

Accessibility of advanced seating services in a Western Cape setting; a qualitative exploration of the experiences of carers of children with cerebral palsy

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Declaration

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Abstract

Background: It is important for health professionals to understand the experiences of carers of children with cerebral palsy (CP) when accessing health care. Understanding their experiences might help providers to make services more accessible.

Aim of the study: To explore the experiences of carers of children with CP (GMFCS IV/V), around the accessibility of advanced seating services at a tertiary healthcare facility in the Western Cape.

Methods: This study implemented an exploratory, qualitative research design. Of the study population consisting of 62 carers of children with severe CP, seven carers were purposively sampled and interviewed. Thematic analysis with an inductive reasoning process was used to analyse and generate themes from the semi-structured interviews that were conducted.

Findings: Carers experienced a great deal of stress around accessing the tertiary healthcare facility for the seating appointment. Four themes were generated: (1) A strenuous experience, (2) Transport, (3) The child and the buggy, and (4) Facilitators to access.

Conclusion: Carers encountered barriers, such as transport, that limited access to the tertiary healthcare facility to attend the advanced seating clinic. Service providers need to take cognisance of the challenges that posture support devices pose to using public transport when prescribing a posture support wheelchair. Service providers should consider decentralizing seating services. There is room for improvement of the current public transport systems to be more inclusive for carers, their children with CP and their posture support wheelchairs by enacting legislation in the Western Cape.

Key Words

Cerebral palsy, Accessibility, Access to services, Advanced seating, Public transport

Abstrak

Agtergrond: Dit is belangrik dat gezondheidswerkers die ervarings van versorgers van kinders met serebrale verlamming (SV) rondom toeganklikheid van gesondheidsfasiliteite verstaan. Begrip vir hulle ervarings mag diensverskaffers help om dienste meer toeganklik te maak.

Doel van studie: Om die ondervindinge van versorgers van kinders met SV (GMFCS IV/V), in verband met die toeganklikheid van gevorderde rolstoel posisioneringsdienste by 'n tersiêre gesondheidsfasiliteit in die Wes-Kaap te ondersoek.

Metodes: Hierdie studie het 'n verkennende, kwalitatiewe studie ontwerp geïmplementeer. Van die studie populasie wat bestaan uit 62 versorgers van kinders met erge SV, is sewe versorgers doelbewus geselekteer en geonderhoud. Tematiese ontledingstrategie met 'n induktiewe redenasie proses was gebruik om temas te analiseer en genereer van die semi-gestruktureerde onderhoude wat gedoen is.

Bevindinge: Die versorgers het baie stres ondervind om afsprake vir gevorderde rolstoel aanpassingsdienste na te kom. Vier temas is uitgelig: (1) 'n Stresvolle ervaring, (2) Vervoer, (3) Die kind en die 'buggy' en (4) Toeganklikheids fasiliteerders.

Gevolgtrekking: Versorgers het hindernisse, soos vervoer, ondervind wat toegang tot die tersiêre gesondheidsfasiliteit vir gevorderde rolstoel posisioneringsdienste beperk het. Diens-verskaffers moet bewus gemaak word van en moet die uitdagings wat postuur-ondersteunende rolstoele inhou vir die gebruik van publieke vervoer in ag neem, wanneer hulle postuur-ondersteunende rolstoele voorskryf. Diens-verskaffers moet dit oorweeg om rolstoel posisioneringsdienste te desentraliseer. Publieke vervoerdienste moet verbeter word en om dit meer inklusief te maak vir gebruikers van postuur-ondersteunende rolstoele en hulle versorgers deur die implementasie van bestaande wetgewing in die Wes-Kaap.

Sleutelwoorde

Serebrale verlamming, Toegang tot dienste, Gevorderde rolstoel posisionering, openbare vervoer

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Introduction

Children with cerebral palsy (CP) classified on the Gross Motor Function Classification Scale (GMFCS) as level IV and V have profound impairments and activity limitations (Palisano, Rosenbaum, et al., 2007). In contrast to children with milder CP or without CP, they need greater, life-long involvement from their carers to assist with their multiple care needs (Raina, O'Donnell, et al., 2005).

They also need posture support wheelchairs. Firstly, an appropriate posture support wheelchair coupled with regular follow-up services to evaluate the on-going effectiveness of the device can be beneficial to the overall health and quality of life of the child, through reducing complications such as the progression of contractures, pressure sores, and by enhancing orofacial and respiratory function (WHO, 2008). Secondly, the posture support wheelchair can reduce the burden of care through facilitating mobility (Geere, Gona, et al., 2012).

Wheelchair services are provided on three levels in South Africa namely, basic, intermediate and advanced. These are based on the level of expertise required from service providers to address the users' support needs as described by the World Health Organisation's (WHO) "The Guidelines on the provision of Manual Wheelchairs in less resourced settings" (WHO, 2008). Advanced seating services are required due to the specialised needs of most children with CP classified at GMFCS level IV or V. In the Western Cape Province, such advanced seating services are delivered at tertiary healthcare facilities by appropriately trained service providers (Department of Health (DoH), 2015a).

Carers of children with CP world-wide (Bourke-Taylor, Howie & Law, 2010; Resch, Mireles, et al., 2010; Hayles, Harvey, et al., 2015) and more specifically, in Africa, express concerns around the accessibility of healthcare facilities (Saloojee, Phohole, et al., 2007; Barratt, 2008; Donald, Samia, et al., 2014; Singogo, Mweshi & Rhoda, 2015; Ndadzungira, 2016; Pretorius & Steadman, 2017), especially as the child with CP gets

older and heavier (Davis, Shelly, et al., 2009; Burkhard, 2013; Geere, Gona, et al., 2012; Donald, et al., 2014; Dambi, Mlambo & Jelsma, 2015). These concerns include the lack of wheelchair-accessible transport and financial strain associated with rehabilitation, transportation, care and assistive devices (Donald, et al., 2014; Singogo, Mweshi & Rhoda, 2015; Pretorius & Steadman, 2017).

No previous published evidence was found on the experiences of carers of children with severe CP when accessing advanced seating services in South Africa. Thus, the aim of this study was to explore the experiences of carers of children with cerebral palsy (GMFCS IV/V), around the accessibility of advanced seating services at a tertiary healthcare facility in the Western Cape.

The objectives were:

- To describe how carers and their children get to the healthcare facility when accessing advanced seating services.
- To identify the barriers experienced by carers of children with CP (GMFCS IV/V) when accessing advanced seating services at the healthcare facility.
- To identify the facilitators experienced by carers of children with CP (GMFCS IV/V) when accessing advanced seating services at the healthcare facility.

Literature review

Literature searches included accessing databases such as PubMed and Google Scholar, utilising search words such as “access*”, “carers/caregivers”, “cerebral palsy (CP)”, “tertiary healthcare”, “experience*”, “Africa”, “wheelchair*”, “adaptive seating”, “adaptive seating system*”, “assistive device*”, “severe”, “adolescent”, “older”, “GMFCS IV and V”.

Background to cerebral palsy

Cerebral palsy is defined as “a group of disorders of the development of movement and posture, causing activity limitation that is attributed to non-progressive disturbances that occurred in the developing foetal or infant brain” (Bax, Goldstein, et al., 2005: 572).

Cerebral palsy is a common cause of disability in children, with a global prevalence rate estimated at 2-2.5 per 1000 live births (Shevell, Dagenais & Oskoui, 2013). Africa has a higher commonness of CP at 2-10 cases per 1000 live births because of perinatal complications such as neonatal communicable diseases and birth asphyxia (Donald, et al., 2014). The prevalence of CP in South Africa is likely to be underestimated, due to the lack of reliable data (Burg, 2016; Eunson, 2012). Prevalence of one study conducted in Kwazulu-Natal estimated up to 10 per 1000 live births (Couper, 2002).

Children with CP present with hypertonia, hypotonia, paresis, dystonia, dyskinesia, and/or ataxia (Gorter, Rosenbaum, et al., 2004). Numerous children with CP also experience other body function and structure impairments related to brain damage, such as impairments of cognition, perceptual function, communication, behaviour and sensation (Donald, et al., 2014; Bax, et al., 2005).

The severity of CP is usually described by the degree of functional mobility as scored by the GMFCS (Palisano, et al., 2007). Where severe impairments are present and the children have little functional mobility, the GMFCS score is IV or V. In these instances, the children require posture support wheelchairs for mobility and to provide pelvic, trunk and sometimes head support (Palisano et al., 2007). Due to their severe postural dysfunction and limited mobility, children with CP (GMFCS IV/V) are dependent on their

carers to assist with mobility and transfers (Palisano, et al., 2007) and for all activities of daily living (Raina, et al., 2005).

A posture-support wheelchair can have a positive impact on impairments, activities and participation as it assists in maintaining normal body alignment (Rosenbaum & Stewart, 2004; McDonald, Surtees & Wirz, 2004; WHO, 2008; Huang, Sugden & Beveridge, 2009). Improved alignment helps to prevent or reduce long-term secondary complications, such as dislocation of the hip, spinal deformities, pressure sores, respiratory problems and contractures (McDonald, et al., 2004; Rosenbaum & Stewart, 2004; WHO 2008). It is also associated with improved eye contact, hand use, communication and swallowing which in turn may result in better activity and participation (McDonald et al., 2004; Angsupaisal, Maathuis & Hadders-Algra, 2015).

As the child with CP grows into adulthood, the changed dimensions of their bodies requires adjustments to their postural support. They experience a decline in mobility due to increased spasticity, pain, changes in muscle flexibility, strength and endurance, falls and fractures, arthritis, fatigue, and changes in spinal alignment (Liptak, 2008; Haak, Lenski, et al., 2009; Hanna, Rosenbaum, et al., 2009; Burkhard, 2013). They might therefore be in greater need of advanced seating services to prevent additional restrictions in activity and participation (Pakula, Braun & Yeargin-Allsopp, 2009). The frequency of follow-up seating appointments depends on the individual needs of the child (WHO, 2008). Usually, six-monthly follow-up appointments are prescribed to ensure optimal fit of the posture support wheelchair, with modifications and replacements done as required (WHO, 2008).

