

Working with Parkinson's Disease: Key Influences, Resources and Supports for
Work Related Decision-Making and Outcomes

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Abstract

Background and Problem Statement: Limited research examines the work-related experiences of individuals with Parkinson's disease (Koerts, Konig, Tucha & Tucha, 2016), despite the fact that individuals with Parkinson's disease (PD) are more likely to be unemployed than the general population (Koerts et al., 2016; Kowal et al., 2013). The present study explored key influences, resources and supports affecting work-related decision-making and outcomes for individuals with PD, examining the following research questions: RQ1: How do working conditions interact with mental and physical health symptoms to influence work-related decision-making and outcomes? RQ2: How does family or social support influence an individual's work outcomes? RQ3: How has the changing nature of work affected employment experiences and outcomes? RQ4: What do healthcare providers view as their role in regards to patient navigation of employment concerns? RQ5: What types of online resources on working with PD are available?

Methods: The present study utilized three distinct data sources. Qualitative interviews with individuals with PD and health care providers, respectively, were conducted, transcribed and analyzed. A thematic analysis approach was used to analyze interview data – a qualitative method of finding and interpreting patterns in the data (Braun & Clarke, 2006). A summative approach to qualitative content analysis was utilized to examine work-related content available on the websites of the American Parkinson Disease Association, Parkinson's Foundation, and the Michael J. Fox Foundation for Parkinson's Research (Hsieh & Shannon, 2005).

Findings The data demonstrated that participants' history of access to workplace accommodations may influence whether work is perceived as benefiting or degrading health within the context of PD. Findings highlighted family members as instrumental in facilitating access to employment, as well as demonstrating how family may influence participants' decisions about continuing to work. Findings illustrated a complicated relationship with technology use in PD, indicating that the extent to which available technologies are assistive may depend on the individual's symptoms and occupation. Health care provider participants described distinct roles in addressing the work-related concerns of patients with PD, but several barriers to accessing non-physician providers were identified. Finally, analysis of content available on three major national PD organizations indicated that the extent to which work-related content was easily accessible varied by website.

Discussion and Implications: The present study extends the limited body of knowledge on employment in the context of Parkinson's disease, and informs early intervention strategies to sustain employment after the onset of PD, as well as highlighting areas for future research. Continued employment after PD-onset has the potential to support individual and family well-being, and is key to reducing or delaying the need for Social Security benefits.

Working with Parkinson's Disease: Addressing Key Gaps in Knowledge

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). Parkinson's disease has significant economic repercussions for affected individuals and families. Individuals with PD are more likely to be unemployed than the general population (Koerts, Konig, Tucha & Tucha, 2016; Kowal et al., 2013). The unemployment rate for persons with a disability in the U.S. was 7.3% in 2019, compared to 3.5% for individuals without a disability (Bureau of Labor Statistics, 2020). Kowal et al. (2013) found that 108,900 patients with PD were employed in 2010, indicating that this figure is 40,200 less than expected for a population with similar demographics but without PD. Schrag et al. (2003) surveyed 141 individuals with PD in the UK and found that 19% of participants were employed full-time, similar to the 19.3% employment rate of people with disabilities in the U.S. in 2019 (BLS, 2020). Kowal et al. (2013) found that the number of individuals with PD receiving Social Security disability benefits in 2010 was approximately 16,200 higher than their cohort without PD, at an estimated cost of \$207 million nationally.

Employment in Parkinson's disease (PD) is understudied (Koerts et al., 2016), and the extant literature on factors affecting the work outcomes of individuals with PD leaves much unclear. The average age of onset for Parkinson's disease has been estimated at 60 years old (Armstrong et al., 2014). However, 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). The present study addresses gaps in the literature on factors influencing the work capacity and experiences of adults with PD (Koerts et al., 2016). The present study drew on findings from this researcher's previous work on employment in PD (Carolan, 2019) to identify and address work-related factors warranting further exploration, with the aim of informing early intervention strategies to support continued employment after PD-onset, thereby reducing or delaying reliance on Social Security benefits.

Examining Key Work-Related Influences, Resources and Supports in Parkinson's Disease

Understanding the Relationship between Health and Work

Work has the potential to promote or degrade both physical and mental health (Berkman, Kawachi, Theorell, 2014; Welsh, Strazdins, Charlesworth, Kulik, & Butterworth, 2016). Anxiety and depression are common symptoms in PD, with approximately 50% of the population experiencing depression and 25 to 40% experiencing anxiety symptoms (Fernandez, 2012; Pontone et al. 2011). Previous work by this researcher generated an original data set consisting of qualitative interviews with adults with PD. Participants spoke of anxiety and depressive symptoms, as well as how their physical health affected work, pointing towards a need for further analysis of the relationship between participants' work life and perceived health. A secondary data analysis examined Research Question 1: How do working conditions interact with mental and physical health symptoms to influence work-related decision-making and outcomes? Increased understanding of the relationship between work and health for individuals with PD can inform interventions to promote access to health-supportive work.

The Effects of Social Support on Work Related Decision-Making and Outcomes

Research has demonstrated a strong relationship between social support and health (Kawachi & Berkman, 2014). Scholars have called for further research to examine the interactions between social support at work and home, and the potential effects on health (Kawachi & Berkman, 2014). Supportive employers and coworkers can positively affect workplace outcomes for individuals with disabilities (Banks & Lawrence, 2006; Blinder, Eberle, Patil, Gany & Bradley, 2017), but the existing literature on PD has not examined how social and family support interact to influence work-related decision-making and outcomes. The present study explored how spouses, adult children and/or other sources of social support provided emotional and concrete support to participants, examining how social support (or lack thereof) facilitated work-related decision-making and outcomes. Secondary data analysis of the original qualitative data set explored Research Question 2: How does family or social support influence an individual's work outcomes?

