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ORIGINAL RESEARCH



Parental experiences on the role of wheelchairs in the lives of their children with mobility impairments: a qualitative exploration in Dubai

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ABSTRACT

Purpose: To explore parental experiences on the role of wheelchairs in the lives of their children with mobility impairments in Dubai.

Methods: Seven participants were recruited through purposive sampling and their experiences were explored by conducting semi-structured interviews. The audio recordings were transcribed and thematically analysed.

Results: The findings showed that wheelchairs were an essential part of the children's lives, which enabled their participation in the home, the school and the community. Procurement processes were difficult owing to a lack of assessment and prescription processes as well as insurance companies providing little assistance with payment. The participants described Dubai as a wheelchair friendly city and two overarching themes emerged; firstly, *The wheelchair: "It is her life"*, and, secondly, *Participation: Isolation versus inclusion*.

Conclusion: The study is the first of its kind in Dubai and indicated that the wheelchair played an important role in the children's lives and allowed participation in life roles that brought joy and fulfilment. Without wheelchairs, children would be isolated and frustrated. However, some of the participants were not satisfied with their child's current wheelchair and felt the chair was not appropriate. Recommendations to specific stakeholders included: the development of policies to guide wheelchair service provision by government. In addition, insurance providers could collaborate with the government to adhere to the policy to ensure healthy lives and promote well-being for all.

ARTICLE HISTORY

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Wheelchair procurement in Dubai; parental wheelchair experiences; children wheelchair participation; parental satisfaction with wheelchairs

► IMPLICATIONS FOR REHABILITATION

- The wheelchair provided children the mobility to participate in life roles instead of being isolated.
- Not all children had appropriate wheelchairs.
- Service providers and medical insurance did not give sufficient support during wheelchair selection and procurement.

Introduction

Wheelchairs are enablers of basic human rights, function and active participation that positively influence social integration and quality of life [1–6]. Without wheelchairs, children with mobility impairments might not be able to participate in routine activities such as attending school, joining in family and social outings, or playing outdoors with friends. With wheelchairs, they can participate in numerous activities such as school and sport, learn new activities and build experiences such as attending friends' birthday parties and even travelling abroad [4–8].

Children who have appropriate wheelchairs, with a good fit to their environment and postural support needs as well as support and acceptance of family, friends and communities can participate and enjoy life with less emphasis on their disability [2,5,9]. However, participation of child and adult wheelchair users can be hindered by social and physical barriers [5,10,11]. Social barriers include negative attitudes resulting in humiliation, stigmatisation, pity and invisibility. Uneven terrain, narrow footpaths, lack of or unkempt sidewalks, curbs, stairs and steps, inaccessibility of

transport, inaccessible public and home entrances as well as inadequate space inside dwellings are but some of the physical barriers that wheelchair users might experience when participating in everyday activities [11–13].

In terms of personal experience, some wheelchair users perceive the wheelchair as part of their self-identity and see it as an extension of their bodies that brings a significant increase in activities and feelings of empowerment. Others find it difficult to accept the wheelchair and struggle with feelings of isolation and dependence [5,11,14].

Acceptance of, and satisfaction with the wheelchair are often influenced by aesthetics and the appropriateness of the wheelchair's features [5]. Inappropriate wheelchairs can cause the child to experience fear, anxiety and isolation [3,15]. User satisfaction is affected negatively when wheelchairs do not provide the necessary postural support, are too big, or are uncomfortable [5,11,16]. Challenges experienced with the wheelchair service delivery such as long delivery times, lack of a holistic approach, incomplete assessments and inadequate procedures during the procurement process can also prevent wheelchair users from reaching their

optimum levels of function, impact user satisfaction negatively, and ultimately affect the physical and psychological welfare of the parents and the children adversely [11,17,18].

User participation in the procurement process plays an important role in ensuring user satisfaction with the wheelchair and services received [5,11]. It also improves functional and mobility outcomes for the user [4,19]. When little attention is paid to the users' needs and environments as well as their aesthetic and feature preferences, users often perceive their wheelchairs negatively and might reject them [11].

The user experiences of wheelchairs and other wheeled mobility devices have been explored in several studies and were ably summarized in a meta-analysis by Ripat et al. [5]. However, the experiences of parents of children using wheelchairs remain relatively unexplored. Glumac et al. [19] and Rodby-Bousquet and Hagglund [6] found that parents value the wheelchair as it provides them with relief, comprises a form of therapy, improves opportunities and enhances the child's participation. Parents also expressed the need to be instructed on wheelchair use, maintenance and repair [19].

