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Coming to terms with the reality of having to take care

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COMING TO TERMS WITH THE REALITY OF HAVING TO TAKE CARE: THE EXPERIENCE OF JAPANESE WOMEN CARING FOR AN ELDERLY PARENT (OR PARENT-IN-LAW) WITH DEMENTIA

by

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DISSERTATION

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[redacted]

Dedication

This work is dedicated to my parents, Mitsuyoshi and Isao Yamamoto. It is because of an amazing love, I understand, that they allowed me to come to the United States and pursue my study, despite their tremendous concern and worry about my health and well-being. I feel very fortunate to be born as their daughter.

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COMING TO TERMS WITH THE REALITY OF HAVING TO TAKE CARE: THE EXPERIENCE OF JAPANESE WOMEN CARING FOR AN ELDERLY PARENT (OR PARENT-IN-LAW) WITH DEMENTIA

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Twenty-six Japanese caregivers were interviewed on their experience of caregiving in order to explore the subjective meanings of this important role in terms of their life course. Interviewees were all daughters and daughters-in-law of persons afflicted with dementia. At the time of interview, their elderly demented parents were either living with them, living independently, or residing in a long-term care setting. Grounded theory is used to analyze the transcribed interview data. Daughter and daughter-in-law caregivers in Japan often experience the sense of their tolerance limit of caregiving, in the juxtaposition of tremendous difficulties arising from various aspects of care, and strong sense of value of care derived from societal norm of filial caregiving and/or attachment with the afflicted parents. Between these values and difficulties of caregiving, they struggle to come to terms with such a reality of having to take care. They manage to continue caregiving largely by resigning and accepting the inevitability of care in the positive attitude, modifying their perceptions of reality, and also occasionally by reducing the level of their care involvement, carefully assessing the possibility of reducing their care-involvement without disturbing the harmonious relationship within the family. The assessment is done through the deliberate balancing among the availability of outer resources that can replace their care, their authority level within the family to successfully negotiate the care-involvement reduction, and whether or not they can justify their limit in themselves in light of value assigned to caregiving. Throughout this struggle to continue caregiving, they also attempt to maintain their psychological well-being (sense of *ikigai*) by identifying specific life experiences as their purposes in life (sources of *ikigai*). All these struggles of the caregivers to come to terms with the reality of having to take care gradually modify the caregivers understanding of self. This study elaborates this process of their constant attempt to come to terms with the reality of having to take care, in which they continue caregiving and maintain the harmonious transaction within the family, without losing their psychological well-being (sense of *ikigai*).

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Introduction

Watashi no jinsei, nandatta no? (What has my life been for?)
The last words a family caregiver left to her husband, when she died of cancer at age 52.
(Asahi Newspaper, 7/21/94)

Caring for a person one loves is often accompanied by a genuine sense of joy, as experienced by generations of parents in the care of their children. In a slightly different context, many nurses also experience a sense of self-worth in their careers of caregiving. However, caregiving also often entails various difficulties, and the joy of giving care can be marred by such difficulties as exhaustion and despair. Taking care of elderly parents with dementia often means a constant battle with various difficulties amid enormous grief over the deterioration of a beloved parent as well as a strong sense of love and respect. For family members, taking care of an elderly parent with dementia is a very complicated experience on which substantial research has not yet shed full light.

Different cultural contexts influence the experience of satisfaction and well-being of the people within the culture. Family caregiving in Japan is likely to present additional features not necessarily salient in the same experience in Western cultures. For the Japanese, one way to pursue how people experience psychological well-being is to ask about their *ikigai* (生きがい). Literally, *ikigai* means the worth (or meaningfulness) in life. Inquiring about *ikigai* opens up a range of issues, related to their meaning of life, and that range is much larger than the term literally suggests. *Ikigai* is a term that the Japanese use to express their positive feelings about their lives and to communicate information regarding specific experiences that generate such a feeling. The caregiver's subjective experiences seem to be better understood when they are related to the individual's experience of *ikigai*. Based on such an awareness, the current research aims to explore the meaning of the experience of caregiving for elderly relatives with dementia in the life course of daughter or daughter-in-law caregivers in Japan. Specifically, this research explores what keeps caregivers involved in caregiving despite the negative aspects of caring for persons with dementia and how caregiving relates to their own lives. By developing a theoretical formulation on this subjective experience, the meaning of caregiving for one's life will be illuminated. Questions regarding *ikigai* will make possible an exploration of the relationship between the subjective experience of caregiving and the overall life of the caregiver.

Structure of Dissertation

Following the chapters of Background and Significance, Literature Review, and Research Method, two short prologues are presented to guide the readers to the findings of this research. The first prologue summarizes the definition and variation of *ikigai* as stated by the interviewees. The second prologue presents a story line depicting how the caregiving experience of daughter or daughter-in-law caregivers is captured in the current research. The following result chapters flow alongside the story line.

The findings of the current research are discussed in the four chapters after the prologues. Chapter 4, the first result chapter, deals with the basic context of the value and difficulties of the caregiving experience. Chapter 5, the second result chapter, discusses the important decision of whether or not the caregiver can reduce the care-involvement level. Chapter 6 explains strategies used by the caregivers to come to terms with the reality of having to take care of their elderly parent(-in-law). This phenomenon is unfolded in the contexts and conditions of caregiving as explained in Chapter 4 and Chapter 5. Finally, in Chapter 7, the overall trajectory of the caregiving experience is addressed. The dissertation is concluded with the examination of limitations and implications to research, theory, nursing, and social policy that are discussed in Chapter 8.

Chapter 1: Background and Significance

Background

This section reviews background data pertinent to the current research: changes in the elderly population in Japan, in family environment, in cultural norms, and changes in formal resources.

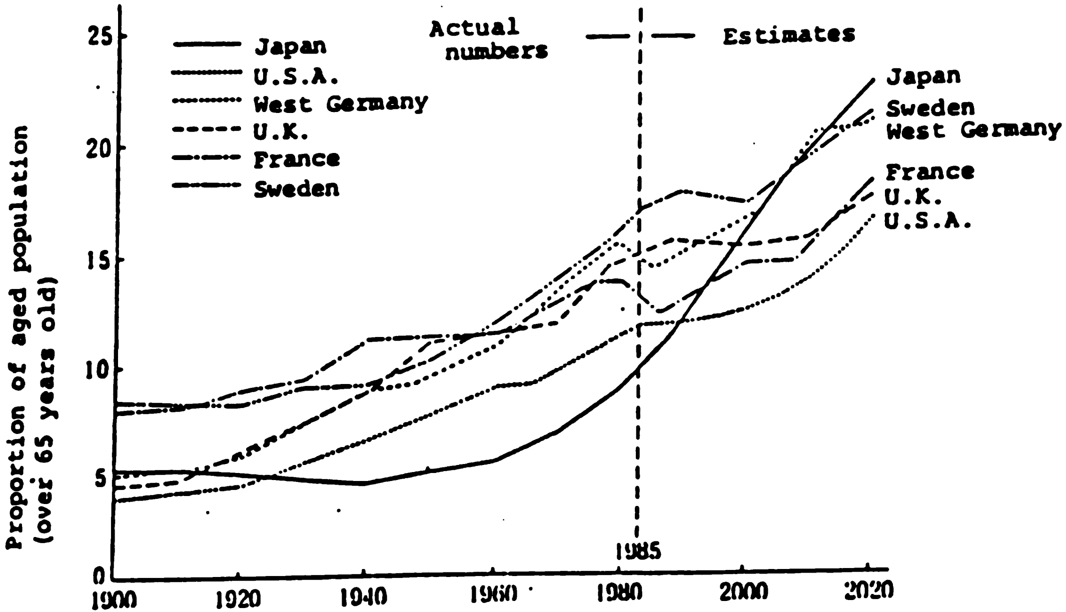
Changes in the Elderly Population in Japan

The increase in the number of elderly is a universal phenomenon, although it is particularly prominent in Japan where the percentage is higher than in other countries (Figure 1). In Japan, the percentage of those who are 65 years old and over was 4.9% in 1950, 13.1% in 1992, and is projected to be 25.8% in the year 2025 (Health and Welfare Statistics Association [HWSA], 1993). This increase is greater than that in the United States, where the numbers begin at 8.1% in 1950, grow to 12.5% in 1990, and are projected to be 17.3% by 2020 (Ministry of Health and Welfare [MHW], 1991a). The proportion of very old people to the younger elderly in Japan is increasing rapidly. For example, in 1950, those 85 years old and over were only 0.1% of the entire population; in 1992, they reached 1.0% -- a ten-fold increase. It is now estimated that they will comprise 4.3% of the population in 2025, a four-fold increase in 33 years (HWSA, 1993). This phenomenon is also occurring in other industrialized countries such as the United States.

Chronic illness, co-morbidity, and disability often accompany aging. Morbidity consistently increases with age (Figure 2) and includes those who are hospitalized, those who are visiting physicians regularly, and those bedfast at home. As shown in Figure 2, all of these increase with advancing age. For example, 75% of individuals between 35 and 44 years of age are without significant illness, whereas the

Figure 1: Proportion of Aged Population In the Advanced Nations and in Japan

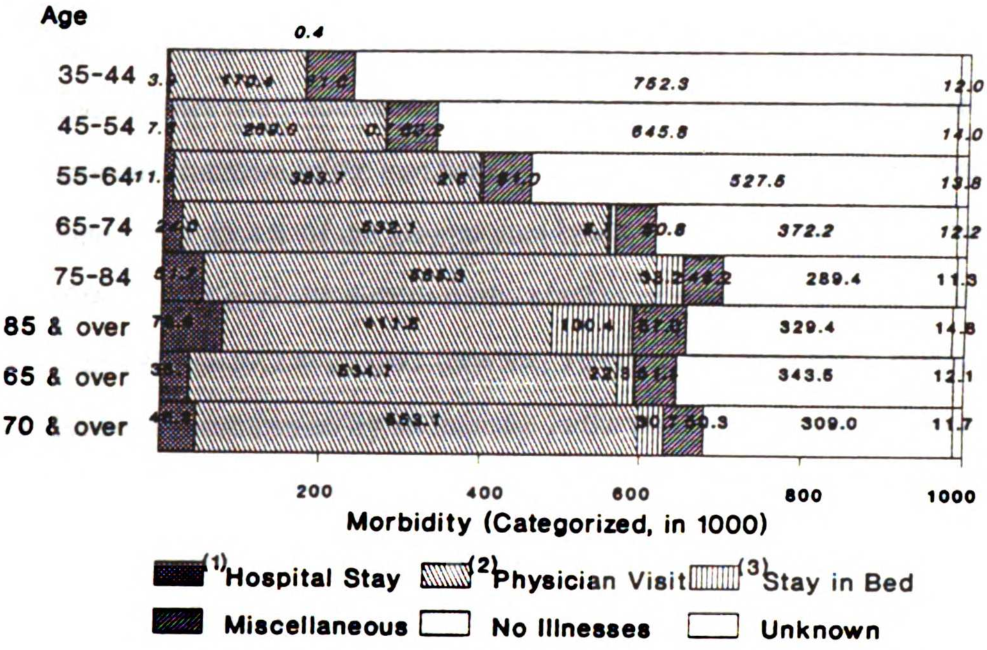
(cited from the Ministry of Health and Welfare, 1991a)



(Source) For Japan, "Census," Statistics Bureau, General Affairs Agency and the estimates made by the Institute of Population Problems, Ministry of Welfare and Health, and for the other countries, UN Population Studies.

percentage is only 31% among those 70 years and over (MHW, 1991b). Co-morbidity in Japan strikes as much as 49.7% of people 65 years and over who visit a physician regularly. As a result, the problem of providing care on a daily basis for the elderly is a prominent social issue in Japan. Approximately 600,000 people 65 years and older were reported to be bedridden for more than 6 months in 1986. This number is projected to be approximately one million by the year 2000 (HWSA, 1993). The most

Figure 2: Morbidity, by Age
(cited from the Ministry of Health and Welfare, 1991b)
(translated by the author)



prominent cause is reported to be cerebrovascular disease (stroke) and dementia (Gasyu et al., 1977). The number of people with senile dementia was estimated to be around 600,000 in 1985, but is projected to be 2.5 million by 2015. In the US, Alzheimer's disease is the major cause of dementia. In contrast, multi-infarct dementia is reported to cause one half of the senile dementia in Japan (Fukunishi, Hayabara & Hosokawa, 1991). Senile dementia, along with becoming bedridden from other causes, is one of the biggest sources of concern for persons who are aging and dreading loss of self-sufficiency (Office of General Affairs, 1989).

Changes in Family Environment

The increasing percentage of aged people in the overall population means fewer young adults are available to care for the number of surviving elderly. This places an increased load on young adults and is certain to become a bigger issue in the future. Additionally, family configuration is also undergoing a significant change. The high degree of industrialization of Japan has affected the family configuration, geographic living patterns, and life styles. One such change is seen in the statistical decrease in extended families (i.e., households that include three or more generations) and a corresponding increase in the number of nuclear families. In 1955, nuclear families constituted only 45.4% of the general population. By 1992, the number had increased to 59.0%. In the opposite direction, the number of extended families decreased from 43.9% in 1955 to 19.2% in 1992 (HWSA, 1993). This decrease in extended families has also been accompanied by an increase in the number of single person households. Also reflecting the decreased number of children in the family, the average family size in 1992 was only 2.99 persons. In contrast, the average family size in the 1920s was approximately five persons (Long, 1987).

The decrease in family size described does not directly mean that adult children have no communication with their aged parents. Rather, it reflects, in part, the recent trend toward adult children preferring to live in the proximity of their parents rather than in the same household. Although households are separated, close communication and supports between adult children and their aged parents are maintained to some extent. However, the ability to carry out the traditional total responsibility for sick or aging parents (and in-laws) becomes more and more difficult due to the diminishing number of adult children available to assume this role.

Changes in Cultural Norms

The statistical changes in family configuration have been accompanied by changes in the societal norms with regard to familial issues. In Japan, care of the aged has been traditionally managed by the succeeding generation of the family. This norm was strongly inculcated under Confucian thought for generations. However, the change in the inheritance law after World War II has obscured the practice of this virtue of filial responsibility. Before the end of World War II, the care of the elderly was considered to be the fixed responsibility of the "first son's" wife (*yome*) within the patrilineal extended family. As a result, a unique characteristic of family caregiving in Japan was that the *yome* was traditionally expected to play an important role. In 1989, 39.2% of bedridden elderly who were not in institutions were cared for by spouses of their children (almost always daughters-in-law rather than sons-in-law). The percentage of daughters taking care of their natal parent(s) was 21.0% and that of spousal care was 28.2% (MHW, 1991b). This moral tradition was financially reinforced through primogeniture, in which the principal family assets were transferred to the successor son upon the death of his father.

After World War II, the new inheritance law abolished primogeniture. Family assets were divided equally among all surviving children, regardless of their birth order and gender, unless special stipulation was made in the will of the deceased parent. Thus, the financial reinforcement for elderly care by the successor couples is no longer legally available. As a result, although many *yome* still take care of their elderly parents-in-law, there seems to be a gradual shift in responsibility because of the abolishment of primogeniture. Elliott and Campbell's (in press) multigenerational study used focus group interviews with Japanese women to support this impression. They explained that the selection of the person(s) who takes responsibility for the parent is based more on the pre-existing affectional bonds than ever before (Elliott & Campbell, in press; Lebra, 1976). Consequently, although the influence of the traditional moral imperative still seems to have an important and strong impact in the minds of those involved, how this filial responsibility is carried out operationally is undergoing gradual change.

Another change in cultural norms is seen in the life course of women. In Japan, as in other countries, the care of the sick and elderly has traditionally been undertaken almost exclusively by women (Iwao, 1993). Currently, however, this responsibility may cause conflict for those women working outside the home. Following the 1950s, wives in Japan began to work outside the home for a portion of their married lives in increasing numbers, especially after their children were in secondary school. In 1955, only 10% of married women with salaried husbands joined the workplace, but by 1982, this had risen to 36%. Moreover, the percentage of "career women" over 30 years old with more than 10 years of work experience has risen from 11% in 1962 to 26% in 1982 (Statistics Bureau of the Prime Minister's Office, 1982). In a 1991 survey, women made up 38% of the total labor force. This did not include females who were self-employed (e.g., seamstresses or small shop owners) or working on farms. Many of these female employees only worked part time. This indicates that more women now spend a significant amount of time outside the home, and that the traditional role of women as potential caregivers for the sick or elderly is likely to conflict with this trend.

Changes in Formal Resources

As the issue of increased numbers of elderly people in need of daily life assistance began to be more broadly recognized in Japanese society, various services were implemented. In 1990, a special 10-year plan ("Gold Plan") to improve the support systems for these elderly people and their families was implemented. The Gold Plan includes the introduction of home care support centers and day care centers as well as the development of long-term care facilities. It has been recognized that such services as homemakers, short transfers to an institution (to provide respite for caregivers) ("short stay"), and day care programs for the elderly are presently the most needed. The Ministry of Health and Welfare plans to increase these services by approximately 10-fold between 1990 and 2000 (HWSA, 1993).

This governmental plan has been precipitated, in part, by rapidly increasing medical costs inflated by long hospital stays of elderly people in acute care settings. In general, the mean length of hospital stay for all conditions is much longer in Japan than in the United States. The main reason is that patients suffering from psychiatric diseases including dementia incur protracted stays in hospital. As much as 46.7% of the hospitalized patients 70 years old and over had been hospitalized for more than 6 months in 1987, whereas the number was only 26.9% among those between the ages of 15 and 34 (MHW, 1991b). In order to reduce the length of hospital stays and control other excessive medical costs for the elderly, the Ministry of Health and Welfare has begun to introduce various strategies, such as a diagnosis-related group system. By setting a limit on the reimbursement for medical costs, hospitals have begun to send elderly patients home sooner than before. The introduction of the "Gold Plan" also is aimed at making early discharge possible in conjunction with the availability of an improved support system for home care.

Support services for families whose elderly parents are demented are, however, still limited. Ideally, those services mentioned above should also be available for elderly persons with dementia and their families but, in reality, behavioral problems of the elderly demented often exclude them from such services as day care and "short stays" arrangements.

Significance

Considering the background discussed thus far, this current research is deemed significant on several points for health care professionals including nurses. First, the issue of family caregiving will continue to be an important social issue in coming years: the increasing number of elderly people and the relative decrease in the younger population will continue to make family caregiving increasingly more problematic. Among various diseases that deprive elderly people of their independence, dementia is a particular challenge.

Second, the changing society and life course of Japanese women put female caregivers in a particularly difficult position. In order to improve the support services for elderly people and their female caregivers, a better understanding of the caregivers' experience with special attention to the cultural context is important. Family caregiving everywhere is strongly influenced by its cultural context, so findings derived from research in the United States may not be applicable to the Japanese population, and investigating Japanese caregivers is crucial to this study. Culturally specific issues need to be addressed, where more and more people are living in cultures foreign to their place of origin; a prominent phenomenon in the United States.

Third, in order to capture the complex nature of the caregiving experience and its influence on the caregivers, a qualitative research method is used in the current research. This also makes this research potentially significant as numerous research projects implemented to date have employed mostly quantitative methods. Such projects use pre-determined conceptual hypotheses that may not necessarily represent the overall experience of caregiving, although they can be highly useful in examining the relationship between individual concepts.

Chapter 2: Literature Review

This chapter contains three sections. First, selected articles published either in the United States or in Japan on the issue of family caregiving are reviewed. Since there has been an enormous amount of research, an overall comprehensive review is not attempted here. Rather, articles have been carefully selected that focus on the impact of caregiving on the caregiver, and those which examine caregiving as a process changing over time.

Second, I discuss the theoretical underpinnings of the current research: symbolic interactionism, conceptualizations of the self, and the career trajectory perspective. Both the conceptualization of self and the conceptual frame of career trajectory in the current research are deeply embedded in the symbolic interactionist perspective. These theoretical underpinnings are congruent with the grounded theory approach that draws on the symbolic interactionist perspective of the Chicago school of sociology. At the end of this section, the theoretical assumptions employed in the current research are stated.

Third, selected books and articles that pertain to the distinctive features of Japanese people are reviewed. This section discusses the following issues: sense of self of Japanese persons, the family in Japan, women's roles, psychological well-being of the Japanese, and the concept of *ikigai*. Based on an examination of past literature on these four topics, research questions for the current research are specified.

Research on Family Caregiving: Selective Review

Research on family caregiving for elderly people with various types of disabilities has expanded substantially in the past decade. Particularly in the Western literature, earlier reports on family caregiving emphasized the magnitude and dimensions of the negative impact of caregiving on family caregivers, followed by an explication of antecedents that contributed to this. More recently a more balanced examination of effective formal services for caregivers has been evident. Such a pathway of development of family caregiver research is understandable in light of an overarching agenda of supporting family members: The difficult aspects of caregiving have been researched in the hope that understanding these will lend some support to professional and family member caregivers. The accumulating research has revealed that caregiving means much more than a negative life experience for supporting family, and that the impact of caregiving on the caregiver needs to be captured using a larger perspective (Collins, Given & Given, 1994; Lawton, Kleban, Moss, Rovine & Glicksman, 1989). I agree with the view that the impact of care leaves more than just burden. This point led me to launch a major research question on the issue of non-negative appraisals of caregiving experience. Moreover, caregiving is not a static proposition but a process or career that continues to differentially influence the life courses of the caregivers over time, resulting in changes in the understanding about themselves (Lindgren, 1993; Pearlin, 1992). Recognition of caregiving as a complex process has led researchers to conceptualize the impact of care as a multifaceted entity as is exemplified by Lawton's research. A direction has been taken of examining the positive as well as the negative impact of care. The research began to capture the positive aspects of care as being independent of the negative: They are not the opposite sides of a single continuum.

Another new direction that research has taken, based on the recognition of caregiving as a complex process, is that caregiving is a trajectory superimposed on the biography of the caregiver. Some researchers have begun to view caregiving as a career that is continuously unfolding across time and has a profound impact on the self-concept of the caregiver (Lindgren, 1993; Pearlin, 1992). The concept of career has not been examined empirically by many researchers, but it is an important perspective that future research should explore.

Impact of Care on the Caregiver

There are various concepts related to the impact of care on the caregiver that have been operationalized into several measures. These have been used both as an outcome of the caregiving experience and as a predictor of various life changes of the caregiver.

Negative impact of care. The conceptualization and development of operational measures of the negative impact of care for the elderly with dementia on the caregiver was first accomplished by Zarit, Reever and Bach-Peterson (1980). Zarit, Todd and Zarit (1986) define caregiver burden as "the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative" (p. 261). The scale they developed for measuring caregiver burden, the Zarit Burden Scale, is a mixture of various aspects containing physical and psychological burden, limitation of social activity, and financial difficulty (Zarit, Orr & Zarit, 1985). Although they define caregiver burden as a perception, their questionnaire asks about several actual changes in life. The burden score is the sum of all items.

Various conceptualizations of the negative impact of care have been addressed by many researchers following the development of the Zarit Burden Scale. These conceptualizations differ from one another with a wide variety of operational measures (Stull, Kosloski & Kercher, 1994; Vitaliano, Young & Russo, 1991b). As the research has accumulated, a number of researchers recognized that the negative impact of care is derived from separate experiences in caregiving. Other researchers continue to use an overall scale to capture the negative impact of care based on their own framework (Morris, Morris & Britton, 1988; Poulshock & Deimling, 1984; Pruchno, 1990;

Pruchno & Resch, 1989; Stoller & Pugliesi, 1989; Strawbridge & Wallhagen, 1991; Vitaliano, Russo & Young, 1991a; Zarit et al., 1985). Many researchers have developed multiple separate dimensions of the negative impact, such as physical and mental health, financial resources, social participation, and so on. The dimensions chosen as separate entities vary among researchers (George & Gwyther, 1986; Kinney & Stephens, 1989; Kosberg & Cairl, 1986; Kosberg, Cairl & Keller, 1990; Novak & Guest, 1989a, 1989b; Reed, Stone & Neale, 1990).

Conceptions with a particular focus on one source or aspect of the negative impact of care are useful when the researcher's interest is focused accordingly, but it is necessary to recognize that these measures examine only limited areas of the negative impact. A study by Reed et al. (1990) shows that negative appraisals of care come, not only from the elderly individual's circumstance, but from other life experiences as well. They argue that diverse life areas, not limited by the care-recipient's symptoms, may be sources of the negative impact of the caregiving.

On the other hand, conceptualizations and operational measures, based on the notion of the multi-dimensionality of the impact of care, make more detailed examinations of the impact of care possible. One major dimensionalization is to divide subjective and objective impacts. The distinction of subjective and objective negative impact of care has been attempted by several researchers, such as Montgomery, Gonyea, and Hooyman (1985), Robinson (1990), or Poulshock and Deimling (1984), although their conceptualizations of subjective and objective impact, again, greatly vary. The subjective-objective separation of the negative impact of care may not be as clear as it seems, since reporting of these objective changes is assessed by the caregiver subjectively.

It seems unnecessary to reach an agreement on how the negative impact of care should be conceptualized because researchers have different interests and agendas for their work. One should be cautious, however, when using existing measurement instruments: Different conceptualizations underlie different measurement scales, and one conceptualization of the negative impact of care may not be compatible with a specific researcher's framework. On the same line, careless comparison of research results is misleading; they may measure slightly different entities under the same concept identification. One problem of such a conceptualization is that only the negative aspects of caregiving are approached. Caregiving of the family contains positive impacts to the caregiver, but that impact is neglected in such conceptualizations as caregiver burden.

Positive impact of care. To date, there are several approaches to research that conceptualize the positive impact of care. These studies focus on the subjective appraisal (rather than objective changes) of the overall impact of care.

Kinney and Stephens (1989) argue that small satisfactions in caregiving ("uplift") may buffer an individual from the consequence of daily caregiving stressors ("hassles"). Their operational measure of uplift is based on the daily tasks related to concrete problems of the care recipient (ADL limitation, cognitive status, behavior, and practical/logistical aspect of care). Their study does not support their hypothesis that uplifts buffer the influence of hassles on caregiver well-being.

Lawton et al. (1989) argue that a general term, "caregiving appraisal," is desirable to refer to all cognitive and affective appraisal of stressors and coping efficacy because not all such appraisals reflect burden. Their study finds three categories (subjective caregiving burden, impact of caregiving, caregiving satisfaction) as separate entities within caregiving appraisal. Later (Lawton, Moss, Kleban, Glicksman & Rovine, 1991), they examine the relationship of burden and satisfaction with two indicators of psychological well-being (positive affect and depression) and find that caregiving satisfaction is significantly related to positive affect among spouse caregivers.

Pruchno (1990) is another researcher who examined uplifts in caregiving and defined them as "the pleasures or compensations afforded by life as a caregiver" (p. 62). Pruchno views her uplift scores as equivalent to psychological well-being. There were no particular correlates for uplifts found in her research.

Some research done in Japan that suggests the presence of a positive component to caregiving. Nakatani and Tojo (1989) and Sakata (1989) examined the subjective burden of caregivers for the elderly with dementia. In the factor analysis of the caregiver burden questionnaire items they found two factors and named these "burden" and "will to continue care." Thus, the authors find that the positive appraisal of care (will to continue care) was independent of the negative appraisal.

With a quite different approach, Guberman and her colleagues (Guberman, Maheu & Maille, 1992) explored reasons why females assume the role of caregiver for their family. They interviewed 40 women who were taking care of frail, elderly or mentally ill relatives; this group included maternal caregivers for ill children and other kin as well as child caregivers for elderly parents (-in-law) with physical and/or cognitive problems. From the qualitative analysis of the interview data, they identified 14 factors accounting for why the caregivers continued in their role: love and feelings of family ties, inadequacy of institutional or community resources, lack of places in institutions, pressure tactics on the part of professionals, absence/deficiency of community support, profound need to help others, feelings of duty and obligation, imposition of the decision by the dependent person, women's socioeconomic dependence, unavailability of other family members, anti-institutional feelings, the caregiving arrangement (the caregivers' decision to become the main caregiver being based on the availability of support from others), religious feelings, caregiver's personal characteristics (e.g., not having children, not being in the labor force but having a schedule that was compatible with caregiving responsibilities), belief in the healing process, the dependent person's health, and family tradition. The authors suggest that the caregivers' motivation to continue providing care should be examined in further research because this area has been long neglected or taken for granted. Their research has much in common with the current research. However, it was conducted in Quebec, Canada and the influence of the cultural norms should be examined in Japanese population. A similar perspective is still employed in the current research: The issue of why the caregivers can continue to render care is specifically addressed in the research question.

It cannot be said that the available research on the positive components of subjective appraisal has been sufficiently extensive. For example, these studies have not always shown statistically significant results, where statistics were employed. However, the presence and influence of positive components in subjective appraisal have been suspected by many researchers (Horowitz, 1985; Schulz, Tompkins & Rau, 1988; Seelbach, 1978; Stoller & Pugliesi, 1989) and they deserve a more detailed examination.

Also, it is not necessarily clear that the conceptualization of positive impact of caregiving in the research conducted so far have been appropriate. There seems to be a slight difference in the conceptualizations by the aforementioned groups of researchers, although the difference is not delineated explicitly. For Kinney and Stephens (1989), "uplift" is a buffer of "hassles" and is no more than a small relief in the burden of caregiving. For Lawton et al. (1989, 1991), caregiving satisfaction seems to mean that caregiving in itself possesses a beneficial aspect for the caregiver that is not reducible to simply occasional relief for caregivers. Pruchno (1990), by defining her uplift as pleasure or compensation, seems to imply both characteristics of the positive impact of care mentioned above (relief versus independent satisfaction). The research by Nakatani and Tojo (1989), Sakata (1989), and Guberman et al. (1992) suggest that the impact of the positive component of caregiving may be better examined with questions exploring the reasons caregivers maintain the resolve will to continue care. These various views of the positive impact of care may be separate entities and need to be examined separately. Additionally, there may be other ways to define and examine the positive impact of care.

Also, unlike the negative impact of care that has been examined in the context of theoretical frames, such as stress and appraisal theory, the positive impact of care has not been theoretically grounded. This is an important task for future researchers.

Having reviewed in this section various conceptualizations of the impact of caregiving on caregivers as either positive or negative, the findings emphasize that (a) the experience of caregiving is multi faceted and many issues should be examined even within the concept of the negative impact of care, and (b) the positive impact of care deserves further examination. The exploration of the non-negative impact of care is a major point of inquiry in the current research.

Caregiving Experience as Process

One characteristic of research on family caregiving is that much of it has been conducted with the view of caregiving as an isolated experience. Even when data collection occurs at multiple times, the research often repeats measurement of a single dimension, such as depression (Shultz, Williamson, Morycz & Biegel, 1993). However, caregiving typically continues over a period of years (Lindgren, 1993) and does not exist as an isolated entity in the caregiver's life. Caregiving is experienced in the context of various other life events concurrently occurring in the caregiver's life. Caregiving and other life experiences exert influence on one another; all of these influence the later life of the caregiver. Therefore, the caregiving experience should be captured as an ever-unfolding process. Moreover, the meaning that the caregiving experience has should be examined in relation to the caregiver's overall life course. The caregiving experience changes over time as the life of the caregiver is changed through the caregiving experience as well as through other experiences in the caregiver's life.

There are researchers who have claimed that the caregiving experience is best explained when it is captured as a process (Aneshensel, Pearlin & Schuler, 1993; Lindgren, 1993; Pearlin, 1992; Wilson, 1989a, 1989b). Lindgren, in a qualitative analysis of interview data from 10 spouse caregivers, developed a process consisting of three stages: entrance, endurance, and exit. Wilson formulated similar phases. These two researchers capture the process from the beginning of caregiving to the death or institutionalization of the recipient. Pearlin (1992), on the other hand, has extended further to include the period following institutionalization and/or death of the recipient as part of the process of caregiving. A common finding of these studies is that the caregiving experience can be characterized by the transition of the caregiver from one stage to the next. Accordingly, the most important characteristic of capturing caregiving as a process, is that the experience of the earlier part of the process has a major influence on the later. This nature is best explained by the model of stress process by Pearlin, Mullan, Semple & Skaff (1991).

I would like to extend this notion of the continuous influence of earlier experiences on later stages and to position the process of caregiving in the biography of the caregiver. That is, the caregiving experience should be captured in the context of the caregiver's life course. Caregiving is experienced in light of past experiences that have been formulated in living in a given cultural context. Also, the experience of caregiving has a major impact on the subsequent life course of the caregiver to the point where the understanding of one's self can be substantially modified through the experience of caregiving.

The impact of the caregiving experience on the self-understanding of the caregiver has been examined by Skaff and Pearlin (1992): "We assume that the profound changes in the organization of people's lives that are often demanded by long-term caregiving can come to reshape self-concepts." (p. 656) Further, they conceptualized the detrimental change in self-concept as "self-loss," and found that self-loss had been experienced by many caregivers over time. However, the impact of care on the self-understanding of the caregiver deserves a broader examination than simply a study of self-loss alone. It is necessary, at least for the Japanese, to implement a more qualitative exploration on how such changes in self-understanding take place and how the caregivers experience those changes.

While the caregiving experience should be examined in its relationship to the biography and self-understanding of the caregiver, another important issue to be addressed is the influence that culture has on the caregiving experience. While a cultural belief or general mentality influences the impact of caregiving on the biography and self-understanding of the caregiver, it also gives a structuring frame to the self-understanding of individuals living within the culture. As Pearlin and Zarit say, "Caregiving and its social and personal consequences do not take place in a cultural vacuum." (1993, p. 157) Research on Japanese caregivers, to date, has been implemented largely using the framework of research conducted in the United States. However, the results of such research, without attention to the cultural differences between the United States and Japan, may yield only limited findings about caregivers in Japan. The issue of cultural influence is largely unexplored in the field of family caregiving. Characteristics of Japanese culture such as the sense of self, family, women's roles, psychological well-being, and the concept of *ikigai* will be addressed later.

This present research is based on the recognition of the gaps listed above; namely, that the issue of the impact of care is not limited to the negative aspect, and that the caregiving experience dynamically affects the life course and self-understanding of the caregiver. In the next section, the theoretical underpinnings of the current research will be discussed.

Theoretical Underpinnings: Symbolic Interactionism, Conceptualization of Self, and Career Trajectory Perspective

Based on the literature review of the research on family caregiving, I believe that it is important to employ a perspective that enables examination of the impact of care on the life course and self-understanding of the caregiver in a way not limited to the negative aspects of the impact of care. Also, the cultural context should be recognized. The symbolic interactionist perspective meets this requirement and therefore has been used for this study.

Following the discussion on the symbolic interactionist perspective, the conceptualizations of self and career trajectory will be explained. In the examination of the conceptualization of self-understanding, I draw heavily on the theoretical constructions of self by George Herbert Mead (1934) and Frank Johnson (1985, 1993). In addition to the perspective of symbolic interactionism and the conceptualization of self, I included the perspective of caregiving as career trajectory suggested by Leonard Pearlin (1992). A framework similar to the perspective of career trajectory has been suggested by Julie Corbin and Anselm Strauss (1991) for understanding the chronic illness; parts of their theoretical formulations will also be discussed. At the end of this section, several theoretical assumptions in the current research are stated.

Theoretical Perspective of the Symbolic Interactionism

Interactionism was developed in sociology from an emphasis on examining the details of actual encounters as a major dimension and unit of study in building social processes, rather than examining the macro structural characteristics, such as class conflict or evolution (Turner, 1991). Influenced by the thought of American Pragmatism, Interactionism assumes that human beings cooperate with each other to survive and adjust themselves to their social environment. Those constant activities of adjustment form the societal process. The chief exponent of interactionism is George H. Mead whose thought can be explained in three categories: mind, self, and society.

Mind. A unique characteristic of the human mind is its use of symbols to designate objects in the environment. With symbols, one can rehearse possible actions, develop common meanings among parties in the interaction, and put oneself in another's position (role taking). These actions are for the purpose of facilitating adjustment and survival (Turner, 1991).

Self. Self is a product of one's mind that serves to symbolically represent oneself as an object. Through interactions with others, one can crystallize transitory self-images into a stable conception of oneself. Thus, for Interactionism, consciousness of self is developed through interaction. Through accumulated interactions, one can develop a stable image of oneself, as seen from generalized others, which in turn gives consistency to one's actions (Turner, 1991). This human ability to see self from the perspective of generalized others makes coordination among larger groups possible. The conceptualization of self by Mead will be discussed later in more detail.

Society. Mead posited that society is "constructed patterns of coordinated activity that are maintained by, and changed through, symbolic interaction among and within actors" (Turner, 1991, p. 376). This is the starting point of symbolic interactionism in sociological inquiry. For Interactionists, social organization is both perpetuated and altered through the adjustive capacities of mind and the mediating impact of self.

Chicago school of symbolic interactionism. On the basis of Mead's thoughts, scholars at the University of Chicago further developed this sociological inquiry: human beings have the capacity to create and use symbols, humans use symbols to communicate with one another, humans communicate and interact by reading and interpreting the gestures of others, what makes human beings unique as a species and enables each individual to possess distinctive characteristics is the result of interaction in society. What is important in the features of symbolic interactionist thought, for the development of the grounded theory approach, is that it is the meaning an individual assigns to his/her experience that decides the action(s) he/she takes, and that this meaning is created based on the shared symbolic interaction among the people that form the society.

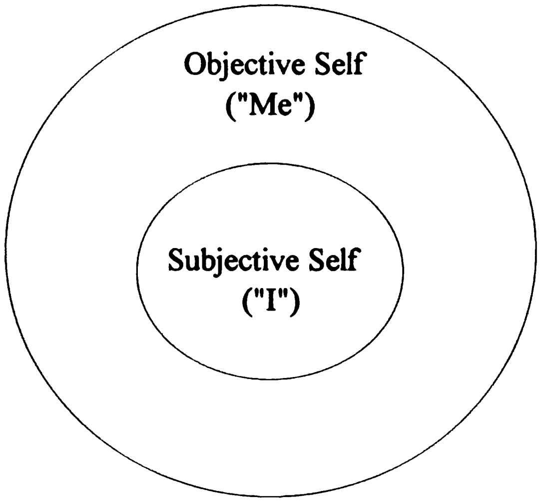
The Chicago School emphasized the ability of humans to create the interactional situation rather than the deterministic nature of the social world, the changing nature of social organization rather than the structural aspects of it, and the importance of inductive thinking and the development of sensitizing concepts rather than deductive thinking and the commonalty of methods in all sciences (Turner, 1991). On the basis of these tenets of the nature of humans and society, the Chicago School utilized extensive field observations and intensive interviews as data-collecting techniques (Strauss, 1987). These methodological characteristics strongly influenced the development of the grounded theory approach.

Conceptualization of Self-Understanding

There has been much discussion and writing on the conceptualization of self, particularly in the Western literature, since the turn of the last century. The current research derives its conceptual foundation of self mainly from the writings by Mead (1934) and Johnson's summary (1985, 1993). Many researchers have examined the Japanese sense of self (De Vos, 1985; Doi, 1971, 1985; Johnson, 1993; Lebra, 1976, 1992; Rosenberger, 1992). All have identified some characteristic differences between the Japanese and Western sense of self. The characteristic features of Japanese sense of self will be discussed in the later section of this chapter. The theoretical basis for the constitution of "self-understanding" (Damon & Hart, 1988) will also be captured in the current research.

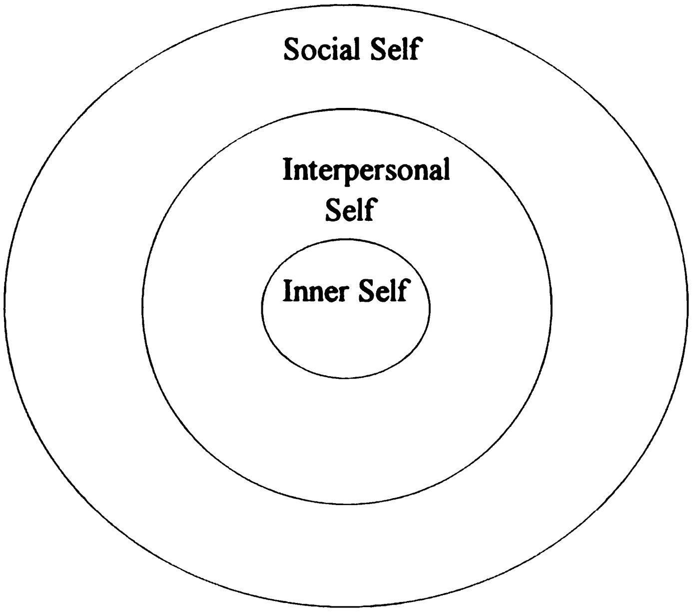
Mead's conceptualization of self. Based on William James' conceptualization of self, Mead (1934) heuristically divided self-understanding into two parts: "I," the subjective understanding of oneself, and "Me," the objective self that is enacted in everyday situations (Figure 3). Subjective self is the personal awareness and consciousness of oneself before objectification, and is characterized by four features: agency, awareness, uniqueness, and continuity (Damon & Hart, 1988). Objective self is the whole entity of self as captured through external verification, and is made up of material characteristics (i.e., body), social characteristics (i.e., role), and what he termed spiritual characteristics (i.e., consciousness, ideas, thoughts). Mead contended that it is possible to explore the subjective part of self scientifically as it is processed by the objective self. In other words, he contended that we can know about one's subjective self by studying one's knowledge of both subjective and objective selves. (Damon & Hart, 1988).

Figure 3: Mead's Conceptualization of Self
(created by the author)



Johnson's conceptualization of self. Reviewing definitions and explanatory systems in the fields of Western psychology and social science, Johnson (1985) used three conventional, existential divisions of personal consciousness explained as: inner self, interpersonal self, and a generalized social self (Figure 4). Although overlap and fluidity among the three divisions is assumed, he suggests that these are useful in acknowledging psychological sets of awareness inherent in an operational, interactive self. Inner self is involved with subjective (internal) experiences involving solitary communication (i.e., fantasy, reverie, introspection, proactive planning, dreaming). Interpersonal self is experienced in various direct and reciprocal interactions within dyadic or small group encounters. The generalized social self is characterized by vague, non-reciprocal interactions (i.e., in crowds, performing repetitive mechanical work in a factory, etc.) (Johnson, 1985, p.96).

Figure 4: Johnson's Conceptualization of Self
(created by the author)



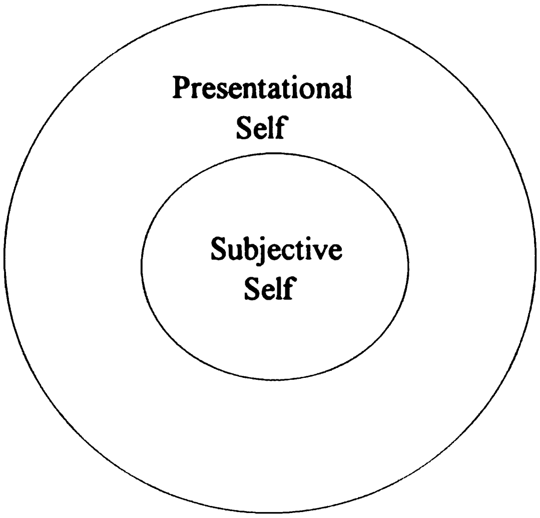
Comparison of Mead's and Johnson's conceptualizations of self. Comparing conceptualizations of self by Mead and Johnson, there exists both commonalties and differences. The self conceptualized as "I" and "Me" by Mead mostly overlaps with the existentialists' inner self described by Johnson, in the sense that the self is experienced through the individual's inner awareness.

Mead also emphasized the influence of social interactions on the development of the self, but essentially juxtaposed self and society as separate entities. Some contemporary theoreticians challenge this (Rosenberger, 1992). These commentators see self-understanding as not necessarily separable from its environmental and social connections. Johnson emphasized this in the context of Asian cultures (including Japan) by the descriptions of interpersonal self, drawing on the thoughts of Hsu (1971). This inseparability of self and society has been emphasized at first in the examination of the sense of self of Asian people, as Hsu did, but there is a notion that such an inseparability can also be considered for the development and consolidation of self in Western people (Rosenberger, 1992).

Conceptualization of self-understanding in the current research. Informed by these views of self, this research design has been based on a conceptualization that uses two terms: subjective self (including Mead's "I" and some portion of "Me", as well as Johnson's "inner self") and presentational self (including some portions of Mead's "Me" and Johnson's "interpersonal" and "social self") (Figure 5).

My conceptualization of subjective self emphasizes the self as both "agency" and "self-awareness," and also documents existential features of self-understanding. My interest in the presentational self emphasizes the social, interpersonal, and interactive aspects of self-understanding which are often captured in roles and role-sets. Therefore, I put less emphasis on the material (corporeal) and spiritual (ideational) aspects of the presentational self. In the acted realm of presentational self, people assume multiple roles that may or may not be directly affected by societal norms, such

Figure 5: Conceptualization of Self-Understanding
(created by the author)



as the role of mother, housewife, the role of a person who enjoys hobbies, or (as in this study) the role of caregiver. In my conceptualization, the role of caregiver is examined as one of a number of roles that a person assumes in the realm of presentational self. Various roles have a profound influence on the nature of subjective self.

Consequently, one's self-understanding is conceptualized as constituted by both the presentational and subjective selves, and these two facets are mutually influential. Subjective self-understanding is sustained and constantly modified based upon the feedback from everyday experiences enacted by the presentational self. Conversely, the presentational self is also governed by the subjective self- understanding, in the sense that the subjective self determines how the presentational self should be enacted. One's self-understandings (both presentational and subjective) are also shaped by personal beliefs and societal norms which have been internalized (as ego-ideals) throughout a life time of interaction within the symbolic world of any given society. Throughout the life course, individuals are involved in a constant, slow evolution and reformation of an emerging self-understanding. One's understanding regarding self is not static, but is always subject to change and modification, reflecting the dynamic, reciprocal interaction with the environment. This notion of a continuing modification of self is derived from the symbolic interactionist perspective originally elaborated by Mead.

