DEVELOPING A HOME-BASED PROGRAMME TO MITIGATE MUSCULOSKELETAL COMPLICATIONS IN CHILDREN WITH SEVERE CEREBRAL PALSY IN RESOURCE-LIMITED SETTINGS: A MODIFIED DELPHI STUDY

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DECLARATION

I, SHAYNE ROBIN VAN ASWEGEN, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Dedication

I would like to dedicate this work to my Father God who has granted me the opportunity to share in His work in my small way. I also dedicate it to every caregiver of a child with cerebral palsy, who has crossed my path throughout my career. Your dedication, humility, strength, and love for your children are truly inspiring.

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Format

The thesis consists of 5 chapters. The 3 sub-studies of the research are presented in Chapters 2, 3 and 4 which are formatted for publication. At the time of submission of this thesis, only Chapter 2 has been published by the South African Journal of Physiotherapy, and can be found at https://doi.org/10.4102/sajp.v80i1.2059. Chapters 1 and 5 provide the introduction and final

conclusion of the research. The total word count, excluding reference lists, tables, figures and appendices, is 31446 words.

Contributions

Shayne van Aswegen: conceptualisation (equal); data curation; funding acquisition; investigation; methodology (supporting); resources; visualisation; writing – original draft (lead); writing - review and editing (equal).

Mark Richards: conceptualisation (equal); supervision (supporting); validation (supporting); writing – review and editing (supporting).

Brenda Morrow: conceptualisation (equal); methodology (main); supervision (main); validation (main); writing – original draft (supporting); writing – review and editing (equal).

TABLE OF CONTENTS

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1. Protocol information

Date (when submitting this form)	5 November 2023		
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LIST OF TABLES

LIST OF FIGURES

ABBREVIATIONS

AACPDM	American Academy for Cerebral Palsy and Developmental Medicine
ADL	Activities of Daily Living
ACRWC	African Charter on the Rights and Welfare of the Child
AGREE II	Appraisal of Guidelines for Research and Evaluation II
APT	Appropriate Paper-based Technology
CHW	Community Healthcare Workers
COPM	Canadian Occupational Performance Measure
CP	Cerebral Palsy
CPG	Clinical Practice Guidelines
ETD	Evidence to Decision
GMFCS	Gross Motor Function Classification System
GRADE	Grading of Recommendations Assessment, Development, and Evaluation
HBIP	Home Based Intervention Programme
HCP	Healthcare Professionals
HIC	High-Income Countries
LL	Lower Limb
ICF	International Classification of Functioning, Disability and Health
JBI	Joanna Briggs Institute
KZN	Kwa-Zulu Natal
LMIC	Low and Middle-Income Countries
MDT	Multidisciplinary team
MSK	Musculoskeletal
NICE	National Institute for Health and Care Excellence
NHI	National Health Insursance
NGO	Non-Governmental Organisations
PEDI	Paediatric Evaluation of Disability Inventory
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRISMA-ScR	Preferred Reporting Items for a Systematic Review and Meta-analysis extension for Scoping Reviews
RLS	Resource Limited Settings
ROM	Range of Motion
RN	Registered Nurses
SA	South African
SCPE	Surveillance of Cerebral Palsy Europe
SDGs	Sustainable Development Goals
UL	Upper Limb
UN	United Nations
WHB	Waikato Health Board
WHO	World Health Organisation

ABSTRACT

Background: Children living in resource-limited settings (RLS) with severe cerebral palsy (CP) are at considerable risk of developing secondary musculoskeletal (MSK) complications, which can cause substantial discomfort and significantly restrict activity and age-appropriate participation. Current clinical guidelines do not adequately address complication prevention or promotion of participation for this population.

Aim: To develop the components of a home-based intervention programme (HBIP) to mitigate musculoskeletal complications in children with severe cerebral palsy (non-or partially ambulant or Gross Motor Function Classification System level III to V), so as to promote inclusion, suitable for use in resource-limited South African (SA) settings.

Method: First, a scoping review of the literature was completed to identify potential programme components, using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR). Focus group discussions were conducted with 15 caregivers of children with severe CP from a peri-urban setting in KwaZulu Natal, SA, to explore their contextual needs and preferences for a caregiver-delivered intervention. Then, in accordance with the Appraisal of Guidelines Research and Evaluation (AGREE II) tool, the results of the scoping review and focus group discussions were collated as statements and presented to an expert panel to produce a proposal for a HBIP, using a modified Delphi methodology. The panel rated their agreement on a Likert scale, requiring three Delphi rounds for modification and re-iteration until consensus was reached. The final proposed HBIP was returned to the caregivers for comment and approval before being finalised.

Results: Fifteen multidisciplinary healthcare experts participated in producing the final set of 62 consensus statements. These statements were grouped into five sections: the importance of the intervention; programme elements; caregiver training; and the implementation and community support mechanisms. Panellists agreed that caregivers should be trained in “24-hour postural management” and “splinting” interventions to prevent musculoskeletal (MSK) deformities, given strategies to assist with activities of daily living (e.g. feeding), and provided with tools for communication, cognitive development, and social participation. Community-based therapists should provide caregiver training and oversight, but community health workers should play a pivotal role in supporting programme implementation.

Conclusion: This consensus guideline document provides a detailed and actionable home-based intervention suitable for resource-limited SA settings, to mitigate complications and increase participation opportunities for children with severe CP. Implementation studies are recommended to determine feasibility, acceptability, and efficacy in real-world settings.

Keywords: Cerebral palsy, rehabilitation, parent-delivered interventions, home programmes, musculoskeletal complications, resource-limited settings

CHAPTER 1: INTRODUCTION

Cerebral palsy (CP) is the most common childhood motor disorder worldwide (Shevell et al. 2013). It is a complex and variable condition that requires an early, coordinated, multidisciplinary approach to prevent complications and optimise functional outcomes for affected children. As part of the World Health Organisation's (WHOs) Rehabilitation 2030 initiative towards attaining Universal Health Coverage (Rifkin 2018), there have been increased efforts in recent years to produce clinical practice guidelines to manage CP. However, researchers have reported a notable lack of reliable primary evidence supporting their recommendations (Damiano et al. 2021). Therefore, the resulting guidelines may not adequately address the management of children with CP in all settings. In low and middle-income countries (LMIC) and other settings where resources are limited, the prevalence of CP is likely to be higher, and the clinical presentation more severe than in high-income environments (HIC) (Donald et al. 2015). Children with more severe sub-types of CP have a higher risk of concomitant co-morbidities and are more vulnerable to secondary musculoskeletal (MSK) complications (Hollung et al. 2020), especially within a structurally and materially limited environment. The resulting higher disease burden from these undesirable sequelae often impacts negatively on their development and can severely restrict participation in age-appropriate activities. This research aims to guide the management of severe CP in resource-limited settings (RSL) by developing a home-based interventional programme (HBIP) aimed at improving participation opportunities for children with severe CP by mitigating MSK complications whilst promoting inclusion in family and community activities. In theory, along with the maintenance of MSK integrity should come a greater repertoire of available movement and activity by the child, and increased potential for social participation within the child's natural environment.

This chapter describes key concepts, the spectrum of clinical presentation and epidemiology of CP, and the burden of disease, considering the differences between higher and lower-income settings. This includes the common orthopaedic complications that develop amongst children with severe CP and the impact these complications have on function and disability status. Consideration is given to some of the important contextual factors and challenges to providing appropriate healthcare to children with CP in RLS within South Africa (SA). The discussion then turns to the knowledge gaps and associated indications for this research. The chapter concludes with the specific aims and objectives of the research and a consideration of the potential significance and limitations of the study.

1.1 Background to the study

According to Rosenbaum et al. (2006) 'The definition and classification of cerebral palsy':

> [D]escribes a group of permanent disorders of the development of movement and posture causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain; the motor disturbances are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and by secondary musculoskeletal problems.

While the primary neurological injury does not change, secondary effects on other body systems and overall development can be widespread and vary according to life stage. As such, CP can present with a complex set of individualised needs that challenge health, education, and social service systems, especially in a low to middle-income country (LMIC). While SA is classified as an upper middle-income country according to the World Bank Group (Metreau et al. 2024), it is also recognised as the country with the highest income inequality in the world, with a Gini Coefficient of >60 and high levels of unemployment, extreme poverty, and unequal access to healthcare facilities (Luebker 2010; Valodia 2023). This thesis focuses on the resource-restricted population living in poor, rural and peri-urban South African areas.

1.2 Epidemiology of cerebral palsy

Data from international registries have shown that in the United States, Europe and Australia, the incidence of CP has either remained stable or decreased from just over 2 per 1000 live births to as low as 1 per 1000 live births over the last 20 years (Van Naarden et al. 2016; Sellier et al. 2016; Galea et al. 2019). In 2009 incidence in the developing world was estimated to be only slightly higher at 2 to 2.5 per 1000 live births (Cans et al. 2008). This is similar to the 2 per 1000 live birth rate reported in a 2004 study conducted in India (Banerjee et al. 2009) and a 2014 study conducted in Egypt, which reported a prevalence of 1 per 1000 children under 18 years (Osama et al. 2017).It is important to note that birth prevalence (incidence) is expected to be higher in this context, and that the figures shown reflect the prevalence of those with CP surviving until the age of 18 years, versus the number of children born with the condition. More recently, however, estimates of CP prevalence for LMICs are as high as 3.4 per 1000 live births, three times higher than in HICs (McIntyre et al. 2022). In SA, there is no formal CP surveillance system or registry, and there are often inconsistencies in health information reporting, delayed identification of CP, as well as limited follow-up for “at risk” infants. Therefore, the prevalence of CP is unknown. A few disparate cross-sectional studies have been conducted over the last 15 years. The 2011 SA Census (StatsSA 2012) reported physical disability related to ‘difficulty with walking and climbing stairs’ in 1% of 5- to 19-year-olds (10 per 1000), using the Washington Group Short Set of Questions. While many children with CP present with this difficulty, other medical conditions also cause physical disability; thus,

this cannot be seen specifically as a CP prevalence. A cluster study in rural KZN reported a CP prevalence of 10 per 1000 children (Couper 2002), while another larger study in rural Mpumalanga reported a prevalence of motor disabilities (not specifically CP) to be 0.5% or 5 per 1000 children (Donald et al. 2014). Therefore, the prevalence of CP in SA should fall between 2 and 10 per 1000 children under 18 years of age.

Importantly, owing to a difference in aetiologies of CP between regions, the more severe types of CP are more prevalent in LMICs, including spastic quadriplegia (40%) and dyskinesia (Gladstone 2010; Van Toorn et al. 2007). These are also the types of CP that tend to fall in the most severely affected (non- or partially ambulant) levels of the Gross Motor Function Classification System (GMFCS), i.e. levels III to V, and often present with advanced MSK complications. Unless early, intentional prevention strategies are implemented, the resulting secondary deformities frequently compound disability and further complicate functional status in these children.

1.3 Aetiology and clinical presentation of cerebral palsy

Whilst the prevalence of CP is fairly consistent worldwide, the clinical profile and spectrum of CP in HICs compared to LMICs appear to differ significantly (Gladstone 2010). This is probably because aetiologies and risk factors for CP are linked to country income, which determines maternal and child healthcare service resource allocations (Cans et al. 2008). Aetiologies, in turn, affect the presenting CP subtype (Rennie et al. 2007). Understanding the relative prevalence of CP subtypes is important for describing the impairment, providing a prognostic indicator of functional status, and predicting and informing health service needs. For example, dyskinetic CP is often found in GMFCS level IV, the functional level where children may learn to self-propel a motorised chair if provided with one (Novak et al. 2012).

In Europe, aetiologies of CP are more commonly attributed to pre-natal factors (75%) (Sadowska, Sarecka-Hujar & Kopyta 2020), whereas studies in South Africa, Botswana and Uganda have shown that peri- and post-natal (acquired) aetiologies account for 59.1%, 50%, and 53.2% of cases, respectively (Van Toorn et al. 2007; Bearden et al. 2016; Kakooza-Mwesige et al. 2015). The most important peri- and post-natal factors identified in a study from Tygerberg Hospital in the Western Cape were prematurity, encephalopathy from birth asphyxia, and infections of the central nervous system, such as meningitis (Van Toorn et al. 2007).

Many HICs use the Surveillance of Cerebral Palsy Europe (SCPE) system to describe CP by tone and topography (Cans 2000). By tone, there are three categories including spastic, dyskinetic and ataxic, although a mixed category is often added. Within the spastic category,

the SCPE only differentiates between unilateral CP (one side of the body) and bilateral CP (both sides of the body), without further division of bilateral CP into the traditional quadriplegia (4 limbs affected) and diplegia (two limbs affected) types (Appendix 1.1). However, where these two subtypes are distinguished, it shows an interesting tendency in the relative proportion of spastic quadriplegia between socio-geographic regions (Table 1.1). Another widely used system is the Gross Motor Function Classification System (Palisano et al. 2007), which categorises CP in several age bands, and uses ambulation ability as a measure of gross motor function rather than the neurological subtype. Level I describes the child with the most independent ambulation, and highest function, and Level V describes a non-ambulant child with the lowest level of independent function (Appendix 1.2). Table 1.1 below shows the comparative distribution of CP subtypes and GMFCS levels from registries in Australia, the USA, and Norway, compared to four studies from large referral hospitals in Africa, namely South Africa, Botswana and Uganda.

Table 1.1: Clinical characteristics of children with CP in HICs vs LMICs

	Australia	US	Norway	South Africa	Botswana	Uganda
CP subtype %						
Study period or date	1995-2016	2008	2008-2017	2003-2004, 2013-2014	2013-2014	2009-2010
Spastic types	83.6	77.4	80.1	81.0	82.3	69.6
- Quad-/triplegia	23.0	49.2	16.3	40.1	45.5	45.9
- Diplegia	36.0		28.8	14.5	4.4	
- Hemiplegia	40.9	28.2	35.0	26.4	23.5	23.7
Dyskinesia	9.5	8.4	5.6	7.4	2.9	12.6
Ataxia/hypotonia	6.9		4.0	1.7	10.2	9.6
Mixed		14.2	1.3	7.4	8.8	
Unknown	6.5		9.0	2.5	4.4	8.1
GMFCS Level %						
Level I	63.2	40.4	73.8	37.0	8.0	
Level II		15.2			20.5	
Level III	11.3	12.3	10.3		11.7	
Level IV	25.5	16.8	15.9	63.0	16.1	
Level V		15.2			41.1	

Unknown	8.7				3.6	

Sources:

Australia: Australian Cerebral Palsy Register, 2024, from https://cpregister.com/wp-content/uploads/2023/01/2023-ACPR-Report.pdf.
USA: Christensen et al. 2008. https://doi.org/10.1111/dmcn.12269.
Norway: Hollung et al. 2018. https://doi.org/10.1016/j.ejpn.2018.05.007.
South Africa: Van Toorn et al. 2007 https://www.ajol.info/index.php/sajchh/article/view/172570; Govender et al. 2015; Coombe 2017.
Botswana: Bearden et al. 2016. https://doi.org/10.1016/j.pediatrneurol.2016.02.010.
Uganda: Kakooza-Mwesige et al. 2015. https://doi.org/10.1186/s13104-015-1140-2.

Legend:

Spastic = Increase in muscle tone in response to a quick stretch of the muscle.
Quadriplegia = where all four limbs are affected, and is usually accompanied by low tone in the trunk and neck muscles. One source distinguishes **triplegia** (3 limbs affected) from quadriplegia.
Diplegia = Two limbs are affected, usually the lower limbs. The upper limbs may have minor involvement.
Hemiplegia, where one side of the body (upper and lower limb) is significantly more affected than the other side.
Dyskinetia = Characterised by fluctuating high and low tone.
Ataxia/Hypotonia = Characterised by generalised low tone.
GMFCS = Gross Motor Function Classification System. Using ambulation ability as a functional measure, children with CP are classified into one of five categories from I (independently ambulant) to V (severe involvement, non-ambulant even with assistance).

In Table 1.1 the prevalence of spastic cerebral palsy (including quadriplegia, diplegia and hemiplegia subtypes) appeared to be relatively consistent in all regions, at around 80%. However, the proportion of quadriplegia was less than 30% in the HICs and between 40% and 50% in the LMICs. Dyskinesia which has been associated with perinatal kernicterus as a diagnosis also emerged more commonly in some LMIC settings (Table 1.1). The higher frequencies of peri-natal causes of CP (encephalopathy of prematurity, birth asphyxia or hypoxic ischaemic encephalopathy, and kernicterus), and of postnatally acquired central nervous system infections observed in LMICs, are likely to account for this (Gladstone 2010; Van Toorn et al. 2007). Importantly, the distribution of severity differed between regions according to GMFCS level, with the LMICs having higher proportions of CP in levels IV and V, indicating severe motor disability. The HICs, on the other hand, tended to have higher proportions of GMFCS levels I and II, describing patients with independent ambulation with or without assistive devices. This summary correlates with the findings of Shevell et al. (2009), where 95% of non-ambulant children with CP such as those with Level IV or V, are classified neurologically as either spastic quadriplegic or dyskinetic, indicating greater severity and lower functional ability (Shevell et al. 2009). Of the spastic hemiplegic and diplegic subtypes, 99% and 98% would fall into either GMFCS Levels I or II.

1.4 The relationship between sub-type, severity, and disease burden

The spastic quadriplegic and dyskinetic subtypes of CP have the highest disease burden owing to the associated co-morbidities that occur both in conjunction with the original neurological insult and as a later consequence of the original impairment (complication).

A Norwegian study reported that children with spastic quadriplegic and dyskinetic quadriplegic forms of CP born between 2008 and 2017, had the highest average number of associated co-morbidities of all CP subtypes – 8.1 (SD 4.0) and 6.5 (SD 3.5) respectively, versus 3.6 (SD 3.0) for children with spastic hemiplegia. The most common co-morbidities were epilepsy, intellectual disability, visual impairment, feeding difficulties, speech impairment and behavioural disorders. The most common secondary complications were musculoskeletal, namely hip displacement, muscle contractures, scoliosis, digestive difficulties and malnutrition (Hollung et al. 2020). The risk of complications seems to increase significantly as the GMFCS level increases and with age (Larnert et al. 2014; Rodby-Bousquet et al. 2013). The incidence of hip displacement in children with CP living in Norway between 2002 and 2006 was 45% for GMFCS level IV and 75% for GMFCS level V before the establishment of population-based hip surveillance (Terjesen 2012). A prospective cohort study in Sweden between 1990 and 2012 reported that in the GMFCS level IV and V categories, 10% of the cohort had developed scoliosis by the age of 5, and at least 55% had developed moderate scoliosis (defined as an obvious curve visible during both extended and forward bending) by the age of 20 (Hagglund et al. 2018). There is very little data describing these complications of CP in South Africa. However, considering our clinical CP profile and inequitable access to health and rehabilitative services across SA (Burger et al. 2020), it is likely that children with severe CP, particularly those living in peri-urban or rural areas with high levels of poverty, have high complication rates. A study at Chris Hani Baragwanath Academic Hospital in SA between 2017 and 2018 found a 57% prevalence of hip dislocations in patients with spastic quadriplegia. However, this was not disaggregated into GMFCS levels (Mahlaba et al. 2020). No studies describing the incidence of scoliosis in children with CP living in SA could be identified, although this complication is commonly observed in clinical practice.

For clinicians working in rural settings in SA, it is common to see severely affected children with CP with secondary complications, and consequently very poor functional ability. From personal clinical experience, caregivers often report that their children have had little, inconsistent, or no preventive interventions either by health professionals or themselves, and the children often present with severe orthopaedic deformities, which have developed as a result (Figure 1.1).

Figure 1.1: Typical MSK complications found in poorly-managed spastic bilateral CP. This child displays a fixed thoraco-lumbar scoliosis with pelvic obliquity; and the "windswept" deformity that includes hip dislocation, and joint contractures
© Shayne van Aswegen, 2018 (photographs are used with parental consent).

To provide an intervention that limits MSK deformities, it is necessary to understand how they develop and how they compound disability. Although neurological and neurodevelopmental signs are usually detectable from a very young age, the MSK system of infants with CP may initially appear radiologically normal. A child with a moderate to severe form of CP (GMFCS level III-V), has a reduced ability to actively change their position. As a result of inherent imbalances in muscle tone, asymmetrical body postures become habitual (Casey et al. 2022). This predisposes the child to the development of fixed spinal and joint deformities, including scoliosis, hip displacement, and multiple joint contractures (Figure 1.1) (Porter et al. 2008). The resulting pain that likely develops is perhaps an underappreciated and overlooked element in the management of children with CP. A 2019 study in Sweden (Westbom et al. 2017), reported a prevalence of pain in 37% of the children and adolescents with CP. Furthermore, the researchers reported that pain prevalence was highest in dyskinetic CP (46%) and children in GMFCS level V (50%). Children experienced pain most frequently in the lower limbs, the spine and the abdomen. However, Novak (2014) reported that up to 75% of children with CP experience chronic, nociceptive, musculoskeletal pain, thought largely to be due to spasticity and contractures.

The impact of established orthopaedic complications on function and general quality of life can be devastating to the child and their family. The following day-to-day sequelae have

frequently been personally encountered by the researcher during clinical situations. Children with significant hip displacement and/or scoliosis often cannot tolerate any single position for an extended period, necessitating frequent changes in position to ease MSK discomfort. Seating with adequate spinal support becomes challenging, the default option being to let the child remain in the asymmetrical semi-supine lying position for most of the day (see Figure 1.1), where very little functional activity can occur. Additionally, the prevalent postures result in a loss of MSK symmetry, because the lower limbs tend to fall to one side. Hip displacement of the upper hip joint is a common result, together with pelvic obliquity and compensatory rotation of the spine. This default positioning with reduced activity leads to loss of flexibility around the joints. Daily activities such as bathing, dressing, and cleaning the perineal area are difficult due to joint contractures and hip displacement, and cause discomfort when the limbs are moved. Safe feeding for a child with severe CP is notoriously challenging and time-consuming and usually requires the child to be propped up to reduce the risk of choking. Due to the challenges of positioning the child in an appropriate seating device (even where available), feeding is often performed with the child seated on the caregiver's lap, with the caregiver having to support their head. Without functional seating options, inclusion in everyday family activities such as communal meals is limited. Furthermore, without a wheeled mobility device, the child will often be excluded from community spheres (social, cognitive, and physical), such as attending school. Where there is access to rehabilitation services, therapeutic intervention options for active functional gains are severely curtailed by restricted joint range. Although surgical solutions may be considered, they tend not to be performed given the scale of remediation required, non-prioritisation of this type of surgery, inaccessibility to post-operative care and the poor general health of the child.

1.5 Describing disability, functioning and participation in life

Socioeconomic factors such as maternal education, poverty and access to quality health services and special education are known to be important environmental and social determinants of overall disability status. According to the International Classification of Functioning, Disability and Health (ICF) adopted by the World Health Organisation in 2002, the concept of disability is an integration of the collective impact of the underlying disease, impairments in physiological and anatomical structures, activity limitations, participation restrictions, and the limits imposed by environmental and personal factors (World Health Organization 2002). The interplay between factors in this framework is multidirectional so that relative impact varies throughout life as circumstances change, as shown in Figure 1.2 below.

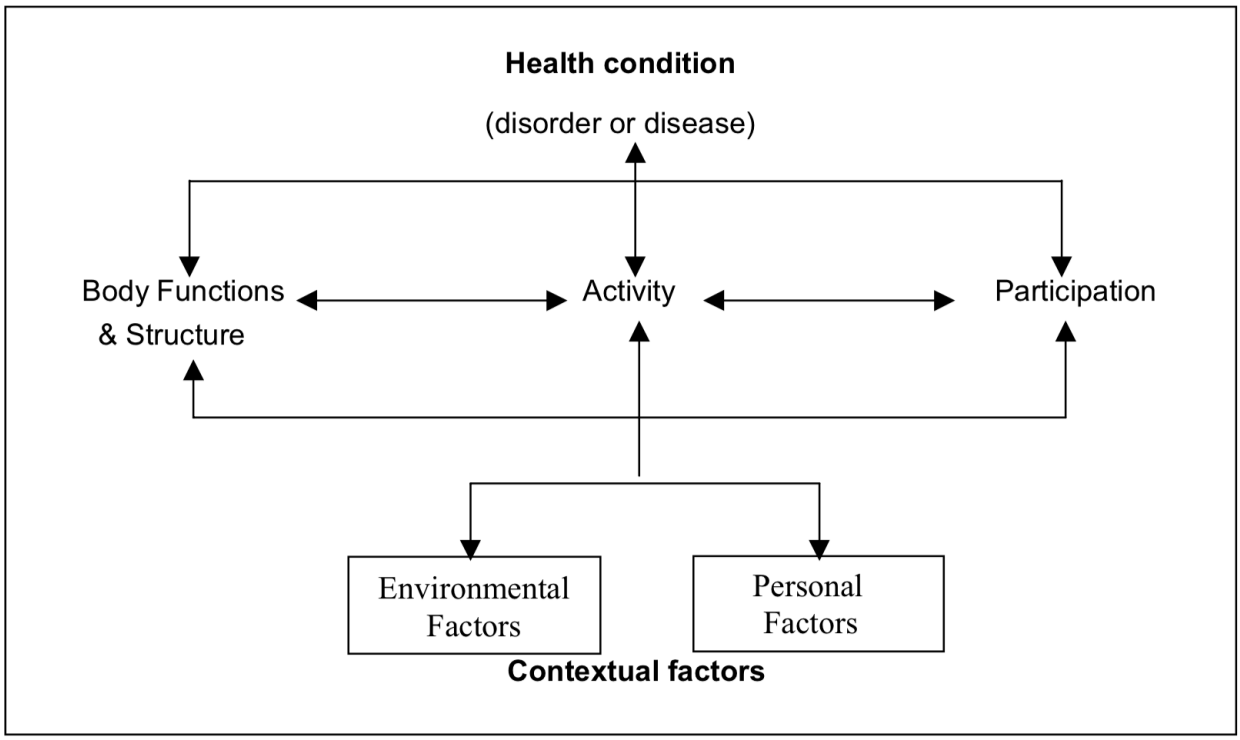

Figure 1.2: International Classification of Functioning, Disability and Health (ICF) Framework
from: https://www.who.int/docs/default-source/classification/icf/icfbeginnersguide.pdf?sfvrsn=eead63d3_4

Using this model for children with CP, impairments of 'Body Functions and Structure' would include both primary and secondary MSK complications, pain, nutritional status, cognitive ability and co-morbidities such as epilepsy. Limitations of 'Activity' would include inability in areas of self-care and gross and fine motor function such as dressing, walking or playing. Restrictions in 'Participation' would include any occasion where the child with CP is unable to be involved in age-appropriate life situations. These may encompass motor, sensory and psychosocial experiences, such as attending school or participating in a family meal or social gathering. 'Environmental Factors' refers to any influence outside of the person, such as housing and basic sanitation amenities; levels of parental education and knowledge about CP; availability of assistive devices; access to transport, schooling, therapy and healthcare facilities; as well as societal support or exclusion. 'Personal Factors' would include demographics, attitudes, beliefs and motivation. The ICF framework implies that, in addition to addressing the primary neurological impairment and preventing complications through medical interventions, the provision of appropriate health services (such as therapy), environmental adaptations (such as wheelchair-friendly public transport), and access to education for special needs are essential for limiting disability and ensuring opportunities for inclusion and meaningful participation in life.

1.6 Environmental factors and their impact on disability and participation

Research shows that even in relatively well-resourced settings such as Australia, Spain and Canada, caregivers of children with CP often report on how their physical, financial and psychosocial well-being is negatively impacted by the burden of care (Smith & Blamires 2022). Concurring with this, a qualitative study undertaken in a RLS in India into caregivers' perspectives highlighted the physical challenges (such as lifting, positioning and performing ADLs for a child with little or no independence, and lack of access to public spaces); the emotional stress of guilt, worry and grief; the financial burden (not being able to be employed outside of the home because of caring obligations, and having extra expenses related to medication, special foods, transport and equipment); and the societal discrimination that accompanies caregiving of children with CP (Vadivelan et al. 2020). Studies undertaken in Zimbabwe and Ghana show very similar themes, but add to the list feelings of inadequacy and ignorance about CP, being "overwhelmed", and feeling unsupported by family and community members (Dambi, Jelsma & Mlambo 2015; Mwinbam et al. 2023). Importantly, the latter two studies emphasise the seemingly widely-held concept of social stigma in their settings related to societal ignorance, fear and cultural beliefs about the nature of disability, and how these factors contribute to the isolation of the whole family together with the child. This finding corroborates those of Koszela (2013) who described the stigmatisation of disablility prevailing in African communities, so that children with disability are "invisible" and therefore excluded from peers and age-appropriate participation (Koszela 2013). As expected, SA studies exploring caregivers' experiences echo all the same physical, financial and psychosocial findings as international studies, with the emphasis on inaccessibility to acceptable and affordable health facilities and services, as well as public spaces (Madzhie et al. 2022; Manyuma et al. 2023; Dlamini et al. 2023; Maronga-Feshete, Pelusa & Dreyer 2024)

Research into the environmental and socioeconomic factors of SA children with CP, who use public health services is scant. However, one can look at the typical environment of a young child growing up in a rural setting to appreciate the varied contextual elements that could impact disability. According to the Children Count report of 2024, based on the General Household Survey and the Statistics South Africa (2022) National Poverty Lines release, 87% of children (under 18 years) residing in rural areas in SA, where the poorest (lowest) socioeconomic levels are found, were below the upper-bound poverty line of R1414 per child per month. This denotes the minimum amount of money required for the most basic nutrition, clothing and shelter (Hall 2024). In a report on access to healthcare in SA, Burger et al. (2020) report that 27% of South Africans faced constraints related to far distances and inconvenient opening times of healthcare facilities. They note that the provinces with the largest rural populations have the lowest overall access to healthcare in terms of availability, i.e., Limpopo

(63%), Eastern Cape (65%) and Kwazulu-Natal (66%), compared to the Western Cape (87%), which had the highest. Burger et al. (2020) also found that 23% of South Africans could not afford to access adequate care despite a “no fee” policy at healthcare facilities, largely due to the transport costs involved. Through personal observation, the lack of public transport for persons with disability compounds this problem as accessing a taxi sometimes means paying double the fee to transport a wheelchair.

Even when access to healthcare is possible, children with severe forms of CP require specialised and multi-faceted care that involves many health practitioners from primary to tertiary levels, working in a coordinated team (Keys & Lewis 2019). Many of these teams may be incomplete at rural health facilities, and in SA they are often staffed by inexperienced therapists and medical officers (Conradie et al. 2022). To accommodate the distances and expense of travel to central services where experienced and comprehensive multidisciplinary therapist teams may be found, CP clinics in public healthcare facilities in SA are usually structured around monthly visits for repeat prescriptions for medication. Therapy interventions in these settings usually consist of one-hour group sessions where there is limited opportunity to train caregivers in individualised daily handling programmes for their child. The wide variation of neurological insult, functional ability, complication rate, frequency of co-morbidities and environmental constraints between individuals with CP warrants personalised assessments and the development of individualised home programmes to some degree. Co-operative partnerships involving individualised and appropriate goal-setting, coaching and support all hallmarks of effective home programmes (Novak & Berry 2014), then become possible.

There is little SA data describing participation of our children with CP living in RLSs. Published subsequently to the original literature review for this research, one study conducted in the resource-poor Limpopo province sought to describe the participation of children diagnosed with CP (all GMFCS levels). For activities of daily living (ADL) such as feeding, bathing, dressing and toileting, 21.05% were fully independent of caregivers, two thirds requiring at least some help; in family and community activities such as household chores and church attendance, 57.89% caregivers reported their child had no community involvement; two thirds engaged in either formal or informal educational activities; while 57.89% were able to participate in play activities, but not necessarily involving others (Africa, Human & Tshabalala 2023). Access to child educational facilities is also heavily dependent on mobility and transport, as well as a school’s capacity for inclusion, especially for children in the GMFCS level III to V categories. Govender et al. (2015) reported that, of the children attending a CP clinic at a major hospital in eThekwini, SA, only 20% were attending a learning facility. In a

study of 94 children with CP in the Umkhanyakude district in rural Kwa-Zulu Natal (KZN), SA, undertaken in 2017, only 21% were attending a school and only 50% of those in the GMFCS level IV and V categories (non-ambulant children) had been issued with a mobility device (Coombe 2017). Currently, the types of assistive equipment purported to be available through public health services include mobility and positioning devices such as manual wheelchairs, posture support seating, side lyers, and standers; equipment such as crutches, surgical boots and callipers; and limited splinting and orthotic devices. However, for various reasons, the actual provision rate is very low and can take years to achieve, if at all (DSD & UNICEF 2012). Without basic mobility equipment for transport, all non-ambulant children with CP and those requiring assistive devices for (GMFCS III to V) will be excluded from participating in most age-appropriate activities.

In terms of children's rights, the ICF framework is supported by the South African Constitution and the Children's Act of 2005. The SA Constitution and the Children's Act prohibit discrimination against any group and lay out a comprehensive list of basic rights for all children residing in SA (Jamieson et al. 2013). The African Charter on the Rights and Welfare of the Child (ACRWC) makes special provisions for children with disabilities including the rights to life and survival, basic healthcare, education, inclusion in social activities, play, and other cultural practices, as well as optimal development (African Union 1999). While these terms are not always well defined in the South African context, it is reasonable to conclude that many SA children living with CP are deprived of these basic rights.

1.7 The research gap

Child development experts recommend early identification of CP and prompt intervention to limit complications, maximise neuroplastic potential and promote age-appropriate participation, using a family-centred approach (Novak et al. 2017; Hadders-Algra 2014). Secondary MSK complications such as those described above may be controlled and minimised with early and deliberate prevention protocols, which have been described in high-income settings. In Sweden, for example, the incidence of hip dislocation was reduced from 8% to 0.5% over 25 years (Hermanson 2017; Hagglund et al. 2014). This was achieved through formalised hip and spinal surveillance for non-ambulant children from the age of 2 years, growth monitoring, and multidisciplinary therapeutic involvement. Moreover, based on earlier theories about motor learning (Shumway-Cook 2007), there has been a recent shift of focus in therapy away from so-called "impairments-based" interventions that focus on the body structure and function domain of the ICF. Instead, a more "child-active" approach is promoted where the child practices real-life activities in everyday situations towards self-selected functional goals (also known as 'goal-directed' training) (Mastos et al. 2007). However,

interventions that target impairments cannot be dispensed with altogether (Wallen & Stewart 2012). The ability to exercise real life activities depends on the child's motor ability, but importantly, it presupposes a MSK flexibility that would allow both the positioning and activity to occur. It would follow that early, preventive interventions, which are frequently incorporated into active daily routines at home, might better the chances of maintaining flexibility and body symmetry, and making action possible. The result would be a wider variety of attainable positions, activities, and increased opportunities for life and learning situations.

Delivering this effectively in an RLS is however, challenging. Very few clinical guidelines exist for the physiotherapy management of children with CP, and most of these do not specifically address the needs of more severely affected children (See Clinical practice guidelines and systematic reviews on clinical recommendations for children with cerebral palsy in Chapter 2). All current available guidelines originate in and are primarily based on evidence from HIC settings, such as Australia, Europe and the USA, where the clinical picture and needs of children with CP often differ significantly from LMICs. Many of the primary interventional studies focus on participants with less severe impairment (i.e. GMFCS levels I to III), and who have earlier access to therapy and other resources, resulting in fewer secondary orthopaedic complications. Thus, most of the strong therapy recommendations from these guidelines can only be fully implemented for children with reasonable underlying active ability and joint flexibility. The few recommendations for children in GMFCS levels IV - V in these guidelines usually involve timely pharmacological and surgical management and often advocate for the use of costly technological devices, which are likely unavailable and/or unsuitable for the RLS (Novak 2019; Jackman 2021; Morgan 2021). Furthermore, children with established orthopaedic complications struggle to use the recommended devices because they lack the requisite joint range of motion required for fitting the device. This illustrates how current guidelines still lack adaptability to low-resource settings, and their usefulness within a rural context in SA is limited. This concurs with Saloojee's (2022) concerns regarding the global applicability of international clinical guidelines for CP.

According to the United Nations' third Sustainable Development Goal (UNDESA 2015) pertaining to 'Good health and Well-being', target 3.8 aims for universal access to effective basic services for all by 2030. However, current public health care services for CP management in SA seem to be far from providing effective management, therapy, training, and support to families who have children with more severe CP, particularly those living in rural and peri-urban settings. As a result, children from these environments frequently develop debilitating complications that are problematic to manage from a healthcare service perspective and contribute significantly to poor quality of life for children and their families. We have already established that preventing and/or limiting MSK complications should be an

important focus of early intervention strategies for CP if activity and participation are to be optimised, especially for those with more severe presentations. One can argue that parents and caregivers of children at levels III to V of the GMFCS are an underutilised resource that could potentially fill some of the current gaps in care if adequately equipped and supported by key healthcare professionals (HCPs) within their natural environments. Development of an evidence-based, context-appropriate, early intervention strategy focused on prevention in the home context is warranted.

1.8 Research aim, objectives and questions

Given the lack of a standardised care protocol for the management of severe CP that is feasible or applicable across public SA healthcare settings, the main aim of this research was to develop the core components and considerations for a home-based intervention programme (HBIP) to be used by caregivers of children with severe CP living in RLS to limit MSK complications.

To produce evidence-based recommendations that are relevant to the target population, the researchers set out to achieve the following objectives:

1. To review and synthesise global literature describing effective physical interventions and programmes for the prevention and control of MSK complications in children with severe CP, appropriate to RLSs.
2. To explore the expressed needs of caregivers of children with severe CP, living in RLSs in SA and to obtain their perspectives on and preferences for an HBIP.
3. To develop a consensus document itemising the essential elements, training, and implementation of an HBIP for SA caregivers of children with severe CP living in RLSs.

The following research questions were posed:

1. What global evidence in the form of clinical guidelines, programmes, and interventions exists for the effective prevention of secondary MSK complications in severe CP?
    a. Which of these might be feasible for use in a typical RLS in South Africa?
2. How do caregivers of children with severe CP living in RLSs describe their needs, daily challenges, and goals for their child?
    a. What are their preferences concerning an HBIP?
3. How can the above results be used to produce a context-responsive, evidence-based HBIP suitable for an RLS?

1.9 Potential contributions of this research

This study will contribute to the body of knowledge on effective interventions for managing severe CP in children by helping to broaden the application of existing guidelines to a wider population. It could provide a practical blueprint for the implementation of a ground-level intervention for RLSs, informed by all relevant stakeholders, both in SA and in any region that has a similar CP profile and resource constraints. The final HBIP should enable caregivers and community healthcare workers to be equipped with a programme that is aligned with the principles of universal health coverage. Conforming to the Alma Ata primary healthcare model from the World Health Organisation and the work of Penchansky et al. (1981), such a programme should meet the goals of effectiveness or quality, acceptability, accessibility, and availability (McLaughlin 2002) as well as the UN's SDGs. In solidarity with these internationally accepted goals, the South African National Health Insurance (NHI) objectives place a strong emphasis on equity, universal access, and affordable, patient-centred care (Department of Health 2020). The HBIP should align well with these aims with its strong focus on availability and access in RLSs, together with the strengthening of primary health services and delivery.

1.9.1 Effectiveness or quality

The programme should provide current, evidence-based everyday interventions that help maintain MSK integrity while promoting function and participation. Importantly, the programme would be inclusive of children higher on the GMFCS scale (level III – V). If caregivers can be trained to implement the programme effectively at an early age, fewer secondary complications should arise, leading to a greater repertoire of activity opportunities in the home and community and relieving some of the burden of care. It also fosters the ICF model of health by optimising activity and participation, because the HBIP will typically occur within the child's natural environment as part of everyday life.

1.9.2 Acceptability

The HBIP would be developed with input from a range of stakeholders, including SA caregivers of children with severe CP from RLSs. As a result, the programme is likely to be acceptable to the end-users. The use of the home environment to supplement effective therapeutic interventions has been found to enhance motor outcomes, especially where the activities are directed towards daily function rather than therapeutic exercise regimes (Novak et al. 2014). Hadders-Algra (2014) attributes improved outcomes to a family-centred approach including parent coaching, that helps to incorporate therapy goals into everyday functional routines. This family and child-centred approach allows for collaborative goal setting, which ensures that the programme addresses the needs of the family (context-specific) and is culturally sensitive and sustainable. Coaching and supporting caregivers empowers them with the skills and

knowledge they need to become experts in the care of the child. This is associated with higher levels of confidence and compliance (Lord et al. 2018).

1.9.3 Accessibility

According to Burger et al. (2020), two of the main reasons for non-attendance at health services in rural SA are the cost of transport and the distance required to travel. The proposed HBIP would be trained and implemented at the community level, ensuring improved physical and financial access to services. Another potential benefit is that awareness about CP and service provision amongst caregivers and the wider community should increase, and any social barriers within the community, such as stigma, could be addressed.

1.9.4 Availability

The sample population and research setting have been specifically selected so that findings would represent caregiver preferences while acknowledging the challenges and views of HCPs and health service resources typically found in peri-urban and rural environments in SA. Because emphasis is placed on strengthening existing structures and providing the highest quality programme using low-cost technologies, increased uptake and wider coverage across a range of socio-economic contexts should follow. In addition to the benefits for the child and their family, a standardised HBIP has the potential to reduce inequities in service availability between different settings. This is particularly relevant in areas serviced by relatively inexperienced HCPs (such as community service physio- and occupational therapists) as it would provide them with a tool that could form part of a basic package of care for the management of CP in SA. This could help to overcome the need for specialised post-graduate training and experience in CP care.

1.10 Potential limitations

This research strives to improve inclusivity for children with CP who have a more severe presentation and necessarily focuses on the impairments and particular challenges of children with this profile, namely MSK deformities and reduced activity. However, CP is highly variable and although a standardised programme offers many benefits, it might not fully meet the specific needs of children with milder forms of CP living in RSLs. The search for relevant literature was worldwide, however it is known that most of the existing evidence for CP interventions originates in HICs, therefore the recommendations might have to be adapted to RLSs. For practical reasons, including accessibility by road, the qualitative survey was conducted in a limited SA setting that is not deeply rural. As RLSs are highly variable in terms of contextual challenges and health service availability, the particular challenges and views of caregivers might differ between areas. This may reduce the generalisability of a standardised programme to all rural and peri-urban settings in SA.

1.11 Thesis structure

Chapter 1 is a broad, introductory literature review describing the context within which this research was undertaken and provides the background needed to understand the challenges of intervention for CP in a resource-limited South African setting. The narrative review highlights the prevalence, aetiologies, clinical profile and secondary complications of children with CP and considers the influence of social and structural determinants. The research aims, objectives and questions are defined, and consideration is given to the research gaps which justify the study, as well as its value and potential limitations.

Chapters 2[1] to 4 present the research components of this study addressing each of the three main objectives respecvtiely. These chapters are structured as individual publication-ready articles with introductory or linking paragraphs between chapters. At the time of completion of this dissertation, only the scoping review (Chapter 2[1]) has been published. Each chapter is presented as a publication-ready manuscript, but there is an additional, comprehensive bibliography and list of appendices for all chapters provided at the end of the thesis. Tables and figures have been labelled according to the chapters and run consecutively through the document.

Chapter 2 presents the first sub-study, a scoping review of literature from numerous global sources describing the evidence for physical (non-surgical, non-pharmacological, 'low-tech'[2]) interventions that can be used to limit MSK complications, with a focus on non- and partially ambulant children in GMFCS levels III – V. The body of Chapter 2 is presented verbatim as per the published article, but minor sections and statements that were required for publication purposes have been removed, such as the abstract and funding statement.

Chapter 3 explores the contextual environment and the perspectives of caregivers of children with CP living in a RLS in KwaZulu-Natal, South Africa, using qualitative and semi-quantitative methods. Included are aspects of health service utilisation, such as equipment provision and therapy attendance. Caregivers' views on the current functioning of their child, and their activity and participation goals were investigated, along with their perceived needs and preferences for a potential HBIP.

Chapter 4 reports on the methodology and results of a modified Delphi study, to develop a consensus document containing the core elements of an HBIP for caregivers of children with severe CP in resource-limited SA settings. A multidisciplinary panel of expert HCPs responded

[1] The sub-study presented in Chapter 2 has been published and can be found at Van Aswegen, S.R., Richards, M. & Morrow, B., 2024, 'Preventing deformities in paediatric cerebral palsy in poorly-resourced areas: A scoping review', *South African Journal of Physiotherapy* 80(1), a2059. https://doi.org/10.4102/sajp.v80i1.2059 The style conventions of the monograph conform to the Aosis Harvard style of the South African Journal of Physiotherapy.

[2] "low-tech" refers to assistive devices and/or equipment that may be affordable, easy to maintain and adaptable to RLSs.

to multiple survey rounds until consensus was reached for all elements. These included the proposed HBIP interventions, methods of caregiver training, the various roles of the multidisciplinary team, and the community support structure that would need to be in place to implement the HBIP.

Chapter 5 presents a discussion of the thesis results as a whole and includes the implications and recommendations for clinical practice, the limitations and strengths of the research, the authors' recommendations for future research and final conclusions.

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CHAPTER 2: EFFECTIVE HOME-BASED INTERVENTIONS TO PREVENT MUSCULOSKELETAL COMPLICATIONS IN SEVERE CEREBRAL PALSY

2.1 Introduction

The essential elements of a home-based routine to mitigate musculoskeletal (MSK) complications in children with severe CP in resource-limited settings (RLS) have not been determined (Van Aswegen et al. 2024). This chapter presents the first of three sub-studies undertaken to achieve the first objective of the research, namely, a scoping review to summarise the worldwide evidence for programmes and interventions that mitigate MSK complications in children with severe CP (Van Aswegen et al. 2024). These results contributed to the evidence base that the Delphi panellists used to make evidence-based recommendations for a home-based intervention programme (HBIP) that would be feasible for a RLS.

At the time of submission of this dissertation, this chapter has been published online in the *South African Journal of Physiotherapy*, an open-access peer-reviewed journal:

van Aswegen SR, Richards M, Morrow B. *Preventing deformities in paediatric cerebral palsy in poorly-resourced areas: A scoping review.* S Afr J Physiother. 2024 Oct 29;80(1):2059. doi: 10.4102/sajp.v80i1.2059

2.2 Background

As a leading cause of childhood motor disability worldwide, cerebral palsy (CP) is a complex long term condition that requires coordinated access to medical interventions, rehabilitation and equipment, all of which are often scarce or unavailable in resource-limited settings (RLSs) (Donald et al. 2015).

In low- and middle-income countries (LMIC), the estimated prevalence of CP is between 2 and 10 per 1000 live births, with higher rates in poorer areas (Couper 2002, Cans et al. 2008). Such RLS likely have higher proportions of the severe types of CP, including bilateral spastic and dyskinetic presentations (Gladstone 2010), which usually occupy the more severe functional levels of the Gross Motor Function Classification System (GMFCS) (Palisano et al. 2007), that is, levels III - V that have no or limited ambulatory ability (Shevell et al. 2009). Children with severe impairments often present with higher rates of co-morbidities, for example, feeding difficulties and orthopaedic complications, of which hip displacement, muscle contractures, and scoliosis are common (Hollung et al. 2020). Unmitigated, these can restrict active movement and reduce the repertoire of participatory possibilities in age-appropriate events such as play and education.,as illustrated by the World Health

Organisation's (WHO) International Classification of Functioning, Disability and Health framework (ICF) in Figure 2.1 (WHO 2002). According to this model, low participation would contribute to lower overall quality of life.

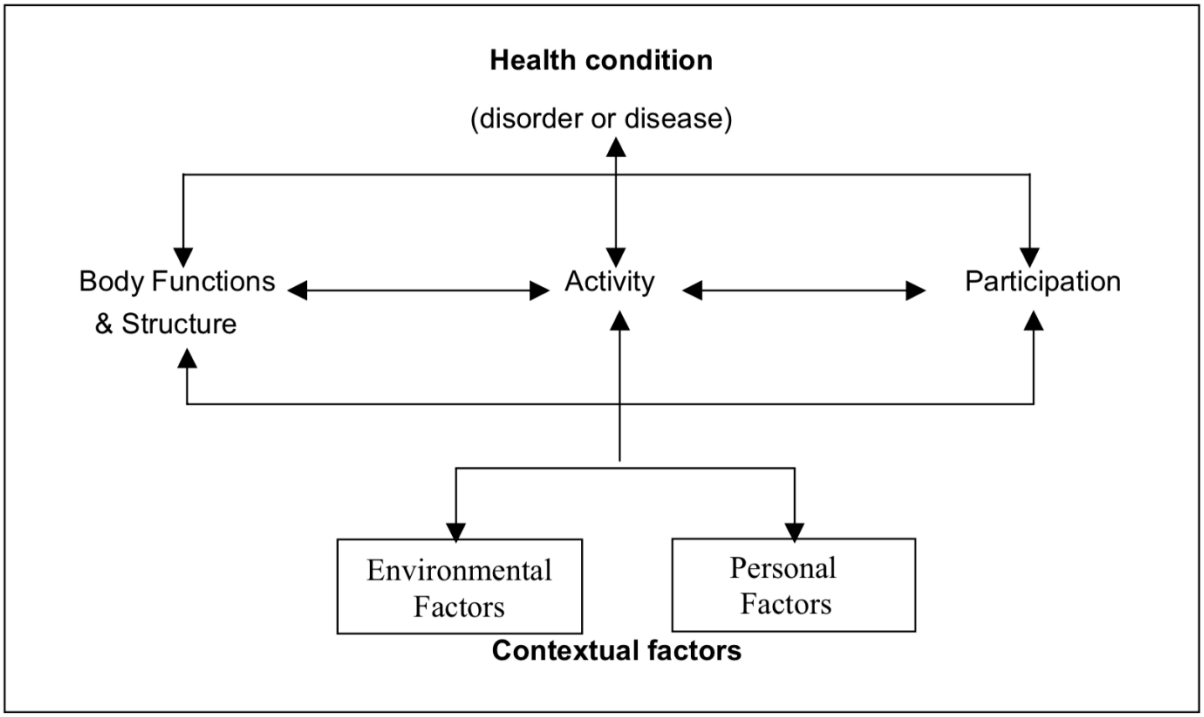

Figure 2.1: International Classification of Functioning, Disability and Health (ICF) framework illustrating the interdependence between the various domains.

