

Social Support and Loneliness Among Parkinson Care Partners

Authors:

Michelle Dunk¹
Heather Engblom¹
Maura Gissen¹
Ellen Joseph¹
Jonah Po-Fai Li¹,
Daniel W. Russell²
Cynthia McRae¹

Affiliations:

¹ Counseling Psychology,
Morgridge College of Education,
University of Denver, Denver, CO,
USA

² Department of Human
Development & Family Studies,
Iowa State University, Ames, IA,
USA

Corresponding E-mail Addresses:

Cynthia McRae
cynthia.mcrae@du.edu
Michelle Dunk
dunk.michelle@gmail.com
Heather Engblom
heather.engblom@gmail.com
Maura Gissen
mauragissen@gmail.com
Ellen Joseph
ellencshupe@gmail.com
Jonah Po-Fai Li
jonali@iu.edu
Daniel W. Russell
drussell@iastate.edu

Abstract

Background: Parkinson's disease (PD) is a chronic, neurodegenerative disorder that leads to increasing debilitation over time. Previous research has shown that care partners of persons with PD are at risk for developing loneliness. Based on the Optimal Matching Model of Social Support (Cutrona & Russell, 1990), the primary aim of this study was to determine the types of social support that are associated with loneliness in this sample which, in turn, may lead to interventions designed to help care partners deal with feelings of loneliness.

Methods: A survey was mailed to care partners of persons with PD on the contact list of a regional Parkinson's association. Response rate was 39%. Only responses from those who lived with the patient were included in the analyses (n=70). Standard measures of loneliness, perceived social support, questions related to care partners' perspectives on patients' disease status, and demographic information were included in the analyses.

Results: Linear regression analyses were conducted to determine which of five types of social support predicted loneliness. Results indicated that Attachment (which reflects emotional support) and Social Integration (which reflects network support) were significant predictors.

Conclusions: Findings indicate that care partners may benefit from specific types of support to lessen feelings of loneliness.

Keywords: Loneliness, perceived social support, Parkinson's disease, care partners, Optimal Matching Theory of Social Support

1. Introduction

Parkinson's disease (PD) is a chronic, progressive neurodegenerative disorder that leads to increasing debilitation in movement, physical function, and quality of life (QoL). Individuals with PD begin to produce less dopamine over time as a result of the malfunction and death of dopamine-producing neurons in the substantia nigra and basal ganglia (Parkinson's Disease Foundation, 2017). Unable to produce normal levels of dopamine, patients with PD experience severe motor impairments which develop gradually over the course of the disease. These symptoms include tremors of the limbs, hands, and face, rigidity in the torso and limbs, bradykinesia or slowness of movement, and impairments in balance and coordination (Mayo Clinic, 2017; Parkinson's Disease Foundation, 2017).

Although Parkinson's disease cannot be cured, medications are available which may lessen symptom severity. However, as symptoms inevitably worsen over time, the physical impairments experienced by individuals with PD lead to a decrease in independence and the need for assistance from others. Care partners of those with PD are typically a spouse or other family member, or a professional providing care services. Due to the progressive nature of Parkinson's disease, the needs of the patient increase over time. This, in turn, influences the role of the care partner as caregiving tasks may become more frequent and demanding with the progression of the patient's disease (Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999; Beeson, Horton-Deutsch, Farran, & Neundorfer, 2000; Bergman-Evans, 1994; Bigatti & Cronan, 2002; Edwards & Scheetz, 2002; Fees, Martin, & Poon, 1999; McRae et al., 2009; Schrag, Hovris, Morley, Quinn, & Jahansahi, 2006; Secker & Brown, 2005).

