# Caregivers at Risk?: Changes in Leisure Participation

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This article examined the likelihood of reducing and/or ceasing leisure activities, reasons for these changes, and the relationship between caregivers' characteristics, caregiving experiences, and leisure participation among a sample of 517 informal caregivers of Adult Day Care clients in Manitoba, Canada. Reduction and cessation of leisure activities were considered separately and in combination. The results indicated that not all caregivers of these older adults changed their leisure participation although there was an at-risk group. A lack of time due to caregiving was the most frequently identified reason for a change. The relationship between caregiver characteristics, the caregiving experience, and leisure participation was complex and varied depending on the dimension of leisure participation examined. Implications for future research and practice are highlighted.

KEYWORDS: Caregivers, leisure, leisure activities, older adults, barriers

#### Introduction

Stress, strain, and negative responses to caregiving are well recognized as issues which can alter a caregiver's lifestyle (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Pearlin, Aneshensel, Mullan, & Whitlatch, 1996). While leisure has been identified as a coping resource (Bedini & Bilbro, 1991; Dupuis & Pedlar, 1995; Keller & Tu, 1994; Sneegas, 1988), the extent to which caregivers change their leisure participation is not clear. The U.S. Select Committee on Aging (1987) noted that "caregivers tend to double up on their responsibilities and to cut back on their leisure time in order to fulfill all of their caregiving tasks" (p. 27). Caregivers have been reported to adjust their lives by reducing participation in, or giving up, activities/interests such as regular exercise, hobbies, free time for oneself, sex life, opportunities to socialize with friends, community involvement, vacations, and leisure time pursuits and activities (Barusch, 1988; Brattain Rogers, 1997; Sneegas, 1988).

The work of Miller and Montgomery (1990) and White-Means and Chang (1994) suggests that some caregivers experience limits to their leisure

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participation due to caregiving while others do not. Drawing on the 1982 U.S. National Long Term Care Survey and the Informal Caregiver Survey, Miller and Montgomery (1990) found that 50% of the 1,167 spousal and adult children caregivers indicated that taking care of their older family member limited their social life or free time. White-Means and Chang (1994) analysed data from 1982-84 National Long-Term Care Channelling Evaluation Project that focused on frail older adults at risk of institutionalization and their informal caregivers. Of the 1,929 caregivers, 69% limited the time they had to spend with family due to caring for the older adult. In addition, 55% indicated that their social life and free time were limited. Overall, 74% of these caregivers experienced limits to family and/or free time.

Results from a qualitative study of 16 female caregivers (Bedini & Guinan, 1996a) also suggest variations among caregivers. These researchers distinguished between four groups of caregivers in terms of their leisure participation. The repressors and resenters were unable to participate in leisure due to caregiving responsibilities, with the former group expressing no need for leisure and the latter being disappointed and displeased about being unable to participate. In contrast, consolidators and rechargers continued to participate in leisure. However, the consolidators had modified their leisure plans.

The likelihood of caregivers reducing the frequency of leisure participation or completely ceasing some activities requires increased attention. There is a need to distinguish between reducing and ceasing leisure participation (Zimmer, Hickey, & Searle, 1997). It is possible that some caregivers reduce the frequency of leisure participation but do not cease specific activities. Other caregivers may cease specific activities while maintaining the frequency of participation in some activities. Still others may reduce their participation in some activities and completely cease others.

The relationship among demographic characteristics, health, caregiving, and leisure participation also warrants attention (Bedini & Guinan, 1996a; Miller & Montgomery, 1990). The limited existing research suggests that female caregivers are more likely than their male counterparts to limit leisure time due to caregiving (White-Means & Chang, 1994). Miller and Montgomery (1990) found that adult daughters who had children under the age of 18 in the household were more likely to report limiting free time due to caregiving than those who did not have children in the household. The same findings did not emerge for adult sons.

Having more years of education has been associated with limiting leisure time (Miller & Montgomery, 1990; White-Means & Chang, 1994) while less discretionary time was evident for employed caregivers in Moss, Lawton, Kleban, and Duhamel's (1993) research. Higher wage incomes have been found to be related to limiting family time but not to limiting free time (White-Means & Chang, 1994). White-Means and Chang (1994) noted that caregivers in poorer health themselves were more likely to limit their leisure time (also see Keller & Tu, 1994).

Co-residence with the care recipient has been found to be associated with limiting leisure time (White-Means & Chang, 1994) and spending less time on recreation and reading (Moss et al., 1993). As well, lower levels of participation in activities such as visiting family/friends, church and club attendance, and less satisfaction with social activities have been reported for caregivers who lived with the care recipient (George & Gwyther, 1986).

Research on the relationship between the elder's health and the caregiver's leisure participation is inconclusive. The older adult's functional limitations, the number of tasks performed by the caregiver, and the number of extra hours spent helping the older persons because of disability may not be as important as subjective appraisals (Miller & Montgomery, 1990). Time pressure (having to give almost constant attention and having to provide care when not feeling well enough), relationship difficulties, and global stress emerged as significantly associated with having to limit free time due to caregiving.

While caregiver characteristics and the caregiving situation appear important, the focus in these studies has tended to be on the likelihood of limiting either family or free time due to caregiving. The extent to which these characteristics are also important when considering reductions in the frequency of participation or ceasing activities remains to be explored.

Lastly, the reasons why caregivers reduce and/or cease their leisure participation need further consideration. The extent to which caregivers experience other constraints more typically considered such as lack of equipment and/or supplies, lack of information, lack of financial resources, lack of others with whom to participate, weather restrictions, lack of time due to work outside the home, family commitments, or lack of interest is generally not known. While these leisure constraints have been examined for various subgroups of the population including women (e.g., Henderson, 1991; Henderson & Bialeschki, 1991; Henderson, Bialeschki, Shaw, & Freysinger, 1989), older adults (e.g., McGuire, 1984; McGuire, O'Leary, Yeh, & Dottavio, 1989; Searle, Mactavish, & Brayley, 1993), and adolescents (e.g., Hultsman, 1992; 1993), relatively little attention has been given to caregivers.

