

A CAREGIVER PERSPECTIVE: ADAPTATION AFTER STROKE

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BY

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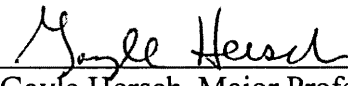
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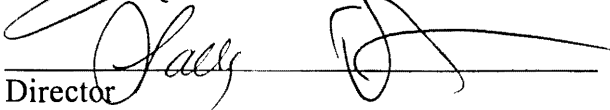
To the Dean of the Graduate School:

I am submitting herewith a dissertation written by Franzina Coutinho entitled "A Caregiver Perspective: Adaptation after Stroke." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Occupational Therapy.



Dr. Gayle Hersch, Major Professor

We have read this dissertation and recommend its acceptance:



Director

Accepted:



Dean of the Graduate School

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This line of research came into being by my introduction to the field of caregiving through Dr. Gayle Hersch who introduced me to Dr. Sharon Ostwald at the University of Texas, School of Nursing. It is here that I began my life as a researcher under the constant tutelage of both these academic individuals. My desire to pursue Caregiving of Informal Caregivers as my line of research was initially supported by Dr. Jean Spencer, my advisor at the time. She was a guiding light who helped me see my way through the initial stages of the doctoral process and helped me initiate the work that is now complete.

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ABSTRACT

FRANZINA COUTINHO

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Three studies were designed to explore the question, “*What physical, social and psychological factors contribute to adaptation in the caregiver’s life following the stroke of a spouse?*” Studies focused on the psychosocial, sociocultural and environmental dimensions of adaptation among the spousal caregivers of stroke survivors.

The first study in this dissertation was a critical literature review of information in the form of articles and editorials related to occupational therapy. Concepts that have evolved within occupational therapy related to informal caregiving were discussed and a comparison was made with literature available in the other fields like nursing and the social sciences. Both qualitative and quantitative studies were considered from peer reviewed journals. Articles from MEDLINE and Cumulative Index to Nursing and Allied Health Literature were selected for review for the period of 1982-2005. Keywords used were: informal caregiving, occupational therapy, environment, occupation, motivation, meaning, and spouse.

In the second study, “A Caregiver Journey: The Process of Recovery after Stroke”, the participants were interviewed at five time points over a year in which the caregiving experience of spousal caregivers of stroke survivors was described. Eight participants (pseudonyms used) were selected to illustrate the adaptation process over time. For the purpose of this mixed design

study interview data from caregivers were analyzed, along with scores from the Caregiver Preparedness Scale.

The third study was a qualitative design and included the same caregivers from Study 2.

The third study, “Occupations Lost and Gained: A Caregiver Perspective”, demonstrated the changes in the occupational lives of the caregivers. A core tenet of occupational therapy is the belief that health is reflected and maintained through participation in occupations: work, play or leisure and self care. The research from these three studies attempted to be thorough by identifying the process involved in adaptation and caregiving and by filling the gaps that currently exist in the profession on this topic.

The holistic view of adaptation was a significant component of this dissertation with a focus on the dyad as a unit viewed together in treatment consideration to achieve more effective outcomes.

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CHAPTER 1

INTRODUCTION

Statement of Problem and Specific Aims

Occupational therapy as a profession strives to restore the highest level of quality function for people with disabilities. However, little emphasis has been placed on identifying and dealing with the needs of people caring for individuals with disabilities, specifically stroke. The topic of research for this dissertation is 'A Caregiver Perspective: Adaptation after Stroke'. The intent is to uncover the holistic process of adaptation by employing caregiving and the several concepts associated with it so as to get a complete understanding of this multidimensional complex phenomenon.

The driving force behind this area of research is to answer two questions,

- 1. What factors contribute to adaptation in the caregiver's life following the stroke of a spouse?*
- 2. What changes occur in the caregiver's life related to participation in old occupations and involvement in new ones over a span of 12 months following stroke?*

This chapter describes the problems related to the area of spousal caregiving and the aims of the three studies. The second chapter will deal with the background and significance of the three studies.

The concept of informal caregiving and adaptation

There are two types of caregiving: formal and informal. Formal care is professionally rendered. Informal caregiving is unpaid care given voluntarily to ill or disabled persons by their family and friends (Informal Caregiving: Compassion in Action, 1998). Various informal groups, such as marital, kin, friends and neighbors, each deliver unique services and because of the more internalized commitment are more likely to make great personal sacrifices to maintain services required for the care receiver, that is, to suffer from caregiving burden (Anderson, 1977; Zarit, Orr & Zarit, 1985). The meaning of caregiving, or how a person interprets his/her experiences, influences how daily care is provided in the home and how caregivers define their needs (Hasselkus, 1988). There is variability in the way caregivers adapt to their experiences and cope differently depending on their stressors (Corcoran, 1992; Williamson & Schulz, 1993).

Adaptation is a frequent subject of occupational therapists (Schkade & Schultz, 1992) as noted by Meyer (1922), Reilly (1962) and the American Occupational Therapy Association (1979). Identification of the adaptive process could improve effectiveness of services provided to spousal caregivers and allow for better prevention and treatment strategies. This dissertation considered adaptation over time to be a significant component in the changes occurring during the caregiving process.

The Problem

As a line of research the process of adaptation among informal caregivers post stroke was proposed. This research addressed issues of adaptation across ethnicity and

gender, paying close attention to temporal changes and specific time points at which adaptation occur.

The following is a succinct list of the major problems related to the lack of research in caregiving within occupational therapy.

1. The literature in occupational therapy is very limited in the area of caregiving of stroke survivors and there is no literature on the process of change in the caregiving process over time.
2. Samples involving mixed racial groups and different research designs are absent from the profession's literature on caregiving.
3. The temporal impact on the caregiving process has been minimally addressed.
4. The adaptive process and similarities and differences between caregivers of different ethnic groups are areas that in need of attention by our profession.
5. The process of occupations gained and lost over time as a result of acquiring new roles (i.e. caregiving for spouse) and adapting to new life situations is a significant area with which occupational therapy has been involved. It is time for our profession to build on the existing research related to this topic.

Statement of Purpose

The purpose of this line of research was to understand the process of caregiving from an occupational therapy perspective with the intention of gaining a holistic picture of the process of adaptation during caregiving, while examining the caregiver's loss and gain of new occupations after assuming the role of caregiver. This line of research included three studies to achieve this purpose.

Gaps in current professional knowledge:

The literature in occupational therapy is very limited in the area of informal caregiving and lacks literature on the process of change in caregiving over time. Samples involving mixed racial groups and different research designs are absent from within the profession's literature on caregiving. The impact that time has on the caregiving process, the adaptive process that occurs among various racial groups, and caregiving by different racial groups are areas that need specific attention within the profession.

In addition, there is insufficient research in areas of how therapists: 1.) address the occupations of the caregiver, 2.) measure changes occurring within the family because of care recipient illness and 3.) facilitate meaningful participation in the daily life of caregiver's.

This line of research aims to address the three areas mentioned above and contribute to the existing knowledge base of the profession.

Methods

This section provides a brief overview of the researcher's perspective, design setting and data analysis that was used in each of the three studies. A more detailed account of these will be provided in the individual studies.

Researcher's Perspective:

As a part of qualitative research, personal bias is an accepted component of the process. Personal bias is a recognized factor in qualitative research and the research being conducted here is no exception. Caregiving for a person with a disability as a part of one's everyday life requires changes to be implemented in the daily routines and

alterations and modifications in occupations for both of the people involved in the caregiving experience, i.e. the caregiver and care recipient. As an occupational therapist I hold firmly to the belief that adaptation occurs through participation in meaningful occupation and what is meaningful evolves over time, and thus the definition of a meaningful occupation changes and is in flux.

Design

This research used interviews from the Committed to Assisting with Recovery after Stroke (CAREs) study which is an interdisciplinary, intervention study (See Appendix A). It also included quantitative assessments of physical and psychological functioning at baseline, 3, 6, 9, and 12 months, for stroke survivors and their spousal caregivers. The aims of the CAREs project were:

1. Improve function, quality of life and perceived health, and decrease depression in stroke survivors by strengthening the dyad's knowledge and skills, their use of social supports and resources, and their problem solving and coping behaviors.
2. Reduce unplanned clinic and emergency room visits, the number, frequency and length of rehospitalization and admissions to hospitals and admissions to nursing homes among stroke survivors.
3. Decrease depression, burden and stress, and improve health experienced by spousal caregivers by strengthening the dyad's knowledge and skills, their use of social supports and resources and their problem solving and coping behavior.

4. Decrease immune imbalances related to the stress of caregiving by strengthening the dyads knowledge and skills, their use of social supports and resources, and their problem solving and coping behaviors.

In general, the research proposed here attempted to capture the essence of informal caregiving and understand it from an occupational therapy perspective. The informal caregiving process was analyzed from three perspectives: available literature in the profession and strengths and gaps existing in it, the caregiver's perspective of the process of caregiving, and finally an analysis of gains and losses of occupations in which the caregiver participates as a result of the caregiving experience.

Research Questions

The primary research questions proposed in this line of research were:

1. How do caregivers of different ethnicity, gender, and socioeconomic background adapt to life after stroke of their spouses?
2. What significance does time have on the process of adaptation after stroke for these individuals?
3. How do caregiver occupations alter after stroke?

Study 1:

The first study in this dissertation was a critical literature review of information in the form of articles and editorials within the profession. Concepts that have evolved within occupational therapy related to informal caregiving were discussed and comparisons were made with literature available in the other fields like nursing and social sciences on the same concepts. Both qualitative and quantitative studies were considered

from peer reviewed journals. Articles from MEDLINE and Cumulative Index to Nursing and Allied Health Literature were selected for review, for the period of 1982-2005.

Keywords used were: informal caregiving, occupational therapy, environment, occupation, motivation, meaning, and spouse.

Study 2:

The second study was a mixed design study. Purposive sampling from eight caregivers was used in the study. The number of caregivers selected depended on the richness of information, achieving redundancy in coding and theme analysis. The clients were participants of the CARES project who have been interviewed over one year. The study included both male and female caregivers, representative of the caregiver population in the grant which is one male caregiver for every four female caregivers. This helped identify differences in caregiving approaches. A mixed ethnic group was selected that included Caucasian, African American and Hispanic caregivers. Caregivers from different ethnic groups were included in the study to note the cultural differences. The Caregiver Preparedness Scale administered at 0, 3, 6, 9, and 12 months was used. The scale is a structured, self-report, written assessment questionnaire with eight items. A Likert scale was used to answer each question, with choices ranging from 1 (not at all prepared) to 5 (very well prepared). All responses from each survey were averaged to arrive at a preparedness score, ranging from 1-5. This tool was used just as a comparison tool to identify scores at different time points and to triangulate with the findings from the qualitative data.

Study 3:

The third study was a qualitative design and included the same caregivers from Study 2. This study aimed at identifying the occupations in which the caregiver was newly involved following the spouse's stroke and occupations the caregiver had to give up because of this new role. The data were from interviews conducted in the CARES project.

The research from these three studies endeavored to be thorough by identifying the process involved in adaptation, by analyzing the caregiving process and filling the gaps that currently exist in the profession.

Setting and Data Collection:

The data for research with the CARES project were collected as part of an interdisciplinary grant funded by the National Institute for Nursing Research, National Institutes of Health (NR05316-01) over a five year period. It dealt with education, support, counseling, and skill training of stroke survivors and their partners need after leaving the hospital or rehabilitation setting. The data were collected from stroke survivors and their spouses initially admitted into hospitals in the southwest area of Houston, Texas. Data collection was done as part of the assessment at home at 0, 3, 6, 9 and 12 months respectively by a blinded nurse practitioner. This included both the client interviews and the information collected from the scales.

Data Analysis:

The dissertation consisted of a first study that used a critical literature review to gauge the information available on informal caregiving within the profession, the areas that have been researched and the gaps and strengths of literature currently available on the subject.

The interviews for the second and third study were from spousal caregivers of stroke survivors who were asked to talk about their experience of stroke on audiotape. These tapes have been transcribed verbatim without names and were analyzed for themes. Purposive sampling was used and 8 caregivers' were selected based on richness of interviews and redundancy of coding and theme analysis. Themes related to adaptation were examined in the second study and were reinforced with analyst triangulation. The data from the Caregiver Preparedness Scale at 0, 3, 6, 9, and 12 months was used just as a comparison tool to identify scores at different time points as a means of supporting any findings from the qualitative data. Data analysis meetings with occupational therapists and nurses were held on a bi-monthly basis and multiple readings of the interview transcripts were carried out. These meetings helped establish an understanding of the themes and added depth to the interpretations (Christ & Tanner, 2003). Transcripts were examined simultaneously within themselves and in comparison with each of the caregivers, thus maintaining individuality and still identifying commonalities among the caregivers. The database was maintained and refined using QSR N6. Trustworthiness of the data was established through analyst triangulation (analysts had backgrounds in nursing and occupational therapy were members of the CARES study). Multiple meetings were held

to recode and confirm established themes and patterns in the data. Coding categories were organized into themes and sub themes and examined for patterns. QSR N6 helped in the development of matrices for identifying themes that occurred at different time points. The third study looked at themes related to occupations and the process of gains and losses of occupations among caregivers following stroke. Analyst triangulation was a part of this study as well. All coding for studies two and three was done in QSR N6.

Thus, the information organized in the studies addressed informal caregiving of stroke survivors from different perspectives. It identified not only the gaps and strengths in literature available within the profession but used this information to further contribute to the body of knowledge by considering the temporal aspects, ethnicity and gender of the caregivers.

CHAPTER 2

BACKGROUND AND SIGNIFICANCE

Informal Caregiving and Adaptation

Chronic disability can be described by certain defining features: caused by non reversible pathological alterations, leaves permanent disability and impairment and the affected individual may require rehabilitation and/or long term care (Craig & Edwards, 1983). Mechanisms of disability include congenital anomalies, illness or progressive disease and trauma (Liveneh & Antonak, 1997).

The World Health Organization (WHO) has gone through the process of reframing the ICIDH and conceptualized the International Classification of Functioning, Disability and Health (ICF) in 2001, in an attempt to include the elements prevalent in both the medical and social model while classifying function and disability. As an example of change in the model, impairment was defined as “disturbance at the level of the organ” (p.14) according to the model in 1980, ‘however based on the revamped model in 2001, body functions and structures are used to identify a problem, impairment or activity limitation. They also take into account environmental and personal factors and thus serve to encompass the human being as a whole.

The Census Bureau states that chronic illness impacts 50% of the American population and approximately 110 million people. By the year 2007, the number of caregiving households in the U.S. for person's aged 50+ could reach 39 million (NAC/AARP, 1997; Health & Human Services, 1998; Spector, 2000). Arno (2002) estimated the value of services family caregivers provide for 'free' to be \$257 billion a year. These numbers give us an inkling of the magnitude of this population and the economic impact made by caregivers all over the country. This dissertation deals with a specific chronic disease; stroke and the various complex aspects of caregiving related to it.

Seven hundred and fifty thousand Americans have a stroke each year. It is the third leading cause of death and a leading cause of profound long term disability in the United States (American Stroke Association, 2005). As longevity increases because of improved health care and decreased mortality, it is imperative to improve the quality of life of this specific population. With the growing population affected by stroke recovery, it becomes vital to identify issues of growing concern among this population. Becoming a caregiver may be a sudden and unexpected challenge. It was thought that caregiving was predominantly a woman's issue but men now make up 44% of the caregiving population (National Family Caregivers Association (NFCA), 2000). Who becomes a caregiver is dependent on the living arrangements of the care recipient (Chappel, 1991; Penrod, Kane, Kane, & Finch, 1995). If married the spouse or significant other becomes the primary caregiver and the next possibility could be the adult child.

According to Pernod and his colleagues, secondary helpers may be present to help the primary caregiver if the primary caregiver is not the spouse. Various theories for caregiving have evolved where one to one interactions have been suggested (Johnson, 1983; Kahana & Young, 1989), and the systems theories have been put forth by others (Copeland & White, 1991; Couper & Shehan, 1987; Harrison & Cole, 1991)

Why does caregiving exist?

The fields of sociology, psychology and nursing have contributed to the knowledge base of caregiving for over half a century. The concept of helping is an underlying theme in caregiving as identified by psychologists and social psychologists. Applied to the family caregiving context two types of explanations have evolved to identify motives for helping (caregiving). Helping could serve an *egoistic or self-serving motive*, while the other caters to *empathy and altruism* (Batson & Coke, 1983). The egoistic explanation argues that helping is motivated by the individual's anticipation of rewards for help given and punishment for not helping (Brody, Poulshock, & Masciocchi, 1978). Guilt may also be a motivating force for individuals who feel they must atone for past sins or are providing care to the parent as repayment of care provided by them at a younger age (Brody, 1985).

Greenberg in 1980, provided *a theoretical basis for indebtedness* as a motive, in which he stated that feeling indebted has motivational properties, such that greater the magnitude the greater the resultant arousal and discomfort, hence greater the need to deal with it or reduce it. A different perspective on human nature is provided by a theory of

helping based on altruistic motivation, where the assumption is that the ability to empathize is based on variables such as kinship, attachment, similarity, prior interaction or a combination of variables, and this seems to be commonly seen in intrafamilial caregiving situations.

Family therapy literature suggests at least four ways in which family involvement may adversely affect the caregivers and hence care receiver's psychological and adaptational well being. Persons, especially those closely involved with someone in distress, may become over involved, develop resentful or hostile feelings toward him or her, or develop symptoms of psychological distress (Coyne et al, 1988). The philosophy of occupational therapy acknowledges the ability of the individual to influence his own mental and physical health as well as his social and physical environment (AOTA, 1996). The theory of occupational adaptation (Schakde & Schultz, 1992) acknowledges that the occupational challenges that occur in life are affected by desire, demand and press for mastery. Understanding this theory then elicits the need to identify significant events occurring during the caregiving process that result in development of the adaptive response mechanism and help in development of prevention and treatment strategies to improve effectiveness of services to this specific population of caregivers.

