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The self-management balancing act of spousal care partners in the case of Parkinson's disease

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Abstract

Background: Living with and caring for someone with chronic illness can lead to limitations in activity and social participation for the care partner. Past research emphasizes the importance of care partners taking care of themselves physically and emotionally so they can stay healthy to support the care recipient. There is little information regarding how the care partner takes care of their own social lives. The purpose of this study was to explore the concept of social self-management from the perspective of spousal care partners of people with Parkinson's disease.

Method: Twenty spousal care partners of people with Parkinson's disease were interviewed three times. A grounded theory approach informed data analysis.

Results: Findings that emerged from the data focused on balance in activities, support, and emotions and were summarized into three main themes: 1) Activities: Caregiving and beyond; 2) Strategies to support self and spouse; and 3) Emotional impact: Burden and compassion.

Conclusion: This research shows that care partners want to retain social participation and provides support for the importance of addressing the socio-emotional needs of care partners of people with a chronic disease. Interventions that guide care partners to take care of their spectrum of needs may lead to healthier, positive relationships.

Keywords

social participation; self-management; spouse caregiver; qualitative research methods; Parkinson's disease

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Declaration of Interest

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Introduction

Human beings are social beings and most of the things we do each day involve social activities. Even when engaging in a task in isolation, such as cooking or writing, it is often to engage with others (e.g., eating with others, communicating with others). Social participation has been linked to health and quality of life among older adults with and without chronic disease [1, 2, 3]. Chronic illness, however, impacts activity and social participation, leading to decreased well-being and quality of life [4]. Self-management interventions for chronic illness in older adults are becoming prevalent as they empower people to take charge of their health, improve quality of life and self-reported health, and decrease health care costs [5]. These interventions typically focus on managing physical factors, for example managing diet or engaging in exercise routines. Despite evidence supporting the importance of activity and social participation for health and well-being, self-management interventions rarely address how individuals manage their own social lives.

Tickle-Degnen et al. [6, p.3] propose the concept of social self-management as, “social participation and management of social activities, informal and formal social networks, and social comfort and overall health and well-being”. They operationalize social self-management to include relationship-building, engaging in social activity, and proactively seeking help as needed. Social self-management provides a lens through which to understand activity participation of older adults with chronic illness and, as importantly, their care partners.

Family care partners provide the foundation of caregiving for many people with chronic illness. While many people speak of family members as caregivers, Miller & Zook [7] initiated the use of the term care partner to focus on the shared features of the relationship. One in five family care partners caring for someone with a chronic illness or disability are a spouse [8] and, compared to nonspousal family care partners, are less likely to receive support from family, friends, and home care aides. Spousal care partners report that their caregiver tasks limit the time they have for themselves [8]. Because of the intimate and often long-standing nature of the relationship, spousal care partners present a unique and important perspective on caregiver self-management.

Evidence suggests that community-based group interventions designed specifically to address the needs of care partners of individuals with chronic disease may be effective in improving care partners’ self-care, self-efficacy, and caregiving experience [9, 10, 11]. These studies, however, primarily focus on strategies to support caregiving and rarely address how care partners manage their own social lives. Care partners may limit their own participation in social activities due to guilt or fear of leaving their partner alone, fatigue from caregiving responsibilities, financial changes, or alteration in daily routines [12].

The life experiences of spouses of individuals with Parkinson’s disease (PD) serve as a paradigm through which to understand social self-management. Close to one million people in the United States are living with PD, a progressive neurodegenerative condition characterized by motor and non-motor symptoms that can impact an individual’s ability to engage in daily activities [13,14]. PD affects the entire family unit. Many people with PD

live in the community, where family members are responsible as the informal caregivers [15].

The person with PD experiences biopsychosocial symptoms, including but not limited to depression, fatigue, cognitive changes, and facial masking that can influence the relationship with the care partner and perceived quality of life for the care partner [17,18]. There is a small body of literature that focuses on spouses of people with PD and on their changed routines, increased responsibilities, and decreased social participation. Spouses play a valuable role in supporting people with PD in participating in daily activities [18,19]. Habermann [20] found that one way spouses coped was by maintaining their own lives, routines, and social connections. Other research shows that care partners often give up participation in valued activities as they take on increased responsibility [18].

In a phenomenological study of 10 couples, where one partner was living with PD, researchers found that although couples figure out strategies to use to reach their goals, they realize they need additional outside support [21]. Wressle et al. [22] interviewed relatives of people with PD in Sweden, asking about how PD affected their daily activities and health. They synthesized the data into aggravating and facilitating factors that influence the caregiving role. Aggravating factors included taking on new responsibilities, decreasing socialization, changing habits to accommodate needs of their family member, and worrying about the future; facilitating factors related to accessibility to health care, available psychosocial support from family and friends, and positive coping strategies. Although some strategies to support health and social participation for care partners of people with PD have emerged in the literature, current evidence does not provide a complete picture of care partner participation in meaningful activities or specific self-management strategies care partners use to stay socially engaged.

The purpose of this study is to explore the concept of social self-management and to understand, from the perspective of spousal care partners of people with PD: 1) the daily activity and social experiences of the care partner; 2) the benefits and challenges of caregiving; and 3) the interrelationship between the care partner's ability to care for themselves and care for their partner with PD.

