



Short Communications

Financial hardship is associated with employment challenges and reduced quality of life in early Parkinson's disease

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ARTICLE INFO

Keywords:

Parkinson's disease

Employment

Disability

Patient reported outcome measures

Financial toxicity

ABSTRACT

Introduction: Motor and nonmotor Parkinson's disease (PD) symptoms can negatively influence employment, which may contribute to financial hardship. This article explores the association between financial hardship, employment challenges, and quality of life in people with early PD.

Methods: We measured financial hardship with a validated summary item (5-point scale, lower score - less hardship) and the Comprehensive Score for Financial Toxicity (0–44, lower score worse toxicity) in a cohort of 60 employed individuals with early PD (<5 years). We used Spearman's Correlations and nonparametric tests to identify associations between financial hardship, demographic characteristics, PD-related factors, employment factors, and quality of life (Neuro-QOL computer adapted measures).

Results: The sample was mostly white (93 %) and male (65 %). The plurality were highly-educated with graduate degrees (42 %). Of the 60 participants, 23 (38 %) reported *a little bit* and 14 (23 %) reported *somewhat or more* hardship. Comprehensive financial toxicity (22.0 ± 8.7) was correlated moderately ($\rho = -0.56$) with the single-item summary score. High financial hardship was associated with reduced confidence in job retention ($\rho = -0.43$, $p = 0.001$) and reduced perceived workplace success ($\rho = -0.352$, $p = 0.006$). Financial hardship was also associated with poorer quality of life in five Neuro-QOL domains: lower extremity function, satisfaction with social roles and activities, depression, anxiety, and stigma ($p < 0.05$).

Conclusion: Financial hardship was common and was associated with employment challenges and poor quality of life. Further work should explore the effects of medical and psychosocial interventions to alleviate financial and employment challenges in individuals with early PD.

Parkinson's disease (PD) can have a significant impact on paid employment, often resulting in reduced hours, leaving the workforce early, lower employment rates, and lower income compared to the general population [1]. Work capacity in people with PD may be reduced by changes in mobility, hand function, cognitive function, and fatigue [2,3]. It is unclear how rehabilitation or other healthcare services can improve employment outcomes in PD.

Loss of employment, medical treatment requiring days off from

work, and the high cost of medications may have negative economic consequences, termed "financial toxicity." [4]. Financial toxicity is associated with lower quality of life, lower patient satisfaction, and non-adherence to treatment in people with cancer [5]. To our knowledge, the relationships between general financial hardship, financial toxicity, employment, and well-being have not been explored in people with PD.

The purpose of this study is to describe the baseline characteristics of what will be a three-year observational cohort study on how healthcare

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<https://doi.org/10.1016/j.prdoa.2023.100225>

Received 3 March 2023; Received in revised form 13 September 2023; Accepted 12 October 2023

Available online 16 October 2023

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services can improve employment outcomes in people with early PD. The objective of this pilot analysis was to explore correlates of baseline financial hardship with demographic, PD-related, and employment variables, and ten Quality of Life in Neurological disorders (Neuro-QOL) scales that included both motor and nonmotor factors. We used the clinically useful single-item financial hardship question as well as the total Comprehensive Score for financial Toxicity (COST) patient reported outcome measures [4].

1. Methods

1.1. Study design

This exploratory analysis used baseline data from the *Parkinson's disease: Intervening Early Concerning Employment (PIECE)* study. PIECE is a prospective, longitudinal, observational study enrolling 60 employed individuals with early PD in the United States to explore the current use of employment support resources in the healthcare system in preparation for future care improvement efforts. We defined early PD diagnosis within the last five years.

Individuals with early PD were recruited from rehabilitation and neurology providers in the greater Chicago and Seattle areas, as well as through a national online education event and related emails through the Parkinson's Foundation between October 2019 and May 2021. Participants respond to phone and online surveys every six months for three years. The study procedures were approved by the Institutional Review Board of Northwestern University. Consent forms were obtained from each study participant.

1.2. Measures

Financial Hardship: The Comprehensive score for financial Toxicity (COST) includes one summary question on financial hardship (question 12): [4] "My Parkinson's disease has been a financial hardship to my family and me." Response options ranged from 0 to 4 (*none, a little bit, somewhat, quite a bit, or very much*). We explored whether this single summary question could be useful for clinicians during their history and physical exams.

Financial Toxicity: The COST measure (see Supplemental Scale 1) is part of the Functional Assessment of Chronic Illness Therapy measurement system that has been validated in patients with cancer. Responses to 11 questions are rated on a 5-point Likert scale (0–4), with the total COST score ranging from 0 to 44. Higher scores indicate better financial well-being, and lower scores indicate more financial toxicity [4].

