

RESEARCH PAPER

Functioning and disability in Parkinson's disease

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Abstract

Objective. To describe functioning and disability of patients with Parkinson's Disease (PD) according to the model endorsed by the International Classification of Functioning Disability and Health (ICF).

Design. Adult PD patients were consecutively enrolled. The ICF checklist and the WHO Disability Assessment Schedule II (WHO-DAS II) were administered in individual sessions. Hoehn and Yahr Staging (HY) was used to define PD severity. Descriptive analyses have been performed to report on HY and WHO-DAS II scores. ICF categories reported as a problem by more than 20% of patients are described in detail.

Results. Ninety-six patients with PD (mean age 64.1, 33.3% females) were enrolled, 48.4% of them were in HY class 2. WHO-DAS II mean score was 18.1 and the most severe limitations are reported in getting around and in participation to social situations. A total of 71 ICF categories reached the threshold of 20%, mostly derived from Activities and Participation domain.

Conclusions. We reported information on a broad set of domains, expanding those PD-specific, such as reduced mobility. Our results are useful to define what dimensions have to be considered to expand disability assessment in patients with PD, considering both symptoms, activities and the role of environmental factors.

Keywords: Parkinson's disease, ICF, ICF checklist, WHO-DAS II, Hoehn and Yahr staging of Parkinson's disease, MHADIE

Introduction

Parkinson's disease (PD) is one of the most common neurodegenerative chronic diseases which usually results in severe disability, especially in later stages, despite the variety of pharmacological and surgical treatment options [1]. Symptoms such as tremors, gait disorders, rigidity, hypophonic voice, painful dystonia, akinesia and bradykinesia, postural abnormalities, sleep disturbances, depression and drug-related problems may progressively lead to falls, social embarrassment and increasing dependence on others for everyday activities, gradually determining reduced health, quality of life and functioning. Since at present PD has no cure, medical treatment and management of patients with PD has primarily aimed at preserving life expectancy [2,3].

Reported prevalence and incidence rates for PD in European countries are 108–257/100,000 and 11–19/100,000 per year, respectively; when only older age groups (>60 years) were included, rates of prevalence and incidence were much higher: 1280–1500/100,000 and 346/100,000, respectively [4]. In Europe, 19% of the global burden of disease, measured through Disability Adjusted Life Years (DALYs), is represented by neuropsychiatric disease, and this percentage raises to 25.5% in high-income countries: PD burden represents 1.6% of total burden of neuropsychiatric disease, and 2.4% among high-income countries [5]. In view of the increasing number of elderly people in developed countries, both the prevalence and the burden of PD are expected to increase as well [4,5]. PD burden

increases due to illness progress, to the appearance of both disease and drug-related problems and to the occurrence of comorbidities, resulting in the extensive utilisation of both health and community services. This increasing burden has substantial economic implications that will be more and more relevant in the next few years, when the increased utilisation of healthcare resources will produce a significant impact on the healthcare systems [6]. Estimated cost of PD per case/year is 7577€; however, data on PD costs needs to be updated because studies are available only in few European countries and new treatments have been introduced since these studies were undertaken, which may have influenced the cost structure [4,7].

In addition to the reduction of disease progression, another main aim of PD treatment is the achievement of the best possible quality of life for patients. In recent years there has been an increased interest in measuring health-related quality of life (HRQoL) and disability in PD. Knowing patient's subjective experience of physical and mental health, functioning in daily living, participation in social networks and general sense of well-being have become an important issue in outcome evaluation [2,8–10]. Disability in PD have been previously measured with ADL scales that focus on independence such as the Unified Parkinson's Disease Rating Scale (UPDRS) [11] and the Functional Independence Measure (FIM) [12], with the Schwab and England scale [13], the Barthel Index [14] and with Activities of Daily Living (ADL) and Instrumental ADL (IADL) subscales of the Older American Resources and Service (OARS) [15]. Hoehn and Yahr Staging of PD (HY) [16] is generally used to classify disease progression and severity.

