

RESEARCH PAPER

ICF in neurology: Functioning and disability in patients with migraine, myasthenia gravis and Parkinson's disease

MATILDE LEONARDI¹, PAOLO MEUCCI¹, DANIELA AJOVALASIT¹,
FRANCESCA ALBANESI¹, MILDA CERNIAUSKAITE¹, VERONICA INVERNIZZI¹,
ROSALBA LEMBO¹, RUI QUINTAS¹, DAVIDE SATTIN¹, FRANCESCO CARELLA²,
LUIGI ROMITO², PAOLA SOLIVERI², GENNARO BUSSONE³, DOMENICO D'AMICO³,
LORENZO MAGGI⁴, RENATO MANTEGAZZA⁴ & ALBERTO RAGGI¹

¹Neurology Public Health and Disability Unit – Scientific Directorate, Neurological Institute C. Besta IRCCS Foundation, Milan, Italy, ²Movement Disorders Division, Neurological Institute C. Besta IRCCS Foundation, Milan, Italy, ³Headaches Division, Neurological Institute C. Besta IRCCS Foundation, Milan, Italy, and ⁴Division of Neuroimmunology and Neuromuscular Disease, Neurological Institute C. Besta IRCCS Foundation, Milan, Italy

Accepted September 2009

Abstract

Purpose. To report and compare functional features of patients with migraine, myasthenia gravis (MG) and Parkinson's disease (PD) with the International Classification of Functioning, Disability and Health (ICF).

Method. Adult patients with migraine, MG and PD were enrolled and the ICF checklist administered. Count-based indexes were calculated for each ICF chapter and domain. Indexes were compared across conditions by means of ANOVA; relationships between ICF domains were evaluated using Spearman's correlation; group based on disability status were defined through cluster analysis and compared with disease groups using χ^2 test. Finally, most prevalent ICF categories were identified.

Results. A total of 300 patients were enrolled and specific differences in BF, BS, A&P and EF indexes are reported. Spearman's correlations reported moderate relationships between BF and A&P indexes, whereas the correlation between A&P and EF is lower. Cluster analysis and χ^2 test show that patients with Migraine and MG are more likely to report moderate and low disability, whereas patients with PD are more likely to report moderate or severe disability. A total of 60 ICF relevant categories, mostly from A&P, were identified.

Conclusions. Our study provided a description of functioning and disability domains in migraine, MG and PD and enabled to report the impact of EF in determining the actual disability experience.

Keywords: ICF classification, disability, migraine, myasthenia gravis, Parkinson's disease

Introduction

The 2002 World Health Organisation Global Burden of Disease study (GBD) reported that neurological disorders constitute 11.2% of GBD in World Health Organisation (WHO) European regions and 6.3% worldwide [1], and projections for 2030 estimate that, worldwide, GBD due to neurological diseases will increase to 6.8% [2]. A recent analysis on the economic impact of brain diseases showed that the annual cost of such diseases is ~€386

billions. Only 35% of these costs are because of direct healthcare costs: the remaining part is because of direct non-medical costs, such as community care, and to indirect costs such as reduced productivity or lost workdays, that alone contribute to 46% of the total costs [3]. Such a burden and cost is mainly because of non-fatal health outcomes, e.g. disability due to a health condition and ageing.

GBD data provides nation-wide information on disability associated with health conditions but, however, does not report on the subjective lived

experience of having a disability. Disability is a state of decreased functioning associated with a disease which, in interaction with contextual factors, is experienced as an impairment, activity limitation or participation restriction [4]. Understanding both the health and the environmental aspects of disability is particularly important in the field of neurological disease because it allows for the examination of interventions that improve the state of health as well as interventions aimed at changing the environment. Analysing the outcome of interventions in the environment is particularly important because in economic terms they represent the most onerous part of diseases' burden [3].

Disease-specific tools for the evaluation of disability are proposed each year, together with updates of existing instruments: they include technical, clinical and patient-oriented measures. In the field of neurological diseases, no common assessment tool to measure disability across different health conditions is available. Some measures have been developed and are used to measure general concepts, such as functional independence (e.g. FIM [5]) or functional levels in lower extremities or in hands (e.g. LEFS [6] and ABILHAND [7]). Such assessment tools provide useful information on single domains of functioning, but fail to provide a consistent picture of the disability, also experience from patients' perspective. To describe and to measure disability, the WHO developed the International Classification of Functioning, Disability and Health (ICF), Disability and Health that responds to the pressing needs for reporting information on non-fatal health outcomes [8]. To enable a direct application of the ICF, some tools, such as the ICF checklist [9] and ICF Core-Sets [10], have been developed together with linking rules to report information derived from different assessment tools [11]. A generic list of ICF categories has also been identified to capture functional features of neurological patients, mainly with cerebrovascular diseases and head trauma [12].

The general objective of this study is to report and compare functional features of patients with three neurological diseases: migraine, myasthenia gravis (MG) and Parkinson's disease (PD) through the implementation of an ICF-based methodology. The ICF was used to describe disability patterns, as disease specific's disability assessment tools do not enable a comparison between the conditions. The only MG-specific disability assessment tool is the Myasthenia Gravis Activities of Daily Living Profile [13], which tests both resistance in sentinel muscles and limitations in performing activities of daily living. Disability in migraine has often been conceptualised in terms of days of work lost due to migraine attacks. Consistently with this frame, the Migraine Disability Assessment score measures the influence of headaches on three

domains of activities such as paid and school work, household work, leisure activities [14]. The Functional Assessment in Migraine [15] was developed partially on the basis of the ICF to measure the impact of migraine on mental functioning and activity and participation: it, therefore, does not provide a full description of patients' with Migraine functioning and disability, and has not been used systematically. With regard to Parkinson's disease, several instruments have been used to measure disability: the Unified Parkinson Disease Rating Scale [16], the Schwab and England scale [17], the Barthel Index [18], the Activities of Daily Living (ADL) and Instrumental ADL (IADL) subscales of the Older American Resources and Service (OARS) [19] and the aforementioned FIM [5].

Several studies relied on symptoms' severity as proxy measures for disability in both MG [20–22] and migraine [23,24], whereas in PD several studies relied on a combination of disease-specific instruments and general health profile measures [25–28]. These studies failed in evaluating and demonstrating the extent to which disability is due to impairments or to the effect of environmental factors. Generic assessment tools, such as the aforementioned FIM, LEFS and ABILHAND, are more reliable in capturing useful information to describe functional issues: however, they are mainly used in the field of rehabilitation, thus making it difficult to capture information that is of interest in the field of disability associated with neurological diseases (e.g. limitations experienced by patients with migraine in the workplace), and particularly failing to picture the environmental effects. Studies that relied on such instruments therefore fail in getting a complete picture of patients' functioning and disability.

