1997

Factors which influence dependency of the elderly on their caregivers : a Japanese perspective

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FACTORS WHICH INFLUENCE DEPENDENCY OF THE ELDERLY
ON THEIR CAREGIVERS: A JAPANESE PERSPECTIVE

A Thesis

Presented to

The Faculty of the Department of Occupational Therapy
San Jose State University

In Partial Fulfillment

of the Requirements for the Degree

Master of Science

by

Eiri Hayashigatani Inenaga

August, 1997

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ABSTRACT

FACTORS WHICH INFLUENCE DEPENDENCY OF THE ELDERLY ON THEIR CAREGIVERS: A JAPANESE PERSPECTIVE

by Eiri Hayashigatani Inenaga

This study reports how cultural factors influence functional outcome. Sixteen clients of an elderly day care center in Tokyo, Japan, participated in a qualitative study using semi-structured interviews. The findings support the concept that the overriding influence for dependency of clients' on their caregivers was the clients' perception of physical impairments, combined with personal and cultural values about dependency in old age and illness. The effect of these values on rehabilitation are also discussed. Finally, differences were found in life satisfaction and self-care skills between genders.

The values and beliefs of many cultures are often in direct conflict with occupational therapy philosophy, therapist's personal values, and institutional guidelines. This study supports the belief that more emphasis must be placed on discovering the value system of the patient and then honoring their beliefs. As reimbursement guidelines for occupational therapy become more rigid, this clinical issue will become a greater dilemma.

ACKNOWLEDGMENTS

There were many people who helped in the development of this study; however, no one as significant as my friend and mentor, Mrs. Teruko Iwasaki. With her vast experience working in geriatrics in Japan, she helped formulate a research topic, gave me much needed advice on conducting research in Japan, assisted me in finding a location for the interviews, helped me collect demographic data, and supplied me with literature. When things became difficult, she was always there to encourage me.

My heartfelt appreciation also to Gordon Burton, Kay Scwhartz, and Carolyn Glogoski-Williams, who as busy as they were, spent many hours reading through the drafts. Without their insights and suggestions, this thesis would not have been completed.

I also could not have done this research without the clients and staff at Shin-Ai day care center who gave me a warm welcome and opened up their hearts and minds. In addition, I want to acknowledge the Japanese Occupational Therapy Association for their assistance in introducing me to occupational therapists, and to all the clients and staff from various hospitals and health care centers for the informative observations and discussions.

Finally, my dearest thanks to my husband, Andrew, whose venture to this country allowed me the opportunity to learn about my own heritage. To my parents, who made great efforts to keep the Japanese language, culture and values alive for me. And to Belle, who throughout this process, never left my side.

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CHAPTER 1

INTRODUCTION

When researching a country's health care system, it is necessary to view the philosophy, infrastructure, provision of services, and utilization of services in the context of the culture. The health care system reflects, as well as reinforces, the social relations within a society (Lock, 1987).

Purpose

The purpose of this study was to identify the values elderly clients of a Tokyo day care center have towards independence in occupational tasks. Further, if increased independence in a particular occupational task was desired, what obstacles did they face? This study attempted to identify ways that occupational therapy interventions in the hospital and community can meet the changing needs of older persons and their caregivers in the Japanese society.

Statement of the Problem

Japan is now in a health care crisis. There is a rapidly increasing proportion of older persons in the population, the costs of health care are rising, and its becoming more and more difficult for family members to continue their previous roles as caretakers (Okamoto, 1992; Iglehart, 1988; Maeda, 1983). Japan currently has the highest life expectancies of men and women in the world. Japan's Ministry of Health and Welfare cites the 1992 life expectancy statistics as 82.2 years for women and 76.1 years for men (Tokyo Metropolitan Government, 1994). As a consequence, the proportion of older

persons in the population are rising. It is estimated that by 2025, the national proportion of people aged 65 or older will be 23.4% (Okamoto, 1992). Older persons accounted for 12.5% of the total population in Tokyo in 1993, and is estimated to peak at 22% in the year 2020 (Tokyo Metropolitan Government, 1994).

Frequent and lengthy inpatient geriatric admissions creates a heavy financial burden on the health care system (Iglehart, 1988; Maeda, 1983). In February of 1983, The Old Age Health Act was adopted to address the increased use of health resources by the aged. One outcome of this national policy was to control "profiteering by hospitals by reimbursing on a diminishing schedule--the longer the stay, the lower the rate" (Kiefer, 1987, p. 93). The reimbursement rates were again revised in 1985 and 1986 to discourage long stays (Kobayashi & Reich, 1993). In addition, to enable earlier discharges, Japan has placed a priority on improving the availability of alternative care facilities such as nursing homes and intermediate facilities. It is also rapidly expanding community based nursing and home helper services for older persons to provide assistance to them and to their family members (Iglehart, 1988; Maeda, 1983).

Currently, the mainstay of rehabilitation occurs during inpatient stays, with little or no rehabilitation once discharged home (Kiefer, 1987). Therefore, as inpatient admissions shorten, more efficient occupational therapy interventions in the hospital or the expansion of occupational therapy service areas in the community will need to be developed. In order to successfully develop occupational therapy programs that will continue to be effective within the changing social welfare and medical structure, there needs to be a better understanding of factors that may influence a client's ability to integrate into the community. This study attempted to identify those factors which influenced the independence level of older persons living in the community with their families, whether it be social, cultural, or environmental. Furthermore, new community programs can be

implemented, but unless this is done in coordination with the education and training of health care providers based on the needs of the society, these efforts will be ineffective.

Research Questions

This study addressed two questions:

1. What occupational task do elderly clients of a Tokyo day care center select as most important for achieving further independence?
2. Which factors do the elderly clients of a Tokyo day care center perceive as most influential in preventing them from achieving greater independence in the occupational task selected above: a) client's perception of their abilities; b) personal and cultural values of the client; c) attitudes and behavior of the primary caregiver; d) environmental barriers in the home; e) environmental barriers in the community; f) attitudes and behavior of the occupational therapists; and g) lack of client and/or family training?

Definitions

1. Culture: a complex system which includes knowledge, values, beliefs, morals, customs, and habits acquired as a member of society.
2. Cultural values: societal ideals, goals, and standards of behavior.
3. Personal values and priorities: individual ideals, goals and standards of behavior.
4. Elderly/older persons: aged 60 years or older.
5. Family caregiver: the family member who provides the majority of the non-professional assistance or care to a relative living at home.

6. Occupational task: activities required within an individual's occupational role which can be categorized into the occupational performance skills of self-care, productivity, and leisure.
7. Occupational performance skill: task areas which are consistent with an individual's roles and developmental stage and include self-care (personal care, communication, functional mobility, and community management), productivity (household management) and leisure (recreation and socialization).
8. Homecare occupational therapy: occupational therapy provided in the home to improve functional performance of clients in the occupational performance areas, taking into account the individual's needs and abilities, as well as the social and environmental components.

Limitations

This study may not be generalizable due to the small sample size and non-randomized sampling method. Only one urban day care center chosen for its convenient location and cooperativeness of staff was studied. Responses from clients living in rural areas may be quite different due to the differences in community health service availability, cultural and societal values, and environment between cosmopolitan and rural areas.

Due to the fact that the participants were all attending a day care center, the sample consisted of older persons who were probably functioning at a higher level than those who were confined to their homes, but were functioning at a lower level than those who had no need to attend a day care center. Attendance at a day care center also suggests that the clients themselves were motivated to engage in outside activities, and/or their family encouraged more activity. Furthermore, these results can only explain the perception of the clients in this particular day care center. The Shin Ai Day Care Center had good facilities

with a well trained staff who had a strong focus on rehabilitation and increased independence in functional activities. The availability and quality of training may be different in other centers.

Other factors which emerged that may influence a client's ability to be independent that were not addressed in this study are the availability of social welfare and medical services. Also, this study did not include those with dementia. Finally, due to my limited Japanese speaking ability, an interpreter was necessary.

Significance of the Study

Knowledge gained from this study sheds light on clients values and priorities, on their experience of illness, and on their experience as care receivers. This information can be used to create more effective rehabilitation and community reintegration programs, as well as educational programs for health professionals. As a societal gauge for the current values and priorities of Japanese older persons, this study can serve as additional information for use in the prioritization of health care programs in the Japanese medical and social welfare system.

Finally, the findings of this study can be used by occupational therapists in other countries when working with families of Japanese heritage. It will assist the therapist in further understanding how culture, environment, goals, values, and family dynamics affect the perceived obstacles to a client's functional performance. Hinojosa and Kramer (1994) state that the effect culture has on occupational performance is one of the least developed aspects of occupational therapy knowledge and should be emphasized in education.

CHAPTER 2

LITERATURE REVIEW

Introduction

As a preliminary study for this research, eight Japanese occupational therapists, four physical therapists, two speech therapists, one nurse, one rehabilitation doctor, and one careworker were informally interviewed by the researcher. These professionals consisted of staff from two community day care centers, three private day care centers, one government chronic care hospital, and two private rehabilitation hospitals which were visited for observation. These health professionals were questioned about obstacles towards independence they perceived older persons faced in the community. Based on these informal interviews and on the literature review, areas that have emerged that may play a role in the functional status of older persons living with their families were: 1) client's perception of their abilities; 2) personal and cultural values of the client; 3) attitudes and behavior of the primary caregiver; 4) environmental barriers in the home; 5) environmental barriers in the community; 6) attitudes and behavior of the occupational therapists; and 7) lack of client and/or family training in occupational therapy. These seven factors formed the basis of the client interviews and will be addressed in the literature review. First, the theoretical basis behind the research will be explained.

Theoretical Framework

The model of occupational performance focuses on the ability of an individual to accomplish the occupational tasks required of their role and developmental stage (Pedretti & Pasquinelli, 1990). Occupational tasks are the activities required within an individual's

occupational role, and can be categorized into the occupational performance areas of self-care, productivity, and leisure. The occupational performance areas and occupational tasks required within this geriatric participant group include self-care (personal care, communication, functional mobility, and community management), productivity (household management), and leisure (recreation and socialization) activities.

As individuals age, physical and mental abilities decline and the ability to adequately participate in occupational tasks are often compromised. These difficulties can be further compounded by multiple illnesses. In such cases, it is the role of the occupational therapist "to facilitate both an appropriate balance and optimal performance of occupational roles" (Pedretti & Pasquinelli, 1990, p. 3). Occupational therapists must not only be concerned with the capabilities of the individual (physical, mental, socio-cultural and spiritual), but must also take into consideration the influences of factors outside of the individual (Law et al., 1994). The purpose of this study was to explore how these outside factors, environmental, physical, societal and cultural aspects, influence performance in occupational tasks.

Health Care for the Aged in Japan

The main differences between geriatric care in Japan and in the West, is that hospitalizations are longer in Japan, with fewer geriatric facilities for the care or rehabilitation of the chronically ill (Kiefer, 1987). These differences are a reflection of the economic, political, medical and social welfare system as defined by the cultural values and customs of the Japanese.

Japan's geriatric medical and welfare system has been poorly developed and coordinated in the past because of the social assumption by policy makers and the public that families will provide care for the elders (Kobayashi & Reich, 1993; Kiefer, 1987).

"The assumption seems to be that for anything short of acute hospital care, family care is ipso facto best, unless the family is physically or economically unable to give care at all" (Kiefer, 1987, p. 98).

Historically, Japan's nursing homes or "Homes for the Aged" were solely public shelters used by the poor aged (Kiefer, 1987; Kobayashi & Reich, 1993). Although presently there is one type of nursing home that provides health services, there continues to be a strong social stigma for placement of family members in nursing homes (Kobayashi & Reich, 1993). The rate of nursing home residents in Japan was 10 per 1000 in 1988 in contrast to the United States 46.2 per 1000 in 1985 (Kobayashi & Reich, 1993).

The social responsibility placed on family members for providing care for older persons has also resulted in a lack of geriatric long-term care facilities (Kiefer, 1987; Maeda, 1983). Often there is a waiting period of one year before admission can be obtained into a nursing home (Kobayashi & Reich, 1993). In 1988, Japan had only 1,995 nursing homes with 145,000 beds, much fewer than in the United States (Kobayashi & Reich, 1993).

