

Social work scope of practice with Parkinson's disease: A qualitative study

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Abstract

● *Summary:* The field of social work has seen increased recognition across many sectors in recent years. Evolving racial, political, and medical paradigms and the COVID-19 pandemic have shown the importance of a person-centered approach to health and mental health. One such area of practice is neurology, specifically work with people with Parkinson's disease (PD), which is the second most common neurodegenerative disease, currently impacting more than 10 million people worldwide. While social workers have long played key roles in multidisciplinary teams in PD care settings, research and

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literature offering assessment and evidence in this area remain limited. This research study used a mixed-methods approach with additional in-depth qualitative interviews conducted with 11 social workers. This article presents findings from the 11 interviewees who are presently working with people with PD using thematic analysis.

- *Findings:* Themes emerging were an in-depth detailed role of the social worker, the importance of strong relationships working with people with PD and their families, multidisciplinary teams, and the community. Institutional challenges were highlighted concerning supporting social work positions and encouraging social work intervention from the beginning of diagnosis to the end stages of the disease. COVID-19 proved very challenging for social workers, multidisciplinary teams, and families, and yet positive practices were identified as well.
- *Applications:* The impact of this study reinforces the essential role specialized PD social workers play in multidisciplinary PD teams and recognition needed to increase their role through early intervention reflected in increasing social work positions in neurology.

Keywords

Social work, ageing, health and social care, medical social work, practitioner research, qualitative research, Parkinson's Disease

Through a professional set of values centered around social justice, service, dignity and worth of a person, and the importance of human relationships, social workers offer versatile and unique skills to navigate complex systems and advocate on behalf of and alongside vulnerable communities (CASW, 2020; Kam, 2014; NASW, 2022). The field of social work has seen increased recognition across many sectors in recent years. Evolving racial, political, and medical paradigms and the COVID-19 pandemic have shown spotlights on healthcare disparities, opportunities for activism, and the importance of a person-centered approach to addressing physical and mental health (Amadasun, 2020; Bilal & Diez-Roux, 2018; Goode et al. 2021; Stanhope et al., 2015; World Health Organization, 2021). While social workers have had a presence in healthcare settings for over a century, providing person-centered care and support to individuals and families living with medical conditions, the multifaceted contributions of social workers on care teams and within specific fields of medicine are still being realized (Ambrose-Miller & Ashcroft, 2016; Craig et al., 2015; Fraser et al., 2018; Stanhope et al., 2015; Zerden et al., 2022). Social work practice within neurology is one such area that is deserving of increased attention and documentation in the literature and medical community.

Parkinson's disease (PD) is a neurological diagnosis that has been identified as necessitating a team of healthcare professionals across multiple disciplines to address the complex needs of people with PD and their families, affording much opportunity for the role of social work in comprehensive PD care (González-Ramos et al., 2019; Zerden et al., 2022). PD is the second most common neurodegenerative disease after Alzheimer's disease, currently impacting more than 10 million people worldwide (Marras et al., 2018; Parkinson's Foundation, 2021). Considered both a chronic and

progressive diagnosis, people with PD live an average of about 15 years from the onset of symptoms, although life expectancy continues to increase through improved care and treatment options (Feigin et al., 2017). While referred to as a “movement disorder,” with attention historically paid to the motor symptoms of tremor, imbalance, slowness of movement, and muscle stiffness, the impact of the non-motor symptoms of PD on quality of life is now well-documented (Duncan et al., 2014; La Bonte, 2021; Pfeiffer, 2016; Rajan et al., 2020; Torneiro, 2022). PD non-motor symptoms can include depression, anxiety, apathy, poor sleep patterns, fatigue, swallowing difficulty, changes to vocal quality, and cognitive impairment primarily in executive functioning (processing speed, multitasking, attention, planning, organization) (Duncan et al., 2014; Mehta, 2015; Pfeiffer, 2016). The symptoms experienced by this disease are unique to the individual and can change and worsen over time, leading to a variety of psychosocial challenges including support system stressors, loss of independence, and difficult considerations and decisions around care (González-Ramos et al., 2019; Macleod et al., 2016; Mosley et al., 2017).