Source: https://cdn.who.int/media/docs/default-source/classification/icf/icfbeginnersguide.pdf?sfvrsn=eead63d3_4&download=true

Using the ICF framework, orthopaedic deformities (Body functions and structure) can prevent the child from being placed in sitting and standing positions, where most functional activities occur (Activity), even where postural devices are available for support. Exclusion from age-appropriate community activities, e.g. school attendance (Participation), is the likely result, indicating compromised functional health. This population warrants special attention to achieve the United Nations (UN) third Sustainable Development Goal for 2030, to "ensure healthy lives and promote well-being for *all at all ages*" (UNDESA 2015:6).

Limiting MSK complications is critical to optimise activity and participation opportunities for children with severe CP living in RLSs. Although this requires input from a multidisciplinary team, specific manual techniques for this purpose traditionally fall within the scope of rehabilitation therapists, which may be a scarce resource in RLSs. Strategies to develop competence in preventing complications within existing rural health structures and within the home are thus warranted.

The value of partnering with primary caregivers to deliver home-based intervention programmes (HBIPs) for chronic conditions is increasingly being recognised even in high-income countries (HICs), where caregivers are trained in the required interventions, then supported and coached by medical professionals (Akhbari Ziegler et al. 2020; Beckers et al. 2020). Adopting this model to manage children with severe CP in RLSs, essential evidence-based interventions aimed at limiting commonly occurring MSK sequelae may be provided by caregivers and/or trained community healthcare workers (CHWs) within the child's natural environment (ICF domain of Environmental Factors). With this aspect adequately addressed, a repertoire of functional activities for the child can be developed (ICF domains of Activity and Participation).

The overall aim of this scoping review was to describe the literature over the last two decades that addresses the prevention of MSK complications in children with non- or partially ambulant CP (GMFCS level III-V) that may potentially be used by caregivers in a RLS, as part of an HBIP.

Specific objectives were to identify:

1. Clinical guidelines for interventions and modalities designed for this purpose and evaluate each recommendation for feasibility in RLSs.
2. Existing HBIP's designed for this purpose and to look at factors affecting programme effectiveness.

2.3 Method

The broad, exploratory nature of our investigation lent itself to a scoping review, which was guided by the Preferred Reporting Items for a Systematic Review and Meta-analysis extension for Scoping Reviews (PRISMA-ScR)[2]

Search terms included four concepts: cerebral palsy in children; musculoskeletal complications; prevention or mitigation; and community-based programmes. Preliminary searches revealed little original research in this area during the last decade. Thus, limits were extended retrospectively to 01 January 2001 and run on PubMed, Scopus, Cochrane Library, CINAHL, Health Source: Nursing/Academic Edition, Africa-Wide Information, Web of Science Core collection and Scielo. Grey literature was identified from Primo, BASE, Clinical Key, EThOS, Google Scholar, and Semantic Scholar, as well as professional society websites, associations, and bibliographies of relevant publications (see Appendix 2.1).

[2] https://www.acpjournals.org/doi/full/10.7326/M18-0850?rfr_dat=cr_pub++0pubmed&url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org.

Records were imported into the 2020 Covidence web-based collaboration software platform[3]. One researcher screened title and abstracts (SvA), and a full text review for eligibility was conducted independently by two researchers (SvA and BM), with conflicts resolved by discussion.

2.4 Inclusion criteria

Articles and clinical guidelines with full-text availability, published in the English language between 01 January 2001 and 31 December 2021 that described therapeutic interventions and programmes designed for the prevention of MSK complications for children aged 0 -18 years with moderate to severe CP (GMFCS level III-V) were eligible. There was no limit on sample size or study design. Where more than one version of a clinical guideline was retrieved, only the most recent was included.

2.5 Exclusion criteria for articles

- Study population: < 50% related to severe CP diagnosis defined as having limited or no independent ambulation, that is, GMFCS level III-V; < 50% were 0-18 years of age; and studies focusing on unilateral CP, that typically classify as GMFCS level I or II.
- Settings: Interventions requiring a specialised environment or expertise not widely available.
- Surgical, radiological and/or pharmacological interventions.
- Outcomes: Not primarily related to prevention or control of MSK complications in CP, or HBIPs not including the prevention or control of MSK complications.
- Publication type: Protocols, letters, non-expert reviews, summaries, and commentaries and/or editorials.
- Full text of the article is not available.

One researcher (SvA) performed two independent extractions and critical appraisals for each article, at a minimum of 8 weeks apart to improve accuracy and consistency. Study details were then extracted onto a spreadsheet recording first author, year of publication, country or region of origin, sample size, age, diagnosis and GMFCS level, other participants, study design, main subject or concept, intervention, outcomes measured, main results or recommendations, adverse effects, and identified gaps in knowledge (See online supplemental file S2). The level of evidence of each record was noted, based on the work of Ackley *et al.* (2008), and methodological appraisal was applied using the AGREE II assessment for clinical guidelines[4], and Joanna Briggs Institute (JBI) checklists for the other

[3] https://app.covidence.org.
[4] https://www.agreetrust.org/wp-content/uploads/2017/12/AGREE-II-Users-Manual-and-23-item-Instrument-2009-Update-2017.pdf.

studies[5]. The JBI checklist and AGREE II scores were reflected as Very low, Low, Moderate and High, based on percentage of agreement with quality criteria for each record (see Appendix 2.2 for methodology).

2.6 Ethical considerations

As this review formed part of a larger study involving human research, ethical approval was obtained for the whole project from the University of Cape Town's Human Research Ethics Committee with reference no. 024/2022.

2.7 Results

We identified 1943 records. After de-duplication, 1481 records were screened by title and abstract and 173 underwent full-text review. A total of 116 records were excluded as detailed in the PRISMA diagram (Figure 2.2), which left 57 records for the final review.

[5] https://jbi.global/critical-appraisal-tools.

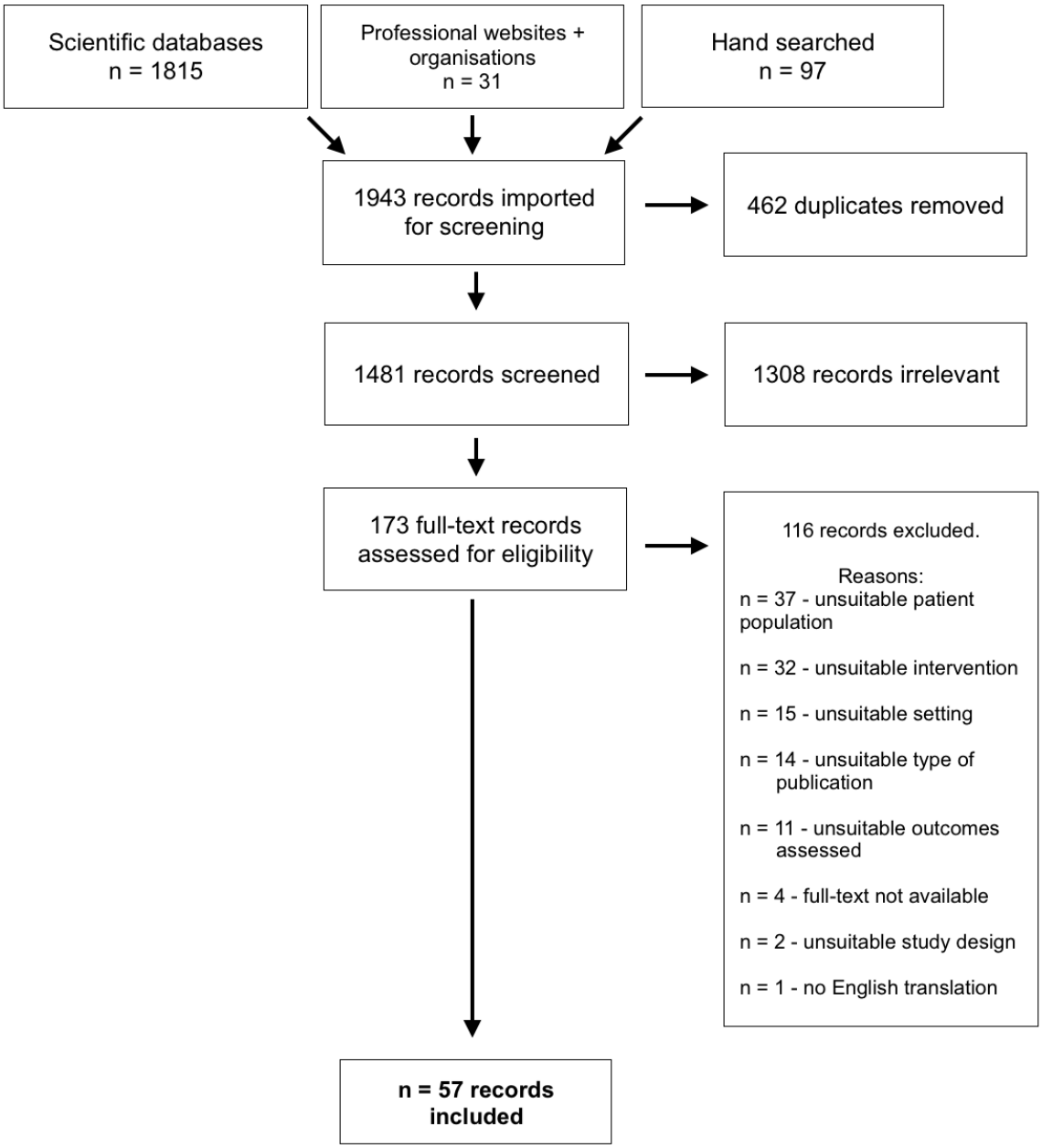

Figure 2.2. Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) flow diagram

The 57 results could be grouped as follows:

1. Clinical practice guidelines (CPG) for children with CP (6 articles, 3 of which were systematic reviews [SRs]);
2. 24-hour postural management (24-h PM) supported seating and standing (27 articles);
3. Stretching interventions (12 articles);
4. Programs and aspects of community-based HBIPs from RLS (12 articles).

Studies in each group were represented chronologically in graphs to illustrate research trends, study type and focus (see online supplementary files).

2.7.1 Clinical practice guidelines and systematic reviews on clinical recommendations for children with cerebral palsy

Three CPGs came from national or regional health websites in HICs - the National Institute for Health and Care Excellence (NICE) in the United Kingdom (NICE 2012), the Waikato Health Board (WHB) in New Zealand (WDHB 2014), and the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) (Paleg *et al.* 2019). Two comprehensive SRs of reviews of therapeutic interventions aimed to guide clinical practice (Novak *et al.* 2020; Morgan *et al.* 2021), and one article was an SR of guidelines for the care of persons with CP initiated by the WHO (Damiano *et al.* 2021). All guidelines adhered to AGREE-II and PRISMA criteria.

The NICE guideline (NICE 2012) and AACPDM Care Pathway (Paleg *et al.* 2019) focused on general medical management of CP and central hypotonia in children. No specific regimens or home programmes were given, but conditional recommendations for interventions targeting the body structures were included. The WHB guided therapeutic management, providing detailed recommendations for assessment, interventions, and equipment needs, all stratified into GMFCS levels, and age bands.

One comprehensive SR addressed evidence-based medical and therapeutic interventions for children with CP, but recommendations for children with GMFCS level IV and V were few and of questionable feasibility in RLSs (Novak *et al.* 2020). An SR on early intervention guidelines (Morgan *et al.* 2021) focused on improving motor function and could make few recommendations in 0- to 2-year-olds for prevention of MSK complications. The WHO review (Damiano *et al.* 2021) only identified five official guidelines for CP of all ages, and relevant recommendations referenced guidelines already retrieved. Table 2.1 summarises the recommended non-medical modalities for prevention of MSK complications from each of the included sources.

Table 2.1 General recommendations for prevention of musculoskeletal complications from the retrieved clinical practice guidelines and systematic reviews

Author, date and study design	**Abbreviated title**	**Population**	**Recommendations for prevention of MSK complications**	**Evidence level and quality rating**
NICE 2012 Clinical practice guideline	Spasticity in under 19s: management	Children with CP, 0-18 years	• Consider 24-hr PM sleeping, sitting & standing with equipment • Consider low load stretching • Consider ankle and wrist orthoses	Level VII 5/7 Moderate (AGREE-II)
Waikato District Health Board 2014 Clinical practice guideline	CP: Clinical practice guideline	Children with CP, 0-18 years	GMFCS IV & V: • 24-hr PM: supported standing; seating in a supportive buggy; sleep positioning systems with night or resting splints • ankle splints/stock boots, gaiters, wrist splints • stretches	Level VII 6/7 High (AGREE-II)
AACPDM (Paleg et al.) 2019 Clinical practice guideline	Care pathways: Central Hypotonia	Children, 0-6yrs with CH (DS, CP and DD)	Conditional recommendations: • ankle orthotics • adaptive equipment, e.g., seating and standers • 24-hr PM	Level VII 4/7 Moderate (AGREE-II)
Novak et al. 2020 Systematic review	State of the Evidence Traffic lights 2019: SR of Interventions for preventing and treating children with CP	247 sources Children with CP, 0-18 years	Yellow light - Probably do it: • 24-hr PM • sleep system • serial casting Yellow light - Probably don't do it: • stretching • orthotics	Level I 8/11 Moderate (JBI)

Morgan et al. 2021 Systematic review	Early Intervention for children aged 0-2 years with or at risk of CP	41 sources Infants at high risk or having CP, age 0 – 2 years	Conditional recommendations: • use of standing equipment • ankle splints • do not use a sleeping system	Level I 8/11 Moderate (JBI)
WHO Damiano et al. 2021 Systematic review	SR of Clinical Guidelines related to care of individuals with CP	5 sources People with CP	• Consider UL and LL orthoses • 24-hour PM - standing for BMD • Stretching routines	Level I 8/11 Moderate (JBI)

Source:
Please see full reference list of Van Aswegen, S.R., Richards, M. & Morrow, B., 2024, 'Preventing deformities in paediatric cerebral palsy in poorly resourced areas: A scoping review',

South African Journal of Physiotherapy 80(1), a2059. https://doi.org/10.4102/sajp.v80i1.2059

Legend:
24-h PM = postural management regime including supported lying, sitting and standing;
BMD = bone mineral density, an indication of bone strength; GMFCS, Gross Motor Function Classification System;
CH = central hypotonia
CP = cerebral palsy
DD = developmental delay
DS = Down's syndrome
JBI = Joanna Briggs Institute
LL = lower limb
MSK = musculoskeletal
UL = upper limb

From the results in Table 2.1, the conditional recommendations for the prevention or control of MSK complications for children with severe CP were:

1. 24-hour postural management, including lying, seating, and standing (5 articles); using sleep systems (4 articles, one of these implied); supported/adapted seating (5 articles, 2 of these implied); standing using relevant equipment (6 articles).
2. Orthotics or splints: for lower limbs (LLs) to prevent loss of range of motion (ROM) in joints and to assist with standing and walking (5 articles) and for upper limbs (ULs) to prevent ROM loss in the wrists (3 articles).
3. Stretching (3 articles)

The next sections discuss the evidence that informs the implementation and application of these recommendations as well as aspects to consider for successful home-based interventions.

2.7.2 24-hour postural management, supported seating and standing

At a Mac Keith Multidisciplinary meeting held in 2006, postural management was defined as 'a planned approach encompassing all activities and interventions which impact on an individual's posture and function' (Gericke 2006). For this review, we developed a narrower definition, that is, 'the supportive positioning of the whole body in lying, sitting, and standing to preserve normal MSK alignment and to provide central support for functional activity'. This would include supported standing but exclude a focused modality such as applying an orthosis.

Of the 27 articles included in this section, all were from HICs, except one from Malaysia (Htwe et al. 2016). Included articles were 18 cohort or quasi-experimental studies (Pountney et al. 2002; Holmes et al. 2003; Vekerdy 2007; Porter et al. 2008; Picciolini et al. 2009; Mol et al. 2012; Kim et al. 2013; Gibson et al. 2009; Martinsson et al. 2011; Macias-Merlo et al. 2015; Macias-Merlo et al. 2016; Htwe et al. 2016; Capati et al. 2020; Tornberg et al. 2020; Martinsson et al. 2021; Paleg et al. 2021; Picciolini et al. 2016; Pountney et al. 2009), seven SR's (Chung et al. 2008; Wynn et al. 2009, Pérez-de la Cruz 2017; Gmelig Meyling et al. 2018; Humphreys et al. 2019; Pin 2007; Paleg et al. 2013), an expert consensus (Gericke 2006) and a narrative review (Kittelson-Aldred et al. 2017).

Interventions in all three positions were represented in the studies, with almost half reporting on standing programmes alone. Outcomes most often related to hip displacement, followed by lower limb ROM. Several sources reported on the functional impact of postural management regimens and qualitative measures, for example, ease of performing daily

activities, and sleep quality when using sleep systems. Tables 2.2 and 2.3 provide detailed results of studies involving 24-hour PM regimes and lying, seating and standing interventions.

Table 2.2 Application of Postural Management: 24-hour regimes, lying and seating interventions

Author, design & subject	Population	Intervention/exposure	Results/recommendations for main outcomes	Evidence level & Quality rating
Pountney et al. 2002 Cohort *Effect of a postural management regime on hip displacement*	59 children with CP, 0 to 9.8 years, Unable to sit, had used postural management for ≥ 2 years including Chailey Adjustable Support systems (CAPS)	SG: "All CAPS"† - (All 3 modalities) for at least 2 years OR "2 CAPS" (any 2 of the 3 CAPS modalities) OR "No CAPS" (any other system) Mean follow up 7 years CG: own controls	<u>Hip migration percentage (MP)</u> % with both hips safe i.e., MP < 33%: -significant difference in hip status between groups that used "All CAPS" vs groups using "2 CAPS", or "No CAPS" ($p<0.05$) - "All CAPS" had 65% both hips safe, vs "2 CAPS" with 41.6%, vs "No CAPS" with 12.5%. Should commence by 18 months of age	Level IV 7/11 Moderate
Holmes et al. 2003 Quasi-experimental *Effect of trunk support position on scoliosis*	16 children and young adults with CP, 6.5 - 20 years, non-ambulant, GMFCS Level III-V	SG: 3 different configurations of lateral pads to support the trunk in sitting: 1. at pelvis only 2. 2-point arrangement - at pelvis, + lat. pads just under axillae, 3. 3-point force arrangement - at pelvis + 2 pads on trunk at different heights CG: own controls	<u>Thoracic posture</u> 3-point force system vs 2-point system: -35% correction in Cobb angle†† vs 18.6% -significant ↓ in mean spinous process angles than either configuration 1 or 2 ($p=0.000$). -seat force ↓ by 16.8%, and a smaller difference in force between trunk pads in configuration 3 (4 Newtons) vs configuration 2 (19 Newtons)	Level III 7/9 High
Gericke 2006 Expert opinion *CPG on PM*	Children with CP, 0-18 years	N/A	Postural management regimes facilitate function, may reduce deformity, and can be guided by GMFCS level -GMFCS IV&V should start in sitting from 6 months and standing from 12 months. -GMFCS III should emphasize postural activity	Level VII 5/6 High
Vekerdy 2007	47 children with CP, aged 1-11 years, GMFCS III-V	SG: Sitting in a custom moulded trunk support (TLSO with SIDO® frame)‡ for an average of 3.9 hours p/day for at least 4 months	<u>Seated posture</u> most improved with ↓ thoracic kyphosis ($p<0.0001$) and ↑ lordosis ($p=0.0025$). -Cobb angle†† ↓ but not significant.	Level III 6/9 Moderate

Quasi-experimental *Effect of seating device on spinal posture and daily activities*		Mean follow up of 12.7 months CG: own controls	<u>Daily activities</u> According to parents: -feeding problems ↓ in 91.4% of children. -trunk posture improved in 88.65%. -average satisfaction with device - 3.9 /5.	
Chung et al. 2008 Systematic review *Effect of adaptive seating on sitting posture and postural control*	14 sources, mostly moderate quality, > 176 children and young adults with CP With varying GMFCS level	Using various approaches to improve seating posture: CAPS II[§], seat tilt, seat inserts, knee blocks, saddle seats, 2-point and 3-point support, modular seating (pelvic symmetry, seat sloped forward, hips in Abd, feet supported), tray tables and child's own chair	Evidence is limited and strong recommendations not possible. <u>Sitting posture for moderate to severe CP</u> -Saddle position - mixed results -Seat tilt: no tilt and a 5° posterior tilt ↑ stability (p=<0.05) -Seat inserts - contoured vs flat foam had significant positive effect on maintaining posture over time (p=0.008), and biofeedback devices ↑ postural stability subjectively. -3-point trunk support vs 2-point significant ↓ in scoliosis (p= 0.000). -Modular seating vs regular seating (e.g., standard wheelchair) improved spinal posture (p=<0.001). <u>Social interaction</u> subjective improvements in social skills, ADL independence and feeding.	Level II 8/11 Moderate
Porter et al. 2008 Cohort *Effect of preferred positioning on hips and spine*	246 children with CP, 0-18 years, median age 10 years 3 months, GMFCS level V	SG: Asymmetrical holding and feeding positioning, and preferred lying posture during first 12 months of life CG: own controls	<u>Musculoskeletal (MSK) deformities</u> -95.5% had lateral curve in their spine, 82.5% had pelvic obliquity, 60.2% had windswept posture and 48.8% at least one displaced hip. -when preferentially using side lying: 69% used one side only -when using supine and prone: >50% consistently rotated head to one side. -Side lying on a preferred side associated with a spinal curve convex to the top hip (p=0.031) and more likely to experience hip problems (displacement) in the top hip (p=0.003).	Level IV 6/11 Moderate.
Pountney 2009	39 children with CP,	SG:	<u>Hip outcomes</u>	Level IV 7/11

Cohort *Effect of PM on hip displacement*	18 months, until 5 years, non ambulant CG: 202	early use of "All CAPS"† postural management programmes or “2 CAPS” moderate use (2 modalities x 6 hours p/day) daily CG: minimal use	-MP <33%: SG had 59% both hips ‘safe’ vs 50% in CG. -% hip problems requiring surgery, BoNT, or a hip and spinal orthosis at 5 years: SG was 18.2% less than for CG (p=0.006) -Hip surgery: SG significantly less likely than CG (p≤0.001)	Moderate
Picciolini et al. 2009 Case series *Effect of PM on hip displacement*	2 children with CP, 0-5yrs	5 hours p/day seated and standing in a customized hip Abd. cast (siège moulé and gouttière) ¶ for at least 2.5 years. CG: own controls	<u>Hip displacement</u> -First case: from 2.5 to 5years of age; seating resulted in restoration of pelvic symmetry, bilateral MP of 20% and no scoliosis. -Second case: started using siège moulé and gouttière 5 hours p/d at age 7; at age 10 years, MP right ↓ from 55% to 16%, and MP left from 20% to 15%.	Level VI 5/10 Low
Wynn et al. 2009 Systematic review *Effects of SS on children & families*	6 sources, mostly of low quality > 100 participants of families & children with CP or 'postural care needs'	Using a sleep system every night for a varying period of 6 months to several years	Very small body of evidence. <u>Parental opinion on daily care</u> -after 1 year, >50% had better symmetry, ↓ tone & pain, care was easier -majority of parents required training in use. <u>Hip MP</u> -significantly ↓ after 6 months of using sleep systems (p<0.05)	Level V 4/11 Low
Mol et al. 2012 Analytical cross section *Effect of night orthoses on sleep and burden of care*	82 children with CP, 6-15yrs	Questionnaires filled out by primary caregiver and physiotherapists Domains: Sleep disturbance; parental burden, parental personality, and sense of competence	<u>Sleep disturbance in CP</u> -Prevalence of 20.7%, most using some type of sleep orthosis; however, no significant difference found between those using night orthoses and not (p=0.28) or between those using them day and night, day only, or night only (p=0.25). -Daytime use only had significant disturbance in initiating and maintaining sleep (p<0.05) compared to day & night use, or night use only. <u>Burden of care</u> -parental extraversion negatively correlated with experienced burden and positively with sense of competence	Level VI 6/8 Moderate

Kim et al. 2013 Cohort *Effect of moulded chair on hip and spine*	34 children and young adults with severe disability, 4-20 years, GMFCS level V	SG: Use of a custom-moulded chair for an average of 3.7 hours p/day for an average of 24 months CG: own controls	<u>Hip and spine outcomes</u> -Femur neck shaft angle‡‡ - significant ↓ in 10 to 15-year-olds "growth spurt group" but group was very small. ($p<0.05$) -Cobb angle†† & MP: no significant difference but hips did not worsen over the period	Level IV 6/11 Moderate
Picciolini et al. 2016 Quasi-experimental *Effect of Abd. seating on hip displacement*	51 children with CP, 6 months – 9 years, GMFCS III-V	SG: 5 hours p/day seated in the siège moulé¶ + neurodevelopmental therapy for 2 years. CG: only neurodevelopmental therapy	<u>Hip displacement</u> Hip MP in SG ↓ from 28% to 26% showing a small improvement, while CG worsened significantly over the 2 years from 23% to 37% ($p \leq 0.0001$).	Level III 6/9 Moderate
Kittelson-Aldred 2017 Narrative review *Evidence summary on PM*	Persons requiring postural support	23 sources	Postural asymmetry is very common, and even obligatory in children with impaired movement especially as they age. -In spite of lack of evidence, 24-hour postural management is widely accepted and used. Most effective when applied over 24 hours, and as an interdisciplinary approach between healthcare professionals, parents, and individuals.	Level VI 4/6 Moderate
Perez-de la Cruz 2017 Systematic review *Effects of PM on hip displacement*	18 sources children with CP 18 months -18 years	Varying use of CAPS† systems: a static Abducted sleep system, Abducted sitting and standing using a siege moulé and gouttière¶	<u>Hip displacement</u> Evidence insufficient for strong recommendations -Hip MP: 24-hr postural management using "All CAPS" or "2 CAPS", MP was significantly ↓ after 2 years. -Early intervention using postural management resulted in significant ↓ in surgery and BoNT after 5 years. -Children using a static Abduction sleep system for 18 months had 11% ↓ in MP, improved hip ROM and gait pattern. However, 50% found sleep systems uncomfortable -Children using Abducted sitting and standing for 5 hours p/day for 3 years had a significant ↓ in MP	Level III 3/11 Low

Gmelig Meyling et al. 2018 Systematic review *Effects of PM on hip migration*	8 sources, mostly of low-quality Children with CP, 0-18 years, GMFCS level III - V	SG: Sleep system every night, siège moulé¶ or Abducted sitting from 1 – 6 hours p/day; Abducted or straddled standing 1 - 5 hours p/day Duration 1-7 years. CG: received usual care (Neurodevelopmental therapy 45 min 3x p/week)	Strong recommendation not possible. <u>Hip outcomes</u> -Siège moulé users had significant ↓ in MP after 2 years (p= 0.03). -Abducted standing /straddled weight bearing had a significant ↓ in MP (p<0.01 & p=0.029) -Children using full 24-hour postural management maintained a stable MP significantly more than CG (p=0.05) Frequency of hip problems in SG vs CG: -postural management in lying, sitting, and standing had significantly ↓ at 5 years (p <0.01). Frequency of children requiring surgery, orthotics and BoNT was significantly ↓ in the SG at 5 years (p=<0.01).	Level III 9/11 High
Humphreys et al. 2019 Systematic review *Effect of night orthoses on hips, sleep, and burden of care*	People with a neuro-disability	14 sources of low to medium quality Sleep systems all night for 8 days - 18 months using commercially available sleep systems - Jenx Dreama, Symmetrisleep, Chailey lying support or unspecified	Weak evidence, therefore strong inferences of benefit not possible <u>Hip outcomes</u> -Pain & comfort: ↓ pain in some children but ↓ thermal comfort. -Hip MP: a significant ↓ in MP on the "worse" hip after 12 months, and 92% MP stability or improvement after 12 months. -ROM: Hip Abduction improved in 66% of patients (small samples and low-quality evidence). <u>Sleep quality, burden of care</u> -No evidence that sleep systems ↓ sleep quality, rather, they sometimes ↓ nocturnal awakenings. -Respiratory function: no significant difference reported between users and non-users. -Quality of life and burden of care: Weak evidence that sleep systems have positive influence -Parent training and adherence: 20 % patients have difficulty adapting to sleep systems (vomiting, reflux, and discomfort): parents felt they needed support while children adapted	Level II 7/11 Moderate

Source:
Please see full reference list of Van Aswegen, S.R., Richards, M. & Morrow, B., 2024, 'Preventing deformities in paediatric cerebral palsy in poorly resourced areas: A scoping review', South African Journal of Physiotherapy 80(1), a2059. https://doi.org/10.4102/sajp.v80i1.2059

Legend:
Abd. = Abduction or abducted (hips), lateral movement in frontal plane away from the midline
Early intervention = applied to children younger than 2 years
Hips 'safe' = having lateral displacement less than 33%
Kyphosis = curvature of the spine in the sagittal plane away from the central axis ('hunch back')
Lordosis = curvature of the spine in the sagittal plane towards the central axis ('sway back')
MP = hip migration %, indicating lateral hip displacement – safe hip has MP < 33%, > 33% the hip is sub-luxed and at 80% the hip is dislocated
Neurodevelopmental therapy = widely accepted manual approach for habilitation of CP that aims to promote efficient movement and optimise function
Pelvic Obliquity= rotation of the hips in the frontal plane, resulting in one iliac crest presenting higher than the other; Saddle position, hips in flexion and abduction, similar to Siège moulé; Scoliosis, lateral curvature of the spine in the frontal plane away from the central axis; Windswept posture, multiple primary and compensatory lateral and rotational deviations of spine, hips and lower limbs from the midline.
ADL = activities of daily living (incl. bathing, feeding dressing, toileting).
BoNT = Botulinum Neurotoxin injection.
CG = control group.
CP = cerebral palsy.
CPG = clinical practice guidelines.
GMFCS = Gross Motor Function Classification System.
lat. = lateral.
MSK = musculoskeletal.
N = Newtons.
N/A = not applicable.
PM = postural management.
QoL = quality of life.
ROM = range of motion.
SG = study group.
†, CAPS = Chailey Adjustable Postural Support Systems
'All CAPS' = involving full sleep system at night, 6 h abducted sitting per day, 1 h standing per day.
‡, TLSO with SIDO® = Thoraco-lumbar-sacral-orthosis, a back brace with a flexible support.
§, CAPS II = modular positioning system (manufactured by Active Design, Ltd 2016) that allows fully customised postural support of the body.
¶, Siège moulé and Gouttière = customised plaster cast seating and standing supports, respectively.
††, Cobb angle = radiological measurement of lateral spinal curvature for scoliosis.
‡‡, Femur neck shaft angle = angle between femur neck and shaft. Normal hips 125° – 135°; >140° is associated with hip displacement.

Table 2.3 Application of Postural Management: supported standing interventions

Author, design & subject	Population	Intervention/exposure	Results/recommendations	Quality – JBI checklist
Pin 2007 Systematic review *Effects of static WB on MSK systems*	10 sources, >100 children with CP, 17 months - 14 years, Various GMFCS levels	Weightbearing (WB) in UL and LL, in various positions and various regimes and dosages ranging from 4 weeks to 9 months	Limited strength of recommendations for all outcomes, except for bone mineral density (BMD) where there is strong evidence. <u>MSK outcomes after static weightbearing in LL</u> -BMD ↑ significantly with 20 mins WB, 3 x p/week for 8 months (p=0.02). -gait: standing in a tilt table for 30 mins led to a significant improvement in gait (p<0.01) -spasticity: ↓ in resistance to passive movement for up to 35 mins (p<0.05) Benefits of WB for UL is inconclusive	Level II 8/11 Moderate
Gibson et al. 2009 Quasi-experimental *Effects of standing programmes on LL deformities*	5 children with CP, 5-10 years, GMFCS IV & V	SG: 2 x Intervention periods of 60 mins standing in a frame p/day, 5 days p/week for 6 weeks, alternating with 2 x non-intervention periods (no standing) for 6 weeks CG: own controls	<u>Knee ROM</u> -improved significantly during the 2 intervention phases (p<0.01 & p=0.03). -↓ significantly during first non-standing phase (p=0.02) <u>Ease of performing ADL's†</u> - ↑ after standing phases (mean scores > 0.0), and a small ↓ following non-standing phases (mean scores <0.0)	Level III 7/9 High
Martinsson et al. 2011 Quasi-experimental *Effect of WB in Abduction on hip stability*	97 young children with CP, 2-6 years, GMFCS III-V	SG: 60 - 90 mins p/day in straddled standing (with hip Abd. of 15-30°) for 1 year CG: usual standing programme without hip Abd. Both SG and CG had 2 subgroups: those who had hip release surgery	<u>Hip MP</u> -Significant correlation between MP and straddled standing (SG1 & SG2) with a mean ↓ of 8.6% (p=0.000). -Significant correlation between having hip surgery (SG1 & CG1) and MP, with a mean ↓ of 11.9% (p=0.000). -In SG1 (surgery followed by straddled standing) mean ↓ in MP was 20.8% (p=0.035) <u>Hip and knee ROM</u>	Level III 6/9 Moderate

		(SG1 and CG1) and those who had not (SG2 and CG2)	-No significant difference between groups for hip and knee Ex. -Hip Abd. improved significantly by a mean of 15° with straddled standing between SG1 and CG1 (p=0.002)	
Paleg et al. 2013 Systematic review *Dosing of paediatric supported standing programmes*	30 sources and >100 young children with CP, Aged 1-6 years, GMFCS II - V	Various regimes and standing devices. 30 – 90min, 3-7 days p/week, with 0°-70° hip Abd. Duration from 3 weeks up to 1 year	Summary and recommendations for all outcomes: - for ↑ ROM in LL: standing with Abd. 45-60 mins p/day from 9 months of age, 3 days p/week (strong evidence) - for ↑ muscle strength: 5 days p/week for 10 mins twice p/day with WBV may ↑ muscle power (good evidence) - for ↓ muscle tone: 30-45 mins standing p/day 3 days p/week (strong evidence) - for ↑ hip stability (↓MP): 30 -90 mins p/day in 60° Abd., 5-7 days p/week may improve hip biomechanics (fair evidence) - for ↑ BMD of spinal vertebrae: ↑ by 6% after 30-90 mins p/day, 5 days p/week; when combined with WBV‡, BMD in tibia ↑ of 18%. - for ↑ GM function: standing may ↓ feeding times, promote social interaction and ease burden of care.	Level I 8/11 Moderate
Macias-Merlo et al. 2015 Cohort *Effect of standing programmes on hip flexibility*	13 young children with diplegic CP, aged 1-5 years, GMFCS III	SG: 70 - 90 mins in a stander with hip Abd. 5 days p/week, 35 mins p/day on weekends until the age of 5 years CG: own control	<u>Hip flexibility (ROM)</u> Mean hip Abd. - at baseline was 42.0° (95% CI 41.0°-43.0°) and at age 5 years was 42.8° (95% CI 41.8°-43.8°) -reduction in scissor gait	Level IV 6/11 Moderate
Macias-Merlo et al. 2016 Cohort *Effect of standing programmes on hip MP (acetabulum development)*	26 young children with diplegic CP, aged 1-5 years, GMFCS III	SG: 70 - 90 mins in a stander with Abd. 5 days p/week, 35 mins on weekends until the age of 5yrs CG: matched but did not participate in standing.	<u>Hip MP and symmetry</u> For the worst hip: maximum MP in SG was significantly ↓ at 5 years - 20.23% (SD 2.42) vs CG at 5 years - 35.15% (SD 7.30) (p=0.000). -mean MP difference: standing group 4.00% SD 2.74 vs CG 18.31%, SD 7.52 (p<0.05). -Hip asymmetry: ranged from 13-23% in SG vs 12-47% in CG which is significant (p<0.01)	Level IV 7/11 Moderate

Htwe et al. 2016 Analytical cross section *Effects of standing programmes on hip displacement*	36 children with CP, Aged 6-12 years, GMFCS III to V	Intervention and results not well-documented. Various standing regimes - for between 1 – 3 hours per day, 5 x p/week for a duration of 4 to 10 years	<u>Hip MP and Acetabular index (AI)[§]</u> -the higher the GMFCS level, the greater the MP & AI[§] values ($p<0.05$) -MP of GMFCS IV & V were 32.5% and 30.0% respectively in children who had been standing for at least 4 years for at least 1 hour p/day at least 5 days p/week, but also having regular postural management and regular physiotherapy	Level VI 4/8 Low
Capati et al. 2020 Case report *Effect of standing programme on hip and knee ROM*	Single subject, adolescent with CP, 16 years, GMFCS V	60 mins 3 x p/week for 15 months in a stander using progressively increasing joint Ex and reducing stander inclination until fully upright Own control	<u>Hip and knee ROM</u> -Hip F contractures ↓ from 25°to 0° on right, and from 40-20° on left -Knee F contractures ↓ from 40-20° on right but ↑ from 30-35° on left <u>Function and ease of care</u> -in participation and activity levels, no change -ease of care: at 7- and 15-months post intervention, reported greater ease with bathing, dressing & transferring, and with bowel care.	Level VI 7/8 High
Tornberg et al. 2020 Quasi-experimental *Effect of static vs dynamic standing on LL ROM and muscle tone*	20 children with CP aged 0-18 years, non-ambulatory (GMFCS IV & V)	SG & CG crossover: 4-month trial: during static standing phase: standard care + static standing 30-90mins p/day. During dynamic standing phase: 30 mins p/day at 30-50 revs p/min in the Innowalk apparatus[¶]	<u>Hip and knee ROM</u> -pre and post intervention ROM improved significantly with both static and dynamic standing ($p = 0.001$), -difference in ROM changes after each session were significantly larger after dynamic vs static standing for all movements (all $p \leq 0.003$). <u>Spasticity</u> - acute ↓ after sessions of dynamic standing were significant for all hip movements (Abduction, Flexion and Extension) (p values all <0.001) vs static standing where only hip Flexion was significantly improved ($p =0.04$) -No significant long-term difference in tone was found between dynamic and static standing pre-and post-intervention.	Level III 7/9 High
Martinsson et al. 2021 Cohort	269 children with CP enrolled in CPUP before 2	SG & CG: Use of a stander/standing shell 10hrs p/week for at least 8 months with SG: 15° hip Abd. or more	<u>Hip MP</u> -mean ↓ in MP with SG was 12%, and a sig. correlation between Abd. standing and change in MP ($p=0.001$)	Level IV 10/11 High

Effects of Abd. standing on hip development and LL ROM	years, age 3-16, GMFCS IV & V	CG: same use of stander with hip Abd of 0-10°	-median MP between SG ↓ by 7% vs CG where MP ↑ increased by 6.5% (p=0.001) indicating a SD Hip and knee ROM -new contracture development in SG vs CG was 0 joints and 41 more joints respectively. -with those undergoing AIT surgery†† prior to intervention, significant ↑ in ROM of hip Abd. and knee Ex were found, (p=0.013 and p=0.04 respectively).	
Paleg et al. 2021 AX *Effect of inclination hip Abd., and orientation on WB in standing devices*	15 children with CP and other conditions (2 typically developing), 3-9years, GMFCS III - V	Standing in a total of 36 positions of varying inclination, orientation, and hip Abd.	Effect of standing position on WB -For hypertonus (spasticity) in limbs: max WB (91%) occurred in prone position, upright, hips in neutral or slight Abd. -for hypotonus (low tone) in limbs: max WB (95%) in supine orientation, upright, hip Abd. of 60%	Level VI 6/8 Moderate

Source:
Please see full reference list of Van Aswegen, S.R., Richards, M. & Morrow, B., 2024, 'Preventing deformities in paediatric cerebral palsy in poorly resourced areas: A scoping review', South African Journal of Physiotherapy 80(1), a2059. https://doi.org/10.4102/sajp.v80i1.2059

Legend:
Abd., Abduction or abducted (hips) = Lateral movement in frontal plane away from the midline.
MP = hip migration percentage, indicating lateral hip displacement – safe hip has MP < 33%, > 33% the hip is subluxed and at 80%, the hip is dislocated.
Scissor gait = legs cross the midline during ambulation because of hypertonus in the hip abductors.
Spasticity (or hypertonus) = increase in muscle tone in response to a quick stretch. It is caused by central hypertonia;
Tilt table = supported standing device that allows inclination from the vertical position.
BMD = bone mineral density (strength)
CG = control group
CP = cerebral palsy
CPUP = National Cerebral Palsy Hip Surveillance Programme
Ex = extension
GM = gross motor
GMFCS = Gross Motor Function Classification System
JBI = Joanna Briggs Institute
LL = lower limb
MSK = musculoskeletal

ROM = range of motion of a joint (flexibility)
sig. = significant; SG, study group; UL, upper limb; WB, weight bearing, usually with respect to standing.
†, ADL = activities of daily living (incl. bathing, feeding dressing, toileting);
‡, WBV = whole body vibration performed by a device (stepping, oscillations, vibrations);
§, AI = acetabular index, a radiological measurement of hip inclination;
¶, Innowalk apparatus = a dynamic supported standing device that allows hip movements that approximate walking;
††, AI = abductor ileo-psoas tenotomy (surgical soft tissue release of inner hip muscles)

For children in GMFCS level IV and V, the expert consensus from 2006 recommended lying or sleeping with postural support at night, sitting from 6 months of age and supported standing from 12 months (Gericke, 2006) The researchers found no revisions or updates for this regimen.

Unsupported holding, feeding and lying positions for children with GMFCS level V tended to result in spinal, pelvic and hip deformities in up to 95% of subjects (Porter et al. 2008). However, using a consistent 24-hour postural management approach in lying, seating with hip abduction for 5 to 6 hours daily (Kim et al. 2013), and/or standing from the age of 18 months and upwards for 30 – 90 minutes per day significantly controlled and/or improved hip migration percentage (MP), and reduced frequency of spinal orthotic prescription, Botulinum toxin injections (BoNT) and hip surgery indications at age 5 (Pountney et al. 2002, 2009; Picciolini et al. 2016, 2009; Pérez-de la Cruz 2017; Gmelig Meyling et al. 2018).
Weak and inconclusive evidence from three studies reported the effects of using commercial sleep systems. Two reported significant reduction of hip MP after a minimum of 6 months and up to several years of consistent use, and hip ROM improved along with MSK comfort levels. Thermal comfort was sometimes reduced, however, and parents required training to use these systems (Humphreys et al. 2019, Wynn et al. 2009). Caregivers reported that sleeping systems did not cause significant sleep disturbance, especially if used night and day (Mol et al. 2012).

Seating that incorporated a 3-point force system (Holmes et al. 2003), or modular or moulded contours with optional tilt, produced a decreased spinal Cobb angle and improved thoracic posture when used for at least 4 h per day (Chung et al. 2008). In addition, caregivers from two studies found trunk-supported seating eased everyday caregiving and improved the child's social interaction (Vekerdy 2007; Chung *et al.* 2008).

Supported standing regimes were reported to significantly improve a range of outcomes, especially when commenced as early as 9 months of age (Paleg et al. 2013). Standing for 30 to 90 minutes per day for 3 to 7 days per week for young children from the age of 12 months up to 5 years significantly decreased hip MP at age 5 years, the effects enhanced with additional total hip abduction up to 60° (Martinsson et al. 2011, 2021; Paleg et al. 2013; Macias-Merlo et al. 2016; Htwe et al. 2016; Martinsson et al. 2021). Standing for at least 30 minutes per day for at least three days per week also improved bone mineral density (BMD) significantly in the LLs and spine, especially when combined with whole body vibration (Pin 2007; Paleg et al. 2013), and reduced spasticity in the LLs for up to 35 minutes post intervention, which in turn led to a less scissored gait pattern (Tornberg et al. 2020; Macias-Merlo et al. 2015; Paleg et al. 2013; Pin 2007). Standing for 45 to 60 minutes per day 3 to 5

days per week for 8 to 15 months was found to significantly increase LL ROM which led to improvements in gait, social interaction, and decreased burden of care (Gibson et al. 2009; Paleg et al. 2013; Macias-Merlo et al. 2015; Capati et al. 2020; Tornberg et al. 2020, Martinsson et al. 2021).

2.7.3 Stretching and splinting interventions

Twelve articles, mostly from HICs, were included in this section, but only three were primary studies - a case-controlled time series from 2003 (Fragala et al. 2003), and two quasi-experimental trials (Uzun Akkaya et al. 2021; Laessker-Alkema et al. 2016). The rest included six SRs (Pin et al. 2006; Wiart et al. 2008; Groppe et al. 2012; Craig et al. 2016; Autti-Rämö et al. 2006; Eldridge et al. 2016), two narrative reviews (Wilton 2003; Physiopedia 2016), and an expert consensus (Lannin et al. 2011). Within the five SR's that included manual stretching, there was considerable overlap in the sources, with several studies repeatedly cited (Pin et al. 2006; Wiart et al. 2008; Groppe et al. 2012; Craig et al. 2016; Eldridge et al. 2016). Overall, the evidence was scarce.

Although stretching is widely regarded as an essential part of conservative joint range maintenance in CP (Wiart et al. 2008), the researchers found no clear consensus on the scope of 'stretching' techniques nor any standardised stretching dosage regimes. All sources described manual (intermittent) stretching of a joint or muscle by a therapist, maintained for up to 60 seconds per repetition. Most also included at least one of the following: manual stretching with the addition of electrical stimulation (ES); active stretching with child participation; positional or sustained stretching, lasting 15 minutes or more and using equipment such as a standing frame or an orthosis; intramuscular stretching (similar to massage); and serial casting where a series of rigid casts were applied to a joint for progressive lengthening of shortened tissues. As the use of orthotics in children with severe CP is largely for joint range maintenance (Lannin et al. 2011), five studies reporting on orthotic use were included here. Outcomes included calf muscle spasticity, LL ROM, and gross motor function. Characteristics of studies on stretching interventions are presented in Table 2.4.

