



Employment Resources for People with Parkinson's Disease: A Resource Review and Needs Assessment

Miriam Rafferty^{1,2} · Laura Stoff¹ · Pamela Palmentera³ · Pamela Capraro¹ · Ivorie Stanley^{4,5} · Allen W. Heinemann^{1,2,4} · Kurt Johnson⁶

Published online: 6 October 2020
© Springer Science+Business Media, LLC, part of Springer Nature 2020

Abstract

Purpose People with Parkinson's disease (PwP) exit the workforce on average 5 years earlier than people without Parkinson's due to motor, cognitive, communicative, and affective symptoms. Decreased employment results in significant individual and societal costs. The objectives of this study were to identify strengths and weaknesses of employment resources and assess the needs of consumer and clinical stakeholders to improve job retention. **Methods** The study used a qualitative content analysis and Quasi Needs Assessment Framework. Sixteen PwP and 10 clinician stakeholders participated in two rounds of stakeholder discussion panels. Main outcomes included (1) the resources identified through the online content search and themes derived from those resources, and (2) the information gained from discussion panels and themes derived from their conversations. **Results** Literature review and online searches yielded 59 resources (30 consumer-focused documents, 17 peer-reviewed articles, and 12 documents supplied by key informants who are experts in Parkinson's disease and/or employment). Themes frequently found in the consumer-focused content but not the peer-reviewed literature included diagnosis disclosure decision-making, the benefits of retiring compared to working, and workplace accommodations. Stakeholders identified three key needs with regard to employment-related support for PwP: (1) knowledge about employment support options; (2) a clinician to start the discussion about employment challenges; and (3) an individualized and flexible approach to employment-related interventions. **Conclusions** Many people with Parkinson's experience unmet employment-related resource and process needs. An individually-tailored interdisciplinary intervention care path could facilitate decisions regarding disclosure and accommodations.

Keywords Parkinson disease · Employment · Rehabilitation · Disclosure

People with Parkinson's disease (PwP) exit the workforce on average 5 years earlier than people without Parkinson's disease (PD) due to motor, cognitive, communicative, and

affective symptoms [1, 2]. Motor symptoms can reduce the ability to move around the workplace safely due to changes in functional mobility, balance, and fatigue. Decreased fine motor control may limit job tasks related to writing, keyboarding, and instrumentation. Public and telephone speaking activities may be limited due to visible tremor, decreased

Electronic supplementary material The online version of this article (<https://doi.org/10.1007/s10926-020-09915-w>) contains supplementary material, which is available to authorized users.

✉ Miriam Rafferty
mrafferty@sralab.org

¹ Shirley Ryan AbilityLab, 355 E. Erie St, Chicago, IL 60611, USA

² Department of Physical Medicine and Rehabilitation, Feinberg School of Medicine, Northwestern University, 710 N. Lake Shore Dr, Chicago, IL 60611, USA

³ Department of Neurology, Feinberg School of Medicine, Northwestern University, 303 E. Chicago Ave, Chicago, IL 60611, USA

⁴ Center for Education in Health Sciences, Institute for Public Health and Medicine, Northwestern University, 633 N. Saint Clair St, Chicago, IL 60611, USA

⁵ Department of Occupational and Environmental Medicine, University of Illinois at Chicago, 835 S. Wolcott Ave, E-144, Chicago, IL 60612, USA

⁶ Department of Rehabilitation Medicine, University of Washington, Box 356490, Seattle, WA 98195, USA

vocal volume or articulation [2]. Cognitive symptoms associated with changes in executive functioning may create difficulty in the workplace including difficulties organizing tasks, learning new material, and managing competing cognitive activities. Non-motor symptoms including anxiety, depression, fatigue, and apathy may also have negative impact on work [2, 3].

The median time to loss of employment is 7 years after diagnosis [2]. Reduced employment in PwP results in significant individual and societal costs. Early exits from the workforce may imperil individuals' financial stability going into retirement, particularly due to the unforeseen costs associated with chronic health conditions. In 2010, over \$2.5 billion of national productivity was lost due to job loss and reduced earnings associated with PD [4]. Reduced earnings can lower Social Security Disability Insurance (SSDI) and retirement benefits. Other employment-related losses include more days of missed work per year, lower household income past age 65, and loss of employer-sponsored health insurance [4–6].

