

Digital Peer-Support for Family Caregivers of Individuals with Neuromuscular Disease: A Randomized Controlled Trial

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Table of Contents

Original Manuscript..... 5

Supplementary Files..... 31

 Figures 32

 Figure 1..... 33

Multimedia Appendixes 34

 Multimedia Appendix 1..... 35

 Multimedia Appendix 2..... 35

 Multimedia Appendix 3..... 35

 Multimedia Appendix 4..... 35

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Abstract

Background: Neuromuscular diseases (NMD) affect nerves and muscles resulting in weakness and often profound disability. Family caregivers of individuals with NMD experience significant burden and negative health effects. Peer support may help to ameliorate these negative impacts.

Objective: To evaluate the effect of a digital peer-support intervention compared to usual care on caregiver mastery, competence, stress, burden, anxiety, and depression among family caregivers of individuals with NMD.

Methods: We conducted a parallel group randomized controlled superiority trial. We recruited family caregivers of individuals (children and adults) with NMD. The 12-week intervention comprised access to a trained peer mentor via aTouchAway (Aetonix, Canada) and weekly digital discussion forums. Primary outcome was caregiver mastery (Pearlin Mastery Scale (PMS)) adjusted for baseline score. Secondary outcomes included caregiver stress, competence, burden, anxiety, and depression. We calculated adjusted (for baseline score) mean differences (aMDs) using analysis of covariance and generated multivariable linear regression models exploring associations with the intervention and caregiver age, years of caregiving, care recipient medical diagnosis, care recipient ventilation type, adjusting for baseline outcome scores.

Results: We recruited 100 participants, mean (SD) age 46.8 (11.6) years, 70% mothers, with mean (SD) length of caregiving 11.8 (7.6) years. We found no difference in 12-week PMS scores (aMD 0.67; 95% CI -1.7 to 3.1). We also found no difference in any of our secondary outcomes. Mentors and participants sent a mean (SD) of 21.3 (33.3) and 17.7 (33.0) messages, respectively. Overall, 62% of participants and 92% of mentors engaged in at least one program element for 8 of the 12 weeks.

Conclusions: Our 12-week digital peer support program had no effect on caregiver mastery or other caregiving or psychological outcomes. This might be due to only moderate fidelity. Future research should focus on peer support interventions that are better tailored to improve intervention fidelity and ultimately caregiver well-being. Clinical Trial: ClinicalTrials.gov NCT05070624; <https://clinicaltrials.gov/study/NCT05070624>

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Original Paper

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Abstract

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Results: We recruited 100 participants, mean (SD) age 46.8 (11.6) years, 70% mothers, with mean (SD) length of caregiving 11.8 (7.6) years. We found no difference in 12-week PMS scores (aMD 0.67; 95% CI -1.7 to 3.1). We also found no difference in any of our secondary outcomes. Mentors and participants sent a mean (SD) of 21.3 (33.3) and 17.7 (33.0) messages, respectively. Overall,

62% of participants and 92% of mentors engaged in at least one program element for ≥ 8 of the 12 weeks.

Conclusion: Our 12-week digital peer support program had no effect on caregiver mastery or other caregiving or psychological outcomes. This might be due to only moderate fidelity. Future research should focus on peer support interventions that are better tailored to improve intervention fidelity and ultimately caregiver well-being.

Trial Registration: ClinicalTrials.gov NCT05070624; <https://clinicaltrials.gov/study/NCT05070624>

Keywords: neuromuscular diseases; caregivers; peer support; caregiver stress; caregiver burden; long-term home ventilation



Introduction

Family caregivers are essential for the care of individuals with neuromuscular disease (NMD) in the home, particularly those using home mechanical ventilation (HMV) [1]. However, family caregiving contributes significant burden, social isolation, and negatively affects caregiver physical and mental health [2, 3]. Mastery and caregiver competency are important constructs that can improve ability to cope with stressors [4-6]. Mastery is the perceived sense of control over life situations [4-6]. Caregiver competence is the self-appraisal of caregiving adequacy and performance [4-6]. The Stress Process Model describes caregiver stress is a consequence of four interrelated domains: caregiving background and stress context, stressors, stress mediators, and stress outcomes or manifestations [4-6]. Therefore, mastery and competence are modifiable factors that can protect against the psychological stressors of caregiving [4-6].

