EMEA survey of ME/CFS patients in Europe

Same disease, different approaches and experiences

By Arild Angelsen and Trude Schei

EMEA
European me alliance

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Our main gratitude goes to the more than 11 000 people with ME/CFS that have responded to the survey. The sharing of their often painful experiences has made this report possible, and the reward will, hopefully, bring more respect and understanding for a disabling illness, and improved services from the health care system and other actors.

We are also grateful to the many EMEA contact persons, and ME organisation/association leaders in the survey countries, who helped with the translation and promotion of the surveys. Their efforts enabled the largest survey (in terms of respondents) of ME/CFS patients in Europe.

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Foreword

In the world of Myalgic Encephalomyelitis (ME or ME/CFS), where decades of misinformation, ignorance, bias and stigma have been allowed to develop and grow without challenge, and eventually influence and then swamp healthcare systems, government policies and media prejudice, people affected by this disease have been left without moral, economic and healthcare support.

The advent of social media has levelled the field somewhat, allowing patient groups to challenge the orthodox view of ME/CFS.

However, the continued lack of any adequate funding for research into the disease, and no serious attempt to find the cause of the disease by national research agencies or policymakers, has led to the lack of the one essential element that is needed to change policies in government.

That element is evidence.

The **European ME Alliance (EMEA) survey of ME/CFS patients in Europe** is a first attempt by patient organisations to bring forward information that can be applied by governments in Europe, and by EU institutions, in order for them to take responsibility for addressing this high burden, under prioritised disease and provide the needed research funding, medical education of physicians, and social support for patients.

The objective behind the survey was to find out whether the situation for ME/CFS patients was similar across European countries.

The survey originated from the excellent work already performed by the authors of this report – Arild Angelsen and Trude Schei – and their impressive work with Norges ME-forening (Norwegian ME Association), an EMEA member, where they have previously surveyed and reported on the situation with ME/CFS in Norway and Denmark and identified similarities between the onset of ME/CFS and other factors impacting people with this disease.

Building upon their work, EMEA members came together to assist in conducting this 'first ever' European patient survey.

The results show that patients everywhere in Europe face similar stigma regarding recognition and knowledge of the disease, with huge delays in diagnosis that may take up to 12 years in some cases. With patients in Europe often being forced into taking deleterious and flawed biopsychosocial-based therapies that are still recommended by some national healthcare authorities, it may be no surprise that the report shows only 7% of patients reporting improvement over the years, with many having to face health deterioration that can last a lifetime.

The survey also indicated that patients who received early diagnosis had better outcomes and were able to manage their energy use earlier by using pacing techniques to avoid over exertion and repeated 'crashes'. The lack of educated medical professionals leads to a failure of healthcare and

welfare systems to provide adequate support – the report highlights the poor level of support for this disease being experienced everywhere.

The results compiled here by Arild Arildsen and Trude Schei demonstrate that it is important that information about this disease is also to be collected from patients – to document their '*lived experience*' as is the currently popular buzzword.

The survey provides evidence.

The survey results should be a call for action.

Investing in ME research will greatly benefit not only the patients, but also the healthcare and social systems as, currently, it takes patients years of medical visits to receive a diagnosis or receive any symptom relief, and their inability to workplaces heavy strains on national insurance and welfare systems.

It is important to note that the research community has the interest and the potential to tackle this disease. EMEA member organisations have established a network of experts – researchers and clinicians, namely the European ME Clinicians Council (EMECC), the European ME Research Group (EMERG), as well as an Early Career Researcher Network (Young EMERG). These are well connected internationally with world-renowned research institutes and already have the capability to coordinate the necessary research that can lead to a correct diagnosis and appropriate treatments for ME/CFS patients. In addition, EMEA supports the annual Invest in ME Research International ME Conference (IIMEC) which brings together world renowned researchers and also includes a 'patient day' which is open to the public where the latest advances related to ME/CFS are presented in a language patients can understand.

Patient organisations play a key role in providing information, guidance and support to ME/CFS patients. EMEA is committed to continue surveying patients in order to provide ongoing data to support urgent and decisive action from policymakers in Europe in order to improve the situation for people with ME and their families in Europe.

The **EMEA survey of ME/CFS patients in Europe** is a valuable part of the resources required as EMEA works to support the implementation of the UN Universal Declaration of Human Rights, the UN Convention on the Rights of Persons with Disabilities, and the UN Political Declaration on Universal Health Coverage, to respect patients' rights and ensure that European government policies do not leave ME/CFS patients behind.

Executive Committee, European ME Alliance

Executive summary

This survey of ME/CFS patients in Europe has been conducted by the European ME Alliance (EMEA), which gives a voice for people with ME/CFS in Europe and is the European partner for facilitating high-quality biomedical research. This report presents the findings from the survey of more than 11 000 ME/CFS patients. The aim was to compare patients' experiences across countries regarding disease characteristics, course of illness, and access to healthcare and support.

The survey

The data are based on an online survey, conducted in May - August 2021. The questionnaire was translated into 15 languages, and the survey was promoted via patient organisations in European countries. The respondents spanned 44 countries, including responses from a few non-European countries. A total of 11 297 responses were analysed.

The questionnaire covered illness characteristics, factors affecting disease course, therapies tried, and support received from healthcare and personal contacts.

Potential biases due to non-random sampling are acknowledged. Severely ill and undiagnosed patients are likely to be underrepresented. However, the large sample size is viewed as providing useful insights into patients' experiences across European countries.

ME/CFS is a serious and debilitating disease

ME/CFS is typically categorised into four degrees of severity: mild, moderate, severe, very severe It can be argued that 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.

In the survey, 24.0% answered that they had mild ME/CFS, 53.8% had moderate ME/CFS (mostly housebound), 16.0% had severe ME/CFS (mostly bedbound), while 2.4% had very severe ME/CFS (bedbound and in need of continuous care). 3.7% described their severity as "better than mild", while only 0.2% said they had recovered. Strong similarities were found among countries for several factors such as 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 coping and support from family and friends.

Almost half report a deteriorating course of illness

Persistent myths exist about ME/CFS being an illness that gradually "burns out". 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.

In the survey, 46% described mainly deterioration (26% had initial fluctuations and then deterioration, and 20% have experience mainly deterioration), while 24% answered that they had experienced major fluctuation throughout their course of illness. In total, 70% of respondents described either deterioration or large fluctuations. Only 7% reported improvement.

Many patients have a severe or very severe degree of ME early on. 33% among the very severely ill had an onset before turning 20 years old, compared with 14% among those with a mild degree.

The health care system fails the 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 experience 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% state that they received poor health care support. Yet some differences are notable, indicating that the public approach matters. This is illustrated by the difference found in an otherwise rather homogenous Nordic region. The portion of respondents reporting that they received no help varies from 15-21% in Iceland, Norway and Sweden, to 35% in Finland and more than half (53%) in Denmark. The latter is known for a strong biopsychosocial approach, where ME/CFS is considered a functional illness by the Danish health authority.

On the positive side, patients with a more recent onset or diagnosis are less dissatisfied with the health care provided, which may suggest a modest improvement over time.

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 experiencing good support from the health care system in their country were more likely to report improvement and less likely to report deterioration.

Early diagnostics and disease management critical to improve the course of illness

Long delays in the diagnosis were common, with the diagnostic period (from onset to diagnosis) averaging 6.8 years across Europe and 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 a course of illness characterised by 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 prospects.

Patients much more satisfied with support from family, friends and fellow patients

3 out of 5 (60%) 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 case support); good support in providing daily care and moral support helps staying within the "energy envelope" and avoiding PEM. A similar relationship is observed for support from friends and fellow patients.

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

Pacing to avoid post-exertional malaise (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 – have sufficient help and support from the environment to make pacing possible.

While pacing is critical to stabilise 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 are factors contributing to the worsening of their symptoms and the overall situation.

Activity-based therapies do more harm than good

With PEM being a characteristic 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 a highly controversial as a treatment for ME/CFS. In the survey we 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 experiences with CBT, both as cure and as coping.

In short, CBT and GET are not only unsuccessful in improving the condition of 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 advice on CBT and GET from their guidelines for ME/CFS.

The Biopsychosocial Model (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. Moreover, the biopsychosocial (BPS) model claims 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, and "push through" and 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 also lacks support from patients and has done harm in its promotion of CBT and GET. The model places the responsibility for both having ME/CFS and for recovery squarely on the patient. This may result in a lack of empathy and sympathy from others, both in healthcare 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 recognise ME/CFS as a serious illness and provide better medical care, financial support, and social services.
- Access to medical care and social support varies across Europe, resulting in both a general but dangerous neglect of the illness, with different approaches taken by national health authorities, impacting courses 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 preventing progression to severe disease.

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1 Introduction

Myalgic encephalomyelitis (ME, also referred to as ME/CFS or CFS/ME, with CFS standing for Chronic Fatigue Syndrome)[1] is a serious disease, with a heavy symptom burden and low quality of life (Falk Hvidberg et al., 2015). It has been recognised by the World Health Organization as a disease of the nervous system since 1969. There is little knowledge about incidence and prevalence, and few studies on prognosis. Despite this, research is underfunded and lagging far behind where it ought to be, given the existing estimates of disease prevalence in the range of 0.5-0.8% of the population (Jason et al., 2020a; Valdez et al., 2019), as well as the extensive disease burden and personal and social costs. There are large areas where knowledge is almost completely lacking.

While differences in diagnosis and treatment in Europe has been documented (Strand et al., 2019), this report presents the results of the first ever survey undertaken by the European ME Alliance (EMEA), which gives a voice for people with ME/CFS in Europe and is the European partner for facilitating high-quality biomedical research. The survey's purpose was to compare the situation and experiences of ME/CFS patients across European countries. With more than 11 000 respondents, the survey is able to paint a picture of the similarities and variation across European countries in how ME/CFS patients experience their situation with regards to course of illness and availability and access to health care and support.

Currently, it is not known what constitutes a normal course of illness for ME/CFS over an extended period, nor is enough known about which factors may have a negative or positive impact on the course of illness.[2]

Patients frequently encounter stigma and disbelief both from health care systems (Kielland, Liu, & Jason, 2023; Scoles & Nicodemo, 2022), social services and friends and family, though attitudes in different countries differ. Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) are often offered as treatment, even if patients claim that these therapies do not help, but often cause harm (as will be documented in this report).

ME/CFS patient surveys have become a critical source of information and knowledge on the situation for ME/CFS patients and their experience with public services. They help shed light on areas where research is lacking. The large number of respondents in many patient surveys, such as

[1] Myalgic encephalomyelitis (ME) is also referred to as ME/CFS, CFS/ME or even CFS (Chronic Fatigue Syndrome). CFS is not accurate and the term is generally used in older, wide criteria sets, such as the Oxford criteria. Our preference is to use the acronym ME. However, due to different terms being used across countries and as ME/CFS is being used in more places, this report will standardise on ME/CFS to avoid confusion.

[2] See the continuously updated research summaries at: https://meassociation.org.uk/research/published-research/research-summaries/

the current one, enables us to move beyond anecdotes and provide a more representative picture of the situation and the experiences of ME/CFS patients.

The results of patient surveys reflect the experiences, views and perceptions of patients. This is extremely valuable. The health care sector exists to care for the sick, and patients' views should be key in any assessment of the health care, social security or other services provided. Ideally, such assessments would be complemented by more objective measures, such as the frequency of visits by doctors, medical assistance, level of welfare benefits, etc.

The idea for a European survey among ME/CFS patients originated when patient surveys in Norway and Denmark identified strong similarities regarding the time of illness onset and which factors the respondents believed impacted positively or negatively on their course of illness. In both countries, a peak of new cases was observed in 2009, the year of the swine flu pandemic. Patients were also asked in open-ended questions which factors they believed had had a negative or positive impact on their course of illness. Respondents from both countries associated pacing with improvement or stabilising the disease, and exertion and Post-exertional Malaise (PEM) as having strong negative impact on the course of illness.

In this European survey, one objective was to explore whether patients across Europe had similar experiences. The survey also aimed to describe differences across countries in terms of the experiences with the health care and welfare systems, and the support received from family, friends, fellow ME/CFS patients and others.

People with ME/CFS have limited energy to respond to long and complex surveys. Therefore, to maximise the number of respondents the survey was kept brief. Information requested in the survey included: time of onset; age at onset; time from onset to diagnosis; the typical course of the illness; positive and negative factors associated with the course of the illness; the availability and experiences with various treatments of symptoms; the experience with the health and social security systems; and the acceptance of ME/CFS among family members and friends.

This report presents the main results of the survey. Section 2 presents the survey and discusses potential biases. Section 3 provides an overview of the respondents in terms of nationality, age and gender. Section 4 gives the status for respondents in terms of ME/CFS-related characteristics. Section 5 presents the typical courses of illness. Section 6 analyses factors that may have contributed positively and negatively to the course, including the patients' experiences with different "treatments" and management strategies. We also explore how patients' characteristics and experiences with public services are associated with different courses of illness. Section 7 discusses the findings and conclusions.

Appendices 1-2 contain additional tables and figures. Summaries of findings for countries with more than 100 respondents are given in Appendix 4.

2 The survey

2.1 Background and aim

The main purpose of the survey was to explore similarities and differences across European countries on a number of aspects related to the illness: distribution of patients across variables such as age, gender, severity, diagnosis period, courses of illness and factors affecting it, experience with health care systems and other public services, and support from family and friends.

The survey was initiated by the European ME Alliance (EMEA) and the Norwegian ME Association (NMEA), itself a member of EMEA. The latter has since 2012 undertaken a total of six large patient surveys, both general ones and on more specific topics. The survey was promoted on the EMEA website (in multiple languages), and through EMEA's social media accounts. A short promotional video was translated into several languages and distributed through social media. The EMEA member organisations also promoted the survey in their own countries, through emails to members, Facebook and other social media.

2.2 The questionnaire

This survey questionnaire is based on a previous survey, conducted in Norway and Denmark in 2019 (Schei & Angelsen, 2021). These surveys, with 5 822 respondents in Norway and 642 in Denmark[3], focused on questions about the course of illness for ME/CFS, and which factors patients believed had an impact on the course of illness. Some questions to this survey were added or altered based on experiences with the Norwegian and Danish surveys. The previous survey asked open-ended questions about factors influencing course of illness, while the current survey does not. While open-ended questions can give valuable information and insights, it would be impractical and too time-consuming to use open-ended questions for a larger survey. Based on answers from the original survey, structured questions were designed.

Our target group was patients who had an ME/CFS diagnosis, those who were currently being evaluated for an ME/CFS diagnosis, and those who believed that they had ME/CFS, but who neither had a diagnosis nor were under evaluation. The reason for casting the net wide was that recognition and attitudes to ME/CFS vary between countries. Anecdotal evidence suggests that it can be very difficult to obtain a diagnosis in some countries.

Carers were asked to answer on behalf of patients who were too ill to answer themselves.

The survey was designed in SurveyMonkey and consisted of 18 questions. It took, on average, 8 minutes to complete. Answers were limited to one answer per language per IP-address. The survey was anonymous. The English-language questionnaires were translated into 15 languages by the

[3] https://me-foreningen.dk/wp-content/uploads/2020/06/Medlemssurvey-2019-561-patienter.pdf

EMEA member organisations in 15 countries. The languages used were: Norwegian, Swedish, Danish, Icelandic, Finnish, English, German, Dutch, French, Spanish, Italian, Croatian, Serbian, Czech, and Hungarian. The survey was open from the beginning of May to the end of August 2021.

The data were analysed in Excel and Stata.

2.3 Potential biases

The survey was based on voluntary participation and not a random sample from a central register of patients with the ME/CFS diagnosis, which would – in theory – have provided a representative sample of patients. Such an approach is not feasible for several reasons. Primarily, this is a survey performed with minimal resources by small patient organisations, with limited budget and manpower. Also, such central registers may not even exist in all countries, either because the illness is not recognised, or the registries being incomplete.[4] In addition, underdiagnosis and misdiagnosis exist, although the extent is unknown.

The survey is more likely to have reached patients who are members of a patient organisation or follow an organisation on social media, since the survey was promoted by the organisations in their respective countries. The age, size, and resources of the patient organisations differ greatly, and consequently the number of patients they can reach.

The number of respondents from each country may therefore largely reflect the size of the patient organisations' membership and their presence on social media. For example, the Norwegian ME Association is 35 years old, has a membership of more than 6 000, and has developed large online networks. The Serbian organisation, by contrast, is very young, and has only a few hundred members, even if Serbia has a larger population than Norway.

Attitudes toward ME/CFS differ from country to country, and so does the knowledge about ME/CFS, both within the health care systems and the population. This will affect whether patients with ME/CFS are diagnosed at all. The survey might not have reached many undiagnosed patients, since patients who do not know that they have ME/CFS are less likely to follow an organisation on social media, and are consequently less likely to have heard about the survey. In short, the variation in number of respondents across countries is most likely reflecting the awareness of the disease and the size and activity level of ME/CFS patient organisations, rather than differences in ME/CFS prevalence.

The higher likelihood of getting respondents from countries with active patient organisations and public recognition of the disease, combined with the fact that the situation for ME/CFS patients and their experience is affected by the recognition, means that the figures presented for the full sample is

[4] An example is Norway: while an ME/CFS diagnosis set by a specialist is included in the national patient registry, a diagnosis set by a family doctor (GP) is not.

painting *too positive* a picture of the situation of ME/CFS patients in Europe. For example, Norwegian MEA patients are generally more satisfied, and they are also overrepresented in the sample. Therefore, for many variables country-level figures are presented.

The survey might not have fully reached those who have recovered, as persons who are recovered are less likely to be members of organisations or follow them on social media. The severely ill may also be underrepresented, as these patients are often too ill to communicate, and may not have heard about the survey.

The information given in the survey cannot be verified, including whether respondents have ME/CFS, or whether what they state about their experiences is true. However, the likelihood that anyone would try to "game" results through deliberately giving false answers or answering more than once seems to be low. In a survey this size, it would also require an extraordinary amount of effort to affect the results.

Due to potential sample biases, this survey cannot claim to give definitive answers to the questions raised, but it can provide valuable insight into the long-term course of illness for ME/CFS, an area that has been little studied. It is hoped that it can help generate hypotheses, and act as an incentive to further studies which, in turn, will facilitate better and more representative policies aimed at people with ME/CFS.

Sample biases affect different statistical analyses differently. They are potentially larger for figures such as the distribution of the severity, while biases typically tend to be smaller for statistics on the relationship between variables, such as the relationship between the diagnostic period and course of illness.

In short, biases are possible. Yet, it is thought that the large number of responses from this survey provides the most representative picture to date of the overall situation for ME/CFS patients in Europe. The results are largely consistent with earlier and more comprehensive national surveys, including the Norwegian surveys (Schei & Angelsen, 2021; Schei, Angelsen, & Myklebust, 2019), a Swedish survey in 2019 among 929 ME/CFS patients (Eriksson & Heiling, 2020), a Danish survey in 2019 with 565 respondents[5]. Moreover, using a statistical sampling approach to obtain representative figures for the full group of ME/CFS patients in Norway, Kielland, Liu and Jason (2023) show results very comparable to the findings in this report on experiences with various interventions/treatments.

[5] https://me-foreningen.dk/wp-content/uploads/2020/06/Medlemssurvey-2019-561-patienter.pdf

3 The respondents

After removing incomplete responses and responses from persons without ME/CFS, there remained 11 297 more or less complete responses. The numbers given for the different analyses may differ, as not all respondents have answered all questions.

3.1 Countries

The survey was actively promoted in Belgium, Croatia, Denmark, Finland, France, Germany, Iceland, Ireland, Italy, The Netherlands, Norway, Serbia, Slovenia, Spain, Sweden, Switzerland and the UK. The majority of responses came from countries with EMEA member organisations, but responses were also received from other European countries, for example, Austria.

Although not actively promoted outside Europe (and not having any intent to include non-European countries), responses were received from some countries outside the continent, in particular the English-speaking ones (USA, Australia, Canada and New Zealand). This is largely due to information about the survey being spread on social media in the patient communities. These responses may be referred to in the analyses as points of interest.

Ten countries had more than 400 respondents each: Denmark, Finland, France, Germany, Norway, Spain, Sweden, The Netherlands, and the UK, in addition to the USA (Figure 1).

Several factors may have affected the uneven number of respondents from each country.

Prevalence may vary from country to country, though this is uncertain. The exact prevalence of ME/CFS in any country is unknown. Two recent American studies suggest a prevalence of 0.8% for adults (Valdez et al., 2019) and 0.75% for children (Jason et al., 2020b). Both studies conclude that many patients are undiagnosed.

The numbers quoted for prevalence is dependent on case definition and diagnostic method (Lim et al., 2020). It is apparent that attitudes to ME/CFS differ between countries, and that different case definitions are used. It is reasonable to assume that the proportion of patients who are diagnosed differ as well.

The knowledge and recognition of ME/CFS varies across countries. If ME/CFS is not considered a "real" disease, fewer patients will receive a diagnosis, and fewer would be likely to follow an ME/CFS organisation on social media. In these countries, the organisations are also likely to have fewer members, a smaller reach on social media, and fewer resources to use on promotion. The media is less likely to be informed or to cover the disease and this again would affect awareness.

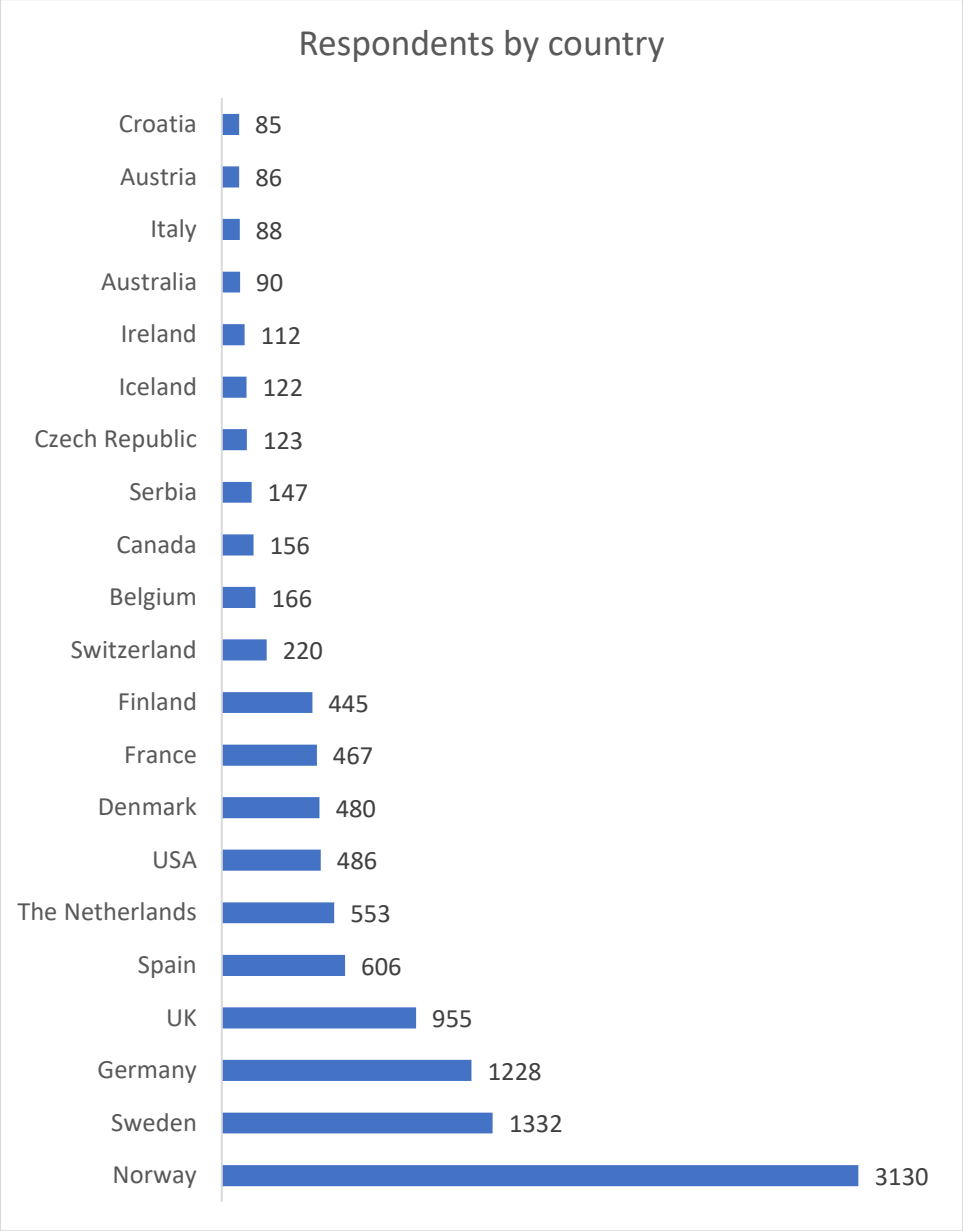


Figure 1: Number of respondents by country, countries with more than 80 respondents (n=11 297).

If one assumes that the prevalence of ME/CFS is similar everywhere, the low number of respondents from many countries may indicate that a large number of patients are undiagnosed. This is worrying, as a correct diagnosis is essential to have access to medical care, disability benefits and community care as well as support from family and friends. Not least, having ME/CFS without the diagnosis is also bewildering for the patient given the heavy symptom load and it easily gives rise to self-blame for not fulfilling expected activity levels and participation expectations from both family and society. Finally, health care budgets and policies are unlikely to be aligned to needs and requirements if the disease prevalence is unknown.

3.2 Gender

ME/CFS is a female-dominated disease. Several studies have found that more women than men get ME/CFS; results in other studies range from 75% to 85% women (Bakken et al., 2014; Gunn, Connell, & Randall, 2007; Jason et al., 1999). In our survey, 84% of the respondents were female, 15% were male, and 1% preferred not to state their gender.

There are more female than male respondents in all countries, but the proportion varies; from Austria, 25% of respondents are male, from Iceland 7%. The cause of the different proportions from different countries may be a result of different practices when it comes to diagnosis, or how ME/CFS is regarded (Figure 2). As women are much more likely to get ME/CFS, it has been widely regarded as a women's disease, potentially resulting in men being less likely to come forward and doctors less likely to use the diagnosis on men.

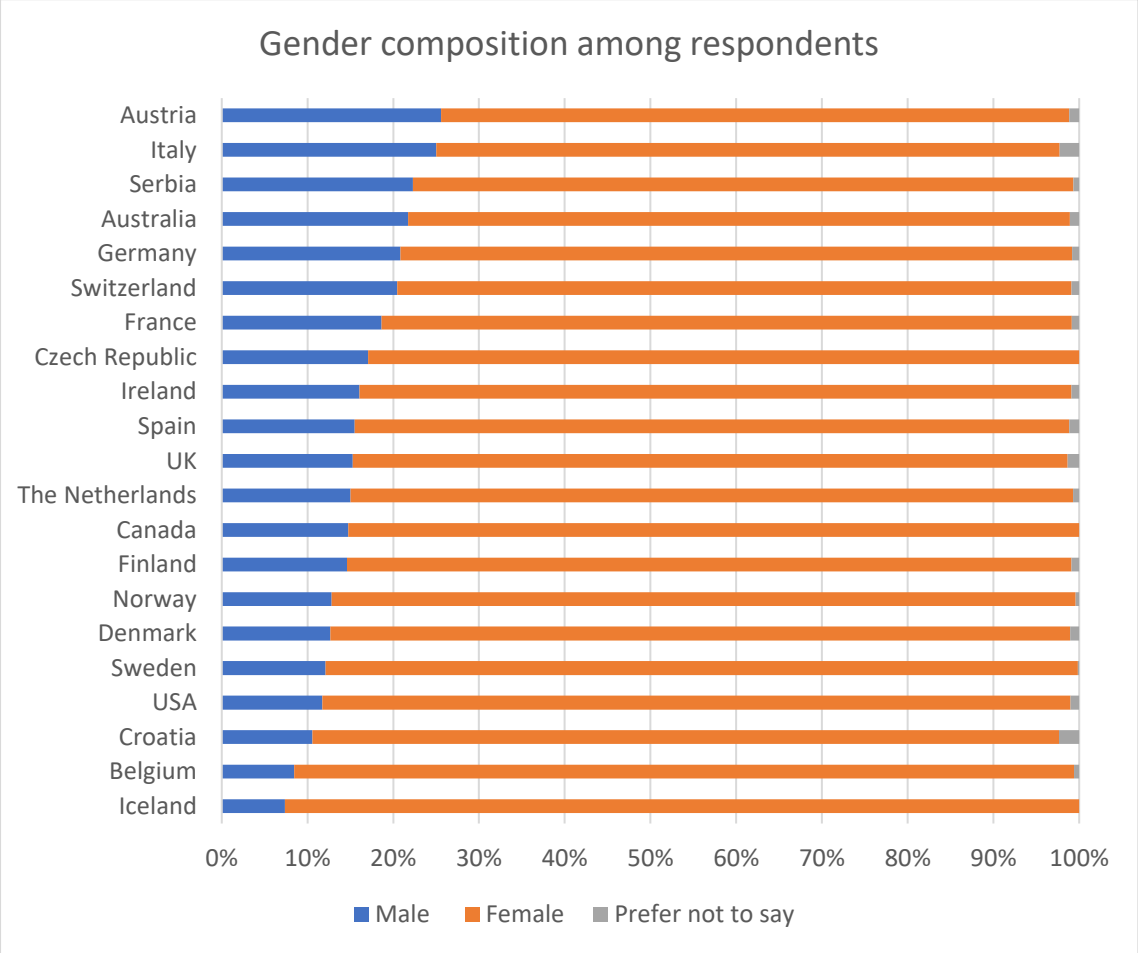


Figure 2: Gender distribution among respondents across countries (n= 11 081).

3.3 Age

The average age of respondents was 50 years of age. The country with the lowest average age was Serbia, with 43 years, while the highest average (among European countries) was in Iceland with 52 years. Relatedly, the distribution across age groups varied, as shown in Figure 3. Serbia and Norway had the highest shares in the groups below 40 years of age.

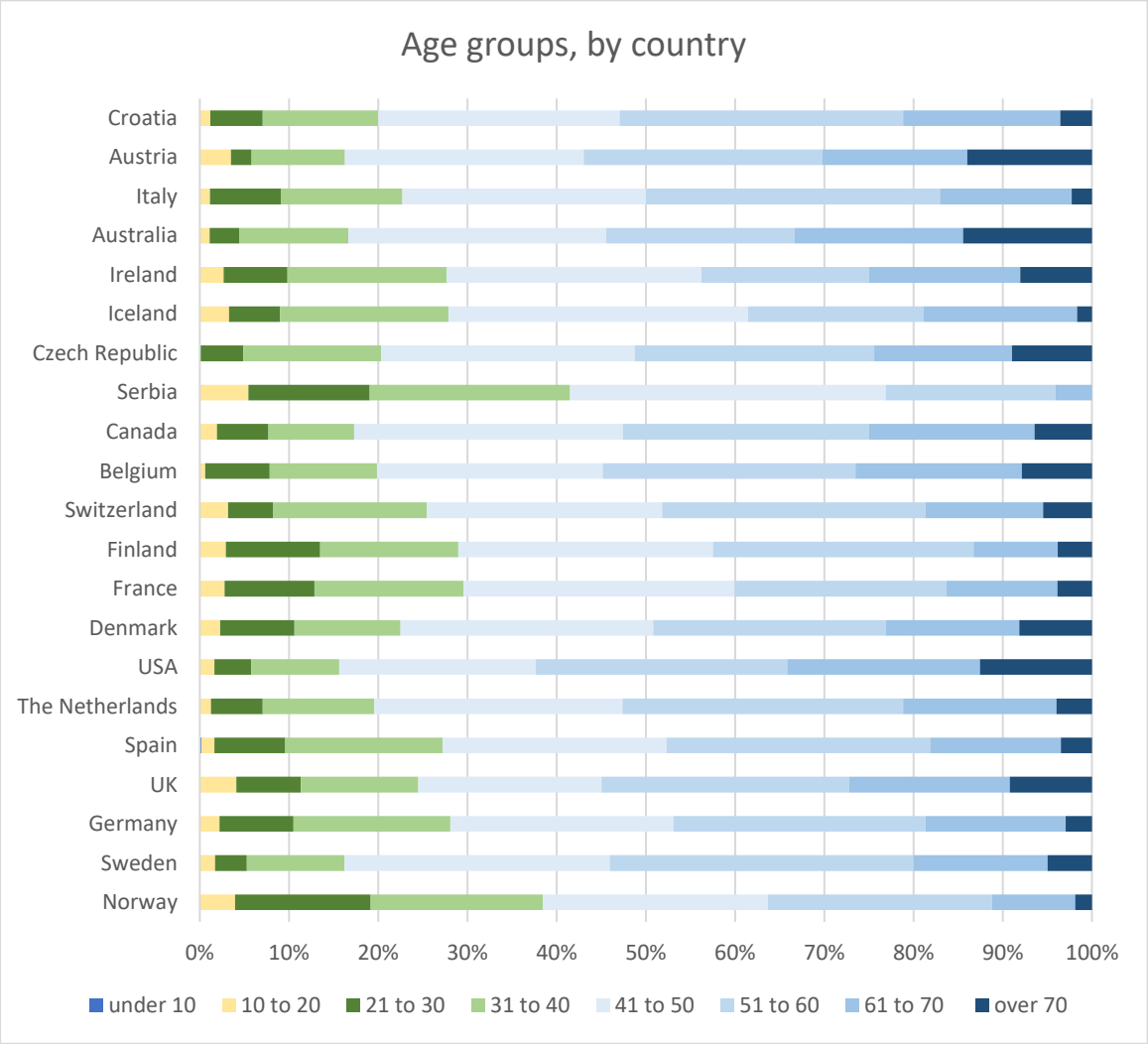


Figure 3: Age distribution of respondents (countries with more than 50 respondents).

3.4 Disease triggers

Onset of ME/CFS can be sudden or gradual. Most patients associate onset with an infectious disease (Salit, 1997).

Respondents were asked if they associated the onset of disease with a particular event or trigger. It was possible to give more than one answer. Infectious disease was the most common trigger associated with disease onset, mentioned by 58% (6 487) of respondents. This is comparable to what was observed by Jason, Yoo and Bhatia (2022) in a population of 1 773 patients, while Salit found that 72% of 134 patients associated onset with an infection. Accident, physical trauma or surgery are mentioned by 18% (1 989) in our survey, while pregnancy and birth are mentioned by 4% of female respondents (Figure 4).

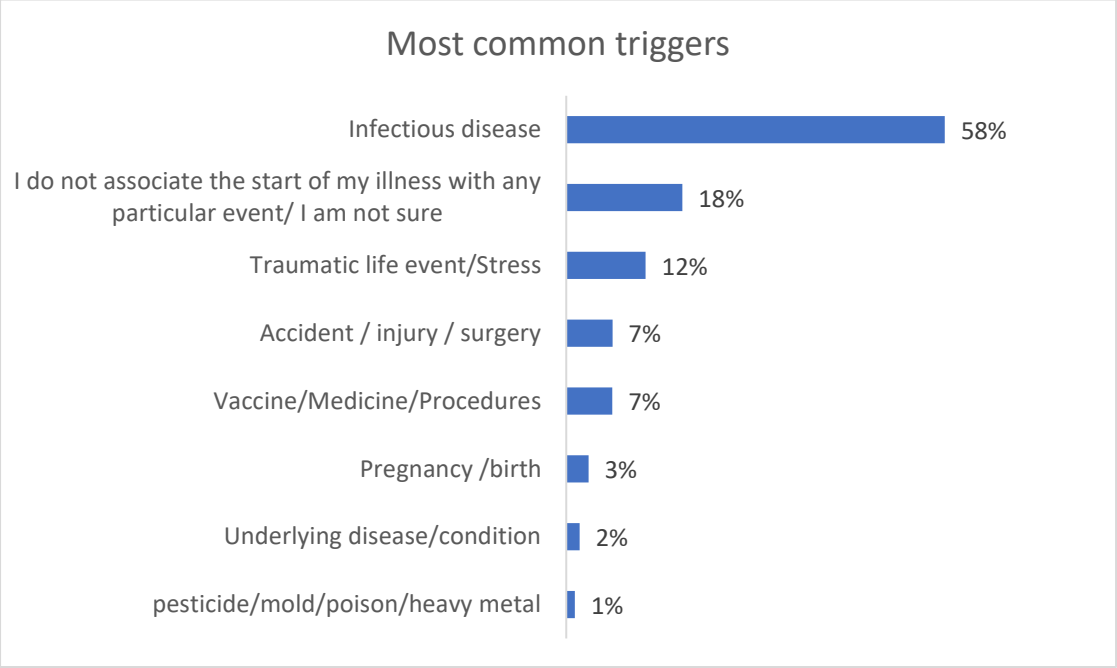


Figure 4: Triggers of ME/CFS (n = 11 274).

Most respondents associated onset with a single event, but 8% of respondents answered that they associated onset with a combination of events. The most common combination was infectious disease in combination with long-term stress or traumatic life event (252) and infectious disease and accident/surgery (153).

Stratifying the respondents by severity of the disease, an infectious trigger is reported slightly more frequently by patients with more severe disease (Figure 5).[6]

[6] The differences are statistically significant at 1% level, using the Kruskal-Wallis test.

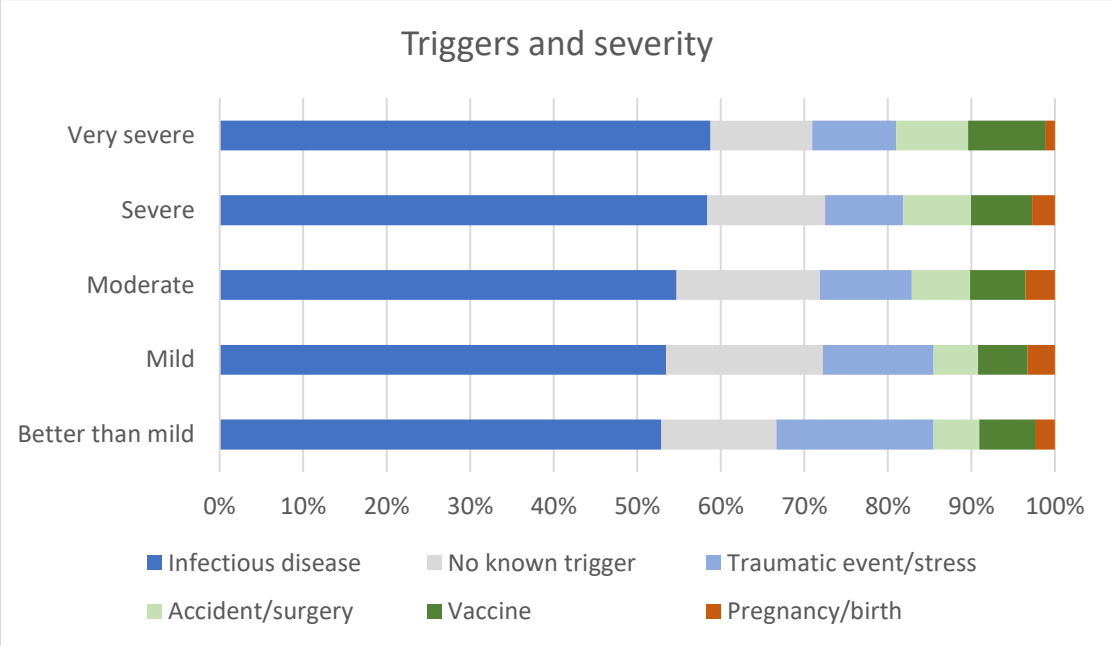


Figure 5: Triggers of ME, by degree of severity (n (triggers mentioned) = 11 591).

3.5 Year of onset

ME/CFS is a chronic disease, and 50% of the respondents became ill before 2009. Figure 6 shows the distribution of the year of onset. In surveys involving recall questions, one typically finds peaks for round numbers (1990, 2000 etc.) and such a recall bias was observed here.

Yet, some interesting observations can be made. First, the data support a hypothesis of an increased incidence of ME/CFS in Europe. The decline in respondents with disease onset after 2017 probably reflects the simple fact that it takes several years from onset to diagnosis. On average, it took 6.8 years to receive a diagnosis (see further discussion in section 3.7). The survey has not been able to reach undiagnosed patients who have become ill during the last five or six years. For example, persons without a diagnosis are less likely to be a member of a patient organisation or answer a disease-specific survey.

The low number of respondents reporting onset before 1980 may reflect that many who experienced onset then are now very old or deceased, or may not be online.

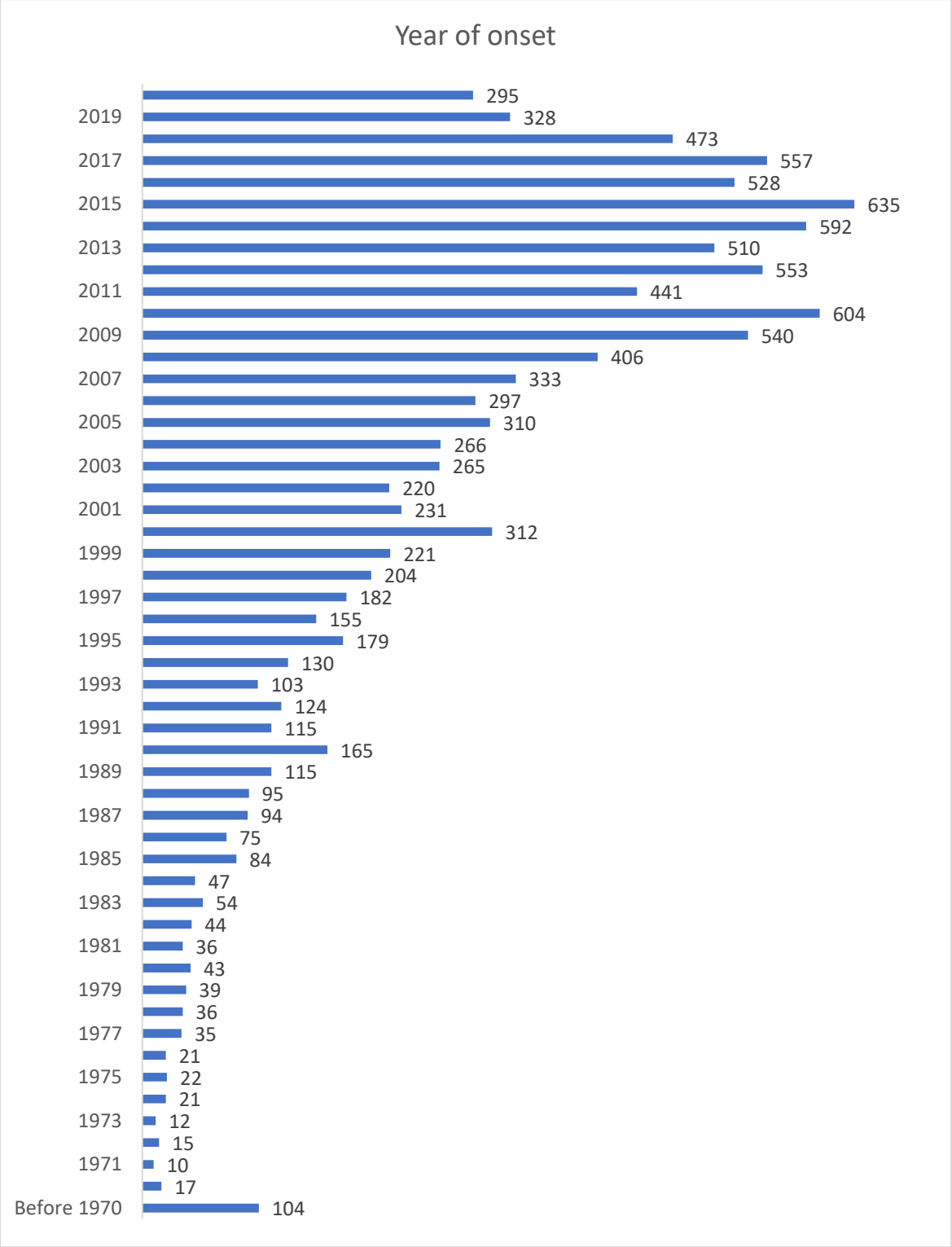


Figure 6: Onset of illness (n=11 298).

Looking at the year of diagnosis, this picture changes: Figure 7 shows a steady increase in the numbers of diagnoses until the survey year (2021). A Norwegian study based on patient registry

data from 2016-2018 found higher incidence rates compared to previous studies (Hilland & Anthun, 2022).

A second observation is the peak in 2009 and 2010, which corresponds with the swine flu epidemic. Another study from Norway showed that the risk of getting ME/CFS was doubled among those that have had the swine flu, whereas there was no increased risk among those that have received the swine flu vaccine (Magnus et al., 2015).

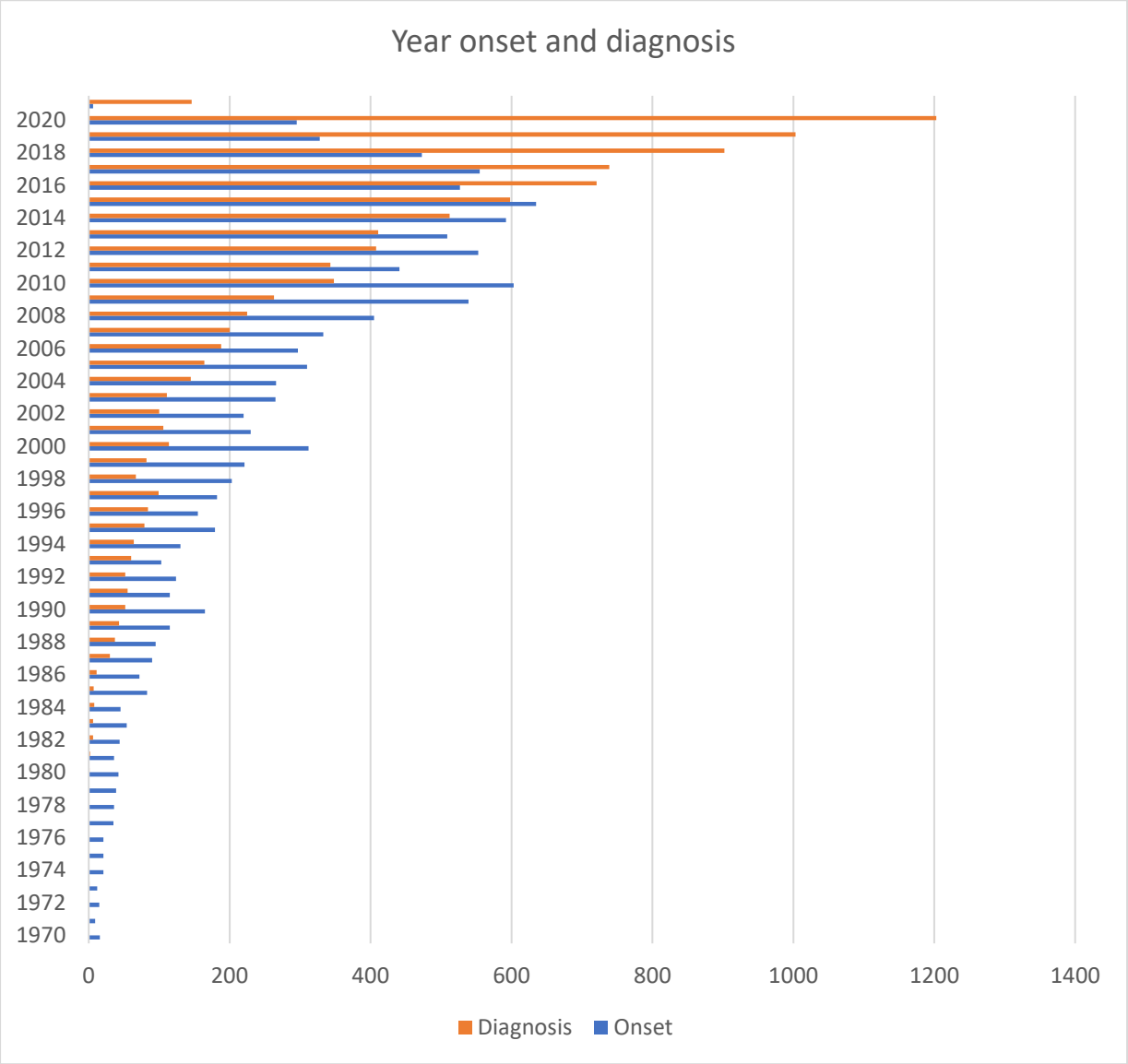


Figure 7: Year of onset and year of diagnosis (n=11 092 and n=9 789, respectively).

3.6 Age at onset

The likelihood of becoming ill varies by age. A peak for women is between the ages 35 and 39, and a smaller peak between 15 and 19 is observed (Figure 8). No similar peaks are seen in men.

There is a large gender difference for all age groups. If one looks at the youngest age group with onset before the age of 20, it is seen that there are more girls than boys even at a young age, but that the difference increases around the onset of puberty.

Two Norwegian studies using registry data from 2014 and 2016-2018 found a similar pattern, with peaks for ages 10-19 and 30-39 years old (Bakken et al., 2014; Hilland & Anthun, 2022). A similar pattern is observed in this survey's data, although it is not very pronounced.

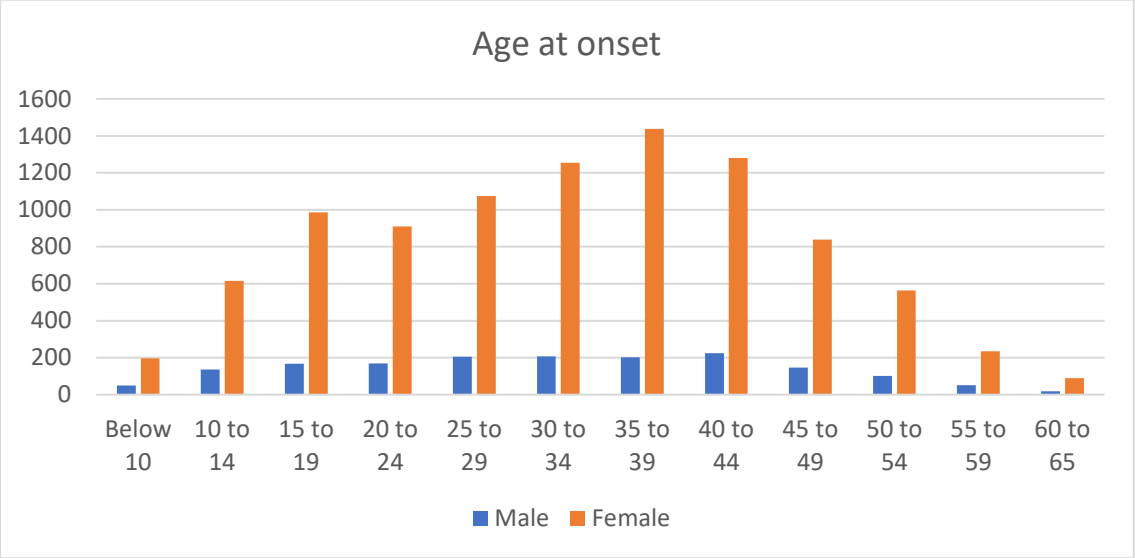


Figure 8: Age at onset for male and female ME/CFS patients (n=11 158).

Many respondents with early onset had been ill for a long time. Many of those who had been ill for 25 years or more became ill as children.

A common assumption is that most ME/CFS patients recover over time. Data from this survey indicate that ME/CFS often lasts for a long time, and in many cases is lifelong.

As discussed, the survey may not have reached patients who have recovered, and there is no data on how many there are, disease duration before recovery, or what their course of illness looked like. One only knows that many patients are ill for a very long time, including those with early onset.

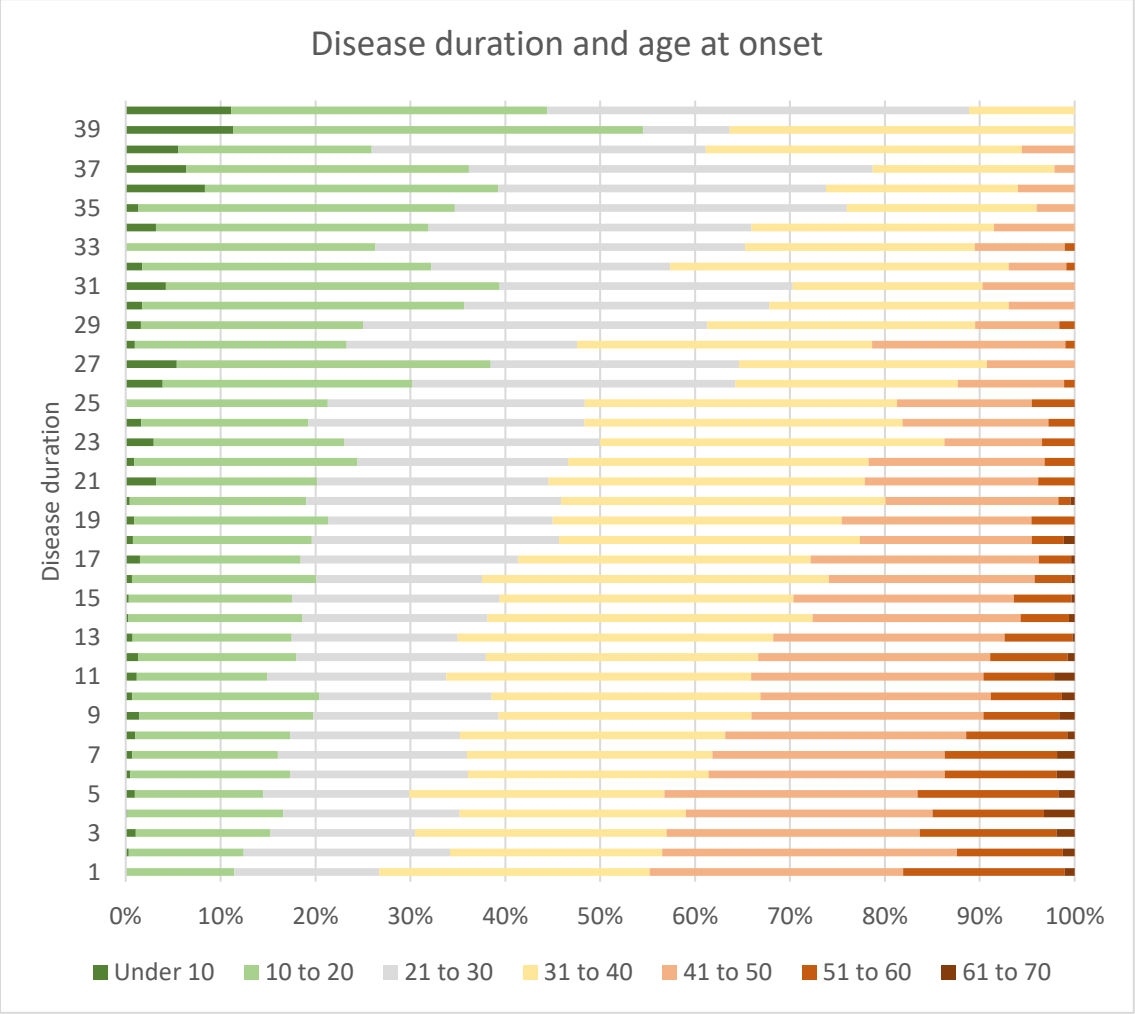


Figure 9: Age at onset and disease duration, for respondents with <40 years disease duration (n=10 894).[7]

3.7 Diagnosis status

The case definition used, diagnosis guidelines and practices vary greatly across European countries. This may reflect the degree to which ME/CFS is accepted as a "real disease", and the knowledge about, and attitudes towards, ME/CFS in the health care system.

The survey was open for diagnosed patients, but also patients currently under evaluation and those who strongly suspect that they had ME/CFS but had not yet been evaluated.

In the UK, 97% of respondents had a confirmed diagnosis, while in Croatia only 32% of respondents had received a diagnosis.

[7] The figure excludes those with a disease duration above 40 years, due to the small number of respondents in the survey in these duration categories. This does not suggest that the disease cannot last longer.

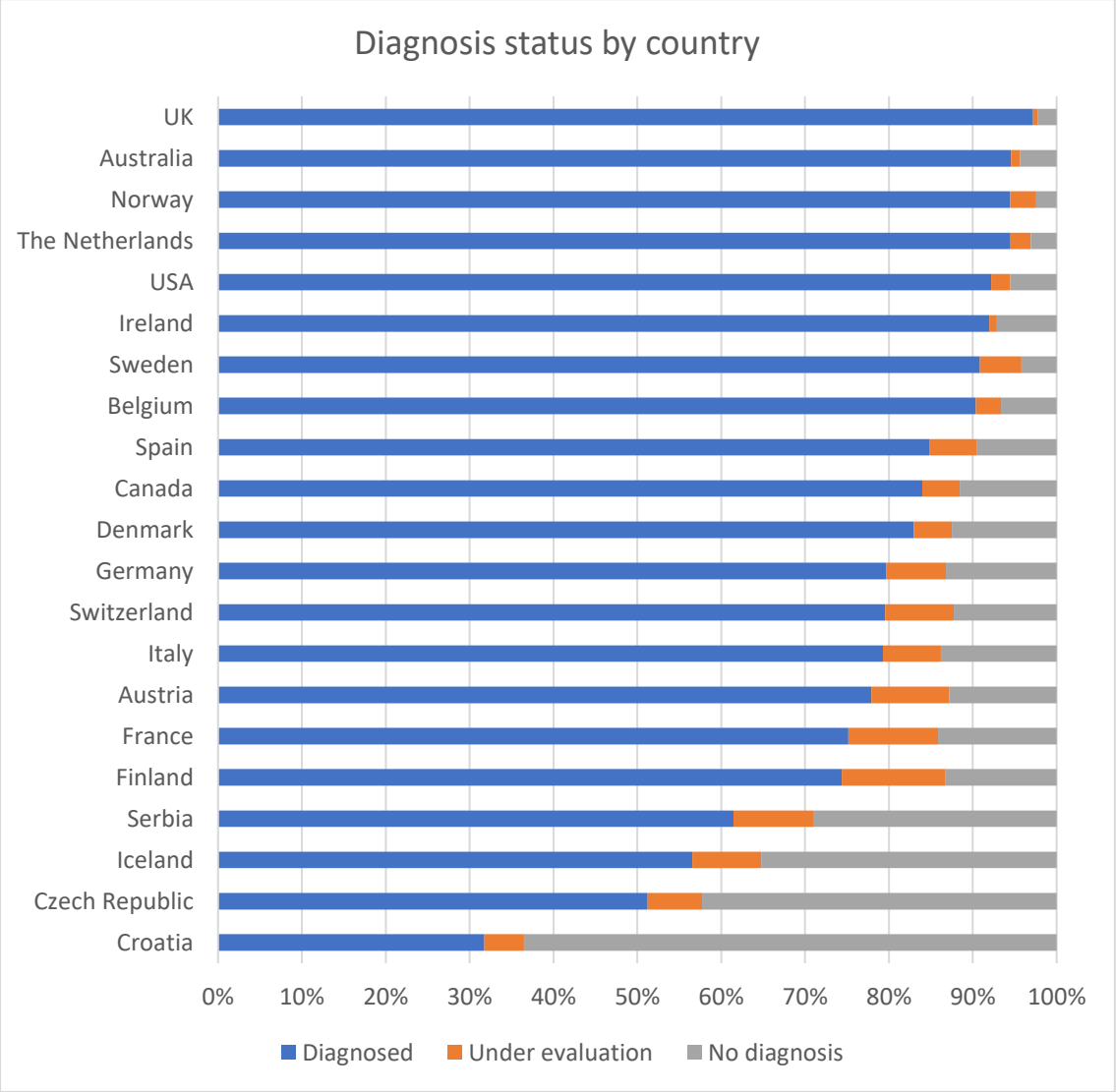
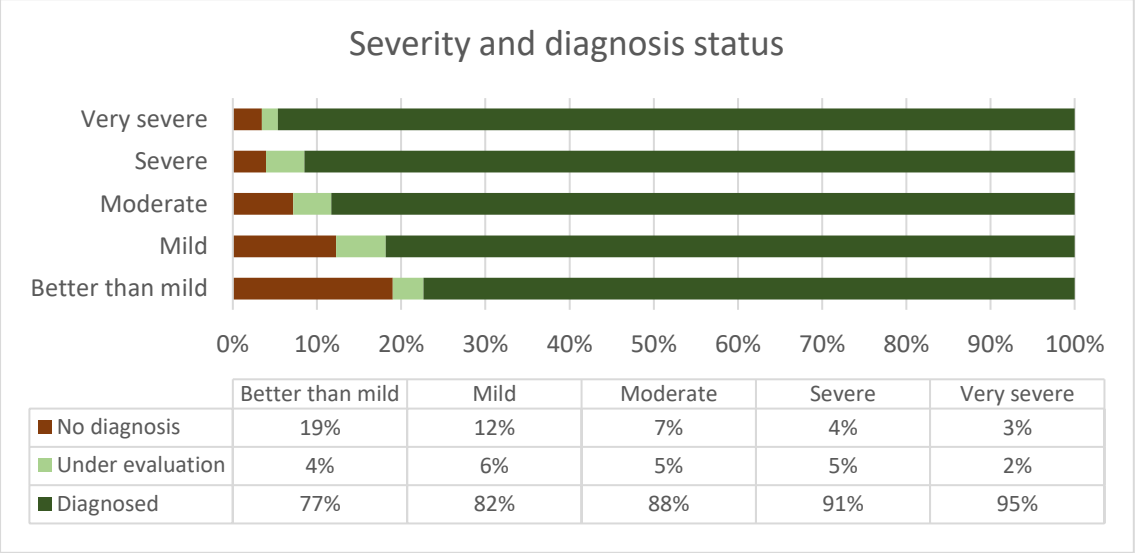


Figure 10: Diagnosis status, countries with more than 50 respondents (n=11 079).

The more severe the disease, the more likely it was that the respondent had received a diagnosis. Among the severely ill, 95% had been diagnosed while the share dropped to 77% among the "better than mild" group (Figure 11).



	Better than mild	Mild	Moderate	Severe	Very severe
No diagnosis	19%	12%	7%	4%	3%
Under evaluation	4%	6%	5%	5%	2%
Diagnosed	77%	82%	88%	91%	95%

Figure 11: Diagnostic status across severity of ME/CFS (n=11 079).

3.8 Diagnostic period

Average (mean) age at diagnosis was 39 years (median 40 years).

Respondents from Italy reported, on average, a 10-year earlier onset (28 years) than respondents from Canada (38 years), though it is not known the reason behind this difference. Average time from onset to diagnosis varies from 5 years (UK, Ireland) to 12 years (Croatia).

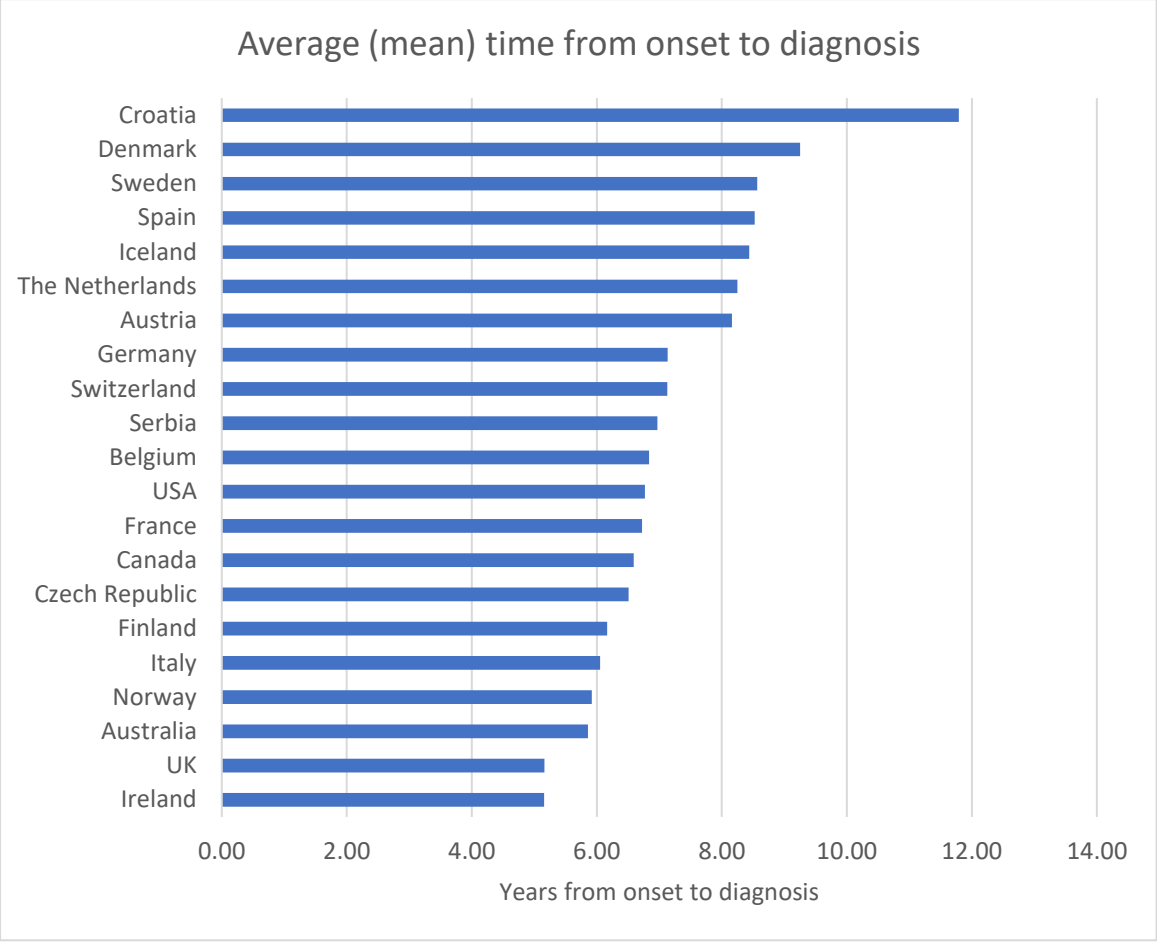


Figure 12: Average (mean) time from onset to diagnosis, by country (n=8 981).

Men were, on average, diagnosed a year earlier than were women (Figure 13).[8] This ties in with research that has found that men are taken more seriously by health care professionals, and are more likely to be prescribed painkillers, while women with the same complaints are given sedatives.[9] This difference was, however, not observed in all countries, and in the UK, The Netherlands, Finland, Switzerland, Serbia and the Czech Republic, female respondents had been diagnosed slightly sooner than male respondents (but the differences are not statistically significant in any of the countries).

[8] Statistically significant 1% level, using the Kruskal-Wallis test.

[9] https://www.health.harvard.edu/blog/women-and-pain-disparities-in-experience-and-treatment-2017100912562

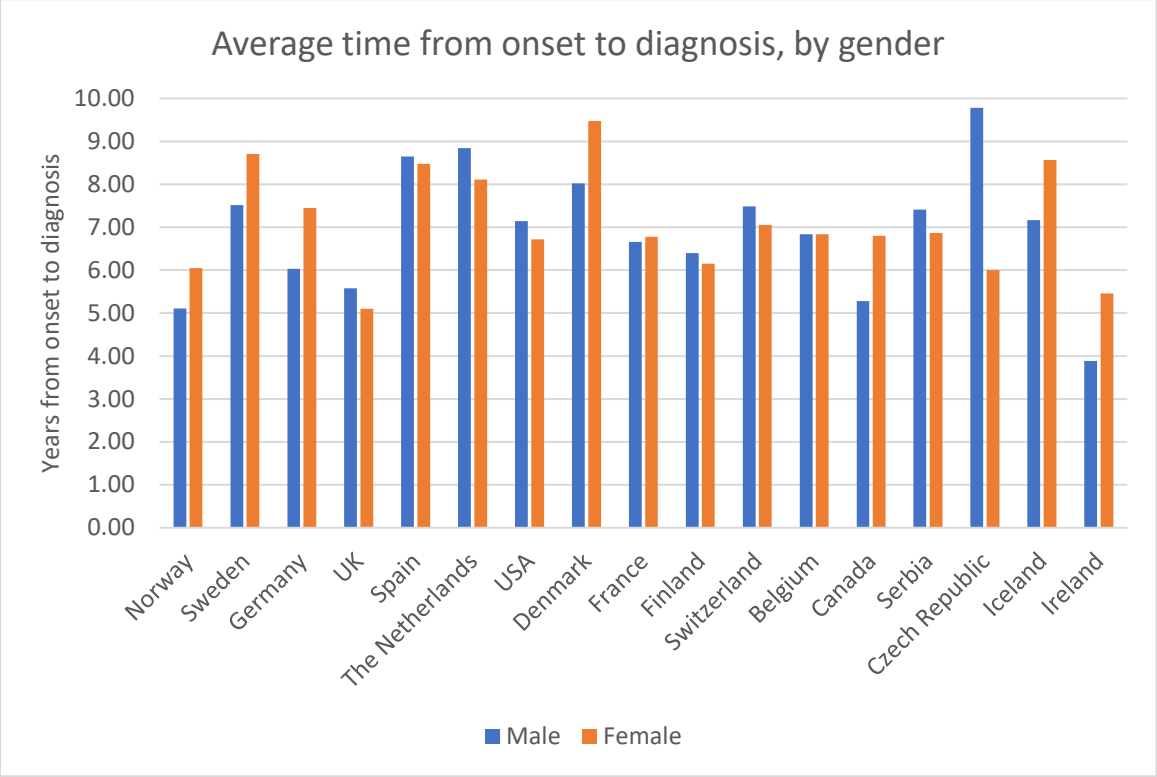


Figure 13: Diagnostic period (mean) for men and women, countries with more than 50 respondents (n=8 981).

4 Symptoms and severity

4.1 Severity

This survey used a severity scale of the ICC diagnostic criteria (Carruthers et al., 2011):

- **"Mild** (an approximate 50% reduction in pre-illness activity level),
- **Moderate** (mostly housebound),
- **Severe** (mostly bedridden), or
- **Very severe** (totally bedridden and need help with basic functions)".

In addition to the four categories in the ICC criteria, two additional categories were introduced:

"Better than mild, but not recovered" and "Completely recovered".

The "better than mild" category was introduced because, while the ICC criteria specify a 50% reduction in pre-illness function, other criteria such as SEID and NICE do not specify a cut-off and patients can be diagnosed as long as the reduction in function is "substantial" (Institute of Medicine, 2015; NICE, 2021).

Many scales of severity exist. The ICC scale was used, as this is the scale used in Norway, and it has been used in earlier, similar surveys. Additionally, ICC criteria are being used more frequently by researchers, such as in the UK Clinical trial on MRT.

It can be argued that the use of the term "mild ME/CFS" is an oxymoron. Even "mild" ME/CFS, as defined by the ICC criteria, is a severe disease, with a substantial loss of function compared to before disease onset.

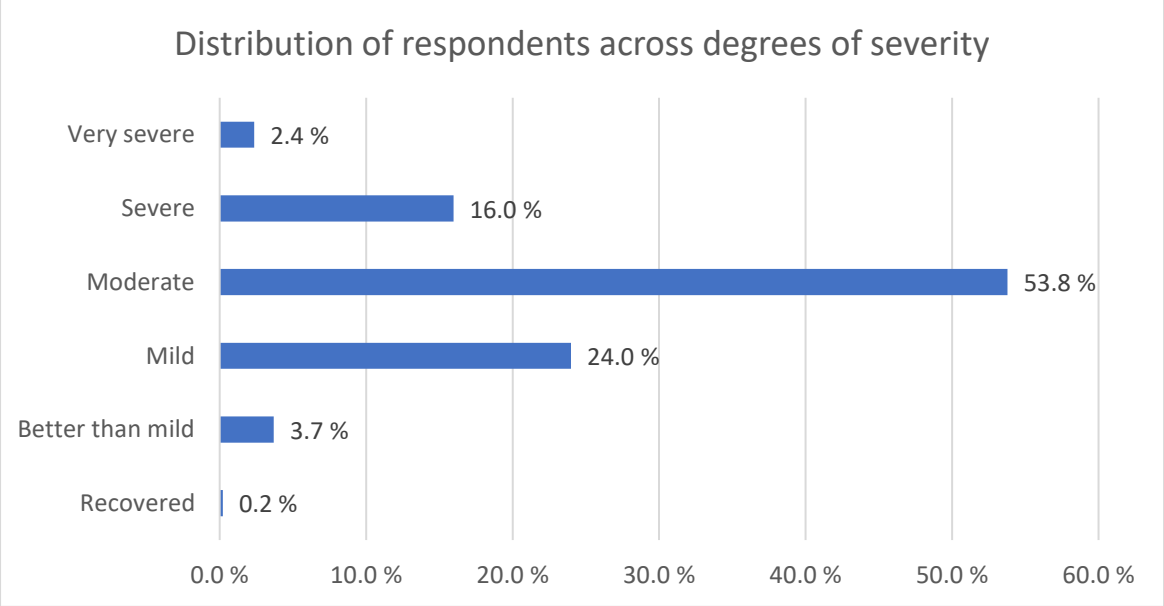


Figure 14: Distribution of respondents across degrees of severity (n=11 109).

3.7% of the patients answered that they had a functional capacity above 50% of normal. i.e., better than mild.

24% answered that they had mild ME/CFS, 53.8% 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 care). Only 0.2% reported to have recovered, and these are in some analyses excluded when focussing on the currently ill.

The distribution of severity was largely similar across countries, but with Croatia and Finland having a higher proportion of respondents with mild disease (Figure 15).

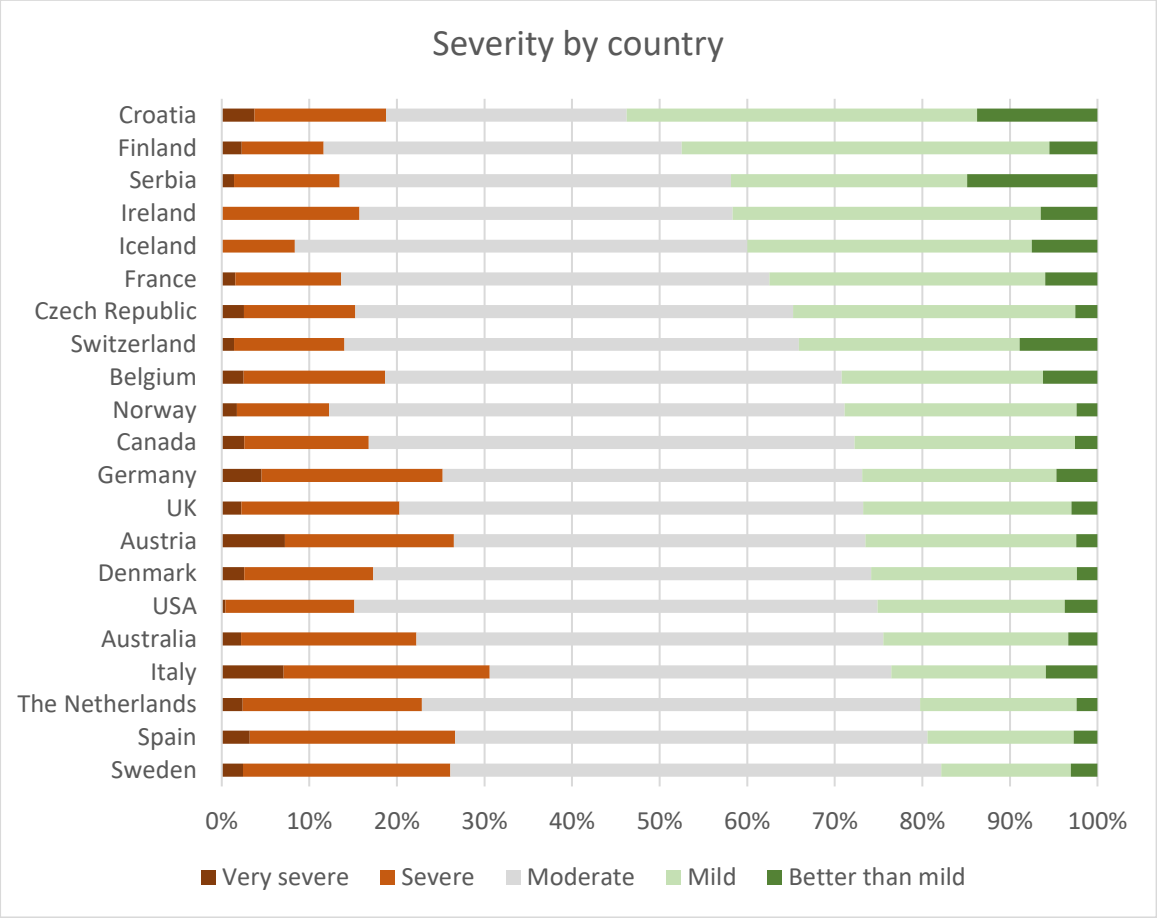


Figure 15: Distribution of patients by degree of severity across countries with more than 50 respondents (n=10 875).

More men than women had mild disease, and more women than men had moderate disease, cf. Supplementary Table 3 in Annex 1. The proportions of severe and very severe ME/CFS are approximately the same regardless of gender.

The younger respondents in the survey tended to have a more severe form of the disease (Figure 16).

Severe disease was also associated with young age. 26% of respondents between 10 and 15 years, and 32% of respondents between 15 and 20 years, stated that they had severe or very severe

ME/CFS. There may, however, be a bias in that parents could answer on behalf of younger patients, while older patients with severe disease may not have been reached or been unable to answer. Another possible bias is that if the disease severity to some extent improves over time, children and young responders may not have had the disease long enough for improvement to have occurred.

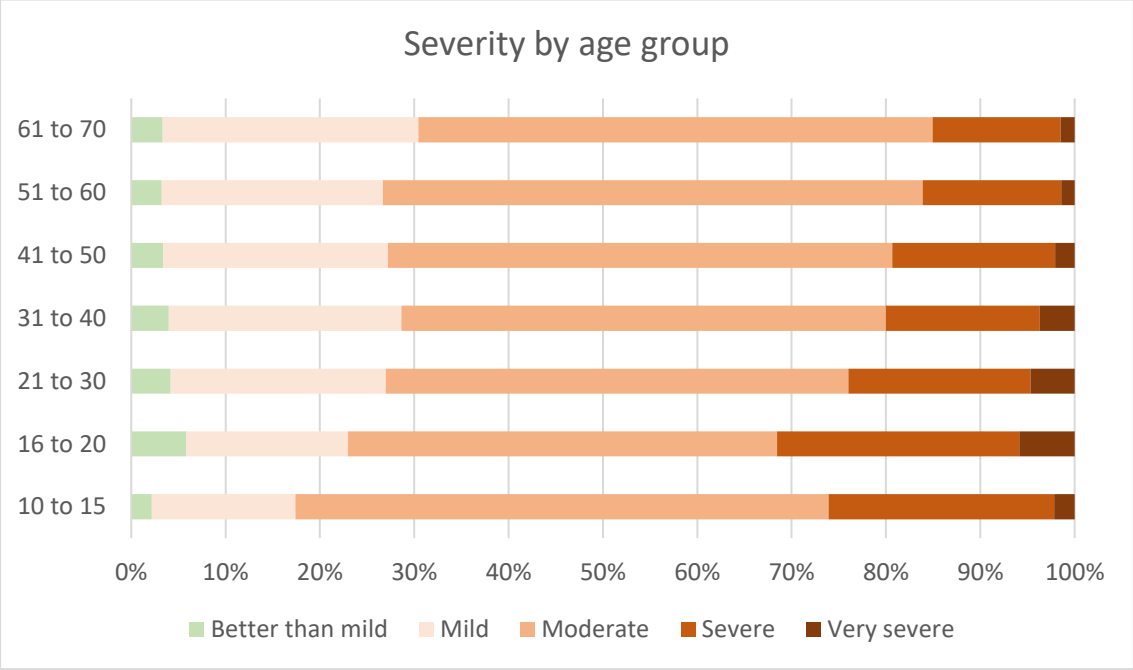


Figure 16: Distribution of degrees of severity across age groups (n=10 599).

There was no data collected on severity at the time of diagnosis.

4.2 Severity and age of onset

Respondents with early onset were overrepresented among those with severe or very severe disease (Figure 17). The portion of currently ill ME/CFS patients that had an onset before the age of 20 years, increases with severity, from 14% and 17% among those with mild and moderate degree, to 25% and 33% among those with severe and very severe degree. It is not known how many patients with early onset recover, but early onset could be a risk factor for severe disease.

A correlation between early onset and more severe disease in Norwegian patient surveys has previously been noticed (Schei & Angelsen, 2020; Schei, Angelsen, & Myklebust, 2019; Sommerfelt, Schei, & Angelsen, 2023), and the same observation has been made in two other studies (Ghali et al., 2022; Lacerda et al., 2019). Only population-based, prospective studies can clarify this correlation further.

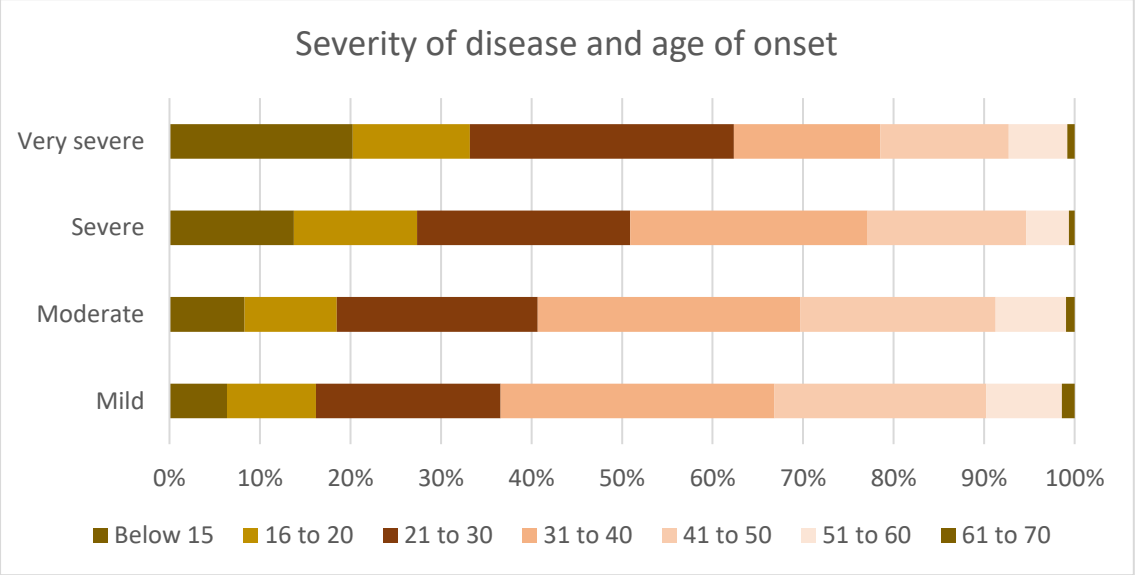


Figure 17: Age at onset and severity of disease (n=10 869).

4.3 Symptom burden

While long-lasting fatigue is considered the cardinal symptom of ME/CFS, several other symptoms must be present for a diagnosis to be made, though case definitions differ. These symptoms include unrefreshing sleep, cognitive problems, pain, gastrointestinal problems and autonomic symptoms (Carruthers et al., 2003; Carruthers et al., 2011; Institute of Medicine, 2015; NICE, 2021). Post Exertional Malaise (PEM, also called Post Exertional symptom exacerbation, PENE) is now considered the most characteristic feature of ME/CFS (Institute of Medicine, 2015; NICE, 2021).

In this survey patients were asked which symptoms hindered them most in activities of daily living, with a Likert scale of five possible responses: not at all (0), a little (1), moderately (2), a lot (3), very much (4). The severity or frequency of symptoms was not asked, only how symptoms affected how the respondents could participate in normal, daily activities.

The most restrictive symptom was symptom exacerbation after exertion (PEM), followed by sensitivity to light, sound and smell. Since most public areas are noisy, often with background music, sensitivity to sound may prevent ME-patients from spending time in, for example, shops, even if they otherwise would be able to do so. Although fatigue and PEM are linked, it is worth noting that (general) fatigue *per se*, the symptom most often associated with ME/CFS, was not rated as the most restrictive symptom, regardless of severity.

Cognitive problems ("brain fog") was – by mistake – not included in the list, possibly due to brain fog among the questionnaire designers (and translators).

Symptoms were rated as restrictive in almost the same order regardless of the patient's severity, but the more severe the disease, the more restrictive the symptom was. Interestingly, patients with mild and moderate ME/CFS found sensitivity to light and sound to be more restrictive than PEM (

Figure 18). More detailed information on the responses across different degrees of severity is given in Annex 2 (supplementary figures 1-4).

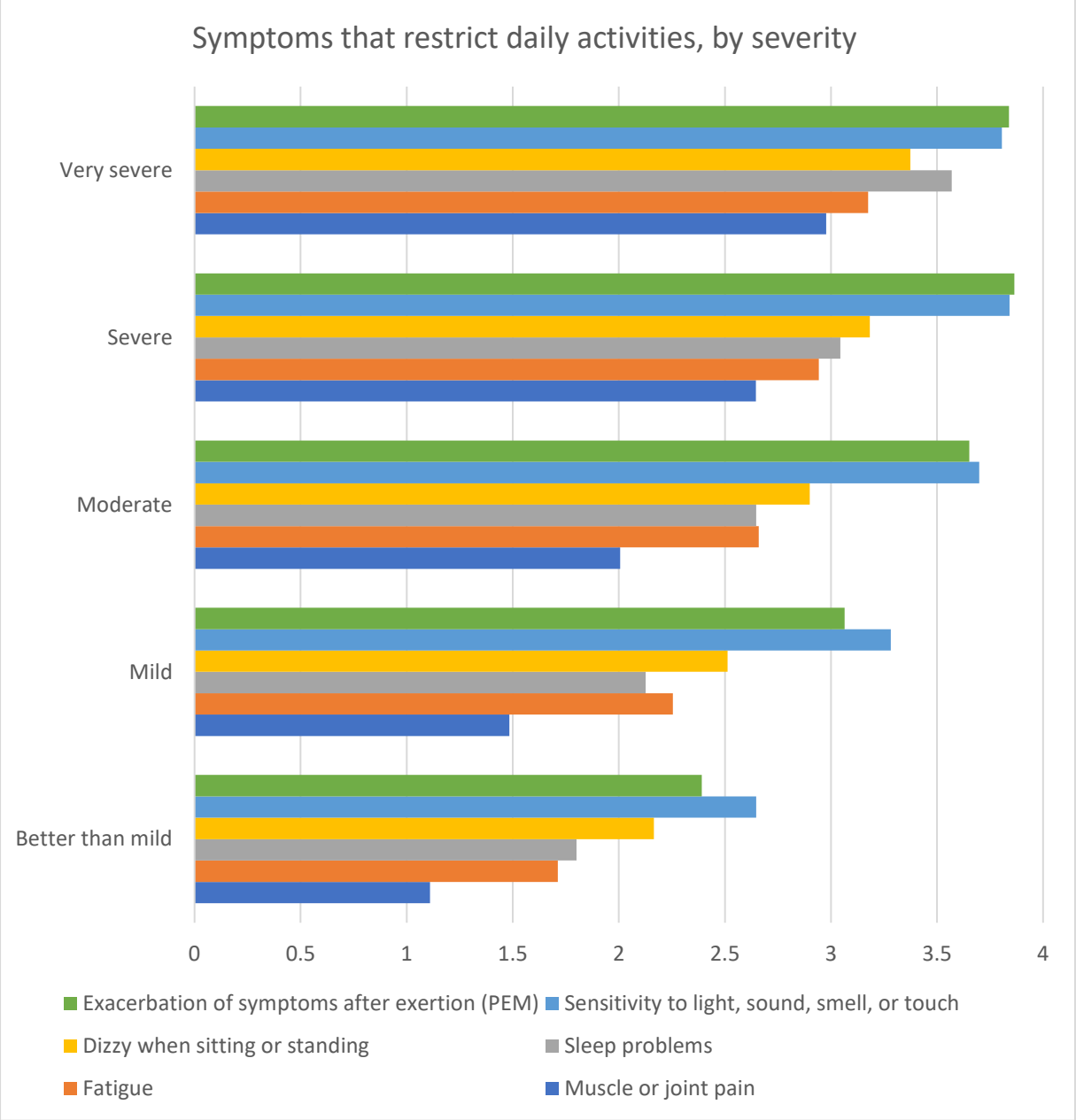


Figure 18: Symptoms that restrict activities of daily living (scores from 0 (not at all) to 4 (very much)) (n=11 109).

4.4 Comorbidities

The ICC criteria lists a number of diseases and conditions as comorbid with ME/CFS (Carruthers et al., 2011). Respondents were asked if they had any of these comorbidities and they were given the option to highlight other comorbidities in open-ended answers.

A large majority - 85% (9 579 respondents) - reported having at least one comorbidity, the most common being irritable bowel syndrome (IBS), allergies, and fibromyalgia.

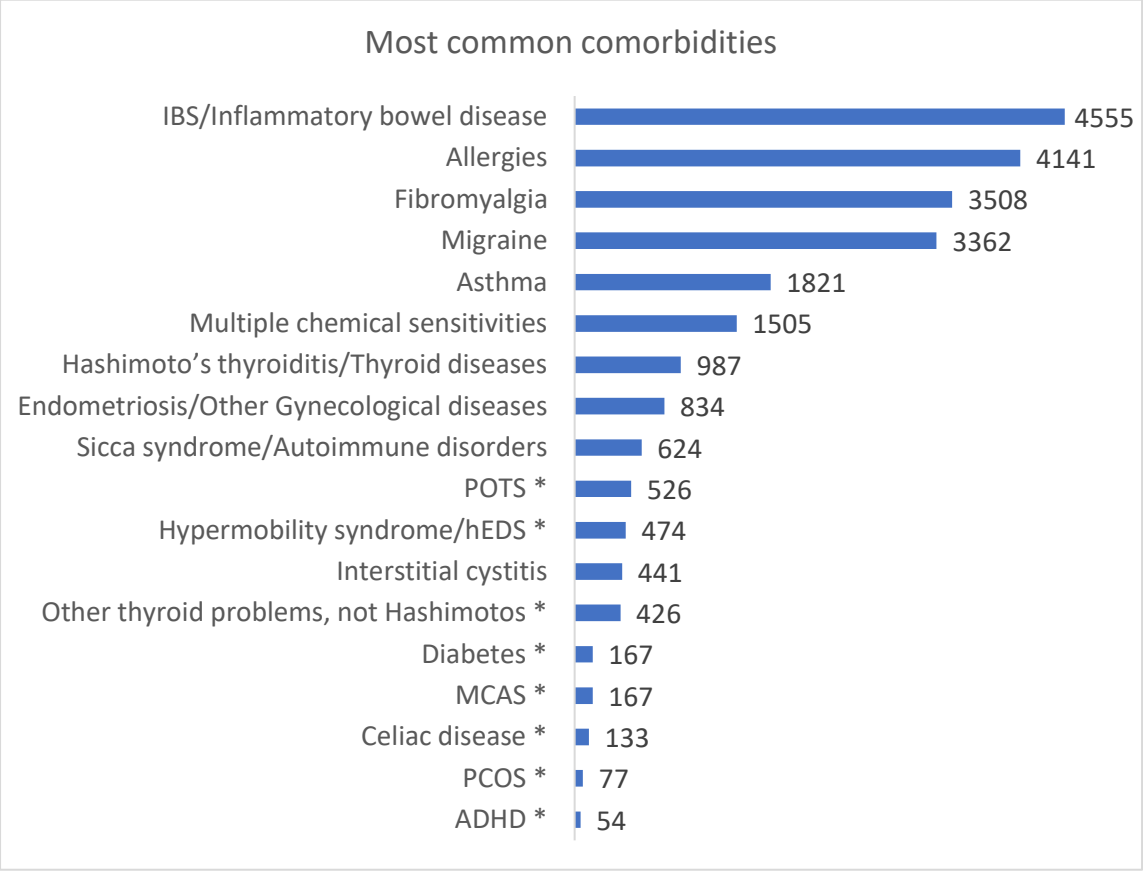


Figure 19: Most common comorbidities (n = 9 579 (comorbidities reported)).

Note: Entries marked with * are from open ended answers.

The most common comorbidities reported in the open-ended answers were postural orthostatic tachycardia syndrome (POTS), hypermobility or Ehler Danlos syndrome, hypermobile type (hEDS), other thyroid problems, diabetes, and mast cell activation syndrome (MCAS) (Figure 19). No attempt has yet been made to ascertain whether any of these diseases are more (or less) common in patients with ME/CFS than in the general population (although a recent survey was initiated by the European ME Research Group (EMERG) to provide data on whether diabetes mellitus may be less prevalent in people with ME).[10]

Among the 9 579 respondents who answered that they had comorbidities, 27% had only one comorbidity, 25% had two comorbidities, while 48% had more than two.