Parkinson's Disease and the Changing Nature of Work

The nature of work has evolved over the last several decades as information technology has advanced many workers' abilities to work from home rather than in an office setting (Linden, 2014). However, research on the extent to which people with disabilities are able to utilize and benefit from telework options is also still evolving (Linden, 2014; Moon et al., 2014). The extant literature has not examined how the changing nature of work affects working capacity for individuals with PD. This researcher's previous work indicated that self-employment may facilitate the continued working capacity of adults with PD (Carolan, 2019). Additional analysis in the present study aimed to understand the extent to which remote work and/or assistive technology may support continued employment after the onset of PD. Research Question 3 explored: How has the changing nature of work – including access to telework and assistive technology – affected employment experiences and outcomes for individuals with PD?

Healthcare Provider Perspectives on Employment in Parkinson's Disease

Healthcare providers have the potential to act as key resources for patients with chronic diseases who may be struggling with work-related concerns and decisions, yet limited research has examined work-related discussions between healthcare providers and chronic disease patients. A UK-based study revealed that medical professionals generally failed to recognize patients' need for work-related support (Gilworth, Haigh, Tennant, Chamberlain & Harvey, 2001). This researcher's previous work shed light on the nature of work-related discussions with healthcare providers from the perspective of individuals with PD, highlighting that exploring these discussions from the provider perspective as well is crucial to understanding health care professionals' ability to act as resources (Carolan, 2019). A pilot study consisting of in-depth key informant interviews with health care providers working with individuals with PD examined Research Question 4: What do healthcare providers view as their role in discussing PD-related employment concerns with patients?

Examining Work-Related Materials on Parkinson's Disease

This researcher's previous work on PD indicated that participants consulted the Internet for guidance on many Parkinson's related issues, yet reported difficulty identifying information specific to working with PD (Carolan, 2019). The identification of this gap led to the development of Research Question 5: What types of online resources on working with PD are available? This research question was examined by conducting a content analysis of employment-related materials available to Internet users via three major national PD organizations: American Parkinson's Disease Association (APDA), the Michael J Fox

foundation and the Parkinson's Foundation. Understanding the breadth and depth of information related to working with PD available to the average individual is crucial to ensuring access to resources on workplace accommodations.

Methods

Qualitative Interview Data

Dohan et al. (2016) argue that qualitative data can provide essential insights into patients' processing and decision-making, understanding that cannot be gleaned from quantitative data. The present study involved secondary data analysis of an original qualitative data set collected by this researcher, in order to examine research questions one through four.

Recruitment

Adults with Parkinson's disease. Recruitment of participants with Parkinson's disease commenced in October 2018 and closed in December 2019. Participants were recruited through a subspecialty clinic and research center for movement disorders within an urban teaching hospital, a satellite clinic, and through the state chapter of a national PD organization. Ongoing referrals were received directly from faculty and staff of the movement disorders center. Over the course of the recruitment period, the researcher visited the subspecialty clinic and the clinic's associated research center to meet with potential participants before or after neurology appointments or clinical trials visits, and made several trips to a satellite clinic. Additionally, the study's participant flyer was posted to the Facebook page of a national Parkinson's disease organization's state chapter, and sent to local PD support group leaders.

Health care providers. Health care provider participants were recruited utilizing several strategies, including through the subspecialty clinic and research center for movement disorders, via email outreach by the program manager and this researcher. Additional recruitment strategies included outreach to the physical therapy department of a local university, outreach to the neuropsychology department of a local hospital, and outreach to a state chapter of a national organization for occupational therapists. Recruitment commenced in October 2019, but was paused to better accommodate the clinical schedules of providers until late January 2020. Unfortunately, recruitment was interrupted by the onset of the COVID-19 pandemic in February and March, the repercussions of which will be discussed further under Limitations. Additional recruitment took place from May until mid-July 2020, to accommodate for the pandemic-related interruption to provider availability.

Sampling

Adults with Parkinson's disease. A non-random, purposive sampling strategy was used. Inclusion criteria included a confirmed diagnosis of Parkinson's disease and being under the age of 65. Participants could be working, retired or unemployed. Sampling had aimed to include participants from a range of racial/ethnic backgrounds, but the researcher had difficulty identifying many eligible individuals who were people of color, an anticipated limitation. The Limitations section includes further discussion of racial/ethnic disparities in PD. Efforts to recruit participants of color included working closely with referring providers to try to identify patients or clinical trials participants who were people of color, and widening recruitment efforts to a satellite clinic and online platforms through a national Parkinson's disease association.

Health care providers. Inclusion criteria involved a history of working with adults with Parkinson's disease as a health care professional. Inclusion criteria specified that health care

providers must have worked with patients with PD who were employed or had stopped working recently or during the course of treatment, which considerably limited the provider participant sample but was necessary to the study aims. Non-random, purposive and snowball sampling strategies were utilized with the aim of recruiting a variety of relevant health care professionals. In addition to direct recruitment efforts, participants were asked to share study information with eligible colleagues, resulting in two successful referrals.

Data Collection

Adults with Parkinson's disease. The researcher conducted one-on-one qualitative interviews with 23 individuals with Parkinson's disease, utilizing a semi-structured interview protocol. Interviews ranged from 35 minutes to one hour and 47 minutes in length, with a mean length of 64 minutes. Interviews took place in several locations: at the subspecialty clinic or research center, at the subspecialty clinic's satellite location, or at a university office. The interview location was selected based on what each participant identified as most convenient. Several participants who did not live locally elected to be interviewed by phone. Participants were provided with copies of the informed consent form, which was reviewed and verbal consent was obtained prior to commencing the interview and recording.

Health care providers. Individual semi-structured interviews were conducted via Zoom with six health care professionals. Interviews ranged from 28 minutes to 47 minutes in length, with a mean length of 35 minutes. The same procedures for informed consent were followed.

