



CAREGIVERS' ROLES IN ENHANCING SOCIO-COMMUNICATION SKILLS IN CHILDREN WITH AUTISM SPECTRUM DISORDER IN A SELECTED NON-GOVERNMENTAL ORGANIZATION FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER, NAIROBI COUNTY, KENYA

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Abstract:

Caregivers (parents and guardians) of children with ASD play an integral role in early intervention for children with autism spectrum disorder (ASD) since they spend more time interacting and providing formal care for their children; they are supposed to provide early diagnosis and ongoing intervention to mitigate socio-communication challenges for their children. Some caregivers, however, lack knowledge and expertise on their roles in this resulting in miscommunication, unmet needs, and frustration. The purpose of this study was to establish caregivers' extent of involvement in Speech and Language Pathology Services (SLP) in enhancing the socio-communication skills of children with ASD. The study was guided by Structural Functional Theory (SFT) by Comte. The study adopted a descriptive survey design with a mixed-method research approach. It targeted a population of 38 respondents comprising of thirty-six caregivers, one occupational therapist from a nongovernmental organization of parents with ASD, and one Speech and Language Pathologist (SLP) outside a nongovernmental organization. The study employed a purposive sampling technique, and the pilot study was undertaken among caregivers of children with ASD b with the same characteristics as the target population. The key research instruments were questionnaires and face-to-face interviews. Quantitative data from closed-ended items were examined and coded. This was followed by analysis with the aid of SPSS version 26. The data was reported

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using descriptive statistics. Qualitative data were read repeatedly to establish patterns and then themes. It was reported narratively. Conclusions were drawn and necessary recommendations were made based on research findings. The research found that caregivers' involvement was critical in enhancing the acquisition of socio-communication skills. The study recommends government and non-governmental organizations of parents with ASD children promote more caregiver participation by creating more awareness of SLP services, recruiting more SLPs locally, offering comprehensive training, and coaching caregivers on SLP strategies.

Keywords: roles, caregivers, communication skills, collaboration, participation, engagement, involvement, speech and language pathologists, ASD

1. Introduction

Autism Spectrum Disorder (ASD) refers to a sub-set of neuro-developmental disorders characterized by socio-communication skill deficit, and repetitive motor behavior, (Ochuka, & Wairungu, 2024).). Although diagnosis can be made as early as 18 to 24 months in highly developed nations such as U.S.A., ASD is a lifelong condition with common symptoms detected at the age of three (Hymen *et al.*, 2020). There is currently 1 child with ASD in every 36 children (in America). This is according to the Autism and Developmental Disability Mentoring Network (Christian *et al.*, 2018). Not much is known about the prevalence of ASD in many developing countries. We do not have enough supporting literature of ASD prevalence in Africa (Mamah, 2022). According to the Autism Society of Kenya, as of 2007, 4% of Kenyans were diagnosed with ASD. Increased cooperation between developed and developing countries is urgently needed, particularly in Africa, to improve healthcare services, raise awareness, and reduce stigma and unfavorable perceptions. Additionally, there is a critical need for training support centers to be developed in Africa so that caregivers can receive the training they need to provide the best possible care for children with ASD (Kruk *et al.*, 2018).

One of the hallmark symptoms of ASD is socio-communication skill deficiencies. This challenges all facets of language and affects caregivers' (parents and guardians) interactions with their children. This leads to unmet needs and frustration (Alli *et al.*, 2015) for both individuals with ASD and their caregivers. Due to their limited capacity to articulate their thoughts and goals, children on the spectrum have difficulty with both receptive and expressive language. This sometimes leads to challenging behaviors. ASD lacks any specific biological indicators, therefore diagnosis is based mainly on clinical behavioral observations and caregiver accounts of social interaction, communication, and repetitive and restricted interests. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V, 2013), contains the criteria for diagnosing ASD which include deficits in social interaction, communication, and repetitive or restrictive patterns of behavior.

