

Perceptions of Leisure by Family Caregivers: A Profile

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Despite the increase in research about the leisure of family caregivers, few studies provide a “profile” of family caregivers’ characteristics and how they relate to various perceptions of their leisure. The purpose of this study was to identify such a profile and examine the relationships between selected caregiver characteristics and their perceptions of leisure. A usable sample of 492 questionnaires provided profile information on 16 demographic and six leisure characteristics of female family caregivers. Results showed that the caregivers valued but missed lost leisure. Chi-square analyses included indications that respondents who valued leisure were more likely to see leisure as activity that is fun, identify as Rechargers, and were less likely to perceive caregiving as financial hardship. Implications for practice and research are presented.

KEY WORDS: *Family Caregivers, Women, Value of Leisure, Financial Hardship*

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Introduction and Purpose

Over the last decade, the body of knowledge about the leisure of informal family caregivers has grown significantly (e.g., Bedini & Guinan, 1996; Dunn & Strain, 2001; Dupuis & Pedlar, 1995; Dupuis & Smale, 2000; Rogers, 1997). Most of the studies that addressed caregiver leisure specifically, however, were based on results from relatively small numbers of caregivers with similar demographic characteristics. In addition, while much helpful information can be gleaned from these studies, at this time, no "profile" exists that would allow practitioners to understand the leisure perceptions and experiences of a large number of caregivers. With the knowledge that leisure activities benefit mental and physical health of older adults in particular (e.g., King, Baumann, O'Sullivan, Wilcox, & Castro, 2002; Silverstein & Parker, 2002; Singh, 2002; U.S. Department of Health and Human Services, 2003; Verghese et al., 2003) and that caregivers want leisure in their lives (e.g., National Family Caregivers Association, 1998), it seems appropriate to explore a substantial data set of family caregivers to understand more about the factors that affect their perceptions and access to leisure experiences.

The purpose of this study was to identify such a "profile" of informal family caregivers especially with regard to their perceptions of leisure. Specifically, this study (a) provided a demographic and leisure profile of informal female family caregivers, and (b) identified relationships between selected caregiver characteristics and perceptions of leisure.

Literature Review

Leisure and Health for Caregivers

The significance of the state of caregiver wellbeing is evident by the fact that one of the initiatives of *Healthy People 2010* (U.S. Department of Health and Human Services, 2003) is the development of interventions to address caregiver health. Unfortunately, caregiver strain has been associated with negative

health conditions and behaviors. In particular, caregiving has been correlated with poor physical health (e.g., Braithewaite, 2000; Collins et al., 1999; Marks, 1996; O'Rourke & Tuokko, 2000). For example, Collins et al. found that 54% of women caregivers had one or more chronic health conditions. King et al. (2000) found that caregivers reported caregiving duties as a significant obstacle to being physically active. In addition, many caregivers, especially women, experience mental health consequences of caregiving such as depression (Collins et al., 1999; Whitlach & Feinberg, 1997; Yates, Tennstedt, & Chang, 1999). Several studies also linked caregiving to the potential for early mortality (Gallant & Connell, 1998; Schulz & Beach, 1999).

What is clear from the research is that leisure is an important part of family caregivers' lives. According to the National Family Caregivers Association (1998), when asked directly, family caregivers identified loss of leisure as one of the top three negative consequences to being a caregiver. Similarly, individual studies noted that caregivers miss their leisure, abandoned as a result of caregiving responsibilities (e.g., Bedini & Guinan, 1996; Cant, 1993; Dupuis & Smale, 2000; Rogers, 1997; Scharlach, 1994). The Caregiver Well-Being Scale (Tebb, 1995) identified high alpha reliabilities for the items, "time for self" (.92) and "leisure activity" (.84), suggesting leisure to be important for caregiver well-being. Unfortunately, despite their desire for leisure, caregivers also find it hard to keep leisure and recreation in their lives when they take on the responsibilities of caring for a loved one (e.g., Chakrabati, Kulhara, & Verma, 1993; Dunn & Strain, 2001; Farkas & Himes, 1997; Mannell, Salmoni, & Martin, 2002; Seltzer & Li, 2000).

Research clearly shows how recreation and leisure pursuits are important to caregivers' psychological and physical health and well-being. In general, leisure activities such as physical fitness and hobbies have been related to decreased physical and emotional stress (e.g., Caltabiano, 1994; King et al., 2002; Mannell et al., 2002). More specifically, Smale

and Dupuis (1993) noted that well-being in caregivers was related to hobbies, crafts, social clubs and organizations, and visiting friends. Similarly, Haley, Levine, Brown, and Bartolucci (1987) found that caregivers who perceived greater satisfaction with their social networks scored higher on measures of life satisfaction.

