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Patients' and caregivers' experiences of the impact of Parkinson's disease on health status

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Background: Parkinson's disease (PD) is a neurodegenerative disease that significantly affects patients' quality of life. The myriad complexities of the disease, including its nonmotor manifestations, are beginning to be more fully appreciated, particularly in regard to the emotional and social effects of PD. Considering that both motor and nonmotor manifestations of PD significantly influence the health outcomes and conditions of patients, and their health-related quality of life (HRQOL), we collected qualitative data from patients with PD, as well as caregivers of persons with PD having cognitive impairment, to assess their perceptions of the impact of PD on HRQOL.

Methods: We conducted eight focus groups and five one-on-one interviews in English and in Spanish between March 2007 and February 2008. Three of the focus groups were conducted with a total of 15 caregivers; the remaining focus groups and all interviews were conducted with 48 PD patients. Study participants were asked about the challenges that PD patients may experience, particularly pertaining to physical functioning, the impact of PD on their emotional status, and social functioning.

Results: Based on analysis of the transcripts, we identified seven overarching domains or themes that reflect patients' perspectives on living with PD, ie, physical functioning, social and role functioning, emotional impact, fears and uncertainty about the future, stigma and other feelings about PD, coping mechanisms, and benefits of having PD.

Conclusion: We underscore the salient aspects regarding the physical effects of PD along with its nonphysical ramifications, offering perspectives into the experience of PD and suggestions on how PD patients and their caregivers may cope with the disease.

Keywords: focus groups, qualitative, neurodegenerative, health-related quality of life

Introduction

Parkinson's disease (PD) is a neurodegenerative disease that significantly affects the quality of life of both patients and caregivers. In one analysis of data from studies of individuals with PD over the age of 50 years, prevalence was estimated as between 4.1 and 4.6 million in 2005, across 15 countries worldwide (Western Europe's 5 most populous and the world's 10 most populous countries).¹ Given the higher prevalence of PD with increasing age, and the projected population structure in these 15 countries in 2030, the prevalence of PD in these countries is projected to approximately double by 2030.¹ About 4% of cases of PD have onset before the age of 50 years.²

Presenting complex challenges that go beyond the most common physical manifestations, PD figures prominently as a progressive disorder on many levels, ie, physical, emotional, cognitive, and social. The myriad complexities of the disease in its nonmotor

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manifestations are beginning to be more fully appreciated, particularly in regard to the emotional and social effects of PD on patients' health-related quality of life (HRQOL).³ Considering that both motor and nonmotor manifestations of PD significantly influence the health outcomes and conditions of patients, the goal of this study was to identify HRQOL domains or themes that reflect patients' perspectives on living with PD in a comprehensive manner. By offering perspectives into the experience of PD, such findings could aid in patient and caregiver education and counseling, by providing PD patients and their caregivers with suggestions that may enhance their day-to-day coping with the disease. Another purpose of our study was to inform the content of a comprehensive measure of HRQOL grounded in patients' experiences of the disease and its manifestations.⁴ Currently available HRQOL instruments developed for Parkinson's disease have been found to have inadequate reliability, poor ability to detect change in HRQOL over time, or both.⁵⁻⁷ A new measure or item bank that incorporates patients' perspectives in its assembly could be used in future PD etiologic, therapeutic, and health services research studies.⁸

Methods

Our overarching goal was to elucidate the impact of PD on HRQOL. To accomplish this, we selected an approach that would enable us to identify the full range of HRQOL themes relevant to persons with PD and that would allow us to underscore the most salient aspects of the physical effects of PD along with its nonphysical ramifications. As a form of qualitative research in which a group of individuals are asked about their perceptions, opinions, and attitudes toward a concept or subject, focus groups were used to collect qualitative data from a diverse group of patients with PD, as well as caregivers of those with advanced PD.⁹ This approach maximizes the ability to elicit the fullest possible range of responses, as well as providing detailed examples. To help assess the salience of each theme, as well as whether there were particular themes that were more associated with one group than another, we counted and compared the number of times each theme was mentioned by different subgroups of participants.

Sample

The sample consisted of PD patients and caregivers recruited from neurology clinics at four locations in three cities around the US. To ensure a diverse sample of persons with PD, we purposefully sought to recruit patients of both genders,

from multiple racial and ethnic groups encompassed in the US, and across a wide range of ages and of disease severity and stage. Participants who had PD without dementia were recruited for the patient focus groups and for one-on-one interviews, which were conducted with patients who had difficulty with voice quality that prevented them from participating in a group discussion. We also purposefully recruited PD patients with early age of onset (defined as aged at or under 50 years), because of the potential for differential impact of the disease on individuals at a point in life for which there are greater financial and childrearing responsibilities and roles. Caregivers were recruited to provide the perspectives of patients with PD who also had dementia and/or cognitive impairment and thus were not capable of participating in focus groups themselves. From one location, we exclusively recruited Spanish-speaking patients and caregivers.

Health care providers were asked to identify patients who had PD, in addition to identifying caregivers of patients who had both PD and dementia. Providers gave the patients or eligible caregivers information regarding the study. Trained staff members from RAND Survey Research Group coordinated the recruitment by providing physicians with flyers that were mailed to potentially eligible patients or were given to patients in person during an office visit. Information regarding the study was also posted in neurology and movement disorder clinics, websites, and newsletters, as well as provided to patients and caregivers during support group meetings. Before being invited to participate in a focus group, those patients and caregivers who consented to the study were screened by trained staff members at RAND, to ensure that participants met a particular group's profile. The number of participants in each focus group was kept relatively small to enable the indepth exploration of themes. The RAND Institutional Review Board reviewed and approved all study recruitment and consent procedures.

Measures

All focus group and interview participants were asked to complete a prefocus group questionnaire designed to collect sociodemographic, clinical, and functional status data prior to the start of the focus group or interview.