Peer support includes emotional, informational, and affirmational support by an individual who has experienced a similar health problem [7-9]. Peer support improves health-related quality of life, self-efficacy and empowerment while decreasing stress in various patient and caregiver populations [10-12]. Furthermore, mastery development is responsive to digital peer support interventions [13]. Given caregiving commitments, in-person peer support is challenging due to geographic limitations and time constraints. Hence, digital peer support is ideal for caregivers of individuals with NMD who have high care needs [14, 15]. Although several digital peer support programs exist for these caregivers [11, 16-18], few programs have been formally evaluated.

We previously designed and beta-tested a digital peer-support program for caregivers of individuals using HMV with an asynchronous interactive chat forum hosted on a bespoke website. These interactions underscored the complexities of caring for an individual requiring HMV [16]. In our current study, the primary objective was to evaluate the effect of a digital peer support intervention for family caregivers of children and adults with NMD on caregiver mastery compared to usual care. Secondary objectives were to determine the effect on caregiver stress, competence, burden, stress, anxiety and depression.

Methods

Trial Design

We conducted a parallel group, multi-centre, randomized controlled superiority trial. This study was conducted and reported in accordance with the CONSORT 2025 checklist and CONSORT E-HEALTH checklist [19, 20] (Multimedia Appendix 1 and 2).

Setting and Recruitment

We recruited participants and mentors from seven sites across Ontario, Canada, through self-referral via social media, and national charities/organizations. Participants were recruited from August 2022 to September 2023. (See Multimedia Appendix 3 for study sites, relevant charities and organizations and trial design). Interested individuals completed an expression of interest form sent via email to the study coordinating centre to determine eligibility and were subsequently recruited.

Participants

Inclusion criteria for study participants were: 1) family caregiver of an adult or child with NMD living in Canada; 2) speaks and reads English; 3) access to internet and computer/tablet; 4) consents to participation. Inclusion criteria for peer mentors were the same as for participants with the additional requirement of completing our digital peer support training. No exclusion criteria were applied.

Ethical Considerations

This trial received research ethics approval: CTO-3590 and was registered (Clinicaltrials.gov: NCT05070624). Participants and mentors provided written informed consent in accordance with the Declaration of Helsinki [21]. Upon completion, participants were provided a CAD \$30 online gift card in lieu of their time.

Randomization and Blinding

Participants were randomized in a 1:1 ratio using an allocation concealed computer-generated randomization schedule with random permuted block sizes of 2 or 4. Due to the nature of the intervention, study participants and personnel were not blinded. Outcome assessors were not blinded

due to resource limitations.

Trial Interventions

Digital Peer-Support Program: We adapted our previously beta-tested peer support program for delivery on the aTouchAway™ app (Aetonix, Ottawa, Canada). This included peer mentor training, private chat between peers, public discussion forums, and weekly moderated chats. The 12-week digital peer-support intervention comprised: 1) private communication (text messaging (asynchronous), voice or video calls (synchronous)) with a peer mentor via the aTouchAway app; 2) asynchronous discussion forum (group chat) via app messaging; and 3) weekly synchronous group discussion sessions hosted via Zoom (Zoom Video Communications Inc, San Jose, California). Weekly discussion sessions were one hour in duration, with a range of topics relevant to family caregivers discussed. This included caregiving, health system navigation, stress management, accessibility for individuals with disabilities, transitioning to adult care, disability and reproductive justice, and mental health. A content expert, i.e., someone with specialized knowledge in a specific topic, was present at each session giving either a formal presentation and/or guiding discussion. These sessions were digitally recorded and shared with all intervention participants if unable to attend in real time.

Participants were matched with a peer mentor based on two factors: 1) adult or child care recipient; 2) use of HMV. Mentors supported between one to seven participants, averaging three to four per mentor. Participants randomized to the intervention arm were onboarded to the aTouchAway app, with instructions provided over the telephone on how to download and use the app while addressing any concerns.

Peer Mentor Training: We previously adapted and tested a digital peer mentor training program from the St. Jude's Research Hospital's (Memphis, United States of America) program for caregivers of children with cancer [22] with subsequent refinement and use in an ongoing United Kingdom trial of caregiver peer support [22]. Twelve peer mentors underwent four one-hour training sessions (led

by FB, NH, SM) held virtually using Zoom. Training focused on mentorship skills building, case scenarios, boundary setting, when to seek help, and ensuring personal well-being as a mentor.

A research coordinator checked in with mentors every two weeks to address any questions/concerns, and to facilitate assistance with participant connection as needed. Participants and mentors were instructed that private communication should be a minimum of once weekly and asynchronous group chat a minimum of twice weekly. Mentors were instructed to contact the study team which included social work and psychiatry members if concerned about a participant's well-being.

