

# The Value of Peer-Led Support Groups Among Caregivers of Persons With Parkinson's Disease

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Many persons with Parkinson's disease are cared for by family members. The strain of caregiving can negatively affect the health of the caregiver and affect long-term care decisions, making caregiver support a priority. This study highlights the importance of peer-led support groups for family caregivers of persons with Parkinson's disease. **KEY WORDS:** *caregiver strain, caregiver support, caregiving, Parkinson's disease, peer-led support*

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Parkinson's disease is a complex, chronic, and progressive neurological disorder with disparate symptoms that can include impaired motor function and balance, compromised bowel and bladder function, mood changes, and cognitive decline.<sup>1</sup> As many as 1 million Americans currently live with Parkinson's disease and more than 50 000 new cases of Parkinson's disease are diagnosed each year.<sup>2</sup> Persons with Parkinson's disease often are cared for at home by informal family caregivers, a role that can cause considerable strain on the caregiver.<sup>3</sup> Informal caregivers often have no training, and they find that the caregiving role requires a significant change in lifestyle. These caregivers are usually elderly spouses or adult children, and the caregiving role can be daunting.<sup>4,5</sup>

Parkinson's disease is incurable, and the unpredictability of symptom presentation and intensity, coupled with an uncertain disease course, can present unique challenges to family caregivers. Motor symptoms such as tremors, impaired balance,

and bradykinesia are common and often mean that the family caregiver must assist such a person with activities of daily living and hygiene. Difficulty swallowing and chewing mean the caregiver must be vigilant during meal times. Urinary and bowel problems may require attention on a daily basis, and fatigue complicates self-care. Sleep disorders in the person with Parkinson's disease may translate into sleep disruption for the caregiver. Nonmotor symptoms including pain, depression, and emotional lability and cognitive changes such as dementia add to the complexity and strain family caregivers experience caring for a person with Parkinson's disease.<sup>3,5,6</sup>

An overwhelming body of research indicates that family caregiving can have a negative impact on caregivers' health and well-being. Numerous studies demonstrate that caregivers experience poorer health and higher mortality rates than noncaregivers.<sup>3,6,7</sup> In addition, the work of caregiving can have a profoundly damaging effect on psychological well-being. A review of studies by Zarit<sup>8</sup> suggested that up to 70% of family caregivers have clinically significant symptoms of depression, with one-quarter to one-half of these caregivers meeting the criteria for major depression. Specifically, symptoms of depression, anxiety, and worsening health status of spousal and filial caregivers of persons with Parkinson's disease are common and greater than those symptoms present in the general population.<sup>9</sup> These affective disorders increase caregiver strain/burden, eventually impacting quality of life.<sup>9</sup> Emerging evidence indicates that social support of family caregivers can reduce caregiver

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strain.<sup>6,10</sup> Furthermore, a growing body of evidence shows that caregiver support can delay nursing home placement and reduce costs of care recipients.<sup>6,11</sup>

Despite widespread agreement that caregivers can benefit from support programs, there is little consensus on what programs are effective,<sup>6</sup> and a gap in the literature exists specifically concerning caregivers of persons with Parkinson's disease. A recently published study by Abendroth et al.<sup>10</sup> found caregiver support to be a crucial element that influenced strain of caregivers of persons with Parkinson's disease and impacted long-term care decision making.<sup>10</sup> The newly developed Parkinson's disease caregiving model proposed in the study illustrated conditions that affect caregiver strain and the triggers that led to institutionalization of persons with Parkinson's disease. As this grounded theory model was developed, the construct of caregiver support, specifically the necessity of a "support network," emerged as a core category in the findings. Subcategories of the support network included peer-led support groups as a valuable means of support.<sup>10</sup> This study explores the views and experiences of caregivers in peer-led support groups that were found to be instrumental in promoting health and well-being of caregivers of persons with Parkinson's disease.

## DATA COLLECTION AND ANALYSIS

After receiving institutional review board approval, participants were recruited using purposeful and snowball sampling techniques from a university-affiliated movement disorders clinic in the southeastern United States. This article reports on a subset of data from a larger qualitative study that explored family caregivers' experiences in caring for a relative with Parkinson's disease and factors

influencing long-term care decision making. The inclusion criteria for the study defined participants as adult men and women without cognitive impairment who were primary caregivers for persons with a diagnosis of Parkinson's disease. Twenty caregiver-care recipient dyads (N = 40) were enrolled in the study. Participant caregivers were predominately married, white, and female caregivers of spouses (see Tables 1 and 2).

