

Commentary

Parkinson's Pals: A Student-Led Program to Facilitate Intergenerational Connections and Promote Psychosocial Well-Being Among Persons with Parkinson's Disease

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Abstract. Parkinson's disease (PD) causes unique motor and non-motor symptoms. Despite symptomatic treatment with pharmacotherapies, many persons with PD report feelings of loneliness and demoralization as their disease progresses. These symptoms greatly interfere with quality of life, necessitating novel treatment strategies. In this report, we introduce a new student-led program to improve psychosocial well-being among persons with PD by pairing them with college students. Through weekly one-on-one meetings, students gain a deeper understanding of PD, while patients gain a new social outlet and purpose. Based on the program's initial successes, we advocate for the adoption of similar programs at universities worldwide.

Keywords: Parkinson disease, loneliness, social isolation, demoralization, quality of life

PARKINSON'S DISEASE AND PSYCHOSOCIAL WELL-BEING

Parkinson's disease (PD) is a chronic neurodegenerative disorder affecting more than 10 million people worldwide [1]. PD is commonly associated with progressive motor symptoms, such as bradykinesia, rigidity, tremor, and gait instability, and non-motor

symptoms, such as dysautonomia, sleep disturbances, and neuropsychiatric symptoms [2]. These symptoms affect quality of life and are commonly managed with pharmacological agents, therapies, and other surgical interventions when indicated. Despite available treatments, patients often report feelings of loneliness and demoralization [3, 4]. As PD progresses, for example, patients can have more difficulty participating in social activities and performing activities of daily living. As a result, PD patients are often restricted to the confines of their homes or assisted living facilities, which further exacerbates perceived social

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isolation, loneliness, and loss of self-worth. These psychosocial symptoms can be difficult to manage in a clinical setting and often go unrecognized and untreated throughout the PD course.

Few studies have explored the impact of psychosocial well-being on persons with PD [3–5]. One prior study showed that demoralization, a psychological state characterized by helplessness, hopelessness, and a sense of failure, is prevalent in approximately 20% of PD patients [6, 7]. Demoralization is also associated with motor dysfunction in PD and may have a greater influence on functionality than depression [4, 7]. Additionally, loneliness among PD patients has been increasingly recognized for its adverse effect on emotional health, physical health, and quality of life. When loneliness and social isolation co-exist, neuropsychiatric comorbidities also increase in the form of apathy, depression, and anxiety [3]. Not surprisingly, the COVID-19 pandemic magnified the risk of loneliness and social isolation among PD patients [5], underscoring the need for improved awareness and novel treatment strategies to promote psychosocial well-being in the post-pandemic era.

Since 2020, telemedicine has been increasingly utilized as a platform for providing care [8]. Although virtual therapies and support groups are available to address psychosocial needs for persons with PD [9, 10], no prior studies to our knowledge have utilized virtual platforms to facilitate intergenerational connections between PD patients and students. To address this unmet need, we developed a novel virtual program called Parkinson's Pals (PD Pals) with the goal to reinvigorate social connectedness among PD patients. This report aims to 1) introduce and describe PD Pals, 2) discuss the program's potential to reduce psychosocial distress and improve quality of life among persons with PD, 3) evaluate the program's benefit to students, and 4) emphasize the need for further research using a PD Pals-based model.

PARKINSON'S PALS

The PD Pals program is a student-led non-profit organization that originated at the University of Pennsylvania and pairs undergraduate students with PD patients to foster intergenerational connections through weekly one-on-one conversations. Prior research has demonstrated that social relationships and interactions can lead to improved psychosocial well-being, physiological processes, and physical

health in all persons [11]. In older adults more prone to social isolation, increased social connectedness and social support can also have a positive effect on health and well-being [12]. For example, in individuals with dementia, as little as one hour of social interaction per week has been shown to improve quality of life and reduce psychosocial symptoms [13]. Building upon this evidence, PD Pals was designed to foster new social relationships between PD patients and students. By facilitating these connections, this program holds the potential to mitigate psychosocial distress and enhance overall quality of life for individuals living with PD.

