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# Who is caring for the caregiver? : a descriptive occupational therapy study

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**Who is Caring for the Caregiver? A Descriptive Occupational Therapy Study**

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**A Masters Thesis presented to the Faculty of the Graduate Program in Occupational  
Therapy**

**Ithaca College**

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**In partial fulfillment of the requirements for the degree Master of Science**

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**By**

**Kelly Potter**

**June 2005**

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**CERTIFICATE OF APPROVAL**

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### Abstract

According to the Administration on Aging, the percentage of people age 65 and older in the U.S. population has risen significantly in the recent past and will more than double to 71.5 million by the year 2030 (Greenberg, 2003). This rise in the population demands a large increase in health care services. The rise also coincides with a healthcare system that is decreasing its resources (Greenberg, 2003). The imbalance between the needs of older adults and healthcare resources results in informal caregivers, whether family or friends, taking on the burden of caring for the elderly.

Research has shown that caregivers experience negative effects such as role loss, depression, and even a higher mortality rate while caring for an elderly person (Plooster, 2003, Schultz and Beach, 1999, Skaff & Pearlin, 1992). Recognizing these risks, researchers have begun to identify how professionals can assist caregivers in their role to ensure a positive outcome (Sorensen, Pinquart, & Duberstein, 2002). Occupational therapists possess many of the skills necessary to assist caregivers. However, few therapists have actually conducted research on the effectiveness of treatment. Furthermore, no research to date has discussed the current roles and practices of occupational therapists when working with caregivers. In order to meet the needs of this population, a study of the current practices must be completed. The purpose of this study was to discover the current practices and beliefs of occupational therapy practitioners who work with caregivers of the elderly.

Ninety-three registered occupational therapists and certified occupational therapy assistants responded to a mail survey. Results indicated that therapists believe that it is the roles of the profession to address caregivers' concerns; however, due to

reimbursement issues therapists are unable to meet the demand. The information gained in this study should be used to address and overcome current barriers to the provision of services.

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## Table of Contents

List of Tables.....	5
Chapter 1: Introduction.....	6
Background.....	6
Issues.....	7
Rationale.....	7
Purpose.....	9
Definition of terms.....	9
Chapter 2: Literature Review.....	11
Being Elderly.....	11
Caregiver Statistics.....	12
What is Caregiving?.....	13
Caregiver Risks and Concerns.....	15
Perceived Problems of Caregiving.....	16
Support to Caregivers.....	18
Occupational Therapy.....	20
Current Suggested Occupational Therapy Practices.....	23
Chapter 3: Methodology.....	25
Overview.....	25
Research Questions.....	25
Subjects and Selection Method.....	25
Study Design/Research Tool.....	26
Operationalization of Concepts into Variables.....	26
Field Testing.....	27
Procedures.....	27
Anonymity and Confidentiality.....	28
Data Analysis.....	28
Scope and Limitations.....	29
Chapter 4: Results.....	30
Participant Demographics.....	30
Work Setting of Participants and Clients.....	32
Current Practices.....	35
Current Practices: Intervention.....	39
Barriers to Serving Clients.....	41
Therapists Perceptions.....	43
Chapter 5: Discussion.....	45
Demographics.....	45
Barriers.....	49
Current Practices.....	50
Further Correlations of Interest.....	53
Chapter 6: Conclusion.....	55
References.....	57
Appendix A: Human Subjects Proposal Materials.....	61
Appendix B: Participant Information Sheet.....	66
Appendix C: Survey Instrument.....	67
Appendix D: Follow-up Postcard Content.....	71

## List of Tables

Table 1: Participant Demographics.....	31
Table 2: Work Setting of Participants.....	33
Table 3: Clients.....	34
Table 4: Skills and Abilities Considered Important for Caregivers.....	36
Table 5: Approaches: Assessment, Education, Consultation.....	37
Table 6: Approaches: Referral, Direct Care.....	38
Table 7: Current Practices: Interventions Employed with Caregivers.....	40
Table 8: Barriers to Serving Caregivers.....	42
Table 9: Therapists Perceptions: Mean Scores for Each Statement.....	44



## Who is Caring for the Caregiver? A Descriptive Occupational Therapy Study

### Chapter one: Introduction

Researchers claim that in the next few decades, the size of the population over the age of sixty-five will double (Greenberg, 2003). Researchers also report that elderly individuals have a higher number of chronic diseases (Greenberg, 2003). The increase in the size of the elder population and their health care demands has caused a major strain on our health care system. Furthermore, researchers expect the increase to continue in such a manner for the next few decades. Unfortunately, the healthcare system has been decreasing access to resources and changing the delivery of services (Greenberg, 2003). In the year 2003, the average length of stay in a hospital for persons aged 65 and older was 5.8 days, five days shorter than the average length in 1980 (Greenberg, 2003). Shorter hospital stays and the presence of chronic conditions have resulted in informal caregivers, whether family or friends, assuming many of the responsibilities that in the past were in the job descriptions of trained health care workers.

#### *Background*

It is estimated that family caregivers provide 80% of long-term care (Plooster, 2003). Of the 285 million households in the United States, 22.4 million households contain an individual who is providing care to an elder (Koppelman, 2002). Caregivers provide an estimated 257 billion dollars worth of free long-term care services, much of which would otherwise have to be funded through government programs (Koppelman, 2002). Family members provide more personal care to the care receiver than they would receive in a hospital. Although the government and the care receiver benefit from this care, the caregivers themselves are often negatively affected (Plooster, 2003).

*Issues*

In today's society, families are getting smaller and more geographically dispersed (Koppelman, 2002). As a result, the burden of care usually falls on a single person, most likely a female adult child or spouse who also has several other roles such as worker and mother (Koppelman, 2002). While caregiving can be a very positive experience, having to balance several roles and take care of an elderly person can have many negative effects on a caregiver. Overwhelming evidence demonstrated that caregivers are at high risk for depression, anxiety, isolation, and role loss (Plooster, 2003). Schulz and Beach (1999) have even found that caregivers who reported feeling stressed have a mortality risk that is 63% higher than non-caregivers. In order to function in the role of caregiver and decrease negative risks, caregivers of the elderly need assistance from health professionals such as occupational therapists.

*Rationale*

Occupational therapy is "skilled treatment that helps individuals achieve independence in all facets of their lives. It gives people the "skills for the job of living" necessary for independent and satisfying lives" (AOTA, 2004). Occupational therapists are in a unique position to assist caregivers since they possess the skills to address a wide range of caregiver concerns. For example, more than half of caregivers who help with activities of daily living (ADL) such as feeding, bathing, or lifting, receive no formal instruction on how to perform these tasks. Yet, many claim ADL assistance is the most stressful activity of care giving (Donelan, Hill, Hoffman, Scoles, et al, 2002). In addition to ADL assistance, many caregivers believe that role balance is virtually impossible when caring for an elderly family member. However, the main goal of occupational therapy

services is to enable individuals to engage in and balance all life roles, including the role of caregiver (Corcoran, Gitlin, Levy, Eckhardt, 2002). Caregivers have also stressed the need for assistance in techniques for managing troublesome behavior, communication techniques for patient and family members, reducing family conflict, improving emotional and instrumental support, and education, all of which an occupational therapist is qualified to address in therapy (Mittelman, Roth, Haley, & Zarit, 2004).

Researchers have acknowledged the usefulness of occupational therapy when working with caregivers and have examined its effectiveness (Corcoran, Gitlin, Levy, Eckhardt, 2002). Suggestions for occupational therapy service include using the practice Model of Human Occupation, viewing caregivers as lay practitioners, increasing coping skills, adapting the environment, and using psychotherapeutic approaches. All of these techniques have shown to lower levels of depression, frustration, and role loss (Corcoran, Gitlin, Levy, Eckhardt, 2002, Corradetti, & Hills 1998).

Despite the documented benefits of occupational therapy, when comparing the occupational therapy research to the current literature on caregivers and services, one finds an imbalance in received assistance (Mittelman, Roth, Haley, & Zarit, 2004). Although receiving some training, caregivers claim they do not feel competent in their roles, are concerned about their own physical and emotional health, and sometimes do not receive any services from healthcare communities despite their requests. According to Stajduhar, (2003) some caregivers even used hospital emergency services to prove they were in need of assistance.

In comparing a number of studies (Stajduhar, 2003, Skaff, & Pearlin, 1992, Schulz, & Beach, 1999, Plooster, 2003), a discrepancy arises between suggested

researched interventions and what is actually happening in the occupational therapy field. Many researchers claim that occupational therapy treatments are successful in the service of caregivers, yet caregivers still report a lack of assistance. A review of the literature revealed that there is a lack of evidence regarding what current occupational therapy practices are being used when working with caregivers of the elderly. Therefore, there is a need for more focused research to discover what roles and practices are used by occupational therapists when working with caregivers of the elderly.

### *Purpose*

As previously mentioned, caregivers are a large underserved population who could benefit from occupational therapy, however, the absence of literature in this area suggests that these services are not being utilized or offered. Without these services, caregiver's health and well-being can decrease and in turn, they will not be able to function in their role. The purpose of this study is to determine what roles and practices are used by occupational therapists when working with caregivers of the elderly. This information can be used as a stepping-stone for future research projects to assist a population that is in dire need of care.

### *Definition of Terms*

1. Caregiver-An individual who cares for and or assists a disabled, ill or frail family member or spouse who is sixty-five years of age or older.
2. Roles- a position in society that has expected responsibilities and privileges. It is dynamic in nature, a person may function in many roles at one time, such as mother, sister, daughter, worker.

