Caregivers' experiences of raising children with intellectual disability in Umgeni Municipality, Kwa-Zulu Natal

Abstract

There is a paucity of research in the South African context on caregivers' experiences in raising children with intellectual disabilities (ID). About 12% of the population of people with disability have IDs, which ranges from mild to profound and are cared for by their families. Raising a child with ID brings significant life challenges to the entire family. The study aims to explore caregivers' experiences of raising children with ID. Sixteen caregivers raising children with an ID were purposefully selected using a qualitative phenomenological research design. A semi-structured interview guide was used to conduct in-depth one-to-one interviews, which were audio-recoded, transcribed, coded, and translated from vernacular to English. Using a thematic approach to data analysis, the themes and subthemes related to the caregivers' experiences of raising a child with an ID were explored. The majority of caregivers face great economic difficulties. Providing a child's necessities, such as food, nappies, medication, and transport for medical appointments, is costly and places financial pressure. Most caregivers have an inadequate support system; they live in isolation without a social life. Emotional and psychological distress is high among caregivers raising children with ID. Religion, support groups, family support, counseling, and traditional healing are the commonly used coping strategies. The multiple challenges experienced by caregivers underscore the need for inter-departmental collaboration to develop community support structures and strengthen policies and interventions which aim to address the needs of caregivers raising children with ID.

Keywords: Intellectual Disability, Caregivers, Disability, Children.

Introduction

Intellectual Disability (ID) is ranked as one of the top twenty sources of the burden of disease worldwide (James et al., 2019; Tomlinson et al., 2014). It is regarded as a very costly developmental disorder that requires on-going medical care, treatment, and rehabilitation services (James et al., 2019). People with ID and their families face multiple inequalities, stigmatization, discrimination, and social exclusion (Ambikile & Outwater, 2012). They are marginalized, face misconception, are denied full participation in society, and experience severe human rights violations on a greater scale than their able-bodied counterparts (Kishore, 2017; McKenzie et al., 2013).

Most people with disabilities live in low- and middle-income countries (Bright et al., 2018). They live in poor conditions with limited resources, poor nutrition, and inadequate infrastructure (Banks et al., 2017). Access to health and social services is urban-centric, whereas people who need care reside in rural areas (Kishore, 2017). Skilled health professionals are scarce to provide holistic care to people with ID (Bright et al., 2018). The caregiver's and children's rights to health care services are often neglected in general health and mental health care (Bertelli & Kishore, 2014; Garcia Iriarte et al., 2014).

In Africa, children with intellectual disabilities are denied access to education (McKenzie et al., 2013). Special schools for children with ID are limited, with strict admission criteria, insufficient funding, unskilled educators, and poor educational programs, which results in poor learning outcomes (Adnams, 2010). In some instances, caregivers do not see the importance of sending a child with ID to school because of poor productivity and their low expectations of the child

(McKenzie et al., 2013). Most families of disabled children are underprivileged, experience ill health, and have low socio-economic status (McKenzie & McConkey, 2016). A caregiver's expectations of a child becoming independent are shattered with little prospect of the child earning a living independently (Gona et al., 2011). In African countries such as South Africa, Ethiopia, Uganda, Zambia and Swaziland, ID is attributed to spiritual and cultural attitudes such as shame, curses, and witchcraft, and children are often subjected to name-calling, rejection, abuse, and neglect (McKenzie et al., 2013; Mkabile et al., 2021; S'lungile et al., 2015).

Caregivers raising a child with an ID undergo pain and devastation (Gona et al., 2011). In most instances, caregivers experience a high level of psychological and emotional distress, which has social implications and leads to indefinite parenting roles that demand advanced healthcare services and on-going social support services (Jung-Hwa Ha, 2011; Lawal et al., 2014). Furthermore, caregivers live in isolation, do not participate in social activities, and have a less social life due to increased parental responsibility (Ergun & Ertem, 2012; Şanlı & Barut, 2016).

In South Africa, about 12 per cent of the people with disabilities have an ID, which ranges from mild to profound, with other associated conditions that cause social and behavioural difficulties (Africa & Lehohla, 2014; Foskett, 2014). Foetal Alcohol Spectrum Disorder (FASD) is a common cause of intellectual disability in South Africa, and the Western Cape Province has the highest prevalence (10%) of children with ID (Foskett, 2014). Specialized healthcare services for adolescents and adults with ID are limited (Adnams, 2010). There is no access to transportation, and caregivers travel long distances to access health services (Donohue et al., 2014). Most families have financial difficulties, and for survival, they depend on a child disability grant, which does not cover all the child's expenses (Geiger, 2012). South Africa has numerous policies and legislation addressing disability (Adnams, 2010). The Constitution of South Africa under the Bill of Rights and Social Assistance Act No. 13 of 2004 make provision for social security for people with disability. National Health Act provides health security through free primary health care for people with disabilities, children and the elderly. The Mental Health Care Act No. 17 of 2002, health policy on rehabilitation and interventions addressing the rights of people with intellectual disability. The Department of Education provides for the inclusion of learners with ID in the mainstream system and specialized education support. Moreover, South Africa is a signatory to the United Nations Convention on the Rights of People with Disabilities (Donohue et al., 2014). Despite South Africa having these policies and legislations addressing disability, caregivers and disabled children are still marginalized (Adnams, 2010; Foskett, 2014; Tigere & Makhubele, 2019).

The province of KwaZulu-Natal has a prevalence of 8.4% of disability (Africa & Lehohla, 2014). Mental health services remain less of a priority in public health, resulting in significantly unmet needs of children with ID and caregivers (Yoder et al., 2016). Amongst six specialized psychiatric hospitals in the province, Umgeni Specialized Psychiatric Hospital is the only state-funded hospital that caters for the needs of people with severe to profound ID. Access to such services is hampered by poor bed utilization for possible admissions, inadequate infrastructure, and long waiting times (Adnams, 2010). These challenges persist in jeopardizing the effort made by caregivers to provide care and support for a child with an ID. Despite the range of challenges that caregivers of children with ID experience, there has been a paucity of research on ID and caregivers' experience in raising a child with ID in KwaZulu-Natal.

