

APCP Annual Conference

21 October 2023

The following abstracts were presented at the APCP Annual Conference in 2023

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

Ahmed ATR ^{*1,2}, Rye C ^{1,3}, Rand S¹, Simmonds JV ¹

1. Great Ormond Street Institute of Child Health, University College London.
2. West London NHS Healthcare Trust.
3. Great Ormond Street Hospital NHS Foundation Trust

**Corresponding author: atiyaturraheemahmed.94@gmail.com*

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 crosscultural 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.

Christine Douglas ^{*1,2}, Jane Simmonds ², Jonathan Wright ¹
1 Royal National Orthopaedic Hospital (RNOH), Stanmore UK 2
Great Ormond Street Institute for Child Health, UCL, UK

**Corresponding author: christinedouglas1@nhs.net*

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.

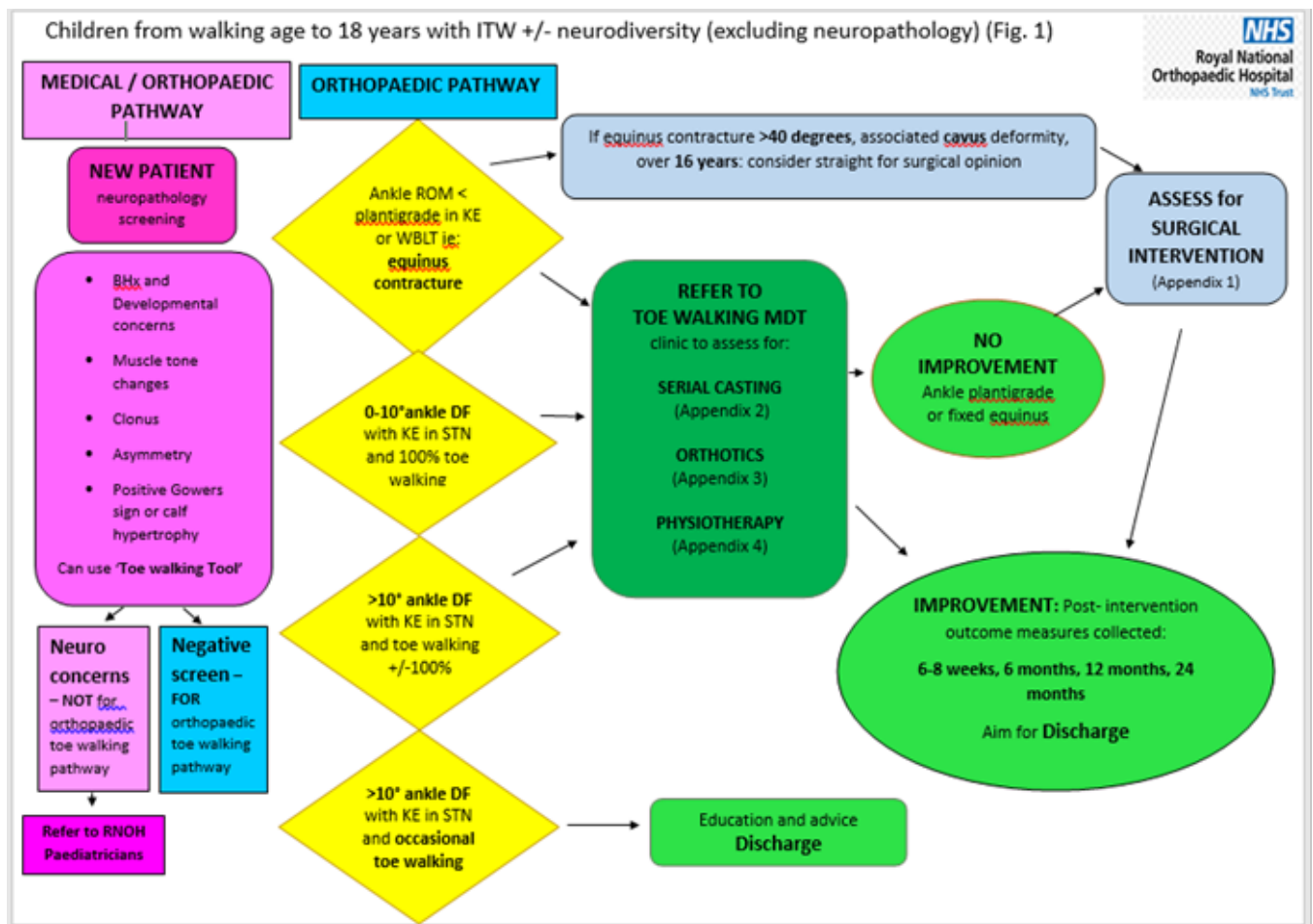
Methodology

- 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.

5. 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.
6. van Kujik, A.A., Kusters, 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, *Pediatric Physical Therapy*, pp 238-243.

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

Claire Kerr*, Oliver Perra, Róisín Keenan, Karen McConnell

*Corresponding author: c.kerr@qub.ac.uk

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 (preCovid) 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/researchcentres/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)

Dr Dawn Pickering, Cardiff University

**Corresponding author: pickeringdm@cf.ac.uk*

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).

Surve ER ^{*1,2}, Coomer A ^{1,3,4}, Rand S ¹, Simmonds JV ¹

1. Great Ormond Street Institute of Child Health, University College London.
2. West London NHS Healthcare Trust.
3. St Mary's Hospital, Imperial Healthcare Trust.
4. St Georges, University of London

**Corresponding author: esha.surve@nhs.net.*

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 EntryLevel Programs.

