

Disability Certification for Parkinson's Disease in India: Challenges and the Way Forward

Arun M, Priya Treesa Thomas, Nitish L. Kamble¹, Ravi Yadav¹, Pramod Kumar Pal¹

Departments of Psychiatric Social Work and ¹Neurology, NIMHANS, Bengaluru, Karnataka, India

Abstract

Disability certification is mandatory for people with Parkinson's disease to avail any schemes and benefits in India. The process of certification of the extent of disability in a complex disorder like Parkinson's needs to be made less cumbersome and streamlined to ensure that people for whom the benefits are meant are able to avail them.

Keywords: Disability, Parkinson's disease, social security benefits

A disability certificate is a mandatory document to avail the benefits and schemes of the Government of India. As per the existing disability rules, an individual must have a benchmark disability to avail the benefits. The purpose for which disability certificate is sought varies from individual to individual. People with low socioeconomic status seek a disability certificate to obtain financial assistance to purchase medication, for enrolling in special schools, and for pension transfers.^[1] Half a decade back, the Government of India formulated Right for Persons with Disabilities Act 2016, where 21 types of disabilities including chronic neurologic conditions, multiple sclerosis, and Parkinson's disease were included.^[2] "Unique ID for Persons with Disabilities" is the current platform to issue documents that certify disability according to this act, aiming at creating a centralized database and issuing a Unique Disability Identity Card to each person with disability.

Parkinson's disease is one of the most common movement disorders that primarily affect those over the age of 60. The number of Parkinson's disease cases worldwide has significantly increased in the last two decades. Parkinson's disease has affected 0.58 million people in India, and this number could rise in the coming decades.^[3] Similar to other neurologic disorders like dementia and locomotor disabilities, this particular condition significantly increases morbidity. Also, it results in 18% Years of healthy life lost due to disability (YLD).^[4] Parkinson's disease, multiple sclerosis, and chronic neurologic illnesses are now recognized as

disabilities under the recently passed Rights of Persons with Disabilities Act of 2016.

The Indian government released implementation rules in 2018 to evaluate physical disabilities, but there is still lack of clarity about how to conduct assessments and issue certificates for the identified diseases. In particular, there is no clear guidance on how to measure and evaluate motor functioning in Parkinson's disease. This limitation has significantly affected the utilization of disability certification among the people who require it. There are situations where it is unclear whether the impairment should be while the person is in the 'on' stage (with medication effect) or 'off' stage (without medication effect). Hoehn & Yahr (H & Y) scale and Unified Parkinson's disease rating scale (UPDRS) assessments have been used in specialty clinics to determine the staging and to measure motor performance. The mechanism to measure and include psychosocial disability faced by the affected individual, often beyond the visible disability, is unclear. The motor scales are difficult and not widely used by non-neurologists, which

Address for correspondence: Dr. Priya Treesa Thomas, Department of Psychiatric Social Work, National Institute of Mental Health and Neuro Sciences, Bengaluru, Karnataka, India. E-mail: priyathomasat@gmail.com

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makes it difficult to obtain disability certificates for eligible people.^[2] This has led to the limited adoption of certification in the primary and secondary health-care facilities. According to the 2017 Rights of Persons with Disabilities Rule, there are two ways of obtaining a disability certification. First, as stated in the applicant's proof of residency, persons with disabilities can go to a competent medical authority at the district hospital. The second option is for the applicant to obtain a certificate from the medical staff of the tertiary care specialty hospital from where the person may be receiving or has recently received treatment. At present, the process of assessment of disability to certify is cumbersome and involves inputs and assessment of multiple health-care professions [Figure 1], which limits the usefulness for those who require certification.

Hence, while the rules are in place, in the community, people with Parkinson's have been facing significant barriers in availing disability certificate. A conspicuous lack of movement disorder specialists, hesitation to quantify the disability in a complex disease, lack of clear guidelines on quantifying the disability, and inability to access tertiary care facility for the purpose of disability certification have all contributed toward increasing the burden of persons with Parkinson's disease and their families. A smooth and speedy disability assessment and issuance of disability certification can create hope among people, which will assist them in various ways.

Some of the possible solutions are as follows:

1. Sensitization and orientation of district hospital medical board members for administering functionality assessment (disability) scales for Parkinson's disease
2. Policy implementation guidelines for the evaluation and certification of disability specifically for movement disorders

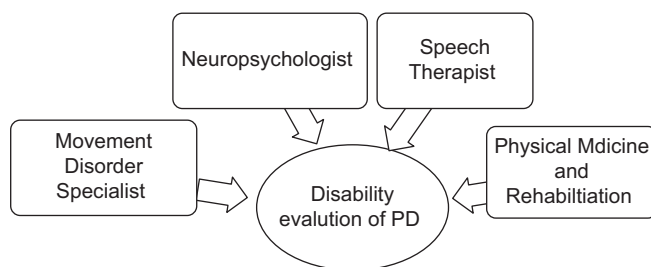


Figure 1: Healthcare professionals involved in the disability evaluation of persons with Parkinson's disease (PwPD)

3. Developing a pathway referral system to tertiary centers that are equipped to assess multisystem disabilities.

For the benefits to reach the needy people, the digitalization and issue process needs to be streamlined and made less cumbersome; otherwise, the very purpose of the scheme itself is not served. There are multiple factors that act as major barriers to people with Parkinson's disease obtaining a disability certificate as described. Due to these obstacles, the majority of them are unable to complete their disability evaluation and certificate process. A collaborative effort and standard operating procedure (SOP) would aid in removing some of the barriers that clinicians face in providing disability certificates to people with Parkinson's disease. A collaborative process among the various disciplines involved in the certification is very much needed and can ideally be co-ordinated by the social worker of the team.

Highlights

1. Parkinson's disease is a complex disorder and affects individuals in a multitude of ways.
2. With more number of people getting affected and diagnosed in younger age groups, it is important to explore avenues to ensure quality of life while living with the disabling condition.
3. Certification of disability for people with Parkinson's disease remains a cumbersome process in the Indian context.

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