Methods

This paper draws on data from a mixed-method prospective cohort study, *Emergence and Evolution of Social Self-Management of Parkinson's Disease* [6], that follows the lives of 90 people with PD and their care partners over three years, exploring how social activities, relationships, and health change over time. Fifty six of the participants with PD had a care partner in this study. Participants were recruited primarily through PD movement disorder clinics and PD support groups from the Boston, Massachusetts area and surrounding communities. Face to face interviews were conducted at baseline and every 6 months thereafter and lasted approximately two hours in duration. Trained research assistants, supervised by the principal investigator (author LTD), conducted the interviews and collected quantitative and qualitative data via interview and surveys that focused on activity participation, social support, and quality of life. Participants with PD and care partners were

interviewed on the same day, in separate rooms by different trained interviewers, using a standardized mixed method protocol, described in detail elsewhere [6]. Parallel questionnaires were used to assess both the person with PD and the care partners' daily life activities, health and quality of life. All procedures and measures were approved by the Tufts University (#1212038) and Boston University Medical Center (#H-32114) Institutional Review Boards. This current study analyzed a subset of data from the larger study, specifically, care partner interview transcripts regarding frustrating and satisfying activities from the baseline, 6 month and one year interviews.

Participants

We used purposeful sampling to select interview transcripts of care partner. Only spousal care partners were included. This was because 99% of care partners in this study were spouses and the care partnering experience may vary if someone is an adult child, other family member, or friend. We included both husband and wife care partners between 60–80 years old. To understand the full range of the care partnering experience, we included care partners whose spouse's condition varied in severity, as determined by their baseline stage on the Hoehn and Yahr scale and their baseline total Movement Disorder Society-Unified Parkinson's Disease Rating Scale scores [23].

This sample of care partners included 12 women and 8 men, all in heterosexual marriages, Caucasian, and with at least a high school diploma. The mean ages of the care partners and their spouses were similar, 67 and 68 respectively. At baseline, the majority of the people with PD were at stage 2 of the modified Hoehn and Yahr scale while their total Movement Disorder Society-Unified Parkinson's Disease Rating Scale scores ranged from 22 to 102 (see table 1). Written consent was obtained from all participants prior to baseline data collection. All names are pseudonyms to protect confidentiality.

Data collection and analysis

Data from the 20 care partners, which included interviews from three time points for 18 participants and two time points for two participants (one participant died, another did not respond to phone calls), were analyzed (total of 58 interview transcripts). We began analyzing transcripts from 15 participants, but because additional codes continued to emerge, we analyzed additional transcripts. Saturation occurred at the end of the analysis of the data from 20 participants. Semi-structured face-to-face interviews were conducted at baseline, six months, and one year. Open ended questions were asked which provided individuals with an opportunity to reflect on feelings about daily activities [24,25]. Care partners were asked to describe a recent frustrating or challenging activity they engaged in over the past week with prompts about what was challenging and if anything they did made it less challenging. They were then asked to describe a recent satisfying or enjoyable activity they engaged in over the past week, with prompts to discuss what made it enjoyable (see table 2). Interviews were audio-recorded, transcribed verbatim via a transcription service, and checked for accuracy by research assistants. Transcripts were imported into NVivo 10, a qualitative data management program.

Qualitative methods, informed by a grounded theory approach, were used to analyze the data. Grounded theory, originated from work by Glaser and Strauss [26] uses data to guide theory development. A key aspect of this method focuses on the researcher being open to what emerges from the data and using an iterative and comparative process [27]. The development of the construct of social self-management [6], specifically for care partnering, was guided by these aspects of a grounded theory approach to data analysis.

Two researchers performed all data analysis (authors SB and TC). Each transcript was coded by the researchers separately. Transcripts were initially read through at least once in their entirety to grasp the care partners' experience as a whole. Following this, open coding was completed on five transcripts using a line-by-line review to identify and label emerging concepts. The two researchers then met to discuss their codes and review similarities and differences. An initial coding manual was developed based on these discussions. The rest of the transcripts were then read and coded line-by-line. The coding manual functioned as a living document to provide consistency on defining each code and was updated throughout when new codes emerged (see table 3). All transcripts were again reviewed line-by-line, this time focusing solely on the portion that addressed caregiving activities and experiences, identifying additional labels, as appropriate. Axial coding followed, identifying the relationships between the initial codes by combining the many line-by-line codes into more focused coding. Finally, theoretical coding occurred where all established codes were related to determine final themes. A process log was used to record all changes made throughout the course of study. Annotations were created to initiate discussions when inconsistencies or clarification in coding occurred. The researchers then reviewed these sections together and recoded transcripts as appropriate. As the researchers who completed the data analysis did not perform the interviews, several meetings were held with the interviewers for triangulation to discuss if the meaning of the data were captured.

We planned on analyzing data by grouping the care partners based on the Hoehn & Yahr disease stage of their spouse but were unable to do this because several of the spouses had different Hoehn & Yahr ratings during the different time points. Subsequently, we used disease severity measures to characterize individuals within the sample. We also looked at the data based on gender and interview time period, but no patterns emerged. Therefore, we primarily analyzed the data as one cohort.

