

# Depression and Burden in Spouses of Individuals with Sensory Impairment

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## Abstract

Vision, hearing, and dual-sensory impairments are common causes of disability in older people. Most care for these individuals rests with their spouses. This study examined the level of burden on caregivers of spouses with visual, hearing, or dual-sensory impairment and age-matched controls and examined the correlation between burden and depression. Spouses (age 65–93) of 19 individuals diagnosed with unisensory or dual-sensory loss and 6 controls completed the Caregiver-Burden Scale and the Geriatric Depression Scale. Mann–Whitney  $U$  tests only indicated a statistically significant higher level of burden in spouses in the control group when compared to those of hearing-impaired participants. When comparing depression scores among groups, no statistically significant differences were found. Pearson's correlation coefficient indicated a statistically significant relation between burden and depression,  $r = 0.65$ ,  $p < .01$ , whereby increased perception of burden was associated with higher depression across all groups. These findings replicate the association between burden and depression in older people and suggest a more widespread link, independent of disability or health status.

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Keywords: burden, depression, spouse, sensory impairment

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## Introduction

Although rehabilitation is typically focused on the client with the impairment, spouses are an integral part of the rehabilitation process, yet their needs are rarely addressed. Service providers are often forced to neglect caregivers and place priority on service delivery for their clients based on budgetary and strategic planning priorities. This paves the way for higher anxiety, increased stress, increased physical

needs, and overall burden in these individuals. A question of much concern is, therefore, how a visual, hearing, or dual-sensory loss can impact the spouse or partner who is also a caregiver. Furthermore, do the effects differ depending on the type of loss and is the level of burden compounded when caring for a person with dual-sensory impairment? The present study examined differences in level of burden on the caregiver of a person with a visual impairment, a hearing impairment, or a dual-sensory loss.

## Demographics and Aging

Today, Canadians live on average 20.4 years longer than at the beginning of the 20th century, are

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financially better off and better educated, have an increased knowledge of technology, and are more active (Turcotte & Schellenberg, 2006). Between 1981 and 2005, there was an increase from 2.4 million to 4.2 million seniors across all provinces and territories. Although health tends to decline with age, Statistics Canada has documented that seniors, in general, are less psychologically distressed and less stressed and have an increased level of well-being than their younger counterparts, citing resilience and life experience as the cause. However, when activity limitations become a consequence of health-related issues, quality of life and integration into society are often affected (Turcotte & Schellenberg, 2006).

## Age-Related Vision Loss

In 2002, Statistics Canada reported that 40.5 percent of the total population aged 65 and older had some type of disability. Vision-related problems were ranked third (after rheumatism and high blood pressure) as the most chronic disabling conditions in later life. Almost 21 percent of the 40.5 percent of seniors with disabilities were afflicted with a vision loss. The percentage of individuals affected with an untreatable vision loss was estimated at 4 percent for seniors aged 75 and older, increasing to 8 percent at age 80 or older. Vision loss was greatly underreported in the elderly population with only 50 percent being appropriately diagnosed. According to the World Health Organization (WHO; 2010), 161 million people worldwide were visually impaired in 2002. Of these, 37 million were blind and another 124 million had low vision. By the year 2020, the WHO estimates that there will be 76 million people who are blind in the world with 54 million being 60 years of age and older. In Canada alone, there are an estimated 666,500 persons who are blind or who have low vision. The main conditions resulting in vision loss in persons aged 65 and older in developed countries include macular degeneration, glaucoma, and diabetic retinopathy (Maberley et al., 2006).

## Age-Related Hearing Loss

Hearing loss is a disability that initially often goes unnoticed, but in fact more than 50 percent of Canadians older than the age of 65 have an inner ear hearing loss (Government Services Canada, 2006). Statistics Canada (2002) reported hearing impairment as affecting 39.6 percent of individuals aged 65 and older, an estimated 575,000 individuals.

