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An online peer-to-peer support programme for family caregivers of technology dependent individuals with motor neurone disease: randomized controlled trial

**Abstract**

Background/scope

There is growing recognition that family caregiving is a serious public health issue requiring supportive interventions. Family caregivers play an essential role in sustaining a stable environment enabling individuals with motor neurone disease (MND) that are technology dependent to live at home. The family caregivers can experience exceptional burden and significant decline in psychological wellbeing due to MND's rapid and progressive nature with profoundly debilitating effects and intensive support needs. Dependence on assistive technology adds an additional level of complexity to family caregiving due to the need to learn how to operate and troubleshoot medical devices, train other caregivers, and negotiate appointments with new specialties within the healthcare system.

Despite the recognized impact of caregiving for individuals with MND, data are scarce as to effective interventions that provide direct practical and psychosocial supports. Difficulty accessing support may increase psychological distress. As the burden of caring increases due to disease progression and increasing technology dependence, access to existing informal support networks may diminish. Online peer support using virtual modalities is a flexible and low cost form of support. Peers, people who have experienced the same health problem and have similar characteristics as support recipients, can be a key source of emotional, informational, and affirmational support. Peer support improves psychological wellbeing of caregivers of people with conditions such as dementia, cancer, and brain injury. Although peer support programmes for family caregivers of people with MND exist, data as to their efficacy are limited. Therefore, we have developed an online peer support programme, completed beta and usability testing and now propose to test the effect on caregiver psychological wellbeing and caregiver burden.

Aim/research question(s)

Overall aim: to determine the efficacy of our 12-week online peer support programme on family caregiver psychological health and caregiver burden.

*Primary research question:*

What is the effect of the online peer support programme on psychological distress measured using the Hospital Anxiety and Depression Scale (HADS)?

*Secondary research questions:*

1. What is the effect on positive affect, caregiver burden, caregiving mastery, caregiving personal gain, and coping?

2. How do participants use the programme (fidelity and reach)?

3. What is the usability and perceived acceptability?

### Methodology

We will conduct a parallel group randomised controlled trial with caregivers allocated to 12-week access to the online peer support programme or a usual care control group. We will enroll caregivers of an individual with MND entering King's clinical staging Stage 4A: nutritional support or Stage 4B: respiratory support. The 12-week peer-to-peer support programme entails: (1) audio, video, or text private messaging; (2) synchronous weekly chat; (3) asynchronous discussion forum; and (4) informational resources.

We will collect demographic and caregiving data including the Caregiver Assistance Scale and Caregiving Impact Scale, and caregiver measures (HADS, Positive and Negative Affect Schedule, Zarit Burden Interview, Pearlin Mastery Scale, Personal Gain Scale, Brief COPE) at baseline and programme completion. We will download use of online peer support programme features, use the System Usability Scale (SUS) to assess usability, and conduct semi-structured interviews to explore acceptability using the Theoretical Framework of Acceptability.

To test for a medium size effect ( $d=0.5$ ), at 5% level of significance (2-sided) with power 80%, we require 64 participants in each arm (128 total). Adjusting for 20% attrition requires 154 participants.

### Proposed findings

The proposed study will demonstrate the effect of our online peer support programme on psychological distress, positive affect, caregiving burden, mastery, personal gain and coping. Data on programme fidelity will enable us to objectively assess acceptability and interpret our study results. Data on usability and acceptability will inform future scalability of our online peer support programme outside of the trial both nationally and internationally, and to other family caregiver populations.

### Dissemination

Our advisory group including caregivers, MND Association representation, and our extensive network of service providers will guide dissemination activities. We will engage patient/family advocacy organisations (e.g. MND Association, Marie Curie Hospices, MND Care Centres), professional societies, and MND clinics to plan study promotion and dissemination activities. We will create a study Twitter account for study updates and results dissemination. Other dissemination strategies will utilize the communication strategies of relevant organisations including websites, newsletters, forums, social media in addition to peer reviewed publications and presentations at scientific, education, and lay forums.