MEDICAL SCIENCES



HEALTH LITERACY, MYTHS AND STIGMA AMONG PATIENTS WITH PARKIN-SON'S DISEASE IN THE REPUBLIC OF MOLDOVA

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Keywords: Parkin- son's Disease; Health literacy; Self- stigma.	o ensure appropriate health-related decisions ity of life for Parkinson's Disease (PD) patients. racy, myths, and stigma among PD patients in Diomid Gherman" Institute of Neurology and al study used descriptive and inferential statis- (52.4% women, 47.6% men; average age 65.5 wledge, Attitude and Practices questionnaire. to stress (61.2%), altered brain blood flow toxic substances (13.6%), with accent in those te tremors with PD, and 21.4% believe PD lim- le 15.5% viewing medication as "toxic", 6.8% ssion. Self-stigma includes feelings of shame 32.0%), and reduced independence (65%). literacy and significant self-stigma among PD ons and social impacts of the disease, especially literacy and addressing stigma are crucial for		
Cuvinte-cheie: Boala Parkinson, al- fabetizare în dome- niul sănătății, au- tostigmatizare.	 ALFABETIZAREA IN DOMENIOL SANATA, II, MITORILE ȘI STIGMATIZAREA PACIEN- ȚILOR CU BOALA PARKINSON ÎN REPUBLICA MOLDOVA Introducere: Alfabetizarea în sănătate - capacitatea de a lua decizii corecte în legătură cu sănătatea proprie, bazată pe cunoștințe, influențează calitatea vieții pacienților cu Boala Parkinson (BP). Acest studiu evaluează nivelul de alfabetizarea în sănătate, miturile și stigma asociate cu BP în Republica Moldova. Materiale și metode: Studiul a fost realizat la Institutul de Neurologie și Neurochirurgie "Diomid Gherman" (2022-2023), utilizând o metodologie de tip transversal cu elemente de statistică descriptivă și inferențială (testul Chi-square, CI 95%). Au participat 103 pacienți cu BP (52,4% femei, 47,6% bărbați; vârsta medie 65,5 ani) cărora le-a fost propus ches- tionarul Cunoștințe, Atitudini și Practici. Rezultate: Pacienții din Moldova atribuie BP stresului (61,2%), fluxului sanguin cerebral al- terat (49,5%), oxigenării cerebrale insuficiente (44,7%) și substanțelor toxice (13,6%); mai accentuate la subiecții cu nivel scăzut al educației (p=0,001). 30,1% asociază tremorul cu BP, iar 21,4% cred că BP limitează speranța de viață. Îngrijorările legate de tratament includ 15,5% care consideră medicamentele "toxice" și 6,8% care cred că L-dopa accelerează pro- gresia bolii. Stigma de sine include sentimente de rușine (46,6%), frica de judecată (44,7%), izolare (32,0%) și independență redusă (65%). Concluzii: Studiul relevă o alfabetizare în sănătate limitată și o stigma de sine semnificativă printre pacienții cu BP din Moldova, evidențiind concepțiile greșite și impactul social al boli, în special la cei cu nivel redus al educației. Îmbunătățiea alfabetizării în sănătate și abor- daraa stiamei sunt acentiele anteru îmbunătățien înariilor. 		



INTRODUCTION

The establishment of the diagnostic of Parkinson's disease (PD) as a chronic disease impacts the patient and his family. The health-related quality of life of those individuals is defined by their understanding of the pathology and the requirements involving treatment and maintenance of the symptoms. Additionally, of great contribution is the image they have of themselves and the way they are perceived in the society. The afore mentioned elements delineate the impact of health literacy and myth circulation in community and the consequently formed stigma around PD (1).

Health literacy accounts for a multidimensional construct that reflects one's capacity to make appropriate health-related decisions. The term equivalates the degree of education of patients translated by their cognitive and social skills required to extract, process and use information about their health (2). One's capacity to choose the best care options can be reflected through one's knowledge, attitudes and practices regarding their diagnosis, an approach we choose through this study focused on patients with PD. Correspondingly, low health literacy in PD was shown to be unfavorable on several levels being associated with poorer clinical status, higher hospitalization rates and burden for the caregivers (3). The lack of understanding of PD lead, overtime, to vulgar constructs explaining its causes, evolution and treatment options that were widely widespread in the community, but wrong in essence. Those represent myths - flawed knowledge that needs to be unlearned to ensure best medical practice. Their broad dissemination in society reflects diminished health literacy - individuals either lack correct medical knowledge or choose to follow cultural beliefs over best medical advice.