The study's first objective was to explore the lived experiences of caregivers raising children with an intellectual disability in Umgeni Municipality, KZN. The second objective was to identify the coping strategies adopted by caregivers and, lastly, to explore the psychological and emotional experiences of caregivers raising children with ID. The study addresses the overall question: What are the caregivers' experiences of raising children with ID?

Methodology

Study Design

The researchers used a phenomenological design. A phenomenological study is a qualitative method aimed at discovering the underlying structure, meaning, and essence of lived experiences of persons or a group of people around a specific phenomenon (Rahman & Learning, 2017)This study design was appropriate because the researchers aimed to explore the caregiver's lived experiences of raising children with ID in Umngeni Local Municipality, KZN.

Study Setting

The phenomenon under study is well known in the province of KwaZulu-Natal, but there was a need to concentrate on one specific setting. In this case, Umngeni Local Municipality was a suitable study setting. The study setting was selected based on its accessibility and convenience of the researcher and characteristic of participants who are likely to have the required information to achieve the objectives of the study. Umngeni Local Municipality is a Category B municipality within the uMgungundlovu District in the KwaZulu-Natal Province. The municipality has ten health facilities: 4 clinics, three mobile clinics, one specialized psychiatric hospital and two private hospitals. The research participants were recruited through Umgeni Hospital and were supposed to have a child with ID cared for at Umgeni Specialized Psychiatric Hospital. Umgeni Specialized Psychiatric Hospital admits people diagnosed with ID, physical disabilities and other related conditions such as Autism and epilepsy. The hospital caters for people of all races from three years and upwards in the KZN province.

Sampling Strategy and Size

A purposive sampling procedure was used to collect data from sixteen participants (Etikan et al., 2017). Amongst the 16 participants, a married couple was interviewed, meaning there were 15 females and one male. All participants were biological caregivers. Of the 16 participants, 15 had one child with ID, and one participant had two children with ID, a male and a female. The participants were selected based on the inclusion criteria that they needed to be caregivers above the age of 18 years (male or female) raising children with ID in Umngeni Municipality, KZN, who are patients at Umgeni Specialized Psychiatric Hospital. The Umgeni Hospital nursing services provided contact details of caregivers who regularly care for children with an ID. Given that nurses have a working relationship with caregivers and had a better position than the researchers to know and contact potential caregivers to be included as a participant in the study. Caregivers were telephonically contacted and recruited to participate in the study, depending on their availability. The children's ages ranged from 10 to 50 years, whilst those of the caregivers were between the ages of 30 to 70 years. Children had moderate, severe, and profound ID with various medical conditions such as epilepsy, cerebral palsy (CP), autism, physical disability and Attention-deficit hyperactive disorder (ADHD). Of the 16 participants, two caregivers were pensioners, three were unemployed, eight were employed, two were retired, fourteen African females, one African male, and one white female.

Data Collection

Data was collected using a semi-structured interview guide. The researcher developed an interview guide, and questions were structured in an open-ended format to delve deeply into participants' experiences of raising children with ID. The interview guide includes questions on the level of children's ID, challenges in raising a child with an ID, support structures, coping mechanisms or strategies caregivers use to overcome challenges, emotional and psychological effects of raising a child with ID and family relations. The following principles guided the researcher in developing the interview guide: aims and objectives of the study, research question and ethical considerations such as anonymity, confidentiality and informed consent.

Interviews were conducted by researcher in IsiZulu and English. The researcher first language is IsiZulu, and is also fluent in English. She is a social worker by profession and skilled in conducting in-depth interviews. The researcher used interview techniques such as listening, summarizing, clarifying, paraphrasing, and probing to seek clarity in an answer. The interview technique maximizes interactive opportunities between the respondent and interviewer, which helps to establish a sense of rapport and reduces the risk of desirable answers. The interviews were audio-recorded using a mobile cell phone voice recorder with the consent of participants. Notes were also taken as a backup in case of poor audio quality and to capture the non-verbal cues/gestures that the audio may not capture. Thereafter, the researcher transcribed the interviews as accurately as possible from IsiZulu into English. Transcribing one interview took approximately a day. The first step of transcribing was to listen attentively to the recordings and write down what was said by the participant word by word in a Word format document. The non-verbal gestures such as laughter, a moment of silence/pauses, and expression of emotions were captured. It was necessary to transcribe the data myself to deeply immerse in data, which helped in the initial process of exploring and analyzing data. Pseudonyms were used to protect the participant's anonymity. All recordings and notes were safely stored to protect the participant's confidentiality.

Data Analysis

Data was analyzed using a thematic analysis approach, an iterative process involving constantly moving backwards and forwards between messy data sets to map essential themes in the data (Nowell et al., 2017). Data was analyzed using the six steps of thematic analysis: familiarizing with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and finally, writing a report (Braun & Clarke, 2012). The initial analysis phase began with thoroughly reading the collected data and then generating initial codes. This was followed by identifying and reviewing the themes that emerge from the data for consideration in the transcript. The researcher then defined and named the themes. Lastly, the report was written and identified main themes and subthemes were grouped to give a meaningful contribution to the research question.

Ethical Considerations

Full ethical approval was obtained from the University of KwaZulu-Natal Bio-Medical Research Ethics Committee (BREC) with the reference number BREC/00000309/2019. The KwaZulu-Natal Department of Health, with reference number KZN_201910_020, granted permission to conduct research in the province. The gatekeeper's permission to conduct research at Umgeni Specialized Psychiatric Hospital was obtained from the Chief Executive Officer of the hospital. The participants were required to sign a written informed consent before participation in the study. Participants' anonymity and confidentiality were protected by using pseudonyms and conducting interviews behind closed doors. The principles of non-maleficence were adhered to throughout the interview and data collection processes.

Trustworthiness: Trustworthiness refers to the degree of confidence in the data, interpretation, and methods used to ensure the quality of the study (Connelly, 2016). To ensure trustworthiness, the researcher adopted four protocols and procedures: credibility, transferability, dependability, and confirmability (Amankwaa, 2016).