Results

The findings focused on balance: balancing activities, balancing support, and balancing emotions. These findings were summarized into three main themes: 1) Activities: Caregiving and beyond; 2) Strategies to support self and spouse; and 3) Emotional impact: Burden and compassion. Subthemes are listed in table 4.

Activities: Caregiving and beyond

Care partners engaged in many instrumental activities of daily living, including driving, housekeeping, and caregiving, but also shared stories about their leisure, social, and work activities. Two activity sub-themes emerged that we called: 1) changes in roles and activities; and 2) there's more to life than caregiving.

Changes in roles and activities—Due to limitations in some abilities of the spouses with PD, care partners took on additional activities, including household tasks. Most of the stories about these additional daily tasks emerged during the conversation regarding a frustrating activity.

Care partners expressed frustration regarding the time and effort it took their spouse to complete household tasks and ten of the care partners interviewed spoke about taking on these tasks themselves. Hannah's husband was diagnosed with PD about 10 years ago but recently, the changes from PD have limited his ability to do many activities. Hannah stated, "...a lot of the tasks, I've taken over entirely...the house, driving, shopping, most everything, I've done just because it's too difficult for him."

Taking on additional roles and activities, letting go of other roles and activities, and the balance between these two are clearly intertwined. Anne, a health care worker whose husband was diagnosed a little more than 8 years ago, discussed taking on new roles and activities. This required a transition for her in other roles not related to caregiving. In her first narrative about a challenging activity, Anne commented, "Part of my frustration is that I now have to take care of things that he once did. So, that's part of why I started treating less patients. Because I need more patience."

Along with an increase in instrumental activities of daily living, care partners struggled to continue to engage in many of their leisure pursuits. Carl, a 70 year old man, lives with his wife who has advanced PD. He spoke about the change in relationships with friends. "When push comes to shove, even with close friends...we probably have less involvement with them than we've had in the past." Even when they do see friends, it is rarely easy and not always enjoyable:

I was really looking forward to being with him [a friend] and having an enjoyable lunch. Well, [wife's name], just as we sat down, dyskinesia...it happened to her throughout her entire lunch. It made it very uncomfortable for her, and I'm sure, made it uncomfortable for my friend and his wife. That was difficult to watch...she was really struggling, it was tough for her to even [eat], when that happens, food gets all over her, and it gets to be embarrassing. It was difficult for her, and it just broke my heart.

Carl and his wife's story exemplifies the challenge of maintaining social roles while living with and caring for someone with PD. He struggles with the balance between staying socially engaged while providing safe and comfortable environments for his wife.

There's more to life than caregiving—In response to the questions related to a frustrating and satisfying activity, 26 of the 58 transcripts didn't refer to caregiving at all, but rather focused on other frustrating and satisfying activities. Three participants didn't speak of caregiving at any of the three interview time points, six people spoke of caregiving at one time point, and five people spoke of caregiving at two time points. Only six people spoke of caregiving at each time point. It is worth noting that those whose spouse had a higher UPDRS score (55–102) appeared to speak a bit more about caregiving than those whose spouse had a lower UPDRS score (22–54; see table 5).

The balance between caregiving and other activities (e.g., work, leisure) was evident in the many activities that emerged from the data. Frank is a 71 year old male whose wife was diagnosed with PD 4 ½ years ago. Throughout his narratives, he does not mention caregiving or PD, but instead focuses on his art. His narratives revolve around this work and frustrations from participating in this activity while coping with changes in his own health due to arthritis. During his baseline interview, Frank states,

I spend a lot of time on it and the more that I get into it, the more it comes together...it's been a lot of fun and I feel very confident that – I'm hoping my health will hold up long enough that I can actually put some of these pieces in a gallery.

When Frank mentioned his wife, he did not mention her Parkinson's, but instead discussed her help with his art. He commented, "I was very, very pleased with the way they came out and [Wife's name] does help me out. She's quite creative, so she always – we always work off each other that way."

While Frank was able to focus on his art, and others did not speak about caregiving, many of the participants, including Hannah, Anne, and Carl continue to work at finding the balance between engaging in their own leisure, social, and productive activities while caring for their partner.

Strategies to support self and spouse

Care partners' stories addressed the tenuous balance between caring for a spouse and caring for oneself. Both of these concepts are closely entangled, as caring for oneself can be more challenging when a spouse requires more care. Within caregiving, the balance between supporting independence and embracing dependence also emerged. We categorized the strategies used into three subthemes: 1) Self-management strategies: Strategies to help me; 2) Caregiving strategies: Strategies to help my spouse; and 3) The interrelationship between self-management and caregiving strategies.

Self-management strategies: Strategies to help me—Care partners use many self-management strategies which help them cope with the responsibility of caregiving, including staying connected with family and friends, implementing coping strategies, planning ahead, and using formal and informal supports. Several participants spoke about the importance of participating in social activities as a way to cope with the stress and responsibility of caring for their spouse. Marilyn, whose husband was diagnosed with PD about 32 years ago, spoke about spending time with family. "I got to watching my grandson. And that's enjoyable to me...It lightens – it makes me stop thinking about Parkinson's." She also mentioned coping strategies such as using positive self-talk, employing visualization techniques, and keeping a positive attitude. For example, Marilyn's husband has hallucinations that are challenging for Marilyn to understand. She commented that when this occurs she will "think about something a little more calming and everything...like springtime or something like that."