Participant Demographics

Adults with Parkinson's disease. Participants ranged in age from 42 to 65, with the majority of participants in their 50s and 60s (averaging to a mean of 58). Of the 23 individuals interviewed, six were women and 20 participants identified as White, with three participants identifying as Black/African-American. Out of the 23 individuals interviewed, eight participants described themselves as either not working or retired, and seven out of those eight participants were receiving Social Security Disability Insurance (SSDI) benefits or Supplemental Security Income (SSI). Eight participants had high school degrees, one had an Associate's degree, and the remaining 14 participants had completed Bachelor's degrees or higher. To ensure adequate protection of participants' anonymity, general employment categories were used in Table 1, rather than exact occupations. For further details regarding participant demographics, please see Table 1 in the Appendix.

Health care providers. Background information was collected on each participant's occupation and years of experience working with Parkinson's disease patients. A total of six health care providers were interviewed: two movement disorder specialists, three physical therapists and one neuropsychologist. Length of experience working with Parkinson's disease patients ranged from 3 to 17 years, with two participants reporting three and four years respectively, and the remaining four participants reporting 13, 15, 17 and 17 years respectively. Movement disorder specialists and physical therapist participants reported long-term clinical relationships with patients, with the neuropsychologist indicating both short and long-term clinical relationships depending on the patient's needs.

Data analysis

All interviews were audio-recorded and transcribed. A thematic analysis approach to data analysis allowed for identification of themes within units of analysis (each transcript) as well as across the data set as a whole (Braun & Clarke, 2006). 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 researcher combined data-driven and theory-driven approaches to thematic analysis (Braun & Clarke, 2006), drawing on the extant literature and seeking to answer the research questions, but remaining attentive to aspects of the data not explained or anticipated by prior attention to theory.

Secondary Data

Data Collection and Analysis

To assess work-related information specific to Parkinson's disease available online, the researcher searched for, categorized and evaluated work-related materials on three major national PD organization websites: American Parkinson's Disease Association (APDA), the Michael J. Fox Foundation for Parkinson's Research (MJFF) and the Parkinson's Foundation (PF). The websites for these organizations were selected as they were mentioned in the participant data as sources of general information and have been identified to this researcher by relevant professionals as reputable sources of Parkinson's information. Work-related content was identified on each website utilizing a systematic approach: 1) The researcher assessed the homepage of each website for any mention of or linked resources related to employment, work or accommodations; 2) website searches were conducted utilizing the keywords "employment," "work," and "accommodations;" 3) the results generated by each keyword were reviewed for relevance. This process was repeated three times in order to identify any new materials, in November 2019, January 2020 and July 2020. A total of 62 relevant articles were identified. A summative approach to qualitative content analysis was utilized (Hsieh & Shannon, 2005). The researcher used the above keywords to identify relevant units of analysis (each article), developed a coding structure for categorizing the units of analysis, and evaluated the text of each unit of analysis in the context of the data set as a whole to identify recurring themes.

Findings

Work and Perceived Health: Access to Workplace Accommodations as a Key Influence

The data demonstrated a connection between history of access to accommodations and participants' perceptions of how work affects their health. The majority of working participants with a history of access described work as supporting physical, cognitive and/or mental health. In contrast, participants who were not working and had a history of denied accommodation requests described the ways in which not working supports health.

Working with access supports health. Participants with a history of access to accommodations perceived work as supporting health. Several participants emphasized that it was even more important for them to continue working, not in spite of but because they have Parkinson's disease. A participant described how working supports mental health:

The working part helps financially but it also helps mentally as well. Well, you're not worried all day about poor me, poor me, because of this Parkinson's I have to... you know like everybody else you have other things on your mind, which is good.

-White male, early 60s, working full-time

Another participant expressed how her work supported her overall health within the context of PD, and articulated her concerns about how her health could worsen if she stopped working:

... I really feel like working is helping me to keep the Parkinson's at bay and I'm just concerned that if I were to just stop cold turkey, I would just go downhill really quickly... I don't know why I think that but it just seems like sometimes when people retire and they have nothing to do, they age very quickly.

-White woman, mid-50s, self-employed

Without access, not working supports health. In contrast, participants who had exited the workforce after having requested and been denied accommodations described not working as supporting their health:

The amazing thing is now having not worked for almost six months, I don't understand how I worked for the last two years. I don't know if I was fooling myself that I was doing better... If I have a bad night's rest I sleep in. If I have a bad night, I take a nap in the afternoon. A whole lot less stress on my life. People have commented that I look so much better than I did while I was working. And it's just being able to ... making sure that I'm doing everything I can to prevent progression and without worrying about ... I don't have to balance it anymore. I can just focus on that. And I don't need to balance that against work anymore.

-White man, early 60s, retired

After retiring, this participant no longer had to manage the mental stress of a difficult work environment while trying to fit in exercise and other measures to take care of his health — taking care of his health was much easier to prioritize.

Family as Essential Resources

The data demonstrated that participants' family members acted as key supports in several ways, including providing accommodation support and influencing participants' decisions to continue or to cease working. However, participants without supportive family members described more restricted work-related options.

Family provide key accommodations. In several cases, family members provided concrete support that directly facilitated participants' ability to continue working. For instance, three participants indicated that they had to give up driving either temporarily or permanently due to the symptoms of PD or side effects of PD medications. Participants' spouses or adult children stepped in to provide transportation: "Driving got to be scary. I never hit anything... I just took my license away from myself. Unofficially, so I could keep my job, my wife used to drive me around to see my accounts for a couple of years." This participant, a White man in his early 60s, working full-time, noted how his wife providing transportation allowed him to continue working. Another participant indicated that his wife now accompanied him on business travel, as he had to stop driving and had difficulty with specific daily tasks, such as buttoning shirt buttons. Also a White man in his early 60s, working full-time, he explained: "Parkinson's has hurt because I don't drive anymore. I haven't driven in six plus years. My wife travels with me because I can't travel by myself."