Parents have a crucial role to play in procuring wheelchairs and motivating their children to then use them. Furthering our understanding of their experiences will contribute to the knowledge on how parents can be supported and ultimately to enhance participation of their children using wheelchairs [20,21]. Therefore, the aim of this study was to explore the wheelchair-related experiences of parents with children who used wheelchairs in Dubai.

The setting

The United Arab Emirates (UAE) is a constitutional federation, consisting of seven emirates of which Dubai is one. The federal government has executive jurisdiction over matters set out in Article 120 of the constitution, which includes health services. The Ministry of Health and Prevention is the federal health authority under which Dubai and the other emirates have their own local health authorities [22].

According to Emirati law, which supersedes Dubai government law, employers are required to provide health insurance to employees and their family members [23]. This ensures that 95% of the UAE's population is enrolled in a health insurance plan [23]. However, health insurance plans are not required to make provision for funding of wheelchairs. Based on the first author's clinical observation, insurance companies in the UAE do not always see the provision of assistive technology (AT) products as a necessity for the wellbeing of the individual and, therefore, do not offer financial support to procure such equipment. As a result the high cost of wheelchairs can put a financial strain on the parent [2,18], who might not always have the financial means to pay for an appropriate wheelchair and may be forced to shop around for the cheapest rather than the most appropriate wheelchair.

Public buildings in the UAE are somewhat wheelchair accessible, fitted with wheelchair bathrooms and lifts, but upon entering the building, wheelchair users are often faced with a curb or steps [24]. In addition, 'wheelchair accessible bathrooms' are not always built to standard regulations and ramps are often steep and narrow [24].

Dubai has one of the largest growing economies and is known for its big, tall buildings and large shopping malls. Most residents live in two-story villas or apartments in the tall buildings. The Government of Dubai launched a national policy in April 2017 to empower persons with disabilities (PWD), by supporting their integration into society [25]. In order to achieve this the Government

of Dubai has a vision to provide a disability-friendly city [26]. There is no mention of wheelchairs or any other assistive devices in the policy.

The first author is an occupational therapist working at a children's hospital in Dubai. In her clinical experience, most assistive products like wheelchairs are imported through vendors, who are often sales-orientated business owners that provide AT products at a high cost. In addition, wheelchairs are not always prescribed by a trained provider. Vendors also often try to sell their own products, whether appropriate to the users' needs or not.

Research method

Design

An explorative qualitative phenomenological design [27] was used to gain an in-depth understanding of parental experiences on the role of wheelchairs in the lives of their children with mobility impairments. Phenomenology allows the presentation of experiences of participants from their own point of view and permits the exploration of multiple perspectives and realities through the study of a few participants [27].

Population, sampling, recruitment and participants

The study population consisted of parents of children (aged two to 18 years), living in Dubai, who used a wheelchair, and who attended out-patient therapy services at a children's hospital in Dubai between January 2018 and April 2018. Employed or other carers who attended out-patient therapy services with the child were excluded from the study since the focus was on parental experiences. Seven parents were purposefully sampled to participate in this study. Children's ages varied between three and 14, they were from both genders and had varying diagnoses as shown in Table 1.

Data collection

Data were collected through one-to-one, semi-structured interviews that allowed participants to share their experiences as is common in phenomenological studies [27] and a personal information form filled out by the parent. Interviews, guided by an interview schedule, were conducted at a venue of the participant's choice, lasted 30–60 min and were recorded with the permission of participants. Questions on the interview schedule were structured around wheelchair related issues including:

- Child's participation in community, school and family activities.
- Process of acquiring the wheelchair.
- Satisfaction with the wheelchair.
- Role of the wheelchair.
- Wheelchair accessibility of Dubai.
- Attitudes and support of others.

Despite most participants' home language being Arabic, all but one chose to be interviewed in English rather than answer through an interpreter. An interpreter assisted with one participant who was more confident to convey her experiences in Arabic.

Data analysis

Audio recordings were transcribed by the primary author; where after an inductive thematic analysis was conducted. Thematic

Table 1. Demographics of the participants and their children.