Credibility: In establishing the study's credibility, the researcher ensured that participants were identified and described accurately (Elo et al., 2014). Pre-interviews with the first three of the 15 participants were done to determine whether the interview questions were relevant and suitable for obtaining rich data needed to answer the research question.

Transferability: Transferability refers to the degree to which the research findings can be transferred to other contexts or settings (Kennedy-Clark, 2012). Transferability was ensured by providing a thick description of the participants, research process, study setting, sample size, and interview guide to enable the reader to assess whether research findings are transferable to their settings (Korstjens & Moser, 2018).

Dependability: Dependability refers to the consistency and reliability of the research findings and the degree to which research procedures are documented, allowing someone outside the research to follow, audit, and critique the research process (Korstjens & Moser, 2018). The study's dependability was ensured by preparing a detailed study protocol throughout the study in consultation with the supervisor and obtaining ethical approval to conduct the study. To maintain the consistency of the study, the researcher documented all the changes, comments and revisions to the study's protocol and kept all the records of when and how changes were implemented ((Forero et al., 2018).

Confirmability: Confirmability refers to objectivity and implies that the data accurately represents the information the participants provided and that the interpretation of data is not invented by the enquirer (Pandey & Patnaik, 2014). To achieve the study's confirmability, the researcher used representative quotations from the transcribed text to show a connection between the data and the result (Elo et al., 2014).

Results

Seven themes and subthemes were identified relating to the objectives of the study. The themes that emerged were accessibility of services, socio-economic aspects, support structure/system, family relations and interaction, common parental challenges experienced by caregivers, psychological and emotional distress and coping strategies.

Theme 1: Accessibility of Services

Five subthemes were identified under this theme: access to a special school, the place of care, health services, staff attitude, and transportation.

Subtheme 1.1: Access to special schools and residential care facilities

Access to special schools and residential care facilities for children with ID is minimal because the facilities were privately owned. The available ones were far from where children reside, with a long waiting list, expensive tuition fees and strict admission criteria that excluded children from enrolment. Some of the participants commented:

"Department of Education (DOE) was not helpful at all. I struggled to get a special school for my child. There was a special school in a neighbourhood, but they rejected my child's application" (CG-04).

"The available schools are far from us and have strict admission criteria or a long waiting list" (CG-08).

Some caregivers expressed dissatisfaction with services rendered and unskilled educators teaching children with ID:

".... The other challenge is poor care and services. My child will come home with bruises; when I make enquiries, the school will not give a clear explanation, but they will say she sustained them during her epileptic seizures. That showed negligence and lack of supervision" (CG-09).

"The Department of Education recommended that children with disabilities be enrolled in mainstream schools, but that is impossible because teachers in mainstream schools are not trained and equipped to educate children with disabilities; therefore, children are neglected because they do not fit in the syllabus and mainstream system" (CG-08).

Subtheme 1.2: Access to Health Services

Children with a disability require a holistic health service beyond what is required by a person without a disability. The participants had challenges accessing health services, and some complained about the non-availability of assistive devices such as wheelchairs. The participant expressed themselves as follows:

"I had a challenge with getting a wheelchair, and I had to carry her on my back to the hospital; later, the physiotherapist applied for it, and the application was approved. She has a wheelchair; it is easy to move around with her" (CG-06).

Waiting time was also a noticeable challenge. Participants indicated that they arrived early at the hospital, intending to return home early, but they were not attended to on time. They indicated that children with ID get irritated and frustrated quickly and then start to throw tantrums, and behavioural problems are triggered, as indicated in this verbatim quote:

"The other challenge is waiting time in the hospital (Pharmacy area) to collect medication; we wait for a long time, and an ID child gets irritable and bored easily, especially in a strange environment with unfamiliar faces" (CG-05).

Subtheme 1.3: Transportation

Almost all the participants had children who used wheelchairs, and some walked with difficulties. They travelled long distances to access health services in the urban area or were compelled to hired a car. Some used public transport, which is challenging because they had to carry a child and walk to the bus stop. The caregivers remarked:

"If you are travelling with a disabled child to the hospital, you need a second person to assist you because you must carry a child and wheelchair and then pay a taxi fare for two people. Some taxi drivers drop us far from the hospital; I must carry her on my back comfortably, ensuring she does not get hurt because of her spasticity and deformities."

(CG-05)

"The main problem was that both my children were attending physiotherapy and unable to walk. I had to hire a car to take them to the hospital and pay double or triple the taxi or bus fee. We had no car at home and could not afford to buy a car" (CG-08).

Subtheme 1.4: Staff Attitudes

Another challenge under this theme is staff attitudes. The caregivers experienced different treatments from staff members; some were treated with respect and dignity, while others were ill-treated. Caregivers narrated their frustration as follows:

"They convey the message with sympathy, they explain it very nicely, and it was not me alone; there were other mothers with a similar condition. They gave us booklets to read at home to equip ourselves to care for an ID child" (CG-07).

".... Therapists do not understand that we do not deliberately miss an appointment, but it is due to circumstances beyond us. Some will be rude as if we neglect the child, not knowing we have a problem with transport" (CG-08).

Theme 2: Socio-economic Status

The results showed that most caregivers face great economic difficulties. They struggle to provide primary child necessities such as food, nappies, and clothes. Most caregivers survived with a disability grant or care dependency grant for children. Furthermore, participants indicated difficulties sustaining their jobs and reported being late because the nanny came late or decided not to work. Caregivers often miss many work days, leaving early or reducing working hours to care for ID children, resulting in lost wages. Quitting a job to care for a child with ID full-time can be rewarding but take an enormous financial toll on a family and a child with ID who depends on caregivers for survival. Participants narrated their experiences in this regard as follows:

"A child with a disability has many needs, as compared to a normal child, such as nappies - and nappies are expensive, special diet, medication, clothing, and transport to the hospital every month or three times in a month; all of these requires money" (CG-06).

"...My daughter attended a day-care centre called Inkanyiso; sometimes the transport would not arrive, then I would not go to work" (CG-07).

".... I had to give up work to care for him" (CG-09).

