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Concealment of Parkinsons disease prevalence and impact on health and quality of life

Badera Naamneh-Abuelhija[1,7], Michal Kafri[2,7]✉, Meir Kestenbaum[3,4], Shmuel Giveon[5], Sharon Kamah[6], Sarit Shved[5] & Galit Yogev-Seligmann[1]

Concealment of diagnosis in chronic conditions has proven benefits as a coping strategy to avoid stigmatization and discrimination and allows people to be treated "normally" by society. However, concealment is related to negative health, physical, quality of life outcomes, exhaustion and loneliness. In addition, diagnosis concealment has a detrimental impact on self-management behaviors. In Parkinson's disease (PD), information regarding the aspects related to concealment is limited. A better understanding of the contributors and consequences of concealment in PD may facilitate the development of strategies to support patients who conceal. We conducted a cross-sectional study to explore concealment in PD by examining rates of diagnosis concealment and associations of concealment with socio-demographic factors, self-management behaviors, stigma, social support, and quality of life. The study was conducted at an outpatient movement disorders clinic or at the participant's home, at the participant's preference. One hundred and fifty people with PD completed questionnaires assessing disclosure of their diagnosis, socio-demographic variables, disease severity, self-management behaviors (knowledge, activation, exercise), stigma, social support, and health-related quality of life (HRQoL). Differences between disclosers and concealers were analyzed and associations between disclosure, stigma, social support and emotional aspects of HRQoL were tested using mediation models. Close to one-quarter (22.7%) conceal their PD diagnosis from their family. Concealers were more often women, Muslim, religious, and lacking academic degrees compared to disclosers. Concealers also had lower patient activation, and less social support. They engaged less in physical activity and experienced greater stigma. Concealment had a significant total effect on lower emotional aspects of HRQoL, mediated by greater stigma but not by social support. Healthcare providers should be attuned to both the prevalence of PD diagnosis concealment and its detrimental impacts on patients' emotional support needs and facilitation of health behaviors. Moreover, treating neurologists should deliver diagnoses carefully, discuss disclosure consequences, maintain open dialogue on concealment, and advise informing family. Interventions targeting stigma reduction in this population may have downstream benefits for emotional aspects of HRQoL.

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Keywords Disease disclosure, Parkinson's disease, Quality of life, Social support, Stigma

Abbreviations

ADL	Activities of daily living
HRQoL	Health-related quality of life
IPAQ-SHORT	International Physical Activity Questionnaire
KPDQ	Knowledge about Parkinson's Disease Questionnaire
MDS-UPDRS	Unified Parkinson's Disease Rating Scale
METs	Metabolic equivalents
MHLOC	Multidimensional Health Locus of Control Scale

[1]Department of Occupational Therapy, Faculty of Social Welfare & Health Sciences, University of Haifa, Haifa, Israel. [2]Department of Physical Therapy, Faculty of Social Welfare & Health Sciences, University of Haifa, Mount Carmel, 3103301 Haifa, Israel. [3]Sackler School of Medicine, Tel-Aviv University, Tel-Aviv, Israel. [4]Neurology Department, Meir Medical Center, Kfar-Saba, Israel. [5]Sharon Shomron District, Clalit Health Services, Netanya, Israel. [6]Quality and Safety Department, Carmel Medical Center, Haifa, Israel. [7]These authors contributed equally: Badera Naamneh-Abuelhija and Michal Kafri. ✉email: kafri.michal@gmail.com

MMSE	Mini-mental state exam
MSPSS	Multidimensional scale of perceived social support
PAM-13	Patient activation measure
PD	Parkinson's disease
PDQ-39	Parkinson's Disease Questionnaire-39
PwP	People with PD

People with chronic diseases often use various methods to conceal their diagnosis from co-workers, friends, or family members, such as maintaining social distance, lying about appointments or meetings related to the concealed diagnosis, or avoiding conversations about it. Rates of concealment range from 7 to 69% and vary across chronic conditions such as Multiple Sclerosis[1,2], HIV[3], and mental illness[4]. Disclosure is generally higher when it comes to partners or parents but tends to decrease when it involves other family members, friends, or co-workers[4–6].

