#### Abstract

**Introduction:** Cerebral Palsy (CP) is a chronic, debilitating condition affecting most spheres of a person’s life. This study aimed to explore the various perceived factors impacting the quality of life (QOL) of the children with cerebral palsy living in the Umzinyathi district of KZN, a rural South African setting.

**Methodology:** The study had a qualitative, phenomenological design with purposeful sampling to recruit children with CP and their parents. Ten individual interviews were used for data collection, two with children with CP and eight with parent proxies. One focus group was also arranged for the parent proxies. Thematic analysis was used to interpret the data.

**Findings:** Three themes emerged from the data: Physical well-being, Activity participation, and Family and community. These themes encompass the subjective lived experiences of the children with CP as well as the identified perceived factors that impact on their QOL. Each theme is further broken down into subthemes, with a total of fourteen subthemes.

**Conclusion:** QOL in rural areas is a complex and multi-faceted construct. When aiming to improve the QOL of children with CP in rural areas, awareness campaigns, anti-stigma messages and support for caregivers are vital.

**INTRODUCTION**

Cerebral palsy (CP), a chronic and debilitating condition affecting movement and posture, is caused by an injury or defect to a developing brain1. CP remains the single largest cause of disability in children across the world2, with suggested prevalence rates in South Africa (SA) ranging between 1% to 8% 3.

Given the pervasive impact CP has on people’s lives, it is imperative to look at more than just the biomedical aspects of CP, to understand all the dynamics that affect the whole person4. Quality of life (QOL) is defined as a multidimensional construct that assesses wellbeing across various aspects of life5, including physical, social, psychological and environmental components. Limited research in the field of QOL of children with cerebral palsy, specifically in rural areas, has led to health services mainly addressing physical symptoms, and minimising discomfort in the children’s daily lives1.

Due to the environmental component of QOL and knowing that activity “participation of children with similar types and severity of CP varies according to where they live”6(p279), it is important to assess the indicators of QOL specific to the setting children live in. Hammal, Jarvis and Colver noted that environmental factors can be as influential in children’s activity participation as the type of CP they have6. We therefore need to assess the whole context in order to treat the child holistically and efficiently. This study aimed at understanding the various factors that impacted the QOL of children with CP in a rural South African setting.

**LITERATURE REVIEW**

Prevalence rates of CP in SA are much higher than the global prevalence rates of 0,2-0,3%2,3. Possible reasons for this can be attributed to poor antenatal care, large numbers of children being born at home, dehydration, malnutrition and poor disease management3. Developing countries do not only have a much higher prevalence of CP, but the presentation of the CP and the co-morbidities are also very different7. A recent study in Botswana indicated that 41% of their children with CP fell into the most severe category of motor impairment (GMFCS V); the majority also had intellectual disabilities (84%) and epilepsy (77%)8. These statistics are not available in SA, but the majority of children with CP accessing public health services presented with multiple and complex impairments2.

Internationally, different instruments are used to measure the QOL of children with CP. Most of these are generic QOL instruments or health-related QOL measures, like the KIDSCREEN-109. This generic measure was not specifically designed for children with CP, but a European study concluded that although it is generic, a specific version, the KIDSCREEN-52, is valid for children with CP from the UK, Sweden, France, Ireland, Denmark, Italy and Germany9.

In contrast, the Cerebral Palsy Quality of life Questionnaire for children (CPQOL-Child) was specifically designed for children with CP10. The developers’ purposefully selected sample consisted of Australian children representative of a spectrum of ages, functional severity, socioeconomic status and geographical location11. Their study used semi-structured interviews with families of children with CP until thematic saturation was reached11. Using the data from their study, the CPQOL-Child (α=0.74–0.91) was designed, consisting of a self-report questionnaire, as well as a primary caregiver-proxy version.

Although relevant for children with CP, there was no evidence of the KIDSCREEN-52 or the CPQOL-Child being tested in developing countries with deep rural areas and high poverty rates, such as South Africa. Therefore, existing measurement tools were not used in this study, but the data collection process used was similar to that of the CPQOL-Child’s developers. Semi-structured interviews using an adapted version of the Australian study’s questions were used for this study11.

QOL is a relatively new field in health research12, and has mainly been studied in developed countries10. Power et al. suggests the reason QOL is often overlooked in developing countries is at least in part “due to the complexities associated with its measurement”5. However it provides an important understanding of the unique issues affecting people’s lives5.

In 2015, a study in the United States, Canada and Australia confirmed that rural people viewed health differently to those living in urban areas 13. Rural people tended to emphasise functional aspects of health, with specific mention of independence and their ability to fulfil social roles. Religious and spiritual health was also considered integral to the overall health of people in rural areas13. This highlighted the importance of understanding QOL in the rural context in order to better engage and assist rural patients.

**METHOD**

**Study design:** The study had a qualitative, phenomenological design14, investigating the participants’ subjective experience of their QOL, as self-reported or through a parent proxy.

**Research setting:** The study was conducted in the Umzinyathi district of KZN, SA, which is one of the most economically deprived areas in the country15,16. The majority of the population belongs to the lower socioeconomic class, and access to basic health and education services is poor15,16.

**Ethics:** Ethical clearance was obtained from the Biomedical and Research Ethics Committee at the University of KwaZulu-Natal (BE059/16), as well as gatekeeper permission from the KwaZulu-Natal Department of Health (117/16). Permission was obtained from the University of Melbourne, Australia, to use the data collection questions from Waters et al.’s study as the basis for tool development11.