Control arm: Participants randomized to the control arm continued to receive usual care which comprised access to existing support services. Upon trial completion, these participants were provided access to the peer support discussion session recordings and resources but had no access to real-time peer mentoring or live group discussions.

Study Outcomes

Our primary study outcome was caregiver mastery measured using the Pearlin Mastery Scale (PMS) at 12-weeks and adjusted for baseline score. The PMS is a valid and reliable [23] 7-item scale with scores ranging from 7 to 49; higher scores indicate higher levels of mastery [24]. The PMS has been utilized in previous studies of caregivers of people with various conditions including respiratory failure and cancer [25-28] and studies of web-based interventions [15]. We also measured PMS at 24-weeks.

Secondary outcomes were measured at baseline, 12 and 24-weeks and included: 1) caregiver stress and competence (Caregiving Stress Scale (CSS); 2) caregiver burden (Zarit Burden Interview (ZBI)); and 3) depression, anxiety, and stress (Depression and Anxiety Stress Scale-21 (DASS21)).

The CSS is a valid and reliable tool [29, 30] comprising 15 independent subscales (score range 1-4); higher scores reflect better outcomes [5]. This scale is used in caregiving research to assess self-appraisal of efficacy in caregiving [31-33]. The ZBI is a valid and reliable tool widely

used to evaluate caregiver burden [34-36]. It has 22 items with total scores ranging from 0 to 88; higher scores reflect higher levels of caregiver burden [37]. The DASS21 (subscale scores range from 0 to 42) is a valid and reliable tool [38, 39] with 21 items; higher scores indicating depression, anxiety or stress. [40]. Participants completed the Caregiving Assistance Scale (CAS) at baseline to assess caregiving contextual factors [41].

Intervention Fidelity

Via the aTouchAway app, we collected data on text message, phone, and video call volume sent by mentors and participants and monitored participation in weekly discussion sessions. We established the following criteria to determine fidelity [22]:

1. $\geq 60\%$ of participants and mentors engage in any program element (i.e., private chat, discussion sessions) for $\geq 8/12$ weeks.
2. $\geq 50\%$ of participants and mentors join the weekly discussion session for $\geq 8/12$ weeks.
3. $\geq 50\%$ of participants post on the asynchronous discussion forum for $\geq 8/12$ weeks.
4. $\geq 50\%$ of participants contact a mentor during the 12-week program for $\geq 8/12$ weeks.
5. Attrition: $\leq 30\%$ of participants withdraw from the study before completion of post-intervention questionnaires.

Data Collection

All study data were collected using case report forms developed in a bespoke Research Electronic Data Capture database (REDCap; Vanderbilt, United States of America) by trained research personnel. Participants completed study measures either independently via this database accessed through an email link with up to three reminder prompts, or with assistance from a research coordinator via telephone, according to their preference.

Statistical Analysis

Sample size: Basing our assumptions on a previous study of a web-based intervention for family caregivers [15], we assumed a minimum clinically important difference in the PMS of 2.95 points,

standard deviation (SD) 4.5, with 90% power and alpha of 5%. We required a sample size of 50 study participants in each group (100 participants total). Therefore, the study was powered to detect a minimum an adjusted mean difference (aMD) of 3.51 for the ANCOVA analysis. We completed a post hoc power analysis to identify the minimum detectable difference for the primary outcome. As the initial sample size calculation was performed using a version of the PMS with scores ranging from 7-28 as opposed to 7-49, the minimal clinically important difference for this study was adjusted to 5.16 with an SD of 7.87 for the post hoc analysis.

We summarized baseline characteristics and intervention fidelity using means and standard deviations (SDs) and counts and percentages. We used analysis of covariance to calculate aMDs and 95% confidence intervals (CIs) for our primary and secondary outcomes adjusting for the baseline score. We used the Holm adjustment to control for multiple testing [42].

We conducted a priori planned exploratory analyses using multivariable linear regression models exploring associations of caregiver age, years of caregiving, care recipient medical diagnosis, ventilation type, and intervention arm while controlling for baseline outcome score. All statistical analyses were conducted using R version 4.4.1 [43] by an independent statistician.

Results

Study Overview

We screened 576 family caregivers referred by our recruiting centers or through self-referral. Of these, 25 (4%) did not meet inclusion criteria; 415 (72%) declined to participate; 36 (6%) caregivers initially gave written or verbal consent but withdrew before randomization. We randomized 100 participants (50 to each arm) with 99 completing the study and providing the primary outcome (i.e., 1% attrition) [See Figure 1].

