Caregivers in residential care facilities' perspectives on the communication needs of children with complex communication and their role in supporting communication

by

Maybuye Azania Ntimane-Halama
Student no: 20762802

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Full names of student: Maybuye Azania Ntimane-Halama

Student number: 20762802

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The author declares that she has observed the ethical standards required in terms of the University of Pretoria's Code of Ethics for researchers and the policy guidelines for responsible research.

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ABSTRACT

Many children with complex communication needs (CCN) are unable to meet their communication needs owing to various challenges like their family circumstances, additional disabilities, and severity of their disabilities as well as barriers within the environment (Finke et al., 2008). Opportunities for meaningful social interactions and participation in the society is significantly limited. Children with CCN in residential care facilities are usually faced with additional challenges that restrict them from participating and contributing in the society when compared to their peers who live with their families. Caregivers working in residential care facilities have a crucial role in supporting the communication of the children as they are usually the most frequent and sometimes the only communication partners for the children (Beukelman et al., 2012). With factors like overcrowding, short staffing and the severe disabilities of the children, caregivers often struggle to fulfil their role in supporting communication of the children. Owing to the hurdles that children with CCN in residential care facilities are faced with, their communication needs remain unmet. The aim of this study is to understand the perspectives of caregivers in a residential care facility regarding the communication needs and skills of children with complex communication needs as well as the role that caregivers in the facility play to support their communication. Seven caregivers from one residential care facility in Tshwane agreed to be interviewed. The interview schedule was developed based on a range of previous studies and aimed to obtain information on (1) biographical information of the caregivers, (2) caregivers' understanding of communication, (3) caregivers' knowledge of the children's communication needs and skills as well as (4) the views of caregivers regarding their roles in supporting communication. The qualitative data were transcribed and analysed using the thematic analysis method. The results obtained indicated that caregivers described the children at the residential facility as having severe to profound intellectually disability with a range of communication impairments. Dominant themes in the description of the children's communication skills were emergent communicators, non-verbal communication with subthemes such as informal unaided communication. Caregivers reported that they used self self made unaided AAC strategies to communicate with children with CCN. However, no formal or aided AAC communication support strategies were mentioned despite the availability of some unused AAC laptops in the facility. Challenges and factors contributing to the limited communication support were identified, namely short staffing, the additional teaching role, the need for training to improve the knowledge and skills of caregivers in supporting communication, and the need for speech therapists knowledgeable of AAC.

***Keywords*:** augmentative alternative communication, caregivers, complex communication needs, children, residential care facilities

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LIST OF ABBREVIATIONS

AAC	Augmentative Alternative Communication
CCN	Complex Communication Needs
DBE	Department of Basic Education
LSPID	Learners with Severe to Profound Intellectual Disabilities
SPID	Severe to Profound Intellectual Disability
UNCRC	United Nations Convention on the Rights of the Child
WCFID	Western Cape Forum for Intellectual Disability

1. PROBLEM STATEMENT AND LITERATURE REVIEW

1.1 Problem Statement

Improvements in the medical management of children born with developmental disabilities have significantly improved the survival rate and life expectancy of children with developmental disabilities (Light & McNaughton, 2012). This decrease in the mortality rate of high risk neonates has led to a significant increase in the incidence of cerebral palsy (CP) and other developmental disabilities (Vincer, et al., 2006). Children with CP often experience motor difficulties that co-occur with communication difficulties which puts them at risk of not being able to meet their communication needs through speech (Smith and Hustard, 2015). Children who struggle to meet their communication needs through oral speech are referred to as children with complex communication needs (CCN), these individuals often find it difficult to understand and produce speech as well as with reading and writing (Beukelman & Light, 2020; Reichle et al., 2019). The increase in the number of children with CCN has led to an increase in the number of children that get referred for Augmentative Alternative Communication (AAC) services (Light & McNaughton, 2012). Owing to difficulties in understanding and in the production of speech, children with CCN face severe limitations in their communication and participation in daily life activities like education, friendships, employment, medical care, and inclusion in the society (Dada et al., 2021). This makes them vulnerable to poverty, crime, illnesses, and other preventable incidents (Peek & Stough, 2010).

Due to the amendments of the Children's Act and the low socio-economic circumstances like lack of resources and support for families of children with disabilities, an increasing number of children with severe disabilities are living in residential care facilities in South Africa (UNICEF, 2012.; Jamieson, 2017). According to (McCool, 2008) children in care facilities have a higher prevalence of communication difficulties and their communication needs are often unmet. However not enough research has been done in this area. Residential care facilities offer short- and long-term accommodation for children who need care away from home with the permission from parents or caregivers (Children's Act 38 0f 2005). Residential care facilities can be used as a partial care and/or alternative care facility. Children in the partial care programme at the residential care facility are children who still have parents playing active roles in their lives (Children's Act 38 0f 2005). Whereas, children in alternative care are children who have been placed at the residential care facility because their parents have had their parental roles revoked, usually owing to abuse or child neglect (Children's Act 38 of 2005). Residential care facilities are also officially referred to as special care centres and in the Children's Act as Youth and Child centres. In terms of developing the communication skills of children with CCN in these facilities, caregivers are required to have adequate skills to communicate effectively with the children. In any environment, effective communication requires skilled communication partners who are able to understand and interpret the non-verbal communication of the children with CCN correctly, whether using formal or informal communication methods (Hemsley et al., 2014). Yet there is limited information on why caregivers sometimes struggle to meet the communication needs of children with CCN in these facilities. Studies have shown that properly individualised AAC systems can support the communication skills of individuals with CCN (Howes, 2019; Reichle et al., 2019). However, children with CCN usually have coexisting sensory and/or physical disabilities that make access to AAC systems difficult (Reichle et al., 2019).

Previous studies on communication support for individuals with complex CCN in residential care facilities have focused on adults, with not enough focusing on the needs of children (Franklin & Goff, 2019). Children with CCN in residential care facilities have been found to engage very little in social interaction as compared to their typically developing peers (van IJzendoorn et al., 2011), and often spend their time in isolation due to a lack of communication opportunities in their environments (Light & McNaughton, 2014). Communication between caregivers and children with CCN in residential care facilities has also been described as a monologue with very little or no expectation of responses from the children (Fylkesnes, 2021).

Despite the awareness of the need for functional communication between caregivers and children in residential care facilities, a general concern exists regarding the impact that the severe communication impairment has on the role of caregivers in supporting communication, considering the inherent demands of the caregivers' work (Hemsley et al., 2001).

All children in South Africa have the right to protection and a safe home environment that allows them to thrive. To fulfil the right to a safe environment for all children; the Children's Act 38 of 2005 (Republic of South Africa, 2005), obliges the Department of Social Development to ensure that vulnerable children who do not have access to care and safety from their families are provided with alternative homes (Tanga & Agere, 2018). Residential facilities have since been developed for children with disabilities and for non-disabled children. Children with severe disabilities require extra care and support, and specialised facilities that will meet these needs were established for the sole purpose of caring for children with disabilities (Koch & Franzsen, 2017). The Department of Education's report on the prevalence of children with disabilities in South Africa indicated that 28% of the children in residential care facilities had disabilities (Department of Education, 2014). Taking into consideration that the residential facilities that the findings were based on included orphanages, special care centres, group homes and other alternative care facilities. A study by Saloojee et al. (2007), conducted at Orange Farm township in Gauteng province, found that one-third of the 156 children with disabilities were unable to communicate verbally Communication impairment was also reported to be amongst the two most prevalent disabilities in children (Statistics South Africa, 2014). Among the total number of children with disabilities, 10% of children were reported as having behavioural or psychological disabilities, whereas 5% of the total number of children with disabilities, had a speech impairment (DSD, DWCPD and UNICEF, 2012). Even with all these findings, there is not a lot of public awareness regarding children with CCN and strategies to include these children in the society. Without efficient communication systems, children with CCN are not able to exercise their human right to communication and participation.

In a study conducted by Dalton and Sweeney (2013) on the communication needs of adults with CCN in residential care facilities, it was found that the communication needs of these adults were not being met. Several issues like staff shortages, staff attitudes, level of intellectual disabilities, and lack of training on communication support strategies were highlighted to be the cause (Dalton & Sweeny, 2013). Caregivers of children with disabilities in residential care facilities usually focused on meeting physical needs like bathing and feeding, while communication needs and stimulation were regarded as minor roles (Geiger, 2012). These findings also correlate with those reported in Fylkesnes (2021), which indicated that caregivers focused on providing nutritional, medical and personal care as their primary role. Children whose communication needs are not met will eventually grow up to become powerless and helpless adults (Tönsing et al., 2019).

Dalton and Sweeny (2013) also indicated that although the communication needs of the residents were not met, some level of support was offered. However, the study did not report on the strategies that caregivers used in an attempt to meet the communication needs of the adults with CCN in the facility. Similar to Dalton and Sweeny (2013), Howes (2019) explored the communication skills, needs, and resources of adults with intellectual disabilities in the Western Cape province of South Africa by interviewing managers of these facilities, and found similar results. It is not clear, however, whether the same results would have been obtained in residential care facilities for children. In addition, many of the studies tend to explore the perspectives of professionals and facility managers and not much focus is on the caregivers who work directly with the individuals with CCN. Focusing on the perspectives of facility managers alone and not on caregivers could increase bias since some interview questions appeared as if the caregivers would be rating their own performances in the facilities, which could cause them to give inaccurate information (DeSimone & Cascella, 2005).

There is therefore a need to understand the perspectives of caregivers in residential care facilities for children with disabilities, especially regarding the communication needs and skills of children with CCN as well as the role that caregivers in these facilities play to support their communication. These caregiver staff work directly with children with CCN and therefore have first-hand experience and views which may differ from those of managers.

1.2 Literature Review

1.2.1 Children with Complex Communication Needs

As described in paragraph 1.1 children with CCN are defined as children who struggle to meet their communication needs through natural means of speech alone (Beukelman & Mirenda, 2012). These children often have motor, language, and sensory impairments as well as intellectual disabilities, which impede their ability to communicate through natural speech (Mandak & Light, 2018). Children with CCN may have little or no speech and usually at beginning communicators level of learning language also known as emergent communication (Thistle & Wilkinson, 2021). Beginning communicators are individuals of any age, who demonstrate intentional communication through pre symbolic means like body language, gestures, vocalizations etc (Thistle & Wilkinson, 2021). Because of their primary disabilities and communication difficulties, children with CCN will require AAC to meet their immediate communication needs (Douglas et al., 2013). Research indicates that the use of AAC can stimulate language development and also improve communication skills (Douglas et al., 2013). Unfortunately, the use of AAC might require the use of expensive equipment and the support of competent communication partners (Light, 1997; Mckenzie & Macleod, 2012).

Communication partners of children using AAC will therefore need training and support to develop their skills and knowledge to be effective communicators (Light, 1997).

Douglas et al. (2013) further indicated that, although AAC can help children with CCN to acquire language and literacy, it is operationally demanding for the children and for their communication partners. Without an effective communication system, children with CCN are not able to participate in social activities like going to school and accessing the education curriculum (DSD, DWCPD and UNICEF, 2012). Over 20% of children with communication disabilities in South Africa usually start school late and not when they are 5–6 years old as their non-disabled peers (Ngwena, 2013; Stats SA, 2014). Communication plays an important role in literacy accessing the education curriculum, relationships, and participation in everyday activities (DSD, DWCPD and UNICEF, 2012). Children with disabilities in residential care facilities experience additional barriers to learning owing to a lack of assistive communication devices (Franklin & Goff, 2019). A study that was conducted on the involvement of children in decision making during placement in care centres and alternative hmes reported that many children with CCN are placed in care institutions without their prior knowledge and consent (McPherson et al., 2021). A similar study by Borić et al. (2021) found that children with CCN who were placed in residential care facilities were not involved in the decision-making process and did not receive explanations about the circumstances that led them to the residential facilities. They elaborated that these children are often placed in residential care facilities as a last resort because of the extra care that they require, which their families are not able to provide. Children in residential care facilities are particularly vulnerable owing to the unfortunate circumstances that led them to be placed in care facilities (Borić et al., 2021). Most of the residential care facilities are not equipped to offer an education curriculum but only provide for the care, safety, and medical needs of the children (Moosa-Tayob et al., 2022). Children with CCN struggle to access quality inclusive education and are less likely to access education compared to individuals with other disabilities (DSD, DWCPD and UNICEF, 2012).

1.2.2 The Situation of Children with Disabilities and CCN in Residential Care Facilities in South Africa

The high level of crime, unemployment, abuse, and the HIV pandemic in South Africa have left many children orphaned or living without one or both of their parent (Jamieson, 2017). This has caused a significant increase in the number of children who require residential facility care, some of whom may also have congenital and acquired developmental disabilities that affect their ability to communicate (Geiger, 2012; Jamieson, 2017). Residential care facilities for children can be defined as care facilities or NGO's that offer accommodation and assisted living to six or more children outside of their homes (Children's Act 38 of 2005, 2006). These facilities or institutions are usually supported and monitored by Department of Social Development or Department of Health, however there is not enough reliable data on the number of residential facilities and the number of children with disabilities in these institutions (DSD, DWCPD and UNICEF, 2012). Although registered care facilities receive support from the Department of Social Development, the Department of Health, and now also the Department of Basic Education; the facilities are still not well equipped to take adequate care of children with disabilities owing to staff shortages and lack of resources (Koch & Franzsen, 2017). Furthermore, children in residential care facilities do not get adequate language stimulation like their peers who stay with their families (Koch & Franzsen, 2017). Koch and Franzsen (2017), also found that infants and toddlers in a residential care facilities spent a significant amount of their awake time without any caregiver interaction. Not much information is available on the rate of interaction for children of school going age in residential care facilities. This lack of information could be influenced by the exclusion of children with sever to profound disability (SPID) in education programmes as well as by the limited access to quality healthcare services (Geiger, 2012). Communication is a human right to which every child should have access (United Nations, 1948). Jamieson (2017) states that, even with all these rights being recognised in residential care facilities, some of them are still not being fulfilled. It was also revealed that caregivers of children with CCN in care facilities were often not aware of communication as a human right. The right to communication is still one of the most overlooked and unfulfilled basic human needs (Geiger, 2012). It is crucial that caregivers are empowered through accredited trainings and provision of resources to enable them to facilitate meaningful interactions and communication development of children in their care (Geiger, 2012).

1.2.3 Right to Basic Education for Children with Disabilities in South Africa

Despite developments in inclusive education policies in South Africa, children in residential care facilities are still excluded from admission to schools owing to their disabilities (Ngwena, 2013). These children were historically denied admission to mainstream schools and special schools and therefore denied their right to education. When most care centres were established, their purpose was to support the service users with activities of daily living

(Moosa-Tayob & Risenga, 2022). This means that children in care facilities did not have the same access to the education curriculum as their peers do (Dlamini, 2016). Every child of school going age should have access to education (South African Schools Act 84 of 1996) (South African Government, 1996). In 2007 the Western Cape Forum for Intellectual Disability (WCFID), which supports and advocates for individuals with disabilities, started a right-to-education campaign for children with severe to profound intellectual disabilities. The forum was formed by parents of children with disabilities. These parents took the government to court regarding the exclusion of their children from admission to schools. A court order was then issued in favour of the forum.

The Department of Basic Education (DBE) responded to the court order with a conditional grant to provide education for learners with severe to profound intellectual disability (LSPID) (Mckenzie, 2013). Through the LSPID conditional grant, the Department of Basic Education has the responsibility to ensure that children with severe to profound disability (SPID) in residential care facilities also have access to learning material, therapy services and training of caregivers on both non-accredited and accredited skills (National Gazette, 2016). The Policy for the Provision of Quality Education and Support for Children with Severe to Profound Intellectual Disability (DBE, 2016) indicates, for example, that learners with SPID should benefit when their education is aimed at developing communication, personal and self-care, as well as practical and conceptual skills rather than academic skills.

Therapists employed by the LSPID grant include physiotherapists, occupational therapists, and speech therapists in the Department of Basic Education and they work in collaboration with Department of Health therapists and other professionals to support children with SPID in residential care facilities through various multi-disciplinary outreach programmes (TEDI, 2019). Intervention specifically by speech therapists can include the provision of assistive devices that should enable children with SPID to access and participate in the education curriculum. However, barriers to the implementation of AAC intervention still exist owing to a shortage of speech therapists and educators who are trained in AAC (Reichle et al., 2019). Most speech therapists in South Africa receive varied levels of AAC training in their undergraduate qualification, which can range from stand-alone modules to a few lectures (Mthonxa, 2022). In South Africa, AAC-accredited training at a postgraduate level is only offered at the University of Pretoria. With the high cost of studying, many therapists and other professionals working with children with CCN may not be able to afford to enrol in the training.

A disadvantage with the LSPID learning programme is that, although its objectives include the improvement of communication and participation, the LSPID grant framework and business plans do not include provision of the facilities with qualified educators to implement the programme. Instead, it aims to train the already overworked caregivers to teach the children (DBE, 2023).

The LSPID curriculum will ensure that children with SPID in residential care facilities have access to quality education that is tailored for their needs (McKenzie et al., 2017). The curriculum includes life skills, mathematics, and language and communication. The three subject categories can be broken into subcategories like gross motor skills, self-care skills etc. According to the LSPID draft policy (DBE, 2016), children with SPID must be grouped and allocated work according to their level of care. The policy also emphasises the DBEs obligation to provide care facilities implementing the LSPID programme with resources and ensuring that caregivers receive adequate training.

Even with the trainings provided by DBE, a lack of skills still remains a barrier to implementing the learning programme (Mckenzie et al., 2018). Children with CCN in residential care facilities have a range of needs unique to each individual child. To meet the education needs of the children, the LSPID draft policy requires caregivers to amend the curriculum and resources to ensure that all children have access to it (DBE, 2016). Noting that the caregivers might not have any professional training background, and expecting them to adjust resources to accommodate learners could be a strain on their part.

1.2.4 Residential Care Facility Staff

In the context of this study, residential facility staff who support children with activities of daily living are referred to as caregivers (Capri et al. 2018). Moosa-Tayob and Risenga (2022) define caregivers as any individuals who render care to people who are unable to care for themselves. Little research has been done on how caregivers encourage children with CCN living in residential facilities to communicate their needs and wants and to participate in decision-making processes (Franklin & Goff, 2019). In a study by Healy and Noonan Walsh (2007), staff nurses reported that it was important for care staff to familiarise themselves with the facility residents. They reported further that getting to know the residents and having a relationship with them enabled them to meet their individual needs.

Franklin and Goff (2019) indicated that the age of caregivers had an impact on the caregivers attitudes towards the children in the care facility. The study also found that younger caregivers communicated and engaged more with the children than the older caregivers (Franklin & Goff, 2019). Older staff did not communicate with children with CCN. They reported that they did not see the need to communicate with the children because they did not understand their communication. Not all caregivers demonstrated adequate skills to care for children in care facilities (Moore et al., 2017). Some caregivers were employed because childcare is their passion; however, some caregivers were employed because it was a job that was available to them. Many caregiver jobs in care facilities do not require professional qualifications. People in the community often apply for these jobs as a temporary source of income while they look for other jobs. Owing to these factors, there is a constant change of caregivers in care centres, meaning that there needs to be constant training and workshops.