Theoretical Models of Informal Caregiving:

A number of caregiving models have evolved in the literature that look at different aspects of the caregiver-care recipient interactions, modes of care provision and involvement of community. Sociologists Kahana and Young (1989) put forth a paradigm,

where caregiving is considered an *adaptive arrangement* in the face of serious or chronic illness and helped organize the framework, using a paradigm of the utility of stress, resources and recovery. Caregiving has been studied as a unidimensional and unidirectional process; however indepth examination has revealed multiple dynamics in caregiving / care recipient interactions. Caregiving models have been divided into static and dynamic caregiving outcome models (Kahana & Young, 1989). *Static* outcome models have been further divided into *asymmetrical* and *symmetrical* models. Asymmetrical models include a *caregiver centered one directional model* which is the most commonly studied, being that of the caregiver and care receiver. It is assumed that the care recipient is responsible for increasing stress and burden and adverse psychological outcomes. Zarit, Orr and Zarit, (1985) carried out extensive research on the impact of caregiving on burden. The *care recipient centered one directional model* is another asymmetrical model that focuses on the impact of caregiving on the care receiver. Kahana and Kahana (1984) used this model in the stress theory and identified that the efforts and actions of the caregiver reduced the impact of the illness on the care recipient. The next model in this group is the *caregiver centered bidirectional model* where positive outcomes as well as negative influences because of stress and burden are a possibility. *Care-recipient centered bidirectional model*, considers adverse effects on the care receiver because of the caregiver stress resulting in abuse (Silverstone & Hyman, 1982; Pillemer & Wolf, 1986). Symmetrical models permit consideration of both the caregiver and the care receiver outcomes and thus explain not only the impact of caregiver and care receiver on each other but also mechanisms by which outcomes are generated.

Dynamic models of caregiving include the *contingency model of caregiving*, which focuses on the reinforcement of dependency which could result in learned helplessness of the care recipient and thus increase burden on the caregiver. *The feedback model of caregiver / care-recipient interactions and outcomes* could result in a non recursive or feedback model of caregiving and dependency in which care recipient activate dependency behaviors and have the caregivers do more and reinforce that cycle of helplessness (Blalock, 1971). The *Congruence model of caregiver behavior and patient dependency* is concerned with match/ mismatch between patient dependency needs and caregiver behavior directed at meeting those needs. Positive outcomes for both care giver and care recipient could occur from a close fit between the degree of patient dependency needs and caregiver responses to those needs, and a mismatch occurs when an imbalance occurs between the needs and care response to them.

Family function is another significant component that has been identified in the caregiving literature. Farzan (1991) listed characteristics of a healthy functional family. Clear delineation of family member's roles and functions with division of labor, open lines of communication and a flexible but stable power system were the key characteristics. However, the way a family adapts to a chronic illness causing disability is dependent on successfully identifying family functioning prior to illness. Harrison and Cole (1991) suggest focusing on certain aspects of family structure while considering family function. Identifying who comprises the family, including extended family is essential. The pool of family caregivers is shrinking as families are smaller and members live at greater distances than they used to (The Institute for Health & Aging, 1996).

Family structures are changing and thus result in shared adulthood of both the parent with the disability, stroke, and the child. Thus the family life stage has an impact on the task of caregiving (Jongbloed, 1994). Copeland and White (1991), Couper and Shehan (1987) and Harrison and Cole (1991) discussed using the general system theories to interpret family function. Being a very interactive theory it is believed that each member is interdependent on the other and interactions between family members affect the entire family, thus a chronic illness, in this case stroke, has an impact on the family system as a whole.

Theoretical Models of Adaptation:

This section looks at different theories of adaptation from within and outside occupational therapy and thus lays a broad base to help understand the concept from different angles. The three theories discussed in this section are: the continuity theory (Atchley, 1989; Becker, 1993; Spencer, Davidson, & White, 1996), the model of psychosocial adaptation to chronic illness and disability (Livneh & Antonak, 1997), and the model of Occupational Adaptation (Schultz & Schkade, 1992; Schkade & Schultz, 1992).

The Continuity Theory was originally introduced as a paradigm to look into the process of aging (Atchley, 1989; Becker, 1993; Spencer et al, 1996). The basic thought behind it is that, even while one experiences change, the structure of one's self identity remains intact. Continuity was considered an adaptive strategy. A central tenet of continuity theory is that, "in making adaptive choices, middle-aged and older adults attempt to preserve and maintain existing internal and external structures and they prefer

to accomplish this objective by . . . applying familiar strategies in familiar arenas of life" (Atchley, 1989, p. 183). Internal continuity refers to the persistence of mental structures about who we are, as reflected in our ideas, temperaments, perceived skills, preferences, and tastes; external continuity, on the other hand, is defined in terms of persistence of activities, environments, roles and relationships (Atchley, 1989; Henderson, Bialeschki, Shaw, & Freysinger, 1996). There is a temporal component of the theory: "To the extent that change builds upon, and has links to, the person's past, change is part of continuity" (Atchley, p.183).

Spencer, Davidson, and White (1996) used continuity theory to add to the concept of adaptation. The person-environment interaction is "a life long cumulative process by which humans remember a repertoire of past occupational experiences and through environmental appraisal evaluate its relevance for envisioning and shaping the future , a way of linking memory and intention"(p.533). This shows a continuous flow from past to present. Livneh and Antonak's (1997) model of psychosocial adaptation to chronic illness and disability shows phases of adaptation. The onset begins with shock, anxiety and denial, and then progresses to depression, anxiety that is internalized and externalized hostility, finally resolving into acknowledgement, acceptance and adjustment. They defined psychosocial adaptation as a "process through which an individual strives to reach an optimal state of person-environment congruence referred to as adjustment" (p.424). The indicators of successful adaptation were demonstration of "1. psychosocial equilibrium or reintegration; 2. awareness of remaining assets and existing functional limitations; 3. Positive self esteem, self concept, and sense of personal mastery; 4.

Successful negotiation of the environment and 5. Active participation in social, vocational, and recreational activities” (p.424). The authors considered disease characteristics, sociodemographic factors, psychologic makeup and environmental factors to be reflective of both internal and external processes of adaptation.

Schkade and Schultz (1992) have studied the concept of adaptation in great detail and refer to it as “The process through which the person and the environment interact when the person is faced with an occupational challenge calling for occupational response, reflecting an experience of relative mastery.” In the framework of Occupational Adaptation, relative mastery is an outcome of interaction between the person and environment. Schkade and Schultz (1992) defined relative mastery as “the extent to which the person experiences the occupational response as efficient (use of time and energy), effective (production of the desired result), and satisfying to self and society” (p.835).

These three theories represent three views of adaptation. The continuity theory and the theory of occupational adaptation flow as a continuum from past to present to future. All three theories consider interactions between person and the environment and acknowledge the presence of both internal and external features in the adaptation process. For the purpose of this dissertation and ensuing studies, adaptation may be defined as a process that occurs in a continuum, in which the client may be in a state of flux but rearranges the self appropriately in relation to his/her environment, resulting in effective output

Kramer (1997) suggested applying relevant theories to generate clear definitions of concepts related to caregiving. She suggested the use of a caregiver adaptation model that considers both caregiver and care recipient characteristics, available resources in the caregiving situation, and assessment of role strain to understand both positive and negative effects of caregiving.

Related Terms and Issues:

Caregiving is a complex multilayered concept and has various key factors that need to be identified. In the past, most of the research in this area was limited to the concepts of burden and stress related to caregiving and areas with negative connotations were investigated. Kramer (1997) and Farran (1997) credited this focus on the negative aspects of caregiving to be a result of the stress and adaptation theoretical perspective. As a result of this there is limited research into the positive aspects of caregiving and definition of these terms and concepts.

Process of Meaning: Knowledge is limited about the process by which families create meaning in caregiving (Ayres, 2000). Extensive research in the early 1990's by Nolan, Grant and Ellis (1990), Motenko (1989), and Farran, Keane-Hagerty, Salloway, Kupferer, and Wilkin (1991) suggested that meaning plays a significant role in caregivers' affective response to caregiving. Farran suggested applying an existential paradigm to improve the concept of stress and adaptation perspective. She argued that the paradigm could add concepts related to "the management and discovery of meaning" (p.254). The complexity of caregiving is deepened by the meaning and purpose the caregiver ascribes to it (Gitlin, Corcoran, & Leinmiller-Eckhardt, 1995). Folkman in 1997 used the stress and coping

framework to study spouse and partner caregivers dying from HIV- AIDS. It was found that when the caregivers searched and found meaning, they were able to encounter positive psychological states even in extraordinary stress.

Interdependency: While considering dependency in a caregiving context it is essential to identify it as being a multidimensional construct (Kahana & Young, 1989). Dependency has increasingly been recognized as a coping mechanism or a mode of gaining passive control over ones environment (Kahana , Kahana & Riley, 1989; Kahana & Young,1989 ; Goldfarb, 1969). This is reinforced when Peloquin (1998) said “Activity selection and treatment goals must have personal meaning for the patient; meaningful choice is essential because it fosters personal control.” This outlines the significance of activity as a mode of effectively using part of the normal caregiving experience toward successful treatment of the client.

According to Kahana and Young (1989) interdependency in a caregiving relationship may exist because of three reasons: a) there is ongoing reciprocity during the caregiver experience, b) there is anticipation of future reciprocity and c) there is acknowledgement of past reciprocity. Hasselkus (1989) enumerated three goals of caregiving: 1. to get things done. 2. to assure care and health of the care recipient and 3. to assure care and health of the caregiver. Thus the process of reciprocity and interdependence serves to benefit both the caregiver and care recipient.

Motivation: Farzan (1991) listed characteristics of a healthy functional family. Clear delineation of family member’s roles and functions with division of labor, open lines of communication, and a flexible but stable power system were the key characteristics.

Attachment has been identified as a motivating factor to provide care as it represents an enduring bond that promotes contact and communication. The forging of family relationships to develop partnerships was suggested by Deci and Ryan (1985) in their self determination theory. In this theory an autonomy supportive environment is one that facilitates motivation to adhere to lifestyle change (Williams, Deci & Ryan, 1998).

Sociologists and anthropologists have focused on distinct concepts of family solidarity and cohesiveness in explaining assistance provided to elders. Attachment may enhance the quality of interaction. Competence coupled with motivation to help is required to sustain a successful caregiving relationship (Adams, 1968).

Roles-gender and family: Providing care to a long term-disabled relative can affect caregiver roles in many ways. As a spouse if a woman is the caregiver she has to readopt a role of caregiving that she gave up when her children grew up and may now have to handle work in the house originally done by her spouse. The literature suggests that men and women approach this role using different models. Fitting, Rabins, Lucas, and Eastham (1986) found that women tend to use the parent –infant model while men use the task–oriented model found in the workplace. Older wives find caregiving chores for dependent husbands particularly restrictive of their social relationships (Noelkar & Wallace, 1985). This would impinge upon leisure activities and thus prevent successful participation in everyday life. Hasselkus (1989), keeping this in mind, suggested that the therapist may be able to collaborate with the caregiver and thus be able to restructure time spent caregiving and provide information for respite and support and identify activities of daily living goals together to improve life satisfaction and decrease caregiver

strain. Stroller and Pugliesi (1989) suggested that *other* roles assumed by a caregiver may enhance the caregiver's quality of life and provide support.

Temporal Dimensions: Caregiving is part of a process of change over time; and dyadic interactions are likely to be affected by the course of illness, the upward or downward trajectory of the patient and the changing life circumstances of the caregiver (Kahana & Young, 1989). Schulz (1990) said, "One of the major shortcomings of caregiving literature is that individuals in very different stages of a disease process are combined and treated as a homogenous group" (p.35). The process of adaptation across the course of each illness is different. However research pertaining to this process of change over time specifically to any one type of diagnosis has not been studied and hence presents a gap in current research where the process of change over time should be a key issue.

Support through family and friends: Evans, Bishop and Ousley (1992) suggested that social support from friends and family can help decrease the caregivers' stress. Evans and Bishop (1990) also suggested education and family counseling early in the caregiving process so as to decrease caregiver stress.

Informal Caregiving and Occupational Therapy literature

Occupation: Since the conception of the profession, occupational therapists have been aware that activities need to have a certain quality to make them therapeutic (Meyer, 1922). Hasselkus (1993) identified what it was to be a caregiver for a person who was dying and how the caregiver through active engagement (through occupations) in the helping process, actively disengages in preparation for impending death. She also stated

that care giving could serve as a means to enter, understand and share the dying experience and identified 5 stages of professional growth for health care workers. Hasselkus, Dickie, & Gregory (1997) wrote 'Geriatric occupational therapy: The uncertain ideology of long term care'. Analysis encompassed three component areas: change (doing), community (interpersonal relationships) and craft (what the Occupational Therapist did and reactions to the act of doing). Tuans' Framework of the good life was used as a support for these themes in analysis. This helped understand and accept the older clients move toward death at the same time that we facilitate return to functional independence and continuity. This process can be applied to clients with chronic illness like stroke as a progressive way of effectively bringing about change in the client and effective treatment techniques simultaneously.

Nelson (1988) identified how occupation can be used in practice by defining occupation as a relationship between occupational form and occupational performance. The form is the format of the activity and the performance is the doing. He advocated identifying activities that the stroke survivor and caregiver performed prior to the illness that impacted their lives and using this knowledge as a framework to encourage doing of activities that are significant to the client. The University of Southern California (USC) faculty and staff have developed a concept of occupational science that consisted of form, function and meaning (Yerxa, Clark, Frank, Jackson, Parham, Pierce, Stein, & Zemke, 1990). They define form as the "directly observable aspects of occupation", function as the "ways in which occupation serves adaptation", and meanings as "the significance of occupation within the context of real lives and in the culture" (p.17).

Thus occupation through the process of informal caregiving has been identified and studied in depth through these studies and work done by scholars in the field who substantiated the use of occupation as the core of the profession and an integral part of informal caregiving. As an occupational therapist while dealing with the concept of meaningful occupations, it becomes necessary that we address the occupations of the caregiver and allow them ways of dealing with and participating in occupations significant to them. These definitions of occupation serve as a foundation to identifying meaning in the client's life based on occupations they were involved in and how occupation as a therapeutic modality can be used to develop rapport with both the client and caregiver.

Routine and Habit: Corcoran (1992) identified gender differences among spousal caregivers of dementia patients. She identified environmental modifications to help in caregiving and assist caregivers to develop a routine for themselves and encourage daily predictable routine. Reilly believed that habits were the foundation of temporal adaptation (Keilhofner, 1977; Keilhofner & Barret, 1998). "Habits are the basic structures by which daily behavior is ordered in time and psychological health is maintained without habit structure, an individual's daily life would be a chaotic series of disjointed events" (Keilhofner, 1977, p.239). Keilhofner, Barris and Watts (1982) proposed that an individual with adaptive habit patterns is balancing demands within the internal system and the external environment in a wide variety of situations. Through routine and being able to know what to expect, the client or caregiver is in a position to deal with changes and transitions in a progressive way and help adapt to the chronic illness their spouse

faces and the new challenges that arise as a result. This leads to stepping stones in treatment planning when the therapist can now identify specific habits and routines with the purpose of restoring and maintaining caregiver health.

Meaning: Gitlin, Corcoran and Leinmiller-Eckhardt (1995) used an ethnographic framework to identify meaning in the life of the caregiver, the way in which caregiving was provided, and the aspects of caregiving that were problematic to the family member. The ethnographic view of informal caregiving that was used represented a cultural activity that had meaning to its participants and reflected the caregiver's values and beliefs about the care recipient and his/her disability. This was followed up by a study that emphasized the importance of the role of therapeutic interaction for engaging family caregivers of elderly persons with disabilities in occupational therapy. Four types of caregiver-therapist relationships were identified: Caring, Partnering, Informing and directing. It was found that including the caregiver in goal formation and plans for their care recipient encouraged caregiver input, meaningful participation, and overall satisfaction (Hasselkus, 1988; Peloquin, 1990), thus strengthening the ability of the therapist to effectively work with and treat the party involved through active involvement of the caregiver. Toth-Cohen (2000) dealt with four therapists who were interviewed to identify their reflections on practice and views on occupational therapy services for caregivers. After analysis, 4 themes were identified. They were: Setting, Timeline, Intervention focus and interactions. These themes helped identify practice contexts requiring collaboration between OT's and caregivers to enable effective treatment.

Mattingly and Fleming (1994) have asserted that a primary and challenging clinical reasoning in occupational therapy is distinguishing the nature of good for each particular client. Treating each client as an individual empowers the therapist to make a more effective treatment plan that enables the caregiver to be in tune with what needs to be done, what can be done and the most effective way to accomplish it. Yerxa (1979) spoke to how occupational therapy's use of 'meaningful' and 'purposeful' activity places value on the patient's view of meaning. She emphasized the importance of creativity, meaning and satisfaction that was determined by the person's life experiences. Fidler (1981) stated that the person independently weighs certain activities and tasks to achieve mastery and competence so as to attain intrinsic gratification, pleasure and satisfaction from doing those activities independently.

Nelson, (1988) described meaningfulness in its relation to occupational form.

Meaning or meaningfulness is the term to be used in labeling the individual's interpretation of the occupational form. Here the meaningfulness of an occupational form refers both to the perceptual sense it makes to the individual as well as to the cognitive associations elicited in the individual.

We can describe an occupational form in terms of the presence or absence of meaningfulness, in terms of its degree of meaningfulness, and in terms of the types of meanings assigned to it by an individual. The meaning of the occupational form to an individual may or may not conform to sociocultural norms. (p.635)

This allows the occupational therapist to be successful in accomplishing the task of enabling the caregiver to participate in meaningful occupation to him/her as an individual and thus enable them to move to a new state of healthfulness.

Outside the profession there is insufficient research done on the concept of 'meaning of caregiving'. Preexisting knowledge in occupational therapy can add to the emerging area of research and help other professions like nursing develop treatment that includes the context of meaning in their treatment plans.

