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Role Change Experienced by Family Caregivers of Adults with Alzheimer's Disease: Implications for Occupational Therapy

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ABSTRACT. *Objective.* This qualitative study explored the phenomenon of role change as experienced by in-home caregivers of individuals with Alzheimer's disease.

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Method. Fifteen caregivers of individuals with Alzheimer's disease received brief questionnaires, which included open-ended questions concerning their caregiving situations. Eight of these individuals volunteered for further preliminary evaluation with the Role Change Assessment (RCA) 2.0 (Rogers & Holm, 1995, 1999). The purpose of using the questionnaires and the RCA 2.0 was to familiarize the researchers with the caregiving situations of participants. Findings from the questionnaires and RCA 2.0 served as a basis for designing the questions for individualized phenomenological interviews. The phenomenological interviews with the eight volunteer participants were the primary means of data collection in this study. The goal of the phenomenological interview was to gain in-depth understanding of how the caregivers perceived their roles, and which roles had changed as a result of involvement in the caregiving experience. Field notes from caregiver support group meetings were also used as a data gathering tool.

Results. Data analysis yielded themes which describe the role changes experienced by the caregivers. These themes demonstrate that the caregivers underwent significant changes in their participation in leisure, relationship, household management, and health and wellness roles.

Conclusion. Findings suggest that caregivers experience significant life-altering role changes as a result of their caregiving responsibilities. These role changes are in important occupational performance areas, and may negatively influence caregiver quality of life. An understanding of these role alterations may allow occupational therapists to develop additional means of providing encouragement, support, and guidance when working with caregivers of individuals who have Alzheimer's disease. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2003 by The Haworth Press, Inc. All rights reserved.]

KEYWORDS. Alzheimer's disease, caregivers' experiences, role changes

Alzheimer's disease afflicts approximately four million people in the United States. It is estimated that more than seven out of ten people with Alzheimer's disease live at home (Alzheimer's Association, 2001). Often it is necessary for family members and friends to assume caregiver roles. Evidence suggests that the amount of time caregivers spend caring for the individual with Alzheimer's disease strongly influences their

experience of stress, leading to feelings of isolation, general strain, and disappointment (Anderstedt, Elmstahl, Ingvad, & Samuelsson, 2000).

The onset of Alzheimer's disease can cause magnification of preexisting family problems or require reorganizing financial arrangements, which can lead to other crises and stress in the family (Salmanson & Robbins, 2003). Neglect and/or abuse may surface if community resources are not adequate (Salmanson & Robbins, 2003). The availability of community and health care resources affects the quality of the caregiving situation.

An internalized role is a person's awareness of a particular social identity and its related obligations. Role internalization guides the individual to behave in a manner characteristic of that role, while providing rhythm between different aspects of self identity (Kielhofner, 1997). Kielhofner and Barrett (1998) said roles influence the manner and content of a person's interactions with others and their daily routine. Baum and Law (1997) said self-identity is shaped by participation in social roles. A positive correlation has been demonstrated between life satisfaction and involvement in meaningful roles (Elliot & Barris, 1990). The process of human adaptation appears to include changing roles throughout life transitions (Carter & Cook, 1995).

When individuals assume caregiving responsibilities, their participation in previous roles and routines is likely to change. Chenoweth and Spencer (1986) conducted a study to explore the experiences of families from the earliest recognition of their loved ones' symptoms of dementia and throughout the course of their illness. The most common problems found by caregivers at home were physical and emotional strain, an inability to get away, and concern over finances. A study by Neundorfer et al. (2001) found that acceleration in caregiver depression is predicted by an increase in patient dependency in instrumental and basic activities of daily living. Bergman-Evans (1994) suggested caregiver depression is significantly related to self-assessed health status and days missed from work. Hills (1998) found more research needs to be done to determine the needs and perceptions of caregivers and the effect of caregiving on role performance.

A number of writers address the importance of the professional relationship between the occupational therapist and the caregiver. Occupational therapists Aitken and Lohman (1996, p. 87) stated: "A proactive approach to addressing caregiver needs and concerns may prevent future problems." Walens and Rockwell-Dylla (as cited in Larson et al., 1996) stressed the importance of collaboration in the OT treatment process. They developed a practice model that emphasizes the value of the

relationship between the patient, family, and therapist. Their model contends that effective practitioner-family collaboration can only occur if the occupational therapist understands the client and family point-of-view (as cited in Larson et al., 1996).

