Determining Caregiver priorities for Musculoskeletal Interventions in Children with Cerebral Palsy.

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DECLARATION

I, *Dr Shiksha Ragunandan*, 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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Shiksha Ragunandan

Date: February 2025

Cape Town, South Africa

DEDICATION

This research is dedicated to all the children whose bravery and resilience inspire me as they fight for their recovery from illnesses and injuries.

SUMMARY

Determining the Goals of Musculoskeletal Interventions for Children with Cerebral Palsy.

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ABSTRACT

Introduction

Cerebral palsy is caused by an insult to the developing brain and typically results in the development of musculoskeletal deformity and resultant physical disability. These deformities are frequently addressed by non-invasive measures such as physiotherapy and splinting, but also by orthopaedic surgery. The musculoskeletal system is affected to varying degrees based on the severity of the cerebral insult and the goals of musculoskeletal interventions will vary accordingly. Little is known about what caregivers' expectations are following non-surgical or surgical interventions for musculoskeletal deformities and treatment is usually based on the expectations of the therapists or surgeons. The aim of this study is to determine the treatment priorities of caregivers of children with cerebral palsy in the context of musculoskeletal intervention.

Methods

Participants were selected from the Red Cross War Memorial Children's Hospital cerebral palsy clinic. Informed consent was obtained from all participants. They were divided into two groups: parents/guardians of children with cerebral palsy who were ambulatory, and those who were non-ambulatory. There were 20 participants in each group who completed the questionnaire regarding difficulties they were experiencing that they expected musculoskeletal interventions would address. A Delphi consensus study design was used to prioritise responses given by participants in the questionnaire. After the first round, all responses were reviewed and a list including all responses was compiled. There were two follow up iterative rounds to prioritise the list of responses given, by asking participants to choose the top four responses relevant to them in the second round and the top 2 responses in the final round. A final percentage agreement of 50% or higher was chosen to denote a consensus.

Results

In the ambulatory group a 60% consensus was reached for the item '*child walks on his/her toes*'. This was the only item that reached more than a 50% consensus. For the items '*difficulty with shoe wear*', '*lack of access to physiotherapy in the community*', and '*difficulty running and playing*', respectively, 45%, 40% and 35% consensus was reached.

No consensus was reached in the non-ambulatory group with only 25% consensus reached for the items *'Difficulty in opening the child's legs for cleaning and changing of diapers*', '*The child is treated differently to other children*', '*Difficulty in carrying the child as they become heavier*' and '*Tight muscles*'.

Conclusions

A consensus was reached in the ambulatory group with correction of a child's '*toe walking'* being the most frequently reported concern. This should be seen as one of the main treatment priorities when assessing treatment options in an ambulatory child.

In the non-ambulatory group, no definitive consensus was reached. This may be due to the fact that children with higher grades of cerebral palsy have many medical complications that have to be addressed, and a child's home circumstances and resources may greatly affect what caregivers prioritise as most important to improve the child's quality of life.

LIST OF ABBREVIATIONS

ADL	Activities of daily living
CP	Cerebral palsy
CPCHILD	The instrument, Caregiver Priorities and Child Health Index of Life
GMFCS	Gross Motor Function Classification System
	with Disabilities
LMICs	Low-and middle-income countries
m	Month
ICF	The International Classification of Functioning, Disability and Health
PODCI	The paediatric outcomes data collection instrument
PEDI	Paediatric Evaluation of Disability Inventory
QoL	Quality of life
RCWMCH	Red Cross War Memorial Children's Hospital
WHO	World Health Organisation
y	Year

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CHAPTER 1: INTRODUCTION

BACKGROUND

Children with cerebral palsy (CP) are often referred to orthopaedic surgeons for review of their musculoskeletal deformities and functional deficits. The degree of disability in these children are varying as a result of the large spectrum of motor deficits that can be present. There are multiple treatment modalities available for managing the musculoskeletal manifestations of CP. Treatment options include observation with physiotherapy and occupational therapy, bracing of limbs and medical and surgical interventions. As healthcare professionals we are trained on how to implement such treatment and offer these treatment modalities based on our own treatment goals and expectations, without fully understanding the parent's/guardian's perspective.

PROBLEM STATEMENT

Little is known about what caregivers of children with CP's difficulties are and what their expectations of treatment is with regards to the improvement of musculoskeletal function in low-and middle-income countries (LMICs). Available functional outcome scores and patient-reported outcome measures for the evaluation of children with CP were all developed in high income countries and are not necessarily applicable in our context[1]. In order to better understand the impact of the treatment we provide to these children, it is necessary to understand what the caregivers of patients with CP's treatment priorities and expectations of treatment are.

LITERATURE REVIEW

CP is a health condition that primarily affects musculoskeletal functions and structures, resulting from damage to the brain in the prenatal, perinatal, or early childhood period[2]. The prevalence of CP can be up to 10 in 1000 live births in parts of rural South Africa[3], which is up to 5-fold higher than in developed countries, posing a significant burden on our healthcare system. CP frequently results in the impairment of musculoskeletal function which may be accompanied by deficits in cognition, sensation, communication, perception, and behaviour[4]. Children affected by CP may have difficulties performing activities of daily living (ADL's) and this may result in a decreased quality of life (QoL) as a result of their disabilities[5].

CLASSIFICATIONS

Many classification systems were developed to describe the functional status and degree of disability in children with CP. The most commonly used functional classification system is the Gross Motor Function Classification System (GMFCS). Patients graded GMFCS I-III are ambulatory, with or without the use of assistive devices, and those classified as GMFCS IV and V are non-ambulatory (Figure 1)[6-7]. Ambulatory patients are often highly functional and are able to perform many tasks independently while many non-ambulatory patients require a significant amount of assistance even with activities of daily living[6]. Correlation between GMFCS and functional outcomes such as mobility and self-care has been investigated using different outcome measures. In a Korean study involving 77 patients, significant correlation was found between the GMFCS score and the Activity and Participation as well as the Function components of the International Classification of Functioning, Disability and Health Checklist[8]. Park et al, evaluating 217 children with CP, found significant correlation between subjects' GMFCS level, the Gross Motor Function

Level (GMFM) and the Self-Care and Mobility domains of the Paediatric Evaluation of Disability Inventory (PEDI)[9].

There are other classifications relating to the topographical distribution of the affected limbs or the type of movement disorder. These classifications are however not useful in assessing response to treatment as they are merely descriptive in nature. The type of movement disorder and topographical distribution may however be predictive of motor function, for instance patients with unilateral CP will nearly always be ambulant and patients with dystonia or dyskinesia are less likely to have functional use of their upper limbs[10].

OUTCOMES OF INTERVENTIONS

Children with CP typically undergo multiple physical interventions such as physiotherapy, occupational therapy and orthotic treatment to optimise and maintain their function[11]. Medical interventions, orthopaedic surgery[12] and neurosurgical interventions can also be used to address musculoskeletal manifestations of CP, with the aim of decreasing spasticity, improving function, and thus improving the child's QoL[13]. This often involves major surgical interventions that hope to improve function or make caring for these children easier for caregivers. Healthcare providers typically have specific treatment goals, such as increased joint range of motion and correction of deformities, however it is not clear whether these therapeutic goals are in accordance with the needs and expectations of the patients and their caregivers. A study from Greece and Italy looked at parent perceptions of CP and their expectations from surgery. Researchers conducted semi-structured interviews of the parents of children with CP during the perioperative period while they were in hospital. These interviews allowed parents to express their opinions on CP and their expectations of the procedures their children were going to receive. In this study

parents saw CP as a medical condition that affected the entire family. With regards to their expectations from surgery, parents wanted to improve their child's QoL and improve their function[14]. This study was performed in a first world setting, with different cultural and societal influences and this topic still needs to be explored in a South African setting, for a better understanding of the population we treat.

The activities of daily living (ADLs) is a term used to collectively describe fundamental skills required to independently care for oneself, such as eating, bathing, and mobility[15]. Treatment is often offered with the aim of improving the ADLs of a patient[14]. Many instruments or scoring systems used to assess outcomes use ADLs to assess improvement in function. A study conducted in Uganda showed that children with CP participated less in the activities of daily living, and among children with CP, children with severe CP participated less than those with milder forms[16].

Quality of life (QoL) refers to the health, comfort and happiness experienced by an individual[17] and the physical disability in children with CP may significantly decrease their quality of life. A systematic review and meta-analysis[18] assessing children and adolescents with CP and their QoL showed that their physical quality of life was invariably affected, however correlation with psychosocial quality of life was less clear. Researchers also commented that when assessing the QoL of children with CP, functional abilities should not be the only items assessed, and psychological and social factors also impact their overall quality of life. The ADLs allows clinicians to objectively quantify a patient's functional abilities, however, QoL is a subjective, multifaceted entity.