Environment: Corcoran and Gitlin (1996) wrote on how home based interventions designed with use the environment to decrease behavioral problems help caregivers of people with dementia function better and decrease stress. Their intervention was based on the framework of a competence-environmental press model and the principle of collaboration. Performance and impact have been mentioned by researchers in the profession while discussing the significance of environment and its role in effective treatment. Reilly (1962) stated "Man must develop and exercise the powers of his CNS through open encounter with life around him" (p.6). Howe and Briggs (1982) said how as Occupational Therapists we are concerned with helping clients interact with the environment, adapt and change it with relation to their immediate setting, the social setting beyond it and the individual so as to bring about ecological adaptation. West (1989) felt that the client is satisfied best when he/she is engaged in an activity that meets the clients internal drives and stressed on how performance was based on an appropriate fit between client and environment as well. Occupational Adaptation sees the environment as an element in which occupation occurs and this imposes a demand for

mastery. This enables effective performance of occupation and thus brings about successful adaptation.

Hope: Callahan eloquently (1988) says

All things may be endurable if the demands are finite in depth and time.

But a future that offers no exit at all, even if the burden on an everyday basis is not utterly overwhelming, can be an obvious source of sadness and depression...No burden can be greater than trying to cope with a future that promises no relief (p.325).

Thus the more recently explored concept of hope in OT literature becomes significant so as to prevent such a mind set and even situation from developing and allow for effective methods of dealing with the situation at hand. Neuhaus (1997) defines hope as a life force for achieving future good and which can include six dimensions: affective, cognitive, behavioral, affiliative, temporal and contextual. Spencer, Davidson, and White (1997) identify hope as having both cognitive and emotional dimensions. The cognitive aspect allows for setting goals and testing feasibility of plans. They have identified hope as being dialectic between limits and possibilities. The concept of hope is in direct contrast to the concept of helplessness. By taking some form of action toward the situation, hope is instilled and some sort of action will result (Magill & Vargo, 1997). Action through meaningful occupation and development of coping techniques will lead to the formation of effective adaptive processes leading to healthier caregiver lives.

Adaptation: As mentioned earlier caregiving is considered an *adaptive arrangement* in the face of serious or chronic illness (Kahana & Young, 1989). Caregiving is part of a process of change over time, and dyadic interactions are likely to be affected by the course of illness, the upward or downward trajectory of the patient and the changing life circumstances of the caregiver (Kahana & Young, 1989). This stresses the need for more research on illness and its effect over time. This dissertation hopes to identify and explain this process with relation to stroke survivors and their spousal caregivers.

As caregivers, the process of adaptation would be best brought about by the family who interact continually with the care receiver and thus achieve continued participation in life and involvement in daily tasks and roles. While caregiving for a family member, there is social construction of one's life continually as a life long process in which maintenance and transformation occur in daily interactions (Charmaz, 1983; Gubrium, 1976). Adaptation is a frequent subject of occupational therapists (Schkade & Schultz, 1997), as previously discussed by Meyer (1922), Reilly (1962) and American Occupational Therapy Association (1979). Adaptation is a change over time as a result of environmental interaction. The expression of time can be understood in terms of evolutionary time period, ontogenesis, or immediate learning (Montgomery, 1984)

Schkade and Schultz (1992) have studied the concept of adaptation in great detail and refer to it as "The process through which the person and the environment interact when the person is faced with an occupational challenge calling for occupational response, reflecting an experience of relative mastery." King (1978) identified adaptation as being a response to stress. She identified four characteristics of the adaptive process:

1) the person adapts to and acts on the environment. 2) demands in the environment calls for adaptation 3) adaptive responses are organized subcortically 4) adaptive responses are self-reinforcing.

Through the research of Schkade and Schultz (1997), ten core concepts on adaptation were identified from the occupational therapy literature to form a strand on adaptation:

1. There is an innate need to affect the environment.
2. Adaptive facility and environmental facility are predictive of person-environment transactions.
3. There is a need to experience mastery in the person-environment transaction.
4. Person-environment transactions occur in the form of occupation.
5. Perception of mastery results from goodness of fit between adaptive facility and expectation.
6. Demand for fit occurs when the 'fit' is adequate.
7. Adaptation is a form of change that occurs in: sensorimotor, cognitive, or psychosocial skills, adaptive responses, physical, social or cultural expectation demands.
8. Mastery over expectations yields satisfaction.
9. The experience of joy resulting from being a successful agent of change fuels the urge to affect the environment.
10. Maladaptation is an unsuccessful attempt to meet expectations (p.469).

These strands speak of both the interactive and holistic nature of adaptation and the profession of occupational therapy. Adaptation has also been viewed over time in the Occupational Therapy literature (Frank, 1996: Spencer, Davidson, & White, 1997).

First, adaptation is an interactive process that occurs between an organism and its environment. This conception will prompt us to think about major life changes, not as something that occurs solely within the individual, but as a change in the relationship between the person and the environment which may involve some changes in both entities and in interactive processes between them. Second, adaptation is a process that is inherently cumulative over time in which the past shapes the future.

(Spencer, Davidson, & White, 1997, p. 527).

When looking at adaptation we need to identify both the immediate outcomes and the outcomes that will evolve within the adaptive repertoire over time. The temporal component in terms of adaptation is lacking research both within occupational therapy literature and outside it. Considering caregiving along a timeline at various time points for a homogenous diagnostic group and following through over time is an area that needs to be investigated.

Gaps in current knowledge: Thus the scope of occupational therapy has evolved by identifying the different associated themes prevalent in this discussion. The literature in occupational therapy is very limited in the area of caregiving of dementia patients and there is no literature on the process of change in the caregiving process over time.

Samples involving mixed racial groups and different research designs are absent from within the profession's literature on caregiving. The impact that time has on the caregiving process, the adaptive process that occurs among various racial groups and caregiving for different racial groups are areas that need specific attention within the profession.

Within the profession there is insufficient research in areas of how we as therapists 1.) address the occupations of the caregiver; 2.) measure change occurring within the family as a result of change because of care recipient illness; and 3.) how to bring about meaningful participation in daily life.

Thus it is essential for this gap to be bridges through research in this specific area of informal caregiving to contribute to the professions knowledge base.

CHAPTER 3

The Impact of Informal Caregiving on Occupational Therapy:

Practice Review and Analysis

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Informal caregiving is becoming a recognized area of practice that requires provision of services by occupational therapists. This article reports the results of a literature review with the aim of: 1) identifying significant themes that directly relate to the core philosophy of occupational therapy (OT); 2) evaluating the role of occupational therapy in informal caregiving and 3) providing information on similar themes described by other disciplines. Themes that emerged from the review included: meaning and motivation, caregiver occupations, gender roles, routines and habits, environmental modification and the adaptative process. Little research was reported in terms of longitudinal studies and mixed racial groups.

Key Words: informal caregiving, occupational therapy, review

Informal caregiving is a complex, multi-layered concept. This article attempts to identify the various components of informal caregiving from an occupational therapy (OT) perspective with emphasis on both the treatment perspective and the role of the caregiver in treating the care receiver. This paper provides a review and analysis of published studies that examine informal caregiving for older adults with chronic disability from an OT perspective. The results of the review followed three basic steps: a)

identification of significant themes that directly relate to the core philosophy of OT (e.g. occupation, meaning); b) evaluation of the role of occupational therapy in informal caregiving (e.g. the occupational therapists role in caregiver selection of appropriate occupations); and c) a comparison of literature from other disciplines with OT (e.g. nursing, social sciences).

Background and Significance

Becoming a caregiver may be a sudden and unexpected challenge. There are two types of caregiving: formal and informal. Formal care is professionally rendered. Informal caregiving is unpaid care given voluntarily to ill or disabled persons by their family and friends (Health and Human Services, 1998). Various informal groups, such as marital, kin, friends and neighbors, deliver unique services and, because of their more internalized commitment, are more likely to make great personal sacrifices to maintain services required for the care receiver, and thus, suffer from caregiving burden (Anderson, Anderson, & Kottke, 1977; Zarit, Orr & Zarit, 1985). It was formerly thought that caregiving was predominantly a woman's issue, but men now make up 44% of the caregiving population (National Family Caregivers Association [NFCA], 2000). Who becomes a caregiver is dependent on the living arrangements of the care recipient (Penrod, Kane, Kane, & Finch, 1995). If married, the spouse or significant other becomes the primary caregiver; the next possibility is usually the adult child. According to Penrod and his colleagues, secondary helpers may be present to assist the primary caregiver if the primary caregiver is not the spouse.

Why should informal caregiving be studied? By the year 2007, the number of caregiving households in the U.S. for person's aged 50+ could reach 39 million (National Alliance for Caregiving and the American Association for Retired Persons [NAC/AARP], 1997; Health and Human Services, 1998). Arno (2002) estimated the value of services family caregivers provide for 'free' to be \$257 billion a year. These numbers provide an estimate of the magnitude of caregiving and the economic impact on the country. As the numbers of aging, informal caregivers continue to increase, it seems essential to review OT literature to identify strengths and current gaps in meeting the needs of this population.

Methods

Articles related to caregiving and OT were retrieved from MEDLINE and Cumulative Index to Nursing and Allied Health Literature, for the period of 1982-2005. Keywords used were: informal caregiving, OT, environment, occupation, motivation, meaning, and spouse. Articles were selected using the following criteria: a) written in English; b) published in peer reviewed journals; c) research studies or review papers; d) involved informal caregiving; and e) related to OT. Articles were also hand searched from the lists of the search engines mentioned above.

Results of the Search Strategy

Eleven studies written by an occupational therapist were identified. Six of the eleven studies used qualitative methodology. The findings from all eleven studies are summarized in Tables 1, 2 and 3. Table 1 consists of a summary of intervention studies

related to informal caregivers; Table 2 consists of a summary of descriptive studies related to informal caregivers; Table 3 consists of qualitative studies that describe other areas of informal caregiving and OT.

Table 1 *Summary of Intervention studies related to occupational therapy and informal caregivers*

First author and year	Methods	Results
Gitlin, 2002	Experimental study Occupational Therapy intervention using Environmental Skill- Building Program (ESP) Regression Analysis	Reimbursement applications Promoting and maintaining (CG) ability and provide CG with skills and support to deal with behavior problems through individualized environmental strategies
Gitlin, 2003	Experimental study Analysis of Covariance (ANCOVA) used as statistical measure	Caregivers receiving intervention reported less upset with memory related behavior, less need from assistance from others, and better affect. Has added benefits for women and spouses

Table 2 *Summary of Descriptive studies related to occupational therapy and informal caregivers*

First author and year	Methods	Results
Corcoran, 1992	Descriptive Description of home based intervention for caregivers of dementia patients	Enhance caregiver use of environment to solve care recipient problems and improve CG health Documentation forms used as evaluation tool Development of collaboration and client centered treatment
Gitlin, 1996	Descriptive Description of home environmental intervention	Improve caregiver well being Improved ability to deal with dementia behaviors Enhance ability to provide daily care and possibly avoid/ delay institutionalization
Corcoran, 2002	Descriptive Description of ESP	ESP approach to wandering, catastrophic reactions and caregiver concerns in dementia patients

Table 3 *Summary of Qualitative studies related to occupational therapy and informal caregivers*

First author, year	Methods	Results
Hasselkus, 1988	Ethnographic Interview	Identified themes for meaning Importance of effective collaboration between professionals and caregivers
Hasselkus, 1993	Autoethnography	Active engagement by CG in the dying process helps the CG to actively disengage in preparation for impending death. Identified 5 stages of professional growth for health care workers
Clark, 1995	Grounded Theory: open and axial coding	Emphasizes the importance of the role of therapeutic interaction for engaging family CG's of elderly persons with disabilities in OT.
Gitlin, 1995	Ethnographic Study	View lay practitioner as a partner in caregiving Intervention strategies evolve from interaction
Toth-Cohen, 2000	Qualitative Study, analyzed using QSR N6	Raises questions about how practice contexts influence delivery of occupational therapy (OT). Identifies practice context requiring collaboration between OT and caregiver
Hoppes, 2005	Autoethnography	Better understanding for future research on family caregiving using grounded theory. Significance of occupation to deal with grief

Discussion

Using an in-depth review, various themes significant to OT emerged. Several significant themes: meaning and motivation, occupation, gender role, routine and habit, environment, and adaptation were discussed. The following is a discussion of those themes.

Meaning and motivation

Within the profession, meaning has been a constant force motivating clients in treatment. The occupational therapist's ability to apply narrative reasoning in understanding the caregiver's meanings and to support the creation of new life stories has made the profession invaluable for family care (Mattingly, 1994; Schell, 2003). This section focuses on articles that target: caregiver's concept of meaning, the meaning attached to caregiving and identification of therapists' roles in helping caregivers identify meaning. Florey (1969) discusses intrinsic motivation stating that occupational therapists select activities that interest the client, and in doing so, assumes the client would experience satisfaction to sustain performance of even painful activity. Hasselkus (1988) carried out interviews with informal caregivers that led to the development of five organizing themes of meaning; sense of self and managing of future, fear or risk, and change in role and responsibility. These five themes came together to form a framework of reflective practice for the informal caregiver. It was found that including the caregiver in goal formation and plans for the recipient encouraged caregiver input, meaningful participation, and overall satisfaction (Hasselkus, 1988; Peloquin, 1990), thus strengthening the ability of the therapist to effectively work with and treat the client

involved by actively involving the caregiver. Gitlin, Corcoran and Leinmiller-Eckhardt (1995) used an ethnographic framework to identify meaning of caregiving, the way in which caregiving was provided, and the aspects of caregiving that were problematic to the family member. They concluded that the complexity of caregiving is deepened by the meaning and purpose the caregiver ascribes to it.

Toth-Cohen (2000) interviewed four therapists who reflected on practice and their views of OT services for caregivers. Four themes were identified: setting, timeline, intervention focus and interactions. These themes helped identify practice contexts requiring collaboration between occupational therapists and caregivers to enable effective treatment. Treating each client as an individual empowers the therapist to make a more effective treatment plan that enables the caregiver to accomplish work and successfully maintain occupational roles. Yerxa (1979) spoke of how OT's use of 'meaningful' and 'purposeful' activity places value on the caregiver's view of meaning. She emphasized the importance of creativity, meaning and satisfaction that was determined by the person's life experiences. Fidler (1981) stated that the person independently weighs certain activities and tasks to achieve mastery and competence to attain intrinsic gratification, pleasure and satisfaction from doing those activities independently. Identification of occupations significant to the caregiver provides meaningful tools to enable the caregiver to participate in occupations to him/her as an individual and thus enable them to move to a new state of healthfulness.

Outside the profession, extensive research was done in the early 1990's by Nolan, Grant and Ellis (1990), Motenko (1989), and Farran, Keane-Hagerty, Salloway, Kupferer,

and Wilkin (1991) who suggested that meaning plays a significant role in the caregiver's affective response to caregiving. Farran (1997) suggested applying an existential paradigm to improve the concept of stress and adaptation perspective. She argued that the paradigm could add concepts related to "the management and discovery of meaning" (p.254). Pearlin, Semple and Turner (1988) and Folkman in 1997 used the stress and coping framework to study spouse and partner caregivers dying from HIV- AIDS. It was found that when the caregivers searched and found meaning, they were able to encounter positive psychological states even under extraordinary stress. Though motivation and meaning have been clumped together, the concept of meaning answers the question about why caregiving happens and the motivation that supports it. Treatment can then be developed that fits the value system of the caregiver and the family unit, thus providing holistic care.

Occupation

As a profession OT, utilizes occupations as a foundation to identify meaning in the client's life based on occupations in which they were involved. Christiansen (1995) has defined occupation as "the ordinary and familiar things that people do everyday" (p.1015). In informal caregiving, occupation serves the same purpose and can be used as a modality to help caregivers in treatment of their family member, and to help the caregiver cope with the process.

Since the conception of the profession, occupational therapists have been aware that activities need to have a certain meaning attached to them to make them therapeutic (Meyer, 1977). Hasselkus (1993) identified what it was to be a caregiver for a person

who was dying and how the caregiver by active engagement (through occupations) in the helping process actively disengages in preparation for impending death. She also stated that caregiving could serve as a means to enter, understand and share the dying experience. Hoppes (2005), a caregiver for his dying father, through an autoethnography identified occupations as a therapeutic tool to address the emotional aspect of caring for a family member. These articles bear testimony to the use of occupation as a therapeutic tool for caregivers.

Nelson (1988) identified how occupation can be used in practice by defining occupation as a relationship between occupational form (format of the activity) and occupational performance (doing the activity). The University of Southern California (USC) faculty and staff have developed a concept of occupational science that consists of form (directly observable aspects of occupation), function (ways in which occupation serves adaptation) and meaning (the significance of occupation within the context of real lives and in the culture) (Yerxa et al., 1990). These descriptions of occupations substantiate the application of OT as a treatment strategy for the caregiver during the caregiving process. As occupational therapists addressing the concept of meaningful occupations for clients, it is necessary that we address the occupations of the caregivers and facilitate ways for them to participate in occupations significant to them.

Gender Roles

This section describes articles that address differences in caregiving based on gender, models that have addressed these differences, and changes in the male-female role because of caregiving. Providing care for a relative with a long term disability can affect caregiver roles in many ways, some influenced by gender differences. If a woman is the spousal caregiver she may have to assume the caregiving role that she gave up once her children were grown. Furthermore, she may have responsibility for housework originally done by her spouse. Corcoran (1992) reviewed the literature about gender differences among caregivers of clients with dementia and found two forms of caregiving based on gender differences. The task-oriented models of caregiving (completion of caregiving tasks in the most efficient manner) found in the workplace was typically used by husbands and the parent-infant model (caregiver's total responsibility for the care and nurturing of the care recipient) was typically used by the caregiving woman (Fitting, Rabins, Lucas, & Eastham, 1986). Female caregivers reported more psychiatric symptoms like depression than their care recipients and provided more hands on care (e.g. responsibility, number of tasks) (Yee & Schulz, 2000). Male caregivers, on the other hand, sought more assistance from family members and other informal services than women but showed more objective burden (Neal, Ingersoll-Dayton, & Starrels, 1997; Schulz, O'Brien, Bookwala, & Fleissner, 1995). This identifies area in which men and women caregivers differ and provides occupational therapists with a better understanding of them.