Theme 3: Support System

Subtheme 3.1 Family Support

The caregivers had different support systems; some were supported by their families, friends, and community members, while others relied on the professionals who formed part of the child's upbringing. Most caregivers receive support from their families as compared to other support structures. Complimenting these findings were the following narratives by the caregivers:

"The family loved her, and they never showed any attitude or felt embarrassed for having a disabled child in the family. They accepted her as their own and as a family member" (CG-07).

"My husband supports me; he is always there for me in difficult times. He will assist me with household chores, suggest I leave other chores, and take a break not to strain myself."

"Our child gets support from the maternal family, particularly my mother, even after she had a stroke, but she still gives her love and support like before" (CG-02).

Some caregivers had to cope with the burden of raising children with ID on their own as single parents, without any support from the biological father or paternal family members. In most cases, the mother shouldered all the parental responsibilities of raising a child with an ID. Fathers were less involved or disappeared once they discovered the child's disability and the demands of care required with endless challenges. This sentiment is aptly captured in the following narratives:

"As a mother, a child with ID became your responsibility; although the father did not abandon us, he was not supportive. Whenever I need money to buy things for the baby, he will not provide it; even if I want someone to look after the child for one day or a few hours, he will not avail himself, that was my challenge, and no one was willing to assist me".(CG-06).

"The father and paternal family were not supportive, and they do not even check on the child's wellbeing. They do not care; they are not helpful; I accepted that I am on my own" (CG-12).

Subtheme 3.2: Support from friends, community members and counseling services.

Counseling from professionals and support from friends or community members were notified as other functional supporting structures. Through counseling, the caregivers could accept the child's condition and gain the strength and courage to deal with the burden of raising a child with an ID. The caregivers described their experiences as follows:

"Ntokozo, whom I met at college, supported me and encouraged me to secure placement at Umgeni Hospital. I took her advice, applied, and my child was admitted" (CG-15).

"I sometimes asked my neighbour to assist me by putting her on the school bus and fetching her after school" (CG-03).

"The social worker helped me to accept her condition by providing counseling, telling me that the condition is permanent and there is nothing I can do to change it" (CG-07).

Theme 4: Family Relationship and Interactions.

Caregivers confessed that having a child with a disability affected the family relationship and interactions either positively or negatively. Most caregivers had good family relationships and interactions and never experienced discrimination. For some caregivers, the family was dysfunctional due to giving birth to a disabled child. They experienced neglect, abuse, and discrimination. Other caregivers were overprotective towards their children. They would not allow them to associate with peers because of fear of exploitation, ridicule and embarrassment.

> *"My uncle used to encourage me to look for another child-minder because my aunt (wife of an uncle who also plays the role of a child-minder) was ill-treating my child. The child's welfare was not good, even if my uncle reprimanded my aunt; she continued abusing the child and told my uncle to look after the child himself. They ended up fighting because of the child" (CG-06).*

Theme 5: Common Parental Challenges Experienced by Caregivers

Caregivers underwent different stages of grief in trying to accept the child's condition. They had to cope not only with a child's disability but with other associated challenges such as self-mutilation, dependency, anticipating the child's needs, and dealing with a deteriorating condition. Most caregivers who participated in the study had limited social interaction with the outside world and lived in isolation. Their lives revolved around caring for a child with an intellectual disability; as a result, they lost friends. Some could not attend any social gatherings in the family or community. Another caregiver had given up hope of being in an intimate relationship and never thought she would find a man who would love her unconditionally and accept her child.

> *"There was nothing else to do besides taking care of my child. I never thought I would have a boyfriend or date again. I thought it was the end of life. I was like, is there a man that will love me and what will happen to my child? Where am I going to leave her? I was asking myself all those questions. I never thought life would go on" (CG-04).*

Some caregivers feared having another child because of the anxiety of giving birth to another child with ID. Finding a reliable child-minder or helper was also a struggle. Child-minders came and went at any given time without notice; they had to employ and teach the new nanny skills and strategies for caring for a child with an intellectual disability. Caregivers described this experience as very traumatic and stressful. Moreover, they had to endure societal attitudes and discrimination. One caregiver experienced discrimination in public. Community members took pity on an ID child and believed they should not be taken to the malls but instead kept indoors.

> *"When I take him to the restaurant, I heard people looking and talking to each other saying that I should not have taken him out" (CG-01).*

Theme 6: Psychological and Emotional Distress

This theme captures the psychological and emotional distress encountered by caregivers. Most caregivers experienced negative feelings such as hurt, sadness, guilt, denial, shame, self-blame, anger, and name-calling. The stress occurred as caregivers noticed delays in the child's developmental milestones compared to children of the same age and discovered that the child has multiple disabilities. The feelings of sadness and guilt manifested as one of the forms of emotional distress encountered by the caregivers. Emotions were also exacerbated by society's reaction towards children and caregivers, like name-calling, exclusion, negative attitudes, discrimination, and lack of knowledge and understanding about people with disabilities. The caregivers expressed their emotions in a variety of ways:

"After receiving the news from the nurse, I cried from Edendale Hospital to the bus stop, carrying the child. I cried all the way; it was painful and hurting."

(CG-10).

"My aunt ill-treated my child by calling him 'isishosha" (Person who is unable to walk)', 'isigobhe" (A person without eyesight) and all sorts of things" (CG-15).

Self-blame and denial were common among caregivers. The narratives indicated that self-blame was more on fathers as compared to mothers. The father blamed himself for impregnating his wife at a young age; worse, she gave birth to a child with a disability. Another father blamed himself for not adding his wife to medical aid. He assumed that if she had added her to the medical aid, it would have avoided prolonged labour, which they firmly believed was the cause of disability.

"I felt terrible; moreover, I felt bad for my wife whom I impregnated at the age of 22, and we had to deal with this, and it was our first child" (CG-14).

"The father blames himself for not adding me to his medical aid immediately after we got married, as prolonged labour could have been avoided" (CG-12).

The feeling of anger was also noticeable. Caregivers were angry at themselves for giving birth to a child with an intellectual disability. Some were infuriated by people's insults and on-going parental challenges. The caregivers expressed their anger using in the following ways:

"I was angry towards myself for giving birth to a disabled child" (CG-03).

"I still have anger towards my aunt (Family member) for what she said to my child and me. Till now, I have not forgiven her for what she has said to me. It was not my choice to give birth to a disabled child" (CG-15).

