

Factors Promoting and Inhibiting Work in the Context of Neurodegenerative Disease:
Preliminary Findings on the Employment Experiences of People with Parkinson's Disease

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Abstract

Background: As of December 2017, 9.5% of former workers receiving Social Security Disability Insurance had a disorder of the nervous system and sense organs (Social Security Administration, 2017). Parkinson's disease (PD) is one of the most common neurodegenerative diseases in the United States (Kowal, Dall, Chakrabarti, Storm, & Jain, 2013), affecting approximately 1 million Americans (American Parkinson's Disease Association, 2016). However, there is limited research on the employment experiences of individuals with Parkinson's disease (PD) (Koerts et al., 2016). This study addressed these gaps in the literature, examining the following research questions: 1) What employment options do individuals with Parkinson's disease perceive as feasible? 2) How does understanding of and access to workplace accommodations influence employment options? What types of accommodations are individuals with PD utilizing? 3) How are individuals with PD discussing work-related issues with healthcare providers?

Methods: Data was collected through semi-structured, individual qualitative interviews conducted by this researcher, ranging in length from 40 to 90 minutes, with 21 individuals with Parkinson's disease. Interviews were audio-recorded and transcribed. Data analysis employed a thematic analysis approach as outlined by Braun and Clarke (2006).

Results: Participant access to accommodations was related to three factors: 1) being in a position of power and autonomy within the workplace; 2) having a highly valued skill set and/or a strong professional reputation and/or 3) having a supportive relationship with their employer or manager. Participants largely identified appropriate accommodations on their own rather than discussing accommodation strategies with healthcare providers, and participants described the need for accommodations specific to the symptoms or treatment of PD. Data demonstrated how the quality of the patient-provider relationship affects a patient's willingness to bring up work-related concerns in medical appointments. The majority of participants were motivated to continue working or return to work in some capacity, but expressed fears of facing disability discrimination if they had to apply for a new job or attempt to enter a new field.

Conclusions: Findings contribute to the limited body of knowledge on the employment experiences of people with PD, with the potential to inform understanding, more broadly, of the experiences of those who acquire progressive diseases in the midst of their adult working lives. Findings inform areas for future research and strategies for intervening early after PD onset in order to support continued employment, reducing, eliminating or delaying reliance on Social Security disability benefits.

Introduction

Employment supports economic well-being (Munnell & Sass, 2008) and has the potential to bolster cognitive (Andel et al., 2007) and physical health (Staudinger, Finkelstein, Calvo & Sivaramakrishnan, 2016). Under healthy working conditions, employment can promote positive psychological well-being, providing a sense of purpose and important social contact (Calvo, 2006). Conversely, unemployment has been demonstrated to be a cause of impaired mental health (Paul & Moser, 2009). Yet, individuals with disabilities lack equitable access to work due to structural barriers that restrict this population's opportunities to pursue and maintain employment (Blinder, Eberle, Patil, Gany & Bradley, 2017).

Chronic disease is the leading cause of disability in the United States (Centers for Diseases Control and Prevention, 2017). Of the 8.9 million Americans aged 65 and under receiving Social Security disability benefits in 2015, 69.3% stopped working due to a chronic, physical health condition or impairment, and 9.4% of this 8.9 million had a disorder of the nervous system and sense organs, rising slightly to 9.5% by 2017 (Social Security Administration, 2015; Social Security Administration, 2017). This underscores the significant impact chronic health conditions and specifically neurological conditions can have on employment trajectories. Loss of employment within the context of chronic disease can lead to a loss of purpose, loss of personal satisfaction and social isolation (Charmaz, 1995; Vassilev, et al., 2014). For individuals whose loss of employment is related to the onset of chronic illness, reconstructing a positive, valued identity outside the context of employment is often extremely challenging (Vassilev et al., 2014).

Research consistently connects being employed to improved quality of life in individuals with other types of chronic neurological illnesses (Johnson, Amtmann, Yorkston, Klasner & Kuehn, 2004; Roessler, Fitzgerald, Rumrill & Koch, 2001). Parkinson's disease (PD) is one of the most common neurodegenerative diseases in the United States (Kowal, Dall, Chakrabarti, Storm, & Jain, 2013), affecting approximately 1 million Americans and 10 million adults with PD worldwide (American Parkinson's Disease Association, 2016). However, there is limited research on the employment experiences of individuals with Parkinson's disease (PD) (Koerts et al., 2016). The extant literature indicates disease severity is not a standalone predictor of employment status in the context of chronic neurological illness (Dyck & Jongbloed, 2000; Schrag, Hovris, Morley, Quinn & Jahanshahi, 2003), and has established factors that contribute to sustaining work, such as access to an accommodating work environment (Banks & Lawrence, 2006; Johnson et al., 2004).

However, there is a dearth of literature on how supportive work environments are facilitated for individuals with Parkinson's disease. It is unclear 1) what types of employment options individuals with PD perceive as feasible after the onset of illness; 2) whether individuals are equipped to identify and advocate for accommodating work environments; 3) the types of decision support they are receiving from healthcare providers. The present study aimed to address these gaps in the literature, by utilizing a qualitative research design to examine the following research questions:

- 1) What employment options do individuals with Parkinson's disease perceive as feasible?
- 2) How does understanding of and access to workplace accommodations influence employment options? What types of accommodations are individuals with PD utilizing?

3) How are individuals with PD discussing work-related issues with healthcare providers?

A better understanding of how individuals understand potential employment pathways after the onset of Parkinson's disease enhances understanding of how to intervene early to promote self-determination in the context of work and support sustained employment after disease onset for this population.