Family members as key work-related decision support. Many participants reported discussing work-related concerns over with family members, namely spouses, often indicating that their spouse provided key problem-solving assistance. Additionally, several participants indicated that their family members provided a valuable outside perspective on the relative costs and benefits of working for the participant. A participant described how her family felt she should stop working, before she was ready to make that decision herself:

I fought back and fought back... before I finally agreed with my family's decision that I should stop. My sister started insisting that I should stop but I thought it was general tiredness too and that I could take care of myself, I would be able to do it and then it became too difficult.

-Black/African-American woman, late 50s, not working

This participant's family recognized that her work was negatively affecting her health. Similarly, another participant indicated that his adult daughter observed how his job was adversely affecting his health, prompting his decision to retire early:

... I thought that I was kind of managing it and what really happened was my daughter... came up for like an extended weekend to visit. And I was having a bad week and she told my wife Dad has to stop work he's doing terrible. And so my wife mentioned it to me and it was kind of like, yeah I kind of knew it, I just didn't want to say it myself.

-White man, early 60s, retired

Other participants reported that their families supported their continued employment as beneficial to their well-being. One participant described weighing early retirement as an option, but being encouraged to continue working by his wife:

She wants me to keep working... she sees the difference. You have a purpose, you have things to worry about, you have to have a reason to get up every day.

-White man, early 60s, working full-time

Lack of family support restricts options. Some participants did not have access to concrete family support, restricting the range of options available to them. A divorced White man in his early 60s, working full-time, indicated that he "has to work," as he cannot rely on his family for financial support or caregiving. He explained:

My children have had issues... I have no place to go. I have a brother and sister. I could probably go to my brother's. I could probably go to my sister's. But my sister, she's had surgeries. She had a heart attack, she had a stroke... I have to provide for myself.

Accommodating Parkinson's Disease: A Complicated Relationship with Technology

The data demonstrated a complicated relationship with technology for participants with Parkinson's disease. Many participants indicated that Internet access allowed them to work at home, facilitating continued employment by reducing or eliminating the need to speak with clients or colleagues in person, affording participants needed flexibility in their daily work schedule and allowing more time for self-care. For some participants, having Internet access at home meant the ability to continue working when they were unable to drive due to symptoms:

A lot of my customers just said don't worry about coming to see us, just call. So I could do my work over the internet... Definitely the internet helped, I'm not sure how many [clients]... whether I would have kept all of them, if I didn't have the internet to contact.

-White man, early 60s, working full-time

Participants also spoke about how the use of technology such as dictation software, or even switching from handwriting to typing, allowed them to accommodate PD symptoms such as tremors, micrographia (abnormally small handwriting) or slowness of movement. One participant described how the onset of micrographia prompted her to transition to the computer:

My handwriting has days that are good, and days that are not good. Work-wise, I've adapted to using a computer for most things. I've learned how to... write checks by computer, your basic things that I just hadn't gone forward with.

-White woman, mid-60s, self-employed

Although speech difficulties can be a symptom of PD, several participants spoke about using voice recognition software to dictate work when symptoms such as tremor or slowness of movement interfered with typing. A White male participant in his early 60s, working full-time, spoke about his use of dictation technology: "Even when I'm having trouble talking I can get voice... Voice dictation, so I can send a note so it worked out pretty good."

However, participants also described how symptoms significantly interfered with technology use, reporting difficulty with typing and/or mouse work and indicating that they had not identified suitable assistive technology. One participant described how symptoms (slowness of movement) significantly interfered with computer work:

Using the computers, yes. I was slow and you had been asked to finish your work during your shift... because I had slowed down, it took me much, much longer to finish charting for the day because I was slow with my hands.

-Black/African-American woman, late 50s, not working

Another participant – a White woman in her mid-50s, self-employed – described how her tremor interfered with her ability to control her computer mouse: "It drives me crazy because you want to use the mouse, yet sometimes, my finger will click when it's not supposed to." She had not yet identified any strategies or assistive technologies for accommodating this challenge.

Importantly, participants also spoke about trying different assistive technologies available to them and finding them insufficient in accommodating PD symptoms, or indicated that the technology was not capable of meeting the needs of their particular work. A White male participant in his mid-60s, who had retired early a few years prior, described how his symptoms interfered with his computer work: "You're trying to type, you're not really sure whether what you're typing is what you really want... my mouse basically goes all over the screen. Sometimes clicking the mouse, I click the wrong thing and so on." He reported sharing these difficulties with his neurologist, who made some suggestions: "I told them that the mouse was going all over the screen and then they suggested switching hands when typing was hard and that's when voice recognition came up." Unfortunately, he did not find switching hands feasible, and described how recognition software was not well adapted for the needs of his profession: "It was kind of hard 'cause I write software... it's not standard English words."

Healthcare Provider Perspectives on Employment in Parkinson's Disease

Providers as Problem Solvers with Distinct Roles

All health care provider participants indicated that discussing the work-related concerns of patients was within their purview as a provider, with five out of the six participants describing active work-related problem-solving with patients. Different provider types described distinct roles, with the data demonstrating that providers' differing expertise meant that they were able to support different aspects of a PD patient's efforts to accommodate symptoms within the workplace. For instance, movement disorder specialists spoke about working with patients to manage the timing of medications to accommodate the needs of their workday and/or work environment, and discussing patient concerns around workplace disclosure. One movement

disorder specialist reported that patients sometimes ask for guidance around whether or not they should continue working, describing how she approaches these interactions: “When they ask that I’ll typically probe a little further: well, tell me about your job... Tell me about some parts that are going well and some parts that are not going so well. And do you still enjoy it...?” Physicians also reported that providing documentation to support patients’ requests for workplace accommodations or applications for disability benefits is a common mechanism of work-related support.