Although care partners spoke of many strategies to conserve energy, such as organization and routines, the most common energy conservation strategy used was planning ahead. Nine care partners emphasized the importance of planning ahead. For example, one care partner

described how he and his wife use a calendar and plan a week in advance. Another care partner explained how they modified their home, installing technology which may be needed in the future.

Anne, the health care worker who cut back her work hours, explained how she has prioritized activities to ensure that she stays engaged in activities she values and believes are important to her health and well-being.

I'm not very good at cutting out time for myself and I have to do it first thing in the morning or my day goes to heck in a hand basket...it's very empowering to take care of yourself first thing, and then, once you've taken care of yourself, then you can take care of all the many disasters that we face every day.

Anne again referred to the importance of doing things for her own well-being when she stated, "I love taking [name of dog] for walks and runs, and I've been trying to take her for some really nice walks. Because it's not just her. It's for me, too."

Finally, asking for help from others, including both formal and informal supports, is a strategy all care partners used. Formal support was received from a variety of service providers, ranging from health care providers to house cleaners. For example, Gladys, a 69 year-old woman whose husband was diagnosed almost 7 years ago, took advantage of services at the airport and laughed as she explained "...he was in a wheelchair, which we've learned to do at the airport. So the wheelchair driver was great and I was running right along".

All participants spoke of the importance of their informal support network, their family and friends. During the initial interview, Gladys spoke of her family.

...my daughters both live in [local city]. They've been great as far as helping. One daughter tries to come in once a week and that gives me a peace of mind to go off and volunteer at the hospital.

Hannah, who spoke about her husband's struggle to do many tasks around the house, also shared stories about the importance of emotional support when she stated, "...to have your loved ones around you, I think, is so important, you know, for me, it's emotional support on one side, and for him, it's also emotional support".

Caregiving strategies: Strategies to help my spouse—Care partners provide their spouses with physical assistance, verbal cues, and emotional support. Although only a few spouses required help with activities of daily living, more than half of the care partners provided physical support in their role as a chauffeur, as their partner was no longer driving. Care partners also reported providing verbal cues and encouragement for a variety of tasks. Elizabeth's husband is 65 years old and living with significant challenges due to his PD. Elizabeth spoke of the myriad of verbal cues she provides for her husband. "...I have to say, get out of the car, put your foot down, pick up the cane, leave the coffee, I'll get that, just put your feet out...I don't touch him. I just say something."

Care partners often provided much needed emotional support. Carl, who spoke about his wife's dyskinesia during lunch with friends, had encouraged his wife to go out to lunch that day. He stated, "...I assured her that these people understood, they're very fine people, and they would empathize with her..."

The interrelationship between self-management and caregiving strategies—

Balancing the needs of one's spouse with one's own needs can be challenging. Many participants spoke of both caregiving strategies and self-management strategies together, as they were often intertwined. The combination of these strategies supported their ability to stay socially engaged. Gladys, the care partner who spoke about traveling with her husband and using the wheelchair services, discussed her husband's need for assistance.

I think there's a fine line between doing things for him and standing back and saying he has to do this for himself. Sometimes when I do that, I feel guilty. Because it would be so much easier for me to get up and get him something...but I don't want him to be completely dependent.

Gladys' story demonstrates the compromises one makes between helping and not helping, supporting independence and allowing dependence, and taking care of oneself while taking care of one's spouse. Strategies for caregiving and self-management also emerged throughout Gladys' narratives.

As long as he stays home safely. I also have a book club, so I can go to my book club once a month. I don't go out as often with friends for lunch and things, because number one, we're running to the doctor's or the physical therapist, and number two, I feel badly leaving him home while I go out to eat. I do it. I know, I realize it's important for me to maintain that contact with my friends.

Later she continued to discuss this balance between caring for her husband and caring for herself.

I'm very well aware that I need to keep myself healthy and well in order to be a support for [spouse], so I make sure that I do that, keeping in mind that I need to make sure he's safe [first].

Many care partners spoke of the changes in dynamics of their relationship due to changes related to PD. This contributed to a desire to reconcile role changes occurring for their partners due to PD with an image of their partners before PD. Care partners, in the context of the loss of their partners' independence, used strategies to make their partners continue to feel productive that may compromise safety. Fran, whose husband was diagnosed with PD about 2 years before the study, discussed her struggles around supporting her husband's independence while still supporting his safety as his orthostatic hypotension worsened. She described a particularly frustrating incident when her husband fell off of a picnic table. Fran articulated her struggle between a desire to keep her husband safe while also supporting his desire to engage in activities that are meaningful to him and his sense of independence.

[Name of husband] decided he was going to scrape a window, which he shouldn't have done, and I tried to tell him that, and then...he put a chair up on the picnic table so that in case he felt dizzy, he could sit on that awhile...Anyway, I just didn't

have a good feeling about it, but I just told him about it as much as I could, and he was determined. So I thought, well, I can't tell him everything, because he's given up driving and certain things he doesn't do anymore...I went to go to the bathroom and I heard a noise...the chair that he was going to rest on had fallen off the table, and he was just lying there...So I said, "Are you OK?" And he said, "Oh yeah, I'm fine"...I said, "Good, then that's it," and I went out and I picked up all the tools. At first, I helped him up, I did do that. And I said, "That's it, this is stupid."