3. Occupational therapy- "Occupational therapy is skilled treatment that helps individuals achieve independence in all facets of their lives. It gives people the "skills for the job of living" necessary for independent and satisfying lives" (American Occupational Therapy Association, 2004)
4. ADL – Activities of daily living. An area of occupation that involves taking care of the body. Such as bathing dressing and grooming.
5. Stress- "reaction of the body to forces of a deleterious nature, infections, and various abnormal states that tend to disturb its normal physiologic equilibrium" (Dirckx, 2001, p. 943).
6. Direct treatment or care- working one on one with a client and focusing intervention on providing solutions to caregiver concerns.

## Chapter 2: Literature Review

*Being Elderly**Population*

According to Greenberg (2003), in 2002 the older adult population of the United States (age 65+) reached 35.6 million, which is an increase of 10.2 % since 1992. This population has also aged over decades with the 85+ age group growing thirty eight times as large. Reduced death rates for children and young adults are responsible for most of this increase. For example, a child born in 2001 could expect to live 77.2 years, about 30 years longer than a child born in 1900. In addition, the past two decades have also seen reduced death rates for the population aged 65-84 (Greenberg, 2003). Life expectancy after the age 65 is also increasing. Currently persons reaching age 65 have an average life expectancy of an additional 18.1 years (Greenberg, 2003).

The rise in the elderly population is projected to increase in the next few decades as the "baby boomer" generation (people born between 1946 and 1964) ages. It is expected that by the year 2030, the older population will more than double to 71.5 million (Greenberg, 2003). As people live to be older and the population expands, new challenges are created that previous generations of elderly individuals or their caregivers did not endure. These challenges include but are not limited to surviving on the low-income bracket while having increased medical needs, decreased access to healthcare, and limited safe housing options.

*Income*

In 2002, the median income of older persons was \$19,436 for males and \$11,406 for females (Greenberg, 2003). According to Greenberg (2003), the major sources of

income for older people included Social Security, income from assets, public and private pensions, and earnings. In the year 2002, about 3.6 million older persons lived below the poverty level (\$ 9,310 individual, \$12,490 couple). Another 2.2 million of the elderly were classified as "near-poor" (income between the poverty level and 125% of this level) (Greenberg, 2003).

### *Health*

The majority of older persons reported experiencing at least one chronic condition in 2001 (Greenberg, 2003). Many reported experiencing several debilitating conditions. Some of the most common conditions include hypertension, arthritic symptoms, heart disease, cancer, sinusitis, and diabetes (Greenberg, 2003).

In addition to living with chronic disease, according to the Administration on Aging (2003), more than half of the older population reported having at least one disability (physical or nonphysical) and over one third report at least one severe disability. As result of these disabilities, 27.3% of the population reported difficulty with one or more activities of daily living (ADLs) such as bathing and grooming. People also reported difficulty with one or more instrumental activities of daily living (IADLs), like home maintenance and banking. These difficulties also increased with age, with over half of the 85 years and older population reporting difficulties with ADLs.

### *Caregiver Statistics*

The increase in the size of the elderly population and their health needs has caused an increase in demand for healthcare services. The healthcare system, due to shortages of personnel and the implementation of increased cost saving measures, has shortened hospital stays and home care services (Plooster, 2003). In 2002 the average

length of a hospital stay for a person 65+ was 5.8 days, five days shorter than in 1980 (Greenberg, 2003). In addition to decreased access to Medicare funded health care, the elder population has a low level of income, which can prevent them from purchasing the care they need, such as personal care aides or living in long-term care facilities. With an increase in healthcare needs, a decrease in healthcare resources, low level of funding, and chronic conditions, the elderly look to caregivers to support their needs.

Currently, out of 285 million households in the United States, 22.4 million households contain an individual who is providing informal care to an elder (Koppelman, 2002). Caregivers are supplying 80% of all long-term services and supports for the elderly (Plooster, 2003). This volume of free care saves the federal Medicare system 257 billion dollars annually (Koppelman, 2002). It also allows care receivers to remain in their home and close to their families.

#### *What is Caregiving?*

A caregiver may be male or female, friend or family member, but typically is a female spouse or child. Seven out of ten caregivers are women and the average age of a caregiver is 46.7 years old (Koppelman, 2002). Caregivers who are in the average age range are considered the "sandwich generation" because they are 41% more likely to be simultaneously caring for a parent and a child under the age of 18 (Koppelman, 2002). Caregivers of this generation also take on several other roles such as husband or wife, volunteer or worker. Studies show that 64% of all caregivers are employed in a full time job (Koppelman, 2002).

The amount of time one spends in the caregiver role varies. On average, caregivers provide care for 4.5 years to a care recipient who is 77 years old who most



likely has at least one chronic condition (Koppelman, 2002). Care is provided for an average of 18 hours per week. The top three reasons for providing care include aging, mobility issues, and dementia. Out of all caregivers studied, only one-fifth live in the same house as the recipient, while over 55% live within 20 minutes (Koppelman, 2002).

Caregivers provide the recipient with an abundance of services; however, the most common service provided are instrumental activities of daily living (IADLs) such as banking, home maintenance, or food shopping. Over 98% of caregivers perform at least one IADL and 81% perform 3 or more.

The second most commonly provided caregiver services are activities of daily living (ADLs) such as bathing and dressing. These services are provided with 51% of caregivers helping with one ADL and 29% helping with three or more. Of all ADLs, transfers, dressing, bathing, and toileting are the most common ADLs that recipients are assisted with (Koppelman, 2002).

Providing care for an elder while simultaneously balancing other roles can be a very stressful and challenging experience. Providers must spend an abundance of time, money, and energy on the caregiver role while attempting to find time for themselves and their family (Donelan, Hill, Hoffman, Scoles, et al, 2002). Caregivers all over the world make up a large group of people who are stressed, burdened, and in need of care Koppelman (2002). Many researchers who have studied the effects of caregiving agree that caregivers are a population that feels isolated and unsupported (Plooster, 2003, Schultz and Beach, 1999, Skaff & Pearlin, 1992).

*Caregiver Risks and Concerns*

Plooster (2003) found that family caregivers who provide 36 or more hours of care per week are two times more than likely than non-caregivers to experience symptoms of depression or anxiety, while caregiving spouses are six times more likely. Caregivers were also two to three times more likely than non-caregivers to use drugs for depression, anxiety, and insomnia. Depression, anxiety, and drug abuse can lead to serious health problems and even death.

Schultz & Beach (1999) found an increased mortality rate to be another risk factor of caregiving. Caregivers who reported stress or strain (over half of the 400 participants) have a mortality risk 63% higher than non-caregivers do. Factors that contributed to higher mortality of caregivers include higher levels of depression, anxiety, lower perceived health, less sleep, less sick rest time, less exercise, and they are less likely to engage in preventive health behaviors (Schulz, & Beach, 1999). Many of these life-threatening experiences can be correlated with the caregiver's lack of time and resources to health services.

While trying to provide care to an elder, others, and themselves, caregivers may experience a loss of self. Skaff & Pearlin (1992) found that caregivers, most notably women spouses and younger adults, tend to express themselves less when their family member is more dependent. They also lose contact with friends and spend less time taking care of their own needs. The higher the dependency of the care receiver, the less opportunity caregivers have to express themselves (Skaff, & Pearlin, 1992). A sense of role loss is also a common theme among caregivers. In the absence of intervention, these feelings are assumed natural by caregivers. Caregiving is a role that often creates a

selfless attitude. To consider ones own needs is often difficult and prevents caregivers from seeking intervention (Koppelman, 2002).

As previously mentioned, caregiving is a burdensome and often stressful role. Healthcare professionals have discovered that taking on this role involves risks such as depression, anxiety, role loss, and even a higher mortality rate (Skaff, & Pearlin, 1992, Schulz, & Beach, 1999, Plooster, 2003). In addition to these stated risks, caregivers perceive other problems when performing as a caregiver. For example, 71.5% of caregivers were concerned about their own physical and emotional health and effectiveness of the caregiver role (Corcoran, Gitlin, Levy, & Eckhardt, 2002).

#### *Perceived Problems of Caregiving*

A study by Stajduhar (2003) found that although caregivers felt they had life-enriching experiences such as becoming closer with the family member and being able to give care when needed; there were problems with the health care system that contributed to negative experiences. Some caregivers reported that the healthcare system and the recipient made them feel pressured to bring the care to their home and take on more caregiving responsibilities (Stajduhar, 2003). They felt there were no other options for care within the health care system. Once the care receiver was brought home, the home environment was transformed. Most reported the home was turned into a hospital-like setting filled with medical equipment. Those fortunate to have access to health care professionals found their constant presence in their home to be a source of stress. Caregivers felt as though they had to mediate between each professional, and the number of professionals that were visiting was overwhelming (Stajduhar, 2003).

Although some caregivers reported too many professionals coming into their homes, others reported a lack of assistance from health professionals. Donelan, Hill, Hoffman, Scoles, et al (2002) found that more than half of the caregivers surveyed who helped with ADLs (such as feeding, bathing, using the toilet or lifting) received no formal instruction on how to perform these tasks. Paid professionals are one of the main sources of support for these instructions yet few identified being assisted by one. In their study of caregivers of Alzheimer patients, Ziff and Schaffner (2000) found that despite asking for help, not one caregiver received any training for ADL skills.