Demographic, PD-related, and Employment Characteristics: Demographic characteristics included age, education, gender, race, and marital status. PD-related factors were self-reported, including confirmation of diagnosis, years since diagnosis, years since symptom onset, and number of PD-related impairments selected in a multiple choice question (e.g. tremor, walking problems). Number of impairments was determined using a multiple choice question with eight activities related to PD and work (e.g. walking, computer use, speaking or voice projection) and option to write in additional factors. Employment factors included average hours of work per week, number of jobs currently held, estimated income, workplace self-efficacy (adapted General Self Efficacy Scale [6] by adding "at my job" to the end of each statement; Supplemental Scale 2), and perceived workplace support (Modified Work APGAR [7]; Supplemental Scale 3). Additionally, perceived workplace success, flexibility, and confidence were measured using single-item, 4-point scales where higher values indicate better outcomes (more perceived success, more flexibility, more confidence (Supplemental Scale 4). To estimate participants' income, we matched their primary job title, field, and task with the U.S. Occupational Information Network (O*NET) system (<https://www.onetcenter.org>). O*NET was developed by the US Department of Labor and provides median wages for 1,000 occupations based on Bureau of Labor Statistics 2020 wage data.

Self-Reported Function and Quality of Life: We included 9 Quality of Life in Neurological disorders (Neuro-QOL) scales: lower extremity function, upper extremity function, cognitive function, ability to participate in social roles and activities, satisfaction with social roles and activities, depression, anxiety, fatigue, and stigma [8]. All were administered as computer adapted tests in Research Electronic Data Capture (REDCap). These brief comprehensive measures are validated in PD [8]. Neuro-QOL scores are population-based and use a T-score metric.

Statistical analyses: Association between financial hardship and financial toxicity was examined using a Spearman correlation coefficient. Due to significant correlation and greater clinical utility, the remaining analyses were only reported on the single financial hardship question.

Demographic, PD, and employment characteristics were summarized using descriptive statistics. Data are summarized by the full cohort ($n = 60$), as well as financial hardship level groupings. Because of a skewed distribution of financial hardship scores, we collapsed the 5-point scale to a 3-point scale, combining participants who reported *somewhat* ($n = 7$), *quite a bit* ($n = 4$), and *very much* ($n = 3$) hardship into a single group *somewhat or more*. We conducted a sensitivity analysis comparing the 3-point scale compared to 4- and 5-point scales, and determined that results were similar.

Differences between financial hardship groups and categorical demographic and employment variables were analyzed using Fisher's exact test because of low cell counts (<5). Associations with ordinal demographic and employment variables were assessed using Spearman's correlation coefficient. We also completed Mantel-Haenszel tests of linear association, which produced results similar to Spearman's rho test, and therefore only Spearman's rho and the associated p-values are reported. Kruskal-Wallis tests were used to assess association between continuously measured variables. We report unadjusted p-values due to the exploratory nature of this analysis. The relationships between financial hardship and each of the 10 Neuro-QOL domains were examined using Kruskal-Wallis tests, with *post hoc* Dunn-Bonferroni tests. All analyses were performed using R statistical software.

2. Results

Table 1 describes the sample's demographic, PD, and employment characteristics at baseline. Most of the participants were male (65 %), white (93 %), and highly-educated (graduate degree or higher, 42 %). All participants were employed. A majority (61 %) of the 60 participants reported at least some financial hardship, with 23 (38 %) reporting a *little bit* and 14 (23 %) reporting *somewhat or more* hardship.

The average medical financial toxicity (COST) score was 22.0 ± 8.7 (range 4–42 out of 44). The single financial hardship score was moderately correlated with medical financial toxicity ($\rho = -0.56$, $p < 0.01$), and negatively associated with employment characteristics, including perceived workplace success ($\rho = -0.35$, $p = 0.006$), flexibility ($\rho = -0.27$, $p = 0.041$), and confidence in job retention ($\rho = -0.43$, $p = 0.001$).

Table 2 shows that five of the Neuro-QOL domains were significantly associated with financial hardship: lower extremity function ($p = 0.019$), depression ($p = 0.023$), satisfaction with social roles and activities ($p = 0.028$), anxiety ($p = 0.023$), and stigma ($p = 0.010$). Pairwise comparisons indicated that those with any financial hardship (a little bit, somewhat or more) had lower quality of life related to lower extremity function. They also revealed that only *somewhat or more* financial hardship was related to higher levels of anxiety and depression. Despite a significant overall relationship between financial hardship and stigma, the pairwise comparisons were not significant.

