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Impact of Progressive Neurological Disorders on Patients' Daily Lives

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Abstract

Background: Progressive neurological disorders (PNDs) are a real public health challenge with significant impact on patients' quality of life. Limited research exists on PNDs social impact in low- and middle-income countries.

Aim: The present study was conducted with aim to explore the impact of PNDs on patients' daily lives in the physical, social, professional, and financial levels.

Method: This cross-sectional study was conducted in 2024 on patients diagnosed with PND within the last 12 months. A survey developed by the authors focused on social and professional activities and financial stability, distributed through social networks communities.

Results: Data collection gathered 89 responses. The findings showed low regular health monitoring (59.5%), insufficient pain medication prescriptions (33.7%), significant decrease in social activities (t=4.920; p<0.005), and occupational activities (t=3.689; p<0.005) accompanied by a need of financial support for a large number of patients

Implications for Practice: The findings advocate for the implementation of specific health programs to manage PNDs from diagnosis to palliative care, build national database and develop research. Recognition of PNDs as disabilities and development of intersectoral collaborations will improve prevention and also living conditions of patients through the facilitation of work-retention and extension of social coverage. Awareness of professionals, community and policy makers must also be strengthened to ensure this category of disease visibility.

Keywords: Degenerative neurologic disorders, Disability, Health policy, Quality of life, Palliative care

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Introduction

Progressive neurological disorders (PNDs) are long-term disabling conditions impairing multiple aspects of patient's life (1, 2), Although their apparent low overall death according to the 2019 GBD (less than 3%), PNDs are among the leading causes of disability-adjusted life years increase (DALYs). PNDs represent a growing public health challenge, not only due to the rising number of diagnosed patients (3, 4), but also because of the substantial financial burden linked to advanced-stage management (5, 6). This burden affects patients, families, and healthcare systems (1, 2), underscoring the need to optimize care strategies where they are most impactful (3).

In high-income countries, where robust data and specialized care frameworks exist (7-9), numerous studies have addressed the impact of PNDs and identified significant changes attributable to these conditions. The impact on patients' quality of life (QoL) has been examined in various ways, including quantitative studies focusing on clinical progression (10, 11), psychological state (12), and the economic burden of the disease (13). Qualitative studies have also been conducted to explore patients' subjective experiences and identify their concerns (12, 14, 15). The social impact of PNDs and access to healthcare has also been analyzed in certain contexts (16-19).

Several studies indicate that PNDs patients experience moderate to severe reductions in QoL (11)**,** depression and anxiety (20), and a decline in independence, often requiring caregiver assistance for daily activities (18). Additionally, stigma and social isolation further exacerbate psychological distress, worsening overall well-being (16, 17). These studies confirm that PNDs have a significant and multidimensional impact based on the patient's environment and care conditions.

Interest in PNDs patients QoL in low- and middle-income countries (LMICs), including Morocco, has only recently emerged. Morocco lacks official comprehensive national data on progressive neurological diseases. Available estimates reveal a growing challenge: 50000-60000 Parkinson's cases (1-2% of adults over 50 years), 6000-8000 multiple sclerosis patients (Moroccan Parkinson's Disease Association, Moroccan Association of Patients with Multiple Sclerosis), and ALS incidence mirroring global rates between 1.7-2.2/100000 (21). The absence of dedicated health programs and national PNDs registries in LMICs limits large-scale epidemiological and QoL studies. These incomplete figures underscore a critical research gap, as the Global Burden of Disease Study 2016 confirmed neurological disorders are rising exponentially worldwide, disproportionately affecting aging populations.

The present study was conducted with aim to explore the impact of PNDs on patients' daily life and propose improvement ways that can lead to better integrated management of these diseases.

Methods

This cross-sectional anonymous study was conducted in 2024. The target population comprises patients aged ≥18 years, able to provide informed consent, with confirmed diagnosis of PNDs established within the last 12 months. Participants were recruited via Parkinson disease, multiple sclerosis or amyotrophic lateral sclerosis social media communities, through questionnaire link distribution in Arabic and French via Google forms.