The roles of caregivers, highlighted in Moore et al. (2017), include nappy changing, bathing, and feeding the children. Some caregivers had additional roles to teach basic concepts to the children. Owing to understaffing, some caregivers had to do caregiving roles as well as support staff roles like cleaning and cooking (Moore et al., 2017). Caregivers often experienced stress and anxiety, also reporting that they did not have adequate knowledge and skills to fulfil their roles (Laletas et al., 2017). As discussed in section 1.2.3, with the LSPID programme implementation in care facilities, the Policy for the Provision of Quality Education and Support for Children with Severe to Profound Intellectual Disability (DBE, 2016), requires caregivers to add the teaching role to their schedule. Considering the amount of work they already have, owing to issues like short staffing, the expectation for them to teach could be strenuous and discouraging, especially noting that the extra role of teaching does not come with an addition to their salaries.

A study that was conducted on caregivers of children with disabilities in Ghana revealed that caregivers were so overburdened with work due to the physical and psychological demands of working with children with disabilities (Moosa-Tayob & Risenga, 2022). Caregiver training about the disabilities of the children as well as involvement in support groups resulted in a significant improvement in the attitudes of caregivers as well as in their mental health (Zuurmond et al., 2019).

1.2.5 Communication Needs of Children with CCN

Children with CCN will have their own range of needs and preferences. Each child's unique communication need will vary depending on a number of factors like their skills, primary diagnosis and disability. For effective communication to take place, interaction must be reciprocal and involving both speaker and a communication partner (Finke et al., 2008). However, children with disabilities like intellectual disability, autism, cerebral palsy may face additional needs in communicating their needs and wants. A study by McCool and Stevens (2011) was conducted on speech, language and communication needs of children in residential care. The findings of the study indicated that there was a high presence of communication needs among children in residential care (McCool & Stevens, 2011). Levin and Haines (2007) also reported that there was a high prevalence of communication impairments among children in residential care facilities. With communication impairments reported to be the biggest barrier to accessing education among children with disabilities; when their communication needs are not met, their education needs will also be negatively impacted (Levin & Haies, 2007).

Dalton and Sweeney (2013) conducted their study by interviewing residential care staff in a facility that cared for adults with intellectual disabilities. Although details of how many adults had communication impairments were incomplete, it was stated that there were adults with communication impairments and that their communication needs were unmet. Another important factor that was raised by the respondents in the study was that they had not received any training on non-verbal communication. A similar study conducted by Howes (2019) in the Western Cape in South Africa also found that the adults with intellectual disabilities in the residential care facilities in the Western cape were also reported to be having communication difficulties and that their communication needs were unmet. Limited access to speech therapy services as well as lack of caregivers training on AAC were indicated to be some of the cause (Howes, 2019). Not enough studies have been conducted on the communication needs of children in residential care in South Africa.

1.2.6 Communication Support and Participation of Children with CCN in Residential Care Facilities

Communication support in residential facilities is important for individuals who depend on others for the interpretation of their verbal and non-verbal messages (Dalton & Sweeney, 2013). In Dalton and Sweeney (2013), caregivers reported that they did not have enough training and professional support from speech therapists to enable them to offer adequate communication support to the residents with CCN. Children with CCN who do not have adequate communication support often remain beginning communicators due to lack of communication opportunities, experience, and AAC methods Thistle & Wilkinson (2021). DeSimone and Cascella (2005) found that participants were aware of their roles in facilitating communication and had frequent support of speech therapists in communication goal setting and implementation. However, they still felt that the facility environment was not set up in a way that supported and promoted communication participation owing to a lack of resources DeSimone and Cascella (2005). Thistle & Wilkinson (2021) also indicated that aided and unaided AAC techniques can support both receptive an expressive communication of children with CCN. Aided communication techniques include low technology devices (like pen and paper and picture symbols), and high technology devices (speech generating devices) such as tablets and computers (Wendt et al., 2011). DeSimone and Cascella (2005) identified lack of communication support resources like training material, assistive devices and adequate staffing to be the reason why the communication needs of adults with CCN remained unmet.

A similar study conducted by Howes (2019), which looked at the communication resources, skills and needs of adults with intellectual disability in the Western Cape, is in agreement that communication support in residential care facilities for adults with disabilities was inadequate with little availability of AAC support. Howes (2019) also found that some facilities had some AAC support for the residents, but that it was not consistent. Only one facility out of 19 had access to speech therapy services. This could be due to the dire shortage of speech therapists in South Africa with most based in the Gauteng (Pillay et al., 2020). None of these studies, however, looked specifically at children with CCN, but rather at adults with disabilities in residential care facilities

Geiger (2012) conducted a study that focused on training caregivers in residential care facilities in the Western Cape, South Africa. Caregivers were trained on supporting communication development and the provision of communication opportunities for children with severe to profound disabilities. It was noted that caregivers had many pictures, pamphlets, and information sheets from previous training on their walls but did not use or understand the information (Geiger, 2012). Caregivers reported that they did not have enough time to study or refer to the training material and that some of the materials were presented in languages that they did not comprehend (Geiger, 2012). A need for continued training and support from the government was highlighted as a priority (Geiger, 2012). Future training could focus on hands-on training with frequent visits for monitoring and support.

A study conducted by Moorcroft et al. (2019) on parents of children with CCN indicated that parents who had prior exposure and training on AAC had more positive views about AAC intervention. When comparing the findings of this study with those that were conducted overseas such as DeSimone and Cascella (2005), South Africa appears still to be far behind in caregiver awareness of their roles in facilitating communication with children with CCN in residential facilities.

The field of AAC is still new in South Africa and almost non-existent in the low socioeconomic class. Hanson and Fager (2017) proved that the use of AAC methods can enhance participation for children with CCN. The communication needs of children with CCN can be supported by eliminating and/or reducing communication opportunity barriers (Beukelman & Light, 2020). Geiger (2012) noted that although the communication needs of children with CCN in residential facilities were not met, there was some improvement when caregivers were trained.

Facility staff and primary caregivers should create environments that motivate or tempt the children to communicate (Parker, 2014). Research shows that the use of visual schedules and AAC displays in the home increased children’s ability to understand their surroundings, have communication expectations, and reduced inappropriate behaviour (Turner et al., 2010).

1.2.7 Residential Care Facility Staff Training to Support Children with CCN

Residential care facility staff are the primary communication partners for children in residential facilities and communication plays a major role in building relationships between the children and the staff (Jooste et al., 2010). Caregivers have the responsibility to provide communication opportunities for children with CCN and to ensure that their communication needs are met.

Facility staff should be trained in effective communication strategies to improve their communication skills so that they can communicate more effectively with children with CCN (Jooste et al., 2010). Caregivers can be trained in non-verbal communication skills, to enable them to interpret and understand communication from the children and also to use formalised non-verbal communication strategies to ensure uniformity, rather than having each individual use their own made-up signs. Training in AAC is also recommended as an effective communication strategy for children with CCN. With the lack of funding in many residential care facilities, AAC training can aim at cheaper options like unaided AAC methods and paper-based AAC systems. In Douglas et al., (2013), paraeducators working with children with CCN who had received training in effective communication skills provided more communication opportunities and more opportunities for children with CCN to communicate. Owing to the lack of funds, many residential facilities in South Africa resort to hiring untrained and unskilled workers and do not have access to regular speech therapy services (Geiger, 2012). This results in understaffing, a high child–caregiver ratio, and more neglect of the social and communication needs of the children (Fylkesnes, 2021). Fylkesnes’s (2021) study supports Geiger’s (2012) on the effectiveness of staff training to improve their communication skills.

2. METHODOLOGY

2.1 Aims

2.1.1 Main Aim

The main aim of this study is to understand the perspectives of caregivers in a residential care facility regarding the communication needs and skills of children with complex communication needs living in the residential facility as well as the role that caregivers in the facility play to support their communication. To achieve the main aim, the following sub- aims were investigated:

2.1.2 Sub-aims

The sub-aims of the study are:

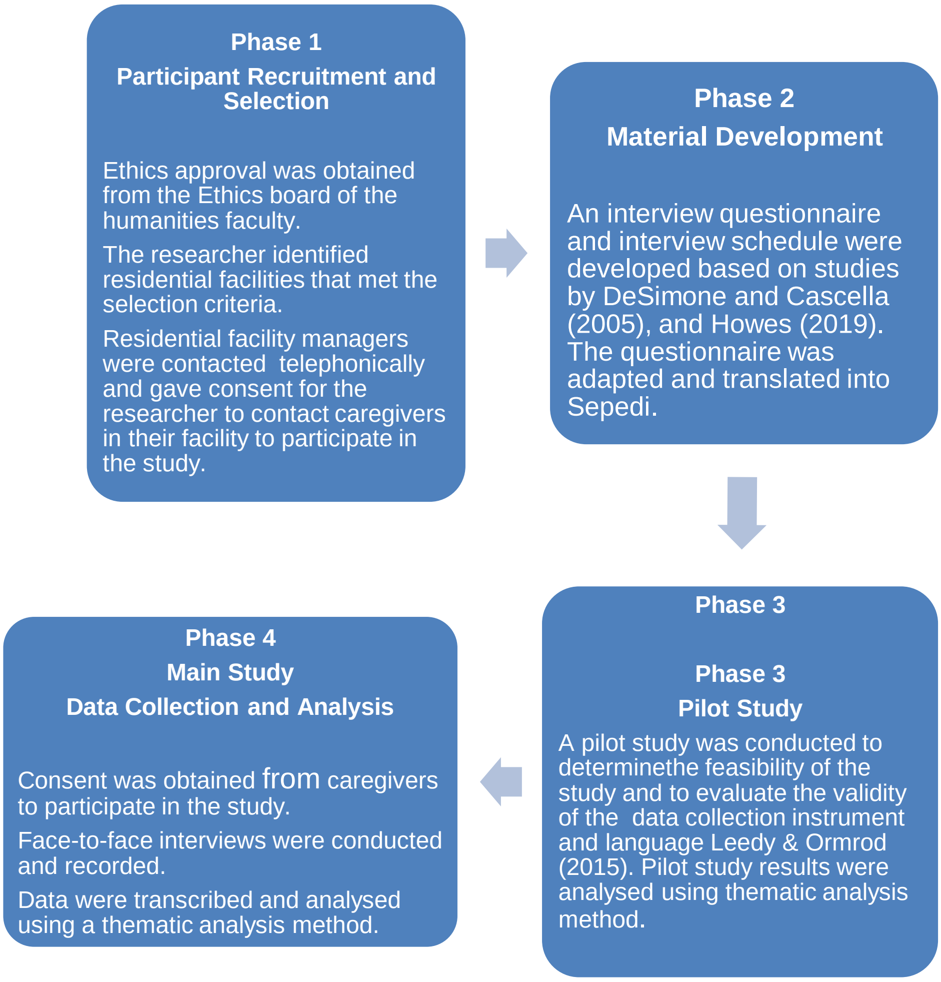
1. To explore the caregivers' understanding of the concept of communication.
2. To understand the caregivers' knowledge of the communication needs of children with CCN.
3. To understand the caregivers' knowledge of the communication skills of children with CCN in a residential care facility.
4. To explore the views of the residential facility caregivers of their roles and responsibilities in supporting the communication needs of children with CCN in their facilities.

2.2 Research Design and Phases

This study implemented a qualitative research design to explore the views, knowledge, and perceptions of caregivers in a residential care facility. Qualitative research design is employed in studies that seek to describe the experiences of individuals within their world (Merriam & Grenier, 2019). An advantage of qualitative research design is that it uses open-ended questions which allow researchers to capture the attitudes and experiences of participants in detail (McMillan & Schumacher, 2010). Data were obtained through semi-structured interviews and analysed through inductive thematic analysis. Semi-structured interviews were undertaken because they use predetermined questions and allow the researcher to ask additional tailored questions to obtain rich detailed information (McMillan & Schumacher, 2010). They also allow the researcher to prompt the interviewee to get more information. By prompting the participants, the researcher was able to get social and personal information about the participant that they would not normally get through numbers in quantitative research (DiCicco-Bloom & Crabtree, 2006).

Another method like focus groups could have been used but was not considered owing to its risk of lack of confidentiality and its limitation on individuals' specific information (DiCicco-Bloom & Crabtree, 2006). A disadvantage of qualitative research design is that the findings of the study cannot be generalised beyond the context in which the study was conducted. However, the findings of qualitative studies give better and more in-depth understanding of caregivers' experiences, perspectives and understanding of their roles in the residential care facilities (McMillan & Schumacher, 2010).

The study was conducted in one residential care facility in Tshwane that provides care for children with disabilities, many of whom have CCN. The details of the facility were obtained from the DSD database of NGO's that cared for persons with disabilities in Tshwane. The facility was selected through purposive sampling method that was employed to ensure that only a facility that met a selection criteria. Not many residential facilities are available in Tshwane; the list was then narrowed down to only care centres that provided residential facilities. However, it was found that the student researcher worked in most of them. The facility for the main study was selected because it was the only one the met all the selection criteria. Although theselected residential care facility had 16 caregiving staff members, the number who agreed to participate was 7 (in the main study), which was adequate for this study since qualitative studies do not require too many participants (Leedy & Ormrod, 2015). Thematic data analysis was used to identify and examine meaningful patterns in the data (Braun & Clarke, 2006). The study was conducted in four phases, namely participant recruitment and selection, material development, piloting, and data collection (see Figure 1).



Phase 1
Participant Recruitment and Selection

Ethics approval was obtained from the Ethics board of the humanities faculty.

The researcher identified residential facilities that met the selection criteria.

Residential facility managers were contacted telephonically and gave consent for the researcher to contact caregivers in their facility to participate in the study.

Phase 2
Material Development

An interview questionnaire and interview schedule were developed based on studies by DeSimone and Cascella (2005), and Howes (2019). The questionnaire was adapted and translated into Sepedi.

Phase 3

Phase 3
Pilot Study

A pilot study was conducted to determinethe feasibility of the study and to evaluate the validity of the data collection instrument and language Leedy & Ormrod (2015). Pilot study results were analysed using thematic analysis method.

Phase 4
Main Study
Data Collection and Analysis

Consent was obtained from caregivers to participate in the study.

Face-to-face interviews were conducted and recorded.

Data were transcribed and analysed using a thematic analysis method.

Figure 1: Phases of the Study

2.3 Ethical Considerations

Because the study involved human participants, ethical approval was obtained from the University of Pretoria’s Faculty of Humanities ethical committee (Appendix A). The managers of residential facilities in the Gauteng province were contacted telephonically to request permission to invite willing residential care staff who met the entrance criteria to participate in the study. Face-to-face meetings were arranged with managers of residential facilities who indicated that they would like their centres to participate in the study.

The student researcher hand delivered information letters and consent forms to care centre managers (Appendix B). This was done to ensure that centre managers received the documents despite load shedding or limitation of resources like internet, email, etc. Participants who met the criteria for participation in the study were requested to sign informed consent forms (Appendix C) and were reassured of confidentiality before they could take part in the study. Participants were also informed that their participation was voluntary and that no one was compelled to participate in the research study. They were also informed that they are free to withdraw from the study at any time.

As stipulated in the World Medical Association Declaration of Helsinki (2013), the study upheld the following ethical principles stipulated in the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research. (1978): Autonomy was upheld by ensuring that all participants were given a choice to participate and to withdraw at any time if they felt uncomfortable or were no longer available. No personal or identifiable information would be published or shared with any third party. The purpose of the study was explained to the residential care facility manager through an information letter, an informed consent letter (Appendix B) as well as through face-to-face communication during a site visit to allow them to ask questions. Participants were also informed of the purpose of the study through participant information letters and reply slips (Appendix C), and verbally on the day of the interview. All participants were reassured that the study would not cause them any harm and that they could withdraw at any time if they were not comfortable to continue.

2.4 Participants

2.4.1 Description of the Context

The population comprised seven caregivers who were employed in a residential care facility situated in the eastern subdistrict of the City of Tshwane Metropolitan Municipality also known as the City of Tshwane or Tshwane. The City of Tshwane is in the northern part of the Gauteng province in South Africa. It is divided into seven administrative regions named Region 1 to 7. These seven regions are Pretoria North, Far North, Central Western, Southern, Pretoria Far East, Eastern, and Bronkhorstspruit. The residential care facility used in the study is in Region 6, which is the Eastern district of Tshwane. According to the information on the official website of City of Tshwane Municipality, Region 6 consists of Pretoria East, Eersterust, Mamelodi and Shere (City of Tshwane, n.d.)

Figure 2: Tshwane Metropolitan Municipality Regional Map

Since the study was meant for a specific type of participant, the student researcher used purposive sampling to identify care facilities that offered residential care to children with CCN. Purposive sampling was employed because it would allow the researcher to select participants who have characteristics and experiences that would meet the research objectives (McMillan & Schumacher, 2010). Purposive sampling also allows the researcher to match the sample to the research aims (Campbell et al., 2020).

According to Statistics South Africa (2014) Tshwane is home to approximately 2.9 million people, which is approximately 26% of the provincial population. Of the population in Tshwane, 37% comprise youth, making it one of the youngest municipalities in South Africa (Stats SA, 2013). Over 80% of the population reside in the urban areas with an unemployment rate of 24.2%. Region 6 had a population of about 60 000 (Stats SA, 2014). Sepedi, Setswana, Afrikaans and English are recognised as the most spoken languages in the area; other languages include Xitsonga and IsiZulu (Stats SA, 2014). Demographic information of caregivers at the residential facility where the study was conducted indicated that Sepedi and English were the two most spoken languages in the care facility and in the surrounding townships.

Approximately 5.3% of persons aged five years and older in Gauteng live with a disability, which is the lowest amongst the nine provinces. Considering the high population of over 15 million people in Gauteng, the disability rate is very low. The quality of healthcare in Gauteng could be the influencing factor for the low numbers of children with disabilities. A study on technical efficiency of healthcare in South Africa found Gauteng province to be the most efficient and well resourced compared to other provinces (Ngobeni et al., 2020). Census 2011 showed that there was a higher prevalence of disability among children aged 5–9. Vision difficulties (11%) were be the highest reported disability, followed by hearing difficulties (3.6%) and mobility difficulties (3.5%) (Stats SA, 2014). The report further stated that screening results of children should be interpreted with an open mind since there is the possibility of down scoring children as not knowing the task, whereas they might just be experiencing multiple difficulties (Howes, 2019; Stats SA, 2014).

City of Tshwane has approximately 30 facilities that care for children with moderate to severe disabilities (Moosa-Tayob et al., 2022). Children who have been removed from their homes owing to abuse or to the death of parents are placed in orphanages, whereas children with disabilities get placed in child and youth care centres which can accommodate their disabilities (Children’s Act 38 of 2005, 2006). Registered facilities in Tshwane are monitored and supported by the Tshwane District Health, Department of Social Development and/or Gauteng Department of Education through the LSPID grant (DBE, 2022.). These services are provided through outreach services conducted periodically by each directorate to ensure that facilities adhere to health and safety regulations: therapeutic services through the provision of assistive devices and treatment; and now the education curriculum by the Gauteng Department of Education. With the unavailability of in-house speech therapists in care facilities, the support services offered by the mentioned departments together may still not be enough (Pillay et al., 2020).