Intervention arm participants had a mean (SD) age of 45.6 (12.5) years; with 76% identifying as female. Care recipients of intervention participants had a mean (SD) age of 21.5 (20.5) years; children mean (SD) age 12.0 (6.5); adults, 55.5 (16.5) years. Most common diagnoses were muscular

dystrophy (40%) and spinal muscular atrophy [SMA (22%)].

Control arm participants had a mean (SD) age of 48.1 (10.7) years; with 86% identifying as female. Care recipients of control participants had a mean (SD) age of 22.2 (19.5) years; mean (SD) age of 14.0 (6.4), and adult patients, 55.5 (19.8). Most common diagnoses were muscular dystrophy (44%) and SMA (12%) [Table 1].

Primary Outcome Analysis

Mean (SD) PMS scores at 12 weeks were 29.8 (9.3) for the intervention group; 29.4 (8.7) for control, with an aMD of 0.67; [(95% CI: -1.75 to 3.10) Table 2].

Secondary Outcome Analysis

We found no difference between intervention and control group scores for PMS measured at 24-weeks; or the ZBI, DASS21 or CSS measured at 12 and 24-weeks (Table 3).

Exploratory Analysis

Controlling for baseline PMS score, we found no association between the 12-week PMS score and caregiver age, years of caregiving medical diagnosis, ventilation type and randomization arm (Table 4).

Exploratory analysis of secondary outcomes (Multimedia Appendix 4) found the following associations controlling for baseline scores: fewer caregiving years (estimate -0.23; 95% CI: -0.45 to -0.01) was associated with lower 24-week PMS score indicating lower mastery; older caregiver age (estimate 0.11; 95% CI: 0.1-0.22) and care recipient SMA diagnosis (reference Amyotrophic Lateral Sclerosis (ALS); estimate 5.21; 95% CI: 0.11 to 10.31) were associated with higher 12-week and 24-week (SMA compared to ALS; estimate 7.07; 95% CI: 1.04 to 13.09) DASS anxiety scores indicating more psychological morbidity. Conversely, male caregiver gender was associated with lower 24-week DASS anxiety scores (estimate -3.01; 95% CI: -5.98 to -0.03) and 24-week DASS stress scores

(estimate -4.82; 95% CI: -8.15 to -1.49) indicating less psychological morbidity. Caregivers of those with a myopathy diagnosis had lower 24-week CSS caregiver competency scores (reference ALS; estimate -2.68; 95% CI: -5.32 to -0.05) indicating less caregiver stress.

Program Fidelity

Thirty-one (62%) intervention participants and 11 (92%) mentors engaged with at least one program component for 8 out of 12 weeks. Among the specific elements, participants and mentors interacted most frequently through app-based messaging. Twenty-one (42%) participants contacted their mentor during 8 out of 12 weeks. Peer mentors sent a mean (SD) of 21.3 (33.3) messages per participant they mentored, while participants sent a mean (SD) of 17.7 (33.0) messages to their respective mentor (Table 5).

Fifteen (30%) intervention participants and two (17%) mentors attended the weekly discussion sessions for 8 out of 12 weeks. Only four (8%) participants posted on the asynchronous discussion forum for 8 out of 12 weeks. One (2%) participant withdrew after completing the 12-week program but before completing post-intervention questionnaires.

Discussion

In this randomized controlled trial of a 12-week digital peer-support intervention for family caregivers of children and adults with NMD, we found no difference between the intervention and control arms for our primary outcome of caregiver mastery measured at twelve-weeks and adjusted for baseline score. Similarly, there were no differences in our secondary outcomes, including caregiver stress, competence, burden, anxiety, and depression. Our exploratory analyses found fewer caregiving years was associated with less mastery; caregiving for an individual with SMA was associated with worse psychological outcomes.

Our study did not observe an effect on caregiver mastery, an outcome that has been infrequently examined in previous trials of digital peer support interventions. Caregiver mastery is

defined as a positive belief in one's own ability to manage the challenges of caregiving. Mastery is derived from a sense of ability to handle caregiving demands, perceived self-efficacy and is protective against stress and the negative mental health sequelae of caregiver burden [15, 24, 27]. We therefore chose caregiver mastery as our primary outcome measure as this best reflected the intended benefits of our virtual peer support program. However, other previous studies on digital peer support for caregivers have focused on outcomes such as caregiving competence, burden, stress, depression, and anxiety [44-50]. Among studies that did measure caregiver mastery, the interventions were mainly structured educational programs or personalized coaching. For example, mastery, measured as a secondary outcome, was significantly improved using an eight-week self-management program for caregivers of individuals with dementia, combining face-to-face coaching by trained psychologists with online forums for peer interaction [46]. In a trial of a web-based intervention for stroke patients and their caregivers that included both peer and professional support via online chat sessions, no direct effect on mastery (secondary outcome) was found; however, reductions in caregiver depression were significantly associated with increased mastery [50]. These studies suggest that caregiver mastery may be more responsive to interventions incorporating self-management or psychoeducational strategies rather than to peer support alone.