The purpose of this qualitative study was to explore the phenomenon of role change as experienced by in-home caregivers of individuals with Alzheimer's disease. Examining the ways in which a caregiver's role changes may allow occupational therapists, and other health professionals, to gain a greater understanding of the caregiving experience. This may help in the development of effective strategies for helping caregivers cope with their responsibilities, and ultimately allow them to perform these tasks with greater ease and satisfaction. A reduction of caregiver burden may also help preserve the emotional satisfaction caregivers and their loved ones obtain from their relationships.

METHOD

Prior to the initiation of the study, the investigators obtained approval from the Institutional Review Board (IRB) at the researchers' university.

Data collection with caregivers was conducted through the use of open-ended questionnaires, support group field notes, and individualized semi-structured interviews employing phenomenological techniques. The Role Change Assessment (RCA) 2.0 (Rogers & Holm, 1995, 1999) was used to gain preliminary information about caregivers, from which individualized semi-structured phenomenological interviews were designed. Phenomenological interview techniques seek to obtain the perspective of the person being interviewed. In phenomenological interviews, questions may begin by saying "tell me about . . .," or "describe to me . . ." The phenomenological researcher uses probes, such as "tell me more about that," to gain further elaboration when interviewees reveal particularly relevant information.

Caregivers

Study participants included a purposeful sample of persons of any age and either gender who at the time of the study were serving as in-home caregivers of individuals with Alzheimer's disease. Caregivers were unpaid family members and were to have been living with care recipients for a minimum of six months from the time the recipients' symp-

toms of Alzheimer's disease began. The researchers felt that a minimum of 6 months of this type of caregiving was necessary for gaining more accurate information about the phenomenon of caregiver role change. Thirteen participants were recruited from Alzheimer's disease support groups in western Pennsylvania; one participant was a personal contact of one of the researchers; and one participant was obtained from a professional referral source. All fifteen caregivers completed questionnaires. All participants spoke fluent English and were capable of giving informed consent. Two of the caregivers were husbands of care recipients, while six were wives, five were daughters, one was a son, and one was a sister. All of the responses to these fifteen initial questionnaires were later analyzed as part of the thematic analysis process.

Eight of the fifteen participating caregivers volunteered to complete the Role Change Assessment (RCA) 2.0 and the in-depth interviews. Six of these eight caregivers were recruited from support groups and two caregivers were referred by occupational therapy practitioners. Two of the caregivers were males and six were females. The eight caregivers, who completed the Role Change Assessment (RCA) 2.0 and in-depth interview, age ranged from forty-nine to eighty-one, with a mean age of sixty-five. Duration of the caregiving responsibilities ranged from one year to nine years, with a mean length of four years. The interviewed caregivers included one individual caring for his wife, three individuals caring for their husbands, two daughters caring for their mothers, one son caring for his father, and one individual caring for her father-in-law. Descriptive information for the eight caregivers participating in the phenomenological interviews is provided in Table 1.

Procedure

Recruitment letters and flyers were passed out at the local Alzheimer's association offices and at Alzheimer's disease caregiver support groups. Fifteen caregivers completed the caregiver questionnaire and eight of these volunteered to participate in the Role Change Assessment (RCA) 2.0 and phenomenological interviews.

Caregiver Questionnaire. The investigators attended Alzheimer's disease caregiver support groups, and explained the purpose and procedures of the study. They asked the caregivers to complete preliminary questionnaires, if the caregivers were willing to be included in this study. Fifteen questionnaires were returned at the meetings and through referrals. The first portion of the questionnaire asked for the length of caregiving time and the relationships to the individuals with Alzheimer's

TABLE 1. Description of 8 Caregivers Participating in Phenomenological Interviews