Concealment of diagnosis is commonly considered as a strategy for minimizing the impact of stigmatization[7]. Stigma is a situation in which an individual possessing an attribute that is profoundly discredited by their society faces social rejection because of this attribute[8,9]. Stigma can be understood as a process in which the responses of others damage one's identity[8]. Moreover, the definition of stigma refers not only to society's responses to individual attributes (termed enacted stigma) but also to a self-stigma process, in which individuals internalize negative beliefs from others and isolate themselves due to embarrassment caused by the anticipated responses of others to the abovementioned attributes[8,10]. A vast literature confirms associations of stigmatization with poor health, psychological distress, and reduced health-related quality of life (HRQoL)[11].

Concealment may have proven benefits as a coping strategy to avoid stigmatization and discrimination for individuals whose stigmatizing attribute is not visible, which allows them to be considered "normal" by society[7,12,13]. However, when one's medical symptoms are visible, disclosure is associated with greater support from others and better health outcomes and well-being[4,6,14,15], despite the risk of stigmatization.

Furthermore, concealment in general is related to negative health and HRQoL outcomes, poorer physical and psychological HRQoL[16] exhaustion and loneliness[17], and stress and fear of being discovered[18] Concealing information has also been found to have a detrimental impact on self-management. This is because the individual is subsequently burdened exclusively with the responsibility for self-management despite the fact that they may even struggle to perform certain essential self-management activities, such as exercise or maintaining a proper diet[19–21].

PD is a common, progressive neurodegenerative disorder, with global incidence estimates ranging from 5 to 35 new cases per 100,000 annually[22,23]. Its etiology is likely due to a combination of factors, including aging, genetic susceptibility, and environmental exposures[24]. Key motor symptoms include tremor, rigidity, bradykinesia, and postural instability, making daily tasks like walking, turning, and writing difficult[25]. Cognitive impairments, including executive dysfunction, visuospatial deficits, and attention and memory problems, worsen over time[26]. Additionally, many patients face psychological challenges, such as anxiety, depression, and social withdrawal[27–29].

PD is accompanied by both enacted stigma and self-stigma[8,30]. As the disease progresses and symptoms become visible, it becomes almost impossible to conceal the disease[8]. Enacted stigma may manifest as staring or avoiding the visible signs of the disease (e.g., tremors, mask face, abnormal movements), as well as disruptions of social relationships[8,31]. Enacted stigma is also associated with stereotypes and misconceptions about the disease (e.g., PD is a disease of old people[32], people with PD (PwP) are frail[33,34], and are considered unreliable and cognitively impaired if they suffer from hallucinations[35]. Self-stigma in PD[8,30,34,36,37] is caused by embarrassment over symptoms[8,33,34] and physical dependence, and results in self-isolation[8,33,34]. Similarly to other conditions, stigma in PD is associated with reduced HRQoL[31,36,38] and emotional distress[37].

Although stigma's proposed role as a main determinant of concealment has been discussed extensively, we find few quantitative studies that explore concealment: The issue is mainly discussed in qualitative studies[32,35] and patients' forums[39]. In one study[40], time from diagnosis to disclosure was assessed among 101 patients with PD. Most of the participants in this study disclosed the diagnosis of PD to their spouses within one month of receiving their diagnosis and 25% delayed the disclosure in their workplace for more than one year after the diagnosis.

As there is only limited knowledge about diagnosis concealment in Parkinson's disease, in the current study we aimed to expand the understanding of concealment and its consequences in PD, and specifically to:

1. explore the proportion of patients with PD who conceal their diagnosis from their family.
2. investigate differences in socio-demographic, clinical, self-management and HRQoL variables between these patients who conceal their diagnosis of PD and those who do not.
3. test associations between concealment and emotional aspects of HRQoL and examine whether stigma or social support mediate these associations.

Method

Study design

This is a cross-sectional study with convenience sampling. This study is part of a larger study exploring self-management in PD.

Study sample

Participants: Individuals with a diagnosis of PD according to the International Classification of Diseases 9th Revision (ICD 9 code = 332)[41], who reside in the Sharon-Shomron district of "Clalit" Healthcare Services were

recruited from primary care clinics and the "Clalit" Ambulatory Movement Disorder Clinic at Meir Medical Center. Patients were included in the study if they had been diagnosed with PD, were older than18 years, and resided in the community. Exclusion criteria included at least one acute hospitalization in the last 3 months, severe co-morbidities that affect daily living, mini-mental state exam[42] (MMSE) score < 20, and patients who are not deemed competent to sign a consent form due to mental conditions. Study procedures were performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of the Faculty of Social Welfare & Health Sciences, University of Haifa (approval number 548/20) and the Helsinki Committee of Clalit Health Services (approval number 0128–19-COM1). All participants signed an informed consent form prior to entering the study.

