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The Leisure of Caregivers of Older Adults: Implications for CTRS's in Non-traditional Settings

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Little research exists that explores perceptions and experiences of caregivers of older adults with specific regard to their leisure. The purpose of this study was to examine the perceptions of leisure and leisure experiences of women who were informal caregivers of older adults. Sixteen respondents, identified through theoretical sampling, participated in tape recorded in-depth interviews. Analysis consisted of constant comparison and analytic induction. Three concepts emerged from this data: leisure experiences of caregivers, changes in leisure since caregiving, and barriers (both internal and external) to leisure as a result of caregiving. Implications and specific strategies generated from the data regarding providing leisure services for caregivers are discussed.

KEY WORDS: *Caregivers, Non-traditional Recreation Settings, Barriers to Leisure*

Predictions indicate that due to the aging of the baby boomers, the population of the United States is going to experience a dramatic increase by the turn of the century. Coinciding with the rise in population is an

increased number of individuals who will need care in later years. This significant increase in older adults will have an impact not only on the health care of these individuals, but also on those who will provide these

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services. As health care costs rise, increasing numbers of spouses and children of ill and dependent older adults will be among those accepting the responsibilities of caregiving.

Informal caregivers, or individuals who care for family members in their home without pay, are typically women (Cantor, 1983). One third of these women have children under 18 years of age in the home, approximately one tenth have given up employment because of caregiving responsibilities, most experience physical and emotional manifestations of stress, and many abandon social interactions, hobbies, church related activities, and fitness pursuits (Stone, Cafferata, & Sangl, 1987; Wilson, 1990).

Caregivers have been identified as a group who, because of the stress of their responsibilities, are in a high risk category for psychological and physical ailments (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; George & Gwyther, 1986; Neundorfer, 1991; Pearlin, Mullan, Semple, & Skaff, 1990; Reese, Gross, Smalley, & Messer, 1994; Stone, Cafferata, & Sangl, 1987). For example, caregivers have scored high on ratings of depression (Gallagher et al., 1989), perceived their own physical health to be negatively affected by the responsibilities of caregiving (Neundorfer, 1991), and experienced diminished self concept (Pearlin et al., 1990). Reese, Gross, Smalley, and Messer (1994) compared caregivers of older adults with Alzheimers' disease to stroke patients. They found that caregivers reported more psychological distress than the stroke group and both groups were more distressed than the non-caregivers controls.

The losses due to caregiving have also included leisure activities such as: (a) regular exercise, (b) time for oneself, (c) interest in activities, (d) sex life, (e) opportunities to socialize with friends, (f) social resources, (g) vacations, and (h) time for leisure pursuits (Barusch, 1988; Cantor, 1983; Reese, Gross, Smalley, & Messer, 1994; Sneeas, 1988; Snyder & Keefe, 1985). Empirical evidence also indicates that caregivers consis-

tently pursued fewer phone contacts and visits with family and friends, reduced the number of visits with family and friends, decreased participation in church and club activities, and spent less time doing hobbies and relaxing (Cantor, 1983; George & Gwyther, 1986; Stone, Cafferata, & Sangl, 1987; Wilson, 1990). A compelling illustration of the impact of caregiving on the loss of leisure is noted by Moss, Lawton, Kleban, and Duhamel (1993). These researchers found that caregivers were able to add 23 minutes of recreation to their day after their care-recipient entered a nursing home.

Leisure researchers exploring the benefits of leisure participation and satisfaction suggest a strong connection between leisure wellness and mental and physical health (Coleman & Iso-Ahola, 1993). Caregivers, however, typically give up their leisure to provide care for their care-recipient (Barusch, 1988; Cantor, 1983; George & Gwyther, 1986; Stone et al., 1987; Reese et al., 1994; Sneeas, 1988; Snyder & Keefe, 1985; Wilson, 1990). Although many studies have identified the loss of leisure as a result of caregiving, few have focused specifically on the caregivers' perceptions and experiences of leisure (e.g., Bedini & Bilbro, 1991). Understanding the caregivers' perceptions of leisure can provide valuable information to health care providers, particularly therapeutic recreation practitioners. By examining the leisure perceptions and experiences of this "at risk" group, therapeutic recreation specialists can identify areas for programming and service delivery for caregivers of older adults. The purpose of this study was to examine the perceptions of leisure and leisure experiences of women who were informal caregivers of older adults. Through the analysis, the authors gained insights into the changes in and barriers to leisure pursuits experienced by these women caregivers. The insights aided in the formulation of strategies for therapeutic recreation specialists to begin to address the caregivers' leisure needs.

Conceptual Framework

The conceptual framework for this study was symbolic interactionism. Schwandt (1994) defined the theory of symbolic interactionism as, ". . . an interpretive science in search of portraying and understanding the process of meaning" (p. 123). In his description of symbolic interactionism, Blumer (1969) suggested that human behavior is based on how people interpret and derive meaning from their social interactions with things, others, and their environment. These interactions generate symbols which, when interpreted, are then used to direct one's behaviors.