Caregiver	Stage of Alzheimer's Disease and Duration of Caregiving Relationship	Caregiver Occupations	Other Available Support
A- 72 year old male caring for 65 year old wife of 48 years.	Early stage. Had symptoms for 1 year and received care for 1 year.	Worked part time; was active in community; involved in church activities; spent time with grandchildren.	Adult son resides in same home as Caregiver A and care recipient.
B- 67 year old male caring for 93 year old father.	Late stage. Had symptoms for 10 years and received care for 9 years.	Retired maintenance worker. Care recipient was in research study to determine effectiveness of an Alzheimer's medication for past seven years.	Caregiver B and care recipient live with caregiver's wife of 11 years (second marriage for both). Caregiver's wife is Caregiver C. Caregiver had intermittent contact with children and grandchildren from first marriage who did not live in the area.
C- 58 year old female caring for 93 year old father-in-law.	Alzheimer's stage unknown. Has received care for 9 years.	Worked part-time as a secretary.	Caregiver C was the spouse of Caregiver B. Caregiver C had daily contact with her adult children from her first marriage.
D- 49 year old female caring for 88 year old mother.	Middle stages of Alzheimer's Disease. Has had symptoms for 2 years and has received care for 1 ½ years.	She worked full time as a secretary.	Caregiver D was married and had adult daughters with whom she was in close contact. When working, placed her mother in adult day care center.
E- 81 year old female caring for 81 year old husband of 58 years.	Late stage. Has received care for 5 years.	Retired.	Caregiver E had close contact with one of her children who lived in the area. Caregiver considering placing her husband in a skilled nursing facility at time of the study.

F- 74 year old female caring for 77 year old husband of 55 years.	Early stage. Had symptoms for 2 years and received care for 2 years.	Retired	Caregiver F had two children living in the area with whom she had close contact.
G- 62 year old female caring for 84 year old husband of 10 years. This was the second marriage for both.	Stage unknown. Had symptoms for 2 years and received care for 1 ½ years.	Caregiver had recently started a new full time job as a receptionist.	Both Caregiver G and her care recipient each had two children from previous marriages. Caregiver G was in search of adult day care center for her husband while she was at work.
H- 57 year old female caring for 87 year old mother.	Middle stage. Had symptoms for 3 years and received care for 3 years.	Caregiver worked full time, second shift, at a hospital. Her mother had been diagnosed with Alzheimer's disease three years ago.	Caregiver H was married and had two children away at college. Lives with her spouse who works the third shift. The care recipient was left alone for several hours each day while caregiver worked.

disease. The second portion of the questionnaire consisted of nine open-ended questions focusing on relationships, time spent in self-care, time spent in leisure activities, time spent in productive activities, overall health, and daily routine.

Field Notes. Field notes were compiled after support group sessions and after the in-depth interviews with the caregivers. Field notes completed after support group sessions contained information such as number of people present, gender ratio, general group affect, concerns of the members, topics discussed, group dynamics, and general observations. Field notes completed after interviews contained researcher impressions of prevalent issues they heard from participants, as well as their observations of participant non-verbal behaviors.

Role Change Assessment (RCA) 2.0. The RCA 2.0 is a semi-structured interview tool for assessing role change experienced by individuals (Rogers & Holm, 1995; Rogers & Holm, 1999). The six role categories it assesses are relationships, self-care/home maintenance, productivity, leisure, organizations, and health and wellness. The researchers were trained to administer the RCA 2.0, prior to administering it to study participants. Within one week following support group meetings, the investigators contacted the participants to schedule times for the RCA 2.0. These assessment sessions lasted approximately one hour and the sessions were audio taped.

Phenomenological Interviews. After completing the RCA 2.0 interviews, the audiotapes were reviewed. Using information obtained from the RCA 2.0 interviews, a second set of interview questions was then individually designed (unique to each caregiver) to obtain information about role performance from the caregiver's perspective. These questions from the findings of the RCA 2.0 addressed the unique concerns of the caregiver, roles that the caregiver missed, and/or new roles adopted since caregiving began. Using these phenomenological questions as a guide, a second, more in-depth semi-structured interview was conducted with each caregiver within two weeks of that individual's RCA 2.0 interview. During these sessions, additional probing questions were asked as appropriate. These sessions were audio-taped and transcribed verbatim by a professional medical transcriptionist.

Data Analysis

The method of analysis used in this study was thematic analysis (Morse & Field, 1995). Thematic analysis involves the identification of common threads that extend throughout an entire interview or set of in-

interviews. In our study, all questionnaires, field notes, and phenomenological interview transcripts were examined to determine common themes.

Means for assuring rigor and thereby trustworthiness in qualitative studies have been demonstrated by numerous individuals (Krefting 1991; Frankfort-Nachmias & Nachmias, 1996; Merriam, 1991). Trustworthiness in our study was achieved by triangulation, in that multiple data sources, methods, and investigators were utilized. There was also an emphasis on peer review and verification. The graduate student researchers analyzed all in-depth interview transcripts, field notes, and caregiver questionnaires to identify common categories of findings, which led to the identification of themes and sub themes.