Table 2.4 Effects of Stretching interventions for children with severe CP

Author, design & subject	Population	Intervention/exposure	Results/recommendations	Quality
Fragala et al. 2003 Case-controlled time series *Effects of regular stretch routine on LL ROM*	7 children with CP, aged 4-18 years, Severe mobility limitations (GMFCS likely III-V)	Intervention phase: Usual care = manual stretches 3 x 60 s of hip, knee, and ankle joints, 1-2 x p/week + classroom positioning for the duration of school term 2x non-intervention phases during holidays of 5 weeks and then 3 weeks Own controls	<u>ROM (hip Flexion, Extension Abduction and Knee Flexion and Extension</u> After first non-intervention of 5 weeks - significant ↓ in LL ROM in 7 subjects (p=0.046) but change after 3 weeks non-intervention was not significant	Level IV 8/11 moderate
Wilton 2003 Narrative review *Effects of orthotics on hand deformities & function*	Children with CP	Casting, splinting, and stretching of the hand	<u>Hand ROM</u> -Stretch is essential to muscle growth and to maintain length after growing stops -Casting 24hrs p/day for 4 weeks ↑ ROM -Intermittent casting for 3-5 hours p/day using splints and casts is best for effective stretch in growing muscles with moderate to severe spasticity. -night splinting to address hand deformities and control the thumb is recommended -for spastic muscles, contractures recur unless stretch routine is maintained <u>Hand Function</u> Improved ROM and addressing deformities do not necessarily improve function	Level VII 4/6 moderate
Autti-Rämö et al. 2006 Systematic review *Summarise effectiveness of UL and*	5 sources, >600 children with CP, GMFCS varied	Any intervention using casts or orthoses for ROM or function in LL's & UL's, dosages and regimes not specified	Results mostly inconclusive <u>ROM</u> -LL orthoses - no evidence to support prevention of ankle deformity; moderate evidence that casting increased ROM in the short term	Level I 8/11 moderate

LL casting & orthoses on ROM and function			-UL orthoses – no evidence that they increase or maintain ROM Casting as an adjunct to therapy for 4 weeks – 6 months ↑ ROM <u>Function</u> -LL: ankle movement improved during gait -UL orthoses may improve grasp but may restrict activity	
Pin et al. 2006 Systematic review *Effectiveness of passive(manual) stretch on ROM and spasticity*	7 sources, >100 children and young adults with CP, aged 3-20 years, various GMFCS levels	Various: Manual stretch of varying dose and duration; standing programmes for 30mins, variable duration and frequency	Conflicting evidence for manual stretching Weak evidence that sustained stretch may be more effective than manual stretching to ↑ ankle movement and ↓ spasticity <u>Spasticity</u> -30 min sustained stretch 3 x p/week x 6 weeks showed a significant ↓ ($p<0.01$) -30 min standing in tilt table led to significant ↓ ($p<0.05$)	Level II 8/11 moderate
Wiart et al. 2008 Systematic review *Effect of stretching on ROM, spasticity, muscle activation and gait*	7 sources, >100 children with CP, aged 3-13 years, GMFCS levels varied	Various: Manual stretching of various dosages and duration; standing programmes for 30 mins with variable duration	Insufficient evidence to support any stretch interventions, despite widespread use <u>Hip and knee ROM & spasticity</u> Inconsistent, insufficient results <u>Muscle activation & gait</u> No evidence to support	Level III 6/11 moderate
Lannin et al. 2011 Expert opinion *CPGs for orthotic management of CP*	People with CP	Orthotics and effects on deformities, gait, and general health	<u>Recommendations</u> In GMFCS level IV and V orthoses may help prevent LL joint deformities and provide a prolonged stretch to maintain muscle length -hip orthoses have poor patient adherence -spinal orthoses may slow the rate of scoliosis. -UL orthoses have inconclusive evidence for improving ROM. -The use of UL orthoses may hinder function	Level VII 5/6 high

Groppe et al. 2012 Systematic review *Effect of stretching on ROM and spasticity*	13 sources, >150 children with CP, aged 2-19 years, GMFCS various	Manual stretch: 3 x 30 – 60sec 1-5 days p/week, one study adding electrical stimulation (ES) of antagonist for 30 mins 3 x p/week applied to LLs for up to 5 months. -sustained positional stretching (sitting with legs in hip Abduction and knee Extension for 20 mins), -serial casts for 3 -12 weeks, -standing for 30 mins applied to LLs	Weak evidence that stretching improves MSK or Functional outcomes <u>Hip and knee ROM</u> -manual stretching + ES led to significant ↑ in knee Ex (p=0.04) in a single study -positional stretching in sitting led to significant mean ↑ in ankle DF (9.25°-) -serial casting for 3 weeks- ↑ ROM LL (all p<0.001) <u>Spasticity</u> -Manual stretching + ES led to significant ↓ (p=0.046) in a single study -Positional stretching in sitting for 20 mins led to significant ↓ in Hoffman reflex† of 5.17mV (SD 3.61) - 3 x 30 mins standing p/week for 5 months led to significant ↓, on average by 50% for up to 35 mins post intervention (p=<0.05). -serial casting for 3 weeks – all participants had significant ↓ using various measures	Level III 6/11 moderate
Craig et al. 2016 Systematic review *Effectiveness of stretch interventions on ROM, BMD, spasticity, and GM function*	16 sources, >4000 children with neuromuscular disabilities, Age and level unspecified and various.	Any stretch technique (manual stretching bracing, splinting & orthoses, positioning programmes, casting) applied to body structure, function, activity, or participation	Limited evidence for benefit to body structures <u>ROM & spasticity</u> -Manual stretching - insufficient and conflicting evidence for efficacy -Sustained stretch (positional or with orthosis for at least 30 minutes) appears more effective than intermittent passive stretching (low evidence). -Orthotics had conflicting and insufficient evidence for efficacy -Supported standing of 30 - 90 min p/day: ↑ BMD (low quality evidence) but for ROM and spasticity had insufficient evidence -Casting - ↑ROM in ankle in short term -Splinting may cause bruising, skin breakdown, or sleep disturbance	Level II 8/11 moderate
Eldridge et al. 2016	4 sources, unreported sample size, children with	Manual stretch of the gastrocnemius 5 x 20 s (calf) performed by HCP vs	Very weak, conflicting evidence that stretching influences ROM and tone	Level III 6/11

Systematic review *Effect of stretching on ROM and spasticity of the calf muscle*	CP, aged 3-14 years, GMFCS level unspecified/varied.	client self-stretch; and 30 min supported standing	ROM (one study) Passive stretching – a transient significant ↑ in both ROM and soft tissue length (all p<0.001) whether performed by HCP or client Calf spasticity contradicting evidence; the study that observed a significant ↓ in tone found that the effects remained after 35 minutes (p<0.05)	moderate
Laessker-Alkema 2016 Quasi-experimental trial *Effect of knee orthotics on ROM, spasticity, and GM function*	10 children with CP, aged 1-15 years all GMFCS levels	Application of splints at least 30 mins p/day for at least 5 days p/week for 8 weeks with Knee-ankle-foot orthoses (KAFO) in maximum knee Extension (Ex) Own controls	ROM Sustained stretch - hamstring extensibility significant ↑ compared to baseline (p=0.005 for both L and R) Knee Ex – significant ↑ (p=0.028 on R, p=0.018 on L) Spasticity hamstrings- significant ↓ in half of the children on both sides (p=0.005) Function and ease of care No change in GM function, but parents and teachers reported that ADLs became easier, and half of the parents intended to continue with the intervention after the research. Adverse effects – knee swelling, muscle cramps	Level III 6/9 moderate
Physiopedia editors 2016 Narrative review *Orthotic management of CP*	People with CP	Various types and uses of orthoses, dosage unspecified.	ROM, posture & spasticity -for GMFCS IV-V, hip Abduction orthotics don't prevent hip displacement but may improve sitting posture and symmetry. - ankle splints manage spasticity and maintain ROM for standing. -Thoraco-lumbar-sacral orthotics may retard or prevent scoliosis progression	Level VII 3/6 low
Uzun et al. 2021	22 children with CP, aged 5-13 years, GMFCS level III-V	10 mins of intramuscular stretching on one calf muscle, and 10 mins of intermittent 15 second passive stretch:15 sec rest on the other side	Weak evidence that manual stretching decreases spasticity Spasticity	Level III 6/9 moderate

Quasi-experimental trial *Acute effects of stretching on spasticity of calf muscles*		Own controls	Both methods → significant ↓ spasticity in the acute phase using MAS§ (p=0.024) -difference between the 2 methods not significant (p>0.05)	

Source:
Please see full reference list of Van Aswegen, S.R., Richards, M. & Morrow, B., 2024, 'Preventing deformities in paediatric cerebral palsy in poorly resourced areas: A scoping review', South African Journal of Physiotherapy 80(1), a2059. https://doi.org/10.4102/sajp.v80i1.2059

Legend:
Casting = serial casting – progressive stretch of a joint using casts to improve ROM
Spasticity = increase in muscle tone in response to a quick stretch, caused by central nervous system damage; Sustained Stretch, means 30 min or more in one position
Tilt table = standing frame with variable angle of inclination from vertical.
ADL = activities of daily living such as feeding, bathing
BMD = bone mineral density
CP = cerebral palsy
CPG = clinical practice guidelines
DF = dorsiflexion of the foot
ES = electrical stimulation
Ex = extension
GMFCS = Gross Motor Function Classification System
GM = Gross motor
HCP = health care professional
KAFO = knee-ankle-foot orthosis
LL = lower limb
MSK = musculoskeletal
ROM = range of motion of a joint
UL = upper limb
ROM = range of motion.
†, Hoffman reflex = test of spasticity, positive sign means increased tone and negative means no increased tone.
‡, MAS = Modified Ashworth Scale: a grading system for muscle spasticity where 0 is normal and 4 is rigid.

There is overall weak and conflicting evidence for stretching interventions. Manual stretching interventions appear to be less effective for preventing deformities than sustained, positional stretching (Pin et al. 2006; Craig et al. 2016). Fragala et al. (2003) found that periods of non-intervention from a school-based manual stretch routine of 3 x 60 seconds per structure, taking place once to twice per week, produced inconsistent changes in LL ROM. The addition of ES to the antagonist during stretching significantly increased ROM and reduced spasticity (Groppe et al. 2012). Uzun Akkaya and Elbasan (2021) reported transient reduction in calf muscle spasticity after just 10 minutes of manual stretching, both with and without concurrent massage. No adverse effects were reported. Wilton (2003), Autti-Rämö et al. (2006), Groppe et al. (2012), Craig et al. (2016) all suggested that joint ROM may be maintained or increased in all limbs and spasticity reduced by an intensive serial casting programme, if sustained for at least 3 weeks.

Positional stretching for 20 minutes using an orthotic in sitting or using a stander for 30 minutes at least three times per week for at least 8 weeks may be effective in increasing LL ROM, and may reduce calf muscle spasticity for up to 35 minutes after the stretch (Craig et al. 2016; Pin et al. 2006; Lannin et al. 2011; Groppe et al. 2012; Laessker-Alkema et al. 2016). Wilton (2003) recommended wrist and hand orthotics be used at night or for three-five hours per day to control deformities where spasticity is moderate to high, although all other studies found inconclusive evidence of efficacy for ULs.

Although no stretching interventions resulted in improved motor function for the child, improved flexibility appeared to assist with symmetry in sitting (Physiopedia 2016), and ease of care when performing ADLs (Laessker-Alkema et al. 2016). Adverse effects included hindrance of hand function while wearing UL orthotics (Autti-Rämö et al. 2006; Lannin et al. 2011; Wilton 2003), and bruising, skin breakdown, sleep disturbance, joint swelling and muscle cramps were reported in a few patients using LL orthoses (Craig et al. 2016; Laessker-Alkema et al. 2016).

2.7.4 Home-based intervention programmes

No studies were found evaluating the effectiveness of HBIPs to prevent MSK complications in severe CP. Twelve articles addressed the population of interest and aspects of HBIPs that influenced success.

Six were conducted in LMICs or involved RLSs. Three were reviews (Paleg 2005; Lord et al. 2018; Branjerdporn et al. 2021), and nine were primary studies, comprising eight qualitative studies (Krüger and Sello 2008; Halvarsson et al. 2010; Bischof et al. 2011; Colver et al. 2012;

Novak et al. 2012; Lillo-Navarro et al. 2015; Naidoo et al. 2019; Rezaie et al. 2020), and one quasi-experimental trial (Zuurmond et al. 2018). Studies explored essential programme components, training needs of caregivers and primary health workers, determinants of successful programme implementation and the impact on child development. Table 2.5 provides further details of each study.

Table 2.5. Home-based intervention programmes for children with cerebral palsy that include prevention of MSK complications: Content, impact and environmental factors

Author, design & subject	**Population**	**Methods & Outcomes**	**Results/recommendations for HBIP's**	**Level, quality and rating**
Paleg, 2005 Narrative review *The role and content of early HBIP (HIC)*	Children with CP, or at risk of CP	Elements of the home programme	• EI† should begin as early as possible at home • seating support from 4 months • supported standing from 9 months • treadmill training from 12 months if ambulation not expected	Level VII 4/6 moderate
Krüger et al. 2008 Qualitative *Education status and training needs of rural parents of CP (LMIC)*	156 Parents of children with CP in rural South Africa	Survey and interviews: -demographics -social function of child -knowledge about CP -confidence to care for CP -programme needs	<u>Caregiver characteristics</u> - 94% were mothers, 59% were unemployed and 83% had only 1° education. - 49% of children never accompanied parents on outings - 87% had never received information about CP and 95% felt it was difficult to care for their child. - 100% wanted a HBIP, and 87% wanted a parent-teacher discussion. Teachers were "experts". <u>Requirements for HBIP</u> • appropriate to education and SES, easily implemented, inexpensive. • should not oppose traditional beliefs, • should incorporate basic brain structure, associated conditions and practical tips for care.	Level VI 6/10 moderate
Halvarsson, 2010 Qualitative *Parent experience of HBIP (HIC)*	10 Parents of children with CP, aged 3-19 years, GMFCS level II-IV	Interviews: Parental role in HBIP (stretching programme), interaction with the child, time, coping strategies, views on professional support	<u>Parental role in HBIP</u> - programme evolved over time, ↑ participation of child in program, parents went from authority to coach - but programme may ↑ stress, ↑ demands on time - managed 30 min stretching maximum - coping with stress very important <u>Views on HBIP</u> • focus on mobility and activity	Level VI 8/10 moderate

			• balance time with child vs family • adequate support from physiotherapists (knowledge, training in techniques, check-ins) • evidence of effectiveness • stress management advice	
Bischof et al. 2011 Qualitative *Prevalence of hip pain during ADLs in GMFCS level IV and V (LMIC)*	13 children and young adults with CP, 8-26y, non-ambulatory in a residential facility in South Africa	Observation of pain response during washing, dressing and transfers for 7 days	<u>Pain prevalence</u> - during hip movement = 32.5%. - pain ↑ if hips dislocated - during washing was significantly ↑ than during dressing (p=0.008) and transfers (p<0.001) - pain not always observed - handling techniques of caregivers affected pain levels and frequency	Level VI 3/10 low
Colver et al. 2012 Qualitative *Association between environment and participation in CP (HIC)*	818 children with CP aged 7-13 years	Home visit survey: Physical impairment and pain, participation in ADL, mobility, social interaction and recreation, school attendance, responsibilities	<u>Home life outcomes</u> - modified environment, hoists, (communication & mobility aids) → significantly positive influence on participation in meals, personal care, and home life (all p=<0.010) <u>Social life</u> - adapted physical home environment, positive attitudes of family, friends, and social support had significantly positive influence on child taking on responsibility (all p<0.001), and relational participation (p ≤0.002) <u>Community life</u> - positive teachers', therapists' and classmates' attitudes had significantly positive influence on participation in school activities (p ≤0.02) - positive attitudes of family, friends, social support led to significantly ↑ recreation participation (p=<0.001)	Level VI 7/10 moderate
Novak et al. 2012 Qualitative	242 Children with CP, aged 0-18 years, all GMFCS levels	Review medical records for equipment types and cost	• GMFCS level and presence of epilepsy predicted the prescription of assistive devices and technology (p=0.000 and p=0.008 respectively). • Children in GMFCS level IV & V had on average 10.00 pieces of equipment (SD 3.17)	Level VI 7/10 moderate

Prediction of equipment needs per GMFCS level (HIC)				
Lillo-Navarro et al. 2015 Qualitative *Parent experiences of HBIPs and therapist teaching style (HIC)*	28 parents of children with disabilities	Focus group discussions. Characteristics & adherence to HBIPs' perceived facilitators and barriers to adherence	<u>Characteristics of HBIPs</u> - included both stretching & functional skill practice (locomotion, hand function, postural stabilisation) - 57% had 6-10 different exercises - 54% did them daily <u>Factors positively affecting adherence</u> • Fun • Not painful • positive effects apparent • integrated into normal routines • not too time consuming • therapists equip, demonstrate, written instructions	Level VI 8/10 moderate
Zuurmond et al. 2018 Quasi-experimental *Impact of GTKCP programme ‡ for CP in Ghana (LMIC)*	75 care givers of children with CP, aged 18 months -12 years, all GMFCS levels	Training with before and after interviews - parents' Quality of life and functional performance, worry, ADLs (mainly feeding), knowledge and confidence, child general health	<u>Quality of life</u> - significant ↑ in median score from 12.5 to 51.4 ($p<0.001$); <u>Knowledge and confidence</u> - significant ↑ ($p<0.001$) <u>Feeding & drinking</u> - significant ↑ in median score from 29.7 to 51.6 ($p<0.001$) <u>Perception about child's general health</u> - physical health → significant ↑ from 34% to 73% ($p<0.001$), emotional health ↑ from 36% to 64% ($p< 0.001$)	Level III 6/9 moderate
Lord et al. 2018 Systematic review *Determinants of effective HBIPs* (HIC)	17 sources, ≥ 145 parents of children with CP, aged 0 – 18 years, GMFCS all levels	- Relational aspects (therapist-parent and parent-child), - coping (feeling capable, supported) - priorities for interventions (training & resources)	<u>Priorities for HCP</u> - build trusting relationships - be accessible and supportive, strengthen the parent-child bond - enable parent coping – feeling capable, finding support, coping strategies - prioritise the intervention – train, provide resources, tailor to the family, evidence-based	Level V 8/11 moderate

Naidoo et al. 2019 Qualitative *CHW's views on their competence and role for disabled children in rural SA (LMIC)*	32 CHWs & key informants in Ethekwini, KZN, employed for at least 1 year	Interviews and focus groups. - CHW's knowledge and skills in childhood conditions. - barriers to service delivery. - training needs	<u>Competence</u> - 100% had exposure to children with disabilities but only 25% had had any specific training. - felt unable to identify children and make referrals <u>Barriers to service delivery</u> - ↓ transport, supervision, clear referral pathways - social stigma <u>Training needs</u> - health specific training - better screening of children - Standard operating procedures and care pathways - knowledge about community resources	Level VI 7/10 moderate
Rezaie et al. 2020 Qualitative *OT's views on factors influencing adherence to HBIPs for CP (LMIC)*	17 OTs from a metropolitan area in Iran, with at least 5 years' clinical experience with CP	Interviews. - Child & family factors - Therapy and HCP factors	<u>Factors negatively affecting adherence</u> - family – severity of disability, low SES, poor family support, disagreement on goals, poor experience of health services, lack of prioritisation of HBIP - therapist – low competence, communication, motivation, therapy- repetitive, long term, "meaningless"	Level VI 6/10 moderate
Branjerdporn et al. 2021 Systematic review *Comparison of Parent-delivered vs HCP-delivered HBIP's in LMIC's*	11 sources, 612 children with CP, aged 0-5 years	Child: -GM function, posture, positioning, feeding, self-care, social function Parent: -stress levels during feeding, positioning skills for feeding, feeding speed and support	Parent-delivered vs HCP-delivered interventions <u>Child outcomes</u> - small negative effect on GM function (Mean difference - 0.41, 95% CI -5.31to 4.49, p= 0.87) but small positive effect on posture, positioning and self-care (Effect size 0.37, 95% CI -0.14 to 0.87, p = 0.16) - small positive effect on social function (Effect size 0.43, 95% CI -0,09 to 0.93, p= 0.10) <u>Parent outcomes</u> - significant ↓ in stress with training for exercise programme (Odds ratio 1.67, 95% CI 0.51 to 5,40; p=0.39) and during feeding (Odds ratio 2.20, 95% CI 1.00 - 4.86; p = 0.05)	Level I 9/11 high

<u>Source:</u>
Please see full reference list of Van Aswegen, S.R., Richards, M. & Morrow, B., 2024, 'Preventing deformities in paediatric cerebral palsy in poorly resourced areas: A scoping review', South African Journal of Physiotherapy 80(1), a2059.

https://doi.org/10.4102/sajp.v80i1.2059

Legend:
ADL = activities of daily living such as feeding and bathing
CHW = community health worker
CP = cerebral palsy
GM = gross motor
GMFCS = Gross Motor Function Classification System
HCP = health care professional, usually a physiotherapist or OT
HBIP = home-based intervention programme
HIC = high-income countries
LMIC = low- and middle-income countries
OT = occupational therapist
SES = socio-economic status.
†, EI = early intervention (children younger than 2 years).
‡, GTKCP = 'Getting to know cerebral palsy', 11-month community-based training program

Three South African studies reported on caregiver and CHWs' views on their capacity for identifying and managing CP in the community. Outcomes included knowledge of the condition, practical handling skills, and pain caused during activities of daily living (ADL). A facility-based study found a moderately high prevalence of pain in children and young adults with severe CP during daily care activities, which they observed to be directly influenced by their handling techniques (Bischof et al. 2011). Community health workers required specific training in CP screening, and clear referral pathways and protocols for further management (Naidoo et al. 2019). Caregivers desired better knowledge of the condition, practical training for everyday routines and ongoing involvement in support groups with health professionals and respected members of their communities (Krüger et al. 2008).

Limited evidence suggests that, in spite of poverty and low education levels of caregivers, parent-implemented interventions in LMICs positively influenced posture, positioning, self-care, feeding, and social function in children, while reducing parental stress (Zuurmond et al. 2018; Branjerdporn et al. 2021). Furthermore, a positive, equipped and informed environment improved overall participation of children with CP at home, in school and the community (Colver et al. 2012).

Factors affecting fidelity and adherence to HBIPs by caregivers were the presence of trusting relationships between child, caregiver, and therapist, and establishing skills and coping strategies (Lord et al. 2018). Priorities from caregivers included evidence-based interventions, the element of fun, the incorporation of the programme into daily routines, and written instructions with demonstration (Lillo-Navarro et al. 2015). Caregivers prioritised programme flexibility and mobility goals for the child, as well as ongoing support for monitoring and programme adaptation over time (Halvarsson et al. 2010). Priorities from therapists included effective communication with families, joint goal-setting, and equipping in CP clinical skills and resources (Rezaie et al. 2020). Zuurmond et al. (2018) found that monthly telephonic or face-to-face check-ins with caregivers, and a group chat via social media for therapists and/or CHWs were effective support mechanisms for their community-based programme.

2.8 Discussion

The dearth of eligible high quality empirical research in this review is notable, an observation also acknowledged in a recent overview of effective interventions for individuals with CP (Liguori et al. 2023). The ethical and methodological challenges of conducting primary research in this population were evident with limitations including non-randomisation, small sample sizes, and low generalisability, hence, the few and broad nature of published guidelines that include prevention of MSK complications in severe CP. However, if pre-emptive strategies are not in place, we know from clinical experience that progressive MSK complications are common in CP and potentially devastating, which concurs with the recent

findings of (Tenaglia et al. 2022) and (Krarup et al. 2024) who strongly advocate a comprehensive, targeted approach to limit MSK complications in children with CP. Although we found overall weak support for the use of 24-hour postural management for the prevention and control of hip displacement, scoliosis, and musculoskeletal contractures (WDHB 2014; NICE 2012; Paleg et al. 2019; Damiano et al. 2021; Novak et al. 2020; Morgan et al. 2021; Pountney et al. 2002; Pountney et al. 2009; Wynn et al. 2009; Chung et al. 2008; Gericke 2006), the importance of postural management regimes in limiting deformities and promoting function is increasingly being recognised (Paleg et al. 2022).

Considering that physical interventions aimed at limiting MSK complications require continuity and assimilation into everyday routines, being most effective when carried out daily or at least three times a week (Gmelig Meyling et al. 2018; Autti-Rämö et al. 2006; Craig et al. 2016; Laessker-Alkema et al. 2016; Groppe et al. 2012; Pin et al. 2006, 2007; Gibson et al. 2009; Macias-Merlo et al. 2015; Macias-Merlo et al. 2016; Martinsson et al. 2021; Tornberg et al. 2020; Picciolini et al. 2016; Paleg et al. 2013), it is reasonable to equip primary caregivers to perform them, where feasible, especially where formal health services are limited. Potential challenges in a RLS would include the early identification of infants at risk of CP so that interventions can be implemented in the home from as young as 4 months of age (Paleg 2005; Paleg et al. 2022), and the availability and affordability of requisite equipment for lying, seating, and standing, which is considerable for children in GMFCS level IV and V (Novak et al. 2012).

Although efficacy of manual stretching techniques for preventing deformities has not been established, regular positional or sustained stretching regimes appear to maintain and improve ROM, and temporarily reduce spasticity, which would likely facilitate positioning, daily care (e.g., perineal hygiene) and function (Laessker-Alkema et al. 2016; Craig et al. 2016; Groppe et al. 2012; Pin et al. 2006). While serial casting and ES require an expert setting, manual and positional stretches would be feasible options for RLSs.

In RLSs, it is common to find relatively poor, less educated caregivers struggling to cope with the care of their child with CP, which they may experience as stressful and demanding. Often the perceived burden of care relates to difficulties with ADLs such as feeding, and general lack of knowledge and confidence. Our review shows that modifying the environment through parent-implemented approaches are acceptable and effective to improve child outcomes (Colver et al. 2012), ease of care and parental stress levels (Zuurmond et al. 2018; Branjerdporn et al. 2021) especially when accompanied by adequate training and support (Lord et al. 2018; Naidoo et al. 2019; Halvarsson et al. 2010).

In RLSs the inexperience and knowledge gaps of primary health workers in identifying families in need and supporting them (Naidoo et al. 2019) may compound these issues. As these health workers are integral to successful implementation and sustainability, it is important to

equip them with early identification tools, provide clear protocols for referral, and train them in the HBIPs so they can better support families.

2.9 Research gaps

Existing studies of PM have focused on the role of sitting and standing programmes in prevention and control of the hip and LL deformities. Neuromuscular scoliosis is another serious, common complication of severe CP (Hagglund et al. 2018) that 24-hour postural management may influence, yet supporting research is lacking. Studies on sleeping systems have been limited to commercially available options. The efficacy of low-cost equipment for lying positions should be a research priority, particularly in children classified as GMFCS Level IV and V who spend a significant portion of the day in the lying position.

Evidenced-based stretching protocols should be developed, including dosage and stretching modalities for different treatment goals. In our review, there were few reported adverse effects, however some MSK discomfort during stretching might be expected. The contribution of any stretching to relieve or exacerbate pain is an important consideration and is likely to affect programme adherence. Other questions should be considered about the psycho-sensory aspects of touch during manual stretches and whether it can be effectively combined with massage. These questions warrant further research.

Our review found very little research into content, efficacy of and adherence to HBIPs in RLSs that include physical modalities designed to prevent MSK complications in severe CP. Further research could help identify structural and social determinants of successful programmes, establish effective protocols, and provide ways to quantify participation and functional outcomes.

2.10 Strengths and limitations

This review charts the existing literature over the past 20 years on manual interventions for limiting MSK complications in severe CP, including general CPGs, and efficacy of individual modalities and home programmes. The existing knowledge and evidence gaps were highlighted, to help prioritise future research for populations living in RLSs.

The search was broad, using multiple sources including online platforms and included quality ratings to support any recommendations made. Using a non-categorical diagnostic approach might have yielded useful studies involving other diagnoses and increased our evidence base. Our limit in terms of language may have excluded some relevant studies from LMICs, but was necessary owing to limited translation services. Several of the retrieved articles were however originally published in other languages. Initial screening, extraction, and quality appraisal by a single researcher could have resulted in selection bias, especially with such a broad scoping purpose, however, this risk was mitigated by establishing clear and detailed exclusion criteria

a priori and bringing in a second, independent reviewer for full text review. Measures were taken to improve intra-rater reliability.

2.11 Conclusion

There is a paucity of high-level research and clinical recommendations for safe, feasible, and effective home-based interventions to reduce MSK complications in conditionally or non-ambulatory children with severe CP living in resource-poor environments. This requires urgent redress if we are to meet the third sustainable development goal of the United Nations, to "ensure healthy lives and promote well-being for *all* at *all ages*" (UNDESA 2015) which would include *all* socio-geographic contexts.

In the meantime, we believe that if clinical reasoning and diligent monitoring are applied, the existing evidence for 24-hour PM, stretching and splinting can be used to guide the development of a context-specific home-based programme to improve the outcomes for children with severe CP in RLSs.

2.12 Competing interests, Author contributions and Funding Information

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

S.v.A. was responsible for funding acquisition and the conceptualisation, visualisation, investigation, methodology, data curation and analysis of this study. S.v.A. also contributed to writing the original draft and editing the review article. B.M. contributed resources, the conceptualisation, methodology and
investigation of the study. B.M. was the main supervisor and involved with the validation, writing and editing of the review article. M.R contributed to the conceptualisation, validation and co-supervised the study. M.R. also proofread and refined the review article.

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2.13 Supplementary content

In addition to the Search terms and Quality rating methodology appendices, the following data and supplementary content are available in the Zivahub open access repository (Van Aswegen et al. 2024) and can be accessed with the URL: https://doi.org/10.25375/uct.23097311.v1

1. File S1. "Search terms and process"
2. File S2. "Data extraction"
   This document details the extraction of data and analysis for each of the retrieved articles and sources.

3. File S3. “Quality rating methodology”
   This file illustrates the methods used to grade the evidence level and methodological quality of each study.
4. File S4. “AGREE appraisals for the three Clinical guidelines” (AACPDM, NICE Spasticity Under 19s and WHB clinical practice guidelines)
5. File S5. “Grading tables for studies”
   JBI appraisals results for each study other than the clinical guidelines
6. File S6. “Research trends : 2001 – 2021”
   This file shows the analysis and graphical illustration of research trends for CPGs and SRs, postural management, stretching interventions and HBIPs.

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CHAPTER 3: CAREGIVERS' PERSPECTIVES AND PREFERENCES FOR A HOME-BASED INTERVENTION PROGRAMME FOR CHILDREN WITH SEVERE CEREBRAL PALSY

3.1 Introduction

The previous chapter summarised the evidence for physical interventions that could be used in a home environment to limit the formation of musculoskeletal (MSK) complications in children with cerebral palsy (CP) having a Gross Motor Classification Scale (GMFCS) level of III to V. In this chapter, consideration is given to how these interventions might be translated into practice in a resource-limited setting (RLS) in South Africa (SA). It describes the qualitative enquiry undertaken by the researchers into potentially relevant environmental influences, the caregivers' perspectives and desired outcomes from an intervention. This chapter is presented in a publication-ready article format. The target journal should focus on studies that describe populations living with CP, including resource-poor settings, as well as interventions and policies for improving quality of life for children with CP, e.g,. The African Journal of Disability (https://ajod.org/index.php/ajod).

3.2 Background

Cerebral palsy (CP) is the most common form of motor disability in children worldwide (Cans 2000), yet we do not currently have reliable prevalence figures for SA. It is estimated that between 2 and 10 children per 1000 live births have CP, with a higher burden in resource-limited settings (RLS) (Couper 2002; Cans et al. 2008; Tsige et al. 2021). Owing to maternal and perinatal risk factors common in RLSs, for example, hypoxic ischaemic encephalopathy (see Section 1.3 of Chapter 1), a higher proportion of the more severe types of CP tend to present, with Gross Motor Classification Scale (GMFCS) levels III to V, i.e. the lowest gross motor functional ability (Gladstone et al. 2010; Van Toorn et al. 2007; Kakooza-Mwesige et al. 2015; Bearden et al. 2016; Jahan et al. 2021). These non- or partially ambulant children with moderate to severe CP have an increased risk of developing secondary musculoskeletal (MSK) complications such as scoliosis, muscle contractures and hip displacement (Kakooza-Mwesige et al. 2015). This can cause significant discomfort and further restrict activity and participation in everyday life, which is already limited by the primary impairment (Coombe 2017). According to StatsSA's 2023 General Household Survey (StatsSA 2023), 73.1% of South Africans rely on public health facilities, the majority of whom can be expected to reside in RLSs. For children living in a peri-urban or rural setting, public health services constraints diminish access to rehabilitation services and appropriate equipment (Burger et al. 2020). Successful prevention of orthopaedic complications has been shown in high-income countries such as Sweden to require a concerted and determined approach involving formalised hip and spinal surveillance protocols, and comprehensive therapeutic input (Hagglund et al. 2014).

A few SA studies using small samples from different settings have described poorly met health needs, and the generally low level of functioning and participation of children with CP living in RLs (Saloojee et al. 2007). Although 50 % of a sample from Limpopo were able to participate in an unspecified educational activity (Africa, Human & Tshabalala 2023), only 20% from two KZN studies were able to attend any kind of eductional facility, and less than 50% have been supplied with approporate assistive devices (Govender et al. 2015; Couper 2002; Coombe 2017;). Recent qualitative research into the social environment in which they live indicate that caregivers lack basic knowledge about the condition, often feel “overwhelmed” and anxious about their child’s future and battle with the financial and physical demands of the daily routines (Madzhie et al. 2022; Manyuma et al. 2023; Dlamini et al. 2023; Maronga-Feshete, Pelusa & Dreyer 2024). A study by Naidoo et al (2019) illustrated that community based healthworkers often lack the knowledge and strategies to adequately support caregivers in RLSs, which would contribute to the current lack of support these caregivers experience (Naidoo et al. 2019).

In resource-limited SA regions, it is essential to develop community-based initiatives that empower primary caregivers and community health workers (CHWs) to implement basic strategies for preventing musculoskeletal (MSK) complications. This could be achieved through appropriate evidence-based home-based intervention programmes (HBIPs). Additionally, effectively addressing MSK deformities is expected to optimise the functional development of these children by allowing the postures and range of motion required by activity. A guideline for a suitable HBIP would subsequently need to be developed for resource-limited settings (RLSs).

In accordance with the Appraisal of Guidelines for Research and Evaluation II (AGREE II) Reporting checklist for the development of clinical guidelines (2016), the views, wishes and experiences of the target users, in this case, the primary caregivers of children with severe non- or partially ambulant CP, should contribute significantly the development of an HBIP. Primary caregivers are considered experts because of their first-hand experiences in caring for children with severe CP (de Loë et al. 2016), and their perspectives would therefore be invaluable to inform subsequent programme development and ensure its relevance and acceptability. Although there are numerous studies both from global and African sources that have investigated caregivers’ views, they overwhelmingly relate to the barriers and challenges associated with care of a child with CP. The researchers found no studies from SA or other low/middle income countries that specifically investigated caregivers’ preferences for a home-based intervention for their children.

3.3 Aim and objectives

This study formed part of a larger research project that aimed, by expert consensus, to develop guidelines for a standardised caregiver-delivered home programme to prevent MSK complications in children with partially or non-ambulant CP (GMFCS level III-V), living in poorly resourced settings. For this sub-study, researchers aimed to understand, through the perspectives of caregivers, the typical environment in which the home-based programme would be implemented, how caregivers perceived their needs, and how to optimise the utilisation of available health structures to ensure its success.

The objectives for this aspect of this study were:

i. to describe aspects of the social and structural environment in which children with severe (non- or partially ambulant) forms of CP (GMFCS III to V) live in a typical low-resource setting in SA which pertain to rehabilitation;
ii. to understand the caregivers' perceptions of their child's current functioning, current daily routines and activities as well as their future goals for them;
iii. to explore caregivers' views on specific needs and desired training outcomes.

3.4 Method

The peri-urban area of KwaNyuswa (parts of Wards 103 and 2) in the valley of a Thousand Hills in KwaZulu Natal (KZN) was selected for the qualitative research (Figure 3.1).

KwaNyuswa was selected for three main reasons: it was within a 50 km traveling distance from Ethekwini Metro where the researcher was based, and both study and follow up would be possible; the researcher had previously conducted outreach work to this area and a relationship existed with the nursing sister (RN) at the local clinic; and, the area was considered a sufficiently representative RLS to make the findings transferable to other rural or peri-urban South African populations.

Wards 103 and 2 form part of a Tribal Authority, which is partially included in the Durban Metropolitan area yet the socioeconomic profile is similar to typical peri-urban settings around South Africa. For example, according to the South African (SA) Census of 2011, the median annual household income for Ward 2 was R29 400, but 76% of the population earned below R40 000 per annum, and 50% earned between R10 000 and R40 000 per annum. While 98.1% of KwaNyuswa inhabitants have electricity supply to their dwellings, only 3.0 % have piped water, 3.8% have flush toilets; and, 3.3% have any higher education (StatsSA 2012).

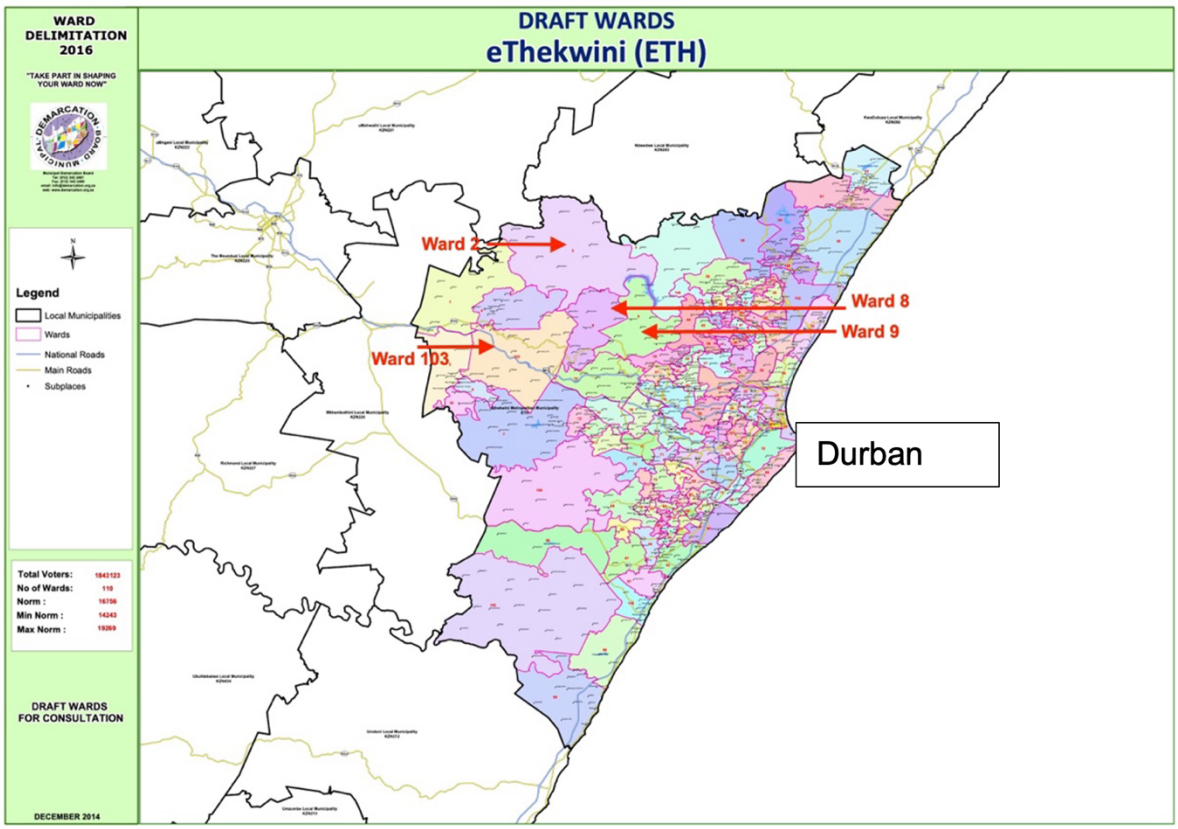

Figure 3.1 Map of Ethekwini, KwaZulu Natal, showing location of Wards 103, 2, 8 and 9
(Adapted from source: Wazimap 2023).

Figure 3.2: A typical dwelling in KwaNyuswa Ward 2 (2022).
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3.4.1 Design

This descriptive, mixed methods study used both positivist quantitative and qualitative inquiry. First, a description of the contextual environment of caregivers and children with severe CP living in wards from KwaNyuswa and KwaNgcolosi in KZN was required. Secondly, an analysis of caregivers' lived experience and how they interpreted and assigned meaning to the child's overall well-being, functioning, and participation in family and community activities was also considered crucial for the successful implementation of a future HBIP in terms of acceptability, fidelity, and sustainability. A phenomenological approach, i.e. learning and developing theories from the experiences of others, based on the work of Edmund Husserl, was thus also warranted (Neubauer et al. 2019). A combination of written (or transcribed) semi-structured questionnaires and focus group discussions were used. (Appendix 3.5). The questionnaire was complied almost exclusively of multiple choice options, with pre-determined themes based both on the literature review and the researcher's clinical experience.

The first section of the questionnaire dealt with specific aspects of caregivers' social context, namely, the demographic data of caregivers, socioeconomic status, employment, education, current health service utilization behaviours and the current educational partipation of the child. The second section of the questionnaire comprised three subsections:

1. the participation of the child in family and social environments;
2. the child's typical daily program and schedule;
3. caregiver views on training needs.

For the qualitative inquiry, each of the three sub-sections concluded with one open-ended question for discussion in the focus groups, from which new or emerging themes could be identified and analysed. Ethical clearance was obtained for the research through the Human Research Ethics Committee at the University of Cape Town (024/22). The ethical clearance can be found in Appendix 3.1.

3.4.2 Participant selection

Study participants were parents and primary caregivers of children with CP that were classified as functionally moderate to severe (GMFCS Level III-V, non-or partially ambulant) and aged 0 – 18 years of age. As per the protocol, the study included 15 caregivers to complement the proposed 15 healthcare experts who together would form the minimum number recommended for an expert Delphi panel (de Villiers, de Villiers & Kent 2005).

After approval was sought and obtained from the ward councilor (Appendix 3.2), the Halley Stott clinic in KwaNyuswa was approached to enlist the help of a registered nurse (RN) and the community healthcare workers (CHWs) based in the area to find potential participants. Having no CP register available from which to recruit caregivers, purposive or convenience sampling was used by CHWs to identify potential parents and/or caregivers for inclusion, using

an ad hoc screening tool, developed by the researcher (see Appendix 3.3). The tool was developed to assist CHWs distinguish children in the community with a likelihood of having CP rather than another disability, e.g., Down Syndrome. The researcher (SvA), (a female physiotherapist with more than 20 years' experience in various paediatric neurodevelopmental settings), accompanied by one or more CHW's fluent in the local language (isiZulu), conducted home visits to meet the candidates, confirm the diagnosis of CP with GMFCS level III – V, and introduce the research project. Eligible candidates were then asked if they were willing to participate in the study. After one month of screening, the researcher established that the study sample was too small and approached the KwaNgcolosi clinic in a neighbouring area (parts of Ward 8 and 9) to help identify partircipants (Figure 3.1). The same process was followed, except this time an RN from the clinic assisted with the screening.

Figure 3.3: A community health worker recruiting a potential participant for the survey in Ward 103, KwaNyuswa (2022). © Shayne van Aswegen, 2022. Photograph used with permission.

3.4.3 Setting of Interviews and Data Collection

Three separate focus group discussions and/or interviews were held with participants, according to their availability, over a five-week period, each session lasting 90 to 120 minutes. Participants were remunerated for transport costs. These took place at the Halley Stott Clinic in KwaNyuswa (six participants), the Sthandokuhle Crèche in KwaNgcolosi (seven participants), and Pathways Special Needs Centre in Westville (two participants). The

meetings were all facilitated by the researcher accompanied by two assistants who also translated as needed. The assistants were selected based on their experience caring for children with CP, their community work background that included working with caregivers, and their ability to translate between English and isiZulu as well as clarify concepts and assist with data collection. Additionally, at each meeting, there was at least one CHW, RN or social worker known to the caregivers.

Figure 3.4: A translator dressed in blue, assisting with a focus group discussion (October 2022) at Sthandokuhle Creche, KwaNgcolosi.

After an explanation of the research, assurance of confidentiality, and signing of informed consent which was available in isiZulu or English (Appendix 3.4), each participant completed their written questionnaire, with translation assistance when required. For each of the three open-ended questions, an informal discussion was initiated between all parties present., Participants were encouraged to discuss the concepts freely and thoroughly, and when they indicated their readiness, each caregiver provided a statement in answer to the question, which was audio recorded. Post-meeting debriefing support and/or counseling was also offered to participants.

3.4.4 Data analysis

To increase the dependability of the response statements, recorded answers in isiZulu were transcribed and translated into English simultaneously by the two translators/assistants, who

conferred to determine the ‘best translation’. This version constituted the final response for each participant. All the statements were entered on an Excel worksheet by SvA, together with caregiver contextual information.

Thematic analysis, as developed by Braun and Clarke (2006), was applied to all the statements and conducted by the researcher. An inductive approach was used, whereby the statements were coded and then grouped to determine sub-themes and final themes. In order to simplify the analysis, for each subsection, the researcher used the ICF framework to determine the broad themes depending on the domain where the caregivers’ statements could be grouped, i.e., body structure & function including physiological factors, activity and/or participation in family or community events, environmental and personal factors, including assistive devices, and support. Each of these themes could be further divided into sub-themes. Data extraction and analysis charts can be found as online supplementary files S6. To preserve confidentiality, recordings were deleted following transcription, and participants were de-identified using numerical representation.

3.4.5 Credibility and acceptability of findings

The acceptability and credibility of the findings were established by approaching the same group of caregivers after the completion of the guideline proposal as detailed in Chapter 4. Caregivers were encouraged to provide feedback on what had been proposed and how it aligned with their expressed needs.

3.5 Results

Fifteen participants were involved in three focus group meetings consisting of six, seven and two caregivers in each group, held between 28 September and 19 October 2022. For the first focus group meeting at the Halley Stott Clinic in KwaNyuswa, nine caregivers were initially identified by the CHWs to take part. After further screening by the researcher (SvA), two were excluded due to incorrect diagnosis of CP. One child died between screening and data collection, and their caregiver chose not to participate further, leaving six caregivers. The second focus group meeting/interview was held in KwaNgcolosi at a local primary school. Of the eight caregivers identified for this focus group, seven attended the meeting. Later in the process, an additional two caregivers were identified from KwaNyuswa and accommodated at a third meeting, which took place at a special needs school in Westville, Durban.

Following the completion of the proposed guidelines for caregiver training by expert consensus—a process which lasted a further nine months— the researcher convened two meetings in KwaNyuswa and KwaNgcolosi. The purpose of these meetings was to present and explain the resulting guidelines to the caregivers and receive their feedback on whether these guidelines addressed their needs and to what extent. Despite several attempts to reach

all 15 participants, only six participants from the original group attended a feedback session. The reasons for non-attendance included the death of the RN who had coordinated the original group, loss of telephonic contact with the CHW, the relocation of the caregiver or CHW, or other reasons such as previous appointments or a new work situation. Of the six caregivers who did attend, all were extremely supportive and appreciative of the proposal, noting that it adequately addressed their needs, and needed no alteration.

3.5.1 Characteristics of caregivers and utilization of services

Ten of the 15 caregivers were mothers (66.7%), and the rest were grandmothers or other female relatives (33.3%). All lived in formal dwellings, and eleven (73.3%) owned a smart cellular device. Four of the children in the study were between four and seven years old (26.6%), four were between eight and 12 years old (26.6%), and seven were between 12 and 18 years of age (46.7%). Five caregivers had obtained a secondary school pass (33.3%), but only one of them had some form of tertiary education (6.6%). All the others had only a primary school pass or indicated that they had received some secondary education. Only three of the caregivers (20.0%) were employed at the time of the meeting and two of these were employed in a part-time capacity only. All participants received one or more social grants, which included child support and care dependency grants. For 12 of them (80.0%), grants were their main source of household income. The contextual information of the caregivers and the child with CP is shown in Table 3.1.

Table 3.1 Primary caregiver characteristics

# N=15	Area of residence	Main income source	Own a smartphone	Highest educational certificate	Relationship to child	Age range of child cared for (years)
01	KwaNyuswa	Social grant	Yes	1°	mother	4-7
02	KwaNyuswa	Social grant	Yes	1°	mother	13-18
03	KwaNyuswa	Social grant	Yes	1°	mother	4-7
04	KwaNyuswa	Social grant	Yes	1°	grandmother	8-12
05	KwaNyuswa	Social grant	No	1°	mother	13-18
06	KwaNyuswa	Social grant	Yes	1°	mother	13-18
11	KwaNgcolosi	Part-time employment	Yes	3°	mother	13-18
12	KwaNgcolosi	Social grant	Yes	2°	mother	8-12
13	KwaNgcolosi	Social grant	Yes	1°	grandmother	4-7
14	KwaNgcolosi	Social grant	No	2°	aunt	8-12
15	KwaNgcolosi	Social grant	No	1°	mother	8-12
16	KwaNgcolosi	Social grant	Yes	2°	mother	13-18
17	KwaNgcolosi	Full-time employment	Yes	2°	sister	4-7
21	KwaNyuswa	Social grant	No	1°	cousin	13-18
22	KwaNyuswa	Part-time employment	Yes	1°	mother	13-18

Clinic use for the child for any health event was generally infrequent, and the reported time taken to travel there by minibus taxi from the home was between 30 and 90 minutes (Table 3.2). Nine children (60.0%) attended their local clinic either ‘never’or ‘rarely’, and only then for an acute health event requiring medication. The remaining six attended monthly, three-monthly, or six-monthly for medication and/or checkups. Only one child was receiving some form of therapy, provided monthly in a 30–60-minute group session at KwaNgcolosi clinic, which was sponsored by a non-government organisation (NGO). Six children currently use a wheeled mobility device (40.0%), but only one of these children had received the device from a public health facility (RK Khan, a regional and district hospital in Chatsworth, eThekwini). This device was a supportive positioning chair or “buggy”. The other devices were all standard manual wheelchairs that had been privately donated. Attendance at any sort of early childhood development or care facility was rare, with only one (6.6%) child having attended such a facility, for approximately one year. The most common reason given for this was unavailability.

Figure 3.5: An 11-year-old child with an ill-fitting donated wheelchair, which was not being used regularly (2022).
© Shayne van Aswegen, 2022. Photograph used with parental consent.

Table 3.2 Therapy attendance, surveillance, equipment, and educational facility use of child

# N=15	Travel time to nearest clinic by minibus /vehicle (min)	Frequency of visit to clinic	Reason for visit	Place of therapy, and frequency	Frequency of therapy	Current equipment use, type and source	Educational facility attendance; frequency and duration
01	30-60	6 monthly	Meds/checkup	none	N/A	None	Never
02	30-60	rarely	Health event	none	N/A	Wheelchair (private donation)	Never
03	30-60	rarely	Health event	none	N/A	None	Never
04	30-60	6 monthly	Check up	none	N/A	Wheelchair (private donation)	Never
05	30-60	never	N/A	none	N/A	Positioning buggy & surgical boots (RK Khan provincial hospital)	Never
06	30-60	never	N/A	none	N/A	Wheelchair (private donation)	Never
11	30-60	rarely	Health event	none	N/A	None	Never
12	60-90	3 monthly	Meds/checkup	none	N/A	None	Never
13	30-60	rarely	Health event	none	N/A	None	Never
14	30-60	rarely	Health event	none	N/A	None	Never
15	30-60	Monthly	Meds/checkup	none	N/A	Not currently. Used to have a positioning buggy.	Not currently. Attended 2-3 d/week for 1 year
16	30-60	Monthly	Meds/checkup	none	N/A	Wheelchair (private donation)	Never
17	< 30	6 monthly	Meds/checkup	Ngcolosi clinic, monthly	30-60 minutes in a	None	Never

					group of 5 children		
21	30-60	rarely	Health event	none	N/A	Wheelchair (private donation)	Never
22	30-60	never	N/A	none	N/A	None	Never

Legend

Meds = medication
Checkup = refers to regular monitoring or surveillance by healthcare professionals at the clinic
d/week = days per week
wheelchair = standard manual wheelchair
positioning buggy = a specialised wheeled device with extra pelvic and trunk support to support the hips, spine and head in symmetry
surgical boots = custom-fitted leather boots with rigid ankle support to maintain ankle alig

3.5.2 Views of caregivers on current functional status of the child,

3.5.2.1 General participation of the child in family and social environments

Twelve of the children (80.0%) spent most of their daytime hours either on a bed or a sofa, with two using the floor and one using a positioning buggy. The most popular body position was either lying on the back or on one side (60.0%) and only three children (20.0%) changed their position more than once between sitting and lying positions throughout the day. When asked about daily activities performed with other family members, it was reported that four children (26.6%) did not participate in any activities with the rest of the family. The others routinely watched television with the family (26.6%), spent time eating and watching television with other family members (13.3%), or interacted with siblings in play, during bathing, eating and exercise routines (33.3%). However, activities with other children and community members were far less frequent, with nine children (60.0%) never or rarely interacting with others outside of the immediate family.