Barriers to healthcare access experienced by persons with disabilities

Accessibility refers to a person's capability to get to and use a healthcare facility or services without facing undue financial, geographical or organisational barriers (Vergunst, Swartz, et al., 2015). Persons with disabilities (PWD), such as the current study population, might experience many barriers to healthcare access. These barriers include transport, natural environment, provider knowledge, skills and understanding,

communication, negative attitudes and affordability (Kahonde, Mlenzana & Rhoda, 2010; Grut, Mji, et al., 2012; Van Rooy, Amadhila, et al., 2012; Maart & Jelsma, 2013; Eide, Mannan, et al., 2015; Vergunst, et al., 2015; Vergunst, Swartz, et al., 2017). Since the focus of this study was getting to healthcare services, relevant barriers were further explored.

The unavailability of transport for PWD, including for carers of children with CP, to access healthcare services has been well-documented in literature (Saloojee et al., 2007; Barratt, 2008; Rhoda, Mpofo & DeWeerd, 2009; Kahonde, et al., 2010; Van Rooy, et al., 2012; Maart & Jelsma, 2013; Cawood & Visagie, 2015; Singogo, et al., 2015; Simpamba, Struthers & Mweshi, 2016; Pretorius & Steadman, 2017; Vergunst, et al., 2017). Challenges were experienced with both public and private transport and specialised or subsidised transport programmes for PWD (Scheer, Kroll, et al., 2003).

The South African White Paper on National Transport Policy (1996) recognises the constitutional right of PWD to have accessible transport (Department of Transport, 1996). The policy states that “the needs of special categories of passengers should be identified by the responsible transport authorities, especially at metropolitan and local level, and these should be addressed in their passenger transport plans” (Department of Transport, 1996:48). The White Paper on Provincial Transport Policy (1997) in the Western Cape also advocates for no discrimination against PWD. This policy declares that “discriminatory practices against specific groups, such as women and disabled persons, must cease, and their special needs must be identified and addressed in all transport plans and programmes” (Department of Transport, 1997:5). The *National Land Transport Transition Act 22 of 2000* was developed to address some challenges that existed in an effort to promote the rights of PWD and states that public modes of transport should care for the needs of PWD.

Public transport services, such as taxis or busses, are not accessible for PWD, often do not stop for PWD, and might charge them extra for transportation of their wheelchair (Kahonde, et al., 2010; Grut, et al., 2012; Ntamo, Buso & Longo-Mbenza, 2013; Simpamba, et al., 2016). Adapted public transport for children who use posture-support

wheelchairs is not readily available (Donald, et al., 2014; Dambi, Mlambo & Jelsma, 2015; Pretorius & Steadman, 2017).

When faced with the problems of using public transport, PWDs (Kahonde, et al., 2010; Van Rooy, et al., 2012; Ntamo, et al., 2013) and their carers (Saloojee, et al., 2007; Simpamba, et al., 2016; Pretorius & Steadman, 2017) often choose private transport, which is expensive to hire and can contribute to the financial burden experienced by PWD (Grut, et al., 2012; Ntamo, et al., 2013) and by carers (Hansen, Siame & Van der Veen, 2014; Simpamba, et al., 2016; Pretorius & Steadman, 2017).

The MyCiti bus service was implemented as part of the City of Cape Town's Integrated Rapid Transport system, aiming to improve public transport for all persons in wheelchairs, by providing level access onto buses if required (MyCiti, 2019). Dial-a-Ride specialised transport services are currently operated with 21 vehicles in the Cape Metro but are only provided to registered users (Morta-Andrews, 2018). The availability of the service is based on four factors: available routes, the demand for a specific route, the availability of space for a specific route and lastly, the time requested by the user (Morta-Andrews, 2018). Even though these specialised transport services are available, challenges are experienced with reliability and bookings (Maart & Jelsma, 2013). HealthNET Services (state-provided transport between healthcare service facilities) are also available. However, PWD are not always aware of or how to access these services (Cawood & Visagie, 2015).

The built environment could also restrict access, through the absence of ramps or underways, narrow or no sidewalks, narrow doorways, and small indoor spaces (Cawood & Visagie, 2015; Singogo, et al., 2015; Huang, Sugden & Beveridge, 2009).

Experiences of carers of children with disabilities when accessing healthcare

The main reasons given by carers of children with disabilities from low socio-economic backgrounds for not attending healthcare services were related to finance and transportation (Saloojee, et al., 2007; Singogo, et al., 2015; Simpamba, et al., 2016), and

environmental challenges such as distance and terrain (Singogo, et al., 2015; Simpamba, et al., 2016).

In Zambia, Simpamba, et al. (2016) reported that mothers of children with neural tube defects received financial support from their families to pay for transport to the tertiary healthcare facility and that family members were able to look after other children who were left at home. Some healthcare facilities also provided transport to the hospital for mothers (Simpamba, et al., 2016). Even though it is important to acknowledge the barriers, such as transportation and financial difficulties that PWD or carers experience when accessing healthcare facilities, it is equally important to look at the facilitators, as this information might assist other carers and make rehabilitation services more accessible (Mlenzana, Frantz, et al., 2013; Pretorius & Steadman, 2017).

Motivation

In my profession as an occupational therapist (OT) who provides advanced seating services to PWD, including children with CP, I have observed that carers sometimes do not attend, cancel or reschedule seating appointments, or only contacted the advanced seating services when the posture support wheelchair of the child with CP, was broken. Identifying the reasons for this observation has become of interest.

As carers of children with CP have such a vital role to fulfil regarding the child's care needs, it was worth investigating the barriers they experience and facilitators they utilise when accessing a healthcare facility (Resch, et al., 2010; Eide, et al., 2015) to attend advanced seating services. The carers' accounts might provide a comprehensive picture of what needs to happen behind the scenes in order to ease access. Due to a complex relationship between poverty, disability and health (Parnes, Cameron, et al., 2009; Mitra, Posarac & Vick, 2012; Grut et al. 2012), carers of children with CP from low socio-economic backgrounds in South Africa might have unique experiences around accessibility of healthcare facilities, which have not been identified by carers in other more affluent settings.

Understanding the experiences and perspectives of the carers might provide a learning opportunity; contribute to the knowledge of clinicians (Bourke-Taylor, Howie & Law, 2010); and, inform best practice in providing services and support for children with CP and their carers in their context (Donald, et al., 2014; Thrush & Hyder, 2014; Eide et al., 2015). The evidence might contribute to policy revision and development (Eide et al., 2015).

Methodology

Study design

This study implemented an exploratory, qualitative research design as it investigated the experience of carers of children with CP when accessing advanced seating services. A qualitative design is useful when one seeks to make sense of a certain event or topic, and to gain in-depth understanding of how a certain group of participants meet their daily roles (Merriam, 1995; O’Leary 2017). This might enrich and enlighten our understanding of the carers’ experiences, and possibly assist in transforming our practices (Thorne, 2000; Adams & Van Manen, 2008).

Research setting

This study was conducted at a tertiary healthcare facility in the Cape Town Metro health district that provides services to a population of over 3.4 million people. More than 107 215 patients are admitted, and 492 670 outpatients visit the hospital annually (Western Cape Government, 2018a). The facility provides a full range of general and sub-specialist services, including advanced seating services at the Occupational Therapy department. On average 7-10 patients are seen for seating services per week, four of whom are for advanced seating services.

Population and sampling strategy

The study population consisted of 63 carers of children with CP GMFCS Level IV and V, who attended the advanced seating clinic at the tertiary healthcare facility between January 2016 and March 2018. This timeframe was agreed upon since the latest data on the population could be obtained from the clinic’s database, which has been kept since January 2016.

Participants had to be the primary carer of the child with CP (GMFCS IV or V), older than 18 years of age and travelling from home to the advanced seating services at the tertiary healthcare facility. Exclusion criteria were carers of children with CP residing outside a 100km radius of the tertiary healthcare facility and carers of children with CP who received

assistance with transport from a day-care centre or school. The ages of the child with CP were not exclusion criteria, because persons with CP might receive care from their parents even when older than 18.

Information from the manual database and Clinicom, an electronic hospital information system, was used to compile a list of the study population on an Excel spreadsheet (Appendix A). The list included information on carers and children with CP, such as the GMFCS level, contact information, age, gender, next follow-up appointment and missed appointments for the advanced seating clinic.

Purposive sampling was used to identify seven participants from this list (Domholdt, 2005; Daniel, 2012; O'Leary, 2017). Carers who had previously voiced their experiences, challenges and possible solutions around accessibility of the advanced seating clinic were handpicked through purposive sampling as it was believed that they would be able to provide rich information on the topic under study.

The recruitment process had two options. Firstly, carers, who had been sampled, whose child with CP had a seating and/or doctor's appointment during the seven weeks of the data-collection period (28 August 2018–18 October 2018) were contacted telephonically a week before the appointment. The study was explained to the carers who were asked whether they were interested in participating. If interested, time was set aside after their children's appointments to conduct the interview. Five participants were interviewed using this process. Secondly, carers whose children with CP did not have a seating and/or a doctor's appointment in the seven-week study period, were contacted telephonically. An interview was arranged at their convenience. Two participants were interviewed using this process.