Procedure

Eligible participants were referred by family doctors or neurologists to the research assistant. The research assistant conducted one 90-min meeting with each participant at the clinic or at the participant's home, at the participant's preference. Participants completed a detailed questionnaire (described below) in their preferred language.

Study variables

Disclosure was assessed by one question regarding the disclosure of the disease to family members ("Does your nuclear or extended family know that you have Parkinson's disease?" Answers to this question were Yes/No).

Personal characteristics included (a) socio-demographics, (b) disease-related variables, (c) self-management behaviors, and HRQoL.

Socio-demographic variables

Socio-demographic variables included age, ethnicity (Arab/ Jew), gender, education (≤ 8 years, 8–12 years, ≥ 13 years), Academic degree (yes/no), degree of religiosity (secular, conservative, orthodox), social support, and health locus of control beliefs. Social support was assessed using the 12-item Multidimensional Scale of Perceived Social Support (MSPSS)[43], on which participants rated their agreement on a Likert-type scale from 1(*very strongly disagree*) to 7 (*very strongly agree*). The MSPSS is comprised of 3 subscales assessing support from significant other, family, and friends. The mean scale score ranges from 1 to 7, while a score of 7 is considered high support. The MSPSS has good internal and test–retest reliability as well as moderate construct validity[43].

Health locus of control beliefs was assessed using Multidimensional Health Locus of Control Scale (MHLOC)[44], an 18-item self-report measure intended for use in the general population to assess an individual's belief on what influences health. The scale assesses three dimensions: (a) internal belief (My health is influenced by my own choices and behaviors), (b) chance belief (My health is influenced by chance or fate and neither me nor my doctor have much influence on it), and (c) powerful others belief (My health is dependent on the competence of my doctor, my health is dependent on the behavior of family members, etc.). For each dimension (Internal, Powerful Others, Chance), scores are obtained by summing the responses to the relevant items. Scores range from 6 (if all items are rated as 1) to 36 (if all items are rated as 6). Higher scores in a subscale indicate stronger beliefs in that particular locus of control domain. The MHLOC subscales generally demonstrate acceptable internal consistency, test–retest reliability, and content validity in multiple studies[45,46].

Clinical (disease-related) variables

The following clinical (i.e., disease-related) variables were assessed: Disease severity was assessed using the Unified Parkinson's Disease Rating Scale (MDS-UPDRS)[47] Part II, which contain items assessing the effect of the motor signs on activities of daily living. This scale contains 13 items that are rated from 0 to 4, with a maximum score of 52. A higher score indicates worse effects of motor signs. The MDS-UPDRS demonstrated high internal consistency, test–retest reliability, and content validity[48,49].

Cognitive impairment was screened using the MMSE[42]. A score of < 24 (of a maximum of 30) is the generally accepted cutoff indicating the presence of minimal cognitive impairment, and a score of < 20 suggests moderate dementia. The MMSE was used for the inclusion criteria and for a brief evaluation of cognitive status. A score of 20 and below was used as an exclusion criterion. The MMSE was originally validated with high reliability and strong validity for differentiating cognitive impairments, including dementia, with practical application in clinical settings. Cronbach's alpha indicated high internal consistency[42].

Self-management variables

Self-management behaviors were assessed using the following questionnaires: Knowledge about Parkinson's Disease Questionnaire (KPDQ)[50] tests general knowledge regarding PD diagnosis, etiology, epidemiology, and treatment. It consists of two parts that are scored independently: recognition of PD symptoms (4 motor, 10 non-motor symptoms) and 10 True/False statements testing general knowledge of PD. The maximum scores for parts 1 and 2 of the questionnaire are 14 and 10 respectively with higher scores indicating higher recognition of the disease symptoms and more knowledge about the disease. To the best of our knowledge, no study has been conducted to examine the psychometric properties of the tool. However, the tool has been used in research to assess the level of knowledge about Parkinson's disease among different populations[50–52].