The initial steps in development of a focus group discussion guide of open-ended questions about different aspects of the impact of this progressive disease were a review of the literature, and input from clinicians who care for patients with PD. Based on these sources, six general topics

were identified for exploration during the focus groups (see Appendix).¹⁰ These included HRQOL domains of physical functioning, emotional status, and social and role functioning; constructs identified as potentially particularly relevant to PD (stigma, fears about the future); and an additional concept of coping and any perceived benefits of living with PD.^{6,11–13}

Data collection

Using this scripted focus group discussion guide, experienced focus group moderators from RAND conducted all sessions, each of which lasted approximately 90 minutes (see sample script in Appendix). Moderators attempted to engage all participants to foster a dynamic and open conversation. The five individual interviews adhered to the same focus group discussion script. Focus groups with Spanish-speaking patients and caregivers were conducted using standard Spanish language, facilitating comprehension by all Spanish-speaking participants.

All focus groups and interviews were audiorecorded, and the focus groups were also attended by a notetaker. Study participants were paid US\$65 at the conclusion of the meeting or interview. Transcripts were produced for all focus groups and interviews. The focus group sessions and one interview that were conducted in Spanish were simultaneously translated and transcribed from the audiotape into English language transcripts. These transcripts were then reviewed against the tape to ensure quality and accuracy.

Analysis

To identify the range of themes and their distribution across types of participants, we analyzed the data in several phases. Focus group data were analyzed by use of a transcript-based analysis in order to minimize moderator or analyst perceptions. To deduce the themes from the focus groups, audiotapes were transcribed into Microsoft Word files (Microsoft, Redmond, WA) and de-identified. Each transcript file was then entered into a text data management software program file (Atlas.ti, Berlin, Germany), where it was marked off into separate segments of text, with each segment of text reflecting a single concept, and each text segment was given a preliminary code for one of the six focus group guide constructs. Then, the text segments and codes were exported into separate rows of a Microsoft Excel spreadsheet, and columns were added to code for types of focus group (early or typical age at onset, patient or caregiver, English or Spanish language). Data (segments of text) from all eight focus groups were then concatenated into

one spreadsheet. Next, we employed a cutting-and-sorting technique, by which each segment of text was printed onto a note card.^{14,15} All text segments (one text segment per card) were then reviewed and definitively sorted into themes and subthemes by a team of PD clinical experts and methods experts working together. As a result of this process, coping and benefits of PD was divided into two distinct themes, yielding seven final themes: physical functioning; social and role functioning; emotional impact; fears and uncertainty about the future; stigma and other feelings about PD; coping mechanisms; and benefits of having PD. Subthemes from the card sort are not presented here. The final coding of each text segment into themes and subthemes were recorded in the spreadsheet. Frequency tables were generated based on these seven overarching themes, sorting according to whether the participant was: a patient with disease onset at or before the age of 50 years (early onset) or onset greater than age 50 years ("typical" onset); a caregiver or a patient; and an English or Spanish speaker. To explore possible associations of these three characteristics with themes, we conducted Chi-square analyses. The one-on-one interviews were reviewed for any additional themes or variance with the comments from the focus groups; however, we did not include them into the formal cutting-and-sorting analysis because the number of comments would be overly weighted due to being individual interviews.

Results

We conducted eight focus groups and five one-on-one interviews between March 2007 and February 2008 (Table 1).^{16,17} Five focus groups (two groups were early age of onset, and three groups were typical age of onset) and five one-on-one interviews were conducted with 48 PD patients; the other three focus groups were conducted with a total of 15 caregivers. Of the eight focus

Table 1 Focus group sites and types

Patient focus groups		
Language	Location	Onset of Parkinson's disease type
English	Los Angeles, CA	Early age of onset ($\leq$ age 50)
English	Tampa, FL	Early age of onset ($\leq$ age 50)
English	Los Angeles, CA	Typical onset ($>$ age 50)
English	Rochester, NY	Typical onset ($>$ age 50)
Spanish	Sylmar, CA	Typical onset ($>$ age 50)
Caregiver focus groups		
English	Tampa, FL	
English	Los Angeles, CA	
Spanish	Sylmar, CA	

groups and five one-on-one interviews, one typical age of onset patient focus group, one caregiver focus group, and a single one-on-one interview were conducted in Spanish; the remainder of the interviews were conducted in English.

Sociodemographic, clinical, and functional status characteristics of the study participants are shown in Table 2. Table 3 shows how the final total of 1022 comments (text segments) collected from the focus group participants were distributed among the seven salient themes (physical functioning; social and role functioning; emotional impact; fears and uncertainty about the future; stigma and other feelings about PD; coping mechanisms; and benefits of PD) and across three subgroups: early onset patient (age of onset $\leq$ 50 years) versus typical onset patient (age of onset $>$ 50 years); patient versus caregiver; and English versus Spanish speakers. Review of the one-on-one

Table 2A Sociodemographic characteristics of PD focus group participants, one-on-one interviewees, and caregivers

Sociodemographic characteristics	Patients in focus groups and interviews* n = 47	Caregivers** n = 15
Female, n (%)	26 (55.3)	13 (86.7)
Age (mean, years)	62.6	71.6
Marital status, n (%)		
Married/living with partner	34 (72.3)	11 (73.3)
Separated or divorced	8 (17.0)	0 (0.0)
Widowed	3 (6.4)	1 (6.7)
Never married	2 (4.3)	2 (13.3)
Education, n (%)		
No formal education	1 (2.1)	–
5th grade or less	3 (6.4)	–
6–11th grade	3 (6.4)	–
High school graduate or GED	6 (12.8)	–
Some college or two-year degree	9 (19.1)	–
Four-year college graduate	10 (21.3)	–
More than four-year college degree	15 (31.9)	–
Race/ethnicity, n (%)		
White	37 (78.7)	10 (66.7)
Hispanic or Latino	10 (21.3)	4 (26.7)
Asian or Pacific Islander	0 (0.0)	1 (6.7)
African-American or Black	0 (0.0)	0 (0.0)
Native American, American-Indian or Alaskan Native	0 (0.0)	0 (0.0)
Relationship to care recipient, n (%)		
Spouse	–	8 (53.3)
Son or daughter	–	2 (13.3)
Other relative	–	5 (33.4)

Notes: *Includes 42 patients who were in five focus groups, and five patients who had one-on-one interviews; one focus group participant did not complete the background questionnaire; **Includes 15 caregivers from three focus groups.