Specific aims of this study are: (a) to comprehensively describe the domains of functioning and disability of patients with migraine, MG and PD, through the implementation of an ICF-based methodology, and comparing patients on the basis of their disease; (b) to cross-sectionally define disability severity using an ICF-based methodology, in the three selected conditions; (c) to identify a list of ICF categories that are relevant to describe functioning and disability in these neurological conditions.

Method

Study design

The study employed a cross-sectional design, in which adult outpatients with migraine, inpatients and outpatients with myasthenia gravis and Parkinson's disease were consecutively recruited at the Neurological Institute C. Besta IRCCS Foundation,

Milan. All recruited patients signed an informed consent form, approved by the institute's Ethical Committee.

Inclusion criteria were, therefore, a diagnosis corresponding to migraine, both with and without aura (ICD-10 codes G43.1 and G43.0, respectively), MG (ICD-10 code G70.0) and PD (ICD-10 code G20). Exclusion criteria were different for each condition. Patients with migraine were excluded if migraine was not a primary diagnosis but rather a comorbidity to other diseases or headaches (e.g. tension-type headache or brain tumours) and if they have been admitted as inpatients to the Besta Neurological Institute for drug detoxification in the 3 months preceding the enrolment. Patients with MG were excluded if they had comorbidities to any other neuromuscular diseases, if they had respiratory dysfunction requiring intubation and if they had not been previously followed at the Institute for <12 months prior to the administration of the protocol. Patients with PD were excluded if they were eligible for non-conventional therapies (e.g. surgical approaches such as deep brain stimulation) and if they had cognitive failure, dementia or psychiatric comorbidities. For each health condition, patients previously enrolled in clinical trials for the three selected conditions in the previous 3 years, and those unable to give their consent were excluded too.

Measures and data collection procedures

The ICF checklist, which is a selection of 128 ICF categories, was used as a basis for collecting data [9]. Categories from the domains of Body Functions, Body Structures, Activities and Participation and Environmental Factors have been used at the second level (e.g. b730, Muscle power functions). In fact at this level they are precise enough to serve the need of describing the different issues (e.g. distinguishing b730-Muscle power from b735-Muscle tone), and generic enough to share their content among different professionals.

Patients were interviewed in individual sessions by researchers who had no a priori information on the severity and other clinical features of patients' diseases. Outpatients were recruited on the occasion of their periodic neurological examinations, or were phoned and asked to participate in the study. Inpatients were recruited within 5 days of their admission, in order to limit the effects of hospitalisation on performing activities (e.g. reductions in performing household activities). The rationale for this choice was the need to detect difficulties and health problems experienced by patients in their daily lives and to refer differences in disability status between inpatients and outpatients only to clinical conditions.

Standardised coding rules, as defined by WHO in the ICF manual and in the international training procedure on ICF, were followed [8,29]. Each ICF category was rated with appropriate qualifiers that indicate the extent to which impairments, limitations and restrictions to full functioning are observed, and the extent to which an Environmental Factor is considered a barrier or a facilitator. Qualifiers were rated when adequate information was available to describe mild (qualifier 1), moderate (qualifier 2), severe (qualifier 3) or complete (qualifier 4) impairments, limitations or environmental barriers or facilitators. If no problem was detected for a specific category, qualifier 0 (no problem) was applied; meanwhile, if a problem was detected, but no adequate information was available to define it according to a specific rating, qualifier 8 (not specified) was applied.

ICF categories not included in the standardised ICF checklist were added whenever patients reported a problem with Body Functions, Structures and with Activities and Participation, or the presence of environmental barriers or facilitators. No a priori selection of additional categories was made; rather, the decision of adding some categories was taken case by case, using the same criterion for applying the categories of the ICF checklist, i.e. the availability of adequate information.

Data analysis

ICF categories rated with qualifier 8 were replaced by each category's median value comprised between qualifiers 1 and 4, and calculated within the patients disease group. If no category was rated, for that category and for a specific disease group, with qualifiers 1–4 (so the median results in a missing value), qualifiers 8 were converted into 1. ICF categories rated with qualifier 9 were converted into missing, because if a category is not applicable by definition, this results in not having information on a problem's presence or severity.

A count-based methodology to analyse data was performed. For each ICF chapter and domain (Body Functions-BF, Body Structures-BS, Activity & Participation-A&P capacity and performance, and Environmental Factors-EF barriers and facilitators) an 'extension' and a 'severity' index was developed. Extension index corresponds to the count of categories in which qualifiers 1–4 (describing the full range from mild to complete problems) were applied; the severity index corresponds to the count of categories in which qualifiers 3 and 4 (describing only severe or complete problems) were applied.

Extension and severity indexes underwent a linear transformation to make them easily and directly

comparable, by means of this procedure: Count/Max*100. Transformed values range between 0 and 100, with lowest values representing complete integrity of BF and BS, complete absence of limitation or restriction in the A&P domains and in the environment higher values represent a complete presence of barriers, or a complete presence of facilitators.

The extent of BF impairments, limitations and restrictions in A&P and the presence of facilitators and barriers within EF have been compared across the different diseases by means of the ANOVA analysis; a P -value <0.05 was set to report significant differences. Correlations between A&P indexes, BF, BS and EF have been performed using Spearman's RHO index and were considered significant if P -value <0.05 . Data have been analysed using STATA 9.0.

Finally, we created groups based upon disability levels using a cluster analysis: A&P-performance indexes, both extension and severity, were entered in the cluster model. The disability would therefore be described both as the total number of areas, expressed by ICF qualifiers, in which limitations are reported, and as the portion of severe limitations in such areas: disability status is therefore operationalised both in terms of 'how many problems' and 'how many severe problems'. Obtained cluster groups were then matched with disease groups to evaluate the relationships between disability severity groups and diagnoses: χ^2 test was used to evaluate the significance of such relationship.

Categories in which at least 30% of the patients reported a problem, from mild to complete ones, were considered relevant for describing patients functional profiles and are reported separately. In A&P component, categories were selected if the threshold was reached by one of the two qualifiers, capacity or performance; in EF the threshold has to be reached by facilitators and barriers together.

Results

A total of 300 patients were enrolled: 102 outpatients with migraine, 102 with myasthenia gravis (32 inpatients and 70 outpatients) and 96 with Parkinson's Disease (23 inpatients and 73 outpatients). Interviews took between 40 and 80 min. Socio-demographic features are listed in Table I.