Existing literature indicates that spousal caregivers of patients with PD face a

significant risk of experiencing loneliness (Aarsland et al., 1999; Beeson et al., 2000; Bergman-Evans, 1994; Fees et al., 1999; Kudlicka, Clare, & Hindle, 2013; Lindgren, 1996; Martinez-Martin, Rodriguez-Blazquez, & Forjaz, 2012; McRae et al., 2009; Navarta-Sanchez et al., 2016; Secker & Brown, 2005). Previous studies suggest that a variety of factors may impact the degree of loneliness experienced by care partners, such as the carer's age, health, ability to take time for self-care, role captivity, social support, depression, the patient's age, and the stage of the disease (Blanton, 2013; Dellman-Jenkins, Blankenmeyer, & Pinkard, 2000; Greene, Cohen, Siskowski, & Toyinbo, 2016; Levine et al., 2005; McRae et al., 2009; Rokach, Findler, Chin, Lev, & Kollender, 2013; Soyulu, Ozaslan, Karaca, & Ozkan, 2016; Trivedi et al., 2014). The influence of these multiple factors suggests that loneliness experienced by care partners is complex and may not be effectively addressed with a unidimensional approach.

Previous research has established that characteristics of care partners impact their experience of loneliness to a greater degree than patient characteristics (Litzelman, Kent, & Rowland, 2016; McRae et al., 2009; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009; Tebb & Jivanjee, 2000). However, patient characteristics (e.g., age, chronicity of illness, stage of disease) also affect the spouse or family care partner. The present study therefore explored the influence of both patient and care partner variables on the subjective experience of loneliness by care providers.

Just as loneliness may result from a variety of sources, different types of social support may be helpful in reducing loneliness, depending on the specific needs of the care partner as well as the status of the patient. The Social Provisions Scale (SPS) was developed by Cutrona and Russell (1987) and expands on the theory of Weiss

(1973, 1974), who proposed that six different “provisions” reflect the various types of social support that an individual may need. The six provisions of social support identified by Weiss include Guidance, Reliable Alliance, Reassurance of Worth, Attachment, Social Integration, and Opportunity for Nurturance.

The present report is a further investigation of data that were presented previously (McRae et al., 2009). In this study, we explore the types of social support that may be helpful for ameliorating loneliness in this sample of caregivers based on the Optimal Matching Model of Social Support (Cutrona & Russell, 1990). This theory suggests that social support is most effective when the type of social support provided matches the individual's specific needs. Some variables which have been shown to influence the different types of support needed are variations in stage of disease, efficacy of medical intervention, and the individual's capacity for coping (Merluzzi, Philip, Yang, & Heitzmann, 2015). If a suitable type of support is provided in a particular context, this may increase QoL and the ability to adjust to current or ongoing circumstances, in contrast to a situation in which the support needed and the support offered are mismatched (Merluzzi et al., 2015).

Cutrona and Cole (2000) suggested that interventions to increase social support vary according to the individual's goal. These goals may include enhancement of mental or physical health, promotion of positive behavior change, or an increase in resources to support both the care partner and patient. While care partners of persons with PD likely experience some similar concerns which contribute to loneliness, it is unclear whether their specific needs may differ along these three dimensions due to underlying individual differences. An investigation of both patient and care partner characteristics is therefore necessary to

determine appropriate interventions to decrease levels of loneliness in this population.

The primary aim of this study was to investigate the types of support that were related to loneliness among PD care providers. In order to explore this aim, hierarchical regression analyses were conducted which included the following variables: patient age, stage of disease, degree of role overload reported by the care partner, care partner's perception of changes in the patient's thinking and/or memory, perceptions of changes in the quality of interactions between patient and caregiver, and the social support received by the care provider.

2. Methods

2.1. Participants

A survey was mailed to care partners of persons with PD on the contact list of a regional Parkinson's association in the western United States. A letter of invitation solicited participation from all care partners regardless of length of time providing assistance. The response rate was 39%. Of the 87 responses received, only those from participants who indicated they were living with the patient ($n = 70$) were included in the analyses. Return of the questionnaire was regarded as participants' consent to participate in the study. The Institutional Review Board of the University of Denver approved the study protocol.