Scoring systems to assess function and outcome measures have been created. Many of these systems use the ADLs to assess the function of the child using linear scoring systems to allow healthcare workers to assess a child's baseline function. Thereafter these

scores would quantify the improvement following interventions and give healthcare workers an impression of whether there is an improved QoL.

The International Classification of Functioning, Disability and Health (ICF) is a classification used by the World Health Organisation (WHO) that standardises the information on how a person's disability affects a person's ability to function. It includes 3 main factors: body functions and structures, activities and participation and personal and environmental factors. This system looks at the interplay between these factors and the effect on the patients' health status. A systematic review[19] was performed using this classification as an outcome measure in children with CP who underwent lower limb orthopaedic surgery. The results of this study showed a mixed response to interventions due to the lack of uniformity and limited number of studies there were to review, making direct comparisons difficult. They found that older children generally had lower functional scores, and that children attending 'special schools' showed greater functional improvement following orthopaedic surgery. However, this study did conclude that more qualitative studies were needed to look into the perspectives of healthcare workers, patients and their families and that personal and environmental factors may influence outcomes.

The instrument, Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) was developed to gain a validated, disease specific measure of caregivers' perspectives. It was developed with input from caregivers, healthcare providers and a review of other measures[20]. After review, 36 items within 6 domains were identified: Personal care/ ADLs, Positioning/ Mobility/ Communication/ Social interaction, Comfort/Emotions & Behaviour, Health; Quality of life and additionally, Caregiver's perspective on the importance of these items to the child's quality of life[21]. This instrument has been validated in over 20 languages including Dutch[22], French[23], Brazilian-Portuguese[24] and Korean[25] showing longitudinal validity in multiple languages. The

CPCHILD is scored as a measure out of 100. During the initial development of this instrument, the mean CPCHILD scores for children in GMFCS Levels I to V were 22.0, 38.2, 23.0, 44.5, and 59.3 respectively ($p<0.001$) [20].' This tool has been shown to be effective in multiple populations, however the questionnaire is very detailed and some of the items may not be applicable to our patient population in South Africa. A study by Kesteren et al looked at the appropriateness of quality of life measurements, including the CPCHILD, in LMIC, and concluded that care should be taken when utilising these instruments in LMIC because they do not take into consideration beliefs and stigma as well as the cultural and contextual nuances in these populations[1]. There is also no validated CPCHILD instrument in any of our 11 official languages, other than English, which makes it difficult to assess many of our South African patients who do not speak English.

A study conducted by Scott el al[26], comparing the paediatric outcomes data collection instrument (PODCI) and the gross motor function measure (GMFM), showed that there was a statistically significant correlation between the two scoring systems with both showing comparable improvement after intervention. The PODCI is a patient-reported outcome measure that is used to assess outcomes after orthopaedic surgery. This instrument measures 86 items broken down into 3 categories: global function, happiness, and expectations, and is filled out by caregivers of children with CP who are under the age of 11[26]. The GMFM is considered the gold standard of assessment of motor function in a child with CP and takes about 45-60 minutes to complete by a registered therapist. Both these systems can be applied prior to and after interventions to assess for improvements in motor function as a result of the interventions performed[27]. Other systems include the Paediatric Evaluation of Disability Inventory (PEDI), and Cerebral Palsy Quality of Life Questionnaire for Children (CP-QOL), which also include a Likert type scaling system over multiple items.

The problem faced when using these scoring systems is that they are very detailed and time consuming and have to be administered on multiple occasions to assess improvement. In a resource strapped setting, this is often not sustainable and many of the items described within the detailed questionnaire may not be applicable to our population's needs. This limits the ability of healthcare providers to objectively assess the impact of interventions on their patients' function and QoL.

CONSENSUS PROCESS

In the medical field, having a consensus with regard to the management of a condition has become vital in providing uniform, good quality healthcare[28]. The Delphi technique is one method that researchers use to come to a consensus[29]. There are many variations to this technique based on the topic being researched and the participants involved, however, it can largely be broken down into two components. Firstly, participants are asked open-ended questions in response to the research question, the researchers then analyse all responses and a list of all the responses are compiled while maintaining anonymity. In the second part, participants receive the feedback of all the responses and are then tasked to prioritise the list. This may be carried out in different manners based on the researcher's preference. Participants' exposure to other ideas and opinions allow them to have a broader insight into the topic and this allows them to potentially prioritise options they may have missed themselves. This may be carried out over multiple rounds, whereby participants are given feedback on the opinions from the previous round and asked to prioritise their responses again.

There is no consensus on the number of participants to insure the validity of a Delphi study with numbers varying, having from 10-1000 participants[30]. A threshold percentage with

regard to a consensus varies between studies, often between 50%-95%[29], and the decision on the percentage threshold is normally set by researchers. Panel members should be considered experts on the topic being researched. An expert can be defined as someone with knowledge and experience on a particular subject matter' however, it is practically difficult to measure experience quantitatively[30]. The use of strict selection criteria for participants who are experts on a topic, strengthens the qualitative recommendations of the panel[30].

The endpoint of a Delphi study is reached when a consensus is reached or in the case of the modified Delphi technique, after a fixed predetermined number of rounds have been completed.

The Delphi technique takes the collective accounts of a group's opinion and processes them in a strictly structured manner. Thus this methodology can be described as a qualitative, quantitative or a mixed methods approach[31].

Delphi studies are still subject to bias, and this may be caused by multiple factors such as participant selection, panel management, dropout from the study and the manner in which the questionnaire is written. As Delphi studies are partially qualitative, bias can also become problematic with data analysis and reporting. Therefore, these concerns should be taken into consideration when designing a study to improve the validity of the result[32].

THE NEED FOR FURTHER RESEARCH

There are many studies that focus on the treatment options available for CP and the different outcome measures that can be used to assess them. Many studies have looked at parent's perception on treatments for CP, however these studies were not performed in a South African setting. Our South African population is exposed to different social

circumstances and their expectations may differ from those of high-income countries. A recent study by Savage et al[33] explored the lived experience of caregivers of children with CP described in 3 categories: physical wellbeing, activity participation, and family and community. Some of the factors contributing to QoL in this study were the ability to play with other children, attending school and being able to sit and back-carry, back-carrying being a unique requisite for people living in developing countries with limited access to public or personal transport. The study gives an insight into what a child's and his/her caregiver's view of their condition is in a rural South African setting, however it was not intervention driven, and did not focus on interventions this population expected/required. There have been no dedicated studies to ascertain what the expectation of treatment is for children with CP. The goal of this study is to prioritise a list of caregivers' priorities for musculoskeletal interventions for children with CP, based on their GMFCS level. For the purpose of this study, we will divide patients into ambulatory (GMFCS I-III) and non-ambulatory (GMFCS IV-V) groups as the functional goals between these two groups would be markedly different.

AIMS AND OBJECTIVES

Aim

To improve our understanding of treatment priorities based on caregiver needs and expectations for musculoskeletal interventions in patients with CP, according to their ambulatory status.

Objectives

Identify difficulties and concerns experienced by caregivers of children with CP.

Determine the caregiver's/parents' expectations of musculoskeletal intervention in improving the child's QoL and ability to perform ADL's.

CHAPTER 2: METHODS

STUDY OUTLINE

The study was carried out in Cape town, South Africa at Red Cross War Memorial Children's Hospital (RCWMCH) Orthopaedic Cerebral Palsy clinic. The study was a prospective, cross sectional, Delphi consensus study.

Level of evidence: V.

STUDY POPULATION

The study population consisted of primary caregivers of children under the age of 16 who were diagnosed with CP and attended the orthopaedic cerebral palsy clinic. Caregivers who were unable to provide consent or who refused to participate in the study were excluded. There was a total of 40 participants in this study.

RESEARCH PROCEDURE

All research procedures were followed in accordance with the University of Cape Town guidelines for conducting research prior to the study being done. Approval was attained by the UCT Departmental Research committee, the UCT ethics committee,

For the purpose of this study, we decided to perform all 3 iterative rounds of the Delphi consensus study in person, on one day, thereby diminishing 'drop-out', improving compliance and eliminating the cost of travel for participants.

Caregivers were identified at the Orthopaedic CP clinic that takes place at RCWMCH in the months preceding the intended data collection date. They were asked if they were willing to participate in the study by answering a questionnaire, and if they were agreeable, they were given a follow-up date that aligned with their regular follow-up date and the date of the intended data collection.

Informed consent was obtained from all willing participants. The consent form was available in English, Afrikaans and Xhosa, the laguages spoken by the majority the patients at the clinic and details were explained to participants in their preferred language by an interpreter if they had any questions.