Prevalence of impairments in the three selected conditions, as defined by ICF chapters of Body Functions and Structures domain, is reported in Figure 1. Figure 1(a) describes BF impairments. For all conditions and all ICF chapters, the majority of BF impairments are mild or moderate. The most problematic impairments are observed in chapter B3-Voice and speech functions and B7-Neuromusculoskeletal and movement-related functions, for patients with MG and PD; patients with migraine report more problems in the functions included in chapters B1-Mental functions and B2-Sensory functions and pain. Mean BF impairments' extension values are 16.7 for patients with migraine, 18.5 for patients with MG and 22.0 for patients with PD ($F=11.2$, $P<0.01$). Specific differences in BF impairments are also reported in Figure 1(a): no difference is observed in B1-Mental functions. Figure 1(b) describes BS impairments. The majority of impairments in BS are reported, for each condition, in S2-Structures of the eye, ear and related structures; patients with myasthenic also report impairments in S4-Structures of the cardiovascular, immunological and respiratory systems. Mean values in BS impairments' extension are 4.9 for patients with migraine, 8.5 for patients with MG and 5.8 for patients with PD ($F=14.0$, $P<0.01$). Specific differences in BS impairments are also reported in Figure 1(b).

Prevalence of limitations and restrictions in A&P is reported in Figure 2. Figure 2(a) describes indexes based upon performance, and Figure 2(b) those

Table I. Sample demographic features.

Characteristics of patients	Migraine ($n=102$)	Myasthenia gravis ($n=102$)	Parkinson's disease ($n=96$)	Total ($n=300$)	%
Gender					
Female	87	70	32	189	63.0
Male	15	32	64	111	37.0
Age (mean \pm SD)	43.4 \pm 11.4	47.1 \pm 15.7	64.0 \pm 11.3	51.3 \pm 15.7	
Marital status					
Never married	36	29	12	77	25.7
Married/cohabitating	61	63	71	195	65.0
Divorced	3	6	6	15	5.0
Widowed	2	4	7	13	4.3
Employment					
Unemployed	24	49	75	148	49.5
Employed	78	53	20	151	50.5

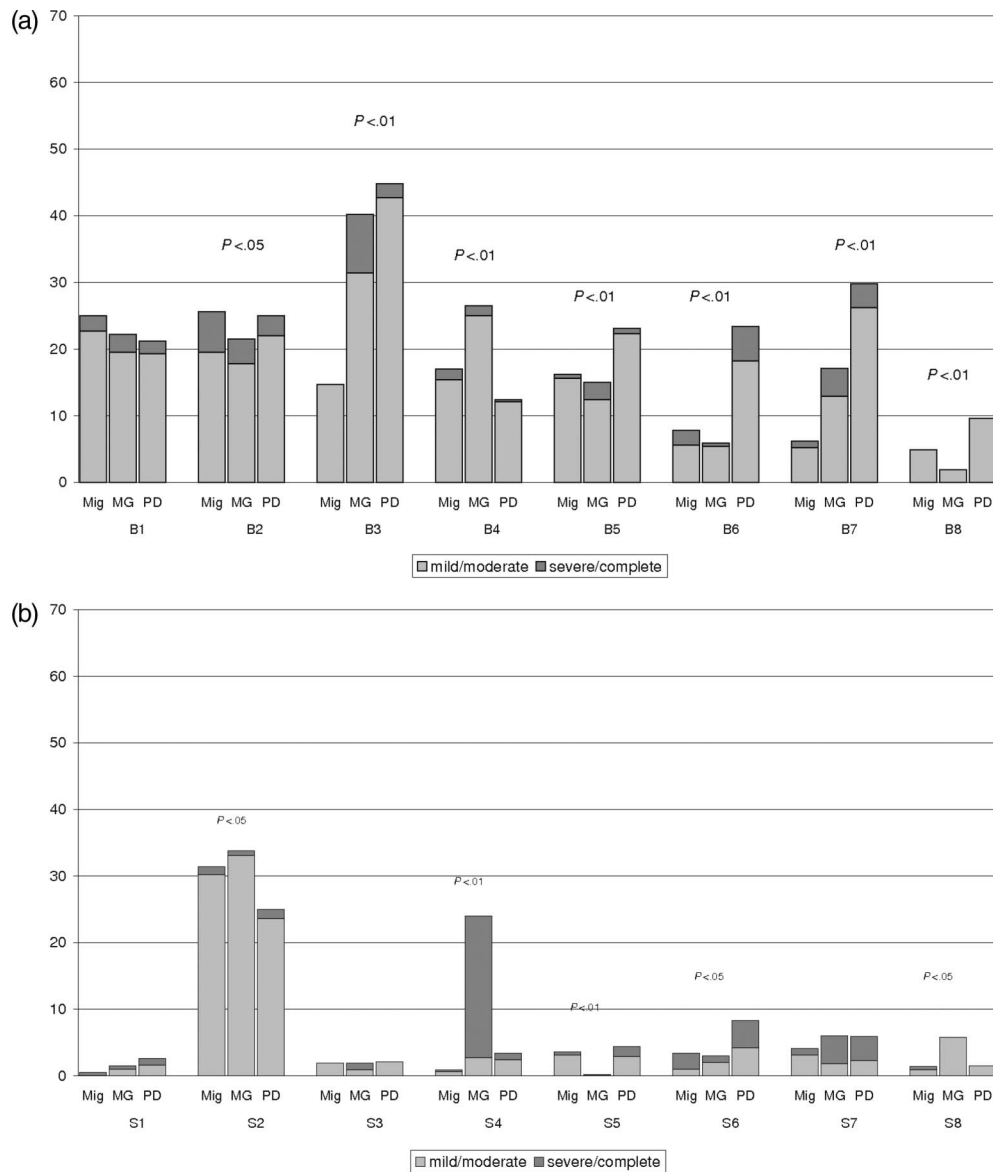


Figure 1. Prevalence of impairments in body functions and structures. (a) Prevalence of impairments in BF indexes; (b) prevalence of impairments in BS indexes.

based upon capacity: for all conditions and for all chapters, performance indexes are lower than capacity ones. Such decrement is particularly evident in chapter D6-Domestic life; on the contrary, it is more limited in chapters D8-Major life areas and D9-Community social and civic life. Global performance index is 15.3 in patients with migraine, 14.5 in patients with MG and 28.7 in patients with PD ($F = 20.5$, $P < 0.01$), while global capacity index is 22.6 in patients with migraine, 28.7 in patients with MG and 32.8 in patients with PD ($F = 16.9$, $P < 0.01$). Among performance indexes, no differences are reported in D3-Communication, D6-Domestic life, D7-Interpersonal interactions and relationships, and D9-Community, social and civic life. Among capacity indexes, no differences are

reported in D6-Domestic life and in D7-Interpersonal interactions and relationships.

