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EVALUATION OF THE USE OF THE CEREBRAL VISUAL IMPAIRMENT MOTOR QUESTIONNAIRE IN THE SOUTH AFRICAN CONTEXT

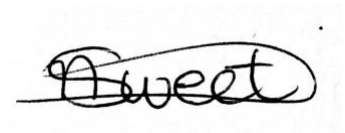
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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, in partial fulfilment of the requirements for the degree of Master of Science in Occupational Therapy

June 2020

Declaration

I, Nikita Ann Sweet, hereby declare that this research report is my own work. It is being submitted for the degree of Master of Science (Occupational Therapy) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.



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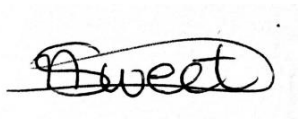
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Abstract

Introduction: Cerebral visual impairment (CVI) is a common comorbidity in children with cerebral palsy (CP) and has a significant impact on their functional capabilities. The various deficits that children with CP may have, make screening and assessing for CVI difficult. An early diagnosis of CVI is important for early intervention. A validated screening tool may assist occupational therapists and physiotherapists in detecting possible CVI in children with CP, and thus assist them in guiding further investigations and preventing costly and unnecessary comprehensive assessments as well as allowing appropriate intervention for CVI.

Methodology: In this study, a descriptive quantitative survey design was used to establish what therapists treating children with CP understand about CVI as well as the current practice in screening for CVI (phase 1). The second part of the study (phase 2) established the content validity, usability and utility of an international validated screening tool called the Cerebral Visual Impairment Motor Questionnaire in the South African context.

Conclusion: There was a total of 38 participants for phase 1, and 14 participants for phase 2. This study showed that majority of the participants understand what a CVI includes, however, a formal diagnosis of CVI in not common practice. There is little to no formal screening and assessment of CVI in children with CP in the South African setting. The CVI-MQ is not valid and usable for some under resourced contexts and inexperienced therapists in the South African context. Rural contexts expressed concerns such as accessibility, relative importance in the setting and time, these must be addressed when suggesting the screening tool for the South African setting.

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Definition of Terms

Cerebral palsy: “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” (Rosenbaum *et al.*, 2007, pg8).

Cerebral visual impairment: “visual deficits of any likely cerebral cause, thereby including a wide range of visual sensory and visual perceptive deficits of known neurological underpinnings, excluding visual deficits due to optical abnormalities” (Salavati et al., 2016, pg2).

Content validity: the measurement of the validity of the domains or constructs of the items in a questionnaire. The content validity of a screening tool is important to ensure a level of confidence in a measurement tool - as to whether a tool measures what it is supposed to measure (Yaghmaie, 2003).

Usability: “The extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use” (Borsci et al., 2019, pg1).

Utility: The necessary components of a clinical assessment and how it relates/contributes to the treatment outcome (Hayes, Nelson & Jarrett, 1987).

Gross Motor Function Classification System: a system which places the individual with cerebral palsy into one of five classifications of gross motor ability according to severity. Level one is the most functional level and level five the most severe. According to literature, as with optical deficits, there is a correlation between the various sub-types of CP and the GMFCS levels (Ghasia et al., 2008).

Strabismus: a condition of the eye that causes the visual axes to be malaligned. This causes misalignment of the eyes. (Bui Quoc & Milleret, 2014).

Nystagmus: “repetitive to-and-fro involuntary eye movements that are initiated by slow drifts of the eye” (Serra & Leigh, 2002, pg615).

Fundus Oculi abnormalities: abnormalities found in the interior of the eye (Griffin, Cline & Hofstetter, 1989).

List of Abbreviations

APA	American Psychological Association
CP	Cerebral Palsy
CT	Computerized Tomography
CVI	Cerebral Visual Impairment
CVI-MQ	Cerebral Visual Impairment Motor Questionnaire
EEG	Electroencephalogram
GMFCS	Gross Motor Function Classification System
ICF	International Classification of Functioning, Disability and Health
LSEN	Learners with Special Educational Needs
LGN	Lateral Geniculate Nucleus
MRI	Magnetic Resonance Imaging
NPO	Non-Profit Organisation
OT	Occupational Therapist
OTASA	Occupational Therapy Association of South Africa
PVL	Periventricular Leukomalacia
SANDTA	South African Neurodevelopmental Therapy Association
SME	Subject Matter Experts
TVPS-R	Test of Visual Perceptual Skills- Revised
VEP	Visual Evoked Potential
VMI	Visual Motor Integration

CHAPTER 1: INTRODUCTION

1.1 Introduction

"Cerebral palsy (CP) is defined as 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" (Rosenbaum *et al.*, 2007, pg9). Although by definition a motor disorder, CP is often associated with numerous non-motor dysfunctions, including disorders "of sensation, perception, cognition, communication and behaviour; as well as by epilepsy and other secondary musculoskeletal abnormalities" (Rosenbaum *et al.*, 2007, pg8).

Since the assessment and treatment of the physical, cognitive and communicative deficits take priority, particularly in children with marked functional limitations, thorough assessment of comorbidities associated with CP is often neglected or are lacking because of the child's already numerous difficulties (Alimović, 2012). The physical, cognitive and communicative deficits in children with CP make the assessment of these various comorbidities, including visual impairments, difficult (Dutton & Jacobson, 2001; Newcomb, 2009). Fairhurst (2012) however emphasised the importance of efficient assessment and intervention in comorbidities associated with children with CP such as the presence of visual disorders including cerebral visual impairment (CVI).

Visual disorders in children with CP include both peripheral deficits within the eye structure and deficits in the central nervous system or CVI (Good et al., 1994). Cerebral visual impairment is caused by damage to the retrogeniculate visual pathways (optic radiations, occipital cortex, visual associative areas). Like CP, CVI is heterogeneous in nature, and there are controversies with regards to its classification. It has been described as visual deficits as a result of cerebral deficits (Salavati et al., 2014). These deficits cover a wide range of visual sensory and visual perceptive dysfunction which result from a known neurological cause but exclude visual deficits due to abnormalities of the eye (Salavati et al., 2016). The clinical manifestations of CVI involve mainly the retrogeniculate pathways, and the presentation of these manifestations are vast. According to Fazzi et al., (2012), these manifestations can include but are not limited to those presented in Table 1.1.

Table 1.1 Manifestations of cerebral visual impairment (Fazzi et al., 2012)

Ocular manifestations	Refractive errors Fundus oculi abnormalities
Visual pathway involvement	Reduced visual field Impaired visual acuity Contrast sensitivity Reduced depth perception Nystagmus
Oculomotor system	Difficulty with fixation Difficulty with smooth visual pursuits Abnormal saccadic movements Strabismus Abnormal ocular movements Strabismus
Visual associative areas	Abnormal visual perception and integration

An early diagnosis of CVI in children with CP is important because there is evidence that early intervention may improve the outcome for a child in terms of quality of life and functioning in every day (Ortibus et al., 2011). The lack of obvious deficits related to the eyes and awareness of CVI in healthcare providers means the condition often goes undiagnosed (Good, 2009; Gorrie et al., 2019). Occupational therapists and physiotherapists are often in a position to identify children at risk for CVI because children with CP are often first seen by these professionals for assessment and treatment. What should be considered in assessment and treatment is how motor and functional ability is affected by markedly fluctuating visual performances, as well as how a CVI affects daily function. It is important to consider functional vision screening and assessment as well as a comprehensive ophthalmological assessment to determine a diagnosis (Ferziger et al., 2011). However, there is a lack of available screening and assessment tools for CVI and therapists use medical history and observations to identify possible indicators or “red flags” for CVI (Salavati et al., 2016). While the presence of CVI can be based on medical history and observations, this is

not sufficient to provide a diagnosis. Given that CVI is a clinical condition based on various signs and symptoms, the recognition of these signs can support further testing using neuroradiological and electrophysiological tests to confirm the diagnosis (Fazzi et al., 2012). Since this type of testing is not always available therapists may either assume the absence or presence of a CVI based on their observations without the diagnosis being confirmed or not consider CVI in their intervention planning at all (Salavati et al., 2016).

1.2 Statement of the problem

Although there is extensive research on assessment and treatment of CP there has been little focus on how CVI affects children with CP and how this can be identified or assessed. Assessment procedures for CVI require extensive training or experience by professionals such as ophthalmologists. The assessment procedures used are not designed to accommodate the other impairments that children with CP have, such as motor deficits. The lack of research on assessment of CVI has been ascribed to the reported difficulty in adapting screening and assessments for CVI for the presence of physical, communicative and cognitive deficits in children with CP (Ferziger et al., 2011; Salavati et al., 2016). In under-resourced areas of South Africa, the formal assessments for CVI are often not available for children with CP, especially those in the public-sector health care system. When assessments are available they are time-consuming and expensive.

Internationally there is limited research on the screening procedures that therapists can use to determine CVI in children with CP with rehabilitation professionals relying on medical history and observations (Salavati et al., 2016).There is also limited information on the effect of CVI on motor ability and daily functioning in children with CP in developing countries (Dutton & Jacobson, 2001; Newcomb, 2009).

Screening tools for CVI in children with CP have not been validated for use in this country and the condition in these children is often under-diagnosed. Although a cost-effective screening tool, the Cerebral Visual Impairment Motor Questionnaire (CVI-MQ), which allows therapists to determine the possible presence of CVI in a child with CP has been published and validated in the Netherlands, this tool has not been

investigated for use in South Africa. It is also not currently known what screening and assessment procedures are used by therapists in South Africa.

1.3 Research question

What is current practice used by occupational therapists and physiotherapists in identifying CVI in children with CP in South Africa?

How do occupational therapists and physiotherapists rate the CVI-MQ for screening for CVI in children with CP within the South African context according to content validity, usability and utility?

1.4 Aim of the study

The aim of this study was to determine the current practice used by occupational therapists and physiotherapists to assess CVI in children with CP in the South African setting and establish the content validity, usability and utility of the CVI-MQ in various South African settings.

1.5 Objectives of the study

This study will have two phases.

Phase 1 objectives:

1. To describe the work-related demographics of occupational therapists and physiotherapists treating children with CP in South Africa.

2. To identify the current understanding of CVI and practice used for diagnosing and screening for CVI in children with CP by occupational therapists and physiotherapists, and how aware they are of how CVI is screened for in various settings in South Africa.

Phase 2 objectives:

3. To establish the content validity of the CVI-MQ for screening for CVI in children with CP in the South African context.

4. To evaluate the usability and utility of the CVI-MQ in screening for CVI in children with CP in various South African settings.

1.6 Significance of the study

In the South African setting, there is not a validated screening tool or assessment tool that can be used by occupational therapists and physiotherapists for early identification of possible CVI in children with CP. Early identification of CVI in children with CP is important for treating therapists to alter intervention plans and facilitate improvement in deficits.

Occupational therapists and physiotherapists often assess and treat motor and other deficits and function in children with CP (Salavati et al., 2016), they may be the first health professionals to notice the effects of CVI on the child's functioning. In many of the South African settings, therapists do not have access to specialists who are able to diagnose CVI in children with CP. Therefore, screening and assessment of CVI in children with CP is usually done through observation based on the medical history of the child. Having a validated screening tool in the South African setting may assist occupational therapists and physiotherapists in detecting CVI in children with CP, and thus assist them in guiding further investigations and providing early intervention.

1.7 Outline of the study

Chapter: 1 Introduction

This chapter introduces the study and looks at the statement of the problem, the aims and objectives of the study and the significance of the study.

Chapter 2: Literature review

This chapter provides a review of the current literature available on CP, CVI and current screening, assessment and intervention for children with CP.

Chapter 3: Methodology

This chapter covers the methods and procedures used to conduct this study. This chapter will be explained in two phases each comprising two parts.

PHASE 1: this phase had two parts

Part 1 - demographic questionnaire to establish the work-related factors for occupational therapists and physiotherapists in South Africa.

Part 2 - CVI questionnaire (developed by researcher) was a survey on the understanding of CVI and the diagnosis as well as the current practice in screening for CVI distributed to occupational therapists and physiotherapists working with children with CP.

PHASE 2: this phase had two parts

Part 3 - Content validity questionnaire used to establish the content validity index of the Cerebral Visual Impairment Motor-Questionnaire (CVI-MQ) for use by occupational therapists and physiotherapists in South Africa.

Part 4 - Usability and utility questionnaire used to establish the usability and utility of the CVI-MQ for use in clinical practice in South Africa.

Chapter 4: Results

This chapter will cover the results from phases 1 and 2 of the study. This chapter considers the results for phase 1 (parts 1 and 2) and phase 2 (parts 3 and 4) separately.

Phase 1, parts 1 and 2: The results are presented according to the participants' demographic information, their current experience working with children with CP, their training experience in working with children with CP, their current practice regarding the screening and assessing of CVI in children with CP.

Phase 2, parts 3 and 4: The results are presented according to the content validity of the CVI-MQ and the usability and utility of the CVI-MQ in the South African context.

Chapter 5 Discussion

This chapter interprets the results from phase 1 and 2 of this study. It also includes the limitations of the study.

Chapter 6 Conclusion

This chapter concludes the main findings of the study according to the objectives. It also includes recommendations of future research and recommendations according to the implications of the study.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter provides a review of the current literature available on cerebral palsy (CP), cerebral visual impairment (CVI) and current screening, assessment and intervention for children with CP. It focuses on the prevalence, demographics, classification and the disorders and difficulties associated with CP, particularly visual dysfunction. The literature on the impact of CVI on children with CP, and how health professionals are screening and assessing for CVI in children with CP are considered, as well as the importance of identification of CVI in children with CP for intervention planning. It aims to highlight the gaps in literature available on screening and assessment for CVI in children with CP.

A search of the literature was conducted using Science Direct, PubMed, Wiley online library, Cochrane and Google Scholar in order to find current research and literature on CP and CVI.

2.2 Cerebral palsy

Cerebral palsy is attributed to non-progressive neurological deficits and the heterogeneous nature of CP results in varying levels of clinical presentation and activity limitation. Rosenbaum, Paneth, Leviton, *et al.*, (2007) reported that it is useful to further classify CP into various categories or sub-groups. Originally, classification focus was on the pattern of distribution and the principal type of tone. However, in order to better understand and manage CP, it is integral that various other components of CP be considered in classification systems. According to these authors, it is recommended that classification be divided into four major components:

- motor abnormalities, including both the type and severity of the tone/movement abnormality, as well as the degree of functional motor ability;
- accompanying impairments;
- anatomical distributions and neuro-imaging results;
- causation and timing of the incident.

Thus, CP by definition remains a motor disorder. Other non-motor disturbances, including disorders of sensation, perception, cognition, communication and behaviour; secondary musculoskeletal abnormalities, (Rosenbaum et al., 2007), epilepsy, intellect, speech and vision are associated with the condition (Steultjens et al., 2004). One of the common visual impairments associated with CP according to Philip and Dutton, (2014) is CVI. Cerebral visual impairment occurs as a result of the central neurological impairment and since the 1990s CVI has been earmarked as the leading cause of childhood visual impairment in children with CP in developed countries (Good et al., 1994).

Although, very little research on CP and associated comorbidities has been reported for the African context, a recent systematic review on African studies, indicated that the comorbidities in countries like Tanzania and Nigeria, were much like those reported in research in developed countries. Epilepsy was the most common comorbidity, followed by deafness and speech impairments, visual impairments and cognitive impairments in between 23% to 47% of children with CP (Donald et al., 2014). Lagunju & Oluleye, (2007) found vision abnormalities in 58% of African children with CP in Nigeria and reported an incidence of 47.7% of children with CVI.

2.3 Cerebral visual impairment

2.3.1 The visual system

The visual system is a complex organisation of function-specific structures that contribute to sight and visual perception. Information in the form of light is taken in from the environment and carried along a visual pathway to the brain for information processing. The visual pathway consists of a system of cells and synapses including the retina, optic nerve, optic chiasm, optic tract, lateral geniculate nucleus (LGN), optic radiations and the striate cortex. Light is converted into a neuronal signal by a sensory cell called a photoreceptor. This signal is synapsed within the retina to various other cells. The axons of the ganglion cells within the retina, and the nasal fibres from each eye, cross over in the optic chiasm. The optic tract then carries these fibres to the LGN. The fibres leave the LGN in the form of optic radiations, which end in the occipital lobe. Information is then carried to visual association areas and neurological centres (Remington, 2012).

2.3.2 Visual system deficits

The visual system, due to its complexity, results in a variety of deficits because over 40% of the brain is dedicated to vision (Dutton & Jacobson, 2001). Damage to the visual system can be caused by many disturbances, including conditions affecting the input from the eye, visual processing disturbances within the brain, impaired eye muscle control and disordered focusing (Dutton & Jacobson, 2001).

Visual deficits associated with the brain can be divided into two streams – firstly, the ventral stream ("what stream") involved in recognition and spatial orientation. The second dorsal stream ("how stream") is involved in perception and movement detection (Goodale & Milner, 1992). The ventral stream runs between the occipital and temporal lobes and the dorsal stream also includes the occipital and posterior parietal lobes and the motor and frontal cortex (Dutton & Jacobson, 2001).

Globally, literature states that damaged visual pathways and/or visual processing centres of the brain, are the most common cause of visual impairment in children, particularly in children with CP (Dutton et al., 2012).

2.3.2.1 Cerebral visual impairment (CVI)

One definition of CVI indicates that the condition includes a variety of visual sensory and perceptive disorders that are of a neurological origin but does not include optical visual impairments (Salavati et al., 2016). This definition of CVI has been challenged in the literature because, like CP, CVI is heterogenous in nature. It has a variety of presentations, therefore CVI has been described as an umbrella term for the varying visual deficits that may present with important differences in neuroplasticity in individuals with a CVI compared to those with an ocular visual impairment (Martín et al., 2016).

The diagnosis of CVI can therefore be a challenge due to its cortical nature, particularly when there is no obvious ocular deficit (Good, 2009). A CVI can range from severely reduced light perception and be present in children with normal visual acuity (Edmond & Foroozan, 2006). The clinical expression of CVI can include oculomotor or visual-cognitive disorders. Thus, there are a wide range of visual deficits which are included

under the umbrella term of CVI depending on the location and severity of the injury to the brain.

Fazzi et al. (2012) found that a large number of children with central nervous system abnormalities presenting with CVI have reduced visual acuity. Approximately half present with reduced contrast sensitivity and two thirds with abnormal optokinetic nystagmus. Oculomotor dysfunction including disorders of fixation, smooth pursuits and saccadic movements were present in between 40% to 60% of children with CVI. They also reported that strabismus was present in three quarters of the participants and involvement of visual associative areas may result in visual perception and integration disorders. This results in behaviour reflected by a short visual attention span and markedly fluctuating visual performances, visual inattention, field losses, difficulty with distance viewing, looking away when reaching, and difficulty viewing novel objects. Dutton (2013) developed a model in which specific visual behaviours that were associated with damage to the ventral and dorsal streams in the brain which included difficulty moving around the environment. Cerebral visual impairment also includes disorders of visual information integration and processing (Dutton & Jacobson, 2001). Of the 25% of participants in their study who were able to complete assessments for visual-perceptual abilities , 88% were found to have visual perception impairment (Fazzi et al., 2007).

2.4 Cerebral visual impairment in children with cerebral palsy

Peri- or post- natal hypoxic ischemia is the most frequently cited cause of CVI in children with CP, although the aetiology can be variable (Fazzi et al., 2012). In a study completed in 2006, CVI cases can be further divided according to pre-term and term births according to the different areas of the brain affected. In a comparative study completed on children with CVI and children without CVI, it was reported that 83% of the children with CVI had medical diagnoses of prematurity and perinatal hypoxia indicating these medical diagnoses are predictive of a high-risk factor for CVI (Van Genderen et al., 2012). In pre-term births, damage to the visual system is generally in the subcortex of the brain around the ventricles while in full term births, damage is generally between major arteries, as well as in the cortex and subcortex (Edmond & Foroozan, 2006).

Cerebral visual impairment has been associated with damage to the retrogeniculate visual pathways which is common in children with CP (Odding, Roebroeck & Stam, 2006) (Fazzi et al., 2012). The resultant white matter injury is termed periventricular leukomalacia (PVL). Other factors causing CV include trauma, infections, toxins and neurological diseases (Good et al., 1994). The higher prevalence of pre-natal causes, such as low birth weight, intrauterine infections and multiple gestation have been associated with CVI in developed countries. In contrast, in developing countries, the risk of CVI is higher due to the greater prevalence of CP which is associated with acquired causes, especially birth asphyxia and neonatal infections (van Toorn, Laughton & van Zyl, 2007).

Globally, according to four research studies, the incidence of CVI in children with CP ranges from 16% - 84% (Alimović, 2012).

Table 2.1 Incidence of cerebral visual impairment in children with cerebral palsy (Alimović, 2012)**.**

Research (year)	**Number of participants with CP**	**Cerebral visual impairment (%)**
Schenk-Rootlieb et al. (1992)	74	84.0
Katoch et al. (2007)	200	28.0
Ghasia et al. (2008)	50	16.0
Elmenshawy et al. (2010)	46	51.4

Statistics of the prevalence of CVI in children with CP in developing countries is limited. However a study conducted in Kenya found the occurrence of CVI in children with CP was the most common ocular deficit (Njambi, Kariuki & Masinde, 2009). A prevalence of 47.7% for CVI in children with CP was reported in Nigeria (Lagunju & Oluleye, 2007).

The disparity in the incidence of CVI in children with CP is accounted for by the difficulty of identifying visual problems which are often masked by communication or motor deficits (Dutton & Jacobson, 2001) and an impairment that is cortical, rather

than an obvious ocular impairment, making it more difficult to recognise (Good, 2009; Ferziger et al., 2011).

In an Italian study, there was a significant correlation found between the different types of CP and various visual dysfunctions. Refractive errors, strabismus, abnormal saccadic movements and decreased visual ability are associated with children with diplegia. Loss of visual field was significantly higher for children with hemiplegia, who also presented with deficits such as strabismus and refractive error. Children with quadriplegia had more severe ophthalmological difficulties. Out of a cohort of 61 children with quadriplegia, 98% had ocular abnormalities, 100% had oculomotor dysfunction and 98% had reduced visual acuity (Fazzi et al., 2012). Similarly, a study conducted in America found the more severe the CP, the more likely a child would have a visual impairment (Ghasia et al., 2008).

2.5 Intervention of cerebral visual impairment in children with cerebral palsy

2.5.1 Screening and assessment of cerebral visual impairment

The various comorbidities associated with CP make it difficult to assess for visual impairments in these children. These comorbidities include, but are not limited to physical, cognitive and communicative difficulties (Dutton & Jacobson, 2001; Newcomb, 2009). When children with CP present with many problems there is often an assumption that their prognosis is poor in terms of function. Therefore thorough assessment of comorbidities associated with CP is not routinely completed or comprehensive (Alimović, 2012), even though it is important that emphasis is placed on comorbidities such as such as the presence of CVI for efficient intervention (Fairhurst, 2012).

An early diagnosis of CVI in children with CP is important because there is evidence that early intervention may improve the outcome for a child (Ortibus et al., 2011). It is vitally important that all children with a neurological dysfunction such as CP be screened for a visual impairment because visual deficits have been associated with delay in functioning and development (Alimović, 2012). Cerebral visual impairment often goes hand in hand with other neurological dysfunctions such as gross and fine motor deficits and cognitive deficits in children with CP (Fazzi et al., 2012). It is

therefore important that CVI is assessed as its own dysfunction and that intervention is specifically altered to address the impairments found in order to improve participation in activities. This is important in addressing the needs of the CP population (Tsoi et al., 2012). Activities of daily living including social interaction and independence in self-care as well as play skills are all affected by CVI.

It is important in management of CVI to note the difference in function for a child that has a CVI versus an ocular visual impairment. Although standardised tests for ocular visual impairment are more readily available, currently screening tools for identifying children at-risk for CVI are lacking and globally assessment of CVI is not time and cost-efficient (Salavati et al., 2016). In developing countries in particular, lack of access to specialists and health care facilities means that CVI in children with CP is often not recognised and it is difficult to have the diagnosis confirmed (Donald et al., 2014). Therefore, identifying children with CP who are at risk for a CVI, often becomes the responsibility of occupational therapists and physiotherapists as they are among the professionals to comprehensively assess and treat children with CP. These professionals are able to observe the child functioning in their everyday environment and often they have to rely on the child's medical history and observations to identify the possible presence of a CVI (Salavati et al., 2016). By identifying and assessing the impact of CVI in children with CP the therapist can review the intervention plan, focusing on the effect of the CVI on every day activities.

This is however not sufficient for a formal clinical diagnosis of CVI (Fazzi et al., 2012). Assessment and diagnosis of CVI entails input from the multidisciplinary team as well as specialised visual techniques if the diagnosis is to be confirmed (Good et al., 1994). Given that the visual manifestations of CVI are broad and depend on the location and severity of the underlying pathology (Dutton & Jacobson, 2001), there are a variety of screening assessments and assessments for CVI.

2.5.1.1. Assessments of body structure and function

The assessments for body structure and function for CVI include three avenues (Chorna, Guzzetta & Maitre, 2017). The assessment of body structure for CVI is routinely done using neuro-ophthalmological and neuro-radiologic techniques such as computerized tomography (CT) or magnetic resonance imaging (MRI) scans as

well as functional MRI's (Fazzi et al., 2007). The second type of assessment for body function include the use of neurophysiological and ophthalmological investigations such as Visual Evoked Potentials (VEP) and electroencephalogram (EEG). These assessments are essential to support the diagnosis of CVI and the associated deficits (Good et al., 1994) and are used to confirm deficits in visual acuity, colour vision, contrast sensitivity, visual fields, movement perception, dorsal stream processing, ventral stream processing, visual memory, control of eye movements, accommodation and cerebral blindness (Dutton & Jacobson, 2001). However ophthalmological testing using VEP (Watson, Orel-Bixler & Haegerstrom-Portnoy, 2010) requires the child to have some level of communication and cognitive ability therefore is not always appropriate for children with CP, given their motor and non-motor impairments (Rosenbaum et al., 2007). Neuro-ophthalmological and neuro-radiologic or MRI procedures as well as VEP are not always available in developing countries such as South Africa due to the lack of access to resources. This has an impact on being able to diagnose CVI in children with CP which has resulted in little to no information on the prevalence and management of CVI in Africa (Donald et al., 2014).

Lastly, behavioural assessments are used to identify the presence of CVI. These behavioural assessments include non-standardised tests for optokinetic nystagmus, visual fields, oculomotor function, visual acuity and visual-perceptual difficulties. For children with CP who can cooperate, optokinetic nystagmus, visual fields, oculomotor function and visual acuity are assessed by introducing objects in the periphery, using light gazing for fixation and tracking, and using preferential looking at cards with patterns. A concern about the use of the behavioural assessments is that these cannot be used for all children with CP, especially those who are more severely impaired (Chorna, Guzzetta & Maitre, 2017). Even obtaining visual acuity for children with CP is difficult due to the accompanying deficits as their clinical picture is often complicated (Opsina, 2007; Fazzi et al., 2012).

All these assessments are focused on the diagnosis of CVI in relation to the constructs of body structure and function rather than the constructs of activity and participation. Children with CVI have unique visual characteristics which require assessment of visual ability and performance as well.

2.5.1.2. Assessments of functional vision – visual ability and performance

When researching the focus and gaps in occupational therapy practice with children with CP in 2017, Anaby et al. found that there has been a move towards performance-based assessment of functional vision which focuses on the visual ability of the child rather than their visual impairment. Recent literature, rather than focusing on the CVI as a body function impairment, considers vison in terms of visual ability and participation in everyday activities (Deramore Denver et al., 2016) where "visual ability" is considered as a measurable construct. This is in line with the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001) and considers how vision is used in activity participation rather than deficits at a body function and structure level (Deramore Denver et al., 2017). Various themes in the article identified how a child uses their vision on a social interaction level and the frequency and efficiency of use of vision in performance of everyday activities.

The inclusion of goal-setting outcomes with parents in terms of the child's visual abilities is also emphasised in a systematic review conducted by Deramore Denver et al (2016). Their review focused on functional vision and the performance of vision-related tasks by children with CP. They concluded that although vision is significantly complex, the use of vision in terms of participation and performance in activities is a measurable construct. In a second review in 2017, Deramore Denver et al. emphasise the importance of assessment tools for visual ability and performance in order to assess how a child with CP participates in daily activities that require vision to identify the presence of CVI. They describe four assessment tools for measuring the use of daily visual performance or functioning, some of which do have proven validity and reliability. However, one of these comprehensive assessments may not be suited to children with CP, while two of the assessments have been designed to be used in conjunction with ophthalmological or VEP assessments for children with CP and motor deficits. The last assessment was designed to use a comprehensive history taking with parents of infants, but not infants with neurological deficits which excludes its use with children with CP (Deramore Denver et al., 2017). None of these assessment tools have been validated for use in developing countries such as South Africa for use in clinical settings by therapists (Ortibus et al., 2011). The four assessments are:

The CVI-Range

A study by Newcomb (2009) explored the CVI-Range, a functional vision assessment developed by Roman-Lantsky. The CVI-Range is an assessment battery used for older children and adolescents. The CVI-Range enables the assessor to determine which of the components of CVI have a negative impact on the child's functional vision. It was found to be a valid and reliable instrument and can be used to determine progress of an intervention programme and this assessment has interrater reliability (r = 0.98), test-retest reliability (r = 0.99) and internal consistency (0.96). There is a question of how much training is needed before an individual is able to conduct the assessment reliably (Newcomb, 2009). This assessment can be purchased in the form of a book and can be expensive and time-consuming to administer.

The Functional Visual Questionnaire

A parent report questionnaire developed in Israel by Ferziger et al. (2011) is to be used alongside a comprehensive ophthalmological assessment and with a visual classification scale. The questionnaire evaluates the daily visual function in task-orientated visual skills and was validated on 77 children with CP and has high values for inter-rater reliability and test-retest reliability. It was found to be a valuable tool in conjunction with a diagnostic performance scale to achieve a comprehensive assessment of visual function in children with CP but no significant difference was found between children with CVI and optic atrophy in terms of their daily visual performance. The questionnaire focused mainly on communication and interactive play because mobility and ADL's were difficult to include for this population of children (Ferziger et al., 2011).

The Visual Skills Inventory

The Visual Skills Inventory was developed in Glasgow by Mcculloch et al. (2007) and was used in conjunction with VEP for children with mild to profound intellectual disability and/or motor impairment. The overall outcomes showed the value in having a Visual Skills Inventory filled out by parents and caregivers to provide valuable information on visual function in children with severe neurological dysfunction.

Although the assessment is suitable for use with children with CP it does not necessarily highlight whether a child has a CVI or not (Mcculloch et al., 2007).

The Preverbal Visual Assessment questionnaire

The Preverbal Visual Assessment was developed by Pueyo et al. (2014) in Spain. It is not a screening tool, but rather a questionnaire used to supplement history taking in a comprehensive assessment. The tool is aimed at infants aged 1 – 24 months. It was found to be a useful scale to determine visual cognitive abilities in children under the age of 24 months (Pueyo et al., 2014). This assessment has not been used in children with neurological deficits and is not necessarily aimed at CVI.

2.5.1.3 Screening of cerebral visual impairment

Since comprehensive CVI assessments are time-consuming and expensive, screening tools have been developed to identify children at risk for CVI and avoid unnecessary formal assessments. Deramore Denver et al (2017) described two tools specifically for screening in their review but one of the screening assessments, may not be suitable for use with children with CP as it does not accommodate motor deficits. Cerebral visual impairment screening assessments need to be cognisant of the different levels of motor function children with CP present with and accommodate differing motor ability.

The review emphasises the importance of the classification of the functional motor abilities of an individual with CP due to the association of motor dysfunction with visual deficits and the impact of vision on motor development. Various classification scales have been standardised and are used to identify the severity of the impairments in children with CP. The most commonly used classification system for motor function used with children with CP is the Gross Motor Function Classification System (GMFCS). This system, places the individual with CP into one of five classifications of gross motor ability according to severity with level one as the most functional level, and level five indicating the most severe motor deficits (Ghasia et al., 2008).

The two screening assessments described in the literature are:

The CVI-Questionnaire

The CVI-Questionnaire is a routine screening tool for the assessment of CVI in children from 2.75 and 6.5 years. It was developed by Ortibus et al. (2011) in Belgium and is a parent report questionnaire. The study showed that the CVI questionnaire was a viable tool with good screening utility which includes domains of attitude; visual fixation; visual field; visual attention problems; and influence of familiar environment. Added items consider ventral and dorsal stream deficits. A good sensitivity and specificity profile and convergence with the Test of Visual Perceptual Skills- Revised (TVPS-R) and visual perceptual subtest of the Beery Visual Motor Integration (VMI) were found. The CVI Questionnaire also has construct validity and high internal consistency (Gorrie et al., 2019).

A study on the questionnaire did not stipulate what level of motor functioning the children were on, and children were excluded if they did not reach a performance age of 6.5 years old. Therefore it was noted that some items in the questionnaire are not appropriate for children with motor disturbances, which is the likely case of a child with CP (Ortibus et al., 2011).

