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Research Article

Challenges Experienced by Caregivers in Communicating with Children with Severe to Profound Intellectual Disabilities

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Abstract

Background: Children with severe to profound intellectual disabilities (SPID) may have complex and numerous disabilities, such as intellectual limits and severe deficits in bodily functions. This disorder is typified by issues with speech, language, mobility, agility, and emotional issues providing quality education in appropriate special care centres for children who present with such complex conditions is challenging. *Objective*: This study explored and described the experiences of caregivers in communicating with children with severe to profound intellectual disabilities in selected special care centres in Gauteng Province. *Method*: This study followed a qualitative approach and data collection was gathered through in-depth semi-structured interviews, observations in the classroom corroborated children and caregiver`s communication behavior, and document analysis. Eight caregivers were purposively selected to participate in the study. The theory underpinning this study are Ubuntu and Attachment theories. The theories provided the study's foundation and emphasized caring as the central component and influence communication. *Result*: The thematic analysis revealed the key areas of support needs. The following themes emerged and are as follows: Communication strategies used for children with SPID and, experiences of caregivers in supporting children with SPID. Through these themes the research questions were answered. *Conclusion*: The study revealed that caregivers' inadequate communication abilities prevent them from responding to the needs of children with SPID. To meet the communication needs of children with SPID, communication requires, relevant communication devices or resources, collaboration with other stakeholders and a qualified trained caregiver.

1. Introduction

The World Health Organization (WHO) defines Intellectual Disability (ID) as a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contributes to the overall level of intelligence, thus, cognitive, language, motor, and social disabilities [6]. It is particularly marked by impairment of skills that manifest during the developmental period and contributes to the overall

level of intelligence. [64] A variety of frequently co-occurring medical disorders are likely to be present in children with severe to profound intellectual disability (SPID), with sensory impairments, epilepsy, and cerebral palsy being the most common [35]. According to WHO [62], children with severe to profound intellectual disabilities are among the most marginalized groups in society. They are vulnerable and excluded from the system of services provided to all school-age children since they do not have access to publicly financed education and support. Even though, there are more and more children with SPID in today's society. However, these children still have a great need for unmet communication help.

This article presents the research on caregivers' experiences in communicating with children with SPID in selected special care centres in Gauteng. The study is based on two frameworks that I specifically chose to use: attachment theory and Ubuntu theory. These frameworks are particularly notable when considering children and the social interactions that shape their communication development. Below is a discussion of the two theories.

2. Theoretical Framework

A theoretical framework is a structure that can hold or support a research study and relates the theory that explains why the research topic under consideration arises [48]. The focus of my research was to examine and characterize the caregivers' experiences in communicating with children with severe to profound intellectual disabilities in SCCs. People find safety, acceptance, and a sense of belonging through connections. As a result, I employed the attachment and ubuntu theory frameworks to support my investigation. A psychological, evolutionary, and ethological hypothesis of human connections is called attachment theory [13]. As a result of the caregiver's ability to provide the infant with safety and security, Bowlby [10] describes attachment as a persistent psychological bond between humans that may be explained in the perspective of evolution. Therefore, the basic principle is that appropriate social and emotional development in early children requires them to form a relationship with at least one major caregiver. The emotional connection that unites people over time and location is profound and long-lasting [10]. As a result, some actions in children, such as wanting to be close to the attachment figure when they feel sad or threatened, are indicative of a bond. According to Groh et al, [25], early interactions between children and caregivers are crucial for the development of children's self-regulation in areas like social emotional adjustment, language acquisition, and cognitive growth. Based on the foregoing arguments, it is clear that caregiver child relationship plays a key role in children communication development. The idea that Ubuntu is humanness led me to select the Ubuntu ideology. Caregiver`s caring, respect, and compassion are all part of what it means to be human. Too often, due to their communication issues and limitations, children with SPID have not been given the

chance to engage in planned community events. This is consistent with a 2015 study by Ngubane [45], which found that the birth of disabled children was viewed by society as a curse and a kind of retribution from God. Children with SPID are therefore not allowed to participate in community events. Ubuntu thereby fosters caregiver`s positive attitude that encourages the integration of children with SPID in the community.