Another reason for decreased usage of nursing homes is the familiar practice of using hospital stays as a respite for family caregivers or for long-term care. Whereas social stigma is attached to nursing homes, hospital admissions appear to be acceptable (Iglehart, 1988; Kobayashi & Reich, 1993; Maeda, 1983; Okamoto, 1992; Tatara et al., 1993). In addition, the Japanese insurance system has no limitations on the length of hospital stays, as well as few guidelines for inpatient admissions (Iglehart, 1988; Kobayashi & Reich, 1993; Okamoto, 1992; Tatara et al., 1993). Although only 1.0% of the aged were in nursing homes in Japan, 2.6% were hospitalized for 3 months or longer in. Combining these two rates of institutionalization bring a percentage comparable to the 4.6% of the aged in the United States who are in nursing homes (Kobayashi & Reich, 1993). These 1988 figures are an indication of the overuse of hospitals for long-term care. Furthermore, a

nationwide "Patient Survey" taken in 1987 showed that older persons consisted of 43% of all inpatients and 27% of outpatients, and 45% of older persons had been hospitalized for 6 months or longer (Kobayashi & Reich, 1993).

To combat the increasing cost of health care services for older persons, Japan had been making many changes in its health and welfare system. Japan placed a priority on improving nursing home availability and experimenting with intermediate care facilities (Iglehart, 1988; Maeda, 1983). Japan also rapidly expanded their community based health care services for older persons. Unfortunately, the wealth of the prefectural and local governments dictated the availability of services, due to the important roles they play in the financing, administration and delivery of public health and social services (Kiefer, 1987). "These 3,255 local care systems are not uniform. Many communities have access to nursing homes, most have medical screening programs; some have home health services. Currently 81 local authorities offer day-care programs" (Kiefer, 1987, p. 94).

Japan's most recent attempt to cope with the pressures for elder care is the Gold Plan, a ten-year strategic plan (1990-1999) which set specific targets for development of geriatric community services. Since the implementation of this plan, the expansion of home helpers, short stay beds, geriatric facility beds, day care centers, and activity centers has met 40 to 50% of its goal. Case management centers and availability in residential facilities has met 20% of its target. Nursing homes have shown the largest increase, meeting 85% of its proposed goal for 1996. Now an emphasis is being placed on the expansion of geriatric (intermediate) facilities (Ministry of Social Welfare, 1994).

Availability of Rehabilitation Services

Although homecare services are expanding in the area of nursing, home helpers, case management, and respite care, little emphasis is placed on rehabilitation services

(Kiefer, 1987). In 1988, 1990, and 1992 reforms of the reimbursement schedule provided economic incentives for the delivery of home care (Kobayashi & Reich, 1993). In fact, until these changes were made to the public health insurance system, "only a small number of hospitals have voluntarily provided home care services, with the hospitals or patients paying the costs covered by insurance" (Kobayashi & Reich, 1993, p. 348). Yet, rehabilitation in home care was not included in these reforms.

Unfortunately, this is not an isolated incident in the home health sector. An emphasis on rehabilitation is lacking in all areas of the health care system. This may account for the statistics of the older persons in all institutions, including hospitals and nursing homes, which demonstrated that 50.6% were in various bedridden conditions (Kobayashi & Reich, 1993). In 1985, only 30% of general hospitals offered rehabilitation (Okamoto, 1992). Currently, only 4.4% of nursing home residents are provided with rehabilitation (Kiefer, 1987). In 1977 a total of 7,251 older persons were getting rehabilitation of any kind. This figure amounts to less than 3 percent of the bedfast aged (Kiefer, 1987).

Once in the community, the main source of rehabilitation is at the day care centers. Day care centers for older persons first began in 1979 to provide rehabilitation and "reactivation services" (Maeda, 1983). These centers were created to assist older persons in being more independent in activities of daily living, as well as providing a few hours of respite for the caregivers (Maeda, 1983). Suwa-Kobayashi, Yuasa, and Noguchi's interviewed (1995) 49 Japanese caregivers of older relatives suffering from dementia who were receiving services at four metropolitan Tokyo day care centers. The effect of the use of day-care services that the most number of caregivers perceived were that facial expressions became more animated; patients became more physically active; and the caregivers were able to relax psychologically. Day care centers provide a much needed service, however, there is a shortage of available day care centers. In a 1982 study by

Nakajima, Saito and Tsukihashi, only 1.6% of caregivers had access to day care, while 20% stated they wanted the service (Kiefer, 1987).

"Lack of rehabilitation services might be explained simply by a lack of financial incentives to develop them" (Kiefer, 1987, p. 102). In fact, even in rehabilitation hospitals, the reimbursement structure of health insurance allows only for group treatments, making it difficult to focus on the individual needs of the patient. This dilemma is exacerbated by the fact that the majority of the hospitals and clinics are privately owned by physicians. In 1988, 81% of the hospitals were privately owned (Kobayashi & Reich, 1993), and in 1986, 90% of the clinics were privately owned by physicians (Iglehart, 1988). Since the provision of services are often based on personal gain, there is high usage of medication and laboratory tests which offer economic incentives, but little focus paid to nursing and rehabilitation which offer low financial incentives (Kobayashi & Reich, 1993). In addition, the powerful lobby of the Japan Medical Association and the unwillingness of physicians to transfer authority to other helping professions has stifled the expansion of rehabilitation services (Kiefer, 1987).

Nevertheless the underlying factors for the lack of rehabilitation services goes beyond struggles with economics, politics, or administration. The difficulties are rooted in the Japanese concept of illness and their views on rehabilitation.

The Japanese Concept of Illness and Rehabilitation

The philosophy of rehabilitation is based on the values and culture of Western, white, middle-class populations and may not be compatible with the Japanese beliefs of illness. The Western medical belief is that illness is a temporary bodily insult that can be remedied by hard work and perseverance. In the American/Northwest European tradition, "the patient feels a strong aversion to his own passivity and presumably feels better

emotionally through the simple process of becoming more active and mobile" (Kiefer, 1987, p. 104). However, in Japanese and other types of East Asian medicine, illness is an imbalance between the individual and the environment (Kiefer, 1987). Eastern methods attempt to adjust this abnormal energy flow by using gentle and non-intrusive techniques as seen in herbalism, acupuncture, moxibustion, massage, and Japanese psychotherapies (Kiefer, 1987).

These Western values of independence, purposeful activity, and individualism (Kinebanian & Stomph, 1992) are in strong contrast to the Japanese belief of dependency. In Japan, during sickness and old age, accepting nurturance and dependency is encouraged among family members, as well as among health professionals. The belief is that bedrest is an important treatment for any illness. This tendency to pamper the sick can be seen in the previously mentioned long hospital stays and the high rates of bedridden elderly (Kobayashi & Reich, 1993).

Rehabilitation violates the patient-healer roles by requiring a more active role to be played by the patient. "Rehabilitation requires the imposition of discomfort on the patient, and in some extent the patient's rejection of nurturing by the caregiver" (Kiefer, 1987, p. 104). This is more true when the caregiver is a family member and not a professional careworker. In the western countries where autonomy is considered a right and an obligation, the motivation for rehabilitation is high for the therapist, patient, and family. However, in Japan, which encourages passivity, the motivation is many times insufficient (Kiefer, 1987). Kiefer further goes on to state that illness is more feared in cultures like Japan where the caregiver must stoically give nurturance and older persons must passively accept it. The following section describes the difficulties caregivers face within their roles as nurturers.

Caregiver Roles in Japan

In Japan, the majority of older persons are still being cared for at home by their family members. More than 60% of older persons live with their extended families, which includes a large majority of the most seriously impaired older persons who are completely bedridden (Kobayashi & Reich, 1993). According to the 1988 Basic Survey of Living Conditions carried out by the Japanese Ministry of Health and Welfare, 43.6% of persons 65 years and older who lived with their spouse, also lived with their children (Takeuchi, Takano, & Nakamura, 1994). The number of older persons living with their children increased to 56.7% when they had lost their spouse. And only 10.4% of older persons lived alone.

Due to strict gender roles in the Japanese society, the greatest burden of caregiving falls upon the women. The largest category for caretakers of the bedridden older men is their wives (61%), followed by their daughters-in-law (22%). For women, their daughters-in-law are the main caregivers (50%), and then their own children (27%) (Maeda, 1983). Fewer than 10 percent of caretakers are men, and over 25% of all caretakers are over the age of sixty (Kiefer, 1987).

As in all industrialized nations, Japan's trend towards nuclearisation of the family and the growing number of women in the work force has been changing the ability of families to care for their elders. Many of the caregivers are elderly themselves, are busy caring for their own family and children, or are working full-time (Maeda, 1983). Yet, no matter how difficult the situation is, the feeling of social responsibility, as well as the lack of alternative resources keep caregivers in their traditional roles.

The tolerance and determination of Japanese caregivers can be seen based upon a 1982 study by Nakajima, Saito and Tsukihashi (Kiefer, 1987) of members from a self-help society for dementia. Their research showed that among these caretakers of family

members with dementia, 92% experienced some distress in their roles. Over half rated their stress as acute, while half stated it was a round-the-clock job. However, this study also found that most of these caretakers were willing to accept the roles (77%), although it was difficult due to conflicting demands of children, work, or lack of community resources. Only 22% did not want to continue, but they felt there was no way out. Older people with fewer roles were more willing to continue being a caretaker. Most interesting was the fact that the more time-consuming the caretaking role was, the less inclined people were to want to quit.

Often the onerous task of caretaking is done without outside assistance due to feelings of social responsibility. "Most caretakers accept their role, either out of personal conviction or as a result of community pressure" (Kiefer, 1987, p. 100). Many daughters and daughters-in-law refuse assistance because family members and neighbors will criticize them for receiving help (Freed, 1990). Maeda's study (1983) found that "less than half of the families who were judged as needing home help service stated that they wanted to use that service" (p. 582). The caretakers first priority is for the comfort and well-being of the care receiver. The second priority is to gain knowledge about the likely progression of the illness. The next priority is placed on occasional respite from caretaking (short-term stays or day care), followed finally by rehabilitative treatment (Kiefer, 1987).

Although the attitude towards family care in Japan has been changing, a majority of the Japanese society still believes the responsibility of older persons falls upon the children. A nationwide survey of the beliefs of middle-aged persons between the ages of 30 to 49 years old found that over 80% stated that their child or child's spouse would care for them, while approximately 10% stated that their own spouse would care for them (Maeda, 1983). Less than 3% stated they would use outside resources such as a paid housekeeper, public home help services, or nursing homes (Maeda, 1983).

Unfortunately, the movement of women to the workforce, as well as the continuation of the overall trend of women having fewer babies will result in fewer caregivers for older persons in the future. The Health and Welfare Ministry reports that the lifetime reproduction rate for Japanese women fell to a record low in 1995, at 1.43 births for those 15 to 49 years old (Japan Times, 1996).

Interaction and Communication Styles

Interaction Styles

Occupational therapists are now beginning to realize the importance caregivers play in the adjustment to disease, in functional outcomes, and in the emotional and psychological aspects which are all part of the rehabilitation process (Clark, Corcoran, & Gitlin, 1995; Gitlin, Corcoran, & Leinmiller-Eckhardt, 1995; Hasselkus, 1988, 1989, 1991; Jongbloed, 1994; Evans, Matlock, Bishop, Stranahan, & Pederson, 1988; Evans, Noonan, Bishop, & Hendricks, 1989). As seen in the previous section, the pressures of caregiving are very high and the needs of the care receiver must be weighed with family and personal needs before deciding upon a course of action. When health professionals are not aware of the family dynamics, treatment methods are often in direct conflict with family needs.