The clinical neuropsychologist described her role as identifying and clarifying cognitive symptoms, and teaching patients compensatory strategies:

So for me, the role of neuropsychology is to clarify for the patient what the possible reasons are for the problems they are having ... if I can break that down for them, to help them understand why they're having this memory problem, then the next step would be to help them understand what steps to take to potentially modify the situation, mitigate the problems with a behavioral intervention or some change in their work style.

The neuropsychologist described an active role in helping patients identify solutions to how cognitive symptoms affect work. Physical therapists described working on problem-solving strategies and exercises to accommodate symptoms that are interfering with the patient’s work functionality – such as difficulties with typing and writing, discussing workstation set up, and thinking through strategies to improve or accommodate impairments in movement that may be interfering with work. One physical therapist described a more indirect form of work-related support she provides:

There's a lot of people who are hiding from others. So I actually have tips to hide, tips to minimize symptoms. If you're public speaking and your hand starts to tremor, like what to do... So a lot of strategies to minimize some of the symptoms.

Barriers to Accessing Non-Physician Providers

The data indicated several potential barriers for individuals with PD to accessing the expertise of non-physician providers. The most essential barrier expressed by non-physician providers is that **physicians act as gatekeepers** – in order to be seen by a neurological physical therapist or a clinical neuropsychologist, an individual must be referred by their physician. For this referral to happen, the patient has to discuss or demonstrate a symptom that the physician then identifies as potentially amenable to intervention by a non-physician health care provider.

Importance of expertise. Non-physician providers discussed the processes utilized to assess and identify the source of a patient’s difficulty in functioning and generate a solution. The data indicated that these may not be the types of solutions that an individual with PD could identify without the input of an appropriate professional. As the clinical neuropsychologist reported, suitable accommodations for Parkinson’s disease are not one-size-fits-all: “It’s a very tailored response. It depends on the person, on what the job is and what the problem is.” In addition, participants such as the physical therapist quoted below highlighted that being referred to a provider with neurological expertise is essential to receiving adequate support:

If a person [with PD] is referred to just a general physical therapy clinic where there isn't a neurologic-specialized physical therapist, I don't think they would get directed in all these different ways... I learned quite a bit when I came to this office that I hadn't realized previously.”

Physical access: Time and distance. Individuals with PD also have to have the time and ability to attend additional medical appointments beyond visits with a neurologist. This may prove challenging for working patients, as a physical therapist explained: “For people who are working full-time, just to get the time to come into the physical therapy appointment was tricky. We are basically nine to five and we happen to be in the city.”

Naming the Power of Stigma

Every health care provider interviewed named disability-related stigma as a central work-related concern of patients with PD. A physical therapist reported that many of her patients had not disclosed PD in the workplace, explaining: “I would say 80% had not informed their employer that they have Parkinson’s disease and for the reason I think that they feared... I’ve had several people discuss, could they be fired based on their medical condition?” Another physical therapist felt that reluctance to disclose in the workplace often stemmed from concerns about employers’ and colleagues’ misconceptions about what having PD actually entails:

I think the most common thing is the misconceptions about [PD]. If they felt confident that people around them understood the disease and the disease progression and the impact, I think they would be fine with [disclosing], but most people's perception is that people don't know and are just going to feel bad for them, going to be worried about them being able to do the job, that kind of stuff.

A movement disorder specialist also spoke about how misconceptions factor into reluctance to disclose at work:

People think Parkinson's disease is kind of a death sentence and they think that it's rapidly progressive and there's little that they can do to kind of treat it... [patients with PD are] afraid that their employer may look at them differently or make assumptions about what they can and can't do... I think people are a little bit afraid of retaliation... They are worried that it might change their standing in the workplace...

Work-Related Content Available to Individuals with PD

As discussed under Methods, 62 units of analysis (articles/pages) were identified as relevant content across the American Parkinson Disease Association (APDA), the Michael J Fox Foundation for Parkinson’s Research (MJFF) and the Parkinson’s Foundation (PF) websites. Each unit of analysis was coded according to the nature of its work-related content and prevalent themes were identified. In addition, the data was categorized according to the extent to which individual units of analysis focused on work. Articles/pages that featured employment in PD as the central topic were categorized as **exclusive work focus**, articles/pages with a wider focus but that featured significant discussion of employment-related issues in PD were categorized as **significant work focus**, and articles/pages containing only minimal references to employment were categorized as **minimal work focus**. Table 2, below, displays the data by category as well as organizational website. Data with a minimal work focus was included in the analysis in order to provide an overview of the overall context in which employment was mentioned. Notably, the majority of data identified were categorized as minimal work focus (Total N = 38), indicating that searching for “employment,” “work,” or “accommodations” most often links to content that does not substantially inform the reader about employment-specific resources.

Table 2. Work-related content by PD organization

Organization	Total	Exclusive work focus	Significant work focus	Minimal work focus
APDA	N=18	N=2	N=2	N=14
PF	N=32	N=5	N=6	N=20
MJFF	N=12	N=5	N=3	N=4

Total work-related content, N= 62 articles

Articles/pages categorized as minimal work focus varied in the extent to which they directly related to employment. The topics of article/pages in this category included: overviews of managing PD or young-onset PD; veteran benefits; government and private disability insurance including Social Security Disability Insurance; legal resources; educational and supportive resources; support groups; access to health insurance; group life insurance; research on the economic burden of PD; impulse control disorders; singing in PD and personal stories. References to employment within this category were relevant but passing. For instance, articles on disability benefits mentioned employment solely within the context of eligibility, such as this explanation of short-term disability insurance: “STD insurance replaces all or a percentage of your income if you cannot work due to a covered disability. While STD coverage can be purchased individually, it is often provided as an employment benefit.” (Parkinson’s Foundation, Retrieved from: <https://www.apdaparkinson.org/resources-support/living-with-parkinsons-disease/disability/types/>).