The problems experienced by PwP related to employment could be addressed by improved support and resources provided by the interdisciplinary healthcare team [7]. However, the team roles related to employment problems are not well-defined in the literature. The UK's College of Occupational Therapists' Occupational Therapy Guidelines for PwP include work-related issues [8], but most research in occupational therapy focuses on activities of daily living [9]. Rehabilitation counselors have been proposed as a potential team member who could help PwP address employment issues [10]. However, rehabilitation counseling, also known as vocational rehabilitation, is not a common specialty included in the interdisciplinary team management of Parkinson's disease [11].

The purpose of this study is to describe the needs of PwP and clinicians related to supporting employment in PwP. The needs assessment used resource review and multi-stakeholder feedback to gather information. A goal was to describe employment and intervention challenges from varied perspectives. The information gathered informs the proposal of an employment intervention care path that could be applied within an interdisciplinary care model, including vocational rehabilitation, social work, and/or occupational therapy.

Methods

The Quasi Needs Assessment Framework by Kaufman and colleagues was used to identify the resource and process needs to improve job retention for PwP [12]. Table 1 summarizes the needs assessment processes to (1) identify gaps between current processes and outcomes compared to the

desired ones; (2) prioritize needs; and (3) select the most important and feasible gaps to address [12]. The needs analysis accounts for perspectives from PwP, clinicians, healthcare organizations, clinical processes, as well as societal influences such as between-state differences in vocational rehabilitation service availability. Data are compiled and compared from existing consumer-focused resources, peer-reviewed literature, expert-provided resources, and multi-stakeholder input from PwP and clinicians. Eligibility criteria for the discussion panel were (1) clinical expertise with PwP and/or employment interventions, or (2) community or employer stakeholder experience with Parkinson's disease, or (3) current employment as a PwP in a skilled or unskilled job. This project was reviewed by the local Institutional Review Board and determined not to be human subjects research.

Resource Review

The resource review drew on three sources. First, a consumer-focused online search gathered publically available resources for PwP by using a search strategy commonly used by PwPs and their family members: "Parkinson's and employment" on the Google search engine. Second, we conducted a pragmatic literature search to find peer-reviewed literature that is quickly accessible to clinicians in PubMed. Search terms included "Parkinson's," "employment," "work," "workforce," and "vocational rehabilitation." Third, we sought feedback from key informants who are experts in Parkinson's disease and employment-related issues. They supplemented the easily accessible resources with information that might not be readily available to consumers and clinicians. Expert informants included an Occupational Health Physician at a large academic medical center, a Clinical Social Worker at a Parkinson's disease and movement disorders clinic, and a Vocational Rehabilitation Counselor at a rehabilitation hospital.

Data were analyzed using conventional (inductive) and directed (deductive) content analysis methods [13]. First, themes were developed through inductive coding of the consumer-focused resources by five interdisciplinary team members (LS, MR, PC, PP, IS) with a spectrum of Parkinson's and employment expertise. Each consumer-focused resource was coded by a minimum of three team members, who met regularly to reach consensus on evolving themes. Then, peer-reviewed literature and the expert-provided resources were analyzed with directed content analysis, assigning codes from the same themes as the consumer-focused literature when possible and only developing new codes when needed. To avoid duplication, codes added from the peer-reviewed and expert-provided literature focused on content of the results rather than the introduction and discussion. We used an iterative process

Table 1 Needs analysis steps and summary. Adapted from Kaufmann et al. (1993)

| Stages and steps | Summary results | |
|---|---|---|
| Identify gaps between current processes and outcomes compared to desired outcomes | Step 1: Specify the desired resources and outcomes | People with PD to feel comfortable seeking care from their healthcare team, including expert SW and VR counselors to help them maximize employment potential |
| | Step 2: Determine the current quality and/or availability resources and outcomes | There appears to be little patient and clinician knowledge on support options in the PD community and within the healthcare system studied. There is concern that knowledge of VR could be worse nationally due to structure of state and physical disability-oriented VR programs |
| | Step 3: Determine the gaps between desired and current status. (<i>i.e. the needs— see Table 4</i>) | *Knowledge need: PwP and clinicians need accurate information *Process need: PwP need someone to start the discussion about employment challenges *Intervention need: employment-related intervention needs to be individualized and flexible |
| Place gaps/needs in priority order | Step 4: Align the process needs identified with the needs at organization (systems/outputs) and societal level (outcomes) | Societal: Help more PwP be productive members of society (inside and outside of Chicago-area) Systems: Consider desired outcome of SW and VR to help people retain employment Processes/People: Consider intervention development for (1) SW, (2) VR, (3) clinician training, and (4) education needs of people with PD |
| | Step 5: Prioritize opportunities based on importance, strengths, weaknesses, and feasibility | 1. Clinician Education 2. Patient Education 3. SW Intervention Plan 4. VR Intervention Plan |
| Select the most important and feasible gaps to address | Steps 6–9 (Intervention Development & Implementation Planning): Identify potential implementation strategies, their pros(+)/cons(–) within local context, consider alternatives | Education info sheets (+ flexible; – potential inconsistent delivery) Group or individual education presentations (– lack of accurate knowledge in communities to provide education) Individual assistance from SW and/or VR (+ SW is more universally available than VR; –VR constraints by location) VR needs differ based on patient needs so need flexible intervention plan |

to review and revise the coding template to clarify ambiguous themes until investigators reached consensus.

