56) "My son and I were surprise when my mother-in-law said a joke and laugh. Then we all laugh together." (B-50) "I sing a song, songs my mother-in-law knows. She is quiet if she can hear my voice. When I sing, my mother-in-law beat time with her hand." (B-48)
Reciprocity	"My mother-in-law said thank you to me once." (B-50)

Concepts Identified in the Unite States (cont.)

Concepts	Examples of Data Bits
Preparedness for Caregiving	"Before I started live with my mother-in-law, I read several books about dementia to know process of illness and key points of caregiving. I had pre-knowledge about caregiving through support group. These make caregiving a little easier." (G-46)
	"To talk with my mother-in-law, I collected information about anything and everything of her past. Then I can guess what she is talking about and we both do not need upset." (R-58)
	"Because I did not have any knowledge about dementia, I did nothing but was twisted around him about in bewilderment." (J-24) (*Lack of Preparedness*)
Predictability of the Caregiving Situation	"Dressing my mother-in-law starts her right hand and left leg. I watched when I assisted her to do. When I help her now, I do the same way she did. Need to think some good devices to help her even just dressing. Once I know her way, it becomes bit easier." (B-37)
	"Everything in our house are in the same place as my mother-in-law was using. She sits the same place. I sit the same place where is the left side of her. When we get up in the morning, change water of flower vase at the family Buddhist altar and recite a short sutra. Then eat breakfast. After finish her toilet, clean rooms and do laundry. Then, go grocery shopping with her. Everything are the same order." (M-40)
	"Even for my demented mother-in-law, there is a rhythm in her life to a certain extent. If a caregiver can live to this rhythm, caregiving will be a little easier." (B-81)
	"My mother-in-law's condition is amazingly up and down. It is very difficult because she changes like a cat's eye." (M-75)
	"It is continuous surprise, everyday is new." (B-12)

Concepts Identified in the Unite States (cont.)

Concepts	Examples of Data Bits
Amount of Negative Life Style Change	"When I am writing a letter or reading a book, my mother-in-law makes sound around me. I don't have any free time." (B-122) "I want to do things I want as much as I can, so I get up earlier and do everything in the morning if I have something I want to do that day." (C-142)
Rewards	
Rewards of Meaning	"Because my mother-in-law look for me always, I sing a song all the time. She sits down calmly and is smiling." (B-48) "My mother-in-law said thank you to me once. Even though it is only once, it make my heart full of pleasure." (B-50) "It is difficult everyday to do caregiving , but it is my *IKIGAI* (worth living, something live for)." (Q-56) "Because my mother-in-law had dementia, I could find meaning in my life." (G-251)
Rewards of Learning	"I learned through caregiving experiences about how much a person's life is important." (Q-56) "I learned through this experience about how to take care." (R-58) "Through this experience, I learn about not only how to take care of someone but also life -- view toward a person." (O-149)
Financial Rewards	"Sometime people talk about an inheritance. Even I can receive something like a that, I would not do caregiving for that. If money is a reason to take care of my mother-in-law, I would have sent her to nursing home for a long time ago." (C-123)

Concepts Identified in the Unite States (cont.)

Concepts	Examples of Data Bits
Caregiver Role Strain from ...	
Direct Care	"(Mother-in-law has incontinence.) I clean up every time, every day, day and night. My back becomes so painful and I cry." (N-70)
	"My mother-in-law has abnormal behaviors such as forgetfulness, repeated same questions, play with fire, unable to differentiate own belongings and others. I quit my job because I was continuously irritated and upset." (B-16)
	"My mother-in-law's story went round in circles, I became angry and went out a room." (M-40)
	"My mother-in-law likes to go out and cannot come back. --- Because she goes out as fancy led her I do not know where I should look for her when she goes out. I become tired and almost collapsed." (U-88)
	"One night, my father-in-law came into my bed. I was just so shock first, then I shouted to him." (F-98)
	"My mother-in-law often just wonders off, anytime, so I can't leave her." (U-88)
	"I had hard time to convince my mother-in-law to take a bath." (G-91)

Concepts Identified in the Unite States (cont.)

Concepts	Examples of Data Bits
Lack of Resources	"My husband is at home only in the morning and at night, so he cannot understand about my mother-in-law's dementia through my report to him. He becomes looking displeased because he thinks I am listing her faults." (B-16)
	"I was awakened many times during night by my father-in-law. He shook a door and said he want go out. I sometimes walked outside with him in the middle of the night. I could not sleep nor rest." (J-92)
	"My husband becomes angry if I talked about my father-in-law's problems. I didn't have anyone I can ask advice or even talk to." (E-15)
	"No help at all from my mother-in-law's family. They didn't take her to their home, they didn't clean her room, even once." (I-114)
Economic Burden	"My husband said to buy anything needs for my mother-in-law's care, but I cannot do so because we do not know how long it continues."
	"I don't know how much more money we need to care for my mother-in-law and how long this situation continues. We need save money for my children's education, too." (N-227)
Worry	"If my mother-in-law becomes unable to walk, how can I give her bath." (N-132)
	"I am anxious if I do not think about (plan for) the future." (G-86)
	I was anxious about what going on inside of mother-in-law." (G-19)

Concepts Identified in the Unite States (cont.)

Concepts	Examples of Data Bits
Communication Problems	"My mother-in-law's first symptom was aphasia. She was very irritated because she could not understand other persons' words. I was at a loss what to do because I could not understand her." (R-58) "It is difficult most for my wife when my mother's words are not understandable. For example, my mother said 'It -- from behind is water. Bring it.' It is reasonable that my wife becomes tearful. --- Because my mother cannot understand words, she became persecution complex. She said 'you are talking bad things about me.' and would not listen to reason." (R-58) "Inconvenience of that a caregiver's words can not reach a care receiver is difficult more than I could imagine." (N-132)
Role Conflict	"I felt, not only my father but also everybody (all family members) expect me to do everything they want. They don't aware that I have a job, too." (T-1) "I wanted to run away, once, because I was so tired to being between caregiving, my job, husband, and children." (I114) " I couldn't spend as much time as I want with my children because it takes a time to care for my mother-in-law. I'm sorry for my children." (O-34) "My father loves my daughter, she is his first grandchild, so sometimes my daughter became a caregiver. But she had hard time to find a study time for her entrance exam to university." (T-118) "It was the most difficult to bring my mother and my children." (H-133)

Concepts Identified in the Unite States (cont.)

Concepts	Examples of Data Bits
Mismatched Expectation	“I felt, not only my father but also everybody (all family members) expect me to do everything they want. They don’t aware that I have a job, too.” (T-114)
	“I cannot ask my husband or my children to do my father’s personal care. So, I need to do, there is no choice, but I feel frustration. Sometime I wonder whether I should do it. My father can do many things, even it takes time, but I cannot wait him.” (T-3)
Increase Tension	"My father-in-law makes a big fuss about his money and belongings were stolen, and talks to guests about it plausibly. He would not listen to my explanation." (F-16)
	"My husband was looking displeased when I talked about father-in-law. We argue a lot. I did not know where I can go to." (E-15)
Feelings of Being Manipulated	“I didn’t know anything about dementia. I felt that my father-in-law lead my around by the nose. It was so hard.” (J-24)
	“My father works me very hard. He said ‘right’ first, then before I finish it he would say ‘left’. I am running around him.” (T-2)
Global Strain	“Because I can’t leave my mother at all, I feel I’m locked up on the house.” (N-12)

New Concepts

Concepts	Examples of Data Bits
Caregiver Role Strain from Relationships with Other Family Members	"Because I am in-law, I could not comment presumptuously about their (husband and his family) decision." (G-19) "I had hard time to be between my husband and sister-in-law. I cannot sleep with father-in-law even though it is calm him down because I am in-law and he is a man." (J-31) "Because there are problems of in-law relationship with my mother-in-law and emotional conflict with relatives, I decide to be just a hired caregiver." (M-40) "I worked very hard, I think, but other people can not understand and they make a comment about what I am doing." (F-115) "I sometimes become so angry because other relative's criticism." (M-115) "If someone in my husband's family show me their kindness, even once, I can continue to take care of my mother-in-law, but ....." (N-240) "I am so sad to hear that my wife's brothers criticize her being dementia." (N-203)
Rewards from Other People	"After my mother-in-law seems to understand where she is taken care of, my sister-in-law's criticism was gone. Through this experience, our relationships became good now." (N-132) "When I become angry and irritate, I call my sister and vent my feelings on her. She always said 'I know, I know.' It help me." (B-121) "I felt so relief when our home doctor said that I have been caring my mother-in-law so good." (O-55)

Appendix B

Content Validity Questionnaire

CONTENT VALIDITY

Instructions:

This questionnaire aims to measure central and related concepts of family caregiving for elderly persons. You are asked to look at the items in the questionnaire and tell if they seem to measure the caregiving concepts.

The questionnaire was divided into three groups, Group A, Group B, and Group C.

Group A includes core concepts of family caregiving on pages 11, 16-17, 19-22, and Q4 and Q5 on page 23. For each concept, you will given a concept label and definition. Then you will be asked to answer five questions for each concept. The response sheets with a concept label and definition are provided. The five questions are:

1) Do the label and definition fit the whole set of items?
2) For each item, does it belong to the label and definition?
3) Is there any item that does not fit Japanese caregivers of elderly persons? (e.g., culturally not appropriate)
4) Is the wording of any item unclear?
5) Is there anything left out?

Group B includes concepts of family caregiving on pages 4-10, 13-15, 18, and 23 except Q4 and Q5. You will given each concept with a label and definition. Then five questions for each set of items will be asked. The five questions are:

1) Do the label and definition fit the whole set of items?
2) Is there any item that does not fit the label and definition?
3) Is there any item that does not fit Japanese caregivers of elderly persons?
4) Is the wording of any item unclear?
5) Is there anything left out?

Group C includes sets of items on all pages other than the pages listed above. You will be asked three questions for each set of items. The three questions are:

1) Is the wording of any item unclear?
2) Is there any item that does not fit Japanese caregivers of elderly persons?
3) Is there anything left out?

Each response sheet has the page number of the questionnaire so that you can match each concept and items that belong together.

RESPONSE SHEET FOR GROUP A SCALES

Page Number(s) in the questionnaire: _______

Concept Label:

Definition of Concept:

Question #1: Read the concept label and definition above. Then read all items on the designated page(s). Do the label and definition generally fit the whole set of items? Answer once for the entire set.

The concept label and definition fit the whole set of items.....

Very well	4
Pretty well	3
Not too well	2
Not at all	1

Question #2: For each item, does it belong to the label and definition? Circle YES or NO next to each item number on this response sheet.

Item #	Does this item belong to the label and definition?		Comments?
1	Yes, it belongs.	No, it does not belong.	
2	Yes, it belongs.	No, it does not belong.	
3	Yes, it belongs.	No, it does not belong.	
4	Yes, it belongs.	No, it does not belong.	
⋮	⋮	⋮	

Question #3: Is there any item that does NOT fit Japanese caregivers of elderly persons?

All items fit Japanese caregivers	1	If items do not fit, which items and how?
Some items do not fit	0	

Question #4: Is the wording of any item unclear?

All items are clear	1	If items are unclear, which items?
Some items are unclear	0	

Question #5: Is anything left off the list of items that you think should be there?

Any other comments about the concept label, definition, and items?

RESPONSE SHEET FOR GROUP B SCALES

Page Number(s) in the questionnaire: _______

Concept Label:

Definition of Concept:

Question #1: Read the concept label and definition above. Then read all items on the designated page(s). Do the label and definition generally fit the whole set of items? Answer once for the entire set.

The concept label and definition fit the whole set of items.....
Very well 4
Pretty well 3
Not too well 2
Not at all 1

Question #2: Is there any item that does **NOT** fit the concept label and definition?

All items fit the concept label and definition 1
Some items do not fit 0

If items do not fit, which items and how?

Question #3: Is there any item that does **NOT** fit Japanese caregivers of elderly persons?

All items fit Japanese caregivers 1
Some items do not fit 0

If items do not fit, which items and how?

Question #4: Is the wording of any item unclear?

All items are clear 1
Some items are unclear 0

If items are unclear, which items?

Question #5: Is anything left off the list of items that you think should be there?

Any other comments about the concept label, definition, and items?

RESPONSE SHEET FOR GROUP C SCALES

Page Number(s) in the questionnaire: _______

Content of the page:

Question #1: Is the wording of any item unclear?

All items are clear............................. 1
Some items are unclear..................... 0

If items are unclear, which items?

Question #2: Is there any item that does **NOT** fit Japanese caregivers of elderly persons?

All items fit Japanese caregivers 1
Some items do not fit........................ 0

If items do not fit, which items and how?

Question #3: Is anything left off the list of items that you think should be there?

Any other comments about the concept label, definition, and items?

質問紙の妥当性の検討についてのお願い

この質問紙は、老人の家族介護に関する概念を測定するために作られたものです。質問紙の項目を見ていただいて、それが介護に関する概念を測定しているかどうか、また、それぞれの項目や説明文は適切かどうかについて、あなたの御意見をお伺いしたいと思います。この質問紙の開発にあたって、あなたのご意見は、大変重要で、必要不可欠なものです。どうかよろしくお願いいたします。

いくつかの意見用紙の中に、概念名として"介護者役割過重"という言葉が出てきます。これは、"Caregiver Role Strain"という概念で、介護者が介護者役割を遂行するにあったて感じる困難のことです。

質問紙は、A、B、Cの3グループに分けられています。それぞれの概念、あるいは、ページ毎に、あなたの意見を書いていただくための意見用紙をセットしてあります。各意見用紙の上には、各概念とそれに属する項目を明確にするために、その概念に対応する質問紙のページナンバーが書いてあります。

Aグループ:　Aグループには、11、16、17、19～22の各ページと、23ページの間4、間5が含まれています。各概念毎に、あなたの意見を書いていただくための意見用紙をセットしてあります。各々の意見用紙の始めには、そのページの概念の名前と定義が書いてあります。その下に、以下の5項目の質問が書いてありますので、各項目毎に、それぞれについてのあなたの御意見をお書きください。

1) 概念の名前と定義は、項目全体に合致しているでしょうか。
2) 各項目は、その名前と定義に属していると言えるでしょうか。
3) 日本の老人介護に合わないと思われる項目はないでしょうか。
4) 使われている言葉は明確でしょうか。
5) 何か抜けていると思われる項目はないでしょうか。

Bグループ:　Bグループには、4～10、13～15、18の各ページと、23ページの間4、間5以外の項目が含まれています。各概念毎に、あなたの意見を書いていただくための意見用紙をセットしてあります。各々の意見用紙の始めには、そのページの概念の名前と定義が書いてあります。その下に、以下の5項目の質問が書いてありますので、各概念毎に、それぞれについてのあなたの御意見をお書きください。

1) 概念の名前と定義は、項目全体と合致しているでしょうか。
2) その名前と定義に合わないと思われる項目はないでしょうか。
3) 日本の老人介護に合わないと思われる項目はないでしょうか。
4) 使われている言葉は明確でしょうか。
5) 何か抜けていると思われる項目はないでしょうか。

Cグループ:　Cグループには、上記以外の全てのページが含まれています。各ページ毎にあなたの意見を書いていただくための意見用紙をセットしてあります。各々の意見用紙の始めには、そのページの質問内容が書いてあります。その下に、以下の3項目の質問が書いてありますので、各ページ毎に、それぞれについてのあなたの御意見をお書きください。

1) 使われている言葉は明確でしょうか。
2) 日本の老人介護に合わないと思われる項目はないでしょうか。
3) 何か抜けていると思われる項目はないでしょうか。

この質問紙は、アメリカで開発されたものを日本語に翻訳したものです。そのために、日本語の表現がスムーズではない部分があるかも知れません。もし、文章の表現や言葉に、日本語としてふさわしくないものやおかしい部分がありましたら、御指摘ください。また、より良い表現について、アイデアがおありでしたら、ご示唆ください。この質問紙全体に対するご意見もお聞かせいただければ、大変ありがたく思います。ご意見は、質問紙の中に直接書き込んでくださってもけっこうですし、別の紙に書いてくださってもけっこうです。

ご協力に、心から感謝いたします。

Aグループについての意見用紙

質問紙のページナンバー:______

概念名:

概念の定義:

1)　まず、上の概念名とその定義を読んでください。それから、質問紙のそのページの中の一つ一つの項目を読んでください。この概念名と定義は、質問紙の中の項目全体と合致しているでしょうか。

非常に良く合致している	4
かなり合致している	3
あまり合致していない	2
全く合致していない	1

2)　各項目は、その概念名と定義に属していると言えるでしょうか。各項目番号の横の"属している"または"属していない"に○を付けてください。

項目番号	この項目はその概念名と定義に属しているでしょうか		ご意見
1	属している	属していない	
2	属している	属していない	
3	属している	属していない	
4	属している	属していない	
5	属している	属していない	
6	属している	属していない	
7	属している	属していない	
8	属している	属していない	
9	属している	属していない	
10	属している	属していない	
11	属している	属していない	
12	属している	属していない	
13	属している	属していない	
14	属している	属していない	
15	属している	属していない	
16	属している	属していない	
17	属している	属していない	
18	属している	属していない	
19	属している	属していない	
20	属している	属していない	

Aグループについての意見用紙 (続き)

質問紙のページナンバー: ______

概念名:

2)　(続き)

項目番号	この項目はその概念名と定義に属しているでしょうか		ご意見
21	属している	属していない	
22	属している	属していない	
23	属している	属していない	
24	属している	属していない	
25	属している	属していない	
26	属している	属していない	
27	属している	属していない	
28	属している	属していない	
29	属している	属していない	
30	属している	属していない	
31	属している	属していない	

3)　日本の老人介護に合わないと思われる項目はないでしょうか。

全項目が日本の老人介護に合っている 1
いくつかの項目が合っていない.................................... 0

<u>合わない項目があるとお答えになった方</u>、それはどの項目で、なぜでしょうか。

4)　使われている言葉は明確でしょうか。

全項目が明確である... 1
いくつか明確ではない項目がある 0

<u>明確ではないとお答えになった方</u>、それはどの項目でしょうか。

5)　何か抜けていると思われる項目はないでしょうか。

何か他にこの概念名や定義、項目について御意見がありましたらお書きください

Bグループについての意見用紙

質問紙のページナンバー:______

概念名:

概念の定義:

1)　まず、上の概念名とその定義を読んでください。それから、質問紙のそのページの中の一つ一つの項目を読んでください。この概念名と定義は、質問紙の中の項目全体と合致しているでしょうか。

非常に良く合致している……………………4
かなり合致している……………………3
あまり合致していない……………………2
全く合致していない……………………1

2)　その概念名と定義に合わないと思われる項目はないでしょうか。

全項目が概念名と定義に合っている……………………1
いくつかの項目が合っていない……………………0

合わない項目があるとお答えになった方、それはどの項目で、なぜでしょうか。

3)　日本の老人介護に合わないと思われる項目はないでしょうか。

全項目が日本の老人介護に合っている……………………1
いくつかの項目が合っていない……………………0

合わない項目があるとお答えになった方、それはどの項目で、なぜでしょうか。

4)　使われている言葉は明確でしょうか。

全項目が明確である……………………1
いくつか明確ではない項目がある……………………0

明確ではないとお答えになった方、それはどの項目でしょうか。

5)　何か抜けていると思われる項目はないでしょうか。

何か他にこの概念名や定義、項目について御意見がありましたらお書きください

Cグループについての意見用紙

質問紙のページナンバー：______

このページの質問内容：

1)　使われている言葉は明確でしょうか。

全項目が明確である…………………………1
いくつか明確ではない項目がある……………0

明確ではないとお答えになった方、それはどの項目でしょうか。

2)　日本の老人介護に合わないと思われる項目はないでしょうか。

全項目が日本の老人介護に合っている…………1
いくつかの項目が合っていない………………0

合わない項目があるとお答えになった方、それはどの項目で、なぜでしょうか。

3)　何か抜けていると思われる項目はないでしょうか。

何か他にこの質問項目について御意見がありましたらお書きください

Appendix C

The Japanese Family Caregiving Inventory

Japanese Family Caregiving Inventory

Purpose

These questions are designed for people who assist a relative or friend who has health or memory problems. In these questions, we use the term **family member** to refer to the relative or friend who has health or memory problems.

Your answers will help me to understand the situation of caregivers like you. Your view will be very helpful to nurses, doctors, and other people who work with caregivers.

Directions

It should take about 1 1/2 hours to answer these questions. You may want to take two or three blocks of time to complete it.

Answer the questions as honestly as you can; there are no correct answers. Please do not consult with other people before you answer the questions. It is **your** view that I need.

I would like to know approximately how long it takes you to answer these questions. If you could keep a rough estimate of the time, it would be useful to me in my future study. If you take breaks, just subtract that time out.

When you are done with these questions, please return it to me in the enclosed stamped envelope. If you have any comments on any specific questions, feel free to write in the blank space around the questions, on the back cover, or on other sheets of paper.