Theme 7: Coping Strategies

The caregivers used various coping strategies. Some caregivers seek spiritual intervention through prayer, consulting a traditional healer, joining a support group, and reading articles / watching YouTube videos on how to raise a child with ID. Other caregivers were fortunate to be supported by family members, whilst others went for psychological counselling.

"We have tried many things, such as spiritual healing; she has been baptized like any other child. We attended so many Passovers, took her to Pastor Sibisi for deliverance and other churches for prayer, hoping she would get better (CG-02)".

Some caregivers attributed the cause of the disability to curses or witchcraft and resorted to traditional healing. They went to different traditional healers with the hope that the child's condition would be normal. Some performed certain traditional rituals such as cleansing to cure disability, which they strongly believe is caused by not adhering to ritual:

"We even went as far as consulting with a traditional healer because family linked the disability of the child with "abantu abadala" (an ancestral calling), especially epileptic seizures. We were trying everything" (CG-10).

In addition, some coped by affiliating with a support group and networking to share their experiences of raising a child with a disability. Surprisingly, other caregivers used media as a coping mechanism; they read articles about disability to gain knowledge and searched on YouTube about ways to raise a child with an intellectual disability:

"Being in a support group has helped me realize that there are other people with similar problems and other conditions/problems are worse than mine". (CG-11).

"I dealt with my child's condition by watching videos on YouTube on how to cope with a child with ID and by socializing with people. At first, it was not easy to talk about the child's condition, but with time, I gained strength" (CG-13).

Discussion

The study's main objective was to explore the lived experience of caregivers raising children with ID in Umngeni Municipality. Accessibility of services and poor service delivery were the major challenges experienced by caregivers. Findings indicated a scarcity of special schools, residential care facilities and strict admission criteria, which excluded children with ID from enrolment or admission. Children were denied constitutional rights to education and cared for at home by caregivers. These findings are consistent with those of previous African studies, where children with ID did not receive education and were denied full participation in society, thus suffering a significant level of severe human rights violations, as compared to their able-bodied peers (Kishore, 2017; McKenzie et al., 2013).

Caregivers in remote areas travelled long distances to access health services in urban areas. A study in sub-Saharan African countries reported similar findings about urban-centric healthcare services (Adugna et al., 2020). In this study, caregivers did not have access to rehabilitation services and medical devices such as a wheelchair. The scarcity of rehabilitation teams to conduct a medical investigation for early detection of ID, holistic management, and a proper referral system for further management have been reported across Africa (Collings et al., 2012; Lazcano-Ponce et al., 2008). Change in the health system is necessary to improve and strengthen the integration of rehabilitation teams into Primary Health Care (PHC). Primary Health Care is the first contact with health services and a pathway to further management (Bright et al., 2018). Rehabilitation teams are fundamental for the early identification of disability and appropriate intervention (Africa., 2009)

Meeting the child's necessities weighed heavily on the caregivers, irrespective of socio-economic status (Lawal et al., 2014). The study findings indicate that most caregivers were employed but experienced financial difficulties meeting the child's needs. Some caregivers had to quit their jobs to meet the care demands of raising a child with an intellectual disability (Paola Di Giulio, 2014). Other caregivers quit their jobs because of unreliable child-minders who resigned unexpectedly. McKenzie et al. (2013) indicated that caregivers stopped working to care for their children, and some caregivers cannot seek jobs due to caregiving demands. In most instances, the mother resigns from work to take over childcare responsibilities (Lawal et al., 2014). This poses a significant financial strain on the entire family and aggravates psychological distress.

A social support system is a multi-dimensional system that can be provided to caregivers formally or informally (Merrick, 2007). Caregivers receive support from different influential people. In this study, most caregivers relied on informal support from family members, friends, and neighbours who provided emotional, psychological, financial, and social support. A study on the role of social support for African-American parents reported that a caregiver with a sound social system showed positive parenting behaviour and low-stress levels (Jung-Hwa Ha, 2011). The caregivers also used formal support from health professionals and organizations providing services for people with intellectual disabilities. Some caregivers did not receive any form of support from the family. Coordinated support services from the non-profit organization, health and social sector are crucial to providing needed support services to enable caregivers and children to function optimally. On-going social support will give caregivers strength and hope and improve caregiving quality (Vidya Bushan Gupta 2012).

The impact of intellectual disability on family dynamics and relationships is well-known (Dyke et al., 2009; Loft, 2011). This study provides further evidence of family dysfunction caused by the birth of a child with a disability. The participants in the study attested to neglect, abuse, and discrimination within the household. Some participants were overprotective and could not allow children to play with peers because of fear of exploitation and embarrassment.

The birth of a child with an intellectual disability affects a couple's relationship in different ways (Lawal et al., 2014; Paola Di Giulio, 2014). The caregivers in this study were hesitant to conceive due to the fear of giving birth to another child with a disability. A study on families with disabled children in different European countries reported similar findings, i.e., that the birth of an intellectually disabled child influenced the couple's decision to have another child (Paola Di Giulio, 2014). Single parenthood is common among caregivers with an intellectual disability (Hogan, 2012). In this study, biological father deserted their children due to disability and failed to provide emotional or financial support. The same sentiments were reported in the study conducted in the Eastern Cape Province, where female caregivers were single parents and fathers were migrant workers who shyed away or were unwilling to play parental role (Mckenzie & Swartz, 2011).

The study points to the need to support the family in couples counseling. The study on myths surrounding albinism in South Africa and Zimbabwe indicates that caregivers who gave birth to a child with special needs should receive information and counseling from Health Care Workers (Baker et al., 2010).

It should be noted that whilst some of the caregivers in this study had low-income family relationships, most caregivers experienced good interactions and relationships with other family members, especially siblings without ID. Caregivers attested that non-disabled siblings accepted the condition, never experienced any judgmental attitude or poor relationship and voluntarily helped with caregiving without feeling obliged. These indicate that siblings become caregivers who positively impact caregivers in reducing the burden of care (Fernández-Ávalos et al., 2020). In that regard, siblings should form part of a multidisciplinary team whereby healthcare providers educate siblings about the potential positive and negative aspects of living with a sibling with an intellectual disability (Dyke et al., 2009).

