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## People with Parkinson's and Care Partners of PwPs' Uncertainty Management Through Information Strategies

Amy Haywood  
*University of South Florida*

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People with Parkinson's and Care Partners of PwPs' Uncertainty Management Through  
Information Strategies

by

Amy Haywood

A thesis submitted in partial fulfillment  
of the requirements of the degree of  
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with a concentration in Media Studies  
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Major Professor: Janelle Applequist, Ph.D.  
Artemio Ramirez, Jr., Ph.D.  
Steven Wilson, Ph.D.

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## **Abstract**

This thesis explores how people with Parkinson's (PwP) and care partners of PwP manage the uncertainty surrounding Parkinson's disease (PD). PD causes both motor and cognitive decline in patients, which may affect each individual differently (Williamson, Simpson, & Murray, 2008). There is no-known cure or cause for PD, meaning it is shrouded in uncertainty from the first symptom to the ongoing management process. This disease also affects care partners because of its variability in symptoms and progression. For this reason, this research, which is part of a larger study, interviewed both care partners of PwP ( $n= 10$ ) and those diagnosed with PD ( $n = 14$ ) in order to understand how they managed uncertainty regarding information management strategies. It was found that care partners and PwP found emotional information seeking through support groups and exercise classes as sources of hope and optimism when navigating PD. These information management strategies were seen as helpful after their negative perception of PD due to their doctor's bedside manner at the time of diagnosis. This thesis is part of a larger study about message design and reader-response theory with the goal of creating educational materials to help those affected by PD better navigate the complexities associated with long-term care and quality of life.

## **Introduction**

Parkinson's disease (PD) is characterized as a chronic neurological condition that deteriorates motor function, which may cause tremors, rigidity, slowness of movement and postural instability (Williamson, Simpson, & Murray, 2008). Individuals with PD may also experience a decline in their cognitive abilities and psychological well-being, which can lead to depression, nightmares, and psychosis (Williamson, Simpson, & Murray, 2008). According to Parkinson's Foundation, nearly one million U.S. individuals will be living with PD by 2020. Roughly 60,000 individuals are diagnosed with PD each year in the United States and more than 10 million people worldwide are living with PD right now (Parkinson's Foundation, n.d.). Given the increasing population of those affected by PD, this is not just a personal issue for those diagnosed and their care partners but may also be viewed as a public health issue.

The official diagnosis of Parkinson's disease is often a slow, painful process, involving many questions, concerns, and even misdiagnoses. Previous research has found that it took patients longer to recognize their motor symptoms and the need for medical help than it took their general practitioner to diagnose PD. However, people/person with Parkinson's (PwP) have expressed the need to visit a number of healthcare providers before they were officially diagnosed with PD and that they felt their general practitioner was unable to recognize the symptoms as PD (Plouvier, Olde Hartman, Boots, Bloem, van Wheel, & Lagro-Janssen, A.L.M, 2015). Most cases of PD occur between 60 and 80 years old, but some PwP are diagnosed before the age of 55 (Ravenek et al., 2017). While PD is known to affect one's motor and sensory systems, one of the reasons it's so difficult to diagnose is because many people who go

to the doctor for these concerns are minimally impacted by the disease at the time of their diagnosis. These motor and non-motor features are prodromal symptoms, meaning they are already present before the typical PD motor signs occur. PwP can experience these prodromal symptoms for years before an official PD diagnosis (Plouvier et al., 2015). This might look like an individual going to the doctor because their arm was stiff, or their flip flop wouldn't stay on their foot while walking. Individuals may go to the doctor with concerns about these seemingly minor instances but emerge from their appointment with a new life-altering diagnosis. The variability of the disease, along with unpredictable symptoms (e.g., side effects, such as tremors or difficulty walking), medication side effects, and the rate of progression may cause newly diagnosed patients to feel overwhelmed and worried about the future, not only for themselves but for their families and partners. The severity of the symptoms and the extent to which they limit independence varies over the course of a PwP's life, which may influence their care partner's concept of time and biography (Barken, 2014). Care partners and PwPs are constantly reinterpreting past memories and identities, the present, and an anticipated future in order to continue on with daily life (Barken, 2014).

Care partner and PwP uncertainty can stem from many sources, such as the nature of the illness, an unknown future, perceived stigma, a lack of information or social support, conflicting diagnoses from health care providers, and the development of new symptoms (Checton, Greene, Magsamen-Conrad, & Venetis, 2012). This research defines a care partner as a person, typically a spouse, who provides support to a person with Parkinson's disease. This uncertainty about daily life and future planning heavily impacts the care partner and family members of the diagnosed patient. Often times the care of the PwP falls on the spouse or close family members, resulting in the PwP's support system being inundated with new experiences and responsibilities.



This research aims to understand how both care partners and PwP manage uncertainty to help each individual affected by PD better navigate the complexities associated with well-being and care.

This research uses uncertainty management theory (UMT), coined by Dale Brashers (2001), to understand how PwP and their care partners navigate the complex ‘unknowns’ that surround PD. This theory has been prominently used in illnesses, such as cancer (Rains, 2014; Rains & Tukachinsky, 2015) and HIV/AIDS (Brashers, Neidig, Haas, Dobbs, Cardillo, & Russell, 2000; Brashers, Neidig & Goldsmith, 2004). While previous research has focused on PwP and their care partners and how they manage uncertainty (Pinder, 1990; Leiknes, Tysnes, Aarsland, & Larsen, 2010; Sanders-Dewey, Mullins, & Chaney, 2001) in regards to psychotic symptoms, few studies have attempted to understand how both the patient and the care partner manage uncertainty, and the information strategies utilized in order to appraise their diagnosis within the first six months of diagnosis. Previous research regarding PD and uncertainty management theory focused on the care partner’s coping strategies as they relate to their partner’s disintegration of both cognitive and motor abilities (Williamson, Simpson, & Murray, 2008). Generally, these findings revealed that the psychological and physical burden caregivers experience was due to the decline of their partners (Bhimani, 2014). A review of the literature of PwP’s uncertainty management resulted in analyses through a similar lens, meaning the focus was on the coping strategies utilized by the PwP in order to understand their decline in cognitive or motor function (Sanders-Dewey, Mullins, & Chaney, 2001). This study aims to understand how each individual manages uncertainty with the hopes of creating tailor-made materials to help both the care partner and PwP navigate the complexities of PD within the first six months of the diagnosis. By understanding the sources of uncertainty, the emotional responses to those

uncertainties and the ways in which both the care partner and PwP manage the information surrounding the disease, each individual may be able to receive information that pertains to their needs within the first six months of a PD diagnosis.

This thesis utilizes uncertainty management theory to better understand how both care partners and PwPs manage the unclear, vague and complexities of PD. It would be difficult to move forward in understanding uncertainty in PD without first understanding the phenomenon of uncertainty within an illness through Mishel's uncertainty in illness scale (MUIS) (1981). While studies had been done on the stressful situations surrounding illnesses, such as the symptoms of the illness itself, the management of treatments and side effects, unfamiliar environments and plans for the future, identifying uncertainty as one of the causes of stressful reactions in a hospital environment had not been explored (Mishel, 1981). Mishel's (1981) MUIS scale pioneered the way in which patients perceive their illness based on vague or unclear information they receive about their illness. When a patient's situation is unclear, vague, unpredictable, may have multiple meanings, or offers a lack of information, a cognitive structure cannot be formed, meaning their subjective perception of their illness is skewed which influences their decision-making skills (Mishel, 1981). After a patient recognizes their situation, they need to classify it or give it meaning. This is similar to the process Brashers' (2001) outlines in his uncertainty management theory (UMT). Mishel (1981) deduced that uncertainty hampers a patient's ability to accurately give meaning to a situation. Brashers' (2001) UMT expands on Mishel's MUIS (1981) in that Mishel believes all sources of uncertainty are appraised as a threat, benign or a challenge. Brashers (2001) believes that uncertainty can be appraised as hope or an opportunity, as a threat, or inconsequential. Mishel (1981) also self admits that secondary appraisals had not been widely studied and what has been studied resulted in actions, such as direct action,

vigilance, or avoidance. Brashers' (2001) UMT acknowledges these actions but takes it a step further, recognizing that once a situation is given meaning, steps are taken afterwards to either increase, reduce, or maintain the level of uncertainty one desires.

## **Literature Review**

### **Uncertainty management theory**

Uncertainty management theory (UMT) offers a framework that attempts to understand, predict, and explain the role of communication in the uncertainty management process.

Individuals experience uncertainty when details of situations are unclear, complex, unpredictable or offer problems (Stiegelis et al., 2004). The desire to manage uncertainty centers around a need to make decisions, to solve problems, to maintain an identity, and to develop and sustain relationships (Brashers, Neidig & Goldsmith, 2004). For patients with chronic health conditions as well as their loved ones, this uncertainty extends beyond just the nuts and bolts of their illness but to their quality of life that is indirectly impacted by their illness (Hurt, Cleanthous, & Newman, 2017).

The major tenet of UMT is that uncertainty must be appraised for its meaning. When individuals encounter uncertainty, they must assign the situation meaning in order to move forward with their communication and behavior. This appraisal may be positive (e.g., uncertainty as a source of hope or optimism), negative (e.g., danger), or neutral (e.g., inconsequential), or even a mixed response (Rains & Tukachinsky, 2015). UMT assumes that the amount of uncertainty one experiences may not necessarily be the amount of uncertainty one desires. Depending on how it is appraised, people may want less uncertainty than they are currently experiencing, but in other cases they may want more uncertainty than they are currently experiencing. Once a situation is appraised, UMT predicts that individuals engage in an array of behaviors in an attempt to manage the uncertainty they are experiencing (Rains & Tukachinsky, 2015). This may look like information seeking, information avoiding or even

reappraising the uncertainty, meaning a situation that was once appraised negatively may actually turn into a positive appraisal, fostering hope and optimism.

When uncertainty is appraised negatively, communication often seeks to provide uncertainty reducing information. For example, past research has found that negative feelings about a genetic condition predicted the desire for individuals to gain control and as a result, foster hope about their situation (Parrot, Peters, & Traeder, 2012). This need for control and hope led to uncertainty management through communication with family members that revolved around feelings of optimism and openness. In this study, information management took the form of positive appraisals (Parrot, Peters, and Traeder, 2012). This is an example of how an initial negative appraisal of a genetic condition led to optimistic feelings among family members, such as hope about the future. When uncertainty is appraised positively, for example, as a source of hope, communication can create, sustain, or increase uncertainty (Babrow & Striley, 2015). People experience various types of uncertainty simultaneously, especially in health situations and may choose to change their uncertainty through information seeking or avoiding.

### **Information seeking**

Information seeking in the context of a health diagnosis may look like a patient or their care partner using various sources, such as health care providers, medical journals, the Internet, and support groups to acquire more information (Rains & Tukachinsky, 2015). Information seeking efforts may be active or passive. Active information seeking is purposefully searching for relevant information from various sources, and passive information seeking may look like a patient or care partner putting themselves in environments where they are more likely to be exposed to new information, such as a support group or informal conversations (Brashers et al., 2000). According to Brashers et al. (2000), the HIV community is an example of a group who

created illness identities and meaningful friendships from being involved in support groups with those who were also HIV positive. Because HIV also deals with uncertainty and rapidly changing information, this group utilized their social network and friendships to compare information and receive frequent updates about HIV as a method of managing their uncertainty (Brashers, et al., 2000). Previous research has found that cancer patients are one example of a population that uses passive information seeking to gather information from other cancer survivors or those with similar diagnoses to help manage their uncertainty (Miller, 2014).