Child's pseudonym	Child's age	Child's gender	Schooling	Diagnosis	Parent inter-viewed	Ethnicity	Marital status	Home language
Lona	14	Girl	None	Cerebral Palsy	Mother & father	Indian	Married	Hindi & English
Mayed	9	Boy	Mainstream Special needs class	Cerebral Palsy	Mother	Emirati	Divorced	Arabic
Jeba	13	Girl	Mainstream	Muscular Dystrophy	Father	Emirati	Married	Arabic
Halima	11	Girl	Special school	Leighs disease	Father	Palestinian	Married	Arabic
Ali	3	Boy	Special school	Cerebral Palsy	Mother	Emirati	Married	Arabic
Mahmood	7	Boy	None	CVA	Father	Syrian	Married	Arabic
Mossa	6	Girl	None	Genetic Disorder	Mother	Emirati	Married	Arabic

analysis was used as it is a flexible, systematic method that allows sorting of data into various themes, allows interpretation of all the meanings of interest in the material, and concludes the findings in a report [28]. Thematic analysis also allowed the exploration of similarities and differences in the parental experiences regarding the phenomenon of their children using wheelchairs. The six steps of thematic analysis described by Braun and Clarke [28] were followed, namely, transcribing data, generating codes, searching for themes, reviewing the themes, defining the themes, and generating the report.

Rigour

Data saturation was achieved with the completion of the sixth interview, but one further interview was conducted to confirm the saturation. The findings presented here provide a true reflection of participants' experiences, includes divergent findings, and are supported with narrative examples. Conclusions drawn from the data is credible as they matched the actual reported parent experiences. The findings of the study are a true reflection that was not influenced by researcher preferences or judgement, which were managed through reflection and bracketing during the research process.

Ethics

The Health Research Ethics Committee of Stellenbosch University (S18/05/099) and the Dubai Health care city Authority ethics committee (AJCH-020) approved this study. Written informed consent was obtained from all the participants prior to data collection. Participants were assured that non-identifiable data would be used and that a copy of the final article would be sent to them after completion. All participant information would be stored, kept confidential and destroyed after five years [29]. The first author remained sensitive to language and cultural barriers, and avoided unnecessary elaboration of culturally-sensitive topics during data collection. Participants' time were not wasted through irrelevant questions [30].

There was no risk that the study could cause physical harm, but the first author was careful not to cause psychological harm, by being sensitive towards possible feelings of anxiety, embarrassment and unpleasant memories that might be evoked through the interview [27]. Basic counselling and debriefing were available, but not required.

The wheelchair; "It is her life"	Participation; Isolation vs. inclusion
<ul style="list-style-type: none"> • The role of the wheelchair • The procurement process • Satisfaction and appropriateness 	<ul style="list-style-type: none"> • At home • In the community • At school

Figure 1. Themes and subthemes identified from the data.

Findings

The data analysis revealed two overarching themes related to parental experiences of the phenomenon of their children using wheelchairs, each with subthemes, as presented in Figure 1.

Theme 1: the wheelchair: "it is her life"

Role of the wheelchair

Participants felt that the wheelchair played a significant role in their child's life and that without it the child would be isolated and excluded from participation in everyday living. They explained that with the wheelchair, came freedom. It also allowed independent function and engagement with other children:

Halima's father: "... she cannot move, she cannot go, she cannot sit. It is her life; this wheelchair you know."

Mayed's mother: "He will have difficulty to involve himself... like playing with his friends and at school... it helps him to take part."

Jeba's father describes the joy an everyday activity gave her and him, despite the effort he had to make to allow her this opportunity.

Jeba's father: "She wanted to go to a ski-resort to experience the first time the snow... she was on her back... she literally draw a butterfly. So when you fall down on your back and you do the moving of your hands and your legs and it becomes a butterfly. She was so happy. And as a parent you will try your best to have the smile being drawn on your baby, your child's face... Ok, it was not easy to drive the wheelchair in a snow area. It is not easy... So the challenges with the wheelchair... there are lots! But again as a parent the joy that she had that day was worth all this."

Parent narratives expressed the frustration and unhappiness the children experienced when they were without a wheelchair:

Halima's father: "Sometimes you know, without it, her brother playing, mother in the kitchen and she is shouting, she is crying, that nobody listens... It is very difficult without it... the chair is a must. She cannot manage her life without the chair."

Ali's mother: "He should go outside, he should move around. He needs a wheelchair... like this we give him the life. Without wheelchair, just sitting at the home, he doesn't have the right life just sitting and not doing anything. Even he will be not happy."