The WHO (2010) estimated in 2005 that 278 million people worldwide have moderate to profound hearing loss in both ears. The most prevalent condition affecting hearing for elderly people is presbycusis, an age-related decline in frequency sensitivity that reduces the perception of high-pitched sounds and certain consonant sounds in speech. This sensory-neural hearing loss is caused by damage to the receptors that can no longer generate electrical signals. Amplification, speech reading, communication strategies, or cochlear implants can be helpful in diminishing the effects of this loss. Finally, tinnitus is a common hearing-related problem. It can be an extremely debilitating condition characterized by the sensation of sound when there is no external noise. The sounds vary from ringing or chirping to buzzing or whistling, to name a few (Government Services Canada, 2006).

## Age-Related Dual-Sensory Loss (Hearing and Vision)

Approximately 9 percent to 21 percent of people aged 70 and older have some degree of dual-sensory loss and the prevalence tends to increase with age (Brabyn, Schneck, Haegerstrom-Portnoy, & Lott, 2007; Saunders & Echt, 2007). Dual-sensory loss can be classified into four categories: congenital deaf-blindness, congenital visual impairment with acquired hearing loss, congenital hearing impairment with acquired vision loss, and acquired hearing and vision impairment. In the context of the present study, the focus was on the lattermost of these four groups because their number is rapidly increasing as the population ages. Research in single sensory impairments can provide us with insight into the losses associated with dual-sensory impairment. However, these individuals present with unique and complex issues pertaining to the combined loss of both hearing and vision. A strong relationship between the two impairments has also been documented, showing that, for each one-line reduction in best-corrected visual acuity, hearing loss prevalence increases by 18 percent (Brabyn et al., 2007).

## Living Arrangements and Care Giving

Kane, Penrod, and the Center for Practice Innovations (1995) reviewed ground-breaking research from over 20 years ago, demonstrating the significance of the family caregiver as the center-

piece of the long-term care system, a situation that has not substantially changed since then. Families now provide 80 percent to 90 percent of assistance to retired individuals. When spouses are available and capable, they are the first to become caregivers. Horowitz (1985) reported similar findings, stating that caregiving to frail elderly was most extensively provided by spouses. Research has shown that approximately 4.2 million Americans provide care to an impaired spouse, a number that has most likely increased by now (Kane et al., 1995). The living arrangements of older people can have a significant impact on the type of care they receive. For example, an older person in need, living with a spouse, has easier access to support and care than one living alone. In 2001, 93 percent of seniors older than the age of 65 were living in private households. Of those aged 65 to 74, 54 percent were living with a spouse, although this number decreased in the over-85 age group due to women's higher life expectancy. Additionally, in 2002, 26 percent of seniors living in private dwellings stated that they received help necessitated by chronic health problems that affected their ability to perform activities of daily living. Persons aged 85 and older were four times more likely to require support than 65- to 75-year-olds (Turcotte & Schellenberg, 2006).

Informal care giving has almost always been associated with increased burden on the family member. Some respite programs and respite strategy courses exist for caregivers; however, the system appears to be failing this important group, evidenced by burnout, stress, and illness in the caregiver. Horowitz (1985) described one of the negative consequences of caregiving to be decreased physical health due to the considerable amount of physical labor. Ekberg, Griffith, and Foxall (1986) found that caregiving spouses exhibit symptoms of emotional and physical exhaustion, resentment, and negativity. Caregivers report poorer physical health and chronic conditions such as hypertension, arthritis, or back pain (Kane et al., 1995). Caregiving has also been shown to cause emotional strain, psychiatric issues, depression, anger, and anxiety. Therefore, the burden associated with caregiving is extremely important to address (Kane et al., 1995).