The majority of the studies that evaluated disability and quality of life in patients with PD used a combination of disease-specific instruments and general health profile measures, whose joint utilisation enables to investigate general domains such as social functioning, emotional functioning, pain and movement-related functions [10,17–19]. Mental and physical impairments can in fact lead to increased disability. Literature findings show that axial impairments is strongly associated with disability [10,20], while less consistent findings are reported on the effect of non-motor and psychiatric symptoms [10,18]. An interesting study focussed on the evolution of disability in PD [19] and reported that loss of ability in performing activities independently arises in the transition between HY stage II and III, and that activities such as walking, housework, dressing moving around are the most limited. These findings are also consistent with that of another study, which identified in functional limitations, more than in physical impairments, the most

problematic aspects of patients with PD [21]. However, these instruments and studies are not able to capture PD patients functioning at all: they are more sensitive to levels of impairments than disability [17]. In fact, components such as services provision and support by family members should be taken into account since they play a relevant role in determining PD patient's actual disability status.

An approach to disability research in PD should instead keep into account disability as the complex interaction between symptoms and contextual factors, considering the level of the body, of the person and the societal level in which disability should be measured [22]. Such an approach is offered by WHO's International Classification of Functioning, Disability and Health (ICF), which provides a common framework for describing functional status information and disability at the level of individuals and populations [23]. To our knowledge, no study relied on the ICF to measure PD-related disability. A systematic review evaluated the effect of exercise on balance by mapping target areas to the ICF, evidencing that the effect of environmental factors is not taken into account [24]. With the ICF, researchers can rely on a globally agreed frame to define a typical spectrum of problems in functioning of patients with each kind of health conditions during the daily activities and appreciate the role of environmental factors in determining the burden of disease.

According to present studies and to estimate on increasing PD costs [4–6], matching ICF-based information on impairments, activities and participation and on environmental factors is of primary interest in research on PD, since it would enable to provide useful information on service utilisation. Such information could in turn improve the definition of health and social services needs as well as related interventions. Aim of the study is, therefore, to describe functioning and disability in patients with PD according to the aforementioned model of disability endorsed by the ICF Classification, in which disability is defined as 'a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors' [22]. We intend to show not only the applicability and feasibility of the ICF to describe PD patients' disability, but also the value added by ICF-based tools in doing this.

Design and methods

Setting and recruitment

This study is part of the 'Measuring Health and Disability in Europe: supporting policy development' (MHADIE) project. Patients seeking treatment for

PD at Besta Institute's Division of Neurology I – movement disorders were consecutively contacted during outpatient neurological examination, or on occasion of hospital recovery, and invited to participate to the study. Patients that agreed were interviewed in individual session by trained researchers [25]; for inpatients, the interview was planned by the fifth day from hospital admission. The study was approved by the institute's ethics committee and patients signed an informed consent form; anti-discrimination rules and standard privacy procedures were followed.

Selection criteria

Adult patients with PD according to the UK Parkinson's Disease Brain Bank criteria [26] (corresponding to ICD-10 category G20) were enrolled in this study. Patients eligible for technological PD treatment (e.g. surgical approaches such as deep brain stimulation, implantation of infusion pump for duodopa or apomorphine), those enrolled in clinical trials in the previous 3 years, those with cognitive impairments or psychiatric comorbidities and those unable to give their consent to the study were excluded.

Materials

Socio-demographic features were collected using MHADIE common clinical protocol which is described elsewhere [27]. In this article, information on the ICF checklist and on the WHO-DAS II are going to be reported [28–30]. The ICF checklist is a selection of 128 ICF categories from the domains of Body Functions (BF), Body Structures (BS), Activities and Participation (A&P) and Environmental Factors (EF). It provides a description of the areas reported as problems or as elements of good functioning, and enables researchers and clinicians to classify the degree of observed problems using severity qualifiers [28]. The WHO-DAS II, on the other hand, is a non-disease-specific, 36-items disability assessment instrument, which provides score on six areas of life and also provides a global disability level [29,30]. PD severity was defined by HY scale [16]. This rating scale has five stages of measurement. Stage 1 and Stage 2 classifies one-sided and bilateral symptoms, respectively, without balance impairment. Stage 3 is used when balance impairment with mild to moderate disease is present, but patients are still physically independent. Stage 4 classifies patients with severe symptoms, but still able to walk or stand unassisted. Finally, Stage 5 classifies patients whose disease severity requires them to be wheelchair-bound or bedridden unless assisted.