3. Literature Review

3.1. Challenges Experienced by Caregivers

Communication is an essential social skill for children with SPID, thus supporting them in this way requires trained staff. According to Department of Basic Education [19], lack of training has made it difficult to deal with communication requirements or skills, and therefore, caregivers feel stressed because they are unable to meet the demands of children with SPID. According to Barker & Hoskins [6], language deficiencies may exacerbate behavioral issues by making it difficult for children to understand and communicate their needs and requests to others, which can have an impact on their ability to regulate their emotions and their conduct. Drozd & Clinch [21] states that, children diagnosed with SPID frequently exhibit problematic behaviors such as violence, self-harm, and severe tantrums. More and more data, however, suggests that the type and degree of communication impairment and the frequency of severity of problems are related. Niewenhuis [44] contends that given that children with SPID have severely limited speech and language development, problem behavior may be their only practical way of expressing basic needs, wants, and emotions [22]. Caregivers, however, find it difficult to understand these kinds of actions.

3.2. Poor Communication Skills

Communication is a critical life skill that enables all human beings to make their needs known and establish relationships with other human beings [3]. In addition, communication is an activity that involves sending, receiving, processing, and comprehending concepts and messages that are presented. This includes verbal, non-verbal, and graphic communication. Armstrong et al. [3] indicates that, communication is a vital life skill that allows everyone to express their needs and build relationships with others. Transmission, reception, processing, and understanding of ideas and information are all part of the activity of communication. This covers graphic, nonverbal, and spoken communication. According to Alzrayer & Banda [2], children with SPID express themselves through vocalization, facial expressions, body language, traditional gestures, objects, and other ways. However, due to alternative communication modalities that rely on their physical, sensory, and

cognitive capacities, children with severe disabilities might not be able to communicate successfully through speech Adams & Jahoda [1].

On the other hand, caregivers could overestimate their use of non-verbal communication and underestimate their own spoken communication. Furthermore, caregivers can be unable to read the facial expressions used by children with SPID to convey their feelings. Thus, to analyze and comprehend them, one needs experience and close observation [4]. This implies that there might be observable obstacles to communication between caregivers and children with severe disabilities [1]. According to reports, caregivers believed that communicating with children who have severe disabilities required a lot of time, which could have an adverse effect on the quality of care that was provided; [4, 11, 27]. Sometimes, caregivers respond to children with severe disabilities in their care in stereotypical ways rather than considering them as individuals with unique needs. For example, Aston et al [4], states that the two most common stereotypes associated with children with SPID are that they are unable to communicate or understand and that they are difficult to manage.

With that in mind, caregivers might be reluctant to engage in communication with children with SPID, if they perceive them as lacking the capacity to understand the interaction or perceive them as difficult [21]. Nieuwenhuijse et al [43] states that caregivers demonstrate a lack of preparation for delivering care to children with severe disabilities. As a result, caregivers reportedly experience a range of emotions and are less likely to feel comfortable, confident, relaxed and optimistic when delivering care to children with SPID.

3.3. Lack of Resources

Manqele [33], indicates that resources are any items that are readily available in an academic setting to help with school administration and make the process of teaching and learning simpler. According to this study, a special care facility is considered to be lacking resources if it does not have the necessary instructional tools or learning materials to improve communication among children with SPID. For instance, the sector of education has limited resources in the form of persons, funds, resources, and qualified specialists [63]. As per the findings of Crnic [16], caregivers in the setting of special care centers view educational resources as indispensable. The uneven distribution of resources that persists as a result of the disparities between the rich and the poor is one of the legacy issues of apartheid, Vlok [57].

The dearth of resources for families of children with SPID worldwide has been documented by researchers [32, 58, 62, 63]. This is especially true in low- to middle-income governments., To improve and facilitate communication between caregivers and children with SPID, various materials are required. In accordance with Naidoo [42], successful teaching and learning are hampered by a widespread shortage of resources. Thus, caregivers' capacity to assist children with

SPID who face communication obstacles in their educational journey is hampered by a lack of resources [42].

3.4. Finance

As stateted by Vaughn [55], children with SPID are disproportionately more likely than other children to grow up in impoverished families, accounting for almost 40% of the population in sub-Saharan Africa. Porterfield et al [46] claim that parental income and educational attainment seem to be major factors in a child's ability to access communication services. Parents who are impoverished and illiterate may have less access to resources and services for their children's intervention [46].