Participants were then asked to fill out a questionnaire regarding the difficulties they experience while caring for their child with CP as well as what interventions they felt may improve or alleviate these difficulties and improve their child's overall function and QoL.

The participants' answers were divided into 2 groups based on the GMFCS level of their child. Level I-III being ambulatory and level IV and V being non-ambulatory.

The 2 groups' answers were compiled into a complete list from all the participants in each respective group and thereafter the participants in each group were asked to prioritise the list based on their experience until a consensus was reached.

CONSENSUS PROCESS

A Delphi consensus study design was used with multiple, iterative rounds of feedback. During the first round, the questions were open ended to avoid any introduction of bias. The questions asked are stated on the attached questionnaire (Addendum 2) and are divided into the main categories that contribute to the activities of daily living and the quality

of life for the child. This was to get a wide spectrum of responses from all the different aspects of the child's life that may be affected by cerebral palsy.

Answers to these questions were compiled, distilled into the two categories and anonymised. Responses which were very similar were combined into single items. Items such as '*my child walks on their toes*', '*my child does not walk on their heels*' and '*my child walks with pointed toes*' would all be grouped into a '*walks on toes*' item. '*My child crosses their legs*', '*my child cannot open their hips*' and '*my child's hips are stiff*' were all grouped under the '*difficulty opening their legs*' item. The questionnaire for round 2 was prepared for each of the two groups after analysis of the responses.

In the second round, participants were able to choose the most important items by selecting the 4 most relevant items from the list provided. In the last round the list of items was reduced by removing the 20% of responses with the least votes. Participants were then asked to choose the top 2 items that they found most relevant to their situation from the remaining items on the list. A percentage of agreement for a specific item was calculated as the number of votes for that item divided by the number of participants multiplied by 100. A final percentage agreement of 50% or greater was regarded as consensus. The list was also prioritised based on the number of votes each response received.

DATA ANALYSIS

The Delphi Study process, as stated above, was used to get the final results for the study. The data collected was analysed and presented using descriptive statistics. A consensus was accepted when the percentage agreement was ≥50%.

ETHICAL CONSIDERATIONS

Informed consent was obtained prior to giving the parents/ caregivers the questionnaire, and they could stop participating at any time during the study.

This study involved asking patients to fill out a questionnaire during their regular follow up visit and no extra visits or costs were incurred by the participants.

There were no risks or benefits to patients who took part in this study, however the information obtained could enable healthcare workers to better tailor treatments to patients with similar conditions in the future.

Patients answered their questionnaires individually to maintain privacy. Information collected was de-identified and no personal information was collected. Information was stored on a password protected computer and the final data set was uploaded to the UCT data storage platform, ZivaHub.

CHAPTER 3: RESULTS

GENERAL DATA

Forty participants completed all three rounds of the Delphi study. There were 20 participants in each group: ambulatory and non-ambulatory. All three rounds of the study were completed in a single day at the orthopaedic cerebral palsy clinic at RCWMCH.

ROUND 1

Within the ambulatory group there were 9 children who were classified as GMFCS II and 11 children classified as GMFCS III. The mean age of the children being treated was 4 years and 7 months. There were 8 females and 12 males. All the children had some form of therapy prior to being seen at the orthopaedic CP clinic. The mean age at which the child was diagnosed with CP was 18 months and the mean age at which they first received some form of physical therapy was 19 months, showing a short interval between diagnosis and initiation of treatment in most patients seen at our clinic. Sixty-five percent of the children had previous surgery and 75% used some form of assistive device such as splints or a walking frame. (Table 1). An array of responses to the questionnaire was received. Parents noted difficulties such as '*[their child] having difficulty opening their hands when doing tasks', '[that their child's] muscles are weak and they can't put on their own shoes', '[their child] always walks on their toes*' and that they were concerned that *'[their child] was treated differently because of their condition*'. With the guidance of the open-ended questionnaire, 16 items were identified by the parents, with which they experienced difficulties when caring for their child with CP and the questionnaire for round 2 was prepared (Addendum 3).

Table 1. Descriptive Characteristics and Distribution of Study Participants		
	Total	%
Ambulatory	20	
Age (mean,(range))	4y 7m, (2y-9y)	
Gender		
Female	8	40
Male	12	60
GMFCS Classification		
GMFCS II	9	45
GMFCS III	11	55
Age diagnosed with CP (mean(range))	18m, (2m-36m)	
Age first seen by a therapist (mean(range))	19m, (2m-36m)	
Had previous surgery	13	65
Use of an assistive device	15	75
Non-Ambulatory	20	
Age (mean(range))	5 y 2m, (2y-11y)	
Gender		
Female	6	30
Male	14	70
GMFCS Classification		
GMFCS IV	14	70
GMFCS V	6	30
Age diagnosed with CP (mean(range))	9m, (2m-24m)	
Age first seen by a therapist (mean(range))	11m, (2m-24m)	
Previous surgery	12	60
Use of an assistive device	18	90

Within the non-ambulatory group there were 14 children who were classified as GMFCS IV and 6 children classified as GMFCS V. The mean age of the children being treated was 5 years and 2 months, there were 6 females and 14 males. As for the ambulatory group, all children seen at the orthopaedic CP clinic had some form of physical therapy prior to referral. The mean age of diagnosis of CP in these children was 9 months and the mean age at which they first received physical therapy was 11 months. This is a much younger age than that noted in the ambulatory group. Sixty percent of patients had previous surgery

and 90% used an assistive device such as a wheelchair or splints. (Table 1). Once again, a large array of responses was received. Parents commented that *'[their child] could not open their legs properly or straighten their arms and legs*', *'[they] find it difficult dressing their child and putting their arms through sleeves*', *'[they] have difficulty carrying [their child] around because [they] are gaining weight'* and *'[they] feel that '[their child] is not treated like a human being and people say that [their child] is weird'.* Many parents commented that they required more accessible physiotherapy as it was difficult and expensive to travel to Red Cross hospital for treatment. With the guidance of the open-ended questionnaire, 23 items were identified by the parents with which they experienced difficulties when caring for their child with CP and the questionnaire for round 2 was prepared (Addendum 4).

ROUND 2

Table 2. Results of round 2- Ambulatory group

	Votes	%
Difficulty finding comfortable shoes/ shoes come off	13	65
Walks on toes	13	65
Difficulty playing sports/running	9	45
Not enough physiotherapy in the community	8	40
Difficulty putting shoes on themselves due to weakness	7	35
Not being given directed programs for at home therapy	5	25
Difficulty using both hands together	5	25
Walkers use a lot of space when travelling	3	15
Arm muscles are tight	3	15
Not receiving enough information about your child's condition	1	5
Poor self-image because they are treated differently in society	1	5
Not enough facilities that accommodate children with special needs	1	5
Better devices to maintain position when sitting and standing	1	5
Child does not get included with other children because of their CP	1	5
Difficulty opening hand	1	5
Treatment needs to be individualised	0	0

During round 2 the participants chose the 4 most relevant items from the list provided. When the data was compiled, it allowed the researchers to prioritise the list in order of the most votes. The breakdown of round 2 is shown in Tables 2 and 3 for the ambulatory and non-ambulatory groups respectively. By removing the items with the least votes, which was equivalent to about the bottom 20%, the questionnaire for round 3 was compiled with 18 items in the non-ambulatory questionnaire and 11 items in the ambulatory questionnaire (Addendum 5 and 6).

Table 3. Results of round 2- Non-Ambulatory group

	votes	%
Having to carry them as they get heavier	9	45
Muscles are very tight	9	45
More physiotherapy in the community.	9	45
Maintaining a sitting position	8	40
Opening their legs to go to the toilet and wash them	5	25
The way they are treated differently to other children	5	25
Wheelchair/ walker uses a lot of space and you can't travel with it	5	25
Putting arms through sleeves while dressing	4	20
Keeping head up	3	15
Pain in hips when pulling the legs apart	3	15
Child does not get included with other children because of their CP	3	15
Arms and legs make big jerking movements	3	15
Chokes while eating	3	15
They look different to other children because they cannot walk or do the same things	2	10
Cannot find transport easily due to them being in a wheelchair or walker	2	10
Unable to use arms independently	2	10
Difficulty standing	2	10
Your child is unable to move from one place to another independently	1	5
Feeding your child without proper utensils	1	5
Not given enough information about your child's condition by healthcare workers	1	5
Better devices for sitting and standing	1	5
Difficulty moving without an assistive device	0	0
Toilets not conducive to wheelchairs	0	0

ROUND 3

The results of round 3 are summarised in Tables 4 and 5. The items were re-evaluated, and the items were phrased as a problem list.