Hasselkus' study (1988) found that the goals of the caregiver and the therapist were often contradictory. While the caregivers were more concerned about having the daily routine run smoothly, of keeping the care receiver out of danger, or of not losing their sense of identity as a caregiver, the therapist was attempting to have the care receiver reach the highest functional level within their abilities (Hasselkus, 1988, 1989, 1991). In these instances, caregivers usually ignored or modified instructions given by health professionals. The caregivers in the study had developed their own strategies to make

caregiving as easy and manageable as possible and did not feel the therapist fully understood the situation. In order to encourage caregiver participation and promote independent problem solving skills, Hasselkus (1988) suggests the use of open-ended and descriptive questions to help convey that the caregiver's perspectives and experiences are important (Hasselkus, 1988). Such collaborative relationships are important not only for the therapist-caregiver, but for the therapist-client as well. More control over the treatment process can improve motivation, energy and follow through (Clark et al., 1994; Gitlin et al., 1995; Hasselkus, 1988, 1989, 1991; Jongbloed, 1994; Northen, Rust, Nelson, & Watts, 1995).

However, the Japanese medical system is modeled after the Western medical model where there is little exchange or interaction between health professionals, patients and their families. The rigid hierarchical system that is pervasive through all aspects of life in Japan is magnified in this situation. Physicians and therapists are very respected members of society, seen as having much knowledge and expertise. Patients or families rarely question health professionals, trusting them explicitly to make all the decisions regarding medication, treatment, length of hospital stay, and discharge plans (Iglehart, 1988; Tierney, M., Minarik, & Tierney, L., 1994). In addition, the vertical orientation of the medical system allows for little collaboration among disciplines about patient care and discharge decisions (Kiefer, 1983; Tierney et al., 1994).

Needless to say, there is little participation of the patient and the family in the therapeutic process of problem-solving and decision-making. If the values of the occupational therapist are different, the priorities or needs of the patient or family may not be addressed. However, Steslicke (1987) believes that the status and the role of the physician is changing, and their decisions are no longer accepted without question. He states that physicians and other medical providers will have to change the way they interact with clients.

Communication Styles

The subtle communication patterns in Japan also affect the interaction between care receivers, caregivers, and health professionals. Since the avoidance of conflict and the maintenance of harmony is more important than individual desires and needs, individuals often express themselves indirectly or suppress their true feelings or intentions. (Tierney et al., 1994). Communication in Japan is also very polite and nonverbal. "There is a relatively pronounced tendency to guess what another person needs and feels without oral communication, more so among persons who are close in terms of kinship or emotional ties" (Suwa-Kobayashi et al., 1995, p. 28). Caregivers and care receivers may have the expectation that the other understands their desires and thoughts without verbalizing them (Suwa-Kobayashi, et al., 1995). Although this expectation can create problems if the right messages are not discerned, Suwa-Kobayashi and colleagues feel that these skills are helpful in becoming aware of the nonverbal signals of those suffering from dementia.

On the other hand, the negative impact nonverbal and non-confrontational forms of communication can have on the perception and management of health, can be seen in Lock's (1987) analysis of somatization among middle-aged women in Japan. Due to the social stigma of verbally expressing dissatisfaction with life, they use somatization as a way of expressing stress and oppression. It is acceptable to complain about physical problems, therefore whether consciously or unconsciously, illness can be used as an "attempt to induce changes in the behavior of the people affecting one's life" (Lock, 1987, pp. 136). An overemphasis on physical weaknesses and ailments may be the way middle-aged women, as well as older persons are expressing dissatisfaction with life.

Environmental Barriers

The infrastructure of a typical Japanese community and the structure and equipment found in the home may create obstacles for the independence of older persons if mobility is limited.

Community

Japan is well known for its small, compact, and extremely crowded cities. This makes mobility for the handicapped very difficult, if not close to impossible. The maze of streets in Tokyo are very narrow, usually with no sidewalks, and often, passages where opposing traffic cannot pass alongside each other. These streets are not only filled with cars, but with bicyclists and pedestrians. If sidewalks are available, the curbs are often very steep. Rarely does one see wheelchairs, walkers, or any other assistive device used on the streets. At most, a cane may be used. Often older persons are confined to their homes because they are afraid to venture out due to the many barriers that will be encountered.

Although getting around Japan for the handicapped is becoming more manageable, it is still difficult. Trains, which are the most common form of transportation for most Japanese, have many obstacles for the handicapped. Lack of wheelchair accessible toilets and stairs are two of the main obstacles that the disabled face in the stations. The number of wheelchair-accessible toilets at major train stations has increased in the past few years; however, due to the greater cost and space requirements of elevators, they are more difficult to construct (Pepper, 1995). Some major train stations are instead becoming equipped with a "specially designed stair lift that can carry a person in a wheelchair up or down" (Pepper, 1995). In recent years, railway stations have seen improvements, "but in a country with so many stations (and sometimes so little space) there's still a lot to be done,

especially at small stations on local lines" (Pepper, 1995). Though Tokyo has been attempting to modify its city to make it more accessible to the handicapped, the lack of space, and the number of renovations that need to take place are daunting.

Impact of Housing on Functional Performance

The housing conditions in Japan create many problems for older persons in functional status related to mobility and activities of daily living. Most urban residents live in a small and narrow house or apartment with limited wheelchair accessibility (Kobayashi & Reich, 1993). Traditional Japanese furnishings include *futons* (mattresses laid directly on to the floor) and *zabutons* (floor cushions to sit on). Use of these furnishings require more quadriceps strength, and more balance than Western style beds and chairs (Lipsitz et al., 1994). Though many Japanese homes now have Western-style architecture, such furniture decreases the amount of space available to care for older persons. In addition, "even the tiniest of modern apartments has a *genkan*, a square or rectangular space at the entrance where people take their shoes off" (Ohnuki-Tierney, 1984). At this entrance, there is always a step that distinctly separates the dirty bottom level and the clean top level. This step often provides difficulties for households using wheelchairs.

In addition, the room for toileting and bathing is extremely small and is often separated from the main house (Zhao, Tatara, Kuroda, & Takayama, 1993). Traditionally, floor level toilets were used in all the homes, however, many have been renovated to the Western styles. The baths commonly used in Japan are very narrow and deep and are more difficult to get in and out of than the lower, and spacious Western style tubs (Zhao et al., 1993). Furthermore, 12% of the houses in Japan do not even have a room for bathing, and a public bath is used (Zhao et al., 1993).

Three recent studies have documented the importance of housing conditions in relation to mortality and in improvement in functional performance. The first study by Zhao et al. (1993) found that the survival of frail older persons living at home in Osaka Prefecture was higher for those with good housing conditions than for those with poor housing conditions. In their study, 48.2% of the participants were considered to have poor housing conditions which included: 13.9% who did not have a room for bathing in the home; 14.4% who did not have their own room; and 39.7% who reported that their style of toilets made use of the toilet difficult. They discovered that older persons with their own room tended to have higher survival rates, although the difference was not considered statistically significant. The authors of this study cite that increased survival rates for those with private rooms may be associated with an increased amount of space for activities of daily living. Yet, housing conditions, education and nutritional factors are all a reflection of socio-economic status and can affect mortality separately. Unfortunately, this study is unable to discriminate between these factors.

A survey of stroke patients (Tamiya, Araki, Yokoyama, Nagami, & Heki, 1990) reported that the renovation of the bathroom, the elimination of steps, and the addition of handrails, etc., created an improvement in the performance of activities of day living (Zhao et al., 1993). Kuroda, Baba, Mizuno, and Tsumura (1994) studied the effectiveness of a home improvement program and found that the proportion of study participants who were bed-ridden decreased with a corresponding increase in improvements made to entrances and approaches to their residences. Home improvement also correlated with an improvement in the level of performance of daily activities. A specially equipped bed correlated with a reduction in caregiver's burden. A reduction in the need for long-term institutional care was related to the family structure and the number of rooms in the home (Kuroda, Baba, et al., 1994).

Finally, a study found that decreased independence of older persons in activities of daily living upon discharge home from a rehabilitation hospital may be related to the housing environment (Ushikubo, Shimanouchi, Yamanobe, & Hosaka, 1993). Though the level of feeding improved, grooming (which included bathing), using the toilet, and dressing was worse than levels found prior to discharge. One of the suggestions was for staff to take into consideration structural problems that may occur at home, especially in the bathrooms and washrooms, before discharging patients home.

The literature reflects that programs to improve housing conditions are important components of home care delivery for older persons. Although a few local governments have created assistance programs for home improvement, a national program is not yet in place (Zhao et al., 1993).

Japanese Research in Activities of Daily Living

Health and social welfare professionals are realizing the importance of improving the activities of daily living (ADL) status of older persons in Japan. Recent studies have found that low ADL status has a correlation with higher mortality risk (Tsuji et al., 1994) and a higher rate of institutionalization (Kuroda, Tatara, Takatorige, Zhao, & Shinsho, 1992; Ishizaki et al., 1995). ADL status was also found to be related to life satisfaction (Hayashi, Ahiko, & Yasumura, 1995).

Tsuji et al. (1994) and Hayashi et al. (1995) studied the prevalence of disability among older persons in activities of daily living. Both studies found that dependence in bathing was the most common, and was also considered to be the most burdensome by caregivers.

Fujita and Hatano (1989) and Yamakawa et al. (1994) researched the level of personal ADL tasks and instrumental ADL (IADL) tasks in relation to age and gender.

Personal ADL's included tasks such as eating, dressing, bathing, toileting, mobility and incontinence; while IADL's consisted of tasks such as cooking, using the telephone, cleaning house, walking, shopping, and using transportation. Fujita and Hatano's (1989) found little difference in the performance of personal ADL's between men and women. However, the status for the IADL tasks of traveling to distant locations, using the telephone, and handling their own money was higher among men than women. Yamakawa et al. (1994) also found that there was no significant difference between genders in the performance of ADL, except for incontinence, which was significantly higher in women than in men. In the area of IADL, men had significantly lower performance rates in cooking; and women had more difficulty using stairs and transportation, and walking. Both studies found that the prevalence of difficulties in performing ADL's increased rapidly with age.

Tamiya et al. (1990) studied factors which affect ADL levels in stroke patients living at home. An interview survey of the caregivers of 68 stroke patients were performed by homecare nurses and public health staff. The two factors which correlated with improved ADL status was the ADL level at the start of homecare, and reconstruction of the bathroom. An interesting point is that the reformation of the bath tub contributed to an increase in other ADL areas, but did not improve independence in bathing. The group that showed improvement in ADL's had significantly lower initial ADL status, and were significantly younger than the participants of the unchanged/ deteriorated ADL group. The researchers suggested that the increase in the ADL status of the lower level ADL patients may have been the result of receiving more attention from home care staff and caregivers.

Fujita and Hatano (1989) emphasize the importance of researching obstacles towards independence, as well as placing more emphasis on prevention and rehabilitation. "It is estimated that in 40 years the prevalence of disabled elderly will increase to three times what it is today" (Fujita & Hatano, 1989). Although the studies mentioned above

have looked at the functioning status of older persons in daily living skills, only one study (Tamiya et al., 1990) looked at the obstacles older persons face in performing ADL. Yet, many important factors, such as community environment, personal and cultural values, and interactions between health professionals and caregivers were not investigated in Tamiya's study.

CHAPTER 3

METHODOLOGY

Purpose

The purpose of this study was to identify the values elderly clients of a Tokyo day care center have towards independence in occupational tasks. Further, if increased independence in a particular occupational task was desired, what obstacles did they face? This study attempted to identify ways that occupational therapy interventions in the hospital and community can meet the changing needs of older persons and their caregivers in the Japanese society.

Questions

This study addressed two questions:

1. What occupational task do elderly clients of a Tokyo day care center select as most important for achieving further independence?
2. Which factors do the elderly clients of a Tokyo day care center perceive as most influential in preventing them from achieving greater independence in the occupational task selected above: a) client's perception of their abilities; b) personal and cultural values of the client; c) attitudes and behavior of the primary caregiver; d) environmental barriers in the home; e) environmental barriers in the community; f) attitudes and behavior of the occupational therapists; and g) lack of client and/or family training?

Participants

Due to the lack of occupational therapists in homecare, it is difficult to establish contacts in the home setting. A day care setting with an occupational therapy program was chosen as a sample of convenience.

