

# ORIGINAL RESEARCH

Access to wheelchairs by persons with mobility impairment in a remote rural district of KwaZulu-Natal, South Africa: therapists' perspectives

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# ABSTRACT:

Introduction: The WHO has estimated that 1% of the world's population need a wheelchair, but few have access. Access to wheelchairs for most of the South African poor population is through accessing rehabilitation services at public health facilities. This study explored access to wheelchair services from the perspective of rehabilitation therapists, within the uMkhanyakude district of KwaZulu-Natal. Therapists' perceptions on access, and its impact on service delivery is under-explored in the literature.

Methods: Semi-structured interviews with 11 rehabilitation therapists in the uMkhanyakude district directly involved with

wheelchair services were conducted. Levesque et al's conceptual framework of access to health care was used to analyse the data. Themes consistent with these dimensions – approachability, acceptability, availability and accommodation, affordability and appropriateness – were identified from the data.

**Results**: Access to wheelchairs was perceived to be facilitated by the establishment of meaningful relationships with wheelchairs users, the ability to eventually provide an appropriate wheelchair for all users, the provision of services close to where people live, the training of caregivers and the use of local peer trainers.

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Perceived barriers were limited outreach by the rehabilitation staff, poor screening of those with mobility impairment by other categories of staff, and limited space and time to provide services. Further barriers linked to the therapists included their uncertainty about their level of competency in the context and lack of peer support for the rehabilitation staff, especially those working alone. Barriers associated with clients were the limited understanding of wheelchairs, and what was perceived to be a lack of responsibility to look after the wheelchairs, which led to poor maintenance.

Conclusion: The aspects of the five dimensions of access of Levesque et al's framework were identified as both facilitators and barriers. The therapists working in this remote rural area have a a strong sense of responsibility about the wheelchair service delivery process and offered clients the best they could with limited human and financial resources. They have a good understanding of the wheelchair users and the environment they function in, which enabled constant adaptation of the services to meet the needs of that specific community.

### Keywords:

rehabilitation, South Africa, therapist perceptions, wheelchair service provision.

# FULL ARTICLE:

### Introduction

An estimated 1% of the world's population use a wheelchair for mobility<sup>1</sup>. According to the WHO, only 5–15% of these individuals have access to an appropriate wheelchair, with the majority resident in low- and middle-income countries<sup>1</sup>. In South Africa approximately 2% of the population aged more than 5 years use a wheelchair<sup>2</sup>. The higher number of wheelchair users in South Africa can be ascribed to many factors, including improved care for the increasing number of chronic diseases of lifestyle such as diabetes, which decreased mortality rates but potentially increased numbers of residual impairments<sup>3</sup>; and the roll-out of the anti-retroviral therapy program, which enabled people with HIV-related permanent neurological impairments to live longer with attendant mobility impairment and therefore anecdotally needing wheelchairs for mobility<sup>4</sup>.

Approximately 84% of all South Africans do not have access to private health care and probably access public health facilities, for example the hospitals and clinics in their residential district<sup>5</sup>. The South African Department of Health is the primary provider of rehabilitation services to people with disabilities<sup>6</sup>, including the provision of wheelchairs<sup>7</sup>. The provision of assistive devices such as wheelchairs is informed by a standardised guideline, which does not stipulate how specific assistive devices should be distributed to users<sup>8</sup>.

Accessing healthcare services implies that a person identifies a need for these services and has the opportunity both to reach and to obtain these services when needed<sup>9</sup>. Levesque et al identified five dimensions of access, each aspect including elements of both the supply and demand side<sup>9</sup>. This study explored the features of the supply side, identified by the following aspects: approachability, acceptability, availability and accommodation, affordability, and appropriateness. In this context, the supply side includes the following aspects:

- Approachability refers to the ability of people with mobility impairment to recognise that there is an available, reachable wheelchair service that could have an impact on their mobility and health. The supply-side elements of approachability include transparency, information about services, screening and outreach services<sup>9</sup>.
- Acceptability relates to social and cultural factors that make it
  possible for people to accept aspects of a wheelchair service
  within their context. The supply-side elements include
  professional values, norms, culture and gender of the
  therapists<sup>9</sup>.
- Availability and accommodation refer to the physical space and those working in it and whether wheelchair users can physically and timeously access these. It covers aspects such as geographic location, hours of opening and the use of appointments<sup>9</sup>.
- Affordability relates to the economic capacity of wheelchair users in terms of resource and time for service utilisation, and includes direct, indirect and opportunity costs<sup>9</sup>.
- Appropriateness refers to the alignment between the service provided and the way it is provided to meet client needs.
   Appropriateness will address the amount of time needed to access services, determine the correct intervention, as well as the technical and interprofessional quality of the service. The supply-side elements include quality and adequacy of the service.

Guidelines to help member states of the WHO set up their own local wheelchair provision system within their healthcare system have been available internationally since 2008<sup>1</sup>. The global barriers to wheelchair access were identified by the WHO in 2011. Further identified barriers include leadership and governance, finance, service delivery, human resources and wheelchair production<sup>10</sup>.

This article reports on an investigation of accessing wheelchair services from the perspective of rehabilitation therapists (occupational therapists and physiotherapists) within the uMkhanyakude district of KwaZulu-Natal (KZN). Views of therapists focused on access to wheelchair services in the areas, and by implication its impact on service delivery. Access to wheelchair services within a rural context in KZN has been under-explored in the literature.

#### Choice of setting

The uMkhanyakude district of KZN is among the poorest districts in South Africa<sup>11</sup>. It is a sparsely populated deep rural area situated far north in KZN, and it lies along the borders of eSwatini and Mozambique. The mainly isiZulu speaking population totals 685 470 people<sup>11</sup>. The population density is 47.3 persons per square kilometre<sup>11</sup>. Most of the population live in formal dwellings (70%)<sup>11</sup>. The unemployment rate is at 42.8%<sup>11</sup> and 94.5% of the population in the district access public health services 12. People access these services largely through using privately owned minibus taxis, at a considerable cost to themselves 12. The terrain in the district varies from very soft beach sand near the coast to rocky mountainous terrain inland, making it very difficult for wheelchair use. Wheelchair users aged 5 years and above were reported as 1.6% of this district's population, which is less than the national average<sup>13</sup>. Most of the wheelchair users receive a government pension – either a disability pension (for those aged less than 60 years) or an old-age pension (if aged over 60 years), which at the time of the study amounted to about R1500 (approximately A\$133) per month.

There are five district level hospitals and 57 fixed clinics in uMkhanyakude <sup>14</sup>. Rehabilitation services including occupational therapy and physiotherapy are available at all five of the hospitals, and rehabilitation outreach services extend to several of the fixed clinics <sup>14</sup>. The permanently employed therapists located at the hospitals are supplemented annually by community service officers. Community service officers are occupational therapy and physiotherapy graduates who are placed by the national Department of Health at a public health facility post qualification for a year before they are able to register as independent practitioners.

At the time of the study there were eight permanently employed occupational therapists and twelve physiotherapists, and eight occupational therapy and six physiotherapy community service officers distributed unevenly among the five hospitals. The permanent therapists had been practising at their respective hospitals for periods of 1–20 years, although they had, in total, been practising for periods of 5– 22 years. The permanent staff all spoke the local language, isiZulu, with varying degrees of proficiency. The majority of were female. Support staff (occupational therapy and physiotherapy technicians) were from the local communities.

Some of the outreach services are offered by community health workers. Community health workers are drawn from the local community and are trained primarily in home-based care, health promotion, and maintenance and treatment compliance 15. They function within ward-based primary healthcare teams led by nurses within the different catchment areas in a municipality 15. They are colloquially referred to as *nompilos* or community caregivers within this district. The community health workers are not considered part of the rehabilitation team, but form part of the outreach into the district that the therapists use to identify potential wheelchair users.

