

## Addressing Leisure Barriers for Caregivers of Older Adults: A Model Leisure Wellness Program

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### **Abstract:**

Approximately 18 million Americans care for ill or disabled family members. Until recently, these caregivers have been ignored as a group who might also need attention for their own health care. In addition to potential physical and psychological health consequences due to caregiver burden, caregivers often abandon or severely alter social/leisure aspects of their lives. The purpose of this research was to design a leisure wellness program that could address unique leisure needs for caregivers of older adults based on theoretical frameworks of stress and leisure. Focus group research from four regions of North Carolina was conducted to solicit expert opinions from professionals who work with or near caregivers of older adults. A total of 122 ideas were sorted into eight categories. Subsequently, a four unit, multidisciplinary model leisure wellness program was designed based on the focus group results. Recommendations for testing and future research are noted.

**KEY WORDS:** Caregivers, Leisure, Continuity, Stress, Barriers, Wellness

### **Article:**

According to Healthy People 2000 (U.S. Department of Health and Human Services, 1990), although people who reach the age of 65 today are expected to live well into their 80s, it is ". . . likely that not all those years will be active and independent ones" (p. 23). The report goes on to state that people over the age of 85 make up a substantial part of those who are not independent in physical functioning. Additionally, according to the National Alliance for Caregiving (Peterson, 1997), older adults are living longer and with chronic illnesses. Older adults who suffer from conditions such as Alzheimer's disease, cancer, heart disease, respiratory disorders, Parkinson's disease, and arthritis will increase in number by the turn of the century.

Due to rising costs of health care, many individuals are turning to informal home care for their ill older relatives. As a result, informal family caregiving makes up a substantial part of older adult nursing care. Informal caregivers are people who care for family members in their homes without pay (Cantor, 1983). According to the National Family Caregivers Association (1997), there are approximately 18 million Americans who are family caregivers. Over 75% of these caregivers are women with a mean age of 59. Forty percent of informal caregivers have children under 18 years of age in the home. Approximately 60% of informal caregivers are in the workforce, 18% of whom quit or alter their work due to caregiving (Caregivers, Inc., 1997; Family Caregiver Alliance, 1996). Additionally, caregivers lose an average of 5 to 12 days per year from work solely due to caregiving responsibilities (Caregivers, Inc., 1997). Most significantly, for the purpose of this study, caregivers severely limit their leisure as a result of their caregiving responsibilities (e.g., Bedini & Guinan, 1996b; Rogers, 1997; Stone, Cafferata, & Sangl, 1987; White-Means & Chang, 1994; Wilson, 1990). Unfortunately, until recently, caregivers have been ignored as a group of individuals who might need attention in terms of their own health care. The intent of this study was to explore strategies that could address unique leisure needs for caregivers of older adults.

### **Impacts of Caregiving**

Often in mid to later life, caregivers frequently manifest psychological conditions such as anxiety and chronic depression, and physical conditions ranging from hernias and ulcers to heart disease and cancer (e.g., Cantor,

1983; George & Gwyther, 1986; Reese, Gross, Smalley, & Messer, 1994; Skaff & Pearlin, 1992; Snyder & Keefe, 1985; Stone et al., 1987). In addition to potential physical and psychological manifestations, caregivers often abandon or severely alter social aspects of their lives. The Family Caregivers Alliance (1995) noted that 51% of caregivers reduced the amount of time spent on leisure -after becoming caregivers. Specifically, research shows that caregivers consistently compromised their participation in hobbies, church related activities, recreation activities, and fitness pursuits (e.g., Bedini & Guinan, 1996b; Pilisuk & Parks, 1988; Rogers, 1997; Stone, Cafferata, & Sangl, 1987; White-Means & Chang, 1994; Wilson, 1990). Specifically, many caregivers have identified caregiving as contributing to a decline in health, which they described as loss of (a) regular exercise, (b) time for oneself, (c) interest in all activities, (d) sex life, (e) opportunities to socialize with friends, (f) vacations, and (g) time for leisure pursuits (Bedini & Guinan, 1996b; Cantor, 1983; Snyder & Keefe, 1985; Thompson, Futterman, Gallagher-Thompson, Rose, & Lovett, 1993).

### **Motivations for Devalued Leisure**

Many circumstances and motivations contribute to caregivers reducing and changing patterns in their lives. In addition to practical reasons identified for caregivers not pursuing leisure, such as decreased available time (e.g., Chenoweth & Spencer, 1986; Rosenthal, Sulman, & Marshall, 1993), increased in-home work load (e.g., Stoller, 1983), and financial limitations (e.g., Chenoweth & Spencer, 1986; White-Means & Chang, 1994), three attitudinal motivations stand out for changes in caregivers' leisure. First, according to Gilligan (1982), women are motivated in their relationships with others through the concept of ethic of care. Gilligan described ethic of care as the connection women experience with others who are significant in their lives. This ethic functions as a foundation for their identity and motivates feelings of care and compassion. Henderson and Allen (1991) suggested that the force of the caring ethic can be so strong that women will place the needs of others above their own, to the point of denying their own needs (including leisure). Searle and Jackson's (1985) research supports this notion. They found that family commitments ranked second among seven constraints or reasons why older women did not pursue leisure and recreation activities. Therefore, since the vast majority of caregivers are women, the ethic of care can be considered a potential contributor to the relinquishing of leisure among most caregivers.