This research was conducted through semi-structured interviews at the Shin-Ai Day Care Center in Tokyo, Japan. Sixteen clients fitting the following criteria participated in the study: 1) over 60 years old; 2) obtained assistance from a primary caregiver in any of the occupational performance skill areas of self-care, productivity, and leisure; 3) the primary caregiver was a relative living with the client; 4) had been living with their primary caregiver at least 3 months; and 5) was identified by the day care center staff as being able to accurately respond to questions regarding their independence level. All diagnosis groups were requested to participate. Twenty five clients at Shin Ai Day Care Center fit this participant criteria. Three chose not to participate due to moderate to severe aphasia, five were absent on the days of the interviews, and one was eliminated due to severe difficulty with hearing. Another interview day was not scheduled for those absent during the interviews since the data was saturated, with no new themes emerging.

Location

Shin-Ai Day Care Center, located in Kiyose City, Tokyo, was chosen for its extensive service areas and large number of participants. Anyone over the age of 40 years, who lived alone, or was dependent upon their families for care or assistance in everyday life, and who were residents of Kiyose City, was able to attend for a nominal fee. There were approximately 80 participants in the day care center, separated into two groups of 40. Each group met twice a week from 10 AM to 3 PM. A minibus was available for those

who required transportation to the facility. There were 2 full-time occupational therapists, a nurse, 3 caseworkers, 3 careworkers, and 3 bus drivers. All of these staff members assisted in coordinating the activities of two programs within the day care center; one section was for physically impaired adults, and the other for those with dementia.

The day care center activities included group exercises, activities of daily living training, individual functional retraining (such as transfer training and gait training), speech training, socialization, recreation, crafts, hobbies, field trips, and cultural events. Apart from the day care center, there were also bathing services, one week caregiver respite services, and consultation services.

Design of Interviews

Due to the non-confrontational and nonverbal style of communication in Japan, Japanese occupational therapists suggested a period of establishing rapport to encourage improved participation and candid responses. Therefore, prior to data collection, the researcher volunteered once a week for two months at the day care center to become familiar with the clients, and to allow the clients to become comfortable with the researcher. After two months of observation and participation in activities, the researcher requested volunteers who fit the previously mentioned participant criteria. These volunteers were given an explanation of the purpose for the research and the type of questions that were to be asked. The consent form (Appendix A) was also presented and explained. If the participants agreed to the conditions stated on the consent form, demographic data from the charts and staff were collected. Volunteers were then given an interview schedule, and a convenient time was scheduled.

The interviews were conducted on three separate days at the Shin-Ai Day Care Center during the time clients regularly attended. Before the start of each scheduled

interview, the participants were given a copy of the previously signed consent form and were asked if they agreed to continue. If they agreed, I asked the interview questions, with the assistance of an interpreter when needed. Each audio taped interview was approximately 30 minutes long.

Design of Instrument

The Daily Living Questionnaire (Appendix B & C), created for the purpose of this study was used for the semi-structured interview process. The Daily Living Questionnaire was designed to identify occupational tasks in which participants desired more independence, as well as obstacles which hindered their ability to be more independent.

Prior to developing the questionnaire, eight Japanese occupational therapists, four physical therapists, two speech therapists, one nurse, one rehabilitation doctor, and one careworker were informally interviewed by the researcher. These professionals consisted of staff from two community day care centers, three private day care centers, one government chronic care hospital, and two private rehabilitation hospitals which were visited for observation. These health professionals were interviewed about the values of older persons towards independence, as well as obstacles towards independence older persons faced in the community. Based on these informal interviews and on the literature review, the questionnaire was drafted. The draft was then reviewed by an occupational therapist with many years of experience with the Japanese geriatric population. This occupational therapist, now a director of an occupational therapy department at a national chronic care hospital in Tokyo, was previously a staff member at the Shin-Ai day care center, as well as a professor of occupational therapy. The occupational therapy staff at the day care center also reviewed the draft. The final phase of developing the questionnaire

included an informal pilot test with one client from the day care center. Revisions were made during each step of the process.

The questionnaire included three parts. Part I (Appendix B) requested client information about demographics, history of rehabilitation services, and living environment. The researcher filled out these objective questions prior to the interview from data collected from charts and day care staff to limit the amount of questions and the time needed for the interview. Due to frequent prior contacts with the participants, rapport had already been established and a period of introductory questions were not necessary in the interviews. Since Part I was not used in the interview, it was not translated into Japanese. Instead, this information was compiled with the assistance of a Japanese occupational therapist with English speaking and writing capability. An interpreter was also consulted as necessary.

The actual interview questions consisted of Part II and Part III of the questionnaire (Appendix C). In Part II, the clients were requested to first identify all problem areas, and to then choose one of these areas where increased independence was a priority. The problem area list was created from the occupational performance skill areas of self-care, productivity and leisure. In Part III, the clients were given a list of possible obstacles in achieving increased independence. They were asked to explain how influential they perceived each of the items were in preventing further independence in the selected priority area. The list of obstacles were created from the categories that had emerged during the informal interviews of health professionals and the literature review. The categories included: 1) client's perception of current abilities; 2) personal and cultural values of the client; 3) attitudes and behavior of the primary caregiver; 4) environmental barriers in the home; 5) environmental barriers in the community; 6) attitudes and behavior of the occupational therapists; and 7) lack of client and/or family training in occupational therapy. An outline of which items pertain to which categories is listed in the Daily Living Questionnaire Key (Appendix B).

Part II and III which were used during the interview, was translated into Japanese by a native Japanese occupational therapist and then checked for accuracy by a Japanese translator. Due to my limited Japanese speaking ability, I had the assistance of a paid interpreter throughout the interviews. During the interview, if the client was unable to read the questionnaire independently, it was read by myself or the interpreter. The sessions, which were approximately 30 minutes each, were audio taped and studied later by myself and the interpreter.

Data Analysis

The data collected was analyzed using qualitative methods. First, problems and concepts were identified and placed into preliminary data categories. Second, data was collected and placed into the appropriate categories, creating new categories, if new concepts emerged. Next, relationships and trends among the data were identified. The final stage was to recheck and refine the data to improve the validity of the findings (Kielhofner, 1982).

The initial categorization of factors which may influence a client's ability to be independent had already been discovered through informal interviews with health professionals. The Daily Living Questionnaire was designed as a tool to identify the appropriateness, as well as the influence of these categories. Initially, a Likert scale was used to identify the degree of influence of the various factors. But because the participants had difficulty using the scale, the questionnaire was modified to include only open-ended questions.

The data collected from medical charts, staff and researcher observations, and semi-structured interviews using the Daily Living Questionnaire were categorized. The only new theme that emerged over the course of data collecting was "public embarrassment". "Public

embarrassment" was described as discomfort when going out in public because of what people may think when they see the participant with a disability. The questionnaire was modified to include it.

After the interviews, the researcher listened to each audio taped interview three times, checking with the translator if there were specific questions from the audio tapes. Notes were taken during the interviews, as well as during the review of the tapes, and were used to develop common themes. Next, charts on the frequency of themes and on functional status in relation to gender and age were created to assist in the development of trends.

The researcher then consulted with the day care center staff regarding the common themes and trends. The staff validated the research findings from their personal experience with the interview participants. The demographic data is described using statistical methods for comparison among participants in the development of major trends. Common themes will be explained using case studies and references to interviews.

Reliability and Validity

Triangulation of data occurred using information from medical charts, pre-interview observations of the client interacting with day care center members and staff, informal interviews with the client and day care staff, audio-tapes of the semi-structured interview session, and consultation with day care center staff on research findings. Throughout the data analysis, notes were kept on the process to explain and validate the final methodological structure (Glaser & Strauss, 1967; Kielhofner, 1982).

The Daily Living Questionnaire appeared to be exhaustive. Only one new theme, "public embarrassment", emerged during the process of the interviews, and was then added to the questionnaire. Interviews were stopped when themes became repetitious, with no

new themes emerging. The content validity of the questionnaire was also verified as the occupational therapy staff at the day care center felt the research findings were consistent with their day to day experiences with the clients.

CHAPTER 4

DATA AND RESULTS

This study attempted to identify which areas Japanese older persons desired further independence, as well as which factors they perceived affected their ability to be more independent. Sixteen clients of a geriatric day care center in Japan participated in a 30 minute semi-structured interview which used open-ended questions to identify themes. Demographic data used to analyze the qualitative data was also collected prior to the interviews.

This chapter begins with a description of the participants, their caregivers, and their housing situation. Next the participants' self-reported functional status and occupational task priorities are provided along with major trends noted in the data. Common themes regarding obstacles to independence will then be described using case studies and references to interviews. Finally, the two research questions of this study will be addressed.

Demographic Data

Description of Participants

The 16 participants were clients of a day care center in the Tokyo prefecture of Japan. They were native Japanese and lived with their families in the city of Kiyose. Eight participants were female and eight were male. Seven of the women were widowed, and one was married. In contrast, only one of the men was widowed, and the other seven married.

The ages of the women ranged from 61 to 90-years-old, with both a mean age and a median age of 76 years. The highest level of education for two of the women were high

school, while the others achieved grade school level education. It was stated several times by participants that it was common during their childhood to only attend grade school which continued up to the eighth grade. Very few people went on to high school, and rarely did anyone go to college. Two of the women were homemakers; two were in allied health professions; one had been a housecleaner; one a dairy farmer; one self-employed at a tempura shop; and one assisted in funeral ceremonies.

The ages and educational status of the men were very similar to the ages of the women participants. The men's ages ranged from 60 to 87-years-old, with a mean age of 75 years and a median age of 77 years. For the men, the highest educational level for one participant was kindergarten, four had graduated from grade school, one had graduated from high school, and two had graduated from college. Three of the men had been self-employed; two had been craftsmen; one had been a laborer; one had been a production process worker; and one had been a cook.

Eleven of the participants had a primary diagnosis of cerebral vascular accident. The onset of their disability ranged from two to 16 years, with a mean time length of nine years and six months, and a median time length of nine years. The other five participants had diagnoses of osteoporosis, cardiac insufficiency, diabetes, hypertension, heart disease, and weakness in the lower extremities. The time period for the onset of their illness ranged from three months to eight years and seven months, with a mean time length of three years, and a median time length of two years. The mean length of time for all illness categories was seven years and six months, with a median time length of five years.

Caregivers

The caregivers for the women participants in the study included three daughter-in-laws; three married daughters; one widowed daughter; and one husband. All of these female caregivers had children of various ages who still lived with them. The caregiver

husband, lived with his daughter's family. The caregivers for the male participants included five wives; one daughter-in-law with no children; one unmarried daughter; and one married son with a teenage child. Of the male participants whose caregivers were their wives, one couple lived with their son and his family with grade school age children; another couple lived with two unmarried sons; and three couples lived alone. One of these couples did not have children.

Rehabilitation

Further demonstrating the long length of hospital stays in Japan, the mean inpatient hospitalization period for eight of the participants who had strokes was 14 months, with a median time period of 10 months. The shortest stay was seven months, and the longest stay was 2 years and 3 months. The length of hospitalization for three of the stroke participants were not included since this information was not available. The participants with other diagnoses either had never been hospitalized, or had been hospitalized for less than one month.

The length of attendance at the day care center for the participants ranged from one month to 16 years, with an average of length of attendance of 4 years and 5 months, and a median length of attendance of 2 years and 6 months. As long as room is available, there is no limit to the length of time one can attend the day care center.

We were unable to obtain information regarding home visits and family training sessions during inpatient stays. However, at the day care center, eight of the participants had a one time home visit from staff members for the assessment of living conditions. These visits included one hour consultations for environmental modifications and safety recommendations. One of the long-time participants had received three separate visits for various home re-modification consultations. These home visits were made upon the request of the client or family, or when the day care staff felt it was necessary for improved

function. The day care center has also recently instituted a guideline suggesting that new participants have this physical and living status evaluation as time and staffing availability permits. These results showed that the participants had the majority of their intensive individualized training during inpatient rehabilitation, with maintenance training provided at the day care center; little training was done in the homes.

Housing and Equipment

Due to previous re-modifications, housing conditions appeared to be satisfactory for all participants. There were a few references to inconveniences, such as a small kitchen, or a wheelchair inaccessible section of the house; however, none of the clients perceived their housing situation as a factor which prevented them from being more independent.