Routine and Habit

“Habits are the basic structures by which daily behavior is ordered in time and psychosocial health is maintained...without habit structure, an individual’s daily life would be a chaotic series of disjointed events” (Kielhofner, 1977, p.239). Caregiving is a complex process, and routine is an integral component to implementing effective treatment techniques. Corcoran and Gitlin (1992), in their research on dementia management, implemented an intervention based on environmental modifications. This intervention enabled caregivers to develop a routine for themselves and to encourage a daily predictable routine for the care recipient. The psychometric properties of the Task Management Strategy Index (TMSI), was studied to identify actions taken by caregivers to simplify everyday care activities for clients with Alzheimer’s disease. Higher use of task strategies was associated with higher education and helped identify the caregivers use of specific behavioral actions to cope (Gitlin et al. 2003). Miller and Butin (2000) defined care management activities as “those concrete, specific daily activities that the caregiver carried out with an impaired person to promote comfort, safety, and efficiency for both” (p. 86). Routines assist the caregiver in dealing with changes and transitions. It also helps the caregiver adapt to the chronic illness their spouse faces and the new challenges that arise as a result. Identifying caregiver routines aids the therapist in treatment planning with the purpose of restoring and maintaining caregiver health.

Environment

Occupational therapy intervention models provide principles and guidelines to home management and modification. This section describes articles that use these

principles to help caregivers achieve better outcomes. Corcoran and Gitlin (1992) researched home based interventions designed to manage the environment in order to decrease behavioral problems by caregivers of people with dementia. Their intervention was based on the framework of a competence-environmental press model (Lawton, 1989; Lawton & Nahemow, 1973) and the principle of collaboration. This work was expanded on in 1996 when Gitlin and Corcoran proposed different levels of environmental modification based on the stages of dementia. Potential caregiver outcomes were multifaceted ranging from increased knowledge of person-environment fit, increased management of dementia, decreased objective/subjective burden and increased feelings of mastery/efficacy. The Environmental Skill Building Program (ESP) was put forth as a standardized yet individualized OT service that empowered caregivers to identify and resolve dementia management issues (Corcoran et al., 2002). A six month analysis of ESP outcomes demonstrated improvement in caregiver well being and objective and subjective burden. This led to improved sense of mastery and less need for assistance from others for caregiving duties (Gitlin et al., 2003). Performance and impact have been mentioned by researchers in OT when discussing the significance of environment and its role in effective treatment. Reilly (1962) stated “Man must develop and exercise the powers of his central nervous system through open encounter with life around him” (p.6). West (1989) stated that the client is satisfied best when engaged in an activity that meets the client’s internal drives and stressed that performance was based on an appropriate fit between client and environment.

Safety and cost have been predominant issues in areas outside OT while studying environment and caregiving. Studies on home environments have focused on caregiver application of environmental modifications to cope with safety primarily (Olsen, Ehrenkrantz, & Hutichings, 1993; Pynoos & Ohta, 1991). A randomized controlled study of home modifications for the frail elderly showed reduced long term care costs and delayed relocation to institutions among the treatment group of frail elders in the study (Mann, Ottenbacher, Fraas, Tomita, & Granger, 1999).

As stated by Howe and Briggs (1982), occupational therapists help clients interact with the environment, adapt and change it with respect to their immediate setting, and the social setting beyond it, to bring about ecological adaptation. Increased attention to the caregiving environment is warranted to address issues such as reduction of care costs, effective caregiver performance, decreased caregiver strain and improved mastery of the caregiver's environment.

Adaptation

The concept of adaptation as noted by various theorists and material in the caregiving literature such as Schkade and Schultz (1992) who have studied the concept of adaptation in great detail. They refer to it as person - environment interaction when the client is faced with an occupational challenge calling for an (occupational) response that reflects an experience of relative mastery. Adaptation has been viewed as an organism-environment interaction that involves changes in both entities and is interactive over time (Spencer, Davidson, & White, 1997). Corcoran and Gitlin (1992, 2002) and Gitlin et al (1996, 2002, 2003) through their work on environmental modification and development

of routines, have enabled caregivers to adapt to the caregiving role and facilitate better outcomes for both the caregiver and care recipient. Hasselkus (1994) describes a process of return to life for both the caregiver and care recipient as a gradual convergence over time to familiar daily patterns, phasing out unusual and unfamiliar routines and activities engaged in during the illness. Mattingly (1994) considers therapists to be “transporters” (p.84) because they help clients find their way back to the real world. Toth – Cohen in 2000 supported this statement through her research, where she identified the roles of occupational therapists providing intervention for caregivers as a new practice area for OT where their services help to make intervention more effective.

Adaptation can also be understood as a change over time as a result of environmental interaction. The expression of time can be understood in terms of evolutionary time period, ontogenesis, or immediate learning (Montgomery, 1984). Adaptation has also been viewed over time in the OT literature (Frank, 1996; Spencer, Davidson & White, 1997). Caregiving is part of a process of change over time; and dyadic interactions are likely to be affected by the course of illness, the upward or downward trajectory of the patient and the changing life circumstances of the caregiver (Kahana & Young, 1989). Schulz (1990) said, “One of the major shortcomings of caregiving literature is that individuals in very different stages of a disease process are combined and treated as a homogenous group” (p.35). The process of adaptation across the course of each illness is different. However, research pertaining to this process of change over time, specifically to any one type of diagnosis, has not been studied and hence presents a gap in current research where the process of change over time should be

a key issue. When assessing adaptation we need to identify both the immediate outcomes and strategies that will evolve within the adaptive repertoire over time. The temporal component of adaptation has not been studied extensively within OT literature. Considering caregiving along a timeline at various time points for a homogenous diagnostic group is an area that warrants investigation.

Conclusion

The scope of OT has evolved as seen by the associated themes identified in the previous discussion. There is a developing foundation in qualitative research that has addressed areas such as adaptation through death and grief process, the significance of the caregiver as a 'lay practitioner', the identification of the role of OT in the caregiving process, and the significance of meaning to both the caregiver and the therapist. The qualitative studies were predominantly related to environmental modification and promotion of caregiver well being and ability.

The literature in OT is very limited in the area of caregiving of persons with dementia and on the adaptation of caregivers while caring for persons with diseases over time. Samples involving mixed racial groups and different research designs are absent from the profession's literature on caregiving. The impact that time has on the caregiving process and the adaptive process that occurs among various racial groups are areas that need specific attention by the profession. Within the profession there is insufficient research of how therapists address the occupations of the caregiver, measure changes occurring within the family as a result of change because of care recipient illness and thirdly bring about meaningful participation for the caregiver in daily life. Research in

these areas can contribute significantly to the knowledge base and clinical practice of the profession.

CHAPTER 4

A Caregiver Journey: The Process of Recovery after Stroke

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Researchers across disciplines have identified caregiving, and the individual's response to it, as a unique experience, having individual meaning and variation among caregivers (Ayes, 2000; Braithwaite, 1996; Davis, 1992; Haley, Levine, Brown & Bartolucci, 1987; Magai & Cohen, 1998). The meaning of caregiving, or how a person interprets his or her experiences, influences how daily care is provided in the home and how caregivers define their needs (Albert, 1992; Gubrium & Sankar, 1990; Hasselkus, 1988). There is variability in the way caregivers adapt to, and cope with, their experiences depending on their stressors (Corcoran, 1992; Williamson & Schulz, 1993). By the year 2007, the number of caregiving households in the U.S. for person's aged 50+ could reach 39 million (National Alliance for Caregiving (NAC) and the American Association for Retired Persons (AARP), 1997; Health and Human Services, 1998). Arno (2002) estimated the value of services family caregivers provide for 'free' to be \$257 billion a year.

Of the various chronic disabilities that affect people in the United States, stroke affects 750,000 Americans each year. It is the third leading cause of death and a leading cause of profound long term disability in the United States (American Heart Association, 2005). Eighty percent of these stroke survivors return to the community and are dependent on their family for support in various areas of daily living (Han & Haley, 1999; Anderson, Linto, & Stewart-Wynne, 1995). The magnitude of these numbers sheds some light on the value of services family caregivers provide and the importance of this caregiving population to occupational therapy.

In this study, adaptation is a central concept in understanding how the caregiver manages the crisis of a stroke and the care of the spousal stroke survivor. Understanding the client's perspective on adaptation has only recently been studied in occupational therapy research. Adaptation has been viewed as an intrinsic mechanism as discussed by various pioneers in the field of occupational therapy, it has also been viewed as an extrinsic process enhanced by the use of adaptive strategies and equipment. Schultz and Schkade (1997), in their Occupational Adaptation Frame of Reference, proposed that an individual's response to intrinsic and extrinsic factors, if successful, results in "occupational performance with mastery and satisfaction" (p.469). Adaptation has also been viewed over time in the occupational therapy literature (Frank, 1996; Kielhofner, 1977; Spencer, Davidson, & White, 1997).

If adaptation has been successful for the caregivers, then adaptation would translate into effective caregiving and satisfaction with life (King, 1978; Meyer, 1977; Montgomery, 1984, Schultz & Schkade, 1997). Participation in meaningful occupation,

practice for real life situations (Burke, 1984); adaptive equipment (Nordenskiöld, 1994; Sonn & Grimby, 1994), and environmental modifications are adaptive strategies that facilitate adaptation. The caregiving literature in occupational therapy, mostly with caregivers of dementia patients, enumerates the use of adaptive strategies that caregivers employ during the process of caregiving, predominantly environmental modifications (Corcoran & Gitlin, 1992; Gitlin, Corcoran, & Leinmiller-Eckhardt, 1994; Gitlin & Corcoran, 1996; Corcoran et al., 2002; Gitlin et al., 2002, 2003). Life goals and satisfaction are connected to adaptive strategies and is an area that requires further investigation (Clark et al., 1996). As conditions surrounding the caregiving experience are unique for each caregiver, variations in adaptation may be noted individually. A definition of adaptation by Spencer, Davidson, and White (1997) builds a bridge between the external and internal components of adaptation and the significance of time.

First, adaptation is an interactive process that occurs between an organism and its environment. This view of adaptation will prompt us to think about major life changes, not as something that occurs solely within the individual, but as a change in the relationship between the person and the environment which may involve some changes in both entities and in interactive processes between them. Second, adaptation is a process that is inherently cumulative over time in which the past shapes the future. (p.527)

Outside the profession, adaptation is a frequently used concept, viewed from an evolutionary, biological, psychological, or sociocultural perspective (Coelho, Hamburg & Adams, 1974; McCubbin, Boss, Wilson, & Lester, 1980; McCubbin & Dahl, 1976;

McCubbin, Dahl, Lester, & Ross, 1975). In his adaptation model, McCubbin and colleagues (1995) define a number of adaptation oriented components that may help to explain the family's behavior involved in the relational process of adaptation. They are: vulnerabilities (life stressors and change), resources (psychological, family and social), appraisal (culture and ethnicity that give meaning), support (intra-family and family-community), patterns of functioning (elimination, modification and institution of patterns), coping and problem solving\and processes (McCubbin, McCubbin, Thompson & Thompson, 1995). Scholars in the field have identified the need for therapists to identify the variation in adaptation between individuals (Carlson, Clark & Young, 1998; Frank, 1996; Schultz & Schkade, 1997; Spencer, Hersch, Eschenfelder, Fournet, & Murray- Gerzik, 1999). Perhaps by applying McCubbin's model to explain caregiving and adaptation, occupational therapists will be better able to apply theory to real practice and encounters with families.

The purpose of this study was to examine the adaptive experiences of eight spousal caregivers of stroke survivors over a 12-month period of time. Adaptive strategies are identified that illustrate their use as they occurred in the daily lives of the spousal caregivers of stroke survivors.

Methods

Design and Participants

This study used a mixed longitudinal research design integrating both quantitative and qualitative data. The study was a secondary analysis of data obtained from the Committed to Assisting with Recovery after Stroke (CAREs) study which is an

interdisciplinary intervention study funded for a five year period by the National Institute for Nursing Research, National Institutes of Health (NR05316). The stroke survivors and their spouses were randomized into a mild intervention group and a home-based intervention group upon discharge from the hospital or rehabilitation setting. The intervention included education, support, counseling, and skill training by advanced practice nurses, occupational and physical therapists. The data were collected from stroke survivors and their spouses at home at baseline, three, six, nine and twelve months respectively by a nurse who was masked to the group assignment. Data were collected separately from the stroke survivors and caregivers. Caregivers completed paper and pencil questionnaires, while the stroke survivors were interviewed. Each assessment included a taped brief interview regarding their experiences, which was also recorded in separate areas. For the purpose of this study only interview data from caregivers were analyzed, along with the Caregiver Preparedness Scale. The study was reviewed and approved for conduct by the university and hospital review boards.

The study used purposive intensity sampling to include an information rich data set. The data set comprised of eight caregivers, both male and female. The caregivers in this data set were chosen to reflect diversity in gender, age, and ethnicity. (See Table 4) They were also selected to compare similarities and differences in adaptation impacted by finances, time related issues, health conditions of the caregivers, and resources like presence or absence of support systems, engagement in occupation and coping and problem solving through adaptive strategies.

Table 4 *Demographic Information for Caregivers*

Caregiver	Gender	Ethnicity	Age	Occupation	Side of Lesion
Alice	Female	Caucasian	65	Executive Secretary	Right
Brandon	Male	Caucasian	82	Sales Manager	Right
Cody	Male	African American	62	Manufacturing Supervisor	Right
Danielle	Female	Caucasian	59	Professor	Right
Elaine	Female	Asian	60	Retail Sales Manager	Left
Fran	Female	African American	55	House wife	Right
Gillian	Female	Hispanic	51	Caterer	Right
Hannah	Female	Hispanic	41	Advertising Executive	Right

Data Source

Demographic information including gender, age, ethnicity, occupation and side of lesion of the stroke survivor and scores on the Caregiver Preparedness Scale was obtained from the CARES database. Tapes of the interviews with the caregivers were transcribed verbatim (without names) by a transcriptionist. Each transcript was reviewed for accuracy by comparing the transcript to the tape; the transcripts were entered into QSR N6 (Non numerical Unstructured Data Indexing Searching and Theorizing) to assist with data management.

The Caregiver Preparedness Scale is a structured, self-report, written assessment questionnaire with eight items. A Likert scale was used to answer each question, with choices ranging from 0 (not at all prepared) to 4 (very well prepared). All responses from each survey were averaged to arrive at a preparedness score, ranging from 0-4. Reliability was assessed using Cronbach's alpha and ranged from 0.67-0.92 (Archbold, Stewart, Greenlick, & Harvath; 1990).

Data Analysis

The interview data were analyzed using hermeneutic interpretive phenomenology. This research methodology is used when the research questions ask for the meanings of a phenomenon with the purpose of understanding human experience (Patton, 2002). Data analysis meetings were held on a bi-monthly basis. The team included members of the CARES group with backgrounds in nursing and occupational therapy. Multiple readings of the interview transcripts were carried out by the group. These meetings helped establish an understanding of the themes and added depth to the interpretations (Christ & Tanner, 2003). Transcripts were examined simultaneously within themselves and in comparison with each of the caregivers, thus maintaining individuality and still identifying commonalities among the caregivers. The data based was maintained and refined using QSR N6. Trustworthiness of the data was established through analyst triangulation (analysts had backgrounds in nursing, occupational therapy, and public health and were members of the CARES study); and multiple meetings to recode and confirm established themes and patterns in the data. Coding categories were organized into themes and sub themes and examined for patterns. QSR N6 helped in the

development of matrices for identifying themes that occurred at different time points. The credibility and quality of this research was assured through meeting the following criteria: 1) trustworthiness, 2) reliability of coding and pattern analysis, 3) generalizability, 4) objectivity of the inquirer, 5) validity of the data, through the masked nurse practitioner collecting the data (Patton, 2002). Pseudonyms were used for the names of caregivers in the study.

Results

There were 159 informal caregivers in the database, including 119 women and 40 men caregivers. Their ages range from 40.5 to 86 with a mean of 62.5. There are 92 Caucasian, 30 African American, 26 Hispanic and 11 mixed or other races. The eight participants (pseudonyms used) selected to illustrate the adaptation process over time were Alice, Brandon, Cody, Danielle, Elaine, Fran, Gillian, and Harold. The demographic information related to the participants is available in Table 4. The results were both of a qualitative and quantitative nature.

Findings from quantitative tool

The scores of the caregivers on the Caregiver Preparedness Scale are tabulated in Table 5. Scores on the Caregiver Preparedness Scale show an improvement in scores from baseline to three months after caregiving for six of the eight caregivers. No trend was seen in the scores over the following time points, but at the end of the year, seven of the eight caregivers reported an increased score in caregiving preparedness.

Table 5 *Scores from the Caregiver Preparedness Scale*

Time (months)	0	3	6	9	12
Alice	2.25	2.625	2.875	2.875	2.75
Brandon	2.5	2.125	2.25	2.625	3.00
Cody	3.25	3.75	4.00	3.625	3.875
Danielle	3.25	3.75	3.875	3.75	3.75
Elaine	2.25	3.25	2.375	2.625	2.375
Fran	2.75	2.25	2.875	2.00	2.125
Gillian	2.25	4	2.625	3.125	3.5
Hannah	2.125	2.25	2.125	2.375	2.625

Participant Profiles

The following profiles provide a short case scenario of the eight participants and significant themes identified in each of their stories.

Alice

Alice was a 65 year old business woman, who managed the business aspects from home while her husband traveled. When asked about her relationship she said that she had been “married for 40 years”, “we get along O.K” and that “He’s not a real fun person to be with”. She was the primary caregiver for her husband after he was discharged from the hospital; she has since maintained small aspects of the business to keep some income while her husband’s part of the business disappeared. Alice had a great deal of stress

related to time, finances, and feelings of conflict between her husband and her during the past nine months. She seemed hopeful that things would improve.

