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Editorial

Welcome to the December 2023 edition of the APCP journal – our first wholly online edition!

In March 2023 APCP National Committee, in line with the APCP five-year plan, made the decision to move to an '**online only**' version of the journal. This decision was taken in response to feedback from membership and to reduce the environmental impact associated with a print journal. Coupled with the move to online, two other significant changes were agreed:

- (1) Firstly, submissions that are accepted for publication in the APCP journal will now have a **digital object identifier** (DOI). A DOI is a string of letters, numbers and symbols used to identify an object uniquely and persistently. Providing DOI's for manuscripts and material published in the APCP journal will allow them to be accessed and cited reliably.
- (2) Secondly, the APCP journal will be **open access**, that is, content accepted for publication will be freely available online to all, with no access fees.

We anticipate that these initiatives will collectively improve the discoverability of the excellent work submitted to the journal, improve citations of APCP journal publications, increase submissions to the journal, and raise the profile of the journal nationally and internationally. It seems fitting that we are introducing these significant changes, and hopefully increasing the reach of the APCP journal, in this 50th year of our professional network.

We continue to have an open submission process across the year; however, manuscripts will be published online as they are accepted, rather than waiting until June or December as was traditional with a print format journal. As before, all manuscripts are subjected to independent peer review. We welcome original research papers (quantitative and qualitative), literature reviews, case studies, case series, service evaluations, audits, translation studies, quality improvement reports and study protocols. If you are considering a submission, please check out the guidance on the [journal webpages](#) or contact the journal via e-mail – journal@apcp.org.uk.

This edition of the journal includes two papers focusing on posture in children and young people with neurodisabilities. George and colleagues provide a robust evaluation of the psychometric properties of an assessment tool designed to assess graded changes in total body alignment deviation, the Clinical Assessment of Body Alignment, whereas Crozier et al explore caregivers' perceptions of the barriers and facilitators to engaging in formal 24-hour postural management training for children with cerebral palsy and other neurodisabilities. These studies provide evidence of the need for robust assessment, evaluation, and consideration of caregiver capacity in postural management in this population that will be of relevance to many APCP members.

We are also delighted to include the abstracts of the papers and posters presented at the 2023 APCP annual conference and hope that you will enjoy reading about the wide range of research and service development activities that are current in paediatric physiotherapy. We would encourage the authors of the abstracts to consider developing their work into a full paper for the journal.

Finally, as is traditional at this time of year, I would like to especially acknowledge the authors, reviewers and APCP administrators for their continued support, expertise, and enthusiasm with our journal. We look forward to continued submissions and success in 2024.

Claire Kerr

Psychometric evaluation of the Clinical Assessment of Body Alignment items for children with cerebral palsy – a preliminary study.

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Abstract

Introduction: To evaluate construct validity, reliability and responsiveness of the Clinical Assessment of Body Alignment (CABA) items for children with cerebral palsy (CP).

Methods: Fifteen independent raters (physiotherapists) assessed 5 children with CP, GMFCS I – V, from photographs in supine, sitting and standing positions, using the Clinical Assessment of Body Alignment scale. Eleven therapists rescored one month later. Construct validity was evaluated based on one-way between subject ANOVA and Tukey HSD test for the raters' scores relative to GMFCS levels. Intra-class correlation coefficients (ICCs) with 95% confidence intervals (CI) evaluated Inter-rater and intra-rater reliability. Responsiveness was evaluated based on paired samples t-test evaluated scores with/without equipment. One physiotherapist who assessed 10 children with CP GMFCS IV (n=5) -V (n=5) aged 3 to 12 years (mean 5yr 4mth). Independent sample t-test compared between GMFCS IV and V.

Results: Construct validity showed significant differences in mean CABA values between GMFCS levels ($p < 0.001$). Excellent intra-rater and inter-rater reliability ($ICC > 0.90$), good responsiveness with/without equipment ($p < 0.001$), and between GMFCS levels ($p < 0.001$) was demonstrated.

Conclusion: The CABA items show strong psychometric properties for children with CP. It enables detection of postural alignment and is responsive to changes in this, thus has utility in supporting evaluation of postural equipment provision.

Introduction

Children with cerebral palsy (CP) have problems with movement and postural alignment (Carlberg & Hadders-Algra, 2005). Postural body alignment is an important component for functional movement, and the impact of this varies within the sub classification of CP (Rosenbaum et al, 2007). The Gross motor function classification system (GMFCS) grades children with CP; a child at level I is able to walk and function independently requiring little to no support for their postural alignment, whereas a child at level V is unable to maintain postural body alignment against gravity without the use of postural equipment (Palisano et al, 2008). Posture management interventions are typically utilised by therapists to correct body misalignment through use of positioning equipment to prevent deformities in alignment and support function (Rodby-Bousquet et al, 2013).

The use of observational assessment in assessing body alignment is part of everyday clinical practice (Hong, 2005). A consistent approach in total body alignment assessment is rarely reliable or reproducible between different raters, especially when used with individuals who have complex alignment such as children with CP (Fortin et al, 2011). There are limited standardised clinical assessments which enable therapists to monitor and

detect changes in whole body alignment in children with CP (George et al, 2020a). Current measures of alignment are either sub-sections of developmental motor assessments or focus specifically on one body segment rather than the whole body. The Posture and Posture ability scale (PPAS) measures postural symmetry and is supported by psychometric properties (Rodby-Bousquet et al, 2016). Scoring is limited to a simple score of yes /no postural deviation from midline. As such, the responsiveness of this assessment to detect graded demarcation in alignment change is limited. Therapists need reliable and responsive assessment methods to easily quantify graded changes in body alignment to support clinical decisions about individual management and evaluate the impact of their postural interventions (Novak et al, 2020).

The recently developed Clinical Assessment of Body Alignment (CABA) is a clinical assessment tool designed to assess graded changes in total body alignment deviation, denoting left and right sides of the body across 3 positions; lying, sitting and standing (George, 2021). The CABA is based on clinically derived postural items which were developed and revised by the clinical expert opinion of 283 paediatric physiotherapists who specialised in postural assessment (George et al, 2020b). The CABA has shown good content validity (percentage agreement >70%), with clinician's overall agreement fair to good ($k=.422$) (Husted et al, 2000). As part of the initial development stage of this tool it was important to establish that the items and scoring system of the CABA were reliable and responsive to clinical change. In test development it is important to ensure the items and scoring system selected are reliable and relate to the construct in which the assessment is intended to be applied (Burton et al, 2000). Reliability reflects not only the correlation but also agreement between measures (Beaton et al, 2001). Ideally, if an assessment was totally reliable the therapist should be able to obtain the same score each time the assessment is undertaken within the exact same conditions. In reality, assessment results vary across administrations due to errors.

Aims

The purpose of this study was to evaluate construct validity, inter-rater and intra-rater reliability and responsiveness of the CABA scoring system in children with CP. Ethical Approval was obtained from the Ethical Review Board of York St John University, UK

Methods

A clinical measurement design was used to examine the inter and intra-rater reliability, construct validity and responsiveness of the CABA.

Participants

A convenience sample was recruited via the Association of Paediatric Chartered Physiotherapists (APCP) mailing list, a special interest group within the field of paediatric physical therapy, to evaluate inter-rater and intra-rater reliability and construct validity. Participants were invited if they worked within the field of posture or postural management with children with CP. Participation was voluntary and consent was gained through participants clicking on the survey link and consent question.

To describe the participant sample, four questions relating to APCP region, years of experience, place of work and area of speciality were asked at the start of the survey. This allowed for analysis of how representative the sample was of the targeted users, paediatric physiotherapists.

A single participant was involved in the responsiveness evaluation: one physiotherapist, the primary researcher, evaluated a random stratified sample of (n=10) children with CP GMFCS Level IV (n=5) and V (n=5) who attended the same school, using the CABA assessment form. The primary researcher was the sole physiotherapist within the school; thus the children were both used to the environment and the lead researcher, therefore, the evaluation had minimal impact on the children's mood, wellbeing and clinical presentation. The primary researcher was also

familiar with the CABA assessment, having been the initial developer of the assessment. This meant that random errors related to misreading items or misinterpreting the scores were limited.

Description of children evaluated

A stratified random sample of children with CP (4-16 years in age) were recruited from a local special school. All children had a confirmed diagnosis of CP and GMFCS level by a consultant paediatrician, no surgical procedures within the previous 6 months, and no injection of botulinum toxin type A within the previous 6 months. Invitation letters and written information was given to the children's families through the schools' communication system. Agreement to participate in this study was indicated by families who returned the written consent form to the research team. Children who met the inclusion criteria and had consented to participate were then grouped into GMFCS levels. A child from each group was then randomly selected and invited consecutively until there was the desired number at each GMFCS level, for each part of the study as outlined below.

A sample of (n=5) children with CP, one at each GMFCS level, was selected for evaluating reliability and validity. A separate sample of (n=10) children with CP GMFCS Level IV (n=5) and V (n=5) was used to examine responsiveness. The responsiveness sample focused on GMFCS IV and V as children at these classifications require support to maintain body alignment against gravity across all their positions (Rosenbaum et al., 2008).

The sample sizes selected for each element of the study equated to three independent observations per child giving a total of 142 scores from each rater, sufficient enough to have the required power value when analysing the data (Bujang and Baharum, 2017). In total fifteen children were recruited for this study (n=5) for reliability and validity and (n=10) for responsiveness.

Instrument

The CABA assessment form is a clinical assessment tool developed to measure body alignment, with established content validity (George et al, 2020b). The CABA is designed to score deviations in body alignment in sitting, standing and lying. Body alignment is graded across 20 items head, trunk, pelvis, legs, arms and feet across all positions and left and right sides of the body. The CABA posture classifications uses a 0-3 scoring system to rank the alignment with 0 indicating a position within 5 degrees, either side of optimal alignment, and three indicating the most significant deviation away from optimal alignment. All CABA items are based on this scoring system with the exception of three items, which score on a 0-2 scale due to the limited joint range from optimal. The CABA has strong clinical utility properties, can be carried out online or on paper, making it highly applicable to everyday clinical practice (George, 2021).

The CABA was used in an electronic questionnaire to evaluate reliability and validity, and in paper form for responsiveness.

Data Collection: Validity and reliability

An electronic questionnaire, using Qualtrics, was devised comprising of photographs of each child and the CABA scoring items. All children were photographed in 3 different positions sitting, lying and standing positions. Each separate set of photographs for each position had 5 views; anterior, posterior, left, right and transverse. Children wore vests and shorts to enable body alignment to be observed and their faces were blanked out to protect anonymity. Photographs of each child were placed alongside the corresponding CABA scoring items in an electronic questionnaire format. Each child had a CABA assessment for each of the three positions. The GMFCS level of each child was hidden to all but the primary researcher. The use of photographs of children with CP, instead of observation in a clinical setting, minimised the amount of random error likely to occur, thus increasing the likelihood of identifying any CABA items with limited reliability.

The devised survey was sent out electronically to all APCP members via their mailing list. Participants were asked to contribute if they worked within the field of posture / postural management with children with CP. Respondents were asked to observe each child's body alignment 3 times, once in sitting, once in lying and once in standing using the CABA scoring system. This produced three independent observations of each child. Instructions on how to score were given at the start and photographs were shown with the **corresponding CABA** assessment item making it quick and easy for participants to score. The specific body alignment component being observed for each photo and a description of how this is rated was given at the top of each question.

Participation was voluntary and consent was gained through participants clicking on the survey link and consent question. Participant information was also provided on a separate link on the same email giving clarity on what was expected and the use of the data. The initial survey was open to APCP members for one month (April 2019 – May 2019).

Respondents were given the opportunity to participate in a repeat of this survey one month later by leaving their contact email address. In this case they were informed that anonymity to the researcher was not possible due to the need to retain participant contact information to send the second survey. Respondent's data for the repeated scores were matched using an individual unique reference number. The repeat survey was open to respondents for one month from June 2019 – July 2019.

Data Collection: responsiveness

In evaluating responsiveness, two frames of reference were used: immediate change in and out of posture management equipment and positional criterion (Beaton et al, 2001; Husted et al, 2000). Internal responsiveness was determined by comparing the CABA scores for each child in and out of postural equipment across three contexts: 1) Ability to detect change across all positions and body segments, 2) The level of change detected and 3) Ability to detect change at both GMFCS IV and V.

In order to evaluate responsiveness of the CABA one physiotherapist, the primary researcher, scored each child's (n=10) body alignment with and without equipment across lying, sitting and standing in a clinical setting. Data was collected using the CABA assessment form, in paper format. This was selected as it was the only format the CABA assessment was available in at the time of this study.

The children's posture was assessed both in and out of their usual equipment as part of their therapy sessions. As the primary researcher knew the children well and interacted regularly within the clinical context of the research, the children were familiar with assessment of their body alignment in everyday practice. Some children required support to maintain positions such as sitting without equipment. Adult support was therefore given if required to support safety, but not to correct or change alignment. Each child was allowed 2 minutes within each position before measurements were taken in order to allow them to adopt a typical alignment representative of how the child's posture would be both with and without their equipment.

Data Analysis

Each participant was assigned a unique reference number and the questionnaire responses were extracted from Qualtrics into the IBM Statistical Package for the Social Science (SPSS version 25) for data analysis. Only responses from therapists who returned complete questionnaires were analysed. Mean scores and standard deviation for the overall ratings of each body segment, each child and each position are reported.

Reliability was evaluated using intra-class correlation coefficients (ICC) with 95% confidence interval examining inter-rater and intra-rater reliability to determine the level of absolute agreement. Based on Bujang and Baharum

(2017) with each rater carrying out a minimum of 3 observations per child (n=5); we had a power value of greater than 0.80 to detect reliability and ICC greater than 0.90, for significance at a p value of 0.05. For interpretation of the results, we adopted the following assessment of the strength of the reliability. ICC values less than 0.5 were indicative of poor reliability, values between 0.5 and 0.75 indicated moderate reliability, values between 0.75 and 0.9 good reliability, and values greater than 0.90 indicated excellent reliability (Koo et al, 2016).

Specifically, inter-rater reliability was examined using ICC estimates and their 95% confidence intervals (CI), based on a mean rating (k=15), absolute-agreement using a 2-way random-effects model. Intra-rater reliability was examined using ICC estimates; 95% CI were calculated using SPSS based on a mean rating (k=11) at two time points, absolute-agreement, using a 2-way mixed-effects model.

Test-retest reliability was examined using ICC and 95% CI to determine the level of absolute agreement between a rater's score on the first and second test of the same children. Overall rater agreement across GMFCS levels, positions and body segments was examined.

Construct validity was evaluated using a one-way between subjects ANOVA to compare raters' scores across position and GMFCS level to determine if scores differed by level of CP severity. Post hoc comparisons using the Tukey HSD test were used to examine differences between pairs of children to determine if the CABA could differentiate between each GMFCS level.

Responsiveness was evaluated using summed scores for all measurements with and without equipment across positional criterion, body segment and GMFCS level. The measurement taken without equipment was considered as the baseline measurement. Paired sample t-tests examined differences in scores across positions and body segments. Independent sample t-tests were used to compare differences in scores between GMFCS IV and V. As this examination involved comparison of four variables the α level was adjusted using a Bonferroni correction, to 0.012, to account for the possibility of type 1 errors. Values were deemed significant at $p < 0.01$ (Field, 2013).

Results

Fifteen independent raters (physiotherapists) assessed 5 children with CP (GMFCS I – V) from photographs in supine, sitting and standing positions, using the clinical Assessment of Body Alignment. Eleven therapists re-scored the same photographs one month later.

Inter-rater reliability

Overall inter-rater reliability was excellent across all positions of sitting, lying and standing (ICC [2,15] 0.93, 95% CI 0.918-0.941) and for all body segments (ICC [2,15] 0.93, (95% CI 0.918-0.941). The values given across individual positions and body segments showed excellent reliability for sitting, lying, head, trunk and pelvis. The ratings for standing, arm, leg and foot had reported lower range 95% confidence intervals from 0.847-0.933 (Foot) to 0.898-0.943 (Leg), demonstrating good to excellent agreement between raters (table 1).

Table 1: Inter-rater and intra-rater Reliability of the CABA Total score (N=355 ratings per rater) for different positions and body segments of children with CP.

	Inter-rater (K=15)		Intra-rater (K=11)	
	ICC(2,15)	95% CI	ICC(2,15)	95% CI
Dimension				
Position				

Standing	0.900	(0.868, 0.926)	0.902	(0.888, 0.914)
Sitting	0.931	(0.912, 0.942)	0.895	(0.864, 0.917)
Lying	0.953	(0.939, 0.966)	0.930	(0.920, 0.939)
Total	0.930	(0.918, 0.941)	0.910	(0.895, 0.921)
Body segment				
Head	0.947	(0.917, 0.968)	0.94	(0.929, 0.95)
Trunk	0.944	(0.917, 0.966)	0.924	(0.908, 0.937)
Pelvis	0.951	(0.926, 0.97)	0.936	(0.919, 0.949)
Arm	0.896	(0.847, 0.933)	0.891	(0.871, 0.908)
Leg	0.923	(0.898, 0.943)	0.876	(0.836, 0.904)
Foot	0.895	(0.847, 0.933)	0.903	(0.883, 0.919)
Total	0.930	(0.918, 0.941)	0.910	(0.895, 0.921)

The inter-rater and intra-rater ICC's when examining children classified by GMFCS levels were >0.910 (table 2). All of the ICC values for inter-rater reliability were excellent for GMFCS levels III to V, and good for Level II. The child at GMFCS I had an ICC (2,15) of 0.731, 95% CI 0.629-0.833 indicating moderate agreement.

Table 2: Inter-rater and intra-rater Reliability of the CABA across GMFCS level

GMFCS Level	Inter-rater (K=15)		Intra-rater (K=11)	
	ICC(2,15)	95% CI	ICC(2,11)	95% CI
I	0.731	(0.629, 0.833)	0.784	(0.712, 0.833)
II	0.865	(0.825, 0.905)	0.86	(0.785, 0.913)
III	0.903	(0.856, 0.95)	0.825	(0.797, 0.849)
IV	0.907	(0.872, 0.942)	0.885	(0.865, 0.902)
V	0.932	(0.905, 0.959)	0.909	(0.885, 0.931)
Total	0.930	(0.918, 0.941)	0.910	(0.895, 0.921)

Intra-rater

Overall intra-rater reliability was good to excellent across all positions of sitting, lying and standing and for all body segments (ICC [2,11] 0.910, 95% CI 0.895-0.921). The ratings for positions sitting, standing and body segments arm, leg and foot had reported lower range 95% confidence intervals from 0.836-0.904 (leg) to 0.888-0.914 (standing), demonstrating good to excellent agreement between raters (table 1). The ICC's and 95% CI values given across lying, head, trunk and pelvis were >0.908, indicating excellent intra-rater reliability.

Examining inter-rater reliability for children classified by GMFCS levels, the ICC values for were good to excellent for GMFCS levels II to V and moderate for Level I. On consideration of the 95% CI scores children at GMFCS IV and V demonstrated good to excellent reliability, whereas GMFCS level I to III demonstrated moderate to good reliability for (Table 2).

Test-retest reliability

In addition, ICC and 95% CI were used to determine the level of absolute agreement between a raters' score (k=11) on the first and second test of the same children, one month apart. Overall rater agreement across GMFCS levels, positions and body segments were excellent (ICC (2,11) 0.910 95% CI 0.895-0.921). Individual rater (K=11) ICCs across all measurements ranged from 0.858 to 0.933, with 6 of the 11 raters (55%) having an ICC > 0.9. This indicates that all raters had a high level of agreement in test and retest situation using the CABA.

Construct Validity

A one-way between subjects' ANOVA compared raters scores at each position and GMFCS level. There was a significant effect across the different GMFCS levels [F(4, 350) = 137.4, p < 0.001]. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for each of the severity levels was significantly different to other severity levels with the exception of Levels II and III (p=0.770) and Levels I and II (p=0.663, where no significant difference was detected (Table 3).