Abbreviation: PD, Parkinson's disease.

Table 2B Clinical and functional status characteristics of PD focus group participants, one-on-one interviewees, and PD care recipients (from caregiver focus groups)

Clinical and functional status characteristics	Patients in focus groups and interviews n = 47*	PD care recipients n = 15**
Length of diagnosis with PD, mean (range), yrs		
Early onset (n = 17 patients)	10.8 (4–10)	–
Typical onset (n = 31 patients)	5.1 (1–12)	–
Care recipients	–	10.3 (4–25)
Difficulties with walking, n (%)		
No difficulty with gait or swing	9 (19.1)	4 (26.7)
Yes, I don't swing arms or I tend to drag my leg	23 (48.9)	2 (13.3)
Yes, I have moderate amount of difficulty with walking, but usually don't need assistance	10 (21.3)	3 (20.0)
Yes, I have severe problems with walking and usually need assistance	3 (6.4)	5 (33.3)
Yes, I can't walk at all, even with assistance	0 (0.0)	1 (6.7)
Missing	3 (6.4)	0 (0.0)
Difficulties with hygiene, n (%)		
No difficulty	13 (27.7)	2 (13.3)
Yes, a bit slow but don't need help	31 (66.0)	7 (46.7)
Yes, slow with hygiene and need help to shower and bathe	2 (4.3)	2 (13.3)
Yes, need help with washing, brushing teeth, combing hair and going to the bathroom	0 (0.0)	2 (13.3)
Yes, need help with all hygiene and have Foley catheter	0 (0.0)	2 (13.3)
Missing	2 (4.3)	0 (0.0)

Notes: *Includes 42 patients who were in 5 focus groups, and 5 patients who had one-on-one interviews; one focus group participant did not complete the background questionnaire; **Includes 15 care recipients whose clinical and functional status characteristics were reported by caregivers from 3 focus groups.

Abbreviation: PD, Parkinson's disease.

interview transcripts did not reveal any additional themes or contradictions to the themes and subthemes identified from the formal focus group transcript analysis.

Physical functioning

In the category of physical functioning, patients and caregivers commented on a wide range of topics pertaining to challenges associated with the disease, especially concerning loss of motor control, lack of facial expression, and difficulties due to impaired cognitive functioning and processing. While the subgroups of participants presented highly shared comments regarding the most prevalent category, physical functioning (more than 40% of all 1022 comments), the intergroup difference between early and typical age at onset patients (36.8% versus 46.4%, respectively) may indicate that perhaps typical

Table 3 Frequency of occurrence of each health-related quality of life theme by focus group characteristics (n = 1022 comments from 43 patient and 15 caregiver focus group participants)

Theme	Comments out of 1022 total n (%)	Early vs typical onset*		Caregiver vs patient		Language	
		Early onset (n = 326) n (%)	Typical onset (n = 412) n (%)	Caregiver (n = 284) n (%)	Patient (n = 738) n (%)	English (n = 828) n (%)	Spanish (n = 194) n (%)
Physical functioning	447 (43.7)	120 (36.8)	191 (46.4)	136 (47.9)	311 (42.1)	349 (42.2)	98 (50.5)
Social and role functioning	109 (10.7)	39 (11.9)	32 (7.8)	38 (13.3)	71 (9.6)	93 (11.2)	16 (8.2)
Emotional impact	76 (7.4)	25 (7.6)	19 (4.6)	32 (11.2)	44 (6.0)	62 (7.5)	14 (7.2)
Fears and uncertainty about the future	64 (6.3)	17 (5.2)	28 (6.8)	19 (6.6)	45 (6.1)	53 (6.4)	11 (5.7)
Stigma and other feelings about PD	150 (14.7)	62 (19.0)	64 (15.5)	24 (8.4)	126 (17.1)	132 (15.9)	18 (9.3)
Coping mechanisms	120 (11.7)	39 (11.9)	59 (14.3)	22 (7.7)	98 (13.3)	93 (11.2)	27 (13.9)
Benefits of having PD	56 (5.5)	24 (7.3)	19 (4.6)	13 (4.5)	43 (5.8)	46 (5.5)	10 (5.2)
Total number of comments	1022 (100)	326	412	284	738	828	194

Notes: *Patient focus groups only; 738 comments; early onset means age of onset/diagnosis $\leq$ 50 years; $P \leq 0.05$ for difference across each bolded pair of comparisons on frequency of theme.

Abbreviation: PD, Parkinson's disease.

age at onset patients appear to be more concerned with the extent of their physical deterioration. In particular, it appears that typical age at onset patients (46.4%) and Spanish speakers (50.5%) had a slightly higher tendency to focus on the physically degenerative aspects of PD (see Table 3).

Loss of the basics

The inability to do basic things in daily life constituted one of the most notable challenges related to patients' physical functioning. Patients with caregivers seemed to have the most severe physical difficulties, usually requiring assistance in carrying out basic daily activities, such as dressing, bathing, and grooming. For patients with early and typical age at onset, the comments pertaining to physical limitations ranged from mild to moderate difficulties in movement (walking, turning or getting out of bed, falling, tremor, and dyskinesias); hygiene (grooming, bathing); manual motor skills (using utensils, handwriting, driving); and sleep (problems falling or staying asleep, nightmares, restlessness). It was common for patients to be acutely aware of their increasingly deteriorating physical functioning, as one patient succinctly pointed out by drawing a sharp comparison between life before and life after disease onset: "I used to hop, skip, and jump. Now it's a shuffle, waddle and a stumble, literally".