The same level of wheelchair service delivery is not maintained from year to year, as at times there may be no service if there is no therapist at the hospital at the time. All the hospitals offer free wheelchairs to those that need them and are classified as indigent. Each of the hospitals has a wheelchair repair facility linked to it, offered by a person with a disability through a joint initiative of the KZN Department of Health and Disabled People South Africa. The workspace, spares and tools are supplied by the hospital, and the therapists oversee this project. All the hospitals repair and recycle wheelchairs to ensure that people that need wheelchairs are provided with one.

#### Methods

#### Data collection

Therapists involved in the wheelchair service delivery process were recruited to participate in the study. Eleven therapists out of the 34 working in the district at the time volunteered to participate in the data collection process. They comprised eight permanent therapists (five occupational therapists and three physiotherapists) and three community service occupational therapists.

The researcher conducted semi-structured interviews with each research participant at their place of work during a 2-week period. The interviews used probe questions based on the WHO service delivery process to guide the discussion. All the conversations were digitally recorded and transcribed verbatim by the principal researcher.

### Self in setting

The principal researcher trained many of the participants, either at undergraduate level or at postgraduate courses and workshops. She is also involved in the process of wheelchair service delivery throughout the province. This added richness to the datagathering process but must be reflected on critically to prevent bias, as described below.

#### Data analysis

Levesque et al's (2013) conceptual framework of access to health care was used to analyse the data<sup>9</sup>, to deductively draw out 'threads' based on the five dimensions of access<sup>16</sup>. Themes and subthemes consistent with the dimensions of approachability, acceptability, availability and accommodation, affordability and appropriateness of the wheelchair service delivery were identified from the data.

Reflexivity through discussions with an experienced researcher who was independent of the interviewing process and only had access to the anonymised data ensured that the research process guided data emerging, rather than relying on the preceding contacts the principal researcher has had with the research participants.

### **Ethics approval**

Ethics clearance was obtained from the University of KwaZulu Natal, Biomedical Research Ethics Committee (approval BE327/15)

and the KwaZulu Natal Department of Health. Confidentiality and anonymity were assured to protect the participants, who were sharing information that they might consider sensitive as employees of the Department of Health. The participants were anonymised and a number was allocated to their respective data for analysis and reporting.

#### Results

The Levesque et al (2013) framework deemed the providers to have the responsibility of the supply side dimensions<sup>9</sup>. The therapists, as wheelchair service providers, identified the perceived facilitators and barriers to wheelchair accessibility. These are reported below.

### **Approachability**

Approachability refers to the ability of people to identify the available reachable services that may have an impact on their access to wheelchairs. The supply-side elements include transparency, information about services, screening and outreach services<sup>9</sup>.

The research participants raised concerns about the information available to clients to help them make decisions about both their need for a wheelchair, or their need for a more appropriate wheelchair. Long-term wheelchair users were aware of the services on offer guided by past services that were available in that area.

There are different levels of service in the province in different places ... what people know and don't know about it changes expectations. (participant 11)

The screening and outreach were done by the community caregivers, who are perceived to have little or no knowledge of disability and wheelchair needs. Some therapists were addressing this shortfall with in-service training.

The CCGs [community caregivers] refer a lot, which can cause problems, as the nompilos promise a wheelchair, and [this promise] is not always appropriate. (participant 4)

Another reported challenge was the limited understanding by the caregiver or the user of the importance of an appropriate wheelchair. This meant that, despite many hours of therapist intervention, the person who needed the correctly adjusted and fitted wheelchair did not always use it.

'... but my wheelchair works fine, why would we change'. The patients think there is only one type of wheelchair. (participant 6)

The number of available therapists influenced provision of outreach services. These services were offered when time allowed, and by using other available human resources such as the staff from the ward-based primary healthcare outreach programs.

We have only been doing intensive home visits for the last year. There are many out there, many not identified by the CCGs [community caregivers]. I have done visits with the nurses on the outreach team to identify appropriate people. (participant 6)

Therapists that had established long term relationships with wheelchair users reported that they were trusted to sort out problems not just with the wheelchair but with other issues within the healthcare system. A permanent therapist felt that the clients generally mistrusted the formal system or were not using it because they were illiterate and fearful, therefore using a known and trusted person. Users of wheelchairs tended to come to the therapists they knew for the needed services, which was apparent even with a community service officer, who had only been there for a year but had built up meaningful relationships with the community.