Background

Research across high-income countries has found a range of unemployment rates for individuals with Parkinson's disease, but overall indicates that individuals with Parkinson's disease are more likely to be unemployed than the general population. In a Finnish study of 937 individuals with PD, only 16% of subjects were still working at the time of survey (participants ranged in age from 29 to 65, with a median of 59 years) (Martikainen, Luukkaala, & Martila, 2006). Schrag et al. (2003) surveyed 141 individuals with PD in the UK and found that only 19% of participants were employed full-time, and 15% were employed part-time. Additionally, 56% of the young-onset participants who were not retired reported being unemployed due to disability for greater than 6 months (Schrag et al., 2003). The average age of onset for Parkinson's disease is 60 years old (Armstrong et al., 2014). With societal expectations – and financial necessity – causing a shift away from the traditional retirement age of 65 for many people, those diagnosed with PD at 60 or younger may have intended to continue working for 5 to 10 years more, at minimum. Young onset Parkinson's disease occurs between the ages of 18 to 50 years old (Calne, Lidstone & Kumar, 2008), and 6,000 to 12,000 new cases of young onset PD are diagnosed every year in the US (APDA, 2016). Adults with young onset PD are more likely to be unemployed due to disability than older adults with PD, despite comparable disease severity and duration (Schrag et al., 2003). To investigate this discrepancy, this study examined facilitators and barriers to sustained employment for adults under the age of 65 with PD.

Gaining Insight into Employment Options

An individual's own assessment of the likelihood of success or failure pursuing specific work-related goals directly influences employment decisions and outcomes (Lent, Brown & Hackett, 1994; Lent, 2013). Yet the limited literature on working capacity in Parkinson's disease has failed to examine individuals' understanding as to how having PD affects the feasibility of different employment options and outcomes. Existing research has explored unemployment rates among individuals with PD and the types of symptoms that impact working capacity, but qualitative research investigating the employment experiences of individuals with PD in depth is largely missing from the extant literature (Koerts et al., 2016).

Disease severity alone does not predict employment status in the context of chronic neurological illness (Dyck & Jongbloed, 2000; Schrag et al., 2003). Research indicates that accommodating employers or coworkers and access to accommodations such as assistive technology and flexible work schedules are significant factors in rendering continued employment possible in the context of chronic disease-related disability (Banks & Lawrence, 2006; Blinder et al., 2017; Dyck & Jongbloed, 2000). In a systematic review examining workplace accommodations for people with disabilities, Nevala, Pehkonen, Koskela, Ruusuvuori & Anttila (2014) identified self-advocacy as a key factor in predicting access to the accommodations necessary to continue or return to work. In order to access workplace accommodations, individuals have to be aware that they qualify for accommodations, identify

what accommodations might be helpful, and be willing to ask employers for accommodations (thus disclosing illness). However, limited research has explored the extent to which individuals with Parkinson's disease are prepared to self-advocate in this manner, and the potential obstacles standing in the way. Existing research has failed to determine if individuals with PD are able to identify useful workplace accommodations (Koerts et al., 2016). Do individuals with PD have a clear understanding of what accommodations might be helpful for them in the workplace? How does this understanding (or lack thereof) influence their employment options?

The attitudes of physicians, family members and employers may be important determining factors of employment status in the context of chronic disease (Johnson et al., 2004). Who are individuals with PD discussing their choices with, as they contemplate their employment options? If they have discussions with healthcare professionals, are those discussions helpful? Do they see healthcare professionals as potential resources in regards to employment? The nature of discussions with healthcare providers on the topic of work appears to be an understudied area in the chronic disease literature. A UK-based study of patients with rheumatoid arthritis, rheumatologists and related medical professionals revealed that medical professionals generally failed to recognize patients' need for work-related support (Gilworth, Haigh, Tennant, Chamberlain & Harvey, 2001). Gilworth et al. (2001) recommended that rheumatologists work to increase their understanding and recognition of employment-related issues their patients may encounter, so that they can be ready to offer appropriate advice and/or referral. In the context of PD, Koerts et al. (2016) assert that both individuals with PD and their employers should be educated on possible workplace accommodations that would be useful. Of the professionals that individuals with PD interact with, who – if anyone – is currently providing such an education? A thorough examination of the extant literature indicates that how healthcare professionals discuss employment with patients with chronic neurological diseases has not been investigated. This represents a key gap in understanding, as physicians, nurses, social workers, physical therapists and other healthcare professionals have the potential to act as resources for and key influences on individuals as they contemplate their employment options after the onset of illness.

Methods

Qualitative research is uniquely appropriate for the pursuit of specific research goals, including understanding meaning and the influence of specific contexts (Maxwell, 2013), rendering a qualitative research design essential for this study. Data was collected through semi-structured, one-on-one qualitative interviews conducted by this researcher, with 21 individuals with Parkinson's disease, ranging from 40 to 90 minutes in length.

Recruitment and Sampling

Initially, this researcher aimed to interview participants with a variety of chronic neurological diseases. However, ongoing consultation with experts in the field of neurology led to the decision to focus sampling on individuals with Parkinson's disease, as the employment experiences of individuals with Parkinson's disease (PD) is particularly understudied (Koerts et al., 2016), with research specifically focused on PD highly needed. Recruitment and sampling occurred at a subspecialty clinic and research center for movement disorders within an urban teaching hospital and through the state chapter of a national Parkinson's disease organization. Participants were recruited in a variety of ways. This researcher met with the subspecialty clinic's program manager and medical director, to explain the purpose of the study, and received

ongoing referrals directly from the program manager, neurologists and research staff. The interviewer spent several days a week at the subspecialty clinic and the clinic's associated research center, in order to meet with potential participants before or after neurology appointments or clinical trials visits, and made several trips to a satellite clinic. Additionally, an explanation of the study and this researcher's contact information were posted on the Facebook page of the national Parkinson's disease organization's state chapter, and sent out to area PD support group leaders. The combination of these strategies allowed this interviewer to recruit participants receiving care from different neurologists. Participants were compensated with a \$20 gift card to Target.

