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Experiences of ME patients with disability assessments by UWV

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Summary

Background

Insurance physicians from the Dutch Employee Insurance Agency (UWV) play an important role in the socio-medical assessments of ME patients who claim benefits through the Ziektewet (Sickness Benefits Act), WIA (Work and Income According to Labour Capacity Act), Wajong (Disablement Assistance Act for Handicapped Young Persons) or WAO (Disablement Benefits Act). According to the advice presented in March 2018 by the Dutch Health Council (Gezondheidsraad, GR) to the Tweede Kamer (House of Parliament), ME/CFS is a serious chronic disease, which is associated with significant limitations in function. The GR states that some of the insurance doctors, on the other hand, believe that ME/CFS is not a specific disease and therefore not a basis for disability, or that ME/CFS can never lead to more than light limitations.

Cognitive behavioral therapy (CBT) and Graded exercise therapy (GET), which have been recommended as treatments for ME in the multidisciplinary 2013 CFS guidelines, are controversial as such. The GR points out the issue that insurance doctors regularly consider the 'recovery behavior' of ME patients who do not choose to undergo CBT or GET to be 'inadequate' or 'medically culpable'. The GR wants to put an end to this practice.

The UWV medical advisor, in response to the GR's recommendations for ME/CFS, does not see it that way. He states that the methods of the UWV are very much aligned with the advice from the GR.

Inquiry

Did the GR get the wrong idea and does the implementation practice of the UWV align with the advice of the GR? What experiences do people with ME have with the assessment by the UWV in recent years? To answer these questions, people with ME who have had (re)assessments by the UWV were surveyed.

Method

Using an online questionnaire, followers of the Steungroep ME en Arbeidsongeschiktheid (Support Group ME and Work Disability), the ME/cvs Vereniging (ME/cfs Association), and the ME/CVS Stichting (ME/CFS Foundation) were able to report their experiences in the past 10 years with the UWV.

Results

A large part of the 382 respondents experienced that insurance physicians did not take the disease seriously. 12% reported that the UWV claimed that it is not a disease. Only 29% reported that their ME diagnosis (or CFS, ME/CFS, or SEID) which was made by their own medical doctor, was accepted by the UWV.

As for the number of hours that respondents can work, there are notable differences between the patient self-assessment and the assessment by the insurance physician: 49% of respondents indicated that they could not work at all whereas the insurance physicians claim that patients cannot work at all in only 19% of the cases. 0% responded that they could work 31 to 40 hours in contrast to the insurance physicians' claims that 20% can work 40 hours per week.

81% of the respondents indicated that the insurance physician did not fully take into account the disabilities they experienced as a result of the disease. A majority of these disabilities are related to endurance, such as post-exertional malaise. 27% of respondents indicated that the insurance physician explained why he took the disabilities less or not at all into account. The insurance physician often insists that ME is not a disease, does not exist, or that the disabilities are not plausible. They also argue that the complaints and limitations are caused by psychological factors or deconditioning, or that CBT or GET are effective, curative treatments.

Furthermore, respondents repeatedly reported that their input and the information from practitioners were ignored and that insurance physicians drew overly firm conclusions based on a single, brief observation.

The vast majority of respondents expected no improvement in health or reduction in their functional limitations. Around two-thirds of respondents have tried CBT and/or GET. 46% of them indicated that they were able to perform fewer activities after CBT or GET, 39% remained the same and 3% could perform more activity. One-third of respondents stated that they were put under pressure by the insurance physician to follow CBT or GET.

Filing objections and appeals against assessments that are perceived as unjust can take a heavy toll according to spontaneous remarks made by a number of respondents. As a result of the disease, the lack of energy and lack of ability to concentrate can in themselves already be great hindrances.

Conclusions

The results of this study confirm the GR's observation of the assessment of ME patients by the UWV.

People with ME regularly experience that occupational physicians and insurance physicians insufficiently take into account the nature and gravity of their disabilities. A part of the insurance physicians believes that ME is not a disease or that ME can never result in more than mild limitations. UWV insurance physicians repeatedly make unrealistic assessments of possibilities for recovery, whether based on the incorrect expectation of CBT and GET or not. They also repeatedly put pressure on ME patients in different ways to choose CBT or GET as a treatment option. In contrast to the statement made by the UWV medical advisor, this practice is not aligned with the advice of the GR.

It is not possible to say with certainty how many insurance physicians and how many assessments the image that this research evokes is exactly applicable to. The 310 respondents who felt that the UWV did not fully take into account their limitations come from all over the Netherlands. This suggests that not all of the insurance physicians involved came from only one or a few UWV locations.

Recommendations

This study explicitly focused on the perspective of the assessed patients themselves. In their responses, they provided feedback on the way in which they were assessed – feedback which insurance physicians, after their brief and often one-time assessment, usually do not receive. The outcomes that arise in this way can supplement or correct existing perceptions in professional practice.

Based on the results of this survey, it is likely that the disability of a part of ME patients is not properly assessed. This can have major negative repercussions on the income of the people concerned, their health, and their possible chance for reintegration. For some, the disability assessment was a traumatic experience. All in all, the results give a worrying sign about the quality of the socio-medical assessment of ME patients in the Netherlands. The assessment can and must be improved. To this end, the GR advice offers good leads. The GR recommends the recognition of ME/CFS as a serious disease that causes significant functional disability. The GR also recommends that the choice to not follow CBT or GET not be labeled as “inadequate recovery behavior” (impeding the healing process or missing the opportunity for recovery). Many problems in the future can be avoided if the professionals involved follow these recommendations. The GR’s recommendation to include ME/CFS as a serious, chronic multisystemic disease in the training and further education of health professionals is also relevant for the professionals in the field of socio-medical assessment.

As a result of the outcomes of this study, some recommendations are elaborated in chapter 3. These deal with the assessment of disabilities and ‘recovery behavior’, education and training of professionals, previous assessments in which prejudices or lack of knowledge played a role, withdrawal of recommendations for CBT and GET, further research into the practice of assessments, and cooperation with patient organizations and the utilization of their expertise.

These recommendations are mainly aimed at the insurance physicians, their organization NVVG, the implementing institute UWV, and the training institutions for company and insurance physicians such as NSPOH and SGBO. As similar problems can also occur in other sectors, the recommendations are also aimed at occupational physicians, labour experts, medical advisors, municipal officials, truancy officers, employees of Veilig Thuis (advice and hotline for domestic violence and child abuse) and other relevant professionals and authorities.

The patient organizations are more than willing to work together with all those who are committed to the desired improvement of the socio-medical assessment of people with ME.

Full report in Dutch: <https://www.steungroep.nl/2017-10-31-11-21-16/2017-10-31-12-44-32/her-keuringen-algemeen/472-ervaringen-van-me-patienten-met-de-medi-sche-beoordeling-van-arbeidsongeschiktheid-door-het-uwv>