Data collection

The method of data collection was using one-on-one, semi-structured interviews with broad open-ended questions. Interviews were audio-recorded and conducted in the preferred language of the study participant and lasted 45-60 minutes. An Occupational Therapist who speaks IsiXhosa as a first language acted as an interpreter to one

IsiXhosa-speaking carer. Each interview commenced with a demographic questionnaire (Appendix B), followed by three core-questions on the Interview Schedule (Appendix C) which guided the interviews:

- Tell me about a typical day for you when you have to get to the tertiary hospital?
- What or who makes it easy for you to get to the hospital?
- What or who makes it difficult for you to get to the hospital?

Further, probing questions were used to assist with data collection.

A pilot study gave the chance to modify or confirm the interview schedule and plan time for interviewing and transcribing (Kim, 2011). Since the sampling frame and methodology remained unchanged, the pilot interview was included in the main study to increase its efficiency (Thabane, Ma, et al., 2010).

The number of interviews depended on the point where no new themes emerged from participants i.e. data saturation (Lincoln & Guba, 1985). By the seventh interview, saturation was reached as I had found that various themes had been repeatedly mentioned during the previous interviews and no new information was emerging.

At the end of the interview, I thanked the participants for their participation, presented them with a R100 voucher as a token of appreciation and reimbursed their taxi-fare or petrol. They were not told about the voucher beforehand so as to not influence their decision to participate in the study or not.

Data analysis

A thematic analysis strategy with an inductive reasoning process was utilised. Thematic analysis was appropriate for this research, which sought to learn through the use of interpretation of both manifest and latent content (Braun & Clarke, 2006). A six-step iterative approach, proposed by Braun and Clarke (2006), was followed:

1. I familiarised myself with the data through transcribing the six Afrikaans tape-recorded interviews. The isiXhosa interview was transcribed into written isiXhosa and translated by a professional translator into English.
2. Initial codes, used to organise data into meaningful groups, were generated.
3. Codes were combined to look for themes.
4. Themes were evaluated.
5. Themes were described and named.
6. Analysis was completed and results reported. Afrikaans quotes were translated by myself to English.

Trustworthiness

Evaluating the research study is vital if findings are to be applied in practice and incorporated into the development of care (Long & Johnson, 2000; Noble & Smith, 2015). Lincoln and Guba (1985) and Schwandt, Lincoln and Guba (2007) proposed four criteria to ensure trustworthiness in qualitative research, namely credibility, confirmability, dependability, and transferability.

Credibility was aspired to by implementing a peer debriefing process, discussing emerging findings and comparing ideas with my supervisor who has qualitative research experience (Morrow, 2005; Mabuza, Govender, et al., 2014). Receiving feedback from the pilot participant helped modify the interview (Kim, 2011). Data saturation also enhanced credibility. Research bias was not completely avoidable but clarifying my background and relationship with the participants could improve credibility (Tong, Sainsbury & Craig, 2007).

Confirmability and the minimisation of the impact of my own bias were pursued by reflexivity (Mabuza et al., 2014) through keeping a reflexive journal (Kim, 2011). Prior relationships to the participants, my current occupation and background might have influenced data collection and analysis. By being honest and vigilant of my pre-existing thoughts, developing theories and beliefs, and by engaging in the self-reflective process of 'bracketing', whereby prior assumptions and knowledge were recognised and

restricted, I achieved the goal of attending to the participant's narratives with an open mind (Starks & Trinidad, 2007).

To enhance dependability, the emerging research design was tracked by keeping a detailed chronology of the research process (Morrow, 2005; Mabuza et al., 2014).

A thorough description of the research topic, the processes, methodology, participants and the study context should enable the reader to decide the transferability of the findings (Morrow, 2005; Mabuza et al., 2014). Furthermore, included in the study sample were a group of participants who differed in gender, age and years of caregiving experience.

Ethical considerations

Combined Ethics approval by the Health Research Ethics Committee (HREC) at the Faculty of Medicine and Health Sciences at Stellenbosch University (S18/05/112) (Appendix D) and from the Western Cape Provincial Health Research Committee (PHRC) and Tygerberg Academic Hospital research committee, via the National Health Research Database (NHRD) (WC_201807_011) (Appendix E), were obtained.

Informed consent was obtained prior to the commencement of data collection from each participant (Appendix F) (DoH, 2015b). The carers were guaranteed that they could pull out from the study on any occasion without negative consequences to them or the services for their child with CP. Participants' identities were protected by assigning each a code, and any distinguishable information was factored out from the results of the research assignment. Recorded and transcribed data were securely locked away for the duration of the study and will be kept for a five-year period, after which it will be disposed of appropriately.

Very little risk was associated with being interviewed in a non-intervention study (DoH, 2015b), but participants may have felt that future sessions for their children with CP might be influenced by what was disclosed during the interview. This discomfort was overcome by being open, honest and building trust with the participant. The only foreseeable risk for participants in the study was that when they share personal details of their lives during

the interviews, they might experience emotional discomfort. None of the participants experienced emotional discomfort or anxiety to the point that they needed to be referred for counselling.

This study aimed to explore how carers of children only diagnosed with CP access services. These carers of children with CP might require the most assistance to access services, as they were likely to experience more barriers around accessibility and might be more creative in their efforts to access these services than the carers of children with other disabilities. Focusing on these participants might potentially benefit carers of children with other disabilities, which assists with the justice of the study.

Findings

Table 1 shows that the ages of the seven carers who participated in the study ranged between 36 and 64 years.

Table 1: Demographic data of participant-carers and their children with CP

Participant code	Age of participant	Gender of participant	Home Language	Status of employment	Marital Status	Nr of years attending advanced seating services clinic	Age of child with CP (years)	Gender of child with CP
P1	36	Female	Afrikaans	Employed	Married	12	16	Female
P2	40	Female	Afrikaans	Employed	Single	12	14	Female
P3	40	Female	Afrikaans	Unemployed	Married	5	17	Female
P4	59	Female	IsiXhosa	Unemployed	Single	16	17	Male
P5	64	Female	Afrikaans	Unemployed	Married	10	41	Female
P6	45	Male	Afrikaans	Part-time employed	Married	13	13	Male
P7	49	Female	Afrikaans	Unemployed	Married	10	26 & 16	Male & male

Table 2 illustrates the four themes that emerged from the data '*A strenuous experience; Transport; The child and the buggy and Facilitators to access*' and the subthemes under each.

Table 2: Themes and Subthemes

	Themes	Subthemes
1	A Strenuous experience	Long, difficult day Careful planning and preparation
2	Transport	Public transport Private transport Subsidised Transport
3	The child and the buggy	The child grew bigger and heavier Size and weight of posture support wheelchair
4	Facilitators to access	Commitment of the carer Spirituality Support

Theme 1: A strenuous experience

The participants said that visiting the advanced seating clinic at the tertiary healthcare facility was a demanding and worrisome experience.

“Just to bring her here is very difficult.” – P3

Their narratives spoke of a *long, difficult day*. They needed to start very early to prepare the child and often arrived home very late.

“When we bring her to [name hospital], we have to rise at 3 o’clock to get her ready...the washing and dressing takes very long, because she cannot help any more...and then we spend the whole day here [at the hospital].” – P5

Participants had to *carefully plan and prepare for the day*. Some arrangements like transport had to be made weeks or months in advance with a reliable person.

“...Two months before her date, I have to get someone...a vehicle...it is someone specific who is reliable, who I can ask “come and fetch me at six o’clock on that morning.” – P3

Transport money must be saved in advance.

“I put it (money from the child support grant) aside, then I know that it is (for) her transport.” – P3

Participants who were employed had to negotiate time-off with their employers.

“Yes, we take a day off. I go to work on a Sunday. I count stock. Then I always take those days for [name child] to do her hospital stuff...my husband does not have that privilege. He takes family responsibility-leave every time.” – P1

Not only did the participant need to prepare the child with CP for the appointment, but must also ensure that other children in the household were taken care of.

“We have a 13-year-old son, who leaves the house at half-past six and a six-year-old, who I have to get to the school before eight. After that I come...to the hospital.” – P1

One participant said that if she was unable to find someone to care for the school-going child, the child would be kept out of school to attend the appointment with them.

“...if there is nobody, we bring her with. Then she just stays out of school for the day. But I will tell the teacher the previous day. And I get a letter from the doctor.” - P7

Theme 2: Transport

Transport was the greatest challenge that the participants experienced when accessing the advanced seating clinic. They voiced concerns with all forms of transport but found using *public transport* especially trying.

When using a *bus*, the biggest struggle for participants was manoeuvring the big support wheelchair (the buggy as participants called it) and a child with CP up the high steps and into the narrow aisle.

“Golden Arrow has the steps...you climb into the bus and then you have to take a turn to the seats. And the wheelchair is too big.” – P5

Participants had to pay for the child with CP even if the child sat on their lap.

“And then he told me I need to pay for her because she is over three years old. I said she does not take a seat; she is sitting on my lap. I was so shocked to think that this child does not take a seat away. The child is sitting on my lap. Why does this child need to pay? She does not take a seat. She does not take up space.” – P3

Participants also had to pay extra for the posture support wheelchair, as it takes up space in the bus.

“It (the buggy) takes up space...especially such a big thing that takes up space where people can sit. Then naturally we must pay for it.” - P6

One participant used the *train* to travel to the tertiary healthcare facility. She preferred to use the train as there was a wheelchair accessible station very close to her home and the train fare was affordable.

“We walk a short distance then we are at the station. They built a ramp at the Eerste River station. It is very comfortable...we save by using the train instead of other transport. We budget a R100 for train-fare and then we also buy something to eat.” – P1

The participant described some problems when travelling by train: trains were crowded during peak travelling times and were not always on time.

“In the morning it’s fine to use the train, as the trains are not that full (after 8 o’clock)...maybe two o’clock, three o’clock, the trains are already full. Then we have to stand and wait till six o’clock the evening for a carriage that does not have that many people, and then we can get in. There is pushing and shoving in the train...and in the mornings the train can be late.” – P1

Another concern for this participant was that the train station at the tertiary healthcare facility was not wheelchair accessible.

