A Feasibility study of an Online Mindfulness intervention for Duchenne Muscular Dystrophy

Pilot Study of an Online Mindfulness Intervention for Duchenne Muscular Dystrophy: Exploring Feasibility, Engagement, and Outcomes

Hub Summary

This study is led by Manchester Metropolitan University and Duchenne UK and approved by the Manchester Metropolitan University ethics committee.

Scientific Rationale
Almost all men with DMD experience pain, which is a contributing factor to lower quality of life (QoL), particularly within the mental health domain. Psychosocial health issues are significantly more prevalent in DMD, with anxiety prevalence reaching 33%, depression prevalence at 19%, and the prescription of associated medication to 28% of men with DMD. Although poor mental health is multifactorial in nature, pain has been associated with both anxiety and depression in DMD. Beyond the behavioral support for higher prevalence of autism spectrum disorders, mental health support and pain management for those adult transitioners and men with DMD lacks emphasis, with currently only cursory mentions to mental health and pharmacological solutions to pain being advocated in the most recent standards of care.

Given the effectiveness of Mindfulness Based Interventions (MBI) within other conditions, MBI may represent a potential intervention for anxiety, depression, pain and QoL in DMD. In conditions with neurological impairment, interventions to support mental health are considered fundamental to improving quality of life. Relevant to DMD particularly, MBI have been shown to:

- Improve mental health and quality of life in people with spinal cord injury
- Reduce psychological distress
- increase self-protective awareness of early physical symptoms and increase proactive condition self-management and autonomy

The current research aims to assess the feasibility of an eight week online mindfulness intervention for people living with DMD (co produced using PPIE and informed by evidence on the efficacy of mindfulness in other chronic health conditions).

Study Number: N/A

Description by Duchenne UK

Focus
Mental health issues and bodily pain are prevalent within men and young adults with Duchenne muscular dystrophy (DMD), part of the multifaceted contributory factors to depression, anxiety and ultimately a lower quality of life (QoL). Current standards of care lack evidenced based interventions for participant directed self-management of mental health, pain and QoL. Based on our development of mindfulness-based interventions for health in Spinal cord injury, this project will conduct a within-participant control intervention of mindfulness for pain, depression and anxiety in young adults with DMD. Through stakeholder/participant involvement, we are already co-developing an 8-wk online mindfulness course (Breathworks, UK), which will be refined by the evidence provided in this feasibility study.

Objectives
1. To implement an 8-week control period (standard care) in people with DMD, followed by an 8-week online mindfulness intervention.
2. Test Participants for meaningful outcomes including pain, anxiety, depression and Quality of Life (QoL) at 3 points: pre-control, pre-intervention and post-intervention.
3. Undertake semi-structured interviews post-intervention to understand participant experiences and refine the intervention to ensure improved delivery of a subsequent mindfulness randomised control trial.

Outputs
1. Published research on the impact of mindfulness on pain, mental health and QoL in DMD.
2. A technical report for Duchenne UK and accessible resources on the study outcomes and possible benefits of mindfulness for men with DMD.
3. An evidence based, co-developed, mindfulness intervention for mental health and pain in DMD.

Impact
The provision of evidence for, and co-development of, a mindfulness intervention for DMD is the first step in providing wider access to a self-directed, pain and mental-health management tool for DMD.

Trial Status
Recruiting

UK Locations
London - Evelina,
Recruiting, London - GOSH,
Recruiting, Alder Hey,
Recruiting, Birmingham,
Recruiting, Bristol,
Recruiting, Cambridge,
Recruiting, Glasgow,
Recruiting, Leeds,
Recruiting, Manchester,
Recruiting, Newcastle,
Recruiting, Oswestry,
Recruiting, Oxford,
Recruiting, Preston,
Recruiting, Queens Square,
Recruiting, Sheffield,
Recruiting, Temple Street,
Recruiting

Trial Sponsor
Duchenne UK

Length Of Participation
2 months

Recruitment Target
12 participants

Ambulatory
Ambulant and non-ambulant

Age
16 years and above

Mutation Specific
All treatment types

Muscle Biopsy
No Muscle Biopsy Required

MRI
No

dmdhub.org

This feasibility study will inform a randomised controlled trial, and through support of stakeholders (e. g. Duchenne UK and The Neuromuscular Centre), access to this intervention for those with DMD who can most benefit.

To find out more about this study and to register your interest in taking part, please contact the study team:

Phone: 07882548753

Email: l.staniford@mmu.ac.uk

Primary Outcome Measures

Questionnaires will assess:
- Participant demographicss
- Pain and pain impact (Brief pain inventory)
- Depression (Beck depression inventory)
- Anxiety (stait anxiety)
- Quality of Life (SF-36)

Secondary Outcome Measures

Semi structured interviews will be used to assess participant experiences of the mindfulness course to better understand how they found the course, what worked for them, barriers and facilitators to their mindfulness practice and any outcomes they had experienced in terms of physical and mental health.

Can I take part?

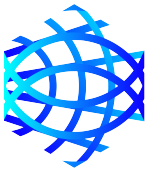
Inclusion Criteria

To participate in the intervention participants have to be aged 16 years and above, have a diagnosis of Duchenne Muscular Dystrophy, be able to log onto the online weekly mindfulness session.

Exclusion Criteria

People without a clinical diagnosis of DMD; people below the age of 16 years old and unable to access the internet for the weekly online mindfulness session.

For contact details and to find out more, please refer to dmdhub.org.



Duchenne UK

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