Your role as a caregiver

I will be asking you many detailed questions because I would like to have a good picture of what you now do to help your family member.

In some questions, I use the term **caregiver** to refer to you. Although you may not think of yourself as a caregiver, I use the term caregiver very broadly as **someone who helps a family member because of the family member's health or memory problems.** The help a caregiver provides includes not only direct care but also giving advice and to just being there to give support.

Some of the questions will **not** apply to you, but try to answer all that you can.

Questions?

If you have any questions about this questionnaire, please contact Iku Inoue at Kochi Women's University, School of Nursing (Phone: 0888-73-7511).

We thank you for your thoughtful answers.

YOU AND YOUR FAMILY MEMBER

Please tell us about you and your family member. If you are caring for more than one older person, please answer about one person who you are caring fro more. For all questions, either fill in the blank or **CIRCLE** the answer that best describes you and your family member.

1. How old is your family member?

_________ years

2. Is your family member female or male?

Female 0
Male 1

3. What is your family member's current marital status ?

Married 1
Widowed 2
Divorced 3
Never married 4

4. With whom does your family member live?

Spouse ( )
Son ( )
Son-in-law ( )
Sibling ( )
Friend ( )
Daughter ( )
Daughter-in-law ( )
Grandchild ( )
Other relative ( )
Live alone ( )
Other ( ) ____________________

5. What is your relationship to the family member you are assisting?
<u>You</u> are his or her:

Wife 1
Husband 2
Daughter.................................. 3
Son 4
Daughter-in-law 5
Son-in-law 6
Other relative 7
Neighbor or friend 8
Other ____________________ .. 9

6. About how many years have you and your family member known each other?

___________ years

7. How many years total, if any, have you lived with him or her?

___________ years

8. At this time, do you and your family member live in the same household?

Yes 1
↓ No 0

8a. If **NO**, how far away do you live from your family member?

(by car, by bus, by walk)

__________minutes

or

__________km

9. How many rooms are there in the house where your family member currently lives? Please count all rooms except kitchen and storage.

__________ rooms

10. Does your family member have his or her own room?

Yes 1
No 0

YOUR FAMILY MEMBER'S CURRENT SITUATION

Because of health or memory problems, does your family member **NEED** help with any of the activities listed below? **CIRCLE** all that apply.

1. Bathing or showering?
2. Dressing?
3. Eating?
4. Getting in and out of bed or chairs?
5. Walking?
6. Getting around outside?
7. Using the toilet, including getting to the toilet?
8. Preparing meals?
9. Shopping for personal items (such as toilet items or medicines)?
10. Managing money (such as keeping track of expenses or paying bills)?
11. Using the telephone?
12. Doing light housework (like doing dishes, straightening up, or light cleaning)?
13. Doing heavy housework (like scrubbing floors or washing windows)?
14. Taking medication?
15. Driving or taking a bus or taxi to where he or she needs to go?
16. Others: ______________________
17. None of the above

18. Has your family member had any medical diagnoses?

No 0
Yes 1

18a. If **YES**, what are they, and when did each diagnosis occur?

Diagnisis	Year	Month

19. Have you or your family member received any services from the government or your community because of his or her health or memory problems? For example, mobile bath, home helper, respite care, day care, meal delivery, renting equipment such as hospital type bed or wheel chair, financial aid for remodeling house to meet his or her health needs.

No 0
Yes 1

19a. If **YES**, what kinds of services have you received?

____
____
____
____
____

Adapted from NHIS, 1-17 (1990)

YOUR FAMILY MEMBER'S CURRENT SITUATION (cont.)

In the past week, on how many days did you **personally** need to deal with the following behavior of your family member? (**CIRCLE** your answer.)

In the past week, on how many days did he or she:	**0 Days**	**1–2 Days**	**3–4 Days**	**5–7 Days**
1. Seem withdrawn and overly quiet?	0	1–2	3–4	5–7
2. Act depressed or downhearted?	0	1–2	3–4	5–7
3. Appear to be not interested in other people or outside events?	0	1–2	3–4	5–7
4. Not talk as much as usual?	0	1–2	3–4	5–7

Now, We'd like to ask you some questions about your family member's memory and the difficulty he or she may have doing somethings. (**CIRCLE** your answer.)

How difficult is it for your family member to:	**Not At All Difficult**	**Just A Little Difficult**	**Fairly Difficult**	**Very Difficult**	**Can't Do At All**
5. Remember recent events?	0	1	2	3	4
6. Know what day of the week it is?	0	1	2	3	4
7. Remember his or her home address?	0	1	2	3	4
8. Remember words?	0	1	2	3	4
9. Understand simple instructions?	0	1	2	3	4
10. Find his or her way around the house?	0	1	2	3	4
11 Speak sentences?	0	1	2	3	4
12. Recognize people that he or she knows?	0	1	2	3	4

Adapted from Pearlin, Mullan, Semple, & Skaff (1990)

CAREGIVING ACTIVITIES LIST

The next set of questions is very long. However, your answers are very important to us because we want to have a really good idea about what you are now doing to take care of your family member. Sometimes helping someone is no problem, but for a number of people, giving this help is very difficult to do, both physically and emotionally.

Below is a list of types of help that may be given to a person who has health or memory problems.

We would like for you to tell us whether you do each type of help and, if so, how it goes for you.

For each question, Circle NO if you do NOT do that type of help or if your family member doesn't have that problem, or Circle YES if you do that type of help.

If you circled **YES**, indicate how hard it is for you to do that type of help.

Please circle **Very Hard ⑤, Pretty Hard ④, Somewhat Hard ③, Not Too Hard ②, or Easy①**

If YES, circle how hard it is for you to do that.

	Do you do this type of help for your family member?	**NO**	**YES**	**Very Hard**	**Pretty Hard**	**Some-what Hard**	**Not Too Hard**	**Easy**
1.	Do you do shopping and errands for your family member?	NO	YES	5	4	3	2	1
2.	Do you have to assist him or her with walking around the house? For example, do you have to give him or her your arm or get him or her a walker?	NO	YES	5	4	3	2	1
3.	Do you have to assist him or her with getting around outside the house?	NO	YES	5	4	3	2	1
4.	Do you have to keep one eye on him or her to make sure he or she is safe?	NO	YES	5	4	3	2	1
5.	Do you assist him or her with his or her medications or shots?	NO	YES	5	4	3	2	1
6.	Do you have to help him or her with eating?	NO	YES	5	4	3	2	1
7.	Do you protect him or her from falls?	NO	YES	5	4	3	2	1
8.	Do you help make major decisions about his or her health care – such as surgery or a change in treatment?	NO	YES	5	4	3	2	1

Archbold & Stewart (1986, 1994)

CAREGIVING ACTIVITIES LIST (cont.)

If YES, circle how hard it is for you to do that.

Do you do this type of help for your family member?	NO	YES	Very Hard	Pretty Hard	Some–what Hard	Not Too Hard	Easy
9. Do you try to keep him or her active and involved in activities that he or she enjoys?	NO	YES	5	4	3	2	1
10. Do you keep the doctor informed about changes in his or her health?	NO	YES	5	4	3	2	1
11. Do you keep nurses and other health care workers informed about changes in his or her health?	NO	YES	5	4	3	2	1
12. Do you lift or transfer him or her from one place to another? For example, do you lift him or her out of a chair, or transfer him or her from a bed to a chair?	NO	YES	5	4	3	2	1
13. Do you have to go with him or her as he or she does shopping and errands?	NO	YES	5	4	3	2	1
14. Do you have to make sure he or she gets the right amount of liquids? (Circle **NO** if he or she can do that on his or her own.)	NO	YES	5	4	3	2	1
15. Do you assist him or her with bathing, washing, or taking a shower?	NO	YES	5	4	3	2	1
16. Do you do any of the driving for your family member?	NO	YES	5	4	3	2	1
17. Do you have to handle his or her paranoia or suspiciousness? (Circle **NO** if he or she does not have that problem.)	NO	YES	5	4	3	2	1
18. Do you take part in leisure activities with your family member such as watching TV, playing games, or listening to music)?	NO	YES	5	4	3	2	1
19. Do you have to handle your family member's crying spells? (Circle **NO** if he/she does not have that problem.)	NO	YES	5	4	3	2	1
20. Do you have to make sure he or she eats the right amount or types of food? (Circle **NO** if he or she can do that on his or her own.)	NO	YES	5	4	3	2	1
21. Do you have to clean up if he or she has a bladder accident?	NO	YES	5	4	3	2	1

CAREGIVING ACTIVITIES LIST (cont.)

If YES, circle how hard it is for you to do that.

Do you do this type of help for your family member?	NO	YES	Very Hard	Pretty Hard	Some-what Hard	Not Too Hard	Easy
22. Do you do writing for him or her? (Circle **NO** if he or she can do that on his or her own.)	NO	YES	5	4	3	2	1
23. Do you have to handle his or her yelling? (Circle **NO** if he or she does not have this problem.)	NO	YES	5	4	3	2	1
24. Do you have discussions with him or her about the future, the meaning and purpose of life, or how he or she has lived his or her life?	NO	YES	5	4	3	2	1
25. Do you cook or help prepare meals for him or her?	NO	YES	5	4	3	2	1
26. Do you have to help him or her with bowel problems like constipation or diarrhea?	NO	YES	5	4	3	2	1
27. Do you have to listen to, and answer questions that he or she asks over and over again?	NO	YES	5	4	3	2	1
28. Do you have to help him or her on stairs?	NO	YES	5	4	3	2	1
29. Do you take care of his or her dentures or brush his or her teeth?	NO	YES	5	4	3	2	1
30. Do you handle or manage medical equipment or machines (such as oxygen, a feeding tube, IV equipment, or catheters)?	NO	YES	5	4	3	2	1
31. Do you help him or her get legal matter taken care of?	NO	YES	5	4	3	2	1
32. Do you have to manage his or her problems with fatigue?	NO	YES	5	4	3	2	1
33. Do you have to watch him or her in case he or she wanders off?	NO	YES	5	4	3	2	1
34. Do you assist him or her with dressing or undressing?	NO	YES	5	4	3	2	1
35. Do you keep other family members informed about his or her health?	NO	YES	5	4	3	2	1

CAREGIVING ACTIVITIES LIST (cont.)

If YES, circle how hard it is for you to do that.

Do you do this type of help for your family member?	NO	YES	Very Hard	Pretty Hard	Some–what Hard	Not Too Hard	Easy
36. Do you sit and spend time with him or her?	NO	YES	5	4	3	2	1
37. Do you have to get up at night to help your family member?	NO	YES	5	4	3	2	1
38. Do you have to help him or her with emotional ups and downs?	NO	YES	5	4	3	2	1
39. Do you assist him or her with banking or paying bills?	NO	YES	5	4	3	2	1
40. Do you have to deal with his or her unsafe driving? (Circle **NO** if he or she does not have that problem.)	NO	YES	5	4	3	2	1
41. Do you have to handle situations when he or she doesn't remember who or where he or she is?	NO	YES	5	4	3	2	1
42. Do you have to check on or treat skin problems that he or she has?	NO	YES	5	4	3	2	1
43. Do you check in on him or her to make sure he or she is OK?	NO	YES	5	4	3	2	1
44. Do you have to handle his or her hallucinations? (Circle **NO** if he or she does not have this problem.)	NO	YES	5	4	3	2	1
45. Do you take him or her to see the doctor?	NO	YES	5	4	3	2	1
46. Do you have to protect him or her from poisoning him or herself (e.g., taking too much medication, household poisons)?	NO	YES	5	4	3	2	1
47. Do you take him or her to other places such as to relatives' or friends' homes, senior center, or out to eat?	NO	YES	5	4	3	2	1
48. Do you have to clean up when he or she has a bowel accident?	NO	YES	5	4	3	2	1
49. Do you check his or her skin and apply lotions?	NO	YES	5	4	3	2	1
50. Do you have to manage his or her nausea?	NO	YES	5	4	3	2	1

CAREGIVING ACTIVITIES LIST (cont.)

If YES, circle how hard it is for you to do that.

	Do you do this type of help for your family member?	NO	YES	Very Hard	Pretty Hard	Some–what Hard	Not Too Hard	Easy
51.	Do you fix things and do odd jobs to maintain his or her house?	NO	YES	5	4	3	2	1
52.	Do you have to help him or her in going to the bathroom?	NO	YES	5	4	3	2	1
53.	Do you change his or her bed linens?	NO	YES	5	4	3	2	1
54.	Do you have to watch out for and treat infections in him or her?	NO	YES	5	4	3	2	1
55.	Do you help him or her use the toilet or bedpan?	NO	YES	5	4	3	2	1
56.	Do you have to deal with him or her because of problems related to keys and locks for doors?	NO	YES	5	4	3	2	1
57.	Do you have to make sure he or she gets enough rest?	NO	YES	5	4	3	2	1
58.	Do you do things for him or her like hold hands or rub his or her back?	NO	YES	5	4	3	2	1
59.	Do you have to help him or her with breathing problems?	NO	YES	5	4	3	2	1
60.	Do you help him or her make major financial decisions?	NO	YES	5	4	3	2	1
61.	Do you have to help him or her with tasks that require fine motor control such as to cut, to button, or to open jars?	NO	YES	5	4	3	2	1
62.	Do you have to handle his or her pain?	NO	YES	5	4	3	2	1
63.	Do you have to handle his or her hitting or pushing people? (Circle **NO** if he or she does not have that problem.)	NO	YES	5	4	3	2	1
64.	Do you do light housekeeping for him or her?	NO	YES	5	4	3	2	1
65.	Do you have to watch out for problems that he or she has with swelling?	NO	YES	5	4	3	2	1
66.	Do you assist him or her with hair care or shampooing?	NO	YES	5	4	3	2	1

CAREGIVING ACTIVITIES LIST (cont.)

If YES, circle how hard it is for you to do that.

Do you do this type of help for your family member?	NO	YES	Very Hard	Pretty Hard	Some-what Hard	Not Too Hard	Easy
67. Do you help him or her to get going in an activity?	NO	YES	5	4	3	2	1
68. Do you help your family member use the phone?	NO	YES	5	4	3	2	1
69. Do you have to handle his or her hiding things and forgetting where he or she put them?	NO	YES	5	4	3	2	1
70. Do you have to deal with his or her agitation or restlessness? (Circle **NO** if he or she does not have that problem.)	NO	YES	5	4	3	2	1
71. Do you have to handle his or her showing sexual behavior or interests at the wrong time or place?	NO	YES	5	4	3	2	1
72. Do you read to him or her?	NO	YES	5	4	3	2	1
73. Do you have to monitor the number of people who come to see him or her?	NO	YES	5	4	3	2	1
74. Do you have to handle emergencies related to his or her illness?	NO	YES	5	4	3	2	1
75. Do you help trim and take care of his or her fingernails or toenails?	NO	YES	5	4	3	2	1
76. Do you help to meet his or her spiritual needs? (For example, do you arrange for a priest to come, take him or her to grave, or read religious book to him or her?)	NO	YES	5	4	3	2	1
77. Do you have to handle his or her swearing or foul language? (Circle **NO** if he or she does not have that problem.)	NO	YES	5	4	3	2	1
78. Do you have to help him or her because of problems with his or her eyesight?	NO	YES	5	4	3	2	1
79. Do you have to help him or her because of his or her slowness in moving?	NO	YES	5	4	3	2	1
80. Do you have to clean up his or her portable toilet (commode)?	NO	YES	5	4	3	2	1

CAREGIVING ACTIVITIES LIST (cont.)

If YES, circle how hard it is for you to do that.

Do you do this type of help for your family member?	NO	YES	Very Hard	Pretty Hard	Some–what Hard	Not Too Hard	Easy
Sometimes people who take care of a family member get extra help from a health or social service agency.							
1. Have you had to help your family member by getting information from a doctor or other professional?	NO	YES	5	4	3	2	1
2. Have you contacted a health or social service agency to find out if they had a service that might assist in caring for him or her?	NO	YES	5	4	3	2	1
3. Have you ever arrange for someone from a health or social service agency to assist him or her?	NO	YES	5	4	3	2	1
4. Have you tried to get help for him or her but have been unable to find someone?	NO	YES	5	4	3	2	1
5. Are there any other things you do for him or her because he or she has health or memory problems?	NO	YES					

(Please describe)____

6. Of the caregiving activities on pages 4 through 10, list the three that are the biggest problems for you now:

1) ____

2) ____

3) ____

EXTENT OF HELP

1. How many days in the past week did you spend time helping him or her? ______ **days**

2. On the days you help your family member, about how many hours per day (including time you get up at night) do you spend in helping him or her? ______ **hours**

3. Altogether, how long has your family member needed extra help from you or someone else because of health or memory problems?

   _______ **years** _______ **months**

4. How long have you **personally** been involved in caregiving for your family member?

   _______ **years** _______ **months**

CAREGIVING PROBLEMS

Sometimes people find that the following problems make it harder to give care to their family member.

Has this been a problem for you?	**Not a problem**	**A small problem**	**A moderate problem**	**A big problem**	**A very big problem**
1. Not having enough money	0	1	2	3	4
2. Your being too tired emotionally	0	1	2	3	4
3. Your being too tired physically	0	1	2	3	4
4. Not having enough time	0	1	2	3	4
5. Not having enough help from other people	0	1	2	3	4
6. Not having enough space in the home	0	1	2	3	4
7. Not having a separate room for him or her	0	1	2	3	4
8. Decreased time you have for sleep	0	1	2	3	4

9. Do you pay other people out of your own pocket to take care of your family member?

   No .... 0 → **(Go on to next page)**
   Yes 1

9a. If YES, how much of a financial burden is it? Would you say:

   Not a burden 0
   A little burden 1
   Some burden 2
   A lot of burden 3
   Overwhelming burden 4

HELP FROM OTHERS IN CARING FOR YOUR FAMILY MEMBER

On pages 3 through 9, we asked you questions about the kinds of things you do to help your family member. Now we would like to know if other people have helped out in these activities.

HELP FROM PEOPLE WHOSE JOB IT IS

1. How much help have people whose job it is (such as a health professional, a paid helper) given to your family member?

None at all	0	**(Go to Q. 4)**
A little	1	
Some	2	
Quite a bit	3	
A great deal	4	

2. About how many people whose job it is have helped out? ____________ *(Number of people)*

3. How happy are you with the help that people whose job it is have given ?

Very happy	4
Pretty happy	3
Somewhat happy and somewhat unhappy	2
Pretty unhappy	1
Very unhappy	0

HELP FROM RELATIVES

4. How much help have relatives given to him or her?

None at all	0	**(Go to Q. 7)**
A little	1	
Some	2	
Quite a bit	3	
A great deal	4	

5. About how many relatives have helped out? ____________ *(Number of relatives)*

6. How happy are you with the help that relatives have given?

Very happy	4
Pretty happy	3
Somewhat happy and somewhat unhappy	2
Pretty unhappy	1
Very unhappy	0

HELP FROM FRIENDS AND NEIGHBORS

7. How much help have friends and neighbors given to him or her?

None at all	0	**(Go to Q. 10)**
A little	1	
Some	2	
Quite a bit	3	
A great deal	4	

8. About how many friends and neighbors have helped out? ____________ *(Number of friends and neighbors)*

9. How happy are you with the help that friends and neighbors have given?

Very happy	4
Pretty happy	3
Somewhat happy and somewhat unhappy	2
Pretty unhappy	1
Very unhappy	0

HELP <u>NOT</u> RECEIVED

10. Is there a person you thought would help you more in caring for your family member, but who has **not** done so?

No	0
Yes	1

10a. If **YES**, how upsetting has it been for you that this person has **not** helped as you expected?

Not at all upsetting	0
A little upsetting	1
Somewhat upsetting	2
Quite upsetting	3
Extremely upsetting	4

AREAS OF CONCERN

We would like to know how much you worry about each of the items listed below.

	How much do you worry about . . .	Not at all	A little	Some	Quite a bit	A great deal
1.	your family member's health condition?	0	1	2	3	4
2.	obtaining enough help for the things you can't do for him or her?	0	1	2	3	4
3.	his or her mood or state of mind?	0	1	2	3	4
4.	financial problems related to his or her care?	0	1	2	3	4
5.	your ability to continue taking care of him or her because of your own health?	0	1	2	3	4
6.	what immidiate family members think about you and your caregiving?	0	1	2	3	4
7.	safety when he or she uses the stove?	0	1	2	3	4
8.	how you can go on if he or she gets worse?	0	1	2	3	4
9.	having to leave him or her alone when you go out? (If you never leave him or her alone, if you **had** to go out and leave him or her alone, how much would you worry?)	0	1	2	3	4
10.	his or her safety because of traffic problems?	0	1	2	3	4
11.	your own future?	0	1	2	3	4
12.	the negative effects of taking care of him or her on the rest of your family?	0	1	2	3	4
13.	who will take care of him or her if something happens to you?	0	1	2	3	4
14.	having to make the decision about whether to put him or her into a nursing home?	0	1	2	3	4
15.	whether the care and advice you receive from doctors and nurses are adequate?	0	1	2	3	4
16.	what your relatives think about you and your caregiving?	0	1	2	3	4
17.	safety when he or she uses lawn, shop, or other equipment?	0	1	2	3	4
18.	the progression of his or her disease?	0	1	2	3	4
19.	whether your caregiving situation will have a negative impact on your relationships with other relatives?	0	1	2	3	4
20.	safety because knives, scissors, or needles are present in the home?	0	1	2	3	4

Archbold, & Stewart (1986, 1993)

COMMUNICATION

The next questions focus on communication between you and your family member. People sometimes have hearing, speech, or memory problems that can interfere with how well they can understand or talk with others.