A similar theme emerged when Gladys described her husband's health conditions in addition to PD. Gladys's husband is pre-diabetic, but she worries that taking steps to manage his diet for him may further decrease his sense of self and independence.

The doctor said to him, "you're eating too much sugar, you're pre-diabetic". And then he doesn't want to change. And it's frustrating, because what is it gonna be like for him if he has diabetes and Parkinson's? And yet, at the same time, I feel, this poor guy, he's lost so much, you're going to take something that he enjoys, that piece of chocolate or whatever, away from him?...Well, when he wants that dish of ice cream, and it's like, you know, you shouldn't have it...I don't get it for him. I make him get it himself. So it's a little bit – if he really wants it, he's got to move for it.

Gladys spoke of the change in the dynamics of their relationship. She struggled to reconcile the changes that occurred due to PD with her image of her husband before PD. Some of the strategies she used to support her husband also served as a means to support herself in her role as care partner. "It's just dealing with Parkinson's, and trying to separate the [spouse] that I know, and knew, before Parkinson's, to try to empathize with what he is going through..."

Charles, a 62 year old family man whose wife has been living with PD for four years, succinctly sums up the interrelationship of caring for oneself while caring for a spouse when he states, "So it's what she does for me and what I do for her. That's what we do."

Emotional impact: Burden and compassion

The care partners often spoke about the emotional impact of caring for a spouse with PD. Eleven care partners spoke of the burden of caregiving. Sometimes this was due to the extra activities and responsibility the care partner needed to do, such as additional instrumental activities of daily living, discussed earlier. Other times, the burden was related to how it influenced the care partners' ability to engage in leisure and social activities. One care partner, Robert, stated, "It feels good to take a little time [for oneself], but it is a little time, because I'm always thinking about getting home..."

On the other hand, care partners also spoke about their compassion for their spouse and nine spoke of being content when their spouse was happy. For example, Elizabeth said, "...[he's] committed to doing it [de-cluttering the house], so we're doing it. It's important to him, so it's important to me."

Most often, however, both burden and compassion were inseparable. This was clearly the case for Fran, who spoke about the time her husband fell off the picnic table. She spoke of compassion for her husband giving up many valued activities but at the same time she was challenged and frustrated by the additional work this caused her.

Giving up driving, that was a big thing...I know he misses that... because he used to just do small trips, like, he'd go get gas or pay a bill, or something, but he doesn't do that anymore...I know he feels bad when he has to ask me. He's constantly saying he's sorry and I'm saying, you don't have to do that.

At the end of the interview she reflected on her experience.

I used to feel bad for myself...but I thought, it could be so many other things, so I started, it's him I should be worried about, and so, that's it, once you lose it, it seems like it's a big change, but once you resign yourself to the fact that's the way it is, it may get better, I mean, not completely better, but it could be a heck of a lot worse.

Discussion

Care partners in this study articulated the challenges of social participation and the strategies they used to manage these challenges in many of their daily activities. Participants expressed difficulty in finding a balance between engaging in social, leisure, and productive activities and instrumental activities of daily living. They spoke of strategies they used to care for themselves and strategies they used to care for their partner. It appears that social self-management for care partners of people with PD involves taking care of one's spouse and taking care of oneself and the balance between both of these tasks.

The dyad of the care partner and the person with PD involved double self-management. They each managed their own lives and this influenced how they managed their lives together. People with PD are often living with other age related medical conditions such as diabetes, hypertension, and sleep apnea [28]. The care partners in our study and their spouses were often both dealing with comorbidities associated with increased age and these factors also influenced their life balance. This balance is dynamic and can change day to day.

Matuska and Christiansen [29] propose a Life Balance model that looks at the relationship between amount and type of activity participation. The data from the current study show the challenges of maintaining balance from the perspective of a care partner of a spouse living with a chronic disease. We propose an understanding of life balance integrated with social self-management. Three key factors influence life balance while caring for a person with PD: activity participation, strategy use, and emotional impact. These factors are not easily separated. For example, some self-management strategies include activity participation such as taking the dog for a walk, while at times emotions influence activity participation (e.g., a care partner's compassion led him to cut short a social event to decrease his partner's struggle).

It is clear that maintaining balance while caring for a person with a chronic disease can be challenging. This balance is tenuous and ever changing, depending on many outside factors, such as doctor's appointments or other commitments, and unexpected circumstances, such as bad weather or a fall. It takes an extraordinary amount of effort to manage the many aspects of caregiving, and this effort can influence the mental and physical health of the care partner. Helping the care partner manage their social lives appears to be one way to facilitate health and foster a positive relationship.

Although there were many similar comments from different participants, it was evident from the data of these 20 spousal care partners that the experience of living with a person with a chronic disease is individualized. The stories shared and activity participation discussed varied greatly. The care partner's ability to engage in activities of choice and stay socially connected depended on individual and contextual factors, such as their support system, own medical history, and past experiences. Care partners spoke of many strategies they used to support their spouse and self-care strategies they used to support themselves. Just as the activity is individualized, so too is the strategy used to stay engaged in the activity.