Stigma refers to the product of misconceptions and attitudes towards an individual leading to one's undervalue implying their lack or loss of qualities. Thus, we can distinguish two forms: enacted-stigma – that corresponds to socially and institutionally constructed stigma; and selfstigma which represents the internalized feelings of a person exposed to the negative outcomes of enacted-stigma (4). Low health literacy in the community creates a favorable milieu for both kinds of stigma, especially in the context of chronic disorders such as PD (3–5). The way one is perceiving themselves with the disease is key, therefore several contributing factors – deter-minants, can influence the severity of stigma such as: feeling ashamed, impaired indepen-dency, questioning self's mental capacities, compromising symptoms in social situations, fear of isolation in the community and distancing from relatives (1, 6).

Therefore, based on the previously reported gaps in the understanding of PD due to low health literacy (7) and its frequent association to stigma (1), more research into this field is required. Our investigation on the subject showed there is limited international literature on this topic and no publication in the Republic of Moldova. Knowledge Attitude Practice (KAP) studies evaluating Parkinson's disease among Moldovan neurologists and medical workers were conducted (8-10). Thus, we aimed to consider a similar approach (KAP questionnaires), but focusing on PD patients, to establish a baseline of health literacy and myths that circulate in the community of people with the disease and to identify determinants of self-stigma.

MATERIAL AND METHODS

The research was carried out at the Diomid Gherman Institute of Neurology and Neurosurgery from January 2022 to December 2023 and represents a cross-sectional study. The study group included patients diagnosed with Parkinson's disease who were able to read, comprehend and independently complete a KAP survey (Knowledge, Attitudes and Practices). The KAP questionnaires were developed, validated, and implemented according to WHO guideline. The questionnaires included open and closed questions upon the knowledge of PD patients about their disease, attitudes, and practices. A total of 103 questionnaires were completed and analyzed: 52.4% (n=54) women and 47.6% (n=49) men, with an average of 65.49±8.38 years old. The studied sample was stratified based on two key factors: level of education (categorized as more or less than 12 years) and gender, to ensure balanced representation across these variables. The data about the knowledge of the patients about the diagnosis, treatment and evolution of PD was extracted from the KAP questionnaires (a quantitative study) and help determine the level of health knowledge.



The myths and stigma determinants were extracted from the in-depth interviews conducted to 10 patients with PD – qualitative study. Descriptive statistics were used to summarize the demographic characteristics of the participants. For inferential analysis, Pearson *Chi-square tests* (CI 95%) were used to examine associations between categorical variables, such as gender, education level, and knowledge of Parkinson's disease. All data were analyzed using Microsoft Excel statistical package.

RESULTS

Knowledge, Attitudes, Practices and Myths surrounding Parkinson's disease

The degree of health literacy in PD patients was evaluated based on the knowledge, attitudes and practices they reported regarding the disease. Results are reported in the following compartments (tab. 1, fig.1):

1. Knowledge and myths about the etiology of PD. When asked about the etiology of the disease, most of the respondents (61.2%) considered that PD is caused by stress or strong emotions, only 13.6% believed it is the contact with toxic substances. Although the majority of subjects (64.1%) knew there was no relationship between infections and PD, a small percentage of subjects (3.9%) believed that there was. An individual response (1.0%)stated PD as a contagious condition. A recurrent opinion among the participants is that altered blood flow to the brain (49.5%) and lack of brain oxygenation (44.7%) leads to PD. This opinion was more frequent in subjects with lower education levels (p=0.001), and had a tendency to prevail in male population specifically regarding the change in blood flow (p=0.052). The majority of educated patients knew PD is not the result of another disease (56.5% vs.9%, p<0.001), whilst a third of them did not know about any connection between PD and other diseases (78.9% vs. 37%,p<0.001). Just over a half of respondents

(55.3%) believed that PD affects not only the elderly, this was noted by 71.7% of people with higher education (p=0.018), while a total of 25.2% believed that it is closely related associated with old age.