Over the past decade, there has been increasing focus on best care practices in the field of neurology and PD more specifically. PD care has been among the first to establish multidisciplinary care (e.g., neurologist, nurse, occupational therapist, physiotherapist, social worker) as the optimal model of care delivery and more recently through increased exploration of the palliative (specialized medical care that focuses on providing relief from pain and other symptoms of a serious illness) (“Mayo Clinic”, 2023) approach to care (Lennaerts-Kats et al., 2022; Miyasaki & Kluger, 2015; Rajan et al., 2020). Parkinson’s Foundation has played a critical role in the advocacy and advancement of both approaches to the care of people with PD. While social workers have long played key roles in the provision of these integrated care models in PD care settings, research and literature offering assessment and evidence in this area remains limited (González-Ramos et al., 2019; Zerden et al., 2022).

Through qualitative interviews with frontline PD social workers, this paper aims to illuminate the scope of current and potential roles of social workers in the provision of comprehensive and team-based care for people with PD and their families and related challenges and needs in this area. This is not a comparative paper between medical social workers working in other areas of health, yet indeed there may be overlaps. The uniqueness of this research is that only social workers working in the field of PD were interviewed, thus adding to only three other studies to date, to our knowledge, that specifically assess the application of social work in PD care, two of which were conducted over a decade ago (González-Ramos et al., 2019; Waldron et al., 2013; Zerden et al., 2022). As such, the results of this study strengthen the argument for the role of social work in PD care, as this disease is a unique health condition that progresses over time with ever-changing needs demanding a breadth of specialized knowledge and targeted ongoing interventions.

Background to study

Waldron et al. (2013) captured social workers’ perspectives on the palliative needs of people with PD, highlighting the importance of specialized knowledge and resources

to improve the palliative care of PD. González-Ramos et al. (2019) laid the foundation of documenting social work practice with PD care through a survey of 36 social workers working directly with people with PD. Findings identified a variety of functions including case management, clinical treatment, education, and interprofessional collaboration, yet the data presented was dated. Zerden and colleagues (2022) looked at these roles again 10 years later, with a particular focus on the impact of the COVID-19 pandemic on social work practice in PD care. Findings underscored the multi-dimensional roles and adaptability of social workers on PD care teams and the impact of COVID-19 on PD care delivery but was primarily descriptive (Zerden et al., 2022). Therefore, this study presents data from semi-structured interviews from social work participants who elaborated on their roles beyond survey responses and opted to participate in follow-up interviews.

Methodology

This study was conducted with a concurrent design of both a quantitative mixed-methods approach and a general qualitative study. Qualitative research is used when little information has been published concerning the topic at hand. It is exploratory research that “studies real-world situations as they unfold naturally...and yields detailed, thick description; inquiry in depth and gathers from interviews people’s personal perspectives and experiences” (Patton, 2015, p. 46). Through inductive analysis, codes, categories, and themes are discovered that give light to the topic being researched (Braun & Clarke, 2006; Silverman, 2016). The survey and interview guide were created, and ethics boards of three different universities approved the research.

Data collection

The research project involved an online survey described in detail by Zerden et al. (2022) ($n = 39$) and included respondents from the USA ($n = 35$) and Canada ($n = 4$). Participants voluntarily opted to participate in a follow-up, more in-depth interview by a research team member. Survey invitations were posted primarily through the Parkinson’s Foundation network of care, including Centers of Excellence and alumni from a Parkinson’s Foundation Team Training Program. The qualitative interview guide was created, with a focus on gathering in-depth personal experiences on their social work roles working with people with PD and their families in clinical settings. Eleven social workers agreed to participate in the follow-up interview.

Semi-structured interviews. All interviews, which took place in January 2021 via Zoom, lasted one to one and a half hours. Of the 11 interviewees, eight were from the USA and three from Canada. Ten were female and one was male. There was a range of time spent in the field of PD care, with the longest at six and a half years to the shortest working for 9 months. Once the interviews were completed, they were cleaned and transcribed using an encrypted code. Interviews were voluntary and uncompensated. All interviews were conducted by the primary author for consistency.