Existing research does suggest that caregivers may experience losses in freedom such as the ability to leave home at their discretion and free time to pursue activities outside of caregiving such as social interaction (Bedini & Guinan, 1996b; Chenoweth & Spencer, 1986; Montgomery, Gonyea, & Hooyman, 1985; Miller & Montgomery, 1990; Sneegas, 1988; White-Means & Chang, 1994). As noted earlier, this lack of time potentially impacts several spheres of the caregiver's life such as limiting a caregiver's social life and contributing to isolation from friends and activities (Chenoweth & Spencer, 1986; Miller & Montgomery, 1990; Stephens & Christianson, 1986; White-Means & Chang, 1994).

To some degree, the lack of freedom and free time may be a result of the caregiver's own attitudes and values (Hughes & Keller, 1992). Responsibility for the care and well-being of care-recipients may limit a caregiver's decision to participate in leisure (Bedini & Guinan, 1996b; Weinblatt & Navon, 1995). Caregivers may view concerns with their own needs as selfish and these may be guilt-provoking (Aronson, 1992; Hooyman, 1990; Pratt, Schmall, & Wright, 1987). Although outside assistance or respite may allow caregivers the opportunity to leave their homes and engage in social activities, caregivers have been reported to believe that it would be wrong to turn the care of their relative over to someone else or they feel guilty for having to ask others for help (Aronson, 1992; Brattain Rogers, 1997). Weinblatt and Navon (1995) have argued that intrapersonal constraints such as perceptions of being in the midst of a constant battle to prolong the care receiver's life play a significant role in the caregiver's decision to participate in leisure.

Overall, although the existing research sheds some light on the caregiving experience and leisure participation, several issues remain to be examined. This study focused on changes in leisure participation among a sample of caregivers and addressed the following questions:

- 1. What is the likelihood of reducing and/or ceasing leisure activities?
- 2. Are there differences in socio-demographic characteristics, health status, and caregiving experiences of caregivers who reduced and/or ceased their leisure activities and those who did not?
- 3. What reasons do caregivers give for reducing and/or ceasing their leisure activities?
- 4. Do caregivers who indicated that a reason for reducing and/or ceasing leisure activities was a lack of time due to caregiving differ from those who did not give this reason in terms of their sociodemographic characteristics, health status, and caregiving experiences?

#### Method

The data are from a 1996/97 province-wide study of Adult Day Care (ADC) programs in the province of Manitoba, Canada. In Manitoba, Adult Day Care is offered through the government-funded Home Care program to individuals who are residing on their own or with family members/friends in the community. The target population includes: people who are isolated due to illness and disability; those who require social stimulation to prevent the deterioration of physical and mental functioning; or, people whose family support system requires some relief in order to continue maintaining those individuals at home. The program was designed to provide "recreational, social and peer group interaction which cannot be provided in a person's home through other resources of the provincial Home Care Program" (Manitoba Health, 1989, p. 1). One objective is to provide relief to families/friends. Thus, a major component to Adult Day Care programs in Manitoba involves relief for informal caregivers.

The study involved interviews with both ADC clients and family or friends who cared for those who attended these programs (see Strain, Payne, Dunn, Kampen, & Blandford, 1997 for a detailed description of the methodology). Of interest here are the caregiver interviews.

#### Sample

The sample consists of 517 informal caregivers (family/friends). At the completion of an interview with the ADC client, s/he was asked to identify the person who helps them or would likely help if needed. Some clients indicated that they were unable to participate, but provided the name of a caregiver to contact. As well, some caregivers who contacted the researchers to report that the client was unable to participate due to mental and/or physical status agreed to participate. Caregivers who were paid, lived outside of the province, or were cognitively or physically unable to complete an inperson interview were excluded.

The refusal rate was 6.3%. Reasons for refusal included not knowing enough about the client (n = 4), being present during the client interview and feeling that there was no additional information to provide (n = 4), being too busy (n = 11), or simply not wanting to participate (n = 16).

## Data Collection

In-person, structured interviews were conducted with caregivers between February 1996 and March 1997. Closed- and opened-ended questions on the caregiver's health/well-being, leisure participation, and socio-demographic characteristics as well as their provision of care, the client's health, and information on Adult Day Care were asked by well-trained, experienced interviewers. The interviews lasted an average of 88 minutes, with a range of 26 to 170 minutes. The majority of caregivers (87%) were interviewed in their own homes.

### Measurement

Leisure participation. Several questions related to leisure participation. Caregivers were asked: "In the last two years, are there leisure activities in which you have ceased participation entirely? By ceasing, I mean you have completely stopped participation in the activity." Similarly, they were asked about activities in which participation was reduced: "In the last two years, are there leisure activities in which you have reduced your participation? By reducing, I mean not participating in an activity as often as you used to." Four variables were used to explore changes in leisure participation. The first one compared reducing (1) versus not reducing (0) at least one activity, irrespective of responses to the question on ceasing activities. The second focused on ceasing (1) versus not ceasing (0) at least one activity, irrespective of responses to the question on reducing activities. The third consisted of any change versus no change (0 = neither reduced nor ceased, 1 = reducedand/or ceased). Finally, only for caregivers who reduced and/or ceased activities, a variable was created with the following categories: reducing only (1); ceasing only (2); and, both reducing and ceasing (3).

Caregivers who indicated reducing and/or ceasing their leisure participation were asked "To what extent have you reduced or given up your leisure activities because of [reason]?" These reasons included lack of equipment and/or supplies, lack of information, lack of financial resources, lack of others with whom to participate, weather restrictions, physical health, being too tired, lack of time due to caregiving, lack of time due to work outside the home, family commitments, too much stress, lack of interest, and lack of freedom. This list was developed for this study from a review of relevant literature (e.g., Crawford, Jackson, & Godbey, 1991; Henderson, Stalnaker, & Taylor, 1988; McGuire, 1984). Categories included not at all, a little bit, somewhat, and a great deal. The question did not distinguish between reasons for reducing an activity and those for ceasing an activity.