Early intervention is used to enhance the communication abilities of children with ASD by a multidisciplinary team. The team includes a physical therapist, a speech and language pathologist (SLP), an occupational therapist, and caregivers (parents and guardians). Speech and language pathologists (SLPs) assess and treat difficulties linked to speech and language as well as social skills and swallowing using evidence-based treatment methods (Strunk *et al.*, 2017). Caregivers of children with ASD are frequently the finest teachers and champions for their children because of their capacity to foster learning opportunities both at home and at school. Caregivers assist their children with ASD with early assessment, diagnosis, and continued intervention to remove obstacles to communication and improve social interaction. Although a multidisciplinary approach is of the utmost significance, it can be challenging to build an effective team, and many children with ASD get care from experts who do not coordinate care across specialties (Brown *et al.*, 2021). Additionally, caregivers of children with ASD claim that they are unaware of the possibilities for assistance that are available to their children (Strunk *et al.*, 2017).

Evidence-based communication intervention strategies have been created to address communication challenges in children with ASD in many developed countries. They include educational and therapeutic strategies (Park *et al.*, 2020). The most popular techniques include Applied Behavior Analysis (ABA) therapy (Wairungu, 2020). A study by Liang *et al.* (2020) found that ABA and Pivotal Response therapy enhanced socialization and expressive language, but did not detect receptive language. It was recommended that more research be conducted to pinpoint the precise potential of an ABA-based intervention for kids with ASD. The tools' value in therapy for better results was revealed in Treatment and Education of Autistic Related Communication of Handicapped Children (TEACCH) by Patricio *et al.* (2018), but they are generic tools, and this presents a challenge in the interventions currently being used. The Hanen Center recognized More Than Words program (MTW) which was created for caregivers of kids with ASD with the idea that caregiver involvement is the key to a child's language and communication development (Lok *et al.*, 2021). According to a meta-analysis study on Chinese families' caregivers found MTW program rewarding because there was a positive outcome of parent-child interaction, however evidence for this claim requires further studies for the pre-treatment caregiver role. There are other AAC tools available for people with expressive communication impairments to use in addition to or in place of speech (ASHA, 2016).

These intervention techniques described are crowned up by speech-language pathological services provided by SLPs, one of the healthcare services that is most well recognized globally. Notably, it is acknowledged in the U.K. and U.S.A., as described by Cummins *et al.* (2020) on the communicative demands of adolescents with ASD. The study report states that laws are continually being changed to address the communicative demands of kids with ASD. For children with ASD, there are still no proven methods for navigating their communication needs. Many difficulties are currently being faced by

SLP services in Sub-Saharan Africa, many of them are caused by a lack of SLP (Khoza-Shangaze *et al.*, 2021). Additionally, Gurayah & Fewester's (2015) study in South Africa on the difficulties caregivers face in interacting with kids with ASD shows a lack of general understanding of ASD and how it affects language. Additionally, there is a dearth of context-specific knowledge regarding the responsibilities of caregivers and the difficulties they encounter in addressing the communication difficulties of kids with ASD.

Speech difficulties in children with ASD are exacerbated by the lack of SLP services in low-income areas and the lack of knowledge about SLP services to improve communication in Kenya (Staley, 2021). According to Masaba *et al.*, (2021), barriers including knowledge gaps within medical systems have been shown to hinder caregiver participation, foster provider mistrust, lead to cultural disparities, and stigma, and prevent timely access to therapies. According to Cloete and Obaingwa (2019), efforts to address ASD-related needs and service provision have been hampered in Kenya by the absence of accurate prevalence records of ASD and the difficulties caregivers of children with ASD encounter in getting critical services.

Similarly, Masaba *et al.*, (2021) point out that the lack of adequate information on ASD conditions from medical personnel leads to desperation among caregivers who end up searching for any treatment option for ASD including witch doctors. Therefore, caregivers are unable to carry out their duties to help children with ASD who have communication deficiencies due to the underlying issues mentioned above (Tahtgur & Kang, 2021). Therefore, this study aims to determine caregivers' awareness of and involvement in fostering the communication abilities of children with ASD in the Kenyan environment.

2. Statement of the Problem

Children with communication difficulties have a hard time expressing their needs and wants, and worse even, they run the risk of being isolated from society. They therefore require early assistance to lessen their communication difficulties. Caregivers are more aware of their children's communication strengths and limitations; they play a crucial role in collaborating with speech and language pathologists (SLP) to reduce communication deficiencies in children with ASDs. Unmet demands, frustration, and ultimately service access are hindrances to collaboration between caregivers and SLPs which emerge from some caregivers being uninformed of their children's communication deficits with developmental milestones.

