

The European Federation of Neurological Associations patients' survey: what insights for neurologists?

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Approximately 175.8 million European citizens suffer from a neurological disease [1], and this number will reasonably increase due to population ageing. Some literature focuses on treatment costs, burden, years lived with disability or years lost due to premature mortality, generally relying on data derived from population-based estimates [2–4]. Conversely, patients' perspectives are less frequently taken into account. Patients' associations play a crucial role in raising awareness on needs and experiences of people with neurological disorders: they can foster political and social initiatives to raise awareness on patients' problems and needs.

The European Federation of Neurological Associations (EFNA) is an umbrella federation of neurological associations, which aims to influence European policy makers to prioritize resource allocation to reduce the burden for people living with a neurological disorder, and to establish alliances also with relevant stakeholders in the scientific, political and clinical arenas. In 2014 EFNA conducted an online European survey to explore issues such as well-being, quality of life, stigma, work and social life in patients with neurological diseases. The protocol developed by EFNA was made available for patients' participation between November 2014 and February 2015, and request to participate in the survey was made directly by EFNA or through the different EFNA member associations. Patients self-identified themselves by reporting the neurological condition they were affected by: in total, 4847 responses were obtained. Since many diagnoses were reported by few patients, groups based on the ICD-10 [5] were created if there were at least 15% respondents and all those not reaching this threshold were grouped as 'other neurological conditions'.

Three main areas are covered by the protocol: overall well-being (i.e. being anxious, depressed, stressed and so on), workplace stigma (i.e. respondents' neurological disease impact on ability to perform at work, discrimination in the workplace and so on) and social stigma (i.e. support and understanding by family members and friends and so on). For each of these areas, a composite score was created using a factor

analysis: composite scores were calculated on a 0–100 basis, with higher scores indicating low levels of well-being and high workplace and social stigma.

The respondents with low-level well-being, relevant social stigma and workplace stigma were identified as those reporting a score higher than the mean and one SD separately in each scale, and their distribution across the main diagnoses and across those patients reporting desire for being more involved in the management of their condition and those reporting not feeling listened to and understood by their doctor was explored. For both these analyses the chi-squared test was used, with $P < 0.05$ to set significance.

Most respondents were female (70%), aged 40–60 (47%), with high school or academic education (90%); 42% of them were employed and 2437 (i.e. 50.3%) were from the Netherlands, the UK or France. Some of the associations strongly involved their associates, and this resulted in very different response rates that do not correspond to a representation of the epidemiology of the disorders. In fact, the most frequently reported diagnoses were restless legs syndrome (RLS, 28.2%), headache disorders (24%), multiple sclerosis (16.7%) and chronic fatigue syndrome (CFS, 15.6%); the remaining 15.5% were classified as 'other conditions', with some conditions being reported by dozens (e.g. stroke by 21 respondents, Parkinson's disease by 42) and others by a few units (e.g. seven reported muscular dystrophy, two reported Ménière's syndrome).

Low-level well-being as well as relevant social and workplace stigma were more frequently reported by respondents with CFS (between 27.9% and 45.3%) and less frequently by those with RLS (5.8%–9%); the others scored in between. In addition to this, low-level well-being and relevant social and workplace stigma were reported 4%–7% more frequently by those who would like to be more involved in the management of their disease and 12%–16% more frequently by those who did not feel listened to and understood by their doctor.

The results tell a story of social and workplace stigma and of reduced well-being, but also reach out for the help of clinicians, and suggest concrete

actions: acting on the doctor–patient relationship could increase patients’ well-being; having a higher recognition of neglected diseases, such as CFS, or misunderstood diseases, such as migraine or RLS, might reduce the perception of stigma; involving the employment sector would build a broader care approach and lead to stigma reduction. Patients’ and doctors’ associations should work together to achieve these purposes, beginning with the training of young neurologists [6–8].

It is recognized that these results are hampered by sampling issues and by the use of non-validated tools: for this reason future research will be needed to increase the scientific value of these results, by planning enrolment with adequate *a priori* methodologies, to avoid the unbalanced distribution of patients by disease group and country which hampers the representativeness of this sample, and by relying on validated measures. This could focus on the most important topic for patients, e.g. the impact on employment.

Despite these limitations the results are a warning that cannot be ignored now. This survey claims the attention of European neurologists and of the scientific and public health community at large, as they represent the voice of those patients whom researchers regularly ask to participate in randomized controlled trials and observational studies, and for whom neurologists work: to find new and more effective therapies, but also to improve the quality of life and reduce the difficulties connected with their diseases.

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