HOBSCOTCH Your Way to Improved Cognition for Patients With Epilepsy

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Effectiveness of a Self-Management Program to Improve Cognition and Quality of Life in Epilepsy: A Pragmatic, Randomized, Multicenter Trial

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Background and Objectives: We conducted a multisite, pragmatic replication trial at 4 New England epilepsy centers to determine the effectiveness of Home-Based Self-Management and Cognitive Training Changes Lives (HOBSCOTCH) in a real-world setting and to assess feasibility of a virtual intervention. Methods: HOBSCOTCH is an 8-session intervention addressing cognitive impairment and quality of life (QoL) for people with epilepsy (PWE). Participants were recruited from epilepsy centers in 4 states and block-randomized into the following groups: in-person HOBSCOTCH (H-IP), virtual HOBSCOTCH (H-V), and waitlist control. Outcome measures were assessed for all groups at baseline, 3 months, and 6 months; intervention groups received long-term follow-up at 9 and 12 months. Results: A total of 108 participants were recruited, of whom 85 were included in this analysis (age at baseline 47.5 ± 11.5 years; 68% female). Participants completing the in-person intervention (H-IP) had a 12.4-point improvement in QoL score compared with controls (p < 0.001). Pairwise comparisons found a 6.2-point treatment effect for subjective cognition in the H-IP group (p < 0.001). There were no meaningful group differences in objective cognition or health care utilization at any time points and the treatment effect for QoL diminished by 6 months. The virtual intervention demonstrated feasibility but did not significantly improve outcomes compared with controls. Within-group analysis found improvements in QoL for both H-V and H-IP Discussion: This study replicated the effectiveness of the HOBSCOTCH program in improving QoL for PWE. The study was conducted prior to the COVID-19 pandemic, but the distance-delivered intervention may be particularly well-suited for the current environment. Future research will explore modifications designed to improve the efficacy of H-V and the sustainability of HOBSCOTCH’s treatment effect.

Commentary

People with epilepsy (PWE) experience multiple comorbidities that can impact their quality of life (QoL). For example, PWE are at an increased risk of developing cognitive dysfunction and psychiatric illness, which can sometimes be more problematic than the seizures themselves. Literature supports that nearly 50% of PWE suffer from cognitive complaints, impacting their memory, attention, productivity, and QoL.1,2 Providing PWE interventions to help manage their cognitive impairments is necessary to improve QoL for both PWE as well as their caregivers. The Home-Based Self-Management and Cognitive Training Changes Lives (HOBSCOTCH) was developed by a funded network dedicated to providing strategies to help improve QoL for PWE. It is an evidence-based self-management intervention that improves QoL by addressing common comorbidities and cognitive concerns. It uses evidence-based strategies to address complaints of cognitive impairment and help build and develop self-efficacy. It is primarily delivered over the phone to avoid common transportation barriers.

The article reviewed in this commentary examined the generalizability and feasibility of HOBSCOTCH, and the long-term outcomes and sustainability of this intervention delivered...
in-person and virtually. HOBSCOTCH uses patient education, self-monitoring, problem-solving therapy (PST), and memory strategies to target cognitive impairment in PWE. The hope was to improve QoL by improving the ability to cope with cognitive challenges. There were 8 sessions delivered by trained coaches who focused on rapport building, validating participants’ memory challenges, and helping them to identify cognition-related problems and develop solutions. The patients were also provided with a toolbox of compensatory memory strategies. The first session provided functional education about memory organizational skills, seizure management, and social skills. In sessions 2 to 8, patients were assisted in applying 7 steps of PST to identify cognition-related problems and develop solutions. The epilepsy centers that participated in this multisite study aimed to assess whether HOBSCOTCH could be disseminated and delivered virtually in a real-world health care setting and maintain effectiveness. This is the first study to test HOBSCOTCH outside of the academic medical center where it was created, across multiple epilepsy centers, to examine its generalizability and applicability.

