CP seating access

by Surona Visagie

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

Abstract

Introduction: Carers of children with cerebral palsy (CP) often experience challenges when accessing health care.

Objective: 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 Province.

Methods: This study implemented an exploratory, qualitative design. The study population consisted of 62 carers of children with CP (GMFCS IV/V). Seven carers were purposively sampled and interviewed. Thematic analysis with an inductive reasoning process was used to generate themes.

Findings: Carers experienced a great deal of stress around accessing the tertiary healthcare facility for the seating appointment. Common transport barriers experienced by persons with disabilities were compounded by the impairments of the child and the cumbersome buggy. Three themes were generated: (1) A strenuous experience, (2) Transport, and (3) A family affair.

Conclusion: The findings affirmed that public transportation services do not accommodate children with CP. The size and impairments of the child and the cumbersomeness of the buggy fed into and compounded transport challenges, while spousal and wider family support alleviated challenges. Service providers must take cognisance of the challenges that posture support devices pose to using public transport.

Key Words

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

Introduction

Cerebral palsy (CP) is, “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”[1:572]. The severity of CP is usually described by the degree of functional mobility as scored by the Gross Motor Function Scale (GMFCS)[2]. Where severe impairments are present and the children have little functional mobility, the GMFCS score is IV or V. Children scored GMFCG IV or V require assistance with most or all functional activities and posture support wheelchairs[2,3,4].

An appropriate posture support wheelchair enhances the child`s mobility, assist with maintenance of body alignment, and is beneficial to the overall health and quality of life of the child. It reduces the occurrence of complications such as contractures and pressure ulcers, and enhance orofacial, upper limb and respiratory function[3,5,6]. Regular follow up of the child`s position in the chair is necessary to ensure that optimal fit and support for the growing child is maintained.

Children with CP (GMFCS IV/V) usually require advanced seating intervention due to the severity of their neuromuscular impairments. In the Western Cape Province, advanced seating services are delivered at tertiary healthcare facilities by appropriately trained service providers[7]. The study setting, a tertiary healthcare facility in the Cape Town Metro health district, provides advanced seating services at the occupational therapy department. Seven to ten patients are consulted at the seating clinic per week, four of whom requires advanced seating services. The frequency of follow-up seating appointments depends on the individual needs of the child, but usually occurs six-monthly.

Carers of children with CP worldwide[8,9,10] and more specifically, in Africa, express concerns around the accessibility of healthcare facilities[11,12,13,14,15], especially as the child gets older and heavier[12,16,17,18,19]. These concerns include the lack of wheelchair-accessible transport, financial strain associated with rehabilitation, transportation, care and assistive devices, and environmental challenges such as distance and terrain[12,13,15,20].

The unavailability of transport for persons with disabilities (PWD), including for carers of children with CP has been well-documented[11,13,15,20,21,22,23,24,25,26]. Challenges are experienced with public transport, private transport and specialised or subsided transport programmes[26].

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 the wheelchair[20,22,27,28,29]. Adapted public transport for children who use posture-support wheelchairs is not readily available[12,15,19]. When faced with the problems of using public transport, PWDs often choose private transport. Hired private transport, while expensive increases autonomy and safety[215,20,26,27,28,30].

As carers of children with CP play a vital role in the child's care needs[2], it is important to investigate the barriers they experience and facilitators they utilise when accessing health care such as advanced seating services. Due to a complex relationship between poverty, disability and health[27,31,32], carers of children with CP from low socio-economic backgrounds might have unique experiences around accessibility of healthcare facilities, which have not been identified by carers in other more affluent settings. Understanding their experiences and perspectives might inform best practice[12,33,34] and contribute to policy revision[34]. Thus, the study question, "What are 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" arose.

Methodology

Study aim

The aim of the 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.

Study design

This study implemented an exploratory, qualitative design as it investigated and sought to enlighten our understanding of carers' experiences[35,36].

Population and sampling strategy

The study population consisted of 63 carers of children/adults with CP (GMFCS Level IV/ V), who attended the advanced seating clinic at the tertiary healthcare facility between January 2016 and March 2018. Participants had to be the primary carer of the child/adult with CP, older than 18 years of age and travelling from home to the advanced seating service. Exclusion criteria were carers of children/adults with CP residing outside a 100km radius of the healthcare facility and carers of children/adults with CP who received assistance with transport from a day-care centre or school.

Information from the electronic hospital information system was used to compile the sample frame. Purposive sampling was used to identify seven participants from this list[35]. Carers who had previously voiced their experiences, challenges and possible solutions around accessibility of the advanced seating clinic were handpicked as it was believed that they would be able to provide rich information on the topic under study. Also, it was ensured that carers of children/adults of different genders and ages were included as well as and carers that in the past missed appointments.

Carers, who had been sampled, were contacted telephonically. The study was explained to them and provisional consent were obtained. The five who visited the health care facility during the data collection period was interviewed at the facility after their children's appointments. The other two were interviewed at a venue and time convenient to them.