In our exploratory analyses, we found a shorter caregiving duration was associated with worse mastery. This may reflect the challenges faced by newer caregivers who are still adapting to their roles and lack established coping strategies. Older caregiver age and an SMA diagnosis were associated with higher anxiety. Anxiety has been linked to increased health concerns and care demands, physical and mental fatigue, social isolation, financial strain, and difficulty engaging with digital platforms [51-58]. Male caregivers reported lower psychological morbidity compared to females, consistent with prior research [59-61]. Myopathy diagnosis correlated with lower caregiver competence, likely reflecting the condition's complexity and limited support [62].

There are several factors that could have contributed to our finding of no effect on caregiver

mastery. First, the 12-week intervention duration may be too short to produce an effect on mastery. Second, inclusion of caregivers for children and adults with any form of NMD introduced sample heterogeneity, potentially limiting the ability to foster meaningful peer connections [63]. Third, the digital format may have reduced interaction quality and therefore homophily [64, 65]. Fourth, some peer mentors were active caregivers themselves while responsible for supporting multiple participants, which may have diluted their capacity to provide consistent or individualized peer support. Fifth, baseline mastery scores were at the mid-range, suggesting participants may already possess a strong sense of mastery or had reached a ceiling, limiting potential for improvement. Sixth, although it is possible that the lack of effect observed in this trial was due to insufficient power, this is unlikely. Post hoc analysis found our study was adequately powered to detect a difference in PMS of 3.56. Finally, intervention fidelity may have contributed. Our qualitative feedback suggested barriers such as time constraints and difficulty feeling connected to their mentor due to differences in caregiving characteristics [66]. While digital interventions help to address barriers such as social isolation and geographical distance, they may not support meaningful connections.

Strengths and limitations

A key strength of this study is its rigorous randomized controlled design, which minimizes bias through randomization and allocation concealment. However, lack of blinding risks performance and detection bias, particularly as our outcomes were subjective in nature. Additionally, a large proportion of eligible caregivers declined participation, introducing potential selection bias, which may limit the generalizability of our findings. It is possible that those who agreed to participate were more confident or capable in their caregiving roles and thus more willing to engage in peer support. Those who declined may have been the individuals who would have benefited most from the intervention. Allowing participants to choose their peer mentor may have enhanced relational depth and tailored support. However, this was not feasible given our small pool of peer mentors. Most participants were existing caregivers with moderate to high mastery and low distress, suggesting our

inclusion criteria could have included measurement of baseline mastery to identify those most at need of the intervention.

Conclusion

This randomized controlled trial evaluated a 12-week digital peer-support intervention for caregivers of individuals with an NMD and found no effect on caregiver mastery, stress, competency, burden, anxiety, and depression measured at 12 weeks and adjusting for baseline scores. While several factors, such as the short intervention duration, potential ceiling effects, lack of homophily, and variability in caregiver engagement may have contributed to the absence of measurable impact, these explanations remain speculative. Future research should consider focusing on caregivers new to the role as well as an evaluation of an individually tailored peer support intervention of a longer-duration to better understand their potential to improve caregiver well-being.

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Conflict of interest: None declared.

Data availability: The data supporting the findings of this study are available within the article and/or its supplementary material.

Authors' Contributions: **Samantha Mekhuri:** Data curation, Formal analysis, Investigation, Writing – Original draft; **Joseph Munn:** Formal analysis, Writing – Review & editing; **Francine Buchanan:** Methodology, Writing – Review & editing; **Nouma Hammash:** Methodology, Writing – Review & editing; **Munazzah Ambreen:** Formal Analysis, Investigation, Writing – Review & editing; **Sara Ahola Kohut:** Methodology, Writing – Review & editing; **Louise Rose:** Conceptualization, Methodology, Validation, Writing – Review & editing, Funding Acquisition; **Reshma Amin:** Conceptualization, Methodology, Validation, Writing – Review & editing,

Supervision, Funding Acquisition.

Generative Artificial Intelligence Disclosure: The author(s) attest that there was no use of generative artificial intelligence technology in the generation of text, figures, or other informational content of this manuscript.