Inclusion criteria included a confirmed diagnosis of Parkinson's disease and being under the age of 65. Participants could be working, retired or unemployed, and were screened for age and educational level. It was essential to the aims of this study to obtain as diverse a sample as possible, particularly in regards to educational level. The study focused on participants under the age of 65 as less is known about the employment and general psychosocial experiences of adults who experience PD onset at younger ages. Additionally, limiting participant age to under 65 provided a sample that is most representative of the age makeup of current US workers in the general population. In 2017, 90.7% of American workers were between the ages of 20 and 65 (Bureau of Labor Statistics, 2018). This researcher aimed to recruit participants from a range of racial/ethnic backgrounds, but had difficulty identifying potential participants who were people of color, an anticipated limitation.

Data was collected via one-on-one semi-structured interviews with participants, relying on an interview protocol developed by this researcher (see the Appendix). Interviews took place in multiple places: at the subspecialty clinic or research center, at the subspecialty clinic's satellite location, or at this researcher's university office. A number of interviews were also conducted by phone with participants who did not live locally and found it more convenient to be interviewed remotely.

Participant Demographics

Participants ranged in age from 42 to 64, with the majority of participants in their 50s and 60s (averaging to a mean of 57). Of the 21 individuals interviewed, six were women and 19 participants identified as White, with two participants identifying as Black/African-American. Out of the 21 individuals interviewed, six participants described themselves as either not working or retired, and five out of those six participants were receiving Social Security Disability Insurance (SSDI) benefits or Supplemental Security Income (SSI). In terms of educational level, six participants had high school degrees, one had an Associate's degree, and the remaining 14 participants had completed Bachelor's degrees or higher. Please see Table 1 in the Appendix for further participant demographics.

Data Analysis

Audio-recorded interviews were professionally transcribed and a thematic analysis approach to analysis was employed. Thematic analysis is a qualitative method of finding and interpreting patterns in the data that consists of six steps: familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing a report (Braun & Clarke, 2006). The first step of thematic analysis, familiarization with the data, began during data collection, by editing transcribed interviews for accuracy, re-

reading transcripts multiple times and beginning to write down initial thoughts and ideas (Braun & Clarke, 2006). Additionally, as this researcher conducted all interviews, memo-writing after interviews was also employed to record initial impressions and potential adaptations to the interview protocol. After reading transcripts multiple times and creating an outline of preliminary ideas, this researcher began initial coding, which involved beginning to identify and group data into relevant categories (Braun & Clarke, 2006). This involved, for instance, beginning to identify facilitators and barriers to sustaining employment and accessing accommodations, and then considering similarities and differences within and across the data set and generating a long list of initial codes. Next, this researcher analyzed the relationships between initial codes, beginning to group initial codes into preliminary themes and subthemes (Braun & Clarke, 2006). At this stage, the full data set was loaded into NVivo 12, a qualitative software program, to assist with organizing the data by themes. This researcher reviewed and refined themes by re-examining coded data within each of the preliminary themes and reevaluating the meaning and significance of each theme in relation to the findings as a whole (Braun & Clarke, 2006). Finally, themes were defined and particularly exemplary quotes were identified in order to support theme validity in the final report.

Results

Factors Facilitating Sustained Employment

The findings indicate that for this sample, successfully sustaining employment after the onset of PD and accessing appropriate accommodations was related to three interconnected factors: 1) being in a position of power and autonomy within the working environment; 2) having a highly valued skill set and/or a strong, long-standing professional reputation within their field and/or 3) having a positive, supportive relationship with their employer or manager. Notably, these factors were associated with continued employment after the onset of PD across different educational levels and types of employment. The majority of participants who were working were either 1) self-employed, operating businesses that predated their PD onset or 2) in positions of relative power within their organization, due to holding formal high-ranking roles or being valued for specific expertise and long-standing experience in their field.

Most participants expressed concerns about disclosing their PD diagnosis within the workplace, but many eventually found it necessary to do so in order to explain visible symptoms of PD and to access accommodations. Like many participants, Participant Seven, a 49-year-old man, initially had concerns that his employer would see him as less capable if he disclosed his PD diagnosis:

How are people gonna react? Are they gonna think, "Hey, this guy may not be able to do what we expect of him with this disease now, from traveling through presenting? What are we gonna do?" And I don't want people to think like that.

Other participants expressed concern about disclosure threatening job security, indicating that despite the legal protections against disability discrimination, disclosure could still lead to job loss. Participant Five, a 51-year-old man, described waiting several years after diagnosis prior to disclosing in the workplace, due to such concerns:

You don't wanna lose your job, because you never know. People can't fire you for that reason, they can't. But they can. 'Cause you're not gonna fight corporate America. I don't care who you are. What are you gonna do? Go out and hire an attorney to fight [big corporation in participant's field] if they let you go because you have a rare disease? People do it, but you know what? You're fighting city hall. Who has the time or the energy to do that? And that takes years and years and years.

Yet despite concerns, participants indicated that as their symptoms became more noticeable to others (such as a visible arm or leg tremor, or altered speech), they felt obligated to disclose in order to explain these visible changes. Several participants expressed concern that if they didn't disclose their Parkinson's diagnosis, employers or coworkers would make assumptions that symptoms were caused by substance abuse. Participant Five, a 51-year-old man, reported giving a presentation to clients and being asked about his tremor: "And they said, 'Were you out drinking a lot last night or something?'" Most participants who had disclosed PD to employers or employees ultimately felt that it was necessary in order to access or explain needed accommodations. Participant One, a 59-year-old man, indicated that he decided to disclose because "it was kind of apparent that I was having issues" and he wanted to explain "why it was taking me sometimes four times longer than normal on a job." Ultimately, he had to disclose in order to access needed accommodations, such as permission for time off "in the middle of the day" to attend PD-specific exercise classes. Disclosing to his employer was necessary in order to access this specific accommodation as well as others, and disclosing to coworkers also felt necessary, to explain his biweekly absence in the middle of the day.

Of the working individuals who were not self-employed, the decision to disclose was facilitated by a position of relative power or value within the organization, or a long-standing, positive relationship with an employer. Participant One, a 59-year-old man, attributed his continued sense of job security to the fact that the organization that had employed him for 41 years knows his abilities and work ethic: "I get the work done, they know I don't leave anything hanging." Despite initial concerns about disclosure, Participant 14, a 62-year-old man, expressed confidence that as long as he had the capacity to "perform" well at work, his specialized skill set would safeguard his continued employment: "I have special skills. There's not many people who do what I do in the world." A few participants expressed confidence that their valuable expertise would bolster their job security or aid their desirability on the job market if they needed to pursue a new job.