In this study, the effectiveness of HOBSCOTCH was one of the primary endpoints. The secondary endpoints were program feasibility and sustainability. The primary outcome measures were (1) change in QoL, as measured by the Quality of Life in Epilepsy (QOLIE-31) and (2) change in health care utilization, as measured by the Healthcare Utilization in Epilepsy survey. The secondary outcome measures included changes in (1) subjective cognitive function (Qol in Neurological Disorders, Neuro-QoL), (2) depression (Patient Health Questionnaire–9), (3) self-management practices (Epilepsy Self-Management Scale), and (4) objective cognition (Brief Test of Adult Cognition by Telephone). In all, 108 participants were enrolled, with 23 withdrawals (survey burden was thought to be responsible for the high attrition rates), leaving 85 participants who were assessed. At 3-month follow-up, the in-person intervention group showed significant improvements in 6 of the 7 subscales of the QOLIE-31 (all but the Seizure Worry subscale). This group also reported better cognitive function on the Neuro-QoL post-HOBSCOTCH. However, by 6 months and beyond, there were no reliable significant differences. In the virtual intervention group, there were no differences in subjective cognitive function on the Neuro-QoL, the objective cognition measure, change in depressive symptoms from baseline, or self-management. The overall QoL scores returned to baseline by the 6-month assessment, but cognitive subscores remained elevated until 12 months.

One of the most important findings of this study was that participants reported better cognitive function after completing the intervention. The HOBSCOTCH technique directly targeted cognitive impairment and used PST to address memory problems, such as forgetting to take medications or inability to link a face to a name in social settings. The program also focused on the role of external factors on cognition, such as diet, sleep, and stress. The intervention taught participants to use compensatory strategies to work around memory problems in order to gain a sense of control over the symptoms of cognitive impairment. Improvements in subjective cognition may have resulted from skill-building and strengthened self-efficacy. Nearly all participants who completed the anonymous satisfaction survey reported that HOBSCOTCH gave them tools for daily life. Despite improving subjective cognitive function, this study failed to replicate the finding from the previous study in which HOBSCOTCH improved objective cognition. This may be explained by the fact that HOBSCOTCH teaches participants how to cope with cognitive impairment rather than how to enhance cognition or regain lost capacity.

One limitation of this study was that it was conducted prior to the COVID-19 pandemic, and thus prior to global acceptance of virtual care delivery. However, given the world of telemedicine has grown exponentially since this research was conducted, we may now possess better insight into the development and necessity for maintenance sessions that may increase long-term benefits. Patients are now more receptive to participating in telemedicine and thus these types of interventions may have a greater impact then they did prior to the COVID-19 pandemic. The results illustrate that the positive effects of HOBSCOTCH were not maintained over time compared with controls. While the improvements in the QOLIE-31 subscales support aspects of the intervention and its feasibility, further adaptation is required to strengthen its long-term efficacy. The need for ongoing support to improve sustainability has been observed for other illnesses and behavioral programs as well.

Despite its limitations, this publication importantly highlights the need for an easily accessible intervention that addresses cognitive concerns in PWE. Cognitive impairment impacts QoL by affecting social relationships, education, employment, and health. Cognitive impairment is also a major cause of disability for PWE. Until now, there have been no evidence-based treatments available addressing a cognitive impairment intervention for PWE: HOBSCOTCH is the only self-management program designed to specifically address cognitive concerns in epilepsy.

In summary, this publication provides support for an easily attainable evidence-based treatment option targeting cognitive impairment in PWE. The epilepsy community should be familiar with this treatment and actively discussing and recommending it for our patients. The results from this study could be used to guide further development of education materials to increase awareness and access to such behavioral interventions as well as help to develop a feasible model for maintenance sessions for improved sustainability. Information and guidance on how to access resources also improves QoL. This article emphasizes the need in our community to address cognitive concerns and their effects on QoL for PWE. Improving education and communication about this topic as well as increasing access to care and sustainability of improvement will ultimately help improve the QoL for PWE.
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