Descriptive statistics were employed for reporting data on HY and WHO-DAS II. ICF categories were analysed using a common methodology throughout MHADIE project: those in which at least 20% of persons reported problems or, in case of Environmental Factors, reported the presence of either facilitators or barriers are described in detail [27].

Results

In total, 96 patients with PD entered in the study, out of 141 contacted (acceptance rate 68.1%). The majority of refusal was due to bad health conditions or difficulties in reaching the hospital if not accompanied by a relative. Interviews completion time ranged between 70 and 100 min.

Patients' socio-demographic characteristics are presented in Table I. Several comorbidities were found: 75% of patients presented at least one associated disease, the most common were visual disease (42.7%), musculoskeletal diseases (30.2%), cardiovascular syndromes (29.2%) and endocrine syndromes (14.6%).

With regard to risk factors, 7.3% of patients were smoking on a daily or non-daily basis, on average for 28.7 years (SD 11.8) and smoked on average 12 cigarettes (SD 9.8) each day; 51% of patients drunk alcoholic products in the last month, and mean drunk units number was 11.5 each week (SD 7.6)

Table I. Socio-demographic characteristics of patients with PD.

Total sample ($n=96$)	
Sex	
Female	33.3%
Male	66.7%
Age (years)	
Mean (range)	64.1 (24–90)
Standard deviation	11.3
Marital status	
Unmarried	12.5%
Married	71.9%
Divorced	6.3%
Widower	7.3%
Cohabiting	2.1%
Education	
Less than primary school	2%
Primary school	28.1%
Secondary school	29.2%
High school	31.3%
College/University	7.3%
Post-Graduate	2.1%
Employment	
Governative employee	4.2%
Non-governative employee	11.6%
Self-employed	4.2%
Employer	1.1%
Not working for paid	78.9%

and there was an equal distribution during the week (~ 1.5 – 1.7 drinks each day).

Regarding PD staging, 7.4% of patients were in HY class 1, 48.4% in class 2, 35.8% in class 3 and 8.4% in class 4. A quote of 40.6% of patients were receiving disability benefits.

WHO-DAS II scores are reported in Figure 1. The most important limitations are reported in getting around and in participation to social situations; mean summary score is 18.1.

A total of 71 ICF categories reached the threshold of 20%: 26 from BF domain, one Body Structure, 31 from A&P and 13 from EF.

Percentage of utilisation of BF and BS categories is reported in Figure 2. The threshold of 20% is reached by 26 BF categories and by one BS category (eye, ear and related structures). Among BF, six categories (b250 – taste functions, b510 – ingestion functions, b535 – sensations associated with the digestive system, b545 – water, mineral and electrolyte balance, b770 – gait pattern functions and b830 – other skin functions) were not included in the ICF checklist and added case by case. The most impaired categories are b765 – involuntary movement, b735 – muscle tone and b152 – emotional functions: they were reported as problems by 79.2%, 78.1% and 77.5% of the sample, respectively. Digestive, metabolic and endocrine functions' chapter is the one that contributes most to the description of PD patients' impairments, being represented by six categories.

In the domain of A&P (Figure 3), 31 categories, mostly derived from Mobility and from Self-care chapters, reached the 20% threshold. Performance qualifiers are less limited than capacity ones in the majority of selected categories. Three ICF categories were added to the standard ICF checklist: d410 – changing basic body position, d415 – maintaining a

body position and d460 – moving around in different locations. Performance qualifier was more limited than capacity in two categories, d410 and d415, while in the other capacity was more limited: the difference is particularly broad in some categories such as d110 – watching (57.3%), d620 – acquisition of goods and services (52.1%) and d510 – washing oneself (50%).