Occupational therapists at each hospital in the district identified possible participants and disseminated invitations and consent forms to invite participation in the study. A group meeting was held where potential participants were given the opportunity to ask questions about the research, and the researcher described the information contained in the invitation package, which included participants’ confidentiality and voluntary participation, participants’ anonymity maintained by the use of pseudonyms, the right to withdraw at any time, and the researcher’s ethical responsibilities. All communication, written and verbal, with potential participants was offered in English and isiZulu.

**Tool development:** The list of eleven questions used by Waters et al. was modified for the rural South African setting to create an interview schedule, a process which was informed by literature17. A pilot study was conducted to test the relevance and comprehensiveness of the new questions. The pilot study was done in the Umvoti subdistrict of Umzinyathi, with participants meeting the inclusion criteria. Changes were made to the questions, and another pilot interview with a new participant was conducted to test the new questions. The final interview schedule was found to elicit the type of rich information required for data collection.

**Sampling:** Purposive sampling was used to ensure maximum variation within the sample. Inclusion criteria were that the participants had to be diagnosed with CP, be between 6-12 years, reside within the Umzinyathi district of KZN and be able to communicate verbally or have a parent proxy who spent a significant portion of the child’s waking time with them. The number of participants recruited was based on the evidence of data saturation11. The sample size was ten, comprising of two children and eight parent proxies.

***Table I:******Demographic information of participants***

**Data Collection:** The researcher conducted ten semi-structured interviews, as well as one focus group for parent proxies, with the assistance of an isiZulu translator. The interviews and focus groups were audio-recorded for analysis. The data collection was done at communal locations convenient for the participants, such as local clinics, hospitals and community halls. Participants were reimbursed for their travel costs and refreshments were provided.

**Data Analysis:** The recordings from the interviews and focus group were transcribed verbatim. The isiZulu responses were translated into English and these were used for data analysis. Thematic analysis was used to analyse the data using an inductive approach and following the six phases as set out by Braun and Clarke18. Familiarisation with the data was done through reading transcripts and listening to audio recordings. Initial codes were generated by highlighting important aspects in the transcripts before searching for themes. Potential themes were reviewed and finally three major themes with thirteen subthemes were defined.

**FINDINGS**

In keeping with McLaren’s work already discussed2, the children with CP that met the inclusion criteria mostly had complex presentations of CP. Moreover, it was difficult to identify child participants who could communicate with unfamiliar people. The two child participants both had speech difficulties, but the researcher considered it important to give them the opportunity to voice their opinions. What follows now, is a combination of the children and the parent proxies’ descriptions of the children’s daily lives, and the factors that impacted the QOL of these children with CP.

Three themes emerged from the data, namely **Physical well-being**, **Activity participation**, and **Family and community**. The diagram below represents the themes and subthemes.

***Figure 1:******Schematic representation of themes***

**THEME 1: PHYSICAL WELL-BEING**

This theme described the children’s physical abilities and heath as they had an impact on the children’s QOL. It is divided into three subthemes: Mobility and posture, comorbidities and communicate on, ensuring a complete understanding of the children’s physical capabilities and health status.

***Mobility and posture***

As CP is a condition that affects movement and posture2, the most visible factor that affect children with CP’s QOL, is their physical limitations. Participants had different mobility abilities. For some, sitting required external support: *‘Sometimes I put down pillows to support her so that she can sit’*. Others were sitting by themselves: *‘I was patient with her until she was able to sit. She is now able to sit.’*, and this had increased the activities they were able to participate in, and the amount of interaction with others. Fezeka verbalised: *‘*[Nolwazi’s] *life is better, she now likes to sit. Her life is not the same as before.’*

With regards to the effect of posture on participation, Nkululeko explained: *‘*[Ngcebo] *is always lying on the bed. When I have to feed her, I pick her up and when I feel tired, I put her on her wheelchair and if she cries I take her back to the bed’.* Ngcebo’s physical size made it difficult for her parents to lift and move her. Buhle mentioned it was the same for Sizwe: *‘He spends most of his time here* [lying on a mattress]*. Sometimes I change his position.’*

Mbali lived with her grandmother and cousins and did not have a wheelchair to use. When asked if Mbali attended community events, Nomfundo (grandmother) said *‘it is difficult because I have to carry her on my back, and as time goes I will not be able to carry her anymore.*’ A much younger Fezeka concurred: *‘The distance from the house to the tar road is long so I have difficulty carrying my child because it is very rocky. She also does not like going on my back anymore because it gets sore since her breasts are developing, so it would be easier if she has a wheelchair.’*

The ability to walk was mentioned by most participants as affecting their QOL. Amahle (child) named walking by herself as something she would like to do. Thabile said *‘my child is able to crawl and I will be committed to helping her get to walking’*. Zanele said Siyanda *‘gets happy when I teach him to walk’.* Being able to walk or move around freely was not only about the movement itself. Although some of these children would probably never walk independently, having mobility (with or without an aid) gave children the opportunity to participate in family life and community events. Nomfundo said *‘I hope that one day* [Mbali] *can have a wheelchair so that she can play with other kids’.*

***Comorbidities***

Comorbidities and secondary problems were also mentioned as impacting on the children’s QOL: *‘He is epileptic’* and *‘He used to be on medication for epilepsy but they said he is fine now’*. One parent said: *‘In summer, sometimes he gets diseases like pressure sores. Then they give him cream to help him’.*

Vision and speech impairments were also cited. Some of the children were unable to see while others just had limited eyesight. Zanele explained that *‘*[Siyanda’s] *eyesight is not good’* but he is able to notice changes in light: *‘when the doors are closed he can tell and when they are open he also knows’.*