The questionnaires, developed by the authors, focus on physical, social and professional activities and consist of closed-ended questions with mandatory responses, divided into five distinct sections. The first section gathers demographic data such as gender, age, marital status, residence and educational level. The second section evaluates health status and health needs, covering areas like polypathologies, motor difficulties, use of technical mobility devices, level of dependence, need for assistance, access to healthcare and services, and pain medication. The third section focuses on social status, examining cohabitation, social relations, assistance in the accomplishment of daily tasks, and communication. The fourth section evaluates financial status, including pre- and post-diagnosis employment, income and financial assistance. Lastly, the fifth section explores social activities, detailing the nature and frequency of these activities before and after diagnosis.

The content validity of the instrument was established through a systematic approach based on critical analysis of pre-validated tools (Neuro-QoL, SF-36), enhanced by targeted literature reviews and expert consultations, particularly neurologists and social workers, achieving conceptual saturation across key QoL domains: physical, psychological, cognitive, and socio-economic. Face validity of the questionnaire was verified through pilot test with 7 representative participants. Reliability of the tool was established by leveraging validated subscales from previous robust instruments. The design of

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the questionnaire inherently incorporates redundant verification mechanisms through multiple complementary items. This approach aligns with Consensus-based Standards for the selection of health status Measurement Instruments methodological frameworks (COSMIN).
Data was extracted and analyzed using SPSS software (version 26) and Microsoft Excel 2016. Numerical coding is used, binary 0-1 for: gender, residence, cohabitation, stable income, financial support; and 0-1-2 for: marital status and educational level. Paired samples *t*-test was used to examine changes in occupational and social activities before and after diagnosis. Logistic regression then determined the effect of demographics characteristics on changes. $p<0.05$ was considered significant.

Ethical Consideration
This study aligns with the principles of the Declaration of Helsinki. Participants were informed of the anonymity of the survey and possibility to withdraw from the study at any time. They were informed that sending the final response is considered as consent. The authors followed the recommendations of the Research Ethics Committee of the Moroccan Association for Research and Ethics (n° 7/REC/21).

Results
A total of 89 individuals consented to participate in the study. The population mean age was 41±17 years, with a male-to-female ratio of 1/3. The distribution by residential environment showed a predominance of patients from urban areas (89.9%). The majority of participants were married (57.3%), followed by singles (31.4%). Moreover, 50.6% of participants have a university level, 35.9% a primary school or illiterates and 13.5% middle to high school level. Financial status data showed that 26.9% of participants were unable to maintain a stable financial situation because of the disease, and 57.3% had to solicit financial support from their relatives or charitable associations (Table 1).

Table 1: Demographic characteristics, social and financial status of the participants

Variable		Women	Men
Demographics	**Number of participants (N (%))**	68 (76,4%)	21 (23,6%)
	Age (year), Mean±SD	39.9±17	47.6±16.8
Social status	**Residence place**		
	Urban	62 (67.7)	18 (20.2)
	Rural	6 (6.7)	3 (3.4)
	Marital status		
	Single	23 (25.8)	5 (5.6)
	Married	35 (39.3)	16 (18)
	Divorced	10 (11.2)	0 (0)
	Educational level		
	Illiterate or primary school	27 (30.3)	5 (5.6)
	Middle and high school	8 (9)	4 (4.5)
	University	33 (37.1)	12 (13.5)
	Cohabitation		
	Yes	55 (61.8)	16 (18)
	No	13 (14.6)	5 (5.6)
Financial status	**Stable income**		
	Yes	49 (55.1)	16 (18)
	No	19 (21.3)	5 (5.6)
	Financial support		
	Yes	12 (13.5)	2 (2.2)
	No	56 (62.9)	19 (21.3)

A wide range of physical limitations and symptoms such as pain, fatigue, and mobility issues were associated with PNDs, which can significantly impact daily functioning. Accordingly, 42.7% of participants suffer from multiple conditions (polypathologies), 10% had motor disabilities and 5.6% used a mobility aid device, whereas 20% need the assistance of a caregiver for mobility. Furthermore, 20.2% need help with daily living tasks. Only 59.5% of participants receive regular health monitoring, and pain medications were prescribed for only 33.7% of participants (Table 2).