Career Trajectory Perspective

As previously mentioned, caregiving has been viewed as a process by some researchers (Lindgren, 1993; Pearlin, 1992). Among them, the theoretical underpinnings of career have been examined carefully by Pearlin and Aneshensel (in press). Also, a similar theoretical explication is seen in Corbin and Strauss' notion of trajectory in examining chronic illnesses (1991).

The perspective of career trajectory has a long history in the sociological schools, mainly by scholars related to the Chicago School (Barley, 1989). It has been used to examine long-term pursuits such as occupations or avocations and emphasizes the changes through time and inter-connections among the various phases; the former experience affects the following experiences.

Pearlin and Aneshensel (in press) conceptualized caregiving in the United States as an "unexpected career," where most of the caregivers become so involuntarily, with no prior expectations of becoming a caregiver. Usually, there is a complete lack of anticipatory socialization to the role. The caregiver career, according to these theorists, consists of several major stages with some changes within a stage: pre-placement, post-placement, bereavement, and recovery.

Corbin and Strauss (1991) have also used the perspective of trajectory (without using the term career) to understand the management of chronic illnesses. They developed eight phases (pretrajectory, trajectory onset, crisis, acute, stable, unstable, downward, and dying) in the process of chronic illness management with certain variations depending on differences in conditions. They also state that the impact of illness is not only day-to-day experience, but also on the life course, or biography, of the affected person: "Biographical impact refers to the manner in which these many aspects of self can be affected or altered by illness or its management, thereby changing the person's life course" (pp. 164-165). Both of these theoretical elaborations (Pearlin and Aneshensel's career concept and Corbin and Strauss' trajectory framework) assume that an experience is captured by several stages and substages, and the experience of preceding stages has a profound impact on those that follow. This notion has similarities with the life course, developmental perspective, such as is detailed by Erickson (1982) or Havighurst (1972). These theorists also developed a number of developmental stages throughout human life, and where former stages are expected to influence the adaptation to later stages. In this sense, the perspective of career trajectory has solid roots within the sociological and psychological schools of thought.

Theoretical Assumptions for the Current Research

Guided by the above theoretical perspectives, symbolic interactionism, the conceptualization of self-understanding by Mead and Johnson, and the perspective of career trajectory by both Pearlin and Aneshensel and Corbin and Strauss, the following key theoretical assumptions are used in the current research:

1. The caregiving experience is a process.
2. There are a number of stages in the experience where common characteristics are seen in people in the same stage, and people move from one stage to another over time.
3. Experiences in former stages have a profound influence on the experience of following stages.
4. People gain self-understanding as they interact with the symbolic world within which they live.
5. Alterations in self-understanding occur throughout each experience and throughout the life course of the person.

In the next section, literature on Japanese culture is reviewed. Because culture means the system of the symbolic world within which a person is constantly forming one's self-understanding, an understanding of the major distinctive features of the culture in which the people live is essential. When examining the caregiving experience of the Japanese people with special emphasis on their self-understanding and life course, it is important to have some conscious understanding of the culture in which they were socialized. One important issue in contemporary research is that the experience of happiness, fulfillment, and satisfaction differ between Japanese and American or Northern European people. Therefore, the Japanese concept of *ikigai* has been included in the current research to examine the meaning of the caregiving experience.

Distinctive Features of the Life of the Japanese and *Ikigai*

There are some obvious and significant differences between Japanese, Europeans and North Americans in behavior, personality, and cultural values, although individual differences may sometimes overpower differences of nationality (De Vos, 1985). In this section, some literature on the distinctive features of Japanese persons is reviewed. The section is divided into five sub-sections: (a) The Sense of Self in Japanese Persons, (b) the Family in Japan, (c) Women's Roles, (d) Psychological Well-Being of the Japanese, and (e) *Ikigai*. The exploration of the psychological well-being of Japanese women within the realm of *ikigai* is important to this study. It should be noted that focusing on the traditional aspects of Japanese culture sometimes exaggerates the distinctiveness between people in Japan and other countries. The actual behaviors of people in modern Japan may not always be as extreme as the following descriptions, partly because of the strong influence of Western views during the past fifty years.

Also, individual differences must be kept in mind. Many Japanese people show a mixture of two perspectives; the traditional Confucian view and Western models.

The Sense of Self of Japanese Persons

Some psychocultural characteristics of self are prominent among Japanese when compared to self as it is experienced by average North Americans or Western Europeans (Johnson, 1993). Several distinctive features observed in Japanese people will be selectively discussed in this section. These include: (a) emphasis on relativity, (b) dual structure of consciousness (Doi, 1973), (c) subjective experience of self, (d) expressed and unexpressed consciousness, and (e) thou-oriented behaviors and *sassuru/omoiyaru*. Additionally, (f) *amae*, *amayakashi*, *enryo*, and *gaman* will be described. Finally, comments on recent changes will follow.

Emphasis on relativity. The Japanese self is characterized by its conscious emphasis on the smooth operations of the interpersonal (or in my conceptualization, the presentational) self (Johnson, 1993; Lebra, 1976). As a result, the subjective as well as presentational experience of self becomes highly relational (i.e., specific) to the interactants and therefore strongly situational. In summarizing a number of authorities, Johnson suggests that "the Japanese concept of self is intensely relational and infused with social cohesion" (1993, p. 233). The subjective experience of self is also strongly affected by the group that a person belongs to or represents in a given situation. Contrastingly, the subjective and presentational selves in Western societies place more conscious emphasis on individuality and a sense of separateness from others. Kondo (1987), has also pointed out the "relational quality of self" (p. 245) among Japanese persons, and Suzuki (1986) commented that "the Japanese self is an undefined, opened-ended state until the appearance of a specific addressee" (p. 149).

Such an emphasis on relativism in the definition of self has been described as a situational ethic (De Vos, 1960; Lebra, 1976). This is opposed to more universalistic system of ethics based on moral absolutes seen in many Western societies. Lebra (1976) used the term social relativism to describe the extreme sensitivity in social relationships displayed by Japanese, and their focus on status relativity which regulates and evaluates behaviors in Japan. Such an ethos yields a high degree of consciousness about social hierarchy along with a careful monitoring of fluctuations encountered in various situational circumstances. As noted repeatedly, this structural characteristic of Japanese society that emphasizes hierarchical relationship has been described as a vertical society by Nakane (1967).

This combination of relativity and situational specificity in the Japanese self can be seen as connected to the cultural and moral imperatives to keep relations smooth and harmonious between individuals and groups. Rather than experiencing well-being as an individual construct, Japanese people tend to identify well-being and security with belonging to a group in a harmonious manner.

Dual structure of consciousness. Factors of relativity and situationality of the self-understanding are associated with the development of a dual structure of consciousness (Doi, 1973, 1985). Doi contends that in Japanese consciousness, there is a clear distinction between *tatemae* ("surface" or "an official stance"), and *honne* ("interior" or "one's real intention") (Kenkyusya's New Japanese-English Dictionary, 1974). *Tatemae* and *honne* as described by Doi, correspond to the group-oriented and individualistic self-understanding respectively and, in most mundane social transactions, only the group-oriented self (*tatemae*) is fully expressed, while the individualistic (egocentric, *honne*) self tends to be suppressed and unexpressed.

The dual structure of consciousness experienced by Japanese people occurs for the following reasons. In the socialization of children, as well as in daily living, the emphasis on relativism in the definition of self is continually reinforced by discouraging individualistic, egocentric self (*honne*) thinking. In order to discourage this expression, a number of Eastern religions and philosophies idealized the attainment of selflessness, ego-lessness, or detachment from narcissistic interests. Derivatively these have been a central component within moral discipline. As a result, when compared to individuals in Western societies, Japanese tend to experience a stronger sense of identity through their consciousness concerning social roles, and their concentration on enacting these according to the expectations of the group.

For example, the roles of wife, husband, daughter, or daughter-in-law are highly specified and idealized within relatively tight normative regulations, when compared to the latitude given these roles by North Americans. Moreover, it is considered inappropriate for Japanese to operate outside of their expected roles--except in very informal or unusual (e.g., urgent) situations. Consequently, there is a clear boundary between individualistic, subjective self and that portion of subjective self derived from group affiliations (group-oriented self). Group-oriented self identity takes a dominant position and discourages (or at least subordinates) individualistic self-understanding. This constitutes an important distinction between Japanese and Westerners.

Subjective experience of self. Sometimes the notions of selflessness, personal humility and lack of egotism among Japanese are seriously misunderstood as a loss of the subjective experience of self. The suppression of the individualistic self in the realm of the presentational makes the Japanese less conscious of their individualistic, subjective self. The suppression of this also makes it difficult for Western researchers to appreciate the type of subjective self experienced by the Japanese. However, the subjective perception that consists of individual as well as group-oriented self is experienced consciously by the Japanese, although it may be different from that experienced by the Westerners.

There are several commentators who have examined the issue of subjective self-understanding of the Japanese. In his review, Johnson (1993) suggests that the difference between Western and Japanese senses of self are mainly quantitative, in that

Japanese experience and transact less of their individualistic selves and maintain a clearer awareness regarding their position within a group or the general society. Lebra (1992) suggests that inner self, an awareness that is privately more stable and immune from the vagaries of social relativity, is sought. Lebra suggests, "It is the inner self that provides a fixed core for self-identity and subjectivity, and forms a potential basis of autonomy from the ever-insatiable demands from the social world" (p. 112). Moreover, contrary to other ethnographers who emphasize the relational quality of self, Lebra, as a Japan-born anthropologist living in the United States, proposes that the inner self claims a kind of moral superiority over the outer self which is highly relational:

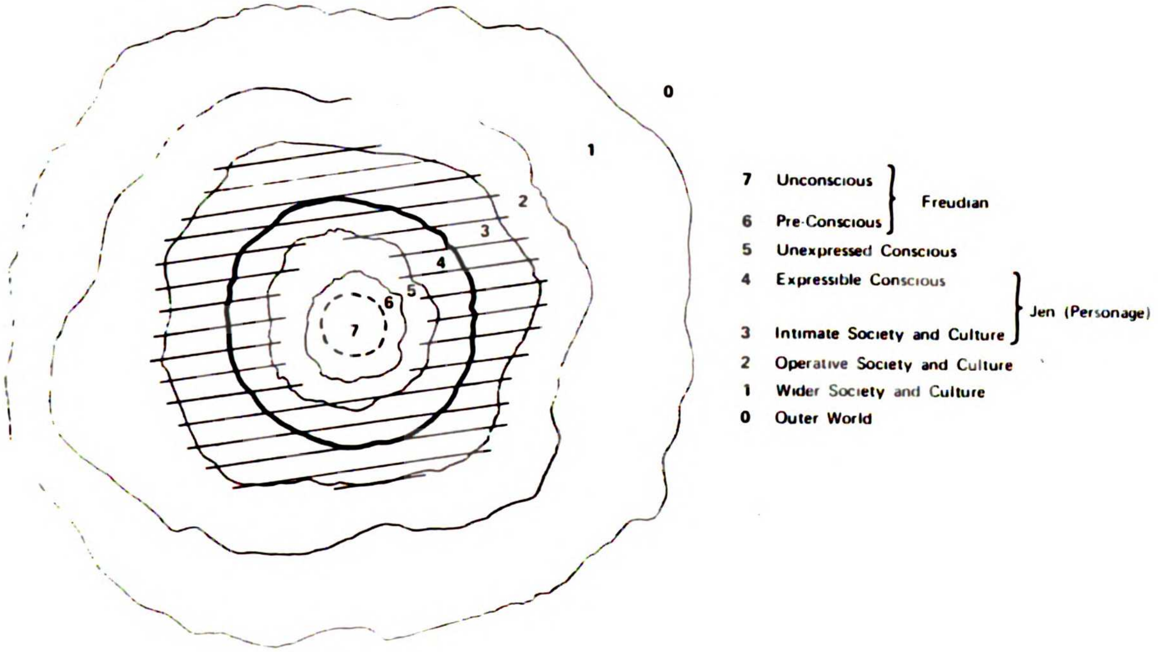
> ... when one is under cross-pressures from inside and outside of self, the inner self may assert itself insofar as its moral superiority is recognized. The imperative of conforming to interactional norms thus may give way to fidelity to one's inner self. "Be faithful to yourself (*jibun ni chujitsu ni*)" becomes a final verdict. (p. 114)

Expressed and unexpressed consciousness. Thinking about individualistic self has been culturally discouraged but this does not mean that individualistic self is not expressed in the interpersonal transaction among the Japanese. Whether individualistic self is expressed or not depends on the situational requirement. For example, in close, intimate, interpersonal relationship, the individualistic, *honne* (interior) component of self may be expressed to a substantial degree.

The distinction between expressed and unexpressed components of self-awareness has been structurally illustrated by Hsu (1971). He developed a psychosociogram to explain human functioning based on psychosocial, rather than mere psychological, organization (Figure 6). According to his model, "persons" can be seen to function at eight levels in relation to their human environment. The process begins with the innermost layers of unconscious and preconscious structures (see numbers 6 &

7 in Figure 6), continues through four intermediate layers (numbers 5 to 2 in Figure 6), and finally extends to two layers of more vague association to the larger mass society

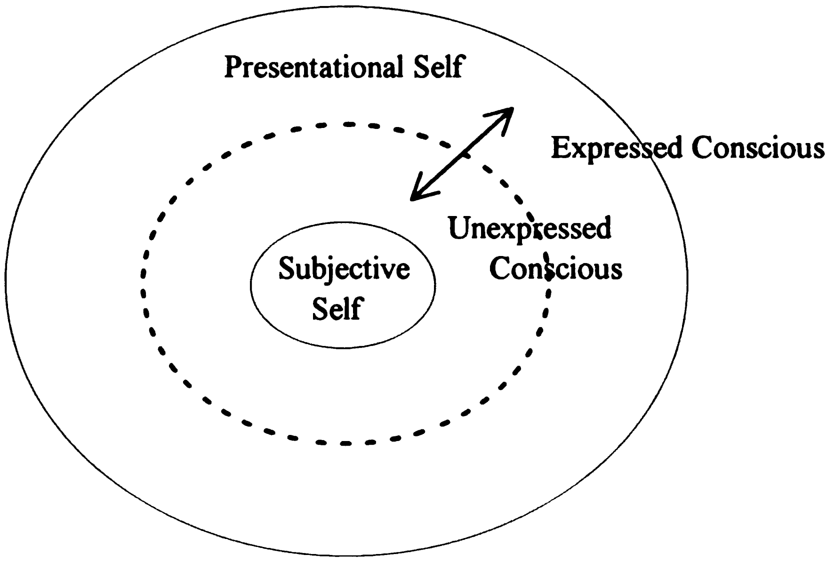
Figure 6: Psychosociogram of Man
(cited from Hsu, 1971)



(numbers 1 & 0 in Figure 6). What is pertinent to the present discussion is layer #5, the unexpressed conscious. In both Hsu's (1971) and Johnson's (1985) taxonomies, unexpressed consciousness belongs mainly to the inner (subjective) self, but overlaps with a portion of the interpersonal (presentational) self. The degree of overlap depends on the characteristics of both cultural and situational variables. In all societies some portion of self-awareness is conventionally (e.g., diplomatically) not expressed in order to preserve smooth interpersonal relationships (Figure 7).

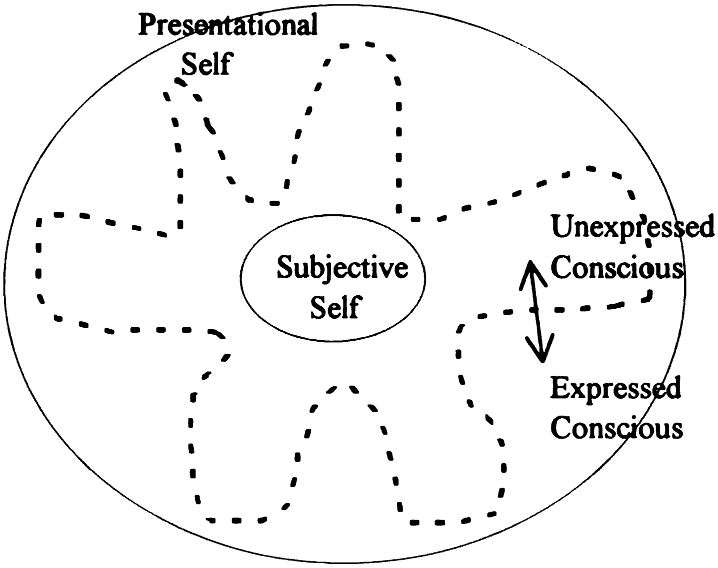
Johnson (1993) contends that the amount of unexpressed conscious is relatively expanded among Japanese people because acting in accordance with others and preserving harmonious communication is given higher importance. Thus, a larger portion of individualistic self tends to be left unexpressed among Japanese. I suggest, in addition to Johnson's notion of expanded unexpressed conscious, that a large portion of individualistic self can be expressed <u>when the situation allows</u>, so the portion of unexpressed conscious of the Japanese is not always larger than that of the Western people (Figure 8).

<u>Figure 7: Western Self-Understanding</u>
(created by the author)



There is another paramount factor which contributes to the concealment of some components of self-understanding: namely, <u>emotionality</u>. Regardless of whether displayed in individualistic or group-oriented contexts, the emotional component of self-understanding is generally difficult for many Japanese to express directly, especially adverse or negative emotions. Some obvious expressions of emotion and feeling are prohibited in any circumstances, and to some extent also in the United States, but the prohibitions are clearly stronger in Japan, again depending on the situation. For Japanese, a good deal of emotionality and feeling are consigned to the unexpressed consciousness insofar as their direct and unfiltered expression in interpersonal communication would be seen as inappropriate, dangerous or rude.

Figure 8: Japanese Self-Understanding
(created by the author)



Instead, nonverbal communication is employed by Japanese people to express deeper emotionality. Nonverbal communication is extremely important in Japan compared to the direct verbal communication.

To repeat, the most influential factor determining the degree of self-expression is located in the situational variables and the normative rules that regulate them. Therefore, as a result of the norm of maintaining harmony (*chowa*) within the group, a large part of individualistic self tends not to be transacted in most interpersonal relationships. Consequently, the self is experienced as highly relational in daily life.

This results in two characteristic communication patterns seen among Japanese: thou-oriented behaviors and *sassuru/omoiyaru*.

<u>Thou-oriented behaviors and *sassuru/omoiyaru*</u>. As a result of discouraging transactions based on the individualistic self, Japanese have developed a pattern of behaviors characterized by a high degree of sensitivity toward other people. This pattern of behaviors is associated with the group-oriented (*tatemae*) self-understanding. To distinguish behaviors based on an individualistic self and those connected to a group-oriented self, Kumagai and Kumagai (1986) use a distinction between I-thou value orientations. They designate ego-asserting behaviors (those aiming at individualistic satisfaction or behaviors based on individualistic self) as being "I-value" oriented. Ego-distancing behaviors (those aiming at the satisfaction of others or behaviors based on group-oriented self) are described as "thou-value" oriented. While I-value orientation tends to be the primary rule in Western countries, thou-value orientations are common in Japan and given greater importance. Japanese people frequently "step in and out" of these orientations depending upon the particular situation. Although I-value oriented behaviors (those based on individualistic self) are systematically discouraged, Japanese can sometimes behave with this orientation. The important point for the smooth transaction among Japanese is to develop sensitivity to those situations where the individualistic self may be expressed and I-oriented behaviors are accepted.

The serious consideration given to smooth interpersonal relationships (*wa*) can also be seen in heightened concern over the feelings of others. The relative absence of openly stating dissent or disagreement makes it necessary for individuals to speculate about the unexpressed consciousness of the other person, using their imagination and observation of subtle, nonverbal cues. This allows the careful observer to behave in accordance with the unexpressed, underlying emotions. This speculation about the other person's unexpressed conscious, and the compensatory action to respond to this feeling are called *sassuru* (noun is *sasshi*) or *omoiyaru* (noun is *omoiyari*), meaning sensitivity about others.

Amae, amayakashi, enryo, and gaman. Another area to be mentioned here in relation to the distinctive Japanese sense of self is the concept of *amae*. *Amae* is defined by Takeo Doi in a series of writings as: "...to depend and presume upon another's benevolence" (Johnson, 1993, p. 63) (Doi, 1956, 1971, 1985). Doi has also described *amae* as a "passive object love," based on Michael Balint's observation concerning psychoanalytic practice. Lebra calls *amae* "indulgent dependency" (1976, p.54). This aspect of an indulgent *amae* is most typically depicted in the relationship of a baby to his/her mother, but can also be witnessed in relationships of older children, or between mature adults in various close partnerships (e.g., husband and wife, teacher and student, boss and employee). Lebra (1976) stated that *amae* is interactional and that, to be effective, the request for *amae* (*amaeru*) must be accepted and responded to by the behavior of another person (*amayakasu*). Kumagai and Kumagai (1986) argued that there are many people who may fulfill the role of *amayakasu*:

> [*Amae*] appears as an individual's need, not merely for love in the general Western sense of the term but for a specifically qualified form of love wherein "the other" attempts to *amayakasu* by offering the individual the freedom "to do what he wills" while taking loving care of him. (p. 308)

This complementary relationship where one actor attempts to *amaeru* and the other seeks to *amayakasu* is not observed only among those who are intimate in Japan. Kumagai (1981) suggested that a similar, although not identical, relationship is also found in more formal relations.

Doi (1971) asserts that the Japanese are distinctive in their unusual sensitivity to, capacity, and needs for emotional dependence (*amae*). Consequently, the *amaeru-amayakasu* relationship is a prominent form of behavioral expectancy. Social relativity seen, and the resultant practice of *sassuru/omoiyaru*, seem to have produced a society in which the expression of *amae* is readily accepted in situations where it is permitted.

Amaeru can be quite active and self-assertive in the sense that it demonstrates one person's attempt to modify another's behavior through requesting or demanding gratification (Lebra, 1976). Therefore, there needs to be counter-forces, within the actor who uses *amaeru*, designed to thwart excessive requests for *amaeru* internally and to preserve the notion of social relativism. Several authors have written on this issue. Doi (1971) has posited that *enryo* works as a "brake" to counter the development of excessive *amae*. *Enryo* is usually translated as humility, hesitation, or modesty that involves a calculated withdrawal of self and is characteristically seen as a prominent interactional norm operating among Japanese. Researchers have focused on the balancing effect between *amae* and *enryo* (Kumagai, 1981; Kumagai & Kumagai, 1986; Lebra, 1976). According to these commentators, *enryo* can be understood as a behavior involving a clear sense of self based on a thou-value orientation. *Enryo* is only possible when the person actively recognizes the boundary between self and other, and acts on the basis of *sasshi/omoiyari* toward the other's unexpressed feelings and expectations.

Takahashi (1984) posits that the cultural value placed on endurance (*gaman*) functions as a balancing and restraining factor on *amae*. According to him, *gaman* is a "curtailment of egoism for the sake of others" (p. 7). Thus, a thou-value orientation can also be seen operating through *gaman*. In daily life, the use of the term *gaman* does not seem to be limited to describe behaviors designed to satisfy others. I partly agree, however, with Takahashi (1984) regarding the point that *gaman* is valued in Japan because of its balancing effect with *amae*.

Recent changes. Some of the distinctive features of the Japanese self discussed above are changing under the influence of increasing contact with Western cultures. Especially among younger Japanese, the dual structure of consciousness is losing its distinctiveness when compared to people in Western Europe and North America. Individualistic experience of self, similar to that of Europeans or Americans, seems to be increasing in prominence to the level that is almost equal to the group-oriented sense of self. As a result, the distinction between *honne* (interior) and *tatemae* (surface) is becoming less clear. Also, the thou-orientation of *sassuru/omoiyaru* is less valued than before, and there is increasing preference given to explicit verbal communication. In observing contemporary, interpersonal relationships in Japan, the traditional awareness of self is still commonly experienced, especially among the pre-war generation, and in persons residing in rural areas. However, it can be said that there is increasing diversity in the individual experience of self, depending upon the individual's regional and generational position in Japanese society.

In ending this section on the Japanese sense of self, it should be mentioned that the examination of the distinctive nature of the Japanese sense of self does not presuppose a total difference between Japanese and Western self perception. The distinction should be understood as relative or quantitative, rather than absolute or qualitative. Examining Western and non-Western concepts of self, Spiro (1993) suggests: "A typology of the self (or of personality) that consists of only two types - a Western and a non-Western - is much too restrictive to accurately describe either, and only serves to distort both" (p. 144). On the other hand, however, one should be cautious about the uncritical reliance on the Western conceptualization of selfhood, characterized by the clear boundary among individuals, in examining the sense of self of the Japanese. Western conceptualization of self may be the product of major ideologies (rather than the empirical reality of individual awareness) dominant in today's Western societies. Therefore, it may not accurately reflect the experience of self for those living within this culture (Murray, 1993).

Family in Japan

Ie or "household". To understand the meaning of family in Japan, the term *ie* should be explained. The *ie* is a Japanese word for family or household and describes traditional characteristics of the multigenerational and ancestral family organization in Japan. In Western terms, the connotations of *ie* are carried by the term house only when the word is used in a phrase such as "the House of Rothchild" (De Vos, 1973, p. 41). According to Lebra (1984), *ie* means (a) "a vertically composite form of nuclear families, one from each generation" (p. 20, citing Morioka, 1967, p. 597), and (b) "the household characterized as a corporate body of co-residents, each performing his/her role to maintain it" (p. 20). The *ie* is a structuralized basic unit in traditional Japanese society, with its emphasis on patrilineal and patrilocal genealogy. Although families in contemporary Japan are losing some of this sense of continuity, the influence of a traditional view of the *ie* is still distinctive, especially when Japanese families are compared to families in Western societies--except for unusual situations like the Rothchilds or European royalty.

Family members as parts of a whole. Each member of the *ie* has his/her role in the household and contributes to the family according to their delegated status, duties, and abilities. Moreover, members traditionally are expected to subordinate their personal satisfactions and goals to those of the collective *ie* as a whole (Hendry, 1981). Such collectivization of group objectives, as contrasted to individual goals, is prominent among Japanese and, for that matter, other Asian societies. This subordination to collective identification is, not only seen in the ie, but in associations at school, the work place, or within friendship groups. The individual is consistently conceptualized as a part of a larger whole (Lebra, 1976). Combined with the characteristic, Japanese, elevated sense of group-oriented self, the primary goal of each individual is to enact an established role within the ie, so the household functions smoothly and in an integrated manner.

Parent-child relationship. The relationship between parents and children within the *ie* is characterized by strict attention to reciprocity and obligation, for which the term *on* is often used. *On* is defined as "a relational concept combining a benefit or benevolence given with a debt or obligation thus incurred" (Lebra, 1976, p. 91). In the parent-child relationship, *on* confers a fixed social credit for the parent(s) and constitutes an inexhaustible social and psychological debt for the children. Due to the unlimited care given by parents to children, their debt is permanent and undischargeable. Parental *on* binds the children to a filial obligation and responsibility (Hendry, 1981). Moreover, the concept of *on* extends the generalized obligation to the larger household (*ie*) to which the individuals also owe their existence. As Lebra (1976) put it: "One is born ... with a birth-debt.... The benevolence of the ascending generations should be regarded as pure and unlimited, and it should be matched only in total devotion by the descending generation" (p.104).

On toward father is more or less structuralized, but the *on* toward mother tends to be heavily emotional and deeply internalized in children, reflecting the strong emotional tie between mother and child (*amae*). If the filial obligation is not met, the children may experience a strong sense of guilt, especially toward mothers who have conspicuously endured hardship and unselfishly dedicated themselves toward their children (De Vos, 1960, 1973).

Recent changes. As in many postindustrial societies, the family in Japan has been changing, and values related to the extended family have been slowly modified. Following World War II, the Japanese Constitution was radically changed under the influence of the occupying forces. Among other renovations, the new constitution proclaimed the equality of men and women in marriage, and established the legal independence of the new couple from their *ie* lineage. Reflecting these changes and the increased industrialization of the country, the number of extended families have decreased while the nuclear families have proliferated (HWSA, 1993). However, the influence of these traditional values connected to the *ie* remains a genuine factor affecting the conceptualization of families in Japan, especially in the rural areas. These still operate in the basic parent-child relationship, preserving Confucian models for filial respect and responsibility toward elders. In this combination of the changing family configuration and continuing influence of traditional values, "individuals are striving to adopt new ways to care for the elderly within an acceptable range of modification" (Elliott & Campbell, in press). Change in family caregiving is not a mere replacement by non-traditional, Western ideas.

Women's Roles

Traditionally, expectations of women were formulated around their status and functions within the *ie* (as patrilineal household). Women looked forward to being a wife of the future successor (*yome* or daughter-in-law), a mother (*haha*), and later a wife of the *kosyu* (as *shutome* or mother-in-law). All of this was to occur within the realm of ie. The *ie* used to be under the control of the oldest surviving male who usually was the oldest son. This required women in the *ie* to enact established roles with a strict obedience to the male kosyu or any other established authority (e.g., a widowed *shutome*). The socialization of women included moral training in accordance with this future requirement and inculcated both through explicit precept as well as observation of how other women navigated their roles.

Moral training for women. In the Confucian tradition, women were held to be categorically inferior to men. Obedience was the prime duty of women; first to their father, then to their husband and husband's parents. When widowed, she was technically beholden to her oldest son, although most mothers wielded considerable influence over their sons, even in adulthood (Hendry, 1981).

Endurance (*gaman*) was another quality that was extolled and required in the character development of both girls and young women. Regardless of gender, hardships were, and are, considered as opportunities for character development among the Japanese (Lebra, 1984). Enduring difficulties and adversity with persistence is regarded as "tap(ping) inner resources that reflect a special capacity" (Johnson, 1993, p. 89). Endurance has been especially valued as a virtue of women: They derive their self-esteem from the reflection of past perseverance (Lebra, 1984). The virtue of quiet endurance and sacrifice for others were strongly inculcated during childhood and adolescence.

According to Lebra (1984), other aptitudes and skills for women include self-reliance (not causing nuisance or trouble for others), diligence, and thrift. These qualities are encouraged from earliest girlhood and are designed to create *rhosai kenbo* [good wives and wise mothers] (Iwao, 1993). Through direct observation, daughters learn to identify with their mother's role, and to acquire these characteristics through imitation and gradual internalization.

Traditional marriage. The two main purposes of marriage were the continuation of the family through procreation (Lebra, 1976), and the development of a wife capable of enacting the pre-determined role of the *yome* or spouse of the successor to the *ie* (*shutome*). In a strongly patrilineal society, for women, marriage meant leaving her natal family to enter into the *ie* of her husband (*yome-iri*). On those occasions when there were only female successors (no sons), the family had the option of selecting a husband for their oldest daughter and to formally adopt him into the family (*muko-iri*).

When a woman married, she then became a bride (*yome*) and was placed under the direct control and supervision of her husband and, more especially, her mother-in-law (*shutome*). She was expected to maintain a high degree of respect for, and subordination to, her husband's parents and to work diligently to fulfill her domestic responsibilities. When she produced children and fulfilled her responsibilities as a *yome*, she would eventually assume the position of *shutome* following the death of the mother-in-law. Thereafter, she would manage all the household matters for kosyu based on the knowledge of the particular family routines and practices gained through waiting on and observing her mother-in-law.

Relationship between husband and wife. Hendry (1981) compared the role-set of the Japanese husband and wife to that of a bureaucrat to a politician: "Men take the official seats [in ceremonial occasions] while women may well advise from the kitchen on the order of proceedings" (p. 94). Thus, on the surface, women are expected to be obedient and quiet; but behind the scenes, women often know much more than men, especially about matters concerning domestic, financial, and child-rearing responsibilities. In the case of household matters, men are allowed to be openly dependent on their wives, although they retain titular control (Lebra, 1984).

Recent changes. Since the end of World War II, women in Japan have been expanding the content of their roles and life styles. Although these changes have not been rapid, role expectations for women, as well as men, have gradually increased. As mentioned before, the number of women working outside the home, both before and during marriage, is increasing. Accompanying these changes in women's roles, there has been more sharing of roles in the family. Gender has become less rigid in terms of distributing domestic duties, especially among young couples who have post-high school education. As a result, the influence of parents or in-laws on young couples has been steadily diminishing.

These changes should be reviewed with caution. Iwao (1993) has described features of women distinctive in three age cohorts: pre-war generation (born before 1935), post-war generation (born between 1945-55), and a younger generation (born between 1960-69). According to her, these three cohorts reflect quite different values in their views of family obligations and women's roles. Even among daughters or daughters-in-law who are involved in the caring for their parents (or parents-in-law) there is a considerable difference in their views regarding the extent of responsibility for caregiving, family maintenance, and the role of women according to generation

(Elliott & Campbell, in press). Among the pre-war generation, the traditional view of the ie, the support for filial responsibility, and traditional women's roles is still observed, whereas caregivers in the post-war generation show more flexibility regarding women's roles and the division of responsibility for taking care of elderly parents.

Psychological Well-Being of the Japanese

Discussing psychological well-being, or other terms pertaining to the global assessment of functioning, such as morale or life satisfaction, is a difficult task (Nydegger, 1977). First, psychological well-being presents a conceptual difficulty because of the instability and elusiveness of the term. Unlike understanding more durable aspects of human traits such as attitudes or values, the subjective perception of psychological well-being is likely to fluctuate within a short period of time, and change according to many situational and contextual variables.

Second, estimations of psychological well-being require a cognitive process to understand and summarize life experiences. This may vary according to cultural values, and also may bias the subjects' perception of their experience. The influence of cultural values permeates not only the perception of the present experience, but also how the past experience is regarded and future projection is anticipated. Regarding this issue, Lebra (1984) has written in her ethnographic research on Japanese women: "The difference between Japanese and American women lies... only in the cultural coding of experience, not necessarily in the experience as such" (p. 296). Thus, the psychological well-being of Japanese women cannot be discussed without a basic understanding of the Japanese self, including an accurate perception of the Japanese family and the accepted social roles of women.

Bearing these difficulties in mind, selected topics revealing the distinctiveness of psychological well-being of the Japanese will be discussed. Topics to be examined are:

(a) rare use of "happiness," (b) the importance of harmony, role-dedication, and belongingness, (c) the cultural meanings of endurance, and (d) *amae*.

Rare use of "happiness". It seems to be characteristic of Japanese that the word happiness is not used in conversation nearly as often as it is in the United States. Minami (1971) suspects that it is because the Japanese have cultivated a habit of hesitation toward undue happiness. First of all, complete happiness is culturally thought to be hazardous because "the gods" ("Ways of Heaven") will cause whatever is thriving to deteriorate or disappear. Confucianism teaches that people should "know their lot," and they should know how to be happy within any given situation. Rather than praying for happiness, one hopes for the absence of illness (*mubyou*), and the avoidance of mishaps through the power of Buddha (*sokusai*) (as noted in *Syogaku-kan*, New Japanese Dictionary, 1973). Another factor affecting this hesitation toward happiness is that the Japanese have been taught that happiness in this world is ephemeral, and therefore not to be trusted.

Such discouragement of happiness does not mean that Japanese do not seek a sense of well-being. Although active pursuit of individual happiness is discouraged, numerous life situations are thought to give joy, fulfillment, and self-esteem. Because of the emphasis on the group-oriented self (as opposed to the individualistic self), the sense of well-being also tends to be experienced in the context of interpersonal relationships, group achievements and shared benefits rather than in rewards for individual persons. Thus, unlike in Western and North American societies, questions regarding morale and well-being tend to elicit collective rather than personal responses.

The importance of harmony, role-dedication, and belongingness. In Japanese socialization, a fundamental rule of social interaction is the maintenance of *wa* (harmony) (as summarized in Johnson, 1993). Even the admission of personal fulfillment is liable to be linked to the achievement of a collective goal. Therefore, an institutionalized way of obtaining self-fulfillment is through dedicating oneself to the given role, either in the occupational group for men, or in the family for women. In either case, self-fulfillment will be sublimated so that the group can function to achieve its goals (Lebra, 1976).

De Vos (1973) has suggested that the concept of role dedication must be grasped in order to understand how Japanese achieve psychological well-being:

> The social philosophy of Confucianism tends to de-emphasize the individual...and to emphasize... the network of particularistic obligations and responsibilities that the individual assumed as a member of his family and of his community. <u>Living in accordance with one's prescribed role is</u>...<u>the ultimate basis of moral values, subjectively sanctioned by one's own conscience and objectively reinforced by the informal sanctions of the community and the legal codes of the state</u>. (1973, pp. 11-12, underlines mine)

For women, the traditional roles that are socially prescribed are those of daughter, wife, mother, and *yome*. Faithfully enacting such roles--typically of helping and nurturing others--yields much fulfillment (Iwao, 1993). Conversely, those who cannot navigate these performances easily tend to feel guilty, since this role expectation is strongly internalized.

The emphasis on the group-oriented self is also related to a sense of belonging which Japanese characteristically seek to maintain. De Vos (1985) has explained that the "Japanese find ultimate satisfaction in belonging" (p. 164). In his observation, they tend to define themselves in relation to others, and this tendency is associated with the need to belong to groups in order to have a sense of identity.

<u>The cultural meaning of endurance</u>. Lebra (1984) argues that perseverance in the face of structural oppression experienced by a young woman when she first marries, may be understood as the basis for her security and comfort later in life: She will be protected and substantiated by the structure of ie. Consequently, endurance is morally

valued and promised to be rewarded in the future. Because of this, the seeming negativity of endurance is (mostly) willingly accepted by women.

Amae. Another fundamental source of psychological well-being is through an interpersonal relationship constituted through *amae* (indulgent dependency). In addition to Doi's (1971) argument that the Japanese have an elevated need for *amae*, De Vos (1985) argues that the indulgent nurturance of the mother encourages the development of children who continue to be mentally dependent upon their family.

According to Kumagai and Kumagai (1986), the act of *amaeru* (to request and receive indulgence from other[s]) is a necessary condition to experience well-being. At the same time, however, the act of *amayakasu* to give indulgence (e.g., a mother attempts to *amayakasu* her baby), is also a source of psychological well-being for the actor of *amayakasu* (Lebra, 1976). For example, when a woman identifies with the role of mother, her well-being is secured by dedicating herself to this role. This is enacted by *amayakasu* because the act of fulfilling the *amaeru* of others is a socially agreed-upon expectation. Thus, the posture of *amayakasu* serves as a prominent source of psychological well-being for Japanese women.

Recent changes. Following the end of the Second World War, the introduction of modern democratic institutions has brought a more individualistic view of the sense of self, family, roles, gender, and human life in general. It goes without saying that such changes have influenced both the sense and expression of well-being of the Japanese. Harmony, role-dedication, and endurance are not valued so blindly as before. This can be seen in the increased divorce rate (77 thousand in 1965 compared to 168 thousand in 1991) (HWSA, 1993).

However, the traditional views of life and the accepted ways to gain psychological well-being are firmly grounded in the older generations. Presently, the children who are serving as caregivers are in-between these new and old generations. They seem to embody the conflict between the traditional and Western view of self and life (Elliott & Campbell, in press). How they accommodate themselves as caregivers depends more upon each individual's perceptions. A variety of perceptions may be seen among the young caregivers.

Ikigai

It was mentioned earlier that Japanese people do not use the word happiness as often as Westerners. Instead, to describe the condition of high psychological well-being, the Japanese often use a complex term, *ikigai*. The word *ikigai* consists of two parts. *Iki* is an adjective, whose primary form is *ikiru*, a verb. The meaning of *Ikiru* is quite similar to that of the English verb, to live. *Gai* is a modified form of *kai*, a noun. In Kenkyusya's New Japanese-English Dictionary (1974), *kai* is translated into such words as effect, fruit, result, worth, avail, use, or benefit. When someone says *Kai-ga-aru* (there is *kai*), this is translated as worthwhile. *Kai-ga-nai* (there is no *kai*) means unavailing. In the Kenkyusya's dictionary, *ikigai-no-aru-seikatsu* (life with *ikigai*) is translated as a life worth living, and *ikigai-wo-kanjiru* (to feel *ikigai*) is to find one's life worth living.

There are no words in English that directly correspond to *ikigai*, although conceptually *ikigai* has been approximated to the expressions morale, life satisfaction, purpose in life, or meaning in life (Koyano, 1982a, 1982b; Koyano, Shibata, Haga & Suyama, 1990; Maeda, Asano & Taniguchi, 1981, 1983; Sugiyama et al., 1981, 1982). Such a lack of direct correspondence probably reflects the distinctive mental structure of the Japanese with regard to all the meanings the word communicates.

Kamiya (1966) says that forceful translations of *ikigai* to other languages, such as meaning in life, emphasize only the logical or philosophical aspects of this term, and do not allude to the ambiguity, special nuances, and suggestiveness which are essential characteristics of the Japanese language. *Ikigai* connotes, not only the logical desirability of finding one's life worth living, but also the feeling that accompanies the discovery of such a value. Also, meaningfulness in life does not need to be logically derived, but can be felt intuitively.

Literature on *ikigai*. According to Kamiya (1966, 1971), the term *ikigai* is used in two ways: to describe the psychic manifestations (sense of *ikigai*), and to describe the sources that generate such psychic dispositions (*ikigai* as object). She further divides the sense (or subjective dimensions) of *ikigai* into two parts: the sense of *ikigai* as emotion and the sense of *ikigai* as cognition. First, the sense of *ikigai* as emotion, notably as a joyful feeling, includes the recognition of experiencing a fulfillment in life. Kamiya (1966) distinguishes this feeling from simple happiness by explaining that the sense of *ikigai* possesses a movement in the direction of future, and the feeling of being engaged in something valuable. The sense of *ikigai* as emotion should be assessed separately from mere happiness, since it is strongly connected to values and commitment of the person.

The sense of *ikigai* as cognition is a conscious awareness regarding the processes through which *ikigai* as emotion is achieved. People may not be conscious about the sense of *ikigai* as emotion in routine, daily life. However, from time to time, especially when facing serious life events, people are forced to ponder how they are obtaining the sense of *ikigai*. On such occasions, the sense of *ikigai* can be seen as a cognitive process.

The term *ikigai* is not only used for denoting the mental state of individuals, but is also used to describe the various sources from which people derive such mental states. Kamiya (1966) called this *ikigai* in the narrow sense, or *ikigai* as object. This object is in effect an objectification of experiences or behaviors through which one feels the sense of *ikigai*. However, in the consciousness of Japanese, it seems that the property of *ikigai* as forms, rather than as experiential processes, is prominently perceived. Such an *ikigai* as object is highly individual.

There are other similar definitions of *ikigai* made by several Japanese commentators. Reflecting the ambiguity of the term, these have both some commonalties and variations. For Kobayashi (1989), *ikigai* is something that imparts a virtual reason for living, because it provides both the courage to live and exemplifies the value of life. Also, *ikigai* is not merely work, hobby, or play but a certain life view consisting of various components such as being, loving, valuing life, meeting people, encountering things, pursuing religion, self-actualization, and *omoiyari*. Among these various components, self-actualization is seen as the most prominent feature of *ikigai* for Kobayashi.

Ueda (1990) also relates the issue of *ikigai* closely to the concept of self-actualization (Maslow, 1968), and sees this as a major means of achieving *ikigai*. He emphasizes that *ikigai* is identity accompanied by certain stipulated values, a description that is close to the psychoanalytic concept of ego-ideal (Johnson, 1993). Kajita (1990), on the other hand, distinguishes between *ikigai* and life view. For him, *ikigai* is mainly the subjective feeling of satisfaction and fulfillment. Contrastingly, one's life view is seen as a rational cognitive structure which shapes the individual's life and contains certain value judgments. Shiraishi (1986) commented that *ikigai* is "the posture of living well and beautifully (i.e., artfully)" (p. 213). According to Shiraishi, *ikigai* means to set an important goal for one's life and to pursue this goal; to create value, to obtain satisfaction, and even to have a revolutionary experience of one's own life view. Similarly, for Umezao (1981), *ikigai* is the combination of life goal, effort, courage, and fulfillment.

Emphasizing the cultural characteristics of the Japanese, Horie (1990) defined *ikigai* for Japanese as the situation in which one's existence is accepted by others as valuable. According to Horie, Japanese seek *ikigai* in the substance of interpersonal relationships. Kobayashi (1990) cited various writings on the meaning of *ikigai* including such comments as "I feel *ikigai* when I recognize how beautiful nature is, or how adorable human beings are" (Ichihara, 1941, p. 279). He quotes Niwano (year unknown): "*ikigai* is the recognition that today I put another goodness on my eternal life," and Yukawa who says, "*ikigai* should be found in the collective effort to make this world better" (Yukawa & Ichikawa, p. 246). Johnson (1993) has commented on *ikigai* in his book on *amae* stating that *ikigai* is a common expression "symbolizing personal identity" and "...it furnishes a crucial point of reference to 'true' or 'ideal' self" (p. 232).

The above literature reveals that *ikigai* involves at least three dimensions: <u>experience</u>, <u>cognition</u> that one's life is meaningful and worthwhile, and <u>feeling</u> of fulfillment and joy. Experience varies enormously depending upon individuals and the particular activities they engage in. Whatever the experience, judgments regarding this experience (made through cognitive process) follow, and the feeling of joy and fulfillment may be obtained. Sometimes *ikigai* as a concrete objectification may be specified, such as in the phrase, <u>my children</u>. At first glance this may not appear to be experiential. However, it seems that the objects (children) are specified in order to symbolize one's diverse experiences (of motherhood) by the specific objects (children) that are associated with both the cognition and feeling of *ikigai*.

There seems to be a difference among the commentators cited above regarding which of these three components should predominate in the conception of *ikigai*. Many emphasize that the notion of *ikigai* includes all three components (Kamiya, 1966; Maeda et al., 1981; Kobayashi, 1989; Shiraishi, 1986; Umezao, 1981). On the other hand, Kajita (1990) stresses the component of feeling in the notion of *ikigai*, while both Ueda (1990) and Kobayashi (1990) highlight the component of experiences involving self-actualization that, in turn, leads to one's identity with certain values. The factors regarding values and ideals may differentiate *ikigai* from other indicators of psychological well-being (i.e., in the case of simple happiness). In relation to values and ideals, it can also be said that *ikigai* communicates a sense of commitment, investment, or dedication.