In this study, a qualitative approach comprising face-to-face semistructured interviews with family caregivers of persons with Parkinson's disease was used. The interview questions were open-ended, allowing participants to relate their caregiving experiences. Examples of the questions included, "Who has been the most helpful to you during this time? Tell me how he or she has been helpful?" and "How have these groups been helpful?" Sampling and participant interviews continued until saturation was achieved and responses were repetitive with no new themes or categories identified. The findings were based on an analysis of caregivers' descriptions of their existing support networks.

The interviews were conducted over a 10-month period at locations selected by the participant, with each interview lasting 1 to 2 hours. The interviews were digitally recorded, transcribed verbatim, and de-identified for analysis. A grounded theory research method that included concurrent data collection and analysis<sup>12</sup> was used. The data were analyzed using dimensional analysis with NVivo 8 qualitative data management software (Version 8; QSR International Pty Ltd., Doncaster, Victoria, Australia). During dimensional analysis, the experiences of the participants were categorized into parts. The parts identified the subcategories that made up caregivers' experiences specific to support networks. The most important subcategories were identified through

**TABLE 1.** Demographic Characteristics of the Sample<sup>a</sup>

	All Subjects (N = 40)	Caregivers (n = 20)	Care Recipients (n = 20)
Age, mean (SD), y	66 (10.1)	64 (11.4)	69 (8.3)
Gender, female	22 (55)	17 (85)	5 (25)
Race, white	40 (100)	20 (100)	20 (100)
Education			
High school	16 (40)	9 (45)	7 (35)
College (2 and 4 y)	16 (40)	7 (35)	9 (45)
Graduate school	8 (20)	4 (20)	4 (20)

<sup>a</sup>The values given are number (percentages) unless stated otherwise.

**TABLE 2.** Demographic Characteristics of Caregivers<sup>a</sup>

Characteristic	
Relationship	
Spousal	17 (85)
Filial (adult daughter)	3 (15)
Work status	
Full-time	5 (25)
Retired	15 (75)
Marital status	
Married	15 (75)
Divorced	2 (10)
Widow/widower	3 (15)

<sup>a</sup>The values given are number (percentages).

clustering, memo writing, open coding, and focused coding.<sup>12,13</sup> Specifically, through this analysis, peer-led support groups were found to be important to caregivers of persons with Parkinson's disease.

Coding and analysis were conducted primarily by the researcher; however, meetings with other researchers versed in qualitative analysis were held both to confirm the interpretation of the findings and to certify that other categories were not overlooked. Scientific rigor was ensured through audit trails and substantive memos.<sup>14</sup>

## FINDINGS

### Sample characteristics

Twenty interviews were conducted with caregivers who had the option of having the person with Parkinson's disease present during the interview. Seventeen of the interviews were conducted only with caregivers, whereas the other 3 interviews were conducted with both caregivers and care recipients. The 3 interviews with the dyads were as follows: (a) caregiving wife–husband with Parkinson's disease; (b) caregiving husband–wife with Parkinson's disease; and (c) caregiving daughter–mother with Parkinson's disease. Seventeen caregivers were female, which is not unusual since the prevalence of Parkinson's disease is mainly in the male population.<sup>15</sup> The spousal caregivers (n = 17) were between 60 and 81 years of age, and the adult daughter caregivers were between 30 and 52 years of age. All persons self-identified as white non-Hispanic, and their education levels ranged from high school to graduate degrees. The majority of the families were retirees,

and household yearly income was greater than \$30 000 for all participants.

The length of time since Parkinson's disease diagnosis ranged from 3 to 23 years, with differing rates of symptom severity progression. For example, 2 persons with Parkinson's disease with a 10-year diagnosis history had greatly differing levels of symptoms. Overall, the persons with Parkinson's disease were at various points in their illness trajectory, ranging from mildly symptomatic to severely disabled.

### The support network

A strong support network, individualized for each family, was crucial for the family structure to survive as a caregiving unit and reduce the risk of caregiver strain. The multifaceted support network was a core category that included multiple informal and formal types of support. For some study participants, friends provided the needed empathy that some families were unable to provide, whereas professional caregivers provided specific services such as nursing care and rehabilitation counseling. Families and friends were present at all hours during a crisis, whereas organizations such as hospice strengthened the support network with professional holistic care. The value of support from many sources was noted by these 2 caregivers. They recommended drawing on one's connections from all parts of one's life and doing this as early as possible in the caregiving process.