Prevalence of Environmental Factors is reported in Figure 3. Figure 3(a) describes environmental facilitators: patients with myasthenia gravis report more facilitators in all areas, with the exclusion of E1-Products and technology, in which no significant differences are observed. Global index within environmental facilitators is 16.7 in patients with migraine, 24.9 in patients with MG and 17.6 in patients with PD ($F = 80.4$, $P < 0.01$). Figure 3(b) describes environmental barriers. Few barriers are reported, with the exception of chapter E2-Natural environment, in which all patients, and more specifically those with migraine, reported the highest number of barriers. No significant differences are observed in

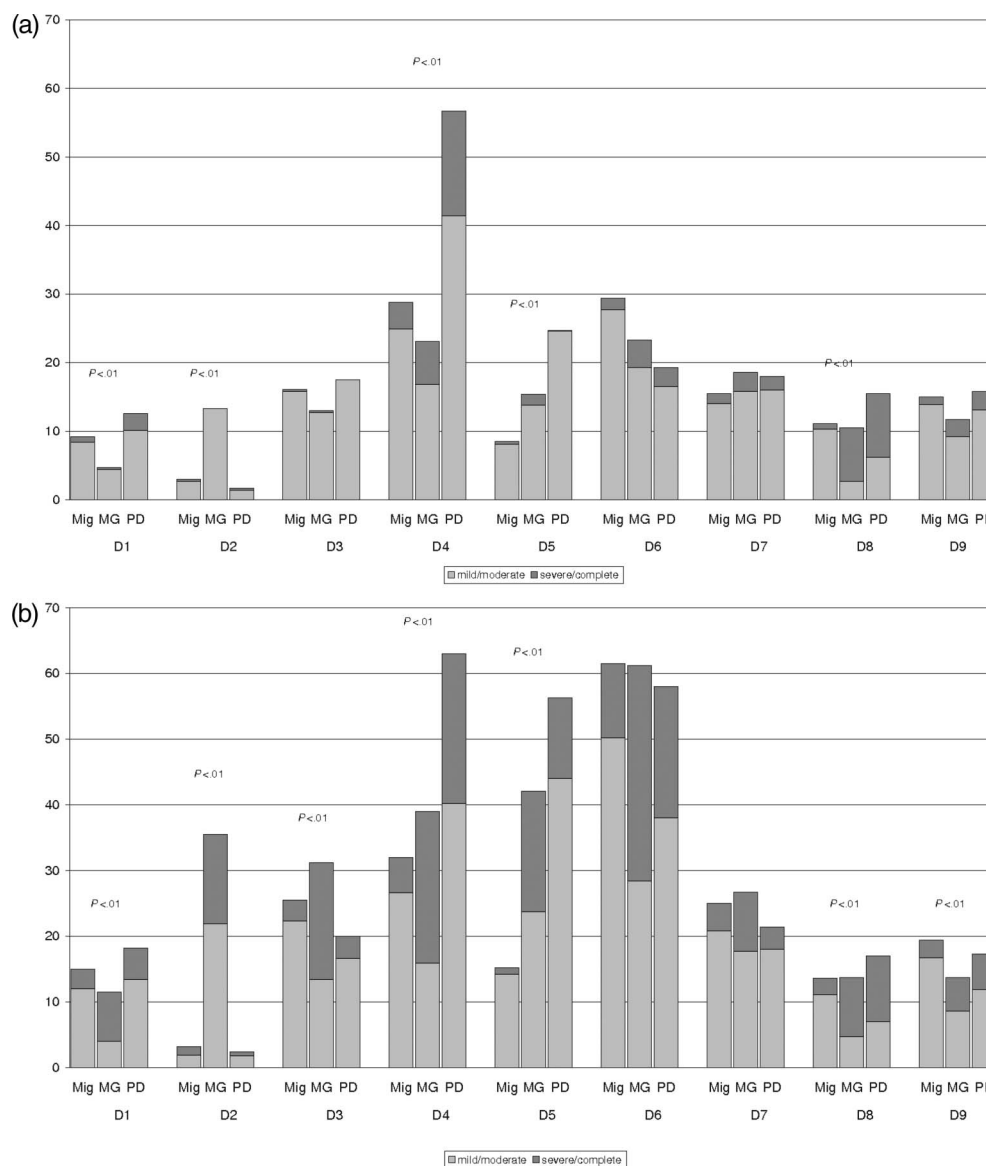


Figure 2. Prevalence limitations and restrictions among activities and participation. (a) Prevalence of limitations in performance indexes; (b) prevalence of limitations in capacity indexes.

chapter E1-Products and technology. Global index within environmental barriers is 7.2 in patients with migraine, 4.2 in patients with MG and 2.6 in patients with PD ($F = 37.2, P < 0.01$).

Spearman's correlations are reported in Table II: considering the whole sample, they account for moderate relationships between impairments in BF and A&P indexes, while the correlation between A&P and EF is lower. Table II also reports correlations for each condition. Among patients with migraine, BF impairments are better correlated with A&P capacity than with A&P performance, and a negative correlation between EF facilitators and A&P performance is reported. Among patients with MG, there is a strong correlation between BF impairments and A&P indexes, especially with performance one. A&P

indexes are also correlated with EF barriers and with BS impairments. Among patients with PD, A&P capacity index is correlated with both EF facilitators and barriers, and a moderate correlation is also reported between BF impairments and A&P indexes.

