University of Applied Sciences and Arts of Southern Switzerland

SUPSI

Energy Management Education (EME) for people with disease-related Fatigue

Development and Research Project 2016-2023

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Background

Primary fatigue

- Disproportionate exhaustion (physical and/or cognitive)
- Can hardly/not be compensated for by resting/sleeping
- Occurs during/after numerous diseases
- Causes not yet understood
- Medically not/seldomly treatable

Consequences

- Reduced performance in all life areas
- Leads to loss of participation and quality of life
- Source of psychological distress

Occupational therapy (OT)

Until 2018, despite positive research results, no systematic, evidence- and OT-based self-management education for people with fatigue available in Switzerland, Austria and Germany due to a lack of a practicable treatment program

Energy Management Education (EME)

Structure

Workbook for EME participants

Methods

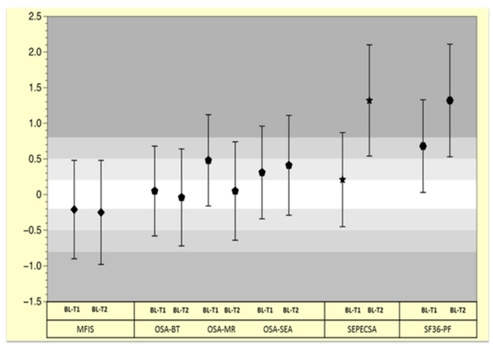
2016-17	Literature review & development of Energy Management Education (EME)
2017-18	**Feasibility study** (mixed methods) with people with **MS:** • **Focus groups** with EME participants & their EME-OTs[1] • **Pilot-RCT:** EME vs. Progressive Muscle Relaxation (PMR)[2]
since 2018	• Continuous updates of materials in three languages (F, G & I) • Training for OTs in three languages • Networking: Website, newsletter, online meetings for EME-OTs • Dissemination: Publications & congress contributions
2020	**Interviews** with EME-OTs working with **cancer survivors**
2021	**Focus group** with EME-OTs on EME for **Long COVID**[4]
2021-22	**RCT** with people with **MS** during inpatient rehabilitation: EME + high-intensity interval training vs. PMR + standard treatment[3]
2022	**Focus groups** with EME participants with **Long COVID** & their OTs[6]
	Feasibility study (pre-post design & survey) with EME participants with **Long COVID** in a day hospital[5]
2022-23	Collaboration on Long COVID Diagnostics & Treatment Guidelines for Swiss general practitioners[7]
from 2024	**Efficacy study (TTE)** with people with **Long COVID** in an outpatient setting: standard treatment (ST) with EME vs. ST without EME

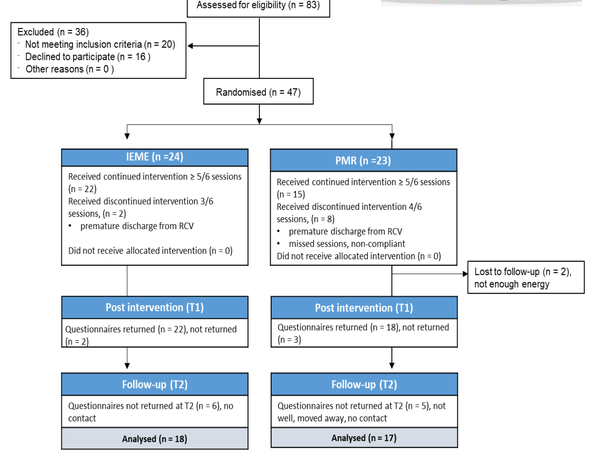
Results: Study with people with MS (2017-2018)[1,2]

1. Focus groups with EME participants (n=12)[1]

- *The peer group supports me*
- *I finally feel taken seriously*
- *I have understood that I am neither lazy nor stupid*
- *The energy profile is a great tool*

2. Pilot-RCT (n = 47)[2]





Significant treatment effects *(Cohen's d >0.8)*:

- Self-efficacy in using energy-management strategies (SEPECSA; p ≤0.05)
- Quality of life: Physical functioning (SF36-PF; p ≤0.05)

Results: Study with people with Long COVID (2022)[5]

Pre-post design (A), before (BL) & after EME participation (T1) and 12 weeks after completion of EME (T2), plus **Survey (B)** after 16 weeks **(n= 17)**

A. Significant increase in self-efficacy expectation in use of energy-management strategies (SEPECSA); even 12 weeks after EME

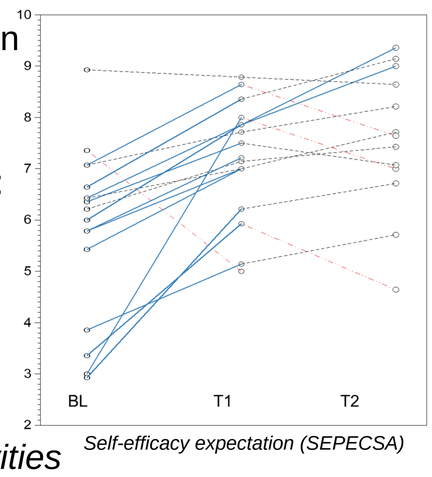
B. Behavioral change in everyday life after EME: in average plus 20% strategies in use

Strongly effective strategies:

- *Breaks before a strenuous activity*
- *Changing the time of day for activities*

Implementation:

- *Easier*: *Setting priorities & simplifying activities*
- *Most difficult: Communicating personal needs & delegating activities*



Self-efficacy expectation (SEPECSA)

Results

Energy Management Education (EME) is a structured OT, evidence-based self-management education program that can be used in outpatient and inpatient settings. It consists of eight self-contained thematic group and/or individual treatments, which are explained in a manual for OTs. A workbook for EME participants is available, too.

Study results show that EME meets the needs of people with MS[1,2,3], cancer survivors and with Long COVID[4,5,6], has positive effects on the self-efficacy of those affected and on the impact of fatigue on everyday life[2,3,5]. Feedback from EME participants and EME-OTs has helped to optimize the treatment protocol[1,4,6].

Since 2018, over 400 OTs have been trained in EME in Switzerland and about 200 Swiss institutions and OT practices offer EME.

Conclusion

The development of a practicable, structured treatment program has significantly promoted the implementation of an evidence-based OT practice with people with fatigue. It has also contributed to the visibility of OT in the healthcare system, which has resulted in collaborating with the development of a Swiss Long-COVID guideline for general practicioners[7].

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