Demographic Factors

It is important to note that not all caregivers are alike. Each has her/his own personal demographic characteristics that might affect one's approach and ability to be a caregiver as well as her/his perception of entitlement to leisure. For example, financial status is a significant issue for caregivers. The National Long Term Care Survey (1999) found that in the U.S., family caregiving cost approximately \$45–75 billion per year. Additionally, caregiving affects all socio-economic groups. Accordingly, research supports that the ability to pursue recreation is affected by lack of "financial adequacy" (Boaz, Hu, & Ye, 1999; Morrissey, Becker, & Rubert, 1990).

Another factor that has been identified as affecting caregivers' leisure was having children under the age of 18 in the home. Several studies indicated that the presence of children in the home can prevent family caregivers from pursuing personal satisfying leisure experiences as well as decrease satisfaction with any leisure time they were able to access (Loomis & Booth, 1995; Miller & Montgomery, 1990).

Perhaps the most significant factor affecting caregivers' leisure choices and pursuits is gender. Women make up approximately 80% of all informal family caregivers. While leisure is considered a right of all people, unfortunately, many women do not access this right. Henderson, Bialeschki, Shaw, and Freysinger (1996) noted that women, for many reasons, deny themselves opportunities to access leisure and recreation opportunities. The authors stated, "Despite the gains made regarding women's rights, many women personally feel

leisure gaps exist in their lives due to lack of balance and because gender profoundly affects what people do in all spheres of life" (p. 2). Freysinger (1995) noted that leisure can be seen as a form of disengaging from daily concerns and stressors, however, women have trouble "disengaging" because of gender roles.

Female caregivers specifically have been found to deny their own right to leisure (e.g., Bedini & Guinan, 1996). Rogers (1997) stated that female caregivers' "obligation" to husband and family "... made leisure, in effect, meaningless and their social lives and leisure dissolved" (p. 45). Rose-Rego, Strauss, and Smyth (1998) found that satisfaction with social activities was significantly less for wives than for husbands who were caring for their ill or disabled spouses. Similarly, in a study by Dunn and Strain (2001), adult daughter caregivers were more likely than adult sons to reduce or cease their leisure activities because of caregiving responsibilities.

Conceptual Framework

The conceptual framework of this study comes from two closely related foundations of entitlement. First, entitlement to leisure by caregivers comes from previous work dealing with female caregivers and their perceptions of leisure. In an interpretive study of 16 female caregivers of adults, Bedini and Guinan (1996) identified a typology of four categories by which caregivers expressed their sense of entitlement to leisure. These typologies included the "Repressor" who rejected the idea of leisure and denies her need for leisure/social activity. The "Resenter" articulated a desire for leisure but did not pursue her leisure because of perceived and real constraints imposed by caregiver burden. The Resenter was bitter for the loss and lack of access for leisure. The "Consolidator" identified both her desire for leisure and recreation opportunities as well as the constraints of caregiver burden. The Consolidator negotiated this situation by including her care-recipient into her leisure activities (bringing her social activities to the

home or her care-recipient to the activity). It is important to note that the Consolidator was content with this method of coping but would like other options. The "Recharger" expressed a strong need for recreation and leisure but only as a means for staying fit (mentally and physically) to meet the care-recipient's needs. The entitlement to leisure categories identified in this study provided the definitional foundation for the "entitlement types" of caregivers in the current study.

The second foundation is based on the feminist perspective of the ethic of care (Gilligan, 1982). The ethic of care suggests that women's lives are affected by sex role socialization and that relationships and connections are important for women in today's society. At the same time, ethic of care has been associated with women's constraints to leisure. According to Henderson and Allen (1991), the ethic of care, "may also preclude one from doing the activities truly desired because of the belief that to do so would be selfish" (p. 100). They go on to note that the ethic of care is "inherent in the family structure" (p. 103). It is important, then, to consider the framework of ethic of care when examining female family caregivers' perceptions of leisure.

Methods

Secondary Analysis of Data Set

The current study was a secondary analysis of a data set that was used in a previous study by Bedini and Phoenix (2000) which sought to design a reliable and valid quantitative instrument that could distinguish among the four leisure entitlement categories in female caregivers noted above. The current study, however, conducted data analysis that addressed the relationship of selected demographic factors to caregivers' perceptions of leisure. The entitlement categories identified in the previous study provided "labels" for examining leisure perceptions by the individual entitlement types.

Subjects

As noted earlier, women are unique regarding entitlement to leisure (e.g., Freysinger 1995; Henderson et al., 1996). In addition, caregiving literature notes how male and female caregivers differ regarding their approach to caregiving (e.g., Grau, Teresi, & Chandler, 1993; Horowitz, 1985; Miller & Cafasso, 1992). Therefore, considering that over 80% of family caregivers are women, the sample drawn for this study was delimited to only women to allow for clear interpretation of data. The sample was taken from the membership list of the National Family Caregiver's Association (NFCA). At the researchers' request, the Association staff removed the male members from the list and then provided the researchers with a sampling frame of 1740 female members. From this total, a systematic random sample of 1000 subjects was chosen. The list was randomized by clerical staff at NFCA and then researchers selected every 7th individual until 1000 were chosen.