Figure 3.6: An 18-year-old boy with severe CP and advanced MSK complications that prevented seating positions (2022).

3.5.2.2 Caregivers' functional goals for their children

During the focus group discussion, caregivers were asked to comment on what kinds of activities they would like to see the children they care for actively participate in with greater frequency (enjoyment goals). The following themes emerged from their responses: physiological health; child activity and development; participation in family activities; and participation in community activities, as illustrated in Table 3.3.

Table 3.3. The themes and sub-themes emerging from answers to the open question: *Which activities would you like your child to be able to do more of (Enjoyment goals)?*

Theme	**Sub-themes**	**Quotation excerpts**
Body Structure & Function - Physiological health	Seizure management	*'.. not having a seizure'. (#05)*
Child activity and development	• Motor skills acquisition Visual and cognitive skills	*'..to stand and use his hands'.(#13)* *'Reading books'. (#22)*
Participation in family activities	• Shared meals Shared recreation	*'…sit at the table with us'. (#01)* *'…watch the TV with us'. (#06)*
Participation in community activities	• Shared outdoor play with others • Attending school Age-appropriate play	*'..being a part of things for children her age. Like school.' (#11)* *'..playing with others like her'. (#22)*

Concerning physiological well-being,one caregiver could give no further activity or enjoyment goals above the control of their child's epileptic seizures, indicating the significant impact the seizures and poor physiological status were having on her and her child's quality of life.

#05 'Nothing. My child is happy if he is not having a seizure'.

With regards to child activity and development, two caregivers' goals for motor skills included standing, manual skills and improved balance to enable seated activities.

#13 'I want him to stand and use his hands'

#21 'She likes to watch the TV, but she can't balance on the sofa nicely'.

The rest of the comments (80.0%) related to goals that would improve family and other social interactions. The shared family goals included eating, watching television and dancing and/or singing together.

#01 'My child likes to eat. That she can sit at the table with us'.

#02 'Radio and cellphone. He is laughing when we do dancing and singing'.

#06 'They can watch the TV with us and eat with us'.

#15 'She likes to sing, and to watch her sister write with a crayon'.

#12 'She likes to look at the cellphone and play the music to sing with us'.

#14 'She needs to hear the radio and a lot of sounds going on'.

Regarding participation in community activites, social developmental goals related to age-appropriate education and play with other children and peers, even if the child's participation was limited to being present at the activity.

#03 'I like him to play outside with the ball and with the other children[s] and go to school'.

#04 'My child likes to look at [other] children playing soccer'.

#11 'I want to see her being a part of things for children her age. Like school'.

#16 'My child likes to see what is going on everywhere outside'.

#17 'She likes to do things with others, but it's not easy to go to play'.

#22 'Reading books and playing with others like her'.

3.5.3 Caregivers' views on the current daily physical routines for the child

In the second section of the structured questionnaire, caregivers were asked about the daily routines they were currently performing for their child. Specifically, we inquired about physical programs such as stretching, and the performance of activities of daily living (ADL) such as feeding, bathing, and changing clothes and diapers. We also asked about the provision and use of equipment for these purposes.

Thirteen caregivers (86.6%) reported that a healthcare professional had, at some point, instructed them on how to perform 'stretching' or 'physio' exercises with the child; however, none of them were performing this routine daily. When asked about the perceived benefits of the current stretching regime, eleven caregivers (73.3%) expressed that they did not find it beneficial for the child.

Of the six caregivers who owned a wheeled mobility device, the only one regularly using theirs, was the owner of the positioning buggy. Reasons for non-use of the other five standard wheelchairs were all due to the child 'not fitting' into the chair, or the chair was broken.

All the caregivers agreed that everyday routines presented challenges for themselves as well as the children in their care. The answers were grouped into three main pre-determined categories: problems relating to the child's body; lack of equipment; and caregiver competence. Caregivers were allowed to choose any answers that applied and reported 23 problems in total.

3.5.3.1 The child's body

Ten caregivers out of the group (66.6%) cited problems with the child's body. Of these, seven reported that the child's joints were 'stuck' or 'stiff,' which made positioning and care either impossible or significantly challenging. Six caregivers (40.0%) reported that their child experienced pain during the daily stretching routine, bathing and/or changing the child's diaper.

3.5.3.2 Lack of equipment

Nine caregivers (60.0%) identified the lack of equipment as a significant factor contributing to difficulties with daily routines due to the child's inability to support themselves. Among these caregivers, five wanted equipment for seating activities and mobility, three caregivers wanted equipment for feeding, and one caregiver wanted equipment for bathing the child.

3.5.3.3 Caregiver competence

Four caregivers (26.6%) expressed that they lacked the necessary skills to properly care for the child: two caregivers felt that they were insufficiently skilled for feeding, one caregiver felt that they were insufficiently skilled for bathing, and one caregiver felt that they were insufficiently skilled for helping their child to be more active.

3.5.3.4. Desired changes to the daily program

In response to the open-ended focus group question of what changes the caregivers would like to make to their daily routine and what they felt they would need to do this, the emerging themes almost exclusively related to the acquisition of suitable equipment and devices that would facilitate ADL, such as feeding and bathing as well as equipment that would provide opportunities for increased participation in family and community life. The thematic analysis of these comments is provided in Table 3.4.

Table 3.4. The themes and sub-themes emerging from answers to open question: What would you like to change about the daily routine, and what would you need to do that?

Theme	Sub-themes	Quotation exerpts
Body structure and function - Physiological health	Seizure management	*'… My child is having a lot of seizures…' (#05)*
Environmental factors - adaptation	• Assistive devices • Adequate space to perform stretches Flat area for wheelchair	*'...bathing is very difficult because I don't have a space'. (#21)* *'...a feeding chair so she can sit'. (#11)*
Child activity and development	• Cognitive development Being busy with activities	*'… A school so she can learn'. (#0)1* *'Let her do something…' (#14)*
Personal factors – Support for caregiving	• Lack of feelings of competence • Physical help with ADLs Training in handling skills	*'.. I don't know how I can help my child'. (#06)* *'I need help to bath her because she is very heavy'. (#17)*

Once again, uncontrolled seizures adversely affected the ease of carrying out the daily program for two caregivers (13.3%), once again highlighting the importance to caregivers of having a child who is well.

#05 '...My child is having a lot of seizures. After the seizure, my child is sick…'

#16 '... it is difficult to hold her. She is having seizures'.

Environmental adaptation to assist with daily care emerged as an important theme. Assistive devices were seen as indispensable for improving the daily routine for most caregivers (66.6%). Five of these caregivers (50.0%) wanted a wheelchair for opportunities to 'sit nicely', to 'go out' and 'go to school'. Four of the caregivers (40.0%) wanted a special chair to support the child during feeding, and one wanted a standing frame for the child to make them 'straight', presumably to support the child in an upright posture. Two of the caregivers referred to other aspects of the environment that affected daily routines. This included having a suitable space in the home to perform everyday care (#21) and having suitable terrain for wheelchair use (#04).

#01 'She need[s] the wheelchair to sit and she can go outside...'

#02 'A wheelchair to go out and in the car. My child must stay always at home if I go somewhere'.
#03 'I want to get a wheelchair [for him] to sit nicely [so] he can go to school'.
#04 'I want a new wheelchair and flat surface to push it [on]'.
#06 'I want a chair to feed my child…'
#11 'I need a feeding chair so she can sit'.
#12 'My child needs a wheelchair for sitting and going out'.
#13 'If I have a feeding chair he can enjoy his food with us'.
#15 'I would get a standing frame so she can be straight'.
#16 'I need a feeding chair because it is difficult to hold her…'
#21 'Stretches and bathing is very difficult as I don't have a space'.

With regards to the theme of child activity and development, three caregivers felt that the daily schedule could be improved with the inclusion of educational development, keeping the child busy with activities, and incorporating more sitting time and play into the day.
#01 '..A school so she can learn'.
#14 'Let her do something instead of lying down'.
#22 'I would like for her to do more sitting and playing'.

A new theme that was repeated by three caregivers was that of outside support. Three caregivers mentioned emotional support and/or physical help with daily caring duties as they found them physically and emotionally taxing, especially as they lacked knowledge and skills.
#05 'I need support from anyone. My child is having a lot of seizures. After the seizure my child is sick. Bathing him is hard'.

#06 '..Emotional support. I don't know how I can help my child'.
#17 'I need help to bath her because she is very heavy'.

3.5.4 Caregivers' views on training needs

The final section of the survey focused on programs and training on how to care for children with severe CP. Caregivers were asked to prioritise elements of training needs, the practical delivery of the training, and opinions about essential elements for inclusion in the training. They were encouraged to include as many of the elements they considered applicable.

3.5.4.1 Elements of the program to be prioritized during training

A total of 37 items concerning daily caregiving activities were selected as priorities by participants for training. The frequency with which they selected each item was as follows: effective stretching (73.3%), positioning the child for a specific outcome (46.6%), bathing

(46.6%), dressing, including diaper changes (40.0%), feeding (26.6%), and playing (20.0%). These responses are reflected in Figure 3.7 below. The desired outcomes of the positioning training goal were to improve the effectiveness of feeding, bathing, and the use of assistive devices for mobility ('going somewhere'), as well as to support standing and enhance comfort while lying.

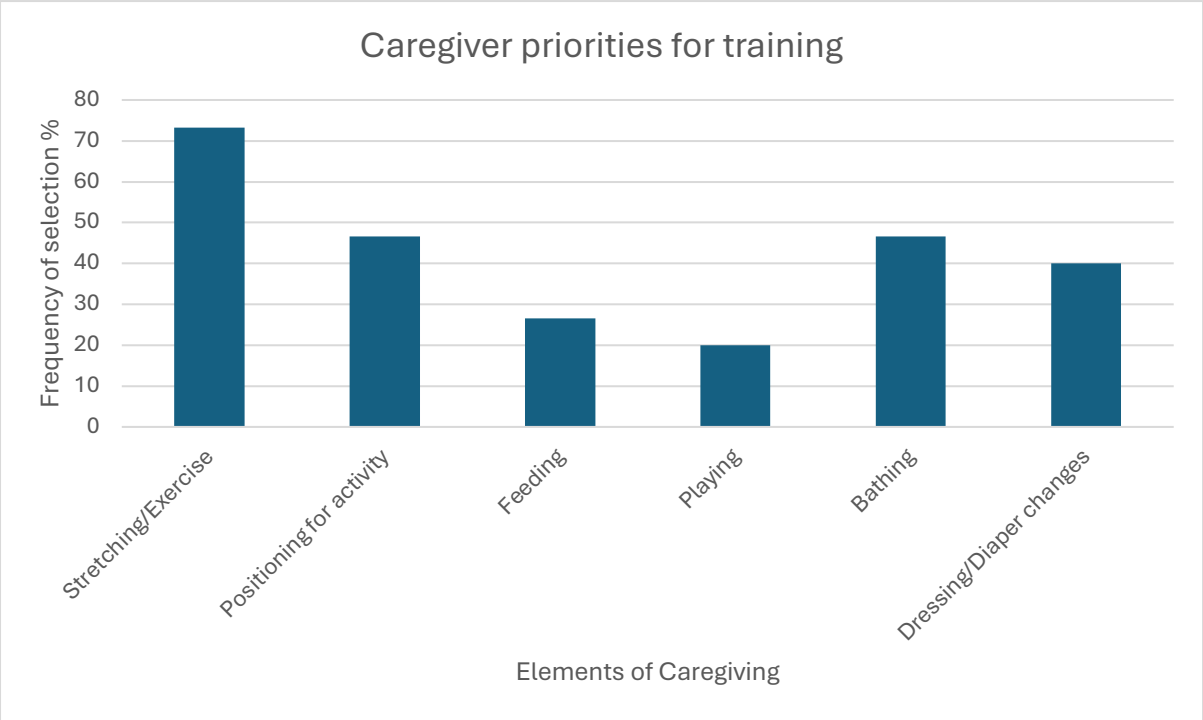

Figure 3.7. Caregivers' priorities for training in daily care activities

3.5.4.2 Aspects of the training

A majority of the caregivers (86.6%) indicated that the training should be delivered at the community health centre or clinic, with only two favouring the home setting for training. All the participating caregivers felt that they needed the training themselves because they were most involved with the care of the children. Further to this, 86.6% noted that they wanted the community health workers and/or registered nurses to be trained to provide additional support. Concerning the training format, all participants indicated that they would prefer training to be provided in person by a health care professional such as a therapist, using demonstration rather than video or written presentation only. Six caregivers (40.0%) felt that the training should be supplemented with a manual and/or a video presentation which could be viewed on their mobile devices.

For the open-ended question, caregivers were asked to discuss and identify one component they felt was not negotiable for inclusion in the training. The responses were categorized into

themes as follows: caregiver handling skills, child activity and development, and social participation, as illustrated in Table 3.5

Table 3.5. The themes and sub-themes emerging from answers to the open question: *What element would you say **must** be included in home program training?*

Theme	Sub-themes	Quotation excerpts
Environmental factors - Caregiver handling skills	• Facilitation of ADL • Preserving musculoskeletal flexibility Positioning	*'..to change the nappy and to give him food'. (#03)* *'Positioning the child to do things'. (#14)* *'What stretching I can do…to help her body'. (#21)*
Child activity and development	• Cognitive development Communication strategies	*'..to read books and to speak..' (#17)* *'..to learn things..' (#22)*
Social participation	• Family involvement Experience of the outside world	*'..be part of our lives'. (#11)* *'..to see what the world is like outside'. (#15)*

ADLs = activities of daily living

3.5.4.3 Caregivers' views on the training curriculum

The majority of caregivers (60.0%) indicated that training in manual handling techniques – specifically those related to increasing body flexibility, improving positioning for balance (presumably for sitting), and facilitating ADLs─would be indispensable. Specifically, these included stretching the child's body, helping the child to find a comfortable position, and feeding, bathing, and changing the child's diaper more effectively:

#01 'How to bath my child'.

#02 'How to move the legs and to bath the child'.

#03 'Stretching the legs and I struggle to change the nappy and to give him food'.

#04 'Stretches for the arms and the legs'.

#05 'How to bath my child.'

#06 'I want to make the child comfortable'.

#12 'I want to know how to stretch my child and make them straight'.

#13 'To put the child in positioning with balance'.

#21 'I need to know what stretching I can do for my child to help her body'.

Another important theme was that of child activity and development. Three caregivers (20.0%) felt that activities that contributed to the child's cognitive development would be the most essential elements for training, including cognitive stimulation and learning strategies, reading books and learning how to communicate:
#16 'Help us to know how to do stimulation so my child can learn something'.
#17 'I would like to teach her to read books and to speak if she has something she wants to say'.
#22 'I want my child to learn things, to be stimulated and to learn'.

The final theme was social participation. For three caregivers (20.0%), the most important aspect of the training was learning how to create opportunities for their child to be involved in family and social activities. This included teaching positioning techniques that would facilitate family interaction, as well as strategies to encourage inclusion in social outings and activities:
#11 'To put her in a position so she can be part of our lives".
#14 'Positioning the child to do things with us'.
#15 'I want her to see what the world is like outside and to go somewhere'.

3.6 Discussion

The findings of this study confirm that the typical child with moderate to severe CP (GMFCS level III to V) living in a RLS in Ethekwini, South Africa currently lacks access to the necessary health resources to enable optimal developmental and participatory opportunities. This concurs with earlier reports about the unmet health needs and opportunities for children with disabilities living in other poorly resourced areas in South Africa (Saloojee et al. 2007; DSD & UNICEF 2012), and suggests that very little has improved for children with CP in RLSs in South Africa over the last decade.

The children in this study generally had poor participation, i.e., did not attend health facilities regularly, except to obtain medication; did not have the use of a wheeled mobility device for positioning or transportation and did not currently receive therapy although some had attended outpatient physiotherapy and/or occupational therapy sessions when the child was younger. The children spent most of their daytime hours lying on their backs or their side on a bed or a sofa at home. Although there were opportunities for daily family interaction during eating, watching television, and playing, interactions with the community were minimal. Attendance at any early childhood development centre or school for any duration was rare, findings that concur with other studies in KZN, (Govender et al. 2015; Coombe 2017) but differ from the study in Limpopo Province (Africa, Human & Tshabalala 2023) where just over 50% had some

access to educational activities, possibly because our sample involved an older cohort of children.

Most caregivers who participated in our survey were unemployed mothers with a primary school pass or limited secondary school education and were strongly reliant on social grants for income. Other studies in RLSs in India, Zimbabwe, and Ghana have found the caregiver profiles, challenges and health service utilisation for children with CP to be remarkably similar to South Africa (Vadivelan et al. 2020; Dambi et al. 2015; Mwinbamm et al. 2023). A recent review on the rehabilitation status and determinants of rehabilitation service access of children with CP found that socio-economic factors relating to caregiver household income and education levels were important predictors of healthcare facility utilisation (Al Imam et al. 2021) concurring with the findings of Africa, Human & Tshabalala (2023). The Care Dependency grant provided by the state at the time of our survey was just below R2000 per month, approximately four times more than the usual Child Support Grant (SASSA 2023). However, Manyuma et al. (2023) report that caregivers living in the Limpopo province of South Africa found the Care Dependency grant insufficient to cover the additional ongoing cost of diapers, an adapted diet to cope with feeding difficulties, and travel costs for healthcare visits, especially when the caregiver was unable to supplement income through employment. Many caregivers in this study had attended at least one therapy session at a district hospital (not the clinic) where they had been shown how to do ‘stretches’ or ‘physio’ with the child, but they had long since ceased to attend. Considering that all but one caregiver lived between 30 and 60 minutes from the nearest clinic, accessing a district hospital would likely require several hours and incur significant costs. Additionally, transporting a non-ambulant child without a mobility device presents further challenges. This is supported by research describing the relatively poor accessibility to healthcare in RLSs over the last two decades in South Africa (Burger et al. 2020). Without sufficient support from health services, it is understandable that caregivers in our survey report felt ill-equipped to promote their child’s development and inclusion. They also expressed a lack of knowledge about the necessary handling skills to manage daily routines. This finding aligns with previous studies that have reported feelings of incompetence and disempowerment among caregivers in other RLSs, as well as a perceived lack of support from health professionals and educators (Vadivelan et al. 2020; Mwinbam et al. 2023; Manyuma 2023).

Another important consideration is the skills that caregivers are taught and trained in during therapy sessions at the district hospitals. Although caregivers admitted some non-adherence to daily intermittent stretching routines they had been shown, most did not feel the program was helping their child, because they still had stiff joints and MSK deformities. According to

international clinical guidelines, the evidence for using intermittent stretching as a preventive technique for MSK complications is weak (Novak et al. 2020). There is much stronger support for using 24-hour postural management regimes (including supported standing), sustained stretching and splinting for this purpose (Meyling et al. 2018; Paleg et al. 2013; Martinsson et al. 2021; Groppe et al. 2012; Capati et al. 2020). Policy-makers and programmes aimed at preventing MSK complications should adhere to current clinical guidelines for interventions and consider strategies to promote programme carryover in the home, such as providing splints or positioning devices.

All the caregivers in the study struggled to some extent with daily physical care routines for the child, identifying two primary challenges. Firstly, their child's body was often 'stuck' or 'stiff' making positioning difficult and eliciting pain during ADL. Secondly, they lacked essential assistive devices for mobility and supported seated activities, such as playing, bathing and feeding. Similar difficulties have been reported by Dlamini et al. (2023) and Smith et al. (2022), who both conducted recent reviews to describe the experiences of caregivers of CP, reporting that the physical and psychological burden of caring for a child with CP was substantial, often described as overwhelming, and lifelong. Therefore, interventions should prioritise alleviating this daily burden by maintaining musculoskeletal flexibility and providing basic essential equipment. One previously underappreciated aspect of care was the importance to the caregiver of having a 'well' child. At least one caregiver reported the negative impact of uncontrolled seizures on the quality of life for the child and family. This was sufficiently distressing that she was almost unable to consider higher functioning and participation goals for the child. This highlights that interventions for habilitative health need to consider the child's physiological functioning and well-being.

3.6.1 Caregiver's perspectives on goals, needs and training requirements

Given the substantial physical challenges in the daily care of the children, it is not surprising that most caregivers prioritised the need for training in manual handling techniques to preserve flexibility and positioning of the body with support for mobility, bathing, feeding, changing diapers and playing. In addition to this, the group deemed it important to include techniques to stimulate cognitive development and communication skills, as well as strategies to increase social participation. Caregivers emphasised their need for adaptive equipment, such as wheelchairs, feeding and activity chairs, standers, and bath aids, to alleviate the daily burden of care. Notably, caregivers also identified adaptive equipment as essential for increasing education opportunities, enabling social interaction, and expanding their child's engagement with the broader world. These views on training components and improvements to the daily routine aligned with the caregivers' enjoyment goals for the child, which were primarily centred

on inclusion in family and community life, even if this was limited to the mere presence of their child at an activity without active involvement. The emphasis on auditory participation for enjoyment (radio, cellphone, music and singing) was notable but unsurprising, as many children with GMFCS level IV and V CP have visual impairment as a co-morbidity (Hollung et al. 2020). This too has implications for what to include when developing caregiver training programmes.

Experiences during the research process pointed to other potential determinants of the overall functioning and health of children in these areas. Firstly, the sample was unexpectedly difficult to gather. According to the National Census of 2011 (StatsSA 2012) and the Community Survey of 2016 (StatsSA 2016), Wards 103 and 2 collectively have an estimated population of approximately 50,000 people, while Ward 8 has a population of around 37 500. Approximately 35% of these populations consist of children under the age of 18 (Wazimap 2023). Considering that the estimated prevalence of CP in South Africa ranges between two and ten per 1000 children under 18 years of age (Couper 2002; StatsSA 2012), one could expect to find between 26 and 130 children with CP residing in the area. It would be anticipated that most of these children would be known to local outpatient clinics and ward-based outreach teams. However, this was not the case for our study, and an ad hoc screening tool had to be developed to help CHWs and registered nurses (RNs) identify the sample. These findings are consistent with those of Naidoo et al. (2019), who found that most CHWs in the South African rural setting feel poorly equipped to identify disability and refer children appropriately. The concern is that without a structured protocol in place to detect and manage these children, the onus for seeking care would be on caregivers, who may have low health literacy and fail to seek appropriate healthcare and support. Secondly, the age of the children identified for our group by the CHWs was relatively high, with no children under the age of four years and more than half of the children, eight years and over. Early intervention for CP, even where a final diagnosis is not fully established is important for limiting MSK deformities and maximising functional potential (Novak et al. 2017). Possible reasons for this may include the failure to report and/or recognise the condition in young children and infants by health professionals and the lack of a structured national CP database for surveillance and guidance for caregivers' utilisation of healthcare. Psychosocial aspects, such as the prevailing social stigma attached to disability in these types of settings (Trani et al. 2020; Koszela 2013), may also play an important role, especially during the younger years when parents are still struggling to accept the disability. Several studies from SA and other LMICs have found that cultural beliefs around punishment for wrongdoing, blame, misunderstanding of the condition and outright rejection of both the child and their family were common experiences across RLSs (Vadivelan et al. 2020; Mwinbam et al. 2023; Dlamini et al. 2023; Smith et al. 2022). These studies also report

the high prevalence of mental strain, depression, and anxiety about the future that caregivers often experience, referring to the 'chronic sorrow' associated with the loss of dreams and expectations they may feel when caring for the child. Both these aspects could well influence health-seeking behaviours and highlight the importance of ongoing, early support for caregivers from health services.

3.7 Strengths and limitations

In keeping with the aims of this study, we used a positivist approach to describe the context of the target population, but we added to this an exploration of caregivers' lived experiences and perspectives on their challenges and needs. The result was a "thick" description of some of the daily realities faced by our disabled community living in a RLS. Their perspectives provided invaluable and nuanced insights that can be used to design future interventions more closely aligned with their perceived needs. This is more likely to result in community-driven adherence and sustainability of such a programme and improve health outcomes for the children with CP living in RLSs like these.

Another strength of the study lies in its exposure of the current contextual challenges that negatively impact the care of children with CP in a typical low-resource community in South Africa. Additionally, caregivers were actively involved in the solution by sharing their opinions on where interventions should be focused, including the participation outcomes they desired for the children, the necessary equipment, the specific skills they needed to acquire, and strategies to ensure that the training intervention would be acceptable, appropriate, and feasible.

Although the communities we studied were considered representative of a large sector of the population, some views expressed by our group of 15 caregivers may have been context-specific. Therefore, caution should be exercised when generalising these findings to all peri-urban South African settings. The stories and reflections arising from this study are meaningful and provide important information for the development of a home-based intervention programme for the daily management of children with moderate to severe CP in their natural environment. It is intended that this population will also be the initial target group for the planned pilot implementation project for the home-based program. The credibility of these results could have been affected by the low number of caregivers who were able to evaluate the final guideline. However, the overwhelmingly positive feedback received and the absence of criticism or suggested improvement from those who were present, suggests that the final guideline is considered acceptable to the caregivers and accurately represents their opinions and preferences.

The researcher's previous clinical experience and conclusions about caregivers and children in this type of setting may have created the potential for bias when selecting the pre-determined categories for the questionnaire. However, using the ICF framework for broad categorisation of themes helped to structure the answers into focused areas for attention. Also, the additional open-ended questions did provide opportunities for novel themes to emerge. For the open-ended questions, data saturation was sought through an iterative process of introducing a topic using guided questions to maintain the focus and then allowing sufficient discussion until caregivers indicated their readiness to answer the question with their statement. The translation from isiZulu to English was a collaborative process undertaken by both translators for each statement, ensuring the highest possible reliability. Using more than one researcher for coding might have yielded greater consistency during theme development. Therefore, the researcher provided explicit illustrations of the thematic analysis and development and included all statements in their entirety.

3.8 Conclusion

Children with severe, non- to partially ambulant CP living in peri-urban areas of South Africa do not have sufficient access to health interventions, appropriate equipment and opportunities for social participation. As a result, many of them have developed secondary physical complications, which, according to their caregivers, increases the burden of care and precludes optimal development and age-appropriate participation in family and community activities. Caregivers would welcome targeted training from health professionals to improve their knowledge, impart practical skills for everyday care activities, prevent MSK complications and provide strategies to promote development, and increased inclusion in family and community life.

3.9 Data availability

In addition to the attached appendices, the following supplementary content is also available in the University of Cape Town's Zivahub open access repository, and can be accessed with the link: https://figshare.com/s/f463096c578f3f1674d4

1. File S1. Ethics approval
2. File S2. Permission letter to the Ward councillor
3. File S3. Screening tool for CHWs
4. File S4. Assent and consent forms for caregivers
5. File S5. Survey questionnaire and focus group discussion
6. File S6. Data extraction

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CHAPTER 4: THE DEVELOPMENT OF A HOME-BASED INTERVENTION PROGRAMME FOR CHILDREN WITH SEVERE CEREBRAL PALSY LIVING IN RESOURCE-LIMITED SETTINGS IN SOUTH AFRICA

4.1 Introduction

Once the scoping review of interventions for the prevention of musculoskeletal (MSK) complications was completed, and a thorough analysis of caregivers' views and needs for a home-based program had been ascertained, the final step in the process of developing the program was to consolidate both sets of results into a set of proposed core elements and implementation considerations. This was achieved by consensus with the help of a team of experts from the health sector with knowledge and experience of working with children living with moderate to severe CP in resource-limited settings (RLS).

This chapter details the steps taken in the consensus process using a modified Delphi methodology. It presents the final consensus recommendations for the implementation and components of a home-based intervention program (HBIP). As with the two prior sub-studies of the research, this chapter is presented in the format of an article ready for submission for publication. The intended journal would be a general medical journal based in a LMIC such as the South African Medical Journal or one that included public health policies and programmes for paediatic health, e.g., the South African Journal of Child Health.

4.2 Background

Cerebral palsy (CP) is estimated to affect between two and ten children per 1000 live births in South Africa and similar low-and middle-income countries (LMICs), which is higher than the prevalence in high-income settings (Couper 2002; Cans et al. 2008; Donald et al. 2014; Murugasen et al. 2024). Due to the common aetiologies related to perinatal factors prevalent in LMICs, for example, hypoxic ischaemic encephalopathy, higher proportions of the more severe clinical presentations of CP are observed compared to high-income countries (HICs) (Kakooza-Mwesige et al. 2015; Bearden et al. 2016; Gladstone 2010). Children with CP living in RLSs in South Africa (SA) often encounter numerous barriers to accessing basic care, including rehabilitation, education and assistive devices (Donald et al. 2014; Murugasen et al. 2024; Burger and Christian 2020). Additionally, those caring for them are often poor, uneducated, and feel ill-equipped to assist the child (Krüger and Sello 2008). Our experience as clinicians is that as a result of the many unmet needs, most of these children have very restricted participation in age-appropriate activities (Saloojee et al. 2007; Coombe 2017).

A child with a moderate to severe form of CP, especially of the spastic bilateral or dyskinetic sub-types, is usually classified as Level III to V using the Gross Motor Function Classification

System (GMFCS) and already has activity limitations (Palisano et al. 2007). Secondary MSK complications, including hip displacement, scoliosis, and multiple joint contractures are common and inevitable to some degree, which increase with age,and are likely due to inactivity and prolonged asymmetrical positioning of joints (Hollung et al. 2020 Larnert et al. 2014; Rodby-Bousquet et al. 2013). These often result in pain, which may be exacerbated by movements, and can increase the burden of care substantially. Usually, the joint and muscle contractures limit activity even further and interfere with positioning, often leading to the exclusion of the child from participating in family and community activities. It is therefore critical to prevent or restrict the development of these MSK sequelae where possible.

Proactive prevention and surveillance programmes to limit MSK complications have been very successful in other settings such as Australia and Denmark (Kentish et al. 2011; Krarup et al. 2024). The current guidelines widely used for orthopaedic CP management are all produced in high-income settings, which likely have very different structures and resource constraints, as well as CP population profiles. Furthermore, they provide few, and often only generalised recommendations for physical interventions that may be appropriate for preventing deformities in moderate to severe CP, due to a worldwide paucity of empirical studies on the subject (Damiano et al. 2021). In addition, pharmacological, surgical, or highly technological solutions are usually the intervention of choice, which may not be available or accessible in RLSs. In these areas, it is necessary to look at evidence-based strategies to strengthen and capacitate the existing health service delivery mechanism and to recruit caregivers as a resource to help deliver basic care to the children. By reducing the prevalence of deformities, opportunities for development and social participation can be multiplied in ways that are meaningful and appropriate for the children and their families in their natural environment.

Using a systematic, evidence-based, expert consensus approach, the overall aim of the study was to establish the essential components of a clinical guideline for home- and community-based management of children with moderate to severe cerebral palsy living in RLSs, specifically targeting the prevention or mitigation of MSK complications. The three-step process comprised a comprehensive review of the evidence for effective interventions (see chapter 2); a caregiver survey with focus groups undertaken in KwaZulu Natal (see chapter 3); and an expert consensus for an HBIP which is reported on here.

The specific objectives for the consensus were to identify:

1. The essential core components of the proposed HBIP.
2. The methods and requirements for caregiver training.

3. Methods to ensure feasible implementation and support of the programme, with a view to future implementation in a semi-rural, resource-limited SA context.

4.3 Methods

The clinical guideline development was based on the Appraisal of Guidelines, Research and Evaluation (AGREE) II tool, using a modified Delphi methodology (Figure 4.1) (Brouwers et al. 2010).

The modified Delphi survey is a well-recognised systematic, iterative process, using questionnaires and controlled feedback, aimed at gathering and synthesising opinions from a group of content experts that possess deep knowledge of the topic by subjective expertise (first-hand experience), mandated expertise (related to job description), and/or objective expertise (academic and research experience) (de Loë et al. 2016).

4.3.1 The selection of healthcare professionals (HCPs) for the panel

The full expert panel consisted of 30 members: fifteen HPCs who had experience in CP management, and 15 caregivers of children with moderate to severe CP living in a RLS (see Chapter 3 for details on caregiver selection). Purposive sampling was used to recruit the HCP contingent via professional societies and neurodevelopmental interest groups. Candidates were required to have at least 5 years' of experience working in RLSs with children with moderate to severe CP and who would have encountered or managed MSK complications in different capacities and settings within the public health sector.

The target group included paediatricians, orthopaedic surgeons, physiotherapists, occupational therapists, nursing sisters, community health workers, and others recommended by peers in the field. The final panel participated in the electronic survey, Delphi rounds 1 to 3. The flow diagram in Figure 4.1 shows the steps of the process, the number of particpants in each stage along with the dates the step was completed.

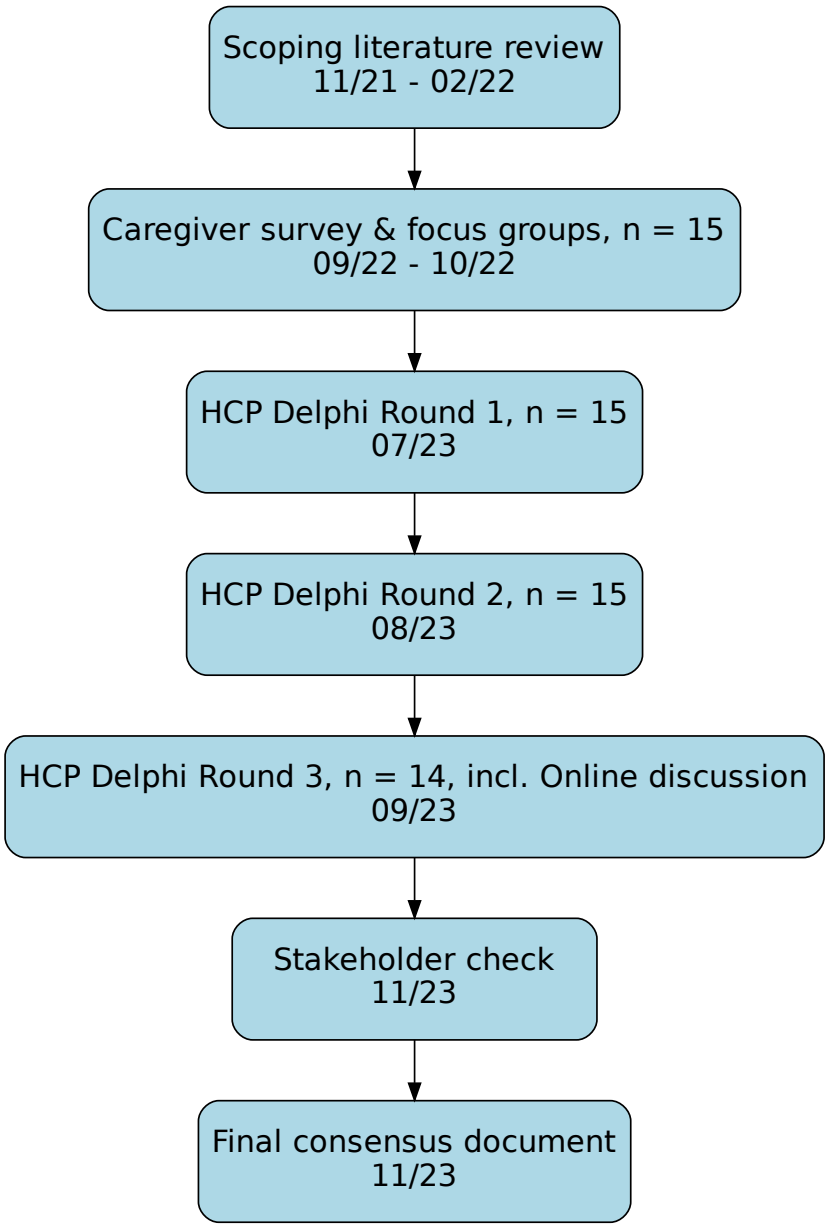

Figure 4.1 Flow diagram showing the steps of the modified Delphi consensus process

4.3.2 The Modified Delphi Consensus Process

The initial phase of the process (Figure 4.1) involved a scoping review of the available evidence for limiting MSK complications in children with moderate to severe CP. This was followed by a mixed-methods sub-study of 15 caregivers of children with moderate to severe CP, using quantitative and qualitative survey and focus group methods, to explore caregivers'

views on their child's current level of functioning, their challenges with the daily care of their child, and their preferences for an HBIP. During the next phase, these two sets of results were combined by the expert HCP panel into the final proposed HBIP via consensus.

The expert panel were provided with information about the study, the expectations and procedures of the Delphi process, along with the summary of the results of the previous studies. Using the GRADE (Grading of Recommendations Assessment, Development, and Evaluation) Evidence to Decision (EtD) framework (Alonso-Coello et al. 2016), a set of initial statements was derived based on the results from the first two steps of the research. These statements were shared as an online questionnaire with panellists in Round 1 using LimeSurvey online software[6]. After consenting to their inclusion in the Delphi panel (Appendix 4.1), HCPs were asked to rate their agreement with each statement using a five-point Likert scale which included the following options: "Strongly agree", "Agree", "Neutral", "Disagree", or "Strongly disagree". The option "No answer" was included to account for the multidisciplinary scope of expertise within the group, recognising that certain statement domains might fall outside the scope of practice for some members, who may therefore prefer to abstain. Each statement also afforded an opportunity to comment, suggest improvements or modifications, and propose novel statements. Anonymity among panellists was preserved by randomly assigning each respondent a different number for every round. Panellists were given one week to respond, and non-responders received an email reminder the day before the deadline. The responses were aggregated, and a group feedback report including the results and comments was provided to all panellists. The questionnaire was then revised for the next Delphi round.

Consensus on a statement was considered to have been achieved if 75.0 % or more of the responses were either "Agree" or "Strongly agree," after excluding those who selected "No answer". For a statement to be "finalised," it needed to achieve consensus and require no modifications to its wording. Finalised statements were omitted from subsequent rounds. The remaining statements were revised based on suggestions, and novel statements were added. After three rounds, a further voluntary online discussion was conducted to finalise four statements where some disagreement remained.

Once the defined level of agreement was reached for all guideline components, the full document was presented to the caregiver participants for a final stakeholder review, which took place at two district clinics. A few suggestions were made by the CHWs at KwaNgcolosi to facilitate the community health support mechanism of the HBIP, and concerning the intial identification of infants that would be candidates for the HBIP. After incorporating these

[6] https://www.limesurvey.org

changes, the document was shared with the HCP expert team for comment and finalisation (Figure 4.1).

4.4 Results

The final subgroup of 15 HCPs consisted of two paediatricians, two orthopaedic surgeons, five physiotherapists, one occupational therapist, one orthotist, one community health worker, one social worker and two registered nursing sisters. Members' experience with CP management came from a wide variety of work environments and affiliations within the public sector in South Africa, which included research experience for 7 of them (Table 4.1).

No orthotists currently working in the public sector responded, however, the orthotist included had worked in a variety of public health settings, had specialised in paediatrics, and was currently serving on the SA Orthotic & Prosthetic Association as well as the Health Professionals Council (HPCSA) assistive devices and technology task team.

The initial questionnaire consisted of 44 statements (see Appendix 4.2), grouped as follows:

1. The importance of a home-based intervention program
2. The elements of the program
3. The caregiver training
4. The roles of the multidisciplinary team (MDT) in service delivery
5. The community health support structure

Comments and suggestions, although voluntary, were provided for every statement in Round 1, which resulted in a high re-iteration rate for statements in subsequent rounds, even where consensus was obtained. The detailed data and comments for every statement in Rounds 1 to 3 are provided in Appendix 4.3.

Table 4.1. Characteristics of HCPs on the expert panel

Panelist	Profession	Working environment and job description
1	Orthotist	Private orthotics practice; Paediatric Developmental therapy Centre, Johannesburg, Gauteng
2	Paediatric Orthopaedic Surgeon	Head of Clinical Unit Paediatric Orthopaedic Surgery, Academic Hospital, eThekwini, KwaZulu-Natal
3	Paediatric Orthopaedic Surgeon	Head of Clinical Unit Paediatric Orthopaedic Surgery, Academic Hospital, Msunduzi, KwaZulu-Natal
4	Physiotherapist	Acting Allied Health Manager and Clinical Supervisor of Physiotherapy Students, at a District Hospital, Bushbuck Ridge, Mpumalanga
5	Paediatrician	1.Senior lecturer at University of Witwatersrand, Department of Paediatrics. 2.Neurodevelopmental Paediatrician at an Academic hospital, Johannesburg, Gauteng
6	Physiotherapist	Maternal and Child health Public Health consultant Lecturer for Malamulele Onward Training for CP, Johannesburg, Gauteng
7	Occupational therapist	Harding Special School for CP and Physical Disability. uMuziwabantu, KwaZulu-Natal
8	Physiotherapist	Chief Physiotherapist at a Regional Hospital, CP Centre of Excellence, Empangeni, KwaZulu-Natal
9	Physiotherapist	1.Physiotherapist, Special Needs Therapy centre 2.Senior Tutor for SANDTA CP Neurodevelopmental Training. Cape Town, Western Cape
10	Paediatrician	Paediatrician, Regional Hospital CP Centre of Excellence, Empangeni, KwaZulu-Natal
11	Physiotherapist	Kwazamokuhle Special School, Umtshezi, Estcourt, KwaZulu-Natal
12	Clinical Nurse Practitioner	KwaNcgolosi Clinic, KwaNgcolosi, eThekwini, KwaZulu-Natal
13	Clinical Nurse Practitioner	KwaNcgolosi Clinic, KwaNgcolosi, eThekwini, KwaZulu-Natal
14	Community health worker	Ward 2, Phila Mntwana Program Facilitator KwaNyuswa, eThekwini, KwaZulu-Natal
15	Social worker	Wards 103 and 2, KwaNyuswa, eThekwini, KwaZulu-Natal

4.4.1 The consensus process

Between one and three panellists per round reported inconsistent access to the electronic questionnaire due to internet and mobile phone tower outages in their areas. They were, therefore, provided with hard copies, and their results were manually added to the electronic results. During Rounds 1 and 2, there was a 100% response rate; however, during Round 3, one participant failed to complete their response before the deadline, resulting in an overall 93.3% response rate.

Table 4.2 provides the pathway to consensus through all three rounds for each section. Section 1 (The Importance of the HBIP) and Section 5 (The Community Health Support Structure) required the fewest modifications and additional statements for finalisation. Section 3 (The Caregiver Training) and Section 4 (The Roles of the Multidisciplinary Team in Service Delivery) had higher statement re-iteration rates and novel statement additions, but both were easily finalised by Round 3. The finalisation of Section 2 (The Elements of the Program) required many statement modifications, novel statements, and an online discussion.

The consensus process for statements in every section, including modifications and additions, (see Appendix 4.4) are summarised below using individual statement codes in brackets, together with the round where the relevant comment was made – R1 to R3.

Table 4.2. Response and consensus rates for each section of the Modified Delphi survey

Section	Round 1					Round 2					Round 3				
	n	√√	√ ⇒	X	N	**n**	√√	√ ⇒	X	N	**n**	√√	√ ⇒	X	Σ
1.The Importance of a Home-based Intervention Program	**8**	5	1	2	0	**3**	1	2	0	1	**3**	3	0	0	**9**
2. The Elements of the Program	**13**	6	6	1	5	**12**	7	2	3	4	**9**	5	4*	0	**22**
3. The Caregiver Training	**10**	4	5	1	1	**7**	6	1	0	2	**3**	3	0	0	**13**
4. The Roles of the MDT in Service delivery	**8**	2	4	2	2	**8**	8	0	0	2	**2**	2	0	0	**12**
5. The Community Health Support Structure	**5**	2	2	1	1	**4**	4	0	0	0	**0**	0	0	0	**6**

Legend

n = number of statements entering a round
√√ = number of statements reaching consensus and finalised in the same round
√ ⇒ = number of statements reaching consensus but requiring modification
X = number of statements not reaching consensus
N = number of novel statements to be added to the next round
Σ = total statements in the final consensus document

*Statements that required a further online discussion for finalisation

4.4.2 The Importance of a Home-based Intervention Programme (HBIP)

Panellists were strongly aligned in their support of such an intervention and commented on the multiple benefits, relating these to their own experience in the field. For the child and their family, these included improving the quality and accessibility of services and empowering caregivers to participate more fully in the health and development of their child. For the public health system, benefits included equipping inexperienced therapists and CHWs working in these areas, improving coverage of expertise and skills in under-resourced areas, and preventing complications that would be costly to remedy. Of concern, however, was the risk of potential harm being done to the child during the execution of an unmonitored home-based programme (G00Q05, R1). Panelists emphasised the importance of effective training, followed by community-based supervision of caregivers by trained personnel, including therapists.

In view of the low health literacy typical in RLSs in SA, and the prevailing stigma surrounding disability, panellists felt that the programme might not be accepted initially in a deeply rural community. It would need to be intentionally and comprehensively promoted among community leaders, educators, health professionals, traditional healers, and tribal leaders (G00Q07, R2).

The alignment of goals between caregivers and health services needed to be explored and explained in greater detail before consensus was obtained. Panellists revisited the evidence from the scoping review about effective strategies to reduce MSK deformities and how these might contribute to the activity and participatory goals of caregivers, as outlined in the survey results. Panellists felt that the promotion of functional activities during physical interventions was important, alongside the preservation of MSK health (G00Q08, R1&2). The addition of an explicit statement about the aims of reducing inequity in health service delivery for this population was also important to the panel (G01Q40, R3).

4.4.3 The Elements of the programme

This section involved the more technical aspects of the composition of the daily programme to be taught to caregivers to mitigate orthopaedic sequelae. The statements concerning the application of the three physical modalities to prevent or limit MSK complications all required modifications, and panellists were divided on the terminology used for four statements, necessitating an online discussion to reach a final agreement. Only four therapists and one paediatrician opted to take part in the discussion.

Panellists agreed strongly that the daily program should include strategies for functional activities of everyday care, such as bathing, dressing, and feeding as well as communication and cognitive stimulation (G02Q16, G02Q17 & G02Q18, R1). Feeding should also clearly include both solid foods and drinking strategies due to the increased risk of aspiration in children with moderate to severe CP. Panellists agreed on the inclusion of 24-hour postural management and the use of splinting as part of a home-based program to limit MSK deformities, both techniques having adequate evidence of efficacy. They also agreed that trained caregivers would be able to perform these techniques effectively with supervision (G02Q28 & G02Q40, R1) and that the provision of equipment for lying and seating should be provided by six months of age to approximate neurotypical developmental milestones of infants, and prevent MSK deformities (G02Q11 & G02Q12, R1). Although panellists had limited experience with 'lying support systems', and commercially available options were very costly, they agreed with the principle of early provision of lying equipment to promote MSK alignment. If unavailable, they suggested that household items could be adapted for this purpose.

For "24-hour Postural Management", the description of the practice was expanded, and two additional statements were added to clarify the age of commencement and dosage progression with age (G02Q10, G02Q44 & G02Q45, R2). Panellists suggested that caregivers also encourage functional activity during the application of postural support. The protocol for the supply of the required equipment for standing was finalised by the end of Round 3 (G02Q13, R3). Concerning "Splinting," panellists queried the use of splints where significant pre-existing joint limitations existed, and a revision was made to this statement to clarify recommended usage (G02Q15, R2).

The widest disagreement among panellists concerned "Stretching" as a technique. Although there was some evidence supporting "Sustained or positional stretching" using a device or a splint to preserve range of motion in limbs, the evidence supporting "Manual stretching" was considered too weak for it to be recommended at all by some panellists. Additionally, in the experience of some, ''Manual stretches'' were synonymous with "Passive movements", a practice widely used despite being unsupported by research evidence and, in their experience, carrying the risk of being performed incorrectly, and causing harm to the child.
They suggested that efficacy in limiting MSK deformities could instead be achieved through 24-hour Postural Management and the movements naturally arising during daily care routines, such as bathing and changing a diaper. Other panellists reasoned that in RLSs, "Manual stretching" was sometimes the only strategy available to caregivers due to lack of positioning and splinting equipment. A weakly-supported technique such as manual stretching, if properly

trained and monitored, would then be preferable to no intervention. For these panellists, “Manual stretching” should not be disallowed, but should instead be clearly defined in the guidelines and limited in scope of application. “Sustained or positional stretching” was therefore distinguished from “Manual stretching,” with the former being recommended over the latter both for efficacy and safety reasons (G02Q37, R3). Specific dosages for each technique were also added (G02Q50, G02Q36, G02Q38 &G02Q51, R3).