Caregivers' socio-demographic characteristics. Several measures of sociodemographic characteristics were examined, including age (continuous), gender (0 = male, 1 = female), education level (0 = high school or less, 1 = at least some post-secondary), marital status (0 = not married, 1 =married), presence of children under 18 years living at home (0 = no, 1 =yes), employment status (0 = not employed outside of the home for pay, 1= employed outside of the home for pay), and perceptions of income (1 =very well, 2 = adequately, 3 = at least some inadequacy/totally inadequate).

Caregivers' health status. Four measures were used to tap both physical and mental health status. Both self-rated health (1 = excellent, 2 = good, 3)= fair/poor/bad) and the number of chronic health problems out of a list of 12 (based on the Manitoba Study of Health and Aging Research Group, 1991/92) were included. Depression was measured using a shortened version of the Center of Epidemiologic Studies (CES-D) scale (Radloff, 1977). Specifically, caregivers were presented with 15 different statements and asked how frequently they has experienced the feelings or had behaved as described in the past week (rarely or none of the time, some or a little of the time, occasionally or a moderate amount of the time, most or all of the time). Examples of the statements include "I was happy."; "I talked less than usual."; "I felt lonely."; and, "I enjoyed life." Scores were summed (Cronbach's alpha = .84) and then collapsed into no depression or possible depression using Radloff's (1977) categories. Life satisfaction was determined by asking caregivers "On a scale of 1-10 with 10 being the highest, in general, how satisfied with life are you these days?"

Caregiving experience. Several measures of the caregiving experience were used in the analysis. These included the caregiver's relationship to the client (1 = spouse, 2 = daughter, 3 = son, 4 = other relatives/friends; recoded as an indicator variable for the regression analyses with daughters and sons being combined as adult children, and other relatives/friends being the reference group). Co-residence with the client (0 = did not live with client, 1 = lived with client) was also included.

Assisting the client at least once a month with three types of tasks was considered (0 = no assistance, 1 = assistance). Basic activities of daily living (ADLs) included assistance with walking, dressing/undressing, and taking care of the clients' appearance (Cronbach's alpha = .84). Instrumental activities of daily living (IADLs) included getting the client to places out of

walking distance, shopping for groceries, and handling money (Cronbach's alpha = .84). Linking the client with the outside world included checking to see how the client was doing (in person or by telephone), driving the client to places, and making appointments for them (Cronbach's alpha = .41).

Caregiver burden was determined using Zarit, Reever, and Bach-Peterson's (1980) 22-item scale (Cronbach's alpha = .91). Examples include: "Do you feel that [name of care recipient] asks for more help than he/she needs?"; "Do you feel that [name of care recipient] is dependent on you?"; "Do you feel that because of the time you spend with [client] that you don't have enough time for yourself?"; and, "Do you feel that your social life has suffered because you are caring for [client]?" Response categories were never, rarely, sometimes, quite frequently, and nearly always. Possible scores ranged from 0 to 88, with a higher score reflecting higher levels of burden. As well, caregivers were asked whether they had thought about nursing home (personal care home) placement for the client (0 = had not thought about placement, 1 = thought about placement).

## Data Analysis

In addition to the use of descriptive statistics, both bivariate and multivariate analytical techniques were employed. Given that previous research has tended to focus on limiting family time and/or free time, the analysis here included comparisons of caregivers who reduced the frequency of participation in at least one activity versus those who did not; those who ceased at least one activity versus those who did not; and, those who reduced and/ or ceased activities versus those who did not. Logistic regression analysis was used as it allows for a dichotomous dependent variable, and categorical or continuous independent variables. A series of logistic regressions were run for each dependent variable. First, all independent variables were included in the model. Second, since the measure of caregiver burden incorporates statements related to limiting free time and social time, the analyses were rerun with caregiver burden excluded from the model.

Tests of multicollinearity were conducted and revealed that self-rated health and the number of chronic conditions were multicollinear; self-rated health was deleted from all subsequent regression analyses. In addition, given the age distribution of the sample, the inclusion of age, employment status, and the presence of children under the age of 18 in the home was problematic. As a result, one set of regressions included age, but excluded employment status and the presence of children under the age of 18 in the home, while a second set did the reverse.

An oneway analysis of variance was conducted to explore differences specifically between individuals who only reduced at least one activity, those who only ceased at least one activity, and those who both reduced and ceased activities. This allowed for consideration of all three groups at the same time. Scheffe's tests were used to compare each pair of means.

#### Results

#### Sample Characteristics

Caregivers included daughters (39%), spouses (24%), sons (14%), and other family members/friends (23%). They ranged in age from 19 to 88 years, with a mean of 57.6 years. Seventy-seven percent were female. Seventynine percent were married; 82% did not have children under the age of 18 living at home. Forty-one percent had at least some post-secondary education; 47% were working outside of the home for pay. Of the 243 who worked outside of the home for pay, 54% were working in professional or managerial positions. Many caregivers (62%) indicated that their income adequately meets their needs.

In terms of health, caregivers rated their overall health as good (52%) or excellent (25%). The number of chronic health problems ranged from zero to eight of a possible 12, with a mean of 2.2. Only 14% showed signs of possible depression. Most were satisfied with their life, with 46% rating it as a seven or eight of a possible 10.

Forty-one percent of the caregivers lived with the client and 37% lived less than nine kilometres away. Caregivers were more likely to help once a month at minimum with at least one IADL (94%) and with activities which link the client with the outside world (98%) than with at least one ADL (52%). The range on the caregiver burden measure was from 0 to 66 out of a possible 88; the mean was 20.9 and the median was 18. Forty-seven percent had thought about placing the client in a nursing home.

#### Changes in Leisure Participation

Not all caregivers made changes in their leisure participation; 268 caregivers reported that they neither reduced nor ceased activities in the past two years. A total of 196 caregivers reduced the frequency of participation in at least one activity (134 reduced only; 62 both reduced at least one activity and ceased at least one activity). A total of 115 caregivers indicated ceasing their participation in at least one activity (53 ceased only; 62 both reduced at least one activity and ceased at least one activity).