Multi-stakeholder Input Discussion Panels

We used a stakeholder-engaged approach to assess the resources and support needs of people with early PD and their interdisciplinary healthcare teams. Three stakeholder discussion panels included: (1) PwP who work primarily in professional settings with high cognitive demands, (2) PwP who work in settings requiring more physical demands, and (3) clinicians with expertise in PD and/or employment-related issues. Participants with PD were recruited from an urban academic medical center with a large Parkinson's disease and movement disorders clinic and rehabilitation program, as well as local PD support groups, including a young onset PD support group. Discussion panel recruitment methods included fliers, email listservs, and word of mouth. Inclusion criteria for the PwP were age 18–65 years; living in a community setting; a PD diagnosis; and current employment, self-employment, desire for employment, or recent unemployment due to PD. Participants were excluded if

they had stopped working more than 3 years ago. Participants for the healthcare provider discussion panel were selected from the same urban academic medical center, and included social workers, occupational health physicians, physical therapists, occupational therapists, speech language pathologists, and neurologists.

Each panel met twice over 2 months, allowing for an iterative process of reflection and intervention development by consumer and provider stakeholders. The first round of discussion focused on (1) information resource and personal support needs, (2) experience with employment resources, and (3) evaluation of resources. An example question was “What resources related to employment with PD have you accessed or provided?” The second round of discussion was used to (1) refine resources developed by the research team following the first discussion and (2) identify alternative solutions to address employment issues of PwP. An example question asked “How would you like to receive this employment support (e.g., through in-person contact, phone, or other support options)?”.

Both rounds of discussion were recorded and transcribed. The transcripts were analyzed first using directed content analysis to determine if the experiences and

opinions of the discussants were similar to those identified in the resource review [13]. Then, we used inductive coding to assign new thematic labels related to the needs assessment that emerged from the discussion panels.

Needs Assessment

Finally experts in social work, vocational rehabilitation, occupational medicine, public health, physical therapy, and PD followed the Quasi Needs Assessment Framework to prioritize the gaps and needs revealed in the data gathering stages. Both importance and feasibility informed the resulting suggestions for addressing job retention in PD. This process is outlined in Table 1.

Results

We included 30 consumer-focused documents, 17 peer-reviewed articles [1, 4, 14–27], and 12 additional resources provided by the experts that were related to Parkinson's or employment, but not both. Of the 30 consumer-focused documents, 18 were published by non-profit organizations, 9 were published by informal sources such as blogs or social media, and 3 were news articles. Of the 17 peer-reviewed articles, 16 were original research and 1 was a review. Of the 16 original research reports, 10 were published outside of the United States. Of the 12 resources provided by the experts, 6 were government documents. References to all 59 resources are provided in Supplementary Table 1. These resources were shared with the expert advisors and a selection of exemplar resources were discussed by the discussion panels.

A total of 16 PwP and 10 clinicians participated in the discussion panels. The PwP sample was diverse in terms of age, sex, and employment. Characteristics of the panel participants are reported in Table 2.

Resource Review

Resource themes are presented in Table 3. Key overlapping areas between consumer and peer-reviewed resources include the impact of PD on work, factors affecting the decision to retire, and the costs associated with early retirement. The “factors affecting the decision to retire” theme included four subthemes that appeared in both the consumer-focused and peer-reviewed literature: mental health, support in the workplace, severity of symptoms, and type of work. The context in which these subthemes was addressed differed between the consumer and peer-reviewed literature. The consumer-oriented content included issues to consider when deciding to retire or disclose their PD diagnosis, while the

peer-reviewed articles presented the information as risk or protective factors associated with retirement.

Large resource gaps were related to “psychosocial experience of working with PD” and “accommodations and support.” Both of these content areas had a significant number of sub-themes discussed in the online content, suggesting that these issues are important and relevant for PwP [28–31]. However, these themes were largely absent in the peer-reviewed literature. Some comprehensive resources, such the Job Accommodation Network Parkinson's disease page, describe myriad accommodations for physical, cognitive, communicative, and affective symptoms [29].

