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# Male caregivers of spouses with Alzheimer's disease: Risk factors and health status

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## Abstract

*Caregiving for persons with Alzheimer's disease (AD) has been shown to pose a challenge to the health of the spousal caregiver. Because most of the caregiving literature focuses on the female caregiver, there is some question about the generalizability of such literature to the male caregiver. This report focuses on male caregivers of spouses with AD and represents a subsample from a larger descriptive study that examined the relationship between risk factors and the health status of spousal caregivers. Twenty-nine male caregivers affiliated with Alzheimer's organizations in Pennsylvania and Ontario, Canada, returned mail surveys. On average, physical health symptoms increased by one-third when comparing pre- and post-caregiving data. Caregivers also were experiencing moderate to severe depression and burden. Male caregivers generally rated their physical health as fair to excellent and exhibited fewer than expected physical health symptoms. Caregiver health was related to perceptions of stress surrounding the provision of activities of daily living (ADL) assistance, the frequency of behavioral problems, perceptions of stress associated with the AD spouse's dysfunctional behaviors, and satisfaction with leisure opportunities.*

*The identification of the role that caregiver perceptions of stressfulness associated with caregiving and the need for leisure satisfaction offer important implications for community-based education and respite services to maintain health status for spousal caregivers.*

*Key words: Alzheimer's disease, caregiving, male caregivers, spousal caregivers, risk factors, stress*

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## Background

In the United States, the home historically has been the location of choice for care of the elderly, and family members are the chosen providers of protection, aid, and support.<sup>1</sup> Literature indicates that 85 percent of the daily care required by the elderly is provided by family members,<sup>2</sup> with more than one-half the number of caregivers being spouses.<sup>3</sup> Male spouses comprise over 36 percent of caregivers for person with Alzheimer's disease (AD).<sup>4-6</sup> Given the nearly four million Americans diagnosed with AD,<sup>7</sup> the number of male spouses that serve as caregivers is considerable.

Because AD is a progressive neurological disorder associated with global impairment of mental functioning, including the loss of language functions, increased inability to engage in abstract thinking, dramatic changes in personality, emotional and behavioral instability, and a loss of orientation to person, time, and place, caregiving can be particularly challenging. With familial responsibility for care being the norm, the expectation is that family members will continue to provide the majority of assistance to elders with AD, regardless of their own care needs or the physical, emotional, and financial resources of the family. Given changes taking place in the structure of the family, such as a decline in birthrates and increased geographic mobility, this reliance on family to carry out the caregiving role may rest more completely with the spouse.

Many spouses wish to carry out the caregiving role as fully as possible, but find that doing so creates varying levels and types of physical, emotional, financial, and social strain for them and their families.<sup>8</sup> Often, the caregiver is close in age to the person with AD and is beginning to experience chronic, age-related illnesses of his own. These natural changes limit the functional capacities of the caregiver, thereby impacting on his self-care abilities as well as his ability to provide daily care for his

AD spouse. As caregiving often requires the placement of extreme physical demands on the caregiver, such as lifting, assistance with ambulation, feeding, toileting, and 24-hour supervision, these tasks may lead to the caregiver's neglect of his own needs for sleep, proper nutrition, and health care. Over time, such neglect can result in caregiver fatigue, exhaustion, and other physical health problems such as malnutrition, impairment of the immune system, etc.<sup>3,8-13</sup> Health problems such as these, while not associated with the normal aging process itself, are associated with caregiving and therefore can interact with age-related changes to result in the caregiver no longer being able to fulfill that role.

Health has been identified as a multidimensional construct that includes both physiological and emotional functioning. Physical health may be defined as an individual's ability to "fully carry out customary or expected duties for his or her age, sex, and social roles in his or her society."<sup>20</sup> Emotional health is built on the concept of adaptation, or, more specifically, an individual's ability to make adjustments in coping. Health may be assessed objectively by using diagnostic or symptomological criteria and subjectively by asking respondents to rate their health status by using a Likert scale. Factors in the literature that affect health may be grouped into three areas: *context for care, lifestyle, and history.*