The data illustrated that for many participants who were working and not self-employed, it was this combination of a supportive employer and power or value within the organization that facilitated employers' willingness to agree to accommodations. Participant 19, a 63-year-old man, describes a supportive relationship with his employers: "That's why my job's secure, because I'm working for a small, family-run business that cares," but also emphasizes that he has a long-standing, significant reputation in his field and is valuable to his company: "I made them a lot of money last year. I get my bonuses I'm supposed to get, I can still compete. I still do my job." Participant Seven, a 49-year-old man, indicates that his decision to disclose was facilitated both by his high-ranking position within the company: "I don't know how many people are in a position that I'm in where I'm basically running the company alongside [my boss]" as well as his positive relationship with his boss: "both personally and professionally [my boss and I] hit it off from the get-go... Had I not been working with him it might've been a different story... I felt comfortable telling him."

Of the working individuals that were self-employed, some participants chose not to disclose to customers/clients due to concerns about potential loss of business. Participant Nine, a 56-year-old woman, describes her concerns: “I didn't want people looking at me and pitying me and saying what are you gonna do? I didn't want clients leaving; I wanted to be able to maintain my business.” Some self-employed participants found it necessary to disclose to employees or customers/clients, but were not necessarily concerned about disclosure given their confidence in the strength of their long-standing relationships with and/or the value of their services to customers. Participant 12, a 64-year-old woman, indicated that she would not be concerned about her customers knowing she had PD: “My customers... They've been with me for years – and they stay with me. The few that have tried elsewhere have come back. It's a very specific niche – and there aren't a lot of us around the country doing it.”

Other self-employed participants were able to adjust their schedules or responsibilities without having to disclose to customers/clients. All self-employed participants described ways in which they have shifted their work schedules and/or responsibilities to accommodate their PD symptoms, accommodations they have the power and autonomy to enact due to self-employment. Participant Eight, a 53-year-old man emphasized that being his own boss allows him to set his own schedule and eliminates the concerns others may have about their employer's reactions to disclosure:

Yeah, so that's probably different than most people you're talking to because of the challenges that a lot of people do have when they have a diagnoses like this. They have a higher up, their boss and I've known people that have been fired because of their diagnoses. It's kind of easier for me...

Use of Accommodations

Participants identified a wide range of ways in which the symptoms of Parkinson's disease required adjustments in the workplace. Notably, all but one self-employed participant had been self-employed prior to PD onset, but all emphasized how self-employment allowed them to design work schedules around their need for breaks, naps or exercise. Many participants utilized common accommodations such as shifting to working from home for all or part of the day or week, working shorter work days and/or taking time off for medical appointments. However, participants also described the need for accommodations specific to the symptoms of or treatment of Parkinson's disease. Multiple participants (both self-employed and working for an employer) took time off during their workday one or more days per week in order to exercise, often attending PD-specific group exercise classes. Several participants discussed the need to carefully time their work schedules around the complicated medication dosing schedule necessary to the treatment of PD, to ensure they are able to take medication on time and at the appropriate interval from eating. Individuals with PD may experience a “wearing off” of medication effects a certain time after dosing, requiring taking medication on a strict timetable in order to avoid extended “off periods,” when symptoms are exacerbated. Participant 18, a 59-year-old man, describes the challenges of managing medication while working a retail shift:

We have a break schedule and a lunch schedule. It's variable, so sometimes you're on a side of lunch that doesn't work for me as far as the timing of my medication and stuff. That's one of the bigger impacts... I think that the most challenging part for me now is just managing my medication. And my on-off, syncing it with the lunch and break, and all that kind of stuff. It's something I think about all day long at work.

Other participants with more flexibility try to adjust work schedules to accommodate for the time it takes for medication to start working after dosage, and are careful about the timing of dosing to ensure medications do not wear off – thus leading to more prominent symptoms – at inopportune times. Participant Seven, a 49 year old man, explains:

What I usually do is work from home just until my medication gets kicked in... and then I'll head into the office a little later... I'm also more aware of when I'm out at a social, a networking function something like that, making sure that I'm timing medication right and there's a place I can sit down.

Additionally, several participants required assistance from coworkers, employees or clients on previously independently completed tasks. Participant 11, a self-employed 61-year-old man, described delegating tasks to employees that PD symptoms had rendered difficult, such as tasks requiring use of a screwdriver, or starting to subcontract out for services that require significant physical exertion. Participant One, a 59-year-old man, reports: "I'm in the middle of a job and I can't, for whatever reason, manipulate my hands, all I'll do is call and they will have somebody stop what they're doing, show up at my job to help me out." Participants reported asking clients to fill out their own paperwork or help with product demonstrations due to PD symptoms such as micrographia (small, illegible handwriting), rigidity and/or tremor. Participant Four, a 42-year-old man, described how coworkers would assist with presentations during conference calls when speech-related symptoms worsened.

Of the six participants not working, early retirement was directly related to an employer's lack of support for needed accommodations for two participants. An additional participant – Participant 17, a 64-year-old man – was still working at the time of the interview but had decided to retire earlier than planned due to an unsupportive employer. Participant 17 had worked for the same company for 27 years, but had new managers – his long-standing coworkers were supportive of his accommodation needs, his new managers were not. Participant Six, a 64-year-old man, had worked for the same company for nearly 2 decades, but the company changed hands and as was the case for Participant 17, Participant Six found himself with a new boss. Instead of allowing continued work from home, his new manager wanted Participant Six to commute into the office: "I said that I didn't want to... That was basically the last straw I guess you can say... It was probably later in the week after that they terminated me." Agreeing to this commute would not have allowed this participant enough time to take care of his health by exercising and getting enough sleep. After being terminated, he decided to retire early and applied successfully for Social Security disability benefits. Ultimately, he feels that retiring was the best decision for his health, but admits: "If they had allowed me to I probably would have continued to work." Participant 13, a 63-year-old man, described the necessity of adjusting his work schedule to manage his health:

Mostly what I found in terms of workload is my job was a 60 hour week job to do it properly. In order to manage my Parkinson's, both my medical appointments and also my exercise, I needed to kind of back down to about 45 hours a week. I eventually took out early morning meetings and late afternoon meetings because I just couldn't do it, couldn't get going in the morning.

