

# Physical activity, participation and health-related quality of life in chronic fatigue syndrome and multiple osteochondromas

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## **Impact**

This thesis provided innovative insights regarding physical activity, HRQOL and associated factors in individuals with chronic fatigue and pain with an impact for future research and clinical practice. This section reflects on the overarching scientific and anticipated social impact of the results found.

### **Measuring the physical activity level**

Chapter 3 and its update identified activity monitors as the most frequently used measurement instruments to evaluate patients' PAL. Although activity monitors have been shown to provide reliable and valid output in populations in which they were validated, ambiguity about the algorithm used to convert the raw output to more easily interpretable output (activity counts or metabolic equivalent of task) makes the translation of results to other (non-validated) populations difficult. Correctly determining the activity level of a person with chronic fatigue is important to establish an appropriate activity program to avoid both over- and underexertion (pacing). In individuals with chronic pain, it is important for graded activity/exercise that baseline levels and graduated increases can be monitored. To achieve this, a healthcare provider needs to be sure that the output obtained through the activity monitor is interpretable and correct, which is unclear at present for certain populations and specific brands of activity monitors that have not been validated in the population of interest. The use of open-source software would allow the algorithms behind the outcome measure to be checked and, if necessary, adapted to the population of interest. Companies are therefore asked to be more open about their activity monitor software and algorithms used to benefit scientific research and clinical practice. Until then, vigilance is required.

### **Measuring health-related quality of life**

Health-related quality of life (HRQOL) is a reflection of a person's quality of life that is influenced by their health status and can be changed by treatment. HRQOL as a concept is thus not only applicable to individuals coping with a chronic disorder, but to all people as the valuation of health is constantly changing throughout a person's life.

Chapter 2 and its update, reported in the general discussion of chapter 7, showed increased attention towards HRQOL in scientific research. Evaluating the impact of interventions, whatever they may be, on HRQOL is an important patient-reported outcome, because it defines whether a person values the result obtained as contributing to a "better quality of life".

It is not only the cost and effectiveness of an intervention on the target parameter that are important, but also in the longer term whether a person sees significant added value from it themselves, especially when it comes to invasive interventions.

Both our studied populations, CFS and MO, reported lower HRQOL than norm scores, confirming the importance of measuring HRQOL and identifying factors associated with

or causing the lower ratings of HRQOL, and more importantly, interventions to address modifiable factors.

Chapter 6 contributed to this knowledge by providing insight into factors associated with a better or worse HRQOL across disorders which cause chronic fatigue and pain. The next step would be to further elaborate on these models and design appropriate treatment interventions.

Healthcare professionals are encouraged to question patients' HRQOL and discuss their personal goals. Setting goals in dialogue with the patient helps healthcare professionals to choose the most appropriate treatment intervention to improve a patient's HRQOL, because HRQOL implies an individual's perception about their own situation, which cannot be judged by anyone else.

### **Opportunities for a preventive approach**

Persons with chronic fatigue or pain are at risk of experiencing activity limitations or participation restrictions, which are more objective measurable subitems of HRQOL. More limitations and restrictions can in turn contribute to the perpetuation of these complaints, causing a vicious circle that is not easily broken. A preventive approach could add value to avoid such vicious circle, but for this, health professionals in clinical practice need an understanding of what factors could potentially lead to its emergence. Factors associated with HRQOL were identified in chapters 5 and 6.

Healthcare professionals are urged to do a thorough evaluation of a person's fatigue and pain intensity, symptoms of depression and anxiety, pain catastrophizing thoughts, the PAL and activity limitations. Assessing mentioned factors should be done in a timely and consistent manner for early detection of additional and increasing symptoms and disability. Even age, which in chapter 6 was found to be associated with physical functioning, and gender, associated with vitality, could provide more insight into patients' perceived HRQOL. Healthcare professionals should be alert to limitations in physical functioning in older individuals and decreased energy in women.

In our studied population, a preventive approach could include educating patients and their network about the possible concomitant consequences of chronic fatigue and pain. It may include questioning about and sharing information on depressive symptoms and catastrophizing thoughts and how to recognize them. With this approach, patients are given the opportunity to self-manage their chronic disorder and associated symptoms, cognitions and behaviors. Additionally, patients should be encouraged to seek timely specialized help when self-management appears to be insufficient or impossible, with the healthcare provider having an important signaling function. Patients should be given information about the guidelines on physical activity and on the positive (preventive) impact of physical activity on their health. The difference between physical activity and exercise should also be explained.