The researchers identified categories when remarks frequently expressed by one individual were expressed by several participants, and/or were particularly emotional or strong. First, the researchers identified categories of information by writing these categories in the margins of the interview transcripts, questionnaires, and field notes. Second, they presented their individual analyses to each other, and recorded all of their proposed categories on a large roll of poster paper. Third, they reviewed these categories and, through active analysis and discussion, reached consensus on categories which could be combined or eliminated. Categories were eliminated only if they were weak, insignificant, or did not appear frequently. These changes were also recorded on the poster paper. Fourth, they sought to group similar categories into common broader themes and sub-themes, and these were recorded as well. These results were then validated by the faculty researchers, who examined the raw data to verify their validity. Each theme was named by looking for the quote that was most illustrative of that particular theme.

Another method in which rigor was ensured was through the maintenance of an audit trail consisting of all documents and data collected during the course of the study. The faculty advisors to this project verified the existence of all documents needed in this audit trail. This increased the confirmability, and thus, the trustworthiness of the study (Trochim, 2001, Confirmability section, para. 1).

Merriam (1998) suggests providing rich and thick descriptions to enhance the transferability of a qualitative study. A detailed description of each caregiving situation is provided in Table 1. Furthermore, the participants' quotes are presented verbatim, to add to this process of rich description.

RESULTS

Six themes relating to caregiving responsibilities and role change emerged from the data analysis. Three of the themes are further divided

into more specific sub-themes. These themes and sub themes are presented in Table 2, and are presented in detail below.

Theme 1: “I Feel Guilty Leaving Her.”

The majority of participants expressed considerable decline in leisure role participation because they needed to be with their loved one or because they felt guilty leaving that person. The caregivers expressed they did not want to burden other family members while they participated in leisure roles. Participant D emotionally commented:

It’s like you raise a family, and then you are thinking you can do what you want, and I am back to square one . . . I feel guilty leaving her with my husband all the time because it is my mom . . . (Crying) . . . so that is the hard part.

Participant F flatly stated:

My activities . . . are affected because I just can’t just get up and go. I have to plan ahead.

The caregivers expressed that they no longer had the time to participate in leisure activities due to their caregiving responsibilities. There was one atypical case identified during the interviews in which leisure participation increased. One possible explanation for this phenomenon is that he appeared to be using leisure as a means of coping with the stress of caregiving.

Theme 2: “Our Roles Have Been Reversed.”

“I Feel Like the Parent.” The caregivers in our study frequently expressed that the dynamics of their relationships with care recipients had significantly changed since they had become caregivers. Analysis of interview transcripts revealed several types of changes. In the situation where the caregiver was a son or daughter, a common characteristic was a feeling of role reversal. When asked to describe her current relationship with her mother, Participant D tearfully stated:

Well, now, it is kind of like parent and child, and I feel like the parent . . . (crying) Sometime(s) I feel like she is supposed to be the

TABLE 2. Themes and Sub-themes

Theme 1: "I Feel Guilty Leaving Her."
Theme 2: "Our Roles Have Been Reversed."
"I Feel Like the Parent."
"I Do Everything."
Theme 3: "Adapt...to What You are Going Through."
"Go to a Support Group."
"It's Really Been...a Form of Education."
"I Definitely Need God's Help."
"Without the Support ... There Would be No Way."
"Now it is Much More Regulated."
Theme 4: "I Have to Cook, I Have to Clean...I am Always Busy."
Theme 5: "Some People Shy Away"
"Some People ... Don't See Us Anymore."
"We Can't Do That Anymore."
"It is Their Mom, Too."
Theme 6: "My Health Care Comes After His."

mom and I'm the kid, and it will never be that way again. So it is hard.

The caregivers also articulated sadness over changes occurring in their loved ones that prohibited them from interacting with them as they previously had. One participant described the current relationship as "changed more to mother/son than wife/husband." During the in-depth interview, Participant H expressed sorrow over the loss of her mother as a confidant:

Before I was more able to communicate with her, telling her things, talking together . . . (I feel) very sad. Because it is not that you only lost a friend . . . the feelings are not the same.