During this online discussion, the description and definitions of “Manual Stretching” were further refined (G02Q14 & G02Q29, R3), and a qualifying statement was added to clearly distinguish this technique from “Passive Movements” (G02Q22, R3). To accommodate settings where positioning equipment may be unavailable to caregivers, the panellists agreed that manual techniques for maintaining flexibility should be allowed. The statement on “Manual Stretching” was renamed “Therapeutic Handling” (G02Q51, R3) so that a variety of manual soft tissue elongation and mobilising techniques currently espoused by neurodevelopmental therapists could be taught to caregivers at the therapists’ discretion— for example, massage and trunk rotations, alongside stretching. Since the program was primarily aimed at children with moderate to severe CP (GMFCS level III to V), the panel recommended that GMFCS levels be re-assessed at the age of two years to evaluate the need for the programme or how it could be optimally adapted for individual needs (G02Q52, R2).

4.4.4 Caregiver training

This section addressed the practical aspects concerning the initial training of caregivers.
In Round 1, only one statement, which related to the qualifications required by the presenters, failed to reach a consensus (G03Q20, R1). Panellists felt that the most likely candidates to be delivering this training in RLS would be community service therapists, who would have very little or no experience in CP management or adult education. As such, it would be advisable to provide the training as a complete tool and either introduce the programme and training tool in undergraduate training programs for physiotherapists, occupational and speech therapists, or require early postgraduate training for community service therapists working in these areas, so that they would be competent to present and teach their relevant skills (G03Q44, R2).

Given the important role that CHWs would play in support of the programme, panellists emphasised the importance of not only training them in the programme but also ensuring that they attend the training alongside the caregivers they would be supervising (G04Q30, R1). They could assist with translation if needed and collaborate with caregivers to determine how each individual child’s daily schedule should be carried out (G03Q22 and G03Q25, R2).

Panellists agreed that improving the quality and uptake of training would require in-person sessions to teach basic theoretical information about CP and practical skills, supplementing demonstrations with a pictorial manual (G03Q21, G03Q22, G03Q23 & G03Q24, R1). Suggestions included the addition of videos narrated in local languages, as well as bringing another adult from each household to the training to support the primary caregiver (G03Q34, R3 & G03Q22, R1). Importantly, there was strong agreement that the caregivers should be given strategies to increase functional participation in the home and community, in line with the concepts of 'context-focused' therapy. To promote the holistic development of the child, it was suggested that these be based on the CanChild's '6 F-words', namely, 'Functioning, Family, Fitness, Fun, Friends and Future' (Rosenbaum and Gorter 2012).

As to the group composition, panelists felt that it would be preferable to train groups with children of similar ages where possible, starting at the age of 6 months, where CP had been diagnosed or the child was considered 'at risk of CP' and presented with abnormal muscle tone (G03Q27, R2 & G03Q32, R3). The most appropriate place to provide training should be any available community facility that would be easily accessed by caregivers, taking into consideration that they may have to pay for transport and not possess a wheeled mobility device in which to bring their child (G03Q19, R2).

4.4.5 The roles of the MDT in service delivery

For the identification of infants at risk of CP, the group agreed on the vital role that doctors in neonatal wards and paediatric neurology clinics play in identifying and adding candidates to an electronic "at risk" register using standardised data capture forms at a district health level (G05Q42 & G05Q42, R2). Regarding responsibility for maintaining the "at risk" register, the panellists felt that this could be performed by a doctor, a registered nurse or a therapist working at the district level, who would then ensure appropriate referral to other HCPs (G04Q42, R2). The panellists also suggested that doctors working at primary healthcare facilities (who were often inexperienced community service doctors) should be required to routinely use simple neuromotor screening tools at follow-up clinics and refer infants for neurodevelopmental assessment if indicated (G04Q53, R2). The panel recommended the mandatory use of the Road to Health Booklet (RTHB) (neurodevelopmental screening tool by nursing staff administering vaccinations at clinics (G05Q43, R2). Considering that this role is often fulfilled by a staff nurse or a "nutritional consultant" in a primary care setting, panellists suggested that training in the use of this tool may be required for all post-natal clinic assistants. Similarly, they agreed that CHWs may encounter children in the community who are not developing typically, and they should have basic screening tools at their disposal, as well as a clear referral pathway (G05Q47, R1). It was suggested that all first referrals should be to paediatric neurology clinics,

whether made by therapists, nursing staff, or doctors at the primary health service level. This approach would ensure inclusion on the register, a comprehensive workup, and appropriate referral.

Once a child was registered, most of the panel agreed that therapists should coordinate caregiver training in conjunction with the local primary healthcare team (G05Q48, R1 & G05Q45, R2), and therapists would then also be responsible for follow-up visits (G03Q55, R3), monitoring and adaptation of the HBIP (G04Q26, R3), and orthopaedic referrals as needed (G05Q49, R2). It was agreed that for every child in a Ward that is part of the HBIP, a CHW trained in the HBIP should be appointed to support the family and provide feedback to therapists (G05Q46, R2).

4.4.6 The community health support structure

Periodic check-ups by therapists and CHWs in homes or community centres were considered by the panel to be crucial aspects of follow-up for the HBIP, with approximately a third of the panel strongly agreeing with these statements. Modifications to the statements were made to allow a context-specific routine to be developed, depending on the area and the availability of therapists (G04Q33 & G04Q35, R1).

Panellists agreed that the basic postural management equipment required should be available to families from community health centres on loan, including positioning cushions, feeding chairs, and standers. This would exclude customised splinting, such as rigid orthotics or a customised positioning seating system provided to individuals (G04Q32, R2). The loan system should be managed by the clinic staff responsible forward-based outreach. A novel statement was added to stipulate that technical support should also be provided by the local clinic for basic maintenance of equipment such as wheelchair brakes, etc. (G05Q41, R2).

With their resources and knowledge, the panel agreed that a social worker, if available, would be ideally situated to assist with community support through parent/caregiver meetings, networks for the families created through advocacy, education and connections with other societies and non-government organisations in the area (G05Q50, R2). The group was divided on the question of using a social media platform, such as a WhatsApp group, as a support group where healthcare professionals or a social worker were included. Some felt that the privacy of the HCP might be abused, for example, after hours, and that the group should be restricted to parents and caregivers. Adjusting the statement so that inclusion by an HCP could be voluntary resulted in full consensus by the panel (G04Q36, R2).

4.4.7 Feedback to caregivers

Feedback on the collated results was presented to a small group of caregivers for comment (see Appendix 4.5). No caregivers or CHWs had reliable internet connections available in their area, necessitating in-person meetings with physical copies of the results. In the KwaNgcolosi area, four of the original seven participants attended one meeting, along with two CHWs, during which the researcher explained the feedback and facilitated a discussion. One absent member of this group subsequently provided telephonic feedback to the researcher. In the KwaNyuswa area, feedback was hindered because the registered nurse who had coordinated the original meetings with CHWs and caregivers had passed away, and her position had not yet been filled. The researcher managed to connect with one of the original eight caregivers through a CHW, but the others could not be reached due to a lack of or changes in contact details, a new employment position, and the relocation of CHWs out of the area. Hence, only six (40.0%) of the original 15 caregivers provided feedback. However, their strong support for the proposed HBIP was unanimous, with only two questions arising regarding the training and transport costs. The finalised home programme proposal is presented below.

4.4.8 Final consensus document: Guideline proposal for the HBIP for CP in RLSs.

PREVENTING MUSCULOSKELETAL COMPLICATIONS IN CHILDREN WITH MODERATE TO SEVERE CEREBRAL PALSY

A HOME-BASED INTERVENTION PROPOSAL FOR RESOURCE-LIMITED SETTINGS IN SOUTH AFRICA

1. Glossary of terms

24-hour postural management – The supportive positioning of the whole body in lying, sitting, and standing to preserve normal musculoskeletal (MSK) alignment and to provide central support for functional activity.

Context-focused approach – Based on the dynamic systems motor theory of learning, where the environment or task is adapted to enable functional activity rather than focusing on improving the child's ability (Darrah et al 2011).

Family-centred care – An approach that prioritises the needs, preferences and partnership of the core family unit in healthcare decision-making and interventions (King et al. 2004).

Goal-directed therapy – Also based on the dynamic systems motor theory of learning, where activity is encouraged by providing opportunities for child-active functional gains towards meaningful self-identified goals (Mastos et al. 2007).

Gross Motor Function Classification System (GMFCS) – A classification system developed for children with CP based on the ability to ambulate (Palisano, Rosenbaum, Bartlett & Livingston 2007).

HINE – Hammersmith Infant Neurological Examination (http://hammersmith-neuro-exam.com/)

Manual stretching – In this context, refers to therapeutic handling techniques performed by a third party that elongate soft tissue structures. These may be associated with proximal (trunk) rotations, massage techniques, and guided movements to effect a slow, controlled release of distal structures near the end of the joint range. It is thus distinct from repetitive, fast, passive movements of the limbs, which can increase spasticity in children with CP.

Stretching – Refers to the elongation of soft tissues around a joint or series of joints and may be provided manually or using a positional device.

Sustained or positional stretching – Elongation is provided to soft tissues by applying a splint or positional device over a significant period of the day.

2. The Programme Elements

2.1 Principles of Programme Implementation

- Early intervention: As MSK deformities begin to develop early in severe forms of CP, entry to the programme is recommended for all infants at risk or diagnosed with CP based on neonatal history, or where atypical neurological signs are detected.
- Community support: Community health workers (CHWs) and key registered nurses (RNs) should already be trained to use the programme so that they can support the caregivers and their children.
- Re-evaluation of children at age 2: Since the program is primarily aimed at children in Gross Motor Function Classification System (GMFCS) levels III to V, and GMFCS levels are only considered stable at the age of 2 years, children in the program should be re-assessed at age 2 to evaluate their suitability for the programme, and their routine adapted accordingly. Children identified later than age 2 years would be classified upon entering the programme.
- Family-centred care**:** Caregivers and healthcare professionals (HCPs) should collaborate in joint goal-setting and the construction of a simple daily schedule that balances the requirements of the programme with the needs and preferences of the family.

- Context-focused approach**:** The elements of the programme should be incorporated into everyday routines where possible through environmental adaptation rather than a rigid therapeutic exercise protocol.
- Customisable assistive technologies: Assistive devices and supportive equipment should promote hip, pelvic and spinal symmetry in lying, sitting and standing. Seating and standing devices should provide head support in the midline if needed, and should have a tilt-in-space feature to facilitate this. Devices must be fitted with brakes, pelvic straps, and a tray table for support and safety.
- Customisable splinting: Splinting should support peripheral joints in biomechanical alignment as needed, whether for resting or weightbearing.
- Goal-directed training**:** Except when the child is sleeping or resting, the use of postural devices should be used with an activity that aligns with a self-selected goal to encourage active functional development and social participation.

2.2 Daily strategies used in the Programme

ELEMENT	**DOSAGE RECOMMENDED**	**RESOURCES RECOMMENDED**
24-hour postural management Indicated for all infants and children with abnormally high, low or fluctuating tone or presenting with postural asymmetry. To take place in all three basic positions: lying, sitting, and standing. There should also be variations within each basic position. For example, the lying position can include supine, prone, and side-lying on alternate sides.	For infants between 6 months and 2 years of corrected age: o Lying support from the commencement of the program, supported seating from 6 months for 2 to 4 hours per day, and gradually increasing periods of supported standing from 9 months of age (e.g., 10 minutes at a time, up to 30 minutes per day by 12 months of age, and 60 minutes per day by 2 years of age), titrated according to individual tolerance. From the age of 2 years, children with non- or partially-ambulant CP, classified as GMFCS level III to V:	Custom supportive pillows*, custom seating device with trunk and head support, stander (e.g., prone board or standing frame). Ankle splints such as rigid ankle-foot orthoses or stock boots may be required to preserve alignment in weight-bearing.

	○ Lying support from the commencement of the program, supported seating with trunk control and hip abduction (total maximum of 60°) for a total of 4–6 hours per day, and supported standing with hip abduction (total of 60°) for 30–90 minutes per day.	
Sustained stretching Indicated for children who have moderate to severe spasticity but no significant loss of joint range of motion (ROM), in order to maintain ROM and temporarily reduce spasticity.	From 12 months of age: ○ From 30 minutes gradually increasing to 60 minutes per day From 2 years of age: ○ 4 to 6 hours per day in total or overnight, titrating the dosage according to individual patient tolerance.	Resting splints for lower and/or upper limbs as needed. These may include static thermoplastic devices, semi-rigid gaiters, or soft (foam) splints as indicated. Customised resting splints for wrists and hands as needed.
Manual stretching/therapeutic handling Indicated for the maintenance of soft tissue and flexibility where the child is unable to assume positions or perform adequate activity on their own. Focus areas: The trunk, hip and shoulder girdles, hip adductors and flexors, knee flexors, ankle dorsiflexors, elbow flexors, and wrist flexors.	These may be applied in various ways and dosages according to the therapist's direction: ○ Stretches held at the end of the comfortable range for 30 seconds, released and repeated three times per joint or muscle. ○ Stretches held once continuously for up to 60 seconds or longer. ○ A sequence of different techniques used together,	None

	e.g., massage, trunk rotations.	
Feeding strategies Indicated for children with swallowing difficulties and those who are at risk of aspiration. These may include optimal positioning, principles and techniques for safe ingestion of solids and liquids. Where tube feeding is required, techniques and maintenance of equipment.	Individualised as per speech therapy/paediatric/dietetic recommendations for feeding according to adequate and balanced nutritional needs.	Feeding utensils such as appropriate spoons, pouches, and feeding tubes where needed. These may include home-made devices and adaptations of household items.
Activities of daily living Strategies to facilitate daily care such as bathing, dressing, cleaning teeth, and changing diapers.	Therapist recommended.	Therapists and CHWs should assist caregivers to use existing household items, e.g., a towel roll or low-cost solutions for these activities based on their context.**
Communication Strategies for verbal and non-verbal communication with the child where they are not able to use speech. These can include the use of symbols, signing, and gestures for choice-making and other communication strategies.	Therapist recommended.	Low-cost and home-made visual, auditory, and tactile signs and objects for symbols, as well as age-appropriate books.
Cognitive development through play Strategies that stimulate cognitive concepts and sensory system	Therapist recommended.	Low-cost/home-made toys, books, and games that use colour, texture, musical

development, using vision, touch, hearing and movement for play.		instruments or a radio.

** Commercial sleeping systems are very costly and not widely available. In the absence of low-cost purpose-built lying support, household items such as towel rolls and pillows may be used. ** Many commercial products are available, but these may not be accessible or suitable for these families.*

3. The Caregiver training

3.1 Principles of training

- Community-based training: Training should be provided at an accessible community centre, such as the local community health centre or tribal court to maximise accessibility.
- Split the training as is feasible: The number of sessions required to complete the training will be fixed, however, these may be trained continuously or divided into sessions for feasibility.
- Therapist-led training: The training of caregivers should be co-ordinated and conducted by group of therapists covering the area, to impart the skills and to individualise the daily physical interventions to prevent MSK complications.
- A standardised training tool: Since many of the therapists working in these areas will be recent graduates and therefore inexperienced in CP care, the program should be provided as a complete training tool, together with a module on adult education.
- Comprehensive coverage: The programme should be offered to caregivers of all infants with confirmed CP or those “at risk” from the age of 6 months, according to the district register. Therapists should ensure that training is completed for all families in need.
- Small groups: The number of trainees included in a group training session should take into consideration the space required to demonstrate techniques, accommodate audiovisual equipment, and the potential time required for translation. Small groups of caregivers are recommended to allow for customisation of the programme as well as the formation of potential support groups. Groups being trained should therefore include caregivers with children of similar ages and/or GMFCS levels, where possible and practical.

- Attendees required: CHWs should attend the training with the particular caregivers they would be supporting. Caregivers should be encouraged to bring one other adult from the household or community to be trained, ensuring someone is available to relieve them when needed. The child should be present for the practical sessions.

3.2. Training structure

1. A team of therapists (physiotherapists, speech therapists, and occupational therapists, where available) delivers the initial instruction and demonstration in person, with a CHW present to translate, if needed.
2. Where feasible, instructional videos are provided in different languages (beginning with English and isiZulu) for caregivers and CHWs to use as a reference.
3. In addition to the elements of the programme above, modules include theoretical instruction about CP and the principles of CP care, the practical demonstration of the techniques to be used, and how to use the equipment safely and effectively.
4. An instruction manual with graphic illustrations of all program elements is provided for each caregiver to use as a reference. Caregivers or CHWs are be encouraged to take photographs of positions, equipment, and splint use with their mobile devices, with parental consent.
5. Suggestions for the physical daily schedule are discussed to help caregivers integrate the programme into an acceptable daily routine for the family. Caregivers' preferences and goals for their child are prioritised, and strategies discussed to increase the child's inclusion in family and community activities, using the "6 F words" framework from Canchild (Rosenbaum and Gorter 2012).
6. Strategies to overcome local health system limitations are presented, such as staff shortages, lack of disability supplies, and infrequent therapist outreach. Adaptations include a session on how to adapt basic household items, and recycling materials to make low-cost toys.

4. The roles of the healthcare professionals in programme implementation

4.1 *Doctors and midwives in neonatal units*

1. Since early identification and intervention are important, doctors discharging newborns from neonatal wards will register children who require follow-up at high-risk clinics based on standardised perinatal risk factors. They may use a standardised

hardcopy form, filled out by doctors or midwives, which can be captured electronically onto a digital district database*.

2. A medical officer, RN, or therapist based at a community health care centre or district hospital is responsible for maintaining the “at risk” or CP register (preferably electronic) for the area or district, to ensure that all “at risk” infants or children later diagnosed are captured and referred.
3. Medical officers and/or consultant doctors at paediatric follow-up clinics, POPD, and paediatric neurology clinics coordinate early assessments and referrals of children with suspected or confirmed CP to therapy teams for management and caregiver training.
4. Medical officers and community service doctors at primary health facilities routinely use simple neuromotor screening of infants at paediatric outpatient clinicse.g., the HINE[7], and refer children for Paediatric neurology follow up if required.

**A register is integral to the identification and follow-up of children at risk of, or with, CP. Since the prevention of MSK complications requires early intervention, and a confirmed diagnosis of CP is often made much later, children under 2 years of age at risk should be added to the CP register, perhaps with an “At risk” or “unconfirmed” designation, and managed with the prevention of MSK complications in mind. Based on whether the diagnosis of CP is later confirmed or eliminated, the child will either remain on the register or be de-registered.*

4.2 *Registered nurses and clinic staff*

1. RNs, enrolled nurses and other clinic staff who perform vaccinations at postnatal clinics will perform specific neurodevelopmental screening at 14 weeks, 6 months, 9 months and 12 months corrected age on all infants attending clinic. They should use the screening tool in the latest Road to Health Booklet (RTHB) (Department of Health, 2020:27).
2. Infants and older children attending both Sick-and Well-child clinics who present with delayed development, are referred as indicated in the RTHB, or to the medical officer for follow up.

4.3 *Community health workers*

[7] Hammersmith Infant Neurological Examination (https://www.mackeith.co.uk/wp-content/uploads/2024/01/Hammersmith-Infant-Neurological-Examination-HINE-Guidance-notes-update-20.12.2023-v2.pdf)

1. CHWs refer children from the community who are not achieving age-appropriate RTHB milestones, and use a basic participation-based screening tool, e.g., not attending an Early Childhood Development facility to the clinic sister or visiting therapist clinics.

2. For every child in a Ward that is part of the CP home program, a trained CHW is designated by the RN or Ward-based Outreach Team (WBOT) leader to oversee the execution of the HBIP and support the caregiver.

4.4 *Therapists*

1. Visiting therapists should coordinate training of caregivers of registered children with CHWs at a convenient location, such as the local community health centre.
2. Therapists* should oversee the training of the caregivers, the provision of equipment, and the customisation of the HBIP (in conjunction with caregivers).
3. The initial training should, where possible, be followed up by a home visit done by a therapist within a given time, e.g., 8 weeks, to monitor and customise the HBIP for the child in their natural environment.
4. Therapists should monitor MSK status and progression of orthopaedic complications of the children, e.g., hip surveillance, and should refer concerns to doctors at the paediatric or orthopaedic clinics if needed.
5. In order to evaluate the programme's success from an activity and participation viewpoint, therapists should work with CHWs to monitor participation outcomes of the children using validated measurement tools, e.g., the Paediatric Evaluation of Disability Inventory (PEDI)[8] or the Canadian Occupational Performance Measure (COPM)[9].

**To adequately equip these therapists, the program should be included in undergraduate therapy training or offered to all new Community service therapists along with CP management training such as that provided by the South African Neurodevelopmental Association (SANDTA) or Malamulele Onward.*

5. The community health support structure

1. Basic 24-hour Postural Management equipment (cushions, chairs, standers and soft splints) will be available from the clinic or district hospital on loan to reduce costs.

[8] Available from: https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Developmental-Early-Childhood/Pediatric-Evaluation-of-Disability-Inventory/p/100000505.html
[9] Available from: https://www.thecopm.ca/about/

Other options might be the use of paper-based technology to create low-cost devices for children to own.

2. At least one person equipped either at the clinic or in the community can perform basic maintenance of the equipment, e.g., fixing brakes on chairs, or sewing up holes in cushions.

3. Once the HBIP has been established in a home, therapists perform regular (e.g., quarterly) visits to the primary clinics, and/or the homes to monitor the program performance and address concerns.*

4. CHWs visit the homes at least twice a month to check on the caregivers and children, and refer to the clinic if required.**

5. A social worker or social auxiliary worker will co-ordinate and promote community involvement and support of the child and family by helping to form networks and liaisons between NGOs, educators, caregivers, CHWs, traditional healers and religious leaders from the community.

6. Support groups in the form of meetings and informal gatherings are coordinated by a CHW or social worker at regular intervals.

7. A social media support group, e.g., a WhatsApp group may be considered for caregivers with the additional voluntary inclusion of CHWs, or social workers.

8. Monthly or quarterly “war room” meetings run by therapists become a means of supporting RNs and CHWs involved in home CP care, where information can be disseminated and issues raised.

**Frequency of follow-up visits by therapists should be determined based on the level of need or the GMFCS level of the child, e.g., monthly for 3 months, then quarterly. However, this needs to be context-specific and realistic for individual health service settings, e.g., based on a staff-to-CP prevalence ratio for the area.*

***To ensure wide coverage, it is envisioned that eventually the regular informal monitoring should be performed by CHWs, RNs, or mid-level workers who have been previously trained and would have some experience. They can refer to therapists or clinics as needed, and the registered nurse (RN) will refer the child if problems with the program are encountered.*

4.5 Discussion

Our guideline development process featured many of the typical highlights and challenges associated with field research using this methodology in RLSs in South Africa. There was a very high level of engagement amongst HCP panellists during the consensus process. This was evidenced by the numerous comments, suggestions, re-iterations, and

additions made to the proposed guideline, as well as the almost 100% response rate over three rounds. The average time to complete the questionnaire was about 35 minutes per round, and the entire consensus process, from Round 1 to finalisation, took over three months to complete. Despite this, only one panellist failed to complete the full process. This indicates the importance of the project to HCPs working in this field, as it addresses a clear and significant need within this population of children in SA.

The variety of opinions amongst HCPs reflects the diversity of clinical experience and exposure in the country as well as the resilience and resourcefulness of clinicians managing children with CP in the face of structural deficits. The conflicting views prevalent in Section 2, which dealt with "Manual Stretching" to prevent secondary MSK complications, were greater than expected. This was surprising because this section of the questionnaire utilised current evidence from the review to formulate the statements, whereas the other sections focused on implementation and support. The close association of 'Manual Stretching' with other undesirable passive movement techniques, to which participants were strongly opposed, and the fact that effective manual stretching requires a level of expertise to perform safely, rendered it unacceptable to some. This suggests that the terminology, scope, practice, and dosage of different stretching techniques are not clearly defined or consistent in therapeutic circles. A similar issue was encountered during the initial scoping review process (see Chapter 2). Furthermore, there has been some disagreement in other circles about the use of Stretching for CP. Following a Cochrane review that found no evidence of efficacy for stretching (Katalinic et al. 2011), Margaret Wallen and Kirsty Stewart (2012) wrote an opinion piece cautioning clinicians against abandoning the technique, noting it has been poorly researched and that using stretching with clinical judgement would be more prudent. Other than 24-hour postural management, supported standing, splinting (or sustained stretching), and casting to limit orthopaedic complications in moderate to severe CP, "Stretching" was the only other technique (i.e., non-pharmacological, non-surgical, and low-tech) for which any evidence was found in our review. This evidence came from a few heterogeneous studies published over the last two decades, which used very small samples, defined "Stretching" and its scope differently, and are summarised in a few reviews all originating in HICs (Wiart et al. 2008; Groppe et al. 2012; Autti-Rämö et al. 2006; Craig et al. 2016; Eldridge and Lavin 2016; Pin et al. 2006).

Although there may be some evidence supporting certain manual techniques such as massage, to reduce spasticity (Güçhan Topcu and Tomaç 2020; Bingöl and Yılmaz 2018), all of the other manual alternatives suggested by the panellists—such as "trunk rotations" and "tone-reducing movements," which are considered integral to "best practice" in paediatric

neurodevelopmental therapy circles— are not clearly described or supported by empirical research (Te Velde et al. 2022). However, It may be argued that these techniques can produce soft tissue lengthening similar to a manual stretch. Where such research gaps exist, opinion, anecdotal evidence, and clinical reasoning create the standards, making disagreement between experts commonplace. While a clinical guideline should primarily include evidence-based techniques and provide clear dosage protocols for users, the researchers felt it was important to make provisions for situations where basic equipment for 24-hour postural management and splinting was unavailable. This is because failure to intervene altogether is known to result in severe secondary deformities in cases of severe CP. For this reason, the statement providing dosage for “Manual stretching” was removed entirely and was replaced by a statement allowing other currently accepted manual techniques or “Therapeutic handling” to be taught to caregivers at the discretion of the therapists conducting the training, provided that reasonable caution and supervision could be exercised. It is hoped that future empirical research will justify or challenge the use of these techniques, enabling evidence-based updates to the guideline.

Panelists repeatedly recommended that despite a heavy focus on the prevention of MSK deformities, the program should still emphasise and promote the ultimate goals of increased activity levels, function, and participation. This aligns with current treatment approaches, such as “goal-directed training,” and “context-focused therapy,” which have moved away from simply correcting MSK impairments and towards environmental adaptations that encourage the child to actively participate in achieving a functional goal (Darrah et al. 2011; Mastos et al. 2007). Importantly, our caregiver focus group discussions revealed that participation in family and community life was also the primary reason caregivers felt they needed assistive devices and desired functional abilities, such as sitting or standing. In the context of this program, this means that the ultimate goal of using a stander is not merely to maintain joint range but also to provide a functional position for a participatory activity such as watching television with the family. Caregivers would require guidance on how to use the techniques to maximise function during the training. These findings align with the principles in the NICE guideline (NICE 2012), and other current clinical practice guidelines (CPG) for the care of children with CP that promote “child-active participation” and “environmental enrichment” which, by definition, would include context-based approaches that are guided by the principles of family-centred care (Novak et al. 2020, Morgan et al. 2021). However, our HBIP proposal is unique in the following ways: firstly, the views and expressed needs of caregivers actually living in RLSs as well as the structural constraints often present in these areas provide the context into which the intervention is built; secondly, the target population is children with more severe forms of CP (GMFCS levels III-V); thirdly, interventions focus on home-based techniques that can be

incorporated into daily routines by primary caregivers rather than therapists; and lastly, the HBIP is designed to be supported by HCWs typically already based in RLSs.

Of note in the comments provided were the numerous references to the support given by non-governmental organisations (NGOs) for the training of therapists and caregivers in SA, such as Malamulele Onward training, and the supply of disability equipment, such as paper-based technologies. These organisations can play a critical role in strengthening health systems, especially in RLSs. However, ensuring equitable coverage of services for CP and the requisite devices for all children in need requires that the provision of assistive devices become part of the nationwide health services structure as a basic package of care. This should be reflected in public policy, undergraduate and post-graduate training of clinicians, and resource management.

4.6 Strengths and limitations

Dialogue in the form of comments, suggestions, and statement modifications is an integral and important element of Delphi methodology (de Villiers et al. 2005), and, in our case, the freedom of expression and strong opinions brought many important aspects to the fore, which we could then further explore. This added depth and perspective to our research. The inclusion of caregivers' viewpoints as part of the Delphi process ensured that the proposals made by the HCP panel remained pertinent to their expressed needs and goals. This is essential to ensure the validity of the intervention, fidelity to the HBIP, and feasibility and uptake within the community it was designed to serve. The final result is a document that provides a much-needed and structured guideline based on current available evidence. However, it also allows adaptation for use in differing RLS in South Africa or other LMICs with a similar health service structure.

The challenges faced during the study process were multifaceted and reflected the structural and social heterogeneity of our communities. Unreliable internet access necessitated the printing and distribution of questionnaires for two community-based HCPs for all three rounds, followed by the collection of questionnaires and manual entry of data by the researchers. All the results had to be manually checked and re-calculated against the electronic responses and analysis, which proved to be time-consuming.

The success of this method of research relied significantly on the time and commitment of the HCP panellists, who participated voluntarily. Ensuring a reasonable response rate required numerous email reminders to respondents and timely feedback to sustain momentum. Establishing and maintaining contact with the 15 caregivers and their relevant CHWs was complicated by the lack of a database and inconsistent telephonic access. Consequently, the

registered nurses based at the local clinic needed to coordinate the meetings on the researchers' behalf. This added to their workload and meant that meetings were dependent on the RNs' availability. In our case, post-survey feedback to caregivers was adversely affected by the loss of the key RN at one of the clinics, making follow-up problematic and ultimately incomplete. This may have affected the validity of our conclusions regarding the acceptability of the proposal. It also calls attention to the need for formalised succession, teamwork and continuity plans for the HBIP.

4.7 Conclusion and recommendations

This study produced a comprehensive, actionable, multistakeholder-approved consensus document that we believe may address some of the current inequities experienced by children with moderate to severe CP and their caregivers living in RLS in SA. Further research is strongly recommended to determine the feasibility and impact of implementing this guideline among caregivers and children currently marginalized and living in limited-resource settings in South Africa.

4.8 Acknowledgement

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4.9 Supplementary content and Data availability

In addition to the attached appendices, the following supplementary content is also available in the University of Cape Town's Zivahub open access repository, and can be accessed with the link: https://figshare.com/s/ac84fda6b7d658d5f03b

1. File S1. Assent and consent forms for HCPs
2. File S2. Initial statements for Delphi Round 1
3. File S3. Consensus process by Round
4. File S4. Consensus process by Section
5. File S5. Feedback of results to Caregivers

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CHAPTER 5: THESIS DISCUSSION, CLINICAL IMPLICATIONS AND RECOMMENDATIONS

5.1 Introduction

In Chapters 2,3 and 4, the results for each sub-study are analysed and discussed in detail. This final chapter brings the findings of the research to conclusion by considering how the final proposal addresses the original research questions and how the home-based intervention program (HBIP) may be implemented in a clinical setting. The strengths and limitations of the research are also presented to evaluate the generalisability of the results and to provide a foundation for future improvements and research.

The main aim of the research was to present a proposal for an evidence-based, actionable, and acceptable HBIP designed to limit musculoskeletal (MSK) complications in children with severe cerebral palsy (CP) living in resource-limited settings (RLSs) in South Africa. This aim was achieved in three main steps. First, through a broad review of the global literature concerning the prevention of MSK complications, we summarised effective physical modalities that could be performed by caregivers and community-based health workers (CHWs) in RLSs. Next, we explored the environment affecting the care of children with severe CP in a typical RLS in South Africa through guided focus group discussions, providing caregivers with the opportunity to share their goals, perceived needs, and preferences for an HBIP. Finally, these results were pooled to produce a set of statements that were presented to an expert panel for the development of the consensus document outlining the details of the proposed HBIP.

5.2 Key findings

5.2.1 Reviewing effective interventions and programs

A few clinical guidelines for CP were found that included recommendations for the prevention of MSK complications in children with severe CP, and all sources originated in resource-rich settings. Recommendations for severely affected children were often unsuitable for application in RLSs because they assumed the availability of technological, pharmacological, and/or surgical inputs and expertise. However, limited research indicates that effective low-tech physical interventions also exist, which may limit MSK complications such as scoliosis and hip displacement while promoting postural symmetry and providing support for everyday function.

These interventions include 24-hour postural management, which had weak support overall (Gericke 2006; Picciolini et al. 2016; Tornberg and Lauruschkus 2020; Chung et al. 2008; Martinsson and Himmelmann 2021; Paleg et al. 2013), and stretching regimes, which had very weak support (Laessker-Alkema and Eek 2016; Wiart et al. 2008; Groppe et al. 2012; Craig et al. 2016). The regime for 24-hour postural management for Gross Motor Function

Classification System (GMFCS) levels III to V should include supported lying, specialised seating, and supported standing using appropriate assistive equipment (Pountney et al. 2009). From the limited evidence available, regular and consistent stretching regimes, especially sustained stretching lasting at least 15 minutes or up to five hours per day using splinting or positioning devices, appear to help maintain joint range of motion (ROM), temporarily reduce spasticity, and promote joint alignment during weight-bearing (Groppe et al. 2012; Wilton 2003). No specific home-based programmes were identified for the prevention of MSK complications in CP. However, studies on existing programmes showed that, despite poverty and low levels of literacy, caregivers in RLSs welcomed community-based initiatives. When properly supported, these programmes resulted in reduced parental stress and a variety of positive outcomes for the children, including improved posture, more effective feeding practices, and increased social participation (Zuurmond et al. 2018; Branjerdporn et al. 2021).

5.2.2 Contextual factors, goals and caregiver perspectives on training needs

The caregivers of children with severe CP involved in our study were unemployed female relatives, only one-third of whom had successfully completed secondary school. For 80.0% of them, the main source of income came from social grants. All relied solely on public transport and, on average, lived 30 to 60 minutes away from the nearest clinic when travelling by minibus taxi. Regarding clinic visits for their children, 60.0% reported that their children attended health facilities either “rarely” or “never”. Those who did attend went primarily for repeat medication prescriptions or sporadically for health events. None of the children were currently accessing therapy from public health facilities or attending an educational facility. Although 40.0% of the children owned either a wheelchair or positioning buggy, most were unable to use these devices as they were either broken or “not fitting”. One-quarter of the children were unable to participate in any shared family activities, such as watching TV or eating a meal together, with 80.0% spending their days lying on a couch. Only 40.0% of the children were involved in any form of social or community activities outside the home.

When discussing quality-of-life goals for the children in their care, 20.0% of the caregivers identified physiological wellness (such as control of epilepsy) or specific gross motor skills as priorities. The remaining 80.0% expressed goals relating to shared family and community activities, such as eating a communal family meal or attending an educational facility with other children. All caregivers reported that caring for the child on a daily basis presented challenges, which they attributed to three main factors: contractures and stiffness in the child’s body that prevented proper positioning and hindered activities of daily living (ADL); lack of appropriate equipment and assistive devices for postural support; and their own lack of confidence in their handling skills. Accordingly, caregivers’ perceived training needs focused

largely on learning how to work with their child's body, including maintaining flexibility and positioning, followed by strategies for ADL such as feeding and bathing, and how to use assistive devices for these purposes. Additionally, 40.0% of caregivers expressed a desire to learn ways to promote age-appropriate development and activity, such as methods for communicating where children were non-verbal and facilitating participation in family and community life. Preferences for the delivery of training included that it should take place within the community at a nearby venue, be conducted by rehabilitation therapists, and that caregivers should be accompanied by CHWs, who would form the basis of the community support structure.

The above data were successfully combined by an expert panel to produce a consensus document, a process that involved high levels of engagement between panellists. Over several weeks, multiple iterations of the original statements, an online discussion, and a feedback session with caregivers resulted in full consensus. From this document, a final guideline proposal was developed, which is presented in Chapter 4.
The document comprises:

1. The elements of the programme
   This includes the guiding principles of application, the components of the daily programme with recommended dosages, and suggested assistive devices.
2. The caregiver training
   This includes the principles of training, practical aspects, and the composition and delivery to caregivers and CHWs.
3. The role of the multidisciplinary team in implementation
   This outlines the roles of health professionals in identifying infants and older children for inclusion in the programme, as well as in training and following up with caregivers.
4. The community health structure
   This provides practical suggestions for the provision of assistive devices, ongoing monitoring and broader community support for families in the programme.

5.3 Evaluating the applicability and usability of the proposed HBIP in a RLS

When assessing the practicalities and potential contribution of the final HBIP proposal to this field of healthcare, it is helpful to evaluate the extent to which it satisfies the tenets of effectiveness (quality), acceptability, accessibility and availability (McLaughlin 2002).

5.3.1 Quality and effectiveness

Although many interventions and programmes exist for the management of children with CP, and many of these appear to have been adopted in standard practice, our review identified a paucity of high-quality evidence for interventions for the effective management of CP— a finding also noted by others developing standardised clinical guidelines (Damiano et al. 2021). To ensure a high-quality product, we synthesised the available evidence from current literature and consulted international clinical guidelines for the effective preservation of the MSK system, using a broad review of multiple sources. Incorporating the views and preferences of caregivers of children in the target population has ensured that the HBIP remains relevant by contributing valuable insights to the intended outcomes and overall vision of the programme for this community, which would likely lead to greater programme adherence. The expert opinions of a diverse multidisciplinary team of health practitioners, experienced in the care of children with CP, have provided the HBIP with a pragmatism suitable for a RLS in a South African environment. The final result is an actionable proposal that is coherent with current clinical practice guidelines. The entire process was governed by the Appraisal of Guidelines for Research and Evaluation II (AGREE II) Reporting Checklist (Brouwers et al. 2010) for the development of robust clinical guidelines and utilised both the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) Evidence to Decision (Alonso-Coello et al. 2016) and Delphi Practice frameworks, which are recognised for their value in translating evidence into practice (de Loë et al. 2016).

The programme aims to maintain flexibility and improve posture, positioning, and performance of ADLs, such as feeding, while incorporating strategies to encourage the child to become more interactive with the family and community. Existing research has suggests that these outcomes can be improved through parent-delivered interventions in low and middle-income countries (LMICs) (Branjerdporn et al. 2021). Recommended dosages for postural management and stretching offer an explicit, standardised regime for application according to the age of the child, to establish clear protocols and facilitate future monitoring and evaluation of MSK and participation outcomes. The proposal recommends that intervention begins as early as 6 months of age so that MSK alignment is optimally preserved in infants and young children, even before a formal diagnosis of CP, which is in keeping with international recommendations (Novak and Morgan 2019). Mechanisms for identifying “at-risk” infants, registering cases, and training caregivers have also been suggested.

In keeping with the principles of family-centred care (King et al. 2004) and context-focused therapy (Darrah et al. 2011), the physical regimes are also adaptable to the needs and wishes of the family and can be integrated into existing daily routines, an approach recommended for

home programmes even in high-income settings (Novak and Berry 2014). To achieve this, the HBIP proposes the development of a mutually agreeable, individualised daily schedule facilitated by therapists over the course of the caregiver training. Studies suggest that fidelity to and sustainability of community-based programmes for children with CP are linked to the environmental adaptions that support them, which in this case would include appropriate assistive technologies (Colver et al. 2012). The HBIP includes recommendations for appropriate adaptive equipment for each of the elements of the intervention. Properly employed, low-tech devices such as splints and standers may increase procedural safety (and effectiveness) because they fit around the joints and ensure proper alignment of MSK structures during stretching and weight-bearing. Accordingly, the use of devices should increase caregivers' confidence in carrying out their child's routine.

Along with competence to perform skills, the caregiver training of the HBIP includes theoretical modules on CP as a condition and the principles of caring for children with CP. Greater knowledge, confidence, and decision-making potential are powerful tools for improving the overall quality of life for caregivers and the children in their care, as observed in recent studies undertaken in Ghana (Zuurmond et al. 2018), Bangladesh (Karim et al. 2021), and Uganda (Asige et al. 2024). With decreased stress levels and the development of coping mechanisms, there should be greater compliance with the programme and overall continuity (Lord et al. 2018), which would likely lead to fewer MSK deformities in the children. Importantly, empowering caregivers should also lead to greater initiative and engagement in community-driven support, which would likely help to address the prevailing social stigma associated with disability in poorly resourced African communities (Trani et al. 2020; Koszela 2013; Sogbossi et al. 2021). With increased acceptance and inclusion of these families and their children, a wider repertoire of opportunities for age-appropriate participation should become possible for the child.

Finally, recommendations for short- and long-term follow-up and support were included, as ongoing support from therapists and other health workers has consistently been found to be critical for programme success in all settings (Lord et al. 2018; Rezaie and Kendi 2020). In addition to regular check-ins, ongoing monitoring and evaluation of efficacy are recommended via routine measurements of appropriate indicators of MSK health, programme adherence, participation, and achievement of caregiver-led goals. Hip and upper limb (UL) and lower limb (LL) range of motion (ROM) and the presence of hip pain during abduction can be assessed by therapists at annual or six-monthly intervals, and appropriate program adjustments and referrals can be made. Participation outcomes of the children, such as age-appropriate play, school attendance, and frequency of family and community engagement, can be measured

by CHWs, alongside quality-of-life indicators for both caregivers and children. Standardised tools, such as the Pediatric Evaluation of Disability Inventory (PEDI) (Haley et al. 2010), may also be administered to monitor and improve the HBIP over time. Thus, if properly implemented, the HBIP proposal has the potential to satisfy a comprehensive range of quality and efficacy requirements in RLSs.

5.3.2 Acceptability

The development of the proposed HBIP incorporated two steps where the views and input of the end-users were sought, viz. the focus group discussions to determine the needs and goals, and the feedback session where the final consensus document was presented to them, together with CHWs, for comment and adjustment.

From a clinical (therapist) perspective, the prevention or limitation of MSK complications was of primary importance in this population due to the resulting activity and participation limitations that otherwise occur (Tenaglia et al. 2022) – hence the focus of our scoping review. It was unclear, however, if these clinical goals would align with what caregivers desired. Based on previous experience with caregivers of children with severe CP, and considering the low levels of health literacy in this population, we had expected there to be at least some discrepancies between clinical and caregiver goals for the focus of the HBIP. For example, a caregiver of a child with GMFCS level V may express a desire for specific motor skill acquisition for their child, such as independent ambulation, or the ability to maintain unsupported sitting—skills that are often unrealistic for that classification. For this reason, the focus group discussion questions were carefully framed. When considering goals, caregivers were asked to think about downstream participatory and “enjoyment” activities for their children, rather than focusing solely on specific abilities they wanted the child to acquire. In our sample, the majority chose age-appropriate participation end goals, such as shared family play or attending school. Barriers to these outcomes, they concluded, included the MSK factors present in their child’s body, their own feelings of incompetence, and the lack of supportive equipment, such as a stander. Training, therefore, should primarily focus on imparting manual handling skills to preserve flexibility and position the child for activity and function, providing equipment, and assisting caregivers in achieving their participation goals for their child. In this way, the important association between MSK flexibility and desired functional opportunities became clearer, considerably influencing the agreement on goals between both groups. This finding highlights the importance of using the ICF framework to collaborate in goal-setting, allowing specific interventions to be viewed within the context of broader goals. It also may suggest that, while skill acquisition per se is often given as an end goal, many caregivers are ultimately interested in their child’s maximal engagement in

meaningful and mutually enjoyable social activities, where the personhood of their child is best developed, namely who they are as an individual.

Our caregivers were all struggling with the day-to-day care of the child, a finding that seems to be common in RLSs and not limited to South Africa (Manyuma et al. 2023; Mwinbam et al. 2023; Dambi et al. 2015; Sadiki 2022). An effective and acceptable intervention should therefore specifically address ADLs in addition to other functional goals. In our HBIP programme, most of the physical interventions would be fully integrated into these daily routines; for example, postural management in seating would be carried out as a preparation for feeding. Accordingly, the interventions would not be perceived as “exercises” but rather as a necessary part of positioning for activity or functional goals. Thus, while following the recommended protocols within a mutually acceptable daily schedule and using suitable equipment, caregiving duties should be simultaneously addressed.

The elements discussed in this section were all included in the final programme and/or the caregiver training, in alignment with the aims of our sample of caregivers. It was, therefore, unsurprising that the proposed HBIP draft was highly acceptable to those who reviewed it and provided feedback, although this particular sample was small. It is hoped that the final guideline will be similarly well-received by other communities in RLSs and perhaps even in other LMICs.

5.3.3 Accessibility

Our qualitative research highlighted how poorly healthcare services were being utilised by caregivers and their children living in RLSs, a finding confirmed by other studies in South Africa (Burger and Christian 2020, Saloojee et al. 2007), and other similar LMICs (Al Imam et al. 2021). Although most of our caregivers had at some point attended 30-to-60-minute therapy sessions at a health facility, and some had prior access to mobility equipment, accessing these services incurred considerable travel and time costs, as they were only offered at regional or provincial hospitals. This model was therefore unsustainable for them in the long term. Our HBIP is both trained, practised, and followed up within the communities themselves, with visiting therapists at a mutually acceptable community centre or the local clinic. Thus, caregivers would not be required to travel outside their area, keeping costs to a minimum. Where possible and feasible, the proposal recommends that therapists conduct a home visit following training to assess the efficacy of the programme in the natural environment and to make any necessary adaptations for individual children. Locally-based CHWs, also trained in the HBIP, would provide regular support for caregivers through home visits and be equipped to advise and liaise with therapists when needed.

5.3.4 Availability

The level of health service provision differs markedly between urban and non-urban regions in South Africa (Burger and Christian 2020), particularly in rural provinces, which significantly impacts the availability and quality of rehabilitation services in a RLS. Given that the current financial and staffing constraints of our health systems are unlikely to change appreciably in the near future, the HBIP's focus on strengthening services where many of these children live represents a pragmatic approach to increasing availability and reducing inequity in health service provision.

The delivery and implementation of the HBIP have been modelled on the existing health delivery structures typically found in RLSs. The programme recommends selected interventions that do not require specialised health professional expertise or advanced technology to perform–only the proper use of low-tech assistive equipment. While clinical expertise and oversight would still be necessary, the ongoing day-to-day support for caregivers and children would be provided by trained CHWs and/or (registered nurses) RNs already stationed in the areas. Certain changes to training curricula of both HCPs, especially therapists and CHWs may be required in order to standardise the implementation of the programme.

With feasibility in mind, it is necessary to reflect on the requirements for successful implementation: a systematic method to identify and register infants and young children with CP or at risk of CP; community-based or visiting therapist teams for training and monitoring; a suitable training venue within the community; low-cost adaptive equipment for postural management, splinting, and mobility; a standardised training tool with materials such as manuals and videos; and trained CHWs to provide ongoing support. As demonstrated, MSK preservation for children with CP relies heavily on the provision and consistent use of appropriate equipment. Currently, several devices are theoretically available through public health services, including wheelchairs, posture buggies, side-lyers and standers. However, actual provision to children with CP in South Africa seems to be poor for various reasons (DSD & UNICEF 2012), usually related to policy, accessibility, and financial constraints (Visagie et al. 2020). Twenty-four-hour postural management, sustained splinting, and supported positioning for functional sitting and standing—interventions for which our review found the strongest empirical evidence—cannot be effectively and/or safely performed without the recommended devices. The only HBIP intervention possible to carry out without any equipment would be manual stretching, which had the weakest support in the evidence base. Anecdotal evidence suggests that manual stretching alone is ineffective at preventing MSK complications and is considered by some therapist clinicians to be potentially injurious—a

debate that emerged strongly during the Delphi consensus process (Chapter 4). Furthermore, without a wheeled mobility device for transportation, children with CP are restricted from accessing health and educational facilities or participating in social spheres. However, low-cost appropriate paper-based technology (APT) has proven to be an effective way to address this issue in other RLSs (Barton et al. 2020) and could be feasible for certain recommended devices, particularly for younger children who require less support. Other low-cost solutions proposed include the use of recycled materials and basic PVC piping for constructing standers and splints, although the efficacy and safety of these solutions have yet to be fully evaluated.

Another important prerequisite for programme success is the training of CHWs. As first-contact health workers in these communities, they would need to be able to identify eligible children for the programme, competently perform the interventions, use and perform basic maintenance of equipment and coordinate and liaise with the local support mechanisms. Serving as a primary link between caregivers and therapists, they would also need to be able to refer cases to therapists when problems arise, such as ill-fitting splints, and collect data for monitoring and evaluation purposes. Studies in rural KwaZulu-Natal indicate that CHWs are not currently equipped for this role (Naidoo et al. 2019), but this could easily be achieved by adding an additional module on community CP care to their basic training.

To ensure equitable availability of the HBIP, both the equipment provision and CHW training and support would require specific resource allocation and considerable governmental commitment.

5.4 The alignment of the HBIP with National Health Insurance (NHI) in South Africa

The overarching policy of the National Health Insurance Strategic Plan of 2020/21 – 2024/25, commits to restructuring existing health services in order to deliver equitable, quality access to healthcare for all South Africans, i.e., Universal Health Coverage, with a particular emphasis on vulnerable population groups (DoH 2020). Essential to this approach is the building up of community health structures at primary level and the coordination and integration of health provision across all strata.

The proposed HBIP aligns closely with this policy's objectives. Firstly, through task-shifting, and training of caregivers, techniques such as basic postural management, feeding and the utilisation of supportive equipment can be implemented, essentially bringing skills closer to where they are needed, as primary level care is strengthened and equipped. As coverage of services increases to previously underserviced areas, the HBIP may also more easily be individualized for a family's needs, because of the existing, trusting relationship the CHWs usually have with families. Caregivers, empowered through training and support, would thus

take ownership of health-related decisions for their child, and take responsibility to administer the HBIP in a way that suits their family.

