RESEARCH ARTICLE

Community mobility: psychosocial experiences of stroke survivors who use wheelchairs in Worcester, South Africa

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ABSTRACT

Background: Despite policies promoting transport inclusivity, persons with disabilities in South Africa experience difficulties when accessing public transport. Poor community mobility hampers community integration and participation in occupations outside the home. This article describes the psychosocial community mobility experiences, of stroke survivors using wheelchairs in a town in the Western Cape province of South Africa
Method: The study used a descriptive qualitative design. The study population were community dwelling stroke survivors, from Worcester, using wheelchairs. Data was collected from eight participants through semi-structured telephonic interviews. Inductive thematic analysis was used.
Findings: The four themes derived from the data were: Freedom of movement *(My power chair, my Ferrari')*, Social anxiety *(People stare at you like they do not have a heart*), Dependency *(I must dance along to his fiddle)*, and Social isolation *(You feel done in, dejected)*. Participants identified wheelchairs, private vehicles, and mini-bus taxis as modes of community mobility.
Conclusion: When transport barriers prevent dignified, spontaneous community integration negative psychosocial consequences (social anxiety, dependency, and social isolation) followed. Community mobility barriers hampered participants' ability to participate in meaningful occupations and left them isolated. Occupational therapists should take cognisance of the community mobility challenges wheelchair users might experience and implement intervention strategies to mediate these.

Implications for practice

- Community mobility is essential to perform occupations outside the residential setting and must be included in occupational therapy assessment and intervention strategies.
- Occupational therapists can empower individuals with mobility impairments with the life skills to manage psychological challenges caused by accessing public transport and decreased community mobility.
- Occupational therapy intervention for wheelchair users accessing public transport should include effective, appropriate transfer strategies to embark and disembark from minibus taxis.
- In certain circumstances the occupational therapist should consider the possibility of a motorised wheeled mobility device to facilitate community integration.

INTRODUCTION

The United Nations report (2018) on disability and development shows that persons with disabilities are still marginalised and excluded from their communities despite recent progress to achieve the sustainable development goals (SDGs). According to the UN report, more than 30% of persons with disabilities experience challenges with accessing transport and public spaces. Therefore, goal 11 of the SDGs, *Making cities and communities inclusive and sustainable for persons with disabilities,* has not been achieved[1].

The aim of the South African (SA) National Development Plan (NDP) 2030[2], is

to reduce poverty and eliminate inequality. However, the NDP does not address transport access and without accessible transport, people cannot get to places where they can develop skills and grasp opportunities for economic growth[3]. The SA White Paper on Rights for Persons with Disabilities[4], recognises transport challenges as a serious barrier to full community integration of persons with disabilities and calls for the rapid development of a flexible public transport structure that is accessible to persons with disabilities.

Despite international agendas and national policies that promote transport inclusivity, persons with disabilities in South Africa still experience difficulties with regards to accessing public transport[5-8]. Challenges are caused by impairments such as speech impairments, hemiparesis, and decreased mobility, in interaction with social and environmental barriers such as negative attitudes, safety concerns, the physical design, transport costs, travelling distance to get to public transport, infrastructure and design of indoor and outdoor spaces connected to transport, transport systems, services and policies[6,9].

Stroke survivors can experience one or more of the above impairments and/or barriers. Physical and cognitive impairments often cause limitations in mobility, communication, and planning after a stroke. Coupled with social and environmental barriers such as stigma, discrimination, and inaccessible environments, they often experience challenges when accessing transport[10], particularly if in a wheelchair.

An overview of commuter transport in South Africa

Some South Africans, especially those living in poverty, do not have access to a private vehicle11. A 2018 General Household Travel Survey found that 36.7% of South African households use public transport[12]. In the Western Cape, 29.3% make use of public transport[12]. Generally, in South Africa, access to public transport is problematic. Historical racial segregation and the development of urban housing projects far from places of employment, education, recreation, shopping centres, health care and other services, mean that commuters must cover long distances, often on a daily basis[3,6,11]. Distances are often compounded by long waiting times in inconvenient, unsafe locations, as well as safety issues in transit and discomfort[3]. Despite numerous policies and strategies as comprehensively described by Walters11, the provision of affordable, safe, and accessible public transport remains a challenge in South Africa[3].

In South Africa, local public transport is mainly provided through bus, commuter rail, minibus taxis and private metered taxi services (Uber, Bolt, Didi, etc). The most common mode of public transport is minibus taxis11. Since these taxis are privately owned and operated, their services are largely unregulated by government. Taxi associations determine routes, fee structures, operating times, and practices. Previous research amongst the general population[11] and persons with disabilities[6] found taxis to be expensive, unreliable, and unsafe. Minibus taxis are the only means of public transport in the current study setting.

Barriers experienced by wheelchair users in accessing minibus taxis

Physical access is problematic, as the design of minibus taxis such as the height difference between the wheelchair and the seat, makes it difficult for wheelchair users to board and disembark[13-16]. Inside the taxi there is little room to manoeuvre a wheelchair[14] or space for the wheelchairs to be stored[16]. The distance from homes to taxi ranks, poor road conditions, unkempt sidewalks, rough and rugged terrain, curbs, and stairs cause further access barriers[13,15,16].

In addition to physical barriers, wheelchair users also experience attitudinal barriers when accessing taxis. Taxi drivers might be unwilling to help and have an impatient attitude and sometimes refuse to transport wheelchair users[6,8,16,17]. It has been widely reported that taxi drivers` attitudes and even the choice not to stop for a wheelchair user, are financially driven. For taxi operators and owners 'time is money'. The extra time wheelchair users need to embark and disembark and load the wheelchair is experienced by them as time that can be put to better use making an extra trip[6,9]. Similarly, fellow travellers are in a hurry and disinclined to wait while a wheelchair user gets on or off a taxi or to assist a wheelchair user[7]. Financial constraints are another concern for wheelchair users in using taxis. The cost of a trip doubles, as they must pay for themselves and the wheelchair, and triples if they are accompanied by a carer[5,17].