Similar to previous research regarding activity engagement of care partners living with people with PD [17,30], we found that care partners take on new roles, such as driving and home management tasks, and to do so they give up some of their valued leisure and social activities. But while much of the literature of care partners focuses on the burden [31,32], the stories the participants shared expressed compassion, as well. The care partners we interviewed spoke about their life beyond caregiving along with their caregiving role. These varied emotions and experiences changed depending on the time, the activity, and outside influences.

Social self-management or taking care of oneself socially appears to be one way to decrease emotional burden of the care partner. Being a care partner for a loved one is often a stressful situation [33] but this study reinforces the literature regarding stress buffers such as doing things with family and friends [34]. Engaging in leisure and social activities also appears to be a strategy to achieve balance, although doing so was at times challenging for the participants in this study. Increased support by paid and unpaid help (including housekeeping services, transportation services, and respite care) may help care partners lead a more balanced life, supporting them to stay healthy mentally and physically so they can continue to support their spouse.

Future research using data from the larger study will try to quantitatively group people with PD and their care partners according to their self-management strategies, exploring which self-management strategies work best for which people and as a combination, for which dyad. Because of the longitudinal nature of this study, future research can explore social self-management from the perspective of the person with PD as this will enable us to better understand the relationship of the dyad and how their social lives are separate and combined. Using a mixed-method case study approach to analyze data from the larger study, we can also delve deeper into the lives of care partners of people with PD to more fully understand this balance/imbalance.

There are several limitations to this study. Data collected may not be representative of all spousal care partners of people with PD. This study had very little diversity as all individuals were white, educated and living in the United States, specifically in Boston, Massachusetts and surrounding communities. Lack of racial and ethnic diversity is a common challenge for recruitment in PD research [35]. Another factor that may influence generalization is that care partners who volunteered to participate in this study may be different than the general population of care partners. It is possible that care partners who feel burdened choose not to participate in research. Despite the homogeneity of the sample and the volunteer bias, the spouses of the care partners we studied varied in terms of disease duration and both motor and non-motor symptoms of PD.

Another potential limitation of this study is that the questions posed during the interview did not specifically ask about caregiving. People spoke about activities that were central to their life the day they were interviewed. The data provide information about the social lives of care partners of people with PD based only on a snapshot of three time periods. However, this way of questioning provided a strategy to understand what was on the minds of the care partners, rather than leading them to talk about caregiving, Parkinson's disease, or even health. The richness of the interviews and variability of the topics discussed provided insight into the lives of spouses of people with PD.

This research provides support for the importance of addressing the needs of spousal care partners. Because the challenges of PD specifically, and chronic illness in general, are shared by family, we must remember to include the care partner in intervention. The experience of caring for someone with a chronic disease is individualized, therefore, a person-centered approach to intervention is key. Past research emphasizes the importance of care partners taking care of themselves physically and emotionally so they can stay healthy to support the care recipient [9,10,11]. We argue beyond that, care partners need to stay socially healthy. Interventions that guide care partners to take care of their physical, emotional, and social needs may lead to healthier, positive relationships.

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References

1. Paggi ME, Jopp D, Hertzog C. The importance of leisure activities in the relationship between physical health and well-being in a life span sample. *Gerontology*. 2016;62:450–458. [PubMed: 26974682]
2. Vozikaki M, Linardakis M, Micheli K, et al. Activity participation and well-being among European adults aged 65 years and older. *Soc Indic Res*. 2017;131:769–795.
3. Levasseur M, Desrosiers J, St-Cry Tribble D. Subjective quality-of-life predictors for older adults with physical disabilities. *Am J Phys Med Rehabil*. 2008;87(10):830–841. [PubMed: 18806510]
4. Bailly F, Flotz V, Rozenberg S, Fautrel B, Gossec L. The impact of chronic low back pain is partly related to loss of social role: a qualitative study. *Joint Bone Spine*. 2015; 82(6):437–441. [PubMed: 26431929]