- Knowledge about the prognostic of PD. A significant number of patients (40.8%) were convinced PD caused a shorter life span, 24.3% believed PD has a fast progression, 5.8% thought it's a life-threatening disease. Stratification based on the education level showed the patients with lower education were more likely to believe PD reduces life expectation (p=0.004) and has rapid progresssion (0.026).
- 3. *Knowledge and myths about the symptomatology of PD.* The major part of the responders (91.3%) were aware the main symptoms of PD include tremor and bradykinesia. However, a third of them (30.1%) took tremor as the definitory sign confirming PD, particularly in less educated individuals (42.1% vs. 26.1%, p=0.001).
- 4. Knowledge, attitudes, and practices upon the diagnostic tools. A considerable number of patients are convinced that PD can be diagnosed either through brain neuro-imagistic exam (60.2%) or lab exam (29.1%). Patients with higher education levels were more reticent to the diagnostic possibilities of those diagnostic tools (MRI 75.4% vs. 41.3%, p<0.001; blood work 36.8% vs. 19.6%, p=0.001). No statistically significant results were observed among genders.</p>
- 5. *Knowledge, attitudes, and practices regarding treatment options.* Opinions about antiparkinsonian medication were divided: several participants (15.5%) consider medication to be "toxic"; 6.8% associate L-dopa treatment to accelerate the disease progression; 6.8% believed L-dopa action to subside only the first 5 years after diagnosis. Very few respondents from both lower (8.8%) and higher (4.3%) education backgrounds believed in the efficacy of L-dopa medication, surpris

	Stratification based on education level			Stratification based on gender		
Parameters	Education <12 years Nr ±SD	Education > 12 years Nr ±SD	р	Males Nr ±SD	Females Nr ±SD	р
Mean age	63.19 ±9.109	68.33 ±6.419	0.002*	65.8 ±7.705	65.2 ±9.021	0.722
Disease duration	6.16 ±3.401	6.57 ±4.708	0.612	6.35± 4.280	6.33 ±3.812	0.797

Table 1. Health literacy determinants registered in Parkinson's disease patients.