2.4.2 Selection Criteria

To be selected for the study, residential care facilities were required to meet a set of criteria (see Table 1).

Table 1: Facility Selection Criteria

Criterion	**Justification**	**Measure used**

Residential care facilities that care for children (0–18 years old) with disabilities.	These facilities will be more likely to have children with complex communication needs.	Checking of NGO databases from Health and Social development departments. Facility managers were called for verbal confirmation. Signed consent forms were obtained prior to the interview.
Staff members at the residential care facility caring for children with complex communication needs.	The participants must have experience of working in a residential care facility with complex communication needs and be able to give responses based on lived experiences.	Facility managers and staff members were notified that participants should have experience of at least six months of working with children with complex communication needs. Participants gave verbal confirmation of their work experience at the beginning of the interview.

Criteria were also set for the type of caregivers/staff members who were required at the residential care facility caring for children with complex communication needs.

Table 2: Participant Selection Criteria

Criterion	**Justification**	**Measure used**
Staff members at the residential care facility caring for children with complex	The participants must have experience of working in a residential care facility that have children with complex communication needs.	Facility managers and staff members were notified that participants should have experience of working with children with complex

communication needs.		communication needs for at least six months. Participants gave verbal confirmation of their work experience in the beginning of the interview.
Staff members must work directly with the children.	The participants must be able to give responses based on their lived experiences.	Participants confirmed through self-report prior to the interview.

2.4.3 Participant Recruitment

As the residential care facilities recruited were non-governmental organisations (NGO), so no departmental permissions were required. The student researcher requested a list of special care centres for children with disabilities in Tshwane from her colleagues who worked at the Department of Social Development (DSD). Another list of special care centres was also requested from the employees at the Tshwane Health District mental health. However, it was found that the database of special care centres from both departments consisted of the same special care centres.

The Department of Social Development database was used to select care facilities that met the selection criteria. The list consisted of 47 NGOs/care facilities, of which 26 offered residential service. Facilities that cared for children with disabilities were targeted for the study as they were more likely to have children who have complex communication needs. Of the 26 residential care facilities, 19 of them cared for adults and geriatrics; only six NGOs offered residential care facilities for children and youth. Among the remaining centres, the student researcher herself had worked in five of the, so they had to be excluded from participating in the main study as bias would increase (Leedy & Ormrod, 2015). Ultimately, only one facility met all the selection criteria in Table 2 and was invited to participate as the main study. However, owing to the limited number of care facilities that met the selection criteria, the pilot study had to be conducted in one of the centres where the student researcher had worked meaning that the centre had not met all the selection criteria. A facility that was disqualified due to the student researcher working there was reselected for the pilot study. The managers of both facilities (Main and pilot study) agreed to have the student conduct research in their care facilities and signed the permission forms (Appendix B)

2.4.4 Participant and Facility Description

The facility from which the participants were recruited is in the Eastern region of Tshwane. The facility is a sub-section of a larger non-government organisation (NGO). The NGO consists of different facilities that care for vulnerable children, adults, and geriatrics. The facilities include an orphanage, a private school, hospice/palliative care, an old age home for geriatrics with disabilities as well as a residential and day care facility for children with disabilities. The study was conducted at the residential centre for children with disabilities which cared for 20 children with severe to profound intellectual and physical disabilities.

The whole facility is made up of brick structures with tiled roof and paved floors. The area was well fenced with a brick wall and palisade fence. All the housing structures in the facility appeared well maintained and safe. However, the orphanage area had outside play area with outside play equipment like swings and sandpits. The area where children with disabilities resided did not have any outdoor play equipment regardless of the amount of open space that was available in the facility.

The children in the orphanage attended school at the private school, whereas the children with severe to profound intellectual disabilities (SPID) remained at their facility where the caregivers assisted them with activities of daiy living. nutrition, medical and personal care. To ensure that the children get access to education, the Gauteng Department of Education supported the facility through the learning programme for learners with severe to profound intellectual disability (LSPID). The centre manager reported that there were 15 caregivers who worked with the children with disabilities All participants were employed as caregivers for children with disabilities in the residential care facility. Some information about the participants was obtained from the facility manager during recruitment as well as in the demographic section of the data collection instrument.

Participants biographical data indicated that all participants were female caregivers with ages ranging from 25 to 61. All 15 caregivers were given an equal opportunity to accept or refuse to participate in the study. A total of seven caregivers who were available at the time of the researcher’s visit to the centre signed reply slips to gave consent to participate in the study. All seven caregivers were considered for interviews. Although seven participants is a small number, it is typical for qualitative studies. The caregivers worked in day- and night shifts. Caregivers' shifts were allocated for them to work 12 hours a day for two consecutive weeks in a month and then spend the following two weeks of the month off work. Simultaneously, another group of caregivers worked 12 hours of 'night shift' for two weeks and were off work for the two weeks that followed. Caregivers rotated between night and day shifts every three months. The student researcher collected data from participants who worked during day shift and few who worked at night. Because night staff could only switch to day shift after three months, arrangements were made with the caregivers working night shift to come off work one hour late to participate in the study. Caregivers reported being too exhausted to stay behind after their night shift. Caregivers also took vacation and urgent leave days off work; therefore, the lists of caregivers in shifts were not always as planned. For safety reasons, the interview could only be done during the day shift.

2.5 Materials and Equipment

This section describes the materials that were used in the data collection phase of the main study. These materials include care centre information letters and reply slips (Appendix B), participants information letters and consent forms (Appendix C), an interview schedule (Appendix D), and an Olympus DM-650 voice-recording device.

Video recorders were not used in this study. Although taking videos of the participants during interviews allows the interviewer to capture the participants' non-verbal interactions; they were not conducted in this study because they are more restrictive and need more technical skills to transcribe (King & Horrocks, 2010). Video recording can also be intimidating to participants, which could lead to their not responding freely to questions. Non-verbal communication like facial expressions were recorded through notes taken during the interview.

2.5.1 Residential Care Facility and Participants Information Letters and Consent Reply Slip

Two sets of information letters and consent slips (Appendices B and C) were developed for the purpose of this study. One was developed for residential facility managers (Appendix B), and the other was developed for the caregivers (Appendix C). The information letters contained details about the study, including the purpose of the study, procedures that would be carried out and what is expected from the care facility managers and the caregivers. Participant information letters and consent forms (Appendix C) were made available in English and Sepedi.

2.5.2 Interview Schedule

The interview schedule (Appendix D) contained questions regarding caregivers' biographical information, characteristics of the children at the care centre as well as questions regarding the children's complex communication needs, their perception about communication support as well as about the roles of caregivers in supporting communication.

Questions in the interview schedule (Appendix D) were based on existing questionnaires by Dalton and Sweeney (2013), DeSimone and Cascella (2005), and Howes (2019). These studies were conducted on a similar topic about the communication needs of individuals with CCN in residential facilities. These studies were found through a literature search using keywords including "residential care facilities," "communication needs," "children with complex communicant needs," "CCN" and "communication support."

The questionnaire in Howes's (2019) study aimed at gathering information regarding the communication needs of adults in a residential care facility in a South African context. The questionnaire was adapted from previous studies by DeSimone and Cascella (2005) and Dalton and Sweeny (2013). These were also used in the formulation of the current study interview schedule. Howes's (2019) questionnaire could not be fully adapted as it was a quantitative questionnaire that was designed for interviewing staff who cared for adults with intellectual disabilities in multiple residential care facilities. The DeSimone and Cascella (2005) study was also conducted in multiple facilities. Their survey was given to facility managers and included speech therapists. However, Dalton and Sweeny (2013) used self-administering questionnaires that were given to support staff instead of to managers. It is important to note that the data collection instruments of all three studies were adapted from the Communication Support Checklist for programmes that work with individuals with severe disabilities (McCarthy, 1998). In this study, the participants did not have to self-administer the questionnaire.

Although the studies mentioned were conducted on an adult population, the objectives and purposes of the studies were like those of the current study. Contributions from data collection instruments used in these studies were used to formulate an interview schedule that was appropriate for the current study population. The interview schedule incorporated biographical questions and the Ten Questions Questionnaire (TTQ) screening tool.

a) Biographical Questionnaire

The biographical section of the interview schedule included participants' personal information like employment status, education level and work experience. Information like date of birth was obtained from the facility manager when giving the student researcher a brief list of staff who were on duty on the day of the interview.

b) Ten Question Questionnaire Screening Tool

Section B of the interview schedule consisted of the TQQ screening tool. This tool was developed by Durkin et al. (1991) as a screening tool to be administers during parent interviews. The purpose of the TQQ is to screen for intellectual disability, motor disability, visual disability, auditory disability, and seizures (Christianson et al., 2002). This screening tool was tested and validated internationally. Christianson et al. (2002) used the TTQ in the rural communities of Bushbuckridge to detect childhood disabilities with the purpose of determining the prevalence of disability in the area. In a similar study conducted on children with intellectual disabilities, it was found that children who were identified as having symptoms of some disabilities were not receiving any accommodations or modifications in schools (Kromberg et al., 2008). A disadvantage was noted with the TQQ, with the TQQ question was that it was designed to be used with children with severe to profound disabilities, this mean that if some caregiver had children with mild disabilities in their care, those children's characteristics would not have been included (Zuurmond et al., 2019).

c) *Interview Questions*

The interview schedule was formulated in English and translated into Sepedi since they are the most spoken languages in the area. Translations were undertaken by a first language speaker of Sepedi who also works as a researcher in various government institutions. A backward translation was also conducted by taking the Sepedi translated interview schedule and giving it to another Sepedi first language speaker to translate it back to English (Degroot et al., 1994). This was done to ensure that the data collection tool is collecting the data that need to be collected and that no meaning was lost during the translation process. Table 2 describes the justifications for the questions and the references.

Table 3: Interview Questionnaire and Justification from Literature

Interview question asked	Justification from literature
A. *Biographical information*	
What is your employment status at the centre?	This question will allow the researcher to determine the experience background of caregivers. In Healy and Noonan Walsh (2007), the nurses who were individually interviewed indicated that experiences of staff had an impact on their competence in meeting the communication needs of the individuals with CCN in their residential facility.
What is your highest education level?	According to Schnitzer et al. (2017), caregivers' education levels had an impact on their physical and mental stress, eventually affecting their perspectives on how they view different roles in their work. This question was asked to determine whether caregivers have matric and post-matric qualifications. Responses to this question enabled the researcher to determine whether there are similarities in caregivers' responses according to their education background.
How long have you been working at the care centre? Did you have any previous experience of working with people with disabilities before you started working at this care centre?	In Healy and Noonan Walsh (2007), the nurses who were individually interviewed indicated that experiences of staff had an impact on their competence in meeting the communication needs of the individuals

Interview question asked	Justification from literature
	with CCN in their residential facility. This question will allow the researcher to determine the experience background of caregivers.
B. *TQQ screener*	The responses to the questions gave the student researcher information about the characteristics of the group of children in the residential care facility. This was also to ensure that children in the research site do meet the criteria of children with CCN. The screening tool represents different kinds of disabilities. A positive result in any section indicates a problem or disability, whereas a negative or ‘no’ response indicates normal development (Durkin et al., 2015).
C. *Caregiver views and knowledge about communication needs, communication support and children with CCN*	
Could you please tell me what you think the word ‘communication’ means? (Remember that there is no right or wrong answer).	The question was obtained from a previous study that was conducted on a similar topic (DeSimone & Cascella, 2005). This question was asked to determine the caregivers’ understanding of communication. People often confuse lack of speech with lack of communication. After the participants gave their definition of communication, the student researcher read to each participant the definition of communication according to the context of the study.

Interview question asked	Justification from literature
Do the children that you care for at the care centre have communication disabilities? If yes, do they have the necessary assistive devices?	This question will be asked to determine whether the caregiver works directly with children with complex communication needs. This will also determine whether there is access to assistive devices. Availability of communication assistive devices will mean that there is an attempt to meet the communication needs of the children (National Department of Social Development, n.d.).
Do you believe that children who do not have speech also communicate somehow? If yes, how do they communicate?	This question was derived from previous studies on a similar topic. Responses to this question determine the caregivers' perspectives about what they regard as communication and their perception of communication of children with CCN.
Describe the communication of children that you work with at the centre in terms of how they express themselves and how they understand what is said to them.	The responses to this question will enable the researcher to determine what the caregivers regard as communication as well as the caregivers' perceptions about the communication of children with CCN.
What kind of communication challenges do the children in your centre have and how you would improve them?	In a study that was recently conducted in Tshwane regarding challenges experienced by caregivers working in care facilities for children with intellectual disabilities; caregivers mostly complained about challenges relating to provision of physical care to the children and very few caregivers mentioned teaching the children concepts (Moosa-Tayob et al., 2022). No challenges were mentioned regarding communication. This could be that caregivers solely focus on the physical needs of the children and do not think that they have a role

Interview question asked	Justification from literature
	to play in enhancing communication or meeting communication needs. Responses to this question gave the student researcher more information on the caregivers' perspectives and role in meeting communication needs of the children; as well as identify some of the challenges that they face.
How do you communicate with the children with communication disabilities to ensure that they understand instructions?	Caregivers working with adults in a residential facility did not expect communication from the adults with CNN. Reduced communication expectations resulted in reduced communication opportunities (Howes, 2019). This question was adapted from previous studies to determine whether caregivers communicated with children with CCN and the strategies that they used.
How familiar are you with AAC and where did you learn about it? AAC refers to devices and signs that are used to help someone with communication difficulties to communicate (example: tablet, communication board, Makaton).	Educators teaching children with communication difficulties in a special needs school indicated that they did not know much about AAC and relied on non-verbal communication as their communication method (Mukhopadhyay & Nwaogu, 2009). Responses to this question gave the student researcher information on how much caregivers know about AAC and who supports them.

Interview question asked	Justification from literature
Are there speech therapy support services for the children at the centre? If yes, how often do therapists see the children for therapy? If there are no speech therapy services, are there any therapists visiting the care centre at all?	The question was asked to determine the availability of services and therapeutic support to meet the communication needs of the children. This question was also asked to determine whether caregivers had awareness of therapeutic intervention, specifically speech therapy.
Could you tell me how the therapists involve you in therapy activities with the children? Do the therapists work directly with the children, or do they work with you as well and talk to you about the children and advise you on what to do with them?	This question was asked to determine the caregivers' role in therapeutic activities and whether those activities include improving the communication and participation of children with CCN.
What kind of trainings have you attended since you started caring for people with disabilities and what were the trainings about? If yes, did you receive these trainings while working in the current care centre or when working elsewhere?	Training improves the communication skills of staff working with CCN (Healy & Noonan Walsh, 2007). Training and knowledge of a particular subject or skill have an influence on how one views or perceives that subject compared to someone with no prior training or experience.
D. Caregivers' experience and perspectives of their roles in a residential facility.	
Can you describe to me your normal work day at the care centre? You can tell me about what you do from when you arrive at the centre until when you leave.	To determine whether the caregivers' work routine includes activities that enhance communication and supporting the communication

Interview question asked	Justification from literature
	needs of the children (Dalton & Sweeney, 2013; Healy & Noonan Walsh, 2007; Howes, 2019)
How has your life changed since you started working as a caregiver for children with disabilities? (Physical, emotional, and social perspectives).	High caregiver burden is associated with poor physical, mental health and overall quality of life of caregivers (Ho et al., 2009). Caring for children with disabilities can be fulfilling and stressful. This question was asked to determine whether caring for children with CCN has impacted the caregivers in a positive or negative way. According to a study that was conducted on caregivers in a similar context as that of the current study, the impact of work on the caregivers affected their ability to fulfil their role effectively (Moosa-Tayob & Risenga, 2022).
What are the difficulties that you encounter in taking care of children with complex communication needs? How do you cope with such difficulties?	This question was asked to determine some of the communication barriers that are experienced by caregivers caring for children with CCN. Responses to this question were to help determine whether there were strategies in place to remedy these challenges to meet the communication needs of children in the residential care facility. A study that was conducted in an orphanage in South Africa found the residential care facility not to be conducive for language development owing to the restrictive environment and the lack of caregiver-to-child communication opportunities (Levin & Haines, 2007).

Interview question asked	Justification from literature
What kind of support do you need to improve your work with children who have communication difficulties?	This question was based on a previous study regarding the support needs of caregivers for children with disabilities in a South African context. The themes that were identified included stress, financial assistance, need for collaboration, etc. All of these factors had an impact on motivation and the level of care (Sandy et al., 2013). This question was asked to identify the support needs that could improve the work of caregivers in caring for children with CCN and in meeting their communication needs.
Is there anything else you would like to tell me about your experience while caring for children with complex communication needs?	This open-ended question was asked to determine whether there was any additional information or feedback from participants.

2.5.3 Voice Recorder

An Olympus DM-650 digital voice recorder was used to record participants' responses during data collection.

2.6 Pilot Study

A pilot study was undertaken to evaluate whether the data collection materials and procedures were understandable to participants and were optimally able to be completed by the researcher. The student researcher assessed the data collection instrument to determine whether the interview instructions were understandable. This enabled the student researcher to anticipate confusions and to rectify them before the main study was conducted (Walliman, 2006).

The pilot study was conducted with caregivers who worked in a residential facility not selected for the main study. Participants for the pilot study were two caregivers of children with complex communication needs in a residential care facility. The residential care facility and caregivers were required to have characteristics that are similar to those in the care facility of the main study and were also required to meet the same selection criteria. Two participants were selected who complied with the selection criteria in the residential facility. Both participants worked directly with the children with complex communication needs. Both participants spoke English as their second language. One participant was a first language speaker of Sepedi and indicated that she was comfortable conducting the interview in Sepedi. The second participant was a Setswana first language speaker but indicated that she was comfortable conducting the interview in English. Both pilot study participants were notified that they were allowed to code switch between languages when they struggled to give some responses only in one language. This is because the area where they reside is multilingual and multicultural, so it is very common for the residents to use multiple languages. Findings from the pilot study were analysed, and the discrepancies were identified and resolved.

Table 4 gives an overview of the aims of the pilot study, the materials and procedures used, the results and the subsequent recommendations in relation to the aims, material, and procedures.

Table 4: Pilot Study

AIM	MATERIALS	PROCEDURE	RESULTS	RECOMMENDATIONS
To test the information letters and consent forms	Information letter and consent form	Participants read the information letters and consent form to the participants. They were then asked to indicate verbally whether they understood everything and whether they had any questions.	The two participants indicated that they understood what the study was about from the information letters and agreed to sign the consent forms. Both participants requested a copy of the information letters and preferred information letters written in English.	No changes were made to the information letters and consent forms.
To evaluate clarity of the questions and language of the interview.	Interview schedule (Appendix D) and voice recorder	Participant interviews and audio recording of the interview.	The participant who was interviewed in English requested definitions and clarity on AAC.	The interview schedule was amended to include definitions of AAC. With the assistance of translators, the Sepedi questions

AIM	MATERIALS	PROCEDURE	RESULTS	RECOMMENDATIONS
			The participant who was interviewed in Sepedi indicated that, although she is a Sepedi language speaker, she found the Sepedi language used in the interview schedule to be very difficult to understand as it sounded more academic and not like the dialect they use on daily basis. The participant indicated that she did not learn Sepedi at school. She requested for some questions to	in the interview schedule were amended to an informal dialect that was spoken in Tshwane.