The Cerebral Visual Impairment Motor Questionnaire

The Cerebral Visual Impairment Motor Questionnaire (CVI-MQ) was developed by Salavati *et al.*, (2016). This screening questionnaire takes into consideration the motor ability of a child with CP using the Gross Motor Function Classification System (GMFCS), as well as the impact of potential visual difficulties to perform motor tasks. It was developed to allow for the identification of children with CP who are at risk for CVI. It has been validated for use in developed countries such as the Netherlands where the screening tool was created.

Psychometric studies on the CVI-MQ showed good face validity (agreement 96%) and good usability (95%) for practical use. The CVI-MQ version for GMFCS levels I, II and III had a sensitivity of 1.00 and specificity of 0.96, while the version for GMFCS levels IV and V had a sensitivity of 0.97 and a specificity of 0.98. This is important as it indicates that the CVI-MQ does fulfil some of the required psychometric properties of

screening tools. However, these have not been established for the CVI-MQ, particularly for use in developing countries.

2.5.1.4 Psychometric properties of screening tools

According to Glover and Albers (2007) the American Psychological Association (APA), indicates that certain psychometric properties of a screening tool need to be considered in order for it to be useful. These include construct and content validity, appropriateness for the intended use, compatibility with the service delivery needs as well as usability and utility.

The content validity of a screening tool is important to ensure a level of confidence in a measurement tool - as to whether a tool measures what it is supposed to measure. To ensure content validity, a criterion called the content validity index can be used. This process involves the following constructs – relevance, clarity, simplicity and ambiguity, all of which are measured on a four-point scale. Those questions in a screening tool that do not achieve above 0.75 must be discarded, as it does not speak to the content that it was intended to measure. Content validity can support the construct validity of an instrument or tool (Yaghmaie, 2003).

A screening tool can be considered useful if it is appropriate for its intended use to predict future problems or to determine current difficulties (Adelman, 1982). A screening tool therefore needs to be appropriate in terms of the intended use. This considers whether the screening tool is appropriate for a certain context and purpose, and whether the screening tool is compatible with service delivery needs within that context. There are a number of considerations that are of importance when considering the usability and utility of a screening tool. Some of these considerations include the appropriateness in terms of administration, appropriateness of the identified outcomes and the relevance in determining an outcome, considering whether the content has been validated in previous research and whether the screening tool is appropriate for the context of the population (Glover & Albers, 2007).

A screening tool needs to be practical to administer, therefore one needs to also consider the usability of a screening tool in terms of the costs associated with the screening tool, the benefits, feasibility and convenience of administration as well as

appropriate infrastructure in terms of resources for the data to be collected, managed and interpreted. There needs to be acceptance of the benefits of the screening tool by stakeholders involved and whether these stakeholders understand the implications associated with the results of the screening tool, and importantly, whether these results are useful in guiding intervention (Glover & Albers, 2007).

2.5.1.5 Importance of early intervention

Increasing evidence of neuroplasticity in literature emphasises the important of implementing early intervention programmes to improve visual function. There are significant implications of a CVI in children with CP, and each aspect of visual dysfunction needs to be assessed in order to formulate intervention and management programmes for children with CP who have a CVI (Good, 2009). This will ensure an optimal management programme for each individual child with CP, considering their individual level of function (Dutton et al., 2012; Dutton, 2013). However, it is becoming increasingly clear that there is not enough evidence of what intervention is effective for children with CP and a visual impairment (Deramore Denver, 2019).

2.5.2 Treatment of cerebral visual impairment in children with cerebral palsy

Treatment for children with CP is often inter-disciplinary as the condition involves numerous aspects of functional difficulties. According to a systematic review completed in 2004, the efficacy of occupational therapy intervention was generally inconclusive due to the low methodological quality of the studies that were reviewed. However, the study was performed when the focus of therapy was on body function and structure and the study showed that there are many factors that need to be considered when planning intervention for a child with CP. These include, but are not limited to, the child's unique individualities, environmental and contextual factors, and the child's symptoms to achieve the highest level of participation in activities of daily living, increase societal involvement and improve general well-being (Steultjens et al., 2004).

In the early 1990's literature has emphasised the importance of intervention for children with CVI. A study conducted in 1991 on 58 infants with visual impairment showed progress in nine aspects of visual function when the infants were provided

with an early development programme for vision, incorporating the plasticity of the brain (Sonsken, Petrie & Drew, 1991). In 1994, a review of cortical visual impairment in children, found evidence that even though there are gaps regarding the prognosis for CVI, that there is hope for some vision recovery (Good et al., 1994). In a study completed in 2006, 21 children with CVI and CP including multiple neurological deficits showed significant improvement in their visual systems after a 4-13 month home intervention programmes confirming evidence of change due to the neuroplasticity in visual systems (Malkowicz, Myers & Leisman, 2006).

Thus, in occupational therapy there has been a move towards performance-based intervention for CVI . Anaby et al. (2017) indicated that the focus of therapy has changed to include activity and participation in the intervention for CVI. Thus occupational therapy treatment for children with CP and CVI now focuses more on improving occupational performance and developing skills required for participation in activities of daily living and the community in which they live as suggested by Palisano, Snider & Orlin ((2004) and Steultjens et al., (2004).

2.6 Summary

In summary, CVI is an important comorbidity experienced by some children with CP that should to be considered in the assessment and treatment of children with CP. Rather than focusing on a CVI as a body function impairment, therapists need to consider vision in terms of visual ability and participation in everyday activities. There are currently no validated CVI screening and assessment tools available in South Africa. The Cerebral Visual Impairment Motor Questionnaire (CVI-MQ) was developed and validated in the Netherlands. This screening questionnaire takes into consideration the motor ability of a child with CP using the Gross Motor Function Classification System (GMFCS), as well as the impact of potential visual difficulties to perform motor tasks. There is a need for a CVI screening tool in South Africa given the importance of CVI in motor function and participation of a child with CP. Screening of a CVI would allow a therapist to make a better decision as to whether a child should be investigated further for a CVI, as CVI assessments and access to specialists is costly and time-consuming and will allow therapists to alter intervention for children with CP.

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter covers the methods and procedures used to conduct this study. It explains the design of the study, site of research, population and sample size, measuring instruments, data collection methods, as well as data analysis. Ethical considerations have also been included in this chapter. The research was completed in two phases with four electronic survey questionnaires. Two questionnaires were used in each phase.

PHASE 1:

Part 1 - Demographic questionnaire to establish the work-related factors for occupational therapists and physiotherapists in South Africa.

Part 2 - CVI questionnaire (developed by the researcher) was a survey on the understanding of CVI and the diagnosis thereof, as well as the current practice in diagnosing and screening for CVI distributed to occupational therapists and physiotherapists working with children with CP.

PHASE 2:

Part 3 - Content validity questionnaire used to establish the content validity index of the Cerebral Visual Impairment Motor-Questionnaire (CVI-MQ) for use by occupational therapists and physiotherapists in South Africa.

Part 4 - Usability and utility questionnaire used to establish the usability and utility of the CVI-MQ for use in clinical practice in South Africa.

3.2 Research design

Phase 1

A quantitative descriptive survey design was used for this phase of the study (Creswell J. W., 2014). This non-experimental approach was used to collect and analyse data regarding the understanding of CVI diagnosis, as well as screening procedures that occupational therapists and physiotherapists are using in various settings when assessing children with CP in South Africa.

This was an appropriate research method as it allowed data to be collected from a large sample at low cost. An electronic survey design is convenient and inexpensive and it allows for a larger target audience to be reached. It allows for data to be compiled efficiently and for quick response rates. The disadvantages of using a survey design, particularly an electronic survey, is non-response and that not all of the sample may be reached (Jones, Baxter & Khanduja, 2013).

Phase 2

A quantitative non-experimental descriptive research design was used to evaluate an internationally-validated screening tool - the Cerebral Visual Impairment-Motor Questionnaire (CVI-MQ) - for content validity and the usability and utility for use by occupational therapists and physiotherapists in their clinical practice for children with CP. This research design was suited to a descriptive study as no variables were manipulated. Descriptive studies are useful in identifying factors which are unknown in a population. However, descriptive studies may not always be representative of a population if the sample size is small (Aggarwal & Ranganathan, 2019).

3.3 Phase 1

3.3.1 Site of research

The survey was first distributed nationwide via the databases of various professional South African occupational therapy and physiotherapy associations, including the South African Neurodevelopmental Therapy Association (SANDTA), Rural Rehab South Africa (RuReSA) and the Occupational Therapy Association of South Africa (OTASA). Snowball sampling was also used. Occupational therapists and physiotherapists were asked to forward the email including the information sheet, questionnaires and CVI-MQ to other occupational therapists and physiotherapists who may also have been working with children with CP.

3.3.2 Population and sample

The study initially aimed to survey therapists working with children with CP. The therapists that are part of SANDTA have more than likely specialised in the treatment of neurological conditions, since this association focuses on neurodevelopmental disorders in children and adults, and the therapists may be trained in

Neurodevelopmental Therapy (NDT), and therefore have a common frame of reference. These therapists were therefore more than likely working in various settings with children with CP, including the private sector (private practices), non-profit organisations, schools for learners with special needs and government hospitals and clinics. The survey questionnaire was also distributed through RuReSA, an association for rehabilitation therapists and physiotherapists working in rural areas of South Africa, and OTASA, a professional association for occupational therapists, to increase the sample size.

Inclusion Criteria

Occupational therapists and physiotherapists who were involved in treating children with CP at the time of the survey were asked to complete the survey.

3.3.3 Sample size

Total population sampling was used and all the therapists on the databases for SANDTA, RuReSA and OTASA, with contact details for more than 3000 therapists, were used. Emails were sent to all members on the databases, some of whom may have been duplicated as therapists belong to more than one association and some of whom may also have been speech therapists. There appeared to be a limited number of therapists working with children with CP. This is based on a previous study which surveyed occupational therapists and physiotherapists registered with SANDTA and working with children with CP in South Africa, where a sample of 48 therapists was achieved (Davies, 2016). This indicates a population of less than 100 therapists for SANDTA members. Approximately one third of the over 500 members are speech therapists and approximately two thirds of the members work with adult patients. Speech therapists were not included in the study because phase 2 involves a motor-based assessment and speech therapists do not look at motor performance.

The exact number of therapists working with children with CP registered with RuReSA and OTASA is unknown, although a sample of 62 therapists were recruited though OTASA in a study on visual problems in children with CP in South Africa (Janse van Rensburg, 2016) indicating a population of < 300 therapists working with children with CP. Therefore, it was assumed that across the three associations there would be approximately 450 members who fulfilled the inclusion criteria for this study. Based on

this population, a sample of 92 was needed to represent the population with a 5% margin of error, as recommended by Cochran's formula for ordinal data (Cochran, 1977). Applying a modification of Cochran's formula (for small sample sizes), assuming p= 0.5 and with 95% confidence intervals, where: e= 0.1 (10% margin of error), a sample size of 66 was required for phase 1 of the study. Participants with more experience with children with CP were invited to participate in phase 2 of the study.

3.3.4 Measuring instruments

3.3.4.1 Electronic Questionnaire – phase 1

The two-part survey questionnaire was developed by the researcher. The survey was transcribed onto the online Research Electronic Data Capture (REDCap) survey programme ("REDCap", 2018).

Part 1: Demographic Questionnaire

A demographic questionnaire which focused on work-related information, qualifications and experience of the participants. The questionnaire included the profession of the participant, whether they were an occupational therapist or physiotherapist, the number of years they had been working and working with children with CP, what province and sector they were working in, and whether they had a qualification in neurodevelopmental therapy. This part of the questionnaire consisted of six questions which took approximately three minutes to complete (Appendix A).

Part 2: CVI Questionnaire (developed by the researcher)

Questions which determined the understanding of, diagnosis and current screening procedures used to identify CVI in children with CP were included in this part of the questionnaire. Closed-ended questions with space for open-ended comments were used. Questions were formulated with guidance from the literature based on CP, CVI and CVI screening procedures. This part of the questionnaire consisted of eighteen questions which took approximately 10-15 minutes to complete (Appendix B). The questionnaire consisted of information regarding the amount of experience the participants had in treating children with CP, how many children were treated within the space of a month, the main age group of children treated and what the most

common GMFCS levels of the children with CP treated were, since the screening tool that is being used in this study requires that the GMFCS level of the child is known.

The questionnaire also explored whether the participants had postgraduate training in the assessment and treatment of children with CP, and in children with CP and CVI. This was asked to determine if there was an interest in this field amongst the participants. Therapists were asked whether they understood what a CVI is. The questionnaire explored how diagnoses for CVI were obtained and the current practice regarding the screening for CVI in children with CP. The questionnaire aimed to establish what screening and assessment procedures were being used in various settings, and questions involved current referral processes, current screening procedures and whether it is difficult to obtain a CVI diagnosis. Questions also determined if therapists were aware of any current CVI screening and assessment tools and whether intervention is altered if a child presented with a CVI.

3.3.5 Research procedure

Ethical clearance was obtained from the Human Research Ethics Committee (HREC) of the University of the Witwatersrand (Appendix C). Permission was requested to disseminate the survey (Appendix D) and permission was obtained from the chairperson of SANDTA (Appendix E) and the offices of OTASA and RuReSA to disseminate the research information sheet and questionnaire to all members. The emails contained an information sheet which explained the study with a link to the questionnaire on RedCAP (Appendix F). It was made clear that therapists who met the inclusion criteria should complete the survey questionnaire, which included the demographic questionnaire and questions regarding current CVI screening procedures.

3.3.6 Data analysis

The questionnaire was formulated such that the data to be analysed were ordinal or nominal. All responses were downloaded from the RedCAP programme into an Excel spreadsheet. The researcher checked all the data and completed descriptive analysis using frequencies and percentages for the closed-ended questions using Statistica v13.2. Comments and open-ended questions were analysed using summative content

analysis and the number of participants making each comment was noted and the frequency of the comments were represented in the results.

3.4 Phase 2

3.4.1 Site of research

This phase of the study included therapists who were registered with SANDTA and who had specialised in the treatment of neurological conditions. They were given the option to participate in phase 2 of the study when completing phase 1 of the study. They were given the option to review the CVI-MQ (Appendix G) and to fill out the content validity index of the CVI-MQ (Appendix H). They were then asked to use the CVI-MQ in clinical practice for one month before completing the usability and utility questionnaire on the assessment tool. The CVI-MQ was included in the email to the therapists. Permission to use the CVI MQ was granted by the developer of the screening tool – Dr Masoud Salavati (Appendix I) (Salavati *et al.*, 2016).

3.4.2 Population

The study was aimed at occupational therapists and physiotherapists who were part of SANDTA. The therapists that are part of SANDTA have more than likely specialised in the treatment of neurological conditions, since this association focuses on neurodevelopmental disorders in children and adults, and the therapists may be trained in Neurodevelopmental Therapy (NDT), and therefore have a common frame of reference. These therapists were therefore more than likely working in various settings with children with CP, including the private sector (private practices), non-profit organisations, schools for learners with special needs and government hospitals and clinics.

Inclusion Criteria

Occupational therapists and physiotherapists who were involved in treating children with CP at the time of the survey were asked to complete the survey with the additional inclusion criteria that the therapists should be aware of CVI and screen for CVI.

3.4.3 Sample size

The sample size was expected to be small as very few therapists routinely screen or assess for CVI in children with CP. From phase 1 of the study less than half the sample reported routinely screening for CVI, so from a sample of less than 100 occupational therapists and physiotherapists working with children with CP and registered with SANDTA, the population for this phase of the study was set at less than 50 therapists and with a 10% margin of error corrected for a small sample, as recommended by Cochran's formula for ordinal data, the required sample size was 30 (Cochran, 1977). However, since this phase of the study required therapists to evaluate the CVI-MQ over a month, it was assumed that very few therapists had the time or context to complete this and a smaller sample would be achieved.

3.4.4 Measuring instrument

3.4.4.1 Electronic Questionnaire – phase 2

Part 3: Content Validity Questionnaire

This questionnaire was set up to assess the content validity of the CVI-MQ. The CVI-MQ content is outlined to provide background to the content validity questionnaire:

> ***The Cerebral Visual Impairment Motor Questionnaire***
>
> The CVI-MQ (Appendix G) consists of two separate CVI questionnaires for children on different GMFCS levels. One questionnaire is used for children with CP classified into GMFCS levels I, II and III (walking), and the other for children with CP classified into GMFCS levels IV and V (crawling and rolling). The two questionnaires "measure the degree of absence or presence of CVI in children with CP", (Salavati et al., 2016, pg3) and the higher the score, the higher the probability that the child with CP presents with CVI deficits. The CVI-MQ items consider the effect of vision on performing motor activities. Cut-off scores for the CVI-MQ are therefore predictive of "the possible presence or absence of CVI in children with CP". (Salavati et al., 2016, pg3)., A negative result for the CVI-MQ presumes the absence of a CVI, and therefore prevents costly and unnecessary comprehensive assessments (Salavati et al., 2016).

The CVI-MQ for GMFCS levels I, II and III consists of 27 questions and the option to choose yes (present), no (absent) or not applicable (considered absent). The CVI-MQ for GMFCS levels IV and V consists of 14 questions and the option to choose yes (present), no (absent) or not applicable (considered absent). The therapist conducting the screening will tick yes, no or not applicable per item in the screening tool according to whether that movement is present in their observations of the child. For example, item 3: “the child bumps into moved toys or furniture when it crawls”. The therapist then decides whether the child does bump into moved toys or furniture, and will assign yes, no or not applicable.

The CVI-MQ items are related to motor movement such as belly crawling, crawling, walking, ball skills, jumping and reaching for GMFCS levels I, II and III. For GMFCS levels IV and V, they focus on the motor movements of head turning, sitting, belly crawling, crawling, mobilising in a wheelchair and reaching. The CVI-MQ’s have a range of items that are simple and complex. Both CVI-MQ’s include items about moving within familiar and unfamiliar environments.

In the scoring, every ‘yes’ is assigned one point and every ‘no’ is assigned zero points. ‘Not applicable’ is considered zero as presence is not observed. ‘Not applicable’ is assigned when the therapist feels the item was too difficult, or the child was too young or too old to perform that item. The CVI-MQ for GMFCS levels I, II and III has a cut-off score of 12 and for GMFCS levels IV and V, there is a cut-off score of 8. A positive score (above the cut-off scores) indicates the probability of the presence of a CVI and a negative score (below the cut-off scores) indicates the absence of a CVI.

The content validity questionnaire to evaluate each item on the CVI-MQ as described above was set up on REDCap. The content validity index was used to rate each item according to relevance, clarity, simplicity and ambiguity on a four-point scale (Yaghmaie, 2003) (Rodrigues et al., 2017) (Appendix H). The four-point scale consisted of the following:

Table 3.1 Scale for content validity index

Relevance:	1 – not relevant	Simplicity:	1 – not simple
	2 – item needs some revision		2 – item needs some revision
	3 – relevant but needs minor revision		3 – simple but needs minor revision
	4 – very relevant		4 – very simple
Clarity:	1 – not clear	Ambiguity:	1 – doubtful
	2 - item needs some revision		2 – item needs some revision
	3 – clear but needs minor revision		3 – no doubt but needs some revision
	4 – very clear		4 – meaning is clear

This questionnaire took approximately 15 minutes to complete.

Part 4: Usability and Utility Questionnaire

The usability and utility survey contained eighteen questions for participants to evaluate and rate the usability and utility of the CVI-MQ when using the assessment in their clinical practice (Appendix J) (Glover & Albers, 2007). This questionnaire took approximately 15-20 minutes to complete and was transcribed onto the REDCap platform to be returned anonymously to the researcher.

The questionnaire was used to evaluate the CVI-MQ, including how appropriate it was, whether it was compatible for service delivery needs, training needed and the relevance of the identified outcomes. The usability of the CVI-MQ was rated according to the costs, feasibility of administration, whether resources were available that were needed for the administration of the CVI-MQ and to provide intervention associated with the outcomes. Utility was rated according to the stakeholders (caregivers, other medical and allied health professionals, teachers) understanding of the implications associated with the assessment outcomes and the usefulness of the outcomes for guiding intervention (Glover & Albers, 2007).

3.4.5 Research procedure

In the survey emailed in phase 1, the questionnaires for phase 2 were included for the therapists at SANDTA. The participants were asked to complete both phase 1 and phase 2 if they met the inclusion criteria. An information sheet for phase 2 was provided and participants were asked to complete the content validity index

questionnaire by rating each question on the CVI-MQ. (Glover & Albers, 2007) (Yaghmaie, 2003).

The occupational therapists and physiotherapists willing to use the CVI-MQ in their clinical practice with children with CP over a period of one month were asked to then complete the usability and utility questionnaire and return it after one month. A reminder was sent out through email after one month for participants that were willing to take part in this phase of the study to ensure submission of the usability and utility questionnaire.

3.4.6 Data Analysis

Data from both questionnaires were extracted from the RedCAP database for each question in the CVI-MQ according to relevance, clarity, simplicity and ambiguity into a Microsoft Excel spreadsheet. All data was checked by the researcher and average scores for content validity for each item in the CVI-MQ were computed. These were converted to an overall percentage for each item.

For usability and utility questions were formulated such that data were nominal. Data were analysed using frequencies.

Comments and open-ended questions for both questionnaires were taken into consideration in data analysis using summative content analysis and the frequency of the comments were represented in the results.

3.5 Pilot study

Once the survey questionnaire sections had been developed, the Demographic Questionnaire, CVI Questionnaire (developed by the researcher), Content Validity Questionnaire and the Usability and Utility Questionnaire were piloted for content validity. Three subject matter experts (SME) were approached (Appendix K) and agreed to take part in the pilot study and review the questionnaires using the questionnaire developed by the researcher (Appendix L).

Inclusion criteria for subject matters experts included:

- More than five years' experience working with children with CP;

- Post-graduate training in working with children with CP and CVI, such as completing the 8-week paediatric NDT course;
- Currently working with children with CP.

The subject matter experts who agreed to assist with the pilot study had between 8-25 years of experience with children with CP and worked in various settings (Table 3.2).

Table 3.2 Demographics of Subject Matter Experts

Subject matter experts	Current work	Years' experience working with children with CP	Post-graduate training	Currently working with children with CP
Subject matter expert 1	LSEN school	25 years	Yes. 8-week paediatric NDT course.	Yes
Subject matter expert 2	Private practice	13 years	Yes. 8-week paediatric NDT course.	Yes
Subject matter expert 3	Government hospital and private practice	8 years	Yes. 8-week paediatric NDT course.	Yes

The content validity index was used (Yaghmaie, 2003) to determine the relevance, clarity, simplicity and ambiguity of each question on a scale of 1- 4 (Table 3. 1) for the questionnaires used in phase 1 and phase 2 of the study. The SME's were able to provide comments and/or suggestions for each question if necessary. Averages for each category for each question was calculated. Questions that received above 0.79 remained in the questionnaire, and those below this threshold were altered. No items had scores below 0.71 so none needed to be discarded (Yaghmaie, 2003; Rodrigues et al., 2017). The comments and suggestions were taken into consideration and questions were added, altered or discarded accordingly.

From the content validity index results and the comments and suggestions made, the following changes were made to the questionnaires:

Demographic questionnaire

- Highest level of education: this item was altered to add the highest level of qualification as an occupational therapist and as a physiotherapist;
- Years of experience: altered to be more specific and included as an occupational therapist and a physiotherapist;
- Sector working in: altered to be more specific such as district, regional or tertiary hospitals; and clinics based in the community or in the hospital;
- Removed this question – “do you have an NDT qualification”? as this is addressed later in the questionnaire. This question was altered to be more general for postgraduate training in treating children with CP;
- Altered the question regarding how many children with CP are treated in a month to make it less ambiguous;
- Altered the question regarding further training in assessing and treating children with CP to make it less ambiguous;
- Altered question regarding referral systems to make it less ambiguous.

CVI Questionnaire (developed by the researcher)

- Altered the question regarding understanding of a CVI to make it less ambiguous;
- Altered the question regarding awareness of when a child is diagnosed with a CVI to make it less ambiguous;
- Included more options in the question: “How do you know that a child with CP has been diagnosed with a CVI?”;
- Added which professionals are able to conduct formal assessments to diagnose a CVI;
- Altered the question regarding screening tools to replace it with informal screening procedures to make it more specific;
- Added two questions regarding whether therapists are aware of any validated screening or assessment tools/procedures for CVI’s in children with CP;
- Altered the question regarding whether the CVI-MQ is developmentally appropriate by making it less ambiguous.

Usability and Utility Questionnaire

- Usability – cost. Altered this question to a yes/no question instead of answering on a scale.

The questionnaires were then transcribed onto RedCAP and this version was then piloted by two occupational therapists to test the usability of the electronic questionnaires. The survey questionnaire was altered several times to make it more user-friendly.

3.6 Ethical considerations

Ethical clearance was obtained from the HREC of the University of the Witwatersrand (M180953) (Appendix C) and permission from SANDTA (Appendix E), OTASA and RuReSA was granted. An information sheet (Appendix F) was emailed with the questionnaires for phase 1 of the study to all members of these organisations. The questionnaires for phase 2 of the study were emailed with an information sheet to members of SANDTA.

Completion of the questionnaire was considered informed consent. It was indicated in the information sheet that participation was voluntary with no consequences for not completing the questionnaire. The questionnaire and survey were completed in the participants' own capacity and they were assured that non-completion would have no consequences. It was indicated that all therapists would remain anonymous by use of the REDCap platform as they also did not need to specify their names and place of work. All data would remain confidential and would only available to the researcher, supervisor and the statistician. Feedback on results would be available on request.

3.7 Summary

This study was completed in two phases. Phase 1 included a demographic questionnaire and a CVI questionnaire (developed by the researcher) which consisted of current knowledge and practise regarding the screening and assessment of CVI in children with CP, which were emailed to and completed members of SANDTA, RuReSA and OTASA and snowballed to other therapists working with children with CP.

Phase 2 of the study was administered to members of SANDTA who were asked to complete the questionnaires for phase 2 having completed phase 1 of the study. Phase 2 aimed to determine the content validity, usability and utility of the CVI-MQ, an internationally-validated screening tool for CVI in children with CP. A copy of the CVI-MQ, a content validity questionnaire to determine the content validity of the CVI-MQ and a questionnaire to determine the usability and utility of the CVI-MQ were emailed to these therapists. Participants were asked to complete the questionnaire once they had used the CVI-MQ in practice over a one-month period.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter considers the results for phase 1 and phase 2 separately.

Phase 1

For phase 1 of the study, 47 participants responded to the questionnaires. Nine of the participants (19%) were not currently working with children with cerebral palsy (CP) and since the inclusion criteria for phase 1 of the study was therapists working with children with CP, only the data for the remaining 38 participants was analysed. Although all the questions of the questionnaire were not completed by all the participants, all questionnaires were included in the analysis. The number of participants who answered each question is indicated in the results. The results are presented according to the participants' demographic information, their current work and training experience with children with CP, their understanding of CVI and their current practice regarding the screening and assessing of cerebral visual impairment (CVI) in children with CP.

Phase 2

In phase 2 of the study, 14 participants completed the content validity of the CVI and six participants completed and returned the usability and utility questionnaire after using the CVI-MQ in their clinical practice over one month. Data from all the questionnaires is included in the results. The results are presented according to the participants' demographic information, the content validity of the CVI-MQ and the usability and utility of the CVI-MQ in the South African context.

PHASE 1

4.2 Part 1: Demographic work information

Participants' experience with children with CP and their training in this field are presented.

4.2.1 Education and training history

4.2.1.1 Profession of participants

Figure 4.1 indicates that most of the participants who answered the questionnaire were occupational therapists (84.2%).

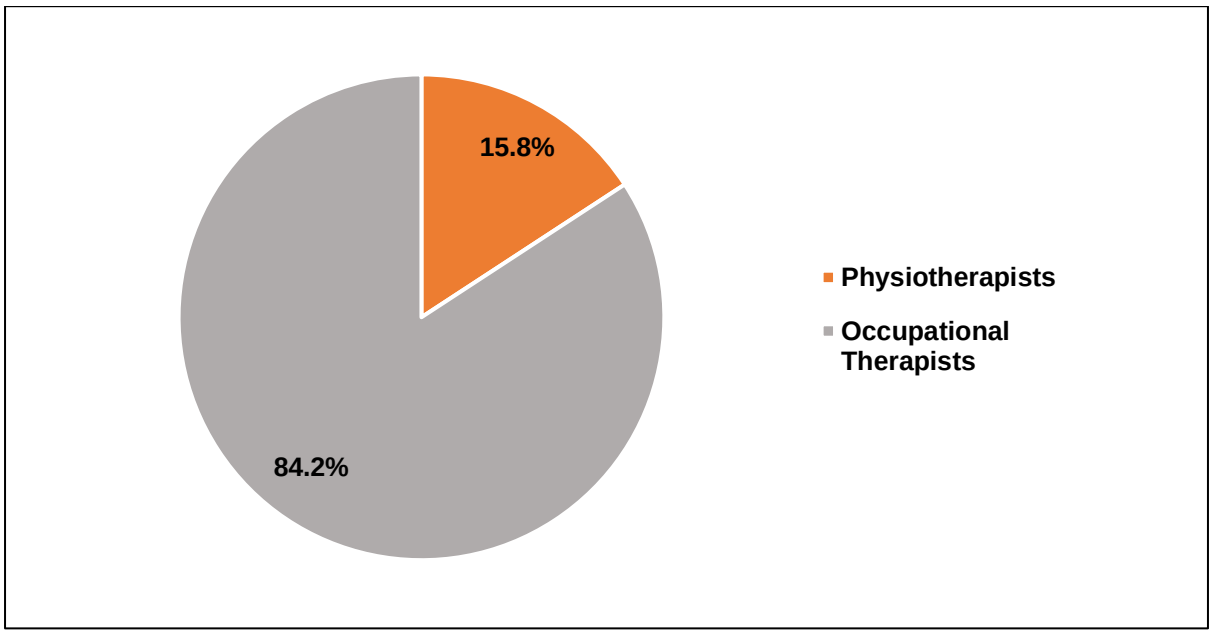


Figure 4.1 Profession of the participants (n=38)

4.2.1.2 Highest level of education

More than half of the 38 participants (63.1%) had an undergraduate degree as their highest level of education (Figure 4.2).

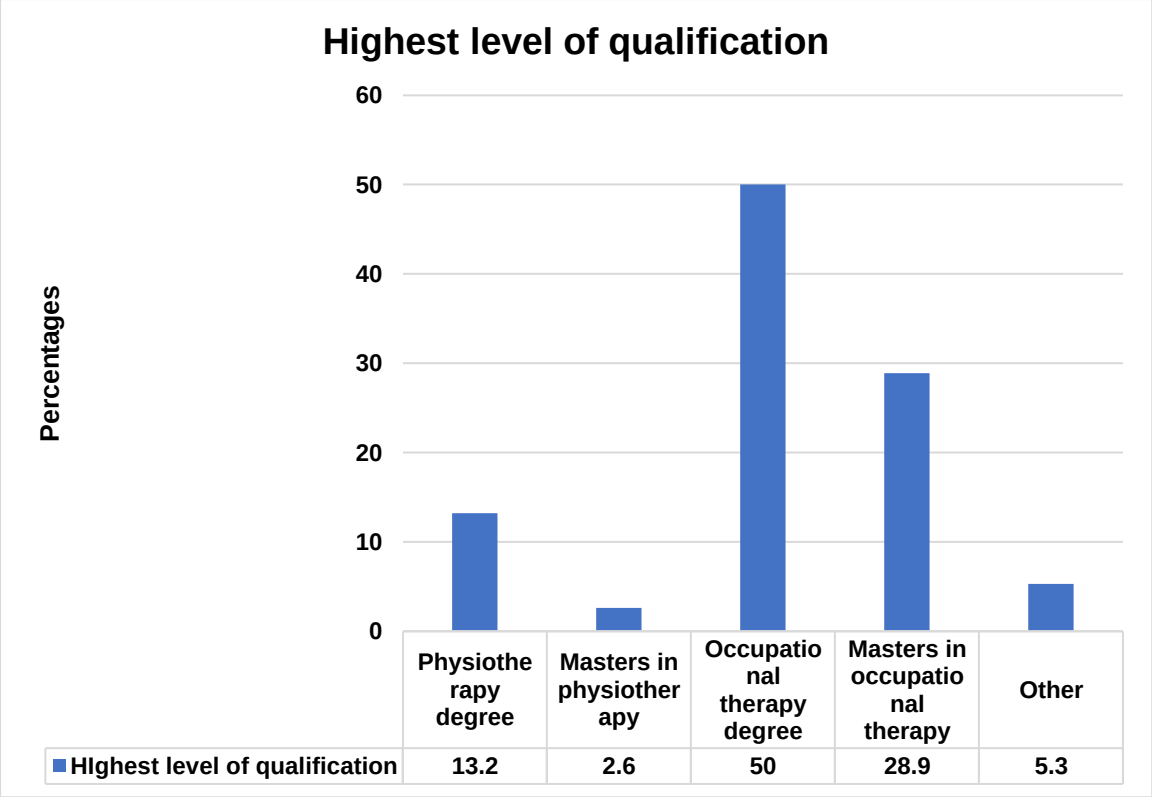


Figure 4.2 Highest level of education of participants (n=38)

Slightly more than one quarter of the participants had master's degrees in occupational therapy (28.9%). One participant had a master's degree in early childhood education, and another participant had a master's degree in public health.