2.2 Assessments

2.2.1 Care Partner Characteristics

The care partners were asked to report their age, gender, level of education, ethnicity, employment status, and relationship to the patient. They were also asked to report the number of years as a care partner and number of hours per day spent

providing care or supervising the patient's activities, and whether or not they attended a caregiver support group. Finally, care partners rated their own physical health on a Likert scale from 1 (very poor) to 7 (excellent).

2.2.2. Patient characteristics

Participants were asked to report the age of the patient and length of time since diagnosis. Care partners also estimated the patient's stage of disease using an adapted version of the Hoehn and Yahr scale (Hoehn & Yahr, 1967), which included descriptions of the stages. This version of the scale was adapted for use by care partners and has been shown to correlate well with neurologist ratings (McRae, Diem, Vo, O'Brien & Seeberger, 2002).

2.2.3. UCLA Loneliness Scale

The UCLA Loneliness Scale (Russell, 1996) was used to assess loneliness among the participants. The scale consists of 20 items rated on a 4-point Likert Scale ranging from 1 (never) to 4 (often); half of the items were reverse scored. Total scores could range from 20 to 80 with higher scores indicating more loneliness. Evidence of reliability and validity of this scale has been presented in other studies with samples of college students, young adults, and older adults (Russell, 1996; Russell, & Cutrona, 1991; Russell, Peplau, & Cutrona, 1980).

2.2.4. Social Provisions Scale (SPS)

The SPS (Cutrona & Russell, 1987) was used in this study to measure perceived social support. The SPS is 24-item scale with each item rated on a 4-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). Total scores could range from 24 to 96 with higher scores indicating greater perceived support. Reliability and validity of the scale have previously been

established in a number of populations (for a review see Cutrona & Russell, 1987).

The six subscales in the SPS fall broadly into two categories: assistance-related and non-assistance-related support. The assistance-related category consists of Guidance and Reliable Alliance, which relate directly to problem-solving skills in the context of stress. The non-assistance related category does not relate directly to problem-solving and consists of Social Integration, Attachment, Reassurance of Worth, and Nurturance (Cutrona & Russell, 1987). Based on the original research, Guidance ($\alpha = .76$) is defined as having accessibility to advice and information. This type of support often comes from mentors, teachers, parent figures, etc. Reliable Alliance ($\alpha = .65$) is defined as assurance that others can be counted on in times of stress for tangible assistance. This type of support most often comes from friends and family. Social Integration ($\alpha = .67$) is defined as a sense of belonging to a group of people while Attachment ($\alpha = .75$) is defined as emotional closeness to others. Reassurance of Worth ($\alpha = .67$) is defined as recognition of one's competence, skills and values by other people. Nurturance ($\alpha = .66$) is defined as having the ability to provide assistance to others (Cutrona & Russell, 1987).

2.2.5. Overload

The Overload measure was originally developed for use in a study of care partners of non-institutionalized individuals with dementia (Pearlin, Mullan, Semple, & Skaff, 1990). Primary and secondary stressors were examined along with the mediating conditions of coping and social support. The Overload subscale ($\alpha = .80$) consists of four statements with each item rated on a 4-point Likert Scale ranging from 1 (strongly disagree) to 4 (strongly agree). Total scores can range from 4 to 16.

2.2.6. Thinking and Memory; Interacting with patient

In order to investigate some of the less recognized effects of PD on care partner loneliness, participants were asked to rate the degree to which “you feel the patient’s thinking or memory has been affected by PD or its medication.” Ratings were made on a 7 point Likert scale ranging from 1 (not at all) or 7 (extremely). Participants were also asked to indicate the degree to which “the patient is able to interact with you in the same ways as always,” using a Likert Scale ranging from 1 (not at all) to 7 (same as always).