In a recent study done by Gudwana[16] with mobility-impaired participants in Knysna, it was found that safety was a concerning matter. Lack of seat belts, reckless driving, and an inability to maintain balance (due to the impairment), enhanced the sense of feeling unsafe when using minibus taxis. Kett, Cole & Turner[9] concurred that persons with disabilities feel unsafe when using minibus taxis. Lorenzo[18] highlighted safety as a barrier in relation to taxi violence in communities, whereby women with disabilities are more at risk due to their mobility impairments. Other safety issues identified by persons with disabilities were overloading of taxis and drivers and not adhering to road regulations, e.g., exceeding speed limits[6].

Occupations, community integration and transport

According to the Occupational Therapy Practice Framework: Domain and Process (4th ed), the term *occupation* as used in Occupational therapy refers to the things people engage in, alone or in groups, that give meaning and purpose to their lives. Occupations have distinct importance and value to a person and is vital to the individual's health, wellbeing, and sense of self. Occupations involve the body, soul, and spirit and as such, are essential to ensure humans to prosper. Ensuring engagement in occupations is the overarching purpose of the occupational therapy profession[19].

Occupational therapists are concerned with the occupation itself as well as the factors that enable a person to participate in a specific occupation[19]. In the context of this study occupations refer to activities related to community integration for example employment, recreation, engaging in shopping, accessing health care, religious, social, and political life, or any other activity that is performed in a setting outside one's immediate place of residence. Community in-

Table I: Participant identification

Sample frame	Sample size	Excluded from study
40	7 (An additional 8th participant was purposively sampled to explore a specific finding further).	Speech & language impairments=7 Relocated= 3 Incorrect contact details/addresses=21 Non-wheelchair user=2

tegration depends on the ability to choose where, when and how to live, work and play. A choice of how, where, and when to do something, implies the ability to move about freely. For that community mobility is a pre-requisite. Therefore, a lack of community mobility creates a barrier that hampers accessing community services and resources and affects participation in meaningful occupations negatively[5,9,20,21]. Conversely, accessible, efficient, and safe transportation facilitates community integration, whereby citizens can access services and opportunities for health care, education, employment and social activities[22,23].

A study done with British teenage wheelchair users, found that poor transport access infringes on their ability to freely move around in their communities. This in turn can lead to social isolation and lack of community integration[21]. Similarly, Kohler et al[20] describe how Malawians with mobility impairments (n=20) experienced participation restrictions and social isolation due to a lack of community mobility. South African studies regarding transport and community integration concurred with the above findings. Maleka, Stewart & Hale[24] conducted a qualitative study in Gauteng and Limpopo with 32 stroke survivors and found that mobility impairments affected their ability to participate in community activities and resulted in social isolation. Other studies identified that persons with disabilities experienced exclusion from accessing health care, employment, and education due to inaccessible transport[5-7]. Focusing on stroke survivors, 88 percent regarded transport as an obstacle to successfully integrating into their communities, according to a study done in the Helderberg Basin in the Western Cape Province[17]. In Worcester, a rural town in the Western Cape and the setting of the current study, 62.5% of stroke survivors identified access to transport as a barrier[10].

A gap identified was that none of the studies investigated, was how stroke survivors specifically, feel about and experience these barriers. Kett, Cole and Turner[9] confirm a dearth of research on what poor access to transport means to persons with disabilities in their everyday functioning in low- and middle-income countries. This paper aims to describe wheelchair dependent stroke survivors' psychosocial experiences when mobilising in the community using private and/or public transport.

METHODS

Study design

The research followed a post-modern worldview, as the study explored multiple realities from a diverse group of participants. The descriptive qualitative design was utilised to discover and understand the phenomenon through the eyes of the stroke survivors. As the reviewed literature shows public transport access for wheelchair users have been researched extensively. However, the influence of transport access or lack thereof on community integration and the persons psychosocial experiences related to that remained rather unexplored[25]. A gap that the current study focussed on.

Population and sampling

The study population included persons who lived in Worcester, Western Cape Province, SA, and had a stroke before August 2019. Worcester is situated in the Cape Winelands District and forms part of the Breedevalley Municipality. The town has a population of 79 000 people. Over 90% of households have access to water; refuse removal, electricity, and basic sanitation. Strokes are the fourth highest burden of disease in the Worcester community[26]. Privately owned vehicles and minibus taxis are the main modes of transport in Worcester. There are also private transport operators that offer shuttle services and services like Uber.

Participants included in the study had to live in town (not on surrounding farms) in the community (not in residential facilities), use wheelchairs for mobility and have access to private and/or public transport. Stroke survivors with speech and language impairments were excluded from the study (because data were collected telephonically due to COVID-19 restrictions). Participants were recruited through the association of the physically disabled (APD) in Worcester. APD's records showed 40 stroke survivors who used wheelchairs for mobility. Of these, 33 had to be excluded based on the exclusion criteria (speech & language impairments, living outside study area) or incorrect contact details as shown in Table I (page above). This left seven possible participants. Due to the small number, the total population was sampled.

During provisional analysis of the data an interesting trend developed. Participants indicated that they thought a power wheelchair would assist them to access the community. We decided to explore this opinion further through purposefully including a stroke survivor that used a power wheelchair in the study. All eight agreed to participate in the study and signed a written informed consent form.

Data collection

The first author collected data via individual, semi-structured telephonic interviews between July and October 2020. The interviews lasted 30 to 45 minutes and were recorded via a digital audio recorder. Seven interviews were done in Afrikaans and one in English as per participant language preference. Telephonic interviews increased the privacy of the participants and allowed for sharing in-depth experiences. It also allowed participants greater power to schedule and terminate interviews according to their wishes. This method was less intrusive, more cost effective, made a need to travel redundant, and protected participants and the data collector from the risk of COVID 19 infection[27].