By sharing information with patients early on about their condition and possible associated symptoms and behaviors, rehabilitation is made more accessible to the general population. Patients are given the necessary knowledge and tools to best manage their disorder, but also to recognize their rehabilitation needs in a timely manner and seek professional help to optimize their functioning and minimize disability. This is

## CHAPTER 7

in line with the WHO Rehabilitation 2023 Initiative aimed at strengthening health systems worldwide to provide rehabilitation to optimize functioning of the population [79].

Discussing patients' current employment status, their satisfaction with the current situation and options for work resumption, if applicable, should also be part of a consultation or therapeutic session. Good follow-up on this may lead to work retention, reduced absences from work, increased job satisfaction and also higher HRQOL by allowing a person to fulfil their physical and social roles. In chapter 5, having a paid job seemed to contribute to higher levels of physical activity, which in turn also contributes to better overall health. Therefore, we dare to hypothesize that improving the ability to perform personally relevant activities may have a greater positive impact on HRQOL than increasing the PAL alone, of which employment is only one aspect. A higher PAL does not guarantee that a person is able to perform their personally relevant and desired activities and is able to participate, thus experiencing a sense of engagement and meaningfulness. Therefore, in the context of increasing physical activity, we suggest starting from the patient's personal goals and focusing on improving the performance of personally relevant activities rather than just exercise.

Given the multiplicity and diversity of factors involved, a monodisciplinary approach does not seem appropriate even in the early stages, but rather requires a multidisciplinary approach.

### **Expanding primary care**

Because this thesis only examined associations and not causal relationships, it is not possible to determine with certainty whether lower HRQOL is the result of a complex interaction of identified (chapter 6), and as yet unidentified, factors, or whether lower HRQOL contributes to the development of modifiable factors. However, according to our hypotheses based on a predefined ICF-model, HRQOL would result from the complex interaction of identified factors and not the other way around. As mentioned, this argues in favor of exploring the added value of a preventive approach. Primary care plays an important role in prevention. Primary care providers are directly accessible and therefore most often consulted. This gives them the most opportunity to screen and question patients about their impairments, limitations and restrictions, and provide early information and guidance to avoid their (further) development. They also have an important signaling function to refer a patient to specialized care if they are unable to help the person themselves. A timely referral most often leads to a better outcome.

We discussed employment and the potential added value of focusing on personally relevant activities to improve HRQOL, which are areas of expertise of the occupational therapist. Ideally, these are guided from primary care, but a major gap in Belgium is the lack of a legal framework for directly accessible occupational therapy. In the Netherlands, every person is entitled to ten hours of therapy annually from an occupational therapist with reimbursement without a medical prescription. This allows people who experience limitations in activities of daily living or are unable to participate to call on the expertise of an occupational therapist when necessary. Occupational therapists can help them

rehabilitate by working towards recovery, teaching compensatory strategies or the use of assistive devices if needed. This also applies to people with chronic fatigue or pain, who can experience limitations at work, at home or during leisure time and can seek therapeutic treatment or guidance in a timely manner. If the situation worsens, the current situation can be re-evaluated and a new plan of action drawn up. In Belgium, the nomenclature for occupational therapy interventions in primary care is limited to people who have completed a full rehabilitation program for locomotor or neurological rehabilitation. This excludes individuals with chronic fatigue or pain which is not the results of a locomotor or neurological disorder. Even though there are multidisciplinary pain centers organized in general or university hospitals, they do not allow brief monodisciplinary interventions by occupational therapists with reimbursement when necessary, such as in case of temporary limitations in performing activities of daily living or participation restrictions. Enabling directly accessible occupational therapy and expanding the nomenclature for occupational therapy in primary care in Belgium is urgently needed to provide appropriate support not only to individuals with chronic fatigue and pain, but to all individuals experiencing limitations in activities of daily living. Evaluating resource allocation and implementing appropriate financing for rehabilitation, making rehabilitation accessible to all individuals, is also part of the WHO Rehabilitation 2030 Initiative [79]. Given the limitations that individuals with chronic fatigue and pain may experience, the occupational therapist is an important partner of the multidisciplinary (primary care) rehabilitation team.