5. Ory MG, Ahn S, Jiang L, et al. Successes of a national study of the Chronic Disease Self-Management Program: meeting the triple aim of health care reform. *Med Care*. 2013; 51(11):992–998. [PubMed: 24113813]
6. Tickle-Degnen L, Saint-Hilaire M, Thomas CA, et al. Emergence and evolution of social self-management of Parkinson's disease: study protocol for a 3-year prospective cohort study. *BMC Neurol*. 2014;14:95. [PubMed: 24885181]
7. Miller K, Zook EG. Care partners for persons with AIDS: implications for health communication. *J Appl Commun Res*. 1997;25:57–74.
8. Reinhard S, Levine C, Samis S. Family caregivers providing complex chronic care to their spouses. Washington, DC: AARP Public Policy Institute; 2014.
9. Hutchinson SL, Doble S, Warner G, et al. Lessons learned from Take Care: a brief leisure education intervention for caregivers. *Ther Recreation J*. 2011;45(2):121–134.
10. Won CW, Fitts SS, Favaro S, et al. Community-based 'powerful tools' intervention enhances health of caregivers. *Arch of Gerontol Geriatr*. 2008;46(1):89–100. [PubMed: 17467080]
11. Yesufu-Udechuku A, Harrison B, Mayo-Wilson E, et al. Interventions to improve the experience of caring for people with severe mental illness: systematic review and meta-analysis. *Br J Psychiatry*. 2015;206(4):268–274. doi:10.1192/bjp.bp.114.147561 [PubMed: 25833867]
12. Keefe J, Hawkins G, Fancey P. A portrait of unpaid care in Nova Scotia. Halifax (NS): 2006 Available from http://caregiversns.org/images/uploads/ACEWH_hbrp_portrait_unpaid_care_NS.pdf
13. Chaudhuri KR, Odin P, Antonini A, et al. Parkinson's disease: the non-motor issues. *Parkinsonism Relat Disord*. 2011;17:717–723. [PubMed: 21741874]
14. Parkinson's Disease Foundation: Statistics on Parkinson's [Internet]. New York (NY); 2017. Available from http://www.pdf.org/en/parkinson_statistics
15. Family Caregiver Alliance. Caregiver statistics Demographics. [Internet]. San Francisco (CA). Available from <https://www.caregiver.org/caregiver-statistics-demographics>
16. Gunnery SD, Habermann B, Saint-Hilaire M, et al. The relationship between the experience of hypomimia and social wellbeing in people with Parkinson's disease and their care partners. *J Parkinsons Dis*. 2016;6(3):625–630. [PubMed: 27285568]
17. Martin SC. Psychosocial challenges experienced by partners of people with Parkinson's disease. *J Neurosci Nurs*. 2015;47(4):211–222. [PubMed: 26153787]
18. Habermann B, Shin JY. Preferences and concerns for care needs in advanced Parkinson's disease: a qualitative study of couples. *J Clin Nurs*. 2017 Available from <http://onlinelibrary.wiley.com/doi/10.1111/jocn.13565/full>
19. McLaughlin D, Hasson F, Kernohan WW, et al. Living and coping with Parkinson's disease: perceptions of informal carers. *Palliat Med*. 2011;25(2):177–182. [PubMed: 20952448]
20. Habermann B Spousal perspective of Parkinson's disease in middle life. *J Adv Nurs*. 2000;31(6):1409–1415. [PubMed: 10849153]
21. Hodgson JGarcia K, Tyndall L Parkinson's disease and the couple relationship: a qualitative analysis. *Fam Syst Health*. 2004;22(1):101–118.
22. Wressle E Living with Parkinson's disease: Elderly patients' and relatives' perspective on daily living. *Aust Occup Ther J*. 2007;54(2):131–139.
23. Goetz CG, Tilley BC, Shaftman SR, et al. Movement Disorder Society-sponsored revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS): scale presentation and clinimetric testing results. *Mov Disord*. 2008;23:2129–2170. [PubMed: 19025984]
24. Takahashi K, Tickle-Degnen L, Coster WJ, Latham NK. Expressive behavior in Parkinson's disease as a function of interview context. *Am J Occup Ther*. 2010;64(3):484–495. [PubMed: 20608279]
25. DeGroat EJ, Lyons KD, Tickle-Degnen L. Favorite activity interview as a window into the identity of people with Parkinson's disease. *OTJR*. 2006;26(2): 56–58.
26. Glaser BG, Strauss AL. The discovery of grounded theory. Chicago: Aldine; 1967.
27. Corbin J, Strauss A. Basics of qualitative research. 3rd ed. Thousand Oaks (CA): Sage Publications; 2008.

28. Csoti I, Jost WH, Reichmann H. Parkinson's disease between internal medicine and neurology. *J Neural Transm.* 2016;123:3–17. [PubMed: 26298728]
29. Matuska K, Christiansen C. A proposed model of life-style balance. *J Occup Sci.* 2008;15:9–19.
30. Mercer CJ. The impact of non-motor manifestations of Parkinson's disease on partners: understanding and application of chronic sorrow theory. *J Prim Health Care.* 2015;7(3):221–227. [PubMed: 26437046]
31. Bhimani R Understanding the burden on caregivers of people with Parkinson's: a scoping review of the literature. *Rehabil Res and Pract.* 2014 Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4179947/pdf/RERP2014-718527.pdf>
32. Hiseman JP, Frackrell R. Caregiver burden and the nonmotor symptoms of Parkinson's disease. *Int Rev Neurobiol.* 2017;133:479–497. [PubMed: 28802929]
33. Oguh O, Kwasny M, Carter J, et al. Caregiver strain in Parkinson's disease: National Parkinson Foundation quality initiative study. *Parkinsonism Relat Disord.* 2013;19:975–979. [PubMed: 23871587]
34. Iso-Ahola S, Park CJ. Leisure-related social support and self-determination as buffers of stress-illness relationship. *J Leis Res.* 1996;28:169–187.
35. Picillo M, Kou N, Barone P, et al. Recruitment strategies and patient selection in clinical trials for Parkinson's disease: going viral and keeping science and ethics at the highest standards. *Parkinsonism Relat Disord.* 2015;21:1041–1048. [PubMed: 26228079]

Implications for Rehabilitation

- The focus of rehabilitation is often on the person diagnosed with the chronic condition.
- Living with and caring for someone with a chronic illness, such as Parkinson's disease, can lead to limitations in activity and social participation for the care partner.
- Including care partners in the rehabilitation process is key to helping maintain their health and well-being.
- Learning caregiving and self-management strategies may help care partners support their loved ones while staying socially engaged.