1. To what extent does your family member have difficulty hearing?

Not at all .... 0 (Go on to Q.2)
A little 1
Some .... 2 } **Answer Q. 1a**
Quite a bit 3
A great deal 4

1a. To what extent does his or her hearing problem make it hard you to provide care to him or her?

Not at all 0
A little 1
Some 2
Quite a bit 3
A great deal 4

2. To what extent does he or she have difficulty with speech?

Not at all .... 0 (Go on to Q.3)
A little 1
Some .... 2 } **Answer Q. 2a**
Quite a bit 3
A great deal 4

2a. To what extent does his or her speech problem make it hard you to provide care to him or her?

Not at all 0
A little 1
Some 2
Quite a bit 3
A great deal 4

3. To what extent does he or she have difficulty with remembering or understanding what is said?

Not at all .... 0 (Go on to Q.4)
A little 1
Some .... 2 } **Answer Q. 3a**
Quite a bit 3
A great deal 4

3a. To what extent does his or her problem with remembering or understanding what is said make it hard for you to provide care to him or her?

Not at all 0
A little 1
Some 2
Quite a bit 3
A great deal 4

4. To what extent do **you** have difficulty hearing?

Not at all .... 0 (Go on to next page)
A little 1
Some .... 2 } **Answer Q. 4a**
Quite a bit 3
A great deal 4

4a. To what extent does **your** hearing problem make it hard for you to provide care to him or her?

Not at all 0
A little 1
Some 2
Quite a bit 3
A great deal 4

YOUR PREPARATION FOR CAREGIVING

We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not now doing that type of care.

	Not at all prepared	Not too well prepared	Somewhat well prepared	Pretty well prepared	Very well prepared
1. How well prepared do you think you are to take care of your family member's physical needs?	0	1	2	3	4
2. How well prepared do you think you are to take care of his or her emotional needs?	0	1	2	3	4
3. How well prepared do you think you are to find out about and set up services for him or her?	0	1	2	3	4
4. How well prepared do you think you are for the stress of caregiving?	0	1	2	3	4
5. How well prepared do you think you are to make caregiving activities pleasant for both you and him or her?	0	1	2	3	4
6. How well prepared do you think you are to respond to and handle emergencies that involve him or her?	0	1	2	3	4
7. How well prepared do you think you are to get the help and information you need from the health care system?	0	1	2	3	4
8. Overall, how well prepared do you think you are to care for your family member?	0	1	2	3	4

Stewart & Archbold (1986, 1993)

YOUR EVERYDAY LIFE

1. How predictable are your family member's needs?

Not at all predictable 0
Not too predictable 1
Somewhat predictable 2
Pretty predictable 3
Very predictable 4

2. How predictable is your caregiving routine, or the activities that you do for your family member?

Not at all predictable 0
Not too predictable 1
Somewhat predictable 2
Pretty predictable 3
Very predictable 4

3. How often is your routine unexpectedly interrupted because of your family member's problems?

Never 0
Rarely 1
Sometimes 2
Usually 3
Always 4

4. How often does your day go pretty much as you planned it or as you expected it to go?

Never 0
Rarely 1
Sometimes 2
Usually 3
Always 4

5. How much do you currently feel in control of your life?

Not at all in control 0
In control a little 1
Somewhat in control 2
Pretty much in control 3
Very much in control 4

6. How predictable is your current life situation?

Not at all predictable 0
Not too predictable 1
Somewhat predictable 2
Pretty predictable 3
Very predictable 4

Take a break here.

REWARDS OF CAREGIVING

We know that some people find aspects of their caregiving situation rewarding and others do not. These questions is about things that you may or may not find rewarding because of caring for your family member. There are no right or wrong answers to these questions.

To what extent...	**Not at all**	**A little**	**Some**	**Quite a bit**	**A great deal**
1. is caring for your family member rewarding for you?	0	1	2	3	4
2. does caring for him or her help you understand your own aging?	0	1	2	3	4
3. does caring for him/her help you feel like you are doing something important?	0	1	2	3	4
4. does caring for him or her help you understand the situation of older people in general?	0	1	2	3	4
5. does caring for him or her help you feel good about yourself?	0	1	2	3	4
6. do you feel glad to be a caregiver because immediate family members look at you as an important person?	0	1	2	3	4
7. does caring for him or her help you show others the importance of caregiving?	0	1	2	3	4
8. does caring for him or her add meaning to your life?	0	1	2	3	4
9. does caring for him or her help you live more comfortably financially than if you put him or her in a nursing home?	0	1	2	3	4
10. does caring for him or her help your whole family feel closer to one another?	0	1	2	3	4
11. does caring for him or her give you a sense of accomplishment?	0	1	2	3	4
12. do you feel glad to be a caregiver because other relatives look at you as an important person?	0	1	2	3	4
13. does caring for your family member help you feel that you are giving back for all he or she has done you?	0	1	2	3	4

Stewart & Archbold (1986, 1993)

REWARDS OF CAREGIVING (cont.)

To what extent...	Not at all	A little	Some	Quite a bit	A great deal
14. is caring for him or her rewarding for you because it keeps him or her out of a nursing home?	0	1	2	3	4
15. is just "being there" for him or her rewarding you?	0	1	2	3	4
16. do you feel glad that **you** are the one who is providing care to him or her?	0	1	2	3	4
17. does caring for him or her allow you to preserve his or her integrity?	0	1	2	3	4
18. do you understand more about the aging process because of caregiving?	0	1	2	3	4
19. do you feel glad to be a caregiver because your neighbors and friends look at you as an important person?	0	1	2	3	4
20. is it rewarding to see the courage he or she has?	0	1	2	3	4
21. has helping him or her brought the two of you closer together?	0	1	2	3	4
22. have you personally grown as a result of being a caregiver?	0	1	2	3	4
23. does caring for him or her help the relationship between you and other relatives get better?	0	1	2	3	4
24. is his or her appreciation a reward of caregiving for you?	0	1	2	3	4
25. have you learned a lot about health and illness because of caregiving?	0	1	2	3	4

26. Do you think caring for your family member give you any financial advantage or disadvantage? Would you describe your thought?

____

____

____

____

YOUR ROLES

These questions focus on the different roles you may have and the extent to which your caregiving interferes with these other roles.

To what extent does caring for your family member interfere with your ability to be . . .	Not at all	A little	Some	Quite a bit	A great deal	√ Check if not applic.
1. the kind of spouse or partner you think you should be?	0	1	2	3	4	☐
2. the kind of parent you think you should be?	0	1	2	3	4	☐
3. the kind of daughter/son you think you should be?	0	1	2	3	4	☐
4. the kind of sister/brother you think you should be?	0	1	2	3	4	☐
5. the kind of grandparent you think you should be?	0	1	2	3	4	☐
6. the kind of relative you think you should be to people other than those listed in Q1–Q5?	0	1	2	3	4	☐
7. the kind of friend you think you should be to other people?	0	1	2	3	4	☐
8. the kind of worker you think you should be outside the house?	0	1	2	3	4	☐
9. the kind of worker you think you should be around or in the house?	0	1	2	3	4	☐
10. the kind of student you think you should be?	0	1	2	3	4	☐
11. active in your temple, church, or religious circle in the way you think you should be?	0	1	2	3	4	☐
12. active in the hobby group or the community in the way you think you should be?	0	1	2	3	4	☐
13. good to yourself?	0	1	2	3	4	☐
14. To what extent do your other responsibilities interfere with your ability to care for your family member in the way you would like to?	0	1	2	3	4	☐

YOU AND YOUR FAMILY MEMBER

Now we would like you to let us know how you and your family member feel about each other at the current time.

	Not at all	A little	Some	Quite a bit	A great deal
1. To what extent do the two of you see eye to eye?	0	1	2	3	4
2. How close do you feel to him or her?	0	1	2	3	4
3. How much do you enjoy sharing past experiences with him or her?	0	1	2	3	4
4. How much does he or she express feelings of appreciation for you and the things you do?	0	1	2	3	4
5. How attached are you to him or her?	0	1	2	3	4
6. How much does he or she help you?	0	1	2	3	4
7. How much do you like to sit and talk with him or her?	0	1	2	3	4
8. How much love do you feel for him or her?	0	1	2	3	4
9. To what extent do the two of you share the same values?	0	1	2	3	4
10. When you really need it, how much does he or she comfort you?	0	1	2	3	4
11. How much do the two of you laugh together?	0	1	2	3	4
12. How much do you confide in him or her?	0	1	2	3	4
13. How much emotional support does he or she give you?	0	1	2	3	4
14. To what extent do you enjoy the time the two of you spend together?	0	1	2	3	4
15. How often does he or she express feelings of warmth toward you?	0	1	2	3	4

YOUR REACTIONS TO HELPING YOUR FAMILY MEMBER

1. Is there some kind of help you think you **should** give to your family member that you are not able to give him or her?

No	0
Yes	1
Unsure	-8

2. Are there things you do for your family member that, after you've done them, you think "It's not really my place to do that"?

No	0
Yes	1
Unsure	-8

3. Are there things that your family member tries to do for him or herself that you think he or she should let you help with?

No	0
Yes	1
Unsure	-8

4. Are there things that you do for your family member that you think he or she should try to do for himself or herself?

No	0
Yes	1
Unsure	-8

5. How often do you feel your family member expects too much from you?

Never	0
Rarely	1
Sometimes	2
Much of the time	3
Always	4

6. How often do you feel that immediate family members do not understand what it is like for you to be a caregiver?

Never	0
Rarely	1
Sometimes	2
Much of the time	3
Always	4

7. How often do you feel that other relatives do not understand what it is like for you to be a caregiver?

Never	0
Rarely	1
Sometimes	2
Much of the time	3
Always	4

8. Is there some help that your family member needs that is difficult for you to provide because it is embarassing for either you or him or her?

No	0
Yes	1

8a. If **YES**, how much stress does this embarassment cause you?

Not at all	0
A little	1
Some	2
Quite a bit	3
A great deal	4

9. At this time, do you provide care for one or more ill persons other than him or her?

No	0
Yes	1

9a. If **YES**, could you please describe this situation and the kind of help you give?

____

____

____

____

____

____

YOUR REACTIONS TO HELPING YOUR FAMILY MEMBER

Now we would like to know whether assisting and having other contact with your family member has negatively affected your life.

Has assisting your family member. . .	Not at all	A little	Moderately	A lot	A great deal
1. decreased the time you have to yourself?	0	1	2	3	4
2. increased the stress in your relationship with him/her?	0	1	2	3	4
3. restricted personal privacy?	0	1	2	3	4
4. increased attempts by him/her to manipulate you?	0	1	2	3	4
5. decreased the time you have to spend in recreational activities?	0	1	2	3	4
6. increased the number of unreasonable requests made of you?	0	1	2	3	4
7. added tension to your life?	0	1	2	3	4
8. restricted the vacation activities and trips you take?	0	1	2	3	4
9. increased the nervousness and depression you have concerning your relationship with him/her	0	1	2	3	4
10. added to your feelings that you are being taken advantage of?	0	1	2	3	4
11. reduced the time you have to do your own work and daily chores?	0	1	2	3	4
12. increased demands made by him/her that are over and above what he/she needs?	0	1	2	3	4
13. increased your anxiety about things?	0	1	2	3	4
14. decreased the time you have for friends and other relatives?	0	1	2	3	4
15. decreased the money available to meet the rest of your expenses?	0	1	2	3	4

Montgomery & Borgatta (undated)

YOUR OVERALL EXPERIENCE

1. From our discussions with many caregivers, we know that for some people, caregiving is very confining, while for others, it is not. How confined do you feel because of all the caregiving things you do for your family member?

Not at all confined	0
Confined a little	1
Somewhat confined	2
Confined a lot	3
Extremely confined	4

2. How often would you say that taking care of your family member is very difficult?

Never	0
Rarely	1
Sometimes	2
Much of the time	3
Always	4

3. How much stress do you feel because of all your obligations, including taking care of your family member?

No stress	0
Very little stress	1
Some stress	2
A lot of stress	3
Overwhelming stress	4

4. How much stress do you feel because immediate family members do not accept the way you are providing care?

No stress	0
Very little stress	1
Some stress	2
A lot of stress	3
Overwhelming stress	4

5. How much stress do you feel because other relatives do not accept the way you are providing care?

No stress	0
Very little stress	1
Some stress	2
A lot of stress	3
Overwhelming stress	4

6. How much of the time do you feel you are patient in caring for your family member?

Never	0
Rarely	1
Sometimes	2
Most of the time	3
Always	4

7. In the balance, would you say that the positive aspects of caring for your family member outweigh the negative, that the negative aspects outweigh the positive, or that the positive and negative aspects are about equal?

Positive outweighs the negative ***a lot***	4
Positive outweighs the negative ***somewhat***	3
Positive and negative are about ***equal***	2
Negative outweighs the positive ***somewhat***	1
Negative outweighs the positive ***a lot***	0

8. The needs of people who are receiving care change with time as do yours. Would you say that, as time goes on, giving care to your family member has:

Become much easier for you	4
Become somewhat easier for you	3
Stayed about the same for you	2
Become somewhat more difficult for you	1
Become much more difficult for you	0

9. What if your family member 's care needs increase? How confident are you that you would be able to provide more care than you are doing now?

Not at all confident	0
Not too confident	1
Somewhat confident	2
Pretty confident	3
Very confident	4

YOUR HEALTH

1. How many times during the past week did you make sure you got some exercise, for example, taking a walk?

None	0
One time	1
Two times	2
Three times	3
Four or more times	4

2. How often do you eat a balanced diet?

Every day	4
Most days	3
Some days	2
Rarely	1
Never	0

3. How often do you take pills to help you sleep or for your nerves?

Never	0
Once a week or less	1
Several days each week	2
Every day	3
More than once a day	4

4. During **the past 12 months**, how many separate times were **you** admitted as a patient in a hospital?

None	0
Once	1
2–3 times	2
4–6 times	3
Over 6 times	4

5. During **the past 6 months**, how many separate times did **you** visit a medical doctor or clinic?

None	0
Once	1
2–3 times	2
4–6 times	3
Over 6 times	4

6. During **the past year**, how many times have **you** felt like going for medical care or follow-up, but did not because of your caregiving and other responsibilities?

None	0
Once	1
2–3 times	2
4–6 times	3
Over 6 times	4

Stewart & Archbold, 1-3, 6(1986, 1994)
Kaiser Permanente, NW Region, 4, 5 (undated)

YOUR HEALTH (cont.)

Some caregivers have the following health problems. If you DO NOT have the problem, CIRCLE NO If you DO have the problem, CIRCLE YES and then indicate how much the problem bothers you by circling ①= **Not At All,** ②= **A Little,** ③= **Some, or** ④= **A Lot.**

			If YES, CIRCLE how much the problem bothers you.			
During the past 4 weeks, have <u>you</u> had a problem with your:	**NO**	**YES**	**Not at all**	**A little**	**Some**	**A lot**
1. Back or hip?	NO	**YES**	1	2	3	4
2. Eyes?	NO	**YES**	1	2	3	4
3. Feet or legs?	NO	**YES**	1	2	3	4
4. Hands or arms?	NO	**YES**	1	2	3	4
5. Shoulder or neck	NO	**YES**	1	2	3	4
6. Hearing or ears?	NO	**YES**	1	2	3	4
7. Heart?	NO	**YES**	1	2	3	4
8. Lungs or breathing?	NO	**YES**	1	2	3	4
9. Memory?	NO	**YES**	1	2	3	4
10. Teeth or dentures?	NO	**YES**	1	2	3	4
During the past 4 weeks, have you had:						
11. Dizziness?	NO	**YES**	1	2	3	4
12. Fainting spells?	NO	**YES**	1	2	3	4
13. A cold or flu?	NO	**YES**	1	2	3	4
14. Headaches?	NO	**YES**	1	2	3	4
15. Minor infections?	NO	**YES**	1	2	3	4
16. Pain?	NO	**YES**	1	2	3	4
17. Skin disorders (ulcers, severe itching)?	NO	**YES**	1	2	3	4
18. Stomach or bowel problems?	NO	**YES**	1	2	3	4
19. Urinary problems?	NO	**YES**	1	2	3	4
20. A fall?	NO	**YES**	1	2	3	4
Do you have:						
21. Arthritis or neuralgia?	NO	**YES**	1	2	3	4
22. Cancer?	NO	**YES**	1	2	3	4
23. Arteriosclerosis or circulatory problems?	NO	**YES**	1	2	3	4
24. Diabetes?	NO	**YES**	1	2	3	4
25. High blood pressure?	NO	**YES**	1	2	3	4
26. A psychiatric disorder?	NO	**YES**	1	2	3	4
Have you had:						
27. A recent fracture or injury?	NO	**YES**	1	2	3	4
28. A stroke?	NO	**YES**	1	2	3	4
29. Any other health problems? (Please specify) ____________	NO	**YES**	1	2	3	4

Adapted from Montgomery & Borgatta, 1-4, 6-10, 21 (undated)
Stewart & Archbold, 11-20, 22-29(1986, 1991)

YOUR HEALTH (cont.)

1. In general, would you say your health is **(Circle One Number)**:

Excellent	1
Very Good	2
Good	3
Fair	4
Poor	5

2. **Compared to one year ago**, how would you rate your health in general **now** ? **(Circle One Number)**

Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same	3
Somewhat worse now than one year ago	4
Much worse now than one year ago	5

The following items are about activities you might do during a typical day. Does **your health now limit YOU** in these activities? If so, how much?

(Circle One Number on Each Line)

Activities	**Yes, I am Limited A Lot**	**Yes, I am Limited A Little**	**No, I am Not Limited At All**
3. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
4. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
5. Lifting or carrying groceries	1	2	3
6. Climbing **several** flights of stairs	1	2	3
7. Climbing **one** flight of stairs	1	2	3
8. Bending, kneeling or stooping	1	2	3
9. Walking **more than a mile**	1	2	3
10. Walking **several blocks**	1	2	3
11. Walking **one block**	1	2	3
12. Bathing or dressing yourself	1	2	3

YOUR HEALTH (cont.)

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

(Circle One Number on Each Line)

How much of the time during the past 4 weeks...	**All of the Time**	**Most of the Time**	**A Good Bit of the Time**	**Some of the Time**	**A little of the Time**	**None of the Time**
13. Did you feel full of pep?	1	2	3	4	5	6
14. Have you been a very nervous person?	1	2	3	4	5	6
15. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
16. Have you felt calm and peaceful?	1	2	3	4	5	6
17. Did you have a lot of energy?	1	2	3	4	5	6
18. Have you felt downhearted and blue?	1	2	3	4	5	6
19. Did you feel worn out?	1	2	3	4	5	6
20. Have you been a happy person?	1	2	3	4	5	6
21. Did you feel tired?	1	2	3	4	5	6

(Circle One Number on Each Line)

How true or false is each of following statements for you?	**Definitely True**	**Mostly True**	**Don't Know**	**Mostly False**	**Definitely False**
22. I seem to get sick a little easier than other people	1	2	3	4	5
23. I am as healthy as anybody I know	1	2	3	4	5
24. I expect my health to get worse	1	2	3	4	5
25. My health is excellent	1	2	3	4	5

26. During the past two months have you experienced a weight gain or loss of more than 2-3kg?

No .... 0 → **(Go on to next page)**
Gained more than 2-3kg .... 1 →
Lost more than 2-3kg 2
Don't know .... -8

26a. Were you trying to gain weight?
No 0
Yes 1

26b. Were you trying to lose weight?
No 0
Yes 1

RAND, 13-25 (1986, 1992)
Stewart & Archbold, 26 (1986)

CAREGIVER'S PERSONAL REACTION INVENTORY

Listed below are a number of statements concerning personal attitudes and traits. Read each item and decide whether the statement is true or false as it pertains to you personally. There are no "right" or "wrong" answer.