Consequently, parents with lesser incomes and levels of education tend to perceive a reduced need for specialized health care services and are unaware of the options that are offered. Rapanaro et al [47] corroborate this finding and add that parents of children with SPID experience significant stress when trying to find appropriate care providers. As a results, p will not seek out those services if they believe their children do not require communication devices [4, 47].

4. Research Methodology

4.1. Research Design

Creswell [15] defines research design as the detailed plan outlining how one plans to conduct research in respect to its setting. McCusker &Gunaydin [38] contend, however, that the most valid and dependable data should be obtained from a research design by employing the methods that best suit the issue at hand. For this study, a phenomenological research design was used as a technique. Ritchie & Abel [49], define phenomenology is a philosophical method that minimizes the researcher's viewpoint and concentrates on the experiences of participants.

4.2. Research Method

Since my research focused on caregiver experiences, I decided to utilize a qualitative research approach. As a researcher, my goal was to become comfortable with the research problem and be able to conduct the study with ease. In a qualitative study, the researcher aims to comprehend phenomena in their natural environments, frequently seeing and interacting with individuals or systems [15].

5. Data Collection Method

As mentioned by Walliman [58], data collection is the act of obtaining and assessing information on relevant variables in a methodical and established way that makes it possible to respond to research questions. It's a crucial component of any

study. Based on Briggs et al [12], the phrase "data collection" refers to the act of gathering and organizing data. Information gathering, record-keeping, decision-making regarding significant matters, and information dissemination are the goals. I employed semi-structured in-depth interviews, document analysis, and observation in my study.

5.1. Semi-Structured Interviews

In-depth interviews employ open-ended questions to elicit information from the participants and facilitate comprehension of how individuals create meanings [39]. Interviewing participants enables the researcher to engage with them more personally, provides an opportunity for mutual understanding, and is a more organic method of gathering data, [38]. Open-ended questions were utilized in-person, semi-structured, in-depth interviews that were conducted utilizing my pre-prepared interview guide (Appendix E). As reported by Walliman [58], semi-structured interviews are advantageous for the investigator since they permit the use of open-ended questions. The researcher was able to comprehend the participants' experiences as a result of the participants being able to reply and express themselves freely to a greater level [40]. It was confirmed that caregivers agreed to participate in the interview in accordance with the schedules once the dates and locations were arranged with the SCC center managers.

5.2. Observation

As pointed out by Walliman [58], semi-structured interviews are advantageous for the investigator since they permit the use of open-ended questions. The researcher can better comprehend the participants' experiences as a result of the participants being able to reply and express themselves freely to a greater level [40]. It was confirmed that caregivers agreed to participate in the interview in accordance with the schedules once the dates and locations were arranged with the SCC center managers. when children were in their classes, during nappy changing, feeding and during learning. I observed how eight caregivers communicated and responded to the needs of these children, how caregivers interacted and their emotions during the process. The observations took approximately 40 minutes to 1 hour. I used an observation sheet (Appendix F) to record the events. I recorded data gathered during observations as field notes [15].

5.3. Document Analysis

As reported by Klein [29], document analysis is a type of qualitative research that examines documented evidence using a methodical process. Compiling documents that provide insight into the ideas under study is crucial [14]. One benefit of document analysis is its accessibility at the researcher's convenience [29]. Because document analysis does not ne-

cessitate direct participant involvement, it is an unobtrusive approach of data collecting [14]. This can be particularly helpful in circumstances when participants might not be able or ready to offer information in other ways [15] Additionally, based on Cohen et al [14], "documents bring together previously unrelated materials which illuminate a phenomenon" (p. 201). The present study involved the analysis of employment paperwork/contract forms, emails including invites to AAC training, and attendance register records across all four SCCs. All four centers provided the employment contract paperwork that were requested and examined. Documents helped me conduct interviews and provided insight into the communication plans that had been made.

