

# Disability and profiles of functioning of patients with Parkinson's disease described with ICF classification

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The objective of this study was to describe the functional profiles of patients with Parkinson's disease (PD), and the relationships between impairment in body functions, limitations in activities, and environmental factors, using the World Health Organization's International Classification of Functioning, Disability, and Health (ICF). Patients were consecutively enrolled, and the ICF checklist was administered. Two count-based indices were developed: 'extension', containing ICF categories rated with qualifiers 1–4 and 'severity', containing ICF categories rated with qualifiers 3–4. Categories rated with qualifiers 1–4 in at least 50% of patients are described separately. Spearman's correlation analysis was carried out to identify the relationships between impairments in body functions (BF) and body structures, activities and participation, and environmental factors (EF); linear regressions were performed to identify the best predictors of performance indices in activities and participation. A total of 96 patients were enrolled; 34 categories rated with qualifiers 1–4 in at least 50% of patients are reported, and most of them describe impairment in movement-related functions and limitations in mobility and self-care. Performance indices are significantly lower than capacity and significant relationships with both BF impairments and EF are observed. High difficulties in activities and participation performance are connected with both presence of severe BF symptoms and relevant barriers in EF. Both BF and EF play a relevant role in improving functioning of the patients with PD. The connection between EF barriers and severe problems in activities and participation performance suggests the need of fostering participation of patients with PD by promoting facilitators among EFs. Methodologies and tools are needed to couple information on symptoms, on the difficulties in executing activities, and on environmental features.

Ziel der vorliegenden Studie war die Beschreibung der Funktionsprofile von Patienten mit dem Parkinson-Syndrom und der Beziehung zwischen Beeinträchtigungen der Körperfunktionen, Einschränkungen der Aktivitäten und Umweltfaktoren unter Zuhilfenahme der Internationalen Klassifikation der Funktionsfähigkeit, Behinderung und Gesundheit (ICF) der Weltgesundheitsorganisation (WHO). Die Patienten wurden konsekutiv rekrutiert, und die ICF-Checkliste wurde angewandt. Zwei zahlenbasierte Indizes wurden entwickelt: 'Erweiterung', d.h. die ICF-Kategorien, die mit den Scores 1–4 bewertet werden, und 'Schweregrad', d.h. die

ICF-Kategorien, die mit den Scores 3–4 bewertet werden. Die mit den Scores 1–4 bei mindestens 50% der Patienten bewerteten Kategorien werden separat beschrieben. Die Korrelationsanalyse nach Spearman wurde durchgeführt, um die Beziehungen zwischen Beeinträchtigungen der Körperfunktionen und Körperstrukturen, Aktivitäten und Teilhabe sowie Umweltfaktoren zu ermitteln; die Durchführung linearer Regressionsanalysen diente der Identifizierung der besten Prädiktoren der Leistungsindizes im Bereich der Aktivitäten und Partizipation (Teilhabe). Insgesamt 96 Patienten wurden in die Studie eingeschlossen. Berichtet wird von 34 Kategorien, die mit den Scores 1–4 bei mindestens 50% der Patienten bewertet werden, von denen die meisten Behinderungen bei den bewegungsbezogenen Funktionen sowie Einschränkungen bei Mobilität und Selbstversorgung beschreiben. Die Leistungsindizes sind signifikant niedriger als die Leistungsfähigkeit, und bei den Beeinträchtigungen der Körperfunktionen und den Umweltfaktoren werden signifikante Beziehungen beobachtet. Große Schwierigkeiten bei Aktivitäten und der Teilhabeleistung stehen sowohl mit der Präsenz schwerwiegender Körperfunktionssymptome und einschlägiger Barrieren bei den Umweltfaktoren in Verbindung. Sowohl die Körperfunktionen als auch die Umweltfaktoren spielen eine einschlägige Rolle bei der Verbesserung der Funktionsfähigkeit der Patienten mit dem Parkinson-Syndrom. Die Verbindung zwischen den Barrieren bei den Umweltfaktoren und schwerwiegenden Problemen bei Aktivitäten und der Teilhabeleistung legen die Notwendigkeit für die Förderung einer Teilhabe von Patienten mit dem Parkinson-Syndrom durch die Förderung der Förderfaktoren (Facilitators) unter den Umweltfaktoren nahe. Dazu sind Methoden und Werkzeuge erforderlich, um Informationen über Symptome, über die Schwierigkeiten bei der Ausübung von Aktivitäten und über Umweltaspekte miteinander zu verknüpfen.