Brandon

Brandon was an 85 year old retired World War II veteran, married for 59 years. He and his wife were actively involved in church. They had children in Houston and in surrounding areas of the state. When asked about his relationship with his wife he said, “wonderful years together”, “we’ve had good times and bad”, and “she’s a wonderful person”. At baseline he also said that “we continue to hope and pray that her recovery will continue”. Brandon talked about the support he received from the church at the three and six month interviews and how faith and prayer are an integral part of their lives. Brandon indicated at three and six months “I’ve had to learn how to turn on the dishwasher, the washing machine, mop the floors and try to make the beds up and cook”. These were occupations which he had never before performed. He talked at 3 and 6 months about his depression because of the loss of control of the situation and stress because of conflict and dependency of the stroke survivor in daily living activities experienced over the course of the past year.

Cody

Cody was a 62 year old manufacturing supervisor, who had been married for 36 years. He had known his wife since they were four years old. When asked about his wife and their relationship he said “we have our little disagreements just like any other couple does but its nothing major couldn’t be major because we’ve been married 36 years.” At baseline he says “this little set back won’t hold her down. I think she’s going to get past

this and get a lot better.” He talked about the new household activities of which he is now in charge and the time spent taking care of his wife over the course of the past year. He talked about his hope and faith in “believing in God’s plan”, through the course of caregiving for his wife.

Danielle

Danielle and her husband were both university professors at the same school. Danielle was a cancer survivor and had been taken care of by her spouse who is currently the stroke survivor. While talking about their relationship she said “We, we have a very strong relationship and always have had since early in our marriage.” At baseline she said “I think his progress has been absolutely wonderful and, and unbelievable.” However, over the course of the year she talked about the great impact caregiving has had on her health; through the follow-up interviews she commented on the immense amount of time spent taking care of him and how tired she seemed to be all the time.

Elaine

Elaine was a store manager who had cared for her husband not only since his stroke, but since 1984 when he suffered severe heart problems. She, too, has developed medical problems that she has had to deal with while caring for her spouse. When talking about her relationship with him, she said “There are times we get along but there are sometimes we don’t. He doesn’t open up and doesn’t say much.” She also talked about the profound effect caregiving has had on her health, because of combined issues of caregiving and her health. She talked about the dependency her husband has on her to

drive him anywhere, to get his meals ready and her having to deal with her physical condition and her own job and his needs simultaneously.

Fran

Fran was a housewife who complained about not having a social life. When asked about her relationship with her husband she said “I love him very much but his illness has put a strain on both of us.” She talked about his dependency on her for things like fixing his food and getting the TV remote. Throughout the year, she talked about how she coped by taking time out for herself, reading self help and spiritual books, having faith in God and having hope that things would get better.

Gillian

Gillian used to work as a caterer and has been married for fourteen years. When asked about her relationship she said “We’ve never been separated from each other” and “He was a very hard working man and um I love him very much”. Over the course of the year she talked about how depressed she was because of so much change in her life and that her spouse did not seem to want to do much for himself. She talked about how the physical impact of caring for him had seemed to worsen her existing physical condition.

Hannah

Hannah and her husband were both advertising executives in high power jobs. She was the youngest of the eight caregivers at forty one years and had two children age two and five years. They had just relocated and had bought a new home prior to her spouses’ stroke. While talking about her relationship with her husband, she said “He’s probably one of the smartest people I know in the business and the part of our

relationship that I miss the most right now is our ability to talk about just about everything.” At baseline, she said “he’s a fighter” and how her husband was working toward recovery through therapy. She talked about having no support as she was new to the city. At all time points through the one year she was interviewed, she talked about the immense financial impact the stroke has put on the family and the imposition on her time and their relationship

Themes

Components that seemed to impact the process of adaptation were health issues, dependency in daily living activities by the stroke survivors; stress related to time and finances, conflict, reduced expectations of recovery and depression, support and use of adaptive strategies and occupations.

Theme: Caregivers feel vulnerable

Um I, I do feel overwhelmed, right now, I feel overwhelmed with, with what I have to do. What with trying to do the business, wanting him to progress. I’ve got a son getting married and I have to arrange an engagement party.

Vulnerabilities have been defined as “additional life stressors and changes that may undermine or curtail the family’s ability to achieve adaptation in the face of family crisis” (McCubbin, Thompson, & McCubbin, 1996, p.23). Throughout the process of caregiving, the caregivers continually faced challenges. The impact on caregiver health or worsening of already existing conditions because of new activities taken over by the

caregiver was commonly reported. Table 6 represents these vulnerabilities for all the caregivers in this study.

Table 6 *Report of theme Vulnerabilities*

	3 months	6 months	9 months	12 months
Alice	My back hurts No salary He had to go to the bathroom 4 times at night He complains about (me) taking control	Have to spend too much time with him I have to help him dress Not able to get business done	Do not have enough time He says I provoke him	Stress of caring for him Hope and pray things get better
Brandon	She can't drive I've had to learn to cook.... Get depressed Have no control when she feels bad	Have to drive her everywhere I really get despondent I try not to argue when she gets on me	Wasn't talented at caregiving I've learnt to vacuum, mop the kitchen	My health is not as good as it used to be It's been kind of a trying experience
Cody	It's stressful waiting for	We'll get through this	We travel, go out for dinner	No complaints

	Metro		Don't expect	
	She takes up		miracles	
	about 80% of			
	your day			
Danielle	It's(caregiving)	He wasn't	I feel out of	I continue to be
	is an	present	control	exhausted
	unbelievable	emotionally or	Caregiving is a	He continues to
	imposition on my	cognitively	wearing	make progress
	time	There's a lot of	process	Caregiving has
	He can't be alone	physical work		become routine
Elaine	Last 3 months	My health has	My health is	
	have been very	hurt a lot	going down	
	stressful	It was a very	Its stressful for	
	It has really hurt	difficult time	me working	
	my health	for all	and running	
			here and there	
Fran	He needs to be	I've had to learn	I thought he'd	He's doing better
	more	things	be doing more	
	independent	Hope	I feel tired,	
		everything will	overworked	
		be O.K.		

Gillian	I can't bend too much	I get very depressed	I'm diagnosed with many things	I make my husbands breakfast, lunch and everything
	He helps in some activities but less than before	He doesn't want to do much for himself		I couldn't sleep
		He gets into little arguments		
		I'm sick too		
Hannah	...I'm not really in control	I have back problems	See husband as a responsibility	I am angry with him
	...I have no time for me	Loss of income	Receiving	My stress level is through the roof
	Afraid about our finances...	Settled into a routine	payments from	
			Disability	

Sub themes.

Health issues related to caregiving: "... the last three months have been very stressful for me, ...taking care of a stroke patient. It has really hurt my health."

Seven of the eight caregivers had health issues related to caregiving. Four of the eight caregivers complained of health related issues over the span of more than six months. These were caregivers that had pre existing medical conditions like cancer, depression, liver problems, and bladder issues. Over time, if the burden of care is excessive, the caregiver's health may break down, with a subsequent loss of support for the 'patient'

(Van den Heuvel, Witte, Schure, Sanderman, & Jong, 2001). One caregiver, Alice said “...getting the wheelchair in and out of the car is just a hassle. I’ve, I’ve, my back hurts most of the time, my arm,...I have to take a muscle, no an anti-inflammatory...for my arm.” These were multiple examples of health issues related to caregiving for the spousal stroke survivors in this study.

Conflict “...he says I provoke him at times...”

Spousal relationships significantly changed for the caregivers due to conflict over control issues. Alice discussed this issue in detail;

He complains about that night, taking control of everything and I can see where, how he would feel that way because I have had to take control of, of things, of the business and, and so on. So that uh, I think that's what we get into arguments about mostly is when I try to um instruct him on how he should walk and, and um use his, his sling and, and so on.

The lack of motivation and depression on the part of the stroke survivor seemed to be the cause for anger and friction between the couple.

Fran said

He ... when he, I'm gonna say he, well he, he's not obedient ... when I ask him to maybe take a walk or get up out the chair. You can't sit in the chair all day, you got to move and ... he doesn't want to move, that makes me angry. I feel that I'm watching him deteriorate um right before my eyes and there's nothing I can do about it,

These are examples of conflict that were evident in the interviews. Five of the eight caregivers had issues related to conflict and were seen at three, six and nine months interviews.

Temporal changes "...she (spousal stroke survivor) takes up about, I would say at least 80% of your day and night too..."

Temporal issues seemed to be affecting the caregivers in two ways. First, the caregivers mentioned how time consuming the caregiving process was; and secondly, because of caregiving, they had very little time for themselves. Alice stated:

... I have been trying to keep up with one of the clients that we have that I've worked with B. with them so I, I know you know can, can figure it out but, uh it's very time consuming. They're in Europe, it's a big conference, uh I spend early mornings and late night writing e-mails, arranging things. And um it's, it's frustrating for me because I, I'd like to spend all, all my spare time caring for him.

Another caregiver Danielle stated:

Well of course the biggest stress is not the care per say (clears throat) not the responsibility per say, it's not leaving D. per say, it's the accumulation and the unbelievable imposition on my time. Um I anticipated that the demands on my time would be enormous and that I might be resentful, I don't so much feel resentful as I feel (clears throat) overwhelmed at times, as if I just don't know where to go to get a breath of air.

Five of the eight caregivers had issues related to time due to the spousal stroke survivor requiring a great deal of their time which resulted in no time for self. In this study time was an issue between three and nine month time intervals.

Theme: Hope “We will continue to hope and pray that her recovery continues”.

Hope for the future was significant in the caregiver’s life as an adaptive tool. Half the caregivers were initially hopeful of good progress and recovery of their spousal stroke survivors. However, over time they realized that recovery was affected by a variety of things like restrictions in time available to the caregiver, caregiver health, financial responsibilities now taken over by the caregiver, and stroke survivor recovery. In this study hope emerged as a themes among three of the eight caregivers after six months of caregiving for their spouses.

Cody said “... advice that I can give to anybody else, don’t expect miracles overnight, it’s gonna take time. But you can’t give up hope. You gotta keep hoping that things are going to improve”.

Hope has been described as dialectic between limits and possibilities, having both cognitive and emotional dimensions. The cognitive aspect allows for setting goals and testing feasibility of plans (Spencer, Davidson, & White, 1997). This concept of hope needs to be utilized by occupational therapists carefully, so as to maintain the fine balance between reality and possibility and not create a false sense of security, in terms of stroke survivor improvement.

Theme: Adaptation and Support “People have brought food, people have come over and, and have offered to stay with him...”

All but one caregiver involved in this study reported support in one form or another during the caregiving experience over the past year. Support from friends, family, neighbors, church and some formal support through an aide was predominantly mentioned at three and six months time intervals. Table 7 presents the themes and quotes related to support and relationships.

Table 7 Report of theme Resourcefulness and Support

	3 months	6 months	9 months	12 months
Alice	Call the neighbors	Have an aide that comes in		Privilege to part of CARES
Brandon	Support from friends at church	A lot of people praying for her		We appreciate the services from CARES
Cody				
Danielle	People bring food, stay with him	The loneliness is grim	People talk about him, to me behind his back	CARES-thank you for everything
Elaine		We take him for prayers		CARES has been excellent for us
Fran	Nobody to talk			My kids help

	to		Visit grandson
Gillian		Visit family	Daughter helps care
		Thank you	for him
		CAReS	
Hannah	We have no	Eldest	
	support	daughter is a	
		mini CG	

For example, Alice said “He has fallen two or three times....I had to call the neighbors those times ...” Brandon said “I think the support we’ve gotten from our church has been invaluable”. Cody spoke about doing things himself for his wife and felt the more he did the easier it got; while Danielle had people come in with food and others stayed with him while she went for groceries and to have some time to herself. Fran and Gillian were able to call on their children for help, and Hannah talked about having no help except for her six year old daughter who had become a “mini- caregiver”.

Theme: Occupations “...I’m beginning to exercise and I’m beginning to eat better...”

Christiansen, Clark, Keilhofner, and Rogers (1995) defined occupation as “the ordinary and familiar things that people do everyday” (p.1018). Schkade and Schultz (1992) stated that participation in occupation provided a medium for adaptation and promoted the desire to adapt. Occupations seem to have multiple roles in the life of these caregivers either as a way for caregivers to deal with the caregiving process by taking time out for self or having a routine that seems familiar in the changed life situation. New

occupations emerged because of the dependency of the spousal stroke survivors on the caregivers to carry out daily living tasks. Table 8 illustrates the significance of occupations among the caregivers.

Table 8 *Report of theme Occupations*

	3	6	9	12
Alice	We laugh a lot Pray	Go on trips alone without him	We have nothing but good hopes	Made a list for better caregiving
Brandon	We lean on GOD quite a bit	Pray for spouse		My prayers to be able to care for her
Cody	The more I do the easier it gets			The more I do the easier it is
Danielle	Thank God I'm working			
Elaine		I let things slide by watching TV, shopping		
Fran	Take time for self	Don't sweat the small stuff	I go to church and pray	Exercise, eat better, trust God

Music, pray

Gillian	Crying spells	Tell him to do	God is great	Go on vacation
		things himself		
Hannah	I don't get		I find things	Have faith
	God's plan		to occupy him	

One of the caregivers, Danielle said

I'm working and thank God I'm working. I'm only gone out of the house for about six hours on Tuesday and Thursday, and those days while they're a royal pain in the neck, and I don't you know, really look forward to them, those help me feel like me and I have students depending on me and that's a whole different thing from doing physical caregiving, that's just been wonderful.

Caregivers used occupations as a means of taking time for self and involvement in leisure. Alice said "I have my hair colored"; Fran says "I go to church and pray"; and another caregiver Elaine reported:

Like last week on Saturday we all went out and when we came back and uh then he stayed at home because we had taken him out and then I just wanted to be alone, so I just went to the mall and bought myself something, bought my daughter something and I came back.

Participation in occupations that were familiar to the caregivers facilitated a sense of routine. It also allowed the caregiver to develop everyday activities into leisure opportunities. Another way occupation is a significant component of caregiving is through the caregiver helping their spouse in activities of daily living (ADL) and instrumental activities of daily living (IADL). Brandon said “I have to drive her everywhere she goes and she’s a shopper”; Alice said “the biggest problem for me anyways, was his having to go to the bathroom so many times”. Of the eight caregivers, six reported dependency by spouse in ADL or IADL at three months. Dependency in these daily activities continued to be an issue among the caregivers which then impacted time spent caregiving, negatively contributing to the health of the caregivers, and increased their stress.

The themes identified and discussed above illustrate the adaptive experiences of the eight caregivers in the study. Themes that emerged such as vulnerabilities represented the additional stressors that could affect adaptation in the lives of the caregivers or resourcefulness and support as well as occupations related to having time for self became strategies used to help adapt to the new life situation of having a spouse with stroke.

Discussion

The quantitative findings of this study indicate that temporal changes occurred over the course of a year. Scores on the caregiver preparedness scale show an improvement in scores from baseline to three months after caregiving for six of the eight caregivers and an improvement in scores for seven of the eight caregivers at twelve months. The adaptive experience was impacted by pre existing physical conditions the

caregiver had, available support systems, and stress related to finances, changing relationships because of conflict with spouse and lack of time. Of the eight caregivers four expressed hope for progress and recovery in their spouses. Five of the eight caregivers had reduced expectations of recovery in their spouses between six and nine months.

Health Issues: Prevention of injury to caregivers may be addressed by home based interventions and home modifications (Corcoran et al, 2002; Gitlin et al, 2002).

Identification of health issues among caregivers that either preexist or develop during caregiving can be addressed during treatment planning and be approached from a preventative standpoint.

Conflict: The caregivers felt conflict because of the spousal stroke survivors' lack of initiative to do things for themselves, lower levels of recovery than expected and the stroke survivor feeling that the caregiver was taking over their life. Smith, Lawrence, Kerr, Langhorne and Lees (2004), found that relationships changed because of the stroke survivor's apathy, unwillingness to participate and decreased motivation. It has been found that more women report conflicting feelings of resentment toward their impaired spouses, while men reported an improved relationship as a result of caring for them (Corcoran, 1992; Fitting, Rabins, Lucas, & Eastham, 1986). From an occupational therapy perspective this would require more gender specific care management plans to address the issue of conflict while participating in everyday occupations.

Temporal Changes: Research done by Smith et al (2004), had findings similar to this study where caregiving was found to be a relentless process affecting caregiver health of

stroke survivors, restricted participation in caregiver occupations and change in relationships. Identification of these temporal changes is of significance to occupational therapists because formulating a treatment plan will depend on identification of areas that require work simplification, provision of services to allow more time for the caregiver and caregiver education by the occupational therapist related to health services.

Hope: This concept of hope needs to be utilized by occupational therapists carefully, so as to maintain the fine balance between reality and possibility and not create a false sense of security, in terms of stroke survivor improvement and caregiver roles. Developing reasonable hopes for the future is integral as they evolve through the client's experience (Chan & Spencer, 2004). Thus it is imperative as therapists to understand the caregiver's hopes and the possible future outcomes so as to establish a reasonable sense of reality in terms of expectations and recovery.

Support: Support received through resources such as family, friends, and church is representative of adaptive strategies to compensate for decreased caregiving capability and achieve a balance and overcome decreased ability. Family resources (Hill's B factor, 1958) include the use of social support network, such as family, friends, and neighbors and problem solving (Aldous, Condon, Hill, Straus, & Tallman, 1971; Klein & Hill, 1979). These are in tandem with the themes and resources identified and used by the caregivers in this study.

Occupation: Occupational therapy is concerned with creating and maintaining meaningful activities so that the client can maintain health, be functional and obtain satisfaction from it (Primreau, Clark & Pierce, 1989). Participation in occupations that

were familiar to the caregivers facilitated a sense of routine, which was familiar to the caregiver. It also gave the caregiver everyday activities as a means of leisure opportunities and engagement in work that established the caregiver as an individual fulfilling his/ her role, and having an identity besides that of a caregiver for their spouse.

The discussion provides a descriptive overview of the themes that emerged over the course of a year and changes that occurred in the caregiver's life as a result of the stroke.