Instrument

Data for this study were collected through the use of 23 of the 49 items found in the Entitlement questionnaire that was distributed for the typology instrument study noted above (Bedini & Phoenix, 2000). The original instrument comprised four sections. The first section, Section A, was the "core" of the original typology instrument study and contained 30 questions presented on a 5-point Likert scale with 5 being "most like me" and 1 being "least like me." Twenty-six of these questions were designed to distinguish quantitatively among the four entitlement categories. Reliabilities for the four typology sub-scales ranged from .67 to .80.

The remaining four questions about the *value of leisure* were the only ones used from Section A for the current study. The specific questions were, "I protect my leisure regardless of my caregiving responsibilities," "My care-recipient has a lot of influence over whether I pursue my leisure/recreation," "I

value my leisure/recreation pursuits,” and “I can do leisure/recreation whenever I want.” Since these were presented as separate questions and not as a sub-scale in the original study, no reliabilities exist for these items.

The second section of the original questionnaire (Section B) asked the respondents to define their concepts of leisure. Specifically, respondents were asked to choose which of four definitions of leisure (activity, state of mind, unobligated time, and freedom from responsibility) most described their perspective. These definitions were taken from traditional descriptions of leisure in the field of leisure studies. These items were used in the secondary analysis.

Similarly, in Section C, respondents were asked to choose which of the four types of entitlements to leisure (Repressor, Resenter, Consolidator, and Recharger) best described them. As noted earlier, the Repressor had little interest in leisure, the Resenter wanted leisure but believed she could not access it and experienced resentment as a result. The Consolidator tried to incorporate her leisure with her caregiving, either taking her caregiver with her to her leisure activity, or bringing her leisure in. The Recharger tried to maintain leisure in her life so that she would be healthy and fit and subsequently a better caregiver. Definitions for each type were phrased based on generic descriptions compiled from the words of the respondents in Bedini and Guinan’s (1996) study. All of these items were also part of the current study.

The last section of the instrument (D) comprised 17 demographic questions. Fifteen of the questions addressed categories such as caregivers’ age, race, income, years of caregiving, primary disability of the care-recipient, level of care required, and types of support they received. In addition, question #16 asked if caregiving caused the respondent financial hardship. If the respondent answered “yes,” to item #16, then she was asked (in question #17) if that hardship affected her ability to access recreation and leisure. This was an open-ended question that was not included in the current

study, rather, only questions 1 through 16 were used in the secondary analysis.

Data Collection and Analysis

The researchers used a modified Total Design Method (Dillman, 1978) to prepare and send the mailing. Each mailed packet contained a 6-page questionnaire, a personalized cover letter, and a return addressed stamped envelope. The packets were mailed first class to the 1000 randomly selected potential respondents during National Family Caregivers Week in November. Two weeks after the initial mailing, a reminder card was sent to all subjects who had not returned their survey.

Data analyses entailed basic descriptive statistics (frequencies and percentages) to present the basic profile. Subsequently, crosstabulations with chi square analyses were conducted to examine relationships between demographic characteristics and items related to value of leisure, definitions of leisure, and caregiver entitlement. All analyses were completed using an SPSS statistical program.

Results

The results of this study yielded two predominant findings. First, the data provided a demographic and leisure profile of informal female caregivers. Second, subsequent analysis showed relationships between the caregivers’ perceptions of leisure and selected caregiver demographic variables.

A total of 524 surveys were returned. Thirty-two surveys were not usable because they were not completely filled out. In several cases, the respondents’ care-recipient had died and they returned the survey blank. Other unusable surveys were from members of NFCA who were not caregivers (e.g., social workers, nurses). Therefore, the final overall usable sample was 492 questionnaires for a 50.8% return rate.

Respondent Profile

Eighty-five percent of the respondents were European-American with a mean age of 55.8

years. Almost three-fourths (73.4%) of the respondents were married or living with a partner. Over half (53%) were caring for a spouse or partner, with another 30% caring for a parent or parent-in-law, and 12% caring for a child. In addition, approximately 6% were caring for more than one family member with a disabling condition. Only 15% of the sample had children under 18 living at home. The respondents had been caregivers for one to 61 years. Most of the care-recipients (58%) lived in the caregivers' homes. The care-recipients had any of 28 different disabilities, the most common of which were Alzheimer's disease (21%), stroke (13%), and multiple sclerosis (10%). Additionally, 16% of the care-recipients had multiple disabilities.

