Abstract

Innovation in the Treatment of Persistent Pain in Adults With NF1: Implementation of the iCanCope Mobile App

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Abstract

Background: Neurofibromatosis type 1 (NF1) is an autosomal dominant genetic condition affecting 1 in 2500 individuals. Over 50% of individuals with NF1 report significant pain and discomfort, which may be associated with benign and malignant tumors, but is often not localized to a structural lesion, thus presenting treatment challenges for patients and their medical caregivers. To date, there are very few treatments aside from surgical intervention to mitigate pain.

Objective: We developed the *iCanCope-NF* mobile app for pain self-management. *iCanCope-NF* is a customized self-monitoring and pain management mobile app designed to provide resources and support for those having chronic pain due to NF1. The app enables users to access daily pain monitoring and quality of life check-ins, allows them to plot interrelated variables on various timelines to observe trends in pain and interference across different areas of life (such as sleep, physical activity, and mood), and provides them with the option to set physiological and psychological goals as well as a robust library of written and video resources to help manage pain symptoms and to better cope with NF1.

Methods: This paper evaluated the *iCanCope-NF* to reduce pain severity and interference in adults with NF1. A total of 80 participants across 3 different groups (control, *iCanCope-NF* access condition, and *iCanCope-NF* contingency management condition where subjects were provided monetary incentives for engaging with the various features within the app [CM]) completed a randomized clinical trial in which evaluations were completed at intake (initial day of participation), discharge (2 months after intake), and 6 weeks after discharge.

Results: Preliminary data analysis demonstrated individuals randomized to the *iCanCope-NF* + CM had greater engagement with the mobile app than individuals who were randomized to *iCanCope-NF*. Additionally, individuals in the *iCanCope-NF* + CM consistently checked in more (SD 59.5/60 days) than individuals in the *iCanCope-NF* group (SD 51/60 days). Pain interference, as measured by the *Pain Interference Index* (PII), was significantly different across all 3 groups at discharge: control (M=6.3), *iCanCope* (M=5.7), *iCanCope* + CM (M=5.1), $P<.05$.

Conclusions: Qualitative interviews completed at discharge for individuals with access to the app indicated that the app was a "wonderful measuring tool" and "provided credibility of my pain symptoms," and that it was a dramatic and distinctive aide in the monitoring and tracking of their pain symptoms. We demonstrated preliminary acceptability and efficacy for *iCanCope-NF* as the first pain self-management tool for individuals with NF1. *iCanCope-NF* + CM was successful in increasing engagement and decreasing pain interference.

Trial Registration: ClinicalTrials.gov NCT04561765; https://clinicaltrials.gov/ct2/show/NCT04561765

Conflicts of Interest: None declared.

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KEYWORDS

neurofibromatosis type 1; mobile app; pain; pain management

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