6. Participants

Creswell [15] defines a sample as a subset of the population whose members were selected so that their attributes would be representative of the group from which they were selected. Using the purposive sampling strategy, I was able to obtain participants for my study that fulfilled certain requirements and could offer data that aligned with my research interests [17]. My research focused on caregivers who have direct experience in communicating with children with SPD. Only eight of the ten participants—whom I had originally purposively selected—were full-time caregivers at the SCCs for children with SPID and ranged in age from 25 to 70. The two individuals who did not take part are both under 70 years old. The caregivers had to be interested in and have experience caring children with SPID.

7. Results

7.1. Caregivers' Experiences in Communicating with Children with SPID

South Africa is a linguistically diverse with 11 official languages, including English. Many of South Africa's multilingual population speak two or more languages, with English regarded as the language of power perceived opportunity [41]. Caregivers uses different languages to communicate with children with SPID. According to Armstrong et al [3], communication is any act by which one person gives to or receives from another person information about that person's needs, desires, perceptions, knowledge or affective states. In addition, communication may be intentional or unintentional, may involve conventional or unconventional signals, may take linguistic or non-linguistic forms, and may occurs through spoken or other modes [2]. Each participants illustrated various ways to make their intentions known e.g., eye gaze, facial expressions, simple motor actions and crying. When participants were asked on how they respond to the needs of children with SPID, the participants responded as follows:

Precious indicated that:

"Aaah… If the child is hungry, I can see when the child is crying, I go to the child and ask if she is hungry. Other children do understand and other they don't. We see them when they cry, others are not happy then I can see that something is wrong with the child. I will offer the child the food and, in most cases, they stop crying when we offer them food."

On the same note Meisie indicated that:

"I use parental skills and I know and learnt as a mother that I must. take the child, check the nappy, feed him or her, give him/her water to drink."

Precious, Bongi and Meisie responded to the children's dire needs by checking on their nappies, temperature and give them food and water. Furthermore, Meisie used her parental skills to respond to the needs of children with SPID. I observed that caregivers use their experiences to respond to children's needs. They drew from what they had learnt over the years and the knowledge they gathered from caregiving process. Therefore, caregivers lack communication skill and relied on their personal experiences.

Mama G indicated that:

"These children do not react the same, but we are able to understand when the child need toilet. The child will indicate the need by kicking indiscriminately and you will understand and know that the child needs a toilet. Those who cannot respond by either talking, they use gestures to show what they need. Some use their sensory parts to show the need. For example, the child will show when the food is tasty. The other indication is when the child dislike the food and he/she will show by means of not opening the mouth. We use different methods to communicate with these children e.g. Radio helps us with different sound i.e., animal sound, vehicle sounds human sounds and music. Music helps to stimulate the children Those that cannot talk, we also use different methods like radio to reach them."

Participants shared various ways of communicating with the children under their care. Such as non-verbal communication, use of pictures, different sounds of animals, music, gestures and facial expressions as a tool to encourage communication. Their responses are in line withBailey [5]. who stated that the picture exchange communication system can be used anywhere, is easy to teach, affordable and facilitates communication skill both in and outside the classroom and has positive effect on social interactions.

Mama T shared her experiences:

"I know my child very well when he cries and make sounds while on the wheelchair that tells me to take him off the wheel- chair and put him on the floor. When he stops crying while on the floor, I will see that he is comfortable. He has a bone on the side that irritate him and once he is tired, I will notice that it is time to change the position."

Tebogo stated that:

"By raising voice and that shows that they can hear me, because they change their facial expression."

Mama G indicated that:

"Those who can talk, they are able to tell us this I can do that I cannot do, and I expect you as a teacher to help me with what I cannot do. Those that cannot talk, we also use different methods like radio to reach them."

The participants' responses indicate that in some instances children with SPID do not use formal communication, such as speech; instead, they tend to rely on facial expressions, vocal sounds, body language and behaviour to communicate. Seliner et al) state that gesture is a movement of body part especially a hand or head, to express an idea, feeling or meaning.

According to Bailey [5], parents engage in non-symbolic communication such as gestures, intonation of vocalisations and facial expressions, because of how quickly they got a message across, familiar communication partners may easily interpret non-symbolic forms of communications, however, I have observed that unfamiliar communication partners have trouble deriving meaning from them. This was noted during feeding process.

