



## Feature Article

## Caregiver tele-support group for Parkinson's disease: A pilot study



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## ABSTRACT

**Background:** Parkinson's disease (PD) is a disabling neurodegenerative disease that typically affects the geriatric population and requires a caregiver. Although caregiver burden reduces quality of life of the caregiver, support groups for caregivers have not been studied. Offering a tele-support group to PD caregivers would be an innovative approach to extending a novel resource.

**Methods:** A single-center pilot study was conducted, enrolling caregivers in an 8-week tele-support group program. Mood state and caregiver burden were assessed at baseline and conclusion of the program using self-report questionnaires. Qualitative feedback was obtained at the conclusion of the program.

**Results:** Seven female spouse caregivers enrolled; 86% completed the program. Although no statistically significant changes in questionnaire scores were found, the mean Geriatric Depression Scale decreased from 4.2 to 3 and qualitative feedback was universally positive.

**Conclusions:** The use of tele-support groups for PD caregivers is a feasible and innovative resource to address caregiver burden.

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## Introduction

Parkinson's disease (PD) is a chronic neurodegenerative disease that includes the loss of dopaminergic neurons in the substantia nigra leading to motor symptoms of tremor, rigidity, and bradykinesia, as well as an array of non-motor symptoms that affect cognition, sleep, behavior, and the autonomic nervous system. Disability from PD varies and typically progresses, therefore it will affect the growing geriatric population, often requiring the assistance of an informal caregiver, whether a spouse, child or close friend.<sup>1</sup> Caregiver burden places emotional, physical and financial demands on the caregiver.<sup>1,2</sup> As the prevalence of PD is expected to more than double by 2030,<sup>3</sup> efforts to recognize and mitigate caregiver burden in PD are important.

The myriad of symptoms in PD makes this particularly challenging for caregivers, and depending on the level of responsibilities, the amount of burden can vary widely with 63% of caregivers spending greater than 50 h a week caring for persons with PD.<sup>4,5</sup>

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Costs to the caregiver's well-being are recognized; among them, an increased prevalence of mood disorders such as anxiety and depression that are associated with disease severity and duration.<sup>6</sup> A caregiver's quality of life diminishes with the degree of perceived burden and disease severity.<sup>7</sup> Eighty percent of caregivers of patients with dementia secondary to parkinsonism feel that people do not understand their burden.<sup>8</sup> Interpersonal relationships with the patient, friends, family, and co-workers are impaired with only 60% of caregivers partaking in social activities, and many caregivers forgoing any leisurely activities.<sup>9</sup> Financial burden is also often cited, with one third of caregivers below age 65 retiring early due to patient needs.<sup>9</sup> The caregiver role is complex and often requires resources and support to help manage this responsibility.

Caregivers often have limited knowledge of resources such as support groups, programs, equipment, and benefits that could potentially reduce their burden.<sup>4</sup> Evidence has shown that caregivers of the elderly or chronically ill patients who participate in support groups that include socialization, counseling, problem solving skills and education have decreased stress and burden, as well as improved emotional health.<sup>10</sup> PD support groups typically welcome patients, as well as family members, who are often caregivers. However, the discussions are focused on disease management and issues related to the patient rather than those of the

caregiver. The benefit of caregiver support groups have been seen in other chronic diseases such as frontotemporal dementia, cancer patients, and in the chronically ill elderly.<sup>11–13</sup> Support groups that specifically focus on the needs of the caregiver are not reported in PD literature and PD caregivers have emphasized the need for such groups.<sup>14</sup> Interventions such as cognitive behavioral therapy, educational programs, and respite care have been offered to PD caregivers in a number of small research studies.<sup>15</sup> Due to the degree of disability of the patient, level of care required, and travel, it is often not feasible for the caregiver to attend such face-to-face programs. Therefore, efforts to increase access to resources lies at the crux of assisting and alleviating the many challenges faced by PD caregivers.

Telehealth and related remote-care technologies are an innovative approach to increasing access to clinical care, and also to educational and support group programs. Research on the use of web-based video conferencing for caregivers in neurodegenerative diseases demonstrated promise.<sup>16</sup> One study showed that caregivers of those with dementia were comfortable using telecommunications technology, making this a feasible intervention.<sup>17</sup> These caregivers found it helpful to communicate with other caregivers, participate in group discussions, and learn about resources.<sup>17</sup> The use of telephone support groups has also been effective in providing educational interventions and emotional support to those caring for persons with Alzheimer's disease.<sup>18</sup> A comparison of traditional and telephone support groups for patients with brain injury found improvement in mood state and caregiver burden in both support groups, suggesting telephone support groups are as effective but more easily accessible than traditional support groups.<sup>19</sup>