Participants also felt that their lives would be challenging without a wheelchair. They would have to carry the growing child, with a risk of dropping the child:

Mayed's mother: "Mayed is 9 years ... and heavy ... and big house. He will need someone to carry him ... all the time."

Mossa's mother: "I need to handle her ... maybe she will fall down, and I don't want this to happen to her."

Procurement process

The participants found procurement of the wheelchair very difficult as they received little support from service providers and usually financed the wheelchair out of their own pockets:

Lona's father: "She was growing and she wasn't fitting in any of the prams or the strollers. The hospital did not suggest ... We saw this company online. We went to the company and the salesman helped us ... He is a salesman, so he didn't know what kind of a chair she wanted. So, we had to describe it to him. We want it this way, that way ... we saw this wheelchair on the catalogue ... they didn't have a chair for her to try. They wouldn't order one. So, we just had to order it randomly. Whether she would fit in that or not later that was to be seen."

About the price, Lona's father said: "It was too steep ... Very pricey ..." Halim's father also talked about the high cost of wheelchairs: "... a wheelchair is AED 45,000 (\$12,350). It is the earning for some people for a full year, you know ... This is very expensive; insurance is not covering."

The selection of wheelchairs without trying out the actual product led to dissatisfaction with the wheelchair amongst parents even when they found the procurement process itself easy:

Mossa's mother: "No, it was not difficult [procuring a wheelchair]. I was in [name hospital]. And there is one of the physical therapists, and she told me about this company ... She called them ... they told me about the wheelchair. They showed me the picture but it's ... they are not honest ... what they made for her ... it is a little bit different. They bring for me one to see ... to look at. Then they bring for me another one, when I got the chair. The cloth of this ... at the back ... it is not good. Not what I see before. They did not put for her a stand for her head. The cover on the wheels ... I told them I want something print. They give me the clear one ... also the support from the feet, I didn't like it."

Another parent explained the long process of procurement when requesting assistance from insurance:

Jeba's father: "... the process was very lengthy until today ... more than a year, we still don't have a chair." (This refers to a replacement of her current wheelchair which does not support her sufficiently anymore, because of the degenerative nature of muscular dystrophy).

In contrast, Ali's mother explained that he was measured by a professional and the insurance (From another emirate, Abu Dhabi) paid for the wheelchair:

"The doctor, make an appointment with the physiotherapist ... they told me that he needed a special chair. So, they take the size ... And each year they are making it bigger ... to his size ... I call the company, and they send me someone to take the measurements and to take it and fix it and make it to his size. No, [in response to the question, 'Do you have to pay for the wheelchair?'] because we have the insurance ... Thiqa ... it is the insurance cover and the government [Abu Dhabi] is paying."

Satisfaction and appropriateness

Most of the parents were not satisfied with their children's wheelchairs. Challenges were experienced with the size, weight and durability of the wheelchairs:

Mayed's mother: "Very big ... quickly broken ... it affects his back ... not in a good way. Because it is not a good measurement for him ... and also for his hands ... it's too far for him ... the brakes ... it is hard for him to use."

Mahmood's father: "I don't like the weight. And for Mahmood it is little big."

One parent adapted the wheelchair himself:

Halima's father: "... it's [the wheelchair] large and not completely fit to her. We put something ... but this is by ourselves ... to support her. So now it gives some back support."

Another explained that a therapist adjusted the wheelchair as it could not be returned to the pharmacy from which it was bought:

Mahmood's father: "... the therapist did a lot of things to the chair. Supporting the legs from down and supporting also from back."

Ali's mother was very satisfied that his wheelchair accommodated his physical, environmental and lifestyle needs:

Ali's mother (the participant with insurance that paid for the wheelchair): "I am too much satisfied ... because I know he is sitting in a safe place. And the wheelchair is big and strong so it can go any place like the sand."

Theme 2: participation: isolation versus inclusion

Participation and inclusion in the home, community and at school were facilitated by the wheelchair, supportive attitudes, the design and construction of buildings and open spaces as well as private transport. Isolation was experienced due to negative attitudes of extended family and community members, and where design and construction limited access.

At home

The wheelchair made involvement in family activities possible:

Lona's mother: "... when I am in the kitchen I take her with me in the chair, she loves being with me."

Halima's father: "In the house, she can push herself. From the bedroom to the hall. She come ... for eating you know ... for TV room, dining room."