In a model of leisure viewed from a symbolic interactionist perspective, Samdahl (1988) suggested that leisure is affected by the individuals' perceptions of their interactions and how they relate to the interactions they face. Symbolic interactionist perspective was useful for the current study to help the researchers to understand the social (symbolic) context within which the caregivers perceived and interpreted their leisure. Additionally, this conceptual framework helped the researchers to identify how these perceptions of leisure led to the definitions and subsequent behaviors of the female caregivers.

Methods

Procedures

Sixteen respondents were identified through theoretical sampling technique. Theoretical sampling is a process of collecting a sample that will represent the concept being studied (Denzin, 1978). Initial contacts with subjects were made through staff at adult day care centers and support groups for older adults and their families. After respondent contacts were made from the identified sources, additional subjects were selected from recommendations of the original respondents using theoretical sampling. For this study, the respondents were selected

based on their contribution to a sample representative of caregivers in North Carolina considering race, age, economic status, and educational level. New respondents were solicited until saturation, or the point where no new information emerged from the data being collected, was achieved.

Each subject participated in semi-structured, in-depth interviews. The interviews (which lasted 45 minutes to 2.5 hours) were conducted to allow the women to express their concerns, experiences, and perceptions of caregiving and leisure. An interview guide format was used with questions relating to the caregiver, the care-recipient's needs, and the caregiver's current perceptions and involvement in recreation and leisure pursuits. The respondents were also given the opportunity to discuss their attitudes and awareness of leisure in their lives before and after assuming the caregiving responsibilities. Interview sessions were audio-taped and transcribed. Participants were invited to review transcripts and tapes to verify the information and make any necessary corrections before the data were analyzed.

Questions for the interview guide were generated from relevant professional literature. The initial interview guide presented questions such as: Describe your care-recipient. What do you currently do for fun? Is there anything about your life before you began caregiving that you miss now? How do you define leisure and recreation? Are your needs currently met through leisure and recreation? Are there things you would like to do but can't do now? How would you like your situation to be different? The second interview asked follow up questions that confirmed emergent themes such as how the women prioritized their leisure, their concepts of freedom in leisure, and access to and use of respite and support.

A second interview was conducted with a sub-sample of four (25%) of the original respondents to confirm themes generated from the initial interviews (Lincoln & Guba, 1985). These "member checks" were con-

ducted to determine validity of the original interpretation of the data. New questions for these interviews specifically represented the patterns raised in the initial interview data. The respondents for the second interviews were chosen based on their demographic representation, their willingness to participate in a follow-up interview, and their ability to confirm and refute emergent themes from the first interviews.

Data Analysis

Constant comparison (Glaser & Strauss, 1967) was used as a method for analyzing the data. In this method, two researchers independently read, re-read, and coded the data to determine concepts, categories, themes, and patterns. Issues of reliability and trustworthiness (Lincoln & Guba, 1985) were addressed in several ways. First, interviewer's notes were analyzed to enhance and confirm the understanding of the themes generated within the data. Second, in addition to respondents, verification of data, member checks (second interviews) of 25% of the respondents were conducted to determine the validity of the original interpretation of the data. Once themes were identified, analytic induction (Bruyn, 1966) was used. This method organizes the data based on the generated themes and subsequently links these themes to new and existing conceptual constructs. Additionally, application of current literature were used for interpretation of the data.

Respondents

The respondents consisted of sixteen women responsible for the informal care of an older adult family member in their homes. The respondents' ages ranged from 34 to 77 years. They approximated the racial diversity of the Triad area in central North Carolina with three African-American and 13 European-American individuals. The majority of the respondents ($n = 13$) were married at the time of the interview. Their education

included some high school ($n = 3$), technical school ($n = 2$), high school graduate ($n = 6$), Bachelor's Degree ($n = 3$), Master's Degree ($n = 1$), and PhD ($n = 1$). All but two of the women had children ranging in age from three to 54 years. Five of the women cared for their children in their homes. Eight of the caregivers were employed at the time of the interview and the remaining eight identified themselves as housewife ($n = 2$), retired ($n = 3$), or unemployed ($n = 3$). Nine caregivers were caring for their mothers, while two were caring for their mothers-in-law, one for her father, one for her great aunt, and three for their spouses. Many of the care-recipients had multiple disabilities resulting in their need for care. Primary conditions of the care-recipients included Alzheimer's/senility, heart and circulatory disorders, cerebral vascular accident (stroke), arthritic conditions, and Parkinson's disease. The length of time that the caregiver had previously cared for the recipient ranged from 1 to 11 years, with an average of 4 years.

Additionally, the caregivers demonstrated medical needs typically magnified by stressful situations such as caregiving. Many of the women described physical and emotional dysfunctions. Physical dysfunctions included conditions such as a benign nervous condition (similar to Parkinson's disease), a heart condition, severe sinus allergies, and a prolapsed vagina. Emotional ailments included conditions ranging from emotional strain to clinical depression.

