Burden is a psychological concept, a subjective interpretation by caregivers of the extent to which the caregiving experience impacts on one’s health, social life, or financial status. In this article, we examine some of the predictors of caregiver burden, and look specifically at the burden experienced by caregivers of individuals with Parkinson’s disease.

Keywords: Parkinson’s disease, psychological health, physical health, caregiver burden

Burden is a psychological concept, a subjective interpretation by caregivers of the extent to which the caregiving experience impacts on one’s health, social life, or financial status.¹ Despite this seemingly straightforward definition of the overall construct, there is substantial variability in the manifestation of burden—and the aspects of daily living that produce stress among caregivers—that depend upon disease state.²

Caregivers are associated with decreased morbidity, reduced mortality, and increased quality of life for those that they care for. Unfortunately, the occupation of ‘caregiver’ can produce persistent stress, impaired psychosocial functioning, and a diminished immune system in the caregiver.³⁴ When caregivers are in distress, they may be...
unable to provide appropriate care. For these reasons, it is important to accurately assess and manage caregiver burden.²

The effects of burden are often expressed as a decline in psychological and physical health, as well as an increase in the number of physical symptoms and physician visits.⁵ The amount of burden experienced by the caregiver is related to: symptom management for the patient; the level of care needed to perform activities of daily living; the perception of control that the patient has over his or her illness; perceived level of social support from family, friends, and community; financial stability; and knowledge of their patient’s disease.⁶

Caregivers are typically called upon to respond to the needs of individuals who were previously independent,⁷ and this creates stress for both the care receiver and the caregiver. In addition to the stress of managing safe and productive activities of daily living, the unpredictability and uncertainty that surrounds the caregiving experience exacerbates the negative effects of caregiving.⁵ It is not surprising, therefore, that the patient’s perception of control over his or her symptoms is inversely related to caregiver burden—possibly due to diminished feelings of self-efficacy, and ultimately an increased reliance on the caregiver.

Burden also relates to the sex of the caregiver—it has been found that women experience a higher incidence of burden than men, being twice as likely to report a burden of caregiving, as compared with men.⁵ This may be due to the fact that there are more female than male caregivers, given the longer life expectancy of women and the higher incidence among men of many chronic diseases, such as Parkinson’s disease.⁴

### Spousal Caregivers of Individuals with Parkinson’s disease

Parkinson’s disease (PD) is a chronic neurodegenerative disease affecting nearly 100,000 Canadians, and 6.3 million people worldwide. Consequence symptoms include the progressive loss over control of movement, affecting walking, balance, coordination and speech.⁸ In addition to the motor disability, Parkinson’s disease is associated with a higher incidence of cognitive and psychological disorders. As Parkinson’s disease worsens, the motor symptoms vary in severity from day to day and from hour to hour. This unpredictability of PD symptoms results in

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**Key Point**

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an even greater lack of control for caregivers. Interestingly, it is the neuropsychiatric disturbances associated with PD—and not the motoric sequelae—that seem most problematic for caregivers. The features of motor and neuropsychiatric symptoms, combined with the unpredictability of the disease, may leave caregivers ill equipped, both emotionally and physically, to provide care. Despite the obvious importance of the caregiver, less than 1% of all published papers concerning PD refer to problems related to caregiving.

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**Considerations for Decreasing Caregiver Burden Among PD Spousal Caregivers**

Activities of daily living are often the focus of research, and serve as the mainstay of information that is geared towards caregivers. This is not, however, the major issue reported by caregivers. Caregivers tend to devote a significant amount of their cognitive resources to concern over the safety of their spouse. This constant ‘watching and worrying’ consumes a significant amount of energy, and can exhaust the caregiver. Exacerbating this is the realization of spousal caregivers that their overt vigilance is causing their spouse to become increasingly aware of his or her decreasing independence. The ‘watching and worrying’ can be partially alleviated through better use of assistive devices within the home (e.g., raised toilet seats, grab bars) and environmental modifications that improve the safety of the home through simple techniques such as eliminating throw rugs, decreasing clutter, and improving lighting conditions. In addition to improving the safety of the patient’s activities of daily living, these types of intervention will foster the patient’s independence.

**Table 1: Markers of Caregiver Stress**

- Declining physical health (i.e. more doctors visits, physical symptoms)
- Declining psychological health (i.e. depression, confusion)
- Financial worry
- Indications of loneliness and depression
Identifying and Managing Caregiver Burden

The independence of the caregiver, and the associated opportunity for decreased burden, is limited by the independence of the care receiver. Accordingly, home-based support is an option that should be considered—if only to serve as partial respite for the caregiver. For this to be a worthwhile solution for the patient and the caregiver, the spousal caregiver will need to establish a rapport with the homecare provider. This sharing of knowledge with the homecare provider will allow the caregiver to feel more comfortable surrendering some level of control over the patient’s care, will allow the patient to experience better management of his or her symptoms; and will allow the homecare provider an opportunity to offer more efficient and effective care within the home environment. Achieving a level of comfort with the homecare provider gives caregivers increased freedom to engage in social activities outside the home, and may improve their quality of life.4

Conversely, some social activities engaged in by caregivers, such as visiting friends or attending an exercise classes with their spouse, may not be an effective relief of burden. Caregivers note that some of these activities act more as a ‘distraction’ than a ‘support.’14 Many caregivers report that participation in support groups that foster an opportunity for caregivers to share concerns in a safe and non-judgmental setting are more beneficial. More emphasis on the development of spousal caregiver support groups as a means of sharing knowledge, resources, and support, should lead to a reduction in caregiver burden.5