Table 3 (Appendix) lists prevalent themes across the work-related content of all three websites that was categorized as having an exclusive or significant work focus. Content in these two categories predominantly focused on: workplace disclosure; the effects of PD on work and work trajectory; and the Americans with Disabilities Act (ADA). Articles/pages normalized that a PD diagnosis prompts questions about work trajectory, normalizing continued employment with frequent mentions of working after diagnosis, and emphasizing that the length of employment after diagnosis is highly variable and depends on individual factors. The decision of whether or not to disclose in the workplace was also described as highly personal. Article/pages reported that many people with PD fear discrimination as a result of workplace disclosure, but emphasized that the ADA offers protection against discrimination. Stories featuring personal narratives demonstrated variable work outcomes, from individuals who successfully worked for decades after diagnosis, to those for whom a PD diagnosis led to early workforce exit.

Differences between organizations. The work-related content of the three organizational websites had many commonalities but there were notable differences in the accessibility and emphasis of content. Neither the APDA or PF included employment, work or accommodations as a heading or subheading on their homepage, meaning that relevant content was only accessible through keyword search. In contrast, the MJFF included “Work & Benefits” as a subheading on through their homepage, linking directly to work-related content. The work-related content of APDA and PF more heavily emphasized disclosure decision-making and job accommodations, with both websites including content that explored the pros and cons of workplace disclosure, discussed sample accommodations, and had articles/pages that linked to the Job Accommodation Network. The MJFF content did not include concrete discussion of accommodations. However, the MJFF had significant content on workplace disclosure, with in-depth guides to navigating discussions with employers, coworkers and clients.

Discussion and Implications

Findings address key gaps in the extant literature on factors influencing the work-related decision-making and outcomes of individuals with Parkinson’s disease, informing directions for

intervention and future research. Findings illustrate how participants' history of access to workplace accommodations may influence whether work is perceived as benefiting or degrading health within the context of PD, and highlighted family members as instrumental in facilitating access to employment. The data demonstrated a complicated relationship with technology use in PD, indicating that the extent to which available technologies are assistive or accessible to individuals with PD may depend on the individual's symptoms and occupation. Health care provider participants described distinct roles in addressing the work-related concerns of patients with PD, but several barriers to accessing non-physician providers were identified. Finally, analysis of content available on three major national PD organizations indicated that the extent to which work-related content was easily accessible varied by website, but that content dedicated to work across the websites primarily focused on workplace disclosure, the ADA, and the effects of PD on work capacity and trajectory. Findings have several important implications for the development of early intervention strategies to support continued employment and prevent early exit from the workforce and reliance on SSDI or SSI.

Supporting Continued Employment: Implications for the Social Security Administration

Research indicates that individuals with PD receive Social Security disability benefits at a significantly higher rate (16,200 higher in 2010) compared to their cohort without PD, at a substantial national cost (Kowal et al., 2013). Individuals who are able to continue working after the onset of Parkinson's disease may be less likely to need Social Security disability benefits or other federal assistance programs, rendering study findings directly relevant to the SSA. Findings highlight several factors that support continued employment in the context of PD, as well as indicating opportunities for early intervention to support sustained employment. The present study demonstrates how access to accommodations may support continued employment by bolstering the perception of work as supporting health, potentially delaying workforce exit and reliance on Social Security disability benefits. Findings also highlight the role of family support in continuing employment after PD onset, suggesting that the SSA could consider access to social support as a factor during the disability determination process, as well as supporting research aimed at bolstering the social support networks of people with disabilities. Lack of access to appropriate assistive technology directly affected the working capacity of several study participants. The SSA could consider supporting additional research on the use of assistive technology in PD – accessible, suitable assistive technology could bolster the ability of this population to continue working after PD onset, reducing the need for Social Security disability benefits. The SSA should also consider supporting research that looks specifically at the role of non-physician health care providers and physician specialists in supporting sustained employment for this vulnerable population, given study findings demonstrating the key accommodation support that can be offered by non-physician health care providers in particular. Finally, the present study highlighted potential areas for improving access to digital work-related content on PD. Accessing crucial information when needed could be essential in supporting continued employment after disability onset, delaying or reducing the need for reliance on Social Security disability benefits. Each of these findings and relevant implications for the Social Security Administration are discussed further below.

The extant literature has established that access to accommodations is essential in facilitating continued employment after disability onset (Bautista & Wludyka, 2007; Blinder et al., 2017). Study findings add to the body of literature in this area by suggesting that access to

accommodations may influence how individuals perceive work as affecting health, a perception that has the potential to influence an individual's decision about continuing to work in the context of chronic, progressive disease. In a prevailing vocational psychology theory, social cognitive career theory, work outcome expectations are understood as the consequences an individual foresees to completing specific actions (Lent, Morrison & Ezeofor, 2013). History of access to accommodations may influence the perceived effects of work on health, affecting work outcome expectations by shaping understanding of how continuing or returning to work might support or degrade health. This finding highlights another mechanism by which access to accommodations may support continued employment after disability onset, potentially reducing the likelihood of early workforce exit and the need to apply for Social Security disability benefits. Findings align with existing research on older adults with chronic health conditions indicating that access to accommodating work environments improves the perceived health benefits of working (Carolan, Gonzales, Lee & Harootyan, 2018).