***Communication and pain***

Some children were able to speak and make their needs known. For Amahle and Mvelo, this meant that outsiders were able to understand their communication and react accordingly. When children did not have meaningful speech, their behaviour became the communication with those around them. Adequate communication, whether verbal or non-verbal, allowed for a sharing of ideas and gave children the opportunity to make choices for themselves. Nomfundo chose Mbali’s clothes and activities based on how Mbali felt about it: *‘She can’t really express what she likes but she laughs if she is happy with it’ and ‘when I give her the clothes that she likes, she shows by her face that she is happy with what I put on’.* Zanele verbalised *‘when* [Siyanda] *is well, he laughs a lot and plays nicely’* and *‘when he is not well he cries a lot’.*

The majority of the children communicated by crying when something was wrong. *‘When she is hungry or something is not right and she is not feeling well, she cries’* (Nkululeko, parent). For most children, crying was also the only way to communicate pain. *‘If something is pinching her such as the wheelchair she cries a lot’* (Nkululeko). This was often difficult for parents, and meant that the cause of the pain was not easily established and treated. *‘When my child is not well I get very hurt because she cannot say where she feels the pain’* (Thabile). Fezeka shared this concern: *‘I never know where the problem is’*.

It is not only crying that serves as communication. Thabiso liked making sounds. *‘I know* [he is well] *when he wakes up in the morning and makes a noise. If he is not well he is quiet.’* Mbali behaved differently if she is sick. *‘She doesn’t like anyone to play with her. Doesn’t do the things she normally does’*. Siyanda used his hands. ‘*If you ask him “are you okay?” he responds by putting his thumb up.’*

The type of communication was not as important as the understanding between the parties involved in the communication. Some children, like Mbali, were able to make their preferences known without speech, but required a grandmother or caregiver who understood her “language” to interpret for those who did not understand.

**THEME 2: ACTIVITY PARTICIPATION**

Theme 2 described the activities rural children with CP participate in or are unable to participate in, as described by the children themselves and parent proxies. Participants felt that participation in these activities had an impact on the children’s QOL. This theme is divided into five subthemes, each describing specific activities children are or are not participating in.

***Learning and schooling***

Mvelo attended a crèche close to his home. Nomusa (his mother) said none of the schools in his area were willing or able to accommodate him. When asked if he would like to go to school, Mvelo said an affirmative *‘school’* and smiled. He would like to start going to school *‘tomorrow’*.

At the crèche, Mvelo was included in the class of about 20 children. However, he said he preferred to play *‘alone’,* rather than with the other children in the crèche. Nomusa added that some of the other children had hit Mvelo in the past to get toys they would like. His teacher did not always understand when he tried to report this, due to his laboured speech.

With the exception of Mvelo, none of the children in this study had ever attended school, or been in a formal learning environment. Buhle (parent) explained that *‘*[Sizwe] *should be in Grade R but can’t speak or walk’.* Another parent echoed Buhle’s words: *‘They should be going to school but they are not. They cannot go because there are no special schools in the area and close to us.’*

Like the others, Amahle had never attended school or any early childhood service, but stated: *‘I would love to’.* It is especially noticed when siblings go to school: ‘*My sister leaves me and goes to school.’* Nompilo (her mom) tried to teach Amahle skills like reading and writing, but her own skills were limited, making it difficult. However, when asked about her favourite activity, Amahle said ‘*I like reading’*. Nompilo clarified that she referred to paging through magazines and newspapers.

Most of the parents had approached local mainstream schools, but they were unwilling or unable to accommodate their children in these schools. The parents showed understanding for this: *‘no one there is competent in working with children with special needs and the teachers can’t manage with normal kids at the same time’.* However, theyfelt it was important for their children to get the opportunity to learn: ‘*The child would be able to get to spend time with other children and learn as well’.*

There was only one public special school in the district; around two hours’ drive away from all the participants’ homes. Nelisiwe had applied to the school for her Thabiso, but *‘he is waiting for space’*. There was a high demand for space in this school, specifically in the hostel, as most children could not travel that distance daily. It was further compounded by the fact that Thabiso was ten years old with no education history, making it difficult for him to integrate into a formal school environment.

Not all the parents were willing to send their children to this school because it would require their children to live away from home. *‘These schools are far and as parents we get worried’* (Thuli, parent). ‘*What I would like is for government to help us with schools for disabled children in our rural areas so that we are able to be closer to our children even when they are at school’* (Nompilo, parent). It was not only the worry of their children being away from home that kept parents from sending their children to school. *‘I am willing for* [Mbali] *to attend a special school but I am afraid that people who are not trained will hit her.* [Mbali] *can’t speak. She can’t say anything if someone hits her’* (Nomfundo, parent).

However, the parents thought that not going to school had an impact on their childrens’ QOL. *‘It affects her because she cannot play with other kids, she cannot go to school’* (Nkululeko). *‘She shows understanding but can’t do what other children do’* (Nomfundo).

Parents tried to make up for not attending school by doing learning activities at home. *‘During the afternoon, I try to tell stories to* [Mbali] *but because of my poor vision I can’t read properly.’* (Nomfundo). She encouraged the school-going siblings to read stories to Mbali when they come home from school.

One parent thought that her child should not attend school yet. *‘When she reaches a stage where she is better, she can start with education’.* This highlighted the fact that the parents did not necessarily understand the chronic nature of CP, and will be discussed later.