El objetivo de este estudio fue describir los perfiles funcionales de los pacientes con enfermedad de Parkinson (EP), y las relaciones entre el deterioro de las funciones corporales, las limitaciones para la realización de actividades y los factores medioambientales, utilizando para ello la Clasificación del Funcionamiento, de la Discapacidad y de la Salud (CIF), de la Organización Mundial de la Salud. Los pacientes se incorporaron al estudio de forma consecutiva, y a cada uno se le pidió

contestar el cuestionario de la CIF. Se crearon dos índices de conteo: 'magnitud', en el que se incluyeron las categorías de la CIF en las que la valoración se realiza mediante los calificadores del 1 al 4, y 'gravedad', en el que se incluyeron las categorías de la CIF en las que la valoración se realiza mediante los calificadores 3 y 4. Se describen, en una sección aparte, las categorías valoradas mediante los calificadores 1 a 4 en al menos el 50% de los pacientes. Mediante el análisis de correlación de Spearman se determinaron las relaciones entre las afectaciones de funciones corporales (FC) y de estructuras corporales, la realización de actividades y la participación en ellas, y los factores medioambientales (FMA). Se realizaron análisis de regresión lineal para determinar los mejores factores pronóstico de los índices de rendimiento en la realización de actividades y la participación en ellas. En el estudio participaron 96 pacientes. Se presentan 34 categorías evaluadas mediante los calificadores del 1 al 4 en al menos el 50% de los pacientes, y la mayoría de ellas muestran la presencia de discapacidad en funciones asociadas a la movilidad y limitaciones en la movilidad y el cuidado personal. Los índices de rendimiento fueron mucho más bajos que los de la capacidad, y se observaron relaciones importantes entre los FMA y las afecciones de las FC. Las grandes dificultades observadas en la realización de actividades y en el rendimiento estuvieron relacionadas con la presencia de intensos síntomas de afecciones de FC y obstáculos específicos asociados a FMA. Tanto las FC como los FMA desempeñan un papel importante en la mejora del funcionamiento en pacientes con EP. La relación entre los obstáculos asociados a FMA y las alteraciones importantes de rendimiento en la realización de actividades y la participación en ellas sugiere la necesidad de fomentar la participación de los pacientes con EP mediante la promoción de facilitadores en los FMA. Deben elaborarse metodologías y herramientas que permitan determinar las relaciones entre los síntomas, las dificultades para la realización de actividades y los factores medioambientales.

**Cette étude avait pour objet de décrire les profils fonctionnels des patients atteints de la maladie de Parkinson (MP) et les relations entre les déficiences des fonctions corporelles, les limitations dans les activités et les facteurs environnementaux, en utilisant la classification internationale du fonctionnement, du handicap et de la santé (CIF) de l'Organisation Mondiale de la Santé. Les patients ont été enrôlés consécutivement, et la liste de contrôle CIF a été administrée. Deux indices ont été**

## Introduction

Parkinson's disease (PD) is one of the most common neurodegenerative diseases, which, despite the variety of pharmacological and surgical treatment options, usually results in severe disability, especially in later stages

développés sur la base d'un décompte: extension, contenant les catégories CIF évaluées avec des qualificatifs de 1 à 4 et sévérité contenant les catégories CIF évaluées avec des qualificatifs de 3 à 4. Les catégories évaluées avec des qualificatifs de 1 à 4 chez au moins 50 des patients sont décrites séparément. Une analyse de corrélation de Spearman a été effectuée pour identifier les relations entre les déficiences des fonctions corporelles (FC) et les structures, les activités et la participation corporelles, et les facteurs environnementaux (FE); des régressions linéaires ont été effectuées pour identifier les meilleurs prédicteurs des indices de performance dans les domaines des activités et de la participation. Un total de 96 patients ont été recrutés; 34 catégories évaluées avec des qualificatifs de 1–4 chez au moins 50% des patients ont été signalées, et la plupart d'entre eux ont décrit des déficiences des fonctions relatives aux mouvements et des limitations de la mobilité et des soins personnels. Les indices de performance sont nettement inférieurs à la capacité, et des relations significatives avec les déficiences tant FC et FE ont été observées. D'importantes difficultés dans les activités et la performance participative sont associées à la présence de symptômes graves au niveau des FC et d'obstacles pertinents dans les FE. Les facteurs environnementaux et les fonctions corporelles jouent un rôle important dans l'amélioration des fonctionnalités des patients souffrant de la MP. La connexion entre les barrières FE et les graves problèmes dans les activités et la performance participative suggère la nécessité d'encourager la participation des patients atteints de MP par la promotion de facilitateurs parmi les FE. Des méthodologies et des outils sont nécessaires pour relier les informations aux symptômes, aux difficultés dans l'exécution des activités et aux caractéristiques environnementales. *International Journal of Rehabilitation Research* 34:141–150 © 2011 Wolters Kluwer Health | Lippincott Williams & Wilkins.

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(Behari *et al.*, 2005). Approximately, 1–2% of the population older than 65 years (3–5% older than 85 years) suffers from PD, with a male–female ratio of 1.58 (Taylor *et al.*, 2007; Alves *et al.*, 2008), and incidence varies between 8.6 and 19 per 100 000 inhabitants (Fahn, 2003;

Twelves *et al.*, 2003; Alves *et al.*, 2008). In view of the increasing number of elderly people in developed countries, the prevalence of PD is expected to increase, as well (Lindgren *et al.*, 2005). PD symptoms may progressively lead patients to an increasing dependence on others. Thus, treatment of PD primarily aims at preserving life expectancy and limiting motor impairments (Quittenbaum and Grahn, 2004; Pandya *et al.*, 2008).