Twelve participants lived in a family owned two-story house; three lived in government housing for the disabled; and one rented a house. All of the women, and two of the men lived in three generational households that included themselves, their children and their grandchildren. Of the other participants, three men lived with their spouse, and three men lived with their married or unmarried children who had no children of their own. All participants had their own bedroom, except for one, who shared the upstairs room with her grandchildren.

All of the participants had previously had their homes remodeled for safety and accessibility with financial assistance from the Tokyo prefectural and city government. Suggestions for re-modification were often provided by the day care center staff, or other community health care staff in coordination with the local government. The most common renovations included changing the Japanese style squat toilet to the western style; and equipping the Japanese style tubs with rails, stairs, or seats. At the time of data collection,

one participant was consulting with the day care center staff regarding modification of his tub.

Three participants used wheelchairs for mobility in their homes. One participant who lived in government housing was able to access all the rooms with the wheelchair; the second participant was limited to the kitchen, bedroom, and toilet; while the last participant had wheelchair access only to the kitchen, and used a cane to reach the toilet and bedroom. Two participants used a cane in the home, but relied on family members to assist them in wheelchair mobility in the community. The other 11 participants used a cane for mobility both in the home and in the community. None of the participants who used wheelchairs used them independently in the community.

The use of western style beds and chairs were common. Only four of the more independent participants used the traditional beds, *futons*, and the cushions, *zabutons*. Two of the participants used portable toilets at night, and the majority had stools to sit on while bathing. Only one participant needed a commode over the toilet; the others had rails placed on the walls.

Functioning Status

Self-Care

Personal care. Apart from toileting, a task area in which all participants were independent, there was a gender difference in functional status in activities of daily living. This was true even among men and women with similar ages, diagnoses, and severity of the illness. All of the women were independent in the areas of grooming/hygiene and dressing, yet five men received assistance in at least one of these areas. One man received assistance in grooming, two men in dressing, and two men received assistance in both grooming and dressing. Three women received assistance in bathing, while seven men

received assistance in this area. Three of the four men who were most dependent in self-care activities were cared for by their spouses. In this study, a male participant's wife placed the covers over him every night, even though he had the use of one arm. The increased dependence of the men may be due to the custom of Japanese wives providing all of the basic needs for their husbands. According to Ohnuki-Tierney (1984), Japanese wives often make all the decisions within the household, including the detailed management of the husband's body, such as assisting in dressing and bathing. By managing her husband's personal needs, the wife can communicate her caring and concern which may not be expressed out rightly.

Bathing was the most common activity of daily living where participants received assistance. Though only seven participants received assistance for transfers into the tub, ten participants received help for washing. Many participants stated they could not adequately wash themselves with only the use of one hand. The reliance on caregivers for bathing could be related to the importance Japanese culture places on cleanliness and purity. The belief is that bathing before bed prevents sickness, and rids the body of the "outside" germs before entering the bed (Ohnuki-Tierney, 1984). It is a very important purification ritual which must be carefully carried out. Bathing is also believed to be important to warm the body and to prevent colds. In addition, because the same bath water is used for family members, it is necessary to wash well before getting into the tub. One client stated that she was offended because her daughter-in-law emptied the tub after the client took a bath. When she reported that family members refuse to use the same bath water, she felt they were implying that she had contaminated the water with her body.

Functional mobility. All participants were independent in functional mobility in the home (except for the shower and tub), using a wheelchair, cane, or structures inside the home for support. Six of the women were independent in the community, while only three men ventured out on their own. However, two men stated they probably could venture out

on their own if they desired. The remaining participants were unable to stand or walk for extended periods, and therefore felt they were unable to go outside alone.

Community management. The participants stated that the main difficulties in community management included public transportation. Riding the trains were hard due to the hurried crowds at the automatic ticket gates; the many stairs at the stations; the gap between the platform and the train; and the balance needed when standing up on a moving train. Riding buses were difficult due to the steps. Four men and three women had not ridden a bus or train since their disability; and four men and one woman used them only with assistance. The only participants able to ride the buses and trains independently were four women. In spite of the problems with trains and buses only one participant, who wanted to see sports events, stated this affected his ability to travel. The other participants preferred the use of family cars or taxis, and felt other forms of transportation were not necessary. In fact, the youngest participant still drove his car.

Though another male participant mentioned the lack of wheelchair accessible facilities, other participants saw few obstacles in the community. This may be because they had lived in these communities all of their lives and were comfortable in the surroundings. In addition, only participants who were able to walk for long distances and climb stairs independently, ventured out of their homes. Personal strength and endurance, and not the community environment, was seen as the obstacle to independence.

Communication. Four men, all with aphasia, stated they had difficulty speaking clearly and being heard. One participant who spoke very little with his wife explained, he had no confidence in people understanding him. Communication between a second man and his wife was complicated by her decreased hearing abilities. The son of this participant served as an interpreter, but was often busy. Another participant stated he became the most angry when people only pretended to listen to him.

Productivity

Household Management. It appears that the traditional expectations of older persons to have their family provide for their daily needs continues to hold. Regardless of gender, age, health, or functional ability, all participants had their meals cooked for them, except one, who bought lunch everyday. Only four participants assisted with household chores—three cleaned their own rooms and one did a little gardening. Ten participants had their caregivers do all their shopping, three bought only personal items, and another three did both personal and some household shopping.

The majority of the women stated they were "satisfied" with their lifestyle of tending to their personal self-care, and allowing their caregivers to do all the household chores. However, the men, even those who did not want to be more independent, stated they were unhappy with their situation. A possible reason for the difference in life satisfaction among genders may be due to their prior roles. In a traditional Japanese family, the roles of older women switch from doing the household chores to managing the household, with the younger generation doing most of the work. The degree of participation in the tasks may change, but the context remains the same. Wives who have worked hard all their lives expect to give up their responsibilities to their daughter-in-laws (Lock, 1987). "As a mother-in-law, the older Japanese woman in a traditional family enjoyed considerable power, freedom, and leisure" (Lock, 1987, p. 148). In Japan, while the older women's identity is linked to the continuation of the household (Rosenberger, 1987), the productivity to which men have been linked outside the home is no longer present. Since men were not engaged in household matters before retirement, they were not expected to assist now. The loss of identity among the men may contribute to dissatisfaction in life.

Personal Management. Six participants, four men and two women, stated they were getting assistance with managing their medication and finances. Three felt they were

able to do it themselves, but wanted to have others do it for them. One male participant wanted to manage his accounts independently, but his wife wouldn't let him because he had difficulty keeping track of things since his stroke.

Leisure Activities

Eleven of the participants stated they had difficulty in leisure activities which included traveling, visiting friends, going to restaurants, participating in clubs, and arranging their own social plans. These participants felt they were unable to participate in outside activities due to such factors as weakness, and poor endurance; being a burden on family members; being unable to use public transportation alone; being an embarrassment in public due to their disability; and lacking confidence in themselves.

Priorities of Occupational Tasks

From the model of occupational performance, occupational tasks are the activities required within an individual's role and can be categorized into the occupational performance areas of self-care, productivity, and leisure. In this study, the occupational tasks in the performance area of self-care included personal care, communication, functional mobility, and community management. The occupational task in the performance area of productivity was household management, and in the performance area of leisure, the occupational tasks were recreation and socialization.

There was not one predominant occupational task that participants stated was a priority for increased independence. Of the women, one chose bathing; two chose cooking occasionally; and one chose traveling as priorities for increased independence. Four women had no desire to become more independent in any areas. Of the men, one chose wheelchair mobility; one chose taking walks in the community; one chose attending sports

events; one chose managing his finances; and one chose bathing as task priorities. Three men did not want to be more independent in any areas. This included one man who wanted his tub remodeled. Six of the seven participants who stated they did not want to become more independent were already independent in functional mobility and self-care needs, aside from bathing. The seventh participant received assistance in dressing as well. Yet, all seven participants had their main cooking, shopping, and home management needs met by their caregivers.

Obstacles to Independence: Common Themes

The following are common themes that emerged when participants were asked to explain how influential they perceived the listed factors were in preventing them from being more independent in occupational tasks. The themes are categorized into the areas of perception of self, personal and cultural values, attitudes and behavior of caregivers, environmental barriers, perception of rehabilitation and attitudes of health professionals.

Perception of Self

Eleven participants expressed that old age, physical weakness, or physical handicaps affected their ability, as well as their desire, to be more independent. Many participants did not strive for independence because of possible dangers, and because of the lack of courage or confidence in themselves. Though most of the participants felt they were limited by their physical status, only three male participants felt that their decreased ability to concentrate affected their independence.

Too old. The oldest man, and the oldest woman perceived that their age affected their level of functioning. Endorsing this theme is Mrs. I., the oldest participant at 90-years of age. Mrs. I. lived with her daughter's family and was independent in self-care

tasks. However, she received assistance from her daughter in shopping, household management (cooking and cleaning), and personal management (medication and finance). Her only leisure activity was coming to the day care center. She stated that it was enjoyable to come and see everyone at the day care center, and her absence at home helped her daughter who was very busy. Though Mrs. I. was happy with her living situation, she felt she had lived long enough. She explained, "one doesn't know how it feels to live until they are 90, until they've done it". Though relatively healthy with only the complaint of painful knees, she had few desires left in life. "My daughter does everything. I don't do anything, I only watch TV...I don't want to do anything. My body doesn't work as well since I'm old." Mrs. I. ended the interview by saying, "My body is healthy. The doctor says I have no problems and can live another ten years...but I don't feel I need to live that long."

Struggling too long. Mr. K., at 83-years of age did not feel he was too old, but that he had been living with his illness for too long. Mr. K., previously a tailor, had a stroke which left him with right sided hemiparesis and aphasia. He relied on his married son for bathing, and also received assistance with transportation, home management, personal management, and shopping. Due to his aphasia, and his wife's poor hearing, his son served as an interpreter when he wasn't too busy. Mr. K. explained that he was tired of living with his illness and had given up on trying to do things on his own. "After 17 years since I became ill, all I can think about is to die." He added, "I come here (day care center) to become refreshed, and change the way I feel about things. But, I am the longest attending member of this Monday/Thursday group." "If I was going to die tomorrow, I would want to die. I have no hope". He stated he did not have many enjoyable things in his life. When asked about his grandchildren, he stated, "I'm too worried about myself to enjoy being with my grandchildren".

Too weak. One male participant and two female participants felt that their lack of strength and endurance prevented them from participating in activities. Mr. T. was unable to take walks around his neighborhood due to the weakness in his legs; Mrs. A. could not cook regularly because she could not stand for long periods of time; and Mrs. K. was unable to travel alone due to weakness in her legs.

Disabled. Seven participants with hemiparesis due to strokes stated that it was not old age or weakness that prevented further independence, but that their "arm wouldn't move" or their "body wouldn't work". Many explained that due to their handicap, they were unable to participate in former activities, such as cooking, shopping, going to restaurants, or visiting neighbors. It appeared that they were so focused on their handicap that they could not perceive what abilities they still had, or what abilities they could yet achieve.

Mrs. S, a 68-year-old participant with right sided hemiparesis from a stroke nine years ago, lived alone with her youngest daughter. She received assistance with shopping, household chores, riding trains, and traveling. Her daughter also cooked for her; however, Mrs. S. said that if she tried, she could do the things that required only one hand, like washing rice or cooking *ramen*. When asked if there were any areas she would like to be more independent in, she answered that she was satisfied with her current lifestyle. She explained that she was unable to do more "since this [right arm] doesn't work....If my right arm worked, I would want to do everything...."

A 67-year-old female participant, Mrs. D., with right sided hemiparesis, also stated she could not cook because of her right hand, and because she could not stand for long periods of time. Even if she washed the rice, she explained, she would be unable to clean up afterwards.

Lack of courage/Dangerous. Nine participants felt that the danger they saw in an activity prevented them from becoming more independent. Four participants felt that their

lack of confidence or courage prevented them from participating in certain activities. Mrs. Y., at 61 years of age, was the youngest female participant. For two years, she has had right hemiplegia from a stroke. She had attended the day care center for nine months and had put much effort into her individualized gait training. Mrs. Y. lived with her oldest daughter's family and received assistance from either her husband or daughter when bathing and transferring into the tub. She would have liked to bathe alone, but had no confidence in herself. Mrs. Y. felt that fear was keeping her back from being more independent in other areas as well. For instance, she knew she was able to go to the toilet independently, but she wanted her husband to accompany her anyway. When asked if specific transfer training would help her be more independent, she stated that she thought it might help, since she was afraid to try it on her own.

