EMEA survey of ME/CFS patients in Europe: Same disease, different approaches and experiences

The report and survey

This Infobrief summarizes the findings from a 2021 survey of more than 11 000 patients with myalgic encephalomyelitis (ME), also referred to as ME/CFS or CFS/ME in some countries. It is the first pan-European patient survey, and compares experiences across countries regarding disease characteristics, course of illness, and access to healthcare and support. The survey was translated into 15 languages and promoted via patient organizations. The questionnaire covered illness characteristics, factors affecting disease course, therapies, and support received from healthcare and other public services, and family and friends.

ME/CFS is a serious and debilitating disease

ME/CFS is typically categorised into four degrees of severity: mild, moderate, severe, very severe. The use of the term “mild” ME/CFS is an oxymoron, as even “mild” ME/CFS is a severe disease, with a major loss of function compared to before disease onset. Most patients cannot work and rely heavily on support.

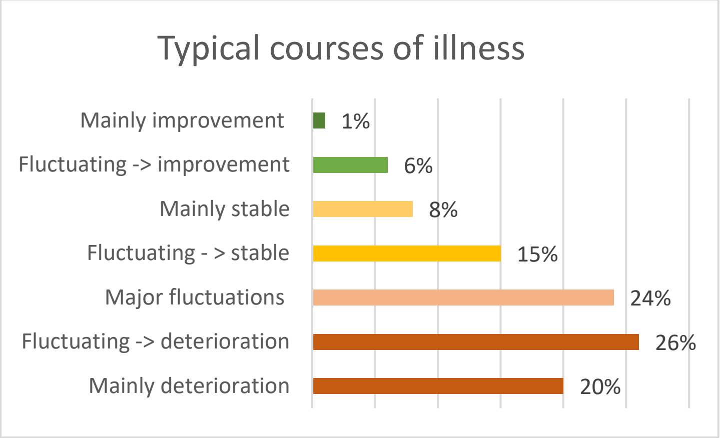
3.7% had better than mild ME/CFS, 24% had mild ME/CFS, 54% had moderate ME/CFS (mostly housebound), 16% had severe ME/CFS (mostly bedbound), while 2.4% had very severe ME/CFS (bedbound and in need of continuous care). Across countries, we found strong similarities for the distribution of degrees of severity, the positive correlation between early onset and disease severity, and the factors associated with a better course of illness, such as pacing and support from family and friends.

Almost half of survey respondents report a deteriorating course of illness

Persistent myths exist about ME/CFS being an illness that gradually “burns out” and that patients recover over time. Some patients do indeed get much better or even recover, but most do not. As high-quality prospective studies on typical courses of illness are lacking, large patient surveys such as the present one may provide the best information available. Whether ME/CFS is seen as a temporary or chronic condition has major implications for welfare benefits and other services provided.

46% described mainly deterioration of their condition, while 24% answered that they had experienced major fluctuation throughout their course of illness (see figure). In total, 70% of respondents described either deterioration or large fluctuations. Only 7% reported improvement.

Early onset and severity are linked. 33% among the very severely ill had an onset before turning 20 years old, compared with 14% among those with mild degree.



Early diagnostics and disease management are critical for a more favorable prognosis

Long delays in the diagnosis were common, with the diagnostic period (from onset to diagnosis) averaging 6.8 years across Europe with large variations across countries. Men are, on average, diagnosed one year earlier than women. Longer delays were associated with a worse course of illness. The risk of experiencing deterioration is more than 50% higher among those with a late diagnosis (10 years or more) compared with those who received an early diagnosis (within 3 years).

The survey confirms what several studies (with smaller samples) have found: delayed diagnosis is a risk factor for severe disease. Early and sound advice on the management of the disease, including pacing to avoid Post-Exertional Malaise (PEM), improves the prognosis.

The health care system fails ME/CFS patients – and that has serious consequences

3 out of 4 patients (74%) felt they received little or no health care support, while only 1 out of 8 (12%) had experienced good or very good support. The dissatisfaction is high across most countries, and even in the best scoring countries (Norway, Iceland, and Sweden), about 65% reported that they received poor health care support.

While no objective diagnostic tests, verified biomarkers, curative medications or treatments for ME/CFS exist, health care support matters for the management of the symptoms and the improvement of functional capacity, and thus the course of illness. Respondents reporting good support from the health care system were more likely to report improvement and less likely to report deterioration.