However, the construction of houses sometimes prevented access to all areas; resulting in isolation from family activities:

Jeba's father: "... we live in a two-story villa ... In the past when she was able ... to move freely ... it was easy. She was able to go up and down as a normal child. Watch TV upstairs, downstairs ... she had the freedom ... see mom in the kitchen while she was cooking but now ... because she is not able to move ... she is pretty much stationed in one corner ... which is her zone."

The children were also accommodated outside of the wheelchair in customary activities:

Jeba's father: "... we like to as an Arab family sit on the floor to eat. So she has a small adjusted back ... just a chair without the legs. Just the seat. So she will sit there."

Ali's mother: "... we take him and put him and keep him in between us [on the floor for mealtime and family socializing]. Because if he stays in the wheelchair he will be far from us."

In the community

Participants explained that they went on family outings:

Lona's father: "She likes to go out. She likes to visit malls... and she also likes the beaches. We take her to the beach... and she likes to put her feet in the water."

Halima's father: "... we take her to the park, take her with the chair. Her sister she will try to combine her in all the activity."

Most of the participants reported on how Dubai as a city accommodated people with disabilities by providing special privileges and accessible public places for wheelchair users:

Mayed's mother: "Most buildings have slides [ramps]... for wheelchair and lifts... in every government building and parks... and have places for wheelchairs to move. And there are specific entrances for wheelchairs in some buildings."

Mahmood's father: "If you will go to any park in the UAE with Mahmood you don't have to pay any one single dirham. Mahmood and his family, I am not paying any one single dirham without showing him any card. If they see this, just Mahmood in the wheelchair they will tell me no need, sorry."

Mossa's mother: "... every mall they have like... now in Dubai... they have for handicap. Even in the beach... Jumeirah beach. They got everything for handicap. For example... they make for her a slide [ramp]. On the beach also, we have area for handicap. Also parking. We have special card for her, from the government."

However, public bathrooms did not accommodate all, limiting family time in, for example, a mall:

Lona's mother: "They got you know the small, for babies, nappy changes... don't have something bigger, her size. We have to rush home."

Community members were experienced as supportive and helpful:

Halima's father: "... people there [in malls] are very friendly. Very friendly, very kind and supportive. Sometimes they give her something some sweets or they pray for her. She is happy you know, she feels the attention everywhere."

Mahmood's father: "You know, people on the street are like surprising about Mahmood, 6-7 years old and he is sitting in a wheelchair. It is like always... they cannot believe. And everyone ask me what happened? But a lot of people helping. One time I went to Doctor. I took Mahmood there... it was an old building. There is no slide [ramp] at the back or something you know for the trolley. Two, three guys they help me to carry the chair and put him inside."

However, negative attitudes were also experienced:

Lona's mother: "... initially we didn't take her out because of that... the stares. But now we decided that that will not stop Lona from going out. Let them stare... it doesn't matter. But then it does hurt us. Ya, it does, it does. And even my second daughter she keeps asking nowadays... why are they looking at Lona like that... why are they staring at her. So, we don't know how to answer her. So... I... We don't want her to get affected... there are other children who are surprised, who ask, ask their mother what's happened to that child? So, when we hear conversation like that we just want to get out of that place immediately or we want to hide her. Just turn the wheelchair so the people will not upset her. So it's not normal to go to a normal place."

Negative attitudes sometimes left the child, and by implication the family, isolated from community activities:

Lona's father: "... it's difficult to adjust even with family. They cannot cope with a child like this in the house... they cannot cope with her crying, her screaming. So, there is always friction between families, not very welcoming. So, we have to stay on our own. We go for parties and marriages. It's embarrassing, we feel embarrassed. Because the way they look. For them it is like an embarrassment. Our family has a child like this. It's like a taboo kinda thing, they don't welcome. So, we

stopped going. So, we don't go even to my grandmother's place, and nobody wants to come and stay with us. Like parents. Even their lives come to a standstill when we ask for help. So, we don't have high expectations, and we understand their situation. So, no bitterness. We just have to get on."

While realising they have no choice but to go on, parents expressed their hopelessness:

Lona's father: "Nobody wants to have a child like this. Your whole life is put to a hold. You cannot do anything else and that's it. Now our lives were great till then. Now no more. There's no life."

Participants found travel in and around town easy as they owned their own vehicles. A special disc entitled them to park on disability parking spaces:

Mahmood's father: "I have a car... I will carry him to put him in the seat of the car. And put the chair back."