His employer initially agreed to these accommodations, but soon made it clear to Participant 13 that he was not happy with his performance. Participant 13 reported struggling to keep up with the demands of his workload within 45 hours a week, in addition to supporting his spouse

through a life-threatening health crisis. He described how after his spouse's treatment ended, he met with his boss:

I told my boss that things are finally settled down and I wanted to take until the end of the summer to figure out if I could do the job at 45 hours a week... and if I couldn't do that I would come back and talk to him at the end of the summer... And their response was, "You don't have until the end of the summer, you just need to do it and we need to work this out quickly." They never did anything but certainly soured me on the job.

Participant 13 was not formally terminated from his job, but his employers made it clear he wouldn't be allowed the time to try to succeed in his role at 45 hours a week. He soon went on medical leave and decided to retire earlier than he had planned. Participant 10, a 58-year-old woman who was not working and receiving SSI, was not able to identify any accommodations that would have allowed her to continue working, and expressed her belief that no accommodations had been feasible within her professional role in a healthcare setting.

Identifying Accommodations and the Role of Healthcare Providers

The majority of participants identified appropriate accommodations on their own, with only two participants reporting concrete accommodation recommendations from a neurologist, and none reporting recommendations from an employer or employing organization. When asked who or what they considered to be the best resources for guidance on working with PD, participants reported looking to close family members, friends, coworkers, other people with PD via support groups or exercise classes, and the Internet. Several participants highlighted a lack of information on the psychosocial impact of living with PD – particularly as a younger person with PD, emphasizing that information available online or from medical providers tended to focus on medical treatment and care. Participant Four, a 42-year-old man, stated: "It's not like when you get diagnosed with Parkinson's, it's like here's your rule book! Welcome to Parkinson's. There's nobody to explain anything other than what to expect physically." Participant Five, a 51-year-old man, explained:

There's not a lot out there on employment with Parkinson's. There isn't. It's not like you can pick up ... You can pick up a brochure on Parkinson's and find out where you can go do boxing, or exercise, or diet, or anxiety, or any of these other things. But nothing that says Parkinson's in the workplace. That type. You can't pick up a brochure that says that, can't read about it, and understand. But I think it's something definitely ... it's gotta be on the forefront of all the younger people's minds. We have to be. 'Cause we have to provide for our families.

When asked if they had spoken with their neurologist or another healthcare provider about work, participant answers varied. A set of participants with the same neurologist reported that this neurologist asked how work was going at every medical appointment, although only one reported accommodation specific discussions. However, participants indicated they would be comfortable bringing up work-related concerns with this neurologist, expressing satisfaction with the quality and nature of care received.

Other participants reported that they had not spoken with their neurologist or another healthcare provider about work after the onset of PD, or stated that work was discussed generally

but did not extend to specific discussion of accommodations. A few participants reported asking neurologists how PD would affect their employment trajectory after diagnosis, receiving projected work trajectories ranging from 5 to 15 years, or a more general response about continuing to work as long as it feels feasible to the participant. A few participants indicated that they had spoken with their neurologist about work, but had initiated the discussions themselves. Participant Five, a 51-year-old man, emphasizes that medical appointments and research studies do not touch on the subject of employment:

No, it's mostly been me bringing it up, yeah. They do ask, you know what they ask about? They ask about how are things at home? Are you sleeping? How is your shaking doing? ...Your activities of daily living, how are your activities of daily living? And a lot of those aren't focused around work. It's can you brush your teeth, can you wash your hair, can you dry yourself, can you eat your dinner, can you pick up with a fork, can you do all those things? I've never seen a question that says, can you send emails? Can you still type? Can you operate the car without a problem? And I filled out a million questionnaires. There's not a lot of questions: what is your future? What about promotions? How do you feel about being promoted at work? Do you think that's gonna impede you from being promoted? Nobody asks those questions.

Participants offered a number of explanations for why employment wasn't discussed during medical appointments, with several participants indicating that – because they were able to come up with accommodations on their own – they didn't find it necessary to bring it up with a healthcare provider. However, other participants indicated that they did not see providing work-related advice as the neurologist's role. When asked if she has ever spoken about work-related concerns with a neurologist, Participant 10, a 58-year-old woman, replied:

No. I go to my doctor for my health concerns and our discussions usually revolve around that and that's it. My feeling is that I have to take care of that work myself. I haven't asked them about that, no. I wouldn't mind asking but I don't know that they would have that information really.

Participant One, a 59-year-old man, reported that his neurologist asks how work is going at most visits, but indicated that he did not see his neurologist as the right person to speak to about addressing the effects of his symptoms on his work capacity:

I would say not because I don't see him as being knowledgeable in the field of work that I'm in. Same way as if somebody wanted to talk to me about medication they're taking. Or work on the car. I know nothing about that kind of stuff.

Some participants appeared not to have even considered speaking with their neurologist about work-related concerns. After this researcher asked if he'd ever spoken with his neurologist about work, Participant 19 – a 63-year-old man who described significant work-related concerns in his interview – replied no, paused and asked: “Would that be an opportunity, an option that I would have?”

Data demonstrated the influence the quality of the patient-provider relationship can have on a patient's comfort level with bringing work-related concerns up in a medical appointment.