Other participants lacked the courage to be seen in public with their disability. Mr. K. stated that he had wanted to go to a friend's restaurant, but he became ill and wasn't able to go. After his stroke, each time he went by, he thought he would like to go in, but he didn't have the courage to go alone. He explained, "Since my body is like this, I can't go." Another client, Mr. W. stated that he didn't take walks around his neighborhood because he didn't want to "advertise" that he was disabled. He explained, "if I use a cane and walk, people will say 'he is disabled'. I don't want them to think that."

Personal and Cultural Values

The functioning level of eight participants appeared to be influenced by the personal and cultural values of dependency during old age and illness. Another cultural factor which affected four participants was the avoidance of conflict through the suppression of feelings and the acceptance of situations.

Want to be taken care of. Four women and four men stated they wanted their families to take care of them due to their handicaps, weakness, or old age. Many felt it was

much easier and faster to receive assistance, or they were too tired to do it themselves. One example was Mrs. T., an 87-year-old woman who had moved from Osaka to Tokyo a few years ago to live with her daughter's family. She had surgery for cataracts and complained of some difficulty seeing. Although her daughter tried to get Mrs. T. to be more independent, the participant preferred to receive assistance with bathing, transportation, and home management. When Mrs. T. asked her daughter to drive her to the store, her daughter told her to walk instead, saying, "its better for the body." Mrs. T. stated her daughter "says things I don't want to hear." The participant also did not want to wash the dishes, even though the situation in the home made her very uncomfortable. She explained, "My household is strange. [My daughter's] husband washes the dishes after dinner...I think my daughter should do more, but she's my daughter, and I guess she has other work." She added that if left by herself, she would be able to do everything; instead, she lets others do it for her.

Mr. O., the youngest participant at 60-years of age, was a college professor, an entrepreneur, and an Olympic skier. Because they did not have children, he lived with his wife. Even with hemiparesis and aphasia for six years, he remained active. He drove a car, enjoyed swimming, painting and traveling. However, his wife assisted him in shaving, some areas of dressing, tub transfers, bathing and home management. Although he would like to be more independent in bathing, it was easier and faster for him to get help. It was also less of a burden on his busy wife to not wait for him to wash slowly.

Maintaining harmony. Mrs. A. perceived the desire to keep peace in the household as the strongest influence on her dependency level. Mrs. A., at 82-years of age, was independent in all activities except for cooking. Although she had the desire to cook sometimes, her desire was outweighed by the problems it would cause. She was unable to cook with her daughter-in-law because they each had their own way of doing things. Because of her weak back, Mrs. A. might be able to cook one day and not the next. She

explained, "that would be bad for my daughter-in-law, so I better give it up since she may expect me to cook all the time....I am not especially good at cooking anything, so everyone won't enjoy it greatly. It's not worth the problems." To keep from disrupting the household, Mrs. A. chose to accept her lifestyle without complaints.

Acceptance of lifestyle. A non-questioning acceptance was observed in a 66-year-old man, Mr. T., who has been unable to walk since his stroke of ten years. He received assistance from his wife for grooming/hygiene, dressing, bathing, mobility in the community, and household chores. When asked what areas he wanted to be more independent in, he replied, "I don't think I especially want to do more." When the researcher restated his thoughts and said, "you don't especially want to be more independent", he corrected the statement by emphasizing, "I don't think. I don't *think* I want to do more". He was unwilling to imagine a different condition. To hope for a better situation could make him unhappy with his present circumstances. He explained, "Even if I wanted to, I couldn't. It won't help thinking about things I can't do."

Although Mr. S., another participant, was also unhappy with his situation, he accepted it without complaints. At 82-years of age, he had lived with hemiparesis, following a stroke, for 15 years. He lived with his oldest son's family and received assistance from his wife for dressing and bathing. Though he was a cook by profession, he never assisted with household chores, such as cooking, even before his illness. His daughter-in-law did most of it. When asked about his goals, he stated, there was nothing he really wanted to do. Mr. S. explained that his hand was becoming more and more contracted and there was nothing he could do. "This hand is very, very hopeless." When asked if he was satisfied with his lifestyle he cried. "I can't say I'm satisfied. But there are people in worse situations...oh, well....at least I have things done for me." Mr. S. was unable to complain, since it could be worse, with no one taking care of him.

In addition, other participants mentioned they had never thought of doing more things on their own, or that they just did what they were told. These participants also appeared to have accepted their situation without question.

Attitudes and Behavior of Caregiver

Participants were aware of the burden they placed on their caregivers. Many stated that their caregivers were busy with their own work and family, so they tried to do as much on their own as possible. Yet, the participants seemed much more dependent than necessary because the caregivers automatically provided them with all their basic needs. The caregiver's sense of responsibility, as well as the concern for the safety of the older family members influenced the amount of assistance they provided.

Family's responsibility. Eleven participants were not more independent because their caregivers provided them with their needs. One of the most commonly heard statements from clients were, "I probably could if I tried, but I don't need to. My family does it for me."

Mr. I., an 87-year-old with lower extremity weakness for the past two years stated he wanted to be able to push himself in the wheelchair, however, he never had the opportunity to try. He explained how his wife never thought to let him be independent. "My wife thought it was her job and she must do it." Another client described the responsibility his family felt for him. "They do (take care of me) since they have to, not because they want to."

Caregiver busy. Two men stated they received assistance since it was easier and faster for the caregiver. Mr. I. explained that few people gave him the opportunity to push himself in the wheelchair. "It's a problem with [others] always being in a hurry."

Family feels its dangerous. Four women and three men mentioned activities that their caregivers felt were too dangerous for them to do independently. The most common

activities were using the gas stove; bathing; riding the train; and traveling. Mrs. Y. felt the warnings from her family and friends decreased her willingness to try. Her family stated, "...it's still dangerous. You don't have to hurry. You'll become able to do it, so don't push yourself."

Environmental Barriers

Only one participant felt his home environment and equipment affected his daily living status; however, at the time of the interview, he was already consulting the day care staff and local government for financial and technical assistance for the remodification of his tub. Mr. A., a 79-year-old, who had right hemiparesis for 19 years, was unable to get into his Japanese style tub. His only goal was to have his bath remodeled. When asked whether he would need individual or family training for transferring into his remodeled tub, he stated, "No. I have had enough, enough training." He stated he did not care whether he transferred in and out independently, only that he was able to get in at all. When asked if he wanted to be able to bathe independently, he explained that it would be too difficult, so he still wanted help for that.

One participant stated the community environment was difficult for increased independence. Mr. W., a 67-year-old with right sided hemiparesis for four years, has tried since his inpatient rehabilitation program, to strengthen his legs to be able to attend a rugby match. But he feels that the stairs at the train station and the stadium are still too difficult for him. However, he does not perceive this as an environmental problem, but a personal problem due to his disability.

Perception of Rehabilitation

All but one participant stated they had received enough training and had come as far as they could. Most felt the group exercises offered at the day care center were sufficient,

and they were "too tired" to go through rigorous training again. In addition, either family training was not needed, or the clients felt that their caregivers were too busy to participate. Mrs. D., who mainly used a wheelchair for mobility, stated that during hospitalization she walked much better. But after being home a month, she became lazy and didn't exercise. However, she was tired now and didn't want any more training.

Another participant, Mrs. S. stated she had come this far because of the day care center. She did not need any more rehabilitation or family training since she tried to do as many things as she could on her own. In addition, she did not want to do any more cooking or cleaning because she only had the use of one hand, and she got tired easily.

Finally, Mr. Z., a 74-year-old man, had a stroke with mild right sided hemiplegia for four years. He lived with his wife, who did all the household chores and financial management. He stated he wanted to be able to keep track of his finances, but, "since my admission [stroke], I am unable to count." He thought that if he had training, it might help, however, he did not want to participate in any training.

Attitudes of Health Professionals

Finally, the attitude of health professionals was mentioned twice as factors which kept clients from trying, or hoping for more. Mrs. Y., who wanted to bathe alone, was told by day care center staff to not hurry or push herself. The staff said it was fine for her family to help her bathe until she was stronger. Mr. T. wanted to go for walks, but did not want to do so in a wheelchair. Although he was independent in transferring, he felt there was no hope in getting stronger. When asked if he thought rehabilitation might help, he stated, "No. I don't think I can, even with training. The doctor said that [I won't ever be able to walk]."

Other Themes

Another theme that emerged was the benefits the participants felt they received from the day care center. Many felt that it was an enjoyable place to meet friends and get a new outlook on life. They felt it was helpful for their busy caretakers since it gave them a specific time during the week where they could have a break from caregiving. Participants also felt that they were doing as well as they were because they had been coming to the day care center.

Research Questions

1. What occupational task do elderly clients of a Tokyo day care center select as most important for achieving further independence?

Participants did not commonly select any one occupational task in which they desired an increase in independence. *The most common response was from seven of the sixteen interviewees who stated they did not have any desire to become more independent.* Yet, all seven of these participants relied on their caregivers for cooking, shopping, and home management. This data demonstrates how participants expect to have their basic needs provided by their families and is consistent with the studies by Kiefer (1987) and Maeda (1983).

A similar trend was noted in an international comparative study which showed that in Japan and Korea, only 30% to 40% of older persons participated in the household chores of cooking, shopping, laundry and cleaning; whereas in the western countries (United States, Germany, and England), 60% performed these tasks (Japanese Government, 1992). Even greater dependency was seen among the men of Japan and

Korea, with 90% relying on their families, in contrast to only 35% to 60% of men in western countries receiving assistance. These researchers (Japanese Government, 1992) believed that the difference in participation of household activities was partly due to the greater number of older persons in Japan and Korea living with their families, and the greater number of older persons in western countries living alone.

2. Which factors do the elderly clients of a Tokyo day care center perceive as most influential in preventing them from achieving greater independence in the occupational task selected above: a) client's perception of their abilities; b) personal and cultural values of the client; c) attitudes and behavior of the primary caregiver; d) environmental barriers in the home; e) environmental barriers in the community; f) attitudes and behavior of the occupational therapists; and g) lack of client and/or family training?

The findings show that based on the perception of the older persons interviewed, a) environmental barriers in the home, b) environmental barriers in the community, c) attitudes and behavior of health professionals, or d) lack of client and/or family training were not the main obstacles to independence. The overriding influence was the clients' perception of physical impairments, combined with the personal and cultural values of the caregiver and care receiver regarding dependency in old age and illness.

The participants' perception of their physical status greatly influenced their desire, as well as their ability to be more independent. Many stated they no longer wanted to participate in former activities due to their old age, physical weakness, or handicaps. The importance the Japanese culture places on physical status is seen in the result of a comparative study between the Japanese and American institutionalized older persons (Kawanishi & Kamakura, 1996). This study reported that the majority of the Japanese residents felt "physical function" was "very important" for quality of life (p. 3). "Japanese

residents felt that the more physically weak they were, the lower their quality of life was. In contrast, American residents seemed to believe that they could maintain their quality of life by other means" (p. 3).

Another comparative study (Japanese Government, 1992) examined the image older persons have about life as an older person. This report stated that the most common response of older persons in Japan and Korea was that their perception of being older was "life after weaker health." The most commonly reported image of older persons of Western countries (America, England, and Germany) was "life after retirement." There appears to be a degree of resignation among the older Japanese persons that weaker health, decreased function, and decreased quality of life follows aging.

The personal and cultural values of old age and illness were also important factors which resulted in the dependence of participants on their caregivers. The Japanese culture places an emphasis on rest and nurturance during old age and illness as a way of recuperation (Kiefer, 1987). Many participants accepted this dependency and stated they wanted to be taken care of. While families took up the burden of caregiving because of the feeling of responsibility and concern for the older members safety. Often heard statements during observations at the day care center were family members and health professionals telling clients to "take it easy" and "not push yourselves."