This is in concurrence to the results of the study conducted by Zaal et al that shows that caregivers find it more difficult to respond to the needs of children with SPID and are more likely to experience negative or unsatisfying interactions with them [64]. Rowland et al, indicates that there may be striking variations between staff members in how they interpret behaviour of children with severe disabilities. Some children are, therefore, likely to receive inconsistent responses when they attempt to communicate with children with SPID [50].

7.2. Collaborative Support

Collaboration is described by Dettmer et al [20] as a shared process in which professionals in special education—such as teachers, therapists, social workers, and psychologists—cooperate as a team to support students in reaching their maximum potential. In South Africa, a plan for creating an inclusive system of context support for an SCC includes collaborative support [19]. When all parties involved work together to plan, solve issues, and make decisions that are in the best interests of the child, that is considered collaboration. On the other hand, I noticed that there is a lack of cooperation and that speech therapists are not included in the Mental Health teams that visit SCCs.

When asked about the support from other service providers, participants reported various ways in which they were supported by the DBE and the DoH. This is what the participants reported.

Nthabi reported that:

"We have a teacher that help us with the learning programme for the children. She also helps us with morning ring because morning ring help us to see the progress of the child. We sing to them, that is where we see if there is communication or not."

Hope echoed:

"They help us with learning programme, how to teach and

communicate with children with SPID.”

Tebogo added:

“Department of Education help us with structuring of the lesson, what to teach and help us to group the children according to their functional group, as a result we see changes.”

Nthabi added that:

“The children benefit from the support given by Department of Education, because older learners can use their hands, can read, and do artwork. The younger learners benefit from the exercises to allow blood circulation. Therapist from the Department of Education are helping us a lot with children and there is lot of improvements.”

7.3. Challenges Experienced by Caregivers in Communicating with Children with SPID

Caregivers face a variety of difficulties and barriers. A network of internal and external support from different stakeholders is necessary for the notion of communication. The SCCs do not receive enough external support., I became aware of a number of difficulties caregivers encounter when interacting with children who have SPID.

Training in Communication (AAC and Makaton)

Caregivers have inadequate skills and insight into how to address communication barrier. Interestingly, most participants in this study, believed that training is of paramount importance, and would benefit caregiver and enhance the quality of life for individuals whom they supported. Geiger [24] study illustrates how engaging with practical and context-relevant training can empower caregivers to provide better support and skills development to children with SPID. This means that caregivers need training to acquire knowledge and skills of communicating with children with SPID. Participants believed that training in communication devices such as AAC and Makaton is of paramount importance and is lacking.

Two participants had attended training once on AAC devices. The training was more theoretical, and the practical part was lacking.

The following extracts indicate how the participants responded:

Precious reported that:

“I attended one training offered by the department of education and it was about communication, AAC devices, so that we can communicate with children with SPID. But it was not enough for me.”

Nthabi asserted:

“I did attend, it was all about communication, but it was more about children that are able to communicate a bit, not the severe to profound ones.”

The caregivers' reactions make it abundantly evident that they were not proficient in interacting with children who have

special needs. Consequently, this caused them to feel inept, uncertain, overburdened, and frustrated. As a result, participants said that receiving training will help them interact with children with SPID. Six individuals said they had gone to separate training sessions. They gave the following account of their experiences.

Tebogo pointed out:

“I attended training that taught us about children with severe to profound but not communication. We attended training like feeding, positioning, and putting the children on the wheelchair.”

Bongi stated that:

“Yes, they took us for training when I started working here. According to me the training was not related to communication, it was about how to feed the children with SPID.”

Hope added that:

“Personally (Nna...) me, I have not had any training in communication. It is something I have learnt along the way. Somewhere, somehow it does but I would like to gain more experience like to know the needs of children with SPID.”

The aforementioned claims unequivocally show that the six participants attended several training sessions on how to feed, care for, and utilize hearing aids with children who have SPID. Although participants understood the relevance of AAC, they lacked information regarding its application.

7.4. Lack of Resources

One participant expressed her concern about resources needed.

Precious indicated that:

“The department of education [needs] to provide the centre with communication devices, so that we can communicate better with the children.”

In order for caregivers to interact with children who have special needs, it is necessary to give them communication equipment, according to the participant's response. The statement above is consistent with findings from other research projects that demonstrated the need for a variety of resources to operate in an inclusive environment. These resources include technical know-how, access to individuals skilled in inclusive practices, and materials that facilitate skill and interest-based differentiation [26]. To meet different communication needs and enable effective and optimal communication, resources are crucial. Caregivers, however, said that their inability to provide the necessary resources limited their ability to assist children with SPID [42].