In the ambulatory group a 60% consensus was reached for the item '*child walks on his/her toes*'. This was the only item that reached more than 50% consensus. For the items '*difficulty with shoe wear*', '*lack of access to physiotherapy in the community*' and '*difficulty running and playing*' respectively, 45%, 40% and 35% consensus was reached.

Table 4. Results of round 3: Ambulatory group

	Votes	%
Walks on toes	12	60
Lack of access to physiotherapy in the community	8	40
Difficulty playing sports/running	7	35
Difficulty finding comfortable shoes/ shoes come off	6	30
Difficulty putting shoes on themselves due to weakness	3	15
Walkers use a lot of space when travelling	2	10
Difficulty opening hand	1	5
Difficulty moving arm muscles, as they are tight	1	5
Not being given directed programs for at home therapy	0	0
Not enough facilities that accommodate children with special needs	0	0
Difficulty using both hands together	0	0

The results of the non-ambulatory group were more varied, and no consensus was reached in this group with only 25% consensus reached for the items '*Difficulty in opening the child's legs for cleaning and changing of diapers*', '*The child is treated differently to other children', 'Difficulty in carrying the child as they become heavier'* and *'Tight muscles'*.

Table 5. Results of round 3: Non-Ambulatory group		
	Votes	%
Difficulty opening their legs for cleaning and changing of diapers	5	25
The way they are treated differently to other children	5	25
Difficulty carrying their child as they get heavier	5	25
Difficulty moving limbs as their child's muscles are very tight	5	25
Their child experiences pain in hips when pulling the legs apart	3	15
Lack of access to physiotherapy in the community.	3	15
Difficulty maintaining a sitting position	2	10
Difficulty standing	2	10
Wheelchair/ walker uses a lot of space and you can't travel with it	2	10
Arms and legs make big jerking movements	2	10
Difficulty keeping their head up	1	5
Their child is unable to move from one place to another independently	1	5
They look different to other children because they cannot walk or do the same things	1	5
They cannot find transport easily due to their child being in a wheelchair or walker	1	5
Their child does not get included with other children because of their CP	1	5
Their child chokes while eating	1	5
Difficulty putting arms through sleeves while dressing	0	0
Difficulty feeding their child without proper utensils	0	0

The results were then further analysed by the reviewers, grouping responses into broader categories. Within the ambulatory group there were 28 responses for the group '*Difficulties with muscle tone and strength in the lower limb',* with some caregivers selecting more than 1 item within this category. *'Lack of access to amenities*' was the second priority that caregivers wanted addressed with 10 responses and the least votes were in the category '*difficulties with muscle tone and strength in the upper limb'.*

Table 6. Analysed responses: Ambulatory group		
	Votes	%
Difficulties with muscle tone and strength in the lower limb	**28**	**140**
Walks on toes	12	60
Difficulty playing sports/running	7	35
Difficulty finding comfortable shoes/ shoes come off	6	30
Difficulty putting shoes on themselves due to weakness	3	15
Difficulties with muscle tone and strength in the upper limb	**2**	**10**
Difficulty moving arm muscles, as they are tight	1	5
Difficulty opening hand	1	5
Lack of access to facilities/ Amenities	**10**	**50**
Lack of access to physiotherapy in the community	8	40
Walkers use a lot of space when travelling	2	10

In the non-ambulatory group, 5 groups of priorities were identified. Seventy-five percent of responses pertained to '*muscle tightness'*, 30% agreed that they had difficulty with '*positioning, transferring and mobility'.* Thirty-five percent of parents agreed that they had '*psychosocial concerns'* about their child's wellbeing, 55% of caregivers agreed that they had '*accessibility difficulties* and only 1 parent felt that '*difficulty feeding'* their child was a problem they faced.

Table 7. Analysed responses: Non-Ambulatory group		
	Votes	%
1 Muscle tightness	**15**	**75**
Difficulty opening their legs for cleaning and changing of diapers	5	25
Difficulty moving limbs as their child's muscles are very tight	5	25
Their child experiences pain in hips when pulling the legs apart	3	15
Difficulty putting arms through sleeves while dressing	0	0
Arms and legs make big jerking movements	2	10
2 Positioning, transferring and mobility	**6**	**30**
Difficulty maintaining a sitting position	2	10
Difficulty standing	2	10
Difficulty keeping their head up	1	5
Their child is unable to move from one place to another independently	1	5
3 Psychosocial concerns	**7**	**35**
The way they are treated differently to other children	5	25
They look different to other children because they cannot walk or do the same things	1	5
Their child does not get included with other children because of their CP	1	5
4 Accessibility difficulties	**11**	**55**
Difficulty carrying their child as they get heavier	5	25
Difficulty feeding their child without proper utensils	0	0
They cannot find transport easily due to their child being in a wheelchair or walker	1	5
Lack of access to physiotherapy in the community.	3	15
Wheelchair/ walker uses a lot of space and you can't travel with it	2	10
5 Feeding	**1**	**5**
Their child chokes while eating	1	5

CHAPTER 4: DISCUSSION AND CONCLUSION

INTRODUCTION

Despite advances in perinatal health care, CP still affects 1-10/1000 children, placing strain on caregivers and society as a whole[19]. A multidisciplinary team approach as well as advances in physical therapy, assistive devices and medical and surgical treatments have contributed to improving the lives of many children with CP in the past few decades[34], however there are still many challenges that children with CP and their parents may face.

A recent study from Brazil looked at family perspectives on 171 Brazilian children with CP using the Canadian Occupational Performance Measure as their data collection tool. This study showed that ADLs followed by items related to body functions, motor skills and play were most prioritised, and were similar regardless of age or GMFCS level. Though this study was undertaken in Brazil which has a similar socioeconomic backdrop as South Africa, the questionnaire was offered only to patients receiving private healthcare and is not necessarily applicable to all LMIC societies[35].

The degree of the children's functional impairments varies widely, making it difficult to standardise treatment priorities. In addition to this, not all patients and caregivers will have the same expectations from treatment and surgery. A study conducted in Benin in West Africa showed that mothers of children with CP, typically with a low education level, did not find health care workers helpful and that they have the perception that CP is a curse or 'god's will'[36]. These types of perceptions in parents will likely alter their expectations of the treatment offered to their child, resigning themselves to their lot and not seeking to interfere with 'god's will' for instance. In contrast to the Benin study, Tsibidaki et al, in their study conducted in Greece and Italy, showed that parents understood that CP is a medical condition and felt that surgeries could improve their child's overall function and quality of

life[14]. In our study the responses of our participants fell between the two above mentioned studies. Though there were participants who identified issues with basic access to transportation and utilities, the majority of participants in both groups prioritised some form of medical intervention they required. This shows their insight into their child's condition and their belief that medical interventions could benefit their child.

Caring for a child with cerebral palsy has significant financial implications. A study performed in Malaysia estimated the cost for caring for a child with GMFCS V CP to be about USD 12 515 per annum[37]. A similar study done in Australia commented that the out-of-pocket costs of caring for a child with CP was almost double for those who were classified as GMFCS III, IV and V versus GMFCS I and II. In South Africa, there is a huge socioeconomic divide in the population and the financial implication of caring for a child with CP may have impacted the caregivers' responses in this study, particularly the responses related to transport and access to care in the community.

AMBULATORY PATIENTS WITH CP

Ambulatory patients with CP can have a vast range of presentations, from having a very subtle motor deficiency to having marked mobility difficulties requiring the use of assistive devices. In the ambulatory group there was a consensus for the item '*child walks on his/her toes'* and the majority of caregivers agreed that their child experienced some form of lower limb difficulty. This is in keeping with the literature, as an equinus contracture is the most common deformity seen in patients with CP and surgical lengthening of the gastrocsoleus muscle-tendon unit is the most common surgical intervention performed for children with CP[38]. These children often exhibiting toe walking as a result of spastic gastrocnemius and hamstring muscles. These deformities are noticed by parents who present with the complaint that their child has difficulty keeping their shoes on, having a strange gait or

walking on their toes. In our unit, toe walking is initially treated with physiotherapy and bracing followed by Botox injections and tendon lengthening as required.

Another notable finding in this study was that the age of presentation and diagnosis of CP in the ambulatory children were a lot later than those with non-ambulatory CP. On average ambulatory patients were diagnosed at about 18 months, which is around when the abnormal motor milestone would be noted as the child fails to start walking. A study by Hubermann et al looked at the age at which children are initially diagnosed and referred with CP to a neurologist. They found that children referred by other medical specialists were younger (13.6 ± 15.7 months) than those referred by primary healthcare providers (28.8 ± 27.1 months) and that children referred from a neonatal intensive care unit were even younger (9.3 ± 10.2 months). It was also noted that half the children with CP did not have a history of complications at birth[39]. This suggests that children with a milder insult to the brain are initially not identified, but children with more severe insults require other medical interventions, prompting their early diagnosis and referral. At RCWMCH there is a High Risk Clinic that accepts referrals from all the obstetric units in our catchment area, which may also contribute to the early diagnosis of the more severely affected children.