***Self-care***

As with mobility, most of the children in this study were dependent on their caregivers for self-care activities. There seemed to be cognitive and motor barriers to children gaining independence in their self-care activities. Zanele said she *‘tried to teach* [Siyanda] *to go to the toilet but he could not learn’.* Buhle said Sizwe *‘cannot go to the toilet and he cannot feed himself because he cannot move his arms’.*

When asked about Thabiso’s feeding, Nelisiwe (his mom) said that she fed him. *‘He cannot hold* [the spoon] *on his own. He drops it*’. This was similar to the other children, and dressing was difficult for most of them. *‘She really can’t dress herself. I help her.’* (Nomfundo). *‘I put his clothes on for him because he cannot dress himself.’* (Nomusa)

Nomfundo also had to bath Mbali, or ask the older female cousins to bath her. Mbali *‘can’t use her hands to wash herself but she grabs the towel with her left hand. She is strong then.’* (Nomfundo).

Amahle and Mvelo were more independent in their self-care activities. In the morning, they bathed and ate independently. They liked eating *‘maas, banana and mageu’* and *‘eat*[s] *porridge and Danone* [yoghurt]*’* (Amahle, child).

***Play***

Play was universally mentioned as something that made the children happy. Toys that made sounds and music were common. Speaking about music, Nompilo said ‘[Amahle] *loves it*’. Fezeka agreed: ‘[Nolwazi] *also likes noise because when the radio is playing I see that she plays with her foot wanting to dance’.*

Three of the parents mentioned that the children played with *‘toys that we borrow from the* [NPO] *programme’.* A local NPO ran a mobile toy library for children with disabilities in some rural areas. It also gave the children the opportunity to play with other children. Nomfundo said that during the day, *‘there is no one* [to play with] *unless she is taken by the disabled pickup* [of the NPO] *to the playgroups where other kids are. I think it comes about three times a week.*’ Playing with other children was not easy for everyone. Nomzamo ‘*takes a while to get used to other kids because at home there are no other kids’* (Thuli, parent)*.*

Amahle said that she played with her sister and one female friend of a similar age in the afternoons. This was similar to Mvelo. After Nomusa (his mom) fetched him from crèche, he played alone at home until his siblings arrived from school. His favourite activity was the *‘swing’*.

For other children, their parent was their only playmate. *‘He can’t go out to play with the others’* (Zanele, parent). *‘When it’s hot, we open the door. He looks at the other children playing outside as though he would like to be there’* (Buhle, parent). *‘It affects her badly seeing other children playing’* (Thuli, parent).

Playing does not always require toys: *‘I sit with her and put her on my lap and play with her. She laughs. I play music on my phone and make her listen to it even though she will not say that she can hear’* (Fezeka). For Sizwe, the best play was just clapping hands. Nelisiwe mentioned that when Thabiso was lying down, she played with him and he showed interest. *‘He tries to lift his neck when you show him something’.*

***Domestic life***

As most of the children were at home during the day, some of them were encouraged to help with the domestic chores at home. Nompilo reported that *‘[Amahle] likes washing a lot’* and she gives Amahle the smaller clothing items to wash, rinse and wring out on her own. Nomusa mentioned that when Mvelo was at home, he helped her with the domestic chores, specifically doing the washing. When asked if he enjoyed doing the washing, Mvelo gave an affirmative *‘hmm’* and added *‘soap’.* His mother explained that Mvelo liked to make bubbles with the washing soap and enjoyed playing with the bubbles.

When asked who did the cooking at home, Amahle responded *‘I know how to’*, with Nompilo, parent explaining that Amahle helped with washing vegetables and stirring food, if her mother assisted with stabilisation. Nompilo, parent mentioned that Amahle even helped with the livestock. *‘She follows the small goats when they go inside the house and chases them out.’*

Some children were unable to help around the house. Nkululeko said that Ngcebo did not participate in domestic life, but she went outside when her mother put her in the wheelchair because *‘she enjoys it when she sees the sun.’*

Nomfundo mentioned that she would like to take Mbali with her when she goes to town to do shopping. Currently she could not carry her all the way from home to the taxi. *‘I would be happy to get a new wheelchair and I will be able to go with her’.*

***Church and religion***

Being part of a community and able to participate in activities with friends and family was important to the participants and their families. However, mostly due to mobility and distances, most of these children were unable to attend community events. Thuli mentioned that *‘it takes about 2 hours’* to walk to church, and it was difficult with Nomzamo on her back. She had to cross a river and walk up a hill, so she could not go every week. *‘I go if there’s a party at church’.* Nomfundo and Buhle felt the same: *‘We can’t go to church’.*

However, Thabile said Ntombi *‘goes to church and when she is there she laughs a lot and makes a lot of noise. When people sing, she starts laughing’.*

Mvelo went to church with his family every week. When asked if he enjoyed church, he gave an affirmative *‘hmm’* and said *‘mkhonzen’.* This is a traditional type of dancing and clapping hands, characteristic of the Nazarene church*.* Nomusa affirmed that Mvelo was always at the front when they were dancing and he laughed and clapped his hands during church.

During her interview, Amahle started singing *‘Nkulunkulu uthando lwakho’* meaning “Lord, your love”, a song Nompilo said they often sang together at home. While Nompilo continued singing, Amahle asked Shembe (God) to make her walk, and stop using crutches or a walking frame. She believed God was able to help her walk.

**THEME 3: FAMILY AND COMMUNITY**

This theme described the contextual factors that had an impact on the children’s QOL. It represented a complete background of the child’s life. It is divided into six subthemes, each describing one aspect of the context the children lived in.

***Family relationships***

The children’s immediate environment would be at home with their families. Universally caregivers expressed their love and care for their children with CP. Comments like *‘I love my child’* (Zanele) and *‘she is a God-given child’* (Nomfundo) were common. However, the acceptance did not come immediately for all: ‘*now I have accepted that my child is like this, but before it was very difficult’* (Fezeka).