Many participants in this sample reported transferring from the initial diagnosing neurologist to a second neurologist due to dissatisfaction with the care provided by the first. Asked about discussions around work with these initial providers, participants indicated that these were not providers they would have felt comfortable asking about work-related concerns. For instance, Participant 18, a 59-year-old man, described challenges with his previous neurologist:

Now that I'm coming to a little more advanced care, it's starting to ramp up as far as what I need, I'm just not comfortable with him. So I went to somebody else. He just doesn't have a good bedside, he's arrogant... Every time I would talk to him about an issue, we somehow got somewhere else. He never stayed true to what I wanted to talk about... Then late in the summer, I started to struggle on and off and I start self-medicating as far as changing the dosage without his consent and he flipped out. I could understand. I didn't have the communication and comfort level to talk to him about it.

Asked specifically if he would have felt comfortable speaking with this neurologist about work, Participant 18 replied: "no... I just didn't get along with the guy." In a patient-provider relationship in which the patient does not even feel comfortable turning to his provider for guidance around worsening symptoms, it is understandable that the patient would not feel comfortable asking about work-related concerns.

Employment Options: Work-Related Goals, Hopes and Perceptions

The majority of participants (19 out of the 21) were motivated to continue working or return to work. Some participants reported having a specific age of retirement as a goal, such as age 65 or 70. Participant Five, a 51-year-old man, reported: "I mean, I have to work, to put my kids through college. So I have to work – we talked to my financial folks – till I'm 70, most likely... So I've got a long way to go." Others expressed the desire to continue working for the foreseeable future and had no plans to retire. Participant 19, a 63-year-old man, explained: "I've always planned to work. I've always said, they're gonna find me with a pad of paper in my hand, and a pen, and my glasses down to the end of my nose, laying on my bed." A participant planning to retire at age 65 hoped to return to work in a part-time capacity after retiring, and four out of the six nonworking participants expressed motivation to return to work part-time or full-time. Many self-employed participants aimed to "slow down" or work less hours eventually, but did not have plans to retire at a specific age. Some participants indicated that when they were initially diagnosed they had concerns about their employment trajectory, but after living with PD for many years they had less concerns about their ability to continue working. Several participants emphasized that they tried to focus on the present, rather than worrying about how the disease may or may not progress in ways that could impact work capacity. Participant 18, a 59-year-old man, explains: "I'm comfortable with [being able to work for] the next year obviously. Past that, I have no idea. Since I've been diagnosed with Parkinson's, I'm more living in the now than looking forward that far." Other participants hoped to continue working but acknowledged concerns about how possible disease progression might impact work capacity, highlighting that the unpredictable nature of PD made it difficult to plan ahead with confidence.

Most working participants felt fairly confident in their current job security, with analysis indicating that this confidence was bolstered by the factors discussed above: 1) being in a position of power and autonomy; 2) having a highly valued skill set and/or a strong, long-

standing professional reputation and/or 3) having a positive, supportive relationship with their employer. However, the majority of participants also expressed fears of being discriminated against for having PD if they had to apply for a new job or attempt to enter a new field. Participants referenced acquaintances with PD who had been fired or pushed to retire, or described the experiences of friends, family and even former colleagues with other types of medical disabilities who had experienced backlash from employers, job loss or discrimination on the job market. Participant Five, a 51-year-old man, explained:

My biggest fear, well, not fear, but what I think about is when I'm interviewing for a job and it comes down to me and somebody else, or two other people, and we're all equally qualified. But I've got Parkinson's and the other two don't have any disease. Who're you gonna pick? Let's be realistic. If everybody's equally qualified, and we're all on an equal ground, and we all have high recommendations, are you gonna pick the guy with the Parkinson's, and take that risk? Or are you gonna pick the other people? ... And they can't say it... Nobody has to say a word about it, but you know darn well that it can come down to that.

Participant Four, a 42-year-old man receiving SSDI benefits, was actively searching for employment but described experiencing discrimination after disclosing his PD diagnosis during phone interviews. He explained:

I had some [phone interviews] that were great and in full disclosure I have told some of them and their tone has changed. Potential employers, the interviewers. I had one lady that I didn't tell her at all until the end and she was like, "Oh, I think we are looking for a specialist instead of a manager." I was like everything I was saying was good enough up until a certain point and once I [disclosed having PD] she was like "I think we are looking for something not quite a manager, but a specialist." I was kind of thrown off by it, because she was saying before we can get you in here and we can start the next step in the process and stuff like that. You can just tell.

Limitations

This qualitative sample may not be representative of the population of people with Parkinson's disease under 65. As with any study that relies on active participation, selection bias is possible. Individuals interested in participating may have been more likely to be those coping well with the effects of the disease or with a higher level of motivation to continue working. The majority of participants in this sample were working – recruiting participants who were not working proved more challenging than this researcher anticipated, and it may be that individuals who are no longer working are less interested in participating in an employment-related study. Future research on employment and Parkinson's disease should aim to recruit a larger sample of nonworking participants under the age of 65. Additionally, although this study employed several recruitment strategies, the sample was composed of participants who were either receiving neurological care at a subspecialty neurology clinic, engaged in a randomized clinical trial at the associated research center, or attending an American Parkinson's Disease Association support group. Individuals with access to subspecialty care, participating in clinical trials or engaged with support groups may be more likely to be highly resourced individuals overall.

The majority of participants were white and male – this was an anticipated limitation due to known challenges in identifying and recruiting people of color in Parkinson’s disease research. Research indicates that the incidence and prevalence of PD is highest among Caucasians, and suggests a lower prevalence among African-Americans, although the extent to which disparities in access to care among people of color may play a role is not yet fully understood (Branson, Ferree, Hohler, & Saint-Hilaire, 2016). The PD literature points to racial disparities in diagnosis and treatment, with African-Americans receiving diagnoses of PD much later in the disease trajectory compared to Caucasians (Branson et al., 2016). Additionally, African-American and Chinese-American older adults may be more likely to perceive initial PD symptoms as part of the normal aging process, due to limited knowledge of the disease, leading to later diagnosis (Branson et al., 2016). Unfortunately, these factors combine to create significant challenges identifying and recruiting people of color with diagnoses of Parkinson’s disease, with previous research demonstrating the particular obstacles to recruiting people of color with PD (Sprague Martinez, Thomas, Saint-Hilaire, McLaren, Young, Habermann, Tickle-Degnen, 2018). There also appears to be a higher prevalence of PD in men than women, although even accounting for lower prevalence rates, PD is understudied in women (Miller, N. & Cronin-Golomb, 2010). It is essential that future research aims to examine the employment experiences of people of color and women with PD, in order to best serve the needs of these populations.