Guilt and obligation are additional contributors to the reduction of leisure in women, particularly caregivers. Henderson, Stalnaker, and Taylor (1988) found that from a sample of 500 women aged 18 to 66, a sense of family obligations and expectations ranked high in obstacles for pursuing leisure. Schulz (1990) listed indebtedness, in particular, as one of the motivations for caregiving. He suggested that the attempt to allay feelings of guilt is manifested in the feeling that the caregiving provided is never enough. More specifically, Brody (1985) identified that 60% of the caregivers in her study noted that they felt guilty about not doing enough for their care-recipients. She illustrated that a sense of owing exists in children of older adults with disabilities-to repay their parents for raising them. Brody (1985) proposed that there exists a ". . . disparity between standards and expectations on the one hand and the unavoidable realities on the other hand" (p. 26). The disparity, in turn, contributes to guilt. Brody also suggested that caregivers of older family relatives often experience and must suppress feelings of resentment and anger, which also contribute to the guilt. Feelings of "never being able to do enough" can redirect caregivers' pursuits from potential leisure and self-care activities to increased caregiving endeavors. In a study of spousal female caregivers, Rogers (1997) found that caregivers who were "consumed" by their caregiving role, experienced guilt as a "prominent theme" (p. 237) in their lives. Rogers noted that, "These participants regularly made personal sacrifices to avoid feeling guilty for not providing the best care possible" (p. 237). She noted that for these individuals, guilt prevented them from feeling entitled to leisure.

A third potential contributor for caregivers dropping leisure in priority could be related to the social perception that leisure is frivolous. Compton (1994) described that leisure has "not been recognized as a universal human need in the literature" (p. 13). Henderson, Bialeschki, Shaw, and Freysinger (1996) stated that "society tends to devalue leisure and think of it as a 'frill,' a reward for hard work, or even a waste of time" (p. 116). According to Henderson and Allen (1991), this is particularly true for women. They explained that, ". . . because many women are never free from obligations and gender roles; 'unobligated time' does not exist" (p. 102). Caregivers

tend to disregard the importance and benefits of leisure, especially when family responsibilities are involved. Ignorance of the benefits of leisure can lead to devalued leisure. As a result, omitting leisure from one's life is likely to increase social isolation and stress, and reduce physical and mental well-being (e.g., White-Means & Chang, 1994).

While leisure services have the potential to facilitate the maintenance of physical and mental health in all people, interventions are needed that can address the unique leisure needs of caregivers of older adults. Little attention has been given to the development of conceptual models of practice, however. Chwalisz and Kisler (1995) called for more theoretically and empirically sound models to direct interventions designed for caregivers. Therefore, the purpose of this research was to explore strategies and design a program model that could address unique leisure needs of caregivers of older adults based on existing literature and the results from focus group research. Specifically, a leisure wellness program will be discussed that focuses on overcoming the caregivers' barriers to accessing their leisure and recreation while aiding them in maintaining their mental and physical well being.

### **Conceptual Frameworks**

Two primary conceptual frameworks provided the underpinnings for this study. Coleman and Iso-Ahola's (1993) model of leisure as a buffer to stress and Atchley's Continuity Theory (1989) were combined to support the benefits of leisure for individuals who are caregivers of older adults.

### **Leisure as a Stress Buffer**

**Stress Outcomes.** The first conceptual underpinning for this study addresses the theoretical relationship between leisure and health. Stress has been identified as a major contributor to reduced and negative health conditions (e.g., Chwalisz & Kisler, 1995). For example, in a study of rural older adults, Johnson, Waldo, and Johnson (1993) found that high reported stress correlated strongly with reduced perceived health.

Substantial research also exists that illustrates the negative effects of stress for caregivers of older adults specifically. Studies demonstrate how stress can negatively affect the health and well-being of adult children (e.g., Chiriboga, Weiler, & Neilsen, 1990) and spouses (e.g., Chwalisz & Kisler, 1995) who are caregivers. Many physical and mental consequences of caregiver stress and burden have been identified including depression, anxiety, anger, fatigue, hypertension, and heart disease (e.g., Pilisuk & Parks, 1988; Schulz, 1990). Additionally, Morgan and March (1992) noted that often friends and social relations withdraw from caregivers and care-recipients due to the latter's illness, thus socially isolating both the caregiver and care-recipient. Being cut off from familiar social patterns and interactions in turn results in substantial/additional stress for the caregivers. Subsequently, caregiver stress can increase as a result of reduced leisure and social interaction (White-Means & Chang, 1994).