PD burden increases due to illness progress, to both disease and drug-related problems and to the occurrence of comorbidities, resulting in the extensive utilization of health and community services. This increasing burden has substantial economic implications, which will be more and more relevant in the next few years, when the increased utilization of healthcare resources will produce a significant impact on the healthcare systems (Findley, 2007). Working capacity of patients with PD is another relevant issue, and previous research findings generally accounted for an early retirement of patients with PD of approximately 6 years (Martikainen *et al.*, 2006; Schrag and Banks, 2006). Early retirement of patients with PD implies substantial economic consequences and is a major driver of the disease's cost. Estimated cost of PD per case per year is 7577€ and almost half of this is related to indirect costs that are strictly connected to work capacity reduction (Andlin-Sobocki *et al.*, 2005; Lindgren *et al.*, 2005).

Previous research findings on working capacity of patients with PD generally accounted for an early retirement of these patients of approximately 6 years (Martikainen *et al.*, 2006; Schrag and Banks, 2006). However, despite the economic relevance of preserving working capacity and the fact that treatments are intended to limit motor impairments, the connection between working capacity reduction and restriction to participation is unexplored. In fact, participation of patients with PD has been measured earlier with activity of daily living scales that focus on independence such as the Unified Parkinson Disease Rating Scale (Fahn and Elton, 1987) and the Functional Independence Measure (Keith *et al.*, 1987), with the Schwab and England scale (Schwab and England, 1969) or the Barthel index (Wade and Collin, 1988).

The majority of studies that evaluated disability and quality of life in patients with PD used disease-specific instruments together with general health profile measures to investigate domains such as social and emotional functioning, pain, and movement-related functions (Muslimovic *et al.*, 2008; Shulman *et al.*, 2008; Tanji *et al.*, 2008). Literature findings show that axial impairment is strongly associated with disability (Post *et al.*, 2007; Muslimovic *et al.*, 2008; Visser *et al.*, 2009), whereas less consistent findings are reported on the effect of nonmotor and psychiatric symptoms (Weintraub *et al.*, 2004; Muslimovic *et al.*, 2008; Gruber-Baldini *et al.*, 2009;

Menza *et al.*, 2009). What is missing is a comprehensive research perspective, which understands disability associated to PD as the complex interaction between impairments in body functions (BF) and contextual factors; 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 (Leonardi *et al.*, 2006). This conceptualization is based on the World Health Organization's International Classification of Functioning, Disability, and Health (ICF; World Health Organization, 2001a). Disability is conceptualized in the ICF as the interaction, in an individual, between the problems experienced as BF and body structure (BS) impairments, limitations in performing activities and restrictions to participation, and the role of environmental factors (EF) or personal factors, which can be facilitating or hindering. The ICF comprises a classification system for BF and BS impairments, for limitations and restrictions in activities and participation, and for EF, whereas it is not available for personal factors. Activities are described considering the possible effect of EF as well as the intrinsic ability of the person. The first case corresponds to the description of an individual's performance: problems experienced in performance are the expression of the difficulties due to BF and BS impairments together with the facilitating or hindering role of EF. The second case corresponds to the description of an individual's capacity; problems in capacity correspond only to the direct expression of BF and BS impairments. The difference between performance and capacity in activities and participation represents the effect of EF.

Few attempts have been made to study them with ICF-based procedures. In a first study (Wynia *et al.*, 2006), the continuum of health problems in patients with multiple sclerosis, PD, and neuromuscular disease was explored. Selected ICF categories indicated a broader scope in studying health problems compared with widely used health status measures. A second study (Ravenek and Schneider, 2009) investigated the influence of social support on physical activity participation in patients with early stage PD, and found positive effects of instrumental, emotional, and informational supports. A direct application of the ICF to patients with PD is described in a recent publication (Leonardi *et al.*, 2009a) in which the profiles of functioning of patients with PD were compared with those of patients with migraine and myasthenia gravis. The comparative analysis showed that patients with PD were more likely to experience moderate-to-severe disability than those with migraine and myasthenia gravis, but poor indication on the relationships between ICF components was included.

An ICF-based approach can contribute to describing which functioning domains, in addition to known PD features, are impaired or limited, and can be useful to

collect information on a broad set of impairments, activity limitations, and EFs that contribute to improving or worsening patients' functioning. The special focus on EF makes it possible to point out patients' needs that can be recognized whenever barriers are reported or when a reasonable performance level is not achieved. Moreover, in an ageing population, such as that of patients with PD, it is also relevant to identify the situations in which facilitators within EF are detected from informal networks (i.e. family members) instead of formal ones (i.e. service providers). Moreover, the description of a profile of functioning and disability is not likely to be adequately accomplished relying on disease-specific measures only (Tanji *et al.*, 2008); rather, information provided through them should be framed into the ICF, together with a description of EF. An ICF-based approach to the study of PD, being broader than standard approaches, enables to collect more and more detailed information on relevant activities and to match activities with symptoms and with EFs that have facilitating or hindering effects.