Nolan & Philip (1999) believe one reason for this lack of assistance is that typically, health professionals do not recognize the caregiver as a member of the healthcare team and their views are then frequently ignored. Another reason for lack of training is that caregivers are not aware that they can receive help. In a national survey, 38% of all caregivers said they do not know if they need help or what type they could receive (Koppelman, 2002). Mittelman, Roth, Haley, & Zarit, (2004) found that when caregivers do realize they can receive assistance their needs are great. They not only ask for assistance in activities of daily living (ADLs) but also in other areas of concern to them such as, techniques for managing troublesome behavior, communication techniques for patient and family members, enhancing skills to reduce family conflict, and skills to improve emotional and instrumental support, and education (p. 30).

Although caregivers mentioned lack of assistance and health care system concerns, most were concerned with the stress and sacrifices that were required. Many claimed caregiving was draining, exhausting, difficult to recover from, and required personal and financial sacrifice (Stajduhar, 2003). Others felt this role demanded too

much time, which deducted from the time they could spend in other critical roles such as wife or mother. Caregivers expressed that the lack of role balance produced unwanted changes in family relationships (Stajduhar, 2003).

### *Support to Caregivers*

#### *Assessment*

Educators and health care professionals are beginning to recognize the need for services to assist caregivers in their roles. In order to assist caregivers efficiently, an assessment should be completed to identify the areas of concern. When assessing caregivers, healthcare practitioners should include an estimate of the caregiver's perception of the caregiving role, the amount of time spent caregiving, and the types of activities that are performed (Corradetti, & Hills, 1998). In addition, a complete assessment of the caregiving process should involve the mental status, level of independence in ADL/IADL of the receiver, perceived expectations of caregiving, and the physical and emotional condition of the caregiver (Corradetti & Hills, 1998). Some of the assessments suggested to use with caregivers include, the Assessment of Burden in Spousal Caregivers (year and author of all of these assessments), the Zarit Burden Interview, the Caregiver Burden Inventory, and the Assessment of Depression (Corradetti & Hills, 1998). Corradetti & Hill cautioned that contradictory findings of these studies might be the result of reductionist thinking about the caregiving process as opposed to seeing caregiving as an interactive process between the therapist, family, and receiver.

#### *Treatment*

As each caregiver's situation is different and dynamic, when providing service to caregivers, health professions have several issues that may need to be addressed

simultaneously. Many studies have examined effective ways of meeting a variety of caregiver concerns. Corradetti & Hill (1998) found that conflict, depression, and physical illness of the caretakers are often a result of an inability to respond to change. They believe that intervention should focus on developing coping skills to address newly acquired roles (Corradetti & Hill, 1998). Positive cognitive coping skills will also decrease anger and depression (Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003). When depression management classes are combined with positive coping strategies, self-efficacy levels increase. Graff, Myrra, Vernooij-Dassen, Hoefnagels, Dekker, & De Witte (2003) found that when a collaborative and client centered treatment was used, including education, problem solving, coping strategies, practical and emotional support, Canadian Occupational Performance Model (COPM) satisfaction levels increased, as well as sense of competence, and the level of care needed of the recipient decreased.

Finally, Sorensen, Pinquart, & Duberstein (2002) performed a meta-analysis on seventy-eight different studies that addressed caregiver interventions. Overall, interventions were found more effective when increasing knowledge and ability than in the areas of decreasing burden and depression of caregivers. Combinations of interventions were recommended to target decreasing burden and depression such as psychotherapy with anger management.

Although many assessments and therapeutic interventions have been successfully applied, Ziff and Schaffner (2000) stress that the needs of individual caregivers are very different and dynamic that intervention should not be standardized (Ziff & Schaffner, 2000).

*Occupational Therapy*

As the elderly population increases, so too will the number of caregivers. Caregivers take on a role that has the potential to be stressful, burdensome, time consuming, and possibly life threatening if not balanced with other occupations. Because of these issues caregivers are a growing population that is in dire need of services from health care professionals. Recognizing this need, researchers have suggested several assessments and intervention techniques that health professionals can incorporate while working with caregivers of the elderly (Sorensen, Pinquart, & Duberstein, 2002, Ziff & Schaffner, 2000, Corradetti & Hill, 1998). Occupational therapists are in a unique position in that they possess the skills necessary to assist caregivers in important issues. The fundamental goal of occupational therapy is to match activity demands with the competence level of a person. (Corcoran, Gitlin, Levy, Eckhardt, 2002). For example, occupational therapists are able to discover the functional level of the care receiver and its impact on the assistance required by the caregiver (Corradetti, & Hills, 1998). They can then teach the caregiver techniques to function in the caregiver role such as instruction in home modification, safety, body mechanics, and instruction in how to assist with activities of daily living, amongst other occupational therapy intervention techniques.

Several occupational therapy models of practice may be used when working with caregivers of the elderly. However, Mary Reilly's Occupational Behavior model allows therapists to address all of a caregiver's needs (Barett, & Kielhofner, 1998). This model draws from the theoretical backgrounds of philosophy, psychology, social psychology,

sociology, and anthropology. Therapists can look beyond the medical aspects of therapy and focus on the human and his or her occupation.

Occupational Behavior (OB) includes activities that occupy a person's time, have meaning, a sense of achievement, and involve interaction with the physical, temporal, and social environment (Barett, & Kielhofner, 1998). Four major conceptual themes- work and play adaptation, motivation for occupation, temporal adaptation, and occupational roles- compose the Occupational Behavior model.

Occupation is the means by which a person learns to adapt. From birth, people are faced with challenges in their occupations through which they adapt. Adaptation is the fundamental way people cope to these challenges. However, if someone does not possess the skills necessary to adapt, then coping will not occur. This concept can be applied to a caregiver's situation. Once a person takes on the caregiver role, several new occupations may arise such as transferring a person from one area to another. If the caregiver does not have the skills to adapt to this new occupation, coping will not occur and stress will result. Using an Occupational Behavior approach, occupational therapists teach the caregivers skills so that they can adapt to their new occupations, which will decrease negative outcomes (Barett, & Kielhofner, 1998).

Once the caregiver learns new skills to adapt to the occupational challenges, they will have an intrinsic motivation to perform these occupations. Humans have the need to achieve mastery over themselves and the environment. "Experiencing oneself as an agent able to achieve desired outcomes is the product of healthy occupation: it is also the foundation for being motivated to engage in occupation" (Barett & Kielhofner, 1998, p. 526). Mastery and motivation are important concepts when working with caregivers of



the elderly. As previously mentioned, caregivers often feel unprepared for the new occupations they must assume. Occupational therapists are trained to provide the caregiver with the skills to achieve mastery and therefore create motivation to continue engagement in caregiver occupations.

Time management is another main concern for caregivers of the elderly. Many feel that their role of caregiver does not allow them to participate in other roles such as mother, sister, or friend. The Occupational Behavior model of practice may be used to guide occupational therapists in this matter as this model advocates that "the achievement of an appropriate balance between the demanding activities of work and the restorative activities of play and rest is seen as essential to health" (Barett & Kielhofner, 1998, p.526). By assisting the caregiver to develop healthy habits, the occupational therapists can assist in the restructuring of the caregiver's activities and environment so that an equal balance between occupations can be achieved.

Occupational Behavior model assumes that occupational roles are the means in which people express occupational behavior. A caregiver's role dictates caregiver occupations. However, caregiver's occupations often result in role strain. Education on coping strategies to reduce role strain may be useful in the intervention of caregivers (Sorensen, Pinguart, & Duberstein, 2002). Using the Occupational behavioral model, Occupational therapists can teach caregivers methods to cope with the strain. "The profession of occupational therapy enhances the abilities of the individuals to engage in all life roles, including that of caregiver" (Corcoran, Gitlin, Levy & Eckhardt, 2002, p. 83).

The Occupational Behavioral Model is one of the foundations for many other occupational models. Several models such as the Model of Human Occupation, Occupational Adaptation, Ecology of Human Performance, and the Occupational Performance Model have emerged from Mary Reilly's work. Although each model has a different subset of beliefs, they each contain the necessary tools to use when working with caregivers of the elderly.

#### *Current Suggested Occupational Therapy Practices*

Although the Occupational Behavioral model allows therapists to work effectively with caregivers, few occupational therapists have begun researching the effectiveness of occupational therapy interventions for this population. Corcoran, Gitlin, Levy, & Eckhardt (2002) created the Environmental Skill-Building Program. This program focuses on enhancing a caregivers' fit to the environment. This program uses a collaborative approach, and through manipulating the home environment, caregivers learn skills and receive support to change modify or control problem behaviors in the receiver and other caregiver issues. For example, Gitlin, Corcoran, Winter, Boyce, & Hauck (2001) found that occupational therapy home visits (five 90 minute sessions over a three month period) that modify caregivers' living spaces had a positive impact on slowing progression of IADL dependence of patients, increasing self efficacy, and reducing upset in caregivers. This type of treatment differs from the traditional occupational therapy practice. Traditionally, reimbursement considerations drive practice so treatment tends to focus directly on the care receiver, not the caregiver or their environment (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001).

Other occupational therapists have made suggestions as to how to approach interventions with caregivers. Clark, Corcoran, & Gitlin, (1994) found that caregivers concerns might not be the same as the occupational therapists, in turn caregivers will not be receptive to suggestion if the occupational therapist does not acknowledge the incongruity. Four types of interaction: caring, partnering, informing, directing are suggested to create a holistic and collaborative approach to therapy (Clark, Corcoran, & Gitlin, 1994). Occupational therapists must work collaboratively with caregivers, acknowledge them as experts, validate their knowledge, help generalize skills, include family values, and fully address the needs of the family within their context.

