“Finding your feet”
The development of a self-management treatment for fatigue in paediatric multiple sclerosis

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What is MS?

**Normal Neuron**
- Healthy myelin

**MS Demyelination**
- Damaged myelin

**Symptoms**
- Bladder and bowel dysfunction
- Dizziness
- Numbness and tingling
- Difficulty walking
- Balance problems
- Loss of vision
- Pain
- Memory problems
- Slower processing speed
- Muscle spasms
- Impaired attention/concentration

**Kids get MS too!**
MS-related fatigue

• Fatigue affects up to 90% of adults with MS

• Cognitive behavioural model of MS fatigue → CBT for MS fatigue

• Fatigue in paediatric MS still poorly understood → effective treatments lacking

Intervention development process

1. Systematic Review
2. Qualitative Study
3. Cross-sectional study

Choose intervention methods
Determine intervention objectives
Develop Model

Develop intervention materials
Public and patient involvement
Refine and feasibility test intervention
Systematic Review

Understanding fatigue in paediatric multiple sclerosis: a systematic review of clinical and psychosocial factors

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AIM Fatigue in children and adolescents with multiple sclerosis (caMS) is currently poorly understood. This review aimed to provide greater insight into this area and direction for future research by evaluating evidence of associations between fatigue and clinical, psychological, and social factors in caMS.
Qualitative Study

Original article

“It feels like wearing a giant sandbag.” Adolescent and parent perceptions of fatigue in paediatric multiple sclerosis

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Themes

Parents

- Emotional Responses to Fatigue and its Impact

The Lived Experience of Fatigue & its Impact

Uncontrollability & Uncertainty of Fatigue

Finding a balance

Social Support & Disclosure

cAMS
Cross-sectional Study

CaMS with fatigue  
\((n = 15)\)  
& parents  
\((n = 15)\)

CaMS without fatigue  
\((n = 15)\)  
& parents  
\((n = 15)\)

Adolescents with CFS  
\((n = 30)\)  
& parents  
\((n = 28)\)

Healthy controls  
\((n = 30)\)  
& parents  
\((n = 27)\)

Aims:

1. To compare fatigue, functional impairment, psychosocial factors & neurocognitive functioning across the four groups

2. To compare primary caregiver reports of their children’s fatigue across groups

3. To compare primary caregiver distress across groups
Cross-sectional Study: Measures

- **Child fatigue severity:**
  - Chalder Fatigue Scale (to separate caMS into fatigued & non-fatigued groups)
  - PedsQL-MFS (Parent and child versions)

- **Functional impairment:** Work and Social Adjustment Scale

- **Cognitive & behavioural responses to symptoms (CBRS):** Cognitive and behavioural responses to symptoms questionnaire

- **Cognitive functioning:** WISC-IV or WAIS-IV (age dependent)

- **Sleep:** Adolescent sleep hygiene scale

- **Psychological difficulties:** Strength and difficulties questionnaire

- **Distress in caregivers:** GHQ-12
Cross-sectional Study: Key Findings

General fatigue

Sleep fatigue

Cognitive fatigue

[Graphs showing data for general fatigue, sleep fatigue, and cognitive fatigue across different groups (MS fatigue, MS non-fatigue, CFS, HC). The graphs compare self-report and parent-report data.]
Cross-sectional study: Key findings

• CBRS equivalent in both fatigued groups and in both non-fatigued groups

• CaMS have impaired neurocognitive functioning regardless of fatigue

• No differences in sleep or psychological difficulties between groups

• Parental distress higher in both fatigued groups than non-fatigued groups

• Parents of all illness groups had more unhelpful cognitive responses to symptoms than parents of healthy controls
Emotions
Depressed
Guilt
Embarrassed
Sad

Frustrated
Concerned
Helpless
Distressed

Physical Symptoms
Fatigue

Thoughts
Perceptions of others’ responses (e.g. think I’m lazy/treat me differently)
Catastrophising about symptoms (e.g. Fatigue is out of my control)
Perceived lack of knowledge (fatigue has uncertain causes/consequences)
Fatigue is a sign of damage/relapse

Behaviours
Pushing through fatigue
Reduced activity
Increased rest
“All-or-nothing” behaviour
Daytime napping
Non-disclosure of MS & fatigue
Parental overprotection

Triggers
MS disease factors
(e.g. inflammation and demyelination)

Physical Symptoms
Fatigue
Intervention objectives

(1) Increase knowledge

(2) Reduce unhelpful behavioural responses to fatigue and increase helpful responses

(3) Reduce unhelpful cognitions about symptoms & increase helpful cognitions

(4) Manage emotions

(5) Increase social support

Intervention design & methods

Design:
• Six-eight week guided CBT self-management booklet

Choosing methods:
• Reviewed components of previous CBT interventions for MS fatigue & CFS (van Kessel et al. 2008; Rimes & Chalder, 2005)

• Tailored content to paediatric MS
Public and patient involvement

- Two YPAG meetings (17 young people, 12-24)
- Individual feedback from 13 young people with fatigue related to LTCs & 5 parents
- Reviewed intervention on:
  - Content
  - Design
  - Language
  - Activities
- Feedback largely positive
- Intervention adapted based on feedback
Intervention Components

1. Understanding MS fatigue
2. Setting goals
3. Sleeping soundly
4. Surviving School
5. Balancing activities
6. Your thoughts about fatigue
7. Your feelings about fatigue
8. Telling others about fatigue
9. Information for parents
10. Information for teachers

Finding your feet: Managing fatigue in paediatric multiple sclerosis

This booklet was designed to help children and adolescents with MS and their parents to understand and manage fatigue. Its content is informed by MS Society-funded research at King’s College London & Great Ormond Street Hospital for Children.

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Next Steps
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