Mossa's mother: "We have the special card for her. From the government. She have two cards one for the car and one for the hospital, because you know first the handicap... it is the first person. Like when you stand in a line you can be first in line."

Challenges were faced when travelling abroad using air transport. Parents agreed that services depended on the airline that one travelled with. Some had to carry their children in the airport while others used an airport courtesy wheelchair. Experiences of wheelchairs being broken on arrival at their destination were also relayed:

Lona's father: "... travelling in the airplane is a very difficult thing... taking her in the aisle, carrying her from the immigration. There is no proper transport like they have the common wheelchair which doesn't have the strap. They don't allow the chair inside the airplane."

Jeba's father: "... during traveling we face getting into the plane challenging, especially if you are not travelling with the famous airlines. I carry her into the plane. Depends on the airline, depends on the logistics support of the airport that you have. Of course, in Dubai we are lucky, we have the very best logistics support from the ground staff. Because we need the wheelchair on the second destination, we need to pack it in a good way so that it lands safely. We had an experience that we used the wheelchair inside the airport, so without using the airport wheelchair, and before you will board into the aircraft they will take the wheelchair. When they deliver it back, it comes like someone opened it... they don't handle the wheelchair in a good fashion. So, what we decided, that whenever we land into an airport, we will use the airport wheelchair. Yes, it is not comfortable, yes it comes in an extra size for my Jeba... but we decided that ok, it is for a short time. And then we at least pack the wheelchair, we wrap it and send it as a check-in luggage. So, at the end of the day, when we land in the destination where we are going we are able to use the wheelchair. It is not broken, nobody tampered with it."

Destinations were also selected with the needs of a wheelchair user in mind:

Jeba's father: "In UAE you should be ok. But when you go outside the UAE. That is another headache. Because of her needs, you need to carry the wheelchair everywhere... even we are as a tourist when we travel... we take the wheelchair with us. And we face challenges. That is why even our tourist destinations we select them carefully so that she is able to adapt

At school

The following narrative illustrated the importance of being included in school activities:

Jeba's father: "What I remember... was a competition of a solar power car which Jeba participated in. The fun part for Jeba was the real competition, which was a real race. You have to race your car amongst other students. She had a tiny car compare to the big macho cars... and she won. You have a circle, a race track with all the obstacles and

the students would race. The students you know they have the remote control... they have to play with the car. That activity was part of the sport activities. For her it was very nice, she has the cheers, from her fellow students and she... was awarded... not only a trophy but money, but still she was so happy that she won."

The wheelchair played an essential role in making it possible to attend school. Still, parents went through lengths to find a suitable school:

Jeba's father: "... we face challenges. Even the type of school that we select... we need an elevator. That was the main reason that we had to leave Jeba's first school... because the school don't have an elevator. So, we move to another school."

Halima's father reported that Halima did not go to school for a period of time as he could not find a school willing to accommodate her needs:

Halima's father: "...there were many schools that rejected to accept her. Two years we were waiting, just to get her in a school."

School accommodation also came at a cost:

Halima's father: "And very expensive, this year they are saying they will increase the fees 100%. The increase is only for the special group... to do for them special classes, special education."

Teacher attitudes were positive and many examples were shared on the support they provided to include the children:

Mayed's mother: "When they make a running competition... the Miss push him and she run with him...because they want to involve him in play."

Ali's mother: "So she knows that Ali is not totally on the same... vision. So she tries to attract him by her voice, when she speaks, by touching. In the exam... the teacher helps him to write... he has to answer and she writes. They are nice at the school."

Special shadow teachers were recommended by schools, which came at a price that further increased the cost of schooling:

Halima's father: "... shadow teacher is a must. And we have to pay for this. And it should not be...like her mother cannot be her shadow teacher."

Discussion

In accordance with previous findings [13,5], the participants felt that the wheelchair can be seen as an extension of their children's bodies and an assistive device that was crucial to the children. Narratives expressed the fulfilment and happiness the child experienced through inclusion in school and family activities, which were possible because of the wheelchair. Parents in turn derived joy from the child's happiness and saw it as ample reward for their efforts to ensure the child had a wheelchair and could participate.

Despite the participation that the wheelchair allowed, children were treated differently by family, community members and teachers. This difference is poignantly exposed by one participant's impression that: "it is not normal to go to a normal place". This family, like many other persons with disabilities, had to deal with social practices that excluded and scorned them and caused feelings of rejection and grief [31]. They made a conscious decision not to let these practices prevent them from including their child in community activities. Even so, their identities were harmed [31] and they resigned themselves to a life full of losses.