Comparison between the notion of *ikigai* and Western thinking. There are some concepts in Western cultures that correspond to part of the notion of *ikigai*. What Kamiya (1966) collectively called the "sense of *ikigai*" included both emotion and cognition; this seems to correspond to the term, morale, in Lawton's (1972, 1975) and Kutner's (1956) definitions. Simply stated, Lawton, who did not distinguish between cognition and emotion, includes the sense of adequacy, attainment, satisfaction, and acceptance of the inevitable in his conceptualization of morale (1975). All of these relate to Kamiya's sense of *ikigai*. George and Bearon (1980) have questioned the utility of the concept of morale because the mixture of cognition and emotion makes the concept fuzzy and unclear. This very lack of clarity, however, is similar to the Japanese word *ikigai*; in fact it is part of the ambiguity that is characteristically, and even essentially, found in *ikigai*.

Life satisfaction is another concept seemingly related to a sense of *ikigai*. Conceptualization of life satisfaction in the United States varies among researchers; because of this it is difficult to compare life satisfaction with *ikigai*. Diener, Emmons, Larsen and Griffin (1985) consider life satisfaction as a cognitive and judgmental process tapping into issues concerning both values and achievement. According to their conceptualization, life satisfaction corresponds only to the sense of *ikigai* as cognition.

There are innumerable types of *ikigai* as object. Many of these have counterparts in Western thinking. The notion of *ikigai* includes them all, while Western thoughts have treated these separately and examine their individual influences in regard to psychological manifestations. The presence of similar thinking in Western countries may suggest the universality of the notion of *ikigai*, and the possible utility of this concept in Western countries. On the other hand, despite the fact that its contents have been discussed separately, the lack of any one inclusive term in Western languages that is equivalent to *ikigai* suggests a serious difference between Japanese ways of thinking and those of Western Europeans and North Americans.

Self-actualization is often discussed by researchers, and is a major concept in humanistic psychology (Maslow, 1968; Rogers, 1980). Maslow publicized this term and posited self-actualization as the ultimate (highest) need of human life (1968). Rogers explained this same principle as guiding patients so that they can improve themselves and grow through personal development (1980). Frankl (1978) mainly examined self-actualization in relation to man's "will to the meaning" (p. 29). Existential psychology also deals centrally with the meaning and purpose in life, and thus shows a similarity to various objectifications of *ikigai* (Frankl, 1978, 1984; Yalom, 1980).

The importance of social relationships is also emphasized in Western writings, research on social support being an example. Weiss (1974) categorizes six types of social support. Some of the previously mentioned descriptions of *ikigai* as object seem to correspond to attachment, one of the types of social support, in designating family and love as objectified *ikigai* (Kamiya, 1966).

Summary and Statement of Research Questions

The first part of this chapter reviewed selected literature on family caregiving with focus on the issue of conceptualization of the impact of care on the caregiver and the issue of the conceptualization of the caregiving experience as a process parallel to the life-course of the caregiver. Based on the literature review, symbolic interactionist perspective is used as a theoretical basis for the current research along with the conceptualization of self by Mead and Johnson, and the perspective of career trajectory as is employed by Pearlin and Aneshensel, and Corbin and Strauss. The theoretical underpinnings of these perspectives are reviewed with the statements of theoretical assumptions underlying this study.

The issue of characteristic features of the Japanese with the emphases on the sense of self, family, women's roles, psychological well-being, and *ikigai* is discussed in the last section of this chapter. Japanese shows a characteristic presentation and subjective experience of self that needs to be understood in order to arrive at an understanding of the caregiving experience of Japanese women. Based on the historical configuration of the family and of women's roles, research on the caregiving experience of Japanese women requires special attention to the implications of various factors such as preserving harmony among people, dedication to one's role as wife and mother, and to the sense of belonging to (or affiliation with) a certain group. This also includes the value of endurance and the retention of *amae* relationship.

Japanese people tend not to use the term happiness to describe their psychological well-being as frequently as Western people do. Rather, they alternatively use the term *ikigai*. This has been conceptually divided into three parts: (a) various experiences in life, (b) the cognition that includes value judgments of these experiences, and (c) the feeling of joy and fulfillment.

Literature on *ikigai* is mostly based on the personal inference of the term; it has not been examined empirically. Surveys on *ikigai* seem to assume that people share a certain common definition. It indicates that it is necessary to clarify the personal meaning when the caregiving experience is examined in terms of *ikigai* in the interview.

Based on the above literature review, research questions for the current research are formulated as follows. These questions are not mutually exclusive and, to some degree, tap into the same area of inquiry:

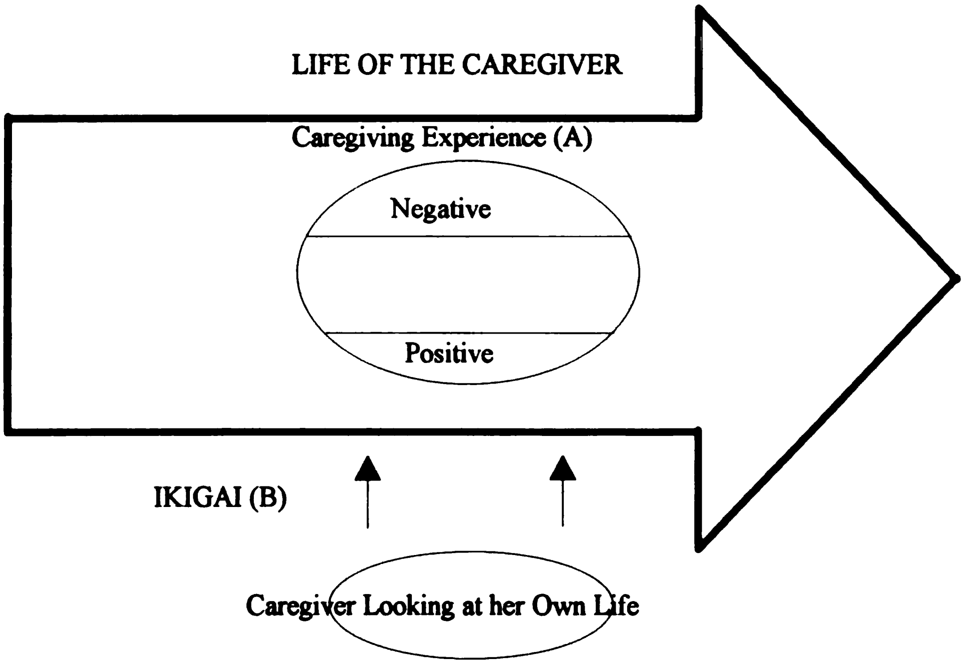
(1) How is taking care of elderly relatives with dementia experienced by Japanese women (daughters and daughters-in law)? What meaning does the caregiving experience have for their lives?

(2) Why can some continue to care for their sick relatives despite the tremendous difficulty? What keeps them going? What are they getting out of their experience?

(3) What does *ikigai* mean to them? Do they have *ikigai* in their lives? What creates *ikigai* in their lives? Has *ikigai* changed over the years? Is there any relationship between their caregiving experience and *ikigai*?

The overall approach of the research questions can be explained using a model (Figure 9). The present research attempts to capture the whole caregiving experience rather than some parts of it that have been conceptualized as the positive or negative experiences (A in Figure 9). Moreover, the subjective experience of caregiving will be explored as it is placed in the life of the caregiver which is articulated through use of the term *ikigai* (B in Figure 9).

Figure 9: Conceptual Model
(created by the author)



Chapter 3: Research Method

To examine the research questions discussed in Chapter 2, grounded theory, a specific form of qualitative research technique, is used here. The purposes of this chapter are: (a) to discuss the advantages of using qualitative research methods in the current research, (b) to discuss the rationale for using grounded theory as the specific form of qualitative method, and (c) to explain the research design of this study.

Advantages of Using Qualitative Research Methods

Qualitative research methods have long been used in the disciplines of anthropology and sociology. Although not strictly distinguishable from quantitative approaches, qualitative approaches have some distinctive features as will be shown below.

Distinguishing Quantitative and Qualitative Research Methods

The difference between quantitative and qualitative research methods has been examined carefully to determine the research methods appropriate to the research questions stated in the former chapter. This section focuses on the distinction between the two approaches.

It should be noted first that the choice of either a quantitative or qualitative method in a research project does not necessarily mean the endorsement by the researcher of either a phenomenological or a positivistic research paradigm (Clarke & Yaros, 1988). Therefore, the following distinction between the quantitative and qualitative approaches should not be automatically identified as the difference between a phenomenological and a positivistic research paradigm.

One of the major points of distinction between qualitative and quantitative research methods lies in the approach to data analysis (Strauss, 1987), rather than in the type of data. Strauss put it:

> In quantitative research, statistics or some other form of mathematical operations are utilized in analyzing data. .... Qualitative analysis may utilize a variety of specialized nonmathematical techniques. .... or as commonly practiced may use procedures not appreciably different from the pragmatic analytic operations used by everybody in thinking about everyday problems. (Strauss, 1987, pp. 2-3)

The lack of, or minimal use of, mathematical operations differentiates qualitative approaches from quantitative approaches.

Duffy (1987) summarized the typical characteristic differences between the two approaches:

1. Outsider/insider perspective
2. Stable/dynamic reality
3. Particularistic/holistic focus
4. Verification/discovery orientation
5. Objective/subjective data
6. Controlled/naturalistic conditions
7. Reliable/valid results.

In my opinion, these distinctions do not separate quantitative and qualitative approaches quite as strictly as Duffy suggests. However, four of Duffy's points of differentiation are useful in illuminating areas where a qualitative research approach is more appropriate for the current research: (a) outsider/insider perspective, (b) controlled/naturalistic conditions, (c) particularistic/holistic focus, (d) verification/discovery orientation.

Outsider/insider perspective. Qualitative research techniques are better at capturing the insider perspective (lived experience of the subject) than quantitative research techniques that tend to attach importance to objectivity and detachment from the subject. This is because qualitative research typically uses linguistic data which is more true to the actual cognitive activities in one's consciousness, while quantitative research mainly deals with analyzing numbers that have replaced the linguistic presentation of a phenomenon.

Controlled/naturalistic conditions. Control of various variables is an important component in quantitative approaches, whereas variation of the context under naturalistic conditions is appreciated in qualitative approaches. This is because qualitative research tries to derive concepts that are most pertinent to explaining the phenomenon of interest; therefore, it is necessary for qualitative inquiries to take a broad view in order to be open to any signs of important concepts. In contrast, quantitative approaches pre-set several concepts to examine, develop operational measures for these concepts, and (typically) test pre-determined hypotheses. Therefore, other variables that may make the relationship of the concepts of interest blurry, tend to be controlled.

Particularistic/holistic focus. Qualitative research usually tries to gain a holistic view of what is being studied, whereas quantitative research methods try to specify what is to be studied within the whole picture of the phenomenon. This is related to the controlled/naturalistic conditions discussed above.

Verification/discovery orientation. Discovery, rather than verification of theory, is a hallmark of qualitative research approaches, while quantitative research methods typically begin with a set of hypotheses to be verified. This distinction may hold less well now that various statistical methods make it possible to explore relationships among variables without specified hypotheses. In addition, qualitative researchers contend that verification should be done in the process of discovering a theory (Strauss & Corbin, 1990).

Characteristics of My Research Question: Rationale for Using a Qualitative Research Approach

The points of distinction discussed above are helpful in understanding the appropriateness of using a qualitative research method for this current research project. First, the emphasis of this study is on the discovery of a basic process of caregiving experience, rather than on the verification of pre-set hypotheses regarding the relationships among the variables. This is because, at this moment, not much is known regarding the research questions described above. After eliciting a basic process and discovering pertinent concepts and possible relationships among concepts within a given phenomenon, a quantitative approach may be useful for testing.

It should be mentioned that, in the field of family caregiving, qualitative research methods have been used in the past (i.e., Bowers, 1987; Guberman et al., 1992; Lindgren, 1993; Wilson, 1989a, 1989b). This may cause one to believe that further research using a qualitative approach may not be necessary. The foci in these studies, however, are various and their research interest is not shared.

Bowers (1987) elaborated the range of acts related to caregiving and expanded the meaning of caregiving activities from only day-to-day physical acts, to various psychological and social, as well as physical, activities to protect the sick relative. Wilson (1989a, 1989b) and Lindgren (1993) elaborated the trajectory of caregiving, through which caregivers struggle to make difficult decisions among negative choices. The research questions in this study which involve the subjective experience of caregiving in light of subjects' lives as a whole have not been examined. The factors to keep the caregivers in the caregiver role have been examined in a qualitative research by Guberman et al. (1992), but one of the major differences between Guberman et al.'s research and this is that the current research examines the caregiving experience of the Japanese. Thus, research on family caregiving in Japan using the grounded theory approach seems beneficial.

Each researcher has his/her own way of looking at a phenomenon, based on his/her past experiences and modes of thinking, so it is natural that a single phenomenon is understood differently. Therefore, the presence of past qualitative research on a given area does not mean that no other attempts are useful. The experience of caregiving needs more research to discover pertinent concepts and their relationships, especially with attention to the meaning of caregiving in the lives of the caregivers and to what keeps them going in difficult situations.

Second, the research question posited here seeks to explore the meaning of the caregiving experience for caregivers themselves. Rather than taking the outsider's view of caregiving only as negative and burdensome, I seek to gain a view of the caregiving experience from the insider perspective. Pre-conceived models and structural questions typically used in quantitative approaches have limited capacity to capture each subject's individual conception of his or her experience. Also, such topics as the meaning of the caregiving experience cannot be easily captured in numerical data. Numerical categorizations would reduce the meaning of the subjects' accounts. At least at this moment, an analysis that keeps the fullness of language used by the subjects seems to be beneficial.

Third, a holistic focus to examine the experience of caregiving is welcomed to explore the full meaning of the experience. If focus is on a particular area (such as the difficulty of care), other implications of the experience for the caregivers' lives could be lost. A holistic focus is preferable also for the exploration of the notion of *ikigai*. Although there are many discussions on this issue, there are few empirical studies on how *ikigai* is defined/viewed by individuals. *Ikigai* seems to be a vague concept whose boundary, as well as structure, is highly variable among people. Therefore, at this moment, looking at the whole picture of their perspective is beneficial for the examination of *ikigai*.

Fourth, naturalistic conditions are needed to pursue the research questions previously stated. Rather than controlling variables, possible variations in data are welcomed in the exploration of the meaning of the caregiving experience.

The above discussion gives rationale for employing the qualitative approach for the current research project. In the next section, the grounded theory approach is explained and its advantages for this research are discussed.

Grounded Theory Approach as a Method of Inquiry

Grounded theory is a research methodology developed by B. Glaser and A. Strauss to generate theory through the analysis of qualitative data. Strauss (1987) explains that grounded theory came from the traditions of American Pragmatism and the Chicago School of Symbolic Interactionism at the University of Chicago.

Grounded Theory

The grounded theory approach is "a qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon" (Strauss & Corbin, 1990, p. 24). Based on the assumptions of the Chicago School of Sociology, Glaser and Strauss emphasize the importance of theories in the development of a discipline, the need to make theories grounded in reality, and the prominence of change, process, variability, and complexity in social life (Strauss & Corbin, 1990).

Generation of theory. Some qualitative approaches such as ethnography or phenomenology primarily aim to describe and understand social phenomena, and to develop concepts or themes from the abstraction of the observed phenomena. The elaboration of the relationship between these concepts is not particularly sought. The primary aim of the grounded theory approach is to generate abstract theoretical formulations or to discover the basic social process. The "development of theoretically informed interpretations is the most powerful way" (Strauss & Corbin, 1990, p. 22) to bring reality to light. It is possible and desirable to compare the theory developed through the grounded theory approach with those derived from other approaches, as the accumulation of related theories is believed to advance the scientific knowledge of each discipline (Strauss & Corbin, 1990).

Methodology as guideline. To generate theory, grounded theory provides an explicitly formulated and systematic set of procedures for coding and testing hypotheses, whereas other research methods such as ethnography tend not to have specific procedural rules. This is a distinctive feature of grounded theory among various qualitative research methods, and it comes from Glaser's recognition of the need for the explicit formulation of research method. However, these procedural rules should be used as guidelines, and the inevitability of contingency and need for discretion are also emphasized (Strauss, 1987).

Social process and its complexity. Grounded theory also focuses on understanding the process of the social phenomenon as well as its complexity. Emerging theory should be able to capture the changing nature of the phenomenon. A theory should account for changes in the process with considerable attention to the whole variety of contexts where the phenomenon takes place, so the theory should necessarily be complex. A number of concepts are to be developed inductively out of the interpretation and abstraction of the observed phenomenon. Through the examination of concepts, conditions for specific actions should be explained.

Appropriateness of the Grounded Theory for the Current Research

There are several reasons why grounded theory is a particularly appropriate approach for this study. First, its most appealing feature is that it aims to generate theory. The current research originates from a literature review that supports the need for a new theoretical explanation of the issue of the subjective experience of caregiving in the life course of the caregiver with an emphasis on why and how the caregiver can continue to give care in difficult and adverse situations. It is true that there have been some viable theoretical frameworks for studying family caregiving, but they mostly focused on the problematic aspects of caregiving and do not necessarily reflect the interest of this research. Therefore, the generation of a new theoretical explanation is sought. Once a theoretical explanation is generated, it is possible to examine a part of the theory in a quantitative research framework; thus the use of grounded theory is an appropriate starting point.

Second, grounded theory emphasizes grasping the subjects' viewpoints for understanding interaction, processes, and social change. The appraisals of caregiving by the family caregiver and their *ikigai* can be examined only through a vigorous attempt to understand the caregivers' viewpoints. Therefore, grounded theory with intensive interview data will serve as an ideal method for the research questions suggested above.

Third, the conceptualization of self by Mead is a significant theoretical underpinning for the current research, and Mead's theoretical stance also serves as the foundation of the symbolic interactionist perspective and the grounded theory method. Also, the perspective of trajectory has been elaborated by Corbin and Strauss (1991) through the grounded theory approach. Thus, all theoretical perspectives utilized in the current research are congruent with its methods of inquiry: grounded theory.

Because of these points, grounded theory appears to be an appropriate approach to take for the current research. Next, the design of the current research will be discussed.

Research Design

In the following section, four issues regarding the research design will be discussed: (a) Research Settings, (b) Interviewees of Research, (c) Data Collection, and (d) Data Analysis.

Research Settings

There were four organizations that participated in the present research: two senior service organizations (K in downtown Tokyo & R in a suburb of Tokyo), one municipal health center (U health center in Y prefecture), and one private hospital (N hospital in Y prefecture).

K is located in the center of Tokyo near a large university. The neighborhood consists of three groups of people: upper middle class, traditional family businesses, and downtown merchants or working class. R is in the suburb of Tokyo, an approximately 1 hour ride from the center of Tokyo. The neighborhood is made up of largely middle to upper-middle class. Both of the senior service organizations have similar service facilities: a skilled nursing facility (*Tokubetsu yougo roujin houmu*), adult day care, physical and occupational rehabilitation, and bathing (There are facilities to give baths to handicapped seniors. Also, several vans are equipped with special bathrooms to give baths to handicapped seniors during home visitations). Meal services are offered (both congregate and home delivery) along with respite services (short stay of the elderly at the skilled nursing facility). Staff is available for family counseling and instruction classes for caregivers. The development of both organizations was funded by the municipal and federal governments. Clients are required to pay a small fee for services, but most management costs are subsidized. Prospective interviewees were recruited through the social workers working for the organizations.

U health center is located in the downtown of U city, a mid-size industrial city in western part of Japan. The health center functions as the primary public health care center, where various screening tests for disease, vaccination, or various educational classes (i.e., maternity class, cooking class for healthful diet, marriage class, support group for family caregivers of people with dementia, etc.) are held as well as administrative matters for public hygiene (sanitary control for the food industry, etc.). Various types of health centers like U health center can be found throughout Japan and every area is covered by any one of them. Clients are basically everyone within the area covered by the health center, and all the services are offered either free or at a very low cost. Recruitment of interviewees was done through a public health nurse who was in charge of the consultation of caregivers and a caregiver support group that is held on a monthly basis at the health center. The public health nurse also introduced me to caregivers who were not attending the support group.

N hospital is located in the mountainous suburb of Y city in western Japan. It is a 40 minute ride from the center of Y city. N is a large, private hospital with 250 hospital beds, available only for elderly people who are chronically ill (either demented or bed bound) for the purpose of long-term care. There also is a special ward set aside for early diagnosis of senile dementia. In addition to the large in-patient wards, it also houses an outpatient area and adult day care setting. Because N is a private hospital, its clients have come from all areas in the western part of Japan, although the majority of clients are residents of Y city or the area around it. Interviewees were recruited through one of the doctors practicing there.

I was allowed to participate in various activities in the day care, bath service, instruction class, or support group meeting and to observe the caregivers' activities while serving as a volunteer or while visiting. Observations made in such settings helped me in the selection of possible subjects for study as well as to gain analytical insights.

Participants of Research

In the current research, only daughter and daughter-in-law caregivers were interviewed. This is because the care of elderly persons with dementia in Japan is most often undertaken by these family members. Since the percentage of female spousal caregivers in the total population is significant, research should be conducted among this group as well in the future. However, when looking at the meaning of the caregiving experience for the life of an individual, the subjective experiences of a daughter and a spouse are likely to show qualitative differences, and totally distinct pictures may emerge. This is because the relationships between the caregivers and the infirm relative are different, and the life stages of the caregivers are generationally differentiated. Similarly, there seems to be significant difference in the subjective experiences of male and female caregivers. For these reasons, only daughter and daughter-in-law caregivers were included in the present research.

The generational differences may create different perspectives about the meaning of the caregiving experience for each cohort. However, in this research, generation was not used to choose (or exclude) subjects. This is because daughter or daughter-in-law caregivers today may well belong to the marginal portion of pre-war and post-war generations; specification of one particular generation (either pre-war or post-war) could produce a serious reduction in the number of possible subjects. Therefore, the generational difference was captured and analyzed as a possible source of variation within the theoretical framework.

Another characteristic of the research subjects that may cause variation in the meaning of caregiving is the type and severity of dementia. For example, in Japan, the number of elderly with multi-infarct dementia is higher than that in the United States (Fukunishi et al., 1991). It is known from past experience that the distinction between

Alzheimer's disease and multi-infarct dementia may not always be clear to the family or even to the staff of K or R or the nurse at U health center. (The diagnoses of elderly people whose caregivers were recruited through N hospital were known to the researcher.) Therefore, in the current research, the type of dementia was not specified for recruitment of subjects, although information regarding this fact was collected whenever possible.

Research subjects were recruited from those who utilize any of the services mentioned earlier. The recruitment was done in either one of the following ways: (a) Based on participant observation and prior analysis of data, I selected the possible interviewee, then informed the social worker, public health nurse, or the doctor; whichever individual seemed to be appropriate. The social worker or the coordinator assessed the acceptability of the interview for the caregiver, and obtained permission from the caregiver for me to contact her with a letter of recruitment from me (Appendices A and B). When the caregiver agreed to listen to the explanation of the research, I approached her and explained the nature of the study; (b) The social worker, public health nurse, or the doctor, upon being told about my study and the range of subjects I was seeking, helped me select prospective interviewees and, upon their next contact with them, spoke to them about participating the research. Actual caregivers were contacted only after they had agreed to participate.

The nature and content of the interviews were fully explained prior to the meeting, but no written consent was taken. This is based on the suggestion of the Committee of Human Research at the University of California, San Francisco, that the interview itself is nonintrusive, and that the notion of written consent does not fit the common style of interviewing for Japanese people. In fact, requesting a signature of release can be perplexing and even threatening for some Japanese.

In grounded theory, subjects were selected using theoretical sampling (Strauss & Corbin, 1990). This means that interviews are planned either (a) to test the hypotheses derived from the prior interviews and analysis, (b) to fill gaps discovered in the emerging theoretical formulation, or (c) to find a case that goes against the emerging theoretical formulation in order to expand it (negative cases). Thus, subjects were recruited with these purposes in mind and according to my judgment about their appropriateness which was evaluated during the sequence of interviews. Practically speaking, however, it was difficult to select an appropriate subject through participant observation alone. Social workers or coordinators at the service organizations already are familiar with the caregivers through daily communication. Therefore, I consulted with social workers, the nurse, or doctor for their independent suggestions about selecting subjects, after carefully explaining the nature and goals of the research. This reliance on the information given by staff members at the organizations may not afford the best selection of subjects, but selection results were better than using my observations alone.

Twenty-six interviews were conducted with 26 caregivers. The demographic information of these interviewees is listed on Table 1, 2, and 3. There are 13 daughter caregivers and 13 daughters-in-law. Range of caregiver age was from 32 years to 63 years old, and that of care recipient was from 63 to 99 years old. Except for one person who was taking care of her father-in-law and one who was taking care of both father- and mother-in-law, all other caregivers were caring for female elderly persons (either mother or mother-in-law). Range of duration of caregiving was, according to their explanation, about 10 months to 13 years. Twenty caregivers were, at the time of interview, either living with the care recipient or living next door. One caregiver was taking care of her mother-in-law once every four weeks. Two caregivers were not living with their care recipients. Three caregivers had the care recipient in a long-term care facility, either for long-term care or due to a temporary arrangement.

At the time of interview, 13 caregivers were full-time housewives, seven were working for the family business, one held a part-time job, and five were working outside the home. Family businesses included such occupations as agriculture or automotive maintenance, which allowed them greater flexibility than those working outside the home. Occupations outside the home included an office worker, public official, and a college professor.

Interviews

Interviews for the current research were held between June 1, 1993 and September 20, 1993 in the areas of Japan specified earlier. Subjects who consented to participate in the present research set up time with me for the interview. Interviews were conducted in either the subjects' own homes or a private room at the service organizations. The interview was begun with a brief description of the research emphasizing that they could abbreviate the interview at any time. Demographic data regarding the caregiver and the care recipient were collected first since this was likely to uncover various caregiving contexts. Since it was expected that the caregiving experience would be differently perceived in different contexts. Demographic data were collected using a form (Appendix C). Some information, such as caregivers' and recipients' names and ages, was supplied by the service organizations. Examples of the type of information collected were: age of the caregiver and the care recipient, behavioral problems of the caregiver, religion of the caregiver, duration of caregiving, types of dementia (Alzheimer's disease, multi-infarct dementia, or others), and educational level of the caregiver.

The interview focused on the caregivers' subjective experiences of caregiving. Questions were of a "prompting" nature and designed to allow the interviewees to speak freely about their experiences occurred (Appendices D and E). Some modification of questions as the interviews accumulated, this is a customary procedure in grounded theory, where the ongoing analysis of data requires different types of

Table 1-1: Demographic Data of the Interviewees

ID	Caregiver (age)	Care recipient (age)	Diagnosis	Occupation (caregivers/ caregiver spouse)	Caregiver children	Siblings	Religion	Care arrangement	Miscellaneous
1	2nd yome (49)	Mother (89)	Alzheimer	Housewife/ banker	Living separately	2 brothers/ 3 sisters		Living together	Father-in-law also needs caregiving/ 13 years of caregiving
2	1st daughter (48)	Mother (81)		Independent business/ same	Living separately	1 brother		Living together	
3	1st daughter (63)	Mother (99)		Housewife/ Independent business	Living separately			Living together	Bedridden
4	2nd yome (50)	Mother (85)		Housewife/ Lawyer	2 daughters	1 sister		Living together	Bedridden
5	1st daughter (53)	Mother (78)	Depression	Housewife/ Office worker	1 son/ 2 daughter	2 brothers/ 1 sister	SGA	Living together	
6	1st yome (51)	Mother (80)	Vascular dementia	Independent business/ same	1 son	2 brothers/ 2 sisters		Living together	
7	1st yome (42)	Mother (75)	Alzheimer	Independent business/ same	3 (16/15/13)	2 brothers/ 1 sister		Living together	Old merchant family
8	3rd yome (58)	Father (93)		Housewife/ Office worker	Living separately/ 1 son/ 1 daughter	1 brother/ 2 sisters		Living together	
9	1st yome (56)	Mother (80)	Dependent dementia	Housewife/ Office worker	Living separately/ 2 daughters	2 sisters		Living together	Past experience of caregiving
10	1st yome (42)	Mother (82)	Alzheimer	Housewife/ Office worker	3 (16/14/11)	1 brother/ 1 sister		Living together	Very violent care recipient
11	1st yome (43)	Mother (78)	Alzheimer	Housewife/ Independent business	2 (14/11)	1 brother/ 1 sister		Living together	
12	1st daughter (61)	Mother (91)		Housewife/ Retired	Living separately			Living together	Living next door
13	3rd yome (53)	Mother (86)		Independent business/ same	Living separately/ 2 daughters	2 brothers/ 1 sister		Living together	Living next door
14	2nd daughter (48)	Mother (76)	Senile dementia	Independent business/ same	Living separately/ 1 (16)	1 brother/ 2 sisters		Living together	
15	1st daughter (40)	Mother (80)	Dementia	Office worker/ Independent business		1 brother	Catholic	Living separately	Recent marriage

Table 1-2: Demographic Data of the Interviewees

ID	Caregiver (age)	Care recipient (age)	Diagnosis	Occupation (caregivers/ caregiver spouse)	Caregiver children	Siblings	Religion	Care arrangement	Miscellaneous
16	1st yome (51)	Mother (80)	Alzheimer	Housewife/ Teacher	Living separately/ 1 daughter	2 brothers/ 2 sisters		Living together	
17	2nd daughter (44)	Mother (75)	Alzheimer	Office worker/ Independent business	3 (17/15/12)	1 sister		Living separately	
18	1st yome (57)	Mother (90)	Vascular dementia	Part time worker/ Public official	Living separately			Hospitalized	Husband living separately
19	1st daughter (51)	Mother (76)	Vascular dementia	Housewife/ Office worker	Living separately	2 brothers		Living together	Living with spouse's parents
20	1st daughter (51)	Mother (72)	Alzheimer	Agriculture/ Office worker	Living separately			Living together	*muko-iri*
21	1st daughter (57)	Mother (83)	Vascular dementia	Professor/ unmarried		1 brother	Catholic	Hospitalized	
22	1st yome (32)	Mother (63)	Alzheimer	Shop worker/ Independent business	3 (8/3/2)	2 brothers/ 1 sister		Hospitalized	
23	2nd daughter (45)	Mother (78)	Alzheimer	Independent business/ same	Living separately	1 brother/ 2 sisters		Living together	Past experience of caregiving
24	1st daughter (44)	Mother (69)	Vascular dementia	Housewife/ widowed	4 (18/15/12/10)	1 brother/ 1 sister		Living separately	Recently widowed/ Living next door
25	1st yome (55)	Mother (80)		Housewife/ Agriculture	Living together	1 brother		Living together	Bedridden
26	1st daughter (57)	Mother (84)		Public official/ unmarried		1 sister		Living together	

- "Mother" where yome is the caregiver means "mother-in-law."
- Children's age are written only when the child is under 18 years old.
- The number of children is written only when living together.

Table 2: Interviewees, by living arrangement

	Yome	Unmarried daughter	Married daughter	Total
Living together	9	1	7	17
Living next door	1	0	2	3
Taking turns among siblings	1	0	0	1
Living separately	0	0	2	2
Hospitalized	2	1	0	3
Total	13	2	11	26

Table 3: Interviewees, by organizations

	Yome	Unmarried daughter	Married daughter	Total
R (Senior Care Center)	4	1	3	8
K (Senior Care Center)	4	0	0	4
U (Public Health Center)	1	0	3	4
N (Elderly Hospital)	4	1	5	10
Total	13	2	11	26

questions as certain categories and theory emerged. Interviews lasted from one to four hours and were audio-taped and transcribed.

Analysis

Data collection, analysis, verification and the development of tentative theoretical explanations were undertaken concurrently. Analysis of initial data guided the subsequent sample selection and direction of further interviews. Analysis was performed according to the procedure developed and explained by Strauss and Corbin (1990) and Strauss (1987). A major analytical technique characteristic of grounded theory is the use of constant comparison. Simply stated, constant comparison involves comparing multiple events, meanings, and perspectives by constructing multiple codes and categories "to help the researcher to break through assumptions and to uncover specific dimensions" (Strauss & Corbin, 1990, p. 84). Major categories pertaining to the research phenomena are identified, and their relationships are formulated through the coding process using these and other techniques. The result is shown as a theoretical formulation of the phenomena being examined, in which multiple categories are shown in relation to one another.

Although it is ideal to collect and analyze data simultaneously in grounded theory approach, in this present study, part of analysis was necessarily done separately from data collection. This is because data were collected in Japan, whereas much guidance and feedback from other researchers and supervisors were received mostly upon return to the United States.

It should be noted here that in Japan communication proceeds in a different manner than in the US. In using the Japanese language, it is generally the case that "unexpressed" nuances and feelings beyond the explicit words are as important as the actual words themselves. Sometimes unexpressed messages, covertly carried through gestures, pauses or silence, are more important than spoken messages. (For more detailed discussion of this issue, readers are referred back to Chapter 2.) Practically, this means that a line-by-line coding of an interview might not have the same meaning in Japanese as in English. However, this distinction in no way negates the use of this coding. Rather, it could be said that analyses involving longer parts of interview data (i.e., one sentence or one paragraph) may be more consequential in Japanese than in English. Moreover, the observation of <u>non-verbal</u> signals, and the intuitive impression of the researcher regarding the interview, play a vital role in data analysis. The values of such intuitive insights were confirmed in subsequent interviews and were based on observations and impressions carefully written down in the field notes. These were later utilized in the analysis.

Verification

Several measures to ensure the rigor of the present study were taken. First, ongoing results were regularly presented to the staff members of each organization; feedback from the staff members was integrated into the analysis. This staff validation was taken as a substitute for member validation, since the actual caregivers were very busy and unavailable for this kind of feedback. Therefore, member validation was not attempted based on the discussion with staff members of the organizations.

Second, my decision-making trails in data collection and analysis were audited by other researchers skilled in the grounded theory techniques residing in and outside of Japan. These researchers advised me both on the evolving research design, and on the analysis and interpretation of data.

Researchers in Japan and in the Unite States had slightly different roles in data analysis, although they advised the present researcher equivalently regarding decision-making points in data collection. Researchers in Japan (Setsuo Mizuno and Yayoi Tamura) were available to help validate the interpretation and analysis of data based on their understanding of Japanese culture and language. This is of particular importance because I used speculation and imagination regarding unexpressed or between-the-lines portions of the interview data in the present research on Japanese caregivers. Audit from other researchers was essential to verify the analysis that relied on such a series of intuitive impressions.

Researchers in the United States had some limitations with regard to understanding the subtle nuances in interview data because of cultural and language barriers. On the other hand, American researchers (Margaret Wallhagen, Laura Reif, Frank Johnson, and Shizuko Fagerhaugh) assisted my data analysis by suggesting an American point of view. Some differences in possible interpretations by the American researchers highlighted underlying narrative and data analysis that were distinctive among Japanese. This cross-cultural perspective made the English translation of data and analysis more accurate, and illuminated the covert meanings otherwise hidden in the linguistic data and their analyses. Also, the American researchers assisted in developing theoretical explanations that were empirically grounded and made thus more accurately understandable for American readers.

Prologue (1) Definition of *Ikigai* and Its Variations

In the interviews with 26 caregivers, *ikigai* was defined in various ways. Demonstrating its vagueness, there are several variations in the caregivers' understanding of *ikigai*. Even one individual defined *ikigai* in several different ways. In a single interview, caregiving, in and of itself, was determined as *ikigai* at one point and not at other. On the other hand, there are several common features that characterize *ikigai*, and most definitions in the interviews touched upon these.

Common Features of the Definition of *Ikigai*

A commonalty that emerged from the perceptions of the term *ikigai* was the sense that it means certain life experiences and/or the positive emotion felt through those experiences. In addition, the experience, either as activities (source of *ikigai*) or as the resultant emotion (sense of *ikigai*), let the caregiver believe that her life was good, valuable, meaningful, and satisfying and that it was worthwhile to continue living because of the experience. *Ikigai* is encouragement to the person to live on; it is a "springboard for tomorrow" (Hideko). (All names used here are fictitious.) Moreover, *ikigai* is something worth struggling for so one does not have future regrets about their life: "I guess *ikigai* means something to encourage you to live on..." (Kaoru). "Courage to live. .... Enjoyment. .... Reason to live. Something makes you happy to live and keeps you going for many years to come. I think it is a different thing to a different person" (Yukiko). Although the emotion invoked through some experiences perceived as *ikigai* is "positive," positive does not necessarily mean "joy" to everyone. On the contrary, some experiences identified as *ikigai* by the caregivers are full of difficulty and negative emotion. Therefore, a sense of joy is not a necessary feature of *ikigai*. Rather, in order for an experience to be one's *ikigai*, it should be judged as meaningful, fruitful, and good in light of the person's own value system.

Throughout life, individuals continue to seek *ikigai* in any given situation. One's *ikigai* is changed over time, sometimes drastically, with changes in the environment. Many caregivers had trouble retaining their *ikigai* with the increasing demands placed on them due to their caregiving role and altered other activities to compensate. As their lives change, their self-understanding gradually changes over time. Since *ikigai* is continuously assessed by the changing self, the experience of *ikigai* also reflects the changed self-understanding. Consequently, activities in life such as caregiving, self-understanding, and the experience of *ikigai* are always influencing one another.

Points of Diversion in the Defining Characteristics of *Ikigai*

The experience of *ikigai* is difficult to capture objectively because it assumes the subjective judgment of its very existence. The individual's overall value system is the basis of the judgment and, therefore, what is designated as the source of *ikigai* will vary among people depending on their value system. Even the defining characteristics of *ikigai* also vary depending on the individual's value system. There are six points of contention in the defining characteristics of *ikigai*: whether or not it is indispensable, multiple, joyous, mundane, abstract, and conscious.

Ikigai as indispensable. For some caregivers, *ikigai* is indispensable in life; one must have *ikigai* in order to thrive. On the other hand, others say *ikigai* is unnecessary while there are many things to occupy their mind. Later in life, when there is less thoughtful activity, they believe they will be ready to pursue their *ikigai*. This relates to the question of whether *ikigai* is mundane or not which is discussed later.

Ikigai as multiple. Some refer to multiple life activities as their *ikigai*, while to others it is a single experience (e.g., raising children): "I guess there are many small *ikigai* when you think about it" (Yoshiko). "There are a lot (of *ikigai*). It may not be *ikigai*, but there are a lot. .... By 'a lot,' I mean, after all, about myself, about me, including now, and future, and about my children, and husband and wife issue..." (Kaoru). "I don't think it is single. So, *ikigai* is, it may be health of all family members, or if one likes cooking, it may be cooking. Various" (Rie). "Everyday if I know that Mother (care recipient) is doing all right, or something very trivial, that I am healthy and going to work, and I can have some relaxing moment with Mother. That's all I ask" (Megumi). When a single issue is identified as *ikigai*, it is often a philosophy in life rather than actual activities.

Ikigai as joyous. For some people, *ikigai* should accompany joy, and the sense of joy serves to encourage one to live on. When you enjoy and concentrate on something to the extent that the passage of time goes by unnoticed, it means you are experiencing *ikigai*: "I guess some enjoyment? The encouragement of life?" (Mayu). "My husband is not my *ikigai*, Grandma (care recipient)... I don't think she is my *ikigai*, I just take care of her because I have to. *Ikigai* means you are happy, doesn't it? That you feel worthwhile because you do it... I wonder what..." (Mayu).

For others, feeling joy at the time of the experience is not important; rather, the value of the experience itself--that one believes it a worthy life investment. This is the important feature of *ikigai* to them.

Ikigai as mundane. Many caregivers speak of double definitions of *ikigai*. This is because *ikigai* is found in mundane activities as well as higher aspirations that go beyond daily life. *Ikigai* is often captured as something mundane that currently exists in life while, at other times, *ikigai* is captured as something special that one invests one's entire life for. For example, the former may be daily activities such as feeding children, sewing, or caregiving, while the latter may be skillful arts such as painting or calligraphy. Many caregivers assign these two definitions to the word *ikigai*. As a result, one caregiver said that doing well in caregiving and child-rearing are her *ikigai*, but when she thinks of *ikigai* in terms of the latter definition:

> It (caregiving) is not all of my life, and it is not *ikigai*. But I don't know what is my *ikigai*... .... So I am trying to do many things. I guess by doing so, I hope to find something that I really want to accomplish or have to do. Then, that will be my *ikigai*. [laugh] Therefore, at moment I may be groping for my *ikigai*. Or, *ikigai* for me now may be to take care of Mother. May be it's not my only *ikigai*, but it could be one of them. (Naoko)

Ikigai as abstract. For some caregivers, *ikigai* refers to certain concrete activities while, for other people, a life philosophy is *ikigai*. To live a life one later deems as non-regrettable and/or fulfilled is portrayed to be one full of *ikigai*:

> *Ikigai*? Well, *ikigai*, I think *ikigai* is something you do, and you wouldn't regret it in the end. Something you feel good about when you look back... at the last stage of your life. (Rie)

Ikigai as conscious. Some caregivers have given much thought to their *ikigai*, while others disregard it almost entirely. It depends to some extent on the personal pattern of thinking and, for some people, the concept of *ikigai* is foreign and not a matter of daily thought: "I don't know. .... I really don't know. I have never thought about it" (Mayu). On the other hand, for some, the issue of *ikigai* is always a part of their thought, and what their *ikigai* is often questioned:

> Before, I was thinking a lot about things I would want to do when my kids were grown up, but I can't even imagine anything like that now. I guess now taking care of Mother may well be my *ikigai*. Sometimes I think so, but I sometimes still wonder what my *ikigai* is. (Emi)

How the Sense of *Ikigai* is Maintained

An important issue to examine in relation to the *ikigai* of caregivers is how *ikigai* experiences are actualized and maintained in their lives. In the interviews, there are two general tendencies. First, when everyday life is not difficult, the caregivers tend not to think about their *ikigai*. They perceive only vague satisfaction and fulfillment in life: "I feel I am having relatively a good life. I feel my life fruitful" (Yoshiko). On the other hand, caregivers who perceive difficulties or sense their tolerance limit, tend to think about their *ikigai*: "Sometimes I still wonder what indeed my life is (meaning "isn't it meaningless?"). Because my health is not so good, as you see, my feelings swing all the more" (Emi).

When everyday life is difficult, caregivers attempt to maintain *ikigai*, consciously or subconsciously, through identifying certain activities in life as the source of *ikigai*. Conversely, when everyday life is not difficult, people tend not to identify specific experiences as the source of *ikigai*. This phenomenon will be explained in detail in Chapter 6.

Prologue (2) Story Line:

Coming to Terms with the Reality of Having to Take Care

The findings are arranged to follow a story line that captures the caregiving experience. The story line is first explained. It is divided into four sections, and the following chapters discuss each part of this story in detail.

Essential Paradox: Values and Difficulties of Care (Chapter 4)

Due to the strong societal norms regarding filial caregiving and/or attachment to the care recipient, taking care of elderly parents or parents-in-law with dementia is highly valued by the caregivers. The caregiver role can constitute a major source of *ikigai* (worth in one's life) for a daughter or daughter-in-law (*yome*). On the other hand, the tasks of caregiving entail tremendous difficulties that often cause caregivers to reach their tolerance limit. As a result, the continuation of caregiving can threaten the caregiver's sense of *ikigai*, although the careless reduction of caregiver involvement level can also threaten her sense of *ikigai* available through the role. This is the essential paradox that forms the basic context of family caregiving in Japan.

Making Decisions in Balancing: To Reduce or Not to Reduce the Care-Involvement Level (Chapter 5)

When the difficulties of care begin to overwhelm the caregivers, there comes a point where their tolerance limit is reached, and they must decide whether they can reduce their level of care-involvement. In making this decision, careful assessment is made of the following three issues in order to avoid damage to the sense of *ikigai* available through the caregiver role by a careless reduction of their care-involvement level: (a) justifiability of the tolerance limit, (b) level of authority within the family, and (c) availability of outer resources. These three issues interact with one another, so balancing them is essential in the decision making.

The caregivers reduce their care-involvement level if: they can justify the tolerance limit to themselves, negotiate successfully with other family members in the given level of authority, and outer resources are available if needed. On the contrary, if the reduction of the level of care-involvement is considered to place the sense of *ikigai* available through the caregiver role at risk, the caregivers do not reduce the care-involvement level. At risk means either they cannot justify their tolerance limit to themselves, successful negotiation with other family members is impossible, or there are no available outer resources (when necessary).