Years of education	9.96 ±1.451	15.87 ±2.655	< 0.001*	12.45 ±3.506	12.75 ±3.712	0.713	
	% (Nr)	% (Nr)	df, p	% (Nr)	% (Nr)	df, p	
Knowledge and myt	ths about the et	iology of PD					
	PD	is caused by str	ess or stron	a emotions			
Ves	64 %(37)	56.5%(26)		57 1%(28)	64.8%(35)		
No	7%(4)	21.7%(10)		16.3%(8)	11 1%(6)		
I don't know	28.1%(16)	21.7%(10)	2.0.093	26.5%(13)	24.1%(13)	2.0.663	
	PD i	is caused by con	tact to toxic	substances		_,	
Voc	10 5%(6)	17 406(9)	tuet to toxic	19 406(0)	0.206(5)		
No	10.3%(0)	$\frac{17.4\%(0)}{52.20\%(24)}$		10.4%(9)	50.0%(27)		
I don't know	47.1%(27)	30.4%(14)	2 0 1 9 5	38.8%(19)	40.7%(22)	2 0 392	
	17.170(37)	PD is cause	ed by infection	ons	10.7 /0(22)	2,0.372	
Yes	1.8%(1)	6.5%(3)	a by injection	2%(1)	5.6%(3)		
No	61.4%(35)	67.4%(31)		59.2%(29)	68.5%(37)		
I don't know	36.8%(21)	26.1%(12)	2,0.279	38.8%(19)	25.9%(14)	2,0.288	
	PD is	caused by alter	ed blood flov	w to the brain		,	
Ves	61 4%(35)	34.8%(16)		59.2%(29)	40.7%(22)		
No	5 3%(3)	34.8%(16)		20.4%(10)	16.7%(9)		
I don't know	33 3%(19)	30.4%(14)	2.0.001*	20.1%(10)	42.6%(23)	2 0 0 5 2	
	 PI) is caused by no	$\frac{1}{100}$	vaenation	1210 /0(20)	2,0002	
Ves	52.6%(30)	34.8%(16)	in prain or	53 1%(26)	37.0%(20)		
No	5.3%(3)	41.3%(19)		22.4%(11)	20.4%(11)		
I don't know	42.1%(57)	23.9%(11)	2.0.001*	24.5%(12)	42.6%(23)	2.0.135	
		PD is an e	lderlv disea	se		,	
Ves	35 1%(20)	13,0%(6)		30.6%(15)	20.4%(11)		
No	42.1%(24)	71.7%(33)		53.1%(26)	57.4%(31)		
I don't know	22.8%(13)	15.2%(7)	2.0.018*	16.3%(8)	22.2%(12)	2.0.446	
PD is contagious							
Ves	1.8%(1)	0%(0)		0%(0)	1 9%(1)		
No	78.9%(45)	91 3%(42)		81.6%(40)	87.0%(47)		
I don't know	19.3%(11)	8.7%(4)	2.0.199	18.4%(9)	11.1%(6)	2.0.382	
DD is the result of another disease							
Ves	5 3% (3)	6 5%(3)	oj unotner	6.1%(3)	5.6%(3)		
No	9%(15.8)	56.5%(26)		34 7%(17)	33 3%(18)		
I don't know	78.9%(57)	37%(46)	2.<0.001*	59.2%(29)	61.1%(33)	2.0.978	
Knowledge about th	e prognostic o	f PD	,			,	
		PD reduces	life expecta	incv			
Ves	49 1%(28)	30.4%(14)		46.9%(23)	35 2%(19)		
No	17.5%(10)	47.8%(22)		28.6%(14)	33.3%(18)		
I don't know	33.3%(19)	21.7%(10)	2.0.004*	24.5%(12)	31.5%(17)	2.0.471	
		PD is a f	atal disease	2		, -	
Yes	8.8%(5)	2.2%(1)		8.2%(4)	3.7%(2)		
No	64.9%(37)	84.8%(39)		73.5%(36)	74.1%(40)		
I don't know	26.3%(15)	13.0%6()	2, 0.065	18.4%(9)	22.2%(12)	2, 0.587	
PD has rapid progression							
Yes	29.8%(17)	17.4%(8)		20.4%(10)	27.8%(15)		
No	26.3%(15)	52.2%(24)		40.8%(20)	35.2%(19)		
I don't know	43.9%(25)	30.4%(14)	2, 0.026*	38.8%(19)	37.0%(20)	2, 0.667	
	<u> </u>	patients can ha	ve a long an	d active life			
Yes	26.3%(15)	67.4%(31)		51%(25)	38.9%(21)		
No	33.3%(19)	6.5%(3)		24.5%(12)	18.5%(10)		
I don't know	40.4%(23)	26.1%(12)	2, 0.001*	24.5%(12)	42.6%(23)	2, 0.153	

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Knowledge, attitudes, and practices upon the treatment options							
PD medication is toxic							
Yes	8.8%(5)	23.9%(11)		14.3%(7)	42.6%(23)		
No	38.6%(22)	50%(23)		46.9%(23)	40.7%(22)		
I don't know	52.6%(30)	26.1%(12)	2, 0.012*	38.8%(19)	16.7%(9)	2, 0.814	
Dopaminergic drugs accelerate PD progression							
Yes	8.8%(5)	4.3%(2)		2%(1)	11.1%(6)		
No	45.6%(26)	76.1%(35)		59.2%(29)	59.3%(32)		
I don't know	45.6%(26)	19.6%(9)	2, 0.007*	38.8%(19)	29.6%(16)	2, 0.154	
Levodopa acts only during the first 5 years of PD							
Yes	8.8%(5)	4.3%(2)		6.1%(3)	7.4%(4)		
No	15.8%(9)	43.5%(20)		30.6%(15)	25.9%(14)		
I don't know	75.4%(43)	52.2%(24)	2, 0.008*	63.3%(31)	66.7%(36)	2, 0.862	
Levodopa side effects outpass its benefits							
Yes	8.8%(5)	4.3%(2)		8.2%(4)	5.6%(3)		
No	35.1%(20)	69.6%(32)		51.0%(25)	50%(27)		
I don't know	56.1%(32)	26.1%(12)	2, 0.002*	40.8%(20)	44.4%(24)	2, 0.843	
*statistically significant results (p<0.05)							



Figure 1. Health literacy determinants registered in Parkinson's disease patients.

ingly a majority of higher educated individuals (69.6%) believed its side effects out passed its benefits (p=0.002).