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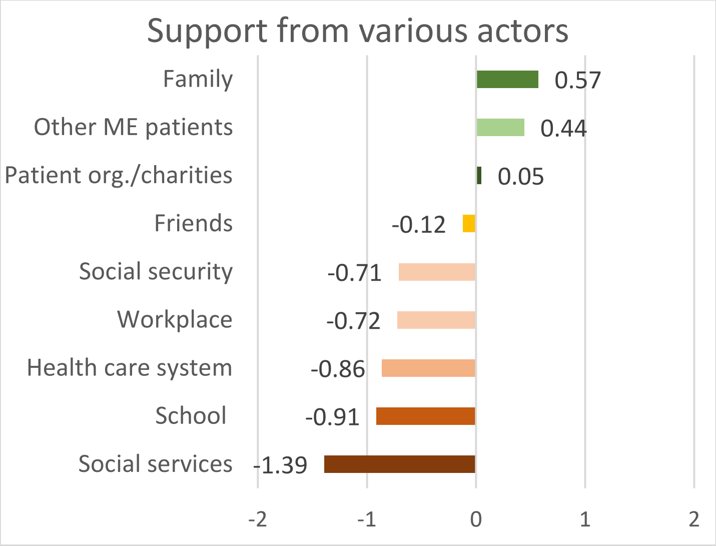
Patients were most satisfied with support from family and fellow patients



The figure reports the average score of the support received from various actors, from very good support (score 2), good support (1), neutral (0), little support (-1), no support (-2). 3 out of 5 (60%) patients stated that they received good or very good support from family members, while 1 out of 4 (25%) had received little or no support. There is a clear relationship between good family support and a lower probability of a deteriorating course of illness (similar to what is observed for health care support); good support in providing daily care and moral support helps staying within the "energy envelope" and avoiding PEM.

Keeping the activity level within the energy envelope (pacing) is the most helpful strategy

Pacing to avoid PEM was viewed as the most helpful strategy. 3 out of 4 respondents (75%) considered pacing to have a positive or very positive impact on their course of illness. Successful pacing also requires that the patient knows what pacing is, and – critically – has sufficient help and support to make pacing possible.

While pacing is critical to stabilize the illness, many struggle to find the right balance and adequate support, and experience regular "crashes" and deterioration of their symptoms (PEM). Caring for their family, their financial situation, and stress and worries were factors contributing to worsening of the symptoms and the overall situation.

Activity-based therapies do more harm than good

With PEM being the hallmark symptom of ME/CFS, meaning that symptoms worsen upon even the slightest physical or mental exertion, therapies focused on increasing activity levels (Graded Exercise Therapy - GET) or changing illness beliefs (Cognitive Behavioural Therapy - CBT) were perceived as harmful by most patients. CBT is highly controversial as a treatment for ME/CFS. The survey distinguished between CBT as a cure and CBT as coping. 3 out of 4 patients experienced a (very) negative affect of CBT as a cure, while 1 in 4 had a negative experience of CBT for coping. Only 5% reported that CBT as a cure to have had a positive effect, compared to 38% in the case of CBT for coping. The more severe the illness, the more negative the experiences with CBT, both as a cure and as a coping.

In short, CBT and GET were not only unsuccessful in improving the condition of the ME/CFS patients but have a very negative impact on the course of illness. Both the CDC in the US and NICE in the UK have removed recommendations on CBT and GET from their guidelines.

BPS - a failed and harmful approach to ME/CFS

The dire situation for most ME/CFS patients across Europe is, in part, the result of both ignorance and lack of knowledge among health professionals, social workers, and policy makers, despite recognition since 1969 by the World Health Organization as a disease of the nervous system. Moreover, proponents of the biopsychosocial (BPS) model claim ME/CFS to be psychological and linked to dysfunctional illness beliefs, a pathological focus on symptoms, fear of activity, and resulting deconditioning.

According to this model, the cure is teaching the patient to ignore, or not to focus on symptoms, to "push through" and to follow an exercise program with set increments. This approach has not only failed to get support from interventional studies, or from research that finds critical biological anomalies in people with ME/CFS; it has done harm in its promotion of CBT and GET. The model places the responsibility for both having ME/CFS and for recovery from it squarely on the patient. This may result in a lack of empathy and sympathy from others in healthcare, social, and welfare institutions, and within the patient's family.

Conclusions

- The survey highlights profound disability levels and unmet needs among European ME/CFS patients. Findings underscore the urgent priority to recognize ME/CFS as a serious physical illness and provide better medical care, financial support, and social services.
- Access to medical care and social support varies across Europe, with different approaches taken by national health authorities impacting the course of illness and disease outcomes.
- Therapies involving fixed increases in activity tend to worsen symptoms and risk a deteriorating course of the illness, rather than leading to improvement.
- Early diagnosis, activity management (pacing) and avoidance of over-exertion (PEM) are key to reduce the risk of progression to severe disease.

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