We repeated the construct validity using the test-retest data set (K=11).. Values showed no change in significant effect at different GMFCS severity levels [F(4, 3900) = 799, p < 0.001], indicating that having experience of scoring with the CABA made no difference on construct validity.

Table 3: Construct validity pairwise comparisons between each GMFCS level based on raters scores at test 1 (k=15).

GMFCS Level	Paired comparisons between GMFCS Levels	Significance level	mean difference
I	II	0.663	-0.094
	III	0.023	-0.174*
	IV	0.000	-.872*
	V	0.000	-1.300*
II	III	0.770	-0.080
	IV	0.000	-.778*
	V	0.000	-1.205*
III	IV	0.000	-.697*
	V	0.000	-1.125*
IV	V	0.000	-.427*

* The mean difference is significant at the 0.05 level.

Responsiveness

Paired t-tests examined difference in scores with and without equipment across positions and body segments. Overall, the CABA's responsiveness to detect change in body alignment was statistically significant across all its postural body segments categorizations (t(9)=24.5, p<0.001 Table 4). Independent sample t-tests compared scores with and without equipment between GMFCS IV and V. The CABA demonstrated responsiveness to change in body alignment when equipment was used at GMFCS level IV (t(4)=20, p<0.001) and V (t(4)=44, p<0.001), indicating that the CABA was able to detect change accurately at both GMFCS IV and V.

Table 4: Internal responsiveness for paired and independent t tests of the CABA for positions, body segments and GMFCS level.

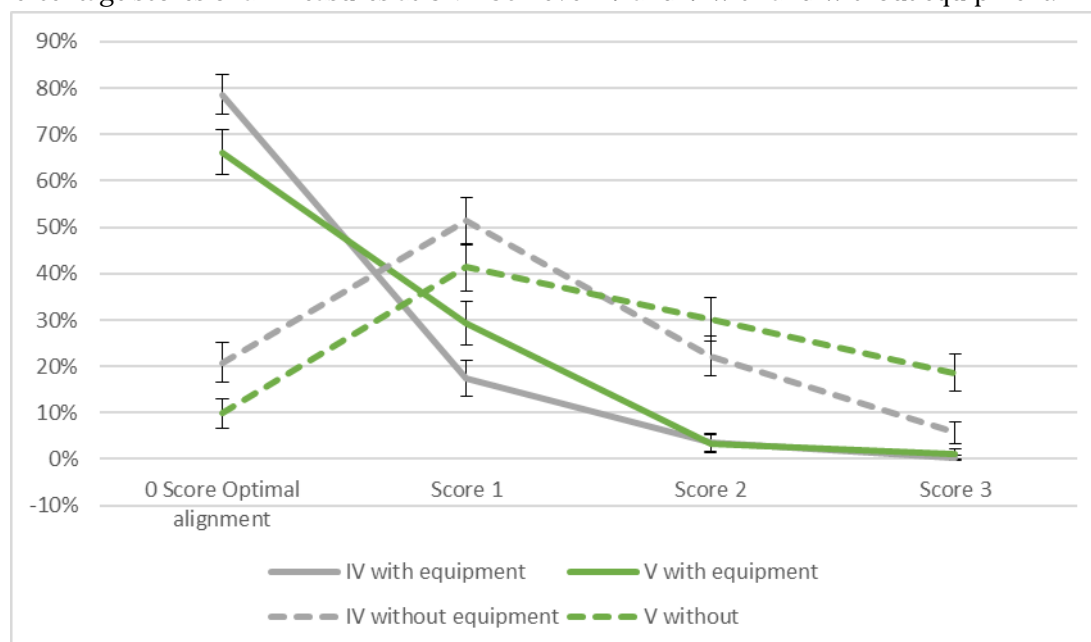
Dimension	Paired t -tests	Independent t-Tests	
		GMFCS Level IV	GMFCS Level V

<i>Position</i>			
Lying	p<0.001	(p<0.001)*	(p<0.001)*
Standing	p<0.001	(p<0.001)*	(p<0.001)*
Sitting	p<0.001	(p<0.001)*	(p<0.001)*
<i>Body segment</i>			
Head	p<0.003	(p=0.114)	(p<0.001)*
Trunk	p<0.001	(p<0.001)*	(p<0.001)*
Pelvic	p<0.001	(p=0.002)*	(p<0.001)*
Arm	p<0.001	(p=0.001)*	(p=0.04)
Leg	p<0.001	(p<0.001)*	(p<0.001)*
Foot	p<0.001	(p<0.001)*	(p=0.002)*
<i>All measures</i>			
Total:	p<0.001	(p<0.001)*	(p<0.001)*

*= Denotes significant result

The mean scores of measurements of all children at each GMFCS level IV (n=5) and V (n=5) increased in line with the CABA scoring criteria towards more optimal alignment with equipment compared to without, across all positions and body segments (figure 1). This indicates that at GMFCS IV and V the CABA is responsive to immediate change in body alignment with equipment across posture categorisations and scoring criteria as set out in the CABA.

Figure 1: Percentage scores of all measures at GMFCS Level IV and V with and without equipment.



Discussion and Implications

The CABA shows excellent intra-rater and inter-rater reliability across all dimensions, demonstrating statistically significant construct validity to differentiate between GMFCS levels. The CABA is responsive to immediate change in body alignment when posture management equipment is used and demonstrates statistically significant ability to differentiate between changes in children with CP GMFCS IV and V.

Reliability

Our results showed excellent overall inter-rater and intra-rater reliability for the CABA for children with CP across all GMFCS levels, with the exception of GMFCS Level I, where moderate reliability was detected (table 2). The reason for this is unclear; there may be different explanations for this including the presentation and order of the ratings with the child at GMFCS Level I always being the first rated and as such, the benchmark case. This discrepancy could also be attributed to the child making an active postural adjustment prior to the photograph being taken. Children at GMFCS level I have good postural alignment and function in walking and postural adjustments (Rosenbaum et al, 2007). Although children were positioned in optimal alignment, it is possible small active postural movement may have occurred prior to the photo being taken. Also, it is possible that some raters expected to see misalignment, although overall rater variability was low. Therefore, reliability of the CABA in children at GMFCS level I may be slightly lower and is an important consideration when using the CABA in clinical practice.

In terms of inter-rater and intra-rater total reliability for the dimensions of position and body segments, the CABA demonstrated excellent reliability (ICC >0.910). Individual ICC's for both inter-rater and intra-rater were good to excellent for each of the specific positions and body segments, indicating that the CABA has substantial reliability across all its dimensions. A recent literature review found only two assessments which demonstrated good to excellent validity and reliability (George et al, 2020a). These were the Posture and Posture Ability Scale (PPAS) (Rodby-Bousquet et al., 2016; Rodby-Bousquet et al., 2014) and the Spinal Alignment and Range of Motion Measure (SAROMM) (Bartlett and Puride, 2005). This suggests that there has been limited research exploring this topic. Whilst aspects of psychometrics of these assessments have been investigated to some extent, neither of these assessments have reported measurement error, content validity, responsiveness or sensitivity (George et al, 2020a).

For assessments to be meaningful, relevant and effective they need to be standardised and demonstrate good performance in psychometric characteristics of validity, reliability and responsiveness (Finch et al., 2003; Terwee et al., 2003). The CABA's ability to quantify observational assessment of body posture enables changes to be determined accurately and quickly as an integral part of a child's day-to-day function, instead of in a one-off specific position, setting or task. The CABA thus provides a consistent method for physiotherapists to identify, describe and evaluate body alignment of a child at a particular point in time.

In terms of variability between the raters, overall scores were shown to be excellent ICC's (2,11) >0.90, indicating that all raters had a high level of agreement in inter-rater and intra-rater situations and the CABA is fit for purpose. Interestingly, all raters had high levels of intra-rater reliability, indicating that raters' clinical experience, their place of work and specialty had little impact on their ability to reliably use the CABA. A possible explanation for this is the extensive content validity process undertaken in the CABA's development, with contribution from over 280 paediatric physiotherapists (George et al, 2000b). The CABA was developed to be a clinically usable tool which can be easily applied to clinical practice, with low user demand.

Construct validity

Early identification and monitoring of body alignment asymmetry are important aspects of managing a child's posture and function (Gericke, 2006). The ability to determine changes in body alignment early can prevent the development of musculoskeletal complications (Hagglund et al, 2014; Porter et al, 2008; Scrutton, 2008) and assist in the effectiveness of posture management interventions (Hagglund et al, 2014; Pountney et al, 2009; Farley et al, 2003). The CABA is able to reliably detect changes in body alignment from optimal, providing a clinical assessment which is consistent in monitoring a child's postural alignment by either the same or multiple therapists.

Construct validity for the CABA scoring was evaluated through its ability to differ between known GMFCS levels in children with CP. Overall the CABA demonstrated statistically significant ability to differentiate between all GMFCS levels ($p < 0.001$) with the exception of GMFCS levels I and II, and levels II and III. The primary differences between children classified at GMFCS levels I, II and III pertain mainly to mobility (Palisano et al, 2008) with little differences described in terms of body alignment support (Rosenbaum et al, 2007). Whilst other postural assessments have only examined psychometric properties from GMFCS Level II (Rodby-Bousquet et al, 2013), the CABA examined body alignment across all GMFCS levels.

Responsiveness

The CABA demonstrated statistically significant differences in detecting changes in body alignment using the posture categorisations across all positions of lying, standing and sitting, and across all body segments ($p < 0.001$). These results may be explained by the fact that postural equipment aims to provide a stable and energy efficient position from which a child can function (Gericke, 2006). The principles of this relate to maintaining an individual's centre of gravity within their base of support (BoS): support is provided to central body segments such as the head, trunk, pelvis and legs which form the BoS and improve stability and function (Dusing & Harbourne, 2010; Harris & Roxborough, 2005). Activity and participation are an integrated aspect of posture management, a collective aim is to prevent body alignment deformity whilst promoting functional skills (Gericke, 2006). Without support from postural equipment alignment can be significantly deviated from optimal, therefore a greater change in body alignment would be expected between alignment with and without equipment. These results further support the association between gravity and postural deviation and deformity in children with CP (Novak et al, 2020; Dewar et al, 2015).

In terms of responsiveness to change at GMFCS level for the dimension of body segments, individual GMFCS IV and V were statistically significant for each body segment with the exception of head GMFCS IV ($p=0.114$) and arm GMFCS V ($p=0.04$). These discrepancies could be attributed to specific body segments and CP classification. The head result could be attributed to the fact that children classified as GMFCS IV typically can maintain independent head alignment (Palisano et al, 2008); consequently, change in CABA scores is lower for this classification group with equipment compared to without. In regard to arm alignment, the reason for this is unclear, but may relate to children at GMFCS IV having more active movement compared to GMFCS V (Palisano et al, 2008). Children at GMFCS IV may be more likely to be able to adjust arm position as a result of improved stability and improved body alignment (Carlberg & Hadders-Algra, 2005); consequently, change in CABA scores is higher for this classification group with equipment compared to without. However no comparable statistical significance was found between GMFCS IV and V at any individual body segment. Whilst these results suggest that the CABA is responsive to changes in alignment at GMFCS IV and V across all its dimensions, the adjusted p level may have resulted in type 2 errors. Therefore, these results need to be interpreted with caution.

Study Limitations

Whilst it is recognised that the CABA is designed to be used as a clinical observation tool the use of photographs may mean that the overall reliability may be lower in a clinical scoring session than reported in the current study. Clinical postural evaluation is a difficult task; the use of photographs in assessment of posture has been used in several studies (Fortin et al, 2011), with a consensus that measurement photographs may be the most comprehensive and rapid way to assess posture. The use of photographs can minimise measurement error and demonstrates merit for clinical based assessment (Do Rosario, 2014; Dunk et al, 2005).

The selection of photographs enabled raters to participate and score 5 children, each across 3 positions, twice. This meant that each rater made a total of 6 observations per child, across all positions at each GMFCS level. Had this study been conducted in a clinical setting it is highly unlikely that this number of raters and observations across the diversity of children would have been possible. It is recognised that in everyday clinical assessment sessions,

scoring is likely to involve a smaller number of children across one or two positions. In this stage of the assessment's development, it was important to establish the reliability of CABA's scoring ability whilst minimising errors in measurement. Further studies examining the CABA's use in clinical settings would further our understanding of the relevance and use of the tool to guide health provision.

As part of the development of this new assessment we acknowledge that the relatively small sample of children with CP may have limited the generalizability of the findings. However, in the conduct of preliminary reliability studies, only a small sample size is required especially when a very high value of ICC is set for result significance (George et al, 2020b). Future studies examining reliability of the CABA against a larger sample of children with CP, and in children with other medical diagnoses and/or neurological disabilities, would further support the generalizability of the results of this study. Evaluation of the tool's use is on-going to assist with refinement of its clinical usability.

Conclusion

The findings from this preliminary study demonstrates that the CABA scoring system has excellent inter-rater and inter-rater reliability across all dimensions of body segments and positions, lying, sitting, and standing. Whilst it demonstrates overall statistically significant construct validity to differ between all GFMCS levels, there are some limitations between lower levels. The CABA has demonstrated responsiveness to immediate change in body alignment when posture management equipment is used and offers clinicians and researchers a rigorously developed clinical tool which has built a platform for further clinical based examination.

Further studies examining the CABA's psychometric properties and role as a standardised outcome measure for alignment in clinical settings is already being undertaken. Further research examining the CABA's usability across a range of conditions, adults, and children, would examine the CABA's role in posture management practices across wider clinical presentations.

Key points:

- The Clinical Assessment of Body Alignment items show high psychometric properties for children with CP.
- In a relatively small sample this study shows the CABA to be a standardised clinical assessment demonstrating excellent validity and reliability.
- Further studies to assess the CABA's responsiveness in response to postural therapeutic interventions are required.

Ethics: Ethical Approval was obtained from the Ethical Review Board of York St John University, UK.

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References

Beaton, D. E., Bombardier, C., Katz, J. N., & Wright, J. G. (2001). A taxonomy for responsiveness. *Journal of clinical epidemiology*, 54(12), 1204-1217.

Bruton, A., Conway, J. H., & Holgate, S. T. (2000). Reliability: what is it, and how is it measured? *Physiotherapy*, 86(2), 94-99.

-
- Bujang, M. A., & Baharum, N. (2017). A simplified guide to determination of sample size requirements for estimating the value of intraclass correlation coefficient: a review. *Archives of Orofacial Science*, 12(1).
- Carlberg, E. B., & Hadders-Algra, M. (2005). Postural dysfunction in children with cerebral palsy: some implications for therapeutic guidance. *Neural plasticity*, 12(2-3), 221-228.
- Dewar, R., Love, S., & Johnston, L. M. (2015). Exercise interventions improve postural control in children with cerebral palsy: a systematic review. *Developmental Medicine & Child Neurology*, 57(6), 504-520.
- do Rosário, J. L. P. (2014). Biomechanical assessment of human posture: a literature review. *Journal of bodywork and movement therapies*, 18(3), 368-373.
- Dunk, N. M., Lalonde, J., & Callaghan, J. P. (2005). Implications for the use of postural analysis as a clinical diagnostic tool: reliability of quantifying upright standing spinal postures from photographic images. *Journal of manipulative and physiological therapeutics*, 28(6), 386-392.
- Dusing, S. C., & Harbourne, R. T. (2010). Variability in postural control during infancy: implications for development, assessment, and intervention. *Physical therapy*, 90(12), 1838-1849.
- Farley, R., Clark, J., Davidson, C., Evans, G., MacLennan, K., Michael, S., Morrow, M. & Thorpe, S., 2003. What is the evidence for the effectiveness of postural management? *British Journal of Therapy and Rehabilitation*, 10(10), 449-455.
- Field, A. (2013). *Discovering statistics using IBM SPSS statistics*. sage.
- Finch, E., Brooks, D., Stratford, P.W. and Mayo, N.E., 2003. Physical rehabilitation outcome measures: a guide to enhanced clinical decision making. *Physiotherapy Canada*, 55(1), pp.53-54.
- Fortin, C., Ehrmann Feldman, D., Cheriet, F., & Labelle, H. (2011). Clinical methods for quantifying body segment posture: a literature review. *Disability and rehabilitation*, 33(5), 367-383.
- Fulford, G. E., & Brown, J. K. (1976). Position as a cause of deformity in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 18(3), 305-314.
- Gericke, T. (2006). Postural management for children with cerebral palsy: consensus statement. *Developmental Medicine and Child Neurology*, 48(4), 244-244.
- George, F. K. (2021) Identification and assessment of body alignment in children with cerebral palsy. PhD thesis, University of Leeds.
- George, F. K., Benham, A., & Gabriel, L. (2020a). Clinical Assessments designed to measure body alignment posture in children with cerebral palsy – a systematised review. *Association of paediatric Physiotherapy Journal*, 11(1), 4-16.
- George, F. K., Benham, A., Gabriel, L., & Purton, J. (2020b) Development and Content Validity of the Clinical Assessment of Body Alignment for Children With Cerebral Palsy. *Pediatric Physical Therapy*, 1;32(2), 137-43.
- Goldsmith, J., & Goldsmith, L. (2009). Goldsmith indices of body symmetry: Protecting body shape. *European Seating Symposium*, 122-124.

-
- Hägglund, G., Alriksson-Schmidt, A., Lauge-Pedersen, H., Rodby-Bousquet, E., Wagner, P., & Westbom, L. (2014). Prevention of dislocation of the hip in children with cerebral palsy: 20-year results of a population-based prevention programme. *The bone & joint journal*, 96(11), 1546-1552.
- Harris, S. R., & Roxborough, L. (2005). Efficacy and effectiveness of physical therapy in enhancing postural control in children with cerebral palsy. *Neural plasticity*, 12(2-3), 229-243.
- Hong, C. S. (2005). Assessment for and provision of positioning equipment for children with motor impairments. *International Journal of Therapy and Rehabilitation*, 12(3), 126-131.
- Husted, J. A., Cook, R. J., Farewell, V. T., & Gladman, D. D. (2000). Methods for assessing responsiveness: a critical review and recommendations. *Journal of clinical epidemiology*, 53(5), 459-468.
- Koo, T. K., & Li, M. Y. (2016). A guideline of selecting and reporting intraclass correlation coefficients for reliability research. *Journal of chiropractic medicine*, 15(2), 155-163.
- Novak, I., Morgan, C., Fahey, M., Finch-Edmondson, M., Galea, C., Hines, A., & Badawi, N. (2020). State of the evidence traffic lights 2019: systematic review of interventions for preventing and treating children with cerebral palsy. *Current neurology and neuroscience reports*, 20(2), 1-21.
- Palisano, R. J., Rosenbaum, P., Bartlett, D., & Livingston, M. H. (2008). Content validity of the expanded and revised Gross Motor Function Classification System. *Developmental Medicine & Child Neurology*, 50(10), 744-750.
- Porter, D., Michael, S., & Kirkwood, C. (2008). Is there a relationship between preferred posture and positioning in early life and the direction of subsequent asymmetrical postural deformity in non-ambulant people with cerebral palsy. *Child: care, health, and development*, 34(5), 635-641.
- Pountney, T. E., Mandy, A., Green, E., & Gard, P. R. (2009). Hip subluxation and dislocation in cerebral palsy—a prospective study on the effectiveness of postural management programmes. *Physiotherapy Research International*, 14(2), 116-127.
- Pountney, T. E., Cheek, L., Green, E., Mulcahy, C., & Nelham, R. (1999). Content and criterion validation of the Chailey levels of ability. *Physiotherapy*, 85(8), 410-416.
- Rodby-Bousquet, E., Persson-Bunke, M., & Czuba, T. (2016). Psychometric evaluation of the Posture and Postural Ability Scale for children with cerebral palsy. *Clinical rehabilitation*, 30(7), 697-704.
- Rodby-Bousquet, E., Czuba, T., Hägglund, G., & Westbom, L. (2013). Postural asymmetries in young adults with cerebral palsy. *Developmental Medicine & Child Neurology*, 55(11), 1009-1015.
- Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D. & Jacobsson, B. (2007). A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl*, 109(suppl 109), 8-14.
- Scrutton, D. (2008). Position as a cause of deformity in children with cerebral palsy (1976). *Developmental Medicine & Child Neurology*, 50(6), 404-404.