Coming to Terms with the Reality of Having to Take Care: Maintaining Sense of *Ikigai* (Chapter 6)

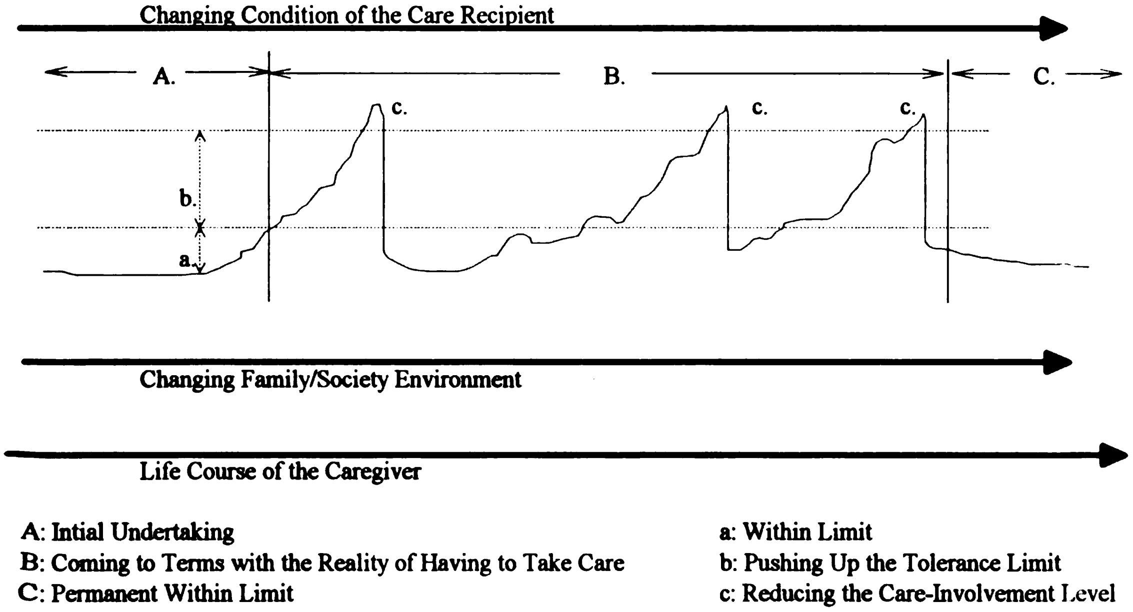
When caregivers reduce their care-involvement level, they can escape from their sense of tolerance limit, at least for the time being. When unable, they continue to take care in the same or gradually elevated care-involvement level, pushing up their tolerance limit. When doing this, the caregivers essentially accept the inevitable with the positive attitude of *shikatanai* (no way out) and *akirame* (giving in, accepting), modifying their perceptions regarding various dimensions of their lives.

The above decisional options seen in their management of the sense of tolerance limit accompany the caregivers' various attempts to maintain the sense of *ikigai*. When the caregivers are successful in reducing the care-involvement level, they find their *ikigai* in sustaining both the caregiver role and other activities they enjoy--in a good balance. When it is necessary to push up their tolerance limit, the sense of *ikigai* is maintained by identifying specific experiences in life as the source of *ikigai*, consciously or subconsciously. In doing so, caregivers constantly attempt to come to terms with the reality of having to take care. It is through such attempts that the caregiver's life, as well as self-understanding, gradually changes.

Trajectory of Caregiving: From Inception to Resolution (Chapter 7)

The overall trajectory of caregiving can be explained as follows (Figure 10): The caregivers take on the caregiver role for various reasons (initial undertaking; A. in Figure 10). As long as this role continues, they are constantly attempting to come to terms with the reality of having to take care (B. in Figure 10). In this attempts, the caregivers go around the three states of "within (tolerance) limit (a. in Figure 10)," "pushing up tolerance limit (b. in Figure 10)," or "reducing the care-involvement level (c. in Figure 10)." The caregivers begin within their tolerance limit, but as the difficulty of care increases, they are taken to the point of their tolerance limit and face the decisions surrounding reduction of their level of care-involvement. The caregivers

Figure 10: Three Stages in Trajectory of Caregiving
(created by the author)



typically push up their tolerance limit, and when the situation allows them to reduce the care-involvement level, they return to a state of within their tolerance limit. However, the gradual deterioration of the care recipient eventually takes the caregiver to another point of tolerance limit. This struggle lasts until the caregivers are able to stay within their tolerance limit permanently (permanent within limit; C. in Figure 10), either by the extensive use of outer resources or by physical deterioration of the care recipient.

Chapter 4: Result 1

Essential Paradox: Values and Difficulties of Care

There are several factors that interact to create the context within which caregiving is experienced by the daughter or daughter-in-law (*yome*) of a person with senile dementia in Japan. They are divided into two groups: (a) the intrinsic value placed on caregiving in Japan, and (b) the difficulties encountered in providing care. The purpose of this chapter is to discuss each of these factors.

Caregiving for impaired, elderly parents in Japan has high intrinsic value for two primary reasons: (a) There are societal norms regarding filial caregiving, and (b) the caregiver (daughter or *yome*) bears a sense of attachment to the care recipient. Because of the fundamental value assigned to caregiving in Japanese society, it is easily possible for a caregiver to perceive caregiving as a source of *ikigai*. The bases for the high value are explained. The value is sustained in many ways throughout the course of caregiving, and the methods used to retain value are also discussed. As an opposing force to the high value, caregiving also entails tremendous difficulties through multiple aspects of care. The types and development of difficulties are also examined.

Daughters or *yome* continue to take care in the context of an essential paradox: The caregivers face a constant dilemma between the value of caregiving and its inherent difficulty. There are three distinctive types in the caregiving contexts: contexts of *yome*, unmarried daughters, and married daughters. The differences among these distinctive types of caregiving contexts are summarized at the end of this chapter.

Caregiving as a Valued Activity

Caregiving of the elderly is valued highly for primarily two reasons: societal norms regarding filial caregiving and emotional attachments to the care recipient. The former is constantly reinforced within the Japanese society; the latter comes from the quality of private, interpersonal relationship between the caregiver and recipient. The type of relationship between the caregiver and recipient, in terms of either the daughter-mother or the in-laws, influences which of the two reasons contributes the most to the high perceived value of caregiving in any given situation.

Societal Norms Regarding Filial Caregiving

The Japanese place high value on caregiving of elderly parents due to their strong sense of filial responsibility. This is mainly derived from Confucianism, and although filial responsibility is also commonly seen among people in Western countries, the level of its influence as a societal norm seems to be much higher in Asian nations. Caregiving by women is also institutionalized in traditional Japanese society, especially for daughters-in-law (*yome*).

Traditionally, the first son's wife assumes the role of caregiver. Thus, currently, the majority of family caregiving of the elderly with dementia is reported to be assumed by *yome* in Japan (Association of Dementia Prevention & Mainichi News, 1991). In cases where a daughter (particularly the eldest) remains unmarried, she also can be a candidate for the role of caregiver. Where there is a wife to the first son and a single daughter, the family member responsible for caregiving becomes less obvious, and the decision is left to each individual family. On the other hand, daughters are considered to have left their original family when they marry. Therefore, the parents and/or children feel it is not appropriate that a married daughter takes care of her own elderly parents. These norms of caregiver selection constitute distinctive contexts of caregiving for the three groups of caregivers: *yome*, unmarried daughter, and married daughter, later summarized.

Respect for the aged. One of the teachings in Confucianism is respect for the aged: Elderly people, particularly one's own parents, are respected because of their seniority. Although the virtue of this respect is said to be lessened in recent years, the influence is still strong among Japanese people.

The concept of *on* (social debt) explains this Confucian idea of respect for the aged (Chapter 2). There are three types of *on* that work between the parent(or parent-in-law) and the child(child-in-law) (Lebra, 1976). One is direct reciprocity. This is more common among daughters than *yome*: The caregiver feels that much *on* from the care recipient has accumulated during her younger days, so she feels it is the time to reciprocate to her beloved mother. The direct reciprocity also accompanies the emotional drive to assign caregiving high value. On the other hand, if the care recipient was not a positive influence for caregiver as a child, this strong obligatory feeling does not exist.

A second type of *on* is indirect reciprocity. This is common among *yome* caregivers: The caregiver feels *on* toward the care recipient because the care recipient has given generously to their spouse. Therefore, on behalf of her husband and her love for him, the caregiver believes she is obliged to reciprocate:

> I love my husband very much, and after all she is my husband's mother. I have been thinking that way. I mean I wouldn't I take care of her if it weren't for my husband. Unless I love him, you know, I don't have to take care of her so much. (Kaoru)

Indirect reciprocity can also be perceived through the caregiver's children: Because the care recipient has been very kind and loving to the caregiver's children, the caregiver again feels obliged to reciprocate on behalf of her children. Another type of indirect reciprocity takes the form of substitution. For example, the caregiver may feel much *on* toward her own mother, but her mother has passed away at a young age. Therefore, instead of taking care of her own mother, the caregiver devotes herself to the mother-in-law. Similarly, the positive memory of the mother-in-law can encourage the *yome* caregiver to continue to take care of her father-in-law.

Finally, the influence of a belief in a generalized reciprocity between older and younger generations still remains in the Japanese society. In the rule of generalized reciprocity, even if you are not related to an elderly person, you must be respectful of them because they have contributed to the society you now enjoy.

Because the norms regarding filial caregiving have been institutionalized, the use of formal facilities was long stigmatized as filial neglect. This stigmatization remains in Japan today to a lesser extent, and constitutes a passive reason caregivers continue to take care. On the other hand, caregiving of elderly parents has been considered a virtue in Japanese society, and therefore, it brings good luck to the family. The virtue of caregiving is passed from generation to generation, and it constitutes a positive reason for continuing to take care.

Women's role in the family. In many families of the caregivers interviewed, there is a shared understanding of the division of labor between a husband and his wife, and this constitutes another societal norm. Taking care of domestic chores is in the role of the wife, while her husband is a breadwinner. Therefore, the status of housewife or *yome* tends to be considered an independent job of which hands-on caregiving is a part. The division of labor is taken for granted by some caregivers due to the accepted societal norm. As a result, many caregivers designate their role of caregiver as their *tsutome* (duty). Moreover, since the caregiver role is respected within the society, the *yome* (or daughter) is praised in the Japanese society when she is a successful caregiver. The norm is internalized by many caregivers to various degrees.

To retain family harmony and happiness is considered to be another role of the housewife. Therefore, the fact that caregiving of elderly parents makes other family members feel happy is another reason caregiving is assigned high value by the caregiver, especially *yome* caregivers. Additionally, one of the virtues of women, especially *yome*, is absolute obedience to their superiors and endurance. In this norm, *yome* caregivers tolerate the difficulties of caregiving with pride.

Patrilineal family (*ie*) and primogeniture. The belief in primogeniture and accompanying caregiver role of the first son's wife remains dominant in Japanese society although, officially, the inheritance law has been altered. As a result, many women expect that, if they marry the first son, they will eventually assume the caregiver role:

> I think it's because I married the first son, I was feeling a big pressure. I mean that I have to take care of my mother-in-law. Yeah. I had the idea that one day I had to take care of my mother-in-law. So without much trouble, I accepted my responsibility. (Toshiko)

Although there are families that do not pass on family property according to the norm of primogeniture, the inheritance of property and caregiving responsibility is often considered to accompany each other. If this does not happen, the neglected caregivers commonly have a sense of resentment toward the child who did inherit the property. They tend to believe that those inheriting the property should, at the very least, share the caregiving responsibility physically and/or financially.

Societal norm as a source of value. Where there are societal norms that value caregiving, the amount of difficulty indicates the goodness of the person as a woman, and most prominently, as *yome*. Most caregivers interviewed said with great smiles on their faces and without much hesitation, "It is so '*taihen*' (hard; difficult)!!" Their faces were brightened with pride. Obviously, in a way, the more difficult caregiving is, the more it is considered worth enduring. When the caregiving is perceived as almost completed, the caregivers can tolerate a maximum level of difficulty because what waits for them is the high honor and pride that comes with successfully accomplishing caregiving to elderly parents. Their pride of being good *yome* does not come from simply taking care of elderly parents; they must take good care of them. Therefore, the care recipient catching a cold is a great dishonor for a *yome*; others might think that her care is lacking. Akiyo says:

> She (care recipient) takes off all her clothes, and she becomes naked. So when it is cold, I try very hard to put clothes back on her, thinking it would be troublesome if I let her catch cold.

Generational difference. Depending on their age, people are influenced by, and internalize, traditional values as well as contemporary, Western values. As a result, the content of "societal norm" has a certain variation across generations, although the generational difference is not the only factor to determine the level of internalization of the traditional view.

The caregivers interviewed in this research can be divided into two generations: The mid-war generation; those born and raised immediately prior to, or in the middle of, the second world war, and the post-war generation; those born and raised after the end of the war. There is a categorization of the "pre-war" generation, commonly used to label those born and raised to young adulthood by the time war began. There are no caregivers presented in the current research who belong to this generation mainly because only daughter or *yome* caregivers were interviewed.

The mid-war generation tends to be influenced more by the traditional view of filial caregiving. Typically, this view is portrayed by a strong belief in the housewife's responsibility as caregiver, and this responsibility is perceived to be a life-long commitment: "It (caregiving) is my job, or rather a part of my job. We split the work (between the caregiver and her husband)" (Mayu). The post-war generation also accepts the responsibility as caregiver that comes from the cultural norm. However, the level of internalization is generally lower and the obligation of care is perceived to be fulfilled with less commitment. Toshiko says: "If this caregiving is obligation, four months of it would be sufficient. [Interviewer: "You mean after that is your *omoiyari* (sympathy/ thoughtfulness to others)?"] I think so."

Geological and familial differences. Societal norm of filial caregiving is also influenced by geological location. In general, caregivers in the rural, agricultural areas tend to have a more traditional view, while caregivers from urban, industrialized areas of Japan tend to be influenced more by Western views. However, depending on the specific needs and characteristics of the district, much variation is possible. For example, in an agricultural area, because of the need of female field labor, elderly parents in need of help are expected to be institutionalized immediately.

The type of family business or trade will also cause a difference in the expectations toward the *yome*, and is reflected in the caregiver's view of her own role. For example, in a traditional merchant family, all children are needed for the business and the married children, other than the first son, tend to keep close contact with the original, lineal family on a day-to-day basis. Other children are necessarily involved in domestic issues such as caregiving. On the other hand, in a traditional agricultural family, children other than the first son tend to marry into other families (i.e., family with daughters only) and the daily contact tends to be minimized. In this scenario, the influence of the other children in caregiving is weaker than described in the merchant family.

Attachment and Its Change

Attachment of the caregiver to the care recipient is also a source of caregiving value. Attachment here, means the emotional bond that the caregiver has toward the care recipient. The level of attachment is on a continuum from high to low. When attachment is high, the caregiver wishes to be with the care recipient and exerts much effort to improve the well-being of the care recipient.

The strong sense of attachment experienced by some caregivers, especially daughters, gives high value to caregiving and is the motivater for continued care:

> I wonder why I want to take care of her. I guess this stems from my relationship with Mother (care recipient) from my childhood. Although it was only for a short while that I lived with her, but how do I say, I guess I was closest to her. [quietly crying] .... So, I think I have kept that feeling all along. (Shinobu)

Where the emotional relationship between the caregiver and the care recipient is negative with a low level of attachment, caregiving is not given high value; on the contrary, it easily becomes a burden.

The basis of attachment is created from the historical interaction between the caregiver and recipient. In the case of daughter caregivers, it involves a life-long history. Therefore, whether the caregiver is daughter or *yome* is of primary importance in the level and quality of attachment. In addition, the attachment the caregiver has with the recipient prior to the onset of illness will naturally vary. A strong attachment is described by such words as "love," "*amaeru*," "*shitau*" (to adore), or "*natsuku*" (to take to). Many *yome* caregivers, especially those who had not lived with the care recipient long prior to the beginning of caregiving, feel a sense of indifference toward the care recipient. This lack of attachment is also experienced by some daughter caregivers. There are caregivers with quite negative emotions toward the recipients, which can be described as *uramu* (grudge, animosity).

The level and quality of attachment change over time in the course of caregiving. Although the past attachment relationship seems to influence the level and quality of current attachment strongly, it is also influenced by the daily interactions between the caregiver and recipient, as well as by the level of deterioration and types of problem behavior presented by the care recipient. Such changes in attachment over the caregiving experience are explained in the bereavement process and in the terms *amaeru* to *amayakasu* discussed below.

Bereavement process. A bereavement process is seen in the course of caregiving. In this context, it means a process in which the caregiver adapts to the gradual loss of her loved one. In the beginning of the bereavement process, the caregivers, especially daughter caregivers with a strong attachment, experience such a sense of loss that the caregiver cannot let the recipient go. In the final stages of the process, the caregivers come to a sense of detachment, by which I mean the caregiver can accept the deterioration of the care recipient and let her go. Indicators of detachment include acceptance of institutionalization as an option, and accepting the mortality of the care recipient.

The bereavement process is influenced by the level of attachment the caregiver has with the care recipient. With a high level of attachment, the loss of the loved one creates a strong emotional reaction causing lengthened bereavement. These caregivers try very hard to delay institutionalization of the care recipient, and efforts to seek cure and treatment are also extensive. For them, the day-to-day tasks of caregiving do not seem difficult when compared to the sense of loss. Their attachment to the care recipient causes some caregivers to allow physical fatigue and deterioration of their own health without even realizing it. Conversely, when the attachment is low, bereavement proceeds with relative ease.

The variation in the ease of bereavement is also explained by two factors: (a) the presence of other objects of attachment, and (b) achievement in caregiving. Some daughter caregivers who were married with children tended to accept institutionalization sooner than single daughters. This may be due to the existence of additional intimate relationship in the lives of the married caregivers. Regardless of the number of friends they have, single daughters view their mother as the sole giver and receiver of love in their lives. It is expressed in their view of institutionalization, as well as how long they want the care recipient to live:

> I never have hoped to be released from this problem after certain years. I never imagine being released so I could write my articles again, when I become alone and return to my previous state in a few years. I don't know how long more she is going to live, one year, or five years, but I want her to live ten years, or even longer. I want her to live as long as possible, and I am going to make any effort to make it happen. (Reiko)

On the other hand, one married caregiver says: "I often say to her jokingly, 'Please don't live too long, because we (the caregiver, her husband, and children) cannot enjoy our lives'" (Hideko).

Whether or not a caregiver actually institutionalizes the care recipient or not depends on many other factors, such as the availability of quality institutions and the caregivers' load of additional responsibilities. Some caregivers, though they want to continue to caregiving in the home, are forced to institutionalize the care recipient for financial reasons. That is especially the case for single daughters who must work outside the home for their income.

The other factor determining the ease of bereavement is the amount of care they have provided and the resultant sense of achievement. After caring for the recipient for quite some time and overcoming the problem behaviors, the caregiver seems to feel satisfied that the most possible has been done and is able to release the care recipient.

As the deterioration of the care recipients progresses, the caregivers repeatedly go through a cycle of loss and grief which constitutes the bereavement process. During this process, caregivers carefully observe the care recipient, constantly assessing the gradual loss of the care recipient's personality. When the initial attachment is strong, this observation is done intensively with strong hope that the caregiver has not lost the recipient completely. As Hatsue said:

> I guess her condition had already begun when she became very irritable. Sometimes she suddenly started to fret about something, and her denture popped

> out (because of the scream). I felt nasakenai (miserable), thinking "This is my own mother!" But recently, I talked to her for two hours. Then she said to me, "Oh, I didn't know I am doing such things lately. I have done such things! Oh, I am making myself a nuisance to you." It was mysterious, but from that remark I felt confident that there was something remaining in her. I wonder if there is something like human right [human dignity] left in her.

This demonstrates that caregivers experience a great deal of mood fluctuation, reflecting the observed level of their mother's(or mother-in-law's) deterioration. When the caregiver is relatively indifferent (low attachment), her observation and assessment are not accompanied by the strong sense of hope for remaining personality nor the emotional tribulation.

The bereavement process is also influenced by the speed of change in the care recipient's condition. If the deterioration of the care recipient is rapid, the sense of loss is felt strongly. If the deterioration is slow with various problem behaviors over a long period of time, loss tends to be sensed with less impact and bereavement progresses smoothly. The detachment that comes in the last part of the bereavement process shows the caregivers' adaptation to the loss of their mother figure. Hideko's remark exemplifies the state of detachment: "She (care recipient) has lived long enough now." The level of gradual acceptance of the loss also corresponds to their recognition and understanding of the illness, as well as the gradual mastery of problem behaviors encountered.

From *amaeru* to *amayakasu*. The quality of attachment also changes over the course of the caregiving experience. This qualitative change in the sense of attachment is largely related to the altered sense of power between the caregiver and the care recipient. Regardless of the level of attachment, until illness recognition occurs, the caregivers' power over the care recipient is generally low because of the seniority of the care recipient. However, with the physical and/or cognitive deterioration of the care recipient, this changes and the care recipient now senses less power and the caregiver more. Consequently, this causes a change in the sense of attachment.

The kind of indulgent love experienced by a younger person toward an older person is often called *amaeru*. This is the dominant emotion that a child has toward his/her mother. However, as dementia progresses, the caregivers gradually lose the person they can *amaeru*; the care recipient is first recognized as being ill; then she is thought to be childlike. The power relationship shifts and the daughter perceives her mother as someone she needs to take care of. In terms of the *amae* relationship, the caregiver gradually learns to offer the type of indulgent love that the strong often feel toward the weak and helpless: *amayakasu*. The sense of *amayakasu* is sometimes enjoyed by the caregiver as if she were taking care of a baby, and many caregivers derive high value from this type of attachment. Akemi says: "I feel like hugging her, she is *kawaii* (cute, endearing)." In this narrative, the image of the mother-in-law has changed from an independent adult person to a child.

Amayakasu is also often experienced by *yome* caregivers who tended to have less sense of *amaeru* when the care recipient was healthy. The *yome* caregivers can experience attachment through a different kind of relationship characterized by *amayakasu*. This relationship tends to occur <u>only</u> after the deterioration of the care recipient has become profound and the recipient childlike, and therefore, the sense of *amayakasu* tends to be increased in the course of caregiving.

An important point is that, even after extensive progression in dementia, the sense of *amaeru* still remains especially in the mind of the daughter caregiver, although it may show quantitative change. Megumi was emphasizing this point in stating that the authority of her mother is maintained above all else:

> Mother still holds the authority as a mother, so when I come home late, she gets mad, and questions me, "Weren't you by yourself? Weren't you scared?" I reply, "So-and-so gave me a ride" or "I was OK because I took a taxi." .... But

> she still worries about me very much. It is my mother's love. On such occasions, I say, "I am sorry I am late," "Thank you, Mom." That comes from dignity [my respect] toward Mother. You know, however she behaves other times, on such occasions, she becomes a typical mother. I think it is Mother's instinct that remains after everything else is gone.

Certain aspects of the mother-daughter relationship won't change in spite of the cognitive deterioration of the mother.

This section explained the variation of attachment and its changes over time. The point is that the sense of attachment in its various forms (i.e., *amaeru* and *amayakasu*) constitutes a fundamental value in care, and that attachment can be a primary reason to continue to take care of the elderly parent. The societal norms regarding filial caregiving and attachment together make it possible for Japanese caregivers to perceive caregiving as a source of *ikigai*. This does not mean that caregiving is a source of *ikigai* for everyone. Rather, it should be emphasized that caregiving in Japan has a fundamental value, perhaps more so when compared to the experience in the United States, and the value is high enough to be perceived as a source of *ikigai* for many Japanese caregivers. The high value assigned to caregiving is maintained and reinforced throughout the course of caregiving, and constitutes a major reason to continue care.

Sustaining the High Value Assigned to Caregiving

The high value assigned to caregiving is sustained through various ways throughout the course of caregiving. Following, the sustaining agents are categorized into three sources: the caregiver (cognitive processing and emotional drive), the social environment, and the care recipient.

High value from the caregiver herself--cognitive processing. Some caregivers cognitively (as opposed to emotionally) perceive that caregiving is worthwhile for two reasons. One is the societal norms regarding filial caregiving as explained in the former section. Another way to assign high value to caregiving through cognitive processing is related to the caregiver's personal principles and/or value system that agree with the societal norms regarding caregiving in a varying degree.

Each caregiver has her own views of life, aging, and death. Some give high value to caregiving because the experience agrees with their life view and philosophy. The source of this life view or philosophy is often religious belief, but is not limited to religion. The most prevalent life view held by the interviewees is the desire to live a life free of regret in the end. Caregiving is accepted as something they must accomplish. Therefore, failure to fulfill the role of caregiver is against their principle of <u>having a unregrettable (good) life</u>:

> I have experienced a lot so far. I sometimes wonder what my life is all about, or who I am. I really hope to lead such a life that I would contentedly say as M (a woman who became princess of Japan) might do that I had a wonderful life when looking it back at the end of my life. [laugh] Therefore, even if I didn't take care of her, I would find something I feel I should do. So I consider taking care of her as a part of my job I should do. (Naoko)

Another type of life principle is that one should remain committed to decisions made in life. Caregivers who are married to the first son of the family often referred to this principle: "No, I can't leave it. This is the life I have chosen, so I have to stay with it" (Naoko). For those who have strong religious convictions, to value the act of caregiving is out of their religion. Some religious thinking is also connected to the promotion of submission (*shikatanai*, *akirame*).

Sometimes new insights regarding aging and death, realization of the inevitability of human illness, aging and dying, and the fact that the caregiver and recipient share the destiny of aging and dying help the caregiver to sustain the high value of caregiving. How strongly the caregiver is influenced by these insights varies.

Some caregivers' insights related to aging and death are not so strong and they simply feel they became more interested in the issues related to aging and caregiving. Other caregivers are enlightened profoundly, and the issue of their own personality development becomes mentally salient:

> I think it is due to my wish to fully develop my own personality... As I study the field that in a way encompasses the theory of life-long education and pedagogy, I consider issues such as how people age, what you learn, and what is the life-long education, to be my own educational problems. The way caregivers, including myself, put ourselves in recipient's place reflects our view towards people. You consider how you educate yourself, and how define yourself. For that I have so much to reflect upon and to learn. (Reiko)

Each individual has a dominant principle that defines an acceptable life to them, and the extent to which it agrees with the societal norm of *yome* or filial caregiving varies among people. This level of agreement influences how they balance between what societal norms prescribe and what they desire for their own lives:

> No, I can't leave it. This is the life I have chosen, so I have to stay with it. But on the other hand, I want to be able to live my own life. My mother(-in-law)'s life is not synonymous to my life. So I want to do whatever I like, taking my future into consideration. I want to go to the United States one day. (Naoko)

The agreement between the societal norm and one's life principle affects how a caregiver understands her caregiving experience. For some, fulfilling their filial responsibility agrees with their life principle; then struggling with caregiving creates a sense of pride and fulfillment. The caregiving itself can be the basic source of encouragement in the caregiver's life. On the other hand, some people perceive their life as a caregiver as empty, even though they value the societal norm of filial caregiving. For such caregivers, caregiving is an inevitable obligation and they struggle to have a certain balance between caregiving and more highly valued activities in their lives.

High value from the caregiver herself--emotional drive. There are several types of emotional drive that sustain the high value of caregiving. One is various forms of attachment previously explained. Another is the sense of pity and sympathy. Due to the physical and/or cognitive deterioration of the care recipient and the reversal of authority between the caregiver and recipient, some caregivers begin to feel a strong sense of pity (*kawaiso, aware*) and sympathy (*omoiyari*, *itawari*) which sustains the high value of their caregiving. Often this sense of pity or sympathy is not felt by the caregiver until she sees the physical deterioration of the care recipient; when only a cognitive problem is present, these senses do not come into play.

High value from social environment. The social environment has various ways of sustaining the high value of caregiving. Encouragement, understanding, and appreciation from the spouse, other family members, neighbors, or staff of community services surround the caregiver. Such positive reinforcement allows the caregiver to feel good about herself, and this motivates the continuation of care. The attitude of the spouse is an especially critical determinant in the continuation of caregiving and the morale of the caregiver.

Encouragement, understanding, and appreciation can be direct words from others: "Whenever somebody urges me, 'Shinobu, *ganbatte* (hold out)!' I tell myself that I should hold out a bit longer. Such reconsideration took place many times" (Shinobu). Understanding can also be given through quiet listening to the caregiver's plight by patient family members. Encouragement can be shown in the form of direct sharing of the caregiving tasks among family members. Also, a good husband encourages the caregiver to be a good wife, particularly denoted by successful caregiving. It is a reciprocity:

> He (caregiver spouse) is such a straight person and I can rely on him, so I have been so happy with him. He doesn't play around, so I cannot complain. He is almost too good to complain. I think that is why I could have hung on until today. (Akiyo)

Such support from family may be influenced by the attitude of the caregiver, or it may originate from the general societal norm. The earnest attitude of the caregiver may move other family members to a supportive attitude toward the caregiver, or the warm encouragement of the family members may motivate the caregiver. There is no ready answer for which comes first. This type of phenomenon is mostly interactional, and they probably occur together.

Sharing of common difficulties also sustains the high value of caregiving thus motivating the caregiver to continue care:

> When I began to come here (the hospital and came to know about other family members) every month, gradually I began to be interested in the issue of dementia. And I began to realize only people who could understand my family situation were those dealing with same problem of dementia. So in that respect, coming here (hospital) once a month became something for me to look forward to. When I come here and talk, somehow I can have a positive outlook. I finally realized I was wanting to escape from the responsibility of caregiving if I could. However, in reality I couldn't find anybody to take care of her for me. So I thought if I could not avoid it myself, I had better learn more about things, such as what dementia is and how I can deal with it. I thought I had better learn about these things as long as I was going to take care of her, rather than just dreading it and trying to escape from it. (Chieko)

High value of filial caregiving is structurally sustained in the fact that filial caregiving is commonly practiced, and is formally acknowledged by society. These conditions reinforce the caregiver's internalization of the norm:

> In this city, those who are taking care of elderly persons are invited to a party once or twice a year. The local Rotary Club organizes it. .... I attended the party last June. .... I could meet other caregivers and we could become friends. The organizers of the party encourage us to do so. Also, the Department of Elderly Welfare of M city hosts meetings for caregivers. We talk about our situations and introduce ourselves, and I get to know people who are more *taihen* (difficult, hard) than myself. It's a meeting to encourage each other. (Mayu)

Another source of high value is that the caregivers' children, living with the recipient grandparents, are being positively influenced. Unlike other young people without the experience of living with the older generation, their children have *omoiyari* (sympathy; thoughtfulness to others), gentleness, or independence. However, this influence on children is not always perceived as positive when the care recipient is belligerent and the caregiver is hurt.

Lastly, high value of care can be sustained by a negative feeling toward others; the resentment toward unsatisfying support from other family members and/or formal organizations creates a fighting spirit (*iji*) and energy in the caregiver: "Probably it is *iji* (to get stubborn and have strong will power). Because they (other family members) didn't help me... Then I thought I will show them how I could do it" (Shinobu). Hence, the caregiver is further determined to protect the care recipient and continues to take care however necessary, <u>because nobody but she would take care of him/her well enough</u>.

<u>High value from the care recipient</u>. Some caregivers are encouraged by the care recipients themselves. One source is the expression of gratitude, appreciation, and other exchanges between them:

> Recently, Mother often says, "Oh, I took a bath today, thanks to you. I appreciate that." It may sound strange, but I am glad I am told such a thing.

> When I see Mother like that, I strongly feel like responding to her and I can be very honest about such a feeling. Yeah, a quite sincere and straightforward feeling. She is trusting me that much, 100%. I guess our relationship of parent and child has been reversed completely. (Michiko)

Conversely, spiteful words or behaviors from the care recipient, even if the caregiver recognizes that it is due to the illness, strongly discourages the caregiver.

The improvement or maintenance of the care recipient's condition is another factor that sustains the high value of care by creating a sense of achievement:

> I complain, "Oh, I'm tired." I complain, but I can also feel satisfied with the feeling of "I am tired." I can feel, "Oh, I have done so much." I can say to myself, "Good job!" [laugh] I can say, "I have done a good job today!" [laugh] "I could have managed things well today, without any accidents." And, I can think, in the morning, "I will try to make today well!" [laugh] I may be able to do this (caregiving) because I think simple and straight. (Naoko)

<u>Detrimental effect of the high value assigned to caregiving</u>. As examined above, there are various sources that sustain high value of filial caregiving in Japan. It should be mentioned that, if caregiving is overvalued, it can be detrimental to the physical health of the caregiver. Some caregivers with physical problems, even life threatening ailments, are still unable to reduce their care-involvement level because of the high value they assigned to caregiving. Similarly, although the societal norms can motivate caregivers in an effective way, they also can be a source of threat to the caregiver when the difficulties in care begin to overwhelm, or when the high value assigned through the societal norm is not greatly internalized. Too many expectations from other family members, as well as neighbors, and the fear of failing these expectations, can be a new source of difficulty in caregiving. Some caregivers cannot justify their

tolerance limit to themselves because of the fear of sanction that their own children will do the same to them:

> I somehow think that, if I do such a thing (like saying NO to caregiving), it would come back to myself. If I show such an attitude, my own children might take the similar attitude in the future. It would come back to me. I guess it is old-fashioned way of thinking. I really believe that things would go that way. .... If I do such a thing, I think I would be thrown away in the same way. I strongly feel so. (Hiroko)

The relationship between high value and sanction is similar to what is known in stress theory: Too much stress is threatening and detrimental, but a certain level can be viewed as a challenge and can elevate one's morale.

Difficulties (*Taihen*) in Caregiving

In much of the research on caregiving, various difficulties in caregiving have been conceptualized as burden, and the content of this concept has been elaborated (Chapter 2). However, what I found through the interview data is slightly different from what the word burden implies. Most caregivers used the word *taihen*, in one way or another, to describe their caregiving experience. In Kenkyusya's Japanese-English dictionary, many English words are shown as translations of *taihen*: serious, grave, horrible, awful, awesome, enormous, and so on. Literally, *taihen* is a combination of two Chinese characters that mean big and change, and it describes positive as well as negative changes in daily life. In this sense, *taihen* does not correspond to the English term burden which has a completely negative connotation. When the caregivers say, "(caregiving) is really *taihen*," it means how enormous the difficulties are that they are experiencing, but these difficulties are not always considered only negative. Therefore, rather than burden, the term difficulty will be used as a translation of *taihen*.

Four types of difficult caregiving experiences are explained with their changes over time and their influencing factors: (a) difficulties in interpersonal relationships, (b) difficulties in constriction in life, (c) difficulties in personal resource exhaustion, and (d) difficulties in the disturbance of self-ideal. Each type of difficulty changes over time in different ways, depending on the different conditions of caregiving. These difficulties are examined in order to explain the paradox that caregivers experience when these occur in juxtaposition with the high value of caregiving.

Any one experience can include multiple types of difficulties. Also, the difficulties are experienced in various contexts, so similar phenomena are experienced differently by different caregivers. For example, soiling and wetting of the care recipient was described to cause much physical exhaustion to a caregiver, while the same problem presents a tremendous sense of loss of the loved one by another caregiver. Also, the difficulties do not exist separately but together they affect the caregivers and drive them, eventually, to the point of their tolerance limit. They feel they cannot continue in the same caregiving arrangement. Having reached this point of tolerance limit, they feel their sense of *ikigai* is seriously disturbed and that changes are necessary to restore it so care can be continued.

Difficulties in Interpersonal Relationships

The difficulties that arise from interpersonal relationships can be divided into two groups: (a) difficulties that come from the care recipient, and (b) difficulties that come from other family members/neighbors. Difficulties that come from the relationship with the care recipient include: (a) sense of loss, (b) power relation change, (c) *enryo/kizukai* (uneasiness), (d) frustration, (e) fear, (f) animosity, and (g) being depended upon.

Sense of loss. The sense of loss discussed here is the grief over daughter's personal loss of a loved mother (or mother-in-law) (*shitau*), to whom she was allowed

to be indulgently dependent (*amaeru, natsuku*), and who loved and recognized her. This particular type of sense of loss was often described with such words as *nasakenai* (miserable; wretched). This sense of loss should not be confused with that related to mourning for the deteriorating care recipient as a person. The latter sense of loss is closer to the pity or sympathy discussed in the section on value of care. Generally, the higher the attachment of the caregiver to the care recipient, the stronger the sense of loss. Therefore, this intense experience is more common among daughters than among it is daughters-in-law (*yome*).

Loss is different from other areas of difficulty in that it does not accumulate and contribute to the formation of tolerance limit by the caregiver. On the contrary, the sense of loss can make the caregiver insensitive or blind to physical exhaustion or constriction of her life. The change over time in the sense of loss is also different from the patterns of change seen in other types of difficulties such as physical exhaustion which accumulate over time. Loss does not accumulate; instead, there are certain fluctuations as the care recipient's condition deteriorates. The level of the sense of loss can be decreased as the caregiver adapts to the altered relationship, whereas physical exhaustion tends not to be decreased without certain changes in the caregiving arrangement.

The sense of loss is felt every time the caregiver faces the deterioration of the care recipient. It can also be felt indirectly as seen in the suffering of caregiver children during changes of their grandparent which can be a source of difficulty for the caregiver.

<u>Power relation change</u>. The difficulty of power relationship change includes various issues that arise as the care recipient deteriorates. Certain power relations are always present in human interactions. Specifically, as referred to here, power means the following five types of perceptions that are at work in the interactions between the caregiver and the recipient:

1) The sense of ability of the care recipient, as is perceived by the care recipient, to control his/her own actions (care recipient nominal autonomy);
2) The sense of ability of the care recipient, as is perceived by the caregiver, to control his/her own actions (care recipient substantial autonomy);
3) The sense of ability of the caregiver to control actions of the care recipient (caregiver authority over the care recipient);
4) The sense of ability of the caregiver to control her own actions (caregiver autonomy; only in relation to the care recipient);
5) The ability of the care recipient to control the caregiver's actions (care recipient authority over caregiver; again, only in relation to the care recipient; other family members may claim power to control the care recipient's actions).

The perception of the care recipient's autonomy often differs between the caregiver and care recipient, and therefore the distinction is made between care recipient nominal (1) and substantial (2) autonomy. In a caregiving situation, the care recipient nominal autonomy is often higher compared to the substantial autonomy perceived by the caregiver. The care recipient's sense of autonomy is preserved, while, in reality, the caregiver controls the care recipient's autonomy to a large extent.

These power relations undergo major changes as the illness of dementia progresses. A basic rule is that, as the care recipient ages, their authority over the caregiver begins to decline; hence, the care recipient's autonomy also gradually declines. Conversely, the caregiver's autonomy begins to increase over time, as well as their authority over the care recipient. Although this change begins even prior to the onset of dementia, the process accelerates as the disease of dementia progresses. The process of this reversal of power, and the difficulties derived from the change of power, is qualitatively different between *yome* and daughter caregivers although some parts of it are shared by them both.

For many *yome* caregivers, the deterioration of the care recipient's power can simply mean that the long-awaited increase in their own power has occurred, and therefore, does not necessarily result in a strong sense of loss. The status of *yome* is expected to be low at the beginning, and they endure the period, waiting. Kaoru said: "Once my brother lamented over my situation, saying that I was abused. I said to him, 'Please wait, brother. Eventually my time will come'" (Kaoru). In this circumstance, *yome* caregivers tend to show little difficulty in accepting this shift. The decline of the care recipient autonomy, as well as their authority over the caregiver, often accompanies the decline of the care recipient's power over the overall management of household matters. Thus, the status of the *yome* within the family is finally established when the matriarch of the former generation has lost her power.

Daughter caregivers often take over the power of their mothers very reluctantly. To begin with, daughter caregivers are not greatly troubled by the care recipient's authority over them because it often implies the love and caring the care recipient has for them. They enjoy and treasure the care recipient's authority, even when the care recipient's cognitive ability is profoundly deteriorated. For daughter caregivers, the power decline of the care recipient corresponds to the gradual loss of their mothers, and the tendency is to deny the care recipient's declining ability to be autonomous.

There is a strenuous time period for both daughter and *yome* caregivers during the power relationship change. It is when the care recipients believe that they still have control over their actions, while in reality their actions should be controlled by the caregiver because of their deteriorating cognitive ability. The caregivers need to make great effort to preserve the care recipient nominal autonomy, which is not always easy.

This period seems to be more strenuous for *yome* than for daughters because *yome* caregivers generally need to keep a respectful attitude toward the care recipients more strictly than daughter caregivers. This requirement of *yome* to be respectful to her parent-in-law causes much difficulty for them: The care recipient does not let go of her autonomy, while the caregiver needs to have higher authority over the recipient, even if only to protect them from injury. As a result:

> If I could have a choice I would rather work in the factory (than to take care of her mother-in-law). That kind of work does not make me think. You just mindlessly take care one task after another. As for Grandma (my mother-in-law), she is a person with her own personality. She is not a child, and she is more difficult. A baby would be far easier to take care of (than my mother-in-law). (Akiyo)

Both *yome* and daughter caregivers use elaborated strategies to maintain the care recipient nominal autonomy. In other words, the caregivers try hard to control the care recipients' problem behaviors without their awareness. Examples of this in practice are: secretly washing dirty dishes after the care recipient washed them, and letting the care recipient work in the family factory making small parts, knowing that more than half of the products are unusable.

Enryo/kizukai (uneasiness). *Enryo* means reservation and deference that is most prominently seen among the behaviors of the caregiver when her interactant is either (a) of higher authority than the caregiver, or (b) unfamiliar to the caregiver. Being with the care recipient causes, therefore, *enryo* to the caregiver. Additionally, she also would have *kizukai* (to spend much energy; worry about) to attend to the recipient's needs. As a result, the caregiver feels uneasy and awkward. Neither *enryo* or *kizukai* has a negative meaning by themselves, but the person would feel this sense of uneasiness and tired; hence, *enryo* is perceived as difficult.

Typically, no matter how long a *yome* caregiver lives with the care recipient, there is still a feeling of uneasiness in front of the mother-in-law because of *enryo* and *kizukai*:

> I feel that she (care recipient) is a *daijina oazukari-mono* (something very precious who is entrusted to the caregiver). If she were my own mother, I

> could be more relaxed about the situation, but because she is my mother-in-law, I feel as if she was entrusted to me, so I *ki-wo tsukau* (worry about) all the more, I have to be attentive. (Akiyo)

Daijina oazukari-mono means that the care recipient is perceived as something very precious entrusted to the caregiver. The treasure (the care recipient) does not belong to the caregiver, therefore, the caregiver does not have authority over the recipient (lower power relation); yet the caregiver has full responsibility for the care recipient's safety and well-being. Although these words, *daijina oazukari-mono*, are used only by this caregiver, it articulates the sense of uneasiness that many *yome* caregivers experience.

This sense of uneasiness for *yome* is most intense during the initial phase of marriage because the authority of the mother-in-law is highest at this time. The longer they live together, the higher the familiarity and the level of uneasiness gradually declines. Consequently, those *yome* caregivers who began to care for their parent-in-law soon after marriage tend to have more difficulty in this area. As time passes and the illness of dementia progresses, the power relation changes and there is a corresponding decline in this sense of uneasiness.

<u>Frustration</u>. Many caregivers suffer from frustration caused by various problem behaviors: Newly cleaned linens are soiled, the bath is filled with water used for laundry, or the toilet bowl is stuck with toilet paper. This constitutes a new type of difficulty, and depending on the problem behaviors of the care recipient, frustration can gradually increase. The mounting frustration can bring on an uncontrollable emotional explosion, during which the caregiver behaves aggressively toward the recipient, screaming or being very harsh.

Some caregivers are profoundly disturbed by their own explosion sensing a strong feeling of guilt which brings additional difficulty to the caregiver. Other caregivers define their explosion as emotional venting and believe it is inevitable and acceptable because the care recipient does not remember. Depending on the level and types of problem behaviors, such explosions are often repeated, regardless of how much the caregiver regrets the ordeal.

Frustration is particularly strong when illness recognition has not been reached by the caregiver. However, even when the caregiver recognizes and understands the nature of dementia, problems in daily life still can continue to promote frustration, unless the caregiver can find effective ways to deal with the care recipient to prevent this specific problem. The frustration is strongest when the problem behavior is aggressive and is aimed at the caregiver:

> Even if she suffers from the same dementia, if she (care recipient) were bedridden and is always saying, "Excuse me, I am causing you much trouble..." or something like that, it would be worth caregiving. My children and I could do it together, wanting to take good care of Grandma together. We could have that *omoiyari* (sympathy). However, nowadays, even the feeling of *omoiyari* is dissipating. If you are screamed at, hit, and bitten, then you cannot think in that way. (Toshiko)

The caregivers gradually learn how they can deal with problem behaviors, but harsh remarks and aggression still hurt their feelings and frustrate them.

Accusations by the care recipient never occurred toward daughter caregivers in the current interviews; rather, the object of accusation was someone outside the home (i.e., in-laws or neighbors). On the other hand, many *yome* caregivers have the experience of being accused by the care recipient. This may be related to the basic trust the recipients have toward daughters compared to *yome* caregivers.

Frustration can also arise from long-standing discord between the caregiver and the recipient. Frustrations due to problem behaviors and relationship problems are often inseparably intertwined and the distinction is not necessarily clear. The quality of the relationship between the caregiver and the care recipient prior to the onset of dementia strongly influences the level of caregiver frustration from problem behavior as well.

Fear. Some problem behaviors are particularly aberrant, aggressive, and unpredictable, which create a sense fear in the caregivers.

Animosity. If the former relationship between the caregiver and recipient was negative and caregiver animosity exists toward the recipient, the prospect of caregiving comes with a sense of burden and despair. Caregivers are not motivated to take care of someone they dislike. Daughter caregivers tend to tolerate with greater ease, because long-standing animosity that is often witnessed between *yome* and mother-in-law is not very common between daughter and mother.

Being depended upon. Often the care recipient, due to their deteriorating memory, develops a strong dependency upon one particular person. The care recipient follows the caregiver everywhere and no one else is acceptable substitute. If the caregiver does not have strong attachment and feels uneasy toward the care recipient, the difficulty of dependency exists:

> I would be grateful if she could forget me. I think it would be good if she wouldn't recognize me at all. But she still can't let go of the thought of me. She is always thinking, "Sister (caregiver is called "sister"), sister." Unless she forgets "sister," I get so exhausted around her. I am the only one special to her. It's heavy. It's so heavy, heavy. I want her to forget me, but she won't. .... Although there are five siblings, she only leans on me. (Akiyo)

Another area of interpersonal difficulty is with other family members and/or neighbors. One of the ways researchers have documented this concept is in the context of family conflict (Semple, 1992), and it represents a major cause of difficulty in caregiving. This type of difficulty is categorized into three groups in the discussion below: (a) differences in understanding/views/opinions regarding caregiving, (b) isolation, and (c) conflict of interest.

Differences in understanding/views/opinions regarding caregiving. It is often the case that the caregivers and other family members and/or neighbors have different understanding/views/opinions regarding caregiving, and these differences cause difficulty for the caregiver, especially when the caregiver is *yome*. The first cause of major difficulty for the caregiver is family members with limited recognition and understanding. Family members, without recognizing the care recipient's illness, sometimes believe a recipient's accusation against the caregiver and worse, accuse the caregiver along with the recipient. Other family members' limited knowledge on managing the person with dementia can also introduce greater difficulty with their careless approach to the care recipient.

