

Family Caregivers and Leisure: An Oxymoron? – Research Update

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Article:

As we enter the 21st century, we are the beneficiaries of a myriad of medical and technological advances. As a result, we are living longer, and often healthier, lives. In many cases, however, we live longer but with compromising medical conditions. Add to this the increased costs of health care and stricter restrictions in managed care. Consequently, many individuals are finding themselves becoming the primary care-providers for ill and disabled family members. According to the National Survey of Families and Households (Arno, Levine, & Memmott, 1999), there were almost 26 million informal family caregivers in the United States in the late 1990s. Based on the 2000 Census, projections suggest that this number may be as high as 54 million.

Family caregivers are made up of spouses, children, parents, and other relatives. They have loved ones who are ill or have disabilities that require care ranging from minimal to 24-hour assistance, and with conditions such as Alzheimer's and Parkinson's disease, cerebral palsy, and Down's Syndrome. The profile of a family caregiver shows that many have responsibilities in addition to caring for their ill or disabled loved one. According to a national study, the average age of a caregiver is 46 years old. Over 75% of family caregivers are female, two-thirds are married, and 41% also have children under the age of 18 living in the home. Additionally, 64% of these caregivers are working, and 52% of these work full-time (The National Alliance for Caregiving and the American Association for Retired Persons, 1997).

Recent research verifies that the loss of leisure for caregivers is related to stress and health problems. The focus of this research update is on describing these findings and discussing what parks and recreation professionals can be doing to help family caregivers lead balanced lives.

Psychological and Physical Effects of Caregiving

With multiple roles and responsibilities to meet, it is logical that family caregivers are going to experience some type of negative consequences from the added stress. Specifically, professional research has identified family caregivers as a group who, because of the stress of their caregiving responsibilities, are in a high risk category for psychological and physical ailments. For example, Marks (1996) found that poorer health is the most likely consequence of caregiving for the caregiver. Additionally, the National Family Caregivers Association/Fortis Report (1998) found that two out of every three caregivers reported experiencing depression since taking on caregiving responsibilities.

Gallant and Connell (1998) found that the caregiving stress process is likely to lead to negative health behaviors in the caregivers. These negative behaviors, in turn, have been associated not only with poor health status but also mortality. Similarly, in the *Journal of the American Medical Association*, Schulz and Beach (1999) identified that family caregivers who experience stress from caregiving are four times more likely to experience early mortality than those who do not.

Caregivers' Leisure (or Lack thereof)

The literature also notes how family caregivers tend to give up things of personal benefit in order to have time and energy to care for their loved ones. For example, in a study of almost 3,000 women 40 years and older,

King et al. (2000) found that caregiving duties and lack of energy ranked as two of the top four barriers to women being physically active. White-Means and Chang (1994) found that there is a 62% probability that caregiving restricts family leisure time and an 81% probability that it will compromise personal free time. Similarly, Ory et al. (1999) found that caregivers of individuals with cognitive disabilities such as Alzheimer's disease reported that they had to give up pleasurable personal activities such as vacations, hobbies, and their own activities. They noted that the caregivers also felt forced to spend less time with other members of their families because of caregiving.

More important than identifying how caregiving restricts leisure, recent studies have demonstrated that caregivers are concerned by these losses. Several studies have identified leisure loss specifically as a significant negative consequence of caregiving. For example, Scharlach (1994) explored the aspects of caregiving that caregivers considered to be most problematic and found that "lack of personal free time" was ranked as the second most problematic (out of seven) personal aspects of caregiving (p. 381). Additionally, the National Family Caregivers Association/Fortis study (1998) found that caregivers identified loss of leisure as the second most difficult aspect to caregiving out of 10 aspects reported.

Relationship between Caregiver Leisure and Caregiver Health

Caregivers often state that they give up leisure because it is something they can live without if they have to. But can they? The positive relationship between leisure and health has been clearly established by many researchers over the years. Of particular note, Iso-Ahola (1994) supported the notion of leisure contributing to mental and physical health. He described how leisure has a positive effect on mood, self-actualization, life satisfaction, increased self-esteem, and reduced loneliness. Also, according to Coleman and Iso-Ahola (1993) leisure provides buffering effects on stressful life experiences that increase the ability to cope.

As noted above, studies have connected caregiver stress specifically with reduced leisure. Therefore, the fact that the absence of leisure can cause severe consequences should be seriously regarded. White-Means and Chang (1994) found that the high probability that caregiving will limit personal free time as well as family leisure time creates increases in emotional and physical stress leading to and decreasing overall life satisfaction. They noted that "... the average caregiver faces a 50% probability of having a high level of overall stress when caregiving responsibilities lead to reduced time spent in family leisure activities ... and 62% when caregiving reduces personal free time" (p. 131). Silliman (1993) found a relationship between levels of restriction in social activities for caregivers and their perception of their own health. She stated that, "Those reporting that caregiving had not restricted the amount of time they had for leisure time activities ... were more likely to have good self-rated health at follow-up" (p. 1044). Similarly, Staight and Harvey (1990) noted for a primary caregiver group a significant relationship between depression scores and satisfaction with the amount of relaxation time. In other words, the more dissatisfied they were with the amount of time for relaxing, the more depressed they were.

Is Respite the Answer?