Caught behind the mask

One effect of PD is the inability to move, similar to a state of constant numbness, freezing, stiffening, or deadening of the body. A common feature noted by some patients was a lack of facial movement, akin to having a "stone face" or a "facial mask". One patient expressed the devastating effect that the

lack of facial expression, what he referred to as "mask face", had on his relationship with his spouse, due to the fact that through facial expressions we can communicate our deepest feelings and thoughts with loved ones:

"It was really hard on her in the beginning because I had symptoms, you know, a few years before and I had the mask face and everything, and ... I'd throw water in my face because I would just be so stiff in that, and evidently she thought that I was losing interest in her, and once I got the Sinemet and we found out what happened and all the dystonia went away, you know, she cried because she thought I didn't love her anymore. She'd say something and I'd ... be smiling at her, but she couldn't really see it".

The disheartening deadening of facial expression can lead to a progressive disconnect with one's sense of identity, feelings, and thoughts, and consequently, to an agonizing alienation from loved ones. The constant stiffening of the body may lead patients to feel trapped in an alternate universe of sorts, as one caregiver described the trance-like state in which her mother would often lie, with eyes half-shut. One patient equated the underlying feeling of suddenly being alone and disconnected from the world to an experience she had being trapped in an elevator early in the morning: "I was caught in an elevator at 7:30 in the morning and it was pitch black, and nothing worked and they didn't come and get me until an hour after that. Nobody knew I was there. And I was shaking so bad I couldn't stand on my feet. I fell in the elevator, like, I couldn't stand up". Yet, far from being temporarily trapped in a pitch black elevator, PD presents the condition of an at times nonresponsive body.

Changes in social and role functioning

PD inevitably results in significant changes in the relationship between patients and caregivers. Both groups commented extensively on the category of social and role functioning, particularly on the debilitating toll that PD has on many social aspects. There appeared to be a variation between early and typical onset patients, which suggests that early onset patients may experience more difficulty accepting and coping with the social and role changes as a result of PD; a similar variation appeared across caregivers and patients (see Table 3).

Shifting roles

Some patients voiced their sense of a progressive alienation from the world around them, lamenting either the gradual erosion or complete loss of some relationships. One patient recognized the accumulation of losses not only in physical activities, but also in emotional wellbeing and in a close relationship, such as marriage: “Losses, yeah. I lost a job. I lost a marriage, too. That’s the painful part. And a loss of activity time. A loss of motivation ... A loss of inspiration ... So it’s all an accumulation of losses”. Moreover, one of the most compelling commonalities among patients was the sense of loss and sadness over not having the same social role they once had in relation to their family members (particularly, not being perceived as the provider, or not being able to partake in family activities or certain social events). One patient, for example, disclosed a sense of feeling obsolete in his former familial role as the provider:

“But all these little duties they’re jerking away from me. And what I don’t mind is that the toilet plunger, in the house whenever the toilet overflowed, I’m your man. When it comes to other things, whether it be driving down to the market for a gallon of milk or shoveling out the walkway so everyone gets in the house alright, these things used to be me. It’s how I identified myself. And now my little girl is, well ... she’s 26. She’s no little kid, but she’s taking over my responsibilities. And I can’t help but feel a little bit pushed, little bit obsolete because of this”.

Quite difficult to accept is the reality of having to reconstitute a new identity as a PD patient: the handyman finds himself needing a hand to do daily tasks, and the emotive consequence is that the newly formed identity as a PD patient inevitably displaces his former one as the provider.

Social networks and communication

Individuals with PD can develop hypophonia (soft voice) which, if severe enough, can adversely affect social

functioning. A patient recounted his experience in losing the ability to communicate effectively with his formerly vast social network, a monthly amateur radio group, which afforded him an open line of communication with friends in many places:

“We had monthly meetings, a radio amateurs association. And I was one of the most active ones. We would get together every month and we would go everywhere. We went to Mexico; we went to many places, all of California ... And now, it’s been over a year since they last heard from me. Before, I would turn on my radio to communicate with people anywhere in the world. I have many friends. They send me letters asking why they don’t hear from me anymore. If I start to talk, I bite my lips”.

The tremendous loss for this patient was his inability to communicate verbally with his social network, now forced to partake in the physical communication of squeezing the microphone in order to indicate his presence: “Oh, I mean, I used to talk a lot with all those people in my town ... And that has affected me a lot, not being able to talk to them now. Just listen. And sometimes they tell me, ‘Hey, XXX, if you are listening, squeeze the microphone to let us know you are there’, and I just squeeze it and they hear me”. Particularly poignant is this patient’s realization that his formerly vast and vibrant social network, which brought him much joy and fulfillment, has now been reduced to the mechanical act of squeezing his hand. The loss of the ability to communicate verbally can thus lead to a loss of social networks, social roles, and self-identity.

Career

PD patients’ progressive loss of physical ability to carry out daily tasks impacted their roles in performing their jobs. Patients conveyed feelings of disappointment and loss after having to relinquish the job they had, reduce the number of hours, or switch to a job that was not as fast paced or physically demanding. Some of the patients commented on how the worsening physical conditions of PD forced them to leave their career, among them a graphic designer, a judge, a nurse, a schoolteacher, and a professional puppeteer. In one example, a teacher felt dispossessed of the skills necessary to educate students, and due to her PD, even the simple yet basic act of reading to students proved challenging: “And it just got worse and worse and worse and worse until I had to leave the job I loved. I can’t even go in and read a story to the kids anymore. The second grade students read more fluently than I do. Where do you go with that?” A similar yet perhaps more emblematic case was that of a puppeteer who used to perform educational shows – the artist who once adroitly

manipulated puppets in a powerful mastery of both motor and speech skills ultimately had to surrender to the seemingly all-consuming physical conditions of PD: "I had to give up my job. I was a professional puppeteer, and this didn't go with the words coming out. These were educational shows ... I was speaking in the back what had to be said but ... the mouth of the puppet wasn't working with what I was saying". Under the advancing grip of PD, the artist who once possessed the skill of carefully concerted manual dexterity found himself captive to the uncontrollable movements of his disease.