Patient activation was assessed using the Patient Activation Measure (PAM-13)[53]. The construct of patient activation encompasses the psychological dimensions of health behaviors, including individuals' understanding, abilities, and self-assurance in handling their well-being. Elevated levels of patient activation signify greater preparedness to embrace behaviors that uphold or enhance health. In contrast to those with low activation levels, individuals with high activation levels are more inclined to engage in health-promoting behaviors such as

sustaining physical activity and are consequently more prone to achieve improved health outcomes[53]. The PAM-13 is a self-reported, validated, and licensed tool to measure a patient's knowledge, skills, and confidence for self-management[53]. We used a validated, licensed Hebrew version of the PAM-13 supplied by Insignia Health https://www.insigniahealth.com/products/pam-survey), which holds the copyrights to the questionnaire. It consists of 13 statements rated on a four-point Likert scale of level of agreement. The PAM-13 score is transformed into a 0–100 continuous scale according to a licensed conversion table (Insignia Health)[54]. The overall score captures the extent to which people feel engaged and confident in taking care of their health conditions, with higher scores indicating stronger activation[53]. The PAM-13 demonstrates high internal and strong construct validity[54–56].

Physical activity was assessed using the International Physical Activity Questionnaire- IPAQ-SHORT[57,58]. Respondents report the number of days and time spent in the last seven days in four categories: vigorous activity, moderate activity, walking, and sitting. Total physical activity is calculated as the sum of Walking + Moderate + Vigorous metabolic equivalent (MET) minutes per week.

Total of less than 600 MET-min/week is considered low activity, 600 to 3000 MET-min/week is considered moderate activity, and more than 3000 MET-min/week is considered as high activity[57,58]. The IPAQ-SF has demonstrated good test–retest reliability, although Concurrent validity with accelerometer data is moderate[59].

Quality of life variables

HRQoL was measured by the Parkinson's Disease Questionnaire-39 (PDQ-39)[60]. This 39-item questionnaire is the most frequently used patient-reported disease-specific measure of health status and HRQoL in PD. It assesses how often PwP experiences difficulties across eight dimensions of daily living, including relationships, social situations, stigma, and communication. It also assesses the impact of Parkinson's on specific dimensions of functioning and emotional well-being. Each dimension is calculated by a formula taking into account the number of items related to the dimension. The total PDQ-39 score is expressed as a percentage, with higher scores indicating a greater negative impact on quality of life. The PDQ-39 demonstrates high internal consistency across most domains, high internal consistency and good construct validity[60,61].

Data analysis

We tested the data for normal distribution using the Shapiro–Wilk test. Data across all variables was not normally distributed, and analysis was conducted accordingly. Differences in variables between disclosing and concealing participants were assessed using chi-square tests for nominal or ordinal variables and Mann–Whitney *U* tests for continuous variables, with $p < 0.05$. Post hoc analysis with Bonferroni correction was conducted to determine which levels of the variable differed significantly for categorical variables with more than two levels. To account for multiple comparisons in the analysis of the self-management and HRQoL, we applied the Benjamini-Hochberg (BH) correction to control the false discovery rate. The adjusted alpha level was calculated for each variable using the formula: adjusted alpha = Adjusted Alpha = α/m X r, where α is the original significance threshold (0.05), m is the total number of comparisons (15), and r is the rank of the p-value (9). Variables with p-values below the BH adjusted alpha were considered statistically significant. This method provides a more stringent criterion for significance in the context of multiple testing.

To test associations between concealment and HRQoL, and whether stigma or social support mediates these associations, we conducted a mediation analysis using Hayes' Process Macro Model 4[62]. HRQoL and stigma were represented in the model by the "emotional well-being" and "stigma" dimensions of the PDQ-39, respectively. Emotional well-being reflects psychological aspects of quality of life in Parkinson's disease including depression and anxiety[63].

Social support was represented by the total MSPSS score.

Results

A total of 150 PwP were recruited, the "disclosing" group consisted of 116 PwP and the concealing group consisted of 43 PwP. The proportion of PwP concealing their diagnosis was 22.66%. The mean age was 73.69 ± 9.17 years in the disclosing group and 70.81 ± 10.72 years in the concealing group ($p = 0.132$). The mean disease duration was similar between groups, with 9.56 ± 8.15 years in the disclosing group and 8.12 ± 6.12 years in the concealing group ($p = 0.356$).