A semi-structured interview guide, developed by the re-

Table II: Demographic details of participants

Pseudonym	Age	Gender	Language	Impairment	Onset	*Income	Wheelchair type	Transport mode used
Dottie (P1)	56	W	Afrikaans	left hemiplegia	June 2019	Disability grant	Four-wheel folding frame	Minibus taxis
Felicia (P2)	31	W	Afrikaans	left hemiplegia	November 2016	Disability grant	Four-wheel folding frame	Private and minibus taxis
James (P3)	56	M	Afrikaans	right hemiplegia	June 2019	Disability grant	Four-wheel folding frame	Private and minibus taxis
Roslin (P4)	49	W	Afrikaans	left hemiplegia	November 2016	Disability grant	Four-wheel folding frame	Minibus taxis
Jan (P5)	66	M	Afrikaans	left hemiplegia	May 2016	Old Age pension [SASSA]	Four-wheel folding frame	Private and minibus taxis
Carol (P6)	67	W	Afrikaans	right hemiplegia	July 2019	Old Age pension [SASSA]	Four-wheel folding frame	Private and minibus taxis
Xolani (P7)	53	M	English	right hemiplegia	July 2018	Old Age pension [SASSA]	Four-wheel folding frame	Private
Chris (P8)	67	M	Afrikaans	left hemiplegia	December 2015	Old Age pension [SASSA]	Powered wheelchair	Powered wheelchair

***At the time of the study the disability grant was R1860, and the old age pension was R1780.**

search team, was used to explore participants' experiences. The following focus areas were explored:

- How participants moved around town
- Participants' experiences with using transport (private and public)
- The role transport plays in participants' ability to do things in and around town

The completed interviews were transcribed and provisionally analysed. Data saturation was reached after six interviews. However, to confirm data saturation, interviews were conducted with all eight persons who adhered to the inclusion criteria.

Data Analysis

The interviews were transcribed by the first author and analysed in the language that the interviews were done. The first author translated Afrikaans quotes into English for reporting purposes. The correctness of the translation was verified by the second author. The recordings and transcriptions are available for audit purposes. An inductive thematic analysis approach was used according to the six steps by Braun & Clarke[28]. After familiarisation with data, the first two authors separately generated codes and developed provisional themes from the codes. An iterative reviewing and refining process followed where the authors reached consensus on themes. During the process some themes merged, others fell away, and others broke into separate themes. Thereafter, themes were defined and named by identifying the essence of each.

Trustworthiness and Ethics

Credibility, transferability, dependability, and confirmability[29] were strived for. Data saturation, narrative examples, and reaching consensus in data analysis enhanced the credibility of the study[28]. A detailed description of the research setting, and methods was provided to allow for determination of transferability[28]. The detailed description also contributes to dependability and confirmability. Dependability was further supported by a proposal detailing the methods of the research project that was approved by the Health Research Ethics Committee of Stellenbosch University. Maintaining an audit trail that included the raw data, field notes, documents that show the data analysis process and a reflective journal enhance dependability and confirmability[28]. A reflective journal was used by the first author (and researcher) to note his feelings, experiences, and opinions to assist him to bracket these and present the experiences and opinions of participants rather than his own. It also provided a record of the daily logistics of the research processes.

Ethical approval was obtained from the Health Research Ethics Committee of Stellenbosch University (S19/10/242). Written permission was received from the APD that provided support in the identifying and recruitment of participants. All participants gave written informed consent. Telephonic interviews ensured that participants were not exposed to COVID-19 because of the study. The data was stored in a password protected computer at the University of Stellenbosch SUNScholar Research Repository[30].

FINDINGS

Participants' demographic information

Demographic detail of participants is shown in Table II (page above). There was an equal representation of men (4) and women (4) in the study. The ages of participants ranged between 31 and 67 years. All participants were dependent on governmental non-contributary social grants for an income.

Emerging themes

Codes were ordered into categories from where themes were developed as presented in Table III (page 86).

Four themes emerged from the data:

- Freedom of movement, My power chair, my Ferrari.
- Social anxiety, People stare at you like they do not have a heart.
- Dependency, I must dance along to his fiddle.

- Social isolation, You feel done in, dejected.

Theme 1: Freedom of movement, *My power chair; my Ferrari*

Privately owned vehicles, mini-bus taxis and wheelchairs were used by participants to mobilise in the community.

> "I will not put my entire business on the taxi if I can get private transport. Or even better if I can also use the [wheel]chair." **[James]**

These three mobility strategies (privately owned vehicles, mini-bus taxis and wheelchairs) were used interchangeably depending on availability, how much funds the participant had at any given time, and the weather. Wheelchairs were often the preferred mode of community mobility and allowed some participants to assist others.

> "I do not really use [transport]. If I must, when it rains, I will take a taxi, otherwise my husband push [with the wheelchair] me where I want to go...I travel in my wheelchair, and I can hang bags at the back, or put them between my legs and on my lap. Perhaps we see one of the older people that live close to us carrying heavy bags. Then I say, 'Come, here is a taxi. Give the bag to me I will take it home for you`. I carry the bags to my house, and they come and fetch it there. That makes them laugh. I help where I can." **[Roslin]**

Wheelchairs had to be pushed by someone else, often at a price.

> "The wheelchair is a big advantage. But it is also expensive. I must hire people to push me where I wanted to go." **[Jan]**

Participants thought that a powered wheelchair might enhance their freedom of movement, community mobility and integration:

> "If I have an electrical wheelchair, I will just go and sit in the wheelchair and drive the wheelchair with my friends." **[Xolani]**

Chris, who used a powered wheelchair, was purposefully identified to participate in the study, to explore the perception of participants that a power wheelchair might improve community mobility. His narrative showed that powered wheelchairs can enhance freedom and ease of movement in the community.