A complete ICF-based description of disability features of patients with PD, in which the description of the most relevant ICF categories is reported jointly with a description of the relationships between them, is lacking. This kind of information is useful to provide preliminary evidence on what areas can be addressed to improve functioning of the patients with PD. The aim of this study was to describe functioning of the patients with PD according to ICF model of disability, and to explore the joint effect of BF and BS impairment and EF facilitators and barrier on limitation experienced in activities and participation.

## Methods

### Study design

This was a cross-sectional observational study, in which patients were enrolled consecutively.

### Participants and setting

Patients were enrolled among those who underwent periodical outpatient evaluation or hospitalization at the Movement Disorders Department of 'Carlo Besta' Institute. The study was approved by the Institute's ethics committee and patients signed an informed consent form.

Inclusion criteria were diagnosis of PD according to the UK Parkinson's Disease Brain Bank criteria (Hughes *et al.*, 1992) and age of more than 18 years. Patients were excluded if they were selected for technological PD treatment (e.g. surgical approaches such as deep brain stimulation, implantation of infusion pump for duodopa, or apomorphine), and if they had cognitive impairment and psychiatric comorbidities. Patients enrolled in clinical trials in the earlier 3 years and those unable to give their consent were excluded too.

## Materials

The ICF checklist, which is a selection of 128 first and second level ICF categories, was used to interview patients (World Health Organization, 2001b). It includes 32 categories from the component of BF (approximately 25% of all ICF BF categories), 16 (29%) from BS, 48 (41%) from activities and participation, and 32 (43%) from EF. As it does not represent an exhaustive set of categories and is not disease specific, other ICF categories can be added, whenever appropriate, to describe specific problems or to report specific EFs.

ICF qualifiers are rated on a 0–4 scale for BF, BS, and activities and participation. Qualifier 0 refers to no impairment/difficulty, whereas qualifiers 1–4 report on the presence of problems:

- (1) mild impairment/difficulty (problem in < 25% of the time, with an intensity a person can tolerate and that happened rarely during the last 30 days);
- (2) moderate impairment/difficulty (problem present at < 50% of the time, with an intensity that interfered with the persons' daily life and which happened occasionally over the last 30 days);
- (3) severe impairment/difficulty (problem present > 50% of the time, with an intensity that partially disrupts the person's day-to-day life and which happened occasionally over the last 30 days);
- (4) complete impairment/difficulty (problem present at > 95% of the time, with an intensity that is totally disrupting the person's day-to-day life and which happened every day over the last 30 days).

The same rating scale is also used for EF, and facilitators are identified by the sign '+' (e.g. +2 identifies a moderate facilitator). Two more qualifiers are available. Qualifier 8 (not specified; or +8 in case of EF facilitators) identifies the case in which it is not possible to define how much a problem was detected in a given ICF category, but a problem has been identified; therefore, it is used when it is not possible to decide for a qualifier in the range 1–4. Qualifier 9 (not applicable) is used when a category cannot be applied to a person by definition (e.g. menstruation functions in men). Few studies evaluated ICF categories metric properties: reported inter-rater reliability  $\kappa$  index varied between 0.36 and 0.71, indicating different ranges of reliability, from moderate to excellent, using different set of ICF categories both in adults and children (Kronk *et al.*, 2005; Okochi *et al.*, 2005; Grill *et al.*, 2007; Uhlig *et al.*, 2007; Soberg *et al.*, 2008; Starrost *et al.*, 2008).

The stage of PD was defined by the Hoehn and Yahr (HY) classification of PD (Hoehn and Yahr, 1967). This is a five-stage scale: stages 1 and 2 classify 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 who are still able to walk or stand unassisted; and stage 5 classifies patients whose disease severity requires them to be wheelchair bound or bedridden unless assisted.

### Procedures

Outpatients were informed about the study on the occasion of a periodical examination; those who agreed were phoned to define the date and time for an individual session interview at the Institute. In contrast, inpatients were interviewed within the fifth day from their hospital admission. Information was collected during semistructured interviews by researchers trained to the use of the ICF checklist by Disability Italian Network (Francescutti *et al.*, 2009). The timeframe for the ICF checklist is the previous month.