Illness recognition and understanding are influenced by the length of time spent with the care recipient. Therefore, illness recognition of those blood relatives not living with the recipient tends to be lower than that of the caregiver who has daily contact. Additionally, many *yome* caregivers speculated that blood relatives, including their husbands who live with the care recipients, do not recognize the extent of the care recipient's problem due to psychological denial out of the strong attachment they have with the recipient. Other conditions that hinder illness recognition are: When the care recipient's behavior change occurred slowly, and when other family members do not have prior experience or knowledge of aging and dementia.

Once other family members begin to recognize the care recipient's illness, some of the caregiver's difficulty can be resolved in areas such as false accusations or effective communication with the care recipient. However, the caregiver's resentment against other family members tends to remain or even increase over time. The relationship discord between the caregiver and other family members can have long-lasting consequences in the later life of all concerned.

The second cause of difficulties arises from the caregiver having no control in the decision-making process regarding caregiving, such as outer resource mobilization, because other family members claim higher authority. The caregiver and other family members sometimes have different views of their authority level in caregiving and an authority struggle commences.

Third, if a caregiver's belief on other family members' responsibility in caregiving is different from that of other family members, the caregiver may experience a strong sense of resentment toward other family members for their unsatisfactory support. This can be experienced by both daughter and *yome* caregivers.

Even when the above differences between the caregiver and other family members are gradually resolved, there remains an essential difference that is hardly ever overcome for *yome* caregivers. That is, the parent-child attachment is qualitatively different from the type of attachment that a *yome* has with her in-law, and what the *yome* perceives reasonable as caregiving may not match other family members' perceptions due to this difference in the quality of relationship. When this difference becomes salient, the reconciliation between blood relatives and the in-law caregiver is rarely possible concerning this issue. Chieko describes an episode of her mother-in-law wandering out with her infant grandchild and found missing:

> At that point, I thought I couldn't continue any longer. I thought I couldn't take care of her any more. .... There wasn't any talk about it (discussion about institutionalization) among my (siblings-in-law) at all! There was no sympathy toward me, "You must have been concerned." All they said was they felt relieved that Mother had been found. There was little concern about my feeling as a mother whose child had been also missing. They were so preoccupied that they only talked about not letting her wonder out again. My husband reacted the same way as they did.

This narrative exemplifies the fundamental cleavage which the *yome* caregivers often face.

"Family boundary". The concept of family boundary is useful to explain difficulties that arise from other family members. Family boundary means the degree to which the stem family (composed of the care recipient's generation, the caregiver's generation, and the caregiver's children) is influenced by other members in the extended family (i.e., siblings(or siblings-in-law) of the caregiver and of the care recipient). Here, the exchanges include material, financial, informational (communication), and authoritarian. There is much variation on the amount of exchange the caregiver (and her husband) had with other family members, and it caused a variety of difficulties for the caregiver.

Some families have strong and clear family boundaries (e.g., agricultural family). The responsibility for, and authority over caregiving is concentrated on the stem family and especially on the caregiver. In this situation, the caregiver is free from the difficulty caused by the decision-making authority claim from other family members, and she and her husband can control the caregiving situation without much friction. On the other hand, the caregiver experiences difficulty when the caregiving becomes very demanding and she desires help from other family members, because the expectation from other family members is that the caregiver should be able to manage caregiving without their support.

Where the family boundary is weak and unclear (e.g., traditional merchant family, modern nuclear family), responsibility for, and authority over caregiving is more dissipated across the extended family. There are frequent and various kinds of exchanges across the boundary. Here, the caregiver's major difficulty is handling the authority claim by other family members. The caregiver cannot control the caregiving situation and must negotiate with other family members every time a modification in the caregiving situation is needed. On the other hand, she feels greater ease in asking for supports when they become necessary. However, in such a case, the caregivers tend not to have strong belief that they should be the sole caregiver, and therefore the frustration of "Why should only I have this much of difficulty?" may cause strong resentment against other family members, if they refuse to help the caregivers.

Married daughters experience a different difficulty with the issue of family boundary. For them, the family boundary is between themselves and the care recipients because they have married outside their families of origin. They suffer the sense of guilt for their married family for crossing the boundary and caring for their own parents:

> My husband does not mind cooking, so when he comes home early, he sometimes cooks for both of us. But if I repeatedly come home late, say around nine, and prepare dinner, and we eat around ten o'clock, his (caregiver's husband) frustration gradually accumulates. Then, he starts to complain to me. I'm the only one he could vent his frustration on, and he makes me feel pressured, saying something like, "Can you do anything about it?" Rationally he understands, but he feels that our day-to-day life is becoming un-natural. His thought wonders from time to time [laugh], but occasionally his frustration becomes visible. [interviewer: "What do you say in such occasions?"] Well, I say, "But, it is *shikatanai*. There is nobody else to take care of her. I wish things are better." And I apologize abjectly to him while wondering if anything can be done. (Michiko)

Isolation. The sense of isolation occurs out of the caregiver's inhibition of disclosing her difficulty due to her *enryo* (reservation, deference) toward her husband, other family members, and friends. Caregivers often carefully conceal deterioration of the care recipient from the recipient's blood relatives because they would avoid hurting them by revealing the problem behaviors. As a result, they cannot confide to other family members how terrible the caregiving experience is, and they are caught in the dilemma of wanting others to understand their difficulty and *omoiyari* (sympathy, thoughtfulness to others) toward other family members.

In the case of daughters, they feel they cannot complain about their difficulties in caregiving to even their husband because their caregiving is not socially prescribed as much as caregiving by *yome*. This inability to talk with other family members leads to the sense of isolation. As the difficulty of care increases, caregivers gradually begin to reveal the problem to other family members, but the inhibition to talk about problem behaviors continues to cause a sense of isolation to a large extent.

The caregivers cannot talk to their friends either. Those who have not lived with an elderly person with dementia cannot understand the experience, and listening may cause them to be uncomfortable:

> There is nobody but me. Even if I tell my friends about such a thing (about caregiving), they don't (understand). People who with the problem of taking care of a person suffering from dementia can emphasize, but those who never had such an experience don't know how to respond to me. They can only say to me, "Oh, it must be hard." After all. When I go out with my friends, even if I know that I could feel a little better by talking about it with them, I can't do that. If I do, our cheerful conversation turns gloomy and my friends cannot think of a word to tell me. So I only talk about it jokingly and convey it like a funny story. Then it becomes hard to tell anybody. <u>I keep everything to myself, and I feel sorry for myself all the more</u>. (Kaoru)

The sense of isolation may also be felt in relation to their own children. Children of the caregiver are often a source of encouragement and understanding but when they are not, the sense of isolation is felt. Isolation also comes from the physical absence of the caregiver's husband. The husband may be transferred to a remote city and the caregiver has to live alone with the care recipient. In such a case, the sense of isolation becomes particularly strong enough to reach the sense of tolerance limit, and the caregiver may resort to institutionalization of the recipient.

Conflict of interest. Many caregivers experience the dilemma of dealing with different parties with conflicting interests. Here, the conflict is experienced within the caregiver; she has difficulty in determining which party should be attended to. This is different from the authority struggle where opinions differ between caregiver and other family members. The number of parties in the circle of the dilemma seems to be larger among married daughter caregivers because of the presence of a spouse and in-laws, although conflict of interest is a common difficulty shared also by single daughter and *yome* caregivers. Usually caregivers attempt to keep a balance between interests of different parties, but often there is not an easy answer, hence the difficulty.

There are various types of conflict of interest in caregiving. First, the interests of the caregiver and the care recipient can be at odds. Although the good condition of the care recipient is satisfying to the caregiver and, although this constitutes the fundamental value of caregiving, caregiving also deprives the caregiver of mental, physical, and financial resources. Second, other family members constitute another party with interests that often conflict with the care recipient's. Caregivers sometimes feel the problem behaviors of the recipients are harmful to the caregivers' children, or enough attention is not being given to the children. Third, problem behaviors can involve people in the neighborhood. Examples include the care recipient accusing a neighbor of robbery, eating out without having enough money to pay, or screaming and making noise embarrassing to the caregiver. Especially when the problem behaviors are against social rules, the caregiver experiences much difficulty in resolution of the problem.

Difficulties in Constriction in Life

The caregiving responsibility often occupies much of the caregiver's daily life and constricts other activities. There are three types of difficulties related here: (a) time constriction, (b) financial constriction, and (c) spatial constriction.

Time constriction. When caregiving is time-consuming, the caregivers often give up other activities due to their caregiving responsibilities, such as traveling, eating out, and other family enjoyment as well as individual activities such as tennis, dance, PTA meetings, or work outside home. This constitutes a major difficulty.

Fitness of caregiving to the life stage of the caregiver. One important condition influencing the difficulty of time constriction is whether caregiving fits the life stage of the caregiver. In the caregiver's life course, there are certain times when caregiving can be perceived as "fitting" or "unfitting." Tomoko says:

> I think it's a part of my life cycle. I mean it's like some stage of my life history. For example, if I divide my life into several stages, among the past stages there were adolescent time and a stage for child rearing. And now is the time for caregiving for me. So it's a part of my life cycle as well.

On the other hand, Toshiko says: "As for mother, it is something I would see in 20 years, rather than now."

The time at which the caregiver perceives caregiving as "fitting" or "unfitting" varies depending on the life course of each individual. Many housewives perceive caregiving as "fitting" when it occurred after child-rearing. However, caregivers who worked outside the home all their life may perceive caregiving as "unfitting" even after their child-rearing period because they were ready to enjoy their retirement. The perception of "fitting" or "unfitting" is an important determinant of when the caregivers reach the sense of tolerance limit.

Financial constriction. For some caregivers, money spent on caregiving can be constrictive, although various external resources in Japan are largely low-cost and do not constrict the budget of caregiving families as much as in the United States. Yet, where this constricted feeling is present, the caregivers feel particularly rewarded by the handicap allowance from the municipal government.

Spatial constriction. Especially in the Tokyo metropolitan area, houses can be small and the presence of the care recipient can constrict the living space of the caregiving family to an uncomfortable level. This is especially true when caregiving becomes necessary without warning. Constriction is particularly hard on caregiver children who must give up their own rooms for the care recipient.

Difficulties in Personal Resource Exhaustion

Physical and mental resources of the caregiver are gradually exhausted as caregiving continues. One characteristic of this type of difficulty is that it accumulates, gradually wearing out the personal resources of the caregiver. The amount of personal resources a caregiver begins with varies. Some are physically fit, for instance, and can continue to follow the wandering care recipient every night for months, while others cannot continue that level of attendance. The same thing can be said about mental resources. Physical and mental exhaustion are discussed separately.

Physical exhaustion. As the caregiving continues, the physical fatigue accumulates and exhausts the caregiver. Especially when the care recipient begins to wander, the caregivers need to keep almost 24-hour vigilance and this accelerates physical fatigue. Incontinence precipitates physical exhaustion as well; cleaning up after the care recipient wets or soils tires the caregiver directly. Incontinence adds difficulty for the caregiver by hindering use of various formal services such as day care, as well as contributing to the sense of loss of daughter caregivers which exacerbates physical exhaustion.

Because of the caregiving load, many caregivers interviewed in the current research have various physical problems such as angina, occasional fainting, backache, or muscle problems. When their health is in danger, and particularly when life-threatening, the caregivers tend to justify their tolerance limit and take steps to reduce the care-involvement level. The degree of physical exhaustion does not depend on the condition of the elderly alone. Caregivers use different ways to deal with the same problem, depending on their illness recognition and understanding as well as personal beliefs. The different ways of dealing with the problem behaviors can result in different levels of physical exhaustion. Additionally, the caregiver's perception of her fatigue depends on other difficulties, such as the sense of loss or isolation.

Mental exhaustion. Mental exhaustion often peaks when the care recipient frequently wanders. The caregiver is not only physically exhausted, but also mentally exhausted because of the constant vigilance required by this unpredictable behavior. The uncontrollable nature of the problem behaviors precipitates mental exhaustion as well:

> She (care recipient) runs out unless we hold her down, but I don't hold her too strongly so that her arms won't brake. But she is so hard to restrain. She is terrible. She hits and pinches my left hand, and it starts to peel. I get blood blisters. I feel like crying. I do cry with my daughter so bitterly. I get so tired, and drained. (Toshiko)

Some caregivers become mentally exhausted by the constant worry over the care recipient's well-being; that they are caring for the parent(or parent-in-law) in the best possibly way. Due to the high level of attachment, this is particularly the case among daughter caregivers; caregiving as *yome* may be easier in this respect than caregiving as the daughter.

Difficulties in the Disturbance of Self-Ideal

There is a difficulty that arises from the perceived discrepancy between the caregiver's actual and ideal life/caregiving. This perception disturbs the caregiver's self-ideal and becomes a difficulty in caregiving. In fact, this can be the major difficulty that leads the caregiver to the sense of tolerance limit (Chapter 5, "Acceptable Level of Occupancy of Self as a Caregiver"). One type of disturbance of self-ideal is derived from the perception of the "fitting" or "unfitting" of caregiving to one's life course. If the caregiving is perceived as "unfit," the present life of the caregiver is against the ideal image of her life.

Another difficulty in the disturbance of self-ideal is the perception of how well she can take care. Caregivers have their own ideal on how caregiving should be, and the more their reality in caregiving is different from what they define as ideal, the more difficult everyday caregiving becomes:

> There are many books about how to take care of the elderly people with dementia. But those books are helpful only to caregivers with noble characters, but not to immature person like me. I feel they aren't helpful to somebody like me. .... I mean, the worst problem in caregiving is not Mother, but me, myself. I can make caregiving work well, if I set my mind to it. I know it won't work unless my mind is stable when I deal with her. I know it, but even though I can understand it mentally, I cannot act upon it in daily life. That's the worst thing. I feel shameful, and miserable. I cannot deal with my own mother calmly. You know, really, I cannot do it. I always wonder how I can have a heart of Virgin Mary, but I can't. That is the most miserable thing. I mean, I earnestly hope I can, but I can't. I hate it, I wonder why I can't. (Sachie)

The uncontrollable, emotional explosion can be the source of difficulty because it severely disturbs the caregiver's self-ideal. Often, those with high ideals in their caregiving performance struggle to take care perfectly, and as a result, they become more easily physically exhausted. The physical exhaustion drives them into an uncontrollable, emotional explosion further disturbing the caregiver. Consequently, they form a vicious cycle of self-blame.

The difficulty in the disturbed self-ideal accumulates over time, particularly when the problem behaviors of the care recipient worsen over time. Part of the caregiver's justification of her tolerance limit is giving up the high ideals associated with caregiving, and through this decline in the ideal, a way is found to continue care.

The issue of the discrepancy between reality and ideal is difficult to capture because of factors that influence this perception. These factors include personal beliefs about an adequate role performance/life held by a caregiver, the past relationship between the caregiver and the care recipient, and the personal characteristic patterns of behavior of the caregiver. They are difficult to grasp and they also change over time.

The above section explained the essentially paradoxical context of caregiving. The basic context of care consists of both the fundamentally high value assigned to caregiving due to the societal norms of filial caregiving and attachment to the care recipient, and the difficulties that often accompany providing care. The context of caregiving has three distinctive types according to the relationship between the caregiver and care recipient. In the next section, I will explain the three caregiving contexts: caregiving contexts of *yome*, unmarried daughters, and married daughters. The following discussion is a summary of the issues discussed above. Using the typology makes it easier to understand the three distinctive contexts in which the caregiving is being practiced.

Typology of Caregiving Contexts

The caregiving contexts of daughter-in-law (*yome*), unmarried daughter, and married daughter have distinctive features in terms of societal norms, attachment to the care recipient, and difficulties. The characteristics of these caregiving contexts have a profound influence when making a decision to reduce, or not to reduce, the care-involvement level. The distinctive features of the three types of contexts are summarized in Table 4.

Table 4-1: Caregiving Context of Yome

VALUES		DIFFICULTIES
Societal Norm	Attachment	
* Normative practice of filial responsibility	* Lack of attachment; indifference or animosity	* Social pressure to continue to take care
* Expected role	* Later the beginning of amayakasu	* Overwhelming burden against the caregiving load
* Accompanied to primogeniture		* Power relation change with the care recipient
* Institutionalized and inherited from former generations		* Uneasiness toward the care recipient
* Social sanction if not practiced properly		* Aggressive problem behaviors of the care recipient
* Institutioanlized division of labor between husband and wife		* Authority struggle with other family members
* Obedience to other family members		* Different illness recognition and understanding of other family members
		* Difference of perception in how to take care with other family members

Caregiving Context of *Yome*

Societal norm. Caregiving of the elderly parent by *yome* (particularly by the first *yome*) is the most common practice of filial responsibility according to the traditional norm. For most first *yome*, caregiving is the expected career from the time of marriage, although the actual content of the caregiving is mostly unanticipated. This is in contrast to the United States where caregiving is considered unexpected (Pearlin & Aneshensel, in press). On the other hand, the second or third *yome* often find caregiving responsibility unexpected unless certain arrangements had been previously made. Responsibility for caregiving often accompanies the norm of primogeniture which designates the first son and his wife the sole successor of the family property.

The strong societal norm of filial caregiving means that if a *yome* does not take on, or quits, the caregiver role, social sanction against her is strong, or she at least feels a sense of guilt for not carrying out her responsibility. In Japan, institutionalization of the elderly parent is still largely stigmatized and family members try to avoid it as much as possible. However, it should be mentioned that this societal norm is changing quite rapidly in modern Japan and the difficulty of caregiving is better understood, decreasing the level of stigmatization regarding institutionalization. Also, the influence of the traditional norm varies depending upon the generation of the caregiver, where the caregiver lives, and the family trade.

Other societal norms designated to women also serve as an important context for the caregiving experience. The women's (particularly *yome*) obedience to male members of the family is traditionally emphasized, so tolerance of the difficulties of care is socially valued. At the same time, taking care of the sick and children are considered to be the role of women in the division of labor within the family. Therefore, many *yome* take it for granted that they will be the caregivers. Caregiving of elderly parents has been maintained from generation to generation, and is often considered to be a virtue that brings good luck to the following generations of the family.

Attachment to the care recipient. *Yome* caregiver's perception of the care recipient is often characterized by indifference or even animosity. Therefore, especially at the beginning of caregiving, the level of attachment is generally low. However, some *yome* begin to perceive the sense of *amayakasu* (to give indulgent love to the care recipient) when the deterioration of the care recipient progresses and the caregiver perceives the care recipient as childlike.

Difficulties. *Yome* caregivers have much difficulty in the areas of societal norms and power relationships with other family members, as well as with the care recipient. The strong societal norms are sometimes felt as pressure, while the lack of attachment or animosity to the care recipient causes a sense of burden where long-lasting caregiving is anticipated. Power relationships with the care recipient are also difficult for *yome* caregivers because they are expected to be more respectful to their parents-in-law as compared with daughters. Because of the position as *yome*, they tend to perceive *enryo* (uneasiness) toward the care recipient. The recipients' aggression is often aimed at the *yome* caregivers, causing them much difficulty.

Power relationships with other family members are also likely to cause difficulty for the *yome* caregivers. Different illness recognition and understanding between the caregiver and other family members hinder the use of appropriate formal services and cause conflict over the ways to deal with the problem behaviors of the care recipient.

Caregiving Context of Unmarried Daughters

Societal norm. Caregiving of elderly parents by unmarried daughters, especially the first daughters, is also accepted as a norm in the Japanese society, especially when there is no son within the family. Unmarried daughters expect to be caregivers of their parents one day.

The unmarried daughters perceive the institutionalization of the care recipient stigmatic, although they expect that society will understand their situation since they must earn an income. The level of internalization of the traditional norm of filial caregiving varies depending on generation, district, and family trade.

Attachment to the care recipient. Unmarried daughters show the strongest attachment of all caregivers, probably because of the lack of other objects of

attachment. This strong attachment gives caregiving a high value and they have much difficulty in the bereavement process, facing the deterioration and eventual loss of their parents. They gradually learn to adapt to the new relationship that involves *amayakasu*. However, the respect and *amaeru* (receiving indulgent love from the other) for the care recipient are largely preserved concurrently.

Difficulties. The societal norm of filial caregiving causes a certain level of pressure to unmarried daughters, although the sense of guilt for institutionalization seems to be less, when compared to *yome*, in terms of societal norm. On the other hand, the strong sense of attachment to the care recipient causes unmarried daughters much difficulty in their sense of loss. Among daughters, the difficulty of physical and mental exhaustion of their personal resources is often ignored in the strong desire to remain with the care recipient.

Table 4-2: Caregiving Context of Unmarried Daughters

VALUES		DIFFICULTIES
Societal Norm	Attachment	
* Normative practice of filial responsibility	* Strong attachment	* Social pressure to continue to take care
* Expected role	* Lack of other objects of attachment	* Sense of loss of the loved one (hard bereavement process)
* Often does not accompany primogeniture	* Gradual change from amaeru to incorporate amayakasu	* If different from successor of property, sense of resentment
* Social sanction if not practiced properly		* Physical exhaustion ignored by oneself
		* Conflict with work

Caregiving Context of Married Daughters

Societal norm. Caregiving by married daughters is generally accepted socially in light of filial responsibility and women's role as caregiver. However, married daughter caregivers may feel their caregiving is a deviation from the societal norm because they considered themselves separated from their family of origin when they

married. They may think they should institutionalize their parent(s) due to the expenditure of time across the family boundary.

Attachment to the care recipient. The level of attachment in terms of *amaeru* (to receive indulgent love from the other) is strong in married daughters, but seems less than in unmarried daughters; probably due to the presence of other objects of attachment (their husbands and/or children). They also gradually learn to acquire the new relationship to offer *amayakasu* (to give indulgent love) to the care recipient. A certain level of the sense of *amaeru* remains in married daughters even after the care recipient's cognitive ability is profoundly deteriorated.

Difficulties. The most distinctive difficulty shown by married daughters is the sense of guilt and conflict over the family of origin (the care recipient) and her married family. They hope to take care of their own parents out of attachment, while they also perceive strong responsibility for caring for their husbands, children, and parents-in-law; they feel pressured in the middle of two families. Married daughter caregivers also suffer from the sense of loss of their parents in the gradual decline of their condition.

Table 4-3: Caregiving Context of Married Daughters

VALUES		DIFFICULTIES
Societal Norm	Attachment	
* Deviation from the common norm (unless muko-iri)	* Strong attachment	* Sense of loss of the loved one (moderate bereavement process)
* General acceptance in the respect for the aged	* Presence of other objects of love	* Guilt toward marital family
		* Sense of "in the middle" between the family of origin and marital family (conflict of interest)
		* If different from successor of property, sense of resentment

Another issue sometimes mentioned is the discrepancy between the successor of family property and the caregiver. If the caregiver is not the heir to the family property, the sense of resentment toward the family member who is (usually the first son) often occurs. This is frequently seen among married daughter caregivers because it is unlikely, unless otherwise arranged (e.g., *muko-iri*), that the married daughters are designated to be the sole successor of the family property.

It should be emphasized that the above explanations of the distinctive features of three types of caregiving contexts are typical conditions that caregivers in each category experienced. Individual differences sometimes overshadow these typical features. The above explanation also does not cover all issues involved in the values and difficulties of care, but only items with distinctive features among the three types of caregiving context were mentioned.

Summary

In Japan, caregiving for elderly parents is assigned a high societal value in light of the Confucian belief of respect for the aged, women's role in the family, and the institution of lineal family. Caregiving is also valued because of the caregivers' attachment to the care recipient. Due to these two major factors, caregiving is valued to a level in which the caregivers can, if they desire, identify caregiving as the source of their *ikigai*. Their reality is, although the care-involvement level differs among caregivers, that they must take care, not only because of the societal pressure, but also in order to maintain their sense of *ikigai*.

On the other hand, the caregiving experience brings difficulties in various aspects of the caregiver's life. The difficulties often accumulate to a point of disturbance in their sense of *ikigai*. Thus, there is an essential paradoxical juxtaposition of values and difficulties that leave the caregivers and other family

members in a constant dilemma. In this chapter, the sources of the high value of caregiving and its sustenance, as well as various difficulties encountered, were discussed. There are three types of caregiving contexts that are distinct from one another on the issues of values and difficulties of caregiving: caregiving contexts of daughters-in-law (*yome*), unmarried daughters, and married daughters. These are important basic contexts in which the caregivers are forced to make decisions regarding the reduction of their care-involvement level. The decision made is important in determining how they manage to continue caregiving, while also maintaining their sense of *ikigai*.

Chapter 5: Result 2

Making Decisions in Balancing: To Reduce or Not to Reduce the Care-Involvement Level

As the difficulties of care begin to intensify in the course of caregiving, there often comes a point where the caregivers reach their tolerance limit and feel they cannot continue the same caregiving arrangement. A simple method of escape is to reduce the care-involvement level. However, such reduction should only be determined after a very careful assessment of the circumstance because the high value assigned to caregiving makes the careless abandonment of the caregiver role disturbing to the caregiver's sense of *ikigai* with the guilt and shame it promotes.

The purpose of this chapter is to explicate the components contributory to careful decision-making. First, how caregivers reach their tolerance limit and factors and conditions that influence this process are discussed. The three major factors involved in decisions surrounding the reduction of their care-involvement level are then explicated: availability of outer resources, level of caregiver authority within the family, and justifiability of their tolerance limit. Finally, the actual process of balancing these three interrelated factors is presented. This decision-making process is an important element for caregivers in determining how to come to terms with the reality of having to take care; i.e., finding a way to continue to take care without losing the sense of *ikigai*.

Reaching the Sense of Tolerance Limit

Many caregivers described the sense of tolerance limit that occurs sporadically throughout their caregiving experience. Words used include: "*mairu*" (feel beaten), "*genkai*" (limit), "*doushiyoumo nai*" ("nothing doing;" powerless; helpless), "*dame-ni*

naru" ("soon, I will be done for"), "*shuraba*" (battlefield; like hell). The sense of tolerance limit is the feeling that they cannot continue to take care any more in the same caregiving situation at the same care-involvement level. It is the sense that the caregivers are on the edge of being broken, and they are, consciously or subconsciously, losing their sense of *ikigai*.

The sense of tolerance limit requires immediate change in the care arrangement. It often signifies the beginning of the decision-making process toward possible reduction in the care-involvement level.

Sense of Tolerance Limit

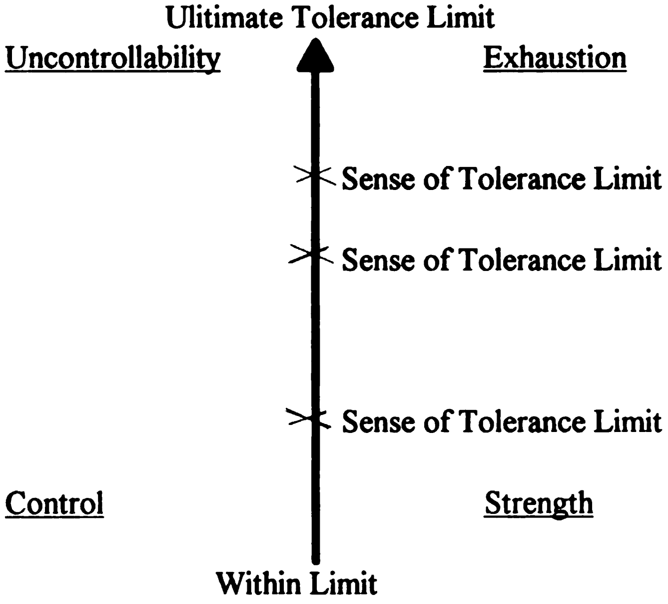
A central feature of the sense of tolerance limit is that the caregiver feels that something must be changed. What should be changed varies depending on difficulties that precipitate these intense feelings. Sometimes the feelings imply the need for temporary respite from caregiving, or the need for diversionary activities such as sports. In other situations, the caregiver cannot take care of the care recipient at home any longer, and institutionalization may be the only solution.

There are two characteristics of the sense of tolerance limit. One is uncontrollability of the situation. The caregiver facing the sense of tolerance limit perceives that the caregiving situation has become beyond her control, and therefore, she cannot manage to continue. The other is exhaustion of the caregiver. She feels that she has exhausted every resource inside herself. With uncontrollability of the situation and exhaustion of personal resources, the caregivers' sense of *ikigai* is profoundly disturbed, even though caregiving still holds high value.

A continuum of tolerance limit. The sense of tolerance limit can be conceptualized as a continuum created by the combination of uncontrollability and exhaustion (Figure 11).

At one end of the continuum are complete exhaustion and uncontrollability (desperate, ultimate limit). At the other end of the continuum is the sense that the caregiver has control over the situation and strength to deal with the difficulties. The sense of control and strength is conceptualized as within limit. Caregivers have used such words as *yoyu* (reserve) or stabilization of mind to describe this situation. There is no sense of danger or urgency that action must be immediate, and the caregiver's sense of *ikigai* is maintained without effort.

Figure 11: Limit Continuum
(created by the author)



How long one can climb on the continuum of tolerance limit to the direction of desperate, ultimate tolerance limit varies among caregivers. When the caregivers continue caregiving, keeping the same or gradually elevated care-involvement level, the caregiver is climbing up this continuum toward reaching a higher tolerance limit. This situation is called, pushing up one's tolerance limit, because the caregivers force

themselves to tolerate the intolerable. On the other hand, when they reduce the care-involvement level, they decline in this continuum back in the direction within limit.

Two types of limit recognition. There are two prototypes seen among caregivers that demonstrate how the sense of limit is reached. The prototype is determined by the combination of levels of uncontrollability of the situation and exhaustion of the caregiver.

One type is that the sense of tolerance limit is experienced mainly through the uncontrollability of the situation. This type of tolerance limit typically shows itself at times of major accidents or acute deterioration in the care recipient's condition. For example, the first experience of fecal incontinence sometimes horrifies the caregivers and they feel they cannot continue to take care in the home. In other instances, the care recipient falls in the bathroom, loses consciousness, and needs to be rushed to the emergency room. When these are the roads leading to a sense of tolerance limit, the sense of uncontrollability precipitates the exhaustion, and the caregivers feel that they cannot continue at the same care-involvement level. On such occasions, the caregiver decides to reduce the care-involvement level relatively quickly and moves toward outer resource mobilization. The sudden change in the care recipient easily convinces the caregiver of the uncontrollability of the situation.

Caregivers tend to experience the tolerance limit precipitated by uncontrollability of the situation in the early period of the caregiving experience. In this stage, caregivers often have no information on dementia and methods of dealing with problem behaviors, have not yet networked to receive morale support from other caregivers, nor received emotional support from other family members. Lack of concrete strategies to deal with problem behaviors makes the situation seem all the more uncontrollable. The sense of uncontrollability is enhanced by lack of morale as well as emotional support.

Another way to reach the sense of tolerance limits is through the physical and/or mental exhaustion of the caregiver due to the duration and accumulation of various difficulties. After a certain period of time, the caregivers begin to feel their inner resources are exhausted, and because of this, the situation seems unduly out of control. Kaoru describes:

> She (care recipient) wanted to go out with me, and she followed me everywhere, even inside the house. It was a two-story building where we lived, and when I was on the first floor, she was also on the first floor. When I went upstairs, she came with me. Everyday she followed me all day long, speaking ill of my father. It was so depressing, and it came to the point where I started to feel SO OFF, and to wonder what would become of me.

When the caregivers reach their tolerance limit through exhaustion, it often takes longer to determine that the tolerance limit has come. They question whether they have reached their tolerance limit or not daily until much time has passed without action. Their minds swing whether today is the day of limit or not.

Degree of the sense of tolerance limit. There is variation in the degree of desperation in the caregivers' sense of tolerance limit. Some caregivers feel "It's my limit" relatively quickly, while others go far longer: Many caregivers subconsciously tolerate and push up their tolerance limit, believing they can continue to take care even when their physical condition is deteriorating. In this sense, continuing to take care at the same level of care-involvement, pushing up one's tolerance limit in strict obedience to the societal norm, is the basic experience of caregiving. Only occasionally do they become aware of the sense of their tolerance limit and begin to assess the situation toward a decision of reduction in the care-involvement level.

The sense of tolerance limit through exhaustion of the caregiver tends not to be recognized, especially in the early period of caregiving. This is because, at the beginning, assessment of the situation almost always results in the caregiver's decision that she must push up her tolerance limit. Only after this has been done many times, does the caregiver become more and more desperate and fully conscious of her sense of tolerance limit. Chieko described her desperation:

> I came to realize that I myself was suffering from something like depression, or psychosomatic disorder. Because, well, I began to say something incoherent, or I started to drink more. Well, how should I put it, even if I told my siblings, they didn't understand me. But when I thought about Mother, my heart palpitated or I had difficulty in breathing. I couldn't get it out of my head that I had to take care of her, and that nobody understands me... But I have to live on. .... I cannot let go of any of them; my children, my mother, and my work. .... When I thought about various things, I really felt suffocated, and I began to think about only bad things. In order to escape from this situation, what should I do. It sounds horrible, but I started to contemplate double suicide. I could not discard such a thought as somebody else's concern. .... If I push Mother in the bath, if I push her only once, then Mother would fall and become bedridden, and then the things may move more smoothly. In sum, I came to think about the unthinkable.

Repetition of the sense of tolerance limit. In most cases, the sense of tolerance limit is not a singular occurrence in the caregiving experience. Rather, for many caregivers, it is repetitive. Even if the caregiver finds a way of escape to return to a state within limit, the condition of the care recipient eventually deteriorates, or the caregiver further exhausts her personal resources. At this time, another tolerance limit is faced. Thus, the caregiver's life becomes a constant struggle to overcome multiple tolerance limit experiences, and to find new ways to continue caregiving (Figure 10). Many cycles of tolerance limit and within limit may be experienced, while, to others, these fluctuations may not occur many times. When difficulties of caregiving are not serious and the caregivers possess many resources, they may not experience their sense of tolerance limit at all. There are also caregivers who institutionalize the recipients following the first experience of tolerance limit and never face it again.

Conditions that Influence the Sense of Tolerance Limit

The sense of tolerance limit is a result of mounting difficulties despite the high value assigned to caregiving. How soon a caregiver reaches her tolerance limit is, however, also affected by several other factors. Those caregivers with much personal resources (e.g., physical and mental strength, stamina) tend to reach their tolerance limit later than those lacking in internal resources. In addition to the basic condition of the caregivers' resources, one major factor is the amount the caregiver role is allowed to occupy daily life.

Acceptable level of occupancy of self as a caregiver. Some caregivers have difficulty in accepting the gradual change of their presentational self (social, interpersonal, and interactive aspects of self-understanding that are acted out in daily life; often captured by roles) which is occupied more and more by the caregiver role (Chapter 4, "Difficulties in the Disturbance of Self-Ideal"). The acceptable level of occupancy of self as a caregiver within the presentational self is low when the presentational self that plays roles other than caregiver is an important source of *ikigai*. In this case, the tolerance limit will be reached relatively soon.

On the other hand, when the presentational self as a caregiver is a main source of *ikigai*, the increase of the caregiver role within the presentational self is likely only to intensify the sense of *ikigai*, even if it means greater difficulties. One's sense of identity is reinforced, and thus the caregiver role brings satisfaction to the caregiver, rather than being considered a threat to other aspects of presentational self. In this situation, the mounting demands of caregiving can be tolerated extensively by the caregiver.

Factors that determine the acceptable level of occupancy of self as a caregiver. Acceptable level of occupancy of self as a caregiver varies among individuals and it can change over time as well. There are several factors that contribute to this change. It is first of all, influenced by the level of value assigned to caregiving (either from the societal norm of filial caregiving or attachment to the care recipient) as well as various agents that sustain high value of care. The sense of caregiving as "fitting" or "unfitting" to the caregivers' lives also accounts for how much the caregiver role is allowed to occupy their lives (Chapter 4 "Difficulties in the Disturbance of Self-Ideal"). Another important factor that influences the acceptable level of occupancy is the length of time estimated for the caregiving. When the duration is estimated to be short, the caregivers are able to devote themselves to giving care wholeheartedly, but when the perceived time is indefinite, the acceptable level of occupancy tends to be low:

> After all, the hardest part is that I'm not sure how long I have to go on like this. Every tunnel has an exit, and that's why you can go in. But this situation is like going into a tunnel without an exit. It's really depressing. This is the hardest part. I think I can endure today, and I can endure tomorrow. But I wonder if this will last for 10 years, 20 years, or 30 years, or until I die. (Kaoru)

When caregivers reach the sense of tolerance limit, they assess three issues, carefully balancing each: availability of outer resources, the caregiver's level of authority within the family, and justifiability of their tolerance limit. The three issues are complex and caregivers elaborate each issue extensively in the interviews.

Availability of Outer Resources

Availability of outer resources is not always assessed for decision-making in reduction of the care-involvement level because some reduction can be achieved by a simple decline in the caregivers' attention level. However, in many situations, the availability of outer resource is assessed carefully, especially when institutionalization is being considered. Family caregivers have various resources outside themselves they can utilize to help escape from the sense of tolerance limit.

Outer resources mean any resource outside the caregiver's personal resources. Outer resources discussed here are limited to substitutions of hands-on care for the caregivers' respite purpose. There are other types of outer resources, such as information, medical services, financial support, and emotional support. The use of informational, medical, and financial resources tend not to be necessarily related to situations of tolerance limit. Therefore, the use of those resources will not be discussed here. Emotional support is discussed as a theoretically separate concept from outer resources, although emotional support in daily life often accompanies other types of outer resources. Respite services and long-term care facilities are used most often after the tolerance limits have been reached, so the use of such resources will be the focus here.

There are informal as well as formal respite resources. Some are within the stem family such as spouse or children; others emerge from the extended family. For example, siblings(or siblings-in-law) are an important resource, and some caregivers mentioned aunts (the care recipient's sisters) or their own mothers. Formal resources come from various sources: adult day care, short stay, home health aid, bath services, and so on. Many hospitals or *tokubetsu yougo roujin houmu* (equivalent of skilled nursing care facilities) now offer respite services for family caregivers. Long-term care is available in multiple settings: elderly hospitals, psychiatric hospitals, or *tokubetsu yougo roujin houmu* (skilled nursing care facilities; private and semi-public).

Because of the societal norm of filial caregiving and/or attachment to the care recipient, caregivers usually use outer resources only after reaching their sense of tolerance limit. However, when the caregivers acquire information on acceptable outer resources passively, possibly by chance, the outer resources can be mobilized without the strong sense of tolerance limit. Respite use usually begins with specific single services, such as bath service, day care or home health aid, and moves from there on to short stays. When the caregiver's sense of tolerance limit is profound, after much endurance of difficulties, the use of long- term care facilities begins to be considered.

Five Criteria of Availability

The availability of outer resources is a relative concept in the sense that each caregiver, in any given situation, has a unique set of criteria for availability. These criteria determine whether or not they perceive that a specific service is available. Therefore, availability is not uniform to all caregivers, even where two caregivers are living in the same area where formal services are offered equally. Availability is also different in a single caregiver at different times. There are five criteria to determine the availability of a resource: quality, distance, sanction, information, and quantity.

Quality. Quality of an outer resource is always the most important criterion to determine if the caregiver can utilize the resource. Caregivers tend to avoid use of outer resources that offer a quality of care much lower than they themselves offer. For example, some caregivers think they can institutionalize their care recipients only when they believe the staff in the institution are professionally prepared and qualified to provide better care than the caregiver can provide. If the quality of care is not good enough, they feel *kawaiso* (pity) for the care recipients and prefer to avoid justifying their tolerance limit; they continue to take care without using the resource.

The criterion of quality gradually changes. The greater the difficulty and intensity of the tolerance limit, the lower the criterion of quality. The level of authority within the family also influences the criterion of quality. The lower the authority, the higher the quality of resources the caregivers require as a substitute for negotiating with other family members.

Quality in terms of benefit to the care recipient strongly influences the continued use of the resource. If the care recipient does not enjoy the use of the resource, or the care recipient receives harmful consequence from the use of the outer resource, the use can be discontinued immediately. On the other hand, favorable reaction from the care recipient motivates the caregiver to continued use of the resource.

Quality varies among resources and districts. In some rural areas, long-term care facilities, as well as hospitals, may offer little respite for the caregivers, because they (often covertly) require that family members visit the facility almost daily to ensure quality care. Consequently, quality of the resources also influences the caregiving experience after the outer resource has been mobilized.

Distance. Caregivers usually prefer facilities near their homes. The city limit is often considered a boundary because many services for elderly people are offered by the city government. However, anyone can qualify for most services offered by private hospitals, and the greater the desperation in the caregiver's tolerance limit, the further the acceptable distance. Some caregivers interviewed use short stay or long-term care facilities that are located even beyond the prefecture boundary.

Sanction. There can be sanctions when the caregivers use an outer resource, and if the sanction is high, they prefer not to use it. The criterion of sanction is often an issue when the caregivers think about asking for help from their sibling (or sibling-in-law). Many caregivers consider that the sanction of creating conflict between themselves and the sibling(or sibling-in-law) is too high, and prefer either to continue to take care by themselves, or to use formal resources. A long-term care facility is often unavailable because of social sanction: The use of such a facility is still stigmatized in many areas of Japan.

Sanction by the care recipients may make some resources unavailable. If the care recipient resists the use of a resource, sanction can be too high for the resource to be perceived as available to the caregiver. Many care recipients refuse to be institutionalized, partly due to the firm traditional belief that elderly parents should be cared for at home and therefore it is a shame to be institutionalized.

However satisfactory the quality of an outer resource may be, use of outer resources can have negative effects on the care recipients. Such negative effects can be deemed unacceptable and the caregiver may not continue to use the resource. Mayu describes the use of a 28-day stay respite setting ("middle stay"):

> We (caregivers) reluctantly place the elderly person in the 28-day stay program, only when there is no other alternative. They (care recipients) come back with some souvenirs. I mean by souvenir, they come back with something they didn't have before. They were among many people, (and staying there triggers the new habits and tendencies). For example, she (caregiver) comes back with very arrogant attitude, even if she was not like that before. She may come back with diapers, even if she didn't have one before. Or, because she walks so much there, she may injure somewhere. The longer I leave her in some place, the more souvenirs she brings back home with her. .... I myself suffer from this afterwards.

However, again, as the caregivers become more desperate, they are willing to accept larger sanctions.

Information. The criterion of information is a critical determinant for assessing availability of outer resources. If the caregiver has insufficient information on outer resources, even if they exist they are not available to them. For example, Reiko believed there were no services that accepted elderly persons suffering from incontinence, so she did not even attempt to search for such a facility. Needed information not only concerns the existence of specific resources, but also their availability in terms of other criteria (quality, distance, sanction, and quantity). If a caregiver receives information that a specific facility is low quality, the facility then becomes "unavailable" for the caregiver. The amount of influence this information has on the caregiver's decision depends on its source. The suggestions of social workers or nurses can be very influential. Suggestions from the physicians are followed without question. Advice from non-professionals is also considered, although the degree of influence is weaker. Information on the quality of specific services is abundant among lay people in neighborhoods, and rumors regarding services have great influence on the caregiver's decision-making.

Some information comes from stereotypes held by the general public about certain services which may not be true. For example, many caregivers believe that care recipients are restrained to beds in a formal facility, and as a result, they disregard institutionalization as an option. This incorrect image of outer resources is sometimes changed through visiting the facilities. On the other hand, a first time visit to a facility in poor condition can be a horrifying experience labeling institutionalization as unavailable.

A caregiver's knowledge of a service can be based on previous experience, although this is rather rare. Mayu had taken care of her bed-bound father-in-law before she began to take care of her mother-in-law, and because of the previous experience with her father-in-law, she knew a specific facility was high quality. On the other hand, a previous negative experience can block the caregiver's desire to use the same facility again.

Many caregivers actively sought information regarding respite services by visiting several elderly hospitals or public health nurses, or buying books. The active seeking of information on possible outer resources is often stimulated by caregivers

reaching their tolerance limit. This active search often leads caregivers to acceptable resources, thereby enabling to justify the tolerance limit with the knowledge of available outer resources.

On the other hand, some come to know about available resources *passively*; such as running into an acquaintance who happens to be the Director of Nursing at an elderly hospital, or being told about resources through staff of the facility they are currently using. This passive seeking of information, if the acceptable resource becomes available, can cause tolerance limit to be justified even if the caregiver is not very desperate. In fact, there are several cases where the outer resource was mobilized without reaching tolerance limit, when newly developed services for the elderly were introduced to the caregivers. These appear to be exceptions.

Quantity. The criterion of quantity is different from other criteria in the sense that it is not influenced by the level of tolerance limit of the caregiver. An outer resource is often unavailable due to the length of waiting lists. However, desperate caregivers may appeal to the staff of formal services to view their circumstance as extreme (e.g., injury of the caregiver) and allow them first consideration. Quantity of services for the elderly varies in Japan in different areas.

Even if certain resources are physically available, problem behaviors of the care recipient, such as wandering, aggressive behaviors, or incontinence can cause the facilities to refuse entry of the care recipient. Health attributes of the care recipients also keep them from taking advantage of the resources. For example, Rumi's mother-in-law was refused by a short stay service because of infection (Hepatitis B). The age of the care recipient can also influence availability of resources; many facilities are available exclusively to those over 65 years old.

Presence of Multiple Options

If there are multiple outer resource options, the caregivers carefully assess the relative worth of each option in choosing between them. For example, institutionalizing Reiko's mother (the care recipient) was assessed as worse than entrusting her to Reiko's brother, but when she learned that her brother was going to institutionalize their mother near his home, she chose to utilize the nearby elderly hospital. She assessed that the nearby hospital was better than the hospital near her brother's house because she herself could frequently visit her mother.