Three groups indicating different disability levels have been identified by means of the cluster analysis: the first group has low disability levels, the second has moderate disability levels and the third has severe disability levels. ANOVA confirms that cluster membership is significantly different: $F = 922.3$ for extension index and $F = 109.4$ for severity index ($P < 0.01$). Table III reports cluster membership for disease groups. χ^2 test reports significant differences between cluster membership by disease: patients with migraine and MG are more likely to report

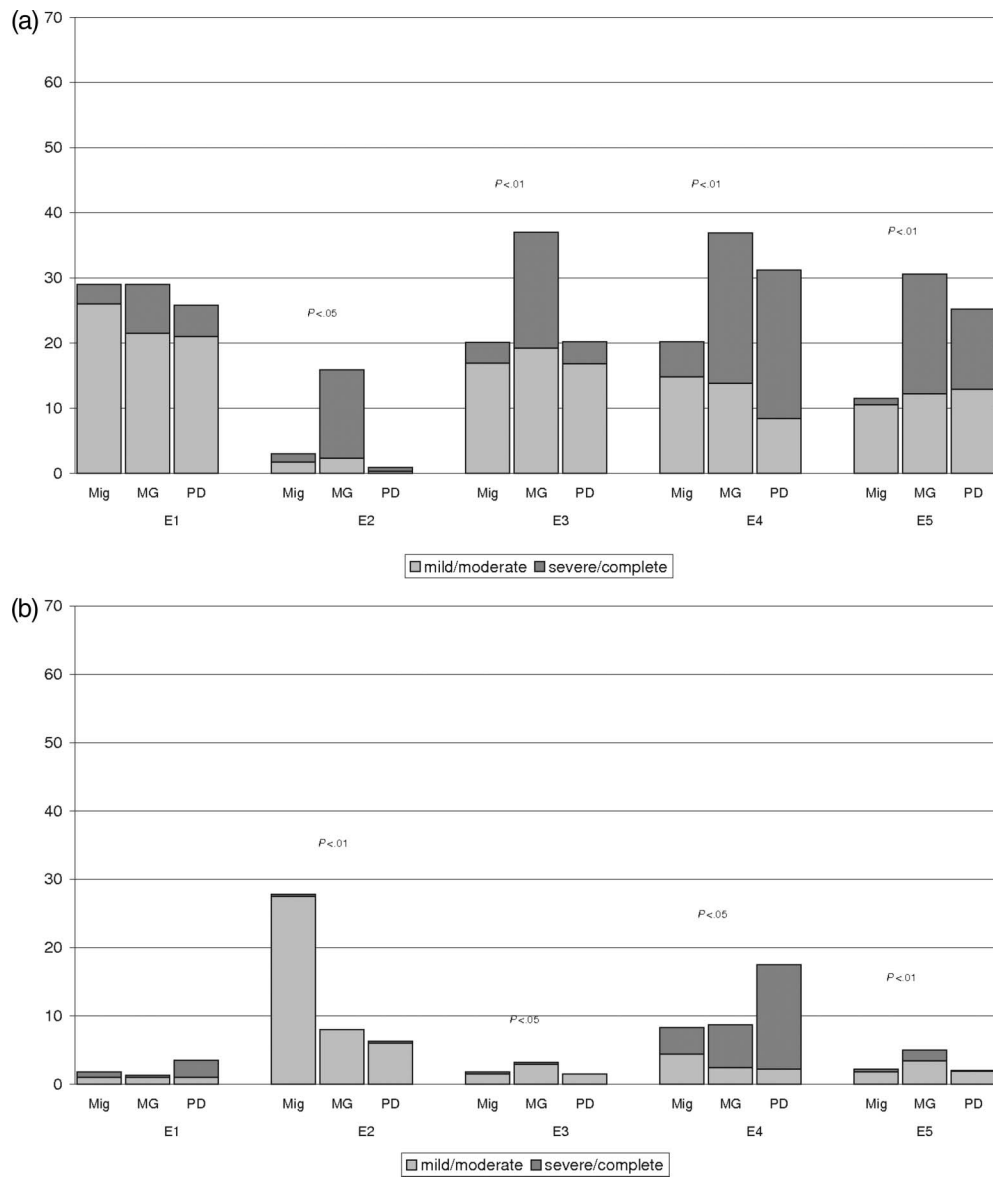


Figure 3. Prevalence of environmental factors' presence. (a) Prevalence of facilitators presence; (b) prevalence of Barriers presence.

Table II. Spearman's RHO correlations between A&P domains, BF, BS and EF.

	Migraine		Myasthenia		Parkinson's disease		All conditions	
	A&P-p	A&P-c	A&P-p	A&P-c	A&P-p	A&P-c	A&P-p	A&P-c
BF	0.28	0.34	0.71	0.53	0.46	0.52	0.52	0.49
BS	ns	ns	0.23	0.23	ns	ns	ns	0.20
EF-f	-0.23	ns	ns	ns	ns	0.22	-0.14	0.12
EF-b	ns	ns	0.26	0.31	ns	0.28	ns	ns

P-value < 0.05; ns, not significant.

moderate and low disability, whereas patients with PD are more likely to report moderate or severe disability.

ICF categories in which qualifiers 1–4 were used in at least 30% of cases are reported in Tables IV, V

and VI. A total of 60 ICF categories reached the 30% threshold: 16 from BF, one from BS, 27 from A&P and 16 from EF. Relevant BF and BS categories are reported in Table IV: the majority is derived from chapters B1-Mental functions and B5-Functions of

Table III. Relationships between disability cluster membership and disease group.

Disability cluster	Health condition			Total
	Migraine	Myasthenia gravis	Parkinson's disease	
A (ext = 5.5; sev = 0.7)	42 (41.2%)	47 (45.1%)	15 (15.6%)	103 (34.3%)
B (ext = 17.9; sev = 2.1)	41 (40.2%)	37 (36.3%)	47 (49%)	125 (41.7%)
C (ext = 33.4; sev = 7.7)	19 (18.6%)	19 (18.6%)	43 (35.4%)	72 (24%)
Total	102 (100%)	102 (100%)	96 (100%)	300 (100%)

$\chi^2 = 24.3, P < 0.01$.

Table IV. Prevalence of impairments within BF.

ICF category	Category description	Impairment (95% C.I.)
b130	Energy and drive	55.7 (49.8–61.3)
b134	Sleep	60.0 (54.2–65.6)
b140	Attention	42.3 (36.6–48.1)
b144	Memory	49.7 (43.8–55.4)
b152	Emotional functions	75.7 (70.4–80.4)
b210	Seeing	75.3 (70.0–80.1)
b280	Pain	72.7 (67.2–77.6)
b310	Voice	33.0 (27.7–38.6)
b420	Blood pressure	35.3 (29.9–41.0)
b435*	Immunological system	47.3 (41.5–53.1)
b510	Ingestion	33.3 (28.0–38.9)
b515*	Digestive functions	31.0 (25.8–36.5)
b525	Defecation	30.3 (25.1–35.8)
b530	Weight maintenance	31.7 (26.4–37.2)
b730	Muscle power	45.0 (39.2–50.8)
b765*	Involuntary movements	33.3 (28.0–38.9)
S2*	Structure of eye and ear	59.0 (53.2–64.6)

*ICF categories not included within the list of Grill et al. [12].

the digestive, metabolic and endocrine systems, and the most impaired functions are b152-Emotional functions, b210-Seeing and b280-Pain. Only one BS category is reported, S2-The eye, ear and related structures. A&P categories reported as a problem are listed in Table V: the majority of them derives from D4-Mobility and from D5-Self care. For most of the categories, performance was less impaired than capacity, with the exception of d410-Changing basic body position, d415-Maintaining a body position, and d460-Moving around in different locations. The most extended problems in capacity are reported in d430-Lifting and carrying objects, d640-Doing housework, and d110-Watching. In regard to capacity qualifiers, the most extended problems are reported in d850-Remunerative employment, d430-Lifting and carrying objects, and d475-Driving. EF categories are reported in Table VI: few barriers are reported, mainly in categories derived from chapter E2-Natural environment, and lots of factors are reported as facilitators. A relevant number of categories were reported with qualifiers 0, meaning no facilitator and no barrier, or left blank.