2.3. Data analyses

Preliminary analyses of care partner and patient demographic information as well as measures included in the study were conducted. Primary analyses involved hierarchical regression analyses to investigate the relative contribution of each of the five selected patient and care partner variables as well as the subscales of the SPS in the prediction of loneliness. Interaction terms were created in order to determine

whether there were any moderation effects of each provision by each of the patient and care partner characteristics. Patient and care partner variables included patient’s age, stage of disease, care partner overload, degree to which the patient’s thinking or memory has been affected, and degree to which interactions with the patient are the same as always. Significance level was set at $p \leq .05$.

3. Results

3.1. Descriptive analyses

Descriptive information related to the sample is presented in Table 1. Care partners reported spending an average of 3.3 (4.1) hours per day “providing personal care” for the patient; scores ranged from 0 to 18 hours. Care partners also indicated that they spent 6.1 (8.2) hours per day “supervising activities” for the patient; scores ranged from 0 to 24 hours. Not surprisingly, the amount of time spent supervising or caring for patients was related to the care partner’s estimate of the patient’s stage of disease ($r = .40; p < .01$).

Table 1
 Demographic characteristics of caregivers and patients.

Caregiver Variables	M (SD) or Percentage	Scored Range
Gender		
Males	26%	
Females	73%	
Age (years)	65.5 (10.2)	40-85
Married	93%	
Education (years)	13.8 (2.8)	8-18
White	97%	
Employed	23%	
Own health ^a	5.2 (1.4)	1-7
Length of caregiving (years)	6.6 (4.9)	1-24

Memory affected by disease ^b	4.0 (1.9)	1-7
Interact same as always ^c	4.3 (1.8)	1-7
Role in life changed due to PD	79%	
Self-care: times per month	5.75 (7.17)	0-30
Attend care partner support group	30%	
Patient Variables		
Age of patient (years)	69.4 (9.1)	45-88
Hoehn & Yahr (care partner version)	3.4 (.95)	1-5
Years since diagnosis (years)	9.2 (6.2)	1-26

^a Possible range = 1 (very poor) to 7 (excellent).

^b Possible range = 1 (not at all) to 7 (extremely).

^c Possible range = 1 (not at all) to 7 (same as always).

Results of descriptive analyses related to the measures included in this study are presented in Table 2. Analyses related to skewness and kurtosis indicated that the UCLA Loneliness Scale and the SPS were

normally distributed in this sample. Since the estimate of reliability for the Nurturance subscale was low ($\alpha = .43$), it was not included in further analyses.

Table 2
 Mean scores, reliability, and scoring ranges.

Scales	<i>M</i> (SD)	α	Scored Range
UCLA Loneliness Scale ^a	40.0 (10.6)	0.90	22-64
Social Provisions Scale ^b	78.1 (10.3)	0.86	51-96
Attachment ^c	12.0 (2.7)	0.66	5-16
Social Integration ^c	13.1 (2.4)	0.72	5-16
Worth ^c	13.2 (2.4)	0.64	6-16
Alliance ^c	13.7 (2.0)	0.64	7-16
Guidance ^c	13.0 (2.6)	0.70	5-16
Nurturance ^c	13.1 (2.1)	0.43	5-16
Coping Scale			
Overload ^c	11.0 (3.0)	0.80	5-16

^a Possible range = 20-80.

^b Possible range = 24-96.

^c Possible range = 4-16.

3.2. Level of loneliness

The level of loneliness in this sample was compared with scores of a large national sample of adults over 45 years of age who completed the UCLA Loneliness Scale in 2010 (Russell, 2017). The average score for the national sample of 2569 individuals was 40 (10.75), which is the same as the score of the present sample. There is no criterion score above which an individual may be classified as “lonely.” However, authors of the national study sponsored by the American Association of Retired People (AARP) suggested that those who scored 43 or higher on the scale should be classified as being “lonely.” In this sample, 45% of the sample scored 43 or above.