[10] European ME Alliance News 2023 - Diabetes Mellitus prevalence in ME/CFS Patients

Patients with more severe disease reported more comorbidities than patients with milder disease, as shown in Appendix 2 (supplementary figure 6).

5 Course of illness

5.1 Course of illness since onset

Little research has been done on prognosis for ME/CFS. The ME Association Index of Published Research from March 2023 lists 18 studies on prognosis and recovery, but many of these are qualitative.[11] It is fair to say that one lacks adequate data and high-quality research on what a normal course of illness for ME/CFS may look like. Given this situation, large patient surveys such as the one presented here, may provide the best available information on typical courses of illness.

Seven possible scenarios for the course of illness were described and respondents were asked to choose the one that was closest to their own experience.

Close to half of the respondents (46%) reported mainly deterioration (26% described a course of illness with initial fluctuations then deterioration, 20% mainly deterioration), and 24% answered that they had experienced major fluctuation throughout the course of illness. In total, 70% of respondents described either deterioration or large fluctuations throughout the course of their illness. Only 7% reported improvement.

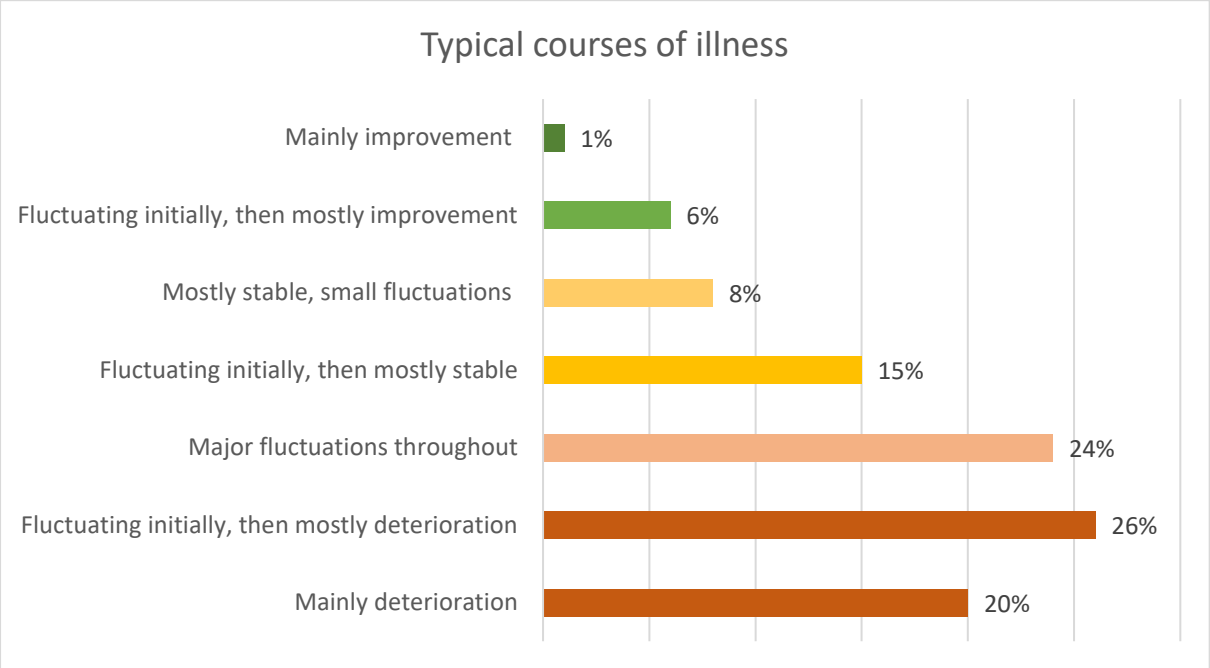


Figure 20: Typical courses of illness (n =11 109).

[11] https://meassociation.org.uk/research/published-research/research-summaries/

The proportion of patients who reported improvement or deterioration varies across countries (Figure 21). As discussed earlier, this may be due to biases, but more likely reflecting the quality of, and the access to, health care and social security/welfare in the country. It was beyond the scope of this survey to obtain relevant data on access to health care, practical assistance and benefits in each country, but investigating this further is an area for future research.

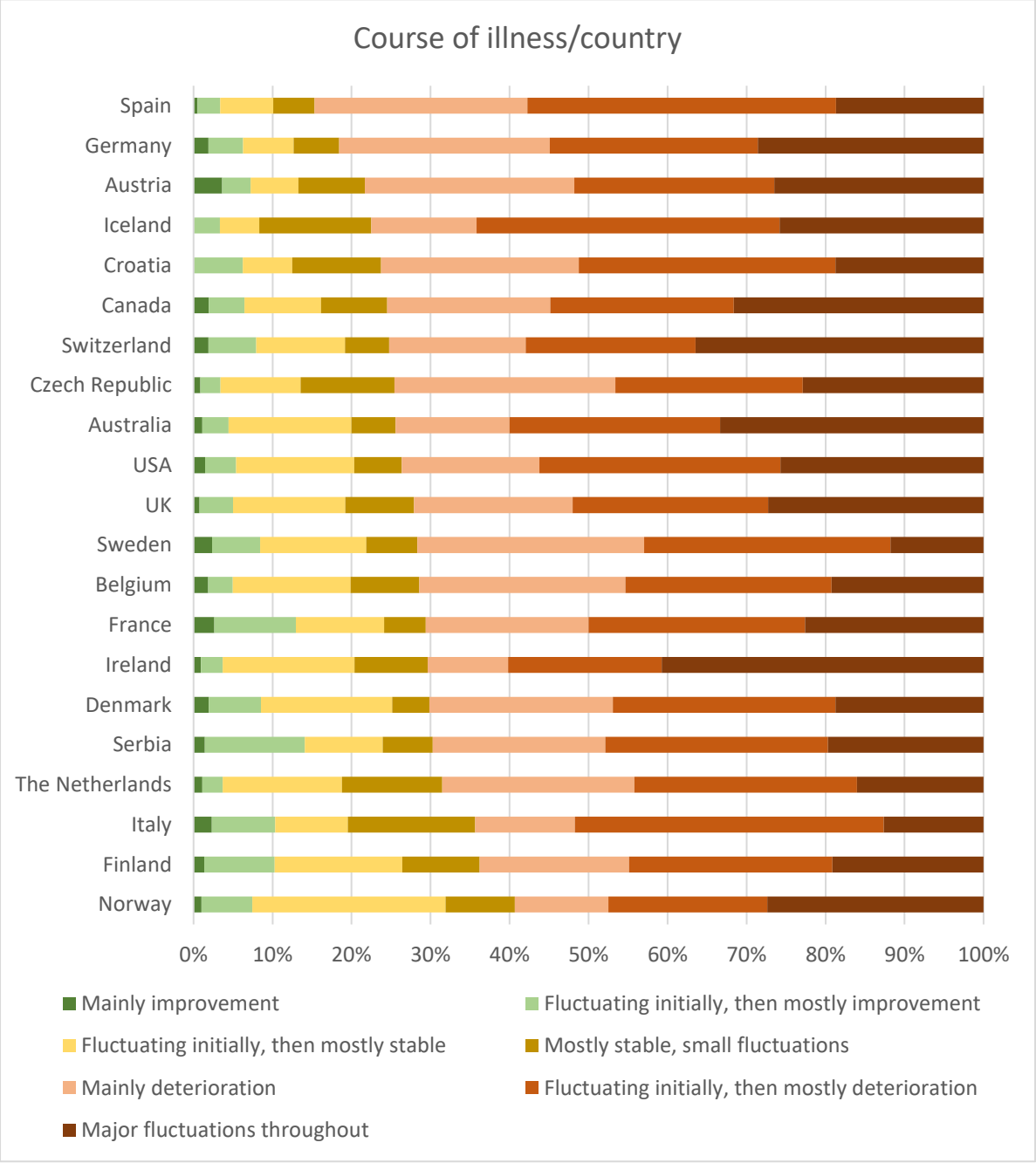


Figure 21: Courses of illness, by country (countries with more than 50 respondents) (n=10 898).

5.2 Course of illness: situation over the last year

In addition to the question concerning the course of illness since onset, respondents were asked whether they had experienced improvement, deterioration, or fluctuations during the previous year, or if their situation had been stable. Only 9% reported improvement during the previous year, 29% said they were mostly stable, 18% had experienced large fluctuations while 44% reported deterioration (Figure 22).

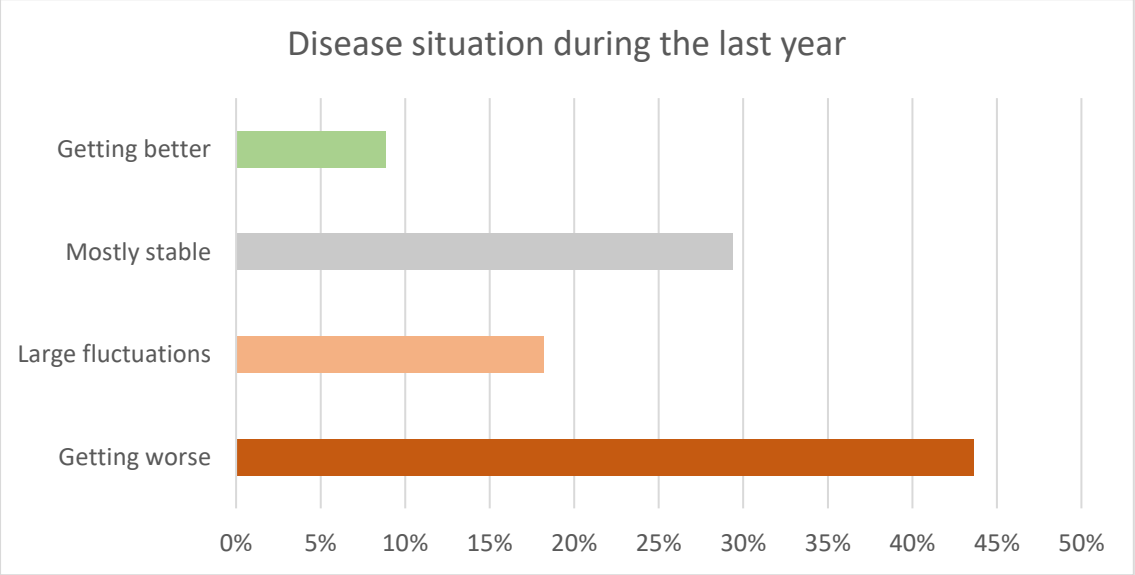


Figure 22: Patient's situation during the last year (n=11 109).

There were quite large differences across countries in how respondents answered the question about disease situation over the last year (Figure 23). Only 3% of Spanish respondents said they experienced improvement, compared to 16% in Austria. It is not known whether this difference reflect sampling biases, or differences in access to health care and disability benefits or other factors.

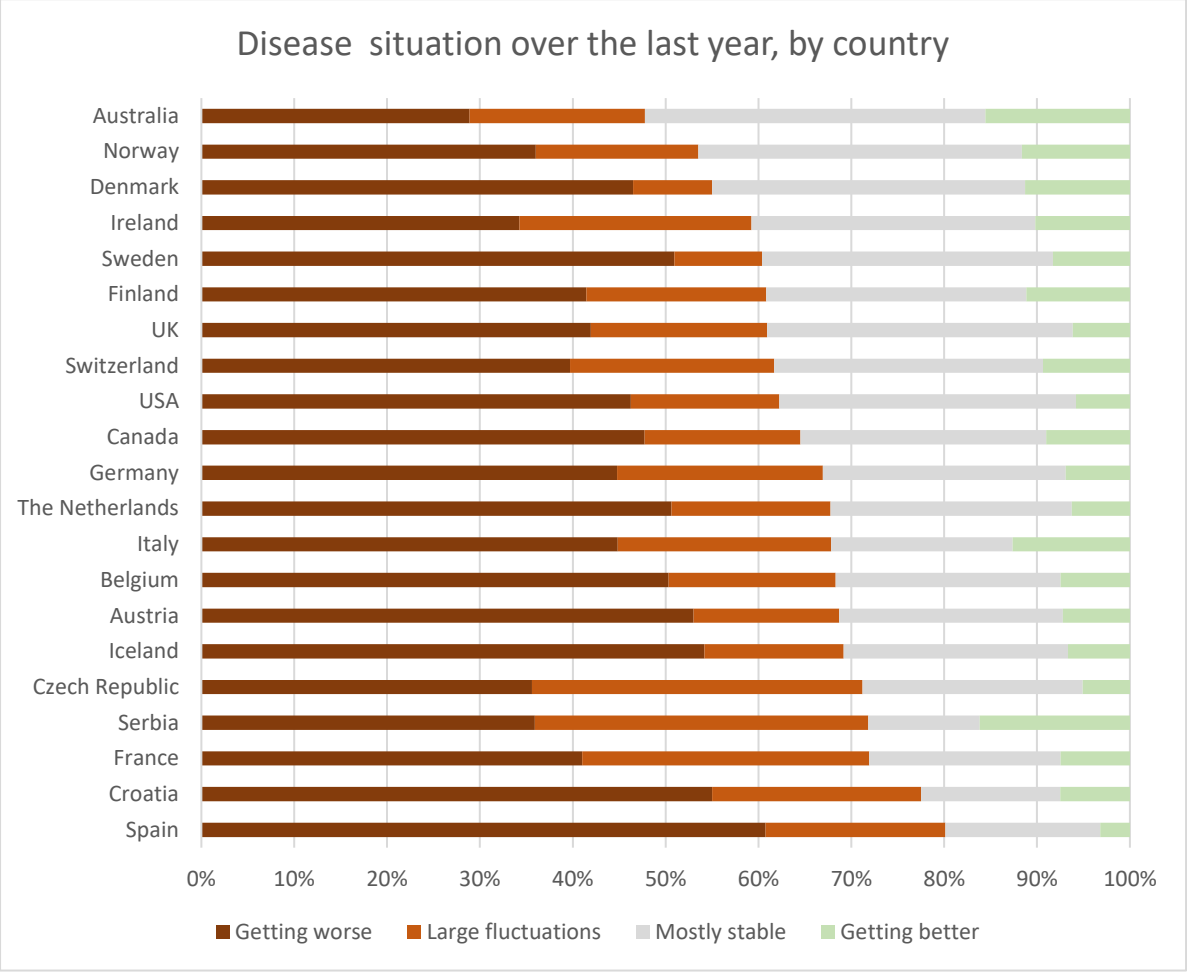


Figure 23: Situation over the last year, by country (n=10 898).

5.3 Course of illness and situation during the last year

There was a strong link between the responses to (i) the reported course of illness over the entire time the respondent has been ill, and (ii) the reported disease progression over the last year (Figure 24). For those who had answered that they had experienced mostly deterioration over the entire course of illness, only 3% had experienced improvement over the last year. Of those who had been mostly stable, 8% reported improvement over the last year, of those who had experienced large fluctuation throughout the course of illness, 10% experienced improvement, while 45% of those who had experienced improvement throughout were still in the improvement phase during the last year.

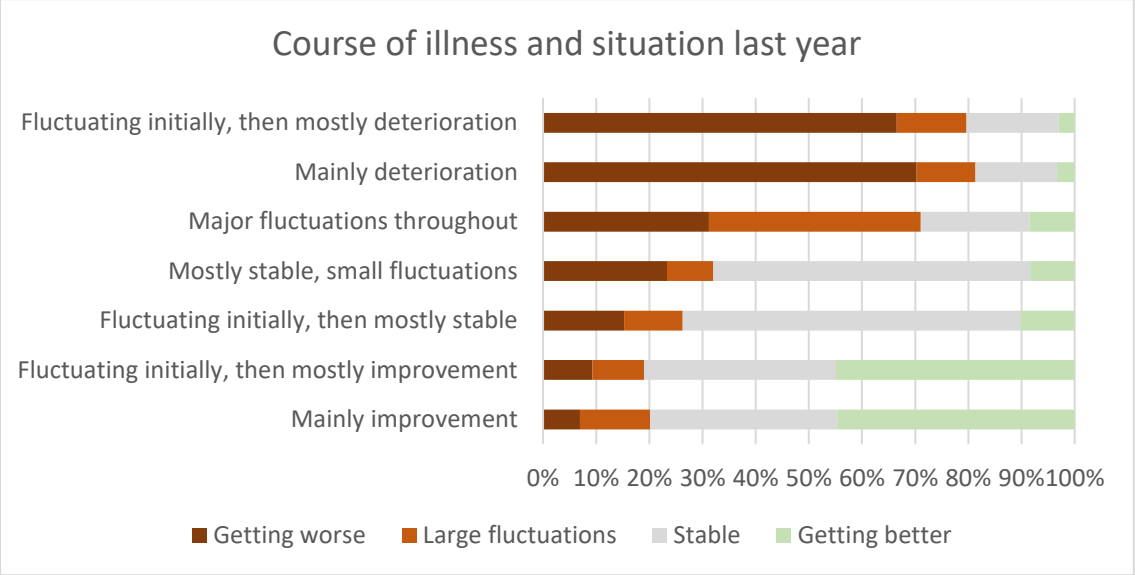


Figure 24: Course of illness over entire disease duration and situation over the last year (n=11 109).

5.4 Course of illness and disease duration

The proportion of respondents who reported improvement during the last year decreases slightly with longer disease duration. Among the respondents with a one-year disease duration, 37% reported experiencing large fluctuations over the last year. The proportion of respondents reporting large fluctuations decreased with disease duration, to an average of 17% for respondents with more than a 4-year disease duration (Figure 25).

It is not known how many patients recovered in any given year.

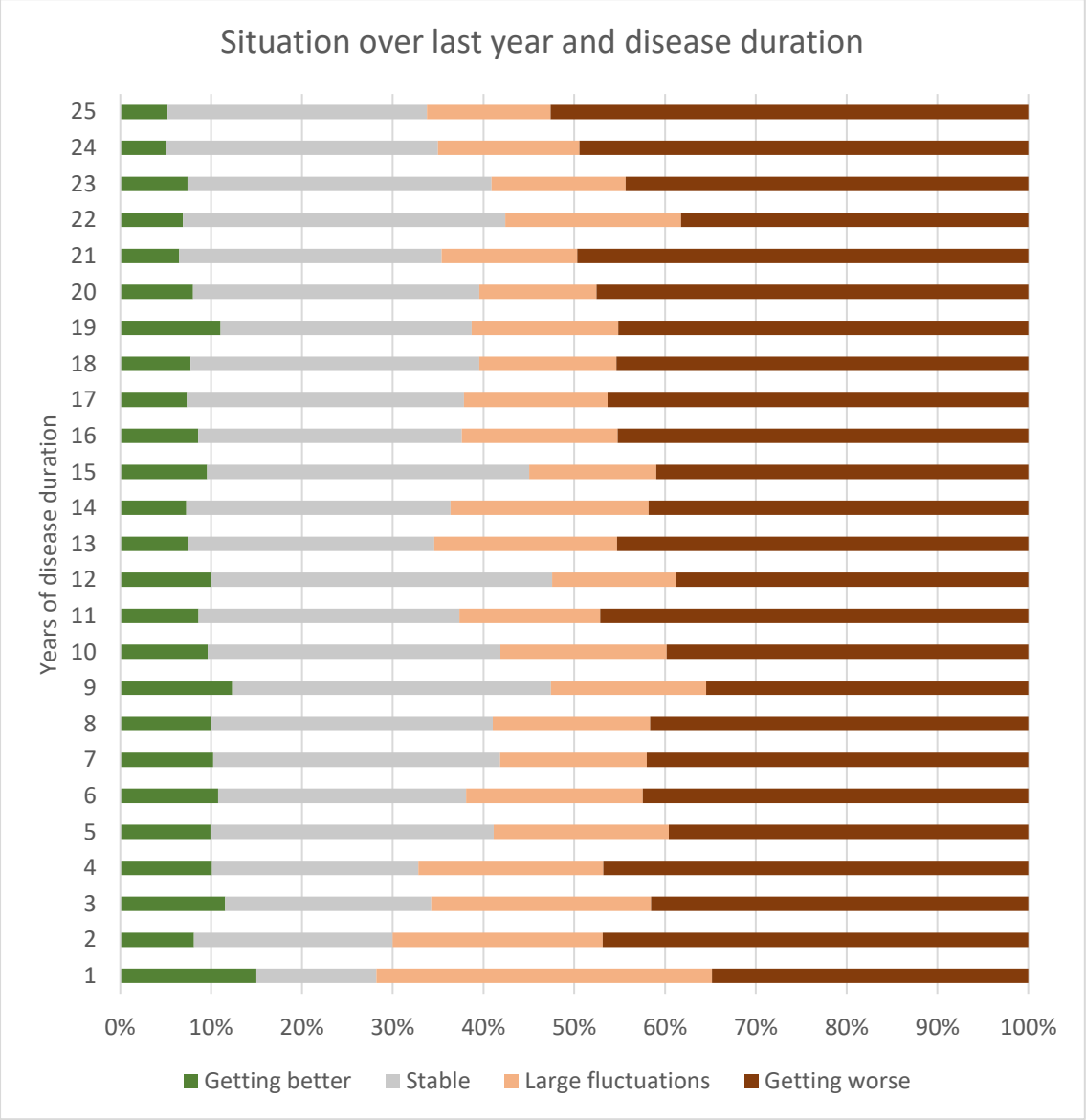


Figure 25: Situation during the last year, disease duration (n=9 300).[12]

[12] Includes respondents with disease duration ≤25 years.

6 Factors impacting the course of illness

Many factors may have an impact on the course of illness. Biological factors, like age at onset, gender and type of trigger might play a role. It is also possible that psychosocial factors may contribute positively or negatively, such as how well the disease is accepted by family and friends, as well as the access to health care and social or financial benefits. There are also management strategies that may have an effect.

In the Norwegian survey of 2019, respondents were given open-ended questions as to what factors they believed had impacted, positively or negatively, on the course of illness (Schei & Angelsen, 2021). 7 602 responses were received. The most common factors associated with *negative* impact was too high an activity level causing PEM, the health care system (late diagnosis, incorrect advice early on, and a lack of symptom relief) stress and worries (often associated with not being believed by actors in the health care, social, or welfare systems, often resulting in lack of help and a difficult financial situation), and having to care for other family members.

The most common factors associated with *positive* impact was pacing/avoiding PEM, good support from the health care system (quick diagnosis, correct advice, good symptom management over time), a stable financial situation, support from friends and family, good pain relief and help with sleep problems.

Based on the concepts most frequently used in the Norwegian 2019 survey, in the present survey structured questions were asked about a set of factors that potentially might have a positive or negative impact on the course of illness. Given that the systems for health care, welfare and social services vary greatly across countries, only generalized questions could be posed about the level of support respondents had experienced from the different services.

6.1 Age at onset

Severe disease is overrepresented in respondents with early onset. This is the case regardless of disease duration, see section 4.2 and Figure 17. It is not known why onset at an early age can be a risk factor for severe disease.

Figure 26 shows that respondents with early onset more often report a course of illness with deterioration or large fluctuations, compared to those that became ill later in life. However, there is also a higher portion of reported deterioration among those with onset late in life (> 60 years old). For persons with late onset, however, it may be difficult to distinguish between normal symptoms of ageing and ME/CFS symptoms.

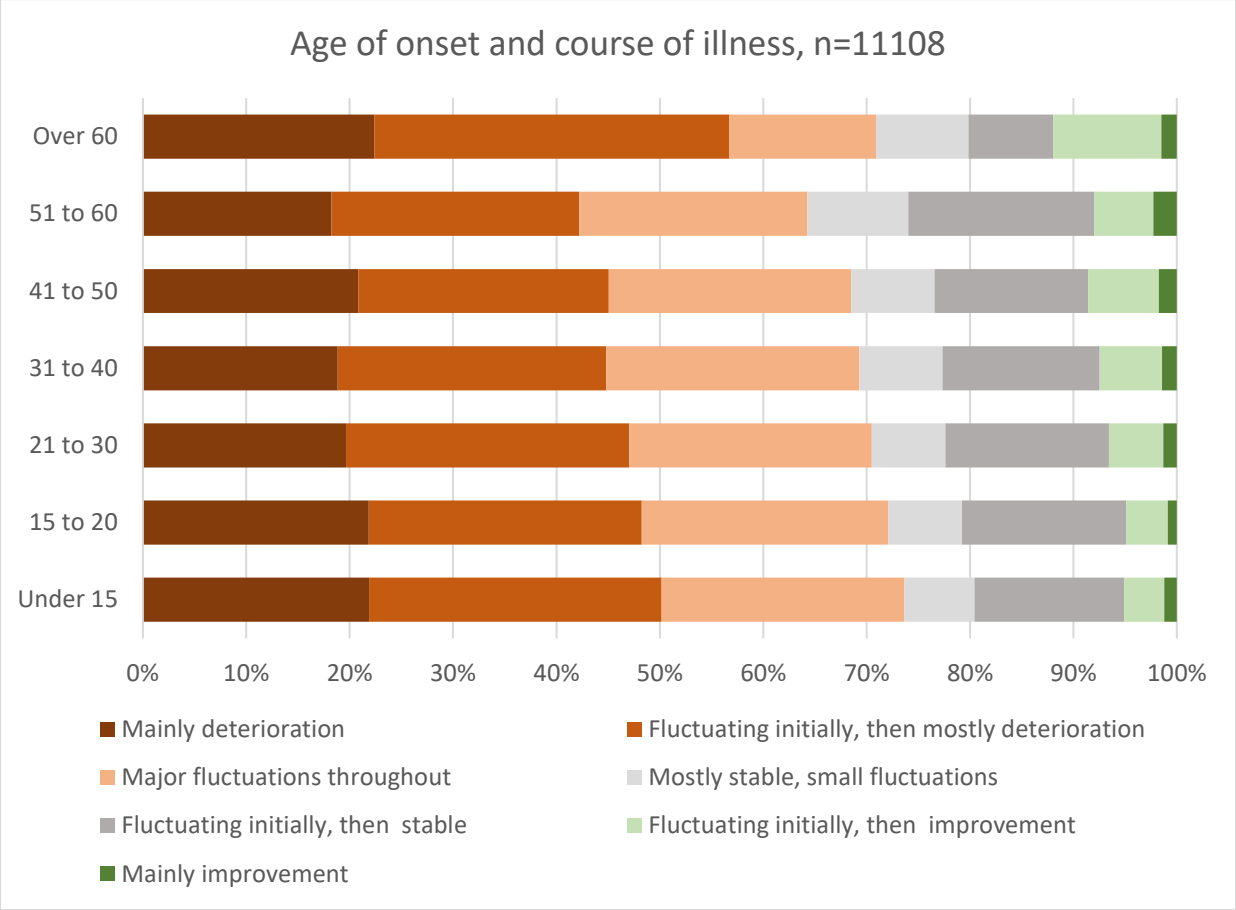


Figure 26: Age at onset and course of illness (n=11 108).

6.2 Diagnostic period (time from onset to diagnosis)

Median diagnostic period for all respondents was 4 years, while average (mean) diagnostic period was 6.8 years. There were large differences between countries. Men were, on average, diagnosed a year earlier than women, though not in all countries.

Pheby and Saffron (2009) identified late diagnosis and (thus higher risk of) mismanagement of disease before diagnosis as risk factors for severe disease. This was also confirmed by Ghali et al. (2022): late diagnosis is associated with a less favourable prognosis.

From the survey it seems that respondents who waited longer to receive a diagnosis more frequently reported a course of illness with large fluctuations or deterioration (Figure 27).

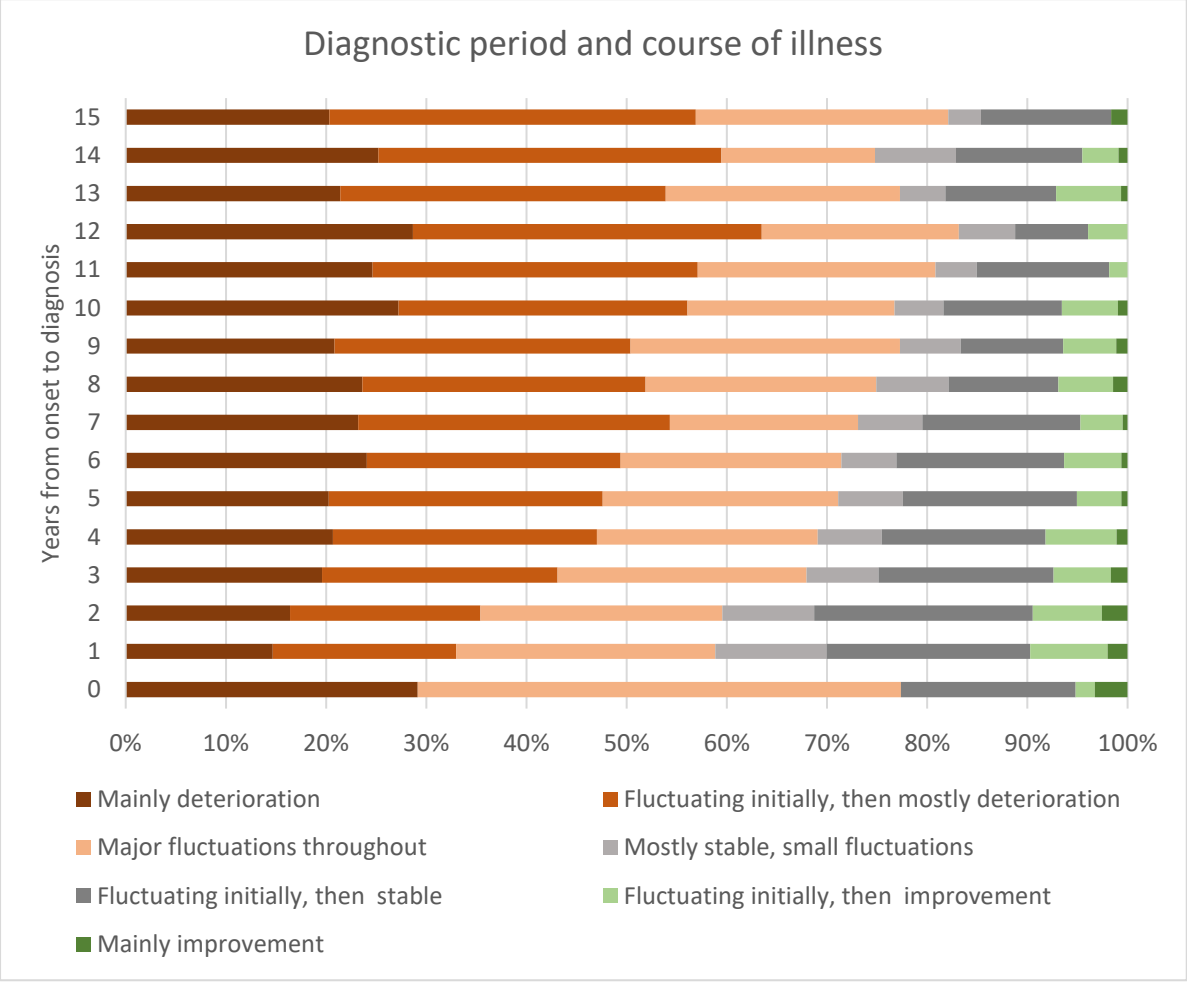


Figure 27: Diagnostic period (years from onset to diagnosis) and course of illness (n = 8 176).

To investigate this relationship further, the two courses of illness that describe mainly deterioration (initial fluctuations then deterioration, and mainly deterioration) were combined. A strong association was found between a longer diagnostic period and a higher risk of experiencing a deteriorating course of illness (Figure 28). Among those with a diagnostic period of 3 years or less, 37% were experiencing a course of illness characterised by deterioration. In contrast, among those with that waited for 10 years or longer before receiving a diagnosis, the total was 56%. In other words, the probability of having a deteriorating course of illness was 54% higher among those that received a late diagnosis than an early diagnosis.

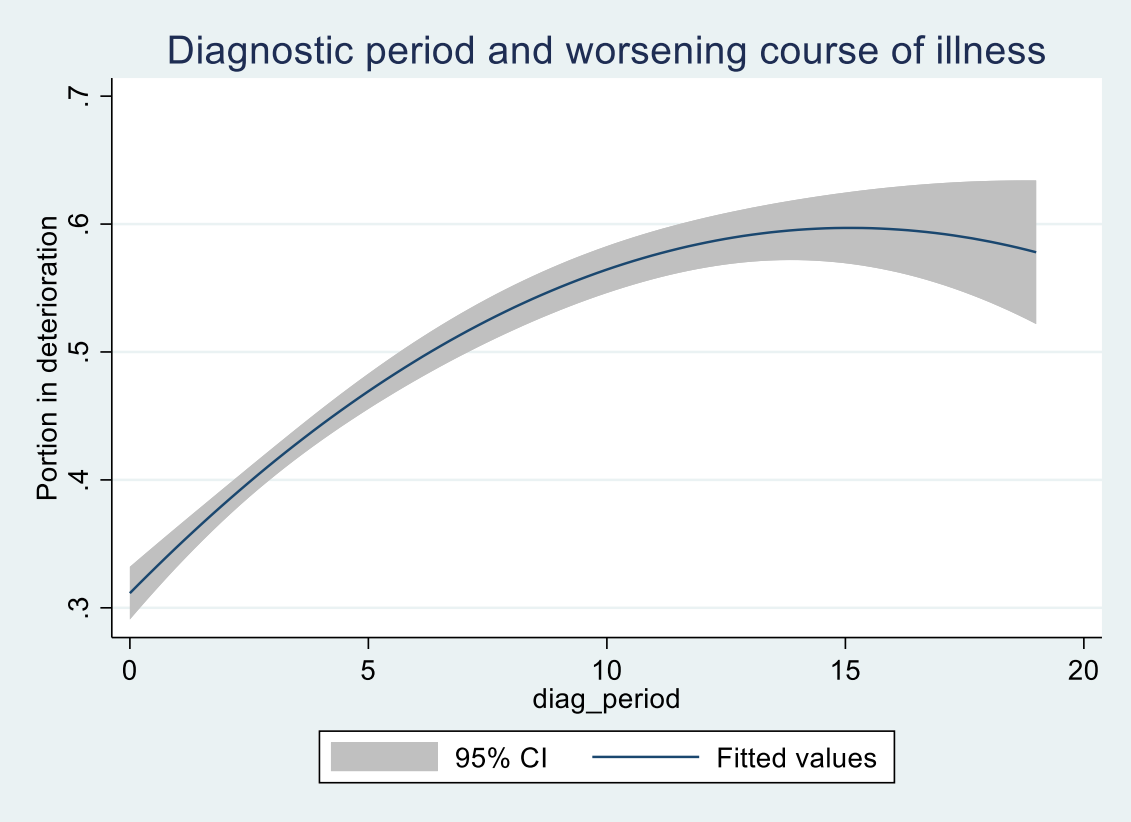


Figure 28: The relationship between diagnostic period and portion of patients with a deteriorating course of illness, at the individual level (n=8 679).[13]

Note: Respondents with diagnosis before 1990 and with a diagnostic period of 20 years or more are excluded in the figure, as the number of observations in these groups is low.

While late (or no) diagnosis was a risk factor, it should be noted that the causality may go both ways. For example, if the condition is deteriorating, it should – in principle – become easier to get a diagnosis.

A negative correlation was found between satisfaction with the health care system and the length of the diagnostic period (Figure 28), i.e., those who have waited a long time for a diagnosis were less happy about the support they had received from the health care system. It might not (only) be the length of the diagnostic period that affects the relationship, but the general support provided by the health care system (which again correlates with the diagnostic period).

[13] The line "fitted values" is the predicted values for a quadratic regression, with the y-axis showing the likelihood of a course of illness with deterioration, as a function of diagnostic period (x-axis). The shaded area is the 95% confidence interval (CI) of the prediction. Several subsequent figures are constructed in a similar way.

To reduce such potentially spurious correlations at the individual level, an alternative is to look at the relationship between course of illness and diagnostic period at the country level, as shown in Figure 29. The picture resembles very much the relationship identified in the previous figure. Countries with a longer average diagnostic period also tended to have a higher portion of ME/CFS patients with a deteriorating course of illness.

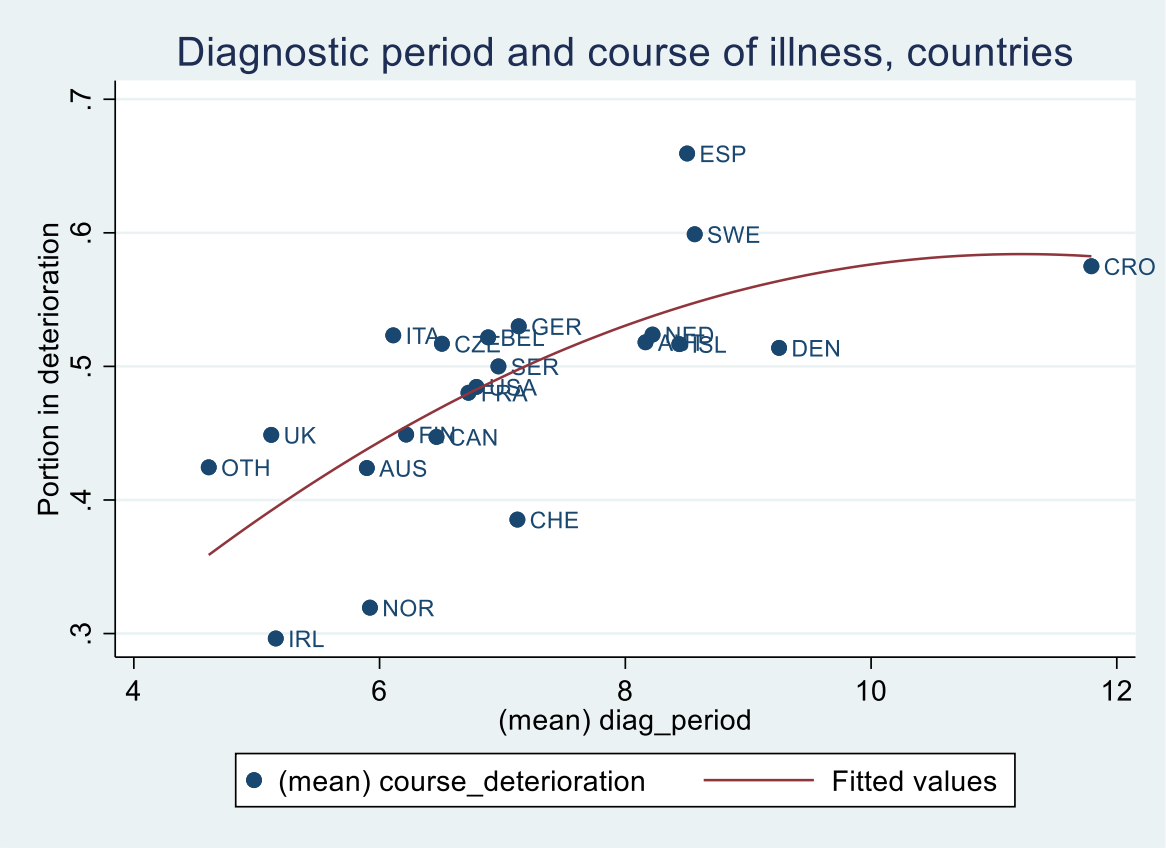


Figure 29: The relationship between diagnostic period (in years, x axis)) and portion of patients with a deteriorating course of illness (y-axis), at country level (n=22).

6.3 Disease Triggers

There are several known triggers for ME/CFS. It is not known if various triggers may be associated with different courses of illness.

Respondents who associate onset with pregnancy and birth reported a slightly more serious course of illness than others, but the differences were small (Figure 30). Overall, the results of this survey do *not* indicate that the trigger of the disease is associated with significantly different courses of illness.

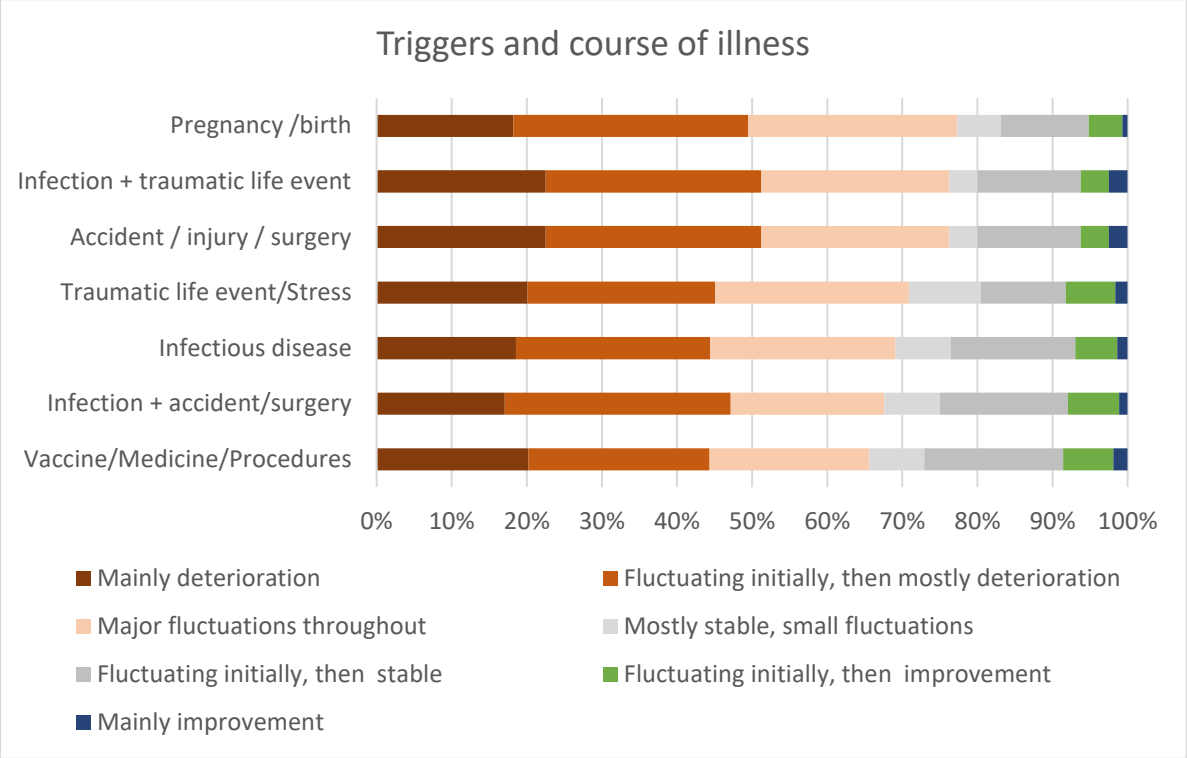


Figure 30: Triggers and course of illness (n=8 145).

6.4 Support from health care, welfare, schools and personal contacts

Mild ME/CFS, as defined by the ICC criteria, means a loss of at least 50% of previous function. As mentioned in section 4.3, most patients are considerably worse off. This means that patients have to rely on support from various external sources, both in the public and the private sphere. In section 6.4 the respondents' experiences with health care, social security/welfare, social services, schools, friends and family, other ME/CFS patients and the wider patient community are examined.

In the Norwegian 2019 survey, open-ended questions identified the health care system, the welfare/social security system, social services, and schools as external parties whose help and support, or lack thereof, had an impact on the course of illness for ME/CFS patients. Respondents also rated support from family, friends and other ME/CFS patients as important.

In this section, only respondents who had been in contact with an external party are included in the figures. For example, respondents with late onset will not have been in school while ill, or children will not yet have been in contact with the welfare/social security system.

Two American studies found that a large portion of patients remain undiagnosed (Jason et al., 2020b; Valdez et al., 2019). The situation is likely to be the same in Europe, but with large variation in the degree of underdiagnosis across countries. The information about the survey is unlikely to have reached most of the undiagnosed people with ME/CFS, thus the scores in this section reflect the experience of diagnosed patients, not all ME/CFS patients.

Respondents were asked about their experience of the help and support that they had received from various actors, and the responses were scored as follows in the analysis: very good support (score 2), good support (1), neutral (0), little support (-1), no support (-2).

The average scores are reported in Figure 31. The scores for the individual countries can be found in Appendix 4. One should also note that there is a positive correlation across those who experienced support from various actors, as shown in the correlation matrix (

	Health system	Social security	Social services	Workplace	School	Family	Friends	Other ME patients	Patient organisations
Health system	1.0000								
Social security	0.3480	1.0000							
Social services	0.3375	0.4341	1.0000						
Workplace	0.3383	0.3697	0.3534	1.0000					
School	0.3630	0.3703	0.4098	0.5618	1.0000				
Family	0.2358	0.1539	0.0943	0.2294	0.2243	1.0000			
Friends	0.2696	0.1994	0.1785	0.3320	0.2755	0.4748	1.0000		
Other ME patients	0.1025	0.0961	0.1676	0.2144	0.2198	0.1607	0.3001	1.0000	
Patient organisations	0.1699	0.1483	0.1953	0.1961	0.2581	0.1829	0.2449	0.5801	1.0000

Supplementary Table 10, Appendix 1). A pairwise positive correlation between factors, such as support from health care and support from friends, means that patients getting little support from the health care system also tend to get little support from friends.[14]

[14] The pattern of positive correlations is robust also when we look at individual countries, or for categories of disease severity, with very few exceptions (e.g., Denmark, where poor experiences with the health care system is correlated with more support from fellow ME/CFS patients and patient organizations).

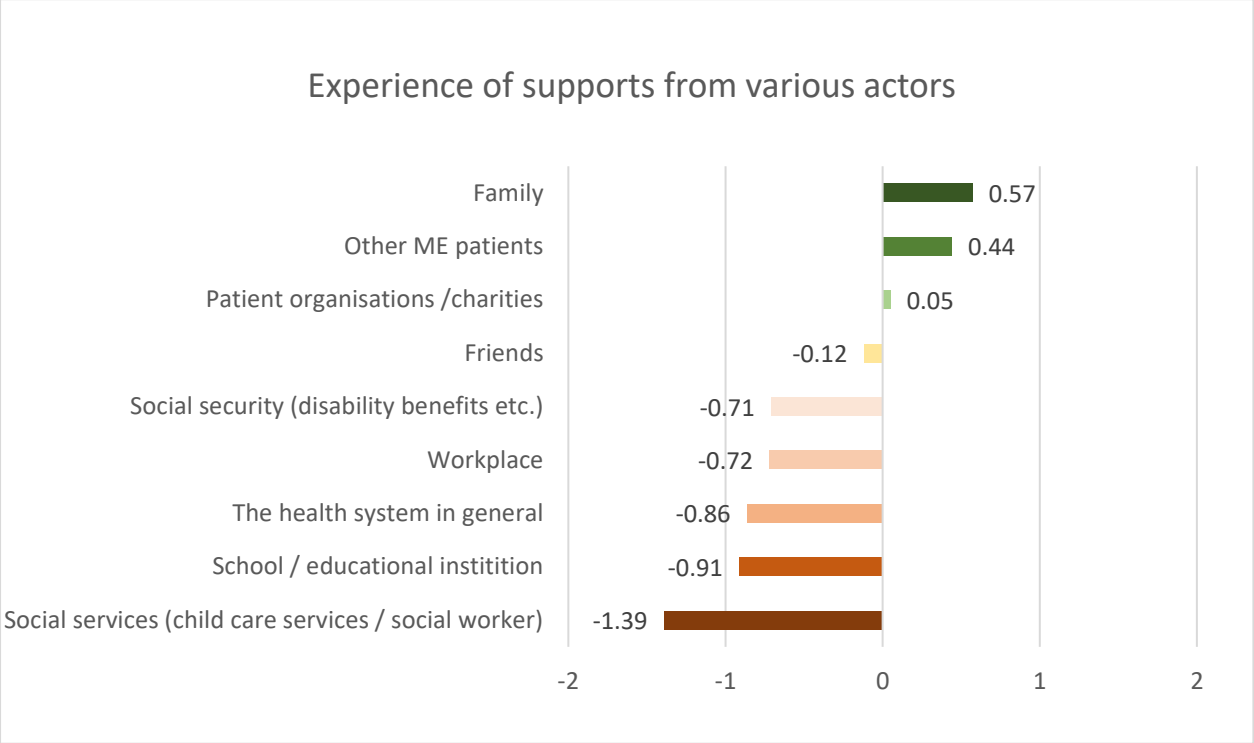


Figure 31: The experience of help and support from various actors (scores from -2 (no support) to 2 (very good support)).

Though answers differed somewhat across countries, ME/CFS patients generally felt that they received most support from family, other ME/CFS patients and patient organisations, and least from the health care systems and social services.

There were some gender differences in how respondents experienced support. Men were more likely to have felt supported by their families, but also felt less supported by the welfare system. Women found more support among other ME/CFS patients (Figure 32).

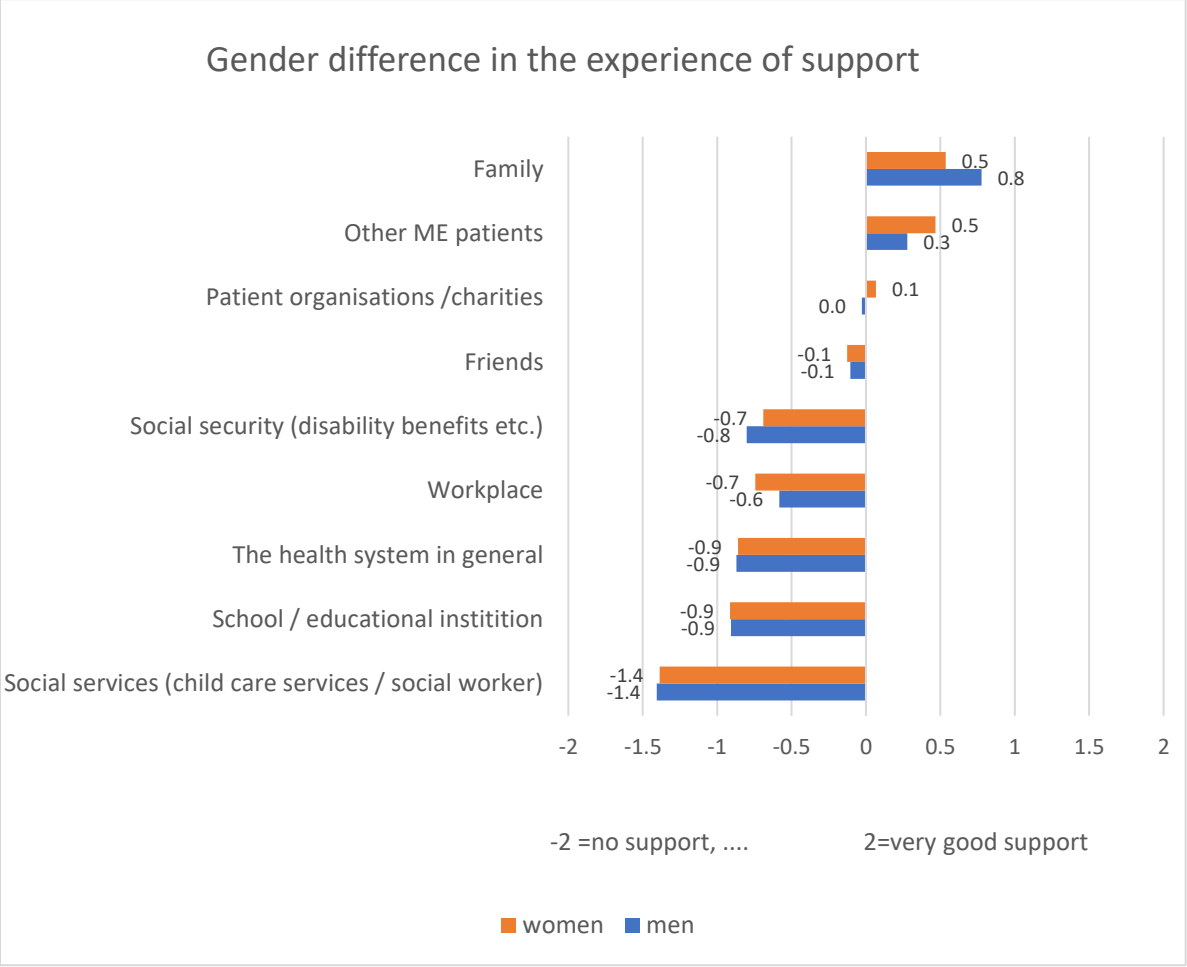


Figure 32: Gender differences in the experience of support from various actors.

Among the European countries in the survey, Norway had the least dissatisfied respondents when it comes to health care support, but even there, only 17% felt they received good or very good support while 65% said they received little or no support. In Austria, 91% felt they received little or no support from the health care system.

Support from social security/welfare systems varied substantially between countries, and 48% of Icelandic respondents said they received good or very good support, while only 1% of Italian respondents felt the same (Figure 33).

Social services (childcare services/social worker) was the area that was felt to give least support, with no country having more than 10% who felt they received good/very good support (Figure 42).

The workplace and schools/educational institutions were not seen to be supportive, though there are large variations between countries. 25% of the Icelandic respondents felt that the schools gave good or very good support, but only 8% of Spanish respondents responded positively. More than 80% of Finnish respondents felt they received little or no support from the schools (Figure 44).

In short, ME/CFS patients feel let down by public institutions like public health care, social and welfare services, and schools and educational institutions, whose sole purpose is to help people, while they found family, friends and other patients to be the most supportive.

In most countries more than half of patients felt that they received good or very good support from their family. Family support, however, may also depend on the general knowledge of, and attitudes towards, ME/CFS in a country (Figure 45).

Below we provide more detailed analyses of the various areas of support, how it varies across countries, and how it may affect the course of illness.

6.4.1 Health care

Most respondents, 94% (10 661), had been in contact with their country's health care system. While there were large differences between countries, and some respondents had had good experiences with the health care system in their countries, 74% of the respondents said that they had received little or no support from their health care system. Only 12% reported that they had had good or very good support.

The fact that 3 out of 4 stated that they had received little or no support does not necessarily imply that they have not received any support at all, but rather that the support received has had no, or even negative, impacts. For example, in Sweden 64% stated that they have received little or no support. In a large Swedish patient survey, a similar number - 68% - stated that they were (very) dissatisfied with the health care received (Eriksson & Heiling, 2020).

In Norway, 17% were satisfied with the support they received, while in Germany, Denmark and Croatia, only 4% answered that they received good or very good support. Although not targeted for the survey, the result from the US respondents is noteworthy: 21% were satisfied with the support they had received through their health care system. The USA has a different health care system than most European countries, who have universal health care. Private health care is available in Europe to varying degrees but is often very expensive. In the US, health care is generally private.

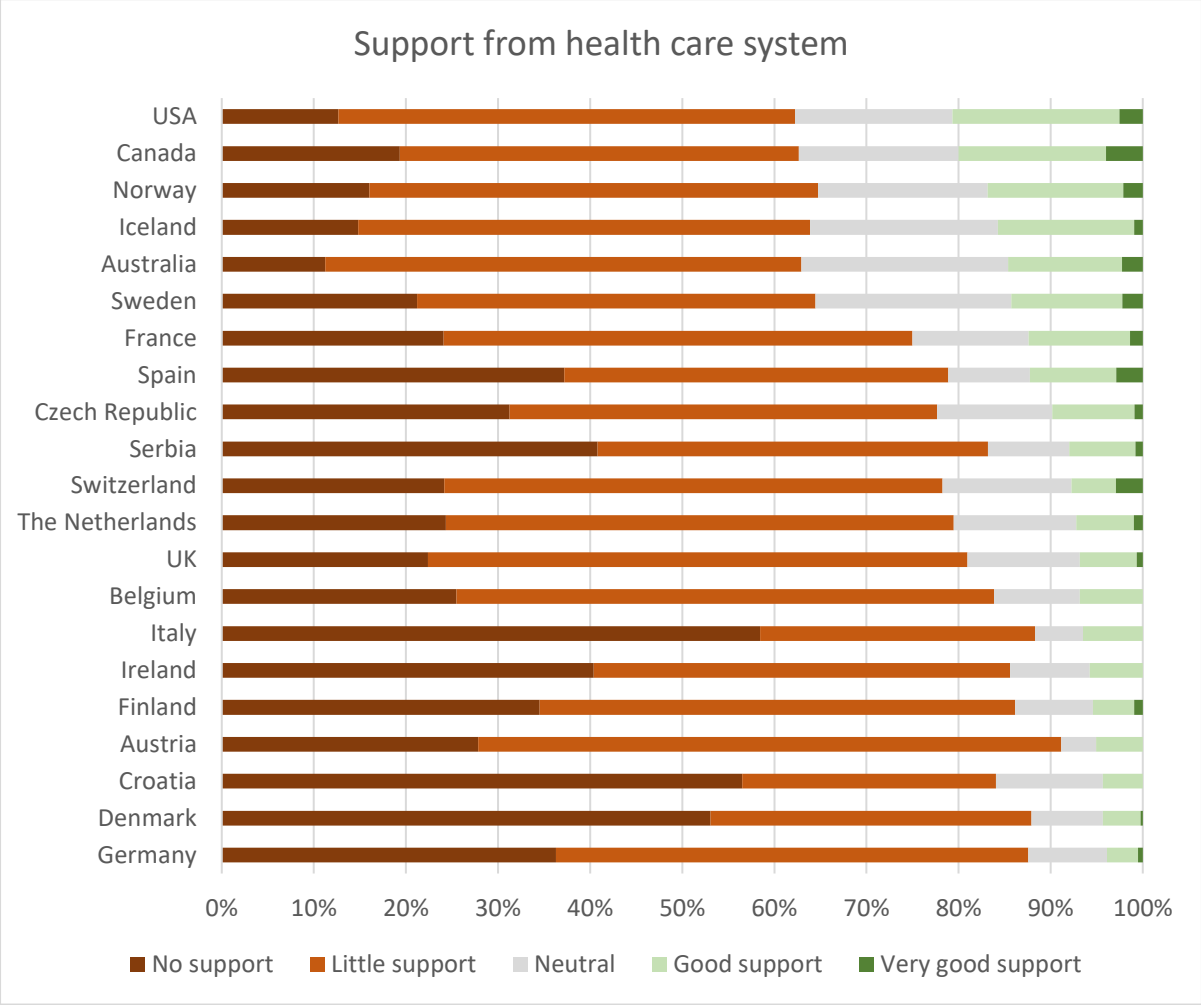


Figure 33: Support from health care system (n=10 661).

The variation across otherwise similar countries remains puzzling. An example is the difference found in an otherwise rather homogenous Nordic region, as illustrated in Figure 34. The proportion of respondents reporting that they received no help varies from a low number of 15-21% in Iceland, Norway and Sweden to 35% in Finland and more than half (53%) in Denmark. These differences most likely reflect differences across country borders in how the disease is perceived among key components within the health care system, with Denmark being known for a strong biopsychosocial approach, where ME/CFS is considered a functional illness by the Danish health authority.

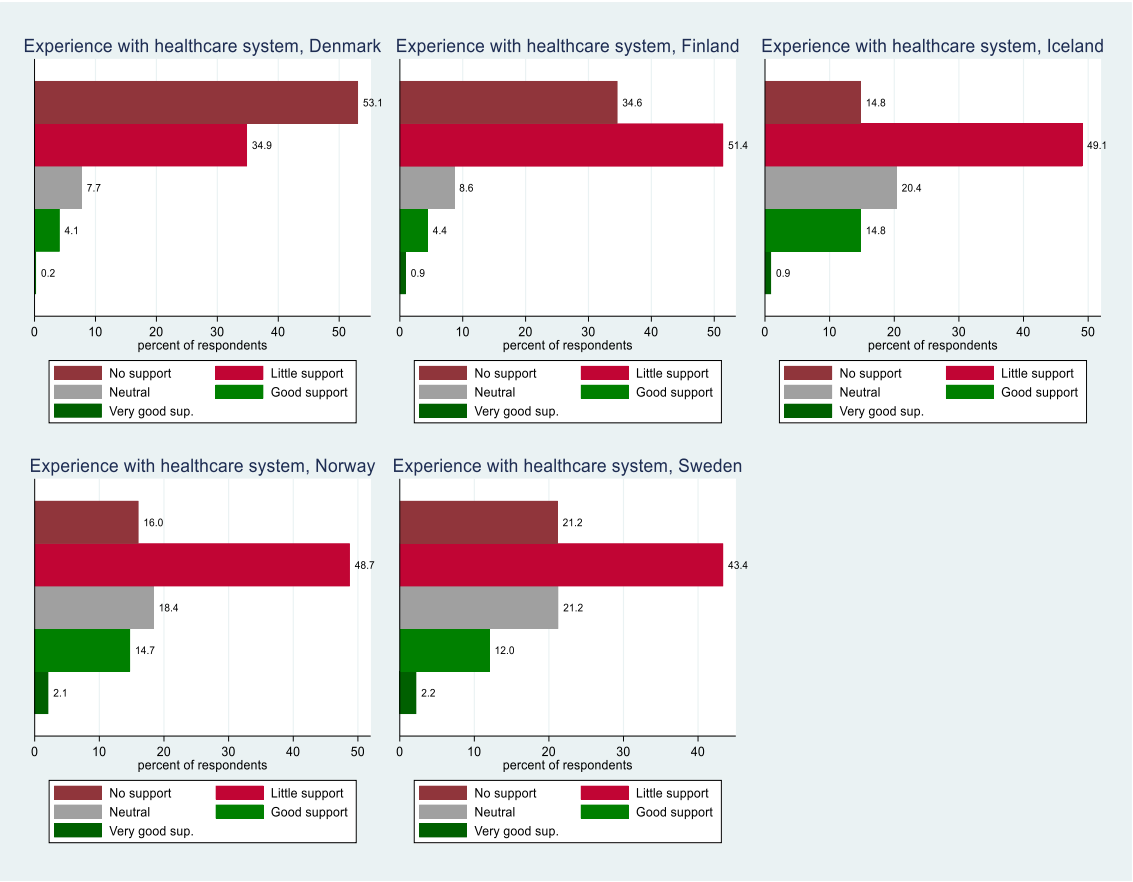


Figure 34: Differences in health care experiences in Nordic countries.

Health care and course of illness

Respondents who answered that they received good support from the health care system in their country are more likely to report improvement and less likely to report deterioration (Figure 35). Causation may, however, go both ways, in that persons who do not deteriorate will have fewer negative views of the health care they have received.

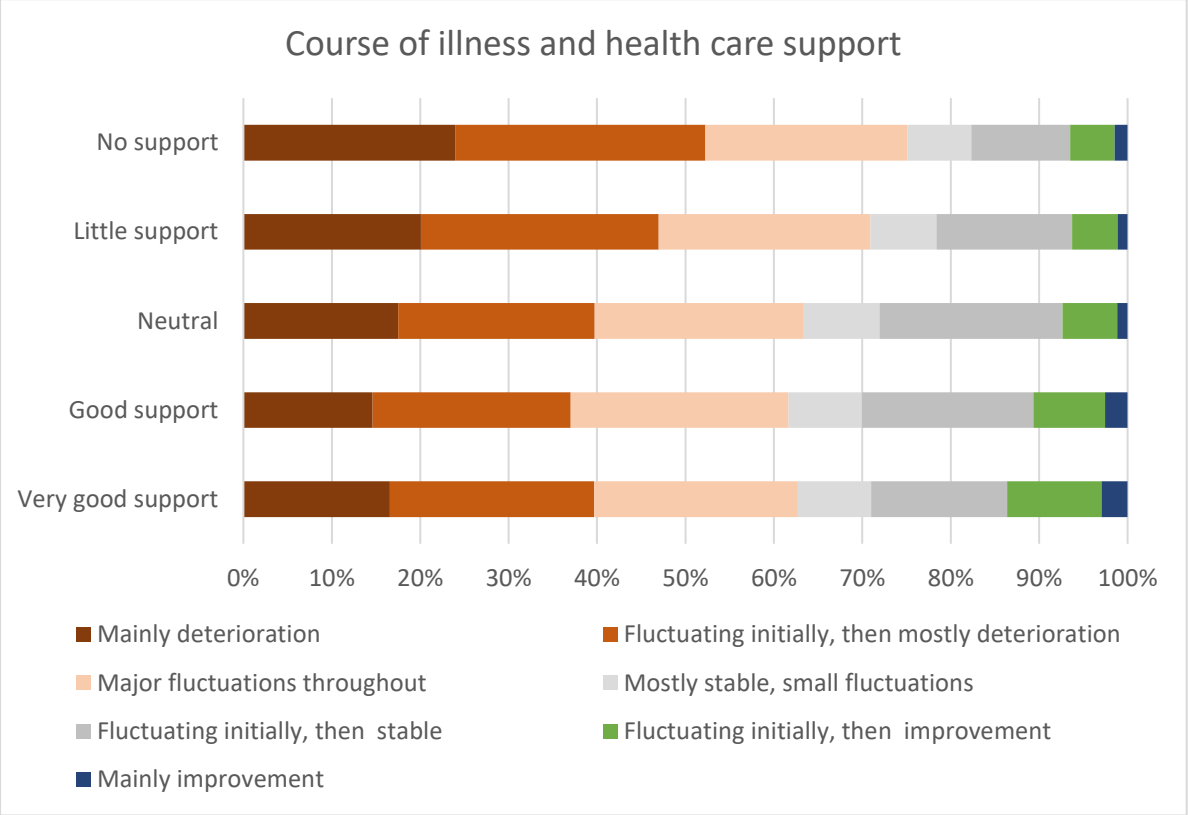


Figure 35: Course of illness and support from the health care system (n=10 662).

Figure 36 provides an even clearer picture of the link between the two variables. The vertical (y) axis measures the likelihood of a deteriorating course of illness, while the horizontal (x) axis is the satisfaction with the health care system, measured on a scale from -2 (no support) to 2 (very good support). Among those reporting good or very good support, 35% had had a deteriorating course of illness, while this risk increased to more than 50% for those who reported no support.

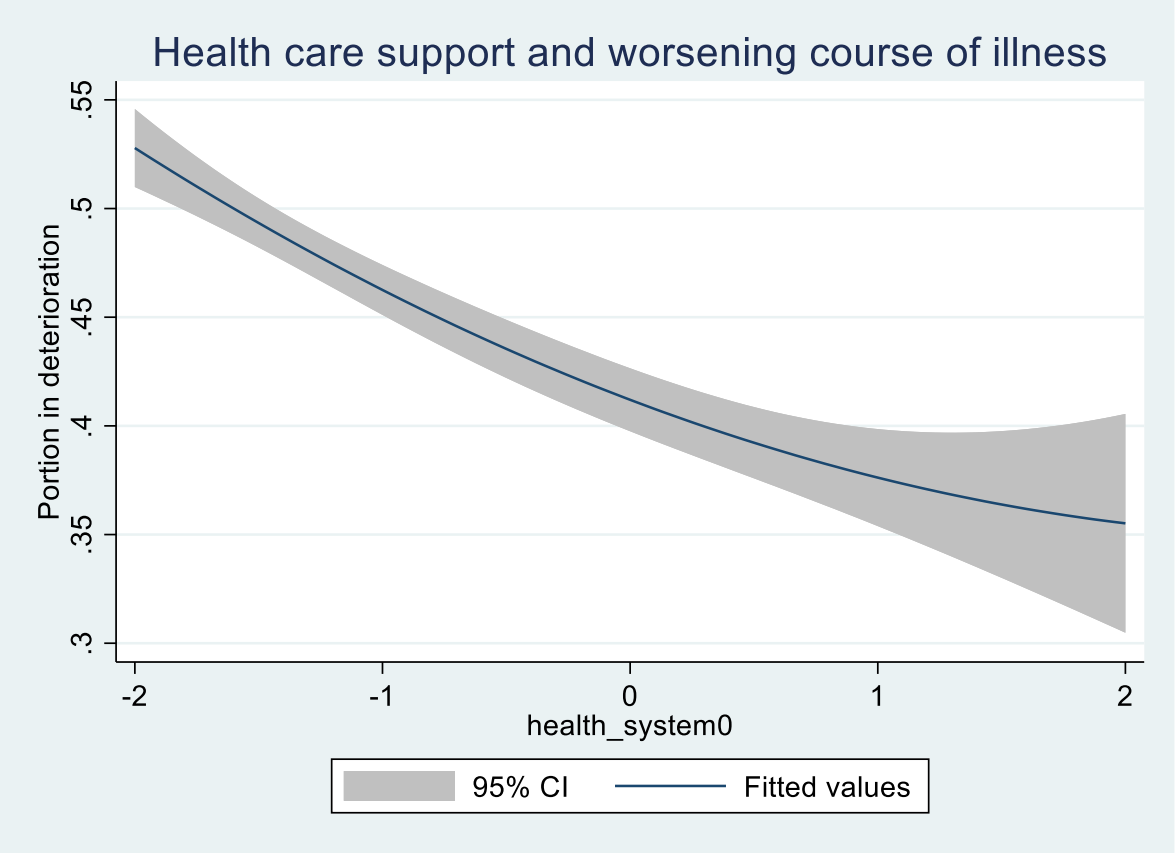


Figure 36: The relationship between health care support and portion of patients with a deteriorating course of illness (n=10 662).

Changes over time

The last few years have witnessed a large increase in the number of scientific articles on ME/CFS, accompanied by more media attention. One may wonder whether that has had an impact on how ME/CFS-patients are received and treated in the health care systems? Ideally, one should have had repeated surveys over time, but in lieu of that, an alternative is to see how the patient experiences depend on the year of onset or diagnosis. The underlying assumptions are that (i) patients have the most contact with the health care system during the early stages (diagnosis), and (ii) that early experiences shape the perception of the health care system.

Below two figures are presented, Figure 37 and Figure 38, for the health care support, based on the year the patients were diagnosed or the year of disease onset. Both figures, in particular the year of disease onset, suggest a modest improvement over time.

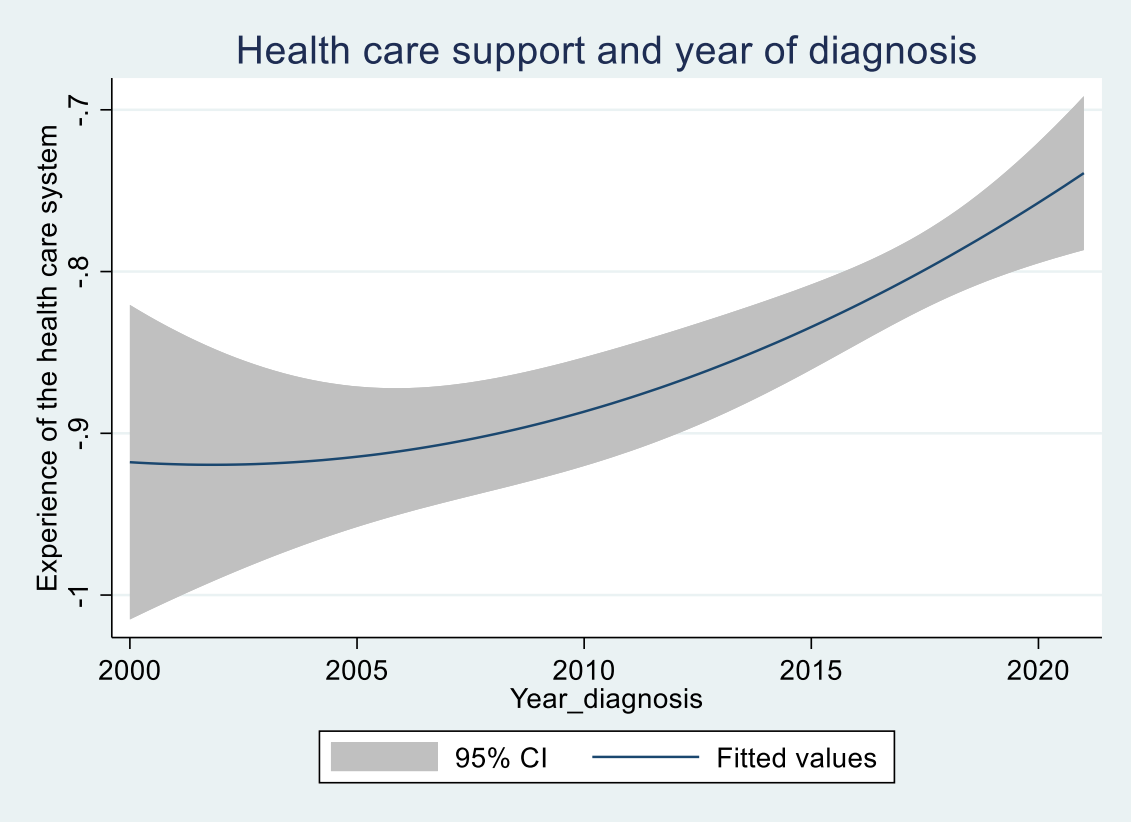


Figure 37: Average score on health care support and year of diagnosis (since 2000) (n=8 525).

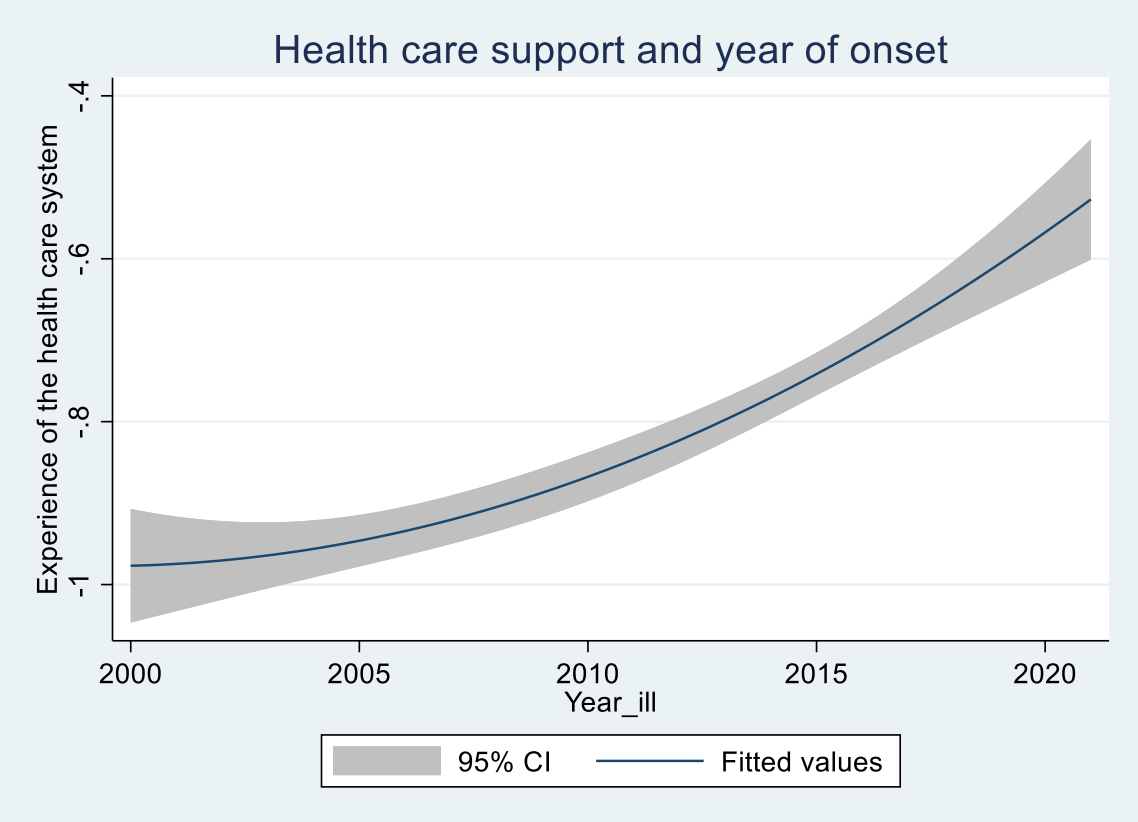


Figure 38: The relationship between on health care support and year of onset (since 2000) (n=8 201).

Health care experiences and diagnostic period

A key part of a positive experience with the health care system is to get an early (and correct) diagnosis. Conversely, a longer period before diagnosis was associated with a lower satisfaction with health services (Figure 39).

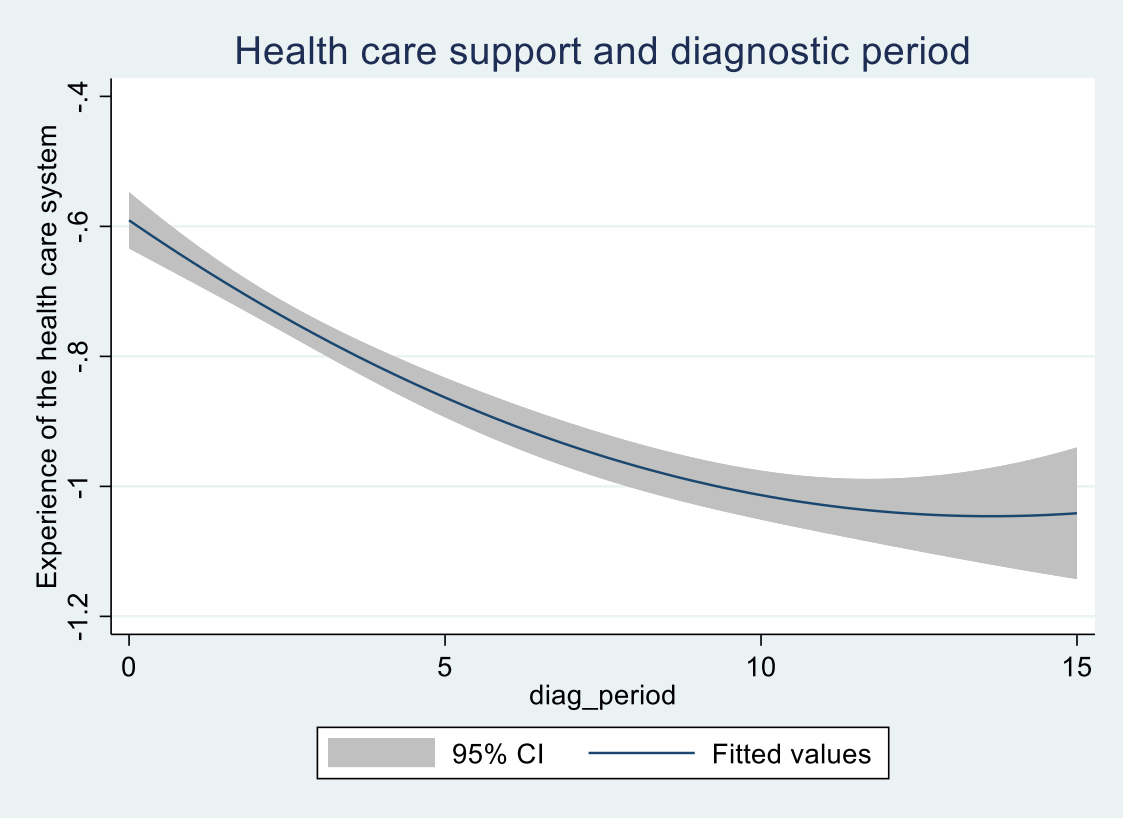


Figure 39: The relationship between health care experiences and diagnostic period (less than 16 years) (n=8 204).

6.4.2 Social security/welfare

As many ME/CFS patients are too ill to work, they depend on their country's welfare system for financial support. In countries where ME/CFS is not accepted as a serious disease, the welfare systems may not recognise ME/CFS as a "real" disability, and therefore affects patients' access to benefits.

Among the 9 785 who responded to the question about support from the social security (welfare) system, a third (34%) stated that they had received no support, while another 27% said they had received little support. Only 3% felt they had received good support.

As for the health care system, a significant correlation was found between poor experiences with the social security system and a deteriorating course of illness (Figure 41).

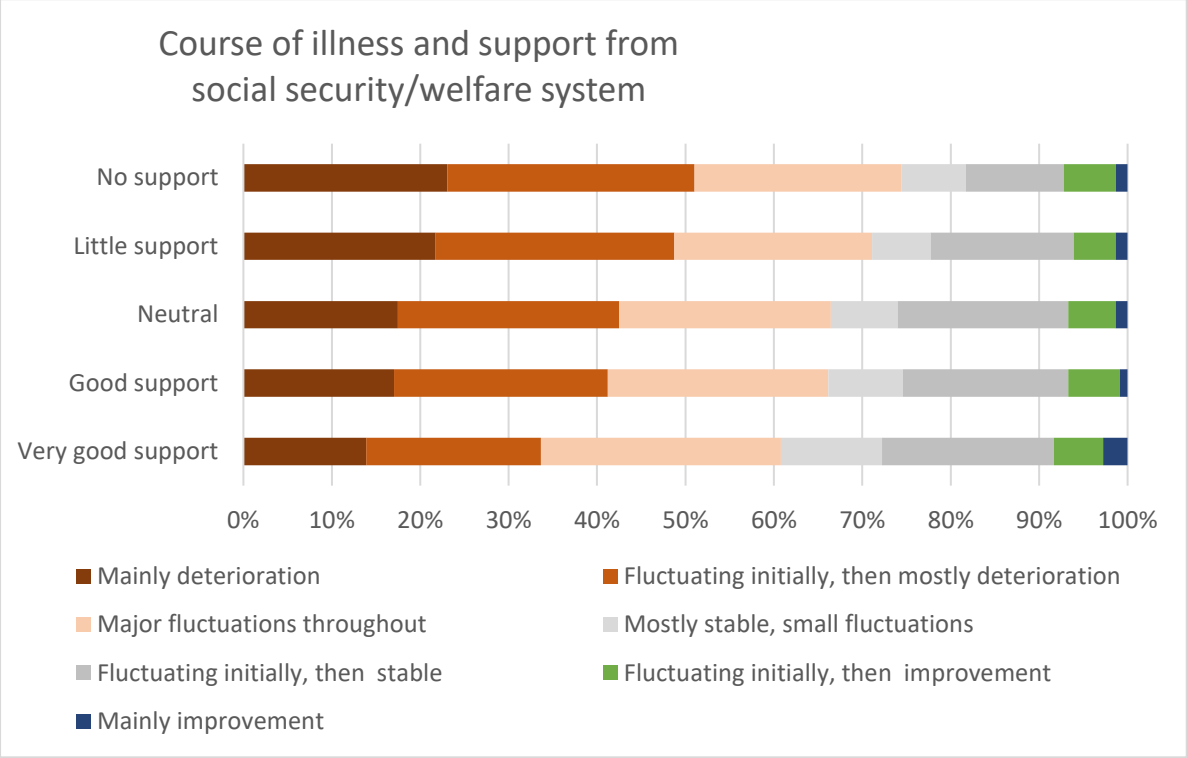


Figure 40: Course of illness and support from social security/welfare system (n=9 784).

There is considerable variation across the countries, as shown in Figure 41. Interestingly, except for Iceland, the three non-European countries included in the figure had the highest portion of experience of (very) good support.

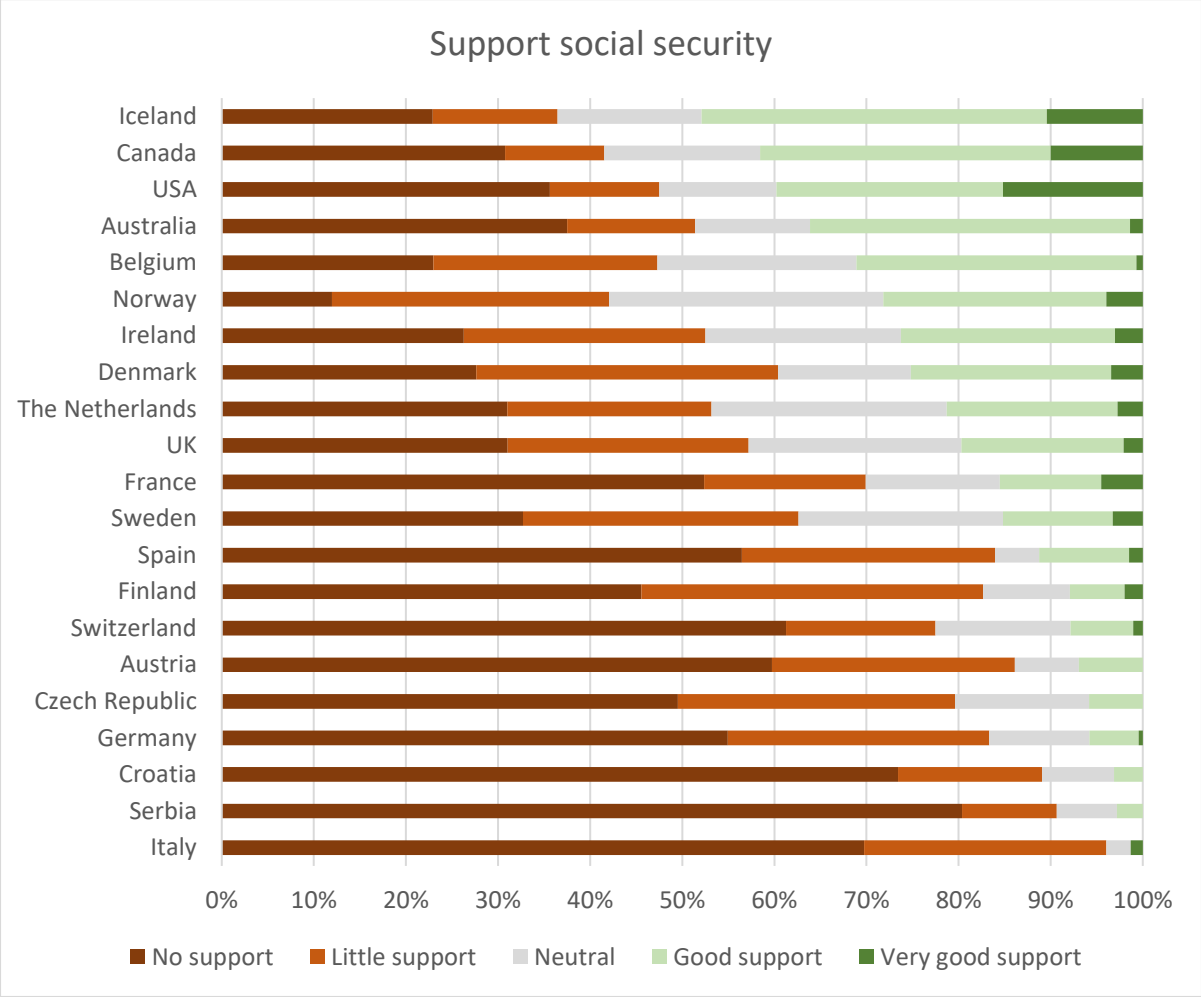


Figure 41: Support from social security/welfare system (n=9 784).

6.4.3 Social services

About 65% of the respondents had been in touch with social services in their country. It is not known what kind of service they had been in touch with (e.g., child protection, home nursing). The majority said they received no support (66%), while only 8% considered the support to be "good" or "very good".

There is less variation across countries compared to social security. In all countries the large majority answered that they had received little or no support (Figure 42).

Unlike for social security, there is no clear correlation between the support from social services and the course of illness.

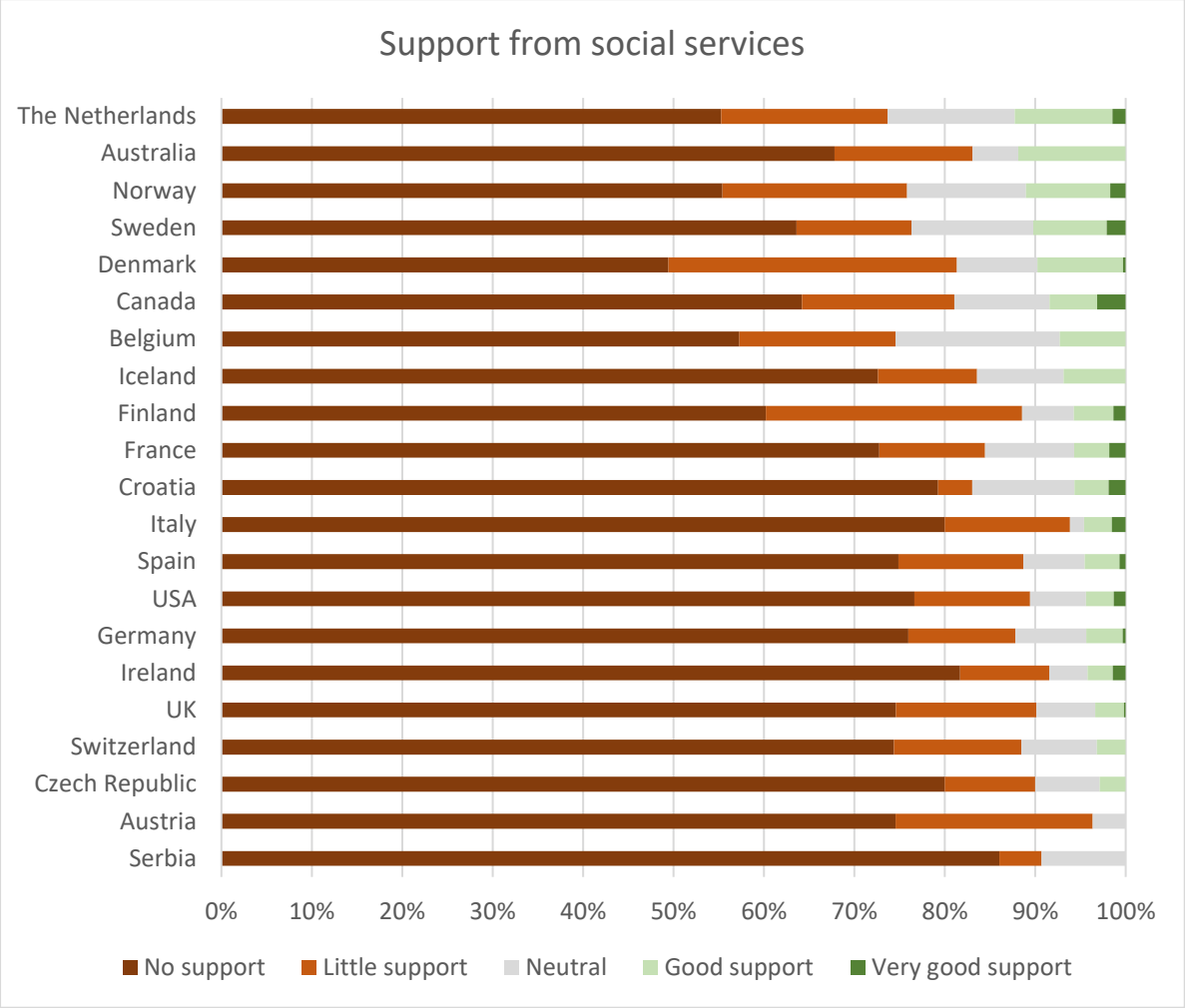


Figure 42: Support from social services (n=7 311).

6.4.4 Workplace

The employment status of respondents is not known in this survey, neither is the period in the course of the illness to which the respondents refer in this question, nor whether this was before or after diagnosis.

Among the approximately 60% that have answered the question about support from the workplace, 42% stated that they had received no support. 23% stated that they had received good or very good support. There is some variation across countries, with Scandinavian countries on top in terms of (very) good support (Figure 43).