Within EF (Figure 4), 13 categories reached the threshold of 20%. They are essentially described as facilitators, with the exception of e225 – climate. Categories are well distributed among chapters, with the exception of chapter e2 – natural environment and human-made changes to environment, represented by only one category. Drugs, family members support and health SSP are the most widespread facilitators (in 99%, 93.7% and 82.3% of the sample, respectively).

Discussion

With this article, we reported ICF-based information on functioning and disability in patients with PD. A broad number of domains from the components of BF, A&P and from EF have been identified. These elements are aspects of patients' functioning, and not a priori disease-specific features. Therefore, the collection of information on body functions impairments did not focus only on common PD-related symptoms, such as impairments related to mobility, emotional disturbances or other problems due to treatments side effects; similarly, the range of activities herein reported was not limited to common problems with mobility or self-care that represent the most relevant problems experienced by patients with PD.

Previous studies focusing on PD patients' disability relied on the evaluation of a limited set of

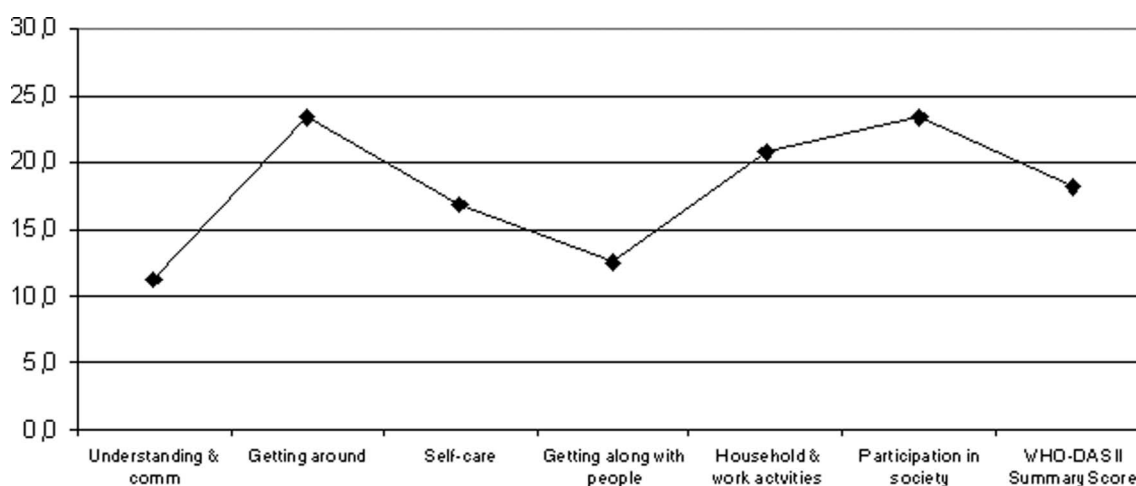


Figure 1. WHO-DAS II score in Parkinson's disease sample.