Two of the grandmothers took on the role of primary caregiver due to abuse or neglect by the child’s parents. ‘[Mbali]*’s father was abusive towards the child, so I’m not willing for him to take her’* (Nomfundo). *‘There has been a big improvement since she has been living here. Her parents neglected her’* (Thuli). However, physical punishment was still present in some homes. Amahle said *‘I am not happy when they hit me at home’*, referring to physical discipline.

Interactions with family members were mentioned as one of the most important aspects of a *‘good life’* (Buhle), and something the children enjoyed. Zanele said she talked to Siyanda, *‘and play with him and he gets happy and laughs’*. ‘*What I have noticed is that* [Nomzamo] *gets really happy when I come back from fetching water because when I open the door, she starts laughing and becomes happy’* (Thuli).

Being at home with their caregiver every day, as well as dependent on them for self-care, formed a strong bond between the child and caregiver. Thuli (parent) mentioned *‘when [Nomzamo] does not see me, she looks around to see where I am but what makes her really happy is seeing me next to her’.* The attachment between them made it difficult for Nomfundo to leave Mbali with anyone else if she needed to do chores: *‘When I am not around, she cries non-stop until I arrive and calm her’.*

When asked about her family, Amahle said *‘I play with granddad’* and *‘dad. I am buzzing him’.* Nompilo (parent) explained that Amahle’s father lived in Gauteng and they only had telephonic contact. *‘I love him’*, Amahle said referring to her dad; then looked at her mother and said *‘you too’*.

*‘After school when all the kids come back from school’* the children with CP had the opportunity to play with siblings (Thabile). Siyanda *‘is very happy when he plays with his sister’* (Zanele)*.*  Amahle *‘has a good relationship with her siblings. That is what I like the most. She is happy when she sees them. Even when there is a visitor at home she becomes happy. She is generally a loving child’* (Nompilo, parent).

***Attitudes towards and beliefs about children with disabilities***

The families of children with CP initially struggled with accepting their children. Attitudes towards children with CP had a direct impact on their acceptance, inclusion in activities and QOL. Although the attitudes of family members were loving and caring towards the children, there was a stark difference in the way parents viewed their children and their abilities. Nkululeko expressed his sadness because his daughter could not play like other children. *‘When I see kids running and sometimes playing on the jumping castle, I feel sorry for* [Ngcebo] *because she cannot do anything.’* In contrast, when asked if there is anything Siyanda could not do because he had CP, Zanele said *‘no’.* She explained that Siyanda likes to play and *‘he gets happy when I teach him to walk.’* Both these children had spastic quadriplegia (GMFCS level V); however their parents’ beliefs of what they were able to do were total opposites.

At healthcare facilities, limited explanations and misinformation had been offered to the parents with regards to the children’s CP. There was ignorance with regards to the cause of CP, and with stigma rife in the community, misunderstandings around CP were common. Thuli explained*: ‘I do not even know what CP is… They didn’t tell me what happened to cause the disability. The people at the clinic said that sometimes it is caused by lack of immunisation.’* This is something she did not understand, as Nomzamo received all her immunisations. Nomzamo developed normally, and then became sick and was diagnosed with CP. Her current understanding of CP was as follows.

*‘They were trying to attack me, but because I am old and strong, maybe that thing attacked the child. Maybe they were jealous. The child was normal. We went to sleep at about eight o’clock. Then* [Nomzamo] *didn’t wake up. When I went to check up on her, she was disabled around one o’clock in the afternoon. I believe it was witchcraft.’*

In the wider context, there were people in the community who did not have such favourable views of children with disabilities. Thuli (parent) said that when people saw Nomzamo, *‘some run away but she is loved by some’*. Other parents said that *‘they don’t bring their children’* to come play at their house out of fear of the children with CP. *‘Even when you take a taxi with the child and they touch the person sitting next to you, the person gives you funny looks.’* (Thabile, parent). Nompilo agreed: *‘we also get discriminated against in our communities because we are not able to attend any gathering, be it funerals or celebrations.’*

The stigma around the cause of CP and the views of others caused some parents to keep their children indoors, and at home most of the time, out of fear of victimisation. ‘*We are discriminated against but our children are the same as all the others’* (Thabile). Fortunately, not all community members had the same view of children with disabilities. According to Zanele, *‘our communities love us’* and it was only a few people who still viewed Siyanda negatively. Thuli and Nomfundo remained hesitant to let their children out of the yard. *‘She is always with me so nothing can harm her’* (Nomfundo).

***Support from the community***

It was not just strangers who treated children with CP differently. Extended family was mentioned as either withdrawing or coming closer to the children because of the CP. *‘The nearby family have changed. The father used to visit before* [Sizwe] *got CP. He never even phones to ask about the child’s condition’* (Buhle).

When the extended families drew closer, it offered the caregivers a positive coping resource. *‘My family is treating the child and I well and they love us both. They encourage me’* (Zanele). *‘The family understands and is very supportive’* (Fezeka, parent). *‘I usually tell my* [older] *children if I had a problem and they console me’* (Thabile, parent).

Without practical support and acceptance from family and the community, parents were often overwhelmed by the role of caring for a child with complex disabilities. *‘You cannot do anything including house chores such as fetching firewood and fetching water. If you ask someone to fetch water for you, they expect to be paid’* (Nelisiwe, parent). Without physical assistance, caregivers were often ‘*forced to leave the child alone in the house and go and wash clothes’* (Zanele, parent). Highlighting the need for respite from caregiving, Nompilo (parent) said *‘it would be nice to have a day where we as mothers are taken to go and buy food in town.’*

***Finances***

Family finances were mostly areas of concern. ‘*Mothers have had the father of their child leave them all alone to support the child’* (Thabile, parent). Sizwe’s father stopped his support after the CP diagnosis. ‘*He doesn’t contribute financially any more’* (Buhle, parent). *‘It’s difficult at the end of the month to buy enough’* (Nomfundo, parent).

