

• Name of the study: Remote rehabilitation for children with cerebral palsy and intellectual developmental disability using an innovative training application

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• Type of research: research

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Abstract

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Background: People with developmental disabilities, including those diagnosed with cerebral palsy (CP) and intellectual developmental disabilities (IDD) exhibit limited motor and functional abilities, and their function often worsens in adolescence and adulthood. On the other hand, the number of healthcare services available to this population decreases with age. Therefore, it is essential to identify available, affordable, and effective treatment methods that can provide these individuals with the possibility of maintaining and improving their capabilities, despite the aging process and the reduction in available treatment.

Remote therapy has been shown to be effective in treating people with developmental disabilities in the past. For example, a physical training app was developed for girls with Rett syndrome with the aim of improving their adherence to a program of increased daily physical activity. This app enables improved follow-up and adherence to the activity training program.

Objective: The purpose of the current study was to test whether a remote physical activity training program first developed for girls with Rett syndrome, would also be feasible and effective for young people with CP and IDD.

Participants: Out of 40 patients with IDD and CP recruited from ALYN Hospital, who lived in the Jerusalem area, 12 participants (4 girls), age 13-20 years (mean age: 17.3, SD: 2.39), at a GMFCF level of 1-3, mean GMFCS: 2.25 (SD: 0.72) participated in the study.

The intervention program: The participants underwent an initial evaluation at ALYN Hospital, after which they were provided with a personal intervention plan that was tailored to their personal characteristics, lifestyle, and areas of interest. Each participant was instructed how to use the physical training app and the activity measurement devices. They were asked to attach the devices for the week preceding the actual commencement of the remote activity program, and to use the devices while implementing the program for following 3 weeks.

Results: Most of the participants were unable to use the physical training app on their own and many had difficulty using the activity measurement devices. However, those who did use the devices showed statistically significant pre-post remote activity training program improvements in outcomes such as the number of steps (p=0.004) and the number of transitions from standing to sitting (p=0.029). In the qualitative results, the participants reported positive changes in terms of balance, the ability to go up and down stairs, and an improvement in participation (walking with friends, reduced fear of falling). Conclusions: The results showing the effectiveness of the remote activity training program support the potential of remote intervention and the need to continue to run similar programs for people with IDD and CP. However, modification of the study design is needed in order to provide a more controlled framework where participants can receive close assistance in using and uploading the training app and devices. Moreover, the researchers recommend using valid clinical outcome measures such as the 6- or12-minute walk tests and Timed-Up-and-Go test to substantiate the qualitative participation results.

Synopsis

This study examined whether a tele-rehabilitation training app originally developed for girls with Rett syndrome could also be used by adolescents and young adults with cerebral palsy and intellectual and developmental disability. Twelve participants aged 13–20 years from ALYN Hospital received a personalized three-week intervention program using the app and wearable measurement devices. Most were unable to operate the system independently, but those who did showed statistically significant increases in step count and sit-to-stand transitions, and qualitatively reported improvements in balance, stair climbing, and social participation. The findings indicate promising potential, provided close guidance and validated assessment measures are implemented.

Keywords

Intellectual Developmental Disability, Remote Care, Application

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