Discussion

Our results show that the utilisation of ICF-based measures to describe patients' functioning and disability enhance the quality of data on non-fatal health outcomes. First, it provides an accurate description of the domains of functioning and disability and, second, it enables reporting of the impact of environmental factors in determining the actual lived experience of a disability. ICF-based data also enable to detect information on populations that are different from those based on DALYs reported by GBD studies [1,2]. DALYs provides information on how many years of healthy life are lost because of the presence of a health condition that is a cause of disability, but provides no information on the extent and severity of such a disability, whereas ICF-based indexes provide a measure, even if a rough one, on such extent. Matching ICF-based information with that provided by DALYs, it will be possible to gather a complete picture of the disability status of the population, together with an indication of what areas of functioning need to be addressed for improving persons' functioning.

ICF clinical implementation enables users to acquire and compare information on a set of impairments and activities, across different health conditions, using a common perspective, and to evaluate the impact of diseases' symptoms on persons' activities. Our sample of patients with neurological conditions reported a broad set of limitations in executing activities, whereas impairments were less numerous and less severe. Known disease-specific features were captured through ICF-based tools: for example the highest prevalence and severity of impairments with voice and phonation in patients with MG and PD compared with those with Migraine, and the lowest prevalence of mobility problems in patients with Migraine compared with those with Myasthenia and Parkinson's Disease. What is missing in the existing literature is a comparison of functional limitations. It is not just a matter of reporting patients with PD to be more

Table V. Prevalence of limitations within A&P.

ICF category	Category description	Performance (95% C.I.)	Capacity (95% C.I.)
d110	Watching	18.7 (14.4–23.5)	76.0 (70.7–80.7)
d175	Solving problems	24.0 (19.2–29.2)	31.3 (26.1–36.9)
d310	Receiving spoken messages	18.7 (14.4–23.5)	32.3 (27.0–37.9)
d330	Speaking	31.3 (26.1–36.1)	53.7 (47.8–59.4)
d350	Conversation	42.0 (36.3–47.8)	65.3 (59.6–70.7)
d410	Changing basic body position	36.3 (30.8–42.0)	25.0 (20.2–30.2)
d415	Maintaining a body position	37.7 (32.1–43.4)	28.0 (22.9–33.4)
d430	Lifting and carrying objects	56.0 (50.1–61.6)	77.0 (71.8–81.6)
d440	Fine hand use	37.0 (31.5–42.7)	54.7 (48.8–60.3)
d450	Walking	45.3 (39.6–76.6)	71.7 (66.2–76.6)
d460	Moving around in different locations	35.3 (32.1–43.4)	22.0 (17.4–27.1)
d470*	Using transporations	26.3 (21.4–31.7)	46.7 (40.9–52.4)
d475*	Driving	47.3 (41.5–53.1)	71.7 (66.2–76.6)
d510	Washing oneself	25.3 (20.5–30.6)	59.7 (53.8–65.2)
d520	Caring for body parts	17.7 (13.5–22.4)	47.0 (41.2–52.8)
d540	Dressing	21.7 (17.1–26.7)	51.0 (45.1–56.7)
d550	Eating	28.3 (23.3–33.7)	62.0 (56.2–67.5)
d560	Drinking	15.0 (11.1–19.5)	42.0 (36.3–47.8)
d620	Acquisition of goods and services	29.7 (24.5–35.1)	74.7 (69.3–79.4)
d630*	Preparing meals	20.7 (16.2–25.6)	67.3 (61.7–72.6)
d640*	Doing housework	35.3 (29.9–41.0)	76.3 (71.1–81.0)
d730	Relating with strangers	30.7 (25.4–36.2)	42.0 (36.3–47.8)
d750	Informal social relationships	21.7 (17.1–26.7)	32.7 (27.3–38.2)
d770*	Intimate relationships	29.3 (24.2–34.8)	36.3 (30.8–42.0)
d850	Remunerative employment	63.3 (57.6–68.7)	75.0 (69.7–76.7)
d910	Community life	25.7 (20.8–31.0)	33.3 (28.0–38.9)
d920*	Recreation and leisure	42.7 (37.0–48.4)	54.7 (48.8–60.3)

*ICF categories not included within the list of Grill et al. [12].

Table VI. Prevalence of barriers and total factors within EF.

ICF category	Category description	EF total (95% C.I.)	Barriers %
e110	Products for personal consumption	98.7 (96.6–99.6)	1.0
e120	Technology for mobility	30.0 (24.8–35.5)	1.0
e125	Technology for communication	67.0 (61.3–72.2)	1.3
e225*	Climate	39.7 (34.0–45.4)	31.3
e240*	Light	39.7 (34.0–45.4)	36.0
e250*	Sound	32.0 (26.7–37.6)	31.7
e310	Immediate family	93.3 (89.8–95.8)	1.7
e320	Friends	60.3 (54.5–65.9)	3.3
e325*	Peers and colleagues	40.0 (34.4–45.7)	6.0
e355	Health professionals	53.7 (47.8–59.4)	0.7
e410	Ind. attitudes of family members	83.7 (78.8–87.6)	10.3
e420*	Ind. attitudes of friends	56.7 (50.8–62.3)	4.7
e450	Ind. attitudes of health professionals	61.7 (55.9–67.1)	5.3
e540*	Transportation SSP	54.0 (48.1–59.7)	12.0
e570*	Social security SSP	53.0 (47.1–58.7)	6.7
e580*	Health SSP	87.0 (82.6–90.5)	7.0

*ICF categories not included within the list of Grill et al. [12].

limited in moving around than migraineurs; rather the matter is to say that migraineurs report half the mobility problems experienced by patients with PD. Patients with Migraine underwent a very moderate change in mobility: in our opinion this could be partially because of the fact that no environmental factors specifically address mobility issues of patients with Migraine, as mobility is not recognised as an

issue for patients with Migraine. Therefore, our results provide a useful indication on what domains of functioning, not explored in previous studies on Migraine, MG or PD, could be of interest.