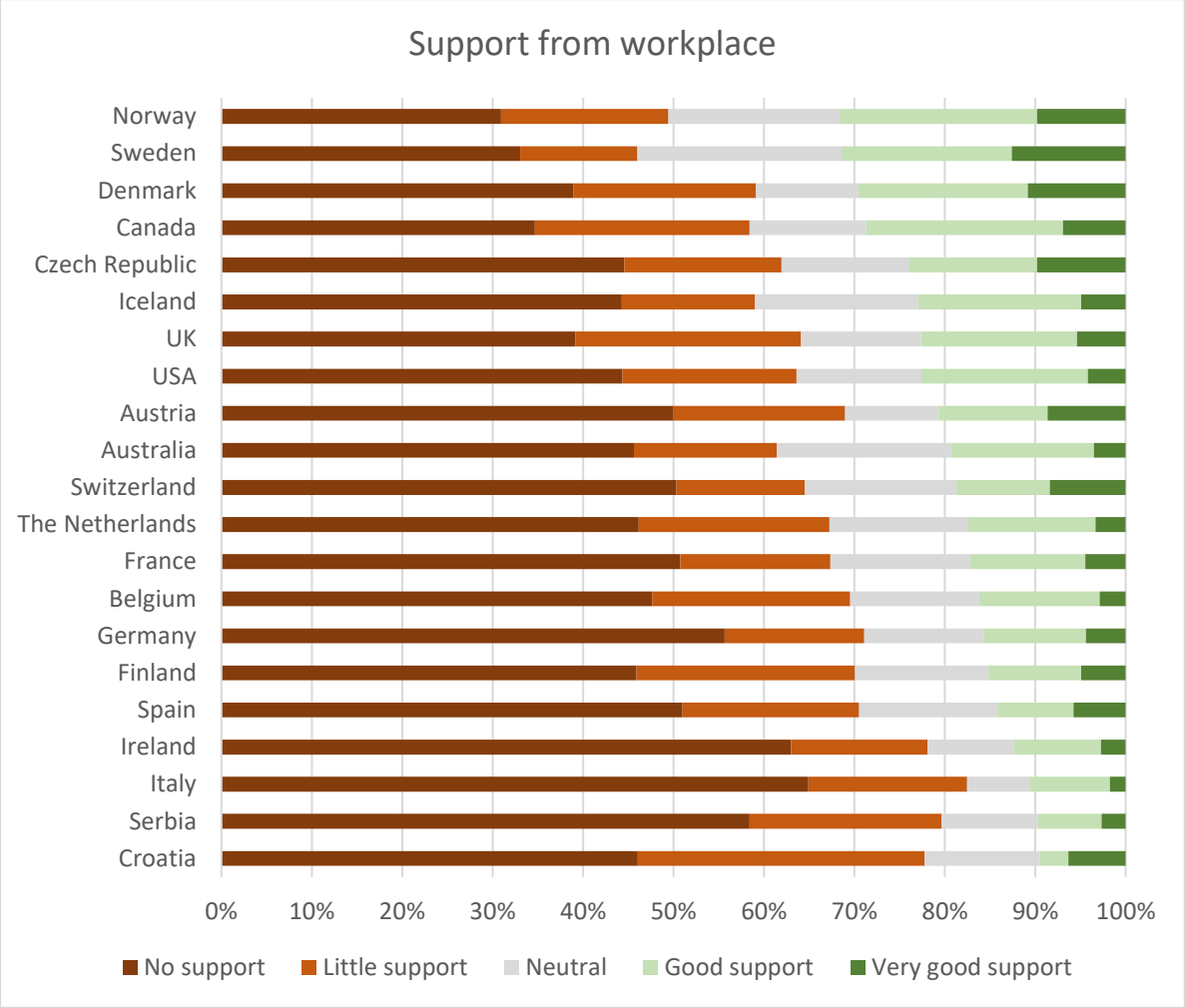


Figure 43: Support from the workplace (n=6 830).

6.4.5 School/educational institution

Most adult ME/CFS patients are not in contact with the educational system, thus the share of responses is only 28%, mostly adolescents and young adults. Close to half (45%) of these respondents stated that they had received no support, while another 21% had received little support. Good support from schools or universities can be critical, and only 3% and 14%, respectively, stated that they received very good support or good support. The country variation is given in Figure 44.

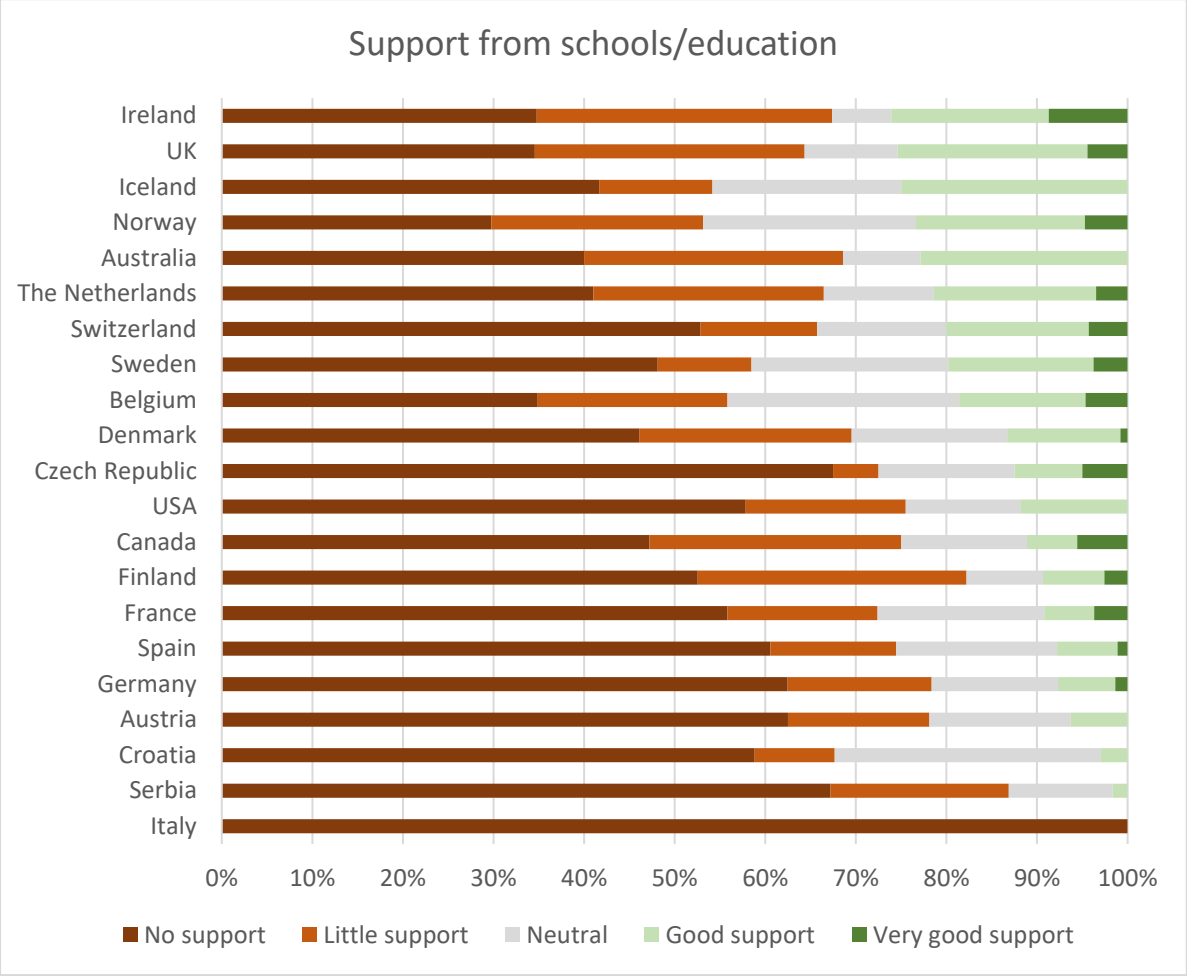


Figure 44: Support from schools or other educational institutions (n=3 120).

6.4.6 Family

Most respondents (94%) answered the question about support from family members, and that family support is important. 60% stated that they received good or very good support from family members, while 25% had received little or no support. There is less variation across countries than, for example, the support from the social security system (Figure 45).

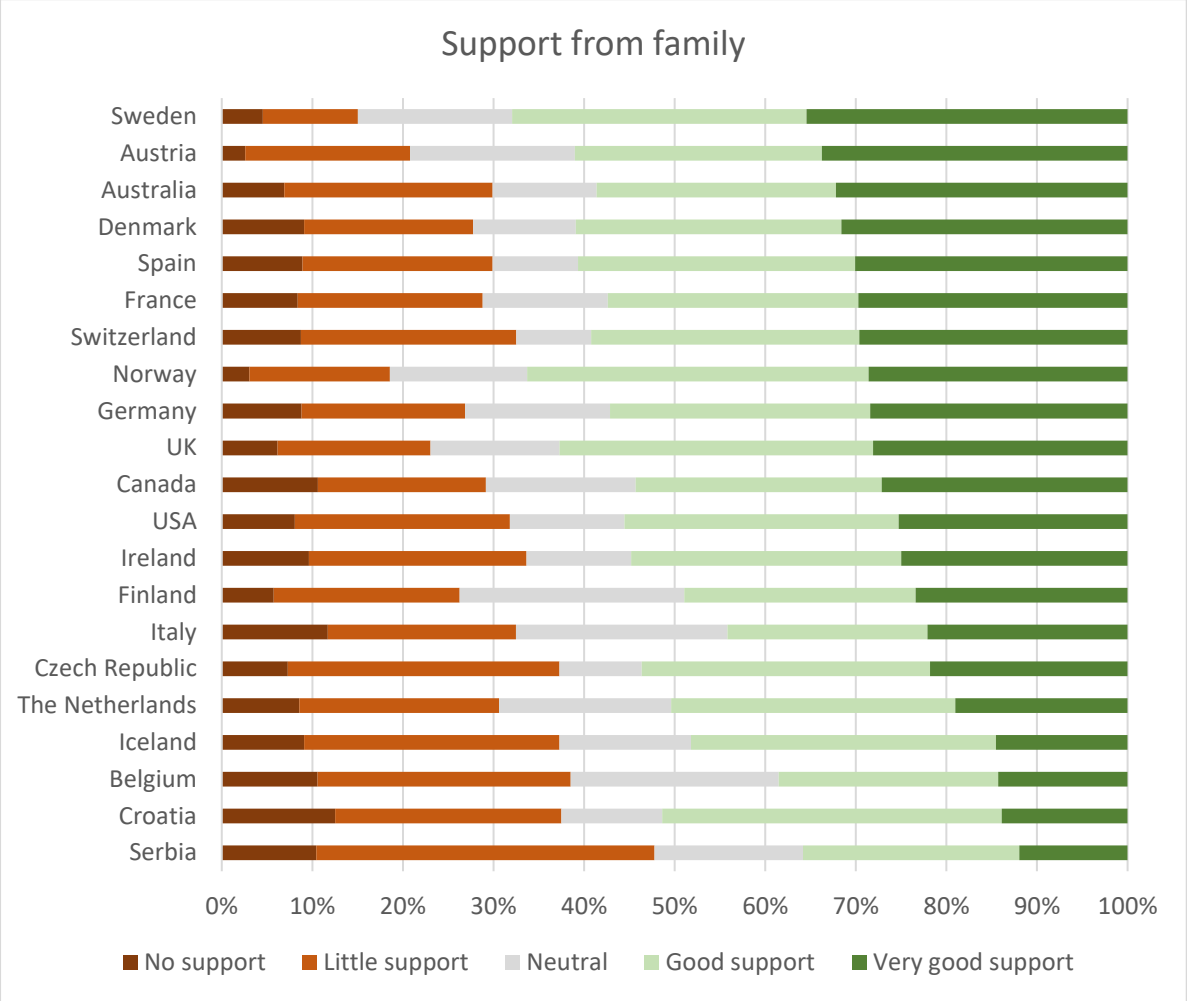


Figure 45: Support from family members (n=10 610).

There is a clear relationship between experienced support from the family and lower risk of a deteriorating course of illness (Figure 46). The needs for family support increases with more severe illness, and one may hypothesise that causality goes the other way, i.e., that the severely ill (i.e., more likely those that have been in deterioration) have higher needs for family care which cannot be met, and thus are more dissatisfied with the level of support provided. This is, however, not the case: Very severely ill patients have an average score on family support of 0.95, compared with 0.58 (0.57) for severe (moderate) degrees (with -2 being "no support", up to 2 being "very good support").

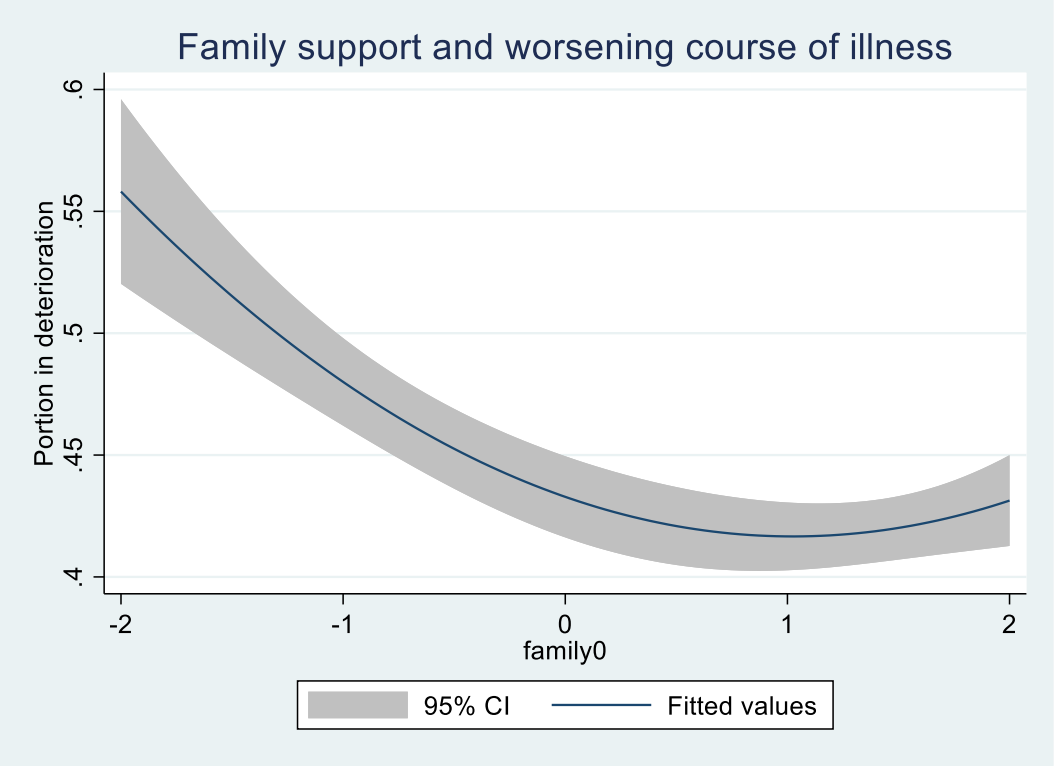


Figure 46: The relationship between deteriorating course of illness and family support (n=10 611).

6.4.7 Friends

About 92% of respondents answered the question about support from friends. In general, the support is much lower than that from family members. 40% stated that they had received little or no support from friends, while 34% felt they received good or very good support. The country differences are – perhaps surprisingly – small (Figure 47).

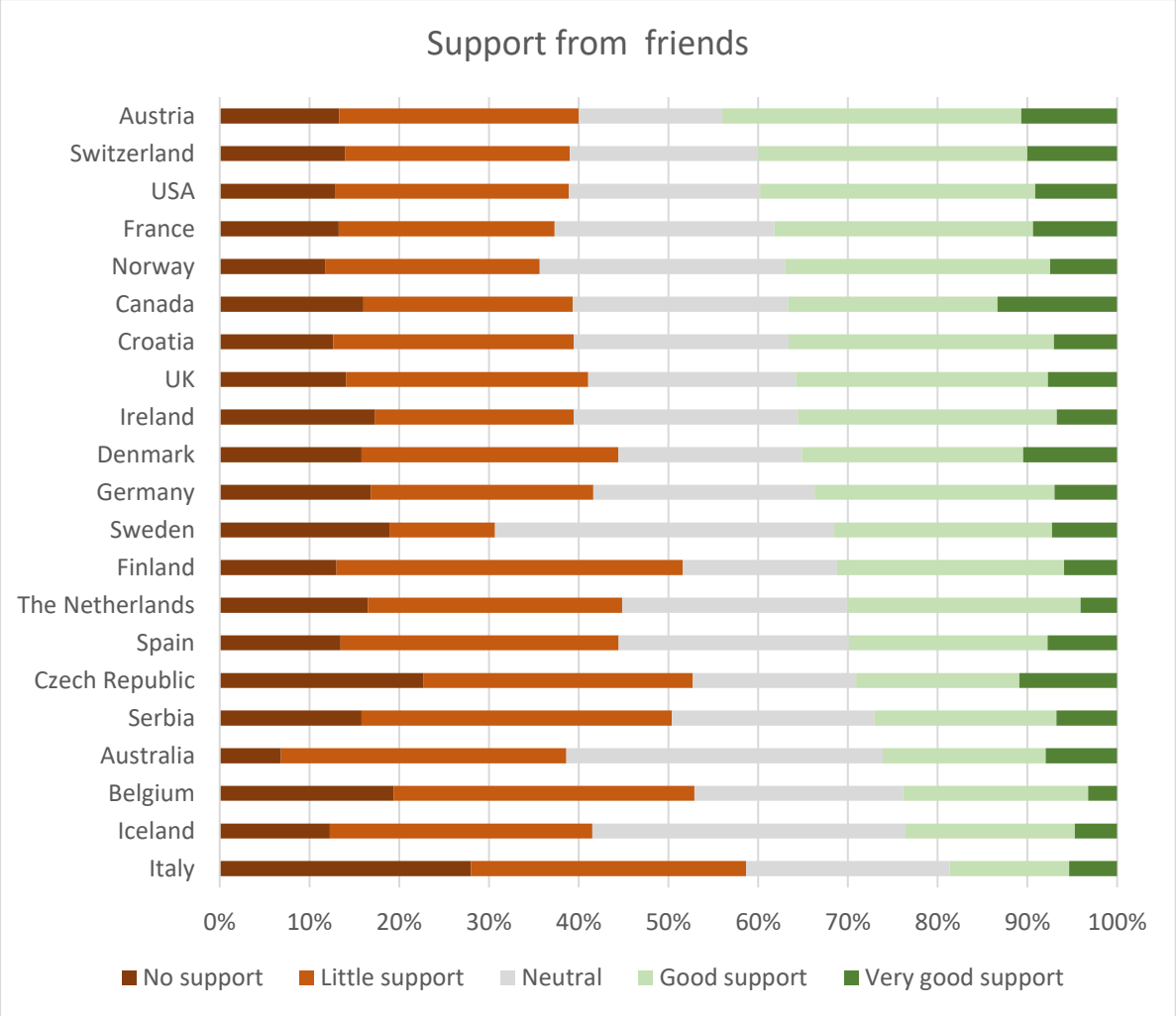


Figure 47. Support from friends (n=10 388).

Respondents with more severe disease reported slightly less support from friends. Severe ME/CFS limits the patient's ability to socialise, and patients may lose contact with friends. Friends may also feel uncertain both about whether the disease is "real", and how to interact with the patient, and pull away (Figure 48).

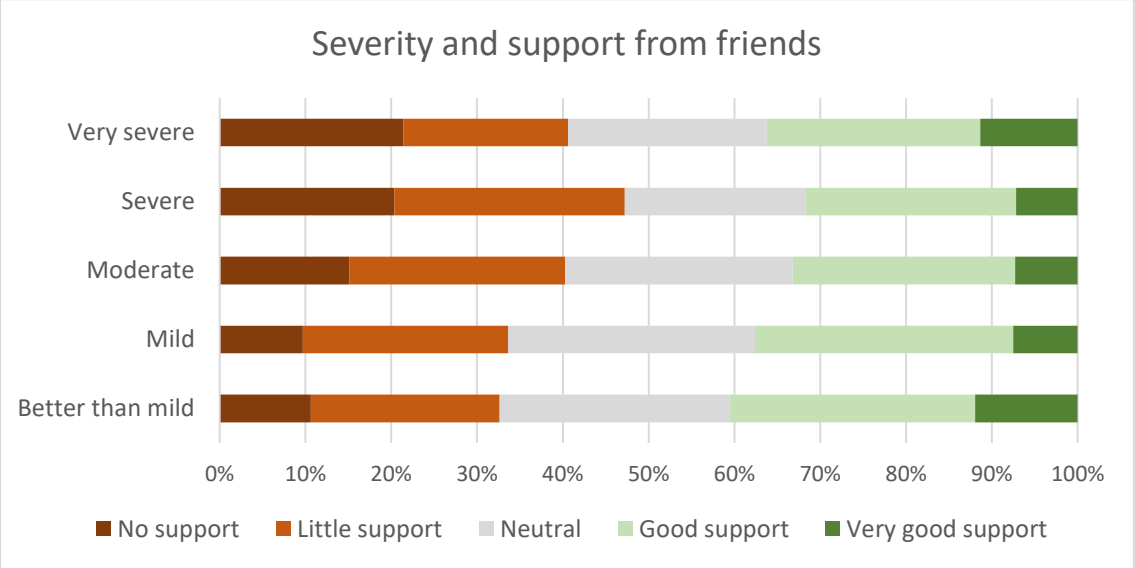


Figure 48: Severity and support from friends. (n=10 388).

As for family support, there is a clear correlation between support from friends and a better prospect for the course of the illness (Figure 49). As for severity, the causality can go both ways.

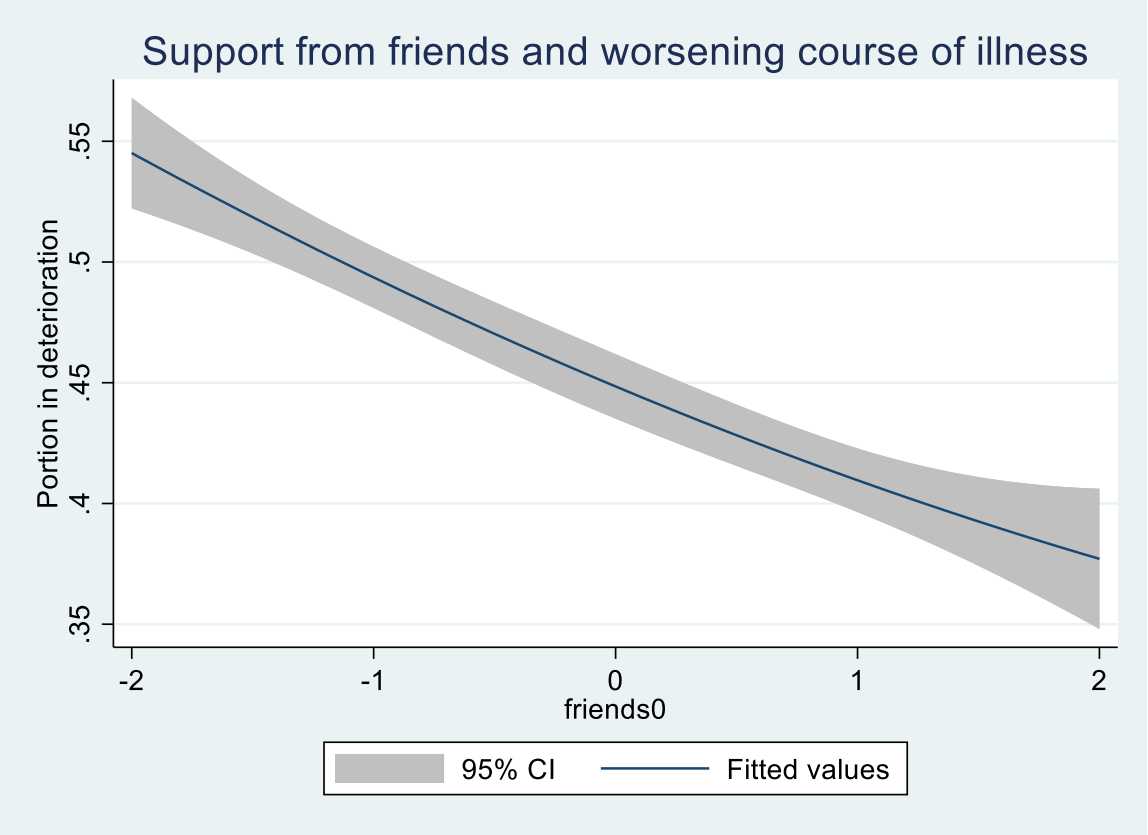


Figure 49: The relationship between deteriorating course of illness and support from friends (n=10 339).

6.4.8 Other ME/CFS patients

About 70% of the respondents had been in touch with other ME/CFS patients. It is not known whether this is through online or offline communities, in groups or one-to-one communication. More than half (56%) stated that they received good or very good support from fellow patients, a proportion well above that from friends, and comparable to the support response from family members.

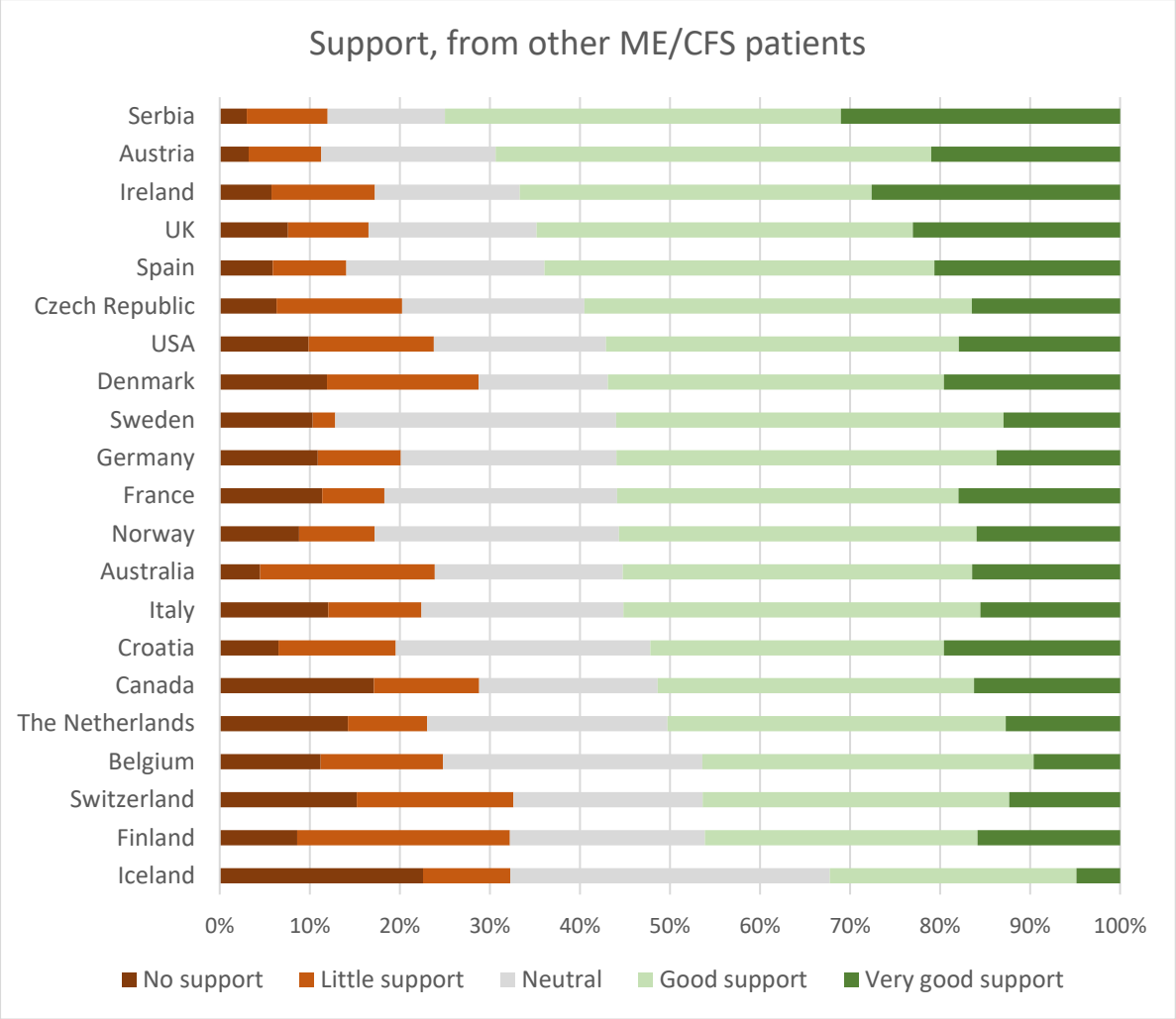


Figure 50: Support from other ME/CFS patients (n=7 960).

The variation across countries is pictured in Figure 50. Interestingly, the support is highest in Serbia, a county that scores the lowest in the support from other actors or groups, as shown in the previous figures. At the country level there is a clear and *negative* correlation between support from fellow ME/CFS patients and the support from public services (health, social security and social services), while a weak positive correlation between patient support and support from family and from friends. This may indicate that when the understanding and support from others is lacking, the support from

fellow patients – who share the same experiences and have a good understanding of the disease – becomes more important.

6.4.9 Patient organisations/charities

About 71% of the respondents answered the question about the support from patient organisations or charities, indicating that they had been in touch with such communities. 42% stated that they had received good or very good support, while 29% had received little or no support.

The large country variation in Figure 51 may reflect, in part, the strength and activities of the ME/CFS patient organisations in the various countries.

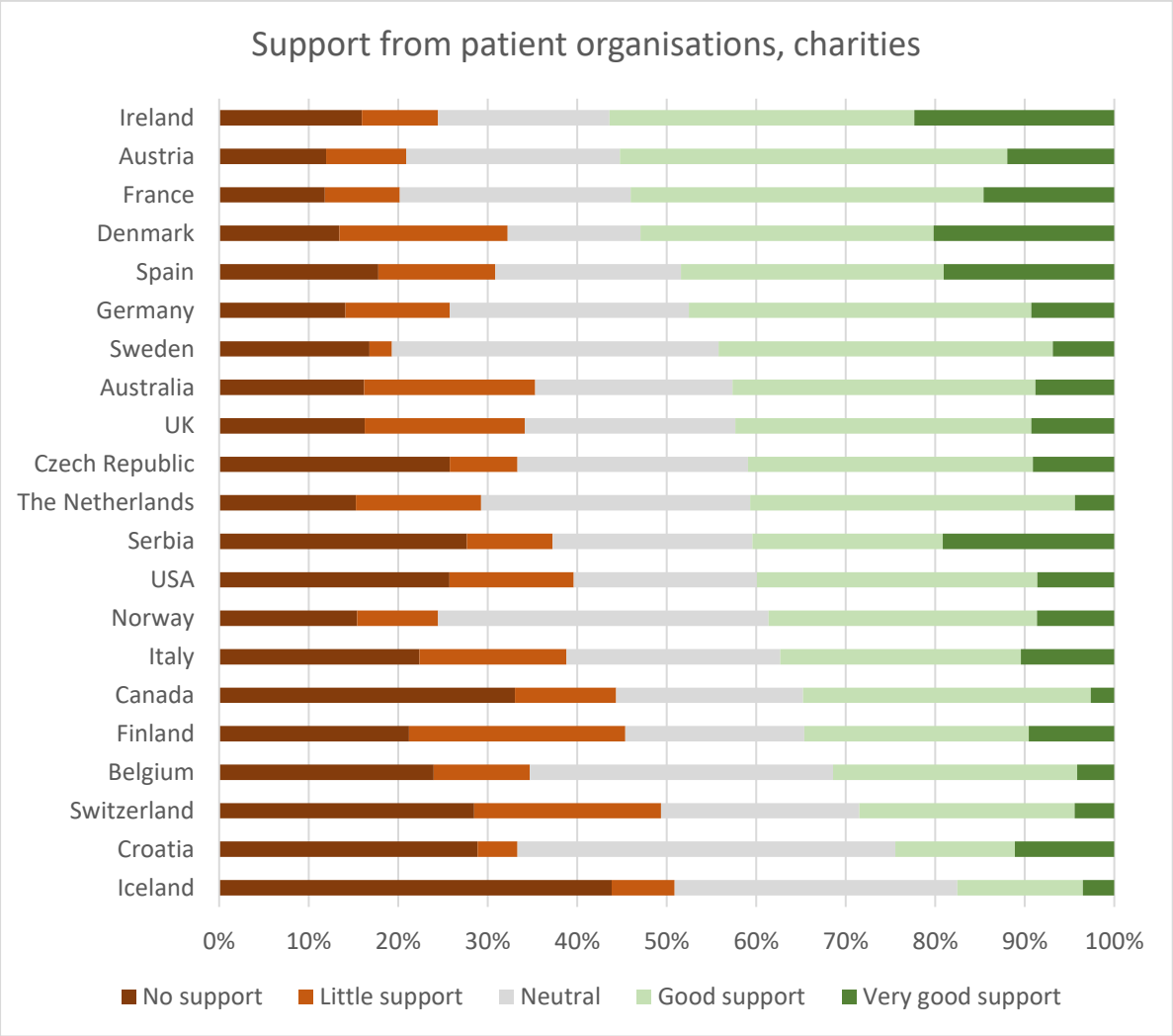


Figure 51: Support from patient organisations or charities (n=7 993).

6.5 Therapies, management strategies and other factors

The subject of management and treatment of ME/CFS is the cause for much discussion in many countries. There is anecdotal evidence that many patients are subjected to "treatments" that make

them worse. In Norway, for instance, the welfare system has long required that patients participate in cognitive therapy before they can apply for disability benefits.

It was important to look at patient experiences with various management strategies and therapies, in addition to a few external factors that may have an impact on the course of illness. Again, the questions were based on open-ended answers in the Norwegian survey (Schei & Angelsen, 2020, 2021).

The following information was sought:

- Acceptance of the disease (coping)
- Pacing (activity management to stay within the energy envelope)
- Physical or mental activity within energy envelope (avoiding PEM)
- Physical or mental activity causing repeated episodes of PEM
- Caring for one's family
- Cognitive Behavioural Therapy as a cure for ME
- Cognitive (Behavioural) Therapy / psychological coping method
- Alternative therapies
- Symptomatic treatment of, for example, pain, sleep disturbances or nausea
- Financial situation
- Stress and worries

Results in this section are given as percentages of those who have tried or been exposed to the respective therapies, management approaches and external factors.

For each, respondents were asked to state the experienced impact, which in the analysis have been given the following scores, as: very positive (2), positive (1), neutral (0), negative (-1), or very negative (-2). Average scores are reported in the figures and tables.

6.5.1 Overview of factors

Pacing, a management strategy that involves finding a balance between activity and rest, and avoiding PEM, was the approach that respondents felt had the most positive impact on the course of illness. Physical or mental activity was seen as positive, as long as the activity did not trigger PEM. Respondents also answered that it was positive to accept one's disease. Cognitive therapy as a coping tool had, on average, a very slight positive impact.

On the negative side were stress and worries, physical activity that causes repeated episodes of PEM, and the type of cognitive therapy that is touted as a cure for ME/CFS (Figure 52).

The most harmful factor was seen to be stress and worries. This should be seen in relation to the answers to questions about support from government agencies and the health care systems (Figure 65).

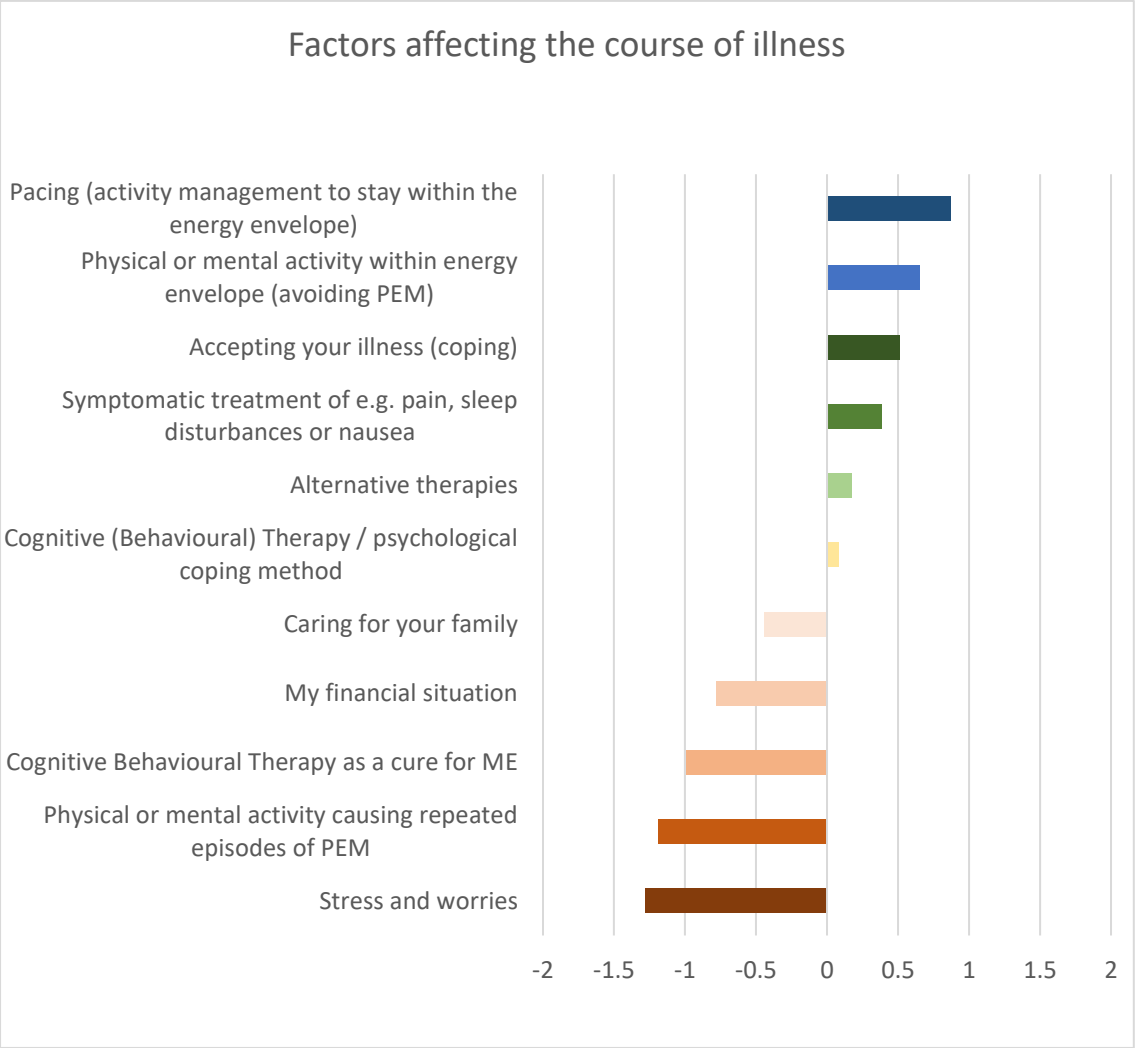


Figure 52: Impact of various factors affecting the course of illness (scores from -2 (very negative) to +2 (very positive)).

There are some gender differences (Figure 53). Women tended to find that caring for one's family had a larger negative impact than it did for men, and women had more positive experiences with alternative therapies.

Men reported a slightly more negative impact from CBT as a coping tool, while women found it slightly more beneficial.

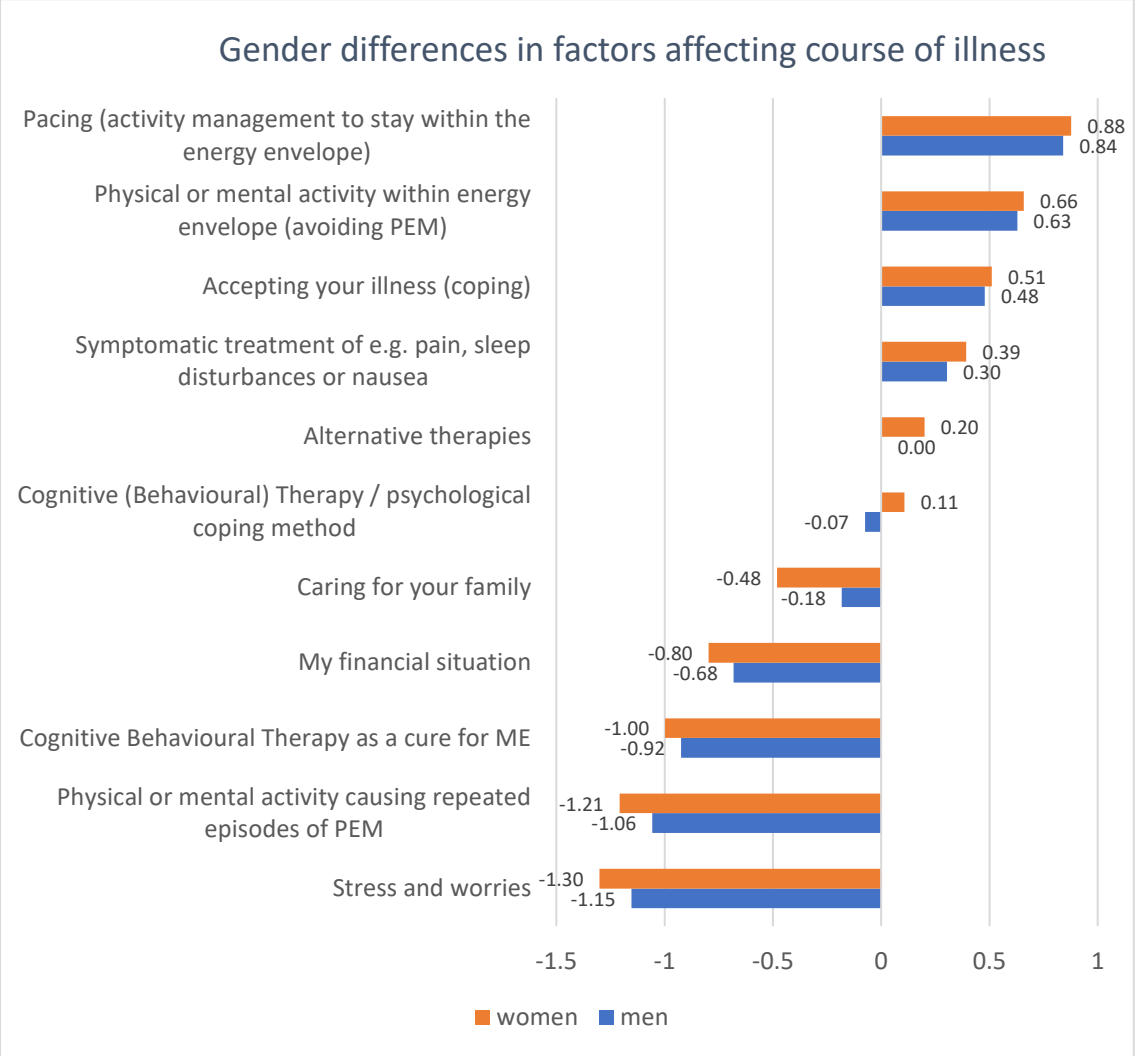


Figure 53. Impact of help and support from various actors on course of illness, by gender (scores from -2 (very negative) to 2 (very positive)).

6.5.2 Cognitive therapy: cure or coping?

Cognitive behavioural therapy (CBT) is highly controversial as a treatment for ME. There is a distinct type of CBT that has been proposed as a cure for ME. The patients are taught not to be afraid of symptoms, to push through, and to increase activity regardless of symptoms. This therapy has its source in the "biopsychosocial model" for ME, which posits that ME/CFS is caused by "dysfunctional illness beliefs" and deconditioning. It is more accurate to call this model "psychosocial", because it lacks a biological dimension.

For those who are unfamiliar with the discussion and controversy around the "biopsychosocial" model for ME, a more thorough discussion can be found in Appendix 3.

In the 1970s, the biopsychosocial perspective was a new way of looking at illnesses; it was a recognition that illness or disease were not exclusively physical phenomena, but that the patient's

condition was also affected by social and psychological factors. This perspective is also relevant in ME/CFS. However, in the ME/CFS discourse the term "biopsychosocial" is used in a particular way. As Joanne Hunt writes: "Simply put, the biopsychosocial model has been applied as a part of a neoliberal project to re-frame chronic health conditions (particularly those surrounded by medical controversy or uncertainty) as primarily psychosocial entities, purportedly perpetuated by psychological and social factors and thus allegedly amenable to psychosocial health care interventions, to 'recovery' and thus a return to work" (Hunt, 2023).[15] It is argued that patients have dysfunctional illness beliefs (i.e., that they have a physical disease), focus too much on symptoms, become afraid of activity, and get deconditioned. The proposed cure is cognitive therapy (CBT) and graded exercise (GET).

Some studies have indicated a very modest positive effect, but have been beset with biases and methodological problems, according to the critique by, among others, Geraghty (2016) and Wilshire et al. (2018) of the PACE trial (White et al., 2011). Patients organisations and several studies have, however, consistently argued that this form of CBT has no effect at best, and at worst is harmful (for a summary of some of the studies, see Marks, 2023). GET has consistently been found to be harmful.

Even so, health authorities in many countries have embraced this model, and ME/CFS patients are routinely offered CBT and GET. In some countries, receiving welfare benefits may be based on the condition of having tried these therapies.

CBT is commonly used in severe diseases to help the patient cope with, and accept, the disease, and the grief that results from loss of health, work or identity. It is important to distinguish between the very specific type of CBT offered as a cure for ME/CFS and CBT used as a management tool (coping) (Figure 54).

The findings of this study clearly underscores the importance of distinguishing between the two forms of CBT. 3 out of 4 ME/CFS patients experienced a (very) negative affect of CBT as a cure, while only 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.

[15] For a more thorough discussion on the role of the BPS model in health and welfare policy discourses, see also Hunt, J. (2022). Holistic or harmful? Examining socio-structural factors in the biopsychosocial model of chronic illness, 'medically unexplained symptoms' and disability. *Disability & Society*, 1-30. https://doi.org/10.1080/09687599.2022.2099250

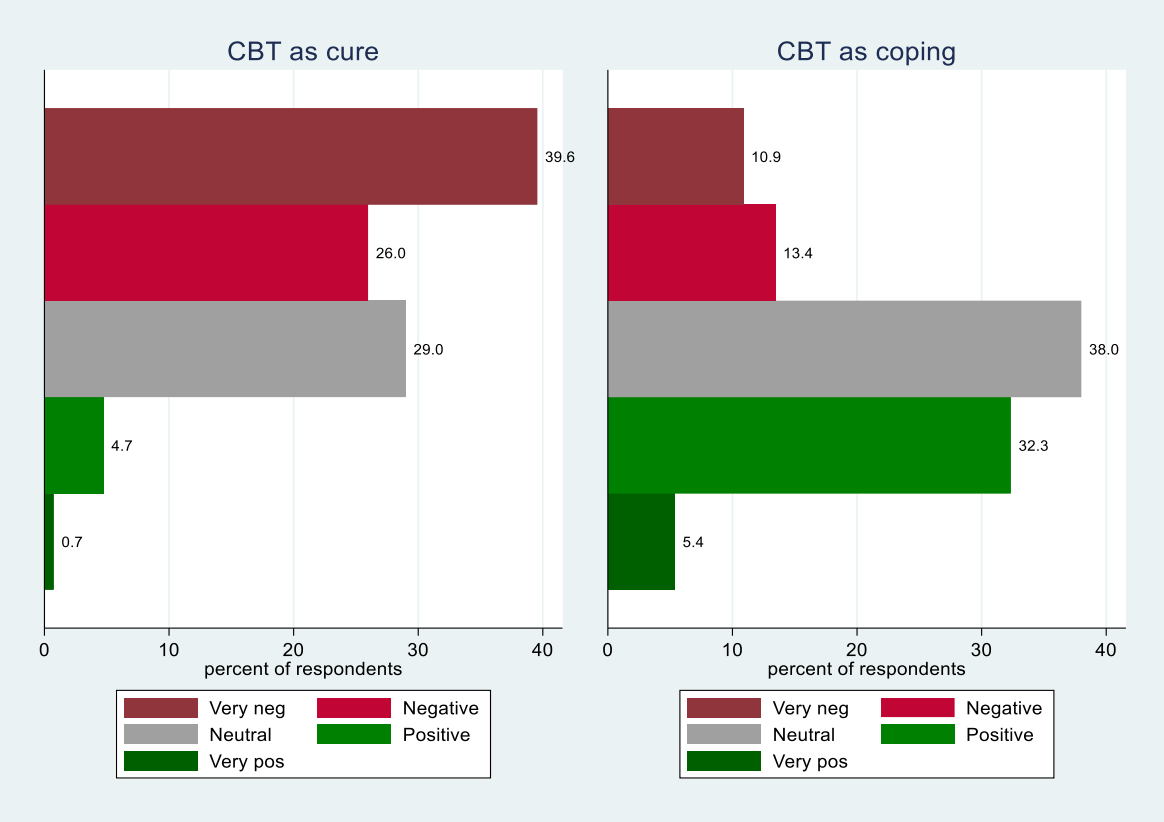


Figure 54: Experiences with CBT as cure vs. CBT as coping.

The severity of ME/CFS was hypothesized to affect the CBT experience. The pattern shown in Figure 55 is remarkably clear: the more severe the illness, the more negative the experiences with CBT, both as a cure and for coping. Even for patients with mild ME/CFS, the experiences were on average negative for CBT as a cure. Regarding CBT for coping, the experience for the (very) severely ill was negative; only the mild and better than mild groups reported a positive score on average. This suggests that even CBT, as a management strategy is likely to have negative effects for the most severely ill patients.

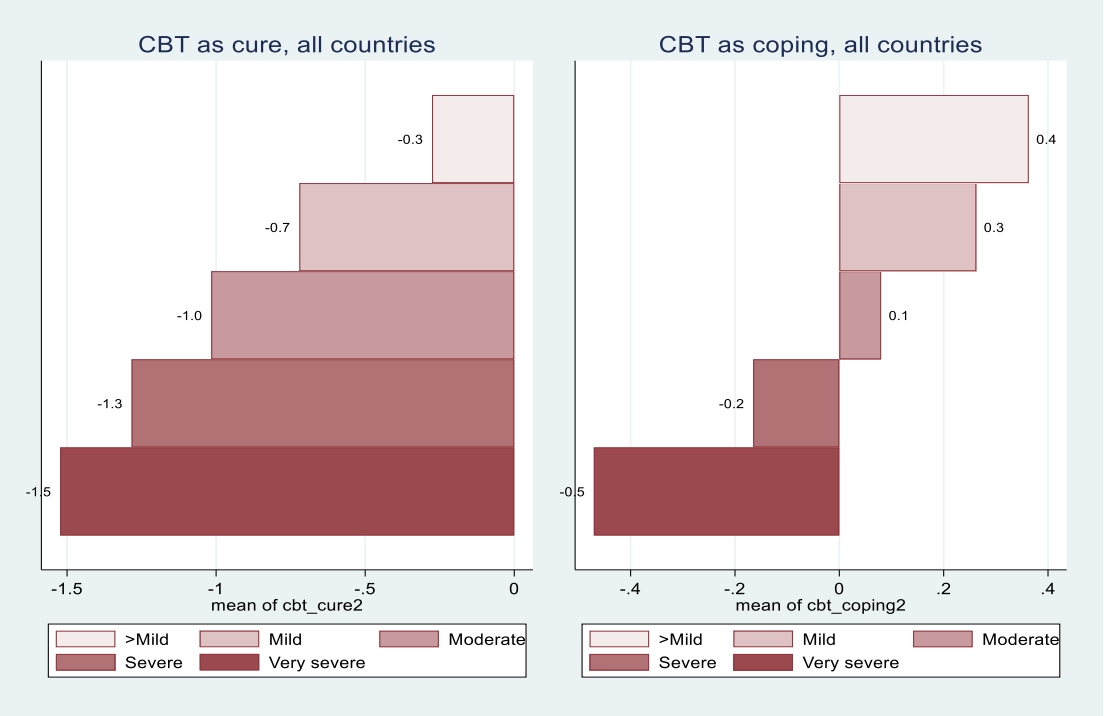


Figure 55: Severity and experiences with CBT as cure and CBT as coping, all countries (scores from -2 (very negative) to 2 (very positive)).

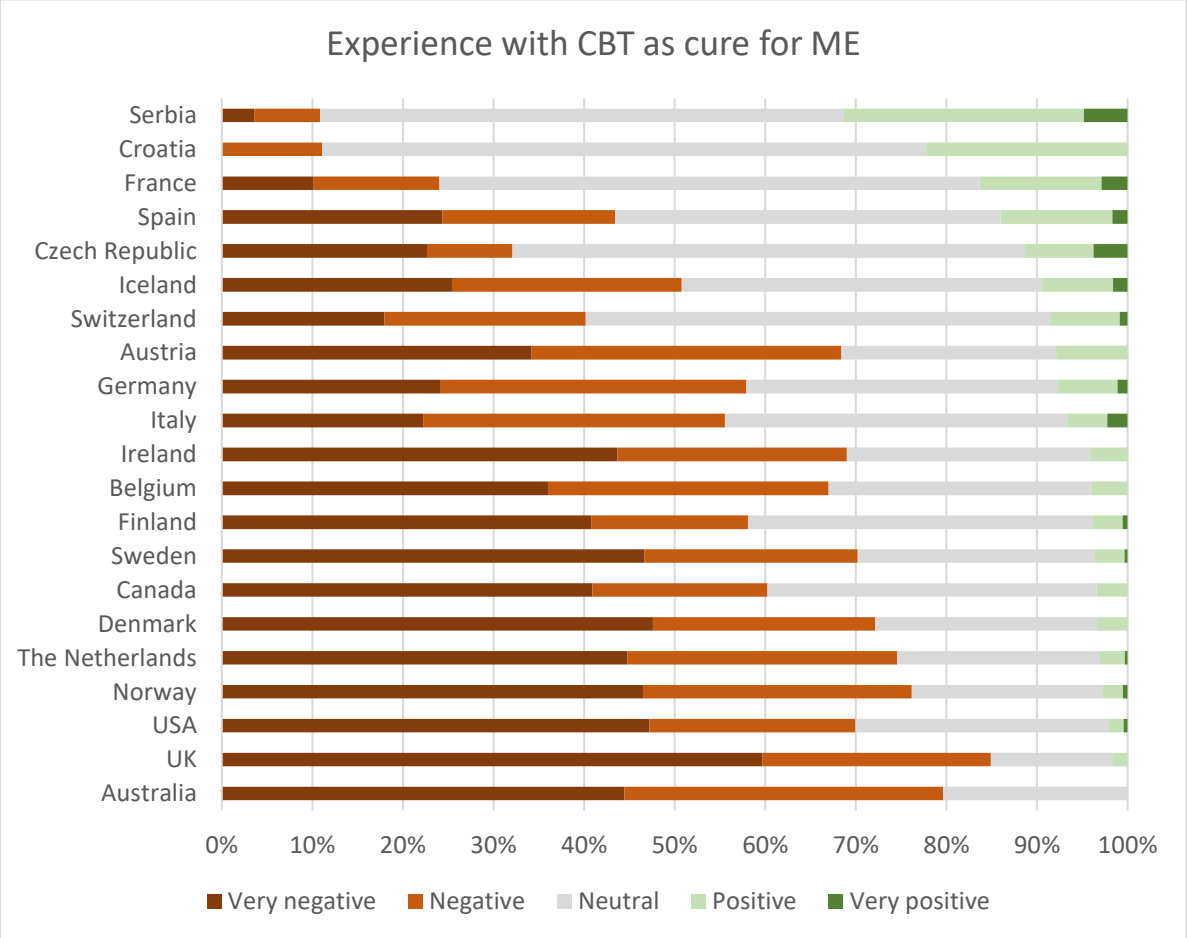


Figure 56: Impact of cognitive therapy as a cure for ME/CFS (n=6 646).

The experiences vary a great deal across countries. The most negative experience in Europe with CBT as a cure is reported from the UK, a country where this form of therapy was promoted by the old, pre-2021 NICE guidelines (Figure 56). In two countries (Serbia and Croatia, both with small samples), a more positive than negative experience is reported.

Also for CBT as a coping tool, the UK (joined with The Netherlands) experience is the most negative (Figure 57). For several countries, there are more negative than positive experiences with CBT for coping.

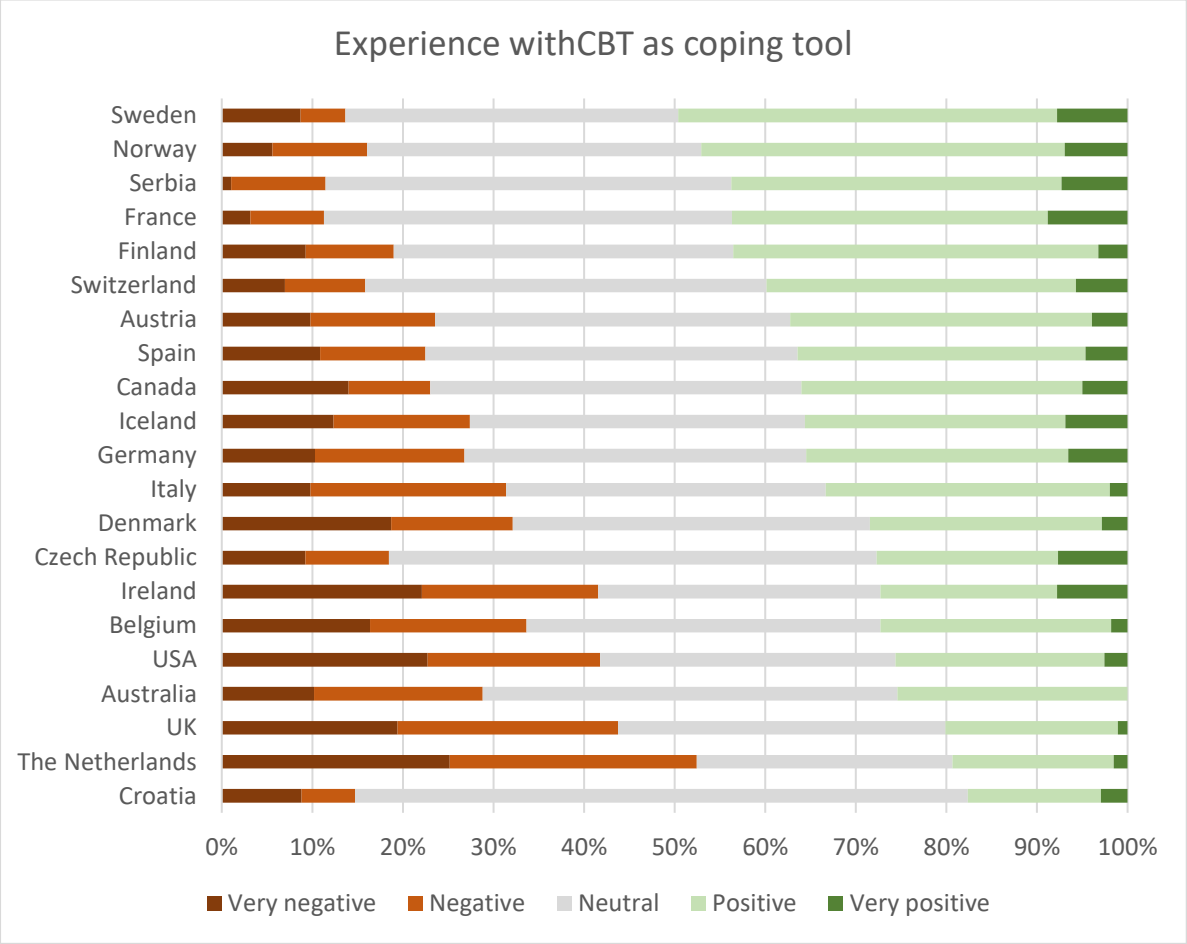


Figure 57: Impact of cognitive therapy as a coping tool (n=5 694).

6.5.3 Physical activity: within or outside the energy envelope?

Similar to cognitive therapy, it is important to make a distinction between physical activity and exercise following a set regime and causing repeated episodes of post-exertional malaise/post-exertional symptom exacerbation (PEM/PESE) (Figure 58), and physical activity within the energy envelope not causing PEM/PESE (Jason, Muldowney, & Torres-Harding, 2008) (Figure 59).

Respondents reported that physical or mental activity that does not cause PEM is beneficial, while repeated episodes of PEM had a negative impact.

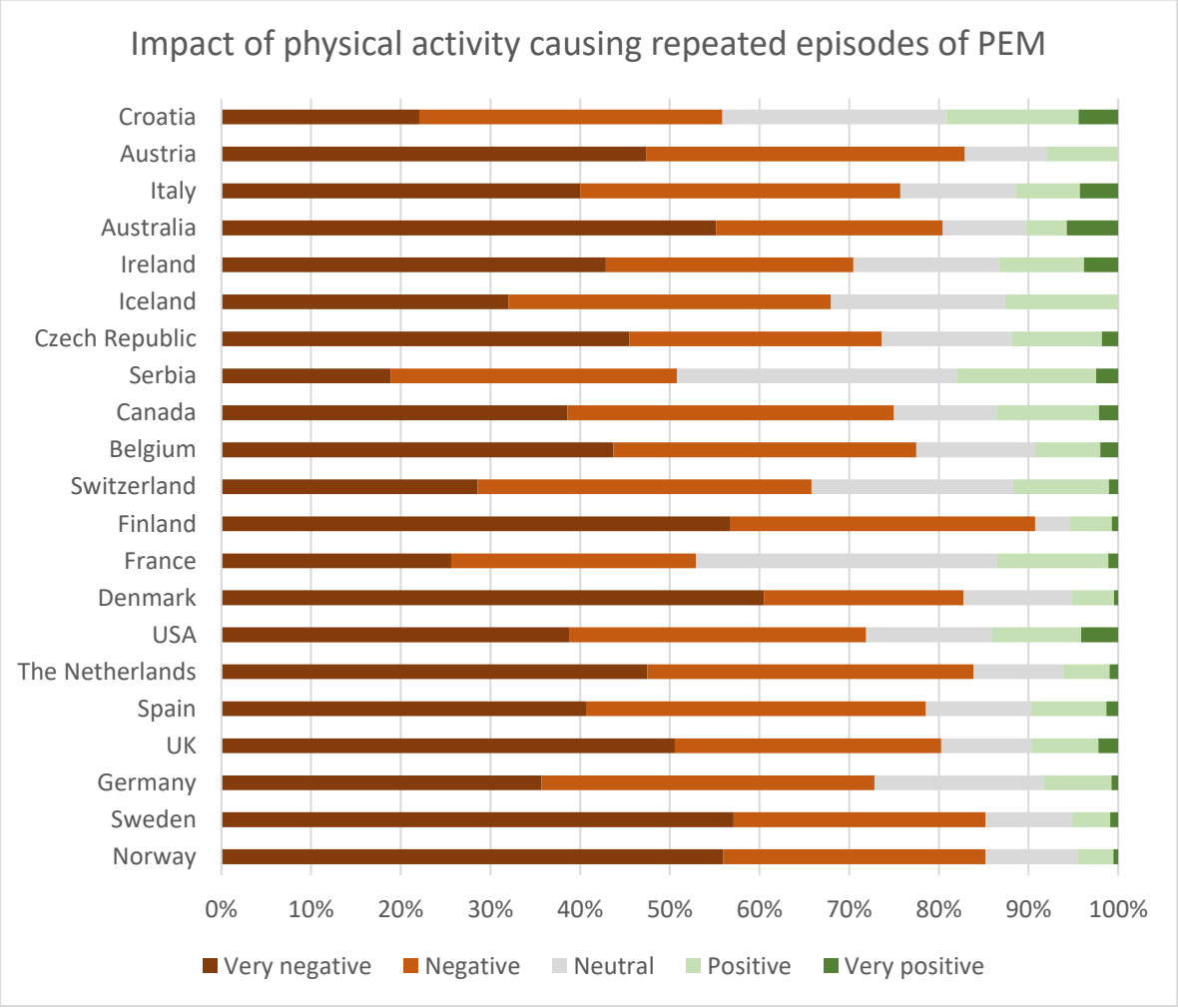


Figure 58: Impact of physical activity causing repeated episodes of PEM (n=10 193).

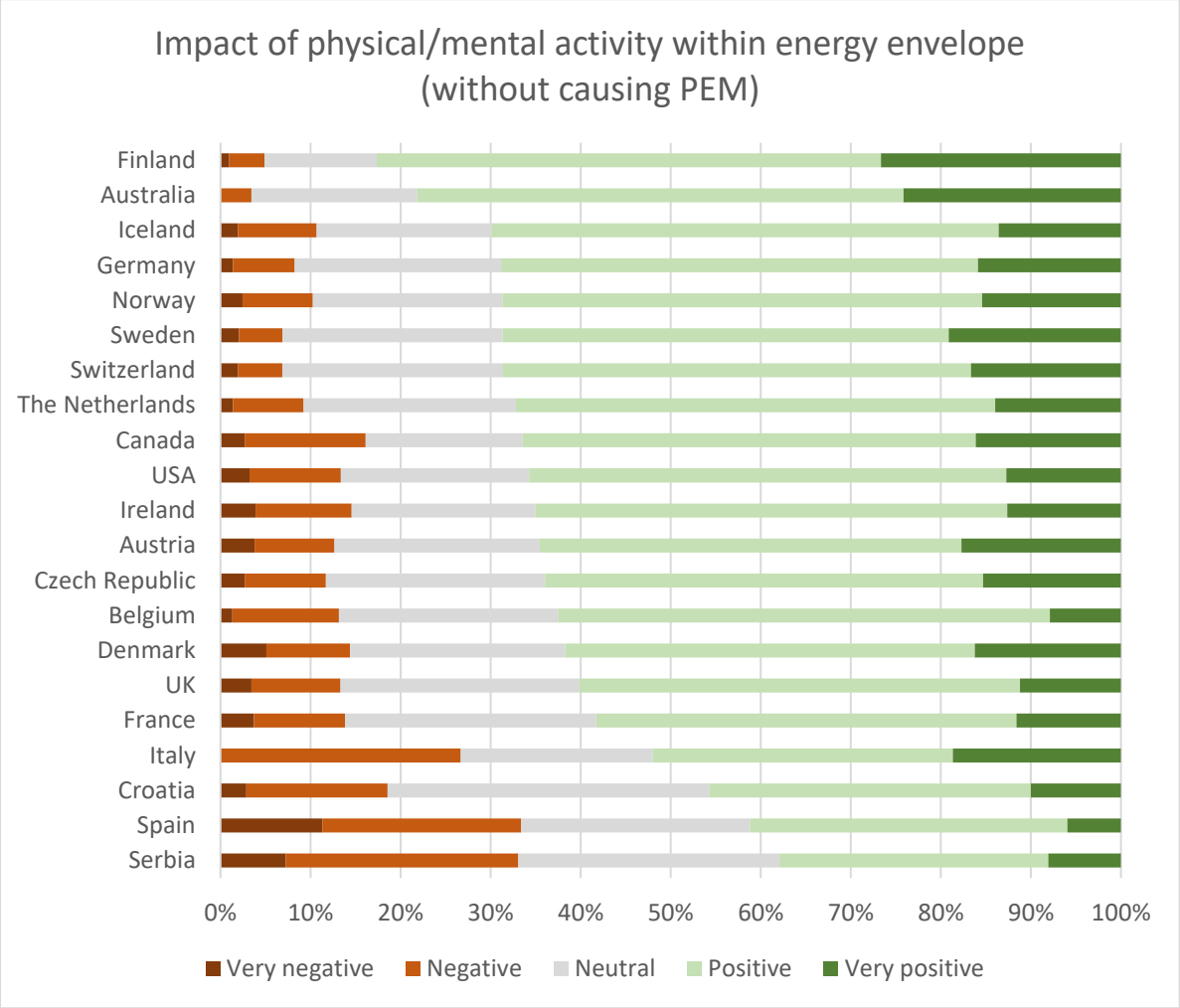


Figure 59: Impact of physical/mental activity within energy envelope (without causing PEM) (n=10 355).

6.5.4 Pacing, and factors that make pacing difficult

The most beneficial approach was seen to be pacing, i.e., finding a balance between activity and rest, staying within the energy envelope and avoiding PEM (Figure 60). 3 out of 4 respondents (75%) considered pacing to have a positive or very positive impact on their course of illness, 17% were neutral while 7% considered it to have a negative or very negative impact (n/a responses excluded). The positive assessment is valuable for all severity levels, although patients with mild or moderate degrees report a relatively larger positive impact.

Several factors can make pacing difficult to do. Many respondents were women at an age where they were likely to have either children or aged parents living at home. Family obligations can make it difficult to set boundaries and care for oneself. Caring for one's family was seen to have a negative impact on the course of illness (Figure 61). Access to welfare benefits and assistance can also affect whether the patient is able to avoid PEM.

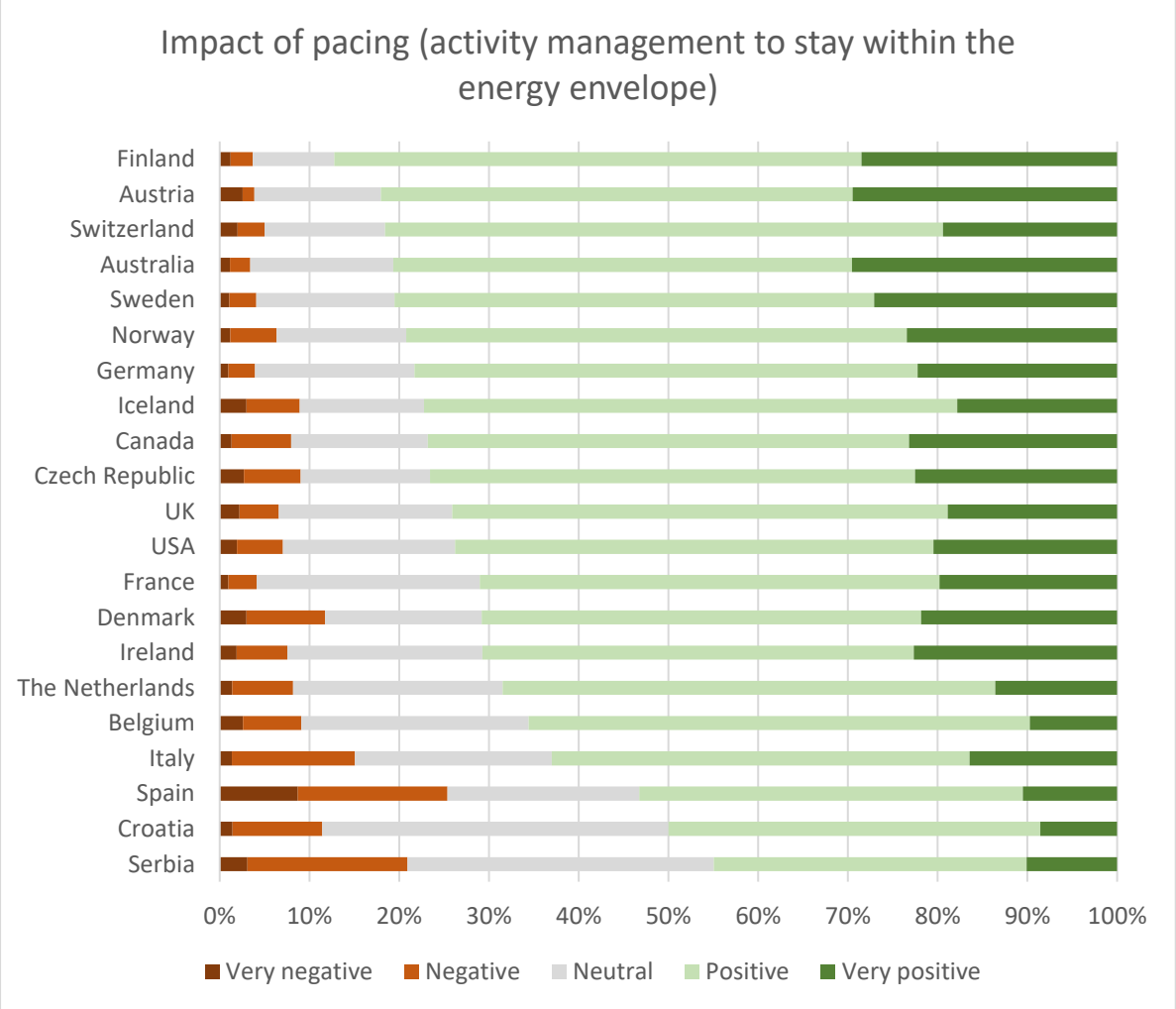


Figure 60: Experiences with pacing (n=10 461).

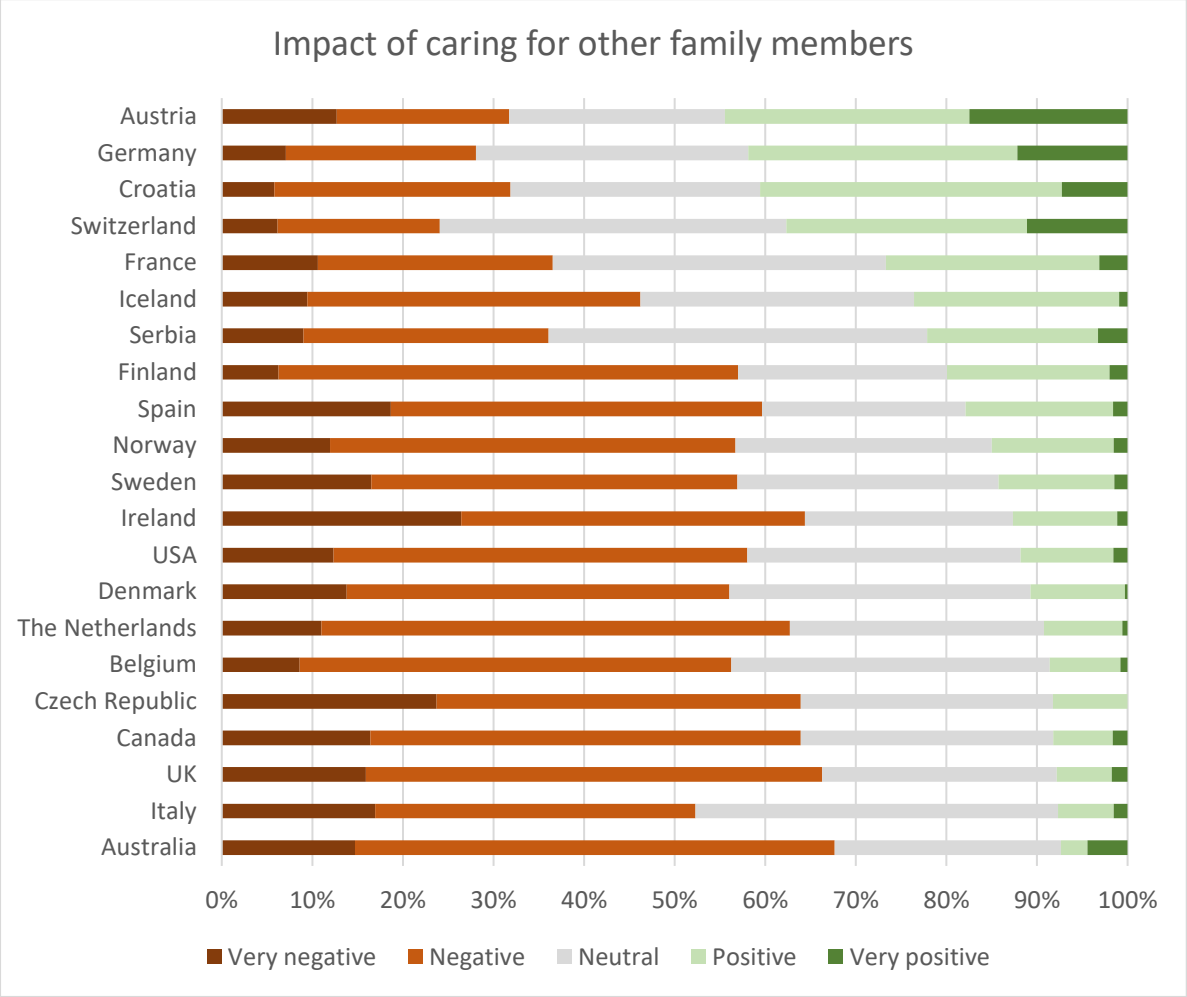


Figure 61: Impact of "caring for your family" on the course of illness (n =8 722).

6.5.5 Symptom treatments, symptom relief

Pain, sleep problems, nausea and stomach problems are common symptoms with ME/CFS. Treating these symptoms do not provide a cure but can potentially give the patient a better quality of life. Helping the patient sleep better, may also lessen fatigue and improve overall health.

14% of respondents answered “not applicable” (N/A) to the question about symptom relief, which indicated that they had not been offered any symptom relief by medical professionals nor tried self-medication (Figure 62).

Symptom relief was seen as largely beneficial.

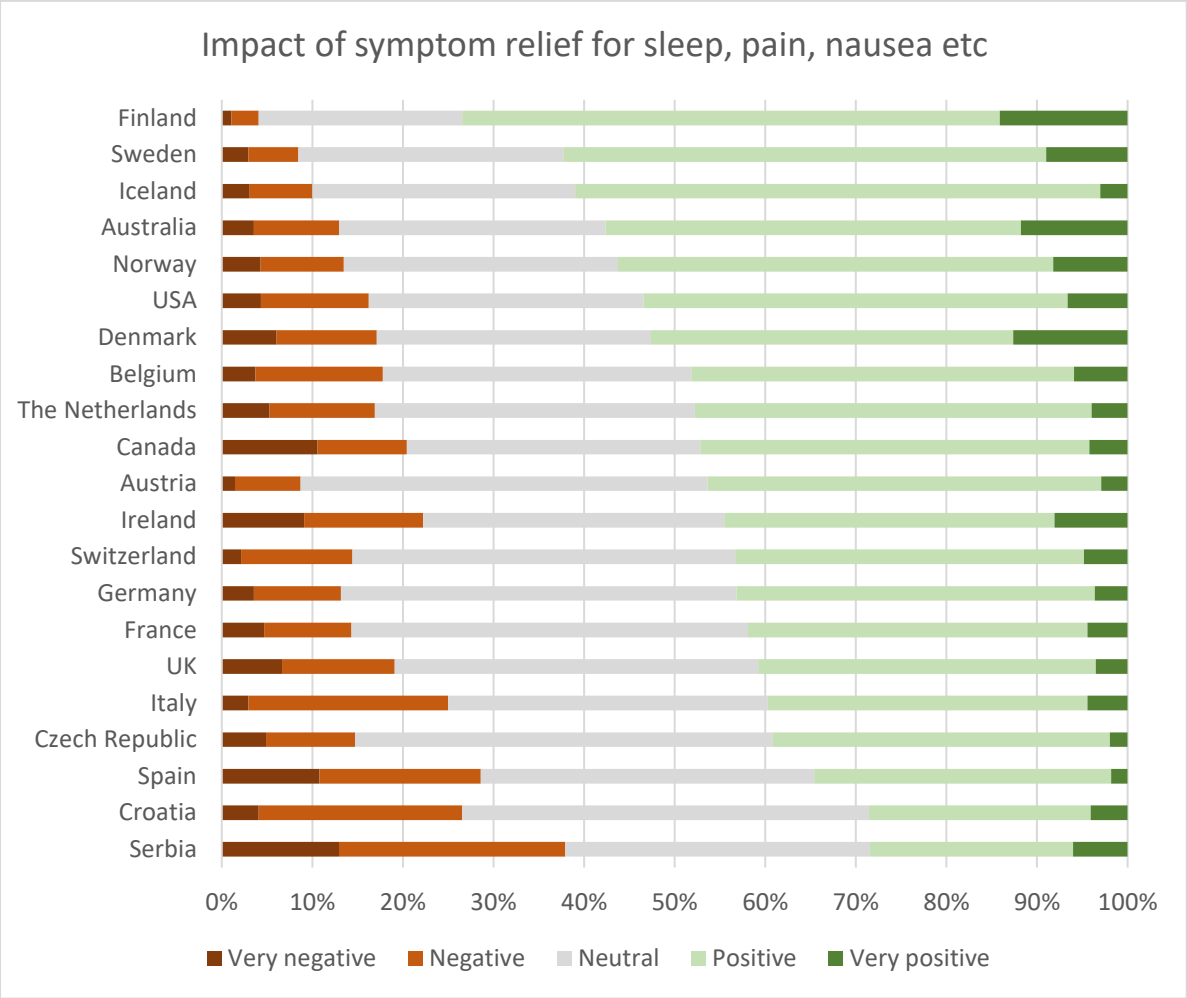


Figure 62: Experiences with treatment of symptoms (pain, sleep, nausea etc.) (n=9 166).

6.5.6 Accepting disease/coping

Accepting the disease can lay the foundation for managing the disease in a way that improves the course of the illness. More than half of the respondents (55%) stated that accepting the disease had had a positive or very positive impact on their own course of illness (Figure 63). One in 10 (11%) stated that it had had a (very) negative impact, while about a third (35%) stated that it had had no impact.

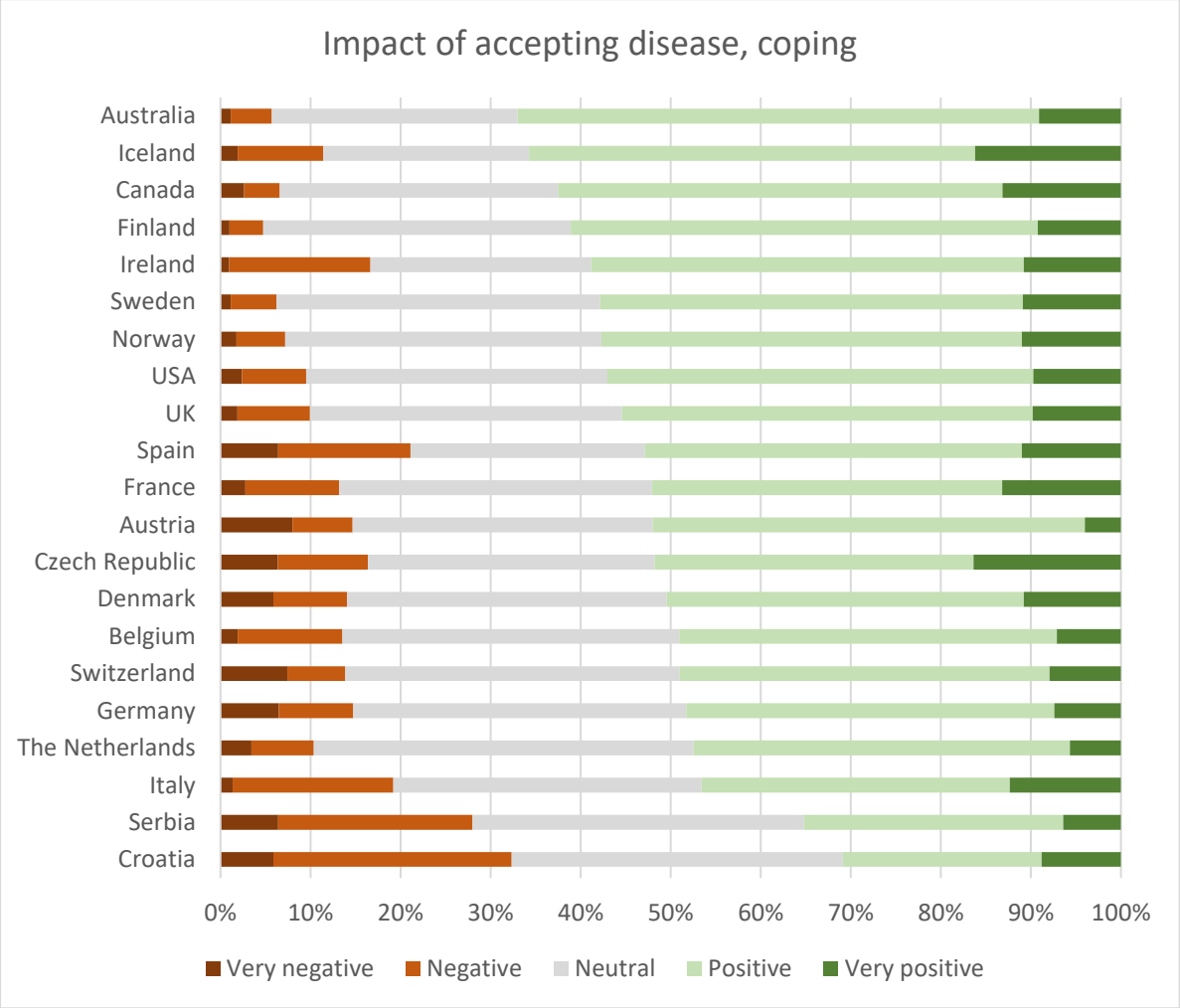


Figure 63: Impact of accepting disease (coping) on the course of illness (n=10 356).

6.5.7 Stress and worries, financial situation

Not unexpectedly, a difficult financial situation, and stress and worries had a negative impact. 62% responded that concerns about their financial situation had a negative impact on their course of illness, while 26% stated that it had no impact (Figure 64).

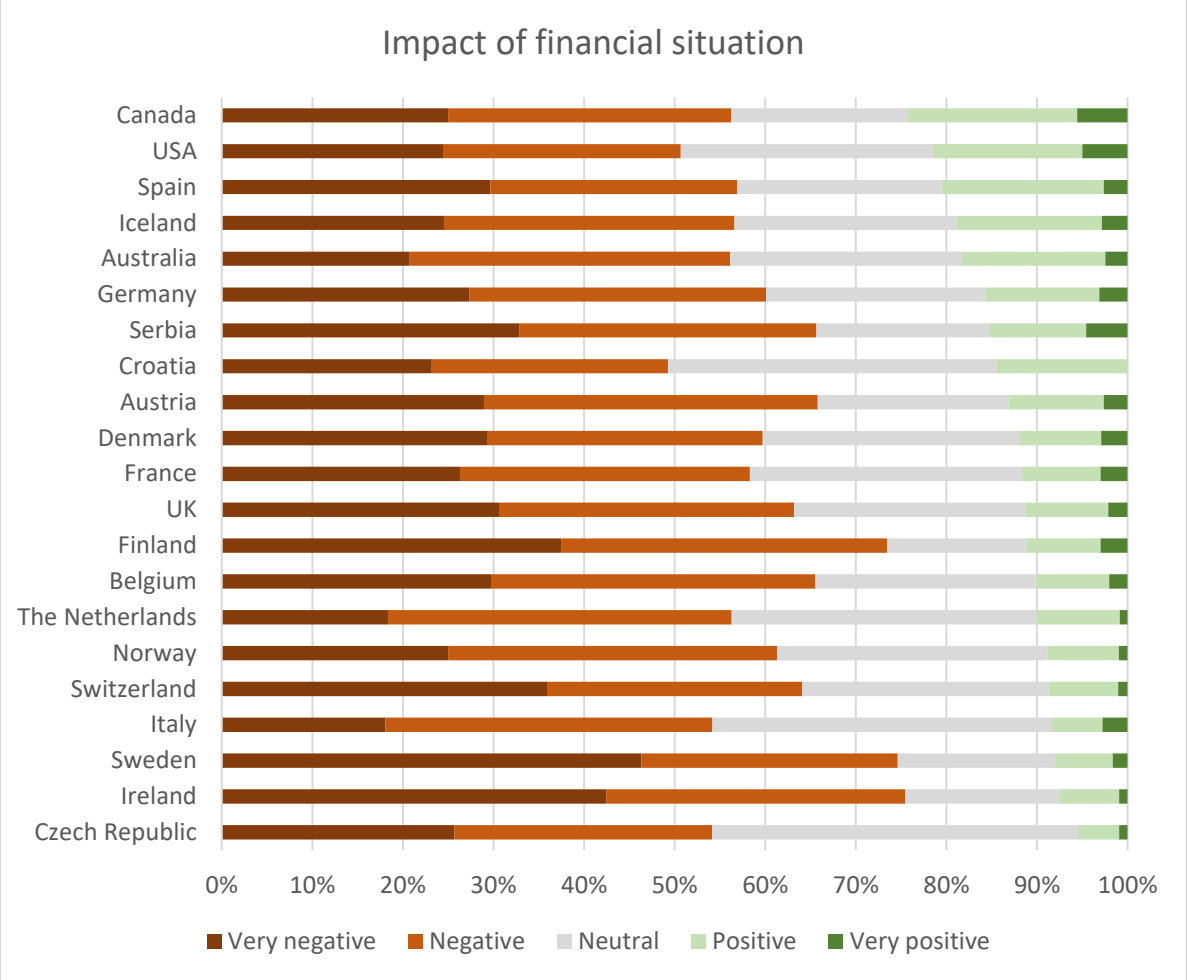


Figure 64: Impact of financial situation on the course of illness (n=10 018).

For the more open question about "stress and worries", a total of 85% stated that it had a negative or very negative impact on their course of illness (Figure 65).

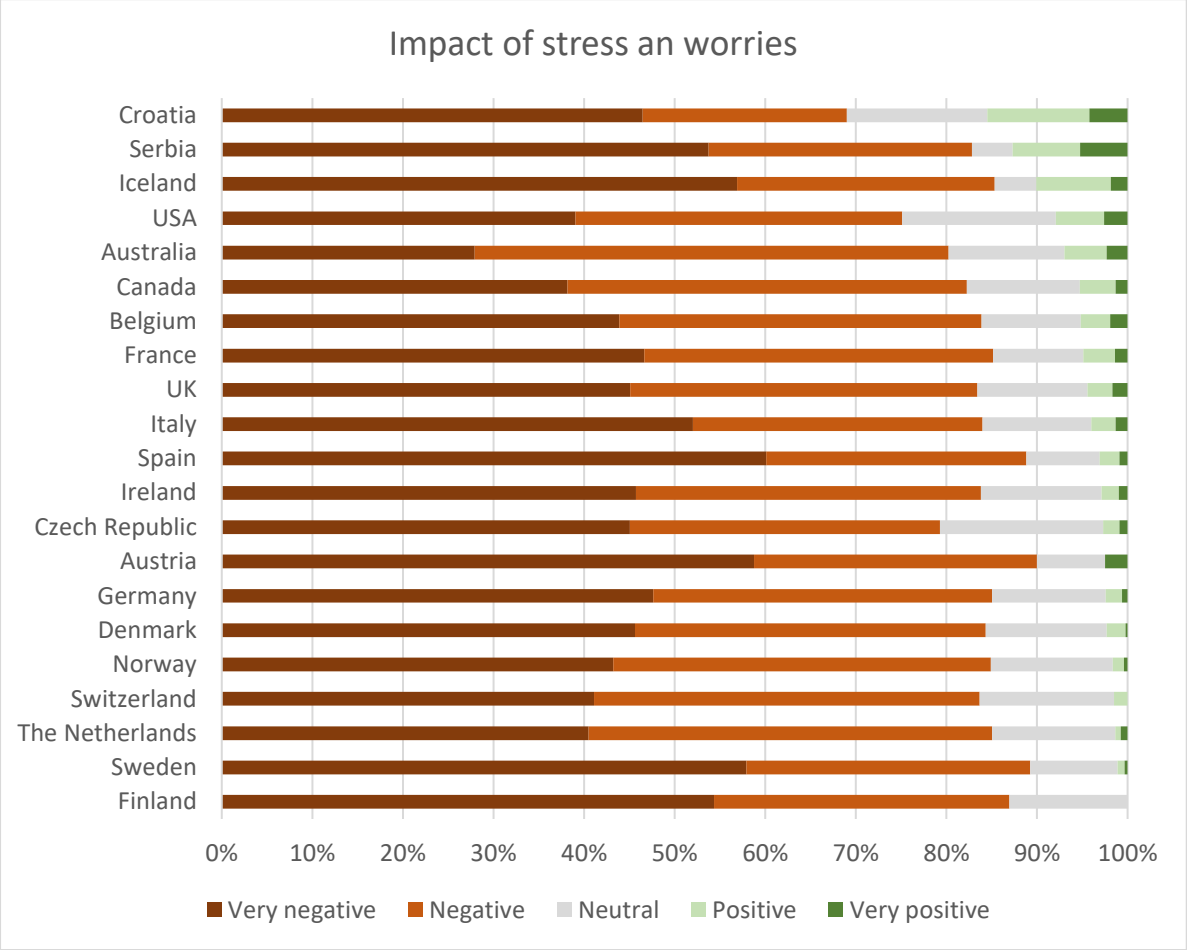


Figure 65: Impact of stress and worries on the course of illness (n=10 131).

7 Discussion and conclusions

7.1 Similar disease patterns, but large variations in health care and support

In this first pan-European survey of ME/CFS patients, one is able to explore similarities and differences across country borders in Europe. Strong similarities were found among countries for several factors such as 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 coping, pacing, and support from family and friends.

Yet, there are large variations in the support from health care and other public services. The share of ME/CFS patients reporting *no support* from the health care system ranges from 15-16% in Iceland and Norway to more than 50% in Croatia, Denmark and Italy.

Another indicator is the diagnostic period – the time from onset to when a diagnosis is given (if at all). The average period varies from 5 years (Ireland and UK) to 9 years in Denmark and 12 years in Croatia.

The support from the health care system has implications for patients. Both on the individual and country level analyses, a strong positive correlation is found between a long diagnostic period and the risk of a course of illness characterised by deterioration. This supports the view that delaying the diagnosis, and the associated risk of incorrect or even harmful advice on, for example, exercise, increases the risk of worsening the disease and the patient ending up with more severe forms of ME.

7.2 An increase in the incidence for ME/CFS?

This survey, like others, has more respondents that have disease onset in recent years, suggesting an increase in incidence. There are, nevertheless, at least five possible explanations for these numbers.

First, ME/CFS patients may recover after a few years and therefore are no longer likely to take an interest in ME/CFS on social media, and have not heard about the survey.

Second, ME/CFS patients may not recover, but may lose some of the initial interest in communicating about the disease and are therefore less likely to respond to patient surveys.

Third, ME/CFS patients may die earlier and therefore are not part of the survey population.

Fourth, a higher number of those suffering from ME/CFS are being diagnosed, and therefore recognise their disease as ME/CFS.

Fifth, there is a real increase in incidence.

The last two explanations are seen as the most probable, in part due it being supported by data from the Norwegian study based on patient registry data (Hilland & Anthun, 2022).

If this is the case, many countries would need to adjust their estimates of the number of ME/CFS patients in their country, and consequently estimates of the societal cost of ME/CFS. Also, undiagnosed patients impose a large hidden cost in increased use of health care services and departure from the work force (Araja et al., 2021).