		True	False
1.	It is sometimes hard for me to go on with my work if I am not encouraged.	T	F
2.	I sometimes feel resentful when I don't get my way.	T	F
3.	On a few occasions, I have given up doing something because I though too little of my ability.	T	F
4.	There have been times when I felt like rebelling against people in authority even though I knew they were right.	T	F
5.	No matter who I am talking to, I'm always a good listener.	T	F
6.	There have been occasions when I took advantage of someone.	T	F
7.	I'm always willing to admit it when I make a mistake.	T	F
8.	I sometimes try to get even rather than forgive and forget.	T	F
9.	I am always courteous, even to people who are disagreeable.	T	F
10.	I have never been irked when people expressed ideas very different from my own	T	F
11.	There have been times when I was quite jealous of the good fortune of others.	T	F
12.	I am sometimes irritated by people who ask favors of me.	T	F
13.	I have never deliberately said something that hurt someone's feelings	T	F

Crowne & Marlowe (1960)

TELL US ABOUT YOU

1. In what year were you born? 19____

2. Are you female or male?

Female	1
Male	2

3. What is your current marital status?

Married	1
Widowed	2
Divorced	3
Never married	4

4. How many years in total did you go to school?

____________ years

5. Are you currently employed?

No, I am retired	1
No, I am looking for employment	2
No, I never have been employed	3
No, I quit work because of my family member's health condition	4
Yes, part–time or on–call	5
Yes, full–time	6
Other__________________	7

6. What kind of work have you done most of your working life?

____

____

7. Counting yourself, how many people live in your household?

___________ people

8. Do you have children under age 18 living in your household or for whom you have caregiving responsibilities?

No	0
Yes	1

If **YES,**

8a. How many? ________

8b. About how many **hours per week** do you spend in caring for them? __________ hrs/wk

9. Which of the following four statements describes your ability to get along on your income?

I can't make ends meet	1
I have just enough, no more	2
I have enough, with a little extra sometimes	3
I always have money left over	4

10. What is the total amount of your yearly **household** income? Please include money from jobs, dividends, interest, net income from a business, farm, rent, social security, and any other money income.

Under $5,000	1
$5,000-$9,999	2
$10,000-$19,999	3
$20,000–$29,999	4
$30,000–$39,999	5
$40,000–$49,999	6
$50,000–$74,999	7
$75,000–$99,999	8
$100,000 or more	9

Stewart & Archbold, 1-8, 10 (1986, 1993)
SSA Retirement History Survey, 9 (1969)

BEFORE YOUR FAMILY MEMBER HAD HEALTH OR MEMORY PROBLEMS

Think back to the time before your family member had health or memory problems. We would like you to describe how you and your family member felt about each other at that time, before he or she had health or memory problems.

Before he or she had health or memory problems	**Not at all**	**A little**	**Some**	**Quite a bit**	**A great deal**
1. How close did you feel to him or her at that time? ...	0	1	2	3	4
2. How much emotional support did he or she give you?	0	1	2	3	4
3. To what extent did you enjoy the time the two of you spent together?	0	1	2	3	4

YOUR VIEW

4. How different does your family member seem to you now as compared to the time before he or she had health or memory problems? Does he or she seem like a different person, or pretty much the same as before?

A different person 1
The same as before 2

4a. If **different**, in what ways is he or she different? ____________________

____

____

____

5. Do you have any regrets about the things that have happened during the time you have been caring for your family member?

No.. 0
Yes 1

5a. If **YES**, what are they? ____________________

____

____

____

Phillips, 4 (1986)
Stewart & Archbold, 1– 3, 5 (1986, 1994)

YOUR VIEW (cont.)

6. Are there any special things that you do on a regular basis for your family member or with your family member that you both count on and look forward to?

No................0
Yes 1

6a. If **YES**, what are they and what makes them special? ______

______

______

______

7. Has your family member's health or memory problems changed the physical intimacy between you and your family member?

No................0
Yes 1

7a. If **YES**, please explain. ______

______

______

______

8. Are there things going on in your life, other than caregiving, that have been especially upsetting or difficult for you?

No................0
Yes 1

8a. If **YES**, please explain. ______

______

______

______

9. Are there any other questions that we should have asked you in order to have a good picture of your situation?

No................0
Yes 1

9a. If **YES**, please explain. ______

______

______

______

Thank you very much for completing this questionnaire. Would you take a few more minutes to give us your candid reactions to the questionnaire?

1. How interesting or boring was this questionnaire?

Very interesting	1
Pretty interesting	2
Somewhat interesting and somewhat boring?	3
Pretty boring	4
Very boring	5

2. Were the questions on this questionnaire clear or confusing?

Everything was very clear	1
Most questions were clear; only a few were confusing	2
Some questions were clear and some were confusing	3
Only a few questions were clear; most were confusing	4
Nearly all the questions were confusing	5

What question or page of questions was most confusing to you? ____________________

____

3. Were any of the questions emotionally upsetting to you?

Not at all	1
A little	2
Some	3
A lot	4

What question or page of questions was most emotionally upsetting to you? __________

____

4. Was the size of the print in the questionnaire large enough so that it was readable?

Yes, the print size was large enough	1
No, the print size was a little hard to read	2
No, the print size made the questionnaire very hard to read	3

Please complete the following sentences:

The thing I liked **most** about this questionnaire was: ____________________

____

____

The thing I liked **least** about this questionnaire was: ____________________

____

____

About how long did it take you to complete this questionnaire? _____ hours _____ minutes

Thank you again for your participation!

Much of this questionnaire was developed using public funds and is available for use by researchers and health and social service providers. Permission to photocopy and use this questionnaire should be requested from:

Barbara J. Stewart or Patricia G. Archbold
School of Nursing
Oregon Health Sciences University
3181 SW Sam Jackson Park Road
Portland, OR 97201–3098.
Phone: (503) 494-3835, FAX: (503) 494-3878

Permission to use scales developed by other researchers should be obtained from those individuals.

Permission to photocopy and use the questionnaire in Japanese should be requested from:

Iku Inoue
School of Nursing
Kochi Women's University
5-15 Eikokuji-cho, Kochi-shi, Kochi 780, Japan
Phone & Fax: (0888) 73-7511

5/1994

日本語版

家族介護質問紙

目的

このアンケートは、健康問題や記憶の障害がある人を身内や友人として介護なさっておられる方々のためにつくられたものです。ここでは、あなたいが介護しておられるご御家族やご親戚を"ご老人"という言葉で表しています。

あなたのお答えは、あなたと同じように誰かの介護をしている人々の立場を理解するのにとても役に立ちます。介護をしておられる方々と一緒に働いている看護婦や医師、その他の医療、福祉に従事している者にとってあなたのご意見が大変参考になります。

答え方

このアンケートは、一時間半から二時間程かかるかと思いますので、2～3回に分けてお答えいただいても結構です。

"これが正しい答え"などというものはありませんので、できる限りご自分の思いに正直にお答えください。質問にお答えになる時、他の人に相談なさらないでください。お聞きしたいのは、あなたご自身の意見です。

このアンケートにお答え頂くのに、実際に、どのくらい時間がかかったのかを知りたいと思います。お手数ですが、大体の時間を計っていただけると、将来の研究に大変役に立ちますので、よろしくお願いいたします。もし、途中で休憩された場合は、その分の時間を差し引いてください。

それぞれの質問やこのアンケート全体について、何かご意見、ご感想などありましたら、その質問の回りの余白でも、裏表紙でも、別紙でも構いませんので、お書き添えください。全部に答え終られましたら、同封の切手を貼った返信用封筒でご返送ください。

介護者とは

このアンケートには、たくさんの細かい質問が含まれています。それは、あなたが現在行っておられるご老人のお世話について、できるだけ具体的に知るためです。

いくつかの質問の中で、"介護者"という言葉を使っています。あなたは、ご自分を"介護者"とは思っておられないかもしれませんが、ここでは、介護者を"健康問題や記憶の障害があるご老人をお世話している人"という広い意味で使っています。また、"世話"には、実際に手助けをすることだけでなく、相談にのったり、精神的な支えになったり、話し相手になったりすることも含まれています。

このアンケートの中の質問があなたのおかれている状況に当てはまらないこともあるかも知れませんが、できるだけ全ての質問にお答えください。

このアンケートに関して、何かご質問がありましたら、高知女子大学 看護学科(電話:73-7511)、野嶋研究室内、井上郁までご連絡ください。

あなたのご協力に、心から感謝いたします。

あなたとあなたが世話しておられるご老人について

あなたとあなたが世話しておられるご老人についてお聞きします。もし、二人以上のご老人をお世話しておられる方は、より多くお世話しておられるご老人お一人についてお答えください。該当する所に数字を入れるか、○をつけてください。

1. あなたがお世話しておられるご老人は、おいくつですか？

満 ________ 歳

2. そのご老人の性別は？

女性.......................... 0
男性.......................... 1

3. そのご老人の現在の婚姻状況は？

既婚.......................... 1
死別.......................... 2
離婚.......................... 3
独身.......................... 4

4. そのご老人は、どなたと一緒にお住いですか？一緒に住んでおられる方全部に印をつけてください。

( ) 配偶者
( ) 息子
( ) 婿
( ) 兄弟姉妹
( ) 友人
( ) 娘
( ) 嫁
( ) 孫
( ) 他の親戚
( ) 老人独り暮し
( ) その他(具体的に ______________)

5. あなたとあなたが世話しておられるご老人との続柄は何ですか？

あなたは、その方の.....

妻 1
夫 2
娘 3
息子.. 4
嫁あるいは義理の娘 5
婿あるいは義理の息子 6
上記以外の親戚 7
隣人または友人 8
その他 ______________ 9

6. あなたとご老人が知り合って、何年くらいになりますか？

________ 年

7. 合計で何年そのご老人と同居していますか？

________ 年

8. 現在、あなたはそのご老人と同居しておられますか？

はい、同居しています 1
いいえ、同居していません 0

↓

8a. "いいえ"と答えた方、どのくらい離れた所にお住いですか？

(バスで、車で、歩いて)

________ 分

あるいは、

________ キロ

9. ご老人が現在住んでおられる家には、部屋数がどのくらいありますか？台所と納戸以外の部屋数を書いてください。

________ 部屋

10. ご老人は、今住んでおられる家で、ご自分専用の部屋をお持ちですか？

はい、持っています 1
いいえ、持っていません 0

あなたが世話しておられるご老人の現在の状況

健康上の問題や記憶の障害を持っているために、あなたの世話しておられるご老人は、次のようなことをするのに手助けがいりますか？手助けが必要なもの全部に○をつけてください。

1. 入浴する、シャワーを浴びる
2. 衣服の脱ぎ着をする
3. 食事をする
4. 寝床への出入り、椅子から立ち上がったり、椅子に座ったりする
5. 歩く
6. 屋外で動き回る
7. トイレ(手洗い)に行く、トイレを使う
8. 食事の準備をする
9. 個人的な物(例えば、ちり紙や薬など)の買物をする
10. お金を扱う(例えば、必要経費の記録や支払いなど)
11. 電話をかける
12. 軽い家事をする(例えば、食器洗い、整理整頓)
13. 力のいる家事をする(例えば、床磨きや窓拭き)
14. 薬を飲む
15. 外出の際に、車を運転したり、バスやタクシーを使う
16. その他:____________________
17. 上記のことについて、何の手助けもいらない

18. ご老人の健康上の問題や記憶の障害に関して、医師の診断を受けておられますか？

いいえ 0

はい .... 1 ↓

18a. "はい"とお答えになった方、診断名は何ですか？その診断はいつ受けられましたか？

診断名	診断を受けた年月
____________	____年 ___月
____________	____年 ___月
____________	____年 ___月
____________	____年 ___月
____________	____年 ___月

19. あなたは、あなたが世話しておられるご老人の健康上の問題や記憶の障害に関連して、役所や地域の人々から何かサービス、例えば、入浴車の派遣、ヘルパーの派遣、ショートステイ(短期収容)、デイケア、食事の配達、介護用品(病院用のベッド、車いすなど)の貸し出し、家の改築費用の貸し付けなどを受けておられますか？

いいえ 0

はい .... 1 ↓

19a. "はい"とお答えになった方、どんなサービスを受けておられますか？

____

____

____

Adapted from NHIS, 1-17 (1990)

あなたが世話しておられるご老人の現在の状況

先週一週間に、次のようなご老人の行動に、あなた自身、どのくらい対応する必要がありましたか？

先週一週間に、ご老人は、何日ぐらい次の様な状態でしたか？	0日	1～2日	3～4日	5～7日
1. 引込みがちで、静かな様子でしたか？	0	1-2	3-4	5-7
2. 意気消沈して、落ち込んでいましたか？	0	1-2	3-4	5-7
3. 回りの人や外の出来事に興味を示しませんでしたか？	0	1-2	3-4	5-7
4. いつもより口数が少ない様子でしたか？	0	1-2	3-4	5-7

次に、ご老人が記憶したり、何かをするのに困難を感じておられるのかどうかについてお伺いします。

ご老人にとって次のことは、どのくらい困難ですか？	全く困難はない	ほんの少しだけ困難	かなり困難	非常に困難	全くできない
5. 最近の出来事を覚えていること	0	1	2	3	4
6. 今日が何曜日かを知っていること	0	1	2	3	4
7. 自宅の住所を覚えていること	0	1	2	3	4
8. 単語を覚えていること	0	1	2	3	4
9. 簡単な指示が理解できること	0	1	2	3	4
10. 家の中で自由に動き回れること	0	1	2	3	4
11 文章を話すこと	0	1	2	3	4
12. 知っている人を見て、それが誰か解ること	0	1	2	3	4

Adapted from Pearlin, Mullan, Semple, & Skaff (1990)

介護活動リスト

次の質問は、健康上の問題や、記憶の障害を持つ人に対してなされるお世話について述べたものです。非常に長いものですが、ご老人のお世話について、あなたが現在どのようなことをなさっているのか詳しく理解するのに、とても大切なものです。

老人のお世話は、多くの人にとって、肉体的にも精神的にも大変難しいことです。

あなたは今、下にあげたようなお世話をしていらっしゃいますか？もし、していらっしゃるのなら、そのお世話をすることは、あなたにとって、どのくらい困難なことですか？

各々の質問について、あなたがしておられる場合には、"はい"に○をつけて、更に、それをすることがあなたにとってどのくらい困難なことなのか、該当する番号に○をつけてください。もし、あなたがしておられないことや、ご老人が必要としていないものがありましたら、"いいえ"に○をつけてください。

ご老人に、あなたは、次のようなお世話をしておられますか？	いいえ	はい	"はい"と答えられた方、それはあなたにとって、どのくらい困難なことですか？				
			非常に困難	かなり困難	やや困難	それほど困難ではない	簡単
1. 老人のために、買物に行ったり、使いに行ったりする	いいえ	はい	5	4	3	2	1
2. 家の中を歩き回るのを手助け(例えば、肩をかしてあげたり杖を取ってあげたり)する	いいえ	はい	5	4	3	2	1
3. 家の外に出る時、手助けをする	いいえ	はい	5	4	3	2	1
4. 老人の安全を守るために常に目を離さないようにする	いいえ	はい	5	4	3	2	1
5. 薬を飲んだり注射をしたりするのを手伝う	いいえ	はい	5	4	3	2	1
6. 食事をするのを手伝う	いいえ	はい	5	4	3	2	1
7. 老人が転ばないように気を付ける	いいえ	はい	5	4	3	2	1
8. 老人が、自分の受ける医療について(例えば、手術を受けるかどうかとか治療の仕方を変えるかどうかとか)の決心ができるように手助けする	いいえ	はい	5	4	3	2	1

介護活動リスト

ご老人に、あなたは、次のようなお世話をしておられますか？			"はい"と答えられた方、それはあなたにとって、どのくらい困難なことですか？				
	いいえ	はい	非常に困難	かなり困難	やや困難	それほど困難ではない	簡単
9. 老人が、活動的で、楽しい活動に参加するように心がけている	いいえ	はい	5	4	3	2	1
10. 老人の状態を主治医に報告している	いいえ	はい	5	4	3	2	1
11. 老人の状態を看護婦や保健婦、他の医療従事者に報告している	いいえ	はい	5	4	3	2	1
12. 椅子から立ち上がるとかベッドから椅子に移るなど、老人を動かす	いいえ	はい	5	4	3	2	1
13. 老人が買物や用事に出かけるのに付き添う	いいえ	はい	5	4	3	2	1
14. 老人が水分を充分に摂っているか気をつける (ご老人が自分で気をつけていられる場合は "いいえ"に印をつけてください)	いいえ	はい	5	4	3	2	1
15. 入浴したり、体を洗ったり、シャワーを浴びたりするのを手伝う	いいえ	はい	5	4	3	2	1
16. 老人が必要な時に車の運転をしてあげる	いいえ	はい	5	4	3	2	1
17. 妄想や疑い深さに対応する (こういう問題がなければ"いいえ"に印をつけてください)	いいえ	はい	5	4	3	2	1
18. 老人と一緒に余暇を楽しむ(例えば、テレビを見たり、ゲームをしたり、音楽を聞いたりする)	いいえ	はい	5	4	3	2	1
19. 老人が突然泣き出した時に対応する (こういう問題がなければ "いいえ"に印をつけてください)	いいえ	はい	5	4	3	2	1
20. 老人が栄養のある食事を充分に摂っているか気をつける (ご老人が自分で気をつけていられる場合は、"いいえ"に印をつけてください)	いいえ	はい	5	4	3	2	1
21. 尿をもらした時、その後始末をする	いいえ	はい	5	4	3	2	1
22. 老人のために、手紙などの書き物をしてあげる (ご老人が自分でできる場合は "いいえ"に印をつけてください)	いいえ	はい	5	4	3	2	1

介護活動リスト

ご老人に、あなたは、次のようなお世話をしておられますか？			"はい"と答えられた方、それはあなたにとって、どのくらい困難なことですか？				
	いいえ	はい	非常に困難	かなり困難	やや困難	それほど困難ではない	簡単
23. 叫んだり怒鳴ったりするのに対応する(こういう問題がなければ"いいえ"に印をつけてください)	いいえ	はい	5	4	3	2	1
24. 老人と将来の事、人生の意味や目的、これまでどのような人生だったかなどを話し合う	いいえ	はい	5	4	3	2	1
25. 老人のために料理を作ったり、食事の準備を手伝ったりする	いいえ	はい	5	4	3	2	1
26. 老人の便秘や下痢など、おなかの具合いの悪い時に対応する	いいえ	はい	5	4	3	2	1
27. 何度も同じことを尋ねるのを聞いてあげたり答えてあげたりする	いいえ	はい	5	4	3	2	1
28. 老人が階段の昇り降りをするのを手助けする	いいえ	はい	5	4	3	2	1
29. 老人の入れ歯の手入れや歯磨きの世話をする	いいえ	はい	5	4	3	2	1
30. 医療器具、器械(例えば、酸素、栄養チューブ、点滴、導尿用カテーテルなど)の取り扱いや管理をする	いいえ	はい	5	4	3	2	1
31. 法律にかかわる問題(例えば、弁護士に会う必要ができた場合や遺言状を書くなど)で、老人の手助けをする	いいえ	はい	5	4	3	2	1
32. 老人の心身の疲労に対応する	いいえ	はい	5	4	3	2	1
33. 突然外に出て行ったりしないように気をつける	いいえ	はい	5	4	3	2	1
34. 着替えを手伝う	いいえ	はい	5	4	3	2	1
35. 老人の状態を他の家族や親戚の人達に知らせる	いいえ	はい	5	4	3	2	1
36. 一緒に座って時を過ごす	いいえ	はい	5	4	3	2	1
37. 夜間、ご老人の世話のために起きる	いいえ	はい	5	4	3	2	1

介護活動リスト

"はい"と答えられた方、それはあなたにとって、どのくらい困難なことですか？

ご老人に、あなたは、次のようなお世話をしておられますか？	いいえ	はい	非常に困難	かなり困難	やや困難	それほど困難ではない	簡単
38. 老人の感情の起伏に対応する	いいえ	はい	5	4	3	2	1
39. 老人が、預金の管理をしたり、いろいろな支払いをするのを手伝う	いいえ	はい	5	4	3	2	1
40 老人の危ない車の運転に対処する(こういう問題がなければ"いいえ"に印をつけてください)	いいえ	はい	5	4	3	2	1
41. 老人が、自分が誰なのか、何処に居るのか解らなくなった時に、対応する	いいえ	はい	5	4	3	2	1
42. 老人の皮膚の状態を観察したり、問題があれば対処したりする	いいえ	はい	5	4	3	2	1
43. 老人に変りがないか、いつも確認する	いいえ	はい	5	4	3	2	1
44. 老人の幻覚症状に対応する(こういう問題がなければ"いいえ"に印をつけてください)	いいえ	はい	5	4	3	2	1
45. 老人を病院の受診に連れて行く	いいえ	はい	5	4	3	2	1
46. 老人が毒になるような物(例えば、薬の飲み過ぎ、家庭内にある薬品など)を飲んでしまわないように気をつける	いいえ	はい	5	4	3	2	1
47. 老人を親戚や友達の家、老人センター、外食などに連れて行く	いいえ	はい	5	4	3	2	1
48. 老人が、便をもらした時、その後始末をする	いいえ	はい	5	4	3	2	1
49. 老人の肌が荒れていないか調べたり、クリームを塗ったりする	いいえ	はい	5	4	3	2	1
50. 老人の吐き気に対応する	いいえ	はい	5	4	3	2	1
51. 老人の家の物の修理や、その他の雑役などをする	いいえ	はい	5	4	3	2	1