The interviews demonstrated that caregivers often felt that the quality of the interactions with their loved ones had declined. Feelings of anger, frustration, sadness, resentment, and grief were frequently noted. The caregivers described the difficulty they had in accepting these changes. Participant B stated:

I would get angry at him, shout at him, swear at him, trying to get him to be his normal self. Of course that is not possible. I just did

the best I could. It is tough when somebody you love isn't there anymore. Like the guy at the last support group, said, "My wife died." Essentially that is what my father has [done]. He is not there anymore, even though he is here . . . After nine years, all I do is see him like he is now. And so, it is no longer a viable thing to remember him.

"I Do Everything." A significant change found in the majority of relationships was that the caregiver was now responsible for assisting the loved one with activities of daily living. These tasks included personal hygiene, bathing, dressing, toileting, feeding, and medication management. Participant D compared her mother's prior level of assistance to her current status:

I used to go to her house and I would help her get into the tub, but then she was on her own. I would wait around and do things, then I would go back when she was ready. But, now I'm actually getting her in. I'm right in there . . . then I get all the clothes and bring them up and get her out and help her dry. Same with her hair. I comb her hair. I do everything. She likes brushing it, but it's not right.

Participant F described her assistance to her husband:

Before, I would get up and take care of myself. Now I get up and make sure he showers, shaves . . . I lay out his clothes for him and make sure he gets dressed. Then I can tend to myself. Then I come downstairs and make his breakfast, put it on the table, and then make my breakfast. The rest of the day he sits on the porch or in the house, but it is the same thing. He is taken care of, and then I take care of what I have to do.

Theme 3: "Adapt . . . to What You Are Going Through."

All interviewed caregivers described methods to help them cope with the stress of caregiving. The most commonly discussed strategies resulted in sub-themes of support groups, self-education, faith, assistance from others, and regulating daily routines.

"Go to a Support Group." A significant number of the caregivers verbalized the importance of the support group in helping cope with the stress of caregiving. The support groups provided ideas on how to han-

dle situations, as well as the support of being with people who were experiencing similar situations. Participant B repeatedly articulated:

The only thing you can do is go to a support group . . . there is nothing out there to tell you what to do or how to do it. Go to a support group. Take what they go through or what they have gone through, and adapt that to what you are going through. There is no other way to learn to take care of someone with Alzheimer's. At least, I knew of nothing, and I still don't think there is anything out there other than support groups that gives you a guess on what to expect.

"It's Really Been . . . a Form of Education." Many of the caregivers spoke of their desire to find information about Alzheimer's disease and caregiving. This quest for knowledge resulted in taking classes, reading books, and attending seminars on these subjects. Many expressed frustration at the lack of information available for caregivers, as well as the need to seek out this information. Participant A stated his frustration:

It's really been a challenge and a form of education. Who needs all this education at my age? It's a part of life.

"I Definitely Need God's Help." Reliance on faith was a reoccurring coping mechanism found in interviews and support group discussions. A number of the support groups the researchers attended had clergy as guest speakers. Discussions took place regarding how reliance on faith could help them cope. Participant H stated:

I don't know how I have the strength to do this, I just pray to God everyday.

Participant A also demonstrated his increased reliance on faith by expressing:

I definitely need God's help in regards to keeping the patience, love, and knowledge in how to handle these situations.

"Without the Support . . . There Would be No Way." Participants frequently mentioned that caregiving without outside assistance would not have been possible. They turned to neighbors, spouses, children, grandchildren, siblings, friends, and community resources for assistance. These people helped by providing paid or non-paid respite care, assisting with

household responsibilities, taking responsibility for some of the care recipient's activities of daily living, and being confidants and sources of support. Participant D stated:

My husband is great. He never minds being with her [mother with Alzheimer's disease]. Without the support of the family, there would be no way. And the day care center of course. I had to have that.

Participant H described her sources of support in the following manner:

(My support is) . . . my family and my friends at work. They tell me ideas and they try to tell me how I have to do (things) with my mom . . . Or the doctors at work. They give me advice. They tell me things. They are a big help.

Participant B described his reliance on his neighbor for assistance in caring for his father:

I check on him first thing in the morning, and the lady across the street comes over and gets him up and dressed, or gets him showered and his breakfast.