Over half of the respondents' care-recipients (52%) required constant care. Fifty percent of the sample received outside support for 10 hours or less per week. The most common sources of assistance were home health care (18%) and family (14%). Almost 12% had no assistance at all. Forty-five percent were employed either full-time (31%) or part-time (14%). Another 30% were retired. Yearly household income ranged from under \$15,000 (9%) to over \$75,000 (15%). When asked if caregiving caused them a financial hardship, 50% of the respondents answered "yes," 45% answered "no," and 5% answered "some-what." See Table 1 for the detailed respondent profile.

Caregivers' Perceptions of Their Entitlement to Leisure

The second purpose of this study was to identify relationships between selected caregivers characteristics and their perceptions of leisure. This was addressed in two ways. First, four questions asked the respondents about their value of leisure. Second, two separate questions in Sections B and C respectively asked respondents to indicate their definition of leisure as well as which definition of caregiver (with regard to entitlement to leisure) they felt best described them.

Value of leisure. The value of leisure was examined through four questions: "I value my leisure/recreation pursuits," "I protect my leisure regardless of my caregiving responsibilities," "My care-recipient has a lot of influence over whether I pursue my leisure/recreation," and "I can do leisure/recreation whenever I want." Overall, approximately 71% of the respondents stated that they valued leisure. When comparing value of leisure to the different relationships that the caregivers had to the care-recipients (i.e., parent, adult child, spouse), caregivers of children with disabilities were less likely to value leisure ($\chi^2(8, N = 433) = 15.61, p = .05$) than caregivers of adults (either parents or spouses). For all subjects, the value of leisure decreased as the level of care required by the care-recipient increased ($\chi^2(6, N = 485) = 13.17, p = .04$); whereas, valuing leisure increased as income increased among all caregivers ($\chi^2(4, N = 374) = 10.74, p = .03$). Finally, analysis indicated that there was a relationship between valuing leisure (79%) not perceiving caregiving to cause a financial hardship. ($\chi^2(4, N = 457) = 18.33, p = .00$).

Despite the high percentage of caregivers who valued their leisure, only 12% reported that they protected their leisure. The only difference among groups that emerged regarding protecting their leisure was in relationship to level of care required by their care-recipients. Those with care-recipients that required more care were less likely to protect their leisure ($\chi^2(6, N = 433) = 18.54, p = .01$). In addition, while no significant differences were evident, it is interesting to note that only 4% of those caring for children with disabilities stated that they protected their leisure.

Sixty-three percent of the respondents reported that their respective care-recipients had a lot of influence over whether they (respondents) pursued leisure. Understandably, this perception of influence increased as level of care required by the care-recipient increased ($\chi^2(6, N = 486) = 17.15, p = .01$). Age and employment also seemed to affect these re-

Table 1.
Respondents' Profile

	Overall (N = 492)	CG of OA (N = 366)	CG of CwD (N = 48)
Caregiver Age			
26–35 yrs	1.6%	1.9%	2.1%
36–45 yrs	16.9%	16.2%	31.9%
46–55 yrs	31.9%	30.1%	46.8%
56–65 yrs	26.0%	27.7%	12.8%
66–75 yrs	18.5%	19.7%	4.3%
76–85 yrs	4.7%	4.1%	2.1%
86–95 yrs	.4%	.3%	00.0%
Race			
African-American	4.3%	4.9%	4.3%
Asian-American	.2%	.3%	00.0%
European-American	84.9%	83.6%	89.4%
Hispanic/Latino	1.6%	1.9%	2.1%
Native-American	6.9%	7.1%	4.3%
Other	2.1%	32.2%	00.0%
Marital Status			
Married/Living w/Partner	73.4%	74.3%	66.0%
Separated/Divorced	8.3%	5.7%	23.4%
Widowed	4.9%	4.9%	4.3%
Never Been Married	13.0%	14.5%	6.4%
Other	.4%	.6%	0.0%
Years as Caregiver			
0–5	41.2%	43.2%	8.3%
6–10	30.5%	34.5%	16.7%
11–15	11.1%	8.1%	33.3%
16–20	8.2%	8.1%	14.6%
over 20	9.1%	6.1%	27.1%
Relationship of Care-recipient [*Note 6.2% taking care of two or more care-recipients at once.]			
Spouse/partner	53.1%		
Parent	30.0%		
Child	12.0%		
Other	4.9%		
Care-recipient (CR) Age			
6–18 years	4.8%		
19–30 years	4.4%		
31–50 years	12.2%		
51–70 years	28.0%		
71–90 years	45.9%		
91–102 years	4.8%		

Table 1. (Continued)