**Stress Buffer Model.** Irvin and Acton (1996) noted the value of self-care in the reduction of the negative effects associated with stress. Research also has connected leisure and recreation, which can be considered a form of self-care, with health and wellness (e.g., Caltabiano, 1994; White-Means & Chang, 1994). Coleman and Iso-Ahola (1993) developed a conceptual model which proposed that leisure and recreation participation can act as a buffer to stress. They suggested that participation in leisure activities can help provide individuals who experience stress (e.g., caregivers) with the resources needed to resist or cope with stress before it results in negative health consequences. Their model identified leisure-generated social support and leisure-- generated self-determination as the two factors which specifically serve to buffer the stress of negative life situations. The first factor, leisure-generated social support, entails the companionships and friendships that are initiated, developed, and maintained through leisure participation. The perceived social support of such friendships helps people cope with life stress. The second factor, leisure-generated self-determination, is the sense that one is able to influence outcomes or affect change in a leisure situation and subsequently, in other areas of life as well. People who believe that they are the source of what happens to them, as opposed to believing they are at the mercy of their environments, are more likely to resist stress-induced illnesses (Coleman & Iso-Ahola, 1993).

These two leisure elements can serve as a buffer against stress thus protecting existing mental and physical health. Without a buffer, a cyclical relationship exists among negative life events, increased stress, and negative physical and mental health. This model has special significance for caregivers of older adults who are likely to take on this cyclical relationship and experience the consequences in through endangering their physical and mental health. (See Figure 1 for details.)

### **Continuity Theory and Caregiving**

Atchley's (1989) theory of continuity served as the second conceptual framework for this study. This theory suggests that as individuals age, they make "adaptive choices" to maintain their "internal and external structures" through life. By attempting to maintain these internal and external structures, individuals prefer to utilize strategies and approaches that are familiar and that have been successful in the past. As individuals age, there are many changes that occur in both their environment and their bodies, but these changes are perceived and interpreted in the context of self, identity, and perceived past. The changes they experience in aging are connected to their personal histories. The adaptations they choose are also based on the individual's perceived past, individual preferences, and social approval. Therefore, continuity refers to consistency of patterns over time rather than sameness or lack of change and is influenced by both personal and societal factors.

According to Atchley, internal structures of continuity are essential in one's ability to change with the aging process. Internal continuity is how an individual connects her or his past with the new, evolving self. It centers on concepts of self and identity, and is important in daily decision-making and subsequently, one's sense of competence. Internal continuity is also directly connected with self-concept and one's ability to meet needs in life. Internal continuity is essential in maintaining a sense of ego integrity, positive self-esteem, and self-identity, thus contributing to mental health.

Atchley's description of external structures of continuity addressed environmental patterns and behaviors. External continuity refers to physical and social environments, role relationships, and activities of individuals. Social support and long-standing behavior patterns of individuals are examples of external continuity; people use familiar skills and experiences to do familiar things. External continuity helps individuals cope with the physical and mental changes and adaptations necessary in the aging process.

Atchley proposed that aging can progress in three forms: "normal," "anomalous," or "pathological." Individuals who progress through normal aging experience expected life patterns and are able to maintain both internal (e.g., self-concept) and external continuity (e.g., social networks, income). Atchley defined anomalous aging as when an individual's particular aging patterns differ from the "norm" but she or he is still able to maintain both internal and external continuity. Pathological aging occurs when individuals experience some life circumstance (i.e., illness, disability, or poverty) which prevents them from maintaining internal or external continuity (see Table 1).

Caregivers' aging could be considered pathological, or anomalous depending on several perspectives. Kelly and Kelly (1994), as well as Kahana, Kahana, Johnson, Hammond, and Kercher (1995), noted that family responsibilities during the life course are typically comprised of predictable role sequences including marriage and raising children. They suggested that normative timing occurs when events in one's life course follow a predictable sequence and duration. According to these authors, responsibilities and roles such as caregiving, which are often sudden, later in life, and of indeterminate duration, demonstrate "non-normative" timing. It is the "off time" events (those that are unpredictable) that can cause stress for the caregivers. Due to the sudden and unpredictable nature of the caring responsibilities and its associated stress, caregivers of older adults could be said to experience anomalous aging if they remain able to maintain both internal and external continuity. For example, if a woman becomes a caregiver for her aging parent yet remains able to balance her concept of herself as a responsible, loving daughter (internal continuity) with her regular recreation activities, job, and time spent with friends (external continuity), she could be said to experience an anomalous aging pattern.



Caregivers' aging could be considered pathological aging if, as a result of the stress of their caregiving duties, they become unable to maintain both internal and external continuity. For example, if a caregiver was able to maintain internal continuity (concept of self as good daughter) but not external continuity (housing, recreation, transportation, income, or social networks), she would be exhibiting pathological aging. As noted above, many caregivers succumb to psychological and physical health conditions, have to alter or quit work, or cannot always meet their needs for recreation and social relationships.