It is not yet known how the numbers will be affected by the Covid pandemic. Post-acute Sequela of Covid (PASC, Long Covid) is experienced by millions people, and the symptoms are highly overlapping with ME/CFS (Komaroff & Lipkin, 2023). Studies find that as many as 50% or more of Long Covid patients meet the diagnostic criteria for ME/CFS (Jason & Dorri, 2022; Mancini et al., 2021).

7.3 ME/CFS is a severe disease, even when classified as "mild" or "moderate"

More than half of the respondents (53.8%) defined themselves a "mostly housebound" (moderate degree of ME/CFS), 16% as mostly bedbound (severe degree), and 2.4% as bedbound and in need of care (very severe degree), while 24% said they have "mild" degree, which still means a 50% loss of function. (3.7% reported "better than mild.)

There is no international consensus on definitions of severity, and several different scales exist, with different definitions. For example, the ICC criteria define "severe" as "mostly bedridden" while the NICE guidelines from 2021 define "severe" as "housebound" (NICE, 2021). Jason has used yet another scale (Pendergrast et al., 2016). Cox has used another definition where "severe" means "extremely restricted mobility" and "very severe" "totally bedbound"(Cox & Findley, 2000). There are also differences in how "housebound" is defined.

Many papers cite that 25% of ME/CFS patients have "severe" disease, but do not define what they mean by "severe" (e.g., Strassheim, Newton, & Collins, 2021; Straub & Powers, 2021). The original source for this percentage is unclear, and the oldest references are from books and not peer-reviewed articles. The oldest reference is to an article from 1988 (Behan & Behan, 1988). The different definitions and scales make it difficult to compare results across studies. There is a great need for a consensus definition of severity. Without it, comparison across studies is impossible.

No matter how the severity of ME/CFS is defined, the disease reduces function to a large degree in most cases. A 50% loss of function means active hours are halved, together with a large symptom burden, including "brain fog", pain and sleep problems. Almost all ME/CFS patients are excluded from regular employment. A large Norwegian patient survey in 2014 found that only 1% of respondents were in any kind of paid work, and these rarely worked more than 20% (Schei, 2014). In most cases, this meant that the patient did not socialize or participate in leisure activities and used weekends to recuperate.

Housebound patients – the moderately ill according to ICC definitions – need considerable help in daily life. The terminology of "mild" and "moderate" degree are misnomers and cause

communication challenges for patients and carers in explaining the disease and gaining respect for it among family, friends, health care, and public support systems. Moderate ME/CFS is a very severe disease that, for the most part, excludes having paid work, severely limits social activities, and makes patients depend on assistance from family and friends for daily chores and self-care.

7.4 Large fluctuations and deterioration are common

There are many myths surrounding ME/CFS, including that it gradually "burns out" or patients recover over time. Some patients do get better, or even possibly completely recover, but, unfortunately, these instances are very few. In the survey, only 7% experienced gradual improvements in their condition, most of these (6%) after an initial period of large fluctuations. 23% experienced a relatively stable situation, also in this case most (15%) after an initial period of large fluctuations. Regarding these numbers, it must be kept in mind that those who have recovered are probably not respondents in the survey. Even those who have significantly improved to a mild or better severity degree may be underrepresented.

Almost a quarter of the respondents (24%) stated that large fluctuation (with no clear trend) is what best describes their course of illness. Finally, the most typical trend is deterioration, reported by 46% of the respondents, with more than half of these reporting large fluctuations in the beginning, followed by a gradual deterioration of their condition (26%).

While many actors in the health care system describe a course of the illness with initial fluctuations followed by a gradual improvement, this is only characterizing a small minority (7%). Having a realistic picture of the prognosis is critical both for management advice, and for granting welfare benefits and the prospects of resuming regular education or work.

One cannot say from the data what constitutes a "normal" course of illness for ME/CFS under ideal conditions. It is possible that the picture would look less bleak if good health care, early diagnosis and practical assistance were readily available.

7.5 Health care and welfare systems fail ME/CFS patients

Overall, 3 out of 4 respondents stated that they received little or no support from the health care systems, with similar dismal proportions for the country's welfare system and social services. 14% received no help regarding symptom relief. While there is some variation across countries, in every country included in this survey at least 60% state their dissatisfaction with the health services provided. Where there is lack of adequate health and welfare services, patients rely even more on support from family and other ME/CFS patients.

The health care provided varies greatly both across and within countries. The findings of this survey strongly suggest that the inadequate health care provided affects the course of illness negatively. On the more optimistic side, this may have improved in patients with more recent disease onset. An

increased awareness and knowledge about the disease can make a difference in reducing severity and improving prognosis.

7.6 An early and correct diagnosis is essential

Earlier studies (Ghali et al., 2022; Pheby & Saffron, 2009) have identified late diagnosis and mismanagement of the disease before an ME/CFS diagnosis as risk factors for severe disease. These results are supported by this survey and should be a key health policy priority. The risk of experiencing a course of illness characterised by 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).

7.7 Graded exercise therapy and cognitive therapy as a cure do not work, and are often harmful

Responses in this survey show clearly that cognitive (behavioural) therapy (CBT) does not work as a *cure* for ME, even though some patients find that CBT as an aid for *coping* may be useful. Graded exercise therapy (GET) in most cases causes harm.

This survey finds that CBT and GET are 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 advice on CBT and GET from their guidelines for ME/CFS.

The questions in this survey do not take into account the timing aspect of factors that may have had a negative or positive impact on outcomes and disease courses assessed. In addition, this is an observational study and, as such, cannot be used to assess reliably the cause and the effect on relationships. One should, however, pose the question: If people with ME/CFS had received a rapid diagnosis, been given correct advice early on, and had been provided with adequate moral support, practical assistance, and a stable financial situation – would more patients have reported improvement? Would fewer patients have had severe disease?

7.8 Pacing works, but may be hard to accomplish

Pacing was considered the most beneficial management strategy, along with accepting one's disease. Physical and mental activity that did not cause PEM (i.e., activities within the energy envelope) was also seen as beneficial.

Successful pacing may be difficult to achieve, as it depends on adequate practical support, a supportive family or friends, and a stable and secure financial situation. While 50% of patients responding to this survey had supportive families, many did not, and even for those with supportive families, many women had obligations that made pacing difficult. On average, caring for one's family was seen to have a negative impact on the course of illness. This underscores the need for

practical assistance for ME/CFS patients, and the importance of scaling the help not only on the individual patient's level of function, but also on the burden of family care.

Successful pacing also requires that the patient knows what pacing is, has a diagnosis that requires pacing (i.e., ME/CFS), and – critically – has sufficient help and support from the environment to make pacing possible.

The new UK guidelines (NICE, 2021) recommend giving patients advice on pacing as soon as ME/CFS is suspected, in order to avoid deterioration. The data from this survey also indicates that pacing is the most beneficial management approach. As already shown, respondents who have waited for a long time to receive a diagnosis have a more severe and serious course of illness than those who have been diagnosed quickly. Patients who have waited a long time for a diagnosis are unlikely to have been given advice on pacing early on and may have overexerted themselves.

7.9 The harmful effects of the biopsychosocial model

The biopsychosocial (BPS) model for ME/CFS has been extremely influential in many European countries (see Appendix 3 for an elaboration). It hypothesizes that ME/CFS is caused by dysfunctional illness beliefs (or in some cases an ongoing stress response), a pathological focus on symptoms, fear of activity and resulting deconditioning. The cure is teaching the patient not to focus on symptoms and "push through", and follow an exercise program with set increments (White et al., 2007).

The BPS model for ME/CFS can only be tested through interventional studies. These have so far only shown modest results, and have been beset by methodological problems (Wilshire et al., 2018): lack of blinding combined with only subjective outcome measures, changes in research protocols, biased/incorrect interpretations of results, and failure to consider negative outcomes and dropouts. Furthermore, the studies have been conducted in study populations where the hallmark symptom of ME/CFS, which is PEM, has not been a mandatory inclusion criterion.

Most of the respondents in this survey answered that repeated episodes of PEM had a negative impact on their course of illness, yet the treatments associated with the BPS model for ME/CFS tells patients to ignore symptoms, push through, and increase activity. However, the BPS perspective can do harm that goes beyond the recommendations of CBT and GET. The model places the responsibility for both having ME/CFS and for recovery squarely on the patient. This may result in a lack of empathy and sympathy from others, both in healthcare and welfare institutions and within the patient's family. In this setting, providing practical assistance and benefits are seen as enabling the patient, and counterproductive to recovery. If friends and family believe that the patient lacks motivation and willpower to recover, they will be less likely to offer help and support. As a result, many patients are left without practical assistance and welfare benefits, causing stress and worries, and making it very difficult to pace and rest enough.

It is a paradox that the BPS model for ME/CFS causes a psychosocial situation in which the ME/CFS patient loses public and private support and experiences a difficult financial situation. This is not a situation conducive to recovery, as described by the respondents in this survey. In other words, the promotion of the BPS model has in a way confirmed the relevance of social factors, but with the opposite and negative effect of what it intended.

The alarming findings of this survey reveal the harmful effects of the BPS model widely used in many European countries. This reinforces the fact that ME/CFS remains underrecognised, underprioritised, underresearched and inadequately handled and funded, not only in health care and social support systems, but also in society in general, resulting in very real, severe, and negative health outcomes as reported by patients in this survey.

References

AHRQ. (2016). *Diagnosis and Treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome*. https://effectivehealthcare.ahrq.gov/products/chronic-fatigue/research

Araja, D., Berkis, U., Lunga, A., & Murovska, M. (2021). Shadow burden of undiagnosed myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) on society: Retrospective and prospective—In light of COVID-19. *Journal of clinical medicine*, *10*(14), 3017.

Bakken, I. J., Tveito, K., Gunnes, N., Ghaderi, S., Stoltenberg, C., Trogstad, L., Håberg, S. E., & Magnus, P. (2014). Two age peaks in the incidence of chronic fatigue syndrome/myalgic encephalomyelitis: a population-based registry study from Norway 2008-2012. *BMC Medicine*, *12*(1), 167. https://doi.org/10.1186/s12916-014-0167-5

Behan, P., & Behan, W. (1988). Postviral fatigue syndrome. *Critical Reviews in Neurobiology*, *4*(2), 157-178.

Carruthers, B. M., Jain, A. K., De Meirleir, K. L., Peterson, D. L., Klimas, N. G., Lerner, A. M., Bested, A. C., Flor-Henry, P., Joshi, P., Powles, A. C. P., Sherkey, J. A., & van de Sande, M. I. (2003). Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Journal of Chronic Fatigue Syndrome*, *11*(1), 7-115. https://doi.org/10.1300/J092v11n01_02

Carruthers, B. M., van de Sande, M. I., De Meirleir, K. L., Klimas, N. G., Broderick, G., Mitchell, T., Staines, D., Powles, A. C. P., Speight, N., Vallings, R., Bateman, L., Baumgarten-Austrheim, B., Bell, D. S., Carlo-Stella, N., Chia, J., Darragh, A., Jo, D., Lewis, D., Light, A. R., . . . Stevens, S. (2011). Myalgic Encephalomyelitis: International Consensus Criteria. *Journal of Internal Medicine*, *270*(4), 327-338. https://doi.org/10.1111/j.1365-2796.2011.02428.x

Cox, D. L., & Findley, L. J. (2000). Severe and very severe patients with chronic fatigue syndrome: Perceived outcome following an inpatient programme. *Journal of Chronic Fatigue Syndrome*, *7*(3), 33-47.

Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science*, *196*(4286), 129-136.

Eriksson, S., & Heiling, K. (2020). Medan livet får förbi: Att (försöka) leva med ME/CFS [While life goes by: (trying to) live with ME/CFS]. Riksförbundet för ME pasienter.

Falk Hvidberg, M., Brinth, L. S., Olesen, A. V., Petersen, K. D., & Ehlers, L. (2015). The health-related quality of life for patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). *PloS One*, *10*(7), e0132421.

Geraghty, K. J. (2016). 'PACE-Gate': When clinical trial evidence meets open data access. *Journal of Health Psychology*, *22*(9), 1106-1112. https://doi.org/10.1177/1359105316675213

Geraghty, K. J., & Esmail, A. (2016). Chronic fatigue syndrome: is the biopsychosocial model responsible for patient dissatisfaction and harm? *British Journal of General Practice*, *66*(649), 437-438.

Ghali, A., Lacout, C., Fortrat, J.-O., Depres, K., Ghali, M., & Lavigne, C. (2022). Factors Influencing the Prognosis of Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Diagnostics*, *12*(10), 2540.

Gunn, W. J., Connell, D. B., & Randall, B. (2007). Epidemiology of chronic fatigue syndrome: the Centers for Disease Control Study. Ciba Foundation Symposium 173-Chronic Fatigue Syndrome: Chronic Fatigue Syndrome: Ciba Foundation Symposium 173,

Harvey, S. B., & Wessely, S. (2009). Chronic fatigue syndrome: identifying zebras amongst the horses. *BMC Medicine*, *7*, 1-4.

Hilland, G. H., & Anthun, K. S. (2022). Estimert insidens av kronisk utmattelsessyndrom/myalgisk encefalopati i Norge mellom 2016-2018: en registerstudie. *Nordisk tidsskrift for helseforskning*, *18*(2).

Hunt, J. (2022). Holistic or harmful? Examining socio-structural factors in the biopsychosocial model of chronic illness, 'medically unexplained symptoms' and disability. *Disability & Society*, 1-30. https://doi.org/10.1080/09687599.2022.2099250

Hunt, J. (2023, 17. May 2023). Examining the political underbelly of ME/CFS and Long Covid. *Newsletter of the UK ME Association* https://meassociation.org.uk/wp-content/uploads/ME-Association-Joanne-Hunt-Article-09.05.23.pdf

Institute of Medicine. (2015). *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*. The National Academies Press. https://doi.org/doi:10.17226/19012

Jason, L., Muldowney, K., & Torres-Harding, S. (2008). The Energy Envelope Theory and myalgic encephalomyelitis/chronic fatigue syndrome. *Aaohn Journal*, *56*(5), 189-195. https://doi.org/10.3928/08910162-20080501-06

Jason, L. A., & Dorri, J. A. (2022). ME/CFS and Post-Exertional Malaise among Patients with Long COVID. *Neurology International*, *15*(1), 1-11.

Jason, L. A., Katz, B. Z., Sunnquist, M., Torres, C., Cotler, J., & Bhatia, S. (2020a). The Prevalence of Pediatric Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in a Community-Based Sample. *Child & Youth Care Forum*, *49*(4), 563-579. https://doi.org/10.1007/s10566-019-09543-3

Jason, L. A., Katz, B. Z., Sunnquist, M., Torres, C., Cotler, J., & Bhatia, S. (2020b). The prevalence of pediatric myalgic encephalomyelitis/chronic fatigue syndrome in a community-based sample. Child & Youth Care Forum,

Jason, L. A., Richman, J. A., Rademaker, A. W., Jordan, K. M., Plioplys, A. V., Taylor, R. R., McCready, W., Huang, C.-F., & Plioplys, S. J. A. o. i. m. (1999). A community-based study of chronic fatigue syndrome. *Archives of internal medicine*, *159*(18), 2129-2137. https://doi.org/doi:10.1001/archinte.159.18.2129

Jason, L. A., Yoo, S., & Bhatia, S. (2022). Patient perceptions of infectious illnesses preceding Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Chronic illness*, *18*(4), 901-910. https://doi.org/10.1177/17423953211043106

Kielland, A., Liu, J., & Jason, L. A. (2023). Do diagnostic criteria for ME matter to patient experience with services and interventions? Key results from an online RDS survey targeting fatigue patients in Norway. *Journal of Health Psychology*, *0*(0), 13591053231169191. https://doi.org/10.1177/13591053231169191

Komaroff, A. L., & Lipkin, W. I. (2023). ME/CFS and Long COVID share similar symptoms and biological abnormalities: road map to the literature. *Frontiers in Medicine*, *10*, 1187163.

Lacerda, E. M., Geraghty, K., Kingdon, C. C., Palla, L., & Nacul, L. (2019). A logistic regression analysis of risk factors in ME/CFS pathogenesis. *BMC neurology*, *19*(1), 275. https://doi.org/https://doi.org/10.1186/s12883-019-1468-2

Lim, E.-J., Ahn, Y.-C., Jang, E.-S., Lee, S.-W., Lee, S.-H., & Son, C.-G. (2020). Systematic review and meta-analysis of the prevalence of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). *Journal of translational medicine*, *18*(1), 1-15. https://doi.org/https://doi.org/10.1186/s12967-020-02269-0

Magnus, P., Gunnes, N., Tveito, K., Bakken, I. J., Ghaderi, S., Stoltenberg, C., Hornig, M., Lipkin, W. I., Trogstad, L., & Håberg, S. E. (2015). Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) is associated with pandemic influenza infection, but not with an adjuvanted pandemic influenza vaccine. *Vaccine*, *33*(46), 6173-6177. https://doi.org/https://doi.org/10.1016/j.vaccine.2015.10.018

Mancini, D. M., Brunjes, D. L., Lala, A., Trivieri, M. G., Contreras, J. P., & Natelson, B. H. (2021). Use of cardiopulmonary stress testing for patients with unexplained dyspnea post–coronavirus disease. *Heart Failure*, *9*(12), 927-937.

Marks, D. F. (2023). Treatment Harms To Patients With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Qeios*.

NICE. (2021). Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management [NICE guideline NG206]. N. I. f. H. a. C. E. (NICE).

Pendergrast, T., Brown, A., Sunnquist, M., Jantke, R., Newton, J. L., Strand, E. B., & Jason, L. A. (2016). Housebound versus nonhousebound patients with myalgic encephalomyelitis and chronic fatigue syndrome. *Chronic illness*, *12*(4), 292-307.

Pheby, D., & Saffron, L. (2009). Risk factors for severe ME/CFS. *Biology & Medicine*, *1*(4), 50-74. https://repository.guildhe.ac.uk/9823/1/Pheby,%20Derek%20Risk%20factors%20for%20severe%20ME%20&%20CFS.pdf

Salit, I. E. (1997). Precipitating factors for the chronic fatigue syndrome. *Journal of Psychiatric Research*, *31*(1), 59-65. https://doi.org/10.1016/s0022-3956(96)00050-7

Schei, T. (2014). *ME-pasienters møte med Nav*. http://www.me-foreningen.info/wp-content/uploads/2016/09/NAVundersokelse-2014.pdf

Schei, T., & Angelsen, A. (2020). *Sykdomsforløp for ME: Hva er typiske forløp, og hva forverrer er forbedrer forløpet?* http://www.me-foreningen.info/wp-content/uploads/2018/08/NMEFrehabiliteringsUS-1.pdf

Schei, T., & Angelsen, A. (2021). The course of the illness for ME patients in Norway: What are the typical courses of the illness, and what can worsen or improve them? https://www.me-foreningen.no/wp-content/uploads/2021/03/Norwegian-ME-Association-2021-Report-on-the-course-of-illness-English-summary.pdf

Schei, T., Angelsen, A., & Myklebust, E. (2019). *De alvorligste ME-syke: Sykdomsbyrde og hjelpetilbud*. https://www.me-foreningen.no/wp-content/uploads/2019/06/De-alvorligste-ME-syke-rapport-og-vedlegg.pdf

Scoles, B., & Nicodemo, C. (2022). Doctors' attitudes toward specific medical conditions. *Journal of Economic Behavior & Organization*, *204*, 182-199. https://doi.org/https://doi.org/10.1016/j.jebo.2022.09.023

Sharpe, M. (1991). A report–chronic fatigue syndrome: guidelines for research. *Journal of the Royal Society of Medicine*, *84*(2), 118-121.

Sommerfelt, K., Schei, T., & Angelsen, A. (2023). Severe and Very Severe Myalgic Encephalopathy/Chronic Fatigue Syndrome ME/CFS in Norway: Symptom Burden and Access to Care. *Journal of clinical medicine*, *12*(4), 1487.

Strand, E. B., Nacul, L., Mengshoel, A. M., Helland, I. B., Grabowski, P., Krumina, A., Alegre-Martin, J., Efrim-Budisteanu, M., Sekulic, S., & Pheby, D. (2019). Myalgic encephalomyelitis/chronic fatigue Syndrome (ME/CFS): Investigating care practices pointed out to disparities in diagnosis and treatment across European Union. *PloS One*, *14*(12), e0225995.

Strassheim, V., Newton, J. L., & Collins, T. (2021). Experiences of living with severe chronic fatigue syndrome/myalgic encephalomyelitis. Healthcare,

Straub, R. K., & Powers, C. M. (2021). Chronic Fatigue Syndrome: A Case Report Highlighting Diagnosing and Treatment Challenges and the Possibility of Jarisch–Herxheimer Reactions If High Infectious Loads Are Present. Healthcare,

The Medical Staff Of The Royal Free Hospital. (1957). An outbreak of encephalomyelitis in the royal free hospital group, London, in 1955. *British Medical Journal*, *2*(5050), 895.

Thoma, M., Froehlich, L., Hattesohl, D. B., Quante, S., Jason, L. A., & Scheibenbogen, C. (2023). Why the Psychosomatic View on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Is Inconsistent with Current Evidence and Harmful to Patients. *Medicina*, *60*(1), 83.

Valdez, A. R., Hancock, E. E., Adebayo, S., Kiernicki, D. J., Proskauer, D., Attewell, J. R., Bateman, L., DeMaria Jr, A., Lapp, C. W., & Rowe, P. C. (2019). Estimating prevalence, demographics, and costs of ME/CFS using large scale medical claims data and machine learning. *Frontiers in Pediatrics*, *6*, 412.

Vercoulen, J., Swanink, C., Galama, J., Fennis, J., Jongen, P., Hommes, O., Van der Meer, J., & Bleijenberg, G. (1998). The persistence of fatigue in chronic fatigue syndrome and multiple sclerosis: development of a model. *Journal of psychosomatic research*, *45*(6), 507-517.

White, P. D., Goldsmith, K. A., Johnson, A. L., Potts, L., Walwyn, R., DeCesare, J. C., Baber, H. L., Burgess, M., Clark, L. V., Cox, D. L., Bavinton, J., Angus, B. J., Murphy, G., Murphy, M., O'Dowd, H., Wilks, D., McCrone, P., Chalder, T., Sharpe, M., & group, P. t. m. (2011). Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. *Lancet (London, England)*, *377*(9768), 823-836. https://doi.org/10.1016/S0140-6736(11)60096-2

White, P. D., Sharpe, M. C., Chalder, T., DeCesare, J. C., & Walwyn, R. (2007). Protocol for the PACE trial: A randomised controlled trial of adaptive pacing, cognitive behaviour therapy, and graded exercise as supplements to standardised specialist medical care versus standardised specialist medical care alone for patients with the chronic fatigue syndrome/myalgic encephalomyelitis or encephalopathy. *BMC neurology*, *7*(1), 1-20.

Wilshire, C. E., Kindlon, T., Courtney, R., Matthees, A., Tuller, D., Geraghty, K., & Levin, B. (2018). Rethinking the treatment of chronic fatigue syndrome—a reanalysis and evaluation of findings from a recent major trial of graded exercise and CBT. *BMC Psychology*, *6*(1), 6. https://doi.org/10.1186/s40359-018-0218-3

Appendix 1: Supplementary tables

	Diagnosed	Under evaluation	No diag-nosis	Male	Female	Better than mild	Mild	Moderate	Severe	Very severe	Total
Norway	2956	98	76	401	2716	73	814	1807	323	53	3130
Sweden	1209	66	56	161	1169	40	195	738	312	32	1331
Germany	979	87	162	256	962	57	269	581	251	55	1228
UK	928	5	22	146	796	28	224	499	170	21	995
Spain	514	34	58	94	505	16	99	320	139	19	606
The Netherlands	522	14	17	83	466	13	97	309	111	13	553
USA	448	11	27	57	424	18	103	288	71	2	486
Denmark	399	22	60	61	415	11	110	266	69	12	481
France	351	50	66	87	376	27	143	222	55	7	467
Finland	331	55	59	65	376	24	184	179	41	10	445
Switzerland	175	18	27	45	173	19	54	111	27	3	220
Belgium	150	5	11	14	151	10	37	84	26	4	166
Canada	131	7	18	23	133	4	39	86	22	4	156
Serbia	91	14	43	33	114	21	38	63	17	2	148
Czech Republic	63	8	52	21	102	3	38	59	15	3	123
Iceland	69	10	43	9	113	9	39	62	10	0	122
Ireland	103	1	8	18	93	7	38	46	17	0	112
Australia	87	1	4	20	71	3	19	48	18	2	92
Italy	69	6	12	22	64	5	15	39	20	6	87
Austria	67	8	11	22	63	2	20	39	16	6	86

Supplementary Table 1: Key characteristics of respondents in countries with more than 50 respondents.

	Diagnosed	Under evaluation	No diagnosis
Croatia	32 %	5 %	64 %
Czech Republic	51 %	7 %	42 %
Iceland	57 %	8 %	35 %
Serbia	61 %	9 %	29 %
Finland	74 %	12 %	13 %
France	75 %	11 %	14 %
Austria	78 %	9 %	13 %
Italy	79 %	7 %	14 %
Switzerland	80 %	8 %	12 %
Germany	80 %	7 %	13 %
Denmark	83 %	5 %	12 %
Canada	84 %	4 %	12 %
Spain	85 %	6 %	10 %
Belgium	90 %	3 %	7 %
Sweden	91 %	5 %	4 %
Ireland	92 %	1 %	7 %
USA	92 %	2 %	6 %
The Netherlands	94 %	3 %	3 %
Norway	94 %	3 %	2 %
Australia	95 %	1 %	4 %
UK	97 %	1 %	2 %

Supplementary Table 2: Diagnosis status, by country.

	Better than mild	Mild	Moderate	Severe	Very severe
Male	5 %	26 %	50 %	16 %	3 %
Female	3 %	24 %	55 %	16 %	2 %

Supplementary Table 3: Severity, by gender.

	Infect-ious disease	Accident / injury / surgery	Traumatic life event/ Stress	Vaccine/ Medicine/ Procedures	Preg-nancy /birth	No known trigger	Combi-nation of factors	post cancer	other	pesticide/ mold/ poison/ heavy metal	Underlying disease/ condition
Norway	1807	185	289	261	122	623	2	10	6	7	52
Sweden	801	90	162	72	49	211	0	3	4	11	31
Germany	813	85	121	69	25	167	2	14	3	37	20
UK	620	56	116	58	27	156	4	3	2	6	16
Spain	205	57	119	18	33	169	0	3	9	8	18
The Nether-lands	329	57	53	24	22	83	1	0	3	8	20
USA	290	43	58	20	11	85	6	3	2	11	12
Denmark	273	45	48	78	13	63	0	5	0	9	8
France	220	36	64	40	20	102	2	2	4	1	12
Finland	247	26	64	61	7	55	0	1	0	28	9
Switzer-land	135	23	23	18	6	29	0	3	0	1	4
Belgium	112	16	23	8	2	24	1	0	0	3	2
Canada	87	10	21	9	6	26	2	1	0	8	5
Serbia	34	4	61	1	7	38	0	0	0	2	2
Czech Republic	81	6	20	2	4	17	0	1	0	0	1
Iceland	39	11	35	6	7	31	0	2	0	3	3
Ireland	69	9	13	4	5	16	1	2	0	1	1
Australia	58	8	8	7	2	15	1	0	2	1	4
Italy	49	4	6	9	0	17	0	1	0	2	0
Austria	46	4	7	7	3	17	0	2	0	0	5
Croatia	32	8	19	5	4	19	0	0	0	0	2

Supplementary Table 4: Events associated with disease onset, by country.

	Mean age diagnosis	Mean age onset	Mean diagnostic period
Norway	36.3	30.5	5.9
Sweden	43.6	35.4	8.6
Germany	40.6	33.9	7.1
UK	36.1	31.1	5.2
Spain	42.7	34.5	8.5
The Netherlands	36.0	27.8	8.2
USA	44.2	37.3	6.8
Denmark	40.7	32.4	9.3
France	42.0	35.2	6.7
Finland	40.4	34.6	6.2
Switzerland	37.8	31.4	7.1
Belgium	36.8	29.9	6.8
Canada	44.1	37.5	6.6
Serbia	39.0	33.5	7.0
Czech Republic	40.0	34.5	6.5
Iceland	42.2	35.3	8.4
Ireland	35.5	30.5	5.2
Australia	36.2	30.7	5.9
Italy	33.8	26.7	6.1
Austria	41.1	32.6	8.2

Supplementary Table 5: Diagnostic period, age at diagnosis, age at onset, by country.

	Mainly improve-ment	Fluctuating initially, then mostly improvement	Fluctuating initially, then mostly stable	Mostly stable, small fluctuations	Mainly deterioration	Fluctuating initially, then mostly deterioration	Major fluctuations throughout
Norway	1 %	6 %	24 %	9 %	12 %	20 %	27 %
Finland	1 %	9 %	16 %	10 %	19 %	26 %	19 %
Italy	2 %	8 %	9 %	16 %	13 %	39 %	13 %
The Netherlands	1 %	3 %	15 %	13 %	24 %	28 %	16 %
Serbia	1 %	13 %	10 %	6 %	22 %	28 %	20 %
Denmark	2 %	7 %	17 %	5 %	23 %	28 %	19 %
Ireland	1 %	3 %	17 %	9 %	10 %	19 %	41 %
France	3 %	10 %	11 %	5 %	21 %	27 %	23 %
Belgium	2 %	3 %	15 %	9 %	26 %	26 %	19 %
Sweden	2 %	6 %	13 %	6 %	29 %	31 %	12 %
UK	1 %	4 %	14 %	9 %	20 %	25 %	27 %
USA	1 %	4 %	15 %	6 %	17 %	30 %	26 %
Australia	1 %	3 %	16 %	6 %	14 %	27 %	33 %
Czech Republic	1 %	3 %	10 %	12 %	28 %	24 %	23 %
Switzerland	2 %	6 %	11 %	6 %	17 %	21 %	36 %
Canada	2 %	5 %	10 %	8 %	21 %	23 %	32 %
Croatia	0 %	6 %	6 %	11 %	25 %	33 %	19 %
Iceland	0 %	3 %	5 %	14 %	13 %	38 %	26 %
Austria	4 %	4 %	6 %	8 %	27 %	25 %	27 %
Germany	2 %	4 %	6 %	6 %	27 %	26 %	29 %
Spain	1 %	3 %	7 %	5 %	27 %	39 %	19 %

Supplementary Table 6: Course of illness, by country

Stress and worries	-1.28
Physical or mental activity causing repeated episodes of PEM	-1.19
Cognitive Behavioural Therapy as a cure for ME	-0.99
My financial situation	-0.78
Caring for your family	-0.44
Cognitive (Behavioural) Therapy / psychological coping method	0.08
Alternative therapies	0.17
Symptomatic treatment of e.g. pain, sleep disturbances or nausea	0.38
Accepting your illness (coping)	0.51
Physical or mental activity within energy envelope (avoiding PEM)	0.65
Pacing (activity management to stay within the energy envelope)	0.87

Supplementary Table 7: Mean impact of various factors on course of illness (-2 = very negative, … 2 = very positive).

Social services (child care services/social worker)	-1.39
School/educational institution	-0.91
The health system in general	-0.86
Workplace	-0.72
Social security (disability benefits etc.)	-0.71
Friends	-0.12
Patient organisations /charities	0.05
Other ME patients	0.44
Family	0.57

Supplementary Table 8: Support from different actors (-2 = very negative, … 2 = very positive)

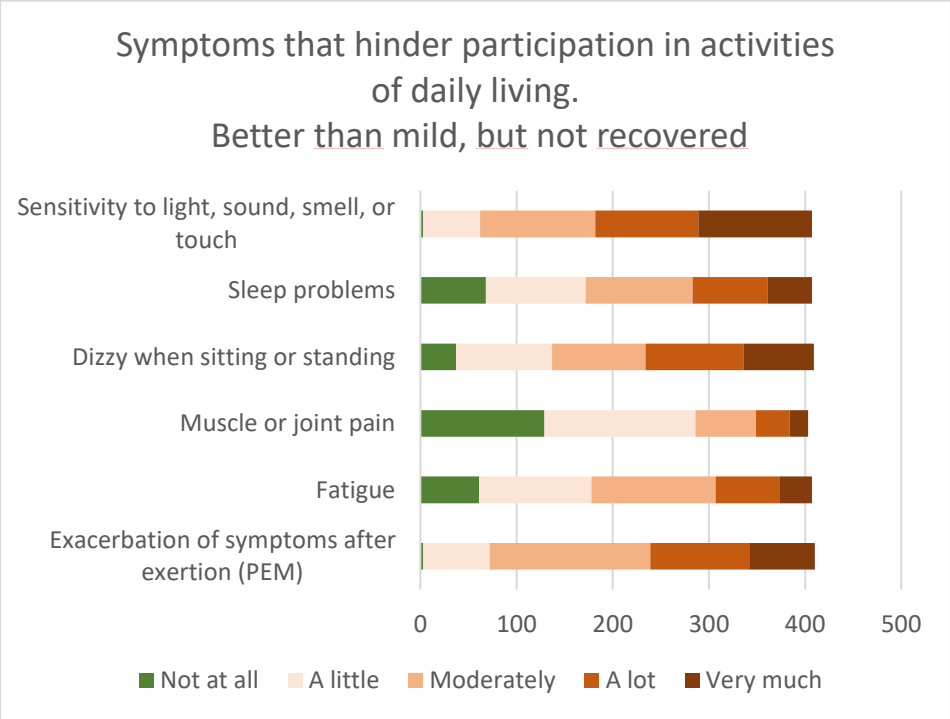
	Mainly deterioration	Fluctuating initially, then mostly deterioration	Major fluctuations throughout	Mostly stable, small fluctuations	Fluctuating initially, then stable	Fluctuating initially, then improvement	Mainly improvement
Accident/ injury/ surgery	18	23	20	3	11	3	2
Infection + traumatic life event	18	23	20	3	11	3	2
Infection + accident/surgery	30	53	36	13	30	12	2
Pregnancy/ birth	53	91	81	17	34	13	2
Vaccine/ Medicine/ Procedures	118	141	124	43	108	39	11
Traumatic life event/ Stress	207	257	266	99	116	68	17
Infectious disease	1094	1529	1456	434	980	330	81

Supplementary Table 9: Triggers and course of illness (n =8 145)

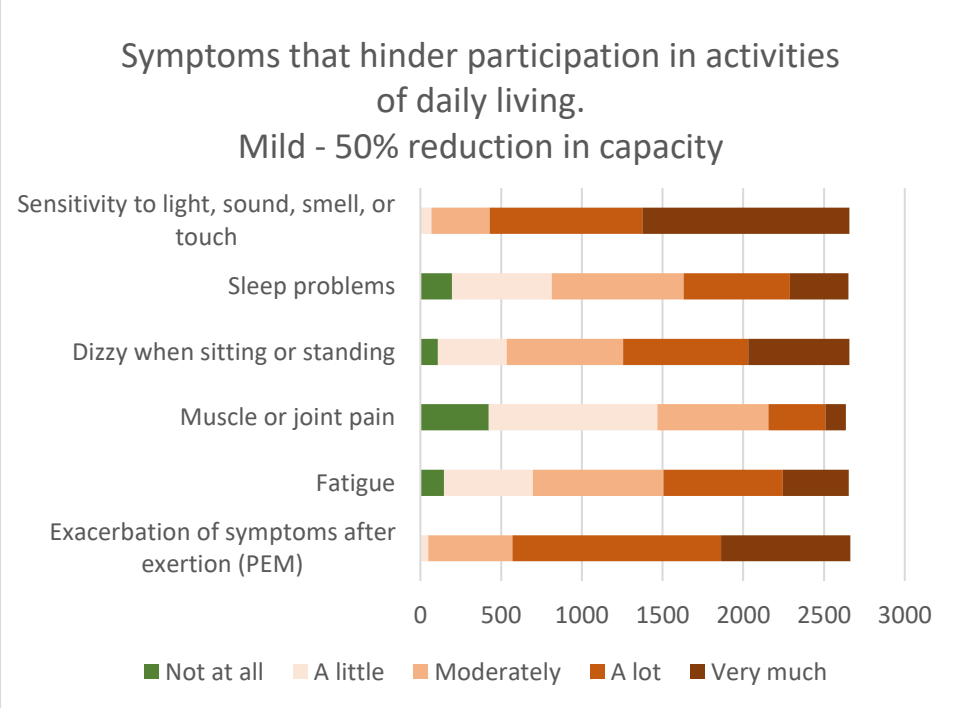
	Health system	Social security	Social services	Workplace	School	Family	Friends	Other ME patients	Patient organisations
Health system	1.0000								
Social security	0.3480	1.0000							
Social services	0.3375	0.4341	1.0000						
Workplace	0.3383	0.3697	0.3534	1.0000					
School	0.3630	0.3703	0.4098	0.5618	1.0000				
Family	0.2358	0.1539	0.0943	0.2294	0.2243	1.0000			
Friends	0.2696	0.1994	0.1785	0.3320	0.2755	0.4748	1.0000		
Other ME patients	0.1025	0.0961	0.1676	0.2144	0.2198	0.1607	0.3001	1.0000	
Patient organisations	0.1699	0.1483	0.1953	0.1961	0.2581	0.1829	0.2449	0.5801	1.0000

Supplementary Table 10: Correlation matrix for support from different actors or groups (individual level).

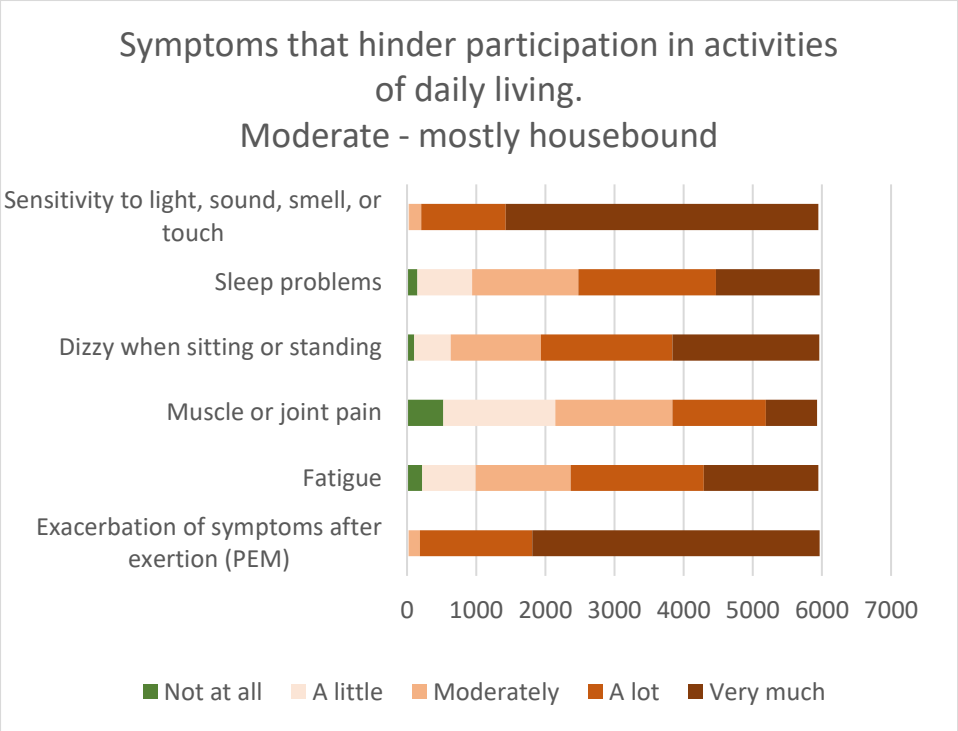
Appendix 2: Supplementary figures



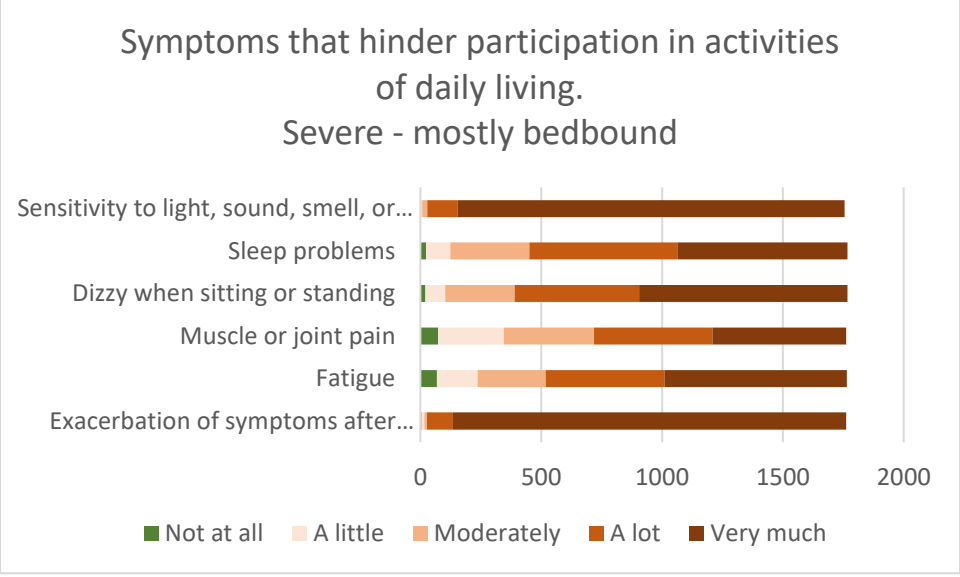
Supplementary Figure 1: Symptoms that hinder participation in activities of daily living. Better than mild, but not recovered.



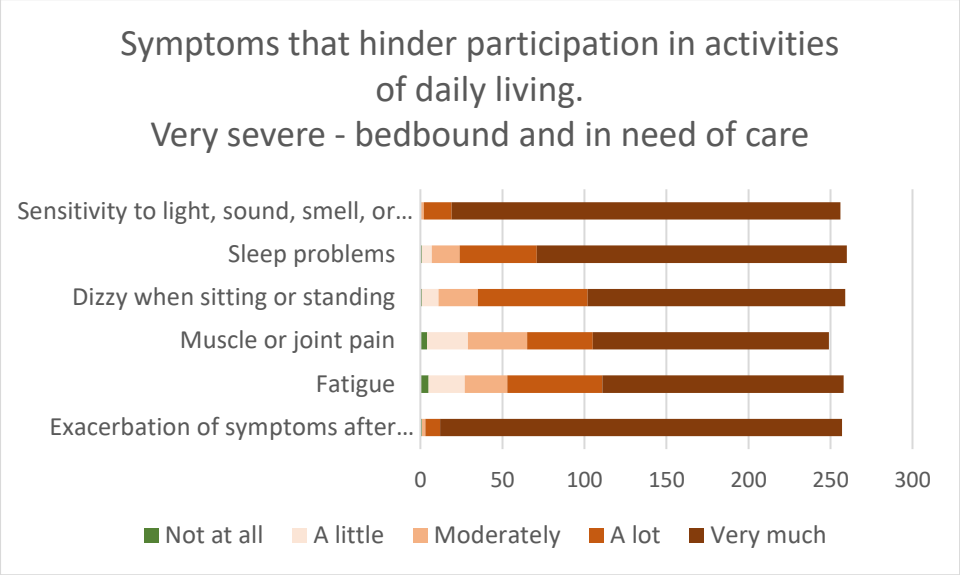
Supplementary Figure 2: Symptoms that hinder participation in activities of daily living. Mild - 50% reduction in capacity.



Supplementary Figure 3: Symptoms that hinder participation in activities of daily living. Moderate - mostly housebound.



Supplementary Figure 4: Symptoms that hinder participation in activities of daily living



Supplementary Figure 5: Symptoms that hinder participation in activities of daily living.

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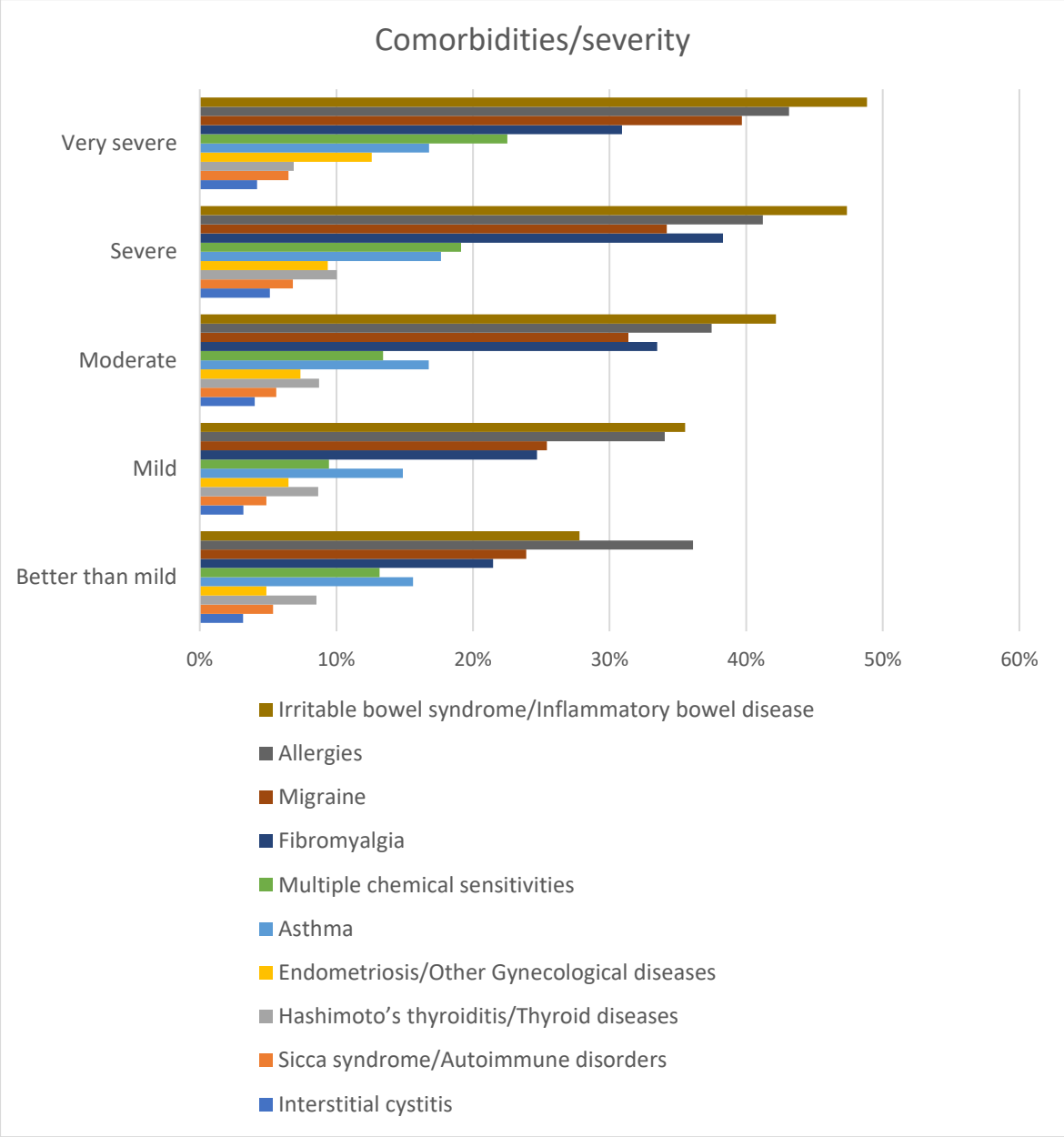


Supplementary Figure 6: Comorbidities by degree of severity.

Appendix 3: The biopsychosocial model for ME/CFS

To understand the controversy surrounding the biopsychosocial model in regards to ME (ME/CFS), it is necessary to understand a little of the history of ME. ME was first described in 1957 and was given the name Myalgic Encephalomyelitis based on the symptoms, which were reconcilable with inflammation in the brain and spinal cord (The Medical Staff Of The Royal Free Hospital, 1957). In 1969 ME was incorporated in the World Health Organisation's coding system as a neurological disease. Early case definitions list fatigue in addition to several other symptoms, as abnormal restitution, cognitive problems, sleep disturbance and pain. Notably, symptom exacerbation after activity that was previously tolerated must be present.

The biopsychosocial model was first conceptualised by Engel (1977). The model was a recognition that illness or disease were not exclusively physical phenomena, but that the patient's condition also was affected by social and psychological factors.

However, in the ME/CFS discourse the term "biopsychosocial" is used in a particular way. As Joanne Hunt writes: "Simply put, the biopsychosocial model has been applied as a part of a neoliberal project to re-frame chronic health conditions (particularly those surrounded by medical controversy or uncertainty) as primarily psychosocial entities, purportedly perpetuated by psychological and social factors and thus allegedly amenable to psychosocial health care interventions, to 'recovery' and thus a return to work" (Hunt, 2023).[16]

In 1998, Vercoulen et al. (1998) proposed the biopsychosocial model for "chronic (subjective) fatigue". Later, Harvey and Wessely (2009) developed Vercoulen's model to encompass all fatigue in all patients, including ME/CFS. These models were used to justify cognitive therapy and graded exercise therapy as cures for ME. In parallel, the definition of ME has expanded and now renamed "Chronic Fatigue Syndrome" by the so-called Oxford criteria, published already in 1991 (Sharpe, 1991). Six months of persistent and unexplained fatigue is needed for a CFS diagnosis, according to these criteria.

The model is based on a hypothesis that while the illness may be triggered by viral disease, it is maintained through psychological and social mechanisms (Geraghty & Esmail, 2016). Patients have dysfunctional illness beliefs (i.e., that they have a physical disease), focus too much on symptoms, become afraid of activity, and get deconditioned. The model places the responsibility both for getting ill and staying ill on the patient.

Patients have protested against this model since its inception. They do not recognise themselves in the model, and claim that the proposed treatments cause harm. This is supported by patient surveys

[16] For a more thorough discussion on the role of the BPS model in health and welfare policy discourses, see also Hunt (2022).

in several countries. Patients also find the model stigmatising, and find that it affects access to health care, practical assistance, and benefits. Thoma et al. (2023) argue convincingly that the model is both "inconsistent with current evidence and harmful to patients".

Studies on these therapies have seemed to indicate a very modest effect, but have been beset with methodological problems, see the critique by, among others, Geraghty (2016) and Wilshire et al. (2018) of the PACE trial (White et al., 2011). Even so, health authorities in many countries have embraced this model, and ME/CFS patients are routinely offered CBT and GET. In some countries, receiving welfare benefits may be conditional on having tried these therapies, e.g., in Norway ME sufferers routinely get applications for benefits turned down if they have not tried CBT.

The BPS theories for ME are increasingly being challenged as not only flawed, but also as harmful to patients. In 2015 the American Institutes of Medicine (IOM) published a complete literature review that concluded that ME is a "serious, chronic, complex, and systemic disease that frequently and dramatically limits the activities of affected patients." The IOM report also states that symptom exacerbation after activity/post exertional malaise (PEM) is the hallmark of the disease (Institute of Medicine, 2015).

In 2016, the Agency for Healthcare Research and Quality in the US did not find evidence of effectiveness of CBT or GET in patients with PEM (AHRQ, 2016). When NICE, the organisation that develops guidelines for the British health care system, revised its guidelines in 2021, they concluded that the quality of the evidence for the effectiveness of CBT and GET was "low" or "very low" (NICE, 2021). NICE has now discarded the (bio)psychosocial model for ME. The new 2021 NICE guidelines warn against graded exercise, and state that CBT only should be offered as a support/coping tool. In the US, the Center for Disease Control and Prevention (CDC) has also removed CBT and GET from its recommendations.[17]

Yet health care systems in many countries still support a psychosocial model for ME/CFS. Danish health authorities, for instance, consider ME/CFS not as a biological disease, but as a "functional disorder". In other countries there are debates about the nature of ME/CFS, and disagreements on both whether it is a "real" disease and the effectiveness of treatments. We see, however, a steady increase in the published evidence that ME/CFS is indeed a biologically-rooted disease, and that this research is slowing changing the perceptions of health authorities and public opinion.

[17] https://www.cdc.gov/me-cfs/treatment/index.html

Appendix 4: Country summaries

This appendix presents comparable figures for the 18 European countries with more than 80 respondents, as well as three non-European countries. Note that we have included the "Age at onset and severity" section only for countries with more than 200 respondents.

1 European countries

1.1 Austria

1.1.1 Respondents

There were 83 respondents from Austria.

78% of respondents had received a diagnosis, 9% were currently under evaluation for a diagnosis, and 13% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.1.2 Age

Average age of respondents was 45.8 years.

1.1.3 Gender

74% of respondents were female, 26% male.

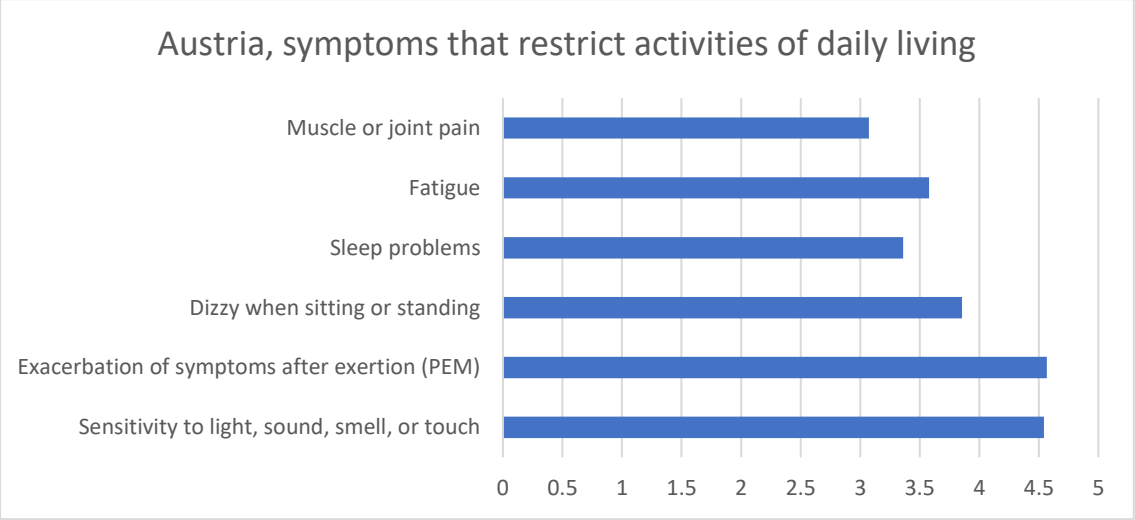
1.1.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

2% of respondents said that their disease was better than mild, 24% had mild, 47% moderate, 19% severe and 7% very severe ME/CFS.

1.1.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found PEM and sensitivity to light and sound, and symptom exacerbation after activity to be the most restrictive symptoms. Pain was rated the least bothersome symptom. Individual profiles had much variation.

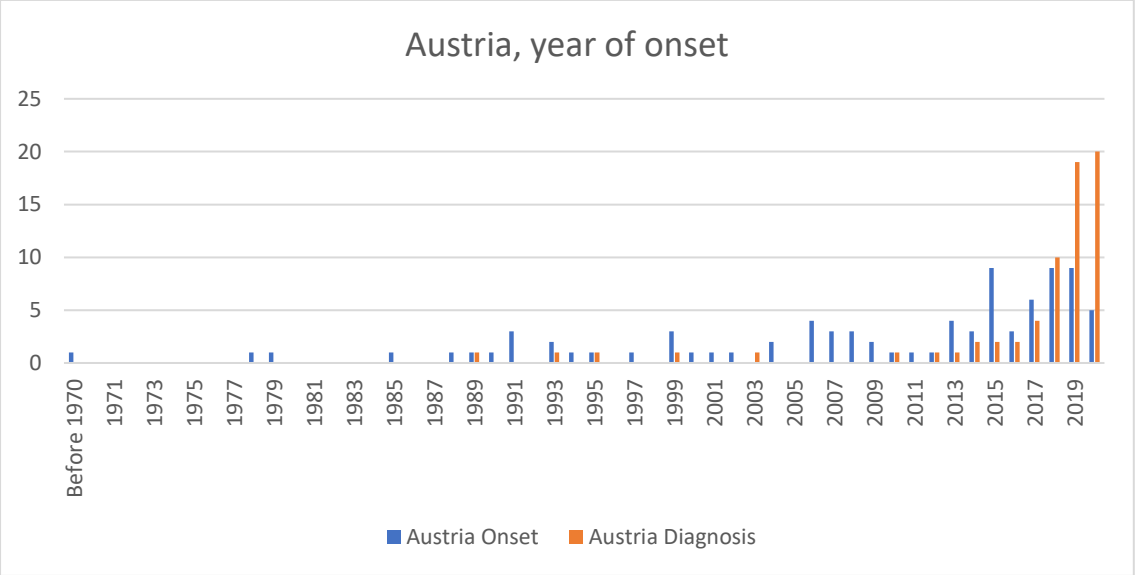


Country Figure 1: Austria, symptoms that restrict activities of daily living, n=83

1.1.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

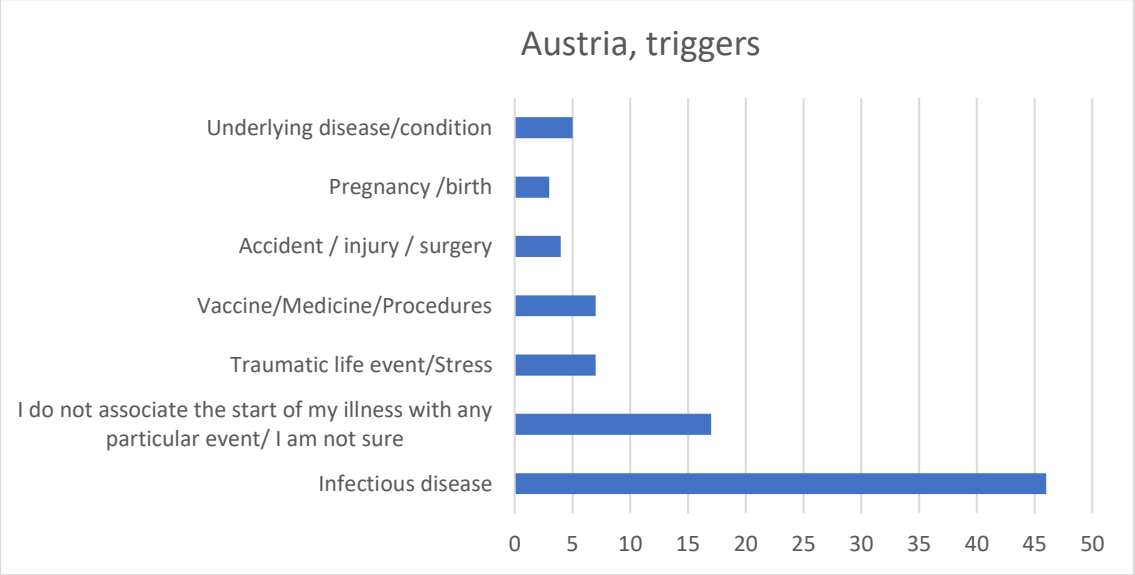
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 2: Austria, year of onset, n=83

1.1.7 Triggers

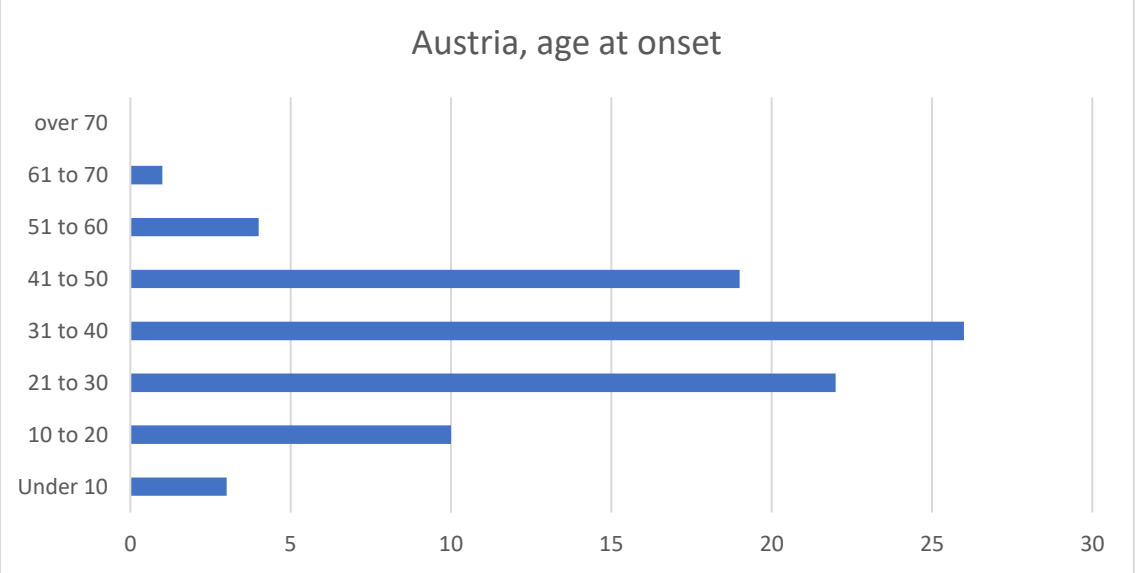
The most common trigger was infectious disease.



Country Figure 3: Austria, triggers, n=83

1.1.8 Age at onset

Average age of onset was 32.6 years. The graph below shows the distribution of age at onset.

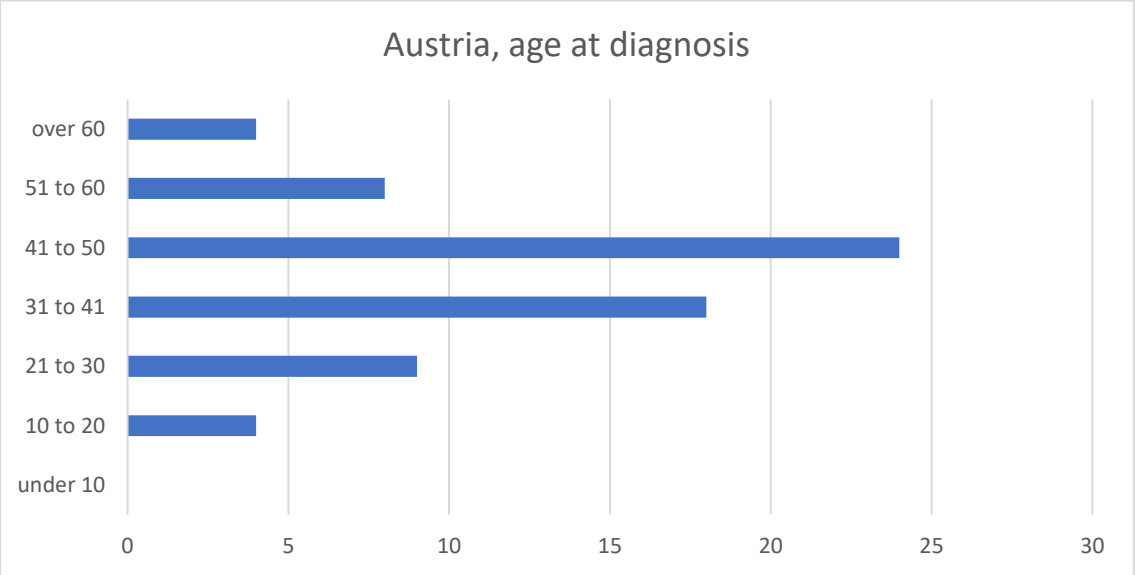


Country Figure 4: Austria, age at onset, n=83

1.1.9 Time from onset to diagnosis

Average time from onset to diagnosis was 8.2 years overall, 7.4 years for men and 8.5 years for women.

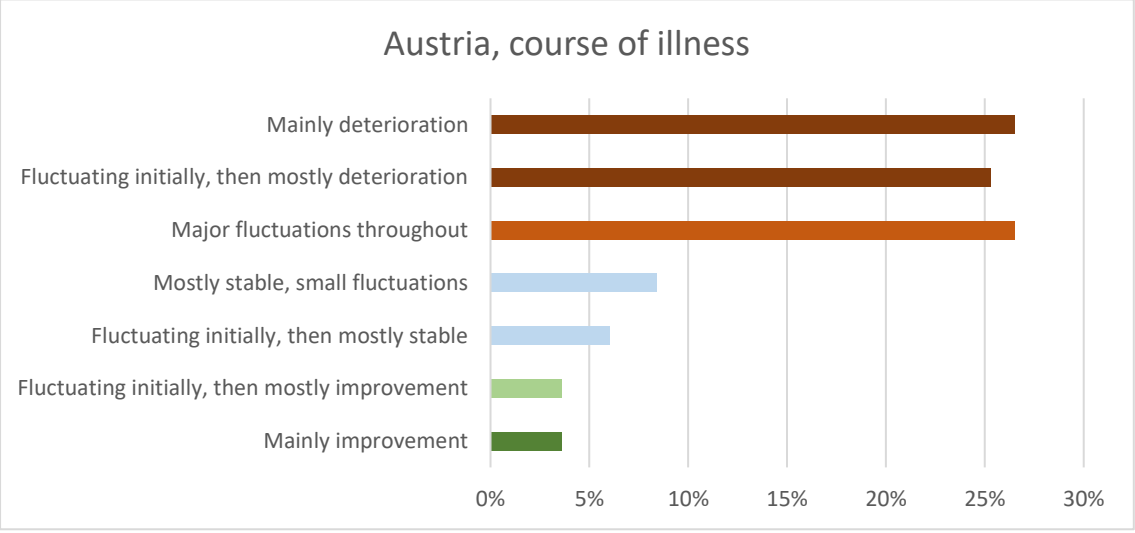
Average age at diagnosis was 32.6 years.



Country Figure 5: Austria, age at diagnosis, n=63

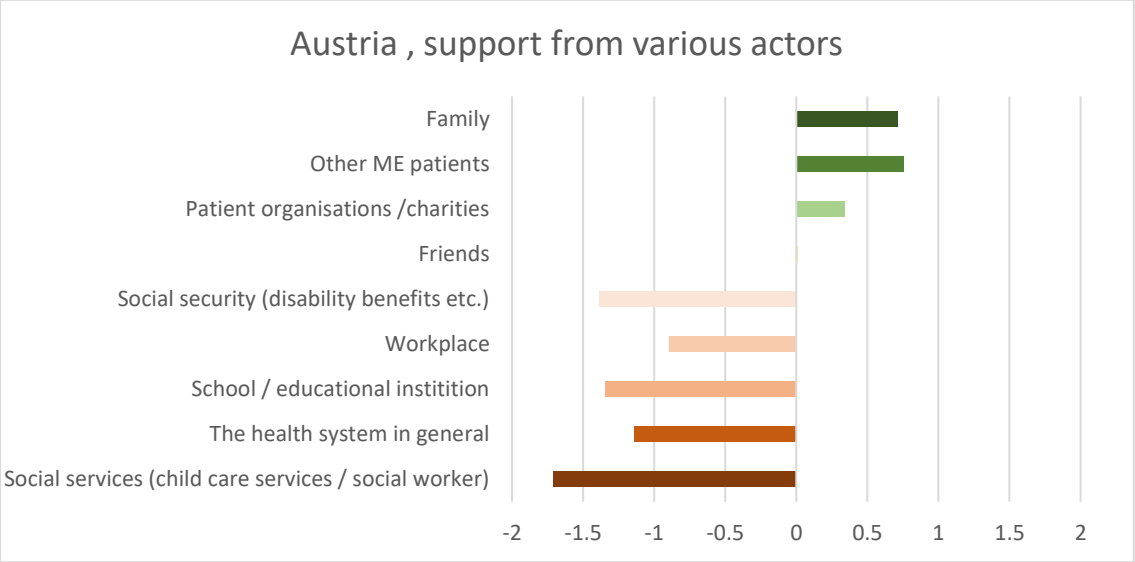
1.1.10 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Austria, 78% of respondents had experienced deterioration or major fluctuations, 14% said they were mostly stable, and 8% had experienced mainly improvement.



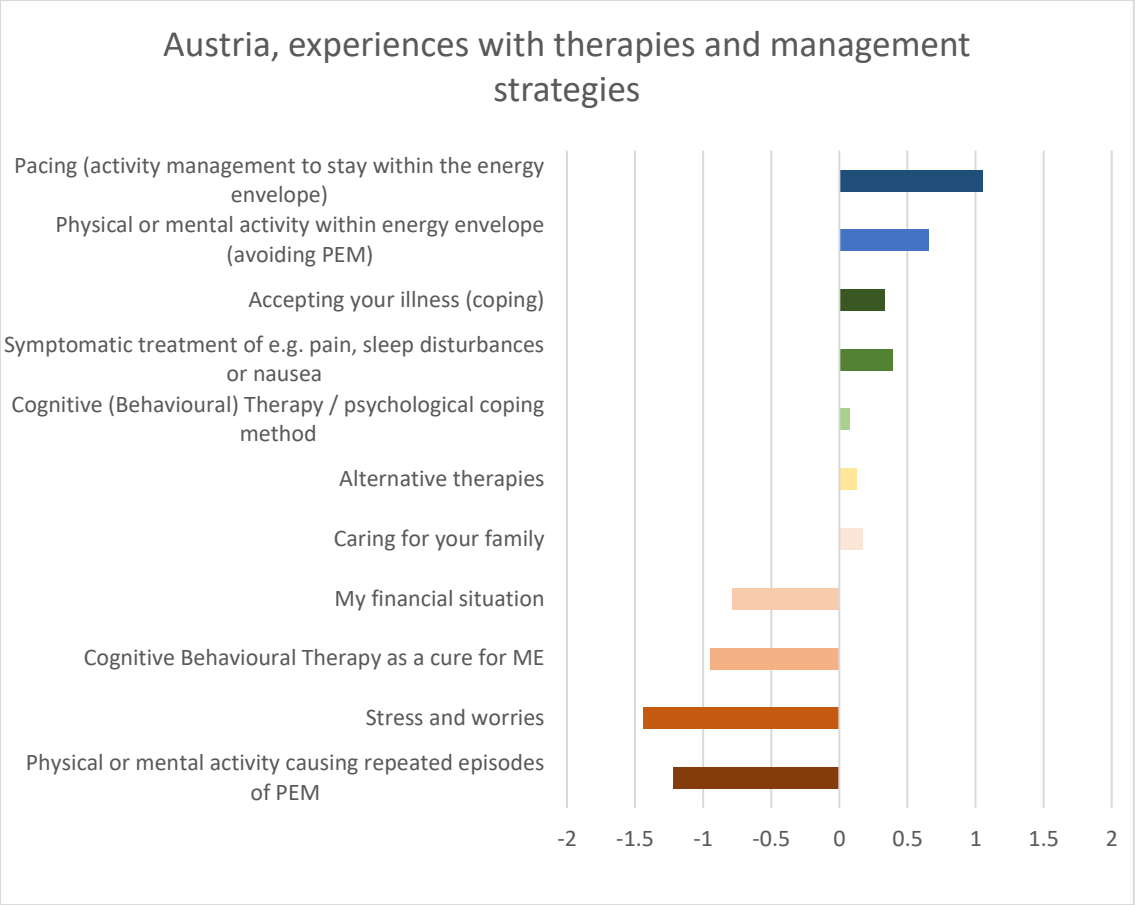
Country Figure 6: Austria, course of illness, n=83

1.1.11 Experienced support from various actors



Country Figure 7: Austria, support from various actors

1.1.12 Experiences with management strategies and therapies



Country Figure 8: Austria, experience with management strategies and therapies

1.2 Belgium

1.2.1 Respondents

There were 166 respondents from Belgium.

90% of respondents had received a diagnosis, 3% were currently under evaluation for a diagnosis, and 7% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.2.2 Age

Average age of respondents was 48.9 years.

1.2.3 Gender

85% of respondents were female, 15% male.

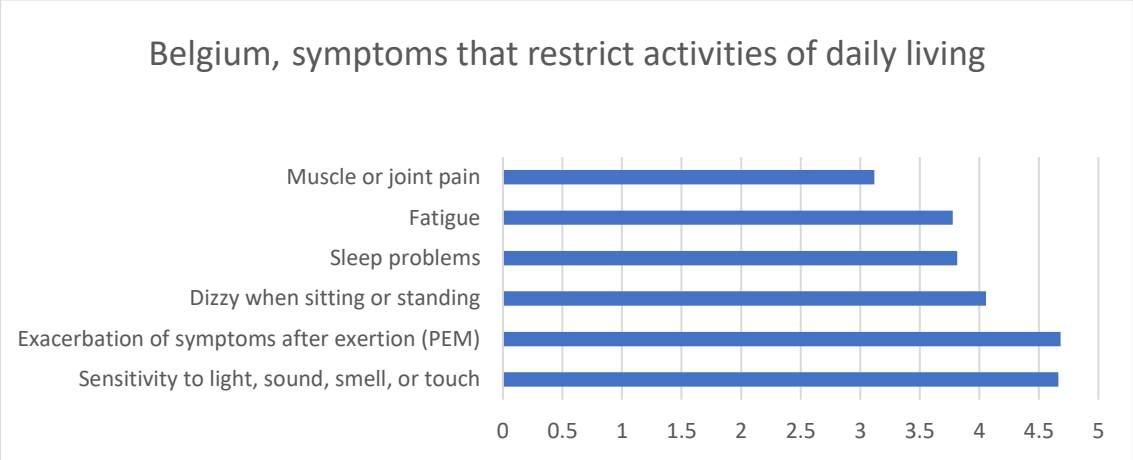
1.2.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

6% of respondents said that their disease was better than mild, 23% had mild, 52% moderate, 16% severe and 2% very severe ME/CFS.

1.2.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found PEM and sensitivity to light and sound and symptom exacerbation after activity the most bothersome symptoms. Pain was rated the least bothersome symptom. Individual profiles had much variation.

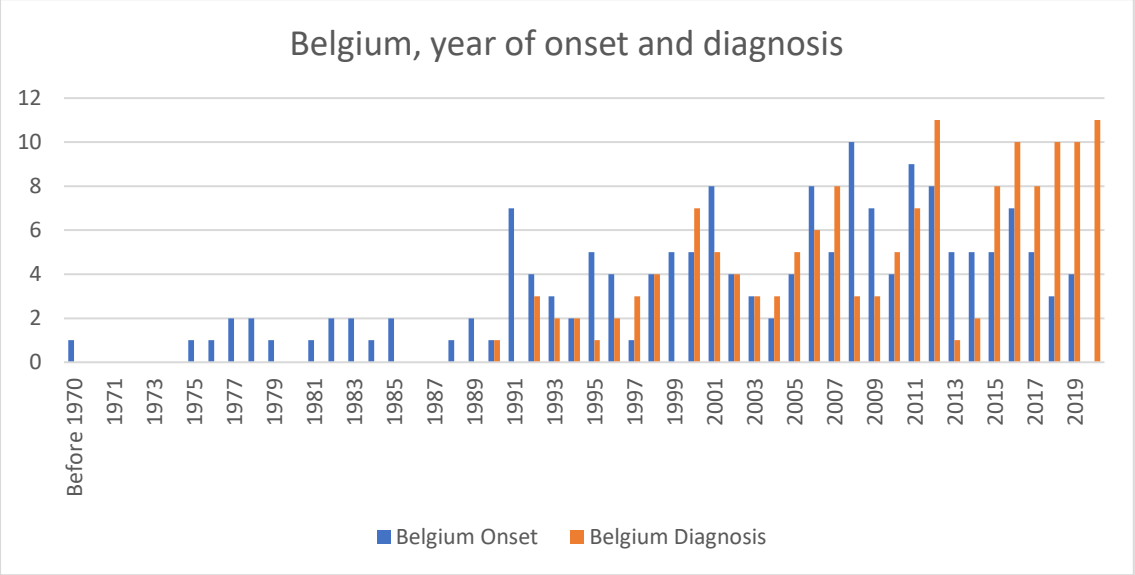


Country Figure 9: Belgium, symptoms that restrict activities of daily living, n=166

1.2.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

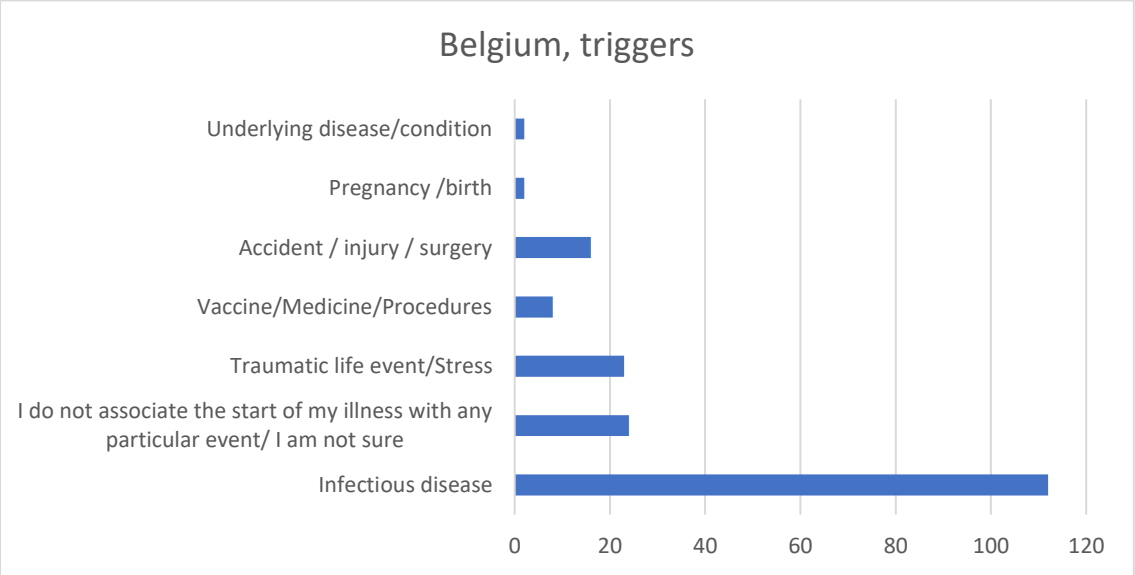
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 10: Belgium, year at onset and diagnosis

1.2.7 Triggers

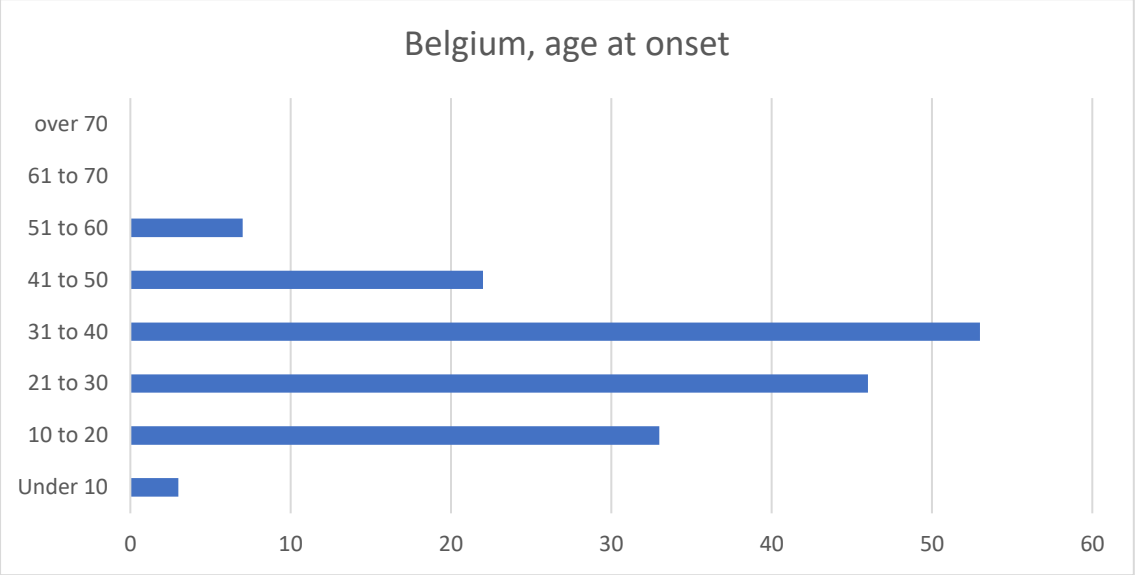
The most common trigger was infectious disease.



Country Figure 11: Belgium, triggers, n=166

1.2.8 Age at onset

Average age of onset was 29 years. The graph below shows the distribution of age at onset.

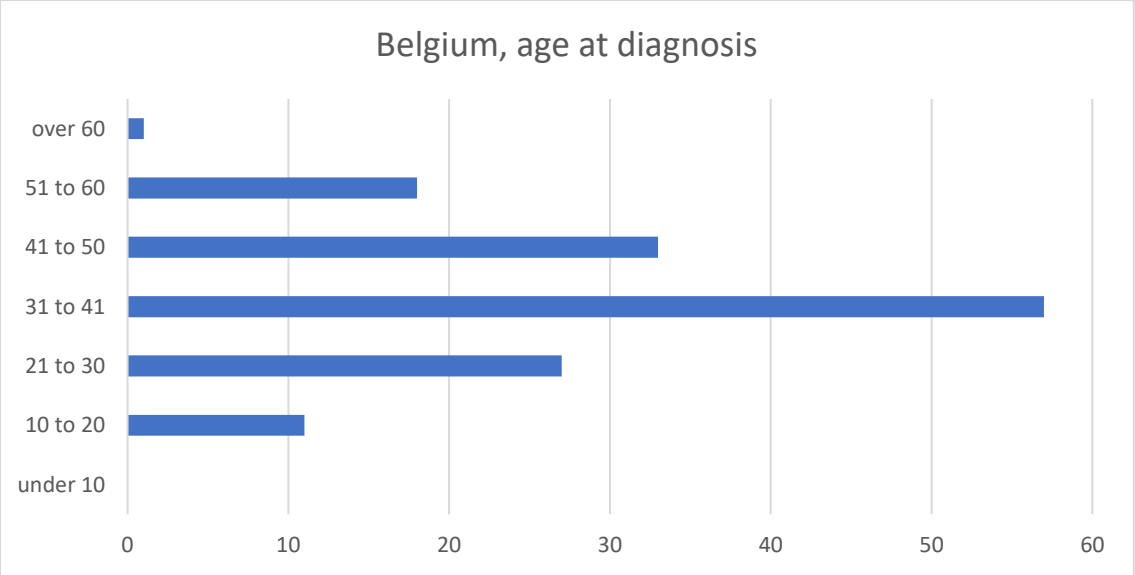


Country Figure 12: Belgium, age at onset, n=166

1.2.9 Time from onset to diagnosis

Average time from onset to diagnosis was 6.7 years overall, 6.6 years for men and 6.8 years for women.

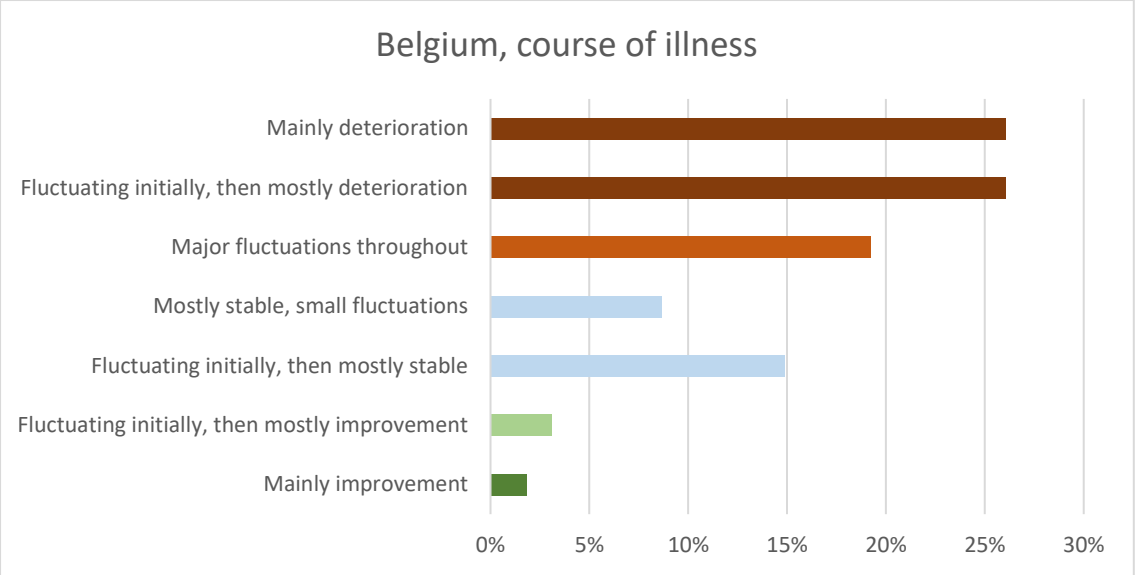
Average age at diagnosis was 36.8 years.



Country Figure 13: Belgium, age at diagnosis, n=141

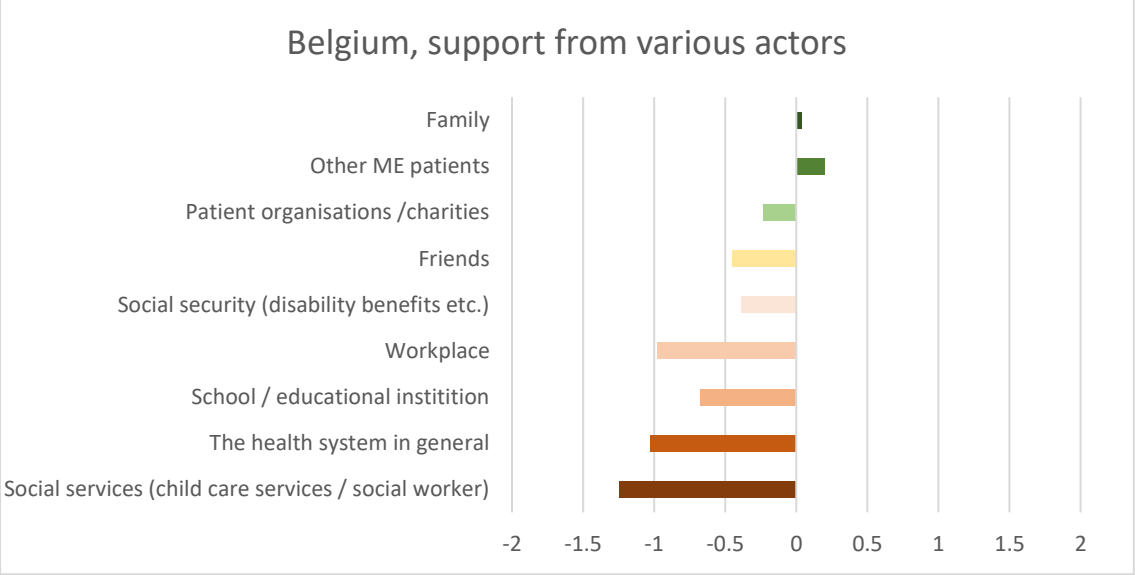
1.2.10 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Belgium, 71% of respondents had experienced deterioration or major fluctuations, 24% said they were mostly stable, and 5% had experienced mainly improvement.



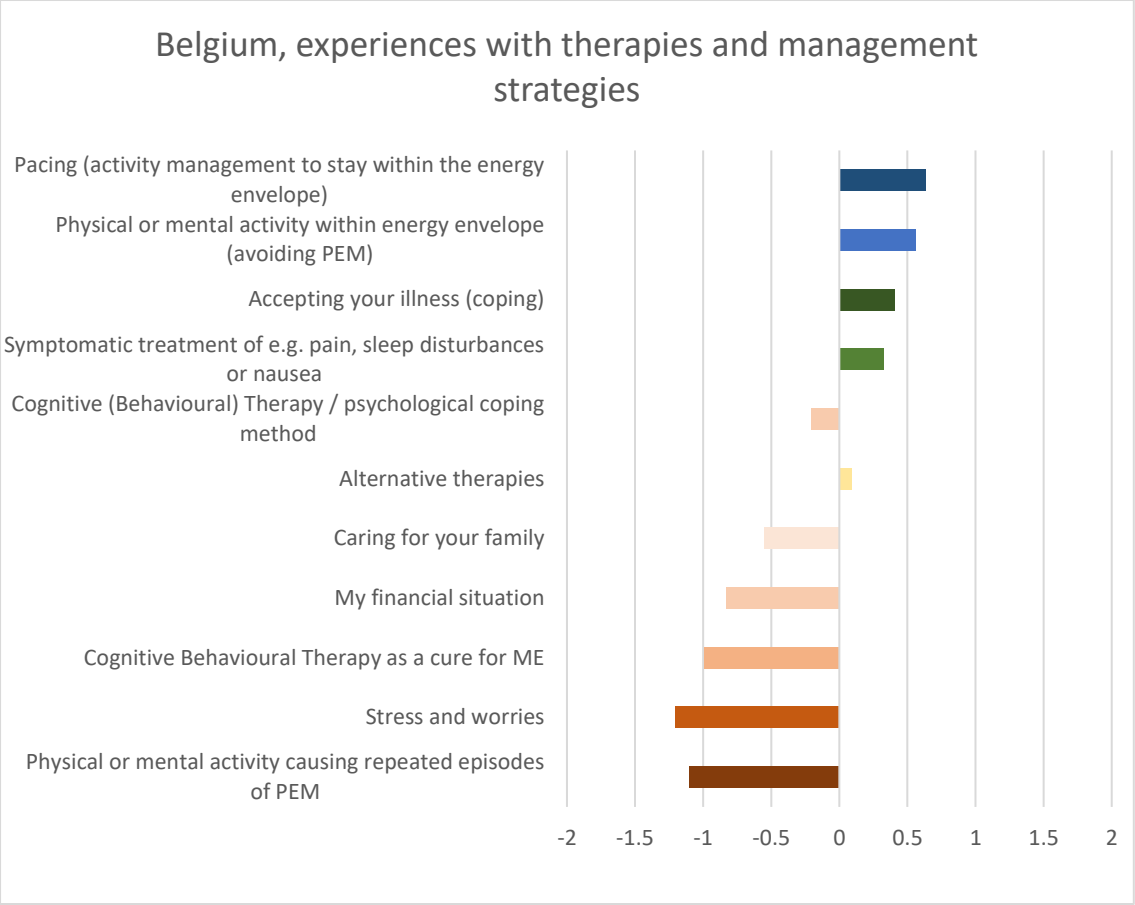
Country Figure 14: Belgium, course of illness, n=166

1.2.11 Experienced support from various actors



Country Figure 15: Belgium, support from various actors

1.2.12 Experiences with management strategies and therapies



Country Figure 16: Belgium, experience with therapies and management strategies

1.3 Croatia

1.3.1 Respondents

There were 85 respondents from Croatia.

32% of respondents had received a diagnosis, 5% were currently under evaluation for a diagnosis, and 64% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.3.2 Age

Average age of respondents was 44.6 years.

1.3.3 Gender

87% of respondents were female, 11% male, 2% preferred not to say.

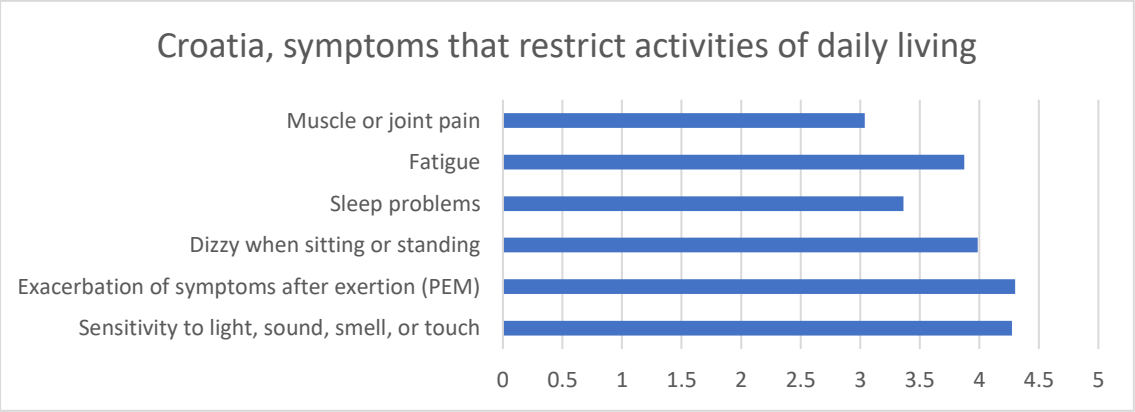
1.3.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

14% of respondents said that their disease was better than mild, 40% had mild, 38% moderate, 15% severe and 4% very severe ME/CFS.

1.3.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found PEM and sensitivity to light and sound, and symptom exacerbation after activity the most restrictive symptoms, slightly worse than dizziness when standing or sitting. Pain was rated the least bothersome symptom. Individual profiles had much variation.

