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Living with Parkinson's disease—managing identity together

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Abstract

The specific aim of this paper is to discuss how individuals living with Parkinson's disease and their main family supports perceive communications with each other, with a focus on their roles related to care. The paper is based on individual interviews conducted with individuals and their main family support person. The transcripts were analyzed based on grounded theory and "managing identity together" emerged as the core category. This is discussed in terms of independence, a sense of self-sufficiency and an overall sense of personhood. Implications for other populations conclude the paper.

Key words: *Parkinson's disease, care, communication, identity, personhood, caregiver, grounded theory*

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Introduction

The global aging population will require more supports than ever before, not only from health care systems and social service delivery agencies, but also from unpaid caregivers[1] (Novak & Campbell, 2006). Parkinson's disease (PD) is commonly diagnosed in individuals over the age of 50 (Public Health Agency of Canada, 2000). The cardinal symptoms of PD include: resting tremor, cogwheel rigidity, bradykinesia/akinesia, and postural reflex impairment (Michigan Parkinson's Foundation, 2003). PD is similar to conditions, such as Alzheimer's, Multiple Sclerosis, and Huntington disease in that these conditions are chronic, neurodegenerative, and progressive in nature (Public Health Agency of Canada, 2000). None has a cure and each may include persons living a long time in the community with slowly decreasing mobility and/or cognitive capacity, as well as associated stigma and isolation as the disease trajectory continues. While we focus PD in this paper, there is an overlap regarding care and social service provision when comparing key issues with other terminal medical conditions that include neurological decline.

In particular, the need to better understand how persons with terminal medical conditions perceive communication with family supports cannot be understated. On the one hand, theorizing about autonomy in a health care setting has taken a front seat in Western societies in the last few years; and, on the other hand, many family systems and the cultural contexts families inhabit actually indicate a relatively strong collectivist nature opposing traditional views of autonomy. Very little research exists, however, on how persons with any type of terminal medical condition perceive communication with key family supports in a way that assist us either in theorizing about autonomy or communication in a more collectivist context. Gathering more information on perceptions of communication, as was the focus of this study, contribute to our understanding of communication within the caregiving dyad. This is a timely new area of investigation, internationally important in the context of today's cost and time restrained health care environments, and given the increasing discussions about autonomy in the context of care. Key objectives of the study include:

1. To analyze how partners perceive their roles in communication.
2. To examine the meanings partners assign to communication experiences.
3. To identify how experiences of communication changed over time.

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This paper in particular will focus on the data collected regarding the perception of communication between family supports and individuals living with PD.

Methods

Ethics approval

The authors prepared an ethics protocol for the most suitable ethics review committee at the local university and this was approved. Components of this protocol include: (a) a script for the research assistant to be used when discussing possible recruitment with relevant organizations and a script to be used when discussing the study with potential future participants; (b) a list of the interview questions; (c) a pledge of confidentiality for the research assistant and the transcriber; and (d) a consent form that described the study, it identified the process that ensured the participant's confidentiality and how this would be maintained over time. The consent form addresses the treatment of the data once the study is complete, how the data will be stored, and when and how the data will be discarded.

Participants and recruitment

After receiving ethics approval from the institutional ethics review board at the University of Manitoba, relevant local centers were contacted. This included the Parkinson's Society as well as senior centers, health care centers, and local hospitals. Recruitment was accomplished by using three primary methods: (a) a recruitment notice for newsletters was created describing the study and this was placed in established and well-known settings, and in newspapers likely to recruit desirable participants, (b) oral presentations of the study were held in suitable professional and community-based meetings, and (c) staff from selected organizations assisted us by letting their clientele know about the study.

Participants with PD and an interest to participate in the study were eligible if they met the following inclusion criteria:

- They understood the primary goal of the study and were able to articulate their thoughts verbally on the topic.
- They were able to provide consent at the beginning of the study by reading the consent form, asking questions about the study, and signing the consent forms.
- They were able to hold a full conversation in English.
- They or a family support was affiliated with one of the selected and recognized institutions.
- A primary diagnosis of PD had occurred as confirmed by a key family support, a physician, social worker, nurse, or patient care manager familiar with the participant's history.
- Over 18 years of age.