It is evident that caregivers raising children with intellectual disabilities are socially isolated and suffer a great deal of stigma associated with intellectual disability, which causes a restriction on participating in any social activities. A study investigating the difficulties of mothers living with mentally disabled children reported similar findings, where caregivers often had less of a social life due to parental responsibility (Ergun & Ertem, 2012).

Literature reveals that caregivers undergo on-going emotional and psychological distress (Crnic et al., 2017; Lawal et al., 2014; Tilahun et al., 2016). In this study, caregivers experienced fluctuating emotions such as anger, fear, and feelings of hurt. Moreover, caregivers blamed themselves for giving birth to a child with a disability, whilst others were in denial because of their high hopes of the child's condition improving with time. The study conducted in low-middle-income countries also reported fluctuations in emotions experienced by caregivers (DePape & Lindsay, 2015).

The study further revealed that society still displays discriminatory attitudes towards people with intellectual disabilities. As highlighted by caregivers in the study, people with intellectual disabilities are not well accepted in public: they are regarded as people who should be locked in the house and not appear in public. In Swaziland, people with disabilities are perceived as a curse by God or ancestors (Dickinson, 2018; Masulani-Mwale et al., 2016; S'lungile et al., 2015). Therefore, they are treated as weak social beings and called derogatory names such as "Isilwane" (Refers to an animal) and "Isishosha" (A person who is unable to walk). Similar findings were also reported in Namibia, where children with disabilities are classified as stupid or incomplete human beings (Taderera & Hall, 2017).

Spiritual intervention in the form of prayer and traditional healing emerges as a caregiver's most used coping strategy. Caregivers in this study believed that God trusted them to raise a child with a disability; therefore, caregivers perceived children with disabilities as a precious gift from God. Some caregivers sought traditional healing as a coping strategy or intervention after exhausting all avenues of treatment. They firmly believed that the disability of a child is associated with witchcraft, a curse from ancestors and punishment from God for being sinful (Vidya Bushan Gupta 2012).

Support groups and social media use emerge as other helpful coping strategies. These platforms promote interaction among caregivers who are confronted with similar parenting challenges and positively impact the quality of life of both the caregiver and the child (Emerson et al., 2010; Merrick, 2007). Due to the lack of support from immediate family members and close friends, social media and support group connections become an additional and consistent support system (Terra, 2020). The same sentiments were narrated by participants who found comfort in sharing their experiences with caregivers with a similar problem.

Limitations of the Study

The study was conducted in one municipality, and the findings may not be transferable to other contexts. The study participants were mainly fifteen female caregivers, with one male. The experiences of male caregivers were only partially captured. Therefore, future studies should focus more on male caregivers' experiences of raising a child with ID. The researcher was not a qualified translator but was proficient in IsiZulu and English. There were sometimes difficulties in translation, and the researcher acknowledges that back translation should be done to ensure consistency and congruency between the source and target language. Due to limited resources and time constraints, the researcher did not use back translation.

Recommendations and health policy implications.

Caregivers and children with ID have multiple challenges beyond those of the everyday routine of caregiving. Considering the research findings and the challenges confirmed by the literature, the following interventions are recommended to improve the lives of caregivers and children with ID. Caregivers and children with ID should have access to a range of services that will improve quality of life and enable caregivers to overcome the on-going challenges of raising a child with ID. Accessibility of services is a human and constitutional rights issue that needs to be addressed in collaboration with all relevant stakeholders. Integrating mental health services within primary health care and community-based care can increase access and help with early detection of ID. Community-based Rehabilitation (CBR) should be reinforced for access to health care services at a community level to eliminate cases where caregivers terminate therapy due to financial constraints or transportation.

The support given to the caregivers and children should give caregivers insight into the possible cause of ID, the treatment available, and resources available in the community, such as rehabilitation services, special schools, respite care and support groups. As part of primary and secondary prevention of ID, Community Health Care Workers (CHCW) can be utilized to provide care, support, and psycho-education. Psycho-education should include preventative measures such as attending the perinatal clinic regularly, good nutrition, and not consuming alcohol or taking drugs during pregnancy. The basic training of CHCW on intellectual disability is essential for effective service delivery.

Support in the form of psychotherapy with a social worker, psychologist, occupational therapist, physiotherapies, dietician, psychiatric doctor or nurse is crucial for caregivers to deal with emotional and psychological distress associated with on-going challenges of raising a child with ID. Family therapy will address the change in family dynamics and the instability that occurs due to the birth of a child with ID. Genetic counseling services are also recommended to investigate the possible risk of a genetic disorder. This can be done by gathering and analyzing the family history of intellectual disability and genetic inheritance patterns of both the maternal and paternal families.

Since caregivers use a combination of spirituality, Western and Traditional medicine, integration of Traditional indigenous medicine and Western biomedicine into the health care system should be strengthened, as some caregivers strongly believe that ID is associated with witchcraft, supernatural powers, and curses from ancestors (Chukwu et al., 2019; Ganjiwale et al., 2016). Religious institutions and preachers should be trained to provide pastoral care, support and counseling to caregivers and their families.

Formulating structured support networks like support groups is recommended for caregivers to share their experiences, learn new skills, and discuss challenges with people with similar problems. The on-going awareness campaigns about ID will minimize the stigma, negative attitudes, discrimination, and misconceptions associated with ID. Government policies such as Batho Pele should be strengthened to minimize staff attitude, a barrier to accessing services. Batho Pele Principle is a South African Government initiative that aims to improve the quality and accessibility of all government services through efficiency and accountability to people.

Conclusions

The study aimed to explore the lived experiences of caregivers raising children with ID. The study met its objective and provided in-depth information about the caregivers' experiences. The findings indicate that numerous challenges impact caregivers who require formal or informal support to overcome the hardships. Furthermore, the government should strive to improve service delivery for people with ID by developing programmes that address the needs of caregivers and their children at the community level.