“[name station] has steps...there is not a ramp or something...that is comfortable for the wheelchair...It is very difficult for me to get down those steps...It is a struggle for me when I am alone at the train station at [name hospital] with those steps.” – P1

She also felt unsafe when walking from the station to the hospital and chose to miss appointments if her husband could not accompany her.

“I am scared...because I have been robbed at the station before....my husband must come with us every time...scoundrels always sit at [name hospital]’s bridge.” – P1

Other participants gave various reasons for not travelling by train to the tertiary healthcare facility.

“I can tell you that coming by train to [name hospital] with the buggies, is a nightmare...I will not do it. Not on my own. Just to think about those steps...you have to go over the bridge. A lot of steps up and then down and then again on the other side...there are no ramps for wheelchairs. There are no facilities like that.” -P7

“The trains are full. There are too few trains. Sometimes the trains do not come.” – P6

All participants raised concerns regarding the use of *minibus taxis*, in particular the size of the posture support wheelchair.

“The buggy is the problem. It will not go into the taxi. The seat she is sitting in will fit, but the bottom part is the problem.” – P2

Participants also experienced negative attitudes from taxi drivers and even from passengers. Some drivers did not stop to pick up the participant with the child in the posture support wheelchair or charged them extra for the wheelchair.

“The taxi [driver] would indicate that I must wait for the next one. I must disassemble this...it takes more space in the taxi, I must pay for a seat. I must pay for [name child] seat; I must pay for my seat.” – P4

“It scares me a bit to ride in the taxi because it feels to me that we are delaying them and for them it is all about making money. Now I have to dismantle the chair...that chair will basically take two seats...it is too much, and I will say no...it will not be fair towards [child with CP]...you might have to deal with a driver and his assistant who is in a rush. The passengers in the taxi also get frustrated. They want to get to work...and then I feel that I am the reason that they might lose money or something. I wouldn't say that I feel inferior. It is just how I feel. I do not want to be a burden on other people. I have to be rushed and quick...and in the process he might get hurt because you are rushed to climb into the taxi...you have to take all of this into consideration.” – P6

Some of the participants were aware of *Uber* services which are on the rise.

“I have heard about Uber...that is an alternative. Yes, that is a good option...if I have to consider using public transport, Uber is a better option.” – P6

Some participants were concerned regarding the use of the service, especially due to the size of the posture support wheelchair.

“I do not know if the buggy will fit in the Uber.” – P3

Other participants were unsure if the services would be cheaper.

“But only if it fits the budget. Everything costs money.” – P7

Participants often preferred to make use of *private transport* to access the tertiary healthcare facility. When hiring private transport, participants needed to consider arranging it well in advance with a reliable person, the costs involved, and that sufficient space would be available for the posture support wheelchair, the child with CP and the participant.

“I have to find someone with a utility vehicle to take us to the hospital...sometimes it is a bit difficult. If I ask one person, then he says no he cannot...we have to worry about the person that said he will bring us...He did say yes, but is he going to arrive...I have to sit in front with her because she is tall. We do not sit comfortably.” – P2

Participants had mixed opinions about the cost of private transport. Some said it was expensive, while others, who had support from family and friends, indicated that it was cheap.

“I hire a car. I pay R300...It makes it easy for me because if I say at 8:30 he’s there at 8:30.” – P4

“Is not that expensive. We give...it depends...sometimes my uncle will drive for free. Or my father-in-law will drive for free, and he says put in R50 petrol.” – P6

One participant said that public transport posed a health risk for the child.

“If it is windy or cold or rainy. Especially if you travel by train or taxi or by bus. It can affect him in terms of he can get sick...and we are very careful to rather travel by car. Because it carries less risk for him to get sick or catch a cold.” – P6

Participants were aware of and previously made use of *subsidised transport* such as Dial-a-ride. While they agreed that this type of service was a good idea, they experienced problems with the timetable and the transport’s administrative service.

“...Dial-a-ride...the timing throws a person out. If my appointment is for 8 o’clock, then Dial-a-ride will only arrive half past 9...because they first pick up the people who work and

the children who have to go to school...And then they come to fetch the people that need to go to the hospital, but then my appointment is already at 8 o'clock. That (Dial-a-ride) I have excluded now. They are also cheap...like I never paid for myself in those days. I did not pay for the child." – P3

One participant explained the paradoxical situation she finds herself in regarding the subsidised transport system. She needed a letter from the healthcare facility, however, was unable to get to the healthcare facility.

"I inquired at Dial-a-ride. They told me that I have to be placed on a waiting list and I have to get a letter from the hospital...for the application that I have to complete...I had to come here for that letter. But there was no transport...Then they delayed and delayed. Because they went over to a different system...different people took over. And nothing happened from that." – P5

Some of the participants were aware of HealthNET services, but did not know how to access the services or were denied the services.

"...I once phoned the bus. Those people that bring you to the hospital. Then they told me that the service is not for us..." – P7

Theme 3: The child and the buggy

According to participants, accessing the seating-clinic became increasingly difficult as *the child grew bigger and heavier*.

"...She is tall, she is heavy. I cannot carry her as I carried her before." – P2

As previously stated under the transport section the *size and weight of the posture support wheelchair* caused a major access barrier when using public transport. Even with private transport the buggy size and weight had to be taken into consideration.

"The buggy is the problem because it cannot fold up...the problem with the buggy is the bottom part. Sometimes it does not fit in the car...it is not easy to get here if I have to come with the buggy. It is very difficult." – P2

A mother with two children with CP explains further.

“It is the “cars” (buggies) that needs to fit in...we have to take the spare wheel out of our car to get the “cars” to fit...because [name eldest child]’s “car” is very big. He takes up all the space in the back...Then we put [name younger child] in his buggy in the car, [name eldest child] sits in the front, then his buggy comes in and then I sit in the back, scrunched.”
– P7

Theme 4: Facilitators to access

Participants reported that some things made it easier to access the tertiary healthcare facility. The first of these was the *commitment of the carers* who had their child’s best interest at heart and were attentive to the child’s health and well-being.

“We see it as our responsibility that we have to attend the appointments...it is important, and it is part of how we can better his living conditions and help him because we do not know everything.” – P6

Participants also draw strength from their *spirituality* and faith.

“...I can always just thank God...I place all my trust in God.” -P6

Participants received *support* from their partners, families, friends and community members when accessing the services.

“His father makes it very easy for us.” - P7

“Yes, our family. We have a strong family bond in terms of support...yes, in terms of the family and friends’ bond. We have a large support network...and there are my family uncles, you know. My uncle brought us in the past. My friends. So, there is a large network. Again, the support network is strong. Friends, family...even the church.” - P6

“...I have friends who make their cars available...so there is enough transport...my friend...this morning he had to be somewhere with his car...when he heard last night that we have to be here, he said no whatever he had to do could wait. Get your child to the hospital. We can also just take my brother’s car or my friend’s car...very calmly, my wife

can get into the car, I can dismantle the thing, without any risks or worry...no problem for other people.” – P6

One participant explained that she felt safer when her partner assisted her.

“It is just me and her dad...always helps me at the train and at the steps by [name hospital]...it feels safer.” - P1

Another participant explained that he and his wife shared the burden of care and always attended the seating appointment together. He resigned his work to assist with caregiving duties.

“Because we have this bond, we both look after him. Go to the day-hospital together. Everything that we do for him, we do together...this is where teamwork comes in.” – P6

Although some participants reported that they experienced negative attitudes from community members when they were attempting to access the tertiary healthcare facility, other participants experienced positive assistance.

“I usually ask them, otherwise they offer themselves.” – P1

One participant reported that she received assistance from a local Non-governmental organization (NGO) who aids carers of PWD.

“The assistance I receive...from Iris House because they send me a carer. Maybe I come to the hospital or I’m going to do shopping, they send me carers. It’s a good thing when people give me support, that’s something to me...It makes me feel good. It’s a relief for me on that day.” – P4

One of the participants stated that she really appreciated that people care about her and her child with CP, however, she did not want to depend on them too much.

“...It makes a person feel good. There are people that care...but sometimes you do not want to depend on family. It looks like you want everything...they give a finger and then you want to grab the whole hand...It is not nice to always...depend on the family’s support.

You want to be alright...I will always try and see if I can find a way to get someplace.” – P7

One of the participants asked for a community outreach programme to assist with the follow-up of the posture support wheelchair.

“If you can come out and check if everything is still fine...” – P1

Discussion

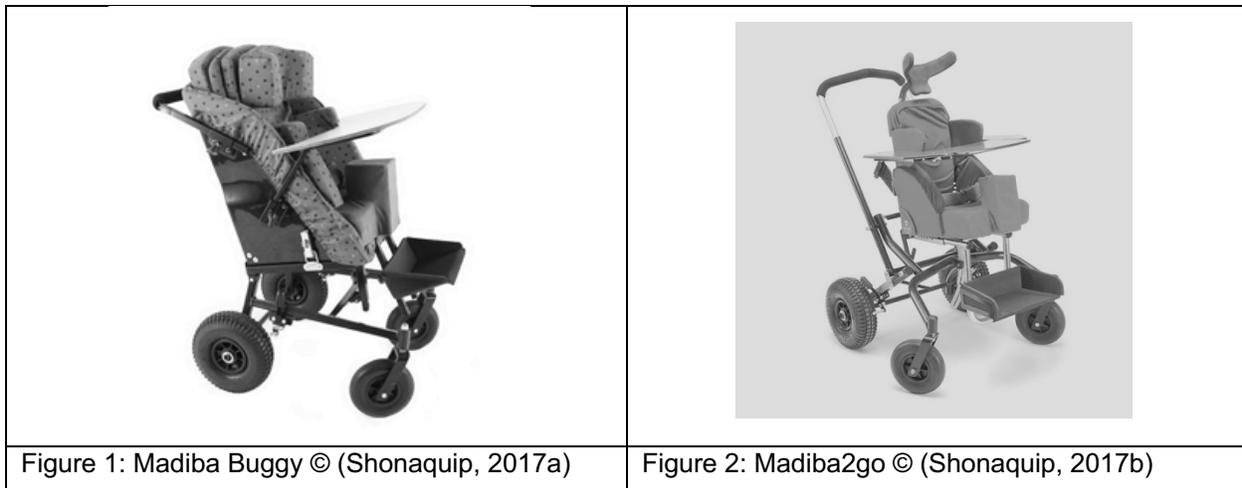
A strenuous experience

It was clear from the findings that the carers experienced a great deal of stress around accessing the tertiary healthcare facility for the seating appointment. Careful preparation and planning needed to take place weeks in advance, such as arranging time off with employers, booking reliable transportation and putting aside money for the visit that takes a full day.