Meisie shared her frustration that:

“The availability of permanent doctors, speech therapist and other therapist might be of utmost importance in terms of helping in diagnosing these children when they are sick and assisting with communication.”

On the same note, Bongi concurred:

“If they can provide us with speech therapist or any other person who has got an experience in dealing with these

children. Training in relation to sign language."

7.5. Poor Communication Skills

The participants reported communication barrier between them and the children with SPID as a significant difficulty in their job. Most of the children with SPID at the SCCs have difficulty in communicating verbally and many cannot communicate at all. Participants were asked if they had communication skills to care for these children. Three participants indicated that they needed more training in relation to communication as indicated below.

Precious responded that:

"I can say I have little knowledge but need more training, more practical training in different types of communication devices."

Tebogo indicated that:

"Yes, I do have but I need more training in communicating with children with severe to profound."

Nthabi reported that:

"Yes, we need more skills because really, we are facing a serious challenge and coming to communicating with the children, we need more, we need more skills."

The three excerpts from Nthabi, Precious and Tebogo show that they did not feel confident as they lacked communication skills and that more training was required. From time to time, the caregivers found it difficult to understand what the children needed, and it became frustrating for caregivers to act on the child's behavior, for example (crying continuously), to meet the child's needs. I observed that lack of such resources and skills means that caregivers support children with SPID with limited knowledge and skills. This was indicated in the following excerpts.

Nthabi expressed her frustrations that:

"Aii…. It is difficult for us to know what the child needs. It is also difficult for them to say or express their feelings to us. As caregivers we must try our best to understand and just estimate as we have been with the children for long. It is a bit difficult for us to respond to their needs because communication with them is difficult."

The above statement indicates clearly that caregivers are facing challenges daily. They lacked adequate skills in communicating with children with SPID which in turn made them feel unsure, overwhelmed, and frustrated. Therefore, training would be helpful in assisting them to support the learners.

8. Limitations of the Study

1) One of the limitations of this study was the small sample size. Initially, 10 participants were purposively selected of whom two withdrew during the process.
2) The group of eight caregivers is not representative of all caregivers supporting children with SPID. The demographic information of the participants in the study could indicate a limitation, as there were no male caregivers

who participated, which could have provided a different perspective.

3) The findings cannot be generalized to other SCCs because of the small number of participants and the research sites [44]. However, the purpose of a qualitative research is not necessarily to generalize but rather to provide an in-depth understanding of the phenomenon being studied [38]. The study also focused specifically on caregivers' communication with children with SPID.

9. Recommendations

1) The majority of the caregivers at SCCs in Gauteng have no formal training post matric. The use of AAC high tech devices with no formal training or continuous support makes it difficult for them to be able to support or use the devices on the learners. Therefore, caregivers should attend ongoing developmental workshops on communication and familiarize themselves with various ways of communicating with children with SPID.

2) The use of multi-modal communication at SCCs would also be beneficial. This requires the use of both non-verbal and verbal communication to communicate with learners with communication difficulties.

3) The high number of children in need of medical support means that there should be a good working relationship between transversal teams, parents, centres, and community-based services from the DoH.

4) It is imperative that rehabilitation services remain in place, with optimal use of additional and interdepartmental communication at the operational level to ensure that every child receives the necessary therapeutic support.

10. Conclusion

The participants believed they lacked communication skills and understanding on how to use AAC devices. Further added that education and training on Makaton would improve their communication skills as well as improving the quality of children`s life. As a result, in real life, caregivers and other professionals ought to be more conscious of their own social interaction with communication techniques. Therefore, Communication skills are vital in enhancing caregiver`s competence in communicating with children with SPID.

Abbreviations

AAC: Alternative and Augmentative Communication
DBE: Department of Basic Education
DoE: Department of Education
DSD: Department of Social Development
PID: Propound Intellectual Disability
SCC: Special Care Centre
SPID: Severe to Profound Intellectual Disability

WHO: World Health Organization

Conflicts of Interest

The authors declare no conflicts of interest.

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