#### Caregivers Who Reduced and/or Ceased Compared to Those Who Did Not

Attention now turns to a comparison of the characteristics associated with various changes in leisure participation. Socio-demographic characteristics, health status, and the caregiving experience were considered. Since at least 90% of the caregivers provided assistance with IADLs or with linking the client to the outside world at least once a month, these characteristics were excluded from the analysis. The sample size varies, depending on the comparison being made.

Reducing versus not reducing. In this analysis, the characteristics of 196 respondents who reduced at least one activity were compared to those of the 321 who did not (268 neither ceased nor reduced; 53 ceased only). Only

two variables emerged as statistically significant in the logistic regression (Table 1). Specifically, providing assistance with basic ADLs and having relatively higher levels of caregiver burden were associated with reducing at least one activity.<sup>1</sup>

	Burden i	n Model	Burden Not in Model		
Independent Variable	b (SE)	Wald	b (SE)	Wald	
Caregiver characteristic					
Gender	.21(.24)	.72	.33(.24)	1.84	
Education	.16(.20)	.64	.20(.20)	1.05	
Marital status	.12(.27)	.18	.18(.27)	.43	
Presence of children in household <sup>a</sup>	.31(.27)	1.29	.40(.27)	2.14	
Employment status <sup>a</sup>	17(.23)	.51	12(.23)	.26	
Perceptions of income adequacy	03(.16)	.03	07(.16)	.23	
Number of chronic health problems	.02(.07)	.11	.04(.06)	.40	
Possible depression	.51(.31)	2.78	.70(.30)	5.62*	
Life satisfaction	.03(.07)	.16	04(.07)	.44	
Caregiving experience Relationship to client:					
Spouse	.13(.41)	.10	.26(.41)	.43	
Adult child	.07(.26)	.07	.17(.25)	.46	
Co-residence with client	29(.29)	.97	12(.28)	.19	
Assistance with basic ADLs	.57(.21)	7.21**	.63(.21)	8.93**	
Caregiver burden	.03(.01)	11.00***	_	_	
Thought about nursing home placement	.30(.21)	2.08	.53(.19)	7.56**	
Model $\chi^2$	56.20	ð***	45.10 <sup>3</sup>	***	
d.f.	15		14		

 Table 1

 Reducing Versus Not Reducing at Least One Activity: Logistic Regressions

\*p < .05, \*\* p < .01, \*\*\* p < .001

<sup>a</sup>When separate analyses that included age and excluded the presence of children in the household and employment status were conducted, the results remained the same.

<sup>&</sup>lt;sup>1</sup>Product terms representing two-way interactions between caregiver burden and each of the other independent variables were calculated and entered into the analysis. The significant interaction term was caregiver burden and assistance with basic ADLs. Caregiver burden was significant when considering only those who provided assistance with basic ADLs. For this group, higher levels of burden were related to a greater likelihood of reducing an activity. Among respondents who were not providing assistance with basic ADLs, caregiver burden was not a significant factor.

Once caregiver burden was removed from the analysis, possible depression and having thoughts about nursing home placement became statistically significant (Table 1). Assisting with basic ADLs remained a significant factor.

Ceasing versus not ceasing. The second comparison involved 115 respondents who ceased at least one activity and 402 who did not (268 neither ceased nor reduced; 134 reduced only). Education, the number of chronic health problems, possible depression, co-residence with the client, and caregiver burden emerged as significant when burden was included in the logistic regression analysis (Table 2). Individuals with post-secondary education were more likely to report ceasing an activity as were those with more chronic health problems. Respondents with possible depression were more likely to

	Burden in	Model	Burden not in Model		
Independent Variable	b (SE)	Wald	b (SE)	Wald	
Caregiver characteristic					
Gender	02(.29)	.00	.07(.29)	.05	
Education	.49(.24)	4.34*	.54(.23)	5.23*	
Marital status	01(.32)	.00	.05(.32)	.02	
Presence of children in	.14(.33)	.17	.20(.33)	.35	
household <sup>a</sup>					
Employment status <sup>a</sup>	08(.28)	.09	06(.27)	.04	
Perceptions of income adequacy	.17(.19)	.77	.13(.19)	.51	
Number of chronic	.17(.08)	5.23*	.18(.08)	5.90*	
health problems					
Possible depression	.86(.32)	7.08**	1.00(.31)	10.22**	
Life satisfaction	.09(.08)	1.05	.03(.08)	.13	
Caregiving experience					
Relationship to client:					
Spouse	29(.46)	.39	20(.46)	.19	
Adult child	16(.31)	.27	07(.31)	.06	
Co-residence with client	.73(.32)	5.29*	.85(.31)	7.29**	
Assistance with basic	.04(.25)	.03	.09(.25)	.13	
ADLs					
Caregiver burden	.02(.01)	4.76*	_	_	
Thought about nursing	.24(.25)	.94	.42(.23)	3.36	
home placement					
Model $\chi^2$	54.84	***	50.10***		
d.f.	15		14		

 Table 2

 Ceasing Versus Not Ceasing at Least One Activity: Logistic Regressions

\*p < .05, \*\* p < .01, \*\*\* p < .001

<sup>a</sup>When separate analyses that included age and excluded the presence of children in the household and employment status were conducted, the results remained the same.