Acknowledgements

The authors thank the Department of Health in KZN for granting the permission to conduct the study. Sincere gratitude goes to the caregivers who participated in the study**.**

References

Adnams, C. M. (2010). Perspective of intellectual disability in South Africa: epidemiology, policy, services for children and adults 436-437, Article 0951-7363. https://doi.org/10.1097/YCO.0b013e32833cfc2d

Adugna, M. B., Nabbouh, F., Shehata, S., & Ghahari, S. (2020). Barriers and facilitators to healthcare access for children with disabilities in low and middle income sub-Saharan African countries: a scoping review. *BMC Health Services Research*, *20*(1), 15. https://doi.org/10.1186/s12913-019-4822-6

Africa, S. S., & Lehohla, P. (2014). *Census 2011: Profile of persons with disabilities in South Africa*. Statistics South Africa.

Africa., G. o. t. R. o. S. (2009). *Intergrated National Strategy on Support Services to Childern with Disabilities.* .

Amankwaa, L. (2016). CREATING PROTOCOLS FOR TRUSTWORTHINESS IN QUALITATIVE RESEARCH. *Journal of cultural diversity*, *23*, 121-127.

Ambikile, J. S., & Outwater, A. (2012). Challenges of caring for children with mental disorders: Experiences and views of caregivers attending the outpatient clinic at Muhimbili National Hospital, Dar es Salaam-Tanzania. *Child and adolescent psychiatry and mental health*, *6*(1), 1-11.

Baker, C., Lund, P., Nyathi, R., & Taylor, J. (2010). The myths surrounding people with albinism in South Africa and Zimbabwe. *Journal of African Cultural Studies*, *22*(2), 169-181.

Banks, L. M., Kuper, H., & Polack, S. (2017). Poverty and disability in low- and middle-income countries: A systematic review. *PLOS ONE*, *12*(12), e0189996. https://doi.org/10.1371/journal.pone.0189996

Bertelli, M., & Kishore, M. T. (2014). Mental health and intellectual disability: Implications for global mental health. In *Essentials of global mental health.* (pp. 222-230). Cambridge University Press. https://doi.org/10.1017/CBO9781139136341.027

Braun, V., & Clarke, V. (2012). Thematic analysis.

Bright, T., Wallace, S., & Kuper, H. (2018). A Systematic Review of Access to Rehabilitation for People with Disabilities in Low- and Middle-Income Countries. *15*(10), 2165. https://www.mdpi.com/1660-4601/15/10/2165

Chukwu, N. E., Okoye, U. O., Onyeneho, N. G., & Okeibunor, J. C. (2019). Coping strategies of families of persons with learning disability in Imo state of Nigeria. *Journal of Health, Population and Nutrition*, *38*(1), 9. https://doi.org/10.1186/s41043-019-0168-2

Collings, S., Llewellyn, G. J. J. o. i., & disability, d. (2012). Children of parents with intellectual disability: Facing poor outcomes or faring okay? , *37*(1), 65-82.

Connelly, L. M. J. M. N. (2016). Trustworthiness in qualitative research. *25*(6), 435.

Crnic, K. A., Neece, C. L., McIntyre, L. L., Blacher, J., & Baker, B. L. J. C. D. (2017). Intellectual disability and developmental risk: Promoting intervention to improve child and family well-being. *88*(2), 436-445.

DePape, A.-M., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative health research*, *25*(4), 569-583.

Dickinson, R. (2018). Parenting a child with disabilities: The intersection of education and cultural perceptions in Southern India. *Journal of Human Rights and Social Work*, *3*(2), 72-80.

Donohue, D. K., Bornman, J., & Granlund, M. (2014). Examining the rights of children with intellectual disability in South Africa: Children's perspectives. *Journal of Intellectual & Developmental Disability*, *39*(1), 55-64. https://doi.org/10.3109/13668250.2013.857769

Dyke, P., Mulroy, S., & Leonard, H. J. A. P. (2009). Siblings of children with disabilities: Challenges and opportunities. *98*(1), 23.

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative Content Analysis: A Focus on Trustworthiness. *SAGE Open*, *4*(1), 2158244014522633. https://doi.org/10.1177/2158244014522633

Emerson, E., Shahtahmasebi, S., Lancaster, G., Berridge, D. J. J. o. I., & Disability, D. (2010). Poverty transitions among families supporting a child with intellectual disability. *35*(4), 224-234.

Ergun, S., & Ertem, G. (2012). Difficulties of mothers living with mentally disabled children. *J Pak Med Assoc*, *62*(8), 776-780.

Etikan, I., Bala, K. J. B., & Journal, B. I. (2017). Sampling and sampling methods. *5*(6), 00149.

Fernández-Ávalos, M. I., Pérez-Marfil, M. N., Ferrer-Cascales, R., Cruz-Quintana, F., Clement-Carbonell, V., & Fernández-Alcántara, M. (2020). Quality of life and concerns in parent caregivers of adult children diagnosed with intellectual disability: A Qualitative Study. *International Journal of Environmental Research and Public Health*, *17*(22), 8690.

Forero, R., Nahidi, S., De Costa, J., Mohsin, M., Fitzgerald, G., Gibson, N., McCarthy, S., & Aboagye-Sarfo, P. J. B. h. s. r. (2018). Application of four-dimension criteria to assess rigour of qualitative research in emergency medicine. *18*(1), 1-11.

Foskett, K. (2014). *Intellectual disability in South Africa*.

Ganjiwale, D., Ganjiwale, J., Sharma, B., Mishra, B. J. J. o. f. m., & care, p. (2016). Quality of life and coping strategies of caregivers of children with physical and mental disabilities. *5*(2), 343.

Garcia Iriarte, E., O'Brien, P., McConkey, R., Wolfe, M., & O'Doherty, S. (2014). Identifying the key concerns of Irish persons with intellectual disability. *J Appl Res Intellect Disabil*, *27*(6), 564-575. https://doi.org/10.1111/jar.12099

Geiger, M. (2012). Communication training for centre-based carers of children with severe or profound disabilities in the Western Cape, South Africa [basic communication; centre-based carer training; non-verbal children; severe and profound disabilities; special care centres]. *2012*, *1*(1). https://doi.org/10.4102/ajod.v1i1.10

Gona, J. K., Mung'ala-Odera, V., Newton, C. R., & Hartley, S. (2011). Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? , *37*(2), 175-183. https://doi.org/doi:10.1111/j.1365-2214.2010.01124.x

Hogan, D. (2012). *Family consequences of children's disabilities*. Russell Sage Foundation.