4.2.1.3 Postgraduate training for treating children with cerebral palsy

Twelve participants (31%) had further training in assessing and treating children with CP presenting with a CVI. This training included workshops held by Malamulele onwards and SANDTA; a low vision tutorial from EyeTek; the Bobath 8-week basic paediatric course; advanced courses such as the advanced baby course and hemiplegia course. Some had attended workshops held by an occupational therapist Christa Scholtz, CVI-range training (three-day workshop) and a cortical visual impairment course called From Theory to Practice presented by Lindsay Hillier in November 2018.

Table 4.1 Further training and courses (n=32)

Further training/courses	%	n
Malamulele onwards course	15.8	6
Bobath NDT 8-week course	28.9	11
Advanced NDT course	13.2	5
MAES	5.3	2
Introduction to CP – one-week course	26.3	10
Paediatric coursework for Masters or Masters topic	5.3	2

4.2.2 Work history

4.3.2.1 Work experience

Figure 4.3 indicates that more than a quarter of the participants had 5-7 years of work experience (26.8%), followed closely by 23.6% of participants having over 8-10 years of experience. Those participants with over 16 years of experience varied between 16 to 40 years with an average of 26.5 years' work experience.

In figure 4.4, of the 38 participants working with children with CP, more than a quarter had 5-7 years of experience (26.3%) followed closely by 3-4 years of experience (23.7%). 39.3% of the participants had over 8 years of experience working with children with CP. Five of the participants (13%) had over 16 years of experience ranging from 16-32 years.

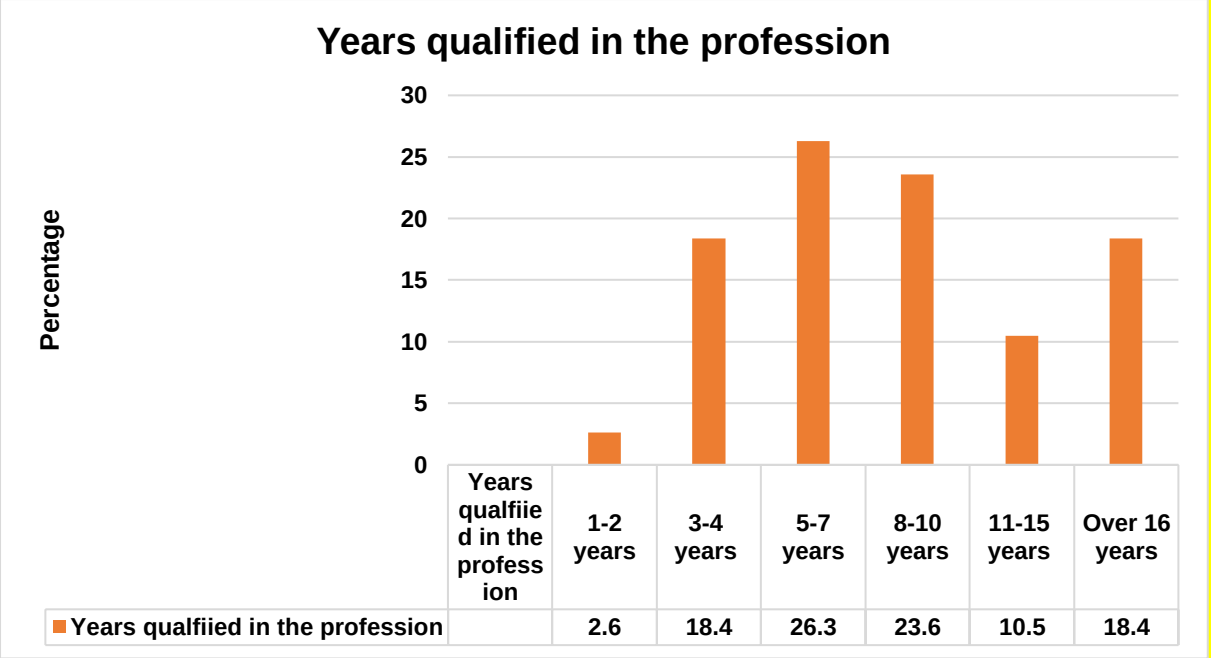


Figure 4.3 Years of experience in the profession (n=38)

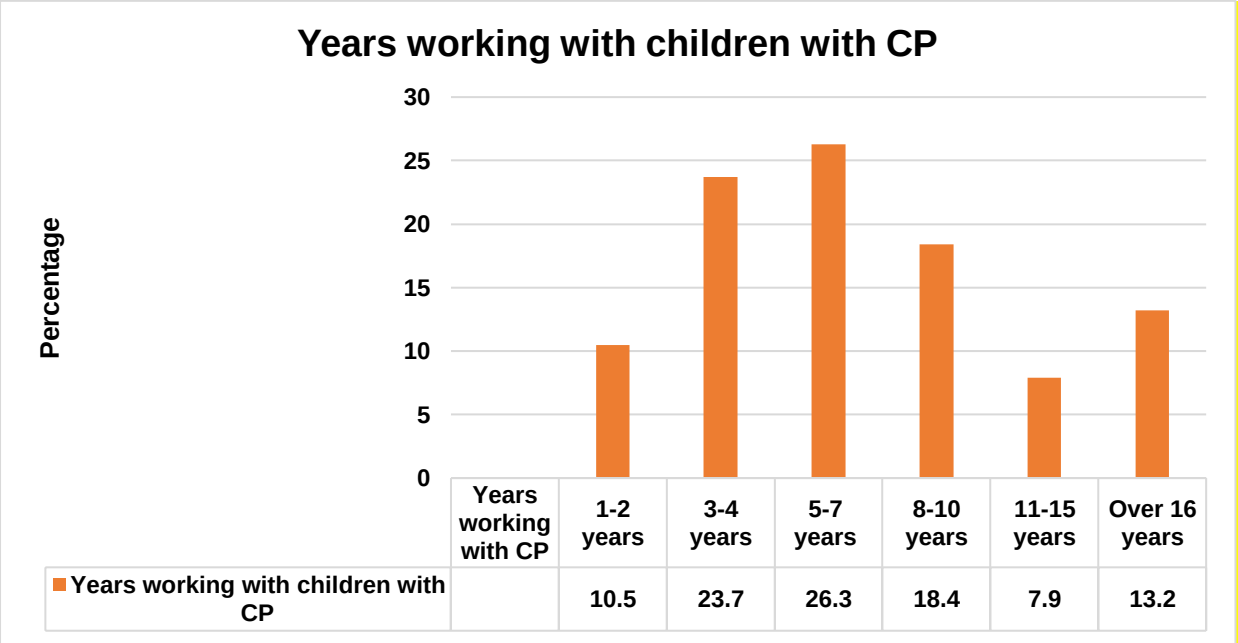


Figure 4.4 Years of experience of working with children with cerebral palsy (n=38)

4.2.2.2 Work location

Table 4.2 shows that the majority of the participants worked in Kwazulu Natal (42.1%) followed by Gauteng Southern (21.0%) and the Western Cape (15.7%). The Gauteng

province totalled 28.8%, with very few participants working in the Free State, Eastern Cape and only one from the Northern Cape.

Table 4.2 Provinces in South Africa where participants currently work (n=38)

South African Provinces	%	n
Eastern Cape	7.8	3
Free State	2.6	1
KwaZulu-Natal	42.1	16
Gauteng - Northern	7.8	3
Gauteng - Southern	21.0	8
Western Cape	15.7	6
Northern Cape	2.6	1

4.2.2.3 Work sector

In this question, the participants were asked to give more than one answer if applicable (n=66). Some of the participants were working in two or more sectors (42%) such as in a school for learners with special needs and a private practice. When considering the public health sector, participants were working in rural, urban, district, regional and tertiary public hospitals (figure 4.5). A total of 25.8% participants were working in the public sector compared to 74.2% working in other sectors – (non-profit organisations, private practices and school for learners with special needs).

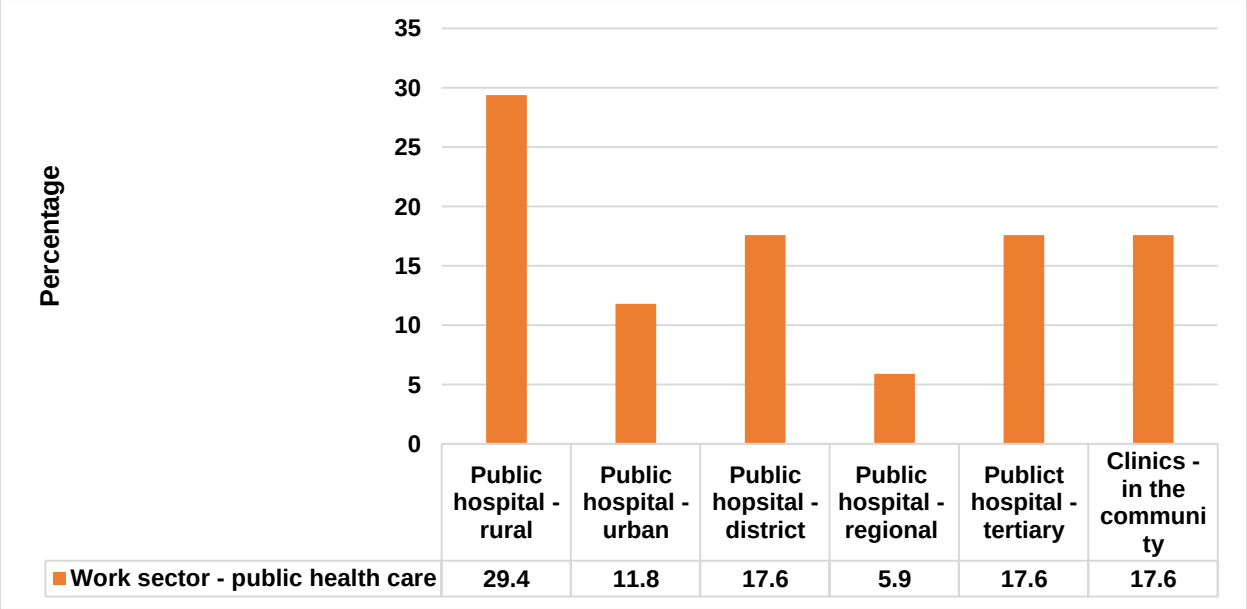


Figure 4.5 Work sector - Public health care (n=17)

When considering the other sectors, 40.8% of the participants were working in private practices on an outpatient basis and 6.1% worked in private practice on an in-patient basis, and 26.6% were working at schools for learners with special needs (LSEN). Just less quarter of the participants worked at non-profit organisations (20.4%) (Figure 4.6).

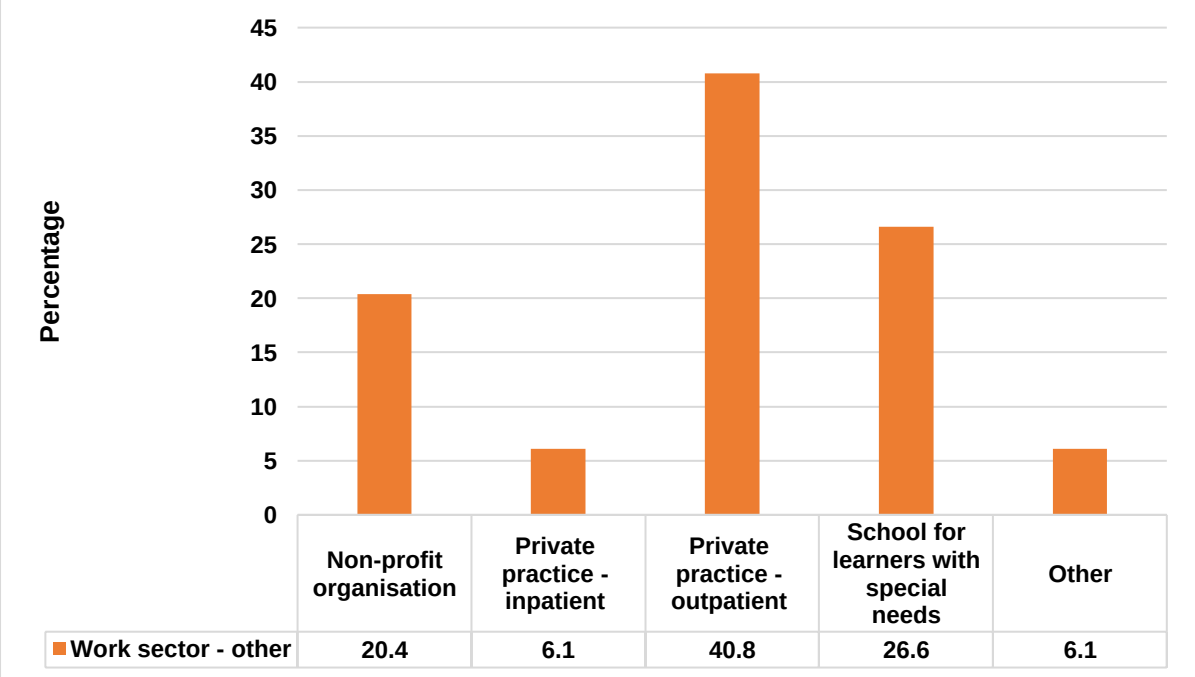


Figure 4.6 Work sector – other (n=49)

There was one participant who worked at a University clinic for children, this participant and one other are involved in academia and supervising students, whilst one other participant works for the Department of Education.

4.2.3 Case load of therapists working with children with cerebral palsy

4.2.3.1 Age of children

Over 85% of the participants report that they treat children with CP who are between the ages of 3-10 years old. No participant reported treating children with CP over the age of 16 years. A few participants treat children between the ages of 0-2 years old (7.9%) and 11-15 years old (5.3%).

4.2.3.2 Number of children treated

Nearly half of the participants treated between 1-5 children with CP per month (44.7%). Slightly more than one fifth of the participants treated between 6-10 children with CP per month (21.1%) (Figure 4.7).

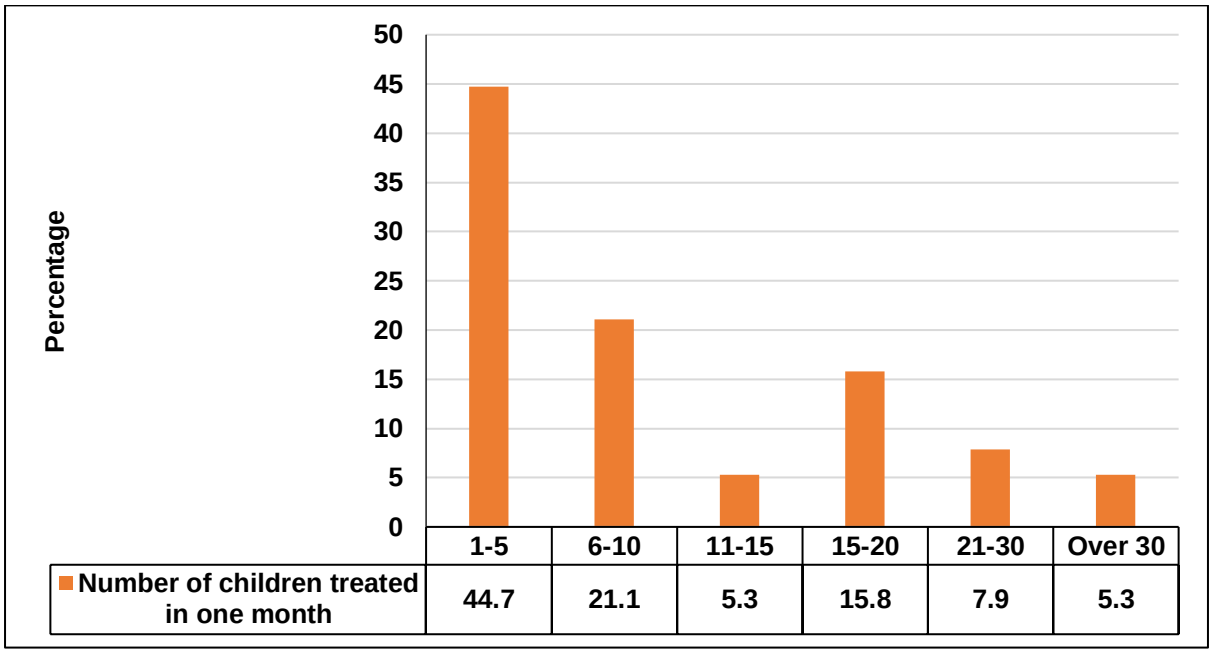


Figure 4.7 Number of children with cerebral palsy treated in one month (n=38)

4.2.3.3 Gross motor level of function of the children

In this question, the participants were asked to give more than one answer if applicable (Figure 4.8).

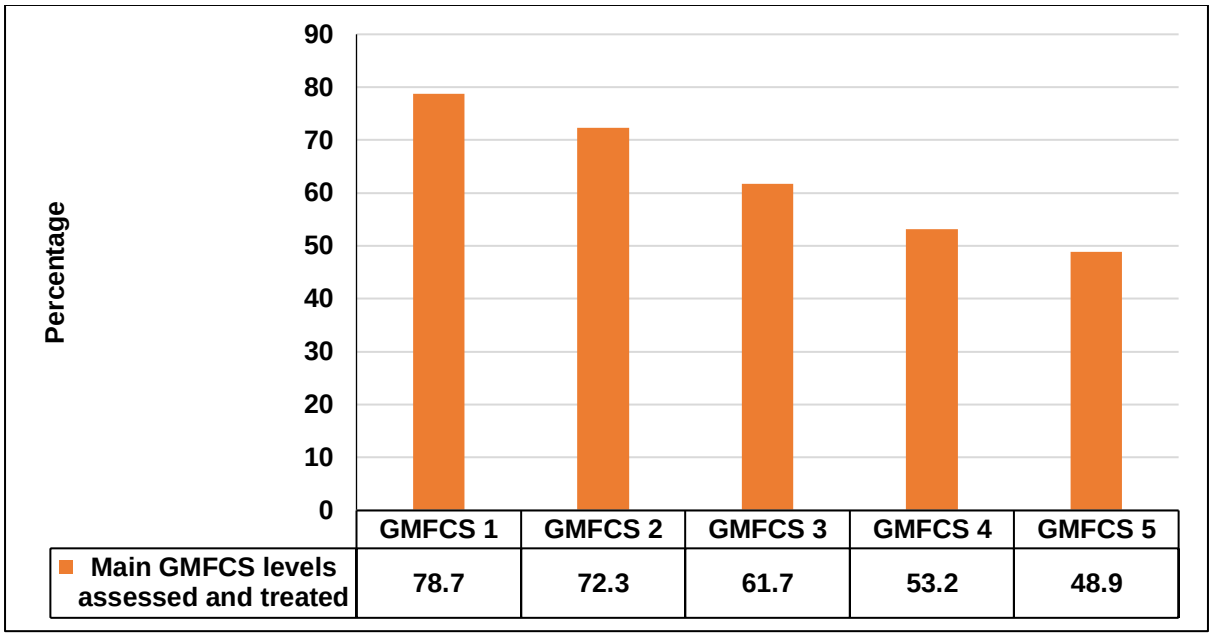


Figure 4.8 Main GMFCS levels assessed and treated (n= 87)

The majority of the participants treat children with CP who are on level 1 of the Gross Motor Functional Classification System (GMFCS) (78.7%), followed by 72.3% of participants reported treating children with CP on GMFCS level II (72.3%). Just under half the participants (48.9%) treated children CP on GMFCS level V.

4.2.3.4 Referral of children to therapy

When indicating how children with CP were referred for therapy, the participants were asked to choose more than one option where applicable. The main referral system for children with CP is through doctors (57.9%) and other allied health professionals (57.9%), such as speech language pathologists, occupational therapists, dieticians and physiotherapists; followed by school teachers (36.8%). These questions were mainly answered by those participants working in private practice and in schools for children with special needs.

Almost a quarter of the participants reported that they received referrals from the caregivers of the children with CP (23.7%). (Figure 4.9).

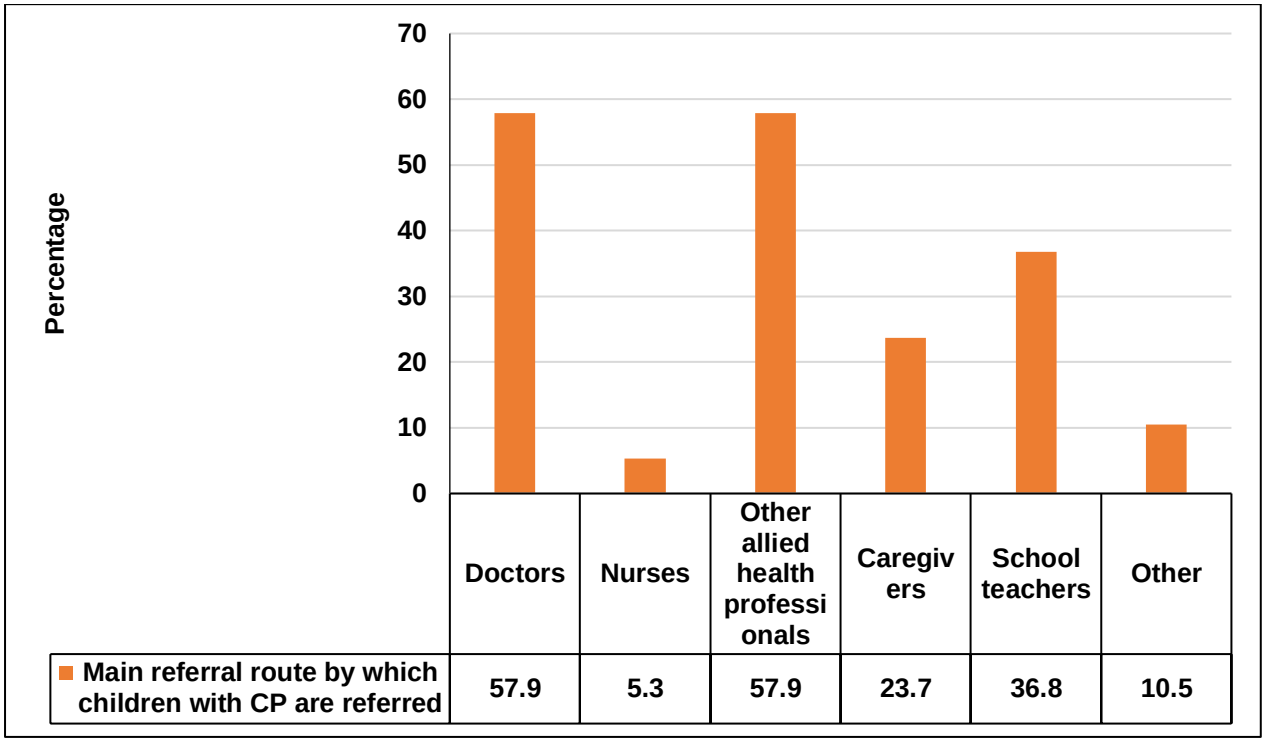


Figure 4.9 Main referral system (n=73)

Few children with CP are referred by nurses (5.3%). Other referral routes included developmental delay clinics where children with CP are identified at an early age; the principal at a non-profit organisation; self-referrals; and via a high-risk baby follow-up programme. One participant worked for a non-profit organisation that is a residence for children with CP.

4.3 Part 2: CVI questionnaire (developed by the researcher)

The results of the questions are presented below:

4.3.1 Understanding of cerebral visual impairment according to the participants

Participants responses were analysed deductively according to the definition of CVI (Table 4.3). Participants reported the following points in their description of CVI:

Table 4.3 Understanding of cerebral visual impairment

Categories	Codes	Number of participants
Cortical deficit rather than an eye structure deficit	• The structure of the eye is intact; however, the interpretation of information is interrupted to varying degrees within the neural tracts/brain • CVI is also known as cortical blindness	22
Deficit in the processing of visual information	• The child is able to see, but the brain cannot interpret what is being seen • Problem lies within the visual processing centres of the brain	13
Effect on vision	• The child is unable to focus on faces, or objects unless adaptations are made e.g. using high contrast, bright light, noise to gain the child's visual attention • A child with CVI might not show any visual response in a normal situation, but when offered high contrast objects/environments, a response can be seen • The child may have difficulty tracking or focusing on an object	11
Visual loss presents differently in every child	• CVI is complex as it may affect one or both eyes • Presentation can vary. Can appear blind, or can have intermittent responses to visual stimuli • These children have specific visual preferences • CVI presents with 3 different stages or levels with the first being the worst presentation	4
Effect on function	• It further limits children with CP, from playing • Great contributor to their gross motor difficulties • Decreased social interaction and general visual awareness in activities of daily living	3

These responses were analysed based on information provided by the creators of the CVI-MQ (Salavati, 2016), thus categories of visual deficits included those of any likely cerebral cause; visual processing deficits, individual differences of CVI presentation and functional implications (Salavati, 2016).

Of the participants that answered this question (n=36), 81% were able to acknowledge that a CVI is a visual impairment as a result of a deficit in the brain. One participant reported that the eye is divided into four quadrants, and the child may use adapted methods to use their vision if one or more of the quadrants are affected. This would mean finding the "sweet spot" of which of the four quadrants the child is able to use to interpret visual information.

Two of the participants reported that they did not know what a CVI was, with one reporting that they had never heard of it before. Two participants indicated that CVI is

common in children with CP but is often not identified. Other difficulties that were reported to be associated with CVI included poor visual skills (1), visual field deficits (2), spasticity of the eye muscles (1), poor eye contact (1), not looking and reaching at the same time (1), visual latency (1), difficulty with distance viewing (1), visual perceptual difficulties (2), inconsistent visual responses (1), and fatiguing in visual tasks (1).

4.3.2 Awareness and diagnosis of cerebral visual impairment,

4.3.2.1 Awareness if a child has been diagnosed with cerebral visual impairment

Of the 35 participants, approximately half (51.4%) were not always aware of whether a child with CP presented with a CVI (Figure 4.10).

Only 11.4% of participants reported they knew when a child with CP was diagnosed with a CVI and 37.1% said that it depended on whether a caregiver would report a possible CVI through saying that the child could not see.

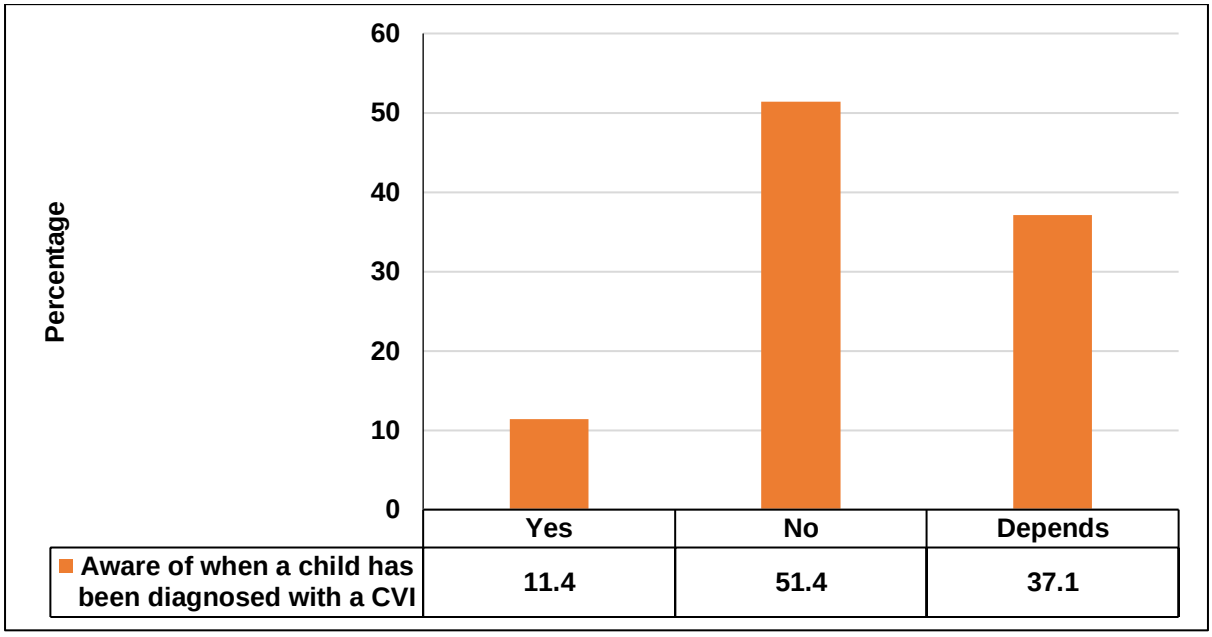


Figure 4.10 Aware if a child has been diagnosed with a cerebral visual impairment (n=35)

4.3.2.2 Formal diagnosis

When asked how they knew that a child with CP had been diagnosed with a CVI, the majority of participants (85.7%) indicated that they did not always know whether the child had been formally diagnosed with CVI.

A formal diagnosis was not always confirmed, as a quarter of the participants (25.7%) reported that the caregivers would inform them of the diagnosis of CVI. Just less than 30% reported that the child's file would report that the child had CVI despite the child not having been formally diagnosed (28.6%). Only one participant, who works in a school for special needs, said that a teacher would inform them of the diagnosis (2.9%) and 31.4% of the participants said that the child was still to be sent for a formal assessment (Figure 4.11).

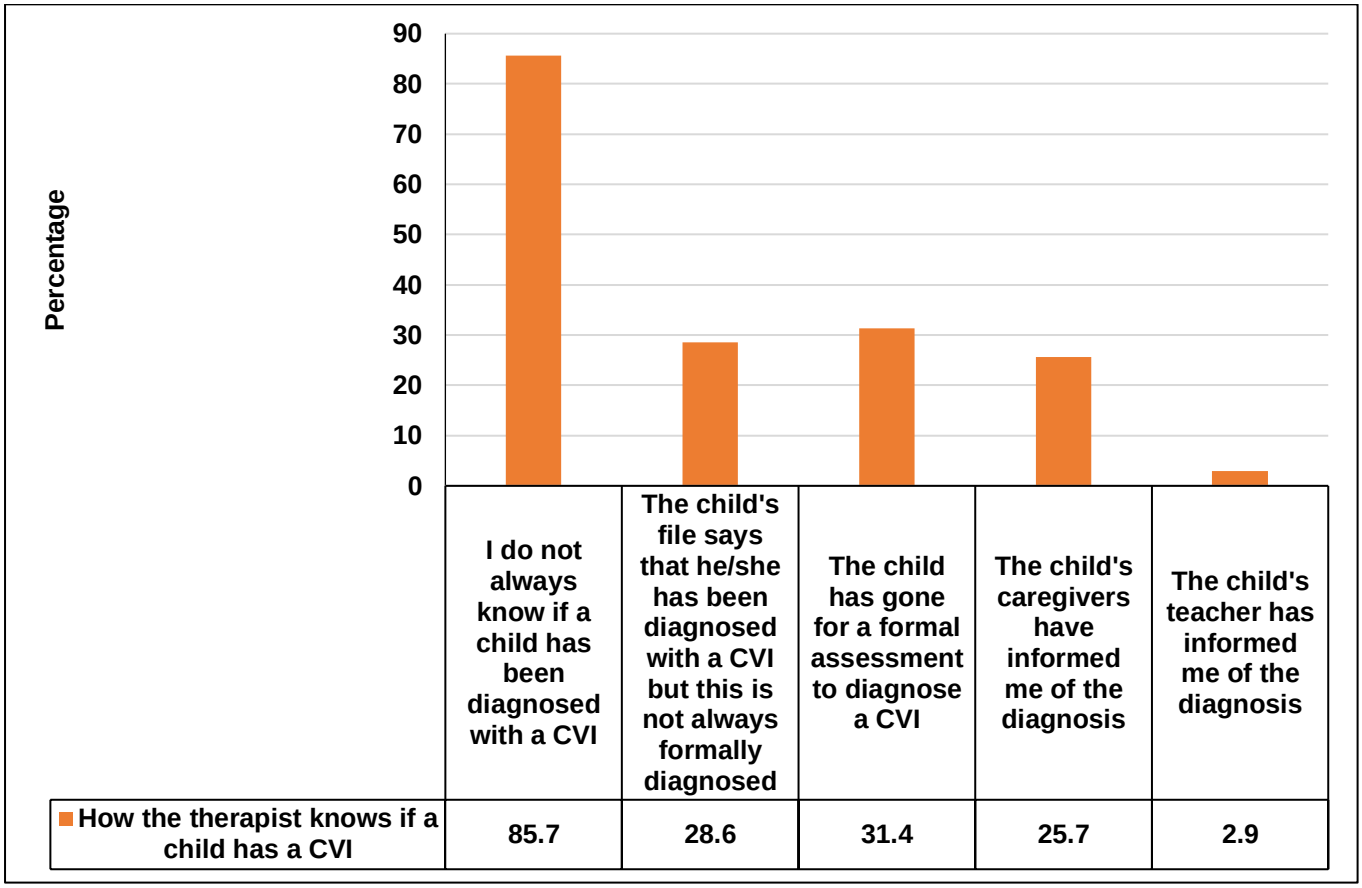


Figure 4.11 How the participants know if a child has been diagnosed with CVI (n=61)

It was reported by one participant that a diagnosis is sometimes not made due to lack of knowledge of the carers or because of the age of the child and that a diagnosis can

be time-consuming and there are often more pressing issues for the parents. Four of the participants mentioned that it depends on whether the child had been seen by the relevant doctors and one of these participants said that in the public health sector children are often misdiagnosed. One participant who worked in a school for special needs said that occasionally a child with CP will have a diagnosis, but this is not common.