Findings

The findings from this study provided helpful insight regarding the understanding of the leisure of women who were caregivers of older adults. Three perspectives of leisure were generated from the data that explored the women's leisure experiences, the changes in their leisure since they began caregiving, and the barriers and constraints they identified as a result of their caregiving responsibilities. Sub-categories were also determined that pro-

vided more detailed examination of the overall topics.

Leisure Experiences

The women in this study described a variety of leisure interests such as exercise class, volunteer work, golf, outdoor activities, reading, travel, music, tennis, movies, bowling, swimming, visits with friends, choir, and eating out. Similar to the profile of most women in the United States, these women also expressed an interest in doing activities that involved their families (Henderson, Bialeschki, Shaw, & Freysinger, 1989). When asked what they actually do for leisure, however, the list of activities was considerably shorter with a few of the women including activities such as "chores" or "laundry" as their leisure. For example, a 44 year old woman caring for her mother with Alzheimer's disease noted, "The leisure time for me was doing the laundry and being able to just catch up on housework, because that's all the time I had to do."

When asked to define recreation and leisure, many of the women spoke in terms of how leisure and recreation helped them accomplish tasks or cope with situations. The women stated that leisure could help them escape, refresh, and handle the burden of caregiving. A 62 year old retired woman caring for her mother-in-law suggested that leisure relaxes her and helps her to cope. She stated, "it [leisure] gets me away from all the things I go through." Other women stated that leisure and recreation helped them to "manage stress," was a "time of re-connecting," provided "relief from immediate responsibility," and it "essentially recharges my battery." A 34 year old woman caring for her mother-in-law who had Alzheimer's disease said she did not know how to describe the value of leisure, but she knew it was beneficial in that it provided escape and enjoyment. She explained that she practiced with her church choir three times a week, and said, "I don't know if I enjoy singing or, you know, just being by myself,

you know, away from everybody . . . so I really enjoy that."

Overall, a theme that emerged from the data suggested that these women saw leisure as freedom from responsibility and worry. Rather than mentioning specific activities/experiences to pursue, most of these caregivers spoke of being away from their respective burdens and concerns.

Perceived Changes in Leisure for Caregivers

The caregivers in this study noted that undertaking caregiving responsibilities necessitated changes in their leisure. Though they valued and desired leisure, many experienced difficulty in accessing it. For example, a 48 year old caring for her mother with Alzheimer's disease stated that:

I've given up a lot. I used to get up and go whenever I felt and do whatever I wanted, you know, play golf, and spring and summer, in the spring I started to play golf, and in the summer, you know, swim, uh I'd go on weekend trips all the time. Before she came down. That stopped.

In addition to the difficulty in accessing leisure, many caregivers experienced feelings of loss of freedom, independence, spontaneity, and social contact. These losses had a direct impact on the leisure perceptions of these women.

Loss of Freedom and Independence

Many caregivers lamented feeling the lack of freedom to do what they wanted to do, when they wanted to do it. In many cases, the caregivers felt tied to the home while addressing the needs of the care-recipients. Consequently, they were unable to pursue their own leisure. For example, a 53 year old woman caring for her mother with dementia shared how she would like the freedom to

just get out. She stated, "I used to go crafting . . . I miss that. I can live without it, but I miss it." Another woman, 52 years old and caring for her mother with Parkinson's disease, expressed resentment toward the loss of her independence due to caregiving. She explained, "I've lost some of my independence because of her [mother] being here. And that makes me angry and upset." Another woman, 51 years old and caring for her mother who had had a stroke, talked about missing the freedom to choose what she wanted to do. She stated:

I miss the fact that I can't sleep as long as I want to, or go to bed when I want to, or sit and watch a movie all the way through without having to get up and see what she's [mother] doing. So, um, I miss that a lot. I guess, the freedom more than anything else and the independence, because I just did what I wanted to.

In other cases, the women's sense of freedom was more emotional than functional. A 47 year old woman who was caring for her great aunt with multiple medical conditions described what she referred to as "mental freedom." She explained that when she was away on a business trip, she was able to go for walks in the morning. She stated, "It was just the whole mental freedom I had, not worrying about someone else, being responsible for someone else."

Several of the women noted that they missed their spontaneity. The ability to "just get up and go" was gone. A 41 year old woman caring for her father with heart disease expressed, "I could just get up and leave the house any time I wanted. I can't do that no more." The loss of spontaneity had particular relevance to their inability to travel. For these women, the responsibility of caregiving severely limited their ability to leave the home for even short periods of time. For example, a 64 year old woman

caring for her mother with failing health stated:

Well, I'll tell you definitely one thing I would like to do would be take short trips with these little tours. I would love to do that, um, and I can't do that, that's the main thing, I would really love to, to be able to do just a little traveling.

Another woman, 70 years old and caring for her husband with Parkinson's disease, noted that she would like to go on vacation but did not feel comfortable leaving her husband behind. When asked what caregiving prevented her from doing, another woman caring for her mother simply stated, "Take a trip. Mmm hmm. I'd like to take a trip."