Socio-demographic variables

Table 1 presents the socio-demographic variables and differences between the groups. The concealing group contained a higher prevalence of women, Muslims, people who identified as religious, and people with no academic degree. The disclosing group contained a higher prevalence of men, Jews, people who identified conservative or secular, and people with an academic degree. They also reported higher levels of social support. There was no difference between the groups in health locus of control.

The only categorical variable (with more than 2 levels in the between-groups comparison) that was significant in the between-groups comparison was the degree of religiosity. Post-hoc analysis revealed that the percentage of religious PwP was higher in the concealing group, whereas the percentage of secular and conservative PwP was higher in the disclosing group.

Clinical variables

Disclosing and concealing patients did not differ in disease severity as measured by MDS-UPDRS part II scores (Disclosing: median = 19.50 (IQR 8.00–33.00), concealing: median = 20.50 (IQR 8.00–35.00)) and MMSE scores (disclosing: median = 28.50 (IQR 25.25–30.00), concealing: median = 26.50 (IQR 24.00–30.00)).

		Disclosing (n = 116) n (%) or mean ± SD or median (25–75% IQR)	Concealing (n = 34) n (%) or mean ± SD or median (25–75% IQR)	χ^2 (DF), p Cramer's V or p
Age		73.69 ± 9.17	70.81 ± 10.72	p = 0.132
Disease duration		9.56 ± 8.15	8.12 ± 6.12	p = 0.356
Sex	Male	74 (63.8%)	14 (41.2%)	χ^2 (1) = 5.55, p = 0.019 0.19
	Female	42 (36.2%)	20 (58.8%)	
Marital status	Married	88 (75.9%)	24 (70.6%)	χ^2 (2) = 0.41, p = 0.813
	Widowed	16 (13.8%)	6 (17.6%)	
	Divorced	12 (10.3%|)	4 (11.8%)	
Religion	Jewish	101 (87.1%)	18 (52.9%)	χ^2 (2) = 18.81, p > 0.001 0.35
	Muslim	15 (12.9%)	16 (47.1%)	
Degree of religiosity	Secular	59 (50.9%)	9 (26.5%)	χ^2 (3) = 23.27, p < 0.001 0.39
	Conservative	37 (31.9%)	5 (14.7%)	
	Religious	20 (17.2%)	20 (58.8%)	
Education	> 12 years	63 (54.8%)	10 (32.3%)	χ^2 (2) = 5.82, p = 0.054 0.2
	8–12 years	43 (37.4%)	19 (61.3%)	
	< 8 years	9 (7.8%)	2 (6.5%)	
Academic degree	Yes	51 (44%)	8 (23.5%)	χ^2 (1) = 4.602, p = 0.032
	No	65 (56%)	26 (76.5%)	
MSPSS score		5.71 (5- 6.54)	4.96 (4.15–6.02)	p = 0.015
MHLOC (internal)		21.50 (17.25–26.75)	22 (14.00–25.25)	p = 0.326
MHLOC (chance)		16.00 (11.00–24.75)	18.50 (12.00–29.00)	p = 0.328
MHLOC (powerful others)		26.50 (22.25–31.00)	27.50 (23.00–33.00)	p = 0.388

Table 1. Socio-demographic variables and health-related attitudes. DF, Degrees of freedom; IQR, Inter-quartile range; MHLOC, Multidimensional Health Locus of Control; SD, Standard deviation.

Self-management behaviors	Disclosing Median (25–75% IQR)	Concealing Median (25–75% IQR)	Sig.
KPDQ recognition of symptoms	9.00 (7.00–12.00)	8.00 (5.75–10.25)	0.054
KPDQ true/false	75.00 (60.00–90.00)	65.00 (50.00–80.00)	0.029
IPAQ total score (METs)	678.00 (151.38–1292.25)	33.00 (0–762)	0.004*
IPAQ vigorous (METs)	0 (0–0)	0 (0–0)	0.568
IPAQ moderate (METs)	240 (0–590)	0 (0–370)	0.041
IPAQ walking (METs)	231 (0–594)	0 (0–210.38)	0.014*
PAM score	59.35 (47.47–70.20)	51.00 (39.40–61.22)	0.021*

Table 2. Self-management behaviors and differences between groups. IPAQ, International Physical Activity Questionnaire; IQR, Inter-quartile range; KPDQ, Knowledge about Parkinson's Disease Questionnaire; METs, Metabolic Equivalents; PAM, Patient Activation Measure. *Variables with p-values below the BH adjusted alpha were considered statistically significant.