	Overall (N = 492)	CG of OA (N = 366)	CG of CwD (N = 48)
Living Arrangements			
CR lives in my home	57.7%	54.2%	81.3%
I live in CR home	10.8%	12.3%	2.1%
CR lives independently	6.5%	6.0%	6.3%
CR lives in nursing home	11.8%	12.1%	10.4%
We live together in our home	11.2%	12.9%	00.0%
Other	2.0%	2.5%	00.0%
CR Primary Disability [*Note—no individual disability in “other” was more than 2%]			
Alzheimer’s/dementia	17.6%	23.8%	2.1%
Cancer	2.5%	3.3%	00.0%
Cerebral Palsy	1.5%	.5%	14.6%
Heart Disease	3.2%	3.8%	00.0%
MR/DD	1.0%	.3%	8.3%
Multiple Sclerosis	9.1%	11.2%	8.3%
Parkinson’s	4.6%	6.3%	00.0%
Stroke	9.1%	12.3%	00.0%
Spinal Cord Injury	5.9%	7.1%	6.3%
Traumatic Brain Injury	2.0%	1.9%	6.3%
Multiple disabilities	13.6%	14.0%	33.3%
Other	29.9%	15.2%	20.8%
Level of disability (assistance required with personal care)			
Little to no assistance	9.3%	9.3%	4.2%
Some assistance	13.6%	15.1%	10.4%
With at least 2 activities daily	24.8%	26.1%	14.6%
Constant care and assistance	52.0%	49.5%	70.8%
Other	.3%	00.0	00.0%
Support type received [*Note—no individual support type in “other” was more than 3%]			
None	11.5%	11.5%	8.3%
Adult day care only	2.7%	3.1%	00.0%
Family members only	13.7%	13.2%	14.6%
Friends only	2.3%	2.5%	4.2%
Hired home aide only	2.3%	2.0%	6.3%
Home health care only	15.8%	14.3%	6.3%
Support groups only	2.7%	3.1%	00.0%
Family and friends	5.5%	5.9%	4.2%
Family and home health	4.7%	5.3%	2.1%
Support groups & family	4.3%	5.3%	2.1%
Other/other combinations	34.5%	33.8%	51.9%
Hours of support received (per week)			
0–5 hours	34.1%	37.0%	25.0%
6–10 hours	15.9%	17.1%	5.0%
11–15 hours	9.1%	10.7%	2.5%
16–20 hours	8.3%	6.8%	7.5%

Table 1. (Continued)

	Overall (N = 492)	CG of OA (N = 366)	CG of CwD (N = 48)
21–25 hours	3.4%	3.9%	00.0%
26–30 hours	8.1%	6.8%	17.5%
31–35 hours	2.3%	2.1%	5.0%
36–40 hours	5.7%	4.3%	5.0%
41 hours and over	13.1%	11.3%	32.5%
Children under 18 years of age in household			
0	85.6%	87.6%	54.2%
1	7.9%	7.4%	18.8%
2	4.9%	3.8%	18.8%
3	1.4%	.8%	8.3%
4	.2%	.3%	00.0%
Employment status (in addition to work as a caregiver)			
Employed Full-time	30.8%	32.4%	33.3%
Employed Part-time	13.9%	14.0%	12.5%
Retired	29.6%	29.1%	8.3%
Self-Employed	.2%	.3%	00.0%
Not Employed	24.1%	22.8%	43.8%
Student	.4%	.5%	00.0%
Combination of above	1.0%	.9%	2.1%
Household Income [optional question]			
Under \$15,000	9.1%	10.0%	4.9%
\$15,000 to \$24,999	13.7%	12.3%	9.8%
\$25,000 to \$29,999	10.0%	9.6%	12.2%
\$30,000 to \$39,999	17.6%	17.6%	12.2%
\$40,000 to \$49,999	15.7%	16.3%	14.6%
\$50,000 to \$74,999	18.4%	17.9%	24.4%
\$75,000 or Higher	15.4%	16.3%	22.0%
Does caregiving cause financial hardship			
Yes	49.5%	50.4%	50.0%
No	45.4%	44.6%	43.8%
Sometimes	5.1%	5.0%	6.3%

Key: CG of OA = Caregivers of Older Adults; CG of CwD = Caregivers of Children with Disabilities.
 Note: Anomalies due to rounding.

sults. Respondents 55 years of age and older ($\chi^2(4, N = 454) = 15.69, p = .00$) and those who were retired ($\chi^2(12, N = 484) = 23.14, p = .03$) were more likely than the younger, employed caregivers to feel that their care-recipient had a lot of influence over their leisure experiences.

For the last value question, “I can do lei-

sure/recreation whenever I want,” caregivers of children with disabilities ($\chi^2(4, N = 434) = 10.85, p = .03$) were less likely to feel free to recreate at their own will. Additionally, those respondents whose care-recipients required a high level of care were least likely ($\chi^2(6, N = 486) = 36.39, p = .00$) to feel this freedom. See Table 2 for details.