Several studies, examining gait parameters and joint range of motion, have demonstrated improvement in these parameters following orthopaedic surgery, particularly improving ankle range of motion and kinematics following calf muscle lengthening[40-41]. This confirms that the main priority that caregivers want addressed, being the '*toe walking*', can be addressed by orthopaedic surgery with overall good results.

The other items that caregivers prioritised with regard to their child's lower limb functions were *'Difficulty playing sports/running,' 'Difficulty finding comfortable shoes/ shoes come off,'* and *'Difficulty putting shoes on themselves due to weakness*.' These items can be

attributed to the child's muscle weakness which is another clinical symptom in children with CP. The muscle weakness is a result of both neural and musculoskeletal factors. The neural pathway is diminished as a result of the cerebral insult and thereafter there are secondary changes to the size, integrity and fascial arrangements of the muscle[42]. The intrinsic pathology of this type of weakness makes surgical treatment difficult however, evidence presented in a review and meta-analysis, shows that muscle strength training, in ambulatory children and adolescents with CP, had 'positive functional effects on muscle strength, balance, gait, speed, and gross motor function without increasing spasticity'[43]. With regard to the items relating to muscle weakness, all patients in this study were receiving either physiotherapy, occupational therapy, or both. It is acknowledged though that the frequency of these therapeutic sessions is not sufficient and can not necessarily result in the same positive outcomes as reported in the literature.

Red Cross Children's Hospital provides services to patients from a large catchment area, and it is noted that many patients were concerned about not receiving enough physiotherapy in their local community and some felt they needed more individualised care. This may highlight that, though the resources are available at large tertiary and regional hospitals, patients from more rural areas are still finding difficulty accessing therapy. Finding appropriate transport that could accommodate their child, and their assistive device further complicated the patient's ability to travel long distances for regular visits to physiotherapists and occupational therapists. Home based therapy is an important part of management in children with CP. A study from Ethiopia assessed parents' response to home therapy and concluded that the methods of teaching parents how to provide home therapy has its limitations[44]. This was postulated to be due to caregivers' lack of family support, limited access to resources to provide therapy at home and poor knowledge of

the condition. Without close follow-up, these factors result in suboptimal therapy for these patients. Though efforts are being made to decentralise primary health resources such as physiotherapy and occupational therapy in South Africa, access to these services appear to still be lacking, based on caregivers' responses in this study.

Patients who are classified as GMFCS I-III can also have different topographical distributions of motor involvement such as being hemiplegic, diplegic or monoplegic. In patients with hemiplegia, the lower limb dysfunction is often negligible and most children with hemiplegia will be able to walk. The upper limb dysfunction is therefore often a greater cause for concern for caregivers. Difficulties relating to the upper limb were reported several times in Round 1 of the study, for instance *'[my child is] unable to use his/her arms independently*', *'[my child has] difficulty opening his/her hand*' or *'[I have] difficulty putting the arm through a sleeve'*. In these patients, lower limb dysfunction was less of a concern. In the second and third rounds, only one caregiver prioritised an upper limb difficulty. This may indicate that a single functioning hand is considered adequate to perform most ADL's or that greater priority is given to good mobility and participating in sports and play, which requires the use of both lower limbs. Treatment of upper limb deformities include extensive hand therapy, splinting, botulinum toxin injections and surgical interventions such as tendon transfers and fusions. Surgery is not as frequently indicated for upper limb dysfunction and deformity, as for lower limbs, as the results of surgery are less predictable and often disappointing. A systematic review examining the effects of upper extremity surgery on activities and participation in children with CP concluded that there was limited evidence to support upper limb surgery in children with CP[45]. Hand therapy therefore remains the treatment of choice for children with upper limb involvement. Botulinum toxin injections can be used as an adjunct to therapy but is not recommended for use in isolation[46].

NON-AMBULATORY PATIENTS WITH CP

In the non-ambulatory group, there was less of a consensus from caregivers as to what was considered a priority requiring intervention. As only a 25 % consensus was reached for the specific items *'difficulty opening the child's legs', 'the way their child was treated differently', 'having to carry them as they get older'* and '*that their muscles are tight*', it was interesting to see that the expectations of patients in this study seemed to be in keeping with an acceptable attainable function, considering the degree of disability of their child. The poor consensus highlights how the needs of each patient and caregiver is individualised, probably based on the severity of the child's impairment and the social circumstances of the family. For example, access to a private motor vehicle drastically impacts the ability to move around with their child however many of our patients are reliant on public transport.

When looking at the broader categories, 75% of caregivers agreed that muscle tightness was a priority that they wanted addressed. This consensus was achieved by looking at the items '*Difficulty opening their legs for cleaning and changing of diapers', 'Difficulty moving limbs as their child's muscles are very tight*', '*Their child experiences pain in hips when pulling the legs apart*' and '*Difficulty putting arms through sleeves while dressing*.' Though the exact site may differ among patients, muscle spasticity and tightness was a category that caregivers saw as a priority that needed to be addressed. Treatment for muscle spasticity is regularly addressed by healthcare workers and treatment modalities include physiotherapy, splinting, botulinum injections and various neurosurgical and orthopaedic procedures[34]. These interventions aim to reduce the spasticity of the muscles in children with CP and improve or prevent contractures of joints. In this category it appears that the aims of health care providers correlate with the priorities that caregivers want addressed.

Difficulties with positioning, transferring and mobility was another broad category that some of the of the items could be grouped into, with 30% of caregivers listing it as a priority. '*Difficulty maintaining a sitting position', 'Difficulty standing', 'Difficulty keeping their head up*' and '*Their child is unable to move from one place to another independently*' were the items that were grouped into this category. In the non-ambulatory child, positioning due to muscle spasticity as well as muscle weakness can be difficult for caregivers to manage. Many children with this type of CP will require assistive devices to aid or maintain the child's position. In this study 90% of children had been given assistive devices to maintain and facilitate positioning and mobility. In this category, caregivers' priorities were also being met by the current care offered at the institution as patients at our institution are provided with specialised wheelchairs, standing frames, spinal braces and other devices. We do however appreciate that these aids are not readily available elsewhere in the country.

Psychosocial concerns had a 35% agreement when the items '*The way they are treated differently to other children', 'They look different to other children because they cannot walk or do the same things'* and '*Their child does not get included with other children because of their CP'* were combined. About a third of caregivers agreed that their children were marginalised as a result of having CP. Some of the specific comments were that '*a doctor said that [their] child looks weird*' and *'people say mean things about the way [their] child looks'.* This is an area in which the healthcare system and society as a whole need to become more aware and proactive in providing the necessary facilities for all people with disabilities. The high prevalence of psychosocial concerns among our participants highlights the fact that a multi-disciplinary involvement in the care of these children is required and is lacking at present.

The items assessed as accessibility difficulties were '*Difficulty carrying their child as they get heavier', 'Difficulty feeding their child without proper utensils', 'They cannot find transport easily due to their child being in a wheelchair or walker'* and *'Lack of access to physiotherapy in the community'.* Fifty-five percent of caregivers agreed that they had difficulties in this category. The item '*Difficulty carrying their child as they get heavier',* is not a difficulty that can be physically improved, however assistive devices for mobility can be attained to accommodate the child as they get older. Some of these devices are offered by our institution, such as wheelchairs, seating supports and standing frames, however more complex devices such as equipment for transferring patients, ramps and stair climbers are not available. The difficulties parents experience with transportation and access to physiotherapy and feeding utensils is a complex issue requiring interventions from multiple stakeholders to implement procedures and allocate resources to reach the peripheral communities. In the interim, as healthcare workers, we can optimise the centralised care when patients do present and offer good quality home-based treatment protocols and assistive devices within the institution's capabilities. Co-ordinating appointments for patients' visits to the hospital will also help alleviate the difficulties caregivers experience with transportation as they will not have to make as many trips.

Three participants stated that children choking when eating was a problem, however this item was not prioritised in subsequent rounds. Although not necessarily a musculoskeletal concern, feeding difficulties are very common in patients with higher grades of CP. In our unit, children who do have feeding difficulties are seen by the surgical team and receive a gastrostomy that aids with feeding, if required.

The results in this group indicate that, even though healthcare workers' treatment aims to optimise seating and mobility for these patients, the difficulties caregivers face is more multifaceted. While physical difficulties such as hip abduction and tight muscles are a

concern, it is weighted equally to other barriers that corrective medical interventions cannot improve, such as carrying the child as they get heavier, and the stigma involved with having CP. When treating a child with CP, it is important to evaluate the medical concerns as well the social factors that affect them, because the caregiver's expectations from treatment prioritises improving difficulties in both areas.