Terwee, C.B., Dekker, F.W., Wiersinga, W.M., Prummel, M.F. and Bossuyt, P.M.M., 2003. On assessing responsiveness of health-related quality of life instruments: guidelines for instrument evaluation. *Quality of life research*, 12(4), pp.349-362

Exploring the Barriers and Facilitators to Caregiver Engagement in Postural Management Training for Children with Complex Neurodisabilities: a qualitative study

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Abstract

Twenty-four-hour postural management (PM) is widely recognised as being important for children with cerebral palsy (CP) and other complex neurodisabilities. Training for caregivers involved in delivering PM is essential. However, engagement with PM training by caregivers is variable. Little research has been conducted to date to establish how to engage caregivers in PM training.

Objectives:

To explore caregivers' perceptions of the barriers and facilitators to engaging in formal 24-hour PM training for children with CP and other complex neurodisabilities.

Design:

Exploratory, qualitative study.

Setting:

Child Development Teams in one Scottish Health Board.

Participants:

Sixteen caregivers of children with CP or other complex neurodisabilities.

Methods:

Semi-structured online interviews, with the option of an online survey to enhance inclusivity. Data were processed and analysed in NVivo 12 and Microsoft Excel, using the Framework method. Interviews aimed to understand participants' perceptions of the barriers and facilitators to engaging in formal 24-hour PM training for children.

Results:

Three key themes were identified:

- (i) Defining postural management: Postural management involves a range of activities, equipment, and stakeholders, and can lead to significant daily challenges.
- (ii) Those promoting the use of postural management need to.

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- Provide knowledge & understanding of all aspects of postural management to facilitate improved care= Giver participation at an early age & stage.
 - Be mindful of potential psychological impacts in caring for a child with a complex neurodisability.
- (iii) Delivering postural management training: Those delivering postural management training needs to use a flexible range of promotional strategies and invitations and provide relevant and motivational information in a variety of formats to encourage stakeholder participation.

Conclusions

This study provides insight into barriers and facilitators to attending PM training and will inform the development and ongoing enhancement of training provision. Barriers included lack of time, caregiver readiness, and lack of clarity on the target audience. The content and mode of delivery, including shared experiences from caregivers of children with complex neurodisability, were viewed as facilitators to engaging in PM training. Consideration of these issues is important when developing and delivering training to this important client group.

Keywords: Posture, Neurological Rehabilitation, CP (Cerebral Palsy), Caregivers, Qualitative research

Introduction

Children with disabilities caused by a motor dysfunction, such as cerebral palsy (CP), are a highly vulnerable group. Prevention of pain and deformity are key treatment priorities for the most severely affected children with CP and other complex neurodisabilities (NICE, 2016). Twenty-four-hour Postural Management (PM) is widely recognised by therapists as a non-invasive, conservative approach adopted to address these priorities (Humphreys et al, 2012). Postural management programmes should be tailored to meet each child's individual needs, and may include specialised equipment, functional activities, active exercise, orthotics, surgical interventions, and individual therapy sessions to increase comfort and reduce deformity (Gericke, 2006). Positioning techniques can be used to enhance functional ability and should be implemented as early as possible to promote development (Wandel, 2000; Goldsmith, 2000).

Stinson et al (2021) highlighted the need to address training and support for families and care companies to successfully implement individualised programmes that incorporate day and night-time positioning. Similarly, in the UK the National Institute for Health and Care Excellence (NICE), 2016) advise that therapists offer relevant and developmentally appropriate information and training to parents and carers.

Training can be a crucial part of raising awareness of the benefits of PM and the consequences of not following this approach. Hotham et al (2017) suggested that a brief postural care training programme could improve knowledge, understanding and confidence. However, it is not known whether training results in adherence with PM or long-term changes in the application of principles (Bacon 2013). Moreover, anecdotal evidence suggests that engagement in training by caregivers may be limited. Little research has been carried out to establish how best to engage caregivers in PM training. Understanding caregivers' experiences of PM training, and their perceptions of the barriers and facilitators to engaging with such training, will help healthcare professionals to tailor training to meet caregivers' needs. Furthermore, by involving caregivers of children with complex postural difficulties, both in identifying the issues addressed and informing the methods adopted, this study aimed to produce findings that can be practically applied to impact those involved in the care of children with significant postural needs.

Research Question and Objectives

The research question articulated for this study was: What do caregivers consider to be the barriers and facilitators to engaging in formal PM training and what strategies can be proposed to enhance caregivers' engagement with formal PM training?

The objectives of this study were to:

1. Gain an in-depth understanding of caregivers' perceptions of the barriers and facilitators to engaging in formal PM training for children with CP and other complex neurodisabilities.
2. Propose strategies for enhancing caregivers' engagement with PM training that can be implemented by those involved in developing and delivering such training.

Methods

The study was ethically approved by the West of Scotland Research Ethics Service (Ref No 20/WS/0120) with management permission granted by NHS Grampian R&D department (Ref No 20/NS/0100).

Study design

This is a qualitative study underpinned by critical realism (CR), which uses components of positivism and constructivism, making it a comprehensive philosophy of science and useful for analysing problems and suggesting solutions for change (Fletcher, 2017). There are few precise guidelines for methods of data collection and analysis from a CR perspective; this study drew from previous applied qualitative research using CR to inform methods of recruitment, data collection, processing and analysis (Fletcher 2017; Ryan 2016). The design allowed in-depth understanding of the perceptions and experiences of parents of children with CP and other complex neurodisabilities, who had or had not attended PM training. The project steering group included four caregivers who carry out 24-hour PM with their child. The range of personal experiences these caregivers brought to meetings helped to inform the recruitment strategy, interview topic guide and best means of disseminating the study findings.

Study setting and participants

The study took place in one Scottish Health Board. The population was caregivers (i.e., parents or carers) and other family members of children with CP or other complex neurodisabilities. Eligibility criteria included: any age or sex; caring for a child(ren) with a complex neurodisability; previously invited to attend PM training. Caregivers were identified by a Child Development Team (CDT) secretary, from those who had previously received an invitation to attend a training event, thus ensuring no researcher bias in the selection process. A letter of invitation and information sheet was sent to 35 caregivers, including those who attended or did not attend the training they were invited to take part in. This process was repeated after two weeks. Invitation letters and information sheets were sent to a further 14 caregivers two months after the initial recruitment date due to the low response rate. In addition, posters promoting the study were shared on Facebook pages of local Additional Support Needs schools, the local CP Association and other local community support groups. Participants returned a reply slip to the research assistant (RA), who responded either by telephone or email, to explain the study in more detail and, where appropriate, to arrange a mutually convenient time to conduct the interview. The RA was a paediatric physiotherapist who had no prior association with the caregivers or their children.

Data collection

1-1 interviews: Fifteen participants provided online, recorded verbal informed consent immediately prior to taking part in semi-structured 1-to-1 interviews conducted by the RA via Microsoft Teams. The RA read through the consent form, word for word, with each participant, documented their responses and signed and dated their

agreements. A copy of the signed form was subsequently sent to participants, and the recording stored separately from the interview recording. An interview topic guide (available on request) was developed by the study steering group which consisted of the research team and four caregivers of children with complex neurodisability. It was informed by the objectives of the study, previous research in the field, and the knowledge and experience of the steering group. It was piloted with two caregivers and two paediatric physiotherapists independent to the study team, with minor amendments being made prior to implementation in the study. Table 1 identifies the areas explored in the interviews. Interviews were conducted by the RA and in keeping with ethical requirements, were recorded using a hand-held audio-recorder, with field notes written by the RA immediately afterwards (Holloway and Wheeler, 2002). Participants were each given a unique identification number before transcription of the interviews, during which any person-identifiable data was anonymised. Although transcription by the researcher can facilitate early immersion in the data, outsourcing transcription was time-efficient; immersion therefore began with the research team reading and re-reading transcripts.

Online survey: To enhance accessibility to the study, an online survey was also developed, providing an alternative method of gathering participants' views and perceptions of the areas covered by the interview. The survey was piloted for face validity by the steering group and was hosted on Jisc Online Surveys, a GDPR-compliant platform, and is available on request. Whilst a survey elicits more brief and superficial responses than interviews, (De Jonckheere and Vaughn, 2019) it enabled participants who did not wish to be interviewed to take part in the study. One further participant, who did not have the time due to work and caring commitments to take part in an online interview, completed the online survey; their responses were analysed alongside the interview data.

Table 1: Topics explored in interviews.

Main topic	Areas explored
Postural management	Understanding and lived experience Perceptions of own and others' roles
Postural management training	Perceptions and experiences of: <ul style="list-style-type: none"> • Invitation process • Information provision • Attendance (or non-attendance) • Barriers to engaging • Facilitators to engaging • Suggestions for enhancing training provision
Other	Anything else related to postural management training that participant wanted to discuss

Data analysis

Data processing and analysis was supported by NVivo 12 Qualitative data analysis software (QSR International) and conducted by four members of the study team (KCr, KCo, SB, RMCD). The Framework method was used (Ritchie and Spencer, 1994), which involved familiarisation, coding, developing the analytical framework, applying the analytical framework to the data, charting data using framework matrices, and interpretation of the data (Gale et al, 2013). Framework analysis is commonly used in health research and is particularly suited to teams of researchers analysing semi-structured interviews (Gale et al, 2013). It is also a good fit with the CR approach as coding is deductive yet flexible (Fletcher, 2017) and allows for abduction (or theoretical description) and retroduction (identifying causal mechanisms and conditions); important aspects of a CR approach and relevant for this study where we wanted to understand what the barriers and facilitators were in order to suggest changes. In this study we operationalised Framework analysis in the following way. Two researchers (KCr, KCo) familiarised themselves with three transcripts, making analytic notes onto the transcripts. Discussion of these

analytical notes led to a coding index being constructed. The coding index was then applied by the researchers independently to three transcripts, with further discussion and refinement of the coding index into a working analytical framework (Gale et al, 2013). Thereafter, the lead researcher (KCr) applied the analytical framework to all transcripts using NVivo 12 software, with regular review by and discussion with the second researcher (KCo). The data was then charted, using Microsoft Excel, which involved summarising the data under broad initial themes. Analysis of the charted data then involved interpreting the data within and between participants to identify categories, which were grouped into classes by similarity of meaning, and finally into key themes. This was an iterative process, involving both researchers and regular discussion.

Results

Sixteen participants took part, including fifteen parents and one respite carer (Table 2). Fourteen participants were recruited via invitations sent by the CDT secretary, with two recruited via public facing materials. Interviews ranged from 21 to 75 minutes (average 46 minutes).

Table 2: Participant demographics (n=16 caregivers)

Personal experience of PM training	Yes 9	No 7
Sex of participant	Male 3	Female 13
Age of participant	≤ 24	0
	25-44	10
	45-64	6
	>65	0
Education level of participant	Currently in ed/ completed high school or college	6
	University	10
SIMD Quintile -(Quintile 1 contain the most deprived data zones in Scotland)	3	3
	4	10
	5	3
Diagnosis of child*	Cerebral Palsy	9
	Other (includes SMA, Foetal alcohol syndrome, Gene mutation/arthrogryposis, Pompe’s Disease, Spina Bifida, Undiagnosed learning disability/ epilepsy)	9
Age of child at time of interview*	≤ 12	10
	13-18	8
Age of child at time of diagnosis*	Under 2	8
	Over 2	5
	Not stated or unknown	5

Key: PMT = Postural Management Training; SIMD=Scottish Index of Multiple Deprivation; SMA=Spinal Muscular Atrophy

*Total 18 as 2 participants had 2 children with complex neurodisabilities

Framework analysis resulted in three key themes, derived from 94 categories and 12 classes of data, following several rounds of independent analysis and team discussion: (i) Defining postural management; (ii) Promoting postural management; (iii) Delivering postural management training. Table 3 provides descriptions of each theme and details the classes of data which contributed to each of the themes. The first theme (defining postural management) did not directly address the research objectives and is therefore not discussed in detail in this paper but is summarised to provide contextual information.

Table 3: Themes and classes of data

Theme	Description of theme	Classes contributing to theme
1. Defining postural management	PM involves a range of activities, equipment, and stakeholders (including parents/carers, schools, Allied Health Professionals and children themselves) which in combination may lead to significant daily challenges	-Shared roles and responsibilities for PM with school/healthcare professionals & wider team around the child -Parents/carers undertake a range of activities, using a range of equipment for PM -Role of the child in their own PM -Equipment: funding, accessing, meeting child& family needs, quality of life, moving and handling, time taken, space/accessibility, benefits
2. Promoting postural management	Those promoting the use of PM need to provide knowledge & understanding of all aspects of PM to facilitate improved caregiver participation at an early age & stage. They also need to be mindful of the potential psychological impacts of caring for a child with a disability	-Those providing training need to provide relevant & motivational information to encourage parents and/or carers/ healthcare professionals to attend training -PM starts early, often from birth -Negative aspects of PM (frustrating/overwhelming/time-consuming/family life balance) -Intrapersonal factors: acceptance; limited understanding; anxieties, frustration, guilt
3. Delivering postural management training	Those organising training need to use a flexible range of promotional strategies and invitations and provide relevant and motivational information in a variety of formats to encourage stakeholder participation	-Those organising training need to use a flexible range of promotional strategies and invitations -Practicalities of PM training: time/timing, venue, childcare -Content/ delivery of PM Training/ different stages -Voices of experience, importance of PM

PM=Postural Management

I: Defining postural management

Participants reported that PM had been a natural part of their daily lives from early in their child's development, with mothers primarily taking a lead role in meeting their child's postural needs and as such feeling they had acquired the necessary knowledge and skills to undertake the range of activities required. Participants felt that having a good understanding of the benefits of and consequences of not using PM was crucial in facilitating engagement by all caregivers, including other family members, paid carers, NHS and education staff. Common challenges such as time constraints, juggling work/ home life balance and the role the child plays in their postural care caused frustrations and anxieties which could become overwhelming. Funding and provision of appropriate postural equipment were also reported as a significant challenge for participants. However, when equipment was working well, participants reported that their child was more comfortable and had improved functional abilities with a positive impact on wellbeing and social inclusion.

II: Promoting postural management

Despite PM largely being seen as part of daily life, some participants highlighted that it could be frustrating, or overwhelming at times, especially when struggling to come to terms with and accepting their child's diagnosis:

"I thought it was a baby thing I didn't know it was a disabled thing. I think I would have persevered with more had I understood the latter effect. However, I don't know if I was ready for that information at that time," [Participant 13, Female]

In this study, mothers tended to be the main caregiver of a child with a disability, especially in the early years, and participants recognised that fathers' acceptance and engagement in their child's care may have taken longer as a result of different work/life priorities:

"He was in a bit of denial at that time, wasn't really coping with everything that was going on and I would say that he is only really got to grips with everything as our son has got older" [Participant 3, Female]

Seeking information on all aspects of PM and knowledge of the long-term benefits and consequences of undertaking PM were viewed as motivators in encouraging and maintaining participant engagement, for example:

"Someone can tell you this is how you need to position him, but unless you know why you are doing that, you don't really know what you're doing". [Participant 6, Female]

The perceived benefits of having a PM programme in place at home and in school was reported by some participants:

"I think she might have been in a worse state in terms of her scoliosis, so I think it has helped as she has grown, but it is hard to tell." [Participant 5, Female]

Some participants had not anticipated changes in their child's body shape as they grew:

"I think that you don't really get that sometimes when they are wee, it is as they get bigger that becomes even more relevant. So it is all about knowledge if we don't do this the knock on effect that is going to have" [Participant 3, Female]

These participants felt it was important to share information with caregivers, regarding potential changes in their child's posture, at an early stage in order to help prevent possible deterioration at times of rapid growth.

In addition, some participants reported frustrations that limited opportunities for PM at home had contributed to a deterioration in their child's posture or abilities:

"You have got that balance of is she no longer able to do that because we have not spent the time with her to do those things?" [Participant 11, Male]

Participants who had attended a PM training event reported that the varied content and delivery methods used were key to enhancing their understanding and thus promoting their engagement in PM:

"It was the course content, the setup of things, you were given handouts, there was like physical demonstrations, you were put in little groups and things, you were given little challenges" [Participant 10, female]

In addition, participants appreciated learning from the personal experiences of other families:

"...anything that would just give us a bit more kind of insight because there would possibly be other people who have got kids at different ages who have been through it as well." [Participant 12, Male]

Suggestions regarding the most appropriate time to attend a PM training event varied; some participants thought it would be most beneficial early in their child's development, whilst others thought that repetition of training during key stages in the child's life may also be of benefit:

"I feel like if right from newborn stage, I'd have known how much easier that could make her life as a toddler, but at that age I would have worked much harder. I just feel like if I got it in a couple of years earlier would have been so beneficial." [Participant 13, Female]

III: Delivering postural management training

Participants agreed on common barriers and facilitators to attending a formal PM training event. One of the main barriers was the duration of the training event itself and taking time out of a busy daily schedule to attend:

“Having a child with a disability your time is, your time is precious.....so trying to juggle work commitments along with appointments as well so then you see a course like that you think oh it’s not an appointment I have to be at, oh I don’t have time for that right now.” [Participant 3, Female]

In addition, the location of the training event may have contributed to transportation difficulties for non-drivers and potential childcare issues due to travel time. Online or pre-recorded training was perceived as being beneficial, by offering caregivers the flexibility to attend an event where these barriers would be of less concern:

“Zoom might work for people, maybe people that don’t drive and also people who are at home,” [Participant 2, Female]

Some participants, however, felt that online training offered reduced opportunity for interaction and sharing of personal experiences with other caregivers and professionals.