Individuals were also asked whether they would provide one key family support person. Yet, a person with PD could take part in this study even if they had no key family support and wanted to select a second health care provider, or their key family support declined but someone else was willing to be interviewed. The definition of the family support person was quite broad including family members, common law partners, neighbors who provide significant frequent care, or another relative doing the same. This individual would also sign a consent form prior to being interviewed. Both the individual and their family support received an honorarium for their participation. Confidentiality agreements as documented through the consent form applied to each participant.

Participants in the study had engaged in communications regarding health care involving a person with PD in the last six months.[2] We aimed for equal representation of individuals in the proposed categories: the individual with PD ($N = 4$) and a family support ($N = 4$). For this paper, three heterosexual spousal couples were interviewed and one male/female sibling pair, each where one person had PD. Participants ranged from 40 to 80 years of age.

Interviews

The initial interview questions were reviewed by two experts and revisions were made that simplified some of the wording and reorganized the order of the questions. These revisions were sent to the university's ethics review committee for re-approval, which was obtained. The outline of the interview was as follows: a demographic section including three introductory questions was used first to assess the emotional state of the person on the day of the interview was used to start the interview process. Then, open-ended questions were used to investigate the primary objectives of the study. Examples are as follows:

- When was your diagnosis? What attitudes did you have about PD before the diagnosis? How did you cope at first with this? What has changed for you since your diagnosis?
- In the last three months, what are some of the care related communications you have engaged in with your [family support] unpaid caregiver? What would you change about your caregiver's

participation in those communications? What would you not change? How do you envision their role as an ideal?
- How would you describe 'independence' for people with this diagnosis? Does this change? If so, how or how not?

New probes for the questions were developed as we continued to collect data, based on the findings in the initial interviews. Each participant was interviewed individually; all interviews were audiotaped and transcribed verbatim. Field notes were made in each interview and these contributed to the ongoing interviews and analysis of the data. None of the participants requested counseling in relation to the interviews, and all participants stated that the interview had been useful for them, in some cases for their family support member also, and had been a positive experience.

Analysis

Grounded theory allows for the study of human behavior in a social context (Glaser & Strauss, 1967) and is an appropriate approach when little is known about the topic of interest. This approach includes an inductive process in that data is analyzed as it is being collected. Key concepts and inherent relationships are generated and analyzed simultaneously moving the data beyond mere description to the development of a core category. In this way, meaning is made of the participant's experiences and how this meaning becomes embedded in a social context. Furthermore, initial hypotheses direct the theoretical sampling in order to saturate categories.

The data was constantly being compared as initial interviews were conducted, transcribed, entered, and coded in an attempt to discover common categories and concepts. NVIVO8, a recognized qualitative data management program, was used to enter data and code all transcribed interviews as they were being conducted. Three levels of coding occurred. In open coding, the first level, all available data was coded line by line. Here, participant words were often used to label codes and codes were compared as the analysis continued. Codes with similar meanings were grouped, allowing for the development of broader and more abstract labels. Emerging broader categories were then compared, and the research team paid attention to variations and the possibility of mutual exclusiveness of specific categories. Eventually, all generated categories were deemed to be saturated given integration of the field notes, the subsequent interviews, and the ongoing analysis. Theoretical sampling had occurred through our search for participants who provided data that confirmed and refined emerging categories. As we continued, theoretical saturation became possible. This process can be described as an iterative constant comparative method in which data collection, coding, and analysis occurred concurrently in order to produce a core category. Throughout this process, interrelationships between and within categories were discovered, explored, compared and verified, and allowed for theoretical coding. Finally, a more abstract elevated analysis was conducted through which a core category emerged, named "managing identity together."

"Managing identity together" summarized an overarching experience of communication as it was perceived by these participants. Participants discussed the benefits and drawbacks of being able to manage change at different points in their disease trajectory, and the important role they perceived that communication with family supports played in managing care/disease related changes. Thus, "managing identity together" provides an important theoretical direction derived from the data for how care related communications were perceived by the participants.

