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## Report Survey summary 'Care for a better treatment for ME'

September 2019

Link to report "Zorg voor betere behandeling bij ME" (Dutch): <https://www.me-cvsvereniging.nl/sites/default/files/documenten/Rapport%20Zorg%20voor%20betere%20behandeling.pdf>

Myalgic Encephalomyelitis (ME) is a serious, chronic and complex multi-systemic illness that often drastically impairs the life and activities of patients. The illness is also referred to as Chronic Fatigue Syndrome (CFS).

This is however a misleading term which led to a lot of ambiguity in the last decades, because the name does not do justice to the nature of the illness. The term 'fatigue' trivialises the severity of the illness. Not the fatigue is the distinctive aspect of the illness, but Post-Exertional Malaise (PEM); an increase in severity of the complaints after minor physical or mental exertion.

In 2015 the Dutch ME/cfs Association executed a survey with ME-patients on the healthcare for ME in the Netherlands. Its outcomes were published in 2016 in the report 'Zorg voor ME' (Care for ME), which was used as a resource by the ME/CFS Advisory Committee of the Dutch Health Council, which published her report in March 2018.

From the 2015 survey a high degree of discontent appeared about the care that was given. Therefore the ME/cfs Association issued another survey among ME-patients in 2017. This report, 'care for better treatment for ME,' reflects the outcomes of this second survey. The purpose of this second survey is to investigate the experiences of the patients with healthcare by general practitioners and the treatments (CBT, CBT/GET and biomedical treatment) in more detail. This was investigated by presenting statements, multiple choice questions and open questions about patient characteristics, about the general practitioner, about the treatment and about knowledge and understanding by those who deliver treatments, to the participants. They were also asked to rate the care by the general practitioner and the treatments they received.

The survey was completed by 449 respondents. The answers of 418 respondents were incorporated in this report. These respondents were selected based on the IOM-criteria (IOM/NAM-report 2015), which will be explained later in this report. These criteria are in accordance with the criteria in the report of the Dutch Health Council. The other 31 respondents did not meet the IOM-criteria.

Almost a quarter of the respondents (23.92%) was younger than 20 years old at the onset of the illness. An overwhelming majority of the respondents (84.89%) has been ill for more than five years. Almost one third (30.22%) has even been ill more than 20 years.

The subpopulations that fall into the categories 'severe' and 'very severe' are better represented in this survey than in the scientific research on the effectiveness of CBT and CBT/GET.

1. An explanatory statement on PEM and other symptoms is being presented in chapter 4
2. CBT is Cognitive Behaviour Therapy and CBT/GET is CBT in combination with a gradual incline of activities, regardless of the possible increase of complaints.

Out of the 418 respondents who were included in the outcomes, 194 (46.41%) were not a member of a patient organisation and 225 respondents (53.59%) were a member. These two groups have been distinguished from each other to check if there is a difference in answering the questions. In the previous survey, critics indicated that there must have been a (negative) distortion of the answers, associated with membership.

Out of the members of the patient organisations, 69.20% is severely or very severely ill, against 52.58% of those who are not members. There is no difference between both groups with respect to the percentage that received CBT or CBT/GET. There is however a clear difference in numbers of respondents that received biomedical treatment: 64.73% of the members against 35,57% of non-members.

The picture that emerges from this survey is that there is no major difference in the evaluation by both groups. Care by the general practitioner and the received CBT and CBT/GET treatments are perceived as (grossly) inadequate by both groups. The conclusion is that membership is not a determining factor in the way treatments are experienced. Guidance by the general practitioner is rated by the respondents with a 4.9 (members 4.8 and non-members 4.9) against an average of 8.3 for general practitioners on Zorgkaart Nederland (based on 30430 ratings in July 2019). The fact that a lot of ME-patients no longer visit the general practitioner, is a big concern.

The negatively perceived attitude of the general practitioner towards ME, the fact that complaints are not taken seriously and the refusal to treat symptoms, are being pointed out as a reason for this. It also appears that general practitioners frequently do not refer for further examination, because ME would be the explanation for (new) occurring complaints. Both facts - not visiting the general practitioner and insufficient referral - lead to the risk that other illnesses will not be discovered or will not be discovered in time. CBT and CBT/GET treatments get very low ratings with an average of 3.7 (3.8 for members and 3.4 for non-members) for CBT and 2.5 (2.1 for members and 3.0 for non-members) for CBT/GET.

A substantial worsening of the health condition has been reported by respondents that received the CBT or CBT/GET treatment. They experience being pushed over the boundary; therapists do not take the increase in complaints into account. A lot of respondents in the CBT group and the CBT/GET group do not feel that they are being approached respectfully. The claim that these treatments are safe, is refuted by these results. Substitution of activities, like the respondents in this report indicate, is not included in the CBT/GET research. Not recording or publishing objective outcome parameters contributes to not recognizing a worsening health condition.

**3. Substitution:** to be able to execute the activities that are imposed during treatment, patients decrease their daily activities and duties.

## Summary

CBT and CBT/GET treatments are based on the theory that there are thoughts that sustain illness and behaviour. More than 90% of the respondents report that the assumed sustaining factors are not present.

They are supported by findings in scientific research. In several scientific studies (amongst others Sunnquist and Jason, 2018, Wiborg et al, 2010) the hypothesis of the perpetuating factors is disproved.

The group receiving biomedical treatment, is the group with the highest number of severely and very severely ill patients. There is an improvement however; there is a decrease in the number of severely and very severely ill patients. Only biomedical symptom focused treatment by a specialised physician is rated on average with 6.3, a 'sufficient' grade (6.5 from members, 5.9 from non-members).

We enquired on who referred for the treatment. A part of the respondents has been referred to CBT or CBT/GET by the occupational physician or the insurance physician. There was also an occasional referral to biomedical treatment.

Although there is no basis in law to force patients to follow a treatment, this does happen in practise because benefit agencies label not following a treatment as inadequate recovery behaviour, with all the consequences that come with it.

In the report of the Dutch Health Council it is pointed out strongly that not following CBT or CBT/GET treatments cannot be classified as inadequate recovery behaviour. Considering the reported worsening, it is medically and ethically irresponsible to impose CBT or CBT/GET treatment. It is important to point out the possible risks of these treatments to the patient.

A clear image of inadequate healthcare and treatment for ME patients in the Netherlands emerges from the survey. The answers to the open questions picture a poignant image of the way ME patients are treated by healthcare providers. A selection of these is spread throughout the report and in appendix 2.

Improvement of healthcare is urgently needed. It is important for the physician/general practitioner to encounter the patient openly, cooperatively and without prejudice. In other words: the physician consults with the patient, takes the patient seriously, refers, thinks along with the patient about the treatment of symptoms and is open to suggested scientific information.

There is a need for treatment in specialised biomedical treatment centres, focussing on alleviating the complaints.

Expanding biomedical research on the cause and mechanism of ME is necessary. It is thereby important to use clear diagnostic criteria to guarantee useful outcomes of biomedical research.

Education for general practitioners, insurance physicians, occupational physicians and other disciplines on ME based on biomedical findings is urgently needed. In particular information is necessary on PEM, one of the most important features of ME.

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