	Burden in	Model	Burden not in Model		
Independent Variable	b (SE)	Wald	b (SE)	Wald	
Caregiver characteristic					
Gender	.20(.24)	.69	.30(.23)	1.69	
Education	.44(.20)	4.91*	.47(.20)	5.70*	
Marital status	00(.27)	.00	.05(.26)	.03	
Presence of children in household <sup>a</sup>	.18(.28)	.43	.26(.27)	.94	
Employment status <sup>a</sup>	.00(.23)	.00	.04(.23)	.04	
Perceptions of income adequacy	.12(.16)	.59	.08(.16)	.25	
Number of chronic health problems	.08(.07)	1.57	.10(.06)	2.27	
Possible depression	1.07(.34)	9.98**	1.22(.33)	13.63***	
Life satisfaction	.05(.07)	.56	.01(.07)	.03	
Caregiving experience Relationship to client:					
Spouse	01(.41)	.00	.11(.40)	.08	
Adult child	.02(.25)	.01	.11(.25)	.21	
Co-residence with client	.10(.28)	.11	.23(.28)	.71	
Assistance with basic ADLs	.36(.21)	2.95	.42(.21)	4.19*	
Caregiver burden	.03(.01)	8.57**	_		
Thought about nursing home placement	.51(.20)	6.12*	.71(.19)	13.61***	
Model $\chi^2$	74.88	***	66.1	5***	
d.f.	15				

 Table 3

 Reducing and/or Ceasing at Least One Activity Versus No Change:

 Logistic Regressions

\*p < .05, \*\* p < .01, \*\*\* p < .001

<sup>a</sup>When separate analyses that included age and excluded the presence of children in the household and employment status were conducted, the results remained the same.

report ceasing at least one activity. Co-residing with the client and higher levels of burden were also associated with an increased likelihood of ceasing an activity.<sup>2</sup>

When caregiver burden was removed from the model, education, chronic health problems, possible depression, and co-residence once again were significant (Table 2). No other characteristics emerged as important.

<sup>&</sup>lt;sup>2</sup>The only interaction term that emerged as significant was caregiver burden and assistance with basic ADLs. Among individuals who were providing assistance with basic ADLs, it was those with higher levels of burden who were more likely to cease an activity. Among respondents who were not providing assistance with basic ADLs, caregiver burden was not a significant factor.

Reducing and/or ceasing versus no change. The third comparison involved 249 respondents who reported reducing and/or ceasing their leisure participation versus the 268 who did not. The logistic regression results indicated that post-secondary education, possible depression, relatively higher levels of burden, and having thought about placing the client in a nursing home were associated with a greater likelihood of reducing and/or ceasing leisure activities (Table 3).<sup>3</sup> These characteristics remained significant when caregiver burden was excluded from the model; assisting with basic ADLs became a significant characteristic.

Reducing only, ceasing only, and both reducing and ceasing. The final comparison involved 134 caregivers who only reduced participation in at least one activity, 53 who only ceased at least one activity, and 62 who had both reduced and ceased activities. The 269 caregivers who had neither reduced nor ceased their activities were excluded here. Results from an oneway analysis of variance revealed differences between the groups in terms of the number of chronic health problems, being a spousal caregiver, co-residence, assisting with basic ADLs, and caregiver burden (Table 4). Scheffé's tests revealed that the differences most frequently were between caregivers who had reduced at least one activity and those who had both reduced and ceased activities; there were no significant differences in the means of any characteristic for the reduced only group and the ceased only group.

Specifically, caregivers who only had reduced the frequency of leisure participation were significantly more likely than those who reported both reducing and ceasing activities to have fewer chronic health problems, to be a non-spousal caregiver, to not co-reside with the older adult, and to have lower levels of caregiver burden. Caregivers who only had ceased at least one activity were more likely than those who reported both reducing and ceasing activities to not assist with basic ADLs and to have lower levels of caregiver burden.

## **Reasons for Changing Leisure Participation**

Turning to the reasons for reducing and/or ceasing leisure participation, 57% of the 248 caregivers who had reduced and/or ceased their activities reported a lack of time due to caregiving as a reason (one caregiver declined to answer this question) (Table 5). Indeed, 28% responded "a great deal" to the question "To what extent have you reduced or given up your leisure activities because of a lack of time due to caregiving for [client]?" At least 10% of the caregivers felt that, to a great deal, they had reduced or given up activities due to their own physical health (18%), feeling too tired (14%), a lack of time due to work outside the home such as a job (13%), and having too much stress in their life (10%). Overall, at least one-quarter of the caregivers reported that their leisure activity participation changed as

<sup>&</sup>lt;sup>3</sup>There was a significant interaction effect of burden and assisting with basic ADLs. Higher levels of burden were related to reducing and/or ceasing an activity only among respondents who provided assistance with basic ADLs.

	Reducing only		Ceasing only		Both reducing and ceasing		
	n	x	n	x	n	x	F
Caregiver characteristic							
Gender	134	.81,	53	.79,	62	.82,	.09
Education	134	.45	53	.53	62	.44	.61
Marital status	134	.80	53	.72	62	.84	1.33
Presence of children in household	134	.20 <sub>a</sub>	53	.13 <sub>a</sub>	62	.19 <sup>-</sup> a	.62
Employment status	134	.49,	53	.51,	62	.32,	2.92
Perceptions of income adequacy	134	1.96 <sub>a</sub>	53	2.11 <sup>°</sup>	62	1.97 <sup>°</sup>	1.26
Number of chronic health problems	134	$2.15_{a}$	52	$2.63_{ab}$	62	$2.79_{b}$	3.82*
Possible depression	134	.17,	53	.28,	62	.31	2.77
Life satisfaction	134	7.45	53	7.32	62	7.00	1.40
Caregiving experience Relationship to client:		ŭ		u		-	
Spouse	134	.23,	53	.26 <sub>ab</sub>	62	$.40_{\rm b}$	3.19*
Adult child	134	.57	53	.51	62	.44	1.49
Co-residence with client	134	.37	53	.53 <sub>ab</sub>	62	.61 <sub>b</sub>	5.60**
Assistance with basic ADLs	134	.60 <sub>ab</sub>	53	.47 <sub>a</sub>	62	.71 <sub>b</sub>	3.42*
Caregiver burden	134	23.08 <sub>a</sub>	53	22.72 <sub>a</sub>	62	$30.00_{b}$	6.14**
Thought about nursing home placement	134	.57	53	.55	62	.56,	.06

 Table 4

 Reducing Only, Ceasing Only, and Both Reducing and Ceasing:

 One-Way Analysis of Variance

\*p < .05, \*\* p < .01, \*\*\* p < .001

Note. Means in the same row that do not share subscripts differ at p < .05 in Scheffé's test.

a result of feeling tired (48%), feeling too stressed (43%), their own physical health problems (40%), weather restrictions (32%), family commitments (31%), and lack of time due to work commitments (31%).

