



# The Impact of Biological, Psychological, and Social Factors on Disability, Quality of Life, and Wellbeing in Neurological Patients

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## 1. Longitudinal changes in functioning in patients with disorders of consciousness (PRECIOUS data)

**Aims** To examine longitudinal changes in functioning in patients with disorders of consciousness (DOC) and to identify associated biopsychosocial correlates using the International Classification of Functioning.

**Methods** An Italian sample of 248 DOC patients was assessed longitudinally. Differences in relative variability (an index of change that controls for baseline levels) between acute and chronic patients and predictors of relative variability in Activities & Participation were examined.

**Results** Results showed that there were subgroups of patients whose functioning improved over time. The number of problems in Activities & Participation decreased in acute patients over time, whereas in chronic patients, an increase was found. The significant difference in relative variability for the environmental factor 'Support and relationships' reflects the increase in facilitators in acute patients, whereas the number of facilitators in chronic patients remained unchanged over time. Age at event, time from event, and relative variability in Environmental Factors were significant predictors of relative variability in Activities & Participation.

**Discussion** It is of clinical relevance that patients with DOC are kept in a supportive and facilitative environment, in order to prevent a decline in their functioning.

## 2. Impact of living with a brain disorder reported by ±5000 patients with various neurological conditions in Europe (EFNA data)

**Aims** To examine 1) how neurological disorders impact on the home, work/educational and social life of those affected; 2) the association between neurological disorders and related conditions/syndromes; and 3) the satisfaction rates with treatment and management.

**Methods** An online survey on the website of the European Federation of Neurological Associations (EFNA) was completed by 5148 patients from 27 European countries. The survey consisted of an *ad hoc* questionnaire created by the EFNA, collecting information on sociodemographic variables, clinical variables, impact on various life domains, social support, psychological symptoms, somatic symptoms, and satisfaction with treatment.

**Expected results** Results will provide more insight into the impact the most prevalent neurological disorders in Europe. In addition, results will provide more insight into the extent to which neurological patients are satisfied with their treatment. Along with the overall results, the sample size also allows to compare results by country and by neurological disorder.

**Discussion** These results will help EFNA to build a 'Book of Evidence' which will be taken to European policy and decision makers, outlining why neurological disorders must be considered a political priority and which concrete actions are needed to improve quality of life of neurological patients.

## 3. Factors associated to employment difficulties in headache patients

**Aims** To systematically assess the literature on headache (HA) and employment difficulties in order to 1) determine the impact of HA on employment and 2) identify factors that are related to employment difficulties in persons with HA.

**Methods** A literature search was performed in PubMed for studies published between January 1993 and October 2013. Studies were selected if they reported quantitative data on any kind of work-related difficulties, or factors associated to these difficulties.

**Results** Results of the 44 studies included indicated that persons with HA had higher unemployment rates, a lower number of workdays per week, higher numbers of missed workdays, days with reduced productivity, lost workday equivalents, and days worked with headache than persons without HA. In terms of related factors, female gender, non-white race, younger age, lower educational level, lower income level, higher HA frequency, higher pain intensity, higher disability, and the presence of depressive symptoms were associated with worse employment outcomes, whereas triptan use and participation to educational HA programs were associated with better outcomes.

**Discussion** These results highlight once again the negative impact of HA on employment outcomes and also show that there is still a lack of knowledge regarding associated factors. There is a pressing need for future studies to pay more attention to these factors.

## 4. Longitudinal changes in disability in migraine patients (FP6 EU MHADIE)

**Aims** To longitudinally analyze the relationship between changes in disability and personal, clinical, and environmental variables in a sample of migraine patients.

**Methods** An Italian sample of 102 migraine patients was assessed at baseline, 6 weeks, and 12 weeks using the WHODAS, the MIDAS, a health care satisfaction measure, and several clinical and sociodemographic variables. Changes in outcomes over time were assessed using repeated measures ANOVA and GEE-analysis.

**Results** WHODAS total score and all domains, except for 'Mobility' and 'Self-care', improved significantly over time. WHODAS total score was significantly associated to MIDAS total score, being unemployed, comorbidity, and average pain intensity. In terms of domains, MIDAS total score was the strongest predictor for 'Life activities', 'Participation' and 'Getting along', whereas comorbidity was the strongest predictor for 'Mobility' and 'Self-care'. Average pain intensity was significantly associated to 'Participation' and 'Mobility'. Regarding sociodemographic factors, being unemployed and a lower age were significant predictors for disability with respect to 'Mobility', 'Self-care' and 'Participation'.

**Discussion** These results indicate that disability in migraine is a multivariate phenomenon involving personal, clinical, and environmental factors. Personalized treatments should take all these modifiable risk factors into account.

## 5. Impact of psychological factors on disability, quality of life, and wellbeing in multiple sclerosis and stroke patients (NeurAge data)

**Aims** To examine the impact of biological, psychological, and social factors on disability, quality of life, and wellbeing in patients with multiple sclerosis or stroke aged ≥40 years.

**Methods** Data will be collected in 200 multiple sclerosis patients and 200 stroke patients, aged 40 years and above. Outcome measures will comprise disability, quality of life, and wellbeing. Predictors will include various biological, psychological, and social/environmental factors. Information on these variables will be collected through self-report measures and non-invasive physical exams.

**Expected results** It is expected that adverse scores on the biological, psychological, and social/environmental measures are positively related to disability and negatively related to quality of life and wellbeing. In addition, it is expected that sociodemographic variables significantly influence these relationships.

**Discussion** A better understanding of these associations will allow to reduce disability and improve quality of life and wellbeing in these patients, by the specific targeting of interventions that aim to promote a healthy lifestyle, improve mental health, stimulate participation, and decrease stigmatization.

## 6. Prevalence of depressive symptoms and associated variables in dementia patients (BDS-R data)

**Aims** To examine the prevalence of depressive symptoms and to identify factors associated to depressive symptoms in a large sample of patients with dementia.

**Methods** Data were collected from 13 different institutions (mental health, nursing homes, and hospitals) in the South of the Netherlands, resulting in a total study sample of 730 patients with different types of dementia. In addition to various sociodemographic and clinical variables (including dementia severity), the presence of depressive symptoms was assessed using the following measures: Geriatric Depression Scale (self-report), use of antidepressant medication, clinical diagnosis of clinical depression, and a history of depression.

**Expected results** It is expected that these data will allow us to identify variables associated to depressive symptoms in patients with dementia.

**Discussion** These results will provide more insight into the prevalence of and factors associated to depressive symptoms in patients with dementia, allowing the early identification and treatment of individuals who are at an elevated risk.

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