## Chapter 3: Methodology

### *Overview*

The researcher conducted a self-designed mail survey for this study. The survey included questions on demographics, current beliefs of practice, current practices used, and barriers to the provision of services. It was mailed to 100 registered occupational therapists and 100 certified occupational therapy assistants who practice in New York and Pennsylvania. The practitioners are also members of the American Occupational Therapy Association. Ninety-three therapists responded and the data was analyzed using the Statistical Package for the Social Sciences 12.0 (SPSS) computer software.

### *Research questions*

1. What are the current practices of occupational therapists while working with caregivers of the elderly?
2. What are the perceived roles of occupational therapists while working with caregivers?
3. What are the perceived barriers to occupational therapists providing services to caregivers?

### *Subjects and Selection Method*

The researcher purchased a list from the American Occupational Therapy Association of 200 randomly selected Registered occupational therapists and Certified occupational therapy assistants who currently work with the elderly in Pennsylvania and New York and have worked with at least one client over the age of sixty-five. The researcher chose to examine practices in Pennsylvania because it has the fifth largest population of the elderly in the U.S. with over 40% of that population experiencing one

or more disability (US Census Bureau, 2004). New York was chosen due to the proximity of the professionals to the researcher.

### *Study Design/ Research Tool*

A self-designed mail survey was used to gather data. The design was chosen for specific reasons. First, a mail survey enables the researcher to answer the research questions by measuring characteristics of a large population and predicting relationships. Second, a mail survey can reach a large number of subjects with relatively little costs. Third, many variables can be measured by a single instrument. Lastly, surveys permit multiple uses of the data (Depoy & Gitlin, 1998).

The survey was designed by the researcher and was based on current literature. Included in the survey were questions pertaining to demographics, current practices of therapists, and beliefs and attitudes about caregiving. The questions were presented in a variety of formats including forced choice, questions with "other" using write in alternative, and likert scales. The first set of likert scale questions, which measured the importance of skills and abilities, used a 5-point scale with 1 being the least important to 5 being the most important. The second set of likert scale questions pertaining to beliefs and practices, utilized a 4 point scale with 1 being strongly disagree and 4 being strongly agree.

### *Operationalization of Concepts Into Variables*

In order to answer each research question, thirty-five variables of interest were included on the survey. Each variable was addressed using a variety of question formats. Appendix C displays each question. Questions 1 through 6 address demographic variables such as age, gender, and setting. These questions yielded nominal and

numerical data. Questions 7, 8, 9-11, 17, 18, and the likert format chart focused on the variables of practice. These questions resulted in nominal and ordinal data. Finally, the likert scale questions in the chart and questions 12-16 addressed the variables of perception, which produced ordinal data. The researcher used concepts in the literature to operationalize the variables.

### *Field Testing*

After approval by the Ithaca College Human Subjects Board, the researcher conducted a field test to establish content validity and lucidity of the survey questions. Nine graduate occupational therapy students and three occupational therapy professors participated in the field test. The researcher then reviewed and altered the survey based upon suggestions from the group.

### *Procedures*

Following Ithaca College Human subject review board approval (Appendix A), the final survey packet was mailed to each subject's institution. The packet included a cover letter, which also served as an informed consent form, a four-page survey, and an addressed pre-stamped envelope. Participants were instructed to read the cover letter/consent form and save it for their records. Subjects were then requested to complete the survey, which should take less than 10 minutes. After completing the survey, the participants placed the survey in an addressed stamped envelope and returned it to Ithaca College, in care of the researcher.

The researcher employed the Dillman format (1978) to ensure the greatest number of returns. This method included sending a set of reminder postcards to all therapists who had not returned the survey after two weeks. Two weeks after the postcards were

sent, a second packet containing the cover letter and survey was sent to all therapists who still had not responded.

The research assistant used a numeric coding system to track all returned surveys. Each participant received a random code number connected to his or her mailing address. The assistant placed the random code number *only* on the preaddressed envelope, which the participants used to return the survey. Participants returned the survey to the research assistant who documented all codes, opened the envelopes, and gave the noncoded surveys to the researcher. The researcher had no knowledge of the coding system and the research assistant will destroy all coding and addresses at the end of the study.

#### *Anonymity and Confidentiality*

Confidentiality of the participants was protected throughout the study. The survey instrument did not ask for the participants name or other identifying information. In order to protect subjects' confidentiality, returned data was stored in a locked cabinet with only researcher and committee members having access. The Human subjects review board, before storage, approved all confidentiality procedures.

#### *Data Analysis*

The researcher examined all data by using a variety of tests in the Statistical Package for the Social Sciences (SPSS 12.0). Descriptive statistics determined the means and valid percents for each question. Relationships between all nominal variables and the four categories of position, age, setting, and years of experience were examined by using the Spearman Rho correlation test. A T-test for Independent Samples was implemented to determine the difference between Registered occupational therapists and Certified occupational therapy assistants responses to Likert scale questions. Finally, due to the

multiple variables in the categories of age, setting, and experience, the Nonparametric Kruskal-Wallis test was used to determine the significant difference of each Likert scale question within each category.

### *Scope and Limitations*

Limitations to the study include a self-designed instrument and a sample of convenience. A self-designed instrument was necessary due to the lack of information and available standardized assessments on the research topic. A self-designed instrument could skew results as it has not undergone the rigorous process of standardization and validity assessment. Although random, the sample, composed of occupational therapy practitioners in only the Northeastern states of Pennsylvania and New York, could affect external validity. A larger national sample would have increased the ability to generalize results; however, it was beyond the capacity of this study. Assumptions such as people answering the survey honestly, receiving a favorable return rate, and people's understanding of the survey could also affect the study. Confounding variables may include age, gender, education, level of experience, and therapists' background.



## Chapter 4: Results

### *Participant Demographics*

Ninety two out of two hundred participants returned their surveys for a return rate of 46 percent. Of the ninety-two participants, 53% were Registered occupational therapists and 46.7% were Certified occupational therapy assistants. Of those 85.6%, therapists were female and 14.4% were male. The average age of participants was 43.85 years old, with those 50-59 years of age being the largest age group to respond. The average years of experience for the participants was 8-10 years, however 37.1% stated they had over 15 years of experience. See Table 1 for participant data.

Table 1

*Participant Demographics*

Survey Items	n	%
<b>Gender</b>		
Male	13	14.4
Female	77	85.6
<b>Age</b>		
20-29	10	11.3
30-39	21	23.8
40-49	24	27.2
50-59	30	34.0
60-69	2	2.2
70-79	1	1.1
<b>Years of Experience</b>		
1-3	11	12.4
4-7	18	20.2
8-10	14	15.7
11-15	13	14.6
15+	33	37.1

Note. Values may not add up to N= 92 or 100% due to invalid data that was not included in analysis.

*Work Setting of Participants and Clients*

Skilled nursing facilities were the most common place of employment. Home health and Other was tied for the second most popular setting with 25.6% and acute hospital was third with 22.2% of the participants. In these settings, the most common diagnosis treated was orthopedic conditions and on average participants treated 8-10 clients per day.

Just over 94% of participants have worked with a client who was receiving care from a caregiver. When asked have you ever had a referral from a health practitioner for a caregiver to receive direct occupational therapy services, 72.2% responded no, while only 27.8% indicated they had. Table 2 and 3 detail these results.

Table 2

*Work Setting of Participants*

Survey Items	n	%
<b>Setting</b>		
Acute hospital	20	22.2
Long term rehab	15	16.7
Outpatient clinic	16	17.8
Assisted living facility	3	3.3
Other	23	25.6
Skilled nursing facility	41	45.6
Home healthcare	23	25.6
Private practice	5	5.6
Developmental	2	2.2
<b>Primary Diagnosis of Clients</b>		
Neurological	27	30.7
Orthopedic	31	35.2
Developmental	2	2.3
Psychosocial	5	5.7
Medical conditions	23	26.1

Note. Values may not add up to N= 92 or 100% due to invalid data that was not included in analysis.

Table 3

*Clients*

Survey Items	n	%
Number of Clients treated per day		
1-3	3	3.4
4-7	29	33.0
8-10	32	36.4
11-15	13	14.8
16-20	5	5.7
21+	6	6.8
Clients who receive care from a caregiver	85	94.4
Have received a referral from a healthcare practitioner to provide OT services to a caregiver	25	27.8

Note. Values may not add up to N= 92 or 100% due to invalid data that was not included in analysis.

*Current Practices*

Tables 4-6 report the survey results relating to the treatment approach and importance questions in the chart on the survey (Appendix C). The first column in the chart described the skills and abilities that occupational therapy practitioners surveyed believed caregivers needed to possess to perform successfully in their role as caregivers. In the next column, the participant was asked to rate the importance of the skill or ability using a likert scale rating one to five, one being the least important five being the most important (Table 4). The last five columns described approaches and therapeutic interventions that therapists can employ to address these skills and abilities (Table 5 and 6). Participants were asked to respond "yes" if they used the approach, or "no" if they did not.

Overall participants felt that all of the skills and abilities were *very* important to address except leisure skills, which they found *somewhat* important. Education was the most common approach to address the caregivers' skills and abilities. Assessments were used with six of the nine skills/abilities. Therapists responded to referral to other professions and direct care for only one skill/ability and responded No to all consultation categories. See table 4, 5, and 6 for results.

Table 4

*Skills and Abilities Considered Important for Caregivers*

Survey Item	Mean
Increase knowledge of community resource	4.30
Increase quality of life	4.59
The ability to carry out activities of daily life	4.81
Increase health and wellness	4.50
Prevention of illness or injury	4.70
Adaptation to successfully meet occupational challenges	4.43
The ability to meet the demands of the client's roles	4.43
Caregiver satisfaction	4.45
Leisure skills	3.95

Note. Likert scale ranking was as follows: one= least important, two= somewhat unimportant, 3= neither important nor unimportant, 4= somewhat important, 5= very important.