3.3. Predictors of loneliness

In order to investigate the types of support that were related to loneliness, a

hierarchical regression analysis was conducted with patient and care partner variables entered in Step 1, social support variables entered in Step 2, and interactions between patient and care partner variables and social support variables entered in Step 3. Results of this analysis are presented in Table 3. Patient and care partner variables (Step 1) accounted for 21% of the variance in loneliness ($p = .05$) with “interactions with the patient being same as always” the only significant predictor ($p < .01$). The social support variables added in Step 2 accounted for an additional 52% of the variance in loneliness ($p \leq .000$). Individual types of support that were significant include Social Integration and Attachment (both $p < .05$). The interaction terms were added in Step 3. Results showed that the change in R^2 was non-significant, indicating there was no moderation of the effects of the social provisions on loneliness by patient and care partner characteristics.

Table 3
 Summary of Hierarchical Regression Analysis for the Variables Predicting Loneliness

Variables	<i>B</i>	<i>SE B</i>	β	ΔR^2
Step 1				.13*
Patient age	-.05	.19	-.04	
Stage of disease	-3.59	2.60	-.29	
Interact same as always	-3.70	1.28	-.60**	
Thinking/memory affected	-.93	.90	-.16	
Overload	-.42	.62	-.11	
Step 2				.66
Patient age	.02	.14	.02	
Stage of disease	-.04	1.71	-.00	
Interact same as always	-.07	.91	-.01	
Thinking/memory affected	.52	.64	.09	
Overload	-.07	.40	-.02	
Guidance	-.63	.58	-.16	
Worth	-.76	.52	-.18	
Integration	-1.27	.53	-.28*	
Attachment	-1.40	.62	-.34*	
Alliance	-.45	.63	-.08	

Note. SPS = Social Provisions Scale. Guidance = Guidance Subscale of SPS; Worth = Reassurance of Worth Subscale of SPS; Integration = Social Integration Subscale of SPS; Attachment = Attachment Subscale of SPS; Alliance = Reliable Alliance Subscale of SPS.
 * $p < .05$. ** $p < .01$.

4. Discussion

This study investigated the types of support that were related to loneliness based on the Optimal Matching Theory of Social Support. It should be noted that although average scores of this sample on the UCLA Loneliness scale were the same as those of a large national sample (Russell, 2017), 45% of the group could be classified as being “lonely.”

The primary aim of the study was to determine which types of social support were predictors of loneliness in this sample of PD care partners. Related to these results, the second aim was to suggest ways of addressing loneliness in this sample through the Optimal Matching Theory.

Results indicated that two of the five SPS subscales included in the analyses were related to less loneliness. Integration, or one’s sense of belonging to a group, was a significant predictor along with Attachment, or emotional closeness to others, which was also a significant predictor. These findings suggest that care partners may benefit from different types of support to address their experiences with loneliness based on conditions that are most salient in their particular experience.

4.1. Optimal Matching Model

According to Optimal Matching Model, the ideal type of social support is dependent upon whether the event is controllable or uncontrollable. In the current study, four of the assessed variables (e.g., patient’s age, stage of disease, memory, and change in ability to interact with the care partner) can be categorized as “uncontrollable,” or circumstances for which instrumental behaviors cannot prevent the circumstance and/or mitigate or remove the consequences (Cutrona, 1990). The fifth assessed variable, overload, can be seen as “controllable,” or a situation which can be

tempered by strategies to lessen the strain on the care partner such as taking breaks for self-care, inviting family or friends to share some of the chores and details of life when roles begin to shift from the patient to the care partner.

The Optimal Matching Model suggests that uncontrollable events are best addressed by emotional support, tangible support, attachment, network support, and esteem support (Cutrona, 1990). Therefore, it appears that since these variables cannot be changed within the caregiving experience, care partners may benefit from proactive psychoeducation related to the potential impact of uncontrollable events. Health providers could discuss the potential for future changes resulting from disease progression, and care partners, in turn, might be able to prepare for these changes by increasing their social support to ensure they have the type of support they need to cope and, ideally, improve their quality of life.