Disability research has indicated that access to social support may act as a protective factor for employment in the context of disability (e.g. Schüssler-Fiorenza Rose et al., 2016). Research on social support in the context of Parkinson's disease has largely focused on the effects of social support on mental health, overall quality of life and/or well-being (e.g. Simpson et al., 2006), with limited research on how access to social support influences employment in the context of PD. Population-based research has suggested an association between social support and continued work capacity in PD (Gustafsson et al., 2015; Vescovelli et al., 2018). Findings from the present study expand understanding of this association by highlighting a specific mechanism through which social support may influence employment outcomes within the context of PD. Family can act as key resources by providing accommodation support when symptoms impair activities essential to an individual's continued employment. Research on marital status in PD has indicated that not being partnered may be associated with higher rates of depression and pain (Rana et al., 2016). The present study suggests another mechanism through which individuals without adequate family support may face challenges in the context of PD. This suggests that an individual's access to adequate social support could be considered as a factor during Social Security disability determination processes, if key social supports have the potential to facilitate employment in the context of disability.

Findings demonstrated that individuals with PD may have contrasting experiences with the use of technology in the workplace. The extent to which technology is useful in facilitating continued employment may depend on the individual's symptoms and occupational needs. Participants' challenges with technology essential to most workplaces – such as computers – as well as with assistive technology such as voice-recognition software indicate that individuals with PD may not have access to appropriate assistive technology, or that existing assistive technology does not meet the needs of this population. Much attention has been given to the use of technology in Parkinson's disease in recent years (e.g. Espay et al., 2016; Godinho et al., 2016). However, recent research has focused on the use of technology in assessing, monitoring and treating PD, such as the use of sensor and wearable technologies (Sanchez-Ferro & Maetzler, 2016). Limited case studies have explored the use of assistive technology in PD and identified promising technology (Begnum & Begnum, 2012; Ferriero, 2012), but have not focused on assistive technology use in a work setting. Future population-level research should examine the use of assistive technology in PD across occupational fields and work environments, to determine the extent to which individuals have access to appropriate technology and identify areas where technology advancement may be necessary to adequately meet the needs of workers with PD. The development and dissemination of improved assistive technology tailored to the

needs of this population has the potential to reduce the need for Social Security disability benefits for individuals with PD, by supporting sustained employment after disease onset.

Previous research found that individuals with PD reported speaking with their neurologists in a general manner about work, indicating that their current neurologist regularly or occasionally asked about work during medical visits (Carolan, 2019; Carolan, 2020). These conversations rarely extended to specific accommodation recommendations (Carolan, 2019; Carolan, 2020). Individuals with PD emphasized that they did not see healthcare providers as appropriate resources for addressing concerns related to working with PD (Carolan, 2019; Carolan, 2020). Present findings on health care provider perspectives both align and contrast with the patient point of view. Patients in this researcher's preceding study primarily spoke about interactions with neurologists, and neurologist participants in the present study did not discuss specific accommodation recommendations as part of their role. However, provider participants in the present study did endorse addressing work-related concerns as part of their professional role. This finding contrasts with previous findings from the patient perspective (Carolan, 2019; Carolan, 2020), as well as extant literature from the provider perspective indicating that health care providers may not see addressing work-related concerns as their role (Denne et al., 2015). In the aforementioned previous study, the data included minimal participant references to non-physician providers, despite the fact that present findings indicate providers such as physical therapists and neuropsychologists have significant expertise to offer individuals with PD facing work-related concerns. Additional research is warranted to further explore a broader range of provider perspectives on addressing work-related concerns in PD, as well as to investigate the extent to which individuals with PD are aware of and/or have access to the expertise of non-physician providers. The relevance of the health care provider role is indicated by the Social Security Administration's investment in demonstration projects such as Retaining Employment and Talent After Injury/Illness Network (RETAIN), which involves a focus on health care provider training and involvement (SSA, 2020). The present study's findings on healthcare provider perspectives adds to the modest body of literature in this area, extending understanding of the perspectives of providers working with an understudied disease population. Findings suggest that the SSA could consider pursuing additional research on non-physician health care providers as key resources in supporting continued employment after disability onset.

Finally, the present study indicated that while relevant disease specific organizations do have work-related content available, the extent to which information is easily accessible from the patient website varies. Organization websites also varied in their work-related emphasis, with the APDA and PF focusing on workplace disclosure decision-making and accommodations, and the MJFF focusing most heavily on strategies for navigating disclosure. Encouragingly, each website includes content overviewing legal protections under the ADA. However, previous research indicates that the extent to which individuals with PD understand ADA protections varies (e.g. Carolan, 2020), suggesting that easily accessible information on the ADA may be beneficial. Each organization should consider the extent to which their work-related content is readily identifiable and adequately covers a range of work-related concerns. Easy access to the right information at the right time can be crucial in supporting an individual's ability to continue working, thus delaying workforce exit and use of Social Security disability benefits.

Limitations

As with most qualitative studies, this study prioritized depth over breadth, and as such, findings may not be representative of the population of people with Parkinson's disease under 65

or of the perspectives of health care providers. As with any study that relies on the active participation of volunteers, selection bias is likely — individuals with PD 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 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 in PD should aim to recruit a larger sample of nonworking participants under the age of 65. The study sample was composed of participants who were either: receiving health care at a subspecialty neurology clinic or satellite clinic; engaged in a clinical trial; attending a PD support group; or active on a national PD organization's social media. As such, participants may be more highly resourced than the population of adults with PD under age 65 as a whole.

Despite efforts to recruit a diverse sample, the majority of participants were White and male — this was anticipated as a likely limitation due to known challenges in recruiting people of color in Parkinson's disease research. Research indicates that the incidence and prevalence of PD is highest among Whites, and suggests a lower prevalence among Black/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 Black/African-Americans receiving diagnoses of PD much later in the disease trajectory compared to Whites (Branson et al., 2016). Unfortunately, these factors combine to create significant challenges recruiting people of color who are diagnosed with PD under the age of 65, with previous research demonstrating the particular obstacles to recruiting people of color with PD (Sprague Martinez et al., 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.