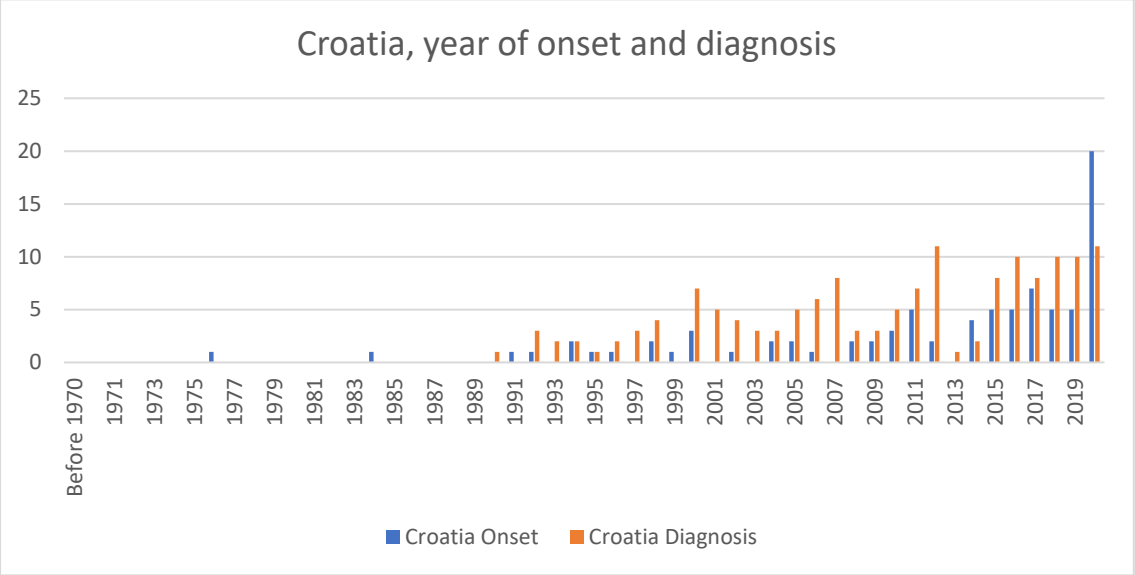


Country Figure 17: Croatia, symptoms that restrict activities of daily living, n=85

1.3.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

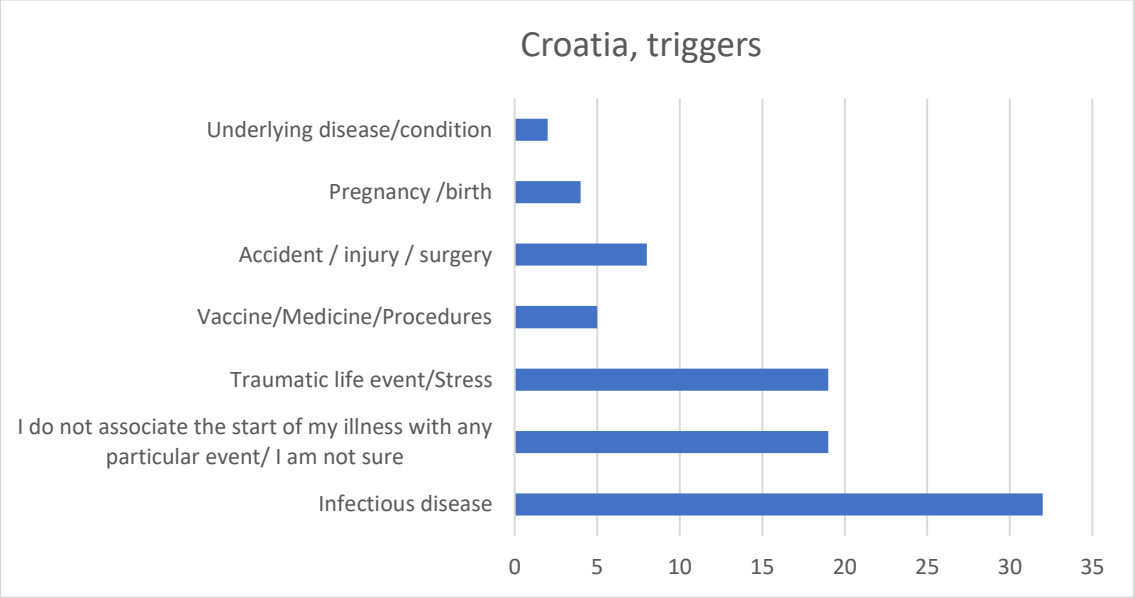
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 18: Croatia, year of onset and diagnosis, n=85

1.3.7 Triggers

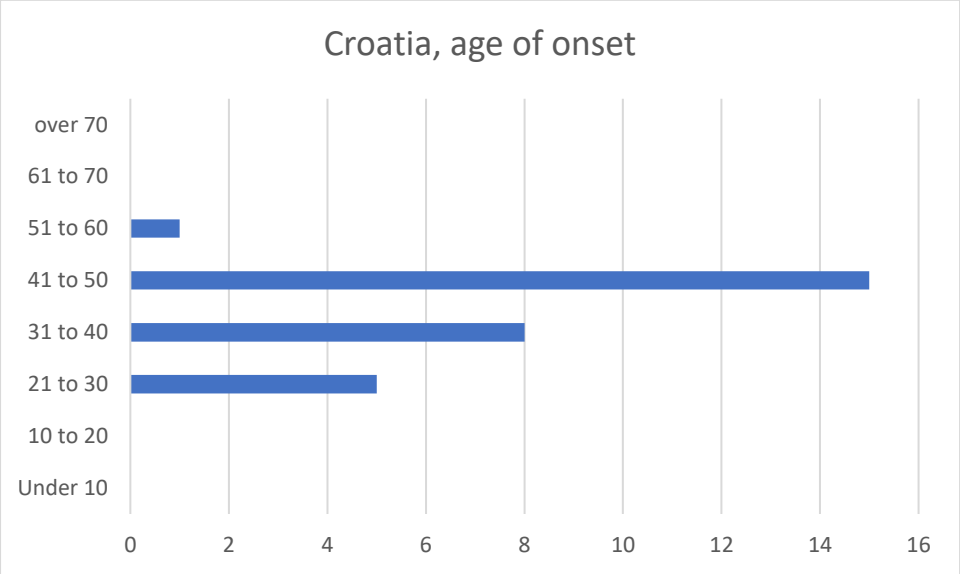
The most common trigger was infectious disease.



Country Figure 19: Croatia, triggers, n=85

1.3.8 Age at onset

Average age of onset was 34.3 years. The graph below shows the distribution of age at onset.



Country Figure 20: Croatia, age at onset, n=85

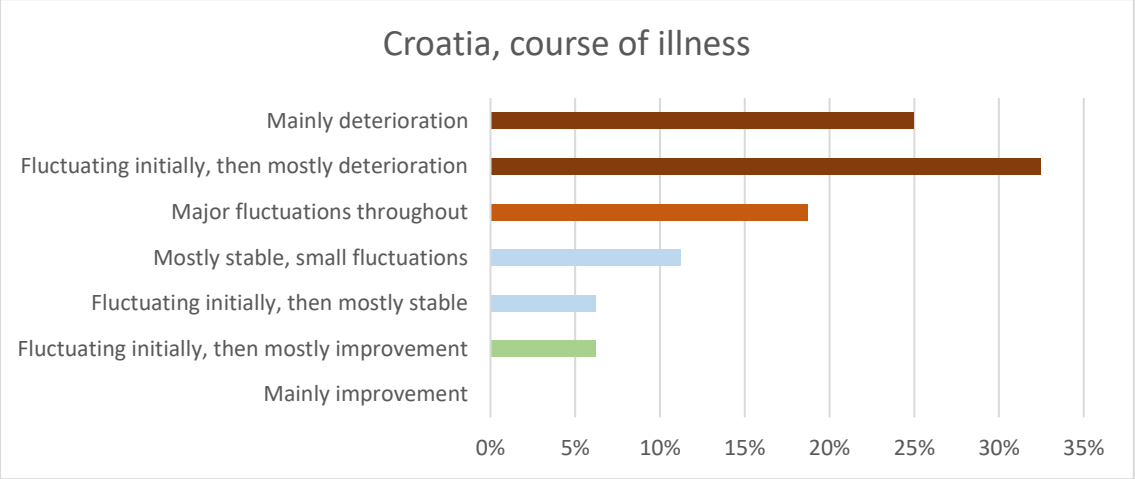
1.3.9 Time from onset to diagnosis

Average time from onset to diagnosis was 11.8 years overall, 14.8 years for men and 11.3 years for women.

Average age at diagnosis was 39.7 years.

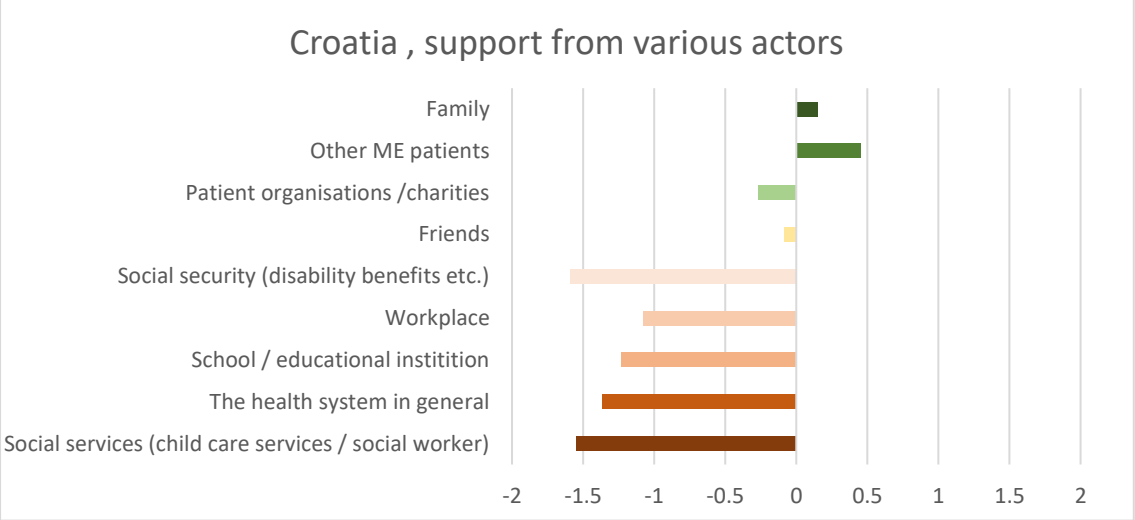
1.3.10 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Croatia, 78% of respondents had experienced deterioration or major fluctuations, 14% said they were mostly stable, and 6% had experienced mainly improvement.



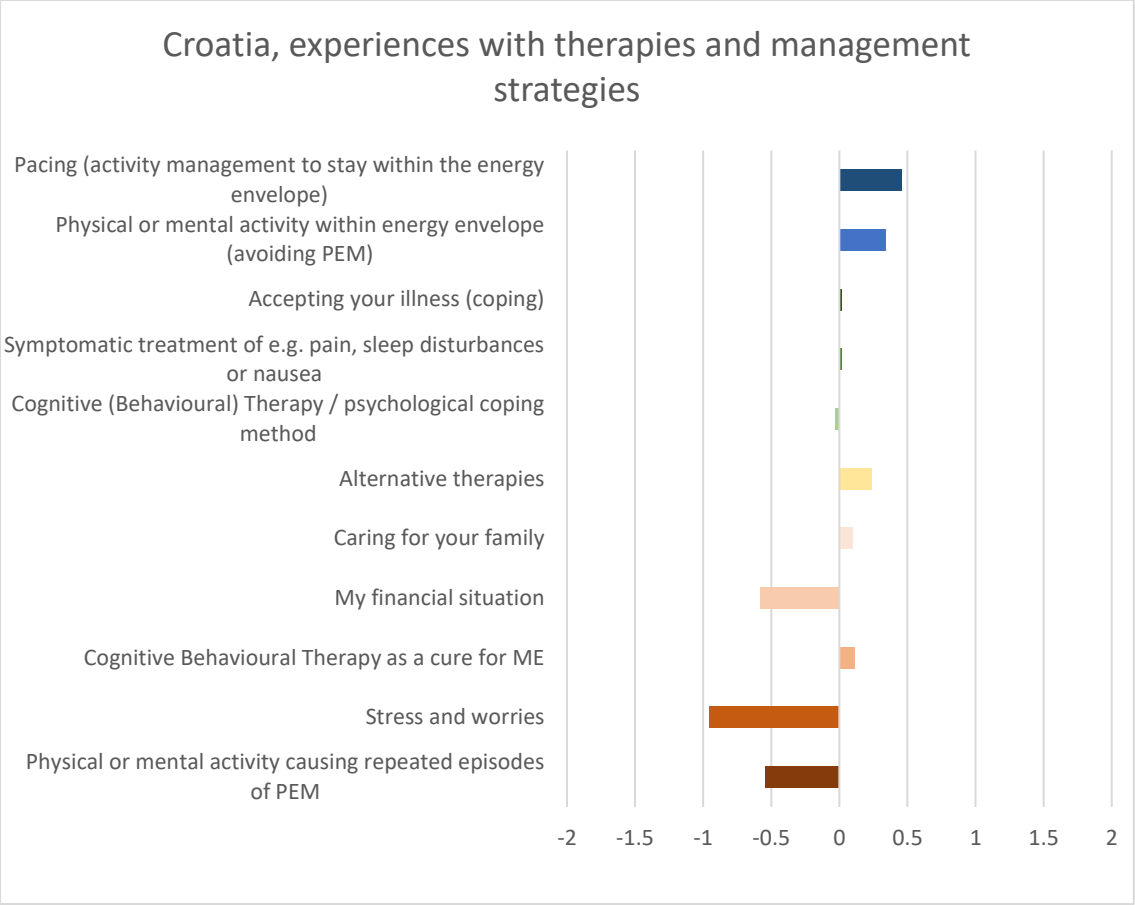
Country Figure 21: Croatia, course of illness, n=85

1.3.11 Experienced support from various actors



Country Figure 22: Croatia, support from various actors

1.3.12 Experiences with management strategies and therapies



Country Figure 23: Croatia, experience with management strategies and therapies

1.4 Czech Republic

1.4.1 Respondents

There were 123 respondents from the Czech Republic.

51% of respondents had received a diagnosis, 7% were currently under evaluation for a diagnosis, and 42% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.4.2 Age

Average age of respondents was 49.4 years.

1.4.3 Gender

83% of respondents were female, 17% male.

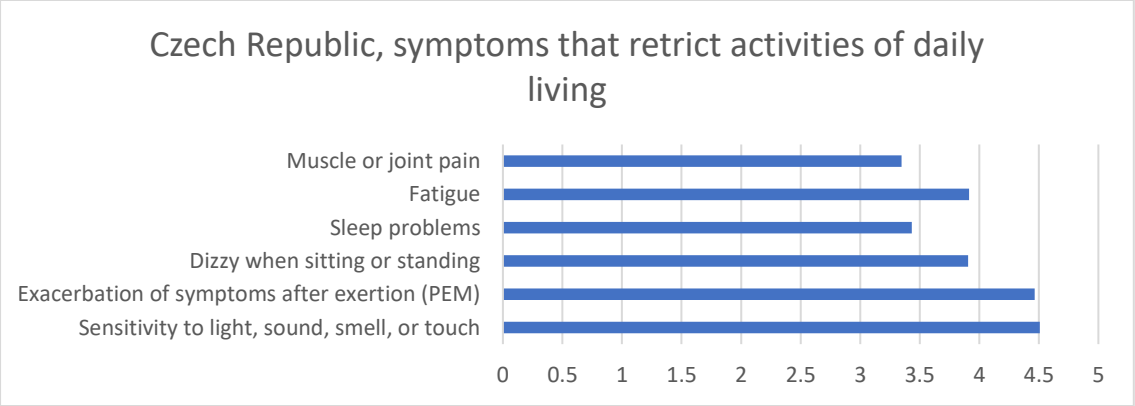
1.4.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

3% of respondents said that their disease was better than mild, 32% had mild, 50% moderate, 13% severe and 3% very severe ME/CFS.

1.4.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found sensitivity to light and sound and PEM the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

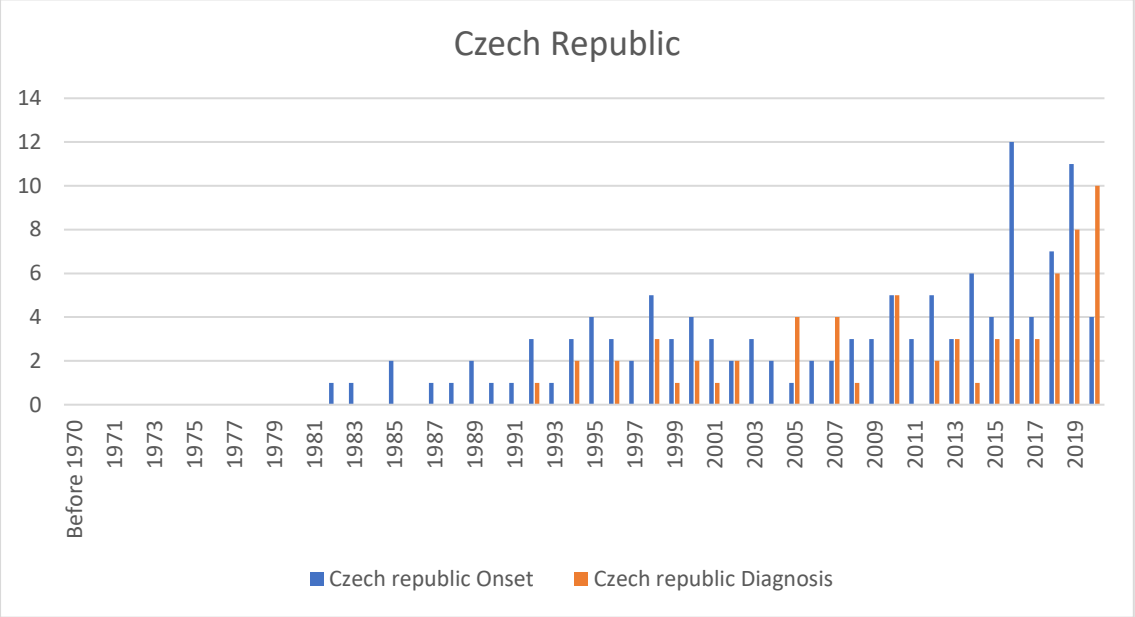


Country Figure 24: Czech Republic, symptoms that restrict activities of daily living, n=123

1.4.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

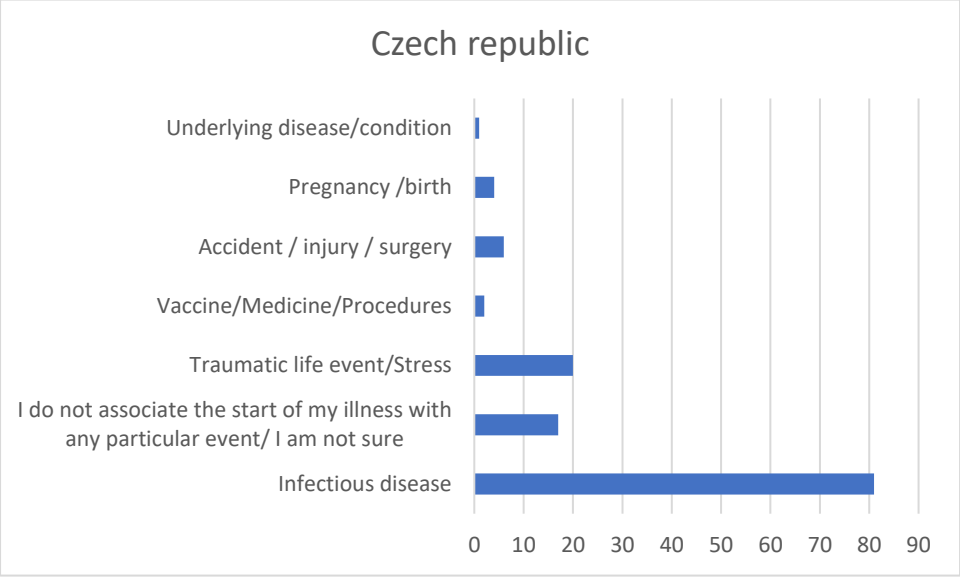
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 25: Czech Republic, year of onset and diagnosis, n=123

1.4.7 Triggers

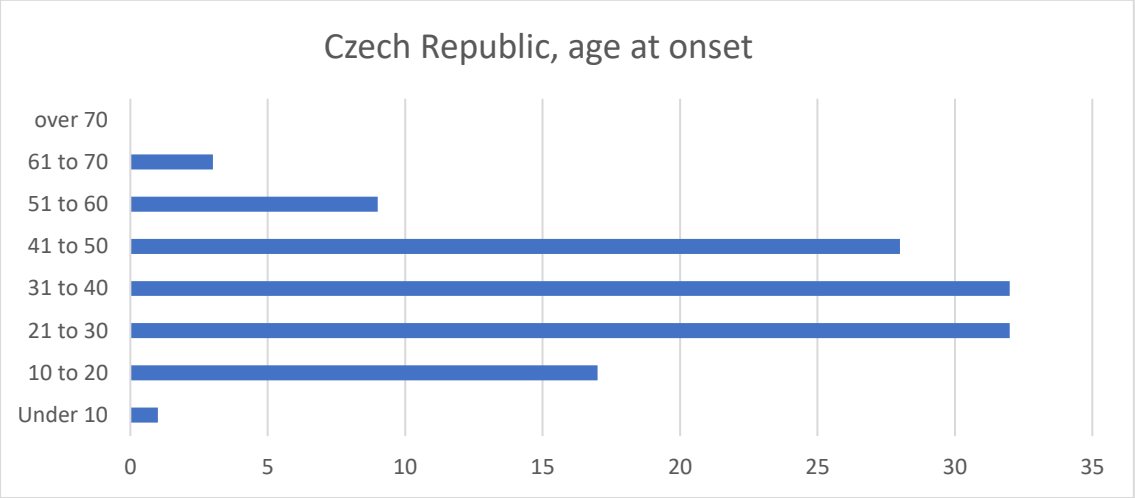
The most common trigger was infectious disease.



Country Figure 26: Czech Republic, triggers, n=123

1.4.8 Age at onset

Average age of onset was 34.5 years. The graph below shows the distribution of age at onset.

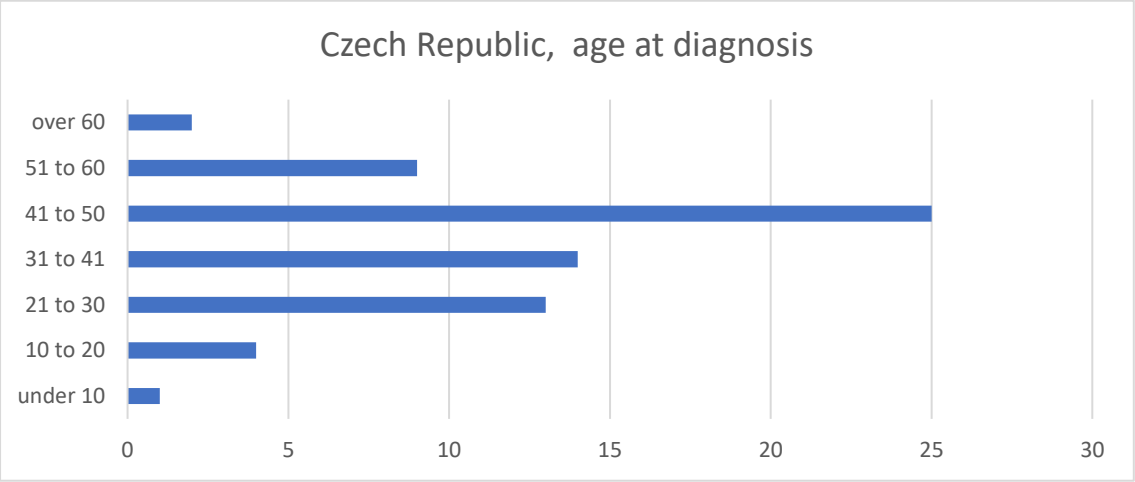


Country Figure 27:Czech Republic, age at onset, n=123

1.4.9 Time from onset to diagnosis

Average time from onset to diagnosis was 6.5 years overall, 9.8 years for men and 6 years for women.

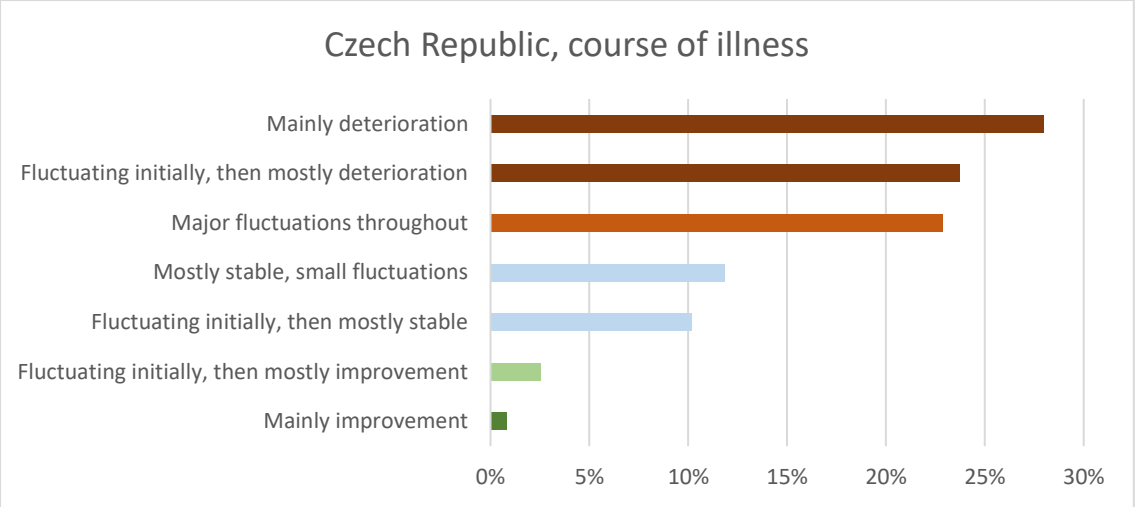
Average age at diagnosis was 34.5 years.



Country Figure 28: Czech Republic, age at diagnosis, n=62

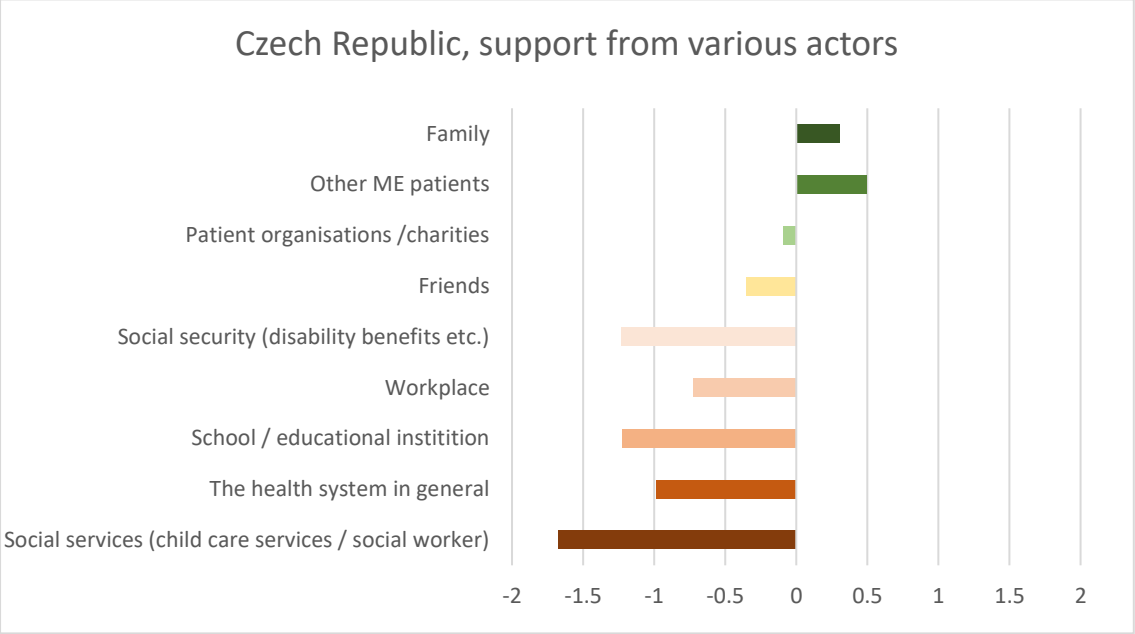
1.4.10 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In the Czech Republic, 75% of respondents had experienced deterioration or major fluctuations, 22% said they were mostly stable, and 3% had experienced mainly improvement.



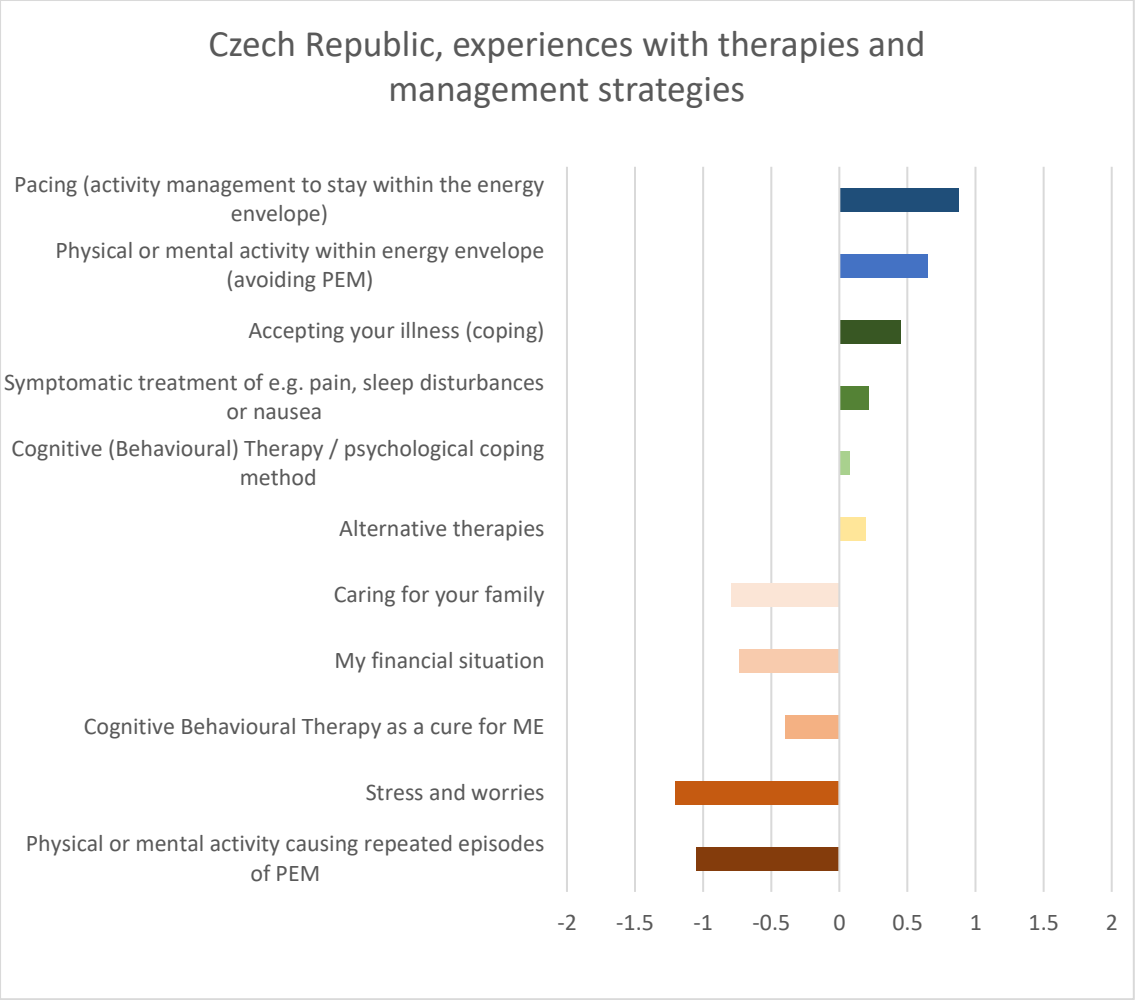
Country Figure 29: Czech Republic, course of illness, n=123

1.4.11 Experienced support from various actors



Country Figure 30: Czech Republic, support from various actors, n=123

1.4.12 Experiences with management strategies and therapies



Country Figure 31: Czech Republic, experience with management strategies and therapies, n=123

1.5 Denmark

1.5.1 Respondents

There were 481 respondents from Denmark.

83% of respondents had received a diagnosis, 5% were currently under evaluation for a diagnosis, and 12% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.5.2 Age

Average age of respondents was 49.5 years.

1.5.3 Gender

87% of respondents were female, 13% male.

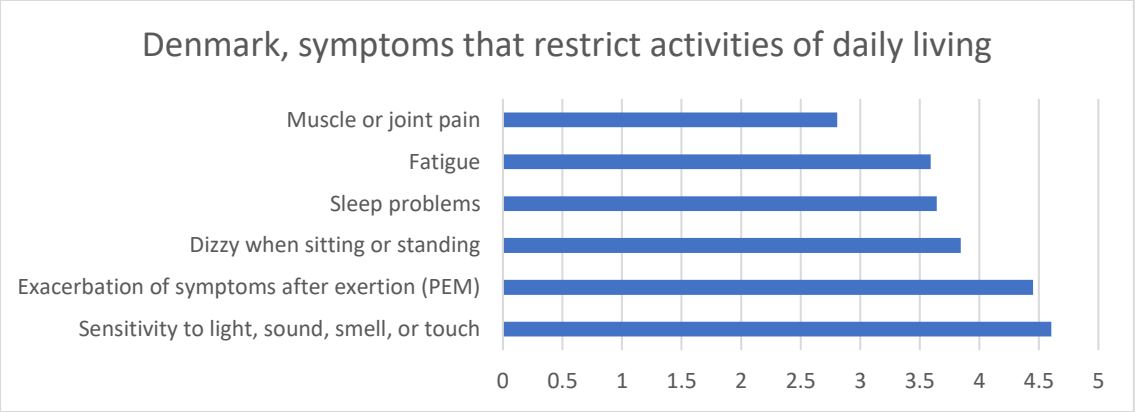
1.5.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

2% of respondents said that their disease was better than mild, 24% had mild, 57% moderate, 15% severe and 3% very severe ME/CFS.

1.5.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found sensitivity to light and sound and PEM the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

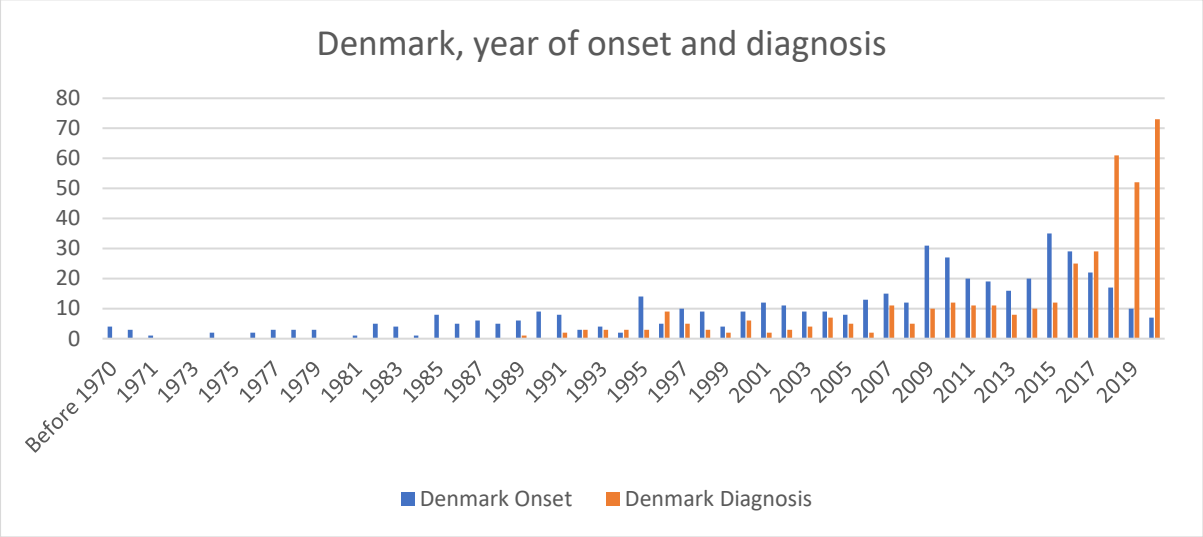


Country Figure 32:Denmark, symptoms that restrict activities of daily living, n=481

1.5.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

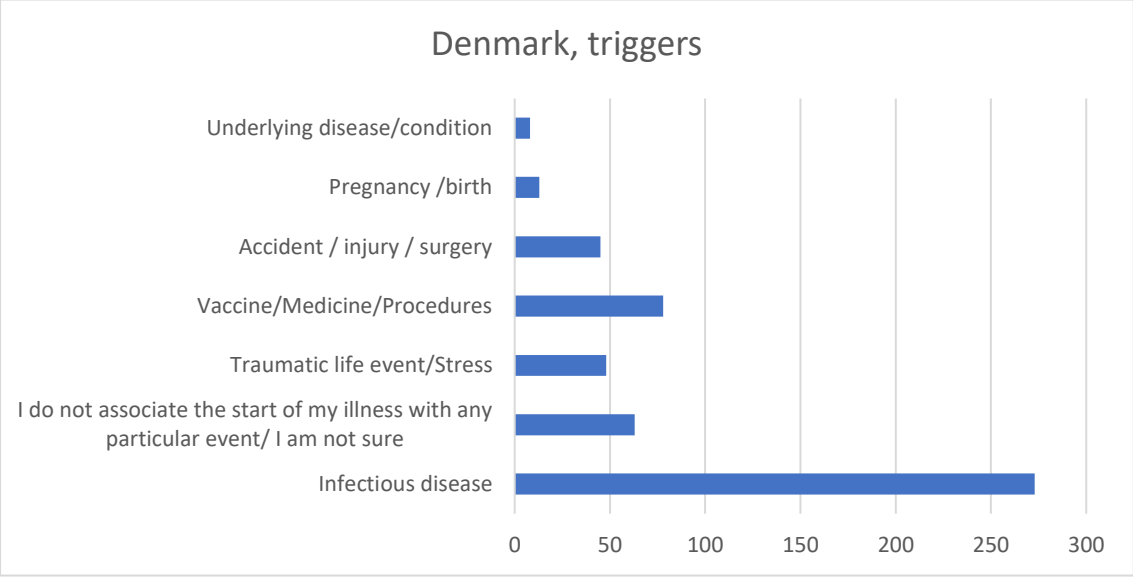
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 33: Denmark, year of onset and diagnosis

1.5.7 Triggers

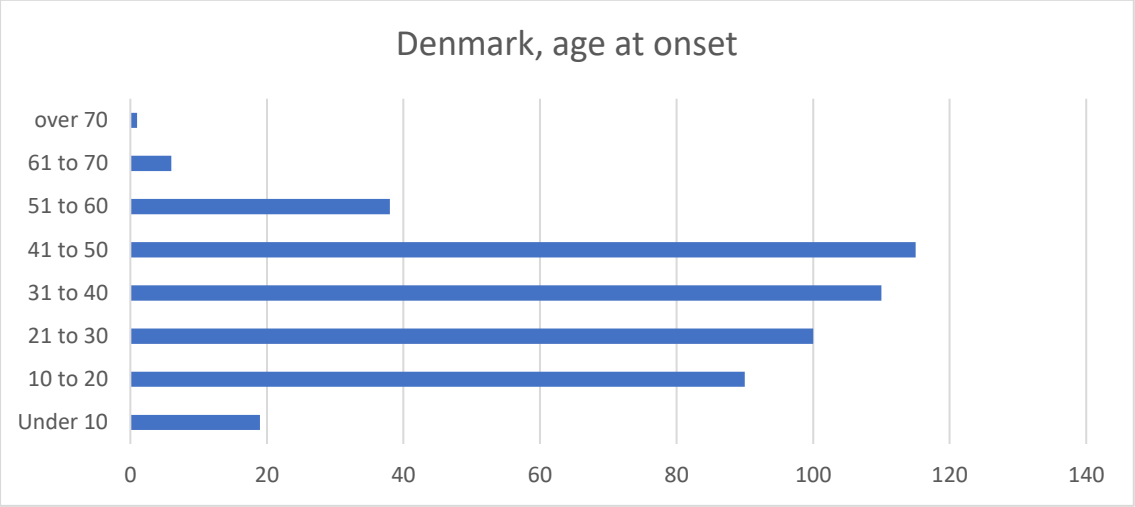
The most common event associated with onset was infectious disease.



Country Figure 34: Denmark, triggers, n=481

1.5.8 Age at onset

Average age of onset was 32 years. The graph below shows the distribution of age at onset.

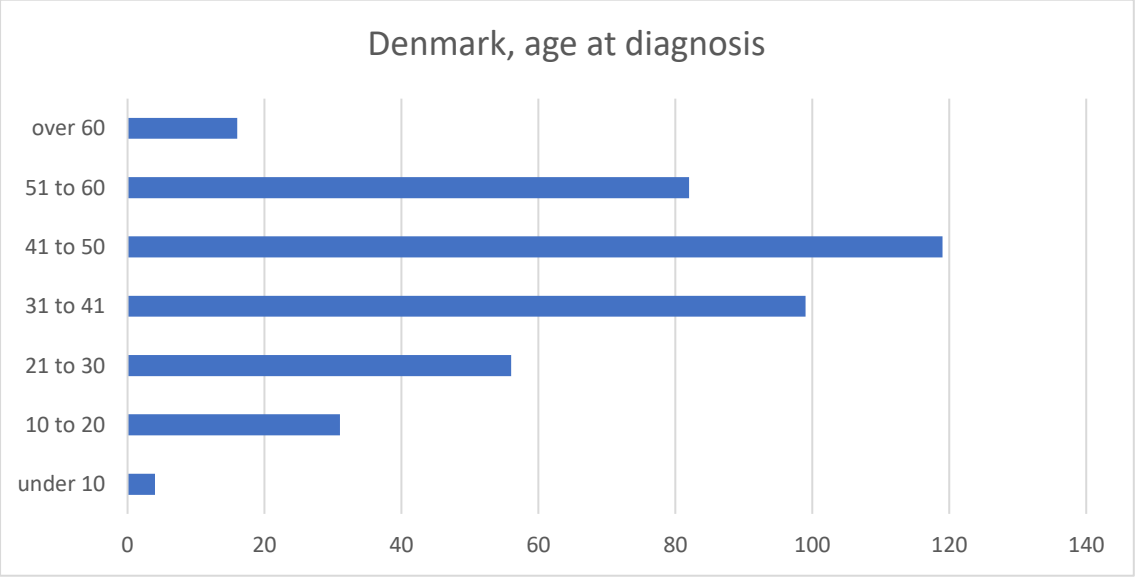


Country Figure 35:Denmark, age at onset, n=481

1.5.9 Time from onset to diagnosis

Average time from onset to diagnosis was 9.2 years overall, 8 years for men and 9.4 years for women.

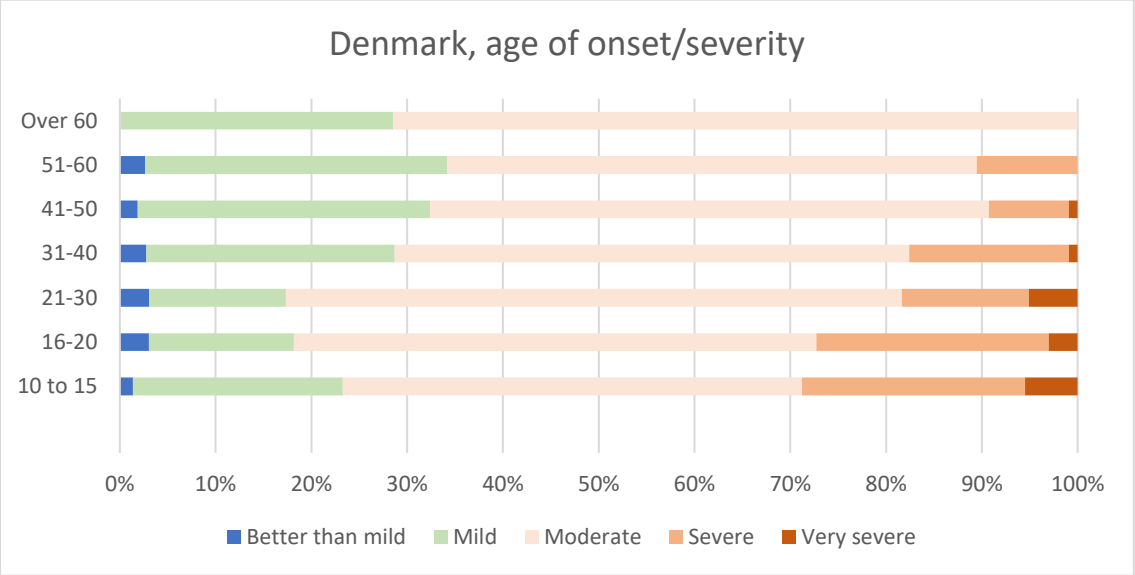
Average age at diagnosis was 40.7 years.



Country Figure 36: Denmark age at diagnosis, n=399

1.5.10 Age at onset and severity

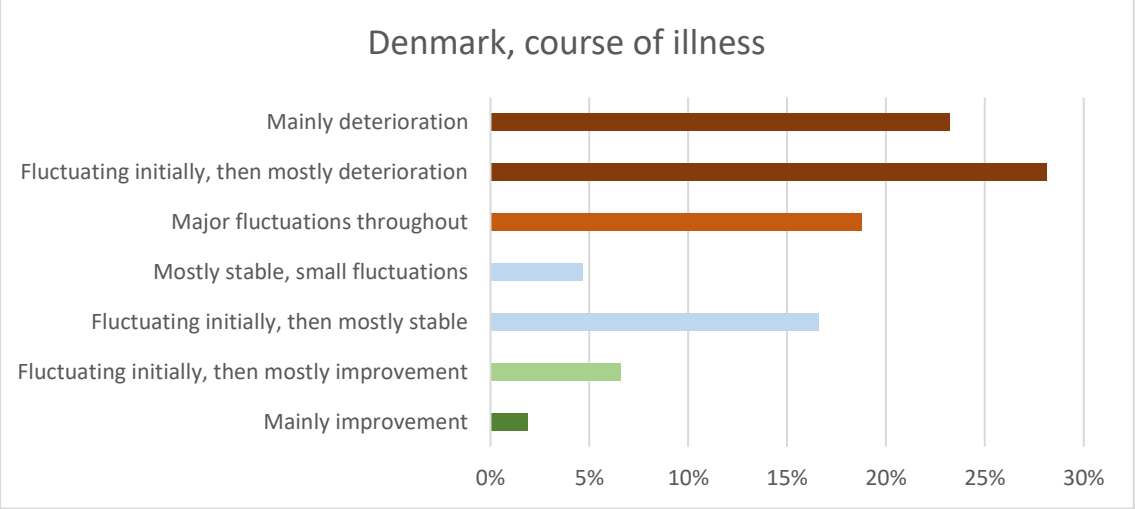
Severe or very severe disease was more common among patients who had early onset, regardless of disease duration.



Country Figure 37: Denmark, age at onset and severity, n=481

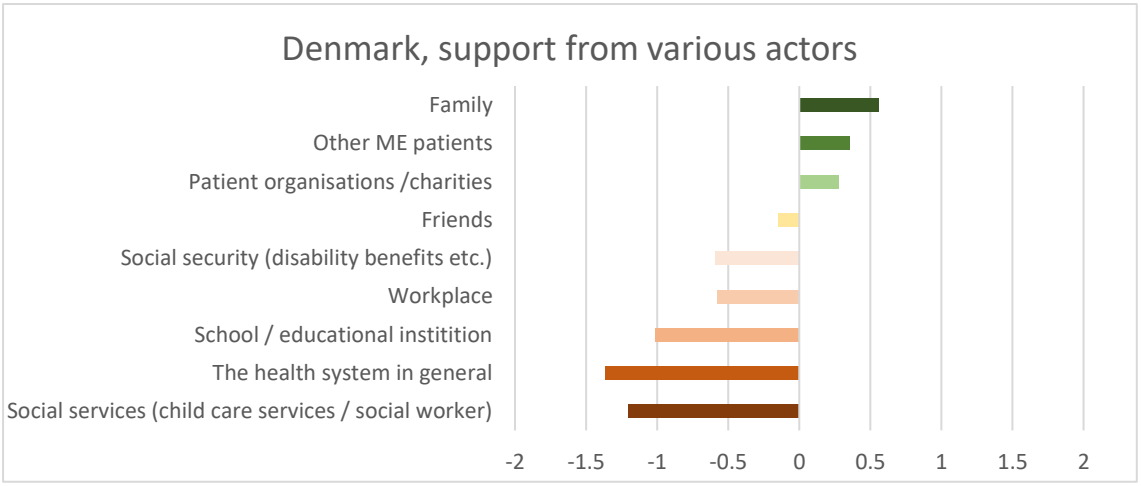
1.5.11 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Denmark, 70% of respondents had experienced deterioration or major fluctuations, 22% said they were mostly stable, and 9% had experienced mainly improvement.



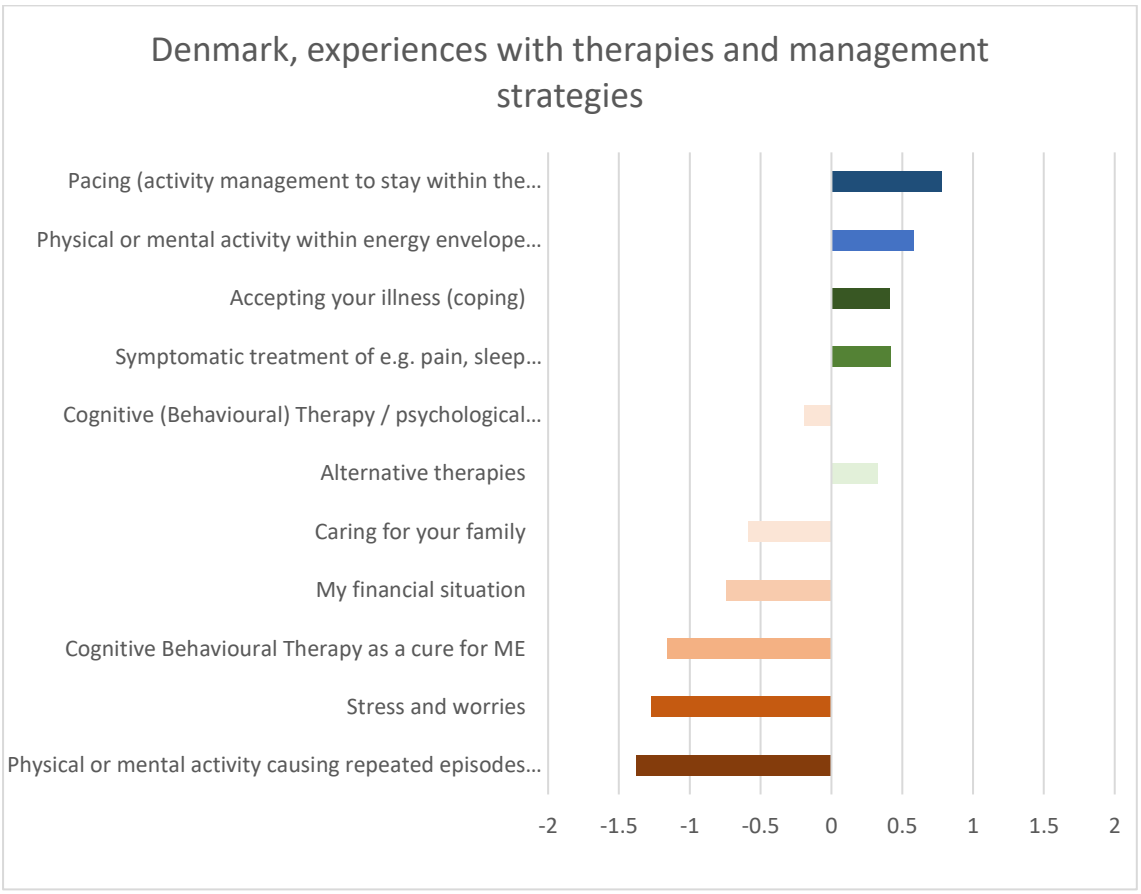
Country Figure 38: Denmark, course of illness, n=481

1.5.12 Experienced support from various actors



Country Figure 39: Denmark, support from various actors, n=481

1.5.13 Experiences with management strategies and therapies



Country Figure 40: Denmark, experience with therapies and management strategies

1.6 Finland

1.6.1 Respondents

There were 439 respondents from Finland.

75% of respondents had received a diagnosis, 11% were currently under evaluation for a diagnosis, and 14% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.6.2 Age

Average age of respondents was 46.8 years.

1.6.3 Gender

85% of respondents were female, 15% male.

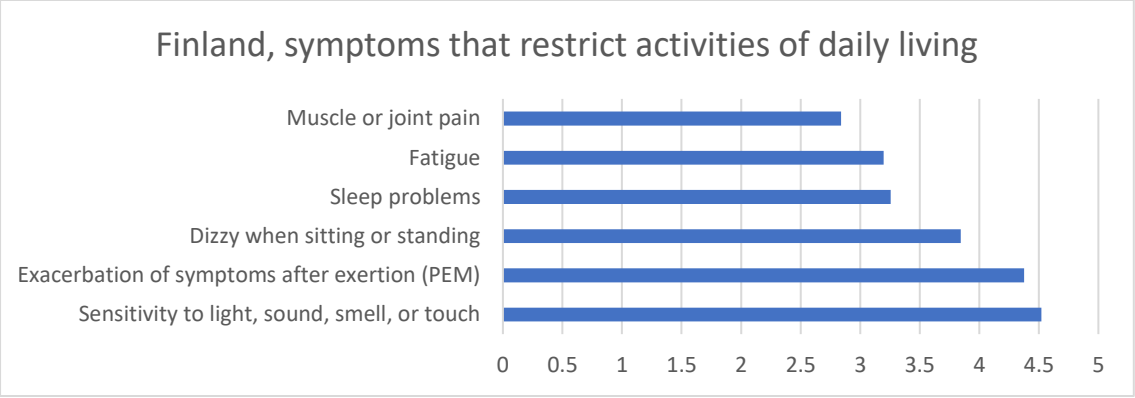
1.6.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

6% of respondents said that their disease was better than mild, 31% had mild, 49% moderate, 12% severe and 2% very severe ME/CFS.

1.6.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found sensitivity to light and sound and PEM the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

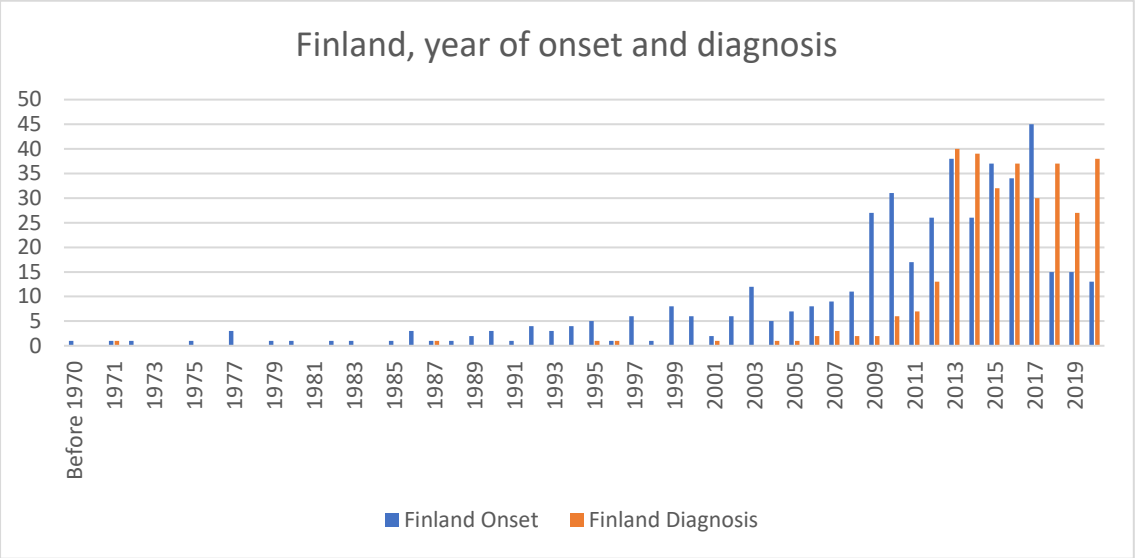


Country Figure 41: Finland, symptoms that restrict activities of daily living, n=439

1.6.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 42: Finland, year of onset and diagnosis

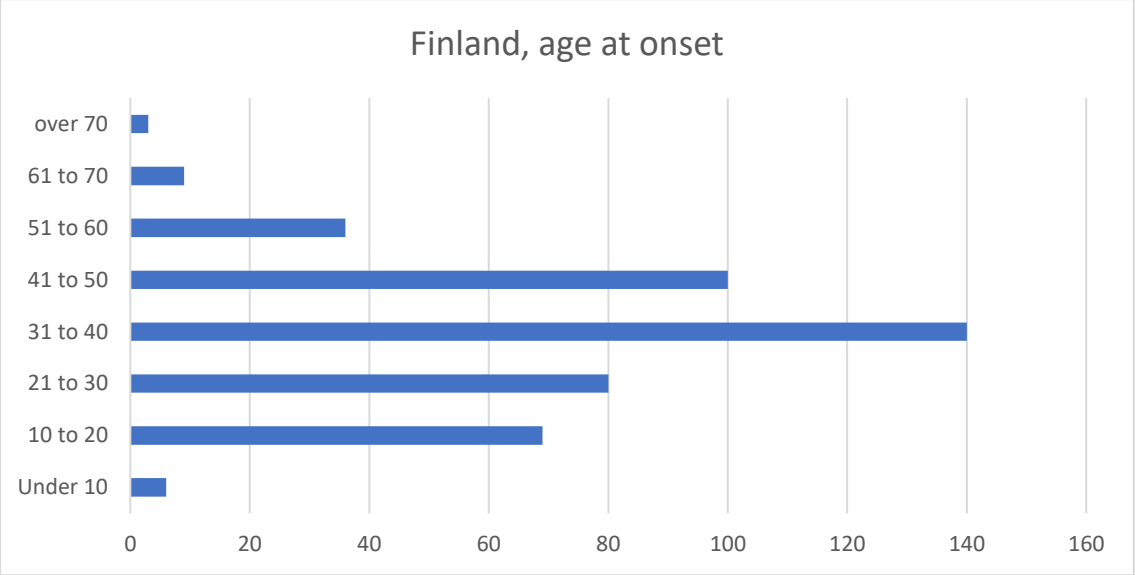
1.6.7 Triggers

The most common trigger was infectious disease.

Country Figure 43: Finland, triggers, n=439

1.6.8 Age at onset

Average age of onset was 34.6 years. The graph below shows the distribution of age at onset.

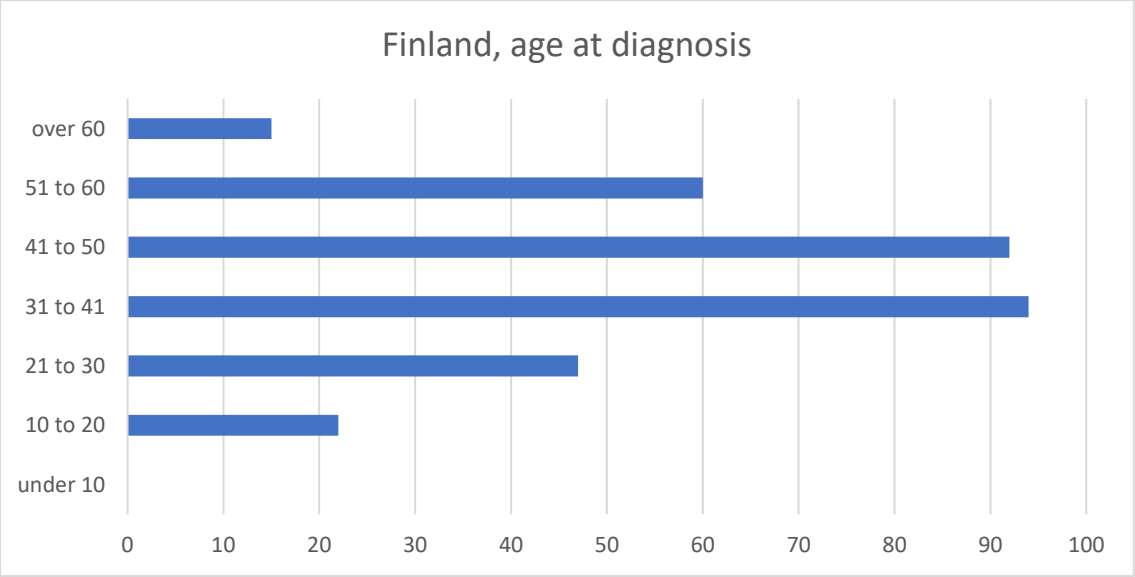


Country Figure 44: Finland, age at onset, n=439

1.6.9 Time from onset to diagnosis

Average time from onset to diagnosis was 6 years overall, 6.2 years for men and 6.1 years for women.

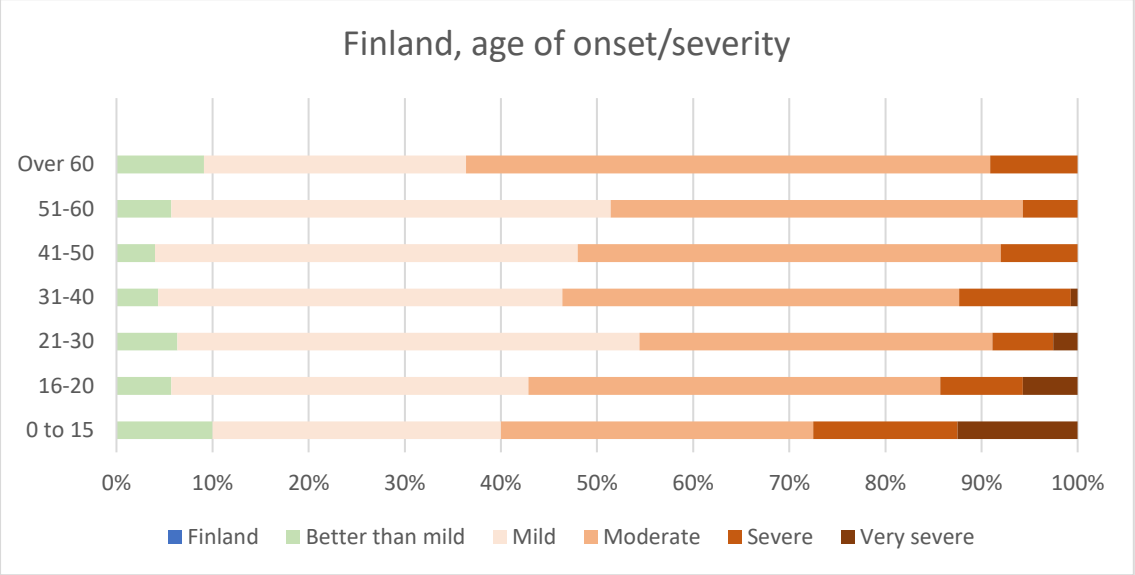
Average age at diagnosis was 40.4 years.



Country Figure 45: Finland, age at diagnosis, n=329

1.6.10 Age at onset and severity

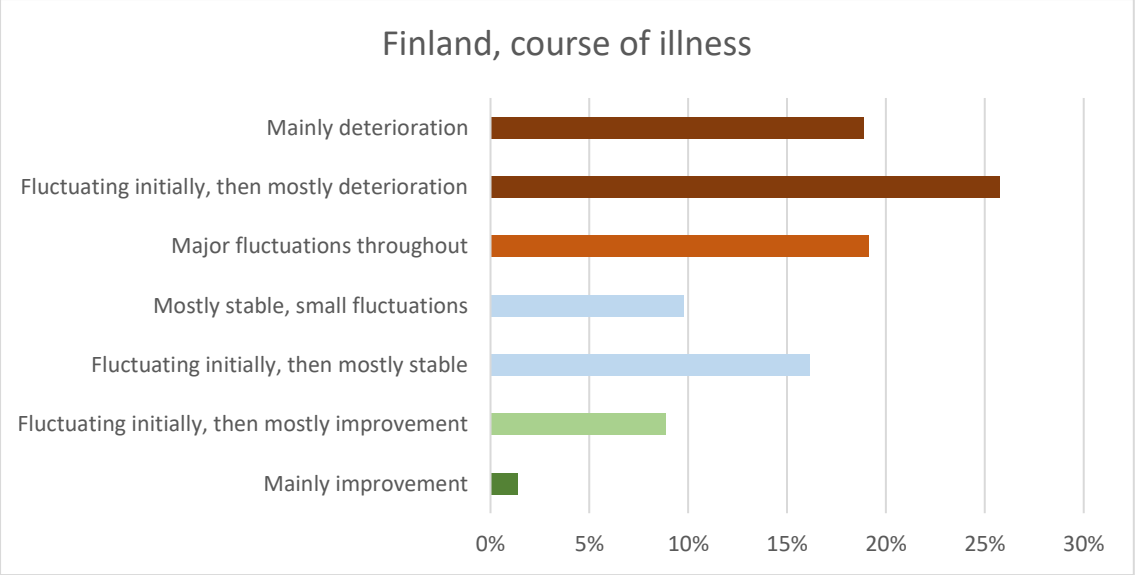
Severe or very severe disease was more common among patients who had early onset, regardless of disease duration.



Country Figure 46: Finland, age at onset and severity, n=439

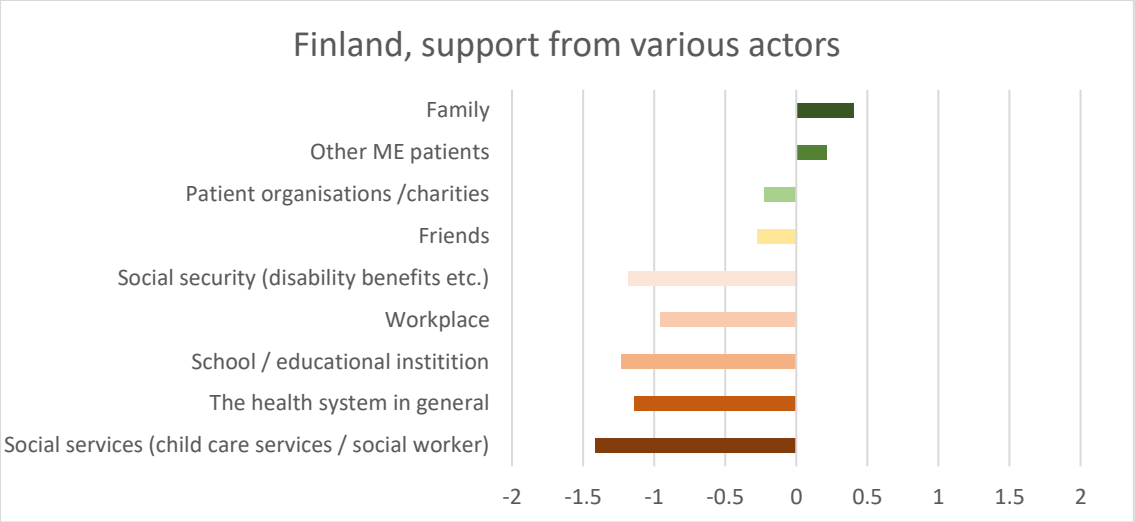
1.6.11 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Finland, 64% of respondents had experienced deterioration or major fluctuations, 26% said they were mostly stable, and 10% had experienced mainly improvement.



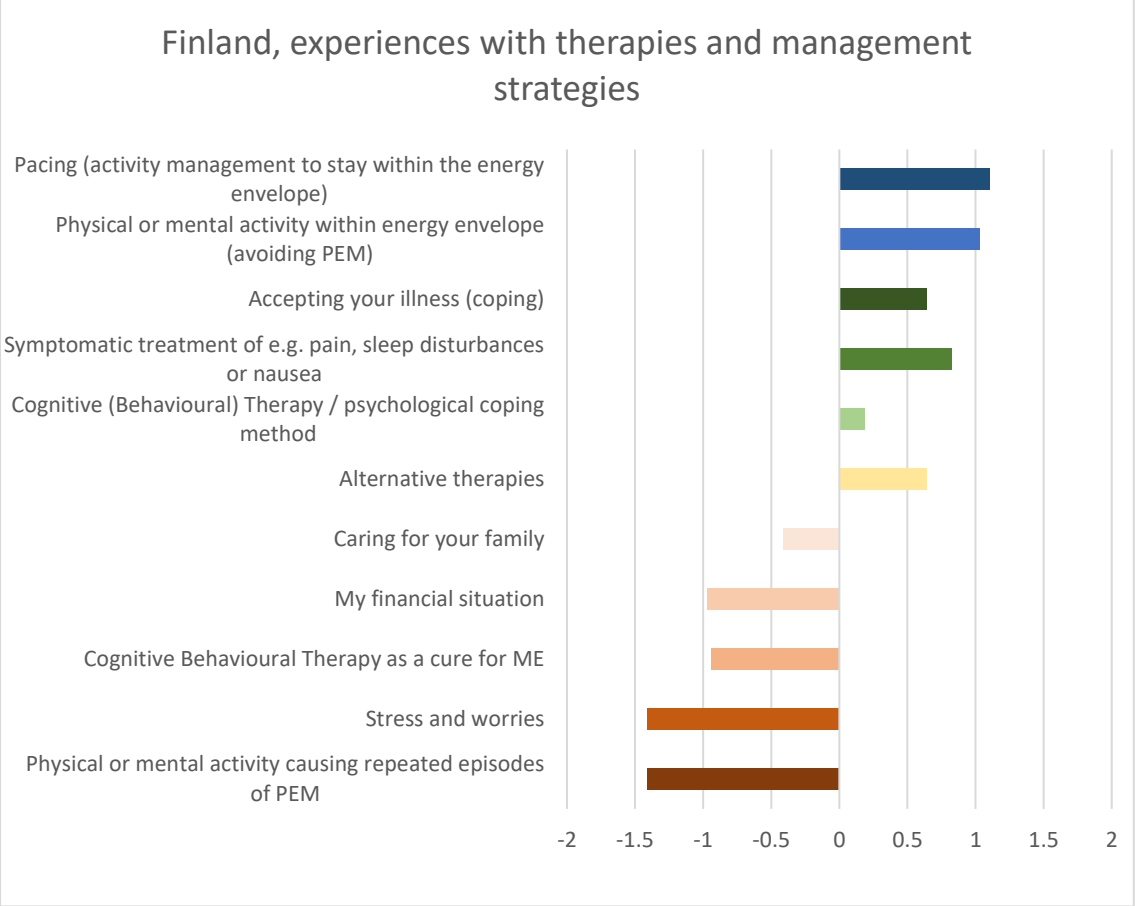
Country Figure 47: Finland, course of illness, n=439

1.6.12 Experienced support from various actors



Country Figure 48: Finland, support from various actors, n=439

1.6.13 Experiences with management strategies and therapies



Country Figure 49: Finland, experience with management strategies and therapies

1.7 France

1.7.1 Respondents

There were 456 respondents from France.

75% of respondents had received a diagnosis, 11% were currently under evaluation for a diagnosis, and 14% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.7.2 Age

Average age of respondents was 48.1 years.

1.7.3 Gender

81% of respondents were female, 19 male.

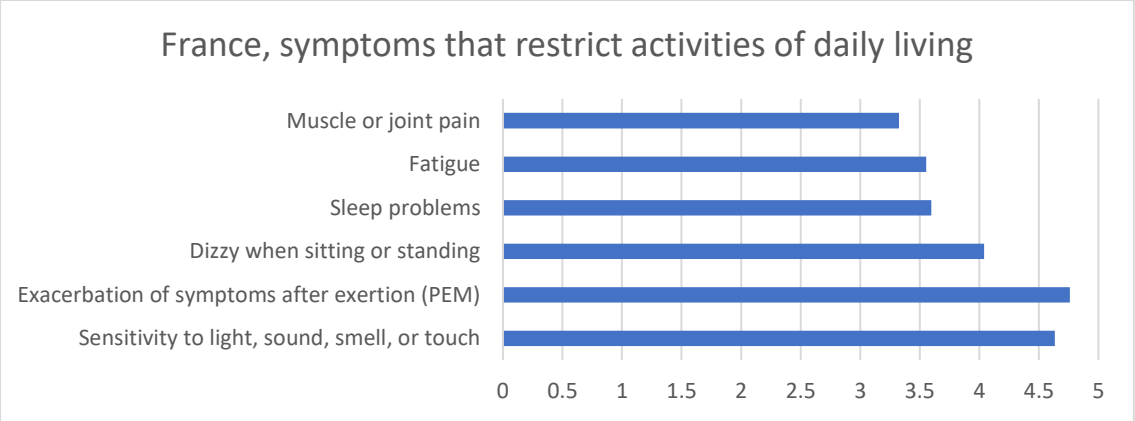
1.7.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

6% of respondents said that their disease was better than mild, 31% had mild, 49% moderate, 12% severe and 2% very severe ME/CFS.

1.7.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found PEM and sensitivity to light and sound the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

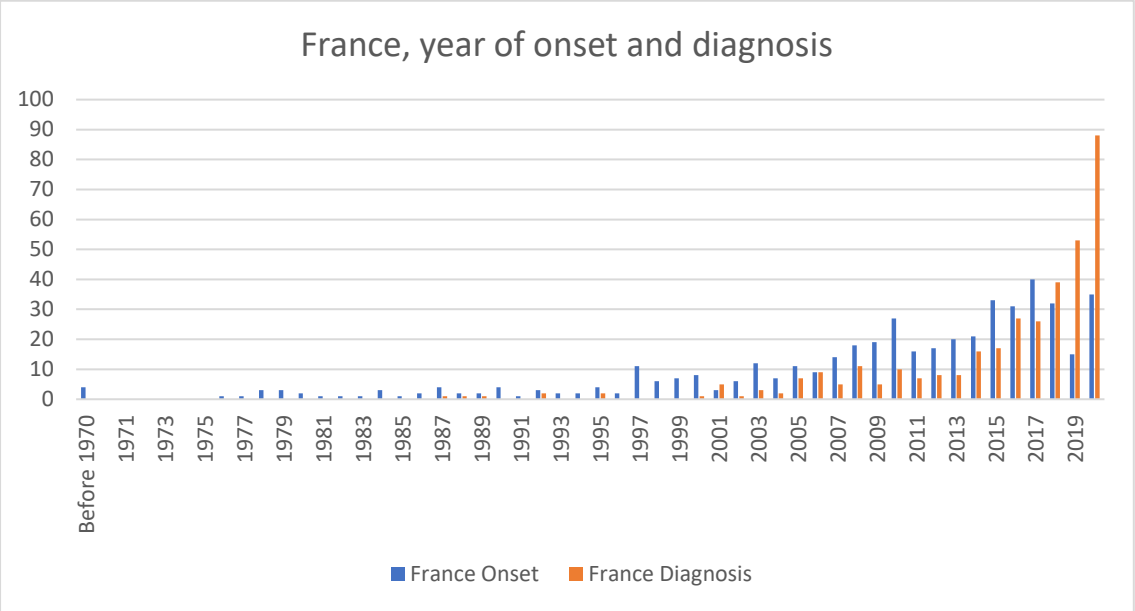


Country Figure 50: France, symptoms that restrict activities of daily living, n=456

1.7.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

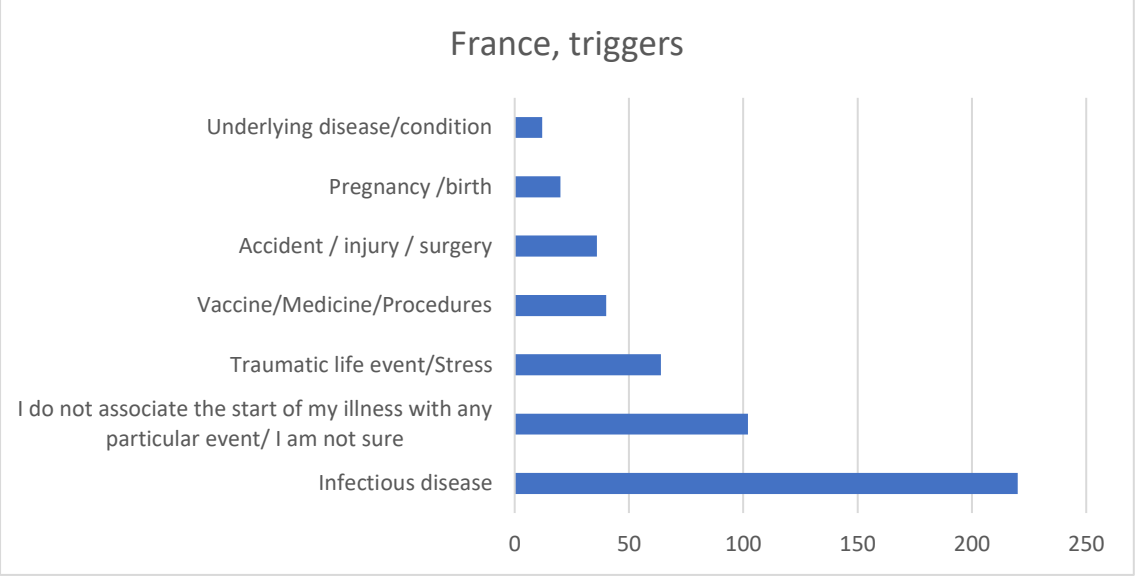
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 51: France, year of onset and diagnosis

1.7.7 Triggers

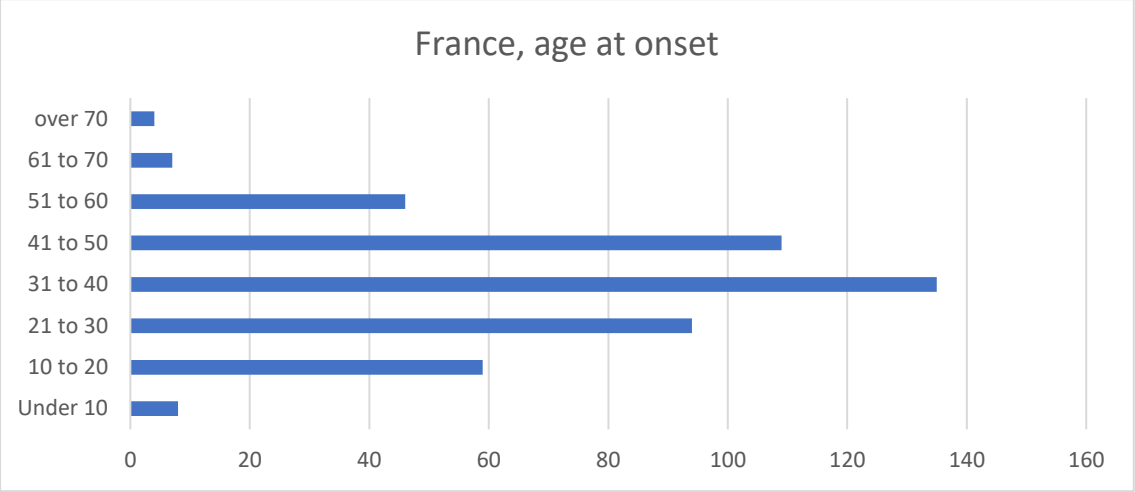
The most common trigger was infectious disease.



Country Figure 52: France, triggers, n=456

1.7.8 Age at onset

Average age of onset was 35.2 years. The graph below shows the distribution of age at onset.

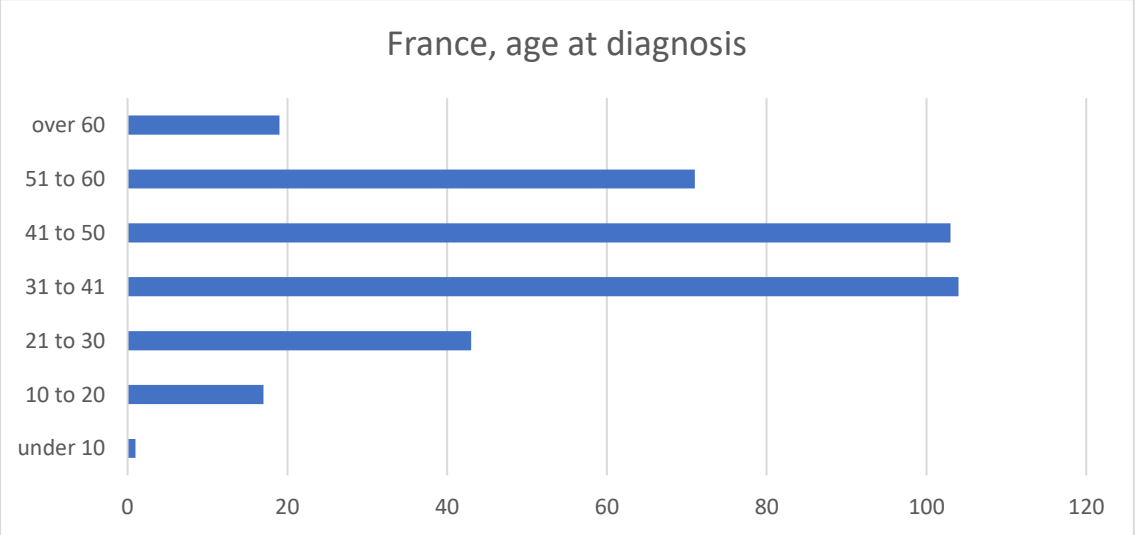


Country Figure 53: France, age at onset, n=456

1.7.9 Time from onset to diagnosis

Average time from onset to diagnosis was 6.7 years overall, both for men and women.

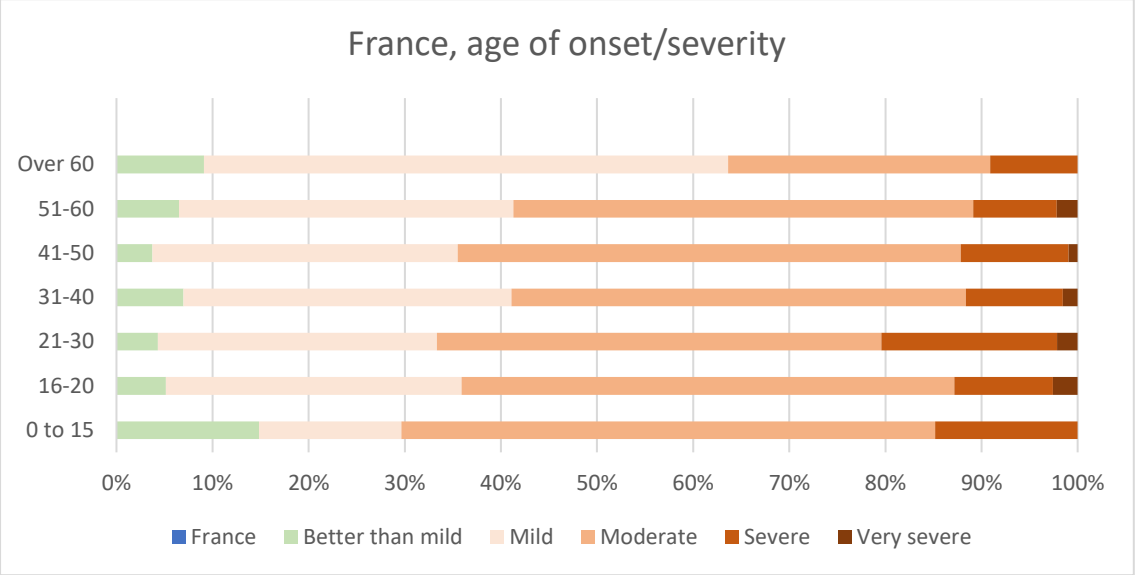
Average age at diagnosis was 42 years.



Country Figure 54: France, age at diagnosis, n=342

1.7.10 Age at onset and severity

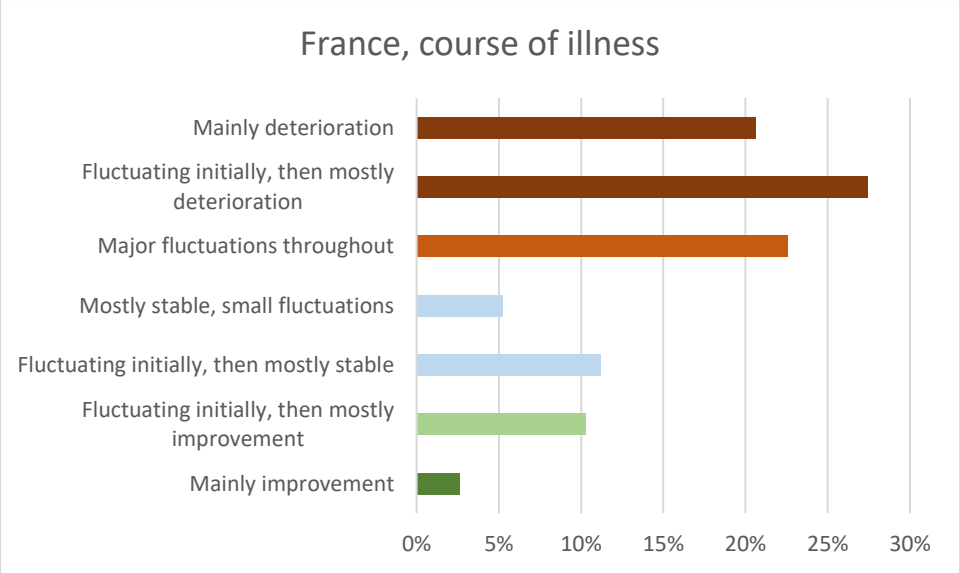
Severe or very severe disease was more common among patients who had early onset, regardless of disease duration.



Country Figure 55: France, age of onset and severity, n=456

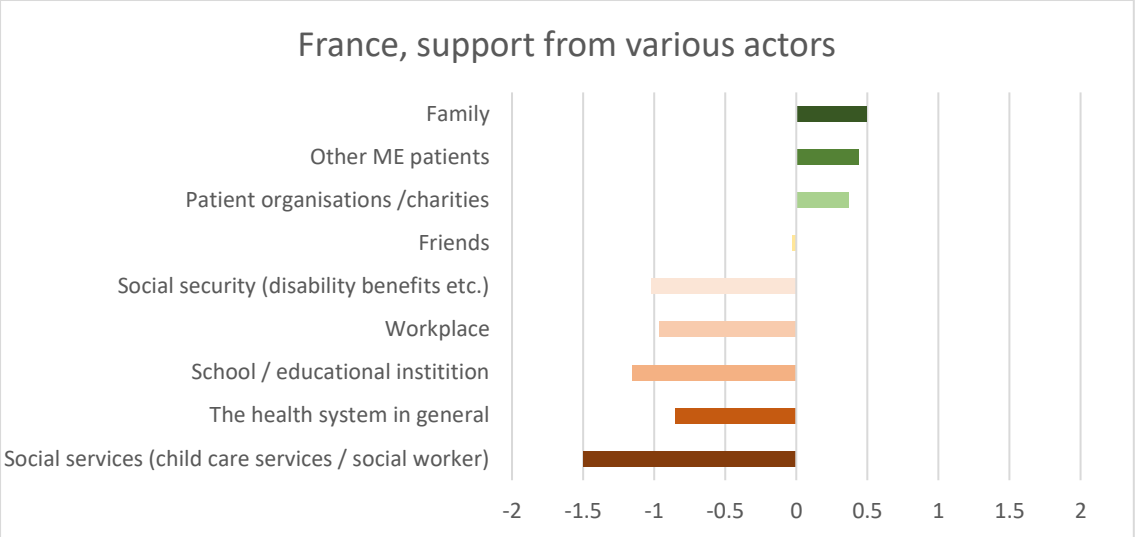
1.7.11 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In France, 71% of respondents had experienced deterioration or major fluctuations, 16% said they were mostly stable, and 13% had experienced mainly improvement.



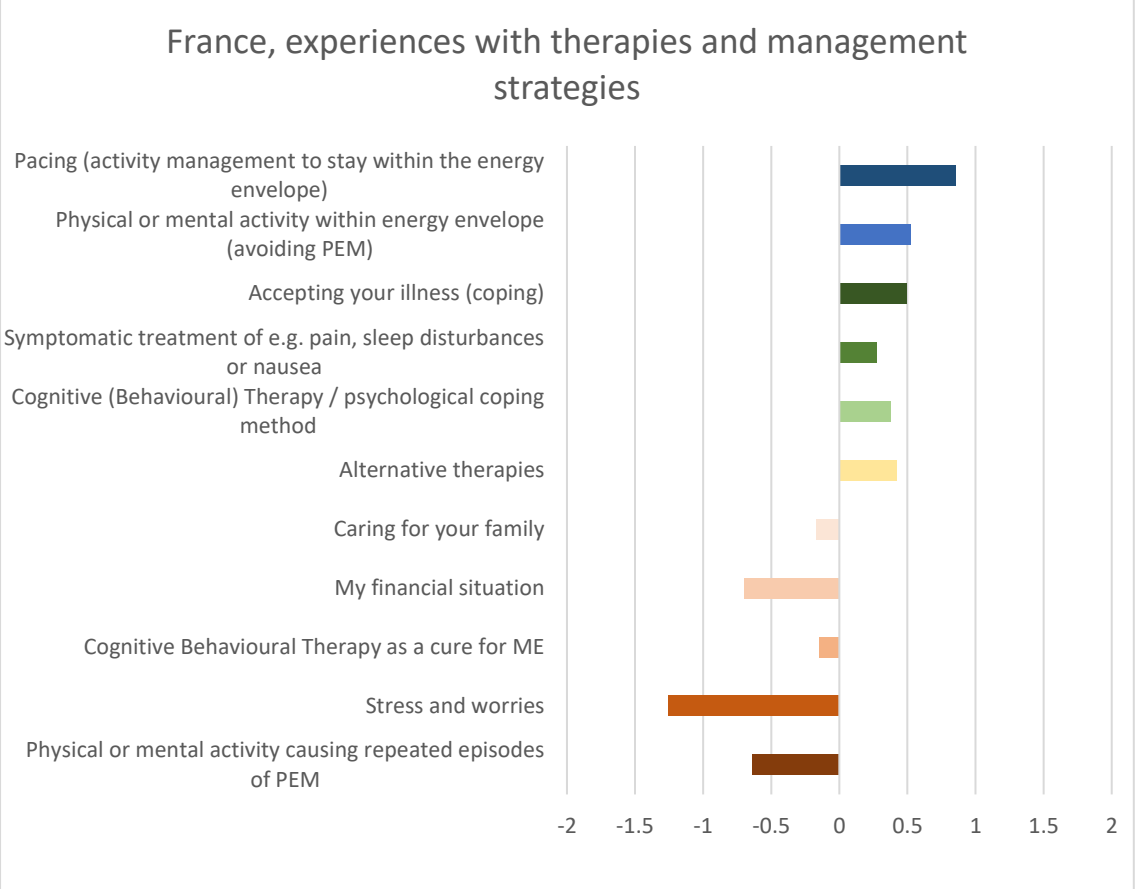
Country Figure 56: France, course of illness, n=456

1.7.12 Experienced support from various actors



Country Figure 57: France, support from various actors

1.7.13 Experiences with management strategies and therapies



Country Figure 58: France, experience with management strategies and therapies

1.8 Germany

1.8.1 Respondents

There were 1228 respondents from Germany.

80% of respondents had received a diagnosis, 7% were currently under evaluation for a diagnosis, and 13% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.8.2 Age

Average age of respondents was 47.7 years.

1.8.3 Gender

79% of respondents were female, 21% male, less than 1% preferred not to say.

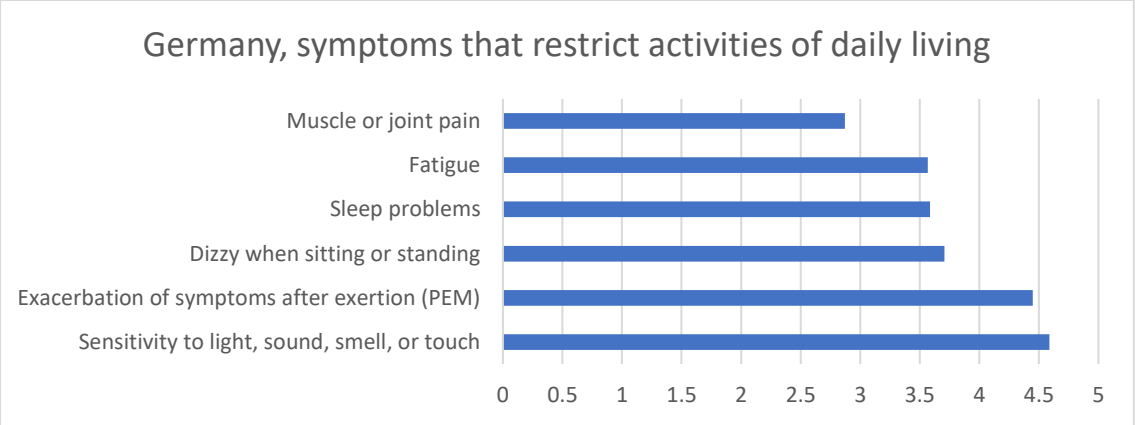
1.8.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

5% of respondents said that their disease was better than mild, 22% had mild, 48% moderate, 21% severe and 5% very severe ME/CFS.