AIM	MATERIALS	PROCEDURE	RESULTS	RECOMMENDATIONS
			be simplified to the informal Sepedi language that is commonly used in Tshwane.	
To determine clarity of the interview questions.	Interview schedule	The student read interview questions in English to the first participant and in Sepedi to the second participant.	Participants gave the same answers for questions 14 & 15. Reading of some Sepedi language questions was difficult owing to the dialect that was used.	Deletion of questions that seemed to be repetitive. Sepedi questions were amended to a much simpler dialect spoken in Tshwane instead of the academic Sepedi, despite that being more grammatically correct.
To determine clarity and quality of the voice recordings.	DM-650 voice recorder	The researcher gave the recorded script to two people to listen and rate it.	The sound quality for pilot study 1 participant was appropriate, and the audio recordings were clear. However, the recordings for pilot	The researcher asked for a quieter space with fewer interruptions. The facility manager ensured that there were adequate staff available during interviews to ensure that the children could continue with

AIM	MATERIALS	PROCEDURE	RESULTS	RECOMMENDATIONS
			study 2 had very loud noises in the background. Owing to staff shortages, she could not be far away from the children.	their daily routines during the interview process.
To assess the data analysis method and determine whether it would be effective in the main study	Microsoft Excel and interview schedule	Pilot study data were transcribed manually and analysed through Microsoft Excel.	Transcription and translation of pilot study recordings were slow.	A translator was hired to transcribe and translate the main study interviews that were done in Sepedi.
To determine whether the questions in the interview schedule answer the questionnaire	Interview schedule	The student researcher conducted interviews in English and Sepedi. Data were analysed to determine whether they answered the research questions effectively and identified areas that needed to be amended.		

2.7 Main Study

2.7.1 Procedures

General Procedures

The student researcher hand delivered the information letter and reply slip to the facility manager and explained to the manager what the study was about and what would be expected from the facility management and the caregivers. The facility manager notified the care facility staff who worked with children about the student researcher's intention to conduct the study in the facility. The facility manager asked whether the staff were comfortable with taking part in the study before she could sign the permission slip (Appendix B). All of the facility staff agreed to have the student researcher visiting their facility to interview them. They were also reassured that participation is voluntary and that each participant would need to sign their own consent form (Appendix C). The care facility manager signed the reply slip (Appendix B) giving consent to the student to conduct the study in their care facility.

Specific caregivers to participate in the study could not be identified in advance because of the nature of their work shifts as it was not possible to predict who would be available on what date, so they were all given consent forms. The care facility manager gave the student researcher brief information about the caregivers on duty on the date of the interview. The brief report included information about how many caregivers were on duty, their ages, and home languages. Although the facility manager did not have information about which caregiver signed consent and which did not, the briefing sessions enabled the student researcher to know how many participants she would be interviewing on that day, the reasons for the absence of caregivers, and how to plan to reach available caregivers.

Translation Process

To accommodate caregivers who did not speak English, participant information letters and interview schedules were translated from English to Sepedi through backward and forward translation. The translation work was carried out by two Sepedi first language speakers who are also fluent in English. Translator 1 works as a researcher in government institutions. Translator 2 is a speech therapist in a hospital in Limpopo province. Translator 1 was given the English interview schedule to translate to Sepedi. The translations of Translator 1 were given to Translator 2 to translate them back to English. This was done to ensure that both versions of the data collection instruments collect the same data (da Mota Falcão et al., 2003). Sepedi language, also referred to as *Sesotho sa leboa*, comprises many dialects that also have their own dialects. Therefore, the translators had to take into consideration these differences in dialects to ensure that the meaning of the questions was not lost   Some of the Sepedi dialects are not standardised and have not been converted into writing (Rakgogo, 2016). To ensure that the translated questions obtained the data that they were intended to get, the student researcher and translators discussions about the words and statements that were likely to be misinterpreted. by the participants. The student researcher had consultations with the translators to create a final interview schedule that would be culturally appropriate for participants in Tshwane.

The two translations were compared to check for similarities, and discrepancies were rectified. The Sepedi translated interview was also assessed through the pilot study to check the cultural appropriateness and whether the questions would be understood by Sepedi speaking people in Tshwane. The findings from the pilot study are provided in Table 5.

Data Collection Procedures

The student researcher explained to all caregivers working the day shift what the purpose of the study was and what was expected of them. The student researcher read the information letters and consent forms (Appendix C) to them, the researcher read the information letters herself to ensure that everyone understood what it was about and also to give them an opportunity to ask questions. Caregivers were also given the information letters to keep or read for themselves. This was done to avoid losing interest due to the presure to read consent letters. According to Leedy and Ormrod (2015) indicated that participant’s literacy can have an impact in their interest to participate in a study. Participants who were interested in taking part in the study signed consent forms (Appendix C). The semi-structured face-to-face interviews were conducted by the student researcher herself without an assistant or interpreter. Participants did not receive the interview questions before the interview session; they only knew the questions on the day of the interview. This was done to avoid discussion of questions and sharing of responses before the sessions.

During data collection, interviewed participants by reading questions on the interview schedule to the particpants. Participants were not given a questionnaire to complete; their responses were recorded by the student researcher using Olympus DM-650 voice recorder and through notes taken during the interviews. This approach was chosen because it eliminated the literacy of participants being a barrier for participating as it would affect the number of participants who met the selection criteria. Caregivers were asked questions regarding their understanding of communication of the children in their care. They were also interviewed about their experiences, their roles and their involvement in meeting the communication needs of the children that they cared for. The interviews were conducted in English and Sepedi. Interviews allowed caregivers to share freely more details about their experiences. However, interviews can be costly, time consuming and biased since participants sometimes wanted to give responses that made them look good rather than give the true reflections of their experiences (McMillan & Schumacher, 2010).

In the TQQ section of the interview, participants were asked information that gave the student researcher information about the characteristics of the children that they cared for. The questions were not directed at specific children but at typical characteristics of the children. The participants were asked to give responses that they felt best described these children.

Data Preparation

Owing to the diversity of languages used in the interviews, voice recordings of interviews that were conducted in English were manually transcribed verbatim by the student researcher. The participants were a multilingual population who often switched between languages during the interview. This would have made it difficult for transcription software to transcribe accurately. The transcribed information included the transcription of non-verbal information such as pauses, background noises and laughter (Leedy & Ormrod, 2015). To ensure accuracy of the transcription, 20% of the transcription was given to a colleague who is a speech therapist and a postgraduate student for review (MacLean et al., 2004). Interviews that were conducted in Sepedi were transcribed and translated into English by Translator 1. The transcriptions and translations were also reviewed by the student researcher. This was done to ensure that the translated data correctly represented the views of the participants.

Data Analysis

Data analysis in qualitative research involves close examination of data to find meaning (Leedy & Ormrod, 2015). A thematic data analysis was used to identify and organise themes systematically in the data (Braun & Clarke, 2006). Thematic analysis allows the researcher to identify the shared meaning and experiences of the residential care facility staff regarding their perceptions of communication support and their roles in supporting the communication of children with CCN (Cooper et al., 2012). Data that was recorded in Sepedi was translated and transcribed in English, all data analysis was based on the English transcripts.

To avoid bias, the researcher followed the six phases of thematic data analysis stipulated by Braun and Clarke (2006). Audio recordings of the individual interviews took place in a room away from other centre staff and children, as described in section 4.1.3. An intelligibility rating was also given by two colleagues for both the Sepedi and the English interviews. The student researcher collected the data herself to ensure that she was familiar with the data from when it was collected. According to Braun and Clarke (2006), some themes in the data can already be identified before the formal coding starts. This gives the researcher a head start in the coding process.

The caregivers who were interviewed worked in the same care facility and some worked with the same children, so their experiences were similar. Themes started to show early, and the student researcher was able to already identify some of the themes. Not much data is available on the research topic, and the researcher employed inductive data analysis to create codes and themes.The student researcher followed the six phases of Braun and Clarke's thematic analysis to analyze the data of the 7 interview transcripts (Braun & Clarke, 2006).

Phase one: Farmiliarization with data

All data collection and some transcriptions were carried out by the researcher. The student researcher farmiliarized herself with the data during collection and transcriptions. Each participants' responses to the 20 questions and biographical information were transcribed verbatim by the student researcher. Responses that were given in Sepedi were translated with assistance of a hired transcriber who was also a translator. All the data from transcripts was transferred to a Microsoft excel spreadsheet for identification of codes.

Phase two: Generation of initial codes

In this phase of data analysis, the student researcher used the Microsoft excel spreadsheet to manually generate codes. Because the student researcher conducted participant interviews herself and transcribed the English recordings verbatim, it gave her prior knowledge of the data before the actual coding took place.

Phase three: looking for themes

From the generated codes on the excel spreadsheet, the student researcher proceeded to the third phase where she sorted the codes into higher level codes. According to Braun and Clarke (2006), this is the step where the researcher sorts codes and identify potential themes. Codes that had similar meanings were grouped under one theme. The student researcher identified themes in all the sections of the transcribed responses.

Phase four: reviewing themes

The researcher went through the identified themes and reviewed them. This was conducted to check if there were any themes that needed to be merged or broken down (Braun & Clarke, 2006).

Phase five: Defining themes

In this stage the themes are analysed in detail by looking at what the theme represents and how it relates to the research question. In this phase, the student researcher arranged the themes in relation to the biographical information, TQQ as well as the caregivers responses in relation to the research topic.

Phase six: report writing

In the sixth phase, a report was written on the results obtained from the Excel data analysis. A Microsoft word table was also created and populated with the summary of themes and sub-themes. In the sixth phase of the study, a column of examplers was added to themes table. All data was analysed in the same excel spread. However, when writing the results the themes were broken down according to the sub aims to ensure that the research questions are all answered.

2.8 Trustworthiness

To ensure trustworthiness of the study, several precautions were taken to ensure that the data collection instruments and procedures were reliable (Thyer, 2009; Vollmer et al., 2008). Data collection instruments were adapted from existing studies that have been tested to ensure that they collected the data that they were intended to collect (McMillan & Schumacher, 2010). A truthful and honestly conducted study also allows clinicians to give feedback to caregivers from whom the data was collected. This was implemented through member checking (Candela, 2019). Initially, the participants were asked if they would like to listen to the recordings of their interviewsto confirm that their responses were recorded correctly (Vollmer et al., 2008). All 7 respondents indicated that they did not want to listen to recordings of themselves. Transcriptions of participants' responses were also printed and given to participants to approve whether their responses had been captured accurately. Some participants indicated that they give the student researcher permission to go ahead and use their recordings but did not want copies of their scripts. Studies found that participants sometimes found reading direct transcriptions of their responses to be embarrassing (Midgley et al., 2013). The student researcher reassured participants that their transcripts would not be published. The pilot study was also conducted and analysed to determine whether there were any errors that could affect the trustworthiness of the main study.

3. RESULTS

This section presents the results of the semi-structured interviews according to the sub-aims outlined in Chapter 2 to answer the main aim, which was to understand the perspectives of caregivers in a residential care facility regarding the communication needs and skills of children with complex communication needs living in the facility as well as the role that caregivers in these homes can play to support their communication.

The data collection instrument consisted of an interview schedule consisting of 20 questions, of which the first four were biographical questions, followed by the TQQ screener; questions 5.1 to 5.11 of the interview schedule. Responses to the questions answered the research questions with respect to the sub-aims of the study. In this chapter, the results from the interviews are presented in relation to answering each sub-aim of the study based on themes that emerged from the interview data. The section begins with a description of the participants, followed by a description of characteristics of the children with CCN in the residential care facility. Thereafter, the results are presented in relation to each sub-aim of the study.

3.1 Description of Research Participants

The intention to conduct the study in the care facility was announced to 15 staff members who worked directly with children with CCN in a residential care facility. A total of seven caregivers gave consent to participate in the study. Five participants indicated that they worked during the day shift, whereas two worked at night. All seven participants were employed as full-time caregivers of the children, with most of them having over five years' experience of working in the facility. Information about the participants was obtained from the participants' responses of the biographical questions. A total of six caregivers indicated that they had studied up to the final year of high school, also known a matric or grade 12. Among them, three caregivers indicated that they had studied further after completing their matric and obtained post-matric qualifications. A total of two caregivers had healthcare diplomas that qualified them to work as caregivers, whereas one was a retired nurse with a nursing diploma. Six participants were first language speakers of Sepedi, whereas one participant was a first language speaker of Xitsonga living in a Sepedi language-dominant area and was therefore also fluent in this language as a second language speaker. Table 4 summarises the participants' biographical information.

Table 5: Participants' Biographical Information

Participant Number	Age	Gender	Highest Education Level	Years of Experience in the Care Facility
1	55	Female	Matric	8
2	39	Female	Matric	10
3	33	Female	Community Healthcare Diploma	5
4	30	Female	Matric	4
5	48	Female	Grade 11	8
6	61	Female	Nursing Diploma	7
7	25	Female	Community Healthcare Diploma	1

3.2 Description of Children with CCN in the Residential Care Facility Cared for by the Participants

The TQQ (Durkin et al., 2015) was used to collect information about the characteristics of the children in the care facility. The results from the TQQ represented the most prominent characteristics of the group of children for whom the caregivers cared at the facility and were not specific to individual children. The participants collectively cared for 20 children with ages ranging from 5 to 23. The facility manager indicated that the majority of the children were below the age of 18. The TQQ consisted of 10 questions that related to various categories of disability in comparison with typically developing children of the same age. The participants gave 'yes' responses to all 10 questions. A 'yes' response was regarded as positive, although not a diagnosis but an indication of a 'problem' (Durkin et al., 2015). The caregivers' responses indicated that all of the 20 children for whom they cared individually in the facility had communication disability with an additional disability like hearing impairment, visual impairment, physical disability and delayed milestones. Information on how many children specifically had hearing and visual impairment, physical disability and developmental delay could not be obtained as the tool was not used to ask directly about the children individually but rather collectively as a group.

Information regarding the specific types of communication disabilities was not collected, since the TQQ is only a screening tool and not an assessment instrument. All of these conditions that have been identified, usually co-occur with communication disabilities (Light & McNaughton, 2012). In a question where participants were asked whether the children for whom they cared could speak or not, three caregivers responded that the children do not speak, whereas four caregivers indicated that some could speak, and some could not speak. In another questions, caregivers were asked whether the speech of the children who could speak was different from other children their age; all seven of the caregivers indicated that the speech of the children whom they say can speak was unintelligible and difficult to understand.

3.3 Caregivers Understanding of Communication

The first sub-aim was to explore the understanding of the concept of communication of caregivers in residential care facilities. Caregivers were requested to define the word "communication" according to their own understanding. Their responses to this question helped the researcher to understand what the caregivers regarded as communication. The caregivers' responses also helped the researcher to understand the caregivers' responses in relation to other questions since their understanding of what communication meant could have an influence on what they might regard as communication disability, communication needs and support. The dominant theme for this sub-aim showed that most caregivers understood communication as receptive and/or expressive communication. Responses from two of the Most of the caregivers associated communication with a form of expression, namely speaking or talking.

It means to talk to each other. P4.

> *It is when two people speak.* P7.

Few caregivers defined communication with respect to receptive language, specifically listening and understanding.

> *My understanding of communication is when we communicate to someone. Yeah. Listening and understanding to each other.* P3.

> *The word communication means a way of people to understand one another. P4*

However, three participants defined communication as working together in unity. All participants were English second language speakers, with the dominant first language of the participants being Sepedi. The majority of the participants who associated communication with work and collaboration were asked the question in English and Sepedi (their first language). A possible influence of the first language could therefore have had an impact on their definition of communication. According to the researcher's experience as a second language Sepedi speaker, in the local vernacular of Sepedi in this community, the word communication can sometimes refer to speaking to solve problems in relationships, work etc. Owing to the influence of the first language, responses from three caregivers implied that communication meant working together and unity.

> *Um, communication is between two people. I can say that, yeah, if they are working together, they must communicate so they can do their work properly and understand it*. P2

> *It means we must understand each other; to be one unit so that we… you find that we work together; you know there must be communication. Eh, do not find yourself working alone; there is no communication there. When you do something, I must tell my partner that this is the way we work so that there is communication.* P5

> *It is to work together… together…* P6

When asked about whether children with communication disabilities could communicate, most of the caregivers responded that they believed that children with communication disabilities do communicate. The dominant theme was that of non-verbal communication methods as a means of communication for the children with communication disabilities. The most frequent form of communication mentioned was crying and unaided communication such as natural gestures.

> *Yeah it's true. with action. When one feels pain, he cries and then you attend.* P1

> *Yes, they communicate by actions. Hmm Okay. As I work with them, like, if... I can say she wants water; she'll go just grab the cup. So, we know that, okay, now she's thirsty, she wants water.* P2

> *…they use the signs. Like they.. some of them they cry when they need something. Maybe if they are hungry, they cry. Yeah, they make noise, you see that other one is making this the yeah, maybe she or he needs something.* P3

3.4 Caregivers' Knowledge of the Communication Needs of Children with CCN.

The second sub-aim sought to understand the caregivers' knowledge of the communication needs of the children with CCN in their care facility. As previously stated, caregivers acknowledged the use of non-verbal communication of the children in the facility by responding to their basic needs. According to most participants, children used non-speech vocalisations like crying and screaming to seek attention or to express basic needs like hunger, thirst, or pain. Participants reported that they sometimes found it difficult to understand these non-verbal communication methods and that that this then resulted in sometimes having some needs not being met.

> *Sometimes I delay to understand what they want to tell me. So, it is a problem because I take time to understand. By the time I get to him/her it is too late. When they scream you have to figure out what it could be about. Sometimes what you think is the problem is not even it. You discover late especially when it is something hidden. Sometimes it's inside the stomach and I can't see. It's a big challenge* P1

The participants described the children's communication as having difficulties in speech production, understanding, and listening. The dominant theme in caregivers' knowledge about communication needs was their challenges in supporting communication. The following sub-themes appeared to influence the caregivers' knowledge of children's communication needs.

3.4.1 Lack of Speech Therapy Support

Participants were asked questions about the availability of therapists in their residential care facility. The most dominant theme in the participants' responses was that speech therapy services were very limited and inconsistent. Some participants also seemed unclear in distinguishing speech therapists from other therapists, which implies that they may not always have had clarity on the roles of these therapists. However, the question further stated that they should then respond based on any therapist that they work with, regardless of the specific profession. Only two participants mentioned therapists by profession and included speech therapists.

