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Feasibility of a Home-Based Exergaming Intervention for Youth With Spinal Muscular Atrophy

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ABSTRACT

Introduction/Aims: Approaches to optimize physical activity in youth with spinal muscular atrophy (SMA) are rapidly evolving. The primary objective of this study was to assess the feasibility of a fit-for-purpose home-based exergaming intervention in children and youth with SMA and peer controls.

Methods: We conducted a 4-week study at two Canadian sites to assess the feasibility of Tales from the Magic Keep, a home-based exergame specifically developed for youth with neuromuscular disorders that targets upper limb and trunk movements. Participants were asked to play the exergame for at least 20 min per session, 4 times a week for 4 weeks, and wear an accelerometer-based wearable device. Adherence, acceptability, and usability evaluations informed feasibility determinations. Adherence was quantified by gameplay frequency and duration. Acceptability and usability were assessed using study-specific questionnaires and the system usability scale (SUS).

Results: We enrolled 12 participants, 8 of whom completed the study: 4 SMA (3 Type II, 1 Type III) and 4 controls. Among those 8, adherence was high, with an average of 4.5 and 3.5 sessions per week for the SMA and control groups respectively, and they found gameplay to be acceptable and enjoyable. The median score on the SUS was 68/100. The wearable device was generally well accepted; participants reported it as comfortable to wear and not interfering with daily activities.

Discussion: The exergame was feasible and acceptable in two thirds of participants. Iterative feedback obtained during this study led to subsequent updates to the game interface to optimize gameplay.

Abbreviations: HFMSE, Hammersmith Functional Motor Scale Expanded; NMD4C, The Neuromuscular Disease Network for Canada; RULM, Revised Upper Limb Module; SMA, Spinal muscular atrophy; SUS, System Usability Scale.

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1 | Introduction

Children and adolescents with spinal muscular atrophy (SMA) benefit from participation in rehabilitation interventions that promote and sustain their performance and function in everyday activities such as self-care, productivity, and leisure. In this regard, home-based exergaming using low-cost interactive video games holds promise. Exergame interventions, in which children use body movements tracked by sensors to play interactive video games, have demonstrated effectiveness for improving strength, coordination, and mobility in children with neuromotor disorders [1–3]. As these games can be played at home, exergaming is a promising way to sustain motivation and incorporate exercise into daily routines, reducing the travel burden on families of on-site rehabilitation interventions. The design of exergames for patients with neuromuscular disorders requires special considerations to minimize risks and ensure gameplay accessibility in the face of movement limitations.

Although standardized observer-based assessments of motor function have been validated in SMA, they can be less responsive to clinically important change over the 6-to-12-month time period needed to guide clinical decisions and may not be reflective of the full spectrum of abilities in individuals with SMA [4]. As they are performed in the clinical setting, these measures are also dependent on participant motivation and provide only a single snapshot of performance. In contrast, measures of movement obtained in the home setting recorded by wearable devices or home-based exergames can capture objective changes in daily movement and are potentially more sensitive to change over short periods of observation. The Syde (Sysnav Healthcare, Vernon, France), a wireless device that is both light (38 g) and small (43 × 33 × 20 mm) enough to be worn as a watch without limiting movement, is a promising option. It allows continuous daily recording of linear accelerations, angular velocity, and the magnetic field in three-dimensional space. From these data, variables of upper and lower limb activity can be computed. Syde is the platform used to measure the first digital endpoint qualified by the European Medicines Agency for gait speed in ambulatory Duchenne muscular dystrophy [5]. It has since been used in several studies in rare disease populations, including SMA (where Syde-based outcome measures have shown excellent test–retest reliability) [6], demonstrating significant potential for validation of upper limb endpoints in non-ambulant patients.

The primary aim of this study was to assess adherence, acceptability, and usability of Tales from the Magic Keep in children and adolescents with SMA and peer controls. The secondary aim of this study was to assess the acceptability of using the Syde wearable device to measure outcomes.