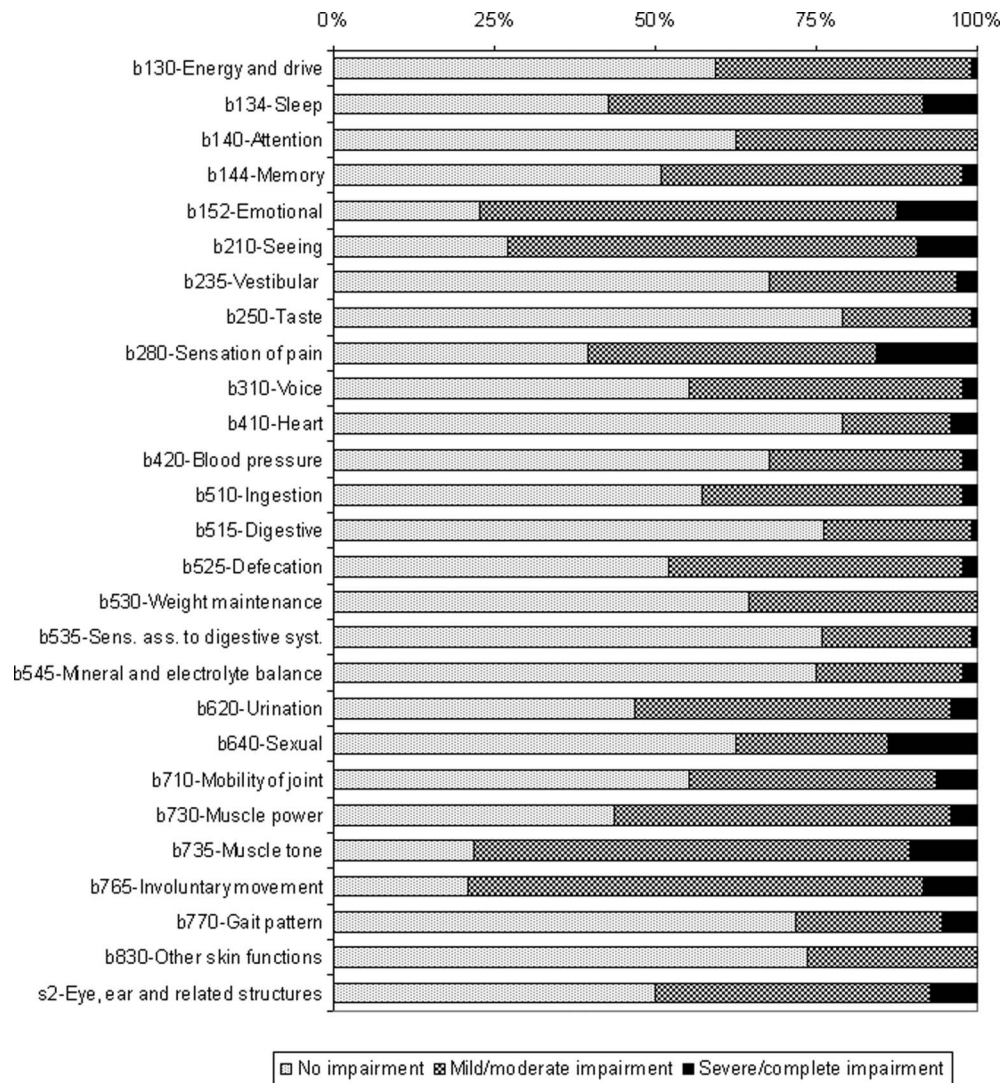


Figure 2. Body Functions and Structures categories reported as a problem by at least 20% of patients with PD.

activities, such as ADL and IADL, and evaluated the impact of a limited set of motor and non-motor symptoms [10,17–21]. Such studies evidenced the relevant influence of symptoms as determinants or correlated of disability in patients with PD [17–19] and the high burden due to motor symptoms, while inconsistent conclusions on non-motor and psychiatric ones are derived. However, these studies failed in representing a comprehensive picture of disability in PD: employed assessment instruments are in fact not able in defining the full range of disability [17]. The description of a profile of functioning and disability is not likely to be adequately accomplished relying on disease-specific measures only [17]: rather, information provided through them should be framed into the ICF, together with a description of EF. It is likely to suppose such failure to be due in an inappropriate conceptualisation of disability [19] that prevented from incorporating all relevant aspects: the level of the body, of the person and of the environment as

defined in the ICF [22,23]. On the contrary, an ICF-based approach to the study of PD, being broader than standard approaches, enables first to collect more and more detailed information on relevant activities, and second to match activities with symptoms and with environmental factors that have facilitating or hindering effects. We reported the presence of several impairments, the majority of whom are related to movement-related functions: no uncommon impairment was detected in the majority of cases. Within A&P, again activities connected to movement are the most affected, but the greatest rate of improvement due to EFs effect were reported in activities connected to domestic life, such as doing housework and preparing meals. Although our data do not enable us to establish causal connections, we deem that this difference between capacity and performance indexes is connected to the facilitating effect of persons providing practical help, such as family members.