However, it should be noted that the type and volume of information one receives or finds influences the success of uncertainty management. Cancer patients found that too much information hindered their uncertainty by creating an abyss of material that was difficult to sort through, especially if the information didn't lead to clear answers (Miller, 2014). Similarly, research on skin cancer found that simply being exposed to web pages containing information about skin cancer prevention or treatment did not affect the information seekers' uncertainty management success (Rains and Tukachinsky, 2015). Successful uncertainty management was defined as a reduced discrepancy between the uncertainty currently experienced and the uncertainty desired. In this study, some types of skin cancer information, such as one's own susceptibility to cancer, was associated with successful uncertainty management (reduced discrepancy), while other information, such as one's severity of skin cancer, was associated with an increase in uncertainty discrepancy. While the type and amount of information is key to managing uncertainty, the Internet may be a valuable tool for uncertainty management and even foster positive health outcomes due to the depth and breadth of accessible information (Rains, 2014). It should also be noted that the timing and relationship between diagnosis and information

seeking may influence the seeker's ability to use the information to cope or re-appraise their situation.

The fibromyalgia population demonstrates the importance of temporal context in information seeking (Chen, 2015, p. 347). For this community, “the longer they had been experiencing fibromyalgia symptoms, the greater their sense of illness coherence was likely to be (Chen, 2015, p. 347).” This illustrates that using health information to learn how to cope may represent reconceptualization or reappraisal, which may result in a higher sense of personal control (Chen, 2015). These findings suggest that when someone begins to suspect they have fibromyalgia, seeking information to understand their illness may not be negative, and seeking information about treatments may allow patients to feel like they have more control over their condition (Chen, 2015). However, as time passes, it may be necessary to encourage patients to focus on coping rather than a continuation of illness understanding. According to Chen (2015), fibromyalgia patients at diagnosis were not able to leverage information in a way that led to greater perception of control. It can be inferred that temporality and context of illnesses may influence the way patients seek information, when they seek information and how they appraise or reappraise their illness. The timing between diagnosis and information seeking is an important and understudied phenomenon of not only uncertainty management, but health communication. Empirical findings claim that information seeking isn't bound chronologically or by problem stage, meaning individuals may not seek out information at the beginning of a problem stage (Savolainen, 2018). For instance, the beginning of a problem stage for a PwP could be at diagnosis. “Instead, information seeking is cumulative, reiterative, holistic, and context bound (Savolainen, 2018, p. 789).”

While information seeking is a common behavior that helps to manage uncertainty, information avoidance is also a strategy some use to increase or maintain their uncertainty.

### **Information avoidance**

Information avoidance typically occurs when uncertainty is appraised as an opportunity, resulting in hope or optimism (Brashers et al., 2000). Individuals may avoid information if it challenges their belief system or requires them to confront distressing knowledge (Brashers et al., 2000). Cancer patients are an example of a group who avoided information for fear of hearing others' negative experiences as well as disturbing information that interfered with their mental health plan for survival (Miller, 2014).

Other types of information avoidance can involve avoiding specific topics in interactions, avoiding a situation where information is likely to be presented, or only selecting certain types of information. This may be avoiding a diagnosis altogether or removing oneself from situations where certain information is shared. Brashers et al. (2000) found that individuals who experienced symptoms similar to those associated with HIV might avoid HIV testing to evade confirmation of infection, maintaining their uncertainty. Some of these HIV-infected individuals avoided support group environments because they view others' declining health or deaths as traumatic (Brashers et al., 2000). Positive illusions, even unrealistic optimism, are important coping mechanisms for individuals and attending support groups may threaten these positive illusions. Brashers et al.'s (2000) finding that HIV-positive support group attendees became overwhelmed with the quantity of negative information led to a desire for these individuals to communicate less. UMT does not view information avoidance as necessarily irrational. In some cases, it may be helpful for fighting the disease or having a decent quality of life to remain hopeful about a patient's own or partner's prognosis.



Topic or information avoidance may be more prevalent in dyadic communication when it comes to one's partner being ill. Individuals not only experience their own uncertainty, but they also feel the uncertainty of their partner, family, and friends (Brashers, Neiding & Goldsmith, 2004). Others' communication patterns may contribute to this uncertainty as well, such as unreciprocated appraisals, or information seeking (i.e., when one partner seeks information while the other wants to avoid it; Brashers, 2000). Information avoidance may be a patient's way to evade conflicting or distressing information, which could increase their uncertainty discrepancy (Miller, 2014).

Information seeking and avoiding is a complex, nonlinear process that is different for each individual. Some patients find reassurance from information seeking, while others may have heightened uncertainty from their findings, which may result in strategic information avoidance to increase or decrease uncertainty discrepancy.

### **Social support**

The supportive acts that help facilitate uncertainty management parallel the process of how people experience, appraise, and manage uncertainty (Brashers, Neidig et al., 2000). This may look like a patient receiving bad news, but their support system appraises the news positively, which may influence the way the patient appraises the information him/herself, setting up future actions for how they will manage this uncertainty. Supportive members surrounding the patient can provide a sense of relational stability by serving as collaborators in information gathering, evaluators of information, and buffers against information, which can encourage decision-making for the patient (Brashers, Neidig et al., 2000).

These conversations and partner reappraisals may be seen during acts of "open communication" among care partners and PwP. Goldsmith and Domann-Scholz (2013) found

that open communication among partners was deemed important and the sign of a healthy relationship but was also polysemy, meaning there were many different elements to a single text that could develop into two or more meanings for that text (p. 268). For example, participants recovering from a cardiac arrest believed that not talking about anxiety could be seen as denying the event, where talking too much about worries could be perceived as “dwelling” on the condition. These findings by Goldsmith and Domman-Scholz (2013) reinforce the complexity and fragility of partner communication when it comes to health uncertainties.

Open communication is imperative because the well partner doesn't have direct access to the partner's physical symptoms or cognitions, making dyadic appraisal imperative. Dyadic appraisal requires communication between partners about the issue and the perception of a supportive and responsive partner, which may result in reduced uncertainty, a new pattern of shared appraisals and dyadic coping (Badr and Acitelli, 2017).

Care partners of PwPs may be confronted with an array of their own uncertainty due to the increased need to provide care and support throughout their partner's illness progression. An increase in symptom severity may also cause care partners to assume new and more cumbersome responsibilities, typically resulting in an increase in emotional, physical, and financial stress (Sanders-Dewey, Mullins & Chaney, 2001). Care partners may utilize a number of coping strategies to handle the stress and uncertainty of taking care of their partner (Williamson, Simpson, & Murray, 2008). These coping mechanisms may be categorized as emotion-focused, problem-focused, or a mix of both strategies. An example of an emotion-focused strategy may be downward social comparison, which means comparing one's condition to someone who is worse off in order to feel better about themselves/their partner (Cramer, Song, & Drent, 2016). Felton and Revenson (1983), found that this type of coping strategy may allow an individual to maintain

an optimistic outlook and redefine the illness in a better light. Accepting the symptoms and how they impact daily life is also an emotion-focused strategy. Problem-focused approaches include information seeking about symptoms and keeping their partner active and involved in order to bring out their “old self.” According to Williamson, Simpson, and Murray (2008), many caregivers felt responsible for their own information seeking because, either they didn’t have much contact with the professionals or their health care providers were not open about the complexities of PD. While caregivers felt it would be beneficial to be made aware of the many symptoms associated with PD, the actual PwP varied in the amount of information they wanted (Williamson, Simpson & Murray, 2008).

Understanding and managing uncertainty for both the PwP and the care partner throughout the PwP’s illness comes with complexities in an ever-changing landscape. To achieve reduced uncertainty discrepancy, both the care partner and the PwP may need to be on the same page in how they manage their uncertainty. Given that PD is a neurological illness that presents an array of symptoms and progressions, management may include conversations about preferences or desires between the PwP and care partner as well various management strategies, such as information seeking and openness. It is important to understand how care partners of PwP manage their uncertainty because they are a rapidly growing demographic. There are roughly 25 million adults in the U.S. who provide informal care to a family member or spouse with a chronic illness. Their work is projected at an economic value of \$196 billion (Navaie-Waliser, Feldman, Gould, Levine, Kuerbis, & Donelan, 2002). Given the nature of PD, uncertainty management may be difficult and constantly changing.

Given that the complex process of information management for both the care partner and PwP is relatively unexplored in the context of PD, this study seeks to investigate:

**RQ:** How do people with Parkinson's (PwP) and care partners of PwPs manage uncertainty through information management strategies regarding their diagnosis and post-diagnosis quality of life?

## **Method**

### **Participants**

Participants were recruited through a southeastern Parkinson's disease support group. Members of this group feature PwPs and care partners, with social support and PD-related information sharing acting as the main features of its consortium. Members of this group are currently championing a new initiative aimed at helping newly-diagnosed PwPs and their care partners navigate the complexities of the disease. The current study, which was part of a larger process of data collection aimed at investigating message design related to the aforementioned initiative, focuses on a series of 10 questions asked of participants directly related to individuals' management of uncertainty surrounding PD. The data collected is part of larger study about message design and acceptance, and pharmaceutical advertising.

Upon receiving IRB approval, support group members were informed about the study opportunity in-person during one of the monthly group gatherings. See Appendix C for IRB approval. In the second phase of interviews, snowball sampling was utilized to gain access to more PwPs and their care partners. Participants who were recruited through snowball sampling received an email detailing the aims of the study and a link to the online informed consent document. Recruitment and data collection ended once saturation was reached, meaning information from participant interviews became repetitive, resulting in no new themes or emerging findings (Tracy, 2020). All participants consented to participate in the study via an online informed consent survey through Qualtrics.

Participants included 12 females and 12 males ranging in ages from 50-80. A majority of the participants identified as Caucasian ( $n = 24$ ) with one participant identifying as American Indian or Alaska Native ( $n = 1$ ) and one participant identifying as Hispanic ( $n = 1$ ). Participants either identified as a PwP ( $n = 14$ ) or a care partner of a PwP ( $n = 10$ ). Of the total participants interviewed ( $n = 24$ ), nine were dyads, who were interviewed individually in order to encourage a dialogue around trust and disclosure without potential repercussions. The other participants either did not have a partner or their partner was unable to be interviewed. Overall, regardless of marital status, all participants were interviewed separately to encourage trust and candidness as previously mentioned.

Participants were asked to fill out a demographic questionnaire about their diagnosis including how long they've been diagnosed, their current stage of PD, their education, employment and marital status as well as the year they were (or their partner was) diagnosed with PD. A majority of the participants ( $n = 13$ ) identified as having stage one Parkinson's, while the rest of the participants identified as stage two ( $n = 4$ ), stage three ( $n = 7$ ) and stage four ( $n = 1$ ). The different stages of Parkinson's represent the typical patterns of progression of the disease. Stage one typically consists of only mild symptoms, which would not interfere with daily activities. A PwP may have tremors on one side of their body or changes in their posture or facial expression (Parkinson's Foundation.org, n.d.). In stage two, a diagnosed individual may still live alone but they would be experiencing tremors and rigidity on both sides of their body as well as poor posture. Stage three is considered mid-stage and while the PwP is still independent at this stage, they may have trouble dressing, eating, and may fall frequently. At stage four, a PwP would have trouble walking and most likely need a walker. Their symptoms would be severe and

limiting and they would not be able to live alone (Parkinson's Foundation.org, n.d.). The participants in this study did not self-report that they were at stage five of PD.