In the current program structure, persons with PD are referred for participation in PD Pals by their movement disorders specialist during routine visits to the PD and palliative care clinics. All PD patients are eligible to participate, but special consideration is given to those who live alone or report feelings of loneliness or isolation. If patients express an interest in participating, they are then contacted by PD Pals leadership. Patients are matched with student volunteers based on personal and professional interests. After the matching process, all students undergo an educational and clinical training session on PD provided by the Davis Phinney Foundation, which includes an overview of PD and related symptoms, guidelines for compassionate patient interactions, and example scenarios for navigating challenging situations with sensitivity and professionalism. Then, each student and patient pair meet by phone or video for one hour every 1-2 weeks for one or more semesters depending on availability. Discussions often involve childhood stories, common interests and hobbies, career aspirations, and lived experiences. Additional motivation to create this program came directly from the founders' familial backgrounds, where loved ones were socially and physically isolated because of their PD diagnosis and symptoms. As a result, PD Pals was created with a mission to help patients who are isolated at home without caretakers or family members, an especially vulnerable population in need of additional support.

We believe that PD Pals represents a novel, non-pharmacological intervention to address psychosocial symptoms in PD and fills a void in the availability of such initiatives for PD patients, though similar programs do exist for persons with dementia [14]. In addition, although the University of Louisville implemented a similar program called the Parkinson's Disease Buddy Program, this program enrolled first-year medical students who met

with their buddies in-person at local coffee shops, parks, and museums [15]. While students and patients reported benefits to participation, in-person meetings may be more challenging for persons with moderate to advanced PD who are often homebound and have the greatest need for social connection. Thus, PD Pals aims to promote psychosocial well-being by facilitating new and lasting friendships between students and PD patients through a sustainable virtual platform.

Importantly, PD Pals can mutually benefit both patients and students. Many older adults with PD are accomplished individuals who have led fulfilling lives. These individuals can serve as personal and professional mentors for students, inspiring them and sharing in their accomplishments. These connections can also provide PD patients with important opportunities to recognize their pre- and post-diagnosis contributions and identities, further emphasizing their importance and worth despite progressive symptoms. In addition, intergenerational relationships are important to promote social growth among younger adults, and students may gain knowledge that will change their perceptions of older adulthood and interactions with persons who suffer from chronic diseases. We hope this program will help students make personal connections and gain valuable insights into the social and neuropsychiatric dimensions of PD, fostering empathy and strengthening communication skills essential for future careers in the health professions and other fields.

INITIAL PROGRAM FEEDBACK

From March 2022 to July 2022, initial feedback was collected from 7 students and 7 patients enrolled in the PD Pals program at the University of Pennsylvania over a 6-week period. Students and patients reported high program satisfaction, and 6 out of 7 students (86%) continued their regular meetings after 6 weeks, which informed the decision to extend the program to one or more semesters. As evidenced by the initial data, continuous participation and engagement emphasizes the program's feasibility and benefit to volunteers who overwhelmingly enjoyed their experience. One student from the initial program said, "Parkinson's Pals is an amazing program to help educate, inspire, and connect the younger generations with people living with Parkinson's. In just 4 weeks, I formed a new friendship and gained new perspectives I never could have without meeting my pal!" A patient participant also stated, "I realized how impressed I

was by the fact that you were taking the time to make Parkinson's Pals a success. I was also very impressed by how well you obviously understood the need for Parkinson's patients to get more social contact than they usually get. I'm sure that you will be a better doctor as a result of your instinctive interest in understanding your patients better and what they are going through. I also have personally enjoyed our conversations and look forward to continuing our discussions."

GROWTH AND FUTURE DIRECTIONS

As of June 2023, Parkinson's Pals has expanded to 8 other universities in the United States in addition to the University of Pennsylvania: Columbia University, Cornell University, Harvard University, Rutgers University, Sophie Davis School of Biomedical Education, Stony Brook University, University of Massachusetts-Amherst, and the University of Wisconsin-Madison (Fig. 1). Over 200 students have volunteered to participate, but given the recency of the program, only 15 PD patients from all chapters have been enrolled or matched with students. Fortunately, numbers are increasing weekly as chapters partner with local PD clinics, and PD Pals hopes to expand to other universities worldwide.