Many barriers prevent family caregivers from including leisure in their lives. Some feel guilty if they "take a break" to partake in their own leisure. Others are too tired, too busy, or lack the energy to engage in leisure pursuits. Many studies suggest that respite, or "free" time, for caregivers might provide the needed opportunity for relaxation and the pursuit of personally satisfying leisure activities. This respite might be available through using the services of in-home care, adult day care, or utilizing family and friends to care for the care-recipient. However, research does not support the relationship between respite and leisure in all cases. While the idea of respite has potential to positively affect a caregiver's leisure, some research suggests that this topic requires a closer look. For example, Deimling (1992) tested a program of respite for caregivers and found that when given "modest amounts of respite," the caregivers did not seem to pursue social and recreational activities. Instead, in most cases, the caregivers used the respite time to "catch up on other responsibilities, to work at paid employment, or simply rest" (p. 129). In essence, the blocks of time were too small and chores took precedent. Furthermore, spousal caregivers who become socially isolated may never use respite opportunities to increase their social and recreational activities (Deimling, 1992). He recommended that if we want respite to increase

opportunities for social and recreational activities and experiences, we need to facilitate large blocks of respite time to be effective.

It is also important to note that for many caregivers a large block of free time is still not enough to help them access their leisure. It seems that many of the studies that addressed caregiving and leisure suggested that "mental freedom" from caregiver burden was a critical element to accessing leisure, regardless of how much respite time was available.

These studies noted that although some caregivers were able to secure respite time, they could not free themselves from worrying about their care-recipient. Some who tried to go away for a vacation (small and big) felt guilty if they were away from their loved ones, and thus could not enjoy themselves. Since they were still "caring" mentally during that "freed" time, they found they could not experience true relaxation or leisure.

Meeting Caregivers' Individual Leisure Needs

Leisure is clearly related to health and wellness. Additionally, caregivers want to be able to include leisure in their lives. Therefore, parks and recreation professionals need to accept the challenge of providing leisure opportunities for family caregivers. Attention is needed to determine how to best help caregivers overcome obstacles that prevent them from identifying and accessing personally fulfilling and meaningful activities. In addition to basic physical access issues, however, several more subtle issues also exist.

While most caregivers do experience caregiver strain, how we, as recreation professionals, go about providing service might vary from caregiver to caregiver. Recent studies suggest that not all caregivers are the same regarding their need for leisure, nor in how they want to pursue it. Therefore, recreation professionals need to be aware of the psychological differences various caregivers may present regarding whether or not they "should" pursue leisure opportunities. Bedini and Guinan (1996) found that in addition to variations in individual leisure interests typical among any group of people, caregivers have differences in their sense of entitlement to leisure, varying greatly regarding how much they feel they deserve it. Dunn and Strain (2001) found that not all caregivers miss leisure in the same intensity and that different demographic variables might have an effect on the level of leisure needed. Therefore, it is important to get the input of the caregivers and to not assume that because they are caregivers, they all have the same leisure needs and interests.

Recreation professionals also need to offer basic accommodations for caregivers that would take the worry out of pursuing their activities of choice. Bedini and Phoenix (1999) conducted focus groups with professionals in recreation as well as health arena. The respondents identified several categories of programs and activities that could meet different caregivers' leisure needs. For example, providing parallel (simultaneous) but separate recreation programs for caregivers and care recipients can not only meet their individual leisure needs, but also remove barriers of time, energy, and worry for the caregiver.

Also, professionals in recreation and parks should consider the importance of shared leisure for both the caregivers and the care-recipients. Often recreation programs are only provided for the individual with the disabilities. Research by Dupuis and Pedlar (1995), for example, highlights the benefits and need for programs that are geared toward the entire family. In light of the research (noted earlier) that family caregivers often feel they have to reduce or give up time with other family members, programs that include the caregiver and the caregiver's family would be welcome.

Finally, it is important for parks and recreation professionals to be aggressive in identifying caregivers in their communities.

Family caregivers typically do not self-identify, nor do they initiate contact with community recreation programs seeking opportunities. Instead, because of the various barriers discussed above, family caregivers try to quietly do what they can. Therefore, recreation professionals need to be mindful and diligent in locating family caregivers as well as making recreation opportunities known to them.

RESEARCH INTO ACTION: CARING MEANS FOR YOUR LEISURE TOO

As we step into the new century, the number of people who are, or will become, a family caregiver is growing. This month's Research Update reviews the effects of caregiving on caregivers' leisure, and looks at ways parks and recreation professionals can help caregivers' to recreate.

Impact of This Information

After summarizing the literature about caregivers and leisure, several things are clear. First, caregiving is stressful for many individuals and causes many physical and psychological consequences. Second, a consequence that is often ignored but important to caregivers is the loss of leisure as a result of caregiving responsibilities. Third, access to, and participation in, leisure has been associated with better health for some caregivers. So, although family caregivers tend to reduce and abandon their leisure, they generally want it in their lives, miss it when it is gone, and need it for their health.

How to Use This Information

When designing or revising community recreation programs, recreation professionals can:

- * be proactive in locating family caregivers, through churches, adult day care centers, and other community agencies.
- * provide opportunities for caregivers to bring care-recipients along to community recreation programs through providing adult care, parallel recreation activities for individuals with mental and physical disabilities, special transportation, etc.
- * include caregivers in planning of recreation programs and activities. Types, quality, and timing could make a big difference and their input could be invaluable.
- * provide programs that can accommodate the entire family, including the caregiver, care-recipient, and other family members.
- * consider in-home outreach recreation services for both caregivers and care-recipients who cannot come out into the community.
- * facilitate the provision of alternative care for large blocks of time to remove one of the major barriers to caregiver leisure.
- * design leisure education programs that focus on teaching the caregiver to "enjoy the moment" during leisure blocks in an attempt to mitigate the emotional burden of feeling constantly responsible (even during times when the loved one is in the care of others).

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The Activity, Adaptation, and Aging journal, published by Haworth Press, is a good resource for information on leisure for family caregivers.

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