Loss of Social Life

Many of the women noted losing the opportunity to visit or socialize with friends and family, after assuming caregiver responsibilities. One woman caring for her mother with Parkinson's disease described how her ability to interact with friends became limited by caregiving responsibilities. She noted:

. . . like after work. I have to pick her up and being that she's so tired, I don't really want to go anywhere. And a lot of times, I would go and call my friends, and say 'hey, let's go out to dinner. Let's take in a movie.'

Similarly, a 68 year old woman caring for her husband with multiple disabilities lamented about missing the times she and her husband spent with other couples. She described:

. . . we had such a good time with friends. We'd get together and play cards. . . . Once a week we'd get together and do things like that together

and, uh, he's [husband] not part of it anymore, and, because his conversation is just not with us anymore. And, uh, if we tried to play cards, maybe he'd hold them the right way and maybe he wouldn't.

Another spousal caregiver shared that after her husband became ill, many of their friends stopped calling. "It's heartbreaking. And to think that . . . even your friends forget you." On the other hand, some women found that the presence of the care-recipient made visits from others uncomfortable. A 62 year old woman caring for her mother-in-law who had memory loss stated that:

. . . it was kind of hard to have friends come in here because she [mother-in-law], you know, she would interfere with everything and she wanted to be in on everything . . . so we just really didn't do a lot of entertaining because of her . . .

In summary, the obligations of being a caregiver seemed to interfere with both the opportunities for social interactions, as well as the nature of these interactions. Regardless, social interactions were often compromised for the caregivers in this study. Some caregivers found it difficult to interact with friends and family outside the home, while others struggled to interact with others inside the home, including their care-recipient.

Leisure Constraints/Barriers

Though most of the caregivers valued leisure and expressed an interest in leisure activities, they discussed their limitations for pursuing leisure in terms of constraints and barriers. The experienced barriers and constraints hindered their involvement in leisure activities and imposed upon their sense of freedom to enjoy the little involvement they managed. The obstacles to leisure were both internal and external.

Internal Barriers and Constraints

Internal barriers and constraints to leisure refer to obstacles related to thoughts and concerns from within the caregiver. The primary internal constraints noted by the caregivers in this study were: (a) perceived responsibility for the care and well-being of the care-recipient, and (b) physical and emotional fatigue.

Perceived Responsibility. The observations of the caregivers within this study supported the findings of Finley, Roberts, and Banahan (1988). They suggested that social responsibility, role expectations, and a sense of indebtedness serve as motives for the caregivers' helping response. Some of the caregivers in our study believed that it was their duty as a daughter or wife to care for their spouse or parent. As stated by one of the spousal caregivers, her responsibility as a wife was "till death do us part."

Other caregivers addressed their sense of responsibility in terms of fulfilling a social role. For example, a 62 year old woman caring for her mother-in-law who had memory lapses stated, ". . . we are supposed to take care of our parents when they can't take care of themselves." She went on to state, "I just do what I know is right to do as far as, I mean, I am the one who volunteered to take care of my husband's mother because no one else [immediate family] would." Still others expressed a sense of indebtedness, feeling that although they had little control over the circumstances, they "owed" it to their care-recipient. A 43 year old woman caring for her mother with heart and circulatory conditions shared that, "as long as I'm livin', my momma never goin' in a nursing home, because she took care of me . . ."

For several caregivers, the sense of responsibility included making sure the leisure needs of their care-recipients were met. For example, a 47 year old woman caring for her great aunt said, "I feel it's not right to just leave her there, doing nothing. . . . I felt it was my responsibility to give her outlets,

you know, play games with her and talk with her and not just leave her there, miserable.”

Although the caregivers’ sense of obligation and duty often included the leisure needs of their care-recipient, these responsibilities typically superseded the caregivers’ personal needs and desires, often precluding their leisure pursuits. A 41 year old woman caring for her father said she would love to be active and to get out more, to “. . . go to the movies or take a vacation, you know. We can’t do that now. But if I didn’t have Daddy, you know, I mean we could go . . .”

Some of the caregivers noted that pursuing their own leisure indirectly made their care-recipient “unhappy” or “frightened.” Other caregivers were fearful of leaving their care-recipient, afraid of what might happen while they were gone. There was also some fear that hired caregivers would be unable to provide appropriate care or that the care-recipient’s health would fail. One woman expressed her conflicting feelings of the desire to get away and the fear of leaving:

. . . I wanna run down here to the store and I cain’t do that, ’cause I feel like, if, if I leave, I thought sometimes before, I said, well, you know, Daddy might be all right if I just run down to the store. And then I git to thinking, well, what if he dies or somethin’ and I come back. What am I goin’ to do? How am I goin’ to feel with myself, you know?

Another woman, 34 years old and caring for her mother-in-law who was suffering from dementia, mentioned a similar fear of leaving the care-recipient. She stated:

I wish that I could feel more comfortable in leaving. You know, it’s the same feelings that a mother has when she leaves her children. . . . I went to the coast for a night, um, and I found myself worrying more about the caregiver [sitter], you know, if they are be-

ing overburdened or if they know how to handle this problem or if they know how to check that or, you know, I found myself being concerned with those types of issues . . . the only answer to that would be having more people that know her, that she is comfortable with, that I could leave her with, and there aren’t any other people.