Authority Level within the Family and Negotiation

Authority means the power any one person or group has over decisions made for oneself or others. In family dynamics, various types of authority are at work, and some specifications are necessary with regard to this section. First, only the authority relationship between the caregiver and other family members (excluding the care recipient) is examined here. Second, authority over overall family matters is distinguished from authority over caregiving. The latter is the main focus here. Third, the perception of one's authority level is individual by nature, and only the perception of the caregiver is discussed, because it is the most influential in determining the caregiver's action. Other family members' perceptions are considered only *via* the caregiver: how the caregiver perceives the other family members' perceptions of the authority of the caregiver and themselves. Fourth, one's authority is a relative perception based on the following four issues:

1. how much authority the caregiver believes she is granted;
2. how much authority the caregiver believes is granted to other family members;
3. how much authority the caregiver perceives the other family members believe they possess; and

4. how much authority the caregiver perceives the other family members believe is granted to the caregiver.

Addressed here is the resultant, relative perception of power the caregiver has over matters of caregiving.

Fifth, the perception of authority is often derived from a dyadic relationship. Therefore, one caregiver's perceived authority level in relation to person A is different from her perceived authority level in relation to person B because the caregiver is aware of the different views of these individuals regarding their authority levels as well as the caregiver's.

Authority level of the caregiver serves as a condition of several phenomena. First, a caregiver's authority level is a significant determinant of which negotiation style she uses with other family members. Further, it also influences whether the caregiver can reduce the care-involvement level. Second, heightened authority through the accumulation of caregiving practice is an important basis toward enabling the caregiver to justify her tolerance limit to herself.

Factors that Determine the Level of Caregiver's Authority within the Family

There are several factors that determine the authority level of the caregiver at any given time. As the conditions of these factors change, the authority level of the caregiver changes. Most factors are recognized by the caregivers themselves. Moreover, the caregivers consciously try to earn higher authority based on knowledge of these factors.

Societal norm on the position of the caregiver in the family. The traditional belief regarding the position of daughters-in-law (*yome*) has been previously explained. With regard to caregiving, the hierarchy of authority within a family is, by principle, as follows: If the spouse of the care recipient is alive, his/her authority claim is generally the highest within the family, especially when the spouse remains income-producing.

Next is the husband of the caregiver, the care recipients' son. Even when the caregiver's authority is relatively high, the opinions of her husband are respected. *Yome* holds the lowest authority with regard to caregiving; many repeatedly said that they could not speak up with regard to caregiving from the position of *yome*.

This societal norm on the position of *yome* is held most strongly by the older generation. The generation gap on the view of this norm often causes family conflict in caregiving. As Naoko says:

> Normally, if both husband and wife are alive and healthy, one of them takes care of the other if either one gets sick. .... We are in that situation, so if Grandpa wants, he can take care of her. He is healthy, and if he really has *omoiyari* (thoughtfulness, sympathy) toward Mother (his wife), he should quit his job and take care of her. I think that's best for Mother and I can help him. But in reality, I guess he wants to enjoy himself. [laugh] When I told him what I thought, he got mad. .... He said, "I cannot do this, now, after all years. I'm embarrassed even to walk together [with his wife].

The authority of daughter caregivers within the family is generally higher than *yome* caregivers because the daughter is a blood relative of the care recipient.

Process of family acceptance. The process of family acceptance is a process in which *yome* is gradually accepted by the married family, and it influences the authority level of only *yome* caregivers. The authority of *yome* over domestic matters is the lowest when she married and came into the new family. Gradually, learning from her mother-in-law, *yome* increases her authority to make decisions based on the family customs. When the mother-in-law loses her ability to function as the matriarch of the family, the *yome* takes over the position and the family acceptance process completes.

The process of family acceptance is based on a principle that those who can be responsible have authority. This principle has been discussed in an examination of the authority of those who are in a weak position within a group (Mechanic, 1968). As time passes, the accumulation of diligent practice as *yome* evidences her ability to be responsible. This gradually elevates the authority of *yome* during the process of family acceptance. The authority level of the caregiver depends on where in this family acceptance process the caregiver is at the time of caregiving. For example, Chieko began to take care of her mother at the time of her marriage when she had the lowest authority level. As a result, she could not make any changes in the caregiving arrangement, even when her tolerance limit had reached a profound state and she was desperate.

The principle that those who can be responsible can have authority is at work, even when caregivers are not aware of it. *Yome* caregivers play their expected role diligently and according to societal norm; after a certain period of time, they begin to feel justified to speak:

> If she were my own mother, I could be more relaxed about the situation, but because she is my mother-in-law, I feel as if she were entrusted to me, and I do much *kizukai* (to worry about attending to the care recipient) all the more. I have to be attentive. But <u>now that I came this far</u>, I have recently assumed a defiant attitude that it's OK if she would fall or whatever would happen to her. (Akiyo)

Some caregivers are conscious of this principle and attempt to earn higher authority through diligent caregiving as well as attending to other family chores:

> I feel we have to change (father-in-law's old style) even if gradually. I can't change drastically. Therefore, <u>I think by doing my best Father would appreciate me, and I feel that I can say what I want as long as I do what I have to do</u>. .... If I put up for 10 years more, it may be possible for me to rule the world [laugh]. I can endure if I think this way. (Naoko)

When the authority is earned by the caregiver, other family members often perceive similar authority elevation of the caregiver. Therefore, heightened authority is acknowledged by all participants smoothly. However, some family members may not share the view of the authority elevation of the caregiver, causing family conflict.

Family boundary. Family boundary, as was explained in Chapter 4, means the extent a stem family is influenced by other members in the extended family. The level of family boundary influences the authority level of the housewife (daughter or *yome*) as caregiver. When the family boundary is strong (e.g., traditional agricultural family), the authority level of the caregiver tends to be high. Conversely, when the family boundary is weak (e.g., traditional merchant family, modern nuclear family), the authority level of the caregiver tends to be low.

The principle that the responsible person can have authority is also at work within this concept of family boundary. If other family members do not spend the time and energy to give care because of the strong family boundary, these members feel they are not entitled to claim authority in caregiving. This heightens the authority of the caregiver. On the other hand, if the caregiver is helped by other family members with caregiving because of the weak family boundary, the caregiver feels that she cannot claim high authority.

Personality styles. Another condition that determines the authority level perceived by the caregivers is the personality styles of both caregivers and other family members. Some individuals tend to claim higher authority in any given situation than others. Therefore, if other family members have a personality style of not conducive to claiming high authority, the relative authority perception of the caregiver can be high. On the other hand, if both the caregiver and other family members have personality styles of claiming high authority, it often promotes family conflict.

Personality style is addressed because the caregivers interviewed, regardless of whether they were *yome* or daughter, perceived their authority at different levels, and the variation cannot be explained by other factors discussed above. For example, Sachie is a daughter caregiver with relatively solid family boundary, yet she cannot use institutions because other distant relatives may disagree: "I imagine it would be very relieving if I can put her in an institution. But I can't. I cannot decide it by myself."

Negotiating with Other Family Members at a Given Authority Level

The level of the caregiver's authority within the family is determined and earned in ways explained above. When the caregivers reach their sense of tolerance limit, they assess if they can attempt reduction of their care-involvement level given their current perception of their authority. If they view the attempt plausible, they negotiate with other family members for the possible reduction, using various negotiation styles appropriate to their authority level.

The caregivers must (at most authority levels) obtain agreeable consent and endorsement from other family members, because disturbing family harmony must be avoided as much as possible. The choice of an appropriate negotiation style is essential in order to maintain this desired harmony. Also, authority is a relative perception and a caregiver feels a different level of authority with different members of the family, therefore, a different style of negotiation is used depending on who he/she is negotiating with.

Generally, as the caregivers' authority increases, their style of negotiation changes from indirect to direct forms. Another condition that allows the caregiver to use a direct style of negotiation is the level of their tolerance limit. Even if the caregivers do not necessarily feel their authority level is high, they may take direct ways of negotiation when their sense of tolerance limit is desperate. In Japan, negotiations in general tend to be more indirect than direct. Therefore, it is possible that a caregiver with higher authority will still use indirect forms of negotiation.

<u>Silence</u>. When the authority level is perceived as low, the caregivers often cannot take any action to negotiate. They can only hope that other family members recognize the need for mobilization of outer resources. As Akiyo says: "I am still

waiting for others to say, 'Sister, it is *shikatanai*, let's put her into the hospital.' But I haven't heard that." This behavior is not strictly negotiation, but it is often seen in caregivers. Only when other family members with high authority appreciate the deteriorated condition of the care recipient and grant outer resource mobilization can the caregiver begin to take action to reduce the care-involvement level.

Revealing. Caregivers with low authority sometimes indirectly appeal, demonstrating that the reduction of their care-involvement level is necessary. The condition of the care recipient is shown in subtle ways for this purpose. This indirect method of communication is an attempt to drive other family members with higher authority to say, "It's time to institutionalize Mother." Akiyo's experience is an example:

> I want them to look at how her daily life has become abnormal. For example, she takes off her clothes and becomes naked. I used to try very hard to put her clothes back on, but nowadays it is warmer so I am not worrying about her catching cold. They usually stop working around 7 o'clock, then they come upstairs and change their clothes. If she was naked then, I used to put back the clothes on her, because I didn't want them see her naked. But now I would like them to see such a situation, so I let her do whatever she likes. Then her sons say, "What are you doing, Grandma!? Have you taken off your clothes again?" So now they know about it.

Borrowing outer authority figure. Caregivers with low authority may borrow the authority of people outside the family in order to persuade other family members into outer resource mobilization. The caregivers may not actively seek outer authority figures for this purpose, but passively meeting someone with authority often results in the use of outer resources. This person with authority can suggest the use of outer resources to other family members for the caregiver. For example, Chieko said to her

husband that <u>the social worker said</u> it was time to think about hospitalization, hence she could institutionalize her mother-in-law.

<u>Seeking consent/confrontation</u>. If the authority level of the caregiver is relatively high and is approximated to that of other family members, they often directly discuss their views on reduction of their care-involvement level with other family members:

> In February last year, she (care recipient) got much worse, I mean her condition. She wandered around at night or even during day time, and got lost every time she went out. .... At that time, because it was so *taihen* (hard) for me, I just couldn't help telling that I was not sure if I could continue for another year. (Akiyo)

At this level of authority, caregivers still seek consent of other family members, and if this is not received, the caregivers often release the idea of reduction in their care-involvement level. Even if a caregiver is the only person in close contact with the care recipient, in the case of *yome*, an attempt is made to obtain consent from blood relatives of the care recipient living some distance away.

<u>Monopoly</u>. Caregivers' authority level is sometimes the highest within the family and they are free to mobilize any outer resources without consulting others. These caregivers often discuss possible outer resource modification with their spouses whose opinion is respected. However, the opinions of other members in the extended family may not be sought. This environment affording a very high level of authority to the caregiver occurs when the family boundary is very strong and the position of *yome* has been established in the process of family acceptance.

Assessment of authority has particular importance in Japan where the hierarchy of a group is given more attention than in the United States (Nakane, 1970). Actions for negotiation and their possible results are carefully thought out based on their

perception of authority. If the caregiver mistakenly assesses her authority and takes an inappropriate negotiation style, it may cause interpersonal friction which should be avoided as much as possible.

Justifiability of One's Tolerance Limit

Justifiability of tolerance limit means whether the caregiver can validate her tolerance limit to herself without damaging her sense of *ikigai* available through the caregiver role. When the caregivers come to sense their tolerance limit, they ask themselves, "Should I tolerate this much difficulty?" There are times when the caregivers can say "No, I don't have to," justifying their tolerance limit as reasonable, while at other times they cannot help saying, "Yes, I still must." This inner questioning is another component of decision-making regarding the reduction of care-involvement level.

Determining justifiability

The central question assessed in determining whether the tolerance limit is justifiable or not is, "Have I done enough to take care of the elderly parent(-in-law)?" Due to the high value of caregiving, based on the societal norm and/or the attachment to the caregiver, it is an underlying assumption by the caregivers that they must take care. The caregivers are freed from this inner imperative only when they have taken care of the parent enough to meet the normative requirement. Akiyo described the sense that she had done enough as a caregiver for her mother-in-law when she justified her tolerance limit:

> I feel as if she were entrusted to me, and I do much *kizukai* (to worry about attending to the care recipient) all the more. I have to be attentive. But now

that I came this far, I have recently assumed a defiant attitude that it's OK if she would fall or whatever would happen to her.

The underlined section denotes her sense of "I have done enough." Because of her achievement, Akiyo could allow herself to justify her limit. As a result, she could accept the possibility of the care recipient's injury due to her reduced level of watchfulness.

The idea of justifiability of their tolerance limit does not enter the caregivers' minds only upon facing the sense of reaching their tolerance limit. Rather, they constantly, consciously or subconsciously, assess their future ability to justify it. This constant assessment gives the caregivers a sense of boundary in the duration of caregiving, instead of perceiving the experience as indefinite. Consequently, the constant assessment seems to lessen the sense of difficulty.

How soon does tolerance limit become justifiable? How soon the caregivers can justify their tolerance limit varies among individuals because of several reasons. Major factors are the internalization of societal norms and the attachment to the care recipient. In principle, the traditional Confucian thought defines that the *on* (debt) children owe their parents for their life-long caring and love is insurmountable, and that the children are required to pay back for the rest of the parents' lives. The actual level of debt perceived by the children, however, varies. If the child (or child-in-law) feels parental *on* very strongly, they cannot justify their tolerance limit easily, while if they do not feel much *on*, their sense of repayment is completed relatively soon and they justify their limit with ease. What counts as fulfilling the debt is not uniform among caregivers, either. The sense of the amount accomplished for the care recipients in relation to their debt does not directly reflect the duration of caregiving; rather, it reflects the level of the tolerance limit. The more desperate the caregivers become in their tolerance limit, the sooner they can justify it to themselves. The overwhelming sense of tolerance limit convinces them that they have done enough.

Another factor determining when the tolerance limit becomes justifiable is personal belief regarding how care should be given. Some caregivers give little thought as to how they communicate with or treat the care recipient; as long as they continue care at home, they feel they are giving enough. Other caregivers feel they can and should justify their tolerance limit when they cannot maintain their compassion and warm feelings toward the care recipient. Chieko thought she should justify her tolerance limit to herself when she found she could no longer be compassionate toward her care recipient:

> In the end I was wondering if I should continue to take care of her, suppressing my emotion, and bouncing back my troubled emotions on her. I was determined not to let it happen by any means, but I felt that such time has come.

<u>Balancing with other issues</u>. The availability of outer resources and the authority level of the caregiver within the family influence the justifiability of tolerance limit, and their influences are mutual. For example, when the caregiver feels that she can justify her tolerance limit, the criteria to determine availability of outer resources may decline, or the caregiver may mobilize negotiation styles that may not be in accordance with her level of authority. Alternatively, the availability of a quality outer resource or higher authority makes it easier for a caregiver to justify her limit.

It seems that the influence of the justifiability of tolerance limit on the other two issues is stronger than the influence of authority and availability on justifiability. That is, once the caregivers can justify their tolerance limit, they tend to change the criteria for available outer resources and the types of negotiation. This is seen more often than the former situation where availability of outer resources or heightened authority allows them justification. This is because the justification involves a redefinition of reality, and the issues of availability and authority are differently perceived according to the new definition.

Level of justifiability. The extent to which the justifiability of tolerance limit can be granted varies, depending on the level of the caregiver's tolerance limit. For example, when the sense of tolerance limit is weak, a large reduction of care-involvement level (e.g., institutionalization) is not justifiable, while short respite use is. However, when this sense is intense, justification can be approved even for the radical change in the caregiving arrangement.

The level of justifiability can be measured by the sacrifice. There are caregivers who are able to justify their tolerance limit in order to keep their jobs, hobby classes, or monthly outings with neighbors, even if it means compromising the well-being of the care recipient. Others are unable to justify their tolerance limit until their own health is at risk. When their own lives are at stake, many are able to justify their tolerance limit, although there are always some who are not able to justify their limit even for the sake of their health.

Justification of the Tolerance Limit

Justifying one's tolerance limit and recognizing one's own limit should be separated conceptually. There are many occasions when the caregivers recognize their limit yet cannot justify it to themselves. Justification often signifies the accumulated work of caregiving that may not have been present at first recognition of tolerance limit.

Justification of tolerance limit involves three phenomena: (a) prioritizing the well-being of the caregiver and other family members over that of the care recipient, (b) acting in defiance of the societal norm, and finally (c) redefining their reality and setting up a boundary.

Prioritization. When the caregivers justify their tolerance limit, the well-being of the caregiver and/or other family members takes greater precedence, even at the cost of reduced attentiveness to the care recipient's well-being. Conflict of interest among family members is a persistent difficulty in the caregiving experience; the best interest of the care recipient is respected to a great extent. However, when the caregivers justify their tolerance limit, the lower degree of attentiveness is mentally accepted by them. This change is most drastically seen when the physical life of the caregiver is threatened:

> There was another woman who was taking care of her mother-in-law in my neighborhood. She suddenly got sick and passed away in one week. .... When I heard that story, even I felt *warui* (sorry, guilty) for my mother(-in-law), I thought I didn't want to shorten my life because of caregiving. I thought, "I want to live at least till I am 70!!" (Akiyo)

When the interests of the caregiver and family are given higher priority, there is often a sense of guilt and pity for the care recipient as Naoko describes:

> I feel sorry for Mother(-in-law) (care recipient), but she doesn't know any more. I feel sorry for her, but we have our own life to worry about. We have to think about our children's future. She began acting strange about the time of the first child's entrance exam, and exams for other kids are still to come.

<u>Acting in defiance of societal norm</u>. Because filial caregiving is the standard norm for the Japanese, justifying any tolerance limit involves the rejection of, and repulsion against, the societal norm. For many caregivers, it constitutes an abandonment of a certain self-ideal developed through internalization of the societal norm. Therefore, the caregivers recognize they should feel negatively, as is observed in the use of derogatory terms: "I thought it's '*shikatanai*' (no way out) even if something happened, and I thought I would go <u>impudently</u>" (Akiyo). However, when they can justify their tolerance limit, they accept themselves as acting in defiance of the societal norm.

The caregivers may need to "muster up" much courage to act in defiance of the societal norm of filial caregiving. Especially daughter-in-law (*yome*) caregivers tend to be unable to justify their limit because acting in defiance of societal norm endangers their treasured self-ideal as a good *yome*, and thus their sense of *ikigai* available through the *yome* or caregiver role is threatened. As a result, the only way to justify their limit may be to become ill and hospitalized:

> At moment, I can escape from her most efficiently by being admitted to the hospital. If my illness gets a little worse and I go into the hospital, there is no better place than the hospital, with three meals and a nap. I enjoyed myself thoroughly for two months while I was hospitalized. [laugh] .... I really enjoyed. .... My friend told me that nobody else would say she enjoyed herself staying in the hospital. I replied to her that I really enjoyed myself [laugh] with three meals, and I could read books as much as I wanted. .... I really enjoyed for two months from the beginning to the end. I didn't care how bad the meals were. I really enjoyed. I felt free, so I want to go again. (Akiyo)

Divorce and leaving the family is sometimes thought as the only escape from the sense of tolerance limit, rather than abandoning the role of caregiver. However, this is commonly hypothetical, and therefore, care is only continued in the same, or gradually elevated, level of involvement:

> Honestly speaking, the idea of divorce crossed my mind then. When I thought how I can escape from this situation, that was the only way. But in reality, we had two small children and I didn't have courage to go ahead with it. (Chieko)

Redefining reality and setting up a boundary (*hirakinaori*). Justification of one's tolerance limit also often involves redefinition of reality. This means the caregivers' perception of reality changes from needing to take care by any means and at any cost to an acceptance of limited caregiving. They still continue caregiving, and in this sense, the basic reality of having to take care does not change; however, now they endorse the idea of limited care. The redefinition of reality reflects the caregiver's change in their beliefs in, and self-understanding of, their caregiver role: They can stop forcing themselves to be cast into the ideal figure of caregiver; devoted, tireless, and forever accepting.

Changed belief in their role allows them to change their behavior to *hirakinaori* (to take a defiant attitude). This means an end to being acquiescent, passive caregivers, quietly suffering, and begin to try to take control over the situation. As a result, they are able to draw a boundary in their roles. This perceptual change leads the caregiver to reduce the care-involvement level: "I am now *hirakinaori*, so I think it is OK she (care recipient) becomes like that. Well, I think it is *shikatanai* even if something happens to her" (Akiyo).

The redefinition of reality and setting up a boundary are seen among *yome* caregivers more prominently than daughters because *yome* have greater tendencies to abide by the societal norms regarding filial caregiving. Japanese *yome*, throughout their life courses, strive to get approval and acceptance from other family members, and to some extent, they are more than willing to sacrifice themselves for the well-being and harmony of the family. For *yome*, sacrifice is a means to achieve the ultimate goal of creating a harmonious and happy family, and in this sense, sacrifice has its reward and value. Therefore, the redefinition of reality to avoid sacrificing themselves completely is a significant turning point for the caregivers, and their self-understanding changes dramatically through this experience.

The redefinition of reality and setting up a boundary sometimes follow the critical acceptance of the difference between the caregiver and other family members. In caregiving, devoted *yome* often liberally sacrifice themselves and still do not receive the expected reward of appreciation from other family members and/or a harmonious, happy family. When they recognize that there is no end in family members' expectations, they decisively stop expecting to satisfy them. This recognition and acceptance (*akirame*) leads to justification of their tolerance limit. Eventually, the caregivers stop worrying about offending other family members' feelings:

> I came to realize that people around me, I mean the members of my husband's family, would take it for granted however much I devoted myself, and would require more and more of me. So I felt that I should draw a line to what extent I went. (Chieko)

The caregivers assess the issues explained above, carefully balancing them.

Balancing

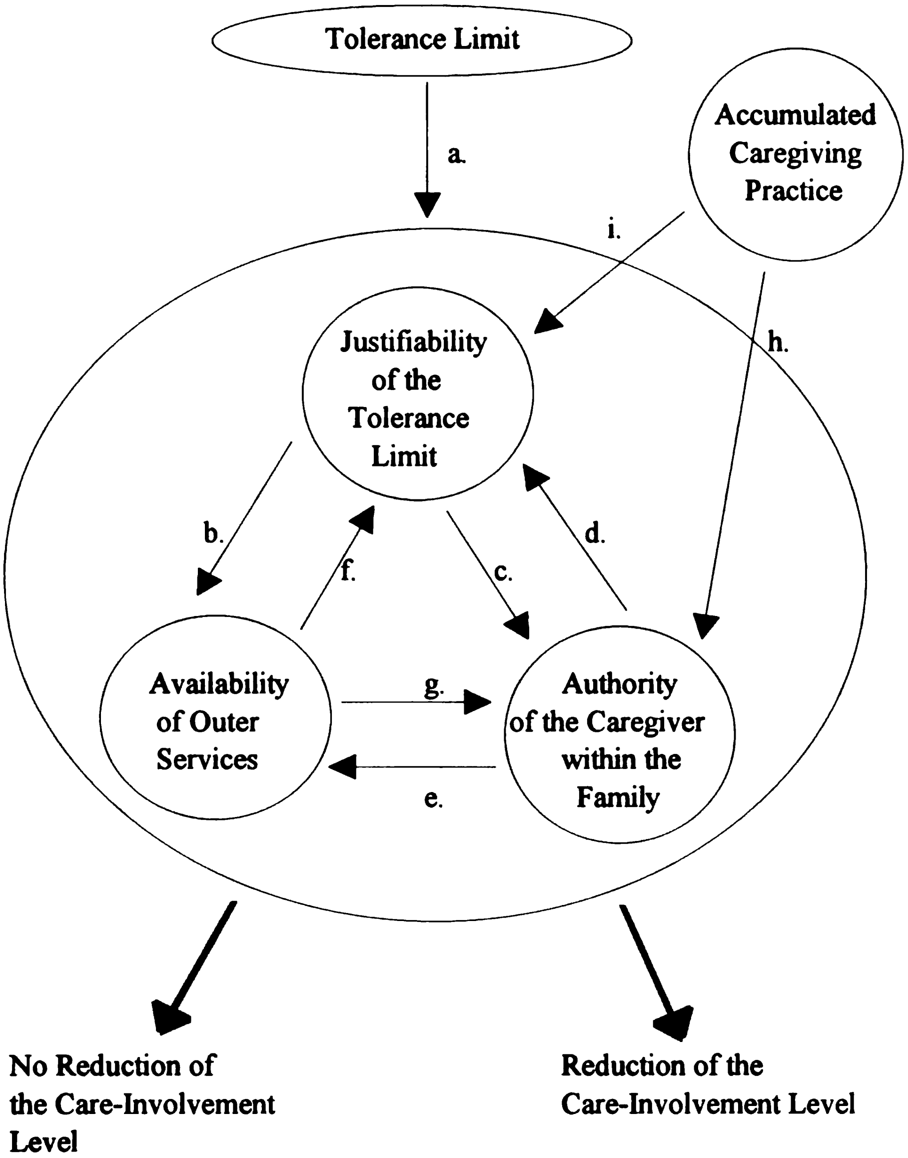
The three issues explained above are mutually dependent, and the final assessment involves a complex balancing of each by the caregivers in order to reach a decision on the reduction of their care-involvement level (Figure 12). The first part of this section summarizes the interrelatedness among these three issues. Secondly, I discuss "swinging mind," a common phenomenon seen among caregivers. Lastly, occasions are cited where caregivers can reduce their care-involvement level, and those where reduction was impossible, forcibly pushing up their tolerance limit.

Interrelatedness of Issues in Balance

There are nine relationships seen among the three issues of availability of outer resources, authority level of the caregiver within the family, and justifiability of tolerance limits as well as other conditions of caregiving (Figure 12).

Although only two issues at a time are related in the following discussion, in reality, the final decisions regarding the reduction of care-involvement level depend on the third issue. For example, high authority within the family tends to allow the aregiver to justify her tolerance limit relatively easily, but unless there are acceptable

Figure 12: Interrelatedness of the Issues in Balance
(created by the author)



outer resources (when necessary), the caregiver still cannot make justification. There are also many other conditions, although their influence is not very strong, that affect the actual decision-making. The focus here is on the relationship of only two issues for clarity.

Tolerance limit and decision-making in balancing (Figure 12[a]). The higher the level of tolerance limit, the more likely the decision to reduce the care-involvement level will be made. Therefore, a higher tolerance limit allows the caregiver to justify her tolerance limit with greater ease, to accept the low criteria of availability of outer resources, and employ more direct forms of negotiation with other family members on the possible reduction of her care-involvement level. Conversely, if the tolerance limit is not high, the caregiver is not likely to consider reduction in her care-involvement level.

Justifiability and availability (Figure 12[b]). If the caregivers are able to justify their tolerance limit, the criteria for availability tend to be lowered. In other words, the more definitively the caregivers justify their limit, the more they tend to accept the low quality, long distance, or high sanction of the facility they use as an outer resource for the reduction of their care-involvement level. Conversely, if the caregivers' justification of their tolerance limit is not definitive, their criteria for availability tend to remain high.

Justifiability and authority (Figure 12[c]). If the caregivers can justify their tolerance limit definitively, they tend to take a more direct method of negotiation within the family, even if their perceived authority is not necessarily high. Conversely, as long as the caregiver's justification of their tolerance limit is not firm, the negotiation may be indirect or barely offered.

Authority and justifiability (Figure 12[d]). The less authority caregivers are given within the family, the more difficult it is for them to justify their tolerance limit. If caregivers are given high authority within the family, the justification is easier. This is congruent with the fact that those who hold low authority tend to have less accumulation of time in the caregiving role and thus have less reason to justify their tolerance limit.

Authority and availability (Figure 12[e]). The higher the authority of the caregiver within the family, the lower the criteria (e.g., low quality, long distance, big sanction) of outer resources need to be accepted by the caregiver. Conversely, the lower the authority, the higher the caregiver's criteria for outer resource availability.

Availability and justifiability (Figure 12[f]). If there is a desirable outer resource available, caregivers tend to be able to justify their tolerance limit with greater ease. In fact, there are some occasions where caregivers decide to reduce their care-involvement level before reaching the strong sense of tolerance limit. On the other hand, if there is not an acceptable outer resource, the caregivers' justification becomes more difficult, even when a strong sense the strong tolerance limit exists.

Availability and authority (Figure 12[g]). If there is a desirable outer resource available, caregivers tend to be able to negotiate with other family members successfully, even with relatively low authority. Conversely, if there is no acceptable resource available, caregivers are likely to be unable to negotiate with other family members for possible reduction of their care-involvement level.

Earning authority through the accumulation of caregiving practice (Figure 12[h]). Caregivers have ways to earn authority within the family; the most common is by accumulating the experience of caregiving. When the caregiver has taken care long enough, their authority within the family tends to increase.

Accumulation of caregiving practice and justifiability (Figure 12[i]). Accumulation of caregiving practice also allows caregivers to justify reaching their tolerance limit more easily. Conversely, when caregivers have not taken care for a long time, they have little basis for justification.

When caregivers consider whether they can reduce their care-involvement level, the inter-relationships among the availability of outer resources, the authority level in the family, and the justifiability of tolerance limits must be balanced. Naturally, it is often very difficult for a conclusion to be reached and the caregivers' minds swing from one possibility to another. This phenomenon is most prominent at times of decision-making.

"Swinging Mind"

In making a decision, there may be multiple options in methods of reducing or not reducing caregivers' care-involvement level, but any choice is likely to have a negative impact on someone in the family. As Wilson (1987a; 1987b) explained in her articles, caregivers are surrounded by negative choices. The balancing of the three issues (availability of outer resources, authority level of the caregiver in the family, and justifiability of tolerance limit) is by no means easy. As a result, most of the time, the caregivers vacillate over the decision of which way to go: The caregiver's mind is constantly swinging among multiple alternatives.

Swinging mind of the caregiver is a characteristic feature of the caregiving experience. It means that the caregiver constantly ponders, without definite conclusions, whether or not her choices in caregiving and her life were, are, and will be, the best possible. Although a swinging mind is most prominently seen at times of decision-making, it characterizes the caregivers' state of mind throughout the course of caregiving: "Well, my mind has been swinging constantly, and after all, how should I put it. I am just dragging the current arrangement as it is, or something like that" (Michiko). Even during an interview, a caregiver's plans about the future and impressions about past caregiving were stated differently on one occasion from another, reflecting this phenomenon.

Three topics of swinging mind. There are three topics on which the caregivers' minds swing. First, the caregivers wonder what was, is, and will be, the best possible care. In taking care of the elderly, often there is no clear answer regarding what is best. The answer is likely to vary, depending on what is considered the most important

aspect of the whole situation. For example, the caregiver's mind swings between what is considered the best for the physical condition of the care recipient and the care recipient's feelings:

> I went to visit her (care recipient), thinking, "Today, I will take her (to the hospital) by any means!" But she said stubbornly that she didn't want to go. She was half crying and said something like she would rather die. At that moment when I saw her in such a state, it occurred to me if it would really help her for me to take her to the hospital against her will. Until then, I really wanted to do something about Mother's condition (delusion that she was robbed). She was also causing some trouble for neighbors. I wanted to do anything to cure her if I could. .... However, when I was looking at her, I wondered the wisdom of my own judgment to force her to go to hospital. (Michiko)

The higher the ideal of role performance of a caregiver, the more her mind tends to vacillate over what is the best, and this causes mental exhaustion of the caregiver.

Second, the caregivers' minds swing between "How long should I continue to take care," and "How long can I continue?" They are recognizing their mounting physical/mental exhaustion, yet they cannot determine if it is acceptable as a daughter-in-law (*yome*) or daughter to voice their state. Endurance is a virtue of women, so they do not want criticism in this area. They must determine the fine line of tolerance limit between the socially-required endurance and the exhaustion of their resources. This is the reason reaching tolerance limit tends to be delayed when exhaustion is the main cause. The caregivers' vacillation becomes most salient when they are deciding upon reduction of the care-involvement level:

> Really, it is a feud between two feelings; that I cannot continue any more and that I wonder if I should continue a little longer. The conflict of these two feelings continued. (Chieko).

Third, the caregivers' minds swing around the question, "Is my life OK as it is?" Caregivers sometimes feel their lives are not acceptable, that they are only giving in to fate and lost in caregiving; at other times, they feel their lives of caregiving are acceptable and worthwhile. As a result, ambivalent feelings on caregiving are experienced:

> There are times when I am very depressed, and Mother's condition is bad, then I really wonder why I have to do this. But there are also good times and bad times for myself, and I swing back and forth between these moments. I am dealing with her as my own conflicts go on. (Michiko)

The essential paradox of care-- high values and extreme difficulties co-existing in caregiving--creates swinging mind over the question of whether their lives are acceptable.

Time dimension of swinging mind. Caregivers' minds swing about future, present, and past. Their thoughts revert to past decisions, and they constantly re-assess those choices even long after the decision was made. This is especially common following a major modification of the caregiving arrangement (e.g., institutionalization of the care recipient). Their thought is most strongly influenced by the consequences of any given choice: If the consequence was acceptable, they believe their decision to be right; if the consequence was unacceptable, they dwell on what other options should have been employed. If the consequence is not acceptable, they may reverse the past decision.

The caregivers' minds also swing on what the best possible care for both the present and future, how long they can and should continue caregiving, and whether their lives are and will be acceptable. Kaoru's mind is swinging over future institutionalization of her mother-in-law:

> If I myself say that it is the limit and I cannot take care of her at home any more, I think he (caregiver spouse) will say, "OK, then we have to think about

> finding some place for her." .... I don't know myself which or what to do. I don't know what is the best. .... I wonder my mother(in-law) would be happier there (long-term-care facility). .... On the other hand, I also think those smiling staff (at the facility) are not your own family. I wonder if she may be happier when she is with her own grandchildren.. Although I am with her, watching closely at her, I cannot judge it. Therefore, the only remaining way to go is that I will decide when I realize myself that her condition has deteriorated to the limit where I cannot take care of her at home any more. .... But even if I decide on moving her, there may be no places to take her with such a short notice (after she decides that she has come to the limit). So I think it is too late to decide at that point. My friend says that I have to wait for several years after I apply for the hospital somewhere. So I have to apply for such hospitals way in advance anticipating when I would reach to that point. But for now, I haven't got to that point yet, so I feel that I can continue to take care of her at home, and I don't know when I should do that (applying for the hospitals).

Caregivers are always uncertain of the best choice, therefore, decisions made are always tentative.

<u>Function of the swinging mind</u>. The caregivers' swinging minds sometimes functions as a coping strategy for caregivers to tolerate an intolerable situation. By not making decisions about the future, the caregiver does not face being overwhelmed by the anticipation of future difficulties. If a decision is made toward continuation of care, it is too difficult to face, so a decision is intentionally avoided. This is balancing their estimation of the duration of care. When the caregiving is estimated to be relatively short, the prospect helps the caregivers cope with the present difficulties. However, if they cannot estimate the duration and feel the caregiving may last indefinitely, swinging mind may help to alleviate the dismal prospect of a long life of caregiving.

Decisions Regarding Reduction of the Care-Involvement Level

The decision-making here is essentially whether or not the caregivers can reduce their care-involvement level, with additional assessment on how that will be accomplished. Caregivers reduce their care-involvement level if they can justify the tolerance limit to themselves; negotiate successfully with other family members at their given level of authority; and, when necessary, outer resources are available. On such occasions, the sense of *ikigai* achieved through being a good daughter or *yome* is secured even after the reduction of the care-involvement level.

On the other hand, caregivers do not reduce the care-involvement level if reduction is considered to put their sense of *ikigai*, available through the caregiver role, at risk. At risk means either they cannot justify their tolerance limit to themselves, successful negotiation with other family members is impossible, or there is no available outer resources (when necessary). On such occasions, caregivers feel either guilty or shameful about reducing their care-involvement level, and this disturbs their sense of *ikigai*. Therefore, they continue to take care at the same or gradually elevated level of care-involvement, pushing up their tolerance limit.

Summary

The three issues assessed in the decision-making toward reduction of the care-involvement level, when they face the sense of tolerance limit, were discussed in the above sections. This important decision is reached through the balancing of availability of outer resources, authority level of the caregiver within the family, and justifiability of tolerance limit. Caregivers decide to reduce their care-involvement level only when the above three issues are resolved. At other times, they can only continue to take care in the same, or gradually elevated, level of care-involvement, pushing up their tolerance limit. Due to the high value assigned to caregiving, caregivers favor pushing up their tolerance limit as much as possible.

Regardless of the decision on reduction of their care-involvement level, they struggle to continue to take care without losing their sense of *ikigai*, using several types of behavioral and cognitive strategies allowed in any given situation. Through such strategies, they attempt to come to terms with the reality of having to take care.

Chapter 6: Result 3

Coming to Terms with the Reality of Having to Take Care: Maintaining the Sense of *Ikigai*

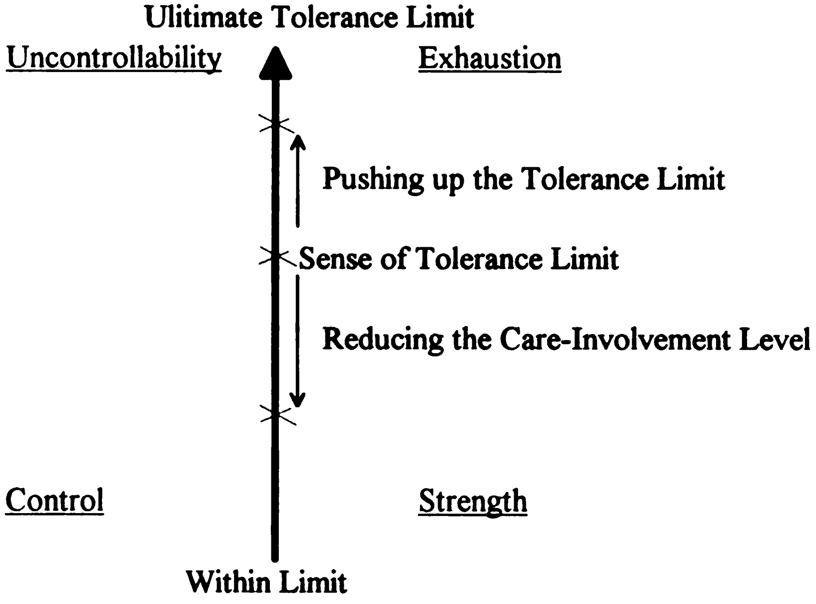
This chapter discusses various strategies caregivers implement to continue caregiving while maintaining their sense of *ikigai*. Through the decision-making explained in the former chapter, caregivers reach either one of the following decisional options: (a) reduce their care-involvement level, or (b) push up their tolerance limit. A reduction of their care-involvement level makes it possible for caregivers to return to a state of within limit. On the other hand, pushing up their tolerance limit enables them to continue providing care in the same or elevated care-involvement level.

This chapter consists of three sections. First, several characteristics of each decisional option taken to continue caregiving are explained. The same characteristics are shared by both decisional options of reducing the care-involvement level and pushing up the tolerance limit, but some are seen mainly in reducing the care-involvement level, while others are mostly seen in pushing up the tolerance limit. Second, various modes of maintaining the sense of *ikigai* are detailed. These are also seen in both decisional options, although, again, an option typically uses some modes while the other often uses other modes. Lastly, the changes in self-understanding that occur during the caregiving experience are discussed. Because the overall process allows these caregivers to continue caregiving and maintain their sense of *ikigai*, it is called a <u>constant attempt to come to terms with the reality of having to take care</u>.

<u>Managing to Continue Caregiving</u>

Each time caregivers face their tolerance limit, they choose to implement either one of the decisional options: reduction of care-involvement level and pushing up their tolerance limit. When the caregivers reduce their care-involvement level, they decide to go down the continuum in the direction of within limit, while when they push up their tolerance limit, they decide to stay at the current level of care or to go up the continuum (Figure 13). Whether reducing their care-involvement level or pushing up their limit, the caregivers continue caregiving; the only difference is in the change of the level of care-involvement. When the choice is to push up their tolerance limit, the care-involvement level is not reduced. When they reduce the care-involvement level, there is less involvement in caregiving, but this does not reflect an abandonment of care responsibilities altogether. For example, institutionalization of the care recipients often allows the caregivers to extensively reduce their care-involvement level. However, even following institutionalization, caregivers are still providing care to elderly parents (or parents-in-law) with frequent visitation. Therefore the caregivers are continuing caregiving in both decisional options.

Figure 13: Pushing up the Tolerance Limit
& Reducing Care-Involvement Level in Limit Continuum
(created by the author)



Although the either one of the two decisional options is taken by the caregiver to manage tolerance limits, they are not the only methods caregivers have available to them to return to the state of within limit. Caregivers' actions are first of all regulated by the condition of the care recipients which is characterized by sporadic ups and downs and times of sudden deterioration due to such incidents as temporary infections or common cold. Such a rapid change in care recipient condition often deprives the caregivers of their sense of control and they often reach the sense of tolerance limit. However, the care recipients' condition can also improve with time and caregivers can return to the state of with in limit without mobilizing either one of the two decisional options upon the care recipients' recovery.

Reduction of Care-Involvement Level

The reduction of the caregivers' involvement level in the act of caregiving is accomplished in two ways: outer resource mobilization or simply decreasing the level of attendance to the care recipient.

When caregivers mobilize any outer resource, the choice of resource depends on various criteria of availability previously discussed. Usually, the resources (services) involving shorter duration are used before those involving longer duration such as short stay or long-term care facilities. This is due to the caregivers' perception that the shorter the duration, the lower the risk to the care recipient. However, the quality of the resource will also be a strong deciding factor.

Some caregivers, upon justifying their tolerance limit, simply decrease the level of attendance. Akiyo describes:

> So, since then, even if she wanders out at night, I say to myself, "If she gets hurt, the hospital will take care of her." I have become impudent. Before, when she wandered out, I had to take the drug (for angina), because my heartbeat got faster (and another attack may come), and I went to search for

> her. But now, I even say to my brothers(-in-law), "Somebody will find her and the police will bring her home, so why don't we just sit and wait?" Thus I became less perturbed. .... Since then, I begin to think if accident happens, it happens. So that's OK. [laugh] Now I am just waiting impudently. Before, I was always worried, but nowadays if I want to have a rest like on Sundays, I lock the door of her house. And now I can let her be alone for a couple of hours. I couldn't do that before, and I had go check on her every so often. .... Now I let her be alone. I began to feel more relaxed, and I hardly have to use nitroglycerine any more.

Decreasing the attendance level causes caregivers to become less watchful, prone to taking risks, and being dependent on others. Prior to this decrease in attendance level, there is assessment of risk.

Diversionary activities. Caregivers sometimes incorporate enjoyable activities to their lives as a means of coping with the difficulties of caregiving; these are refereed to as "diversionary activities." Such activities often can only be realized along with justification of their tolerance limit and reduction in the care-involvement level, but some time can be devoted to such activities while retaining the former care-involvement level. What is perceived as diversionary activity varies among individuals. Examples include playing sports such as tennis or golf, studying in the community college, painting or dancing, working part time, volunteering, and so on. One caregiver described taking care of her sister-in-law as a good diversionary activity.

Diversionary activities help the caregivers forget the difficulties of caregiving temporarily, and provide a sense of enjoyment in their lives. As a result, they feel compensated for the difficulties and they can escape from the sense of tolerance limit.

Caregivers are often able to justify their tolerance limit and the time spent in diversionary activities only because the activities enable them to continue caregiving.

For example, Mayu was clear that a caregiver has to take care of herself and justify her tolerance limit, to some extent, <u>in order to continue caregiving</u>:

> I tell my friend (who is also a caregiver) to take care of her self, instead of telling her that she is noble (great). It is useless to be told that you are great for a million times. I tell her to take care of herself and to make most of (short stay of) R and M. .... I tell her to stop making excuses for using short stay and to utilize those services as much as she can. I tell her if she becomes ill, her mother will be in trouble. I tell her to take care of herself. There is no other way. I have never told her she was great. It is not the issue here whether you are great or not. I don't think there is anything great about not taking care of oneself.

<u>Consequence of reduction in care-involvement level</u>. The reduction of the care-involvement level is usually effective in allowing the caregiver to escape from the sense of tolerance limit and go back to the state of within limit. Kaoru described the relief of this escape when she began to use day care:

> Well, I felt really different. Two days a week, I had free time. <u>I felt as if the view in front of me turned so bright</u>. I experienced two occasions in which I feared I would be finished before long if things didn't change.

Reduction of the care-involvement level is not a frequent occurrence. More often, caregivers cannot accomplish reduction and tolerate the intolerable, pushing up their tolerance limit.

<u>Pushing up the Tolerance Limit</u>

Pushing up one's tolerance limit means that the caregiver, upon balancing the issues in caregiving (availability of outer resources, authority level within the family, and justifiability of tolerance limit), takes no action toward reducing their care-involvement level. Caregiving is continued at the same or gradually elevated involvement level without mobilizing outer resources. There are two characteristics in the phenomenon of pushing up one's tolerance limit: *shikatanai* (no way out) and *akirame* (giving in; acceptance), and perceptual modifications.

Shikatanai and *akirame*. A central feature of pushing up one's tolerance limit is recognizing the state of no way out (*shikatanai*) and acceptance of the inevitable (*akirame*). When caregivers assess that the care-involvement level cannot be reduced, they feel *shikatanai* and accept the reality of having to take care without the reduction of their care-involvement level.