One participant mentioned that doctors rarely make a diagnosis of CVI when they refer a child with CP. However, she is aware of a CVI when the referral is from a doctor but not from other professionals, such as teachers. Two of the participants reported that they often observe the signs of CVI before the child has been given a diagnosis and refer the child for further assessment.

Obtaining a formal diagnosis

Obtaining a formal diagnosis for CVI is difficult as agreed to by more than two thirds of the participants (70.8%). Three participants were neutral (8.6%) and three participants disagreed (8.6%) (Figure 4.12).

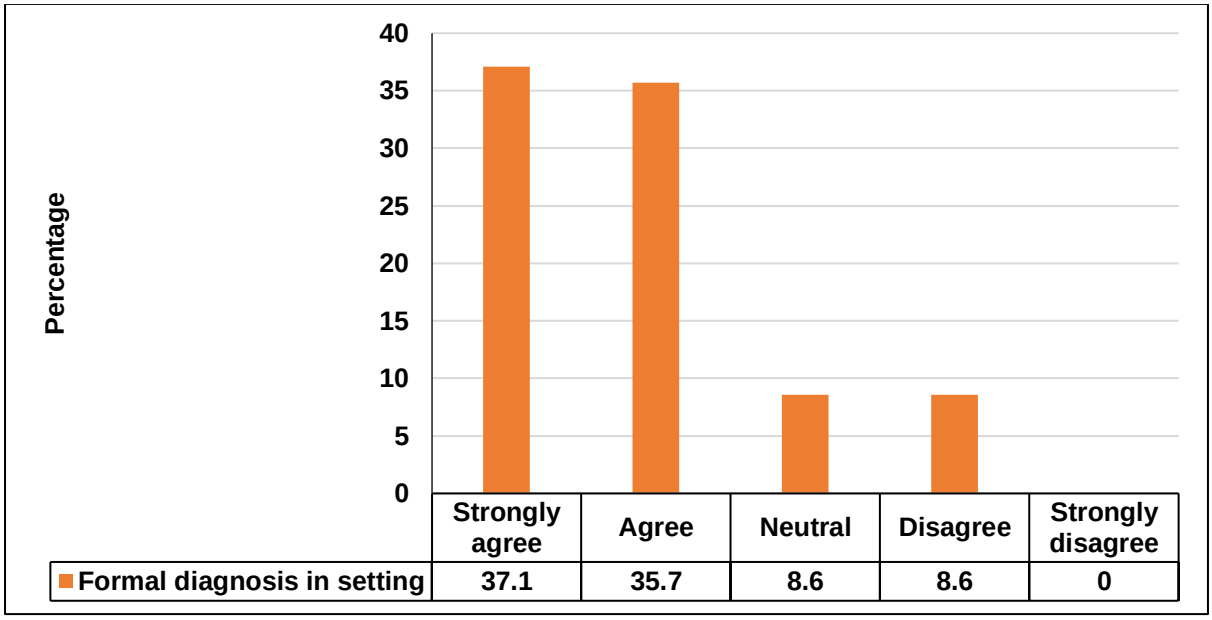


Figure 4.12 Difficulty to get a formal diagnosis of a CVI in my setting (n=35)

Three of the participants reported that CVI is not always a priority for the caregivers or for health professionals as there are often more urgent matters with regards to a child

with CP, such as feeding and seizures. This was especially noted in children being treated in the public health sector.

The main reason expressed for the difficulty in getting a formal diagnosis of CVI was that medical professionals do not know how to test for functional vision. The child is assessed using tests that test the eye structures but not necessarily for CVI, which is a neurological condition. The participants reported that in their experience doctors, optometrists and ophthalmologists either refuse to assess children with CP; do not know how to assess for CVI; or do not have the knowledge of the functional implications of a CVI on a child with CP. Some health professionals do not know when to refer a child for a CVI assessment and that doctors are not always prepared to commit to a diagnosis.

The fact that a child with CP can have communication difficulties makes it even more difficult for a formal assessment to be conducted. Two participants mentioned decreased cognitive level of functioning as well as physical motor deficits in children with CP, which add to this difficulty. One participant who worked in a non-profit organisation school for special needs reported that it was difficult to arrange for children with CP to go for a formal assessment as there was only one CVI clinic in Johannesburg and in other catchment areas it was difficult due to the limited number of eye clinics within that area. This causes long waiting times for appointments and for a diagnosis. Logistically, in a school, if a child has not been formally diagnosed while they were in the health system, it is difficult to then obtain a diagnosis when in the education system. If the parents or caregivers have funds to do a formal assessment, then the therapists report that they will do a screening at school and suggest a formal assessment.

Three participants were neutral in their response to the difficulty of obtaining a CVI diagnosis. One participant reported that they only see one child with CP who is high functioning, another participant reported that CVI is not one of the diagnoses they consider in children with CP. There were three participants who disagreed with the statement. These participants reported that they use an international CVI screening assessment while another participant who worked in a school for special needs and private practice reported that they have created a CVI kit to evaluate the children. In the third case it was reported that most of the children get referred to the eye clinic to

be assessed but since the participant was a physiotherapist who was not able to refer children to the eye clinic it made it difficult for her to evaluate the effectiveness of this service.

4.3.3 Screening for cerebral visual impairment

4.3.3.1 Screening

Less than half of the participants (45.7%) reported that they would always screen for a CVI in children with CP that they are seeing (Figure 4.13). Nine participants said they would sometimes screen for a CVI (25.7%) while three participants said that they would never screen for CVI (8.6%).

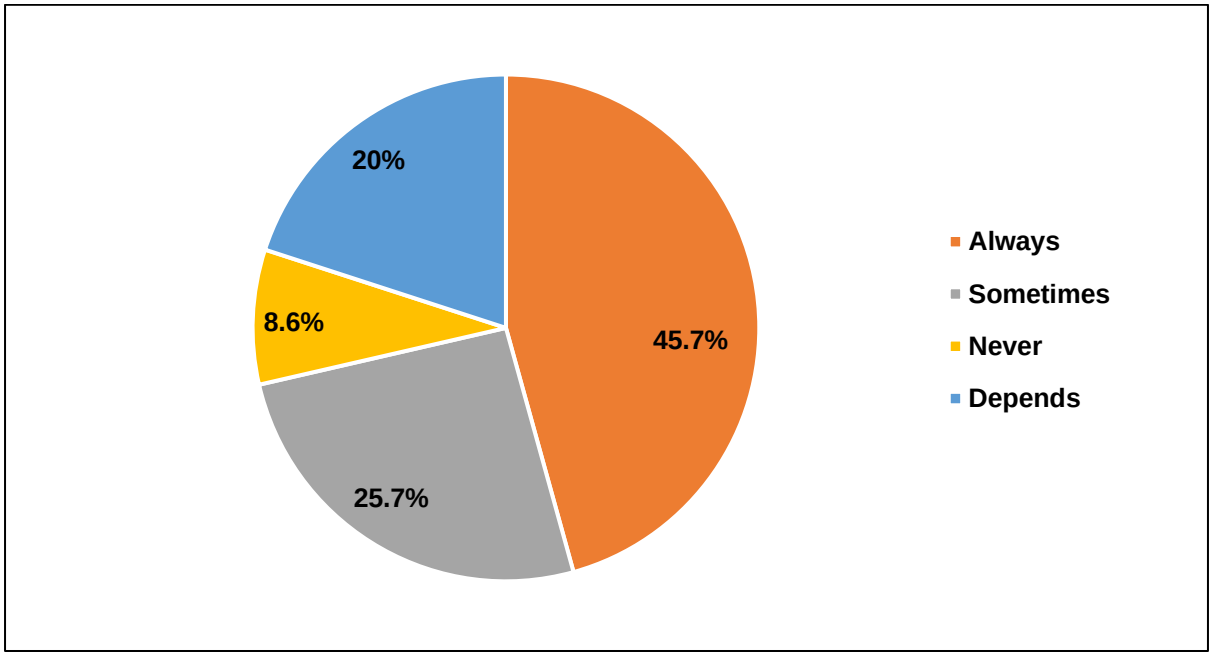


Figure 4.13 Frequency of screening for a cerebral visual impairment in a child with cerebral palsy (n=35)

The remaining participants (20%) reported that it depends on whether a visual impairment is suspected. Concerns are usually verbalised by the caregivers, or the therapist would see inconsistencies in the child's visual function when interacting with their environment or in other assessments. Participants indicated that observations of visual difficulty are often vague as they had no formal assessment and they were more

likely to carry out a screening for a CVI when the child is on GMFCS level I, but less so in a child who is on a lower level.

4.3.3.2 Methods of identifying the need for screening for a cerebral visual impairment

Participants were able to give more than one option in this question. Most participants (88.6%) indicated that they make their own observations in assessment and therapy sessions during functional tasks to identify the need to screen for CVI. A large majority of participants rely on caregiver reports that the child is blind or cannot see (65.7%). One fifth (20%) of participants reported that teachers reported the child had visual problems. Only 11 (31.4%) participants reported that they were aware of problems with vision from the child's medical history from a doctor (Figure 4.14).

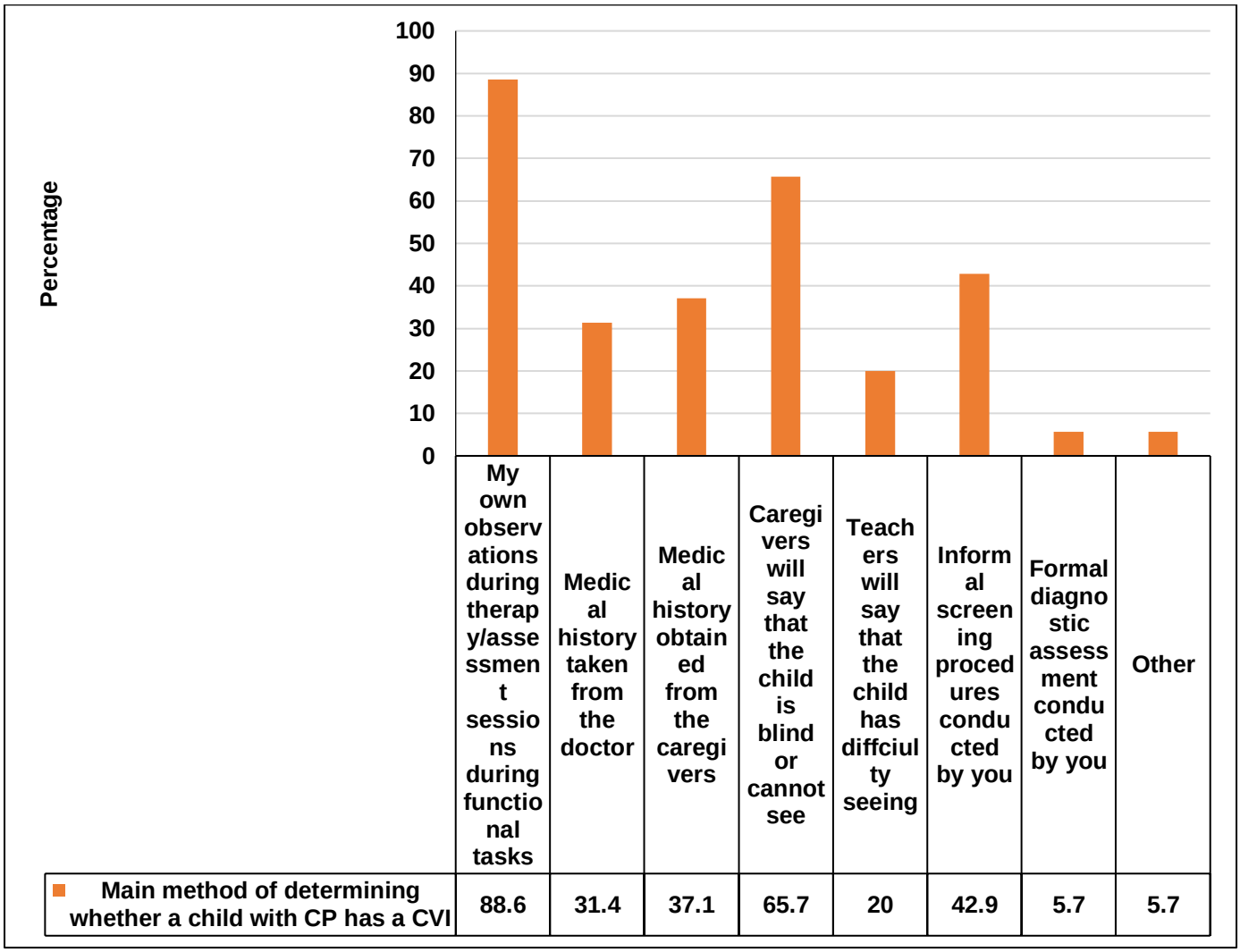


Figure 4.14 Main method of determining whether a child with cerebral palsy has a cerebral visual impairment (n=104)

Participants reported that they would refer to the eye clinic or a vision clinic run by an occupational therapist and an optometrist if the visual deficit was severe and they have a major concern for the child. One participant also referred to Specsavers who will sometimes assist with a free test and glasses fitting.

4.3.3.3 Screening procedures used

Fifteen of the participants reported that they use informal screening procedures (42.9%). Of the 15 participants, 13 of these explained that they simply include tracking of an object as an informal screening procedure. Other procedures are listed in Table 4.4, as most participants gave more than one method of informal screening procedure used.

Table 4.4 Screening procedures for cerebral visual impairment used by participants

	Informal screening procedure used	**Number of participants**
Oculomotor control	• test whether a child can follow an object • monocular and binocular visual tracking of objects • finger test in front of eyes • converging	10
Reaction to lights	• looking at the toys with lights, and a reaction when lights are switched on and off • eyes following torch light, moving targets and eyes searching for and fixing on objects such as mobiles • in a dark room, light is introduced at the periphery of the eye and check for localisation and then tracking • light box or shining a light on an object	7
Localizing	• observe whether a child looks directly at objects • observe whether a child makes eye contact • observe whether a child fixates on an object or on the therapist's face • eyes searching for and fixing on objects such as mobiles	6
Contrast	• colour contrast • 3D objects • high contrast, item (e.g. black, white, yellow, red item)	4
Observations in functional activity	• during feeding / dressing / in therapy in response to activities • functional table top tasks	3

Sound	• ability to track to a sound and find object • response to stimuli	2
Reflexes	• eye jerk observations and blink response when introducing stimuli • pupillary reactions and eye reflexes	2
Size	• various size items (from bouncy ball to hundred and thousand ball) to estimate visual acuity	1

4.3.3.4 Screening and assessment instruments for cerebral visual impairment

Only five participants were aware of validated screening and assessment tools/procedures (20%) and named the CVI-Range by Christine Roman-Lantsky. Two other participants mentioned the GMFCS (does not assess for CVI) and the HAR assessment – which was not expanded on by the participant, and could not be identified by the researcher.

4.3.4 Procedure if a cerebral visual impairment is suspected

Participants were given the option to choose more than one procedure going forward if a CVI was suspected. The majority of the participants reported that they would refer to a specialist if they suspected a CVI in a child with CP because they have access to specialists in their setting (65.7%). These specialists included ophthalmologists, optometrists, paediatric neurologists, behavioural optometrists, neurologists, medical officers, developmental doctors and experienced occupational therapists (Figure 4.15).

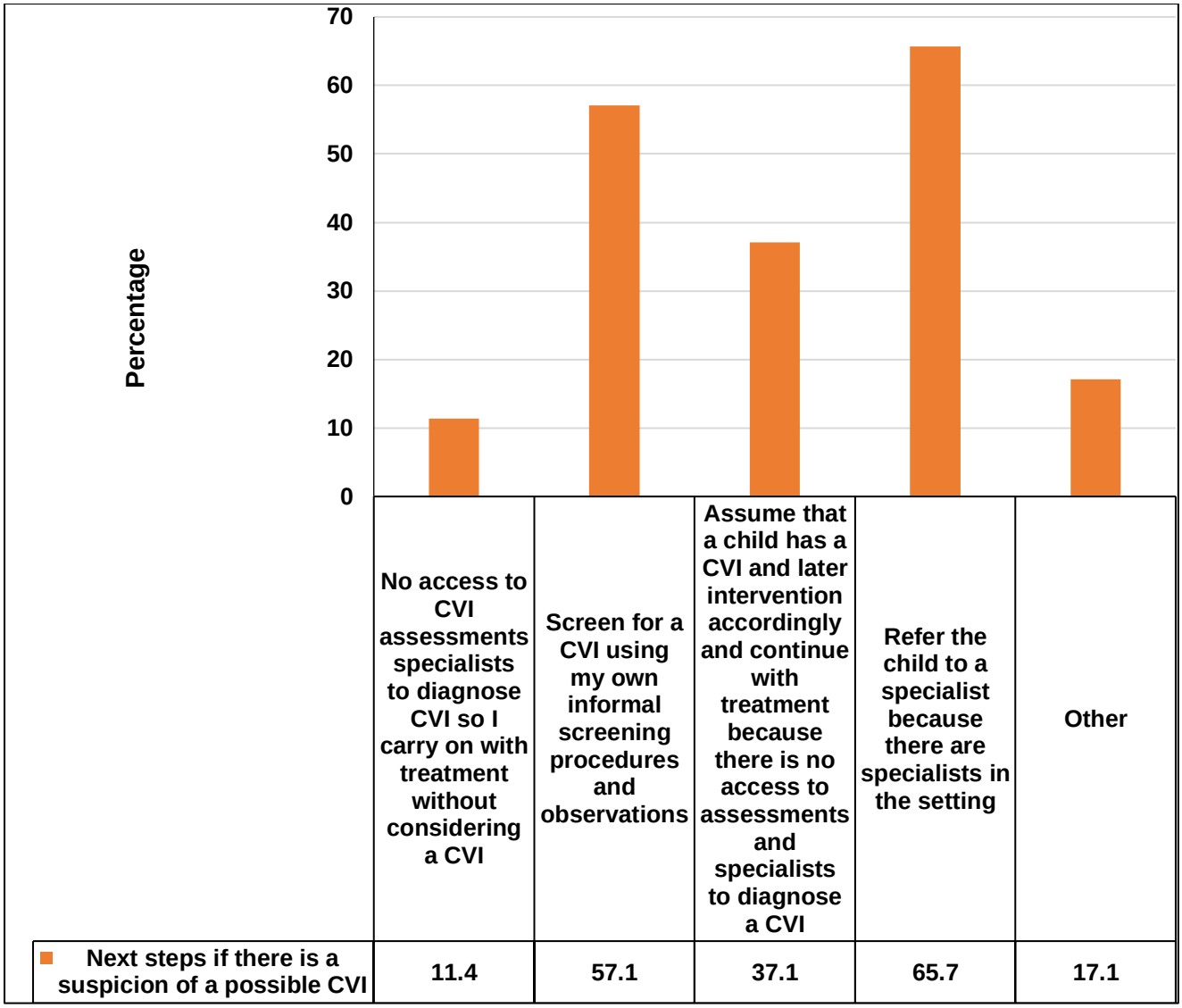


Figure 4.15 The next steps if there is a suspicion of a possible cerebral visual impairment (n=66)

Participants also reported that they would use their own informal screening procedures and observations (57.1%). Thirteen of the participants (37.1%) reported that they would assume that a child has CVI and alter their intervention accordingly, but continue with treatment since they do not have access to assessments and specialists to diagnose CVI. Other participants (11.4%) reported that they would carry on with treatment without considering CVI because they do not have access to assessments and specialists to diagnose CVI.

One participant mentioned that a diagnosis of CVI would not make a difference in their setting, which was an NPO. The children at the NPO have little access to intervention,

so unless the child was going to be referred to school and a diagnosis was needed, would a referral be made. The participant who was aware of the CVI-Range uses this to asses a child and does not routinely refer to a specialist unless they feel a child requires glasses.

4.3.4.1 Does the presence of a cerebral visual impairment alter intervention

Figure 4.16 indicates that the majority of the participants reported that they would alter their intervention if they were aware of CVI (68.6%). Seven participants reported that CVI would not change their intervention (20%) and four participants reported that sometimes their intervention would alter if there was CVI (11.4%).

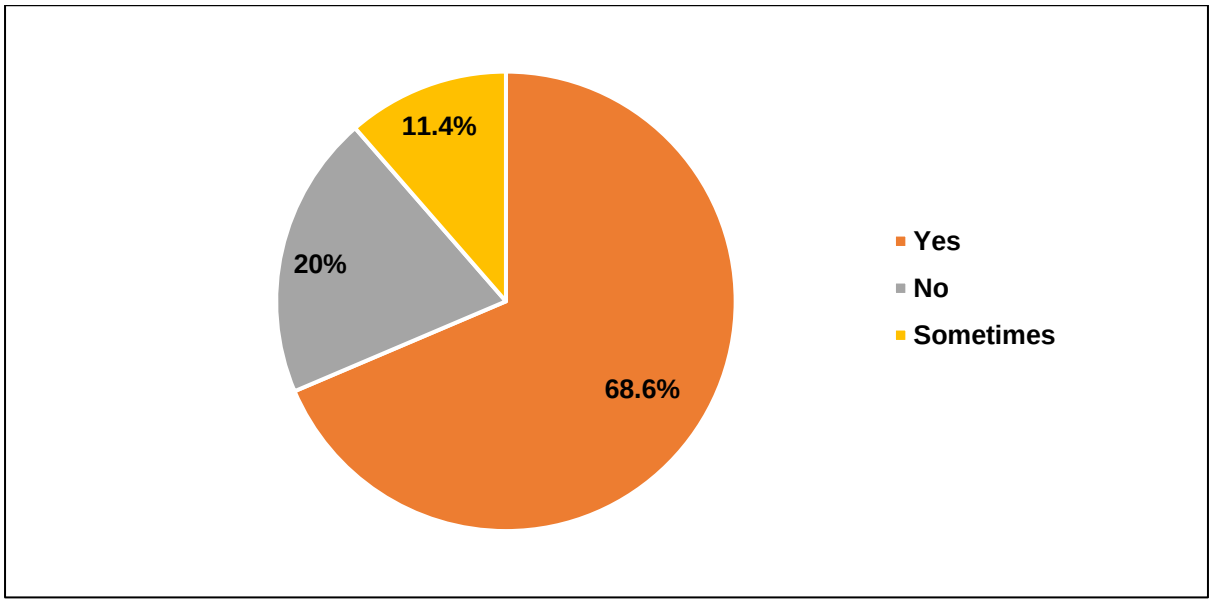


Figure 4.16 Does the presence of a cerebral visual impairment alter intervention (n=35)

PHASE 2

4.4 Part 3: Content validity of the Cerebral Visual Impairment Motor Questionnaire

4.4.1 Demographics of the participants who completed the content validity questionnaire

4.4.1.1 Profession of participants

Of the 14 participants, the majority were occupational therapists (64%) and the remaining participants were physiotherapists (36%) (Figure 4.17).

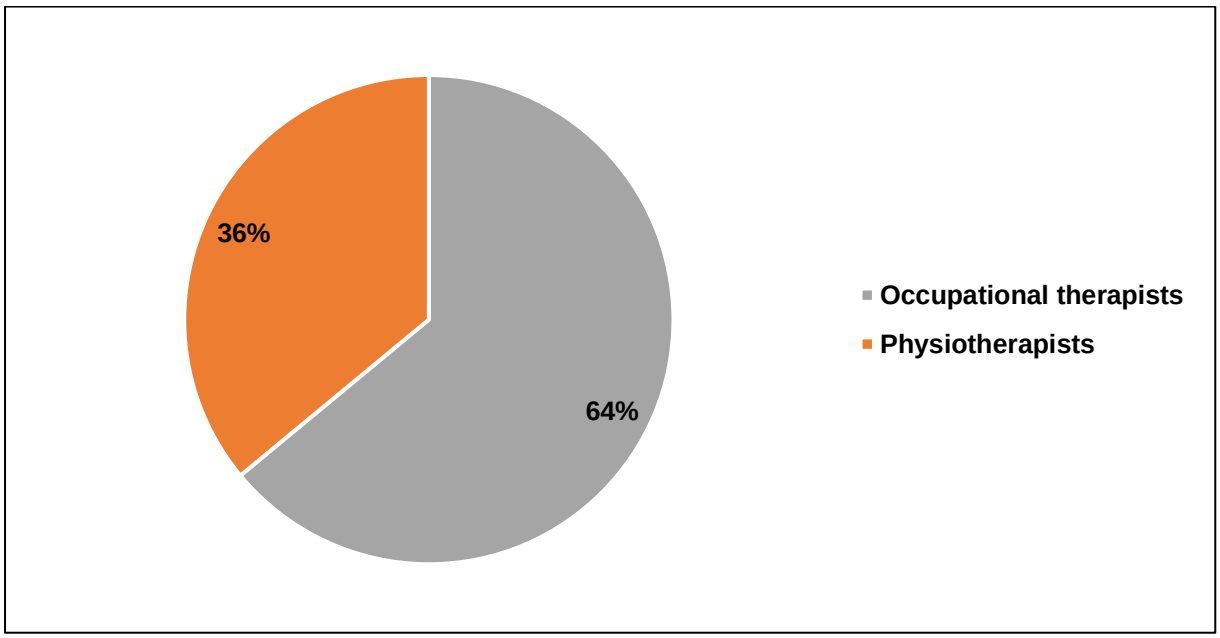


Figure 4.17 Professions of the participants (n=14)

4.4.1.2 Clinical experience and further training

The majority of participants had 8-10 years of work experience in their profession (35.7%) followed by 5-7 years of work experience (28.6%). This means that a large majority of the participants had more than five years of work experience in their profession (85.7%). Only 14.3% of participants had less than 5 years of work experience in their respective profession as an occupational therapist or physiotherapist (14.3%) (Figure 4.18).

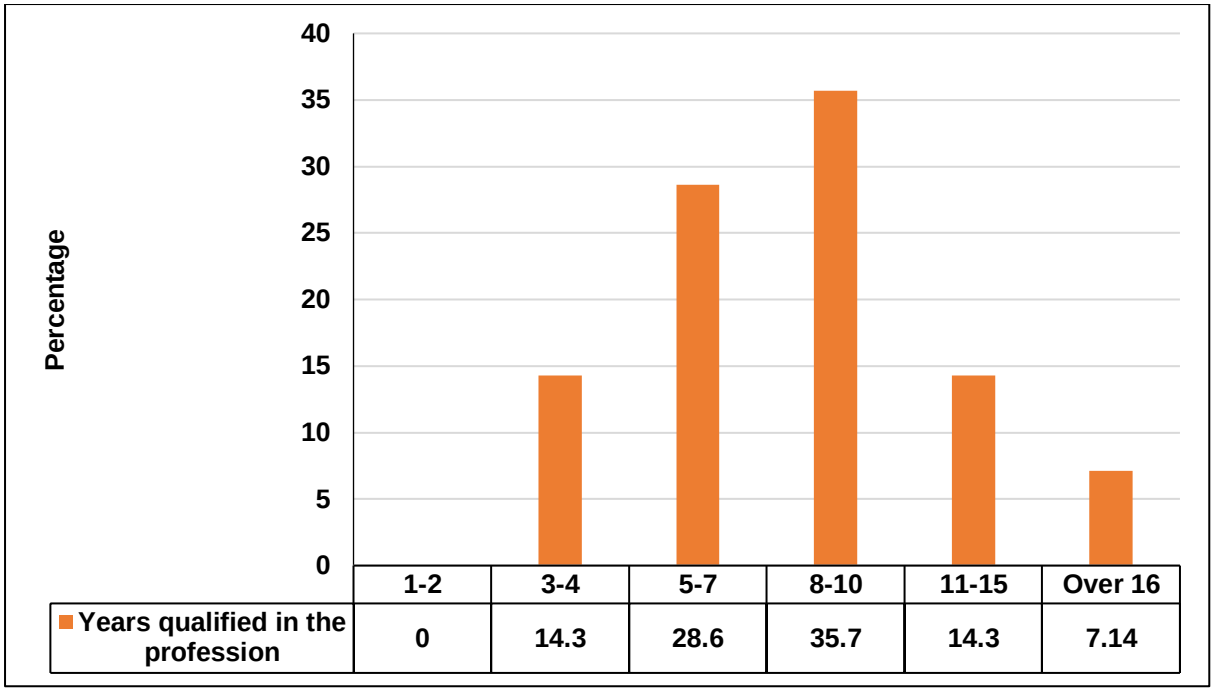


Figure 4.18 Years qualified in the profession (n=14)

The participants reported that all their work experience had been with children with CP. The majority of the participants had over five years of work experience working with children with CP (71.3%). 21.4% had 8-10 years of experience, 35.7% had 8-10 years of experience, and 14.2% had more than 11 years of experience.

Of the occupational therapists, a third had a master's degree in occupational therapy (33.3%), and the rest had an honour's degree in occupational therapy (66.7%). Of the physiotherapists, one of the participants had a master's degree in physiotherapy (20%).

A large majority of the participants had postgraduate training in assessing and treating children with CP (93%). Half of the participants had completed the one-week introduction to the assessment and treatment of CP held by the South African Neurodevelopmental Association (SANDTA) (50%).

Nine of the participants had completed the eight-week neurodevelopmental course in paediatrics held by SANDTA (64%). Three of the participants had advanced training in the assessment and treatment of children with CP (21.4%). This training included courses such as the advanced baby course held by SANDTA. One participant had

done the Malamulele Onwards one-week course in assessment and treatment of children with CP. One of the participants had done multiple courses, including the advanced baby course; numerous advanced neurodevelopmental level II therapy courses; functional walking course; the early assessment and treatment of Infants with Cerebral Motor Disturbances; evaluation and treatment of children with CP focusing on the upper limb; basic and intermediate seating courses; and care of the preterm infant.

Four of the participants reported that they had postgraduate training in the assessment and treatment of children with CP including CVI. These postgraduate courses included the eight-week paediatric NDT course; CVI training on the CVI-Range assessment course; CVI continuous professional development courses (CPD); and a course called Cortical visual impairment: From theory to practice presented by Lindsay Hillier in November 2018.

4.4.2 Content validity index of the Cerebral Visual Impairment Motor Questionnaire for GMFCS levels I, II and III:

4.4.2.1 GMFCS levels I, II and III

Item content validity index

All the questions on the CVI-MQ achieved a satisfactory content validity index for items for GMFCS levels I, II and III, except for those represented in Table 4.5 Scores below 0.79 indicate the need for revision and scores below 0.70 indicate that the item should be eliminated (Rodrigues et al., 2017) (Appendix M).

In the CVI-MQ for GMFCS levels I, II and III, question 19 was the only question that achieved less than a total of 0.70 in the content validity index. The other 26 questions all achieved above 0.79 for the content validity index. Question 3 received less than 0.79 for clarity (0.71). Question 8 received less than 0.79 for relevance (0.71). Question 14 received less than 0.79 for relevance and ambiguity (0.71). Question 15 received less than 0.79 for relevance (0.71). Question 21 received less than 0.70 for clarity (0.64) and ambiguity (0.73).

Table 4.5 Item content validity index of the Cerebral Visual Impairment Motor Questionnaire for GMFCS levels I, II and III

Question	Relevance	Clarity	Simplicity	Ambiguity	Total content validity
3. The child bumps into moved toys or furniture when it crawls (n=14)	0.86	0.71	1.00	0.79	**0.84**
7. The child will walk up an unfamiliar staircase one step at a time, always leading with the same foot, whereas it will walk up a familiar staircase with alternating feet at each step (n=13)	0.77	0.93	0.85	0.92	**0.87**
8. The child will walk down an unfamiliar staircase one step at a time, always leading with the same foot, whereas it will walk up down a familiar staircase with alternating feet at each step (n=14)	0.71	0.79	0.86	0.86	**0.80**
14. The child does not jump off an elevated platform (n=14)	0.71	0.79	0.93	0.71	**0.79**
15. The child does not jump forwards*, sidewards*, or backwards* (n=14)	0.71	0.79	0.86	0.79	**0.79**
19. The child has difficulty estimating the distance and speed of other road users (n=13)	0.69	0.54	0.69	0.54	**0.62**
20. The child has difficulty finding the route to the class or the school playground when walking at school (n=13)	0.85	0.92	0.92	0.92	**0.90**
21. The child reaches behind/bumps into small objects. The child only grabs the object after touching it (n=11)	1.00	0.64	0.82	0.73	**0.80**

The scale-level content validity index is calculated using the number of items in a tool according to relevance. For the CVI-MQ the scale-level content validity index was 0.86, indicating overall acceptable content validity for this assessment tool since the value is higher than the cut-off point of 0.80 (Rodrigues et al., 2017).

Concerns with each of the items which needed alteration or elimination from the CVI-MQ are presented in Table 4.6.