Participants in the discussion panels found the resource list informative, but that its comprehensive nature may be daunting for PwP or their employers. Other consumer resources were more generic, focusing on the Americans with Disabilities Act (ADA) [32, 33].

Expert informants provided resources and information focused primarily on workplace accommodations and government support programs. This information is publically available online, but does not target PwP. It can be difficult to access or understand by PwP and may be difficult for clinicians to apply the generic knowledge to PwP.

Discussants shared their experiences accessing employment resources. Most participants reported seeking employment information from the internet and several spoke with peers at a support group. Many PwP did not know that social workers or vocational rehabilitation counselors could help with employment-related issues. Only a few reported seeking assistance from a social worker, vocational rehabilitation counselor, or lawyer. These cases were generally the results of an employment issue rather than proactive intervention.

Other employment-related experiences of the discussants were consistent with the themes described in the existing resources. They reported: (1) impact of PD symptoms on work performance (cognitive, communicative, and motor); (2) pros, cons, and processes of disclosure; (3) a desire to maintain control and make employment-related decisions on their own terms; (4) accommodations or self-adjustments they made or wish they made; and (5) experience seeking disability and retirement benefits from Social Security, employer-provided short- and long-term disability, and other benefits.

Needs Assessment and Intervention Suggestions

The Quasi Needs Assessment Framework allowed us to identify three key needs: (1) Knowledge: PwP and clinicians need accurate information regarding potential employment challenges and resources, (2) Process: Healthcare teams should establish a process to identify people who are at risk for difficulties maintaining employment and

Table 2 Characteristics of participants in focus groups (N = 26)

| N (%) or mean \pm SD | People with PD (Group 1) | People with PD (Group 2) | Clinicians |
|---|--------------------------|--------------------------|------------|
| Number | 9 | 7 | 10 |
| Age | 55.9 \pm 9.5 | 56.6 \pm 2.8 | N/A |
| Male | 4 (44.4%) | 5 (71.4%) | N/A |
| Employed in full-time position | 5 (55.6%) | 4 (57.1%) | N/A |
| Employed (or previously employed) in desk job | 8 (88.9%) | 2 (28.6%) | N/A |
| Employed (or previously employed) in physically demanding job | 1 (11.1%) | 5 (71.4%) | N/A |
| Changed job role because of PD | 2 (22.2%) | 5 (71.4%) | N/A |
| Disclosed diagnosis at work | 7 (77.8%) | 4 (57.1%) | N/A |
| Requested accommodation at work | 2 (22.2%) | 2 (28.6%) | N/A |

their employment challenges, and (3) Intervention: Needs to be individualized, flexible, and delivered by experts to address concerns across the spectrum of symptoms and job categories.

Subthemes of these needs are described and illustrated with exemplar quotes from PwP and clinicians in Table 4. Knowledge gaps relate to PwP having adequate information to anticipate challenges and make proactive decisions regarding accommodations for common PD-related employment challenges. Participants observed that they did not have adequate knowledge of the roles of varied members of the healthcare team who might be able to help navigate employment challenges. PwP's process concerns included their neurologist not having time to address employment-related questions, even though their neurologist was their preferred provider to discuss PD-related employment challenges. Furthermore, PwP and providers observed that screening protocols for employment concerns were not in place. PwP further identified a preference for intervention early after diagnosis to help them prepare for, and possibly prevent work problems. PwP and clinicians agreed that any interventions should be flexible depending on the type of job, the workplace culture, symptoms, and the PwP's readiness to retire or consider job-related changes.

Discussion

Gaps in knowledge and processes to support job retention interventions in PwP were clearly exposed by this study. Results suggest that proactive education about disability, case management, and workplace accommodations can help the aging population retain employment [34]. The results provide practical guidance to inform the development of intervention care paths for the interdisciplinary teams that serve PwP. Intervention development is important as employment issues are under-identified, but of

critical importance for people who are newly diagnosed, particularly those with early-onset PD.

The experiences of our stakeholders support research done in and outside the United States on the employment challenges experienced in motor, cognitive, communicative, and affective domains [10]. Although our resource review uncovered online information regarding these common challenges, our discussants believe that this knowledge is insufficient because the resources were either too generic to be applied to their specific needs, so thorough that they were overwhelming, and/or found too late to avert an employment crisis.