> *Yes, speech, and physio, and… and occupational* P1

> *Yes, they do come. OTs they come and speech therapists yesterday. Maybe two times in a month. Yeah.* P7

Participants were further asked about the extent of their involvement in therapy activities. The theme that emerged was that caregivers were mostly directly involved in therapy activities on rare occasion when therapists visited the centre. Although visits of therapists to the facility were inconsistent, in the rare cases when therapists did come to the facility, they reported that therapists involved them in their sessions in some way.

> *Ahh when they come, they teach us what we can do to the children. What we can do to support them.* P3

> *They were working with us, showing us how they work.* P5

It can be inferred from this that, although specific training topics on communication needs were not mentioned specifically, the therapists appeared to encourage hands-on involvement of caregivers. However, there were no specific indications as to how therapists supported caregivers in communicating with or understanding the communication needs of the children.

3.4.2 Lack of Knowledge in the Use of AAC

Participants were asked questions about the availability of AAC services to determine their knowledge of supporting the communication of the children through AAC. Responses from the majority of participants reflected that caregivers were not familiar with the concept of AAC until it was explained to them what AAC was. After being read out the definition of AAC, most of the caregivers indicated that they were familiar with AAC because they were told about it but were not implementing it. In a similar study that was conducted on adults, it was found that even though care centre staff mihght have an idea of what AAC was, they still did not have much experience in using it (Howes (2019).

> *What is it? Oh, we do have tablets, Education brought them. But only two can participate. But the rest can't because of their hand. They are deformed. We have two tablets that they have brought, they…* (pretends to press). P1

> *I am a bit familiar with the name but I cannot make up where I heard it … (*Interviewer interjects*). No. Because it is not long ago since we have received the tablets. Yes. At least… it can speak. There is this one who can point to it (*the tablet*) and react to it laughing as she does. Everything. Animals and everything else. She can understand it. But she… it is not long ago since we got these things from the Education (*Department of Education*). But well, it is time. It is not that long ago when we got it. At least… I feel like it helps us a lot. But it is not all children who can understand it. Yes. You see.* P6

Although the caregivers indicated that they were familiar with tablets as AAC devices that were available in their facility, when asked of the different strategies that they used to support communication, most of the participants did not mention the use of AAC in their communication support strategies. Their responses also appeared to indicate that they were not specifically trained on how these could be used to support children's communication attempts.

3.5 Caregivers' Knowledge of Communication Skills of the Children with CCN

The third sub-aim explored the caregivers' knowledge of the communication skills of children with CCN in a residential care facility. Participants were asked to describe the communication skills of the children in their facility in terms of how these children mostly communicate. All participants described the children as having some degree of communication challenges in terms of receptive language, expressive language, and social behaviour. A total of six caregivers agreed that children who do not have speech can communicate in another way. The predominant theme was that they communicated mostly through unaided methods.

> *Yes, they communicate by actions. Hmm Okay. As I work with them, like, if... I can say she wants water, she'll go just grab the cup. So, we know that, okay, now she's thirsty, she wants water.* P2

> *They use the signs. Like they… some of them they cry when they need something. Maybe if they are hungry, they cry. Yeah, they make noise, you see that other one is making this the yeah (a child in the next room was making a loud humming sound), maybe she or he needs something.* P3

> *Who do not have speech? Yes, I do believe they can communicate physically. They communicate physically using their hands. Body language.* P7

However, one participant responded that children who do not have speech cannot communicate owing to their inability to speak.

> *Them (surprised)? Can they speak to each other? No (they cannot communicate) That is because they do not seem like they can speak.* P5

The participant's response indicates that she regarded communication as verbal language only with low expectations of children with CCN to communicate. This was confirmed by her understanding of communication as noted in the previous section where she was unsure of the meaning but eventually described it as understanding and associated it with working together.

> *What do you mean?* (asks for clarity). *It means we must understand each other; to be one unit so that we… you find that we work together; you know there must be communication. Eh, do not find yourself working alone; there is no communication there. When you do something, I must tell my partner that this is the way we work so that there is communication.* P5

Furthermore, all the participants indicated that most of the children were completely dependent on caregivers to try to figure out their communication attempts.

> *Some make sounds, and you just see that they need help.* P1

> *No. No. These ones… they cannot speak, but they can cry.* P5

> *Yes, they do* (referring to communication disabilities). *But do not have devices.* P7

In terms of receptive language skills, two participants described the communication of some of the children as not being able to follow instructions, and indicated that some children were even non-responsive.

> *It's challenging because they don't understand what we are saying.* P4

> *Like this one I speak about. If I can… when I have a bowl (of water) … I can… she can open her mouth (*Interviewer acknowledges*) … like I realise that here she can understand what I want to do.* P6

One participant indicated that she was not certain whether the children who were not reacting to speech, were simply not understanding speech, or whether they actually had a hearing impairment.

> *When you take out instruction, only few that can hear. There are those who will do nothing. They will do nothing, when you speak a word, you speak for them all. Not all of them participate. They don't hear. I don't know if they really can't hear but there are those who cannot hear at all. They don't do anything.* P1

Based on the caregivers' descriptions of children's expressive language, it would appear that they can be classified mainly as emergent communicators, i.e., non-symbolic communicators who use gestures, vocalisations and facial expressions that are usually understood only by familiar communication partners (Dowden, 1999).

All participants' responses about the children's communication skills indicated that the children communicate by crying, actions, non-speech vocalisations, facial expressions and hand gestures that still required them to interpret the meaning of their communication attempts to understand them.

> *Some like when you are feeding them, they don't want to be fed. If he's not hungry you won't open his mouth or her mouth, or he'll just look outside; you know that he doesn't want those foods. Or if he's not full. We're feeding him and is not full. He will cry, so you know that this child still wants food.* P2

> *OK, some of them. When they're hungry, they bang the doors or when the nappy is full, they come over at the butler (*door*) and then they stand there. And some, when the nappy*

> *is full they will cry until you change the nappy. And if they are full they will just talk with using their hands, showing that they are cool/full*. P7

> *Okay, our children are different. Some of them, if you speak to them, they can hear, but they cannot respond or speak out. Some of them, you must just listen to their body language. Some, you can ask them, show me your eyes, they will point. Raise your hands, they will do. That's another way of others that you communicate because they can hear you, but they are not able to respond towards what you are saying*. Q9 P4.

The children used these unaided communication modes to express their needs and wants. None of their methods had been standardised. This implies that the outcome of the children's communication efforts are dependent solely on the caregivers' interpretation.

> *By crying. You find that he/she is forever crying. Crying uncontrollably nonstop. You can see from that, that this one wants food; you can judge for yourself that this one's nappy is full. You must change the nappy. Water. You can see that this one is thirsty and wants water. You will realise that this one… you could be wondering what could be bothering this one when he/she cries nonstop: that would mean that he/she has pooped/defecated and that he/she needs to be changed the pampers. That he/she needs water, needs food*. P5

3.6 Caregivers' Views of Their Roles and Responsibilities in Supporting the Communication of Children with CCN.

This sub-aim explored the views of the residential facility caregivers on their roles and responsibilities in supporting the communication needs of children with CCN.

3.6.1 Support in Daily Routine Activities Role

Most participants described their role in supporting children with CCN in terms of daily routines but rarely referred to their roles in supporting children's communication (Levin & Haines, 2007). In describing their roles in the daily routine activities, the support of the physical care needs of the children was the predominant theme. Most of these related to activities of daily living, for example, helping the children with feeding and bathing.

In the morning we welcome them, we carry them from the transport, re yaba koka (English: we carry pick them up), we put them where we are supposed to and then we welcome *one another. We've got boards with their names; we sing we pray and then 8h00 they get the breakfast. We wipe them, we change them the nappies, they get water and then after we prepare them to sing. For the day we sing, massage them, put others on the chair, it's a daily thing and then we've got time for lunch. Re na le nako ya lunch (English: we have lunch time). And then after feeding we get water, we wipe them. Fortunately, others they go with the transport with the school children. Always about 14:15, 14:10 the transport starts to take them. till 4h00, but the thing is we have day shift and night shift for those who are sleeping. So, that's why that day shift must work until 4h00. We only have 3 hours to prepare for the night. And the night staff comes.. because it's 6 to 7. Re tsammaya ka 7 Ka 6, babangwe bat sena (English: We leave at 7 and then the next shift people enter at 6.* P1

> *Yeah. (Sepedi) I will talk about day. Okay when I get here, I sign my register, and… I warm up their food. The patient's food, then I feed them. After feeding them I make sure they bath, give them medication around 8:00 (pm) and I give them blankets, they sleep. I knock off at 7:00 in the morning* P7

3.6.2 Teaching Role

Another dominant theme identified on the views of caregivers about the roles and responsibilities was the additional role of teaching that is expected of them from the Department of Basic Education (DBE). Most participants mentioned teaching as their additional role. However, caregivers were not specific about what this teaching role entailed or whether it included communication support.

> *Okay, when we arrive at work, we start by, uh, we start by going to prayer, and then after, it's, uh.. breakfast for the kids, feeding the kids and then after then we have a programme where we teach them and then we have a time for, for teaching them and then for.. I have time for music. It's many activities for music. Sometimes, sometimes they go outside to play.* P2

> *We receive the children in the morning. When we receive them, we write down (register) which driver brought them in, and what the name of the child is… then we gently put*

> *them on the chairs… you find… It is like a lot of them. When we are through we teach them for a little while… from there it is time to fetch them food… put them orderly on their chairs, and then start feeding them.* P6

They did, however, mention that this additional teaching role added more strain to their workload.

> *The challenge is like, now we are caregivers, so now there's a, being in Department of Education, they have programmes which we must do, and also we have the programme of being a caregiver, which we must do, and which is a lot of work. So the challenge is time, and then the other thing is like we work under pressure.* P2

> *What I would like to ask is about education, we are expected to teach these children. Ok, we are caregivers, maybe it is part of our job, but I feel like it is too much for us because we are doing a lot daily.* P3

As this facility follows the Department of Basic Education (DBE) learning programme for learners with severe to profound intellectual disabilities (LSPID), which includes language and communication activities (DBE, 2022.), it can be inferred that teaching may also relate to language and communication. One participant mentioned that she taught the children how to write. Information about the literacy level of the children was not asked since the information background of the facility indicated that the group of children who were taken care of by the participants had severe to profound intellectual disabilities and did not attend formal school.

> *From 10:30 is study time, yeah. We teach them how to write, we sing. We have a.. what do you call them? Schedule, yes schedule that we follow.* P2

A dominant subtheme in the learning activities was singing activities and the greeting routine in the morning. These activities would require some form of communication between the children and caregivers.

3.5.3 Communication Support Role

As previously stated, caregivers rarely referred to their roles in supporting the communication needs or skills of the children. One caregiver specifically mentioned that, owing to short staffing, she did not have enough time to communicate with the children. Therefore, she tended to focus on activities of daily living like feeding, bathing, and toileting.

> *Communicating with them, I think that is the biggest challenge. In my department being the shortage of staff that makes us not to pay attention to the children in time.* P4

For this caregiver it would appear that not enough attention might be paid to the facilitating the children's communication.

3.6.3 Caregivers' Skills and Strategies Used to Support Communication

Although caregivers did not frequently refer to their role in supporting communication, in other sections of the interview, most participants did mentioned some techniques and strategies that they used to communicate with the children. However the strategies were not adequate as there was no mutual understanding between them and the children. Most of the caregivers' efforts were one sided, the children were not given enough opportunities to communicate their own needs and wants.

Caregivers were requested to describe how they communicated with the children with CCN. This was done to identify the different strategies that they used to communicate with children with CCN in their facility. The dominant theme from the participants' responses was the limited use of communication strategies that supported communication. This could be linked to the lack of training received owing to the inconsistent availability of speech therapists in the facility, as noted in section 3.3. Owing to the inconsistent therapeutic support services and limited training by therapists, caregivers did not have many functional strategies that they could use to support communication. A few caregivers mentioned that they talk to the children and also augmented this with unaided techniques.

> *Uh, we normally talk to them, even though they can't communicate. We talk to them by actions, uh, by toys, so they can understand.* P2.

> *Okay, some of our children, you need to make them move because some they can see you and then whatever movement you'll be doing they'll be aware of what you're doing. So you need to, we communicate with them in a different way. Some, when you talk to them, they won't be able to respond but they can hear what you're saying. So now you need to know that this person I have to communicate physically with them, I have to communicate with movement with that child. So, you have to understand that their communication is not the same. So, yet some you just have to make your body movement and then they will see what you are talking about.* P4

As mentioned in 3.3, on the rare occasions when therapists visited their facility, caregivers worked directly with the therapists in sessions where they may have picked up some of these strategies.

How They Communicated with Children with CCN

Most of the communication strategies that caregivers reported mainly targeted receptive language skills to enable the children to understand what the caregivers wanted to communicate to the children. Caregivers reported on strategies that were in place foor the children to communicate with the caregivers. Therefore, not many strategies encouraged the children's expressive language.

From an expressive communication perspective, most participants spoke about how the children are not responding to their communication, and therefore not many expressive communication strategies were mentioned. Only one participant mentioned that she sings with the children and that can sometimes result in a laughter response.

> *Yes… for my part, regarding the ones I see, I do have that belief. Yes… because when I joke around with them or saying …* (Participant makes non-verbal; gestures that shows her clapping her hands in a playful manner of playing with children*) … and start singing, especially with regard to this one called "***". When you start singing, Yoh! She laughs very hard… you can see that she can realise what I am saying. … and start singing.* P6

Another participant mentioned that part of her morning routine includes greeting the children and calling them by name; however, she did not elaborate further on whether the children respond to these greetings or whether she expect responses at all.

> *When a child arrives, we welcome them. We communicate with the child. "Hello, ***, hi ***, welcome, welcome back'. We sing for them and then after we pray.* P3

Caregivers' Training

All caregivers indicated that they have been trained on one or more topics by the student therapists that conducted outreaches in their care facility or by the Gauteng Department of Education personnel. Some caregivers indicated that they were trained on feeding, positioning, general information on caring for the children as well as on communication.

> *Students (university therapy students) used to train us. We would do positioning, feeding, exercises.* P1

> *I attended education training. Yeah, educational only. The topics were about communication, how to handle autism, uhm how to handle autism patients, mentally and CP patients.* P7

Three caregivers mentioned that they were trained on communication but did not elaborate further on what the communication training entailed and whether it included topics like AAC. They received all the mentioned trainings while working at the current care facility.

4. DISCUSSION

As discussed in Chapter 1, the main aim of this study was to understand the perspectives of caregivers in a residential care facility regarding the needs and skills of children with complex communication needs living in a residential facility as well as the role that caregivers in this facility play to support their communication. This chapter discusses the results recorder in Chapter 3 in relation to the current literature.

As stated previously, children with CCN often have other disabilities. Owing to these disabilities, mainstream creches and schools in South Africa usually deny them admission because of the extra care that they require (Geiger, 2012). This situation has forced parents to place their children with disabilities in care facilities where they would be provided with physical care (bathing, feeding, etc) and medical care. Traditionally, these facilities provided a hospital-like setup where the children were treated as though they were sick patients (Geiger, 2012). In recent years, the Department of Basic Education (DBE) has introduced the social model guided LSPID programme in an effort to do away with the medical model in care facilities in South Africa. The facility in the current study was reported to be following the (LSPID) programme. However, the facility is still new to the programme and is struggling to implement it effectively. Caregivers mentioned challenges like short staffing, lack of motivation and lack of stakeholder collaboration as hindering factors to the full implementation of the programmes related to the social disability model. These findings concur with those of Moosa-Tayob and Risenga (2022), where caregivers identified their main role as providing basic care to the children in their care facility and found stimulation activities an additional stretch on their daily duties.

4.1 Communication Needs and Skills of the Children with CCN vs Caregivers' Communication Knowledge and Skills

The children in the residential care facility relied on non-verbal communication methods to communicate their needs and wants, with most of their communication strategies being non-symbolic and idiosyncratic signs. Caregivers also tried their own informal non-verbal communication methods to co-communicate. This poses a risk of misinterpretations between caregivers and the children with CCN. Without effective communication skills, children with CCN will continue to live in isolation with minimal interaction from the people around them (Light & McNaughton, 2014). Furthermore, the communication level of the children in the residential care facility was described to be of beginning communicators level. unavailability of formal communication strategies like aided and unaided AAC may hinder the language learning process of the children causing them to remain beginning communicators Thistle & Wilkinson (2021). For effective communication to take place, it will require competent communicators and communication partners (Geiger, 2012). Hands-on caregiver training in effective communication strategies will enable them to pass the skills to the children. In the current study, caregivers did not have adequate training in non-verbal communication and AAC strategies. This explains their continuous use of self made AAC symbols and signs and, their frustration over the breakdown in communication between them and the children. Children with CCN do have the ability to communicate when given the opportunity (Franklin & Goff, 2019), regardless of the severity of their disability. Speech therapists have the responsibility to train caregivers and the children on communication strategies and to empower them to engage in meaningful social interactions (Geiger, 2012). Thistle & Wilkinson (2021) recommends the use of AAC systems as the primary communication strategy for children with CCN. Speech therapists will need to equip themselves with AAC knowledge to ensure that they are competent communicators themselves before they can train caregivers (Light & McNaughton, 2014). In a similar study conducted in facilities that care for adults with intellectual disabilities, Howes (2019) suggested that the use of AAC is highly recommended to improve expressive language, but with the reported lack of speech therapy services this becomes a challenge to fulfil since AAC requires professional knowledge.

Speech therapists can work in collaboration with other rehabilitation staff and the caregivers to create a communication-supportive environment for the children and caregivers. Current results indicate that the majority of the caregivers were also overwhelmed by the amount of work that they had to do and their lack of skills to perform additional roles in supporting communication (Laletas et al., 2017).

Most caregivers recognised gestures, signs and vocalisations as communication but did not always know how to interpret them. This correlates with the caregivers’ responses in another study conducted to determine the communication of children with severe disabilities in group homes (Fylkesnes, 2021). Fylkesnes (2021) reported that, attending to the physical needs of children were prioritised when a child cried. For example, caregivers had to check their body to ascertain whether they were hurt, check their positions to determine whether children might be uncomfortable or check whether they needed a nappy change, etc. The responses of most participants in the current study agree with this, but they added that it was challenging to go through the process of checking the child everywhere and still not to find the cause of the crying. They found this breakdown in communication to be frustrating for both caregivers and the children. Even though only a few caregivers thought that children who do not have speech do not communicate, most of the caregivers did not know how to support both receptive and expressive communication of children with CCN in their care. This could result in learned helplessness and having the children with CCN communicating less as they struggle to get positive feedback from their communication attempts. Lack of social interaction could impact the language development of the children negatively, resulting in no improvement in communication skills, a delay in literacy development and an inability to form relationships in future. A study conducted in an orphanage found that many children who reside in care facilities had communication problems ranging from mild to severe with some previously identified and some unidentified (McCool & Stevens, 2011). When compared to the children in the Koch and Franzsen (2017) study, the caregivers in the current study had more interaction with the children owing to their implementation of the LSPID learning programme that required them to teach the children for at least three hours. This somehow forced the caregivers to do some stimulation activities that were not activities of daily living like toileting, bathing, feeding etc. However, the communication was structured and usually done in compliance with the daily schedule. Responses from caregivers who worked night shifts did not mention any activities that required them to spend time with the children. A dominant theme in responses from night shift caregivers was personal care, with activities like bathing, feeding, medical care and sleep, and none related to communication.