In addition, many clients stated that they did not want any more training. Rehabilitation required hard work and often instigated pain. In the Japanese society where dependency is a familial and institutional expectation, the motivation to be independent may not be enough to overcome the efforts of rehabilitation (Kiefer, 1987). The length of time the participants had their illness was also an indication of their openness towards rehabilitation. The participants who had lived with their disability for many years had come to accept and adapt to their limitations, and therefore had less motivation to put in the effort needed for change.

CHAPTER 5

SUMMARY AND IMPLICATIONS

Summary

This study attempted to identify the values of Japanese elderly clients towards independence in occupational tasks, as well as to identify the factors they perceived were obstacles to independence. Sixteen clients in a geriatric day care center in Japan participated in a 30 minute semi-structured interview which used open-ended questions to identify recurring themes. An equal number of men and women participated who ranged in ages from 61 to 90 years old. The main diagnosis of participants in this study was cerebral vascular accident. All participants were living with their families and received some form of assistance in the occupational performance areas of self-care, productivity, or leisure. Similar to previous studies (Kiefer, 1987; Maeda, 1983), the majority of the caregivers were women. For the male participants, most of the caregiving was done by their wives, who were older themselves. For the women participants, the caregivers were their daughter-in-laws or daughters, who often had young children to care for. Most of the households were three generational.

Although the ages and diagnostic groups for men and women were similar, the functional status was significantly higher for women in the area of self-care. Male participants whose primary caregiver was their spouse had the lowest functioning status of all the participants. The researcher of this study suggests that this is due to the traditional role of women in Japan to care for the daily needs of their husbands. Disability status was similar among all participants in home management, personal management, public transportation, and leisure. The self-care task requiring most assistance was in bathing.

Dependency in this area occurred for both men and women, most likely due to the importance Japanese culture places on cleanliness and purity.

Gender differences were also seen in life satisfaction. More women than men stated they were "satisfied" with their lifestyle. This may be due to the loss of identity older disabled men feel as their productive role outside the home no longer exists, and they have little perceived power in the home. Though women may no longer carry out the daily household tasks, their management of the household on a consultative basis continues.

There was not one commonly chosen area where participants desired more independence. However, seven of the sixteen interviewees stated they had no desire to be more independent. Most participants held the traditional expectation that their caregivers should provide for their daily needs (cooking, shopping, cleaning).

The data shows that the main obstacle towards independence was the client's perception of the effects of physical impairments, combined with the personal and cultural values of both the caregiver and care receiver regarding expectations of dependency during old age and illness. The image Japanese older persons have of themselves as weak or disabled, greatly affected the client's belief in his/herself, as well as the desire to perform activities. A sense of resignation towards their disability was seen in the acceptance of their dependency, and a reported lack of motivation to improve. This was especially true for those participants whose illness and rehabilitation had occurred many years ago, where the participant and their caregivers had already adapted to the limitations of the disability. The dependency of the participants was also perpetuated by the caregivers feeling of responsibility for the care and safety of older members.

Environmental barriers in the home and community were rarely perceived as obstacles towards independence. Housing conditions were perceived as satisfactory for all participants due to remodifications carried out with the financial and technical assistance from the government and community health centers. In addition, participants tended to

internalize their problems. They felt their lack of independence in the community stemmed from personal difficulties, such as physical weakness, lack of confidence, or embarrassment to be seen in public, rather than physical barriers in the environment.

The majority of the participants also perceived that they had received enough rehabilitation training, and declined suggestions for how therapy might improve their functioning level. This finding was unexpected since most of the individualized rehabilitation occurred during the participants' inpatient stay, with maintenance training available at the day care center. There was little or no training in the homes, even though providing treatment in the home environment in conjunction with the training of caregivers is recommended to improve carry over and follow through from rehabilitation center to home (Hasselkus, 1988, 1991). In fact, the extensive inpatient stay (average of 14 months for CVA) may even be detrimental for patients in achieving greater independence. During the hospitalization, all of the patients' basic needs are automatically provided, and they are given a structured schedule, which allows them little opportunity to take control over their lives.

Since there is often the expectation that those patients returning home to their families will have most of their personal needs provided for them, the main focus of occupational therapy is to improve basic functions such as functional mobility, toileting and eating. Improvement of quality of life is also encouraged through participation in leisure activities.

Importance of Further Research

Currently, the expectations of the Japanese society is for older persons to be taken care of by their children, and resources are still adequate to allow this. However, this value is at odds with the increase in the number of working women, the nuclearisation of the family, and the cultural changes that are taking place. A crisis stage will soon be reached,

especially in the metropolitan areas of Japan. Most of the participants in this study live in three generational households, where the caregivers are working or raising their own children. The caregivers who are spouses are often older adults themselves. Many of the clients stated that they felt they were a burden on their families and seemed to be aware of the demands being placed upon the family.

Japan is now in a transitional state where the traditional family responsibilities will be forced to become more and more overlooked and decisions regarding caregiving will be increasingly based on convenience and practicality. In addition, as the number of children born decline (Japan Times, 1996), the availability of children to care for their parents will decline as well. Due to the changing socio-economic and demographic conditions, and the diminishing ability of families to care for their aging parents, more and more older persons will have to live independently for longer periods.

Other societal changes include the current attempt by the Japanese government to curb the overuse of inpatient hospital stays, where a majority of rehabilitation takes place, by expanding geriatric services in the community (Kobayashi & Reich, 1993). To develop effective community rehabilitation programs, further research must be done on the needs of older persons who live alone in the community.

Implications for Occupational Therapy

Conflicts in Values

Sanchez (1964) expressed concern over the therapeutic approach that was being espoused according to the value structures of individual occupational therapists, which was often in direct conflict with the values of their patients. Health professionals in America, largely from the middle-class, typically carry the values of individualism and independence. The "doing" orientation encompasses the importance of change, striving for competence,

and controlling situations (Sanchez, 1964). Other cultures, such as the dominant lower class society of Latin America has the strikingly differing values of group loyalty, dependence, and the "being" orientation, with little planning or control of the future (Sanchez, 1964). These Latin American values are very similar to the mainstream culture in Japan.

As early as 1964, Sanchez warned that we must not use therapy as "a chance to modify as much as possible the value structure of the patient contributing, as many believe, to the progress of the community" (p. 5). He continued, that if a change in the structure of the community is desired for progress in health, it must be a concerted effort with all community agencies and institutions, and not just with the individual patient and family. In fact, attempting to change the individual might create a maladjustment of the patient to his family and the community.

Yet, the focus in occupational therapy continues to be in overcoming limitations created by a disability and regaining as much functional independence as possible. In 1992, Yerxa defined the values of occupational therapy as goal-directed and active. She stated that "the profession was founded upon visionary ideas about the nature of human beings and their vital need for activity" (p. 79). She impresses the importance of a person who is "active", "capable", "free", "self-directed", "integrated", and "purposeful" (p. 79).

Unfortunately, family caregivers and patients do not always appear to share this same value of independence and autonomy (Hasselkus 1988, 1991). In 1993, Gitlin looked at how the framework of functional independence impacts the clinical reasoning process of occupational therapists in physical disabilities. This study found that if independence was not a shared goal by the patient and their family, the therapists often tried to convince them about the importance of therapy based on the framework of independence. Those patients that did not endorse the therapists goals for independence were seen as unmotivated. Gitlin believes that current practices in rehabilitation which tries

to return a person to their normal level of functioning is based on principles from younger patients and "may not be applicable to the physiologic and psycho-social needs of older adults with chronic disability" (p. 12).

In psychosocial occupational therapy, Barris (1987) reported that in the initial evaluation process, therapists either focused on only the issues that fit within their framework, or reshaped or redirected the patient's statements so that they began to fit.

Occupational therapists often believe they are considering the value orientations of their patients, through the use of the wholistic approach, or through such frames of reference as the Occupational Performance Model or Model of Human Occupation, which looks at the physical, social, and spiritual factors of the individual. Yet, the previous literature demonstrates how often times the philosophy and frames of reference are biased by the therapists own beliefs of what is important.

Eliciting Patient Values

How can therapists begin to understand the framework that patients and caregivers are working from? By first clarifying and defining our own values as therapists, we can begin to understand how our framework may lead to biases of another perspective. We can then assist clients in identifying their values, in order to examine the options available for treatment based on those values (Hasselkus, 1991). In order to accomplish this Mattingly (1991) suggests the narrative approach which encourages patients to discuss their feelings about what the illness and the disability means to them. More collaboration between the therapists, patients, and caregivers are also needed in the clinical reasoning process to ensure that the values and goals of the patient and family are taken into consideration (Gitlin, 1993; Hasselkus, 1991; Northen et al., 1995). We also can allow more autonomy and decision making by the patients and their caregivers regarding the management of activities of daily living (Gitlin, 1993).

Therapy within the home is critical, not only for the therapist to better understand the social and physical environment, but for the patients to be able to formulate their own plans regarding adaptation to the disability. Gitlin (1993) states that patients may be more open to pursuing methods of adaptation or arrangements for activities of daily living when at home. They may need to be able to "contextualize the experience of disability in their own home and learn from doing in real-life situations" (p. 17).

In addition, we need to change the focus of our frames of reference. For example, in the Occupational Performance Model, instead of working towards return in functioning or in designing adaptations to perform previously held roles, the therapist can assist the patient in working out new role patterns (Jongbloed, 1994; Kinebanian & Stomph, 1992). In non-Western societies where accepting and honoring the decisions of others is valued, and where dependency is a respectable choice, the focus of occupational therapy can be placed on the shift in roles and tasks as adaptations to the disability, rather than independence (Kinebanian & Stomph, 1992).

Fleming (1991) categorizes conditional reasoning as the process of understanding the person within their social and physical context in order to discover the meaning of the illness for the individual. However, this ability to integrate the "complex social reasoning", as well as to "project an imagined future condition or situation for the person" is acquired through clinical experience (p. 1007).

How can we prepare students and new therapists for this challenge? Schwartz (1991) discusses the importance of teaching various modes of reasoning to students by moving away from paper exams to more innovative teaching methods. She describes teaching reasoning through experiential learning, such as videotaping a student working with a patient. Or through the connected teaching approach, which uses experiences, such as personal stories, case studies, or fieldwork to illustrate theory and problem solving techniques.

Conclusion

Surprisingly, environmental barriers in the home and community, and the lack of individualized training in the home were not perceived as factors in preventing greater independence for clients of a geriatric day care center. Instead, the client's perception of the effects of physical impairments, and the caregiver and care receiver values regarding old age and illness were perceived as the main influences for dependency.

This study demonstrates how the influence of cultural factors may exceed the importance of environmental conditions and rehabilitation efforts. The results suggest that therapists working with older persons of Japanese descent should have an understanding of the different cultural values and belief systems Japanese persons have about old age and illness, dependency and rehabilitation. Therapists must also have a better understanding of how interaction patterns directed at the maintenance of harmony in the society and in the home, can affect rehabilitation goals and services provided to individuals in the community.

Though many of the pioneers of occupational therapy in Japan received their education and training in the United States, it was molded to fit into the value system of their culture. Therefore, more emphasis in rehabilitation is placed on improving the quality of life through leisure activities, a philosophy particularly seen in the geriatric day care centers. The day care centers appear to be a cost-effective way to provide maintenance therapy, socialization, respite for the caregivers, and leisure activities for the improvement in quality of life, and could also be a beneficial service in America.

The clients in this study were viewed within the framework of the Japanese culture and generalizations were made for the purpose of discovering themes and trends related to older adults in this culture. However, there were unique differences in each client that must also be considered when looking at the influences of functional status. Family structure and interactions, life experiences, personal interests, and personal values all affect their

motivation for independence. Culture only provides a context in which to view the individual; the therapist must then discover the needs and desire of the clients to make treatment relevant and worthwhile. Although cultural values and beliefs are important to be aware of, one must not forget to look beyond the generic socio-cultural values to understand how they influence the personal values and goals of the individual (Hinojosa & Kramer, 1994).

Often therapists feel that such in-depth analysis of the patient is difficult due to time constraints and economic limitations, difficulty involving family members, and limited opportunities to visit the home. Many times we ask, how much of this can we afford to do given the limitations of our current service delivery system? Instead, let us begin asking ourselves, how much of this can we afford not to do, given the implications it has for providing purposeful and ethical treatment to our clients.