### Impact of Visual Impairment on Spouse

Very few studies exist examining the effect of vision impairment on a spouse. In one study by

Strawbridge, Wallhagen, and Shema (2007), a spouse's vision impairment was correlated with partner depression, decreased physical functioning, decreased well-being, limited social involvement, and decreased marital quality. Pearlin (1989) described visual impairment as the primary stressor on the caregiver, whereas secondary stressors would be the physical and psychological effects. Strawbridge et al. (2007) specifically examined to what extent the vision impairment of an older spouse can impact his or her partner's health and well-being. A range of variables were explored, such as physical functioning, mental health, social involvement, and marital quality. The results demonstrated that a spouse's vision impairment was significantly correlated with negative partner outcomes in all variables studied with the exception of social involvement. However, getting the caregiver involved in and educated about the rehabilitation process has been shown to be beneficial by, for example, reducing the level of perceived burden (Dumas & Sadowski, 1984).

### Impact of Hearing Impairment on Spouse

Research evaluating the impact of hearing loss on intimate relationships is more readily found but still remains scant. Hallberg and Barrenäs (1993) documented the impact of middle-aged men's noise-induced hearing loss on their intimate relationships. Variables of interest included severe communication problems, a perception that the relationship had become less personal, and irritation and aggressiveness of the partner in relation to annoying behavior (not answering the telephone or setting the volume of television or radio too high). In interviews with men affected by noise-induced hearing loss, the spouse was often described by the husband as the person with the least understanding of the disease (Hallberg, 1996). Héту, Jones, and Getty (1993) evaluated the effects of hearing impairments on the intimate relationships of older people. They believed that the onset of the hearing impairment leads to a process of adaptation and ambiguity for both partners, which could have a straining effect on the intimate relationship. In adjusting to the sudden or progressive hearing loss, each partner may experience increased effort, stress, anxiety, isolation, negative self-image, and difficulties in family relationships as a result of communication breakdown. Problems reported by the unimpaired partner include

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stress, tension, irritation, fatigue, frustration, anger, resentment, and guilt. A longitudinal study by Wallhagen, Strawbridge, Shema, and Kaplan (2004) examined the relationship between a spouse's hearing loss and the partner's physical, psychological, and social well-being 5 years after onset. Their results demonstrated statistically significant impacts in all spheres—physical, psychological, and social.

## Impact of Dual-Sensory Loss on Spouse

Very little research exists concerning the effects of a dual-sensory loss on an individual or a caregiver. Much of the research is based on combining the effects of the vision loss with that of the hearing loss, but the simultaneous loss of vision and hearing creates a unique experience with its own characteristics. The situation makes all aspects of daily living more complicated and unsafe. The double loss affects communication, self-esteem, and self-perception and alters relationships (Heine & Browning, 2002). It is believed that the effects of the dual loss far outweigh that of a single sensory impairment due to the fact that the person cannot rely on the other sense (Saunders & Echt, 2007).

The present study examined the level of burden experienced by the caregiver of a person with a visual, a hearing, or a dual-sensory loss as well as age-matched persons with no sensory impairments. It was hypothesized that the spouses in the sensory loss groups would report statistically significantly higher levels of both burden and depression when compared to age-matched normals. In addition, spouses of individuals with dual-sensory impairment were expected to report higher levels of burden and depression when compared to either unisensory impairment group. Previous work demonstrated that increased levels of burden have consistently been associated with an increase in depression among caregivers of patients affected by cancer (Stommel, Given, & Given, 1990), stroke (Han & Haley, 1999), Alzheimer's disease (Mittelman et al., 1995), and dementia (Covinsky et al., 2003). Therefore, it was hypothesized that depression would be more prevalent when levels of burden were increased for the sensory-loss population.

## Method

The protocol received approval from the institutional ethics review board at the University of

Montreal and adhered to the Canadian Tri-Council Statement for Research Conducted with Humans.