介護活動リスト

ご老人に、あなたは、次のようなお世話をしておられますか？			"はい"と答えられた方、それはあなたにとって、どのくらい困難なことですか？				
	いいえ	はい	非常に困難	かなり困難	やや困難	それほど困難ではない	簡単
52. 老人がトイレ (手洗い)まで行くのを手助けする	いいえ	はい	5	4	3	2	1
53. 老人のために寝具(シーツ)などを片付けたり交換したりする	いいえ	はい	5	4	3	2	1
54. 老人が感染症にかかっていないか注意したり、それに対処する	いいえ	はい	5	4	3	2	1
55. 老人がトイレや便器、ポータブルトイレを使うのを手伝う	いいえ	はい	5	4	3	2	1
56. 家の鍵や戸締りについての問題に対応する	いいえ	はい	5	4	3	2	1
58. 老人が充分に休息を摂っているか気をつける	いいえ	はい	5	4	3	2	1
59. 老人の手を握ってあげたり、背中をさすってあげたりする	いいえ	はい	5	4	3	2	1
60. 老人の呼吸の障害のために、手助けをする	いいえ	はい	5	4	3	2	1
61. 老人が家の売買とか財産分与などの大きな財産上の決定をするのを手助けする	いいえ	はい	5	4	3	2	1
62. 老人が、物を切ったり、ボタンを掛けたり、ビンの蓋を開けたりなどの手先の細かい動作をするのを手伝う	いいえ	はい	5	4	3	2	1
63. 老人の痛みの訴えに対応する	いいえ	はい	5	4	3	2	1
64. 老人が人を叩いたり、押したりするのに対応する (こういう問題がなければ "いいえ"に印をつけてください)	いいえ	はい	5	4	3	2	1
65. 老人のために、簡単な家事をする	いいえ	はい	5	4	3	2	1
66. 老人にむくみがないかどうか注意する	いいえ	はい	5	4	3	2	1
67. 老人が髪を洗ったり整えたりするのを手伝う	いいえ	はい	5	4	3	2	1

介護活動リスト

"はい"と答えられた方、それはあなたにとって、どのくらい困難なことですか？

ご老人に、あなたは、次のようなお世話をしておられますか？	いいえ	はい	非常に困難	かなり困難	やや困難	それほど困難ではない	簡単
68. 老人が何かをし始める時に、手助けをする	いいえ	はい	5	4	3	2	1
69. 老人が電話をかけるのを手伝う	いいえ	はい	5	4	3	2	1
70. 老人が持ち物を隠したり、それをどこに隠したのか忘れたりした時、それに対応する	いいえ	はい	5	4	3	2	1
71. 老人が興奮したり、落ち着かない時、それに対応する (こういう問題がなければ "いいえ"に印をつけてください)	いいえ	はい	5	4	3	2	1
72. 老人が性的な行動を示したり、時や場所をわきまえず性的な興味を示したりするのに対応する	いいえ	はい	5	4	3	2	1
73. 老人に本などを読んであげる	いいえ	はい	5	4	3	2	1
74. 老人に会いに来る人の数に注意する	いいえ	はい	5	4	3	2	1
75. 老人の病気に関連する緊急事態に対処する	いいえ	はい	5	4	3	2	1
76. 老人が、手や足の爪を切ったり、手入れしたりするのを手伝う	いいえ	はい	5	4	3	2	1
77. 老人の宗教的な欲求を満たすための手助けをする (例えば、お墓参りに行く、僧侶に連絡する、宗教の本を読んであげるなど)	いいえ	はい	5	4	3	2	1
78. 老人が悪態をついたり、下品な言葉を使ったりするのに対処する (こういう問題がなければ "いいえ"に印をつけてください)	いいえ	はい	5	4	3	2	1
79. 老人の目が悪いので、いろいろと手助けをする	いいえ	はい	5	4	3	2	1
80. 老人の動作が遅いので、いろいろと手助けをする	いいえ	はい	5	4	3	2	1
81. 老人が使ったポータブルトイレの後始末をする	いいえ	はい	5	4	3	2	1

介護活動リスト

"はい"と答えられた方、それはあなたにとって、どのくらい困難なことですか？

ご老人に、あなたは、次のようなお世話をしておられますか？	いいえ	はい	非常に困難	かなり困難	やや困難	それほど困難ではない	簡単
ご老人の介護をしておられる方々は、しばしば、医療機関や保健所、社会福祉サービス施設などからの援助を受けておられます。							
1. 医師やその他の専門家から情報を得て、ご老人のお世話をしなければならないことがありましたか？……………………	いいえ	はい	5	4	3	2	1
2. ご老人の世話をするにあたって、医療機関や保健所、社会福祉サービス施設などに、援助を受けられるかどうか問い合わせたことがありますか？………	いいえ	はい	5	4	3	2	1
3. 今までに、それらの機関から、誰かご老人の援助に来て貰えるように手配したことがありますか？………………………	いいえ	はい	5	4	3	2	1
4. ご老人のための援助を探しても見つからなかったことがありますか？………	いいえ	はい	5	4	3	2	1
5. ご老人の健康問題や記憶の障害のために、上記の他に何かあなたがしておられることがありますか？………………	いいえ	はい					

("はい"と答えられた方、具体的に説明してください)________________________________

6. ４～１０ページにあげた介護活動の中で、現在、あなたにとって一番大きな問題は何ですか？ ３つあげてください。

1)________________________________

2)________________________________

3)________________________________

援助の範囲

1. あなたは、先週、何日間、ご老人のお世話をされましたか？　＿＿＿＿ 日

2. ご老人のお世話をされる日は、一日何時間ぐらいお世話されますか？夜、ご老人のために起きる時間も含めてください。　＿＿＿＿ 時間

3. ご老人が、健康上の問題や記憶の障害のために、あなたや他の人からの援助を必要とするようになってから、どのくらいになりますか？
＿＿＿＿ 年　＿＿＿＿ カ月

4. あなたご自身が、ご老人のお世話をするようになってから、どのくらいになりますか？
＿＿＿＿ 年　＿＿＿＿ カ月

介護にあたっての問題

介護にあたって、次のような問題が生じて、介護をより困難なものにすることがあります。下記のことは、あなたにとって、どの程度、問題ですか？

これらのことはあなたにとって問題ですか？	問題ではない	小さな問題	中くらいの問題	大きな問題	非常に大きな問題
1. お金が十分ない	0	1	2	3	4
2. あなたが精神的に疲れ過ぎている	0	1	2	3	4
3. あなたが肉体的に疲れ過ぎている	0	1	2	3	4
4. 時間が十分ない	0	1	2	3	4
5. 他の人達からの援助が十分ない	0	1	2	3	4
6. 家の広さが十分でない	0	1	2	3	4
7. 老人専用の部屋がない	0	1	2	3	4
8. 睡眠時間が減った	0	1	2	3	4

9. ご老人のお世話に関係した人や機関への支払に、あなた自身のお金を使いますか？

いいえ、使いません .... 0 → (次のページへ進んでください)
はい、使います 1

9a. "使う"と答えた方、それは、どの程度の経済的負担ですか？

負担ではない 0
ほんの少し負担 1
いくらか負担 2
かなり負担 3
やり切れないほど負担 4

介護に関する他の人からの援助

4-10頁では、あなた自身がご老人の世話で、どのようなことをしておられるかについておたずねしました。ここでは、他の方からの援助や手助けについておたずねします。

介護を職業としている人からの援助

1. 全体として、保健、福祉の専門家や有料ヘルパーなど、介護を職業としている人から、ご老人の介護に対してどの程度の援助を受けていますか？

全然受けていない.......................... 0 (問 4へ)
ほんの少し受けている 1
いくらか受けている 2
かなり受けている.......................... 3
非常にたくさん受けている 4

2. 介護を職業にしている人、何人から援助を受けていますか？　(　　　　)人

3. その人達から受けた援助にどの程度満足していますか？

とても満足している 4
満足している................................. 3
いくらか満足でいくらか不満... 2
不満である 1
とても不満である.......................... 0

家族や親戚の人からの援助

4. 全体として、家族や親戚の人から、ご老人の介護に関してどの程度の援助を受けていますか？

全然受けていない.......................... 0 (問7へ)
ほんの少し受けている 1
いくらか受けている 2
かなり受けている.......................... 3
非常にたくさん受けている 4

5. 家族や親戚の人、何人から援助を受けていますか？　(　　　　)人

6. その人達から受けた援助にどの程度満足していますか？

とても満足している 4
満足している................................. 3
いくらか満足でいくらか不満... 2
不満である 1
とても不満である.......................... 0

友人やご近所の方からの援助

7. 全体として、友人やご近所の方から,ご老人の介護に関してどの程度の援助を受けていますか？

全然受けていない.......................... 0 (問 10へ)
ほんの少し受けている 1
いくらか受けている 2
かなり受けている.......................... 3
非常にたくさん受けている 4

8. 友人やご近所の方、何人から援助を受けていますか？　(　　　　)人

9. その人達から受けた援助にどの程度満足していますか？

とても満足している 4
満足している................................. 3
いくらか満足でいくらか不満... 2
不満である 1
とても不満である.......................... 0

援助をしてもらっていないこと

10. ご老人の介護に関して、"もっと援助してくれてもいいのに、してくれない"とあなたが感じている人がいますか？

いいえ 0
はい 1

10a. "はい"とお答えになった方にお聞きしますが、その人が援助してくれないことに対して、どのくらい気分悪く、不満に思われますか？

全く気分悪く思わない 0
少しだけ気分悪く思う 1
いくらか気分悪く思う 2
かなり気分悪く思う.......... 3
非常に気分悪く思う.......... 4

あなたの心配なこと

次は、あなたが下記のようなことをどのくらい心配しておられるかお尋ねします。

	全く心配していない	ほんの少し心配	いくらか心配	かなり心配	非常に心配
1. ご老人の健康状態について	0	1	2	3	4
2. 自分ができないことをご老人に提供してくれる、他からの充分な援助の確保について	0	1	2	3	4
3. ご老人の気分や精神状態について	0	1	2	3	4
4. 介護上の経済的な問題について	0	1	2	3	4
5. 自分自身の健康状態のために、ご老人の介護が続けられるかどうか	0	1	2	3	4
6. 家族の方たちがあなたのしている介護についてどう思っているのか	0	1	2	3	4
7. ご老人がガスやコンロを使う時の安全性	0	1	2	3	4
8. ご老人の状態が悪化した時に介護が続けられるかどうか	0	1	2	3	4
9. ご老人を一人置いて外出すること(一人置いて外出したことがなければ、そうしなければならないと仮定して答えてください)	0	1	2	3	4
10. ご老人が交通事故に遭う可能性	0	1	2	3	4
11. あなた自身の将来について	0	1	2	3	4
12. 介護をすることがあなたの家族に悪い影響を与えるのではないか	0	1	2	3	4
13. 万一あなたに何かあった時、誰がご老人の世話をしてくれるのか	0	1	2	3	4
14. ご老人を老人ホームに入れるかどうかの決断を迫られること	0	1	2	3	4
15. 医師や看護婦から受ける治療や看護、助言などの適切さ	0	1	2	3	4
16. 親戚の人ががあなたのしている介護についてどう思っているのか	0	1	2	3	4
17. ご老人が大工道具などを使う時の安全性	0	1	2	3	4
18. ご老人の病気の進行について	0	1	2	3	4
19. 介護をすることがあなたと親戚の方との関係に悪影響を与えるのではないか	0	1	2	3	4
20. 包丁やはさみ、針などの危険な物が家の中にあること	0	1	2	3	4

Archbold, & Stewart (1986, 1993)

ご老人との意思の疎通

聴くことや話すこと、あるいは、記憶に障害がある場合、その人を理解したり、その人と話をすることに、支障をきたすことがあります。

1. あなたが世話しておられるご老人は、あなたや他の人が話すことが聴こえ難いことがありますか？

全く問題がない	0	(問 2 へ)
ほんの少し耳が遠い	1	(問 1aへ)
いくらか耳が遠い	2	
かなり耳が遠い	3	
ほとんど聴こえない	4	

1a. ご老人の耳が遠いことで、介護がどの程度難しくなっていますか？

全く困難はない	0
ほんの少し困難	1
いくらか困難	2
かなり困難	3
非常に困難	4

2. あなたが世話しておられるご老人は、話をするのがどの程度困難ですか？

全く問題がない	0	(問 3 へ)
ほんの少し困難	1	(問2aへ)
いくらか困難	2	
かなり困難	3	
ほとんど話せない	4	

2a. ご老人が話をすることに障害があるために、介護がどの程度難しくなっていますか？

全く困難はない	0
ほんの少し困難	1
いくらか困難	2
かなり困難	3
非常に困難	4

3. あなたが世話しておられるご老人は、言われたことを理解したり思い出したりするのがどの程度困難ですか？

全く問題がない	0	(問 4 へ)
ほんの少し困難	1	(問3aへ)
いくらか困難	2	
かなり困難	3	
非常に困難	4	

3a. ご老人に理解力や記憶力の問題があることで、介護がどの程度難しくなっていますか？

全く困難はない	0
ほんの少し困難	1
いくらか困難	2
かなり困難	3
非常に困難	4

4. あなた自身、人の話すことが聴こえ難いことがありますか？

全く問題がない	0	(次頁へ)
ほんの少し耳が遠い	1	(問4aへ)
いくらか耳が遠い	2	
かなり耳が遠い	3	
ほとんど聴こえない	4	

4a. あなた自身の耳が遠いことで、介護がどの程度難しくなっていますか？

全く困難はない	0
ほんの少し困難	1
いくらか困難	2
かなり困難	3
非常に困難	4

介護の準備や心構え

誰かの介護をする時、良く準備や心構えができていると思う部分分野とそうでもないと思う部分とがあるものですが、あなたは、自分自身、どれくらいできていると思いますか。それぞれの内容について、最もあなたの気持ちに近いものを数字で選んでください。現在、実際にはやっていないことについても答えてください。

	全くできていない	あまりよくはできていない	まあまあよくできている	かなりよくできている	たいへんよくできている
1. ご老人の身体的な介護をすることについてはどうですか？	0	1	2	3	4
2. ご老人の心の介護をすることについてはどうですか？	0	1	2	3	4
3. 医療や保健、福祉機関など外部からの必要なサービスを利用することについてはどうですか？	0	1	2	3	4
4. 介護する上でたまってくるストレスに対応することについてはどうですか？	0	1	2	3	4
5. 自分にとってもご老人にとっても介護を楽しくすることについてはどうですか？	0	1	2	3	4
6. 世話をしているご老人が緊急を要する状況になった時の対応についてはどうですか？	0	1	2	3	4
7. 医療や保健、福祉機関から必要な情報を得ることについてはどうですか？	0	1	2	3	4
8. 総合的にみて、介護をすることについてどれくらい良く準備や心構えがができていると思いますか？	0	1	2	3	4

Stewart & Archbold (1986, 1993)

あなたの毎日の生活

1. あなたが世話しておられるご老人が何を必要としているか、どの程度予測できますか？

全く予測できない 0
あまり予測できない 1
いくらか予測できる 2
かなり予測できる 3
非常に良く予測できる 4

2. 毎日の介護の手順や内容がどの程度予測できますか？

全く予測できない 0
あまり予測できない 1
いくらか予測できる 2
かなり予測できる 3
非常に良く予測できる 4

3. 世話しておられるご老人の状態によって、あなたの日課が突然乱されることがどのくらいありますか？

全くない.................................. 0
めったにない 1
時々ある.................................. 2
よくある.................................. 3
いつも 4

4. あなたの一日は、どのくらい計画していた通り、あるいは、期待していた通り進みますか？

全くそうならない 0
めったにそうならない 1
時々そうなる.......................... 2
よくそうなる.......................... 3
いつもそうなる 4

5. あなたは、どのくらい毎日の暮しが自分の思うようにいっていると感じますか？

全くそう感じない 0
めったにそう感じない 1
時々そう感じる 2
よくそう感じる 3
いつもそう感じる 4

6. あなたの今の生活状況は、どのくらい予測できますか？

全く予測できない 0
あまり予測できない 1
いくらか予測できる 2
かなり予測できる 3
非常に良く予測できる 4

少し休みましょう！

介護に対するあなたの気持ち

介護にやりがいを見いだす人とそうでない人とがいらっしゃいます。あなたの考えを聞かせてください。"これが正しい答えだ"というものはありませんので、あなたの気持ちに一番近いものを選んでください。

	全くそう思わない	少しはそう思う	いくらかそう思う	かなりそう思う	非常にそう思う
1. 自分が世話している老人の介護はやりがいのあることだと思う	0	1	2	3	4
2. 介護をすることが自分自身の老いを理解するのに役立っていると思う	0	1	2	3	4
3. 介護をすることが、とても大切なことをしていると感じさせてくれる	0	1	2	3	4
4. 介護をすることが、一般的な老人のおかれている状況を理解するのに役立っていると思う	0	1	2	3	4
5. 介護をすることで自分自身に対する評価が良くなった	0	1	2	3	4
6. 介護をすることで、家族の自分に対する評価が良くなったと思う	0	1	2	3	4
7. 自分が介護をすることが、他の人に介護の重要さを示すのに役立っていると思う	0	1	2	3	4
8. 介護をすることで、より生きがいを感じられるようになった	0	1	2	3	4
9. 老人を家で介護する方が、老人ホームや老人病院などに入れるより経済的に楽である	0	1	2	3	4
10. 老人の介護をすることで、家族全体のきづながより強くなったと思う	0	1	2	3	4
11. 介護をすることが達成感を味あわせてくれる	0	1	2	3	4
12. 介護をすることで、親戚の人達の自分への評価が良くなったと思う	0	1	2	3	4
13. 介護をすることで今までその人にしてもらったことへの恩返しをしていると思う	0	1	2	3	4
14. 老人が家で暮していられることに、介護のやりがいを感じる	0	1	2	3	4

Stewart & Archbold (1986, 1993)

介護に対するあなたの気持ち

	全くそう思わない	少しはそう思う	いくらかそう思う	かなりそう思う	非常にそう思う
15. その人のために、自分がただそこに居るだけでも価値のあることだと思う	0	1	2	3	4
16. 介護をしているのが他の誰でもなく"私だ"と思えることがうれしい	0	1	2	3	4
17. 自分が介護をすることでその人の人間性を保ってあげられると思う	0	1	2	3	4
18. 介護をしていることで老化の過程について理解が深まったと思う	0	1	2	3	4
19. 介護をすることで、友人や近所の人の自分に対する評価が良くなったと思う	0	1	2	3	4
20. 世話している老人ががんばっているのを見て報われた思いがする	0	1	2	3	4
21. 介護をすることで、老人とのきづなが強くなったと思う	0	1	2	3	4
22. 介護をすることで、自分が人間的に成長したと思う	0	1	2	3	4
23. 介護をすることで、親戚の人との関係が良くなったと思う	0	1	2	3	4
24. 老人から感謝の言葉を聞くことで、報われたと感じる	0	1	2	3	4
25. 介護をすることで健康や病気についてたくさん学ぶことがあったと思う	0	1	2	3	4

26. 介護をすることで、経済的にプラス、マイナスがありますか？それは、どんなことですか？

あなたの役割

ここでは、あなたが介護以外に担っておられる役割とそれらの役割を果たすことの難しさについてお聞きします。あなたが介護の役割をとることが、どのくらい、他の役割を果たすことの妨げになっていますか？あなたの気持ちに一番近いものを選んでください。もし、該当しない役割の場合は、右端の□に✓を入れてください。

	全く妨げていない	ほんの少し妨げている	いくらか妨げている	かなり妨げている	非常に妨げている	自分には該当しない
1. 自分が望むような妻あるいは夫でいること	0	1	2	3	4	□
2. 自分が望むような親でいること	0	1	2	3	4	□
3. 自分が望むような娘あるいは息子でいること	0	1	2	3	4	□
4. 自分が望むような兄弟姉妹でいること	0	1	2	3	4	□
5. 自分が望むような祖父母でいること	0	1	2	3	4	□
6. 自分が望むような(上記以外の)親戚でいること	0	1	2	3	4	□
7. 自分が望むような友人でいること	0	1	2	3	4	□
8. 自分が望むような職業人でいること	0	1	2	3	4	□
9. 自分が望むような家庭内での働き手でいること	0	1	2	3	4	□
10. 自分が望むような学生でいること	0	1	2	3	4	□
11. 自分が望むように、お寺や神社、教会での役割やその他の宗教的な集まりに参加すること	0	1	2	3	4	□
12. 自分が望むように、趣味などのサークルや地域の活動に参加すること	0	1	2	3	4	□
13. 自分自身を大切にすること	0	1	2	3	4	□
14. 逆に、上記のようなあなたの役割は、あなた自身がやりたいと思う介護をどの程度妨げていると感じますか？	0	1	2	3	4	□