Data collection

Data was collected through one-on-one, semi-structured interviews by the first author. Interviews were guided by broad open-ended questions. An interview schedule with three core questions were used:

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

Interviews were audio-recorded, conducted in the preferred language of the participant and lasted 45-60 minutes. All but one participant preferred to be interviewed in Afrikaans. The IsiXhosa interview was done with the assistance of an interpreter, who is an occupational therapist at the study hospital. By the seventh interview, saturation was reached as various themes were mentioned repeatedly and no new information emerged.

Data analysis

A thematic analysis strategy with an inductive reasoning process was utilised[37]. A six-step iterative approach, proposed by Braun and Clarke[37], that includes familiarising with data, generating of initial codes, combining of codes and development of themes, evaluating of themes, defining of themes and write up was followed.

Trustworthiness

Credibility was aspired to by purposive sampling, achieving data saturation, implementing a peer debriefing process, discussing emerging themes with the second author and reaching consensus.

Confirmability and the minimisation of the impact of my own bias were pursued by reflexivity through keeping a reflexive journal[38,39]. A detailed chronology of the research process was kept. A thorough description of the research topic, the processes, methodology, participants and the study context should enable the reader to decide on transferability of the findings to other similar settings[39].

Ethical considerations

Ethics approval were obtained from the Health Research Ethics Committee of Stellenbosch University (S18/05/112) and the Western Cape Provincial Health Research Committee (PHRC) (WC_201807_011). Voluntary informed consent and permission to use an audio recorder was obtained prior to the commencement of data collection from each participant[40]. Participants' identities were protected by assigning each a code and factoring out any distinguishable information from the findings.

Findings

Table I shows that the carers were mostly 40 years or older while the ages of the child/adult with CP varied between 13 and 41.

[Insert table I here]

Table II illustrates the three themes, with subthemes, that emerged from the data.

[Insert table II here]

Theme 1: A strenuous experience

Visiting the advance seating clinic was a demanding and worrisome experience for the carers. They had to show fortitude and determination to actually make it happen. Advance planning was required to ensure that everything from transport to care for other children was in place. The actual day involved rising early, complex preparations, an often arduous journey, long hours at the hospital and getting home rather late and tired. Participant narratives spoke of a *long, difficult day*.

> "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…and then we spend the whole day here [at the hospital]." – P5

Furthermore, accessing the seating-clinic became increasingly difficult as the child grew.

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

Participants had to *carefully plan and prepare for the day*. Some arrangements like transport had to be made well in advance with a reliable person and money to pay for transport must be saved.

> "…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. I put it (money from the child support grant) aside, then I know that it is (there 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…takes family responsibility-leave every time." – P1

Other children in the household must be 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

However, the child`s wellbeing was important enough to the carers to make the effort to get to the seating clinic.

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

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. Participants concerns included physical access, the size of the posture support wheelchair, cost, feeling harassed and hurried, and negative attitudes. Physical access was a hurdle when using busses, trains and taxis. The buggy was heavy and cumbersome, making it difficult to negotiate the step/s into busses and taxis, go down narrow aisles and negotiate the flights of stairs at railway stations.

> “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

> “I can tell you that coming by train to [name hospital] with the buggies, is a nightmare…I will not do it. 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.” -P7

Participants also felt unsafe walking from the station to the hospital.

> "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

Thus, even while the train was the cheapest option not many considered it. When using busses and taxi`s the cost of transport increased, as the carer had to pay for the space taken by the buggy as well as for themselves and the child.

> "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

> "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

Fellow commuters and taxi drivers were often in a hurry as time translates into money for them. This led to impatience with the carer who needed to disassemble and load the buggy, all while handling the child with care to ensure stress and injury does not occur.

> "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

Crowding at peak times could lead to long waiting times. Participants felt that waiting for public transport in inclement weather poses a health risk to 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" – P6

Uber services were given some consideration, but participants thought the cost might be prohibitive to using it.

Thus, participants preferred to use of *private transport* to access the tertiary healthcare facility. Private transport had to be arranged well in advance with a reliable person. As with public transport the size and cumbersomeness of the buggy had to be taken into consideration as it did not fit into all cars. The vehicle must have enough space for the posture support wheelchair, the child with CP, the carer and the driver.

> "I have to find someone with a utility vehicle to take us to the hospital…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. 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

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

Participants were aware of and previously made use of *subsided 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 subsided transport. 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

A participant suggested community outreach programmes to assist with the follow-up as this will reduce the burden of having to travel to the hospital.

Theme 3: A family affair

Mothers and fathers often shared the responsibility of care and accessing the facility.

> "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

Extended family members, friends and community members also provided support.

> "Yes, our family. We have a strong family bond in terms of support. 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. Friends, family…even the church…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

Discussion

National[41] and provincial policy[42] states that public transport should be accessible to all. However, current findings and previous studies showed that the design of public transportation does not accommodate wheelchair users[12,15]. The three transport systems in the City of Cape Town, MyCiti bus services, Healthnet and Dial-a Ride, which were developed with a view to improve transport access for persons with disabilities did not benefit the current study participants. The MyCiti bus services only operate in certain sections of the city[43] and none of the current participants had experience of using this service. Participants knew about HealthNet and Dial-a-ride, but were unable to access the services due to administrative barriers as also previously noted by other researchers[11,23,24] and described in media reports[44,45].