Information on the presence of problems referred to BF and BS was taken from medical records, in particular those regarding known impairments related to PD (e.g. muscle tone, involuntary movements, and urinary functions), and were directly asked to participants when not included in standard records (e.g. seeing functions). Information on limitations and restrictions in activities and participation and on the presence of facilitator and barriers among EFs were asked to participants only. Nonstructured questions were made to participants; ICF categories were rated with the most appropriate qualifiers on the basis of definition of the problem severity provided by respondents. In activities and participation, performance qualifiers are first rated and for each single-category patients were asked on the effect on the impact of EF that are relevant for that specific category. Therefore, to classify capacity, we rely on the current environment and adjust for estimated effect on performance of environmental barriers or facilitators. In this way it is possible to get a realistic description of capacity and of the gap between performance and capacity that represents a rough estimate of the impact of a person's environment on the performance predicted by this capacity. For example, measuring capacity in mobility poses relevant ethical issues, as patients with PD are always under treatment with medications that reduce mobility problems. Therefore, you can adjust for estimated effect on EF in mobility asking patients about their difficulties when, for example, they take medication late and their effect is reduced.

### Data analysis

ICF categories rated with qualifier 8 were replaced by the median value of each category comprised between qualifiers 1 and 4; the rationale for this is that qualifier 8 is used when it is not possible to decide among qualifiers 1–4. Therefore, replacement with the median value alters in the least significant way the variation for

each category among patients. In case a category was rated only with qualifier 8 and never with qualifiers 1–4 (so the median results in a missing value), qualifiers 8 were converted into 1. The rationale for this is that qualifier 1 describes a situation in which the level of problem reported by a patient is not clinically relevant. We decided on this replacement as we supposed that a person that has no cognitive problems should be able to understand and report on the presence of a problem. ICF categories rated with qualifier 9 were converted into missing, because if a category is not applicable by definition, as a result there is no information on a problem's presence or severity.

A count-based method to analyze data was performed, and for each ICF domain (BF, BS, activities and participation, and EF) the following two indices were developed: 'extension' and 'severity'. The first is the count of categories in which qualifiers 1–4 (describing the full range from mild-to-complete problems) were applied, whereas the second is the count of categories in which qualifiers 3–4 (describing only the range of severe and complete problems) were applied. These count-based indices were then transformed into percentage scores to make them easily and directly comparable, by means of this procedure:  $\text{Count/Max} \times 100$ . Transformed values range varies between 0 and 100, with lowest values representing complete integrity of BF and BS, complete absence of limitation or restriction in the activities and participation domains, and in the environmental higher values represent a complete presence of barriers, or a complete presence of facilitators. The paired-sample *t*-test was used to evaluate the extent to which significant differences are accounted for performance and capacity indices, such a difference is an indirect measure of the effect of EFs.

The Spearman's correlation analyses were carried out between extension and severity indices of activities and participation, BF, BS, and EF. Linear regressions were performed entering BF, BS, and EF indices as predictors and entering performance indices as dependent variables, as in the ICF model the actual level of performance results from the joint effect of impairment and of EFs. The multicollinearity test was carried out; tolerance levels higher than 0.20 and a variance inflation factor lower than 5 indicate the absence of multicollinearity problems and, therefore that basic requirements for linear regression were met. For each component, ICF categories rated as a problem (or as a facilitator in EF) in more than 50% of patients, and therefore representing the core problems for each specific domain, are reported separately. We decided to rely on this threshold to focus on the most relevant problems of our patients with PD who, in consideration of their age, are likely to report several problems that might not be strictly related to PD. With such a high threshold, we should be able to avoid the

reporting of issues that are not related to the disease but to other reasons, such as comorbidities or age.

**Results**

A total of 96 patients (66.7% male), aged 24–90 years (mean age 64.1) were enrolled. At inclusion, 13.5% of patients were in HY stages 1–1.5, 57.3% in stages 2–2.5, 22.9% in stages 3–3.5, and 6.3% in stage 4. A total of 74% of patients were married or cohabitating. Seventy-six were not working for pay, those not working were significantly older than those working at an independent sample *t*-test (mean age difference was 15.6 years, *t* = 6.62, *P* < 0.01).

Means and standard deviations of transformed counts for each domain are reported in Table 1. The paired-sample *t*-test shows that performance indices, both extension and severity, were significantly lower than capacity ones, being mean extension index of 20.2 in performance and 33.7 in capacity, whereas severity indices were 2.2 and 9.7, respectively. Within EF, facilitators presence is six times higher than that of barriers. The most relevant categories are listed in Table 2: 34 categories were reported, eight from BF domain (three of them are neuromusculoskeletal and movement-related functions, e.g. muscle tone), 18 from activities and participation (eight of them are from mobility chapter, e.g. walking and fine hand use), seven from EF, essentially reported as facilitators (e.g. support from immediate family members). Only one category from BS (the eye, the ear, and related structures) was reported by more than 50% of patients.