あなたとあなたが世話しておられるご老人について

次は、あなたとあなたが世話しておられるご老人との関係についてお聞きします。

	全く そう ではない	ほんの 少しそう である	いくらか そう である	かなり そう である	非常に そう である
1. あなたとあなたが世話しておられるご老人とは、意見が合いますか？	0	1	2	3	4
2. その方を身近に感じますか？	0	1	2	3	4
3. その方と昔話をするのは、楽しいですか？	0	1	2	3	4
4. その方は、あなたやあなたがしてあげたことに対して、感謝の気持ちを表しますか？	0	1	2	3	4
5. その方に愛着を感じますか？	0	1	2	3	4
6. その方があなたの手助けをしてくれていると感じますか？	0	1	2	3	4
7. その方と座って話をするのが好きですか？	0	1	2	3	4
8. その方に愛情を感じますか？	0	1	2	3	4
9. お二人は同じ価値感を持っていますか？	0	1	2	3	4
10. あなたが辛い思いをしている時、その方は慰めてくれますか？	0	1	2	3	4
11. お二人で一緒に笑うことがありますか？	0	1	2	3	4
12. あなたは、その方と、心を開いて話しますか？	0	1	2	3	4
13. その方は、あなたにとって、心の支えになっていますか？	0	1	2	3	4
14. お二人で一緒に過ごす時間は楽しいですか？	0	1	2	3	4
15. その方はあなたに対して暖かい気持ちを表しますか？	0	1	2	3	4

介護に対するあなたの気持ち

1. ご老人の介護に関して、"してあげなければ"と思いながらできないでいることがありますか？

いいえ、ありません 0
はい、あります 1
わかりません .... -8

2. 何かご老人にしてあげた後で、"これは本当は私がするべきことではない"と思うことがありますか？

いいえ、ありません 0
はい、あります 1
わかりません .... -8

3. ご老人が自分でやろうとすることで、"私に手伝わせてくれればいいのに"と思うことがありますか？

いいえ、ありません 0
はい、あります 1
わかりません .... -8

4. 何かご老人にしてあげていることで、"自分でやってみればいいのに"と思うことがありますか？

いいえ、ありません 0
はい、あります 1
わかりません .... -8

5. ご老人があなたに期待しすぎていると感じることがどのくらいありますか？

一度もありません 0
めったにありません 1
時々あります 2
よくあります 3
いつもそうです 4

6. 家族の方達があなたの気持ちをわかってくれないと思うことがどのくらいありますか？

一度もありません 0
めったにありません 1
時々あります 2
よくあります 3
いつもそうです 4

7. 親戚の方達があなたの気持ちをわかってくれないと思うことがどのくらいありますか？

一度もありません 0
めったにありません 1
時々あります 2
よくあります 3
いつもそうです 4

8. ご老人が必要としている援助で、本人か、あるいは、あなたが恥しくてしてあげるのが難しいことがありますか？

いいえ 0
はい 1

6a. "はい"とお答えになった方、こういうお世話はどのくらいストレスになりますか？

全くならない 0
ほんの少しなる 1
いくらかなる 2
かなりなる 3
非常になる 4

9. そのご老人以外に、あなたが介護をしておられる病人がいますか？

いいえ 0
はい 1

7a. "はい"とお答えになった方、ごめんどうですが、どんな状況で、どんなお世話をしておられるのか教えてください。

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介護に対するあなたの気持ち

何らかの障害のあるご老人のお世話をしたり、一緒に暮らしたりすることで、あなたの生活に良くない影響を及ぼしていることはないでしょうか。次のそれぞれの質問を読んで、あなたの気持ちに一番近いと思われる番号を選んでください。

	全く ない	ほんの 少しある	いくらか ある	かなり ある	非常に よくある
1. 自分のために使える時間が減った	0	1	2	3	4
2. 世話しておられるご老人との関係にストレスが増えた	0	1	2	3	4
3. プライバシーが護れなくなった	0	1	2	3	4
4. 世話しておられるご老人が、自分の思うようにあなたを動かそうとすることが多くなった	0	1	2	3	4
5. あなたが余暇を楽しむ時間が少なくなった	0	1	2	3	4
6. ご老人があなたに対してわがままや無理を言うことが多くなった	0	1	2	3	4
7. あなたの生活に緊張が増した	0	1	2	3	4
8. 旅行などができなくなった	0	1	2	3	4
9. 神経質になったり、落ち込んだりすることが多くなった	0	1	2	3	4
10. ご老人にうまく使われていると思う気持ちが強くなった	0	1	2	3	4
11. あなた自身の仕事や家事をする時間が減った	0	1	2	3	4
12. ご老人が必要以上の要求をするようになった	0	1	2	3	4
13. 心配事が増えた	0	1	2	3	4
14. 世話をしておられるご老人以外の身内の人や友人過ごす時間が減った	0	1	2	3	4
15. 介護以外の支出に使えるお金が減った	0	1	2	3	4

介護にかかわるあなたの経験

1. 老人の世話をしている方の中には、介護することで多くの制限を受け、閉じ込められているように感じる人とそうでもない人とがいます。あなたはどう思いますか？

全くそうは思わない	0
ほんの少しそう思う	1
いくらかそう思う	2
かなりそう思う	3
非常にそう思う	4

2. 介護は難しいと思うことは、どのくらいありますか？

全くない	0
めったにない	1
時々ある	2
よくある	3
いつも	4

3. 介護も含めて、あなたが責任を持っているすべての役割や仕事からどの程度ストレスを感じていますか？

全くない	0
ほんの少しある	1
いくらかある	2
かなりある	3
耐えられない程ある	4

4. 家族の方たちがあなたの介護の仕方を認めてくれないことでストレスを感じることがありますか？

全くない	0
ほんの少しある	1
いくらかある	2
かなりある	3
耐えられない程ある	4

5. 親戚の方たちがあなたの介護の仕方を認めてくれないことでストレスを感じることがありますか？

全くない	0
ほんの少しある	1
いくらかある	2
かなりある	3
耐えられない程ある	4

6. 介護をする上で、自分が我慢強いなと思うことはどのくらいありますか？

全くない	0
めったにない	1
時々ある	2
よくある	3
いつも	4

7. ご老人の介護をすることは、良い面と悪い面を比べると、どちらが多いと思いますか？

良い面がずっと多い	4
良い面がいくらか多い	3
良い面と悪い面が同じくらい	2
悪い面がいくらか多い	1
悪い面がずっと多い	0

8. 介護を受けている人の必要としていることも、他の人と同じように、時と共に変わります。時間の経過に伴って、介護することは、あなたにとってどう変わりましたか？

ずっとやり易くなった	4
いくらかやり易くなった	3
ほとんど変わらない	2
いくらか大変になった	1
ずっと大変になった	0

9. もし、この先ご老人のお世話の量が増えたらどうですか？現在しているよりもっと多くの介護量を担うことに、どれくらい自信がありますか？

全く自信がない	0
あまり自信がない	1
まあまあ自信がある	2
かなり自信がある	3
非常に自信がある	4

Archbold & Stewart (1986, 1991)

あなたの健康について

1. ここ一週間の間に、何回ぐらい自分で努めて散歩などの運動をしましたか？

全くしない	0
1 回	1
2 回	2
3 回	3
4 回以上	4

2. 栄養のバランスのとれた食事をどれくらいとりますか？

毎日	4
ほとんど毎日	3
時々	2
めったにない	1
全くない	0

3. どれくらいの頻度で睡眠薬や精神安定剤を飲みますか？

全く飲まない	0
週 1 回以下	1
週のうち数日	2
毎日	3
一日一回以上	4

4. 過去 1 年の間に、あなた自身、何回入院しましたか？

0 回	0
1 回	1
2～3 回	2
4～6 回	3
7 回以上	4

5. 過去 6 カ月間に、あなた自身何回医者にかかりましたか？

0 回	0
1 回	1
2～3 回	2
4～6 回	3
7 回以上	4

6. 過去 1 年の間に、あなた自身のことで病院に行きたいと思いながら介護や他のしなければならないことのために、行けなかったことが何回ありますか？

0 回	0
1 回	1
2～3 回	2
4～6 回	3
7 回以上	4

Stewart & Archbold, 1-4, 7 (1986, 1994)
Kaiser Permanente, NW Region, 5-6 (undated)

あなたの健康について

介護者の中には、次のような健康上の問題を抱えている人もいます。あなたがこのような問題を持っておられなければ、"いいえ"に○を付けてください。もし、問題があれば、"はい"に○を付けて、それがどの程度あなたを悩ましているのか該当する番号を選んでください。

			"はい"と答えた方、それはどの程度あなたを悩ましていますか？			
過去4週間のうちで、あなたは、以下の体の部分に何か変調を感じましたか？	いいえ	はい	全くない	ほんの少しある	いくらかある	非常にある
1. 背中や腰	いいえ	はい	1	2	3	4
2. 目	いいえ	はい	1	2	3	4
3. 足	いいえ	はい	1	2	3	4
4. 手や腕	いいえ	はい	1	2	3	4
4. 肩や首	いいえ	はい	1	2	3	4
5. 聴力あるいは耳	いいえ	はい	1	2	3	4
6. 心臓	いいえ	はい	1	2	3	4
7. 肺あるいは呼吸	いいえ	はい	1	2	3	4
8. 記憶	いいえ	はい	1	2	3	4
9. 歯あるいは入れ歯	いいえ	はい	1	2	3	4
過去4週間のうちに、以下のような症状を感じたことがありますか？						
10. めまい	いいえ	はい	1	2	3	4
11. 気を失う	いいえ	はい	1	2	3	4
12. 風邪やインフルエンザ	いいえ	はい	1	2	3	4
13. 頭痛	いいえ	はい	1	2	3	4
14. 切傷などへの軽い感染症	いいえ	はい	1	2	3	4
15. 痛み	いいえ	はい	1	2	3	4
16. 皮膚病(皮膚の潰瘍やひどいかゆみ等)	いいえ	はい	1	2	3	4
17. 胃腸の調子が悪い	いいえ	はい	1	2	3	4
18. 泌尿器の調子が悪い	いいえ	はい	1	2	3	4
19. 転倒	いいえ	はい	1	2	3	4
あなたは、以下のような病気を持っていますか？						
20. 神経痛、リュウマチ	いいえ	はい	1	2	3	4
21. がん	いいえ	はい	1	2	3	4
22. 動脈硬化、血液循環障害	いいえ	はい	1	2	3	4
23. 糖尿病	いいえ	はい	1	2	3	4
24. 高血圧	いいえ	はい	1	2	3	4
25. 精神障害	いいえ	はい	1	2	3	4
あなたは、以下のような経験がありますか？						
26. 最近、骨折や他の怪我をした	いいえ	はい	1	2	3	4
27. 脳卒中をおこしたことがある	いいえ	はい	1	2	3	4
28. その他の健康上の問題	いいえ	はい	1	2	3	4

("はい"と答えた方、具体的に書いてください) ____________________

Adapted from Montgomery & Borgatta, 1-9, 20 (undated)
Stewart & Archbold, 10-19, 21-28 (1986, 1991)

あなたの健康について

1. 一般的にあなたの健康状態はいかがですか？(一つに○をつけてください)

最高に良い	1
とても良い	2
良い	3
まあまあ	4
悪い	5

2. 一年前と比べて、今のあなたの健康状態はいかがですか？(一つに○をつけてください)

一年前よりずっと良い	1
一年前よりいくらか良い	2
ほとんど同じ	3
一年前よりいくらか悪い	4
一年前よりずっと悪い	5

以下の項目は、日常あなたがされるような動作についてです。健康上の理由でできないことがありますか？

(一つに○をつけてください)

	ほとんどできない	少しだけできる	十分できる
3. 激しい運動、たとえば、走る、重い物を持ち上げる、激しいスポーツをする	1	2	3
4. 中くらいの運動、たとえば、テーブルを動かす、掃除機をかける、ボーリングやゴルフをする	1	2	3
5. 食料品、日用品などの買物を持ち運ぶ	1	2	3
6. 階段を何階分か登る	1	2	3
7. 階段を一階分登る	1	2	3
8. 体を曲げる、ひざまずく、かがむ	1	2	3
9. １～２キロ以上歩く	1	2	3
10. ４００～５００メートル歩く	1	2	3
11. １００～２００メートル歩く	1	2	3
12. 入浴したり着替えたりする	1	2	3

あなたの健康について

ここからは、過去4週間にあなたが感じたことやあなたの状況について伺います。それぞれの質問に対して、あなたの気持ちに一番近い番号を選んでください。

(一つに○をつけてください)

過去4週間のうちで、どのくらい.....	いつも	ほとんどの時間	かなりの時間	いくらかの時間	ほんの少しの時間	全くそんなことはない
13. 元気いっぱいだと感じましか？	1	2	3	4	5	6
14. 神経質になりましたか？	1	2	3	4	5	6
15. 何を見ても明るい気分になれない程ひどく落ち込みましたか？	1	2	3	4	5	6
16. 静かで落ち着いた気分でしたか？	1	2	3	4	5	6
17. 気力に溢れていましたか？	1	2	3	4	5	6
18. 意気消沈して優鬱でしたか？	1	2	3	4	5	6
19. 精も根も尽きたと感じましたか？	1	2	3	4	5	6
20. 幸せに感じましたか	1	2	3	4	5	6
21. 疲れたと感じましたか？	1	2	3	4	5	6

(一つに○をつけてください)

以下の項目は、どのくらいあなたに当てはまりますか？	全くそのとおり	ほぼそうだ	わからない	ほぼ違う	全く違う
22. 私は、他の人より病気にかかりやすい	1	2	3	4	5
23. 私は、私が知っている人達と同じくらい健康である	1	2	3	4	5
24. 私の健康状態は悪くなっていくと思う	1	2	3	4	5
25. 私は、健康そのものである	1	2	3	4	5

26. 過去2カ月の間に2～3キロ以上の体重の変動がありましたか？

いいえ .... 0 → (次のページへ進んでください)
2～3キロ以上増えた .... 1 → 26a
2～3キロ以上減った .... 2 → 26b
わからない .... -8

26a. 太ろうと努力したのですか？
いいえ 0
はい 1

26b. やせようと努力したのですか？
いいえ 0
はい 1

RAND, 13-25 (1986, 1992)
Stewart & Archbold, 26 (1986)

個人的態度についての質問

下にあげた文章は、人間の特性や態度について書いたものです。まず、ひとつひとつの文章を読んであなたに当てはまるかどうか考えてください。そして、その文章があなたに当てはまる場合には "正" に、当てはまらない場合には "誤" に、そのいずれかに ○印をつけてください。

1. 人に励まされないと、自分に課せられた事を続けていくことが、時々難しくなります。…………　正　誤
2. 自分の思うようにならない場合、時には、腹立たしく思うことがあります。…………　正　誤
3. 時には、自分の能力に自信がもてなくて、物事を投げ出すことがあります。…………　正　誤
4. 相手が正しいとわかっていても、目上の人に対しては、反抗したくなることがあります。…………　正　誤
5. 相手が誰であろうと、私はいつも良い聞き手です。…………　正　誤
6. 人を利用することも、時にはあります。…………　正　誤
7. 自分が間違った時には、いつも快くそれを認めることができます。…………　正　誤
8. 人の自分に対する仕打に対して、水に流すよりも、時々仕返しをしようとします。…………　正　誤
9. たとえ、気の合わない人に対しても、いつも礼儀正しくふるまいます。…………　正　誤
10. 人が自分と違った意見を延べたからといって、決していやな思いをしたことはありません。…………　正　誤
11. 他人の幸運がうらやましくてしかたのない時もあります。…………　正　誤
12. 人に頼み事をされた時など、時々いらいらさせられます。…………　正　誤
13. 人の気持ちを傷つけるようなことを、故意に言ったりは決してしません。…………　正　誤

Crowne & Marlowe (1960)

あなたご自身について

1. あなたはおいくつですか？

満 ________ 歳

2. あなたの性別は？

女性 0
男性 1

3. あなたの現在の婚姻状況は？

既婚 1
死別 2
離婚 3
独身 4

4. あなたは、合計で、何年間学校に通いましたか？

________ 年間

5. あなたは、現在職業をお持ちですか？

いいえ、定年退職しました 1
いいえ、求職中です 2
いいえ、職についたことはありません 3
いいえ、介護のために仕事を辞めました 4
はい、パートタイムで働いています 5
はい、常勤で(正職員として)働いています 6
その他 (具体的に書いてください)
________________ 7

6. あなたが今までにしてきた主な職業は何ですか？

____

____

7. あなたを含めて、同居している人は何人ですか？

________ 人

8. １８歳以下の、同居の、または扶養義務のある子供がいますか？

いいえ、いません 0
はい、います 1

"いる"とお答えになった方、

8a. 何人いますか？ ________ 人

8b. その子供の世話にかかる時間は、だいたい週何時間ぐらいですか？

週 _____ 時間

9. 以下の家計を表わしている4つの文のうち、あなたのご家庭を一番よく表わしているのはどれですか？

いつも赤字でやっていけない 1
ぎりぎりで何とか足りるが、余分はない 2
充分やっていけるし、時には余分も出る 3
いつもゆとりがある 4

10. あなたの家の年収(年間総世帯収入)は、下記のどの項目に当てはまりますか？この質問に答える場合、仕事からの収入(給料)ばかりでなく、商売や農業からの収益、配当金、利子、地代や家賃、年金などあらゆる収入を含めて考えてください。

年収 100万円以下 1
年収 100万円～199万円 2
年収 200万円～299万円 3
年収 300万円～399万円 4
年収 400万円～499万円 5
年収 500万円～599万円 6
年収 600万円～699万円 7
年収 700万円～999万円 8
年収 1000万円以上 9

Stewart & Archbold, 1-8, 10 (1986, 1993)
SSA Retirement History Survey, 9 (1969)

世話しておられるご老人に健康問題や記憶の障害が起きる前のこと

ご老人に健康上の問題や記憶の障害が起きる前のことを思い出してください。その頃、あなたとご老人との間柄はどうだったでしょうか？

	全くそうではなかった	ほんの少しそうだった	いくらかそうだった	かなりそうだった	非常にそうだった
1. その頃、あなたはご老人をどれくらい身近に感じていましたか？	0	1	2	3	4
2. ご老人は、あなたにとってどのくらい心の支えになっていましたか？	0	1	2	3	4
3. お二人で一緒に過ごす時間は、どのくらい楽しいものでしたか？	0	1	2	3	4

あなたの御意見

4. 健康上の問題や記憶の障害が起きる前と今とでは、世話しておられるご老人はどのように違って見えますか？別人のように違いますか？それとも、以前とほとんど同じですか？

別人のようである 1
以前と同じである 2

4a. "別人のようだ"とお答えになった方、どういうところが前と違いますか？

5. ご老人の介護をしてこられて、何か後悔しておられることがありますか？

いいえ、ありません 0
はい、あります 1

5a. "ある"とお答えになった方、それはどんなことですか？

Phillips, 4 (1986)
Stewart & Archbold, 1– 3, 5 (1986, 1994)

あなたの御意見

6. あなたが今、ご老人のために、または、その方と一緒に、定期的にしていることで、何か特別にお二人ともが大切に思っている、あるいは、楽しみにしておられることがありますか？

いいえ、ありません 0
はい、あります 1

6a. "ある"とお答えになった方、それはどんなことですか？どういう点で特別ですか？ ____________________

____

____

7. ご老人が健康上の問題や記憶の障害をもったことで、あなたとその方との身体的接触という意味での親密度は変わりましたか？

いいえ、変わりません 0
はい、変わりました 1

7a. "変わった"とお答えになった方、それはどんな点ですか？ ____________________

____

____

____

8. 現在、介護以外のことで、あなたの生活の中で、特に感情を害するようなことや困難に思うことがありますか？

いいえ、ありません 0
はい、あります 1

8a. "ある"とお答えになった方、それはどんなことですか？ ____________________

____

____

9. 今までの質問の中で、お聞きしなかったことで、あなたのおかれている状況を良く理解するためにお伺いすべきだったことがありますか？

いいえ、ありません 0
はい、あります 1

9a. "ある"とお答えになった方、それはどんなことですか？ ____________________

____

____

このアンケートにお答えくださって、本当にありがとうございました。もう少しお時間を拝借して、このアンケートについてのあなたの素直な御意見をお聞かせ願えませんでしょうか？

1. このアンケートは、興味をそそるものでしたか、それとも退屈なものでしたか？
   - 非常に興味深かった……1
   - かなり興味深かった……2
   - 興味深い部分と退屈な部分とがあった……3
   - かなり退屈だった……4
   - 非常に退屈だった……5

2. このアンケートの質問は、明確でしたか、それとも、わかりにくかったですか？
   - 全部明確だった……1
   - ほとんど明確だったが、わかりにくい質問も少しあった……2
   - 明確な質問とわかりにくい質問とがあった……3
   - 明確だったのは少しだけで、大部分はわかりにくかった……4
   - ほとんど全部の質問がわかりにくかった……5

   一番わかりにくかったのは、どの質問、あるいは、どのページでしたか？

   (　　　　　　　　　　　　　　　　　　　　　　　　)

3. 聞かれて不快に思われるものや感情を害されるような質問がありましたか？
   - 全くなかった……1
   - ほんの少しあった……2
   - いくつかあった……3
   - たくさんあった……4

   一番不快に思われたのは、どの質問、あるいは、どのページでしたか？

   (　　　　　　　　　　　　　　　　　　　　　　　　)

4. アンケートの字は読みやすい大きさでしたか？
   - はい、充分な大きさだった……1
   - いいえ、字が小さくて、少し読みにくかった……2
   - いいえ、字がとても小さくて本当に読みにくかった……3

次の文を完成させてください。

このアンケートについて、私が一番気に入ったのは.....