Table 5

*Approaches: Assessment, Education, Consultation*

Survey Items	I have formally or informally assessed caregivers for:		I have provided education for:		I have provided consultation for:	
	n	%	n	%	n	%
Increasing knowledge of community resource	38	45.8	73	88.0	28	33.7
Increasing quality of life	42	50.6	58	69.9	23	27.7
The ability to carry out activities of daily life	57	68.7	70	84.3	24	28.9
Increasing health and wellness	40	48.2	61	73.5	26	31.3
Prevention of illness or injury	51	61.4	73	88.0	31	37.3
Adaptation to successfully meet occupational challenges	50	60.2	62	74.7	27	32.5
The ability to meet the demands of the client's roles	49	59.0	62	74.7	23	27.7
Caregiver satisfaction	43	51.8	42	50.6	17	20.5
Leisure skills	33	39.9	46	55.4	18	21.7

Note. Values may not add up to N= 92 or 100% due to invalid data that was not included in analysis.



Table 6

*Approaches: Referral, Direct Care*

Survey Items	I have referred the caregiver to other professionals for:		I have provided direct care for:	
	n	%	n	%
Increasing knowledge of community resource	50	60.2	26	31.3
Increasing quality of life	29	34.9	32	38.6
The ability to carry out activities of daily life	23	27.7	49	59.0
Increasing health and wellness	35	42.2	32	38.6
Prevention of illness or injury	26	31.3	41	49.4
Adaptation to successfully meet occupational challenges	23	27.7	41	49.4
The ability to meet the demands of the client's roles	26	31.3	29	34.9
Caregiver satisfaction	18	21.7	24	28.9
Leisure skills	19	22.9	29	34.9

Note. Values may not add up to N= 92 or 100% due to invalid data that was not included in analysis.

*Current Practices: Interventions*

The therapists that responded yes to using direct care for any of the skills and abilities, were asked to answer questions 9 and 10 (Appendix C). Question 9 asked how many caregivers they currently provided direct care to who care for someone more than 18 hours per week. Nearly 60% of participants replied two or less. The second question addressed interventions; when providing direct care, what types of interventions have you employed with caregivers? Table 7 demonstrates that the top three interventions therapists most commonly used include safety techniques, functional transfer training, and body mechanics training. The least common interventions were drug abuse education and group counseling.

Table 7

*Current Practices: Interventions Employed with Caregivers*

Survey Items	n	%
Safety education/awareness	53	86.9
Body mechanics education	53	86.9
Functional transfer training	53	86.9
ADL/IADL training	51	83.6
Adaptive equipment	49	80.3
Environmental modifications	49	80.3
Coping strategies	37	59.7
Referral to other services	34	55.7
Family teaching	34	54.8
Time management	33	54.1
Preventive health	23	37.7
Relaxation techniques	23	37.1
Group counseling	5	8.1
Drug abuse education	3	4.8

Note. Values may not add up to N= 92 or 100% due to invalid data that was not included in analysis.

*Barriers to Serving Caregivers*

In addition to researching current practices, the researcher wanted to discover the barriers to the provision of services for caregivers. Therefore, the survey included the question; "In your experience what are the barriers to the provision of direct occupational therapy services for caregivers?" Table 8 displays all responses.

Table 8

*Barriers to Serving Caregivers*

Survey Items	n	%
Reimbursement	59	66.3
Lack of referrals	50	56.8
Lack of knowledge about occupational therapy services	45	51.1
Time	31	35.2
Scheduling	26	29.5
Refusal by the caregiver	24	27.3
Another profession is already providing services to the caregiver	18	20.5
Lack of services by the occupational therapy profession	13	14.8
Caregivers are a liability to treat	7	8.0
Other	5	5.7

Note. Values may not add up to N= 92 or 100% due to invalid data that was not included in analysis.

*Therapist's Perceptions*

The survey also included seven likert scale questions pertaining to the therapist's perceptions about caregivers and occupational therapists' role in the service of caregivers. Participants were to read each statement and respond to the likert scale as to whether they strongly disagreed (rating of 1), somewhat disagreed (2), somewhat agreed (3), or strongly agreed (4).

Table 9

*Therapists Perceptions: Mean Scores for Each Statement*

Statement	Mean	% of highest rated response
When providing services to caregivers, occupational therapists should focus on increasing a caregiver's knowledge and skills.	3.73	77.5% strongly agreed
Providing services to caregivers is a role of occupational therapy practitioners	3.64	69.7% strongly agreed
When providing services to caregivers, occupational therapists should focus on decreasing a caregiver's depression and anxiety.	3.25	48.3% somewhat agreed
The risks caregivers face were addressed at least once during my occupational therapy education	3.00	36.0% strongly agreed
When working with caregivers, occupational therapists should view the caregiver as an expert in the needs of the care receiver	2.81	52.3% somewhat agreed
Within the last year, I have suggested to a caregiver that they should receive direct occupational therapy services	2.03	43.7% strongly disagreed
Within the last year, a caregiver has voiced concerns and expressed their desire to receive direct occupational therapy services	1.95	40.7% strongly disagreed

Note. Participants were asked to respond to each statement using the following scale: *strongly disagrees* (1), *somewhat disagree* (2), *somewhat agree* (3), *strongly agree* (4).

## Chapter 5: Discussion

Although many researchers have conducted studies addressing the risks of caregiving (Skaff, & Pearlin, 1992, Schulz, & Beach, 1999, Plooster, 2003), few to no other studies have posed the question, who is caring for the caregiver? This study intended to discover the roles, perceptions, and practices that professionals in the field of occupational therapy were employing in relation to caregivers of the elderly.

*Demographics*

The reported statistics relating to gender, age, experience, and position of the participants, created a sound sample to represent the population in New York and Pennsylvania. With an even amount of Registered occupational therapists and Certified occupational therapy assistants, the majority of the participants were females in the 50-59 year old age range with 15+ years of experience. The majority of the participants' years of experience allows for a wide range of abilities and variety of perceptions. The gender of most respondents is typical to the profession; however, the largest age range of 50-59 years olds is surprising and may have resulted for several reasons. This age range may be more likely to belong to the national organization to which the participant list was purchased. According to the American Occupational Therapy Association, "the median age of members has increased slowly over time, rising from 36 to 39 in the past decade for OTs, and from 33 to 40 for OTAs" (AOTA, 2005). In addition to the higher rates of membership, this age range represents the population of people who are more likely to be caregivers. Therefore, they may be more likely to respond due to a personal interest in the subject matter. Researchers such as Martin, (1994) and Roberson & Sundstrom, (1990) reported that topic salience is the key influencer of return rate for mail surveys. Other



demographic information gathered indicated that therapists treated an average of 8-10 clients per day. This average is higher than the reported national level. In 2000, the AOTA stated that in a typical day, respondents saw a median of six patients for individual treatment. Having to work with a large number of clients could leave little time to address caregiver issues.

When asked to rate the skills and abilities that caregivers need to be successful in their roles, therapists rated almost every skill as *very* important (5 rating). For example, respondents reported that being able to adapt, possess knowledge of resources, and prevent illness, are all very important abilities that are necessary for a caregiver to possess. Therapists may have highly rated all skills and abilities because most agreed that they had the risks of caregiving addressed at least once during their occupational therapy education. For example, one participant stated, "My instructors at school always stressed to us as students the importance of assisting and educating the caregivers as well as the client." If therapists are aware of the skills needed in caregiving, they would be more likely to find them important.

The only skills participants rated *somewhat* important (4 rating) were leisure skills. This finding is not surprising since current literature suggests that occupational therapy practitioners do not value leisure skills as much as work or self-care skills despite the fact that leisure is in the scope of practice. According to Suto (1998), society's focus on productivity has led to therapists neglecting leisure. A 15-year retrospective study of two North American occupational therapy journals revealed only eight articles addressing leisure (Suto, 1998). It is unfortunate that therapists are not focusing more effort on leisure because of its documented positive characteristics. Suto (1998) explains that

leisure has the ability to “promote health, well-being, and overall life satisfaction” (p. 272). Leisure also promotes self-actualization, ability to cope, and increases opportunities for socialization and self-expression (Suto, 1998). Because of the documented benefits, therapists should address leisure with all populations in all settings.

Caregivers are a population where leisure skill education and training become extremely important. The role of a caregiver requires a lot of time, money, and sacrifice of other roles. Due to these factors, a caregiver’s ability to participate in leisure skills severely declines. According to Skaff & Pearlin (1992), caregivers lose contact with friends and have a decreased ability to express themselves. Leisure becomes the last priority of caregivers as they struggle to meet the demands of their role. Therapists need to value leisure and recognize the importance of addressing it while providing caregiver services.

Respondents also stated that during treatment they address knowledge and abilities before depression and anxiety. This prioritization agrees with Sorensen, Pinquart, & Duberstein’s (2002) research that interventions are more effective when increasing knowledge and ability than decreasing burden and depression. When a caregiver’s knowledge increased, their burden and depression decreased, creating an inverse relationship.