Discussion

Findings add significantly to the limited body of knowledge on the employment experiences of people with Parkinson’s disease, with the potential to inform understanding, more broadly, of the experiences of those who acquire progressive diseases in the midst of their adult working lives. This study highlighted specific facilitators and barriers to sustaining employment after the onset of PD, exploring how individuals with PD identify accommodations and what accommodations are used. Importantly, this study explored interactions between patients and healthcare providers, mainly neurologists, on the subject of work – an area of study which appears to be under-examined in PD and the chronic disease literature overall. Findings inform areas for future research and strategies for intervening early after PD onset in order to support continued employment, reducing, eliminating or delaying reliance on Social Security disability benefits.

Lower educational levels are associated with higher rates of unemployment in the context of disability (Bureau of Labor Statistics, 2017), a pattern that translates directly to chronic neurological disease, with research consistently associating lower educational levels with a lower likelihood of employment in this population (Marinas et al., 2011; Roessler 2001). However, educational background or type of work was not related to employment outcomes or access to accommodations in this qualitative sample. Holding a position of power and having considerable autonomy within the workplace were identified as facilitators of sustaining employment and accessing accommodations, as well as having a highly valued skill set and/or long-standing professional reputation. In a broader context, people who have higher levels of education may be more likely to have senior positions and a higher level of control over their work schedules. In this sample, most working participants had a decade or several decades of experience in their field, building strong reputations and/or valued skill sets – either working for an employer or self

employed, with varying levels of education and in different fields – and it was participants' expertise that appeared to function as a protective factor.

Schrag et al. (2003) found that adults with young onset PD are more likely to be unemployed due to disability than older adults with PD, despite similar disease severity and duration. This study's qualitative results may help to explain this finding from the quantitative literature – older adults may be more likely to have worked for the same employer or in the same field for longer periods of time, increasing their expertise and value to employers. Older adults who worked for the same employer for a longer period of time may also be more likely to have a positive relationship with their employer. However, participants in this study described supportive relationships with varying lengths of employment – it is also possible that support from employers may be more related to how valuable they consider an employee to be rather than length of employment. It is noteworthy that several participants were self-employed, placing them in a position of authority over any changes that needed to be made to work schedules or responsibilities, and eliminating potential concerns about how an employer might react to a PD disclosure. However, self-employment predated PD onset by decades in most cases, so it is harder to know what the experiences and outcomes might be for individuals launching a business after the onset of PD.

Findings demonstrated that most individuals identified accommodations themselves, and relied on input from people in their personal and professional circles when problem-solving work-related concerns, rather than healthcare providers or employing organizations. While many participants did speak with their neurologists in a general manner about work, conversations rarely extended to specific accommodation recommendations. Other participants had never spoken with their healthcare providers about work, and several emphasized that they did not see healthcare providers as appropriate resources for addressing concerns related to working with PD. Additionally, the patient-provider relationship was identified as a facilitator or barrier in terms of patient comfort level bringing up work-related concerns with their providers. Findings have potential implications for both patient and provider education, and for further research. Healthcare settings are a built-in point of contact for people with PD and chronic and/or progressive diseases, in general, and as such have the potential to provide resources for patients with disease-related work concerns. Do healthcare providers see addressing work-related concerns and providing accommodation recommendations as within the scope of their practice? What barriers prevent providers from engaging in work-related discussions? Qualitative research to explore work-related interactions from the perspective of providers is warranted. Findings from the present study can also inform the development of surveys to assess patient-provider interactions on the subject of work among patients cross-sectionally.

Participants also noted the lack of available information regarding working with PD. These findings have important implications for patient education – intervening early after the onset of PD to educate patients on the impact symptoms may have on work capacity and potential accommodation strategies could help to prevent job loss for some patients. Chronic disease self-management programs can improve participants' health-related outcomes, communication with healthcare providers and systems, and increase health-related self-efficacy (Lorig, et al., 2001). Further research should examine the potential of integrating work-related education into chronic disease management programs for people with PD. The creation of written materials on working with PD should also be explored as an intervention strategy, and future research could evaluate the quantity and quality of work-related content specific to PD available in online resources.

Findings also pointed to several PD-specific accommodations, including scheduling work days to allow employees time to exercise. Exercise is an essential part of a PD treatment regimen, as it has been found to slow disease progression and improve motor symptoms (Corcos et al., 2012). Yet, less supportive employers might deny employee requests for time off during the day or shorter work days in order to attend an exercise class, due to lack of sufficient understanding of exercise as treatment. Timed medication dosing schedules may also be more difficult for workers with less flexible work schedules and less control over the timing of work tasks, breaks and mealtimes. Many of the participants in this study had considerable control over the timing of breaks and meals, either because they were self-employed, worked from home, or had task-oriented, self-paced work. Individuals with PD in shift work or other types of work with rigid scheduling may struggle to maintain their medication dosing schedule appropriately, leading to “off” periods when symptoms are more prominent and may therefore have a greater effect on work capacity. PD-specific accommodations like these require employees to disclose illness and to educate their employers as to why these accommodations are necessary, leaving employees at the mercy of the employer’s decision as to whether or not they consider accommodation requests reasonable.

Lack of access to accommodations led to work loss and/or the need for early retirement for four participants. It is important to note that two of these participants reported initial distress about job loss but ultimately felt that retiring early was best for their health, while a third hoped to return to work but in a less stressful field. It may not be best for an individual’s health or well-being to continue working after the onset of PD or another chronic or progressive disease, thus, continued employment should not be the goal for every individual. However, it should be the decision of the individual, not dependent on an employer’s willingness to provide accommodations.