Targeting the appropriate audience and highlighting the potential benefits of PM for their child were also suggested facilitators to encourage caregivers to attend a training event:

“...they may feel like I can’t attend that because it is more sort of for OT’s and not for me,” [Participant 9 Female]

The means by which participants were invited to a training event could act as a barrier or facilitator to attendance. Some participants thought that invitations sent by post or email were the best means; however, others reported being overwhelmed by the amount of correspondence they received regarding their child’s care. Word of mouth from therapists or other parents, and advertisement via social media or posters displayed in hospital and community clinics were suggested by many participants as being an appropriate means of sharing information about training more widely:

“I guess it is just being recommended, [name] a family support sort of group on Facebook and things like that so they could say to their families oh look by the way there is this course available, here is what it is.” [Participant 11, Male]

Discussion

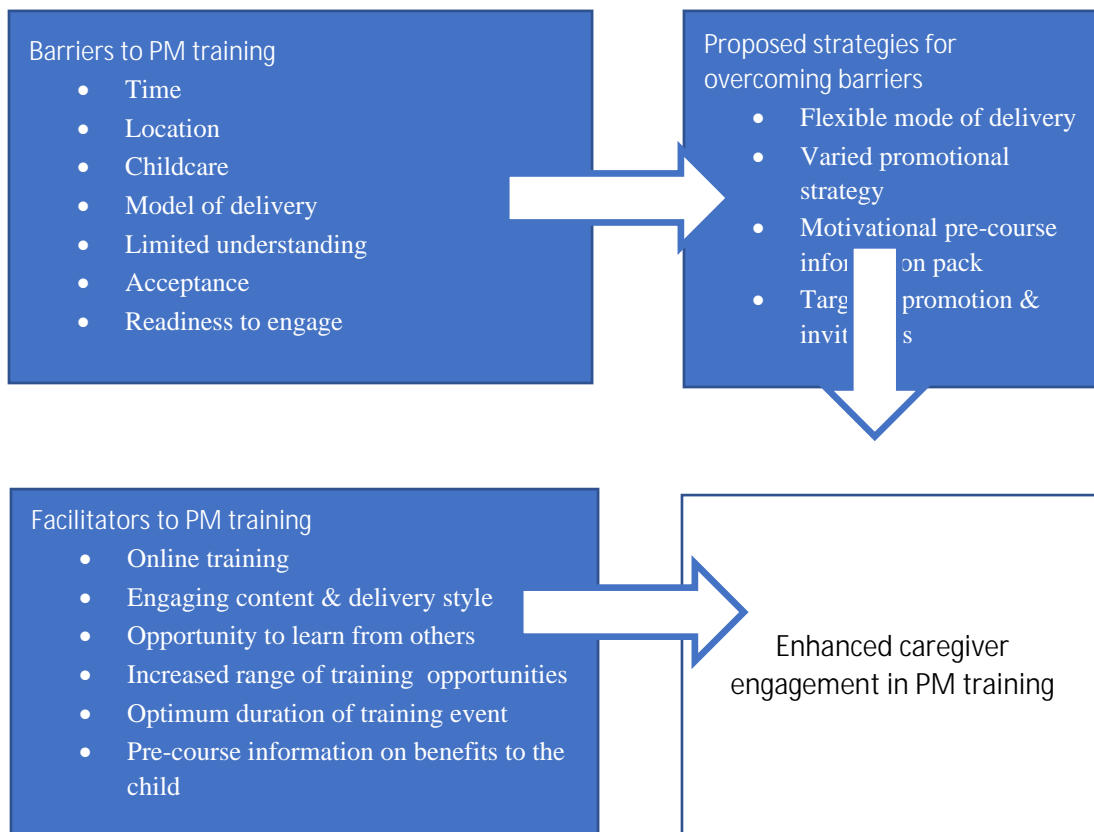
The findings identified key barriers and facilitators to engaging with PM training from the caregiver’s perspective. These are summarised in Figure 1, along with proposed strategies for overcoming the barriers, also informed by the study findings.

The finding of practical issues such as time, location, and childcare posing as barriers to attending PM training, were identified by most participants, and particularly those caring for younger children. This is in-keeping with previous research by Tadema and Vlaskamp (2009) who found that children are dependent on caregivers for all basic care tasks during the day and night and that learning to live with the needs of a child with multiple disabilities is more difficult for younger parents than for those of an older child. The finding of being overwhelmed and frustrated with the additional daily responsibilities faced by caregivers in managing their child’s posture are also in keeping with previous research (Moorcroft et al ,2019), with higher rates of stress, depression and burnout having been reported by family caregivers of children with a disability compared to those of typically developing children (Nicolson et al, 2012).

Strategies to overcome these barriers, such as online and asynchronous delivery, as suggested by the participants in the current study, could offer additional flexibility for busy caregivers. This may be particularly relevant today, due to the widespread uptake of virtual modes of communication during the COVID-19 pandemic (Wright and

Clayton, 2020), making virtual delivery of training potentially more acceptable than in the past. However, a recent randomized trial of two online training programs (Hutson et al, 2021) found that although caregivers receiving training by interactive videos showed greater self-rated competence, the actual positioning abilities of this group were no greater than those of the caregivers who received summary information with web-links, with some practical tasks requiring additional hands-on training for competence.

Figure 1: Key Barriers and Facilitators to caregivers attending postural management training



Engaging in PM training, as for engaging in any health promotion activity, requires an element of behaviour change by caregivers (Goldsmith, 2000). Boland et al (2019) in their systematic review of the barriers and facilitators of shared decision making in paediatric practice from the perspectives of HCPs, parents, children, and observers, suggested that the emotional status and stage of acceptance of the caregiver, and the quality of information about the condition and whether it was tailored to the child and family’s literacy needs, may act as potential barriers to changes in behaviour. In our study we observed that participants experienced psychological barriers such as denial, frustration, and guilt with the realisation that their child was not going to improve, which they found physically draining and impacted on their readiness to engage with PM. An understanding of behaviour change theories, such as those incorporated in the behaviour change wheel (Michie et al, 2011), and associated techniques to positively support behaviour change, may be useful for therapists working in the field of complex neurodisability. Appropriate techniques could be used to help address caregivers’ psychological barriers and facilitate better uptake and engagement with PM training and clinical services. For example, discussing the risks and rewards related to managing their child’s posture, as suggested by participants in this study, is congruent with the behaviour change technique of ‘health consequences’ (Michie et al, 2013), and may help to motivate the adoption of behaviours that promote ongoing PM.

Participants in this study appreciated learning from the personal experiences of the trainers and other caregivers, relating it to their own life experiences, demonstrating the equal importance of professional and lived experience.

Bacon (2013, pp31) also found that parents “enjoyed talking to other parents in similar situations” in their study that evaluated whether a PM training programme improved the understanding of the importance of PM for children with complex movement disorders. Co-production (Filipe et al, 2017) of future training events, whereby there is shared decision making by caregivers and service providers in the design and delivery of training and training materials (Boland et al, 2019), may help to facilitate increased engagement by the target audience by creating a more relevant and acceptable training programme. In addition, delivering training in a less formal way, such as during a mother and baby group, may help to facilitate engagement with caregivers who might otherwise be reluctant.

Most of our participants were caregivers of children above 10 years of age, therefore the findings may not be generalisable to caregivers of younger children. However, most had been introduced to and were actively involved in their child’s posture from an early age and consequently recognised, from personal experiences, the benefits of early intervention. It was not possible to ascertain from the data whether participants had been invited to attend training in the early stages of their child’s development, but it was known that they attended at a relatively later stage. Despite a targeted approach by therapists towards caregivers of children at an early age, challenges remain regarding engagement in PM training at this crucial stage. In the current study, only 50% of participants who had attended a PM training event did so before their child reached the age of 5-years, which may have been due to limited availability of appropriate training events. The inaugural report of a UK All-Party Parliamentary Group on CP (2021) suggests the need for effective, early intervention, to improve life outcomes and minimise secondary complications. Guidance by NICE (2021) advises NHS staff to offer children, young people and their caregivers’ information about the potential risks and benefits of healthcare options to allow them to make informed decisions. Offering training at key stages in a child’s development could be highly beneficial in supporting the changing needs of the child and their caregivers and may serve to reinforce the importance of effective PM in the longer term. It is important that providers of training acknowledge this when designing future training offerings.

Strengths and limitations

We have presented an in-depth exploration of caregivers’ perceptions of barriers and facilitators to PM training, with suggestions for overcoming some of the key barriers. Our findings should therefore be useful for anyone designing new or enhancing existing PM training opportunities for caregivers of children with complex neurodisability. We recruited both males and females from a range of socioeconomic backgrounds to take part in the study. However, participants from socially disadvantaged groups were under-represented, potentially due to the study taking place in one Scottish Health Board. We also recruited caregivers of relatively older children, and it is therefore difficult to generalise the results of this study to caregivers of younger children. Further study with a more diverse sample is indicated as there may be barriers specific to socially disadvantaged groups and caregivers of younger children that we have not identified. Our interviews also generated extensive data on the topic of ‘PM Equipment’, particularly in relation to its funding and provision. This was not the focus of the current study but was clearly of significant concern to many caregivers and may be worthy of exploration in future research.

Conclusion

This study provides insight into the barriers and facilitators to attending PM training which will be used to inform future service provision, by the study team, and we hope by others. Restrictions posed by the COVID-19 pandemic resulted in the research team adapting their existing training for virtual delivery. The study findings have also influenced how we promote PM training, resulting in invitations and promotional materials being advertised and distributed more widely via social media and family support groups, resulting in increased attendance to recent training. Further initiatives such as the co-production of training programmes and a blended

approach to delivery, including both online tutorials and practical face to face elements are avenues for future exploration.

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Conflict of interest: Kay Cooper is vice-chair of the Chartered Society of Physiotherapy Charitable Trust Scientific panel. The other authors have no conflicts of interest to declare.

References

Bacon, H. L. (2013) 'Does a PM Training Programme Improve understanding of the Importance of PM for Children with Complex Movement Disorders?' *APCP Journal*, Vol 4 Number 1, pp27-36

Boland, L., Graham, I. D., Légaré, F., Lewis, K., Jull, J., Shephard, A., Lawson, M. L., Davis, A., Yameogo, A. & Stacey, D. (2019) 'Barriers and facilitators of pediatric shared decision-making: a systematic review.' *Implementation Science* 14:7

<https://doi.org/10.1186/s13012-018-0851-5>, accessed 21st February 2023

De Jonckheere, M. & Vaughn, L. M. (2019) 'Semistructured interviewing in primary care research: a balance of relationship and rigour.' *Family Medicine and Community Health Volume 7, Issue 2*, pp1-8

Filipe, A., Renedo, A. & Marston, C. (2017) 'The co-production of what? Knowledge, values, and social relations in health care.' *PLoS Biol* 15(5): e2001403 <https://doi.org/10.1371/journal.pbio.2001403>, accessed 30th March 2023

Fletcher, A. J. (2017) 'Applying critical realism in qualitative research: methodology meets method.' *International Journal of Social Research Methodology* 20(2): pp181-194

Gale, N. K., Heath, G., Cameron, E., Rashid, S. & Redwood, S. (2013) Using the framework method for the analysis of qualitative data in multi- disciplinary health research. *BMC Medical Research Methodology*, 13:117, pp1-8

Gericke, T. (2006) 'PM for children with cerebral palsy: consensus statement.' *Developmental Medicine & Child Neurology*, 48(04), pp244.

Goldsmith, S. (2000) 'The Mansfield Project: Postural Care at Night within a Community Setting: A Feedback Study.' *Physiotherapy*, 86, 10, pp528-534.

Holloway, I., Wheeler, S. (2002) *Qualitative research in medicine* (Second edition). Oxford: Blackwell Publishing

Hotham, S., Hamilton-West, K. E., Hutton, E., King, A. & Abbott, N. (2017) 'A study into the effectiveness of a postural training programme aimed at improving knowledge, understanding and confidence in parents and school staff.' *Child: care, health, and development*, 43, 5, pp743-751

Humphreys, G., Mandy, A. & Pountney, T. (2012) 'Posture and sleep in children with cerebral palsy: a case study.' *Association of Paediatric Chartered Physiotherapists*, 3(1), pp48-56

Hutson, J. A., Hodges, S., Snow, L. (2021) 'Educating caregivers of persons with cerebral palsy in night-time postural care: A randomized trial comparing two online training programs.' *Clinical Rehabilitation* Vol. 35(9) pp1317-1328

Michie, S., van Stralen, M. M. & West, R. (2011) 'The behaviour change wheel: A new method for characterising and designing behaviour change interventions.' *Implementation Sci* **6**, 42 <https://doi.org/10.1186/1748-5908-6-42>, accessed 12th March 2023

Michie, S., Richardson, M., Johnston, M., Abraham, C., Francis, J., Hardeman, W., Eccles, M. P., Cane, J., Wood, C. E. (2013) 'The Behavior Change Technique Taxonomy (v1) of 93 Hierarchically Clustered Techniques: Building an International Consensus for the Reporting of Behavior Change Interventions,' *Annals of Behavioral Medicine*, Vol.46, Issue 1, pp81–95

Moorcroft, A., Scarini, N. & Meyer, C. (2019) 'I've had a love-hate, I mean mostly hate relationship with these PODD books: parent perceptions of how they and their child contributed to AAC rejection and abandonment.' *Disability and Rehabilitation: Assistive Technology*, <https://doi.org/10.1080/17483107.2019.1632944>, accessed 28th March 2023

NICE guideline (updated 29 November 2016) Spasticity in under 19s: management <https://www.nice.org.uk/guidance/cg145/chapter/1-Guidance#principles-of-care>, accessed 28th March 2023

NICE guideline (25 August 2021) Babies, children and young people's experience of healthcare. www.nice.org.uk/guidance/ng204, accessed 30th March 2023

Nicolson, A., Moir, L. & Millsteed, J. (2012) 'Impact of assistive technology on family caregivers of children with physical disabilities: a systematic review.' *Disability and Rehabilitation: Assistive Technology*, 7(5), pp345–349

Ritchie, J. & Spencer, L. (1994) 'Qualitative data analysis for applied policy research.' In: Bryman, A. & Burgess, R. G. editors. *Analyzing Qualitative Data*. London, Routledge

Ryan, G. S. (2016) 'Enhancing nursing student success: A critical realist framework of modifiable factors.' *Archives of Nursing Practice and Care* 2(1): pp57-70

Stinson, M., Crawford, S. & Madden, E. (2021) 'Current clinical practice in 24-hour PM and the impact on carers and service users with severe neurodisability.' *British Journal of Occupational Therapy*, Vol. 84(6) pp355–365

Tadema, A. C. & Vlaskamp, C. (2009) 'The time and effort in taking care for children with profound intellectual and multiple disabilities: a study on care load and support.' *British Journal of Learning Disabilities*, 38, pp41-48

UK All-Party Parliamentary Group on Cerebral Palsy (2021) Early identification, intervention and pathways of care of infants and young children with cerebral palsy: The case for reform and investment.

Wandel, J. (2000) 'Positioning and handling.' JW Solomon (Ed) *Paediatric Skills for Occupational Therapy Assistants*, St Louis: Mosby

Wright, R. & Clayton, S. (2020) 'Postural Care in the age of Covid-19: Executive Summary.' <https://www.posturepositive.co.uk>, accessed 30th March 2023

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The translations and cross-cultural adaptation of the Scoliosis Research Society Revised (SRS-22r) into Urdu

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Background

Adolescent idiopathic scoliosis (AIS) is the most common spinal deformity and occurs within the age range of 10-18 years. Health problems that individuals with AIS experience are back pain, mental stress and respiratory dysfunction which affect quality of life. Therefore, the need to explore the domains restricting these individuals in their ability to be fully capable to perform daily life activities is necessary ¹. Few patients reported outcome measures (PROMs) specific to health-related quality of life (HRQoL) are available for patients with AIS. The Scoliosis Research Society Questionnaire-22r (SRS-22r) is a unique patient reported quality of life measure which addresses a range of health domains from pain, mental health to function. SRS-22r can be used with other objective tools for AIS to develop a more integrated approach in treatment and patient's understanding of their condition ². The scale is in English which limits its applicability internationally and in an Urdu speaking population such as in Pakistan. Henceforth, this study aims to translate and culturally adapt SRS-22r into Urdu.

Aims

To develop an Urdu version of the SRS-22r which would be conceptually equivalent to the original English version.

- 1) To translate the original English version of the SRS-22r into Urdu, using a forward-backward translation methodology, based on cultural differences and expressions.
- 2) To perform blind backward translation of the synthesized forward translated scale and compare it to the original scale.
- 3) To systematically perform and analyse the steps involved in the translation process.
- 4) To identify and resolve discrepancies between the original and final translated versions of SRS-22r.

Methodology

No ethical approval was required for this translation work as confirmed by University College London Ethics Committee. The SRS-22 is freely accessible and free of copyright.

The translation methodology adopted was the forward-backward methodology for cross-cultural adaptation ^{3,4}. Four bilingual forward-backward translators from Pakistan collaborated with the primary researcher to translate and resolve discrepancies.

Results

The forward translation was more time consuming and challenging as compared to the backward translation process which was straightforward with very few complexities to resolve. Several discrepancies were discovered which were further subdivided within the 'vocabulary' category. The discrepancies were resolved following a set of strategies such as, 'adaptation', 'transposition' and 'condensation', and the final Urdu version of SRS-22r was formed.

Conclusion / Implications for practice

The translation of the SRS-22r into Urdu was effectively achieved. No modification of the structure was done when compared with the original version. A culturally adapted and conceptual equivalent outcome measure was created by the end of the study.

References

1. Negrini, S., Aulisa, A.G., Aulisa, L., Circo, A.B., De Mauroy, J.C., Durmala, J., Grivas, T.B., Knott, P., Kotwicki, T., Maruyama, T. and Minozzi, S., 2012. 2011 SOSORT guidelines: orthopaedic and rehabilitation treatment of idiopathic scoliosis during growth. *Scoliosis*, 7(1), pp.1-35.
2. Alamrani, S., Rushton, A.B., Gardner, A., Bini, E., Falla, D. and Heneghan, N.R., 2021. Physical functioning in adolescents with idiopathic scoliosis: a systematic review of outcome measures and their measurement properties. *Spine*, 46(18), pp.E985-E997.
3. Schuster, C., Hahn, S. and Ettlin, T., 2010. Objectively assessed outcome measures: a translation and cross-cultural adaptation procedure applied to the Chedoke McMaster Arm and Hand Activity Inventory (CAHAI). *BMC medical research methodology*, 10(1), pp.1-9.
4. Peters, M. and Passchier, J., 2006. Translating instruments for cross-cultural studies in headache research. *Headache: The journal of head and face pain*, 46(1), pp.82-91.

Development of an evidence-based pathway of care for children presenting with Toe-Walking gait to the Royal National Orthopaedic Hospital.

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Background

Studies estimate that 5% of healthy children can adopt a toe-walking (TW) gait.¹ Interventions aim to resolve fixed equinus, with expectation that gait changes will follow. Current evidence fails to identify parameters for treatment and parents have described the journey of healthcare management as 'a rollercoaster'.² Without a national or local guideline, current management of toe-walking children is practitioner dependent, with paucity

of agreed outcomes to determine efficacy of intervention.^{3,4} Implementation of an evidence-based pathway will allow local standardisation of care and audit of collected outcome measures will improve quality of intervention.

Aim

To standardise a care pathway and incorporate outcome measures to audit treatment efficacy for TW children at RNOH.

Objectives

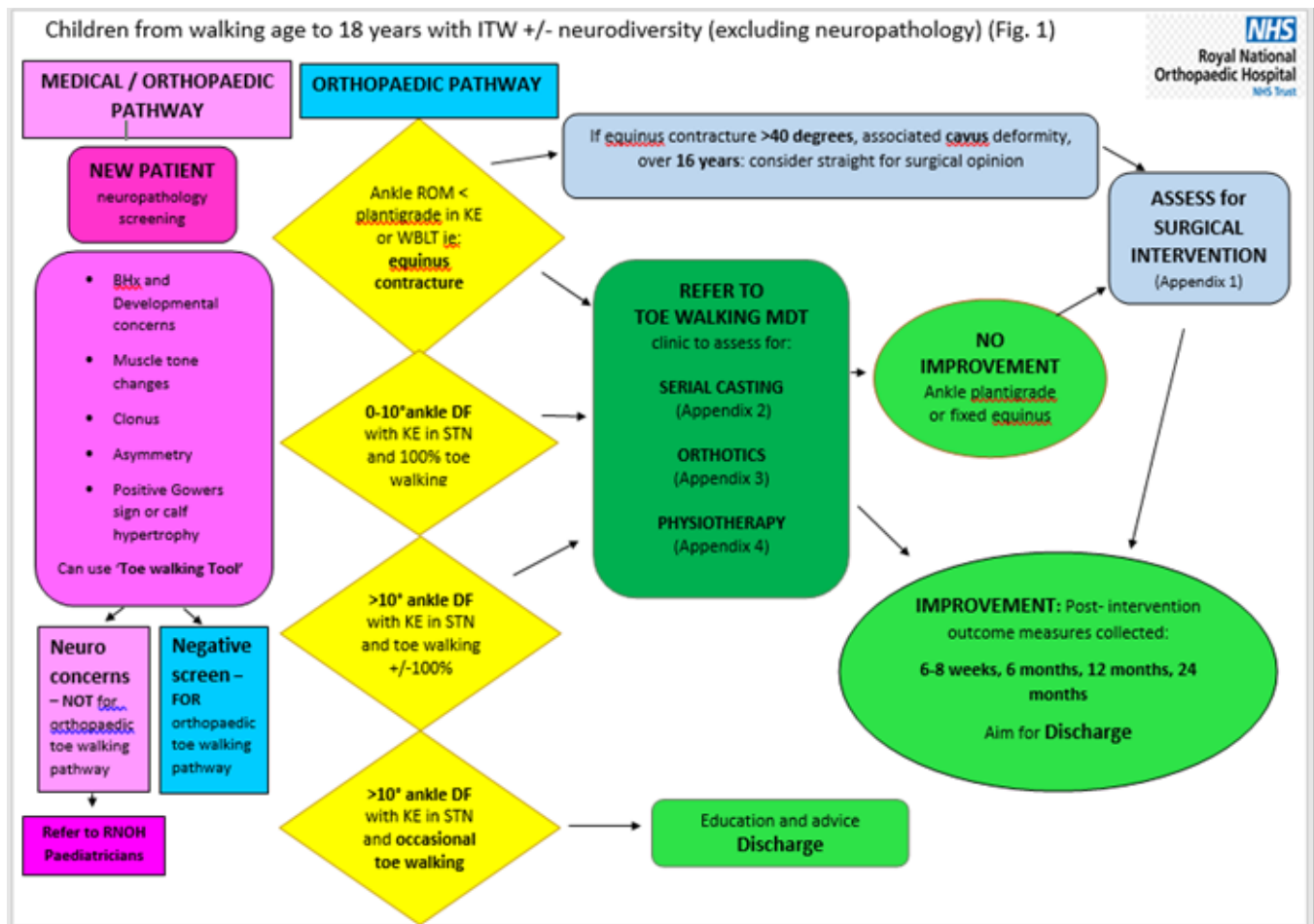
- To understand current service provision and potential for change.
- To appraise current evidence for robust selection of outcome measures.
- To design and implement new pathway of care for TW children.