Although therapists understood the demands of the caregiver role, they did not validate or listen to caregivers concerns. When questioned if caregivers should be viewed as experts in the needs of the care receiver, about 30% stated that they should not. One participant stated, “Caregivers should not be viewed as experts because they are often unrealistic.” This finding agrees with Nolan & Philip’s (1999) study which

reported that health professionals do not recognize the caregiver as a member of the healthcare team and frequently ignore their views. This behavior by therapists creates distrust in the therapist-caregiver relationship, which in turn could convince caregivers to not request or refuse assistance. Over 70% of all therapists stated that a caregiver has not voiced their concerns or expressed their desire to receive direct occupational therapy services. The results of this study beg the question: "Why would one request services from a professional who will not listen to their concerns or value their input"?

Ineffective communication and false assumptions are not the only reasons caregivers do not receive services. Caregivers are also unaware that they can receive assistance from professionals such as occupational therapy practitioners. According to a national survey, 38% of all caregivers claimed they do not recognize that they need support or understand which services they could receive (Koppelman, 2002). The participants of this survey also believed that caregivers lacked knowledge of services an occupational therapist could provide. At the same time, over half of the participants reported that while they recognize the risks of caregiving, they do not suggest occupational therapy services. This result could lead one to believe that occupational therapy practitioners do not consider working with caregivers as a role of occupational therapy. However, an overwhelming percent (94.4%) said that providing services to caregivers is a role of occupational therapists. One participant stated, "OT is the primary discipline that should be involved with caregivers and care recipients. Function, roles, activity performance and mental health are just a few areas OTs are experts". These incongruencies between action and perception on the behalf of occupational therapy practitioners could lead to further confusion of the caregiver.

*Barriers*

This study found that therapists believed that it is the role of the occupational therapy profession to provide services to caregivers of the elderly. Conversely the study discovered that therapists are not suggesting direct services. Barriers to intervention were cited in Question 11 of the survey. (Appendix C). The survey listed 10 barriers that therapists may perceive as hindering the ability to provide services. Therapists stated that reimbursement was the number one barrier that prohibited therapists' support of caregivers. One therapist stated, "In our facility so much is reimbursement driven. I can't imagine that administration would allow us to provide direct caregiver services for so many hours that are non-billable". Researcher Sandra Hubbard (2005) stated that most therapists wish that the healthcare system was driven by values, justice, and the Hippocratic Oath. Unfortunately the healthcare profession is more a market competition, driven by the interest of politicians and big business (Hubbard, 2005). It has been demonstrated that costs of healthcare have risen while reimbursement has declined. To keep business strong, providers are forced to refuse treatment to populations which payers do not feel require services (Hubbard, 2005). If facilities are not going to receive payment for their services, the therapists are less likely to offer assistance. As caregiver issues become more prominent and research demonstrates lack of services, insurance companies and government programs may be more inclined to reimburse professionals for direct care. According to Koppelman (2002), caregivers save the government 257 billion dollars per year. It would cost the government billions of dollars if this valuable population becomes unhealthy.

Therapists cited lack of referrals as the second most common barrier. This barrier was proven through this study which found that only 27.8% of therapists have received a referral from a health professional to provide services to a caregiver. Although this percent is higher than the researcher anticipated, it is too low to address the needs of this population. It is necessary for the occupational therapy profession to continue to educate physicians and other health care referral sources about the skills that they possess that make them a vital resource for caregivers. Educating physicians and other health care referral sources may also affect the reimbursement system. The American Medical Association employs a large group of lobbyists who have a powerful effect on Congress's decisions towards healthcare (Glabman, 2002). If the American Medical Association were more aware of the benefits of occupational therapy in this realm they may lobby accordingly.

#### *Current Practices*

Despite many barriers including reimbursement, time, and referrals, occupational therapy practitioners are providing some services to caregivers. The most widely used approach to caregiver services was education for the caregiver while treating the care receiver. This type of approach may be used most commonly because it is encouraged and reimbursed by Medicare. One therapist commented, "Caregiver education is an integral part of every session with my home health care clients. Medicare wants to see documentation of this and considers it a valuable and valid part of my service". However, these results contradict Donelan, Hill, Hoffman, Scoles, & et al (2002) who stated that more than half of the caregivers surveyed received no formal instruction on how to perform tasks such as transfers or activities of daily living.

Alongside the results of education as an intervention, formal and informal assessments were used to evaluate almost all caregiver skills and abilities. This finding supports Corradetti, & Hills (1998), who stated that assessing caregivers is an essential step in the treatment of caregivers.

A small minority of therapists also provided direct treatment to a caregiver. The researcher defined direct treatment as focusing intervention solely on problems the caregiver was experiencing. Direct care did not include providing services to a caregiver through the care receiver's referral or treatment plan. Around 30% of all therapists provided direct care at some point for most skills and abilities. When providing care, the three most common treatment modalities utilized were safety education/awareness, body mechanics education, and functional transfer training. These findings support those of Sorensen, Pinqart, & Duberstein (2002) who performed a meta-analysis on seventy-eight different studies on caregiver interventions and found that increasing abilities within the role to be very effective. These techniques may also be taught because they directly relate to the care of the care receiver.

When providing direct treatment, over half of the therapists worked with caregivers on coping strategies and time management skills. These skills are extremely important for caregivers who are performing in a stressful, time consuming role. The fact that therapists are using these techniques is very encouraging since Stajduhar (2003), claims that most caregivers felt their role limited them from performing other roles such as wife or father. They also expressed that the inability to cope with unbalanced roles created strain and changes in their family dynamics.

Although some essential techniques were utilized, therapists did not focus on preventive health or drug abuse education which is very important for caregivers of the elderly. According to Schulz, & Beach, (1999) caregivers are less likely to engage in preventive behaviors such as exercise due to lack of time, emotional, and physical issues directly related to their role. If the caregiver does not take the time to employ preventive strategies, they risk the chance of becoming ill or injured and may be forced to abandon their role. It is the function of occupational therapy practitioners to enhance clients' abilities to perform in life roles. By teaching preventive behaviors, we can assure a successful performance throughout the caregiver experience.

Only 4.8% of the participants surveyed focused treatment on drug abuse education. However, Plooster (2003) found that caregivers are two to three times more likely to abuse drugs, especially to combat depression and insomnia. Caregivers are two times more than likely than non-caregivers to experience symptoms of depression or anxiety and if they are not taught effective coping strategies, they may be more inclined to abuse drugs (Plooster, 2003). Therapists need to be aware of this risk and address this issue with all caregivers.

The survey also demonstrated that therapists do not provide consultation services to caregivers. As previously discussed with regards to direct care, if individuals do not understand the role of occupational therapy, it is sensible to assume that it will negatively affect the amount of consultative requests. The role of occupational therapy practitioners as consultants may change as caregiver issues become more prominent in the community. This role may be easily acquired as this study found that practitioners are performing

assessments on caregivers, the next logical step could be to provide direct intervention or consultations.

### *Further Correlations of Interest*

Although it goes beyond the scope of this study, the researcher performed further statistical analysis to determine if there was a relationship between any of the variables and demographic factors of setting and attained professional license. Some correlations were noted and are discussed in this section.

It was discovered that the setting a therapist worked in correlated with the treatment techniques employed. For instance, there was a relationship between the acute care setting and using coping strategies, increasing knowledge of community resources, and decreasing focus on leisure. This finding supports current research on acute care. Griffin & McConnell (2001) found that therapists in acute care setting focus on assessing and discharge with little time for treatment. This could be why therapists do not focus on leisure when working with caregivers in this setting. They must focus only on the skills that will allow the caregiver to bring the care receiver home as soon as possible. These skills include making sure the caregiver has proficient coping skills to perform his or her role. Caregivers coping skills determine if they are in a proper mental state so that they can care for the receiver. The study also stated that therapists believed providing information about follow-up services was extremely important in the acute care setting (Griffin & McConnell, 2001). This finding explains why therapists working with caregivers focused on increasing knowledge of community resources.

The variables and the demographic factor of attained professional license were also examined for relationships. The analysis revealed few, but some differences



between the Registered occupational therapists and Certified occupational therapy assistants responses. Overall, Registered occupational therapists provided more consultation, assessments, and referrals. This finding is not surprising, given the role of a Registered occupational therapist position. Other differences were found that were not easily explicable. Registered occupational therapists provided more direct care, had the risks of caregiving addressed in their education, focused more on time management, and less on leisure. Certified occupational therapy assistants believed that focusing on depression was more important and that lack of knowledge about occupational therapy was a larger barrier.

## Chapter 6: Conclusion

Currently 22.4 million homes contain individuals who are providing care to an elder (Koppelman, 2002). In the next few years, this population of caregivers will grow and become even more prominent in society as the "baby boomer" generation ages. The risks and health concerns of this population will also increase with time. The current research suggests that caregivers are in dire need of services to decrease risks of depression, physical illness, role loss, and even mortality. Unfortunately, due to rising healthcare costs and decreased services, the needs of caregivers will go unmet unless health professions recognize the needs and provide services.

Occupational therapy practitioners possess knowledge and skills necessary to support this population. They have been educated on the physical, emotional, and psychosocial demands a caregiver faces in his or her role. They understand and can employ the techniques required to ensure successful performance as a caregiver.

This study examined the current practices of occupational therapy practitioners when working with caregivers of the elderly. It also investigated perceived roles and barriers of therapists working with caregivers. The results indicate that therapists believe that providing services to caregivers is a role of the profession. They provide education to prevent or decrease the risks of caregiving. However, many barriers such as lack of reimbursement and referrals prohibit the direct provision of services.

If occupational therapy practitioners believe that it is our role to treat caregivers of the elderly, then we need to address the barriers of providing services. We need to consider reimbursement, referrals, and caregivers perceptions of occupational therapy. Alternate routes of reimbursement should be examined such as grants or private

practices. Referral sources and more importantly caregivers need to understand how occupational therapy can support caregivers in their role.