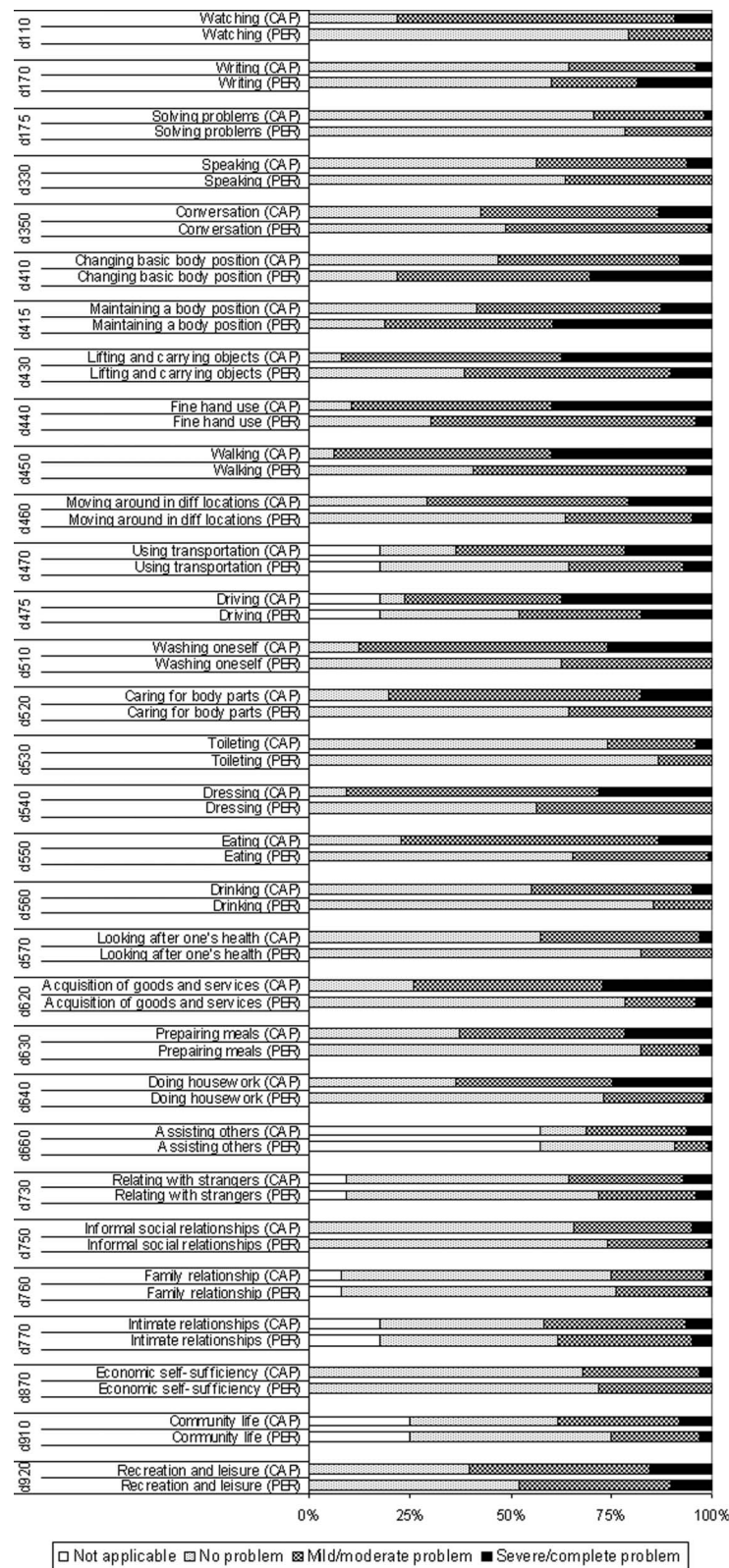


Figure 3. Activities and Participation categories reported as a problem by at least 20% of patients with PD.