### **Acceptability**

Acceptability is related to social and cultural factors that make it possible for people to accept aspects of the wheelchair service, including the professional values and norms, and culture- and gender-based issues related to the service providers<sup>9</sup>.

The therapists were aware that their service did not comply sequentially with the WHO steps, but were confident that they offered a service that ensured the most appropriate, correctly adjusted wheelchair and training to use it for the clients in that particular context.

We can't differentiate according to the WHO steps. We find the CCG [community caregiver] will tell us 'the lady or mkhulu [older man] can't walk'. We will go out to the patient, start to assess and measure. We know what stock is available. We then deliver to the clinic or the client. (participant 6)

The provision of a correct wheelchair while a patient was still hospitalised offered a chance for the person to have a life of participation rather than restriction. Hospital-based wheelchair provision was considered an enabling factor.

In the ward we issued a wheelchair to a gogo ['granny'] who was not compliant for other treatment by the other staff, the wheelchair gave her the 'wow' to be able to mobilise, she was singing and kissing everyone. (participant 6)

One therapist of the same culture and language group as the clients mentioned her frustration linked to culture.

They don't even come to get repairs done as this is their level of function – the culture and passivity ... People won't come for the wheelchair to be serviced – they don't care. After a year the wheelchair is broken, then they expect a new wheelchair. There is a sense of entitlement. (participant 2)

#### Availability and accommodation

Availability refers to the physical space and staff offering the service, and whether the area can be reached physically and in a timely manner within the geographic location. Accommodation refers to the hours of opening, the use of appointments and mechanisms to enable these<sup>9</sup>.

Therapists were very aware of the distances that users needed to

travel to access services, and they did home visits where practical and possible. These therapists looked for ways to improve access by moving services closer to the users or seeking to offer this when possible. They worked from a centralised hospital or clinic base, which was not always convenient for access by their clients because of the remoteness of the client's home.

Everything is centralised at present, from next year we will be at the clinics. (participant 7)

The lack of available work space was considered a barrier to service delivery. Despite this limitation, services were offered in these less than optimal circumstances.

There is limited space at the clinic to work, especially if there is myself, the CSO [community service officer], client and a caregiver in the room – we may have a hospital bed and nothing else. (participant 10)

The hours of operation at the hospital relative to the patient load were more acceptable compared to the time available for consultation at clinics. The time available to engage with each patient was limited, especially at the clinics, due to the high volume of patients wating for intervention and the variety of presenting problems.

Time is a problem at the clinic as we often have six or more patients to see, while it is not a problem in the hospital. (participant 6)

### **Affordability**

Affordability relates to the ability of people to use both their economic resources and time, directly and indirectly. These costs include the cost of the service itself, the transport costs, and the cost of having to pay someone to look after dependents while the person is away at the hospital or clinic<sup>9</sup>.

The perception of the therapists was that the peripheral costs associated with the wheelchair service and upkeep prevented people from accessing these services.

Transport to and from the hospital or clinic was expensive, particularly if a helper was needed to accompany the wheelchair user to the hospital or clinic, or if the wheelchair needed to be transported as well. All the therapists reported this as an inhibiting factor.

It is difficult to seat complex cases at home, even if they are on the bed, as space is a problem, but complex seating cases have complex transport needs. Here it costs R700 [about 45% of the government disability or old age pension] to come to the hospital. (participant 6)

A client with complex seating needs – for example a person with physical needs such that the wheelchair or accessories to be adapted to enable maximal function –had to be available at the hospital or clinic for extended periods. This took the client away from other tasks, and meant they cut short the sessions if they had transport waiting.

If a patient is told to come for more complex seating and told it will take some time ... by 11h30 or 12h00 they want to go as their transport leaves. (participant 6)

#### **Appropriateness**

Appropriateness is the fit between the service and a client's needs, timeliness, the amount of care used in assessing wheelchair needs, determining the correct intervention, as well as the technical and interprofessional quality of the service. Quality and adequacy of the service, as well as coordination and continuity, form part of appropriate services.