The peer-reviewed literature was largely from outside the U.S., and generally focused on the challenges experienced by PwP and predictors of employment status [1, 15–17, 19–24, 26, 27]. While some experiences are likely to be similar across countries, the processes to address employment can be quite different due to differences in national safety net systems for disability and job accommodations. There was a lack of information on how to navigate these systems in the U. S. in the consumer-focused and peer-reviewed literature. Our discussants confirmed experiencing these gaps in their healthcare delivery processes. Intervention paths to help PwP preserve employment were not found in the literature nor could members of the focus groups propose clear intervention paths. Even our urban area with multiple academic medical centers and a vocational rehabilitation program optimized for people with physical disabilities did not have a strongly established support pathway to assist PwP to proactively identify and address employment problems.

Multi-stakeholder feedback suggested that tailoring of the proposed intervention is necessary due to the variation in symptoms, financial resources, personal preferences related to work and quality of life, readiness to retire or consider disclosure, job requirements and workplace cultures, state policies, and local resources. Additionally, varied composition of interdisciplinary teams, including lack of vocational

Table 3 Themes of physical resources on employment for people with Parkinson's disease

| Super-theme | Theme | Sub-theme | Online content on employment in PD | Results of peer-reviewed literature on employment in PD | Supplemental resources provided by experts (not PD-specific) | |
|--|--|---|------------------------------------|---|--|---|
| Psychosocial experience of working with PD | Decision-making regarding maintaining work | Job gives sense of purpose | ✓ | | | |
| | | Financial security | ✓ | | | |
| | Decision-making regarding early retirement | Stress relief | ✓ | | | |
| | | Time for other activities | ✓ | | | |
| | | Control over decision to retire | ✓ | | | |
| | Disclosure | Pros & cons of disclosure | ✓ | | | |
| | | Process of disclosure | ✓ | | ✓ | |
| | Compiled personal anecdotes | Personal anecdotes | ✓ | ✓ | | |
| | Workplace experience | Workplace experience | Control of PD in workplace | ✓ | ✓ | |
| | | | Controlling the workplace | | ✓ | |
| Accommodations and support | Workplace accommodations | Formal accommodations | ✓ | ✓ | ✓ | |
| | | Environmental adjustments (informal accommodations) | ✓ | ✓ | ✓ | |
| | Government support | Federal laws | ✓ | ✓ | ✓ | |
| | | Assistance | ✓ | ✓ | ✓ | |
| | Conflict resolution | Legal counsel | ✓ | | ✓ | |
| | | Medical experts | ✓ | ✓ | ✓ | |
| | | Support from union, EAP | | | ✓ | |
| | | Community resources | ✓ | | ✓ | |
| Factors associated with work status | Factors affecting the decision to retire | Demographics (age, income) | | ✓ | | |
| | | Mental health | ✓ | ✓ | | |
| | | Support in workplace | ✓ | ✓ | | |
| | | Age of onset/diagnosis | | ✓ | | |
| | | Severity of symptoms | ✓ | ✓ | | |
| | | Duration of disease | | ✓ | | |
| | | Type of work | ✓ | ✓ | | |
| | Impact of PD on work | Symptoms that impact work | ✓ | ✓ | | |
| | | Liability concerns | ✓ | | | |
| | | Costs of early retirement | Costs to individual | ✓ | ✓ | ✓ |
| Costs to society | | | ✓ | | | |

rehabilitation provided by experts in PD, may create barriers to a uniform intervention. Thus, intervention implementation plans would not be successful with a one-size-fits-all approach across clinical settings.

Stakeholder suggestions to fill the gaps in knowledge focused on earlier exposure to the topic of employment

challenges through education by their PD interdisciplinary teams, led by neurologists. Each interdisciplinary team should identify key personnel to provide personalized support and proactive accommodation recommendations to avoid crises. This team member could be a clinical social worker, a resource nurse, a vocational rehabilitation