Methodology

- Approved by RNOH R&D SE22.14 on 10/05/22
- An online survey of RNOH paediatricians, orthopaedic surgeons, orthotists and physiotherapists (n=19) explored current practice and potential for change.
- Retrospective evaluation of treatment and outcomes in surgical and serial casting treatment cohorts, using patient records from 01/04/21 to 31/03/2022
- Critical appraisal of current evidence to assess established pathways, feasibility, reliability and validity of outcome measures.

Results

- A 74% return produced 14 completed surveys. Analysis revealed variability of assessment, treatment and outcomes collected. 93% of clinicians (n=13), advocated for a new pathway and 8 interested clinicians formed the consensus group.
- 24 patients were treated with casting or surgery over 12 months. Casting patients had a median age 7.5 years (range 1-11), 58% had equinus $\leq 20^\circ$. Surgical patients had a median age 10 years (range 3-15), 75% had equinus $\geq 20^\circ$. No validated outcomes were recorded. Treatment rationale is practitioner dependent and variable for age and presentation.
- Critical appraisal of evidence identified one established pathway of care in the USA.⁵ Three systematic reviews revealed no consensus on treatment protocols or outcome collection.^{4,6,7} Two outcome measures have been validated in this group; ankle dorsiflexion in weight-bearing lunge⁸ and the '50 foot walk test'.⁹
- Stakeholder consensus was obtained for new care pathway (see figure 1)



Conclusion and implications for practice

There are significant gaps in existing evidence, with a lack of clarity on optimal care for TW children. Evaluation of current practice at RNOH showed variability of service provision, and paucity of outcome data. The new pathway will provide a framework to improve equity of care. Collection of valid and reliable outcome measures and subsequent audit will drive quality improvement through treatment parameter refinement.

References:

- Engstrom, P. & Tedroff, K. (2018) Idiopathic Toe-walking: Prevalence and natural history from birth to ten years of age, *The Journal of Bone and Joint Surgery*, 100: pp 640-647.
- Williams, C., Robson, K., Pacey, V. & Gray, K. (2020) American and Australian family experiences while receiving a diagnosis or having treatment for idiopathic toe walking: a qualitative study, *BMJ Open*, 10: e035965.
- Bartoletta, J., Tsao, E. & Bouchard, M. (2021) A retrospective analysis of nonoperative treatment techniques for idiopathic toe walking in children: Outcomes and Predictors of success, *American Academy of Physical Medicine and Rehabilitation*, 13: pp 1127-1135.
- van Bemmell, A.F., van de Graaf, V.A., van den Bekerom, M.P. & Vergroesen, D.A. (2014) Outcome after conservative and operative treatment of children with idiopathic toe walking: a systematic review, *Musculoskeletal Surgery*, 98: pp87-93.
- Le Cras, S. Bouck, J., Brausch, S. & Taylor-Haas, A. (2011) Evidence based care guideline: Management of Idiopathic toe walking in children and young adults ages 2 through 21 years, *Cincinnati Children's Hospital Medical Center*, 040, pp 1-17.
- van Kujik, A.A., Kosters, R., Vugts, M. & Geurts, A.C. (2014) Treatment for idiopathic toe walking: A systematic review of the literature, *Journal of Rehabilitation Medicine*, 46: pp 945-957.

7. Caserta, A., Morgan, P. & Williams, C. (2019) Identifying methods for quantifying lower limb changes in children with idiopathic toe walking: A systematic review, *Gait & Posture*, 67: pp 181-186.
8. Williams, C., Tinley, P., Curtin, M. & Neilsen, S. (2013) Foot and ankle characteristics of children with an idiopathic toe walking gait, *Journal of the American Podiatric Medical Association*, 103, 5: pp 374-379.
9. Christensen, C., Haddad, A. & Maus, E. (2017) Reliability and Validity of the 50-ft walk test for idiopathic toe walking, *Paediatric Physical Therapy*, pp 238-243.

Trends in notification of cases to the Northern Ireland Cerebral Palsy Register

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Background

Cerebral palsy (CP) is a lifelong condition often requiring physiotherapy input. Clinical presentation varies widely but numbers and needs of people with CP are not well captured by routine healthcare data coding^{1,2} thus CP registers represent a good data source on prevalence of the condition³. The Northern Ireland CP register (NICPR) is well established⁴. Confirmed or suspected cases of CP are notified to the NICPR by healthcare professionals and families. Understanding trends in case notifications is important to ensure ongoing quality of the NICPR.

Aims/ Objective

This study sought to explore trends in case notification to the NICPR from 2018-2022 to assess impact of the Covid-19 pandemic on the register. Specifically, we aimed to compare notification data during 2018/19 (pre-Covid) to 2020-2022, including:

1. the number of notification cards submitted each year,
2. the unique number of cases notified each year,
3. the proportion of cases multiply notified,
4. the proportion of cases notified by different health professionals,
5. the age (of the case) at time of first notification.

Methodology

The NICPR has ethical permission from the Office for Research Ethics Committees Northern Ireland (Reference 18/NI/0180). Descriptive analysis of cross-sectional data was undertaken frequency counts and percentages are presented.

Results

Over the past five years 396 notification cards were submitted to the NICPR. Approximately half of these (n=195, 49%) were submitted pre-Covid. Of these, 226 represented unique cases. Case notification was reduced for operational reasons in 2018 (n=22) but returned to usual levels in 2019 and 2020 (n=67, n=64 respectively) before decreasing in 2021 and 2022 (n=37, n=36 respectively). Of the 226 unique cases, 19% (n=43/226) have, to date, been notified multiple times.

The proportion of cases multiply notified was higher pre-Covid (n=31/89, 35%). Paediatricians notified 55% of cases (n=124/226). Remaining cases were notified by physiotherapists and occupational therapists (n=52, 23%), neonatologists (n=18, 8%) or other informants/routine checks. These proportions remained similar over time.

Finally, the median age at time of first notification was 2.30 years. The median age was younger pre-Covid (2.12 years) than for 2020-2022 (2.50 years).

Conclusion and implications for practice

The decline in NICPR notification activity, evident from 2020, potentially relates to reduced patient contact and redeployment of staff during the pandemic. Renewed engagement with clinicians (including physiotherapists) and families, in addition to routine database checks, are required to maximise case notifications to maintain the quality and robustness of the NICPR.

References

1. Carter B, Verity Bennett C, Bethel J, Jones HM, Wang T, Kemp A. Identifying cerebral palsy from routinely collected data in England and Wales. *Clin Epidemiol.* 2019 Jun 5;11:457-468. doi: 10.2147/CLEP.S200748. PMID: 31239784; PMCID: PMC6556471.
2. The National Confidential Enquiry into Patient Outcome and Death. *Each and Every Need.* 2018. London
3. Carter B, Bennett CV, Jones H, Bethel J, Perra O, Wang T, Kemp A. Healthcare use by children and young adults with cerebral palsy. *Dev Med Child Neurol.* 2021 Jan;63(1):75-80. doi: 10.1111/dmcn.14536. Epub 2020 Apr 20. PMID: 32314347.
4. Northern Ireland Cerebral Palsy Register website (accessed 07/06/2023) <https://www.qub.ac.uk/research-centres/NorthernIrelandCerebralPalsyRegister/>

**Moving towards a better understanding of well-being for children with complex disabilities who use a robotic device, the Innowalk ©Made for Movement
(This research is supported by an APCP bursary 2022-2023)**

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Background

Researchers have not yet developed a valid and reliable measure for well-being for children with profound disabilities. Well-being in this context is referring to how these children are able to indicate they are enjoying activities in their environments.

Consultation took place with some disabled adults, children and young people and their parents, to discuss and develop the domains of the proposed well-being scale. Based upon this and previous doctoral research, well-being indicators included calmness, comfort, creativity, energy levels, engaging with others and expressing joy. The Innowalk is reported to have health and well-being benefits for non-ambulant people but is expensive and requires technical set up.

Aims / Objective

Research question: How can the well-being of children and young people with complex disabilities be better understood, from using the Innowalk?

Objectives:

1. To develop and pilot an observational well-being scale with children and young people with complex disabilities.
2. To obtain child and parental opinions by written diary records and an interview related to well-being, following them using the Innowalk.

Methodology

Ethical approval was granted by the School of Healthcare sciences at Cardiff University August 2022 REC895.

A case study series observed children, three times using the Innowalk in a special school. Field notes were made, and these were mapped onto two existing scales the Be-Well checklist and PRIME-O, as well as the proposed new well-being scale (WEBS). Data was supported by their parents keeping a diary during this time, followed by interviews with the child and or parent. The observational scales were analysed descriptively. Interview, field notes and diary data were analysed thematically, and three themes were identified.

Results

Ten children participated aged between four and eighteen years (mean age 11.9). The three themes were:

1. Well-being-Mood and achievements.
2. Participation: Anticipation and Tolerance.
3. Physical effects: Improved self-regulation of sleep, bowel and muscle tone.

The WEBS has been illustrated to show the levels of comfort, calmness, creativity, energy, engagement, and joy experienced. Despite being a passive motion, parental perceptions were that it was a form of exercise. Two children actively participated in the leg motion and some children illustrated the diaries. Parents felt a sense of achievement for their child to participate in the Innowalk, and it lifted their mood.

Conclusions / Implications for practice

The WEBS scale showed some consistency; however, it needs to be tested in a larger population to establish the feasibility and content validity.

References

- Clarke, V., & Braun, V. (2013). Successful qualitative research: A practical guide for beginners. *Successful qualitative research*, 1-400.
- King, G., Chiarello, L. A., Thompson, L., McLarnon, M. J., Smart, E., Ziviani, J., & Pinto, M. (2019). Development of an observational measure of therapy engagement for pediatric rehabilitation. *Disability and Rehabilitation*, 41(1), 86-97.
- Lauruschkus, K., Jarl, J., Fasth Gillstedt, K., & Tornberg, Å. B. (2022). Dynamic Standing Exercise in a Novel Assistive Device Compared with Standard Care for Children with Cerebral Palsy Who Are Non-Ambulant, with Regard to Quality of Life and Cost-Effectiveness. *Disabilities*, 2(1), 73-85.

Made for Movement, 2021 <https://www.madeformovement.com/innowalk> [Accessed 1.12.22]

What works wellbeing (2022) Definition of wellbeing [About wellbeing - What Works Wellbeing- accessed 13.01.2022]

Mpundu-Kaambwa, C., Chen, G., Huynh, E., Russo, R., & Ratcliffe, J. (2018). A review of preference-based measures for the assessment of quality of life in children and adolescents with cerebral palsy. *Quality of Life Research*, 27, 1781-1799.

Oliver, C., Adams, D., Allen, D., Crawford, H., Heald, M., Moss, J., ... & Woodcock, K. (2020). The behaviour and wellbeing of children and adults with severe intellectual disability and complex needs: the Be-Well checklist for carers and professionals. *Paediatrics and Child Health*, 30(12), 416-424.

Pickering D, Gill P. and Reagon C. (2023) A kaleidoscope of well-being to authentically represent the voices of children and young people with complex cerebral palsy: a case study series.

Disability and Rehabilitation Online

<https://www.tandfonline.com/eprint/CWZNSAXMCIAQNQKREMJD/full?target=10.1080/09638288.2023.2194680>

Translation and cross-cultural adaptation of Indian (Hindi) version of the Paediatric Motor Activity Log Scale-Revised (PMAL-R).

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Background

Spastic Unilateral Cerebral Palsy (CP), a common type of CP is characterised by unilateral loss of functions of upper and lower extremity. This form of disability influences the overall development of a child while impacting their daily functions and quality of life. To be able to gauge this impact is essential for setting rehabilitative goals focusing on improving overall functions. The Paediatric Motor Activity Log Scale-Revised (PMAL-R) is a parent reported outcome measure which assesses the quality and quantity of use of affected upper limb in a non-clinical setting in children with CP1. The use of this measure helps assess and track the progress of use of affected upper extremity. PMAL-R was developed in English and is translated into Turkish, Portuguese and Chinese. To increase the accessibility of its use in the Indian population, this study aimed to translate and culturally adapt the PMAL-R to Hindi.

Aims / Objective

This study aimed to develop a Hindi version of the PMAL-R using elaborate translation steps thereby making the Hindi version semantically and conceptually equivalent to the original English version of PMAL-R with the following objectives.

- 1.To primarily develop a Hindi version of PMAL-R using forward translation, aiming for semantic, conceptual and cultural equivalence.
- 2.To carry out blind translation of forward translated PMAL-R back to English.
- 3.To elaborately document and analyse each step of translation.
- 4.To compare back translated English version with the original English PMAL-R.
- 5.To resolve any discrepancies between the translated and original versions.

Methodology

No ethical approval was required for this translation work as confirmed by University College London Ethics Committee. The PMAL-R is freely accessible.

Forward-backward translation method was selected after scrutinising the available literature on translations in health outcome measures^{2,3}. Four independent bilingual forward-backward translators along with an expert working in the field of paediatric physiotherapy in India collaborated with the primary researcher to translate and resolve discrepancies in different versions of translations.

Results

The forward-backward translation process was completed. The completion time for forward translation was less than that for backward translation. There were several discrepancies between translators. These were more common during forward translation as compared to back translation. Discrepancies were successfully resolved at every step of translation through mediated discussion by the researcher to formulate the Hindi PMAL-R.

Conclusions / Implications for practice

A successful conceptual and semantic translation of PMAL-R to Hindi along with its cultural adaptation for Indian population was formulated. Further validation research can be undertaken with an Indian Hindi speaking patient population.

References

- 1.USWATTE, G., TAUB, E., GRIFFIN, A., VOGTLE, L., ROWE, J. & BARMAN, J. 2012a. The pediatric motor activity log-revised: assessing real-world arm use in children with cerebral palsy. *Rehabilitation Psychology*, 57, 149.
- 2.SOUSA, V. D. & ROJJANASRIRAT, W. 2011. Translation, adaptation and validation of instruments or scales for use in cross-cultural health care research: a clear and user-friendly guideline. *J Eval Clin Pract*, 17, 268-74.
- 3.MANEESRIWONGUL, W. & DIXON, J. K. 2004. Instrument translation process: methods review. *J Adv Nurs*, 48, 175-86.

The Paediatric Physiotherapy Curricula Landscape: A Survey of United Kingdom Entry-Level Programs.

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Background

Entry-level physiotherapy programmes aim to adequately prepare students with graduate ready skills to meet regulatory bodies proficiency standards. Currently, no standardised approach to the content required to cover the field of paediatric physiotherapy in the United Kingdom (UK) exists. Therefore, students may not be formally assessed regarding their safety, competence and confidence to provide appropriate assessment and treatment of children and young people, unless it is explicit within their taught curriculum.

Aims / Objective

The aims of this study were to:

- 1) identify the paediatric curriculum content covered in UK entry-level physiotherapy programmes.
- 2) understand the perceived importance of paediatric content by teaching faculty,
- 3) identify the mode of delivery and assessment in entry-level programmes and
- 4) identify strengths, weaknesses, barriers, and facilitators, to the implementation of paediatric content in entry-level programmes.

Methodology

A cross-sectional online questionnaire captured entry-level physiotherapy programme leaders' perceptions of paediatric programmes. A total of 77 email invitations were sent. The School of Health and Life Sciences Ethics Committee at Teesside University approved the study (ID9279). Likert scale questions were treated as numeric variables with mean and standard deviations (SD) calculated for combined responses across each potential answer. Data from dichotomous and multiple-choice questions were converted into proportions with lower and upper limits of the 95% confidence interval.

Results

55 responses were submitted, providing a 67% completion rate. Faculty perceived that students' felt the inclusion of paediatric content within the curricula was 'Important' (Mean 3.60 ± SD 0.74). Of 30 diagnoses surveyed only two were covered 'Well' within curriculums, despite 23 rated at least 'Important' by respondents. Of the 18 assessment/examination components 13 were covered 'Well' with five 'Somewhat'. All were considered to be at least 'Important'.

Perceived strengths were grouped into three main categories:

- 1) integrated/lifespan approach,
- 2) links to clinical specialists and,
- 3) a broad/detailed curriculum.

Perceived weaknesses included curriculum time pressures and paediatric placement availability. Five programmes did not include any paediatric content with the curricula and a further 22 failed to assess student paediatric competency.

Conclusions / Implications for practice

The majority of paediatric conditions were only somewhat covered by UK curriculums, despite respondents in the main believing they should be an important element of the entry-level syllabus. Some UK physiotherapy entry-level students may not be exposed to any paediatric teaching or clinical placements. Minimal required standards set by accrediting bodies may facilitate the introduction of a formal paediatric curriculum ensuring parity across programmes.

Physiotherapy and Occupational Therapy Hip Hop Collaboration

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Background

Sheffield Children's Hospital Neurology and Oncology therapy team collaborated with Hip Hop Artist Nathan Geering, to add dance into their standard Physiotherapy and Occupational Therapy sessions with inpatients.

Physical Activity (PA) is important for the health and wellbeing of all children ¹. For children and young people with a neurological or oncology condition, they may have significant changes in their ability to take part in PA and require specific help with adaptation and goal setting ¹.

Treatment for cancer can be intense and require prolonged hospital stays. Limited opportunity to socialise with peers, attend school and take part in sports can all lead to a dramatic reduction in physical activity compared to healthy peers ^{2,3} with long lasting effects.

Aims / Objective

To look at improving participation and physical activity for hospitalised in-patients undergoing rehabilitation for cancer and neurological conditions.

Methodology

The Hip Hop sessions were open to all children under the neurology and oncology therapy team.

- A total of 20 sessions ran between March – October 2022
- 7 children and young people, 2 females and 5 males took part, between the ages of 7 and 15 years old.
- Diagnosis of the children who took part included Acquired brain injury, Spinal cord injury, Guillan Barre syndrome, Burkitt's Lymphoma and Bone Marrow transplant.
- Average length of inpatient stay at SCH 122 days with a Range of 3 – 255 days
- Therapist and Hip-Hop artist discussed eligible patients and what the patients goals and abilities were, with an outline of what the therapy session was aiming for and how Hip Hop moves and routines could be included.
- During the session, the therapist would suggest if rest breaks or adaptations were needed.