Emotional impact

The feelings elicited by the questions dealing with emotional wellbeing present a range of responses from both patients and caregivers. The category of impact on emotional status was shared by all participants, and it is noteworthy that the English and Spanish speakers appeared to have equal representation. One of the most notable variations could be seen within this category, in which caregivers provided comments almost twice as much as patients (11.2% versus 6.0%). One intriguing possibility for this difference is that caregivers were significantly impacted by having to face a double dilemma, ie, dealing with the patient's emotional needs in addition to their own.

Most patients commented on their initial depression or anger upon being diagnosed, while others reported that they became overly sensitive and easily driven to tears. Some patients noted that they experienced a sense of low self-esteem and of general uncertainty about themselves. One patient, presenting what may be at first glance a humorous occurrence at a social event, revealed a sense of embarrassment upon losing control of even the most basic physical functions, such as the ability to cut food: "I shouldn't tell you, but the other day I was at a Christmas luncheon and I was struggling trying to cut a piece of chicken ... and all of a sudden, half the chicken piece flew behind me and I hope it didn't land in the guest speaker's lap. At first, I truly found myself with just tears. I was so embarrassed". The sense of embarrassment and awkwardness that is implicit in such a social context was but one facet of the complex emotions intricately tied to the physical deterioration associated with PD.

Fears and uncertainty about the future

The primary concern among PD patients was that they would become a burden to loved ones, evoking fears regarding the loss of independence. One patient evocatively compared the experience of PD, and the underlying fear over its advancement, to

a roller coaster ride of sorts, the outcome of which would be unpredictable: "You know you're on this roller coaster and you know you're going downhill, but you don't know whether it's the kiddy coaster or the rocket from hell".

The primary fear experienced by caregivers centered on the uncertainty inherent in PD, particularly with regard to the future, of how the disease would progress and its toll on both the patient and loved ones. The children of PD patients expressed concern over the possibility of developing the disease. The fear of an intensifying sense of loneliness and alienation was also expressed by caregivers who witnessed the daily battle that a patient can face in dealing with dementia and forgetfulness. One spouse attested to the poignantly painful condition of seeing how PD progressively deprived her husband of his presence of mind, for which she felt a sense of constant fear that she would no longer be able to communicate with him:

"I really worry about the dementia. I mean, the physical part, I couldn't care less. I don't care that he can't walk, I'm strong, and I can manage that. It's the dementia and the absence of my husband that I worry about terribly. I mean, I have him physically there, I can see him, and I'm happy about that. But I miss him terribly. That's why I worry about the deterioration that way".

In this sense, PD not only can erode a patient's cognitive faculties and awareness, thereby transforming the patient's sense of identity, but can also destroy the most basic communication between patients and loved ones. In the case of PD with dementia, the patient's communication with the outside world is compromised not only by the physical impairment in speech, but also by the reduced cognitive awareness and acuity associated with dementia.

Yet fear of the future with PD also transcends the particular, at times encompassing a total sense of uncertainty and isolation from the world. One Spanish-speaking patient divulged an all-consuming fear of fear itself, so generalized and persistent that every aspect of daily life seemed plagued by a sense of unshakable uncertainty: "Fear of fear. Fear of going on the freeway. Fear of dawn. Fear of sunset. A fear that doesn't go away".

Stigma and other feelings about PD

The prevalent comments within the category of stigma and other feelings about PD reveal a constant preoccupation among both patients and caregivers. A sense of stigma manifested itself when the patient or caregiver had to interact in social settings or in the workplace, but not in the privacy of

the home. Some patients communicated a sense of stigma induced by the physical manifestations of PD, noting that they felt embarrassed by their inability to perform physical tasks, or perceiving that others may feel sadness, anxiety, pity, shame, or even feel resentful toward them due to their disease.

Within the category of stigma and other feelings about PD, there was a notable variation between nondemented participants with PD versus demented PD patients, as judged by their caregivers' comments, as well as between English and Spanish speakers. The finding that caregivers offered half as many comments as patients may point to the possibility that patients may feel a sense of stigma (embarrassment, shame) to a much higher degree than their caregivers. Surprisingly, not all comments related to stigma and other feelings were perceived as negative, because several patients noted how they had received overwhelming support from family and friends.

Stigma in social networks

Many patients noted that friends and family members exhibited a sense of unease, of being uncomfortable with the physical symptoms of PD. In this sense, the patients' perceived stigma is imposed upon them from external situations in which they have a heightened sense of awareness of their physical awkwardness or inability with basic motor skills. One caregiver declared surprise that her husband wanted to reveal his disease to everyone he knew, in what she amusingly referred to as a mass mailing:

"I had to tell my husband who wanted to announce it to the world when he first found out. He got these leaflets from Parkinson's, your friend has Parkinson's, and your family member has it, and here's what you're going to see, so you shouldn't be shocked. I was mortified! I did not want him to do this mass mailing to everybody. It's not that I didn't want him to say he had Parkinson's, but I didn't want him to make everybody feel uncomfortable or sorry for him".

Stigma in the workplace

Stigma in the workplace appears to be a significant concern for some patients, particularly because others' reactions to the symptoms of PD, such as tremor, may induce or exacerbate a sense of stigma in the patient. One patient expressed her embarrassment and stigma due to others' comments, which directly contributed to her decision not to divulge that she had PD: "One person did see me shake and go, 'Oh my god, I hope it's not Parkinson's'". One patient conveyed frustration over having to tell or explain to others at work about the

disease: "Sometimes I wish I could wear a badge that says 'don't ask, I have Parkinson's disease'". Another patient in this study, a health care provider, pointed to the instances of awkwardness and embarrassment in explaining to her own patients that her symptoms of PD would not interfere with her ability to perform her job:

"I work so hard trying to control my shaking that my patients wouldn't or their families wouldn't see it. But, you know, it got to the point where I couldn't do that anymore. And they were very bold about it. They go, 'how come your arm shakes?' Well, I have a disease that requires me to take medication ... you know, I want to let you know that it doesn't affect my brain or my ability to take care of you".