Table 4 Proposed intervention emerging from stakeholder discussion panels

| Need | Need subthemes | Quotes |
|---|--|--|
| <i>Knowledge</i> PwP and clinicians need accurate information | PwP need information on roles of clinicians and how they could address employment problems | <p>“It’s kind of like the onus is now on me to interpret based on what they’ve given me, as to what accommodations I’m gonna ask for...so for me, it would kinda be nice if there was ... somebody that would like step in and...help me figure out, ok this is what they’ve given me, these are the so-called requirements I have to meet, what accommodations would be helpful to meet these? I mean, is that my doctor’s responsibility, is there someone else out there that could help me?”—PwP</p> <p>“So I think sort of helping to define roles and empowering the patient to know ...can be addressed...I’ve realized it’s fluid...but I think the power of knowing the expectations of the role within the team is also very helpful.”—Clinician (PT)</p> |
| | PwP need resources on employment including information about disclosure, accommodations, government support systems, SSDI, and legal concerns | <p>“...When I was diagnosed I went to the...website...and there is one little tab on employment. And it’s very vague about, you can decide what to tell your employer. And like, I read it. And I was like, well that does me no good. Like what am I supposed to do? It was of absolutely no help.”—PwP</p> <p>“... Just because we have access to these resources...I don’t know how great they necessarily are ...I think people need support...I feel like it is risky when you give these things um, because it sounds so easy but I don’t think it’s easy.”—Clinician (OT)</p> |
| | Healthcare providers need specialized knowledge on screening for employment challenges in PwP, and in treating those challenges within their scopes of practices | <p>“I mention that at some point it would be very helpful to speak with a voc. rehab counselor because of like the ADA...because I don’t know exactly how that works, um for when they can no longer fulfill their job duties, um so I talk about that, and I think it’s kind of just like these little bullet points, um but nothing that is ever really addressed further after that.”—Clinician (OT)</p> <p>“...It depends on the culture and what you’re doing and kind of like what’s going on with Illinois laws, and like, but honestly, I, I’d refer you to [vocational rehabilitation counselor] because she can go into this in so much more detail, even if you meet with her the first time then you’d have your contact resource, and I can, having this education whether it’s a flowchart, or like a one-hour webinar just gives me a little bit more like knowledge to sell it better, than probably how I’ve been selling it...”—Clinician (OT)</p> |
| <i>Processes</i> PwP need someone to start the discussion about employment challenges, preferably before it is an employment crisis | Healthcare professional at the neurology appointment (neurologist, RN or medical assistant at neuro clinic, social worker) needs to identify that there is an employment challenge and refer to appropriate services or let neurologist know | <p>“...I think you have a lot of things to cover with the ... you aren’t gonna be able to cover everything in your appointment, but if they have the ability to, they have the knowledge, the information, but then they can refer you to specialists that can work with you one on one that can give you the help that you need, I think that would be beneficial. But, but it has to, they have to at least know about it to be able to refer you to someone else to get the help.”—PwP</p> <p>“...So I think, from the physician standpoint, understanding someone’s ability, the nature of their job, their ability to do their job is really important, um for our role to get them to the next place, whether that’s OT, PT, social work, tech, vocational...kind of as the gatekeeper of that conversation.” Clinician (neurologist)</p> |
| | PwP prefer neurologist to have a role in providing employment-related referral and to validate the PwP’s need to use a proactive approach to employment challenge, but recognize process challenges related to their neurologist’s time | <p>“Well, I just think that the neurologist is the only person I’m gonna faithfully go to, so if my neurologist tells me something, then I am definitely gonna find out about it. And none of these other services are something that I would, without fail, go to.”—PwP</p> |

Table 4 (continued)

| Need | Need subthemes | Quotes |
|---------------------|--|---|
| | Specialist with employment expertise should provide 1:1, personalized assistance when there are complex employment challenges | <p>“Somebody that has the availability to someone that’s sort of specialized in this could really help. Because you know how there’s the questions of what do I do...sometimes you have to do it in a stealthy way. Maybe that person could help with the stealth work.”—PwP</p> <p>“...Even if I have this information of recommendations...I think they need that person who follows up. Because so I could tell them, but again I think I would want to refer, because I think they need that relationship with a person who focuses in on that...”—Clinician (OT)</p> |
| | Timing of intervention (preferably if identify employment challenge proactively, before it is an employment crisis) | <p>“I’d hate to find out that I could have done X and I didn’t.”—PwP</p> <p>“Under...review of systems...and...home environment...if [work] became part of that sort of checklist for physicians to start that conversation, it might help get [PwP] to the ... appropriate [support] people, sooner, or start that conversation.” – Clinician (neurologist)</p> <p>“...I think social work gets involved almost when it’s quote unquote too late, instead of earlier on, and so people are already looking at disability or retirement.” – Clinician (SW)</p> |
| <i>Intervention</i> | Flexible approach to employment-related intervention delivered based on how the person interacts with the healthcare system. Options include (1) in-person services scheduled 1:1 with provider; (2) in-person services through informal conversations with provider at support groups or community events; or (3) personalized conversation or resources shared over the phone or email | <p>“I think part of the problem with Parkinson’s is there’s such a variety and diversity in everyone...and jobs. And I don’t, I can only imagine it being helpful or beneficial if we still categorized stuff. Like job tasks and symptoms. But, because everyone, even everyone in this room has different issues.”—PwP</p> |

counselor, an occupational therapist, or another member of the allied health team with appropriate training and experience. Individually-tailored support needs should include: discussion and consideration of early retirement including potential reduced salary and costs of maintaining health insurance as well as the potential benefits; discussion of potential formal and informal accommodations; navigation through disclosing PD status to an employer or changing job roles; and exploration of benefits that are available during different stages of employment or disease, such as the Family and Medical Leave Act (FMLA) or SSDI.