Analyses of data. Using Braun and Clarke's (2006) approach to thematic analysis, three team members were given transcripts to analyze at three levels: line-by-line coding, categorizing codes into an organized chart, and refining themes developed from the codes and categories.

First-level coding. Each of the analyzers went line by line to identify codes. A coding chart was developed to organize the codes presented and how many times they appeared in the transcripts. A total of 131 codes were identified by the three analyzers.

Second-level coding or categories. Next, the analyzers narrowed the 131 codes to 80 based on the frequency they appeared in the transcripts. The analyzers then agreed on and identified 13 categories to help further distill themes the 131 originally identified codes in level 1 of the coding processes.

Third-level coding or themes. Analysis revealed four overarching themes gleaned from the interviews: (1) the social work role, (2) relationships, (3) utilization of services, and (4) COVID-19 which are explained below supported by in-depth data.

Research findings

Across all 11 interviews, the social workers' commitment to attending to the needs of people with PD and their families as part of an integrated care team was clear. One interviewee described the social work role as they saw it: "I think with any person or any illness, that taking care of the whole person, family-centered care, meeting patients where they are, will lead to the most successful outcomes" (#2, USA). Addressing the person in their environment through a strength's perspective is key. A primary theme across all 11 interviews was the breadth of social work roles in comprehensive team-based PD care.

Social work role

Holistic care. Historically, PD was primarily treated pharmacologically for symptom relief, which was managed by a neurologist. Thematic analysis of the social work interviews revealed an appreciation of the need to care for PD holistically from the approaches of multiple clinical disciplines working together. This has important implications for the potential for social workers to assist in the management of non-motor symptoms and support overall quality of care and life, which was evident during interviews. One social worker shared:

I can appreciate the analogy that one of the neurologists uses when he is a guest lecturer for our course and he has a photo of an iceberg and how the tip of the iceberg are the physical symptoms, and then the non-motor is the main iceberg. So, he gets it. (# 8, Canada)

Along with holistic care given to persons with PD and their families is support through counseling.

Counseling. A principal role of social workers in PD care was performing a clinical psychosocial assessment, a tool to gather a full picture of how their diagnosis and symptoms impact their life, primary psychosocial stressors and coping mechanisms, support system, strengths, and needs. Social workers utilized this information to make tailored referrals to different team members or outside agencies and to provide education, support, and connection to community resources.

Several social workers offered direct counseling as an additional clinical service on the care team. Clinical counseling often focused on family care partner well-being, safety needs, reflection on stigma, and self-identity related to living with a PD diagnosis and planning for the future. A frequent conversation social workers have with people with PD is around the all-important question “what will this journey look like?” reflecting a common psychosocial challenge for them concerning the uncertainty of the future, especially for those who are newly diagnosed. PD is complex, with many different unknown factors of what constitutes PD and why some peoples’ disease progresses rapidly while others’ disease progresses more slowly. Evidence-based knowledge of PD and experience with these complexities are what social workers uniquely offer people with PD and their families, helping to validate and process related questions as well as emotional support throughout their journey.

Mood changes, namely, depression and anxiety, are increasingly recognized as primary non-motor symptoms of PD that impact health-related quality of life for people with PD, while apathy, another common symptom, has been found to be particularly challenging for family care partners. Social workers reported frequently addressing these mood challenges as part of their role as counselors. An interviewee explained:

Providing emotional support is also part of the comprehensive care; a lot of the patients we work with, you know, their anxiety is a challenge and can be somewhat managed by medication, but there are other kinds of strategies, so providing some interventions or strategies to help them when they are feeling stressed out. (# 3, USA)

Recognizing and addressing the physical and mental health needs were also identified as essential in the provision of care for family care partners.

Family support. Working directly with PD care partners was a common role for social workers. They assessed the emotional well-being and coping skills of care partners as well as their comfort with and ability to care for the person with PD in the home. Many social workers described educating care partners on signs of burnout and the importance of self-care and providing connections to resources such as professional home care or respite services, support groups, counseling, or long-term care. An interviewee stated the following: “With regards to carer support, I would say I spend more of my time with carers than I do with patients” (# 8, Canada).