STUDY OUTCOMES

This study highlights the vast array of difficulties caregivers face when caring for a child with CP. It also shows how the expectations are very different based on the severity of the child's CP. Among the ambulatory children, optimising walking and shoe wear was the greatest concern, and a consensus was reached for these items.

In the non-ambulatory group, there was no outright consensus. Though we were unable to reach a consensus in this group, the lack of a consensus is also important. It indicates that a simple classification like GMFCS can't holistically differentiate between patients with such varying degrees of disability, when regular goals of treatment, such as walking and eating are not attainable. In this group the social circumstances and support structure may also influence what caregivers see as a priority that needs to be addressed. Most of our patients are reliant on healthcare provided by the state and are not able to personally fund the significant cost of care for a child with CP. They may therefore prioritise non-medical concerns such as transport and carrying the child above others, as these are the challenges they face daily.

Goal setting is a crucial part of treating patients with CP and caregivers play an important part in this decision-making process. It is important to include caregivers and create a

trusting relationship where family goals, values and individual circumstances can be discussed[47]. It is therefore important to take into consideration caregivers' perspective of their children's condition as this will allow healthcare providers to address the condition in a holistic manner. The findings of our study highlights some of the difficulties that caregivers of children with CP experience in our context.

LIMITATIONS

There were some limitations to this study. Patients were recruited from the orthopaedic CP clinic, which means that they have already been treated to some degree and referred to orthopaedics. Many of the patients have been in the healthcare system for some time and may have internalised the priorities of healthcare providers as treatment goals. In addition, caregivers of children who have already had treatment may no longer prioritise some conditions as their child has already been treated adequately. The participants were from the orthopaedic CP clinic, this may also show a selection bias, as only patients referred for possible orthopaedic intervention where recruited.

The study had a small sample size although considered adequate for a Delphi study[30]. A larger sample size would add more variation and depth to the responses.

There was a lack of consensus in this study, especially in the non-ambulatory group. It was discussed earlier that this may be due to the socioeconomic divide in the population sampled. In future studies the socioeconomic status of participants could be assessed in addition to their expectations in order to see if there is a correlation with the subcategories.

CONCLUSION

A consensus was reached in the ambulatory group with correction of a child's toe walking being the most frequently reported concern. This should be seen as one of the main treatment priorities when assessing treatment options in an ambulatory child.

In the non-ambulatory group, no definitive consensus was reached. This may be due to the fact that children with higher grades of CP may have many medical complications that have to be addressed, and a child's home circumstances and resources may greatly affect what caregivers prioritise as most important to improve the child's quality of life. The views of caregivers and their social circumstances need to be taken into consideration when creating a treatment plan for children with CP because the concerns that parents face are multifaceted, and they all need to be acknowledged and considered when treating children with CP.

CONTRIBUTION

A/Prof Anria Horn: Conceptualisation, editing and manuscript revision
The RCWMCH CP clinic staff and the orthopaedic team for their assistance with data collection.

RECOMMENDATIONS

Based on the responses received in this study, efforts need to be made to make physiotherapy and rehabilitation facilities more accessible to the community especially in this population where a child's mobility is impaired and access to transport can be limited. Parents feel that their children are often marginalised and treated differently by society in general, as well as in the healthcare system. More effort needs to be put into community awareness on cerebral palsy as well as transforming as a society to becoming more inclusive and accommodating of people with disabilities. As healthcare workers, we play a vital role in advocating and protecting these children. Studies with larger sample sizes need to be performed regarding caregiver expectations and also including the subtypes of CP that affects the child, as this affects the child's potential function.

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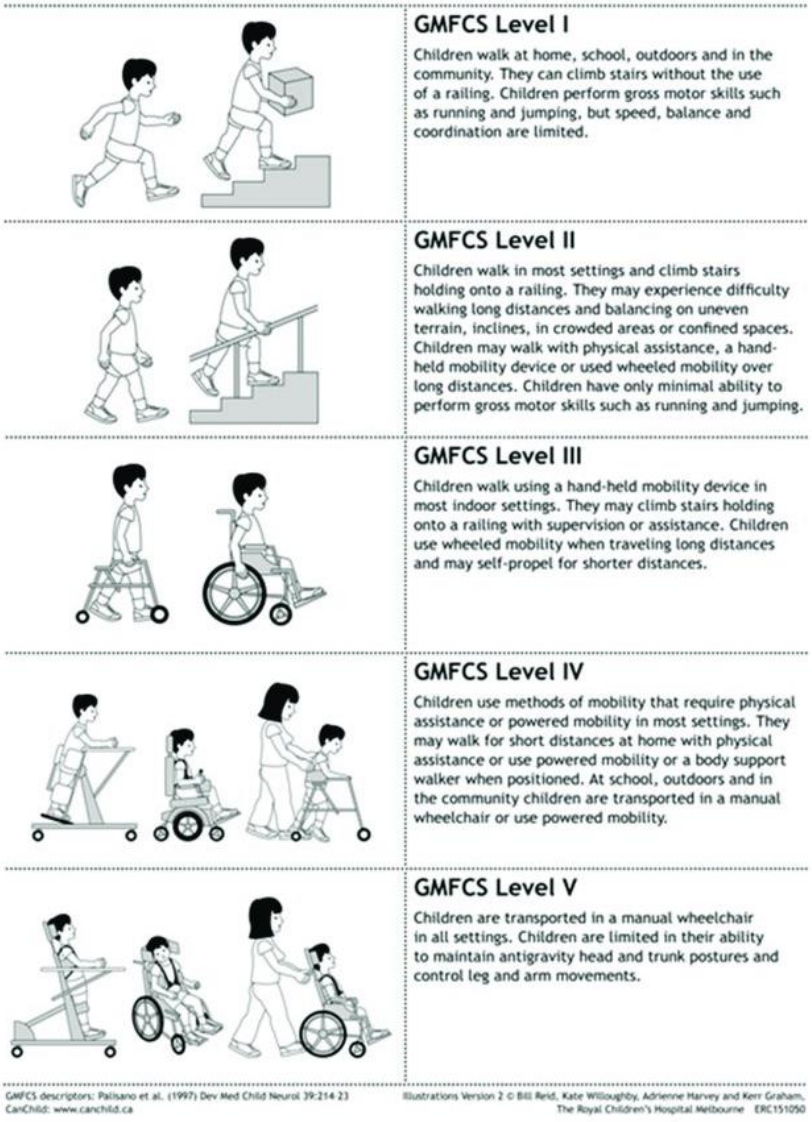
FIGURES

Figure 1: GMFCS Classification system



ADDENDUM 1: Consent Form

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e-mail: shiki.rags@gmail.com

Consent Form

Determining the Goals of Musculoskeletal Interventions for Children with Cerebral Palsy.

Summary
This form is to request permission to carry out a questionnaire about you and your child and the goals of treatment you would like to see. We are trying to gather information to do research into the problems you as a parent face when caring for a child who has cerebral palsy and the ways in which you would like to be helped or see an improvement. This information will help us better understand the needs of our patients and their parents and will allow us to better address the needs of children with cerebral palsy.

What research is being done?
We are caring out a questionnaire to ask parents of children with cerebral palsy what difficulties they face and what interventions may help their child.

Why have you been asked to take part?
You are the parent or guardian of a child with cerebral palsy and know the daily challenges that may occur when caring for a child with cerebral palsy.

How long will the research take?
The questionnaire and your input will be concluded today by the end of the clinic. The information will then be gathered assesses written up as formal research by next year.

Are there risks involved?
No, there are no risks involved for you or your child.

Are there any benefits to taking part in this study?
There are no direct benefits to you or your child but the information received will hopefully help improve treatment for all children with cerebral palsy in the future.

Do I have to take part?
No, it is entirely your decision. You can change your mind at any time and this won't affect the standard of care you receive.

What will happen if I agree to take part?
We will ask you to sign this consent form and answer a short questionnaire. We will ask you a few questions that should take about 10 minutes to answer. Once we have a list of multiple answers to the questions we will ask you a few more questions to prioritise the most important difficulties you and your child face that could be improved by treatment.

What will happen to the information?
All information you give us will be kept strictly confidential. Your personal information will not be shared with anyone at any time.

Who has reviewed this research study?
This study has been reviewed by the UCT FHS Human Research Ethics Committee (Room E52-24 OMB Groote Schuur Hospital, (021) 4066429). There are no specific risks or benefits to taking part in the study.
More information?
If you require any more information you can contact the Principal Investigator, Dr Shiksha Ragunandan.