Participant C agreed with her husband (Participant B) on the importance of their neighbor in caring for her father-in-law:

We have been so lucky to have her (neighbor) . . . I mean, if we didn't have her, we wouldn't be so well.

"Now it is Much More Regulated." Many of the caregivers described the importance of having a regulated daily routine. This involved keeping the individual with Alzheimer's disease in a familiar environment, following the same schedule everyday, and planning ahead. When asked how she coped, Participant H stated:

I have to keep my schedule always the same. I know where I put things. I know what I have to do, and how I have to do it. I just do it automatically.

Participant D described her schedule in the following manner:

Now it is much more regulated. I can't just make the short little trips like I used to because I have (my mother) with me all the time. I am also working full time now, so that doesn't give me as much time either. It's getting myself ready and her ready . . . I am waking her up. I am getting two people dressed instead of just one and then I drop her off at the center on my way to work, go to work, pick her up after work . . . I don't have the freedom I used to have.

Theme 4: "I Have to Cook, I Have to Clean . . . I Am Always Busy."

A frequent finding was a change in the household management role. Participants reported having more household responsibilities, but less time to do them. Caregivers were responsible for tasks such as cooking/meal preparation, washing dishes, laundry, errands, cleaning, and driving. These tasks often dominated their days. Participant H described her household management responsibilities in the following way:

I have to leave everything ready. . . . The syrups, the juices, her medication. I make her lunch or dinner. I have to have everything ready for her before I leave. I have to cook, I have to clean . . . I am always busy.

The caregivers were now often responsible for performing tasks that were previously done by the individual with Alzheimer's disease. Participant A described a typical day:

I am basically doing the same thing I did 2 or 3 years ago, but it is involving more doing things around the house that she basically used to do. She is doing very little of this, such as cooking, meals, doing dishes, and doing laundry.

Another spousal caregiver, Participant G, stated:

He can't help with anything anymore, so it is pretty much that I do everything He thinks he is helping me, but he is not. He does not get the dishes clean, so I have to watch everything that he does and must make sure the dishes are clean. Most of them I have to do over again. So, he is hardly a help at all.

Theme 5: "Some People Shy Away."

"Some People . . . Don't See Us Anymore." Not only was the quality of the caregivers' interactions with the individuals affected, but their re-

relationships with others changed as well. One individual wrote that since her husband has had Alzheimer's disease, her interactions with others have "become increasingly different. Some people shy away and don't see us anymore." Similarly, Participant E discussed how she and her husband no longer participated in their former social circle due to her husband's inappropriate behavior, which in turn affected her relationships with these people. Participant D described her interactions with her siblings as almost exclusively about the care of their mother.

"We Can't Do That Anymore." A frequent discussion topic during interviews and support groups was having less time for social interactions due to caregiving responsibilities. Caregivers felt they were spending less time with their children, grandchildren, and friends. As Participant G stated:

I used to go and play cards a lot. [My husband] will go with me. So I don't go a lot because I don't think he'll enjoy it. We used to do the bulletins for the church and we can't do that anymore. It's just that I have so little time with everything else I have to do.

Participant F regretfully articulated these feelings as well:

[My relationship with my daughter has changed because] I don't get to see her as much anymore. I used to see her every week.

"It is Their Mom, Too." The topic of the caregivers' desire for additional family support was discussed during multiple support groups and interviews. The caregivers lamented that they experienced stress, while family members not living with the individual provided very little assistance. Participant D, who was caring for her mother, hesitantly said:

I do sometimes wish that I would get more help . . . I wish other family members would volunteer instead of me asking. I know if I asked, they'd help, but I feel like, why do I have to ask? It is their mom too. I feel like everyone else has gone on and nothing has changed for them. But for us, everything has changed.

Participant G expressed frustration over her husband's sons not assisting in his care:

It is very disappointing because when I ask, they say, "Oh yes, we understand. We'll be up to help." Not once, not once have they helped. And I asked them in July. Two and a half months ago.

Theme 6: “My Health Care Comes After His.”

Caregivers frequently described a decrease in their overall health. One caregiver explained: “My time spent in maintaining health and wellness has taken a back seat to his care and well-being.” Another individual wrote on the questionnaire: “My time for my own needs of health care come after his needs.” The health and wellness of the caregiver was also a common topic at support group meetings, with group facilitators often emphasizing the need for caregivers to take care of themselves.