Appropriate posture support wheelchair (the child and the buggy)

It is important that a child's posture in the posture support wheelchair is reviewed every six months so that repairs, adaptations and replacements can be made to ensure comfort and stability as the child grows and support needs change (WHO, 2008). However, transporting a child with severe physical impairments as well as a cumbersome posture support wheelchair was difficult. The posture support wheelchair, an important reason why the child needed to attend the advanced seating clinic, was also one of the biggest barriers to accessibility.

The most commonly prescribed posture support wheelchair for children with CP (GMFCS IV/V) in the Western Cape is the Madiba buggy © (See figure 1). It is designed for children who need more postural support than a traditional wheelchair can provide. The posture support wheelchair offers modular, full body and head support cushions, which can be configured to optimally fit young and growing bodies, an adjustable tilt-in-space feature and large off-road wheels (Shonaquip, 2017a). According to the carers, the design characteristics of the Madiba buggy © (rigid fibre-glass seat and back unit, adjustable foam inserts, and rigid base), make it difficult to transport as it is heavy and does not fold and/or break down into a smaller unit or units. This device comes in the sizes baby 1, baby 2, small, medium and large.



The Madiba2go© posture support wheelchair is available on government tender (See figure 2). This posture support wheelchair offers rigid, adjustable full-body and head support, tilt-in-space and backrest recline. The special feature of the Madiba2go© is the rugged, folding base frame, making it easier to transport and store (Shonaquip, 2017b). The Madiba2go© comes in the sizes baby 1, baby 2, small, medium and large, but costs 15% more than the more commonly prescribed Madiba buggy © (South African Treasury, 2017). Prescribing the latter posture support wheelchair would assist carers with transport but carries cost implications for the healthcare facility and provincial government. However, a 15% price difference is not excessive and might not influence the number of people who can be assisted.

In some cases, the child/adult with CP is too large for the largest size of the Madiba buggy© and Madiba2go© and will be prescribed with a basic, folding-frame wheelchair with posture support devices attached, such as a headrest, height adjustable armrest, tray-table, and back support system. The basic folding-frame wheelchair with its posture support devices might, in some instances, cost more than a single Shonaquip device (CE Mobility, 2019; South African Treasury, 2017). The basic folding-frame wheelchair will, however, be easier to break down into smaller units for travel purposes. In South Africa the healthcare budget is under strain and decisions regarding service provision must include costs and need (Bateman, 2012; Visagie, Scheffler & Schneider, 2013). In this

instance, therapists might need to choose between providing more people with a device that does not allow easy travel or providing fewer with a device that does.

A long waiting-list and delayed provision also influences the decision of therapists on which devices could be issued (Visagie, et al, 2013). The commonly prescribed buggy is also more familiar to service providers and carers, as it has been on the tender list for a long time (approximately 25 years). Due to this familiarity, service providers might prescribe the buggy 'out of habit' (Visagie, Duffield & Unger, 2015).

Transport

However, wheelchairs should be appropriate and allow access to transport. An appropriate posture support wheelchair is a instrument to obtain basic human rights, such as the means to access healthcare services, reduce the need to hire private transport, and reduce the burden of care (DoH, 2003; WHO, 2008; Geere, et al., 2012).

The design of public transportation – trains, buses and minibus taxis – does not accommodate wheelchair users (Donald, et al., 2014; Pretorius & Steadman, 2017). This suggests the requirement to improve public transport vehicles' accessibility in accordance with national policy documents, as discussed in the literature review, and by adhering to principles of universal design. However, this endeavour will be costly (McManus, Michelsen, et al., 2006).

As identified by other studies, wheelchairs were not always allowed on board minibus taxis by operators (Grut, et al., 2012; Cawood & Visagie, 2015; Ntamo, et al., 2013; Vergunst, et al., 2015; Pretorius & Steadman, 2017). Lister and Dhynpath (2016:32) argued that the reason why taxis refused to transport PWD was that in order *“to maximise profits, taxi operators may ignore the elderly, women and children and PWD. These groups are seen as a burden because they take longer to board, compromising the driver’s ability to transport more able-bodied customers in order to improve their take-home pay.”* Some taxi operators might also exploit PWD by charging an extra fee for the wheelchair (Venter, Bogopane, et al., 2002; National Department of Transport, 2012; Grut, et al., 2012; Cawood & Visagie, 2015; Ntamo, et al., 2013; Vergunst, et al., 2015;

Pretorius & Steadman, 2017). This places an extra financial burden on the carers and other wheelchair users. Transport costs are already doubled as carers have to pay for themselves and their children. The addition of the posture support wheelchair will triple the cost. Minibus taxis operating within the City of Cape Town are privately owned; their services are less regulated, and owners are not required by law to conform to the principle of universal design (National Department of Transport, 2012; Venter, et al., 2002). Taxi operators might not feel obligated to render a transport service to persons with physical disabilities.

The stress caused by the whole experience of accessing transport, influences not only the carers, but might also affect the children with CP. When children with CP experience stress for any reason an increase in spasticity usually follows, and feeling rushed to get into a taxi, might trigger such a response (Bhimani, McAlpine & Henly, 2012). This might cause further delay getting into the taxi and create difficulty with the taxi-operator. One carer was concerned that the child might get injured in the process.

This study found that carers did not commonly utilize the bus as a mode of public transport as the steps used to board Golden Arrow buses posed a barrier for people with mobility impairments, similar to findings by Venter et al. (2002). Bus operators also used their own discretion to charge a fee for the posture support wheelchair. The MyCiti bus service is the only accessible public transport system in Cape Town that adheres to universal design and caters to the needs of PWD (Morta-Andrews, 2018). However, the MyCiti bus services can only accommodate one or two wheelchairs at a time and only cover certain sections of the city (Morta-Andrews, 2018). In the current study, none of the participants had experience of using this service.

Travelling by train is an affordable form of transport, but the limitations associated with travelling by train outweighed the benefits. Several carers commented on the lack of ramps at some train stations. In the current study, this was a particularly big problem as one had to negotiate flights of stairs to cross the bridge over the railway lines at the station closest to the hospital. The absence of ramps or subways which created barriers to rail

transport was also mentioned by participants in other studies (Venter, et al., 2002; Cawood & Visagie, 2015; Singogo, et al., 2015).

Safety *en route* from the station to the hospital was another concern in the violent society of the Western Cape where robbery is a common occurrence (South African Police Service (SAPS), 2017). Females are seen as especially easy targets for thieves, due to the fact that they are regarded as easier to subdue and thus requiring less violence when targeted by perpetrators (SAPS, 2017). Fear of being attacked and actual narratives of attacks have been described by Scheffler, Visagie and Schneider (2015).

The above-mentioned issues and the stress that it caused contributed to the decision of most carers in this study to hire private transport, similar to earlier findings (Donald, et al., 2014; Dambi, Mlambo & Jelsma, 2015; Singogo, Mweshi & Rhoda, 2015; Pretorius & Steadman, 2017). The carers in this study had mixed experiences regarding the costs of private transport. While those who received support from family and friends found it affordable, others found it more expensive than public transport. Other studies found that hiring private transport was expensive and could cause a financial burden (Hansen, et al., 2014; Singogo, et al., 2015; Simpamba, et al., 2016; Pretorius & Steadman, 2017). Even when hiring private transport, the size of the posture support wheelchair was a concern as it does not fit into all vehicles.

None of the carers received any assistance from subsidised transport. Although HealthNet and Dial-a-ride services are available, carers were unable or unaware of how to access the services. This challenge was previously noted by Barratt and Penn (2009), Cawood and Visagie (2015) and Maart and Jelsma (2013). Members of Dial-a-ride have raised concerns in the media. Challenges were highlighted and included an ineffectual booking system (Ground Up News, 2016), a permanently engaged toll-free number (IOL News, 2006), transport arriving too early or late, and commuters missing their transport (Ground Up News, 2017). Participants in the current study were unable to even register for these services.

Facilitators to access

The carers stated that as a constant part of their role as parent, they have their child's best interest at heart and that seek ways to access the healthcare facility.

They described how their trust in God, prayer and deep, spiritual faith gave them strength and internal 'drive' when faced with these challenges. Spirituality has been described as a strategy to overcome barriers by Hansen, et al. (2014) and Van der Mark and Verrest (2014) and for emotional satisfaction (Gona, Mung'ala-Odera, et al., 2011). One carer also described getting external spiritual support from the church, which was also previously found by Hansen, et al. (2014).

Findings on support by partners and other family members is similar to findings by Simpamba, et al., (2016). A Non-governmental organisation also helped one carer in the form of assistance and relief by caring for other children with disabilities in the household. This correlates with findings by Gona et al. (2011) where external support was provided to carers.

Carers in this study also reported that friends and neighbours assisted them in accessing the healthcare facility by lending their vehicles. Even strangers on their way to the healthcare facility assisted them. This was previously noted in the literature as a few mothers experienced support from extended family in the form of financial assistance to pay for transport (Simpamba, et al., 2016).