The Spearman’s correlation analyses between the different ICF domains are reported in Table 3. Moderate correlations are reported between the number of BF impairments and the number of limitations in activities and participation, higher when severity indices were considered. Lower correlation indexes were on the contrary observed between EF and activities and participation indices; they are stronger between the number of severe barriers and severe limitations in performance, and between the number of very relevant facilitators and the number of severe limitations in capacity. Moderate correlations have been found between the extension index of capacity and both the extension and severity indices of

**Table 1 Descriptive statistics for ICF checklist components**

	Extension index mean (SD)	Severity index mean (SD)
Body functions	24.5 (11.4)	2.3 (3.5)
Body structures	7.3 (6.8)	1.9 (3.4)
Activity and participation-performance	20.2 (11.2)*	2.2 (3.6)**
Activity and participation-capacity	33.7 (9.7)*	9.7 (10.7)**
Environmental factors (barriers)	2.9 (3.2)	0.3 (1.2)
Environmental factors (facilitators)	18.8 (5.1)	6.2 (4.6)

SD, standard deviation.

\*Paired-sample *t*-test: *t* = 15.04, *P* < 0.01.

\*\*Paired-sample *t*-test: *t* = 8.88, *P* < 0.01.

**Table 2 List of ICF checklist relevant categories, reported with qualifiers 1–4 in at least 50% of patients**

Percent of impairments in body functions (%)	
b765, involuntary movement functions (n=88)	79.1
b735, muscle tone functions (n=88)	78.1
b152, emotional functions (n=88)	77.1
b210, seeing functions (n=86)	72.9
b280, sensation of pain (n=80)	60.4
b134, sleep functions (n=88)	57.3
b730, muscle power functions (n=77)	56.2
b620, urination functions (n=86)	53.1
Percent of impairments in body structures	
s2 The eye, the ear, and related structures (n=69)	50.0
Percent of problems in activities and participation (capacity qualifier)	
d450, walking (n=95)	93.8
d430, lifting and carrying objects (n=93)	91.7
d540, dressing (n=96)	90.6
d440, fine hand use (n=92)	89.5
d510, washing oneself (n=96)	87.5
d520, caring for body parts (n=87)	80.2
d415, maintaining a body position <sup>a</sup> (n=91)	80.2
d110, watching (n=94)	78.17
d550, eating (n=95)	77.1
d410, changing basic body position <sup>a</sup> (n=91)	77.1
d475, driving (n=79)	76.0
d620, acquisition of goods and services (n=76)	74.0
d460, moving around in different locations <sup>a</sup> (n=91)	69.8
d640, doing housework (n=67)	63.5
d470, using transportation (n=79)	63.5
d630, preparing meals (n=64)	62.5
d920, recreation and leisure (n=90)	60.5
d350, conversation (n=95)	57.3
Percent of environmental factors (% of barriers only)	
e110, products or substances for personal consumption (n=96)	99.0 (0.0)
e310, immediate family (n=90)	93.8 (0.0)
e580, health services systems and policies (n=81)	83.4 (2.0)
e570, social security services systems and policies (n=77)	80.2 (7.3)
e410, individual attitudes of immediate family members (n=72)	74.0 (12.5)
e125, products and technology for communication (n=68)	68.7 (1.0)
e320, friends (n=50)	50.0 (3.1)

Note that for environmental factor, percent of barriers is reported separately between brackets, whereas general percentage is referred to the sum of barriers and facilitators.

<sup>a</sup>Not included in the standard International Classification of Functioning, Disability, and Health checklist and were added case by case.

performance; this correlation is strong when severity index of capacity is considered.

The first linear regression, in which performance extension index was entered as dependent variable, is reported in Table 4. The model explains 29% of variation (regression sum of square = 3973.5; residual sum of square = 7895.5); BF extension and severity indices were the best predictors. The second linear regression, in which performance severity index was entered as dependent variable, is reported in Table 5. The model explains 62% of variation (regression sum of square = 780.3; residual sum of square = 432.5); BF severity, BS severity, EF barriers severity indices were the best predictors. In both regression models, no problem with multicollinearity was detected.

**Discussion**

The aim of this cross-sectional study was to describe functioning of the patients with PD according to the ICF model of disability, and to explore the joint effect of impairments in BF and BS and of facilitators and barrier

**Table 3 Spearman's correlations between count-based indices in activities and participation, body functions, body structures, and environmental factors domains**

	Activities and participation performance extension	Activities and participation performance severity	Activities and participation capacity extension	Activities and participation capacity severity
Activities and participation performance extension	–	–	–	–
Activities and participation performance severity	0.62*	–	–	–
Activities and participation capacity extension	0.62*	0.50*	–	–
Activities and participation capacity severity	0.76*	0.70*	0.62*	–
BF extension	0.42*	0.34*	0.51*	0.43*
BF severity	0.46*	0.55*	0.43*	0.67*
BS extension	ns	ns	ns	ns
BS severity	ns	ns	ns	0.22
EF barriers extension	ns	0.32*	0.25	0.21
EF barriers severity	ns	0.29*	ns	ns
EF facilitators extension	ns	ns	0.27*	ns
EF facilitators severity	ns	0.25	0.25	0.38*

Unmarked correlations are significant at  $P < 0.05$ .  
 BF, body function; BS, body structure; EF, environmental factors; ns, not significant.  
 \* $P < 0.01$ .