2 | Methods

Tales from the Magic Keep, a home-based exergame, was designed and developed specifically to promote upper limb and core activity for youth with SMA. Input from patients, physiotherapists, and physicians was gathered in an iterative fashion, using online surveys and semi-structured interviews about needs, preferences, and barriers to implementation for an exergame tailored to the SMA population. Players in the game are tasked with creating potions of increasing difficulty, in which they use specific upper limb and core motions (shoulder horizontal abduction, elbow flexion, wrist and finger flexion, head rotation, and thoracic extension). Movements are tracked using the Microsoft Azure Kinect developer kit (Redmond, Washington, US), which has previously been shown to reliably track upper limb movements in children and adolescents with SMA [7]. An individual calibration on the targeted movements is integrated to optimize the gameplay interface.

We conducted a 4-week feasibility study among children and adolescents with SMA and peer controls. Peer controls were recruited to differentiate challenges experienced with the exergame due to the exergame itself and those related to different physical abilities of participants, as well as to explore whether digital endpoints can differentiate between the two groups. Participants were recruited from two Canadian sites: McGill University Health Centre (Montreal, Quebec) and the British Columbia Children's Hospital (Vancouver, British Columbia). Institutional research ethics board approval was obtained at both participating sites. Informed consent was obtained from parents/caregivers, and assent was obtained from the participants.

2.1 | Inclusion/Exclusion Criteria

To be eligible for this study, children and youth with SMA had to meet the following inclusion criteria: 1) have a confirmed genetic diagnosis of 5q SMA; 2) be between the ages of 6 and 18 years; 3) be able to stay seated independently for at least 10 s; 4) have a score of at least 2 points in entry item A of the Revised Upper Limb Module (RULM) [8] ("Can raise 1 or 2 hands to the mouth but cannot raise a 200 g weight in it to the mouth"); 5) be treated with disease-modifying therapy; 6) be receiving care at either the Quebec or British Columbia INFORM Rare pediatric centres. There were no exclusion criteria based on *SMN2* copy number.

Peer controls were eligible for this study if they met the following criteria: 1) aged 6–18 years old; and 2) age-appropriate motor development. Peer controls were excluded if they had any co-occurring disorder affecting motor function. Any participants who were judged to be potentially noncompliant with study procedures (as determined by a parent and study investigator) were excluded.

2.2 | Recruitment

Eligible youth with SMA and their parents/caregivers were approached by the study coordinator at their regularly scheduled clinic visits. Information about the study was also shared on social media platforms (Cure SMA Quebec and INFORM RARE network). Peer controls were recruited from the community through recruitment flyers shared locally at the two study sites and on social media through Cure SMA Canada and NMD4C.

2.3 | Study Procedures

After a phone call to confirm eligibility and record demographic information including age, sex, SMA type, and most recent

functional motor scores (Hammersmith Functional Motor Scale Expanded (HFMSE) [9] and RULM), participants attended an in-person baseline visit during which they were introduced to the exergaming equipment (gaming laptop and Kinect), trained on its use and its home setup, and completed a calibration of the gaming system under the guidance of the study coordinator. Lastly, instructions on the use of the Syde were provided, detailing continuous daily wear for the duration of the 4-week study, targeting 100 h of recording. The participants were equipped with the exergaming system including the Kinect, a gaming laptop, and HDMI cable, and Syde during the visit to take home with them.

Participants were asked to play the exergame at home for a minimum of 20 min per session, 4 times a week for 4 weeks. Weekly virtual meetings were held on Zoom (San Jose, California, US) between the study participant and the study coordinator to discuss gameplay sessions and any difficulties experienced during the prior week, which the participant recorded on their gameplay log. Participants were encouraged to contact the study team for additional troubleshooting sessions if difficulties were encountered at any time between weekly meetings. All study data was maintained on the LASSO data management platform [10].