Literature findings show that axial symptoms are strongly associated with disability, but no consistent reports were found on non-motor and psychiatric

symptoms [10,18,20,31–33]. The connection between the progression of disease and ability in performing activities independently was studied in

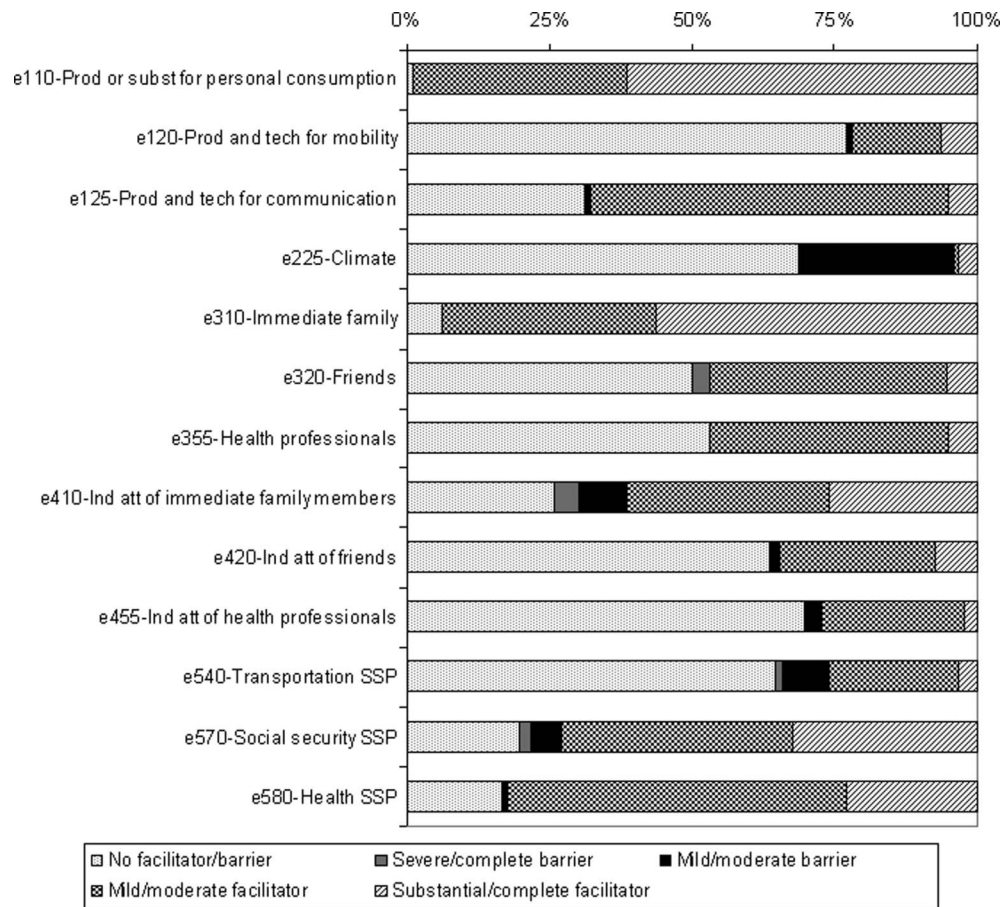


Figure 4. Environmental Factors categories reported as barriers or facilitators by at least 20% of patients with PD.

previous studies [19]. The transition between HY stage II and III increased functional disability in activities such as walking or doing housework, which in our sample were reported as problems in a proportion of patients comprised between 44.2% and 81.4%. A previous research concluded that functional limitations, and not physical impairments, were the most problematic aspect of PD patient's disability profile [21]: our findings are consistent with them, since the majority of relevant categories – 31 out of 71 – were from the A&P domain.

Our study provides the evidence of the utility of the ICF to describe PD-associated functional problems, at the level of body impairments as well as at the level of limitations and restrictions in A&P. The added value in using the ICF to describe PD patient's functioning and disability, instead of relying on a limited number of known and disease-related issues, lies in the possibility of obtaining a profile of functioning that is realistic and specific for each person. This, in turn, makes it possible to tailor the outpatient management of PD consistently with each individual patient's profile. Although we did not detect uncommon issues in this group of patients, this does not mean that single elements can be

relevant for a little number of patients. For example, those in the early stage of PD do not usually face the great amount of mobility problems but, being younger, usually have problems in activities related to job and employment. These issues are usually considered as indirect costs in studies on the cost of disease, but in PD they are almost underestimated [7] as they tend to conflate into retirement due to age, and because the proportion of patients with PD in working age is usually small.