## **Procedure**

Given the sensitive nature of the disease and the desire to understand how each individual manages their uncertainty, interviews were decided as the best approach to fully understand the nuances of everyday life and the effects of Parkinson's disease and the uncertainty it may cause. Interviewing is a valuable method to gather large, valuable, relevant and interesting information from individuals with different experiences and backgrounds (Brennen, 2013). To accommodate individuals with a variety of schedules and locations, online interviews were chosen as the method for data collection. Following consent, participants signed up to be interviewed through an online calendar system. Interviewees were then sent individual links to access their interview via *GoToMeeting*, an online video conferencing platform. This platform was chosen due to its ability to provide video call features (face-to-face conversations via webcam), screen-sharing, conversation recording, and rough transcription. Video conferencing, video chats or telephone interviews have become more common to conduct qualitative interviews (Irvine, Drew, & Sainsbury, 2013). It allows for more anonymity when discussing sensitive topics as well as cost and time effectiveness when communicating with harder to reach groups (Sturges & Hanrahan, 2004). Sturges and Hanrahan (2004) found that phone interviews resulted in similar quality data as face-to-face interviews.

## **Data Collection**

Semi-structured, in-depth online interviews were performed using questions derived from a review of relevant literature to identify questions of interest related to uncertainty management theory. Using a pre-interview process modeled on Weathers, Canzona, and Fisher (2019), several

actions were taken to create comfort and trust with the participants. First, the interviewees were told the basic structure of the interview. Then, the participants were told they would be asked to think back to when they themselves, or their partner was first diagnosed with PD. Next, participants were asked questions regarding feelings of uncertainty surrounding PD, such as uncertainty about symptoms, progression, daily life, as well as coping strategies, such as communication, information seeking and information avoiding. Use of the term uncertainty was also phrased as “not knowing” to create a more open dialogue with participants. See Appendix A for a complete list of interview questions. The lead researcher was trained by her thesis chair for approximately 10 hours in interviewing protocol and practices prior to conducting the first interview.

In-depth, online interviews were conducted with participants from February-April of 2019 and then a second phase of interviews were conducted from September-November of 2019. Interview times ranged from 58-138 minutes. All interviews were recorded, with a rough first-version of transcription provided by the video conference platform. Two graduate-level research assistants completed all second-draft transcription, watching the individually recorded interviews to ensure that transcription was accurate. This produced roughly 350 pages of double-spaced transcription. Detailed memos were also completed by interviewers immediately following each interview session to aid in phases of data analysis.

### **Data Analysis**

As part of a larger study relating to message design and pharmaceutical advertising, data about uncertainty management experiences were analyzed in this study.

Code development occurred by reviewing and revisiting relevant uncertainty management theory literature. The code development adapted the major categories and themes



from Brashers' et al. (2000) manuscript, "Communication in the management of uncertainty: The case of persons living with HIV or AIDS." Because the lead researcher's inquiries and strategies were being informed by uncertainty management theory, she developed codes pertaining to information management, and uncertainty management experiences. See Appendix B for the final codebook. The lead coder initially conducted independent open coding where she assigned words or phrases that captured the essence of the data and theory tenets from the aforementioned Brashers (2000) findings (Tracy, 2012). This included words and labels like sources of uncertainty, emotional responses, and uncertainty management efforts. These specific codes could be said to identify both the key points of the data and the turning points of the data, meaning they represented personal moments from the participants and the turning points conveyed decisions and actions they took (Lindlof & Taylor, 2002). Codes also included labels, such as information strategies, such as active information seeking, passive information seeking, experiential information, avoiding information, chronic uncertainty management, and perception of information based on doctor's bedside manner. The coder reviewed the data from several close readings and adjusted the aforementioned criteria from Brashers et al. (2000), to adapt a PD context (Lindlof & Taylor, 2002).

The lead researcher and trained research assistant analyzed 10 transcripts (five PwP and five care partner) using detailed open coding to examine paragraphs of data regarding uncertainty management and emotional responses among PwP and care partners. This research adapted a similar approach to codebook creation and analysis as Brashers et al. (2000), meaning, "the unit of analysis was the speaker's turn and only the participant's dialogue was coded (Brashers et al., 2000 p. 69)." The lead researcher was trained in coding and codebook creation for months, resulting in revisions and revisiting relevant literature and the raw data. Both coders

independently coded 10 transcripts to identify explicit mentions of sources of uncertainty, emotional responses, and uncertainty management efforts. The purpose of this step was to clearly label these instances to aid in later categorization. After the two coders came together to discuss agreements and discrepancies, the lead researcher revised the codebook to accurately reflect the raw data. The lead researcher spent roughly 10 hours teaching the research assistant in coding and how to utilize the codebook. It took roughly 20 hours in total to reach reliability for the codebook.

This also meant adjusting the code labels and definitions to relate to those affected by PD opposed to HIV/AIDS, which was the original context for the code concepts and definitions (Brashers et al., 2000). For example, under managing information, the codebook originally had codes for characteristics of information and credibility of information. The code, known as characteristics of information, was defined as. “information the PwP or care partner sought was unavailable, provided discrepancies, or contradictions or if the doctor disagreed with what they’ve found (Brashers et al., 2000, p. 69).” While this was certainly a pain point discussed in participant interviews, they described their frustrations with information management as more of a result of their doctor’s bedside manner. Instead of labeling this code as characteristics of information, it made more conceptual sense to label it as “perception of information based on doctor’s bedside manner.”

The above example resulted in a revised codebook and strategy to code for quantity and quality of the codes (DeCuir-Gunby, Marshall, & McCulloch, 2011). Coders not only coded for prevalence of the code but also for how the code was being utilized within the transcript. For example, if one coder wrote down passive information seeking within a transcript, both coders had to agree that passive information seeking meant that the participant put themselves in a

situation where they would hear information through informal conversations, such as support group settings. This meant they both had to write down and code for “support groups” specifically in order for the code to be considered an agreement.

Disagreements meant a code was either not utilized by both coders or the coders had strong differences in the way they used the code within the transcript. If a code could not be discussed to result in an agreement, it was considered a disagreement.

Similar to DeCuir-Gunby (2011), the researchers reached coder reliability by utilizing Miles and Huberman’s (1994) formula for reliability, which consists of calculating the number of agreements divided by the total number of agreements plus disagreements. Using this formula, the coders came together, analyzed the codebook and refined and revised the terms. After the first round of reliability testing, the researcher revised the codebook and re-analyzed the 10 transcripts. Using Miles and Huberman’s (1944) formula, the researchers reached 94 percent agreement, which is considered excellent.

Once reliability was ensured and a consensus was found across transcripts, all transcripts were coded independently by the lead researcher.

The data was analyzed using open, axial, and selecting coding. This research used a deductive approach to data collection and data analysis, which included codebook creation that relied on a theoretical framework. First, the researcher used open coding, meaning descriptive codes were utilized to address who, what, where, when, how. This resulted in creating sub-codes underneath the codes identified from UMT in the codebook, such as misdiagnosis, pre-diagnosis symptoms and being shut out by partner. Next, the coder engaged in axial coding, where she reassembled data under hierarchical categories that made conceptual sense (Tracy, 2012). This resulted in making meaning from aforementioned open codes, such as pre-diagnosis symptoms,

as a representation of the already-changing role of the care partner who noticed their partner's odd behavior and encouraged a doctor's appointment.

Because the codes/labels were adapted from an existing manuscript and are theory-driven, some of the codes will be used as categories to help with further categorization and explanation. For example, sources of uncertainty and emotional responses were analyzed to find major sub-themes relating to PD under these two categories. These categories may be viewed as turning points for the participants, meaning the source of uncertainty and the coinciding emotional response may correlate with a care partner taking action in the form of information management.

According to UMT, information management helps aid in appraising the uncertain situation. Understanding the beginning processes and emotions tied to the turning points for such actions may help create relevant and effective materials to help PwP and care partners better navigate PD within the first six months of a diagnosis.

This next step of analysis included reshaping the categories to produce a deeper meaning (Lindlof & Taylor, 2002, p. 220). This step included understanding the context in which these codes are being utilized and the actions in which the codes are being handled or carried out (Lindlof & Taylor, 2002, p. 221). For example, as mentioned above, sources of uncertainty may be anchored in the context of a PD diagnosis and daily life. As mentioned previously, these sources of uncertainty along with the context of emotional responses from these sources may correlate with actions being carried out, such as information management strategies.

Finally, the lead coder performed selective coding, which featured all categories as unified around a "core" category to ensure conceptual density (Corbin & Strauss, 1990). In sum, all data were analyzed to identify uncertainty management and information strategies among

PwPs and care partners. Aforementioned categories for coding were adapted from relevant uncertainty management literature, which primarily consisted of creating codes from Brashers et al. (2000) and reworking categories as the data were read and coded to accurately reflect the major tenets of the theory. Transcripts were examined to identify and coincide with recurring concepts, phrases, and themes.

Credibility revolves around a researcher's data and findings being dependable and trustworthy (Tracy, 2020). Qualitative credibility can be achieved through thick description, triangulation and member reflections (Tracy, 2020). Because this thesis is part of a larger project, triangulation was used. The research team consisted of three individuals, which meant each interviewer and coder was able to confirm the transcripts and data collection as transparent and accurate. Using the online video conferencing platform also allowed each interviewer to go back and re-watch the interview, confirming the accounts told by the participants were truthful and valid. This thesis used thick description through the use of detailed memos and video recordings of interviews as well as multiple perspectives from three researchers to establish the credibility of the findings. Along with detailed memos, the interviewers utilized member reflections by using clarifying language during the interview as well as inviting participants to add any information post-interview to make sure the participant's statements were understood properly.

## Findings

The results of this study reveal that managing uncertainty for a PwP and a care partner is complex. The following sections delve into ways in which both care partners and PwP handle uncertainty management through information strategies. Semi-structured interviews conducted for this research relied upon uncertainty management theory. Thus, a deductive and phronetic iterative approach to data analysis was used to investigate uncertainty management in the context of PD (Lindlof & Taylor, 2002).

As previously mentioned, uncertainty is defined as a situation that offers complex or vague information that is unclear or provides future problems (Stiegelis et al., 2004). Because this thesis focuses on how both PwP and care partners manage uncertainty, it's important to understand the sources of uncertainty each individual may experience regarding a PD diagnosis because their realities surrounding the disease are different, resulting in varied appraisals of uncertainty, which would indicate different educational materials needed to cater to each individual affected by PD. Brashers et al., (2000) grouped sources of uncertainty, emotional responses, and uncertainty management efforts together in his manuscript in order to report how they all intertwined throughout the appraisal process for living with HIV. However, this thesis has chosen to report sources of uncertainty and emotional responses in addition to uncertainty management efforts because of its goal to create educational materials for a non-profit organization.

According to the researcher's codebook, a source of uncertainty was defined as "a situation that offers vague or unclear problems, such as a doctor's visit that resulted in anything

other than PD, the first sign of PD symptoms, a misdiagnosis before an official PD diagnosis, the unpredictability of the trajectory and symptoms of PD, etc.”

### **Care partners’ sources of uncertainty**

**Physical symptoms before a diagnosis.** When an individual is diagnosed with PD, often times, a care partner is also in the picture, meaning they too, are confronted with life-altering news. This may cause a care partner to assess not only the life and future of their diagnosed partner, but also themselves. The diagnosis itself was a source of uncertainty for all care partners and PwPs, however there were layers below the diagnosis that resulted in sources of uncertainty for the care partner. The reason pre-diagnosis symptoms were included in the care partner analysis because it shed light on the transition from spouse/partner to care partner of someone who is diagnosed with PD. By noticing the pre-diagnosis symptoms, care partners are already experiencing what it means to be on the outside of the disease, meaning their perception of their partner’s actions will be the guiding indicator of future actions. The researcher found that overall, care partners felt uncertainty about the physical symptoms their partner experienced before a diagnosis, the diagnosis itself, and as life continued after the diagnosis, the communication within the relationship.