## Methods

This study employed focus group research procedures with professionals who served caregivers of older adults. Understanding the conceptual foundations of stress and aging, as well as the perceived constraints to pursuing leisure identified by the caregivers themselves (Bedini & Guinan, 1996a), the researchers found it logical to consult with individuals who currently, or have the ability to, provide leisure and recreation opportunities to this population. Professionals in human services and health care were chosen for focus groups to solicit suggestions and possible solutions regarding how community professionals can address barriers to leisure as identified by caregivers. As noted, these specific barriers were determined from recent research with caregivers conducted by Bedini and Guinan (1996a, 1996b). Their research gathered and analyzed data from in-depth interviews collected from 16 women who were informal family caregivers of older adults in 1995-- 1996. Through constant comparison and analytic inductive techniques, the researchers determined that these women felt little entitlement to leisure but greatly missed its presence, as well as what it stood for (e.g., spontaneity, freedom, relaxation) in their lives. The interview respondents identified several barriers to their leisure pursuits; however, they strongly concurred that their sense of responsibility to their care-recipients was the primary reason they often chose not to pursue and/or participate in recreation or leisure programs. In addition to these interviews, related literature that addressed caregivers' barriers to leisure and recreation was analyzed.

The results from these interviews, as well as the literature review, served as the foundation for designing specific questions asked of the professionals in this study. Focus group participants worked in arenas that did or could potentially provide recreation and leisure programs to informal family caregivers of older adults, such as community recreation programs, adult day care centers, social work, and community and home health care. These individuals were convened in four separate focus groups to address how professionals in recreation and related fields could overcome the barriers to recreation and leisure pursuits identified by informal family caregivers of older adults.

The focus group is "a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-- threatening environment" (Krueger, 1994, p. 6). Focus groups were chosen as an appropriate method for this study because they solicited expert opinions from a diverse group of professionals who worked with or near caregivers of older adults.

For this study, four groups comprised of five to nine professionals each were convened in four different regions of North Carolina (Mountain, Triad, Triangle, Coastal). Each group discussed the same set of questions dealing with barriers to caregiving and strategies for overcoming these barriers.

A semi-structured interview guide for the focus groups consisted of four sections: (a) background of the study being conducted, (b) profile of caregivers and their needs, (c) potential barriers to service provision to caregivers of older adults, and (d) questions and probes addressing how to develop strategies to overcome the identified barriers. The background section discussed previous research and literature, and explained the purpose of the focus groups to the participants. The profile of caregivers was developed from literature and discussed demographic as well as leisure and social needs and issues of this population. The barriers to leisure presented were summarized from literature and research with caregivers themselves. The barriers included lack of time, guilt and extended feelings of responsibility toward the caregiver, inability to trust outside respite help, financial limitations, few recreation opportunities that were appropriate, and time constraints regarding when and how long activities were offered. The actual questions presented to the focus groups addressed how professionals can encourage caregivers of older adults to pursue their own leisure. Specifically, the respondents

were asked to consider the aforementioned barriers and issues, and to develop strategies for providing leisure opportunities that were "guilt free," psychologically safe for caregiver and care-recipient, and financially affordable. Overall, this guide was broad in nature and partially dependent on the direction of the dialogue within each group.

All group discussions were audio-taped and transcribed. Additionally, detailed notes were taken by one of the researchers and a diagram of the seating arrangement were used to aid in understanding who was speaking. Each group discussion lasted approximately 90 to 105 minutes. After transcriptions of the audio-tapes were completed, all ideas were listed, duplicates were removed, and the remaining individual ideas were grouped by function and intent. This list was then sent to each participant for review and comment.

## **Respondents**

The minimum recommended number of focus groups is three and the ideal size of a group is 7 to 10 individuals (Krueger, 1994). We employed four focus groups to increase the likelihood of participation from all regions of the state. We invited an average of 10-12 participants for each focus group. Two groups had only 5 participants, one group had 6, and one group had 9. A total of 25 professionals participated in the four focus groups. Participants were professionals identified by and obtained from parks and recreation departments (n = 13), adult day care facilities (n = 7), senior centers (n = 3), public health offices (n = 1), and a proposed caregiver retreat center (n = 1). Seven of the participants were male and 18 were female. Twenty-three were European American[White and 2 were African-American/Black.

## **Data Analysis**

Krueger (1994) noted that a data analysis of focus groups is greatly dependent upon how the researchers design and collect the data. Per his suggestions, the researchers conducted several focus groups to estimate responses to questions and allow for modifications. During the focus groups, the researchers also listened for vague or inconsistent responses, which were then probed for clarity by the researchers. Field notes were taken by one of the researchers during the discussions to identify "key points.... notable quotes, and important observations" (Krueger, p. 147). Next, the researchers held a debriefing to compare initial reactions regarding important themes, unexpected findings, and the need for adjusting methods. Finally, after tapes were transcribed, the researchers conducted transcript based analysis in which the words, context, internal consistency, frequency of comments, intensity of comments, specificity of responses, and "big ideas" were analyzed (Krueger, 1994). Procedurally, the researchers read transcripts and field notes systematically. Then, we looked for emergent themes and coded categories accordingly.