Limitations

The sample comprised individuals who resided within a 100km radius of the tertiary healthcare facility, people who have to travel further might experience greater challenges. This decision was due to time constraints of the research assignment. Carers were mainly Afrikaans speaking and from only two sub-districts, thus a more homogenous sample than was ideal.

Recommendations

Service providers must be made aware of the challenges that the Madiba buggy© poses to using public transport and should consider prescribing the Madiba-to-go© or basic folding frame wheelchair with posture support devices in instances where the family is dependent on public transport.

The South African White Paper on National Transport Policy (1996), the White Paper on Provincial Transport Policy (1997) and National Land Transport Transition Act 2 of 2000 regarding the transport needs of PWD needs to be implemented. Areas of specific focus should include buses with lower steps, hydraulic 'kneeling' devices to tilt or lower the front axle down to normal curb height, reserved seating on buses and train carriages, and ramps and subways at train-stations. Further consideration should also be given for legislation to be enacted which exempts PWD from paying a fare for the assistive device (Morta-Andrews, 2018).

It is recommended that in the attempt to improve transport services for PWD, the MyCiti bus services routes be expanded to include this and other tertiary healthcare facilities.

Seating service providers should consider providing outreach services to various communities. Some structural barriers that affect access to healthcare facilities will be removed when rehabilitation services and resources are decentralised (Wegner & Rhoda, 2015).

Recommendation for future research:

- A study on the feasibility of therapists providing follow-up seating services through outreach clinics in communities;
- A study on public transport providers' attitudes on providing transport to wheelchair users;
- Explore the costs and feasibility of ramps at train-stations;
- Explore the possible interest in a subsidy system for taxi operators for each PWD that they transport.

Conclusion

Although carers received support from different facilitators to enable access to the tertiary healthcare facility, it was still apparent that the carers experienced several barriers that made it taxing to access the tertiary healthcare facility to attend the advanced seating clinic, especially transport. The findings of this study affirmed that most public transportation services and systems do not accommodate carers and their children with CP and are inaccessible for them and the posture support wheelchair. Carers were worried about the negative effect of stress of using public transport on the children's health. There is thus a great need to improve the current public transport systems to be more inclusive and accessible.

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References

Adams, C. & Van Manen, M. 2008. 'Phenomenology', in Given, LM (ed.), *The SAGE encyclopedia of qualitative research methods*, Thousand Oaks, California: SAGE Publications Inc., 615-619, [Accessed 17 March 2018], doi: 10.4135/9781412963909.n317.

Angsupaisal, M., Maathuis, C.G. & Hadders-Algra, M. 2015. Adaptive seating systems in children with severe cerebral palsy across International Classification of Functioning, Disability and Health for Children and Youth version domains: a systematic review. *Developmental Medicine & Child Neurology*, 57(10): 919-930.

Barratt, J.F. 2008. *The experience of caring for a child with cerebral palsy in Tonga, Mpumalanga: caregivers' stories*. Unpublished Masters dissertation, University of the Witwatersrand, Johannesburg, South Africa.

Barratt, J. & Penn, C. 2009. Listening to the voices of disability: Experiences of caring for children with cerebral palsy in a rural South African setting. In M. MacLachlan & L. Swartz (Eds.), *Disability & international development* (pp. 191–212). New York: Springer.

Bateman, C. 2012. 'One size fits all' health policies crippling rural rehab: therapists. *SAMJ: South African Medical Journal*, 102(4):200-208.

Bax, M., Goldstein, M., Rosenbaum, P., Leviton, A., & Paneth, N. 2005. Proposed definition and classification of cerebral palsy. *Developmental Medicine & Child Neurology*, 47: 571–576.

Bhimani, R.H., McAlpine, C.P. & Henly, S.J. 2012. Understanding spasticity from patients' perspectives over time. *Journal of advanced nursing*, 68(11): 2504-2514.

Bourke-Taylor, H., Howie, L. & Law, M. 2010. Impact of caring for a school-aged child with a disability: Understanding mothers' perspectives. *Australian Occupational Therapy Journal*, 57(2):127-136.

Braun, V. & Clarke, V. 2006. Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2):77-101.

Burg, J. 2016. *Development of a self-care inventory for children with cerebral palsy living in poorly resourced contexts in South Africa*. Unpublished Masters dissertation, University of the Witwatersrand, Johannesburg, South Africa.

Burkhard, A. 2013. A different life: caring for an adolescent or young adult with severe cerebral palsy. *Journal of pediatric nursing*, 28(4):357-363.

Cawood, J. and Visagie, S. 2015. Environmental factors influencing participation of stroke survivors in a Western Cape setting. *African journal of disability*, 4(1).

CE Mobility. 2019. *Standard-Economy Wheelchair Products*. [Online] Available: <http://www.cemobility.co.za/Wheelchairs/Sub-Category/16/Standard-Economy.php> [Accessed 1 July 2019].

Couper, J. 2002. Prevalence of childhood disability in rural KwaZulu Natal. *South African Medical Journal*, 92(7):549-552.

Dambi, J.M., Mlambo, T. & Jelsma, J. 2015. Caring for a child with cerebral palsy: The experience of Zimbabwean mothers. *African journal of disability*, 4(1):1-10.

Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K. & Davern, M. 2010. The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. *Child Care Health Dev*, 36(1):63-73

Department of Health (DoH), 2003. *Standardisation of provision of mobility assistive devices in South Africa*, Department of Health, Pretoria.

Department of Health (DoH), 2015a. *Framework and strategy for disability and rehabilitation services in South Africa (2015–2020)*. [Online] Available at: http://ilifalabantwana.co.za/wp-content/uploads/2016/07/Framework-25-may_1_3.docx. [Accessed 17 November 2017].

Department of Health (DoH), 2015b. *Ethics in health research: Principles, processes and structures*. [Online] Available at: <http://www.commerce.uct.ac.za/Downloads/Ethics%20in%20Health%20Research%20Final%20A%20used.pdf> [Accessed 5 May 2018].

Department of Transport. 1996. *White Paper on National Transport Policy*. Pretoria: Department of Transport.

Department of Transport. 1997. *White Paper on Western Cape Provincial Transport Policy*. Western Cape Government: Department of Transport.

Domholdt, E. 2005. *Rehabilitation research: principles and applications* 3rd ed., St. Louis, Mo.: Elsevier Saunders.

Donald, K.A., Samia, P., Kakooza-Mwesige, A. & Bearden, D. 2014. Pediatric cerebral palsy in Africa: a systematic review. *Semin Pediatric Neurol* 21(1):30-35.

Eide, A.H., Mannan, H., Khogali, M., Van Rooy, G., Swartz, L., Munthali, A., Hem, K.G., MacLachlan, M. & Dyrstad, K. 2015. Perceived barriers for accessing health services among individuals with disability in four African countries. *PLoS One*, 10(5).

Eunson, P. 2012. Aetiology and epidemiology of cerebral palsy. *Paediatrics and Child Health*, (22):361–366.

Geere, J.L., Gona, J., Omondi, F.O., Kifalu, M.K., Newton, C.R. & Hartley, S. 2012. Caring for children with physical disability in Kenya: potential links between caregiving and carers' physical health. *Child Care Health Dev*, 39(3):81-392.

Gladstone, M. 2010. A review of the incidence and prevalence, types and aetiology of cerebral palsy in resource-poor settings. *Annals of Tropical Paediatrics*, (30):181–196.

Gona, J.K., Mung'ala-Odera, V., Newton, C.R. & Hartley, S. 2011. Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? *Child: care, health and development*, 37(2):175-183.

Gorter, J.W., Rosenbaum, P.L., Hanna, S.E., Palisano, R.J., Bartlett, D.J., Russell, D.J., Walter, S.D., Raina, P., Galuppi, B.E. & Wood, E. 2004. Limb distribution, motor impairment, and functional classification of cerebral palsy. *Developmental medicine and child neurology*, 46(7):461-467.

GroundUp News. 2016. *Public transport is a nightmare for the disabled*. [Online] Available at: <https://www.groundup.org.za/public-transport-nightmare-disable/> [Accessed: 3 March 2019].

GroundUp News, 2017. *Dial-A-Ride users say the service is deteriorating*. [Online] Available at: <https://www.groundup.org.za/article/dial-ride-users-say-service-deteriorating/> [Accessed: 3 March 2019].

Grut, L. Mji, G., Braathen, SH. & Ingstad, B. 2012. Accessing community health services: challenges faced by poor people with disabilities in a rural community in South Africa. *African Journal of Disability*, 1(1) 19.

Haak, P., Lenski, M., Hidecker, M.J.C., Li, M. & Paneth, N. 2009. Cerebral palsy and aging. *Developmental Medicine & Child Neurology*, 51:16-23.

Hanna, S.E., Rosenbaum, P.L., Bartlett, D.J., Palisano, R.J., Walter, S.D., Avery, L. & Russell, D.J. 2009. Stability and decline in gross motor function among children and youth with cerebral palsy aged 2 to 21 years. *Developmental Medicine & Child Neurology*, 51(4):295-302.

Hayles, E., Harvey, D., Plummer, D. & Jones, A. 2015. Parents' experiences of health care for their children with cerebral palsy. *Qualitative health research*, 25(8):1139-1154.

Huang, I.C., Sugden, D. & Beveridge, S. 2009. Assistive devices and cerebral palsy: Factors including the use of assistive devices at home by children with cerebral palsy. *Child: Care, Health and Development*, 35(1):130-139.

IOL News. 2006. *Wheels coming off Dial-A-Ride*. [Online] Available at: <https://www.iol.co.za/news/south-africa/wheels-coming-off-dial-a-ride-for-disabled-286382> [Accessed: 31 March 2019].