Group work was another way to support both the person with PD and their families.

Work with groups. Social workers took pride in group work, feeling that it was a way to support the larger PD community and foster connections between people living with a PD

diagnosis. One interviewee described the benefit of these groups as an additional layer to the support network for people with PD and their families:

Emotional support, I would say. Having a support group, a network of people that they can connect with and share some of their life experiences. This can be really powerful in terms of boosting overall wellbeing which is going to help with some of their symptoms. (# 3, USA)

Some social workers also facilitated support groups for people with young onset PD: those who are diagnosed at age 50 or younger. Social workers felt that this is an important service as people with young onset PD “do not have the same needs, as they have children and work...where most groups are for older people in advanced stages” (#5, Canada).

Advocacy. A few social workers found their role included advocating on behalf of their person with PD within their care teams. One interviewee expressed appreciation that others on the team recognize this crucial role and how it contributes to the provision of holistic care: “I am privileged enough to be a part of a team that really values our work and our perspective, I have a voice, and I am able to advocate for my patients” (#11, USA).

Representing the voice of the people with PD and their families is a cornerstone of person-centered care practices. Another social worker spoke to how this is both a challenging and fulfilling endeavor as well as the opportunity for the profession to pursue advocacy on the macro scale:

It is challenging because of all the different moving parts, but it is rewarding when you get all those moving parts together! Given the different systematic issues, it would be easier to provide the services to our patients if we form an advocacy group for policy change! (#4, USA)

Advocacy is also seen on the micro and mezzo levels, in educating people with PD and their families about their diagnosis leading to self-advocacy and a more general awareness of PD.

Education. Social workers offered education on PD individually, in groups, and in the community. For people with PD and their families, education focused on the PD diagnosis and options for care and support from new diagnosis through the end of life. One social worker explained her educative role “Informal will be meeting with people one on one, or in family settings, in the clinic, or pre-COVID it could also be in their home. It would be sharing of educational material, and it would be also through discussion that would be education” (#8, Canada). Social workers also frequently offered community education in support group settings and through local PD-related associations or other voluntary or community organizations including community gatherings such as markets and community centers. Due to the increase in PD worldwide, community work has become an increasingly important educational tool unique to their job. Other roles not highlighted in this article are helping with financial paperwork, transitioning

to long-term care, helping with advanced directives/will, grant writing, Parkinson's Foundation coordinator, and family work.

Relationships

The social work profession's value of human relationships was apparent in the roles described across all 11 interviews. These relationships were not only with persons with PD and their families but also with the professional teams with which the social workers closely collaborated to provide care. One social worker described the relationship with their team in this way: "I can talk to everybody ... I mean at the end of the day the doctor makes more of the decisions, but they always listen to us because it is a relationship. It is a relationship of trust" (#5, Canada). Team cohesion and respect of different perspectives and expertise across different disciplines were described as foundational to the provision of comprehensive PD care.

Multidisciplinary teams. All 11 social workers worked in clinical care settings within teams, including neurologists, nurses, and rehabilitation therapists, with whom they closely collaborated to manage the complex needs of people with PD. Many felt that their social work services and support balanced the pharmacological approach to PD symptoms. One interviewee explains their role within the multidisciplinary team: "The biggest thing that I or social work does is to support the medical team, so that the medical team can really focus on the patient's treatment, whether it is medication, or therapy or whatever the case may be" (#1, USA). A few interviewees likened their role to a bridge between team members. For example:

Social work has been the person to connect and be that middle ground between the neurologist, surgeons, physicians, medical - type fields and the patient. It is that bridging and ensuring that people can meet their needs and meet their goals, their personal goals, while still living with Parkinson's. (#7, Canada)

For some however, needing to educate other professionals on the care team about social work was necessary, especially new team members. For a few social workers, it took some time for their role to be established. This transition was described by one interviewee:

For some of our newer staff/providers it does take a little more education around "Here is what my role looks like and here is how I can support you and your patients", but once we sort of bridge that education kind of gap, then usually it is kind of like a waterfall and they really do buy-in. (#7, Canada)

Not only was it important for the teams to value the social work role, but a positive relationship with persons with PD and their families was at the core of their practice.