Parameters influencing self-stigma

A significant proportion of diagnosed patients (46.6%) stated "It's a shame to have Parkinson's Disease", mostly seen in less educated subjects (p=0.001). 49.5% stated "It is shameful to walk using crutches or walking frames", this idea also prevailed among those with lower education

(p=0.001) (tab. 2).

A third of the subjects interviewed (33.0%) are convinced that PD caused dementia – 47.8% out of the patients with higher degrees supported this idea (p=0.001); meanwhile two thirds (65.0%) believed it caused dependency upon other's help – result rather constant among subjects from different educative backgrounds and gender. 44.7% stated PD made them subjected to judgement form others, a concern in 52.6% of the less educated (p=0.028). Additionally, 30.1% said PD al-

	Stratification based on education level		Stratification based on gender			
Parameters	Education <12 years	Education > 12 years	р	Males	Females	р
	% (Nr)	% (Nr)	df, p	% (Nr)	% (Nr)	df, p
		PD is caused by a	mental illnes	SS		
Yes	38.6%(22)	52.2%(24)		46.9%(23)	42.6%(23)	
No	14.0%(8)	28.3%(13)		14.3%(7)	25.9%(14)	
I don't know	47.4%(27)	19.6%(9)	2, 0.010*	38.8%(19)	31.5%(17)	2, 0.332
	· · · ·	PD causes de	ementia			
Yes	21.1%(12)	47.8%(22)		30.6%(15)	35.2%(19)	
No	17.5%(10)	32.6%(15)		24.5%(12)	24.1%(13)	
I don't know	61.4%35()	19.6%(9)	2, 0.001*	44.9%(22)	40.7%(22)	2, 0.874
	All PD pa	itients use wheelcl	hairs or are	bedridden		
Yes	29.8%(17)	17.4%(8)		22.4%(11)	25.9%(14)	
No	15.8%(9)	41.3%(19)		32.7%(16)	22.2%(12)	
I don't know	54.4%(31)	41.3%(19)	2, 0.013*	44.9%(22)	51.9%(28)	2, 0.494
PD causes loss of independency						
Yes	61.4%(35)	69.6%(32)		63.3%(31)	66.7%(36)	
No	22.8%(13)	28.3%(13)		26.5%(13)	24.1%(13)	
I don't know	15.8%(9)	2.2%(1)	2, 0.066	10.2%(5)	9.3%(5)	2, 0.937
	PD causes a	ltered relationshi	os with fami	ly and friends		
Yes	45.6%(26)	10.9%(5)		26.5%(13)	33.3%(18)	
No	54.4%(31)	82.6%(38)		67.3%(33)	66.7%(36)	
I don't know	0%(0)	6.5%(3)	2, 0.001*	6.1%(3)	0(0)	2, 0.157
		PD causes socid	al isolation			
Yes	43.9%(25)	17.4%(8)		30.6%(15)	33.3%(18)	
No	49.1%(28)	76.1%(3)		36.3%(31)	59.3%(32)	
I don't know	7%(4)	6.5%(3)	2, 0.014*	6.1%(3)	7.4%(4)	2, 0.910
	It's a she	ame to use crutche	s and walki	ng frames		
Yes	66.7%(38)	28.3%(13)		40.8%(20)	57.4%(31)	
No	31.6%(18)	69.6%(32)		57.1%(28)	40.7%(22)	
I don't know	1.8%(1)	2.2%(1)	2, 0.001*	2%(1)	1.9%(1)	2, 0.240
Fear of judgement in the community						
Yes	52.6%(30)	34.8%(16)		38.8%(19)	50.0%(27)	
No	19.3%(11)	43.5%(20)		38.8%(19)	22.2%(12)	
I don't know	28.1%(16)	21.7%(10)	2, 0.028*	22.4%(11)	27.8%(15)	2, 0.187
It's a shame to have PD						
Yes	64.9%(37)	23.9%(11)		34.7%(17)	57.4%(31)	
No	35.1%(20)	71.7%(33)		63.3%(31)	40.7%(22)	
I don't know	0%(0)	4.3%(2)	2, 0.001*	2%(1)	1.9%(1)	2, 0.068
*statistically signific	ant results (p<0.05	5)				

Table 2. Self-stigma	determinants in	Parkinson's	disease patients
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ters relationships among close and distant family members, 32.0% affirmed "PD leads to social isolation" (fig. 2).