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Table 2: Patients' health conditions and needs

Health conditions and needs	Women N (%)	Men N (%)	Total N (%)
Do you have polypathologies?			
Yes	24 (27)	14 (15.7)	38 (42.7)
No	44 (49.4)	7 (7.9%)	51 (57.3)
Are you regularly followed for your pathologies?			
Yes	39 (43.8)	14 (15.7)	53 (59.5)
No	29 (32.6)	7 (7.9)	36 (40.5)
Do you have a motor disability?			
Yes	7 (7.9)	2 (2.2)	9 (10.1)
No	61 (68.5)	19 (21.3)	80 (89.9)
Do you use a mobility aid device?			
No	65 (73)	19 (21.3)	84 (94.4)
Yes and I am autonomous	1 (1.1)	1 (1.1)	2 (2.2)
Yes and I need someone to help me	2 (2.2)	1 (1.1)	3 (3.4)
Does your health condition require assistance from another person?			
Yes	14 (15.7)	4 (4.5)	18 (20.2)
No	54 (60.7)	17 (19.1)	71 (79.8)
Is there any specific pain treatment among your medication?			
Yes	26 (29.2)	4 (4.5)	30 (33.7)
No	42 (47.2)	17 (19.1)	59 (66.3)

Occupational activity is a cross-section of financial and social considerations. A statistically significant overall change was observed (t=3.689; p<0.005), while demographics did not significantly affect this component. Pre- and post-diagnosis comparison reveals full-time work decrease by 13.5%, while unemployment and part-time work increase by 10.1% and 3.4%, respectively (Figure 1).

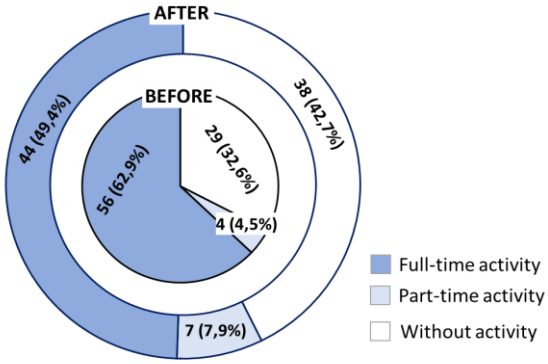

Figure 1: This graph illustrates the changes in participants' occupational activity following the announcement of PND diagnosis. The internal disc shows data before diagnosis, while the external ring shows data afterwards, with the number of respondents and percentages in brackets.

Participation in regular social activities decreased from 11.2% before diagnosis to only 4.5% after diagnosis. Casual social activities also decreased from 46.1% before diagnosis to 25.8% after diagnosis. This situation increases the number of patients who do not engage in any social activity, including walking in public places, from 42.7% to 69.7% (Figure 2).
A statistically significant change was observed (t=4.920; p<0.005) for the entire sample. Among demographic characteristics, only gender showed significant influence (p=0.022).

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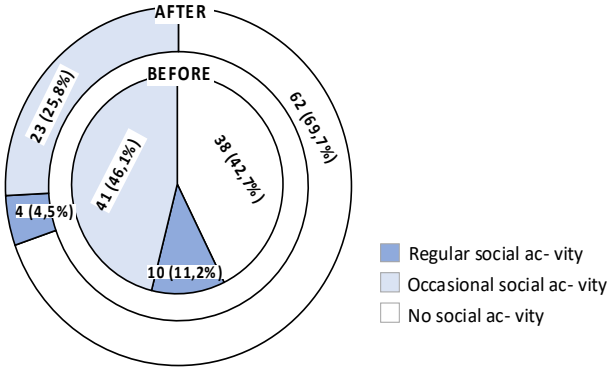

Figure 2: This graph illustrates the changes in participants' social activity following diagnosis of PND. The internal disk shows data before diagnosis, while the external ring shows data after diagnosis, with the number of participants being indicated, with the corresponding percentages in brackets. Three levels of activity were selected: regular social activity, occasional social activity and absence of social activity.