Secondly, home-based initiatives are more cost effective. While caregivers have fewer travel requirements, there is a reduced burden on secondary and tertiary level institutions and therapists can take on more of a coaching and managerial role for these cases, in turn requiring fewer community visits. Additionally, if successfully implemented, MSK complications should be reduced, helping to minimise costly secondly and tertiary remedial healthcare. Thirdly, the equipping of the existing community healthcare staff promotes an integrated approach, allowing better continuity of care. At community level, more children needing the HBIP can be identified and registered earlier, leading to caregiver training before MSK complications and developmental delays occur. At the same time clearly established referral pathways to therapists and clinics also allow access to specialised healthcare so that each child can be given the quality and level of services they need. Lastly, the HBIP addresses the problem of stigma because local knowledge about CP would increase through the formation of community support networks, allowing opportunities for inclusion of families and ultimately, participation of children with CP.

5.5 The potential contribution and limitations of the research

The HBIP proposal provides a comprehensive, context-sensitive approach to improving the care and functional outcomes of children with severe CP living in RLSs. It expands the application of current therapy provision and international clinical guidelines for CP management by prioritising the integrity of the MSK system and the importance of maintaining flexibility in those presenting with more severe subtypes. As such it enhances the applicability of existing guidelines in RLSs, where the global majority of children with severe CP reside. Recognising the constraints that prevail in these environments, the HBIP proposal emphasises increasing capacity at the community level through training, the provision of equipment, and caregiver empowerment. The HBIP offers a standardised regime that could be used by policymakers to address inequity in an affordable way while aligning with current best practice guidelines for care. A standardised protocol is also valuable for health system budgeting and planning resource allocations. Furthermore, it has applicability in medico-legal cases, where a quantifiable prediction of service needs is required for affected individuals. To our knowledge, this is the first home-based initiative developed with caregiver input that specifically addresses the needs of children with severe CP in RLSs.

The limitations of this research require consideration. Our review (Chapter 2) was broad but included relatively few resources from LMICs and RLSs due to the lack of quality data for our study population and the exclusion of reports in other languages for practical reasons. It is

possible that other relevant sources of data from LMICs, which could have provided valuable input for the development of the HBIP, were excluded due to these criteria. The qualitative sub-study (Chapter 3) utilised a small sample population of caregivers, and the setting was not deeply rural. This may limit the generalisability of the programme to all rural and peri-urban settings in South Africa, particularly with respect to contextual challenges and health service structure. However, the health professional experts (Chapter 4) brought a wealth of personal experience from a wide variety of public sector work environments, which likely increased the applicability of the final HBIP proposal across diverse settings in South Africa. Although standardising practice is useful where expertise and other resources are unequally distributed, a one-size-fits-all approach cannot address the full range of needs of all children with CP living in RLSs in South Africa, given the wide variability in CP presentation, individual needs, and caregiver goals. For this reason, it is recommended that ongoing monitoring of children in the programme is implemented, with daily schedules and equipment individually adapted to meet their specific needs.

Our research has highlighted the crucial role of assistive technology in supporting a community initiative such as ours. The assistive devices required for the HBIP would likely constitute a significant portion of the cost, which may raise questions about feasibility in a RLS. However, a comparison of the cost of increasing coverage of formal rehabilitative health services and personnel in these areas would likely demonstrate that the HBIP offers long term cost savings. Incorporating a preventive approach, the programme is expected to reduce the burden on the health system by minimising the need for corrective surgeries and other specialised services to address MSK complications, as well as reducing the personal costs carried by the children and their families.

5.6 Recommendations for Policy, Implementation and Research

In LMICs, the numerous and varied areas of health need often attract input from non-government organisations (NGOs) and international health bodies, which can serve as valuable partners in service provision. However, these organisations are not always well-regulated or integrated into a systems approach, leading to inconsistent and inequitable coverage. Additionally, in South Africa, it is common to find young and inexperienced therapists (and medical officers) placed in poorly resourced areas (Conradie et al. 2022). Standardised protocols and care pathways help to mitigate this by reducing the reliance on specialised expertise at the point of care. We, therefore, recommend that the proposed HBIP be incorporated into a prescribed national standard package of care for children with CP, comprising a caregiver-provided daily intervention protocol, a training component and a community support network as detailed in Chapter 4.

As the HBIP is heavily reliant on the supply of assistive technologies, the development and provision of locally produced, low-cost equipment should be prioritised. Innovations in this area could be encouraged through collaboration with other economic sectors and disciplines, such as biomedical engineering. The use of these devices should adhere to industry standards for safety and efficacy so that all children receive products of consistent quality.

We also recommend that a cost-benefit analysis be conducted for budgeting purposes, and that the Department of Health establishes partnerships with other sectors, such as the Departments of Education and/or Social Development, as well as NGOs and other donors, to coordinate resource provision and implementation. Most of the caregivers in our study population owned a mobile device capable of supporting smart technology. Where feasible, and where cellular infrastructure permits, telehealth platforms and innovations incorporating artificial intelligence could further reduce costs and improve accessibility to certain aspects of training and support.

From a future research perspective, a pilot study should be conducted to establish the feasibility of the HBIP in a non-urban RLS similar to the community where the primary research was conducted. Using the suggested response indicators— namely joint ROM, pain with movements, frequency of participation in family activities, frequency of participation in age-appropriate play, education and social engagement, and caregiver quality of life measures— the programme's efficacy in meeting its aims over time can be assessed. The development of evaluation and monitoring tools specifically suited to the SA setting would be a useful addition to the HBIP. A pilot study should also identify the structural and social determinants of the programme's success and inform future adaptions and trials in other RLSs.

5.7 Conclusions

Children with severe forms of CP who live in a RLS in South Africa are not currently accessing the rehabilitation services and support they need to prevent secondary MSK complications. As a result, many experience extremely poor outcomes in terms of function, social development and participation. Their caregivers are typically less educated, low-income mothers or other female relatives who face multiple challenges in accessing health services and providing daily care for their child. Despite these difficulties, caregivers maintain hopes that their children will be able to participate more fully in shared family activities, engage in age-appropriate pursuits, and be included in social and community events. Caregivers would, therefore, welcome a context-responsive, community-based initiative. Utilising three distinct phases in the research, we have produced a context-specific proposal for an HBIP involving a wide range of stakeholders to address the difficulties faced by these caregivers, and improve outcomes for this vulnerable group of children. The HBIP presents a detailed, evidence-based,

and practicable proposal that addresses these needs and can be effectively performed by caregivers if they are adequately trained and supported. What is required is a commitment by policymakers to empower and equip these marginalised communities to take a more active role in their own health service provision. This approach aligns with the global best practice principles of family-centred care, is well-allied with the principles of the NHI in SA, and advances the World Health Organisation's third Sustainable Development Goal to "ensure healthy lives and promote well-being for *all at all ages*", ensuring that no child is left behind (UNDESA 2015).

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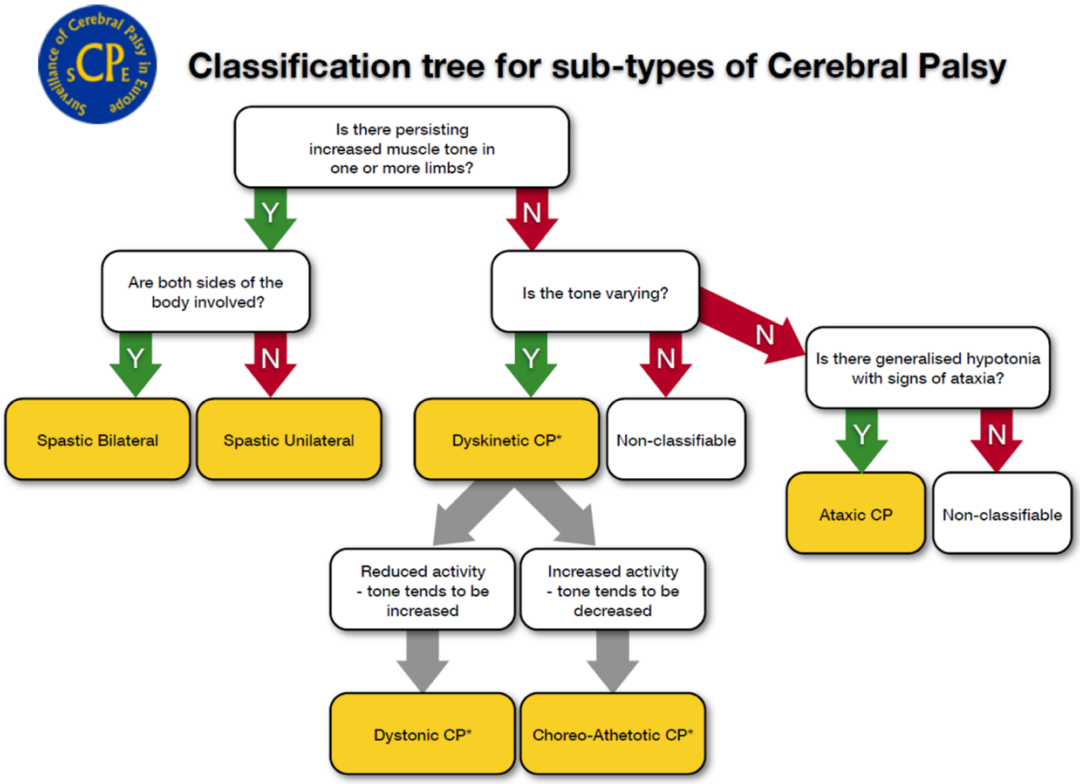
APPENDICES

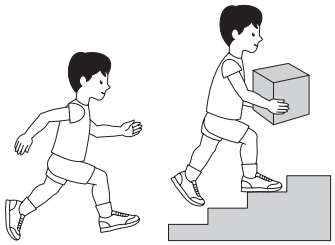
Appendix 1.1: SCPE Classification of CP subtypes



Source: SCPE Collaborative group. Surveillance of cerebral palsy in Europe: a collaboration of deverebral palsy surveys and registers. *Developmental Medicine and Child Neurology.* 2000;42:816-24

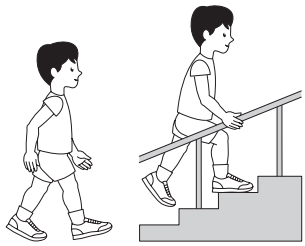
Appendix 1.2: Gross Motor Function Classification System (Expanded and Revised)

GMFCS E & R between 6th and 12th birthday: Descriptors and illustrations



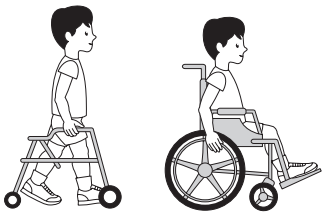
GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.



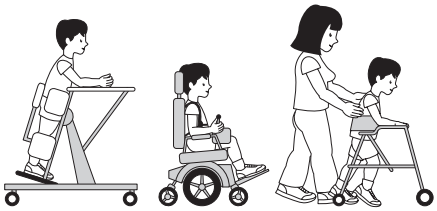
GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.



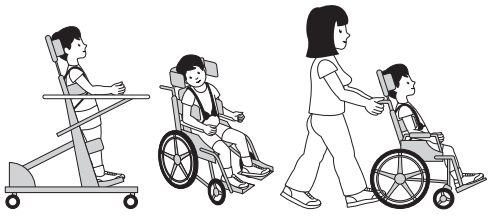
GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.



GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

Appendix 2.1: Search Process

Research title : Increasing Participation Opportunities for Children with severe Cerebral palsy in South Africa by limiting Musculoskeletal Complications : a Home-based approach
S van Aswegen, B. Morrow, M. Richards

Part 1 : WHAT ESSENTIAL ELEMENTS OF HOME-BASED CARE COULD EQUIP RURAL CAREGIVERS TO LIMIT MUSCULOSKELETAL COMPLICATIONS IN CEREBRAL PALSY?:

DATABASE, PLATFORM & ACCESS DATE	MESH/FIELDS	KEYWORDS	RECORDS
PubMed 22/01/22	All Fields	All fields	
	"Cerebral Palsy"[Mesh]	“cerebral palsy” OR spastic	54,527
		AND	
	"Child"[Mesh] OR "Adolescent"[Mesh] OR "Infant"[Mesh] OR "Child, Preschool"[Mesh]	child OR children OR childhood OR infant OR infants OR infancy OR teenager OR teenagers OR adolescent OR adolescents OR adolescence	4,570,155
		AND	
	"Tertiary Prevention"[Mesh]	“ tertiary prevention” OR prevent OR prevention OR reduce OR reduction OR minimize OR minimise OR limit OR manage OR management	9,950,842
		AND	
	"Joint Deformities, Acquired"[Mesh] OR "Scoliosis"[Mesh] OR "Contracture"[Mesh] OR "Joint Dislocations"[Mesh]	“orthopaedic complications” OR “orthopedic complications” OR “musculoskeletal complications” OR deformity OR deformities OR contracture OR contractures OR windswept OR asymmetry OR scoliosis OR obliquity OR	1,553,358

		“femoral migration” OR dislocation OR subluxation OR displacement OR dysplasia	
		AND	
	"Physical Therapy Modalities"[Mesh] OR "Occupational Therapy"[Mesh] OR "Exercise Therapy"[Mesh] OR "Home Nursing"[Mesh]	“occupational therapy” OR “physical therapy” OR physiotherapy OR “physical therapy techniques” OR “physiotherapy modalities” OR “physical therapy modalities” OR “exercise therapy” OR “postural management” OR rehabilitation OR casting OR positioning OR stretching OR splinting OR “supported standing” OR “therapeutic intervention” OR “therapeutic interventions” OR “home nursing” OR “natural environment” OR “primary health setting” OR “primary health settings” OR “context focused” OR context-focused OR “community based” OR community-based OR “home based” OR home-based OR “home program” OR “home	1,670,217

		programs” OR “home programme” OR “home programmes” OR “home intervention” OR “home interventions” OR “home treatment” OR “home treatments” OR “home-based therapy” OR “home-based therapies” OR “parent delivered” OR parent-delivered	
			907
Filter: Date	From 2001/1/1 – 2021/12/31		710
Language	English		**661**

Search: (((((("Cerebral Palsy"[Mesh]) OR ("cerebral palsy" OR spastic)) AND (("Child"[Mesh] OR "Adolescent"[Mesh] OR "Infant"[Mesh] OR "Child, Preschool"[Mesh]) OR (child OR children OR childhood OR infant OR infants OR infancy OR teenager OR teenagers OR adolescent OR adolescents OR adolescence))) AND (("Tertiary Prevention"[Mesh]) OR (" tertiary prevention" OR prevent OR prevention OR reduce OR reduction OR minimize OR minimise OR limit OR manage OR management))) AND (("Joint Deformities, Acquired"[Mesh] OR "Scoliosis"[Mesh] OR "Contracture"[Mesh] OR "Joint Dislocations"[Mesh]) OR ("orthopaedic complications" OR "orthopedic complications" OR "musculoskeletal complications" OR deformity OR deformities OR contracture OR contractures OR windswept OR asymmetry OR scoliosis OR obliquity OR "femoral migration" OR dislocation OR subluxation OR displacement OR dysplasia))) AND (("Physical Therapy Modalities"[Mesh] OR "Occupational Therapy"[Mesh] OR "Exercise Therapy"[Mesh] OR "Home Nursing"[Mesh]) OR ("occupational therapy" OR "physical therapy" OR physiotherapy OR "physical therapy techniques" OR "physiotherapy modalities" OR "physical therapy modalities" OR "exercise therapy" OR "postural management" OR rehabilitation OR casting OR positioning OR stretching OR splinting OR "supported standing" OR "therapeutic intervention" OR "therapeutic interventions" OR "home nursing" OR "natural environment" OR "primary health setting" OR "primary health settings" OR "context focused" OR context-focused OR "community based" OR community-based OR "home based" OR home-based OR "home program" OR "home programs" OR "home programme" OR "home programmes" OR "home intervention" OR "home interventions" OR "home treatment" OR "home treatments" OR "home-based therapy" OR "home-based therapies" OR "parent delivered" OR parent-delivered)) Filters: English, from 2001 - 2021 Sort by: Most Recent

Scopus 29/01/22	TITLE-ABS-KEY		
		“cerebral palsy” W/4 child* OR teenage* OR adolescen*	
		AND	
		“tertiary prevention” OR prevent* OR reduc* OR minimize OR minimise OR limit OR manag* W/4 “orthopaedic complication*” OR “musculoskeletal complication*” OR deformit* OR contracture* OR windswept OR asymmetry* OR scoliosis OR obliquity OR “femoral migration” OR dislocat* OR sublux* OR displace* OR dysplasia	
		AND	
		“occupational therapy” OR “physical therapy” OR physiotherapy OR “physical therapy technique*” OR “physiotherapy modalit*” OR “physical therapy modalit*” OR “exercise therapy” OR “postural management” OR rehabilitation	2,017

		OR casting OR positioning OR stretching OR splinting OR “supported standing” OR “therapeutic intervention*” OR “home nursing” OR “natural environment” OR “primary health setting*” OR “context focused” OR context-focused OR “community based” OR community-based OR “home based” OR home-based OR “home program*” OR “home programme*” OR “home intervention*” OR “home treatment*” OR “home-based therap*” OR “parent delivered” OR “parent-delivered”	
Filters: Date	From 2001-2021		1,813
Subject area	Health professions		361
Type	Include only articles, reviews, conference papers		306
Source	Only Rehabilitation, paediatric and Neurology, physiotherapy and occupational therapy sources		294
Language	English		**279**
("cerebral palsy" W/4 child* OR infan* OR teenage* OR adolescen*) AND ("tertiary			

prevention" OR prevent* OR reduc* OR minimize OR minimise OR limit OR mana g* W/4 "orthopaedic complication*" OR "musculoskeletal complication*" OR deformit* OR contracture* OR windswept OR asymmetr* OR sco liosis OR obliquity OR "femoral migration" OR dislocat* OR sublux* OR displace* OR dysplasia) AND ("occupation al therapy" OR "physical therapy" OR physiotherapy OR "physical therapy technique*" OR "physiotherapy modalit*" OR "physical therapy modalit*" OR "exercise therapy" OR "postural management" OR rehabilitation OR casting OR positioning OR stretching OR splinti ng OR "supported standing" OR "therapeutic intervention*" OR "home nursing" OR "natural environment" OR "primary health setting*" OR "context focused" OR context-focused OR "community based" OR community-based OR "home based" OR home-based OR "home program*" OR "home programme*" OR "home intervention*" OR "home treatment*" OR "home-based therap*" OR "parent delivered" OR "parent-delivered") AND (LIMIT-TO (PUBYEAR , 2021) OR LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2010) OR LIMIT-TO (PUBYEAR , 2009) OR LIMIT-TO (PUBYEAR , 2008) OR LIMIT-TO (PUBYEAR , 2007) OR LIMIT-TO (PUBYEAR , 2006) OR LIMIT-TO (PUBYEAR , 2005) OR LIMIT-TO (PUBYEAR , 2004) OR LIMIT-TO (PUBYEAR , 2003) OR LIMIT-TO (PUBYEAR , 2002) OR LIMIT-TO (PUBYEAR , 2001)) AND (LIMIT-TO (SUBJAREA , "HEAL")) AND (LIMIT-TO (DOCTYPE , "ar") OR LIMIT-TO (DOCTYPE , "re") OR LIMIT-TO (DOCTYPE , "cp")) AND (EXCLUDE (EXACTSRCTITLE , "Human Brain Mapping") OR EXCLUDE (EXACTSRCTITLE , "Journal Of Advanced Pharmacy Education And Research") OR EXCLUDE (EXACTSRCTITLE , "Journal Of Orthopaedic And Sports Physical Therapy") OR EXCLUDE (EXACTSRCTITLE , "Journal Of Orthopaedics Trauma And Rehabilitation") OR EXCLUDE (EXACTSRCTITLE , "Journal Of Physical Education And Sport") OR EXCLUDE (EXACTSRCTITLE , "Journal Of Sport Rehabilitation") OR EXCLUDE (EXACTSRCTITLE , "Journal Of Ultrasound In Medicine") OR EXCLUDE (EXACTSRCTITLE , "Language Speech And Hearing Services In Schools") OR EXCLUDE (EXACTSRCTITLE , "Movement And Sports Sciences Science Et Motricite") OR EXCLUDE (EXACTSRCTITLE , "Radiologic Technology") OR EXCLUDE (EXACTSRCTITLE , "Scandinavian Journal Of Medicine And Science In Sports") OR EXCLUDE (EXACTSRCTITLE , "Topics In Geriatric Rehabilitation")) AND (LIMIT-TO (LANGUAGE , "English"))

Cochrane Library 28/01/2022		“cerebral palsy” OR spastic*	
		AND	
		Child OR infant OR teenager OR adolescent	
		AND	
		“occupational therapy” OR “physical therapy” OR physiotherapy	79 reviews

		OR “physical therapy technique” OR “physiotherapy modalit” OR “physical therapy modality” OR “exercise therapy” OR “postural management” OR rehabilitation OR casting OR positioning OR stretching OR splinting OR “supported standing” OR “therapeutic intervention” OR “home nursing” OR “natural environment” OR “primary health setting*” OR “context focused” OR context-focused OR “community based” OR community-based OR “home based” OR home-based OR “home program” OR “home programme” OR “home intervention” OR “home treatment” OR “home-based therapy” OR “parent delivered” OR “parent-delivered”	
Filters: date	From 2001 - 2021		77
	Type: Interventions		75

	Topics: child health, neurology		**53**
53 Cochrane Reviews matching "cerebral palsy" OR spastic in Title Abstract Keyword AND Child OR infant OR teenager OR adolescent in Title Abstract Keyword AND “occupational therapy” OR “physical therapy” OR physiotherapy OR “physical therapy technique” OR “physiotherapy modalit” OR “physical therapy modality” OR “exercise therapy” OR “postural management” OR rehabilitation OR casting OR positioning OR stretching OR splinting OR “supported standing” OR “therapeutic intervention” OR “home nursing” OR “natural environment” OR “primary health setting*” OR “context focused” OR context-focused OR “community based” OR community-based OR “home based” OR home-based OR “home program” OR “home programme” OR “home intervention” OR “home treatment” OR “home-based therapy” OR “parent delivered” OR “parent-delivered” in Title Abstract Keyword - (Word variations have been searched)			
CINAHL, via EBSCOHost 22/01/22		“cerebral palsy” OR spastic*	
		AND	
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		AND	
		“orthopaedic complication*” OR “musculoskeletal complication*” OR deformit* OR contracture* OR windswept OR asymmetr* OR scoliosis OR obliquity OR “femoral migration” OR dislocat* OR sublux* OR displace* OR dysplasia	
		AND	
		“occupational therapy” OR “physical therapy” OR physiotherapy OR “physical therapy	124

		technique*” OR “physiotherapy modalit*” OR “physical therapy modalit*” OR “exercise therapy” OR “postural management” OR rehabilitation OR casting OR positioning OR stretching OR splinting OR “supported standing” OR “therapeutic intervention*” OR “home nursing” OR “natural environment” OR “primary health setting*” OR “context focused” OR context-focused OR “community based” OR community-based OR “home based” OR home-based OR “home program*” OR “home programme*” OR “home intervention*” OR “home treatment*” OR “home-based therap*” OR “parent delivered” OR “parent-delivered”	
Filters: Date	01/01/2001 to 31/12/2021		104
Language	English		**104**

Health Source: Nursing/Academic Edition via EBSCOHost 22/01/2022		As for CINAHL	46
Filters: Date	01/01/2001 to 31/12/2021		46
Language	English		**46**
Africa-Wide Information via EBSCO Host 22/01/2022		As for CINAHL	12
Filters: Date	01/01/2001 to 31/12/2021		12
Language	English		**12**
(“cerebral palsy” OR spastic*) AND (Child* OR infant* teenager* OR adolescen*) AND (“ tertiary prevention” OR prevent* OR reduc* minimize OR minimise OR limit OR manag*) AND (“orthopaedic complication*” OR “musculoskeletal complication*” OR deformit* OR contracture* OR windswept OR asymmetr* OR scoliosis OR obliquity OR “femoral migration” OR dislocat* OR sublux* OR displace* OR dysplasia) AND (“occupational therapy” OR “physical therapy” OR physiotherapy OR “physical therapy technique*” OR “physiotherapy modalit*” OR “physical therapy modalit*” OR “exercise therapy” OR “postural management” OR rehabilitation OR casting OR positioning OR stretching OR splinting OR “supported standing” OR “therapeutic intervention*” OR “home nursing” OR “natural environment” OR “primary health setting*” OR “context focused” OR context-focused OR “community based” OR community-based OR “home based” OR home-based OR “home program*” OR “home programme*” OR “home intervention*” OR “home treatment*” OR “home-based therap*” OR “parent delivered” OR “parent-delivered”)	Limiters - Published Date: 20010101-20211231 Expanders - Apply equivalent subjects Narrow by Language: - english Search modes - Boolean/Phrase		
WoS Core collection via Web of Science 24/01/22		As for CINAHL	540
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Language	English		**468**
https://www.webofscience.com/wos/woscc/summary/19c27ff5-42f6-4274-bcb8-7d4b06248b98-20738d7d/relevance/1			
Scielo via Web of Science 24/01/22		AS for CINAHL	3

https://www.webofscience.com/wos/scielo/summary/d7bfc92a-3645-4692-b1fe-30b8e5d0ca91-207410ce/relevance/1			
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		Home program	
		Physical therapy	12,103
Filters: Type	Dissertations, conference proceedings, reviews, government documents, reports, text and web resources		
Date:	2001-2021		
Subject	Cerebral palsy, rehabilitation, child, care and treatment		
Language	English		**27**
https://uct.primo.exlibrisgroup.com/discovery/search?mfacet=rtype,include,dissertations,1&mfacet=rtype,include,conference_proceedings,1&mfacet=rtype,include,reviews,1&mfacet=rtype,include,government_documents,1&mfacet=rtype,include,reports,1&mfacet=rtype,include,text_resources,1&mfacet=rtype,include,web_resources,1&mfacet=searchcreationdate,include,2001%7C,%7C2021,1&mfacet=topic,include,Rehabilitation,1&mfacet=topic,include,Child,1&mfacet=topic,include,Cerebral%20Palsy,1&mfacet=topic,include,Care%20And%20Treatment,1&mfacet=lang,include,eng,1&mode=advanced&offset=0&query=any,contains,cerebral%20palsy,AND&query=any,contains,infant%20OR%20child%20OR%20adolescent,AND&query=any,contains,home%20program,AND&query=any,contains,physical%20therapy,AND&search_scope=MyInst_and_CI&sortby=rank&tab=Everything&vid=27UCT_INST:27UCT&came_from=search_history			
Grey literature: BASE 04/02/22		Parent delivered care of cerebral palsy	92
Filters: language	English		78
Type:	Articles AND		35
	theses		4
			39

parent delivered care of cerebral palsy	Language: English Additional word forms: On Boosting: Open access documents	78

parent delivered care of cerebral palsy		Language: English Document Type: Article contribution Additional word forms: On Boosting: Open access documents	
parent delivered care of cerebral palsy		Language: English Document Type: Doctoral and postdoctoral the Additional word forms: On Boosting: Open access documents	
Grey literature: CLINICAL KEY 21/02/22	Guidelines :	cerebral palsy clinical guidelines	3 (see NICE guidelines)
	Clinical overview:	cerebral palsy	1 (not homebased)
Filter: guidelines, neurology			
https://www-clinicalkey-com.ezproxy.uct.ac.za/#!/search/cerebral%20palsy%20%20in%20children%20clinical%20guidelines/%7B%22start%22:0,%22group%22:true,%22showExpandedResult%22:true,%22fullTextOnly%22:true,%22facetquery%22:%5B%22+contenttype:PG%22,%22+subjmain:Neurology%22%5D%7D			
Grey literature: EThOS : e-theses online 19/02/22		Cerebral palsy AND home treatment	5
Filter: dates	Since 2001		**4**
https://ethos.bl.uk/SearchResults.do			
Grey literature: GOOGLE SCHOLAR 21/02/22	parent-delivered home-based daily physical management of children with cerebral palsy		131
Filter: dates	2001-2021		**105**
https://scholar.google.com/scholar?q=parent-delivered+home-based+daily+physical+management+of+children+with+cerebral+palsy&hl=en&as_sdt=0%2C5&as_ylo=2001&as_yhi=2021			
Grey literature: SEMANTIC SCHOLAR 21/02/22	home-based physical management of children with cerebral palsy		10
Filter : dates	2001-2021		8
Publication type	any		**8**
https://www.semanticscholar.org/search?q=home-based%20physical%20management%20of%20children%20with%20cerebral%20palsy&sort=relevance			
WEBSITES			
Health organisations, associations and professional societies	Manual searches for material relating to home-based clinical practice guidelines and interventions for children with cerebral palsy		

NICE 25/02/22		Cerebral palsy	**3**
https://www.nice.org.uk/search?om=[{%22ndt%22:[%22Guidance%22]}]&ps=15&q=cerebral+palsy&sp=on **https://www.nice.org.uk/search?q=cerebral+palsy+clinical+guidelines**			
Waikato District Health Board 25/02/22	Clinical guidelines	Cerebral palsy	**1**
https://silo.tips/download/cerebral-palsy-clinical-practice-guideline-cp-cpg			
AACPDM 28/02/22	Care pathways 24 hour postural management Central hypotonia Dystonia in cerebral palsy	Cerebral palsy	**6**
https://www.aacpdm.org/search/?cx=017903999552188581036%3Abnmseufhj1s&cof=FORID%3A11&ie=UTF-8&q=24+hour+postural+management **https://www.aacpdm.org/publications/care-pathways**			
IAACD 28/02/22	Knowledge Hub, Teaching materials, Cerebral palsy for Healthcare practitioners		**1**
https://iaacd.net/wp-content/uploads/2022/02/CP_Fact_Sheet5_IAACD_Managing-Complexity-FA.pdf			
KZN Health dept. 28/02/22	Guidelines for management of CP		**1**
Made for Movement 28/02/22	CP management		**4**
https://blog.madeformovement.com/24-hour-posture-care-management-key **https://blog.madeformovement.com/clinical-recommendations-supported-standing-programs-children-cp?utm_campaign=RSS-emails%20%5BNewsletter%20and%20notifications%5D&utm_source=hs_email&utm_medium=email&utm_content=73253632&_hsenc=p2ANqtz-_izDW2N-Ag62c4xScSMJvVOvOkPXPbcQSl-Kkgj6BZ24C0o0zKqWrBktojQFAi4RlbMeaSLjcvlpecXodmnChs_l278Q&_hsmi=73253632** **https://blog.madeformovement.com/5-things-you-should-know-about-scoliosis** **https://blog.madeformovement.com/eacd-2019-innovation-participation?utm_campaign=RSS-emails%20%5BNewsletter%20and%20notifications%5D&utm_source=hs_email&utm_medium=email&utm_content=74209166&_hsenc=p2ANqtz-8x-4sGDshDQ5EUjgy_M6X_TM6H-BSHaJj4AzlOSQVbfvU_GEE86YjbqLOSZCazdWcBREEngfndC37R63CT3Ov48Mhgwg&_hsmi=74209166**			
APTA Pediatrics 03/03/22	Fact sheets	Early intervention,	**2**

		Natural environments Team based service delivery	
https://pediatricapta.org/consumer-patient-information/pdfs/Service%20Delivery.pdf https://pediatricapta.org/consumer-patient-information/pdfs/Natural%20Env%20Fact%20Sheet.pdf			
Braceworks. 03/03/22	Cerebral palsy	Splinting Cerebral palsy	**1**
https://braceworks.ca/2018/09/25/devices/lower-limbs/afo/updated-evidence-on-the-efficacy-of-afos-in-children-with-cerebral-palsy/			
Physiopedia. 03/03/22	Cerebral palsy	Orthotics in children with cerebral palsy	**1**
https://www.physio-pedia.com/Orthotics_in_Cerebral_Palsy			
RESNA 21/02/22	Position papers	Postural management	**3**
Royal children's Hosp Melbourne 21/02/22	Cerebral palsy	Clinical practice guidelines: cerebral palsy	**1**
https://www.rch.org.au/clinicalguide/guideline_index/Cerebral_palsy/			
WHO 22/02/22	Cerebral palsy	Clinical practice guidelines: cerebral palsy	**0**
Mobility management 03/03/22	Cerebral palsy	Various blog posts	**4**
https://mobilitymgmt.com/articles/2016/08/01/posture-management.aspx			
Rehab Pub/ Rehab Management 03/03/22	Cerebral palsy		**3**
https://rehabpub.com/conditions/neurological/cerebral-palsy/24-hour-posture-care-management-supporting-people-night-day/			
			1846 articles

Appendix 2.2 Level of evidence and methodological appraisal

Level of evidence	Description
Level I	Evidence from a systematic review or meta-analysis of all relevant RCTs (randomised controlled trial) or evidence-based clinical practice guidelines based on systematic reviews of

	RCTs or three or more RCTs of good quality that have similar results.
Level II	Evidence obtained from at least one well-designed RCT (e.g. large multi-site RCT).
Level III	Evidence obtained from well-designed controlled trials without randomization (i.e. quasi-experimental) or evidence from systematic reviews of cohort studies.
Level IV	Evidence from well-designed case-control or cohort studies.
Level V	Evidence from systematic reviews of descriptive and qualitative studies (meta-synthesis).
Level VI	Evidence from a single descriptive or qualitative study, case studies, case series.
Level VII	Evidence from the opinion of authorities and/or reports of expert committees.

Adapted from: "Evidence-based practice in nursing & healthcare: a guide to best practice" by Bernadette M. Melnyk and Ellen Fineout-Overholt. 2005, page 10.

JBI checklist and AGREE II rating system

Study type checklist	Yes %			
Rating	Very low (+-25% or lower)	Low (26-50%)	Moderate (51 – 75%)	High (+-75% and higher)
JBI for Systematic review (SR)	0-2	3-5	6-8	9-11
JBI for Randomised controlled trial (RCT)	0-3	4-6	7-10	11-13
JBI for Quasi-Experimental (QEx)	0-2	3-4	5-6	7-9
JBI for Cohort (Co)	0-2	3-5	6-8	9-11
JBI for Analytical X-section (AX)	0-2	3-4	5-6	7-8
JBI for Qualitative research (QuR)	0-2	3-5	6-8	9-10
JBI for Case series (CS)	0-2	3-5	6-8	9-10
JBI for Case report (CR)	0-2	3-4	5-6	7-8
JBI for Prevalence	0-2	3-4	5-6	7-9
JBI for Expert opinion (ExO) or Narrative review (NR)	0-1	2-3	4	5-6
AGREE-II for clinical practice guidelines (CPG)	1	2-3	4-5	6-7

Adapted from:

JBI critical appraisal tools at https://jbi.global/critical-appraisal-tools and AGREE-II checklist at https://www.agreetrust.org/wp-content/uploads/2017/12/AGREE-II-Users-Manual-and-23-item-Instrument-2009-Update-2017.pdf

Appendix 3.1: 1 Ethical Approval

3.1.1 HREC Approval for Research Project 2021

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room 45 E-52-E-Floor- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-enquiries@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

31 January 2022

HREC REF: 024/2022

Prof B Morrow
Paediatrics and Child Health
5th Floor, ICH Building
Email: brenda.morow@uct.ac.za
Student: shaco2@me.com

Dear Prof Morrow

PROJECT TITLE : INCREASING PARTICIPATION OPPORTUNITIES FOR CHILDREN WITH SEVERE CEREBRAL PALSY IN SOUTH AFRICA BY LIMITING MUSCULOSKELETAL COMPLICATIONS: A HOME- BASED APPROACH (MPHIL DEGREE – MRS SHAYNE VAN ASWEGEN)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

- If it is anticipated that most participants would read IsiZulu preferentially, then the HREC would recommend a translation of the consent form into that language.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020: 06 July 2020 & 01 July 2021.

Approval is granted for one year until the 28 February 2023.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: Mrs Shayne van Aswegen will also be involved in this study.

Please quote the HREC REF 024/2022 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

3.1.2 Ethical Approval for Research Project 2023/24

UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	30.11.2024
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee		Date Signed	6/11/2023

Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.
Please clarify your plan for research-related activities during COVID-19 lockdown.
Please use the latest form found on our website:
http://www.health.uct.ac.za/fhs/research/humanethics/forms

HUMAN RESEARCH ETHICS COMMITTEE
- 6 NOV 2023
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

Comments to PI from the HREC
Thank you for your Study Deviation HREC Chair Signature Date: 6/11/2023

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	5 November 2023		
HREC REF Number	HREC REF: 024/2022	Current Ethics Approval was granted until	28/2/2023
Protocol title	Increasing participation opportunities for children with severe cerebral palsy in South Africa by limiting musculoskeletal complications: a home-based approach.		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?		☐ Yes	X No
If yes, could you please provide the HREC Reference number for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Prof. Brenda Morrow		

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Appendix 3.2: Permission letter to Ward Councillor

To: Councillor Mthetheleli Sibisi
Ward 103 Councillor
KwaNyuswa
BOTHA'S HILL
3660

September 2021

Dear Mr Sibisi

I hope you are well.

My name is Shayne, and I am a physiotherapist specialising in the treatment of children with cerebral palsy.

I have been in touch with Zipho Mkhize, a social worker operating in your area, about a Master's research project involving caregivers of children with cerebral palsy in a peri-urban area. I am aiming to develop some guidelines on a home-based program that will educate and train parents and caregivers to better manage some of the difficulties that having a child with severe CP entails. To do this well, I need a good understanding of the environment and difficulties these families are facing. I therefore need to meet with about 15 suitable caregivers that can represent this group from a community like yours.

The project will run from January 2022 and will involve the following:

1. Identification of the representative group of caregivers by Ms. Mkhize and myself.
2. A meeting with half the group at a time, held at a community centre in KwaNyuswa in January or February, 2022.
3. After giving informed consent, the parents will participate in a discussion, with the help of a translator.
4. The subjects for discussion will cover the particular challenges for disability in the area (health facilities, therapy, schools, distance to clinics, etc), as well as the challenges they face in caring for their child (training and education, equipment, basic everyday activities, and level of participation in social and family life).
5. The problems raised at these meetings will be included in an opinion survey of medical experts who will help to develop the program.
6. Thereafter, I would like to meet with the caregiver groups once again to see if they will find this program acceptable. This should take place by June 2022.

If you are agreeable, I suggest that we meet maybe in Botha's Hill or Hillcrest to discuss the way forward.

I look forward to hearing from you.

Kind regards

Shayne van Aswegen

6 BUCKINGHAM PLACE • WOODSIDE • 3610 • SOUTH AFRICA
☎ +27 83 262 9960 • SHAYNEVANASWEGEN@GMAIL.COM

Appendix 3.3: Ad hoc Screening tool used by Community health workers

SCREENING FOR CEREBRAL PALSY IN THE COMMUNITY

For children who are not doing what other children of their age can do.
Put a tick in the box if the statement is CORRECT or TRUE.

The child's movements and posture

1. Slow to develop rolling, sitting, crawling and standing ☐
2. Cannot walk or run ☐
3. Cannot balance on their own in sitting ☐
4. The head is flopping when the child is sitting up ☐
5. Must be carried OR use a wheelchair to go out somewhere ☐
6. Cannot use the hands properly ☐
7. Spends a lot of time lying down during the day ☐

The body

1. The muscles are very stiff when moving or have spasms ☐
2. The joints are stuck or twisted ☐
3. The spine is twisted out of shape ☐
4. The legs cross over when they are picked up ☐
5. One leg is shorter than the other ☐
6. The hands are clenched in a fist ☐
7. The child has pain with movement ☐

Feeding & Speech

1. Needs help with feeding and drinking ☐
2. Chewing and swallowing is difficult ☐
3. Drools a lot ☐
4. No speaking or difficulty with speaking ☐

Sensory

1. Cannot see properly ☐
2. Cannot hear properly ☐
3. Doesn't understand properly when you speak ☐

Health and Everyday activities

1. Has seizures/epilepsy ☐
2. Takes medication for seizures/epilepsy ☐
3. Cannot bath & dress themself ☐
4. Needs to use a nappy ☐

Images from Disabled Village Children
https://www.dinf.ne.jp/doc/english/global/david/dwe002/dwe00211.html

For 12 or more ticks, please fill in the details below, and return the form to the clinic.

++

Full name of child _____

Date of birth _____

Home address _____

_____

Caregiver's name _____

Cell phone no _____

Appendix 3.4: Consent and Assent forms for Caregivers

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM - CAREGIVER

TITLE OF THE RESEARCH PROJECT:

INCREASING PARTICIPATION OPPORTUNITIES FOR CHILDREN WITH SEVERE CEREBRAL PALSY IN SOUTH AFRICA BY LIMITING MUSCULOSKELETAL COMPLICATIONS : A HOME-BASED APPROACH

PRINCIPAL INVESTIGATOR: Prof Brenda Morrow
CONTACT NUMBER: 0729094347
STUDENT INVESTIGATOR: Shayne van Aswegen
CONTACT NUMBER: 0832629960

I am a Master's Degree student at the University of Cape Town**.** You are being invited to take part in my research project, because you are caring for a child with severe cerebral palsy. Please take some time to read the information presented here, which will explain the details of this project. Please ask me any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you understand what this research is about and how you could be involved.

Your participation is **entirely voluntary** and you are free to say no to this invitation. If you say no, this will not affect you or your child negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the University of Cape Town's Faculty of Health Science's Human Research Ethics Committee and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki (2013), South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?
Many parents and caregivers in South Africa care for disabled children every day, often without proper training or support from health services. Children with cerebral palsy often develop problems in their bodies, like stiff joints and muscles, which may be painful. This can mean that looking after these children is very difficult. Many of these problems can be reduced by correct day-to-day handling of the child. I am aiming to develop some guidelines for a program that can be used to train caregivers on how to prevent or reduce these body problems.

Why have you been invited to participate?
As a caregiver in this situation, you have a lot of knowledge about caring for your child. I would like to find out about what challenges you have with handling your child, and what problems this can cause. I would also like to learn from you what you think about training caregivers, and what you think they need to know.

What will your responsibilities be/ what will happen if you agree to take part?
I will call you to be part of two meetings (called focus groups) held in your area. During the first meeting, a small group of caregivers will meet with myself and the social worker. We will talk about your home, what therapy your child receives, how you are managing with your child at home and what support you would like from training. Personal information will be recorded on a written questionnaire, and the discussion will be recorded on a video so that

we can remember all the important things that have been said. Your child does not need to be part of this meeting.
Once we have come up with a proposal for a program, I will ask you to meet with me again to so that you can check to see if the program is suitable.

Will you or your child benefit from taking part in this research?
Even if we manage to agree on a suitable program, it is unlikely that we will be able to put it into action for some time. So, it may not help you or your child directly. However, your contribution will be very important to future caregivers and their children who have the same challenges.

Are there any risks involved in your taking part in this research?
By taking part in the group, you will be giving permission (consent) for the discussion points to be used in the research to develop the training program proposal. It is possible that harm could be caused to you if somebody at the meeting shared your personal comments outside of the meeting with somebody else. Although I will ask everybody *not* to share anything outside of the meeting, I will not be able to ensure that every other caregiver keeps all the information secure. Talking about how you cope with caring for your child might raise some difficult feelings – if you are feeling upset, angry, worried (or any other feelings), please let us know – you do not need to answer any questions that make you uncomfortable, and/or we can refer you for counselling if needed. The social worker from your area will also be present and able to assist if needed.

Who will have access to your information?
The questionnaire with your personal information will be filled in on paper by you (with an assistant or translator if needed) and this won't be discussed at the meeting. Only the researchers will be allowed to read this and use the information, but we will do so without identifying who you are.

For the group discussion, only the people present will hear what you say, and the video recording won't be available to anyone but myself and the social worker who may be asked to help me interpret what was said. As soon as we have the necessary information from the video, it will be deleted.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study but your transport and refreshment costs will be covered for each study visit. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

- You can contact Shayne at 083 262 9960 if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-650 1236 if you have any concerns or complaints that have not been adequately addressed by your researcher.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I ……..……. agree to take part in a research study entitled “Preventing musculoskeletal complications in children with severe cerebral palsy in South Africa : a home-based approach”.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2005.

..... **.....**

Signature of participant Signature of witness

Declaration by investigator

I *(name)* ……..…… declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2005.

..... **.....**

Signature of investigator Signature of witness

Declaration by interpreter

I *(name)* ……..…… declare that:

- I assisted the investigator (*name*) ……. to explain the information in this document to (*name of participant*) ……..…….. using the language medium of isiZulu.

- I encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) .....…..……. on (*date*) ……...……..

..... **.....**

Signature of interpreter Signature of witness

Appendix 3.5: Caregiver survey: Information questionnaire and Focus group discussion

Caregiver information sheet

Date:

#:

Please circle the most correct answer.

Personal	
Name of caregiver	
Dwelling type	Formal / informal / traditional
Main income source	Employment Grant(s) Family member None
Do you own a smart device or cellphone?	No/Yes
Highest education cert.	1° 2° 3°
Relationship to child	Parent /grandparent/relative/non-relative
Age of child with CP	0-3/ 4-7/ 8-12/ >12
Health information of child with CP	
Nearest CHC name	
Time by taxi/motor	5 – 30 min / 30 min – 1 hour / 1 – 1.5 hours min/ > 1.5 hours
Frequency of visits with doctor or RN (for child with CP)	Weekly/2 weekly/monthly/3 monthly/6 monthly/annually
Reason for visits	Meds check up health condition
Place of therapy	None CHC: Hospital:
Time by taxi/motor	5 – 30 min / 30 min – 1 hour / 1 – 1.5 hours min/ > 1.5 hours
Frequency of therapy How often?	Weekly/2 weekly/monthly/3 monthly/6 monthly/annually
Therapy time	30 min – 1 hour / 1 – 2 hours
No in session	Individual/group: 1-5/>5
Wheelchair or buggy?	No/Yes : Number:
Other equipment?	
Education or daycare	
Is there an option for your child to go?	No / Yes
Does child attend now? Have they ever attended before?	No/Yes No/Yes
If yes, frequency	Daily/ 2-3 x p week / 1-2 x per month

Delphi Round 1 Focus group discussion questions

Participation [explain]

Tell me about the activities your child can be part of during the day:

1. Where does your child spend most of the day?
   [bed/chair/sofa/wheelchair or buggy/other]
2. In which position do they spend most of the day?
   [lying on back/lying on side/sitting/other]
3. Which activities does your child do every day *with* the family?
   [eating/ watch TV/play/sit in lounge/sleep/other]
4. Which activities does your child regularly do outside the home, e.g., with friends?
   [play/shopping/school/religious/other]

*What activities do you know make your child happy, that you would like them to be able to do more?

Current daily program [explain]

If you attend or have attended therapy:

1. What have you been shown how to do?
2. Are you using the equipment provided? [No/Yes]
3. If not, why? [broken/old/not fitting/CG competence/other]
4. What challenges do you have with the program?
   [Child problem/equipment lack/CG competence/other]
5. Do you think the program is helping your child?
   [No/somewhat/Yes]

*What would you change about your current program?

Caregiver training [explain]

If we were to bring a program to help you to care for your child:

1. Which parts of daily care do you need training?
   [stretches/positioning/feeding/playing/bathing/dressing/
   stimulation/communication]
2. What equipment do you think you need for this?
   [Wheelchair/buggy/feeding chair/stander/positioning cushions/other]
3. Where would you like the training to take place?
   [hospital/CHC/home]
4. Who would need to be trained?
   [parent/other relative/CHW/RN]
5. How would you like it to be presented?
   [HCW presenting/ videos/ book with pictures]
6. Do you have a smart cellphone? E.g., WhattsApp [No/Yes]

*What would you say MUST be included in a home program training?

Appendix 4.1: Consent and Assent forms for Healthcare Professionals

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM – EXPERT PANEL

TITLE OF THE RESEARCH PROJECT:

INCREASING PARTICIPATION OPPORTUNITIES FOR CHILDREN WITH SEVERE CEREBRAL PALSY IN SOUTH AFRICA BY LIMITING MUSCULOSKELETAL COMPLICATIONS : A HOME-BASED APPROACH

PRINCIPAL INVESTIGATOR: Prof. Brenda Morrow
CONTACT Number: 0729094347
STUDENT INVESTIGATOR: Shayne van Aswegen
CONTACT NUMBER: 0832629960

I am registered for a Master's Degree in Maternal and Child Health at the University of Cape Town. I would like to invite you to take part in my research project as an expert panel member. Please take some time to read the information presented here, which will explain the details of this project. Please ask me any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research is about and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the University of Cape Town's Faculty of Health Science's Human Research Ethics Committee and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki (2013), South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?
Many parents and caregivers in South Africa, especially in more rural settings, have to care for children with severe cerebral palsy (CP) every day without proper training and support from health services. The resulting high rates of secondary complications often lead to pain, restrict activity and participation, and negatively impact caregiving. The aim of this research is to produce a consensus from CP experts in a variety of disciplines on how best to reduce musculoskeletal complications to help optimise participation in a South African setting, using a home-based program.

Why have you been invited to participate?
According to the research specifications, your expertise, experience and/or knowledge on the subject of CP management in public health in South Africa suggest that you will be able to make a meaningful contribution to the expert panel. We would greatly appreciate your expert contributions to developing this consensus paper.