The attitude of *shikatanai* and *akirame* is deeply embedded in the Japanese way of thinking (Chapter 2). Because of their fatalistic view of life, Japanese people tend to accept their *un* (luck, fate, destiny) without much resistance. One's *un* can be good or bad at different times, and good behaviors in daily life are considered to call for good *un*. Therefore, by working hard and diligently in providing care to the elderly parents, caregivers can hope for future good luck. That you must *akirame* and accept your lot is a teaching passed from generation to generation, and emphasized at times of adversity:

> My mother used to say, when she was alive, "Human being is not good when everything is satisfactory and fulfilled. That means you are only going to lose something. Having one bad thing in life is, therefore, a good status." So, I think this is the time for this bad thing. I think it is the hardest now. I have done with child-rearing, so I think this is the worst time in my life. (Akiyo)

It should be emphasized that *shikatanai* or *akirame* is not used only in the negative sense of desperation in the caregiving experience. The word *shikatanai* or *akirame* is also not a blind submission to fate. It assumes earlier rigorous struggles to search for a way out of the trouble. Therefore, when *shikatanai* is heard, it sends the message that everything within human power was done and it is time to accept the inevitable. Furthermore, *shikatanai* or *akirame* signifies a turning point; a place to gather the momentum necessary to make a change in their perceptual reality. By putting an end to the constant search for an escape, caregivers attempt to transcend their emotional disturbance and provide their best in the situation. In this sense, *shikatanai* or *akirame* is not a mere resignation but implies a positive attitude, similar to when people consider stressful events as challenge. As a result, daily life is tolerable:

> Since sometimes around the last fall, I began to think that whatever I told my siblings, in the end I have to take care of her. It's my feeling (the sense of resentment). .... Because I have to do by myself anyway, it was *shikatanai* (of no use) to complain and criticize them. Once I decided that I was going to do it by myself, it took a weight off my mind. (Shinobu)

The Japanese often feel the excessive struggle to resist *un* (luck, fate) ugly ("being a bad loser"). There is a sense of sophistication felt in the notion of *shikatanai* and *akirame*; it is an ethos inculcated in Japanese socialization. A similar attitude is seen also in Western societies: playing the hand you are dealt. However, it seems that this resignation is encouraged more in Japan, as indicated by the fact that there is no literal equivalent of *shikatanai* in conversational English used as commonly.

Aspects of caregiving taken as *shikatanai*. *Shikatanai* and *akirame* are used for several aspects of caregiving. First, *shikatanai* can be felt regarding the illness of dementia and aging of the care recipient. The gradual recognition and understanding of the illness guide the caregivers to accept inevitable human aging and dependency, and they lead them to have sympathy (*omoiyari*) and a sense of pity (*kawaiso*, *aware*) for the care recipients. Together, these feelings can build a strong motivation to continue caregiving, even at times of extreme difficulty (Chapter 4). They occur especially when the caregivers keenly recognize the pathetic deterioration of the care recipients. In other words, feelings of sympathy and pity do not occur as long as the authority level of the care recipients remains high. These feelings can sometimes help the caregivers resolve a long-standing grudge or animosity toward the care recipients. Rie, who had much to grudge against her father-in-law, noticed that her negative feelings melted when she perceived him as a weak, old man:

> I felt sorry for him when I heard he did nothing but worrying about money while he (the care recipient) was in the hospital lying in the bed. However often we told him not to worry, he worried the same. ... So I said to him, "You can stay here. Don't worry. This is your son's house, so you can stay here as long as you want." I feel a little bit *kawaiso* (pitiful; pathetic; sorry) when I imagine him worrying about it all night. .... Well, he grew old, and it is something like my sympathy toward the old, the infirm. (Rie)

Some caregivers feel *shikatanai* regarding an <u>unsatisfactory level of outer resources</u>, and it helps them to push up their tolerance limit. They accept other family members' lack of willingness to help, illness recognition and understanding, and they accept the essential difference between themselves and other family members. They also accept the unavailability of formal resources, regarding it as *shikatanai*. The strong sense of resentment caregivers sometimes adopt immediately after recognizing the unavailability of a certain resource can be overcome when they can feel *shikatanai* toward the situation. *Shikatanai* signifies a turning point where they discontinue looking to others for help.

The amount of time before caregivers feel *shikatanai* in respect to the unavailability of informal resources depends on their level of expectation toward the resources. If expectations are high, it takes time for the caregiver to feel *shikatanai* when those expectations are not met, and strong resentment ensues. Caregiver expectations are influenced by several attributes of other family members and the level of family boundary. Typically, the care recipient's male children, especially if they are single, are not expected to assist with caregiving. If a male child is married, the caregiver expects help from his wife. Expectations toward the caregiver's own husband regarding physical, hands-on assistance are usually not high, as long as the husband shows understanding and appreciation toward the caregiver. The physical condition of other family members (e.g., illness), age of their children, and geographical distance also influence the level of the caregiver's expectations. Additionally, when the family boundary is low and there is much exchange of various kinds, the caregiver's expectation toward other family members regarding assistance in care is usually high (Chapter 4).

The caregiver's sense of *shikatanai* and *akirame* can be focused on the caregivers' <u>perceived reality that they have to take care</u>. The feeling of *shikatanai* toward the aspects of aging and illness or unavailable outer resources can be seen in the other decisional option of reducing the care-involvement level, but *shikatanai* toward the reality of having to take care is essential in the option of pushing up one's tolerance limit:

> After all, she (care recipient) cannot do anything by herself. So I cannot leave her alone. People often tell me that I work so hard, but I say to them, "Everybody would do the same, if she were in my position." Unless somebody takes care of her, that family goes to pieces and ruined, and she herself becomes a wreck. If you live with her, you have to take care of her. However much you hate it, you have to help, because I don't think there is anybody who can leave a person in such a condition alone. If you have to see her every day in front of you, and she talks to you, you have no choice but to do it. (Akiyo)

> Now I think it is my fate. When I came here to be *yome* (daughter-in-law), she was healthy and a good mother-in-law to me. She was quite nice to me. She was a nice person. But since 10 years ago, she has been suffering from this illness. While Grandpa was around, it was still OK. But after a while he passed

> away, and she got worse. I cannot get out of this predicament, however much I hate it. I am already in it, so I think this is a destiny. (Akiyo)

Perceptual modifications. Another characteristic involved in pushing up the tolerance limit is the conscious or subconscious modification of the caregiver's perception of reality so they can tolerate the difficulty of caregiving. Perceptual modification is explained as a coping strategy in Western literature (e.g., Pearlin & Schooler, 1978), but this strategy is emphasized more in Japan in relation to the attitude of *shikatanai* and *akirame*.

There are several ways of perceptual modifications used in pushing up the tolerance limit. Accepting the reality of having to take care itself requires a perceptual modification. Caregivers tell themselves, again and again, to accept caregiving as their fate based on the cultural notion:

> I think I happened to be unlucky. I met these two people by chance (caregiver's husband and care recipient). So it's my destiny. I always call it my destiny. .... I chose him... and it is my fate. So I think it's *shikatanai* because it is my destiny. Of course I feel I am unfortunate, and I don't like it. Compared with more fortunate people, I wonder when I will be able to go on a trip by myself. .... I wish I could travel somewhere without worrying about preparing meals or being rushed by time. .... But I cannot do so because of my destiny, but I don't feel I am happy being in this situation. .... But I don't envy others, because it is their destiny. As for me, caregiving was brought forth by the person I chose (to marry), so it is my destiny. (Mayu)

Additionally, caregivers modify their perception of themselves and caregiving; some can even regard their difficulties and troubles as worthwhile. Caregivers intentionally and forcefully make themselves think in certain ways to enable continuation of caregiving. One example is when the caregiver attempts to normalize the situation to adjust to it, as Chieko describes:

> At first we didn't take a bath because the water was so dirty. But when the weather got colder, it was *shikatanai*, so we resigned ourselves to taking a bath. But human nature is so strange. We could take a bath even in such dirty water. We began to think it's O.K. and at least we got warm this way. We knew we were not getting sick by taking such a bath and we thought we had better be thankful for a warm bath. It is a matter of getting used to, and it is a part of living, a part of a family life.

The meaning of caregiving for caregivers themselves also receives perceptual modification. For example, Naoko modified the meaning of caregiving from the act of love for her family to a "job" as *yome*. This modification enabled her to stop seeking reward in the appreciation and understanding of other family members; instead, she found reward in diversionary activities. Whether caregivers can modify the meaning of caregiving partially depends upon their illness recognition and understanding, and their level of tolerance limit. When the sense of tolerance limit is profound, perceptual modification is not easy. When illness recognition is not enough, the modification of perspective is often impossible:

> Now I have some room to think (that my life is also important), and I wonder now may be the time I can do this. I wasn't in such a frame of mind before. Until we were told of her Alzheimer's disease, I didn't know what to make of her. I didn't even want to see her face. (Naoko)

Some caregivers use positive thinking, rather than keeping themselves in despair: "I think there is no other way but to try finding some enjoyment within that difficult situation" (Tomoko). Another way to modify perception is negative comparison. Caregivers often console themselves by comparing themselves to another in worse condition.

Perceptual modifications sometimes include a change in how the caregivers view their future. They often assess how soon in their future they can justify their tolerance limit, and the image of the goal helps them to alleviate the sense of difficulty and to push up their tolerance limit (Chapter 5). A more crude strategy is to deny visualizing the probable future with a swinging mind: Indefinite duration of caregiving can be overwhelming for caregivers, hence the attempt to continue care without assessing the future (Chapter 5).

Factors to Continue Caregiving

There are several factors making continuation of care possible. These are seen regardless of whether caregivers reduce the care-involvement level or they push up their tolerance limit. The strongest factors are the high values assigned to caregiving based on the societal norm and/or attachment, as well as the various factors that sustain this high value. The cultural ethos of *shikatanai* and *akirame* also play an important role. In addition to these factors, there are other conditions that make it possible for caregivers to continue caregiving.

Caregivers can sometimes continue caregiving because of rewards that come separately from caregiving itself. One common reward is diversionary activities. Small joys experienced in caregiving (e.g., good mood of the care recipient; occasional outings with family) are also rewarding. These rewards are small and not enough to form motivation to continue caregiving by themselves, but they help alleviate the difficulty of caregiving. These are "uplift" similar to those examined by Kinney and Stephens (1989). Financial benefit from caregiving is an important motivation. Although the cost of institutionalization is supported partially by the government, it can still be high. Especially if the caregiver is a housewife, continuing caregiving at home saves money for long-term care.

Other factors enabling the caregiver to continue caregiving are not active, but passive, situational determinants (e.g., no siblings). Such situational determinants prevent the caregivers from quitting caregiving, and indirectly motivate them. Some caregivers expressed that had there been any siblings, they could not have continued caregiving because it would have seemed as unfair difficulty for them.

Several caregivers emphasized the consequential gains that are separate from the actual caregiving. For example, Michiko mentioned that she met people she never would have otherwise. Many caregivers stated that caregiving grew them to be more tolerant, generous people. They also had opportunities to think about their own aging and death; another example of consequential gain. The importance of the consequential gain lies in the fact that the caregivers can be satisfied with their experience when looking back on their past days of caregiving, and rest knowing that they have done a good thing. They can accept the caregiving experience as an achievement, rather than looking back with regret. This positive appraisal of their past motivates the caregivers to continue caregiving even further.

Caregivers sometimes find that the mere knowledge that a certain outer resource is available when they become desperate helps them to continue. Although the present caregiving arrangement is unchanged, just the knowledge that a future safeguard is there allows them to push up their tolerance limit and to continue caregiving.

Personality style is an indirect influence on endurance:

> To begin with, I think, I have been like that all my life. Since I was a small child, I have been doing what others don't like to do. .... I did what others don't want to do. .... By doing it, if the other person felt good, I felt good, too. .... Also as for the job of *yome*, I do it because I like to see others pleased, enjoy the food, and feel happy in the clean rooms. So if others are happy about something, then I am happy about it, too, and I am pleased with what they are pleased about, too. I think I take things simple and easy. .... So, if Mother(-in-law) or Father(-in-law) is pleased with what I do for her, (I don't mind taking care of her at all). (Naoko)

The caregivers' personality is added as a factor to continue caregiving because the factors mentioned above do not explain all of the variation seen in the interviews. Individual caregivers not only possess very different personality traits but also have very different past experiences that shape their self-understanding and characteristic behavior patterns. It is therefore important to address the influence of personality style on the caregiving experience along with other conditions.

Maintaining One's Sense of *Ikigai*

In the former section, I explained how the caregivers manage to continue caregiving, either by reducing their care-involvement level or by pushing up their tolerance limit. In this section, I revisit the same phenomenon of managing to continue caregiving, but I visit this issue now from a different perspective--how the caregivers maintain their sense of *ikigai* throughout the struggle of continuing caregiving. Caregivers are not only managing to continue caregiving, but they are doing so while struggling to restore or maintain their sense of *ikigai*. This makes the overall process of caregiving a constant attempt to come to terms with the reality of having to take care.

Japanese Caregivers' Pursuit of *Ikigai*

Japanese caregivers are struggling to maintain or restore their *ikigai* within the extreme difficulty of caregiving. Although it may appear they are merely tolerating the intolerable in acquiescence, pushing up their tolerance limit, they are, in reality, not simply allowing their fate of difficulty to assault them and make them feel miserable. They do accept difficult caregiving as their fate but moreover, they are struggling to maintain their *ikigai* as well, going beyond the mere acceptance of fate.

An overarching purpose of various modes of *ikigai* pursuit, as seen below, is to live a life true to one's value, although one's value may change over time. In this sense, it seems that Western ways of seeking happiness and Japanese pursuits of *ikigai* share the same ground. However, the Japanese caregivers' modes of maintaining *ikigai* emphasize different points from those of Western people seeking happiness. The Japanese caregivers' way of maintaining *ikigai* often cannot be as straightforward as quitting caregiving, because of the very high value assigned to caregiving. Casually quitting caregiving also causes guilt, because, in Japanese society, one's happiness is not sustained alone but by the happiness of those around you. Therefore, caregivers' strategies to maintain *ikigai* need to be more perceptual and careful, preserving the well-being of those around them. The value system also varies among Japanese, and this difference is reflected in the variation seen in the definition of *ikigai* as well as the modes of *ikigai* maintenance they choose.

Modes of maintaining *ikigai* and the level of tolerance limit. There are several modes of how they maintain their sense of *ikigai*. Various conditions, in particular the level of tolerance limit, influences the choice of *ikigai* maintenance modes. However, it should be mentioned first that an individual's definition of *ikigai* according to their value system largely determines which mode is used, and that there is no single formula to determine which caregiver, in what kind of condition, will use which mode of maintaining their sense of *ikigai*. Also, multiple modes are often used at any given time. In this sense, the level of tolerance limit is but a small factor of influence in the choice of the mode of *ikigai* maintenance. This is a cautionary point to consider in the following text.

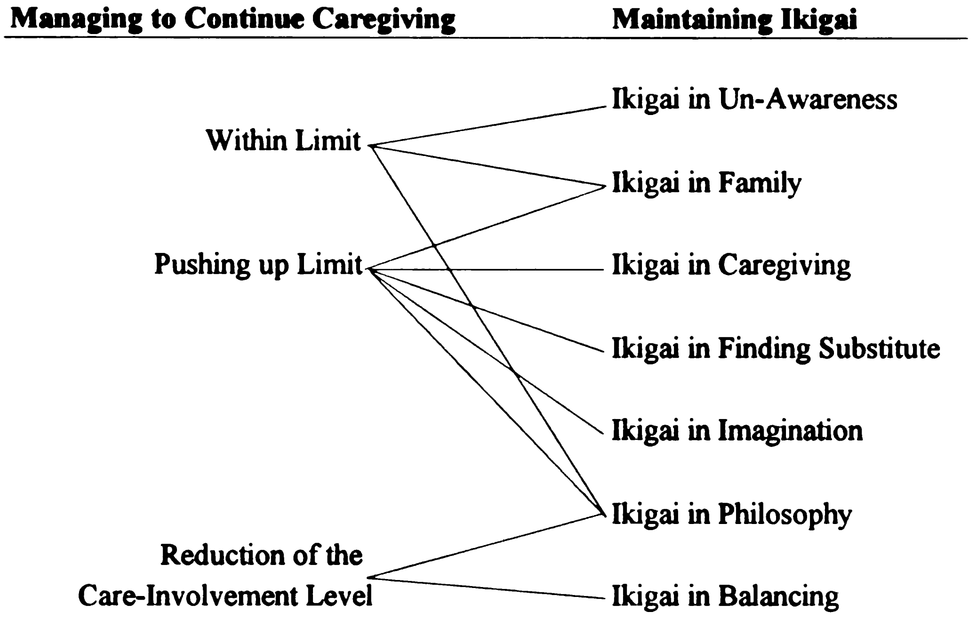
When caregivers are not sensing their tolerance limit, the sense of *ikigai* is maintained in un-awareness. As the caregiving increases its difficulty, caregivers begin the attempt to restore or maintain the sense of *ikigai* that is at risk because of the difficulty in caregiving. This is done by identifying one (or more) specific experience(s) in life as their source of *ikigai*. The specification of the source of *ikigai* is done for the most part subconsciously, but depending on their definition of *ikigai*, caregivers may have a clear awareness of what experience serves as the source of their *ikigai*, no matter how much the level of their tolerance limit is.

Modes of maintaining one's *ikigai*. There are seven modes of maintaining the sense of *ikigai* seen in their interviews: (a) maintaining *ikigai* in un-awareness, (b) maintaining *ikigai* in caregiving, (c) maintaining *ikigai* in family, (d) maintaining *ikigai* in finding a substitute, (e) maintaining *ikigai* in imagination, (f) maintaining *ikigai* in philosophy, and (g) maintaining *ikigai* in balancing. The situation of losing the sense of *ikigai* is also explained.

These modes are essentially not mutually exclusive; rather, they are overlapping one another. For example, a certain diversionary activity may be sought as a way to find a substitute (mode (d)), and balancing between the diversionary activity and caregiving may be a caregiver's way of maintaining her sense of *ikigai* (mode (g)). The reason the seven modes are presented is that they reflect how the caregivers themselves perceived and described their *ikigai* maintenance in the interview. Some caregivers focus on the fact that they are carefully balancing the conflicting roles, while some other caregivers focus more on the fact that they found a substitute for their past source of *ikigai*. This variation essentially reflects, again, each caregiver's value regarding their daily activities.

Many modes of maintaining the sense of *ikigai* are perceptual modifications and therefore are seen in pushing up one's tolerance limit. However, some modes are also seen through the reduction of the care-involvement level. The general relationship between the decisional options and the various modes of maintaining *ikigai* is summarized in Table 5.

Table 5: Typical Relationship between Decisional Options and Modes to Maintain Ikigai



Maintaining *Ikigai* in Un-awareness

Caregivers sometimes have no idea what their *ikigai* is, and this constitutes one mode of *ikigai* maintenance. This lack of awareness is due, in part, to the individual's definition of *ikigai*. That is, some define *ikigai* as a private enjoyment which they cannot indulge when they are busy with work, caregiving, and child-rearing. *Ikigai* is considered a luxury, and therefore the caregivers currently have no conception of it. In addition, however, there is a tendency that *ikigai* is not in cognition when life goes smoothly without difficulty. When people are totally absorbed in daily life with a certain level of satisfaction, and therefore, their lives present no reason for them to question their lives in light of their value, the thoughts on *ikigai* tend not to surface. As a result, *ikigai* is maintained in their un-awareness. This condition has also been explained by Kamiya (1966).

In the context of caregiving, maintaining *ikigai* in un-awareness is often seen when caregivers are in the state of within limit--where they have the personal resources in reserve and when the situation is more or less controlled. Some difficulties may exist in caregiving or other areas of their lives, but these are minor and the values of caregiving and other life experiences easily overpower the difficulties. Alternatively, *ikigai* is not regarded when the caregivers' belief in the value of caregiving is strongly held and they are not challenged in their daily lives. Mayu says:

> Because I am intent on living wholeheartedly, because I live wholeheartedly, I guess it is serving as my *ikigai*. Because I devote myself to accomplish everything, I lose myself in them. .... I have no time for pondering about such a thing as *ikigai*. I have to go to give her (care recipient) a bath every other week, and on Tuesdays I distribute boxed lunches. I have been working in the lunch distribution program for a long time, and I do this even when it rains or no matter what. So, I never have time for thinking about *ikigai* or something to live for. I don't even know how to answer to such a question. .... I don't have anything like that (*ikigai*). Instead, I just do things because I live wholeheartedly.

Elevating Difficulty and Awareness of *Ikigai*

Even when there is no crisis in life, people sometimes wonder what their *ikigai* is. This questioning often accompanies feeling of vague frustration in their lives or discomfort. Then they begin to review their lives and seek answers to such questions as: "Is my life acceptable in this way?" In other words, one begins to take a close, conscious introspective look at one's subjective self: "Who am I? What is my life?": "I sometimes wonder what my life journey is for" (Chieko).

> I feel anxious with hurry. I ask myself, "Is it all right to get old and die in this way? For what I have been living so far?" .... Because I have done nothing but working. .... In our day, when you became of age, your parents hurried you to marry. I married that way, too. .... After marriage, I got busy with

> work. [laugh] I worked day and night, and for the rest, I just raised children. .... I want to do something, but... .... I wonder what my life has been. I only worked and raised children. (Hiroko)

In the context of caregiving, elevating difficulty and a mounting sense of tolerance limit precipitates the conscious thought of *ikigai*. Caregivers may still be in a state of within limit, but they are beginning to sense the elevating difficulty. They then begin to identify specific experiences or activities in life as their source of *ikigai*. There are some variations in what is identified as the source of *ikigai*, as explained below.

Maintaining *Ikigai* in Caregiving

When internalization of the societal norms regarding filial caregiving is strong and there is no way out of caregiving for an extensive period of time, caregivers sometimes come to perceive caregiving as the source of their *ikigai*, even subconsciously at times. Akemi, a *yome* caregiver providing care to her parents-in-law for over ten years said, without hesitation, that caregiving is her *ikigai*. For her, caregiving is also a source of great pride as a housewife. In fact, she and her family have been the focus of a national TV program as "a model family of home care." Thus, once caregiving is believed to be a source of *ikigai*, working as a caregiver can, in turn, give the caregiver energy to live an active life with contentment. Many of the normative roles assigned to women are experienced in a similar manner: child-rearing, cooking, and other household chores. These roles are often assigned high value, and proper actualization of the role is considered to be the sources *ikigai* for women.

When a caregiver cannot find a way out of caregiving, she may force herself to consciously think that caregiving is the source of her *ikigai*, in order to maintain her sense of *ikigai*. Thus, identifying a certain experience as *ikigai* can be conscious and forceful as well as subconscious and natural. This intentional and forceful perceptual modification is necessary in order to believe that one's life is good and acceptable, thus avoiding the sense of despair:

> Now I think taking care of Mother is something like my *ikigai*. I sometimes think so. From time to time, I wonder what my *ikigai* is. .... Well, I think the main *ikigai* of mine is caregiving of my mother. Sometimes I feel wretched if I don't think that way. Sometimes I wonder what my life has been. [laugh] .... I have to believe that taking care of Mother is my *ikigai*. I have to believe that, otherwise I feel empty. I sometimes wonder what my life is. I think that how you do in caregiving depends on how your mind is set. My feeling swings, too. Sometimes I feel if I tell myself that caregiving of my mother is my *ikigai*, my hope can be diverted. But sometimes I still wonder what indeed my life is (meaning "isn't it meaningless?"). Because my health is not so good, as you see, my feelings swing all the more. (Emi)

One caveat for maintaining *ikigai* in caregiving is that the caregiver may lose their sense of *ikigai* following the death of the care recipient. Several caregivers spoke of their neighboring family caregivers becoming severely depressed after their care recipients passed away. Losing their source of energy to continue, they became depressed. This condition is referred to as caregiving dementia (*kaigo boke*) by the caregivers. These caregivers had gradually lost other roles in their lives due to their involvement in caregiving, so when the need for caregiving disappeared, they felt they had nothing else to live for.

Maintaining *Ikigai* in the Family

Given the societal norm that grants high value to the women's role in the family, it is not surprising that many caregivers cite maintenance of family harmony and health as their first and primary *ikigai*. Taking care of elderly parents is considered to be a part of the whole mission to maintain family harmony and health:

> Caregiving, well, and *ikigai*, after all for me, all of them, how should I put it, they are inseparable. They are myself, my husband, children, and that I am able to do what I like. I feel all of these things together make one *ikigai* for me. [interviewer: "So, you mean a matter of Grandma (care recipient) is also embraced in it?"] Yes, it is like a set. Yes. (Kaoru)

Caregivers' source of *ikigai* can be their own children, especially when their children are young. In this case, caregiving may not be included in their *ikigai*, and watching their children grow gives them the encouragement needed to live the current difficult life of caregiver.

Maintaining *ikigai* in the family is seen mainly in the state of within limit or pushing up the tolerance limit. Family as the source of *ikigai* tends not to be identified in clear awareness. It is only when asked by the interviewer that these caregivers, with much consideration, verbalized what was felt as their *ikigai*, as shown in the interview above. In other words, family as *ikigai* is taken for granted by many caregivers and therefore they tend not to consciously identify it as such.

Maintaining *Ikigai* in Finding a Substitute

There are some occasions where *ikigai* is maintained in finding a substitute for the activities that were given up due to the increasing demand of care. Some of the activities they had to give up may constitute an important source of *ikigai*. In this situation, their sense of *ikigai* is threatened. Alternatives are then sought to meet their individual need for satisfaction. Even if the alternative activities do not satisfy the caregiver as much as the ones they once enjoyed, a compromise is accepted because the value of caregiving itself serves as a source of *ikigai*:

> Each time when you have something you cannot do (because of the roles you have to play such as caregiving), even if you want to, you find something else you can do instead of the very thing you want to do but you can't. Then it is *shikatanai*, so for the time being you go ahead with what you can, and save what you really want to do till you can. .... What you want to do now is, of course naturally what you really like to do, but the circumstance does not allow you to do. Going on a trip may be one of my *ikigai*, even though I cannot travel now. But I am free to think that I want to do it when the circumstance allows me to do it. .... Yeah, I nurse it (in my mind), and at moment I do what I can, such as knitting or sewing. I can do these things here and now. .... I am happy about what I am doing now, because I'm creating something by knitting and sewing. If my daughter goes to work wearing it, that makes me happy in its own way. Even if I have some dress-up clothes, I didn't put them on at all last summer, because I was so busy with caregiving and no time for going out. I cannot dress up and go out now, but I can let my daughter have some nice clothes. That is one *ikigai*. The time comes when the circumstance allows me, I have many things I want to do. But if I do them now, that causes trouble. (Rie)

Thus, caregivers try to enjoy the replaced *ikigai* as much as possible within the circumstances of their caregiving arrangement. Because enjoying such activities still offers some satisfaction, and therefore encouragement to her life, it works to allow the caregiver to continue providing care.

The higher the value the caregiver assigns to caregiving, the less it matters what she can do in her limited leisure time. Simple diversionary activities may suffice. However, when a caregiver cannot assign high value to their caregiver role, giving up certain activities may be very difficult, and finding a substitute may not maintain the sense of *ikigai*. Also, when the caregivers have to give up important activities for their sense of *ikigai*, finding a replacement can be difficult.

Maintaining *Ikigai* in Imagination

When caregiving becomes demanding and there is no time to spend for other activities at all, some caregivers turn to imagining or day-dreaming about their future freedom from their caregiving responsibilities. Such dreams cannot be realized now because of their caregiver role, but they keep the thoughts active in their minds, nurturing them for later realization:

> Recently I think there is no *ikigai*. But after I send Mother off (meaning when she completes caregiving), well, I shouldn't think about that, but sooner or later she will depart from life, then I think I will be able to have my *ikigai*. (Miho)

The imagined *ikigai* is a hope for the future that enables them to tolerate today's difficulty. These caregivers retain hopeful expectations that their lives following caregiving will be joyful and lucky as reward for the virtue of filial caregiving. For Akemi, the expectation that she can play tennis as much as she wants when she completes caregiving makes it possible to tolerate her present difficulties. The hope for future luck may be further encouraged by other family members as well. For example, Akemi's husband wrote in his photo journal of caregiving, "After this, there will surely be something good waiting for us. So let's hold out, just for some more time."

Imagined future *ikigai* may be related to current difficulties, and current difficulties can have value in connection to future *ikigai*. For example, Toshiko and Chieko are considering future careers in helping other family caregivers in similar situations, thereby making good use of their own experiences. They expressed that such an occupation could be their *ikigai* in the future. This future planning is done in order not to lose their current sense of *ikigai* by feeling their life being sacrificed by

caregiving. Rather, in order to make sense out of their current life, they cultivate hopeful expectations of using the caregiving experience for their future *ikigai*.

Thinking about the future is practiced frequently when the duration of caregiving can be estimated. When estimation is difficult and caregivers cannot visualize their goal, imagination may be a fantasy of better life almost unrealistic to their future. Again, the word *ikigai* is equated to hope. Rie dreams about going to Disney Land, knowing that it is impossible in the near future. Akiyo can continue caregiving by fantasizing about being alone. In fact, she actually purchased an apartment room to be alone, and she occasionally enjoys solitude there. This partial realization of her fantasy is a symbol for her hope, and it is her safety valve when extreme difficulty ensues.

Maintaining one's *ikigai* in imagination is often used when a caregiver pushes up her tolerance limit extensively. However, it is also observed with reduction of the care-involvement level, when the reduction is necessary to maintain minimum hope for the future. Akiyo justified her tolerance limit and reduced her care-involvement level when she realized her life was at risk: "When I get through this (caregiving), I believe I will be free and I earnestly hope to be healthy at that time. It will be rotten if I am not healthy when I am 60 or 70 years old" (Akiyo).

Maintaining *Ikigai* in Philosophy

For some caregivers, their philosophy of life serves as their source of *ikigai*, regardless of the circumstances in caregiving. These caregivers achieve satisfaction when daily life meets requirements of their philosophy, and what they actually do does not matter: "I don't think it really matters to a person whether one can or cannot do something" (Reiko).

Concrete activities perceived as actualization of philosophy vary: caregiving, keeping family harmony and health, balancing caregiving and other personal activities,

and so on. This mode of maintaining *ikigai* is seen among caregivers in both decisional options. Some caregivers' philosophy may work to justify their tolerance limit and in reducing their care-involvement level, while others' philosophy may help caregivers push up their tolerance limit and in the further endurance of difficulties of caregiving.

Maintaining *Ikigai* in Balancing

Many caregivers find life fulfilling when they are able to keep a balance between their responsibilities as housewife and their needs for personal enjoyment. Balancing multiple roles successfully becomes a source of *ikigai*:

> *Ikigai*? It may be going to work. It may be handling various things, continuing my work outside home, taking care of children to some extent, and seeing my old age. .... If I am asked what my *ikigai* is, I'll say it is to stay on my job, reconciling home duties and my job. (Hatsue)

The societal norm calls for Japanese women to be supportive to others (especially family). It therefore often constitutes one source of *ikigai*. However, doing things for others only is not sufficient for them as an individual. Naoko says:

> It is really sad if caregiving is my *ikigai*. Somehow. Because caregiving constantly requires suppressing myself. After all, caregiving is to put yourself in a care recipient's place, thinking what is the best for that person, isn't it? When you think about it, there is very little concern for myself. Therefore, it is hard to keep on caregiving only.

Naoko also said afterward that caregiving is <u>one</u> of her *ikigai*. It is a juxtaposition of the group-oriented, presentational self (to do things for others) and the individualistic, presentational self (to do things for myself) that is needed by these caregivers: "Grandfather (care recipient) is not <u>all</u> of my *ikigai*" (Rie). This is the reason balancing can be a source of *ikigai*. The mode of maintaining *ikigai* in balancing is often

employed when the caregivers reduce their care-involvement level, or when caregiving is still within tolerance limit.

When balancing multiple roles is successful, these roles are mutually enhancing. For example, due to limitations in areas of her family responsibilities, Naoko can diligently enjoy her English classes, and concurrently, because she is enjoying herself in these classes, she is further motivated to fulfill her responsibility as *yome*. Thus, one can make one's life fruitful and satisfying by balancing multiple roles.

The balancing of the caregiver role and other activities is influenced by the estimation of how soon caregiving can be completed. When the condition of the care recipient is profoundly deteriorated and the caregiver can anticipate completion of caregiving soon, outside enjoyment can easily be temporarily sacrificed. On the other hand, if the duration is unknown, they cannot wait until caregiving is over. Thus, the desire to balance caregiving responsibility with personal enjoyment is likely to be stronger in the case of caregiving of relatives with chronic illnesses. Although unconfirmed, this distinction can be seen in comparisons between caregivers of people with acute illnesses and those with other chronic illnesses.

Failure in Maintaining *Ikigai*

When any of the above attempts to maintain *ikigai* are unsuccessful, there is a point where desperation overwhelms the caregiver and they are unable to identify a source for their *ikigai*: "*Ikigai*... I guess *ikigai* means to live on without committing suicide" (Sachie). Some caregivers had physical problems (e.g., angina pectoris, occasional fainting, backaches), excessive alcohol consumption, or various negative thoughts including hurting the care recipient. Such situations can be explained as final failure in maintaining *ikigai*.

Maintaining the Sense of *Ikigai* and Caregiving

The various strategies to maintain the sense of *ikigai* reveal caregivers' struggle to make sense of lives that are not always under their control. The life view of many women in Japan is deeply embedded in societal norms: roles as *yome*, wife, daughter, and mother. Therefore, their *ikigai* cannot be maintained in a form that threatens their identity as *yome*, wife, or daughter. Japanese caregivers attempt to pursue their *ikigai* in a way that is compatible with their given environment, rather than creating conflict between their *ikigai* and caregiving role.

The societal norm of filial caregiving, expected mainly of women in Japan, sometimes conflicts with the principles of independent pursuit of well-being which are more prevalent in Western societies. Japanese caregivers also seek individual fulfillment and happiness. Rather than blatantly rebelling against the valued societal norm, however, Japanese caregivers interviewed have developed strategies to find a compromise between the societal norm and individual fulfillment, although this is not easy. Their strategies are perceptual modifications and careful reduction in their care-involvement level, for the purpose of maintaining the sense of *ikigai* in the continuance of care.

Such decisional options and modes of maintaining one's *ikigai* may be criticized as a result of oppression by the societal values of Japan. However, these strategies are highly adaptive, given the fact that caregiving is respected and valued by society and by the caregivers themselves. The above strategies offer an effective means for the caregivers to maintain sense of *ikigai* without disturbing what is most treasured by them: family harmony and health.

These decisional options and modes of maintaining *ikigai* explained here are not new. Such attempts to modify perceptions, along with slight behavioral changes within the acceptable range, are commonly seen among the Japanese, particularly among Japanese women. Their methods of coming to terms with the reality could be regarded

as an almost institutionalized way of life in Japanese society; one that creates a particular culture, especially for Japanese women.

Changes in Self-Understanding

In the repetitive attempts to maintain the sense of *ikigai* when facing tolerance limits, the caregivers' self-understanding gradually changes (Figure 14). "Self-understanding" means the overall cognitive representations people have with regard to themselves, which consists of presentational and subjective selves (Chapter 2). The changes in caregivers' self-understanding and emergence of new self-understanding in the course of caregiving are explained in this section.

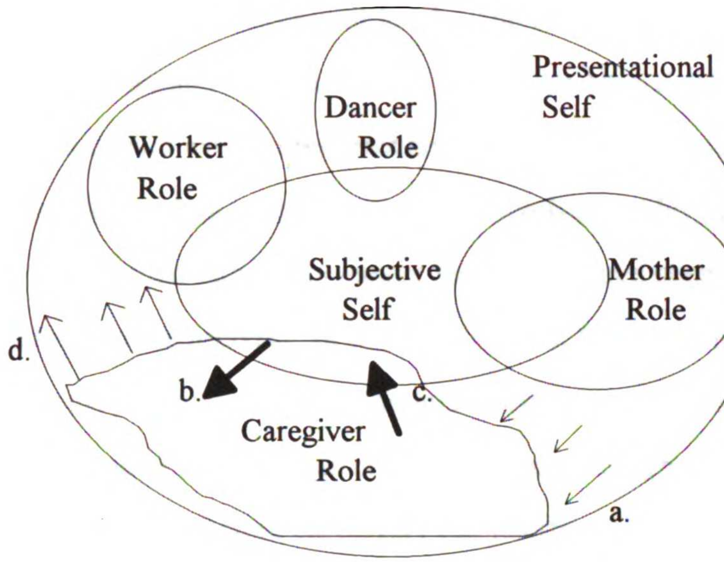
First, how the self-understanding of caregivers changes during their constant attempts to come to terms with the reality of having to take care is explained. Second, the influence that societal imperatives have on the change in self-understanding is addressed.

Lastly, the relationship between self-understanding and *ikigai*, as well as their changes, are summarized.

Changes in Self-Understanding through Caregiving Experience

The caregivers' self-understanding often changes when faced with the sense of tolerance limit and forced to deal with it. The sense of tolerance limit accompanies a threat to the current self-understanding, because the part of the caregiver role is becoming difficult to sustain. The sense of tolerance limit means that the role as caregiver no longer provides enough feedback to the subjective self that caregiving is satisfying, because elevating difficulty overpowers the value of care and various factors that back up the value of care. Therefore, caregivers feel they cannot continue in the same formation of self.

Figure 14: Self-Understanding and its Change
(created by the authror)



a.: Setting up Boundary
b.: From the Change in Subjective Self to the Change in Presentational Self
c.: From the Change in Presentational Self to the Change in Subjective Self
d.: Extending Caregiver Role

However, the caregiver role must be preserved due to its high value; the consequences of abandoning the caregiver role would also be overpowering. Struggling to come to terms with this essential paradox, caregivers shift their understanding of caregiving and themselves--they alter the meaning of their lives and their identity (subjective self), as well as how they act out their roles (presentational self).

When caregivers are in the state of within limit, such a change in self-understanding is not likely to occur. The caregivers' lives continue smoothly; each role in the presentational self can be actualized without serious conflict and various roles can co-exist. Under such a circumstance, self-understanding is not likely to be questioned, and therefore, no major change is necessary.

There are two ways of changes seen in self-understanding. One begins with the change in the subjective self which in turn changes the presentational self. This is often observed in reduction of their care-involvement level. The other type begins with a gradual change in the presentational self which then leads to an altered subjective self. This type of change often occurs while caregivers are pushing up their tolerance limit.

Changes in self-understanding when reducing care-involvement level. When caregivers are able to reduce their care-involvement level, they have been able to justify their tolerance limit to themselves. In this justification, they redefine their reality and set up a boundary (*hirakinaori*) around their caregiving responsibilities (Arrow a. in Figure 14)(Chapter 5). *Hirakinaori* is actualized through a major change in the caregivers' subjective self. Before caregivers can justify their tolerance limit, they attempt to retain their self-understanding that they are people who strive to materialize the ideal figure of caregiver, tolerating the intolerable. However, at the time of justifying their limit, the old ideal is given up and they accept an alteration in the ideal. Caregivers come to accept new subjective selves that can declare that they cannot be passive, obedient, and ever-enduring ideal caregivers any longer. Thus, a new self-understanding has been created.

For example, Akiyo abandoned her ideal figure of *yome* when she faced danger to her own life. She had previously devoted herself to the caregiver role even to the point of searching for the care recipient who wandered out at night. However, when she learned of her angina, she began to remain home, waiting for the telephone call from the police. For her, this results from a major shift in subjective self-understanding, from an obedient and dedicated *yome*, to self as a person who can act in defiance of the societal norm assigned to *yome*.

Change can be also seen in the belief regarding the meaning of caregiving which also constitutes subjective self-understanding. For example, Naoko shifted the meaning of caregiving from an act of love for her husband to one of her jobs as a *yome*. Due to

this change she was able to stop expecting reward from other family members in the form of appreciation and gratitude, and she started seeking rewards from diversionary activities. This change in the meaning of caregiving was necessary for her to continue caregiving which she still values as an important part of her self-understanding.

The changes in subjective self-understanding with regard to the belief in caregiving and/or themselves often occur consciously. As a result of conscious change in the subjective self-understanding, they can alter their daily behaviors; the change in presentational self follows the change in subjective self (Arrow b. in Figure 14). Caregivers set a boundary as to the amount the caregiver role will be allowed to occupy their presentational self, and they keep the remaining part of presentational self for other roles. This change in presentational self becomes possible because of the change in their subjective self.

Changes in self-understanding when pushing up one's tolerance limit. When caregivers are pushing up their tolerance limit, change in the presentational self precipitates the change in subjective self (Arrow c. in Figure 14). As the caregivers push up their tolerance limit, the caregiver role gradually extends in the presentational self-understanding (Arrow d. in Figure 14) while other roles gradually shrink. They eventually cease to enjoy activities such as aerobics, golf, or taking lessons, and their daily lives begin to revolve solely around the fact that they are caregivers of their elderly parents (or parents-in-law).

Sometimes the change in the presentational self is a conscious reduction of work outside the home. As Reiko says:

> As for myself, compared to last year I can hardly do research on what I want to do. But I decided to give up (my research), believing it's my fate. Research, that's what I thought I was going to give up. I will do my duty bound job. I will do what I have to do as a professor here. .... Until then, I was wishing to write at least three articles, or to make presentations in several

> conferences every year. I worked that way for a long time. But I didn't think I could keep up with that, even if it's not good to settle with low level of work. It was *shikatanai*, and I could not help sacrificing for it.

In the extreme situation, caregivers may need to abandon a new expected role due to caregiving responsibilities. For example, Chieko was persuaded by her husband to abort her pregnancy twice because there was no way to raise more children while the care recipient needed so much attendance and care.

With such a change in the presentational self, the caregivers often experience their identity and meaning in life (subjective self-understanding) being derived only from their role as caregiver. This happens because the subjective self-understanding is influenced largely from daily actualization of presentational self. With this change, the sense of identity and meaning in life acquired through other parts of presentational self gradually decay and the self as a caregiver becomes the only source of identity and meaning in life. This change in subjective self is often gradual and therefore unnoticed by the caregivers themselves.

This type of change in self-understanding is called "role engulfment" or "loss of self" by Skaff and Pearlin (1992). Important point is, however, is that "role engulfment" does not necessarily mean total loss of self, at least for Japanese women. Rather, self can be changed constantly in a way that is compatible with any given situation, and the loss of certain aspects of presentational self may not correspond to an overall loss of self. Japanese caregivers often accept the situation in which their presentational self must be changed in the ethos of *shikatanai* and *akirame*. They also expect the change in subjective self-understanding that corresponds to the change in presentational self. Upon this acceptance, they still struggle to find new ways to maintain their *ikigai* compatible with their given circumstances.

Because pushing up one's tolerance limit is seen more frequently than the reduction of care-involvement level, many caregivers experience this type of gradual

change in self-understanding that reflects the demands of life. This type of change is actually an expected way of life for traditional Japanese women. Their ideas about their own life are primarily regulated by the requirements of their family, and if the situation demands change in their presentational self, it is expected and they are ready to change.

With the ever-mounting demands of caregiving, caregivers struggle hard to change their presentational and subjective self-understanding in such a way that they can maintain their roles as *yome*, daughter, or caregiver while maintaining their sense of *ikigai*. In fact, far from losing self, some caregivers can broaden their presentational self as caregiver to the point where they fear losing the care recipient because it would bring with it their own loss of their current identity and thus *ikigai* (caregiving dementia).

Changes in Self-Understanding and the Societal Imperatives

Changes in the self-understanding of Japanese caregivers occur out of the vital necessity to continue caregiving while maintaining the sense of *ikigai*, and the necessity comes from the societal norm that they must continue caregiving. The entire course of caregiving is in the context of the basic societal imperative to respect filial caregiving, to respect the woman's role in the family, and to appreciate harmony within a group, especially the very important, primary group called family. Because of this strong imperative, self-understanding of Japanese caregivers may change more readily compared to Americans.

The strong influence of societal norms that respect harmony within a group means that the group-oriented self is more expressible than the individualistic self (Chapter 2). In this regard, the meaning of such roles as mother, wife, or caregiver, for a Japanese woman, is qualitatively different from the meaning of her role as a person who enjoys her hobbies. Roles of mother, wife, or caregiver derive from the

group-oriented self, while roles as a person who enjoys her hobby derive from the individualistic self. Thus societal imperatives determine the overall direction of change in self-understanding in pushing up one's tolerance limit.

Caregiver's Self and *Ikigai*

In the course of caregiving experience, the caregivers' self is constantly changing and they are continually re-discovering the emerging self. Along with such changes in self-understanding, the experience of *ikigai* is constantly changing because people assess their *ikigai* with the eyes of their newly emerging self. Their *ikigai* is constantly appraised and modified in the judgment of the ever-changing self.

How does *ikigai* relate to self-understanding? In assessing the actions of the presentational self, the subjective self reaches the awareness of self with a certain value, and this is the sense of *ikigai*. Having the sense of *ikigai* means that some experiences in the presentational self create general feelings of satisfaction in light of the ideal held by the subjective self. In other words, people feel they are living a life true to their values. Thus, the sense of *ikigai* is experienced in the realm of subjective self, while the source of *ikigai* is experienced in the roles and actions of presentational self.

Based upon the appraisal of *ikigai*, the subjective self-understanding may command change in the presentational self. The performance of the new presentational self brings more appraisal material back to the subjective self. If one role is assessed as fulfilling and satisfying, the subjective self senses *ikigai* and the role in the presentational self is recognized as a source of *ikigai*. The role may be extended to enhance the sense of *ikigai*. On the other hand, if the role is not worthwhile, the subjective self senses less *ikigai* and the role is not recognized as the source of *ikigai*. The subjective self may then initiate change in the presentational self. The change in presentational self gradually affects the change in the subjective self-understanding and the changed subjective self will appraise its *ikigai* in a different way, which may again

initiate change in the presentational self. Thus, the presentational and subjective selves interact via *ikigai*, and they all constantly evolve as an individual grows through various experiences in life.