Relationship-building with families. Building rapport with people with PD and their families was important to the interviewees. In fact, many expressed frustrations that they often did

not have enough time to spend with them. Sometimes their families may not always fully understand what a social worker can offer in their care, and some can be reluctant to engage with a social worker due to misconceptions of social work roles. However, many social workers felt that once they were able to build a solid relationship with the person with PD and their family, their services were appreciated, regardless of how often they would connect.

At the same time, social workers felt that people with PD and their families sometimes often had high or unrealistic expectations for what social work support could offer them in this journey, despite an ultimately progressive disease. This was described by one interviewee: "Some of the challenges that we see daily is sometimes the expectations on the team...the expectation of a cure or find new medication and always maintain the level of functioning that is optimal" (#5, Canada).

Still, given the chronic nature of PD, social workers stayed in touch with persons with PD and their families over many years, and these relationships continuously strengthened or grew and changed over time, depending on the individual needs that arose. These long-term relationships often minimized or mitigated crisis situations. If the social worker already knew the person with PD and their family, urgent situations could be dealt with quickly and efficiently. Many social workers described the desire to connect with people with PD earlier in the diagnosis so that they could be a source of support for them over their course of their disease journey. Along with a strong relationship with the person with PD and their family, relationship-building with the community was crucial to effective service delivery.

Community. Social workers frequently connected to outside agencies and resources as supplemental levels of support to clinical care and social work assessment. This required social workers having an awareness of resources in the community. Building relationships with different agencies, community leaders, and support networks enhanced the effectiveness of the multidisciplinary team and the social worker's practice.

Several interviewees mentioned specific concerns of marginalized communities having limited access to specialized PD services, putting them at risk for falling through the cracks and receiving lower quality of care. One interviewee explained, "I would love to see more services for people reaching communities where folks have lower socioeconomic status, for maybe specific support for people of colour with Parkinson's" (#2, USA).

Recognizing the needs of these underrepresented people reflected the social work profession's dedication to social justice and was an impetus for many social workers to build relationships with community resources, to create a network of care for their PD person and their families. The need to utilize social workers to their full capacity was an important theme for the interviewees.

Utilization of social work

For social workers to work and be utilized effectively, they need the support of their team, the community, and larger systems in which they work. The social workers interviewed

recognized their contributions to comprehensive PD care but also felt that their services were not always understood or supported to the full extent: “I think social work is underutilized, in general. I think it would benefit everybody and even the medical system, and healthcare in general, to access social work more frequently and utilize social workers more – maybe one day” (#7, Canada). Results from this study indicate that obstacles existed in the provision of social work in the care of persons with PD, as well as opportunities for growth and increased utilization of a social worker in this niche field and beyond.

Institutional barriers. Social workers described challenges to the utilization and provision of comprehensive social work services for PD within the larger systems of healthcare and long-term care. Several social workers pointed out that insurance plans do not cover essential services needed for people with PD, specifically “An insurance plan will pay for physiotherapy, occupation therapist, RN to come in but they won’t pay for a home help aid. Someone just to be there and be with them and help them live” (#11, USA).

Given that people with PD often require increased support, monitoring, and hands-on care over time, such respite and long-term care services are critical supports for the sustainability of wellness for these families. Lack of insurance coverage or high costs of such care limits resources to which social workers can refer to support those they serve and leads to difficult decisions.

Another barrier to care involved the challenges related to rural living. Although most of the social workers worked in medical centers located in larger urban cities, many shared that their service areas can be large and persons with PD traveled from long distances to seek specialty care at their center. Weather, transportation costs, and time can be factors that prevent some, living in rural areas, from easily accessing the care they need, although the acceleration of telehealth use has ameliorated this in many ways, especially during the pandemic.