I mean really get you a network going. Yeah, not one but a network of support, network [emphatic tone]. I'm talking about whether it's friends, family, community, doctors . . . Yeah, not one, but a network. I have friends here . . . the other couple in Michigan is my long distance support group. I can call them.

Don't wait too late to call for help. Set up your network of friends and family, times and for someone to come to relieve you. I think that [the network size] depends on your circle of friends. I had two daughters, and two good friends, and my wife was in a sorority.

### Peer-led support groups

The value of a caregiver support network highlighted, in particular, the role of peer-led support groups. These were informal gatherings providing support for families caring for persons with Parkinson's disease. The need for this type of group was apparent, as noted by this caregiver:

Nobody has taken on getting caretakers together on a regular basis. That has to happen [emphatic tone]. They have to have, I feel, they have to have a safe place that they can come and just sort of say, “Oh, he messed up all his meds today and he was so screwed up I didn’t know what to do.”

Another type of peer-led group described by a male caregiver was a couples’ support group unique to persons with Parkinson’s disease and their spouses. In this couples’ group, either the husband or wife had Parkinson’s disease. The group met every few weeks to share experiences, gain advice, and socialize.

It was clear that peer-led groups served as a type of “oasis” since they were safe environments in which to express fears and frustrations. Such oases provided a place to rest, express needs, and reenergize. The findings revealed 4 themes (illness uncertainty, broken connections, intimate connections, and a lifeline to other caregivers) that characterized the process of experiencing peer-led support groups (Figure).

### **Illness uncertainty**

Each person’s experience with Parkinson’s disease is unique because clinical presentation of symptoms and progression of the disease vary among individuals.<sup>16</sup> Persons with Parkinson’s disease have days that are unpredictable in nature, even when interventions are carried out appropriately. One caregiver reflected on these daily uncertainties while caring for her husband with Parkinson’s disease.

You can take your medications just exactly right, consistently; you will have two days that are terrible, three that are good, one that is terrible, two that are good. There is no consistency with Parkinson’s. Our

friends will tell you . . . you can go to eight out of ten of them [the friends]. They’ll tell you what I just told you; doesn’t matter. It’s [symptom progression] not predictable. And with my husband it may have been even more difficult because of the dementia.

Sharing experiences of such uncertainties related to Parkinson’s disease presentation and progression were important to the caregivers in the study. The unpredictable day-to-day symptom inconsistencies due to situations such as the effects of different new medications were an ongoing concern. Moreover, the manner in which the disease progresses can vary among persons with Parkinson’s disease. For example, severe cognitive deficits and hallucinations may be a part of disease progression for some but not all persons with Parkinson’s disease.<sup>17</sup> Some families were unprepared for such symptoms, as noted by this caregiver:

I didn’t know that delusions and dementia and all of this could be a part of Parkinson’s. When I quit reading, I hadn’t done that part of it. I was caught as off guard as could be because like I said, I guess I missed that part when I was reading on the Internet and I was dumbfounded.

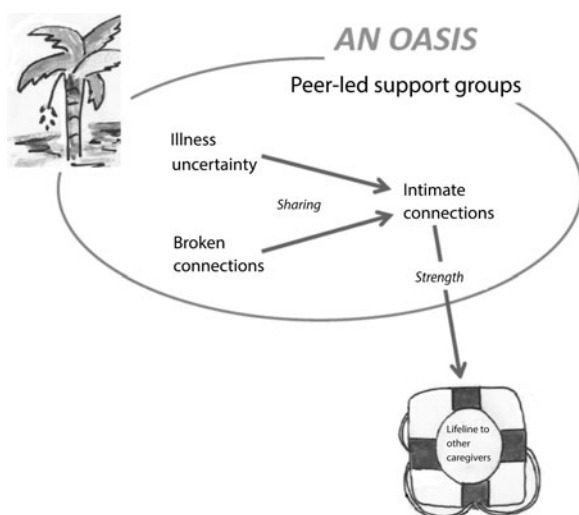
Not knowing the seriousness of disease progression also caused fear, especially when families attended general facilitator-led support groups consisting of caregivers and persons with Parkinson’s disease, as noted here:

We went to one of the support group meetings, and he [person with Parkinson’s disease] saw people shuffle in and he saw people in wheelchairs and those who were in a frozen state, and it alarmed him more than it helped him. So, we didn’t go back to any more of those meetings.