3. Discussion

This study revealed a high prevalence of financial hardship in people

Table 1

. Demographic, PD-related, and Employment variables by level of self-reported financial hardship from the Comprehensive Score for financial Toxicity (COST).

Table 1: Demographic, PD-related, and Employment variables by level of self-reported financial hardship from the Comprehensive Score for financial Toxicity (COST)							
		Full cohort (n=60) Mean ± SD or n (%)	Financial Hardship Level			P-value	Spearman's rho
			None (n=23)	Little Bit (n=23)	Somewhat or more (n=14)		
Demographic Variables	Age	56.5 ± 7.7	58.1 ± 6.6	55.1 ± 7.4	56.3 ± 9.7	0.352 [†]	-0.12
	<50	12 (20%)	3 (13%)	6 (26%)	3 (22%)		
	50-64	39 (65%)	16 (70%)	14 (61%)	9 (64%)		
	65+	9 (15%)	4 (17%)	3 (13%)	2 (14%)	0.119 [†]	0.20
	Education						
	High school/Associate's degree	12 (20%)	6 (26%)	4 (17%)	2 (14%)		
	Bachelor's degree	23 (38%)	10 (43%)	9 (39%)	4 (29%)	0.648 [‡]	
	Graduate/professional degree	25 (42%)	7 (31%)	10 (43%)	8 (57%)		
	Gender					0.535 [‡]	
	Male	39 (65%)	13 (57%)	16 (70%)	10 (71%)		
Female	21 (35%)	10 (43%)	7 (30%)	4 (29%)	0.632 [§]		
Race							
White	56 (93%)	22 (96%)	22 (96%)	12 (86%)			
Non-white	4 (7%)	1 (4%)	1 (4%)	2 (14%)	0.632 [§]		
Marital status							
Married	43 (72%)	16 (70%)	18 (78%)	9 (64%)			
Unmarried/Other	16 (27%)	7 (30%)	5 (22%)	5 (36%)			
PD-related Variables	Years since diagnosis	2.03 ± 1.43	1.65 ± 1.21	2.27 ± 1.47	2.24 ± 1.67	0.278 [¶]	
	Years since symptom onset	3.90 ± 2.66	3.64 ± 3.14	3.92 ± 1.98	4.29 ± 2.91	0.621 [¶]	
	Number of impairments	4.55 ± 2.31	3.82 ± 2.06	4.87 ± 2.49	5.21 ± 2.22	0.171 [¶]	
Employment Variables	Average hours of work per week	41.3 ± 9.79	42.13 ± 10.59	41.26 ± 10.03	39.86 ± 8.47	0.494 [¶]	
	Number of jobs					0.513 [‡]	
	One	53 (88%)	21 (91%)	21 (91%)	11 (79%)		
	Two or more	7 (12%)	2 (9%)	2 (9%)	3 (21%)	0.332 [§]	
	Estimated income**	\$98,533.85 ± \$48,184.00	\$97,931.07 ± \$50,414.41	\$102,498.10 ± \$49,916.21	\$93,011.88 ± \$44,237.84		
	Perceived workplace success: "To what extent do you feel you are successful at work?"					0.006 [†]	-0.352
	Very successful	25 (42%)	12 (52%)	11 (48%)	2 (14%)	0.041 [†]	-0.27
	Moderately successful	31 (52%)	11 (48%)	12 (52%)	8 (57%)		
	Moderately unsuccessful	4 (7%)	0 (0%)	0 (0%)	4 (29%)		
	Perceived work flexibility: "To what extent do you feel like you have the flexibility to accommodate your PD symptoms on your own at work?"					0.001 [†]	-0.43
	To a great extent	33 (65%)	15 (65%)	14 (61%)	4 (29%)		
	Somewhat	22 (37%)	7 (30%)	8 (35%)	7 (50%)		
	A little	2 (3%)	0 (0%)	0 (0%)	2 (14%)		
	Not at all	3 (5%)	1 (4%)	1 (4%)	1 (7%)		
	Job retention confidence: "How confident are you that you will be able to retain your job for as long as you would like?"					0.056 [¶]	
Very confident	12 (20%)	7 (30%)	5 (22%)	0 (0%)			
Somewhat confident	33 (55%)	13 (57%)	15 (65%)	5 (36%)			
Somewhat not confident	11 (18%)	3 (13%)	2 (9%)	6 (43%)			
Very not confident	4 (7%)	0 (0%)	1 (4%)	3 (21%)			
Self-efficacy in the workplace Modified (work-related) General Self-Efficacy Scale	33.8 ± 4.78	34.78 ± 5.33	34.30 ± 3.61	31.21 ± 4.90	0.075 [¶]		
Perceived workplace support Modified Work APGAR (n=56)	9.5 ± 3.38	9.23 ± 2.23	10.05 ± 3.05	12.21 ± 2.73	0.075 [¶]		

Definition: PD, Parkinson's disease.