Given the limited data on loneliness, social isolation, and demoralization in PD, PD Pals also offers important research opportunities. As the cohort grows, we plan to study the effectiveness of PD Pals in promoting psychosocial well-being and quality of life among persons with PD by administering validated patient-reported outcome metrics before and after program participation, such as the UCLA Loneliness Scale, Cohen's Social Network Index, Diagnostic Criteria for Psychosomatic Research-Demoralization (DCPR-D) interview, Kissane Demoralization Scale (KDS), Scales for Outcomes in Parkinson's Disease-Psychosocial Functioning (SCOPA-PS), and Parkinson's Disease Questionnaire (PDQ-39). We are also interested in comparing the characteristics of patients who agree or decline to enroll in PD Pals to improve recruitment and program development over time. Lastly, we hope to evaluate the program's impact on students by tracking their educational journey to determine associations between participation and future careers in the health professions and/or neurosciences. We believe that PD Pals has the incredible potential to serve as a novel, reciprocal intervention that not only treats often overlooked psychosocial symptoms in persons with PD, but also teaches stu-

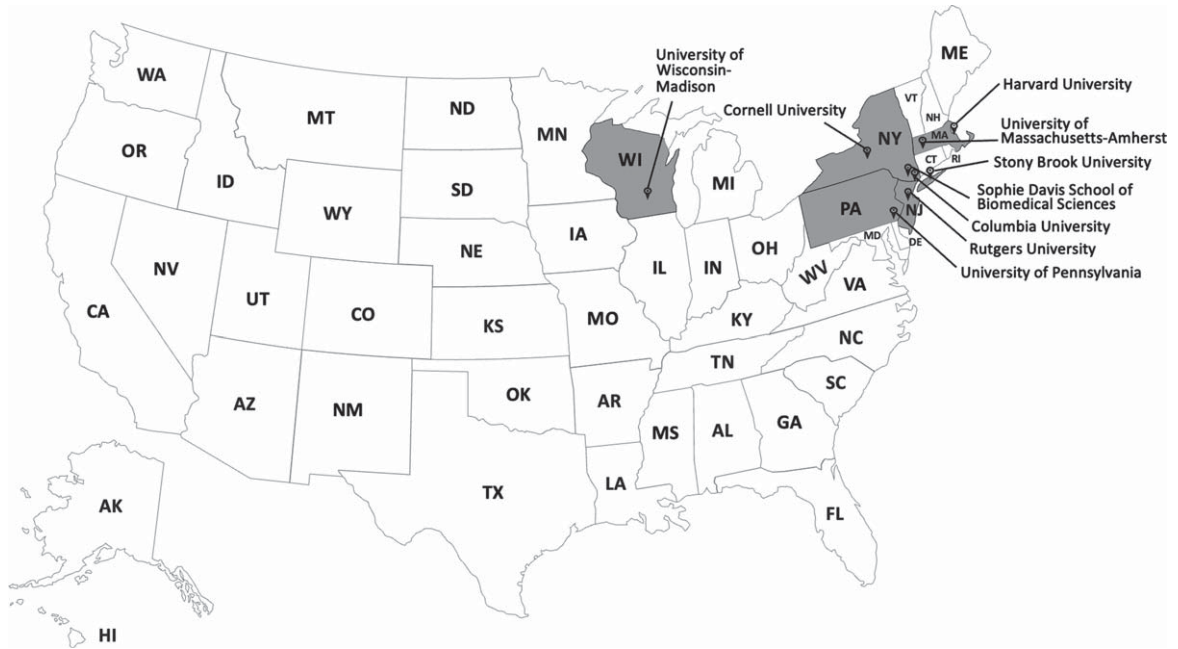


Fig. 1. Parkinson's Pals chapters in the United States (9 chapters as of June 2023).

dents about PD and life with an age-related disorder. We advocate for the creation of similar programs at universities worldwide.

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CONFLICT OF INTEREST

The authors have no conflict of interest to report.

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