James, G., Chuaqui, J., Wilson, D. R., & Arredondo, E. (2019). The Global Impact of Intellectual Disability and Other Mental Disorders in Children. *The International journal of childbirth education: the official publication of the International Childbirth Education Association*, *34*, 14-17.

Jung-Hwa Ha, J. S. G., Marsh Mailick Seltzer. (2011). Parenting a child with disability: The role of social support for african american parents *NHI PUBLIC ACCESS*, 405-411. https://doi.org/10.1606/1044-3894.4150

Kennedy-Clark, S. J. A. A. f. R. i. E. (2012). Design Research and the Solo Higher Degree Research Student: Strategies to Embed Trustworthiness and Validity into the Research Design.

Kishore, M. T. (2017). Service delivery models for people with intellectual disabilities in low and middle income countries: Strategies and solutions can emerge from within. *Journal of Intellectual Disabilities*, *21*(3), 201-202. https://doi.org/10.1177/1744629517721344

Korstjens, I., & Moser, A. J. E. J. o. G. P. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *24*(1), 120-124.

Lawal, H., Anyebe, E., Obiako, O., Garba, S. J. I. J. o. N., & Midwifery. (2014). Socio-economic challenges of parents of children with neurological disorders: A hospital-based study in North West Nigeria. *6*(4), 58-66.

Lazcano-Ponce, E., Rangel-Eudave, G., & Katz, G. (2008). Intellectual disability and its effects on society %J Salud Pública de México. *50*, s119-s120. http://www.scielo.org.mx/scielo.php?script=sci_arttext&pid=S0036-36342008000800001&nrm=iso

Loft, L. T. G. J. I. J. o. S. (2011). Child health and parental relationships: Examining relationship termination among Danish parents with and without a child with disabilities or chronic illness. *41*(1), 27-47.

Masulani-Mwale, C., Mathanga, D., Silungwe, D., Kauye, F., & Gladstone, M. (2016). Parenting children with intellectual disabilities in Malawi: the impact that reaches beyond coping? , *42*(6), 871-880. https://doi.org/doi:10.1111/cch.12368

McKenzie, J., & McConkey, R. (2016). Caring for Adults with Intellectual Disability: The Perspectives of Family Carers in South Africa. *29*(6), 531-541. https://doi.org/doi:10.1111/jar.12209

McKenzie, J., McConkey, R., & Adnams, C. (2013). *Intellectual disability in Africa: Implications for research and service development*. https://doi.org/10.3109/09638288.2012.751461

Mckenzie, J. A., & Swartz, L. (2011). The shaping of sexuality in children with disabilities: AQ methodological study. *Sexuality and Disability*, *29*(4), 363-376.

Merrick, I. K. a. J. (2007). the child with a disability:Parental Acceptance, management and coping. *The scientific World Journal* 1799-1809. https://doi.org/10.1100/tsw.2007.265

Mkabile, S., Garrun, K. L., Shelton, M., & Swartz, L. (2021). African families' and caregivers' experiences of raising a child with intellectual disability: A narrative synthesis of qualitative studies. *African Journal of Disability (Online)*, *10*, 1-10.

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic Analysis:Striving to Meet the Trustworthiness Criteria. *16*(1), 1609406917733847. https://doi.org/10.1177/1609406917733847

Pandey, S., & Patnaik, S. (2014). ESTABLISHING RELIABILITY AND VALIDITY IN QUALITATIVE INQUIRY: A CRITICAL EXAMINATION. *Jharkhand Journal of Development and Management Studies*, *12*, 5743-5753.

Paola Di Giulio, D. P., and Ina Jaschinski. (2014). Families with disabled childern in different Europen countries. *Families and Societies* (23), 1 -44, Article 320116.

Rahman, M. S. J. J. o. E., & Learning. (2017). The Advantages and Disadvantages of Using Qualitative and Quantitative Approaches and Methods in Language" Testing and Assessment" Research: A Literature Review. *6*(1), 102-112.

S'lungile, K. T., Ntinda, K., Hlanze, B. J. J. o. E., & Studies, T. (2015). Lived experiences of parents' of children with disabilities in Swaziland. *3*(4), 206-215.

Şanlı, E., & Barut, Y. (2016). *The Determination of the Needs of the Families with a Mentally Handicapped Child According to Their Mood* (Vol. 19). https://doi.org/10.5782/2223-2621.2016.19.3.68

Taderera, C., & Hall, H. (2017). Challenges faced by parents of children with learning disabilities in Opuwo, Namibia. *African journal of disability*, *6*(1), 1-10.

Terra, A. A. (2020). *Connections: Social media and parents raising children with profound multiple disabilities* University of the Pacific].

Tigere, B., & Makhubele, J. C. (2019). The experiences of parents of children living with disabilities at Lehlaba Protective Workshop in Sekhukhune district of Limpopo province. *African journal of disability*, *8*(0), 528-528. https://doi.org/10.4102/ajod.v8i0.528

Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., & Hoekstra, R. A. (2016). Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey. *BMC Health Services Research*, *16*, 152-152. https://doi.org/10.1186/s12913-016-1383-9

Tomlinson, M., Yasamy, M. T., Emerson, E., Officer, A., Richler, D., & Saxena, S. (2014). Setting global research priorities for developmental disabilities, including intellectual disabilities and autism. *Journal of intellectual disability research : JIDR*, *58*(12), 1121-1130. https://doi.org/10.1111/jir.12106

Vidya Bushan Gupta , P. M., Naveen Mehrotra. (2012). Parental stress in raising a child with disability in India. *23 No. 2, 2012*, 41-52. https://doi.org/10-5463/DCID.v23i2.119

Yoder, H. N., Tol, W. A., Reis, R., & de Jong, J. T. (2016). Child mental health in Sierra Leone: a survey and exploratory qualitative study. *International journal of mental health systems*, *10*(1), 1-13.