Focusing the needs assessment on one urban center in the U.S. limits its generalizability to other regions of the U.S. and the world. Federal-state vocational rehabilitation programs may vary state by state, but by and large will not focus on helping PwP retain employment. Additional resources need to be identified to support early intervention for PwP seeking to continue their employment. The themes developed in our multi-component needs assessment may be biased to the populations studied in published articles and the experiences of our stakeholder panels. Thus, we included two discussant panels with both white-collar and blue-collar workers. Future work should attend to unique employment issues in non-skilled workers in rural areas.

Conclusion

Three needs for improving proactive employment support for PwP are: (1) PwP and clinicians need accurate information regarding employment challenges and resources, (2) health-care teams should establish a process to identify employment challenges, and (3) interventions must be individualized, flexible, and delivered by experts to address concerns across an array of PD-related impairments as they relate to individuals’ essential job functions. The results inform a proposed proactive employment care path for PwP that includes social work, vocational rehabilitation, and other members of the interdisciplinary care team. We propose that the intervention care path should begin with neurologist identification of employment challenges in PwP when they are newly diagnosed. When challenges are noted, the neurologist should refer to a vocational rehabilitation counselor with experience working with PwP. Unfortunately, the needs assessment and resource review found vocational rehabilitation to be a very limited resource in most communities. State agencies or educational programs for vocational rehabilitation may be good sources of local information. Future research and clinical quality improvement efforts should examine and disseminate employment-related knowledge

and vocational rehabilitation approaches to neurologists, social workers, clinic nurses, occupational therapists, and other members of the interdisciplinary teams working with PwP. Furthermore, PD clinics should attempt to develop relationships with vocational rehabilitation counselors in their communities to help develop PD-related expertise.

Acknowledgements Research reported in this publication was supported by the Rehabilitation Research and Training Center on Employment for People with Physical Disabilities (RRTC), funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) (Project Grant No. 90RTEM000101). We would also like to thank the key stakeholders who provided insight into the needs of people with Parkinson's, as well as our advisory committee for helping to guide the direction of the project.

Data availability The data are available online at <https://www.icpsr.umich.edu> [35].

Compliance with Ethical Standards

Conflict of interest All the authors declares that they have no conflict of interest.