Parents mentioned that the social grant they received from the government was not enough to pay for the extra expenses they incurred, such as transport to clinics and diapers for the children. Being unable to work and earn an income due to full time caregiving, made it difficult for families who had to live on only the child’s social grant. ‘*If possible, we would like the government to pay us a separate grant as parents of these children so that we are able to help ourselves and our children better’* (Nompilo). *‘Some of us do not have people who support us financially, which means that you do everything with the child’s grant, and you cannot go to look for work because you do not have someone who will look after your child’* (Thabile).

***Available services***

Access to health care remained difficult, especially with the children’s mobility challenges and the vast, hilly nature of the terrain where they lived. All these families attended local primary healthcare clinics in their rural areas. Nurses manned the clinics, with therapists and doctors visiting once a month. Nomusa (parent) stated *‘there has been a lot of improvement with the limited services that there are. It’s better than nothing at all’*, but Buhle (parent) believed *‘it won’t be enough’*.

As mentioned before, health professionals did not always explain the children’s diagnoses to the families. Thabile also did not receive an accurate explanation about Ntombi’s condition. *‘I was told that the child has Down syndrome.’* Ntombi did not have Down syndrome, and was diagnosed with CP after therapists referred her back to the doctor for reevaluation.

Dissatisfaction with the health care they received was common. Fezeka (parent) said *‘I would have to go to private doctors since you usually wait long hours at the* [public] *hospital and sometimes not get the help that you need. It is better if you wake up early in the morning and find the doctor.’*

The lack of information to parents had also caused some of them to have unrealistic expectations of their children in terms of function *‘if she could walk, sit or got to the toilet I would be happy’* and schooling ‘*when she reaches a stage where she is better, she can start with education’.*

Although health services were limited, the families showed gratitude for the mobile rehabilitation teams. Nomfundo said she was happy with the therapy that Mbali had received. *‘I have seen the therapists give her something and now she can hold onto it. One of her legs is straightening as a result of therapy.’* Nelisiwe agreed: *‘through the assistance we get, he might be able to speak and stand. That’s my hope’.* Zanele shared their sentiments: *‘The clinic really works. It has helped me a lot.’*

Transport challenges had an effect on children’s QOL. *‘We find a lot of difficulty when using public transport’* (Nompilo, parent). This was due to the attitudes of others on the taxis, as well as the distances to the taxi stops. More worrying for the parents was the fact that *‘the ambulance takes a very long time to get where we are’* (Nomusa)*. ‘If she is not well, I have to call an ambulance which takes very long to arrive’* (Fezeka)*.* The parents did not think this would change soon. *‘We do not receive any assistance, and the way I see it the District does not even know that we exist’* (Thabile, parent).

***Thinking about the future***

Despite the adversity, caregivers had positive dreams and hopes for their children’s futures. *‘One day* [Sizwe] *will have his own bathroom, bedroom and a proper education at school’* (Buhle, parent). Caregivers also mentioned that having a child with CP had taught them some lessons. *‘*[It] *has helped me with learning to love. I used to love my child but now it has grown’* (Thabile, parent).

Older caregivers had some fears about the future of their children. *‘I am worried that one day I will no longer be around and then no one will look after* [Mbali] *because her aunt has her own family and the other siblings are still young. I’m praying that God will keep me until the other siblings are old enough. But when I die, the right department must take* [Mbali] *to a safe place, although that is not the best for her’* (Nomfundo).

When asked what she wished she could do, that she could not do now, Amahle said: *‘I will take my flip flops, put them on and walk to church. I will also wear my church garments.’* Amahle was able to express what was important to her: she had a desire for more independence in terms of dressing and mobility. Amahle wanted to walk to church, something Nompilo (parent) described as a happy, communal walk, hinting at inclusion and acceptance for Amahle. Lastly her spirituality was important, not only in what she dreamed to achieve, but also the fact that she trusted God to help her walk.

**DISCUSSION**

This study provided insight into the daily lives of rural children from the Umzinyathi district in KZN with CP, as well as their experiences and thoughts about their QOL. The results of this study give a clearer understanding of how QOL is experienced by children with CP in rural areas.

Various authors have described the different domains of QOL19–21, but no consensus exists on what should comprise the different domains. Examples include physical, mental, emotional, social or interpersonal and material well-being, as well as development and activity, social inclusion and personal determination19. However, whether these domains are valid or relevant for children with CP in rural areas, or how these domains are applied in the rural context have not been established.

The findings of this study highlighted certain domains of QOL that were important to the participants, as set out in the themes. Physical well-being, material well-being, activity participation, and social inclusion and well-being were some of the most mentioned domains. The participants’ responses also offered more information regarding their experiences of these domains, which can be seen as the practical application or indicators that are relevant to this context for each domain of QOL. This is helpful to therapists working in the rural context, as indicators can be used to formulate specific, measurable goals for treatment and intervention.

Theme 1 (Physical wellbeing) highlighted how the children’s physical abilities impacted on their inclusion, participation and QOL. Participants mentioned that children’s inclusion and interaction with others improved once they started sitting independently. Parents reported that it was difficult to get the children involved in activities if they were unable to sit. The impact of physical abilities on QOL was further seen in the activities Mvelo was involved in. He had the most gross motor abilities and was the only one who was attending formal schooling, although it was only a crèche.