Physical and Emotional Fatigue. The caregiving responsibilities often placed considerable demands upon the caregivers, draining them of physical and emotional energy. As noted by one woman, who was 64 years old and caring for her mother with failing health, she felt tired and “emotionally drained.” Another woman who was 58 years old and caring for her mother who had dementia described the feeling as being “tired emotionally.” She noted that her “job is very demanding. I have to work sometimes to 6:30 or 7:00 pm and then when I get home I don’t really feel like doing anything.” These sentiments were shared by a 70 year woman caring for her husband with Parkinson’s disease. She talked about being so tired she was afraid she would not be able to drive home without falling asleep at the wheel. She explained, “I’m so tired that I don’t, I mean, you know, I could just sit down. I could lay on this floor and let people walk over me and it wouldn’t bother me.”

In summary, social and role expectations posed powerful limitations to the access of leisure for these caregivers. Although for most of these women the barriers to pursuing leisure came from within themselves, they seemed to feel unable to control or change these constraints, thus creating a conflict.

External Barriers and Constraints

External barriers and constraints to leisure refer to the obstacles that occur due to factors outside the caregiver. The primary external barriers and constraints noted by the

caregivers in this study were: (a) lack of time, (b) lack of outside help, and (c) financial strain.

Lack of time. The time demands of caregiving clearly affected the caregivers' ability to access leisure. One woman described how caring for her mother with failing health added to a demanding schedule that already posed many constraints on her time. She stated:

. . . like today, I am going to bake my daughter-in-law a birthday cake because her birthday is tomorrow and this is something, my daughter-in-law is very good to me and I feel I should do, um, okay, I have to get the wallpaper and carpet which is not easy to do . . . I should, I have to take my car in today . . . it's always something and it's not always related to mother. It's the other things I have to do too and I have very little what you would call leisure time.

A 51 year old woman caring for her mother who had heart and respiratory disorders discussed having less time to talk on the phone, a favorite leisure activity prior to caring for her mother. Another 70 year old woman caring for her husband explained how even when she went out to "circle meeting," she felt in a rush. She stated:

. . . I feel like, I've got to hurry home because whoever's with Daddy's [her husband] got to go to work in the morning. It kind of puts you in a strain. I hurry to get up and hurry to go to bed and hurry to do this and hurry . . .

Some of the caregivers found it difficult to complete even the day-to-day tasks. For example, a 52 year old woman caring for her mother who has dementia, experienced difficulty attending to personal work, including housework. She noted:

I would like to have time to get my house clean. I would like to have time to do my own work, I'm kind of letting that go now, because she is constantly needing to know where I am. If I walk out of the room, she calls and says, where are you?

Lack of Outside Help. Many of the care-recipients required constant care or supervision. If the caregiver desired to do something outside of the home or separate from the care-recipient, it was necessary to find someone to fill the caregiving role. When asked about her interest in pursuing leisure and recreation, one caregiver noted:

I just wish that, (long pause) I guess that the, that I could have somebody sometimes, you know, (crying while talking) that I didn't have to worry about with my family. And then, you know, somebody that I knew could stay that I wouldn't have to worry, you know. Just, you know, where once in a while, not all the time, 'cause I'm doin' it 'cause I want to . . .

At first, it appeared that there were many potential resources for outside help. Caregivers could seek assistance from friends, family, churches, community organizations, adult day care centers, or private agencies. Upon further examination, however, it was apparent that each option was accompanied by its own set of problems or conflicts. In the final analysis, it was evident that the resources for outside help for the caregivers in this study were minimal.

Many of the caregivers in this study, especially those who worked outside the home, relied upon the services of an adult day care center to care for their care-recipient during the daytime hours. The adult day care programs offered recreation and special programs for the care-recipients, and the caregivers praised the centers they were using. Unfortunately, using the centers was not

without problems. Adult day care centers were described as expensive and were typically closed during evening and weekend hours, times that were often desired for personal leisure activities.

Home health care agencies were similar to the adult day care center, except that they provided personnel to care for care-recipients in the home. The caregivers who mentioned these services noted varying experiences, however. Some felt that outside caregivers coming to their homes was a blessing. This outside help provided a block of time to go out with friends or spouses, to do personal chores, or to simply have a break without worrying about their family member. A 51 year old woman caring for her mother who had heart and respiratory disorders talked about feeling excited at the prospect of getting an aide to come in on a Sunday. When asked why, she stated:

I'm gonna go, stay in that room [bedroom]. I have a TV back there. I get my shower. I come in the kitchen and get what I want to eat. It'll be just like I'm not here. And if I decide to go shop or to the mall, . . . But, uh, I just plan on just really resting. . . .