Conclusion

Implications for Practice

The findings of this study presents the following components: complex interaction between the adaptive process, the factors that make caregiving difficult, and strategies used by the caregiver through the adaptive process like hope, support and resourcefulness, and occupations. The factors that make the caregiver vulnerable identified in this study need to be understood by occupational therapists as existing problems and should be addressed to make the therapeutic process for the stroke survivor more effective and by getting insight into the caregiver's life and the issues that exist for them. Preexisting health issues and those that could evolve need special attention through provision of information and environmental modifications. Conflict should be addressed by making the caregiver aware of the problems related to personality changes following stroke and recovery that is realistic. Identification of support systems will enable the therapist to help the caregiver adapt. Understanding the areas in which caregivers receive and require support is important as it allows the occupational therapist to work more in

tandem with the caregivers needs beyond the therapeutic interaction. The ever increasing need for occupation-based therapy (American Occupational Therapy Association [AOTA], 1999) is emphasized in this study as participation in meaningful occupations for all the caregivers was a motivating factor in the adaptive process. This is reinforced by the caregiver's use of occupations to adapt to the new life situation of caregiving for the stroke survivor.

Qualitative research provided the caregiver's perspective of their lives and routines rather than an outsiders' perspective as seen in medical research (Kleinman, 1988). The longitudinal aspect involved in this qualitative research allowed for depth and richness not found in studies based on large homogenous groups (Chan & Spencer, 2004; Morse, Swanson & Kuzel, 2001). This study provides evidence of the need for longitudinal studies as they provide therapists with insight on the process of adaptation and thus can introduce appropriate services to improve quality of life and treatment to this growing population of caregivers.

Future Research

Adaptation is an ever changing process and with additional challenges of health considerations of the caregivers, time constraints and change in lifestyle. It becomes essential to include identification of meaningful occupations and support systems early in the goal setting phase so as to know what areas need more attention and how to help the caregiver become more competent and strengthen a sense of mastery, competence and thus satisfaction with caregiving.

Future research including a larger sample with additional qualitative and quantitative tools would add to this existing knowledge base. Further study should include persons with different chronic conditions to identify consistencies and differences that may exist based on the illness.

CHAPTER 5

Occupations Lost and Gained: A Caregiver Perspective

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Stroke is the third leading cause of death and a leading cause of profound disability in the United States (American Heart Association, 2005). It affects approximately 750,000 Americans each year. Eighty percent of stroke survivors return to the community and many are dependent on their families for support in activities of daily living (Han & Haley, 1999; Anderson, Linto, & Stewart-Wynne, 1995). These family members then deal with the multiple physical, emotional and psychosocial impairments inflicted by the stroke (Dorsey, & Vaca, 1998). Family members' lives can be disrupted because of the strain of caregiving, forcing them to make major changes in their lives (Bugge, Alexander, & Hagen, 1999). While there is extensive research on caregiving (Dowswell, Lawler, Dowswell, Young, Foster, & Hearn, 2000; Bugge et al., 1999; Low, Payne, & Roderick, 1999; Scholte op Reimer, Rijnders, de Hann, Limberg & van den Bos, 1998), little is known about the experiences of spousal caregiving of stroke survivors, changes in their daily life, and loss of established routines and beginnings of new occupations.

The occupational therapy literature includes studies on the ‘meaning of caregiving, problems encountered during the caregiving process (Gitlin, Corcoran & Leinmiller-Eckhardt, 1995; Hasselkus, 1988), and the occupational therapist’s view of provision of practice and occupational therapy services for caregivers (Toth-Cohen, 2000). While there is literature to support an evidence-based approach that occupational therapists use to provide environmental modifications for patients with chronic disabilities, such as stroke (Corcoran & Gitlin, 1992; Corcoran et al 2002; Gitlin & Corcoran, 1996; Gitlin et al, 2003), the occupational therapy literature has very little research on occupations that caregivers participate in once the caregiving process begins.

A core tenet of occupational therapy is the belief that health is reflected and maintained through participation in occupations: work, play or leisure and self care. Since the conception of the profession, occupational therapists have been aware that activities need to have a certain quality to make them therapeutic (Meyer, 1922). One such therapeutic quality is occupation, the organizing force behind human activity (Yerxa et al., 1990). Since caregivers lives are disrupted due to the spouse’s stroke, occupations are a major way to achieve a balance in life. Occupational therapy is concerned with creating and maintaining meaningful and organizing activities so that the client can maintain health, be functional and obtain satisfaction from those meaningful activities (Primreau, Clark & Pierce, 1989).

Fidler (2000) has challenged occupational therapists and occupational scientists to consider the fit between the individual and the activity. By analyzing the fit occupational therapists can provide a unique perspective which is occupation based and assess the

effects of occupations on the individuals participating in them. Caring for a stroke survivor raises a set of questions about the occupations of the family caregiver as it relates to the care recipient. What is the role of occupations in the life of the caregiver dyad? How do these occupational roles change post stroke? How do these occupational changes contribute to adaptation?

In the discourse of occupational therapy, adaptation has been used as a term to deal with the management of occupational changes in daily life. Schultz and Schkade (1997) defined adaptation as “a change the person makes in his or her response approach when the person encounters an occupational challenge” (p.474). They also describe occupational adaptation as a process of interaction between the person and the environment. The concept of relative mastery, as explained by Schkade and Schultz (1992) in their theory of occupational adaptation, provides a foundation to evaluate the concept of ‘fit’. According to Schkade and Schultz (1992), relative mastery is a constantly evolving state that involves the assessment of outcomes of each “occupational response as efficient (use of time and energy), effective (production of the desired result), and satisfying to self and society” (p. 835). The degree to which an occupational response meets these criteria determines the degree of relative mastery and thus the degree of adaptation or dysadaptation.

This study explored the nature of occupation in the context of caregiving for a spousal stroke survivor. It focused on the changes between the environment and the person, resulting in engagement in different occupations. The purpose of this study was to identify the use of occupation in the life of the spousal caregivers of stroke survivors

over a one year period, and to gain a deeper understanding of the occupations the caregivers gained and lost as a result of caregiving during that year.

Methods

Design and Participants

This study is a secondary analysis of qualitative data obtained from a larger mixed methods study, entitled Committed to Assisting with Recovery after Stroke (CAREs). The larger study was an interdisciplinary intervention study funded for a five year period by the National Institute for Nursing Research, National Institutes of Health (NR05316). Stroke survivors and their spouses were randomized into a mild intervention group (these clients received: Stroke Recovery booklet, monthly letter on stroke, subscription to Stroke Smart magazine, and a monthly telephone call) and a home-based intervention (these clients received: Stroke Recovery booklet, monthly letter on stroke, subscription to Stroke Smart magazine, and a monthly telephone call and multidisciplinary home intervention using standardized protocols) group upon discharge from the hospital or rehabilitation setting. The intervention included education, support, counseling, and skill training by advanced practice nurses, occupational and physical therapists. The larger study was reviewed and approved for conduct by the university and hospital review boards as well as this study being given approval by the author's University review board.

Data Collection Procedure

The data for this paper were collected in a brief interview with spousal caregivers of stroke survivors in the privacy of their own homes by a nurse who was masked to their group assignment. At baseline, 3, 6, 9, and 12 months post discharge, spouses were asked to talk about their experiences. Their responses were audio taped in an area separate from the stroke survivors. At the first interview, the caregivers were asked to share their thoughts about the stroke survivor and in subsequent interviews they were asked the following questions.

I'd like for you to tell me how things are going for you now. Please tell me about your experiences as a caregiver during the last 3 months. What are the things that have been stressful for you and how do these things make you feel? How have you coped with difficulties? How has your life changed? Are there some lessons that you have learned that you would like to share with other spouses who are just bringing their spouses home from the hospital?

A sample of 8 caregivers was chosen from the 159 available for analysis. The study used purposive intensity sampling to include an information rich data set, so that the samples were diverse in gender, age, and ethnicity reflecting the larger database. (See Table 1) Demographic information including gender, age, ethnicity, and occupation were obtained from the CArES database.

Table 9 *Demographic Information for Caregivers*

<u>Caregiver</u>	<u>Gender</u>	<u>Ethnicity</u>	<u>Age</u>	<u>Occupation</u>
Alice	Female	Caucasian	65	Executive Secretary
Brandon	Male	Caucasian	82	Sales Manager
Cody	Male	African American	62	Manufacturing Supervisor
Danielle	Female	Caucasian	59	Professor
Eliane	Female	Asian	60	Retail Sales Manager
Fran	Female	African American	55	Nurse's aide
Gillian	Female	Hispanic	51	Caterer
Hannah	Female	Hispanic	41	Advertising Executive

Tapes of the interviews with the caregivers were transcribed verbatim (without names) by a transcriptionist. Each transcript was reviewed for accuracy by comparing the transcript to the tape. The transcripts were entered into QSR N6 (Non numerical Unstructured Data Indexing Searching and Theorizing) to assist with data management.

Data Analysis

The interview data were analyzed using hermeneutic interpretive phenomenology. This research methodology is used when the research questions ask for the meanings of a phenomenon with the purpose of understanding human experience (Patton, 2002). Data

analysis meetings with occupational therapists and nurses were held on a bi-monthly basis and multiple readings of the interview transcripts were carried out. These meetings helped establish an understanding of the themes and added depth to the interpretations (Christ & Tanner, 2003). Transcripts were examined simultaneously within themselves and in comparison with each of the caregivers, thus maintaining individuality and still identifying commonalities among the caregivers. The database was maintained and refined using QSR N6. Trustworthiness of the data was established through analyst triangulation (analysts had backgrounds in nursing and occupational therapy were members of the CARES study). Multiple meetings were held to recode and confirm established themes and patterns in the data. Coding categories were organized into themes and sub themes and examined for patterns. QSR N6 helped in the development of matrices for identifying themes that occurred at different time points. The credibility and quality of this research was assured through meeting the following criteria: 1) trustworthiness, 2) reliability of coding and pattern analysis, 3) validity of the data, through the masked nurse collecting the data (Patton, 2002). Pseudonyms were used for the names of caregivers in the study.

Results

In the CARES database there were 159 informal caregivers, including 119 women and 40 men. Their ages ranged from 40.5 to 86 years with a mean of 62.5 years. There were 92 Caucasians, 30 African Americans, 26 Hispanics and 11 mixed or from other races. The eight participants selected were Alice, Brandon, Cody, Danielle, Elaine, Fran, Gillian, and Harold. The following case studies provide information about the caregivers'

prior occupations, relationship with their spouses, and changes that occurred at baseline pertaining to occupations lost and gained following the stroke. The demographic information related to the participants is available in Table 1.

Alice

Alice was a 65 year old business woman, who managed the business aspects from home while her husband traveled. When asked about her relationship, she said that she had been “married for 40 years”. “He’s not a real fun person to be with because he doesn’t really enjoy ... doing much but working”. She was the primary caregiver for her husband after he was discharged from the hospital. To maintain some income, she maintained small aspects of the business for which she and her husband had shared responsibility prior to the stroke. Over the course of the year she talked about his dependency on her for activities of daily living and how overwhelmed she was because of his dependency and lack of time to get everything done. She also talked about leisure activities in which she participated which make her feel good about herself.

Brandon

Brandon was an 85 year old retired World War II veteran, married for 59 years. He and his wife were actively involved in the church. They had children in Houston and in surrounding areas of the state. When asked about his relationship with his wife he said, “wonderful years together”, “we’ve had good times and bad”, and “she’s a wonderful person”.

“I’ve had to learn how to turn on the dishwasher, the washing machine, mop the floors and try to make the beds up and try to cook ... I didn’t know how to do any of it and ...I didn’t want to know how to do it.... “

These were occupations which he had never before performed. He talked at 3 and 6 months about his depression because of the loss of control of the situation and stress because of conflict and his wife’s dependency over the course of the year.

Cody

Cody was a 62 year old manufacturing supervisor, who had been married for 36 years. He had known his wife since they were four years old. When asked about his wife and their relationship he said “we have our little disagreements just like any other couple does, but it’s nothing major, couldn’t be major because we’ve been married 36 years.” At baseline, he said “...she does try to do some things; she assists me in getting her dressed”. He talked about the new household activities of which he is now in charge and how time consuming taking care of his wife had been over the course of the year.

Danielle

Danielle and her husband were both college professors at the same university. Danielle was a cancer survivor and had been taken care of by her spouse who is currently the stroke survivor. While talking about their relationship, she stated, “We, we have a very strong relationship and always have had since early in our marriage.” At baseline she said “That doesn’t seem to bother me that we work long hours because we’re always in the house together and we’re always interruptible to one another”. However, over the course of the year she talked about the great impact caregiving has had on her health.

Through the follow-up interviews she commented on the immense amount of time spent taking care of him and how tired she seemed to be all the time. At three months, she talked about how returning to work at University had helped her feel like herself again.

Elaine

Elaine was a store manager who had cared for her husband, not only since his stroke, but since 1984 when he suffered major heart problems. She, too, had developed medical problems with which she had to deal while caring for her spouse. When talking about her relationship with him, she said “There are times we get along, but there are sometimes we don’t. He doesn’t open up and doesn’t say much.” She talked about his expectations and comments, “...sometimes his demands are too high and he wants things to be done right away and, which is really hard on the family and myself. Because everybody knows we all have to work”. She also talked about the profound effect caregiving had had on her health. She talked about the difficulty of dealing simultaneously with preparing her husband’s meals and driving him everywhere, while dealing with her own physical condition and job.

Fran

Fran was a housewife who complained about not having a social life. When asked about her relationship with her husband, she said “I love him very much, but his illness has put a strain on both of us.” She talked about his dependency on her for things like “fixing his food” and “getting the TV remote.” Throughout the year, she talked about how she coped by taking time out for herself, reading self-help and spiritual books, having faith in God and hoping that things would get better.

Gillian

Gillian used to work as a caterer and had been married for 14 years. When asked about her relationship she said “We’ve never been separated from each other” and “He was a very hard working man and ... I love him very much”. Over the course of the year she talked about how depressed she was because of so much change in her life and how her spouse did not seem to want to do much for himself. She talked about how the physical impact of caring for him had seemed to worsen her existing physical condition.

Hannah

Hannah and her husband were both advertising executives in high power jobs. She was the youngest of the eight caregivers at 41 years and together they had two children age two and five years. They had just relocated and had bought a new home prior to her husband’s stroke. While talking about her relationship with her husband, she said “He’s probably one of the smartest people I know in the business and the part of our relationship that I miss the most right now is our ability to talk about just about everything.” She talked about having no support as she was new to the city. Throughout the year, she talked about the immense financial impact the stroke had put on the family and the need to continue working to maintain an income. She also talked about how caregiving was an imposition on her time, along with having to work, take care of the children and follow up with his therapy and medical appointments.

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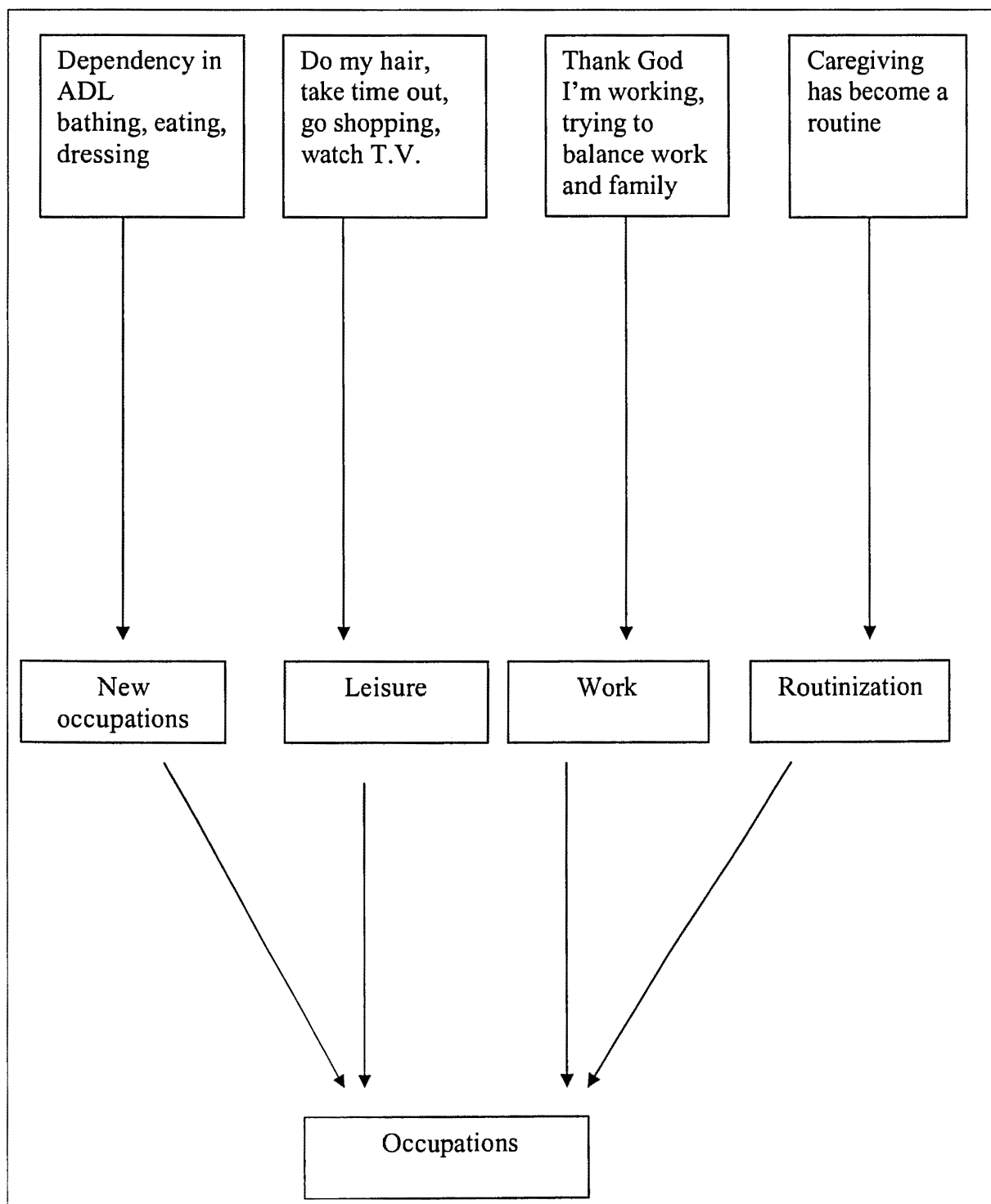
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Themes

The following section describes the significant themes pertaining to occupational changes among caregivers, including occupations that have been introduced into their lives because of caregiving and those that no longer exist because of the caregiving role. The evolution of these themes can be seen in Table 10.