Abbreviations:

ALS: Amyotrophic Lateral Sclerosis

aMD: Adjusted Mean Difference

CSS: Caregiver Stress Scale

DASS: Depression, Anxiety, and Stress Scale

HMV: Home Mechanical Ventilation

NMD: Neuromuscular Disease

PMS: Pearlin Mastery Scale

SMA: Spinal Muscular Atrophy

ZBI: Zarit Burden Interview

Multimedia Appendix 1

Consolidated Standards of Reporting Trials 2025 checklist.

Multimedia Appendix 2

Consolidated Standards of Reporting Trials E-HEALTH checklist.

Multimedia Appendix 3

Recruitment Overview.

Multimedia Appendix 4

Exploratory Analyses.

Table 1. Baseline characteristics for mentors, intervention, and control groups.

Characteristics		Control N=50	Intervention N=50
Caregiver Age, mean (SD)		48.10 (10.69)	45.58 (12.48)
Caregiver Gender, n (%)			
	Female	43 (86)	38 (76)
	Male	7 (14)	12 (24)

Caregiver Relationship, n (%)			
	Mother	37 (74)	33 (66)
	Father	3 (6)	8 (16)
	Other	10 (20)	9 (18)
Length Caregiving Years, mean (SD)		13.0 (7.9)	10.7 (7.2)
Ethnicity, n (%)			
	White	21 (42)	28 (56)
	South Asian	10 (20)	11 (22)
	Asian	4 (8)	5 (10)
	Arab	5 (10)	2 (4)
	Latin American	4 (8)	0 (0)
	Black	3 (6)	1 (2)
	Prefer Not to Say	2 (4)	2 (4)
	First Nations	0 (0)	1 (2)
	Mixed Race	1 (2)	0 (0)
Caregiver Education Level, n (%)			
	Received University or College Degree/Diploma	34 (68)	38 (76)
	Some Post-Secondary (University or College)	6 (12)	7 (14)
	Completed Secondary School	5 (10)	4 (8)
	Did Not Complete Secondary School	5 (10)	1 (2)
Employment, n (%)			
	Full-Time	21 (42)	21 (42)
	Other	29 (48)	29 (58)
Gross Household Income, n (%)			
	Less than \$50,000	7 (14)	8 (16)
	\$50,000-\$79,999	4 (8)	2 (4)
	\$80,000-\$99,999	13 (26)	10 (20)
	\$100,000 or more	12 (24)	21 (42)
	Prefer not to answer	14 (28.0)	9 (18.0)
Patient Age Years, mean (SD)		22.21 (19.50)	21.55 (20.47)
	Adult Patients	55.10 (19.77)	55.45 (16.48)
	Pediatric Patients	13.99 (6.40)	11.98 (6.49)
Diagnosis, n (%)			
	Muscular Dystrophy	22 (44)	20 (40)
	Spinal Muscular	6 (12)	11 (22)

	Atrophy		
	Myopathy	5 (10)	5 (10)
	Amyotrophic Lateral Sclerosis	4 (8)	3 (6)
	Other	13 (26)	11 (22)
HMV, n (%)			
	Noninvasive	32 (64)	28 (56)
	None	12 (24)	17 (34)
	Invasive	6 (12)	5 (10)

Abbreviations: HMV, home mechanical ventilation

Table 2. Unadjusted primary and secondary outcomes (baseline, 12 weeks, and 24 weeks)

		Control, N=50 Mean (SD)	Intervention, N=50 Mean (SD)	Overall, N=100 Mean (SD)
Pearlin Mastery Score				
	Baseline	31.20 (9.19)	30.92 (8.01)	31.06 (8.58)
	12 Weeks	29.36 (8.71)	30.52 (9.39)	29.94 (9.03)
	24 Weeks	28.78 (7.71)	28.50 (7.79)	28.64 (7.71)
Zarit Burden Interview				
	Baseline	31.26 (15.02)	29.98 (15.16)	30.62 (15.03)
	12 Weeks	33.14 (15.02)	32.84 (13.03)	32.99 (13.99)
	24 Weeks	34.24 (16.89)	35.42 (13.64)	34.83 (15.28)
DASS Depression				
	Baseline	7.44 (7.13)	9.16 (8.06)	8.30 (7.62)
	12 Weeks	6.64 (5.50)	9.16 (8.32)	7.90 (7.13)
	24 Weeks	7.88 (7.68)	8.64 (8.6)	8.26 (8.12)
DASS Anxiety				
	Baseline	5.56 (6.11)	5.88 (6.68)	5.72 (6.37)
	12 Weeks	5.08 (5.38)	5.68 (7.54)	5.38 (6.52)
	24 Weeks	5.64 (6.83)	5.16 (6.36)	5.4 (6.57)
DASS Stress				
	Baseline	10.84 (6.79)	12.12 (8.13)	11.48 (7.48)
	12 Weeks	10.88 (6.71)	11.28 (8.02)	11.08 (7.36)
	24 Weeks	12.2 (7.73)	12.08 (8.81)	12.14 (8.25)
CSS Caregiving Competence				
	Baseline	13.94 (2.03)	12.90 (2.48)	13.42 (2.31)
	12 Weeks	13.60 (2.16)	12.96 (2.36)	13.28 (2.27)
	24 Weeks	13.70 (2.35)	13.44 (2.71)	13.57 (2.53)