Table 4.6 Content validity issues for items identified with problems on the Cerebral Visual Impairment Motor Questionnaire for GMFCS levels I, II and III

Item	Item	Concerns with the item
3	The child bumps into moved toys or furniture when it crawls	Clarification of item needed. This item is age-dependent. Items do not consider other reasons a child may move/not move/experience difficulties with an item. May be due to spatial awareness difficulties or due to a physical impairment such as dyskinesia or ataxia or tends to move in a preferred direction due to tone.
7	The child will walk up an unfamiliar staircase one step at a time, always leading with the same foot, whereas it will walk up a familiar staircase with alternating feet at each step	Items do not consider other reasons a child may move/not move/experience difficulties with an item. Similarity of questions.
8	The child will walk down an unfamiliar staircase one step at a time, always leading with the same foot, whereas it will walk up a familiar staircase with alternating feet at each step	Items are not always relevant to a CVI/specificity to CVI not sufficient. Items do not consider other reasons a child may move/not move/experience difficulties with an item.
14	The child does not jump off an elevated platform	Items do not consider other reasons a child may move/not move/experience difficulties with an item. Specific information of an item not always given.
15	The child does not jump forwards*, sidewards*, or backwards	Clarification of item needed. This item is age-dependent. Items do not consider other reasons a child may move/not move/experience difficulties with an item. Specific information of an item not always given.
19	The child has difficulty estimating the distance and speed of other road users	Clarification of item needed. This item is age-dependent. This question to be ambiguous is the child was driving or walking on the road.
20	The child has difficulty finding the route to the class or the school playground when walking at school	Items do not consider other reasons a child may move/not move/experience difficulties with an item.
21	The child reaches behind/bumps into small objects. The child only grabs the object after touching it	Clarification of item needed.

The comments that participants made in relation to the items on the CVI-MQ for GMFCS levels I, II and III were analysed to determine what alterations could be suggested to improve the content validity of the tool for use in South Africa. Categories

included clarity and relevance of items, age appropriateness of items, repetition of items, vocabulary and specificity of items for CVI only (Table 4.7).

Table 4.7 Content validity discussion of the Cerebral Visual Impairment Motor Questionnaire for GMFCS levels I, II and III

Categories	Codes	Number of Items
Clarification of items needed	• Clarity for the following should be addressed o if the child was seeing an object moving or if the child was being moved, o high contrast toys", o difference between sound production and verbal support. o moving spontaneously or "follow" as in behind or next to someone, o hesitates at entrance/exit. or struggled to find the frame/entrance of the room. o lower colour/lower contrast ball means. o whether the child was driving or walking on the road. o object was on a table or on the floor and if the object was familiar o add the types of manipulation such as rotational and linear. o whether the object had to have all of the stated qualities in each group or just one quality. • Some items are not a yes/no answer. • Examples should be provided. • Some questions are highly loaded with many options.	14 items
Age-appropriateness of the item needs to be considered	• Items include movements such as crawling, walking and running • age brackets should be added to some question. • children are too young to use the road alone. • age appropriateness of questions must be noted.	10 items
Items do not consider other reasons a child may move/not move/experience difficulties with an item	• children move for different reasons at different times and a child could bump into objects for other reasons such as hemiplegia, postural control when moving - children with CP struggle with control • the cognitive level of the child could affect this task. • seldom see a child where a CVI is the primary problem. • children on a GMFCS level I cannot jump forwards, sideways or backwards	10 items
Specific information of an item not always given	the heights of objects should be given. Item 13: Three participants questioned how big the obstacles are and that these should be specified. Item 14: Two participants questioned how high the platform is and that this should be specified. Item 15: One participant questioned whether it was bilateral jumping or single leg jumps. Item 23: One participant suggested specifying what the figure is, e.g. circle, line or cross. Item 24: One participant said that it is dependent on hand dominance, contrast of an object and/or moving centrally or peripherally. Item 26: One participant questioned where the object was placed.	7 items

Items are not always relevant to a CVI/specificity to CVI not sufficient	• add crawls **ONLY** if stimulated by one or more of the following for stronger indication of a CVI. • items are not sensitive enough to CVI. • relate items to visual cues i.e., the problem corrects when others are wearing high visibility clothes. “does his ability to navigate obstacles become better when they are in specific high visibility colours”? • change wording in some items- 'notices and/or reaches' for object.	7 items
Vocabulary is not always appropriate	• the words “fluorescence” “sound production” and “verbal support” – should be changed.	3 items
Familiar versus unfamiliar environment	• observed a child in their natural environment, and children with special needs are not comfortable in an unfamiliar environment • not be relevant for a child that you are seeing for the first time in an unfamiliar environment.	3 items
Inappropriate wording of some items	• the use of the word “it” instead of “he/she/child”.	2 items
Similarity of questions	• items 6 and 7: similar to item 4.	2 items
Item not appropriate for the South African setting	• the roads in South Africa are not safe for the children to use alone especially children with CP.	1 item

4.4.2.2 GMFCS levels IV and V

Item content validity index

All the questions on the CVI-MQ achieved a satisfactory content validity index for items for GMFCS levels IV and V, except for the items represented in Table 4.8 (Appendix N). A score below 0.79 indicates the need for revision and a score below 0.70 indicates that the item should be eliminated (Rodrigues et al., 2017).

Table 4.8 Item content validity index of the CVI-MQ for GMFCS levels IV and V

Question	Relevance	Clarity	Simplicity	Ambiguity	Total content validity
5. The child bumps into moved toys or furniture when it belly-crawls (n=12)	0.67	0.67	0.83	0.67	**0.71**
6. The child crawls/belly-crawls slower in an unknown environment with the same surface as a known environment (n=12)	0.75	0.83	0.83	0.83	**0.81**

In the CVI-MQ for GMFCS levels IV and V, question 5 was the only question which received less than 0.79 for the content validity index with a score of less than 0.70 for relevance, clarity and ambiguity. Question 6 had a score below 0.79 for relevance.

The scale-level content validity index is calculated using the number of items in a tool according to relevance. For the CVI-MQ the scale-level content validity index was 0.92, indicating overall acceptable content validity for this assessment tool since the value is higher than the cut-off point of 0.80 (Rodrigues et al., 2017).

Concerns with each of the items which needed alteration or elimination from the CVI-MQ are presented in Table 4.9

Table 4.9 Content validity issues for items identified with problems on the Cerebral Visual Impairment Motor Questionnaire for GMFCS levels IV and V

Item		**Concerns with the item according to the theme**
5	The child bumps into moved toys or furniture when it belly-crawls	Clarification of items needed. Items do not consider other reasons a child may move/not move/experience difficulties with an item. Familiar versus unfamiliar environment. Specific information of an item not always given
6	The child crawls/belly-crawls slower in an unknown environment with the same surface as a known environment	Items do not consider other reasons a child may move/not move/experience difficulties with an item. Familiar versus unfamiliar environment

The comments that participants made in relation to the items on the CVI-MQ for GMFCS levels IV and V were analysed to determine what alterations could be suggested to improve the content validity of the tool for use in South Africa. Categories included clarity and relevance of items, age appropriateness of items, repetition of items, vocabulary and specificity of items for CVI only (Table 4.10)

Table 4.10 Content validity discussion of the CVI-MQ for GMFCS levels IV and V

Categories	Codes	Number of Items
Clarification of items needed	• an explanation of terms is needed. • add the word 'unintentionally' as sometimes the child may bump into objects as a way of engaging with it. • clarify if the furniture and toys being moved from their usual spots • clarify out of a wheelchair. • does the object needs to have all the characteristics mentioned	7 Items
Vocabulary is not always appropriate or easily understood	• electric or power wheelchair rather than electric/mechanic wheelchair. • add the words “notices or reaches” for this item.	2 Items
Items are not always relevant to a CVI/specificity to CVI not sufficient	• may not navigate in a wheelchair despite physical abilities as this is more relevant to this level of CP. • change working to be more specific to CVI: -does not at all engage visually with an object while exploring-.	2 Items
Items do not consider other reasons a child may move/not move/experience difficulties with an item	• some children at GMFCS IV and V do not have the head control to turn their head. • child on GMFCS levels IV and V are unlikely to belly crawl. • motor functions shouldn't affect the test results- ability to see the object and to get there are two different things so dyskinesia and the ability of a child to reach for an object should be considered • cognitive ability needs to be considered.	11 Items
Familiar versus unfamiliar environment	• include 'known environment'. • the 'child is reluctant /fearful to move in unfamiliar environments'.	2 Items

Specific information of an item not always given	• include what moved - furniture or toys.
	• provide information around the type of objects as in the other questionnaire (for GMFCS levels I, II and III.
	• information is needed on
	  ○ contrast of the objects and where it is moving.
	  ○ where the object is in the child’s visual field.
	• Item 12: object should be familiar to child.
	• no specific measurement of reach and grasp such as over or undershooting.
		6 Items

Inappropriate wording of some items	• use of the word “it” instead of “he/she/child”.	1 Item

4.5 Part 4 Usability and utility questionnaire

4.5.1 Demographics of the participants who completed the usability and utility questionnaire

There were six participants who agreed to take part by using the CVI-MQ in their clinical practice. Of these six participants, four of them were occupational therapists (66.7%) and two of them were physiotherapists (33.3%) (Table 4.11).

Table 4.11 Profession and years of experience of participants

Participants	Profession	Years of work experience (years)	Years of experience working with children with CP (years)	Work sector	GFMCS levels treated
1	Occupational therapist	5-7	3-4	Non-profit organisation LSEN school	II
2	Occupational therapist	3-4	1-2	Private practice LSEN school	II, III
3	Occupational therapist	8-10	8-10	Public - rural	V
4	Occupational therapist	5-7	5-7	Non-profit organisation Private practice – outpatient LSEN school	II, III, IV, V
5	Physio-therapist	3-4	1-2	Private practice – outpatient LSEN school	I, III, V
6	Physio-therapist	8-10	8-10	Public - tertiary	I, II, III, IV, V

Five of the six participants had postgraduate training in the assessment and treatment of children with CP. This postgraduate training included the one-week introduction course to the assessment and treatment of children with CP through SANDTA (33.3%); the one-week Malamulele Onwards CP course (16.7%); and the eight-week paediatric NDT course held by SANDTA (50%). One of the participants reported that they had postgraduate training specifically in CP and CVI which was the eight-week paediatric NDT course. Other participants also participated in this course but it is not clear if CVI was part of the curriculum for the years in which they completed the course.

4.5.2 Usability of the cerebral visual impairment motor questionnaire

The results of this questionnaire are presented according to the headings and questions by appropriateness, usability, feasibility of administration and acceptability.

4.5.2.1 Appropriateness

Time for administration

Participants were asked to rate appropriateness of the CVI-MQ for the intended use in their setting in terms of the amount of time it takes to administer the assessment. Half of the participants agreed that the CVI-MQ is appropriate in terms of the time it takes to administer, whereas two participants were neutral (33.3%) and one participant disagreed that the time taken to administer the CVI-MQ was appropriate (Figure 4.18).

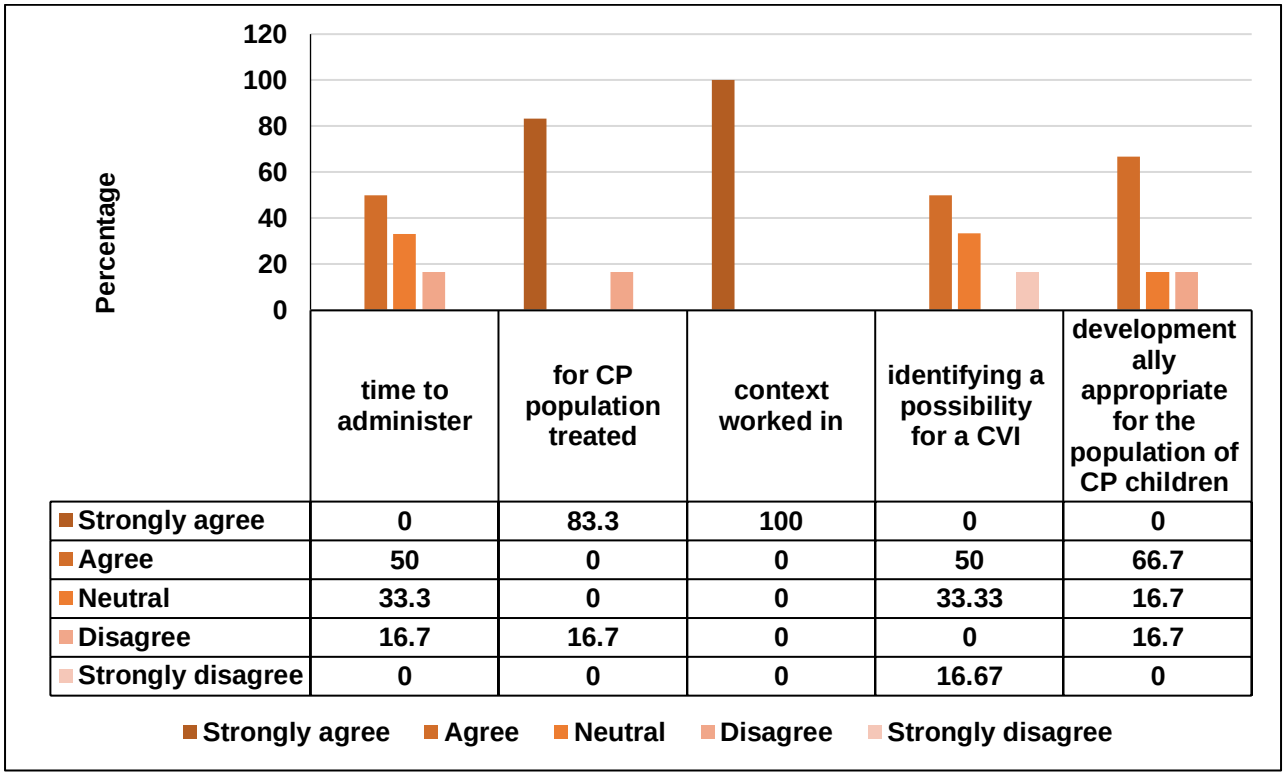


Figure 4.19 Appropriateness of the cerebral visual impairment motor questionnaire (n=6)

Population of children with CP and work context

Appropriateness of the CVI-MQ for the setting in which the participants work in terms of the population of children with CP, particularly in relation to the GMFCS levels and

the context (government, school for special needs, private practice, NGO) was commented on. The majority of the participants strongly agreed that the CVI-MQ was appropriate in terms of the population that the participants treat (83.3%) and in terms of the context that the participants work in (100%) (Figure 4.18).

Identification of cerebral visual impairment

When asked if the CVI-MQ was useful in identifying a possibility of CVI in a child with CP, 50% agreed with this statement, whereas two participants were neutral (33.3%) and one participant (16.7%) strongly disagreed. The majority of participants agreed that the CVI-MQ is developmentally appropriate (according to the level of function of the children with CP assessed, on the two separate questionnaires for GMFCS levels) while one participant was neutral (16.7%) and one participant did not agree that the CVI-MQ was developmentally appropriate (16.7%).

4.5.2.2 Usability

Access and cost

All of the participants had access to the CVI-MQ in their work place as they were able to photocopy the CVI-MQ (100%) (Figure 4.19).

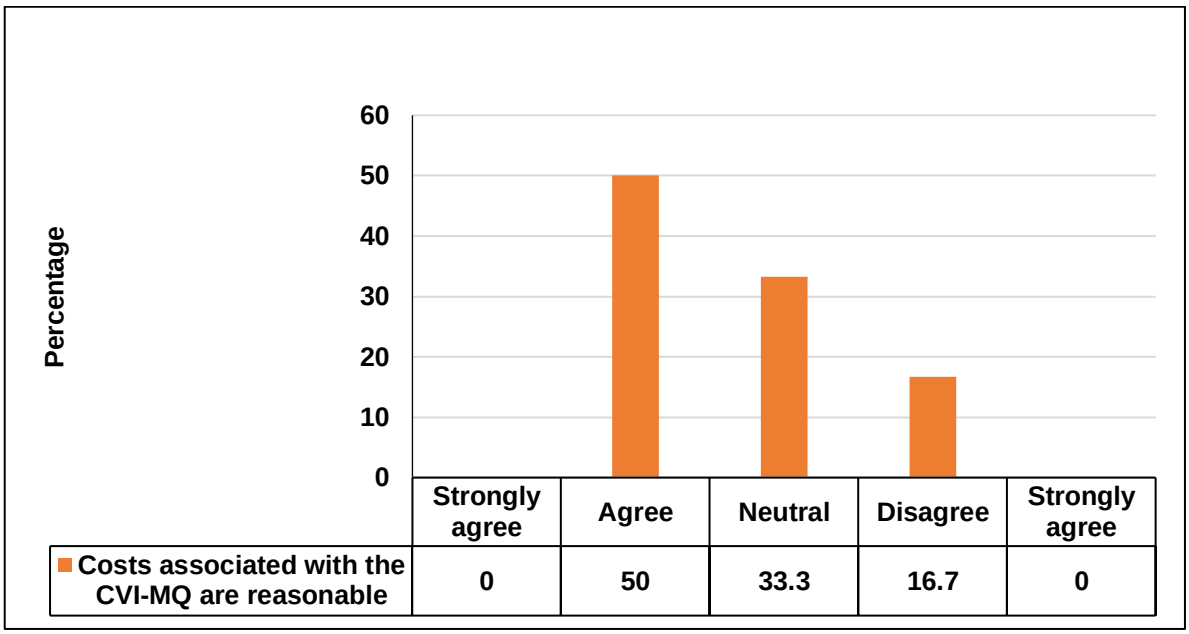


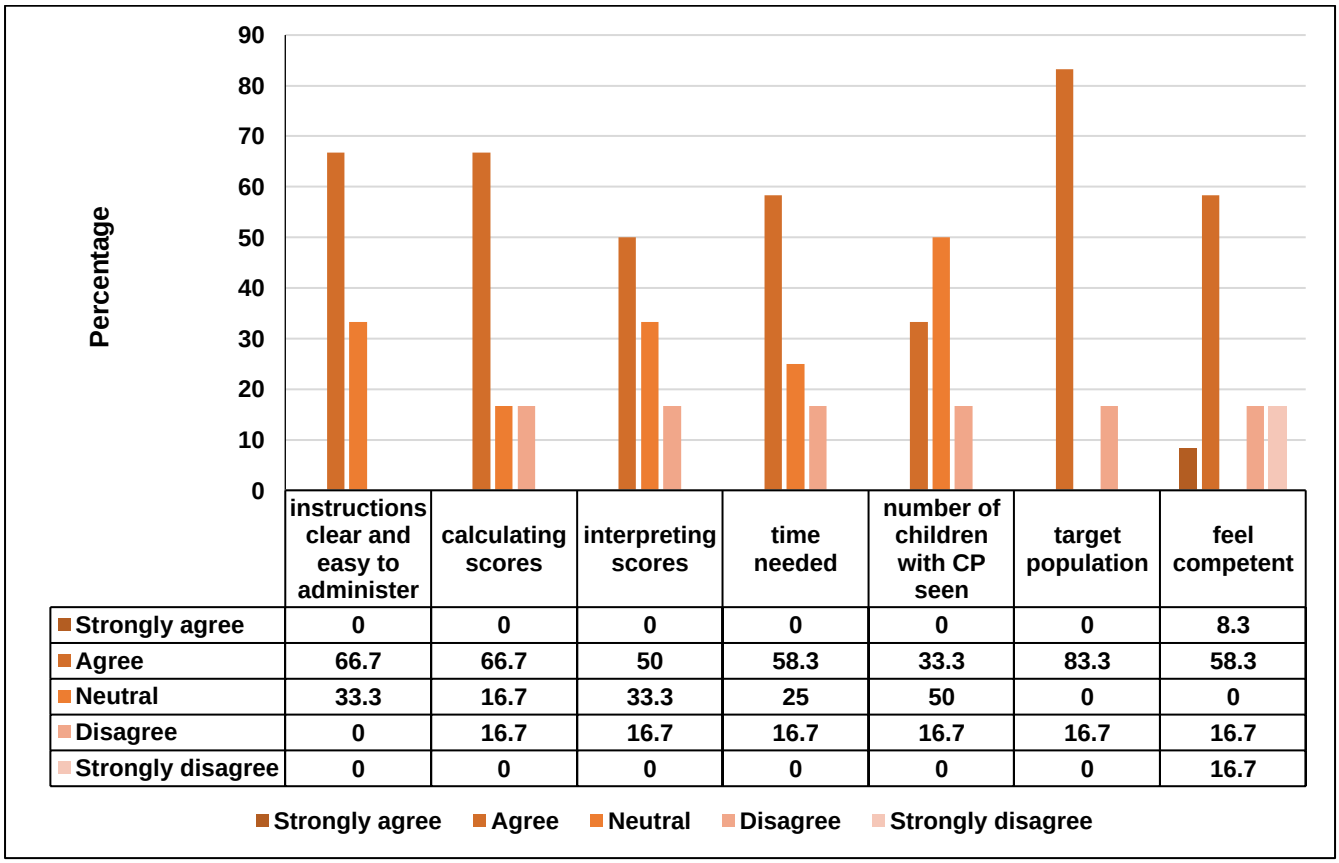
Figure 4.20 Costs associated with the CVI-MQ (n=6)

Half of the participants agreed that the costs associated with the screening tool are reasonable (50%), two participants were neutral (33.3%) and one participant did not find the costs reasonable (16.7%).

4.5.2.3 Feasibility of administration

Instructions

The majority of the participants found the CVI-MQ manageable and appropriate in terms of the instructions and if they were clear and easy to follow (66.7%). Two of the participants were neutral in their response (33.3%) (Figure 4.30).



	instructions clear and easy to administer	calculating scores	interpreting scores	time needed	number of children with CP seen	target population	feel competent
Strongly agree	0	0	0	0	0	0	8.3
Agree	66.7	66.7	50	58.3	33.3	83.3	58.3
Neutral	33.3	16.7	33.3	25	50	0	0
Disagree	0	16.7	16.7	16.7	16.7	16.7	16.7
Strongly disagree	0	0	0	0	0	0	16.7

Figure 4.21 Feasibility of administration of the CVI-MQ (n=6)

Scoring

The majority of the participants found the CVI-MQ manageable and appropriate in terms of scoring the screening tool and interpreting the scores (66.7%). One participant was neutral (33.3%) and the other did not agree that the CVI-MQ was

manageable and appropriate in terms of scoring and interpretation of these scores (33.3%).

More than half of the participants agreed that the amount of time taken to complete the scoring and interpret the results on the CVI-MQ was manageable and appropriate within their setting (58.3%) and a quarter of the participants felt neutral (25%) and one participant did not agree that the time taken was appropriate and manageable (16.7%).

Number of children referred

Half of the participants were neutral in that the CVI-MQ was manageable and appropriate in terms of the number of children that they see in their setting (50%). Two participants agreed (33.3%) and one disagreed (16.7%). The majority of the participants found that the CVI-MQ was manageable and appropriate in terms of the target population, namely children with CP (83.3%). One participant disagreed (16.7%).

Competence in administration

The majority of the participants agreed (58.3%) and strongly agreed (8.3%) that they felt competent in administering the CVI-MQ. One participant disagreed (16.7%) and one participant strongly disagreed (16.7%) that they felt competent in administering the CVI-MQ as they had not used it before.

4.5.2.4 Acceptability

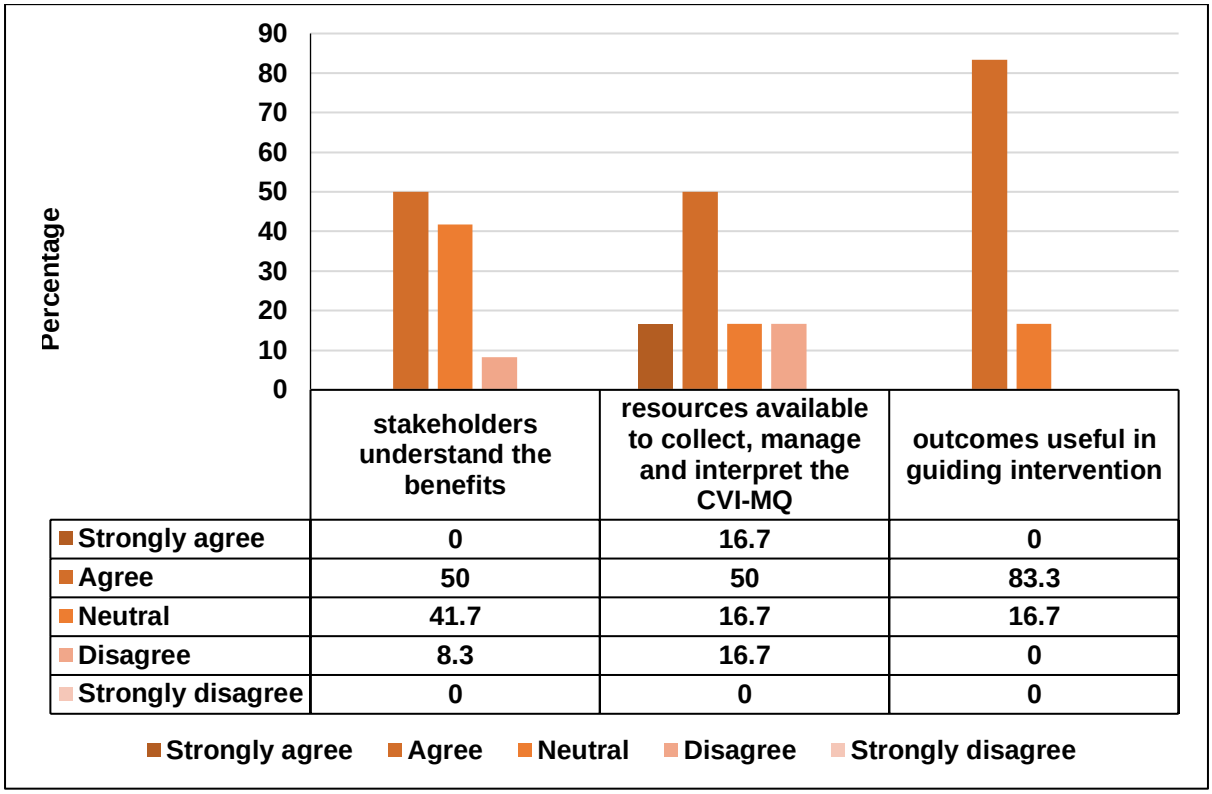
Stakeholders' understanding

Half of the participants agreed that stakeholders (caregivers, treating doctors, other allied health professionals and teachers) understood the benefits associated with the CVI-MQ, whereas one participant felt neutral and disagreed with the statement (16.7%) and just less than half of the participants felt neutral about the statement (41.7%) (Figure 4.21).

Resources available

Half of the participants agreed that there were resources available to collect, manage and interpret the CVI-MQ (50%), with one participant who strongly agreed (16.7%).

One participant felt neutral (16.7%) and one participant disagreed that they had the resources to collect, manage and interpret the CVI-MQ (Figure 4.21).



	stakeholders understand the benefits	resources available to collect, manage and interpret the CVI-MQ	outcomes useful in guiding intervention
Strongly agree	0	16.7	0
Agree	50	50	83.3
Neutral	41.7	16.7	16.7
Disagree	8.3	16.7	0
Strongly disagree	0	0	0

Figure 4.22 Acceptability of the CVI-MQ (n=6)

Useful in guiding treatment

The majority of the participants agreed that the CVI-MQ was useful in guiding treatment and intervention (83.3%), whereas two participants felt neutral (16.7%).

4.6 Summary

The first part of the study aimed to identify the current CVI screening procedures used by occupational therapists and physiotherapists in children with CP in various settings in South Africa. The majority of the participants were occupational therapists and many of the participants worked in more than one sector. Just over half of the participants were working in private practices on an outpatient basis and many are working at schools for learners with special needs. Very few participants were working in rural,

urban, district, regional or tertiary public hospitals. The children treated by the participants were mainly between the ages of 3-10 years old and on GMFCS levels I and II. Doctors and other allied health professionals made up the majority of referrals of children to the participants.

Screening for CVI is not always a common practice as only less than half of the participants reported that they would screen for CVI. The remaining participants would only sometimes screen if a visual impairment is suspected and the others would not screen for CVI. The main method used by participants to determine whether a child with CP has CVI is through their own observations/screening procedures used in therapy sessions. The majority of the participants reported that they would use their own screening procedures which involved screening whether the child is able to track, looking for reaction to lights, localising, contrast, sound, size, reflexes and observations during a functional activity. There was one validated screening/assessment tool mentioned and this was the CVI-Range by Christine Roman-Lantsky.

Participants reported that they would refer the child to a specialist if they suspected CVI. A large majority also reported that they would just use their own screening observations and alter their intervention accordingly and continue with treatment assuming CVI is present. There were a few participants who said they would carry on with treatment without considering a CVI because they were not able to get a formal diagnosis.

The second part of the study aimed to determine the content validity and usability and utility of the CVI-MQ. The CVI-MQ's content was favourable according to the participants, however there were some concerns regarding the clarification of items; that some items were not always applicable to CVI; and some language used was not always appropriate. Participates indicated that some of the items were age-dependent and dependent on the motor skills of a child with CP, and one question was deemed not appropriate for the South African setting. The majority of the participants found that the CVI-MQ was usable within their setting, except for one participant who worked in a public hospital in a rural area. These results will be discussed further.

CHAPTER 5: DISCUSSION

5.1 Introduction

This chapter considers the results and the participants' demographic information; their current experience working with children with CP; their training experience in working with children with CP; and their current practice regarding the screening and assessing of CVI in children with CP. The screening procedures used by the therapists are considered as well as the content validity and usability and utility of the CVI-MQ. This screening tool is further considered in terms of its applicability in the South African context according to the opinions of therapists working in South Africa. It must be noted that this discussion will show that while there are benefits in using a screening tool in South Africa compared to the current CVI practice, there are certain factors which limit the validity of the screening, and were evident in this study.

5.2 Response rate to the study

In phase 1 of the study, 38 participants who met the inclusion criteria of working with children with CP responded to the questionnaire. This is a response rate of less than 10% of the assumed population of therapists targeted with emails. The benchmark response rate for online surveys is 25-30%, which the current study did not achieve (Nulty, 2008). This is similar to and better than the response rate reported in other studies which sent out surveys to therapists working with children with CP in South Africa on which the sample size was based (Davies, 2016; Janse van Rensburg, 2016).

There are a few possible reasons as to why this study received a small sample size. It was impossible to email only those members that were treating children with CP, therefore the survey was sent to a generalised population. It was difficult to know how many members of OTASA and RuReSA were working with children with CP. Cerebral visual impairment is considered a specialised field and has only been introduced as a topic in the SANDTA eight-week paediatric NDT course curriculum in recent years as awareness of how the condition impacts function has been researched (Ferziger et

al., 2011). The sample may also have been limited in favour of therapists who were aware of and screen for CVI as response to email surveys are highly related to the research interests of the participants. Trespalacios & Perkins (2016) found that 90% of participants would be more likely to complete a survey if they were interested in the topic. Although the emails were sent from a reliable source, the response rate may have been affected by a lack of personalisation as well as participants email checking behaviour and the accuracy of the contact details on the organisation databases (Saleh & Bista, 2017).

In phase 2, 14 participants from SANDTA responded to the content validity section (response rate 14%) and six to the usability and utility of the screening tool after using the CVI-MQ in their practice (response rate 6%). This low response rate was not increased by making the survey available for approximately four months with intermittent reminders for the survey to be completed. The survey, which included phase 1 and phase 2, was very long as it included the content validity and usability and utility of the CVI-MQ. This could have been a contributing factor to a low response rate. Research shows that the longer the survey, the greater the chance of a low response rate as there is a threshold for response rates according to the length of the survey (Jepson et al., 2005).

The low response rate means that the results must be interpreted with caution and are not generalisable for other therapists working with children with CP in South Africa. However, data analysis did provide information which can be used in considering the use of the CVI-MQ in screening for CVI in children with CP.

5.3 Demographic work-related factors of the participants

The first objective of the study was to describe the demographic work-related factors of occupational therapists and physiotherapists treating children with CP in South Africa.

Most of the 38 participants in phase 1 of the study were occupational therapists (84.2%) and this could be because the survey was not only administered through SANDTA, but it was also sent through OTASA which targeted only occupational therapists. It was not possible due to the anonymity of the survey to identify which

organisation therapists replied from but in phase 2 there were more physiotherapists represented as this survey was not administered through OTASA, and only through SANDTA.

The participants in the study had work experience ranging from 1-32 years, although they had fewer years of experience in working with children with CP. Results therefore indicate that therapists with different levels of experience are currently working in the field of CP. However, nearly two thirds of therapists working with children with CP can be considered as experienced (more than four years of work experience) or experts (more than 10 years of work experience) (Schell & Schell, 2008). A large majority of the participants have postgraduate training in the assessment and treatment of children with CP (84.2%) showing their particular interest in this field. This is in line with another South African study where 72.2% of the participants had completed postgraduate courses in the field of CP (Janse van Rensburg, 2016). The most common postgraduate course attended was the Bobath NDT 8-week paediatric course and since it is hosted by SANDTA, it is likely that participants were members of SANDTA because they had completed courses with this association. In terms of postgraduate training on CVI, just under a third of the participants reported that they had done postgraduate training through SANDTA or the CVI-Range training workshops held by Christa Scholtz. Christa Scholtz was listed as an important source of CVI knowledge in a previous study on visual deficits in children with CP in South Africa (Janse van Rensburg, 2016). It therefore appears that many of the therapists who responded to the survey had postgraduate training in CVI confirming that there is an interest in this field.