To address communication difficulties in children with ASD, caregivers are expected to schedule and plan for therapy visits, take part in therapeutic sessions, and attend frequent seminars. However, Kenya has a dearth of SLPs, and caregivers have little knowledge of speech and language pathology, which makes it difficult to be involved. It has also been discovered that the stigma attached to ASD children causes

parents to hide their children rather than seek appropriate services. Children with ASD continue to struggle with communication difficulties that significantly lower their quality of life due to a lack of coordination between caregivers and SLPs. They become dependent and unemployable, which causes them to continue to be a drain on society and the government as a whole. However, nothing is known regarding the level of caregiver engagement in Kenya, particularly in Nairobi, in reducing communication among children with ASD. The study may offer professionals and caregivers ideas for early intervention programs as well as strategies for successfully implementing speech and language pathology services in Kenya. Thus, the study seeks to assess the roles of caregivers in enhancing the communication skills of children with ASD.

2.1 Limitation of the study

There was concern that some respondents may fear freely sharing information owing to possible stigma associated with Autism in the immediate culture and community. Preliminary visits and lengthy informal interactions were used to build confidence and trust between the researcher and respondents.

2.2 Delimitation of the study

The study took place in Nairobi City County. It targeted parents and caregivers of children with Autism who are beneficiaries of services provided by a given non-governmental organization in Kenya. Only parents and caregivers of individuals between ages three and eighteen years were considered. One speech therapist and one occupational therapist practicing in Nairobi were also part of the respondents.

3. Caregivers' level of involvement in SLP services to enhance communication skills of children with ASD

Larkin *et al.* (2019) focused on the proposal provided by the National Research Council Committee of Education Intervention for children with ASD in their study of caregivers' ways of interacting with their ASD children in Spanish developing nations. The study aimed to help speech and language pathologists (SLPs) with knowledge on how to teach caregivers of children with ASD communication skills in a way that is sensitive to their culture. According to the recommendations, caregivers should be seen as their children's primary communicators and interventionists. In general, caregivers spend more time interacting with and teaching their children, so they are more aware of their communicative talents and limitations (Swanson *et al.*, 2020).

The ideal form of support for children with ASD involves a team of professionals who include speech and language therapists for communication rehabilitation, occupational therapists for motor and sensory integration, physical therapists for musculoskeletal and mobility, behavior therapists for behavioral problems, speech and language pathologists (SLPS) for evaluating and treating speech and language disorders,

social skills as well as swallowing using evidence-based strategies. According to Strunk, *et al.* (2017), all these professionals work collectively in providing, assessment diagnoses and interventions tailored to the individual child. However, the study notes that while a multidisciplinary approach is crucial, effective teamwork is difficult to develop and many children with ASD receive assistance from professionals who do not coordinate care across different specialties. Additionally, caregivers claim to be ignorant about the services that are offered to their children with ASD (Khoza-Shangaze *et al.*, 2021). Caregivers are expected to engage as partners through carrying out therapeutic activities with professionals. Professionals who administer early intervention gain a greater understanding of the individual nature of each family's strengths and needs as they gather reliable information from caregivers to improve communication outcomes. However, this cannot be the case if caregivers are unaware of service options available for their children to mitigate communication challenges (Reinhard *et al.*, 2008).

To reduce socio-communication difficulties in children with ASD, caregivers collaborate with speech and language pathologists. According to Cummins *et al.* (2020), on the communicative needs of adolescents with ASD in the U.K., speech and language pathology service is one of the healthcare services that is most widely recognized globally, especially in developed nations like the U.S.A. and U.K. According to the study, the law in the United Kingdom is still changing to address the communicative needs of children with ASD. As a result, there are still no established, clear-cut methods for navigating the communication demands of children with ASD, and more work has to be done (Cummins *et al.*, 2020). However, speech and language pathology service as a major healthcare for the navigation of socio-communication challenges in children with ASD should not be taken for granted. It plays a crucial role in increasing awareness of the direct benefits of children with ASD from SLP service as well as highlighting communication differences and ways caregivers can be involved.