Abbreviations: DASS, Depression and Anxiety Stress Scale; CSS, Caregiver Stress Scale

Table 3. Adjusted Primary and Secondary Outcomes

Variables		12 Weeks			24 Weeks		
		aMD	95 CI	P Value	aMD	95 CI	P Value
Pearlin Mastery Scale		0.67	-1.75 to 3.10	0.59	-0.40	-2.83 to 2.03	0.75
Zarit Burden Interview		1.78	-1.67 to 5.22	0.31	0.93	-3.46 to 5.32	0.68
DASS							
	Depression	1.13	-0.69 to 2.96	0.23	-0.39	-2.75 to 1.96	0.74
	Anxiety	0.45	-1.42 to 2.31	0.64	-1.18	-3.45 to 1.09	0.31
	Stress	-0.49	-2.56 to 1.58	0.64	-0.92	-3.46 to 1.61	0.48
CSS Caregiving Competence		0	-0.71 to 0.70	0.99	-0.03	-0.98 to 0.92	0.96

Abbreviations: aMD, Adjusted Mean Difference; CSS, Caregiving Stress Scale; DASS, Depression and Anxiety Stress Scale

Table 4. Linear regression model exploring variables associated with the Pearlin Mastery Scale score measured at 12 and 24 weeks controlling for baseline scores.

Predictors		Pearlin 12 Weeks			Pearlin 24 Weeks		
		Estimate	CI	P Value	Estimate	CI	P Value

Allocation (Reference Control)							
	Intervention	0.54	-1.99 to 3.07	0.67	-0.29	-2.87 to 2.30	0.83
Pearlin Baseline		0.77	0.62 to 0.92	<0.001	0.56	0.41 to 0.71	<0.001
Caregiving Years		-0.03	-0.24 to 0.18	0.77	-0.23	-0.45 to -0.01	0.04
Caregiver Age		-0.14	-0.28 to 0.00	0.06	0.14	-0.01 to 0.28	0.06
Caregiver Gender (Reference Female)							
	Male	0.38	-3.00 to 3.76	0.82	0.92	-2.53 to 4.36	0.60
Diagnosis (Reference ALS)							
	Muscular Dystrophy	-1.44	-7.97 to 5.09	0.66	5.41	-1.25 to 12.07	0.11
	Myopathy	-4.22	-11.27 to 2.82	0.24	4.3	-2.88 to 11.48	0.24
	Other	0.06	-6.64 to 6.77	0.99	6.01	-0.82 to 12.85	0.08
	Spinal Muscular Atrophy	-4.34	-11.20 to 2.52	0.21	4.48	-2.51 to 11.48	0.21
HMV (Reference Invasive)							
	None	1.13	-3.23 to 5.49	0.61	1.93	-2.51 to 6.38	0.39
	Non-Invasive	0.93	-3.22 to 5.09	0.66	1.05	-3.19 to 5.28	0.63

Abbreviations: ALS, Amyotrophic Lateral Sclerosis; HMV, home mechanical ventilation

Table 5. Patient program fidelity

Variables		Overall, N=50
Texts sent by participant		
	Mean (SD)	17.72 (33.03)
	Median [IQR]	4.0 [2.0, 14.8]
Texts sent to participant		
	Mean (SD)	21.28 (33.26)
	Median [IQR]	8.0 [4.0, 18.8]
Video calls to participant		
	Mean (SD)	0.12 (0.59)
	Median [IQR]	0.0 [0.0, 0.0]
Video calls from participant		
	Mean (SD)	0.22 (0.68)
	Median [IQR]	0.0 [0.0, 0.0]
Voice calls to participant		
	Mean (SD)	0.06 (0.31)
	Median [IQR]	0.0 [0.0, 0.0]
Voice calls from participant		
	Mean (SD)	0.18 (0.52)
	Median [IQR]	0.0 [0.0, 0.0]