Table 2.
Value of Leisure

Q1 I value my leisure/recreation pursuits.			
	Overall (N = 423)	CG of OA (N = 366)	CG of CwD (N = 48)
Exactly like me	34.3%	32.8%	41.7%
A lot like me	36.9%	38.3%	27.1%
Somewhat like me	19.1%	20.5%	12.5%
Not much like me	5.4%	4.6%	10.4%
Not at all like me	4.3%	3.8%	8.3%
Q2 I protect my leisure regardless of my caregiving responsibilities.			
	Overall (N = 412)	CG of OA (N = 355)	CG of CwD (N = 48)
Exactly like me	2.7%	2.8%	2.1%
A lot like me	9.5%	10.4%	2.1%
Somewhat like me	27.4%	26.8%	35.4%
Not much like me	33.3%	31.5%	43.8%
Not at all like me	27.2%	28.5%	16.7%
Q3 My care-recipient has a lot of influence over whether I pursue my leisure/recreation.			
	Overall (N = 422)	CG of OA (N = 365)	CG of CwD (N = 48)
Exactly like me	30.3%	29.3%	39.6%
A lot like me	32.9%	33.4%	29.2%
Somewhat like me	22.3%	22.7%	18.8%
Not much like me	9.7%	10.1%	8.3%
Not at all like me	4.7%	4.4%	4.2%
Q4 I can do leisure/recreation whenever I want.			
	Overall (N = 423)	CG of OA (N = 366)	CG of CwD (N = 48)
Exactly like me	2.4%	2.5%	00.0%
A lot like me	3.8%	3.8%	2.1%
Somewhat like me	10.9%	11.5%	4.2%
Not much like me	23.6%	25.1%	14.6%
Not at all like me	59.3%	57.1%	79.2%

Key: CG of OA = Caregivers of Older Adults; CG of CwD = Caregivers of Children with Disabilities.
Note: Anomalies due to rounding.

Definitions of leisure. Four definitions of leisure were presented to the respondents as part of this survey. Over half of the respondents defined leisure and recreation as “unobligated time” (58%). The remaining 42% chose the definitions of “freedom from responsibility” (19%), “activity that was fun” (15%), and “state of mind” (8%). Additionally, just

less than 1% of the respondents created their own definitions of leisure. For example, one woman added the words, “body and spirit” to the definition about state of mind. Also, several noted that they could not pick just one definition and combined two or more definitions.

For all but one comparison, there was no

statistically significant difference among the respondents regarding their definitions of leisure. Some patterns were evident, however. The definition of "unobligated time" was chosen most often by caregivers of children with disabilities (72%). Conversely, defining leisure as "activity that is fun" (4.3%) as well as "freedom from responsibility" (4.3%) were notably low among caregivers of children with disabilities. No significant differences existed among leisure definitions and the relationship of the caregiver to her care-recipient.

The leisure definition, "unobligated time," was also selected by 52% of the caregivers who were caring for spouse or partner and by 63% of adult children caring for a parent or parent-in-law. In addition, whether caregiving caused financial hardship was statistically significant when viewed in terms of definitions of leisure. ($\chi^2(3, N = 443) = 9.95, p = .02$). In particular, those who defined leisure as "freedom from responsibility" (60%) answered "yes," and those who defined leisure as "activity that is fun" (65%) answered "no."

Self-definitions of entitlement to leisure. The respondents were asked to describe themselves in terms of how entitled they felt to leisure based on the four entitlement categories identified by Bedini and Guinan (1996). Results showed that over half (54%) identified themselves as Resenters who had to "give up a lot of my leisure because of caregiving responsibilities" and "this situation makes me sad and sometimes resentful." Just over one fourth of the respondents (27%) defined themselves as Rechargers by selecting, "I make sure I have my recreation/leisure because it is essential to help me maintain the energy and attitude I need to care for my care-recipient." Twelve percent of respondents identified themselves as Consolidators saying they "still pursue my leisure/recreation but I can do it only if I involve my care-recipient in the activities." Approximately 3% were Repressors who had "little to no interest in recreation/leisure." Additionally, 4% of the respondents created their own definition. For example, several respondents did not like the term "resentful" in the

second definition and suggested omitting it. Others talked about guilt along with their chosen definition. Still others wrote long notes explaining under what circumstances they might choose one definition versus another.

It is interesting to note that there was a significant difference among entitlement types in relation to the question of whether caregiving caused the respondents financial hardship ($\chi^2(3, N = 429) = 18.50, p = .00$). The majority of Repressors (77%) and Resenters (57%) answered "yes," however, the majority of Rechargers (65%) answered "no."

Relationship between definitions of leisure and perceptions of entitlement to leisure. The most popular definition of leisure, "unobligated time," was chosen by over half of the Resenters (63%), and Consolidators (58%), respectively. For the category of Repressor, the definitions of leisure, "activity that's fun," and "freedom from responsibility" were each chosen 37% of the time.