The burden of PD, measured in terms of years of healthy life in GBD studies [5] is not sufficient to define how much of a decrement in functioning is experienced on the basis of the disease. Analysis of PD cost, which focussed on both direct and indirect cost [4,7], contributed to a wider vision, which however needs to be enriched by patients-derived information: the WHO-DAS II is a feasible and easy-to-use tool that provide valid and reliable data on what areas of functioning need to be challenged. The WHO-DAS II in fact provides a measure of the intensity of disease-related problems, since patients are asked to report how many problems they had in undertaking several activities. Moreover, the utilisation of the WHO-DAS II enables the comparison of

disability severity in different health conditions and, among studies aiming to measure disability in PD, it enables to evaluate the determinants of disability upon ICFs well-defined framework. In 2009, Federici et al. [30] reported data on 500 Italian adult subjects, of whom 229 persons with a disability and 271 'normal adults' that were administered the WHO-DAS II. Patients from our sample reported higher scores in all WHO-DAS II scales compared to Federici's 'normal adults' and, only for 'Self-care' scale, data were higher also in comparison to the group of persons with a disability.

This study has some limitations that potentially hamper the generalisability of its results. The study was carried out using a consecutively enrolled convenient sample with no control on HY severity classes. A second potential limitation is related to the setting: Besta Institute Movement Disorders Department is a specialty centre that carries out clinical research on innovative therapies and pathways for diagnosis and treatment of PD. Therefore, our sample cannot be considered as representative of the general Italian or European population of patients with PD. To minimise these limitations, selection criteria excluded patients that participated to clinical trials or that were considered as eligible for technological PD treatment.

Conclusions

Our findings are of primary interest for researchers and clinicians because for the first time a broad list of impairments, activity limitations, participation restrictions and environmental factors are summarised in a comprehensive study. The application of an ICF methodology to report on the role of EF enables to detect it in two ways: first, recording what are the most relevant environmental barriers and facilitators for each patient; second, analysing the difference observed between capacity and performance qualifier for each category, and so identifying which activities mainly benefit from facilitators. We found that patients with PD benefit from environmental factors in several activities, and in majority of them there is a wide ratio of improvement (especially in the area of movement, self-care and domestic life). The difference between capacity and performance underlines the facilitating role of EF: treatments, together with familiar and social support, are helpful at the level of everyday activities and of participation. However, there are some areas in which environmental factors' intervention is less effective on the achievement of a good performance: in particular for activities related to communication and in the domain of personal relationships. Such kind of finding is almost impossible to achieve relying on traditional and

disease-specific measurements of disability, because they do not comprehend such an extended set of impairments and limitations in performing activities: moreover, they do not include the role of relevant environmental facilitators and barriers. On the contrary, extending the number of activities beyond those usually considered, and including the role of environmental factors such as family members or colleagues that provide tangible support to the patients, is crucial to the definition of clinical management and provision of social services to patients with PD. Therefore, the results of this study will also be useful in defining which dimensions have to be considered in order to enhance disability assessment for patients with PD, at the body, the person and the societal levels, including the role of all environmental factors [22]. This in turn will make it possible for clinicians to tailor interventions on the real needs of patients.

Our results are not intended to define the connection between impairments, activity limitations, participation restrictions and the role of environmental factors, which require a correlational approach. Our suggestion is that these issues need to go beyond purely clinical and health-related management, and should be better captured by a public health perspective. PD in facts does not impact only on the individual, in terms of limitations in performing daily activities, but also on families and societies, primarily in term of disease's costs. Health services might use this information to plan better support and care, to the patients and to their families.

Declaration of interest

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