2.4 | Outcomes

Feasibility of the exergaming intervention was determined by assessing adherence, acceptability, and usability. Adherence as measured by frequency and duration of gameplay was quantified by the Azure Kinect, which captured kinematic data during each gameplay session. Acceptability was rated by each participant at the end of the 4-week study using a questionnaire developed with input from youth and parent advisory committees to gain insights into the perceived value, experience, and satisfaction with the exergaming intervention. The questionnaire contained 20 items and used a 5-point Likert scale (0-Strongly Disagree to 5-Strongly Agree). Usability was assessed using the System Usability Scale (SUS) at the end of the 4-week study period. The SUS is a 10-item questionnaire which captures efficiency, intuitiveness, and ease of product use, as well as user satisfaction with the product [11]. Participants rated each SUS item on a 5-point Likert scale (1-Strongly Disagree to 5-Strongly Agree). Mathematical adjustments are made to the scores obtained, leading to obtain an SUS score that ranges from 0 to 100, with the average reported score in the literature being 68 [11, 12]. The feasibility of using the Syde to measure outcomes was assessed using a 3-item questionnaire assessing ease of use, comfort, and impact on activities of daily living. Each item was rated on a Likert scale (1-Strongly Disagree to 5-Strongly Agree). All 3 questionnaires are in the Supporting Information S1.

2.5 | Data Analysis

Descriptive statistics were calculated to obtain a profile of the study participant characteristics. Response options for the acceptability and Syde feasibility questionnaires were combined as follows: Disagreement (1-Strongly disagree and 2-Disagree), Neutral (3-Neutral), and Agreement (4-Agree and 5-Strongly agree). Differences in SUS scores between SMA and peer-control groups were assessed using the Mann–Whitney *U* test.

3 | Results

3.1 | Participant Characteristics

A total of 14 participants were screened for study inclusion and 12 enrolled in the study. The reason for screen failure was not captured. Four participants withdrew in the first 2 weeks of the study, leaving a total of 8 participants (4 participants with SMA and 4 peer controls) who completed the 4-week period. Participant characteristics are outlined in Table 1.

3.2 | Withdrawals

Of the 4 participants who withdrew from the study, 3 were in the SMA group and 1 was a peer control. The average age of participants who withdrew (mean 10.6 years old, range 8.1–13.7 years old) was nominally lower than that of those who completed the study (mean 13.1 years old, range 9.6–16.8 years old) (raw mean difference (RMD) 2.7 years, 95% CI −1.1 to 6.5). Participants with SMA who withdrew were nominally weaker than those who completed the study (HFMSE RMD 5.8, 95% CI −20.1 to 31.7; RULM RMD 5.1, 95% CI −5.4 to 15.6). Participants who withdrew did so early in the study, with the timing of their withdrawal ranging from 1 day to 2 weeks into the study. These participants did not play the game for the recommended duration, with most sessions lasting 5 min or less. Three of the 4 withdrawals occurred when the exergame was introduced over an extended holiday period. Reasons cited for withdrawal included difficulty with gesture recognition when playing the game (e.g., difficulty attaining the precision required by the Kinect sensor), fatigue when performing selections that required successive gestures, and disinterest in the game concept.

3.3 | Exergame Feasibility

3.3.1 | Adherence

In the SMA group who completed the study, the weekly per-session mean duration of gameplay sessions remained above 20 min for all 4 weeks (Figure 1) with the highest weekly mean duration of gameplay seen at study week 3 (mean 36.5 min, range 28.5–43.8 min). The weekly mean duration of gameplay sessions was above 20 min in the peer control group, except for study week 4 where it decreased to slightly below 20 min (mean 18.1 min, range 14.3–20.2 min). The mean number of sessions per week for participants with SMA was 4.5 (range 3.7–6.3 sessions) and 3.5 for peer controls (range 2.0–5.7 sessions).

3.3.2 | Acceptability

At the end of the 4-week study period, when asked if they enjoyed themselves whilst playing the game, all participants who completed the study either agreed ($n = 4$, 50%) or were neutral ($n = 4$, 50%). When asked if they felt good about themselves after

TABLE 1 | Participant characteristics.