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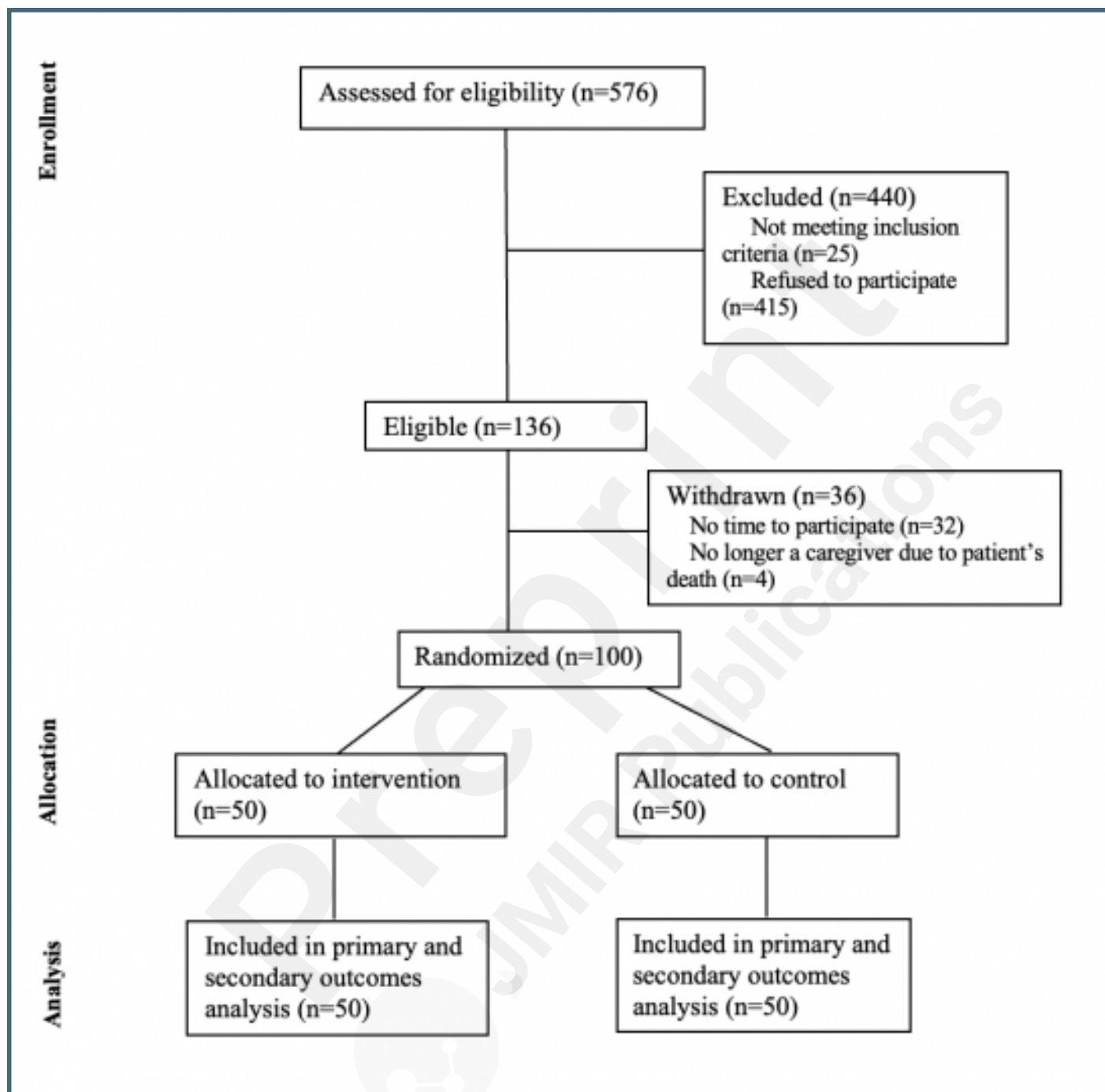
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Supplementary Files

Figures

Consort Diagram for Study Enrollment and Randomization.



Multimedia Appendixes

Consolidated Standards of Reporting Trials 2025 checklist.

URL: <http://asset.jmir.pub/assets/f4b37ff98fd5476c7be332d11403ac3c.docx>

Consolidated Standards of Reporting Trials 2025 checklist.

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Recruitment Overview.

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Exploratory Analyses.

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