Seventy percent of participants interviewed discussed noticing odd behavior in their partner revolving around physical symptoms. This odd behavior included a lack of control when it came to using utensils when eating, stiff and rigid arm movements and leg movements, and the inability to do leisurely physical activities they once loved, such as cycling, running, or kayaking. These initial sources of uncertainty were mostly appraised as a danger or threat, meaning the uncertain symptoms offered problems, urging active information seeking by way of doctor’s visits and consultations. When an uncertain situation is appraised negatively, the

individual giving the meaning may feel tense, anxious or worried about the future. When a situation is appraised negatively, individuals may want to reduce their uncertainty by finding solutions that answer their questions or they may want to re-appraise the situation and increase their uncertainty, which means they may find more solutions and treatments, offering hope and optimism. As one participant stated.

“It started with a little twitch in his index finger and him not moving his arms anymore, slowing down is what I started to notice and I’m like there’s something definitely wrong going on here.”

– Participant 5

The situation expressed by Participant 5, exemplifies the uncertainty management appraisal process in the beginning stages before a PD diagnosis.

This displays the initial source of uncertainty for a care partner at the beginning of the diagnosis journey, which involves the care partner playing both an outsider role but also as a role of moderator, meaning they may suggest a doctor’s visit. As stated in the literature, care partners’ role throughout the PD diagnosis journey and aftermath is evolving and changing. Due to the uncertain nature of PD symptoms and progression, care partners may feel like both a teammate and moderator in their partner’s post-diagnosis life, meaning they can view odd behavior and symptoms from the outside, which may prompt information seeking strategies in order to find solutions. While physical symptoms were prominent as a source of uncertainty for care partners, other sources of uncertainty spanned across emotion-focused situations and unclear directions about the future.



**Future after diagnosis.** Care partners for those with a chronic illness deal with large amounts of uncertainty, one being that they experience the disease through their perceptions of how their partner is acting. Sixty percent of care partners expressed uncertainty, worry, and fear about what their future with their partner will look like after their PD diagnosis. Participants expressed uncertainty around how they plan their day to accommodate their partner to being uncertain about the future, to wondering how communication will continue throughout the disease. Aside from the tenets of the disease itself, emotion-focused sources of uncertainty were commonly discussed as a danger appraisal, meaning an uncertain future and uncertain level of relationship satisfaction offered problems or concerns. Because care partners' roles are ever-changing and adjusting in their relationship post-diagnosis, they may want more stability than they are currently experiencing, whether that be through communication or enacting a plan for the day or months to come. Participant 26, whose partner has been diagnosed for four years and is in stage 1 of PD discusses that her uncertainty about the future revolves around the pressure of having a ticking clock in the back of her mind.

“How much time do we really have? You know, really full on Parkinson’s that you see is very debilitating. Those are the things that are sometimes challenging to deal with emotionally because you see yourself and you think we both think I’m appalled. Oh my god, that’s you know where I’m heading and I think oh my god, that’s where he’s heading but we don’t know.” –

Participant 26

Because Participant 26’s husband has had a slow progression in the four years since he was diagnosed, the ticking clock may feel more prevalent because they can see what the future of

PD can look like, which may involve violent tremors and cognitive decline. This partner expresses feeling uncertain and shock about the future because she knows the disease may become quite debilitating and their life, along with her role as a partner, may change at any point in the future. This not knowing about what tomorrow or the next year will bring can be quite jarring for care partners and requires them to juggle contradicting realities and futures. They must notice their partner's behavior and plan accordingly to help with symptoms, but they must also plan for a declining future that may or may not present itself in 10 months or 10 years. Thinking about the future and progression of the disease was common for care partners when discussing the thought of attending support groups shortly after their partner's diagnosis. This type of uncertainty reinforces the role of care partners as the moderator for the quality of life for the couple as a whole, not just themselves and not just for their partner.

Sixty percent of care partners expressed their worry about communication with their partner throughout the disease and felt a sad premonition on how the disease will affect their relationship. This participant expresses the lack of communication with her partner as the biggest threat Parkinson's holds for her.

"If there's anything that scares me the most about Parkinson's, it's the idea that the relationship he and I have could be negatively impacted by just the inability to talk about it." – Participant 13

A care partner's role is primarily on the outside of the disease, and they can either challenge, guide, or validate their partner's appraisals, which supports Brashers' et al. (2004) findings that communication is a tool for managing appraised uncertainty. Care partners who feel shut out may be on the receiving end of a partner who would not like to re-appraise their

uncertainty, meaning they are not open to hearing certain information that could threaten either their positive or negative appraisal of the situation. The lack of communication may cause tension within the relationship if the care partner's appraisal process collides with his/her partner's desire to reduce their uncertainty discrepancy. For this reason, it's important to understand how care partners manage uncertainty, especially if it revolves around communication with their partner. If care partners feel shut out by their partner and desire to manage their uncertainty with a PwP who has enacted a different uncertainty management strategy or who desires a different level of uncertainty, the care partner may feel stuck or at a loss of how to move forward. Because sources of uncertainty are appraised for their meaning, they are usually accompanied by an emotional response, which indicates the unclear situation, such as a PD symptom, the diagnosis itself or feeling shut out. A source of uncertainty can be deemed positive for its hope or optimism about the future or negative, presenting danger for the care partner.

### **Care partners co-creating emotional responses with doctor at diagnosis**

These sources of uncertainty were often intertwined with subsequent emotional responses, which Brashers et al. (2000) coded for in his manuscript as a way to categorize appraisals as a result of a source of uncertainty. Emotional responses were used as an indicator of a "turning point," which represents an action taken by the care partner, such as information seeking. For this reason, emotional responses will be included in the analysis to better understand what information strategies are useful for care partners and how these findings can be used to create educational materials for PD non-profit campaigns.

Emotional responses from care partners ranged from relief to shock and anger. Care partners' emotional responses to the diagnosis were co-created by the doctor's bedside manner,

the care partners' past experiences, and the care partners' illness efficacy at the time of diagnosis.

**Positive appraisal of diagnosis.** Thirty percent of care partners expressed relief or acceptance at their partner's diagnosis because it meant they finally had a confirmation to the symptoms they were noticing their partner experiencing, or they thought the situation was much worse.

For Participant 2, the diagnosis was a source of relief because the disease had a long trajectory and didn't symbolize an impending "end date." For this participant in particular, she had been a caregiver in the past for both of her parents and her daughter, which resulted in her experiences with short illness trajectories. Brashers et al. (2000) describes this type of information management as experiential information, meaning past experiences helped inform appraisals and decisions about the uncertain situation. This care partner experienced loss relatively quickly after the diagnoses of her family members, felt relief and energized knowing that PD did not mean terminally ill. Her doctor's information about the longevity and challenges of the disease along with her past experiences with terminal illnesses, allowed the care partner to create a positive appraisal of the PD diagnosis. These situations influenced her immediate emotional response, which can be seen below.

"With Parkinson's, I have 20 years to worry about that. So, you see where my mind was going. The clearinghouse was, this is a sigh of relief for me on Parkinson's, and of course, [the doctor] said you're going to be dealing with this for a long time, and he said which was you know, that was wonderful to me. I didn't take that negatively." -Participant 2

As stated in the literature, care partners' appraisals of an uncertain situation can energize and help their partners make appraisals or re-appraise their current situation, such as a diagnosis (Brashers et al., 2004). In the emotional responses following the diagnosis expressed above, it can be inferred that the situation was immediately appraised positively, meaning hope or optimism was associated with PD. For those care partners, the diagnosis was a confirmation of the odd symptoms that their partner had been experiencing for years as well as relief that they could still live life with their partner for many years to come. For this reason, care partners' role as moderators of the disease from the outside remains crucial for being an ally for themselves and their relationship, overall. Care partners' role includes managing their own uncertainty as well as being a teammate for their partnership, meaning they may be able to help turn negative appraisals into positive ones or vice versa.

**Negative appraisal of diagnosis.** Seventy percent of care partners described the diagnosis as lacking information about what life with PD would be like. These emotional responses often symbolized the appraisal of the diagnosis itself as negative. The following participant expresses their shock and disappointment at the bedside manner of their doctor during the life-altering diagnosis of her partner.

“I just couldn't believe what I was hearing, so back in those days the bedside manners of these doctors were not very good. They were not telling you what you needed to hear, not handing you any literature or anything—just more or less, ‘Here's a prescription, get a pill, and I might come back in three months.’” – Participant 5

This care partner's reaction to the diagnosis heavily dealt with her perception of how the doctor acted and treated the situation. Perceiving the illness based on the doctor's behavior can also be seen within Brashers' et al. (2000) work with the HIV community, which found that doctors and patients disagreeing or presenting different information may influence the patient's appraisal process and thus information management strategies in order to re-appraise the uncertain situation. This thesis has found that doctor's bedside manner most prominently influenced information management strategies, such as information seeking at the time of diagnosis. Care partners didn't necessarily disagree with the information presented to them, such as the findings in Brashers et al. (2000), but the doctor's communication did influence their appraisal of the diagnosis itself, which allowed them to take action steps such as information seeking to re-appraise the diagnosis.

The need for proper educational materials for care partners whose partner is newly diagnosed is evident based on the sources of uncertainty and linked emotional responses at the time of diagnosis. Participant 11 shares that the communication around the official diagnosis lacked hope or optimism, or even alternative solutions on how to live well with PD.

“He [PwP] went to see him and [doctor] said after watching him walk and watching his everything, you know, they know what to look for. He said, ‘You do have Parkinson’s. You’ll probably be in a wheelchair or even dead in three months and there’s some medicine here that will help you with the tremors and all that.’ But he said sometimes the medicine is worse than the disease and I can wish you well and I’ll see you in six months.”– Participant 11

Participant 11 expresses a lack of empathy and politeness about the disease or any hope for the future, which could be appraised negatively, meaning information strategies would be enacted in order to reduce uncertainty management opposed to re-appraising the situation positively, which would foster hope.

This finding highlights the importance and stature of the doctor and their communication strategies at the time of diagnosis. The bedside manner of the doctor at diagnosis helped create the emotional response of the care partner, allowing them to appraise the diagnosis negatively. Doctors need to be educated in communication practices and strategies when it comes to relaying life-altering information, such as a PD diagnosis. These strategies may involve doctors assessing the requirements, expectations, and desires of the receiver in order to practice communication that centers around the patient's or care partner's communication style and needs (White, 2015). According to Bottorff et al., (1998), when it comes to discussing risk, such as a diagnosis or test results, recipients feel that the sensitivity and skill in which doctors report and disclose results is highly important and doctors need to be highly skilled in providing positive information and emotional support.

The above sections discussing sources of uncertainty and emotional responses as a result of doctor's behavior, all work in tandem to assist in care partners' appraisal process and their intended action steps in order to reduce their uncertainty discrepancy. Care partners' roles in the PD journey start at the first symptom, working as a moderator who noticed irregular behavior in their partner and stands side-by-side as an ally for problem-solving. These sources of uncertainty may be accompanied by emotional responses, such as sadness and worry about a life-altering diagnosis or relief that the diagnosis still allows for years of togetherness. It would be remiss, to discuss emotional responses at diagnosis without discussing the doctor's role. For these care

partners, a lack of information at diagnosis resulted in frustration and concern about their partner and their relationship being affected by PD. These all serve as a turning point for a care partner to take actionable steps to either re-appraise the diagnosis or maintain the appraisal through information seeking or information avoiding.

### **Information management strategies for care partners**

According to uncertainty management theory, individuals take actionable steps through information seeking or information avoiding to increase, decrease, or maintain the level of uncertainty they desire. Given that this research aims to understand how care partners and PwP manage uncertainty with the goal of creating educational materials for newly diagnosed PwP, it's imperative to understand which information strategies were deemed successful at reducing uncertainty discrepancy among care partners of PwP as they serve as both a leader and teammate in uncertainty management efforts.