	SMA ($n=7$)		Control ($n=5$)		
Participants status	**Completed**	**Withdrawn**	**Completed**	**Withdrawn**	**Total**
Sex					
Male	2 (50%)	2 (67%)	3 (75%)	1 (100%)	8 (67%)
Female	2 (50%)	1 (33%)	1 (25%)	0	4 (33%)
Age (years): mean (range)	13.3 (11.7–16.8)	11.2 (8.1–13.7)	12.8 (9.6–15.4)	9.0	12.2 (8.1–16.8)
Current motor function					
Sitting without support	1 (25%)	2 (67%)	0	0	3 (25%)
Walking with assistance	2 (50%)	0	0	0	2 (17%)
Walking unsupported	1 (25%)	1 (33%)	4 (100%)	1 (100%)	7 (58%)
SMA type					
SMA type II	3 (75%)	2 (67%)	NA	NA	NA
SMA type III	1 (25%)	1 (33%)	NA	NA	NA
Functional motor scores: mean (range)					
HFMSE	38.8 (27–60)	33.0 (13–53)	NA	NA	NA
RULM	32.3 (28–37)	27.3 (18–37)	NA	NA	NA

Abbreviations: HFMSE, Hammersmith Functional Motor Scale Expanded; RULM, Revised Upper Limb Module; SMA, spinal muscular atrophy.