## **Results**

Each of the four focus groups generated a list of ideas about how to develop and structure programs to meet the unique leisure/recreation needs of caregivers of older adults. These ideas were summarized and after removing the duplicates, a total of 122 different ideas remained. These ideas were then sorted into eight categories based on the general nature of the program or service suggested. These categories were: (a) education/activity programs for caregivers, (b) respite programs, (c) provision of resource information, (d) support for caregivers, (e) education of others/ advocating for caregivers, (f) networking among community agencies, (g) financial ideas/assistance, and (h) timing of programs. Many of the ideas dealt with how to directly meet the leisure needs of caregivers of older adults (i.e., direct provision of leisure programs for caregivers), whereas other ideas focused on how to address internal or external barriers to pursuing leisure (i.e., guilt, time management, provision of respite care).

## **Education/Activity**

The education/activity category included ideas such as well-being workshops, time management classes, and legal and financial classes. The respondents noticed that since these programs would be of direct and obvious practical value to the caregivers, they may be more willing to attend. For example, a social worker from an enrichment center for older adults stated that a lot of older adults come to his fitness center because they believe exercise has practical benefit for them. He noted, "It is like the doctor has to tell them you know this is good for

you ... so then they go exercise, but not before then." Other specific ideas within this category were classes that would teach caregivers about leisure activities that they could do with their care-recipient. Research demonstrated that although caregivers compromise their own leisure needs, they are concerned about meeting the leisure needs of their care-recipients (e.g., Bedini & Guinan, 1996a). Therefore, classes of this nature might have merit in the eyes of the caregiver. Additional ideas within this category described programs aimed at educating participants about the benefits of physical fitness, leisure, and recreation as well as providing instructional and participatory programs (i.e., walking programs, aerobics, workout video libraries).

### **Respite Care**

The second category was respite care. Caregivers reported that lack of outside help was a principle external barrier to caregivers pursuing their leisure (Bedini & Guinan, 1996b). For caregivers to have the freedom and ability to meet their leisure needs, they must consider who will care for their care-recipient while they do so. Ideas to address this barrier included leisure consultants who would go into the home and provide leisure to the care-recipient, separate programs for caregivers and care-recipients held at the same facility, company sponsored day care, and bartering respite among a group of caregivers.

### **Provision of Resources and Information**

Often there are agencies in a community that provide services needed by caregivers but of which the caregivers are unaware. This situation is especially true with regard to military families who move frequently and thus, are in the position of leaving a known community. One suggestion was to establish a telephone hot-line (i.e., "First call") or a written brochure that lists all agencies in the community which provide services that may be helpful to caregivers. Events, such as caregiver fairs and assistive technology fairs, could also provide a variety of information to caregivers regarding services that are available in the community.

### **Social Support**

For the fourth category, focus group participants suggested that caregivers might be more likely to pursue their leisure and recreation if they had the support of other caregivers to encourage them to do so. It is important to structure these as opportunities for breaks rather than "therapy," however. Although support groups are helpful to some caregivers, several focus groups noted that when some caregivers had been involved in a support group for a certain period of time, they began to be looked upon as an expert. Caregivers who were new to the support group began to lean on these "old-timers" often resulting in the experts leaving because they did not want to provide care and assistance to anyone new in their life. They came for support but could not receive it because others expected them (or they expected themselves) to give it. A program coordinator of an adult care program cautioned:

I think caregivers need to recognize that they are going to reach a point where they are not going to be able to do it all and they need to develop social support systems to catch them when they fall ... to call on and say, 'listen I need to go to a movie,' 'I need to go out and have dinner.'

The focus groups recommended alternative support opportunities. Theme specific support groups, caregiver retreat centers, caregiver newsletters, and "drop in" spaces in the community (i.e., at a senior center or an adult day care center) were suggested as ways to provide support and time for bonding among caregivers yet avoid the "expert syndrome." Computers also provide ways to alleviate the social isolation experienced by caregivers of care-- recipients who are homebound through correspondence via e-mail and caregiver chat rooms. Though not all caregivers have access to computers in their homes, places such as local libraries often provide computer use for caregivers.

### **Education/Advocacy**

The fifth category was educating people in the community (non-caregivers) and advocating on behalf of caregivers. Three out of the four focus groups noted that churches/synagogues were a potential source of support for caregivers but that they were (a) probably unaware of the fact that caregivers existed within their congregation and (b) unsure of how to provide support for those caregivers within their congregations.

Educating religious organizations about the needs of caregivers and how best to assist these individuals would ultimately benefit caregivers within their congregation. Educating human resource personnel in businesses and corporations also was seen as important since approximately one fifth of caregivers who work outside of the home alter or quit their jobs due to responsibilities associated with caregiving. Convincing doctors and other health care professionals to recommend leisure to their caregiving clients was seen as a way to legitimize the need for leisure in caregivers' lives. According to several respondents, health care professionals such as doctors have "clout" and caregivers could be relieved of some of the guilt about pursuing their own leisure if it were prescribed to them by their physicians and related health care professionals. For example, a social worker from an enrichment center for older adults stated that a lot of older adults come to his fitness center on the recommendation of the doctor. He noted, ". . . a medical doctor-- ... traditionally has been a person-if they say something, you do what they say."