## Participants

The sample of participants was drawn from spouses of registered clients of the MAB-Mackay Rehabilitation Center, an agency that serves individuals with vision and/or hearing loss. The criteria for participation were the following: English speaking; age 65 and older; and spouse or partner of a person exhibiting a visual, hearing, or dual-sensory impairment according to the Quebec Ministry of Health criteria: visual acuity in each eye less than 6/21 (20/70) or a visual field in each eye less than 60° in the 180° and 90° meridians after correction by appropriate ophthalmic lenses and/or mild to profound hearing loss of 25 dB or greater (Regie de l'assurance maladie du Quebec/RAMQ, 2006). The control group (individuals with no sensory impairment whose spouses are without sensory impairment) was recruited from spouses of family, friends, and colleagues of the primary researcher.

A total of 25 participants was recruited. There were 6 (24 percent) participants who were partners of persons diagnosed with age-related vision loss, 8 (32 percent) participants were partners of individuals diagnosed with age-related hearing loss, and 5 (20 percent) were partners of individuals diagnosed with age-related dual-sensory loss (at least partially sighted and ranked as having a mild to profound hearing loss), as well as 6 (24 percent) age-matched control participants from couples where neither partner experienced sensory impairment. Of the 25 participants, 16 (64 percent) were women, and their ages ranged from 65 to 93 years ( $M = 75$ ,  $SD = 7$ ).

## Materials

The Caregiver Burden Scale was administered to each participant and determined the level of burden experienced by the spouse (Zarit, Reever, & Bach-Peterson, 1980). This measure has previously demonstrated high levels of sensitivity and specificity in populations such as caregivers for Alzheimer's patients (Martin-Carrasco et al., 2002) as well as good internal validity (Martin-Carrasco et al., 2010). Four of the 29 questions were reverse-scored. Topics covered by the measure included caregiver's health, psychological well-being, finances, social life, and the relationship between the caregiver and the receiver of care. The respondents indicated how much

**Table 1.** Descriptive Statistics of the Participant Groups

Impairment of Spouse	<i>n</i> (M/F)	Age <i>M</i> ( <i>SD</i> )	Burden Score <i>M</i> ( <i>SD</i> )	Depression Score <i>M</i> ( <i>SD</i> )
Visual	6 (1/5)	80.2 (8.3)	16.7 (12.9)	9.2 (8.4)
Auditory	8 (3/5)	76.0 (6.2)	6.8 (7.7)	2.8 (2.8)
Dual	5 (2/3)	76.4 (6.7)	23.2 (25.6)	11.6 (12.2)
None	6 (3/3)	68.0 (3.2)	28.4 (16.4)	6.8 (4.3)

discomfort their concern caused them by selecting the most appropriate response from 0 (*not at all*) to 4 (*extremely*). A total burden score was calculated and used in the analysis with the four reverse-scored items being subtracted from the total according to previous scoring methodologies (Zarit et al., 1980). Higher scores indicated higher levels of burden.

The Geriatric Depression Scale (Yesavage et al., 1982) was administered to each participant and determined level of depression. This measure also shows high levels of sensitivity and specificity in populations such as older hospitalized patients (Koenig, Meador, Cohen, & Blazer, 1988) as well as persons with visual impairment (Shmuelly-Dulitzki & Rovner, 1997). This scale consists of 30 questions with yes or no answers. Participants were asked to respond in reference to feelings over the past week. Ten of the 30 questions were framed positively and scored with one point for a “no” answer. The 20 negatively framed questions were scored with one point for every “yes” response. Scores below 9 indicated a normal state (no depression), scores 10 to 19 equaling mild depression, and scores 20 and over equaling severe depression.

**Procedure**

Potential participants were identified by professionals of the MAB-Mackay Rehabilitation Center during their global assessment of needs. Basic information was provided to each participant such as the researcher’s name, research institution, and goals and procedures of the study. If a client expressed interest, written informed consent was obtained with the knowledge that he or she could withdraw from the study at any time. After having signed the consent form, either the Caregiver Burden Scale or the Geriatric Depression Scale was randomly presented first and completed by the participant during regular service delivery to their partner or spouse. All data were coded without

identification on the questionnaires in order to preserve anonymity and privacy at all times.