Some of the caregivers reported being on medication for depression and/or anxiety. Others reported being on blood pressure medications due to their stress levels. Participant A described his mental health:

I would say for the last six to nine months I have been having more typical and emotional depression and anxiety, due to the fact of caregiving. I’ve had problems in this way . . . I had to go to the doctor and get different medications.

DISCUSSION

It is suggested that adaptation is necessary to help a person restore the equilibrium lost due to role changes (Rogers & Holms, 1999). Adapting to the role changes posed by the caregiving experience seems essential for caregiver survival. Caregiver coping strategies identified in past studies include the use of support groups and limited informal assistance from others (Clark & Bond, 2000; McGrath et al., 2000). Clark and Bond (2000) found that caregivers accessed resources such as respite care, support groups, and community resources. The majority of individuals in our study found support groups to be a beneficial method of coping. Admittedly, this was not surprising since the primary participant recruitment strategy was a presentation conducted at a support group meeting. Additionally, the caregivers in our study identified additional coping strategies such as self-education, faith, and a regulated daily routine.

Merrill (1997) indicated that the care of aging parents has a significant degree of role reversal in middle and working class families. Feelings of role reversal were frequently discussed during the support groups in our study. At a recent Harvard Symposium, researchers in the field of social work noted that role reversal is a frequent phenomenon in the family dynamics of caregiving (Salmanson & Robbins, 2003).

The caregivers in the study experienced a change in household management. Not only did the frequency of participation in household tasks increase, but also participation in this role dominated their entire day. A previous study found that caregiving can have a negative impact on the major life areas that collectively define a person's occupational performance, including self care, productivity, and leisure activities (McGrath et al., 2000).

Our findings expand upon the results of a prior study which noted that the primary caregiver progressively assumes many new responsibilities and tasks as the loved one's functional status declines (McGrath, Mueller, Brown, Teitelman, & Watts, 2000). Similarly, Clark and Bond (2000) examined spousal caregivers of individuals with Alzheimer's disease. Their findings revealed that the caregivers' greatest involvement was in the area of providing care for their spouses.

In a study by Clark and Bond (2000), caregiving spouses of persons with Alzheimer's disease scored extremely low in the social activity category of the Adelaide Activities Profile. Other studies have demonstrated the decline in social relationships often experienced by caregivers. George and Gwyther (1986) investigated the impact of caregiving for adults with Alzheimer's disease through an examination of four generic categories of well-being. These categories included physical health, mental health, social participation, and financial resources. It was found that caregiver stress predominately affected an individual in the areas of mental health and social participation.

Rogers and Holm (1999) stated that role loss has the potential for exerting a wide range of effects on well-being and life satisfaction. Kielhofner (1997) suggested that when one's roles have been altered, or a role has been lost, the change is detrimental. This disruption in role performance may also cause psychosocial dysfunction.

Caregiver well-being is an important issue, since it influences the ability of the caregiver to provide home care for people who might otherwise be institutionalized (Clark & Bond, 2000). Bergman and Evans (1994) suggested caregivers often experience physical conditions in which their complaints were ignored or neglected. Some of the interviewed caregivers reported the need for therapeutic services. The problems and conditions they manifested were related to the additional stresses they faced. Multiple studies have found physical and emotional deficits generated by the stress on the caregiver as a result of the caregiving process. In particular, depression was identified as a common health detriment associated with pressures produced by caregiving (Stone et al., 1987; George & Gwyther, 1986; Neundorfer et al., 2001). Our study

found a decline in participation in caregiver health and wellness roles. Some caregivers stated that they placed the needs of the care recipients before their own health and wellness needs, while others expressed that their own health had been so dramatically affected (i.e., depression and anxiety) that they had begun seeking medical attention.

The findings of our study indicated a decrease in caregiver's overall health. Ziff and Schaffner (2000) found caregivers were often too busy to care for themselves, leading to physical and mental health problems. The caregivers interviewed felt they no longer had time to enjoy hobbies and leisure interests (Ziff & Schaffner, 2000). Others found that the daily stress of taking care of a parent, grandparent, or spouse often resulted in frustration and burnout (Morris & Gainer, 1997).

In previous studies, the responsibility of caring for aging parents was largely taken on by women (Spitze & Logan, 1990). It is worth noting that 6 of the 8 caregivers who volunteered to be interviewed for our study were females. Although not an exclusively female responsibility, in the situations we studied, caregiving seems to be a role more common to females than males. In spite of increased blending of traditional male and female roles in our society, American culture may still have the expectation that females be caregivers and nurturers.