Self-management behaviors variables

Table 2 summarizes self-management behaviors and differences between groups. Participants in the concealing group had had more limited engagement in physical activity (in walking, and total score), and lower patient activation.

HRQoL variables

Table 3 presents scores on the PDQ-39 dimensions. The concealing group had lower HRQoL as indicated by the PDQ summary score (Concealing group: median = 44.45, (IQR = 19.33–59.19); Disclosing group: median = 27.76, (IQR = 13.67–40.78)). Specifically, the concealing group had lower HRQoL, compared with the disclosing group in three dimensions: stigma, social support, and bodily discomfort.

PDQ-39 domain	Disclosing Median (25–75% IQR)	Concealing Median (25–75% IQR)	Sig.
PDQ-39 Mobility	47.5 (15–79.38)	66.25 (30–97.50)	0.092
PDQ-39 ADL	41.67 (12.50–79.17)	50.00 (15.63–89.58)	0.145
PDQ-39 Emotional well-being	25.00 (8.33–50.00)	41.67 (8.33–81.25)	0.092
PDQ-39 Stigma scoring	9.38 (0–29.69)	56.25 (23.44–100)	< 0.001*
PDQ-39 Social support	0 (0–41.67)	33.33 (0–60.42)	0.004*
PDQ-39 Cognition	28.13 (12.50–43.75)	37.50 (12.50–64.06)	0.135
PDQ-39 Communication	16.67 (0–33.33)	20.83 (0–58.33)	0.148
PDQ-39 Bodily discomfort	33.33 (16.67–58.33)	58.33 (29.17–83.33)	0.002*

Table 3. PDQ-39 scores and differences between groups. ADL, Activities of Daily Living; IQR, Inter-quartile range; PDQ-39, Parkinson's Disease Questionnaire-39. *Variables with p-values below the BH adjusted alpha were considered statistically significant.

	Disclosing level	Stigma	Social support	Emotional aspects of HRQoL
Disclosing level	1.000			
Stigma	0.409**	1.000		
Social support	− 0.199*	− 0.196*	1.000	
Emotional aspects of HRQoL	0.138	0.474**	− 0.212**	1.000

Table 4. Correlation matrix of variables in the mediation model. HRQoL, Health-related quality of life.

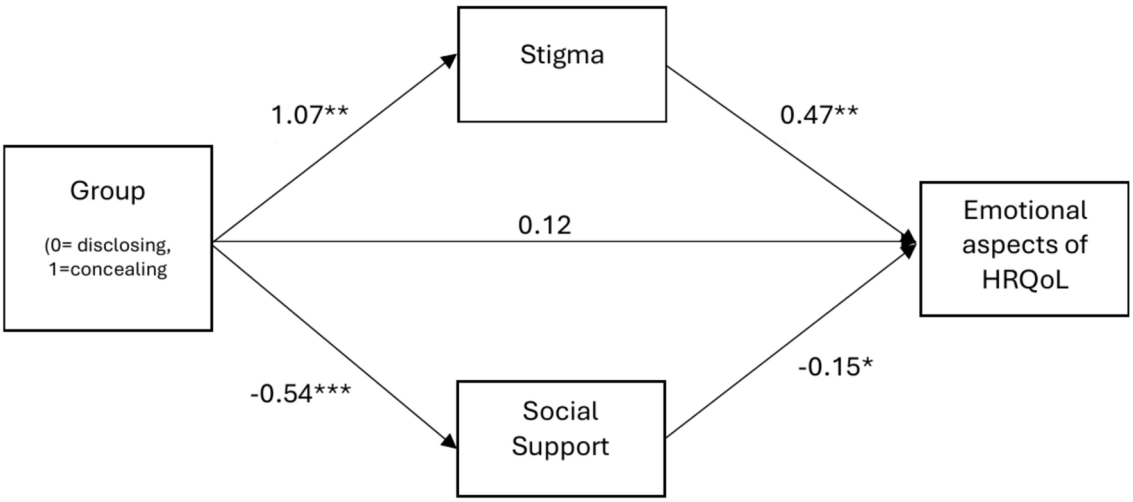

Fig. 1. The Mediating Role of Stigma and Social Support in the Association between Disclosing and emotional aspects of HRQoL. Values on arrows: β; *p < 0.05, **p < 0.01, ***p < 0.001; lower HRQoL is indicated by a higher score. HRQoL, Health-related quality of life.