Participants worked in the mostly populated provinces, which is congruent with another recent study which surveyed therapists working with children with CP in South Africa and, as with this study, the majority of the participants were working in the private sector and schools for learners with special needs (LSEN) (Davies, 2016). It is possible that this is where other services which deal with CVI are available, making therapists more aware of the condition, but both studies indicate a possible paucity of services in more rural provinces and public hospitals where the prevalence of children with CP and the severity of the condition may be greater (Coombe, 2017). In the current study, a diversity of settings were reflected in the sample allowing the current

practice for the screening procedures for CVI currently used by occupational therapists and physiotherapists to be determined.

Nearly half of the participants treat between 1-5 children with CP per month, followed by 20% who see 6-10 children with CP per month. This relatively small caseload could be due to the participants working in practices where they see patients with other diagnoses, both in the private sector and in the public sector (Davies, 2016). The higher caseloads of children with CP are seen by therapists working in LSEN where higher numbers of clients may present with CP.

The severity of CP for the children treated in terms of GMFCS levels were well represented in the study. It would appear that the participants in the public sector are more likely to treat children on the more severe levels compared to private where GMFCS levels I and II are seen (Coombe, 2017).

The participants who completed part 3 and part 4 of the electronic questionnaire were SANDTA members, who more than likely have an interest in NDT, and over 90% had further training in the assessment and treatment of children with CP. Fourteen participants chose to participate in the content validity section of the survey, most of whom were occupational therapists and all of whom had more than four years of work experience with children with CP. These therapists can be considered as experienced with higher levels of professional knowledge and clinical reasoning, which makes them suited to inclusion for evaluating the content validity of the CVI-MQ. According to the guide by Yaghmaie (2003), the inclusion of five to ten experienced or expert professionals in the field is important in judging the content validity of a tool. Four of the fourteen participants had specific training in CP and CVI, adding to their expertise in the field.

In the usability and utility section, there were six participants of whom four where occupational therapists. Only four of the six participants had postgraduate training in treating children with CP. These four participants had more than four years of experience while two of the participants only have one to two years' work experience with children with CP. Although this can be considered a limitation in this study because these two therapists had limited experience, the input from all these participants on the usability and utility provided insight as to the use of the tool in

different settings, including an under-resourced rural setting for therapists with various levels of expertise (Davis et al, 2004). The reality is that in South Africa many children with CP are seen in under-resourced settings by inexperienced therapists so it is important to establish if screening tools are suitable for use by all therapists irrespective of experience if services are to be more equitable (Glover & Albers, 2007; Coombe, 2017).

5.4 Understanding of cerebral visual impairment and diagnostic and screening procedures currently used for this condition in South Africa for cerebral visual impairment

The second objective of the study was to identify the current understanding of CVI and diagnostic practice as well as current screening procedures for CVI in children with CP that occupational therapists and physiotherapists are using in various settings in South Africa.

5.4.1 Therapists' understanding of cerebral visual impairment

In phase 1 of the study, 95% of the participants were aware of what a CVI was and had been exposed to CVI in practice or learning. However, two participants had never heard of a CVI before, even though they were working with children with CP at the time of the study. According to Salavati et al. (2016), it is often therapists who first identify the possibility of CVI in children with CP, therefore it is important that therapists are aware of CVI in the South African setting. Although it is a concern that some participants had not heard of CVI, the knowledge of what a CVI is among the other participants was accurate. This could be due to the fact that over 80% of the participants had postgraduate training in the assessment and treatment of children with CP, so they would have been more likely to have been exposed to information about CVI after their undergraduate training. This supports a study done in South Africa on visual deficits in CP where the participants reported that they felt that their undergraduate training was not sufficient in managing visual deficits in children with CP (Janse van Rensburg, 2016).

Nearly a third of participants were also aware of varying presentations of CVI, including tracking and localization difficulties; unique visual and behavioural characteristics,

such as being attracted to high contrast objects; visual latency; and visual perception difficulties. This heterogeneity of what different participants reported is congruent with CVI studies that report that there is still no consistency as to what constitutes CVI (Salavati et al., 2016). However, only 8% of participants noted that CVI would limit function in daily life, despite other studies reporting that children with CP and CVI have greater limitation and slower development in terms of mobility, self-care and socialization (Ghasia et al., 2008; Anaby et al., 2017; Deramore Denver et al., 2017). It seems that the participants in the current study focused on impairments and symptoms related to CVI rather than participation in occupations (Anaby et al., 2017), even though it is recommended that CVI in children with CP be assessed on how children use their vision to perform daily living activities (Anaby et al., 2017; Deramore Denver et al., 2017).

5.4.2 Awareness of the presence of and diagnosis of a cerebral visual impairment

Half of the participants were not always aware if a child with CP had CVI. There could be a number of reasons for this finding. Identifying CVI can be a challenge as there is not often an obvious ocular deficit due to its cortical nature (Good, 2009). There is also a wide range of visual deficits included under the umbrella of CVI, which therapists, teachers and caregivers may not always be aware of. Participants reported that they used observation to look for signs of CVI if the child had not been diagnosed and if they felt that the child was at risk for CVI they may send the child for further assessment. However, there were limited options for referral for further assessment reported by participants. There appears to only be availability for formal assessment at one CVI clinic in Johannesburg.

It appears that a diagnosis of CVI, even if it is not formal, is reported for nearly a third of children with CP seen by the participants in the study. This diagnosis was reported by parents and teachers, while another third indicated that the diagnosis was reported in the child's medical file. More than two thirds (72.8%) of participants agreed that it is difficult to obtain a formal diagnosis of a CVI, especially in the public sector where limited resources and expertise meant children are often misdiagnosed or not diagnosed at all. This occurs because doctors that are assessing the children with CP

for CVI are often newly qualified interns or community service doctors who are not trained to identify CVI as their clinical decision making skills are not yet competent (Reid, 2018; Maphumulo & Bhengu, 2019). Ophthalmological assessments are integral in supporting a CVI diagnosis, but these require specialised equipment making them expensive and are rarely used even in the private health sector for the assessment of CVI (Good, 2009; Salavati et al., 2016). In the current study, none of the participants mentioned the use of formalised assessments reportedly used globally for CVI, such as CT, MRI and functional MRI's (Fazzi et al., 2007), Visual Evoked Potentials and EEG's (Good et al., 1994). This could be because the knowledge of the use of these assessments for CVI is limited or the assessments are not available in the South African setting. Donald (2014) supports this and indicates that in developing countries, access to specialists and health care facilities make it difficult for management of comorbidities such as diagnosing of CVI in children with CP. This confirms the difficulties experienced by the participants in the current study in receiving a formal confirmed diagnosis of CVI, as accessibility and logistics were reported as a major concern.

The participants reported that other health professionals have a lack of knowledge about CVI and do not acknowledge the functional implications of CVI in a child with CP (Dutton & Jacobson, 2001; Newcomb, 2009). This is reflected in the limited literature on the assessment of CVI in children with CP, which indicates a lack of knowledge and research internationally on the assessment and treatment of this condition in this diagnostic group (Anaby et al., 2017). This has been ascribed to the fact that in children with CP, CVI is often outweighed by the importance of other comorbid deficits, which include, but are not limited to physical, cognitive and communicative difficulties (Dutton & Jacobson, 2001; Newcomb, 2009). The participants reported that other concerns which impact function for a child with CP, such as feeding and seizures, take priority. There is often an assumption that the child with CP has a poor prognosis and there are often more pressing medical concerns, so a comorbidity such as CVI and the resultant functional implications are not considered (Alimović, 2012).

Occupational therapists and physiotherapist appear more aware of CVI and the functional implications of the condition because they assess and treat function in terms

of client factors and participation in children with CP (Salavati et al., 2016). The results of the study are contradictory, as although participants felt that other health professionals lacked knowledge and expertise to diagnose CVI, 65.7% reported that they would still refer to a specialist if they suspected CVI in a child with CP. This included medical doctors, ophthalmologists, optometrists and experienced occupational therapists. Literature shows that these professionals are most commonly involved in functional vision assessment, including for CVI (Good, 2009). These participants may reflect those who work in the private sector and LSEN schools where access to more experienced and specialist health care for children with CP is available (Barratt & Penn, 2009).

However, participants did mention that they were more likely to screen a child with CP for a CVI when they were on a higher GMFCS level as opposed to a lower GMFCS level. The difficulty in screening or assessing a child on a lower GMFCS level may be due to the greater number of comorbidities experienced by these children, which are often a barrier to the effective screening and assessment of CVI. These children are often unable to communicate or cooperate during the assessment. Cognitive, motor and speech and language difficulties have to be considered when assessing for CVI and although, as suggested by Salavati et al. (2016), occupational therapists and physiotherapists are trained to manage the comorbidities found in children with CP, they may not easily be able to observe the possible presence of CVI in children with lower GMFCS levels as a result of their behaviour in their everyday environment.

This was emphasised by some participants when commenting on the content validity of the CVI-MQ, where differentiating the effects of a CVI from other factors that impact on mobility and function is a problem. Irrespective of these difficulties, nearly half of the participants did report that they would always screen a child with CP for CVI. It is of concern, however, that more than 50% of participants who were mostly aware of CVI only sometimes screen or never screen for CVI. Literature indicates the importance of screening for CVI in view of the impact that CVI has on functional mobility and quality of life in children with CP (Ortibus et al., 2011). The importance of this screening has been further highlighted by the high occurrence of CVI in children with CP in developing countries, such as Kenya, where CVI is the most common ocular deficit (Njambi, Kariuki & Masinde, 2009).

5.4.3 Screening and assessment of cerebral visual impairment by therapists

Participants reported that their screening for CVI in children with CP were mostly based on their own observations, reports from caregivers and on history taking, and less so as a result of reports from doctors and medical files. This is because caregivers are usually most able to give clear descriptions of the effect of visual functioning as suggested by Philip & Dutton (2014). There was a strong indication that therapists also used other screening methods and procedures to screen or assess for CVI. None of these were standardised and included assessment of tracking ability, localization ability, reaction to lights, contrast, using sound to test vision, varying the size of objects, reflexes and observations in functional activities. These assessment methods are similar to those reported in the literature and are called behavioural assessments. Chorna, Guzzetta and Maitre (2017) describe these assessments as a "battery of behavioural assessment" which consist of the non-standardised assessments of optokinetic nystagmus, visual fields, oculomotor function, visual acuity and visual-perceptual difficulties. It must be noted that this form of assessment was recommended for children with less severe forms of CP. Therefore, although only 20% of participants were aware of and possibly use formalised screening assessments, the current practice of the participants in this study is in line with global practice for screening for CVI in children with CP.

More than two thirds (68.6%) of the participants reported that a presence of CVI would alter their intervention and it seems that they were well aware of the importance of acknowledging CVI and the functional implications thereof in their treatment of children with CP (Alimović, 2012). This is supported by another South African study where participants reported they would alter their intervention if they discovered that a child with CP had a visual impairment (Janse van Rensburg, 2016).

The findings of the current study confirm the importance of introducing assessments such as CVI-MQ, which allow occupational therapists and physiotherapists to formalise the screening for CVI while accommodating for comorbidities found in children with CP. This quick and inexpensive assessment may be suited to the South African context where formal diagnosis of CVI is difficult to obtain. The use of this

motor questionnaire as an additional tool can help therapists screen the child with CP for CVI and to adapt therapy via manual and verbal support (Salavati et al., 2016). However, since the CVI-MQ was not developed for use in a developing country, it was important to determine the content validity and usability in the South African context.

5.5 Content validity of the Cerebral Visual Impairment Motor Questionnaire

The third objective was therefore to establish the content validity of the CVI-MQ for screening for CVI in children with CP in the South African context.

The content validity index was used to assess the content validity of the CVI-MQ as it allows for the assessment to be comprehensively evaluated in terms of what it is measuring (Yaghmaie, 2003; Rodrigues et al., 2017). The scale-level content validity index for the CVI-MQ GMFCS for levels I, II and III and the CVI-MQ GMFCS for levels IV and V showed the overall scale had adequate content validity. The scores of 86% and 92% were slightly less than those reported by Salavati et al. (2016) when the screening tool was being developed. There was a 97% agreement by experts on the content for the first CVI-MQ and 96% agreement for the second CVI-MQ. These lower scores were due to concerns with items on the screening tool expressed by the participants in the current study. This could be because not all of the participants in this current study had a full understanding of the effects of CVI on motor function.

In the CVI-MQ for GMFCS levels I, II and III only item 19 (“the child has difficulty estimating the distance and speed of other road users”) achieved less than 0.70 in the content validity index, indicated that this item should be discarded (Rodrigues et al., 2017). According to the developers of the screening tool, this item was included as one of the more complex tasks testing the difficulties children with CVI experience with distance viewing and depth perception (Salavati et al., 2016). The participants however felt that this item was ambiguous as it did not explain whether the child is driving, walking or in a wheelchair in relation to “other” road users. The difficulty or ambiguity with this question could also be because it does not indicate whether the child is using the road independently, and participants felt that children with CP in the South African setting would not typically be using the road without assistance. This could be a disparity between the developed and the developing world.

Ten other items on the CVI-MQ's did not achieve a satisfactory content validity index score of 0.79 (Rodrigues et al., 2017) which indicated the need for revision. These questions had low scores for relevance with some concern about their clarity and ambiguity. These items included the child walking up and down stairs and jumping off an elevated platform in the CVI-MQ GMFCS for levels I, II and III; and belly crawling in the CVI-MQ GMFCS for levels IV and V. The participants felt that these items were not relevant to the population that was being screened. Jumping in particular would be very difficult for a child with CP. Participants felt that the content of the items needed to be changed even though the developers of the CVI-MQ had included the "not applicable" option in the scoring of the CVI-MQ to accommodate for the difficulty of a motor skill according to the child's GMFCS level and these items don't need to be scored. The current study showed congruency with the original article and confirmed that a "not applicable" option is important to assign a total score for each child as not all items can be scored depending on the child's age and comorbidities affecting their ability to perform complex items (Salavati et al., 2016). However, some participants in the current study indicated that they felt these movements were outside the abilities of the children they assessed and they would not expect a child to perform these so it was not necessary to include jumping and belly crawling in the CVI-MQ.

Participants noted that some items were age-dependent, particularly items 4, 13 and 19, which was congruent with what the developers of the CVI-MQ reported. They indicate that these items may be age-dependent and provided a "not applicable" option in the scoring to accommodate this (Salavati et al., 2016). Having the "not applicable" option assists the examiner in assigning a total score, as not all items can be scored due to age-dependency and difficulty of the motor task. The participants in the current study also questioned age-dependency in eight other items.

Other concerns about the content of the CVI-MQ emerged from the analysis of the comments made by participants. A number of categories identified in relation to these components warrant possible changes to the CVI-MQ screening tool. Participants reported that clarification on 21 items was needed, and an explanation of terms would be useful in order to increase the understanding of their use in the screening tool. For example, in items 1 and 2, one participant felt that the items did not clarify if the child

was seeing a moving object or if the child moved towards a moving object and this would influence whether this was a positive or negative answer.

One participant did not feel that “high contrast toys” was clear enough and wanted clarity on how much contrast was being asked. Contrast could indicate black and white contrast items or bright colours on a dull background or it could mean light and dark. Clarification was also requested for the difference between verbal support and sound production as the participant felt that these two were similar and sought clarification on the difference between the two. Another important area of clarification needed was whether objects in the items were familiar or unfamiliar to the child, as the participants felt the child might engage more readily with a familiar object. All of these concerns could be addressed in a short instruction manual for the CVI-MQ or by adding words into the items.

The participants suggested that more familiar words than the words “fluorescence” and “sound production” be used in the CVI-MQ, since these are words that are not familiar to South African therapists. They did not report that they did not understand the words used, but perhaps it would be more appropriate to use more familiar words. A number of participants did not agree with the wording of some items when they referred to a child as “it” instead of he/she/child. These concerns could be due to cultural preferences as well as the translation of the screening tool from Dutch. These concerns are easily addressed.

Although the developers of the CVI-MQ indicate that they made changes to some of the items to make them more suitable to the motor function of children with CVI according to expert opinion, the participants in this study still felt that some items needed to be changed to make them more applicable to screening for CVI (Salavati et al., 2016). Due to the heterogeneity of CVI, the developers of the CVI-MQ also indicated that the screening tool was created almost entirely for motor functioning according to depth perception (Salavati et al., 2016). This supports the concerns of the participants in the current study who felt that the CVI-MQ was not specific enough to the many deficits associated with a CVI and to adequately screen for and identify a CVI. They suggested that the items could be worded differently or include more descriptions of visual cues which would make them more specific to screening for CVI. For example, Item 8: “The child will walk down an unfamiliar staircase one step at a

time, always leading with the same foot, whereas it will walk up down a familiar staircase with alternating feet at each step" could be replaced by "Walks more easily up a set of stairs if the edges are marked appropriately in a high visibility colour". For item 10, "the problem corrects when others are wearing high visibility clothes", colour could be included as children with CVI may have a strong colour preference (Dutton & Jacobson, 2001).

The participants in the current study were therefore able to identify many characteristics of CVI which are not targeted in the CVI-MQ such as colour preference, visual latency and light gazing due to their knowledge of CVI and what it encompasses (Salavati et al., 2016). They confirmed the suggestion of the developers that other screening tools need to be used to identify other CVI characteristics and that the CVI-MQ content is limited and not adequate for comprehensive screening for CVI (Salavati et al., 2016).

The CVI-MQ considers the impact of visual impairments on the motor ability of children with CP and participants in this study were concerned that some items did not consider reasons other than CVI that may result in a child moving/not moving/experiencing difficulties with an item. The comorbidities reported by the participants include other physical, cognitive and gross motor skills. In the development of the CVI-MQ, children with severe intellectual disability were excluded (Salavati et al., 2016). This exclusion criterion was not specified when the participants were asked to rate the CVI-MQ, so they may have evaluated items related to children who have severe intellectual disabilities, which may affect their evaluation of the content validity of certain items. This must be considered in the future use of the CVI-MQ in a context such as those reported in the current study.

The participants felt that some of the items were not appropriate if the screening was carried out in an unfamiliar environment as children with CP may not feel comfortable in an unfamiliar environment. In the development of the screening tool, the screening was carried out by occupational therapists and physiotherapists who were familiar with the child but it did not specify where the screening took place. It is assumed that it was performed in the Royal Dutch Visio and allied healthcare practices where the participants were recruited. The children may have been familiar with the environment but familiarity with the environment remains unknown. However, the developers of

the CVI-MQ did list amongst their concerns the fact that a child with CP might have difficulty moving in an unfamiliar environment compared to a familiar environment, which is congruent with the concerns of the participants in the current study (Salavati et al., 2016). Seven items on the CVI-MQ for GMFCS levels I, II and III and the CVI-MQ for GMFCS levels IV and V were identified as problematic by the screening tool developers in terms of unfamiliar environment. Five of these were also identified by the participants in the current study, which included moving in a familiar environment could be as a result of a learnt automated patterns rather than being vision-related (Salavati et al., 2016).

Some of the participants in the current study also suggested that more information needs to be provided for some items to add to the consistency of the screening. For example, the heights of platforms (item 14) and specifying what drawing needs to be done (item 23). This lack of detail means that some of the items could be interpreted differently by different therapists, and the participants questioned whether the screening tool should be more uniform in how it is administered. However, having more specific information may not be appropriate for a screening tool as its purpose is not to diagnose CVI, but to complete a quick screening to determine those children who warrant further assessment and investigation. The addition of specific information may make the screening tool time-consuming and expensive if uniform items have to sourced and used (Salavati et al., 2016).

Although the participants reported a number of concerns with the content of the CVI-MQ, which may need item revision in terms of wording, their other concerns were similar or had been addressed by the developers of the screening tool. Overall, the CVI-MQ was considered suitable in terms of content for use in the South African context. It is clear, however, that more information should be provided with the tool in terms of its purpose and limitations when used in this context by therapists.

5.6 Usability and utility of the Cerebral Visual Impairment Motor Questionnaire

The usability and utility for therapists and stakeholders of the CVI-MQ was also established to further understand whether the screening tool can be used in South Africa. In the questionnaire, the therapists were given the option to make comments on usability and utility of the CVI-MQ, however, no comments were made.

According to Glover and Albers (2007), guidelines to determine the usability and utility of a screening tool indicate that it needs to be practical to administer and it needs to be appropriate and acceptable for the setting in which it is being administered. The appropriateness for the intended use of a screening tool should consider the population and context it is used for.

All the participants strongly agreed that the CVI-MQ was appropriate for use in the context in which they worked. This included settings such as the public sector (rural and tertiary), private practice, schools for learners with special needs and non-profit organizations and even though the sample is small, all settings were represented. This was probably due to the fact that the CVI-MQ can be administered without any special equipment and most therapists, irrespective of their setting, have the items needed as standard in their practices. In terms of usability, there was congruency with the study by the developers of the CVI-MQ since they found the CVI-MQ's usable and relatively easy to administer (Salavati et al., 2016).

The participants, with the exception of one, found that the CVI-MQ was appropriate in terms of the populations that they treat across all levels of CP according to the GMFCS. The one participant who did not agree that the CVI-MQ was appropriate for the population of children seen is the participant who works in the public rural sector, and mainly sees children on GMFCS level V. The participant did not substantiate but may have found the CVI-MQ inappropriate because the items were too difficult for the children who likely had severe intellectual disability. The CVI-MQ excludes children with severe cognitive deficits as explained above so may not be appropriate for a setting where children who are severely affected are treated (Salavati et al., 2016).

Participants were in less agreement about whether the CVI-MQ was developmentally appropriate and was supported by the comments in the content validity part of this study. Some of the items are age-dependent which is supported by the developers of the screening tool (Salavati et al., 2016). There was a range of agreement as to whether the CVI-MQ was useful in detecting CVI in children with CP. Only 50% agreed that it was useful in the identification of CVI. This is in contrast to the study on the development of the CVI-MQ, where there was 95% agreement for the usability and practical use of the screening tool (Salavati et al., 2016). It must be noted that in the original study by the developers, the participants administering the CVI-MQ's had prior knowledge of whether a child with CP had a CVI, which was considered a limitation in their study (Salavati et al., 2016). The purpose of the CVI-MQ is to identify the presence of CVI when therapists are unaware a child with CP has a CVI, so the tool may not be as useful when used in these circumstances. This is important in the South African context where prior knowledge of a CVI is rare according to participants of the current study.

The CVI-MQ should take about 10-12 minutes to administer. However, the participants in the original study by the developers of the CVI-MQ were CP and CVI experts, which may have influenced the time taken to administer the CVI-MQ (Salavati et al., 2016). Only 50% of participants agreed that the amount of time the CVI-MQ took to administer was appropriate but did not comment on how long it took them. The time may have been longer as only one participant in the current study had postgraduate training in CVI in children with CP. One participant disagreed that the amount of time was appropriate and since this participant is inexperienced it may have taken the participant longer to observe the behaviours on the CVI-MQ as there was less familiarity with assessing children with CP. The caseload in the rural setting in which the participant worked could be much higher than that of other settings. This is congruent with a study done in rural Kwazulu Natal which stated that the prevalence of CP in rural areas is higher than that of urban areas so less time is available for screening and assessments (Coombe, 2017). This participants' caseload probably does not only include children with CP, providing little time for assessment of individual patients.

While all the participants were able to photocopy the CVI-MQ form, only 50% agreed that the CVI-MQ was appropriate in terms of cost. This could be due to low resources of some contexts where not all the items, such as bright toys, may have been available. Two thirds of participants, however, agreed that there were resources available in their setting to collect the required information, manage and interpret the items on the CVI-MQ. This may indicate that in some contexts in South Africa, poor or low resources may affect the use of this screening tool.

Two participants with 1-2 years of work experience with children with CP reported that they did not feel competent in administering the CVI-MQ's and one of them did not find the CVI-MQ manageable in terms of the instructions given and calculating and interpreting scores. Thus, it appears that the screening tool is more usable for those who can observe behaviour based on clinical reasoning more effectively due to their experience with children with CP (Schell & Schell, 2008). When considering utility, or the acceptability of the CVI-MQ results by stakeholders, half of the participants agreed that the stakeholders, including other health professionals and the child's parents, would understand the benefits associated with the CVI-MQ and the identification of CVI in the child with CP. Again, the one inexperienced participant disagreed, confirming that the CVI-MQ may not be suitable for use by inexperienced therapists. These therapists may need specific training in the administration and interpretation of the CVI-MQ before other stakeholders can benefit from the results. Due to the inexperience of some therapists, there may be focus on other significant concerns and comorbidities such as auditory impairment, feeding and seizures (Shevell, Dagenais & Hall, 2009). In the rural setting where one of the participants worked, CVI may not be a significant concern for the therapists and various stakeholders since there may be more pressing concerns, particularly when the population of children seen are on lower GMFCS levels and time for therapy is limited (Naidoo, van Wyk & Joubert, 2017).

A large majority (83.3%) of the participants agreed that the CVI-MQ is useful in guiding intervention based on the presence of CVI. This can be interpreted in view of the usefulness of the CVI-MQ in detecting the possibility of a CVI, allowing therapists to provide more comprehensive treatment, and which is congruent with the original study (Salavati et al., 2016).

Thus, both the setting in which the child with CP is seen and the experience of the therapists appear to influence the usability of the CVI in the current study. The CVI-MQ may only be appropriate for therapists with more clinical experience as those with little experience felt incompetent in its administration.

The CVI-MQ can be considered to have satisfactory usability and utility according to the results of the current study, however, this needs to be considered with caution because of certain limitations, including the inexperience of some of the participants and the small sample size that participated in this section of the study. The CVI-MQ can be used in most contexts of South Africa. In the rural setting, which reflects a developing context with few resources, high caseloads and inexperienced therapists who do not have access to guidance from more experienced colleagues may require more support and training to use the CVI-MQ in practice (Naidoo, van Wyk & Joubert, 2017). The population in relation to the co-morbidities associated with children with CP served and the amount time available to assess individual patients may also play a role.

5.6.1 Limitations of the study

The biggest limitation of this study was the low response rate for phase 1. Cerebral palsy and CVI are specialised areas of interest which means that the population of therapists was small but the response rate did not achieve an acceptable percentage. This means that the data collected cannot necessarily be representative of all therapists working with children with CP in South Africa. The study was not extended to the South African Society of Physiotherapy (SASP), which could have reached more therapists and thus had a better representation of physiotherapists in this study, as well as increase the sample size. Those interested in CVI were more likely to have answered the surveys, and is therefore not representative of the screening procedures that all therapists working in South Africa with children with CP are currently using. Even though therapists from various sectors chose to answer the questionnaire, this is not a representation of various work sectors.

Although experienced therapists, most of whom have postgraduate training in treating CP, were asked to rate the CVI-MQ according to the content validity, the inclusion criteria for this part of the study may have not been stringent enough. The results may

have been more valid if only those considered experts (10 or more years of experience) were included.

Phase 2 of the study, where participants were asked to use the CVI-MQ in practice over a one-month period, included two participants who would not be considered experts in the field of CP and CVI due to their lack of clinical experience. This could mean that their opinions about the CVI-MQ were not well-informed due to their lack of knowledge and inexperience. This did however provide important information on the use of CVI-MQ for the study.

5.7 Summary

In this discussion, the response rate to the study was discussed and was found to be congruent with other South African studies. The demographics of the participants differed to other studies where participants were recruited through SANDTA, as more participants were occupational therapists compared to physiotherapists. Most participants had a special interest in CP as most participants had postgraduate training in the assessment and treatment of children with CP.

Most participants were aware of the varying and various characteristics of CVI but did not use any form of standardised screening or assessment procedures for CVI. Observations or behavioural assessments are commonly used by participants to screen or assess for CVI. It is difficult for therapists to obtain a diagnosis of CVI in various settings in South Africa, mostly due to a lack of knowledge and expertise in the diagnosis of CVI in the medical and health setting. Not all participants screen for CVI, which is concerning given the importance of CVI on function in children with CP.

According to the content validity index of the CVI-MQ, the scales achieved adequate content validity, although some items needed revision and one item should be discarded (Rodrigues et al., 2017). A few participants raised important points when considering the content of the CVI-MQ, most of which were congruent with the findings of the developers of the CVI-MQ. This includes the points that some of the items were age-dependent, some items were limiting if the child was not familiar with the environment and some motor skills were too difficult for children to perform. This led to the developers of the CVI-MQ to add the “not applicable” option in the scoring to

achieve a more accurate score. The participants were also concerned that some items were not specific enough to CVI, yet they did not consider that the CVI-MQ was developed particularly for motor skills related to depth perception.

The CVI-MQ was mostly found to be usable in the various South African settings represented. One participant who worked in a rural South African setting found the CVI-MQ to be inappropriate and not usable within their setting.

CHAPTER 6: CONCLUSION

6.1 Conclusion

This study aimed to determine the screening procedures used by occupational therapists and physiotherapists for CVI in children with CP in various South African settings, and to determine the content validity, usability and utility of an internationally-validated screening tool, the CVI-MQ. The demographics of the participants were described and their experience, knowledge and practice regarding CP and CVI were investigated. It was determined that CP and CVI are specialised areas of interest due to the low response rate and the majority of the sample having postgraduate training in CP and CVI.

6.1.1 Screening procedures used by therapists in various South African settings

There is a lack of research on the screening and assessment procedures that therapists can use to determine the presence of CVI in children with CP, both locally and internationally. This study provides information about screening procedures that are currently being used in various South African settings and explored whether therapists are aware of any validated CVI screening and assessment tools in South Africa. Most sectors and provinces were represented in the sample. Screening for CVI is not always a common practice. Less than half of the participants reported that they would screen for CVI; the remaining participants would only sometimes screen if a visual impairment is suspected and the others would not screen for CVI. The main method used by participants to determine whether a child with CP has CVI is through their own observations and screening procedures used in therapy sessions. The majority of the participants reported that they would use their own screening procedures which involve observing whether the child is able to track; react to lights, contrast, sound, objects; localise; reflexes and observations during a functional activity. This is congruent with research which found that occupational therapists and physiotherapists use observations and medical history to make a diagnosis due to the lack of available screening and assessment tools for CVI (Salavati et al., 2016). The

CVI-Range by Christine Roman-Lantsky was the only validated screening tool/assessment tool mentioned. However, this tool is not validated in the South African setting, requires training and is not specific to children with CP. The CVI-Range is used by one participant who has a particular interest in CVI in children with CP. This participant has developed their own assessment kit for CVI which includes the CVI-Range.

According to international literature, it is difficult to diagnose comorbidities such as CVI because children with CP have communicative, physical and cognitive difficulties (Dutton & Jacobson, 2001; Newcomb, 2009). This did not prove to be a significant factor in the South African context, with only one participant mentioning that it was more difficult due to communication difficulties that children with CP often exhibit. The main reason expressed for the difficulty in establishing a formal diagnosis of CVI was that medical professionals do not know how to test for functional vision. The child is assessed using tests that test the eye structures but not necessarily for CVI, which is a neurological condition.

Research suggests that therapists will often assume the presence or absence of a CVI (Salavati et al., 2016) which is congruent with this study where the majority of participants would assume the presence of a CVI and alter their treatment accordingly, while some participants would not consider a CVI because they do not have access to assessments or specialists. Some participants also mentioned that CVI is not the most important aim in their treatment because there are more urgent concerns for a child with CP, such as feeding and seizures. This was particularly the case for one participant who works in a rural setting where the children seen have severe CP (GMFCS levels IV and V) which accounts for more serious and severe comorbidities.

There are many challenges that face occupational therapists and physiotherapists in screening and assessing for CVI in children with CP. The importance of a CVI diagnosis is also an important consideration for therapists who work with children with CP. These challenges include a lack of knowledge of CVI by professionals, a lack of access to specialists and formal CVI screening tools and assessments, and diagnostic difficulties due to multiple comorbidities in children with CP. The majority of the participants reported that they would alter intervention if they were aware of a CVI, but

having access to formal screening and assessment tools is not always possible and children therefore often go undiagnosed.

6.1.2 Content validity, usability and utility of the CVI-MQ

Having a validated screening tool in the South African setting may assist occupational therapists and physiotherapists in detecting the possibility of CVI in children with CP. This may assist them in guiding further investigations and preventing costly and unnecessary comprehensive assessments if they have access to them. The CVI-MQ was validated in the Netherlands, but has not been used or validated in South Africa.

Although the sample sizes were small, the participants mostly had experience in working with children with CP. Most participants felt that it gave a good indication of whether a child with CP did or did not have CVI. There were a number of concerns however for almost all of the items in the CVI-MQ. The screening tool is also only targeted at motor ability and depth perception, and depth perception is only one characteristic of CVI. This means that although this screening tool is relatively quick, easy and inexpensive to use, it would need to be used in conjunction with other screening tools and assessments to determine if the child with CP displays other CVI characteristics.