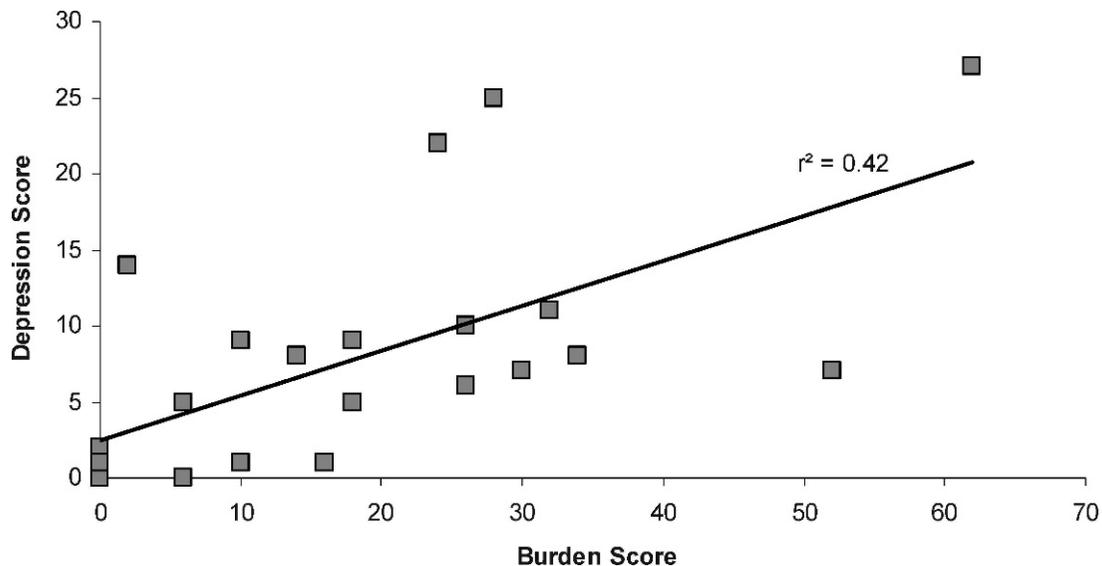
**Results**

Summary descriptive statistics of the participants are listed in Table 1. Two-tailed Mann–Whitney *U* tests were used to conduct pair-wise comparisons among the four groups on their total scores on each measure because the sample sizes were small and the data were not normally distributed. A total of 6 comparisons for each level of burden and depression were carried out. For the results on perceived burden, only one comparison showed statistically significant differences: comparing the level of burden between the spouses of hearing-impaired participants and those in the control group, the level of burden was higher in the control group,  $U(8, 6) = 40, p < .05$ . None of the comparisons on depression were statistically significantly different. A Pearson’s correlation coefficient indicated a statistically significant relationship between level of burden and depression,  $r = 0.65, p < .01$ , across all participants indicating that, as burden increased, so did depression (see Figure 1). The sample sizes for subgroup correlations were too small to be meaningful.

**Discussion**

This pilot study focused on the impact that a spouse’s visual, hearing, or dual-sensory impairment has on the level of burden or level of depression in the partner. It was hypothesized that there would be a significant difference in level of burden and depression among the four groups (vision, hearing, dual, and control). In all comparisons but that between spouses of the hearing impaired and the control group with regard to level of burden, no differences were found.

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**Figure 1.** Depression scores as a function of burden scores for all participants. Depression and perceived burden by spouses were statistically significantly correlated across all participants, independent of whether the spouse had impaired vision, hearing, or both or was unimpaired. As depression scores increased, so did perceived burden scores, and vice versa.