The possibility that the reasons for the change vary among caregivers who reduced but did not cease at least one activity (n = 133), who ceased but did not reduce activities (n = 53), and those who both reduced and ceased an activity (n = 62) were explored by cross-tabulating each reason and the type of change in participation (Table 6). Caregivers who reported both reducing and ceasing activities (73%) were more likely than either those who reduced only (54%) or those who ceased only (47%) to indicate that the lack of time due to caring for the client was a reason for the change. A similar pattern was evident for two other reasons, specifically having too

	% of Caregivers Giving Reason $(n = 248)^a$						
Reason	Not at all	A little bit	Somewhat	A great deal			
A lack of time due to caring for [client's name]	42.7	12.9	16.1	28.2			
Feeling too tired	52.0	14.5	19.8	13.7			
Too much stress in your life	57.3	18.5	14.1	10.1			
Your physical health	60.1	12.5	9.7	17.7			
The weather such as snow, ice, or heavy rain	67.7	16.9	10.5	4.8			
Having too many family commitments	69.0	9.7	12.5	8.9			
A lack of time due to work outside the home such as a iob	69.4	8.5	9.7	12.5			
Having no one to participate with	77.0	7.3	9.3	6.5			
Not having enough money left over to spend on your activities	78.2	10.1	7.7	4.0			
A concern about your safety such as night travel or personal safety	85.5	5.6	5.2	3.6			
Lack of interest in leisure activities	85.5	10.5	2.0	2.0			
A lack of freedom to choose the activity that you wanted to do	91.1	3.6	4.4	0.8			
A lack of equipment and/or supplies needed for the activities	96.8	0.4	1.2	1.6			
A lack of information about what activities and events are going on in your community	97.2	2.0	0.8	0.0			

 Table 5

 Reasons for Reducing and/or Ceasing Leisure Participation

 $^{a}n = 248$  as one caregiver declined to answer this question.

much stress in their life and the weather. No differences were found for other reasons such as feeling too tired, their own physical health, having too many family commitments, or a lack of time due to work outside the home such as a job.

## Lack of Time due to Caregiving as a Reason for Reducing and/or Ceasing at Least One Activity

Differences between caregivers who indicated reducing and/or ceasing a leisure activity because of a lack of time due to caregiving (n = 142) and

	Type of Change in Leisure Activity (% Responding a Little Bit, Somewhat, A Great Deal)						
Reason	Reducing only <sup>a</sup> (n = 133)	Ceasing only (n = 53)	Reducing and/or Ceasing (n = 62)	X <sup>2</sup>			
A lack of time due to caring for [client's name]	54.1	47.2	72.6	8.68*			
Feeling too tired	45.1	45.3	56.5	2.38			
Too much stress in your life	36.1	39.6	59.7	9.88**			
Your physical health	34.6	47.2	45.2	3.45			
The weather such as snow, ice, or heavy rain	29.3	17.0	51.6	16.81***			
Having too many family commitments	33.1	28.3	29.0	0.56			
A lack of time due to work outside the home such as a job	36.1	28.3	21.0	4.72			
Having no one to participate with	20.3	20.8	30.6	2.75			
Not having enough money left over to spend on your activities	17.3	26.4	27.4	3.40			
A concern about your safety such as night travel or personal safety	12.0	5.7	27.4	N/A <sup>b</sup>			
Lack of interest in leisure activities	14.3	5.7	22.6	N/A <sup>b</sup>			
A lack of freedom to choose the activity that you wanted to do	7.5	5.7	14.5	N/A <sup>b</sup>			
A lack of equipment and/or supplies needed for the activities	5.3	0.0	1.6	N/A <sup>b</sup>			
A lack of information about what activities and events are going on in your community	1.5	0.0	8.1	N/A <sup>b</sup>			

Table 6										
Reasons	for Reducing	and/or	Ceasing	Leisure I	Particij	bation	by 🕽	Гуре	of (	Change

\*p < .05, \*\* p < .01, \*\*\* p < .001\*n = 133 as one caregiver declined to answer this question.

<sup>b</sup>Due to small cell sizes, tests of significance were not conducted.

those who did not give this as a reason (n = 106) were also explored. Given that relatively few caregivers responded a little bit or somewhat, it was necessary to combine these with the category a great deal. Again, sociodemographic characteristics, health status, and the caregiving experience were considered. As well, the nature of the change (reduced only, ceased only, both reduced and ceased) was taken into account.

Results of the logistic regression indicated that caregiver burden was the only statistically significant characteristic related to reducing and/or ceasing leisure participation due to caregiving (Table 7). Specifically, caregivers with relatively higher levels of caregiver burden were more likely to indicate that caregiving was a reason for reducing/ceasing activities.

When the analysis was re-run with caregiver burden excluded from the model, gender, education, life satisfaction, having thought about nursing home placement, and the type of change in leisure participation emerged as significant.<sup>4</sup> Specifically, females and those with post-secondary education were more likely to indicate that they had reduced and/or ceased activities as a result of a lack of time due to caring for the client. Individuals with lower life satisfaction and those who had thought about nursing home placement were also more likely to offer this reason. Finally, those who had both reduced and ceased activities were significantly more likely to indicate a lack of time due to caregiving than those who had ceased but not reduced activities. In addition, there was a slightly greater likelihood of those who only reduced at least one activity to give this reason than those who only ceased at least one activity.

#### **Discussion and Conclusion**

This study examined the issue of leisure participation among a sample of caregivers. Of particular interest was the likelihood of reducing and/or ceasing leisure activities, the reasons for these changes, and the relationship between socio-demographic characteristics, health status, caregiving experiences, and leisure participation.

Although caregivers have been reported to adjust their lives to accommodate their caregiving responsibilities by giving up activities/interests, only 10% of the caregivers had ceased at least one activity during the previous two years, 26% had reduced participation in at least one activity, and 12% reported both reducing the frequency of participation in at least one activity and ceasing at least one activity. In other words, individuals do not necessarily reduce or cease leisure activities when they are providing care to older individuals whose care needs have led to attendance in Adult Day Care programs. At the same time, there is a group of caregivers who experience changes in their leisure participation.