According to the case study done on 12 caregivers on caregivers' perception of SLP services by Porter (2020), therapeutic alliances do not only exist between the SLP and the child but also with the caregivers for the SLP to provide optimal services. Poor collaboration between caregivers and SLPs results in the discontinuation of the intervention support. Caregivers need to make observations of their children who go through multiple referrals by the multidisciplinary team to legitimize the observations. Porter (2020) further, in his research, explains that communication skills training on feedback from caregivers is essential to enhance a positive attitude toward intervention and promote compliance with the intervention. The study also points out, that caregivers and therapists play a crucial role in enhancing socio-communication skills in individuals with ASD as they construct shared opinions on the communication intervention process through initiation of the therapy, decision making, and giving consent as well as maintaining the therapy.

A qualitative study on 10 caregivers of children with ASD was undertaken in South Africa by Alli *et al.* (2015) to explain the communication challenges parents

encounter when speaking to their ASD-affected children showed that, while therapy carryover was limited, caregivers were happy with the strategies the SLP gave. Despite the fact that SLPs and caregivers are at the core of service delivery in addressing the socio-communication requirements of children with ASD, numerous studies have revealed challenges to caregivers' participation. Fewster and Gurayah's (2015) study on the lived experiences and coping mechanisms of caregivers in South Africa found out a detriment to caregivers' access to SLP services due to the paucity of literature on public awareness of ASD and its implications for language. In addition, according to Khoza-Shangaze *et al.* (2021) study on the success and challenges of speech and language pathological service implementation in Western Kenya, caregivers are unaware of options available for SLP services since they are inadequate and can be only accessed in urban centers (Staley, 2021). Moreover, the caregivers who are aware lack the skills and preparation required to utilize SLP services to support the socio-communication needs of their children and hence may require targeted training and awareness creation. Khoza-Shangaze *et al.* (2021) study further highlight the knowledge gap within the medical system as another factor that prevents caregivers' involvement in speech and language therapy services to combat socio-communication difficulties in children with ASD resulting in service provider mistrust thus, the study suggests equity of speech and language health care services available and accessible in both minority and majority world context.

Obure (2018) in his research at Tenwek Hospital about caregivers' involvement in intervention programs for children with communication disorders reveals that caregivers' frequent interaction with their children in a more unstructured and natural atmosphere strengthens their bond and emotional attachment. The research also points to the necessity for speech-language pathologists and caregivers to develop suitable communication methods to support a child with ASD to achieve functional communication. Obure (2018) also reveals that some caregivers lack understanding of the procedure and importance of clinic appointments, while others lack knowledge of the disorder and repercussions of noncompliance. Gona *et al.* (2016) in the study carried out in Kilifi on investigating coping strategies of parents of children with ASD concluded that inadequate information on SLP services, knowledge gap among medical personnel, unavailability of SLP services, financial constraints, and other competing priorities decrease the chances of caregivers seeking relevant services. Instead, the caregivers look for any available treatment option for individuals with ASD including witchdoctors.

Knowledge is of great importance in designing community-based interventions where caregivers play a vital role in the implementation and evaluation of an intervention. Individual stress and burdens that caregivers experience when seeking healthcare services and providing direct assistance in daily activities and adjustment issues may also be a hindrance to caregivers in achieving communication skills in ASD children as stated by Cloete *et al.* (2019). The caregivers' participation is deemed to be a breakthrough in the early intervention framework, though the literature on the aspect of

their role is limited. The current study focuses on establishing the level of caregivers' involvement in SLP services to improve communication skills in children with ASD.

4. Materials and Methods

This is a mixed-method research that adopted a descriptive research design. A descriptive research design allows the researcher to describe the phenomena in their natural environment without manipulation of variables (McCombes *et al.*, 2022). The design was appropriate because it allowed the researcher to collect information from the subjects in their natural environment without being obtrusive (Hatch, 2002). The study used an accessible population of 32 respondents comprising 30 caregivers who seek services at a non-governmental organization of parents with children with ASD and two therapists, one occupational therapist (OT) who is a member of the nongovernmental organization, and one speech and language pathologist who was not a member. The study employed a purposive sampling technique and used all accessible populations. Data was collected by administering questionnaires to the caregivers and interview guides to the therapists. Interviews were conducted recorded and transcribed. Member checking was conducted to ensure the credibility and trustworthiness of qualitative data (Birt *et al.*, 2016). Quantitative data from closed-ended items in the questionnaire were examined and coded. This was followed by analysis with the aid of SPSS version 26. Data was then presented using descriptive statistics. Qualitative data from the open-ended items from caregivers' questionnaires and interview guides from the therapists were thoroughly examined and read repeatedly to identify patterns and themes. Data were reported narratively (Hatch, 2002).