The significant difference in level of burden between spouses of the hearing-impaired individuals and the control group is intriguing, considering the fact that the level of burden for the control group was higher. In fact, the levels of burden and the levels of depression in the control group varied widely and were, at times, higher than the levels found in the caregivers of spouses with sensory impairments. Considering that the participants were chosen from a rehabilitation center, it could be argued that these couples were receiving some support that, in itself, could contribute to the well-being in both the person with the impairment and his or her spouse. The control group may not have a similar support system in place, indicating that the beneficial effects of rehabilitation extend beyond the impairment and the actual client.

The considerable variability in the scores, the small sample size, as well as the presence of burden and depression among the groups indicate that burden and depression may be a regular part of the aging process, irrespective of health and disability. Perception of burden and the presence of depression may depend on other factors not considered within this study protocol, such as personality traits, prior family dynamics, economic factors, and family or social support. These factors may significantly

contribute to the perception of burden and depression and are worthy of further investigation.

The previous issues point to some limitations of the study. The inclusion and exclusion criteria for control subjects did not consider the possibility of other stressors or impairments in the relationship that may impact burden or depression. Furthermore, several physical, economic, social, and/or personality factors can contribute to the perception of burden or depression and may have contributed to the variability in the data. In addition, recruitment of control individuals from the social circle of the primary researcher may have caused a bias with regard to their social strata. The limited number of participants also weakened the results. Finally, caregiver was defined as a person who is responsible for assisting his or her spouse with activities of daily living. This definition did not take into consideration that even couples with no identifiable health impairment or need for assistance in activities of daily living could be experiencing caregiver burden and depression.

The physiological, social, and psychological changes related to the aging process could impose a similar burden on the spouse. Although older individuals in general are less psychologically distressed than younger people, quality of life often

decreases in the older population and could be reflected in the increased levels of burden and depression (Turcotte & Schellenberg, 2006). Studies examining the association between changes related to the normal aging process and levels of burden and depression could provide valuable insight into the support that couples require as they age.

The positive correlation between level of burden and depression does not indicate which variable caused the other, although they replicate previous findings that level of burden is associated with depression (Covinsky et al., 2003; Han & Haley, 1999; Mittelman et al., 1995; Stommel et al., 1990). Several theories may help to explain why vision impairment can impact a spouse or caregiver's well-being. According to Strawbridge and colleagues (2007), the communication theory explains how a relationship can be affected by changes in communication patterns that often rely on nonverbal cues. When a spouse has a visual impairment, much communication and interaction may be lost through unseen gestures, facial cues, and body language, thus having an effect on understanding between the partners. This interpretation, however, needs to be considered carefully because previous research on the constructs of burden and depression has indicated that the general emotional states associated with depression may be reflected in (and thereby largely explain) burden perception (Stommel et al., 1990).

It has been demonstrated that burden is strongly associated with caregiving (Desbiens, Mueller-Rizner, Virnig, & Lynn, 2001; Hallberg & Barrenas, 1993; Hannum Rose et al., 2007; Heine & Browning, 2002; Hetu et al., 1993; Strawbridge et al., 2007; Uttl, Santacruz, Litvan, & Grafman, 1998; Wallhagen et al., 2004); however, not all of these studies made comparisons to age-matched control groups. The positive correlation between burden and depression indicates that when completing an evaluation of client needs, it may also be important to evaluate the spouse's level of burden and/or level of depression in order to provide the necessary support to the client as a whole.

In summary, care giving is most frequently provided by a spouse (Kane et al., 1995), burden is associated with care giving, and burden and depression are positively correlated. This leads to important areas of investigation that have not

received substantial attention in recent years, such as whether spouses are caring for their partners effectively, whether any type of support is offered to spouses during the rehabilitation process, and what other variables may have an impact on perception of burden and depression. Although spouses are consistently invited to participate in the rehabilitation process of their partner, clinicians typically provide services to the client only with little consideration of the partner. The results of the present study indicate a link between the client's well-being and the level of burden and depression in the caregiver, pointing toward the need for increased psychosocial intervention with the couple, liaison with community resources, and increased participation from the spouse as a means of improving the rehabilitation process and decreasing levels of burden and depression.

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