Results

The core category of "managing identity together" emerged as participants revealed how they did not want to be seen as unusual by their family and friends, now that they had this diagnosis. At the same time, what makes the core category of "managing identity together" so poignant, was that participants had to recognize the need to address, communicate, and manage real changes associated with PD. Although participants with PD were experiencing an increasing lack of control over their bodies, and new emotions as they processed these changes, they stressed the value and importance of remaining themselves—for example, a "partner" in their personal relationships rather than a "patient." This was linked to their dislike of the label "unpaid caregiver" given to their partners. In the context of long standing relationships with their family supports, achieving a balance between "managing identity together" and retaining "normalcy" was critical to them. Not only did they want to continue doing what they had always done, they wanted this normalcy to continue for their family support person as well. A diagnosis of identity was a process that was deeply motivated by wanting to remain the same.

Three categories were labeled that relate specifically to the core category, "managing identity together." These categories described strategies employed by the participants in order to handle new situations in relation to communicating with their family supports and in an attempt to manage change: (a) the participants described their "first moments" of acceptance and communication about the condition; (b) the participants described how they communicated about "daily care" needs with an intent to manage changes related to the disease, while also trying to achieve a sense of previous normalcy; (c) all participants stated that "helping others" in the same situation by communicating what they had learned was an important way to manage/accept their own changes. The findings reveal how participants were newly forced to communicate about physical experiences, newly acquired dependencies, and growing fears with more frequency. This occurred in a way that fundamentally changed their daily interactions with family supports and how they were used to relating to each other, requiring them to "manage change" as part of daily life.

The first moment of change after diagnosis

Participants spoke about the first moments they realized they might be very sick, while others spoke about the moment of diagnosis itself. This moment was fundamental in that participants were forced to change the way that they perceived themselves in relationship to others—"I am not the same" was in competition with being motivated to continue or imagine that they were the same for quite a while. Janelle reflects on her initial thoughts about possibly being sick:

> I was at work actually and I was telling somebody about the book, and I said, oh wouldn't that be weird if I had PD, and of course everybody said, oh what are you talking about? You don't have PD. And I just laughed at first, and I thought, okay I'm just being weird. Just at that moment, I said, wouldn't that be funny if I did, and after everybody left, I kinda had a few tears because I pretty much knew I had it. Yeah, I don't know why, I just knew it.

The growing acceptance that something did not feel right in Janelle's body had led to initial conversations with others, as seen above. Janelle later states that when she was diagnosed, she did not feel sorry for herself, but she did say that she was just "very angry." When she communicated her diagnosis to Daniel, her husband, he wept with her. He said that he knew instantly that "things would never be the same again." A terminal diagnosis is a diagnosis of identity as well—beyond changes in the body—the first moments of recognizing that one has a terminal condition renders a diagnosis of the self and identity simultaneously.

Finding normalcy for oneself in these early phases of recognition was seen as critical for all participants, including the family supports. Initially, normalcy was seen through the lens of "what had been" rather than creating a new normal, which emerged later in the process of acceptance. Since the changing disease trajectory would bring about many changes for the participants subsequent to their diagnosis, they were reminded that these first moments of recognition ("I have a terminal disease and I will die from it" was a stark juxtaposition between "what has always been me" and "changes now to come"). Managing identity together meant a constant interplay between these three concepts, at times in large sweeping and smooth transitions and at times in fear and anxiety.

Margareta similarly reports on her intense anger which began at the moment of diagnosis. She says she continues even now to swear and yell to relieve her anger and she admitted that she had perhaps become "more of a mean person" because of this. Since her husband is deaf, the interviews revealed that she believes he doesn't hear these responses, resulting in her frequent conversations with long standing girlfriends. Participants with PD felt a tangible emotional pain upon discovering that they had a terminal condition and certainly, this was intensified when communicating the diagnosis to their caregivers. They began right away to consider that they were dependent on this person, and yet, none of the participants with PD found that an easy or smooth transition. Daniel, Janelle's husband, said they always had to prepare themselves now that they might have a bad day, that symptoms could arise at any time, and that they might have to excuse themselves from pre-planned activities. Again, the concept that a terminal diagnosis resulted in a diagnosis of a changed identity was mirrored in the spouse's reactions as well. Their identity as a couple would fundamentally change, not just as individuals.