While the caregivers reported to have attended several trainings provided by student therapists and some by Gauteng Department of Education (GDE), only a few of these trainings appeared to be about communication or about AAC. In a study by Howes (2019), the majority of the caregivers indicated that there was a need for AAC training. This could be linked to the few previous trainings that they had attended which had given them some background knowledge about AAC. In the Western Cape facilities where Howes (2019) conducted her study, some facilities had access to speech therapy services from the community as well as AAC resources. Although the speech therapy and AAC service delivery was said to be inadequate, it was more frequent, and the facility staff were more aware of the services than those of the current study. However, with little or no training background in AAC, it would be difficult for caregivers to recognise that need for AAC training. This explains why the majority of the caregivers in the current study did not mention AAC as a need for future training. Without this additional knowledge and specific training on AAC the risk is that children in these displayed facilities will remain as beginning communicators. The caregivers described the communication of the children in the current study as that of beginning communicators, who are still in the process of developing functional communication skills. Without functional communication skills, the children in the residential care facility will not be able to participate effectively in school and home activities. The use of AAC will allow the children to develop functional communication skills, to improve cognitive skills, social participation and independence (Drager et al., 2010). Children who use non-verbal communication methods tend to struggle to expand their communication beyond the emotion, sign or a tantrum (Midtlin et al., 2015). A risk is therefore that children will use challenging behaviours when their communication attempts are not understood (Geiger, 2012). Children who frequently used challenging behaviour to communicate tend to be undesirable and are often excluded from social interactions, which will then cause an increase in the challenging behaviour with this cycle continuing. Caregivers will need to be trained on challenging behaviour and how they can regulate it to avoid making it worse. In Geiger (2012) it was reported that paying attention to the children with challenging behaviour encouraged them to participate in activities without having to execute the challenging behaviour to seek caregivers' attention.

Irregular speech therapy services in the current study can be seen as an additional contributing factor to caregivers' lack of knowledge and skills, which resonates with the results of a study by Moosa-Tayob and Risenga (2022), who identified lack of rehabilitation services like speech therapy as contributing to having caregivers who were not skilled. The study reiterates that caregivers need to receive training on how to communicate with the children with CCN (Moosa-Tayob & Risenga, 2022). Regular support and monitoring visitations and training by speech therapists will improve their hands-on experience in communicating with children with CCN. In the current study, caregivers reported that speech therapists' visits to the residential care facility were so far apart that, by the time the speech therapist returned, they had forgotten what they had been trained on the previous time. Some caregivers seemed unsure about whether the speech therapist was among the teams of therapists that visited their residential care facility. Some of the residential care facilities in Howes' (2019) study received speech therapy services from volunteers and local institutions. The residential care facility of the current study is close to the University of Pretoria and Sefako Makgatho Health Science Universities, so arrangements could be made with the universities to allow students to conduct their practical training in the facility, as they had done in the past. Studies conducted by (Dalton & Sweeney, 2013; Howes, 2019) in residential care facilities prove the need for caregiver training on communication strategies to improve the communication skills of individuals with CCN.

4.1.1 AAC Services and Communication Support Strategies

Prior studies have noted the importance of AAC in stimulating language development and improving communication skills (Douglas et al., 2013). The caregivers relied mostly on unaided informal communication without the guidance of an expert in AAC. On numerous occasions, caregivers mentioned the availability of AAC tablets in the care facility. It was later discovered that there were two tablets in the whole facility. Considering that there were 20 children with complex communication needs (CCN) in the facility, two tablets were not sufficient and they cannot be individualised to children’s specific needs. This means that the communication rights of the children in the facility have been diminished by the lack of communication resources. These results reflect those of Dalton and Sweeney (2013),who also found that communication support resources were not available sufficiently for adults with intellectual disabilities in residential facilities. One challenge that was mentioned was that a child would not be able to go everywhere with the tablet. This implies that the tablet would somehow restrict the child’s movements, which is understandable noting that the children were also reported to be having physical disabilities and motor challenges. The limitations in AAC implementation can be linked to the lack of speech therapy services which are similar to the findings of Howes (2019) in adult care facilities in South Africa.

One of the roles described by caregivers of speech therapists was training. Caregivers did not display many skills or knowledge in supporting the children’s communication through AAC. Dalton and Sweeny (2013) argue that the communication training of residential care staff must be prioritised. This training should also encourage staff to reflect on their attitudes and beliefs regarding communicating in addition to teaching functional communication through the use of AAC, especially also to facilitate their participation in educational activities. As previously mentioned, Geiger (2012) suggests the use of hands-on skills transfer as an effective training method since caregivers might find formalised trainings to be time consuming and they hardly get time to read notes. Speech therapists must conduct hands-on

AAC training with the caregivers within their care facilities and allow them to practise with the children with CCN in their residential care facility. The training must include instructions on how caregivers can create their own AAC material and the various strategies that they can apply to implement AAC to achieve functional communication.

4.1.2 Participation of Children with CCN in Education Activities

Although there is not sufficient information in describing their teaching roles, caregivers appear to make some effort to involve the children in education activities by ensuring that they include activities of the learning programme in their daily schedule. Children with CCN in residential care facilities are some of the most segregated children as they spend most of their time away from the public enjoying very little interaction with their peers. Involvement in education activities allows the caregiver to spend at least three hours of contact time with the children. As was previously discussed, children in residential care facilities spent almost half of their awake time without human contact. An advantage of the implementation of the LSPID programme in residential care facilities is that it guarantees an increase in interactions. The LSPID programme enrols children aged 5 to 21. For effective operation of the programme, the Department of Basic Education must employ qualified educators to teach the children rather than forcing caregivers to take on the teaching role without giving them any choice.

4.2 Caregivers’ Challenges in Supporting Communication of Children with CCN

4.2.1 Short Staffing

Caregivers reported that they were overloaded with work, and most of the complaints were about the added new role of teaching. In addition to their caregiving role, they are now also expected to teach the children in the facility.

Caregivers spent most of their work day doing activities in their structured routine, and little to no time socialising with the children. Although it is reasonable to give education access to children with severe to profound disabilities as it is their constitutional right, caregivers felt overwhelmed by the amount work that came with the role of teaching. This also left them with little time to facilitate communication with the children during those structured interactions with very little random socialisations. Dalton and Sweeney (2013) emphasise the role of caregivers in creating social interaction opportunities for the caregivers and making an effort to understand the non-verbal communication of the caregivers. Geiger (2012) found that the caregiver-to-child ratio was very high meaning that one caregiver was responsible for more children than they should have and, because of that, they did not have enough time to do additional work like studying after a training or workshop. This contributed to the ineffectiveness of the trainings that were conducted with the caregivers. Therefore, short staffing not only affected the daily work of the caregivers, but it also had a negative impact on trainings. Caregivers had to make time out of their busy schedule to attend training and thereafter, had to study training material and pamphlets. However, the staff that was interviewed in the Dalton and Sweeney (2013) study, were aware that communication support would improve the quality of lives of the residents, but unfortunately they did not always have the necessary skills and resources to support the adults with intellectual disabilities.

In the current study, caregivers complained about short staffing and having to add the teaching role for the implementation of the LSPID learning programme. Caregivers often mentioned that they were hired to take care of the children and now they are expected also to be teachers. Caregivers' daily routine activities included teaching and learning activities like greetings, morning rings, singing, basic concepts and life skills activities like toilet training and feeding. With the training opportunities that come with the programme, one would assume that all caregivers would gladly welcome it for the skills development benefits. In contrast, caregivers emphasised their caregiving role as their main role, and not teaching. The driving force behind this reluctance could be that caregivers were not given a choice to decide whether they wanted the teaching role or not. Another downside to the LSPID programme could be that the programme adds extra work for the caregivers with no incentive. Caregivers were not motivated to perform their teaching role, which could lead to lack of determination and even to the risk of mental health challenges. The LSPID draft policy (DBE, 2016) also states that the children and caregivers will be supported by a multi-disciplinary team of therapists but, based on the findings of the study, that has not been well implemented as therapy visits to the residential care facility have been reported to having been very limited.

5. CONCLUSIONS AND RECOMMENDATIONS

The purpose of this study was to understand the perspectives of caregivers in a residential care facility regarding the communication needs and skills of children with complex communication needs living in the residential facility as well as the role that caregivers in the facility play to support their communication. The results revealed that, while caregivers had good attitudes and beliefs in the abilities of children with CCN in these facilities to communicate, they lacked the knowledge and skills, especially in relation to AAC, of how to facilitate children's communication beyond the level of emergent communicators. Furthermore, owing to the varied number of roles played by residential care facility staff, the communication of children with CCN was not prioritised. This has implications, not only for the development of children with CCN in these facilities but also for how they can access education opportunities within residential care facilities.

5.1 Implications for Practice

A significant clinical implication of this study is that there is a high prevalence of communication disabilities among children with disabilities in residential care facilities. Their current needs do not appear to have been met owing to poor service delivery to these facilities which has impacted on the competencies of staff in these facilities to facilitate the communication development of children with CCN and their quality of life. The training of residential care staff needs to be addressed urgently, especially in relation to AAC strategies that should include low-technology as well as high-technology AAC options. Speech therapy support services in these facilities therefore need to be more consistent as this will go a long way towards improving communication support by caregivers (Geiger, 2012; Howes, 2019).

Owing to residential care facilities being registered with Department of Social Development, Department of Health, and Gauteng Department of Education, the sister departments will need to work in collaboration on common goal to improve participation of children with CCN in daily life and social activities as equal members of society. The Gauteng Department of Education needs to ensure that children with CCN in residential care facilities have access to quality education by monitoring and supporting the LSPID programme and ensuring that there is adequate staff to support the children. Furthermore, the burden of care as well the additional teaching roles, as required by the LSPID programme of the Department of Education, will need to be considered in relation to the workload of these caregivers and the lack of therapeutic support provided by the Department of Education in South Africa.

5.2 Critical Evaluation of the Study

5.2.1 Strengths

This study among the very few studies to attempt to explore the perspectives of caregivers in residential care facilities regarding the communication needs and skills of the children with complex communication needs living in a residential care facility as well as the role that the caregivers play to support their communication.

The one-on-one interview format allowed for an extensive conversation between the student researcher and each participant. The student researcher was able to follow up on interesting responses from participants and asked for clarification where there was confusion or unclear responses. Interviewing one participant at a time also allowed the participants to speak freely without fear of reaction from other participants as it might have been in a focus group. All participants who were interviewed cared for the same children. The student researcher ensured that she interviewed all the caregivers who were at the facility during the shift of the interview to avoid discussion of questions by participants.

The outcomes of the study could guide education, health, and social services in supporting children and caregivers in residential care facilities. The study highlights communication needs, skills and challenges that hinder the children from participating in education as well from exercising their human right to communication and participation, the findings of the study can guide government stakeholders in drafting policies and implementing services that can improve the livelihood of the children with CCN in care facilities. Improvement of services would also alleviate the caregivers from the strains and challenges that they are currently facing owing to working with children with whom they cannot communicate effectively.

5.2.2 Limitations

The current study was based on a small sample of caregivers from the same residential care facility. Although precautions were taken to ensure that caregivers do not share their questions, it is a bias that cannot be completely eliminated because the interviews were not all conducted on the same day. The use of a small sample and the qualitative design do not allow the findings to be generalised despite the wealth of information obtained. Findings are therefore not representative of caregivers in all care centres.

On reflection, an area that could have been explored more in this study would have been to understand how caregivers in a residential care facility implement AAC services with the resources that they have currently, since most caregivers responded that they had some AAC tablets in their care facility. No further questions were asked to prompt the caregivers to give more information regarding how exactly they are using those tablets to support communication and whether they used them at all. This would have allowed the researcher to identify whether there are any barriers hindering the caregivers or the children from using the AAC tablets. Two participants who worked night shifts were interviewed in the morning, an hour after their shift ended. Two other participants were interviewed towards the end of their day shift. All four of these participants were interviewed at a time when they were tired, and their exhaustion reflected in their voice recordings. One of the night shift workers gave responses that were very brief even after prompting by the student researcher. This was understandable since the participant was interviewed at a time when she would rather have been at home sleeping. Most of the participants commented about how their work requires physical strength, since they must carry the children to bath them, feed them and move them around; thus they were feeling tired.

The cultural and language background of the participants had some influence on their interpretation of questions, their understanding of concepts as well their perception,; for example, the participants' understanding of the word "communication".

Methodological limitations

Methodological limitations were experienced related to lack of previous studies on the subject. Due to lack of prior research to address the research problem, shortcomings were experienced during formulation of the data collection tool. The data collection tool was based on previous studies that were conducted on adults with intellectual disabilities in residential care facilities. The TQQ section of the data collection tool is a screening tool that is normally used to screen individual children(Finke et al., 2008) (Mantri-Langeveldt, 2019) and not a group screening. The TQQ screening tool was designed to for respondents to give yes and no responses, the researcher had to constantly prompt the participants to give open ended responses. Future research will need to ensure that the data collection tool is well designed to suit the data collection method.

5.3 Recommendations for Further Studies

This study offers an initial impression on the perspectives of caregivers from one care facility in a specific geographical location in South Africa regarding communication needs and skills of children with CCN as well as the roles of caregivers in the care facility in supporting communication. Further research can be aimed at caregivers from various facilities in different locations. This would eliminate bias related to language and cultural differences. Conducting the study in a larger area with more participants would also allow for generalisation of the results.

Most of the participants in the study were found to have matric and were therefore literate. Further studies should also look at written questionnaires online or on paper. This would also allow the researcher to reach more participants and enable the participants to write their views without the discomfort of being recorded.

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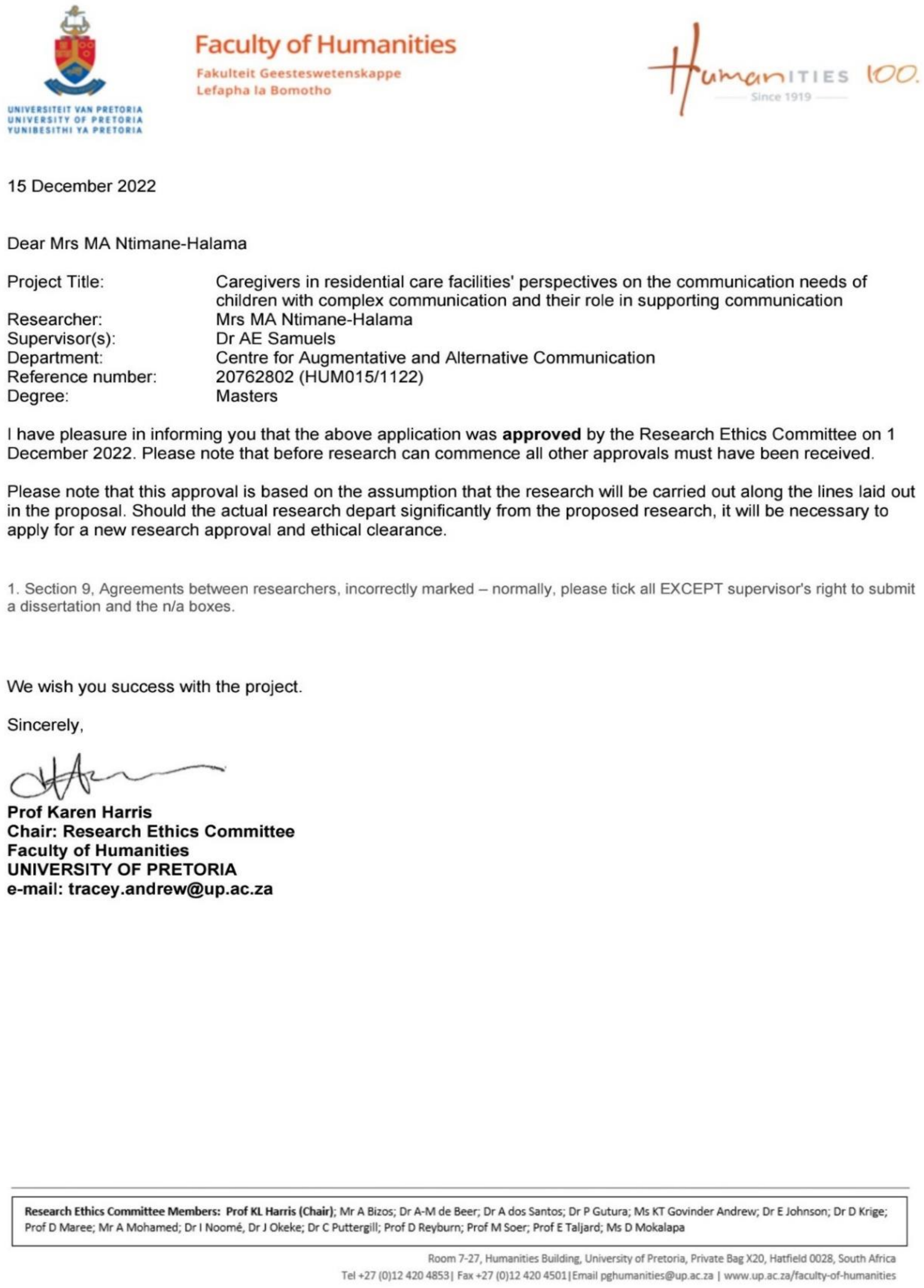
Appendix A: Ethical clearance letter



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Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

HumanITIES 100.
Since 1919

15 December 2022

Dear Mrs MA Ntimane-Halama

Project Title:	Caregivers in residential care facilities' perspectives on the communication needs of children with complex communication and their role in supporting communication
Researcher:	Mrs MA Ntimane-Halama
Supervisor(s):	Dr AE Samuels
Department:	Centre for Augmentative and Alternative Communication
Reference number:	20762802 (HUM015/1122)
Degree:	Masters

I have pleasure in informing you that the above application was **approved** by the Research Ethics Committee on 1 December 2022. Please note that before research can commence all other approvals must have been received.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

1. Section 9, Agreements between researchers, incorrectly marked – normally, please tick all EXCEPT supervisor's right to submit a dissertation and the n/a boxes.