Many participants expressed concern about the impact of disclosure on their job security and/or work-related opportunities, while simultaneously concluding that disclosure felt necessary in order to “explain” visible symptoms and to access accommodations. Notably, the majority of participants expressed that if they had to pursue a new job or enter a new line of work, they would be concerned about facing discrimination if they disclosed having Parkinson’s disease – in fact, some participants expressed a feeling of certainty that they would face such discrimination. The only participant who was not working and actively pursuing re-employment reported experiencing discrimination on the job market related to PD disclosure. Findings have implications for strategies to prevent and address disability discrimination. While existing legislation such as the Americans with Disabilities Act offers workplace and hiring protections, as participants pointed out, disability discrimination can be hard to prove and challenging to fight. Additionally, existing legislation leaves considerable room for employers to determine what constitutes a reasonable request for accommodation (Autor & Duggan, 2010). Identifying strategies for improving existing policy such as the ADA may help to reduce work loss, and patient education interventions could also be developed to make newly diagnosed patients more aware of their rights as a person with a disability. Such strategies may not directly affect Social Security Administration practice and policy, but early intervention strategies can help to prevent work loss and thus reduce or delay the need for reliance on Social Security benefits (Hollenback, 2015; Stapleton et al., 2015).

However, participants’ concerns about facing discrimination on the job market and fears of being seen as less capable if they disclose a PD diagnosis also highlight persistent societal attitudes about the capacity of people with disabilities. Many participants referenced common

misconceptions about PD as feeding concerns about disclosure, including the inaccurate belief that PD is a terminal diagnosis or equating a PD diagnosis with a dementia diagnosis. Continued efforts to educate the public about PD and medical disabilities in general are essential to uprooting deep-seated societal prejudices and internalized disability stigma that contribute to the challenges individuals may encounter in sustaining employment after the onset of disability.

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Appendix

Table 1. Participant Demographics

Participant Demographics	N= 21
Age	
Under 50	2
50-54	4
55-60	6
61-65	9
Race/ethnicity	
Black/African-American	2
White	19
Gender	
Female	6
Male	15
Education	
High School Degree	6
Associate's Degree	1
Bachelor's Degree	7
Graduate Degree	7
Employment Status	
Working	15
Self-employed	5
Not working or retired	6
SSDI/SSI*	5
PDI only**	1
Employment Type	
Professional	12
Manual	2
Sales	4
Service	3

PDI: Private Disability Insurance; **SSDI:** Social Security Disability Insurance; **SSI:** Supplemental Security Income

Interview Protocol: Understanding Employment in the Context of Parkinson's Disease

Background Information

- What is your age?
- Race/ethnicity?
- Who do you live with/marital status? Children?
- Educational level?
- Are you currently working?
- Most recent job?

Medical Background

When were you diagnosed?

Tell me a little bit about what having PD has been like for you.

- Prompts: most bothersome symptoms? Biggest concerns?

Employment

- How have your symptoms affected you at work? (How did they affect you at work?)
- Do you have any concerns about continuing to work? About how your symptoms may affect your work in the future?
- Have you told/did you tell your employer about your illness?
Prompts: If so, what was their reaction? If not, what led you not to disclose?
Prompts: any concerns about how you would be treated at work if you disclose?
- Can you tell me about your understanding of your legal rights as a person with PD?
- What about telling coworkers? Coworkers' reactions? What do your colleagues think about your challenges related to work?
- What messages are/were you getting from your employer about your work?
- Have you ever known anyone else with a serious chronic or progressive disease or disability? Do you know how that impacted their work?

Understanding of options:

- If you had to stop working at your current job due to your symptoms, what would you do?
(When you stopped working at your most recent job, what did you see as your options for income?)
- Prompts: Would you consider trying a different line of work/field/different job?
Do you think there's anything else you could do that would be a better fit now?
Would you consider going back to school/getting training in a different line of work?
What would get in the way of you changing to a different field?
- If you had to stop working immediately, what would your biggest concern be?
- (Would you consider applying for disability benefits? How would you feel about applying for disability benefits?)

- Have you ever known anyone who has switched to a different type of job/field? Why was that?
- Prior to your diagnosis, did you expect to stay in this line of work? Have you changed fields before?

Accommodations

- Do you think there are any changes or adjustments that could be made at work that would help? Any adaptations tried?
Prompts: What kind of adjustments? Was this an adjustment you thought of/found? Someone else's suggestion?
- Has anyone at work spoken to you about any types of adaptations that might help/have helped you continue working?
- If no adjustments yet: Do you feel comfortable/prepared to ask your employer for these adjustments?
Prompts: What gets in the way of you asking for adjustments? What concerns do you have about asking for accommodations at work?)
- What do you think your employer's reaction would be?
- If asked for accommodations: Did you have any concerns about asking for adjustments? How did your employers react?
- Do you or have you known anyone else who has asked for accommodations? (At work, in personal life etc.)

Healthcare providers

- When your symptoms started affecting your work and/or you started to have concerns, did you talk to anyone about those concerns?
- Who or what do you consider the best resource(s) for information about working with PD?
- Prompts: Have you talked to your doctor about your work related concerns? (Which doctor? Other providers: nurse, social workers?)
- Can you tell me about that conversation? (Prompt: did you find it helpful? Did you bring it up or did they?)
- If not: Is work something you would consider bringing up with your provider? Do you think they would be able to help you?
- Is there anything you wish you had known earlier about working with PD/MS?

Stigma/discrimination

- Do you think anything would be different for you at work if your employer/coworkers knew you have PD?
- Do you feel that you have been treated differently at work since disclosing? Do you feel that you have been treated differently at work because of your illness?
- Would you have any concerns about looking for a new job?

- Do you ever have the sense that other people feel uncomfortable talking about or acknowledging your disease?
- Have other people ever reacted to your symptoms or disclosure of your disease in a way that made you uncomfortable or upset?