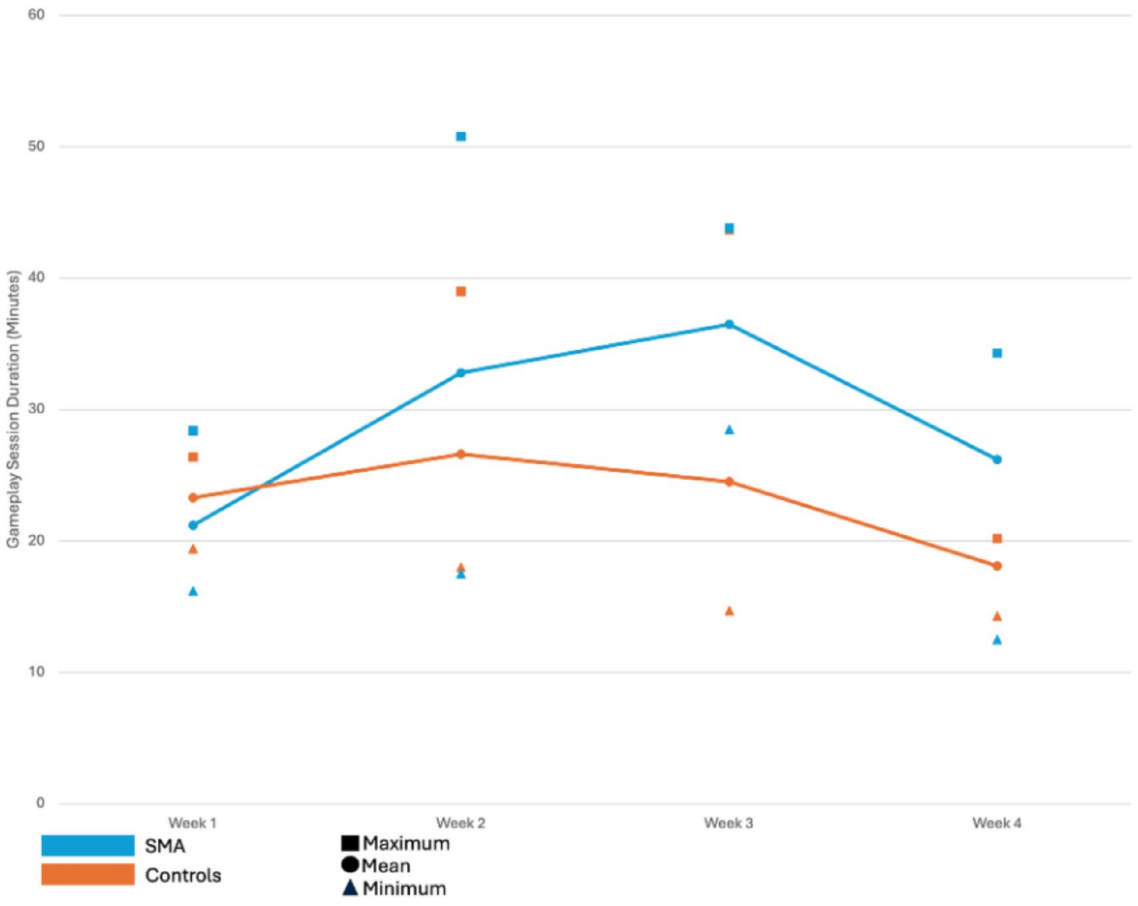

FIGURE 1 | Weekly average duration of a gameplay session shown by study group with ranges indicated. SMA, Spinal muscular atrophy.

playing, 6 participants (75%) agreed that they felt good about themselves, while 2 were neutral (25%). Difficulties with gesture recognition were reported by most participants ($n = 6$, 75%; 3 children with SMA and 3 neurotypical controls). This feedback was used to update the game's programming architecture to improve gesture recognition. When asked if they were challenged by the tasks in the game, 3 participants with SMA (75%) agreed, while 1 (25%) was neutral. Among the peer controls, there was more variation, with 1 participant (25%) reporting being unchallenged by the tasks, 2 (50%) being neutral, and 1 (25%) finding the task challenging. Most ($n = 7$, 88%) participants felt accomplished playing the game, while 1 (12%) disagreed.

3.3.3 | Usability

The majority (75%) of participants with SMA felt that the game was difficult to set up, while all peer controls agreed that the game was easy to set up. The median score for the SUS was 67.5 for all participants and was 67.5 and 60.2 for participants with SMA and peer controls, respectively, with no statistically significant difference between groups ($U = 9.50$, $p = 0.661$).

3.3.4 | Syde Feasibility

Of the 8 participants who completed the study, data were reliably captured on 6 participants with more than 100 h of Syde recordings. All participants agreed that it was comfortable to wear and that it did not interfere with their daily activities. One participant received a device with a defective sensor, leading to missing data, as a mechanism for feedback from the company had not been established to alert the team.

4 | Discussion

Tales from the Magic Keep was acceptable and usable as a home-based exergaming intervention to two-thirds of participants. The usability meets the average SUS score of other health apps. Younger participants found the game more challenging. A higher reading comprehension level is helpful to read gameplay instructions on the screen and complete the sequence of gestures. Participants also reported the need for patience to understand and perform the required gameplay gestures. Optimizing gesture recognition is imperative for future game use to ensure participant engagement and reduce frustration. Iterative feedback from this study was used to optimize the algorithm for Tales from the Magic Keep and improve the sensitivity of gesture recognition. We also developed a troubleshooting information sheet to highlight optimal gameplay setup, including lighting, background, and sensor setup. The addition of a tripod to stabilize the height of the Azure Kinect to the participant's level, as determined in the initial calibration session, will also optimize future gesture recognition.

Studies using home-based exergaming interventions in children have measured adherence either through the time logged by the device used [13] or via self-report diaries [14]. We used both gaming logs and Kinect-based use data to track adherence and found no failure of data capture from the Kinect device, which provided more accurate use data. The duration of each gameplay session used in previous studies also supports the use of shorter 20–30 min sessions, as children can become unenthusiastic after playing too long [15].

Retention of study participants is widely variable in home-based exergame intervention studies. To optimize retention, regular visits with site personnel have been used to support initial exergame set-up and throughout the study to allow both opportunities for troubleshooting and to motivate participants to continue [16]. Most withdrawals in this study took place when the game was introduced to participants just prior to an extended holiday period. Disinterest in the game concept was a reason for some of the participants' withdrawals, as these participants only played for very short periods before discontinuing. Ensuring participants understand the study requirements and procedures, either through a demonstration video or other tool, can support informed decisions and improve retention. Virtual support and close follow-up by the study team are imperative in ensuring any challenges in home game set-up and play are quickly addressed, and this can also mitigate the risk of non-adherence to the intervention. Demonstration of the game during the screening visit could also help participants decide if this is an intervention with procedures to which they can adhere.