### *Context for care*

Context for care may be broadly defined as the situation or experiences regarding caregiving. As the person with AD becomes increasingly unable to complete her own activities of daily living (ADLs), responsibility for the performance of these activities falls on the spousal caregiver. In a recent study, male and female caregivers reported spending on average 91 hours each week providing care to a loved one with AD, an amount of care that would appear physically burdensome by any standard.<sup>21</sup> In addition, some spousal caregivers experienced greater physical and emotional discomfort completing such care. Men in particular report great psychological distress when required to complete such previously private activities as bathing and toileting for a female spouse.<sup>12,22</sup>

The need for supervision also is a unique and critical component in care of an elder with AD. Supervision often results in the caregiver feeling trapped and increasingly burdened due to the inability to schedule caregiving, social or leisure, and other life activities, including self-care tasks, rest, and relaxation. While a substantial body of knowledge exists regarding the phenomena of caregiver burden, research has focused extensively on the experiences of women.<sup>14-19</sup> Consequently, the impact

of the supervisory role on male spouses has yet to be fully examined.

Behavioral changes consistent with the disease process can lead to embarrassment for the caregiver of the AD spouse. Also, this may result in loss of instrumental and social support from friends and extended family through spontaneous withdrawal of others and the potential subsequent caregiver reluctance to ask for help. The literature clearly indicates that caregivers of persons with AD without adequate social support are more likely to exhibit increased episodes of physical illness and report poorer overall health than controls.<sup>8</sup>

### *Lifestyle*

Lifestyle may be identified as an individual's interactions with others and his ability to utilize such relationships in shaping the environment. Alterations in lifestyle are necessitated by the caregiver role, with possibly the most important alteration being changes in the marital relationship. Spousal caregivers find themselves in a unique conjugal situation. While the AD person may continue to exist physically, she progressively ceases to be a partner in the relationship. This change in the relationship leads to the caregiver living within a marital dyad with no reciprocal marital relationship. Kvale and Bohlen<sup>25</sup> have identified common changes that occur in the marital relationship of AD caregiver and care recipient: "changes in marital role patterns; loss of an egalitarian division of labor; loss of sexual intimacy; cessation of reciprocal communication of love and affection; and conflicts between traditionally held marital commitments and the caregiver's interest in developing new relationships"<sup>25</sup> Not only does the caregiver become estranged from his spouse, but social relationships enjoyed while a member of a couple also may be lost to the caregiver. Thus, while the caregiver continues to exist within the marital relationship, he or she is no longer able to enjoy or count on many of the more positive and fulfilling aspects of the relationship. The social isolation that results from such lifestyle changes is particularly problematic in that, for female spousal caregivers, it is associated with caregiver experiences of increased feelings of depression, anxiety, anger, and grief.<sup>8,26</sup> Such feelings may also be manifested in acute physical and emotional symptoms and an overall decline in health status for the caregiver.<sup>8,12,17,24,27</sup> While male caregivers have historically reported less social isolation than female caregivers,<sup>15,23,28</sup> little is known about the impact social support changes have on men.

### *History*

History may be conceptualized as the historical

relationship network the male spouse brings to caregiving. The quality of the pre-illness relationship potentially is an important feature of the spousal caregiving relationship. Within the interactions of this earlier relationship, longstanding patterns of affection, cohesion, and reciprocity enjoyed by a couple have been established.<sup>29</sup> These patterns of interaction provide a foundation for coping that the caregiver carries with him into the caregiving relationship. As such, the quality of the pre-illness marital relationship impacts on the caregiver's reaction to the initial diagnosis of AD, motivation for providing care, and hands-on abilities in the caregiving realm.<sup>30,31</sup> Those caregivers who enjoyed a positive pre-illness marital relationship appear more willing to take on the caregiver role, and, while initially experiencing increased feelings of depression, exhibit more positive mental health characteristics throughout the years of in-home caregiving.<sup>32,33</sup>

Caregivers struggle daily to provide care to spouses with AD, often with little concern for their own physical and emotional well-being. While one may not be able to cure AD or make the stresses inherent in caregiving disappear, much can be done to assist caregivers in reducing their stress and burden and maximizing the positive qualities of caregiving. While individual characteristics and requirements of the caregiving role have been explored with regard to their impact on the health of female caregivers, research that examines these same features in male spousal caregivers is sparse at best.