> "[I use] a battery powered chair. Everywhere in town, I go where I want to go and get where I want to get. Even to the hospital that is about 5km from here [his house]. There are a lot of shops in Worcester that I can drive into. Sundays I can go to church. Drive into the church with my chair. I drive to them [his friends] with my power chair. It is my Ferrari." **[Chris]**

Chris`s experiences also juxtaposed the difference between needing someone to push the wheelchair and being able to control it himself.

> "It is way better. Way, way better joh. That normal chair, I struggled to find someone to push me where I want to go and then he wants money and I do not always have money. I had to pay the man just to get where I want to go... It's a huge difference...there is no more money involved. This freedom of movement had a positive emotional impact." **[Chris]**

> "It is very nice. Since I have this chair, all is well with me. Very well. Before I had this chair it was bitter. I had to sit at home every day." **[Chris]**

Theme 2: Social anxiety, *People stare at you like they do not have a heart*

Social anxiety and experiences of feeling ashamed especially when using minibus taxis were described. Not being able to get into and out of the taxi as quickly and in the same manner as before the stroke seemed to be at the core of these feelings. It seems social anxiety was as much due to internal struggles related to what the participant imagines co-commuters might be thinking as it was generated by overt and covert actions of taxi drivers and co-commuters.

> "... [quiet]...sometimes people stare at you like they do not have a heart. They [co-commuters] stare and it seems like, `What is it? Does she have to get in here?` That always make me sad...That is not a good feeling. It is an awkward feeling. Because everybody is looking at me and they must wait before they can drive off. It takes time one to two minutes before I am out of the taxi or climb into the taxi. There is some on their way to work who says, `Ai jinne this auntie cannot get out quick enough`. But I cannot and that make me feel awkward. Sometimes I have feelings that I do not want to use the taxi because of the people. It feels as if they are watching me. I am human too. I have feelings too...It seems like, maybe it is my brain telling me this, but it is as if the people make a fool of me. I feel hurt, dejected." **[Dottie]**

> "You feel hurt; you do not feel comfortable, because not all your limbs work a 100%. That is the problem, and then you feel uncomfortable. You feel ashamed because you need assistance from others. The other people are not friendly, and all people are not helpful. As a person you do not always feel like asking, 'Sir, please help me or young man help me, pull me up?' Because you are human, you feel ashamed." **[Jan]**

Participants` descriptions showed that boarding the taxi was often an undignified process.

> "...someone must help lift my body from behind, to lift me into the taxi." **[Felicia]**

> "I sit on the step and turn and twist my body. That works." **[Jan]**

Table III: Visual presentation of themes, categories, and codes

<table>
<tr><th>Themes</th><th>Categories</th><th>Codes*</th></tr>
<tr><td rowspan="4">Freedom of movement</td><td>Taxi</td><td>Driver's attitude:
The taxis do not always want to load us with strokes who use wheelchairs (P2)
He wanted a cooldrink or something to eat, a bribe (P2)
Disrespectful (P2,4)
Uncaring (P4)
Unfriendly (P5)
Little patience (P5)
Fellow commuters' attitude:
Impatient (P1)
Stare (P1,2)
Careless - bump into you (P3)
Disrespectful (P3)
Complaining (P4)
Unsupportive (P5)
Unfriendly (P5)
Boarding and disembarking:
Difficult (a struggle) (P1,2,3)
Slow (P1,5, 3, 7)
Need help (P1,3,7)
Can hurt self (P3)
Stressful (P3,5)
Little space (P3)
Cost:
Cheaper than private (P1)
Pay for carer (P1)
I cannot afford it (P1)
Pay for wheelchair (P2)
No credit (P3)
Pay double (P8)
Reliability:
Not reliant timewise (P1)
They have a schedule (P5)
Not all bad:
Some taxi drivers supportive and helpful (P1,2,4,5,8)
House calls:
Pick up at home, drop off at destination (P3,5)
Cost double (P5)</td></tr>
<tr><td>Private car</td><td>Comfortable (P2,3)
Boarding and disembarking:
Easier than taxi (P1,2,7) depends on size of car (P6,7)
Not rushed (P3,6)
Driver assists (P2,3,6)
Cost:
Pay (P3,6)
Do not pay (P2)
Not always money for petrol (P7)
Availability:
Not always available (P3,5,7)</td></tr>
<tr><td>Wheelchair</td><td>Replaces walking (P3,4,7)
Requires someone to push chair: (P1,2,3,4,5,7,8)
Pay pusher (P 4,5,8)
Struggle to find pusher (P1,2,7,8)
Weather permitting:
Not in rain, strong wind (P3,4)</td></tr>
<tr><td>Power chair</td><td>Spontaneous thoughts on power chairs:
Wheelchairs with batteries (P3)
I need to get somewhere, but cannot get there because the wheelchair is not electric, and I have no one to push me (P4)
With that electric wheelchair if I want to go, I can go. I don`t have to ask (P7)
I will just go and sit in the wheelchair and drive the wheelchair with my friends. It can assist me big time. (P7)
Purposively sampled participant's experience with power chair:
Mobility:
Just sit and drive (P8)
Much better (than manual chair) (P8)
Go with friends (P8)
Everywhere in town (P8)
Shops, hospital (5kms), church, child's birthday (P8)
I go when I want to, I get where I want to go (P8)
My Ferrari (P8)
Practicalities:
Charge battery at night (P8)
Load shedding (P8)
Not in rain (P8)
<table>
<tr><th>Before:</th><th>After:</th></tr>
<tr><td>I sat at home every day (P8)
It felt alone Pp8)</td><td>A world of difference (P8)
I am happy (P8)</td></tr>
</table>
</td></tr>
</table>