Other important information regards the problems in domestic life activities which among the three conditions are almost equally distributed, even if with different degrees of severity. With regard to

environmental factors, patients with MG report more facilitators: we deem that, compared to the others, they have more opportunities to face social situations in which support and positive attitudes from other persons can have a significant impact, and they are also likely to benefit more, at least in Italy, from supportive policies, such as those provided by health and labour sectors.

The capacity index, which describes information on the health component of functioning, accounts for widespread differences among health conditions, which can be explained on the basis of clinical features; such differences are not always significant in the performance index. The observed reduction is mainly because of the effect of environmental factors: the more facilitating they are, the less extended are the limitations in performance. The area in which the widest change between capacity and performance indexes was detected is Chapter D6-Domestic life, and the widest difficulties are reported by patients with Migraine. This is partially surprising: limitations and restrictions due to the impossibility of undertaking activities, and the effect of medications in reducing such limitations, are in fact quite known in patients with Migraine [30,31]. However, as Migraine symptoms do not quantitatively and qualitatively compromise mobility to the same degree of MG and PD symptoms, the extent to which such limitations interfere with patients' daily lives was difficult to predict and compare against patients with other health conditions.

The direction and extent of correlations between facilitators and the performance index provide an indication of a strong relationships between A&P and BF impairment indexes. Correlations also report different effects on the impairments and environmental factors of patients' functioning: for example, patients' with Migraine functioning is strictly dependent on the presence of Environmental Facilitators. High facilitators' index are directly correlated to low performance's index, and the correlation between BF impairments index is higher with capacity index than with performance one.

One of the most useful aspects of ICF clinical implementation is the possibility of defining patients' functional profiles on a continuum. According to the ICF model, disability does not correspond only to symptoms severity or only to limitations in performing a limited number of activities. Rather it arises out of the interaction between a health condition and the environmental factors of the context in which the person lives, and it should be evaluated both at the level of the body, in terms of impairments, and at the level of the person, in terms of limitations, and also at the societal level, in terms of restrictions to participation [4]. Several research approaches measured disability relying on (few) ADLs and on

symptoms as a proxy measure of disability [20–28], being therefore able to follow the course of disability as a function of the disease's progression and to compare subgroups with clinical differences, or undergoing different treatments. However, they failed in evaluating and comparing patients with different diseases on the basis of functioning as a common dimension and, moreover, by relying on *ad hoc* and disease-specific definitions of disability, they do not gather useful information for a global public health perspective. The main reason for such a failure is that the aforementioned studies relied on an inappropriate definition, and therefore operationalisation, of disability. The utilisation of ICF's biopsychosocial model to evaluate the continuum of disability, on the contrary, makes it possible to highlight what areas need to be specifically addressed to improve patients' functioning. Our data (for example) show that patients' with MG disability level is much more determined by symptoms severity and environmental barriers than by facilitators' effect, and that the majority of patients experience low-disability status. It is known that medical therapies do completely change patients' with MG ability to perform daily activities and it is reasonable to think that most of the differences between capacity and performance levels are due to their effect. From a public health perspective, therefore, the reduction of barriers should be the target of interventions to further improve patients with MG level of functioning. Data herein presented do not enable one to exactly detect what kind of barriers should be addressed: analysis that specifically focuses on single A&P and EF domains should be performed, but this was not within the aims of our study.

We identified a selection of most used ICF categories, using the same criteria as Grill et al. [12]. Compared with Grill's list, ours is much shorter, but it contains 18 previously unreported categories. This difference is surely dependent upon patients' clinical features in BF and BS list: the majority of Grill's patients suffer in fact from cerebrovascular disease and head injuries. Differences related to A&P list could in turn be due to the context in which the evaluation was performed: our sample was composed of both inpatients and outpatients, whereas Grill's was enrolled from a neuro-rehabilitation setting in which patients could not be expected to perform some activities, e.g. using transportations and preparing meals. We also included EF from Chapter 5 – Services, Systems and Policies: we deem in fact that their contribution towards improved health outcomes is essential, e.g. in terms of access to health care.

Our study has some limitations that need to be carefully considered. The main limitation lies in the sample selection. It was composed of consecutive patients, and the total number of patients per condition

does not respect the epidemiology of each of the three conditions. However, this is intended as an observational study, the aim of which is not to generalise results to the general population. Rather, it is intended to highlight differences and similarities in functioning and disability between patients with different health conditions. The second limitation is in the utilisation of an interview to gather functional profiles. The application of the ICF checklist was, however, subject to intense training procedure and >90% of case report forms were filled in by four interviewers: this should limit interview procedure variability.

Another issue to be considered in evaluating our results lies in the content of extension and severity indexes. They do not directly correspond to the extent to which body functions or activities are impaired or restricted. Rather, being based upon counts of ICF qualifiers, they provide an indication on the extent to which limitations and restrictions are present in a domain of functioning, and to the extent to which they are severe/complete or mild/moderate. Therefore, such indexes fit well for descriptive purposes and for action planning, but should not be considered as direct assessments of disability status, as they are based upon an assessment of limitations or impairments.

In conclusion, our cross-sectional results stressed the value of an implementation of such ICF-based methodology that provided an accurate description of the domains of functioning and disability in migraine, myasthenia gravis and Parkinson's disease and enabled to report the impact of environmental factors in determining the actual disability experience. Similarities and differences in functioning and disability between health conditions, and the relationship between the continuum of functioning and patients' clinical features, are evidenced.

Acknowledgements

The research was partly funded by the European Commission's MHADIE project (Measuring Health and Disability in Europe: supporting policy development), Sixth Framework Programme. Contract Number: SP24-CT-2004-513708 thematic priority 'Scientific Support to Policies'. Authors would like to thank Marcella Spano for language revision.

References

- Mathers CD, Bernard C, Moesgaard IK, Inoue M, Ma Fat D, Shibuya K, Stein C, Tomijima N, Xu H. Global burden of disease in 2002: data sources, methods and results. Geneva, World Health Organization, 2004 (GPE Discussion Paper No. 54, February 2004). Electronic Citation. <http://www.who.int/healthinfo/paper54.pdf>. Last accessed April 2009.