Support for social work positions. A common theme among interviewees was the fragility of financial support for social work positions in the healthcare system, which intersected with the ease and sustainability of providing their services for people with PD. This came from US social workers working in that healthcare system. One interviewee spoke of having to pay a fee to book a room to see their families. Multiple social workers expressed that a unique challenge in their role on the care team was not bringing in financial support to their institution since they could not, or did not, bill for their services as physicians, advanced care providers, and rehabilitation therapists do. At the same time, they recognized the benefit to people with PD and families if they do not have to pay for social work services. A US interviewee explained this dilemma:

The fact that we don’t bill is amazing. It removes a huge barrier in access to care...Now, it comes up as a challenge when purse strings are tight at work, and people look at the social worker and say, “How are you bringing in revenue?” You must convince folks that caring for the care partner, the outreach programming, and the ability to talk to anybody whenever wherever is worth it to them. (#2, USA)

Social workers recognized their own value of their services for people with PD and families, although they are often not able to provide the objective evidence of their value that is often sought after in the corporate business model of healthcare. A few social workers expressed uncertainties around their job security due to limited financial support from the system in which they operated. Some social workers feared they might not have a job next year due to potential funding cuts and, thus, felt the need to justify their positions or had to dedicate time and effort on grant applications to support their salaries.

Role capacity. Effectively assessing the multifaceted needs of people with PD and offering comprehensive support and services can be time intensive. Most of the interviewees felt they needed more time to practice, including building relationships with the people with PD and families they served, although this was often hampered due to their volume and complexity of cases. Many social workers shared that in their clinic, there may be multiple neurologists and hundreds of people with PD, but they were the only social worker.

Time constraints also caused difficulty with the social workers' ability to build new programs and resources as they would have liked. One interviewee shared, "There is just so much that we want to do, and frankly, we do have financial support, and we are really lucky to have that, but we can't get approval for more positions, it is hard to do that because we are not revenue generating" (#2, USA). One interviewee also described the barrier of not having enough time in their practice as someone who only worked part time while the neurologists and other allied health professionals were employed full time and added, "ultimately if there were to be an improvement in overall clinic services it would be adding an increase to the social workers" (#8, Canada). With this desire for more social workers to meet the case load and need at their clinics was also the aspiration to have social work introduced and intervene earlier with people with PD and their families.

Early intervention. When asked the question "In an ideal world, how would you provide social work services to persons with PD and their families?" most interviewees responded that they wanted to have their care team refer persons with PD to them earlier in their diagnosis or when first establishing care at the center. One interviewee made specific suggestions around establishing connections when someone is first diagnosed:

Ideally, we would start right away with a new diagnosis... I would meet with them probably a couple of weeks to a month later, once they have had a chance to settle, and let them know all the resources, enroll them in a Parkinson's disease 101 class and a local support group that would exist in every county...at least once a year be able to touch base with them and check in and make sure there are no major changes and be able to be with them as they transition to needing in-home care, to needing facility care or end of life care, and really developing that relationship. (#6, USA)

Meeting people and their families at the time of being newly diagnosed would be an opportunity for social workers to provide education on PD as well as on their roles on the

team and how they can support the family along the disease continuum. When these relationships are established early, social workers can assess basic functioning and needs as well as assist people with PD and their family to more easily follow up as needed.

Social workers can offer support through the entirety of the PD journey. The results of this study confirm that social work is a valuable service for people with PD and their families, adding to the growing evidence of the need to hire and support more social workers in PD care settings.

COVID-19

This social work research was created prior to the COVID-19 pandemic. As the pandemic hit and its impact on the healthcare system became apparent, the research team felt that it was important to understand how this affected social work practice with people with PD and their families, and a question was added to the interview to directly address this. The pandemic challenged work practices, but it was clear that the social workers responded with flexibility and persistence to continue to meet the care needs of their person with PD and their families.

Challenges to PD care during the pandemic. Social workers consistently reported experiencing and observing new challenges in the provision of care and support for their families because of the pandemic, namely, related to strained resources, increased stress for family care partners, and limited access to care. One social worker expressed her sadness in this realm stating, “I feel as if my toolkit has been practically wiped out” (#8, Canada). Given that connection to resources is a common and critical role of social workers, COVID-19 created barriers to the provision of social work care for people with PD in a multitude of ways.