What will your responsibilities be/ what will happen if you agree to take part?
Using a modified Delphi survey methodology, you will be asked to participate in at least 2 rounds of an electronic survey where you will rate your agreement with a set of statements

or recommendations, using a Likert scale. Your suggestions and comments will also be welcome. If there is lack of consensus after the first two rounds, a third and final round may be required which will take the form of a virtual discussion with online voting, using a platform like Zoom.

Will you benefit from taking part in this research?
You are unlikely to benefit directly from the research. You will instead be contributing to a strategy to improving the lives of these children and their caregivers. If this research is published, your authorship will be acknowledged, provided you manage to complete the required involvement and review the final manuscript.

Are there any risks involved in your taking part in this research?
There are no physical risks to yourself in taking part. Confidentiality requirements of POPIA will be adhered to during the survey so that participants and their survey responses cannot be identified by other participants. However, the virtual discussion will expose the group members to one another, and the researcher cannot guarantee that what you say will not be shared by others in the panel. As all members of the panel are health professionals, the HPCSA regulations require confidentiality.

Who will have access to your information?
The student researcher alone will have your personal details.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study but there will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

- You are welcome to contact Shayne at 083 262 9960 if you have any questions, need any clarifications or encounter any problems
- You can contact the Health Research Ethics Committee at 021-650 1236 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- **Clicking on the link to the survey below indicates your willingness to take part in this study (consent)**

By clicking on the link to the survey, you are declaring that:

- you have read this information and consent form and it is written in a language with which you are fluent and comfortable.
- you have had a chance to ask questions and all your questions have been adequately answered.
- you understand that taking part in this study is **voluntary** and you have not been pressurised to take part.
- You may choose to leave the study at any time and you will not be penalised or prejudiced in any way.

Appendix 4.2: Delphi Statements for Round 1

1. The importance of a home-based intervention program
    - In spite of the lack of accurate data about the numbers of children with severe CP in South Africa, a community-based program for the prevention of musculoskeletal complications is a priority.
    - Most colleagues with similar experience and expertise as myself would agree with the previous statement.
    - The benefits of limiting musculoskeletal complications to the child with CP and their family would be significant.
    - The benefits of limiting musculoskeletal complications in these children to the public health system would be significant.
    - Any undesirable or harmful effects of such an interventional program would be minimal.
    - The benefits of the program would probably outweigh any drawbacks such as cost of training and assistive equipment required.
    - There is high stakeholder agreement (between health professionals and the children or caregivers) on the importance of the program.
    - There is sufficient alignment of goals between health professionals and the children or caregivers on the content of the program.

2. The elements of the program
    - There is sufficient evidence to recommend the use of 24-hour Postural Management in the program to prevent musculoskeletal complications in severe CP.
    - 24-hour Postural Management must include all 3 basic positions, i.e., lying, sitting and standing.
    - The caregivers in a low-resourced setting will be able to perform 24-hour Postural Management if properly trained and supported.
    - Low-cost lying support (or a sleeping system) should be provided for infants with CP or at risk of CP from 6 months of age upwards.
    - For infants with CP or at risk of CP, low-cost seating with trunk support and hip abduction should be provided from 6 months of age upwards.
    - For infants with CP or at risk of CP, simple low-cost standers should be provided from the age of 9 months upwards.
    - There is sufficient evidence to recommend the use of Muscle Stretching in the intervention program
    - The caregivers in a low-resource setting will be able to perform safe and effective Stretching if properly trained and supported.
    - Where there is spasticity in the limbs, lower and upper limb splints for Sustained Stretching of the joints should be provided to prevent muscle contractures and support the joints in alignment.
    - Caregivers in low-resource settings will be able to use splinting devices effectively if properly trained.
    - The program should include strategies for Feeding and Bathing the child.
    - The program should include strategies for Communicating with the child.
    - The program must include basic stimulation and child development strategies using Music and Play.

3. The training of the caregivers
    - The training of the program should be provided at the community health centre to small groups of caregivers.
    - The training should be delivered by a team of therapists with at least 2 years' CP experience and expertise.

- The training should include theoretical instruction about CP and the principles of CP care.
- The training should also include practical demonstration of the techniques to be used, as well as equipment use, e.g., a stander.
- The training should use in-person instruction rather than video instruction.
- The training should provide an instruction manual with graphic illustrations for the caregiver to use as a reference.
- The training should provide a suggested daily schedule to help caregivers to integrate the program into an acceptable daily routine for the family.
- The training should provide suggestions for ways to help the child be included in family and community activities.
- Caregivers of infants as young as 6 months should be trained where CP has been diagnosed or there is a risk of CP.
- Community health workers need to be trained in the program so that they can support the caregivers and their children

4. The role of the multidisciplinary team
    - The medical officers and consultants running the paediatric clinics should identify and register children to monitor for possible program intervention based on perinatal risk factors.
    - Medical officers and/or consultant doctors should co-ordinate early referrals of children with suspected CP to therapists to implement training, and children with confirmed CP to relevant specialist services, e.g., orthopaedic.
    - Registered nursing sisters should perform specific neurodevelopmental screening at 4 - 6 months corrected age on all infants attending clinic, and create and maintain the local register for those children with developmental delay.
    - A registered nursing sister should co-ordinate training of caregivers and community health workers with visiting therapists at the local community health centre.
    - Registered nursing sisters should appoint a trained community health worker to work with and support the caregiver and child with CP in program implementation.
    - Community health workers should screen and refer children from the community who are not developing typically, to the designated clinic sister.
    - Therapists should oversee the training of the program, the initial program set up for the family and child around shared goals, and monitor and adapt the program as needed.
    - Therapists should monitor musculoskeletal status and progression of orthopaedic complications the children and should refer concerns to doctors at the paediatric or paediatric neurology clinics if needed.

5. The community health support structure
    - Basic postural management equipment (cushions, chairs, standers and splints) should be provided on loan from the community health centres.
    - Therapists should perform regular (e.g., quarterly) visits to the community health centres, and/or the homes to monitor the program performance and address concerns.
    - Community health workers should visit the homes monthly to check on the caregivers and children, and refer to the clinic if required.
    - A social worker should co-ordinate and promote community involvement and support of the child and family by helping to form liaisons between educators, caregivers, community health workers and religious leaders from the community.
    - A social media network such as a WhatsApp group should be established for caregivers with at least one community health worker, nursing sister or social worker included.

Appendix 4.3: Statements and comments for Rounds 1-3

Supplementary Table : Survey responses for Round 1

Answer ID	Agree %	Statement of consensus	Comments/ Suggestions
Section 1 - The importance of a Home-based Intervention program			
G00Q01	93.3	In spite of the lack of accurate data about the numbers of children with severe CP in South Africa, a community-based program for the prevention of musculoskeletal complications is a priority.	#7 The lack of all services to children with CP and their families should be a priority, CP is the leading cause of childhood disability and the lack of training in all undergrad medical and allied professions is astounding this together with an under resourced health system creates many issues in terms of health provision for these children. #8 There is limited access to facilities (hospitals and even clinics) for children with CP in many of the rural areas. Barriers include transport costs and time taken to travel. Furthermore, when a child reaches a facility, they are often not holistically assessed or managed by the primary managing professional (especially if this is a doctor), so the importance of referring for an intervention that could prevent further musculoskeletal problems is not prioritised. A community based programme that could find these children in need, and manage them as close to home as possible (ideally in the home) would be ideal. #16 Lack of financial resources to attend hospitals visits far from home #23 Information sharing is crucial especially to people living in rural areas.
G00Q02	100.0	Most colleagues with similar experience and expertise as myself would agree with the previous statement.	#7 It is a commonly discussed issue amongst my colleagues, the remedy is not often so clear- cut, and offers scope for more dialogue and discussion. . #17 Working in a rural setting will strongly influence a therapist to agree with the first statement
G00Q03	100.0	The benefits of limiting musculoskeletal complications to the child with CP and their family would be significant.	#7 But this would require more than a program just addressing the musculoskeletal components of CP, as there are many factors that contribute, from CVI, to malnutrition , pain , socioeconomic challenges as well as caregiver/family trauma/understanding etc. #16 Improve functional positioning and ease of care of patient #8 Access to skill and services to manage musculoskeletal problems in severe CP once they are established is extremely limited in my setting (e.g. Botox, tendon release, hip surgery); furthermore children with severe CP very often have co-morbidities that make surgery risky. These complications impact their quality of life, especially pain, hygiene (nappy changes) and the psychosocial/participation aspects. If the focus is on training primary care teams (caregivers/community health workers/primary healthcare staff) in preventative techniques and non-surgical interventions this could reduce the development of severe MSK complications that would increase their suffering. #22 Without a doubt. Notably with regards to caregiver burnout, improved participation, and transport/access.
G00Q04	93.3	The benefits of limiting musculoskeletal	#7 See above answers would need a concerted effort from all professionals involved and a CP registry would be the starting point

		complications in these children to the public health system would be significant.	#16 Children would still require serial follow up as per protocols but would limit surgical intervention #8 Related to the above answers... reduced need for tertiary type interventions (surgery) and the other complications that would require more visits to healthcare facilities (e.g. for pain control, or pressure care)
*G00Q05	64.2	Any undesirable or harmful effects of such an interventional program would be minimal.	#7 I feel that the risks of people only understanding the basics and then passing on the information could have many undesirable effects. Such as the harmful effects of passive movements which are still being used and encouraged by inexperienced therapists. #12 I would state "should" instead of "would". I would add: "The interventional program will include education of the caregivers and monitoring from therapists to detect difficulties and complications from the interventions (e.g. pressure sores from splints) #16 Aggressive positioning or may lead to an increase in fractures in osteopenic bone #10 The program should include CVI/vision, play, eating and drinking, communication etc. and not only musculoskeletal otherwise a "harm" could be that the family only focus on musculoskeletal complication prevention and it's a lost opportunity to address the other body systems/areas of development at the same time. However, this is not "harmful". #15 caregivers just need to be trained properly not to overstretch and handle and position the children. I have seen trained caregivers + midlevel workers work very well + safely with cp. Any minimal chance of harmful effects are outweighed by the overwhelming positive effects. #19 Would need further clarification on possibilities here. ie. Fractures? frequency may be low, however severity would be high.
G00Q06	92.8	The benefits of the program would probably outweigh any drawbacks such as cost of training and assistive equipment required.	#7 I do not know what the program would cost or what the assistive equipment would cost. According to the literature -in order to be effective this equipment would have to be reviewed and updated at least twice yearly by a qualified therapist. So am not sure how the program will run.
*G00Q07	80.0	There is high stakeholder agreement (between health professionals and the children or caregivers) on the importance of the program.	#7 Parents/Caregivers will often voice support for any intervention, as they are often so marginalized and would appreciate any assistance. #15 In your sample the moms are keen on training. Some moms in remote rural areas might not realise its importance, especially in older children with existing contractures. They might not realise the importance of preventing contractures from getting worse Most therapists have seen what happens when caregivers are not properly trained or when they do not follow the home programme #8 Much of the healthcare system is hospital/facility focused; despite the push towards care as close to home as possible (supported by the PHC re-engineering policy for example), the systems and infrastructure to support this not implemented to any significant degree. As a result, many health professionals find it difficult to adopt and support community based programmes as the health system does not support it. Some passionate health professionals have engaged effectively with NGOs to implement similar programmes, e.g. Manguzi Hospital

*G00Q08	60.0	There is sufficient alignment of goals between health professionals and the children or caregivers on the content of the program.	#7 i don't feel that I have enough information to support or disagree with this statement. #27 It is important because they need help from home, because it is very difficult to travel by taxis to get help. #12 There is some disagreement on who should provide this (nurses and community health care workers versus therapists) and on where it should be provided. I think the caregivers would find the Intervention's report agreeable. #16 There is a need for training in community with support from local health staff #21 The caregivers included other aspects besides the musculoskeletal complications including participation, socialization and communication. #15 caregivers don't mention splints caregivers put a lot of emphasis on improving communication, caregivers + health professionals emphasise function #17 Often the goals of the health professionals are not aligned with those of the caregiver and child. #23 I strongly feel that the Programme is needed to the the health facilities, coo unity care wokers and families.
G01Q39		Section comments:	#15 This is essential for caregivers to learn and implement. Support groups + home visits can help support them in doing this. Each caregiver should bring another person along to all trainings/ therapy sessions, to ensure 2 people in the household learn to support each other. #21 Besides the musculoskeletal component, the other important aspects would be improving participation of the caregivers in the care of their child and feeling empowered to assist their child. It would strengthen relationships between the caregivers and healthcare providers as the parents would be valued as members of the team, actively contributing to the child's wellbeing. Attachment and bonding would improve if the caregiver spends positive time together with the child. #16 District clinics could be utilised with out reach programmes by community service allied health staff
Section 2. The Elements of the program to be taught			
*G02Q09	86.6	There is sufficient evidence to recommend the use of 24-hour Postural Management in the program to prevent musculoskeletal complications in severe CP.	#12 I do not think there is sufficient evidence to state " to prevent musculoskeletal complications in severe CP" and would remove this phrase. This would imply preventing contractures or progressive hip subluxation. #15 We have seen it work well, but not in isolation. Splints, massage and stretches and trunk rotations are also needed together with this programme
*G02Q10	100.0	24-hour Postural Management must include all 3 basic positions, i.e., lying, sitting and standing.	#7 The positions must aid in activity or participation in order to be meaningful. #10 But hoping that the programme has more details with this: Lying should include supine, sidelying and prone (or modified prone if possible or no prone if not possible due to extent of contractures). Sitting should be sub-type of CP dependent ("opposite to what the body is always doing") so long sitting or sitting on wedge with pelvis in anterior tilt if child has spastic CP. Sitting with increased flexion if child is dystonic and pushing back. Sitting with weightbearing through arms for a child with choreoathetosis. And variety being key here- sitting in buggy, couch (and how to make that helpful), in bucket, on bench with

			caregiver, on floor with caregiver etc. Standing should include perched sitting if standing is not possible due to contractures or pain, sandwich standing, standing in standing frame etc. #15 also prone lying + alternate side lying #23 Basic therapeutic apparatus shall be included.
*G02Q28	100.0	The caregivers in a low-resourced setting will be able to perform 24-hour Postural Management if properly trained and supported.	#7 As long as they and their support team are sufficiently trained and supported on an ongoing basis. #8 Provided that the necessary equipment is supplied #15 There must be at least 2 people trained per household + caregiver must train every other older child and adult + neighbours/ friends to help her. #16 They may need support if primary parent due to the needs of other family members #22 They will definitely need to be supported, and provided with tools/ways to provide/create low cost equipment. Check-ins and adjustments as the child grows.
*G02Q11	86.6	Low-cost lying support (or a sleeping system) should be provided for infants with CP or at risk of CP from 6 months of age upwards.	#10 I have only seen a handful in rural but they were all not used. This could be lack of support or training. #15 I have no experience with this system #16 Diagnosis can only be made at age two but support for hip abduction should be encouraged #22 If caregivers are provided with 'sleep' support from early on - whilst it is more manageable with a younger smaller child - the carry over/routine and lifestyle of posture management is more likely to be sustainable.
*G02Q12	100.0	For infants with CP or at risk of CP, low-cost seating with trunk support and hip abduction should be provided from 6 months of age upwards.	#7 The degree of abduction would have to be carefully graded and monitored. The seating would have to be variable and consider activity and participation to promote development in all domains #16 Sitting support from 6 months is reasonable #23 CP chair is also highly recommended. #15 It depends on the GMF level and the tone. A very floppy baby with no head control will need some adaptations
*G02Q13	93.3	For infants with CP or at risk of CP, simple low-cost standers should be provided from the age of 9 months upwards.	#7 Feet position and orthotics would be essential in order to ensure correct alignment. #15 It depends on the child. Definently once they get older. A mom will be able to support a small, light child with not too much tone in standing easily #16 There maybe delayed milestones 18 months to 2 years more reasonable for standing support #10 Age wise though, 9 months may be a bit young. Personally, I have found it to work better from 15 months.
*G02Q14	66.6	There is sufficient evidence to recommend the use of Muscle Stretching in the intervention program	#7 I feel strongly that the word stretching together with any manual technique leads to passive movements. Which increase hypertonicity, cause joint pain and stiffness and are emotionally stressful for both child and caregiver. i would rather include low load, prolonged lengthening activities (including soft splinting) and movement within all activities of daily living. #10 Positional stretching- strongly agree. "Passive movement" type stretching- strongly disagree. In my courses, mentoring from advanced NDT tutors and my own experience, passive movements cause more harm and have no benefit. Usually on home visits, caregivers will show violent passive movements and the child will be in visible pain if you ask them to show you how they help their child. What I do is dependent on the subtype of CP. If the child is dystonic, then using off-centre/asymmetrical techniques for the child to let go. If child is spastic or has a different type of CP but has non- neural changes then I do rotation techniques

			proximally, and sustained stretching (in extension, abduction, external rotation) with rotation/rocking and then massage techniques (encouraging extension, abduction, external rotation) and the maintaining range gained with soft splinting/rolling towel around limb. #15 It seems from your research that there is a scarcity of research on stretches. From experience, physios will tell you that contractures develop/ develop worse where stretches haven't been done. Of course in combination with other interventions, such as reducing tone.
*G02Q29	80.0	The caregivers in a low-resource setting will be able to perform safe and effective Stretching if properly trained and supported.	#7 See answer above. #10 Postural stretching-yes. But if stretching is "intermittent stretching" which sounds like passive movements then strongly disagree #15 They need support to stretch effectively from the start. Some stop immediately when their child complains, as they are scared to hurt them. This is where support + teaching is necessary #8 Provided that the necessary equipment is supplied #22 Navigating stretching of severe hypertonicity has been a challenge for some caregivers – this has been in cases where contractures have begun and not from a 'preventive measures' perspective. Care givers are able to learn pain indicators quickly and therefore are able to perform safely. Effectively has been more of a challenge.
*G02Q15	93.3	Where there is spasticity in the limbs, lower and upper limb splints for Sustained Stretching of the joints should be provided to prevent muscle contractures and support the joints in alignment	#7 As long as the splinting is soft, well fitted, regularly reviewed and that the dosage has been carefully graded for each child's requirements from a musculoskeletal, sensory system, quality of life and participation point of view. #15 Also ask the doctor to prescribe medication to reduce tone #16 This should be patient specific - severe contractures will not benefit #21 The duration of the splinting must be clarified in the statement. #22 Splints have been an effective measure of reducing loss of AROM/PROM.
*G02Q40	100.0	Caregivers in low-resource settings will be able to use splinting devices effectively if properly trained.	#7 See above answer, there are many aspects to consider and the potential for harm is great. #8 Provided that the necessary equipment is supplied #22 Demonstrations, and step by step pictorial methods (personalised) of ensuring splints are fitted correctly and KPCs have assisted in seeing splints being worn correctly. #23 Maintaining of splinting devices training s also crucial.
*G02Q16	100.0	The program should include strategies for Feeding and Bathing the child.	#7 Each child would require a individual assessment for feeding as it is complicated and the potential for life-threatening harm is ever present. No global intervention could address the many complex needs safely. Bathing is a very good ADL for including movement and mobilizing strategies. #15 This is what caregivers indicated they needed in your sample, others would agree with it #16 All aspects of daily living should be included on #22 I think program strategies/techniques would need to be trial run and adapted/personalised.
*G02Q17	100.0	The program should include strategies for Communicating with the child.	#7 This would be a great starting point for the implementation of the program. Can the child tolerate the intervention? Is the intervention assisting them to use their strongest systems? Is it helping the child interact with their surroundings and family in a more efficient way? how is the child communicating these aspects? Can the caregiver receive and interpret these

			communication signals. #16 Communication devices / apps are under utilized in South Africa #22 To facilitate natural family participation, engagement where possible. #15 Yes, your sample indicated this need. I think our CP mothers would agree. All aspects of CP need to be addressed, while also addressing prevention of musculo-skeletal complications. Communication strategies can be practised when stretching, when doing trunk rotations, when applying splints, when in a standing frame etc.
*G02Q18	93.3	The program must include basic stimulation and child development strategies using Music and Play.	#7 this would have to be individualized for each child, according to their level of function, their strongest systems, and their age and interests. #21 Play is how a child learns and masters new skills and so is essential for development. Children with physical challenges must not be deprived of having fun and participating in activities. #15 Play and use music/ singing when being positioned. Positioning must always be combined with some stimulation #22 Giving the caregiver tools to interact and build relationship is so vital to improving their confidence to care for their own child.
G02Q39		General section comments	#8 Does the use of 24hr positioning and muscle stretching have the same/similar impact when used alone (without pharmacological intervention) compared to using it alongside drug therapy? #15 Include how a buggy/ wheelchair/ standing frame works and how to prepare the child's body and position him well in a device. Even in a low resourced environment cp children need buggies, they are so good for positioning e.g. for feeding + play #21 All aspects of the child's development will improve if the child has improved posture. #10 Programme should also include drinking safely. And vision/cerebral visual impairment (CVI). CVI is very common in children with GMFCS 4/5. Vision also affects posture (for example, child may have head permanently to one side because of vision being affected more on one side or be pushing back/neck extension due to upper visual field involvement. Vision also affects communication and play as well as feeding. #16 Whilst there can be guidelines - it should also be divided by the gmfcs when over 2 years old . There should be autonomy to adjust programme according to severity of Cp
Section 3. The training of the Caregivers			
*G03Q19	80.0	The training of the program should be provided at the community health centre to small groups of caregivers.	#7 The training would have to be adapted according to each groups level of understanding as well as previous experience. On going support and evaluation would be required #8 As close to the home as possible, with easy access #27 But not small groups of caregivers - big groups of caregivers. #15 This is what your sample requested. This would work well if there are enough therapists. There other models: 1. A training course for caregivers and children at a centre/ NGO. They would stay there for 1 - 2 weeks. Malamulele Onwards does this very successfully 2. A training course of parent facilitators (parents of children with CP) who then run training worshops for other parents. See what is done at Malamulele Onwards 3. Doing the training at the local hospital with groups of

			caregivers and their children. (A thought: We haven't started doing group therapy sessions again in our cp clinic since Covid. We now have different comserves. It takes so much effort to get things going again...) #16 Also builds social support networks for caregivers who attend at the same time #19 ? there are simply too many challenges in patients and care givers reaching the resouce centre consistently. However cost of an out reach would be significantly higher. #22 Would it be possible to initiate training this way, and then move to training in home visits where feasible? #10 It will be beneficial from a transport perspective for caregivers but space at CHC will need to be obtained. #21 The training could also be done effectively in the child's home environment. This would enable the health care provider to see the challenges the child encounters in their home environment i.e. uneven floor, steps, bathroom facilities. The environmental context of the child is important. Hihopes is an organisation for hearing impaired children and they have effectively provided home based caregiver education sessions across SA.
*G03Q20	73.3	The training should be delivered by a team of therapists with at least 2 years' CP experience and expertise.	#7 It would be beneficial if the the therapists had some experience or training in adult education or training. #10 I agree about a therapist having CP experience but also CP training- that they have attended a Malamulele Onward Intro course (which is specific on rural CP in South Africa) or a SANDTA course so that they have practical CP skills and knowledge because university knowledge on CP is not enough in my opinion to be running this training. #16 It should be delivered by someone trained #17 The majority of the therapists involved should be NDT trained #21 The trainer should be experienced in CP care and management. Translators are highly recommended when conducting the training. #8 To consider training "expert" CHWs and parents who could potentially continue training with others in the community, so as to increase the reach of the training and sustainability. Example of Malamulele Onward model of parent-facilitators #15 Other lay people, like trained parent facilitators or trained DPSA field workers, can also be involved. It can be less that 1 years' experience, depending on the person's intensity of experience and interest. #22 Whilst this would be ideal - the demand to the therapist ratio would make this impractical as far as I have been exposed.
*G03Q21	100.0	The training should include theoretical instruction about CP and the principles of CP care.	#7 This would have to be carefully thought out to be specific enough to be meaningful but broad enough to include the complexity of CP . The F word article by Can Child team could be a starting point from which to build this aspect of the program. #17 Important is to develope an understanding that CP is a lifelong condition #15 Yes, some theory is needed, but make sure there is practical in each session. Please look at the content of the Malamulele Onward parent facilitator workshops. They are structured very well. The first session is on what is CP and the GMF(sic) classification. Caregivers then classify their own children. This is important to help the caregiver understand what can be expected of her child if at a specific level.

			#21 The theoretical information must be at the level that the caregiver understands. Information empowers the family as they better understand their child,
*G03Q23	100.0	The training should also include practical demonstration of the techniques to be used, as well as equipment use, e.g., a stander.	#7 Would be very beneficial to have the children and equipment present and to try it out together. To discuss what is working and what not? What is aiding function,? Can the child tolerate it? etc. Because the gap between theory and practice is immense and all hypothesis need to be tested. #16 Demonstration as well as training caregiver with child #10 Practical demonstration on the children with CP who will be using the equipment because putting children into standing frames is very different depending what type of CP they have but also the child and caregiver's body proportions makes the process a bit different for every pair.
*G03Q22	93.3	The training should use in-person instruction rather than video instruction.	#8 This will allow the asking of questions and trouble-shooting issues #27 training should use both person and video instruction #12 A most caregivers have a smartphone, instructional videos may be useful. I know the caregivers stated in-person rather than video, but as an adjunct to in-person instruction it may have value. #16 Video support should be available online for caregivers to revise when necessary #15 If possible. Language is also a barrier and can be overcome during in-person training and opportunity for questions.
*G03Q24	93.3	The training should provide an instruction manual with graphic illustrations for the caregiver to use as a reference.	#7 A manual could be helpful but a contact person to discuss issues with would be more beneficial. With a chain of support depending on the issue. #16 If caregivers have smart phones an app or online website maybe more appropriate #21Will there be different languages used in the manual or will there be translators available? #22 Step by Step pictures for each position/application would be helpful.
*G03Q25	93.3	The training should provide a suggested daily schedule to help caregivers to integrate the program into an acceptable daily routine for the family.	#7 To be discussed with each family according to their resources , challenges and needs. and implemented accordingly #10 Every caregiver's life and home situation are very different. Perhaps more helpful and realistic is for caregiver's to develop their own schedules during the training based on their own situation. #15 But it needs to be modified for each child #21 The program must be feasible for the family to implement otherwise it will fail. #8 This would be really helpful, especially if there is instability in the home or change of caregivers.
*G03Q26	100.0	The training should provide suggestions for ways to help the child be included in family and community activities.	#15 It will prevent child and caregiver isolation and will help the caregiver get some practical help from the community #21 Absolutely See the CanChild - Fwords that use the basics of the ICF!!
*G03Q27	92.8	Caregivers of infants as young as 6 months should be trained where CP has been diagnosed or there is a risk of CP.	#8 Earlier awareness and interventions will improve long term outcomes, and also allow caregivers to adjust to the diagnosis of and expectations for their child, and make the necessary changes to the home and lifestyle #15 The younger, the better #21 Early intervention is key #10 I do agree that all caregivers should receive the training. However, caregivers of babies/toddlers with CP

			are new on their journey with the condition and while we want to prepare them for the future (and being around caregivers further on their journey is sometimes helpful), we also do not want them to "lose hope" or to get overwhelmed when exposed to teenagers with CP for example. Perhaps a separate training among babies and toddlers with CP where the content is the same but they interact with other caregivers of children similar ages? #16 Cp is not usually formally diagnosed till after age 2 , but if there is a risk or suggestion of Cp they should be trained
G04Q30	100.0	Community health workers need to be trained in the program so that they can support the caregivers and their children	#10 Potentially NPO caregivers as well as they also do home visits and support mothers of children with disabilities (such as Malamulele Onward Parent Facilitators who have children with CP themselves and are trained to run 5 workshops and do home visits (they are based in 17 sites in SA) or mentor mothers? #16 Local support is important #15 They are a useful resource that can be used more. In Tzaneen we did a very basic rehab training for a group of community health workers, followed by practicals in the homes of people with disabilities in their communities, supported by the clinic nurses and occasional visits from the therapists who taught them. This was quite successful.
G03Q40		General comments and suggested additions	#7 Caregiver training is an ongoing process and needs constant adjustment and input in order to be effective. The support for the health workers as well as the caregivers needs to be in the form of open conversation with frequent times for reflection and learning. The training cannot occur in a once off vacuum format as this has proved to be very ineffectual and often leads to misunderstandings and poor implementation, often with harmful effects. #10 CP is a complex condition and therapists should have CP training after university to be able to run the training. This article explains further: https://journals.co.za/doi/abs/10.4102/ajod.v9i0.610 #16 Care giver training must be provided either in first language of caregivers or with a translator
Section 4. The roles of the multidisciplinary team in service delivery			
*G05Q42	92.3	The medical officers and consultants running the paediatric clinics should identify and register children to monitor for possible program intervention based on perinatal risk factors.	#8 Identification of high risk children should begin at discharge from the neonatal unit (if applicable), with clear guidelines as to who should be seen in the high-risk follow-up clinic. More training is needed amongst doctors to apply screening tools that can predict and detect early signs of CP, especially in the setting of very limited and late neuro-imaging . A user- friendly, easy to learn and reproducible tool would be best. Example is the Infant Neuromotor Assessment used in the Cape Town hospitals. Systems need to be put in place to allow easy access to the MDT, including registration for the this programme, is necessary. Lack of communication, infrastructural issues, and lack of awareness of the value of the non-medical teams are barriers. #15 Even nurses from paeds clinic can refer suspected CP/ developmental delay #16 Registry would be needed or on ehealth system an alert for conditions #17 There shoukd be a data base of all CP / at risk babies #22 Absolutely. Most CP cases caregivers may have been aware of difficulties at birth but had no counselling/awareness of the possible risk factors

			and/or CP. #12 Training should extend to the medical officers working at district hospitals (not necessarily in a paediatric department, but taking care of children), as well as those working in the paediatric departments at regional and tertiary hospitals. #21 Some infants following up at the primary care clinic may be missed if it's just medical doctors referring the high-risk infants.
*G05Q44	85.7	Medical officers and/or consultant doctors should co-ordinate early referrals of children with suspected CP to therapists to implement training, and children with confirmed CP to relevant specialist services, e.g., orthopaedic.	#8 Given the above comments about lack of awareness and training amongst doctors themselves, we do need to consider whether therapists (who may be better trained in neurodevelopmental assessment, and more used to the MDT approach) could be equally responsible in referring high risk children to doctors and coordinating their care #15 But not only doctors: Everyone can refer these children for therapy: community members, DPSA field workers, CHWs, creche teachers, nurses #16 Once risk or diagnosis identified - child should be referred to all allied health services #21 The statement isn't clear. The children's caregivers with confirmed CP should also be referred for the training. #12 See previous comment. A deficiency of the MDT in CP is that there is no clear leader (or coordinator), and the referring doctor from the district hospital often fulfills this role poorly. Often these children are only referred to Orthopaedics, and not to Paeds neurology, speech therapy, occupational therapy, physiotherapy, etc..)
*G05Q43	86.6	Registered nursing sisters should perform specific neurodevelopmental screening at 4 - 6 months corrected age on all infants attending clinic, and create and maintain the local register for those children with developmental delay.	#8 This is so important as they are the first contacts for many children; the milestone chart in the Road to Health can be used. #12 and refer these children to a specialist paediatrician for neurological assessment #16 With staff shortages , this maybe ideal but difficult to put into practise - should be done at all vaccination visits #10 Nurses should be doing the developmental screening within the Road to Health Booklet and referring based on these results. Specific neurodevelopmental screening by a nurse may not be with workload realities or within scope but the RTHB screening is already within scope. Referrals based on results of these or any parent concern can then be made. #15 They have to screen in any case (see road to health booklet). I'm not sure if they have a register, but this is a good idea. They should refer each of these children for OT/ PT/ ST #17 Early identification and early intervention with CP children is critical in preventing secondary complications
*G05Q45	73.3	A registered nursing sister should co-ordinate training of caregivers and community health workers with visiting therapists at the local community health centre.	#8 I think this could also be a community-based rehab worker #15 I think it is better if the therapists organise it and co-ordinate it with the help of the parent facilitators, clinic sisters, community health workers + strong leaders among the mothers of CP children, etc. #16 Coordination of training can be done by the nurse but training should be done by therapists #10 The rotation of nurses within a CHC/clinic may make this unfeasible and if the clinic is very busy, then this would also be unrealistic from a workload perspective. The WBOT team leader could co-ordinate the training or potentially a therapist?

*G05Q46	73.3	Registered nursing sisters should appoint a trained community health worker to work with and support the caregiver and child with CP in program implementation.	#7 the community health worker should receive support from the nursing sister who should be supported by the therapists. #10 Ratio of CHW to population is different country wide. If this is possible then it will be great. This could work. they could do weekly home visits. The caregiver will also need some therapy input/ home visits/ visits to CP clinic a the hospital and ere te CHW could make sure they attend and attend some sessions with them as well. #25 Therapiats acan also a point people wh they think can work well wifh CP patients #16 Community health workers should be trained by the allied health workers , nursing sisters may not have authority to appoint staff - this should be coordinated at a district level
G05Q47	100.0	Community health workers should screen and refer children from the community who are not developing typically, to the designated clinic sister.	#10 They could screen using the developmental screening within the RTHB severe CP would fail the screening and present with red flags as well. #15 Yes, and also refer the child to the ST/ OT/ PT outreach team when they visit the clinic or to the therapy departments at the hospital.
*G05Q48	86.6	Therapists should oversee the training of the program, the initial program set up for the family and child around shared goals, and monitor and adapt the program as needed.	#15 ? "the training of the programme" ? #16 There must still be patient specific goals and treatment #22 Whilst I agree with this in principal - therapists in our district are extremely limited. Especially at clinic level.
*G05Q49	93.3	Therapists should monitor musculoskeletal status and progression of orthopaedic complications the children and should refer concerns to doctors at the paediatric or paediatric neurology clinics if needed.	#12 Diagnosis of CP, identifying the cause, and the treatment and monitoring of neurological complications should be provided to paediatric or paediatric neurology clinics prior to the development of orthopaedic complications. Once orthopaedic complications develop the child should be referred to orthopaedics and paediatrics. #21 Words appears to be missing from the statement. should say '... the musculoskeletal status and progression of orthopedic complications of the children' #15 I think you left out a word: "orthopaedic complications of the children" I wish we had paediatric neurology clinics to refer to.
G04Q49		General comments and suggestions	#15 Involve OTs and STs in the training as well #16 The therapists would need to lead this service
5. The Community health support structure			
*G04Q32	93.3	Basic postural management equipment (cushions, chairs, standers and splints) should be provided on loan	#15 It is better to get an NGO to make APT chairs or standing frames and to sell a low cost to patients. Then patients take ownership. Therapists at the local hospital can co-ordinate the measurements, orders, collection and fitting of devices. In our hospital OT organises the APT chairs and PT the standing frames. If someone cannot afford a device, we try find a donor. One cannot have splints for general use at a clinic: Each splint

		from the community health centres.	needs to be custom made. OTs make the hand splints, and for leg splints we refer to the orthopaedic workshop. #21 Paper based technology for seating and positioning devices is an economic alternative that would then be the family's to keep.
*G04Q33	93.3	Therapists should perform regular (e.g., quarterly) visits to the community health centres, and/or the homes to monitor the program performance and address concerns.	#12 More frequent visits (monthly) will be required, especially initially. #15 They can be assisted by CHWs, parent facilitators, DPSA field workers etc. #16 Ensuring the programme is working , equipment provided is appropriate and surveying for unexpected problems #17 Home visits are critical to understand the challenges experienced by the caregiver in their home context
*G04Q35	93.3	Community health workers should visit the homes monthly to check on the caregivers and children, and refer to the clinic if required.	#15 They can be helped by parent facilitator, DPSA field workers, DOT supporters etc. They need to refer problems observed to the therapists. #16 Visits could be according to gmfcs - milder cases May only require 3 monthly visit
*G05Q50	92.8	A social worker should co-ordinate and promote community involvement and support of the child and family by helping to form liaisons between educators, caregivers, community health workers and religious leaders from the community.	#10 Or a Social Auxiliary Worker #15 Not only the social worker. The caregiver and family must be empowered to take the lead. They need to have the courage to take their child places. CP caregivers need regular support groups to encourage each other to do this. DPSA field workers are a great help in this regard. #22 Stigma from community is one of the main barriers faced when trying to gain access to resources due to community beliefs. A large part of my scope is communicating and providing feedback to community to facilitate acceptance and action to take steps that are best for the child. This is a huge part of the treatment process. I wonder if a social worker is the ideal candidate realistically due to the nature of their immense workload with other social ills?
*G04Q36	71.4	A social media network such as a WhatsApp group should be established for caregivers with at least one community health worker, nursing sister or social worker included.	#8 it would be ideal if the caregivers in this group could build a relationship in person with each other prior to creating a virtual group, e.g. during in person rehab group sessions #10 Or a therapist on the Whatsapp group to also address any technical aspects? #12 I am not sure about the confidentiality of the WhatsApp platform, this needs to be investigated. In terms of the members: the CHW should have a group of the patients they are supervising, and the RN and Therapist should have a group with the CHW they are supervising. #16 Personal phones should not be encouraged to be used - abuse of this maybe seen out of working hours . A helpline contact or an app such as vula maybe better utilized . #15 Good idea for your sample, or where people have smart phones. In our area not everyone has whatsapp or data/ electricity. It often is the grannys looking after the kids (not so good with technology as well). Physical support group meetings are great, We have cp support groups in our rehab unit one morning every 2 months. We help the moms elect a committee and then draw up a programme for the year. We thrn get speakers for the topcs they have chosen and facilitate the running of the

			group, provide tea etc. #21 This may be suitable for some families but network issues, available minutes/data and confidentiality issues should be addressed.
G04Q41		General comments or suggested additions	#16 Parent support groups should also be encouraged #23 Bathing and feeding would be highly recommended as part of the training as well.

Supplementary Table: Survey responses for Round 2

Answer ID	Agree %	Statement	Comments/ Suggestions
Section 1 - The importance of a Home-based Intervention program			
G00Q05	78.5	If the program includes education of caregivers, careful instruction and demonstration of evidence-based interventions, and is then regularly monitored by trained therapists, any undesirable or harmful effects of such an interventional program should be minimal.	#14 If the program is closely monitored there should be no risk of harm to the child #20 I believe that there will be no harm to the child ad the family. #16 Each child with CP will have variable factors putting them at risk but in principle there dhoukd be no harmful effects
G00Q07	92.8	There is generally high stakeholder agreement (between health professionals and the children or caregivers) on the importance of the program, but the program may need to be properly promoted in more remote settings.	#8 Think need to do promotion and education first to establish needs of caregivers more comprehensively and importance of program to them #12 Although there may be strong agreement about the importance of the program between HCPs and caregivers, I am concerned that the program will have to overcome many health system challenges to be successfully implemented... Examples - lack of trained HCWs (numbers and skill), physical access to healthcare, lack of space to run the training, lack of equipment, ongoiing monitoring of what has been taught and ongoing support etc. Perhaps more guidelines/tips for the HCPs on how to overcome these challenges in rural settings can be included in the programme #20 I agree that Programme like this is highly needed. #11 It needs to be promoted in all settings, not only remote rural. People in cities may also not be aware of the importance of a home exercise programme to prevent musculoskeletal problems in CP.
G00Q08	85.7	The program's emphasis on maintaining musculoskeletal integrity and the caregivers' goals of having their child participate more in family and social spheres would align sufficiently for the	#8 need to address other systems involved depending on child #16 Yes the 2 goals align but it has to be acknowledged that there can be compromise on body structure/ positioning to achieve function and participation in an activity #11 It depends on how it is taught. It would

		program to be acceptable to all stakeholders.	align if functional examples and reasons for the programme are given throughout.
G01Q39		General comments/suggestions	#18 in remote settings - the correlation between disability and belief of shame on the family is high. Partnering with the chiefs, councillors etc to explain the program being rolled out will have a massive impact on the views of disability. We've had great success in explaining in simple parent meetings/councillor meetings why special needs intervention at an early age is important. Its changed from refusing consent for assessments to requesting assessments - setting up simple community meetings in the areas the program is being implemented may go a long way to promoting child participation in social spheres, thereby increasing the success of the program. Communicating the program at a community level could have a powerful effect on the success of the program. #20 Home base Programme is highly recommended. Every home is unique therefore families will adapt and utilize the Programme at their best. #17 Caregivers should have a manual in the language of their choice to refer to when at home setting for reference - either electronic or printed
Section 2. The elements of the program			
G02Q10	85.7	24-hour Postural Management must include all 3 basic positions, i.e., lying, sitting and standing over the period of a night and day, and includes varieties within those 3 basic positions in order to protect the musculoskeletal system, maintain flexibility and provide supportive positioning for function.	#14 We should aim for 24 hours but this is obviously not without challenges practically. #16 Not certain of postural management in standing always being possible as in severe CP
G02Q44	100.0	From the age of 2 years, children with non-ambulant CP, classified as GMFCS level III to V, the 24-hour Postural management regime should include lying support, supported seating with trunk control and hip abduction (total maximum of 60°) for a total of 4-6 hours per day, and supported standing for 30 - 90 minutes per day.	
G02Q45	100.0	Infants between 6 months and 2 years of corrected age who are diagnosed with CP or at high risk of CP can begin a modified 24-hour postural management that includes lying support, supported seating from 6 months for 2 to 4 hours per day, and gradually	#11 Whether supported standing is done by the caregiver holding the child or with the use of a standing frame shouldn' t depend only on the age. It also depends on how heavy the child is, how strong the mom is and other individual factors. How standing can best be achieved needs to be assessed for each child individually.

		increasing periods of supported standing from 9 months of age e.g., 10 minutes at a time up to 30 minutes, supported by the caregiver.	#17 Time and increase in positions Needs to be adapted to each individual child
G02Q11	85.7	Low-cost lying support (or a sleeping system) should be provided for infants with CP or at risk of CP from 6 months of age upwards.	#10 There is insufficient evidence that sleeping systems can alter the natural history of postural asymmetry in CP. See PMID: 26524348 #11 It sounds good, but I don't have experience with such a system. Thanks for the links, but I cannot access them while busy doing the survey. Please can you send us all the links in this round in a separate email.
G02Q13	78.5	For infants with CP or at risk of CP, simple low-cost standers should be provided from the age of 2 years and upwards. Prior to this, the child can stand with caregiver support.	#11 One can start earlier, then the child gets used to a standing frame and accepts it easily. It depends on how heavy the child is, how strong the granny/ mom are etc. #16 Standers must be used only if good alignment can be achieved #14 I would recommend that 2 years is too late and the child should be encouraged to stand earlier than this. If they are relying on the caregiver being available to assist with the standing position it will limit the time spent in standing which is essential for bone density and cognitive stimulation.
G02Q14	78.5	There is sufficient evidence to recommend the use of Muscle Stretching, preferably sustained or positional stretching, in the intervention program for prevention of musculoskeletal complications such as contractures.	#8 I think manual (intermittent) stretching should altogether be discouraged and we need to find another word for the positional lengthening we promote and the movement in ADLs we encourage. #12 Answering as a non-therapost... from the others responses and the literature it seems the consensus is passive stretching is totally out and can be harmful, and that sustained/positional stretching is the correct way. Considering that the practice of passive stretching may still be widespread, its important to define stretching; and positional stretching promoted. This will impact on equipment needs... #14 Stretching should be defined. #16 Defnitely no quick repeated passive movements or stretching should be done. So defnitely to explain the difference. Rather prolonged slow stretching using varied body/limb positions with body weight being used #17 Cost implications for device and replacement as child grows . This is for prevention but Severe established contractures will not benefit #20 Demonstration, manual and divices should be utilized. #11 Yes, we need to define stretching and distinguish it from passive movements Yes, there is a place for stretching in a prevention programme for low-resource areas. Types: 1. Use 30 s or longer stretch after tone reducing methods, e.g. trunk rotations 2. use positional stretching with weight bearing 3. use stretches provided by a splint, which is applied after tone reducing techniques, e.g. trunk rotations

			No, manual intermittent stretching should not be discarded. Both are needed. Children do need splints. #18 I do tend to agree that passive stretching can be difficult to teach safely and effectively, especially in the cases of sever hypertonicity. In these cases, could "preparation stretches" (hoovering, gentle shaking etc) be taught instead to assist with getting into positions (Standing, sitting etc) So using stretching principles for the sake of positioning, not for stretches? I agree in terms of "sustained positional stretching". #19 Thank you for the changes already made here, however, I am still not comfortable with "preferably" as it still allows passive movements. How about "muscle stretching (defined as sustained or positional stretching that does not include passive movements)"?
G02Q50	71.4	Sustained stretching using a resting splint or positional device (e.g., a stander) should be carried out for a minimum of 90 minutes for joint range maintenance and for up to 5 hours per day to improve joint range.	#11 Standing frame use recommendations are usually 1 hour a day. We have found that if children are left in the standing frame for too long, it can become tiring/ painful. Some children tolerate 30 min twice a day better. I don't have experience with how long resting splints are to be worn. #15 Patient Dependent, not all tolerate the 90minutes #16 The prescription of time is difficult as each child will have different yolerance #17 Severe deformities and established contractures may not benefit from splinting
G02Q51	66.6	Slow and controlled manual stretching can be carried out for 40 - 60 seconds, 3 to 5 times per joint as needed, especially where 24-hour postural management and/or sustained stretching is not possible.	#11 If tone reducing techniques are done first #12 Agree if this has been shown to have benefit (more than passive stretching/no stretching) #19 I would prefer sustained, prolonged stretches at end of range (using soft splints or resting splints or rolled towels) rather than stretching 5 times because between each "set" you are losing what you have gained in range with the techniques. If I can get literature link on this I may be willing to change my vote, but from experience, I would rather do one sustained stretch after loosening techniques if child has spastic CP and off-centre handling techniques to help a child with dystonic CP relax/let-go rather than forcing symmetrical stretching regime. If a child has choreo-athetosis CP, then this level of stretching would not be necessary.
G02Q29	73.3	If properly trained in the techniques and principles of Stretching and with the oversight of trained Community health workers, the caregivers in a low-resource setting will be able to perform safe and effective stretches on their child.	#11 oversight can also be via trained nurses, trained parent facilitators etc. #19 Depending on the sub-type of CP, different techniques would be needed. If stretching is appropriate for that child, then stretching technique should be one sustained stretch so to "maintain what we have gained" in range. #18 If CHW's are able to be well taught in recognising increased tone, child body language and the ratio of CHW's to clients is feasible to have regular check ins.

G02Q15	92.8	Where there is spasticity but no severe joint contractions in the limbs, appropriate lower and upper limb splints for Sustained Stretching of the joints should be provided to prevent muscle contractures and support the joints in alignment.	#8 As long as they do not limit activity or participation and are easily tolerated. dosage/ training/ regular review #12 Progression of splinting individulaised for the child, with adequate pain control and with muscle relaxants on board #16 Resting night splints are important #10 The term “no severe joint contracture” is unclear. It would be better to state that there is no fixed contracture, and that appropriate splints (omit sustained stretching) should be provided to prevent contractures and support joints in alignment.
G02Q40	93.3	Caregivers in low-resource settings will be able to use splinting devices effectively if properly trained and have regular oversight from trained Community health workers.	#11 Oversight can also be via trained nurses or trained parent facilitators. With splint regular checking by an OT or orthotists (the profession who made the splint) is also needed. #17 Prevention of pressure sores must be covered #18 We've had success with videos and step by step pictures of each step and sequence of donning the splits correctly. As well as recognising warning signs to discontinue splint use. #20 Schedule or time table should be provided where the caregiver and the Community health care worker will be keeping track of compliance records
G02Q52	86.6	Since the program is aimed at Gross Motor Function Classification System levels IV and V, and GMFCS levels are only fully determined at the age of 2 years, children should be re-assessed at age 2 and adaptations made to their program according to need.	#11 Not only at age 2. They should be re-assessed regularly, e.g. every 6 months #19 There is a "before 2nd birthday" section on the GMFCS , but I do understand depending on an 8 month vs 23 month old there may be differences within this. GMFCS level III children will still benefit from standing frame/seating to prevent contractures and deformities despite self-propelling or using a rollator, but I do understand the priority to non-ambulent children.
G02Q39		General comments/suggestions	#12 Possibly look at the contribution of medication when combined with stretching - is it always necessary?
3. The training of the program			
G03Q19	80.0	The initial training of the program should be provided at the community health centre or other community centre such as the Tribal court to small groups of caregivers. It should be followed up by home visits done by therapists to further customise the program for the child.	#8 The children should be with the caregivers for practical training and problem solving #12 What are the practicalities of securing the site? Mention the other stakeholders (i.e. community elders, councillors etc) who need to be involved, and the practicalities of this for the trainer. #11 Any venue that can be reached by the caregivers, it could also be at a stimulation centre, a church hall, a clinic #17 Home visits are ideal but not practical for the numbers of Cp we see. Group and individual sessions should be considered
G03Q20	93.3	Since techniques such as feeding and drinking, postural management, stretching and splinting require skill to perform safely and effectively, it would	#8 maybe each therapy team needs at least one NDT trained therapist #14 The initial training session should be done by NDT trained therapists. Community health care workers should be part of the training sessions so that they can assist

		then follow that trained therapists (physio-, speech and occupational therapists where available) should deliver the initial instruction and demonstration at least of these interventions.	with the home visits and be the bridge between the families and the NDT trained therapist. If the NDT trained therapists cannot be at the initial training session, then there should be a media player that has prerecorded videos demonstrating the skills to the families. These MUST be in the language that the community is comfortable with. The local clinic nurses and community health care workers should be present at the initial training session to provide the families with demonstrations of the skills seen in the video and to answer questions. The NDT therapist could be available online/virtually to answer questions that arise during the training. There may be a role of telecommunication if the community has access to a smart device and internet. WhatsApp support groups may play a role. #11 It would be great if all the trainers were NDT trained or had attended a CP course, such as the Malamulele Onwards course for therapists. This is not realstic. Therapist with experience with or interest in CP or enthusiasm for teaching can also be used. NDT trained/ CP skilled therapists could also teach other therapists to become instructors. Skilled parent facilitators can be of great help. The need for CP intervention is so great that we cannot use the excuse that we haven't specialised in CP as a reason for not helping caregivers with training. We need to share our knowledge of CP , even if it is just from undergraduate training with caregivers. it will help them greatly. #16 In the absence of a full team of therapists, therapists can train caregivers of CP children to train other caregivers, as in the Malamulele carer to carer programme. Therapists can give oversight in the initial stages of the training
G03Q44	86.6	Since many of the therapists that work in these areas will be newly graduated, and therefore not experienced in CP care, the program should either be included in undergraduate therapy training or offered to all new Community service therapists as a complete tool, together with a module on adult education.	#8 Think it would be invaluable to offer the training to community service therapists #11 Good idea #16 New graduates are out of their depth as far as GMFCS 4+5 so they defnitely need the tools to implement any effective program #18 This would be brilliant if possible to establish. #17 Training should be from undergraduate , especially as medicolegal cases may be treated in state setting #19 Week long CP courses are available for newly graduated therapists (such as Malamulele Onward or SANDTA) that would give therapists suffiecient background in CP to implement the training but also cover content such as handling techniques for the different types of CP and more holistic treatments such as CVI and its effect on postural management. Therapists having this foundation to individualise certain elements for children as well as the specific program would be a good combination.