Although the CVI-MQ was felt to be mostly appropriate and usable, one participant who works in the rural sector found that it has poor usability. This is to be expected in the rural setting where children with CP may present with more severe comorbidities and there are other constraints which need to be considered such as time, accessibility and the relative importance of CVI in this setting. However, given that this was the opinion of only one participant, it is not necessarily representative of all therapists working in rural areas and would need to be researched further. Although the CVI-MQ was found to be valid and usable in the Netherlands, it would appear from this study that this is not the case for inexperienced therapists and therefore some concerns related to context and experience must be addressed when suggesting the screening tool for the South African setting.

6.2 Recommendations

Recommendations for OT practice:

- Investigating and improving knowledge of CVI for all health care professionals in South Africa through adding this knowledge in undergraduate training.
- It is suggested that more support is given to those therapists who are more inexperienced in using screening and assessment tools.
- Doctors should be made aware of CVI in children with CP through presentations and awareness campaigns especially for newly qualified interns.

Recommendations for future research:

- A larger sample size is needed for the content validity, usability and utility of the CVI-MQ in a South African setting. Participants with more clinical experience in the assessment and treatment of CP and CVI should be recruited to determine the content validity, usability and utility of the CVI-MQ.
- The CVI-MQ was found to be mostly valid and usable in the South African setting but would need to be modified according to the language suggested by the participants of this study and by providing a guide for some items in the form of a manual.
- It is clear from the study that there is a great need for validated screening and assessment tools for CVI in the South African setting. This warrants further research of other internationally-validated screening tools and whether they would be valid and usable in the South African setting.
- A South African screening tool for CVI which includes factors other than motor function should be developed for children with CP.
- The effects of CVI on children with CP and their motor abilities needs to be researched further.
- It is recommended that this study is extended to a qualitative study to better understand the need for a screening tool and therapists'' understanding of a CVI.

Dissemination of results:

- Disseminate the results of this research through publishing article in journals, participating in workshops and in presenting at research presentations.

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Appendices

APPENDIX A: Demographic survey

Evaluation of the use of the Cerebral Visual Impairment Motor Questionnaire in the South African context

Phase 1

Please tick (√) where applicable.

DEMOGRAPHIC QUESTIONNAIRE

1. What is your qualification?
    - Physiotherapist
    - Occupational Therapist

2. How many years have you been working for?
    - 1-2 years
    - 3-4 years
    - 5-7 years
    - 7-10 years
    - Over 10 years

3. What province do you work in?
    - Eastern Cape
    - Free State
    - KwaZulu - Natal
    - Northern Gauteng
    - Southern Gauteng
    - Western Cape
    - Other
    - If other, please specify:

_____
_____

4. What sector do you work in?
    - Government hospital
    - Non-profit organization
    - Private practice
    - School for learners with special needs
    - Other
    - If other, please specify:

_____
_____

5. Do you have a Neurodevelopmental Therapy (NDT) qualification?
    - Yes

- No

6. Are you currently working with children with cerebral palsy (CP)?
    - Yes
    - No

APPENDIX B: Screening for CVI questionnaire (developed by researcher)

For the second part of the questionnaire, cerebral visual impairment is defined as the following:

"CVI is defined in terms of visual deficits of any likely cerebral cause, thereby including a wide range of visual sensory and visual perceptive deficits of known neurological underpinnings, and excluding visual deficits due to optical abnormalities" (Salavati et al., 2016).

7. How many years of experience do you have working with children with CP?
    - 1-2 years
    - 3-4 years
    - 5-7 years
    - 7-10 years
    - Over 10 years

8. How many children with CP do you treat in the space of a month? (number of children treated, not the number of treatment sessions)
    - 1-5
    - 5-10
    - 10-15
    - 15-20
    - Over 20

9. What is the main age-group of children with CP that you treat?
    - 0-2 years old
    - 2-10 years old
    - 10-15 years old
    - over 15 years old

10. What is the main GMFCS level of the children with CP that you treat? (you may indicate more than one if this the case)
    - GMFCS I
    - GMFCS II
    - GMFCS III
    - GMFCS IV
    - GMFCS V

11. Do you have any further training in assessing and treating children with CP?
    - Yes
    - No
    - If yes, please specify:

_____
_____

12. Have you had any further training in assessing and treating children with CP as well as CVI?
    - Yes
    - No
    - If yes, please specify:

_____
_____

13. What is the main referral system in your setting?
    - Doctor
    - Nurses
    - Other therapists
    - Caregivers
    - School teachers
    - Other
    - If other, please specify:

_____
_____

14. What is your understanding of a CVI?

_____
_____
_____

15. I am always aware that a child with CP has been diagnosed with a CVI.
    - Strongly agree
    - Agree
    - Neutral
    - Disagree
    - Strongly disagree

16. How do you know that a child with CP has been diagnosed with a CVI?
    - I do not know if a child has been diagnosed with a CVI
    - The child's file says that he/she has been diagnosed with a CVI
    - The child has gone for a formal assessment to diagnose a CVI
    - The child's caregivers have informed me of the diagnosis
    - The child's teacher has informed me of the diagnosis

17. How frequently do you screen/assess for a CVI in the children with CP that you treat?
    - Always
    - Sometimes
    - Never
    - Depends
    - If depends, please specify:

_____
_____

18. It is difficult to diagnose children with CP for a CVI in your setting.
    - Strongly agree
    - Agree
    - Neutral
    - Disagree
    - Strongly disagree
    - Please explain further:

_____
_____

19. What is your main method of screening/assessing children with CP for a CVI? (you may indicate more than one in this case)
    - My own observations during assessment sessions
    - Medical history taken from the doctor
    - Medical history obtained from the caregivers
    - Caregivers will say that the child is blind or cannot see
    - Teachers will say that a child has difficulty seeing
    - Screening tools conducted by you
        i. If this is the case, what assessment do you use?

_____
_____

    - Formal diagnostic assessment completed by you
        i. If this is the case, what assessment do you use?

_____
_____

    - Formal diagnostic assessments completed by general practitioners
    - Formal diagnostic assessments completed by ophthalmologists
    - Formal diagnostic assessments completed by optometrists
    - Other
    - If other, please specify:

_____
_____

20. If you suspect that a child has a CVI but are unable to formally diagnose it, what will your next step in intervention be?
    - Screen for a CVI using my own observations.
    - Assume that a child has a CVI and alter intervention accordingly.
    - Continue with treatment because I do not have access to doctors and specialists to diagnose a CVI.
    - Refer the child to a specialist
        i. Please specify what kind of specialist:

_____

21. If you are aware that a child with CP has a CVI, does this alter your intervention?
    - Always
    - Sometimes
    - Never

APPENDIX C: Human research ethics committee clearance certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Ms N Sweet

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M180953

NAME: (Principal Investigator)	Ms N Sweet
DEPARTMENT:	School of Therapeutic Sciences Department of Occupational Therapy Medical School University
PROJECT TITLE:	Evaluation of the use of the cerebral visual impairement motor questionnaire in the South African context
DATE CONSIDERED:	28/09/2018
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Ms D Franzsen
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	15/02/2019

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on 3rd floor, Phillip V Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.
I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date of the meeting when the study was initially reviewed. In this case, the study was initially reviewed in **September** and will therefore reports and re-certification will be due early in the month of **September** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

16/02/2019
Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX D: Permission letter to SANDTA

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Department of Occupational Therapy
Wits Education Campus

School of Therapeutic Sciences, Faculty of Health Sciences, 7 York Road, Parktown, 2193, South Africa

Tel: +27 11 717 3701 | Fax: +27 717 3709 | Email: leilane.bogoshi@wits.ac.za | www.wits.ac.za

Andrea Fourie

Chairman of the National Executive Committee

SANDTA

I, Nikita Sweet, am an Occupational Therapist, completing an MSc (Occupational Therapy) degree by coursework and research through the University of the Witwatersrand. The title of my research project is:

Evaluation of the use of the Cerebral Visual Impairment Motor Questionnaire in the South African context

I am requesting if you can please assist me in this regard by sending the questionnaire to all the occupational therapists and physiotherapists on your data base? And for a reminder after one month to all occupational therapists and physiotherapists to fill out part 4 of the questionnaire if they have chosen to use the CVI-MQ in clinical practice.

The purpose of this research is to investigate the current cerebral visual impairment (CVI) screening procedures used by occupational therapists and physiotherapists in various clinical settings in South Africa for children with cerebral palsy (CP). Currently, screening tools for identifying children at-risk for CVI are lacking and globally, assessment of CVI is not time and cost-efficient. The purpose of this study is to evaluate the use of the Cerebral Visual Impairment Motor Questionnaire (CVI-MQ) for children with CP in the South African context.

The study will focus on descriptions and views from occupational therapists and physiotherapists currently treating children with CP. This survey questionnaire will consist of four parts developed by the researcher. The survey questionnaire will be transcribed onto an online survey programme - REDCap.

Part 1

A demographic questionnaire which focuses on demographic information, qualifications and experience of the participants.

Part 2

Questions which determine the current screening procedures used to identify CVI's in children with CP.

Part 3

The CVI-MQ will be included in the email to the participants. The participants will be asked to rate the content validity of each question in the CVI-MQ.

Part 4

The survey will also contain questions for them to evaluate and rate the usability and utility of the CVI-MQ when using the assessment in their clinical practice if they wish to do so.

Please will you inform me of what process to follow in order for this questionnaire to be distributed. If you have any questions or concerns please contact me on the details below,

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for your assistance.

Kind regards,

Nikita Sweet
0814231531
nikitaannsweet@gmail.com

Denise Franzen
Supervisor
011 7173701

APPENDIX E: Permission letter from the chairperson of SANDTA

SOUTH AFRICAN SANDTA NEURODEVELOPMENTAL THERAPY ASSOCIATION

08 January 2019

To Whom It May Concern,

Ms Nikita Sweet has requested permission for her questionnaire for her masters research study titled *Evaluation of the use of the Cerebral Visual Impairment Motor Questionnaire in the South African* context to be distributed to the members of the South African Neurodevelopmental Therapy Association (SANDTA).

The questionnaire will be sent to SANDTA members through the SANDTA database by the office and therefore all members confidentiality will be maintained.

As the Chairperson of the SANDTA National Executive Committee I hereby grant permission for Ms Sweet to send her questionanire to the SANDTA office for distribution.

If you require any additional information please do not hesitate to contact me.

Kind regards



Andrea Fourie
SANDTA NEC Chairperson

APPENDIX F: Information sheet to participants

INFORMATION SHEET (Occupational Therapists and Physiotherapists at OTASA and RuReSA)

Title: ***An evaluation of the use of the Cerebral Visual Impairment Motor Questionnaire in the South African context.***

Dear Colleague,

I, Nikita Sweet, am an occupational therapist and master's student in occupational therapy at the University of Witwatersrand. As part of my postgraduate degree, I am completing a research project to investigate the current cerebral visual impairment (CVI) screening procedures used by occupational therapists and physiotherapists in various clinical settings in South Africa for children with cerebral palsy (CP) and to evaluate the use of an internationally-developed screening tool in the South African context. Currently, valid screening tools for identifying children at-risk for CVI are limited and globally, assessment of CVI is not time and cost-efficient.

The purpose of this study is to evaluate the use of the Cerebral Visual Impairment Motor Questionnaire (CVI-MQ) for children with CP in the South African context. The CVI-MQ is a screening tool developed in the Netherlands to screen children with CP for a CVI. This is not a diagnostic tool, but rather a tool used to detect the possibility of the risk for CVI in children with CP. The CVI-MQ contains two questionnaires - one questionnaire for children with CP on Gross Motor Function Classification System (GMFCS) levels I, II and III and a second questionnaire for children with CP on GMFCS levels IV and V.

I am inviting you to take part in the study. Your participation includes completing a four-part survey questionnaire transcribed onto an online survey programme called REDCap. The link can be accessed here. (Link to be provided). The questionnaire is being sent to occupational therapists and physiotherapists who are currently working with children with cerebral palsy. The four-part questionnaire entails the following:

Part 1 of the questionnaire

This is a demographic questionnaire which focuses on your demographic information, qualifications and experience in working with children with cerebral palsy.

Part 2 of the questionnaire

Questions which determine the current screening procedures you currently use in your practice to identify CVI's in children with CP. Closed ended questions with space for open ended comments will be used.

The questionnaire will take about 20 minutes to complete. Your participation in this research project is highly appreciated. Taking part in this study is completely voluntary, and if you wish to withdraw – you may do so without any repercussions. Participating

in the questionnaire will be considered informed consent. All questionnaires will remain anonymous to ensure confidentiality as this is a feature of the online survey programme REDCap. All data will remain confidential and will only be available to the researcher, supervisor and the statistician. Feedback on results will be available on request.

If you have further queries regarding the study, please contact me on 0814231531 or nikitaannsweet@gmail.com.

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for your assistance.

Nikita Sweet

INFORMATION SHEET (Occupational Therapists and Physiotherapists at SANDTA)

Title: ***An evaluation of the use of the Cerebral Visual Impairment Motor Questionnaire in the South African context.***

Dear Colleague,

I, Nikita Sweet, am an occupational therapist and master's student in occupational therapy at the University of Witwatersrand. As part of my postgraduate degree, I am completing a research project to investigate the current cerebral visual impairment (CVI) screening procedures used by occupational therapists and physiotherapists in various clinical settings in South Africa for children with cerebral palsy (CP) and to evaluate the use of an internationally-developed screening tool in the South African context. Currently, valid screening tools for identifying children at-risk for CVI are limited and globally, assessment of CVI is not time and cost-efficient.

The purpose of this study is to evaluate the use of the Cerebral Visual Impairment Motor Questionnaire (CVI-MQ) for children with CP in the South African context. The CVI-MQ is a screening tool developed in the Netherlands to screen children with CP for a CVI. This is not a diagnostic tool, but rather a tool used to detect the possibility of the risk for CVI in children with CP. The CVI-MQ contains two questionnaires - one questionnaire for children with CP on Gross Motor Function Classification System (GMFCS) levels I, II and III and a second questionnaire for children with CP on GMFCS levels IV and V.

I am inviting you to take part in the study. Your participation includes completing a four-part survey questionnaire transcribed onto an online survey programme called REDCap. The link can be accessed here. (Link to be provided). The questionnaire is being sent to occupational therapists and physiotherapists who are currently working with children with cerebral palsy. The four-part questionnaire entails the following:

Part 1 of the questionnaire

This is a demographic questionnaire which focuses on your demographic information, qualifications and experience in working with children with cerebral palsy.

Part 2 of the questionnaire

Questions which determine the current screening procedures you currently use in your practice to identify CVI's in children with CP. Closed ended questions with space for open ended comments will be used.

Part 3 of the questionnaire

Part 3 of the questionnaire will ask you to rate each question on the CVI-MQ screening tool. This will be done by filling out a content validity survey of the CVI-MQ. The content validity index will be used to rate each question on the CVI-MQ according to relevance, clarity, simplicity and ambiguity on a four-point scale.

Part 4 of the questionnaire

If you are able to use the CVI-MQ in clinical practice over a one-month period, then you will be asked to complete part four of the survey to rate the usability and utility of the CVI-MQ after the one-month period. You will be asked to evaluate the CVI-MQ according to a 5-point scale (strongly agree, agree, neutral, disagree, strongly disagree), including how appropriate it is, whether it is compatible for service delivery needs, training needed and the relevance of the identified outcomes. The usability of the CVI-MQ will be rated according to the costs, feasibility of administration, whether resources are available that are needed for the CVI-MQ and provide intervention associated with the outcomes while the utility will be rated according to the stakeholders (caregivers, other medical and allied health professionals, teachers) understanding the implications associated with assessment outcomes and the usefulness of the outcomes for guiding intervention. A reminder will be sent to you via email after one month to fill out part four of the survey questionnaire.

The first three parts of the questionnaire will take about 30 minutes to complete. You can complete these parts and submit, and save the fourth part to submit later. The fourth part requiring you to trial the CVI-MQ in your clinical practice, if you wish, and thereafter completing the fourth and final questionnaire will take a further 15 minutes to complete.

Your participation in this research project is highly appreciated. Taking part in this study is completely voluntary, and if you wish to withdraw – you may do so without any repercussions. Participating in the questionnaire will be considered informed consent. All questionnaires will remain anonymous to ensure confidentiality as this is a feature of the online survey programme REDCap. All data will remain confidential and will only be available to the researcher, supervisor and the statistician. Feedback on results will be available on request.

If you have further queries regarding the study, please contact me on 0814231531 or nikitaannsweet@gmail.com.

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg (“Committee”). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for your assistance.

Nikita Sweet

APPENDIX G: Cerebral visual impairment motor questionnaire (CVI-MQ) for children with cerebral palsy (CP)

Instructions for filling out the CVI-MQ:

The CVI-MQ consists of two separate CVI questionnaires for children on different GMFCS levels. One questionnaire is used for children with CP classified into GMFCS levels I, II and III (walking), and the other for children with CP classified into GMFCS levels IV and V (crawling and rolling). The two questionnaires “measure the degree of absence or presence of CVI in children with CP”, (Salavati et al., 2016, pg3) and the higher the score, the higher the probability that the child with CP presents with CVI deficits. The CVI-MQ items consider the effect of vision on performing motor activities. Cut-off scores for the CVI-MQ are therefore predictive of “the possible presence or absence of CVI in children with CP”. (Salavati et al., 2016, pg3)., A negative result for the CVI-MQ presumes the absence of a CVI, and therefore prevents costly and unnecessary comprehensive assessments (Salavati et al., 2016).

The CVI-MQ for GMFCS levels I, II and III consists of 27 questions and the option to choose yes (present), no (absent) or not applicable (considered absent). The CVI-MQ for GMFCS levels IV and V consists of 14 questions and the option to choose yes (present), no (absent) or not applicable (considered absent). The therapist conducting the screening will tick yes, no or not applicable per item in the screening tool according to whether that movement is present in their observations of the child. For example, item 3: “the child bumps into moved toys or furniture when it crawls”. The therapist then decides whether the child does bump into moved toys or furniture, and will assign yes, no or not applicable.

The CVI-MQ items are related to motor movement such as belly crawling, crawling, walking, ball skills, jumping and reaching for GMFCS levels I, II and III. For GMFCS levels IV and V, they focus on the motor movements of head turning, sitting, belly crawling, crawling, mobilising in a wheelchair and reaching. The CVI-MQ’s have a range of items that are simple and complex. Both CVI-MQ’s include items about moving within familiar and unfamiliar environments.

In the scoring, every ‘yes’ is assigned one point and every ‘no’ is assigned zero points. ‘Not applicable’ is considered zero as presence is not observed. ‘Not applicable’ is assigned when the therapist feels the item was too difficult, or the child was too young or too old to perform that item. The CVI-MQ for GMFCS levels I, II and III has a cut-off score of 12 and for GMFCS levels IV and V, there is a cut-off score of 8. A positive score (above the cut-off scores) indicates the probability of the presence of a CVI and a negative score (below the cut-off scores) indicates the absence of a CVI.

GMFCS LEVELS I, II AND III

GMFCS level I, II and III items	YES	NO	N/A
1. The child belly-crawls if stimulated by movement*, sound production*, fluorescence*, high-contrast toys* or verbal support*			
2. The child crawls if stimulated by movement* sound production*, fluorescence*, high-contrast toys* or verbal support*			
3. The child bumps into moved toys or furniture when it crawls			
4. The child is more uncertain when it walks in an unfamiliar environment compared with a familiar environment			
5. The child has difficulty anticipating differences in height when it walks, e.g. stepping down from the sidewalk to the road			
6. The child walks slower in unfamiliar environments			
7. The child will walk up an unfamiliar staircase one step at a time, always leading with the same foot, whereas it will walk up a familiar staircase with alternating feet at each step			
8. The child will walk down an unfamiliar staircase one step at a time, always leading with the same foot, whereas it will walk up down a familiar staircase with alternating feet at each step			
9. The child bumps into obstacles/persons when it walks			
10. The child bumps into obstacles/persons when it runs			
11. The child walks significantly slower when there is no person to follow			
12. The child hesitates when it moves from one room to another; this occurs when the child both leaves and enters a room			
13. The child falls* and/or trips* over obstacles			
14. The child does not jump off an elevated platform			
15. The child does not jump forwards*, sidewards*, or backwards*			
16. When catching a ball, the child misses a non-sound-producing* and/or non-fluorescent*, non-high-contrast* ball			

more often than a sound-producing*, fluorescent*, high-contrast* ball			
17. The child kicks behind/next to the ball when kicking a non-sound-producing*, non-fluorescent*, lower-colour*/-contrast* ball			
18. The child rolls*/throws* a ball towards a person if there is verbal support			
19. The child has difficulty estimating the distance and speed of other road users			
20. The child has difficulty finding the route to the class or the school playground when walking at school			
21. The child reaches behind/bumps into small objects. The child only grabs the object after touching it			
22. The child manipulates the toy with its hands instead of exploring it with its eyes			
23. The child has difficulty copying figures with a pencil			
24. The child reaches more precisely when reaching for moving objects			
25. The child reaches more precisely towards sound-producing*, high-contrast*, fluorescent*, illuminating* objects compared with non-sound-producing*, non-high-contrast*, non-fluorescent*, non-illuminating* objects			
26. The child does not reach for and look at an object at the same time			
27. The child reaches towards toys but has difficulty finding the toys in a crowded background. E.g. finding a block on a full table or in a basket filled with toys			

CEREBRAL VISUAL IMPAIRMENT MOTOR QUESTIONNAIRE (CVI-MQ) FOR CHILDREN WITH CEREBRAL PALSY (CP)

GMFCS LEVELS IV AND V

GMFCS level IV and V items	YES	NO	N/A
1. The child turns its head to follow, if encouraged by sound production*, fluorescence*, high-contrast* toys or verbal stimulation*			
2. The child lifts its head when lying on its stomach, if encouraged by sound production*, fluorescence*, high-contrast* toys or verbal stimulation*			
3. From a sitting position the child lifts its head, if encouraged by sound production*, fluorescence*, high-contrast* toys or verbal stimulation*			
4. The child belly-crawls, if encouraged by sound production*, fluorescence*, high-contrast* toys or verbal stimulation*			
5. The child bumps into moved toys or furniture when it belly-crawls			
6. The child crawls/belly-crawls slower in an unknown environment with the same surface as a known environment			
7. The child has difficulty finding the route to the class or school playground when driving a wheelchair (mechanic/electric)			
8. The child bumps into objects/persons when driving a wheelchair (mechanic/electric)			

9. The child reaches more precisely for moving objects than for non-moving objects			
10. The child reaches more precisely towards sound-producing*, high-contrast*, fluorescent*, illuminating* objects compared with non-sound-producing*, non-high-contrast*, non-fluorescent*, non-illuminating* objects			
11. The child looks away when it grabs an object			
12. The child reaches for a toy but has difficulty finding the toy in a crowded background, e.g. finding a block on a full table or in a basket filled with toys			
13. The child grabs an object if it produces sound			
14. The child explores*/manipulates* toys with its mouth or hands instead of exploring it with its eyes			

APPENDIX H: Content Validity - Cerebral Visual Impairment Motor Questionnaire (CVI-MQ) for children with Cerebral Palsy (CP)

Guide to Scoring Indices		
i	RELEVANCE	1 - not relevant
		2 - item needs some revision
		3 - relevant but needs minor revision
		4 - very relevant
ii	CLARITY	1 - not clear
		2 - item needs some revision
		3 - clear but needs minor revision
		4 - very clear
iii	SIMPLICITY	1 - not simple
		2 - item needs some revision
		3 - simple but needs minor revision
		4 - very simple
iv	AMBIGUITY	1 - doubtful
		2 - item needs some revision
		3 - no doubt but needs minor revision
		4 - meaning is clear

1	The child belly-crawls if stimulated by movement*, sound production*, fluorescence*, high-contrast toys* or verbal support*	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
2	The child crawls if stimulated by movement* sound production*, fluorescence*, high-contrast toys* or verbal support*	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
3	The child bumps into moved toys or furniture when it crawls	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
4	The child is more uncertain when it walks in an unfamiliar environment compared with a familiar environment	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
5	The child has difficulty anticipating differences in height when it walks, e.g. stepping down from the sidewalk to the road	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
6	The child walks slower in unfamiliar environments	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
7	The child will walk up an unfamiliar staircase one step at a time, always leading with the same foot, whereas it will walk up a familiar staircase with alternating feet at each step	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
8	The child will walk down an unfamiliar staircase one step at a time, always leading with the same foot, whereas it will walk up a familiar staircase with alternating feet at each step	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4

1
2
3

9	The child bumps into obstacles/persons when it walks	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
10	The child bumps into obstacles/persons when it runs	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
11	The child walks significantly slower when there is no person to follow	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
12	The child hesitates when it moves from one room to another; this occurs when the child both leaves and enters a room	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
13	The child falls* and/or trips* over obstacles	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
14	The child does not jump off an elevated platform	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
15	The child does not jump forwards*, sidewards*, or backwards*	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
16	When catching a ball, the child misses a non-sound-producing* and/or non-fluorescent*, non-high-contrast* ball more often than a sound-producing*, fluorescent*, high-contrast* ball	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
17	The child kicks behind/next to the ball when kicking a non-sound-producing*, non-fluorescent*, lower-colour*/-contrast* ball	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4

18	The child rolls*/throws* a ball towards a person if there is verbal support	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
19	The child has difficulty estimating the distance and speed of other road users	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
20	The child has difficulty finding the route to the class or the school playground when walking at school	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
21	The child reaches behind/bumps into small objects. The child only grabs the object after touching it	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
22	The child manipulates the toy with its hands instead of exploring it with its eyes	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
23	The child has difficulty copying figures with a pencil	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
24	The child reaches more precisely when reaching for moving objects	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
25	The child reaches more precisely towards sound-producing*, high-contrast*, fluorescent*, illuminating* objects compared with sound-producing*, non-high-contrast*, non-fluorescent*, non-illuminating* objects	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4

1
2
3
4

26	The child does not reach for and look at an object at the same time	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
27	The child reaches towards toys but has difficulty finding the toys in a crowded background. E.g. finding a block on a full table or in a basket filled with toys	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4

* Circle as applicable

Cerebral Visual Impairment Motor Questionnaire (CVI-MQ) for children with Cerebral Palsy (CP)

GMFCS IV and V

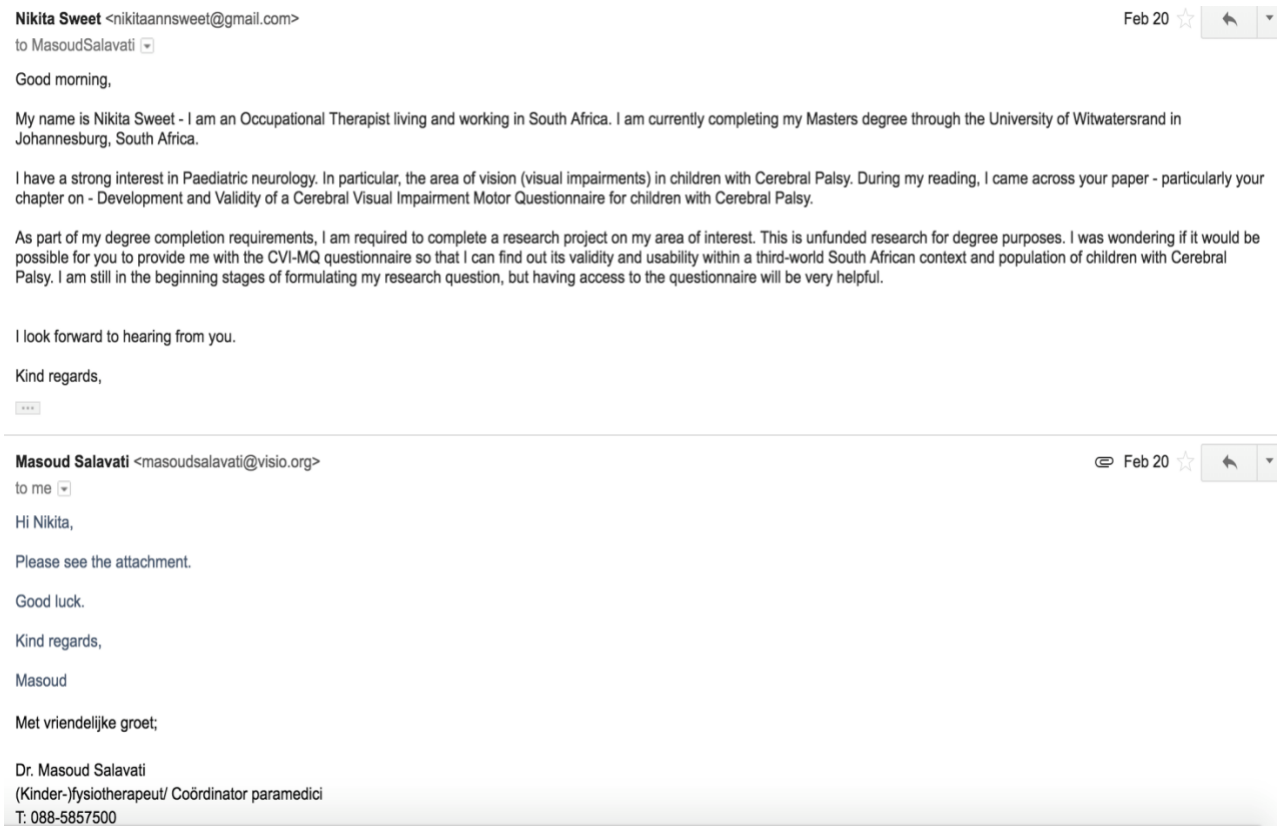
1	The child turns its head to follow, if encouraged by sound production*, fluorescence*, high-contrast* toys or verbal stimulation*	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
2	The child lifts its head when lying on its stomach, if encouraged by sound production*, fluorescence*, high-contrast* toys or verbal stimulation*	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
3	From a sitting position the child lifts its head, if encouraged by sound production*, fluorescence*, high-contrast* toys or verbal stimulation*	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
4	The child belly-crawls, if encouraged by sound production*, fluorescence*, high-contrast* toys or verbal stimulation*	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
5	The child bumps into moved toys or furniture when it belly-crawls	**Y N**	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
	The child crawls/belly-crawls slower in					

6	an unknown environment with the same surface as a known environment	**Y**	**N**	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
7	The child has difficulty finding the route to the class or school playground when driving a wheelchair (mechanic/electric)	**Y**	**N**	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
8	The child bumps into objects/ persons when driving a wheelchair (mechanic/electric)	**Y**	**N**	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
9	The child reaches more precisely for moving objects than for non-moving objects	**Y**	**N**	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
10	The child reaches more precisely towards sound-producing*, high-contrast*, fluorescent*, illuminating* objects compared with sound-producing*, non-high-contrast*, non-fluorescent*, non-illuminating* objects	**Y**	**N**	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
11	The child looks away when it grabs an object	**Y**	**N**	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
12	The child reaches for a toy but has difficulty finding the toy in a crowded background, e.g. finding a block on a full table or in a basket filled with toys	**Y**	**N**	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
13	The child grabs an object if it produces sound	**Y**	**N**	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
14	The child explores*/manipulates* toys with its mouth or hands instead of exploring it with its eyes	**Y**	**N**	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4

* Circle as applicable

1

APPENDIX I: Email permission from Dr Masoud Salavati to use the Cerebral Visual Impairment Motor-Questionnaire in the South African setting



Nikita Sweet <nikitaannsweet@gmail.com> Feb 20

to MasoudSalavati

Good morning,

My name is Nikita Sweet - I am an Occupational Therapist living and working in South Africa. I am currently completing my Masters degree through the University of Witwatersrand in Johannesburg, South Africa.

I have a strong interest in Paediatric neurology. In particular, the area of vision (visual impairments) in children with Cerebral Palsy. During my reading, I came across your paper - particularly your chapter on - Development and Validity of a Cerebral Visual Impairment Motor Questionnaire for children with Cerebral Palsy.

As part of my degree completion requirements, I am required to complete a research project on my area of interest. This is unfunded research for degree purposes. I was wondering if it would be possible for you to provide me with the CVI-MQ questionnaire so that I can find out its validity and usability within a third-world South African context and population of children with Cerebral Palsy. I am still in the beginning stages of formulating my research question, but having access to the questionnaire will be very helpful.

I look forward to hearing from you.

Kind regards,

Masoud Salavati <masoudsalavati@visio.org> Feb 20

to me

Hi Nikita,

Please see the attachment.

Good luck.

Kind regards,

Masoud

Met vriendelijke groet;

Dr. Masoud Salavati
(Kinder-)fysiotherapeut/ Coördinator paramedici
T: 088-5857500

Dr Masoud Salavati attached the questionnaire for use.

APPENDIX J: Usability and utility of the CVI-MQ survey

Survey once CVI-MQ has been used in clinical practice

Appropriateness for the intended use

1. Do you think that the CVI-MQ is appropriate for your setting in terms of:
    a. The amount of time it takes to administer the CVI-MQ?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

    b. The population of children with CP that you see in your setting?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

    c. The context that you work in? (government, school for special needs, private practice, NGO)

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

2. Do you think that the CVI-MQ is useful in identifying a possibility for a CVI in a child with CP?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

3. Is the CVI-MQ developmentally appropriate for the population of children that you see in your setting?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Usability

Cost

4. Were you able to photocopy the CVI-MQ within your setting?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

5. Are the costs associated with the screening tool reasonable?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Feasibility of administration

6. Did you find the CVI-MQ manageable and appropriate to administer in terms of the following:
    a. Instructions were clear and easy to follow?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

    b. Calculating the scores of the CVI-MQ was manageable?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

    c. Interpreting the scores of the CVI-MQ was manageable?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

    d. Amount of time needed to fill out the CVI-MQ was manageable within your setting?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

    e. The number of children with CP you see in your setting? (In other words, were you able to administer the CVI-MQ to all children with CP you see in your setting?)