There have been limited studies published in the occupational therapy literature related to intervention strategies for the caregivers of individuals with Alzheimer's disease. One recent and promising development is the *Disability Assessment for Dementia* (Gelinias, Gauthier, & McIntyre, 1999). This instrument is an assessment of functional performance which is designed to be used for persons with Alzheimer's disease who are living in the community. Occupational therapy clinicians working in the home health sector may benefit from utilizing an instrument such as this to gain more detailed information on their clients, and to thus better provide intervention which can ease caregiver stress.

CONCLUSION

The caregivers in our study portrayed feelings of role reversal when discussing their situation. Caregivers in our study indicated there was a decrease in the amount of time, as well as the quality of the time, they were able to spend in relationships with others outside of the caregiving situation. There was a significant increase in the supervision and assistance necessary with activities of daily living of the care recipient. A

few of these caregivers expressed a desire for increased family support in the caregiving process.

A possible intervention is the provision of caregiver instruction and support which could include training in time management skills, use of relaxation and stress management techniques, and an emphasis on continuous participation in leisure activities. Occupational therapy practitioners could also provide information to caregivers on existing community resources, such as educational classes, support groups, adult day care centers, home health services, assistance in transportation and financial management.

One study examined caregiver perceptions of occupational therapists working with persons with Alzheimer's disease, and made four critical recommendations (Toth-Cohen, 2000). These were the need for occupational therapists to: (a) join forces with patients, families, and other professionals, (b) recognize the knowledge of others, (c) consider the family point of view, and (d) comprehensively meet client needs in the home environment. Such actions may do much in alleviating care-giving burden. In addition, members of other health care professions may be wise to more attentively consider caregiver needs. This can improve quality of life for clients and families through a broader and more holistic health care program.

The ever-rising number of chronically ill elderly in the United States pose a huge and growing challenge to a complicated health care system strained by astronomically high costs and intricate bureaucracy. Caregivers of persons with Alzheimer's disease and other disabling chronic conditions are assuming a vital medical, economic, and social responsibility, and are an essential component of the country's health care infrastructure.

Although in the fast-paced world of health care the importance of the role of the caregiver is sometimes overlooked, the occupational therapy profession continues to recognize the significance of the family and others in the client's home situation. The occupational therapy theoretical knowledge base places much emphasis in this area. Fidler and Velde's (2000) Lifestyle Performance Model highlights how family and relationships, and the broader social and cultural environment, affect a person's occupational performance. Law's (1998) description of client-centered occupational therapy also recognizes the importance of family involvement in health care decision-making.

It is imperative that caregivers of individuals with chronic conditions such as Alzheimer's disease receive support and understanding. This can help the caregivers function more effectively and has the ultimate po-

tential of reducing the demand placed upon the health care system by the rising number of chronically ill elderly. The holistic occupational therapy perspective stresses the importance of viewing the client within the context of his or her total environment, and this includes familial circumstances and relationships with others. Occupational therapists possess a keen awareness of how family and caregivers contribute to client wellness, and are ideally suited to function as effective liaisons with caregivers.

RECOMMENDATIONS

This investigation has demonstrated how caregivers often find it difficult to fulfill the duties and responsibilities of their chosen life roles, due to the demands of helping others. Often caregivers do not have the time or energy to devote to their own health and happiness. Occupational therapists can help resolve this problem by placing more emphasis on assessment of family and caregiver needs. Such assessment will illuminate the challenges faced by individual care providers, and may indicate the need for caregiver support. Caregiver assessment strategies are in need of further development both in home care and in other community and institutional settings. This includes informal interview and observation techniques as well as more formalized evaluation tools.

Occupational therapists may also be pivotal in recommending valuable strategies to improve caregiver role performance and quality of life. These include making recommendations for support group involvement, counseling and/or medical services, and health and wellness programs. Occupational therapy entrepreneurs may also consider developing their own community wellness programs, of which caregivers may be participants. There are many options for expanding the interaction between therapists and caregivers, and they are only limited by time and creativity. The economic, medical, and social benefits that can be reaped from acknowledging caregiver needs and promoting healthy caregiver role performance cannot be understated.

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