Table 10: Evolution of Themes



Engagement in Occupations

“...I make breakfast, ... lunch,...take him to rehab...I drop him home and go back to work... ”

Christiansen, Clark, Keilhofner, and Rojers (1995) defined occupation as “the ordinary and familiar things that people do everyday” (p.1018). Occupations for these spousal caregivers are everyday activities that the caregivers now perform or help their spouses perform following the stroke. Occupations seem to have multiple roles in the life of these caregivers. There are a wide variety of occupations that are new to the caregivers that need to be done following their spouses’ stroke.

New occupations: “... I help her with her shower...”

Occupation is a significant component of caregiving. Due to the spouses’ dependency in activities of daily living (ADL) and instrumental activities of daily living (IADL) caregivers had to adapt to ‘new’ occupations along with their own everyday roles. Brandon said “I have to drive her everywhere she goes and she’s a shopper”; Alice stated “the biggest problem for me anyways, was his having to go to the bathroom so many times”. Danielle said

...I feel slightly out of control. And part of that comes from just, I know how much energy it’s gonna take to help him get going or make sure that the, you know, that somebody is here or that he’s cared, or that he’s warm you know...

Cody said

You're the one that does all the cooking, the washing, the cleaning, and also, that's just the household care. That's not taking care of your loved one too. You have a lot, she takes up about, I would say at least 80% of your day and night too...

Of the eight caregivers, six reported dependency by their spouses in ADLs or IADLs at three months. Dependency in these daily activities continued to be an issue that impacted time spent caregiving, and negatively contributed to the health of the caregivers and increased their stress. Stroke survivor dependency on caregivers in ADLs and IADLs decreased by the nine and twelve month interviews.

Leisure: "I go and I read and listen to my relaxing music ..."

According to Primeau (1996), leisure consists of three viewpoints: 1) leisure as time; 2) leisure as activity and 3) leisure as an experience or state of mind. Caregivers in this study used leisure occupations as a means of taking time for self and involvement in enjoyable activities.

- Alice said "I have my hair colored"; she also said " ...I still do things that I need to do to feel good about myself so I can ..., so I can not get so depressed";
- Fran said "I go to church and pray"; and another caregiver,

Elaine, reported:

Like last week on Saturday we all went out and when we came back and then he stayed at home because we had taken him out and then I just wanted to be alone, so I just went to the mall and bought myself something, bought my daughter something and I came back.

Fran, said

...the way I escape ...my anger and anxieties, I have a lot of self help books I read. I read positive thinking and ... that I would, no matter what I go up (to her room) for an hour, no matter how he hollers...

Thus, all three viewpoints proposed by Primeau are represented by the spousal caregivers of the stroke survivors in this study. However, the other end of the spectrum is the inability to participate in leisure activities because of caregiving. Brandon said "...my life has changed, I don't play (golf)...". Another working caregiver Hannah said "I feel like everybody's so needy and I'm getting lost in the process of trying to find time for me".

Inability to participate in leisure activities significant to the spousal caregiver could affect caregiver health and result in depression and poor adaptation. Leisure is a tool utilized by caregivers at different points along the one year time span to cope with the stress of caregiving. Participation in leisure did, however, depend on the caregivers needing to take time out for self as a strategy to cope with caregiving and their other responsibilities.

Work: "I already have a stressful job to begin with...I think they've defined the category for stress".

Participation in their work and career were major adaptive strategies used by the caregivers to deal with the caregiving process either as a means of taking time out for self or having a routine that was familiar in their newly changed life situation. One of the caregivers, Danielle, said

I'm working and thank God, I'm working. I'm only gone out of the house for about six hours on Tuesday and Thursday, and those days, while they're a royal pain in the neck, and I don't, you know, really look forward to them, those help me feel like me, and I have students depending on me, and that's a whole different thing from doing physical caregiving; that's just been wonderful.

The caregivers used work as a tool to deal with caregiving and reinforce the significance of self (the caregiver). Involvement in work emerged as a significant theme by the spousal caregivers of stroke survivors. However, the two roles of working spouse and primary caregiver add to caregiver stress as seen by many caregivers in this study. Alice said;

...since January he hasn't been able to work so there's no salary coming in , there's no money coming into the business, there's no salary being paid to us. So ...I have to keep up with one of the clients...I spend early mornings and late night writing emails and, arranging things. And it's very frustrating to me because I would like to spend all, all my spare time caring for him.

Hannah, another working caregiver and mother of two young children said; “I think over the last three months what has become increasingly stressful for me is just coordinating the family logistics and trying to balance work and my family, knowing that my family has special needs where my husband is concerned”. Thus, work has a two fold effect: it is a means of holding on to what is familiar to the caregiver and at the same time it may be a hindrance to the caregiver in terms of spending time with their spouse and then cause a sense of guilt.

Routines: “...his caregiving has become routine”.

Routines have been defined by Hagedorn (1996) as a “chain of tasks with fixed sequence which become automated and habitual” (p.81). Participation in occupations that were familiar to the caregivers facilitated a sense of routine. Everyday activities gave the caregiver a means of structuring life to bring order to it following the stroke. Danielle at 12 months said “... I think in many aspects his caregiving has become routine. This sentiment was expressed by Hannah as well. Cody at 3 months said “...it seems the more I do it, it seems like it’s getting a little easier, certain things”.

These identified themes provide a picture of the occupations in which the caregivers participated in following their spouses’ stroke and the loss of pre-existing occupations that were significant to the caregivers. It puts into perspective the significance of occupations and the changes in participation and evolution of new occupations over time.

Discussion

In this study the spousal caregivers of stroke survivors participated in a variety of occupations depending on the needs of the spouse, self and environment. The following is an in-depth explanation and review of the occupations in which the caregivers participated in and the impact of these occupations upon their lives and their spouses'.

New Occupations

Variability existed in the way caregivers adapted to, and coped with, their experiences depending on their stressors (Corcoran, 1992; Williamson & Schulz, 1993). In this study, caregivers had to take over new occupations centering around the care their spouses to help meet their daily living needs. These were occupations that the caregivers may have had to learn for the first time in their lives (cooking, helping spouse bathe) or an activity of which they were partially involved prior to the stroke (financial responsibility). As seen in earlier research by Hasselkus (1988), caregivers have a 'sense of managing' and taking over care for their family members as part of their new role as caregiver. This increased responsibility that was taken on by the caregiver could lead to issues with caregiver health, increased stress and burden, and loss of support to the stroke survivor (Van den Heuvel, Witte, Schure, Sanderman, & Jong; 2001).

Leisure

Davidson (1991) said "leisure is a time away from work and responsibilities, a time to restore oneself and find meaning in life" (p.162). Hasselkus (1988) discusses 'concern for self' as a theme, where the caregiver feels that he/she is being neglected in the process of caregiving. In this study the caregivers used leisure as a tool to allow

time for self and establish a sense of well-being. Leisure promotes social interaction, self identity, and internal control mechanisms (Silbereisen, Noack, & Eyferth, 1986). Leisure provided these spousal caregivers with a means of adapting to the caregiving process and enhanced their self image.

Work

Spencer et al (1998) in their qualitative study on work emphasized the positive aspects of work which included: 1) enjoyment of the activity in and of itself; 2) attainment of immediate extrinsic rewards; and 3) contribution to aspects of one's identity. These positive aspects of work were noted by only one of the caregivers in this small sample of 8 caregivers. The other aspect of work was negative and focused on the stress it placed on the caregiver and was viewed as an additional responsibility. Work has also been defined as a burden, something that is forced and without choice (Ruiz Quintanilla, & England, 1996). In the case of some of the caregivers in the study, work was required for financial stability and an occupation in which they had to participate to support themselves and their families.

Routines

In 1991, Reich and Zatura defined routinization as a personality trait that was conceptualized as the extent to which the person reports structure and routine in his/ her life. Research done by Reich in 2000, suggests that routinization may help improve mental health among clients with medical problems and coping efforts may be more effective when people who are routinized are encouraged to engage in greater active coping. Hasselkus (1988) discussed the caregiver's sense of managing (caregiving)

through use of elaborate rituals and routines. This concept of routinization has significance to the caregivers of stroke survivors. The evidence of caregiving becoming routine may allow for meaningful structure in the caregiver lives and elicit active coping to deal with the caregiving process. Gitlin, Corcoran and Leinmiller-Eckhardt (1995) discussed the significance of routines to caregivers of elderly persons in the home. They suggested that occupational therapists, having identified routines, can provide suggestions and changes to help the caregiver deal with caring for the spousal stroke survivor and make caregiving simpler.

Implications

Identification of the various ways in which occupations impact the lives of the spousal caregivers of stroke survivors is of major significance to occupational therapists. By better understanding the different areas of occupations that impact caregivers and the meaning and significance they attach to them, therapists can obtain another perspective on how these occupations impact the caregiver's lives and thus the stroke survivors themselves. Occupations used by the caregivers ranged from being required, in terms of taking over their spouses ADL's and work to continue monetary support to the family, to leisure to help cope with caregiving and make their lives more meaningful. Routine, in terms of caregiving, is also identified as being of significance in helping the caregiver bring order to the caregiving process.

This study provides important information to the profession as it details how occupations are used by spousal caregivers of stroke survivors over a period of time and demonstrates this process of change in terms of use and significance of these various

occupations over a one year duration. Work and leisure continue to be used as occupational tools to maintain a sense of identity; and it is essential that occupational therapists strive to maintain this sense of ‘unique being’ of the clients and their caregivers. This study outlines the occupations in which the caregivers were involved. This will impact tax dollars spent on caring for the spousal stroke survivors by understanding the needs of the caregiver and maintaining a balance between stroke survivor and caregiver health and wellness, leading to better stroke survivor care. Keeping this in mind will allow therapists to lay the foundation of improved occupational performance by facilitating adaptation of the caregiver to their new life role using occupation as a mediating tool.

Future Research

Future research that addresses a larger sample size and a more heterogenous group would increase generalizability of the study’s findings. Future research with quantitative tools to measure use of occupations would be recommended. Qualitative research across disabilities would provide useful information on similarities and differences seen in different populations.

CHAPTER 6

CONCLUSION AND IMPLICATIONS

The preceding chapters described the results of three related articles that pertain to caregiving and explored the question, “What comprises adaptation among spousal caregivers following their spouse’s stroke?” In this chapter the results will be discussed as a total.

Types of Research

The research is comprised of three studies that were conducted and submitted for publication in peer reviewed journals. The first study was a literature review that focused on existing literature in occupational therapy pertaining to informal caregiving. This provided a background to understand the key ideas related to caregiving that were addressed in occupational therapy, had evidence based practice studies and areas in occupational therapy that lacked research. The second study was a mixed design with emphasis on the caregiver’s adaptation process over a year’s time post stroke. The third study was a qualitative study that identified changes in occupations in which the caregivers participated following the spouse’s stroke and over a one year period and included; those occupations both lost and gained as a result of caregiving.

The nature of the questions places these studies within basic and applied research. Mosey (1992) said; “Basic knowledge is about seeking knowledge – to make what is unknown, known” (p. 113). Basic science is concerned with knowledge for its own sake. The first study sought to identify the research prevalent in occupational therapy literature related to informal caregiving and describes informal caregiving from an occupational therapy perspective. In contrast, Mosey’s explanation of applied scientific inquiry states, “a form of investigation that uses the methods of science and either theoretical information or research designs for the purpose of arriving at immediate practical ends” (p.4). The second and third studies laid the foundation for the application of occupational therapy related to informal caregiving.

The importance of narrative and life story to occupational therapy, the value of mixed design, the main findings of the three studies of this dissertation, and the implications and limitations of these studies findings to practice and research are discussed in this chapter.

Analyzing the data from eight spousal caregivers of stroke survivors at five time points over a one year continuum was conducted. These eight caregivers were asked questions pertaining to their experiences as caregivers, changes in their lives, how their relationship with their spouses had changed following the stroke, stressors they faced and their modes of coping with these stressors. Several key ideas emerged while in the process of analyzing the data for this dissertation. These ideas have significance to occupational therapy and are discussed as relevant findings of the studies. Through exploration of the adaptation process shared by the participants in these studies, subtle

differences between the caregivers based on their individual stories emerged. The discussion in this chapter further reflects upon these findings.

The Importance of Narratives to Occupational Therapy

Narrative analysis extends the idea of text to include in-depth interview transcripts, life history narratives, historical memoirs and creative nonfiction. This has direct impact on the hermeneutical perspective that is based on interpretation and context (Patton, 2002). The second and third studies focused on narratives of the spousal caregivers of stroke survivors. Narratives play a significant role in occupational therapy. They allow the occupational therapist to understand the life stories of their clients and give the therapist insight to their client's lives. Therapists, then, use clinical reasoning as a tool to analyze the narratives and form and attain certain pertinent goals essential to the client's well-being. To achieve these therapeutic goals, the client and occupational therapist establish an intervention plan and prioritize goals based on the client's needs. Thus, narratives are used as a treatment tool to facilitate implementation of practice and development of treatment goals. The narratives used in this research provided the researcher with information rich interviews about the spousal caregivers. The interview questions focused on relationship information, at baseline and questions related to the current situation every three months following the stroke with emphasis on stressful factors, life changes, and lessons learned. Thus, the rich information provided through the interviews in this dissertation was a significant contributor to the future development and understanding of informal caregivers of stroke survivors and problems both specific to this population and shared by informal caregivers of clients with varied chronic illnesses.

The Importance of Mixed Design

Data triangulation using mixed research design can strengthen a study (Patton, 2002). Creswell (2003) enumerates six methods of mixed design. Concurrent triangulation strategy is one of the six and implies use of both qualitative and quantitative data to cross validate and confirm findings (Creswell, 2003). The second study in the dissertation uses such a design and draws in data from the Caregiver Preparedness Scale, a structured, self-report, written assessment questionnaire with eight items, and interview data at the same time intervals at baseline, 3, 6, 9 and 12 months respectively. Scores on the Caregiver Preparedness Scale show an improvement in scores from baseline to three months after caregiving for six of the eight caregivers. No trend was seen in the scores over the following time points; but by the end of the year, seven of the eight caregivers reported an increased score in caregiving preparedness. This was reinforced by the qualitative data from the taped interviews, where routinization of caregiving lend structure to the caregiver by 9 months and dependency by the spousal stroke survivors also decreased making caregiving a less difficult task. This study exemplifies the value of mixed design and the way in which qualitative and quantitative data can be supportive of each other leading to stronger research design and findings.

Summary of Findings

The first study, “Informal Caregiving in Occupational Therapy: Review and Analysis” laid the foundation for identifying available literature in occupational therapy related to informal caregiving. This study reported the results of a review of articles with the aim of identifying significant themes that directly related to the core philosophy of occupational therapy, that evaluated the role of occupational therapy in informal caregiving and organized literature that provided related information on the same themes available from other disciplines. Through an in-depth review of the articles various themes significant to occupational therapy emerged. Several significant themes: meaning and motivation, occupation, gender role, routine and habit, environment, and adaptation were discussed. The scope of occupational therapy has evolved as seen by the different associated themes identified in the discussion of Chapter 3. There is a developing foundation in qualitative research that has addressed areas such as adaptation of caregivers through death and grief process, the significance of the caregiver as a ‘lay practitioner’, the identification of the role of occupational therapy in the caregiving process, and the significance and meaning of caregiving to the caregiver. The qualitative studies were predominantly related to environmental modification and promotion of caregiver well being and ability. However little research was reported in terms of longitudinal studies and mixed racial groups.

In the second study, “A Caregiver Journey: The Process of Recovery after Stroke”, the participants had a series of interviews at five time points over a year that described the caregiving experience of spousal caregivers of stroke survivors over that

time period. Eight participants (pseudonyms used) were selected to illustrate the adaptation process over time. It was a mixed design study. For the purpose of this study only interview data from caregivers were analyzed, along with scores from the Caregiver Preparedness Scale. The inclusion criteria was 1) Stroke within the last 12 months, 2) age 50 or older, 3) married or committed relationship, 4) going home from hospital with partner, 5) lives within 50 miles of Texas Medical Center, 6) understands and speaks English, 7) has a telephone, 8) both stroke survivor and caregiver agree to participate in study. The adaptive experience was impacted by pre existing physical conditions the caregiver had, available support systems, and stress related to finances, changing relationships because of conflict with spouse and lack of time. Seven of the eight caregivers had health issues related to caregiving. Health issues either pre existing or those that emerged as a result of caregiving were a significant themes that emerged. Four of the eight caregivers complained of health related issues over the span of more than six months. Conflict was another significant theme. Spousal relationships significantly changed for the caregivers due to conflict over control issues. The lack of motivation and depression on the part of the stroke survivor seemed to be the cause for anger and friction between the couple. Temporal issues were a theme that seemed to be affecting the caregivers in two ways. First, the caregivers mentioned how time consuming the caregiving process was; and secondly, because of caregiving, the caregivers had very little time for themselves. Hope for the future was significant theme in the caregiver's life and was identified as an adaptive strategy. Half the caregivers were initially hopeful of good progress and recovery of their spousal stroke survivors. However, over time they

realized that recovery was affected by a variety of things like restrictions in time available to the caregiver, caregiver health, financial responsibilities now taken over by the caregiver, and stroke survivor recovery. Support was another theme that evolved and was identified in All but one caregiver involved in this study reported support in one form or another during the caregiving experience over the past year. Support from friends, family, neighbors, church and some formal support through an aide was predominantly mentioned at three and six months time intervals. Occupations were the final theme that emerged. Occupations seemed to have multiple roles in the life of these caregivers either as a way for caregivers to deal with the caregiving process by taking time out for self or having a routine that seems familiar in the changed life situation. New occupations emerged because of the dependency of the spousal stroke survivors on the caregivers to carry out daily living tasks. Caregivers used occupations as a means of taking time for self and involvement in leisure.