Social workers reported that challenges in their provision of care as a direct result of the pandemic were when home support services first came to a standstill, followed by widespread short staffing in long-term care. Reduced options for respite and long-term care caused strain on people with PD and their families. Despite challenges to practice experiences during COVID-19, social workers also shared many positive experiences.

Positive developments in social work practice under lockdown. Social workers reported that over time, they, their care teams, and the person with PD and their families gained comfort in utilizing telehealth services and online meeting platforms. For those in rural areas, this was a new opportunity to connect with their healthcare providers without having to travel to the center, sometimes living 2–4 h away or with limited transportation options. Additionally, social workers who facilitated support groups shared that, because of moving these groups to meeting virtually, they had increased attendance. Social workers recognized that this new opportunity for people with PD to connect with their healthcare teams and to support or educate was a way for social workers to expand their reach beyond the walls of the clinic and to reduce certain barriers to access to care.

Discussion

These qualitative interviews further delineate the central roles social workers play in teams working with persons with PD and their families. Findings identified four principal themes, each of which provides deeper insights into the unique perspectives and functions of social work in this field. Social workers described a dynamic set of clinical skills and an approach to care through a social justice lens, echoing the limited but growing literature in this area (González-Ramos et al., 2019; Waldron et al., 2013; Zerden et al., 2022). From new diagnosis through the end of life, social workers function as coordinators, bridge-builders, advocates, and educators as well as a point for assessment, emotional support, and connection to resources for those they serve. Thematic analysis additionally illustrated the challenges and opportunities in PD-focused social work practice brought about by COVID-19, reaffirming previously published survey results of this study as well as literature indicating the effect of the global pandemic on the well-being of people with PD (Shalash et al., 2020; Zerden et al., 2022). Social workers described working directly with people diagnosed with PD, family care partners, support groups, community organizations, the larger PD community, and PD clinical care teams, reflecting social work's application at the micro, mezzo, and macro levels and the profession's value of human relationships at each of these levels (Matz et al., 2020). For those navigating the healthcare system and many years of a complicated neurological disease, having someone on the care team offering multi-pronged and multi-level support is critical to both quality of care and quality of life with PD.

Study results reinforce institutional barriers that continue to exist within the healthcare system which impact social workers caring for people with PD. One of the concerns that the interviewees had, particularly those from the USA, was the frequent lack of support for their positions within their department or larger medical system. With a corporate business model, social workers are often at a disadvantage for job security and support, especially compared to other healthcare professionals, because the benefit of their roles is difficult to quantify. This model puts healthcare services at risk, including the quality of care and retention of qualified health personnel through an emphasis on outcomes and profit-making (Kreitzer et al., 2020). These policies have been well-researched and have identified the negative effects of these types of financing model on healthcare service delivery (Austin et al., 2013; Baines, 2004, 2011; Carniol, 2010; Dominelli, 2010; Dustin, 2007; Lundy, 2011; Payne & Askeland, 2008). When money is the prime object of a health institution, healthcare professionals experience the effects of these policies and often show increased levels of stress, burnout, and compassion fatigue (Austin et al., 2013). This underscores the continued general undervaluing and vulnerability of the social work position within this model of healthcare. This is particularly the case, as reflected in the interviews, for those in specialized, ancillary roles in healthcare, like social workers in PD, whose positions may be the first to be cut when budgets are tight, and who may experience isolation if they are the only PD social worker in their department and community. Thus, the importance of more literature concerning the benefits of social work with PD teams is clear.