Not all caregivers perceived professional help from outside agencies as a positive alternative. Some of the caregivers related bad experiences, while others did not use the services due to financial concerns or skepticism about the type of care that would be provided. One woman caring for her mother noted she had hired a professional caregiver, and the woman spent her time watching television and smoking cigarettes. Another woman expressed her skepticism of outside help when she stated, "Well, now, every time I go out to do anything, I have to ask one of my children to stay because, I mean, no stranger is not going to stay."

Friends and family members provided another potential resource for caregiving assistance. Several of the women talked about

how, without their friends or relatives, they would not have the chance to get away. For example, a 58 year old woman caring for her mother with Alzheimer's disease shared how her sons were very helpful and supportive in caring for their grandmother. Not all caregivers were able to count on family members for support or assistance, however. Some caregivers had no relatives to call on, while others found it difficult to rely on their relatives. One woman spoke of how her sister used to help care for her mother, but "since momma's moved in with me, Peg [sister] has not come up that often." Another woman had nine siblings, all of whom refused to help with the care of their father (suffering from a heart condition). In one instance, she shared:

Just like, I tried to get one of my brothers to come and he said, well, I don't come around up there and stuff, you know, 'cause I know you taking care of him. But, I need some help sometimes, you know?

The same woman noted the impact the lack of family support had upon her ability to access leisure, saying,

Well, like before, you know, I (pause) I would be able to do the things, you know, and go and go. Now, I don't want to think about them no more because I know I cain't do 'em, you know, (voice gets quiet) I'd like to go somewhere or, uh, me and Bill [husband] together and stuff, but then, I, I get to thinkin', well, I don't want to ask nobody to come over here. I feel like when I ask 'em, you know, I'm doin' somethin' wrong. But, it's like they, you know, you took it on, that's your responsibility.

Financial Burden. Based on the caregivers' experiences, the financial burden of caregiving can be substantial. It was espe-

cially evident when the caregivers spoke of getting outside help to be with the care-recipient. As previously noted, it was often necessary to find someone to fill the caregiving role if the caregiver desired to do something outside of the home or separate from the care-recipient. A 51 year old woman, caring for her mother who had had a stroke, spoke of experiencing the financial burden of professional help. She stated,

... momma's been in this house six months and she had spent \$12,000 for caregivers. I said, 'no utility bills, no medical bills.' . . . and the money is running out fast. I mean, it would have cost her over \$36,000 a year, just spent out on caregiving and her medical bills when they were first trying to find out what she could take and what she could not take. Those bills were astronomical.

Another woman considered using professional assistance to care for her mother, but could not afford it. Her mother was in the beginning stages of dementia, but was very independent and, with help, would have been able to remain in her own home. But the financial burden associated with professional agencies was much too great. Still another woman, caring for her husband with multiple medical conditions, discussed the general financial strain of caregiving. She forfeited her own medications because there was not enough money to purchase the necessary medication for both her and her husband.

The financial burden of caregiving had an impact on the caregivers' access to leisure. Some found it difficult to partake in activities outside the home, having no one to care for the care-recipient, while others were unable to afford special activities, even if they had help with the caregiving responsibilities. One woman, a 51 year old caring for her mother with heart and respiratory disorders, described how she could not afford a vacation because of the cost of a professional

caregiver for her mother while she was gone. She said:

Because first place, I would [pause] pay someone to take care of her [care-recipient]. I have a dog. He's mean. I would have to put him in the vet and that would cost and so, I say, well, I might as well stay at home, you know.

Another woman, 47 years old and caring for her great aunt with multiple medical conditions, stated, "You know, to get uh, help, it costs quite a bit. And you know, it causes, it causes financial pressure."

Conclusions

The subjects of this study expressed interest in leisure and conveyed an appreciation for the value and benefits of leisure, although they experienced significant changes in their leisure as a result of caregiving. The pursuit of their leisure interests was hampered by internal and external constraints associated with caregiving responsibilities. The demands influenced some caregivers to neglect their own personal needs and desires, including their leisure.

One of the overriding themes that emerged from the data dealt with how the women perceived leisure as a form of escape and freedom. Henderson et al. (1989) suggested that leisure provides two types of freedom for women: "freedom from" and "freedom to." "Freedom from" describes being able to leave stresses and obligations behind. "Freedom to" refers to overcoming or negotiating barriers that pose an obstacle to accessing one's leisure. Though most of the caregivers valued leisure and expressed an interest in pursuing leisure activities, they discussed their desire for leisure in terms of being free from constraints and barriers. For example, many of these women expressed a common perception of leisure as something that denoted escape or freedom from caring for their loved one. Few of the women spoke in terms

of specific activities or experiences as representing their leisure. For most of the women, leisure was the opportunity to get away from worry and responsibility. This finding supports, in part, Samuel's (1995) proposition that women need time for leisure for themselves, free from caring about others.

A second significant theme addressed how intertwined individual barriers were for these women with regard to their leisure. Henderson (1991) addressed these complexities by encouraging researchers to attempt to understand constraints within the context of women's lives. The actual task responsibilities as well as the feelings of obligation inherent in caring posed internal barriers characteristic of the caregivers in this study. Additionally, although external barriers, such as money and time, were more commonly expressed, the lack of outside help that could be trusted was a constraint that seemed unique to this group. Furthermore, the barriers and constraints experienced by these women often overlapped with each having an impact on other barriers or constraints.