Jennifer Chesterton, Faculty of Health Science and Wellbeing, University of Sunderland.
Paul Chesterton, School of Health and Life Sciences, Teesside University

**Corresponding author: jen.chesterton@sunderland.ac.uk*

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 entrylevel 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 entrylevel 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

Jenny Thomas, Advanced Physiotherapist, Sheffield Children's Hospital *

**Corresponding author: Jennifer.thomas12@nhs.net*

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-centred ⁷. 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

Karen McConnell ^{*1}, Claire McFeeters², Joanne Marley², Alix Crawford³, Katy Pedlow²

1. School of Nursing and Midwifery, Queen's University Belfast,
2. School of Health Sciences, Ulster University,
3. Mae Murray Foundation

**Corresponding author: k.mcconnell@qub.ac.uk*

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.

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)

- 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

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'

Lynsey Cunningham and Clare Gardiner* (South Eastern H&SC Trust)
Lee Campbell (Athletics Coach)

**Corresponding author: Clare.gardiner@setrust.hscni.net*

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 cofacilitated 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

Naomi Winfield*, University College London, Milton Keynes University Hospital

Madeline Pilbury, Stockport NHS Foundation Trust

Carolyn Aitken Arbuckle, NHS Lothian

Jason Kettle, Lincolnshire Community Health Services NHS Trust

Samantha Grace, St George's Hospital London

Laura Lowndes, Cambridge University Hospitals NHS Trust.

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

Nikita Dcruz*, Cambridgeshire Community Services NHS Trust
Professor Jane Simmonds, University College London
Naomi Winfield, University College London, Milton Keynes University Hospital

**Corresponding author: n.dacruz@nhs.net*

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

Sarah Brown*, Susan Leiper, Barry Johnstone

**Corresponding author:
sarah.brown6@ggc.scot.nhs.uk*

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 recommending 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

1. ATACP 2015, Guidance on good practice in aquatic physiotherapy
2. CSP 2023, Protect your aquatic physiotherapy service, viewed 4th October 2023, <https://www.csp.org.uk/campaigns-influencing/campaigns/aquatic-physiotherapy>
3. 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](https://www.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

Crombie S*, Sellers D, Kapur A, Hillman G, Baskerville J, Morris C, Bremner S, Lundin J.

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, WeeRen

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.

Busby, V ^{1,2}, Ewer, E, ^{1,3} Simmonds, J.V. ^{1,4}

1. UCL Great Ormond Street Institute of Child Health,

2. Buckinghamshire Healthcare NHS Trust,

3. Hounslow and Richmond Community Healthcare NHS Trust,
4. London Hypermobility Unit, Central Health Physiotherapy

**Corresponding author: victoria.busby.20@ucl.ac.uk*

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?

Clare Grodon (Whittington Health NHS Trust)
Harriet Shannon (UCL Great Ormond Street Institute of Child Health)
Paul Bassett (Statsconsultancy Ltd)

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 threemonths 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.

Susan Booth* (studying at University of Salford) Lecturer in Paediatric Physiotherapy, University of Bolton

Professor Garry Crawford (University of Salford)

Dr Nicky Spence (University of Salford)

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 prequalifying 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.

Tanya M. McGrath*, Senior Lecturer, University of the West of England, Bristol, England (UK) Shea T. Palmer, Professor of Physiotherapy, Cardiff University, Wales (UK)

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.

Rebekah Moynihan, Physiotherapist, Leckey

**Corresponding author: Rebekah.moynihan@leckey.com*

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

Holly Heighway* - MSc Paediatric Physiotherapy, University College London. Daniel Armitage – Lecturer (Teaching), University College London. Sarah Rand – Lecturer (Teaching), University College London.

Dr Louise Kedroff - Lecturer (Teaching), University College London

**Corresponding author: Holly.heighway@nhs.net*

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.

McNee AE^{1*}, Noble J², Evans S¹, Zeigler K¹, Ng Man Sun S¹, Hulme A¹, Fry NR², Shortland AP².

¹Paediatric Orthopaedic Team, Chelsea and Westminster Hospital, London ²One Small Step Gait Laboratory, Evelina Children's Hospital, London

**Corresponding author: annemcnee@nhs.net*

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° (SD10.9°) for TW and -6.5° (SD7.2°) 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.

**Children and Young People (CYP) with acute finger injuries do not need referral to
Physiotherapy.**

Nikki Thorpe,
Royal Free NHS Trust, Barnet Hospital
Children and Young People's Musculoskeletal outpatient service.

Corresponding author: nikki.thorpe@nhs.net

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.

Candiss Argent^{*1}, Claire Ingleby¹, Elizabeth Thompson¹, Malabika Ghosh¹, Sarah Edney^{1,2}

1. Lancashire Teaching Hospitals NHS Foundation Trust, UK,
2. Newcastle University, UK

**Corresponding author: Candiss.argent@lthtr.nhs.uk*

Background

Neurodisability forms the largest group of disabled children and young people, with an estimated prevalence of 34% 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-neurodisabilitycommissioning-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). *JBIM 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

Rachel Rapson*, Bernie Carter, Jos M. Latour, Wendy Ingram, Jonathan Marsden.

**Corresponding author: rachel.rapson@nhs.net*

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.

Rachel Rapson*, Bernie Carter, Jos M. Latour, Wendy Ingram, Jonathan Marsden.

**Corresponding author: rachel.rapson@nhs.net*

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™, Innovoid, Denmark) enables children to exercise against resistance whilst standing, but its efficacy is uncertain.

Aims / Objective

To explore the feasibility of the **A**bility and quality of life for **C**hildren with **C**erebral **P**alsy **T**rial (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 Pediatric 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.