This study has raised several important questions that could be used for future research. Which settings would be the most conducive to providing caregiver services? What are caregiver perceptions of Occupational therapy and barriers to services? Is there a difference between Registered occupational therapists and Certified occupational therapy assistants when working with caregivers? Lastly, does age or years of experience influence the current practices of therapists working with caregivers of the elderly?

Perhaps through researching these questions and addressing service barriers, the question "who is caring for the caregiver" will no longer need to be asked.

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## Appendix A: Human Subjects Proposal Materials

ALL-COLLEGE REVIEW BOARD  
FOR  
HUMAN SUBJECTS RESEARCH  
COVER PAGE

Investigators: Kelly Potter OTS, Mindy Cozzolino OTD, OTR/L, MS, CRC,  
BCN

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Department: Occupational Therapy

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Telephone: (610) 462-4625 Home

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Project Title: Occupational Therapy Practice with Caregivers of the Elderly

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**Abstract: (Limit to space provided)** Having to balance several roles and take care of an elderly person can have many negative effects on a caregiver. Researchers documented that caregivers are at high risk for depression, anxiety, isolation, and role loss (Plooster, 2003). In order to function in the role of caregiver and decrease negative risks, caregivers of the elderly need assistance from health professionals such as occupational therapists. The purpose of this study is to describe the current practices of occupational therapists working with caregivers of the elderly. This information can be used as a stepping-stone for future research projects to assist a population that is in dire need of care. The researchers chose a mail survey design for this study. Two hundred subjects will be selected from a list of American Occupational Therapy Association Registered occupational therapists and Certified occupational therapy assistants that work with the elderly in Pennsylvania and New York States. In order to protect subjects' confidentiality, returned data will be stored in a locked cabinet with only researcher and committee members having access. The researcher will implement the Dillman format to ensure validity. This format has been proven to secure a high return rate in mail survey research. Data analysis will include descriptive statistics using SPSS. Likert scales will be analyzed using a more powerful statistical test based on the results. The researcher will also examine the relationships between variables. The study will begin after approval from the IRB and end in March 2005.

**Proposed Date of Implementation: October 2004- March 2005**

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Kelly Potter OTS Advisor: Mindy Cozzolino

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Print or Type Name of Principal Investigator and Faculty Advisor

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Signature (Use blue ink) Principal Investigator and Faculty Advisor

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**ALL-COLLEGE REVIEW BOARD  
FOR  
HUMAN SUBJECTS RESEARCH  
CHECKLIST**

**Project Title: Occupational Therapy When Working with Caregivers of the Elderly**

**Investigator(s): Kelly Potter OTS, Mindy Cozzolino, OTD**

**Investigator HSR Use**

**Use Only Items for Checklist**

- |                                     |  |
|-------------------------------------|--|
| <input checked="" type="checkbox"/> | 1. General information   |
| <input checked="" type="checkbox"/> | 2. Related experience of investigator(s)   |
| <input checked="" type="checkbox"/> | 3. Benefits of the study   |
| <input checked="" type="checkbox"/> | 4. Description of subjects   |
| <input checked="" type="checkbox"/> | 5. Description of subject participation  |
| <input checked="" type="checkbox"/> | 6. Description of ethical issues/risks of participation  |
| <input checked="" type="checkbox"/> | 7. Description of recruitment of subjects  |
| <input checked="" type="checkbox"/> | 8. Description of how anonymity/confidentiality<br>will be maintained.   |
| <input type="checkbox"/>            | 9. Debriefing statement  |
| <input checked="" type="checkbox"/> | 10. Compensatory follow-up   |
| <input type="checkbox"/>            | 11. Appendix A - Recruitment Statement   |
| <input checked="" type="checkbox"/> | 12. Appendix B - Informed Consent Form (or tear-off<br>Cover Page for anonymous paper and pen/pencil<br>surveys) |
| <input type="checkbox"/>            | 13. Appendix C - Debriefing Statement  |
| <input checked="" type="checkbox"/> | 14. Appendix D - Survey Instruments  |
| <input type="checkbox"/>            | 15. Appendix E - Glossary to questionnaires, etc.  |

Items 1-8, 11, and 12 must be addressed and included in the proposal. Items 9, 10, and 13-15 should also be checked if they are appropriate - indicate "NA" if not appropriate. This should be the second page of the proposal.

1. **General Information about the study**
  - a. Funding for the researcher project will be contributed by the graduate occupational therapy department account. Expected expenses include purchasing a mailing list from the American Occupational Therapy Association and duplicating the survey instrument.
  - b. The survey will be distributed through the mail and take place in each participant's place of employment.
  - c. Upon approval by the IRB and Ithaca College Occupational Therapy Department, the researcher will conduct the study beginning October 2004 and ending March 2005.
  - d. The results of the study will be reported in the Master's thesis of the researcher. The researcher will also seek out to publish the findings in an article in an occupational therapy journal.
2. **Related Experience of the Researcher(s) and Faculty Advisor(s)**
  - a. The primary researcher of this study has volunteer experience at the Ithaca College occupational therapy clinic and has completed all research classes required by the occupational therapy department, including research methods and biostatistics. The primary advisor, Dr. Mindy Cozzolino is the graduate chair in the occupational therapy department at Ithaca College and has recently completed her OTD (occupational therapy doctorate) through Creighton University.
3. **Benefits of the study**
  - a. Benefits of this study include identifying the practices used and the barriers occupational therapists encounter while providing services to caregivers of the elderly. This information can then be used to develop further intervention strategies for this population.
4. **Description of the Subjects**
  - a. The study will include 200 subjects to assure a large enough return for valid results.
  - b. The subjects will be selected from a list of American Occupational Therapy Association Registered occupational therapists and Certified occupational therapy assistants who currently work with the elderly in Pennsylvania and New York. Pennsylvania was chosen since it has the fifth largest population of the elderly in the U.S. with over 40% of that population experiencing one or more disability (US Census Bureau, 2004). New York was chosen as a sample of convenience. In addition the therapists must work with at least one client who is 65 years of age or older.

## 5. Description of the Subject Participation

- a. Individual packets will be sent to each subject's institution. The packet will include a cover letter, which also serves as an informed consent form, a four-page survey, and an addressed envelope. Participants will be asked to read the cover letter/consent form and keep it for their records. Then the subjects will be asked to complete the survey, which should take less than 10 minutes. The survey questions pertain to demographics, current practices of therapists, and beliefs and attitudes about caregivers.
- b. After completing the survey, the Participants will place the survey in an addressed stamped envelope and return the survey to Ithaca College.
- c. Once the surveys are returned, data will be analyzed using SPSS and descriptive statistics. The results will be compiled and reported in the thesis paper.

## 6. Ethical Issues- Description

- a. Participants do not face the risk of physical harm in this study. Mild anxiety may be experienced when responding to certain questions that pertain to demographics or beliefs and attitudes.

## 7. Recruitment of Subjects

- a. In order to recruit participants, the researcher will purchase a randomized member mailing list from the American Occupational Therapy Association. The list will contain names and addresses of practicing registered occupational therapists and occupational therapy assistants. The researcher will then mail a survey packet to 200 subjects in Pennsylvania and New York. The packet will contain a tear of consent form, a survey, and a preaddressed stamped envelope that includes the participant's randomized code number. The Dillman format will then be utilized to ensure the highest return rate. This method includes sending a set of reminder postcards to all therapists who have not returned the survey after two weeks. Two weeks after the postcards are sent, a second packet containing the cover letter and survey will be sent to all therapists who still have not responded. A coding system created by the research assistant will be used to track returned surveys. Throughout the process, therapists always have the option to participate or not.
- b. Participants will not receive any enticement to participate in this study

## 8. Confidentiality/ Anonymity of Responses

- a. Confidentiality of the participants will be protected throughout the study. The survey instrument does not ask for the participants name or social security number. Envelopes containing the returned surveys will not have a return address. All data will be kept in a locked cabinet with only the

researcher and the thesis committee gaining access. The research assistant will use a numeric coding system to track all returned surveys. Each participant will receive a random code number connected to his or her mailing address. The assistant will place the random code number *only* on the preaddressed envelope, which the participants will use to return the survey. Participants will return the survey to the research assistant who will document all codes, open the envelope, and give the noncoded surveys to the researcher. The researcher will have no knowledge of the coding system and the research assistant will destroy all coding and addresses at the end of the study.

9. Debriefing

- a. Debriefing statement is not required for this study.

10. Compensatory Follow-up

- a. The researcher believes that any mild anxiety experienced by the participants will not require a compensatory follow up. Furthermore, the instructions on the survey suggest participants stop the survey or skip any questions if they experience any discomfort. However, if the participant feels a follow up is necessary or they would like to obtain a copy of the study results they will be encouraged to contact the researcher by the information given on the cover letter.

## Appendix B: Participant Information Sheet

Dear Participant,

My name is Kelly Potter and I am a graduate occupational therapy student from Ithaca College. Thank you for considering participating in my Thesis research study entitled *Occupational Therapy When Working with Caregivers of the Elderly*. If you choose to contribute, the survey should take no longer than 10 minutes to complete. This information sheet will explain the study purpose, participation requirements, research procedures, confidentiality, and anonymity.

**Purpose:** The purpose of this study is to describe the current practices of occupational therapy practitioners when working with caregivers of the elderly. This information can be used as a stepping-stone for future research projects and serve as a guide for identifying the best practice and program development for the caregivers.