### **Agency Networking**

Networking among community agencies was a category highly emphasized in all four focus groups. Several respondents described cooperative programming for caregivers in which they were involved, such as a parks and recreation department working with the council on aging. Because of the varied types of services needed to enable caregivers to pursue their leisure (respite care, funding, timing, transportation, and emotional freedom), no single agency or program alone could meet all of the needs of caregivers. One suggestion to address this problem was the formation of a federation of agencies. Each agency would retain its autonomy within the federation, but agencies would coordinate among themselves the types and timing of programs to be provided. This cooperative effort would address the myriad barriers typically presented to caregivers, thus allowing them to pursue their leisure. Another idea entailed the construction of adult day care centers adjacent to parks and recreation community centers. In this manner, both groups could serve caregivers but retain their autonomy and individual agency missions. Networking with community and nonprofit agencies such as Girl/Boy Scouts and YMCA/YWCAs was also suggested as an important and often overlooked way to offer programs. Often, professionals look to government agencies when seeking to provide human services, yet there are many nongovernmental agencies that can provide programs and services once the need is made known. Cooperation and coordination with the Council on Aging, the American Association of Retired Persons, and the United Way were other specific ideas within this category.

### **Financial Assistance**

Caring for others places a financial stress on caregivers that poses a barrier to their pursuit of leisure. For example, the Community Alternative Program, which finances day care in the home, is funded by Medicaid and is overseen by the Department of Social Services. Similarly, North Carolina adult day care centers are trying to get Medicaid and Medicare to reimburse their services. The focus groups suggested that other agencies could join the effort to lobby government and private insurance programs to reimburse for this type of services, thus alleviating the financial burden to caregivers. Another idea was to query local and state governments about the possibility of caregiving for seniors being defined under "mental health." In this way, respite funding could be made available to caregivers of older adults like it is for people who care for care-recipients with developmental disabilities. Agencies also could pursue foundation, government, and community grants to fund programs that address the needs of caregivers. A very direct and practical way to financially assist caregivers in pursuing their leisure could be the solicitation of "two for one" coupons from community restaurants, museums, and movie theaters. This strategy would allow caregivers to pursue community leisure activities with their care-recipients yet mitigate the related financial strain.

### **Programs/Activities**

In many communities, existing adult day care centers, senior centers, and recreation centers can be utilized by caregivers to allow them to pursue their leisure and recreation. A problem that was consistently identified, however, is that these agencies typically are not open in the evenings or on weekends. The need for leisure programs and respite services during evening hours and weekends was expressed by many of the focus group participants. Another observation within this category was that it is better to offer scheduled recreation programs less frequently but for longer periods of time. A great deal of time is needed to prepare and transport



care-recipients to their respite caregivers (formal or informal) and a class that meets every evening for only one hour is probably not going to be attended given all that would be entailed. If, however, the same class were offered once a week for a three hour block of time, it would be worth caregivers' efforts to arrange care for their care-recipient and therefore, it would be more likely that they would attend.

### **Leisure Wellness Program Model**

In a meta-analysis of interventions to relieve caregiver stress, Knight, Lutzky, and Macofsky-Urban (1993) identified several weaknesses in interventions between 1980 and 1990. They noted, in particular, insufficient use of theory as the foundation to guide the development of interventions. The conceptual/ theoretical frameworks of Coleman and Iso-Ahola's model of leisure as a buffer to stress, and Atchley's continuity theory were used not only as the concepts that guided the focus group research, but also in consideration of the actual development of the proposed model. Based on the results of the focus group research, it is clear that caregivers of older adults are a population of individuals who are unique in two ways: (a) because of the stress they experience due to their caregiving, they are likely to experience health consequences due to stress; and (b) they resist leisure participation due to ethic of care, feelings of guilt, and sense of responsibility to their care-recipient. This resistance becomes a leisure constraint that inhibits their ability to access leisure, hobbies, fitness, and social contacts; in turn, it potentially leads to reduced physical and mental health and well-being (see Figure 2).

As Coleman and Iso-Ahola's (1993) model suggested, leisure participation can serve as a buffer to stress, thus reinforcing the ability to resist or cope with stress. The model presented in Figure 3 addresses the identified leisure barrier common to caregivers (their resistance to participating in leisure/social activities). By addressing caregivers' resistance to leisure, the proposed Leisure Wellness Program model facilitates their ability to cope with the burden of caregiving, thus buffering stress and contributing to the maintenance of physical and mental well-being. Additionally, the model is structured so that internal continuity (that they are responsible caregivers) is maintained by the caregivers (see Figure 3).

### **"How to be A Better Caregiver:" A Leisure Wellness Program**

While the individual program ideas generated by the focus group research could be used separately, a model that incorporates these ideas collectively and addresses specific caregiver issues regarding accessing leisure may be useful. With this in mind, the authors conceptualized the model leisure wellness training program entitled, "How to be a Better Caregiver." The premises of the stress buffer model as well as continuity theory, ideas and concepts from the focus group research, and previous literature were used in the development and design of this model program. As noted, focus group participants confirmed that caregivers expressed a desire for leisure; however, even if presented with time, money, or respite, they often resisted pursuing their own leisure due to feelings of guilt, responsibility, or ethic of care. A coordinator of community recreation services noted, "I still think leisure ... is going to help a lot, but we still need a hook." The focus group respondents suggested the importance of accepting the resistance of the caregivers and understanding the strength of their reasoning. Acknowledging these perspectives of the caregivers coupled with the suggestions from the focus groups provided the framework for incorporating the needed leisure awareness, education, and resource identification into a program that would meet caregivers' perceived need—that of being a better caregiver. The focus group respondents emphasized that if caregivers saw a program that would help them to care better for their care-recipient, they would attend. This finding is consistent with Atchley's proposal for the need for internal consistency.