According to UMT, information seeking can be further broken down into two categories: active information seeking and passive information seeking. This thesis uses the term instrumental information seeking in lieu of Brashers' active information because participants expressed purposely gathering information from multiple sources specifically to find out more about PD, such as medicine, progression, etc. This was seen as searching on the Internet or at the library, meaning instrumental information seeking lacked interactivity or information gathering via other PwP or care partners. Passive information seeking was further operationalized as emotional information seeking because participants expressed the informational and emotional benefits from putting oneself in a situation where they are likely to be exposed to new information. In this thesis that meant going to support groups, talking to others in doctors' offices and attending seminars, etc.



**Instrumental information seeking for care partners.** Instrumental information seeking was prevalent in 60 percent of care partners' information strategies. Most care partners voiced "we" statements when discussing their information seeking practices. This supports Brashers et al.'s (2004) findings that social support can act as a guide or ally in information seeking.

Care partners' perception of their doctor's bedside manner at diagnosis could be seen as a turning point for the care partners to enact information management strategies. It's also important to understand the timing in which care partners chose to start seeking information. Instrumental information seeking (looking for information online for the sole purpose of finding out more about what PD is) for care partners typically started immediately following the diagnosis. This may further emphasize the active and ever-evolving role care partners are in pre- and post-diagnosis. To reiterate, their role started as the observer or moderator at the time of a first symptom, which often led to a doctor's visit, resulting in an eventual PD diagnosis. Care partners may not feel they received adequate information about PD at the time of diagnosis, which would allow them to take an actionable step in order to reduce their uncertainty discrepancy. In a PD diagnosis context—instrumental information seeking may transform their role from observer to active teammate in terms of fighting for a quality of life with PD.

Participant 26 immediately dove into research after she heard the diagnosis of her partner, using "we" statements, further emphasizing the role of care partner as ever evolving as a teammate. However, care partners also expressed the fervent need for information dwindled within the first-year post-diagnosis.

"We really started right away. I mean right away. There was no waiting for us. We looked from what we could do without you know needing a doctor. We looked at diet. We looked at exercise.

But just a lot of research and looking at articles. I mean [my partner] is all over the internet all the time and he's always looking for something and once we really were connected with the doctor's office. I mean if we went armed with these trials and we heard about, are you going to be doing them?"- Participant 26

Like other care partners, information searching can become too encompassing, resulting in the illness consuming all aspects of their life. These findings are supported by (Chen, 2015), meaning that information seeking is valuable in the beginning of a diagnosis but for a chronic illness, it's not deemed beneficial after a certain passing of time. The need to take a step backward from information seeking can be seen below.

"You can't save every article. You can't just do all of this stuff. I went through and threw away everything in the binder." – Participant 13

This type of instrumental information seeking for answers about the nuts-and-bolts of the disease may have been beneficial shortly after a diagnosis appointment that did not provide clarity on PD. However, for care partners who are not physically experiencing the disease, the breadth and depth of information may be overwhelming and all-consuming. This may force them to re-appraise the situation as a threat or a danger, which may make them confront their current appraisal or thoughts about living with PD. Participant 17 sought out information from the bookstore and online for roughly six to nine months after the diagnosis of their partner and then felt consumed by the literature, resulting in her stopping her research.

“When we came home, we started to go on our websites, googling things, finding books. And at that time, we hadn’t told anybody. We would order books online. We wouldn’t go to the Barnes & Noble. We did not open up yet. Yeah, we did this for about six to nine months, and I was like I can’t do this anymore. I had read it. It felt like I knew the language but obviously, I put it down and like [my partner] said, it is what it is.” -Participant 17

Instrumental information seeking often times led to care partners and PwPs finding support groups, where they were able to acquire more information about how to live well with PD and increase their social network while seeing others’ progression for better or worse.

**Emotional information seeking for care partners.** Emotional information seeking through support groups had its pros and cons for care partners. Similar to Brashers et al., (2000) findings that support groups may help build social networks and be beneficial for frequent information updates, they can also threaten the appraisal one has about the illness if they see others who are in a worse state than their partner. As mentioned earlier, all participants in this study are part of a support group, meaning they all believe in the benefits of being social and sharing information through conversations with others. Ninety percent of care partners explicitly mentioned being involved in support groups or putting themselves in situations where they received information. However, care partners expressed the sadness and worry associated with going to support groups in the beginning stages of their partner’s diagnosis because it represented a negative future consisting of a decline in their partner’s motor and cognitive abilities.

These findings also emphasize the importance of the timing of information seeking when it comes to a chronic illness with an unclear and vague future. While instrumental information

seeking happened quickly after the diagnosis in order to reduce uncertainty, emotional information seeking through support groups was typically utilized as an information management strategy after instrumental information seeking, meaning the disease was re-appraised positively and the support groups helped increase uncertainty, meaning more options were available in order to live with PD.

Participant 26's experiences of getting into the flow of seeking out information through others came with ups and downs for their mental health.

“We did get into a sort of Parkinson's flow, I guess. We attended all sorts of educational things to try to be active and understanding and proactive and what we can do and trying to you know help ourselves, to help live the best life that he can and not be defined by Parkinson's but it was not fun.” – Participant 26

Emotional information seeking through support groups exemplifies a complicated dynamic, often times involving pros and cons of comparing a partner's situation to others, gathering more information about the disease, and being social.

“We're very involved. We're in two support groups. And then in one of the support groups we got to meet other folks. One of the couples, where one has Parkinson's and the other doesn't, and we've gone to lunch with them. We've met a lot of people and it's good for [my partner] because he's not a social butterfly. I'm the social one, so it's really been good for him and I've enjoyed it too. We learned tango last week.” – Participant 17

Support groups and having a network can help care partners relate to others as well as discover information that may be useful for their partner. Care partners expressed the importance of support groups as a way to validate their own feelings and appraisals of their partner's diagnosis as well. Through communication with peers, care partners were able to re-appraise their sources of uncertainty, such as their partner's diagnosis or communication with the partner to be positive or negative.

This is particularly helpful if PwP don't see their doctor on a regular basis and care partners have questions about typical symptoms or certain changes in behavior, which proved beneficial, can be seen in the follow excerpt.

“Yes, and like even if you have the best doctor, but you only see them every six months how much how much can they provide you with all of that kind of stuff? Whereas if you meet weekly with 20 other people [you] gain so much information” – Participant 13

Overall, emotional information seeking allowed care partners to either maintain their uncertainty or re-appraise their partner's diagnosis as an opportunity for more solutions and treatments, meaning that emotional information seeking was highly beneficial for care partners. By understanding that support groups provided more options and alternative treatments, such as exercise for PwP, care partners can view their partner's diagnosis as an opportunity or hope, meaning uncertainty is increased. Because this study focuses on empirical results in order to create educational materials about support groups and social networks for those affected by PD, it would be valuable for care partners to be educated on the PD community quickly after diagnosis.

The socialization and validation of experiences care partners can receive from support groups is one of the emotionally beneficial aspects of these gatherings. As care partners are the ones experiencing PD on the outside, they are confronted with a life changing experience that they can only perceive through the actions of their partner. Once again, this requires them to think about the present and possibilities of the future all at the same time while also wanting to help their partner, even if they are feeling shut out. These findings are in line with those from the long-term breast cancer survivor community in which it was found that distraction via friends and social support lessened the threat and anxiety around breast cancer recurrence (Mishel, Germino, Gil, Belyea, LaNey, Stewart, Porter, and Clayton, 2005). Participant 7 expresses the benefits of feeling validations from other care partners who may experience the same situations with their partner, such as lack of communication or a difference in behavior.

“Little specific things like you know, like [my partner] is driving me crazy doing this or that or not doing this or that. Are you experiencing that? And that's what I'm hearing that from so and so is having a tough time with whatever, 'Have you and [your partner] gone through that?' Just the little things.” -Participant 7

Socialization is beneficial for those with PD, but it's also beneficial for the care partners whose role is changing, and their behavior adapts to the needs of their PwP. While yes, care partners' attitudes may affect the diagnosis appraisal, they also need support and validation from peers as well. Care partners may feel lonely or lost at times when it comes to navigating their life and role, post-diagnosis. These sentiments are echoed from participant 26.

“I think what it feels like is, you know, you’re always I mean we try to be optimistic I guess and not dwell on, ‘Oh my god. This is what we’re going to be facing,’ because that doesn’t really help and even though you know, there are days when it’s like, oh shoot, you know, this is not getting any easier. But you know, sometimes you feel a little bit alone trying to find your way and a lot of the things, that’s it.” – Participant 26

Participant 26 identifies that while care partners have changing roles and attempt to help their partner appraise their diagnosis as positive, it can be challenging to maintain optimism and feel connected to others. This is why it’s important for care partners to socialize with other care partners, not only for information sharing about the disease but also for community support and validation of feelings. While it may not be common practice to start the PD journey with support groups, care partners have deemed support groups and being involved in the PD community as holistically beneficial for both themselves and the PwP through building social networks, validating current feelings, and sharing and exchanging useful information. For this reason, doctors’ offices at diagnosis may encourage support groups or make their patients aware of such resources for their overall health and well-being. This may mean educating doctors on holistic practices, which may include emotional and physical prescriptions, such as socialization and exercise.

### **Managing chronic uncertainty for care partners**

This particular demographic has been diagnosed with PD for at least two plus years, meaning they’ve been able to experience life post-diagnosis and understand the disease. According to Brashers et al. (2000), when uncertainty persists over a long period of time, individuals may manage it through relief or acceptance. The results of this research support those

of Brashers et al. (2000). Over time and through actively participating in support groups and PD-focused exercise classes, care partners were able to accept the chronic uncertainty that is PD, which can be seen below.

“I think having had known important things, like that with medication it’s a manageable disease, that it’s not the end of the world, it’s not like cancer which can be three months to live. It’s a manageable disease. It is a disease but it’s manageable. And knowing that there were support groups available, which there are a lot of them.” – Participant 15

Managing chronic uncertainty through accepting the diagnosis also presented itself in terms of living in the present. Because the future is highly uncertain with PD, care partners must be present but plan for the future by knowing to check in with their partner and observe for signs of decline. This offers a myriad of options and changing roles for care partners of PwP.

“So, I believe together that we’re going to have a really positive good life for a long time. And this on that and year things could go differently than I expect, and I know that I tell myself that we just take it as it comes and if time comes that I have to adjust my expectations. We’ll deal with that. You know, I’m trying to live in the right now.” – Participant 13.

While care partners discussed immediately information seeking to learn more about PD, they started reducing their uncertainty discrepancy once they got involved in support group settings, such as exercise classes and educational meetings. This empirical evidence suggests that



helpful educational materials would cater to community involvement and engagement for those affected by PD.

### **PwPs' sources of uncertainty**

Care partners' sources of uncertainty revolved around their changing role from their partner's first symptom, the diagnosis itself, and what it means for their relationship, overall. PwP sources of uncertainty stemmed from similar areas, such as communication with their partner, but they also had more uncertainty about the variability of the disease in general. The disease itself, is a source of uncertainty for both parties, but because this thesis aims to understand uncertainty management post-diagnosis in order to create educational materials, sources of uncertainty about what the diagnosis caused for the PwP is the focus of these findings. For this reason, communication with partners and the variability of the disease have been deemed ongoing sources of uncertainty.

**Setting communication boundaries with care partner.** When talking about their partner, PwP expressed uncertainty as to how to make them understand what they're going through without worrying them more or shutting them out. Fifty percent of PwPs discussed feelings of uncertainty when it came to talking with their partner or what information to divulge to them to keep them informed but not worry them. PwPs expressed feeling "bad" for putting their partners in this situation through their diagnosis but commented on the difference between experiencing the diagnosis and being the partner of someone who is diagnosed. Participant 8 expresses these concerns.