<sup>&</sup>lt;sup>4</sup>When separate analyses that included age and excluded the presence of children in the household and employment status were conducted, age was not significant. In addition, life satisfaction did not emerge as significant when age was in the model that excluded burden.

	Burden i	n Model	Burden not in Model		
Independent Variable	b (SE)	Wald	b (SE)	Wald	
Caregiver characteristic					
Gender	.67(.47)	2.05	.95(.39)	5.80*	
Education	.70(.37)	3.54	.76(.32)	5.70*	
Marital status	.43(.49)	.76	.49(.41)	1.39	
Presence of children in household <sup>a</sup>	-64(.42)	2.32	34(.35)	.93	
Employment status <sup>a</sup>	87(.49)	3.13	31(.42)	.56	
Perceptions of income adequacy	.47(.32)	2.08	.05(.27)	.03	
Number of chronic health problems	19(.12)	2.67	05(.10)	.24	
Possible depression	35(.52)	.44	.23(.43)	.29	
Life satisfaction	04(.14)	.11	26(.11)	5.48*	
Caregiving experience Relationship to client:					
Spouse	33(.76)	.19	.18(.65)	.08	
Adult child	.13(.47)	.08	.37(.39)	.87	
Co-residence with client	.81(.52)	2.46	.83(.43)	3.73	
Assistance with basic ADLs	.10(.38)	.07	.59(.32)	3.44	
Caregiver burden	.13(.02)	39.80***	—	_	
Thought about nursing home placement	05(.38)	.02	.88(.31)	8.25**	
Type of change:					
Reduced only	39(.45)	.72	62(.38)	2.61	
Ceased only	95(.55)	3.05	-1.14(.46)	6.11*	
Model $\chi^2$	123.5	4***	63.80*	**	
d.f.	17		16		

 Table 7

 Lack of Time Due to Caregiving as a Reason For Reducing and/or Ceasing

 Activities Versus Not Giving This Reason: Logistic Regressions

\*p < .05, \*\* p < .01, \*\*\* p < .001

<sup>a</sup>When separate analyses that included age and excluded the presence of children in the household and employment status, age was not significant. In addition, life satisfaction did not emerge as significant when age was in the model that excluded burden.

As the change in leisure participation could be due to a variety of reasons including, but not exclusive to caregiving, a higher rate of both reducing and ceasing activities may have been anticipated. At the same time, caregivers may receive some respite through the Adult Day Care program and possibly other formal services, which minimizes changes in their leisure participation. Only one-half of the caregivers who reported a change in their leisure activities indicated that the lack of time due to caregiving was a reason for reducing and/or ceasing activities. If considered as a proportion of the total sample, only 27% of caregivers reduced and/or ceased activities due to time constraints from caregiving.

Comparisons to previous research are difficult as other researchers have focused on limits to family and/or free time due to caregiving (Miller & Montgomery, 1990; White-Means & Chang, 1994) and the definitions of "caregivers" are not consistent across the studies. The percentage of caregivers who reduced and/or ceased activities for any reason in the current study (48%), however, is lower than the 69% who indicated that their social life and free time were limited and the 74% of caregivers who experienced limits to family and/or free time in White-Means and Chang's (1994) research. This illustrates the need to specify the nature of the limits to leisure participation and reasons for any changes. Asking caregivers about reductions in the frequency of leisure participation or about cessation of activities irrespective of the reasons is a different approach than asking about limits to family or free time and potentially provides a broader picture of the situation of caregivers.

In terms of characteristics associated with both changes in leisure participation and reducing and/or ceasing activities due to time constraints from caregiving, the caregiving experience itself was more important than specific caregiver characteristics. As noted, comparisons to the existing literature are hampered by the differences in the questions on leisure participation and the lack of consistency across studies in the definition of caregivers.

Considering first the caregiving experience, caregivers who reduced and/or ceased their leisure participation appear to be individuals who face relatively high care demands. For example, caregivers who reduced and/or ceased their leisure participation were more likely to experience at least some caregiver burden and to have thought about placing the client in a nursing home than caregivers who neither reduced nor ceased their activities. They were also more likely than either those who ceased only and those who reduced only to indicate that reasons for the change in their leisure participation were the lack of time due to caring for the client and having too much stress in their life.

Miller and Montgomery's (1990) argument that the subjective appraisals of the nature of providing care are more important than the objective care demands was supported in part by the findings presented here. Caregiver burden, which can be considered a subjective appraisal, consistently emerged in relation to changes in leisure participation and to the lack of time due to caregiving being a reason for the change. However, once caregiver burden was excluded from the analysis, the provision of assistance with ADLs was frequently a significant characteristic in terms of changes in leisure participation.

Increased attention to the subjective appraisals of caregiving and their relationships to leisure participation is needed. The measure of caregiver burden used here was global and included questions on feelings that one does not have enough time for oneself because of the time spent with the care recipient and that their social life has suffered because of caring. Specific appraisals such as relationship difficulties and beliefs/attitudes about caregiving warrant consideration.

The influence of co-residence varied depending on the dimension of leisure participation being studied. Specifically, living with the client was only significant in the comparison of those ceasing activities and those not doing so. While Adult Day Care may not provide sufficient respite for caregivers who co-reside with the tenant to avoid cessation of some activities, it may allow these caregivers to continue, albeit with a reduced frequency of participation, with other activities.

Turning to caregiver characteristics, the health status of the caregiver emerged as important when considering certain changes in leisure participation. Possible depression was related to reducing at least one activity (when burden was excluded from the analysis), with ceasing at least one activity, and with reducing and/or ceasing leisure participation. Having more chronic health problems was related to ceasing at least one activity. This is similar to the findings of Keller and Tu (1994) and White-Means and Chang (1994). Coleman and Iso-Ahola (1993) have argued that leisure can "buffer" the negative health effects of life stress. Further investigation of the relationship between the caregivers' health and leisure participation is needed to address the question of their causal link.