* Statistically significant at alpha < 0.05.

Statistical technique: [†] Mantel-Haenszel; [‡] Fisher's Exact; [§] Chi-square; [¶] Kruskal-Wallis

** Based on gross estimated income for job title or most similar job title, job field, and job tasks as described by the U.S Occupational Information Network (O*NET), adjusted by participant reported average hours worked per week

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Statistical technique: † Mantel-Haenszel; ‡ Fisher's Exact; § Chi-square; ¶ Kruskal-Wallis.

†† Based on gross estimated income for job title or most similar job title, job field, and job tasks as described by the U.S Occupational Information Network (O*NET), adjusted by participant reported average hours worked per week.

Table 2
NeuroQOL domains by level of self-reported financial hardship from the Comprehensive Score for financial Toxicity (COST).

		Full cohort (n = 60) Mean ± SD	Financial Hardship Level			P-value
			None (n = 23)	Little Bit (n = 23)	Somewhat or more (n = 14)	
NeuroQOL Domains	Lower extremity function	51.5 ± 7.6	54.8 ± 6.1 ^{a,b}	49.7 ± 8.0 ^a	49.2 ± 7.9 ^b	0.019*
	Upper extremity function	42.5 ± 7.2	43.8 ± 6.0	41.7 ± 7.6	41.9 ± 8.2	0.111
	Cognitive function	49.0 ± 7.7	50.1 ± 6.7	49.3 ± 6.5	46.8 ± 10.5	0.354
	Ability to participate in social roles and activities	52.3 ± 6.8	54.5 ± 5.9	51.2 ± 6.5	50.5 ± 7.9	0.060
	Satisfaction with social roles and activities	48.7 ± 5.7	50.6 ± 5.4	47.9 ± 4.9	47.1 ± 7.0	0.028*
	Depression	48.7 ± 5.5	47.0 ± 6.0 ^a	48.3 ± 4.1 ^b	52.2 ± 5.5 ^{a,b}	0.023*
	Anxiety	52.6 ± 6.7	50.9 ± 8.0 ^a	51.4 ± 4.2 ^b	57.4 ± 6.0 ^{a,b}	0.023*
	Fatigue	47.7 ± 7.2	46.5 ± 8.0	48.9 ± 6.3	47.6 ± 7.4	0.313
	Stigma	49.9 ± 5.1	48.2 ± 5.7	49.6 ± 3.3	53.0 ± 5.2	0.010*

Definition: NeuroQOL, Quality of Life in Neurological Disorders Measures

* Statistically significant at alpha < 0.05. When Kruskal-Wallis tests were significant, post-hoc pairwise Dunn-Bonferroni tests were used to perform pairwise comparisons. When significant, pairs are noted with superscript letters.

with early PD, which was associated with employment concerns. More financial hardship was associated with lower self-reported lower extremity function, worse self-reported nonmotor symptoms (depression, anxiety), and less satisfaction with social roles and activities. Although all participants were in the first five years since PD diagnosis, their average comprehensive medical financial toxicity score was similar to individuals with advanced cancer [4,5]. There were no significant associations between financial hardship and demographic characteristics, which differs from larger scale cancer research [4,5], likely due to the relatively highly educated, higher income, white sample. Yet, this exploratory study provides valuable data supporting the importance of continuing research on employment and financial security with greater racial, ethnic, and socioeconomic diversity.

We observed significant correlations between PD-related financial hardship and employment factors, specifically confidence in job retention and perceived workplace success. It could be important for the healthcare team to ask their patients about employment stability and workplace success to better identify and address financial stress in patients with early PD. The larger PIECE trial will explore employment challenges and interventions to address these challenges.

Financial hardship was significantly associated with four nonmotor and one motor Neuro-QOL domains: satisfaction with social roles and activities, depression, anxiety, stigma, and lower extremity function. The potential impact of non-motor symptoms on financial hardship are similar to other employment-related research showing that nonmotor symptoms, including depression, anxiety, and overall psychiatric distress, but not PD severity, were associated with leaving the workforce [2]. Additionally, lower extremity motor impairments such as gait and balance deficits may lead to difficulty performing work functions and can be less responsive to medications, making medical management difficult [9]. Future research should explore the impact of early assessment and treatment of depression and anxiety in early PD, as well as early physical therapy for lower extremity function, on financial hardship and employment-related concerns.