In considering social networks, it is important to note the difference between social activities that

Table 2: Predictors of Caregiver Stress

- Length of time spent caring for a spouse with PD
- Age of caregiver
- Ineffective / inappropriate social network
- Decreasing independence
- Increasing social isolation
- Hyper-vigilance (typically related to patient safety)
- Severity of the disease in the spouse with PD
- Presence of both motor and neuropsychiatric PD symptoms
- Perception of lack of control over PD symptoms
- Lack of knowledge of the Parkinson’s symptoms and disease
- Progression of unpredictability of the PD symptoms

Key Point
Achieving a level of comfort with the homecare provider gives caregivers increased freedom to engage in social activities outside the home, and may improve their quality of life.
are geared towards the needs of the caregiver, and social activities that meet the needs of the couple. As Parkinson’s disease progresses, the affected individual is less able to engage in social activities that may have been a part of the couple’s daily lives. This may be due to disease progression, the unpredictability of symptoms, the strict medication regimens, and the general discomfort of the individual with PD. The couple will experience a gradual decrease in the scope of relationships—first with work-based relationships, then friends, and finally family interactions. This loss of social interactions affects the ability of both the caregiver and the individual with PD to engage socially as a couple – particularly in the later stages of the disease. Couples are often faced with an inability to follow through with retirement plans, and in combination with the steadily increasing limitations associated with the disease, weighs heavily on both spouses. As clinicians, we need to recognize that both caregivers and care receivers are going through a continual grieving process as successive aspects of their ‘old’ life fade. More importantly, we need to increase awareness of resources that they might utilize for emotional guidance throughout the process.

**Clinical Implications**

Unfortunately, there is no simple diagnostic tool that may be used to determine who is at the greatest risk of being overwhelmed by the caregiving process. There is no common universal burden experienced by all spousal caregivers, and this is especially true for diseases such as PD, in which there is substantial inter- and intra-individual variability. Furthermore, a caregiver’s ‘burden profile’ will change as the disease progresses, suggesting that the physical, mental, and emotional health of the individual with PD will continue to evolve, impacting the caregiver’s ability to manage the caregiving role.

**Table 3: Strategies for Alleviating Caregiver Burden**

- Assess the caregiver’s unique burden profile
- Periodic assessment of caregiver burden as the disease progresses
- Facilitate discussion with the caregiver about his or her needs
- Be knowledgeable about available resources, coping mechanisms, skills and caregiver support groups
- Include caregivers in the care plan
- Facilitate home based support or respite programs
- Initiate occupational therapy assessment of home safety issues and environmental modification to improve safety

*Key Point*

There is no common universal burden experienced by all spousal caregivers, and this is especially true for diseases such as PD, in which there is substantial inter- and intra-individual variability.
Identifying and Managing Caregiver Burden

Summary of Key Points

Burden is a psychological concept, a subjective interpretation by caregivers of the extent to which the caregiving experience impacts on one’s health, social life, or financial status.

The effects of burden are often expressed as a decline in psychological and physical health, as well as an increase in the number of physical symptoms and physician visits.

Achieving a level of comfort with the homecare provider gives caregivers increased freedom to engage in social activities outside the home, and may improve their quality of life.

There is no common universal burden experienced by all spousal caregivers, and this is especially true for diseases such as PD, in which there is substantial inter- and intra-individual variability.

caregiver should be evaluated during appointments at which the primary patient is assessed. This is an important additional consideration as this is not an evaluation that is likely to occur ‘naturally’ during the course of evaluating the individual with PD. By the time levels of burden are peaking (i.e., after several years of caring for the individual with PD), a spousal caregiver has become so focused on discussing the needs of his or her spouse, that it is incumbent upon professionals to focus discussion on the caregiver, in order to elicit meaningful information in this regard.

Clinicians that open discussions of this sort should expect to be faced with questions concerning the availability of resources that may be accessed by the patient, and so it is important to keep a current list of local support groups, as well as a supply of relevant documentation that caregivers can reference when they are faced with questions concerning their spouse’s illness.

The main implication for healthcare professionals, however, is that caregivers should be included in care plans. Caregivers are at a high risk of decreased health-related quality of life due to the amount of time and energy they expend in providing care. Ensuring that the quality of life of the caregiver does not decrease is of utmost importance, as caregiver and patient quality of life are closely linked.

The selflessness of caregivers leads them to ignore their own health and well-being. Caregivers are often so focused on discussing the needs and care of their spouse they do not discuss their own health-needs and concerns. The simple act of asking how a car-

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Identifying and Managing Caregiver Burden

Clinical Pearls

Clinicians need to recognize that both caregivers and care receivers are going through a continual grieving process as successive aspects of their 'old' life fade.

A caregiver’s ‘burden profile’ will change as the disease progresses, suggesting that the physical, mental, and emotional health of the caregiver should be evaluated during appointments at which the primary patient is assessed.

Caregivers should be included in care plans. Caregivers are at a high risk of decreased health-related quality of life due to the amount of time and energy they expend in providing care.

egiver is coping will increase their sense of value within the healthcare team and improve their quality of life, which in turn improves quality of care.

References