Neil and Flora present a very different and important reality. Neil reflected on a pre-existing spinal condition which was troubling him and led to a visit to the doctor, and this led to a subsequent diagnosis of PD. Both he and his wife Flora had already adjusted to changes due to this first spinal condition, so that when the diagnosis of PD was communicated to them, they both stated they only had to tweak existing care practices (and communications about care). Identities were not under assault here—either individually or as a couple. Anger and shock did not appear to be part of their experience. Their example demonstrates important variations to our earlier example in responding to such a serious life event.

The moment of diagnosis and how participants communicated about it, was centrally affected by their stage in life and in their relationship, their previous experience with this or other illnesses in their families, what they knew about the health care system, and the nature of their communication as a couple. No two terminal diagnoses can be said to be the same, rendering individual stories as important teachers for others. In developing a better understanding of the role of spouses/family in communicating about the early moments of a diagnosis, these variations must be kept in mind.

Managing identity together: a part of ongoing daily experience

After the first shock and the moment of diagnosis or recognition, participants had a range of responses regarding their ongoing process of managing change in a daily way. Daniel suggests about Janelle:

> Yes it has, because I want, I guess I want to make sure that she knows and understands everything that I say to her thoroughly. I want to make sure that she knows how I feel and I think she needs to know all that before, before something happens to her. . . . I don't want her to miss out on the things that she should be doing, or at least try and live every day to the max while she's still on this planet, to experience the things that she should be experiencing, if not with me, but for herself, things like that.

At another point, Daniel also described this new experience as being a "rollercoaster ride" and that it was not always easy on him. For example, he described going shopping with Janelle on a good day and how glorious he felt. However, on a "bad day" they suddenly had to turn back home, because despite their best planning efforts Janelle wasn't feeling well. His disappointment was palpable. Janelle suggested that Daniel sometimes accused her "of just giving up" and that she had promised him she would never do this. The struggle to assess on any given day whether it was her will or her mood, or the PD and related symptoms, that led to a negative outcome preoccupied both Janelle and Daniel. Communication could become hidden and coded for both of them, trying to guess what the other was thinking, how the other was feeling. While most relationships can be qualified like this to some degree, this aspect appeared to intensify for Daniel and Janelle once PD was diagnosed. More importantly, they learned they had to communicate more clearly about a new range of physical experiences and emotional worlds, given the unexpected and constant fluctuations in Janelle's condition. In fact, it is critical to understand the extent to which the disease experience became a "partner" in their ongoing daily communications in a way it had not been previously. The disease became part of their identity as a couple.

For Neil, accepting PD was more measured for a number of reasons: he had experienced PD in his family before and this awareness of his familial history was understood by his wife Flora. Given other work in this area (Roger, 2006a, 2006b; 2007a, 2007b), it is apparent that family stories shape the realities of a terminal condition in significant ways. The history of others in one's own family, their behaviors, and their responses are told about in ways that shape their current responses. It is obvious that previous experience with PD in the family teaches people a wide range of skills and knowledge, including those related to care. Neil says:

> Well, it's something I knew my family had had. My grandfather had it. He became a legend in his own time way back when I was quite young. In as much as he had, the mouth dries out so, and he carried a mickey bottle of water and when his mouth dried out, he'd pull the flask out and take a sip. So we used to joke about that. I don't know. People have different diseases, so you accept what you got.

Friedrich sounded very matter of fact in regards to daily aspects of care and his acceptance of Margareta's PD: "it's something that happens to other people and it happened to us this time. So, you know, it's something that you have to live with right now." Their older age (over 80) may have changed the kind of response they would have to terminal illness. Friedrich repeats those words over and over again throughout the interview, and one wonders whether he is convincing himself or comforting himself. It is possible that his hearing losses have already taught him something about managing the diagnosis as one of the "self" as well (it can happen to anyone including me) and now "something" has happened to his wife to change her identity as well. This seemed to be more acceptable to Friedrich than some of the other spouses.