Results

The hip hop and physiotherapy collaborative sessions were welcomed by children and young people, families, and therapists, with the experience being overwhelmingly positive. Parental feedback centred around the sessions improving energy, motivating and boosting mood. Therapist feedback referred to the sessions being fun,

meaningful, connecting with children positively and being able to better understand a child's ability and potential.

Conclusion / Implications for practice

The feedback from parents supports the encouragement of physical activity which is fun, safe and family-centred⁷. It was tailored to each child's abilities, interests and goals.

Future research into inpatient group sessions and a follow-on programme on discharge would be areas to pursue.

References

1. Association of Paediatric Chartered Physiotherapists(APCP), Neurodisability Committee (2021) Guidance for Paediatric Physiotherapists managing children and young people with an Acquired Brain Injury.
 2. Yelton, L., & Forbis, S. (2016). Influences and barriers on physical activity in pediatric oncology patients. *Frontiers in Pediatrics*, 4, 131
 3. Munsie, C., Ebert, J., Josky, D., Ackland, T. (2022) A randomised controlled trial investigating the ability for supervised exercise to reduce treatment related decline in adolescent and young adult cancer patients. *Supportive Care in Cancer* 30:8159–8171
 4. Götte, M., Gauß, G., Dirksen, U., Driever, P. H., Basu, O., Baumann, F. T., & Kesting, S. V. (2022). Multidisciplinary Network ActiveOncoKids guidelines for providing movement and exercise in pediatric oncology: Consensus-based recommendations. *Pediatric Blood & Cancer*, 69(11), e29953.
 5. Ospina, P. A., & McNeely, M. L. (2019). A scoping review of physical therapy interventions for childhood cancers. *Physiotherapy Canada*, 71(3), 287-296.
 6. Cheung, A. T.;Li, W. H. C.;Ho, L. L. K.;Ho, K. Y.;Chan, G. C. F. and Chung, J. O. K (2021) *Journal of Cancer Survivorship : Research and Practice* 15(6), pp. 876-889
 7. Wurz, A., Ellis, K., McLaughlin, E., Mrklas, K. and Culos Reed, S.N.(2021) *Pediatric Blood and Cancer. Conference: 53rd Annual Congress of the International Society of Paediatric Oncology, SIOP 2021. Virtual.* 68(SUPPL 5)
 8. Peterson, N.N., Larsen, H.B, Populier, A., Schmidt-Anderson, P., Thorsteinsson, T., Schmiegelow, K., Fridh, M.K, (2022) Childhood cancer survivors' and their parents' experiences with participation in a physical and social intervention during cancer. *Journal of Advanced Nursing* DOI: 10.1111/jan.15381
- Children's Cancer and Leukaemia Group. (2022) CLG Keeping your child active during and after treatment Practical information for parents about physical activity, sport and exercise for children and young people with cancer keeping-active-during-and-after-treatment-2022-web.pdf (cclg.org.uk)
- Devine, K. A., & Kwok, G. (2022). Improving Physical Activity in Pediatric Cancer Survivors, Engaging Parents. *JAMA Network Open*, 5(6), e2219327-e2219327.

Community-based gym exercise for non-ambulant adults with childhood onset disability

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Background

Adults with childhood onset disability (COD) are less physically active than the general population¹ and have less opportunities to participate in physical activity and exercise. In addition, those with non-ambulant COD are less physically active than their ambulant counterparts². Community-based exercise in gyms may provide a way to increase physical activity and exercise in non-ambulant adults with COD.

Aims / Objective

To explore community-based gym exercise for non-ambulant adults with COD. Study objectives included to establish:

- (1) demand for exercise in community gyms for this population,
- (2) practicalities of exercising in community gyms from the perspectives of non-ambulant adults with COD, and
- (3) practicalities of exercising in community gyms from the perspectives of those who designed/delivered the study.

Methodology

Ulster University's Research Ethics Committee granted ethical approval for this mixed methods study.

Non-ambulant adults with COD were recruited via social media and relevant organisations. Participants attended exercise sessions in a privately owned gym, once per week for four consecutive weeks. Exercise sessions were tailored for each participant and co-facilitated by research physiotherapists, exercise professionals and personal support assistants. Demand for community-based gym exercise was recorded via uptake and attrition and undertaking focus groups with participants. Participant perspectives were obtained through weekly surveys and focus groups. Perspectives of those who designed/delivered the study were gathered via weekly debrief meetings. Quantitative data were analysed descriptively, and qualitative data were analysed thematically.

Results

Ten non-ambulant adults with COD participated in the study. No participants withdrew and 70% completed all exercise sessions.

Focus groups identified two themes. 'Gym-based exercise isn't an option' described the lack of opportunities for exercise in gyms. 'We can do better' had two sub-themes (1) problem solving and (2) 'ingredients' for community-based exercise.

Weekly participant feedback identified enablers including staff support and adaptive equipment, whilst individual impairments were reported as a challenge to completing exercises. Weekly debrief meetings highlighted the importance of adapting existing gym equipment in addition to purchasing assistive devices, and collaboration between physiotherapists, exercise professionals and personal support staff to ensure participant safety and staff confidence.

Conclusion / Implications for practice

There is a need for community-based exercise in gyms for non-ambulant adults with COD. However, there remains a lack of inclusive gyms. Co-design of an inclusive gym guide and condition-specific physical activity referral pathway may enhance opportunities for participation in gym-based exercise for adults with COD.

References

1. Ryan J, Cassidy E, Noorduyn S, O'Connell N. 2017. Exercise interventions for cerebral palsy. Cochrane Database of Systematic Reviews (6).
2. Ganz F, Hammam N, Pritchard L. 2021. Sedentary behavior and children with physical disabilities: a scoping review. *Disabil Rehabil* 43(20):2963-2975.

Burden or Blessing? Evaluating parental satisfaction of a parent-mediated approach to a pilot interdisciplinary therapy Early Intervention Programme.

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Background

In 2022 we piloted a parent-mediated, interdisciplinary, weekend therapy programme for children 0 – 4 years with complex needs. Whole families were invited to attend half days on 3 Saturdays per term, for 3 terms.

Aim

The aim of this service evaluation was to measure parental satisfaction of our pilot Early Intervention Programme using an online parental questionnaire, particularly as parent-mediated programmes can be viewed as burdensome by some parents as they are given more daily tasks to do with their child ¹.

Methodology

In December 2022, parents were sent an online Survey Monkey questionnaire, containing 13 items which recorded demographic information and collected information on the parents' experience of using the service. The questionnaire contained 7 closed questions which used both an 11-point rating scale and a Likert 5-point scale – with labelling.

The comments from the 6 open questions were analysed using thematic analysis. The questionnaire was expected to be completed within 3 minutes. The questionnaire was not a validated satisfaction questionnaire but designed specifically to analyse parental experiences and satisfaction for this pilot Early Intervention Programme and collate how the service could be improved.

Ethics / R & D approval needed: The HRA decision-making tool confirmed the analysis that this pilot EIP programme study is a service evaluation and not research.

Results

Completed questionnaires were returned for 13 (35%) out of the 34 children attending the programme. These 13 children were 6 girls and 7 boys aged between 14 months and 3.5 years, mean 2.5 years. The children had attended between 2 and 7 sessions throughout the year, mean 3 sessions.

10 (77%) parents thought the programme was excellent (Rating score 9 -10) and 3 (23%) very good, (Rating score 7 – 8).

13 (100%) parents were extremely likely to recommend the programme to others.

Positive emergent themes for the open comments were:

- 1) programme accessibility and inclusiveness,
- 2) multi-professional support for their child's condition,
- 3) parental empowerment, and
- 4) opportunity to use the Centre's facilities.

Negative comments included: that there was no time allocated (within the programme) to chat with other parents and the use of the hydrotherapy pool should always be included.

Conclusion

Parents did not find the parent-mediated intervention burdensome but appreciated being taught skills to improve their child's development, especially in the areas of communication and physical abilities. Parent satisfaction was high for this Early Intervention Programme. The 35% of parents who returned the questionnaire gave good feedback and suggestions, however this low response rate could mean that there is some respondent bias. The authors are aware of the limitations of using a non-validated questionnaire, and focus groups are planned to evaluate this year's programme.

References

David McConnell, Miriam Parakkal, Amber Savage & Gwendolyn Rempel (2015) Parent-mediated intervention: adherence and adverse effects, *Disability and Rehabilitation*, 37:10, 864-872, DOI: 10.3109/09638288.2014.946157

Rouder, Jessie, Olivia Saucier, Rachel Kinder, and Matt Jans. 2021. "What to Do With All Those Open-Ended Responses? Data Visualization Techniques for Survey Researchers." *Survey Practice*, August. <https://doi.org/10.29115/SP-2021-0008>.

Walk tall and look the world right in the eye: A service evaluation of a 4-week trial to assess if the Innowalk Pros could provide physical activity for children with complex neuro-disabilities within a Special School

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Background

The new UK Government guidelines (2022) ¹ recommendation is for disabled children to do 20 minutes of physical activity per day. The Innowalk Pro is described as a Robotic motorised, dynamic standing frame ² that allows users with moderate to severe physical disabilities to stand and move ³.

Aim

A service evaluation of a 4-week trial in November 2021 to assess if the Innowalk Pros could provide physical activity within a special school for children with complex neuro-disabilities.

Methodology

9 children participated in the study: 7 girls and 2 boys, from 6 – 14.2 years, mean age 9.6 years.

Two Innowalk PROs, full training, and ongoing support during the trial were provided by the “MadeforMovement” Team. Each child was timetabled to have 4 sessions per week of the trial. For each child the total number of sessions, the distance achieved, and the duration of each session was recorded.

Ethics: The HRA decision-making tool confirmed the analysis that this Innowalk Pro study is a service evaluation and not research.

Results

2 children withdrew from the trial. One was due to absence through illness unrelated to the trial. The second child initially tolerated the Innowalk Pro well, but then from the third session the child indicated obvious discomfort and they were withdrawn from the trial.

The total number of sessions per child was 9 to 14 compared to our target which was 16 sessions.

The mean session duration for each child ranged from 14 minutes to 25 minutes, the mean was 19 minutes.

The mean distance each child walked ranged from 0.5km to 1.5km, the mean was 0.94km.

Conclusions

During the trial, the Innowalk Pros enabled 7 children out of 9 with complex neuro-disabilities to have access to a walking activity over a 4-week period. The mean session duration was 19 minutes so this can contribute to the UK Government’s guidelines of physical activity for disabled children. All the children achieved 2 - 3 sessions per week which was less than our target, but within the pilot scheme there was no time to reschedule Innowalk Pro sessions which were missed through illness or competing demands on the children’s time.

References

-
1. Physical activity guidelines: disabled children and disabled young people - GOV.UK (www.gov.uk) – accessed 1/6/2023
 2. Innowalk Pro (madeformovement.com) – accessed 01/06/2023
 3. Trial of an Innowalk PRO within a Special School setting | Association of Paediatric Chartered Physiotherapists (csp.org.uk) – accessed 21/01/2023. 3. Trial of an Innowalk PRO within a Special School setting | Association of Paediatric Chartered Physiotherapists (csp.org.uk) – accessed 21/01/2023.

FUNDamentals in Athletics'

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Background

A new physiotherapy programme (Fundamentals in Athletics) was developed to meet the needs of children who reported that they didn't want "boring" physiotherapy home exercise programmes; they wanted to be outdoors, in their community, to have fun, be social and to engage in sport. The programme was developed by paediatric physiotherapists and SET Outdoors; an innovative service commissioned to deliver health priorities (outlined in South Eastern H&SC Trust strategic policies) by inspiring services to utilise outdoor therapy to enhance the health, wellbeing and quality of life of vulnerable young people.

Aims/ Objective

To evaluate the impact of the pilot 'Fundamentals in Athletics' programme, focusing on participant emotional and physical well-being.

Methodology

A service evaluation was conducted.

Young people were eligible to participate if they met the following criteria: currently receiving paediatric physiotherapy services, aged 13-15 years, independently mobile (with or without walking aids), had treatment goals related to community-based physical activity, and willingness to participate. Young people who did not meet these criteria were not eligible to participate.

Participants attended once per week for six weeks at a local athletics track. Sessions (1 hour in duration) were co-facilitated by a paediatric physiotherapist and qualified athletics coach.

Assessments were conducted by the physiotherapist before and after the programme. Mental well-being was assessed using the World Health Organisation- Five Well-Being Index (WHO-5). Physical well-being was assessed using the timed single leg balance test (both legs assessed). Verbal feedback on the programme was also sought.

Results

Four participants took part, of whom three completed outcome measurements and provided feedback. Improvements on the WHO-5 and in timed single leg balance were observed for all participants. Verbal feedback was very supportive: "I have become more positive and open, and I have made new friends" (Young Person); and "It helped with my child's mental health; it helped their anxiety" (Parent).

Conclusions / Implications for practice

This small pilot evaluation of a new community-based exercise programme, co-delivered by physiotherapists and exercise professionals, demonstrated improvements in mental and physical well-being. Feedback from participants also suggested improvements in confidence, engagement in activities of daily living and quality of

life. The programme offered young people a positive experience of sport; setting down healthy beliefs and behaviours that protect against ill health as recommended by Sport England (2021).

Based on the success of this pilot, four 'Fundamentals' groups were co-facilitated during summer 2022 and further groups are planned for 2023.

A call to action: gasping for attention

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Background

Children with severe neurodisability (ND) are gasping for attention; respiratory causes are the leading cause of death and hospital admission for children with ND (Gibson et al 2021, Kansra 2016). Reduced mobility altered muscle tone, scoliosis, impaired swallow and impaired cough leave children with severe neurodisability vulnerable to respiratory illness (Legg et al 2023, Kansra 2016, Winfield et al 2014). Respiratory admissions average 2.5 times longer in children with cerebral palsy (CP) compared to the general population (Meehan 2017), but their needs seldom receive focus from those who plan and commission healthcare services. Many are not seen by a respiratory physician, nor do they have regular respiratory assessment. Care tends to be reactive and instigated only after serious illness has occurred.

In 2021 'Prevention and management of respiratory disease in young people with cerebral palsy: consensus statement' (Gibson et al 2021) was published. The researchers identified risk factors for respiratory illness, and because of a dearth of evidence, used a Delphi approach to produce a consensus guideline.

Methodology

The Association of Paediatric Chartered Physiotherapists (APCP) respiratory committee pledged to use the publication to drive change for this vulnerable patient group in the United Kingdom. We formed a working group 'consensus to action' with paediatricians from the British Academy of Childhood Disability (BACD) and Speech and Language Therapists from the Paediatric Dysphagia Clinical Excellence Network (PDCEN). Future stakeholder engagement is planned to ensure the voice of children and families is heard.

The group has identified three main themes that are barriers to improving care:

- 1) Identification of children who are at risk
- 2) Services to treat children once identified
- 3) Evidence to support treatment approaches

Change begins with identification of at-risk children and collection of data, which in turn can support development of targeted services. Respiratory physiotherapy is outside of the comfort zone of many physiotherapists, so we are producing a simple risk assessment matrix which can be used during routine physiotherapy assessment, with a suggestion to use alongside the CPIP assessment or other annual reviews. The matrix comprises simple questions for children and families and does not require any knowledge of respiratory physiotherapy. Alongside this we are producing a guide to support both new and existing paediatric respiratory

services and have created an online space using the Future NHS platform, where clinicians can share cases and problem solve.

Our aim in disseminating our work at conference is to galvanise the support of non-respiratory physiotherapists in identifying children at risk of respiratory morbidity. We hope that with the support of our colleagues, we can begin carrying away the small stones that will eventually move the mountain for these vulnerable children, allowing them to breathe more easily.

References

Kansra S, Ugonna K. Arch Dis Child Educ Pract Ed 2016;101:226–231

Gibson, N., Blackmore, A.M., Chang, A.B., Cooper, M.S., Jaffe, A., Kong, W.-R., Langdon, K., Moshovis, L., Pavleski, K. and Wilson, A.C. (2021), Prevention and management of respiratory disease in young people with cerebral palsy: consensus statement. Dev Med Child Neurol, 63: 172-182.

Meehan, E., Reid, S.M., Williams, K., Freed, G.L., Sewell, J.R., Vidmar, S., Donath, S. and Reddihough, D.S. (2017), Hospital admissions in children with cerebral palsy: a data linkage study. Dev Med Child Neurol, 59: 512-519

Legg et al (2023) BTS Clinical Statement on the prevention and management of community-acquired pneumonia in people with learning disability. Thorax;78(suppl 1):22–52

Winfield NR, Barker NJ, Turner ER, Quin GL. Non-pharmaceutical management of respiratory morbidity in children with severe global developmental delay. Cochrane Database Syst Rev. 2014 Oct 19;2014(10)).

The translation and cultural adaptation of the Paediatric Balance Scale to Hindi

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Background

Balance difficulties are related to health conditions and are linked to specific body structure and function dysfunctions. However, they impact the individual's ability to perform activities independently and their participation in life situations (Cruz et al., 2015). Therefore, improving balance could be crucial in achieving the aims of improving independence or participation (Franjoine et al., 2003). The Paediatric Balance Scale (PBS) is a unique tool developed to assess functional balance in children with mild to moderate balance impairment and is available in English, thereby limiting its use among the predominantly Hindi speaking population of the Indian subcontinent. Therefore, this study aimed to translate and culturally adapt the PBS to Hindi.

Aims / Objective

To develop a Hindi version of the PBS which would be conceptually equivalent to the original English-version

Methodology

The approach chosen for this cross-cultural translation research was a forward-backward translation. This was done by four voluntary translators. In addition, the principal researcher collaborated with two paediatric therapists working in the India to revise the translated instrument and adapt it for usage in a different setting.

Results

The forward translation was more time-consuming and difficult for the translators than the backward translation. Several discrepancies were found between the translations, which were split into two main groups: 'grammar' and 'vocabulary.' Consensus was reached for the discrepancies, and the final Hindi version of the PBS was acquired.

Conclusions / Implications for practice

Since the PBS Hindi version was conceptually equivalent and the structure was not modified on comparison with the original English scale, it can be concluded that the PBS translation to Hindi was successful.

The Hindi version of the PBS requires validation before being used in clinical practice. For the validation process, a further study would be required to investigate the correlation of the PBS and other outcome measures which can be a feasible MSc project for a future student. I am happy to willingly collaborate with anyone wishing to do this.

References

- CRUZ, J., MARQUES, A., JACOME, C., GABRIEL, R. & FIGUEIREDO, D. 2015. Global Functioning of COPD Patients With and Without Functional Balance Impairment: An Exploratory Analysis Based on the ICF Framework. *COPD*, 12, 207-16.
- FRANJOINE, M. R., GUNTHER, J. S. & TAYLOR, M. J. 2003. Pediatric balance scale: a modified version of the berg balance scale for the school-age child with mild to moderate motor impairment. *Pediatr Phys Ther*, 15, 114-28.

Re-SPLASH - Re-Starting Physiotherapy Led Aquatic Therapy Services in Hospital

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Background

Aquatic Therapy (AT) is recognised as a valuable treatment option for children and young people (CYP) in the management of a chronic condition or to facilitate rehabilitation. AT involves prescribed exercises completed in a warm, accessible hydrotherapy pool with a physiotherapist and/or assistant¹.

As with all centres across the UK, the hydrotherapy pool at the Royal Hospital for Children (Glasgow) had to close due to the covid-19 pandemic. Many pools have since failed to re-open or are at risk of closure². Closures can impact CYP who benefit from AT over land-based therapy.

In July 2022, a Quality Improvement (QI) initiative was commenced to re-open the hydrotherapy pool at RHC.

The re-opening provided an opportunity to re-evaluate and enhance the AT service being provided.

Aims / Objective

Our primary aim was to effectively re-open the hydrotherapy pool to acute and local community paediatric physiotherapy services.

Our secondary aims were:

- To encompass a more person-centred and goal-oriented approach to AT
- To develop staff knowledge and skills in AT

Methodology

A quality improvement approach was incorporated for this service development.