Kahonde, C.K., Mlenzana, N. & Rhoda, A. 2010. Persons with physical disabilities' experiences of rehabilitation services at Community Health Centres in Cape Town. *South African Journal of Physiotherapy*, 66(3):2-7.

Kim, Y. 2011. The pilot study in qualitative inquiry: Identifying issues and learning lessons for culturally competent research. *Qualitative Social Work*, 10(2):190-206.

Lincoln, Y.S. & Guba, E.G. 1985. *Naturalistic inquiry* (Vol. 75). Beverly Hills, California: Sage.

Liptak, G.S. 2008. Health and well-being of adults with cerebral palsy. *Current opinion in neurology*, 21(2):136-142.

Lister, H.E. & Dhunpath, R. 2016. The taxi industry and transportation for people with disabilities: implications for universal access in a metropolitan municipality. *Transformation: Critical Perspectives on Southern Africa*, 90(1):28-48.

Maart, S. & Jelsma, J. 2013. Disability and access to health care—a community based descriptive study. *Disability and Rehabilitation*, 36(18):1489-1493.

Mabuza, L.H., Govender, I., Ogunbanjo, G.A. & Mash, B. 2014. African Primary Care Research: Qualitative data analysis and writing results. *African journal of primary health care & family medicine*, 6(1):1-5.

McDonald, R., Surtees, R. & Wirz, S. 2004. The International Classification of Functioning, Disability and Health provides a model for adaptive seating interventions for children with cerebral palsy. *British Journal of Occupational Therapy*, 67(7):293-302.

McManus, V., Michelsen, S. I., Parkinson, K., Colver, A., Beckung, E., Pez, O., & Caravale, B. 2006. Discussion groups with parents of children with cerebral palsy in Europe designed to assist development of a relevant measure of environment. *Child: Care, health and development*, 32:85–192.

Merriam, S. 1995. What Can You Tell From An N of 1?: Issues of validity and reliability in qualitative research. *PAACE Journal of lifelong learning*, 4: 50-60.

Mlenzana, N.N., Frantz, J.M., Rhoda, A.J. & Eide, A.H. 2013. 'Barriers to and facilitators of rehabilitation services of people with physical disabilities: A systematic review'. *African Journal of Disability*, 2(1).

Mitra, S., Posarac, A. & Vick, B. 2012. Disability and poverty in developing countries: a multidimensional study. *World Development*, 41: 1-18.

Morrow, S.L. 2005. Quality and trustworthiness in qualitative research in counseling psychology. *Journal of counseling psychology*, 52(2):250.

Morta-Andrews, N. 2018. *A case study of transport services for physically disabled citizens in the city of Cape Town*. Unpublished Masters dissertation, University of the Western Cape, Cape Town, South Africa. <http://hdl.handle.net/11394/6273>

MyCiti. 2019. *Special Needs*. [Online] Available: <https://myciti.org.za/en/passenger-information/universal-accessibility/special-needs/> [Accessed 5 July 2019].

National Department of Transport, 2012. *Making public transport universally accessible for all: Portfolio committee on women, children and people with disabilities*. South Africa: National Department of Transport.

National Land Transport Transition Act 22 of 2000. *Government gazette*. 422 (21493). 23 August. Government notice no.844. Pretoria: Government Printer.

Ndadzungira, A. 2016. *The experiences of primary caregivers caring for children with physical disabilities in Hardap region of Namibia* (Doctoral dissertation).

Noble, H. & Smith, J. 2015. Issues of validity and reliability in qualitative research. *Evidence-based nursing*, 18(2):34-35.

Ntamo, N. P., Buso, D. L., & Longo-Mbenza, B. 2013. Factors affecting poor attendance for outpatient physiotherapy by patients discharged from Mthatha general hospital with a stroke. *South African Journal of Physiotherapy*, 69(3):19-24.

O'Leary, Z. 2017. *The essential guide to doing your research project*, 3rd edn., Sage. Los Angeles, London, New Delhi, Singapore, Washington DC, Melbourne.

Pakula, A.T., Braun, K.V.N. & Yeargin-Allsopp, M. 2009. Cerebral palsy: classification and epidemiology. *Physical Medicine and Rehabilitation Clinics*, 20(3):425-452.

Palisano R, Rosenbaum P, Bartlett D & Livingston M. 2007. The Gross Motor Function Classification System – Expanded and Revised. CanChild Centre for Childhood Disability Research. [Online] Available at:

https://canchild.ca/system/tenon/assets/attachments/000/000/058/original/GMFCS-ER_English.pdf [Accessed 29 June 2019]

Parnes, P., Cameron, D., Christie, N., Cockburn, L., Hashemi, G. & Yoshida, K. 2009. Disability in low-income countries: issues and implications. *Disability and Rehabilitation*, 31(14):1170-1180.

Pretorius, C. & Steadman, J. 2017. Barriers and Facilitators to Caring for a Child with Cerebral Palsy in Rural Communities of the Western Cape, South Africa. *Child Care in Practice*, 1-18.

Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S.D., Russell, D., Swinton, M., Zhu, B. & Wood, E. 2005. The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115(6): e626-e636.

Resch, J.A., Mireles, G., Benz, M.R., Curenwelge, C., Patterson, R. & Zhang, D. 2010, Giving parents a voice: Qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology*, 55:139-150.

Rhoda, A., Mpofo, R., & DeWeerd, W. 2009. The rehabilitation of stroke patients at community health centres in the Western Cape. *South African Journal of Physiotherapy*, 65(3):3-8.

Rosenbaum, P. & Stewart, D. 2004. The World Health Organization International Classification of Functioning, Disability, and Health: a model to guide clinical thinking, practice and research in the field of cerebral palsy. In *Seminars in pediatric neurology* (Vol. 11, No. 1, pp. 5-10). WB Saunders.

Saloojee, G., Phohole, M., Saloojee, H. & IJsselmuiden, C. 2007. Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township. *Child: care, health and development*, 33(3):230-235.

South African Police Service (SAPS), 2017, *Annual Crime Report 2016/2017*, [Online]

Available at:

https://www.saps.gov.za/about/stratframework/annual_report/2016_2017/gpw_crime_stats_2017.pdf. [Accessed 2 March 2019]

Scheer, J., Kroll, T., Neri, M., & Beatty P. 2003. Access barriers for persons with disabilities: the consumers' perspective. *Journal of Disability Policy Studies*, 13(4): 221-230. doi:10.1177/104420730301300404.

Scheffler, E., Visagie, S. & Schneider, M. 2015. The impact of health service variables on healthcare access in a low resourced urban setting in the Western Cape, South Africa. *African journal of primary health care & family medicine*, 7(1):1-11.

Schwandt, T.A., Lincoln, Y.S., & Guba, E.G. 2007. Judging interpretations: But is it rigorous? trustworthiness and authenticity in naturalistic evaluation. *New Directions for Evaluation*(114), 11- 25.

Shevell, M., Dagenais, L. & Oskoui, M. 2013. The epidemiology of cerebral palsy: new perspectives from a Canadian registry. In *Seminars in pediatric neurology* 20(2):60-64.

Shonaquip. 2017a. *Madiba Buggy*. [Online] Available:

<https://shonaquip.co.za/product/madiba-buggy/> [Accessed 31 March 2019].

Shonaquip. 2017b. *Madiba2go Buggy*. [Online] Available:

<https://shonaquip.co.za/product/madiba2go-buggy2/> [Accessed 16 April 2019].

Simpamba, M.M., Struthers, P.M. & Mweshi, M.M. 2016. Access to health care for children with neural tube defects: Experiences of mothers in Zambia. *African journal of disability*, 5(1):1-11.

Singogo, C., Mweshi, M. & Rhoda, A. 2015. Challenges experienced by mothers caring for children with cerebral palsy in Zambia. *South African Journal of Physiotherapy*, 71(1):6-pages.

South African National Treasury. 2017. RE233-2017 Contract circular, *Supply and delivery of wheelchair, seating systems, positioners and commodes to the State of the period 1 November 2017 to 31 October 2020*, Department of National Treasury, South Africa.

South Africa (Republic of). 1996. The Constitution of the Republic of South Africa. Pretoria: Government Printers.

Starks, H. & Trinidad, S.B. 2007. 'Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and Grounded Theory'. *Qualitative Health Research* 17(10): 1372–80.

Steadman, J. & Pretorius, C. 2015. *The experience of caring for a child with cerebral palsy in rural communities of the Western Cape, South Africa*. Unpublished Masters dissertation, Stellenbosch University, Faculty of Arts Social Science, Department of Psychology, Stellenbosch, South Africa.

Thabane, L., Ma, J., Chu, R., Cheng, J., Ismaila, A., Rios, L.P., Robson, R., Thabane, M., Giangregorio, L. & Goldsmith, C.H. 2010. A tutorial on pilot studies: the what, why and how. *BMC medical research methodology*, 10(1):1.

Thorne, S. 2000. Data analysis in qualitative research. *Evidence-based nursing*, 3(3):68-70.

Thrush, A. & Hyder, A. 2014. The neglected burden of caregiving in low-and middle-income countries. *Disability and health journal*, 7(3):262-272.

Tong, A., Sainsbury, P. & Craig, J. 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care*, 19(6):349-357.

Van der Mark, E.J. & Verrest, H. 2014. Fighting the odds: Strategies of female caregivers of disabled children in Zimbabwe. *Disability & Society*, 29(9):1412-1427.

Van Rooy, G., Amadhila, E.M., Mufune, P., Swartz, L., Mannan, H. & MacLachlan, M. 2012. Perceived barriers to accessing health services among people with disabilities in rural northern Namibia. *Disability & Society*, 27(6):761-775.

Venter, C., Bogopane, H., Rickert, T., Camba, J., Venkatesh, A., Mulikita, N., Maunder, D. Savill, T., & Stone, J. 2002. Improving accessibility for PWD in urban areas. *Proceedings: CODATU X. Lome*.