The caregivers had a strong sense of responsibility to the health and well-being of their care-recipient. Caring for their spouse or family member resulted in increased chores and duties. The caregiving duties were often assumed in addition to employment responsibilities, family care, and chores around the home. The increased duties created increased time demands, and thus, time pressures. The increased duties coupled with a sense of responsibility also contributed to physical and emotional fatigue. Though outside help might have relieved some of the time pressures and personal fatigue, most of the caregivers were unable to access the help they needed or desired due to availability, finances, trust, the ability to ask for assistance, or the fear of what might occur while they were away. Without help, it was difficult for the caregivers to have the time or energy for leisure. As Henderson (1991) noted, "leisure constraints clearly are not univariate and to fully

understand them, additional research questions and methods will be needed" (p. 375).

Implications and Recommendations for Therapeutic Recreation Specialists

The respondents in this study defined leisure in a variety of ways, were constrained by internal limitations manifested as cultural/social expectations as well as external limitations (i.e., time, money, and outside support), and experienced significant losses in areas of independence, freedom, and ability to interact socially. The external barriers identified by these women present familiar challenges to many therapeutic recreation professionals. Implications exist, therefore, for therapeutic recreation specialists who work in non-traditional recreation settings such as adult day care centers, community recreation programs, senior centers, home health care programs, or other related organizations to design strategies to allow caregivers to address the unique interaction of internal and external barriers to the caregivers' leisure experiences.

First, it is important to acknowledge the caregivers' desire to be free from responsibility as well as their profound sense of responsibility toward their care-recipients. Practitioners are cautioned, however, to accept rather than attempt to change the perceptions of these women. While the caregivers' sense of responsibility interfered with their own pursuit of leisure, the importance of their feelings and behaviors should not be underestimated or devalued. The goal should incorporate the caregivers' sense of responsibility into their opportunities for leisure. Programs should focus on helping the caregivers to access leisure while fulfilling their caregiving identities and responsibilities, a challenging, yet crucial, goal. Additionally, it is important to acknowledge the complex interactions of both internal and external barriers for these women.

Parallel recreation programs for caregivers and their care-recipients should be considered. Separate recreation programs that are provided simultaneously for both caregivers and care-recipients would allow respite, as well as opportunities to pursue activities outside the home for the caregiver. For example, craft or fitness activities for the care-recipients could be conducted at the same facility as other activities geared toward women who make up the caregiver population. As one woman noted, there are many programs for Senior Citizens, but few that address the unique needs of Senior Citizens with disabilities.

Second, it may also help to initiate the use of companions or "recreation buddies," similar to what has been used in programs for children with disabilities (c.f., Richardson, Wilson, Wetherald, & Peters, 1987). These buddies, provided through community recreation programs, can participate with or near the care-recipient to accommodate their needs. The presence of a buddy for the care-recipient during recreation activities can take some of the pressure off of the caregiver to meet the care-recipient's leisure needs as well as to provide the caregiver the opportunity to pursue her own leisure. By relieving the caregiver of some of her responsibilities, this type of program might be able to provide valuable time similar to that gained by caregivers after their care-recipients went into a nursing home (Moss, Lawton, Kleban, & Duhamel, 1993).

Third, some of the caregivers noted a desire to be at home without worrying about their care-recipient. One woman suggested hiring someone to come in and just "be" with her mother. Home-visit leisure programs sponsored by the recreation agency could be designed to fill this need. For example, one woman caring for her disabled mother-in-law stated that she was seriously considering ". . . paying someone to come at night and keep her from 5:00 pm to bed-time and let me not necessarily go somewhere, just not be responsible to have to do

everything for her and with her." It would be important, however, to provide trained personnel who could be trusted by the caregiver. Outside help within the home can decrease the caregivers' worry, allowing the subsequent freedom to pursue her own leisure and establish social contacts independently of the care-recipient.

Fourth, the lack of trained personnel and financial burdens may present a barrier to both the caregiver and the recreation agency when implementing some of the previous suggestions. In these situations, consideration can be given to the use of practicum and internship students from college and university settings. Therapeutic recreation students who have been screened and specifically trained for work with older adults could benefit greatly from "hands on" interactions. In turn, they could provide the trusted respite the caregivers need. Internships and practicums have the advantage of providing advanced training for students preparing for the profession, while also providing personnel for the agency attempting to implement diversified programs. Together therapeutic recreation students and professionals can tackle the formidable challenge of creating strategies to help caregivers to access leisure.

Finally, these findings indicated that although most of the women appreciated the value of leisure, many were unaware of the variety of resources available to facilitate their pursuit of leisure experiences. Leisure education, provided through adult day care or community recreation agencies, could promote an increased awareness and use of community and personal resources for leisure. In addition to increasing the awareness of the availability of resources for caregivers, expanded recreation programs (night and weekend) need to be considered. Adult day care programs and community parks and recreation programs should consider providing evening and weekend recreation respite for caregivers to promote independent leisure opportunities for caregivers outside the work

day and at times when family and friends are free to join them.