1.8.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found sensitivity to light and sound and PEM the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

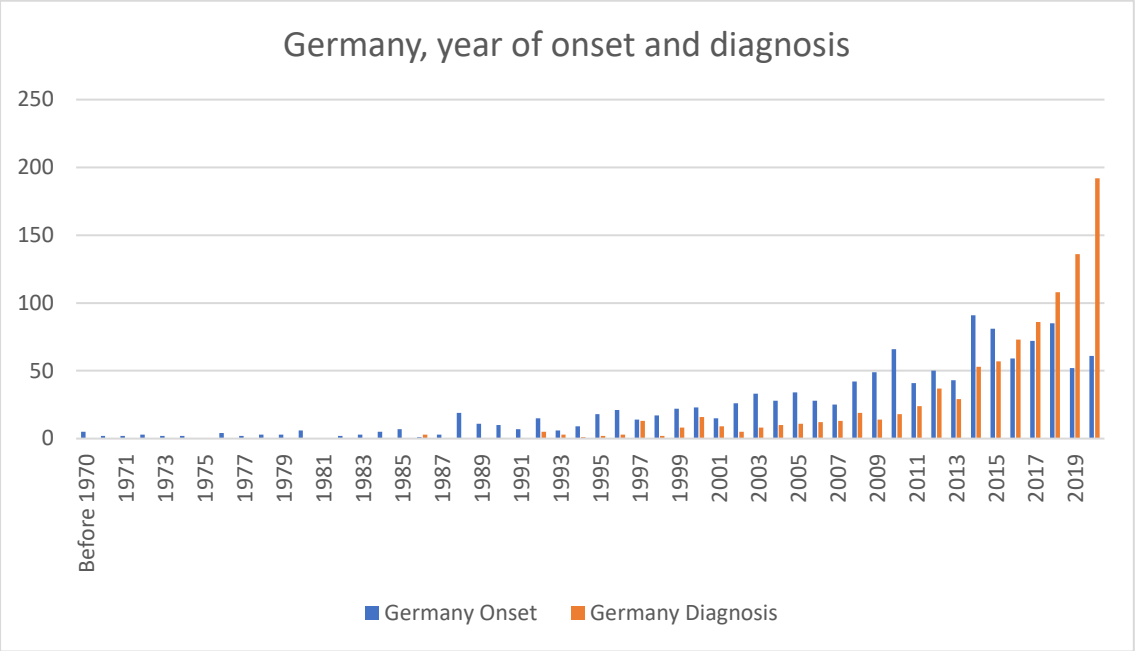


Country Figure 59: Germany, symptoms that restrict activities of daily living, n=1228

1.8.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

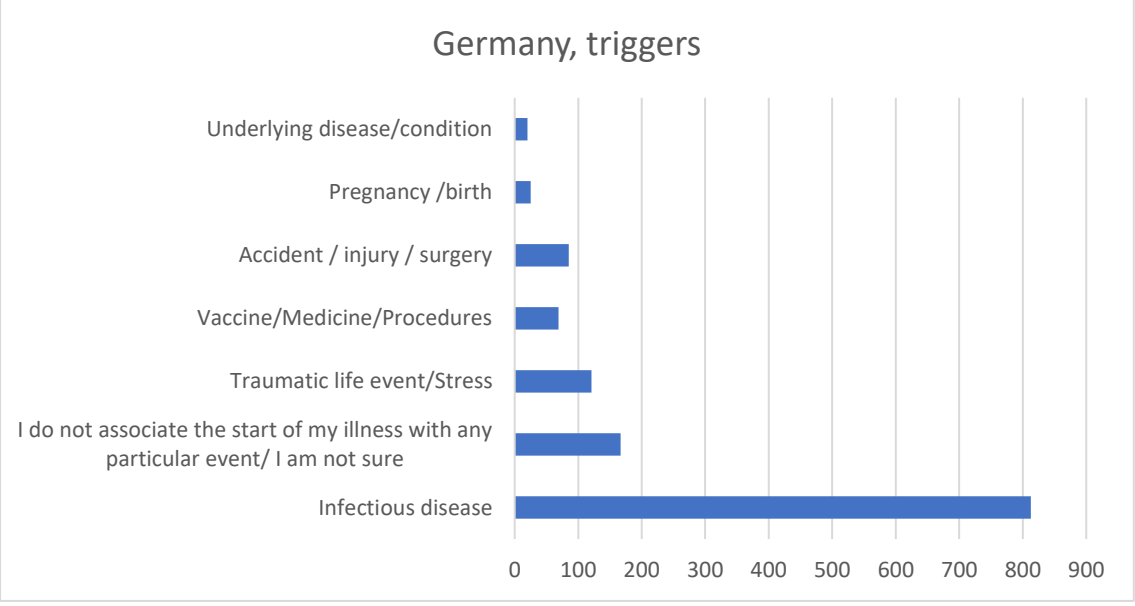
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 60: Germany, year of onset and diagnosis

1.8.7 Triggers

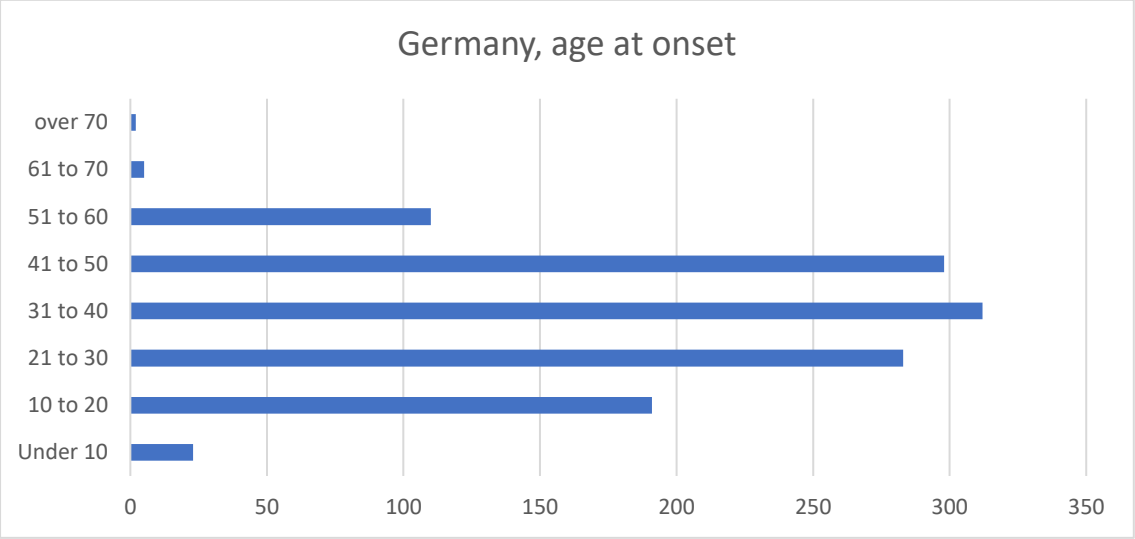
The most common trigger was infectious disease.



Country Figure 61: Germany, triggers, n=1228

1.8.8 Age at onset

Average age of onset was 33.9 years. The graph below shows the distribution of age at onset.

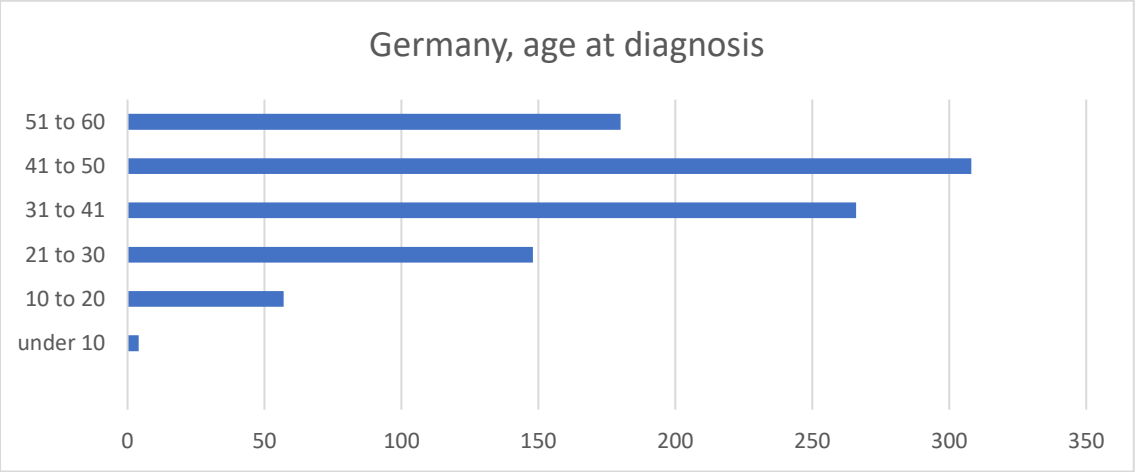


Country Figure 62: Germany, age at onset, n=1228

1.8.9 Time from onset to diagnosis

Average time from onset to diagnosis was 7.1 years overall, 6 years for men and 7.4 years for women.

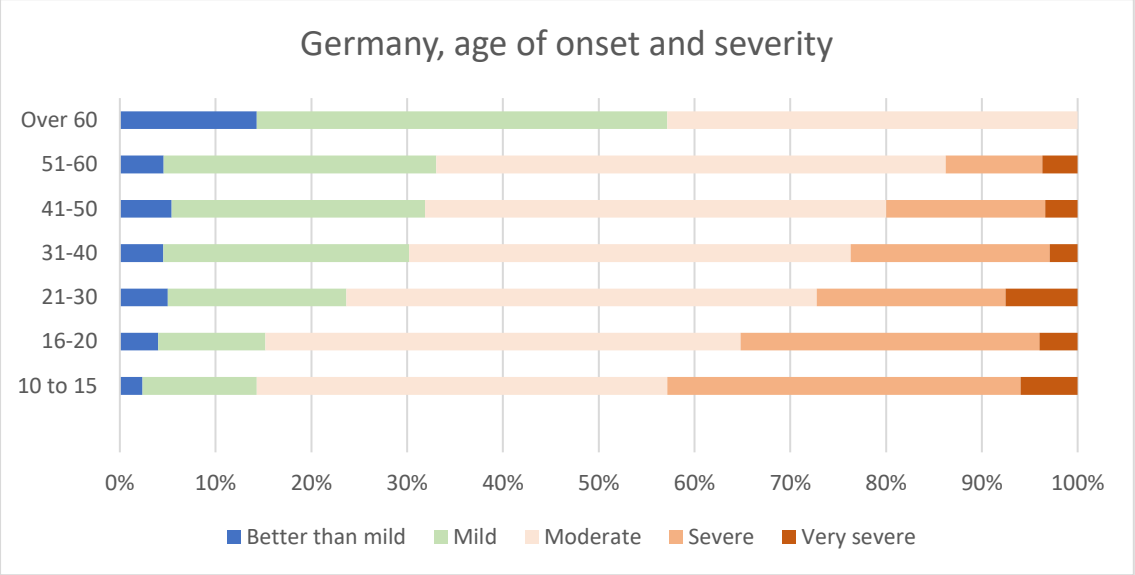
Average age at diagnosis was 40.6 years.



Country Figure 63: Germany, age at diagnosis, n=982

1.8.10 Age at onset and severity

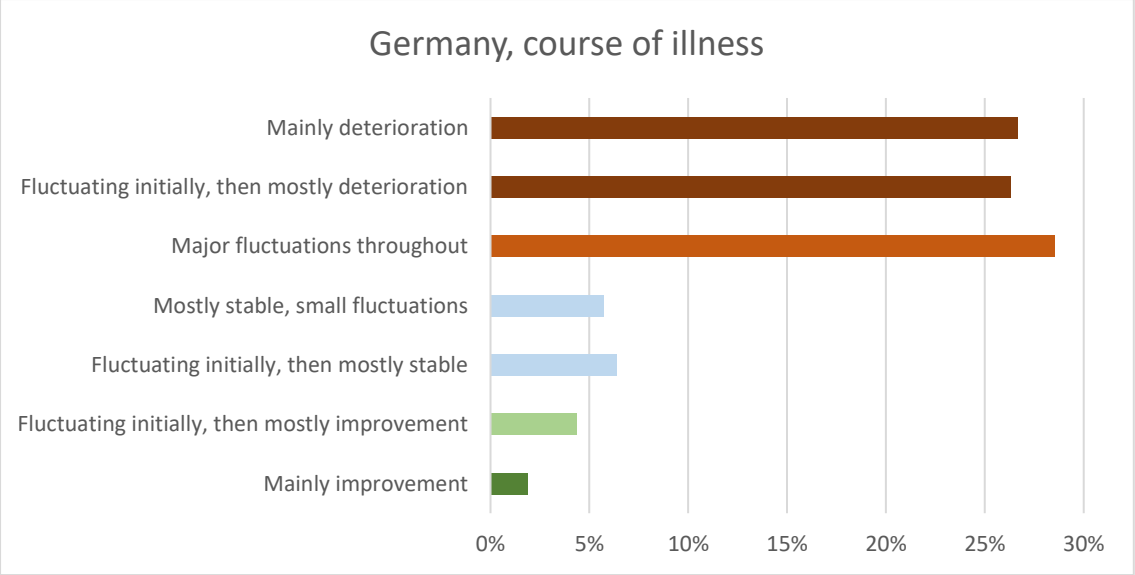
Severe or very severe disease was more common among patients who had early onset, regardless of disease duration.



Country Figure 64: Germany, age at onset and severity, n=1228

1.8.11 Course of illness

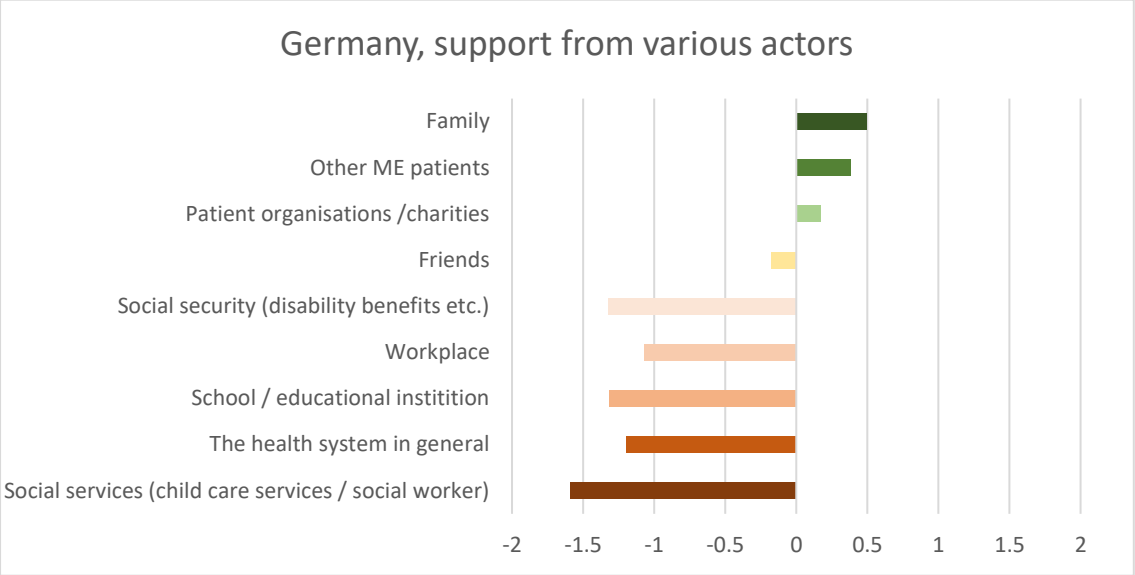
We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Germany, 82% of respondents had experienced deterioration or major fluctuations, 12% said they were mostly stable, and 6% had experienced mainly improvement.



Country Figure 65: Germany, course of illness, n=1228

1.8.12 Experienced support from various actors

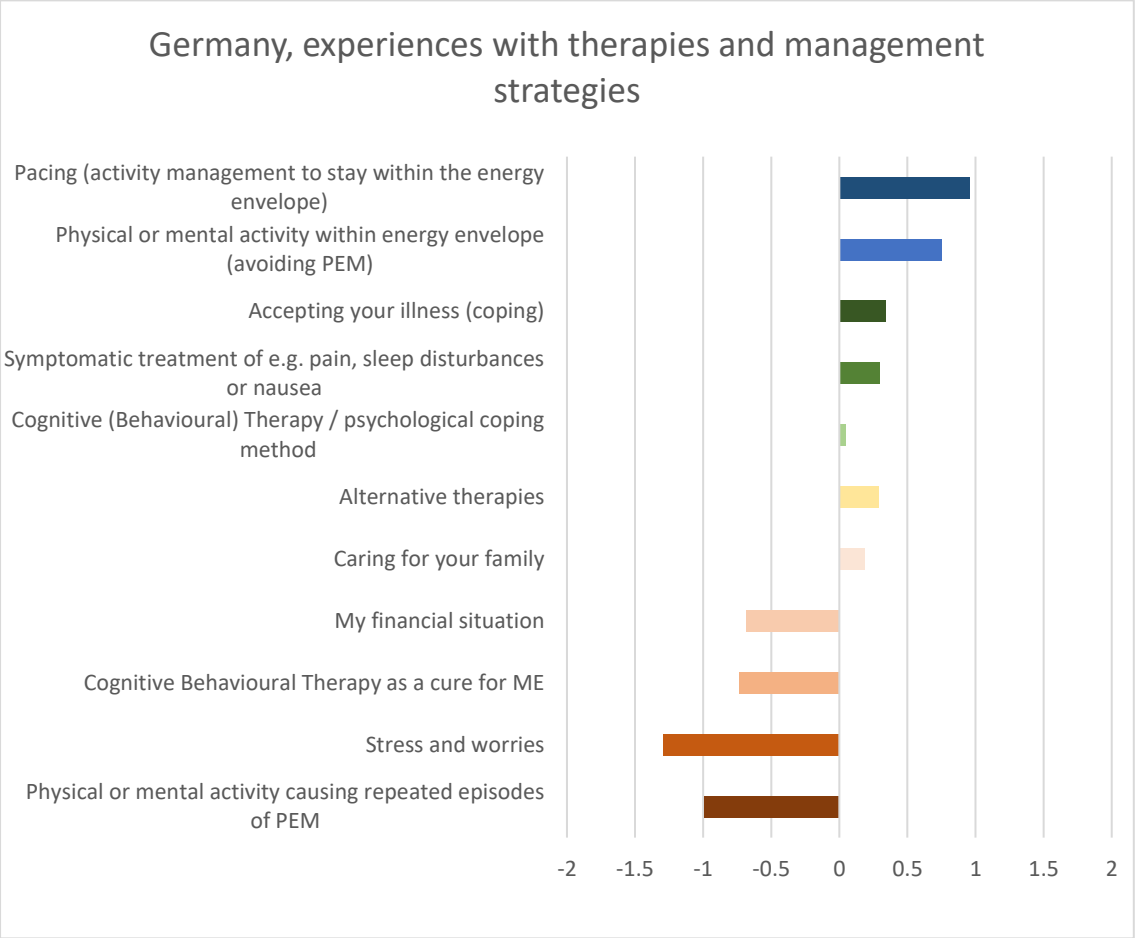
German respondents fell that the only actors who have given some support are family, other ME patients and patient organisations/charities.



Country Figure 66: Germany, support from various actors

1.8.13 Experiences with management strategies and therapies

"Stress and worries" was the factor that was having the largest negative impact on the disease. Cognitive therapy as a cure for ME, together with activity causing repeated episodes of PEM are also seen to have a negative impact. The most positive management strategy is pacing, or finding a balance between activity and rest that avoids PEM.



Country Figure 67: Germany, experience with therapies and management strategies

1.9 Iceland

1.9.1 Respondents

There were 122 respondents from Iceland.

57% of respondents had received a diagnosis, 8% were currently under evaluation for a diagnosis, and 35% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.9.2 Age

Average age of respondents was 52.4 years.

1.9.3 Gender

93% of respondents were female, 7% male.

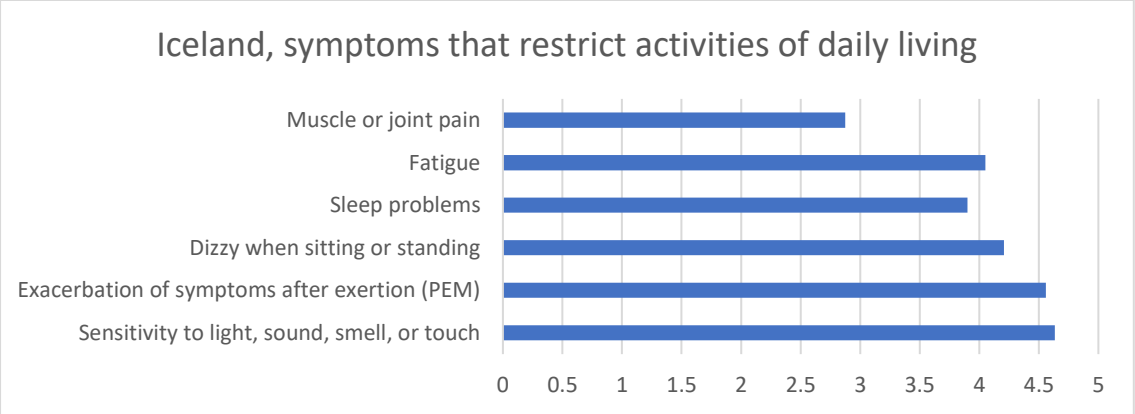
1.9.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

8% of respondents said that their disease was better than mild, 33% had mild, 52% moderate, 8% severe and none very severe ME/CFS.

1.9.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found sensitivity to light and sound and PEM the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

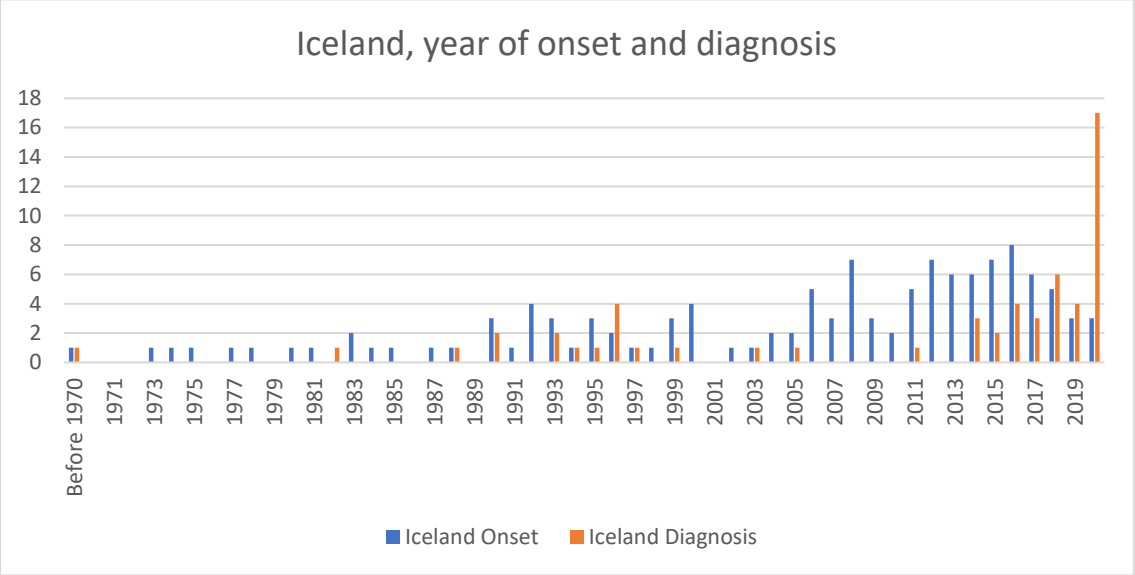


Country Figure 68: Iceland, symptoms that restrict activities of daily living, n=122

1.9.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

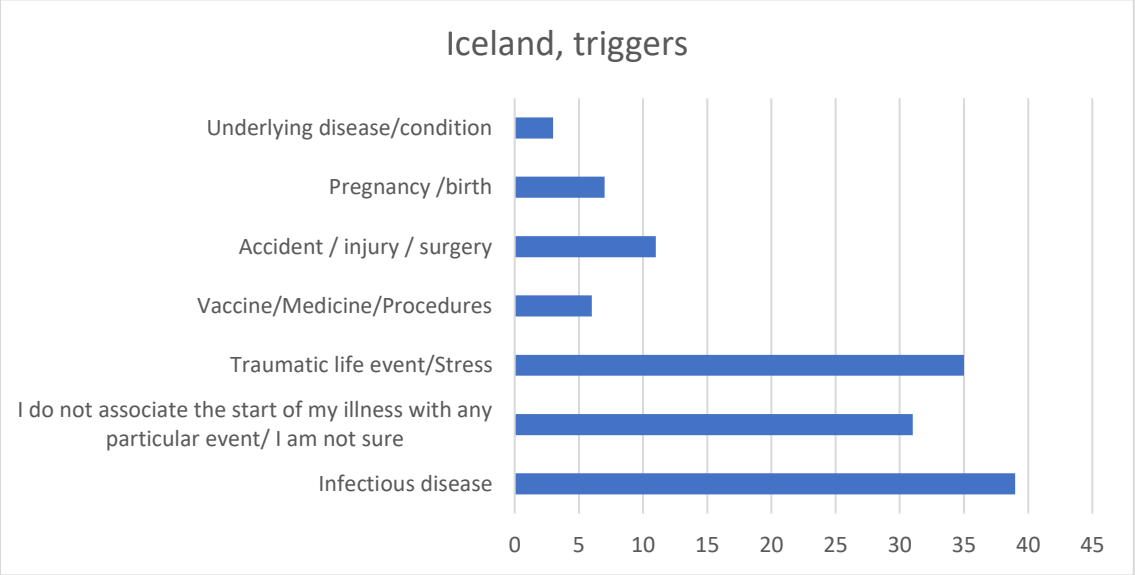
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 69: Iceland, year of onset and diagnosis

1.9.7 Triggers

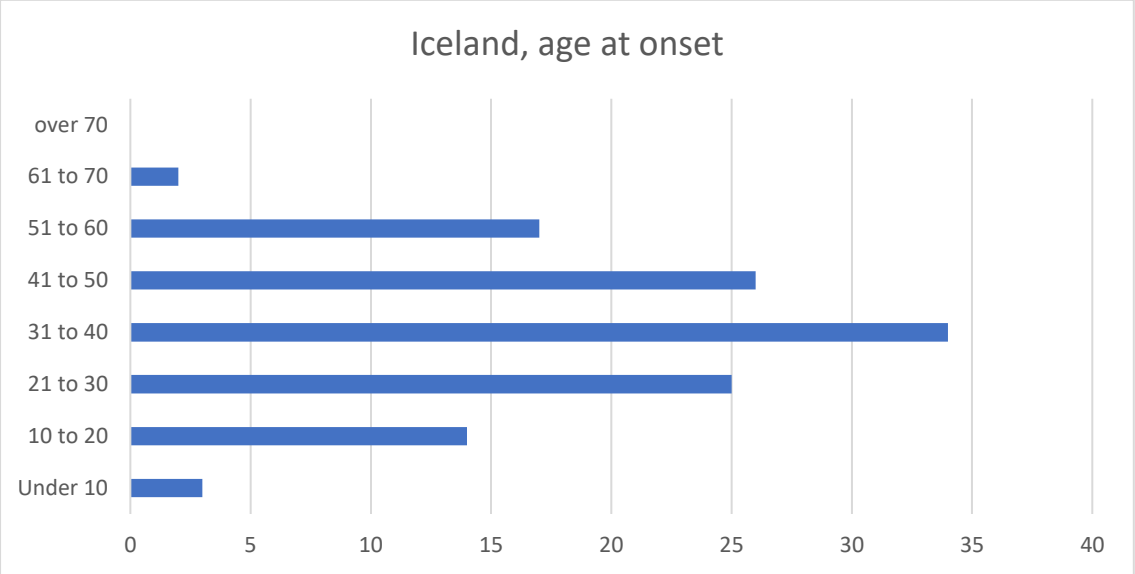
The event most often associated with onset was infectious disease, though many also associated onset with traumatic life events.



Country Figure 70: Iceland, triggers, n=122

1.9.8 Age at onset

Average age of onset was 35.3 years. The graph below shows the distribution of age at onset.

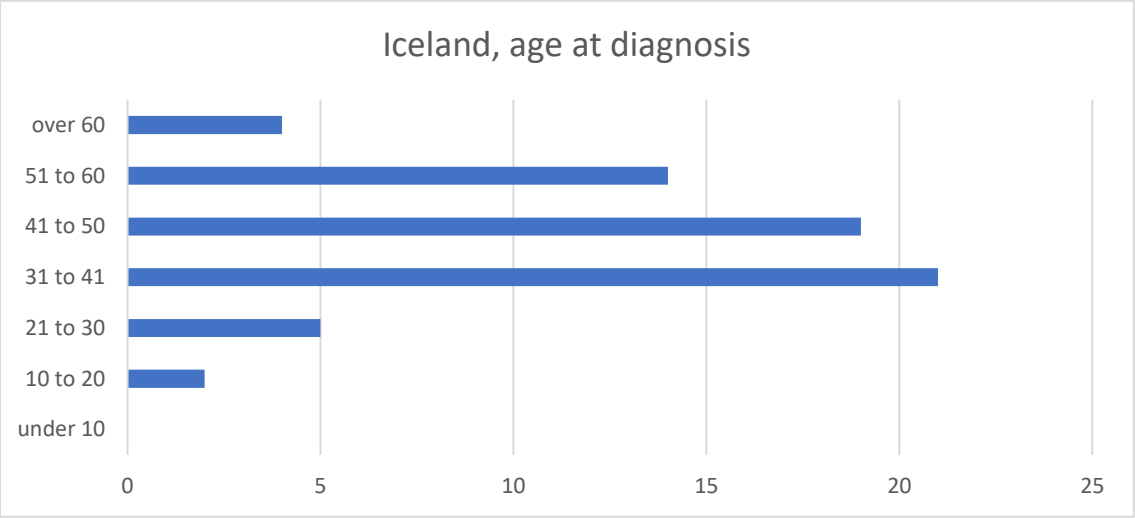


Country Figure 71: Iceland, age at onset, n=122

1.9.9 Time from onset to diagnosis

Average time from onset to diagnosis was 8.4 years overall, 7.2 years for men and 8.6 years for women.

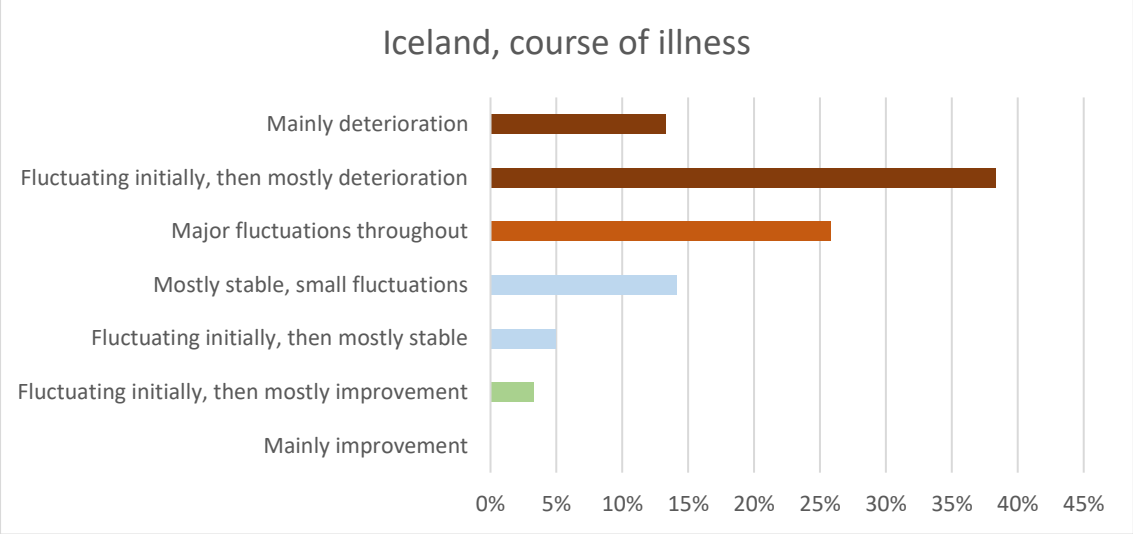
Average age at diagnosis was 42.2 years.



Country Figure 72: Iceland, age at diagnosis, n=69

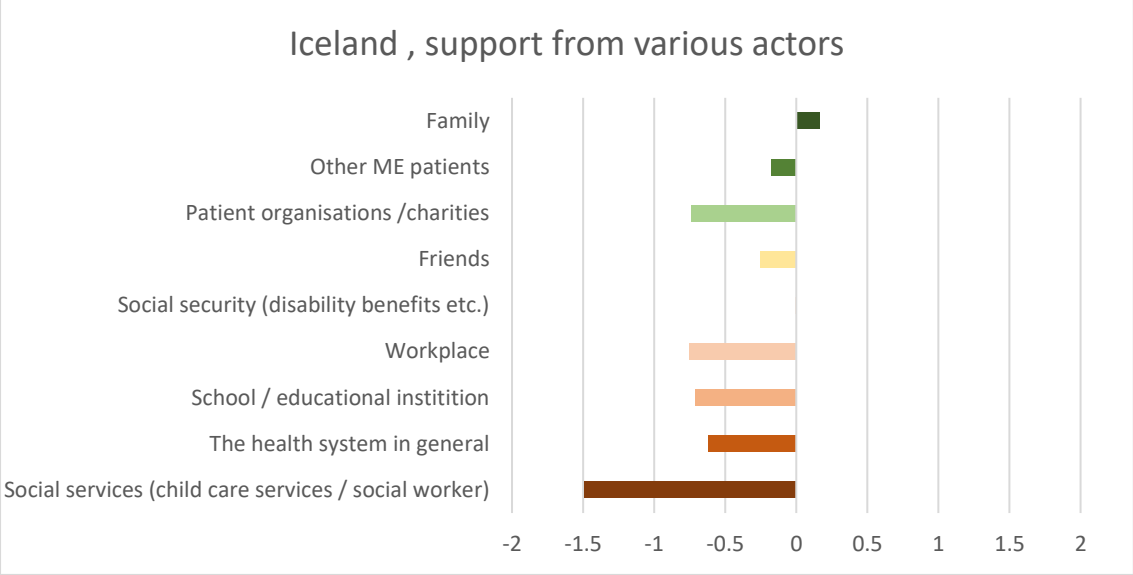
1.9.10 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Iceland, 78% of respondents had experienced deterioration or major fluctuations, 19% said they were mostly stable, and 3% had experienced mainly improvement.



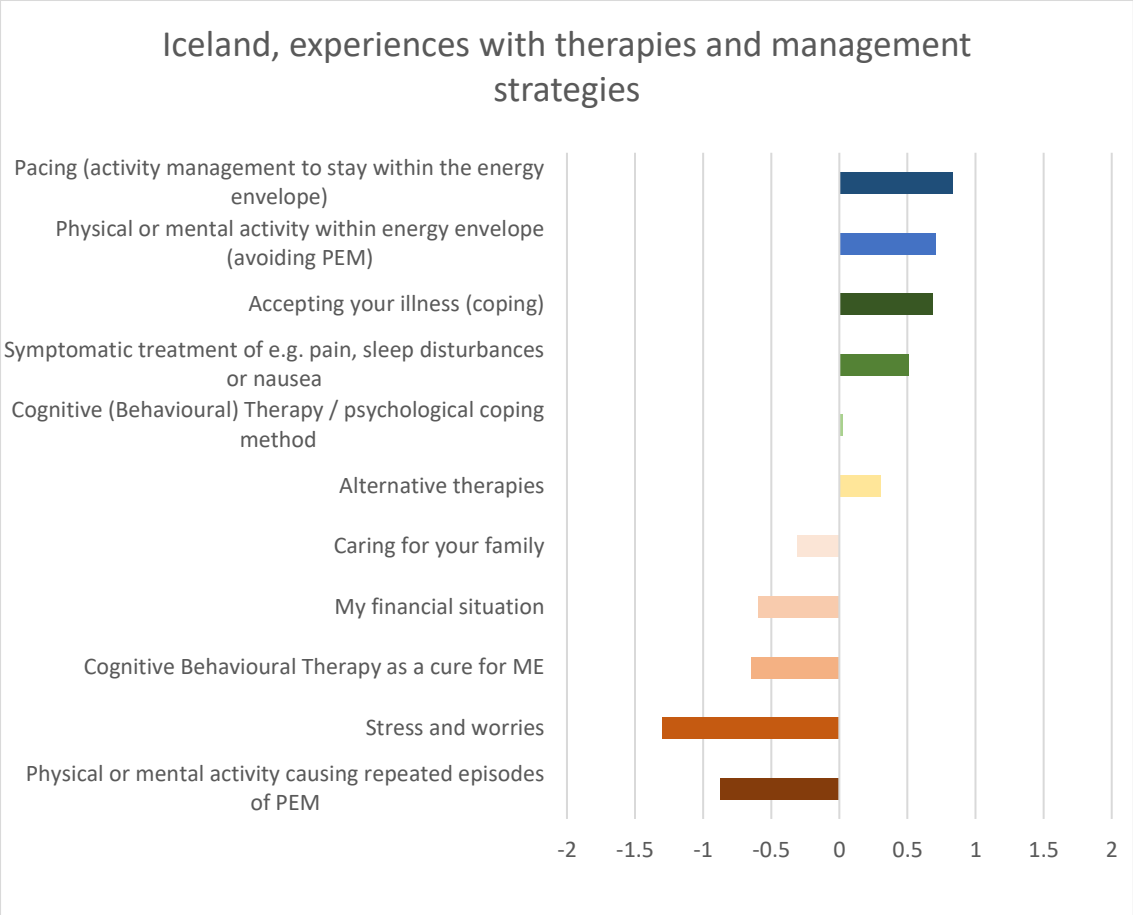
Country Figure 73: Iceland, course of illness, n=122

1.9.11 Experienced support from various actors



Country Figure 74: Iceland, support from various actors

1.9.12 Experiences with management strategies and therapies



Country Figure 75: Iceland, support from various actors

1.10 Ireland

1.10.1 Respondents

There were 112 respondents from Ireland.

92% of respondents had received a diagnosis, 1% were currently under evaluation for a diagnosis, and 7% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.10.2 Age

Average age of respondents was 50 years.

1.10.3 Gender

84% of respondents were female, 16% male.

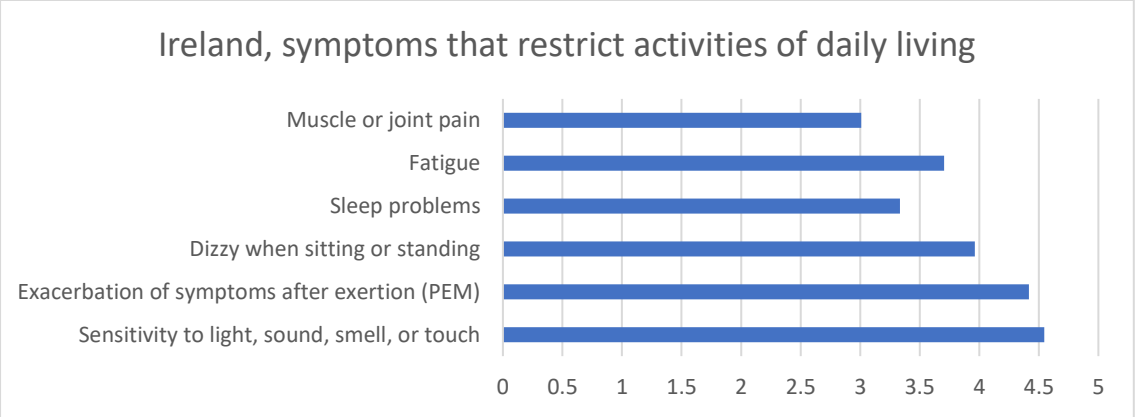
1.10.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

6% of respondents said that their disease was better than mild, 35% had mild, 43% moderate, 16% severe and none very severe ME/CFS.

1.10.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found sensitivity to light and sound and PEM the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

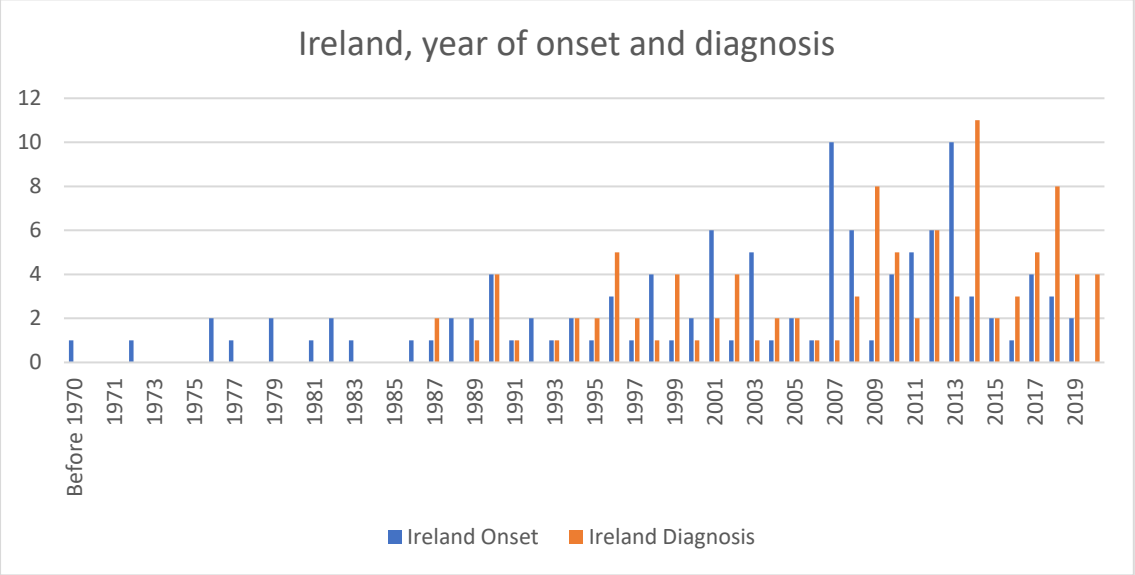


Country Figure 76:Ireland, symptoms that restrict activities of daily living, n=112

1.10.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

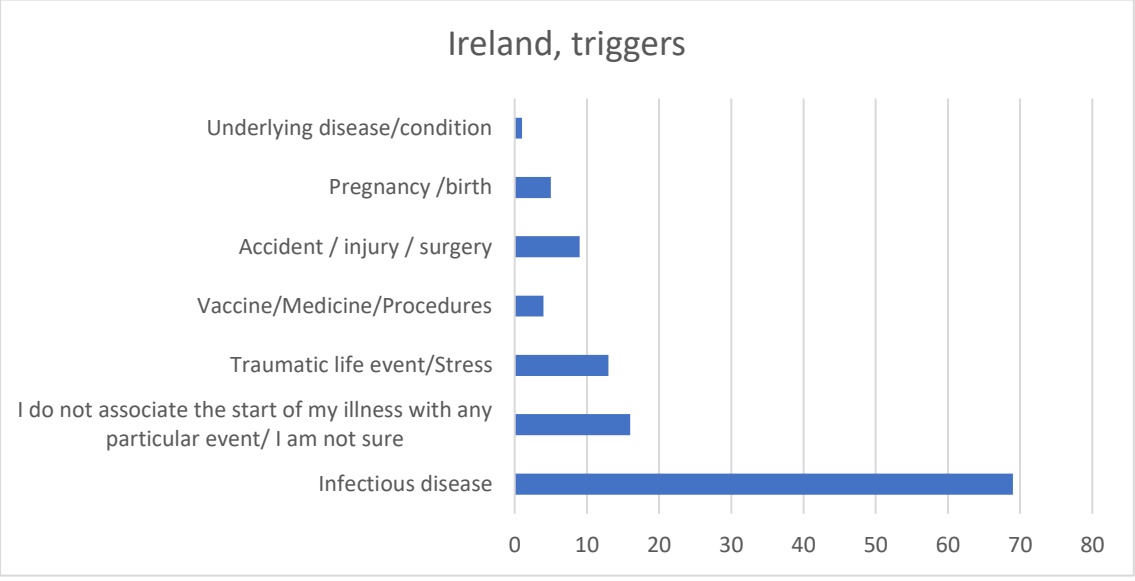
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 77: Ireland, year of onset and diagnosis

1.10.7 Triggers

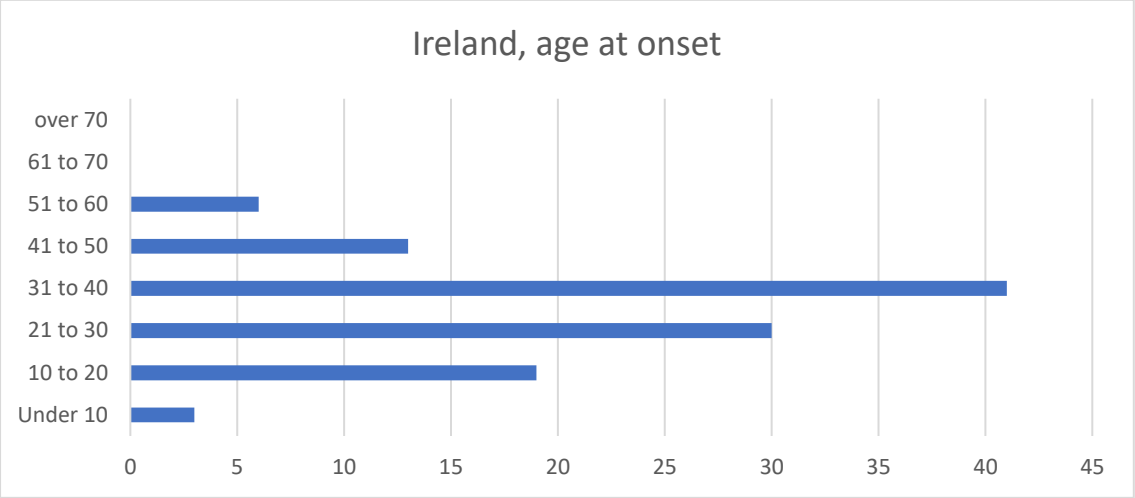
The most common trigger was infectious disease.



Country Figure 78: Ireland, triggers, n=112

1.10.8 Age at onset

Average age of onset was 30.4 years. The graph below shows the distribution of age at onset.

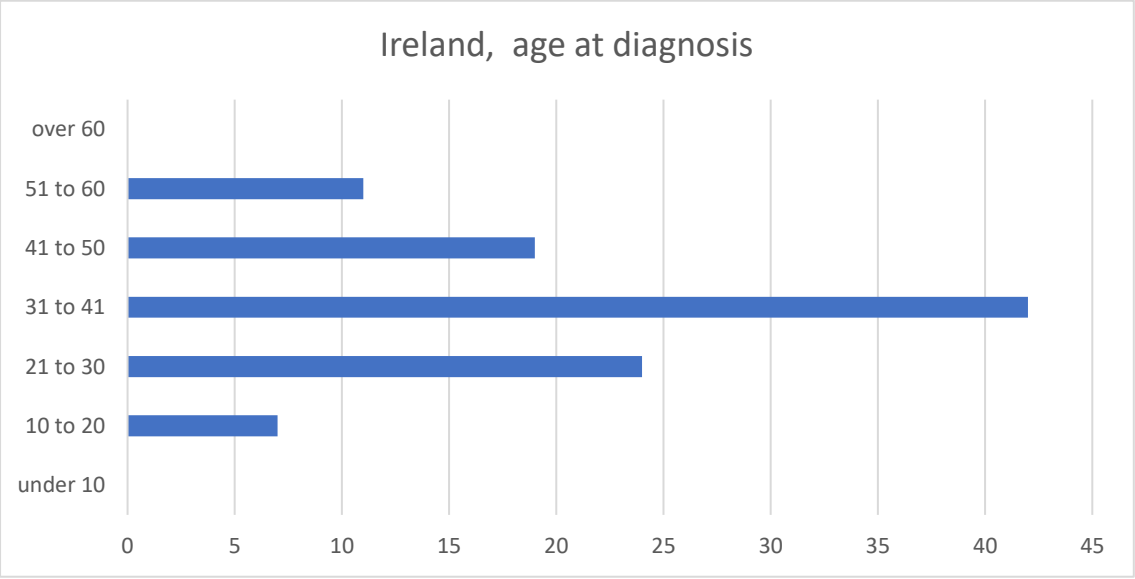


Country Figure 79:Ireland, age at onset, n=112

1.10.9 Time from onset to diagnosis

Average time from onset to diagnosis was 5.2 years overall, 3.9 years for men and 5.5 years for women.

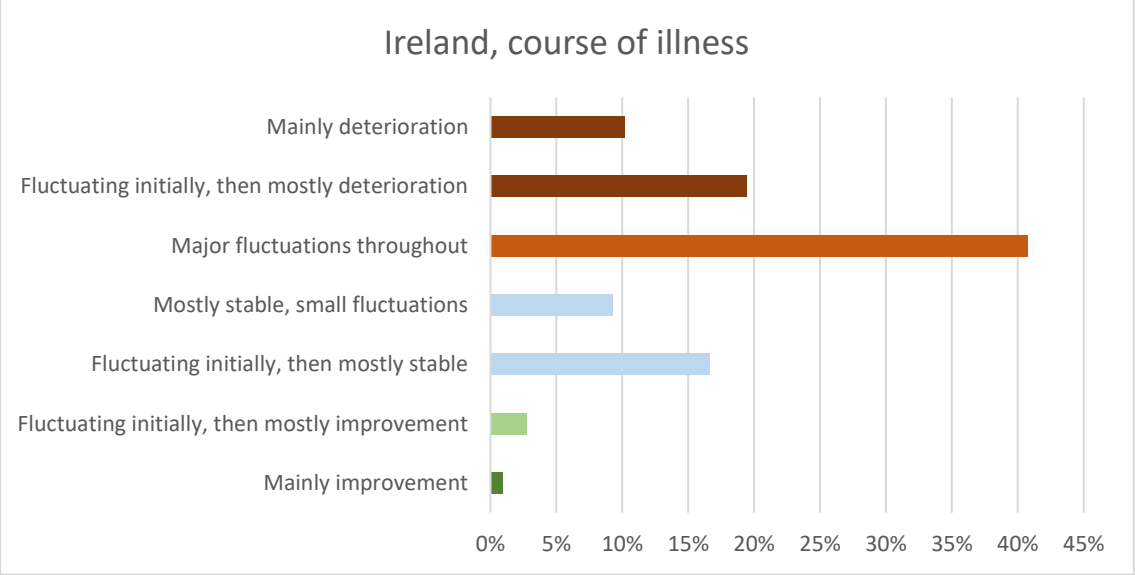
Average age at diagnosis was 35.5 years.



Country Figure 80: Ireland, age at diagnosis, n=103

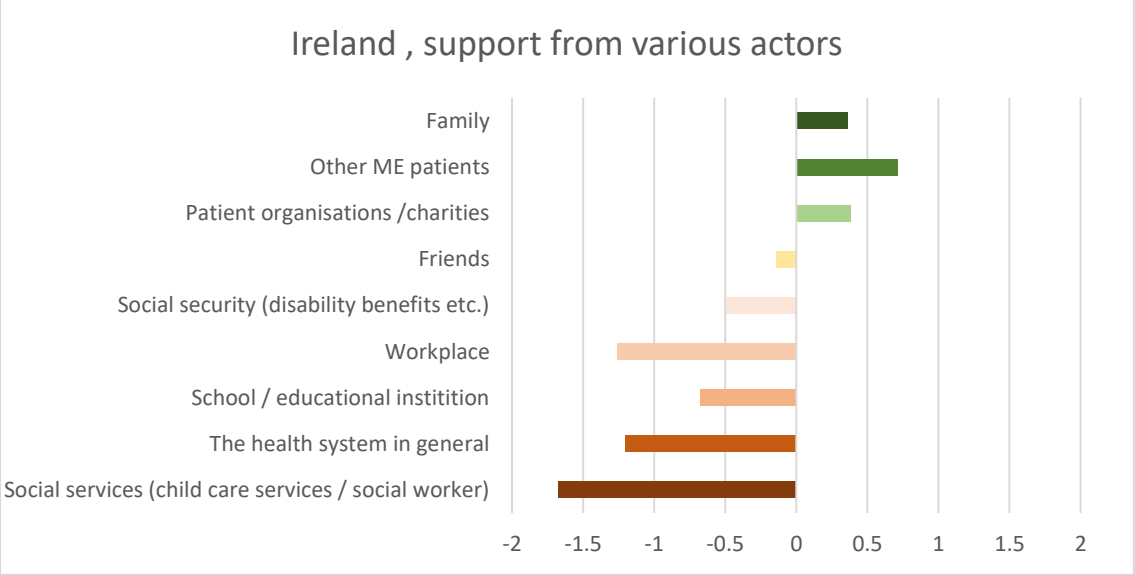
1.10.10 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Ireland, 70% of respondents had experienced deterioration or major fluctuations, 26% said they were mostly stable, and 4% had experienced mainly improvement.



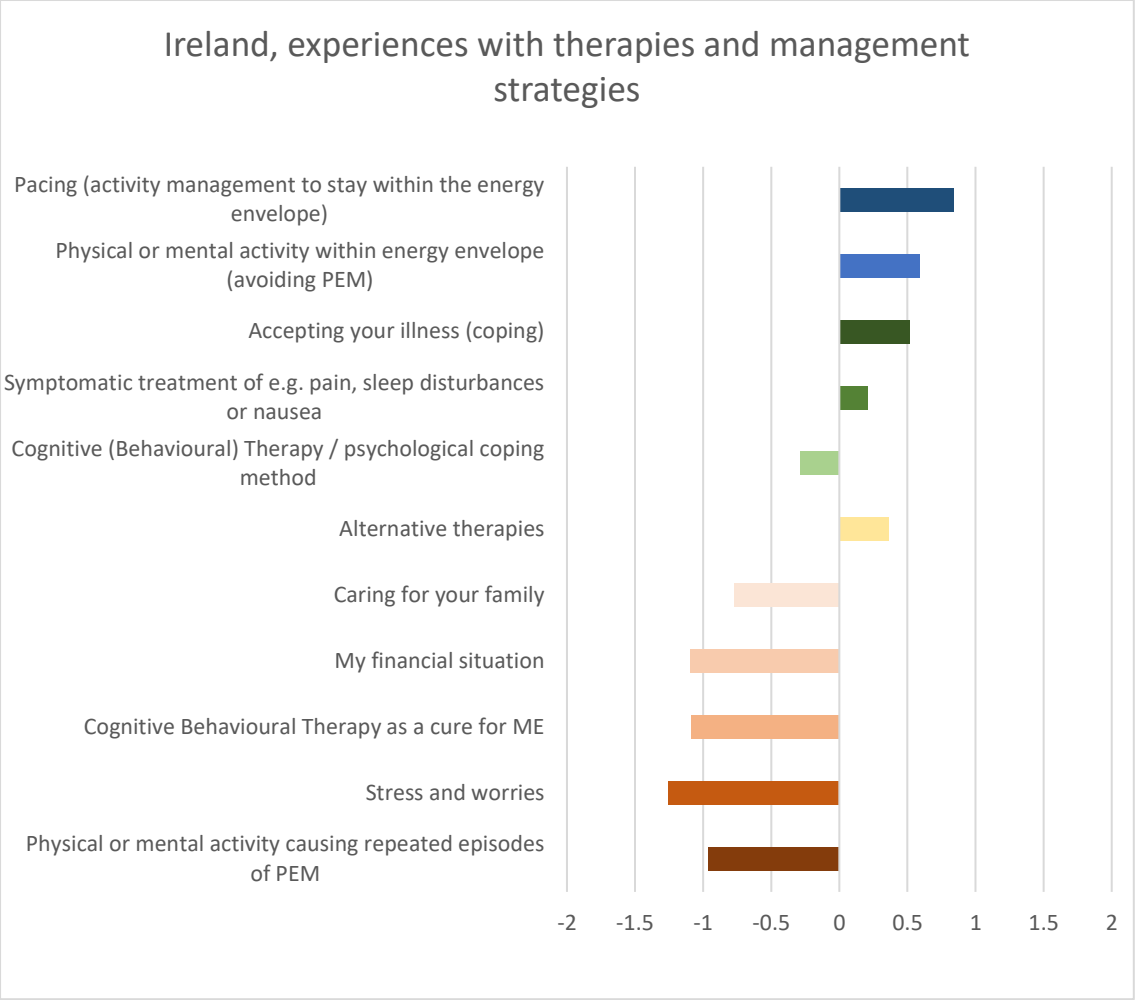
Country Figure 81: Ireland, course of illness, n=112

1.10.11 Experienced support from various actors



Country Figure 82:Ireland, support from various actors

1.10.12 Experiences with management strategies and therapies



Country Figure 83: Ireland, experiences with management strategies and therapies

1.11 Italy

1.11.1 Respondents

There were 87 respondents from Italy.

79% of respondents had received a diagnosis, 7% were currently under evaluation for a diagnosis, and 14% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.11.2 Age

Average age of respondents was 44.7 years.

1.11.3 Gender

74% of respondents were female, 26% male.

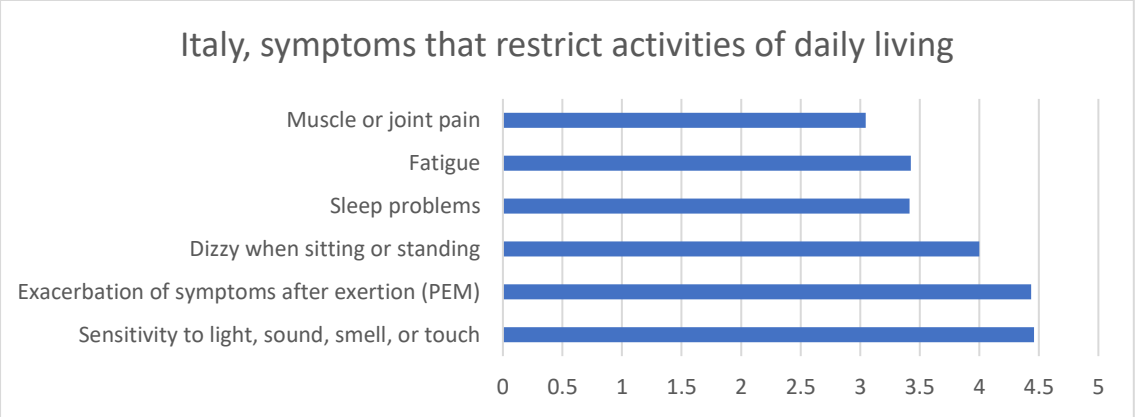
1.11.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

6% of respondents said that their disease was better than mild, 18% had mild, 46% moderate, 24% severe and 7% very severe ME/CFS.

1.11.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found sensitivity to light and sound and PEM the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

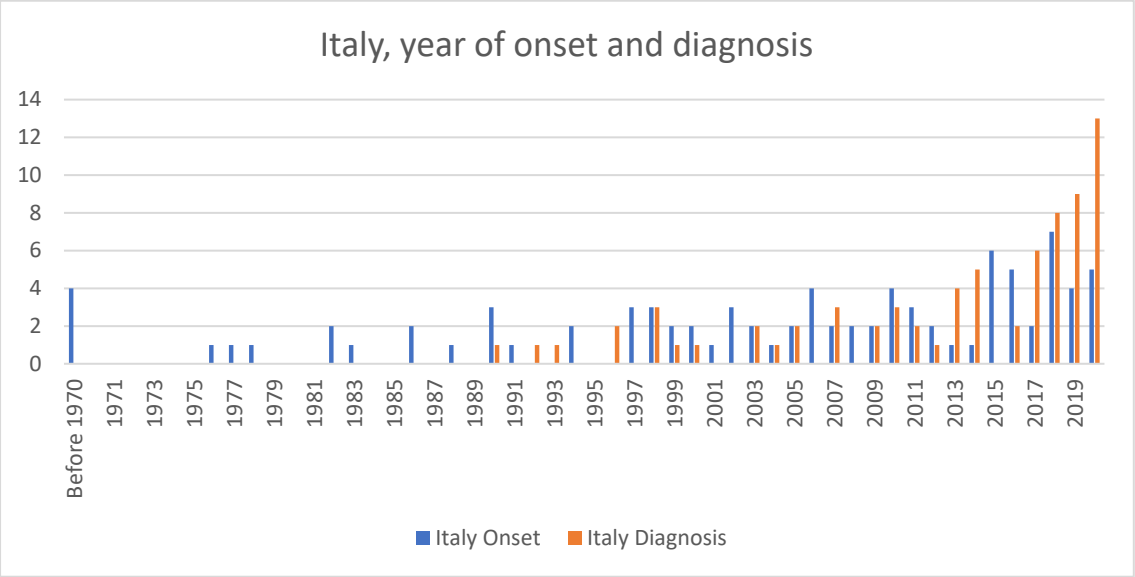


Country Figure 84: Italy, symptoms that restrict activities of daily living, n=87

1.11.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

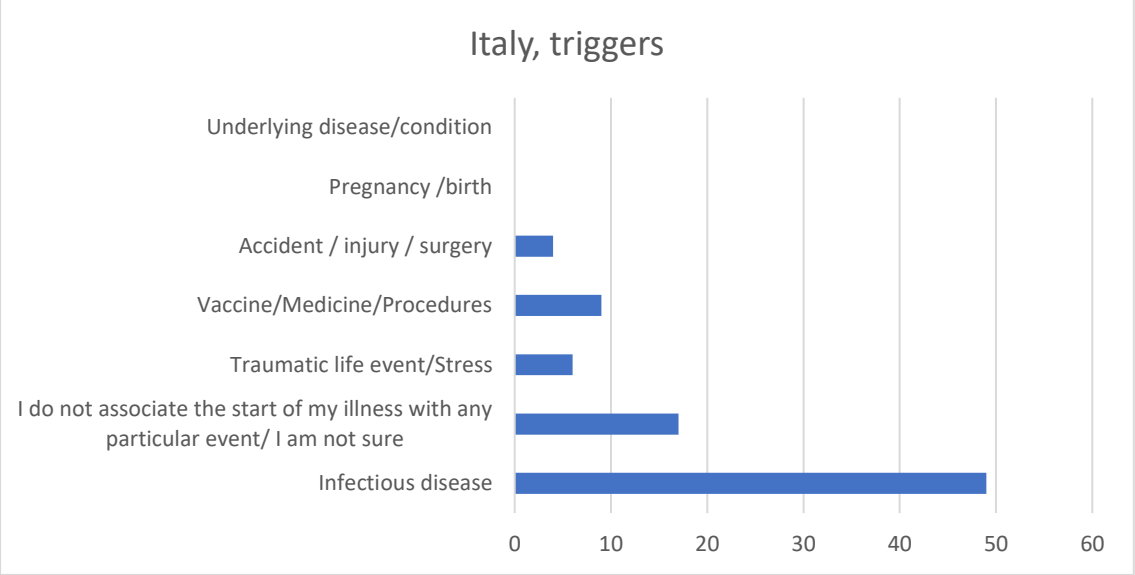
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 85: Italy, year of onset and diagnosis, n=87

1.11.7 Triggers

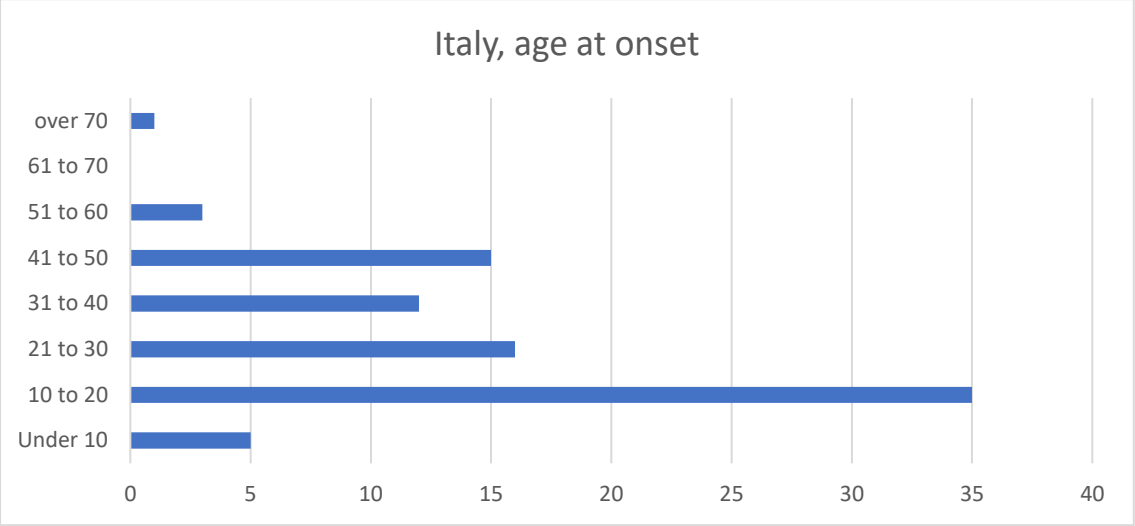
The most common trigger was infectious disease.



Country Figure 86: Italy, triggers, n=87

1.11.8 Age at onset

Average age of onset was 26.7 years. The graph below shows the distribution of age at onset.

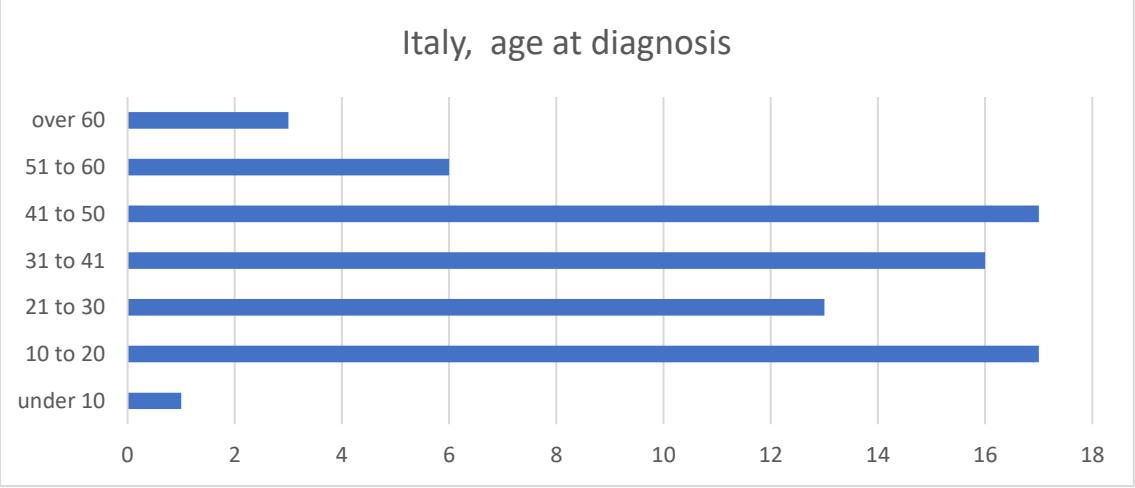


Country Figure 87: Italy, age at onset, n=87

1.11.9 Time from onset to diagnosis

Average time from onset to diagnosis was 6 years overall, 3.6 years for men and 6.6 years for women.

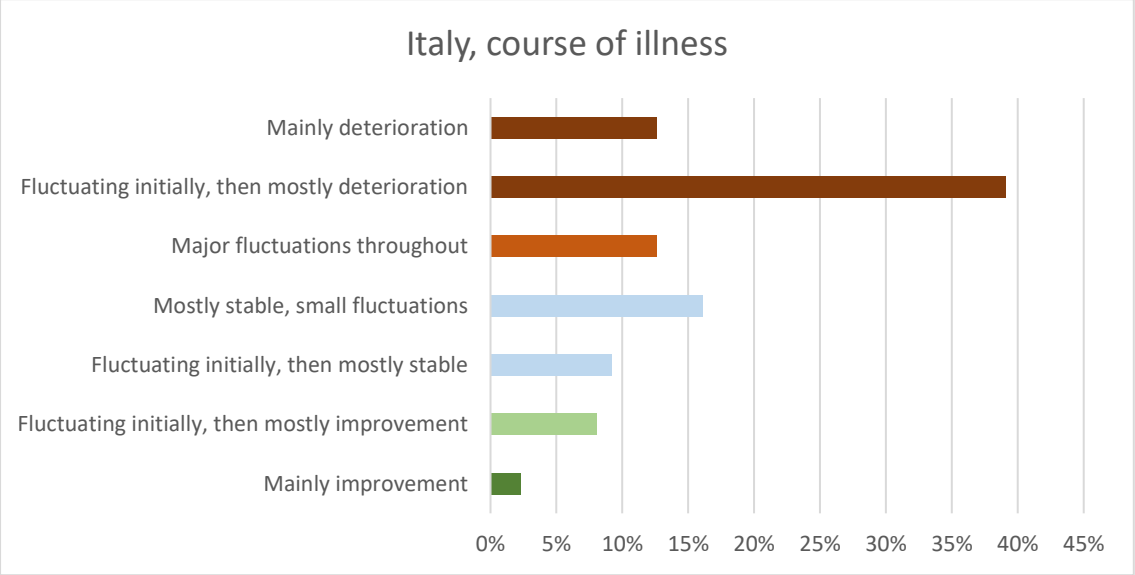
Average age at diagnosis was 33.8 years.



Country Figure 88: Italy, age at diagnosis, n=69

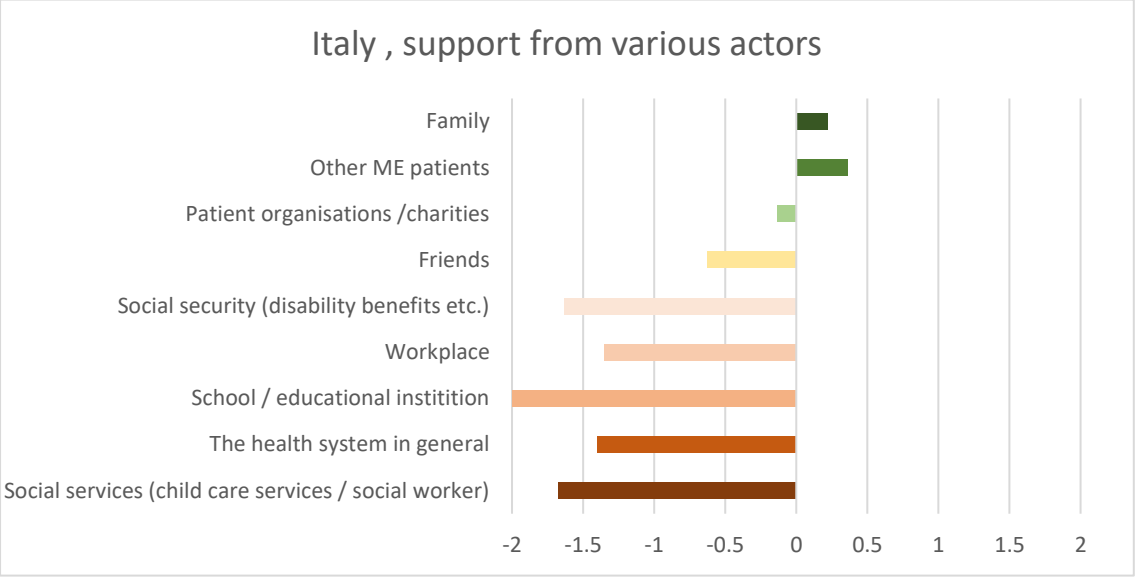
1.11.10 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Italy, 64% of respondents had experienced deterioration or major fluctuations, 25% said they were mostly stable, and 10% had experienced mainly improvement.



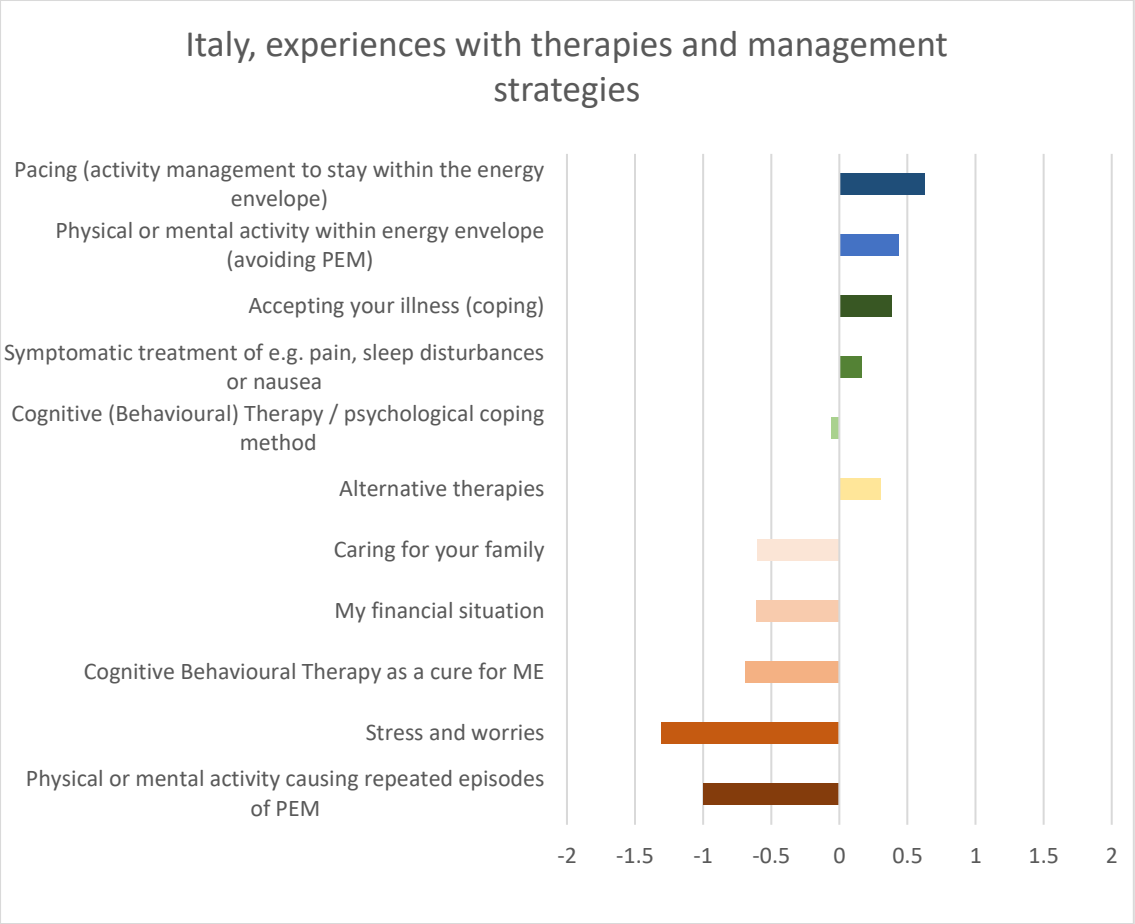
Country Figure 89: Italy, course of illness, n=87

1.11.11 Experienced support from various actors



Country Figure 90:Italy, support from various actors

1.11.12 Experiences with management strategies and therapies



Country Figure 91: Italy, experience with therapies and management strategies

1.12 Norway

1.12.1 Respondents

There were 3117 respondents from Norway.

2956 of respondents had received a diagnosis, 98 were currently under evaluation for a diagnosis, and 76 believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.12.2 Age

Average age of respondents was 44.3 years.

1.12.3 Gender

87% of respondents were female, 13% male, less than 1% preferred not to say.

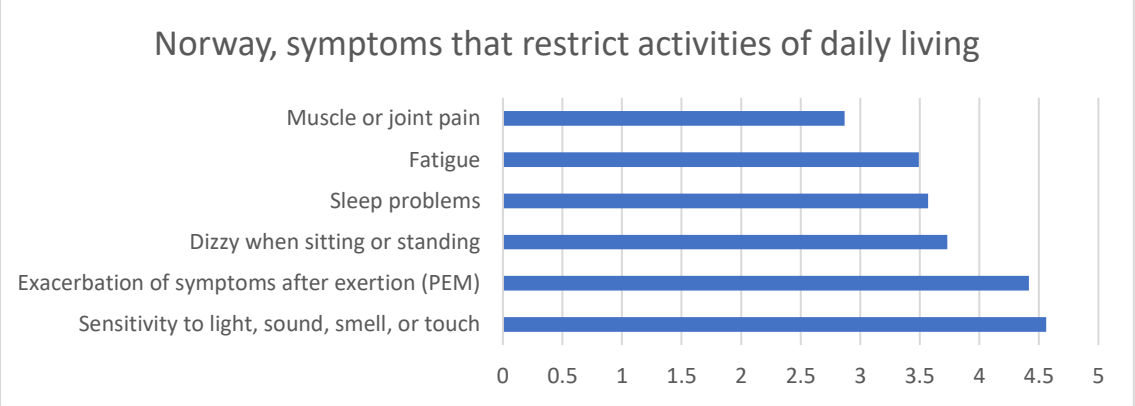
1.12.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

2% of respondents said that their disease was better than mild, 27% had mild, 59% moderate, 11% severe and 2% very severe ME/CFS.

1.12.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found sensitivity to light and sound and PEM the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

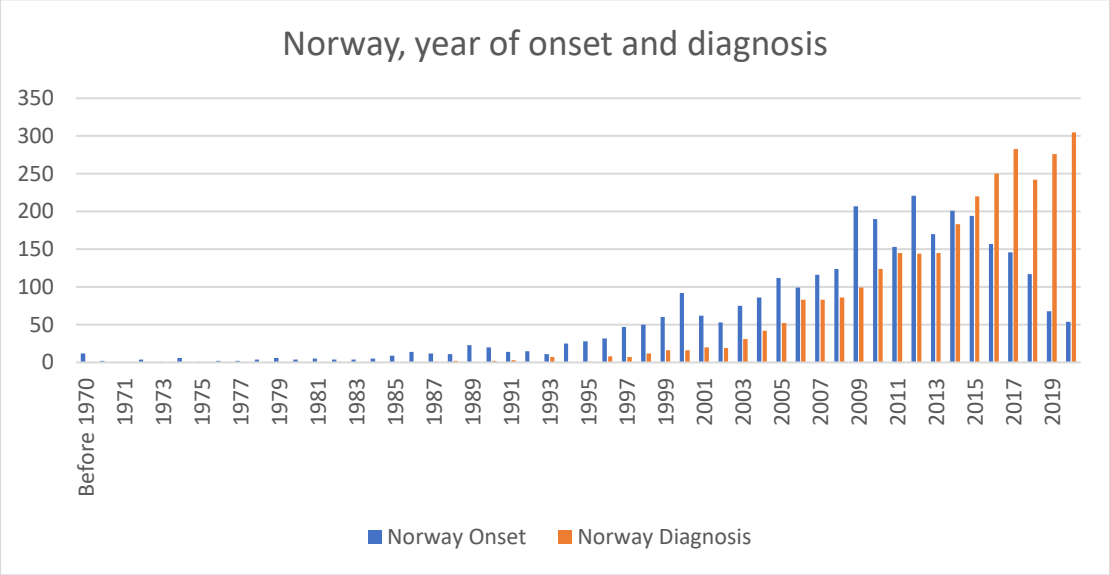


Country Figure 92: Norway, symptoms that restrict activities of daily living, n=3117

1.12.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

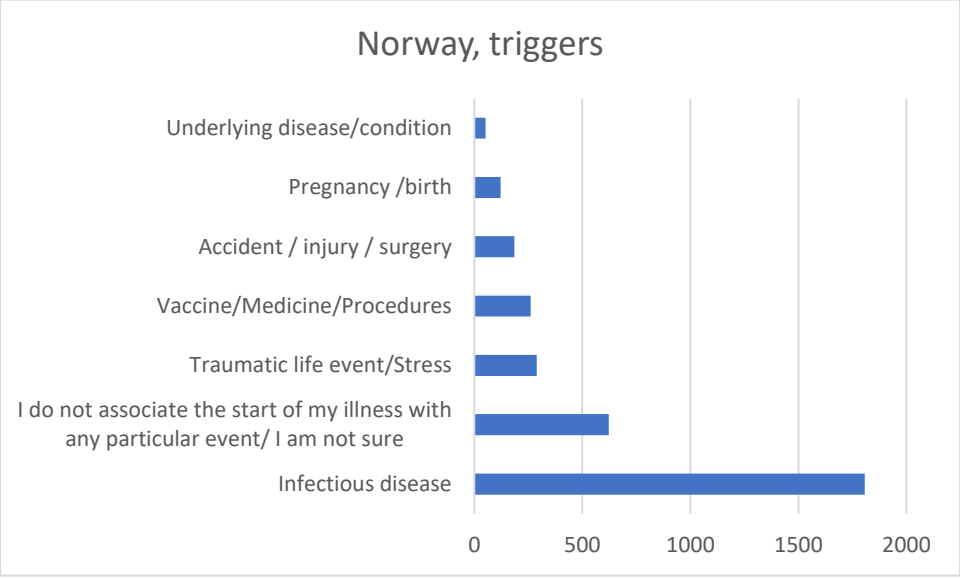
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 93: Norway, year of onset and diagnosis

1.12.7 Triggers

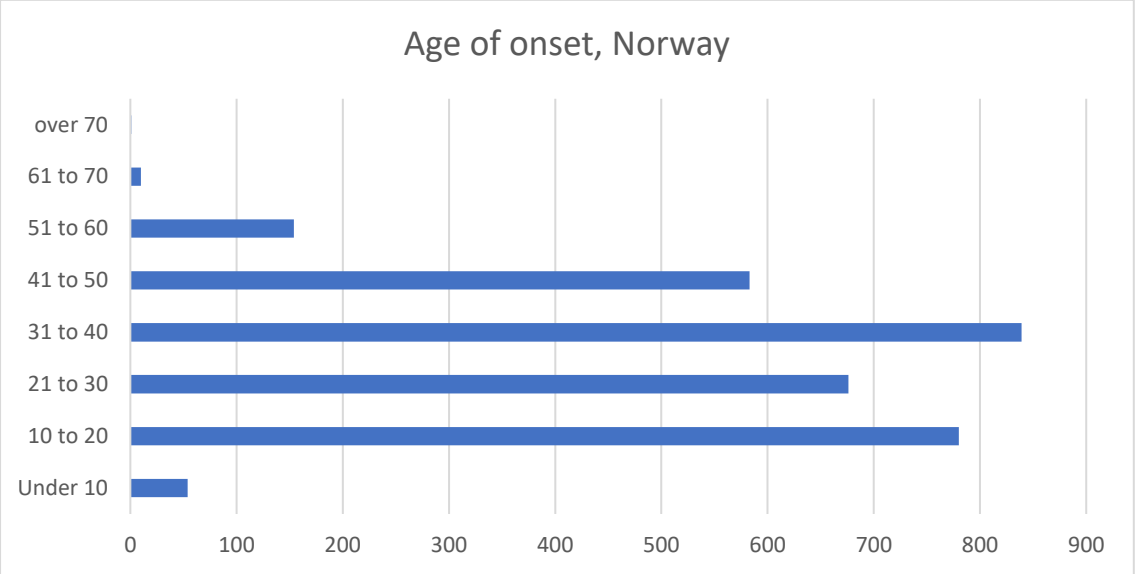
The most common trigger was infectious disease.



Country Figure 94:Norway, triggers, n=3117

1.12.8 Age at onset

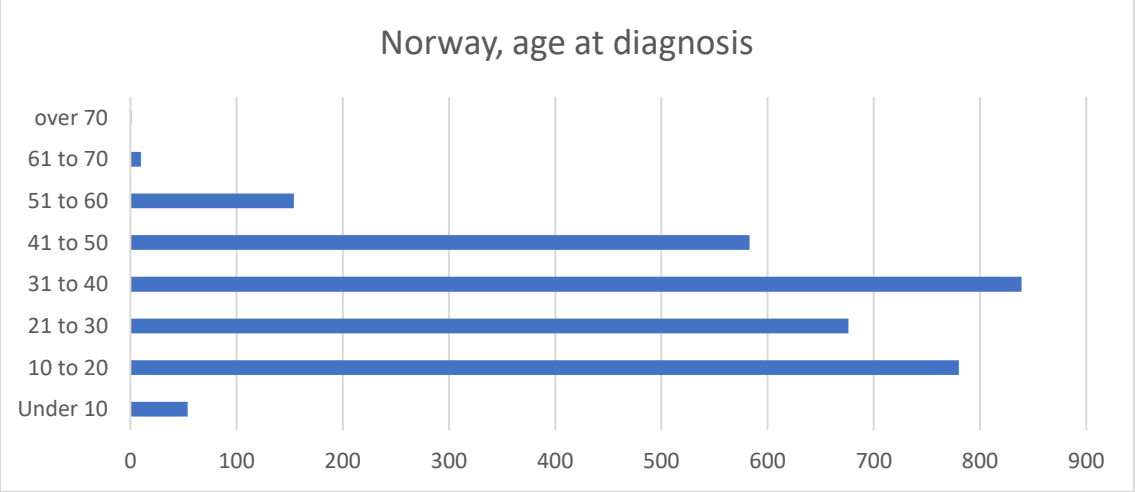
Average age of onset was 30.5 years. The graph below shows the distribution of age at onset.



Country Figure 95: Norway, age of onset, n=3117

1.12.9 Time from onset to diagnosis

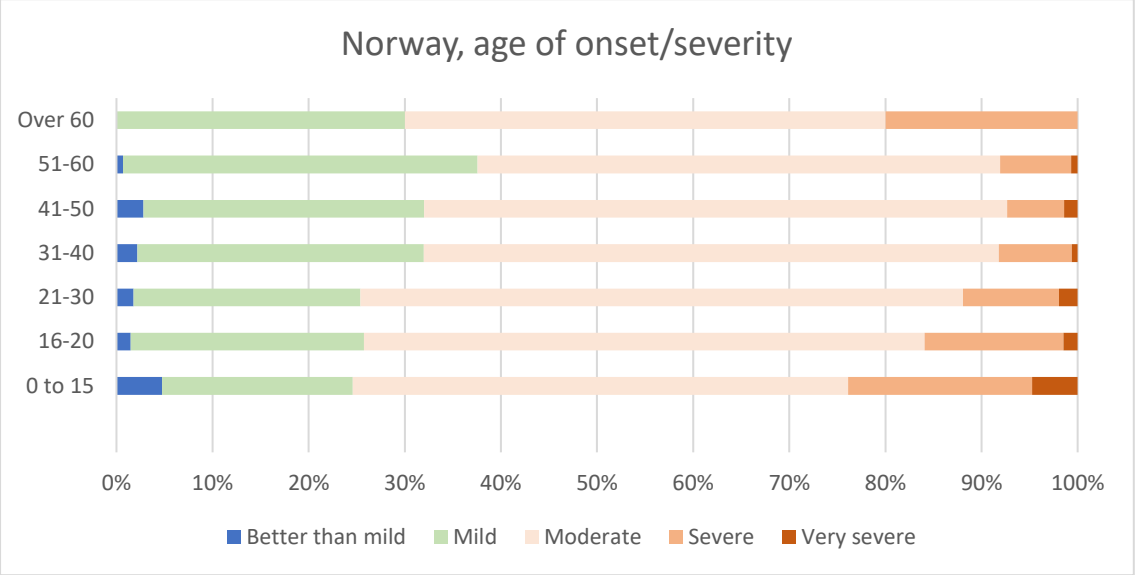
Average time from onset to diagnosis was 5.9 years overall, 5.1 years for men and 6 years for women. Average age at diagnosis was 36.3 years.



Country Figure 96: Norway, age at diagnosis, n=2956

1.12.10 Age at onset and severity

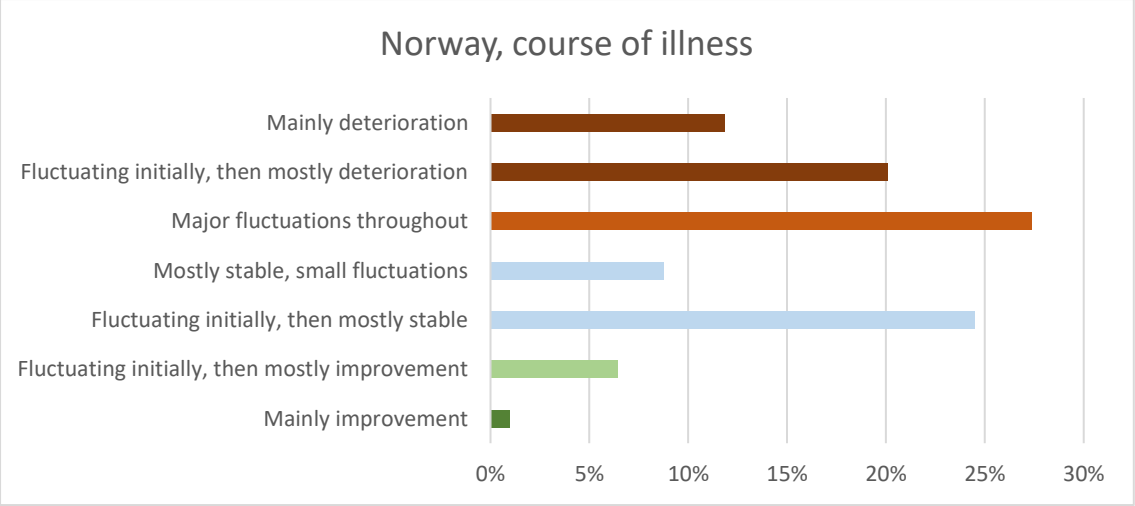
Severe or very severe disease was more common among patients who had early onset, regardless of disease duration.



Country Figure 97: Norway, age at onset and severity, n=3117

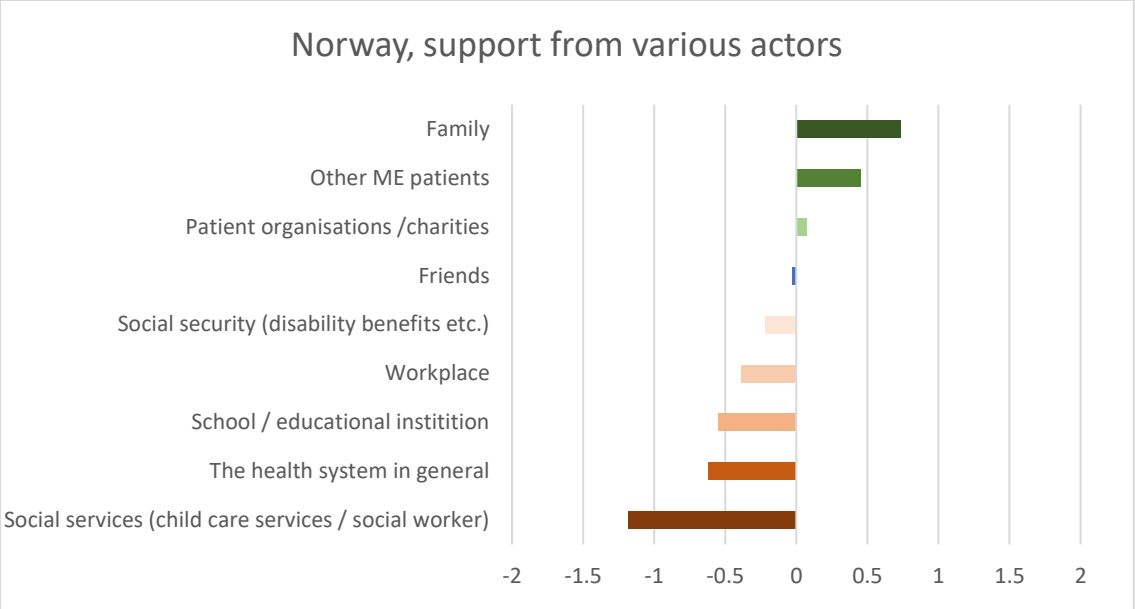
1.12.11 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Norway, 59% of respondents had experienced deterioration or major fluctuations, 35% said they were mostly stable, and 7% had experienced mainly improvement.