I, _____, consent to taking part in this study.

_____	_____	_____	_____
Signature	Witness 1	Witness 2	Date

"OUR MISSION is to be an outstanding teaching and research university, educating for life and addressing the challenges facing our society."

ADDENDUM 2: Questionnaire round 1

Questionnaire Round 1

General information

Folder number	
Age	
Date of Birth	
Gender	

Medical History

GMFCS Level
How old was your child when they were diagnosed with cerebral palsy?
How old was your child when they were first seen by an occupational therapist/ Physiotherapist or orthopaedic surgeon?
What treatment does your child currently receive? Please tick ☐ Physiotherapy ☐ Occupational therapy ☐ Splints ☐ Wheelchair ☐ Walking frame ☐ Medical to prevent spasms ☐ PEG ☐ Orthopaedic surgery ☐ Botox ☐ Other: _____
What surgical procedures has your child had?

Activities of daily living

With regards to maintaining the hygiene (toileting and bathing) of your child, what difficulties do you experience?
What do you think we can do to make this easier?
With regards to dressing your child, what difficulties do you experience?
What do you think we can do to make this easier?
With regards to your child being able to move around i.e. walk, sit, stand, what difficulties do you experience?

What do you think we can do to make this easier?
With regards to feeding your child, what difficulties do you have?
What do you think we can do to make this easier?
Does your child experience pain and why?
What do you think we can do to improve their pain?
Do you think that having CP effects your child's self-image?
What do you think we can do to improve this?
Is it difficult for your child to communicate?
How could we improve this?

ADDENDUM 3: Questionnaire round 2: Ambulatory

Questionnaire Round 2- ambulatory

Thank you for taking part in this study.

For this questionnaire please tick the 4 most important/relevant answers from the lists provided.

What are the most important concerns you have for your child with CP

Difficulty finding comfortable shoes/ shoes come off
Not receiving enough information about your child's condition
Difficulty putting shoes on themselves due to weakness
Difficulty playing sports/running
Poor self image because they are treated differently in society
Not being given directed programs for at home therapy
Not enough facilities that accommodate children with special needs
Better devices to maintain position when sitting and standing
Treatment need to be individualised
Child does not get included with other children because of their CP
Walks on toes
Difficulty opening hand
Walkers use a lot of space when travelling
Arm muscles are tight
More physiotherapy in the community
Difficulty using both hands together

ADDENDUM 4: Questionnaire round 2: Non-Ambulatory

Questionnaire Round 2- non ambulatory

Thank you for taking part in this study.

For this questionnaire please tick the 4 most important/relevant answers from the lists provided.

What are the most important concerns you have for your child with CP

Maintaining a sitting position
Keeping head up
Opening their legs to go to the toilet and wash them
The way they are treated differently to other children
having to carry them as they get heavier
putting arms through sleeves while dressing
pain in hips when pulling the legs apart
Your child is unable to move from one place to another independently
They look different to other children because they cannot walk or do the same things
Cannot find transport easily due to them being in a wheelchair or walker
Difficulty moving without an assistive device
Feeding your child without proper utensils
Not given enough information about your child's condition by healthcare workers
Better devices for sitting and standing
Unable to use arms independently
Child does not get included with other children because of their CP
Difficulty standing
Wheelchair/ walker uses a lot of space and you can't travel with it
Arms and legs make big jerking movements
Chokes while eating
Muscles are very tight
Toilets not conducive to wheelchairs
More physiotherapy in the community.

ADDENDUM 5: Questionnaire round 3: Ambulatory

Questionnaire Round 3- ambulatory

Thank you for taking part in this study.

For this questionnaire please tick the 2 most important/relevant answers from the lists provided.

What are the most important concerns you have for your child with CP

Difficulty finding comfortable shoes/ shoes come off

Difficulty putting shoes on themselves due to weakness

Difficulty playing sports/running

Not being given directed programs for at home therapy

Not enough facilities that accommodate children with special needs

Walks on toes

Difficulty opening hand

Walkers use a lot of space when travelling

Arm muscles are tight

More physiotherapy in the community

Difficulty using both hands together

ADDENDUM 6: Questionnaire round 3: Non-Ambulatory

Questionnaire Round 3- non ambulatory

Thank you for taking part in this study.

For this questionnaire please tick the 2 most important/relevant answers from the lists provided.

What are the most important concerns you have for your child with CP

Maintaining a sitting position

Keeping head up

The way they are treated differently to other children

having to carry them as they get heavier

putting arms through sleeves while dressing

Your child is unable to move from one place to another independently

They look different to other children because they cannot walk or do the same things

Cannot find transport easily due to them being in a wheelchair or walker

Feeding your child without proper utensils

Child does not get included with other children because of their CP

Difficulty standing

Wheelchair/ walker uses a lot of space and you can't travel with it

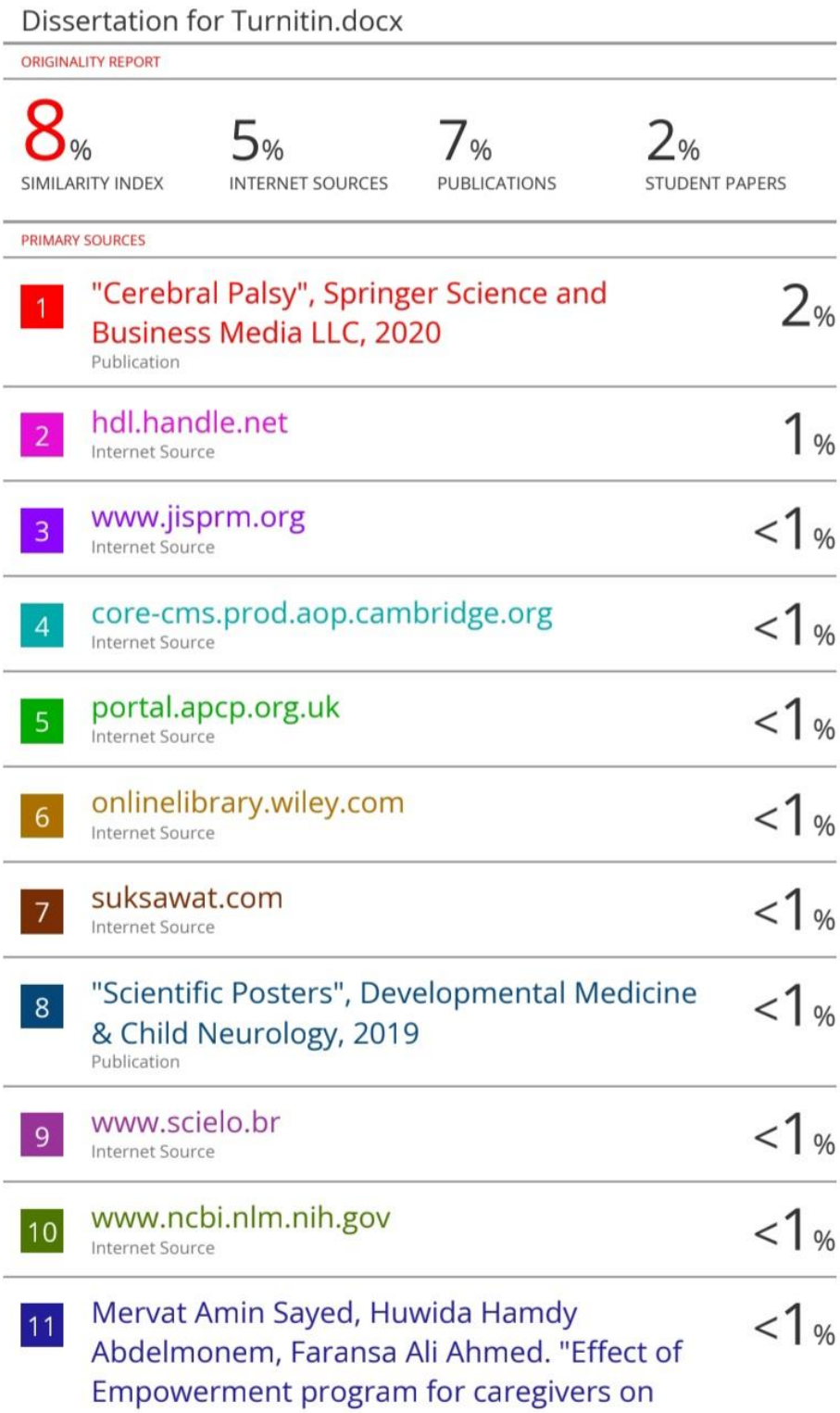
Arms and legs make big jerking movements

Chokes while eating

Muscles are very tight

More physiotherapy in the community.