Summary

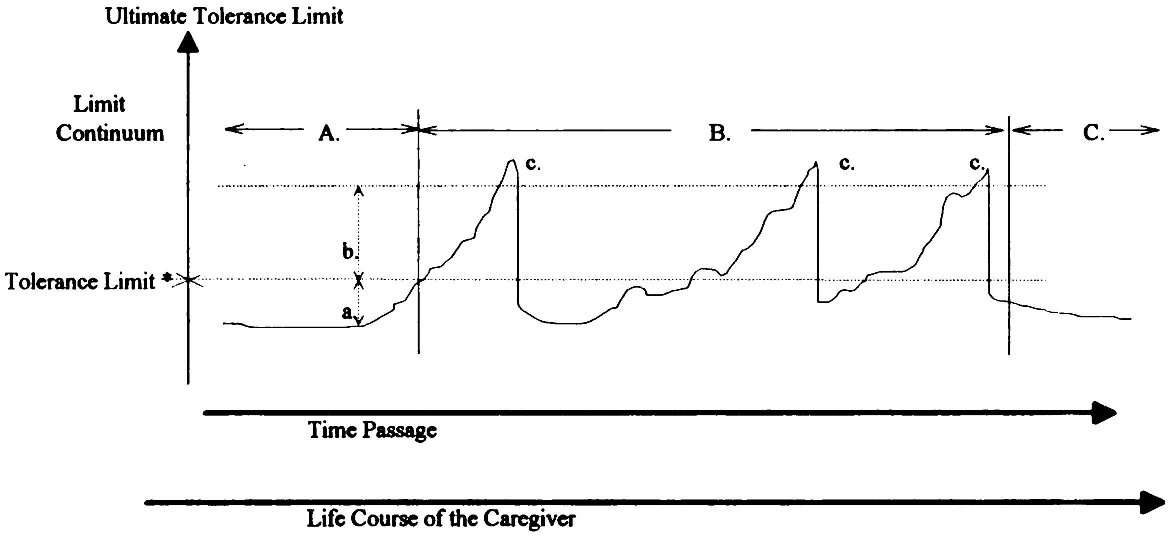
This chapter explained the caregivers' constant attempts to come to terms with the reality of having to take care. Based on the decision regarding whether they can reduce the care-involvement level, caregivers employ various methods to manage to continue caregiving. In this struggle, caregivers also try to maintain their sense of *ikigai* in various modes. In this process, the caregivers are attempting, sometimes desperately, to make sense of their lives by finding ways to come to terms with the reality of having to take care. It is also shown that this process accompanies constant changes in the self-understanding of the caregivers.

Chapter 7: Result 4

Trajectory of Caregiving: From Inception to Resolution

A three stage trajectory model, similar to those developed in the past (e.g., Lindgren 1993; Pearlin, 1992; Wilson 1987a, 1987b), has been constructed in the current research (Figure 15). The three stages are termed <u>initial undertaking</u>, <u>coming to terms with the reality of having to take care</u>, and <u>permanent within limit</u>. Initial undertaking (A. in Figure 15) is the entry to the caregiver role. Coming to terms with the reality of having to take care (B. in Figure 15) is a constant struggle for caregivers to continue providing care while maintaining their sense of *ikigai* as well. Permanent within limit (C. in Figure 15) comes when the caregivers' constant struggle ends and they no longer need to endure the sense of tolerance limit.

<u>Figure 15: Coming to Terms with the Reality of Having to Take Care</u>
(created by the author)



A: Intial Undertaking
B: Coming to Terms with the Reality of Having to Take Care
C: Permanent Within Limit

a: Within Limit
b: Pushing Up the Tolerance Limit
c: Reducing the Care-Involvement Level

* Level of tolerance limit can change over time.

It should be emphasized that the overall trajectory of caregiving is, first of all, regulated by the changing condition of the care recipient, although this is not extensively elaborated in this research. For example, the initial undertaking of the caregiver role begins with the problem behaviors of the care recipients, and in many cases, their gradual deterioration usually pushes the caregivers to the sense of tolerance limit. The condition of the care recipients is also the primary factor of any outer resource mobilization including institutionalization, and institutionalization is a major factor in determining when the caregivers move to the stage of permanent within limit. The condition of the care recipient usually deteriorates over time, but this deterioration is not uniform among elderly people with dementia. Some show a rapid decline in cognitive ability, while others stay at the same level of functioning for an extended period of time.

Initial Undertaking

Initial undertaking is the period when caregivers first enter the role of caregiver (A. in Figure 15). Reflecting the societal norms regarding filial caregiving, entry into the caregiver role is usually not a sudden incident that occurs without anticipation. However, there are several variations in how much the role of caregiver was expected. How they initially take on the caregiver role can influence the later stages of the caregiving trajectory. There are several factors that influence how much a woman anticipates the caregiver role.

History of former decisions. The determination of who takes on the caregiver role among multiple family members is a result of accumulated decisions made throughout the lives of all family members. It is not decided overnight when the care recipient's condition deteriorates. By the time caregiving becomes necessary, many caregivers that were interviewed felt it was natural that they should take care of their parents (or parents-in-law). There is a specific family status that causes women to anticipate the caregiver role, and they more or less accept the caregiver role in the future when they decide to go into the status, far prior to the actual beginning of the caregiver role.

Marriage is the strongest determinant of whether women will eventually face caregiver responsibilities for elderly parents (or parents-in-law). Of all interviewed that were first son's wives, only one did not realize, at the time of marriage, that the union they were entering also included a future caregiver role providing care for their parents-in-law. (One exception was where the first son left the family at a younger age.) Therefore, when faced with the situation where caregiving became necessary, these wives of the first sons relatively easily accepted the caregiver role. However, not all first son's wives abide by this societal norm uniformly, and some clearly refuse to accept the caregiver role. Reiko's sister-in-law, and Sachie's as well, were both first son's wives and firmly refused the caregiver role. Especially among the modern, nuclear families, there are occasions when societal norms have limited power to force the first son's wives to assume this role.

Marriage determines the caregiver role also in the case of daughters. Daughters who married the second or third son of a family are freer to take care of their own parents without feeling guilty toward their married family. Hideko, a daughter caregiver, deliberately chose a second son for her spouse. In the case of *muko-iri*, where the husbands formally marry into the wives' family, caregiving is expected of the first daughter.

Another influential factor is succession of family business. When husbands take over their parents' business, their wives expect their future caregiver role, even if the husbands are not first sons. The same is true when a daughter takes over the family business. Hideko was anticipating her caregiver role ever since she took over the family business, a bicycle shop, soon after she graduated from high school. She is the second daughter with one elder brother and sister.

Preference of the care-recipient also plays an important role in determining who takes the caregiver role. Elderly parents sometimes make it clear, long before the actual start of caregiving, who they want taking care of them, and it is based on their life-long relationship. The care recipients' preference may be congruent with the societal norm, and it may not, depending on the quality of the relationship. In this situation, even if the family members do not have definitive communication regarding this responsibility, it is often taken for granted by all family members who the caregiver will be. The preference of the care recipient is not always answered by the preferred child. Sachie had a difficult time because her mother could not give up her hope that her first son's wife should take care of her, which was refused by the first son's wife.

Initial undertaking without pre-determination. If the long-held plan of who would assume the caregiver role has to be changed, there is a difficult time deciding who should. For example, in Rie's case, the first son, whose spouse was to be the caregiver, died prematurely. The wives of the second and third sons, as well as daughters, suddenly face the possibility of being chosen for the caregiver role. Under such circumstances, the caregivers, especially the daughters-in-law (*yome*), often comply and assume the role, even if reluctantly. Although it is valued, the caregiver role entails tremendous difficulty, and therefore, it is not a relished by those who did not anticipate it. However, rejecting the caregiver role means disruption of the very things she had been striving for: family harmony and health. Refusing the caregiver role then can also seriously disturb her sense of *ikigai*, so it is accepted because it is *shikatanai* (no way out). In their eyes, there is no one else:

> I thought my husband would be in trouble if I persisted on not accepting them. If I said no, they had to be put into some facility after all. My husband told them that I didn't feel confident. .... Then my sister-in-law urged my husband to hurry, but Grandfather didn't want to move. My husband had to try to

> persuade him to move. And my husband complained that he had to beg me so much and asked me to imagine how I felt if I were in his position. .... So I made up my mind. (Rie)

On such occasions, the personality style of the caregivers is also an influential factor that determines if they do or do not accept the caregiver role. Some comply easily, some with difficulty but regard the situation as *shikatanai* (no way out). There are others who would refuse the caregiver role under any circumstances.

Whether they anticipated the caregiver role or not does not seem to have much impact on the later stages of the caregiving trajectory, as long as they can regard the situation *shikatanai* and accept (*akirame*) it. Once they, however reluctantly, accept their fate and assume the caregiver role, they tend not to dwell on their reluctance and begin to try to offer their best in caregiving. Various experiences in the caregiving can work to motivate them to continue further. However, if one cannot mentally accept the role, the acceptable level of occupancy of self as a caregiver tends to be low and the tolerance limit is reached relatively soon. This situation is called "role captivity" by Aneshensel et al. (1993).

After assuming the caregiver role. Even after beginning caregiving, caregivers are often unaware that they are providing care, until they begin to feel difficulty and/or reach their tolerance limit for the first time. The first experience of tolerance limit is the point where the caregivers move from the stage of initial undertaking on to the next stage. It signifies a change in the meaning of caregiving for them, from a part of daily, normal life, to an independent role separate from their housewife role. At this point, the caregivers enter the second stage where dealing with the caregiver role becomes a salient issue in their lives.

Coming to Terms with the Reality of Having to Take Care

The second stage, "coming to terms with the reality of having to take care," is a repetitive cycle of reaching the sense of tolerance limit and struggling to deal with it (B. in Figure 15). The details of each cycle (i.e., how the caregivers manage to continue caregiving while maintaining their sense of *ikigai*) have been explained in former chapters.

Three states in the limit continuum. While caregivers remain in this stage, they can be in one of three states: within limit (a. in Figure 15), pushing up the tolerance limit (b. in Figure 15), or reducing the care-involvement level (c. in Figure 15). Caregivers are first in the state of within limit where they have enough resources and can control the situation (a. in Figure 15). Here, the sense of *ikigai* is maintained without effort and a change in self-understanding is unlikely to occur.

As the difficulty of caregiving increases, they reach the sense of tolerance limit and face the decision of whether to push up the tolerance limit or reduce their care-involvement level (b. and c. in Figure 15). When they reach their tolerance limit, they feel exhausted and the situation is felt uncontrollable. Their sense of *ikigai* is threatened so something must be done. Their self-understanding cannot be sustained in the same formation.

On such an occasion, caregivers usually push up their tolerance limit (b. in Figure 15), continuing caregiving in the same or gradually elevated involvement level. In this state of pushing up the tolerance limit, caregivers struggle to maintain their sense of *ikigai*, trying to identify specific experiences in life as a source of *ikigai*. Here, the caregiver role gradually extends in the presentational self, also changing their subjective self-understanding.

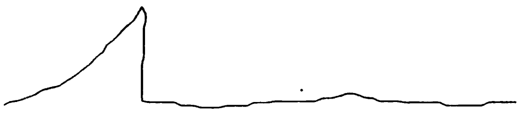
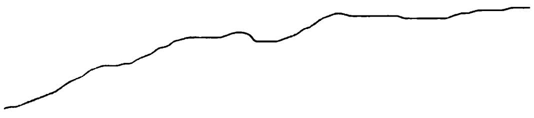
Occasionally, caregivers can reduce their care-involvement level (c. in Figure 15). By doing this, they can restore their threatened *ikigai* by balancing activities they enjoy and the caregiver role. They set up boundary and limit the amount the caregiver role is allowed to occupy their presentational self, based on the change in the meaning of caregiving for them and the change in themselves that occurs in their subjective self-understanding.

By utilizing either decisional option and various strategies within these options, caregivers can return to the state of within limit (d. in Figure 15). However, the gradual deterioration of the care recipient eventually takes the caregiver to another tolerance limit. Thus, these three states are repeated in wave-like forms in the course of caregiving.

Variation in the wave forms. How many times this cycle of "within limit," "pushing up the tolerance limit," and "reducing the care-involvement level" is repeated varies (Figure 16) depending on numerous conditions and factors as explained in the former chapters.

There are caregivers who do not experience a sense of tolerance limit at all (a. in Figure 16). Because this sense is the result of uncontrollability of the situation and

Figure 16: Variation in the Wave Forms
(created by the author)

a.		No experience of tolerance limit
b.		One experience of tolerance limit and reduction of care-involvement level
c.		multiple experiences of tolerance limit
d.		No reduction of care-involvement level

exhaustion of the caregiver's personal resources, the sense of tolerance limit may not occur to a very resourceful caregiver in a relatively stable situation. For those caregivers who do not experience tolerance limit, caregiving is just a part of their everyday life and does not present issues perceived as overwhelming. Their sense of *ikigai* is maintained in almost un-awareness, without radical changes in their self-understanding.

Some caregivers, after experiencing only one tolerance limit, mobilize outer resources extensively (e.g., institutionalization), and they enter the next stage of permanent within limit (b. in Figure 16). This occurs when extensive outer resource mobilization and reduction of the care-involvement level are possible. In this situation, the caregivers' sense of *ikigai* is threatened seriously only once, and is restored quickly with the reduction of the care-involvement level. Major changes in self-understanding are unlikely to occur except for during the short period of time when the care-involvement level is reduced.

There are caregivers who experience repeated cycles for an extended time (c. in Figure 16). The tolerance limit is pushed up many times, and the reduction of the care-involvement level occurs only gradually. The caregivers remain involved in caregiving, so they eventually face another tolerance limit with the deterioration of the care recipient. This often occurs when a very high value is assigned to caregiving. The sense of *ikigai* is threatened many times, but caregiving is often identified as the source of *ikigai*. As a result, the gradual change in the presentational self (extended caregiver role) may cause a profound change in the subjective self-understanding of the caregiver.

If caregivers cannot reduce their care-involvement level at all, the sense of tolerance limit must be tolerated at an excessive level, and the caregivers' sense of *ikigai* may be damaged severely (d. in Figure 16). This is often the case when the caregiver's authority level within the family is very low. These caregivers constantly tolerate the intolerable, and after various strategies to maintain their sense of *ikigai* have been exhausted, they may fail to maintain their *ikigai*.

Permanent within Limit

The constant struggle sooner or later moves into the third stage where the caregivers can remain permanently within limit (C. in Figure 15). This point is not examined extensively in the current research because most caregivers interviewed were in the middle of the stage of "coming to terms with the reality of having to take care." More interviews are necessary to establish the hypotheses in this third stage of the caregiving trajectory.

Permanent within limit does not necessarily mean that caregiving is completed, but it is the stage where the caregivers no longer experience the sense of tolerance limit. This stage is reached in one of two ways: the extensive deterioration of the care recipient, or the extensive use of outer resources including institutionalization.

When the care recipients' physical condition is deteriorated profoundly and they become bed-bound, many caregivers state that caregiving is easier because the recipients are immobilized. The caregivers do not have to follow wandering care recipients, the recipients do not soil in different areas, nor do they turn on the stove. Thus, 24-hour vigilance is no longer required. Although caregiving of the bed-bound person is still difficult, it is perceived by many caregivers to be much better than the earlier stage of caregiving and the situation no longer seems uncontrollable. Shinobu says:

> I feel sorry for Mother (care recipient), she can't move any more. But for me it is easier. Yes, it has gotten easier. It may sound strange to say it is easier [laugh]. Since she can't move by herself, I have to move her. So it is *taihen* (hard) in that sense. But this one is a better *taihen* than before. It was really *taihen* before. [laugh]

Caregivers may still feel exhausted and out of control, but outer resources for bed-bound elderly are more available than those for wandering elderly with dementia. Therefore, caregivers can use various outer resources more readily. Thus, the physical deterioration of the care recipients to the level of being bed-bound is one way to reach the stage of permanent within limit.

Another pathway to reach the permanent within limit is the extensive use of outer resources; the most typical being institutionalization. Caregivers who have institutionalized care recipients usually can reduce their care-involvement level extensively, and their state of within limit is permanent. Caregiving still continues in the sense that the caregivers frequently visit the facilities and take care of the care recipient in many aspects of their lives. However, the level of care-involvement is decreased, and therefore, the sense of tolerance limit is unlikely to be experienced again, as long as the care recipients remain institutionalized.

There is an exception to this pathway leading to the stage of permanent within limit. If family members must visit their relatives regularly to do various chores for them, it is possible that the institutionalization, on the contrary, increases the physical exhaustion of the caregiver. This was often heard from those living in rural areas of Japan.

Chapter 8: Conclusions

In this concluding chapter, several limitations of this research and implications of the findings for future research on family caregiving and theory development, for practicing health professionals, and for social policy will be discussed.

Limitations of the Research

Limitations Related to the Interview Subjects

The main limitation of this research is related to the population interviewed. First, interviewees were limited to daughter or daughter-in-law (*yome*) caregivers, and this makes the findings of the current research possibly inapplicable to male caregivers and spouse caregivers. This research intentionally focused on daughter (or daughter-in-law) caregivers because of the possible differences between spouses and children (or children-in-law) and between males and females in the nature of their caregiving experience. Interviews with male and/or spouse caregivers should be considered in future research for comparison.

Some features of daughter (or daughter-in-law) caregiving found in this research are expected in other types of caregiving as well. For example, spouse caregivers are also likely to experience the sense of tolerance limit and use a similar decision-making process regarding reduction in their care-involvement level, although the types of difficulties may be different. The issue of availability of outer resources would be similarly seen in spousal caregiving, while the issue of caregiver authority within the family may not be salient. Societal norms regarding caregiving will impact male caregivers differently.

Second, there is a sampling bias. Attempts were made to sample caregivers from diverse situations in terms of various structural and situational conditions.

However, these may not typify the experience of those who were not interviewed. One caregiver refused to participate in the research. Quite presumably, she may have negative opinions on caregiving and is therefore unwilling to discuss the subject. In addition, social workers in service facilities refused to approach some caregivers regarding participation in the research. In the social workers' assessment, they were in an unstable condition for various reasons and talking about the research itself might harm the caregiver/social worker relationship. This may have resulted in interviews with only those in a stable condition, and therefore, the research findings may reflect only the limited ideas of family caregivers.

Third, there was no access to caregivers outside formal services. The types of organizations helpful in the recruitment of interviewees were various (a hospital, public health center, home care support center, and elderly care center with a variety of services), but I could not reach those who were not connected with these services. Caregivers who do not use any services should be interviewed in future research in order to learn how support services can function effectively for this population.

Fourth, those who have already bereaved the care recipient were not interviewed. The caregiving experience does not end at the time of institutionalization, nor even at the time of the care recipient's death (Mullan, 1992). The experience of bereaved caregivers should be further studied in order to learn how the experience of caregiving affects the caregiver in later life.

Fifth, other family members were not interviewed, and this limits the scope of information. For example, it may have been informative, not only to interview other family members but also the care recipients themselves, in order to examine several issues that became salient in the current research, such as authority of the caregiver within the family. Interviewing other family members for validation of the caregivers' narrative was deemed unnecessary, because the purpose of this research was to learn the subjective experience of the primary caregivers. Hence, the credibility of the caregiver's narrative is not an issue. However, for the purpose of finding ways to effectively assist caregivers, it is necessary, in future research, to learn more about how other family members, including the care recipient, influence the behaviors of caregivers. Interviewing the care recipient is difficult because of the nature of dementia; other methods of data collection (e.g., participant observation) may be required.

Limitations Related to the Timing of the Interview

Caregivers were interviewed only once in this research because of geographical limitations. As a result, the caregiver's chronological change in their self-understanding and their understanding of the caregiving experience are known only through their memory recollected at the time of the interview. Although memory is an important source of information for past experience, it cannot reflect past, subjective experience perfectly. Interpretation of past experiences changes depending on the viewpoint at the time of retrospection. Therefore, multiple interviews would have been preferred.

Limitations Related to the Language Barrier

The best possible translations have been attempted for the Japanese narratives cited in the result sections so that their meanings are correctly understood in English. As for several words that have no exact equivalent in English (e.g., *akirame*), the original word was used and explained carefully. In addition, several researchers and a professional translator were asked to read the narratives, analytical memos, and early drafts of this research, to confirm the truthfulness of the translation. However, the English translation and explanation hardly conveyed the full meaning of some words and subtleties in the narratives. This seems to be an inevitable limitation in research that uses a foreign language.

Implications for Research and Theory

There are several implications for future research and theory developments that derive from the current study. They are discussed in sections (a) Impact of Care, (b) Caregiving as Process, (c) Why and How can They Take Care? and (d) *Ikigai*, Self, and Coping Theory.

Impact of Care

Difficulties of caregiving should be examined in relation to the high value assigned to caregiving by each caregiver, at least when examining the Japanese population. Therefore, difficulties of care should not be automatically interpreted as "burdensome." It was a basic assumption of the current research that caregiving should not be equated only with burden. This assumption was supported in the interviews in which the word "*futan*" (burden) was rarely used as compared to the frequent use of *taihen* (hard; difficult). The meaning of caregiving should always be incorporated when studying the impact of care on the caregivers. Similar argument has been made by Farran, Keane-Hagerty, Salloway, Kupherer, and Wilken (1991).

In the same sense, the concept of "role captivity" should be examined carefully. Role captivity, defined as "situations in which people are unwilling incumbents of social roles," has been discussed extensively by Aneshensel et al. (1993, p. 56). These researchers examined the longitudinal change in role captivity in relation to the cessation of home care (Aneshensel et al., 1993) and in relation to the phenomenon of "role engulfment" ("the very being of the caregiver becom(ing) engulfed by caregiving activities" (Skaff & Pearlin, 1992, p. 657)) and loss of self. These concepts are important indicators in examining the impact of care on caregivers' lives, but how and why role captivity occurs to some and not to others should be examined. As Skaff and

Pearlin's 1992 study shows, even if role engulfment occurs to many people, it does not necessarily relate to role captivity or the sense of self-loss directly.

Several conditions examined in this research suggest possible explanations for the result of their research, at least for the Japanese caregivers. First and foremost, the level of value assigned to caregiving by an individual caregiver, either through internalized societal norms regarding filial caregiving and/or attachment to the care recipients, along with their gradual changes throughout the course of caregiving, dictates the acceptable level of occupancy of the caregiver role in the presentational self. This acceptable level influences the role captivity. Availability of outer resources, authority level of the caregiver within the family, and justifiability of the tolerance limit also influence how much the caregivers can reduce their care-involvement level, and thus influence how much they feel captivated by the caregiver role.

Loss of self should be also understood in relation to the value of care. When caregivers find high value in caregiving, even if a large part of the former presentational self is lost to the increasing demands of care, the loss of former self may not be perceived negatively. In reverse, where caregiving is not valued compared to other activities in the caregivers' lives, even a slight change in the presentational self due to caregiving can be perceived negatively, and the caregivers may experience the sense of self-loss. It is here that the difficulties of care are perceived as "burdensome" to the caregiver.

Thus, the concepts of burden, role captivity, and self-loss should always be studied in their relationship to the values assigned to caregiving, as well as various other conditions, in order to gain a better understanding of the caregivers' experience and to enable development of effective interventions.

Important conditions that influence role captivity and self loss, such as societal norms, attachment, availability of outer resources, and caregiver authority within the family, vary among individuals and also change in the course of caregiving, as explained throughout this research. The societal norms regarding filial caregiving are internalized to different degrees among the Japanese population, depending on various factors such as the position of the caregiver in the family (daughter, daughter-in-law, the eldest of siblings or not), geographical location (i.e., urban or rural), family business (merchant, agriculture, or office worker, etc.), or caregiver personality styles. The attachment level is also influenced by such factors as the position of the caregiver in the family, history of relationship quality, or availability of other objects of attachment for the caregiver. The changes in the value of caregiving also reflect change in the level and types of attachment throughout the course of caregiving. These conditions and their changes over time should be born in mind for further research on the impact of care.

Another important implication is the difference in the meaning of difficulties of care across cultures. Choi (1993), in a quantitative research study on caregivers in South Korea, discussed that the effect of cultural norms on caregiver burden was not as strong as she/he anticipated. However, the important difference among different cultures lies in the interpretation of the difficulty, therefore, indicators Choi used as caregiver burden may not be interpreted as <u>burden</u> by Korean caregivers, although they may be <u>difficult</u>. As a result, Choi may not have examined the relationship between cultural norm and caregiver burden, but between cultural norm and difficulty. A different approach to the research question may have shown a significant difference between Korean and American caregivers.

Caregiving as Process

Along with other researchers who developed stages in the process of caregiving (Lindgren, 1993; Wilson, 1987a, 1987b), a three-stage model is found useful in this research in order to give structure to the caregiving experience for better understanding. Three stages are developed in the current research from the initial undertaking to the point where the caregivers do not face the sense of tolerance limit any longer. Pearlin's (1992) model of the careers of caregivers includes the period following bereavement. This period seems to be worthy of more detailed examination in the future, because it is clearly indicated in this research that experiences at one point affect later life of the person. How the caregiving experience altered later lives of caregivers is an important topic to examine.

Self-understanding changes over time reflecting accumulated experiences including caregiving. The view of caregiving as a process enables us to see the change in self-understanding as a result of the interaction between the caregivers' experiences and their self-understanding. Change in self-understanding through the notion of *ikigai* has been elucidated in Chapter 6. In addition, this research shows that the *yome*'s caregiving is a part of the process of her acceptance into the married family (Chapter 5, "Process of Family Acceptance"). The caregiving experience thus relates to how *yome* caregivers proceed through their life courses. The daughters' personality development is also influenced by their gradual relationship change with their mothers: from *amaeru* (to depend indulgently) on their mothers only to *amayakasu* (to give indulgence) to their mothers as well (Chapter 4, "From *Amaeru* to *Amayakasu*"). In what other ways does the caregiving experience affect the life-long development of the caregiver? This is an important question toward learning the meaning of caregiving throughout the life course of the caregiver, even after bereavement, for future research.

Why and How can They Take Care?

The current research revealed that the value assigned to caregiving through either societal norms or attachment is the primary motivater for the caregiver to continue caregiving. In addition, there are other factors that help the caregivers continue caregiving and prevent them from extensive reduction of their care-involvement level. Several of the factors found in this research are similar to those identified by Guberman et al. (1992) in their study of Canadian caregivers for mentally impaired relatives. For example, love and feelings of family ties, inadequacy of institutional and community resources, absence/deficiency of community support, feelings of duty and obligation, imposition of the decision by the dependent person (that the care recipients determine who should take care of them), unavailability of other family members, anti-institutional feelings, the caregiving arrangement (e.g., presence of other family members who can partially support the caregiver), religious feelings, caregiver's personal characteristics (e.g., absence of competing obligations), the dependent person's state of health, and family tradition.

There is, however, an important difference between the findings of the current study and those of Guberman et al. (1992). The difference lies in the intensity and meaning of societal norms regarding filial caregiving. The norm of filial responsibility is strongly held in Japan, especially for unmarried daughters and *yome*. In addition, societal norms in general have a strong conforming power in the Japanese society. As a result, the impact of the societal norms of filial caregiving seen in Japan is qualitatively and quantitatively different from that of the norms that Western societies prescribe to women. Rather than feeling that they end up with caregiving because there is nobody else to take the role, most Japanese caregivers interviewed felt that they simply received the expected job, due to the norms in Japan which honor the role of caregiving as part of the status symbol attributed to women, especially *yome*. Yoshiko said, "I feel people cannot die without going through this process." The role would not be easily abandoned due to the intensity of societal norms.

Ikigai, Self, and Coping Theory

The notion of *ikigai* highlights the relationship between the everyday activities expressed in presentational self and subjective self-understanding (Chapter 6), and may

contribute to the conceptualization of self-understanding for Japanese people. Evaluating their lives in light of *ikigai*, Japanese caregivers constantly modify their self-understanding. Moreover, in assigning various meanings to caregiving and other experiences, they develop the sense of *ikigai*. Searching for *ikigai* in their changing environment, they find ways to live with a high sense of well-being in their given situations. The variation in these caregivers' modes of *ikigai*-pursuit underlines the Japanese people's flexibility and resilience in the face of adversity.

The notion of *ikigai* may also serve to extend the stress and coping theory of Lazarus and Folkman (1984). The stress and coping theory focuses mainly on how life experiences can lead to negative changes in psychological well-being. The notion of *ikigai* demonstrates how various life experiences can lead to positive, as well as negative, changes in psychological well-being. Certain life events (sources of *ikigai*) work to enable the individual to live with a high level of psychological well-being (high sense of *ikigai*), while lack of such experiences places a person in a vulnerable position for low psychological well-being. Moreover, a higher sense of *ikigai* can be attained with the identification of specific life experiences as their source of *ikigai*.

The other point the notion of *ikigai* among Japanese caregivers shows is that the pursuit of *ikigai* is usually accomplished through perceptual modifications. Strategies used by caregivers to maintain their sense of *ikigai* correspond to some of the strategies mentioned in coping theory as perceptual modifications, such as control of the meaning of experience or fantasizing (Pearlin & Schooler, 1978). Coping theory originally emphasized that perceptual modifications as well as problem-solving strategies can be effective ways of coping, depending on the situation. However, under the dominant beliefs in control, independence, and individuality in Western society, many researchers and practitioners seem to view that problem-solving is the only effective coping style (e.g., Harvis & Rabins, 1989). In the situation of *shikatanai* (no way

out), however, perceptual modifications are the only way to alleviate difficulties of caregiving, and they can be functional, as seen in this research.

This strategy of maintaining *ikigai* through perceptual modification may be particularly functional only for the Japanese, who have learned to regard certain situations as *shikatanai* (no way out) and *akirame* (to give in, accept) through various elements in their lives such as cultural aesthetics, socialization, or language. However, some research on family caregiving suggests that similar perceptual modifications, such as acceptance, are employed with success by people in other cultures (e.g., Pruchno & Resch, 1993). Further study of this area in light of the concept of *ikigai* may benefit further understanding of the relationship between environment and psychological well-being.

Implications for Nursing

There are several points that may better enable practicing health care professionals in assisting family caregivers. These implications are discussed in three sections: (a) *Ikigai* Maintenance as an Issue of Caregiver Health, (b) Formal Service Use, and (c) Public Education.

Ikigai Maintenance as an Issue of Caregiver Health

The importance of maintaining *ikigai* is emphasized in assisting family caregivers. Because meanings of caregiving and other activities in life vary among caregivers, health care professionals should assess the level and sources of these values assigned by the caregivers to caregiving and other activities, as well as their difficulties. They may then assist caregivers in discovering new sources of *ikigai* in their changing environment which would facilitate the maintenance of the sense of *ikigai*.

In Japan, the importance of diversionary activities has been taught in classes for family caregivers. However, the emphasis is not on spending time in diversionary activities themselves, but on maintaining the sense of *ikigai* in daily life through these activities. Therefore, diversionary activities may not be very effective for some caregivers. Caregiving itself may be the sole source of meaningfulness for some caregivers. In such instances, helping them recognize their achievement in caregiving may be more effective than beginning diversionary activities, at least in the short-term. When caregiving is the sole source of *ikigai*, caregivers may experience extremely low self-esteem when they make mistakes or fail in a particular activity of caregiving, however minor the mistake may be. Also, for those who are too focused on caregiving, care should be taken after the death of the care recipient, because it seems this time that the caregivers are most vulnerable to suffering from the loss of *ikigai*.

Formal Service Use

Health care professionals should realize that any outer resource would not be used effectively unless the caregivers can reduce their care-involvement level in light of these three issues: justifiability of the tolerance limit, availability of outer resources, and their authority level within the family. When they cannot reduce their tolerance limit successfully, careful assessment of the reasons is needed.

Health care professionals should assist caregivers in justifying of their tolerance limit at a reasonable level. Tolerance in general, and especially the tolerance of the difficult tasks in caregiving, is regarded as a virtue by Japanese women. This makes the difficulties worth tolerating and, by virtue of this difficulty, caregiving becomes all the more meaningful. Under such a societal aesthetic, the assessment of difficulties in caregiving in itself is not enough for health care professionals to examine in order to assess the possibility of formal service utilization. Only when the relative difficulty greatly exceeds the meaningfulness of the caregiving, and when the caregivers believe

they have done enough to meet the requirement of the cultural aesthetic, will they justify their tolerance limit.

The current research indicates that caregivers sometimes delay reduction of the care-involvement level even at the cost of their own physical health due to the above logic. Some formal services should be utilized to protect the physical health of the caregiver. However, mere coercion to use outer resources, without the caregiver's own justification, may lead to an undue sense of guilt from failing to live up to their self-ideal. In such instances, their physical health and psychological well-being are at odds. While respecting the caregivers' own decisions, health care professionals should seek ways to encourage them toward the best possible options beneficial to the maintenance of both their physical and psychological health. The notion of *ikigai* helps health care professionals assess psychological well-being, and makes it possible for them to assist caregivers in enhancing psychological well-being by searching for new sources of *ikigai* available in any given situation.

Also important is the assessment of the authority level of the caregiver within the family. This is especially the case in Japan where the hierarchical relationship among members of a group has strong impact on the behaviors. For example, where the authority of family members other than the caregiver is very high, intervention might be oriented to empower the caregiver in terms of authority. Examples of intervention include having the caregiver borrow the authority of the health care professional, or reinforcing the caregiver's idea of her accomplishments in caregiving, in order to let her have a higher sense of authority.

When there is an authority struggle among family members, the health care professional may assume an intermediary role, promoting a constructive discussion among family members. When there is no one who can make decisions within the family, the health care professional needs to take an active role to guide the family to effective decision-making.

Additionally, health care professionals must ensure accurate information on formal services is received by the caregivers and other family members, because negative or outdated stereotypes of such services are common. On the other hand, some services are in fact unavailable in terms of their quality, distance, sanction, information, and quantity. Health care professionals are also held accountable to appeal to policy-makers for further improvement of formal services.

One important finding in this research is that the three issues that the caregivers assess upon determining whether to reduce their care-involvement level are in balance with one another. Therefore, even with no effective intervention possible for one issue, approaches to other issues may alter the balance and afford caregivers the ability to reduce the care-involvement level.

Public Education

Finally, education of the general public is an important issue. Caregivers are living in a society whose participants, including other family members, may have limited knowledge of the ordeal they are going through, and a societal norm has a strong impact on their behaviors and psychological well-being. Public education to raise the consciousness and understanding of the difficulties of caregiving could decrease situations where extreme tolerance limits are experienced. On the other hand, care should be taken at the same time that the value of caregiving not be abandoned altogether, since this also serves as a strong motivater for some caregivers. The important point is that caregivers can choose their options, regardless of whether it is home care or extensive use of formal services, without undue societal sanctions. In this sense, public education is also a responsibility of health care professionals to which they should be held accountable.

Implications for Social Policy

Flexibility and resilience to come to terms with the reality of having to take care is a precious quality in Japanese caregivers and allows them to maintain their *ikigai*. This attitude of regarding specific situations as *shikatanai* (no way out) and *akirame* (give in; accept), however, is also allowing the social policy regarding the care of the elderly in Japan to remain heavily dependent on family caregivers. Strong societal norms regarding filial (and spousal) caregiving also makes such a policy accepted in the society. As a result, most formal services for the elderly in Japan still assume the commitment of family members, especially females. However, what has been observed in this research is that such a social policy can pressure, as well as encourage, daughters or *yome* caregivers to the point of depriving them of any source of *ikigai* in their lives.

This policy has a profound gap in terms of social justice. Care of the elderly should not be assumed only by specific unlucky individuals whose elderly parents happened to be afflicted by physical or cognitive impairments. Caregiving for the elderly should be a social issue shared by every participant of society. Therefore, services for the elderly population should be offered without excessive expectation of the physical and financial commitment of family members. The fundamental philosophy of elder care needs reconsideration in this era of an increasing elderly population and an extended longevity which is often accompanied by severe impairments.

The most important point is to give the family members options. The cultural norm of filial responsibility seen in Asian countries is essentially a precious virtue that should be preserved carefully; however, it should not be practiced in a way unduly restrictive to the lifestyle choices of specific, unlucky individuals. For example, a daughter's (or daughter-in-law's) commitment to care of her parents (or parents-in-law)

should not deprive her of other roles in the society, if they are desired. The responsibility of society to provide enough quality services to make this important justice possible is not a matter of feasibility; rather, it is a matter of philosophy of human life in a society.

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Appendix A: Prospective Interviewee Recruitment Letter (Japanese)

お年寄りを介護されている方へ

私はカリフォルニア大学サンフランシスコ校看護学部の博士課程に在学している者で、日本でのお年よりのお世話の様子を勉強するために、（施設名）に伺わせて頂いています。勉強の一環として、実際にお年よりのお世話をしているご家族の方に、そのご経験についてお話を伺いたいと思い、お願いの手紙を書いております。

お年よりのお世話を続けてゆかれる上で、難しいことが多々おありになることと思います。その様に困難な中で、介護を続けてゆかれるお気持ちはどのようなものでしょう。このような内容についてお話を伺いたく思います。お宅など、ご都合の良い場所と時間に、１時間から２時間程度お時間を頂けると幸いです。皆様からのお話は、個人名の分からない形で論文にまとめ、看護婦が今後高齢者の在宅ケアを行なうために役立たせる形で活かさせて頂きます。

お話の内容が、誰が話したか解る形で他人に伝わるという事は決してございませんし、（施設名）のスタッフの方に、個人名がわかる形でお話しすることも絶対にございません。看護婦として仕事を続けてゆく上で、実際に介護をなさる方々のお考えを伺うことは非常に貴重です。ご協力くださいますよう、どうかよろしくお願い申し上げます。

カリフォルニア大学サンフランシスコ校
看護学部博士課程
山本則子

Appendix B: Prospective Interviewee Recruitment Letter (English translation)

Dear Caregivers:

I am a student of the University of California, San Francisco, School of Nursing, and I am visiting (name of organization) to learn the caregiving of the elderly people in Japan. As a part of the study, I am hoping that I can interview some family caregivers who are taking care of the elderly person at home. This is why I am writing to you now.

I imagine there are many difficulties in continuing to take care of the elderly person. I wonder how you feel when you continue to take care in such difficulties. I would like to interview you on such a topic. I would greatly appreciate if you can spare me one or two hours, either at your home or at one of the rooms at (name of organization). I am planning to write a thesis based on the interview to some family caregivers. The thesis will be used to improve the care that nurses offer to the elderly people and their family caregivers.

Contents of the interview will never be revealed with the identity, and I will never discuss the contents of the interview to the staff of (name of organization) in the way they can guess who talked specific topics. It is very important for nurses to learn the thoughts of the family caregivers. I hope you will understand my intention and will help me to learn.

Sincerely,

Noriko Yamamoto
Doctoral Student
University of California, San Francisco,
School of Nursing

Appendix C: Demographic Data Sheet

フェイスシート（Demographic Data Sheet）

１）介護者氏名（Caregiver Name）　年齢（age）
２）お年よりの氏名（Care Recipient Name）　年齢（age）
３）続柄（Relationship）
４）病気のタイプ（Illness Diagnosis）
５）介護期間（Years since caregiving began）
６）家庭の職業（Occupation）
７）宗教（Religion）
８）教育年限（Education）
９）家族構成（Family Structure）

10）他の家族員からの支援（Support from Other Family Members）
　　手伝い（Hands-on Help）
　　金銭的援助（Financial Support）

11）生活形態（１週間／一日の生活）（Daily/Weekly Schedule）

12）お年よりの行動上の問題点（Problem Behaviors of the Care Recipient）

Appendix D: Modal Questions (Japanese)

１）まず始めに、お年よりの調子が悪くなり始めてから今までを簡単に説明してくださいますか。

２）介護によってご自身の生活がどのように変わりましたか。
♪初めにお世話し始めた頃から比べて、ご自身の介護に対する態度や気持ちは変わりましたか？どうして変わったのでしょう。
♪今までの間に、いろいろな感情を味わわれたことと思います、その気持ちがどのように変わって来たかお話しいただけますか？逆に、変わらない心というものはありますか？
♪例えば、お年寄りをお世話し始めた最初の頃から、ここまでやろうと心に決めていらっしゃいましたか？

３）どうして今日までお世話を続けてこられたとお思いですか？どうしてここまで頑張ってこれたのでしょう。
♪今までの間にお世話することを辞めてしまっていたら、どんな気持ちがしただろうと思いますか？

４）人生のなかで、介護を行なっているためにどんな影響があったと思われますか？良いこと・悪いことについてお聞かせください。

５）将来のことについてはお考えになったことがありますか？お年よりの世話をどのようにしてゆこうとお考えでしょう。
♪お年よりのお世話をあとどれくらい続けられるとお考えですか？ご自身でお世話できなくなった場合、どのようにしようと思っておられますか？
♪今のお年寄りと同じ様な状態にご自身がなった場合、娘さんかお嫁さんに世話してもらいたいとお考えですか？

６）もし介護する必要がなかったら（することがなかったら）、今頃どんな生活を送っていたと思いますか？

７）お年寄りの介護を引き受けたきっかけについて少しお話し頂けますか？その時のご自分の気持ちと、今の気持ちはどのように違いますか？

８）ご自身の生活にとって、いま、介護とは何だと思われますか？

９）痴呆のある親を引き取るかどうか悩んでいる人がいたら、何について、どのようにアドバイスしますか？

１０）介護の経験を通じて、ご自分がどのように変わったと思われますか？

(Appendix D continued)

次に、介護自体の問題から少し離れて、ご自身の生活についてお尋ねしたいと思います。

１１）学校を卒業されてから今までの生い立ちを、お話し頂けますか？。
　♪家庭生活は、今まで充実していたと思われますか。家庭の主婦としての生活を楽しんでこられましたか？
　♪ご自身にとって、家庭とはどのような意味を持つものでしょう。

１２）（職業のある場合）家庭の外でのお仕事を楽しんでこられましたか？家庭外での仕事は、ご自身にとってどのような意味をもつものでしょう。

今までの介護者の方へのインタビューで、生きがいという言葉がよく使われてきたように思われます。

8）ご自身にとって、生きがいとはどのようなものですか？

9）ご自身の現在の生きがいは何だと思われますか？
　♪ご結婚当初（介護をはじめる前）、生きがいは何だったでしょう？生きがいということについてお考えになったことがない場合は、ご自身の人生の中でもっとも大切な事は何だとお考えでしょう？
　♪それは時を経るに連れてどのように変わってきたでしょう？

10）お年よりのお世話を始める前とあととで、生きがいは変わってきたと思われますか？もし変わってきた場合、どのように変わって来たかお話しただけますか？
　♪生きがいということについて、よく考えるようになりましたか？自分の人生において大切なものは何かということについて、よく考えるようになりましたか？
　♪以前に比べて生きがいを感じるようになりましたか？それとも反対に、自分の人生に生きがいが感じられなくなってきましたか？

11）ご存じの方の中で、生きがいを強く持っていると思われる方を何人か挙げてください。その方々にとって、生きがいとはなんでしょう？

長時間ありがとうございました。

Appendix E: Modal Questions (English translation)

The following questions are used only when necessary, as the narrative unfolded.

1. To begin with, would you explain to me from the time when the elderly person's condition began to decline to this day?

2. How has your life changed because of the caregiving?

- Have your attitude and feeling toward caregiving changed compared to when you first began to take care of him/her? Why do you think it has changed?
- I imagine you have experienced various feelings. Would you tell me how your feelings have changed over the period? Or, are there any feelings that do not change during this period?
- Had you decided that you were going to take care of him/her this much from the beginning?

3. Why do you think you could continue to take care until today? Why do you think you could make this much effort?

- What influence do you think taking care of him/her had to your life course? Anything good or bad things are welcome.

4. Have you thought of future? How are you going to take care of the elderly person from now?

- How long do you think you can continue to take care of the elderly person? What are you going to do when you cannot continue any more?
- If you become like the elderly person in the future, do you want your daughter or daughter-in-law to take care of you?

5. If you didn't have to take care of the elderly person, what kind of life do you think you would be having nowadays?

6. Would you tell me how you became to be the caregiver for the elderly person? How were you feeling at first? Did your feeling change over time?

7. What does caregiving mean to you now, for your life?

8. If you see somebody who is thinking about taking care of the elderly parents with dementia, how and on what would you give advice to her?

9. How do you think you have changed through the experience of caregiving?

(appendix E, continued)

Next, leaving the issue of caregiving it self a little while, I would like to ask you about your life in general.

10. Would you tell me about your life after you finish school?
- Do you think your family life has been fruitful so far?
- What does family mean to you?

11. What kind of work do you do outside home? How long have you continued to work?
- Have you been enjoying your work?
- What does work outside home mean to you?

In the interviews I have conducted so far, I have heard several caregivers talk about their *ikigai*.

12. What does the word *ikigai* mean to you?

13. What do you think is your *ikigai* now?
-If you have not thought about your *ikigai*, what do you think the most important thing in your life is ?
- Do you think you feel more *ikigai* nowadays? Or is there no change? Or has your sense of *ikigai* declined nowadays?

14. Please name some people who you think have strong *ikigai*. What does *ikigai* mean to those people?

Appendix F: Human Subjects Approval

COMMITTEE ON HUMAN RESEARCH
OFFICE OF RESEARCH AFFAIRS, Box 0962
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

CHR APPROVAL LETTER

TO: Margaret I. Wallhagen, Ph.D.
Box 0610

Noriko Yamamoto, R.N., M.H.S.
Box 0602

RE: Family Caregiving of the Elderly with Dementing Illnesses in Japan

The Committee on Human Research, the UCSF Institutional Review Board holding Department of Health and Human Services Multiple Assurance #M-1169, has reviewed and approved this application to involve humans as research subjects, with the following

COMMENT: Since the risks to the subjects are minimal, the members suggested using an information sheet rather than a consent form as an unsigned document would better protect subject privacy and loss of confidentiality. If you agree, the consent form submitted could be revised by deleting the signature lines and changing the heading to read "Information Sheet."

APPROVAL NUMBER: H6362-09193-01. This number is a UCSF CHR number and should be used on all consent forms, correspondence and patient charts.

APPROVAL DATE: May 6, 1993. **Expedited Review**

EXPIRATION DATE: May 1, 1994. If the project is to continue, it must be renewed *by the expiration date*. See reverse side for details.

ADVERSE REACTIONS/COMPLICATIONS: All problems having to do with subject safety must be reported to the CHR within ten working days.

MODIFICATIONS: All protocol changes involving subjects must have prior CHR approval.

QUESTIONS: Please contact the office of the Committee on Human Research at (415) 476-1814 or campus mail stop, Box 0962.

Sincerely,

Reese T. Jones, M.D.
Chairman
Committee on Human Research

HEPC Project # 93009193