In light of the current study’s findings regarding the integral role of Integration and Attachment for care partners’ loneliness, ways to increase these specific types of support should be considered. For instance, a care partner who would benefit from Integration may find this kind of support in groups that share similar interests and concerns, such as religious groups, a book club or exercise group, in order to create or reinforce a greater sense of belonging with others. A care partner who would benefit from more Attachment, on the other hand, may find care partner support groups, both in-person and/or online, to be helpful in providing a deeper sense of emotional connection with others. Ideally, the health care provider would be able to suggest groups or activities in the community where care partners as well as patients could go for assistance. Overall, caregivers’ loneliness may be more appropriately addressed if the type of social support matches their specific

needs, as described in the Optimal Matching Model (Cutrona, 1990).

4.2. Implications of the Results

One implication of the study is the importance of recognizing the psychosocial needs of care partners as well as patients. For example, it would be helpful for healthcare professionals to be aware of local options for support groups, exercise classes specifically geared to PD, upcoming PD seminars that provide education and resources for both patients and care partners.

Religion or spirituality may be another asset to build social support for care partners. Research shows that participation in religious activities tends to develop social support systems, which is a predictor of good health (Ellison & Levin, 1998; Krause, Ingersoll-Dayton, Liang, & Sugisawa, 1999). Connecting with internet support groups may be helpful for some individuals who have become isolated over time because of caregiving responsibilities. Even virtual connection can lessen the sense of social loneliness (Cotten, Anderson, & McCullough, 2013).

It is important to note that the majority (73%) of the sample was female and that the results reflect this perspective. Because men are diagnosed with Parkinson's disease approximately 1.5 times more frequently than women (Wooten et al., 2004), these results are not surprising. Prior research shows that the ways in which males and females reach out for and obtain social support may differ for a number of reasons. According to the gender-role socialization framework (Gilligan, 1982), the gender-role expectation framework (Barusch & Spaid, 1989) and theories of labor market segregation and household labor (Barusch & Spaid, 1989; Ross, 1987), women offer more care, in both time and duration, than do men. Research also supports the popular belief that men are reluctant to seek help

from health professionals and that men seek psychiatric services, psychotherapy, and counseling less often than women (Gove, 1984; Gove & Tudor, 1973; Addis & Mahalik, 2003), which may also be due to the socialization of gender roles, norms, and expectations.

The approaches to caring also generally differ between men and women. Caregiving husbands tend to adopt task-oriented and managerial approaches, while caregiving wives are more likely to take an emotionally focused orientation and relational approach (Hong & Coogle, 2016). Thus, while results did not vary by gender, the differences noted above may be helpful in determining the type of support that might be most helpful according to the Optimal Matching Model.

4.3. Limitations of Present Study

There are several limitations of the present study. One limitation is related to the relatively small sample size ($n = 70$). Thus, findings cannot be generalized to the broader community based on this study alone. Another limitation is cultural representativeness of sample; the majority of the sample was White and female. Attention will be needed in the interpretation of the present findings in different cultural contexts. In addition, the selection of participants may be a limitation. Because of the inclusion criterion of living with the patient, most of the participants were patient spouses. Other care partners such as siblings, friends, or children of the patient were not included in the analyses, but may also be experiencing loneliness related to the patient and PD.

4.4. Future Directions

Considering the aforementioned limitations of the current study, future research should aim to recruit larger, more representative samples. In regard to the

results and the Optimal Matching Model of Social Support (Cutrona, 1990), future research should examine the effectiveness of providing or encouraging participation in the types of support (e.g., Integration, Attachment) that appear to be most helpful in addressing loneliness in this sample. Although literature on the effectiveness of social support interventions has long suggested they do not work very well

(Cutrona & Cole, 2000), in the previous report of this study (McRae et al. 2009), results indicated that participants who attended care partner support groups reported less loneliness and more support (both $p < .05$) than those not attending support groups. For the care partner as well as the related impact on the patient, further research is clearly needed on this topic.

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