このアンケートについて、私が一番気に入らなかったのは.....

このアンケートに答え終えるのにどのくらいかかりましたか？ ______ 時間 _____ 分

ご協力ありがとうございました！

この質問紙の英語版は、アメリカ合衆国において、公の研究費を使って開発されたものです。コピーをお撮りになりたい方、使用許可を希望される方は、下記の住所のDr.Barbara Stewart、または、Dr. Patricia Archboldまで御連絡ください。

Barbara J. Stewart or Patricia G. Archbold
School of Nursing
Oregon Health Sciences University
3181 SW Sam Jackson Park Road
Portland, OR 97201–3098, U. S. A.
(503) 494–3835, FAX (503) 494–3878

Dr.Stewart、または、Dr.Archbold以外の研究者が開発した部分に関しましては、直接その方にご連絡ください。

日本語版に関しましては、下記まで御連絡ください。

井上郁
〒780
高知市永国寺町 5-15
高知女子大学 看護学科
(0888)73-7511

1994, 3

Appendix D

Protection of Human Subjects

Before collecting data, the investigator sent the proposal of this study to Institutional Review Board (IRB) of the Oregon Health Sciences University. The IRB gave the study "exempt" status, and indicated that the risk to participants in this study was minimal and the proposed study procedure was reasonable. Because responses could be anonymous, no consent was required. Return of questionnaire implied consent.

The main costs to participants were the time required to respond and the possibility of emotional difficulty when answering some questions. Although there were no direct benefits for the participants, they might have some indirect benefit through the opportunity to be of use by sharing their experiences and contribute to better understanding of family caregiving situations. Some participants of previous studies conducted by Stewart and Archbold (Stewart, personal communication, 1993) reported that they had satisfaction in being able to help someone, and found that reflection on and sharing their experiences were beneficial. Through an explanatory letter from the investigator, subjects were assured that their participation was voluntary, their answers were anonymous, they might choose not to answer any question, and they might withdraw from the study at any time without any affect on their health care or services.

A copy of the cover letter and a request form for a summary of the study findings to accompany the JFCI questionnaire is included. The letter and the request form were translated into Japanese.

To participants of the study

First I would like to thank you for volunteering to complete the enclosed questionnaire. The purpose of the study in which you have agreed to participate is to see if the questionnaire can provide a reliable and valid picture of what it is like for caregivers in Japan to take care of a frail older family member.

The enclosed questionnaire should take about an hour and a half to complete. Feel free to take a break if you need to. You may want to take two or three blocks of time to answer the questionnaire.

Your participation in this study is voluntary. Your answers will be anonymous unless you have enclosed the form requesting study results; in this case your name will not be linked to your questionnaire in any way. If there is any question you prefer not to answer, just skip that question.

If you have any questions or concerns about the questionnaire, please call me at the number listed below. If I am not available when you call, just leave your name and number and I will get back to you as soon as possible.

After you have completed the questionnaire, please mail it back to me in the enclosed, stamped return envelope.

Thank you again for sharing your experiences and opinions with us.

Sincerely,

Iku Inoue, RN, MSN
Ph.D. student, Oregon Health Sciences University
c/o Dr. Sayumi Nojima
Kochi Women's University, School of Nursing
(0888) 73-2156

Summary of the Study Findings

Thank you very much for sharing your experience and opinion with me. Your answers will be very helpful to me in getting good idea of what it is really like for caregivers in your situation.

Would you like for me to send you a summary of the study findings, probably in the spring of 1995?

If so, please complete the following and send it back to me with the questionnaire or, if you wish, in a separate envelop.

Name: ______________________________

Address: ______________________________

____

____

My address :
Iku Inoue
c/o Dr. Sayumi Nojima
Kochi Women's University, School of Nursing
5-15 Eikokuji-cho, Kochi-shi, Kochi 780

Thank you again for your participation!

介護者調査への御協力のお願い

拝啓　風薫る五月、皆様には益々御健勝のことと存じます。

　初めてお便りさしあげます。私は、元高知女子大学看護学科の教員で、現在はアメリカのオレゴン州にありますオレゴンヘルスサイエンス大学で看護の勉強をしている学生で、井上郁と申します。今回その勉強の一環として、高知市保健婦センターと高知市役所の高齢者対策課の御協力を得て、老人の介護をしておられる方々を対象に、アンケート調査を行うことになりました。つきましては、あなた様に御協力をお願いいたしたく、お便りをいたしました。

　この調査の目的は、御家庭で老人の介護をしておられる御家族の方々の状況をより良く把握し、今後のサービスを考えてゆくための情報を得ることです。アンケートは無記名ですし、どれがどなたのお答えかということは、誰にも解りません。もし、質問の中にお答えになりたくないものがありましたら、飛ばして先に進まれるのもご自由です。

　5月25日前後にアンケートをお送りさせていただきますので、調査の主旨を御理解いただき、是非御協力をお願いいたします。アンケートにお答え頂くのに約一時間半から二時間程かかると思いますが、もちろん、途中で何度か休憩を取りながらお答えいただいてもかまいません。また、今回のアンケートの結果が、来年(平成７年)の夏頃には出せると思います。もし、御希望でしたら、簡単な結果のまとめをお送りできると思います。

　もし、今回御都合がお悪く御協力いただけない方は、お手数ですが5月16日から21日の間に、高知女子大学看護学科野嶋研究室内(下記連絡先)の井上まで御連絡ください。私が席をはずしておりました場合には、お名前と御主旨をご伝言ください。

　また、このアンケート調査についてのご質問やご意見も下記連絡先井上まで御連絡ください。私が席をはずしておりました場合には、お名前とお電話番号をご伝言いただければ、できるだけ早くご連絡させていただきます。

　どうぞよろしくお願いいたします。

敬具

平成６年５月１３日

井上　郁

記

連絡先住所：　〒780
高知市永国寺町 5-15
高知女子大学看護学科 野嶋研究室内
井上　郁

電話：　(0888) 73-7511

介護者アンケートへのご協力のおねがい

拝啓　さわやかな季節になってまいりました。あなた様にはお元気でおすごしのことと存じます。

　はじめてお便りさしあげます。私は、元高知女子大学看護学科の教員で、現在はアメリカのオレゴンヘルスサイエンス大学で看護の勉強をしている学生で、井上郁と申します。今回その勉強のひとつとして、高知市保健婦センターと高知市役所の高齢者対策課のご協力で、老人の介護をしておられるご家族の方々へのアンケート調査をすることになりました。

　このアンケートは、お家で老人のお世話をしておられるご家族にいろいろなことを教えていただいて、これからのサービスに役立ててゆくためのものです。アンケートにはお名前を書きませんので、どれがどなたのお答えかは、誰にもわかりません。もし、お答えになりたくないところがありましたら、とばして先に進まれるのもご自由です。

　５月２５日ごろにアンケートをお送りさせていただきますので、ぜひともご協力をおねがいいたします。アンケートにお答えいただくのに少し時間がかかると思いますが、もちろん、何回かにわけて答えていただいてもかまいません。

　もし、今回ご都合がお悪くご協力いただけない方は、お手数ですが５月１６日から２１日の間に、下の連絡先(高知女子大学 看護学科 野嶋研究室内の井上)までご連絡ください。また、このアンケートについてのご質問やご意見もお聞かせください。私が席をはずしておりました時は、お名前とお電話番号、ご用向きなどをご伝言いただければ、できるだけ早くご連絡させていただきます。

　どうぞよろしくおねがいいたします。

敬具

平成６年５月１３日

井　上　郁

連絡先住所：　〒780
高知市永国寺町 5-15
高知女子大学看護学科
野嶋研究室内
電話：　(０８８８)７３-７５１１

調査にご協力いただける方へ

老人介護についてのアンケート調査にご協力いただきましてありがとうございます。先日のお手紙にも書きましたが、このアンケート調査の目的は、ご家庭で老人のお世話をしておられるご家族の方々の状況をより良く把握するための情報を得ることです。

このアンケートに答えて頂くのに、約一時間半から二時間程かかると思いますが、もちろん途中で休憩を取りながらやっていただいてもかまいません。

アンケートは無記名ですし、もし、質問の中にお答えになりたくないものがありましたら、飛ばして先に進まれるのもご自由です。このアンケートの結果をお知りになりたいということで、お名前とご住所を知らせていただいた場合でも、あなたのお答えは、あなたのお名前とは別々に保管されますので、どれがどなたのお答えかということは、誰にもわかりません。

もし、このアンケートについて何かご質問やご意見がございましたら、下記の連絡先、私の所までご連絡ください。私が席をはずしておりました場合には、お名前とお電話番号、ご用向きなどをご伝言いただければ、できるだけ早くご連絡させていただきます。

アンケートに答え終られましたら、同封の返信用封筒で、私宛に送り返してください。

ご協力に心から感謝いたします。

井上　郁

所属：米国オレゴンヘルスサイエンス大学
看護学部　博士課程

連絡先住所：〒780
高知市永国寺町５－１５
高知女子大学看護学科
野嶋研究室内
電話：(0888)73-7511

アンケート結果のまとめについて

あなたのご経験やご意見をお聞かせせいただきまして、本当にありがとうございました。ご協力いただいたこのアンケートから得られた情報は、今後、老人の介護状況をより良く把握するために、大変役に立つものだと思います。

今回のアンケートの結果が、来年（平成７年）の夏頃には出せると思います。もし、ご希望でしたら、簡単な結果のまとめをお送りできると思います。ご希望の場合は、下にお名前とご住所をお書きの上、アンケートに同封してご返送いただくか、別便で、下記の住所までお送りください。

あなたのお名前: ______________________

あなたのご住所: ______________________

____

____

返送用住所連絡先:

〒780
高知市永国寺町５－１５
高知女子大学看護学科
野嶋研究室内
井上　郁

このアンケートへのご協力に心より感謝いたします。

Appendix E

Review of the Research Literature

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Abel (1990)	To explore the experience of family caregiving from the framework of public policy.	Exploratory Descriptive (S) Purposeful sampling through support agencies (N=51, women) (M) Grounded theory methodology. Open-ended In-depth interview focused on attitudes and experiences in caregiving, use of formal services, social networks, and relationships with CR. (A) Grounded theory methodology	(1) 75% cared for CR with dementia. (2) Most of CG used formal services substantially. (3) Emerging themes: Concern for CR's dignity (4) Caregiving was perceived in terms of maintaining CR's overall well-being rather than as a series of tasks.
Archbold (1980)	To describe the impact of parent caring on Caucasian women.	Exploratory Descriptive (S) 30 Caucasian adult women (M) Grounded theory methodology. Intensive interview, participant observation, and assessment by questionnaire. (I) OARS Multidimensional Functional assessment Questionnaire (A) Grounded theory methodology. Descriptive statistics	(1) 2 caregiving roles were categorized: Providers of care & Managers of care. (2) Managers identify more benefits to the relationship (a sense of meaning, satisfaction, & increased knowledge of aging). One of the earliest studies in family caregiving. The results suggested that CG perceive positive aspects in caregiving.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Archbold, Stewart, Greenlick, & Harvath (1990)	To examine how well mutuality and preparedness for caregiving explain the variance in aspects of CG role strain, after controlling for predictors commonly found to be related to role strain.	(S) All possible participants were contacted by letter. Of 243 dyads whose eligibility for the study was confirmed during a telephone call, 103 agree to participate. Data from 78 CG and CR dyads who completed both 6-week and 9-month interviews was analyzed. (M) Interviews with instruments at 6 weeks and 9 months after hospital discharge at CR's home by 2 trained interviewers. (I) <u>Family Caregiving Inventory</u>: Structured interview instruments for CG & CR. (A) Descriptive and psychometric statistics were used for each measure. Then, a hierarchical multiple regression analysis was used to determine whether mutuality and preparedness for caregiving were related to lower CG role strain.	(1) After controlling for five other variables commonly focused to be related to CG role strain, mutuality and preparedness for caregiving ameliorated some but not all aspects of CG role strain. a) Strain from direct care, increased tension, & global strain appeared lower when higher levels of mutuality and preparedness were reported by CG. b) Strain from economic burden was not reduced by either mutuality or preparedness. c) Mutuality did not ameliorate strain from worry & lack of resources. d) Preparedness did not ameliorate strain from role conflict.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Deimling & Bass (1986)	To examine the relationship between CG's stress and CR's symptoms of mental impairment which focused on cognitive incapacity, social functioning, and the presence of disruptive behavior.	(S) 586 spouse and daughter CG chosen from 614 CG who were randomly selected from over 2,000 referrals. Stratified by geographic areas of residence, race, and generational configuration. (I) a) ADL impairment: the variety of functional impairment of six areas of ADL (bate, dress, toilet, feed, & 2 in-house mobility items) b) Cognitive incapacity: 8 items, item loading=.38-.65, a=.75. c) Social functioning: 8 items, item loading=.49-.70, a=.81. d) Disruptive behavior: 7 items, item loading=.38-.69, a=.74. e) Negative elder, CG, & family relationships: 11 items, item loading=.46-.75, a=.88. f) Activity restrictions: 8 items, item loading=.50-.70, a=.80. g) Physical health change: single item asking whether their physical health had been affected by caring for their CR. h) Depression: Zung Scale (A) Path analytic approach was used to test the direct effects of each of three symptoms of mental impairment on CG stress. Path analysis also allows the calculation of indirect effects between variables.	(1) Cognitive incapacity had a less important direct influence on the stress effects than ADL impairment, disruptive behavior, & social functioning. (2) Cognitive incapacity played a more important role through its indirect effect on disruptive behavior & social functioning. (3) ADL impairment had little indirect effect on stress through disruptive behavior & social functioning. (4)The four measures of CR's impairment explained 48% of the variance in negative family relationships. The strongest direct effects produced by disruptive behavior & social functioning. Cognitive incapacity had a higher indirect effect on impaired family relationships.

SOURCE	PURPOSE	DESIGN: (S) Sample (I) Instrument (M) Method (A) Analysis	RESULTS
Fitting, Rabins, Lucas, & Eastham (1986)	To examine the effects of age and gender differences on CG psychological adjustment	Descriptive correlational (S) Convenience sample of spouse CG (28 husbands & 26 wives) (M) (I) a) Zarit Burden Interview b) Family Environment Scale (FES) c) Social Network Scale: 9 items d) MMPI e) 3 open-ended questions about caregiving experiences	(1) No differences between men and women on FES, social network, or burden. (2) Women experienced more depression hysteria, and paranoia than men.

SOURCE	PURPOSE	DESIGN: (S) Sample (I) Instrument (M) Method (A) Analysis	RESULTS
George & Gwyther (1986)	To understand the impact of caregiving on the family CG by measuring CG burden in terms of discrete dimensions of well-being.	(S) 510 persons who are giving some care to a person with dementia were drawn from the mailing list of family support program (a statewide technical assistance program for CG of dementia). (I) a) Well-being measure: mental health (stress symptoms, affect balance scale, life satisfaction, psychotropic drug use), physical health (Doctors visits, self-rated health), financial well-being (income, perceived ES), social participation (phone contact with family/friend, visits with family/friend, church attendance, club attendance, time spent in hobbies, time spent relaxing, satisfaction with social activities). b) Caregiving contexts: CG & CR relationship, CR living arrangements, CG perceived need for social support. c) CR illness characteristics: duration of illness, severity of symptoms.	(1) CG appeared similar to other populations on physical health. (2) CG were most likely to experience problems with mental health and social participation. (3) Characteristics of the caregiving situation were more closely associated with CG well-being than were illness characteristics of CR. (4) Adult child CG reported the lowest levels of visits with family/friends and time spent relaxing. (5)Both spouse & adult child CG showed lower satisfaction with social activities tan other groups. (6) CG who live with CR reported most likely to use psychotropic drugs, highest level of stress symptoms, lowest level of affect and life satisfaction, but not related to physical health.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Hirschfeld (1978)	To explore factors influencing families' abilities to live with and care for an older individual with dementia versus consider institutionalization of the CR.	Exploratory descriptive (S) A non-random sample of 30 demented elderly and family CG dyads. [CR] age 59-92, 60% males, 64% severely cognitive impaired. [CG] 73% female, 2/3 spouse. (M) a) Grounded theory methodology (In-depth interviews & observations): Both CG and CR were interviewed and their verbal & non-verbal interactions were observed. b) A questionnaire was used along with a). (I) OARS Multidimensional Functional Assessment Questionnaire (OMFAQ)	(1) Mutuality: The major factor in CG's ability to care for CR. Grow from the CG's ability to fined gratification in the relationship with CR & meaning from caregiving situation. Influenced the decision to institutionalize rather than socio-demographic or impairment variables. (2) Management ability, morale, tension: Strongly correlated with mutuality. Contributed to the decision to institutionalize.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Kosberg, Cairl, & Keller (1990)	To describe a study, and analysis of findings, of a measure of burden that comprises empirically derived components.	Correlational (S) 127 informal CG of AD were recruited through AD support groups. CG is providing some level of care to a cognitively impaired patient as indicated by a physician diagnosis. (M) Structured interview with questionnaires. (I) a) The Cost of Care Index (CCI): 20 items, multidimensional measure of caregiving burden. 4 items in each of 5 dimensions: personal & social restrictions, physical & emotional problems, economic costs, value investment in caregiving, and the perception of the older person as a provocateur (a=.79). b) Short Psychiatric Evaluation Schedule (SPES): 15 items, a measure of psychiatric symptomatology (psychopathology).	(1) Burden (CCI) was significantly related with female CG, CR's behavioral problems, CR's functional impairment, & CG's mental health problems (39% of the total variance in CCI). (2) Personal & social restrictions were significantly related with proximity (35% of the variance for this component by IVs). (3) Physical & emotional problems were significantly related with CR's functional impairment, CR's behavioral problems, CG's mental health problems, & CG's physical health problems (47% of the variance for this component by IVs).

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Kosberg, Cairl, & Keller (1990) (Cont.)		c) <u>OARS</u>: 4 items measured mental health problems of CG (a=.69), 3 items measured physical health problems of CG (a=.75), 14 physical & IADL items measured functional impairment of CR (a=.93). d) <u>Functional troubles attributed to physical health (ADL trouble)</u>: Difficulty with 11 IADL items (a=.75). e) <u>Functional troubles attributed to CR</u>: Difficulty with 11 IADL items (a=.76). f) <u>Zarit Behavior Checklist</u>: 18 behavioral problems (a=.72). g) <u>Short Portable Mental Status Questionnaire (SPMSQ)</u>: 10 items measured cognitive impairment.	(4) Economic costs of caregiving was significantly related with CG higher education, income, being a spouse, & living with CR, CR's cognitive impairment, CR's ADL impairment, CG's mental health problems (30% of the variance for this component by IVs). (5) Value scores were significantly related with being female CG & educational level (20% of the variance for this component by IVs). (6) Provocateur component was significantly related with being female CG & CR's behavioral problems (26% of the variance for this component by Ivs).