To re-open the hydrotherapy pool, operational aspects were addressed including updating infection control policies, reviewing day-to-day running of the pool, process-mapping the patient journey and recommencing staff training.

Outcome measures were established to ensure a person-centred goal-oriented approach and documentation adapted to incorporate patient feedback.

Evidence based practice has been developed through analysis of pool use, reviewing outcome measures and appraising the current literature.

Ethical approval was not required for this Quality Improvement³ project.

Results

The hydrotherapy pool re-opened in March 2023. In the first 6 months there were 35 patients and 95 AT sessions. Training of staff has included in-house AT practical sessions, journal clubs to appraise current literature and evacuation training for hospital staff (n= 60).

Goal attainment scaling (GAS) goals for all CYP using AT has been implemented to promote a person-centred approach to therapy.

Conclusions / Implications for practice

The hydrotherapy pool at RHC has now been effectively reopened with consistent use across our service. Though challenging, the pandemic has given opportunity to evaluate and develop the use of the hydrotherapy pool. QI methodology has been a valuable guide in systematically implementing this service development and would be a useful method for other services looking to reopen the use of hydrotherapy pools. It is important that paediatric physiotherapists continue to contribute to the evidence-base of AT to support its use.

References

ATACP 2015, Guidance on good practice in aquatic physiotherapy

CSP (Chartered Society of Physiotherapy) 2023, Protect your aquatic physiotherapy service, viewed 4th October 2023. <https://www.csp.org.uk/campaigns-influencing/campaigns/aquatic-physiotherapy>

HQIP 2017, Guide to managing ethical issues in quality improvement or clinical audit projects, viewed 4th October 2023, [guide-to-managing-ethical-issues-in-quality-improvement-or-clinical-audit-projects.pdf](https://www.hqip.org.uk/guide-to-managing-ethical-issues-in-quality-improvement-or-clinical-audit-projects.pdf) (hqip.org.uk)

Breathe-Easy: a pilot study to examine the acceptability and feasibility of a novel postural management night-time intervention to improve respiratory health of children with complex neuro-disability

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Background

Children and young people (CYP) with complex neuro-disability are at high risk of respiratory illness, with consequent frequent hospitalisations and premature death. With limited movement ability and eating, drinking and swallowing difficulties, respiratory illness may be triggered by aspiration, when saliva, food, liquid or stomach contents enter the lungs. Aspiration risks increase at night-time when children are positioned on their backs, which is a common position prescribed for night-time postural management

Aims / Objective

This study aimed to investigate the acceptability and feasibility of a novel night-time postural management intervention to improve CYP's respiratory health.

Methodology

Ethical approval - IRAS project ID: 288217. REC reference: 20/LO/1239

CYP with complex neuro-disability were recruited to a six-month intervention.

Inclusion criteria: aged 2-18 years; dependent on others to move their bodies; swallowing difficulties; fed via gastrostomy or jejunostomy; and under respiratory consultant care.

A mixed methods design was utilised incorporating a before-after observational study and qualitative interviews. Intervention included semi-prone positioning on a flatbed to promote upper airway drainage. Quantitative measures of respiratory health and sleep were collected at baseline, 3 and 6 months. Semi-structured interviews were conducted with parents, CYP, health, education and care professionals involved with the CYP. Data analysis included descriptive statistics and thematic analysis.

Results

Eleven CYP were recruited to trial the intervention. Eight participants completed the 6-month trial at home or in a residential setting. Twenty-nine interviews were conducted. Respiratory health and sleep data showed stepwise improvements from baseline to six months, with reductions in hospitalisations, use of antibiotics and chest infections. Themes from the interviews included improved chest health and sleep, easier breathing and improved secretion management. Changing usual practice from supine lying was an important theme: parents viewed this positively, but physiotherapists expressed some concerns regarding tissue viability and long-term orthopaedic issues. An individualised approach was found to be important with careful assessment and using the protocol to adapt to the needs of the child.

Conclusion / Implications for practice

This pilot study has demonstrated acceptability and feasibility of this intervention in one community service. All parents are planning to continue with the intervention. A multi-centre feasibility trial is now planned to examine its effectiveness in other services. The results from this trial has implications for practice to consider respiratory health as well as posture when advising on night-time positioning for children with complex neurodisability.

References

- Prevention and management of respiratory disease in young people with cerebral palsy: consensus statement. Noola Gibson, Amanda M Blackmore, Anne B Chang, Monica S Cooper, Adam Jaffe, Wee-Ren Kong, Katherine Langdon, Lisa Moshovis, Karolina Pavleski, Andrew C Wilson
<https://pubmed.ncbi.nlm.nih.gov/32803795/>
- G. Glover and M. Ayub, "How people with learning disabilities die.," Improving Health and Lives: Learning Disabilities Observatory, Vols.
http://www.improvinghealthandlives.org.uk/uploads/doc/vid_9033_IHAL2010-06%20Mortality.pdf, 2010.
- N. Young, A. McCormick, T. Gilbert, A. Ayling-Campos, T. Burke, D. Fehlings and J. Wedge, "Reasons for hospital admissions among youth and young adults with cerebral palsy.," Archives Physical Medicine Rehabilitation, vol. 92, pp. 46-50, 2011.
- A. Blackmore, N. Bear, E. Blair and et al., "Predicting respiratory hospital admissions in young people with cerebral palsy.," Archives Diseases in Childhood, no. doi: 10.1136/archdischild-2017-314346., 2018.

Validation of the Spider, a multisystemic symptom impact tool for symptomatic hypermobility.

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Background

Pain, joint instability, and soft tissue injury are the most commonly reported symptoms of joint hypermobility¹. However, symptoms often extend multisystemically with manifestations that significantly impact quality of life^{2,3}. Without routine screening, these symptoms often go undetected. The Spider, a 31-item symptom impact questionnaire was developed to evaluate the symptoms of hypermobility across eight domains: pain, fatigue, neuromusculoskeletal, cardiac dysautonomia, gastrointestinal, urogenital, depression and anxiety⁴. Construct validity has been established for each domain in turn^{5,6,7}. The aim of this study was to determine if total scores aggregated across the domains provide a valid measure of the magnitude of the symptom impact of hypermobility on daily life in adolescents.

Objectives

1. To examine the known-group validity of the Spider to determine if total scores can differentiate between those with and without symptomatic hypermobility.
2. To examine the convergent validity of the Spider total scores using an established measure of daily functional ability, the Paediatric Quality of Life Inventory (PedsQL).
3. To explore which of the multisystemic manifestations (Spider domains) have the strongest associations with poorer functional ability.

Methodology

This study was an observational, cross-sectional study. Ethical approval was granted by the UCL Research Ethics Committee. Participants aged 13 to 18 years with and without symptomatic hypermobility were invited to complete the Spider and PedsQL questionnaires online via advertisement through 3 hypermobility charities (EDS UK, The ED Society, HMSA) and a private physiotherapy hypermobility unit. Data was analysed using descriptive and inferential statistics in SPSS.

Results

441 adolescents completed the study. Known-groups validity was evidenced by the significant between-group differences in Spider scores for those with and without hypermobility (median difference 42.34, $p < 0.001$). Convergent validity testing demonstrated a strong inverse correlation between the Spider and PedsQL scores. As Spider scores increased, indicative of greater symptom impact, PedsQL scores decreased accordingly ($r = -0.750$, $p < 0.001$). Multiple linear regression analysis of the domain scores revealed that the fatigue, cardiac dysautonomia and depression domains were the mostly strongly associated with poorer functional ability in adolescents.

Conclusion

Results support the aggregation of scores from the eight Spider domains as a valid measure of the impact of hypermobility on functional ability in daily life in adolescents. Total Spider scores can be used by clinicians to indicate the magnitude of symptom burden alongside domain scores which assess the symptom profile to direct and prioritise patient care. Future research will determine the utility and responsiveness of total scores to change, either over time or in response to intervention.

References

1. PACEY, V., TOFTS, L., WESLEY, A., COLLINS, F. & SINGH-GREWAL, D. 2015b. Joint hypermobility syndrome: a review for clinicians. *Journal of Paediatrics and Child Health*, 51, 373-80.
2. PACEY, V., TOFTS, L., ADAMS, R. D., MUNNS, C. F. & NICHOLSON, L. L. 2015a. Quality of life prediction in children with joint hypermobility syndrome. *Journal of Paediatrics and Child Health*, 51, 689-695.
3. MU, W., MURIELLO, M., CLEMENS, J. L., WANG, Y., SMITH, C. H., TRAN, P. T., ROWE, P. C., FRANCOMANO, C. A., KLINE, A. D. & BODURTHA, J. 2019. Factors affecting quality of life in children and adolescents with hypermobile Ehlers-Danlos syndrome/hypermobility spectrum disorders. *American Journal of Medical Genetics Part A*, 179, 561-569.
4. DE WANDELE, I., TANG, E., NINIS, N., ROWE, P. & SIMMOND, J. 2020. Development and initial validation of The Spider, a multisystem symptom impact questionnaire for patients with joint hypermobility (Part One). EDS Echo Virtual Summit.

5. EWER, E., BARRETT, C. & SIMMONDS, J. 2021a. Validation of the anxiety and depression domains of The Spider Assessment tool. APCP national conference. Virtual.
6. EWER, E., BARRETT, C. & SIMMONDS, J. 2021b. Validation of the gastrointestinal, urogenital, cardiac dysautonomia and neuromusculoskeletal domains of The Spider assessment tool.
7. TANG, E., DE WANDELE, I., KAZKAZ, H., NINIS, N., ROWE, P. & SIMMONDS, J. 2020. Development and initial validation of The Spider, a multisystem symptom impact questionnaire for patients with symptomatic hypermobility (Part two). EDS ECHO Virtual Summit.

The heROIC trial: Does the use of a Robotic rehabilitation trainer change Quality Of Life, range of movement and function In children with Cerebral Palsy?

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Background

Children with severe cerebral palsy (CP) (GMFCS IV/V) can find it difficult to access equipment that allows them to exercise effectively, potentially impacting their quality of life.

Children with significant physical impairments related to CP often have additional issues with pain and physical wellbeing (Houlihan et al, 2004). Physiotherapy management of children with CP focuses on improving/maintaining gross motor function, activities of daily living and preventing secondary complications such as contractures and deformities (Maher et al, 2016, Patel, 2020). An increase in repetition, motivation, and intensity of therapy, defined as more than three times a week, could increase rehabilitation potential.

Aims / Objective

This study explored whether the Innowalk Pro, a robotic rehabilitation trainer, could influence quality of life (measured by the CPCHILD questionnaire as primary outcome measure) , in children with CP, alongside, joint range of movement, spasticity and functional goals of the lower limbs, measured by goniometry, modified Tardieu scale and goal attainment scoring, GAS, respectively. Further analysis reviewed the differences between primary and secondary age students.

Methodology

A prospective single-arm, pre-post-trial was undertaken, sponsored by Whittington Health NHS Trust and ethics approval granted by London-Camden and Kings Cross Research Ethics Committee, REC reference: 19/LO/1721. The Innowalk Pro was used four times a week for 30 minutes alongside usual physiotherapy care in a school setting over a six-week period. Outcomes were evaluated immediately pre/post intervention and at six-weeks and three-months post intervention. Analysis also explored differences between primary and secondary age participants.

Results

Twenty-seven participants aged 5-18 years with a diagnosis of CP GMFCS IV/V (10 female, 17 male, mean age 12 years) were included from a convenience sample in a special school. Quality of life improved in 36% of participants (MCID 6 units), the majority of these being secondary-aged. Knee extension reduced significantly three-months post intervention. There were no meaningful changes in spasticity. GAS goals improved in 88% of participants after using the Innowalk Pro but tended to decline after a break from using the equipment, with 21% declining by two or more units at three-months post intervention.

Conclusions / Implications for practice

A six-week course of the Innowalk Pro can improve quality of life and functional goals for children with CP aged 5-18 years. After a break of 6-12 weeks, functional goals tend to return to baseline. Given the known benefits of exercise, further suggestions to research how the Innowalk Pro could impact earlier in life on complications secondary to disability such as pain, weight gain and gastro-intestinal function is advised.

References

Houlihan CM, O'Donnell M, Conaway M, Stevenson RD. Bodily pain and health-related quality of life in children with cerebral palsy. *Dev Med Child Neurol.* 2004 May;46(5):305-10. doi: 10.1017/s0012162204000507. PMID: 15132260.

Maher, Toohey and Ferguson (2016) Physical activity predicts quality of life and happiness in children and adolescents with cerebral palsy, *Disability and Rehabilitation*, 38:9, 865-869, DOI: 10.3109/09638288.2015.1066450

Patel, D. R., Neelakantan, M., Pandher, K., & Merrick, J. (2020). Cerebral palsy in children: a clinical overview. *Translational pediatrics*, 9(Suppl 1), S125–S135. <https://doi.org/10.21037/tp.2020.01.01>

Making sense of 'sport as a therapy choice' for paediatric physiotherapists working with young people who have disabilities.

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Background

The professional lifeworld of physiotherapists is influenced by the challenge of maintaining patients' engagement with physiotherapy and it consistently appears in their top ten research priorities (Chartered Society of Physiotherapy, 2021). Some paediatric physiotherapists have successfully employed sport and physical activity (PA) to address this issue in young people with disabilities (YPwD). However, within the research literature, there has been no exploration of the meanings attributed to 'sport as a therapy choice' nor how paediatric physiotherapists make sense of it, among those who routinely use the term and the approach.

Aims / Objective

Therefore, this project explores paediatric physiotherapists' beliefs and lived experiences to examine how they make sense of 'sport as a therapy choice' in their physiotherapy practice.

Methodology

Accordingly, a qualitative research paradigm using Interpretative Phenomenological Analysis analyses data from semi-structured individual interviews with sixteen UK-based paediatric physiotherapists working in both public and private healthcare. Participants were recruited through the APCP.

Ethical approval for this study was granted by the University of Salford Ethical Approval Panel on 21.05.20 (HSR 1920-070).

Results

Findings and interpretative analysis revealed six superordinate themes –

1. Shaped by contexts.
2. It's all about the kids.
3. Relationship of physiotherapy and sport/physical activity.
4. Sport/physical activity – a tool in the toolbox.
5. Locating identity.
6. Embodiment of models.

The themes highlighted the multiple ways in which 'sport as a therapy choice' was experienced and enacted by contemporary paediatric rehabilitators.

Conclusions / Implications for practice

Accordingly, suggestions for changing the emphasis within future paediatric physiotherapy practice and pre-qualifying physiotherapy education are presented.

As no study has previously explored how paediatric physiotherapists experience 'sport as a therapy choice,' this study provides a unique contribution, enabling exploration of implications of practitioners' varying contextual influences, alongside their knowledge and philosophical perspectives.

Keywords

Physiotherapy, Young people with disabilities, Sport, Physical activity, Engagement.

Effectiveness of integrated hip care pathways for pain, function, and quality of life in children with Cerebral Palsy: A systematic literature review.

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Aims / Objective

To systematically review evidence of the effectiveness of integrated hip surveillance pathways on outcomes relating to pain, function, and quality of life in children with Cerebral Palsy (CP).

Methodology

A systematic literature review, designed, conducted, and reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA). Inclusion criteria: confirmed diagnosis of CP, management under recognised international hip surveillance pathways, outcome measures of hip displacement plus at least one other outcome measure relevant to pain, function, or quality of life (QOL).

Results

100 potential articles were identified. 12 full text articles were screened, four (1 – 4) met the inclusion criteria. Reduced range of movement was associated with hip pain in children with CP. Increasing age, Gross Motor Function Classification Score (GMFCS) level and migration percentage (MP) were indicators of increased hip pain. Mean outcome scores relating to general health decline with increased age. Increased MP and GMFCS level are associated with interruption to activities of daily living. Outcomes in function and QOL are under-researched in the current integrated hip surveillance pathway evidence-base.

Interpretation

Effects of spasticity are not fully understood due to methodological inconsistencies. Wider outcomes related to function and quality of life need to be included to capture the impact on children and young people.

What this paper adds

Increased hip pain with decreased ranges of movement.

Increased pain with increased age and Gross Motor Function Classification Score.

Early intervention for hip displacement does not successfully mitigate pain.

Effectiveness of integrated pathways on function and quality of life is under-researched.

Studies investigating integrated pathways and holistic outcomes are needed to inform practice.

References

1. Marcstrom A, Hagglund G, Alriksson-Schmidt AI. Hip pain in children with cerebral palsy: a population-based registry study of risk factors. *BMC Musculoskeletal Disorders*. 2019; 20 (1): 1-10
2. Schmidt SM, Hagglund, G, Alriksson-Schmidt A. Bone and joint complications and reduced mobility are associated with pain in children with cerebral palsy. *Acta Paediatrica*. 2020; 109 (3): 541–549.
3. Larsen SM, Ramstad K, Terjesen T. Hip pain in adolescents with cerebral palsy: a population-based longitudinal study. *Developmental medicine and child neurology*. 2021; 63 (5): 601–607.
4. Larsen SM, Terjesen T, Jahnsen RB, Diseth TH, Ramstad K. Health-related quality of life in adolescents with cerebral palsy; a cross-sectional and longitudinal population-based study. *Child : care, health & development*. 2023; 49 (2): 373–381.

The differences between skeletal muscle in children with Cerebral Palsy and children who are typically developing.

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Overview

Cerebral Palsy (CP) is the most common cause of physical disability in childhood with muscle contractures being a significant secondary complication. Previously, significant focus has been given to the treatment and management of extrinsic clinical features, such as muscle spasticity, with the hope that targeting this will reduce the likelihood of contracture formation. However, despite this approach, contractures still occur and have wide reaching implications into many aspects of a child's life. This leads us, as clinicians, to question what other factors could play a role in the formation of contractures and whether, by exploring more intrinsic features such as the pathomorphology of the muscle itself, the likelihood of contracture formation could be reduced in this population.

Key Questions

1. What are the main differences between the skeletal muscles of children with CP and children who are typically developing (TD)?
2. How do those differences affect the likelihood of contracture development?

Methodology

A literature search was completed using PubMed, Cochrane, and Ovid Medline to identify relevant studies published within the last 10 years (2013-2023). Search terms included 'cerebral palsy', 'muscle morphology', 'muscle contractures' and 'skeletal muscle'. Overall, 187 papers met the inclusion criteria and, after being screened by 2 reviewers for eligibility, 11 articles were included for final analysis.

Results

Using evidence from the literature search, there were 6 main differences in skeletal muscle in children with CP when compared to TD children.

These were:

- Increased amount of connective tissue
- Reduced sarcomere stiffness
- Reduced number of satellite cells
- Increased sarcomere length but reduction in number
- Reduced muscle volume/ cross-sectional area
- Increased inter and intramuscular adipose tissue

Application to Clinical Practice

To disseminate this information, the above differences have been summarised in poster form along with a brief description about how that difference would affect the likelihood of the development of contractures. This poster will provide clinicians with a visual reminder of the differences in CP skeletal muscle and should be of benefit for assessment, management and treatment of children with CP.

Conclusion

Current research suggests that there are significant cellular and subcellular differences in CP muscle and clinicians should be aware of these differences to implement a more personalised treatment and management plan.