5. Discussion and Results

5.1 Caregivers' extent of involvement in SLP services to enhance socio-communication skills of children with ASD

The study sought to establish the extent of caregivers' involvement in SLP services to enhance the socio-communication abilities of children with Autistic Spectrum Disorder. Both quantitative and qualitative data were collected from the caregivers and therapists respectively. The quantitative data collected from the caregivers is based on two items assessing caregivers' knowledge of SLP services, and if SLP services are beneficial in improving communication skills in their children with Autistic Spectrum Disorder.

Table 1.1 below shows researchers' findings from the responses of caregivers that were recorded.

5.2 Knowledge of SLP services to enhance communication abilities in children with ASD

Table 1.1: Caregivers knowledge of SL services to enhance communication skills

	No		Yes	
	Freq.	%	Freq.	%
Do you have any knowledge about SLP services?	11.0	36.7	19.0	63.3
Do you think SLP services are useful in improving communication with your child?	1.0	3.3	29.0	96.7

Table 1.1 above clearly shows that less than half 11 (36.7) of the respondents did not know about the existence of SLP services while slightly more than half of the respondents 19 (63.3) knew about SLP services. They had sought the services and acknowledged their involvement helped to improve the interaction with their ASD children. On a more contradictory note, Khoza-Shangaze *et al.* (2021) in the study of the success and challenges of speech therapy in Western Kenya claimed caregivers are ignorant of the services that are offered to their children with ASD. The study findings reveal that the majority of the caregivers were informed of ASD services available for their children. This might be a benefit accrued by the membership of the non-governmental organization. A similar observation was made by Obure (2018).

5.3 Caregivers' level of involvement in SLP services

Table 1.2 shows caregivers' level of involvement in enhancing socio-communication skills in children with ASD. A five-point Likert scale was used to measure the level of caregivers' engagement in the intervention process. The 6 items on caregivers' involvement were positively stated with the responses ranging from Never 0, Rarely 1, Sometimes 2, Very 3, and always 4. Never coded as 0 implying no engagement hence ineffective communication while always coded as 4 implying the highest level of engagement hence effective communication as shown in Table 1.2. below.

From the result above in Table 1.2, it can be observed that almost half of the caregivers 13 (43.3) confirmed that they were always involved in speech and language therapy services for their children. On the same note, slightly less than half of the caregivers 11 (36.7) rated that they were very involved in the therapy process. The result implies that the caregivers play a vital role in the early intervention process and that their consistent engagement is of great importance as stated by Loos *et al.* (2020). To attain substantial caregiver involvement, the therapists need to engage in discussion with the caregivers on decision-making and feedback from therapy sessions. The findings of the current study are also supported by Porter *et al.* (2020). They assert that communication skills training and feedback from caregivers are essential to enhance positive attitudes towards intervention. It also promotes compliance with the intervention.

Table 1.2: Showing caregivers' level of involvement in SLP services

Items	Never	Rarely	Sometimes	Very	Always
	F(%)	F(%)	F(%)	F(%)	F(%)
Do you seek speech and language therapy services for your child?	1(3.3)	5(16.7)	11(36.7)	11(36.7)	13(43.3)
Do you express your concern to the speech therapist?	1(3.3)	1(3.3)	3(10)	13(43.3)	12(40)
Does the therapist explain the communication challenges to your child?	1(3.3)	1(3.3)	3(10)	13(43.3)	12(40)
Are you given some instructions on how to continue with the therapy outside therapy sessions?	0(0.0)	1(3.3)	5(16.7)	13(43.3)	12(40)
Do you adhere to the instructions given for treatment by the therapist?	2(6.7)	5(16.7)	5(16.7)	4(13.3)	11(36.7)
Do you have therapy appointments regularly?	1(3.3)	2.(6.7)	8(26.7)	13(43)	8(26.7)
Would you be willing to attend a workshops and seminars concerning speech and language therapy?	1(3.3)	0(0.0)	0(0.0)	2.(6.7)	26(86.7)

More than half of the caregivers indicated that they were always engaged. They were occasionally given a chance to explain the problem of their children. It can also be observed that nearly two-thirds of the caregivers confirmed that the therapists always explained to them the condition of the child before carrying out the intervention. More than a quarter of the caregivers also indicated that therapists were committed to giving explanations. However, less than a third of the caregivers reported sometimes the information from therapists was insufficient and did not yield positive results.