Caregivers talked about their fears of disease progression in smaller peer-led support groups. Being able to share such uncertainties and fears in a more intimate setting produced a safer environment (ie, an oasis) to express such feelings.

### **Broken connections**

The theme of broken connections signified relationships that became strained or nonexistent between caregivers and others outside the support group setting such as friends, family, and even health care providers. Listening to caregivers’ stories in peer-led group settings fostered a sense of validation and subsequent healing from these broken connections. These relationships were “broken” for various reasons that were fueled by a lack of clear



**FIGURE.** Oasis Schematic of Themes.

communication. For instance, caregivers thought that their friends no longer called because they felt helpless or fearful when they saw the person with Parkinson's disease fall down or exhibit symptoms of dementia, hallucinations, or obsessive-compulsive behavior. These broken connections led caregivers to have feelings of abandonment, especially if their friends were previously an integral part of their lives. A sense of isolation was present for this caregiver who felt she had no connection to others with similar experiences:

Nobody sees my husband's full condition. Nobody sees it. The children don't see it. Somebody just needs to stay with him a week or maybe 24 hours. I think they'd be shocked that he's lost so much of his abilities.

Another caregiver, despite having support from family and friends, still had feelings of abandonment, signifying a broken connection to the outside world, as he stated here:

. . . there will be a sense sometimes of loss, that you're lost and abandoned and really start feeling sorry for yourself, when you got clothes to wash and dishes to wash and your spouse or parent or whoever is calling you every two seconds.

Another type of broken connection existed between caregiving families and their adult children who had difficulty relating to the reality of their parents' declining health. Such caregivers spoke of their adult children as denying the realities of the illness, as shared by this caregiver:

Our kids really are deniers. They don't see that there is much wrong with [the person with Parkinson's disease] at all. If I ever say well you know dad has had some problems. "Oh it's just age mom, we all get like that." That's been real interesting, but you're always on top of your game when you are with your kids.

Broken connections also existed between caregiving families and health care providers. For example, one participant said that her health care providers did not see the importance of family-centered holistic care when receiving medical treatment as stated here. "Even doctors, primary care, they treat him, they treat me. I'm not so sure they really even know we're a couple." These types of broken connections placed added strain on caregivers, especially those caring for persons with advanced illness. Being able to share such frustrations and concerns in intimate peer-led support group settings served to validate and support caregivers.

### *Intimate connections*

The theme of intimate connections was defined as the shared relationship that caregivers had with one another in peer-led support groups. Such settings allowed caregivers to let their guard down. Relationships were built on trust and included opportunities to validate each other's feelings and experiences, as noted by this caregiver:

I do think it is like a sisterhood. I think we can all have empathy for each other and I think somebody said, unless you live with someone 24 hours a day, you don't know what they're like. And when she said that, the stories I've heard from the other women flashed back to me, and I thought that is so true . . . as sisters you both know, you understand . . . the caregiver group, I think is excellent, I think it gives us a chance to see sides of that person you may not see otherwise.

In addition, such intimate connections were fostered by a peer-led group consisting of spousal couples whose partners were at different stages of the illness. This tailored group provided strength for these families in unique ways, both as an outlet for social support and a source of valuable information, as expressed by this caregiver:

There's a group that got formed by a woman here in town whose husband is stricken [with Parkinson's], and he's further along than my wife. She wanted to set up a little dinner situation every couple months . . . One [spouse] of each of the five couples has the disease. This is like a support group thing that we do once every couple months. We're all in the same boat on this thing. I've developed a rapport with these people to an extent, and so it's a social event for me, and it's a support thing for her.

Some of the persons with Parkinson's disease in this group had undergone deep brain stimulation surgery, and this experience was shared with the other couples in the group who had thought about such an intervention for the persons with Parkinson's disease. The members of this intimate group provided important opportunities to learn about treatments and fostered support related to common experiences among the caregivers and persons with Parkinson's disease. As such types of intimate connections grew, caregivers realized the value of these peer-led support groups as stated here: "The people in that group seem to really care about each other. They're not just all concerned with what they're going through, but they really seem concerned with each other, to help each other."

The participants in the study found importance in tailored peer-led groups, especially for caregivers.

Over time, as connections strengthened, the caregivers talked about reaching out to others outside of the group.