Table III: Visual presentation of themes, categories, and codes

<table>
<tr><th>Themes</th><th>Categories</th><th>Codes*</th></tr>
<tr><td rowspan="2">Social anxiety</td><td>Humiliating</td><td>Embarking and disembarking:
Undignified (P1,2,5,6)
Difficult (P1,2,5,6)
Interaction with fellow commuters:
The people watch me, It is not a nice feeling (P1)
Ai jinne the auntie cannot get out fast enough (P1)
It makes me feel different (P1)
It makes me emotional (P1)
My brain tells me the people are making a `gai` of me. I feel hurt, despondent (P1)
People have no heart, they stare…It makes me sad (P2)
They say the uncle is not lekker (P3)
You feel hurt, you are not relaxed, you feel shame because you need help from others (P5)</td></tr>
<tr><td>Fear when using taxis</td><td>Do not feel safe (P1,3,5)
Afraid of falling (P2,3,6)
Afraid of injury (P2, 6)
Taxis not always in good repair (P5)</td></tr>
<tr><td rowspan="3">Dependency</td><td>Reliant on others</td><td>To push the wheelchair (P1,3,5,7,8)
To drive private car (P2,3,5,6,7)
To transfer (P1,2,4,5,6)</td></tr>
<tr><td>Loss of control</td><td><table><tr><td>Before stroke:</td><td>After stroke:</td></tr><tr><td>Walked (P3,7)
Drove (P6,7)
Independent (P3,6,7)</td><td>Need to ask (P2,3,6,7)
Reluctant (P1,2,6)
Difficult to get transport (P3,4)</td></tr></table></td></tr>
<tr><td>Scheduling</td><td>Wait for taxis, drivers (P2,5,6)
Driver/car not always available (P3,5,7)
Must adapt (P3)
Advance planning needed (P6)</td></tr>
<tr><td rowspan="4">Social isolation</td><td>Loss of community occupations</td><td>I was very busy, work, community work, church work. I cannot get to the things I always did. (P1)
I have to leave stuff because I cannot get there (P1)
If I could walk, I would have been there already (P1)
Cannot participate in activities (P6)
…can I not be like the man who is going to work? (P3)
Your heart is on fire because you cannot visit family (P3)
It is difficult for you to go anywhere you want to go (P7)
Miss clinic appointments and go without medication (P7)
I am not a gym member anymore because I cannot get there (P7)
I can`t go and watch soccer (P7)</td></tr>
<tr><td>Negative feelings</td><td>Why do you have to be like this? (P1)
Done in (P1)
Dejected (P1)
It is not nice to sit at home and do nothing. It is not pleasure; a long road (P3)
Worthless (P4)
You are dependent on others, that is tough on the heart (P6)
Sad story (P6)
I feel no good (P6)
It makes me feel bad (P7)
I am not expecting any good stuff after I stroke (P7)</td></tr>
<tr><td>Excluded</td><td>Not part anymore (P1,6)
Stay at home (P3,6,7)</td></tr>
<tr><td>Try to adapt</td><td>I have to live with it; I have to be satisfied (P3)
I told myself not to think too deep (P3)
You have to work on yourself and accept things (P4)
Get used to it (P6)
You have to accept it (P6)
Not the end of the world (P6)</td></tr>
</table>

Sometimes drivers requested extra incentives.

> He [taxi driver] had this way, I had to buy him a cool drink or something to eat…it looked like I had to bribe him to get into the taxi. **[Felicia]**

She further indicated that if she refused to do this the driver refused to let her ride in the taxi.

> Then he gets angry and he does not allow me to get in the taxi. **[Felicia]**

Participants with access to private vehicles preferred that to minibus taxis. This preference was due to convenience, the ease of getting into and out of the vehicle, and a more relaxed atmosphere.

> When I have to get into a taxi, maybe in passing my crutch get stuck or my foot get stuck in a hole, Oh jissou sorry missus, or sir. Understand. Everything involved. I have to move quickly. But when I go with the car… I get in, in my own time. Put my sick leg in first and then my body; take hold of the car`s door frame, lift myself onto the

> seat. When I am in, I close the door, put my crutch next to me. But the taxi is a complicated thing, and it is also a bit dangerous you know. For getting stuck while hurrying and things like that. **[James]**

However, all was not negative. Individual taxi drivers and co-commuters sometimes showed goodwill and consideration.

> When you go to town the taxi has specific pick-up points, but when they see me with the wheelchair they turn and come to me, and they assist me into the taxi. And some people are in a hurry to jump off, but when they see there is a disabled person, they wait for the person to get off calmly and then they drive away…usually they do not make us [people who move with difficulty] sit deep inside. Usually, we can sit in front if we can get in there. **[Roslin]**

> There is sometimes one who is very decent. He will say, come lady I will pick you up, at the taxi rank specifically. **[Felicia]**

> When the guard or the driver see your circumstances, they provide help. They support you. **[Jan]**

Theme 3: Dependency, *I must dance along to his fiddle*

Regardless of whether participants used privately owned vehicles, mini-bus taxis or their wheelchairs, they were reliant on others to reach services and activities in the community. This led to a sense of dependency.

> I must dance along to his [owner of the private vehicle] fiddle, I must fall in with what he says. I must arrange things in his favour. That it doesn't count in my favour, because I can't just tell him what he must do. [James]

> The schools have started again so now I cannot bother her [sister who owns a car] anytime, and she gets home after three in the afternoons. **[Felicia]**

The change from being independent and being able to go where they want to when they want to having to ask and wait on others for every trip created frustration, distress, and even despair.

> It is a terrible adjustment, a terrible adjustment you have to know. I drove…I did not have to ask. When I wanted to go somewhere, I got into my car and there I go…It is miserable to have to ask, 'I want to go, will you please take me? **[Carol]**

> The time I was walking, I did my own thing, but now I must ask someone to…to help me…Even having my own car, if I want to go somewhere I must ask my son, 'Can you please take me to town?' I can't drive myself. **[Xolani]**

> I could move as I saw fit. If I have an appointment at 10, I was there at 10. Now I must wait for a lift before I can go. **[Jan]**

Participants indicated that they no longer drive because of their insecurities regarding their capabilities and based on their doctor's advice.