Table 1:

Participant Demographics

Participant (pseudonym)	Gender (Care Partner)	H&Y stage	MDS-UPDRS	Yrs. diagnosis	Age (Care Partner)	Age (Person with PD)	Education (Care Partner)
Alice	F	2	32	3	70	69	Doctorate
Anne	F	2	33	8	62	66	Doctorate
Emily	F	2	39	6	63	65	Bachelors
Sharon	F	2	41	1	63	67	Associates
Florence	F	2	48	7	66	70	Bachelors
Fran	F	2	55	2	73	75	HS +
Evelyn	F	3	56	20	61	67	Associates
Tracey	F	3	59	10	74	77	Bachelors
Hannah	F	3	77	10	65	70	Masters
Gladys	F	3	80	7	70	71	Masters
Elizabeth	F	4	93	15	63	66	Bachelors
Marilyn	F	4	95	32	71	72	Bachelors
Average	-	-	59	10	67	70	-----
(Range)			(32–95)	(1–32)	(61–74)	(65–77)	
Frank	M	2	22	5	71	62	HS +
Gerald	M	2	35	5	63	63	HS
Phillip	M	2	43	7	61	61	Doctorate
Harold	M	2	48	5	67	67	HS +
Marvin	M	3	59	2	78	76	Bachelors
Robert	M	3	84	5	71	70	Doctorate
Charles	M	2	85	4	62	61	Masters
Carl	M	4	102	22	71	70	Bachelors
Average	-	-	59.75	7	68	66	-----
(Range)			(22–102)	(2–22)	(61–78)	(61–76)	
Average			59.38	9	68	68	
(Range)			(22–102)	(1–32)	(61–78)	(61–77)	

Note: H&Y = Hoehn & Yahr (baseline); MDS-UPDRS = Movement Disorder Society-United Parkinson's Disease Rating Scale (baseline); HS = high school; HS + = some college

Table 2:**Interview Guide**

Frustrating Activity Question: ***We have been talking about a lot of your activities. Now I'd like you to describe one particularly frustrating or challenging activity or event in your daily life during this past week.***

- What was challenging [OR hard] about this activity [event]?
- What did you do when you encountered the challenging [OR hard] activity?
- Is there anything about this activity you would have liked to do better?
- Did anything you do make this activity less frustrating/challenging/hard?

Enjoyable Activity Question: ***Describe a particularly satisfying or enjoyable activity or event that occurred in your daily life during the past week.***

- Why did you find this activity [or event] to be satisfying [OR fun]?
 - What was satisfying [OR fun] about this activity [or event]?
 - What do you typically do to be able to participate in this or similar activities?
 - What routines or strategies help you participate in this or similar activities?
-

Table 3:

Small portion of strategy use section of codebook

Strategy	Examples
Activity as strategy	<i>The use of an activity as a strategy to enhance quality of life.</i> Attend book group as “my time”, Attend church, Volunteer
Adaptive equipment	<i>Equipment designed to help compensate for limitations</i> Obtain or use equipment for now or future use, such as transfer bench, grab bars, canes
Assist from another person	<i>Assistance can be physical, psychosocial, financial</i> Informal help (e.g., from siblings, friends, etc.) Formal help (e.g., housekeeper)
Attitude	Optimism, Humor, Staying positive, Negative attitude
Avoiding tasks	To keep away from, stop oneself from, or give up on engaging in a certain activity Visit less with friends, Cut back on work
Coping strategies	<i>Behavioral and psychological efforts that people use to deal with stressful events</i> Take deep breaths, Attend support group, Laughter
Education	Attend workshops, Read articles about PD
Energy conservation	<i>Activities and strategies that save time or energy</i> Time management - Plan ahead, Use calendars, Ask for help

Note: Directions

- Code all strategies the care partner used to help engage in any activity mentioned
- If a strategy can also be coded as an activity (or vice versa), make sure to code both under the “Activity” and “Strategy” nodes.
- If a strategy is identified as more than one type of strategy, then you can code it into all appropriate nodes. For example, laughing may be coded under attitude and coping strategies.
- If the same strategy is said multiple times and it is used for the same activity, then code it once where it is first mentioned. If the same strategy is used differently for another activity, then code it again because it is used for another activity.
- If there are strategies that do not fit into the child-nodes, then code it under “other” for further review later on. You can also include annotations to record comments that arise.

Table 4:

Themes and subthemes

Activities: Caregiving and Beyond
Changes in roles and activities
There's more to life than caregiving
Strategies to support self and spouse
Self-management Strategies: Strategies to help me
Caregiving strategies: Strategies that help my spouse
The interrelationship between self-management and caregiving strategies
Emotional Impact

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Table 5:

Care partners who spoke about caregiving and UPDRS score of spouse

Number of time points where caregiving was mentioned	Number of participants	UPDRS score of spouse
0	3	22, 32, 43, (M=32)
1	6	35, 48, 48, 59, 77, 85 (M=59)
2	5	39, 41, 55, 56, 59 (M=50)
3	6	33, 80, 84, 93, 95, 102 (M=81)