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

    f. The target population for the CVI-MQ?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

7. Did you feel competent in filling out the CVI-MQ when administering it to a child with CP?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Acceptability

8. Do you think that stakeholders (caregivers, treating doctors, other allied health professionals and teachers) understand the benefits associated with the CVI-MQ?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Infrastructure requirements

9. Are resources available to collect, manage and interpret the screening tool? E.g.: the time within your setting to complete the CVI-MQ, calculator to calculate the scores.

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Utility

10. Are the outcomes of the CVI-MQ useful in guiding treatment/intervention?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

APPENDIX K: Information letter to subject matter experts for pilot study

INFORMATION SHEET (Subject matter experts)

PILOT STUDY

Title: ***An evaluation of the use of the Cerebral Visual Impairment Motor Questionnaire in the South African context.***

Dear Colleague,

I, Nikita Sweet, am an occupational therapist and master's student in occupational therapy at the University of Witwatersrand. As part of my postgraduate degree, I am completing a research project to investigate the current cerebral visual impairment (CVI) screening procedures used by occupational therapists and physiotherapists in various clinical settings in South Africa for children with cerebral palsy (CP). Currently, valid screening tools for identifying children at-risk for CVI are limited and globally, assessment of CVI is not time and cost-efficient.

The purpose of the study is to evaluate the use of the Cerebral Visual Impairment Motor Questionnaire (CVI-MQ) for children with CP in the South African context. The CVI-MQ is a screening tool developed in the Netherlands to screen children with CP for a CVI. This is not a diagnostic tool, but rather a tool used to detect the possibility of the risk for CVI in children with CP. There is one questionnaire for children with CP on GMFCS levels I, II and III and a second questionnaire for children with CP on GMFCS levels IV and V.

The study will focus on descriptions and views from occupational therapists and physiotherapists currently treating children with CP. This survey questionnaire will consist of four parts developed by the researcher. The survey questionnaire will be transcribed onto an online survey programme - REDCap. A link will be given in an email to the participants. The questionnaire will be distributed through the South African Neurodevelopmental Association database to all occupational therapists and physiotherapists.

The participants who agree to participate in the study will complete a four-part survey questionnaire via the RedCAP online survey programme. Parts 1, 2 and 4 of the questionnaires have been developed by the researcher.

As you have experience working with children with cerebral palsy, I am inviting you to please take part in rating the content validity of parts 1, 2 and 4 of the questionnaire developed by the researcher before I disseminate it to occupational therapists and physiotherapists. The parts to be validated involve the following:

<u>Part 1 of the questionnaire</u>

This is a demographic questionnaire which focuses on the demographic information, qualifications and experience of the participants working with children with CP.

Part 2 of the questionnaire

Questions which determine the current screening procedures currently used in clinical practice to identify CVI's in children with CP. Closed ended questions with space for open ended comments will be used.

Part 3 of the questionnaire

Part 3 of the questionnaire will ask the participants to rate each question on the CVI-MQ screening tool. This will be done by filling out a content validity survey of the CVI-MQ. The content validity index will be used to rate each question on the CVI-MQ according to relevance, clarity, simplicity and ambiguity on a four-point scale.

Part 4 of the questionnaire

If the participants are able to use the CVI-MQ in clinical practice over a one-month period, then they will be asked to complete part four of the survey to rate the usability and utility of the CVI-MQ after the one-month period. They will be asked to evaluate the CVI-MQ according to a 5-point scale (strongly agree, agree, neutral, disagree, strongly disagree), including how appropriate it is, whether it is compatible for service delivery needs, training needed and the relevance of the identified outcomes. The usability of the CVI-MQ will be rated according to the costs, feasibility of administration, whether resources are available that are needed for the CVI-MQ and provide intervention associated with the outcomes while the utility will be rated according to the stakeholders (caregivers, other medical and allied health professionals, teachers) understanding the implications associated with assessment outcomes and the usefulness of the outcomes for guiding intervention. A reminder will be sent to the participants via email after one month to fill out part four of the survey questionnaire.

This study has been provisionally approved by the Human Research Ethics Committee of the University of the Witwatersrand, Johannesburg provided that I receive permission from SANDTA to distribute the questionnaire and complete the pilot study.

Your participation in this research project is highly appreciated.

If you have further queries regarding the study, please contact me on 0814231531 or nikitaannsweet@gmail.com.

Thank you for your assistance.

Nikita Sweet

APPENDIX L: Pilot study survey – content validity of the surveys developed by the researcher for phase 1 and phase 2

PILOT STUDY for survey developed by the researcher.

Instructions to Subject Matter Experts:

Please rate each question in the questionnaire according to relevance, clarity, simplicity and ambiguity on a four-point scale. A table is provided under each question. Please tick where appropriate.

Guide to Scoring Indices		
i	RELEVANCE	1 - not relevant
		2 - item needs some revision
		3 - relevant but needs minor revision
		4 - very relevant
ii	CLARITY	1 - not clear
		2 - item needs some revision
		3 - clear but needs minor revision
		4 - very clear
iii	SIMPLICITY	1 - not simple
		2 - item needs some revision
		3 - simple but needs minor revision
		4 - very simple
iv	AMBIGUITY	1 - doubtful
		2 - item needs some revision
		3 - no doubt but needs minor revision
		4 - meaning is clear
Comments:		

Evaluation of the use of the Cerebral Visual Impairment Motor Questionnaire in the South African context

Questionnaire Part 1 and Part 2

Please tick (√) where applicable.

DEMOGRAPHICS

1. What is your qualification?
   - Physiotherapist
   - Occupational Therapist

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

2. How many years have you been working for?
   - 1-2 years
   - 3-4 years
   - 5-7 years
   - 7-10 years
   - Over 10 years

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	

iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

3. What province do you work in?
    - Eastern Cape
    - Free State
    - KwaZulu - Natal
    - Northern Gauteng
    - Southern Gauteng
    - Western Cape
    - Other
    - If other, please specify:

_____
_____

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	

		4 - meaning is clear	
Comments:			

4. What sector do you work in?
    - Government hospital
    - Non-profit organization
    - Private practice
    - School for learners with special needs
    - Other
    - If other, please specify:

_____
_____

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

5. Do you have a Neurodevelopmental Therapy (NDT) qualification?
    - Yes
    - No

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

6. Are you currently working with children with cerebral palsy (CP)?
    - Yes
    - No

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	

iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

If you answered yes, please continue with the rest of the questionnaire. If you said no, thank you for your willingness to participate. You do not need to answer any further questions.

For the second part of the questionnaire, cerebral visual impairment is defined as the following:

"CVI is defined in terms of visual deficits of any likely cerebral cause, thereby including a wide range of visual sensory and visual perceptive deficits of known neurological underpinnings, and excluding visual deficits due to optical abnormalities" (Salavati et al., 2016).

7. How many years of experience do you have working with children with CP?
    - 1-2 years
    - 3-4 years
    - 5-7 years
    - 7-10 years
    - Over 10 years

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	

		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

8. How many children with CP do you treat in the space of a month? (number of children treated, not the number of treatment sessions)
    - 1-5
    - 5-10
    - 10-15
    - 15-20
    - Over 20

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

9. What is the main age-group of children with CP that you treat?
    - 0-2 years old
    - 2-10 years old
    - 10-15 years old
    - over 15 years old

Please tick where applicable

i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

10. What is the main GMFCS level of the children with CP that you treat? (you may indicate more than one if this the case)
    - GMFCS I
    - GMFCS II
    - GMFCS III
    - GMFCS IV
    - GMFCS V

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	

		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

11. Do you have any further training in assessing and treating children with CP?
    - Yes
    - No
    - If yes, please specify:

_____
_____

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

12. Have you had any further training in assessing and treating children with CP as well as CVI?

- Yes
- No
- If yes, please specify:

_____
_____

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

13. What is the main referral system in your setting?
    - Doctor
    - Nurses
    - Other therapists
    - Caregivers
    - School teachers
    - Other
    - If other, please specify:

_____
_____

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	

ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

14. What is your understanding of a CVI?

_____
_____
_____

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	

Comments:

15. I am always aware that a child with CP has been diagnosed with a CVI.
    - Strongly agree
    - Agree
    - Neutral
    - Disagree
    - Strongly disagree

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

16. How do you know that a child with CP has been diagnosed with a CVI?
    - I do not know if a child has been diagnosed with a CVI
    - The child's file says that he/she has been diagnosed with a CVI
    - The child has gone for a formal assessment to diagnose a CVI
    - The child's caregivers have informed me of the diagnosis
    - The child's teacher has informed me of the diagnosis

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	

		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

17. How frequently do you screen/assess for a CVI in the children with CP that you treat?
    - Always
    - Sometimes
    - Never
    - Depends
    - If depends, please specify:

_____

_____

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	

iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

18. It is difficult to diagnose children with CP for a CVI in your setting.
    - Strongly agree
    - Agree
    - Neutral
    - Disagree
    - Strongly disagree
    - Please explain further:

_____

_____

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

19. What is your main method of screening/assessing children with CP for a CVI? (you may indicate more than one in this case)

- My own observations during assessment sessions
- Medical history taken from the doctor
- Medical history obtained from the caregivers
- Caregivers will say that the child is blind or cannot see
- Teachers will say that a child has difficulty seeing
- Screening tools conducted by you
    i. If this is the case, what assessment do you use?

_____

_____

- Formal diagnostic assessment completed by you
    i. If this is the case, what assessment do you use?

_____

_____

- Formal diagnostic assessments completed by general practitioners
- Formal diagnostic assessments completed by ophthalmologists
- Formal diagnostic assessments completed by optometrists
- Other
- If other, please specify:

_____

_____

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

20. If you suspect that a child has a CVI but are unable to formally diagnose it, what will your next step in intervention be?
    - Screen for a CVI using my own observations.
    - Assume that a child has a CVI and alter intervention accordingly.
    - Continue with treatment because I do not have access to doctors and specialists to diagnose a CVI.
    - Refer the child to a specialist
        i. Please specify what kind of specialist:

_____

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

21. If you are aware that a child with CP has a CVI, does this alter your intervention?
    - Always
    - Sometimes
    - Never

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	

		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

Other comments or suggestions:

_____
_____
_____
_____

Questionnaire Part 4

Survey once CVI-MQ has been used in clinical practice

Appropriateness for the intended use

1. Do you think that the CVI-MQ is appropriate for your setting in terms of:
    a. The amount of time it takes to administer the CVI-MQ?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	

		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

b. The population of children with CP that you see in your setting?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

c. The context that you work in? (government, school for special needs, private practice, NGO)

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

2. Do you think that the CVI-MQ is useful in identifying a possibility for a CVI in a child with CP?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	

ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

3. Is the CVI-MQ developmentally appropriate for the population of children that you see in your setting?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	

		4 - meaning is clear	
Comments:			

Usability

Cost

4. Were you able to photocopy the CVI-MQ within your setting?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

5. Are the costs associated with the screening tool reasonable?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

Feasibility of administration

6. Did you find the CVI-MQ manageable and appropriate to administer in terms of the following:
    a. Instructions were clear and easy to follow?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	

		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

b. Calculating the scores of the CVI-MQ was manageable?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

c. Interpreting the scores of the CVI-MQ was manageable?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

d. Amount of time needed to fill out the CVI-MQ was manageable within your setting?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	

		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

e. The number of children with CP you see in your setting? (In other words, were you able to administer the CVI-MQ to all children with CP you see in your setting?)

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

f. The target population for the CVI-MQ?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

7. Did you feel competent in filling out the CVI-MQ when administering it to a child with CP?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	

ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

Acceptability

8. Do you think that stakeholders (caregivers, treating doctors, other allied health professionals and teachers) understand the benefits associated with the CVI-MQ?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	

		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

Infrastructure requirements

9. Are resources available to collect, manage and interpret the screening tool? E.g.: the time within your setting to complete the CVI-MQ, calculator to calculate the scores.

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

Utility

10. Are the outcomes of the CVI-MQ useful in guiding treatment/intervention?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

1 Other comments:

Please tick where applicable			
i	RELEVANCE	1 - not relevant	
		2 - item needs some revision	
		3 - relevant but needs minor revision	
		4 - very relevant	
ii	CLARITY	1 - not clear	
		2 - item needs some revision	
		3 - clear but needs minor revision	
		4 - very clear	
iii	SIMPLICITY	1 - not simple	
		2 - item needs some revision	
		3 - simple but needs minor revision	
		4 - very simple	
iv	AMBIGUITY	1 - doubtful	
		2 - item needs some revision	
		3 - no doubt but needs minor revision	
		4 - meaning is clear	
Comments:			

2
3

APPENDIX M: Content validity index results for CVI-MQ GMFCS levels I, II and III

Content validity index of the CVI-MQ for GMFCS levels I, II and III (Yaghmaie, 2003):

Question	Relevance	Clarity	Simplicity	Ambiguity	Total content validity
1. The child belly-crawls if stimulated by movement*, sound production*, fluorescence*, high-contrast toys* or verbal support* (n=14)	0.93	0.86	0.86	0.79	**0.86**
2. The child crawls if stimulated by movement* sound production*, fluorescence*, high-contrast toys* or verbal support* (n=14)	0.93	0.86	0.86	0.86	**0.88**
3. The child bumps into moved toys or furniture when it crawls (n=14)	0.86	0.71	1.00	0.79	**0.84**
4. The child is more uncertain when it walks in an unfamiliar environment compared with a familiar environment (n=14)	0.86	0.93	0.86	0.93	**0.89**
5. The child has difficulty anticipating differences in height when it walks, e.g. stepping down from the sidewalk to the road (n=14)	0.93	0.86	0.86	0.86	**0.88**
6. The child walks slower in unfamiliar environments (n=14)	0.79	0.93	0.93	0.93	**0.89**
7. The child will walk up an unfamiliar staircase one step at a time, always leading with the same foot, whereas it will walk up a familiar staircase with alternating feet at each step (n=13)	0.77	0.93	0.85	0.92	
8. The child will walk down an unfamiliar staircase one step at a time, always leading with the same foot, whereas it will walk up down a familiar staircase with alternating feet at each step (n=14)	0.71	0.79	0.86	0.86	**0.80**
9. The child bumps into obstacles/persons when it walks (n=14)	0.86	0.93	0.93	0.79	**0.88**
10. The child bumps into obstacles/persons when it runs (n=14)	0.86	0.93	0.86	0.79	**0.86**
11. The child walks significantly slower when there is no person to follow (n=14)	0.86	0.93	0.93	0.79	**0.88**
12. The child hesitates when it moves from one room to another; this occurs when the child both leaves and enters a room (n=13)	0.85	0.85	0.92	0.85	**0.87**
13. The child falls* and/or trips* over obstacles (n=14)	0.86	0.93	0.93	0.79	**0.88**

14. The child does not jump off an elevated platform (n=14)	0.71	0.79	0.93	0.71	**0.79**
15. The child does not jump forwards*, sidewards*, or backwards* (n=14)	0.71	0.79	0.86	0.79	**0.79**
16. When catching a ball, the child misses a non-sound-producing* and/or non-fluorescent*, non-high-contrast* ball more often than a sound-producing*, fluorescent*, high-contrast* ball (n=14)	0.93	0.93	0.93	0.93	**0.93**
17. The child kicks behind/next to the ball when kicking a non-sound-producing*, non-fluorescent*, lower-colour*/-contrast* ball (n=14)	0.86	0.79	0.86	0.79	**0.82**
18. The child rolls*/throws* a ball towards a person if there is verbal support (n=14)	0.86	0.93	0.93	0.79	**0.88**
19. The child has difficulty estimating the distance and speed of other road users (n=13)	0.69	0.54	0.69	0.54	**0.62**
20. The child has difficulty finding the route to the class or the school playground when walking at school (n=13)	0.85	0.92	0.92	0.92	**0.90**
21. The child reaches behind/bumps into small objects. The child only grabs the object after touching it (n=11)	1.00	0.64	0.82	0.73	**0.80**
22. The child manipulates the toy with its hands instead of exploring it with its eyes (n=12)	0.92	1.00	0.83	0.83	**0.90**
23. The child has difficulty copying figures with a pencil (n=12)	0.75	0.92	0.92	0.92	**0.88**
24. The child reaches more precisely when reaching for moving objects (n=12)	1.00	0.92	1.00	0.92	**0.96**
25. The child reaches more precisely towards sound-producing*, high-contrast*, fluorescent*, illuminating* objects compared with non-sound-producing*, non-high-contrast*, non-fluorescent*, non-illuminating* objects (n=12 for relevance, clarity and ambiguity. n=11 for simplicity)	1.00	0.92	0.91	1.00	**0.96**
26. The child does not reach for and look at an object at the same time (n=12)	1.00	0.92	1.00	0.92	**0.96**
27. The child reaches towards toys but has difficulty finding the toys in a crowded (n=12)	1.00	1.00	1.00	0.92	**0.98**

1

2

APPENDIX N: Content validity index results for CVI-MQ GMFCS levels IV and V

Content validity index of the CVI-MQ for GMFCS levels IV and V:

Question	R	C	S	A	T
1. The child turns its head to follow, if encouraged by sound production*, fluorescence*, high-contrast* toys or verbal stimulation* (n=12)	1.00	1.00	0.92	1.00	**0.98**
2. The child lifts its head when lying on its stomach, if encouraged by sound production*, fluorescence*, high-contrast* toys or verbal stimulation* (n=12)	1.00	1.00	0.92	0.92	**0.96**
3. From a sitting position the child lifts its head, if encouraged by sound production*, fluorescence*, high-contrast* toys or verbal stimulation* (n=12)	1.00	0.92	0.83	0.83	**0.90**
4. The child belly-crawls, if encouraged by sound production*, fluorescence*, high-contrast* toys or verbal stimulation* (n=12)	0.83	0.92	0.92	0.83	**0.88**
5. The child bumps into moved toys or furniture when it belly-crawls (n=12)	0.67	0.67	0.83	0.67	**0.71**
6. The child crawls/belly-crawls slower in an unknown environment with the same surface as a known environment (n=12)	0.75	0.83	0.83	0.83	**0.81**
7. The child has difficulty finding the route to the class or school playground when driving a wheelchair (mechanic/electric) (n=12)	0.92	1.00	1.00	0.92	**0.96**
8. The child bumps into objects/persons when driving a wheelchair (mechanic/electric) (n=12)	0.83	0.92	0.92	0.92	**0.90**
9. The child reaches more precisely for moving objects than for non-moving objects (n=12)	0.92	0.92	0.92	0.83	**0.90**
10. The child reaches more precisely towards sound-producing*, high-contrast*, fluorescent*, illuminating* objects compared with non-sound-producing*, non-high-contrast*, non-fluorescent*, non-illuminating* objects (n=12 for relevance, n=11 for clarity, simplicity and ambiguity)	1.00	0.91	1.00	1.00	**0.98**
11. The child looks away when it grabs an object (n=12)	1.00	1.00	1.00	1.00	**1.00**
12. The child reaches for a toy but has difficulty finding the toy in a crowded background, e.g. finding a block on a full table or in a basket filled with toys (n=12)	1.00	1.00	0.92	1.00	**0.98**
13. The child grabs an object if it produces sound (n=12)	1.00	1.00	1.00	1.00	**1.00**
14. The child explores*/manipulates* toys with its mouth or hands instead of exploring it with its eyes (n=12)	1.00	1.00	1.00	1.00	**1.00**

APPENDIX O: Comments on the content validity of the Cerebral Visual Impairment Motor Questionnaire (CVI-MQ)

Content validity discussion of the CVI-MQ for GMFCS levels I, II and III

Themes	General comments
Clarification of items needed	Items 1 and 2: One participant felt the question did not clarify if the child was seeing a moving object or if the child was being moved towards a moving object. One participant did not feel that “high contrast toys” was clear enough, and requested clarification of the difference between sound production and verbal support. Item 3: Two participants queried whether the furniture was being moved – clarification of the item is needed. Item 11: One participant questioned whether it was “follow” as in behind or next to someone, or when someone is holding their hand. Item 12: One participant questioned whether this question referred to moving spontaneously around or when following another person? One participant questioned whether the question meant that the child hesitates only at entrance/exit or inside the room. One participant queried whether the question meant that the child struggled to find the frame/entrance of the room. Item 15: One participant felt that this is not a yes/no answer. Item 16: One participant reported that an explanation of terms is needed. Item 17: One participant was unsure of what this question is testing or asking. One participant said there needs to be clarification of what lower colour/lower contrast ball means. Item 18: One participant questioned what verbal support involved and that this needs to be clarified. Item 19: A number of participants found this question to be ambiguous as they did not understand whether the child was driving or walking on the road. Item 21: One participant reported that the word 'behind' is confusing. One participant questioned whether the object was on a table or on the floor and if the object was familiar or not. One participant said there were two aspects in one question. Item 22: One participant suggested adding the types of manipulation such as rotational and linear. Item 24: One participant said that an example should be provided. Item 25: One participant said that this question is relevant but highly loaded with many options. One participant questioned whether the object had to have all of the stated qualities in each group or just one quality. One participant said that an explanation of terms is required. Item 26: One participant said that this question should come before the reach question above to improve clarity. One participant questioned where the object was placed.
Age-appropriateness of the item needs to be considered	Item 1: Two participants commented that the question is age-dependent. Item 2: Two participants commented that the question might not be relevant for children who are not crawling. Item 3: One participant mentioned that there is too much focus on a child crawling when they could not be crawling. Items 4 and 5: One participant questioned what about the child that does not walk. Item 10: One participant commented about what if the child does not run. Item 15: One participant felt there is a developmental element to this question and perhaps an age bracket should be added to this question. Item 19: One participant mentioned that the children are too young to use the road alone.

	Item 22: One participant mentioned that this will be a hard question to answer depending on the child's age. Item 23: One participant mentioned that it is important to note the age appropriateness of this question.
Vocabulary is not always appropriate or easily understood	Items 1 and 2: One participant reported that the word "fluorescence" is not a common word as well as "sound production" and suggested using words such as sounds and noises, and for "verbal support" – to rather use verbal encouragement. Item 16: one participant mentioned that a more common word for fluorescent should be used.
Items are not always relevant to a CVI/specificity to CVI not sufficient	Item 2: One participant suggested that the wording be changed: 'The child crawls ONLY if stimulated by one or more of the following'. She reported that this would be a stronger indication of a CVI. Item 8: One participant felt that this item and other items are not sensitive enough to CVI. He/she felt that it would be more appropriate to link stair-climbing with visual cues. E.g.: Walks more easily up a set of stairs if the edges are marked appropriately in a high visibility colour. Item 9: One participant expressed that the question needs to be more specific to exclude spatial awareness difficulties such as: "is spatial awareness improved with the appropriate visual cues". Item 10: One participant suggested that the question needs to related to visual cues i.e., the problem corrects when others are wearing high visibility clothes. Item 13: One participant suggested that this question be linked to visual cues such as: "does his ability to navigate obstacles become better when they are in specific high visibility colours"? Item 22: One participation said that perhaps consideration of adding the observation such as: 'Looking at object first and then looking away while touching it'. Item 24: One participant suggested changing the wording to 'notices and/or reaches' for object.
Items do not consider other reasons a child may move/not move/experience difficulties with an item	Items 1 and 2: One participant reported that it is ambiguous because children move for different reasons at different times. Item 3: One participant expressed that their experience of children bumping into furniture is due to spatial awareness difficulties and not necessarily CVI and that children with a CVI usually display a high degree of caution and you would not usually see a child bumping into things. One participant reported that a child could bump into objects due to a physical impairment. One participant mentioned that it could depend on if the child has dyskinesia or ataxia or tends to move in a preferred direction due to tone. Items 5 and 6: One participant said that the cognitive level of the child could affect this task. Items 7 and 8: One participant felt that the questions do not consider other problems that the child is experiencing such as hemiplegia. This participant reported that he/she seldom sees a child where a CVI is the primary problem. Item 9: One participant commented that there could be motor reasons and not purely visual problems. Item 10: Two participants commented on postural control when moving rapidly as opposed to visual concerns and that children with CP struggle with control anyway. One participant expressed that this could be due to motor problems and not necessarily vision. Item 13: One participant said the reason could be separation anxiety as opposed to vision. One participant mentioned that this could be due to motor problems. Item 14: One participant mentioned that this could be due to gravitational/postural insecurity as opposed to vision. Two participants mentioned that jumping is a high requirement for some children with CP in terms of their physical difficulties.

	Item 15: One participant felt that this question relies too heavily on co-ordinated gross motor skills and that most of the children that she sees when on a GMFCS level I cannot jump forwards, sideways or backwards and that. Item 17: One participant mentioned that the child's motor function should be considered. One participant mentioned that some children do not have the motor planning to kick a ball. Item 20: One participant mentioned that memory could be the concern. Item 23: One participant mentioned that there are many contributing factors to this challenge which may not indicate a CVI.
Familiar versus unfamiliar environment	Item 4: One participant said that it would be not be easy to determine if one has not observed a child in their natural environment, and that a lot of children with special needs are not comfortable in an unfamiliar environment so this question is not sensitive. Item 6: One participant felt that this question would not be relevant for a child that you are seeing for the first time in an unfamiliar environment. Item 10: One participant suggested the addition of a question whether the child is able to move quickly within a known environment.
Specific information of an item not always given	Item 5: One participant said that it might be a good idea to have the heights of objects into this item. Item 13: Three participants questioned how big the obstacles are and that these should be specified. Item 14: Two participants questioned how high the platform is and that this should be specified. Item 15: One participant questioned whether it was bilateral jumping or single leg jumps. Item 23: One participant suggested specifying what the figure is, e.g. circle, line or cross. Item 24: One participant said that it is dependent on hand dominance, contrast of an object and/or moving centrally or peripherally. Item 26: One participant questioned where the object was placed.
Inappropriate wording of some items	Items 4, 5 and 22: One participant did not like the use of the word "it" instead of "he/she/child". Items 9 and 10: Two participants did not like the use of the word "it" instead of "he/she/child".
Similarity of questions	Items 6 and 7: One participant felt that this question was similar to item 4.
Item not appropriate for the South African setting	Item 19: One participant mentioned that the roads in South Africa are not safe for the children to use alone especially children with CP.

Conclusion of the concerns for each item for the CVI-MQ for GMFCS levels I, II and III:

Item	Concerns with the item according to the themes
1	Clarification of item needed. This item is age-dependent. Vocabulary is not always appropriate or easily understood. Items do not consider other reasons a child may move/not move/experience difficulties with an item.
2	Clarification of item needed. This item is age-dependent. Vocabulary is not always appropriate or easily understood. Items are not always relevant to a CVI/specificity to CVI not sufficient. Items do not consider other reasons a child may move/not move/experience difficulties with an item.
3	Clarification of item needed. This item is age-dependent.

	Items do not consider other reasons a child may move/not move/experience difficulties with an item.
4	This item is age-dependent. Familiar versus unfamiliar environment. Inappropriate wording of some items.
5	This item is age-dependent. Items do not consider other reasons a child may move/not move/experience difficulties with an item. Specific information of an item not always given. Inappropriate wording of some items.
6	Items do not consider other reasons a child may move/not move/experience difficulties with an item. Familiar versus unfamiliar environment. Similarity of questions.
7	Items do not consider other reasons a child may move/not move/experience difficulties with an item. Similarity of questions.
8	Items are not always relevant to a CVI/specificity to CVI not sufficient. Items do not consider other reasons a child may move/not move/experience difficulties with an item.
9	Items are not always relevant to a CVI/specificity to CVI not sufficient. Items do not consider other reasons a child may move/not move/experience difficulties with an item. Inappropriate wording of some items. Item not appropriate for the South African setting.
10	This item is age-dependent. Items are not always relevant to a CVI/specificity to CVI not sufficient. Items do not consider other reasons a child may move/not move/experience difficulties with an item. Familiar versus unfamiliar environment. Inappropriate wording of some items.
11	Clarification of item needed.
12	Clarification of item needed.
13	Items are not always relevant to a CVI/specificity to CVI not sufficient. Items do not consider other reasons a child may move/not move/experience difficulties with an item. Specific information of an item not always given.
14	Items do not consider other reasons a child may move/not move/experience difficulties with an item. Specific information of an item not always given.
15	Clarification of item needed. This item is age-dependent. Items do not consider other reasons a child may move/not move/experience difficulties with an item. Specific information of an item not always given.
16	Clarification of item needed. Vocabulary is not always appropriate or easily understood.
17	Clarification of item needed. Items do not consider other reasons a child may move/not move/experience difficulties with an item.
18	Clarification of item needed.
19	Clarification of item needed. This item is age-dependent.
20	Items do not consider other reasons a child may move/not move/experience difficulties with an item.
21	Clarification of item needed.
22	Clarification of item needed. This item is age-dependent.

	Items are not always relevant to a CVI/specificity to CVI not sufficient. Inappropriate wording of some items.
23	This item is age-dependent. Items do not consider other reasons a child may move/not move/experience difficulties with an item. Specific information of an item not always given.
24	Clarification of item needed. Items are not always relevant to a CVI/specificity to CVI not sufficient. Specific information of an item not always given.
25	Clarification of item needed.
26	Clarification of item needed. Specific information of an item not always given.
27	No concerns.

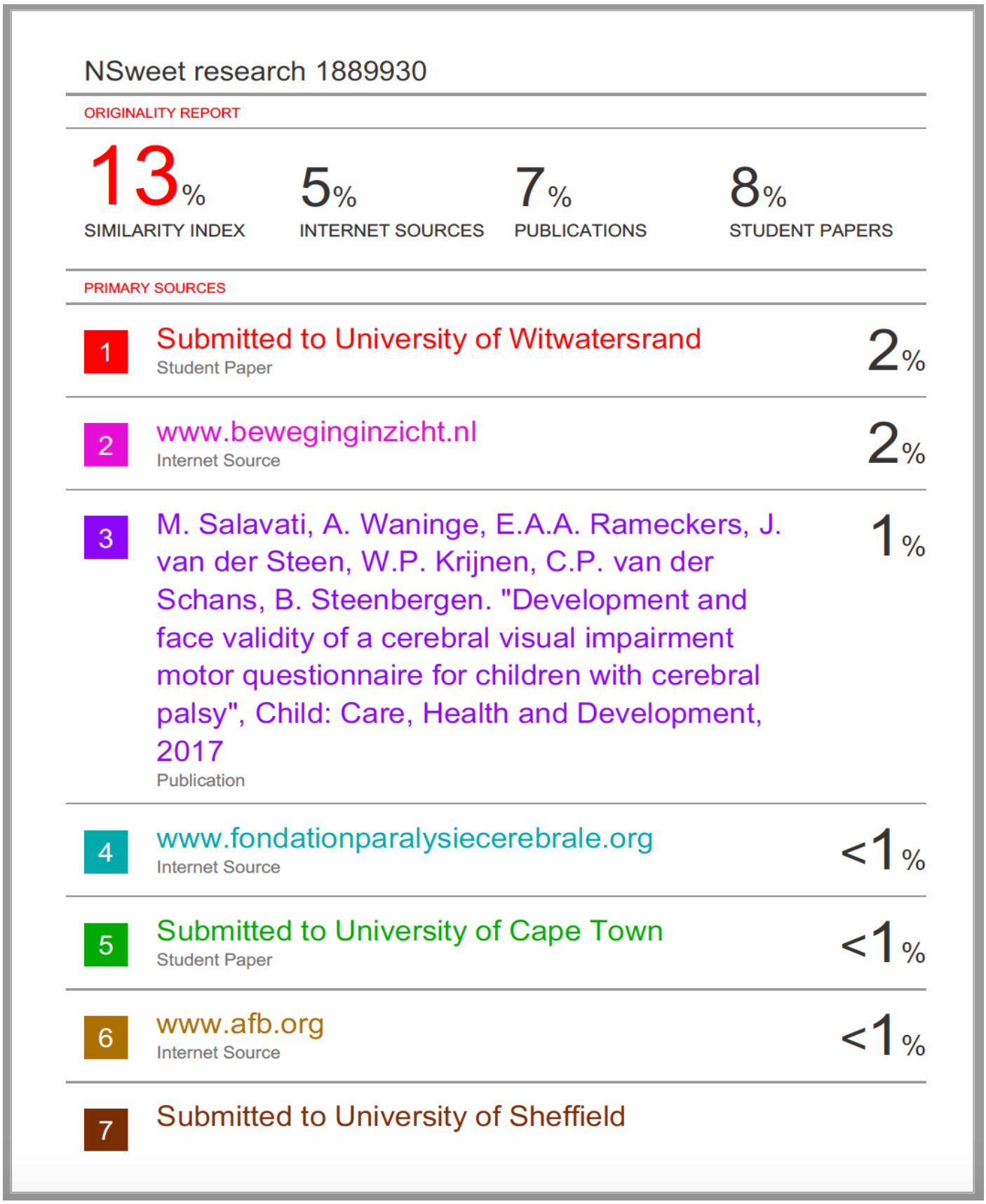
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APPENDIX P: Turn it in report



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