> …the doctor told me not to drive anymore…, I am also scared that I might cause an accident for others on the road. I will never drive again. **[Carol]**

The dependence meant a loss of spontaneity. Thought and planning were necessary for things as mundane as going to the shops or visiting friends. Going somewhere on the spur of the moment became impossible. When participants knew about appointments, they organised transport. However, one does not always know where one might need or want to go days or even hours before the time.

> On the Monday already I make arrangements and tell him [friend with car] what time I have to go to the physio and whether he is available…but you don't always know beforehand that you need to go to the doctor the next day or sometimes you feel in the morning you want to go somewhere…then I must call and look for someone to take me where I need to be. **[Carol]**

Theme 4: Social isolation, *You feel done in, dejected*

The dependency and loss of spontaneity resulted in an overall sense of social isolation. Participants vocalised that it was not by choice that they did not participate in community activities, but often due to an inability to get to the activities.

> You do not have transport. You want to go to places, but you cannot get there. Then you feel done in, dejected. Ai jinne, why, if I could walk, I would have been there already…I have to leave stuff [things she did before the stroke], I am not part of it anymore, because I cannot get there…because I cannot walk anymore, and I do not have anyone that can push me in my wheelchair. **[Dottie]**

> If I do not have transport, it is difficult for me to go anywhere that I want to go. **[Xolani]**

Money to pay for transport was often a determining factor whether participants could participate in community activities.

> A Taxi must be paid. I cannot just pick up the phone and ask, 'Take me to town, take me to church.' They want to be paid and there is not always money to pay. There are times that I cannot get to the hospital for my appointments because I do not have the money to pay for transport. **[Dottie]**

Participants have resigned themselves to the situation, but the dream to move about freely in the community remains.

> Some days it is a sad story. But you get used to it. It is not the end of the world. But it will be nice to again be able to go everywhere that you have to go. **[Carol]**

DISCUSSION

Freedom of movement, *My power chair, my Ferrari.*
Wheelchairs became the `feet` of participants who previously walked to access the community. Instead of walking they now rolled where they wanted to go. This finding underscored the importance of providing persons with severe mobility impairments with wheelchairs. It is possible that a powered wheelchair or other powered mobility device can enhance community mobility even more than push chairs. Once obtained, this expensive device decreases or eliminates the day-to-day cost of transport. It can create a sense of independence and enhance community mobility and participation[31].However, not every person who had a stroke will be able to mobilise with a powered wheeled device. Physical impairments caused by the stroke such as hemianopia, decreased motor coordination, impaired cognition and/or memory and slow reaction time will negatively impact a person`s ability to operate a power wheeled device safely. Environmental barriers like community infrastructure (poor road conditions, narrow entrances, stairs/hills/slopes), adverse weather conditions (rain, wind, and heat) and negative attitudes can hamper community mobility of both manual and powered wheeled device users[32]. Violence and crime in South Africa are additional challenges with regards to the safety of wheelchair users when accessing communities[17,18,33.] Finally the cost of powered devices might be prohibitive to it being issued in the South African Government sector. Occupational therapists should consider issuing a powered wheeled device only after comprehensive assessment and careful consideration of all the variables that might impact an individual's ability to use it to enhance community mobility. Current findings on the usefulness of a powered wheeled device to enhance community mobility after stroke is preliminary and must be explored through further study.

Social anxiety, *People stare at you like they do not have a heart.*
Current findings highlighted the undignified and degrading nature of transfers in and out of minibus taxis. This experience had a ripple effect, which led to social anxiety when using taxis. Pyer & Tucker[21] referred to this phenomenon as transport anxiety, and highlighted similar emotional discomfort experienced when accessing public transport among a group of young wheelchair users in Britain. In the study setting, minibus taxis lacked adaptive equipment to facilitate navigating in and out of them independently. Therefore, a carer was needed for whom an extra fee had to be paid. Alternatively, assistance had to be sought from taxi guards and/or fellow commuters who are probably not skilled in providing the necessary assistance. Thus, the risk of injury to either party increases. To counteract these experiences, adaptations such as lifts or ramps, and wheelchair docking stations should be investigated[21,34]. The role of occupational therapists is to advocate for adaptations to public and/or private transport to provide dignified access for wheelchair users to these modes of transport. Occupational therapists will have to look at the most effective and appropriate transfer strategies for wheelchair users into and out of minibus taxis to prevent social anxiety when making use of minibus taxis. It is also important that wheelchair users, caregivers, taxi drivers and their guards are trained in appropriate transfer techniques for wheelchair users.

The topic of negative attitudes of taxi drivers and fellow commuters has been widely reported [6,8,16,17] and again it showed its presence in the current findings. Especially telling was the exploitation of a participant to the extent of bribery. This illustrates the power imbalance between minibus taxi drivers and wheelchair users and furthermore highlights the dependency of wheelchair users as also described by others[21,34]. Occupational therapists can explore workshops or group discussions with the hope of changing the negative practices.

A less frequent reported finding was the positive attitudes, respect, patience, and goodwill shown by some taxi drivers, guards, and fellow commuters. The findings showed that attitudes and behaviour of taxi drivers and fellow commuters were not negative across the board as the popular narrative seems to indicate. As in all spheres of life there is a spectrum from the positive to the negative. It is important to acknowledge the positive and to start building a body of evidence in that regard. Acknowledgment can also strengthen individuals in their actions.

Dependency, *I must dance along to his fiddle.*
Participants, previously independent individuals, were now dependent on others for community mobility and thus community integration. The dependency decreased their autonomy[21], led to frustration, and negatively influenced their motivation and ability to participate in community occoupations[34]. An American study with a group of diverse wheelchair users[35], and a British study with teenage wheelchair users[21] also highlighted the increased dependency wheelchair users face in order to participate in community activities.