Beyond stigma

Not all feelings related to PD are negative, because patients noted that most family members, friends, and coworkers had been helpful and supportive. One patient commented how others' reactions to her PD were positive, even in a public venue in which everyone is watching: "I tripped down the steps and everybody in the bus just went (made gasping noise) and everybody stood up to try to help me. I mean, I would've thought they would've thought that I was drunk or on drugs, or something. It was so beautiful". In this example, the patient had the expectation that others would make her feel embarrassed and self-conscious after a fall, yet complete strangers' desire to help without passing judgment suggested to her that others may not deliberately intend to inflict stigma.

Coping mechanisms

The comments pertaining to coping mechanisms represent the third most salient category across all subgroups. The impairment of physical functioning associated with PD motivated both patients and caregivers to find creative solutions, thereby enabling both groups to cope with the reality and consequences of the disease. In comparing patients with caregivers, the former offered twice as many comments related to the category of coping mechanisms, which suggests that PD patients without dementia may be more actively engaged in their quest to find ways to mitigate the symptoms of their disease than are PD patients with cognitive impairment.

The three most identifiable coping mechanisms relate to personal attitude and mental outlook, the attempt to control the environment, or the attempt to control the signs and symptoms of PD. Most patients and caregivers reported that there are specific things they can do to mitigate the symptoms of PD, ranging from doing certain physical

activities (yoga, walking, riding a stationary bicycle) to fostering positive thinking and an optimistic attitude as a way to cope with challenging situations. The latter finding coincides with a study reporting that the majority of coping mechanisms of PD patients are psychological, such as focusing on psychosocial stressors related to the disease.¹² One coping mechanism noted by patients and caregivers was the need to take the medication according to an established routine, proving particularly helpful when the patient takes the medication within a specific timeframe before engaging in activities that may be demanding.

Partaking in activities outside of the daily routine could also be beneficial to patients. One caregiver, for instance, mentioned benefits associated with leaving the house, such as going to a movie once a week, or even more adventurous, going horseback riding: "It's called hippotherapy, and she goes once a week and does physical therapy on horseback. And it blows your mind, she can't do it in her wheelchair, but get her up on a horse, and it just amazes me what she can do, so that's the high point of her week". One patient expressed the sense of accomplishment for finishing a 10 km bike ride, with the help and support of family: "Now, I had to ride on the back of a tandem bike with my husband, but we did it. My daughter rode along with us. And I had to walk the last part because my legs started moving around so much I was banging it against the bike, so I had to get off and walk the last part of the ride, but I finished it". Sheer determination and stamina can have clear benefits, among the most important being the fostering of a positive outlook and the preservation of some sense of normalcy.

Benefits of having PD

In the category pertaining to benefits of having PD, responses centered on both patients' and caregivers' profound appreciation for life, and on strengthening meaningful relationships with loved ones. Intergroup variations were relatively minimal. Some patients and caregivers declined to acknowledge that there could be any benefits of having PD when posed the question. However, some patients manifested a sense of relief or gratitude that they did not have a worse disease, such as cancer. One patient even jokingly referred to his disease as a strangely convenient benefit that enabled him to avoid tasks he would rather not do: "And I do use my Parkinson's card in my favor at times when my wife asks me to wash the dishes. I'm, like, 'you really want me to wash the dishes?' I use it to my favor sometimes". While quite humorous in its undertones, this perspective seems therapeutic in turning a physical impairment into an advantage. Another patient expressed a more philosophical view about living

with PD, pointing out that the slowing down of physical activity has also led to a more leisurely appreciation of life and its winding path: "I always remember a saying that somebody said a long time ago, and I think Parkinson's sort of makes you think about that is 'life is not a race, it's a journey to be enjoyed'. And I think it slows you down a little bit, but I think you enjoy the journey a lot more, too".

While both patients and caregivers commented on the sense of loss that accompanies PD, members from both groups pointed out that the experience had led to the forging of closer and more meaningful relationships. One caregiver, for instance, commented on the dichotomy of balancing the negative repercussions of the physical deterioration with the more positive outcome of strengthening spousal and familial ties:

"I know that for me, it's made me a much stronger person and I guess it's because I have such intense feelings for my husband. He's the love of my life and even though we have this illness which has deprived us, robbed us of so much, it has made our life so much more meaningful in many ways. While we may be restricted in many things we may do, we have a very rich wonderful life and our kids on both our sides have also been touched by that. I think it's made all of us much closer – actually we've always been close – but I think this has made us appreciate each other so much more and has made us so much more empathetic toward others who may have these challenges".

Thus, the experience of PD, while diminishing the quality of life of both patients and caregivers, also appears to sometimes enhance the sense of appreciation for life and for each other. In the face of much adversity, patients and caregivers noted the benefit of refocusing on what is important in their lives, such as love and the strengthening of their familial relationships.

Discussion

This study examined the broad HRQOL consequences of Parkinson's disease from the patient's perspective, and provides insights into possible remedies that health care providers can apply in their care of these patients. HRQOL has been a growing area of importance in the past three decades, particularly among patients with chronic diseases.¹¹ It is recommended that such measures be grounded in qualitative research to incorporate the perspectives of persons with the disease.^{4,6,11} However, there is a dearth of literature that has qualitatively explored HRQOL issues in the field of Parkinson's disease and incorporated these data into HRQOL measure development.¹¹

Emotional consequences of the impairment in physical functioning

Similar to qualitative studies of other neurodegenerative diseases, in our study patients discussed changes and adapting to the changes in physical functioning.^{18,19} The impairment in physical functioning due to symptoms of PD, which accounts for more than 40% of all comments, is an undeniable reality that affects both patients and caregivers. The emotional, social, and cognitive impact of the problems associated with physical functioning in PD patients may seem unfathomable, because it permeates to the very core of their social role and functioning, ie, their unique place in the world. For instance, a study examined perspectives of women who have PD in household tasks often delegated to females, such as grocery shopping and meal preparation. The women were struggling to maintain independence and keeping up with these types of duties vis-à-vis their changing health condition. Ultimately, this revealed the underlying need to evaluate psychosocial and stress factors in PD patients' daily life situations.²⁰

It is particularly poignant to see, for example, how PD gradually depletes patients of basic motor and eventually cognitive skills necessary to perform their jobs. Yet, far from representing an antithetical aspect to the physical functioning problems presented by PD, the remaining comments are in fact intricately related. The nonphysical ramifications of PD, therefore, in part appear to stem from the primary condition of having difficulties with physical functioning, and the emotional and social consequences extend well beyond the gnarly, knotted roots of the vast tree that constitutes the experience of having PD.