The mediating role of stigma and social support on the relationship between disclosure level (i.e. disclosing or concealing) and emotional aspects of HRQoL

First, a correlation matrix was generated, as shown in Table 4. The table indicates that the disclosing level is related to both mediators (stigma and social support) but not to quality of life. Additionally, the mediators were correlated with the emotional aspects of HRQoL.

The results of the mediation model are illustrated in Fig. 1. The mediation analysis revealed that disclosure level had a significant total effect on emotional aspects of HRQoL (b = 13.07, β = 0.46, SE = 5.43, p = 0.017).

Specifically, concealing was associated with lower HRQoL. Its direct effect, however, was not significant (β = 0.12, b = − 3.31, SE = 5.43, p = 0.543). Disclosure had a significant effect on the mediators: Concealing was associated with higher stigma (β = 1.07, b = 36.00, SE = 5.90, 95%CI [24.34, 47.66]) and with lower social support (β = − 0.54, b = − 0.77, SE = 2.72, 95%CI [− 1.31, − 0.23]). The mediators were significantly associated with emotional aspects of HRQoL, such that higher stigma (β = 0.47, b = 0.39, SE = 0.07, 95%CI [0.26, 0.53]) and lower social support (β = − 0.15, b = − 2.98, SE = 1.48, 95%CI [− 5.91, − 0.05]) were associated with lower emotional aspects of HRQoL. The indirect effect through stigma was significant (β = 0.50, b = 14.09, SE = 4.19, 95% CI [6.94, 23.39]) but the indirect effect through social support was not (β = 0.08, b = 2.30, SE = 1.86, 95% CI [− 0.27, 6.81]).

Discussion and conclusion

Discussion

This study aimed to expand the understanding of concealment in Parkinson's disease (PD) by examining the proportion of patients who hide their diagnosis from family, comparing personal traits between those who conceal and those who do not, and exploring the associations between concealment and emotional aspects of HRQoL, with a focus on the mediating roles of stigma and social support. We conducted a cross-sectional study to investigate diagnosis concealment in PD, examining its prevalence and associations with socio-demographic factors, self-management behaviors, stigma, social support, and quality of life.

The results of this study indicate that PwP who conceal their disease differ from those who disclose in their socio-demographic characteristics, self-management behaviors, and HRQoL. They did not differ, however, in disease-related characteristics. Furthermore, findings show a positive association between disclosing and emotional aspects of HRQoL and that this association is mediated by stigma.

According to the demographic differences, a higher prevalence of disease concealment is found among PwP who are women, Muslims, religious and do not have academic degree. These identities are often intersected and associated with health exclusion and disparities[64,65], including disparities in diagnosis and treatment of health conditions and access to health care. Regardless of stigma, we speculate that these demographics may be related to societal roles and norms that may affect a person's decision to disclose or conceal their diagnosis. For example, in HIV, women are in general more afraid of disclosing their status than men, because they are more concerned about their roles as caregivers, and they are more fearful of the far-reaching consequences and the potential loss of custody of their children[66,67]. Furthermore, chronic illness was shown to be a risk factor for marriage dissolution, in particular, wife's illness onset is associated with elevated risk of divorce[68,69]. Although studies have found that the relationship between illness and divorce may vary by specific illness[69], we suggest that these findings, shown for illnesses other than PD, may in part explain concealing among women with PD.

Similarly to our finding, studies also showed associations between social support and disease disclosure. For example, among people with cystic fibrosis, disclosure was associated with higher social support[5] and people with rheumatic disease who never/sometimes disclose their diagnosis reported significantly lower support[6].

Our study revealed that groups did not differ in disease severity (MDS-UPDRS part II scores), physical (PDQ-39 "mobility" and "ADL" dimensions) or cognitive (MMSE score) aspects. In the context of disease severity, it was previously shown that as long as symptoms are not visible, more patients choose not to disclose as a strategy to reduce stigma[3,33]. In our study, participants had mild to moderate severity (based on their MDS-UPDRS part II scores), and therefore may have been at the stage where medications can still reduce significant visible symptoms such as tremors. It is possible that at in a sample of patients in the advances stages of PD, in which symptoms (e.g., tremor, freezing of gait, gait disturbances) are clearly visible, rates of concealment are lower.