Social isolation, *You feel done in, dejected.*
Social anxiety and dependency resulted in a loss of spontaneity when it came to community activities. The restrictions to movement and accompanying emotional distress can create a sense of social isolation. Similar findings were documented by others[9,20,21]. Psychologically, feelings of loneliness, worthlessness, and heartbreak can develop, that negatively impact individual health and well-being and increase stress levels and suicide ideation[36].

Occupational therapy intervention concentrates on facilitating participation in life roles and meaningful occupations. To achieve that the occupational therapist is concerned with bodily impairments, the requirements of different occupations important to the client, and the factors that empower or disrupt engagement in a specific occupation[19]. The current study findings are important to occupational therapy practice as it identifies a barrier to meaningful participation in community occupations. The negative impact that insufficient community mobility might have on community integration and occupations that are performed in settings outside the home makes it imperative that community mobility is included in occupational therapy assessment and intervention strategies. Occupational therapists can also empower individuals with mobility impairments with the necessary life skills to address the psychological

challenges due to decreased community mobility.

Study limitations

Caregivers, taxi drivers, stroke survivors living on the surrounding farms, and those who could not converse over the phone were not included in the study. Due to COVID-19 restrictions the study population could not be identified with the assistance of community-based therapists as proposed. Therefore, the population sampled from were smaller than anticipated and purposive sampling could not be done. A further limitation imposed by COVID-19 restrictions was the use of telephonic data collection and thus exclusion of people who could not converse over the phone. With in-person data collection persons with communication impairments would have been accommodated. Communication difficulties might lead to additional challenges when accessing transport.

Recommendations

- While not appropriate for everyone, it is recommended that in certain circumstances, after a thorough assessment, stroke survivors be issued with powered wheelchairs for community mobility via DOH or donor funding.
- The taxi drivers who showed goodwill to participants can be approached by DPOs to act as activists to create positive change within the taxi community toward wheelchair users.
- The possibility of placing an identifiable sticker on the taxis of drivers who are happy to provide transport to stroke survivors and other wheelchair users should be explored.
- The possibility of fitting some taxis with adaptations such as ramps, lifts, and wheelchair docking stations, and funding models for these adaptations should be explored in further study.
- The perceptions and attitudes of taxi drivers and/or taxi guards and co-commuters re the use of minibus taxis by wheelchair users must be explored in future research.
- Further research into the use of powered wheelchairs on the enhancement of community integration within the African context, is also called for.

CONCLUSION

Community mobility barriers hampered participants' ability to participate in occupations they found meaningful, increased their dependence, and left them isolated. It is important that occupational therapists are aware of the community mobility challenges stroke survivors and other wheelchair users might experience and implement strategies to mediate these during intervention. The study exposed the negative psychosocial consequences where transport access barriers prevent dignified, spontaneous community integration. It also shows that using a wheelchair, and even more so a powered wheelchair, might negate some of these consequences.

Author contributions

The research was done in partial fulfilment of the requirements for the degree of Masters in Human Rehabilitation Studies at Stellenbosch University for the first author, Waldo Bradley Visagie. He conceptualised the idea, collected and analysed data and drafted the article. Surona J Visagie and Jerome Peter Fredericks were his supervisors and provided input during conceptualisation and data analyses. They were part of the write up and drafting of the article and were involved in submission and revision.

Conflict of Interest

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

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REFERENCES

1. United Nations. Flagship Report on Disability and Development. Realization of the Sustainable Developmental Goals by and for people with disabilities. United Nations. 2018. https:/social.un.org/publications/UN-Flagship-Report-Disability-Final.pdf (Cited 29/05/2022)
2. The Republic of South Africa. National development plan. Vision for 2030. 2011.
3. Venter C, Mahendra A, Hidalgo D. From mobility to access for all: Expanding urban transportation choices in the global south. World Resources Institute, Washington, DC, pp.1-48. 2019. https:/www.wri.org/research/mobility-access-all-expanding-urban-transportation-choices-global-south (cited 24/05/2022)
4. Republic of South Africa. National Department of Social Development. White Paper on the Rights of Persons with Disabilities. 2015
5. Mudzi W, Stewart A, Musenge E. Community participation of patients 12 months post-stroke in Johannesburg, South Africa. African Journal of Primary Health Care and Family Medicine. 2013;5(1):1-9. http:/doi:10.4102/phcfm.v5i1.426 .
6. Lister HE, Dhunpath R. The taxi industry and transportation for people with disabilities: Implications for universal access in a metropolitan municipality. Transformation: Critical Perspectives on Southern Africa.2016;90:28-48. https:/muse.jhu.edu/issue/33620 DOI: 10.1353/trn.2016.0009 [Accessed 03/03/2023]
7. Hussey M, Maclachlan M, Mji G. Barriers to implementation of the Health Rehabilitation Articles of the United Nations Conventions on the Rights of Persons with Disabilities in South Africa. International Journal of Health Policy and Management. 2017; 6(4):207-218. https:/dx.doi.org/10.15171%2Fijhpm.2016.117
8. Joseph C, Scriba E, Wilson V, Mothabeng J, Theron F. People with spinal cord injury in Republic of South Africa. Am J Phys Med Rehabil. 2017;96(2):S109-111 http:/doi.org/10.1097/PHM.0000000000000594
9. Kett M, Cole E, Turner J. Disability, mobility and transport in low-and middle-income countries: A thematic review. Sustainability. 2020;12(2):589. http:/doi.org/10.3390/su12020589
10. Scheffler E, Mash R. Surviving a stroke in South Africa: Outcomes of home-based care in a low-resource rural setting, Topics in Stroke Rehabilitation. 2019;26(6):423-434.