It is important to note, also, that subsequent analyses to determine if a statistical relationship existed between household income and the above variables (i.e., entitlement to leisure, definition of leisure, value of leisure) were not significant. Therefore, it is clear that these results are not because one group (i.e., Rechargers, those who defined leisure as "freedom from responsibility") was more financially secure than the other groups. Rather, all groups were statistically equal. This suggests that these findings were a result of their definitions and sense of entitlement rather than their financial status.

Discussion

Limitations

The purpose of this study was to identify a "profile" of informal female family caregivers especially with regard to their perceptions of leisure, relationships between different caregiver characteristics, and patterns from open-ended questions dealing with the relationship of financial hardship and leisure for caregivers. Two limitations should be considered. First,

the sample for this study was predominantly white, lacking much racial or ethnic diversity. Thus, the results represent a homogenous and ethnically limited population. Second, the respondents were, in some respects, self-selected in that they had already self-identified as a caregiver by being a member of the National Family Caregiver's Association, the source of the sample. As a result, the perspectives of caregivers who do not self identify as a caregiver were absent from this profile.

Conclusions

It is clear from the results that this sample of female family caregivers valued their leisure greatly. For the overall sample, over 70% stated that valuing their leisure was "exactly like me" or "a lot like me." Also, less than 3% of the respondents defined their sense of entitlement as "having little or no interest in leisure." However, the respondents also reported having difficulty accessing leisure due to a number of barriers. Eighty-two percent of the caregivers of adults and 92% of the caregivers of children with disabilities reported they could not access leisure whenever they wanted. The constraints appeared to be attitudinal as well as functional. For example, 63% of the respondents noted that their care-recipients had influence over their pursuits of leisure.

"Unobligated time to do as I please" was the most common definition of leisure (58%) among the respondents. This definition is somewhat consistent with that of other older adult women studied by Siegenthaler and Vaughn (1998). The women in their study were older adults who lived in retirement communities and did not identify as primary caregivers. Siegenthaler and Vaughn found that the women in their study viewed leisure and recreation as "freedom to explore self, to make decisions, to choose" (p. 64) which parallel the current study's respondents wanting to "do as they please." Other perceptions of the current respondents, however, vary from the perceptions from the Siegenthaler and Vaughn study. While the women in the retirement community

identified "enjoyable activities" (p. 63) as a significant part of their leisure and recreation, very few of the current study's subjects identified leisure and recreation as activity (15%). Most surprising, however, was that only 18.5% of the respondents of this study identified "freedom from responsibility" as their definition for leisure. Considering the additional roles, stress, and burden imposed by caregiving responsibilities, it would seem that the majority of these women might choose the definition of recreation and leisure that addressed responsibility. Taken together, these results indicated that conceptually, this seems to boil down to the issue that freedom, in whatever form, is an essential element to leisure. Henderson et al. (1996) noted that freedom includes both "freedom from" and "freedom to" which for these respondents might explain the desire of freedom "to" do as they please while experiencing freedom "from" responsibility.

It is interesting to note that the most popular definition of leisure, "unobligated time," was also chosen by almost two-thirds of the Resenters (63%). This makes sense considering that this type of caregiver was more likely to struggle with their situation of being a caregiver. In other words, perhaps Resenters, by nature of how they defined their entitlement to leisure, were more likely to wish for time where they could do as they pleased.

A slight majority of the sample identified their sense of entitlement to leisure as a Resenter. These respondents chose the description, "I had to give up a lot of my leisure because of caregiving responsibilities. This situation makes me sad and sometimes resentful." With over half of the respondents feeling sad and frustrated with not being able to access leisure, issues of access as well as coping strategies are raised. Clearly, these individuals either do not feel comfortable accessing leisure under their current circumstances or they are not aware of how to access it.

Perhaps the most intriguing results of this study were found regarding the caregivers' perceptions of financial hardship. Those who

were least likely to perceive caregiving as a financial hardship also were most likely to define leisure as “activity that is fun,” had higher value for leisure, and defined themselves as the “Recharger” type in terms of their sense of entitlement to leisure. Conversely, the Repressors, who defined themselves as having little or no interest in recreation or leisure, were most likely to perceive the financial hardship of caregiving. In fact, over 75% of the Repressors found financial hardship in caregiving. Similarly, those who defined leisure as “freedom from responsibility” perceived financial hardship of caregiving while those who defined leisure as “activity that is fun” did not. Since data analysis indicated that none of these groups was statistically significantly wealthier or poorer than the others, other reasons should be considered to explain these results. In fact, the reasons for their differences on this question might be found simply in perceptions rather than demographics. For individuals who do not value nor perceive they need leisure (Repressors), financial hardship seemed to be more relevant and of concern. Conversely, individuals who perceived leisure as something that is “fun” and who functioned as Rechargers, who “make sure I have my recreation/leisure because it is essential to help me maintain the energy and attitude I need to care for my care-recipient,” did not perceive the financial hardship. Perhaps, the Rechargers who saw leisure as fun did not see the financial hardship because if an activity only had to be fun to be considered leisure, it might likely be free. Regardless, if attitude and perception are the root of these responses, approaches to address how the caregivers view life situation and their leisure might prove useful.