G03Q23	93.3	The training should include practical demonstration of the techniques to be used, as well as equipment use, with the child and usual caregiver present. Caregivers should also be encouraged to bring one other adult from the household or area to be trained who would then be able to relieve them when needed.	#14 Handouts with pictures demonstrating the techniques to be used could be given so that the family can refer back to them with ease.
G03Q22	93.3	The training should mainly use in-person instruction, with a community health worker present to translate if needed. Instructional videos can be provided in different languages for caregivers to use as a reference.	#11 The community health worker should not only translate, but practically learn the techniques together with the caregiver #14 The local clinic nurses should also be involved. #16 Home language translation is essential so translators are important but must be trained in correct terminology
G03Q25	100.0	The training should provide suggestions for the daily schedule to help caregivers to integrate the program into an acceptable daily routine for the family. The development of the daily schedule can be incorporated into the training so that it can be individualised.	
G03Q27	86.6	Caregivers of infants as young as 6 months should be trained where CP has been diagnosed or there is a risk of CP especially where the child is presenting with abnormal muscle tone.	#11 Even younger #18 Parents who have been educated on possible risk factors are more observant as well as accepting of later diagnosis - and motivated to implement interventions presented to them . #12 Agree with a previous comment - to cohort the younger age group as the CP is still evolving and outcomes (GMFCS levels) may be quite different in the long term. More effective (and less concerning for parents perhaps) to see children and situations similar to their own, especially as they will be trained in groups
4. The roles of the MDT in service delivery			
G05Q42	92.8	Since early identification and intervention is key to success in preventing musculoskeletal complications and promoting development, neonatal doctors discharging infants should register children who require follow up at high-risk clinic based on standardised perinatal risk factors.	#11 Use "Doctors working in neonatal wards" instead of "neonatal doctors". Neonatal specialists are rare. Nursing sisters in these wards can also register and refer these children #16 Data base on high risk babies is important for keeping track #17 A national registry for children at risk , and a separate one for children with Cp should be developed
G04Q53	92.8	Medical officers and community service doctors at primary health facilities should be trained to use simple neuromotor screening of infants and be given clear referral	#16 Referral to therapists with a knowledge of neurodevelopmental disorders would be the ideal referral pathway

		pathways and protocols to follow for these children.	
G05Q44	85.7	Medical officers and/or consultant doctors should co-ordinate early assessments and referrals of children with suspected or confirmed CP to therapy teams for management and caregiver training, and to relevant specialist services, e.g., paediatric neurology work up and orthopaedic surveillance.	#11 A paediatric sister could probably also do this. #12 As these medical/neurodevelopmental and specialist referrals usually happen in a hospital setting, the hospital-based team should aim to create "one-stop-shop" clinics so as to make access easier for patients and to ensure holistic assessments. In KZN, the main coordinators of this care is being shifted to the therapy team (known as the "core team") as the medics are (generally-speaking) don't do this well. I am not sure what the best way forward is. Perhaps 2 general champions - one medical, one therapist - can work together? At least it requires someone that knows alot about the multiple needs of CP, who the child needs to see when, and perhaps a check-list to follow. #17 Case managers should be coordinating the multidisciplinary team assessments
G04Q42	85.7	Medical officers and/or a Registered nursing sister based at district hospitals should be responsible for maintaining a CP register (preferably electronic) for the district to ensure that all at risk children are added, assessed and referred appropriately.	#11 Therapists can do this better, but using such a register will need team work. #17 Data capturers should be responsible for admin , health care staff to identify patients #19 Could the therapy team not be responsible for this though? #12 Again as above - I agree that the role of the nurse can be important here, but should we consider a therapist? Ideally this can be included in the data set that is counted on a district level (i.e. DHIS)
G05Q43	85.7	Registered nursing sisters at primary care facilities should perform specific neurodevelopmental screening at 4 - 6 months corrected age on all infants attending clinic, and refer them to the Paediatric OPD or to Paediatric neurology clinics for check-up if needed.	#11 Children attending clinic should be screened developmentally every time they come for their vaccinations, not only at 4 - 6 months of age. They need to be referred to OT/ PT/ STA if needed. #12 They can simultaneously refer to the rehab therapists, as both doctor and therapist will need to assess and intervene. This will save time #14 The GMCD (Guide for monitoring Child development) is a simple monitoring tool that is approved for use in low- and middle-income countries. The nursing sisters need to have a free and readily available tool that ideally should be incorporated into the RTHC. The parents should be encouraged from as early as the antenatal visits to be aware of the importance of watching their child's development and reporting concerns. #17 Referral should be to a paediatrician , and if necessary then to a paeds neurologist #19 There is a screening in the Road to Health booklet already which has sketchy implementation at clinic level. I would rather have the nurses complete the RTHB screening routinely than add another screening.
G05Q45	92.3	In conjunction with a designated clinic staff or WBOT member, visiting therapists should co-	#11 What is WBOT?

		ordinate training of caregivers and community health workers at the local community health centre.	
G05Q46	92.8	For every child in a Ward that is part of the CP program, a trained community health worker should be designated by the registered nursing sister or WBOT leader oversee the program and support the caregiver.	#11 “to” oversee
G05Q49	100.0	Therapists should monitor musculoskeletal status and progression of orthopaedic complications of the children and should refer concerns to doctors at the paediatric or orthopaedic clinics if needed.	#11 With CHWs, parent facilitators etc. assisting
5. The community health support structure for the program			
G04Q32	85.7	Except for custom-made rigid splinting such as an ankle-foot orthosis, basic postural management equipment (cushions, chairs, standers and soft splints) should be available from the clinic or district hospital on loan so as to reduce costs. Other options might be the use of paper-based technology to create low cost devices for children to own.	#11 On loan is OK, but ideally the CP child should have his own equipment. cushions, soft splints etc. dion't last very long. Find an NGO that can help make standing frames/ wedges/ therapy benches which the caregivers can then buy for a small amount. You care better for things you own. #16 A loan system for assistive devices is a good idea but splints need to be made to fit the individual. Paper based technology is time consuming and needs to be made by a person with knowledge on the purpose of the device #15 We need to consider the maintenance and safety of said devices when out on loan. If devices are returned, will they be refurbished / Serviced?
G05Q41	100.0	There should to be at least one person identified either at the clinic or in the community with sufficient technological skills who can perform basic maintenance of the equipment, e.g., fixing brakes on chairs, or sewing up holes in cushions.	#11 good idea #17 And sanitising equipment that is returned that can be reused
G05Q50	85.7	A social worker, social auxiliary worker or a worker from the Department of Public Service Administration (DPSA) should co-ordinate and promote community involvement and support of the child and family by helping to form networks and liaisons between NGOs, educators, caregivers, community health workers and religious leaders from the community.	#11 You have the wrong DPSA. The Department of Pubic Service and Administration work with salaries etc of department of Health Employees. The DPSA (Disabled People South Africa) field worker has a role to play in CP. Mpumalanga Province employs these people, who have a disability themselves, to provide peer counselling and help with community integration. I agree with the statement if you state the correct Disabled People SA (DPSA). #20 Traditional healers may be part of the Programme #16 A CRF (Community rehab faciltator) is the ideal person to coordinate this part of the program. ie to be from the community

			and know the principles of community developement and rehabilitation . A social worker does not have enough knowledge on disability
G04Q36	100.0	Meetings and informal gatherings co-ordinated by a community health worker or social worker at regular intervals could also serve as a means of ongoing support for caregivers. A social media support group, e.g., a WhatsApp group could also be encouraged for caregivers with the additional voluntary inclusion of community health workers, or social workers.	#16 A whatsapp group is a good idea for shared ideas and problems amongst caregivers #17 Partially agree. Caregivers should be encouraged to be in contact with each other for support . Staff should not be on groups with personal phone numbers but the local clinic rather used as a contact point.
G04Q41		General comments/suggestions	#18 These are fantastic strategies.

Supplementary Table: Survey Responses for Round 3

Answer ID	Agree %	Statement of consensus	Comments/ Suggestions
Section 1: the Importance of the program			
G00Q05	85.7	If the program includes education of caregivers, careful instruction and demonstration of evidence-based interventions, and is then regularly monitored by trained therapists, any undesirable or harmful effects of such an interventional program on the child should be kept to a minimum.	#8 I personally believe that the Program will bring no harm or risk to the child and or family. #12 No serious risk would be anticipated. #13 I doubt that there would be any serios harm caused. Risks can be minimized with the regular monitoring by therapists. A "red flag" system could be used
G00Q08	85.7	The program's emphasis on maintaining musculoskeletal integrity, but inclusion of strategies for promote functional development in other areas would mean it aligns with caregivers' goals of having their child participate more in family and social spheres.	#15 If the child has good musculoskeletal integrity, it can be positioned in a buggy or in a standing frame more easily and thereby be upright, to see what the family is doing + participate better. Mom can take the child to places more easily if the child can sit in a buggy. A child with severe deformities that just es on the floor scares other people in the community and an lead to isolation of the family.
G01Q40	92.8	A program for the effective daily prevention and management of musculoskeletal complications in children with CP living in resource-limited settings should help to diminish inequities in health service delivery.	#7 The key statement is properly implemented

G01Q39		General comments/suggestions	#13 A home based programme for caregivers of CP kids is the only way to MANAGE the child's condition as a lifelong condition, requiring continuous ideal positioning and handling techniques
Section 2: The Elements of the program			
G02Q13	92.8	For infants with CP or at risk of CP, simple low-cost standers should be provided from the age of 12 months and upwards. Prior to this, from the age of 9 months, the child can stand for shorter periods with caregiver support.	#13 Standers are to be used only if correct alignment can be achieved. General provision of standers is not advisable #15 It depends on the size of the child and strength/ flexibilty of the caregiver. A very spastic child being looked after by a granny with OA of her hips and knees might need a stander at an earlier age.
G02Q14	78.5	There is sufficient research evidence to recommend the use of Stretching in the daily program to promote joint and muscle flexibility, and to reduce muscle tone. The term "Stretching" refers to the elongation of soft tissues in and around a joint or series of joints, and may be provided manually or using a positional device.	#7 I have seen too many ineffective passive movements been taught and implemented to have any confidence that it would be effective and not cause trauma and harm. #10 "reduce" muscle tone does not fit fluctuating tone of dystonic CP which is the most common type of CP in our setting. Since research on the efficacy of passive manual stretching is very scarce and from my professional experience of passive stretching/movements being ineffective and harmful I have to say "strongly disagree" for this statement about the inclusion of stretching in the daily program. I would rather describe methods of preparation for the different types of Cerebral Palsy (dystonic, spastic, choreo-athotosis) to be very clear. Such as trunk rotation, limb elongation with massage and sustained postural stretch with soft splints for children with spastic CP. Off-centre trunk supported sitting or asymmetrical limb or handling techniques to manage tone in children with dystonic CP. Weightbearing and midline activities for children with choreo-athetosis CP. #15 The techniques of 'muscle preparation', 'trunk mobilisation', 'limb elongation' are very important. If sustained for 30 s plus, they are a form of manual stretching. It is NB to define "Stretching" very clearly. Just add to your statement: "stretching does NOT means repetitive quick passive movement, as this increases muscle tone"
G02Q22	78.5	"Manual stretching" as it is used in this context refers to techniques performed by a third party that elongate soft tissue structures while reducing muscle tone, and may include a combination of proximal (trunk) rotations, massage techniques and slow, controlled release of distal structures near end of joint range. It is thus distinct from repetitive, fast passive	#7 These techniques would have to be individualized for each client and family and require understanding from all members of the team #15 I agree with the start and end of your statement, but not with the middle. We cannot have a different definition of stretching for CP than for all other conditions. Massage is massage, it isn't stretching. My suggestion: " "Manual stretching" as it is used in this context refers to techniques performed by a third party that elongate soft tissue structures while reducing muscle tone. It may be preceeded by a

		movements of the limbs which can increase muscle tone in spastic CP.	combination of proximal (trunk) rotations and massage techniques. It involves slow, controlled release of distal structures near end of joint range. It is thus distinct from repetitive, fast passive movements of the limbs which can increase muscle tone in spastic CP. "
G02Q37	100.0	In accordance with current available evidence, sustained stretching using a positional device or a resting splint is preferable to manual stretching for maintaining and/or increasing joint range in terms of efficacy. The use of positional devices may also be less technique-sensitive in terms of safety to the child.	#15 More research is needed. There is room for both. It is better to do passive manual stretches than nothing.
G02Q50	100.0	For children aged 2 years and older who are unable to stand independently, sustained stretching in a stander should be carried out for 60 to 90 minutes per day for joint range maintenance, titrating the dosage and regime to individual patient tolerance.	#13 This will depend on factors such as head control, joint alignment. Caution to be applied to a general prescription #14 May need to be done in divided doses during day
G02Q36	85.7	From the age of 12 months, infants with CP or at risk of CP who are unable to stand independently should perform sustained stretching in a stander for up to 30 minutes per day, which should be incrementally increased to 60 minutes per day by age 2, titrating dosage according to individual patient tolerance.	#15 I think cp children of 1 year old can stand for 1 hour, but you start with 15 min a day when they get their standing frame. Then you increase by 5 min every day/ few days until they can stand for 1 hour. The effect of the prolonged standing is very important and 30 min may be too short. The programme must depend on each child's tolerance.
G02Q38	100.0	Sustained stretching using a resting splint should be carried out for a minimum of 5 hours per day in total, titrating the dosage according to individual patient tolerance.	#10 Daytime or nighttime
G02Q51	78.5	Where 24-hour postural management and/or sustained stretching is not possible due to lack of resources such as a standing device, slow and controlled manual stretching of the limbs can be carried out for 40 - 60 seconds, 3 to 5 times per joint as needed, provided that they are preceded by tone-reducing techniques such as trunk rotations.	#7 I feel that even with very limited resources positioning and alternative positions are more valuable than manual stretching. a towel or blanket can be used for positioning as a soft splint etc. #10 The research on the the efficacy of this is low. I would rather recommend sandwich standing with caregiver (supported standing) or perched standing (sitting so hips are higher that knees but child is taking weight through both legs) as there are functional benefits. Using household items can be a replacement to equipment such as sitting in a good

			position on the couch or in a wash bucket or in a tyre using pillows/blankets/towels to obtain desired effects.
G02Q29	78.5	If properly trained in the techniques and principles of safety and effectiveness, and with the oversight of trained Community health workers and therapists, the caregivers in a low-resource setting should be able to perform appropriate Stretches on their child.	#7 manual stretching is not a skill that can easily be transferred in a way that does not cause harm. massage would be preferable #10 My problem with the statement is "stretches" word. I agree that caregivers can safely perform techniques such as trunk rotations, massage, limb elongation with massage, maintaining limb elongation with towel wrapped around arm or splint.
Section 3. The Training of the program			
G03Q19	100.0	The initial training of the program should be provided at an accessible community centre such as the local community health centre or Tribal court to small groups of caregivers at a time.	
G03Q34	100.0	Caregivers should be encouraged to bring one other adult from the household or area to be trained who would then be able to relieve them when needed.	#15 At least 1, even 2 would be great
G03Q32	100.0	Groups being trained should try to include children at similar ages and/or GMFCS levels where possible and practical.	#12 This will also assist with the families forming support groups. #15 This might not always be possible. Training can be given to a mixed group. This will help caregivers build social bonds with other caregivers and support each other, regardless of differences in GMFS levels.
Section 4. The roles of the MDT in service delivery			
G03Q55	100.0	The initial training should be followed up by a home visit done by a therapist within a given time, e.g., 8 weeks, in order to monitor and customise the program for the child in their natural environment.	#15 The home visit should be done by the therapist and parent facilitator/ Disabled People SA field worker/ Home Based carer/ community rehabilitation facilitator/ community OT technician/ PT assistant/ technician, to help with subsequent follow ups, which can be done by them. #17 Where practical and feasible
G04Q26	92.8	In order to evaluate the program's success from an activity and participation viewpoint, therapists should monitor participation outcomes of the children using validated measurement tools, e.g., the Paediatric evaluation of Disability Inventory (PEDI).	#12 Caregivers will be motivated by seeing any improvement in their child's functioning. It will also benefit the parent in playing an active role in caring for their child and it will improve attachment. #15 Not only validated measurement tools, but also individual interviews/ questionnaires to the caregivers #13 The caregivers will be motivated to continue on experiencing their child's improved participation and function.
Section 5. The Community health support structure			
G04Q41		General comments/suggestions	#8 I suggest the community health structure should also provide basic education through awareness programmes to promote prevention.

			#13 There is a need in rural settings to have mid level workers with training that includes OT ST and PT related to CP. So the suggestion is having a rehab worker specializing in CP. There is limited chance that there will ever be enough therapists with experience in CP in rural settings. Concern is about CHWs and registered nurses having adequate knowledge and experience to do the regular informal monitoring. #18 Community education and stigma erradication is important in managing CP #12 A WhatsApp support group with a healthcare worker monitoring the posts, could benefit parents who have questions regarding the program. #15 Involve the sisters in charge of the clinics, community health workers and any rehab personnell at the clinics and the clinic committees. They should be involved even if the venue of the training is not at the clinic. The local chief/ induna and other community leaders (e.g. pastors) must also be involve before the start of the training.

Appendix 4.4: Consensus process for statements by section

Supplementary Table: Consensus process for Section 1: The Importance of a Home-based Intervention Program (HBIP)

Statement code	Statement	% Agree overall	% Strongly Agree
G00Q01	#1In spite of the lack of accurate data about the numbers of children with severe CP in South Africa, a community-based program for the prevention of musculoskeletal complications is a priority.	93.3	73.3
G00Q02	#1Most colleagues with similar experience and expertise as myself would agree with the previous statement.	100.0	26.6
G00Q03	#1The benefits of limiting musculoskeletal complications to the child with CP and their family would be significant.	100.0%	66.6
G00Q04	#1The benefits of limiting musculoskeletal complications in these children to the public health system would be significant.	93.3%	40.0
G00Q05	#1 Any undesirable or harmful effects of such an interventional program would be minimal.	64.2	28.5
	#2 If the program includes education of caregivers, careful instruction and demonstration of evidence-based interventions, and is then regularly monitored by trained therapists, any undesirable or harmful effects of such an interventional program should be minimal.	78.5	14.2
	#3 If the program includes education of caregivers, careful instruction and demonstration of evidence-based interventions, and is then regularly monitored by trained therapists, any undesirable or harmful effects of such an interventional program on the child should be kept to a minimum.	85.7	21.4
G00Q06	#1 The benefits of the program would probably outweigh any drawbacks such as cost of training and assistive equipment required.	92.8	20.0
G00Q07	#1 There is high stakeholder agreement (between health professionals and the children or caregivers) on the importance of the program.	80.0	26.6
	#2 There is generally high stakeholder agreement (between health professionals and the children or caregivers) on the importance of the program, but the program may need to be properly promoted in more remote settings.	92.8	35.7
G00Q08	#1 There is sufficient alignment of goals between health professionals and the children or caregivers on the content of the program.	60.0	6.6

	#2 The program's emphasis on maintaining musculoskeletal integrity and the caregivers' goals of having their child participate more in family and social spheres would align sufficiently for the program to be acceptable to all stakeholders	85.7	21.4
	#3 The program's emphasis on maintaining musculoskeletal integrity, but inclusion of strategies for promoting functional development in other areas would mean it aligns with caregivers' goals of having their child participate more in family and social spheres.	85.7	28.5
G01Q40	#1 A program for the effective daily prevention and management of musculoskeletal complications in children with CP living in resource-limited settings should help to diminish inequities in health service delivery.	92.8	35.7

Legend

Round 1; Round 2; Round 3: statements appearing in each round

#1, #2, #3: each iteration of a statement towards consensus or acceptable modification.

Supplementary Table: Consensus process for Section 2: The Elements of the Program

Statement code	Statement	% Agree overall	% Strongly Agree
G02Q09	#1 There is sufficient evidence to recommend the use of 24-hour Postural Management in the program to prevent musculoskeletal complications in severe CP.	86.6	26.6
G02Q10	#1 24-hour Postural Management must include all 3 basic positions, i.e., lying, sitting and standing.	100.0	46.6
	#2 24-hour Postural Management must include all 3 basic positions, i.e., lying, sitting and standing over the period of a night and day, and includes varieties within those 3 basic positions in order to protect the musculoskeletal system, maintain flexibility and provide supportive positioning for function.	85.7	28.6
G02Q44	#1 From the age of 2 years, children with non-ambulant CP, classified as GMFCS level III to V, the 24-hour Postural management regime should include lying support, supported seating with trunk control and hip abduction (total maximum of 60°) for a total of 4-6 hours per day, and supported standing for 30 - 90 minutes per day.	100.0	23.0
G02Q45	#1 Infants between 6 months and 2 years of corrected age who are diagnosed with CP or at high risk of CP can begin a modified 24-hour postural management that includes lying support, supported seating from 6 months	100.0	15.3

	for 2 to 4 hours per day, and gradually increasing periods of supported standing from 9 months of age e.g., 10 minutes at a time up to 30 minutes, supported by the caregiver.		
G02Q28	#1 The caregivers in a low-resourced setting will be able to perform 24-hour Postural Management if properly trained and supported.	100.0	33.3
G02Q11	#1 Low-cost lying support (or a sleeping system) should be provided for infants with CP or at risk of CP from 6 months of age upwards.	86.6	20.0
	#2 Low-cost lying support (or a sleeping system) should be provided for infants with CP or at risk of CP from 6 months of age upwards.	85.7	21.4
G02Q12	#1 For infants with CP or at risk of CP, low-cost seating with trunk support and hip abduction should be provided from 6 months of age upwards.	100.0	33.3
G02Q13	#1 For infants with CP or at risk of CP, simple low-cost standers should be provided from the age of 9 months upwards.	93.3	26.6
	#2 For infants with CP or at risk of CP, simple low-cost standers should be provided from the age of 2 years and upwards. Prior to this, the child can stand with caregiver support.	78.5	7.1
	#3 For infants with CP or at risk of CP, simple low-cost standers should be provided from the age of 12 months and upwards. Prior to this, from the age of 9 months, the child can stand for shorter periods with caregiver support.	92.8	21.4
G02Q14	#1 There is sufficient evidence to recommend the use of Muscle Stretching in the intervention program.	66.6	6.6
	#2 There is sufficient evidence to recommend the use of Muscle Stretching, preferably sustained or positional stretching, in the intervention program for prevention of musculoskeletal complications such as contractures.	78.5	7.1
	#3 There is sufficient research evidence to recommend the use of Stretching in the daily program to promote joint and muscle flexibility, and to reduce muscle tone. The term "Stretching" refers to the elongation of soft tissues in and around a joint or series of joints, and may be provided manually or using a positional device.	78.5	14.2
G02Q22	#1 "Manual stretching" as it is used in this context refers to techniques performed by a third party that elongate soft tissue structures while reducing muscle tone, and may include a combination of proximal (trunk) rotations, massage techniques and slow, controlled release of distal structures near end of joint range. It is thus distinct	78.5	14.2

	from repetitive, fast passive movements of the limbs which can increase muscle tone in spastic CP.		
G02Q37	#1 In accordance with current available evidence, sustained stretching using a positional device or a resting splint is preferable to manual stretching for maintaining and/or increasing joint range in terms of efficacy. The use of positional devices may also be less technique-sensitive in terms of safety to the child.	100.0	28.5
G02Q50	#1 Sustained stretching using a resting splint or positional device (e.g., a stander) should be carried out for a minimum of 90 minutes for joint range maintenance and for up to 5 hours per day to improve joint range.	71.4	7.1
	#2 For children aged 2 years and older who are unable to stand independently, sustained stretching in a stander should be carried out for 60 to 90 minutes per day for joint range maintenance, titrating the dosage and regime to individual patient tolerance.	100.0	28.5
G02Q36	#1 From the age of 12 months, infants with CP or at risk of CP who are unable to stand independently should perform sustained stretching in a stander for up to 30 minutes per day, which should be incrementally increased to 60 minutes per day by age 2, titrating dosage according to individual patient tolerance.	85.7	21.4
G02Q38	#1 Sustained stretching using a resting splint should be carried out for a minimum of 5 hours per day in total, titrating the dosage according to individual patient tolerance.	100.0	7.1
G02Q51	#1 Slow and controlled manual stretching can be carried out for 40 - 60 seconds, 3 to 5 times per joint as needed, especially where 24-hour postural management and/or sustained stretching is not possible.	66.6	0.0
	#2 Where 24-hour postural management and/or sustained stretching is not possible due to lack of resources such as a standing device, slow and controlled manual stretching of the limbs can be carried out for 40 - 60 seconds, 3 to 5 times per joint as needed, provided that they are preceded by tone-reducing techniques such as trunk rotations.	78.5	14.2
G02Q29	#1 The caregivers in a low-resource setting will be able to perform safe and effective Stretching if properly trained and supported.	80.0	20.0
	#2 If properly trained in the techniques and principles of Stretching and with the oversight of trained Community health workers, the caregivers in a low-resource setting will be able to perform safe and effective stretches on their child.	73.3	13.3

	#3 If properly trained in the techniques and principles of safety and effectiveness, and with the oversight of trained Community health workers and therapists, the caregivers in a low-resource setting should be able to perform appropriate Stretches on their child.	78.5	21.4
G02Q15	#1 Where there is spasticity in the limbs, lower and upper limb splints for Sustained Stretching of the joints should be provided to prevent muscle contractures and support the joints in alignment.	93.3	13.3
	#2 Where there is spasticity but no severe joint contractions in the limbs, appropriate lower and upper limb splints for Sustained Stretching of the joints should be provided to prevent muscle contractures and support the joints in alignment.	92.8	14.2
G02Q40	#1 Caregivers in low-resource settings will be able to use splinting devices effectively if properly trained.	100.0	33.3
	#2 Caregivers in low-resource settings will be able to use splinting devices effectively if properly trained and have regular oversight from trained Community health workers.	93.3	20.0
G02Q52	#1 Since the program is aimed at Gross Motor Function Classification System levels IV and V, and GMFCS levels are only fully determined at the age of 2 years, children should be re-assessed at age 2 and adaptations made to their program according to need.	86.6	26.6
G02Q16	#1The program should include strategies for Feeding and Bathing the child.	100.0	60.0
G02Q17	#1 The program should include strategies for Communicating with the child.	100.0	73.3
G02Q18	#1 The program should include basic stimulation and child development strategies using Music and Play.	93.3	40.0

Legend

Round 1; Round 2; Round 3: statements appearing in each round

#1, #2, #3: each iteration of a statement towards consensus or acceptable modification.

Supplementary Table: Consensus process for Section 3: The Caregiver training.

Statement code	Statement	% Agree overall	% Strongly Agree
G03Q19	#1 The training of the program should be provided at the community health centre to small groups of caregivers.	80.0	20.0
	#2 The initial training of the program should be provided at the community health centre or other community centre such as the Tribal court to small groups of	80.0	33.3

	caregivers. It should be followed up by home visits done by therapists to further customise the program for the child.		
	#3 The initial training of the program should be provided at an accessible community centre such as the local community health centre or Tribal court to small groups of caregivers at a time.	100.0	50.0
G03Q34	#1 Caregivers should be encouraged to bring one other adult from the household or area to be trained who would then be able to relieve them when needed.	100.0	50.0
G03Q32	#1 Groups being trained should try to include children at similar ages and/or GMFCS levels where possible and practical.	100.0	60.0
G03Q20	#1 The training should be delivered by a team of therapists with at least 2 years' CP experience and expertise.	73.3	26.6
	#2 Since techniques such as feeding and drinking, postural management, stretching and splinting require skill to perform safely and effectively, it would then follow that trained therapists (physio-, speech and occupational therapists where available) should deliver the initial instruction and demonstration at least of these interventions	93.3	6.6
G03Q44	#1 Since many of the therapists that work in these areas will be newly graduated, and therefore not experienced in CP care, the program should either be included in undergraduate therapy training or offered to all new Community service therapists as a complete tool, together with a module on adult education.	86.6	73.3
G03Q21	#1 The training should include theoretical instruction about CP and the principles of CP care.	100.0	26.6
G03Q23	#1 The training should also include practical demonstration of the techniques to be used, as well as equipment use, e.g., a stander.	92.3	61.5
	#2 The training should include practical demonstration of the techniques to be used, as well as equipment use, with the child and usual caregiver present. Caregivers should also be encouraged to bring one other adult from the household or area to be trained who would then be able to relieve them when needed.	93.3	66.6
G03Q22	#1 The training should use in-person instruction rather than video instruction.	93.3	53.3
	#2 The training should mainly use in-person instruction, with a community health worker present to translate if needed. Instructional videos can be provided in different languages for caregivers to use as a reference.	93.3	33.3

G03Q24	#1 The training should provide an instruction manual with graphic illustrations for the caregiver to use as a reference.	93.3	33.3
G03Q25	#1 The training should provide a suggested daily schedule to help caregivers to integrate the program into an acceptable daily routine for the family.	93.3	20.0
	#2 The training should provide suggestions for the daily schedule to help caregivers to integrate the program into an acceptable daily routine for the family. The development of the daily schedule can be incorporated into the training so that it can be individualised.	100.0	40.0
G03Q26	#1 The training should provide suggestions for ways to help the child be included in family and community activities.	100.0	53.3
G03Q27	#1 Caregivers of infants as young as 6 months should be trained where CP has been diagnosed or there is a risk of CP.	92.8	53.3
	#2 Caregivers of infants as young as 6 months should be trained where CP has been diagnosed or there is a risk of CP especially where the child is presenting with abnormal muscle tone.	86.6	20.0
G04Q30	#1 Community health workers need to be trained in the program so that they can support the caregivers and their children	100.0	80.0

Legend

Round 1; Round 2; Round 3: statements appearing in each round

#1, #2, #3: each iteration of a statement towards consensus or acceptable modification.

Supplementary Table: Consensus process for Section 4: The Roles of the MDT in Service delivery

Statement code	Statement	% Agree overall	% Strongly Agree
G05Q42	#1 The medical officers and consultants running the paediatric clinics should identify and register children to monitor for possible program intervention based on perinatal risk factors.	92.3	46.1
	#2 Since early identification and intervention is key to success in preventing musculoskeletal complications and promoting development, neonatal doctors discharging infants should register children who require follow up at high-risk clinic based on standardised perinatal risk factors.	92.8	42.8
G04Q53	#1 Medical officers and community service doctors at primary health facilities should be trained to use simple	92.8	50.0

	neuromotor screening of infants and be given clear referral pathways and protocols to follow for these children.		
G05Q44	#1 Medical officers and/or consultant doctors should co-ordinate early referrals of children with suspected CP to therapists to implement training, and children with confirmed CP to relevant specialist services, e.g., orthopaedic.	85.7	42.8
	#2 Medical officers and/or consultant doctors should co-ordinate early assessments and referrals of children with suspected or confirmed CP to therapy teams for management and caregiver training, and to relevant specialist services, e.g., paediatric neurology work up and orthopaedic surveillance	85.7	46.1
G04Q42	#1 Medical officers and/or a Registered nursing sister based at district hospitals should be responsible for maintaining a CP register (preferably electronic) for the district to ensure that all at risk children are added, assessed and referred appropriately.	85.7	46.1
G05Q43	#1 Registered nursing sisters should perform specific neurodevelopmental screening at 4 - 6 months corrected age on all infants attending clinic, and create and maintain the local register for those children with developmental delay.	86.6	46.6
	#2 Registered nursing sisters at primary care facilities should perform specific neurodevelopmental screening at 4 - 6 months corrected age on all infants attending clinic, and refer them to the Paediatric OPD or to Paediatric neurology clinics for check- up if needed.	85.7	21.4
G05Q45	#1 A registered nursing sister should co-ordinate training of caregivers and community health workers with visiting therapists at the local community health centre.	73.3	13.3
	#2 In conjunction with a designated clinic staff or WBOT member, visiting therapists should co-ordinate training of caregivers and community health workers at the local community health centre.	92.3	23.0
G05Q46	#1 Registered nursing sisters should appoint a trained community health worker to work with and support the caregiver and child with CP in program implementation.	73.3	20.0
	#2 For every child in a Ward that is part of the CP program, a trained community health worker should be designated by the registered nursing sister or WBOT leader to oversee the program and support the caregiver.	92.8	35.7

G05Q47	#1 Community health workers should screen and refer children from the community who are not developing typically, to the designated clinic sister.	100.0	33.3
G05Q48	#1 Therapists should oversee the training of the program, the initial program set up for the family and child around shared goals, and monitor and adapt the program as needed.	86.6	46.6
G03Q55	#1 The initial training should be followed up by a home visit done by a therapist within a given time, e.g., 8 weeks, in order to monitor and customise the program for the child in their natural environment.	100.0	38.4
G05Q49	#1 Therapists should monitor musculoskeletal status and progression of orthopaedic complications the children and should refer concerns to doctors at the paediatric or paediatric neurology clinics if needed	93.3	42.8
	#2 Therapists should monitor musculoskeletal status and progression of orthopaedic complications of the children and should refer concerns to doctors at the paediatric or orthopaedic clinics if needed.	100.0	28.5
G04Q26	#1 In order to evaluate the program's success from an activity and participation viewpoint, therapists should monitor participation outcomes of the children using validated measurement tools, e.g., the Paediatric evaluation of Disability Inventory (PEDI).	92.8	28.5

Legend

Round 1; Round 2; Round 3: statements appearing in each round

#1, #2, #3: each iteration of a statement towards consensus or acceptable modification.

Supplementary Table: Consensus process for Section 5: The Community Health Support Structure

Statement code	Statement	% Agree overall	% Strongly Agree
G04Q32	#1 Basic postural management equipment (cushions, chairs, standers and splints) should be provided on loan from the community health centres.	93.3	26.6
	#2 Except for custom-made rigid splinting such as an ankle-foot orthosis, basic postural management equipment (cushions, chairs, standers and soft splints) should be available from the clinic or district hospital on loan so as to reduce costs. Other options might be the use of paper-based technology to create low cost devices for children to own.	85.7	35.7

G05Q41	#1 There should to be at least one person identified either at the clinic or in the community with sufficient technological skills who can perform basic maintenance of the equipment, e.g., fixing brakes on chairs, or sewing up holes in cushions.	100.0	28.5
G04Q33	#1 Therapists should perform regular (e.g., quarterly) visits to the community health centres, and/or the homes to monitor the program performance and address concerns.	93.3	35.7
G04Q35	#1 Community health workers should visit the homes monthly to check on the caregivers and children, and refer to the clinic if required.	93.3	28.5
G05Q50	#1 A social worker should co-ordinate and promote community involvement and support of the child and family by helping to form liaisons between educators, caregivers, community health workers and religious leaders from the community.	92.8	57.1
	#2 A social worker, social auxiliary worker or a worker from the Department of Public Service Administration (DPSA) should co-ordinate and promote community involvement and support of the child and family by helping to form networks and liaisons between NGOs, educators, caregivers, community health workers and religious leaders from the community.	85.7	35.7
G04Q36	#1 A social media network such as a WhatsApp group should be established for caregivers with at least one community health worker, nursing sister or social worker included.	71.4	42.8
	#2 Meetings and informal gatherings co-ordinated by a community health worker or social worker at regular intervals could also serve as a means of ongoing support for caregivers. A social media support group, e.g., a WhatsApp group could also be encouraged for caregivers with the additional voluntary inclusion of community health workers, or social workers.	100.0	28.5

Legend

Round 1; Round 2; Round 3: statements appearing in each round

#1, #2, #3: each iteration of a statement towards consensus or acceptable modification.

Appendix 4.5 Final results of Delphi for feedback to caregivers

PREVENTING MUSCULOSKELETAL COMPLICATIONS IN CHILDREN WITH SEVERE CP LIVING IN RESOURCE-LIMITED SETTINGS: A GUIDELINE PROPOSAL

The importance of a Home-based Intervention program

1. In spite of the lack of accurate data about the numbers of children with severe CP in South Africa, a community-based program for the prevention of musculoskeletal complications is considered a priority.
2. Most medical healthcare professionals working in the field are likely to agree with the previous statement.
3. The benefits of limiting musculoskeletal complications to the child with CP and their family would be significant.
4. The benefits of limiting musculoskeletal complications in these children to the public health system would be significant.
5. A properly-implemented program for the effective daily prevention and management of musculoskeletal complications in children with CP living in resource-limited settings should help to diminish current inequities in health service delivery.
6. If the program includes education of caregivers, careful instruction and demonstration of evidence-based interventions, and regular monitoring by trained therapists*, any undesirable or harmful effects of such an interventional program on the child should be kept to a minimum.
7. The benefits of the program would probably outweigh any drawbacks such as cost of training and resources required.
8. There is generally high stakeholder agreement (between health professionals and the children or caregivers) on the importance of the program, but the program may need to be actively promoted amongst local chiefs, councillors, tribal leaders and traditional healers in more remote settings.
9. The program's early emphasis on maintaining musculoskeletal integrity of the child, and inclusion of strategies to promote activity and functional development in other areas would align with caregivers' goals of greater participation in family and social spheres.

Definitions and explanations

**Trained therapist – there is concern that the current level of training and experience of new or community service therapy graduates may not equip them adequately to offer effective training and support. The panel advises that focused training in CP management, such as the short courses offered by the South African Neurodevelopmental Therapy Association (SANDTA) be mandatory for Com.Serv therapists prior to presenting the program.*

The Elements of the Program

1. There is sufficient evidence to recommend the use of 24-hour Postural Management in the program to limit musculoskeletal complications such as hip displacement, scoliosis and joint deformities in severe CP.
2. 24-hour Postural Management must include all 3 basic positions, i.e., lying, sitting and standing over the period of a night and day, and includes varieties within those 3 basic positions in order to protect the musculoskeletal system, maintain flexibility and provide supportive positioning for function.
3. From the age of 2 years, children with non-ambulant CP, classified as GMFCS level III to V, the 24-hour Postural management regime should include lying

support, supported seating with trunk control and hip abduction (total maximum of 60°) for a total of 4-6 hours per day, and supported standing for 30 - 90 minutes per day.

4. Infants between 6 months and 2 years of corrected age who are diagnosed with CP or at high risk of CP can begin a modified 24-hour postural management that includes lying support, supported seating from 6 months for 2 to 4 hours per day, and gradually increasing periods of supported standing from 9 months of age e.g., 10 minutes at a time up to 30 minutes per day by 12 months of age, and 60 minutes per day by 2 years of age, titrated according to individual tolerance.
5. The caregivers in a low-resourced setting should be able to perform 24-hour Postural Management if properly trained and supported.
6. Low-cost lying support encouraging hip, spine and pelvic symmetry should be provided for infants with CP or at risk of CP from 6 months of age upwards.
7. For infants with CP or at risk of CP, low-cost seating with trunk support and hip abduction should be provided from 6 months of age upwards.
8. For infants with CP or at risk of CP, simple low-cost standers should be provided from the age of 12 months and upwards. Prior to this, from the age of 9 months, the child can stand for shorter periods with caregiver support.
9. There is sufficient research evidence to recommend the use of Stretching in the daily program to promote joint and muscle flexibility, and to temporarily reduce spasticity. The term "Stretching" refers to the elongation of soft tissues around a joint or series of joints, and may be provided manually* or using a positional device.
10. In accordance with current available evidence, Sustained Stretching using a positional device or a resting splint is preferable to manual stretching for maintaining and/or increasing joint range in terms of efficacy.**
11. For children aged 2 years and older who are unable to stand independently, Sustained Stretching in a stander should be carried out for 60 to 90 minutes per day for joint range maintenance, titrating the dosage and regime to individual patient tolerance.
12. From the age of 12 months, infants with CP or at risk of CP who are unable to stand independently should perform Sustained Stretching in a stander for up to 30 minutes per day, which should be incrementally increased to 60 minutes per day by age 2, titrating the dosage according to individual patient tolerance.
13. Where there is spasticity but no significant loss of joint range in the limbs, appropriate rigid and/or soft splints for lower and upper limbs for Sustained Stretching of the joints should be provided to prevent muscle contractures and support the joints in alignment for weightbearing.
14. Sustained Stretching using a resting splint should be carried out for a minimum of 5 hours per day in total, titrating the dosage according to individual patient tolerance.
15. Where 24-hour Postural Management and/or Sustained Stretching is not possible due to lack of assistive devices, an individualised therapeutic handling program aimed at lengthening of soft tissues should be prescribed by a trained therapist.
16. If properly trained in the techniques and principles of safety and effectiveness, and with the oversight of trained Community health workers and therapists, the caregivers in a low-resource setting should be able to perform appropriate Stretching on their child.
17. Since the program is aimed at Gross Motor Function Classification System levels III to V, and GMFCS levels are only considered stable at the age of 2 years, children should be re-assessed at age 2 and adaptations made to their program according to need.
18. The program should include strategies for Feeding and Bathing the child.
19. The program should include strategies for Communicating with the child.

20. The program should include basic stimulation and child development strategies using Music and Play.

Definitions and explanations

**Manual stretching, as it is used in this context refers to therapeutic handling techniques performed by a third party that elongate soft tissue structures. These may be associated with proximal (trunk) rotations, massage techniques and guided movements to effect a slow, controlled release of distal structures near end of joint range. It is thus distinct from repetitive, fast passive movements of the limbs which can increase spasticity in children with CP.*

*** Using a positional device or splint may also be less technique-sensitive in terms of safety to the child when compared to manual techniques, and therefore easier to train and monitor in RLS.*

The Caregiver Training

7. The initial training of the program should be provided at an accessible community centre such as the local community health centre or Tribal court to small groups of caregivers at a time.
8. Caregivers of infants as young as 6 months should be trained where CP has been diagnosed or there is a risk of CP especially where the child is presenting with abnormal muscle tone.
9. Community health workers and possibly registered nurses should be trained in the program so that they can support the caregivers and their children.
10. Groups being trained should try to include children at similar ages and/or GMFCS levels where possible and practical.
11. Caregivers should be encouraged to bring one other adult from the household or area to be trained who would then be able to relieve them when needed.
12. Since techniques such as feeding and drinking, postural management, stretching and splinting require skill to perform safely and effectively, trained therapists (physio-, speech and occupational therapists where available) should deliver the initial instruction and demonstration at least of these interventions.
13. Since many of the therapists that work in these areas will be newly graduated, and therefore not experienced in CP care, the program should either be included in undergraduate therapy training or offered to all new Community service therapists as a complete training tool, together with a module on adult education.
14. The training should mainly use in-person instruction, with a community health worker present to translate if needed. Instructional videos can be provided in different languages for caregivers to use as a reference.
15. The training should include theoretical instruction about CP and the principles of CP care.
16. The training should involve practical demonstration of the techniques to be used, as well as equipment use, and have the child and usual caregiver present.
17. An instruction manual with graphic illustrations should be given to each caregiver to use as a reference.
18. The training should provide suggestions for the daily schedule to help caregivers to integrate the program into an acceptable daily routine for the family. The development of the daily schedule can be completed during the training so that it can be individualised.
19. The training should provide strategies to help the child be included in family and community activities such as the “6 F words” framework from Canchild.

20. A module on strategies to overcome health system limitations might be useful in RLS.

The roles of the MDT in identifying appropriate children and training caregivers

Doctors

1. Since early identification and intervention is key to success in preventing musculoskeletal complications and promoting development, neonatal doctors discharging new-borns should register* children who require follow up at high-risk clinic based on standardised perinatal risk factors using a form filled out by doctors and captured electronically onto a digital district database.
2. Medical officers and/or consultant doctors at paediatric clinics should co-ordinate early assessments and referrals of children with suspected or confirmed CP to therapy teams for registration if needed, management and caregiver training.
3. Medical officers and community service doctors at primary health facilities should be trained to use simple neuromotor screening of infants and be given clear referral pathways and protocols to follow for these children.

Registered nurses

4. A medical officer, registered nursing sister or therapist based at a district hospital may be responsible for maintaining the “At risk”/CP register (preferably electronic) for the district to ensure that all “at risk” infants, or children later diagnosed are captured and referred appropriately.
5. Registered nursing sisters at primary care facilities should perform specific neurodevelopmental screening at 4 - 6 months corrected age on all infants attending clinic, if not at every vaccination visit, and refer them to the Paediatric OPD or to Paediatric neurology clinics for check- up if needed.

CHW

6. Community health workers should use a basic screening tool and refer children from the community who are not developing typically, to the designated clinic sister or visiting therapist clinics.
7. For every child in a Ward that is part of the CP program, a trained community health worker should be designated by the registered nursing sister or WBOT leader to oversee the program and support the caregiver**.

Therapists

8. In conjunction with a designated clinic staff or WBOT member, visiting therapists should co-ordinate training of caregivers of registered children and community health workers at the local community health centre.
9. Therapists should oversee the training of the program, the initial program set up for the family and child around shared goals, and monitor and adapt the program as needed.
10. The initial training should be followed up by a home visit done by a therapist within a given time, e.g., 8 weeks, in order to monitor and customise the program for the child in their natural environment.
11. Therapists should monitor musculoskeletal status and progression of orthopaedic complications of the children, e.g., hip surveillance, and should refer concerns to doctors at the paediatric or orthopaedic clinics if needed.

12. In order to evaluate the program's success from an activity and participation viewpoint, therapists should monitor participation outcomes of the children using validated measurement tools, e.g., the Paediatric evaluation of Disability Inventory (PEDI).

Comments

*A register is integral to identification and follow up of children at risk of or with CP. Since prevention of MSK complications requires early intervention, and a confirmed diagnosis of CP is often made much later, children under 2 years of age at risk should be added to an "At risk" register and managed accordingly. Based on whether the diagnosis of CP is confirmed or eliminated at age 2 years, the child will either remain on the register, or be de-registered. Thereafter, other children identified can be added by a designated RN or therapist who then ensures that all caregivers are trained.

The Community Health support structure

1. Basic 24-hour Postural Management equipment (cushions, chairs, standers and soft splints) should be available from the clinic or district hospital on loan so as to reduce costs. Other options might be the use of paper-based technology to create low cost devices for children to own.
2. There should to be at least one person identified either at the clinic or in the community with sufficient technological skills who can perform basic maintenance of the equipment, e.g., fixing brakes on chairs, or sewing up holes in cushions.
3. Therapists should perform regular (e.g., quarterly) visits to the community health centres, and/or the homes to monitor the program performance and address concerns.*
4. Community health workers should visit the homes at least twice a month to check on the caregivers and children, and refer to the clinic if required.**
5. A social worker or social auxiliary worker should co-ordinate and promote community involvement and support of the child and family by helping to form networks and liaisons between NGOs, educators, caregivers, community health workers and religious leaders from the community.
6. Meetings and informal gatherings co-ordinated by a community health worker or social worker at regular intervals could also serve as a means of ongoing support for caregivers. A social media support group, e.g., a WhatsApp group could also be encouraged for caregivers with the additional voluntary inclusion of community health workers, or social workers.

Comment

**Frequency of follow up visits by therapists, e.g., monthly for 3 months, then quarterly, as determined by the level of need or GMFCS level of the child. However, it needs to be context-specific and realistic for individual health service settings, e.g., be based on a staff to CP prevalence ratio for the area.*

***In order to ensure wide coverage, it is envisioned that eventually the regular informal monitoring should be performed by CHWs and RNs or mid-level workers who have been previously trained and would have some experience. They can refer to therapies/clinic and the RN will refer if problems with the program are encountered.*

RESEARCH GAPS

1. Prevalence data of CP in SA – where to begin?
2. Current status of equity in health service provision for CP in SA
3. Developing a CP registry – purpose, scope, implementation, support
4. “At risk” register form to be constructed.
5. Cost of intervention to health services: training and equipment vs costs of managing complications.
6. Sourcing and/or developing and piloting effective, locally made low cost equipment for 24 hour postural management.
7. RTHB development screening – what is current usage and why? Does it need revision?
8. Screening tool for CHWs
9. NGO support for CP – where, who and what? What is our current reliance on them?
10. What are the important barriers to our intervention ito implementing and sustaining, e.g., system breakdowns, service delivery, buy in from MDT