The purpose of this paper is to describe the caregiving role and identify those risk factors that influence the health of male spousal caregivers. The identification and understanding of these factors is vital for the development of the social and health care services that may enhance physical and mental health and lessen the burden experienced by male spousal caregivers.

## Methods

This descriptive study sought to identify the risk factors that are related to the health status of the caregiver of an AD spouse. This paper is part of a larger study that assessed the relationship between risk factors and health for both male and female spousal caregivers.

The study population included those spousal caregivers associated with the Alzheimer's Association of Northeastern Pennsylvania (Wilkes-Barre, Pennsylvania), the Alzheimer Society of Kingston (Kingston, Ontario, Canada), and the Alzheimer Society of Ottawa-Carleton (Ottawa, Ontario, Canada). Use of a purposive sample facilitated access to adequate numbers of individuals who met the participation criteria of the study. Mail surveys were sent to 616 caregivers. The survey

included items that assessed caregiver and care recipient demographic characteristics as well as risk factors and health status. Standardized measures with acceptable levels of reliability and validity were used almost exclusively in the survey instrument. In total, 66 caregivers returned usable surveys, 29 being from men. Male respondents represented nearly 44 percent of the study sample, a proportion unapproached in the existing literature.<sup>3,14,22,34</sup>

"Health" included both physical and emotional health measures. An inventory of physical symptoms of ill health was used to document physical health status in the year prior to caregiving as well as the previous 12-month period.<sup>35</sup> Caregivers also were asked for a subjective rating of their physical health status for the past year and the year prior to caregiving, using a single Likert scale rating. Caregiver emotional health was assessed by using the Center for Epidemiologic Studies Depression (CES-D) Scale.<sup>36</sup> Caregiver burden was measured using the Revised Caregiver Burden Scale.<sup>37-39</sup>

Risk factors assessed in the study included the following: level of care required by the AD person; caregiver stressfulness associated with required care; degree of behavioral change exhibited by the AD person; caregiver stressfulness associated with behavioral change; availability and adequacy of social support; caregiver satisfaction with leisure opportunities; and quality of the pre-illness marital relationship.

## Findings

As seen in Table 1, the study sample consisted of 29 male spouses. Site breakdown for the sample included five (17.2 percent) caregivers responding from northeastern Pennsylvania, 15 (51.7 percent) responding from Ottawa, Ontario, and nine (31.0 percent) responding from Kingston, Ontario. Differences in the demographic variables among caregivers in the three sites were not statistically significant.

Male spousal caregivers in the sample were overwhelming Caucasian (93.1 percent) and well-educated with only five respondents (17.2 percent) that had less than a high school education. Ages ranged from 59 to 88 years and the average age reported was 75.5 years. The marital relationships examined were long in duration with a range of two to 59 years and an average marital duration of 41.9 years. New and seasoned caregivers were noted, where years in the caregiver role ranged from 1.5 to 8.0 years and an average caregiving career of 3.9 years. Incomes varied with a range of \$580 to \$4640 per month, but, on average, respondents reported a comfortable monthly income of \$2222.

Also in Table 1 is information about the female spouses with AD. Like their husbands, wives with AD were

**Table 1. Demographic information on caregivers and AD spouses (N = 29)**

Variables	Caregivers		Care recipients	
	f	%	f	%
Geographic location				
Northeastern PA	5	17.2		
Ottawa, ON	15	51.7		
Kingston, ON	9	31.0		
Race				
Caucasian	27	93.1	24	92.3
Other	2	6.9	2	7.6
Education				
Non-high school graduate	5	17.2	5	17.8
High school graduate	5	17.2	13	46.2
Completed some college	6	20.7	6	21.4
College graduate	9	31.0	2	7.1
Completed graduate studies	4	13.8	2	7.1
<b>Variables</b>	<b>Observed range</b>	<b>Mean</b>	<b>SD</b>	<b>Median</b>
Caregiver age (years)	59 - 88	75.5	6.9	76.5
Care recipient age (years)	57 - 86	73.7	6.9	74.5
Years married	2 - 59	41.9	18.0	48.0
Years in caregiver role	1.5 - 8	3.9	2.1	3.5
Years elapsed since diagnosis	0 - 8	3.5	2.1	3.0
Income/month (US \$)	580 - 4640	2222.6	1026.8	2262.0

overwhelmingly Caucasian (92.3 percent). While only five care recipients (17.8 percent) did not complete high school, wives were less educated, on average, than their spousal caregivers. Care recipients ranged in age from 57 to 86 years with an average age of 73.7 years.