- World Health Organization. Global burden of neurological disorders: estimates and projections. In: WHO. Neurological disorders: public health challenges. Geneva: WHO; 2007. pp 27–39.
- Andlin-Sobocki P, Jonsson B, Wittchen HU, Olesen J. Cost of disorders of the brain in Europe. *Eur J Neurol* 2005; 12(Suppl 1):1–27.
- Leonardi M, Bickenbach J, Ustun TB, Kostanjek N, Chatterji S, on behalf of the MHADIE Consortium. The definition of disability: what is in a name? *Lancet* 2006;368:1219–1921.
- Linacre JM, Heinemann AW, Wright BD, Granger CV, Hamilton BB. The structure and stability of the Functional Independence Measure. *Arch Phys Med Rehabil* 1994;75:127–132.
- Binkley JM, Stratford PW, Lott SA, Riddle DL. The lower extremity Functional Scale (LEFS): scale development, measurement properties, and clinical application. *North American Rehabilitation Research Network. Phys Ther* 1999;79:371–383.
- Penta M, Thonnard JL, Tesio L. ABILHAND: a Rasch-built measure of manual ability. *Arch Phys Med Rehabil* 1998;79:1038–1042.
- World Health Organization. The international classification of functioning, disability and health: ICF. Geneva: World Health Organization; 2001.
- Ewert T, Fuessl M, Cieza A, Andersen C, Chatterji S, Kostanjsek N, Stucki G. Identification of the most common patient problems in patients with chronic conditions using the ICF checklist. *J Rehabil Med* 2004; 36(Suppl 44):22–29.
- Cieza A, Ewert T, Ustun TB, Chatterji S, Kostanjsek N, Stucki G. Development of ICF Core Sets for patients with chronic conditions. *J Rehabil Med* 2004;36(Suppl 44): 9–11.
- Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustun TB, Stucki G. ICF linking rules: an update based on lessons learned. *J Rehabil Med* 2005;37:212–218.
- Grill E, Lipp B, Boldt C, Stucki G, Koenig E. Identification of relevant ICF categories by patients with neurological conditions in early post-acute rehabilitation facilities. *Disabil Rehabil* 2005;27:459–465.
- Wolfe GI, Herbelin LR, Nations SP, Foster B, Bryan WW, Barohn RJ. Myasthenia gravis activities of daily living profile. *Neurology* 1999;52:1487–1489.
- Stewart WF, Lipton RB, Kolodner K, Liberman J, Sawyer J. Reliability of the migraine disability assessment score in a population-based sample of headache sufferers. *Cephalalgia* 1999;19:44–51.
- Pathak DA, Chisolm DJ, Weis KA. Functional assessment in migraine (FAIM) questionnaire: development of an instrument based upon the WHO's international classification of functioning, disability, and health. *Value Health* 2005;8:591–600.
- Fahn S, Elton RL. Unified Parkinson's disease rating scale. In: Fahn S, Marsden CD, Calne D, Golstein N, editors. *Recent developments in Parkinson's disease*. Florham Park, NJ: MacMillan Health Care Information; 1987. pp 153–163.
- Schwab RS, England AC. Projection technique for evaluating surgery in Parkinson's disease. In: Gillingham FJ, Donaldson IMI, editors. *Third symposium on surgery in Parkinson's disease*. Edinburgh: Livingstone; 1969, pp 152–157.
- Wade DT, Collin C. The Barthel ADL index: a standard measure of physical disability? *Int Disabil Stud* 1988;10:64–67.
- Duke University Center for the Study of Aging and Human Development. *Multidimensional functional assessment: the OARS methodology, a manual*, 2nd ed. Durham, NC: Center for the Study of Aging and Human Development, Duke University; 1978.

20. D'Alessandro R, Casmiro M, Benassi G, Rinaldi R, Gamberoni G. Reliable disability scale for myasthenia gravis sensitive to clinical changes. *Acta Neurol Scand* 1995;92:77–82.
21. Guy-Coichard C, Bguyen DT, Delorme T, Boureau F. Pain in hereditary neuromuscular disorders and myasthenia gravis: a national survey of frequency, characteristics and impact. *J Pain Symptom Manage* 2008;35:40–50.
22. Lavnric D, Vujic A, Rakocevic-Stojanovic V, Stevic Z, Basta I, Pavlovic S, Trikić R, Apostolski S. Cyclosporine in the treatment of myasthenia gravis. *Acta Neurol Scand* 2005;111:247–252.
23. Stovner LJ, Hagen K, Jensen R, Katsarava Z, Lipton RB, Scher AI, Steiner TJ, Zwart JA. The global burden of headache: a documentation of headache prevalence and disability worldwide. *Cephalalgia* 2007;27:193–210.
24. Lipton RB, Liberman JN, Kolodner KB, Bigal ME, Dowson A, Stewart WF. Migraine headache disability and health-related quality of life: a population-based case-control study from England. *Cephalalgia* 2003;23:441–450.
25. Muslimovic D, Post B, Speelman JD, Schmand B, de Haan RJ; CARPA Study Group. Determinants of disability and quality of life in mild to moderate Parkinson disease. *Neurology* 2008;70:2241–2247.
26. Tanji H, Gruber-Baldini AL, Anderson KE, Pretzer-Aboff I, Reich SG, Fishman PS, Weiner WJ, Shulman LM. A comparative study of physical performance measures in Parkinson's disease. *Mov Disord* 2008;23:1897–1905.
27. Weintraub D, Moberg PJ, Duda JE, Katz IR, Stern MB. Effect of psychiatric and other nonmotor symptoms on disability in Parkinson's Disease. *J Am Geriatr Soc* 2004;52:784–788.
28. Shulman LM, Gruber-Baldini AL, Anderson KE, Vaughan CG, Reich SG, Fishman PS, Weiner WJ. The evolution of disability in Parkinson Disease. *Mov Disord* 2008;23:790–796.
29. Leonardi M, Bickenbach J, Raggi A, Sala M, Guzzon P, Valsecchi MR, Fusaro G, Russo E, Francescutti C, Nocentini U, Martinuzzi A. Training on the international classification of functioning, disability and health (ICF): the ICF-DIN basic and the ICF-DIN advanced course developed by the disability Italian network. *J Headache Pain* 2005;6:159–164.
30. Dahlöf C, Loder E, Diamond M, Rupnow M, Papadopoulos G, Mao L. The impact of migraine prevention on daily activities: a longitudinal and responder analysis from three topiramate placebo-controlled clinical trials. *Health Qual Life Outcomes* 2007;5:56.
31. D'Amico D, Solari A, Usai S, Santoro P, Bernardoni P, Frediani F, De Marco R, Massetto N, Bussone G; Progetto Cefalee Lombardia Group. Improvement in quality of life and activity limitations in migraine patients after prophylaxis. A prospective longitudinal multicentre study. *Cephalalgia* 2006;26:691–696.