"So, a lot of times Parkies will not share a lot of what's going on in the moment with a care partner because they don't need the interaction, right. And the way Parkies like to say is like if I

need your help, I will ask for it. It's really frustrating for care partners because they don't know what's going on until you're living inside of it. You really fully appreciate it and then they feel like they're being shut out which in a sense, they are. That's not really the intent for a PwP, but that is the result or perspective of the caregiver. But you know, 'you're pushing me away, you're shutting me out,' there's a lot of friction and tension there and you really have to talk through that a lot and it takes a long time and it takes reinforcement. I don't think it ever really subsides completely or goes away or resolves itself you know it just keeps kind of coming back out and to get back into, 'Well this is my goal. This is why I have this goal, and this is why I'm doing what I'm doing. I hope you can appreciate and respect that and work within those boundaries.'-

Participant 8

While PwP understand this can be frustrating for their care partner, they expressed their worry about how their care partner handles the transition of their identity changing from their former self to a PwP as well, which will be discussed under emotional responses.

**Variability of disease.** Because PwPs are the ones experiencing the symptoms and diagnosis, their sources of uncertainty dealt with symptom progression and how quickly their progression will occur. They were more concerned with the nuts-and-bolts of the disease because they can feel the difference and what is no longer normal for them. While care partners also felt uncertain about the future of the disease, it was more in terms of how much time they have left together as the couple they currently are. Seventy-nine percent of PwPs felt uncertain about the variability of the disease and the trajectory of their illness. Participant 14 discusses what it's like being diagnosed with a disease that is different for each person who has it.

“So, the first thing I did is, you never know how your life is going to change, the impact its [PD] is going to have, mainly because every case is unique. Every patient is different. There are no absolute answers to how fast this will progress. You don’t know when your life will be really unmanageable so, you have no clue and the doctors cannot help a lot. They cannot say ‘Your Parkinson’s will advance quickly. Your concerns will advance, you have 10 years left in you.’ I mean there’s no answer. So that’s a problem.” -Participant 14

PwPs expressed uncertainty about how their life will unfold having a disease that has no known trajectory and manifests itself in each patient differently with different symptoms. Similar to care patterns, the temporality of the disease was front-of-mind when thinking about the ‘unknowns.’ However, PwPs’ uncertainty stemmed from wanting the ability to take the future and progression of the disease in their own hands. PwP wanted to remain themselves as long as they could, desiring a way to not lose more of themselves each day.

### **PwPs’ emotional responses**

**Relief and confirmation at PD diagnosis.** Seventy-one percent of PwPs felt a sense of confirmation and relief at their diagnosis because it meant they had an answer for their symptoms. PD itself is hard to diagnose and the process can consist of years of misdiagnoses or appointments with general practitioners and specialists. Once PwPs were given a reason for their stiffness, anxiety or overall motor decline, an appraisal could be made and then action steps taken to reduce uncertainty discrepancy. Since the diagnosis itself is a source of uncertainty, it’s important to understand how PwP appraised their PD diagnosis, which prefaced an information management strategy in order to move forward with their life. The following participant labeled the diagnosis as relief or a confirmation, which helped her create a plan for next steps.

“So, then I knew everything made sense and you could see that the puzzle finally came together to give you the accurate diagnosis, before it’s just like pieces all over the map. So, then my loss of smell makes sense, the loss of equilibrium, the freezing episodes, the handshaking, the neck pain, the hip pain, everything made sense, but by then three years have passed.” -Participant 14

By the time Participant 14 was diagnosed, she had experienced years of uncertainty with no clear answers to her pain and discomfort. Her diagnosis, three years later, came as a relief and confirmation because this meant she could move forward with appraisals and information management strategies. Sources of uncertainty need to be appraised for their meaning so PwP can take actionable steps to increase, reduce, or maintain their desired level of uncertainty. For PwP who struggled to get an accurate PD diagnosis, their appraisal process was finally starting at the time they heard they had PD. This differs from the emotional response behind the relief care partners felt at their partner’s diagnosis. When care partners felt relieved at the PD diagnosis of their partner, they expressed it came from their past medical experiences with a loved one, meaning experiential information helped create a positive appraisal at the diagnosis. For PwP, their relief and confirmation of the diagnosis came from a place of misdiagnoses and years-long process of uncertainty, further emphasizing the different roles and players in the PD community. PwP felt relief at finally having an answer to the variability of their pre-diagnosis symptoms. Care partners felt relief when they realized they would have many more years with their partner. Once again, this emphasizes the importance of medical professional training on patient-centered communication. By the time these individuals go to see a neurologist, they’ve experienced months and sometimes years of appointments without answers to their physical symptoms.

**Denial and shock at PD diagnosis.** While a majority of the PwP felt a sense of relief or confirmation at their diagnosis, others expressed being in denial and avoiding the knowledge that their life was changed by their PD diagnosis. Those who expressed shock and denial about PD admitted to not knowing much about PD at the time of diagnosis or wanting to know more information from their doctor. This will be later addressed in relation to their doctor's bedside manner and may be considered a turning point for active information seeking.

“He [doctor] said [Participant 3] don't worry about Parkinson's because you won't die from it, but you will die from the residuals. And I said well, ‘What do you mean?’ Well that lot of times you'll get pneumonia, kidney disease. I'm thinking to myself hold the phone what I mean. This is the best you can do? and then I said but what do I do? He said well just take your prescription and you know, that's it and I was really surprised that the medical community had no better advice or console to understand that my brain just went through 180 degrees and now I'm panicking. I'm thinking I walk out tomorrow and am dead on the street. So, I was really apprehensive. I was upset. I was scared, just to name a few emotions, but then I got to try to start searching and I think that was really what I needed.” -Participant 3

For those who were shocked at the diagnosis, their doctor's lack of empathy and/or communication resulted in fear and anxiety about their new PD diagnosis. This doctor offered little to no information on how to live outside that doctor's room except for taking medication. This participant explicitly stated that his negative appraisal started to shift into positive once he started instrumental information seeking, giving him a sense of control. These findings are in line with Stiegelis et al.'s (2004), research on individuals utilizing radiotherapy, which found that a

lack of information about the illness may result in feeling a lack of control and a high level of uncertainty and that when patients have information about their illness and treatment they are able to adjust to the news better.

**The positives and negatives of changing identities.** PwP also struggled with coming to terms with a new identity that involved no longer being able to do the things they once loved. For some PwP, this felt like losing a little bit of themselves each day or finding a new part of their personality or talents because of PD. Because PD has an unknown progression and symptom trajectory, PwP are invited to think about their life pre-diagnosis and their current life, post-diagnosis. This requires them to be in a perpetual state of changing identities, from their former self, to their current progression, to the possibility of decline in the future. Participant 10 described his experience watching his old passions change throughout his diagnosis.

“I am no longer riding my bike across the states or jumping off mountains on a mountain bike, which I did regularly even in my 60s. I sold my bike, sold my kayak, which is very painful. So, I changed what I do.” -Participant 10

Forty percent of PwPs felt grief and a changing identity that echo the findings of Ravenek et al.’s (2017), whose research involved the young onset PwP community. However, the participants in this study expressed the notion of a changing identity years after their diagnosis, while Ravenek et al.’s participants felt fear and grief about their diagnosis right away.

Other PwP felt that PD allowed them to truly be themselves and even discover new qualities and talents. The following participant describes what it’s like to witness new passions because of her PD diagnosis.

“I took it as an opportunity to do something that I had always wanted to do, which was draw and design. I can say that Parkinson’s gave me the opportunity to be truly happy, which not many people can say and that’s when I was 52 years of age. My life changed, so I was able to do what I really wanted.” – Participant 14

PwP either took their diagnosis as a positive or negative appraisal, meaning they saw it as a threat or an opportunity. Those who saw PD as an opportunity, expressed feeling grateful and truly happy with their current quality of life. However, these positive emotions were expressed years after the official diagnosis, meaning they had time to understand their chronic uncertainty surrounding PD. While Brashers et al.’s (2000) findings support that chronic uncertainty can be appraised as acceptance, these individuals expressed gratefulness and many silver linings in their life due to PD. This symbolizes that even if the diagnosis itself isn’t appraised negatively it can take years for PwP to see a silver lining to their chronic illness. Seeing others living well with PD may be a powerful educational tool for those who are newly diagnosed. Information regarding life with PD from someone who has experienced the disease for years may provide newly-diagnosed PwP and care partners with hope for the future.

Whether the diagnosis was appraised positively or negatively, action steps need to be taken in order to reduce uncertainty discrepancy. Overall, PwP dove into research quickly after their diagnosis and this was typically linked to the lack of information they felt they received at the time of their diagnosis.

## **Lack of information as a turning point for information seeking**

Even though a majority of PwP felt a confirmation or relief at their diagnosis, they did admit to having more questions about the diagnosis and the future even after their official diagnosis with a specialist. Seventy-nine percent PwP felt a lack of information from the medical community when it came to knowledge about how to live well with PD. Once they understood there is no-known cure or cause for PD, many PwP wanted solutions or treatment options aside from surgery or prescribed pills. The lack of information about community programs or lifestyle treatments, such as diet and exercise can be viewed as a turning point for PwP, causing them to seek out information to increase their uncertainty and know about more options or reduce their uncertainty, ultimately reducing the threat. The following participant discusses what he wanted to hear at the time of diagnosis.

“Why couldn’t he [the doctor] tell me about Rock Steady Boxing? Why couldn’t he tell me about the Loud and the Big, and they couldn’t communicate to me or they wouldn’t. Almost verbatim, so sorry to tell you but you’ve got Parkinson’s and that’s a neurodegenerative disease that has no cure. Here’s a book and here’s some pills, see you in six months, you know, and I almost felt like a death warrant.” – Participant 1

This participant’s experiences echo other diagnosis stories, even those who felt a confirmation or relief at the diagnosis, described wanting more information from their doctor about community programs at their official diagnosis. This participant mentions two PD-specific



programs (The Loud and the Big, and Rock Stead Boxing) that help manage physical symptoms of PD, such as speaking and physical exercise. Those who immediately felt relief at their PD diagnosis still went through a series of appraisals and reappraisals when confronted with a lack of information about how to live well with PD. This emphasizes the important role doctors' bedside manners play in the co-creation of appraisals at the time of diagnosis. While those who teetered between relief and wanting felt upset by the lack of lifestyle treatments, those who felt denial and sadness also wanted more information at the time of diagnosis. When it comes to a chronic illness shrouded in uncertainty, PwP may be searching for an authoritative figure to validate their feelings and increase their uncertainty by presenting multiple options for living well with PD.

Because it takes months, more often years, to officially receive a PD diagnosis, doctors may need to be trained in patient-centered communication, meaning they assess the social and emotional norms as well as personality traits of a patient when giving a diagnosis (White, 2015). Overall, doctors need to adapt to the receiver in order to reduce the communication discrepancy between sender and receiver of sensitive information, such as a diagnosis.

The following sections delve into the information management strategies PwP engaged in to reduce their uncertainty discrepancy.

### **Information management strategies for PwP**

Because PwP are experiencing the changes PD has caused in both their mind and body, it's important to understand the strategies they use in order to achieve the amount of uncertainty they desire. Instrumental information management means the individual searches for information online or at the library with the intention to find information regarding medical, symptomatic, or progression information from authoritative sources. Instrumental information seeking lacks the

interactivity of emotional information seeking, which is primarily finding information through conversations, interactions in-person.

**Instrumental information seeking and reappraisals for PwP.** A majority of PwP expressed information seeking online or at the library as a first step in order to reduce their uncertainty discrepancy. Seventy-nine percent of PwP explicitly stated that they actively sought out information from numerous resources, such as the library, webinars, and most commonly used, the Internet. Instrumental information seeking was used as an information management strategy shortly after the PwPs' official diagnosis or when PwP had specific questions about a symptom, such as active sleeping, freezing spells or medical trials. 60 percent of PwP stated they actively sought out information about PD shortly after their diagnosis.