Our findings showed differences in self-management behaviors between the groups that indicate the consequences of concealing. Associations between disclosure and engagement in self-management behaviors have also been documented in other conditions such as diabetes[70]. Participants in the disclosing engaged less in regular exercise (moderate physical activity and walking), and exhibited lower patient activation. Their knowledge about the disease was lower than the disclosing group, though this difference approached but did not reach statistical significance. Effective self-management of a chronic disease requires patients to actively engage in tasks such as understanding disease symptoms and possible treatment options and adopting healthy lifestyle changes that help cope with the challenges imposed by the disease in order to maintain function and well-being. The capacity to engage in these behaviors over the long term is important in chronic diseases such as PD. Therefore, the fact that participants who did not disclose their diagnosis showed reduced self-management skills suggests that they are less equipped to deal with the disease for the long term.

Beyond the visible symptoms, PD presents significant self-management challenges that can influence disclosure decisions. Daily life with PD requires complex management of nutrition, timing meals around medication schedules and complex medication management. These aspects of self-management can significantly impact one's sense of control and autonomy. The need to explain these complex management routines to others, particularly in social or professional settings, may influence an individual's decision about when and how to disclose their PD diagnosis[71,72].

Group differences in HRQoL strengthen the findings of previous quantitative studies and patient reports on the role of concealment in patients' HRQoL[31,36,38]. The results support partial mediation, whereby degree of disclosure influenced emotional well-being largely by increasing stigma rather than exclusively through a direct effect. Overall, these findings highlight the complex interrelationships among disclosure, stigma, and HRQoL in Parkinson's disease and highlight the negative effect of stigma. The mediating role of stigma in emotional well-being has been previously documented. For instance, stigma has been shown to mediate the relationship between self-compassion and psychological distress in PwP[73].

Interventions targeting stigma may have downstream benefits for emotional health in this population, although such interventions may be challenged by the complexities of factors contributing to enacted stigma (e.g., cultural factors) and self-stigma (e.g., personal beliefs about disability).

Study limitations

Our study has several limitations. The study sample did not include PwP with severe or very mild disease, therefore the finding external validity to these populations of PwP is limited. It should be noted, however, that our measure for severity was based on the MDS-UPDRS part II scale, and possibly a more standardized measure of PD stage would have yielded different conclusions regarding the study's external validity. The group of patients who chose not to disclose their diagnosis was significantly smaller than the group who disclosed it. In addition, concealment was assessed by one question, as this was part of a larger study. The study was conducted within a specific country and cultural context, which may limit the generalizability of the findings to other settings. Future studies may evaluate concealment in a more comprehensive approach.

Conclusion and practice implications

In conclusion, the findings in this study support a positive association between PwP disclosing the diagnosis and emotional aspects of HRQoL, and that this association is mediated by stigma.

From a clinical perspective, it is essential for treating neurologists to carefully consider the process of delivering the diagnosis. They should also engage in discussions with the patient about the potential positive and negative consequences of disclosure. Furthermore, it is imperative that the attending physician maintains an open and supportive dialogue regarding the issue of concealment in future visits. Healthcare professionals should be aware of the consequences of concealing. Such patients may require further emotional support and may benefit from additional encouragement to engage in health behaviors such as exercise and to learn strategies for enhancing activation.

Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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Author contributions

B.N.A.—conceptualization, methodology, investigation, formal analysis, writing—original draft; M.K.—conceptualization, methodology, funding acquisition, formal analysis, writing—original draft, writing—review and editing; Me.K.—investigation, writing—review and editing; S.S.—project administration; S.G.—supervision, writing—review and editing; S.K.—supervision, writing—review and editing; G.Y.S.—conceptualization, methodology funding acquisition, analysis, writing, editing of final version of the manuscript.

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Declarations

Ethics approval and consent to participate

Study procedures were performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of the Faculty of Social Welfare & Health Sciences, University of Haifa (approval number 548/20) and the Helsinki Committee of Clalit Health Services (approval number 0128-19-COM1). All participants signed a consent form prior to entering the study.

Competing interests

The authors declare no competing interests.

Additional information

Correspondence and requests for materials should be addressed to M.K.

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