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Maeda & Shimizu (1984)	(1) To explore the factors which determine the level of subjective CG burden.	(S) 322 subjects who need and have family CG, from 457 elderly disabled persons at home and their families. (M) Secondary analysis from a big survey study done by Tokyo Metropolitan Institute of Gerontology in 1982. (I) 12 item questionnaire, 4-point scale from "0: Not at all" to "3: Very much in trouble". Total a=0.952 (a=0.686 to 0.919 for 9 dimensions) (A) Factor analysis	[CG] 35.4%-spouse, 36%-daughter-in-law, 19.5%-daughter; 40.1% in age >60, 32.3% in age <49; [CR] 187-F, 135-M; 54.6% in age 75-84; Dementia: (+)63, (-)28 Factor 1 - burden related to CGing for demented/difficult elderly persons (ex. number of CR's psychiatric symptoms, CR's physical conditions) Factor 2 - burden related to lack of man-power, employment, and financial problems (ex. CG's employment, CR's age, CR's interaction with others, CR's ADL) Respondents were not necessarily the same as main CG (28.9%-spouse, 35.4%-daughter-in-law, 20.2%-daughter, 9.9%-son). No information about measures nor reliability and validity of them - need to check the report from the original study.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Nakatani & Tojo (1989)	(1) To develop a measure of subjective CG burden. (2) To explore the factors (objective CG burden) which influence subjective CG burden.	(S) Approached main CG of 600 elderly persons who are at home and on the list of "elderly persons with some psychiatric symptoms and/or behavioral problems" from Health and Welfare Department in Tokyo area. 426 CG were participated and 401 of them were used for analysis. (M) Structured interview with the questionnaires (I) <u>Subjective Burden Scale</u>: 12 items questionnaire developed by authors. Measure 6 dimensions of CG burden (anxiety; fatigue; relationships with other persons; restrict in social activities; demand for free from CGing; lack of CGing will). 4-point scale from "1: Strongly agree" to "4: Strongly disagree". a=0.82 (A) Component analysis was done to get total score of subjective CG burden (weighted scores of each items ??). ANOVA and ANCOVA were used to explore factors which determine CG burden.	(1) 2 factors, Subjective CG burden and Will to continue CGing, were found. - Will to continue CGing is independent from Subjective CG burden and the will is not affected by the level of burden. (2) CG's low health status, CG's unemployment, absence of secondary CG, and existence of CR's hallucination/ delusion, high anxiety/depression, and aggressive behaviors were positively related to high subjective CG burden. Mentioned about face validity, content validity, and criterion validity in some way. There are some problems in content validity. CG's health status is subjective health - Is it different from objective health status ? Employed CG had lower burden - "health worker" effect or because they can have free time from CGing ?? Social support ?? Secondary CG - who, what condition, what relationship, etc. may make difference ?? Behavioral problems (ex. wandering) did not significantly related to Subjective CG burden -- Because of less influential or less occupance ??

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Niina, Sakata, Yatomi, & Homma (1990)	To develop the Psychological Stress Response Scale (PSRS)	<u>1st Step</u> (S) Young group - 111 (53-F, 58-M), collage students, Mean age 20.9 (SD=1.0). Middle age group - 110 (70-F, 40-M), governmental worker and their spouses, Mean age 36.3 (SD=8.5). (M) self report about experiences of stressful events and feelings, thinking, and behaviors related to it. (I) open-ended questionnaire (A) content analysis <u>2nd Step</u> (S) 718 adults who have high school age children. 500 of them responded (357-F, 143-M), Mean age 43.6 (SD=4.3). (M) Delivered the questionnaire to the subjects through their children. Each subject was asked to describe recent stressful event, then answer (Yes/No) each item of the questionnaire about the described event. (I) 145-item questionnaire about psychological stress responses	<u>1st Step</u> : 1569 responses toward stress were described by respondents, and 121 items were developed from them. 24 additional items were included from psychological theories. Total 145 items were divided by 2 subscales which are Emotional Responses Subscale (37 items) and Cognitive-Behavioral Response Subscale (108 items). <u>2nd Step</u> : Emotional Response Subscale - 4 factors and 26 items (depressive affect-8, anxiety-8, irritation-5, & anger-5) were abstracted and chosen. Cognitive-Behavioral Response Subscale - 9 factor and 27 items (loss of self-confidence-3, distrust-3, hopelessness-3, worry-3, slowness of thinking-3, unrealistic wishes-3, helplessness-3, withdrawal-3, restlessness-3) were abstracted and chosen. Finally, PSRS, which contain 2 subscales total 13 categories and 53 items, were developed.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Niina, Sakata, Yatomi, & Homma (1990) (Cont.)		(A) Delete <10% occupance items which were 1 item of Emotional and 12 items of Cognitive-Behavioral Response Subscale. Factor analysis about 132 items to make sure these 2 subscale are independent each other. Factor analysis about Emotional Response Subscale (36 items) and examined item-subscale correlation. Factor analysis about Cognitive-Behavioral Response Subscale (96 items) and examined item-subscale correlation 3rd Step (S) 409 1st year college students (all-F), Mean age 18.1 (SD=0.4) - 247 live in the dormitory, 162 live at home. (M) Give PSRS to the students through a manager of dormitory or at a class. (A) Exam reliability coefficient of 13 categories. T test was used to compare mean scores of 2 groups.	3rd Step : Reliability (alpha) - depressive affect-0.926, anxiety-0.885, irritation-0.782, & anger-0.884; loss of self-confidence-0.787, distrust-0.724, hopelessness-0.748, worry-0.748, slowness of thinking-0.789, unrealistic wishes-0.694, helplessness-0.734, withdrawal-0.745, restlessness 0.653. The results from T test showed significant difference between 2 groups. These results supported theoretical prediction. 4th Step : Reliability - alpha of 13 categories were between 0.565-0.919. The results from T test showed "worry" was significantly lower after the exam, and "anger" & "hopelessness" were also lower after the exam. These results supported theoretical prediction.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Niina, Sakata, Yatomi, & Homma (1990) (Cont.)		<u>4th Step</u> (S) Group 1 - 142 4th year college students (71-F, 71-M), Group 2 - 175 4th year college students (89-F, 86-M) include 81 (47-F, 34-M) duplicated sample of Group 1. Mean age 19.0 (SD=0.9) (M) Group 1 answered the PSRS before an exam week and Group 2 answered after that. (A) Exam reliability coefficient of 13 categories. T test was used to compare means of pre- and post-exam scores among 81 students who answered both time.	

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Niina, Yatomi, Homma, & Sakata (1989)	(1) To explore the factors which influence subjective CG burden based on the survey study about dementia. (2) To explore the relationships between the subjective CG burden and stress reaction.	(S) 91 respondents from 135 main CG of elderly persons with possible dementia (N=467) who participated to the survey study in Tokyo (4586 respondents from 5040 randomly sampled from 1.1 million, 65<, at home). (M) Structured interview with the questionnaires during the time a big interview survey study about elderly persons with dementia done by psychiatrists. (I) a) <u>Caregiver Burden Scale (CBS)</u>: 28 items, semi-structured interview format, developed by authors. Measure 9 dimensions of CG burden (Burden from help/care for ADL; manage dementia symptoms; concern about future; trouble with family/relatives; restrict in daily/social activities; physical health problems; mental health problems; costs; lack of social services). 28 items, 4-point scale from "0: No trouble" to "3: Very much in trouble". Total a=0.952 (a=0.686 to 0.919 for 9 dimensions). b) <u>Stress Response Questionnaire</u>: Included Emotional Response Subscale (26 items) and 9 items of Cognitive-Behavioral Response Subscale (27 items) from Psychological Stress Response Scale (Niina, et al, 1990) to measure psychological stress responses,	[CG] 80-F, 11-M; Mean of age: 59.5 [CR] 54-F, 37-M; Mean of age: 80.7; Dementia: (+)63, (-)28 (1) Study about cost was excluded because the area was too private. (2) Factors affected on CG burden: help/care for ADL (R2=0.405), Manage dementia symptoms (R2=0.538), Concern about future (R2=0.136), Trouble with family/relatives (R2=0.316), Restrict in daily/social activities (R2=0.247), Physical health problems (R2=0.498), Mental health problems (R2=0.249), Lack of social services (R2=0.269). CG burden from CGing itself determined by psychological & physical functions of CR, & CG burden to show low CG well-being determined lack of human network to support CG, but did not determine by either level of dementia or psychiatric symptoms.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Niina, Yatomi, Homma, & Sakata (1989) (Cont.)		& 10 items from Physiological Response Scale (Yatomi, et al, 1988) to measure physiological stress responses. 4-point scale from "0: Not at all" to "3: Totally Agree". c) <u>Demographic Data of CG</u>: age, time commitment of CGing per day, health status based on negative effects on CGing, helper(s) for CGing, alternative CG, advisor(s) about CGing, emotional support from the family, & other CGing responsibility. d) <u>Health Status of CR</u>: ADL, incontinent, level of dementia, communication ability, psychiatric symptoms, & behavior problems. (A) 30 items of the original CBS was reduced to 28 items based on occurrence rate. Factor analysis was done to examine whether these items fit pre-chosen 9 dimensions. Multiple-regression (Stepwise) was done to explore the factors which influence subjective CG burden based on 8 dimensions of CG burden (except costs) as dependent variables and 8 demographic factors as predict variables.	(3) Effects of CG burden on psychological-physiological stress responses: emotional response (R2=0.343 to 0.282 with manage dementia symptoms, concern about future, & trouble with family/relatives), cognitive-behavioral response (R2=0.35 with trouble with family/relatives), physical response (R2 =0.173 with trouble with family/relatives). 6 factors from factor analysis explained 68.3% - could be main dimensions of subjective CG burden CBS - a=0.952 is too high ? which means redundant, as the same in some dimensions (ex. a=0.919 for manage dementia symptoms). No information about validity.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Poulshock & Deimling (1984)	To examine the relationship between CG's stress and CR's symptoms of mental impairment which focused on cognitive incapacity, social functioning, and the presence of disruptive behavior.	Descriptive correlational (S) 586 spouse and daughter CG chosen from 614 CG who were randomly selected from over 2,000 referrals. Stratified by geographic areas of residence, race, and generational configuration. (I) a) Burden: 23-item scale measuring the CG's interpretation of how upsetting the disturbing behaviors were. b) ADL impairment: the variety of functional impairment of six areas of ADL. c) Cognitive incapacity: 8 items. d) Social functioning: 8 items. e) Disruptive behavior scale: 23 items. f) Negative elder, CG, & family relationships: 11 items. g) Activity restrictions: 11 items. h) Zung Depression Scale (A) Path analytic approach was used to test the direct effects of each of three symptoms of mental impairment on CG stress. Path analysis also allows the calculation of indirect effects between variables.	(1) Magnitude of correlations between measures of CG impairment and corresponding measures of burden greater than between non-corresponding measures of burden. (2) Moderate correlations between impact, burden, and CR impairment. (3) Measures of impact best explained when burden mediates between impairment and impact.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Pratt, Scgmall, Wright, & Cleland (1985)	(1) To clarify the concept of caregiving burden. (2) To urge multidimensional perspective of caregiving burden. (3) To make suggestions about measurement techniques that will prove useful for other researchers in the field.	(S) 240 CG of Alzheimer's patients (I) Survey at educational seminars a) Caregiver Burden Scale b) Family Crisis-Oriented Personal Evaluation Scale c) Investigator-designed insturument: To gather descriptive information about CG and the nature of their Cging responsibilities (A) crosstab, chi-square, correlation, t-test	(1) The magnitude of the correlations between measures of CR impairment and corresponding measures of burden were greater than the correlations between non-corresponding measures of burden and impairment. (2) There were moderate correlations between measures of impairment and impact measures. (3) There were moderate correlations between measures of burden and measures of caregiving impact measures. (4) Negative impact on ECF is the best explained when burden from ADL impairment is a mediator between ECF and CR's disruptive behavior, between ECF and CG depression. (5) CG activity restriction is the best explained when burden fro ADL impairment is a mediator between ADL impairment & CG depression and CG restriction.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Robinson(1983)	To develop Caregiver Strain Index (CSI)	(S) 85 individuals who had been named by elderly ex-patients as the person who had helped the most after they had returned home from an acute hospitalization. (M) (I) Caregiver Strain Index (CSI): 13 item with yes/no response (a=.86)	(1) Evidence of construct validity was obtained in 3 areas: CR characteristics, subjective perceptions of the care-taking relationship by CG, & emotional health of CG. (2) The CSI is a brief, easily administered instrument which identified strain. (3) Further development of the CSI is being undertaken for predicting assessment package that examines intergenerational relations involving dependency and care.
Sakata (1989)	To examine the relationship between caregiver burden and willingness of continuing caregiving	(S) 600 possible family caregivers were approached in 2 cities and 4 districts in Tokyo area. 401 were used for analysis. [CR] 63%-F, 37%-M; 66% in age >80, 34% in age <80. [CG] 89%-F; 35%-daughters-in-law, 29%-daughters; 25%-wife, 4%-husband. (M) Structured interview with the questionnaires included burden scale. (I) The 12 item-burden scale were used. (A) correlations between caregiver burden, willingness of continuing caregiving, and psychological symptoms of older persons.	Caregiver burden has a positive correlation with psychological symptoms and willingness of continuing caregiving has a positive correlation with cognitive disorder. Older persons' physical mobility correlated with willingness of continuing caregiving, however it did not has relationship with caregiver burden. Caregiver's health status correlated with both caregiver burden and willingness of continuing caregiving.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Sato (1989)	To examine the difficulty and care needs related to family caregiving for demented older persons.	(S) 600 possible family caregivers were approached in 2 cities and 4 districts in Tokyo area. 401 were used for analysis. [CR] 63%-F, 37%-M; 66% in age >80, 34% in age <80. [CG] 89%-F; 35%-daughters-in-law, 29%-daughters; 25%-wife, 4%-husband. (M) Structured interview with the questionnaires included burden scale. (I) The 12 item-burden scale were used. (A) Descriptive statistics	[CR] 66% bed-redden; about half memory problem, and cognitive impairment; 20-40% behavioral problems. [CG] 30% some kinds of health problems; 50% quite a job because of caregiving; economic status; 25% difficult, 54% moderate, 21% comfortable.
Scharlach(1987)	To examine the impact of CG adult daughter role strain on the quality of emotional support and psychological well-being perceived by CR mother.	Correlational descriptive (S) Convenience sample of 40 daughter was recruited. 24 mothers were also interviewed. (M) Interviews with questionnaires administered to both daughters and mothers. (I) For daughters: a) Zarit's Burden Interview, b) Bengtson's Affectual Solidarity Scale, c) Perceived role overload For mothers: d) Bradburn Affect-Balance Scale, e) Perceived loneliness and happiness	(1) Mothers' both scores were combined and standardized as psychological well-being because they were highly correlated. (2) Mothers' psychological well-being was inversely correlated with daughter's role strain. (3) Daughters' three variables explained 38% of mothers' psychological well-being.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Shimizu (1989)	To explore the types of objective. difficulty related to family CGing for demented older persons.	(S) 600 possible family caregivers were approached in 2 cities and 4 districts in Tokyo area. 401 were used for analysis. [CR] 63%-F, 37%-M; 66% in age >80, 34% in age <80. [CG] 89%-F; 35%-daughters-in-law, 29%-daughters; 25%-wife, 4%-husband. (M) Structured interview with the questionnaires included burden scale. (I) The researchers developed the questionnaires. The 12 item-burden scale were used. (A) Cluster analysis and factor analysis.	6 factors were identified as the types of psychological and cognitive impairment. 4 clusters that were identified as psychological disability among older persons. 24 types of objective difficulty were compared and discussed about service needs.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Shimizu & Honma (1978)	(1) To explore the situation in which family CG of disabled elderly persons live. (2) To explore the difficulty related to CGing and influential factors.	(S) 761 possible disabled elderly person were approached from 4800 elderly persons at home in 2 cities in Tokyo area. 408 were selected from respondents out of 761 based on the level of ADL. [CR] 59%-F, 41%-M; 59% in age >75, 41% in age <75. [CG] 90%-F; relationships-wife, daughters-in-law, daughters. (M) Structured interview with the questionnaires. Interview was done with one of family members unless the elderly person live alone. (I) The researchers developed the questionnaires. (A) Descriptive statistics and cross-tab were examined.	[CR] disability - 27% physical severe, 29% physical moderate; 29% psychiatric (+). 71% live the same household with CG (51% with married son, 11.3% with married daughter, 14.2 with unmarried daughter, 9.3% with spouse only, 5.9% alone). content of CGing - outing (50%), bed making (43), dressing (40), cooking (39), toileting (37), feeding (20%). [CG] 90%-F (68% wife, 22% daughter-in-law for men; 54% daughter-in-law, 30% daughter for women). 28% employed, 22% health problem, 41% with secondary CG. CR who live with unmarried child and married son are more severely disabled. "married son" CG - difficult because of dual CGing responsibility (between elderly care and child care) but has more potential man-power "unmarried" & "spouse only" CG - difficult because of lack of man-power within the household but has more help from outside of household.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Shimizu, Sato, Okamoto, Nakatani, Maeda, Sakata, Noguchi, & Tojo, (1989)	(1) To explore the subjective and objective difficulty and burden related to family CGing for demented older persons. (2) To explore influential factors related to those difficulty and burden.	(S) 600 possible family caregivers were approached in 2 cities and 4 districts in Tokyo area. 401 were used for analysis. (M) Structured interview with the questionnaires included burden scale. (I) The researchers developed the questionnaires. The 12 item-burden scale were used. (A) Cluster analysis and factor analysis.	[CR] 63%-F, 37%-M; 66% in age >80, 34% in age <80. [CG] 89%-F; 35%-daughters-in-law, 29%-daughters; 25%-wife, 4%-husband. 4 clusters were identified as psychological disability among older persons: 1) physical slight with problematic behavior and cognitive severe, 2) physical very severe with problematic behavior severe, with cognitive severe, 3) physical very severe with problematic behavior severe, and cognitive slight, 4) physical very severe with problematic behavior severe. 4 clusters were identified as difficulty of caregiving. 16 types of objective difficulty were identified by combination of those 8 clusters. Caregivers' health status and employment, having a secondly caregiver, severeness of psychological symptoms and problematic behavior were related to caregiver burden.

SOURCE	PURPOSE	DESIGN: (S) Sample (I) Instrument (M) Method (A) Analysis	RESULTS
Walker & Allen (1991)	To explore outcomes in intergenerational family caregiving using a social exchange theory.	Qualitative descriptive (S) 29 daughter and unmarried/widow mother dyads were recruited through advertisement. (M) Semi-structured open-ended interviews included questions regarding mothers' health status, nature of caregiving activities, situation in general, and nature of the dyadic relationship. (A) Data were analyzed for positive and negative caregiving patterns and sorted for themes using social exchange theory.	(1) 3 distinct relationship patterns: Intrinsic, ambivalent, and conflicted. a) Intrinsic dyads (N=13): Distinguished by their mutuality, participated in mutual & beneficial activities, and described themselves as equals. Had shorter caregiving careers, daughter with fewer children than the other two groups. b) Ambivalent dyads (N=10): Rewards were experienced with significant costs. c) Conflicted dyads (N=6): Experienced few rewards, frequent costs, and great conflict in the relationship.

SOURCE	PURPOSE	DESIGN: (S) Sample (M) Method (I) Instrument (A) Analysis	RESULTS
Zarit, Reever, & Bach-Peterson (1980)	(1) To investigate factors related to amount of burden experienced by principal CG of older persons with senile dementia. (2) To identify sources of burden in order to facilitate development of investigations to reduce CG burden. (3) To examine CG feelings of burden affected by impairments manifested by the dementia patient and by various aspects of the home care situation.	(S) Older persons with dementia (N=29) and their primary CG (N=29) (M) Interviews at CR's/CG's home (I) a) Interview guide: To assess the level of burden experienced by CG in relation to behaviors affected by senile dementia, degree of functional & cognitive impairment, social factors affecting care, and other situational characteristics. b) Burden Interview: 29 items self reported inventory, covers areas frequently mentioned by CGs as problems. c) Demographic data: Age, gender, education, income, relationship of CG & CR, duration of illness, formal social or health services. (A)	(1) Only frequency of family visits had a significant effect upon the degree of CG's feelings of burden. (2) Authors suggest that it is the presence of social support which is the key variable in coping with the burden of caring for someone with dementia, not the presence or severity of the problems per se.

SOURCE	PURPOSE	DESIGN: (S) Sample (I) Instrument (M) Method (A) Analysis	RESULTS
Zarit, Todd, & Zarit (1986)	(1) To identify factors affecting the course of caregiving, especially the decision to institutionalize. (2) To determine if differences between husbands and wives found at initial testing remained stable over time. (3) To determine if the CG's initial level of burden is associated with NHP. (4) To determine if the subjective experience of burden is mediated by similar variables at 2 years as at the initial interview.	Longitudinal follow-up 2 years after initial testing (S) Original sample comprise of 22 wives and 31 husbands caring for their respective spouses. These 53 spouse CG were convenience sample. (M) CG were contacted after a 2 year interval from initial study and asked about current status of CR. They were re-interviewed. (I) a) Burden: 20-item revised version of BI. b) Severity of impairment c) Social support d) Quality of relationship f) Placement decision (A)	[Time 1] (1) Subjective factors were more important than the severity of illness in determining burden; severity of symptoms were not related to burden. (2) Husbands reported less burden than wives. (3) For wives, both the quality of the past relationship and the cross-product score for the Memory and Behavior Problem Checklist were significantly associated with burden, while of husbands, only the cross-product score were significant predictor.

SOURCE	PURPOSE	DESIGN: (S) Sample (I) Instrument (M) Method (A) Analysis	RESULTS
Zarit, Todd, & Zarit (1986) (Cont.)			[Time 2] (1) No difference between husbands and wives in terms of outcome, except higher death rate among male CR. (2) Burden at time 1 was significantly higher for those CGs who had place CR in NH at time 2. (3) Severity of symptoms at time 1 were not related to NHP at time 2. (4) Average burden scores for men and women were essentially the same at time 2; with women's burden scores showing significantly decrease from time 1.