The third study, “Occupations Lost and Gained: A Caregiver Perspective”, demonstrated the changes in the occupational lives of the caregivers. A core tenet of occupational therapy is the belief that health is reflected and maintained through participation in occupations: work, play or leisure and self care. Since the conception of the profession, occupational therapists have been aware that activities need to have a certain quality to make them therapeutic (Meyer, 1922). One such therapeutic quality is occupation, the organizing force behind human activity (Yerxa et al., 1990). Caring for a stroke survivor raises a set of questions about the occupations of the family caregiver as it relates to the care recipient. What is the role of occupations in the life of the caregiver

dyad? How do these occupational roles change post stroke? How do these occupational changes contribute to adaptation? The spousal caregivers of stroke survivors in this study participated in different occupations depending on the need of the spouse, self and the environment. The findings identified elements of the caregiving experience in terms of new occupations related to leisure, work and routine and loss of old occupations because of caregiving. New occupations were a significant component of caregiving. Due to the spouses' dependency in activities of daily living (ADL) and instrumental activities of daily living (IADL) caregivers had to adapt to 'new' occupations along with their own everyday roles. Leisure was another significant occupation. Caregivers in this study used leisure occupations as a means of taking time for self and involvement in enjoyable activities. Another theme: work, was also noteworthy. Participation by caregivers in their work and career were major adaptive strategies used by the caregivers to deal with the caregiving process either as a means of taking time out for self or having a routine that was familiar in their newly changed life situation. The caregivers used work as a tool to deal with caregiving and reinforce the significance of self (the caregiver). Involvement in work emerged as a significant theme by the spousal caregivers of stroke survivors. However, the two roles of working spouse and primary caregiver added to caregiver stress as seen by many caregivers in this study. Participation in occupations that were familiar to the caregivers facilitated a sense of routine. Everyday activities gave the caregiver a means of structuring life to bring order to it following the stroke.

Studies 3 and 4 are linked by the arching theme of adaptation that encompassed the word of the eight caregivers and by the term of occupation that seems to be integrally woven in the fabric of caregiving.

Implications for Practice

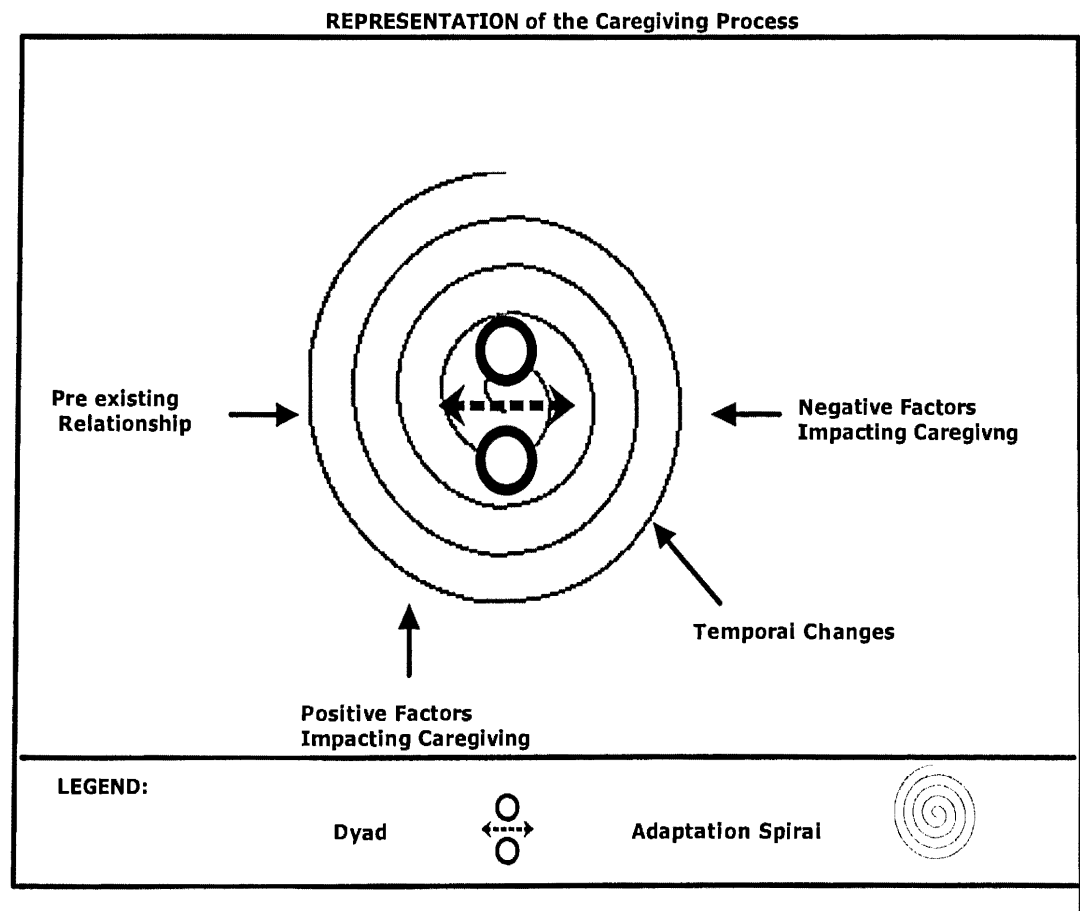
The studies evolved from a line of research that asked the question: “What constituted adaptation of spousal caregivers of stroke survivors?” Additional questions asked were: 1) what literature exists pertaining to informal caregiving for older adults with chronic disability from an OT perspective? 2) how does adaptation over time occur in the caregiver’s life? 3) what are the factors that precipitate adaptation at different time points 4) what outcomes present themselves as a result of adaptation 5) what is the role of occupations in the life of these caregivers? 6) how do occupational roles change in the lives of spousal caregivers? and 7) are occupational changes a part of adaptation? The studies provided some answers and led me to consider discussion of certain areas related to these questions. The next section provides a discussion of these areas including: 1) the caregiving process; 2) community and support; 3) significance of cultural differences or lack thereof; 3) quantifying occupation and 4) the holistic experience.

The Caregiving Process

Informal caregiving of a stroke survivor can be envisioned as a dynamic spiral influenced by such factors as the pre - existing spousal relationship, temporal changes, and various positive and negative factors impacting the stroke dyad. The temporal changes can affect the caregiving process either positively or negatively depending on the life experiences occurring during the time frame following the stroke.

As seen through the participants in the CARES research study, a second stroke could negatively impact the adaptation process and thus have the dyad revert back in time to an earlier point of adjustment and adaptation. However, positive experiences like support and help during the time of crisis (i.e. stroke) could help the caregiver deal with the caregiving experience better.

Figure 1



Stroke is a devastating disease and the third leading cause of death in the United States (American Heart Association, 2005). The disease initiates the need for caregiving by spouses based on the severity and impact of the stroke. The spousal caregiver comes

into the arena with only life experiences and learned adaptive strategies as a buffer to help deal with the new caregiver role. This results in a fluctuating state of caregiving preparedness depending on the phase (immediately following the stroke, after a few months or a year latter) at which (time) the caregiver questions and how proficient they have become with caregiving. Their life experiences and improvement or regression of their spouse would impact the adaptation process. Thus, time is a significant component to identify both the caregiver ability to deal with the dependent spouse.

Community and support

The participants in these studies relied on adaptive strategies, including reaching out to others, to achieve a level of successful adaptation to the new situation of caring for their spouses. The pre existing community involvement and support systems that existed were brought to the fore at the time of stress or crisis i.e. the stroke. The caregivers had a wide variety of support: both formal and informal. The caregivers had community help from the immediate environment in the form of neighbors coming in to help and visits from immediate family. Church and visits from friends from that sphere of the couple's life were also an integral part of the support they received from the community. Formal support from the intervention group i.e. CARES, and the intervention team including therapists and nurses, along with employed aides, were present as support systems.

The experiences of Danielle, a working university professor and cancer survivor represented her difficulty with caregiving because of the lack of support and loneliness she experienced as her spouse was her true confidant and the person she depended on the most. The work environment was not friendly to her spouse who was a professor at the

same university when he decided to go back to work. Danielle felt her husband's colleagues were against him and she felt desolate and alone. Her lack of support made adaptation to her new caregiving experience a difficult transition. Elaine, on the other hand, had a pre existing medical illness herself and had been taking care of her husband before the stroke because of other medical issues. She was of Asian decent and culturally it was her responsibility to care for and support her husband. Elaine expressed concern for her own health and was solely responsible for his caregiving. This led to her feeling unable to deal with the caregiving process. These are examples of caregivers in the sample that represent a population that may be slower to adapt because of lack of community support at various levels of the transition.

Significance of cultural differences/commonalities

Through the process of analysis of the data in studies 2 and 3, no differences in caregiving strategies and adaptation to the caregiving process were evident among the caregivers based on ethnicity. Though a small sample size, it does demand mention as this result varies from the current data available in the literature that states African Americans have lower anxiety and better coping than Caucasian caregivers (Haley WE, et al., 2004). Informal caregiving had similar management by all ethnicities with similar coping styles and problem solving. This is another significant area that needs attention to with larger populations and with informal caregivers of different diseases.

Quantifying Occupations

Occupations are another significant area that are not appropriately or sufficiently quantified based on this need. An instrument/tool to help measure and quantify changes

in participation of occupations within informal caregivers is an outgrowth of study 3. (Appendix B). This tool includes constructs pertaining to occupations such as: 1) work, 2) leisure, 3) household activities, and 4) competence in caregiving. A higher score indicates higher participation in meaningful occupations in the caregiver's life. Questions 1 through 10 are scored normally and question 11 is reversely scored. This tool can provide occupational therapists with significant information to identify areas that are troublesome in terms of occupational participation, and caregivers can be reassessed using the same scale at a later time once the occupational therapist has suggested changes and provided resources to see if participation has improved. This tool can be administered at 3 months and then at timely intervals to identify initially areas of occupation that are impaired and then latter to see if occupational therapy intervention and adaptive strategies have helped deal with the (occupational) problems identified.

Significance of the Holistic experience

The data from this dissertation emphasizes the reality that in facing the challenge of the stroke the dyad was a unit and managed the situation together. The caregivers were significantly responsible for the well-being of both self and spouse through the adversity of the stroke. The experience in and of itself was identified as holistic because neither caregiver nor spouse can be considered separate entities as they go through the adaptive process together. It becomes significant, then, as occupational therapists to identify the importance of family centered practice among this population and to lobby for application of this mode of treatment. Facilitating movement toward co-intervention of

family members not only contribute to the well-being of the stroke survivor, caregiver and in sum, the couple, but is also economically beneficial to the health of the country.

The data from these studies could influence a therapist's perspective of intervention with stroke survivors and their families. By understanding problems that may exist among informal caregivers the therapists may be better able to provide resources and direct caregivers through appropriate channels to help them deal with the impact of stroke, so as to improve wellness in their lives, and to understand anticipate other problems that could arise because of their spouses' disability, wellness in their own lives could improve.

Limitations

1. The studies for this dissertation were conducted with spousal caregivers of stroke survivors. Addressing a larger group of informal caregivers like siblings and children would give the study a more diverse population and thus the findings could be compared to identify similarities and differences between groups of informal caregivers.
2. The caregivers were from within an urban southwest city and have lived in the United States for their entire adult lives. Though this study included multi-ethnic backgrounds, a comparison study between informal caregivers from different cultures in their home countries would be desirable to add to the existing knowledge base.

3. The caregivers were followed and assessed over a one year time frame. Questions pertaining to the caregiving experience over a longer time frame and observing temporal changes in the experience could be conducted.

Directions for future research

Ideas have related to the dissertation have changed since the beginning of the process and caregiving is currently viewed as a multi layered, complex experience. Part of the change in these ideas can be attributed to understanding the process of caregiving and understanding the conceptualization of it with other ideas. This line of research remains of unrelenting interest to the primary author. In the immediate future, further exploration and reflection on some of the concepts that emerged to the forefront following this research should be considered: adaptive strategies, occupational fit, and significance of occupation through application of the Caregiver Occupation and Participation Tool. The relationship between adaptive repertoires and life experiences merits further research as well.

Study 1 predominantly outlined the caregiving literature as it appears in occupational therapy; however, the literature in occupational therapy is very limited in the area of caregiving of persons with dementia as well as on the adaptation of caregivers while dealing with chronic diseases over time. Samples involving mixed racial groups and different research designs were absent from within the profession's literature on caregiving. The impact that time has on the caregiving process, the adaptive process that occurs among various racial groups and differences that exist in caregiving in different racial groups are areas that need specific attention by the profession. Hope is just

beginning to be addressed as a component of the caregiving literature and also needs more study. Within the profession there is insufficient research in areas of how we as therapists a.) address the occupations of the caregiver, b.) measure changes occurring within the family as a result of change because of care recipient illness and c.) how to bring about meaningful participation for the caregiver in daily life. Research in the areas mentioned above is needed and can contribute significantly to the knowledge base of the profession.

Studies 2 and 3 only begin to reveal the experiences of the 8 participants in the study. The transcripts contain very rich data and a series of further research could be done to identify and outline other areas of scientific interest. One project could be a comparison between stroke survivor and caregiver narratives to delve further into the complex caregiving process. Another project could analyze the significance of environmental context and its influence on adaptation. Future research that addresses a larger sample size and a more heterogeneous group would increase generalizability of the study's findings. Future research with quantitative tools to measure use of occupations would be recommended. Qualitative research across disabilities would provide useful information on similarities and differences seen in different populations.

The questions posed at the outset of this research "A Caregiver Perspective: Adaptation after Stroke", still remains significant to the primary author. Application of a variety of research methods and development of a quantifiable tool to measure adaptation would be a significant next step. It is the hope of the author of this line of

research to gain an inner perspective into the lived experiences of these caregivers that will enable occupational therapist's to have insight into developing tools and using the information from this dissertation as a knowledge base to enhance adaptation among caregivers and promote wellness.

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APPENDIX A

Questions for 5 Minute Interview Questions

Questions for 5 Minute Interview Questions

Baseline

Caregiver: I'd like to hear your thoughts about (stroke survivor's name) in your own words and without my interrupting you with any questions or comments. When I ask you to begin, I'd like you to speak for 5 minutes, telling me what kind of a person (stroke survivor's name) is and how the two of you get along together. After you have begun to speak, I prefer not to answer any questions. Are there any questions you would like to ask me before we begin?

3,6,9,12-Months:

Caregiver: I'd like for you to tell me how things are going for you now. Please tell me about your experiences as a caregiver during the last 3 months. What are the things that have been stressful for you and how do these things make you feel? How have you coped with difficulties? How has your life changed? Are there some lessons that you have learned that you would like to share with other spouses who are just bringing their spouses home from the hospital?

APPENDIX B

Caregivers, Occupations and Participation Test (COP Test)

Caregivers, Occupations and Participation Test (COP Test)

Instructions

Read the following questions and circle the response that most describes how you feel about the statement.

The numbers represent the following answers. If the question does not apply, circle not applicable (N/A).

Never	Hardly Ever	Sometimes	Often	Most of the time	Not Applicable
1	2	3	4	5	N/A

Relationship to Care Recipient:

Time since caregiving began:

Date of Test completion

Gender of Caregiver

Caregiver Age:

Ethnic Background: Caucasian----- African America ----- Hispanic-----

American Indian----- Asian----- Other-----

1. Most of my time is spent caring for the care recipient

Never	Hardly Ever	Sometimes	Often	Most of the time	Not Applicable
1	2	3	4	5	N/A

2. I am able to successfully complete most caregiving tasks.

Never	Hardly Ever	Sometimes	Often	Most of the time	Not Applicable
1	2	3	4	5	N/A

3. Caregiving is wearing me out.

Never	Hardly Ever	Sometimes	Often	Most of the time	Not Applicable
1	2	3	4	5	N/A

4. I receive services to help me to caregive

Never	Hardly Ever	Sometimes	Often	Most of the time	Not Applicable
1	2	3	4	5	N/A

5. I spend more time doing activities I enjoy than caregiving.

Never	Hardly Ever	Sometimes	Often	Most of the time	Not Applicable
1	2	3	4	5	N/A

6. I have time for leisure activities (sewing, golf, watching movies, reading)

Never	Hardly Ever	Sometimes	Often	Most of the time	Not Applicable
1	2	3	4	5	N/A

7. I have time for household activities (cooking, cleaning, paying bills)

Never	Hardly Ever	Sometimes	Often	Most of the time	Not Applicable
1	2	3	4	5	N/A

8. I have time for work (professional occupations, if employed prior to caregiving)

Never	Hardly Ever	Sometimes	Often	Most of the time	Not Applicable
1	2	3	4	5	N/A

9. I can manage caregiving and all household and personal activities.

Never	Hardly Ever	Sometimes	Often	Most of the time	Not Applicable
1	2	3	4	5	N/A

10. Since I began caregiving I have been able to spend time with friends.

Never	Hardly Ever	Sometimes	Often	Most of the time	Not Applicable
1	2	3	4	5	N/A

11. Caregiving has negatively influenced my health and/or made pre existing health issues worse.

Never	Hardly Ever	Sometimes	Often	Most of the time	Not Applicable
1	2	3	4	5	N/A

12. Looking back on a typical day are there specific activities/occupations you cannot participate in now because of caregiving.

APPENDIX C

Reviewer's Comments for Informal Caregiving in Occupational Therapy: Review and Analysis

Reviewer's Comments for Informal Caregiving in Occupational Therapy: Review and Analysis

Reviewer's Comments

Replace Occupational Therapy with OT throughout the paper except at beginning of sentences.

Grammatical corrections.