On the other hand, however, Flora describes how needing to make care-related decisions daily, sometimes without communicating with Neil, forced her to come to terms with her own limits:

> Like I'm not, if you think I'm gonna be standing there with the needle kind of doing the injections. Forget that. That was my limit. So that was, but it

> was a care decision. He periodically has skin issues and then it's always this care decision about whether we call in the nurses again. Whether you go, it's always like okay you've got this problem, who do you see first? (Int.: When the decision was made about the insulin, how did you guys make that decision?) Actually it was sort of, it was obvious that it had to happen and actually by the time the whole system got active, you get to the doctor. You get to the nurse specialist and she starts talking about it and doing it, it was sort of like, let's get this on with this. This is taking too long now. So by that time, the decision felt very comfortable. It wasn't unsure at all. And then knowing the technology of doing injections and the fact that he can do it himself, like put all my issues away. In terms of I'm not gonna do this. Well he can do it himself.

People would offer her (or them) their help and she would say—"thanks for offering, but no because it has become such an almost a choreographed dance between us that we have to do this move and that move, even to accomplish simple things, and we have to keep talking about it." They had developed such a personalized way of communicating, that when one nurse turned to Neil and demanded he say thankyou to his wife, they told the nurse that they said thank-you once a day, something she was not aware of. In this way, communication between patient and caregiver also becomes like a finely tuned machine that outsiders cannot always understand or have access to. Autonomy had disappeared and instead, the relationship had become one intertwining identity. In this context, daily care was already embedded in Flora and Neil's relating to each other, before the diagnosis of PD. Understanding the patterns of communication as perceived by participants becomes an invaluable tool when assessing the types of care and resources, programming or health care assistance individual couples need. The question is not to ask what "individuals" need, since these couples demonstrate life together as part of the diagnosis.

One can argue, given these examples, that to impose a generic package of care and to assume that patients will make decisions on their own behalf, can only work in some rare cases and as we have seen, is unsuitable for others. For example, developing care services in the context of terminal illness requires an intimate knowledge and experience of how patients and their family supports have previously "managed change." An understanding is critical, of how they are now and have in the past communicated about decisions, what has been successful about that process, and when a patient's wishes were not followed, what were the outcomes.

Assisting others as part of managing identity together

It was clear that the participants experienced communicating to others what they had learned about PD as a very meaningful activity in their own process of managing a change in their identity. Daniel spoke at length about how family supports need to keep in mind the person behind the disease, that this was the person they had known for a long time. To his mind, patience was truly a virtue. In fact, Daniel had appeared reticent initially to participate in this research but subsequently said, "if this can help anyone, anyone at all, then my time here was worth it." His willingness to share his knowledge with others was demonstrated throughout the interview. Janelle felt it was important for people to know that things had been much worse for people with PD 20 years ago. She stressed that having hope was very realistic, and she encouraged others to have it, given the changes she had witnessed in her lifetime regarding care for PD. Flora had spent her life as a social worker and from the beginning of the diagnosis, shared "stop thinking and get planning" as her best advice. It was important to accept that life doesn't always have all those choices one hopes for.

Friedrich's recommendations to others with PD compared with how he had handled his wife's condition as well—"this is life" and one should accept it. Margareta's approach was to read lot, talk with her friends, and become very involved in community based activities. She also mentioned that "praying a lot" was a helpful activity. At one point in the interview, Margareta communicates how much she enjoys helping others as a way of processing her condition. She admits that that was her purpose for participating in this study as well—to hopefully help others. In this way, several participants communicated that participating in this study was their hope to do something good for others, but they also agreed that participation brought them some relief in talking about their experiences and sharing them. Making meaning of a difficult situation clearly hinged on their impact also on other people.