These findings are in line with a South African study of teens with CP’s participation in physical activities. Physical limitations such as strength, range of motion and physical pain were identified as barriers to participation for the teenagers22.

Mvelo and Amahle were included in household activities more regularly, as they were able to use their hands in a more coordinated manner than the other children. Hand function has been mentioned as having a direct impact on children with CP’s QOL regardless of where they reside22,23. Recommendations by Kołtuniuk, Rozensztrauch, Budzińska and Rosińczuk pointed to the importance of improving hand function for more activity participation and therefore higher QOL23. This study’s findings are therefore in line with international QOL research and rural occupational therapists ought to prioritise the improvement of children with CP’s hand function, as this is one of the main ways in which children explore the world around them and participate in activities.

The parents’ worries about communication, specifically with regards to pain had also been documented by other studies. An American study24 mentioned that the aetiologies of pain were often difficult to determine if children had limited cognitive and communication abilities. They further mentioned that “pain had an impact on the child’s quality of life and participation”24(p308), which corroborated with the parent proxies’ responses. The link between pain and poorer QOL has been shown in recent studies of children with CP25,26.

Although it was difficult to identify children who could communicate on their own behalf, the two children who did participate gave their account of what they enjoyed, providing us with true subjective aspects that impacted on their QOL. With both of them, it was important to have their mothers at the interview to qualify or explain what their children were trying to say. However, the information captured gave us a unique look into the lived experience of young children with CP in rural settings.

Activity participation as described in Theme 2, described the specific activities that were important to the children to experience a high QOL. The availability of appropriate schooling, engagement in community activities, chores at home and playing with others were all mentioned by both the children and the parent-proxies as being important for a high QOL. These are similar to the results from an Australian study of the QOL of children with CP11. The difference from the Australian study would be the availability of services such as schools for children with disabilities. While both the participants in this study and the Australian participants considered schooling important, the children of this study did not have the option of going to a school in their communities, highlighting the importance of a comprehensive understanding of the settings these children lived in and the effect of wider systems on the QOL of the rural South African children.

Participation in occupation is an integral part of QOL, and of specific significance to occupational therapists. WHO stated that community-based rehabilitation (CBR) needs to focus on enhancing the QOL of people with disabilities as well as their families by meeting the families’ basic needs and ensuring inclusion and participation27. According to the World Federation of Occupational Therapists (WFOT) the primary goal of OT is “to enable people to participate in the activities of everyday life”31(p1). The children’s participation in activities is where OTs have the biggest influence in improving the QOL of children with CP in rural areas. The findings mentioned specific activities that are important to the children and their families and provide the rural therapist with the indicators for QOL that need to be addressed in interventions.

The findings revealed the limited variety of activities rural children with CP were able to participate in. However, it is not just the variety of activities that have a limiting effect on these children’s QOL, but also the frequency of participation. This is in keeping with a recent comparative Serbian study that found that children with CP “participated in fewer activities at home and in the community, less frequently and had lower levels of involvement” compared to children with typical development32(p78).

As known from previous studies, the degree of participation in activities of children with disabilities is at least in part “a product of their environment”6(p292). It was therefore imperative to fully understand the children’s limitations within their specific environment (Theme 3 – Family and community).

What was highlighted in the third theme is the fact that caregivers were major role players in their children’s QOL. It is known that the wellbeing of caregivers are inextricably linked to the wellbeing of those they care for4,30, but this study also highlighted the impact of caregivers’ beliefs and abilities on children’s QOL. Children with similar physical abilities were exposed to different activities because of the attitude or beliefs of the parent. One parent said his daughter could not do anything, while another said there is nothing her son could not do.

A Polish study of the QOL of children with CP found that the children with higher QOL scores on the PedsQL QOL measure were those whose parents had an attitude of acceptance of CP, where parents accepted their children's lives and felt the need to provide them with help and support23.

It is not only the caregivers’ attitude towards CP that affect the children’s QOL. Some children were limited in their community interaction due to their caregivers’ age and inability to carry them to events. Children with older caregivers had limited participation whereas the physical demands of carrying a child with CP was something a younger and stronger caregiver could cope with, leading to more interaction with others and higher activity participation. This is in contrast to the Polish study mentioned above where it was found the age of the caregiver and child had a limited impact on the physical aspects of a child’s QOL23.

Caregivers were also the ones who would look and advocate for services for their children, or just accept the limited services that were available, stating these were better than nothing, showing learned helplessness30.

Attitudes in community were both reported as limiting and contributing to the children’s QOL, depending on their communities. Stigma about disabilities were the biggest problem mentioned. This correlates with a South African study comparing the environmental barriers of rural and urban people with disabilities. Maart, Eide, Jelsma, Loeb and KaToni found that the rural people reported significantly more barriers with regards to friends, practices and ideologies, assistance and society as a whole31. They further mention that beliefs in rural settings tend to be more traditional and superstitions are common, reinforcing the negative attitudes experienced by people with disabilities in rural areas31.

The lack of services was evident in the environment these children lived in. It was striking that many of the parents were misinformed about their children’s diagnoses, or the chronic nature of the condition. Stigma about the cause of CP was still evident in the communities where they lived, and one caregiver believed the CP was caused by witchcraft. Lack of comprehensive explanations and adequate health services mean these beliefs continue to be perpetuated.

All the children in this study attended regular therapy at their local primary healthcare clinics, yet many of them still did not have a wheelchair or mobility device to improve their access to services. Caregivers mentioned that children become too heavy to carry, leading to a life lived only in and around the home. The vast, hilly landscape meant the closest points of access were still many kilometres away from their homes. They often had to cross rivers and walk steep hills, making it difficult to navigate to clinics or schools, especially if the child had to be manually carried. By motivating for and issuing wheelchairs to children with CP, OTs can have a concrete impact on the QOL of these children.