PwP revealed the difficulties associated with being their own health advocate. They conveyed having to sort through large amounts of information to find authoritative websites and credible information online, which further emphasizes the importance of needing appropriate and authoritative educational materials for newly diagnosed PwP. Participant 8 describes his experience as being his own information advocate and immersing himself in literature as a process.

“My symptoms were pretty much motor and at that point in time and very minor motor symptoms and I pretty quickly concluded after reading the literature and I devoured a lot of literature I just spent hours and weeks and weeks and weeks' time, hours every day scouring the Internet and there's a lot of junk out there but you get into authoritative articles. I had to separate the weed from the chaff and what you're reviewing and adjusting pretty clear for me, there is no treatment for the disease, just treatment for the symptoms.” -Participant 8

PwP who sought out information on their own shortly after their diagnosis are navigating a complex and unclear situation looking for answers in order to achieve the amount of uncertainty they desire. After diagnosis, PwP are in the midst of appraising their current situation and looking to either reduce their uncertainty by finding options to make PD less of a threat or they are looking to increase their uncertainty by appraising PD as hope or optimism with the goal of finding more resources to help them. This all makes wading through information online a process of constant re-appraisal.

Participants' frustrations with finding relevant information online speaks to the importance of health literacy and its ability to influence patient communication with doctors as well as their ability to find and utilize information that is authoritative and accurate. Health literacy is when an individual has the ability to gain access to, process, and utilize information to maintain or increase their health (Nutbeam, 1998). It's important for all individuals to be health literate, but it's particularly important for those who are affected by a disease to know how to communicate and understand the information they receive, how to find information, and how to use it properly to promote good health. Because individuals can receive and seek out health information not only from their medical providers but from different sources, such as the Internet, the need for health literacy or eHealth literacy is vital (Neter & Brainin, 2019). Poor health literacy has been associated with patients not understanding or missing their chronic regimens, inaccurate health reports, missed doctors' appointments and even hospitalization (Neter & Brainin, 2019). For this reason, individuals, especially PwP and care partners must have proper educational materials to increase their health literacy to maintain, increase or promote good health.

For those who avoided information seeking after their diagnosis, they voiced the need to process their diagnosis first and only after they started seeking out information about PD, their perspective on the disease and their life changed in a positive way. This may be seen as an important step for living well with PD. Overall, PwP felt more empowered and confident when they knew more information about their disease, but for some, it took time to acknowledge their current situation and face it head on. This finding is in line with Stiegelis et al. (2004), that the more information one has about their illness and treatment, the more in control they feel, allowing them to adjust better to their current situation. Participant 3 illustrates the re-appraisal process PwP may go through when it comes to understanding their diagnosis and how to reduce their uncertainty discrepancy. For this participant, his social network aided him in becoming his own advocate and actively seeking out instrumental information about PD, which helped him re-appraise his situation positively.

“But then I got to try to start searching and I think that was really what I needed. I talked to several people about ‘[Participant 3], you know, you need to go get on the Internet, go to the library, start your search and try to keep your brain occupied to find out what you’re up against and that was really a godsend and I was just with the next door neighbor and he said ‘Hey [Participant 3], why don’t you just go get on Google and find out what’s going on? And so that’s really and you can see the open chasm there. Where, how do you take the patient from a comfort zone to our comfort zone to your comfort zone and I think that’s what we’re doing is just right on target.” -Participant 3

Unlike care partners, PwP did not discuss feeling overwhelmed by purposely seeking information about PD through books and online channels. Where care partners discussed stepping back from letting PD take over their lives, PwP felt the opposite. Once they started to purposely seek out instrumental information about PD, they felt better and wanted to know more treatment options, strategies and ways to get involved. This can be viewed for some as a re-appraisal process, meaning those who once felt bad about their diagnosis felt more empowered and hopeful after information seeking. Those who already felt confirmation or relief may have maintained their desired level of uncertainty or even increased it through finding more solutions and options for treatment and care, thus emphasizing the importance of information seeking strategies for managing uncertainty surrounding PD.

**Emotional information seeking for PwP.** This process of re-appraising the situation closely reflects how PwP felt around emotional information seeking, which for this thesis, is defined as being active in support groups and PD exercise classes.

**The temporality and risks and rewards of support groups.** As addressed with care partners, support groups were deemed vital outlets for support and information when it came to reducing uncertainty discrepancy. However, being involved in support groups also coincided with feelings of worry and fear about what the PwP future with PD may look like. Similar sentiments were divulged in PwPs' feelings and temporality of passive information seeking.

All participants interviewed are active in some type of support group, whether it be one they created, one they attend or a PD-specific exercise class. However, participants expressed variations in the timing in which they felt that attending support groups and talking with peers was beneficial and actually provided a sense of hope for them. Half of PwP mentioned not joining support groups or social networks right away. This was due to a myriad of reasons

including, lack of information from doctors about community resources, avoiding the diagnosis in general, or fear of seeing others who were further along in their symptom progression.

Brashers, Neidig & Goldsmith's (2004), findings support this current phenomenon that diagnosed individuals may want to avoid support groups because it represents their future and may threaten their current beliefs about their disease. For participant, 12, support groups and exercise classes represented a future he was not ready to confront.

“I'm the type of person that when something happens that's really, really big. I kind of stopped. I don't have to react. I have to kind of sit back and sit down before I react to it. So, I would have to say I really didn't think about it. I can't think of the word. I'm trying to say, I really didn't accept the diagnosis probably till about maybe a year later, a year and a half later. So, it just took me some time and of course everybody's different but I just had to think through the process and also come to grips with a lot of different things. The one thing that really I guess that bothered me the most was my first experience of going to rock steady boxing and seeing others with Parkinson's and problems that they had to deal with because I wasn't quite there yet, which I'm very fortunate but then when you when you see it face-to-face and you see others that have the disease, then you finally hit you, finally realize wow, that's that could be me down the road then. That was really hard. It was really difficult for me” -Participant 12

While this participant stated the PD-focused exercise class caused him the most distress in the first-year post-diagnosis for fear of the future, he is very active in the PD exercise community and encourages others to get involved as well. This further emphasizes the role of support groups and social support as a way of re-appraising PD through validation and

camaraderie, as well as successfully reducing uncertainty discrepancy. It may be beneficial to educate PwP and care partners on lifestyle treatments, such as exercise through community and validation. While participant 12 was fearful of PD exercises classes at first, after giving it time, he later started promoting the classes and deemed it the most helpful act in terms of living well with PD.

" So, that that's helped me in many ways, but I try to get the word out and try to get others to understand that this is the way you know, this is where you need to go. You need to come to class because you have friends there because they'll help you if you have questions, but you know exercise is the best and what we work on first, but you can learn about meeting others and getting a partnership with someone that will help you in this because it takes, it takes a family, it takes it, takes more than just yourself. You can't do it by yourself because one of the things that really will affect you is your brain like for an example in boxing, I thought I was hitting the bag pretty hard and then when I saw a video of myself then I looked at it. I went wow, you're really not, so my brain was telling me yeah, you're doing a great job, but then when you turn around and see it from the outside, you're not, so your brain can trick you so that's why you need someone or some you know, as a partner of some sort or helper that will remind you. Hey, you know, you're not really doing it, you know, you need to do this or that, so it really helps."-

Participant 12

A majority of the PwP who explicitly mentioned support groups felt it provided them with valuable information about the disease and treatment options as well as emotional support. Ninety-three percent of PwP explicitly mentioned being involved in forms of emotional information seeking, such as social support groups, exercise groups, and educational meetings

and groups. All PwP who explicitly mentioned being involved in these forms of gathering information also expressed the emotional, mental, and physical benefits of regularly attending these types of social gatherings. Participant 16 revealed that being involved with others who were also diagnosed with PD actually helped him reduce his uncertainty through feeling validated.

“Meetings with professionals were usually very brief, of necessity but meeting with other people with Parkinson's you could chat with them in person, call them on the phone. There was another guy who's diagnosed about the same time I was, about my age. He would call me frequently and say has this ever happened to you? So, and so ever happen to you? Shared information that way. I believe it was helpful to him and also helpful to me. It was helpful in reducing uncertainty. It was also helpful somewhat in reducing the stress as you realized you're not the only person in that particular boat. You know, I found that helpful in those ways.” -Participant 16

Social networks through support groups serve many roles for PwP. However, the ability to talk with others who have been in similar positions came with risks and rewards for PwP. They felt comfort seeing others in similar situations who could share information about symptoms, treatments, and medicine but they also risked seeing PwP who have progressed faster and are in worse decline than they currently are. These findings are supported by Brashers et al. (2000), who found that optimism, even unrealistic optimism is highly beneficial when it comes to managing an illness. Support groups could potentially threaten that optimism, which is why some may deem them scary and avoid them. However, support groups also provide PwP with the ability to share information and communicate with people who understand their situation and



have experienced similar positive and negative situations. For this reason, emotional information seeking through support groups and feelings of validation from peers is holistically beneficial for PwP and care partners alike who strive to successfully manage their uncertainty. The need for each individual to be able to communicate with like-minded peers is insurmountable in terms of learning to manage chronic uncertainty as well as successfully managing uncertainty discrepancies.

Overall, the majority of PwP specifically discussed the benefits of exercise support groups. This mostly consisted of learning new physical activities, such as boxing or tango. Even when PwP mentioned attending regular support groups that didn't involve exercise, they also made a point to talk about the physical activities they were involved in and how confident it made them feel. Seventy-one percent of PwP mentioned utilizing exercise classes. They expressed feeling confident and supported by completing a physical activity with their peers. They also felt their exercise classes made an impact in slowing down their progression, which gave them hope and optimism about their disease and their future. Through physical activities and social support, PwP were able to feel more positive about their current state, validated by their peers, and confident in their abilities to help their body help itself. Participant 1 expresses the emotions associated with being active as an individual with PD, which can be seen as a positive appraisal of his disease.

“And the point I make about boxing or tennis, it gives us hope and without hope what have you got and so hope has helped me a heck of a lot, you know to know that I can do something. I'm not, I'm not just going to sit there and wait for it to run over me like a steamroller.” -Participant 1

Unanimously, PwP attended many forms of support groups and even wished they had attended them sooner after their diagnosis. While care partners expressed avoiding support groups out of fear for their future, PwP expressed not being aware of support groups in their area, being told to avoid them, or fearing what it will do to their emotions to see other PwP who were in worse decline.

However, support groups provided valuable emotional and physical benefits to both PwP and care partners. Participant 10 poignantly expresses what he needed to hear at his diagnosis, which can be viewed as one of the reasons community resources may be one of the more valuable sources of information and validation for the PD community.

“I don’t much care about the physical diagnosis at that point, it was a soul thing and a heart thing. I was scared. I just needed to have somebody listen to me and care for me and tell me it’s going to be okay who’s walked the walk.” -Participant 10

The need for emotional support and validation from someone who has experienced the same diagnosis was deemed important in order to assist in appraising the situation for the PwP. Participant 10 felt that an authoritative and trusting source would have been someone who had been diagnosed with PD as well. For participant 10, the only information he needed to know was from someone who had experienced a similar process and journey to his own.

### **PwPs’ managing chronic uncertainty**

Similar to care partners, PwP have accepted their diagnosis and life with PD. Seventy-nine percent of PwP expressed managing chronic uncertainty through acceptance. For PwP, managing chronic uncertainty presented itself in acceptance of the disease and acceptance of the

activities they can and can't do because of the disease. This meant slowing down on certain projects, avoiding stressful situations, or accepting the mysteriousness of the disease itself. Their acceptance also manifested itself in PwPs' willingness to try new activities and remain focused on what they know may be beneficial to slow down their progression, such as socializing and physical activities, like exercise. For participant 21, acceptance resembled not giving up and being patient with himself.