References

- Gustafsson H, et al. Parkinson's disease: a population-based investigation of life satisfaction and employment. *J Rehabil Med*. 2015;47(1):45–51.
- Murphy R, et al. Parkinson's disease: how is employment affected? *Iran J Med Sci*. 2013;182(3):415–419.
- Martinez-Martin P, et al. The impact of non-motor symptoms on health-related quality of life of patients with Parkinson's disease. *Mov Disord*. 2011;26(3):399–406.
- Kowal SL, et al. The current and projected economic burden of Parkinson's disease in the United States. *Mov Disord*. 2013;28(3):311–318.
- Whetten-Goldstein K, et al. The burden of Parkinson's disease on society, family, and the individual. *J Am Geriatr Soc*. 1997;45(7):844–849.
- Schenkman M, et al. Longitudinal evaluation of economic and physical impact of Parkinson's disease. *Parkinsonism Relat Disord*. 2001;8(1):41–50.
- Giladi N, et al. Interdisciplinary teamwork for the treatment of people with Parkinson's disease and their families. *Curr Neurol Neurosci Rep*. 2014;14(11):493.
- Aragon, A.K., Jill. Occupational therapy for people with Parkinson's: best practice guidelines. 2010; https://www.parkinsons.org.uk/sites/default/files/2017-12/otparkinsons_bestpracticguidelines.pdf.
- Foster ER, Bedekar M, Tickle-Degnen L. Systematic review of the effectiveness of occupational therapy-related interventions for people with Parkinson's disease. *Am J Occup Ther*. 2014;68(1):39–49.
- McDaniels B. Employment issues and vocational rehabilitation considerations for people with Parkinson's disease: a review of the literature and a call to action. *J Vocat Rehabil*. 2018;48(3):297–303.
- Keus SH, et al. The ParkinsonNet trial: design and baseline characteristics. *Mov Disord*. 2010;25(7):830–837.
- Kaufman RA, Rojas AM, Mayer H. Needs assessment: a user's guide, vol. 16. Englewood Cliffs: Educational Technology Publications; 1993. p. 190.
- Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277–1288.
- Armstrong M, Gruber-Baldini AL, Reich SG, Fishman PS, Lachner C, Shulman LM. Which features of Parkinson's disease predict early exit from the workforce? *Parkinsonism Relat Disord*. 2014;20(11):1257–1259.
- Banks P, Lawrence M. The Disability Discrimination Act, a necessary, but not sufficient safeguard for people with progressive conditions in the workplace? The experiences of younger people with Parkinson's disease. *Disabil Rehabil*. 2006;28(1):13–24.
- Cholewa J, Gorzkowska A, Kunicki M, Stanula A, Cholewa J. Continuation of full time employment as an inhibiting factor in Parkinson's disease symptoms. *Work*. 2016;54(3):569–575.
- Jennum P, Zoetmulder M, Korbo L, Kjellberg J. The health-related, social, and economic consequences of Parkinsonism: a controlled national study. *J Neurol*. 2011;258(8):1497–1506.
- Johnson S, Davis M, Kaltenboeck A, Birnbaum H, Grubb E, Tarants M, Siderowf A. Early retirement and income loss in patients with early and advanced Parkinson's disease. *Appl Health Econ Health Policy*. 2011;9(6):367–376.
- Kikichi E. Daily living abilities and work abilities of people with Parkinson's disease. *Work*. 1998;13(3):239–248.
- Martikainen KK, Luukkaala TH, Marttila RJ. Parkinson's disease and working capacity. *Movement Disord*. 2006;21(12):2187–2191.
- Mullin RL, Chaudhuri KR, Andrews TC, Martin A, Gay S, White CM. A study investigating the experience of working for people with Parkinson's and the factors that influence workplace success. *Disabil Rehabil*. 2018;40(17):2032–2039.
- Murphy R, Tubridy N, Kevelighan H, O'Riordan S. Parkinson's disease: how is employment affected? *Irish J Med Sci*. 2013;182:415–419.
- Schrag A, Banks P. Time of loss of employment in Parkinson's disease. *Movement Disord*. 2006;21(11):1839–1843.
- Timpka J, Svensson J, Nilsson MH, Palhagen S, Hagell P, Odin P. Workforce unavailability in Parkinson's disease. *Acta Neurol Scand*. 2016;135(3):332–338.
- Zesiewicz T, Patel-Larson A, Hauser RA, Sullivan KL. Social Security Disability Insurance (SSDI) in Parkinson's disease. *Disabil Rehabil*. 2007;29(24):1934–1936.
- Kaya C, Leslie M, McDaniels B, Cuevas S, Wu H, Rumrill P, Wehman P, Chan F. Vocational rehabilitation factors associated with successful return to work outcomes for clients with Parkinson's disease. *J Vocat Rehabil*. 2020;52(2):145–156.
- McDaniels B. An exploratory survey of the employment concerns and experiences of people with Parkinson's disease: implications for rehabilitation research, policy, and education. *Rehabil Res Policy Educ*. 2019;33(1):104–110.
- Madhavan S, et al. Corticospinal tract integrity correlates with knee extensor weakness in chronic stroke survivors. *Clin Neurophysiol*. 2011;122(8):1588–1594.
- Latimer-Cheung AE, et al. Developing physical activity interventions for adults with spinal cord injury. Part 2: motivational counseling and peer-mediated interventions for people intending to be active. *Rehabil Psychol*. 2013;58(3):307–315.
- Dolhun RF, Marti. Sharing your Parkinson's diagnosis at work. 2018. https://files.michaeljfox.org/100915_MJFF_WORKPLACE.pdf.
- Dolhun RF, Marti. Talking about Parkinson's at work. 2018. https://files.michaeljfox.org/052617_MJFF_WORKPLACE_PT2.pdf.
- Rubin M. Americans with Disabilities Act (ADA) Overview. 2019. <https://parkinson.org/living-with-parkinsons/legal-financial-insurance/legal/Americans-with-Disabilities-Act>.

33. Nooijen CF, et al. A behavioral intervention promoting physical activity in people with subacute spinal cord injury: secondary effects on health, social participation and quality of life. *Clin Rehabil.* 2017;31(6):772–780.
34. Bruyère SM. Disability management: key concepts and techniques for an aging workforce. *Int J Disabil Manag.* 2006;1(1):149–158.
35. Rafferty MR. RRTC employment for people with physical disabilities - Parkinson's intervening early concerning employment

(PIECE) needs assessment. Ann Arbor, MI: Inter-university Consortium for Political and Social Research [distributor]; 2020. <https://doi.org/10.3886/E120911V1>.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.