Discussion

This study demonstrates a decrease in physical activity, a decline in social interactions and a disruption of occupational activity for a large number of patients within the first twelve months after diagnosis of PND. Pain, excessive fatigue, decline in overall fitness or even dependency on caregivers, domestic workers or health care professionals for mobility or to perform simple daily life tasks (22) can lead to frailty among patients (23,24). Physical activity health effects should therefore be discussed early with the patient and counseling sessions organized, to adapt it according to individual abilities and clinical status (25,26). Numerous studies ensures benefits of physical activity to support control of neurodegenerative diseases (27) or provide recommendations and advice for safe exercise (28).

The fact that only 59.5% of participants receive regular health monitoring highlights the need to reevaluate medical care delivery to ensure better coverage to this category of patients, care continuity and more satisfactory symptoms management. Promoting telemedical follow-up, home visits and home hospitalizations may be more suitable for these patients (29, 30). Extending health coverage can also improve quality of life while avoiding catastrophic health expenditures (31).

Social activities such as sports, participation in family and friends' meetings and social events also decreased significantly after diagnosis. Impaired quality of social interactions or even social isolation can lead to psychological consequences and establish a situation of continuous stress due to sudden physical limitations, the ambiguity of the disease evolution, but also social constraints (32, 33). This indicates the importance of early psychological support and the need to involve caregivers from the time of diagnosis. Developing caregiver-centered communication can help to effectively engage caregivers in the care project and provide valuable support to the patient. Openness to civil society volunteers can also foster social ties (34, 35), and create new ones to promote acceptance of the disease, such as patient talk groups (36).

Maintenance of an occupational activity plays a dual role: first, as a financial security, but also as a daily occupation that helps patients not to sink into social isolation (37). A large group of participants are forced to cease professional activity due to severe disability and must probably seek financial support from family members or charities (38). For this group, the generalization of social security coverage and its extension seem to be an appropriate solution. The recognition of their condition as disability will also allow patients to benefit from social support guaranteed in Law n° 97.13 on the protection and promotion of the rights of persons with disabilities. The involvement of civil society organizations could provide additional support.

Finally as research serves as a cornerstone for enhancing clinical practice, developing and improving service performance, advancing education, establishing evidence-based health policies, and

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ultimately, optimizing patients' quality of life, a specific national registry for these conditions will provide a valuable database to develop research and support evidence-based practice at all stages of the disease from prevention to palliative care (39-41). The generalizability of the results of the present study requires larger trials for validation. Moreover, the relatively small and homogeneous sample, drawn exclusively from populations with social media and internet access, probably does not represent the entire population. This digital recruitment approach inherently excludes individuals without reliable internet connectivity or digital literacy skills, potentially limiting the socioeconomic diversity of our participant pool, making it difficult to generalize the results. Moreover, the study does not examine all factors that may influence the health and socioeconomic status of participants, hence the interest of conducting qualitative studies which will provide more subjective answers.

Implications for practice

Patients with PNDs face multiple physical, economic, and social challenges that require a holistic approach. Specific health programs can ensure better management from diagnosis to palliative care, build a national database and develop research. Raising awareness among professionals, community and decision-makers will ensure visibility for these diseases.

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Conflicts of interest

The authors declared no conflict of interest.

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Authors' Contributions

N.E contributed to the conception and design, data acquisition, data analysis and interpretation and manuscript writing. I.A performed data acquisition and manuscript writing. A.L contributed to the conception and design, data analysis and interpretation. M.R critically revised the manuscript. A.G critically revised the manuscript. All authors have read and agreed to the published version of the manuscript.

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