Patient statements with regards to PD

Some of recurrent themes emerged from the indepth interviews. When asked about what Parkinson's disease is, all patients said it's "an old age disease", seven out of ten stated it's "when there is tremor in your hands" and that it represents "a mental illness".

Stress was widely regarded as a cause, with varying degrees of belief: "the disease appeared because I was always stressed," "this tremor started after a big scare and never went away," and "the daily struggles of life made me sick." Some pati-



ents explained the origin of the disease based on their understanding of medical information: "one of my neck vessels is shorter than the other, so that made my brain sick," and "a few years ago, during an investigation (after a Doppler ultrasound), my doctor told me that my neck veins are not symmetric, so the blood doesn't reach my brain properly."

Living with PD is a significant source of distress for patients: "I feel bad for my children because they have to take care of me," "We used to have big family gatherings when we were younger, but now I feel embarrassed to attend because I struggle to eat properly," "I rarely see my neighborhood friends anymore – they might think I'm drunk because of my tremor."

Regarding treatment, many respondents expressed reluctance: "The medication doesn't work; I feel even worse," "I stopped taking the drugs my doctor prescribed." Two patients believed that dopaminergic treatment worsened their symptoms: "I feel worse when I take levodopa/carbidopa (active compounds substituted for brand name); I experience strange sensations on the left side of my face."



Figure 2. Self-stigma determinants identified in Parkinson's disease patients

DISCUSSIONS

Based on the collected responses, most individuals believed their condition to result from exposure to extremely stressful situations (61.2%) or to happen in the context of mental disorders (44.7%). This association might be due to the increased self-reported severity of PD symptoms in relation to acute and chronic stress exposure and the diminished effect of medication in that context (11). The pathophysiological explanation resides in the loss of the dopamine-dependent adaptative mechanisms involved in the stress management in the central nervous system. Although the neuroplastic abilities of the nigro-striatal system are compromised and may predispose to PD they don't mandate the onset of the disease (12). Patients also associated PD to disrupted blood flow (49.5%) or poor oxygenation (44.7%), especially in the patients with lower levels of education (p=0.001), probably as result of embedded myths in the community that cervical blood vessels' asymmetry of flow is at the basis of an umbrella of neurological disorders, as highlighted the statements form the in-depth interviews. A minority of respondents thought PD is a contagious (1%) or infective disease (3.9%). Those findings show a profound lack of knowledge and misinformation of the patients about the nature of their disease – a synucleinopathy.

In addition, our results showed that a third of the respondents (35%) – 42.1% of those from a lower educative background (p=0.001); believe tremor to be the hallmark sign of PD. A similar observation was made in a study made in Tabuk City, Saudi Arabia, where 93.66% of the respondents portrayed tremor as a common trait of PD(13). Low awareness about the various phenotypes of the disease may lead to disbelief in the accuracy of the diagnosis and create reluctance in following diagnostic procedures and initiation of treatment. Furthermore, the general misconception that PD is an old age only disease (1, 14, 15) – myth registered in up to 25.2% of the questioned subjects; can cause hesitancy in younger patients towards accepting and adhering to treatment along to accentuated self-stigma as per the feeling of loss of their value to the familial cell/society.

The efficacy of therapeutic approaches is highly questioned among patients, some of them being concerned about the toxicity of the medication (15.5%) or believe L-Dopa has more side-effects than benefits (6.8%) and causes a faster progression of the disease (6.8%). This erroneous understanding may be a consequence of: ineffective communication and education of the patient about the way L-Dopa functions; wrong posology; unawareness of the side effects and the lack of their management or prevention. Data showed that most of the subjects with higher education levels had statistically significant greater confidence into antiparkinsonian medication. A KAP study evaluating practices of neurologists in the Republic of Moldova about management of PD showed negative approaches in regard to L-Dopa treatment - 30.4% of them delaying as much as possible initiation of the treatment (8). Thus, the practitioners' reticence into prescribing the appropriate medication regimen can reflect upon the assurance patients have in its overall need. Some of the uncertainty surrounding L-dopa may be the result of earlier studies on the oxidative stress induced by PD treatment on substantia nigra which was latter disproved but persists in a minority of the medical community (16).