According to Hagerty et al., subjective indicators of wellbeing or QOL (referring to an individual’s perception and evaluation of their QOL) was essential, yet not sufficient to capture the totality of life experience32. Similarly, objective QOL conditions (aspects that can be measured independently) may have very little to do with a person’s perception of their wellbeing32. This study captured the children with CP's thoughts on their wellbeing, as well as some information from their parents. The parent-proxies provided information that is important for the children’s QOL, but that the children might not be aware of, whether due to age or intellectual abilities. Combined, these findings provide occupational therapists and other health professionals with a detailed understanding of the QOL of children with CP in rural areas.

**Recommendations**

The findings confirmed that QOL was multi-faceted, with various aspects that led to a high QOL. In a complex rural setting, this became an even greater phenomenon to understand. Factors affecting QOL that were identified by participants include physical health and resources, educational services and inclusion in family and community life. Some of these factors fell within the personal sphere, some on the societal level and others on a wider systemic level. While some, like providing a wheelchair and working on improving hand function are relatively easy to achieve, those that fall within the societal and systemic spheres might take longer and more dedicated input to change33. However, as physical well-being is the most severely impacted domain of QOL in children with CP34, some of the easier interventions could provide the greatest QOL improvements.

It is clear that caregivers play a pivotal role in the QOL of children with CP in rural areas. Health education and support programmes for caregivers of children with disabilities should be enhanced. Improved training of health professionals will decrease misdiagnoses and misinformation being shared with parents. Empowered parents will also advocate for better services for their children and seek the best services to help their children.

Awareness campaigns in the communities should be used to decrease stigma and promote understanding of CP, leading to better inclusion and acceptance for the rural children with CP.

System changes such as increasing the number of special schools in rural areas, improved healthcare and more regular therapy were also needed to improve the QOL of children. For example, one of the policies currently being used for the advocacy of special education, is the Department of Education’s White Paper 6. Although published nearly 20 years ago in 2001, it remains the most recent document the government has published on the matter and some of the foundational aspects of this policy are yet to be implemented35. Advocacy for better schooling for these children should include advocating for the implementation of already existing policies such as these to improve the rural children with disabilities’ QOL.

**Limitations of the study**

Using the hospitals for identifying possible participants meant that only children with CP that attended therapy were included in this study. Children with less support needs who did not attend regular therapy, were not included in this study, making it difficult to identify children in this age band who could give a subjective account of their QOL. This study therefore only included two children who could communicate with the researcher, and caregiver-proxies were used for the rest. Furthermore, due to the landscape, children with CP were not often known to the services, unless they accessed services. A child who is completely housebound might have a different QOL to the children in this study.

**CONCLUSION**

QOL is a complex construct that has not been extensively researched in rural areas such as the Umzinyathi district. This study provided valuable insight into the aspects that affected the QOL of children with CP in the rural South African context. Limited resources and finances made it difficult to implement change on a large scale.

Although health and education services were lacking in rural areas, it was important to note that all the parents were satisfied with the service and treatment they received from the rehabilitation teams at their local clinics. This provided evidence that despite hardships in rural areas that impacted on QOL, therapists had the opportunity to positively impact on the QOL of rural children with CP.

The OT’s role in improving the QOL of rural children with CP would be to provide support and information to caregivers on CP, as well as offering practical ideas for inclusion and stimulation. It is important that caregivers feel empowered to advocate for their children in these communities where they might experience animosity on a regular basis. Furthermore, it is imperative that OTs listen to children with CP, and understand what is important to them. As health professionals, OTs are also in a strategic position to advocate for expansion of health and education services to rural areas, thereby facilitating the process of improving these children’s QOL.

**TABLES AND FIGURES:**

**Table 1:** **Demographic information of participants**

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Pseudonym** | Amahle | Nomzamo | Mvelo | Sizwe | Mbali | Thabiso | Ngcebo | Siyanda | Ntombi | Nolwazi |
| **Age** | 8 | 6 | 6 | 7 | 10 | 10 | 12 | 9 | 9 | 11 |
| **Gender** | Female | Female | Male | Male | Female | Male | Female | Male | Female | Female |
| **Type of CP** | Ataxic | Athetoid | Ataxic | Spastic quadriplegia | Spastic hemiplegia | Spastic quadriplegia | Spastic quadriplegia | Spastic quadriplegia | Spastic quadriplegia | Athetoid |
| **GMFCS Level** | IV | V | II | V | V | V | V | V | IV | V |
| **CFCS** | II | V | II | V | IV | V | V | IV | V | V |
| **Type of reporting** | Self-report | Parent proxy | Self-report | Parent proxy | Parent proxy | Parent proxy | Parent proxy | Parent proxy | Parent proxy | Parent proxy |
| **Home language** | isiZulu | isiZulu | isiZulu | isiZulu | isiZulu | isiZulu | isiZulu | isiZulu | isiZulu | isiZulu |
| **Religion** | Nazarene (Shembe) | Nazarene (Shembe) | Nazarene (Shembe) | Nazarene (Shembe) | Catholic | Christian | Christian | Christian | Nazarene (Shembe) | Christian |
| **Primary caregiver** | Nompilo | Thuli | Nomusa | Buhle | Nomfundo | Nelisiwe | Nkululeko | Zanele | Thabile | Fezeka |
| **Relationship to child** | Mom | Grand-mother | Mom | Grand-mother | Grand-mother | Mom | Father | Mom | Mom | Mom |

**Figure 1:** **Schematic representation of themes**