ADDENDUM 7: Turn it in certificate



Dissertation for Turnitin.docx

ORIGINALITY REPORT

8%	5%	7%	2%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	"Cerebral Palsy", Springer Science and Business Media LLC, 2020 Publication	2%
2	hdl.handle.net Internet Source	1%
3	www.jisprm.org Internet Source	<1%
4	core-cms.prod.aop.cambridge.org Internet Source	<1%
5	portal.apcp.org.uk Internet Source	<1%
6	onlinelibrary.wiley.com Internet Source	<1%
7	suksawat.com Internet Source	<1%
8	"Scientific Posters", Developmental Medicine & Child Neurology, 2019 Publication	<1%
9	www.scielo.br Internet Source	<1%
10	www.ncbi.nlm.nih.gov Internet Source	<1%
11	Mervat Amin Sayed, Huwida Hamdy Abdelmonem, Faransa Ali Ahmed. "Effect of Empowerment program for caregivers on	<1%

	Quality life of children with Cerebral palsy", Egyptian Journal of Health Care, 2021 Publication	
12	Submitted to Queen Mary and Westfield College Student Paper	<1%
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15	Hadi Gerami, G. Hossain Shahcheraghi, Mahzad Javid. "Tendon transfer in spastic cerebral palsy upper limb", Journal of Pediatric Orthopaedics B, 2023 Publication	<1%
16	Ahmet Maslakci, Lütfi Sürücü, Harun Şeşen. "Does the entrepreneur intention vary among university students?", Journal of International Education in Business, 2024 Publication	<1%
17	journals.lww.com Internet Source	<1%
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19	"Scientific Presentation", Developmental Medicine & Child Neurology, 2021 Publication	<1%
20	www.frontiersin.org Internet Source	<1%
21	www.disabilityrightsca.org Internet Source	<1%

22	"European Academy of Childhood Disability Annual Meeting 2003, 2–4th October", Developmental Medicine & Child Neurology, 10/2003 Publication	<1 %
23	Zachary Boychuck, John Andersen, Darcy Fehlings, Adam Kirton et al. "Current Referral Practices for Diagnosis and Intervention for Children withCerebral Palsy: A National Environmental Scan", The Journal of Pediatrics, 2020 Publication	<1 %
24	www.researchgate.net Internet Source	<1 %
25	"American Academy for Cerebral Palsy & Developmental Medicine 2004", Developmental Medicine & Child Neurology, 09/2004 Publication	<1 %
26	Beatriz Revilla-Nuin, Pascual Parrilla, Juan Jose Lozano, Luisa F. Martínez de Haro et al. "Predictive Value of MicroRNAs in the Progression of Barrett Esophagus to Adenocarcinoma in a Long-Term Follow-up Study", Annals of Surgery, 2013 Publication	<1 %
27	Audrey Combey, Rachel Bard-Pondarre, Lionel Erhard, Emmanuelle Chaleat-Valayer. "Retrospective study of functional benefits and satisfaction in multisite upper-limb surgery in children with unilateral cerebral palsy", Hand Surgery and Rehabilitation, 2023 Publication	<1 %

ADDENDUM 8: DRC Approval Letter

UNIVERSITY OF CAPE TOWN

Department of Surgery
Departmental Research Committee
A/Prof Maritz Laubscher
Groote Schuur Hospital
Observatory 7925
South Africa
Tel (021) 404 5108
Email: maritz.laubscher@uct.ac.za

29 Jun 2024

Dr S Ragunandan

Department of Surgery
University of Cape Town

Dear Dr Ragunandan

RE: Project 2024/235

PROJECT TITLE:

The above protocol has been reviewed by the Department of Surgery Research Committee. I am pleased to inform you that the committee approved the scientific merit of the study, and endorse the protocol for submission to the relevant ethics committee.

Although this letter serves as confirmation that the above protocol has successfully passed through the surgical DRC, respective ethics committees still require DRC chair signature before submission.

Please use the above project number in all future correspondence,

Yours sincerely

Signed by candidate

A/PROF MARITZ LAUBSCHER
CHAIR SURGICAL DRC

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ADDENDUM 9: HREC Approval Letter

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

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E-52 — Room46, E-Floor, Old Main Building
Groote Schuur Hospital
Observatory 7925
Email: hrec-submissions uct.ac.za
Website: htt s: /health.uct.ac.za home/human-research-ethics

02 August 2024

HREC REF: 503/2024

Dr A Horn
Department of Orthopaedic Surgery
OMB
Email: Anria.horn@uct.ac.za
Student: Shiki.rags@gmail.com

Dear Dr Horn

PROJECT TITLE: DETERMINING THE GOALS OF MUSCULOSKELETAL INTERVENTIONS FOR CHILDREN WITH CEREBRAL PALSY-
(MSC CANDIDATE-GLOBAL SURGERY-DR SHIKSHA RAGUNANDAN

Thank you for your response letter received 01 August 2024, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

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

Approval is only granted for one year until the 30 August 2025.
Please submit a progress report, using the standardised Annual Progress Report Forms (FHS016) or (FHS 017) if the study continues beyond the approval period. Please submit a Standard Closure form (FHS 010) when the study has been completed, this includes after publication or thesis submission and final completion.
(Forms can be found on our website: www.health.uct.ac.za/fhs research humanethics/forms)

The HREC acknowledge that the student: Dr Shiksha Ragunandan will also be involved in this study.

Please quote the HREC REF 503/2024 in all your correspondence.

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.

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

Yours sincerely

Signed by candidate

PROFESSOR MARC IAN BLOCKMAN

1/3

CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637. Institutional Review Board (IRB) number: IRB00001938 NHREC-registration number: REC-210208-007

HREC REF NO, 503/2024

This serves to confirm that the University of Cape Town Human Research Ethics Committee compiies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for
Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DOH 2020), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH
Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

ADDENDUM 10: NHRD Approval Letter

Red Cross War Memorial Children's Hospital
Department of Health and Wellness
Dr M Salie
Acting Manager: Medical Services

Queries: Ellen.Thomas@westerncape.gov.za
Tel: +27 21 658 5383

Western Cape Government

Date: 25 September 2024

Dr S Ragunandan
Orthopaedic Surgery

Dear Dr Ragunandan,

RESEARCH: RCC 447 / WC_202408_014

PROJECT TITLE: Determining the Goals of Musculoskeletal Interventions for Children with Cerebral Palsy.

Thank you for submitting your study to the Red Cross War Memorial Children's Hospital Research Committee for review.

It is a pleasure to inform you that the Red Cross Children's Hospital Research Committee has formally approved your application to conduct above-mentioned study.

Approval is granted until **30 August 2025** as per your ethics approval **HREC 503/2024.**

Kindly submit a renewal request if your study continues beyond the approval period with a progress report. If the study is completed within the approval period, please inform the committee. A copy of your final document to be submitted after completion of your project.

Kindly quote the reference **RCC 447 / WC_202408_014** in all your correspondence.

Yours sincerely,

Signed by candidate

DR M SALIE
ACTING MANAGER: MEDICAL SERVICES

ADDENDUM 11: Title change approval letter

D9 – Approval of Change of Title - 2015

University of Cape Town

Faculty of Health Sciences

Form D9: Approval for Change of Title

Please complete and return to Vuyi Mgoqi (Vuyi.Mgoqi@uct.ac.za) in the Postgraduate Office

Name and student no	Shiksha Ragunandan RGNSHI001
RGDegree name (e.g. MSc(Med) in Physiology)	
UCT Student Email address for correspondence	rgnshi001@myuct.ac.za
Student signature:	
Date:	21/01/2025

Qualifications	MSc Global Surgery
Old Title	Determining the goals of musculoskeletal interventions for children with cerebral palsy.
Proposed new title	Determining caregiver priorities for musculoskeletal interventions in children with cerebral palsy
Proposed title change supported by Departmental Research Committee (DRC)	Name of Chair, Department Research Committee: Dr Claire Warden Signature: Signed by candidate

Please give reason for the need for to change your thesis/dissertation title:

After compiling and analysing the data the adjustment to the title encompasses the results more accurately as the original title is quite broad, while the new title includes the population that was assessed..

(if you require more space than this then please attach a separate page)

I support / do not support the thesis/dissertation title change as requested by this student			
Supervisor name and signature:	Name: Anria Horn	Signature: Signed by candidate	Date: 21/01/2025
I recommend / do not recommend the thesis/dissertation title change as requested by this student			
HOD name and signature	Name: Professor Robert Neil Dunn	Signature: Signed by candidate	Date: 21.1.2025
I approve / do not approve the thesis/dissertation title change as requested by the above student			
Deputy Dean: Postgraduate Affairs:	Name: Professor Collet Dandara	Signature: Signed by candidate	Date: 24.01.2025