Throughout the research, several common themes emerged, highlighting the majority of parents' sentiments towards SLP and its impact on their children's communication skills. A recurrent notion among the parents is the belief that SLP services can train children to articulate words correctly and improve their overall communication abilities. This idea reflects the parents' recognition of the significant role SLPs play in developing speech and language skills in children. The parents who had not personally utilized these services expressed uncertainty regarding the usefulness of SLP therapies due to a lack of personal experience. The current study concurs with the study conducted by Cummins *et al.* (2020) on the communicative needs of adolescents with ASD in U.K. It observed that speech and language pathology services are a major healthcare service for the navigation of communication deficits in children with ASD and should not be taken for granted.

The research findings reveal that language therapy services aren't one-size-fits-all as stated by Banire *et al.* (2023). SLP assists children with speech impairments to develop alternative forms of communication tailored toward individual communicative needs. Below is a response from one of the parents.

“Speech therapy has helped my child to increase some vocabulary and also has learned how to articulate those words. Now my child can produce some sounds of speech although are not clear but we can use them to communicate and also, he uses some gestures.”

Parents expressed that SLP services can enable nonverbal children to learn how to express themselves using gestures or other nonverbal means. This enhanced their ability to communicate effectively. Furthermore, caregivers highlighted that SLP services not only facilitate speech development but can also help improve social skills and functional communication in their children. One parent wrote

“Speech therapy has helped my child to use gestures such as pointing and also, he has improved on concentration span and turn-taking. “

The majority of the caregivers shared positive outcomes that their children have achieved through speech and language therapy services. These include increased vocabulary, the ability to produce sounds and words, the use of gestures and pointing, and the development of social skills. Additionally, parents reported advancements in their children's ability to engage in turn-taking and improved attention and concentration spans, indicating positive effects on their overall communication abilities. While the majority of feedback was positive, there were a few parents who expressed dissatisfaction with the impact of SLP services on their child's speech development. They noted that despite attending several sessions, their child's speech did not significantly improve and the therapist was harsh, leading them to discontinue therapy.

“I used to go but there was no improvement in communication for my child. I attended several sessions but did not give good results as far as communication with my child was concerned and I gave up.”

This perspective highlights the importance of individual differences and varying progress rates in therapy outcomes. The caregiver-therapist relationship seems to be a key factor for caregivers' engagement which includes the process of inquiry for diagnosis, decision-making, examination prescription, and treatment. Porter (2020) in the case study of 12 caregivers on caregivers' perception of SLP services emphasized how poor collaboration between caregivers and SLP results in the discontinuation of the intervention support.

In summary, the majority of caregivers' responses recognized the potential benefits of SLP services in enhancing their children's communication skills. The caregivers recognized the importance of alternative forms of communication, improvements in speech and language, social skill development, and the utilization of gestures and pointing. However, it is also important to note that therapy outcomes can

vary among individuals, highlighting the need for consistent attendance and understanding that progress rates may differ.

5.4 Types of caregivers' involvement to support communication abilities of children with ASD

Table 1.3: Types of caregiver involvement to support communication abilities

Type of Involvement	Frequency	%
Attending therapy	15	50
Attending seminars and workshops	5	16.67
Communication with the therapist in decision-making	16	53.3
One-on-one instruction	16	53.3
Counseling sessions	9	30

Table 1.3 above displays various ways caregivers are involved in enhancing communication skills in their children. Half of the caregivers 50% engaged in speech therapy, and slightly more than half of the caregivers 53.3% participated in one-on-one instruction and also had mutual communication on decision-making. More than a quarter 30% of the respondents attended counseling sessions while less than a quarter 16.7% attended seminars and workshops. From the research findings, the current study concurs with the previous studies that caregivers play a key role in communication interventions for their children with ASD. They contact their children more frequently and formally, and as a result, they are more cognizant of their strengths and limitations in terms of socio-communication (Swanson, 2020). However, the responses given by some parents reflect the barriers they faced in accessing Speech-Language Pathology services (SLP) for their children. These barriers were predominantly centered around financial constraints, limited availability of services, social stigma and children being over age.