https:/doi.org/10.1080/10749357.2019.1623473
11. Walters J. Overview of public transport policy developments in South Africa. Research in Transportation Economics. 2013;22(1):98-108. https:/doi.org/10.1016/j.retrec.2012.05.021
12. Statistics in South Africa. (2018). General Household Travel Survey. Pretoria: Statistics South Africa.
13. Chiwandire D, Vincent L. Wheelchair users, access and exclusion in South African higher education. African Journal of Disability. 2017;6(0):353. https:/doi.org/10.4102/ajod.v6i0.353
14. Vanderschuren M, Baufeldt J, Phayane S. Mobility barriers for older persons and people with universal design needs in South Africa. International Conference on Mobility and Transport for Elderly and Disabled Persons.2015;14:1-17. https:/www.researchgate.net/publication/282756122_MOBILITY_BARRIERS_FOR_OLDER_PERSONS_AND_PEOPLE_WITH_UNIVERSAL_DESIGN_NEEDS_IN_SOUTH_AFRICA (Cited 26/05/2022)
15. Pretorius C, Steadman J. Barriers and facilitators to caring for a child with cerebral palsy in rural communities of the Western Cape, South Africa. Child Care in Practice. 2017;24(4)1-18. https:/doi.org/10.1080/13575279.2017.1347146
16. Gudwana K. Experiences of persons with mobility impairment in using public transport in Knysna townships in the Western Cape Province. Unpublished Master's dissertation, University of Stellenbosch, Cape Town, South Africa.2019.
17. Cawood J, Visagie S. Environmental factors influencing participation of stroke survivors in a Western Cape setting. African Journal of Disability. 2015;4(1):198-206. https:/doi:10.4102/ajod.v4i1.198
18. Lorenzo T. We are also travellers: An action story about disabled women mobilising for an accessible public transport system in Khayelitsha and Nyanga, Cape Metropole, South Africa. South African Journal of Occupational Therapy. 2008;38(1):32-40.
19. Boop C, Cahill SM, Davis C, Dorsey J, Gibbs V, Herr B, Kearney K, Metzger L, Miller J, Owens A, Rives K. Occupational therapy practice framework: Domain and process fourth edition. AJOT: American Journal of Occupational Therapy. 2020 Aug 15;74(S2):1-85. DOI: http:/dx.doi.org.ez.sun.ac.za/10.5014/ajot.2020.74S2001
20. Kohler RE, Tomlinson J, Chilunjika TE, Young S, Hosseinipour M, Lee CN. "Life is at a standstill". Quality of life after lower extremity trauma in Malawi. Quality of Life Research. 2017;26(4):1027-1035 https:/doi.org/10.1007/s11136-016-1431-2
21. Pyer M, Tucker F. With us, we, like, physically can't: Transport, mobility and the leisure experiences of teenage wheelchair users. Mobilities.2017;12(1):3652. https:/doi10.1080/17450101.2014.970390
22. Sze NN, Christensen KM. Access to urban transportation system for individuals with disabilities. IATSS research. 2017;41(2):66-73. http:/dx.doi.org/10.1016/j.iatssr.2017.05.002
23. World Health Organization (WHO). (2011). World Report on Disability. Geneva. Avaiable: https:/www.who.int/publications/i/item/9789241564182 [Cited 03/03/2023]
24. Maleka M, Stewart AS, Hale L. The experience of living with stroke in low urban and rural socioeconomic areas of South Africa. South African Journal of Physiotherapy.2012;68(3), 25-29.
25. Bradshaw C, Atkinson S, Doody O. Employing a qualitative descriptive approach in health care research. Global Qualitative Nursing Research. 2017;4(1):1-8. Https:/doi10.1177/2333393617742282
26. Department of Health: Western Cape. (2018). LO2 : Rural Health in Context Community Oriented Primary Care Design and Plan Appropriate Interventions. Worcester.
27. Drabble L., Trocki KF, Salcedo B, Walker PC, Korcha RA. Conducting qualitative interviews by telephone: Lessons learned from a study of alcohol use among sexual minority and heterosexual women. Qualitative Social Work.2016;15(1):118-133. https:/doi.org/10.1177/1473325015585613
28. Braun V,Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology.2006;3(2):77-101. https:/doi.org/10.1191/1478088706qp063oa
29. Nowell LS, Norris, JM, White DE, Moules NJ. Thematic analysis: Striving to meet the trustworthiness criteria. International Journal of Qualitative Methods.2017;16(1):1-13. https:/journals.sagepub.com/doi/pdf/10.1177/1609406917733847
30. Department of Health: Republic of South Africa. Ethics in Health Research: principles, processes and structures. Second edition. Pretoria. South Africa. 2015
31. Frank AO, De Souza LH. Problematic clinical features of children and adults with cerebral palsy who use electric powered indoor/outdoor wheelchairs: A cross-sectional study. Assistive Technology. 2017;29(2):68-75. https:/doi.org/10.1080/10400435.2016.1201873
32. Rushton PW, Kairy D, Archambault P, Pituch E, Torkia C, et al. The potential impact of intelligent power wheelchair use on social participation: Perspectives of users, caregivers and clinicians. Disability and Rehabilitation: Assistive Technology. 2015;10(3):191-197. https:/doi:10.3109/17483107.2014.907366
33. Scheffler E, Visagie S, & Schneider M. 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. 2015;7(1):1-11. https:/doi.org/10.4102/phcfm.v7i1.820
34. Learmonth YC, Rice IM, Ostler T, Rice LA, Motl RW. Perspectives on physical activity among people with multiple sclerosis who are wheelchair users: Informing the design of future interventions. International Journal of MS Care. 2015;17(3):109-119. https:/doi:10.7224/1537-2073.2014-018
35. Hammel J, Magasi S, Heinemann A, Gray DB, Stark S. et al. Environmental barriers and supports to everyday participation: A qualitative insider perspective from people with disabilities. Archives of Physical Medicine and Rehabilitation. 2015;96(4):578-588. http:/dx.doi.org/10.1016/j.apmr.2014.12.008
36. Velho R. Transport accessibility for wheelchair users: A qualitative analysis of inclusion and health. International Journal of Transportation Science and Technology. 2019;8(2):103-115. https:/doi.org/10.1016/j.ijtst.2018.04.005