**Participant Requirements and Information:** If you are a registered occupational therapist or certified occupational therapy assistant who works with clients who are 65 years of age or older, you are eligible for this study. You will be asked to complete a 3-page survey that should take approximately 10 minutes. The survey consists of questions and statements that pertain to the following:

1. Demographic information
2. Your current experience in working with caregivers
3. Your beliefs or attitudes about care giving and occupational therapy

*YOUR COMPLETION AND RETURNING THIS SURVEY SERVES AS INFORMED CONSENT. PLEASE SAVE THIS COVER LETTER FOR YOUR RECORDS.*

You CAN refuse to answer any of the questions in the survey or withdrawal your participation at any time.

**Procedures:** On the next 3 pages, please read the directions and complete the survey accordingly. After completion place and mail the survey in the addressed stamped envelope contained in this packet.

**Anonymity and Confidentiality:** In order to preserve anonymity and confidentiality, participant names and institutions are not recorded on the survey. Each participant will receive a random code for data analysis. In addition, all returned surveys will be kept in a locked filing cabinet with access only allowed to the researcher and members of the thesis committee.

**Contact Information:** If you have any questions or would like to receive a copy of the study results please contact me:

Kelly Potter [kpotter1@ithaca.edu](mailto:kpotter1@ithaca.edu)  
Ithaca College Occupational Therapy Department  
Address as shown on letterhead

## Appendix C: Survey Instrument

**DEFINITION:** For the purpose of this study CAREGIVER will be defined as anyone 18 years of age or older who is taking care of someone 65 years of age or older. The caregiver can be a family member(s) or friend(s) who takes care of the person's needs including bathing, cooking, home maintenance, grocery shopping, etc. Personal care aides or any other "paid" caretaker is not considered a caregiver in this study.

For the questions 1-7 please place an X on the line to represent the answer that most closely reflects your status.

1. Gender: M \_\_\_\_\_ F \_\_\_\_\_ Age: \_\_\_\_\_
2. Which of the following currently describes your position?  
Registered Occupational Therapist \_\_\_\_\_  
Certified Occupational Therapy Assistant \_\_\_\_\_
3. Please indicate the type(s) of setting in which you are currently employed:  
Acute hospital \_\_\_\_\_ Skilled nursing facility \_\_\_\_\_  
Long-term rehab \_\_\_\_\_ Home healthcare \_\_\_\_\_  
Outpatient clinic \_\_\_\_\_ Private practice \_\_\_\_\_  
Assisted living facility \_\_\_\_\_ Developmental \_\_\_\_\_  
Other (please specify) \_\_\_\_\_
4. What is the most common type of diagnosis treated in your facility?  
Neurological \_\_\_\_\_ Developmental \_\_\_\_\_  
Orthopedic \_\_\_\_\_ Psychosocial \_\_\_\_\_  
Medical Conditions (i.e. cancer) \_\_\_\_\_
5. How many years of experience have you had in the occupational therapy profession?  
1-3 \_\_\_\_\_ 8-10 \_\_\_\_\_ 15+ \_\_\_\_\_  
4-7 \_\_\_\_\_ 11-15 \_\_\_\_\_
6. What is the number of clients you currently provide services to in a typical work day?  
1-3 \_\_\_\_\_ 8-10 \_\_\_\_\_ 16-20 \_\_\_\_\_  
4-7 \_\_\_\_\_ 11-15 \_\_\_\_\_ 21+ \_\_\_\_\_
7. Have you ever worked with a client who was receiving care from a caregiver?  
Yes \_\_\_\_\_ No \_\_\_\_\_
8. Have you ever had a referral from a health practitioner for a caregiver to receive Occupational therapy services?  
Yes \_\_\_\_\_ No \_\_\_\_\_

**Please complete the following chart. The first column has skills and abilities a caregiver may require. The second column is a Likert scale ranking of importance for these skills. The last 4 columns represented how you may have addressed these skills in your therapy session. Please mark an X all skills you have addressed using that particular modality.**

Skills and abilities caregivers need	Importance of these skills when working with a caregiver  ( please circle a number with 1 being least important and 5 most important)	I have formally or informally assessed caregivers	I have provided education	I have provided a consultation	I have referred the caregiver to other professional	I have provided direct care
Increase knowledge of community resource	1 2 3 4 5					
Increase quality of life	1 2 3 4 5					
The ability to carry out activities of daily life	1 2 3 4 5					
Increase health and wellness	1 2 3 4 5					
Prevention of illness or injury	1 2 3 4 5					
Adaptation to successfully meet occupational challenges	1 2 3 4 5					
The ability to meet the demands of the client's roles	1 2 3 4 5					
Caregiver satisfaction	1 2 3 4 5					
Leisure skills	1 2 3 4 5					

***If you have marked an X in the last column (I have provided direct care for these skill) please move on the question 9. If you did NOT mark at all in the last column please move on the question 11.***

9. What is the number of caregivers you currently provide direct services to who take care of someone more than 18 hours per week?

2 or less \_\_\_\_\_ 6-8 \_\_\_\_\_  
 3-5 \_\_\_\_\_ 9+ \_\_\_\_\_

10. When providing direct services, what types of interventions have you used with caregivers?

Relaxation techniques _____	Time management _____
Coping strategies _____	Adaptive equipment _____
Group counseling _____	Environmental modifications _____
Drug abuse education _____	Preventive health _____
Family teaching _____	Safety education/awareness _____
ADL/IADL training _____	Body mechanics education _____
Referral to other services _____	Functional transfer training _____

11. In your experience what are the barriers to the provision of direct occupational therapy services for caregivers?

Reimbursement \_\_\_\_\_  
 Lack of services by the occupational therapy profession \_\_\_\_\_  
 Scheduling \_\_\_\_\_  
 Refusal by the caregiver \_\_\_\_\_  
 Lack of referrals \_\_\_\_\_  
 Time \_\_\_\_\_  
 Lack of knowledge about occupational therapy services \_\_\_\_\_  
 Another profession is already providing services to the caregiver \_\_\_\_\_  
 Caregivers are a liability to treat \_\_\_\_\_  
 Other \_\_\_\_\_

***For questions 12-18 read each statement and circle the number that corresponds with your level of agreement. 1 = strongly disagree 4= strongly agree***

12. The risks caregivers face were addressed at least once during my occupational therapy education.

1. Strongly Disagree	2. Somewhat Disagree	3. Somewhat Agree	4. Strongly Agree
----------------------------	----------------------------	-------------------------	-------------------------



13. Providing services to caregivers is a role of occupational therapy practitioners

- |                            |                            |                         |                         |
|----------------------------|----------------------------|-------------------------|-------------------------|
| 1.<br>Strongly<br>Disagree | 2.<br>Somewhat<br>Disagree | 3.<br>Somewhat<br>Agree | 4.<br>Strongly<br>Agree |
|----------------------------|----------------------------|-------------------------|-------------------------|

14. When working with caregivers, occupational therapists should view the caregiver as an expert in the needs of the care receiver

- |                            |                            |                         |                         |
|----------------------------|----------------------------|-------------------------|-------------------------|
| 1.<br>Strongly<br>Disagree | 2.<br>Somewhat<br>Disagree | 3.<br>Somewhat<br>Agree | 4.<br>Strongly<br>Agree |
|----------------------------|----------------------------|-------------------------|-------------------------|

15. When providing services to caregivers, occupational therapists should focus on increasing a caregiver's knowledge and skills.

- |                            |                            |                         |                         |
|----------------------------|----------------------------|-------------------------|-------------------------|
| 1.<br>Strongly<br>Disagree | 2.<br>Somewhat<br>Disagree | 3.<br>Somewhat<br>Agree | 4.<br>Strongly<br>Agree |
|----------------------------|----------------------------|-------------------------|-------------------------|

16. When providing services to caregivers, occupational therapists should focus on decreasing a caregiver's depression and anxiety.

- |                            |                            |                         |                         |
|----------------------------|----------------------------|-------------------------|-------------------------|
| 1.<br>Strongly<br>Disagree | 2.<br>Somewhat<br>Disagree | 3.<br>Somewhat<br>Agree | 4.<br>Strongly<br>Agree |
|----------------------------|----------------------------|-------------------------|-------------------------|

17. Within the last year, a caregiver has voiced concerns and expressed their desire to receive direct occupational therapy services

- |                            |                            |                         |                         |
|----------------------------|----------------------------|-------------------------|-------------------------|
| 1.<br>Strongly<br>Disagree | 2.<br>Somewhat<br>Disagree | 3.<br>Somewhat<br>Agree | 4.<br>Strongly<br>Agree |
|----------------------------|----------------------------|-------------------------|-------------------------|

18. Within the last year, I have suggested to a caregiver that they should receive direct occupational therapy services.

- |                            |                            |                         |                         |
|----------------------------|----------------------------|-------------------------|-------------------------|
| 1.<br>Strongly<br>Disagree | 2.<br>Somewhat<br>Disagree | 3.<br>Somewhat<br>Agree | 4.<br>Strongly<br>Agree |
|----------------------------|----------------------------|-------------------------|-------------------------|

19. Comments?

## Appendix D: Follow-up Postcard Content

December 1, 2004

Two weeks ago you were mailed a survey about occupational therapy when working with caregivers of the elderly. You are one of a small number of occupational therapists chosen for this study and your response is vitally important. Please return the survey as soon as possible. If you have lost your copy of the survey and would like a new one, please email me at [kpotter1@ithaca.edu](mailto:kpotter1@ithaca.edu). I would like to take this opportunity to thank you for your participation in this research project.

Sincerely,

Kelly Potter, OTS