Vergunst, R., Swartz, L., Hem, K.G., Eide, A.H., Mannan, H., MacLachlan, M., Mji, G., Braathen, S.H. & Schneider, M. 2017. Access to health care for persons with disabilities in rural South Africa. *BMC health services research*, 17(1):741.

Vergunst, R., Swartz, L., Mji, G., MacLachlan, M. & Mannan, H. 2015. 'You must carry your wheelchair'—barriers to accessing healthcare in a South African rural area. *Global health action*, 8(1).

Visagie, S., Duffield, S. & Unger, M. 2015. Exploring the impact of wheelchair design on user function in a rural South African setting. *African Journal of Disability*, 4(1).

Visagie, S., Scheffler, E. & Schneider, M. 2013. Policy implementation in wheelchair service delivery in a rural South African setting. *African Journal of Disability*, 2(1).

Wegner, L. & Rhoda, A. 2015. The influence of cultural beliefs on the utilisation of rehabilitation services in a rural South African context: Therapists' perspective. *African Journal of Disability*, 4(1).

Western Cape Government, 2018a. *Tygerberg Hospital*. [Online]. Available: https://www.westerncape.gov.za/assets/departments/health/tygerberg_hospital_information_pamphlet_-_2016.pdf [Accessed 1 May 2019]

World Health Organisation (WHO), 2008. *Guidelines on the provision of manual wheelchairs in less resourced settings*.

WHO, 2010. *Increasing access to health workers in remote and rural areas through improved retention*. Geneva: World Health Organization.

Appendices

Appendix A: Study population

Study Population													
Number	Surname	Name for carer	Name of child with CP	Age of child with CP	Gender of child with CP	Folder number of child	GMFCS (IV/V)	Level of Seating	Suburb	Cape Town sub districts	Contact details (telephone)	Next appointment date	Number of missed appointments
1													
2													
3													
4													
5													
6													
7													
8													
9													
10													
11													
12													
13													
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17													
18													

Appendix B: English demographical information questionnaire

This form will be completed by the researcher in an interactive process.

Name and Surname:

Age:

Gender: Male/ Female

Home language:

Area of Residence:

Contact number:

Name of child with CP who you care for:

What is your relationship to the child with CP (mother, father, sister, aunt, uncle, etc.):

.....

How old is (name child) _____:

For how long have you and (name child) been attending the seating clinic (years):

Appendix C: English semi-structured interview schedule

- Welcome.
- Thanks for taking the time to come and share your experiences.
- Go through consent form together, sign.
- Complete demographical information form.
- Switch on the recorder.

Questions (with prompting questions in bullets):

1. Can you tell me about a typical day for you to bring (name child) to the seating clinic at Tygerberg Hospital.

- Are there any plans that you need to make before the day of the appointment? Work? Other children?
- How did you and (name child) get to the seating/doctor's appointment today?
- You mentioned _____, tell me what that was like for you.
- You mentioned _____, describe that in more detail for me.
- You mentioned _____, what were you thinking at that time when it happened?
- You mentioned _____, how did you feel when it happened?

2. What or who makes it easy for you to get to Tygerberg Hospital?

- Do you have a support system? Who or what assist you to get to this appointment?
- Do you receive any financial support? If so, where or whom? What do this process entail?
- Have you received any assistance from someone or an institute to get to this appointment? If so, who?
- You mentioned _____, tell me what that was like for you.
- You mentioned _____, describe that in more detail for me.
- You mentioned _____, what were you thinking at that time when it happened?
- You mentioned _____, how did you feel when it happened?

3. What or who makes it difficult for you to get to Tygerberg Hospital?

- Is it very expensive? Do you need to save money?
- Is it physically difficult to bring (name child) in?
- Are there any emotional experiences that make it difficult for you to attend the seating clinic, for example anger, frustration, sadness?
- You mentioned _____, tell me what that was like for you.
- You mentioned _____, describe that in more detail for me.
- You mentioned _____, what were you thinking at that time when it happened?
- You mentioned _____, how did you feel when it happened?

What is your experience with other types of transport?

Why do you use..... and not (train, taxi, private, Uber) ?

Do you have anything else you would like to tell me about this?

Do you have any questions?

If you have any concerns and any further questions, you can discuss it with me or support can be provided with a referral to a counsellor to the CHC or OT at the CHC. If you need to contact me afterwards, my details are on the consent form. You can also contact me at the OT department.

Give token of appreciation.

Greet and thank.

Appendix D: HREC ethics approval notice



Health Research Ethics Committee (HREC)

Approval Notice

New Application

06/07/2018

Project ID :7375

HREC Reference #: S18/05/112

Title: Accessibility of advanced seating services in a Western Cape setting; a qualitative exploration of the experiences of carers of children with cerebral palsy.

Dear Ms Gwen-Lynn North,

The **Response to Stipulations** received on 05/07/2018 17:23 was reviewed by members of **Health Research Ethics Committee 2 (HREC2)** via **expedited** review procedures on 06/07/2018 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **This project has approval for 12 months from the date of this letter.**

Please remember to use your **Project ID [7375]** on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Please note you can submit your progress report through the online ethics application process, available at: [Links Application Form Direct Link](#) and the application should be submitted to the HREC before the year has expired. Please see [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website <https://applyethics.sun.ac.za/ProjectView/Index/7375>

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Francis Masiye ,

HREC Coordinator,

Health Research Ethics Committee 2 (HREC2).

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)-REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)-IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix E: Permission to conduct research at Tygerberg Hospital



Western Cape
Government

Health

TYGERBERG HOSPITAL

REFERENCE:

Research Projects

ENQUIRIES: Dr GG

Marinus

TELEPHONE:021 938 5752

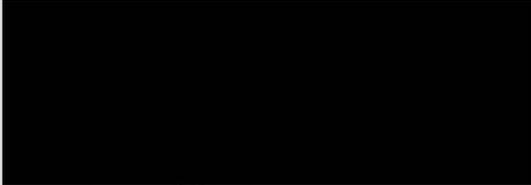
Ethics Reference: **S18/05/112**

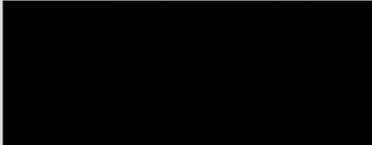
TITLE: Accessibility of advanced ^{scoring} services in a Western Cape setting: a qualitative exploration of the experiences of carers of children with cerebral palsy.

Dear Ms Gwen-Lynn North

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL.

1. In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.
2. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).


MANAGER, MEDICAL SERVICES


CHIEF EXECUTIVE OFFICER

Date: 23 July 2018

Administration Building, Francie van Zijl Avenue, Parow, 7500
tel: +27 21 938-6267 fax: +27 21 938-4890

Private Bag X3, Tygerberg, 7505
www.capegateway.gov.za

Ethics Reference: S18/05/112

TITLE: Accessibility of advanced ^{services} in a Western Cape setting: a qualitative exploration of the experiences of carers of children with cerebral palsy.

BY 
An authorized representative of Tygerberg Hospital

NAME 

TITLE CEO

DATE 23 July 2018

Appendix F: Information leaflet and consent form

INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: Accessibility of advanced seating services in a Western Cape setting; a qualitative exploration of the experiences of carers of children with cerebral palsy.

REFERENCE NUMBER: S18/05/112

PRINCIPAL INVESTIGATOR: Gwen-Lynn North

ADDRESS: Cape Town, 8001

CONTACT NUMBER:

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask me any questions about any part of this project that you do not fully understand. It is very important that you are happy that you clearly understand what this research is about and how you could be involved. Also, your participation is **entirely voluntary**, and you do not have to take part. If you say no, will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- This study aims to explore the experiences of you the carers of children with cerebral palsy (CP) (GMFCS IV/V) when you bring the child for advanced seating services at Tygerberg Academic Hospital.

- Approximately 6-10 people will take part in this study. I will first ask you some questions about yourself and the child. Then we will talk about your experiences on getting to the advanced seating services at Tygerberg Hospital. Each interview will be approximately 45-60 minutes long. With your permission, the interview will be tape-recorded to ensure that I remember correctly what you have said.

Why have you been invited to participate?

- You have been invited to take part in this study because you are providing care to a child with CP and you travel from home to attend the advanced seating service at Tygerberg Hospital.

What will your responsibilities be?

- Your only responsibility in this study is to answer questions as truthfully as you can during the interview.

Will you benefit from taking part in this research?

- There will be no direct benefit for taking part in this study. However, the findings of this study might bring more understanding to the problems faced by the carers of children with CP, such as yourself, when you access healthcare services. It might also be a way of sharing ways to make access easier.

Are there in risks involved in your taking part in this research?

- The only risk for you is that you may experience emotional discomfort or distress during the interview, as you will be sharing personal details of your life. If required, you will be referred for counselling.

Who will have access to your medical records?

- Only I will have access to your child's medical records. Any information that is obtained in this study will be treated as confidential and any information that can be connected to you will not be disclosed without your permission. Your identity will be

protected by assigning a code instead of using your name. Only my supervisor and I will have access to the information obtained during the study. All the collected data will be kept in a locked cabinet in my office and it will be appropriately destroyed five years after the study is completed.

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

- You will not be paid to take part in this study; however, you will be compensated for any travel expenses.

Is there anything else that you should know or do?

- You can contact Surona Visagie or if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your researcher.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled “Accessibility of advanced seating services in a Western Cape setting; a qualitative exploration of the experiences of carers of children with cerebral palsy.”

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*)2018.

.....

.....

Signature of participant

Signature of witness

Declaration by investigator

I (*name*) declare that:

I explained the information in this document to

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

Signed at (*place*)on (*date*)2018.

.....

.....

Signature of investigator

Signature of witness

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

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

.....

.....

Signature of interpreter

Signature of witness