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 principles of universal design[46]. Taxi operators might not feel obligated to render a transport service to persons with physical disabilities[47]. Lister and Dhynpath[29:32] argues, *"to maximise profits, taxi operators may ignore the elderly, women and children and persons with disabilities. 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."* The finding that people are charged extra for their wheelchairs is a common one,[15,22,25,27,28,46,47] and related to the take-home pay as the wheelchair takes up the space of a paying customer.

Being removed from the support of the buggy and feeling rushed or unsafe during boarding or using transport might trigger stress in the child with CP[48]. When children with CP experience stress an increase in spasticity usually follows[48]. This might cause further delay in accessing transport, more impatience amongst operators and fellow commuters and further stress. The child might start crying, will be more difficult to manoeuvre physically due to increased tone, and are at risk of injury.

It seems like travelling by train might be an option as it is cheaper, the child can remain seated in the posture support device, and trains usually have more interior space. Crowding might be dealt with by adding a coach designated for persons with disabilities. However, the lack of ramps or subways at some train stations as also previously described[13,24,47] renders this option mute.

Safety *en route* from the station to the hospital is another concern in the violent society of the Western Cape where robbery and assault are common occurrences[49]. Women and those who are ill, weak or physically impaired are at great risk of being attacked. Scheffler, Visagie and Schneider[50] have described people being accosted and attacked on their way to health care services in the Western Cape. This risk has been addressed by the study hospital through the posting of security officers at the most dangerous point on the route.

Appropriate posture support wheelchair

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[5]. However, 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 commonly prescribed posture support wheelchair for children with CP (GMFCS IV/V) in the Western Cape Province is the Madiba buggy© (Figure 1). This buggy 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[51]. The findings showed that the rigid fibre-glass seat and back unit, and rigid base of the Madiba buggy©, makes it difficult to transport as it is heavy, and does not fold and/or break down into a smaller unit or units.

[Insert figure 1 here]

The Madiba2go© posture support wheelchair is also available on government tender (Figure 2) and have similar characteristics as the Madiba buggy© with the additional feature of a rugged, folding base frame which makes it easier to transport[52]. The Madiba2go© costs 15% more than the more commonly prescribed Madiba buggy ©[53]. A basic, folding-frame wheelchair with posture support devices, that can be disassembled can also provide the necessary support, but are more expensive than the Madiba buggies[53].

The South African healthcare budget is under strain, and it is common to encounter wait lists for assistive products[54]. Thus, decisions regarding service provision must include deliberations on costs and need. Therapists might have to choose between providing more people with a device that does not allow easy travel or providing fewer with a device that does. However, a 15% price difference is not excessive and might not influence the number of people who can be assisted.

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.

Recommendations

South African policy regarding universally accessible transport needs be implemented by the City of Cape Town. Areas of specific focus should include buses with lower steps, hydraulic 'kneeling' devices to tilt or lower the front axle down to curb height, reserved seating on buses and train carriages for persons with disabilities, and ramps and subways at train-stations, especially the station at the current study hospital. It is also recommended that the MyCiti bus services routes be expanded.

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 the basic folding frame wheelchair with posture support devices for users dependent on public transport.

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;

Conclusion

The findings centred on the fortitude required from the carers to ensure that the child keeps their seating appointments. The findings affirmed that most public transportation services and systems do not accommodate carers and their children with CP. Finding accessible, trustworthy and safe transport were a concern that compounded the stress of the visit. The size and impairments of the child and the cumbersomeness of the buggy fed into and compounded the transport challenges, while spousal and wider family support alleviated challenges.

Acknowledgements

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

Participant code	Age of participant	Gender of participant	Home Language	Employment Status	Marital Status	Nr of years attending advanced seating 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 II: Themes and Subthemes

	Themes	Subthemes
1	A Strenuous experience	Long, difficult day Careful planning and preparation
2	Transport	Public transport Private transport

		Subsided Transport
3	A family affair	

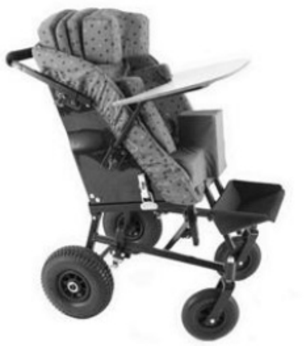	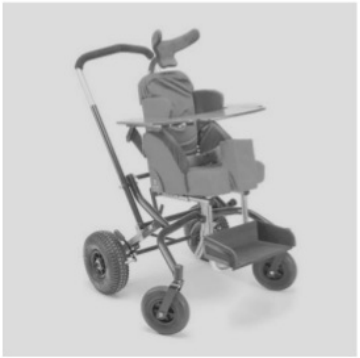
Figure 1: Madiba Buggy © (Shonaquip, 2017a)	Figure 2: Madiba2go © (Shonaquip, 2017b)

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