“I guess you just take one day at a time. You try things and what works you continue to try and what doesn't work, you don't. You just discard what doesn't work. And you just deal with it one day at a time.” -Participant 21

For PwP, acceptance didn't equate to no longer trying alternative solutions and treatment options, but it meant accepting that a quality of life and a potential cure is still worth fighting for and that living well with PD is possible, but it takes effort.

### **Limitations and future research**

A few limitations of this thesis should be noted. All participants were recruited from support groups, meaning their unanimous consensus on their importance for reducing uncertainty seems likely. However, their temporality of utilizing support groups as a source of information allowed for the researcher to understand when support groups may be deemed as a threat versus an opportunity. The sample size could also be more diverse in the future. The demographic was primarily Caucasian between the ages of 50 to 80 years old, which may impact stories and experiences with the diagnosis. While the male to female ratio was even, the PwP to care partner ratio was skewed.

The temporality of information management strategies surfaced through the data, but researchers may also want to specifically ask for timelines about diagnosis, community involvement and active researching in future studies to establish patterns. A final outcome of future research may be to focus more on mental and emotional health outcomes and changes due to uncertainty management strategies.

## **Conclusion**

PD is a neurological illness with no-known trajectory, cause or cure. Given the international projection of diagnosed individuals will be ten million and the economic value of informal caregivers is estimated at 196 million, educating newly diagnosed PwPs and care partners on how to live well with PD and manage uncertainty is a public health responsibility (Parkinson's foundation, n.d.; Navaie-Waliser, 2002). Participants in this study discussed the processes and temporality of information management strategies in order to reduce their uncertainty discrepancy regarding PD. The empirical evidence found in this study will be used to create educational materials for newly-diagnosed PwP and care partners for a non-profit organization. Overall, educational materials focusing on communication, changing identities, and the importance of socialization, and exercise would be beneficial for both PwP and care partners to have within the first six months of diagnosis. Care partners and PwP were both able to appraise or re-appraise PD positively through attending support groups. Socialization and support groups were valuable for care partners who felt worry or fear about the future of their relationship with their partner as well as for PwP who felt they shut out their partners. Feelings of validation and information-sharing through support groups were found to be holistically beneficial for both parties. Support groups and PD-specific exercise classes provided both care partners and PwP with hope and optimism about PD and their future. These findings will serve as the focal points for the educational materials.

The ability to manage information effectively and the strategies used to achieve desired uncertainty all worked in conjunction with emotional responses and sources of uncertainty.

Emotional responses and sources of uncertainty were separated as individual categories in order to best understand what information would be deemed useful for care partners and PwP individually.

While care partners and PwP may have had similar sources of uncertainty and uncertainty management efforts, the nuances of how they perceived these sources of uncertainty and the appropriate information management strategies were revealed through these semi-structured interviews.

Care partners' sources of uncertainty revolved around witnessing the changes in their partner and their relationship as a whole. These sources of uncertainty were associated with feelings of sadness and worry. However, care partners who had experiences with other medical diagnoses felt a sense of relief about their partner's diagnosis because it meant they had more time to spend together as a couple. Overwhelmingly, care partners co-created their appraisal of the diagnosis with the doctor, which served as a turning point for information management strategies. Care partners' perceptions of the doctor's bedside manner and delivery at the diagnosis of their partner helped them co-create the diagnosis as a positive or negative situation. This led them to utilize information strategies post-diagnosis in order to increase or reduce their uncertainty.

Care partners typically either took the lead in instrumental information seeking online or served as a teammate and ally in the process. Through research, care partners were able to find community resources and support groups, which have been defined as strategies that fall under emotional information seeking. At first, support groups symbolized a threat to care partners and they chose to avoid them. However, through re-appraising the diagnosis from instrumental

information seeking, care partners deemed support groups as a huge benefit in achieving the level of desired uncertainty.

PwPs' sources of uncertainty revolved around communicating with their partner and fear of shutting them out and the variability of the disease itself. PwPs' emotional responses ranged from acceptance and relief at diagnosis to shock and denial when hearing they had PD, once again emphasizing the power doctors have in co-creating appraisals of a diagnosis, which further emphasizes the need for medical training to include communication strategies. The majority of PwP felt confirmation at their diagnosis that they finally had an answer to their symptoms. PwP also felt emotional about their changing identity post-diagnosis, which is common for those dealing with a chronic illness and uncertainty management (Brashers, Neidig, & Goldsmith, 2004). Some felt PD allowed them to be happier and braver than before, while others felt like their former self was slipping away each day. These emotional responses symbolize the re-appraisal process and how it can change throughout an illness. Emotions about changing identities and the diagnosis itself served as a turning point for PwP and their information management strategies.

A majority of PwP utilized instrumental information seeking shortly after their diagnosis in order to learn more about the disease and how to live with it. Being their own health advocate presented challenges when it came to sorting through information online and finding authoritative sources. However, unlike care partners, PwP did not feel overwhelmed or inundated by searching for PD information. A majority of PwP felt they successfully reduced their uncertainty discrepancy the most through emotional information seeking, which took the form of support groups and PD-specific exercise classes. PwP felt validated, motivated, and confident about their diagnosis after being a part of a support group.

PwP and care partners felt community support and physical activity helped reduce their uncertainty discrepancy and that illness appraisals can shift and change over time depending on how they assign meaning to the uncertain situation presented before them. Educational materials best-suited for newly diagnosed PwP and care partners of PwP will include messages of hope and optimism, solutions for living well and care as well as information and knowledge about PD community resources with action-messages that encourage involvement. These findings from this study will be the guiding content for educational materials so PwP and care partners can live well within the first six months of diagnosis.



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## Appendix A

[Note: The following questions are designed to be semi-structured in nature, meaning that the moderator will be able to engage in a conversation with the participants. Follow-up questions related to the research questions will be asked when appropriate.]

Today, I'd like to ask you a series of questions related to you (or your partner's) Parkinson's disease diagnosis. The goal of *Me Over PD* is to help newly diagnosed patients and care partners better navigate the complexities of care associated with Parkinson's disease. To begin our interview, however, I'll be asking you to tell me a little more about yourself. I'd like for you to think back to when you (or your partner) were diagnosed with Parkinson's disease.

1. When were you (or your partner) first diagnosed with PD?
2. Do you remember your first thoughts after you heard your (or your partner's) diagnosis? What were they?
3. Can you tell me about the doctor's visit when you (or your partner) were diagnosed? Was anyone there with you? How did you feel before and after?
4. Can you tell me about your life since your (or your partner's) diagnosis?
5. Did you feel like you knew a lot about PD when you (or your partner) were diagnosed? How did this "knowing" versus "not knowing" feel for you?
6. Can you tell me about anything in your life that makes you feel unsure or has caused you to have more questions about PD?
7. How has not knowing or uncertainty affected your life? The life of your family (if applicable)?
8. How do you manage not knowing about how your (or your partner's) symptoms will progress?
9. If your partner is feeling uncertain about something, what do you do to help manage this stress?
10. What are some of the coping strategies you used when you were first (or your partner) was diagnosed with Parkinson's disease? In what ways were those strategies helpful or not helpful?

## Appendix B

Codebook for understanding uncertainty management among PwPs and care partners.

### Rules for coding:

1. Apply codes/labels to specific areas where they are seen within the transcripts.
2. Address HOW the code is being used. For example, if the source of uncertainty is part of a participant discussing their misdiagnosis, please write “source of uncertainty” by the misdiagnosis so each coder knows that is how she interpreted the misdiagnosis. This applies for all codes.

Preliminary/ First step coding: As a preliminary level of analysis, each coder will identify uncertainty, sources of uncertainty, and uncertainty management efforts. The coder and second coder were required to do this to clearly label these occurrences to aid in further categorization.

**Uncertainty:** When a situation is vague, complex, unclear, or offers potential problems in the future (Stiegelis et al., 2004).

**Sources of uncertainty:** Coder should look for sources of uncertainty, such as doctor’s visits, first sign of PD symptom, a misdiagnosis before an official PD diagnosis, the unpredictability of the trajectory and symptoms of PD, their past experiences with PD, such as a family member having PD symptoms without an official diagnosis. By identifying a source of uncertainty, the coder will be able to read the transcripts and identify actions taken to manage uncertainty.

**Uncertainty management efforts-** Uncertainty management efforts can be defined as the steps one takes in order to increase, maintain, or reduce their uncertainty. This may look like information seeking, information avoiding or accidentally receiving information. This may occur when a care partner or PwP discusses the role of too much information seeking, like the illness taking over their lives or causing distress. This may also look like the PwP or care partner discussing that they sought out information generally or were told to go to a support group. This label is used to recognize the efforts taken to manage uncertainty. If this label is used, one of the following will most likely be used as well.

**Emotional responses-** The emotional response that is associated with the appraisal by the PwP or care partner. For example: Uncertainty that is appraised as danger is associated with emotions such as anxiety or distress; whereas opportunity appraisal is associated with emotions, such as hope or optimism (Brashers, Neidig, Haas, Dobbs, Cardillo & Russell, p. 66, 2000).



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Information strategies:

- **Active information seeking-** When a PwP or care partner purposely seeks out information from various sources (Brashers, Neidig, Haas, Dobbs, Cardillo & Russell, p. 70, 2000).
- **Passive information seeking-** When care partner or PwP puts themselves in environments where they would likely be exposed to new information through information sharing from others or informal conversations (Brashers, Neidig, Haas, Dobbs, Cardillo & Russell, p. 70, 2000).
- **Experiential information-** PwP or care partners reducing their uncertainty through their past experiences.
- **Avoiding information to maintain uncertainty-** “Information avoidance can involve avoiding specific topics in interactions, avoiding situations where information may be presented, or selectively attending to information (p. 72).”
- **Managing appraisal of chronic uncertainty-** When a PwP or care partner’s emotional response may range from resignation to relief to acceptance.

Receiving information

- **Perception of information based on doctor’s bedside manner-** If the information the PwP or care partner is seeking is unavailable, provides discrepancies, contradictions or if the doctor disagrees with what they’ve found. This may look like a care partner or PwP having an emotional response upon hearing information or lack thereof from their doctor. How they hear or perceive information from the doctor may influence if they seek or avoid information.

The codes have been adapted from Brashers’ manuscript: Brashers, D.E., Neidig, J.L., Haas, S.M., Dobbs, L.K., Cardillo, L.W., & Russell, J.A., (2000) Communication in the management of uncertainty: The case of persons living with HIV or AIDS, *Communications Monographs*, 67:1, 63-84, DOI:10.1080/03637750009376495

## Appendix C



RESEARCH INTEGRITY AND COMPLIANCE  
Institutional Review Boards, FWA No. 00001669  
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799  
(813) 974-5638 • FAX (813) 974-7091

1/24/2019

Janelle Applequist, Ph.D.  
School of Advertising and Mass Communications  
4202 E. Fowler Ave.  
CIS 3099  
Tampa, FL 33620

RE: **Expedited Approval of Amendment**  
IRB#: Ame2\_Pro00034242  
Title: Perceptions of Message Design for a Parkinson's Disease Campaign

Dear Dr. Applequist:

On 1/23/2019, the Institutional Review Board (IRB) reviewed and **APPROVED** your Amendment. The submitted request and all documents contained within have been approved, including those outlined below, as described by the study team.

They would like to add three co-PIs to the study (Emilie Madsen, Amy Haywood, and Heather Harger). These individuals will be able to assist with data collection, data analysis, and manuscript write-up.

The IRB does not require that subjects be reconsented.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with USF HRPP policies and procedures and as approved by the USF IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) business days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

A handwritten signature in blue ink that reads "Melissa Sloan". The signature is fluid and cursive, with a large loop at the end.

Melissa Sloan, PhD, Vice Chairperson  
USF Institutional Review Board