Our analysis focused on the simple single financial hardship question as a clinically feasible tool, rather than the full COST score. Despite the prevalence of financial hardship observed in this sample, there is little research on financial hardship in PD. One qualitative study indicated that financial hardship, particularly related to loss of employment by the individual with PD or their care partner, was a theme suggesting the

importance of palliative approaches in PD [10]. However, similar to findings in cancer, financial toxicity could be more common in younger, working individuals [5]. The moderate correlation between financial hardship and financial toxicity in this sample indicates that research is needed to understand better the contributions of medically-related financial concerns to financial hardship. The multifactorial COST score assesses numerous areas of medical expenses, such as out-of-pocket medication and rehabilitation costs, employment, and savings [4]. Larger studies should explore the contributions of different COST score items on financial hardship.

Medical management of individuals with early PD should include screenings of financial hardship and workplace challenges. Neurologists should consider inquiring about work, work performance, work limitations, and financial hardship. Responses to a single question about if PD has created financial hardship for the individual or their family could trigger referral to an appropriate counseling service. Counseling options include social workers, certified rehabilitation counselors, and vocational rehabilitation counseling to support job retention or to help an individual prepare for future changes in employment status. Helping people with early PD to plan ahead could reduce financial stress and employment crises such as threat of termination [11].

4. Limitations

Generalizability of this exploratory study's findings is limited due to a small, homogeneous sample that over-represents white and highly educated individuals, as is common in PD research [12]. We did not collect comorbidities or actual personal or household income at baseline, but our estimation of participants' income based on their job titles indicates relatively high incomes, limiting our ability to generalize results to people with greater risk for financial distress due to low income, less household support, or multiple comorbidities. Lower income individuals with PD may experience even greater financial hardship. Future research in a heterogeneous sample should measure associations between financial hardship and race, ethnicity, education, comorbidities, and actual personal or household income. Finally, the exploratory nature of our study and multiple comparisons without corrections may inflate the risk of Type I error. Future studies could build on these findings as larger more representative samples will allow for multivariable analyses that will help improve our understanding of the

relationships between financial hardship, medically-related financial toxicity, quality of life, and employment factors in people with PD.

5. Conclusion

Financial hardship is common in employed adults with PD, even those with post-secondary education. Clinicians should consider asking people with early PD about their financial hardship and employment. Identifying financial hardship in people with early PD who are employed could trigger the use of medical, social work, or vocational rehabilitation counseling interventions, which could improve quality of life.

Funding Sources: Funding for this work was provided by the 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. 90RTEM0001-01).

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We would like to acknowledge Laura Stoff, MPH; Ella Nettin, BS; Kevin Smaller, BS; and Paulo Aco, MS for their assistance with the PIECE study.

Financial Disclosures for the previous 12 months: Over the last 12 Months, Dr. Rafferty received funding from Office of the Assistant Secretary of Defense for Health Affairs United States Department of Defense CDRMP Neurotoxin Exposure Treatment Parkinson's (W81XWH-19-PRP-EIRA, PI Rafferty), National Institutes of Health's National Institute on Aging (P30AG059988, PI Linder/Wolf), Parkinson's Foundation, Eunice Kennedy Shriver National Institute of Child Health and Human Development's National Center on Medical Rehabilitation Research (1P2CHD101899-01, PI Lieber/Rymer), National Institute on Disability, Independent Living, and Rehabilitation Research Sensor Technology RERC-90REGE0010 PI Rymer/Jayaraman). Danny Bega, MD is on the speaker's bureau for Teva Pharmaceuticals, Neurocrine Biosciences, Supernus Pharmaceuticals, Acorda Therapeutics, AbbVie, and Kyowa Kirin. He has served as a consultant for Teva, Guidepoint, GE Healthcare, LEK Consulting, Deerfield Institute, Alexion Pharmaceuticals, Acel Health, ACADIA, WebMD, Atheneum, and Clearview Consulting. He has received honoraria from the American Academy of Neurology, and the American Neurological Association. He has received grants from the Huntington Disease Society of America and the Parkinson Foundation.

The content is solely the responsibility of the authors and does not represent the official views of any funders.

Funding sources

This work was supported by the 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).

Disclosures

Funding Sources: Funding for this work was provided by the 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. 90RTEM0001-01). The authors declare that there are no conflicts of interest relevant to this work.

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Ethical Compliance Statement

The Northwestern University Institutional Review Board approved this study. Participants provided written informed consent, obtained by mail or email (e-signature). We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.prdoa.2023.100225>.

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