The use of telehealth in PD itself is emerging and it has been implemented into general care of PD patients via web-based video conferencing directly into the patient's home,<sup>20</sup> but still remains scarce. Many caregivers are unable to travel outside the home for an extended period of time due to caregiving responsibilities, especially those in rural areas. Physicians and support staff have observed this for many years. Given telehealth's use for caregiver support in other disease states,<sup>17–19</sup> we aimed to evaluate the feasibility of a Parkinson's disease caregiver telephone support group focused on providing emotional support and problem solving skills to caregivers via teleconferencing, as it may provide a novel and innovative resource for PD caregivers. We hypothesize that tele-support groups are feasible, and will lead to decreased caregiver burden and improved mood state.

## Methods

### Study design

A single-center quasi-experimental pilot study was conducted at the Philadelphia VA Parkinson's Disease Research, Education and Clinical Center (PADRECC) enrolling seven PD caregivers in an 8-week curriculum-based tele-support group program. The study was open to all English-speaking caregivers of Veterans with Parkinson's disease actively receiving treatment at the Philadelphia PADRECC. The protocol was approved by the Philadelphia Veteran's Affairs Medical Center's Institutional Review Board, and each subject gave verbal informed consent prior to participation.

### Study population

Fourteen caregivers were identified by PADRECC clinicians as being active in their loved one's care and eligible for the study. Introduction letters were mailed to these 14 caregivers informing them about the study and a follow-up phone call determined who was interested. Eight of these caregivers expressed interest in the group

and enrolled in the study, with one participant declining to continue after enrollment due to the time commitment the group required.

### Intervention

The telephone support group model is based on federally funded research done by Senior Services of Albany, an Area Agency on Aging, in conjunction with the Institute of Gerontology, University at Albany.<sup>21</sup> Key elements of the model which were replicated in this support group included four key components: (1) education about caregiving, (2) skills training, (3) problem solving, and (4) support.<sup>21,22</sup> The group met once a week via teleconference for eight weeks, 90 min per teleconference (Table 1). A participant manual outlining topics to be discussed along with a book, "The Caregiver's Guide to Self-Care: Help for Your Caregiving Journey"<sup>23</sup> was given to each subject in order to cover relevant caregiver topics. The book prepared subjects for the upcoming group discussions, which facilitated meaningful conversations about practical ways to manage caregiver stress, maintain their health and preserve their capacity to care. Participants were asked to review chapters from the book and answer questions about caregiving for self-reflection. This "homework" was not required, and completion was not tracked.

The groups were actively led by a nurse specialized in caregiver education and co-facilitated by a social worker and nurse, both of whom specialize in the care of PD patients. During the first teleconference, participants were asked to share personal goals for joining the group. Specific topics were discussed at each session in the following order: the caregiver role, caregiver stress, caregiver self-care, cultivating a supportive community, and conserving and replenishing caregiver energy. The facilitators provided a brief review of the previous meeting and at the conclusion of each session suggested activities to complete prior to the next meeting. Participants shared a pressing problem or self-care goal to teach them how to implement techniques to reduce caregiver burden.

### Study outcomes

Caregiver demographic information such as age, gender, ethnicity, marital status, relationship to patient and living situation, was obtained through a questionnaire mailed to the caregiver. Caregivers were also asked to report duration of disease and complete the Schwab and England Activities of Daily Living Scale, which assesses a PD patient's ability to perform daily activities by considering speed and level of independence. The rating is based on a percentage scale with 100% indicating complete independence and 0% indicating complete dependence. Additional patient information was obtained through chart review. This included age and an objective measure of disease severity, the modified Hoehn & Yahr scale, which ranges from 0 [no sign of disease] to 5 [wheelchair bound/bedridden state], and is determined by the provider.

Attendance of each participant was tracked throughout the study to assess components of feasibility such as demand, acceptability, implementation, and practicality. Outcomes of caregiver burden and mood state were assessed at baseline and conclusion of the program using a number of self-report questionnaires which were mailed to the caregivers: American Medical Association Caregiver Self-Assessment, Geriatric Depression Scale, Zarit Burden Interview and Family Caregiver Assessment.

The AMA Caregiver Self-Assessment Questionnaire is an 18-item yes/no self-assessment tool used to measure emotional and physical distress.<sup>24</sup> A high degree of caregiver distress is present if participants respond "yes" to 10 or more questions.<sup>25</sup> The Geriatric Depression Scale (short form) is a validated 15-item self-assessment used to identify depression in the elderly.<sup>26</sup> Assessment scores range from 0 (normal) to 15 (severe

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