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APPENDIX A

Consent Form (English & Japanese)

**Agreement to Participate in Research
San Jose State University**

Responsible Investigator: Eiri Hayashigatani Inenaga

Title of Protocol: *Factors which Influence Dependency of the Elderly on their Caregivers*

I have been asked to participate in a research study that is investigating factors affecting the performance of daily living activities for elderly clients.

I understand the following:

- 1) I will be asked to participate in an interview which will be audio taped.
- 2) I will be asked to fill out a questionnaire, with the help of the researcher, if necessary.
- 3) The risks of this study is that I may be asked to reveal personal information.
- 4) The benefits of this study is that I can share, as well as reflect upon my experiences as a care receiver.
- 5) The results from this study may be published, but any information that can be identified with me will remain confidential.
- 6) Any questions about my participation in this study may be addressed to Eiri Inenaga at (0425)-77-9549. Complaints about the research may be presented to Kathleen Barker Schwartz, Ed.D at 011-1-408-924-3073. Questions or complaints about research or subjects' rights may be presented to Serena Stanford, Ph.D., Associate Vice President of Graduate Studies and Research at 011-1-408-924-2480.
- 7) I may refuse to participate in the study or in any part of the study, and that at any time I may withdraw from the study without prejudice to the subject's relation with this facility.
- 8) I have received a copy of this consent form.

Signing below indicates that I have read the information provided above and that I have decided to participate in the study.

Subject's Signature_____

Date _____

Investigator's Signature_____

Date _____

同 意 書

サンホセ大学による調査の参加協力への同意

インタビュー責任者：稲永英理

調査の主要原案：高齢者の介護人への依存に影響を及ぼす要因

私は高齢者の日常生活動作に影響を与える要因についての調査研究に参加協力することを依頼されている者です。

私は以下の事を了承します。

- 1) インタビューをテープに録音される事について了承します。
- 2) 必要に応じて調査者の助けを借りながら質問事項に記入いたします。
- 3) この調査では個人的に立ち入った質問をされる事について了承します。
- 4) この研究調査による恩恵を、介護を受ける者として、その生活に反映させる事ができるだけでなく、共に享受する事ができます。
- 5) この研究結果は出版される可能性があります、個人にかかわる情報は秘密厳守とされます。
- 6) この研究調査への質問は、稲永英理 0425-77-9549 まで。
調査への苦情は、キャサリン・ベイカー・シュワルツ(Kathaleen Barker Schwartz)011-1-408-924-3073 まで。
調査及び調査を受ける者の人権についての質問・苦情は、セレナ・スタンフォード(Serena Stanford) 大学院生研究調査機関副代表 011-1-408-924-2480 において受け付けられます。
- 7) 調査内容によっては参加協力を拒否する事もあり、いつでもこの調査からおりの事ができます。しかしその事で、この調査機関に対し何らの偏見も抱く者ではありません。
- 8) この同意書のコピーを一部受け取ります。

私は上記事項を読み、この調査に参加協力する事を決めましたので、以下に署名いたします。

被調査者署名 _____ 日付 _____

調査者署名 _____ 日付 _____

APPENDIX B

Daily Living Questionnaire Part I: Demographic Data (English Only)

Daily Living Questionnaire Key

Demographic Data

This first section of the questionnaire, Part I, which included background information, history of rehabilitation, and living environment, were objective questions filled out prior to the interview. This limited the amount of questions and time needed for the interview. The information from these sections was collected from medical charts and day care center staff. There was only an English version for this section since it is solely for my own use.

Background Information: Demographic information regarding age, previous occupation, educational level, marital status and gender were requested since they often influence personal values, beliefs, attitudes, or functioning levels of occupational tasks.

History of Rehabilitation: Home care occupational therapy, family training, and day care service questions were included due to the influences they may have on functional outcome. This section also provided information regarding diagnosis for hospitalization and length of time since discharge from hospitalization. All diagnosis groups were asked to participate, except for those clients with dementia. Only clients who had been living in the community with the caregiver for three months or longer were asked to participate in the study. Within this time frame, a set routine between the client and the caregiver would have been established.

Living Environment: Housing conditions, accessibility within the community, and available equipment was established through these questions.

Interview Questions

Part II and Part III consisted of the interview questions. In Part II, the client was asked to identify all problem areas from the list, and to then choose one problem area that was most important in which to achieve independence. The problem areas included the three occupational performance areas of self-care (personal care, communication, functional mobility, and community management), productivity (household management) and leisure (recreation, socialization).

In Part III, the priority area was questioned in detail regarding factors which the client perceived as being influential in preventing them from being more independent. The questions refer to the influences as noted below.

Perception of current abilities	1, 2, 12, 13
Personal and cultural values of the client	8, 10, 14, 16, 19
Attitudes and behavior of the primary caregiver	9, 11, 17, 18
Environmental barriers in the home	5, 7
Environmental barriers in the community	6
Attitudes and behavior of the occupational therapists	15, 18
Lack of client and/or family training	3, 4, 7
Other	20

DEMOGRAPHIC DATA

DATE: _____

BACKGROUND INFORMATION

1. Code _____ Age _____ Sex: M F
2. Previous Occupation _____
3. Education Completed _____ Grade School
_____ High School
_____ College
_____ Graduate School
4. Marital Status _____ Single
_____ Married
_____ Divorced
_____ Widowed

HISTORY OF REHABILITATION

1. Primary diagnosis _____
2. Onset of illness _____ 3. Discharge date of most recent hospitalization _____
4. Number of occupational therapy home visits (during hospitalization and after discharge) _____
Purpose for visits _____
5. Number of family training sessions (during hospitalization and after discharge) _____
Purpose of training _____
6. Length of time attending day care center _____ (months)
7. Day care activities participating in:
- a) group exercises (mat, rail) _____
 - b) individual training (gait training, stairs, hemi, standing frame, pulleys) _____
 - c) functional OT training _____
 - d) craft (individual, group) _____
 - e) socialization (birthday party, holiday celebrations, tea time)
 - f) other _____

LIVING ENVIRONMENT

1. City: Kiyose 2. Most frequent mode of transportation _____
3. Nearest train station: Seibu Ikebukuro Senkyosei 4. Distance to bus stop _____
5. Primary caregiver: Husband Wife Married daughter (Son) Daughter-in-law
Unmarried daughter (son)

6. Number of people living with in household ____

Family diagram of relationships:

7. Housing: Number of rooms ____ Have own room : yes / no

8. Own: (house, apartment) Rental: (government, private) Stories: 1, 2, 3 or more
If needed, which are W/C accessible rooms

9. Type of equipment used:

Futon / Bed Western / Squat toilet Cushion / Chair Shower / Japanese bath (at home)

10. Type of assistive devices used:

Wheelchair Walker Cane Commode Shower chair Eating Device
Others _____

APPENDIX C

Daily Living Questionnaire

Part II & III: Interview Questions (English and Japanese)

DAILY LIVING QUESTIONNAIRE: Interview Questions
SHIN AI DAY CARE CENTER

First, **check** the areas that you feel you have problems with. Then **circle** one area that you would like to be more independent in.

1. ___ Eating
2. ___ Grooming/Hygiene
3. ___ Upper Body Dressing
4. ___ Lower Body Dressing
5. ___ Toileting
6. ___ Bathing
7. ___ Moving in bed
8. ___ Getting in and out of bed
9. ___ Getting on and off the toilet
10. ___ Getting up and down from chairs
11. ___ Getting up and down from bed
12. ___ Getting in and out of the shower
13. ___ Getting in and out of the tub
14. ___ Moving about the house (walking, wheelchair)
15. ___ Moving about the community (walking, wheelchair)
16. ___ Using transportation (car, taxi, train, bus)
17. ___ Home management (meal preparation, housekeeping)
18. ___ Personal management (personal finances, medication)
19. ___ Shopping (groceries, clothes, household items)
20. ___ Leisure activities (social planning, traveling, visiting, restaurants, clubs)
21. ___ Communication (understanding, being understood, being heard)

Code _____

I want to be more independent in _____.

Which of the following influences your ability to be independent. Please explain.

1. I am too weak.
2. I am not able to do it because I am forgetful, cannot concentrate or cannot problem-solve.
3. I do not have the training to do it alone (set-up, transfers, equipment, etc.).
4. My caregiver does not know how to let me do it by myself (set-up, transfers, equipment, etc.).
5. It's too difficult because of the structure of the house (small, narrow, has many stairs, etc.).
6. It's too difficult to get around in the community (crowded, narrow, many stairs, trains or buses hard to ride, etc.).
7. My present equipment is not appropriate (bathing, toileting, sleeping equipment, etc.).
8. It is faster and easier for myself to receive assistance.
9. My caregiver is too busy to wait for me to do it slowly.
10. I don't want to burden my caregiver with extra requests.
11. My caregiver feels that doing it on my own is dangerous.
12. I feel it is too dangerous by myself.
13. I feel I am too old, sick, or disabled.
14. I've never thought to try it on my own.
15. Health professionals at hospitals and health centers told me not to do it on my own.
16. I do what others tell me to do.
17. My caregiver wants to take care of me.
18. No one ever asked what I want to do for myself.
19. I feel uncomfortable being seen in public because I am disabled.
20. Other _____

毎日の生活についての質問表

信愛デイケアセンター

■次の項目の内、御自分が困難だと感じているものにレ印をつけ、更に、自立したいと思っている問題領域に一つ〇印をつけて下さい。

- 1 _____ 食事
- 2 _____ 整容
- 3 _____ 上着の着脱
- 4 _____ 下着の着脱
- 5 _____ トイレ動作
- 6 _____ 入浴動作
- 7 _____ 寝返り
- 8 _____ 起き上がり
- 9 _____ トイレの出入り
- 10 _____ 椅子からの立ち座り
- 11 _____ 寝床へ寝る起きる
- 12 _____ シャワーへの出入り
- 13 _____ 風呂への出入り
- 14 _____ 家の中を動く（車椅子でも可）
- 15 _____ 近所の散歩
- 16 _____ 乗り物の使用（自家用車、タクシー、電車、バス）
- 17 _____ 家事（食事の用意、掃除）
- 18 _____ 自己管理（お金の管理、服薬）
- 19 _____ 買い物
- 20 _____ レジャー（旅行、訪問、レストラン、同好会など、自分からこれらの活動に積極的に企画、参加できる）
- 21 _____ 会話（人の言うことがわかる、自分の言うことを理解してもらえる、自分の言うことに耳を傾けてもらえる）

C o d e _____

私は、この問題領域 でもっと自立したいと思います。

自分一人の力ではできない理由は、以下のどのことが影響していますか？
説明してください。

- 1 体が弱いため
- 2 忘れっぽい、集中力がない、自分の手に負えない等
- 3 自分一人の力でやる訓練を受けていないから（やりやすい環境が整っていない、移動困難、設備不足等）
- 4 私が自分一人ですることができるようになるための訓練を、家族が受けていない（やりやすい環境が整っていない、移動困難、設備不足等）
- 5 家の構造のため（家が小さい、狭い、階段が多い等）
- 6 住んでいる地域に出掛けるのが困難なため（狭い、階段や段差が多い、電車やバスに乗るのが難しい等）
- 7 家の設備が合わないため（風呂、トイレ、寝具等）
- 8 人にやってもらった方が、早いし、簡単だから
- 9 家族が忙しくて、時間がなく、私がのろのろやっているのを待てないから
- 10 余分な頼みごとをして家族に迷惑をかけたくないから
- 11 私が自分でやるのは危険だと家族が思っているから
- 12 私がやると危ないと自分で思うから
- 13 私は老人だし、病人または障害者だと思っているから
- 14 今まで自分でやってみようと思ったことがないから
- 15 病院や施設の専門家が、一人でやってはいけないと言うから
- 16 人に言われるままにやっているだけだから
- 17 家族が私の面倒をみたがっているから
- 18 自分一人の力で何をやってみたいか誰も聞いてくれないから
- 19 障害者であるため、人の目が気になるから
- 20 その他