Finally, the onset of the COVID-19 pandemic in early 2020 significantly impacted recruitment of health care providers. Providers faced changing and increased patient needs as early as February, as well as increased family needs, in some cases, as local lockdowns increased. The initial aim of this pilot study was to gather a modest sample, however, the pandemic forced additional limits on the sample size due to changes in provider availability.

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Appendix

Table 1. Participant Demographics

Participant Demographics	N= 23
Age	
Under 50	2
50-54	4
55-60	6
61-65	11
Race/ethnicity	
Black/African-American	3
White	20
Gender	
Female	6
Male	17
Education	
High School Degree	8
Associate's Degree	1
Bachelor's Degree	7
Graduate Degree	7
Year of diagnosis	
2018	2
2014 – 2017	6
2010 – 2013	9
2004 – 2009	6
Employment Status	
Working	15
Self-employed	5
Not working or retired	8
SSDI/SSI*	7
PDI only**	1
Employment Type	
Professional	13
Manual	3
Sales	4
Service	3

*Social Security Disability Insurance/Supplemental Security Income; **Private Disability Insurance

Table 3. Themes across the work-related content of the APDA, PF and MJFF websites

Theme	Illustrative Quote
PD diagnosis prompts questions about work trajectory	<p>“For many people, one of the first questions after a Parkinson’s disease (PD) diagnosis is, ‘How long will I be able to work?’ This question is especially important to people with young-onset PD, who may be far from retirement. A Parkinson’s diagnosis does not mean your career is over.”</p> <p>(Parkinson’s Foundation. (2019). <i>Employment with Parkinson’s Disease: Working It Out</i>. Retrieved from: https://www.parkinson.org/pd-library/fact-sheets/Employment-Working-It-Out)</p>
Normalizing continued employment after diagnosis	<p>“The good news is that many people are able to continue with their work for quite some time after diagnosis if they wish to, and with the right information and support, many people can extend their time in the workforce a fair amount.”</p> <p>(American Parkinson Disease Association. (2019). <i>Employment and Parkinson’s Disease</i>. Retrieved from: https://www.apdaparkinson.org/article/employment-and-parkinsons-disease/)</p>
Workplace disclosure is a personal decision	<p>“Whether and when to disclose your diagnosis to coworkers and employers are personal decisions.”</p> <p>The Michael J. Fox Foundation for Parkinson’s Research. (Date not given). <i>Young-Onset Parkinson’s Disease</i>. Retrieved from: https://www.michaeljfox.org/news/young-onset-parkinsons-disease</p>
Length of work after diagnosis varies	<p>“Some people continue to work for many years after a Parkinson’s diagnosis, while others may find that the physical and mental stresses of their job become too challenging, too quickly.”</p> <p>(Parkinson’s Foundation. (2019). <i>Employment with Parkinson’s Disease: Working It Out</i>. Retrieved from: https://www.parkinson.org/pd-library/fact-sheets/Employment-Working-It-Out)</p>
Normalizing fearing discrimination due to disclosure	<p>“Many newly diagnosed people with Parkinson’s disease avoid telling their employers and coworkers about their condition because they fear they will be unfairly treated.”</p> <p>Parkinson’s Foundation. (Date not given). <i>When & How Should I Talk to My Employer and My Coworkers?</i> Retrieved from: https://www.parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Advice-for-the-Newly-Diagnosed/When-and-How-Should-I-Tell-My-Employer</p>
Emphasis on the importance of making work-related contingency plans	<p>“Even if you do not intend to stop working any time soon, it is advisable to make contingency plans. Sometimes a career change or move to a less stressful job with more flexible hours or one that allows you to work from home will help you remain in the workforce.”</p> <p>American Parkinson Disease Association. (Date not given). <i>Can I work if I have Parkinson’s disease?</i> Retrieved from:</p>

	https://www.apdaparkinson.org/resources-support/living-with-parkinsons-disease/employment/
Workplace disclosure affords access to accommodations, protection under the ADA	<p>“If you do need to ask for an accommodation at work, then it is time to disclose. Those who ask for an accommodation at work due to a disability are protected by the Americans with Disabilities Act.”</p> <p>American Parkinson Disease Association. (2018). <i>To Disclose or Not to Disclose: That is the Question</i>. Retrieved from: https://www.apdaparkinson.org/article/when-to-disclose-parkinsons/</p>
Personal stories authored by or featuring individuals with PD, variable work outcomes	<p>“...I was the primary breadwinner in the family. I worked extremely hard to become the youngest and only female member on my leadership team at work. I wanted my results, not my disability, to continue to define me at work and in life. For the most part, my symptoms cooperated.</p> <p>Then, about a year ago, I realized that things needed to change. My symptoms progressed and I needed to invest my time and attention on preserving my health and well-being. I left my 27-year career in management and started managing through the reality that I have a life altering movement disorder that affects not just me, but all those around me.”</p> <p>Parkinson’s Foundation. (Date not given). <i>Anna Grill</i>. Retrieved from: https://www.parkinson.org/get-involved/my-pd-story/anna-grill</p>
Overviews of the Americans with Disabilities Act	<p>“The ADA clearly establishes that garden variety discrimination is prohibited (e.g. a covered employer cannot refuse to hire or promote due to disability) as are screening mechanisms that have a disparate impact on PWDs.”</p> <p>Parkinson’s Foundation. (Date not given). <i>Americans with Disabilities Act (ADA) Overview</i>. Retrieved from: https://www.parkinson.org/living-with-parkinsons/legal-financial-insurance/legal/Americans-with-Disabilities-Act</p>