This multidisciplinary program is composed of four separate units structured to be taught by a variety of professionals including physicians, social workers, massage therapists, therapeutic recreation specialists, and other related health professionals. The units are designed to first address practical barriers; then conceptual barriers; then to create support; and finally, to develop knowledge and skills to independently pursue satisfying leisure. The four corresponding units are: "resources," "mental and physical wellness," "managing stress," and "leisure education." Figure 4 illustrates the content of each of the units.

**Resources.** The resources unit was designed to help the caregiver identify and access financial, legal, respite, and recreation resources. The results from the focus groups suggested that caregivers did not readily have access to this information and that they experienced anxiety about not knowing where they could find this type of support. Focus group participants stressed that although practical resources (i.e., financial, legal, respite) were essential to identify and access, recreation and leisure resources were particularly significant to caregivers' well-being and equally hard to identify and access.

A major focus of the resource category is getting the caregivers and the resources connected. Despite their desire for resources, caregivers often do not talk about the fact that they are caregivers and they are not willing to ask about where certain services are offered. Therefore, it is important that resource identification materials be placed where caregivers may encounter them in their usual routines. One suggestion from the focus groups was for community recreation programmers to place advertisements or public service announcements about caregiver issues on local radio and television stations. Knowledge of community agencies and services enables caregivers to access and utilize those services to facilitate their pursuit of leisure and recreation. For caregivers who have access to computers, there are many types of resources on the internet (e.g., Caregiver Network, Eldercare Information and Referral Service, Family Caregiver Alliance, National Caregiving Foundation). These organizations address issues ranging from finances, social services coordination, and medical information, and they provide opportunities for interaction among caregivers via chat rooms.

**Physical and Mental Wellness.** Researchers such as Irvin and Acton (1996) found that self-care is extremely valuable in preventing negative effects of chronic stress. It was evident from research that because of caregivers' investment in guilt (Brody, 1985), responsibility (Schulz, 1990), and ethic of care (Gilligan, 1982), they needed a "rationale" or justification to take care of themselves. The resources unit was designed to address caregivers' needs for identification and connection with practical resources. The second unit was designed to decrease caregivers' resistance to self-care by helping them understand the need for physical and mental wellness. The unit consists of five content areas designed to be taught by physicians, nurses, and other health care workers. If health consequences and how to avoid them are presented by "credible" staff (i.e., physicians, nurses, psychologists), caregivers might be more likely to accept and use the advice. A professional from an adult day care center stated, "I think that leisure professionals can work with social workers in the community and doctors in educating them [caregivers] about perceived benefits or benefits of utilizing their free time. It is not only for physical well-being but for mental well-being."

Specific content areas in the mental and physical wellness unit include: (a) time for self or time management, (b) social support, (c) coping with guilt, (d) patterns and habits, and (e) problem solving. Making time for one's self is a challenge for most people in society; however, caregivers have been identified as particularly poor in this area (Deimling, 1992; Moss, Lawton, Kleban, & Duhamel, 1993). To access opportunity for any facet of this wellness program, participants must be able to allot time for pursuing selected activities and resources. Time for self was often noted in self-report research as a loss due to caregiving responsibilities (Snyder & Keefe, 1985). Another specific time concern is allotting time to spend with friends and families. Learning how to manage one's time can give caregivers the foundation to develop appropriate strategies for organizing the many responsibilities associated with caring for others and themselves.

Social support was a critical factor for caregiver well-being that surfaced repeatedly in the focus group suggestions. Though it is significant in well-being, it is often absent from caregivers' lives. Johnson, Waldo, and Johnson (1993) identified that loneliness and a decrease in number of friends were two significant life events that contributed to stress and strain in older adults. Similarly, social relationships were particularly important for the psychological well-being of caregivers of older adults (Chiriboga, Weiler, & Neilsen, 1990; Uhlenberger, 1996). Therefore, it is essential that caregivers factor in time to maintain their social networks and continue to build new ones. This unit stresses to caregivers the importance of maintaining social support and contact with others, and strategies for attaining them. One suggestion from the focus groups was to have a place at an adult day care center or recreation center where caregivers could meet and socialize. Providing coffee, books, and a separate phone line would provide opportunities for informal support while still offering the security being able

to be contacted if necessary. This idea is similar to a project by Smythe and Harris (1993) whereby caregivers used telecommunications for accessing information and social support opportunities.