### *Lifeline to other caregivers*

The fourth theme signified the outcome of participating in the peer-led support group experience. Specifically, the theme of lifeline to other caregivers exhibited a 2-fold perspective. First, it acknowledged the need caregivers placed on reaching out to others outside the peer-led group, and, second, it illustrated ways in which caregivers offered support to others outside the group. For instance, this caregiver identified how another person caring for someone with Parkinson's disease could benefit from becoming involved in peer-led support groups:

And she really needs help, and I would like to see her get more involved with the group if possible . . . It's not easy for her to get away. And she has her mother living with her, so she can leave her husband [with Parkinson's disease]. If she's not working, she can leave, but there are a lot of people out there, and you would like to see them become a part of the group. Because you know it could be helpful to them, probably could be helpful to them.

Several caregivers who were in peer-led groups realized the importance of reaching out to others, particularly those who neglected their own needs, as noted by this caregiver:

I see caregivers that themselves need to be cared for. Maybe they have stress, maybe they have depression, maybe they have whatever, but they almost need a caregiver themselves, they're not in a condition to be a good caregiver.

Caregivers also felt that respite, even for a short period of time, was essential for health and well-being. Members of peer-led groups had opportunities to become more closely connected over time and felt the need to offer assistance to others needing time away from their caregiving responsibilities. The following caregiver suggested ways to provide respite for families in need: "You can have somebody bring them [persons with Parkinson's disease] meals, you can have somebody take them for a walk, you can have somebody play checkers with them, and you can have someone see that they get their medications . . ."

Members of one of the peer-led support group also identified ways to enhance support group meetings with informational sessions for caregiving families about practical matters. One caregiver suggested inviting speakers to the group who were

knowledgeable in areas such as finance and disability insurance coverage, as reflected here:

I know we have people in our support group system that are still working and have families still at home, and I think those people need to understand what are some of the problems involved with getting disability . . . They [caregiving families] need to find out about that, learn about it.

Reaching out to others was an important way for caregivers to bring others into a community of supports since it was a rich environment of empathy and caring that could strengthen and validate their similar struggles. Caregivers in these support groups realized the value of empowering other caregivers to help themselves face the challenges and uncertainties of illness progression in Parkinson's disease.

## DISCUSSION

Caregivers of persons with Parkinson's disease are unique among caregivers in that they face a wide variety of symptoms that range from unsteady gait, constipation, and difficulty swallowing to hallucinations and dementia. Furthermore, the incurable nature and uncertain progression of Parkinson's complicate both caregiving and care planning. The distinctive challenges faced by this set of caregivers truly necessitate research on tailored approaches to support.

This qualitative study found that peer-led support was significant and provided an oasis (ie, a safe restful haven) for these caregivers. Within this oasis, the caregivers realized they shared a common situation, which was the experience of uncertainty of illness. Not only was the course of Parkinson's disease progression unknown but also daily caregiving experiences often were varied, ranging from a quiet day adhering to the medication schedule to a chaotic day seeing the person with Parkinson's disease experience labile emotions, freezing gait, and numerous falls.

The caregivers in the support groups began sharing stories of broken connections they had with family and friends who had difficulty relating to these caregiving families and in some cases abandoned them. Caregivers realized this was a common problem and expressed feeling validated in the safe environment of the peer-led support group. Over time, the caregivers developed intimate connections by sharing similar experiences. Caregivers believed that caring for persons with Parkinson's disease is a



process and that the social support and positive healing energy within these groups were valuable.

As caregivers became reenergized in this oasis-like environment, they felt strengthened to reach out to others experiencing the strain of caring for persons with Parkinson's disease. This sentiment was reflected by this caregiver, "The people in the group seem to really care about each other. They're not just all concerned with what they are going through . . ." This outcome illustrated a support group strategy that could promote self-sustaining social support and possibly reduce or prevent caregiver strain among this vulnerable population.

Reducing strain in family caregivers of persons with Parkinson's disease may positively impact the health and well-being of caregivers as well as delay nursing home placement and reduce health care costs for care recipients, making caregiver support a priority. Nurses are uniquely positioned to promote holistic care of patients with Parkinson's disease and their caregivers by including the family caregiver in education and suggesting support strategies accentuating health and healing rather than focusing on the disease process. Encouragement of peer-led support for this group of caregivers may be an effective strategy for nurses to propose. Nurses might facilitate the development of peer-led support groups by promoting them to caregivers, suggesting meeting spaces, providing refreshments, and advertising meeting times.

Further research on the unique needs of caregivers of persons with Parkinson's disease and tailored strategies to support them is needed. Research on the impact of peer-led support groups for caregivers of persons with Parkinson's disease is crucial to validate and enhance the findings of this qualitative study.

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