PD seems to be so devastating for many patients because it is akin to being “trapped” in an emotionless, uncontrollable body with which people are highly uncomfortable. While in the early stages, it is more commonly a physically pain-free disease, its toll is emotionally and socially painful. For the patient, PD represents an unspeakable void, including loss of movement, loss of former social roles, activities, and network, and loss of one's former identity. The loss of facial expression, in particular, seems emblematic of the PD experience. What has been termed a “facial mask” in fact becomes an iconic representation of the reality a PD patient endures as the disease progresses: the patient feels trapped in a mask. It is the impassive facial mask that can be readily interpreted as an emotional and cognitive detachment, and which can lead to the lack of emotive communication and to a state of disengagement from the world. In this sense, the facial mask is the ultimate symbolic representation of the transformative and life-altering process that is PD. As the patient's

ability to communicate with the outside world diminishes over time, those around may not fully understand the patient's eventual inability to express emotions such as love and tenderness. The face that previously smiled at the touch of a light kiss becomes the “mask face” that to others may seem imperturbable and devoid of the most basic human emotions. In PD, the metaphor can become reality.

A PD patient's impairment in physical functioning may lead to the feeling of being trapped in an uncontrollable and unpredictable body, one which may seem unresponsive to the most basic cognitive processes. Being trapped in a body that is progressively unresponsive and unmanageable, the individual with PD may become progressively constrained physically, cognitively, emotionally, and socially. The sense of being trapped in a body that is nonresponsive may also lead to the loss of social connectivity, in which some family members, friends, and coworkers may drift away and disconnect with the patient. Inevitably, the withering of the social network, coupled with the constraint and limitations of a nonresponsive body, may lead to a pronounced state of loneliness, which may persist to the point in which the patient may feel the burden of dying alone.

Suggestions to remedy or mitigate adverse conditions

One of the greatest challenges that both patients and caregivers face is how to negotiate the uncertainty in performing basic physical tasks, how to mitigate the adverse conditions of PD, which encompass not only the physical symptoms, but also the emotional and social consequences of the disease. The uncertainty of what the future holds, coupled with the unpredictable facet of losing physical and emotional control, may not be entirely remedied, yet patients and caregivers may be able to take steps to cope with this uncertainty, and with the sense of loss encountered as a result of the inevitable changes in identity and social roles.

One possibility that patients faced, which is far from ideal, was to lower expectations by taking themselves out of the need to cope, that is, by withdrawing from life. For instance, some patients, revealing a state of heightened sensitivity due to what others around them might think or feel in response to their disease, may have been deterred from openly communicating to others that they have Parkinson's.

Among the suggestions we offer both PD patients and their caregivers, the most important is to prepare for the inevitable changes upon receiving the diagnosis of the disease. Issues reported in another study were congruent with the findings in this study that it is critically important for patients and caregivers

to communicate openly about the disease, understanding that while frustrations will arise, an open line of communication about physical and role changes will help them in living with the disease.²¹ In establishing communication between patients and caregivers, it is also critical to recognize that communication may manifest itself in ways that are not entirely verbal, eg, familiar gestures, signs, or codes may prove to be an effective mode of communication for patients whose speech may be impaired. Finally, in dealing with the possible stigma associated with PD, both patients and caregivers may be empowered in knowing that such feelings may be controlled by the way in which they respond to social situations.

Therefore, one way to establish a sense of order and reliability in the face of constant physical and emotional challenges is to build a daily regimen that may reduce the uncertainty. The daily routine may include therapeutic activities that prove helpful in mitigating both the physical and emotional toll of PD, such as yoga, tai chi, and other forms of exercise being investigated in PD treatment.^{22–24} Although it presents a significant challenge both to patients and caregivers, another way to diminish the uncertainty involved in the progression of PD symptoms is to create and maintain a healthy social network of family and friends. One critical step in fostering and maintaining a vital social network is to find mechanisms for expressing emotion. For instance, one possibility is to devise a code for significant others, by which three taps may mean “I love you”. Developing a code for emotions may help patients in alleviating some of the frustration and anxiety related to living with PD.

Limitations

There are several limitations of this study. While we attempted to recruit participants from all ethnic and cultural groups, our focus groups were nearly entirely comprised of Caucasian and Hispanic participants. While we were able to capture in this study views from Hispanic participants, which comprise the largest racial and ethnic minority, as well as the fastest growing group in the US (see <http://www.census.gov/>), perspectives of several other racial/ethnic groups were not incorporated. In addition, we did not have representation from cultures outside the US. Another limitation is that we cannot ascertain whether some opinions may have been overly represented, despite the fact that experienced moderators attempted to encourage equal participation among all participants.