Discussion

Bioethicists identify the number one challenge people face in health care settings was disagreement between patients, families, and health care members regarding treatment and care (Breslin, MacRae, Singer, & University of Toronto Joint Centre for Bioethics Clinical Ethics Group, 2005). Although there is a waning of paternalism within the health care system, the subsequent understanding of people's roles can remain unclear to individuals and their family members. For example, Caron, Griffith, and Arcand (2005) found that family caregivers did not know what was expected of them in care related communications and the level of involvement in care as they felt they did not receive any clear direction from the medical team. At the same time, while a great deal of literature documents the critical role that family and friends play in maintaining the person in the community for as long as possible, often providing 24-hour care at the risk of their deteriorating health (Hawranik & Strain, 2007; Roger, 2006a, 2006b, 2007a, 2007b); little if any research has investigated how care-related communication occurs within intimate relationships. Our findings begin to explore the role of communication between the individual living with PD and their family supports.

In this context, communication becomes more complex given that the individuals living with PD begin to experience either memory losses, emotional liability, mobility limitations, and concurring health conditions, or all of the above. Capacity and relational engagement change over time in the selected conditions, often in very individual ways, leaving family supports, family and health care providers to the task of communicating differently with the patient and determining their needs (Medved & Brockmeier, 2008). Since very little is known about how patients communicate about care with their family support, this study begins to address some of those gaps by revealing perceptions about communication as described by our participants.

All the participants in this sample talked about continuing to find meaning in their relationships and lives after the diagnosis, but clearly this was a process that involved constantly managing inevitable changes by communicating with their loved one or family support. Being practical and task oriented appeared to be helpful to some participants, others used their faith to assist them, and others depended on social activities to carry them through continuing challenges. Managing the household was balanced with responding to each other's feelings in a satisfactory manner; managing daily appointments was balanced with not feeling that the person with the condition was a burden; engaging in social activities with others also included being able to experience meaning and articulate that to each other in one's daily lived experience. Throughout this process, all participants worked against the concept of "changing" at all, even while their need to communicate about daily changes clearly shone through.

Evidence is also provided that the participants had established cooperative identities rather than solitary or "autonomous" realities. This suggests that participants constructed their daily lives through and with each other. Making meaning of their situation was referred to as "living well" while being terminally ill, "being normal" while adjusting to changes. A disease focus was not always the priority, although it most clearly underpinned their daily lived experience in increasing ways. The ability to work together to construct meaning of simple and complex realities resulted in a resilient foundation through which positive management of change appeared to be quite possible. Since change was a primary constant for these participants, their ability to communicate clearly and work together through ongoing changes clearly provided them with much needed additional resilience.

Since little research has explored how persons with PD and their family supports communicate, one objective of this study was to simply begin to better understand how participants perceived communication. The next step will be to review how we might better link participants and their family supports to the health care system, so that professionals can better respond to participants and families engaged in care in similar cases. According to our literature, families do not always know how best to interact with professionals given their knowledge of the patient and simultaneous lack of knowledge of the health care system. Disagreements and poor care can result on either side. This data has illustrated that managing a new identity is informed by the disease trajectory, but certainly also by intimate and long standing characteristics of individual relationships. Ultimately, it is the goal of continuing research to continue to develop and then test a model through which communications can be clearly depicted, and recommendations can be made to formal health care teams and families as they continue to engage in care of this and similar populations.

Other implications

While this paper has focused on persons with PD, the data should prove informative for other groups such as those living with Alzheimer's disease or some subtypes of Multiple Sclerosis where affected individuals and their family supports face similar issues. Affected individuals in these and other groups are known to require long-term support in order to maintain their independence, a sense of self-sufficiency, and an overall sense of personhood. This is inevitably done in the context of care relationships, often with one or two main family support persons. Since stigma and increasing social isolation can more easily occur over a long period of time for each of these conditions, and individuals live a long time in the community, these relationships change the way we might understand care and decision-making. Furthermore, these populations can be linked in the development and provision of community services, regarding the expertise required regarding treatment and health care, and the concerns that arise when communicating about and making decisions regarding an individual's daily care. Expanding our understanding then of care relationships as they might shape decision-making will prove beneficial for populations beyond those living with PD.

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Notes

1. Participants do not like the term "unpaid caregiver" for their main family support as it seemed to instrumentalize their relationship with their spouse or family member; as such this term was changed to main family support.
2. The total sample of the study was 16 participants, which included formal care providers. The formal care providers' data will be discussed in a second paper.

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