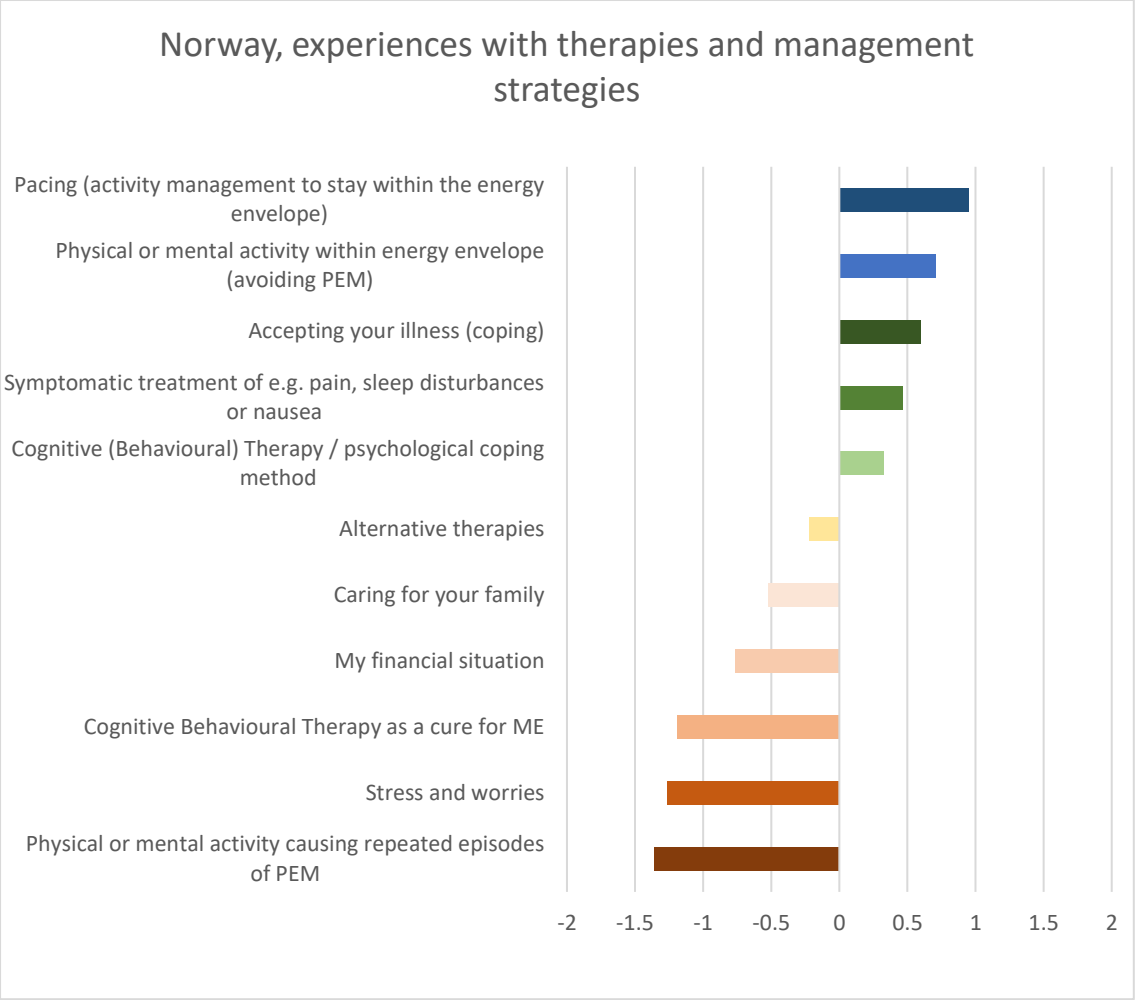
Country Figure 98: Norway, course of illness, n=3117

1.12.12 Experienced support from various actors



Country Figure 99: Norway, support from various actors

1.12.13 Experiences with management strategies and therapies



Country Figure 100: Norway, experience with management strategies and therapies

1.13 Serbia

1.13.1 Respondents

There were 142 respondents from Serbia.

61% of respondents had received a diagnosis, 9% were currently under evaluation for a diagnosis, and 29% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.13.2 Age

Average age of respondents was 42.9 years.

1.13.3 Gender

78% of respondents were female, 22% male.

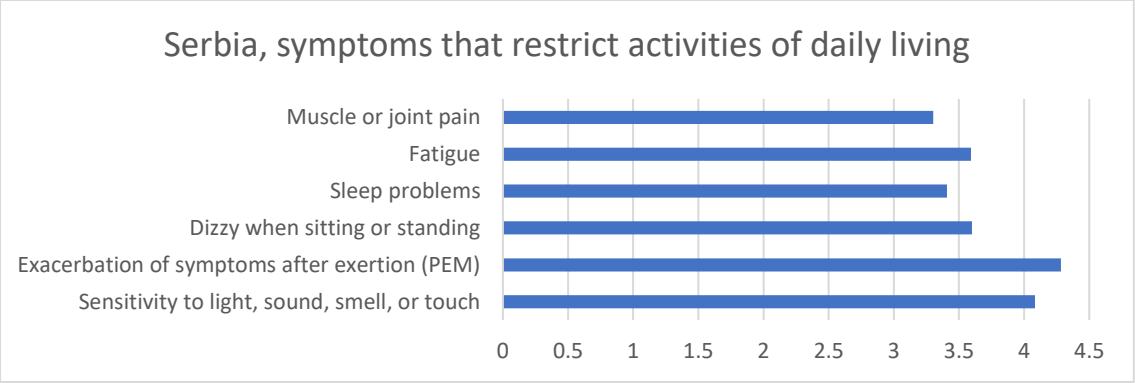
1.13.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

15% of respondents said that their disease was better than mild, 27% had mild, 45% moderate, 12% severe and 1% very severe ME/CFS.

1.13.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found PEM and sensitivity to light and sound the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

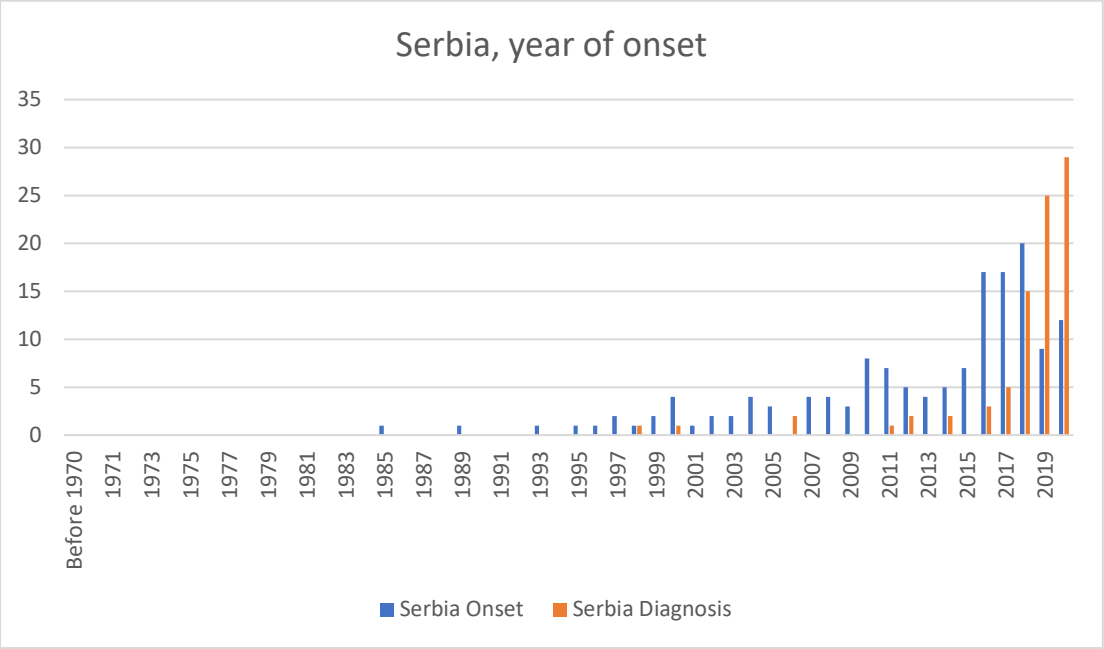


Country Figure 101: Serbia, symptoms that restrict activities of daily living, n=142

1.13.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

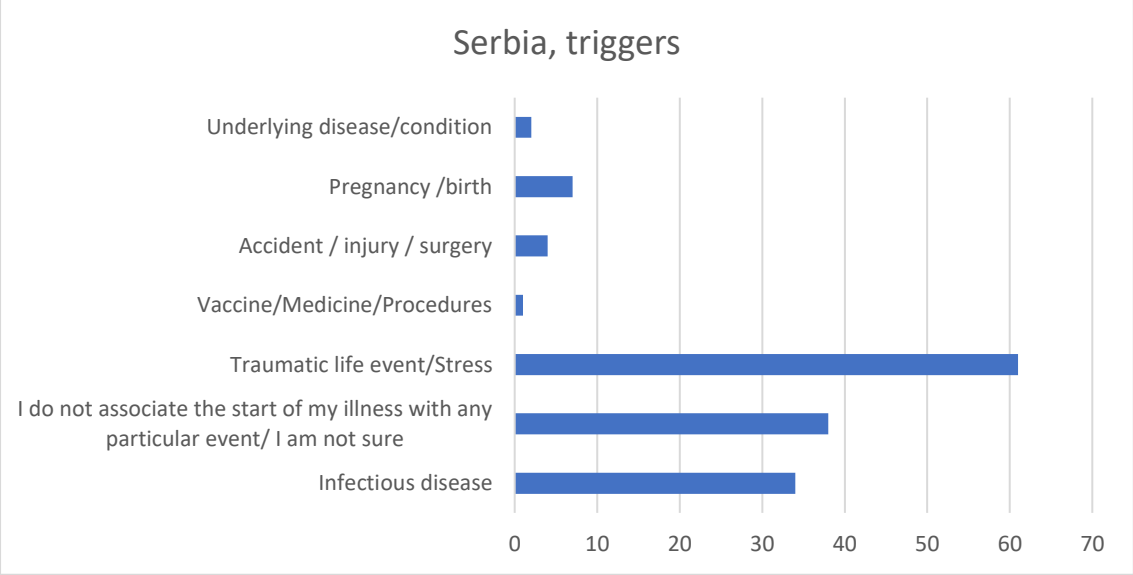
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 102: Serbia, year of onset, n=142

1.13.7 Triggers

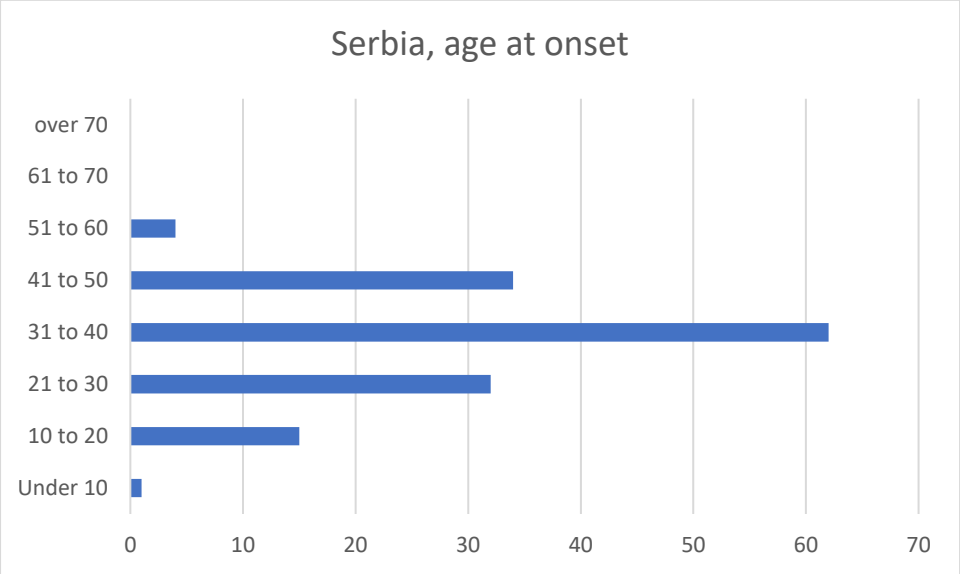
The event most often associated with onset was traumatic life events. Serbia is the only country where onset is not associated with infectious disease.



Country Figure 103: Serbia, triggers, n=142

1.13.8 Age at onset

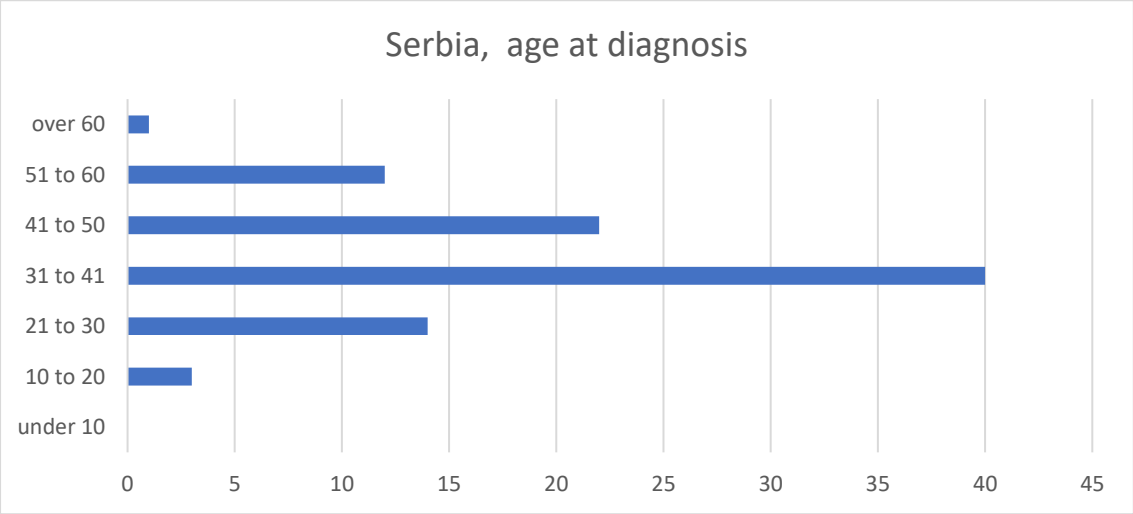
Average age of onset was 33.5 years. The graph below shows the distribution of age at onset.



1.13.9 Time from onset to diagnosis

Average time from onset to diagnosis was 6.7 years overall, 7.4 years for men and 6.6 years for women.

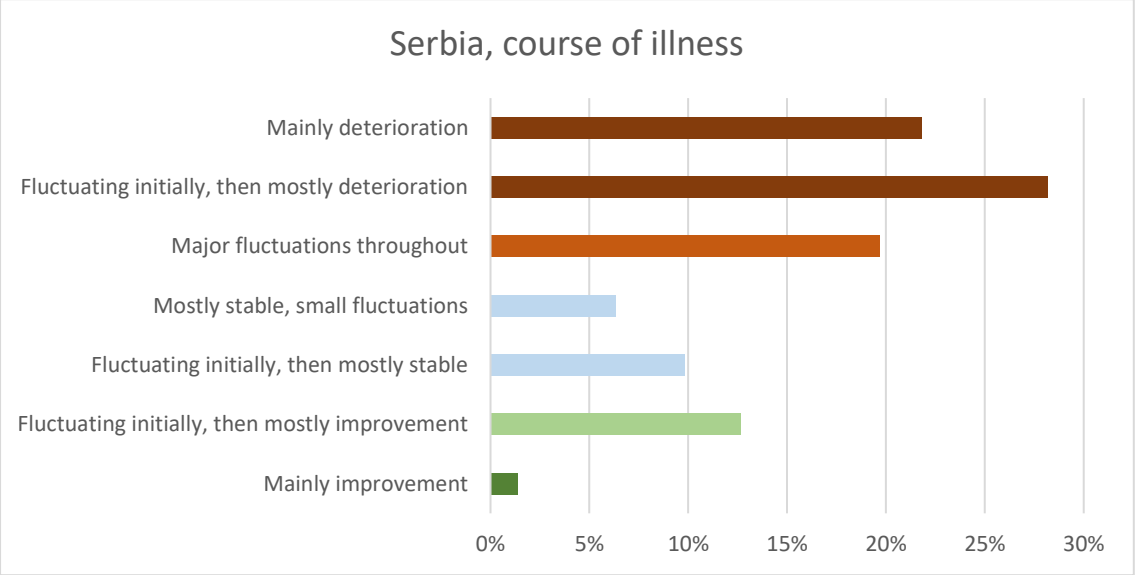
Average age at diagnosis was 39 years.



Country Figure 104: Serbia, age at diagnosis, n=86

1.13.10 Course of illness

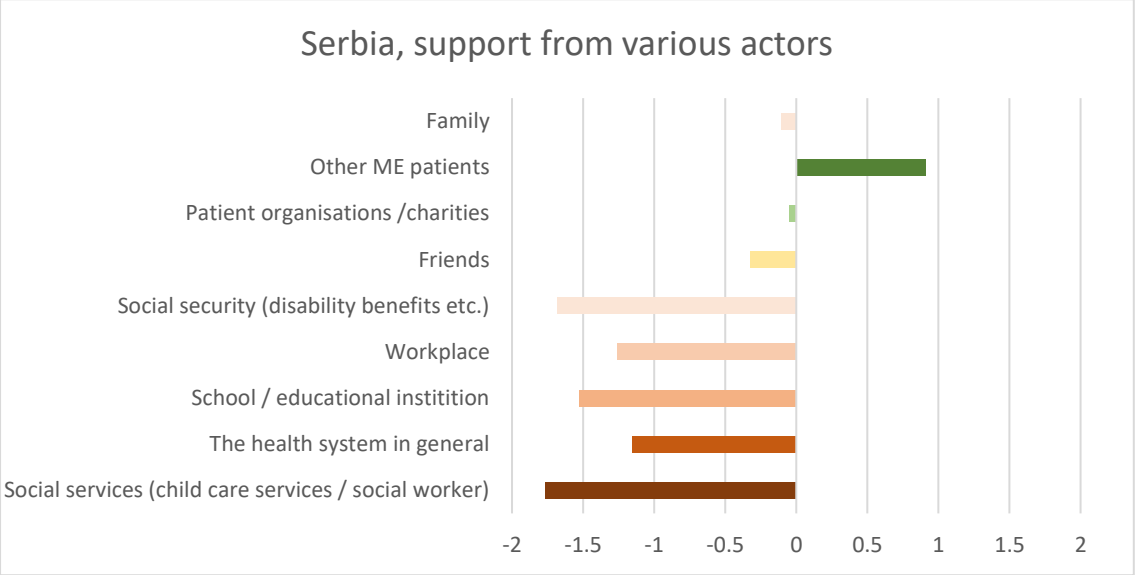
We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Serbia, 70% of respondents had experienced deterioration or major fluctuations, 16% said they were mostly stable, and 14% had experienced mainly improvement.



Country Figure 105: Serbia, course of illness, n=142

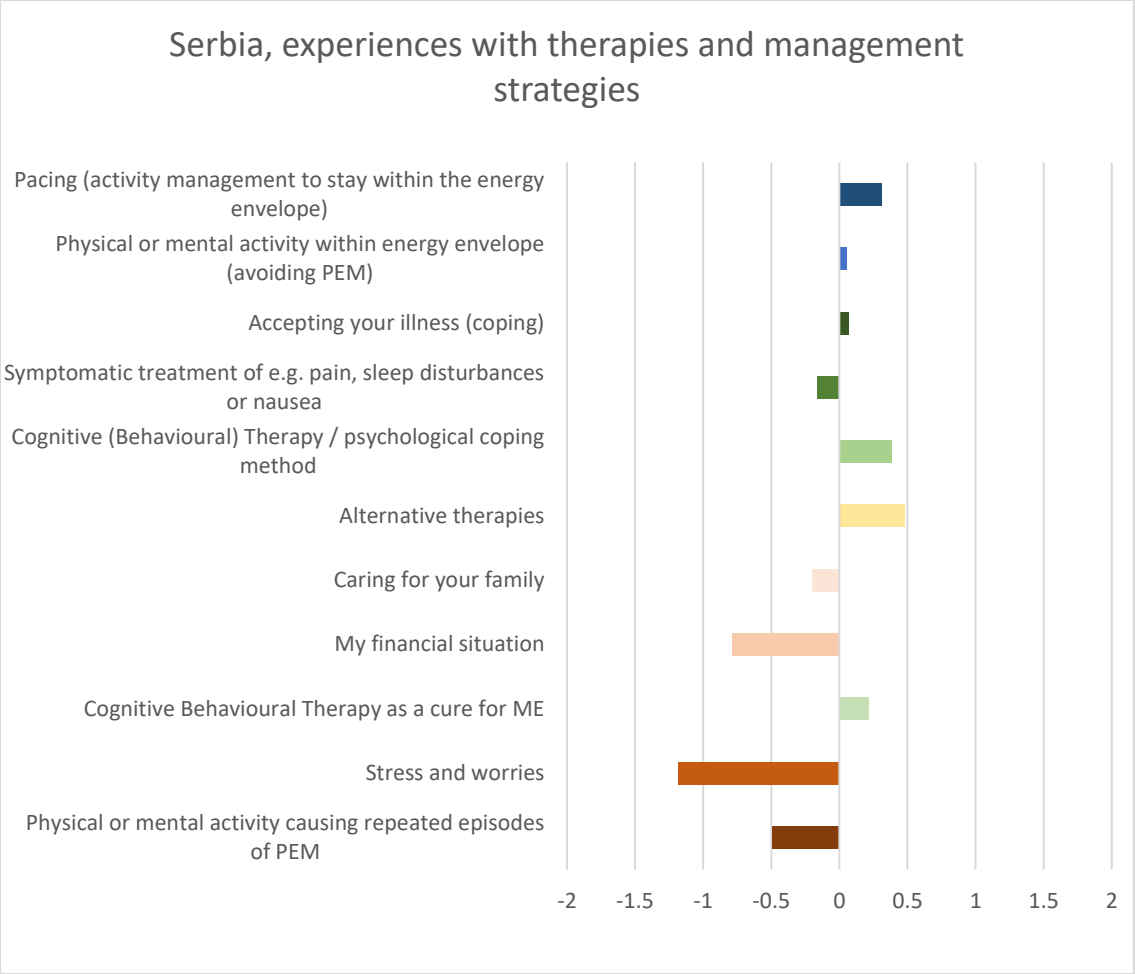
1.13.11 Experienced support from various actors

Respondents in Serbia describe a situation where the only support they receive is from other ME/CFS patients.



Country Figure 106: Serbia, support from various actors

1.13.12 Experiences with management strategies and therapies



Country Figure 107: Serbia, experience with therapies and management strategies

1.14 Spain

1.14.1 Respondents

There were 593 respondents from Spain.

85% of respondents had received a diagnosis, 6% were currently under evaluation for a diagnosis, and 10% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.14.2 Age

Average age of respondents was 51.3 years.

1.14.3 Gender

84% of respondents were female, 16% male, less than 1% preferred not to say.

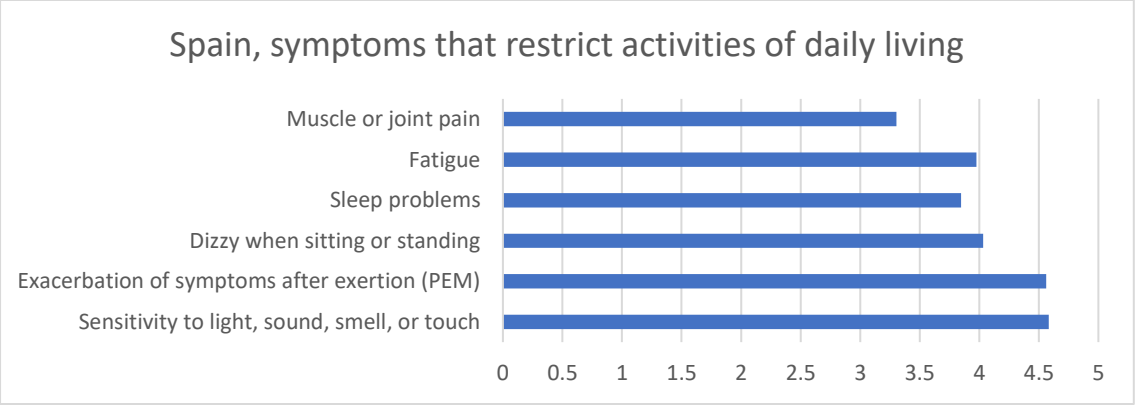
1.14.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

3% of respondents said that their disease was better than mild, 17% had mild, 54% moderate, 23% severe and 3% very severe ME/CFS.

1.14.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found PEM and sensitivity to light and sound the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

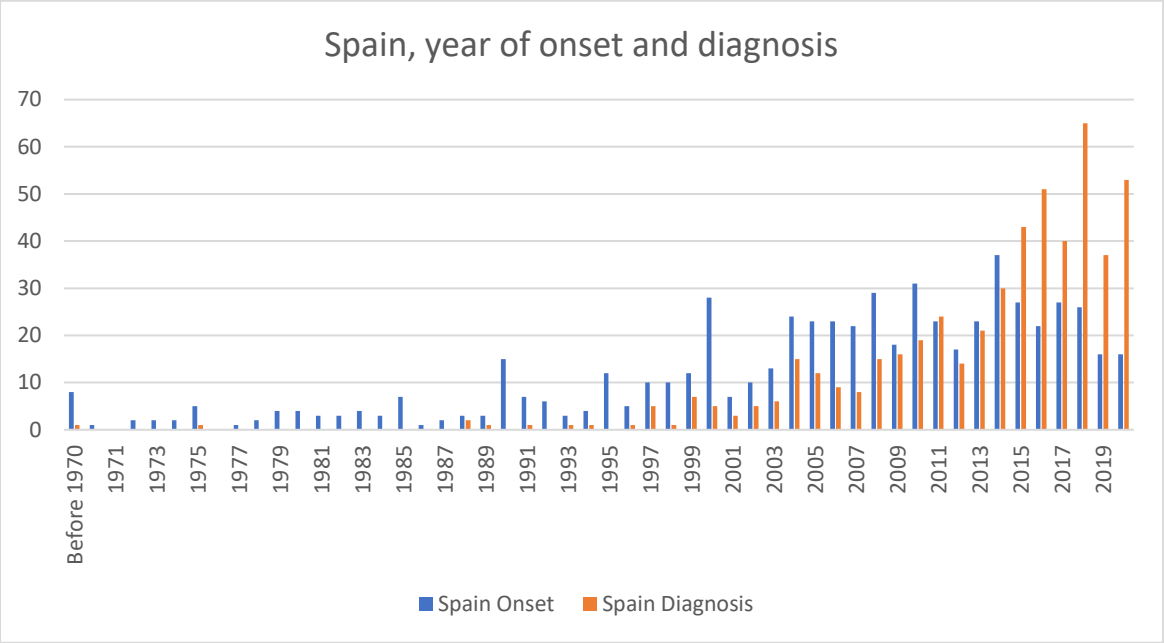


Country Figure 108: Spain, symptoms that restrict activities of daily living, n=593

1.14.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

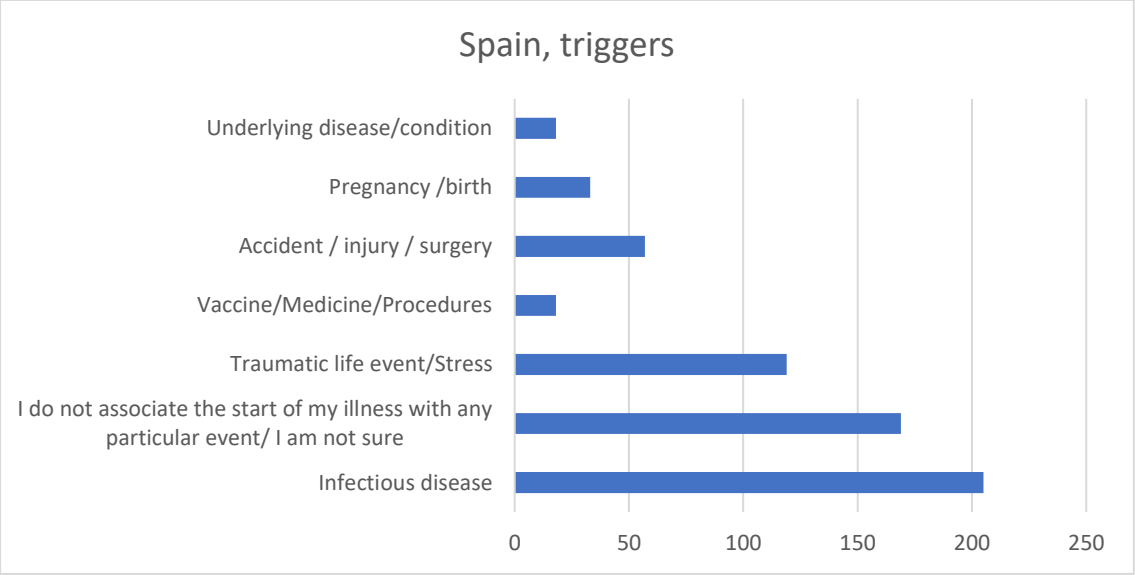
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 109: Spain, year of onset and diagnosis

1.14.7 Triggers

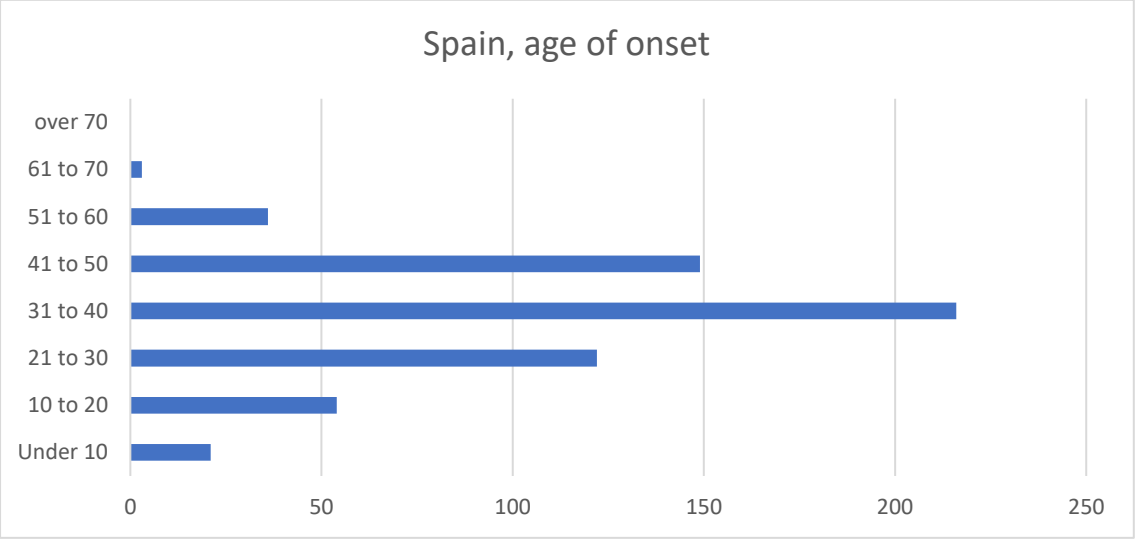
The most common trigger was infectious disease.



Country Figure 110: Spain, triggers, n=593

1.14.8 Age at onset

Average age of onset was 34.5 years. The graph below shows the distribution of age at onset.

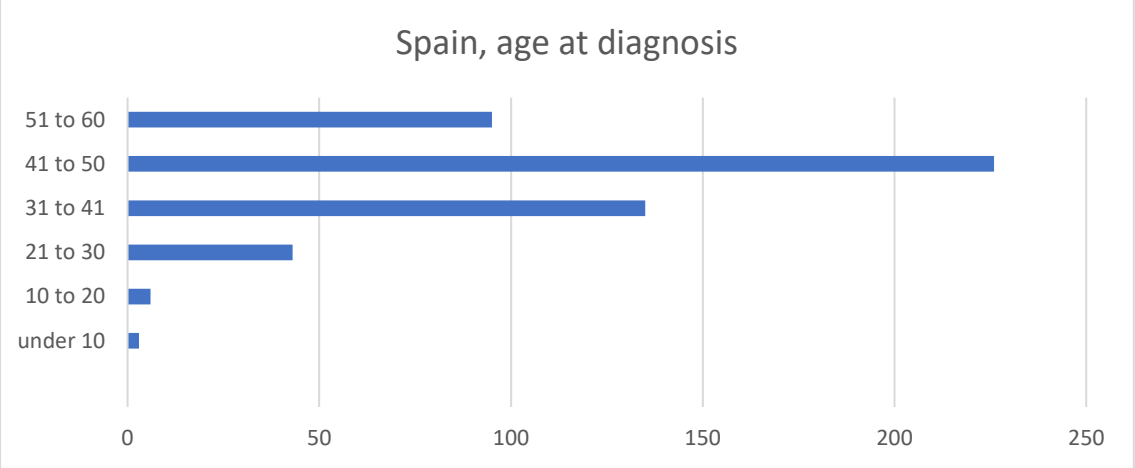


Country Figure 111: Spain, age at onset, n=593

1.14.9 Time from onset to diagnosis

Average time from onset to diagnosis was 8.5 years overall, 8.6 years for men and 8.5 years for women.

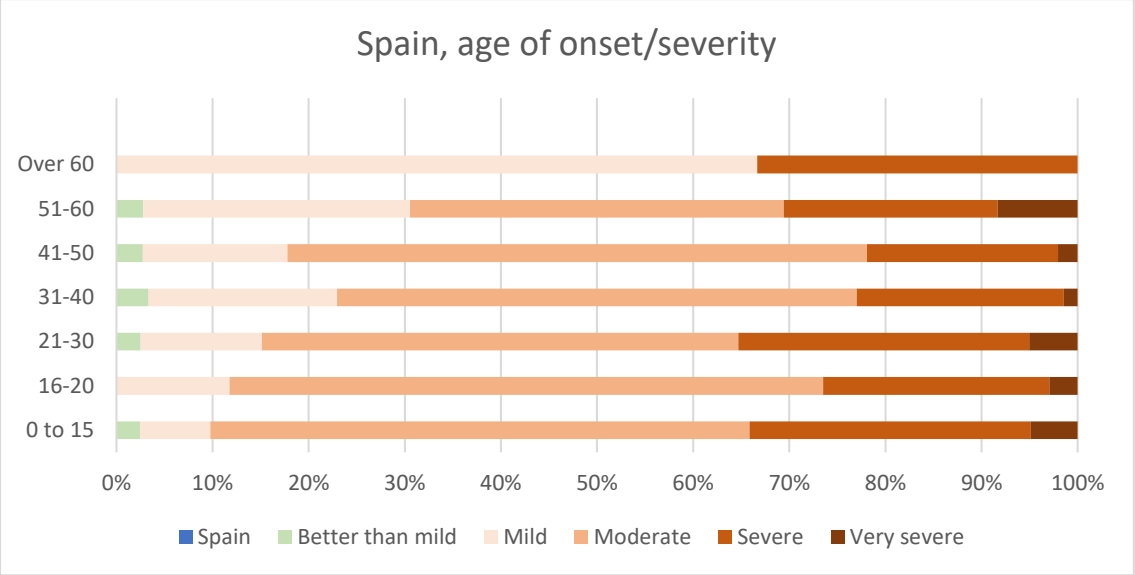
Average age at diagnosis was 42.7 years.



Country Figure 112: Spain, age at diagnosis, n=504

1.14.10 Age at onset and severity

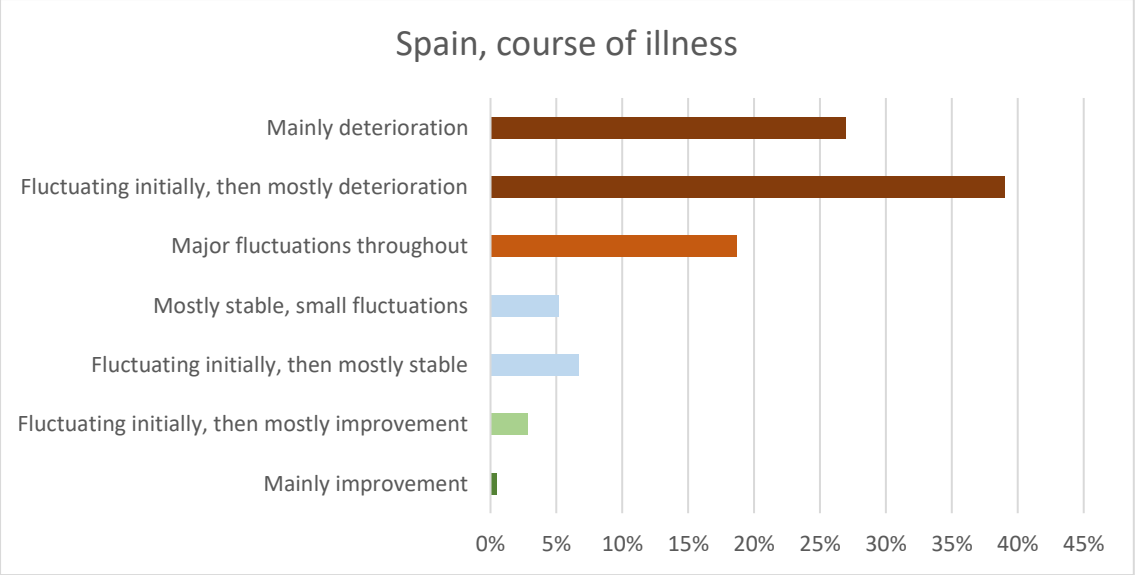
Severe or very severe disease was more common among patients who had early onset, regardless of disease duration.



Country Figure 113: Spain, age of onset and severity, n=593

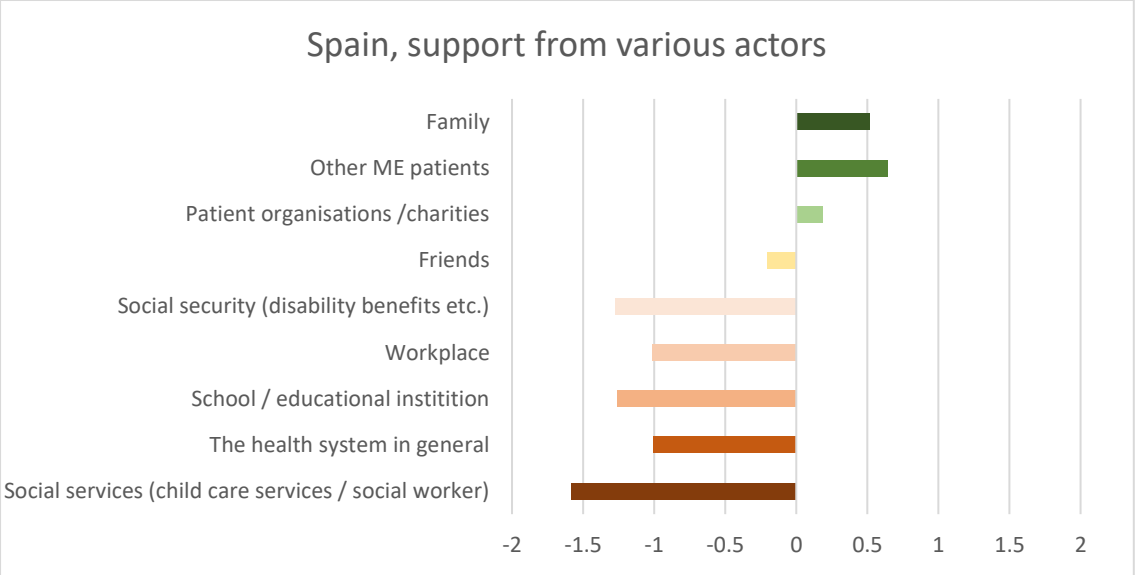
1.14.11 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Norway, 85% of respondents had experienced deterioration or major fluctuations, 12% said they were mostly stable, and 4% had experienced mainly improvement.



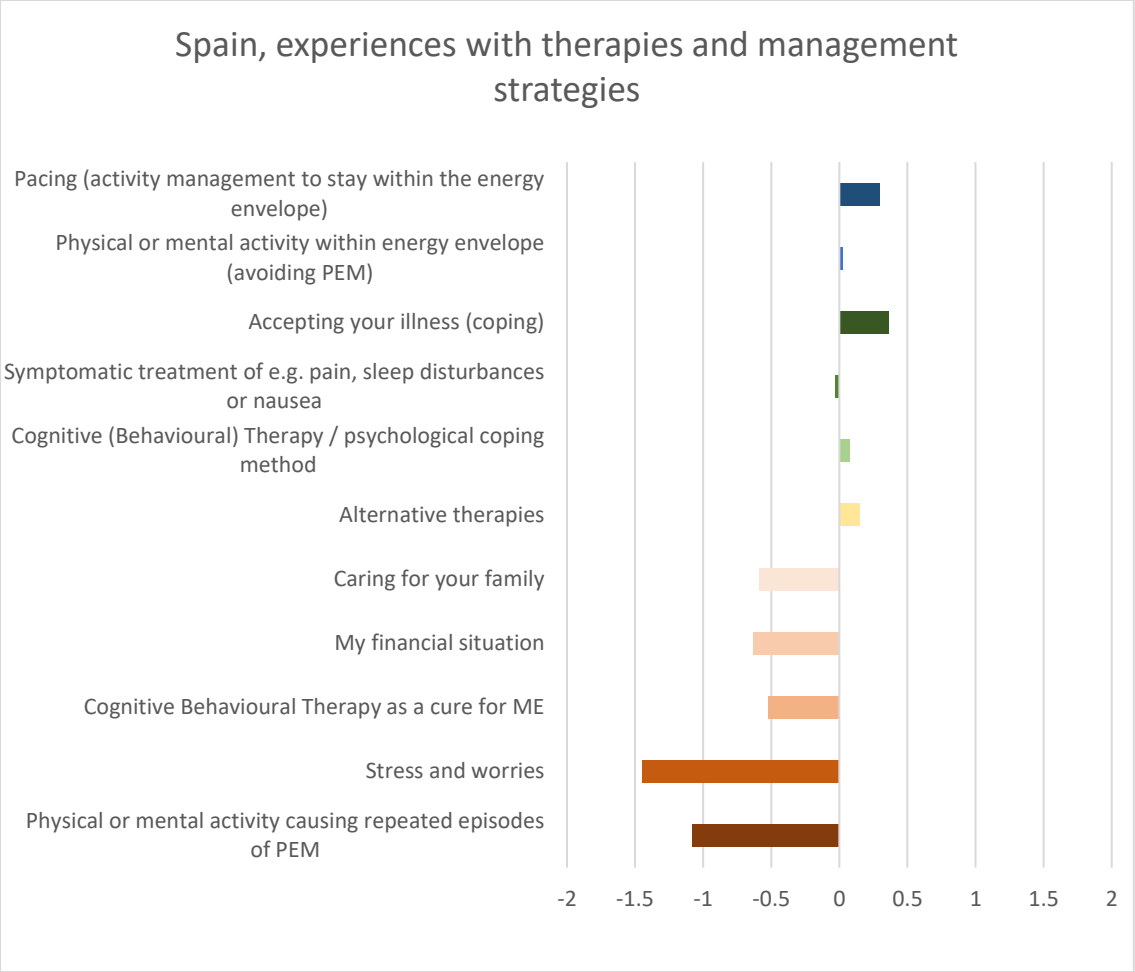
Country Figure 114: Spain, course of illness, n=593

1.14.12 Experienced support from various actors



Country Figure 115: Spain, support from various actors

1.14.13 Experiences with management strategies and therapies



Country Figure 116: Spain, experience with management strategies and therapies

1.15 Sweden

1.15.1 Respondents

There were 1331 respondents from Sweden.

91% of respondents had received a diagnosis, 3% were currently under evaluation for a diagnosis, and 2% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.15.2 Age

Average age of respondents was 52.1 years.

1.15.3 Gender

87% of respondents were female, 13% male, less than 1% preferred not to say.

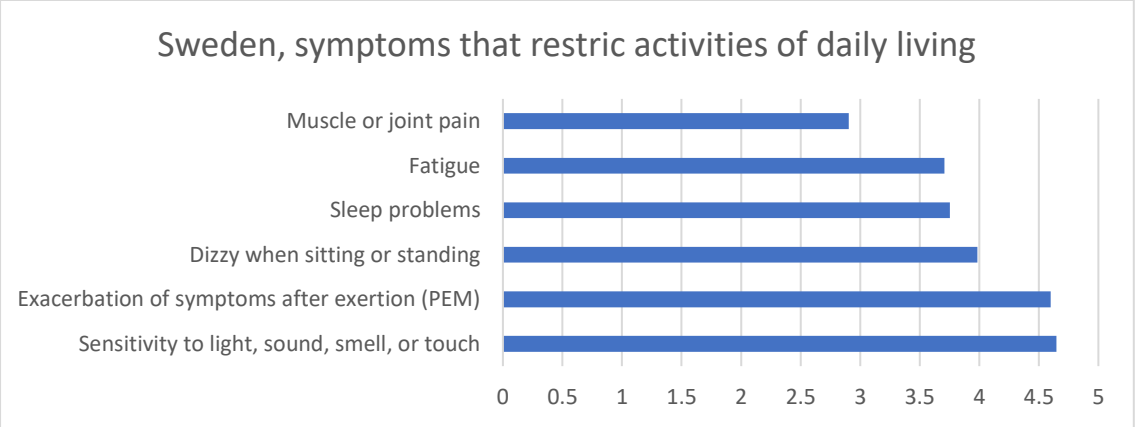
1.15.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

3% of respondents said that their disease was better than mild, 27% had mild, 56% moderate, 24% severe and 2% very severe ME/CFS.

1.15.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found sensitivity to light and sound and PEM the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

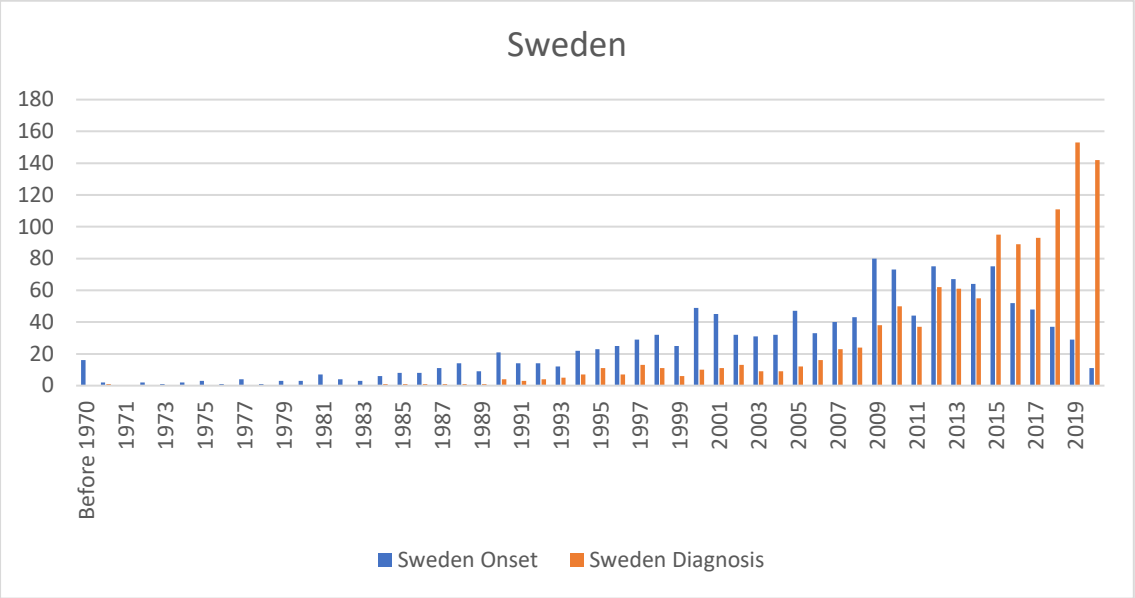


Country Figure 117: Sweden, symptoms that restrict activities of daily living, n=1331

1.15.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

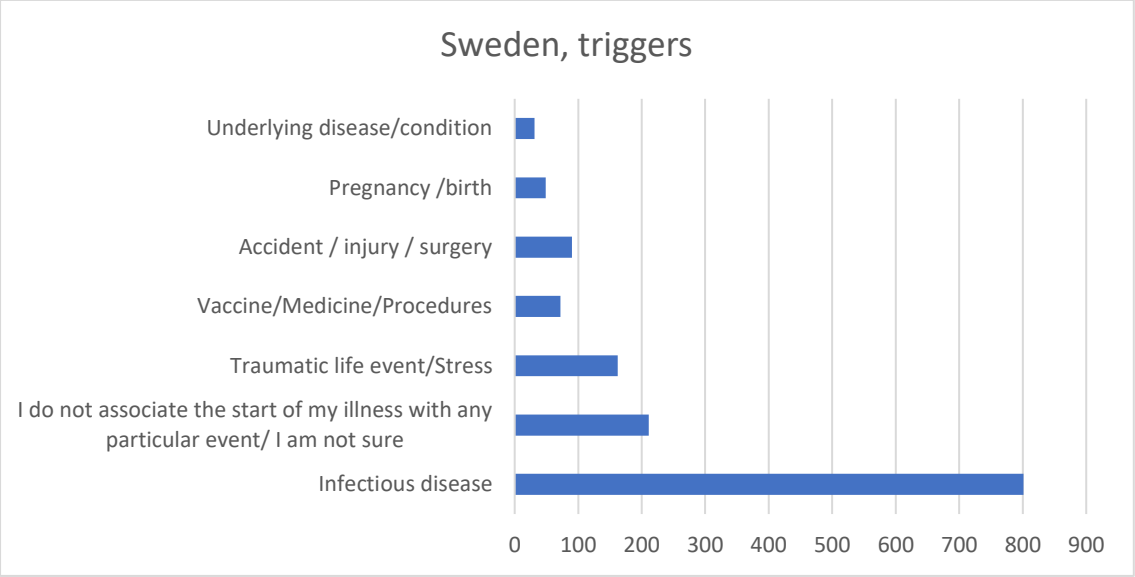
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 118: Sweden, year of onset and diagnosis

1.15.7 Triggers

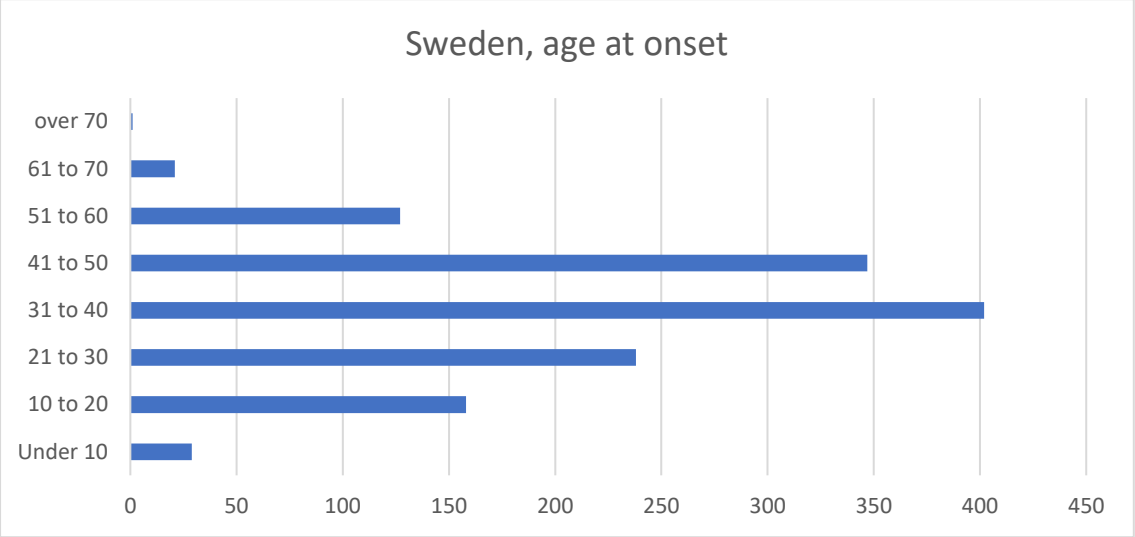
The most common trigger was infectious disease.



Country Figure 119: Sweden, triggers, n=1331

1.15.8 Age at onset

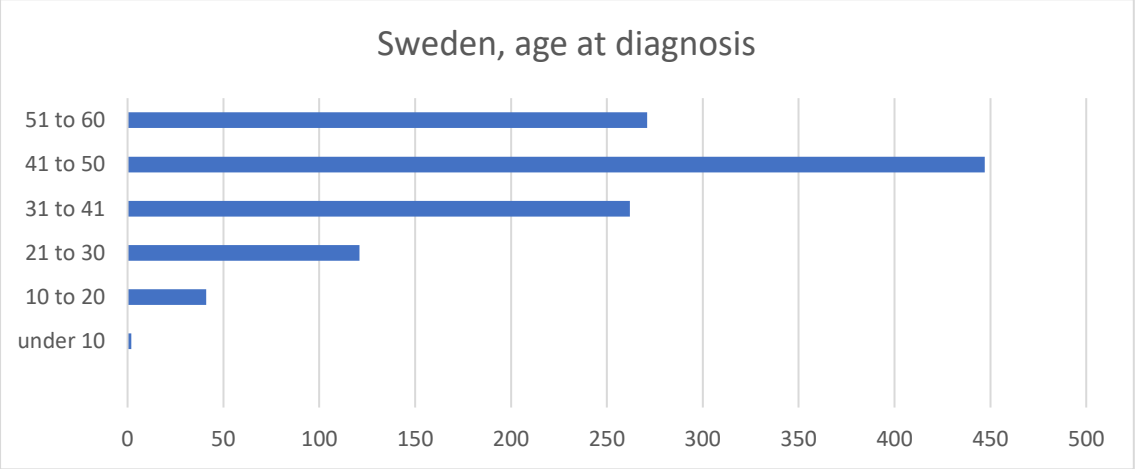
Average age of onset was 35.4 years. The graph below shows the distribution of age at onset.



Country Figure 120: Sweden, age at onset, n=1331

1.15.9 Time from onset to diagnosis

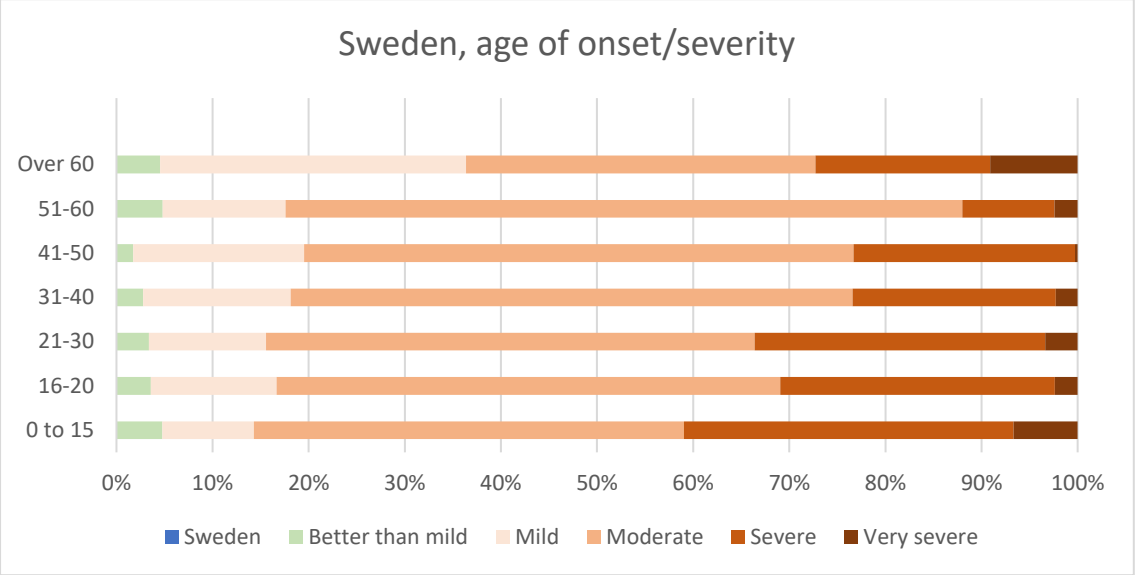
Average time from onset to diagnosis was 8.5 years overall, 7.2 years for men and 6 years for women. Average age at diagnosis was 43.6 years.



Country Figure 121: Sweden, age at diagnosis, n=1211

1.15.10 Age at onset and severity

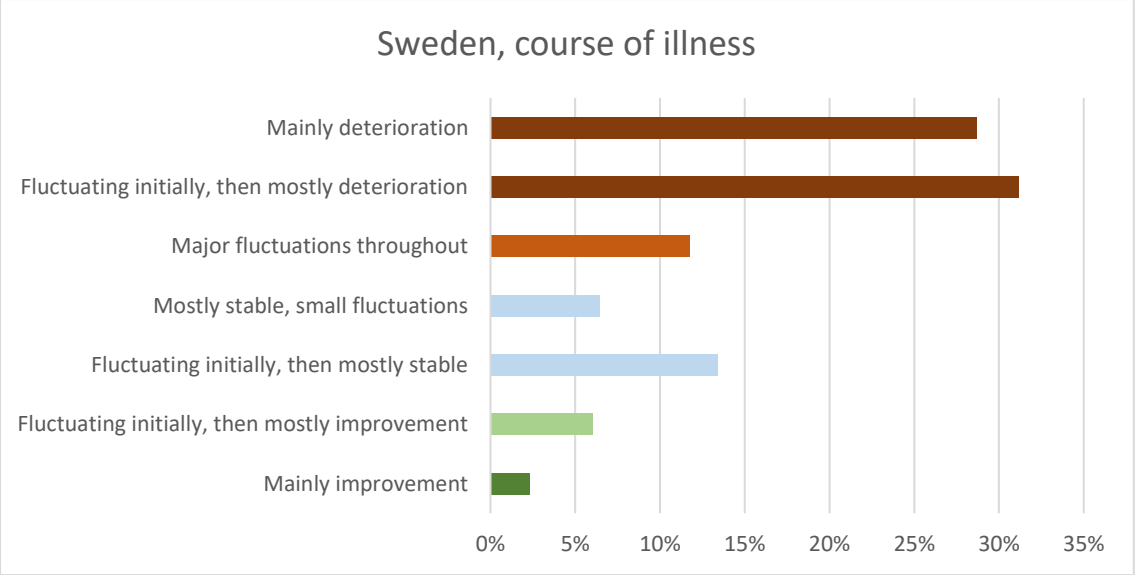
Severe or very severe disease was more common among patients who had early onset, regardless of disease duration.



Country Figure 122: Sweden, age of onset and severity, n=1331

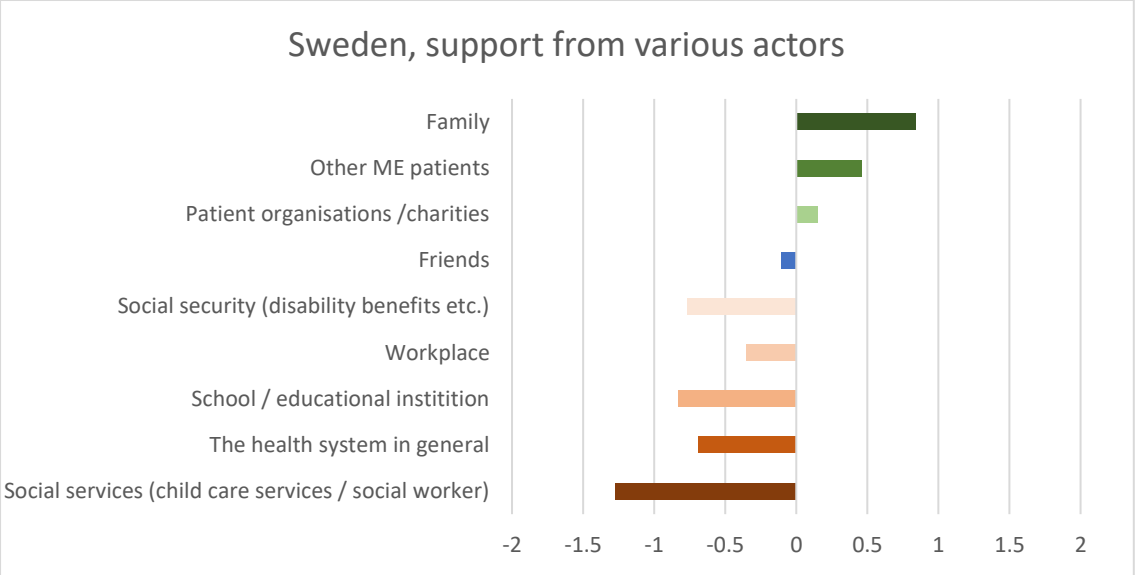
1.15.11 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Sweden, 72% of respondents had experienced deterioration or major fluctuations, 19% said they were mostly stable, and 7% had experienced mainly improvement.



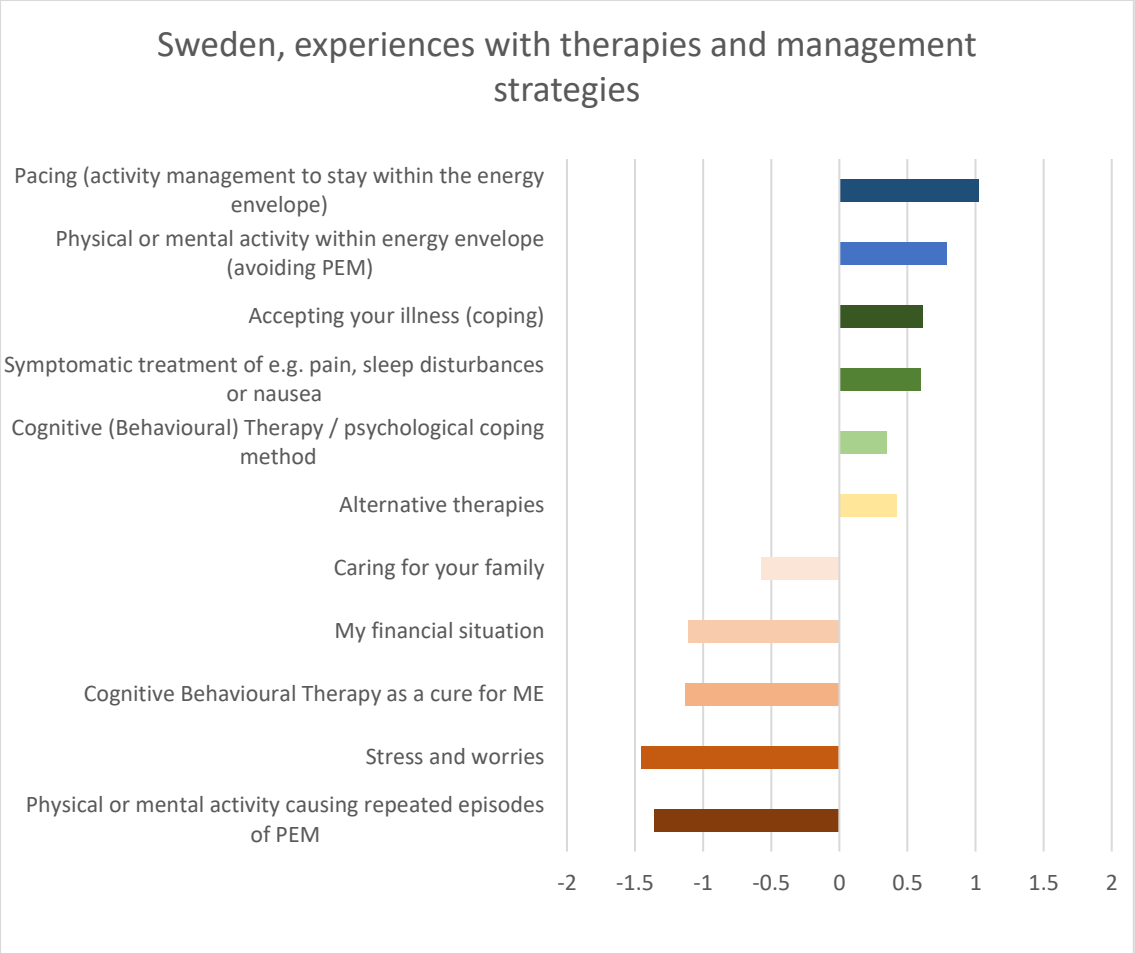
Country Figure 123: Sweden, course of illness, n=1331

1.15.12 Experienced support from various actors



Country Figure 124: Sweden, support from various actors

1.15.13 Experiences with management strategies and therapies



Country Figure 125: Sweden, experience with therapies and management strategies

1.16 Switzerland

1.16.1 Respondents

There were 220 respondents from Switzerland.

80% of respondents had received a diagnosis, 8% were currently under evaluation for a diagnosis, and 12% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.16.2 Age

Average age of respondents was 46 years.

1.16.3 Gender

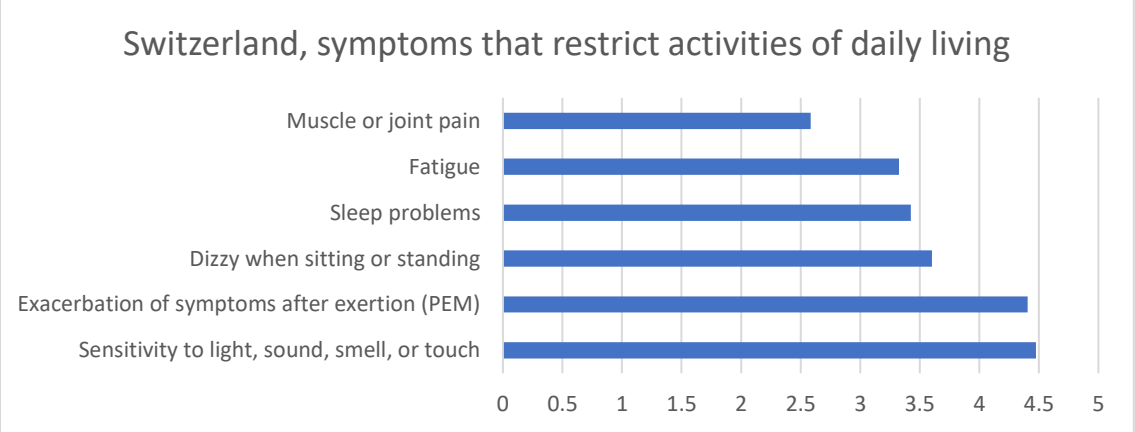
79% of respondents were female, 21% male.

1.16.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care. 9% of respondents said that their disease was better than mild, 25% had mild, 52% moderate, 13% severe and 1% very severe ME/CFS.

1.16.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found sensitivity to light and sound and PEM the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

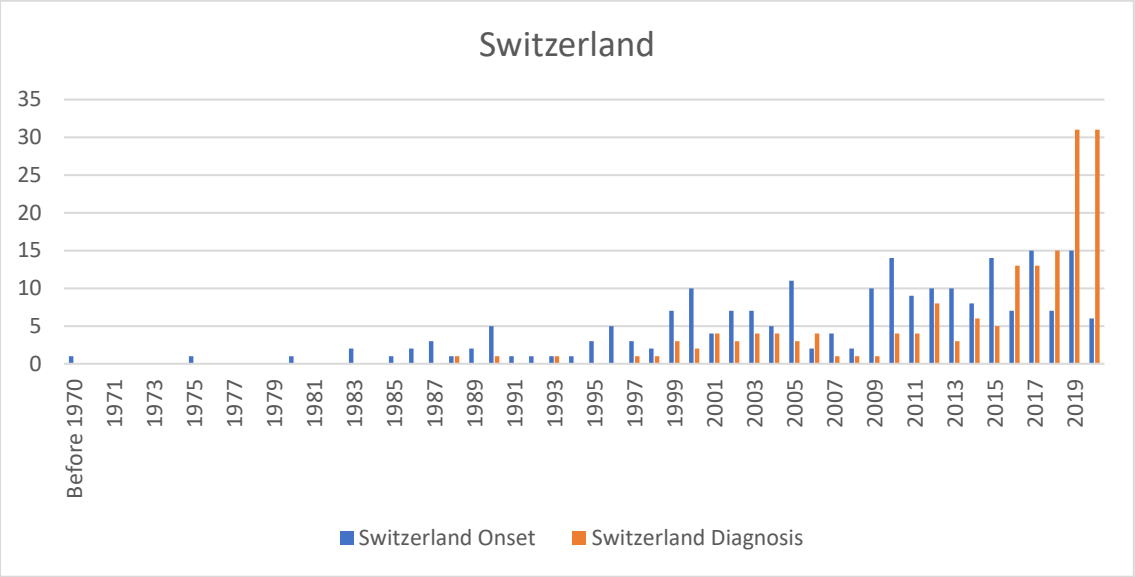


Country Figure 126: Switzerland, symptoms that restrict activities of daily living, n=220

1.16.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

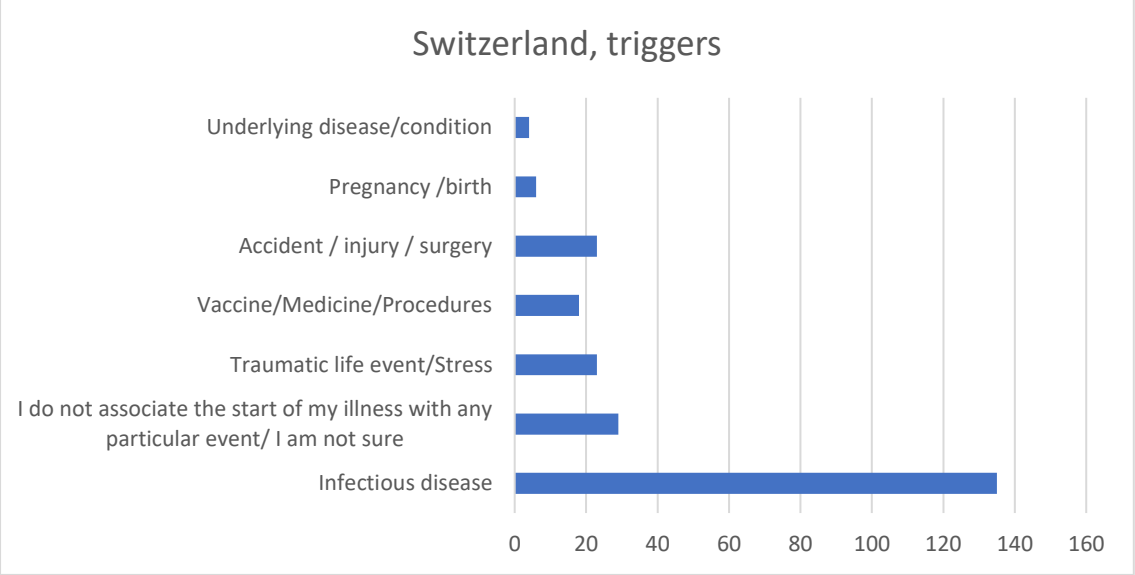
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 127: Switzerland, year of onset and diagnosis

1.16.7 Triggers

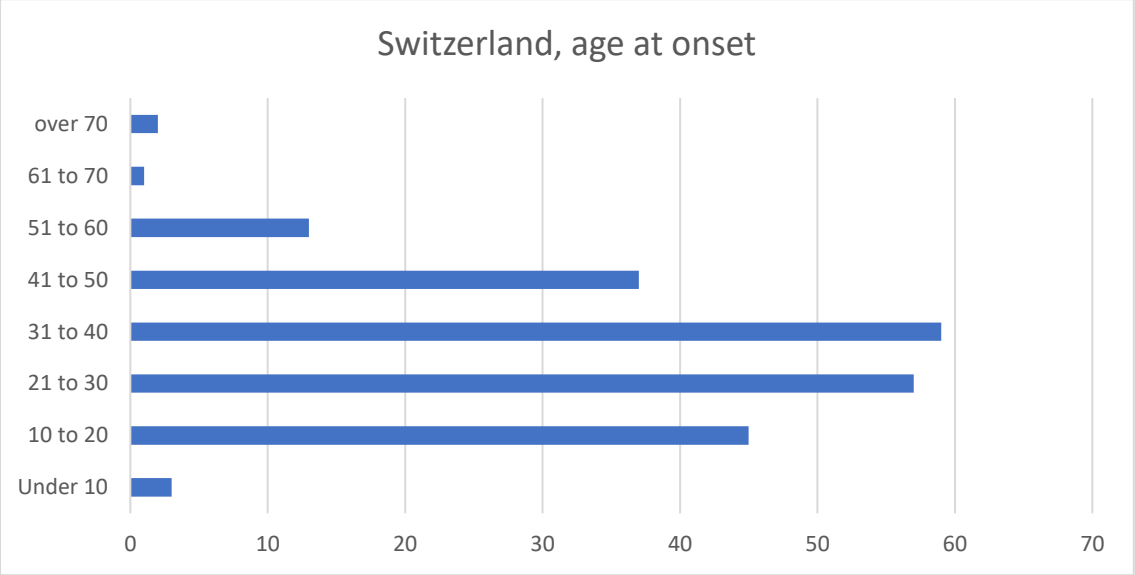
The most common trigger was infectious disease.



Country Figure 128: Switzerland, triggers, n=220

1.16.8 Age at onset

Average age of onset was 31.4 years. The graph below shows the distribution of age at onset.

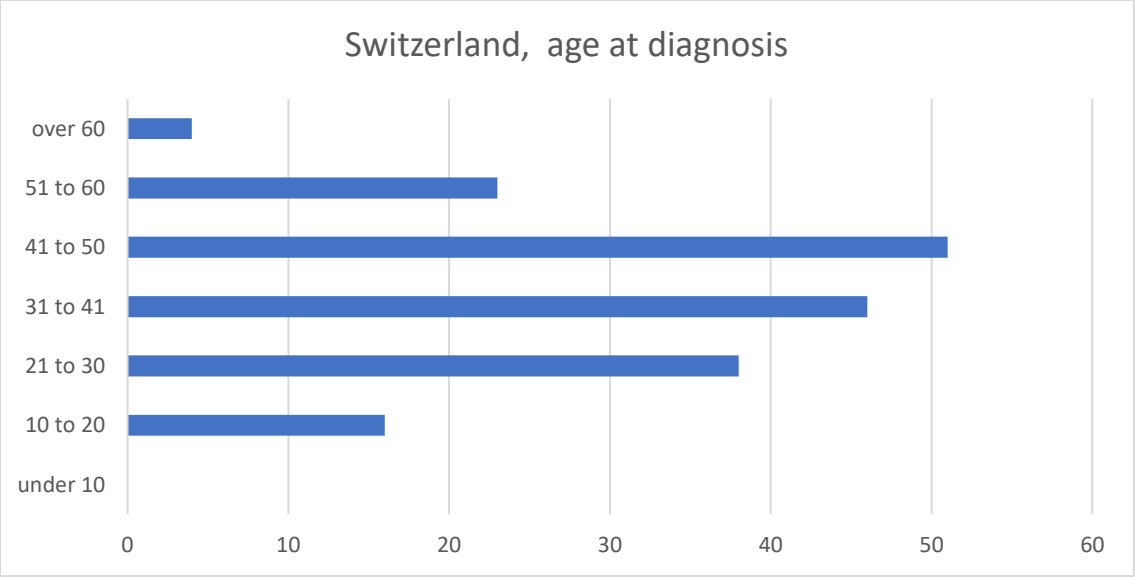


Country Figure 129: Switzerland, age at onset, n=220

1.16.9 Time from onset to diagnosis

Average time from onset to diagnosis was 7.1 years overall, 7.5 years for men and 7 years for women.

Average age at diagnosis was 37.8 years.

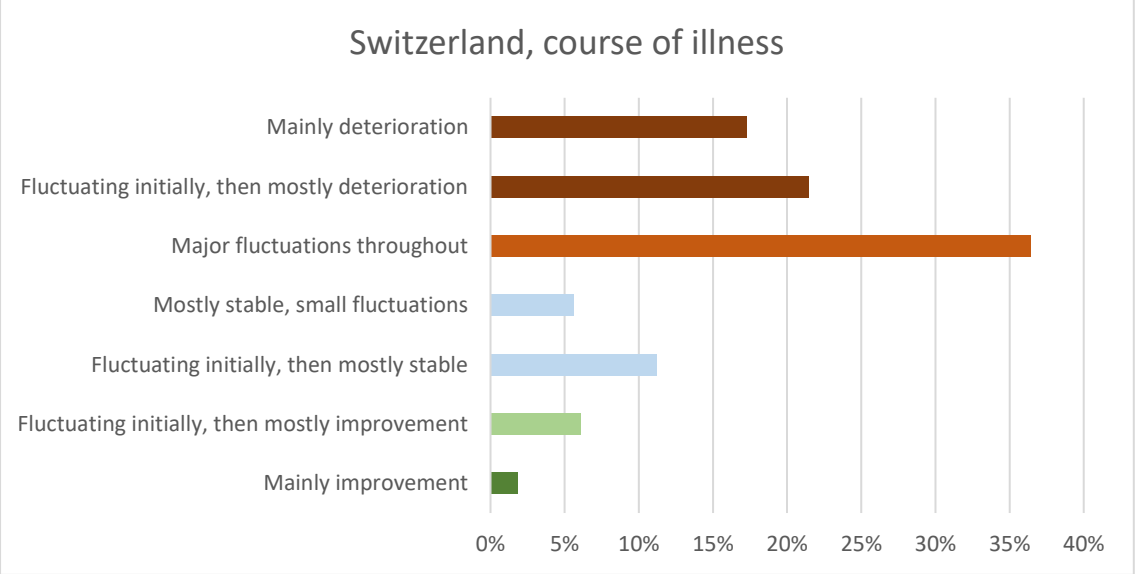


Country Figure 130: Switzerland, age at diagnosis, n=176

1.16.10 Course of illness

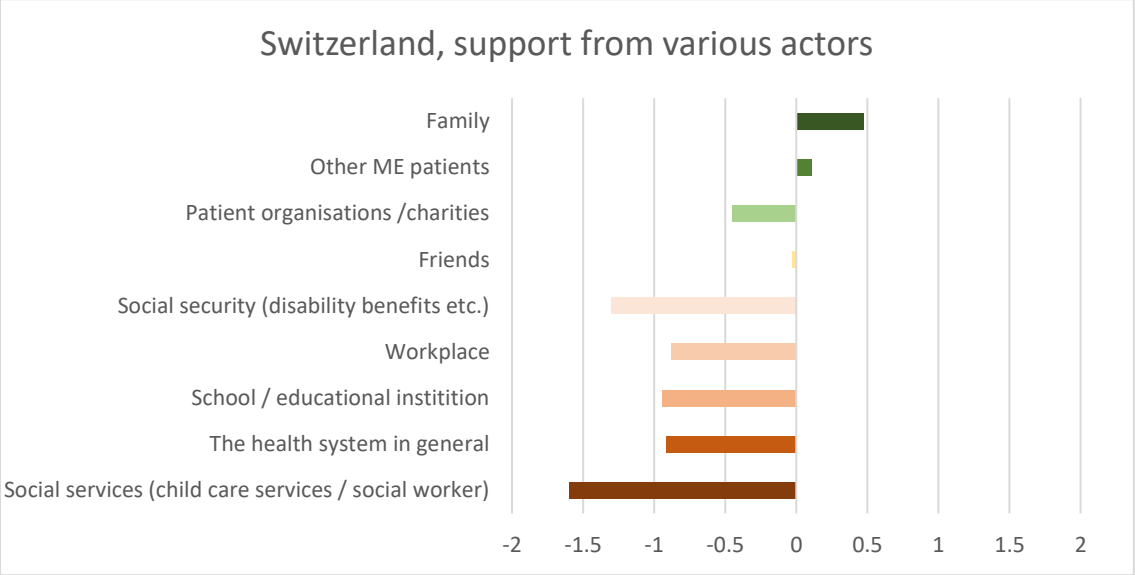
We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Switzerland, 75% of respondents had experienced deterioration or

major fluctuations, 17% said they were mostly stable, and 8% had experienced mainly improvement.



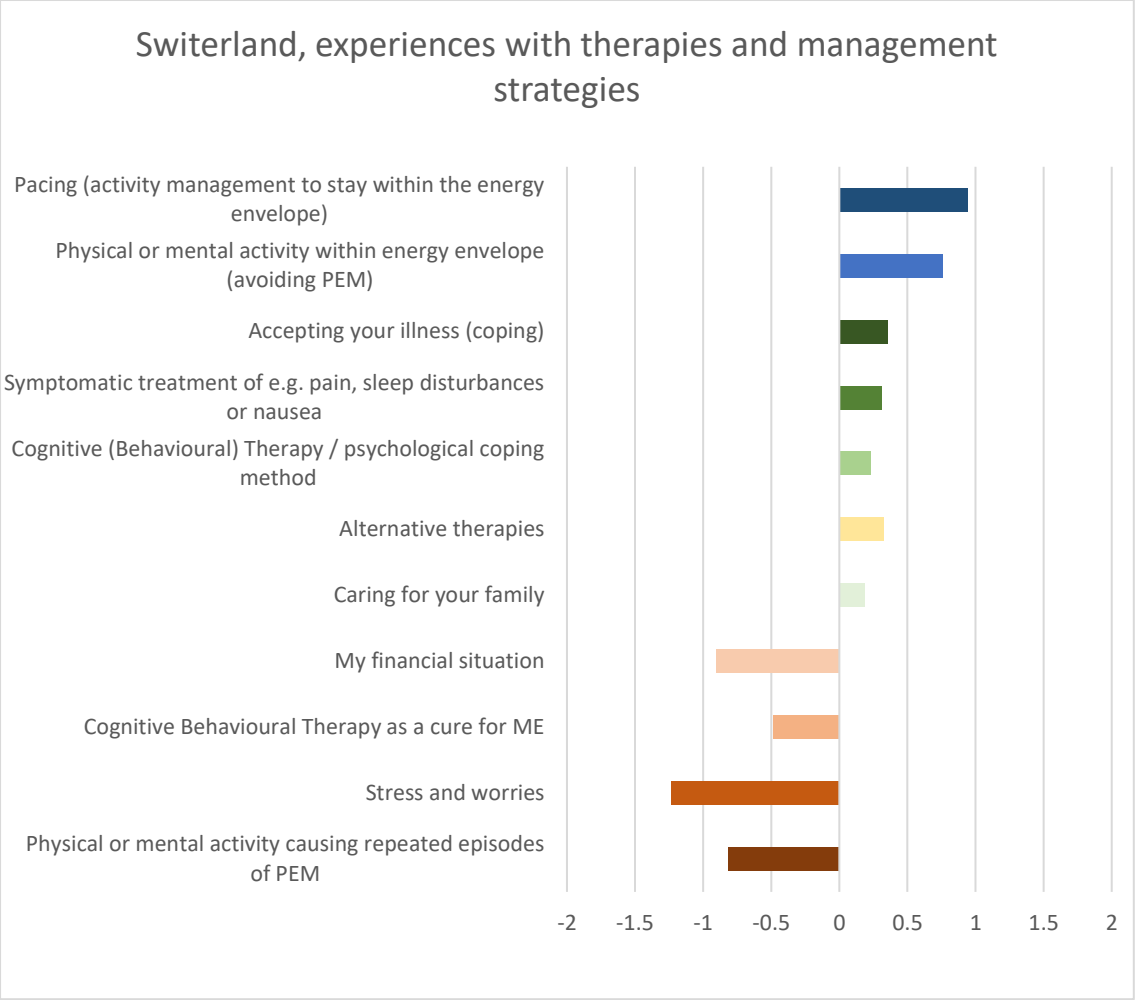
Country Figure 131: Switzerland, course of illness, n=220

1.16.11 Experienced support from various actors



Country Figure 132: Switzerland, support from various actors

1.16.12 Experiences with management strategies and therapies



Country Figure 133: Switzerland, experience with therapies and management strategies

1.17 The Netherlands

1.17.1 Respondents

There were 553 respondents from The Netherlands. 94% of respondents had received a diagnosis, 3% were currently under evaluation for a diagnosis, and 3% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.17.2 Age

Average age of respondents was 46.2 years.

1.17.3 Gender

85% of respondents were female, 15% male.

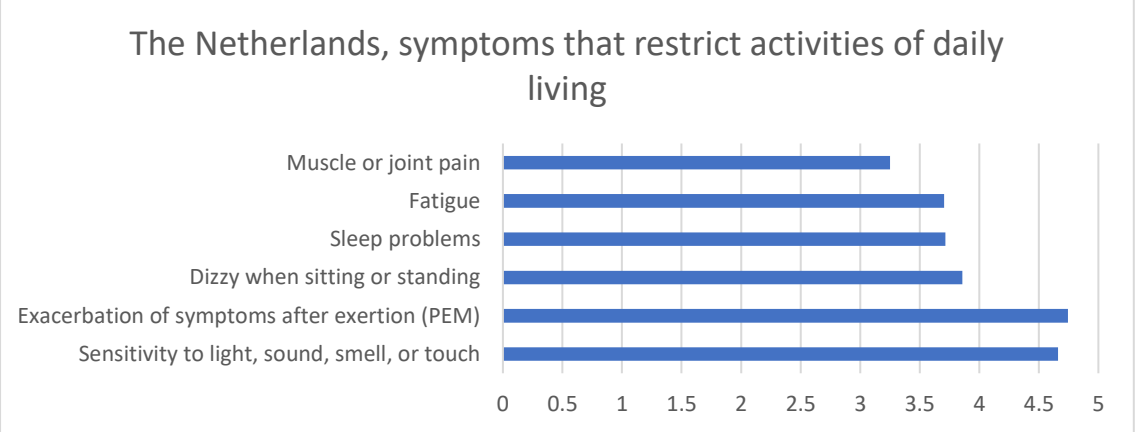
1.17.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

2% of respondents said that their disease was better than mild, 18% had mild, 57% moderate, 20% severe and 2% very severe ME/CFS.

1.17.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found PEM and sensitivity to light and sound the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

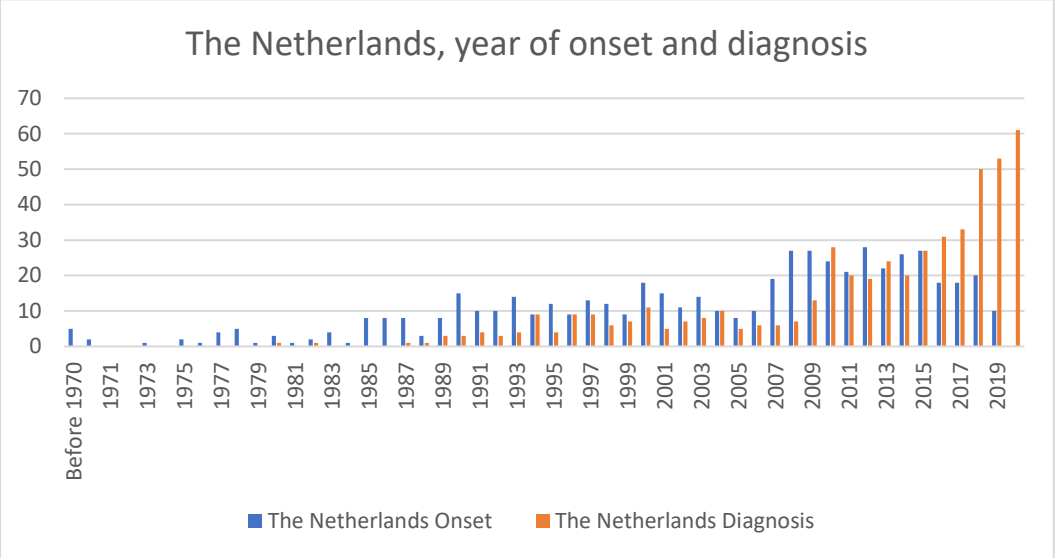


Country Figure 134: The Netherlands, symptoms that restrict activities of daily living, n=553

1.17.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

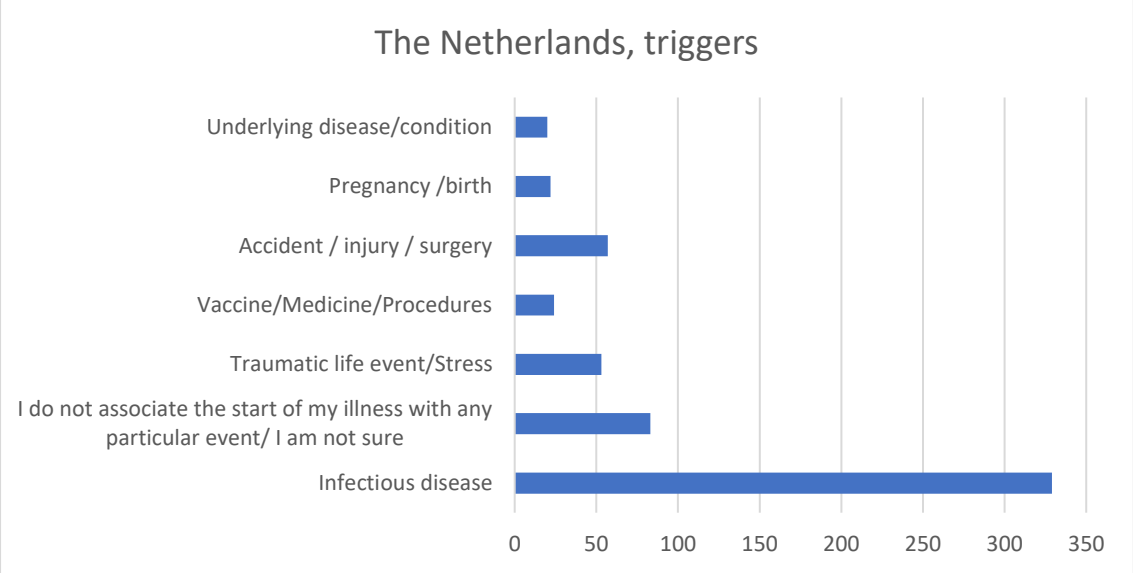
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 135: The Netherlands, year of onset and diagnosis, n=553

1.17.7 Triggers

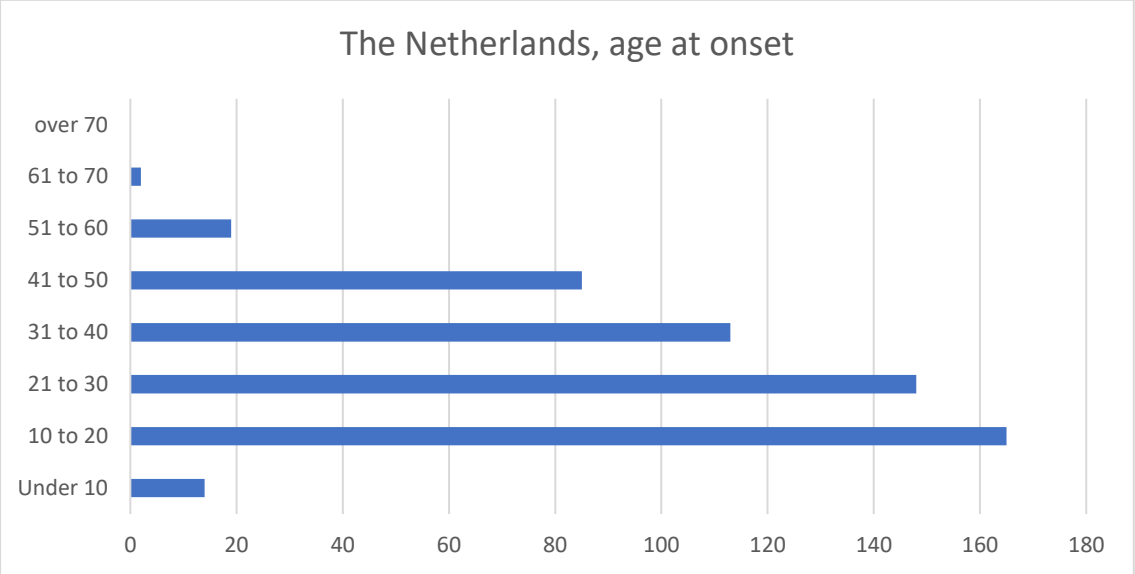
The most common trigger was infectious disease.



Country Figure 136: The Netherlands, triggers, n=553

1.17.8 Age at onset

Average age of onset was 27.8 years. The graph below shows the distribution of age at onset.