Recommendations

Recommendations for Practice

It is clear from these results that leisure is not easily abandoned by people who care for others. Results indicated that the majority of caregivers experience a loss regarding the leisure they must give up and retain a desire to be

able to access it. Programmers in recreation services as well as in health care and social services need to acknowledge female family caregivers’ desire for leisure. It is important for professionals in all health and social service arenas to provide or facilitate appropriate accommodations for leisure and recreation access to meet these caregivers’ needs. Also, since leisure has been determined to improve physical and mental health, it is imperative that more is done to provide accessible and meaningful leisure to female family caregivers of older adults and children with disabilities. For example, programs that provide respite should factor in the caregiver’s desire for leisure as well as her need for mental and emotional security. If “burdened” mentally, the caregiver cannot truly experience leisure. Programs that can provide safe programs for the care-recipients as well as meaningful recreation and leisure for the caregiver at the same time could address these concerns. One suggestion would be providing parallel programs in community centers whereby caregivers can bring care-recipients while caregivers participate in their own recreation activities. This scenario has potential to lift some worry whereby the caregivers know that their care-recipient is not only safe, but also enjoying their own leisure.

Furthermore, programmers should provide more than just respite time away from care-recipients. Results indicated that in order to be experienced as leisure, it is essential that this time is free of obligations mentally, physically, and emotionally. The respondents of this study indicated that factors such as the influence of their care-recipients, having a child with a disability, and higher levels of required care were associated with reduced value and protection of leisure. Programmers should explore methods to empower these caregivers to increase their perceptions of leisure as a valuable commodity that deserves to be protected. For example, leisure programs for caregivers as well as care-recipients in their homes should be considered by related professionals. The caregivers clearly want leisure but often

cannot functionally or emotionally justify outside assistance to pursue it. Outreach programs that go into caregivers homes to provide recreation as well as leisure education services for both caregivers and care-recipients can address some of the mental and physical needs of family caregivers.

These results also suggest that perhaps the respondents' perceptions of financial hardship are more a matter of attitude than actual financial status. If that is the case, then programs should attempt to address the caregivers' own attitudes, value, and access to leisure (activity that is fun), in turn reducing their perceptions of financial hardship. Recreation programmers can work to design leisure education programs through social services as well as medical offices. These programs would be beneficial and address the caregivers' reticence and guilt regarding pursuing their own leisure. With the "sanction" and referral of community medical professionals encouraging leisure education, perhaps caregivers can justify this pursuit.

Recommendations for Research

Further research is indicated for female family caregivers and their leisure. First, a more diverse sample is warranted. This sample was purposely delimited to only females, however, learning more about the sense of entitlement to leisure as well as perceptions of financial hardship from male family caregivers could be useful. Additionally, other types of diversity should be pursued. This sample was predominantly white and married. More needs to be learned about caregivers who are people of color from differing ethnic backgrounds as well as diverse relationships (i.e., same sex partners, grandparents as caregivers).

Several of the results noted how caregivers of children with disabilities were statistically significantly different from the caregivers of adults. Further examination of the caregivers of children with disabilities might yield insight to additional barriers and constraints experienced by this unique group of caregivers.

Another result that seemed to illustrate a

type of barrier to caregivers' leisure pursuits was the fact that caregivers in this sample felt that their care-recipients influenced their leisure. This concept should be explored in more depth to determine its full effects on caregiver's leisure as well as the dynamics involved in the process.

Finally, future research should attempt to determine a causal relationship between perception of financial hardship and attitude toward value of leisure. Implications exist for exploration of the relationship between entitlement types, perceptions of leisure as fun, and the respondents feelings of greater value of leisure.

In summary, the purpose of this study was to identify a "profile" of female family caregivers with regard to their perceptions of leisure. Results indicated that the caregivers in this study missed their leisure, however, demonstrated differing senses of entitlement to leisure. These results are consistent with previous literature about female family caregivers (Bedini & Guinan, 1996; Rogers, 1997). Perceptions of caregiving causing financial hardship varied based on different perceptions of entitlement, how the respondents defined leisure, and how much they valued leisure, all of which suggested that one's perception of leisure might have a direct effect of their perception of negative consequences to caregiving. Additionally, an interaction of financial, time, and assistance barriers suggested by qualitative responses to open-ended questions in this study raise implications for both practice and research.

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