Using the Syde was found to be both feasible and acceptable, aligned with numerous previous studies in neuromuscular conditions which have successfully implemented the use of this device. Participant training on the use of the docking station and early data capture verification to identify equipment failure would optimize the data capture.

5 | Conclusions

Tales from the Magic Keep, once updated to improve gesture recognition, could be feasible for home-based exergaming intervention in select older children and youth with SMA who are interested in the video game concept and have moderate upper limb function allowing for gameplay engagement. Findings from this feasibility study will inform the protocol for a future randomized controlled trial.

Author Contributions

Ihsane Iraqi: writing – original draft, writing – review and editing. **Pamela Ng:** methodology, data curation, project administration, writing – review and editing. **Xing Chen:** conceptualization, methodology, software, resources, writing – review and editing. **Niamh Cushen:** conceptualization, investigation, writing – review and editing. **Juergen Gottowik:** conceptualization, methodology, software, supervision, funding acquisition, resources, writing – review and editing. **David Herzig:** conceptualization, methodology, software, formal analysis, supervision, funding acquisition, project administration, resources, writing – review and editing. **Shaainthabie Karthigesu:** investigation, writing – review and editing. **Danielle Levac:** supervision, writing – review and editing. **Alex MacKenzie:** conceptualization, writing – review and editing. **Jean K. Mah:** writing – review and editing. **Slawomir Opalka:** software, resources, writing – review and editing. **Beth Potter:** conceptualization, methodology, supervision, funding acquisition, project administration, resources, writing – review and editing. **Kathryn Selby:** investigation, resources, writing – review

and editing. **Jordan Sheriko:** conceptualization, writing – review and editing. **Maureen Smith:** methodology, writing – review and editing. **Sarah Turgeon-Desilets:** conceptualization, investigation, writing – review and editing. **Angelina Woof:** conceptualization, investigation, writing – review and editing. **Maryam Oskoui:** conceptualization, methodology, data curation, investigation, validation, formal analysis, supervision, funding acquisition, project administration, resources, writing – original draft, writing – review and editing.

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Ethics Statement

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Conflicts of Interest

I. Iraqi, P. Ng, N. Cushen, S. Karthigesu, D. Levac, JK Mah, B. Potter, A. Mackenzie, J. Sheriko, M. Smith, S. Turgeon-Desilets, and A. Woof authors declare no conflicts of interest. The institution of K. Selby has received personal compensation in the range of $500–$4999 for serving on a Scientific Advisory or Data Safety Monitoring board for Roche. The institution of Dr. Selby has received research support from Biogen, Italfarmaco, and Reverogen. The institution of M. Oskoui has received research support from Roche Genentech, Muscular Dystrophy Canada, the Canadian Institutes of Health Research (CIHR), and Santhera. D. Herzig has received personal compensation for serving as an employee of F. Hoffmann-La Roche AG. He has stock in F. Hoffmann-La Roche AG. J. Gottowik has received personal compensation for serving as an employee of F. Hoffmann–La Roche AG. X. Chen has received personal compensation for serving as an employee of F. Hoffmann–La Roche AG. S. Opalka has received personal compensation for serving as an employee of Transition Technologies PSC. He has received personal compensation for serving as an employee of Technical University of Lodz. He has received personal compensation in the range of $500 to $4999 for serving as an Academic teacher with Technical University of Lodz. He has received personal compensation in the range of $10,000 to $49,999 for serving as a PhD candidate with Technical University of Lodz.

Data Availability Statement

De-identified study data is available upon request by a qualified investigator.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Data S1:** mus70032-sup-0001-Supinfo.docx.