A significant number of patients believe PD influences negatively life expectancy (40.8%), followed by 24.3% concerned about the rapid progression of the disease. However, a greater number of educated subjects had positive perspectives about life with PD diagnosis (p=0.001). The subject of mortality and disease associated risks must not be ignored - early disclosure of all aspects of the disease including complications and mortality rates is the first step into ensuring the patient and its family is prepared (3, 17). Complementary, patients must be informed of the major threat surrounding PD, notably: aspiration pneumonia as a result to dysphagia and immobility, especially as the disease progresses(18). Preparation in advance of the patient and relatives is key into providing qualitative years lived with the disease.

The findings exposed above are in alignment to the results obtained in a study lead at the University of Pennsylvania's Parkinson's Disease and Movement Disorder Center in 2015, were 30% of respondents had poor health literacy although they had higher degrees of education (3). A scoping review profiled various barriers to providing appropriate care for PD patients, which included low health literacy, exacerbated by the belief held by most patients that treatment related discussion should be solely initiated by healthcare providers (17). This observation shows the impact the initial disclosure of the diagnostic can have - probably the first time the patient has ever heard about PD. Clear description of the clinical presentation, etiology, disease evolution and management options are of essence. Health literacy of the patients with PD is of utter most importance as symptoms can be confusing, sometimes the disease is fully installed at young age and medication regimens are rather complex. Insufficient explanations can result in wrong conceptualization of the disease, low adherence to treatment and decreased life quality. In the previously conducted KAP study, up to 64.4% of the Moldovan neurologists disclosed lacking theoretical skills and 62.2% practical skills with PD patients (10), fact that could contribute to the overall poor health literacy in PD patients in the Republic of Moldova, as a variety of erroneous perceptions about the disease prevailed in the studied sample.

Furthermore, the research allowed the evaluation of the effect several determinants of selfstigma have on subjects diagnosed with PD. Fear of losing independency represents the greatest concern of patients (65%) followed by mobility impairment in 49.5% of cases. Other key factors of concern re-emerging are of psychosocial nature, such as: feelings of shame 46.6%, fear of community judgement 44.7%, associating PD to mental illnesses. Approximately a third of the respondents expressed anticipation of social isolation (32%) and strained relationships with friends or family members (30.1%).

Self-stigma in patients with PD is the result of the stereotypes and the discrimination individuals experience in their community(4,15). Elements such as the degree of self-compassion and health literacy proved to strongly influence the degree of self-stigma(3,4). A review of publications realized by a Luxembourg team of researchers, through a thematic synthesis, identified 87 determinants of self-stigma which included the ones described in our study (6). In addition, the typical symptoms associated to PD (tremor, rigidity, bradykinesia, on/off phenomenon, incontinence, drooling or troubles swal-



lowing) along to the increased clumsiness caused by the progression of the disease is a source of embarrassment and patients have a tendency to try and dissimulate them(15,16). In a Kenyan research, upon questioning a patient with incipient stage of PD disclosed being afraid of showing symptoms in the future, thus manifesting anticipatory-stigma (14). Social interactions can also suffer as a result of the symptoms of PD. Patients may be mistaken to be drunks due to postural instability or their intentions may be misunderstood in regard to their hypo-/amimia(1). Those could cause social avoidance of the diagnosed individual and emphasize enacted stigma.

CONCLUSIONS

- 1. This research showed limited health literacy among PD patients by revealing widespread misconceptions and myths regarding diagnostic procedures, clinical presentation, disease progression, and treatment efficacy – factors that ultimately affect adherence to best clinical practices. Additionally, patients exhibited signs of self-stigma driven by their symptoms and disease progression, which negatively impacted their family and social relationships. These findings were more pronounced in individuals with lower levels of education.
- 2. Thus, the tendency of patients to rationalize their symptoms by associating them to familiar concepts reflects gaps in the medical care provided. Effective communication of the diagnosis, along with patient and family education on the etiology, progression, treatment, and management of PD, is essential to reducing frustration, addressing misunderstandings, and increasing awareness of the condition's specific challenges.

CONFLICT OF INTEREST

Authors have no conflict of interest to declare.

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ETHICAL APPROVAL

The research was approved by the Committee of Ethics in Research of the *Diomid Gherman* Institute of Neurology and Neurosurgery (No. 1 from 24.02.2022).

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