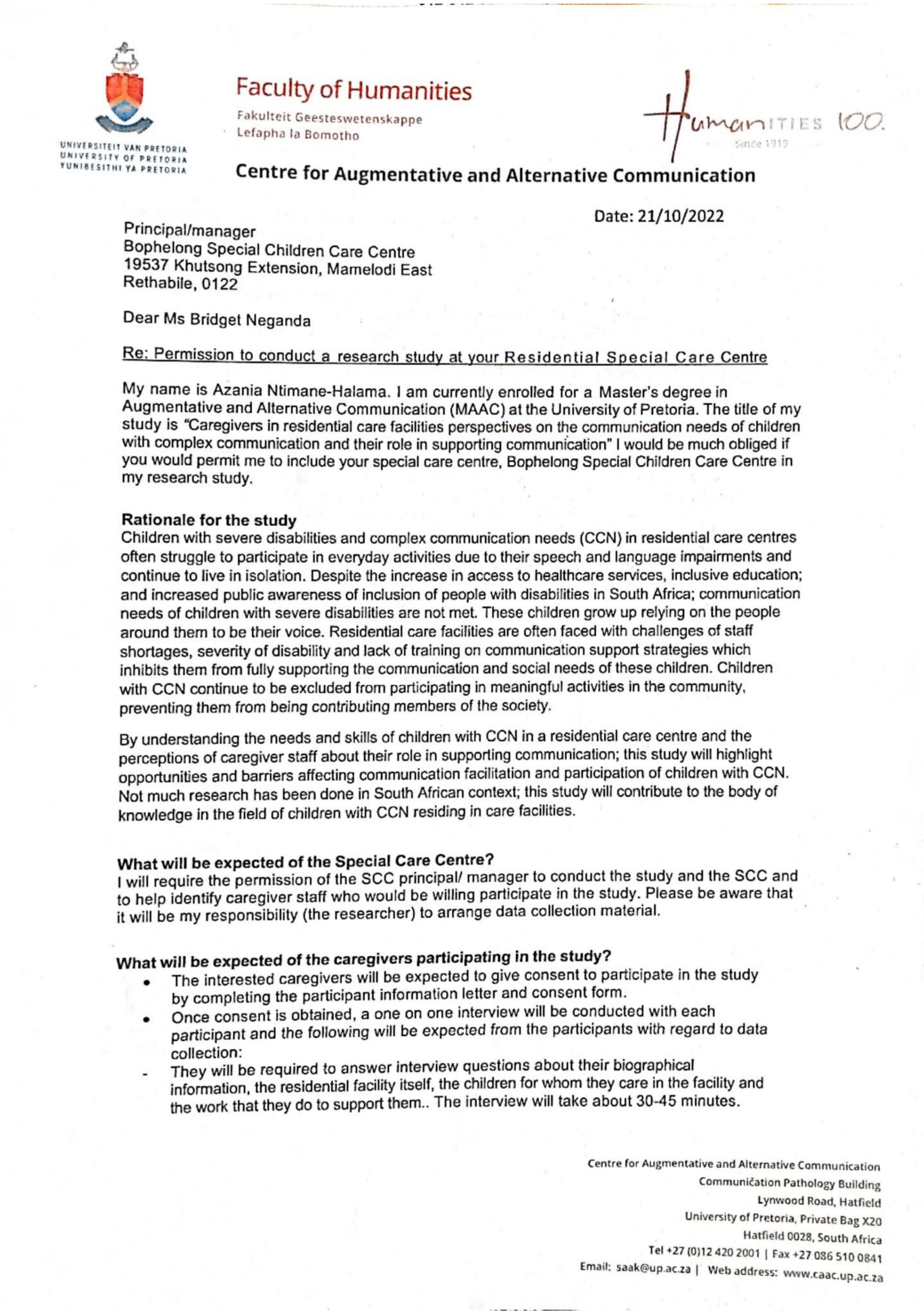
We wish you success with the project.

Sincerely,

Prof Karen Harris
Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: tracey.andrew@up.ac.za

Room 7-27, Humanities Building, University of Pretoria, Private Bag X20, Hatfield 0028, South Africa
Tel +27 (0)12 420 4853| Fax +27 (0)12 420 4501|Email pghumanities@up.ac.za | www.up.ac.za/faculty-of-humanities

Appendix B: Residential care facility information letter and consent form



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Centre for Augmentative and Alternative Communication

Date: 21/10/2022

Principal/manager
Bophelong Special Children Care Centre
19537 Khutsong Extension, Mamelodi East
Rethabile, 0122

Dear Ms Bridget Neganda

Re: Permission to conduct a research study at your Residential Special Care Centre

My name is Azania Ntimane-Halama. I am currently enrolled for a Master's degree in Augmentative and Alternative Communication (MAAC) at the University of Pretoria. The title of my study is "Caregivers in residential care facilities perspectives on the communication needs of children with complex communication and their role in supporting communication" I would be much obliged if you would permit me to include your special care centre, Bophelong Special Children Care Centre in my research study.

Rationale for the study

Children with severe disabilities and complex communication needs (CCN) in residential care centres often struggle to participate in everyday activities due to their speech and language impairments and continue to live in isolation. Despite the increase in access to healthcare services, inclusive education; and increased public awareness of inclusion of people with disabilities in South Africa; communication needs of children with severe disabilities are not met. These children grow up relying on the people around them to be their voice. Residential care facilities are often faced with challenges of staff shortages, severity of disability and lack of training on communication support strategies which inhibits them from fully supporting the communication and social needs of these children. Children with CCN continue to be excluded from participating in meaningful activities in the community, preventing them from being contributing members of the society.

By understanding the needs and skills of children with CCN in a residential care centre and the perceptions of caregiver staff about their role in supporting communication; this study will highlight opportunities and barriers affecting communication facilitation and participation of children with CCN. Not much research has been done in South African context; this study will contribute to the body of knowledge in the field of children with CCN residing in care facilities.

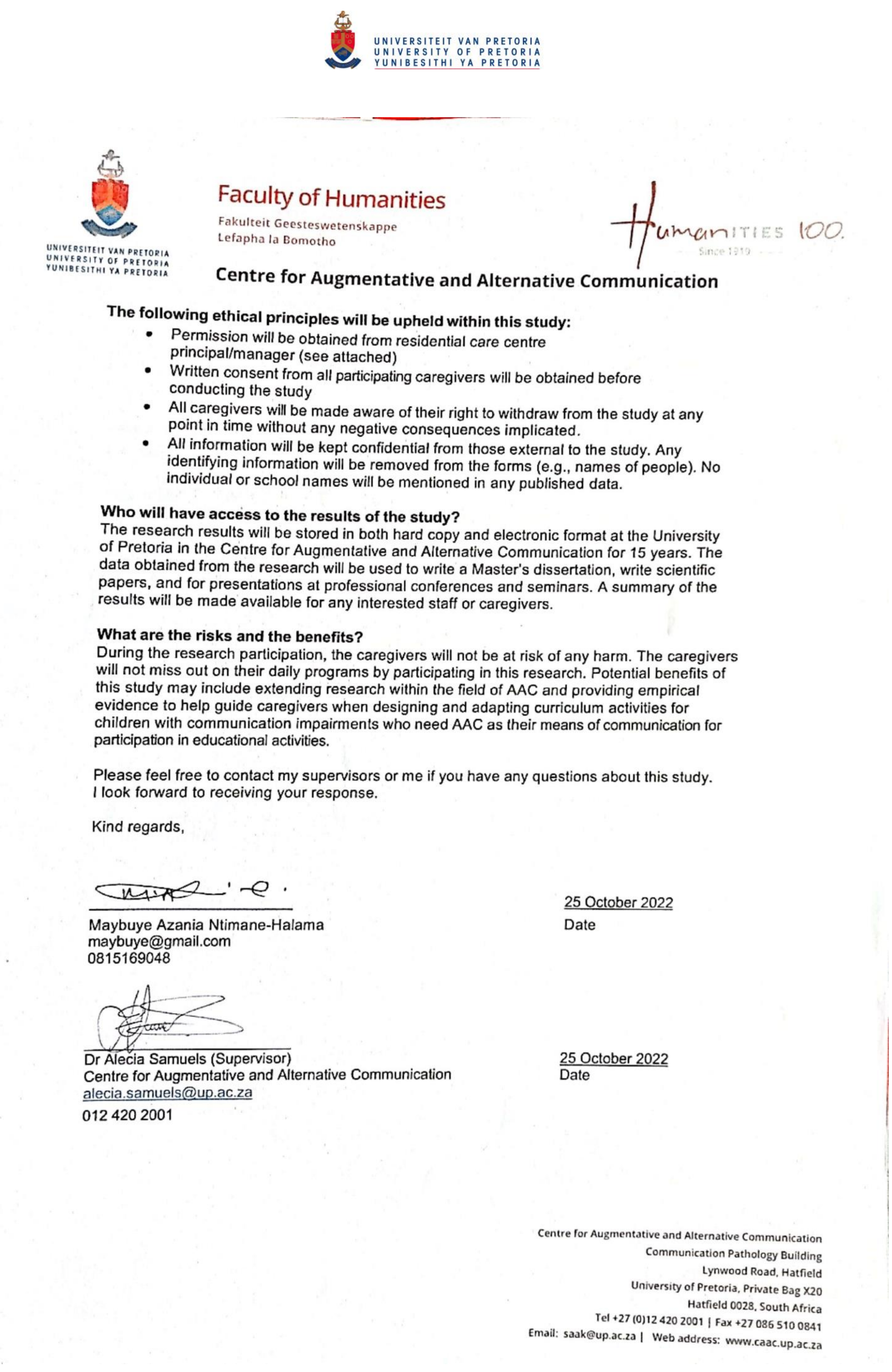
What will be expected of the Special Care Centre?

I will require the permission of the SCC principal/ manager to conduct the study and the SCC and to help identify caregiver staff who would be willing participate in the study. Please be aware that it will be my responsibility (the researcher) to arrange data collection material.

What will be expected of the caregivers participating in the study?

- The interested caregivers will be expected to give consent to participate in the study by completing the participant information letter and consent form.
- Once consent is obtained, a one on one interview will be conducted with each participant and the following will be expected from the participants with regard to data collection:
- They will be required to answer interview questions about their biographical information, the residential facility itself, the children for whom they care in the facility and the work that they do to support them.. The interview will take about 30-45 minutes.

Centre for Augmentative and Alternative Communication
Communication Pathology Building
Lynwood Road, Hatfield
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2001 | Fax +27 086 510 0841
Email: saak@up.ac.za | Web address: www.caac.up.ac.za



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The following ethical principles will be upheld within this study:

- Permission will be obtained from residential care centre principal/manager (see attached)
- Written consent from all participating caregivers will be obtained before conducting the study
- All caregivers will be made aware of their right to withdraw from the study at any point in time without any negative consequences implicated.
- All information will be kept confidential from those external to the study. Any identifying information will be removed from the forms (e.g., names of people). No individual or school names will be mentioned in any published data.

Who will have access to the results of the study?
The research results will be stored in both hard copy and electronic format at the University of Pretoria in the Centre for Augmentative and Alternative Communication for 15 years. The data obtained from the research will be used to write a Master's dissertation, write scientific papers, and for presentations at professional conferences and seminars. A summary of the results will be made available for any interested staff or caregivers.

What are the risks and the benefits?
During the research participation, the caregivers will not be at risk of any harm. The caregivers will not miss out on their daily programs by participating in this research. Potential benefits of this study may include extending research within the field of AAC and providing empirical evidence to help guide caregivers when designing and adapting curriculum activities for children with communication impairments who need AAC as their means of communication for participation in educational activities.

Please feel free to contact my supervisors or me if you have any questions about this study.
I look forward to receiving your response.

Kind regards,

Maybuye Azania Ntimane-Halama
maybuye@gmail.com
0815169048

25 October 2022
Date

Dr Alecia Samuels (Supervisor)
Centre for Augmentative and Alternative Communication
alecia.samuels@up.ac.za
012 420 2001

25 October 2022
Date

Centre for Augmentative and Alternative Communication
Communication Pathology Building
Lynwood Road, Hatfield
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 2001 | Fax +27 086 510 0841
Email: saak@up.ac.za | Web address: www.caac.up.ac.za

Principal/Manager permission reply slip

Principal/manager
Bophelong Special Children Care Centre
19537 Khutsong Extension, Mamelodi East
Rethabile, 0122

Project title: Caregivers in residential care facilities perspectives on the communication needs of children with complex communication and their role in supporting communication.

Researcher: Maybuye Azania Ntimane-Halama
(MA AAC Student University of Pretoria)

Supervisor: Dr. Alecia Samuels
(Centre for Augmentative and Alternative Communication: University of Pretoria)

Project Title: *Caregivers in residential care facilities perspectives on the communication needs of children with complex communication and their role in supporting communication.*

I, Bridget Neganda (Name and Surname), in my capacity as the

Manager (designation) of Bophelong Special Children Care Centre

Please tick box that applies

☑

Give permission to Maybuye Azania Ntimane-Halama to recruit the residential facility caregivers from the special care centre named above for possible participation in the study entitled; "*Caregivers in residential care facilities perspectives on the communication needs of children with complex communication and their role in supporting communication* ", conducted by Maybuye Azania Ntimane-Halama, under the supervision of Dr Alecia Samuels. This permission is voluntary, and I understand that I may have it at any time. I understand that participating caregivers will be audio-recorded. I understand that the data will be stored for 15years at the CAAC and that all data will be treated confidentially. I understand that the data may be re-used for analysis. I understand that the data may be used for scientific articles and conference presentations. I understand that all information used and obtained in this study will be treated as confidential

OR

☐

Do not give permission to Maybuye Azania Ntimane-Halama to recruit residential facility caregivers from the special care centre named above for possible participation in the study entitled; "*Caregivers in residential care facilities perspectives on the communication needs of children with complex communication and their role in supporting communication*".

B Neganda
Signature

Date: 31/10/2022

Centre Stamp

BOPHELONG CENTRE
FOR DISABLED
P.O. BOX 77422 MAMELODI WEST 010
2022 -10- 31
19477 MOLEPO STREET
KHUTSONG EXT. MAMELODI
TEL: 012 772 3301 / 012 812 3218
FAX: 086 661 4067

Appendix C: Participant Information letter and consent form

Date: 21 October 2022

Letter of informed consent

Dear Residential special care centre caregiver

Permission to conduct a research study at your residential special care centre

My name is **Azania Ntimane-Halama**. I am currently enrolled for a Master's degree in Augmentative and Alternative Communication (MAAC) at the University of Pretoria. The title of my study is **"Caregivers in residential care facilities perspectives on the communication needs of children with complex communication and their role in supporting communication"**

It would be appreciated if you would be willing to participate in my research project.

The rationale for the study:
Children with severe disabilities and complex communication needs (CCN) in residential care centres often struggle to participate in everyday activities due to their speech and language impairments and continue to live in isolation. Despite the increase in access to healthcare services, inclusive education; and increased public awareness of inclusion of people with disabilities in South Africa; communication needs of children with severe disabilities are not met. These children grow up relying on the people around them to be their voice. Residential care facilities are often faced with challenges of staff shortages, severity of disability and lack of training on communication support strategies which inhibits them from fully supporting the communication and social needs of these children. Children with CCN continue to be excluded from participating in meaningful activities in the community, preventing them from being contributing members of the society.
By understanding the needs and skills of children with CCN in a residential care centre and the perceptions of caregiver staff about their role in supporting communication; this study will highlight opportunities and barriers affecting communication facilitation and participation of children with CCN. Not much research has been done in South African context; this study will contribute to the body of knowledge in the field of children with CCN residing in care facilities.

What will be expected of the caregivers participating in the study?

- As an interested caregiver, you will be expected to give consent to participate in the study by completing the participant information letter and consent form.
- Once consent is obtained, a one-on-one interview will be conducted with you and the following will be expected from the participants with regard to data collection:
  - You will be required to answer interview questions about your biographical information, the residential facility itself, the children for whom you care in the facility and the work that you do to support them. The interview will take about 30-45 minutes.

The following ethical principles will be upheld within this study:

- Permission will be obtained from Special care centre principal/manager (see attached), and each participant
- Written consent from all caregivers will be obtained before conducting the study

- All caregivers will be made aware of their right to withdraw from the study at any point in time without any negative consequences implicated
- All information will be kept confidential from those external to the study. Any identifying information will be removed from the forms (e.g., names of people). No individual or school names will be mentioned in any published data

Who will have access to the results of the study?
The research data will be stored securely in both hard copy and electronic format at the University of Pretoria in the Centre for Augmentative and Alternative Communication for 15 years. The data obtained from the research will be used to write a Master's dissertation thesis, write scientific papers, and for presentations at professional conferences and seminars. A summary of the results will be made available for any interested staff or caregivers.

What are the risks and the benefits of participating in this study?
During the research participation, the caregivers will not be at risk of any harm. The caregivers will not miss out on their daily programs by participating in this research. Potential benefits of this study may include giving awareness of the current practices between caregivers and children with complex communication needs in residential care centres.

Please feel free to contact me or my supervisor if you have any questions about this study. I look forward to receiving your response.

Kind regards,

____
Maybuye Azania Ntimane-Halama
MA AAC student
maybuye@gmail.com
0815169048

____
Dr. Alecia Samuels
Centre for Augmentative and Alternative Communication
Research supervisor
alecia.samuels@up.ac.za
012 420 4727

Caregiver consent form

Project title: Caregivers in residential care facilities perspectives on the communication needs of children with complex communication and their role in supporting communication.

Researcher: Maybuye Azania Ntimane-Halama
(MA AAC Student University of Pretoria)

Supervisor: Dr Alecia Samuels
(Centre for Augmentative and Alternative Communication Lecturer)

I, ____,(name and surname)

(Please tick the box below that applies)

☐

Give permission to (Maybuye Azania Ntimane-Halama) to participate in the study entitled; "*Caregivers in residential care facilities perspectives on the communication needs of children with complex communication and their role in supporting communication* ", to be conducted under the supervision of (Dr Alecia Samuels). This permission is voluntary, and I understand that I may have it at any time. I understand that the data collected will be stored for 15 years at the CAAC and that all the data and information obtained in this study will be treated confidentially. I understand that the data may be re-used for analysis. I understand that the data may be used for scientific articles and conference presentations.

OR

☐

Do not give permission to (Maybuye Azania Ntimane-Halama) to participate in the study entitled; "*Caregivers in residential care facilities perspectives on the communication needs of children with complex communication and their role in supporting communication"*.

____
Signature

Date:________________________

Appendix D: Interview schedule

CAREGIVERS SEMI-STRUCTURED INTERVIEW SCHEDULE

LENANEO LA POLETŠIŠO YE E HLAHILWEGO GO SE FIHLE KAE YA BAHLOKOMEDI

Date of interview*:* (dd:mm:yy)________________________
Letšatšikgwedi la poledišano: (letšatši:kgwedi:ngwaga)

Language: *Polelo*:	English	Sepedi

A. BIOGRAPHICAL INFORMATION/ TSHEDIMOŠO YA BIOGRAPHIC

1. What is your employment status at the centre?

Maemo a gago a mošomo mo senthareng ye ke afe?

Full time/ *ka nako e tletšego*	Part time/ *ka nako e itšego*

2. What is your highest education level? / *Maemo a gago a thuto ya godimo ke afe?*

____

Prompt: What Grade/standard were you in when you left school?
Tšhitšhinya: O be o le go grade mang or standard mang ge o tlogela sekolo?

____

3. How long have you been working at the care centre?
O na le nako ye kaakang o šoma mo senthareng?

4. Did you have any previous experience of working with people with disabilities before you started working at this care centre?

If yes, did you work with adults or children? ____________________________________
Na o bile le "experience" a peleng a go šoma le batho bao ba goseitekatela pele o thoma go šoma senthareng?

B. TEN QUESTION QUESTIONNAIRE (SCREENER)

5. I have a list of 10 questions that I would like to ask you first before we start with the interview. Your responses to these questions will give me an overview on the characteristics of the children that you care for at the care centre.