Some parents saw the way in which strangers interacted with the child in the wheelchair in a positive light. However, while the interaction might be more positive it is still othering as it is not 'normal' practice for strangers to approach, pray for and give

sweets to a girl in her teens. To us, the authors, this is an example of "a hum of othering behind kindness" as described by Watermeyer [31].

Similarly while the support and assistance of teachers are commendable the nature of assistance and inclusion in schools must be further explored. Yeo and Tan [32] caution that children with disabilities who are included in a mainstream school should be supported to participate as their peers do. Pushing a child in a wheelchair as part of an athletics competition does not provide him with an opportunity to participate as his peers do. On the other hand the radio controlled car race, described by a participant, allowed the child to compete and experience the joy of being cheered on by peers. Findings on accommodations made by the schools and adaptations to the design and construction of school buildings, which are crucial to inclusion of children in wheelchairs [33,34], were mixed.

Procuring an appropriate wheelchair was not always an easy task with both monetary support and assistance of trained providers being in short supply. In most instances, the cost of the wheelchair was not covered by medical insurance. This might be due to a focus on curative medical care amongst insurance providers and insufficient understanding of the functional and health benefits an appropriate wheelchair provides. Wheelchair features were also often ill matched to the child's physical requirements. A situation that can negatively impact function and lead to falls, the development of secondary complications and even death [35]. The WHO manual [9] was developed to guide procurement of appropriate wheelchairs in less resourced settings. However, these guidelines could have been of assistance to provide appropriate wheelchairs in Dubai, a well-resourced setting too.

In 2018, the World Health Assembly aimed to develop, implement and strengthen policies that would improve the access to AT [26]. The need to improve the provision of AT, such as wheelchairs was further emphasized by the Global Research, Innovation, and Education on Assistive Technology (GREAT) summit [36,37]. The Government of Dubai could improve wheelchair service delivery to its citizens by developing a national policy based on these international guiding documents.

Participants shared positive experiences related to the design and construction of public places where they enjoyed family outings in Dubai. Dubai's vision of 2021 [38] is to transform the city to be 'friendly' to 'people with determination', the official phrase used in Dubai to refer to persons with disabilities by including and integrating them into society. Current findings suggest that city authorities were well on their way to achieving this vision through ensuring availability of special parking, lower counters, ramps and/or elevators and accessible bathrooms in malls, parks and other public spaces, especially beaches. This was similar to findings on the accessibility of public buildings in another emirate of the UAE, Al Ain [24].

Participation was not only limited to the community of Dubai, families also travelled to other destinations by air. Barriers experienced during air travel infringed on current participants' rights to enjoy memorable travel experiences [39] and be included in all aspects of society. The humiliation of being carried can cause a loss of pride, distress and frustration [40,41]. Damage to wheelchairs during transit constitutes a big problem and can lead to an unpleasant holiday experience [40]. Not allowing the child's wheelchair beyond a certain point, forced parents to carry their children, sometimes teenagers, or used a courtesy wheelchair that did not accommodate for the postural support and safety needs of the child.

Limitations

Some of the participants struggled to express themselves in English, but the use of an interpreter also created challenges as the first author observed that the interpreter relayed information that was not reported by the participant in the one interview where an interpreter was used. The authors are not able to fully relate to or understand the cultural traditions of the families as they are from a different cultural and religious background.

Conclusion

By addressing environmental barriers the City of Dubai ensured a wheelchair friendly environment. However, by not providing policy guidance on the procurement of appropriate wheelchairs, policy makers hampers children and parents opportunity to enjoy this wheelchair friendly city optimally. The wheelchair played a significant role in the child's life and allowed participation in life roles that brought joy and fulfilment, with resultant pleasure to parents. Attitudes of community and family members hampered inclusion as the children were often treated differently from their peers.

Recommendations

It is recommended that the Government of Dubai develop policies to guide wheelchair service provision in the country. In addition, insurance providers should collaborate with the government to adhere to the policy to ensure healthy lives and promote well-being for all.

Disclosure statement

The first author provides therapy services to some of the children. This could have influenced the interviewees' responses as they could have been seeking her approval. This was addressed by ensuring the interviewees prior to the interview that their answers will not affect the therapeutic relationship with the child.

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