**Table 4 Linear regression model**

	<i>R</i>	<i>R</i> <sup>2</sup>	Adjusted <i>R</i> <sup>2</sup>	<i>F</i>	Collinearity statistics	
Model	0.58	0.34	0.29	7.47*		
Coefficients	B	Standard error	β	t	Tolerance	VIF
BF extension	0.37	0.11	0.37	3.25*	0.55	1.80
BF severity	0.96	0.34	0.30	2.79*	0.64	1.57
BS extension	– 0.29	0.17	– 0.18	– 1.75	0.73	1.38
EF barriers severity	1.37	0.82	0.15	1.67	0.95	1.05
EF facilitators extension	– 0.24	0.22	– 0.11	– 1.09	0.76	1.32
EF facilitators severity	0.27	0.25	0.11	1.06	0.70	1.43

Dependent variable: activities and participation performance extension index.  
 BF, body function; BS, body structure; EF, environmental factor; VIF, variance inflation factor.  
 \* $P < 0.01$ .

**Table 5 Linear regression model**

	<i>R</i>	<i>R</i> <sup>2</sup>	Adjusted <i>R</i> <sup>2</sup>	<i>F</i>	Collinearity statistics	
Model	0.80	0.64	0.62	32.47**		
Coefficients	B	Standard error	β	t	Tolerance	VIF
BF severity	0.74	0.07	0.73	11.18**	0.92	1.08
BS extension	0.05	0.04	0.10	1.28	0.60	1.67
BS severity	– 0.21	0.08	– 0.20	– 2.44*	0.60	1.65
EF barriers severity	1.00	0.19	0.34	5.19**	0.94	1.07
EF facilitators extension	0.08	0.05	0.11	1.75	0.93	1.08

Dependent variable: activities and participation performance severity index.  
 BF, body function; BS, body structure; EF, environmental factor; VIF, variance inflation factor.  
 \* $P < 0.05$ .  
 \*\* $P < 0.01$ .

within EF on limitation experienced in activities and participation. Our results show several impairments, mostly in movement-related functions, and a distinct pattern referred to the dimensions of performance and of capacity. Limitations in activities and participation are much more connected and due to impairments in BF than due to presence of EF.

The burden of PD cannot be predicted through an analysis of incidence and prevalence only. Such an analysis can provide reasonable estimates of PD health-care costs, which account for approximately half of the total disease costs (Andlin-Sobocki *et al.*, 2005; Lindgren *et al.*, 2005), but poor indication on cost due to reduced ability to perform activities is connected to work.

The distinction between ICF dimensions of capacity and performance is a controversial issue (Nordenfelt, 2006). The results of our analysis show that the two dimensions are diverse, as proved by the fact that extension and severity indices, although correlated, report different score ranges, in particular when severity indices only are taken into account. We are likely to suppose that the two indices underline two different constructs and this hypothesis is reinforced by the fact that direct and significant correlations are observed between barriers in EF and performance severity index, and that BF are more correlated with capacity than with performance. Although capacity is directly related to BF impairments' presence, and so more numerous and severe impairments determine more and more severe capacity problems, performance is determined by the joint effect of impairments and EF effect. Our results highlight two different points. First, severe performance problems are strongly connected to the presence of severe barriers, in addition to the presence of impairments that have a pervasive effect. Second, it is likely to conclude that there is a difference between the performance and the capacity qualifier, and that while capacity is described with qualifiers 3 or 4, performance is often described with qualifiers 1 or 2, this means that EF sometimes are able to 'resolve' problems, but in a relevant number of situation or cases, problems can only be eased.

With regard to EF, we observed an interesting finding, namely, that the number of significant association between EF factors and activities and participation was higher with capacity than with performance. The analysis shows that facilitators are significantly connected (even if the correlation is low) with capacity indices and this correlation is higher between EF facilitator's severity and activities and participation severity capacity indices. In theory, capacity should be independent of EF, but what we actually observe is the relationship between relevant problems in capacity and the presence of facilitators that contribute to easing these problems: this is what, practically, is observed when the difference between capacity and performance is taken into account. Basically, this means that those patients experiencing a high number of severe difficulties in performing activities (e.g. those connected to mobility and self care) are also those exposed to a higher number of relevant facilitators (e.g. medications and support from family members). In other words, these are the situations in which patients' needs are met.