Risk factors and caregiver health information are depicted in Table 2. Differences in risk factors and health measures among the three data collection sites were not statistically significant, and, as a result, respondents from all sites were treated as a single sample. By using symptom ratings, caregiver health was quite positive, despite the average age of males in the sample. While the number of reported symptoms was reasonably low, symptoms of stress-related illnesses, on average, increased by one-third from the year prior to the initiation of caregiving to the 12 months preceding the study. Subjectively, caregivers rated their health as fair or better.

In completing the CES-D depression scale, respondent scores ranged from zero to 32 with an average score of 14.8. Nearly 31 percent of the sample recorded depression scores of 16 or more, indicating clinical depression. Excessive burden appeared less problematic for the male spousal caregivers in the study. While burden scores ranged from four to 60, only 17 percent of the respondents recorded burden scores equal to or greater than the measured midpoint of 44. This suggests that the vast majority of caregivers were experiencing only mild to moderate burden associated with the caregiver role.

In summarizing the health data for the sample, caregivers generally rated their health status as fair to excellent and reported fewer symptoms than might be expected for a senior citizen population. However, many respondents were experiencing moderate to severe depression and mild to moderate burden.

Risk factors assessed within this study included the context of care, lifestyle changes, and history. In the context of care, the study evaluated the care requirements of the person with AD, the behavioral problems manifested by the AD person, and the caregiver's perceptions of stress surrounding the performance of ADLs and the behavioral problems exhibited. With regard to the care requirements of the AD person, 61 percent of care recipients had an ADL score higher than the measure midpoint (14), suggesting moderate to severe functional impairment. While providing substantial ADL assistance, caregiver stress associated with ADL care remained low (mean = 16.3).

To evaluate the frequency of AD behaviors, caregivers were asked to identify how often each of 25 behaviors had occurred in the past week. By using a potential range of zero to 100, the average behavioral frequency score recorded by respondents was 32.5. Fifteen percent of the care recipients exhibited moderate

to severe behavioral dysfunction, as evidenced by a behavioral frequency equal to or greater than 50. As was the case with ADL stress, the male spousal caregivers in this study reported lower than expected stress associated with the AD person's behavioral change. Less than 12 percent of the male caregivers surveyed reported moderate to extreme stress related to the behavioral dysfunction of their spouse.

The impact of lifestyle issues was examined using the following risk factors: availability and adequacy of informal support services and access to leisure activities. On average, male caregivers in the study reported receiving regular assistance from 2.0 family members and 1.7 friends. Availability of assistance from family and friends was further assessed to document the amount of assistance provided with 10 activities: help when ill, shopping, financial assistance, home repair, home maintenance, companionship, problem solving (financial and nonfinancial), transportation and meal preparation. By using a scale of zero to 40, family members were noted to provide a minimal amount of assistance to caregivers with an average score of 7.0. Friends were similarly evaluated and an average assistance score of 5.7 was noted. The only area of assistance consistently provided by both family and friends was companionship. In spite of limited hands-on assistance, the help provided by both family and friends was rated as highly adequate by the caregivers. On an adequacy scale of zero to 10, family helpers received an average rating of 8.3 and friends 9.1. Interestingly, although the amount of assistance provided by friends is less than that provided by family members, assistance from friends was rated as more adequate.

The third element of lifestyle that was evaluated in the study was availability and satisfaction with leisure activities. Respondents reported spending 10.2 hours per week on a hobby activity and 11.3 hours per week on relaxation activities. It is encouraging that none of the caregivers studied reported an absence of opportunities for relaxation. Leisure satisfaction was calculated by using caregivers' responses to four questions that examined satisfaction with a variety of leisure opportunities. By using a scale ranging from four to 16, the average satisfaction rating recorded was 8.1, suggesting that respondents were at least moderately satisfied with leisure resources.