As Brody (1985) noted, guilt is a driving force behind the denial of one's own needs. Succumbing to guilt helps neither the caregiver, nor the care-recipient. Within each focus group there was at least one participant who either was currently or had in the past been a caregiver. These individuals spoke of the need to educate caregivers that "guilt is natural, but get over it!" and to encourage caregivers not to put their lives on hold while they were providing care to their recipient. This portion of this unit focuses on helping the caregiver to identify the self-defeating nature of guilt feelings and why they should not feel guilty in taking care of themselves. The final two sections in this unit focus on identifying unhealthy patterns/habits, and then applying practical problem-solving techniques to develop more healthy behaviors and choices. Familiar patterns and habits, although often not productive, can provide a sense of safety and security for individuals attempting to cope with stress. A social worker with older adults in day care stressed that we need to "make leisure a habit." Creative solutions exist for breaking old habits and developing new healthy patterns for caring and coping through problem-solving. For example, Hagan, Gallagher, and Simpson (1997) demonstrated that an educational-support program was able to increase problem-solving skills and the ability to cope with one's own stress.

***Managing Stress.*** While the physical and mental wellness unit addresses the negative consequences of stress on well-being, the managing stress unit focuses on the practical identification and alleviation of stress specifically for the caregiver. This unit includes (a) stress identification and its consequences, (b) relaxation techniques, and (c) stress reduction techniques. Stress management and relaxation techniques that can be done independently in the home, such as imagery, meditation, tai chi, breathing exercises, muscle relaxation, and visualization as taught by trained professionals.

***Leisure Education.*** The last unit includes content areas that address the importance of leisure in the caregiver's life and then how to negotiate the obstacles that are presented to leisure attainment. Thompson, Futterman, Gallagher-Thompson, Rose, and Lovett (1993), the developers of the Social Life Restriction Scale, noted that social interaction for fun and recreation "appears to be the most important in diminishing the burden of caregiving" (p. S245). While leisure and recreation issues are evident in the first three units, this unit focuses specifically on identifying attitudes, values, and pragmatic constraints that pose as barriers to caregivers' pursuit and access of leisure. By this point in the program, the caregivers should know the importance of caring for self and how their own perceptions can prevent this pursuit. Several models exist for leisure education programs for caregivers of older adults (e.g., Hagan, Green, & Starling, 1997/98; Hughes & Keller, 1992; Keller & Hughes, 1991). None has been tested, however. Regardless, these and tested models for other populations (e.g., Dunn & Wilhite, 1997; Searle & Mahon, 1993) agree on several components. Therefore, the current model includes four specific content areas: (a) leisure awareness, (b) leisure values, (c) identification of leisure barriers/constraints, and (d) strategy development for overcoming barriers.

## **Conclusions**

The purpose of this paper was to use the results from recent research to explore programming possibilities that can address the unique leisure needs of caregivers of older adults. The described Leisure Wellness Program was developed from a series of research studies beginning with in-depth interviews of caregivers of older adults regarding their leisure time. Subsequently, these results were presented to professionals in health care, aging, and recreation and leisure to identify practical ways to overcome the unique barriers to caregivers. Based on the results from the focus groups, the model Leisure Wellness Program was developed using Atchley's (1989) continuity theory and Coleman and Iso-Ahola's (1993) stress buffer model as the conceptual/ theoretical foundation. Atchley (1989) discussed continuity theory as the attempts by middle-aged and older adults to preserve both internal (i.e., ideas, temperament, and self-concept) and external (i.e., social environments, role-relationships, and activities) continuity throughout the aging process. Individuals who are successful in these attempts are said to experience normal aging, which consists of (a) a lack of physical or mental disease, (b) adequate housing, (c) health care, (d) nutrition, (e) recreation, and (f) networks of social relationships. The program "How to Be a Better Caregiver" provides ways in which caregivers can maintain internal continuity by

affirming and valuing their sense of responsibility toward care-recipients, yet also empowering them to maintain external continuity by encouraging them to maintain their existing social support networks and leisure activities.

Coleman and Iso-Ahola (1993) identified leisure generated social support and leisure itself as providing a buffer to stress, thus contributing positively to physical and mental health. Given that caregivers experience an inordinate amount of stress as a result of providing care, it is pertinent to identify ways to mitigate this stress. The proposed model wellness program addresses both internal and external barriers that prevent or discourage caregivers from pursuing their leisure and recreation. Additionally, it potentially develops social support and self-determination as noted by Coleman and Iso-Ahola. Caregivers may then be empowered and enabled to pursue their leisure activities and social interactions which could provide a "buffer" to the stresses of caregiving. The result is improved quality of physical and mental health for the caregivers.

Although the proposed wellness model has not been tested to date, it has potential for meeting the unique needs of caregivers of older adults. Additionally, this program can provide support for or challenge to the idea of leisure as a buffer to stress. As Chwalisz and Kisler (1995) cautioned, few interventions for caregivers are based on conceptual foundations. Therefore, the authors recommend that this theoretically-based model be implemented, tested, and revised appropriately. Designing and testing models similar to the Leisure Wellness Program can provide insight into the various ways of addressing caregivers' unique leisure needs, as well as perhaps building upon existing theoretical frameworks.

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