References

- Lieber, R. L., & Fridén, J. (2019). Muscle contracture and passive mechanics in cerebral palsy. *Journal of applied physiology*.
- Howard JJ and Herzog W (2021) Skeletal Muscle in Cerebral Palsy: From Belly to Myofibril. *Front. Neurol.* 12:620852. doi: 10.3389/fneur.2021.620852
- Lieber, R. L., & Theologis, T. (2021). Muscle-tendon unit in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 63(8), 908-913.
- Dayanidhi, S., Dykstra, P. B., Lyubasyuk, V., McKay, B. R., Chambers, H. G., & Lieber, R. L. (2015). Reduced satellite cell number in situ in muscular contractures from children with cerebral palsy. *Journal of Orthopaedic Research*, 33(7), 1039-1045.
- Mathewson, M. A., & Lieber, R. L. (2015). Pathophysiology of muscle contractures in cerebral palsy. *Physical Medicine and Rehabilitation Clinics*, 26(1), 57-67.
- Matthiasdottir, S., Hahn, M., Yaraskavitch, M., & Herzog, W. (2021). Muscle and fascicle excursion in children with cerebral palsy. *Clinical Biomechanics*, 29(4), 458-462.
- Romero, B., Robinson, K. G., Batish, M., & Akins, R. E. (2021). An emerging role for epigenetics in cerebral palsy. *Journal of Personalized Medicine*, 11(11), 1187.
- Howard, J. J., Graham, K., & Shortland, A. P. (2022). Understanding skeletal muscle in cerebral palsy: a path to personalized medicine. *Developmental Medicine & Child Neurology*, 64(3), 289-295.
- Lieber, R. L., Roberts, T. J., Blemker, S. S., Lee, S. S., & Herzog, W. (2017). Skeletal muscle mechanics, energetics, and plasticity. *Journal of neuroengineering and rehabilitation*, 14, 1-16.
- Dayanidhi, S., & Lieber, R. L. (2014). Skeletal muscle satellite cells: mediators of muscle growth during development and implications for developmental disorders. *Muscle & nerve*, 50(5), 723-732.
- Lorenzo, T. M., Rocon, E., Caballero, I. M., & Lara, S. L. (2018). Medial gastrocnemius structure and gait kinetics in spastic cerebral palsy and typically developing children: a cross-sectional study. *Medicine*, 97(21).

A focus group of experienced paediatric physiotherapists sharing their perspectives on physiotherapy management of Patellar Dislocation

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Background

Patellar dislocation, a common adolescent knee injury, has a high recurrence rate, often leading to painful instability and patellofemoral degeneration. Current management of patellar dislocation includes a variety of operative and non-operative approaches and as there is little evidence to support physiotherapy management, it is unclear what guides practice.

Aims / Objective

To explore the understanding and knowledge of patellar dislocation in experienced paediatric physiotherapists and how this informs their clinical reasoning and management of this condition.

Methodology

This qualitative study gained ethical approval and used purposive sampling to recruit experienced UK-based musculoskeletal paediatric physiotherapists, to virtual focus groups lasting 90 minutes. The focus groups explored: the rehabilitation pathway, management of patellar re-dislocation risk and patient psychosocial well-being, outcome measures, criteria for returning to sports, discharge advice, and future research. Focus group meetings and data collection took place in July 2022 recordings were transcribed verbatim. Subsequently, exploratory thematic analysis was undertaken.

Results

Nine physiotherapists (5 to over 20 years clinical experience) from the NHS and private practice attended the focus groups. Participants' reflections were categorised into themes including early management, rehabilitation pathway, measuring change and future practice. Although theoretical saturation was not achieved, rich and in-depth data were collected.

Areas discussed included the need to manage patellar dislocation based on prior experience and research from other MSK domains, variations in or lack of protocols and referral pathways for acute management, and the perceived importance of addressing patient's fear and anxiety. All the therapists acknowledged a need to minimise risk of recurrence with their rehabilitation programme and believed that increased duration of rehabilitation would lead to better outcomes and return to sport but were restricted by a lack of resources, time, space, and equipment. Clinical outcome measures collected included muscle strength, global measures such as percentage improvement, and visual analogue scale scores for pain. Despite an awareness of more validated measures such as PEDI-IKDC, few therapists acknowledged using them. Return to sport criteria were also mostly derived from the ACL literature, using tests such as single leg hop.

Conclusions / Implications for practice

Limited evidence and available guidelines in paediatric patellar dislocation have led to a lack of standardised management approaches. Physiotherapists agree on many aspects of management thereby supporting the case for standardisation. Further research into this condition, in conjunction with the development of clinical guidelines, would help reduce variability in care and improve outcomes.

Ankle plantarflexor volume appears reduced in some Idiopathic toe walkers. A service evaluation.

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Introduction

Plantarflexion contractures are often the focus for intervention in children who toe walk (TW). Reduced plantarflexor strength¹ and greater proportions of type 1 fibres in the plantarflexors² have been identified in TW. There are variable but mild kinematic differences between children with mild bilateral cerebral palsy (CP) and

TW^{3,4}. Children with CP have reduced muscle volumes compared to typically developing children⁵. Plantarflexor morphology in TW has not yet been described.

Methodology

Eight children (5 male) aged 7-15yr (mean=11.86yrs) referred to orthopaedics for toe walking/plantarflexion contracture, with no underlying diagnosis, had a routine examination in the gait laboratory. They were matched for age and sex to children with CP (GMFCS I-II) who had also been examined. Assessment included gait analysis and 2D ultrasound imaging of the lateral gastrocnemius (LG). Muscle volumes were estimated⁶, normalised to mass. Selective motor control was assessed using the SCALE score⁷ and Functional mobility using the Gillette Functional Assessment Questionnaire (GFAQ)⁸. Data was compared to a database of controls (unpaired t-test) and between groups (paired t-test). One limb per subject was randomly selected for analysis.

Results

All children had plantarflexor contractures: mean dorsiflexion range (knee extended) of -9.4° (SD 10.9°) for TW and -6.5° (SD 7.2°) for CP. TW had close to normal motor control (SCALE: Median=10, Range=8-10) whereas CP had a greater variability (SCALE: Median=9.5, Range=5-10). Walking function was normal for TW (GFAQ Median=10 Range=8-10) but variable for CP (GFAQ Median=8 Range=5-10).

No difference in speed/cadence was found between groups ($p=0.5/p=0.86$), all within normal limits. All children were in plantarflexion at initial contact (no difference between groups, $p=0.48$). Mean ankle dorsiflexion in stance and swing were not different between groups ($p=0.94$, $p=0.84$).

For four TW children, normalised mean LG volume was significantly smaller than controls (1.07vs1.53 ml/kg) ($p<0.01$) but no different to CP (1.01ml/kg) ($p=0.64$). The other TW had LG CSA which was too great for the US field of view.

Conclusions / Implications for practice

TW with a plantarflexion contracture showed less variability in selective motor control and functional mobility to a matched CP group, but had similar cadence, speed and ankle kinematics. A subgroup of TW had reduced Plantarflexor volume compared to controls, comparable in size to CP. Other TW's muscles were larger and could not be measured. This suggests subgroups of TW having different muscle morphology. Further work is required to further elucidate plantarflexor muscle morphology in TW, and its relationship with motor function to help us understand aetiology and improve management.

References

1. Caserta A, Morgan P, McKay M, Baldwin JN, Burns J, Williams C. (2022) Children with idiopathic toe walking display differences in lower limb joint ranges and strength compared to peers: a case control study. *Journal of Foot and Ankle Research* 15(70)
2. Eastwood D, Dennett X, Shield L, Dickens R. (1997) Muscle abnormalities in idiopathic toe-walkers. *Journal of Pediatric Orthopaedics B* 6(3):215-218
3. Kelly IP, Jenkinson A, Stephens M, O'Brien T (1997) The kinematic patterns of toe-walkers. *J Pediatr Orthop.* 17:478-480.
4. Hicks R, Durinick N, Gage JR. (1988) Differentiation of idiopathic toe-walking and cerebral palsy. *J Pediatr Orthop.*;8:160-163

5. **Noble JJ, Fry NR, Lewis AP, Keevil SF, Gough M, Shortland AP (2014) Lower limb muscle volumes in bilateral spastic cerebral palsy. *Brain and Development* 36 (4): 294-300**
 6. Vanmechelen I, Shortland A, Noble J (2018) Lower limb muscle volume estimation from maximum cross sectional area and muscle length in cerebral palsy and typically developing individuals. *Clinical Biomechanics* 51, 40-44
 7. Fowler E, Staudt L, Greenberg MB, Oppenheim WL (2009). Selective Control Assessment of the Lower Extremity (SCALE): development, validation, and interrater reliability of a clinical tool for patients with cerebral palsy. *Dev Med Child Neurol.* 51(8):607-14.
 8. Novacheck TF, Stout JL, Tervo R (2000) Reliability and validity of the Gillette Functional Assessment Questionnaire as an outcome measure in children with walking disabilities. *J Pediatr Orthop.* 20(1):75-81.
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Children and Young People (CYP) with acute finger injuries do not need referral to Physiotherapy.

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Background

A return to school and PE lessons post-covid resulted in an increased number of finger injury referrals in a short space of time, highlighting a need to review the orthopaedic pathway. Barnet Hospital Children and Young People's (CYP) Physiotherapy musculoskeletal out-patient service identified a consistent pattern that CYP with finger injuries heal well without requiring routine referral to Physiotherapy.

Aims / Objective

- Evaluate practice to confirm that CYP with finger injuries do not require referral to Physiotherapy for a safe discharge from the Emergency Department or Fracture Clinic (ED/VFC).
- Ensure management in the best interests of the young person and family whilst optimising Physiotherapy resource allocation.

Methodology

Research Portfolio Manager, Theme 3 (NIHR Divisions 3 & 5), Royal Free London NHS Foundation Trust confirmed that this was a service evaluation and not research and therefore ethical approval was not required.

We:

- Observed that finger injuries were all healing well by the time of initial Physiotherapy contact, thereby not requiring a 30-minute face-to-face or telemedicine appointment.
- Discussed and agreed with Orthopaedic consultants which finger injuries should be included in our evaluation of practice: all soft tissue and avulsion finger injuries.
- Identified all appropriate finger injury referrals via triage on electronic patient records (EPR).
- Devised a finger injury patient information leaflet, including photos of exercises with Physiotherapy email and telephone contact details.

- Contacted the young person's parent/carer via phone, reassured that finger injuries heal well in young people and sent a leaflet via email, advising parents to make a patient-initiated follow-up (PIFU) if required in the event of ongoing problems after 4-6 weeks.

If unable to contact the family via phone, information was sent by post.

Results

Between July 2021 to May 2023, 128 patients with soft tissue or avulsion finger injuries have been managed with a telephone call and provision of an information leaflet. There has been no contact from any parent/carer for PIFU.

Conclusion

Young people with finger injuries do not require blanket referral for a 30-minute Physiotherapy appointment; they are currently managed with a brief telephone call and advice leaflet. This provides early intervention with appropriate advice, reduces unnecessary Physiotherapy appointments to optimise resource allocation, and saves parents and young people time attending appointments.

Data was shared with Orthopaedic consultants who endorsed this approach. The next phase is underway to change Electronic Patient Record processes for young people with finger injuries so they can be safely discharged directly from ED or VFC with an advice leaflet, without referral to Physiotherapy.

Consequently, Adult Physiotherapy services within the Trust are undertaking their own evaluation of management of finger injuries, mirroring the current CYP service.

Barriers and Facilitators for families of children with neurodisability participating in research: implications for physiotherapy research design and delivery.

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Background

Neurodisability forms the largest group of disabled children and young people, with an estimated prevalence of 3-4% in England ⁽¹⁾. It is anticipated this number will rise as a consequence of improved neonatal survival ^(2,3,4). A lack of research involving children with neurodisability makes providing evidence-based interventions challenging ⁽⁶⁾; therefore, it is essential to increase research and research participation for children and families affected by neurodisability.

Aims / Objective

The aim of this scoping review was 1) consider barriers and facilitators to families of children with neurodisability participating in clinical research 2) identify practices to improve research access for these families.

Methodology

The JBI methods ⁽⁵⁾ for scoping reviews were used. Criteria and search terms were refined via a preliminary search, undertaken in collaboration with a hospital librarian. Full searches of Embase, Medline, PsycINFO, CINAHL were conducted in August 2022. Titles and abstracts of each record were screened by a minimum of two authors. Data from full texts meeting criteria were extracted by at least one author then discussed with the team. Screening of reference lists of included papers was carried out and subsequent citations of these were also screened.

Results

Once duplicates were excluded, 10,728 records were yielded from database searches. Screening of 52 papers, including review papers resulted in a total of 3 papers and an additional 12 papers sourced via reference lists and citation searching being included. Of these 15 papers, 3 used mixed methods and 12 used qualitative methods and. Parents/carers and health professionals participated.

The review identified a key facilitator is altruism and the likelihood of engagement is heightened by clinicians having a good rapport with families. Key barriers identified included time commitment and other parental responsibilities, concerns for their child's wellbeing, health status, and their child's ability to take part in the study. Gatekeeping could be a factor influencing clinicians' decision to approach families about research.

Conclusion

Reasons for participating or not participating in research within this population group are multi-factorial. Paediatric physiotherapy research design needs to accommodate the busy lives of families of children with neurodisability, carefully considering location of assessment and intervention. Furthermore, trust needs to be built between the physiotherapist and parents to reassure that their child's wellbeing is paramount to the clinicians. Physiotherapists should be mindful to approach all families with opportunities to participate in research to reduce gatekeeping.

References

1. NIHR (2022) "Self care of children and young people with neurodisability"
<https://www.nihr.ac.uk/documents/2290-self-care-of-children-and-young-people-with-neurodisability-commissioning-brief/31014> [accessed May 2023]
2. Royal College of Paediatrics and Child Health <https://paediatrics2040.rcpch.ac.uk/our-evidence/data-and-evidence/summary/> [accessed June 2023]
3. Haak P, Lenski M, Hidecker MJ, Li M, Paneth N. (2009) "Cerebral palsy and aging." *Dev Med Child Neurology*; 51 Suppl 4(0 4):16-23. doi: 10.1111/j.1469-8749.2009.03428.x. PMID: 19740206; PMCID: PMC4183123.
4. Strauss, D., Shavelle, R., Reynolds, R., Rosenbloom, L., Day, S. (2007) "Survival in cerebral palsy in the last 20 years: signs of improvement?" *Developmental Medicine and Child Neurology*. 49(2).
5. Peters MDJ, Godfrey C, McInerney P, Munn Z, Tricco AC, Khalil, H. Chapter 11: Scoping Reviews (2020 version). In: Aromataris E, Munn Z (Editors). *JBI Manual for Evidence Synthesis*, JBI, 2020. Available from <https://synthesismanual.jbi.global>. <https://doi.org/10.46658/JBIMES-20-12>
6. [Kelly, G.](#) (2018) "Single case experimental design: maximising the potential for research within paediatric physiotherapy." *APCP Journal*, 9(1).

“It kind of hurts ...I still do it because it’s my physio’: Children’s experiences of physiotherapy within a feasibility RCT

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Background

Children with cerebral palsy (CP) are frequently supported to carry out daily exercises with to maintain mobility. Motivation to exercise is an important factor in adherence to therapeutic programmes. The ACCEPT study¹ tested the feasibility of a 10-week physiotherapy intervention using the Happy Rehab™ (Innovaid, Denmark) interactive gaming training device. The Happy Rehab enables children to exercise, whilst standing, with assistance and resistance delivered through motors in the device. A series of motivating, interactive games are controlled by sensors in the footplates and knee pads. However, little stakeholder-centred evidence exists on Happy Rehab.

Aims / Objective

To understand the experiences and views of children with CP, their parents and physiotherapists on usual care, Happy Rehab and participating in the trial (ISRCTN80878394).

Methodology

Qualitative methods (semi-structured interviews, e-diary, and photographs) were used. Interviews were transcribed. Data were coded into categories and themes using thematic analysis. (North of Scotland Research Ethics Committee approved (20/NS/0018)).

Results

Nine parent- child dyads and three physiotherapists were interviewed. The children were aged between 7-16 years. Five themes were identified: (1) Fitting therapy into normal life: parents spoke of the challenge of finding time to engage their children in therapeutic exercise. (2) Motivation to exercise: participants felt that gaming would improve adherence to therapeutic exercise. (3) The opportunity to try something new: Happy Rehab was welcomed as a change from usual physiotherapy “boring and repetitive” routines. (4) Physiotherapists out of their comfort zone; physiotherapists were unsettled by the unfamiliar equipment. (5) Altruism and the challenge of participating: children expressed the desire to take part in research for the benefit of other children.

Overall children were positive about trial although several children talked about trial-related procedures that they disliked (e.g., removing adhesive skin tape) or that hurt them.

“it’s kind of felt weird and it hurt when they took all this stuff off” (Gabby, aged 7).

Some children explained they do usual care exercises, even though they hurt.

“It kind of hurts here (shows ankle). [I still do it] because it’s my physio and I have to do it” (Isaac, aged 11)

Physiotherapists, children, and parents thought the gaming aspect of Happy Rehab to improve motivation to exercise.

Conclusion

Children with CP tend to comply with physiotherapy procedures, even if they hurt. They found the gaming aspect of the Happy Rehab fun and motivating. Gaming may provide distraction from uncomfortable stretching exercises. Exercise trainers that encompass gaming may increase motivation and adherence to therapeutic programmes.

References

¹Rapson, R., et al., Multicentre, randomised controlled feasibility study to compare a 10-week physiotherapy programme using an interactive exercise training device to improve walking and balance, to usual care of children with cerebral palsy aged 4–18 years: the ACCEPT study protocol. *BMJ Open*, 2022. 12(5): p. e058916.

A feasibility randomised controlled trial of an interactive exercise-training device for children with cerebral palsy.

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Background

Many children with cerebral palsy undertaking physiotherapy programmes to improve mobility require support to exercise in a functional position. A novel interactive exercise trainer (Happy Rehab™, Innovaid, Denmark) enables children to exercise against resistance whilst standing, but its efficacy is uncertain.

Aims / Objective

To explore the feasibility of the **Ability and quality of life for Children with Cerebral Palsy Trial (ACCEPT)** randomised controlled trial (RCT)¹ (ISRCTN80878394).

Methodology

Fifteen children with cerebral palsy (gross motor function classification system I-III) were randomised to either 10 weeks of training with Happy Rehab™ or usual physiotherapy. A measure of dynamic balance (Next Step test²) while stepping and the Paediatric Balance Scale (PBS) were primary outcomes measures, tested at 10 and 20-week follow-up. Ethical approval was granted by North of Scotland Research Ethics Committee (20/NS/0018).

Results

Twenty-one children were assessed for eligibility, three declined to participate, one withdrew, and one did not receive the intervention. Two serious adverse events were recorded. Participants were recruited at a rate of 0.73 per month, limited by the availability of devices. 100% PBS and 87% Next Step outcomes were completed at baseline, dropping to 75% and 65% respectively at 10 and 20 weeks. Three children reached ceiling scores in PBS and was not suitable for more mobile children. Some children with autistic traits could not tolerate wearing motion analysis markers for the Next Step test.

Gains in passive range of motion were larger in the Happy Rehab group (average of 3.1° at 10 weeks, 3.75° at 20 weeks). Spasticity reduced more in the Happy Rehab group (average 0.6° at 10 and 20 weeks). Gains in muscle strength were larger in the usual care group at 10 weeks (average 1.6kg more per muscle group). The Happy Rehab group made larger gains in strength at 20 weeks (average 2.5kg) more per muscle group. Recruitment and the technical support for the intervention were negatively impacted by the COVID pandemic.

Conclusion

The Next Step test measured dynamic balance in children with higher functional balance, however the PBS was more complete. The proposed RCT requires further work to determine the primary outcome measure and

technical support in the UK for the devices. The Happy Rehab intervention showed signs of efficacy. This physiotherapy intervention was acceptable to children and families, who were willing to accommodate the device for 10 weeks.

References

¹Rapson, R., et al., Multicentre, randomised controlled feasibility study to compare a 10-week physiotherapy programme using an interactive exercise training device to improve walking and balance, to usual care of children with cerebral palsy aged 4–18 years: the ACCEPT study protocol. *BMJ Open*, 2022. 12(5): p. e058916.

²Rapson, R., et al., 2023. A cross sectional study investigating dynamic balance when stepping to targets in children with cerebral palsy compared to typically developing children. *Gait & Posture*, 101, pp.154-159.