The need for more awareness of social work is apparent. The benefit of niche social work roles is the unique perspective social workers bring to their area of expertise within health and social domains. Evidence-based knowledge specific to PD and the experience of working with people with PD gives these social workers an opportunity to deliver targeted care and utilize skills beyond those of social workers practicing in other areas of medicine. Social workers shared that overall, they felt valued by people with PD and their family care partners, community organizations, and PD care teams yet still underrecognized within the field of neurology and the larger medical system. Social workers described the desire to have more time to spend with persons with PD and their families and to have opportunities to intervene at earlier stages of the disease. However, underutilization and limited understanding of social work services from the team, as well as time constraints to care for such a large caseload, often with complex care needs, functioned as barriers to this comprehensive social work support. This could be addressed through both education of other healthcare providers on the roles of social workers, the hiring of additional social workers on neurology teams, and additional evidence-based literature on social work interventions in PD care. Still, despite any perceived challenges and barriers, pride in their roles and career with PD teams was evident from social workers across all 11 interviews.

Future research

At the end of the interview, many interviewees expressed their excitement and gratitude that this research was taking place. Most stated that their role in multidisciplinary teams and in the care of PD has not yet been fully recognized or their skills not always utilized effectively or to their potential, underlining the need for more literature in this area. Specifically, one interviewee stated:

When I read the [survey description and consent] statement that I signed, I was like wow, this is important. It is certainly going to shed light on where we can be used most effectively because there are social workers out there who are put in situations and who are not used to the best most effective [way]. (# 10 USA)

This is one of now four published papers in the past decade directly addressing social work services in PD care. As approaches in multidisciplinary care delivery for PD continues to be appreciated, more qualitative and quantitative data on the roles of social workers with people with PD and their families is warranted. This can include exploration of the best practices of psychosocial assessment and interventions in early stages of the disease, social work strategies with specific non-motor symptoms, and the functions of social workers in palliative PD care. Additionally, future research in social work and PD care would benefit from larger and more diverse samples, especially those expanding farther beyond the Parkinson's Foundation network into other movement disorder clinics and general neurology settings. A comparison between the experiences of medical social workers working with persons with other neurological disorders would be useful. Such research in this social work subspecialty would not only offer further evidence-based documentation of social work contributions in the care of people with PD but can also be applied within the team-based healthcare model.

Limitations to the study

As stated earlier, this qualitative data is part of a larger, mixed-methods research project looking at the full role of social work with people diagnosed with PD, multidisciplinary teams, and the community. Limitations to this study include the lack of diversity in the sample size and the method of recruitment by gaining access to more social workers in neurology care settings. It is likely that there are far more social workers working in PD care than who participated in this study, whose perspectives were not captured in this research. The information collected from the 11 social workers interviewed may reflect a sample bias of those who intentionally chose to share additional perspectives on their social work practice. Additionally, there are social workers in many countries beyond the USA and Canada who work with people with PD and their families, and it was hoped we would have more of an international sample size to better understand social work care of PD across cultures and healthcare systems.

Conclusion

The documentation of first-hand insights and experiences of PD-specialized social workers captures the breadth of social work offerings within these multidisciplinary care teams. This article is an up-to-date reminder of how social work can improve overall quality of life and contribute to the potential reduction in national healthcare costs by working alongside physicians to address the needs of people living with PD. Findings affirm the need to take a proactive approach to reducing hospitalizations and improving wellness with PD by providing early social work interventions. This research is useful in providing justification to healthcare organizations for funding social work positions.

Through qualitative interviews that thematically centered on the social work role, relationships, utilization of services, and COVID-19, this study further validates that social workers act as bridges between people with PD and their families, the medical team, and the services available to them in the community and are integral in creating a circle of care throughout this disease journey. Findings can help inform evidence-based holistic management of PD and will invigorate neurology teams to integrate social work in their comprehensive care services.

Ethical approval

Ethical approval for this project was approved by the University of Calgary (REB20-1323), University of British Columbia (H20-02906), and the University of North Carolina at Chapel Hill (IRB20-1520).

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Declarations of conflict of interests

The authors confirm that they have no conflict of interest in respect of the material submitted in this article.

Author's contributions

All authors contributed to the developing and testing of the interview instrument. Linda Kreitzer conducted the interviews. Linda Kreitzer, Jessica Shurer, and Elaine Book coded the transcripts. Linda Kreitzer and Jessica Shurer wrote the first draft. Elaine Book, Lisa Zerden, and Ting Guan edited the paper through the different revisions.

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