All the therapists, except for one community service officer, had completed at least the basic level of WHO training in wheelchair service delivery. Three had also completed the intermediate level and two the advanced level, indicating that the majority were well trained in the service delivery process according to the WHO. However, there was a feeling of uncertainty by some of the therapists about their level of competency for the context of practice. The WHO guidelines were not considered sufficiently helpful to the therapists within this context.

It is difficult to know what is best for the patient – for example, do we give buggies which are good for seating, but they can't use in this terrain. (participant 6)

The permanent therapists that worked alone offering wheelchairs and seating services felt the lack of support most keenly, but nevertheless thought they served the clients to the best of their ability.

I think we get the basics right, but there is limited support. (participant 11)

Wheelchair users dependent on transport to access services incur greater financial costs due to the need for extra space and the time taken to load a wheelchair. Some clients then leave their wheelchairs at home limiting their mobility when arriving at the service point.

We have not ordered buggies in a while, as they usually pose a problem to mothers as they are problematic when using public transport as they require a lot of disassembling. We ordered [trade name] buggies and it wasn't convenient for the mothers to use the buggies, as they have to pay for an extra seat for the buggy. (participant 3)

Most of the therapists tended to work closely with the other staff, including nurses, doctors, support staff and the community caregivers, as they depended on them to identify those in need of wheelchairs, or those with wheelchairs that were defective.

Therapists considered giving accurate and appropriate information as essential to the successful use of a wheelchair.

We do basic education for the patients – we expect them to know simple things like getting over a step, because they really do not know – so training is vital. (participant 4)

The therapists' perception was that clients often do not adhere to

the recommended protocols related to wheelchair care and maintenance, which impacts on the life span of the wheelchair.

The terrain here means wear and tear to the chair is fast – and the clients don't maintain them well. (participant 3)

Caregiver support was offered routinely to those caregivers that visited the client or accompanied the client to appointments, but often they were not reachable, unless home visits were done. This was considered important.

We get the family involved early with education on wheelchair transfers. If we left it to the final day, they are bombarded with information so it is better to stagger the information. (participant 2)

#### Discussion

The ability to identify a reachable, available service was highlighted in the areas where the therapists had an established relationship with the people with disabilities and the community caregivers. The therapists' perception was that although wheelchair services were available, they were not always easily accessible to all. Expectations of the long-term users, who were aware of the wheelchair services in their area, were strongly influenced by their past experience. The community caregivers conducted screening for wheelchair needs but they had little or no knowledge of disability. This caused frustration with the therapists as people were often referred for a wheelchair who did not need one, which caused unnecessary friction between the therapist and the client. This limitation was addressed wherever possible with in-service training and by empowering other available staff. This highlighted the importance of rehabilitation staff being deployed, not just being available, at all levels of care<sup>7</sup>.

The challenge of limited understanding of caregivers or users, and the beliefs about the abilities of those that need a wheelchair, were a further challenge to address, mainly due to the few wheelchair users who actively participate in activities within the community. This is partly due to environments that were not conducive to wheelchair use, and the poor infrastructure. Poor awareness of disability and its influence on seeking intervention is not unique 17. The therapists who built a relationship with wheelchair users over time reported that the wheelchair users knew and trusted them to sort out problems, rather than the formal structures in the hospital. Evidence exists that healthcare professionals who have had close contact with wheelchair users have fewer negative biases and prejudices toward wheelchair users that influence service delivery 18.

Although seeking health care within an acceptable service is reported to be influenced by social and cultural factors <sup>19</sup>, only one therapist, who was of the same culture and language group as her clients, mentioned this as a frustration. Her perception was that the general passivity and sense of entitlement was linked to the societal belief that having a disability meant one did not carry any responsibility. The social aspects, such as community held beliefs linked to the inadequacy of people with disabilities, were more common. This was linked to wheelchair users not being active in

communities.