Having post-secondary education was associated with ceasing at least one activity, and with reducing and/or ceasing activities. Education also emerged as a characteristic associated with the lack of time due to caregiving being a reason of reducing and/or ceasing participation but only when caregiver burden was excluded from the analysis. Both Miller and Montgomery (1990) and White-Means and Chang (1994) reported that limiting family and/or free time was related to having more education. Caregivers with higher levels of education may have more choices in their leisure pursuits and may be more aware of changes in their leisure participation.

No differences between male and female caregivers were evident in relation to the change in leisure participation. The relationship of the caregiver was also not significant. Females were, however, more likely to indicate that a lack of time due to caregiving for the older individual was a reason for reducing and/or ceasing activities once caregiver burden was excluded from the model. To examine this further, gender, the relationship of the caregiver, and changes in leisure participation were explored. No statistically significant differences emerged with considering husbands and wives. However, adult daughters (43%) were more likely than adult sons (24%) to reduce participation in at least one activity rather than not doing so. As well, adult daughters were more likely to reduce and/or cease activities than their male counterparts (53% versus 33%) and to identify a lack of time due to caregiving as a reason for changes in their leisure participation (62% versus 26%). These results must be interpreted with caution due to the relatively small number of sons. At the same time, the likelihood of daughters facing more demands than sons when caring for an older family is well documented in the literature (e.g., Aronson, 1992; Miller & Montgomery, 1990).

Interestingly, neither employment status nor the presence of children under the age of 18 were significantly related to any type of change or to reducing/ceasing activities as a result of a lack of time due to caregiving. Subsequent analyses examining the association between the relationship of the caregiver, employment status, and changes in leisure participation revealed no significant differences. These findings support the work of Miller and Montgomery (1990) who noted that, among adult daughters and sons, employment status was not significant. In addition, these researchers found that adult daughters who had children under the age of 18 in the household were more likely to limit free time due to caring for an older adult than those without children; there were no differences for adult sons. Here a further exploration of the association between the presence of children under the age of 18, the relationship of the caregiver, and changes in leisure participation revealed no statistically significant differences for either daughters or sons. It may be that the sample sizes are insufficient to detect differences.

Overall, while caregiver characteristics and the caregiving situation appeared important, the results varied somewhat depending on the dimension of leisure participation being studied. The complexity of the relationship to leisure participation is clearly evident.

While this study has added to an understanding of leisure participation among caregivers, its limitations must be acknowledged. Several questions for future research are evident. For example, the focus here has been on a particular group of caregivers, namely those who were receiving some respite through the client's attendance at Adult Day Care and possibly other formal services. A comparison group of caregivers who do not have an opportunity for respite is needed to determine the extent to which reduction and/or cessation in leisure participation occurs in different situations. Such caregivers may be more likely to reduce or cease their leisure participation.

Attention needs to be given to the types of activities that were reduced and/or ceased and the frequency of leisure participation. Such information may assist service providers who work with caregivers to determine whether these activities are important to them and whether the activity should be replaced with a similar activity more suited to their situation. As well, the possibility that caregivers start new activities in conjunction with reducing and ceasing other activities needs to be studied. Iso-Ahola, Jackson, and Dunn (1994) have argued that starting, ceasing, and replacing leisure varies across the lifespan. As starting new activities was not examined here, the influence of caregiving on such patterns cannot be determined.

In addition, while this study examined whether or not the caregiver provided assistance with various tasks, other factors such as the amount of care provided and the availability of other caregivers need to be taken into account. Caregivers who provide higher amounts of care and those who do not have other caregivers with whom to share caregiving responsibilities may be more likely to change their leisure participation.

Lastly, caregivers were asked to reflect on their leisure participation over a two-year period. This time frame may be too long for people to recall which activities they have reduced and/or ceased. Longitudinal research is needed to study the interweaving of leisure participation with caregiving careers and the extent to which a hierarchy exists in changes to leisure participation. Dupuis and Smale (1998), in their study of 38 adult daughters caring for a parent in a long-term care facility, argued that the meaning of leisure changed over the caregiving career from being constrained by caregiving to being more available. In terms of participation, caregivers may first reduce the frequency of participation or cease an activity, and when the demands and responsibilities of caregiving increase, they may have to both reduce and cease participation. The extent to which such changes occur is largely unknown.

The study suggests some implications for practice. Indeed, the findings regarding the frequent reasons for reducing and/or ceasing activities may be most important for practitioners who work with caregivers. These reasons included a lack of time due to caring for the client, followed by feeling too tired, having too much stress in their lives, and their own physical health. Given the potential for leisure to act as a coping resource (Bedini & Bilbro, 1991; Sneegas, 1988), these issues could be addressed through programs and services directed at respite and opportunities for leisure participation for the caregiver. Leisure education programs may also assist caregivers in identifying their attitudes toward caregiving and leisure participation (Hughes & Keller, 1992). Dupuis and Pedlar (1995) suggested that a structured family leisure program may provide a "buffering mechanism" for caregivers which may serve to moderate the impact of caregiver stress on psychological health and well-being. As a preventative program for caregivers who have not reduced and/or ceased their leisure participation, leisure education programs may provide caregivers with the tools to deter or minimize some of the negative effects of caregiving. This, in turn, may assist caregivers in maintaining older adults in the community for as long as possible and assist with their ability to cope.

In conclusion, this study adds to the growing body of literature on caregiving and leisure participation. It appears that there is considerable variation in the leisure experiences of caregivers. Not all caregivers reduce the frequency of leisure participation or cease activities. However, there are some caregivers who can be considered "at-risk" for reductions in their leisure participation. The relationship among caregivers' characteristics, the caregiving experience, and leisure participation is clearly complex. Future research on the leisure participation of caregivers needs to take into account the context of both caregiving and leisure participation. Particularly important is a recognition that an individual providing care is "more than caregiver." They may be a wife or daughter to that older person; they may be employed. They may have children who place demands on them. They may be in poor health themselves. In other words, the lives of caregivers are complex. It is only by studying this complexity that a better understanding of the changes in leisure participation will emerge.

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