The impact of caregiver history was evaluated through an examination of the quality of the pre-illness marital relationship. Participants responded to 10 questions regarding the quality of interactions they had enjoyed with their spouses prior to the onset of AD. The male caregivers overwhelmingly rated their pre-illness relationship as highly positive (mean = 34.3).

Correlations between risk factors and caregiver health

**Table 2. Health status and risk factors (N = 29)**

<b>Variable</b>	<b>Potential range</b>	<b>Observed range</b>	<b>Mean</b>	<b>SD</b>	<b>Median</b>
Symptom score (present)	0 - 125	3 - 53	21.7	13.0	19.0
Symptom score (prior)	0 - 125	0 - 41	14.1	11.4	10.0
Health rating	1 - 5	3 - 5	3.8	.6	4.0
Depression score	0 - 60	0 - 32	14.8	9.5	13.0
Burden score	0 - 88	4 - 60	29.8	14.3	32.0
ADL function score	0 - 28	4 - 28	16.8	7.4	17.0
ADL stress score	0 - 70	0 - 40	16.3	10.1	14.0
Behavior frequency score	0 - 100	0 - 63	32.5	16.4	32.5
Behavior reaction score	0 - 100	0 - 64	24.8	16.0	23.0
Number of family supports	_	0 - 12	2.0	2.3	1.0
Number of friend supports	_	0 - 4	1.7	1.4	2.0
Family support score	0 - 40	0 - 18	7.0	4.9	6.0
Friend support score	0 - 40	0 - 34	5.7	6.8	4.0
Family adequacy score	0 - 10	0 - 10	8.3	3.2	10.0
Friend adequacy score	0 - 10	0 - 10	9.1	2.5	10.0
Hobby hours/week	_	0 - 48	10.2	9.6	8.0
Relaxation hours/week	_	1 - 28	11.3	7.9	11.0
Leisure satisfaction score	4 - 16	4 - 12	8.1	1.8	9.0
Pre-illness marital relationship score	10 - 40	26 - 40	34.3	4.5	34.0

**Table 3. Correlation of risk factors and health status (N = 29)**

Risk factors	Health status	r	p
ADL stress score	Burden score	.406	.0386
Behavior frequency score	Burden score	.611	.0007
Behavior stress score	Symptom score	.427	.0287
Behavior stress score	Depression score	.426	.0372
Behavior stress score	Burden score	.658	.0002
Leisure satisfaction	Health rating	.557	.0038
Leisure satisfaction	Symptom score	-.426	.0205
Leisure satisfaction	Burden score	-.535	.0023

status is depicted in Table 3. Each risk factor was correlated with each health factor, but only those risk factors that displayed statistical significance are presented in this paper. Four risk factors were identified as significant predictors of caregiver health. The stressfulness of the level of care provided to a female spouse was a significant predictor of burden score in the men surveyed. Frequency of behavioral dysfunction in the care recipient also significantly predicted caregiver burden score. The stressfulness of behavioral dysfunction was significantly correlated with burden score, physical symptom score, and depression score. Finally, caregiver satisfaction with leisure was significantly correlated with the subjective health rating, symptom score, and burden score.

## Implications

Given the absence of comprehensive studies of male spousal caregivers, the findings of this study are rather unique. Additional studies focusing on male caregivers need to be conducted in order to validate the findings of this study and to assure that generalizations to other male caregivers are appropriate.

With regard to race, age, income, and years in the caregiving role, caregivers in this study were similar to those described in the literature.<sup>3,8,12,13</sup> Educationally, caregivers in the literature have generally been identified as having a high school education or less.<sup>3,14</sup> Eighty-two

percent of caregivers in this study had a minimum of a high school education. Given the potential impact of education on health status, future studies might focus on such a relationship.