In addition to implications for practice, several suggestions for continued research exist. It is evident from the themes generated in this study that these women have real and perceived barriers to accessing their leisure. Researchers should explore applications to the development of recreation programs that can meet their unique leisure needs and circumstances. Identifying the barriers that exist for leisure service providers might aid in the development of strategies to address these constraints. These strategies could provide the foundation for designing and testing model programs in community agencies which may provide the leisure opportunities that these women lack. Additionally, quantitative analysis of the same constructs might prove useful. Researchers could test the prevalence of the themes generated from this study (loss of freedom, loss of social life, and specific internal and external barriers) and compare them based on varying life experiences (financial status, social support, personal health) of the caregivers. Finally, longitudinal studies need to be conducted to determine if and how the perceptions of leisure change for female caregivers over time. Little is known about the entire process of caregiving as it relates to one's leisure experiences and decisions.

In summary, caregivers of older adults present new and diverse challenges to the therapeutic recreation practitioner. Through careful design and implementation of innovative programs, therapeutic recreation specialists can attempt to increase the leisure opportunities, social contacts, and perceived time available for the caregivers, while decreasing their emotional and physical fatigue.

References

- Barusch, A. S. (1988). Problems and coping strategies of elderly spouse caregivers. *The Gerontologist*, 28(5), 677-685.
- Bedini, L. A. & Bilbro, C. W. (1991). Caregivers, the hidden victims: Easing caregivers' burden through recreation and leisure services. *Annual in Therapeutic Recreation*, 2, 49-54.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice Hall.
- Bruyn, S. (1966). *The human perspective in sociology*. Englewood Cliffs, NJ: Prentice Hall.
- Cantor, M. H. (1983). Strain among caregivers: A study of experience in the United States. *The Gerontologist*, 23, 597-604.
- Coleman, D. & Iso-Ahola, S. E. (1993). Leisure and health: The role of social support and self-determination. *Journal of Leisure Research*, 25, 111-128.
- Denzin, N. K. (1978). *The research act*. New York, NY: McGraw Hill Book Company.
- Finley, N. J., Roberts, M. D., & Banahan, B. F. (1988). Motivators and inhibitors of attitudes of filial obligations toward aging parents. *The Gerontologist*, 28, 73-78.
- Gallagher, D., Rose, J., Rivera, P., Lovett, S., & Thompson, L. W. (1989). Prevalence of depression in family caregivers. *The Gerontologist*, 29, 449-456.
- George, L. K. & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist*, 26, 253-259.
- Glaser, B. G. & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine Publishing.
- Henderson, K. A. (1991). The contribution of feminism to an understanding of leisure constraints. *Journal of Leisure Research*, 23, 363-377.
- Henderson, K. A., Bialeschki, M. D., Shaw, S. M., & Freysinger, V. J. (1989). *A leisure of one's own: A feminist perspective on women's leisure*. State College, PA: Venture.
- Lincoln, Y. & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Moss, M. S., Lawton, M. P., Kleban, M. H., & Duhamel, L. (1993). Time use of caregivers of impaired elders before and after institutionalization. *Journal of Gerontology: Social Sciences*, 48, S102-S111.
- Neundorfer, M. M. (1991). Family caregivers of the frail elderly: Impact of caregiving on their

- health and implications for interventions. *Family Community Health*, 14(2), 48-58.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583-594.
- Reese, D. R., Gross, A. M., Smalley, D. L., & Messer, S. C. (1994). Caregivers of Alzheimer's disease and stroke patients: Immunological and psychological considerations. *The Gerontologist*, 34, 534-40.
- Richardson, D., Wilson, B., Wetherald, L., & Peters, J. (1987). Mainstreaming initiative: An innovative approach to recreation and leisure services in a community setting. *Therapeutic Recreation Journal*, 21(2), 9-19.
- Samdahl, D. M. (1988). A symbolic interactionist model of leisure: Theory and empirical support. *Leisure Sciences*, 10, 27-39.
- Samuel, N. (1995, May). Some leisure of their own: One of the keys towards women's autonomy. Paper presented at the International Conference on Women and Leisure: Toward a New Understanding, Athens, GA.
- Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry (118-137). In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research*. Thousand Oaks: Sage Publications.
- Sneegas, J. (1988, October). *The role of leisure for caregivers of individuals with Alzheimer's disease*. Paper presented at the meeting of the Leisure Research Symposium, National Recreation and Park Association, Indianapolis, IN.
- Snyder, B. & Keefe, K. (1985). The unmet needs of family caregivers for frail disabled adults. *Social Work in Health Care*, 10, 1-14.
- Stone, R., Cafferata, G. L., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. *The Gerontologist*, 27, 616-626.
- Wilson, V. (1990). The consequences of elderly wives caring for disabled husbands: Implications for practice. *Social Work*, 35, 417-421.