Moderate association between performance indices and BF impairments is observed, whereas the association with barriers in EF is low, and regression models show that impairments in BF are independent predictors of extension index. Although only when the most severe performance limitations are taken into account, presence of severe barriers and of BS impairments have a role too. This means that severe problems in performance might

be due to the persistence of barriers in EF, but also to the presence of impairments with both BF and BS. In a neurodegenerative disease such as PD, symptom severity increases consistently with disease progression, and medical treatments can only partially ease patients' problems in areas such as mobility, communication, or self care. Literature findings show that axial symptoms are strongly associated with disability, but no consistent reports were found on nonmotor and psychiatric symptoms (Weintraub *et al.*, 2004; Post *et al.*, 2007; Muslimovic *et al.*, 2008; Gruber-Baldini *et al.*, 2009; Menza *et al.*, 2009; Visser *et al.*, 2009). The connection between the progression of disease and ability in performing activities independently was studied in earlier research (Shulman *et al.*, 2008). The transition between HY stages II and III increased functional disability in activities such as walking, housework, dressing, and moving around, which in our sample were reported as problems in a proportion of patients comprised between 63.5 and 93.8%. Another study found functional limitations, more than physical impairments, to be the most problematic aspect of disability profile of the patients with PD (Schenkman *et al.*, 2002); our findings are consistent with them, as the majority of relevant categories, 18 of 34, were from the activities and participation domain.

One of the main problems in the application of the ICF is that it is generally difficult to interpret ICF-based information. The main reason for this is that this kind of information, being essentially descriptive, is difficult to be synthesized into summary scores or indices. For this reason, a great number of papers showed ICF-derived data only through the presentation of the most relevant ICF categories, which provided useful information on the prevalence of problems in different areas, as well as the prevalence of EF. In contrast, the utilization of extension and severity indices provides a synthetic indication of both the amount of problems (the extension index) and of the relative number of severe or complete problems (the severity index) in a given area of functioning. The user will decide whether single chapters of the ICF taxonomy, or more general domains, are of interest. This methodology proved to be sensitive in fluctuating diseases such as migraine and myasthenia gravis (Leonardi *et al.*, 2009a, 2009b; Raggi *et al.*, 2010a, 2010b), as well as in obesity (Raggi *et al.*, 2010a, 2010b).

Integrating a methodology based on extension and severity indices with a methodology based on the reporting of the most prevalent problems can also help the intervention and rehabilitation planning. At a macrolevel, ICF-based data provide information on prevalence and severity of problems as well as distribution of EFs. At the personal level, they enable to improve an overview of the person's profile of functioning that includes both his/her clinical situation and the difficulties due to this situation and to the presence or absence of EFs. In this way, can



adequate changes in the person's environment be planned and monitored. In fact, we found that PD patients rely on family members for most of their needs in daily life activities. This information can be useful for administrators of social systems, who could consider the possibility of providing them with a professional help, which can be useful to lift the burden of care from family members with positive consequences for both family relationships and patients' health outcomes.

Some limitations need to be taken into consideration with regard to the interpretation of our results. The first limitation lies in the clinical sample and in the fact that the study design is cross-sectional. The sample is composed of both inpatients and outpatients attending a specialized center, mainly coming from Lombardia region, and mainly in HY stages 2–2.5. Therefore, it is not representative of a population of patients with PD. Another critical issue is the application of ICF categories and qualifiers through a semistructured interview. Despite patients being encouraged to report on the presence of problems, also when not directly asked by the interviewers, we cannot exclude the possibility that some relevant elements were not detected. It is questionable whether the ICF checklist does contain an adequate set of categories to describe PD. However, the ICF checklist is not intended to be exhaustive, and the user has the possibility of adding other categories. In our study, some categories have been added, and three of them reached the threshold of 50% (d410, changing basic body position, d415, maintaining a body position, and d460, moving around in different locations). At the same time, some ICF categories were used in a few cases, and seem to be less important to describe the functioning of patients with PD. With regard to qualifiers, their utilization is consistent with World Health Organization guidelines, but is subject to patient's self reporting, which represents a general limitation for several types of research. It must be considered that ICF qualifiers are not intended as assessment indicators. Rather, they are a part of a classification whose rating has to be based upon the evaluation, even patient reported of the amount of problems referred to a specific category (or the degree in which an EF is a barrier or a facilitator).

## Conclusion

PD is one of the major causes of disability among the neurological diseases occurring in the older population, and is a significant cause of economic burden on societies (Andlin-Sobocki *et al.*, 2005; Lindgren *et al.*, 2005). The majority of published researches focus on the effect of symptoms, mainly motor ones, on a given set of activities of daily living, but fail in identifying the relationship between activity limitations and the effect of EFs. Our findings partly confirm previous research, specifically with regard to the set of BF impairments and activities

and participation limitations, but also stress the role of EF in determining the actual disability profile. Severe limitations and restrictions in participation are the result of the joint interaction between severe BF impairment and presence of very relevant barriers in the environment.

ICF-based information can be used in the documentation of persons' problems, including their microsocial context, as well as in a macrolevel, at which prevalence of problems and presence of EF provide a general picture of the areas to consider. Moreover, such information and perspective can be merged, thus enabling to plan strategies that aim to improve the participation of patients with PD. Relying on ICF-based measures is an adequate and viable methodology for reporting on the effectiveness of the intervention designed to pursue this objective.

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