Consistent with the literature, caregiver burden was predicted by perceptions of stress surrounding the provision of ADL assistance and behavior dysfunction as well as the frequency of behavioral outbursts. To minimize these negative changes in health status, interventions must focus on the development of services that provide education and access to social supports. The existing publicly funded medical and social services for caregivers and persons with AD focus on diagnosis and institutional care. While many long-term care facilities provide specialized care for persons with AD and staff training, such training is not routinely made available for spousal caregivers. Educational programs that provide the caregiver with insight into the disease process and predictability of behavioral change are relatively inexpensive to operate, and the provision of such information to families may be supportive of the caregivers' health. Funding for in-home and day-care respite programs could be made available to permit caregivers to attend educational programming offered by organizations such as the Alzheimer's Association. The creation of publicly funded custodial care (*i.e.*, services that provide supervision and therapeutic activity, but not assistance with ADLs) and behavioral modification programming also might be beneficial in educating and supporting caregivers. With

improved tools for coping and caring, spousal caregivers may experience less burden and stress, which may, in turn, facilitate the maintenance of their health and thereby continuation of the caregiving relationship.

In exploring the impact of lifestyle risk factors, the study identified the role of leisure satisfaction as a significant predictor of caregiver subjective health ratings, symptom score, and burden score. The role of leisure satisfaction in maximizing caregiver health must be clearly communicated to caregivers, physicians, service providers, and policy-makers alike. As the literature has demonstrated,<sup>24</sup> as AD progresses, caregivers are required to spend greater amounts of time providing care, and thus have less time available for their own leisure pursuits. As this study demonstrated, however, those with fewer leisure opportunities reported poorer health. Thus, it is not a matter of caregivers "taking time to take time off," but taking the time to maintain their health and their ability to continue caregiving.

Caregivers often are unable to give themselves permission to relax and enjoy hobbies. Education must be implemented to make caregivers aware of health outcomes associated with such lifestyle choices. A simple prescription from a physician or recommendation from a trusted health or social service professional may be the first step toward caregivers taking care of themselves, even with minimal leisure activities to sustain health. Along with such education, respite programming must be in place to support caregivers' utilization of both in-home and out-of-home leisure pursuits.

Male spousal caregivers in this study were experiencing compromised physical and emotional health. While respondents reported fewer symptoms of physical illness than might be expected for an elder population, an increase in symptom score by one-third was noted from the year prior to beginning the caregiving role to the past 12 months. Additionally, there was no statistically significant correlation between age and symptom score to suggest that changes in symptom scores were related to age. Depression levels were also elevated in a manner consistent with those noted in the caregiving literature.<sup>3,8-13</sup> Given the relatively positive health of the male caregivers in this study, the need for interventions that maximize or maintain health status is strongly supported. To ensure that male spouses remain healthy and able to continue in their role as caregivers, monitoring their physical and mental health on a very regular basis is important so that, when illnesses arise, medical and social service interventions may be provided. In addition, such monitoring and proactive referral to social and health services may limit the development of stress-related illnesses. Such services would best use an outreach model to provide linkages that men in particular

might need to access mental health and other services. Given the well-established role of the Alzheimer Society (Canada) and Alzheimer's Association (US) chapters as support, information, and referral sources, these agencies may be a good starting point for the utilization of outreach services.

In this study, the level of care required by the person with AD, frequency of behavioral problems, caregiver perceptions of stressfulness of behavioral dysfunction, and leisure satisfaction were identified as significant predictors of the health of male spousal caregivers. This study did not identify all possible variables responsible for health, but does provide a substantial view of the health concerns of male spousal caregivers that has heretofore been absent from the literature. Examination of caregivers' health over time would be beneficial for both caregivers and persons with AD. Given the established relationships between family caregivers and the Alzheimer Society and Alzheimer's Association, organizations involved in AD may be a tremendous resource to facilitate the completion of this important longitudinal research. Due to the chronic nature of AD, physical and emotional health changes experienced by the caregiver may take place over the course of many years. Research that evaluates participants over time is required for accurately identifying the physical and emotional health outcomes of long-term caregiving while controlling for age-related changes in health. Such data may facilitate the development of support services that effectively alleviate stress and strain during particular phases of caregiving. In addition, a more qualitative research approach is appropriate in order to document the reality of caregiving for men and identify the services or resources that decrease burden and maintain health.

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