Appropriate wheelchairs that ensured a fit between the user and the environment they function in were being provided, with adequate training and follow-up of the user<sup>10,20</sup>. Although the therapists were not following the WHO steps sequentially, they were ensuring the best possible wheelchair for the clients, within the constraints of the service. Previous studies concluded that the steps for service delivery might be based on insufficient evidence<sup>21</sup>. The present study found that service delivery in this area operated within the Convention on the Rights of People with Disabilities and the spirit of the WHO wheelchair service delivery steps, by combining steps, or skipping steps<sup>22</sup>, which has been identified in previous research<sup>23,24</sup>.

Therapists often had to offer services in restricted space in the clinics, or in the homes of the clients, all of which made perceived adequate intervention difficult. However, therapists were aware of the cost involved for the clients and were able to offer services in these less than optimal spaces as a way of improving access. Time constraints for the therapists limited the number of clients seen, especially where keeping an appointment is difficult for the client due to the challenges of access<sup>24</sup>. Therapists were aware of the home environment of wheelchair users, the area the wheelchair was stored in, and other uses of the wheelchairs, all of which influenced durability of the wheelchairs. These were all perceived to be barriers to effective service delivery, which have previously been identified<sup>24</sup>. Transport as a significant barrier to access was identified, which is not unique to the uMkhanyakude district<sup>24,25</sup>. Therapists were aware that the most expensive part of the service for the wheelchair users was the transport to and from the hospital or clinic, which they tried to minimise wherever possible. The service, the wheelchair and the repairs were offered free of charge to indigent users, as the wheelchair service in this area only served indigent users. The perception was that this led to neglect of the wheelchair by the user, and that users expected to receive a new chair if their old one broke. This was not addressed in intervention, and is not supported by literature. The time constraints, especially if the wheelchair user had to pay a private person to take them to hospital, was limiting intervention. They had to be ready to leave when their transport was leaving, even if intervention was not complete. This was an inhibiting factor and was addressed by informing the clients beforehand that the process was time consuming. It was felt that this was met with little understanding by the user. This limitation has been reported previously in the literature<sup>24</sup>.

Alignment between the client needs, the environment they function in and the wheelchair was reported as challenging. Therapists, even those with advanced training, reported uncertainty about the quality of service they were offering clients. This was partially attributed to the lack of peer support received by these therapists, and not due to their knowledge. In the hospital where the most staff were engaged in the wheelchair service, there were fewer expressions of concern and more gratitude for the amount of support they received and were able to give others, which was common to service providers in general <sup>17</sup>. All the therapists worked closely with other members of staff, volunteers

and peer supporters to ensure the best outcomes for the users, which is in line with the white paper on the rights of persons with disabilities<sup>26</sup>. Therapists offered in-service training to a variety of people, professional and lay people, users and caregivers, to ensure the current or potential wheelchair user was identified and offered an appropriate service. If there were problems with the wheelchair that the user had not identified, they were referred promptly to the repair service at the hospitals. This was seen as a facilitator.

#### **Limitations and recommendations**

This study explored one remote rural area. It is recommended that more attention to dimensions of access be explored within other remote rural regions and small towns. Little is known about the perceptions of therapists in urban areas, particularly those serving areas where wheelchair users live in semi-formal or informal housing. This could enhance the picture of therapists' views to access. The ability to identify and compare facilitators and barriers to access could facilitate planning to improve access for wheelchair

users to services. Attitudes and perceptions are known facilitators and barriers to effective service provision, so an exploration of these factors could enhance the services offered.

#### Conclusion

The therapists working in the uMkhanyakude district of KwaZulu-Natal have a a strong sense of responsibility about the wheelchair service delivery process. They offer clients the best they can with limited human and financial resources to ensure access to wheelchairs. They are hampered by limitations outside of their influence, but do not allow this to overwhelm them. They have ensured they have a good understanding of wheelchairs, wheelchair users and the environment in which they need to function despite the barriers. This enables them to constantly adapt the services to meet the needs of that specific community as they identify them. Their commitment to the provision of wheelchairs to those who need them drive the therapists to advocate for and provide the extension of the service through outreach to improve access for the client.

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