Ke na le dipotšišo tše 10 tšeo ke ratago go le botšiša pele pele re thoma ka poledišano. Dikarabo tša gago go dipotšišo tše di tla mpha kakaretšo ya dimelo tša bana bao o ba hlokomelago lifelong le la tlhokomelo.

5.1. Compared with other children, do the children that you care for in the centre have any serious delays in sitting, standing, or walking?	Yes/ Ee	No/ Aowa
Ge o ba compera le bana ba bangwe, na bana bao o ba hlokomelago mo senthareng ba na le ditiego le ge e le dife tše dikgolo tša go dula, go ema goba go sepela?		

5.2. Compared with other children, do the children that you care for have difficulties seeing either in the daytime or at night? ***Ge o ba compera le bana ba bangwe, na bana bao oba hlokomelago mo senthareng ba na le bothata bja go bona, e ka ba mosegare goba bošego?***	Yes/ Ee	No/ Aowa
5.3. Do the children in your centre appear to have difficulty hearing?	Yes/ Ee	No/ Aowa
Na bana ba o ba hlokometšego mo senthareng ba bonala ba na le bothata bja go kwa?		
5.4. When you instruct the children to do something, do they seem to understand what you are saying?	Yes/ Ee	No/ Aowa
Ge o botsa bana gore ba dire selo se itšego, na go bonagala ba kwešiša seo o se bolelago?		
5.5. Do the children that you care for at the centre seem to have difficulty in walking or moving his/her arms or does their have weakness and/or stiffness in the arms or legs?	Yes/ Ee	No/ Aowa
Na bana bao o ba hlokomelago mo senthareng ba bonala ba na le bothata bja go sepela, goba go šišinya matsogo a bona, goba na ba na le bofokodi le/goba go thatafala matsogong goba maotong?		
5.6. Do the children you work with sometimes have fits, become rigid, or lose consciousness?	Yes/ Ee	No/ Aowa
Na bana bao o šomago ka bona ka dinako tše dingwe ba ba le bolwetši bja go wa, ba a thatafala goba ba idibala?		
5.7. Do they learn to do things like other children their age?	Yes/ Ee	No/ Aowa
Na ba ithuta go dira dilo go swana le bana ba bangwe ba nywaga ya bona?		
5.8. Do the children you care for speak at all? Can they make themselves be understood using words; can they say recognisable words?	Yes/ Ee	No/ Aowa
Na bana bao o ba hlokomelago ba a bolela le gatee? Na ba ka itira gore ba kwešišege ge ba šomiša mantšu; na ba ka bolela mantšu ao a lemogegago?		
5.9. For 3-to-9-year-old children ask: Is their speech in any way different from normal (not clear enough to be understood by people other than their immediate family)?	Yes/ Ee	No/ Aowa
Go bana ba mengwaga ye 3 go ya go ye 9 botšiša gore: Na polelo ya bona goba 'speech' sa bona se fapana ka tsela efe le ye e tlwaelegilego (ga e hlake ka mo go lekanego gore e kwešišwe ke batho ba bangwe ntle le lapa la bona la kgauswi)?		
5.10. For 2-year-old children ask: Can they name at least one object (for example, an animal, a toy, a cup, a spoon)?	Yes/ Ee	No/ Aowa
Bakeng sa bana ba mengwaga ye 2 botšiša: na ba ka bolela bonyenyane selo se tee (mohlala, phoofolo, toyi, komiki, lepula)?		
5.11. Compared with other children of their age, the children that you care for appear in any way to be intellectually disabled?	Yes/ Ee	No/ Aowa
Ge ba 'compera' le bana ba bangwe ba nywaga ya bona, bana bao o ba hlokomelago ba bonagala ba sa itikanela mo tlhaologanyong ka tsela efe?		

C. CAREGIVER VIEWS AND KNOWLEDGE ABOUT COMMUNICATION NEEDS, COMMUNICATION SUPPORT AND CHILDREN WITH CCN.

DIPONO LE TSEBO YA MOHLOKOMEDI KA GA DINYAKWA TŠA KGOKAGANO, THEKGO YA KGOKAGANO LE BANA EUTH CCN

6. Could you please tell me what you think the word “communication” means? (Remember that there is no right or wrong answer).

Aa le ka mpotša gore le nagana gore lentšu le ba rego ke “kgokagano” goba “communication” le ra go reng? (Gopola gore ga go na karabo ye “right” goba “wrong”).

7. In this study, communication refers to an exchange of information and expressing of needs, wants and feelings (Beukelman and Mirenda, 2013)”.

- ***“Mo nyakišišong ye, kgokagano or “communication” e šupa phapantšho ya tshedimošo le go tšweletša dinyakwa, dinyakwa le maikutlo (Beukelman le Mirenda, 2013)”.***

- Children with complex communication needs refers to those children who have speech and language difficulties with other severe disabilities.

(For example, a child with cerebral palsy or CP who has communication difficulties and not able to sit or walk on his own)

- ***Mo nyakišišong ye, bana bao ba nago le de “complex communication needs” e šupa go bana bao ba nago le mathata a polelo le maleme, go kopantšha le go bo seitikanele bo bogolo ka tsela engwe. (go tshwana le ngwana ona leng cerebral palsy or CP asa kgoneng go itsamayela, go dula mogo le go bolela)***

7.b. Do the children that you care for at the care centre have communication disabilities? If yes, do they have the necessary assistive devices?

Na bana bao o ba hlokomelago 94ifelong la tlhokomelo ba na le bogole bja poledišano? Ge go le bjwalo, na ba na le didirišwa tše di nyakegago tša go thuša?

8. Do you believe that children who do not have speech also communicate somehow? If yes, how do they communicate?	Yes/ Ee	No/ Aowa

Na o dumela gore bana bao ba se nago polelo le bona ba boledišana ka tsela e itšego? Ge go le bjwalo, ba boledišana bjang?

9. Describe the communication of children that you work with at the centre in terms of how they express themselves and how they understand what is said to them.

Hlaloša kgokagano ya bana bao o šomago ka bona mosenthareng go ya ka fao ba itlhalosago ka gona le ka fao ba kwešišago seo se bolelwago go bona.

10. What kind of communication challenges do the children in your centre have and how you would improve them?

Ke ditlhohlo tša mohuta mang tša kgokagano tšeo 94ifelon 94ifelong la gago la tlhokomelo ba nago le tšona, le gore o be o tla di kaonefatša bjang?

11. How do you communicate with the children with communication disabilities to ensure that they understand instructions

O bolela bjang le bana bao ba nago le bo se itikanela bja dikgokagano go netefatša gore ba kwešiša ditaelo?

12. How familiar are you with AAC and where did you learn about it?
    AAC refers to devices and signs that are used to help someone with communication difficulties to communicate (example: tablet, communication board, makaton)

O tlwaelane le AAC gakaakang le gore o ithutile kae ka yona?

AAC ke di didirišwa le di “signs” tše diberekiswang go thusa batho ka kgokgano. (example: tablet, pampiri ya ditshwatso tsa go bolela ka tsona le di “signs” tša Makaton)

13. Are there speech therapy support services for the children at the centre? If yes, how often do Therapists see the children for therapy? If no speech therapy services, are there any therapists visiting the care centre at all?	Yes/ Ee	No/ Aowa

Na go na le ditirelo tša di speech therapist go bana ba mo senthareng? Ge e ba ee, ba bona bana gakae?
Ge ose na le ditirelo tša di speech therapist, ke di therapist tše di fe tše di etelang senthara e?

14. Could you tell me how the therapists involve you in therapy activities with the children? Do the therapists work directly with the children, or do they work with you as well and talk to you about the children and advise you on what to do with them?

Di therapists di go akaretša bjang medirong ya kalafo le bana? Na ba šoma thwii le bana, goba na le bona ba šoma le wena gomme ba bolela le wena ka bana le go go eletša ka seo o swanetšego go se dira ka bana?

15. What kind of trainings have you attended since you started caring for people with disabilities and what were the trainings about?

    Ke dithuto tša mohuta mang tšeo o tsenego go tšona ga e sa le o thoma go hlokomela batho bao sitikanela mo meleng goba tlhaloganyo gomme dithuto tšeo di be di bolela ka eng?

15.b. Did you receive these trainings while working in the current care centre or when working elsewhere?

? Ge go le bjwalo, na o hweditše dithuto tše ge o be o šoma senthareng ye goba ge o be o šoma lefelong le lengwe?

D. CAREGIVERS’ EXPERIENCE AND PERSPECTIVES OF THEIR ROLES IN A RESIDENTIAL CARE FACILITY.

MAITHELELO A BAHLOKOMEDI LE DIPONO TŠA DIKAROLO TŠA BONA LEFELONG LA TLHOKOMELO YA BODULO

16. Can you describe to me your normal workday at the care centre? You can tell me about what you do from when you arrive at the centre until when you knock off.

Na o ka ntlhalosetša ka letšatši la gago la mošomo le le tlwaelegilego mosenthareng? O ka mpotša ka seo o se dirago go tloga ge o fihla senthareng goeseng go fihla ge o fetša mošomong.

17. How has your life changed since you started working as a caregiver for children with disabilities? (Physical, emotional, and social perspectives).

Bophelo bja gago bo fetogile bjang ga e sa le o thoma go šoma bjalo ka mohlokomedi wa bana bao ba seitikanela? (Dipono tša mmele, tša maikutlo le tša leago).

18. What are the difficulties that you encounter in taking care of children with complex communication needs? How did you cope with such difficulties?

Ke mathata afe ao o kopanago nao ge o hlokomela bana bao ba go seitikanela meleng le go se boleli? O ile wa lebeletšana bjang le mathata a bjalo?

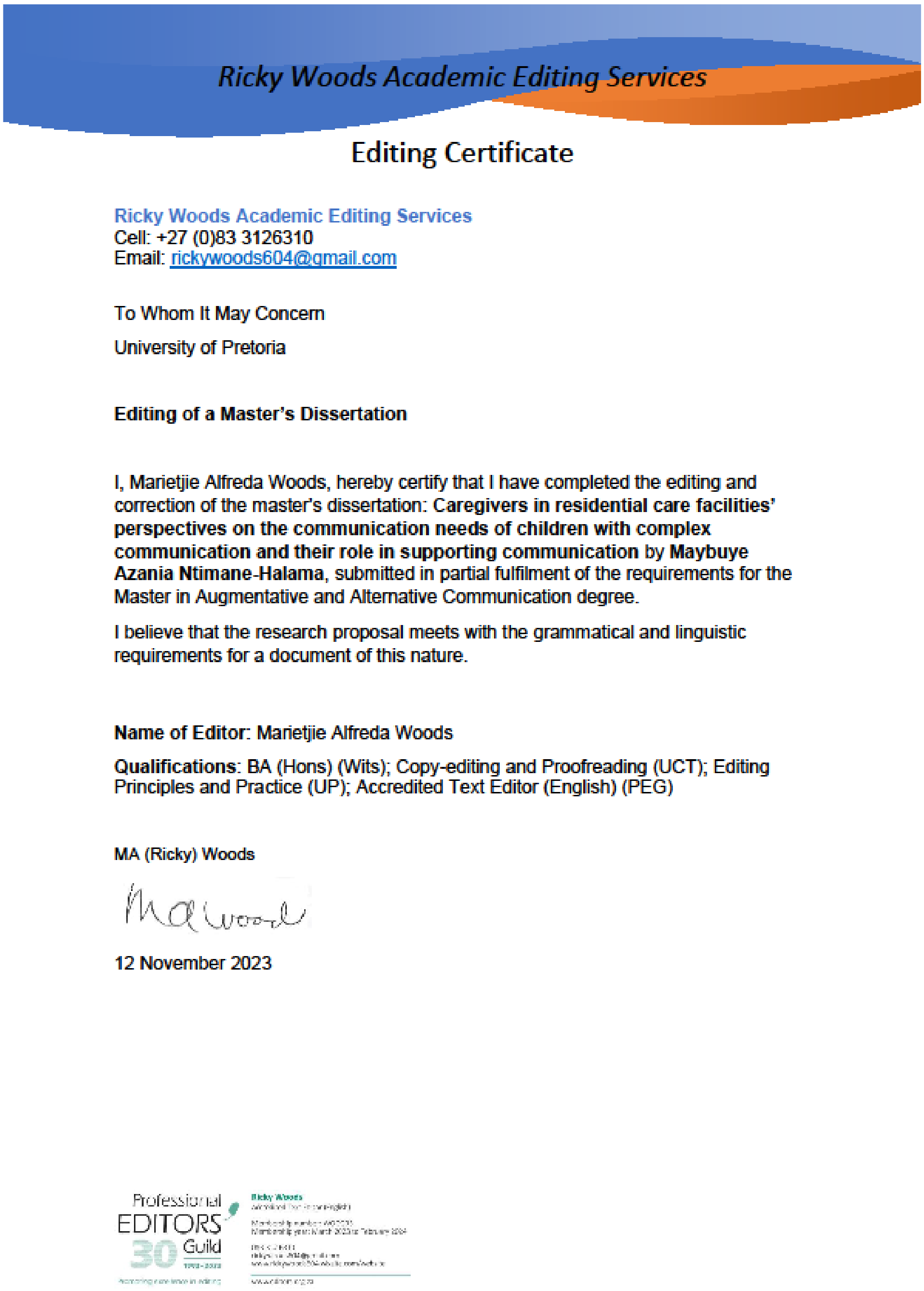
19. What kind of support do you need to improve your work with children who have communication difficulties?

Ke thekgo ya mohuta mang yeo o e hlokago go kaonafatša mošomo wa gago le bana bao ba nago le mathata a go bolela?

20. Is there anything else you would like to tell me about your experience while caring for children with complex communication needs?

Na go na le selo se sengwe seo o ka ratago go mpotša sona ka phihlelo ya gago ge o dutše o hlokomela bana bao ba nago le bothatha ba o bolela le go seitikanela?

Appendix E: Editing certificate



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Editing Certificate

Ricky Woods Academic Editing Services
Cell: +27 (0)83 3126310
Email: rickywoods604@gmail.com

To Whom It May Concern

University of Pretoria

Editing of a Master's Dissertation

I, Marietjie Alfreda Woods, hereby certify that I have completed the editing and correction of the master's dissertation: **Caregivers in residential care facilities' perspectives on the communication needs of children with complex communication and their role in supporting communication** by **Maybuye Azania Ntimane-Halama**, submitted in partial fulfilment of the requirements for the Master in Augmentative and Alternative Communication degree.

I believe that the research proposal meets with the grammatical and linguistic requirements for a document of this nature.

Name of Editor: Marietjie Alfreda Woods

Qualifications: BA (Hons) (Wits); Copy-editing and Proofreading (UCT); Editing Principles and Practice (UP); Accredited Text Editor (English) (PEG)

MA (Ricky) Woods

MA Woods

12 November 2023

Appendix F: Themes, subthemes and codes

Sub-aim	**Themes**	**Subtheme**	**Examples of codes**
1. Caregivers understanding of communication	**Receptive and expressive language**	Verbal communication	*It means to talk to each other*. P4.*It is when two people speak*. P7.
		unaided	*Yeah it's true. with action. When one feels pain, he cries and then you attend*. P1 *Yes, they communicate by actions. Hmm Okay. As I work with them, like, if... I can say she wants water; she'll go just grab the cup. So, we know that, okay, now she's thirsty, she wants water*. P2
2. Caregivers' knowledge of the communication needs of children with CCN	**Caregiver challenges**	Lack of AAC knowledge	*I've never heard of it. (After definition by interviewer): Oh, okay, I forgot. It's not the first time. We did from Department of Education.* P2 *I am a bit familiar with the name but I cannot make up where I heard it … (Interviewer interjects) . No. Because it is not long ago since we have received the tablets. Yes. At least… it can speak. There is this one who can point to it (the tablet), and react to it laughing as she does. Everything. Animals and everything else. She can understand it. But she… it is not long ago since we got these things from the Education*

			(Department of Education). But well, it is time. It is not that long ago when we got it. At least… I feel like it helps us a lot. But it is not all children who can understand it. Yes. You see. P6
3. Caregivers' knowledge of communication skills of children with CCN	**Beginning communicators**	Non-verbal communication Unaided informal AAC	*Yes, they communicate by actions. Hmm Okay. As I work with them, like, if... I can say she wants water, she'll go just grab the cup. So, we know that, okay, now she's thirsty, she wants water.* P2 *Who do not have speech? Yes, I do believe they can communicate physically. They communicate physically using their hands. Body language.* P7
4. Caregiver's views of their roles and responsibilities in supporting communication	**Support in daily routine activities**	Caregiving activities (bathing and feeding)	*In the morning we welcome them, we carry them from the transport, re yaba koka (English: we carry pick them up), we put them where we are supposed to and then we welcome one another. We've got boards with their names; we sing we pray and then 8h00 they get the breakfast. We wipe them, we change them the nappies, they get water and then after we prepare them to sing. For the day we sing, massage them, put others on the chair, it's a daily thing and then we've got time for lunch.*

			Re na le nako ya lunch (English: we have lunch time). And then after feeding we get water, we wipe them. Fortunately, others they go with the transport with the school children. Always about 14:15, 14:10 the transport starts to take them. till 4h00, but the thing is we have day shift and night shift for those who are sleeping. So, that's why that day shift must work until 4h00. We only have 3 hours to prepare for the night. And the night staff comes.. because it's 6 to 7. Re tsammaya ka 7 Ka 6, babangwe bat sena (English: We leave at 7 and then the next shift people enter at 6. P1
	Teaching role	Extension of caregiver roles	*What I would like to ask is about education, we are expected to teach these children. Ok, we are caregivers, maybe it is part of our job, but I feel like it is too much for us because we are doing a lot daily.* P3 *Okay, when we arrive at work, we start by, uh, we start by going to prayer, and then after, it's, uh.. breakfast for the kids, feeding the kids and then after then we have a programme where we teach them and then we have a time for, for teaching them and then for.. I have*

			time for music. It's many activities for music. Sometimes, sometimes they go outside to play. P2
	Caregivers' skills and communication strategies	Non-verbal communication (signs, real objects, gestures negative behaviour and crying)	*Uh, we normally talk to them, even though they can't communicate. We talk to them by actions, uh, by toys, so they can understand.* P2. *Okay, some of our children, you need to make them move because some they can see you and then whatever movement you'll be doing they'll be aware of what you're doing. So you need to, we communicate with them in a different way. Some, when you talk to them, they won't be able to respond but they can hear what you're saying. So now you need to know that this person I have to communicate physically with them, I have to communicate with movement with that child. So, you have to understand that their communication is not the same. So, yet some you just have to make your body movement and then they will see what you are talking about.* P4
		Caregivers training	*Students (university therapy students) used to train us. We would do positioning, feeding, exercises.* P1

			I attended education training. Yeah, educational only. The topics were about communication, how to handle autism, uhm how to handle autism patients, mentally and CP patients. P7
	Communication support role	Short staffing	*Communicating with them, I think that is the biggest challenge. In my department being the shortage of staff that makes us not to pay attention to the children in time.* P4