Conclusion

For a PD patient experiencing a downward spiraling of physical functioning, which is accompanied by complex emotions,

it may seem particularly daunting to transcend the widening gap that is perceived between self and others. One of the challenges posed by the deadening or stiffening of bodily movements, which is most emblematically represented by the facial mask of patients as the disease advances, is how to re-establish and maintain the sense of normalcy and comfort that comes with open and engaging lines of communication. In this respect, caregivers or family members can perform a critically important role in enabling lines of communication between the patient and the outside world through the fostering of a healthy social network, therefore finding creative ways with which to cope, endure, and provide relief for the patient. In light of the emotive impact of PD in both patients and caregivers, one recommendation is for clinicians to elicit more information about feelings such as embarrassment, shame, humiliation, and stigma, all of which appear to play a significant role in how effectively a patient may cope with the disease. By being particularly attentive to PD patients' difficulties in coping with the emotional consequences of PD, both caregivers and clinicians would be better able to identify ways in which patients can take steps toward improving their quality of life.

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Disclosure

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Appendix

Sample script from the Parkinson's disease quality of life study, patient focus group discussion guide.

"The protocol below outlines the topics that will be covered during the focus groups and provides examples of the

types of open-ended questions that we plan to ask. However, we will follow the lead of participants and will ask additional questions if necessary to discuss a particular topic fully, or pursue other topics if they are raised in the group as being important".

Welcome

Welcome. I want to thank you for coming today. My name is _____ and I will be the facilitator for today's group discussion. I am a researcher and I work for the RAND Corporation. We also have _____ present to take notes for us. [My colleague(s) _____ are also sitting in on today's discussion and they may have a few questions for you later on]

We invited you to take part in this group discussion today because you have been diagnosed with Parkinson's disease. We would like to talk with you today about your health and health care, about the impact the disease has had on your day-to-day life, on your family, on your ability to do things, about the problems you face as a result of the disease, and about how you feel about having Parkinson's in general

What we learn from today's discussion will help us better understand the impact Parkinson's disease has on the people who have it and this information in turn will help us develop treatments or services to help improve the quality of life for people who have Parkinson's disease

Ground rules

Before we begin, I would like to review a few ground rules for the discussion

- a. I am going to ask you several questions and I'd like to give everyone a chance to give their opinions. We do not have to go in any particular order but we do want everyone to take part in the discussion. We ask that only one person speak at a time
- b. We're interested in your opinions and whatever you have to say is fine with us. There are no right or wrong answers. We are just asking for your opinions based on your own personal experience. We are here to learn from you
- c. Don't worry about having a different opinion than someone else. But please do respect each other's answers or opinions
- d. If there is a particular question you don't want to answer, you don't have to
- e. Feel free to treat this as a discussion and to ask questions of each other and to respond to what others are saying, whether you agree or disagree
- f. We will treat your answers as confidential. We are not going to ask for anything that could identify you and we are only going to use first names during the discussion. We also ask that each of you respect the privacy of everyone in the room and not share or repeat what is said here in any way that could identify anyone in this room
- g. We are taperecording the discussion today and also taking notes because we don't want to miss any of your comments. However, once we start the tape recorder we will not use anyone's full name and we ask that you do the same
- h. We will not include your names or any other information that could identify you or your family in any reports we write. We will tear up our notes and destroy the audiotapes after we complete our study and publish the results
- i. Finally, this discussion is going to take about two hours and we ask that you stay for the entire meeting. At the end of the discussion we will give you \$65 to thank you for participating

Does anyone have any questions before we start?

Introduction

I'd like to go around the table starting on my right and have each person introduce him or herself. Please tell us your first name only and tell us how long you have had Parkinson's.

Group discussion

Parkinson's disease affects different people in different ways. Today we would like to talk about the effect Parkinson's disease has had on your life

Topic 1. Physical functioning

The first thing that we'd like for you to discuss is how Parkinson's disease has affected you physically

1. How has Parkinson's disease affected your ability to do things?
2. Tell us about any physical activities that you have stopped doing because of your Parkinson's disease?
3. Tell us about any physical activities that you now need help with as a result of your Parkinson's disease?
4. Tell us about any physical problems you've experienced as a result of Parkinson's disease?
5. If necessary: How has Parkinson's disease affected your sleep?

Topic 2. Impact on emotional status

Now, we'd like to discuss how Parkinson's disease has affected you emotionally

6. How has Parkinson's disease affected you emotionally?
7. Tell us a little about how you are coping or feeling now about your Parkinson's disease?
8. Tell us about any emotional problems or issues you may have experienced as a result of your Parkinson's disease?

Topic 3. Social and role functioning (family, work, and others, public versus private life)

Now I'd like you tell us a little about how having Parkinson's has affected your day-to-day life

9. How has having Parkinson's affected your day-to-day life?
10. How has having Parkinson's affected your daily routine?
11. Are there any activities that you can no longer do because of your Parkinson's disease? (eg, work, hobbies, sports, social events, etc)
12. How has having Parkinson's affected your family?
13. How has having Parkinson's affected the things you do with your family?
14. How has having Parkinson's affected your social life?

Topic 4. Stigma and other feelings about Parkinson's

Now I'd like us to talk about how you think Parkinson's has affected your relationship with other people

15. Are there any activities that you have given up or that you prefer not to do anymore because of your Parkinson's disease? Tell us about that
16. How have your friends and relatives reacted to your Parkinson's disease?
17. Do you tell people that you have Parkinson's disease?
18. Why or why not?
19. Do you think people treat you differently than they normally would because you have Parkinson's?
20. If yes: Tell me about that. How do they treat you?
21. How do you feel about having Parkinson's?

Topic 5. Fears

22. Do you have any concerns about what is going to happen to you in the future as a result of the Parkinson's disease?
23. What do you think is going to be worse for you in the future?

Topic 6. Coping mechanisms and positive feelings

Now I'd like us to talk about different things you do to cope with your Parkinson's disease and the problems that you have as a result of your Parkinson's disease

24. Is there anything in particular you are doing to help treat or deal with your disease?
25. Finally, there are lots of ways people experience illnesses such as this – some bad and some good. Are there any good things or benefits to having Parkinson's disease?
26. Has anything in your life changed for the better since you found out you had Parkinson's disease?
27. If yes: Tell us about that.

10. Review and wrapup

Thank you for coming today and for sharing your opinions with us. We hope you enjoyed the discussion today

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