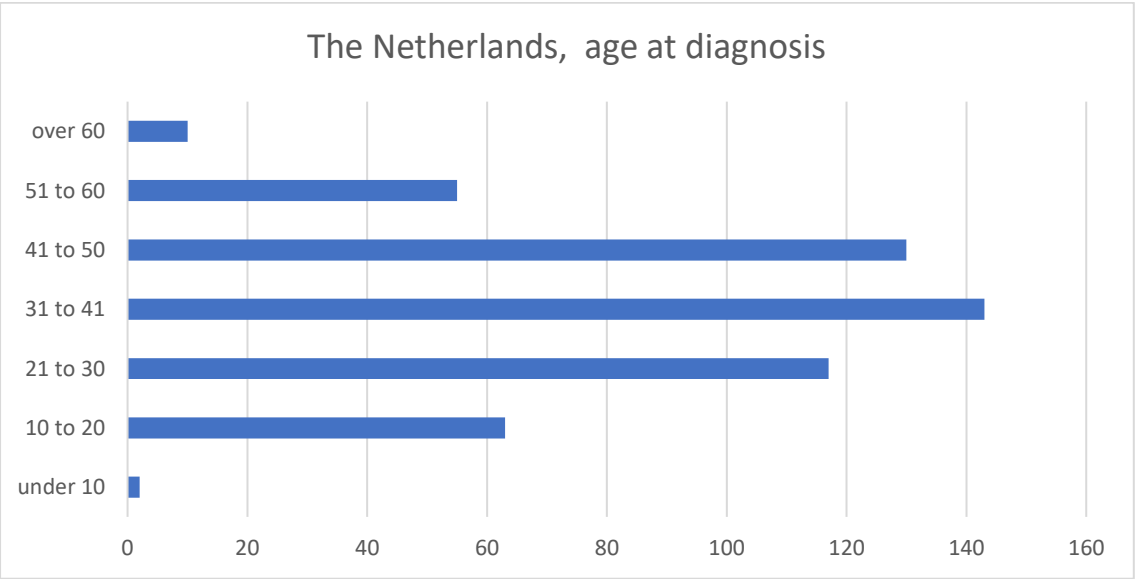


Country Figure 137: The Netherlands, age at onset, n=553

1.17.9 Time from onset to diagnosis

Average time from onset to diagnosis was 8.3 years overall, 8.8 years for men and 8.1 years for women.

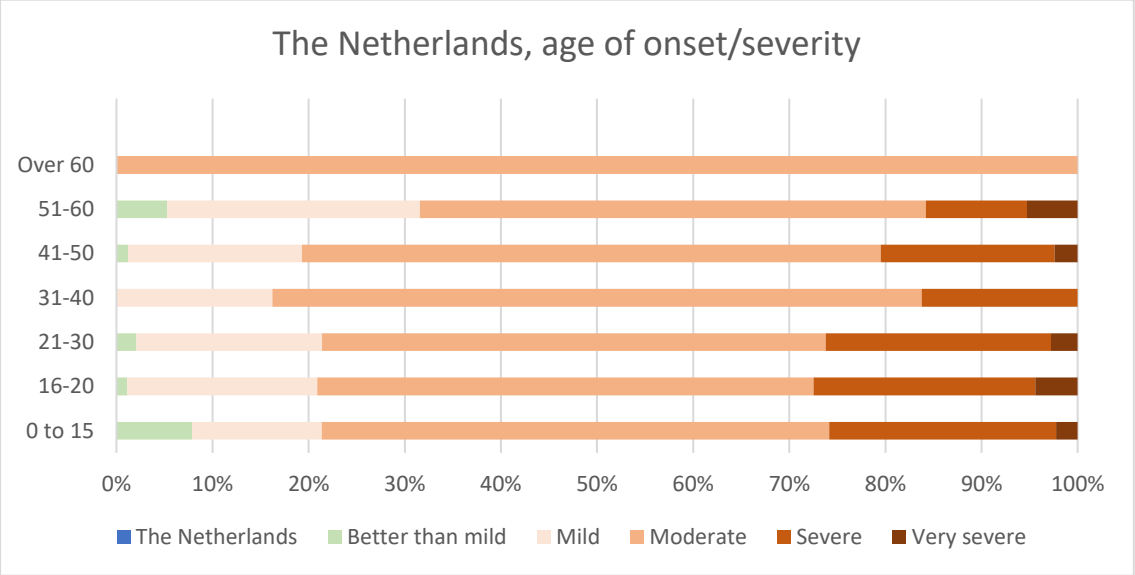
Average age at diagnosis was 36 years.



Country Figure 138: The Netherlands, age at diagnosis, n=519

1.17.10 Age at onset and severity

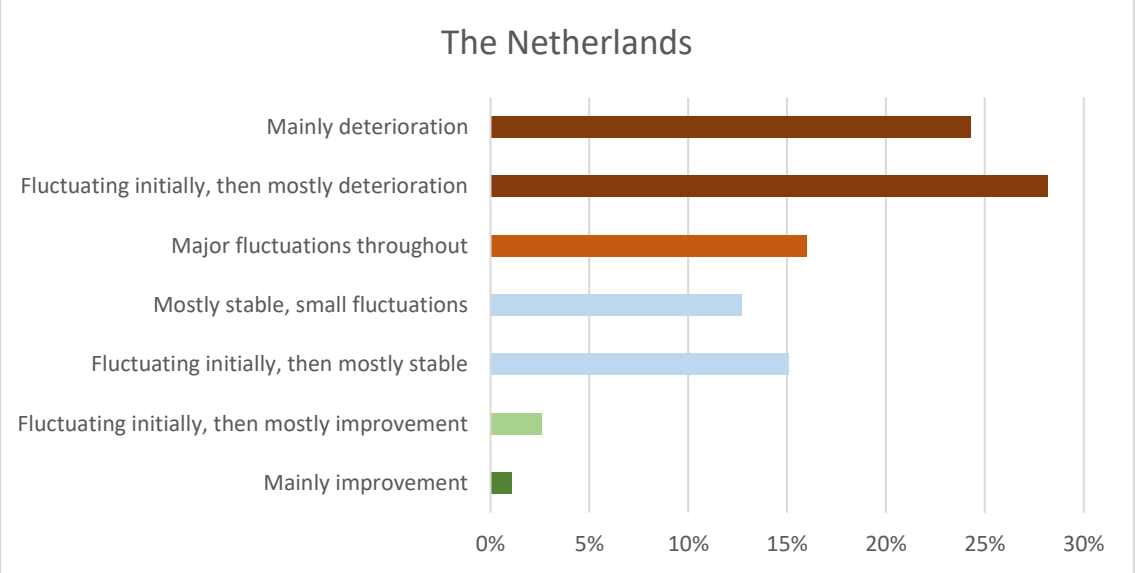
Severe or very severe disease was more common among patients who had early onset, regardless of disease duration.



Country Figure 139: The Netherlands, age of onset and severity, n=553

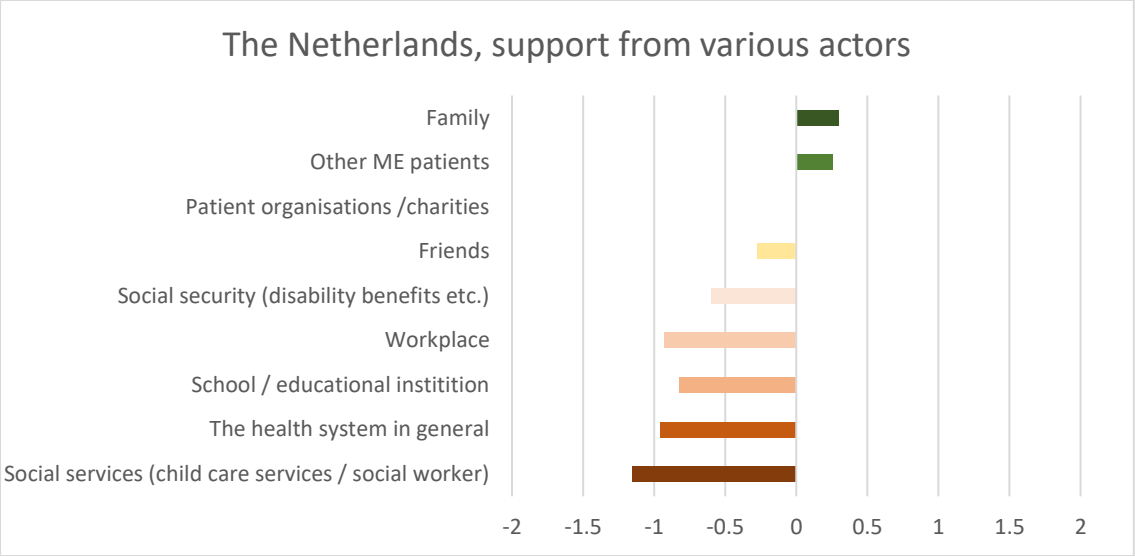
1.17.11 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Norway, 69% of respondents had experienced deterioration or major fluctuations, 28% said they were mostly stable, and 4% had experienced mainly improvement.



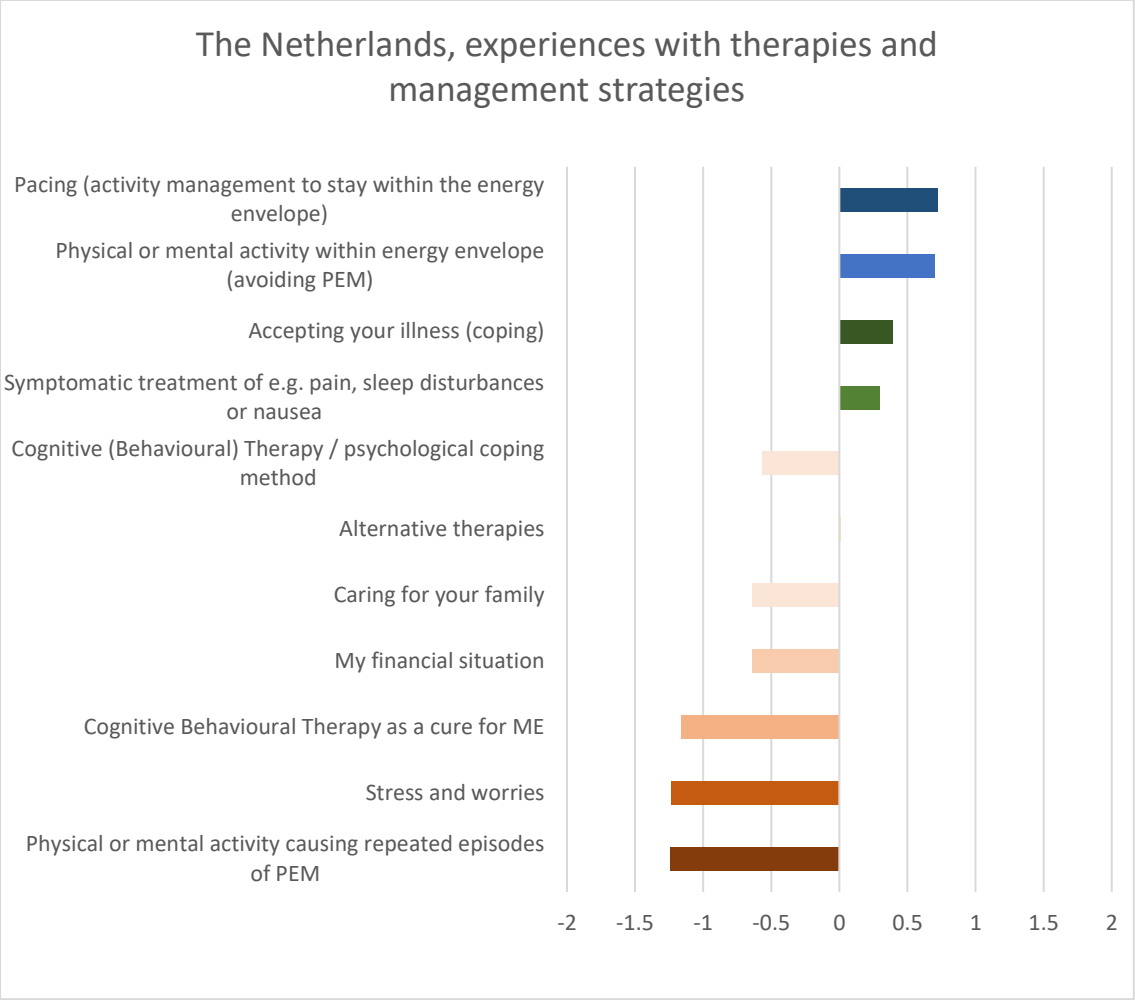
Country Figure 140: The Netherlands, course of illness, n=553

1.17.12 Experienced support from various actors



Country Figure 141: The Netherlands, support from various actors

1.17.13 Experiences with management strategies and therapies



Country Figure 142: The Netherlands, experiences with management strategies and therapies

1.18 UK

1.18.1 Respondents

There were 942 respondents from the UK. 97% of respondents had received a diagnosis, 1% were currently under evaluation for a diagnosis, and 2% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

1.18.2 Age

Average age of respondents was 50.6 years.

1.18.3 Gender

85% of respondents were female, 15% male, less than 1% preferred not to say.

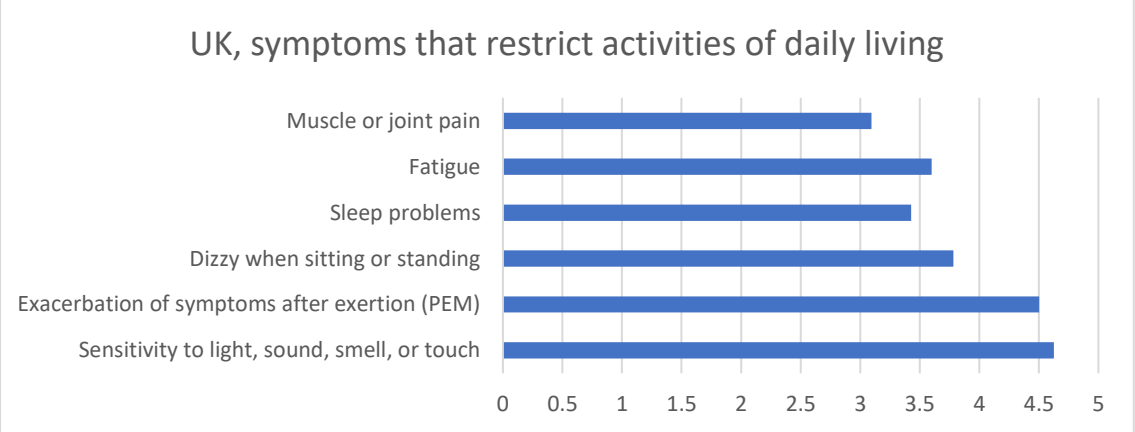
1.18.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

3% of respondents said that their disease was better than mild, 24% had mild, 53% moderate, 18% severe and 2% very severe ME/CFS.

1.18.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found sensitivity to light and sound and PEM the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

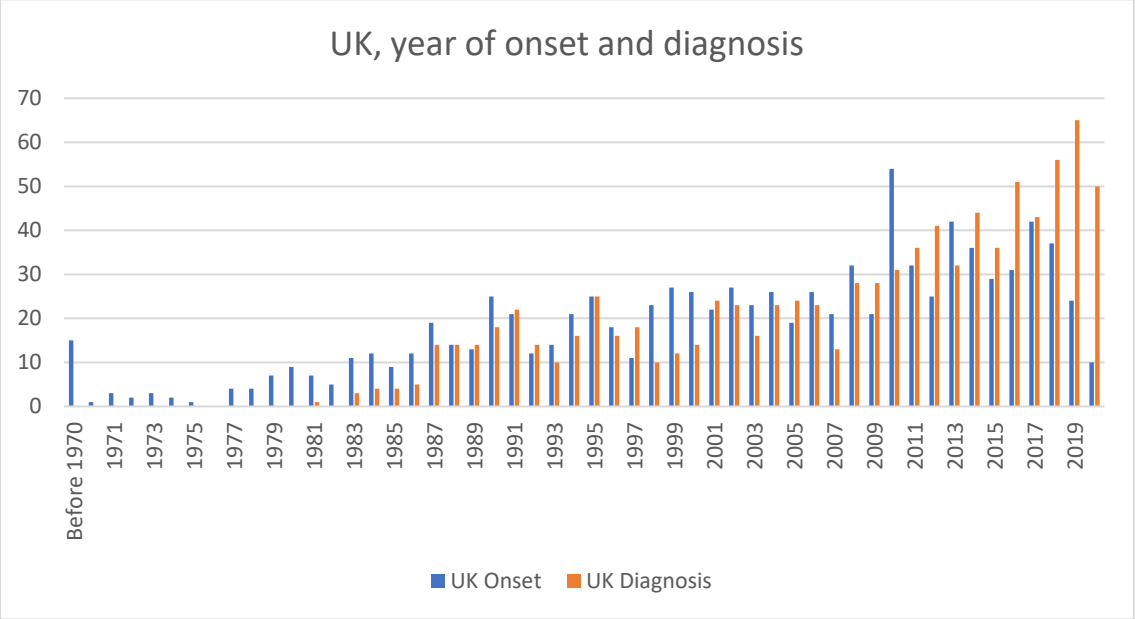


Country Figure 143: UK, symptoms that restrict activities of daily living, n=942

1.18.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

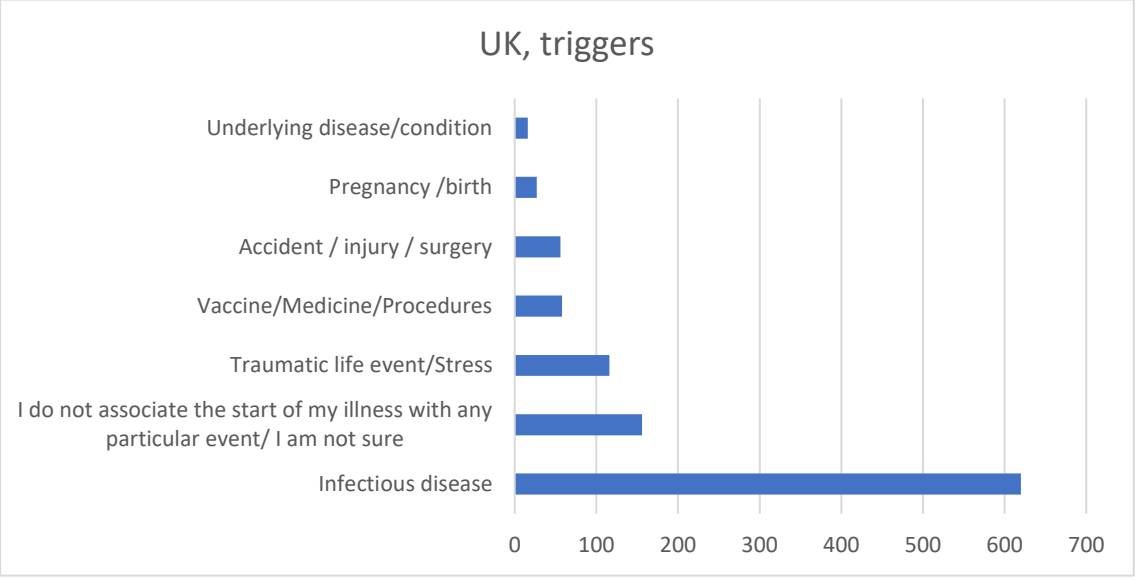
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 144: UK, year of onset and diagnosis

1.18.7 Triggers

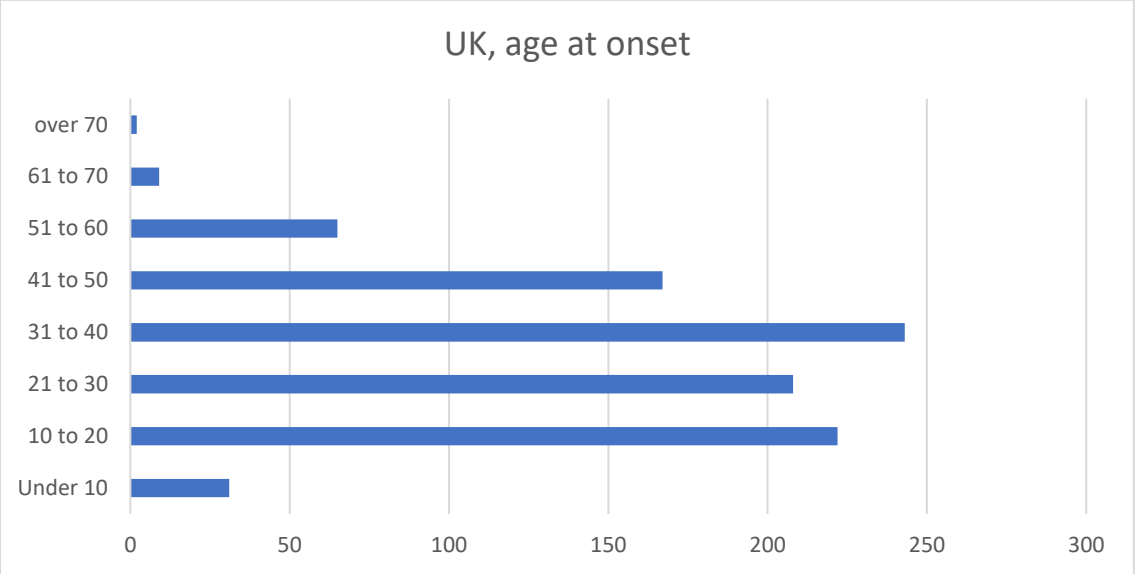
The most common trigger was infectious disease.



Country Figure 145: UK, triggers, n=942

1.18.8 Age at onset

Average age of onset was 31 years. The graph below shows the distribution of age at onset.

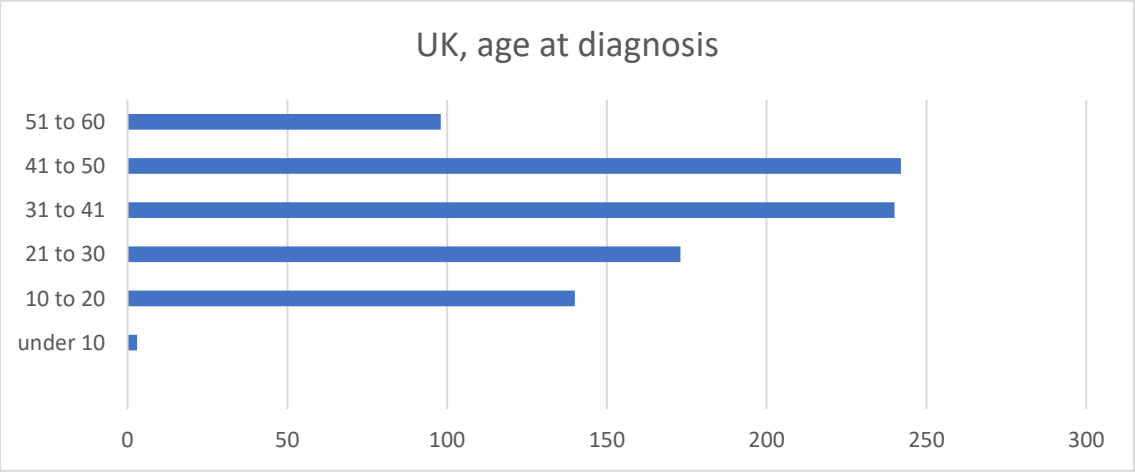


Country Figure 146: UK, age at onset, n=942

1.18.9 Time from onset to diagnosis

Average time from onset to diagnosis was 5.2 years overall, 5.58 years for men and 5 years for women.

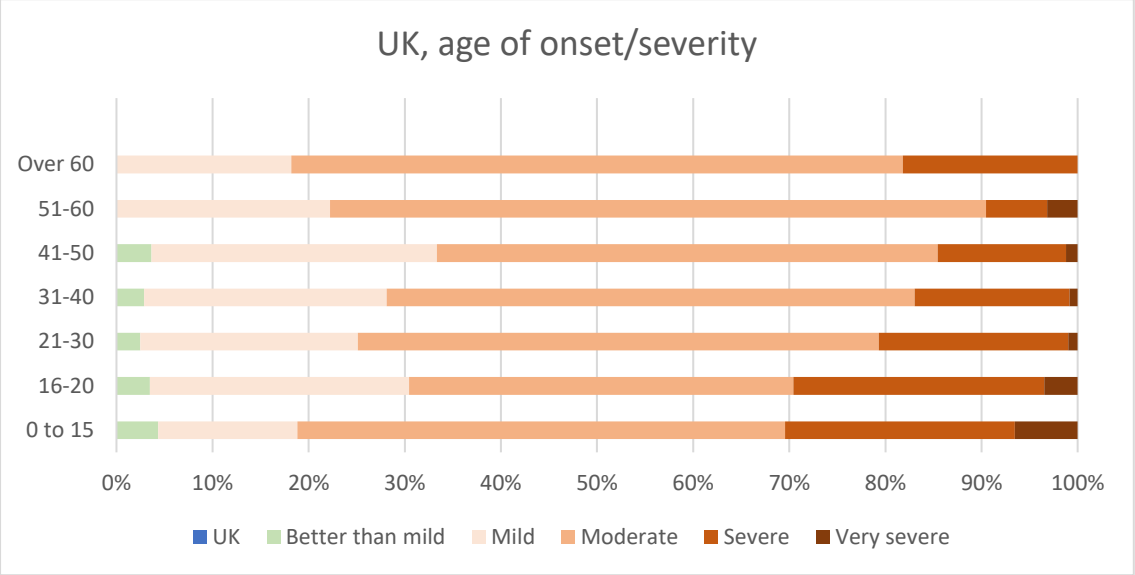
Average age at diagnosis was 36.1 years.



Country Figure 147: UK, age at diagnosis, n=914

1.18.10 Age at onset and severity

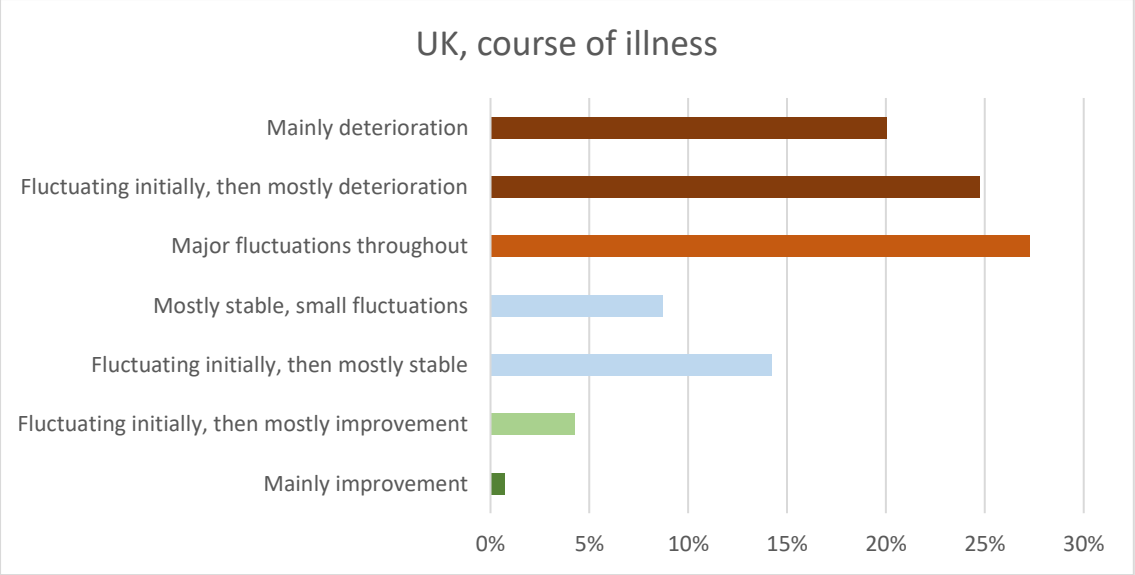
Severe or very severe disease was more common among patients who had early onset, regardless of disease duration.



Country Figure 148: UK, age of onset and severity, n=942

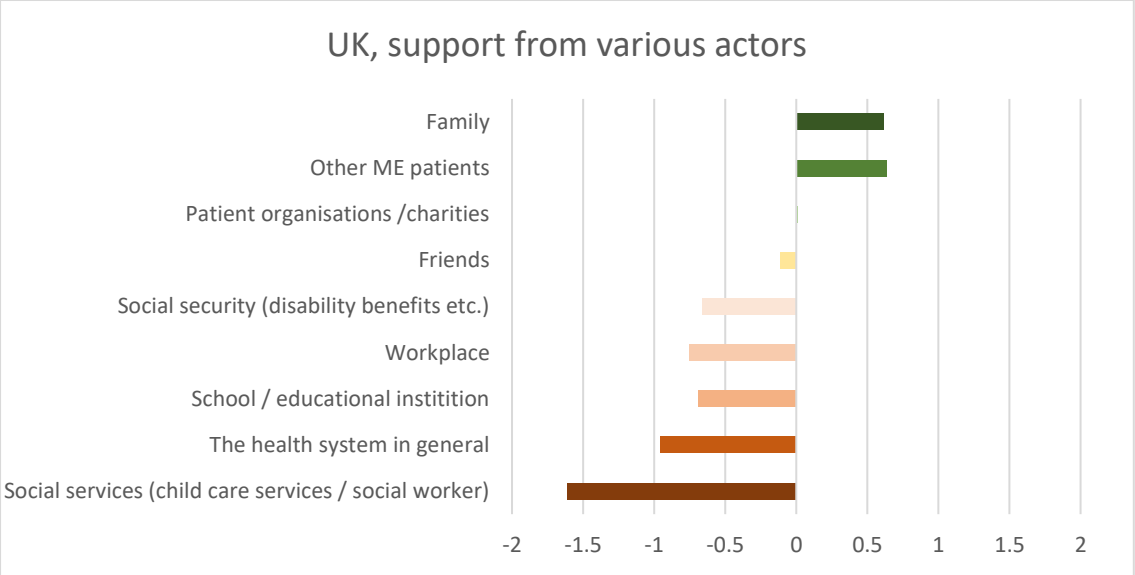
1.18.11 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In the UK, 72% of respondents had experienced deterioration or major fluctuations, 23% said they were mostly stable, and 5% had experienced mainly improvement.



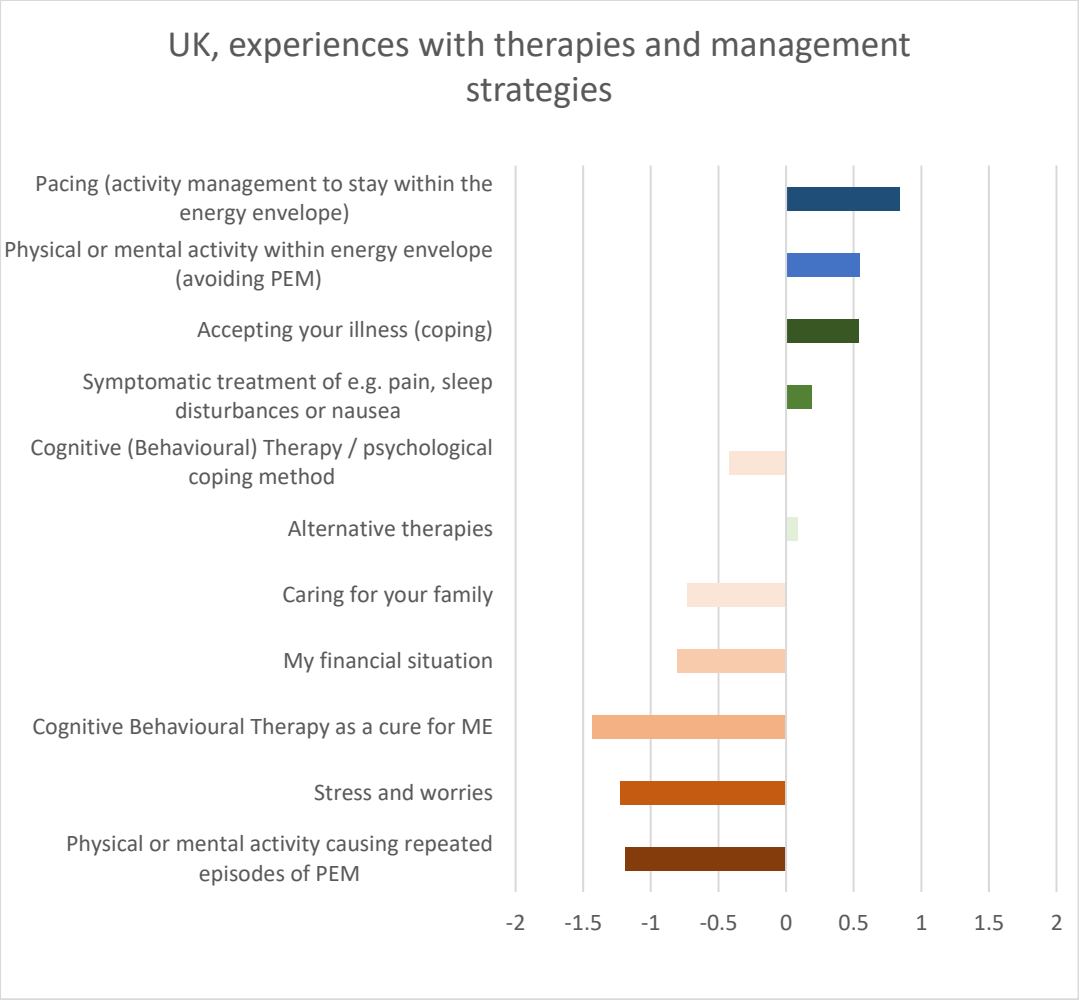
Country Figure 149: UK, course of illness, n=942

1.18.12 Experienced support from various actors



Country Figure 150: UK, support from various actors

1.18.13 Experiences with management strategies and therapies



Country Figure 151: UK, experience with management strategies and therapies

2 Non-European countries

2.1 Australia

2.1.1 Respondents

There were 90 respondents from Australia. 95% of respondents had received a diagnosis, 1% were currently under evaluation for a diagnosis, and 4% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

2.1.2 Age

Average age of respondents was 51.5 years.

2.1.3 Gender

78% of respondents were female, 22% male.

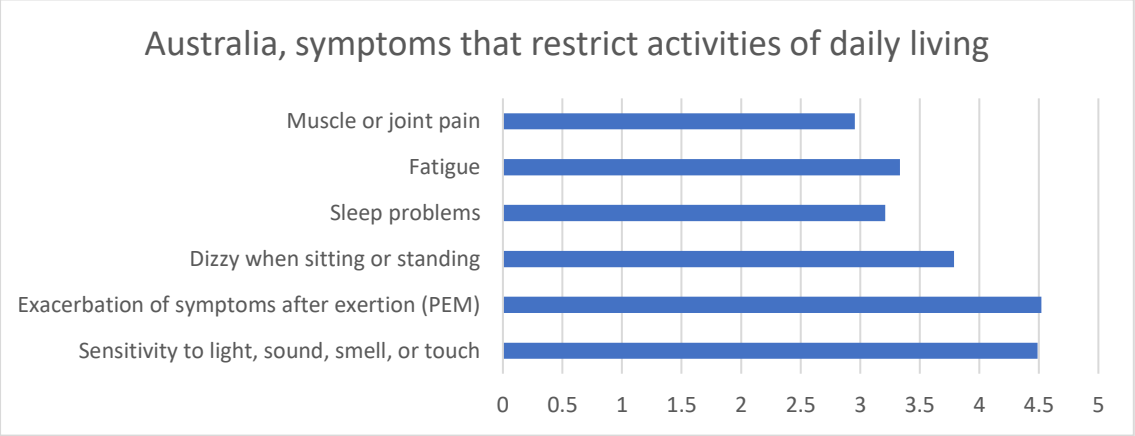
2.1.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

3% of respondents said that their disease was better than mild, 21% had mild, 53% moderate, 20% severe and 2% very severe ME/CFS.

2.1.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found PEM and sensitivity to light and sound, and symptom exacerbation after activity the most restrictive symptoms. Pain was rated the least bothersome symptom. Individual profiles had much variation.

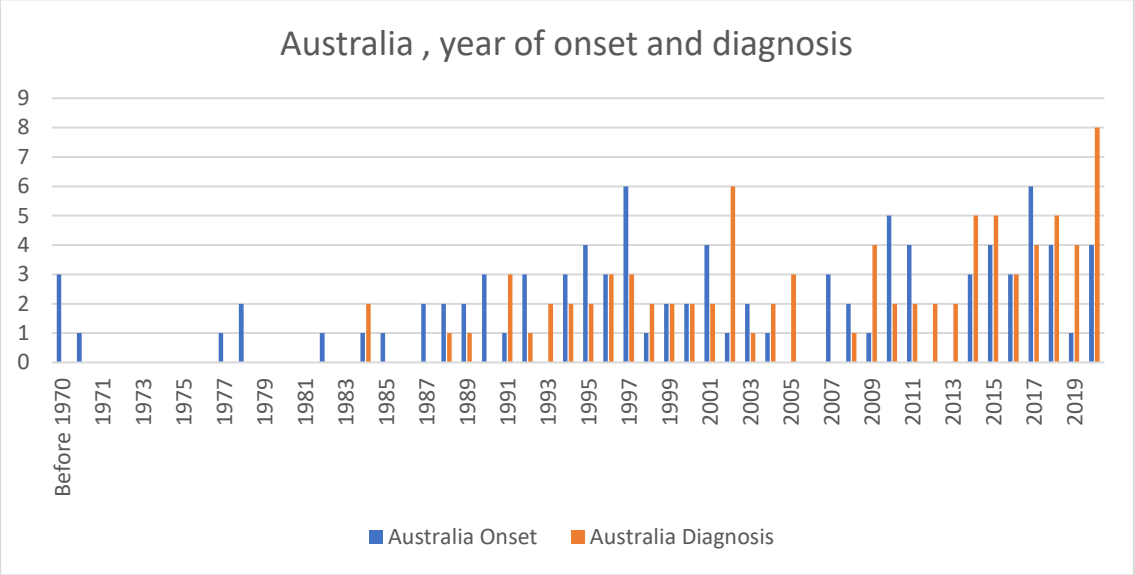


Country Figure 152: Australia, symptoms that restrict activities of daily living, n=90

2.1.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

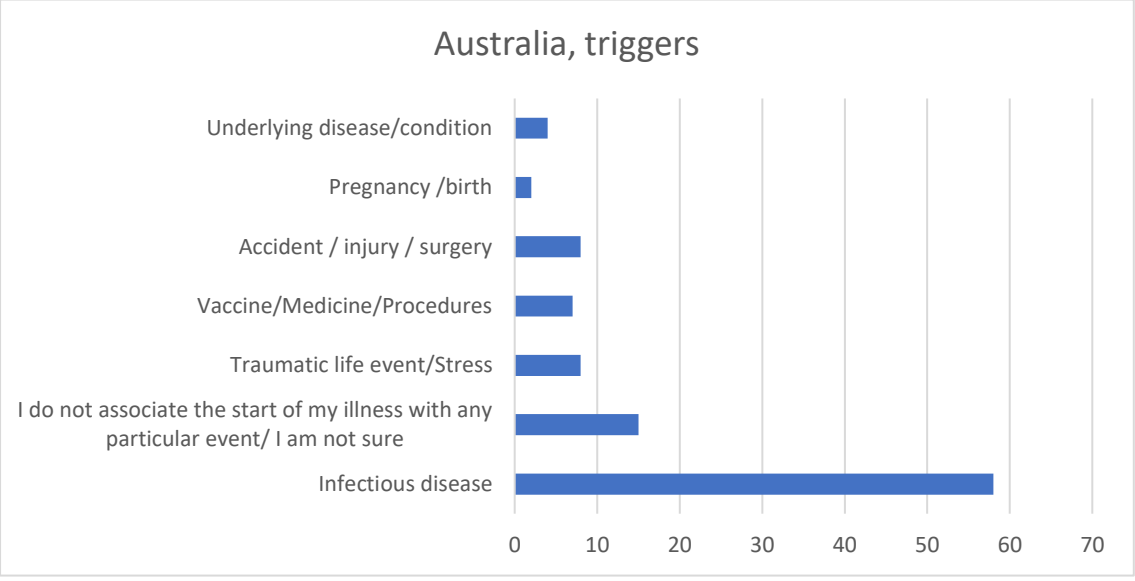
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 153: Australia, year of onset and diagnosis

2.1.7 Triggers

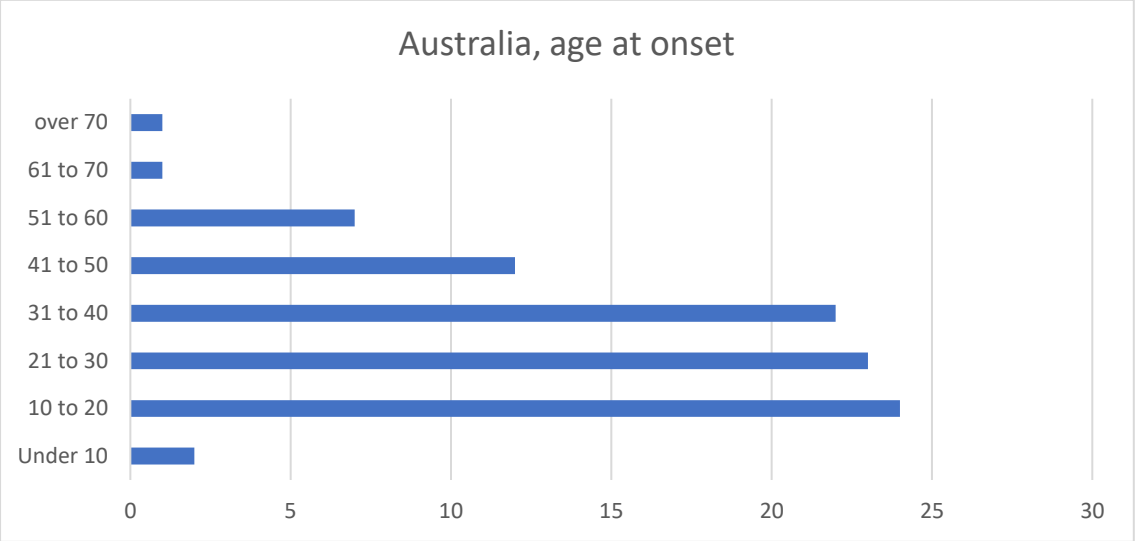
The most common trigger was infectious disease.



Country Figure 154: Australia, triggers, n=90

2.1.8 Age at onset

Average age of onset was 30.7 years. The graph below shows the distribution of age at onset.

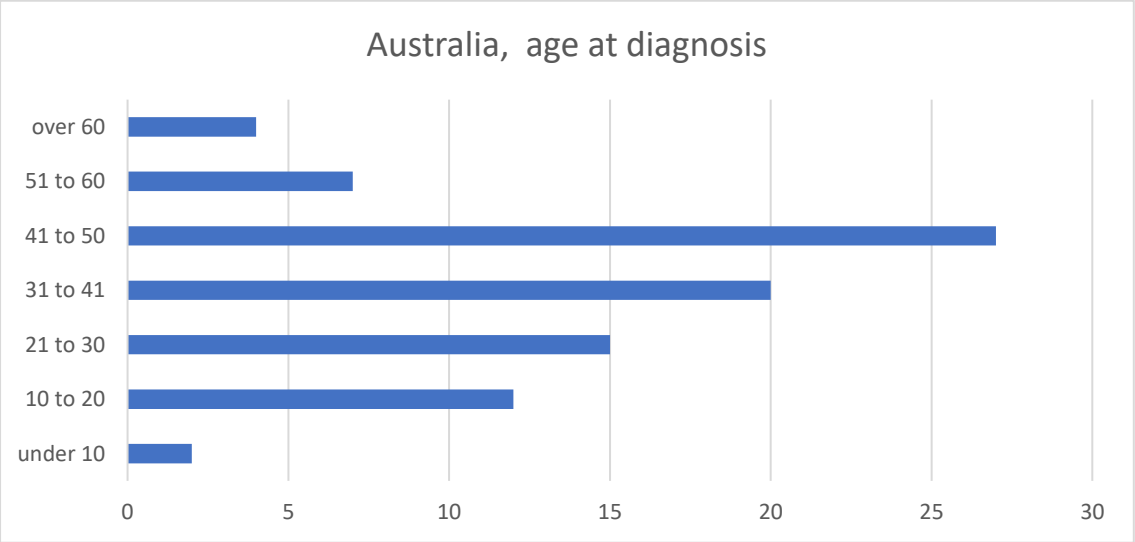


Country Figure 155: Australia, age at onset, n=90

2.1.9 Time from onset to diagnosis

Average time from onset to diagnosis was 5.8 years overall, 1.3 years for men and 6 years for women.

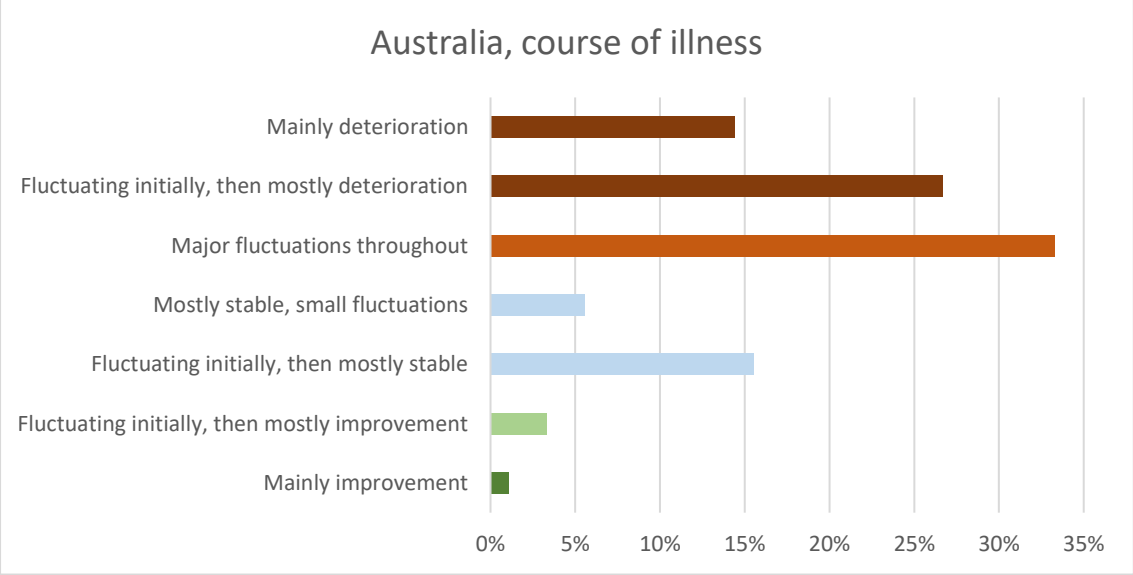
Average age at diagnosis was 36.2 years.



Country Figure 156: Australia, age at diagnosis, n=84

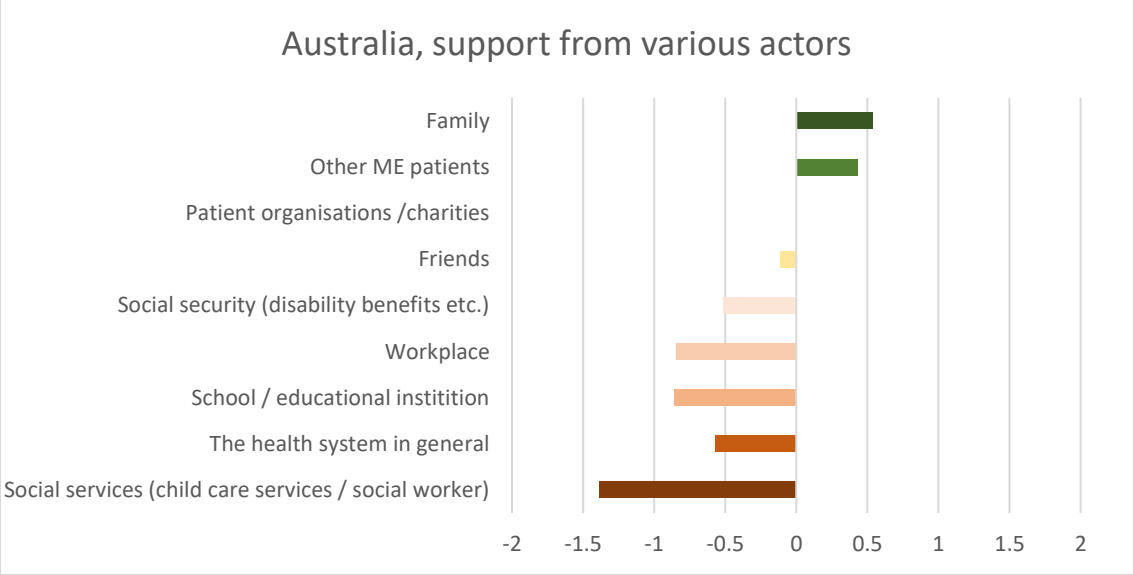
2.1.10 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Australia, 74% of respondents had experienced deterioration or major fluctuations, 9% said they were mostly stable, and 4% had experienced mainly improvement.



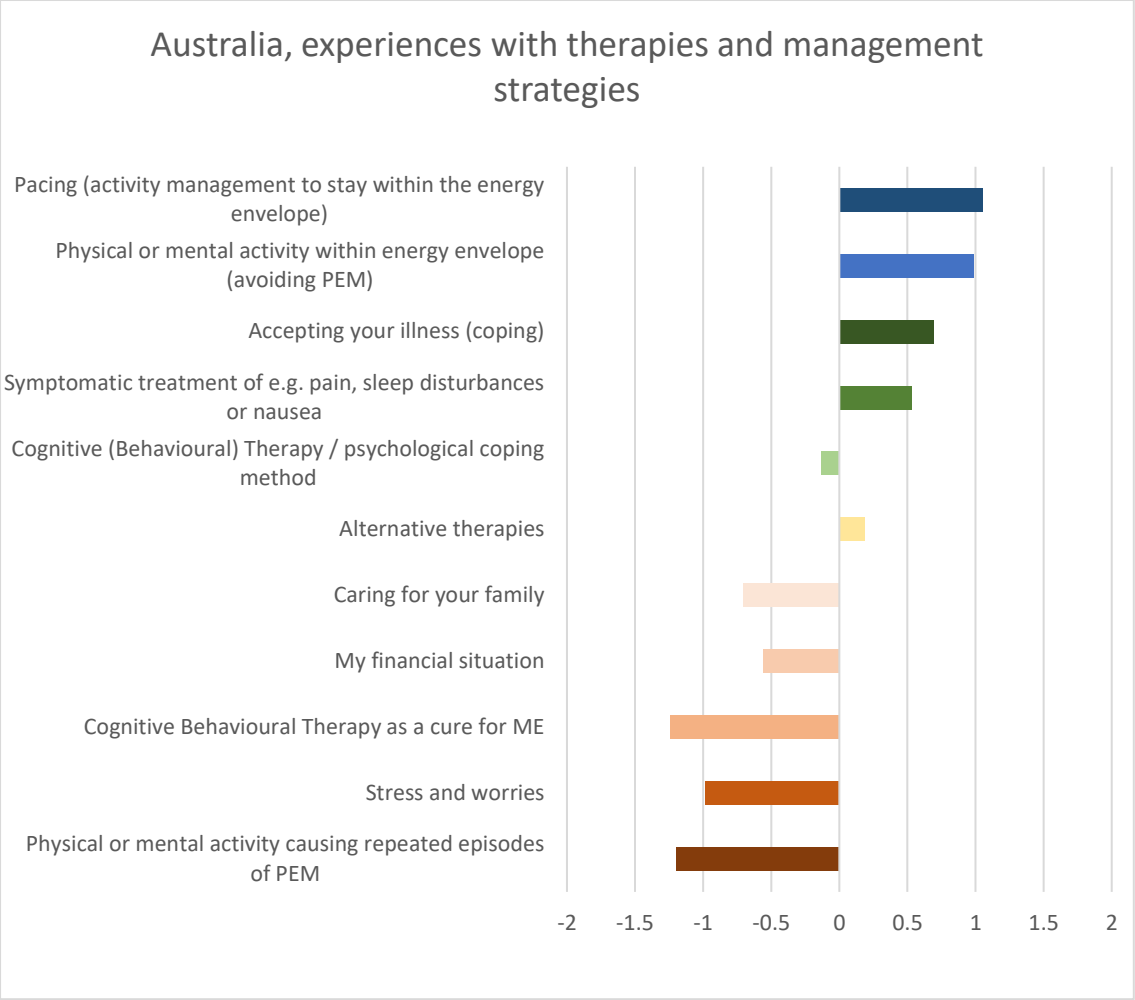
Country Figure 157: Australia, course of illness, n=90

2.1.11 Experienced support from various actors



Country Figure 158: Australia, support from various actors

2.1.12 Experiences with management strategies and therapies



Country Figure 159: Australia, experience with management strategies and therapies

2.2 Canada

2.2.1 Respondents

There were 156 respondents from Canada. 84% of respondents had received a diagnosis, 4% were currently under evaluation for a diagnosis, and 12% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

2.2.2 Age

Average age of respondents was 58.3 years.

2.2.3 Gender

85% of respondents were female, 15% male.

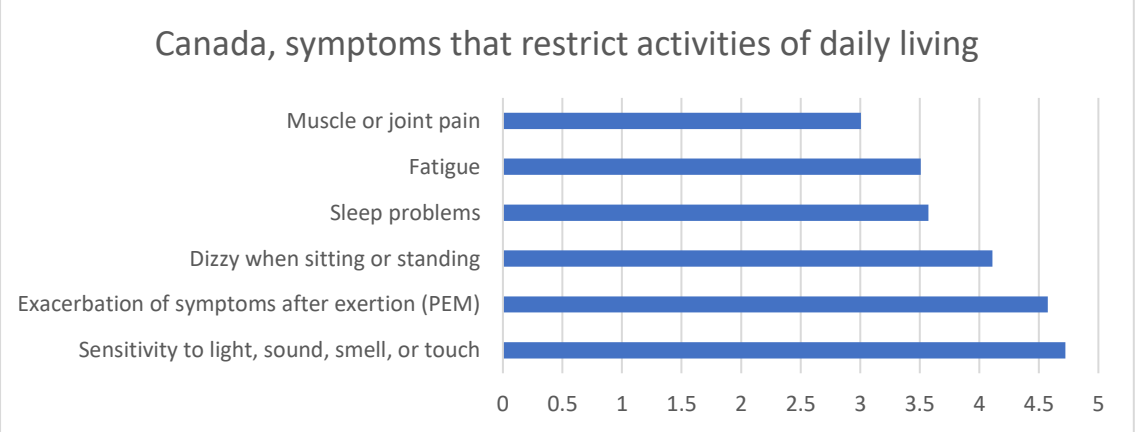
2.2.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

3% of respondents said that their disease was better than mild, 25% had mild, 55% moderate, 14% severe and 3% very severe ME/CFS.

2.2.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found sensitivity to light and sound and PEM the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

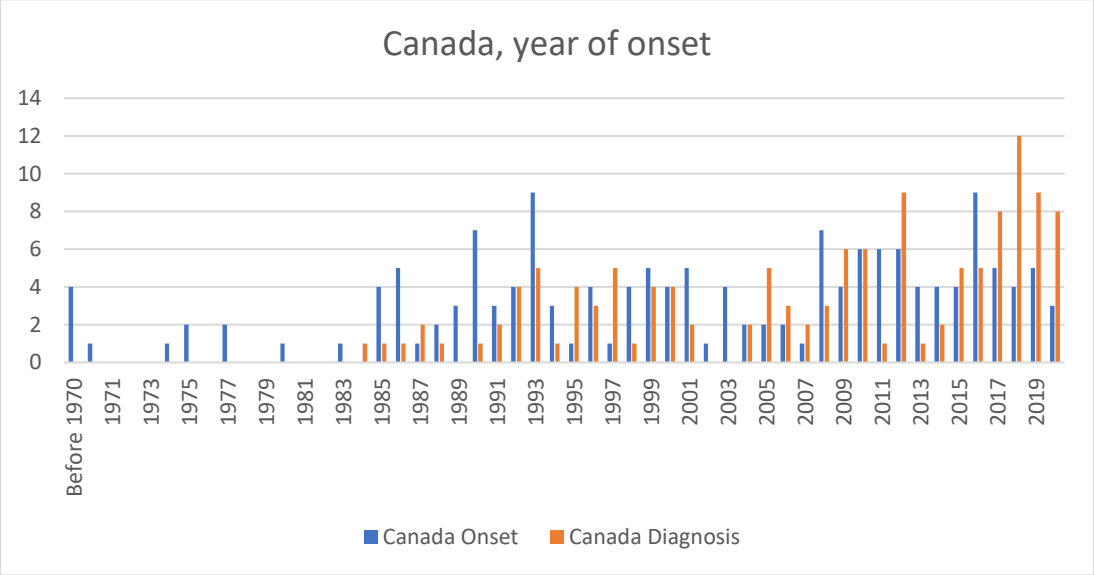


Country Figure 160: Canada, symptoms that restrict activities of daily living, n=156

2.2.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

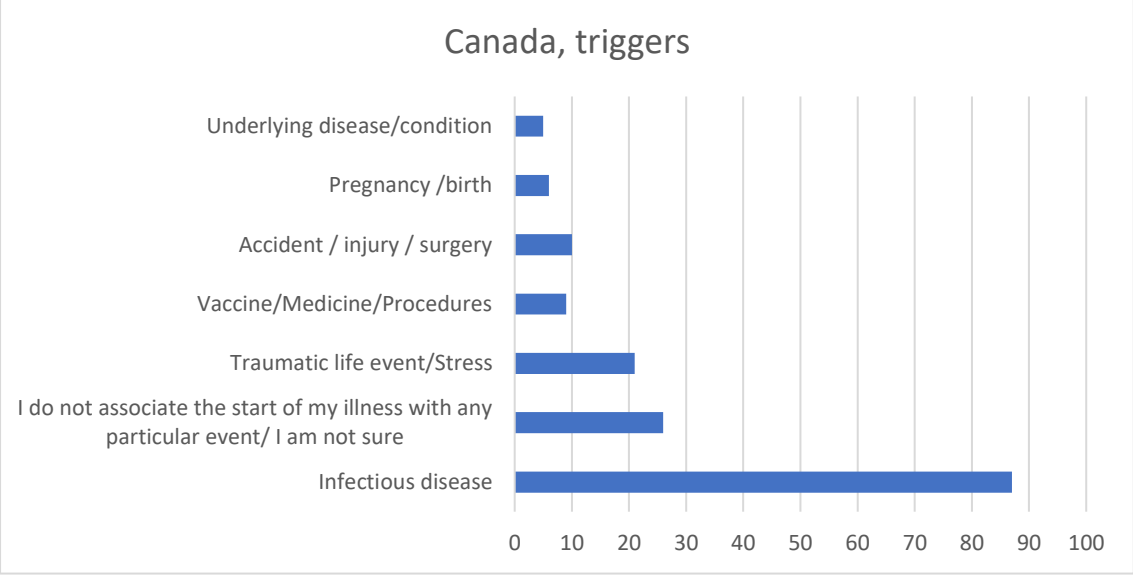
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 161: Canada, year of onset, n=156

2.2.7 Triggers

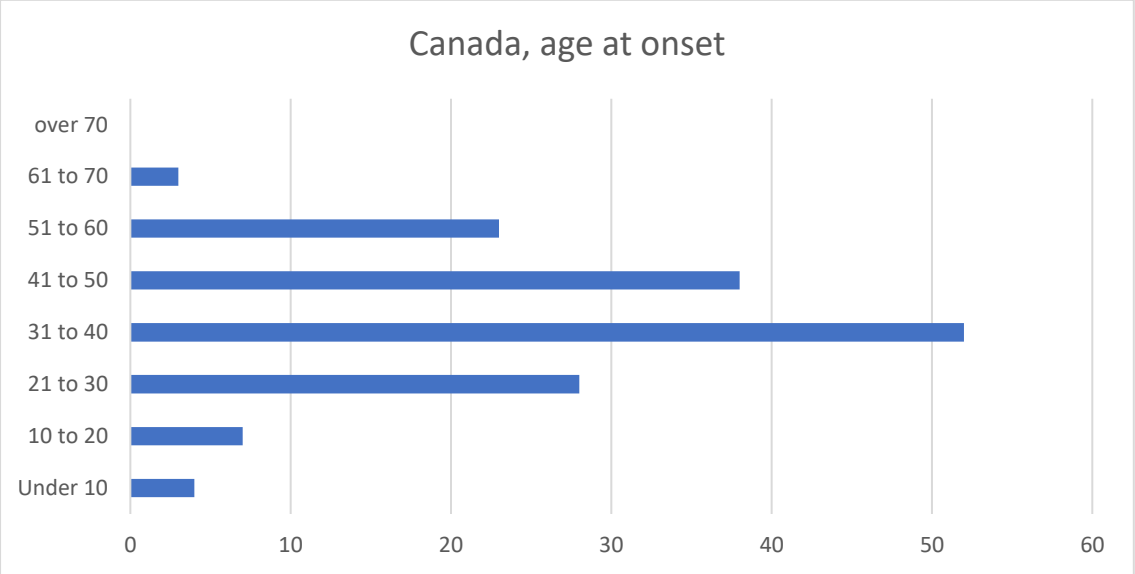
The most common trigger was infectious disease.



Country Figure 162: Canada, triggers, n=156

2.2.8 Age at onset

Average age of onset was 37.5 years. The graph below shows the distribution of age at onset.

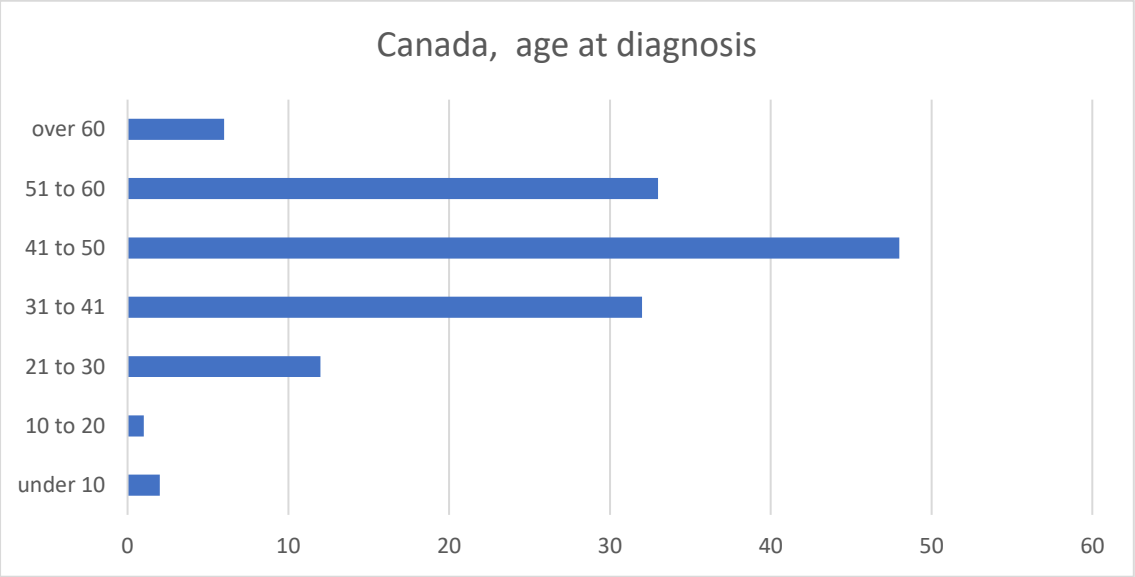


Country Figure 163: Canada, age at onset, n=156

2.2.9 Time from onset to diagnosis

Average time from onset to diagnosis was 6.6 years overall, 5.3 years for men and 6.8 years for women.

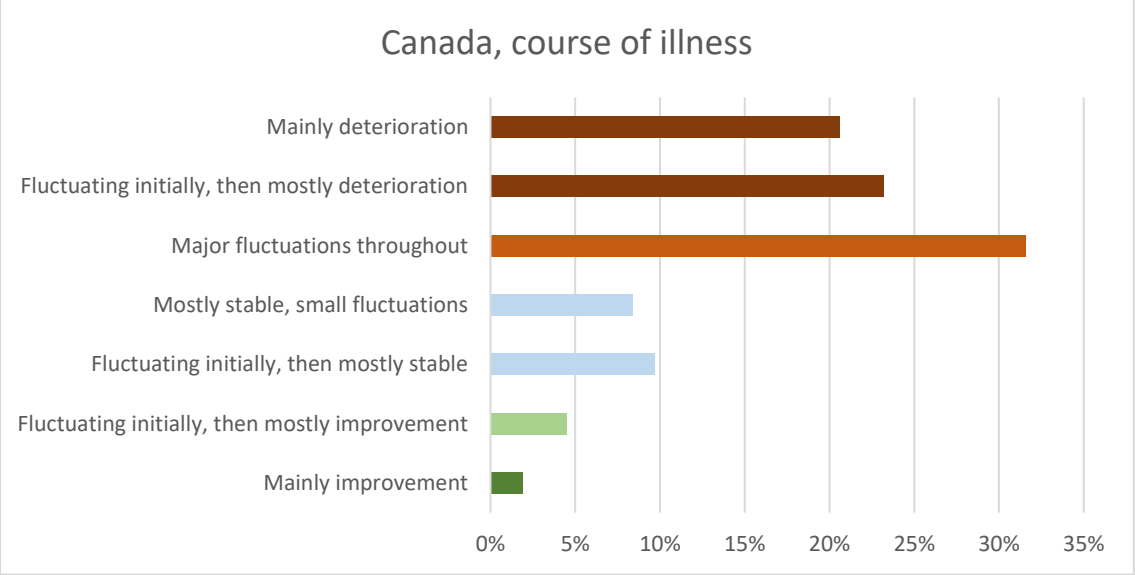
Average age at diagnosis was 44.1 years.



Country Figure 164: Canada, age at diagnosis, n=131

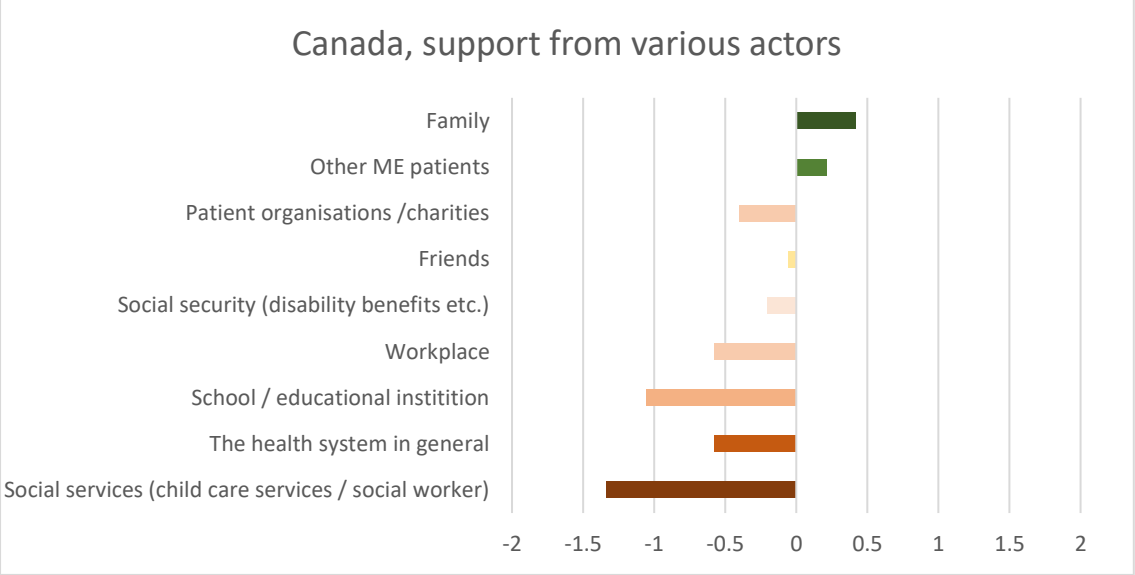
2.2.10 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In Canda, 75% of respondents had experienced deterioration or major fluctuations, 18% said they were mostly stable, and 7% had experienced mainly improvement.



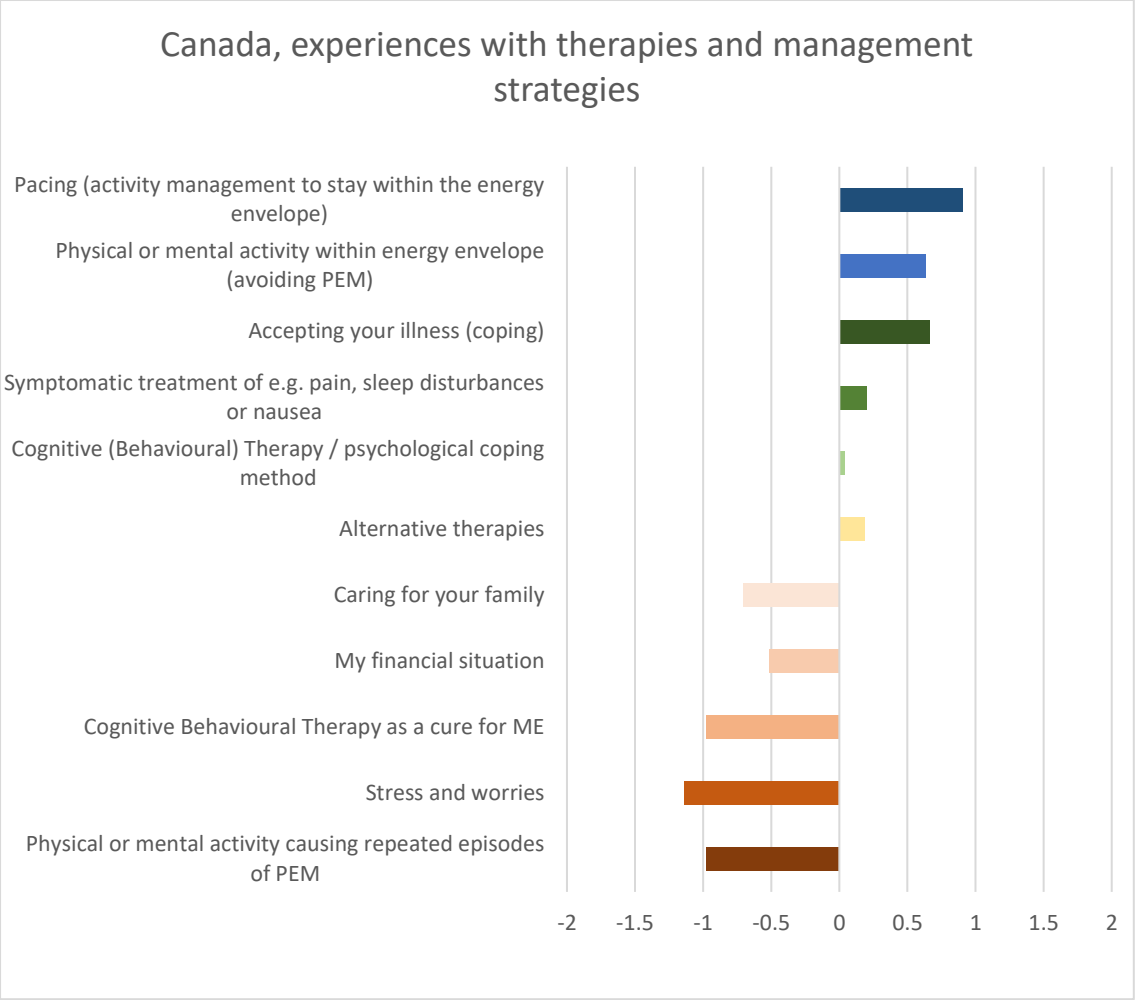
Country Figure 165: Canada, course of illness, n=156

2.2.11 Experienced support from various actors



Country Figure 166: Canada, support from various actors

2.2.12 Experiences with management strategies and therapies



Country Figure 167: Canada, experience with management strategies and therapies

2.3 USA

2.3.1 Respondents

There were 486 respondents from USA. 92% of respondents had received a diagnosis, 2% were currently under evaluation for a diagnosis, and 6% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.

2.3.2 Age

Average age of respondents was 61.9 years.

2.3.3 Gender

88% of respondents were female, 12 male.

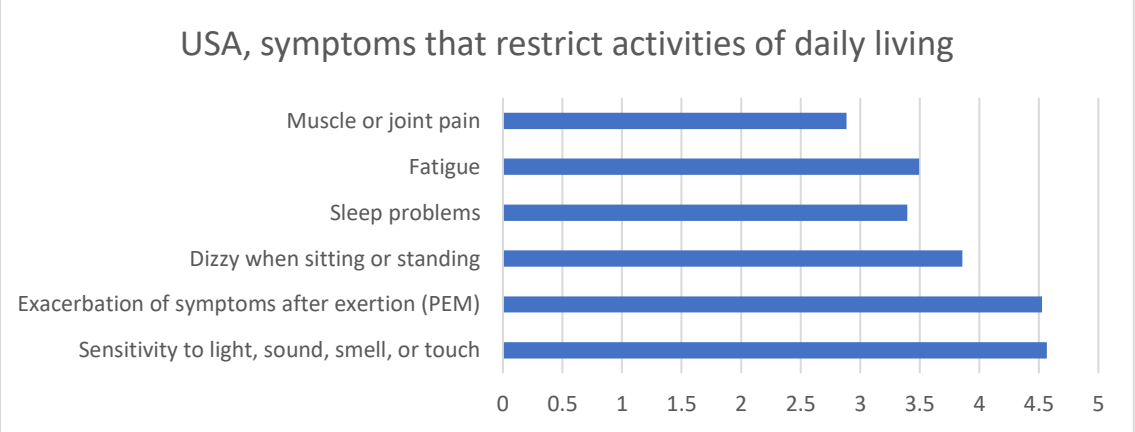
2.3.4 Severity

The severity scale was based on the ICC criteria, where "mild" ME means at least a 50% loss of function, "moderate" means that the patient is mostly housebound, "severe" that the patient is mostly bedbound, and "very severe" that the patient is bedbound and in need of care.

4% of respondents said that their disease was better than mild, 21% had mild, 60% moderate, 15% severe and none had very severe ME/CFS.

2.3.5 Symptoms that restrict activities of daily living

NB! We did not ask about cognitive problems, by mistake. Respondents found sensitivity to light and sound and PEM the most restrictive symptom, slightly worse than symptom exacerbation after activity. Pain was rated the least bothersome symptom. Individual profiles had much variation.

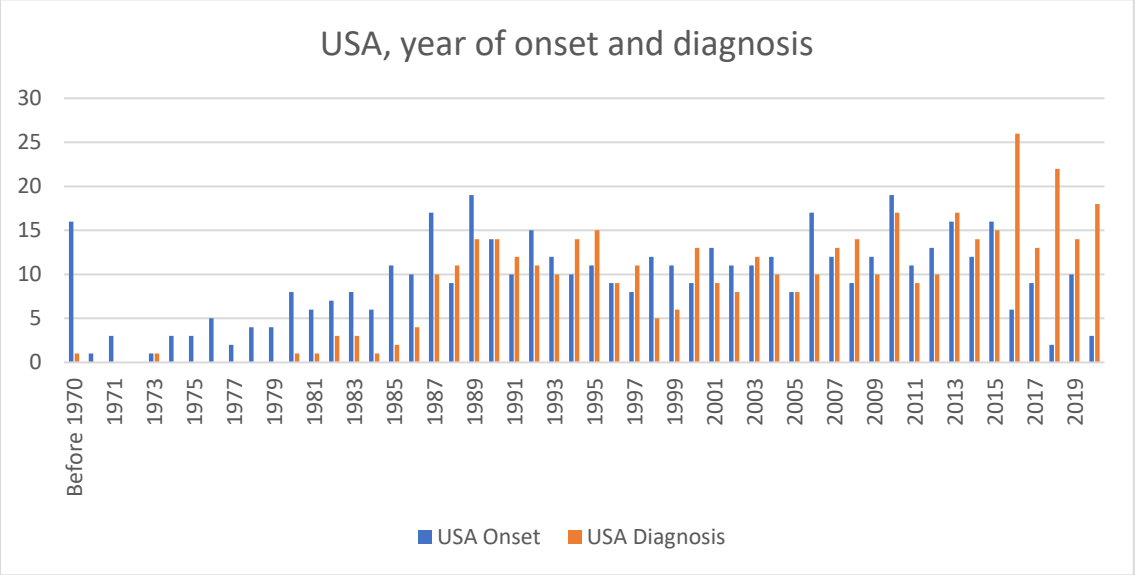


Country Figure 168: USA, symptoms that restrict activities of daily living, n= 486

2.3.6 Year of onset

The graph shows when respondents fell ill, and when they were diagnosed.

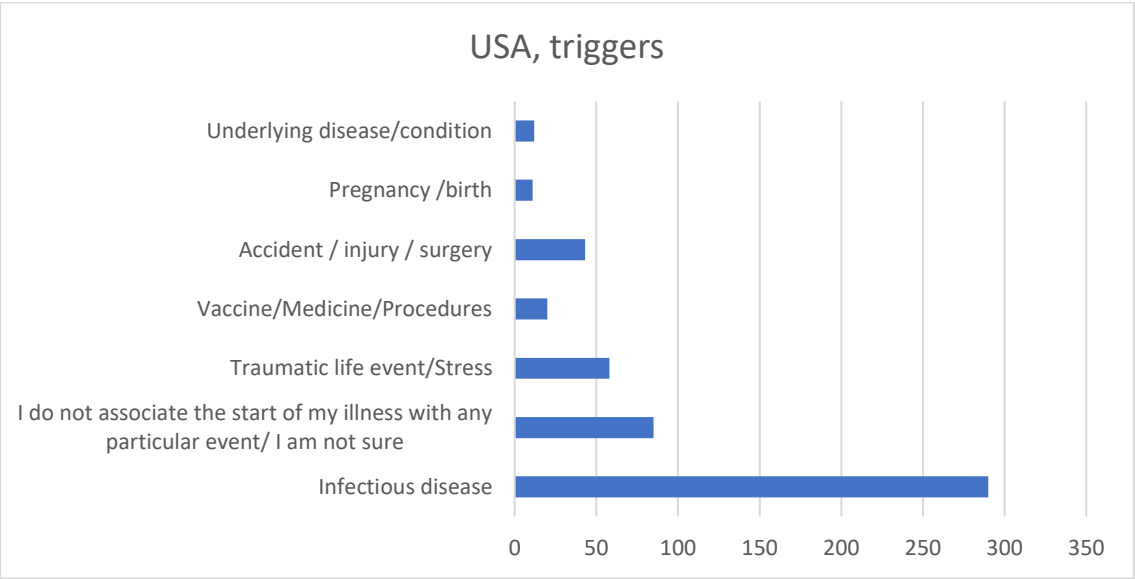
The decrease in new "onset" cases over the last years reflects the time it takes to get a diagnosis, as undiagnosed patients are less likely to follow ME/CFS support groups or organisations online, and less likely to hear about the survey.



Country Figure 169: USA, year of onset and diagnosis

2.3.7 Triggers

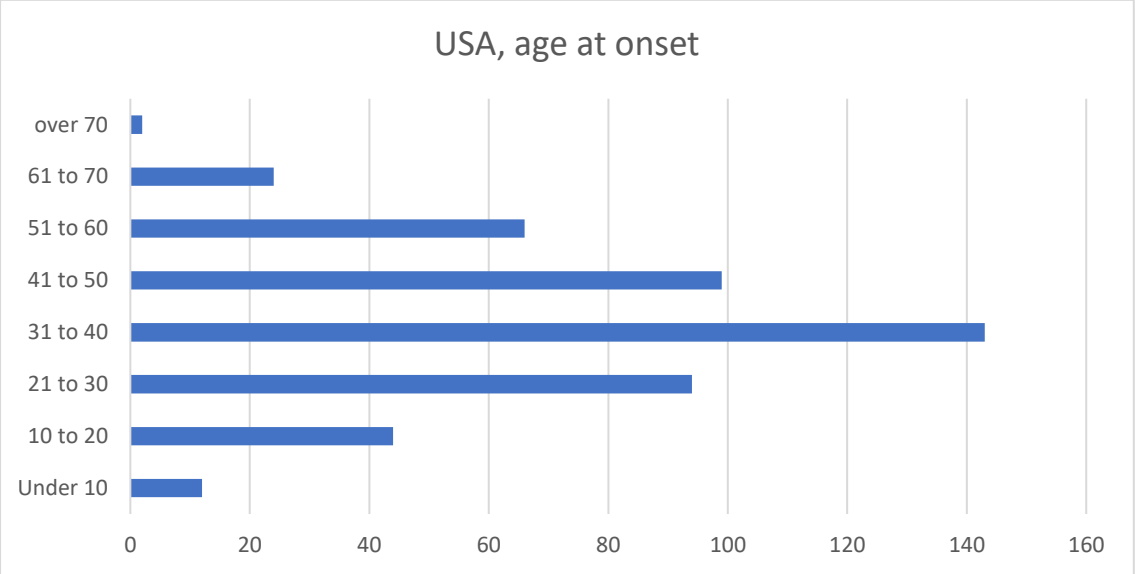
The most common trigger was infectious disease.



Country Figure 170: USA, triggers, n=486

2.3.8 Age at onset

Average age of onset was 37.3 years. The graph below shows the distribution of age at onset.

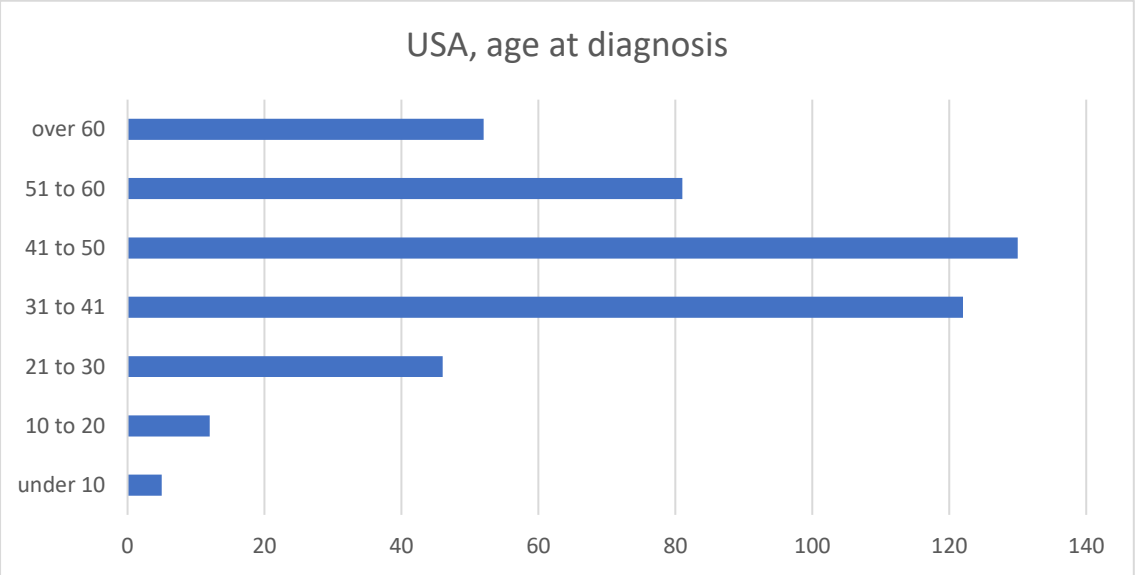


Country Figure 171: USA, age at onset, n=486

2.3.9 Time from onset to diagnosis

Average time from onset to diagnosis was 6.75 years overall, 7.1 years for men and 6.7 years for women.

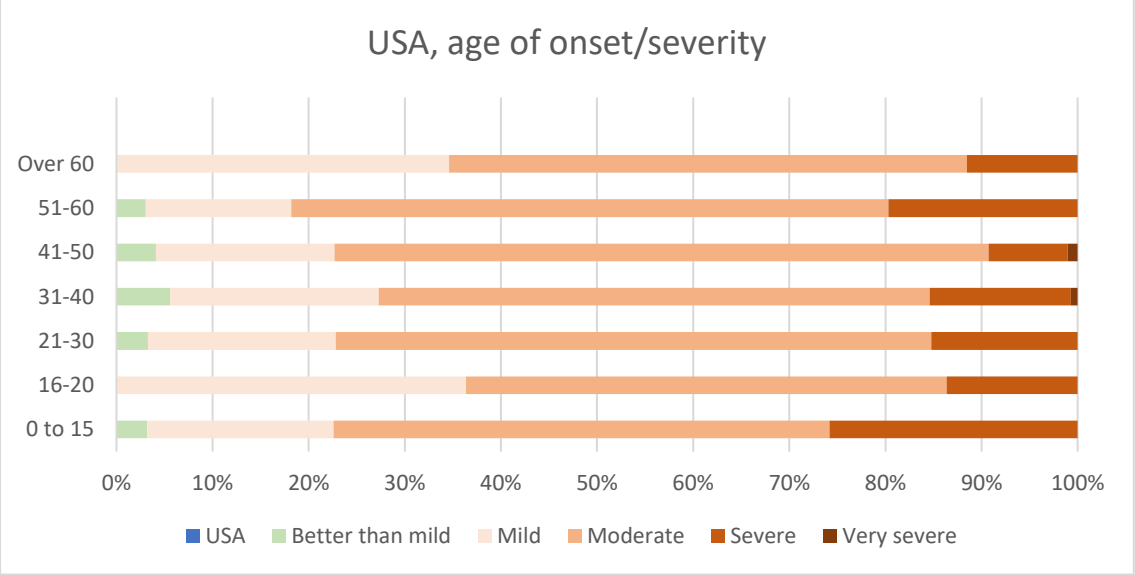
Average age at diagnosis was 44.2 years.



Country Figure 172: USA, age at diagnosis, n=447

2.3.10 Age at onset and severity

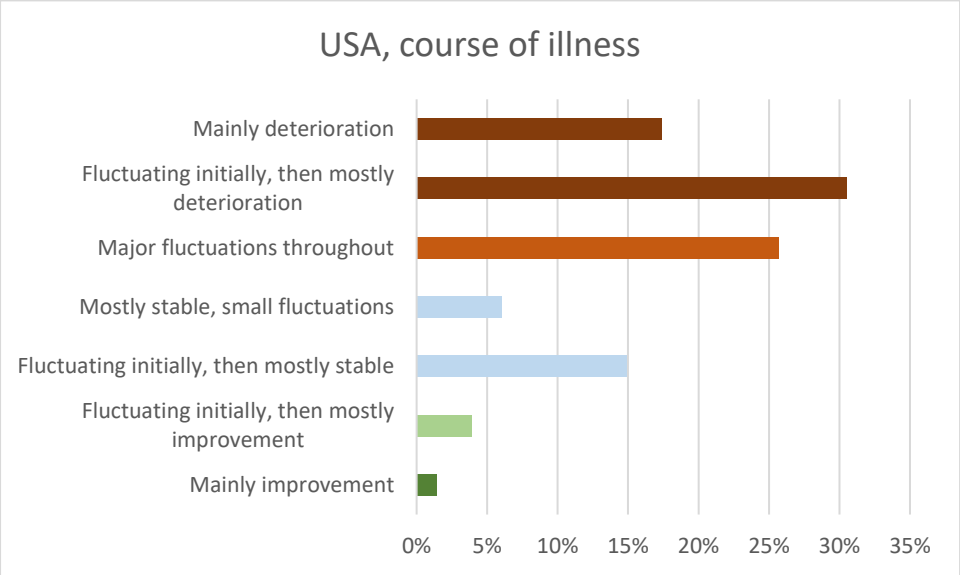
Severe or very severe disease was more common among patients who had early onset, before the age of 15, regardless of disease duration, though this pattern is less clear among American respondents than among European respondents.



Country Figure 173: USA, age of onset and severity, n=486

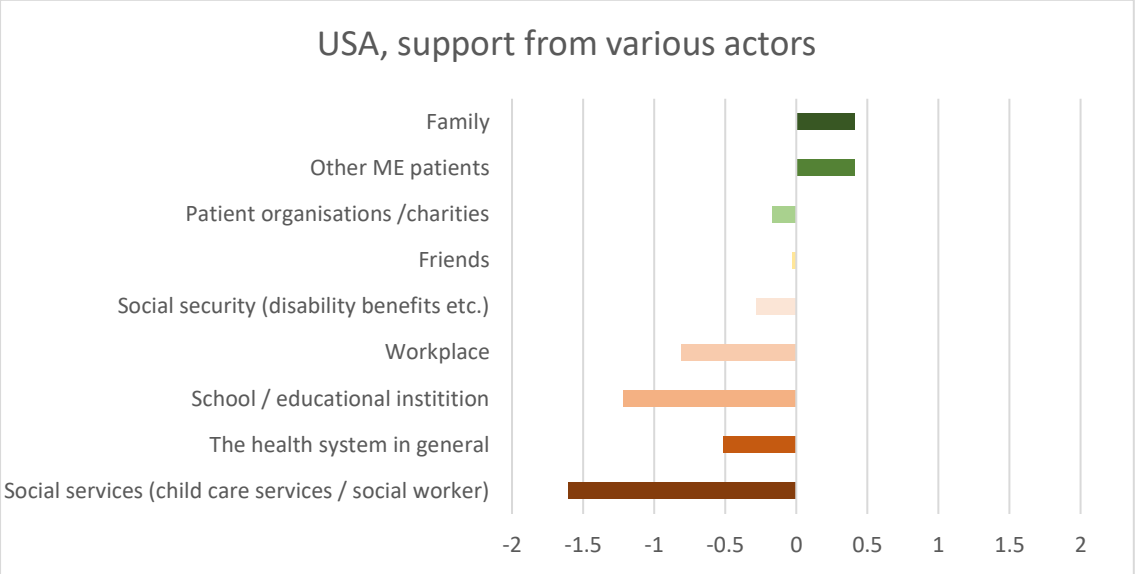
2.3.11 Course of illness

We described seven likely courses of illness, and asked respondents to choose the one closest to what they had experienced. In USA, 74% of respondents had experienced deterioration or major fluctuations, 21% said they were mostly stable, and 5% had experienced mainly improvement.



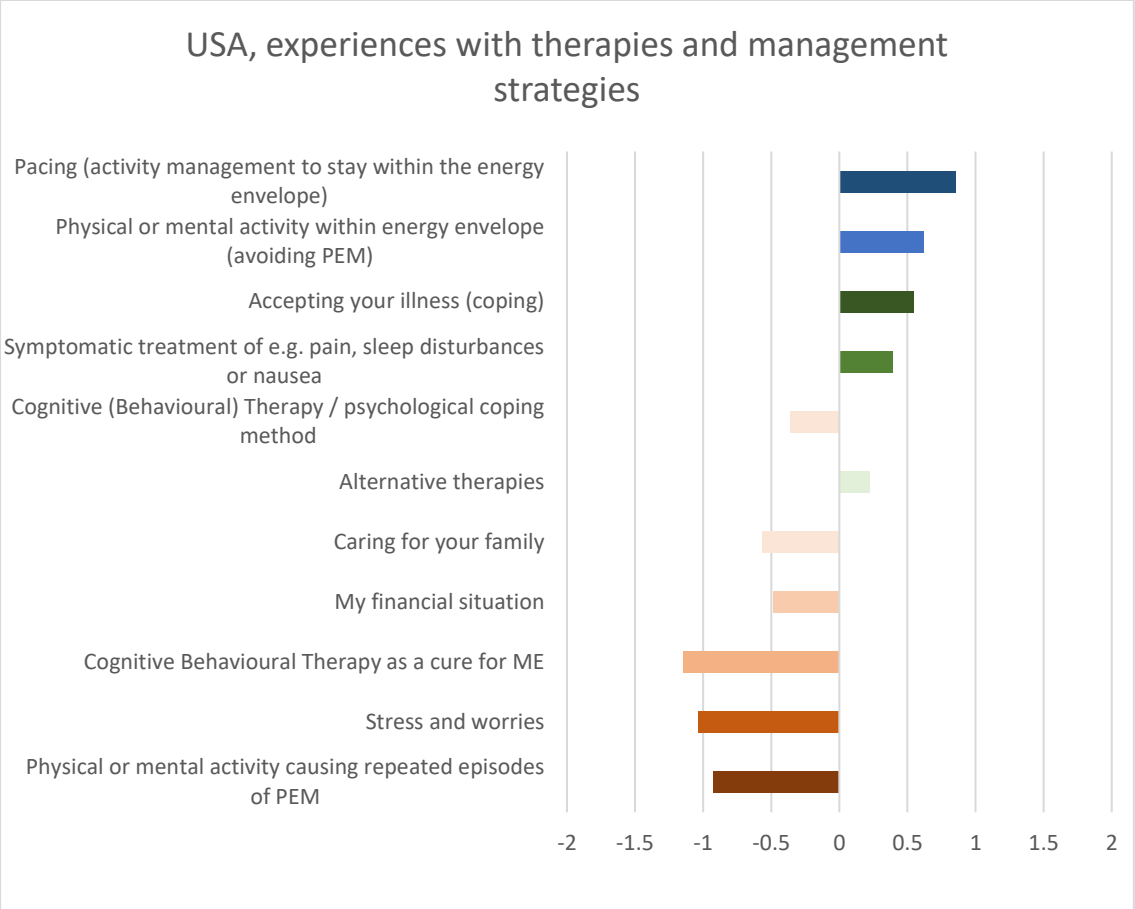
Country Figure 174: USA, Course of illness, n=486

2.3.12 Experienced support from various actors



Country Figure 175: USA, support from various actors

2.3.13 Experiences with management strategies and therapies



Country Figure 176: USA, experiences with management strategies and therapies