"Sometimes I could not go for the therapy services because I lacked money for the therapy services because other children needed to be catered for. Also, they were very expensive and the distance was long." (Caregiver)

Many parents expressed their inability to continue with therapy due to financial difficulties. They mentioned that the therapy services were expensive and they did not have sufficient funds to afford the sessions. Additionally, some parents stated that they had other children with needs that required financial attention, making it challenging to allocate resources to SLP services. The cost of therapy is a significant factor in the majority of cases, preventing them from accessing the necessary services for their children. On the other hand, both SLPs and OT during the interview guide discussed almost similar challenges that they faced when enhancing socio-communication skills. Financial

constraints were a major concern, as some parents struggled to afford the cost of therapy services.

Another critical aspect highlighted by the majority of caregivers was the distance and limited availability of SLP services. They mentioned that the therapy centers were located too far away, making it difficult to reach them. Some parents also noted that the services were only accessible in private hospitals, which further limited their options. In these cases, the combination of distance and exclusivity posed significant challenges for parents to access SLP services for their children.

"...the distance was long and fare on a weekly basis was a challenge". (Caregiver)

On the other hand, a minority of caregivers mentioned their lack of awareness about speech and language therapy services. They stated that they did not have information about these services, which prevented them from seeking help for their children's communication difficulties. Additionally, a few parents expressed their disappointment with the effectiveness of the therapy sessions, stating that they attended several sessions but did not witness significant improvements in their child's communication skills. This is consistent with Cloete *et al.* (2019) who asserted that knowledge gaps among medical personnel hamper caregivers' access to crucial services to support the communication abilities of their children. Individual stress and burdens that caregivers experience when seeking healthcare services and adjustment issues may be a hindrance to caregivers in enhancing communication skills in ASD children.

In summary, the majority of parents faced financial barriers and limited accessibility to SLP services, which prevented them from seeking therapy for their children. They highlighted the expenses involved in therapy sessions, the competing needs of other children, and the distance to therapy centers as significant obstacles. On the other hand, a minority of caregivers mentioned their lack of awareness about SLP services, and a few expressed dissatisfaction with the effectiveness of the therapy sessions and were discouraged by speech since their children were over-age and delayed in seeking early intervention.

5.5 Speech and language therapist (SLP) and occupational therapist

During the interviews with an occupational therapist (OT) and speech and language therapist (SLP), several themes emerged regarding caregivers' needs and challenges to enhancing socio-communication skills in their children. Occupational therapists expressed the need to help caregivers achieve speech and language goals and emphasized the importance of training and coaching caregivers to be acquainted with skills and knowledge to support their children's communication. They also highlighted the benefit of home-based program activities assigned by the occupational therapist and speech therapists, to support therapy carry over until the appointment. The study is

supported by Strunk *et al.* (2017) who asserted that a multidisciplinary approach is of utmost significance in the mitigation of communication challenges of children with ASD.

During the interview guide with the speech therapist, they both emphasized the importance of caregivers acquiring skills transfer to effectively support their children's communication development. She believed that caregivers, who spend extended periods of time with their children, are in the best position to provide immediate support and understand their socio communication abilities. Information provided by caregivers helps SLPs devise appropriate interventions to suit each child. This is supported by Swanson (2020) and Poter (2020). Additionally, therapists educated caregivers on tools and resources they could use at home to further support their children's communication, such as engaging in parent-child therapy activities. Some caregivers were however reported not to be very collaborative.

"Some younger caregivers don't want to get tired and disturb themselves, therefore they claimed continuing with therapy activities at home was tiresome and the strategies were complicated. They also claimed lack of time due to busy schedule at work." (Speech therapist)

Time constraints were also mentioned, particularly for full-time working parents who found it difficult to schedule therapy appointments for their children. Lack of awareness about the importance of speech therapy and limited availability of speech therapists in the country were additional hurdles identified by the minority. It was reported that some caregivers expressed a preference for immediate results and a focus solely on verbal communication, overlooking the significance of alternative means of communication and social skills development.

"Some caregivers want immediate results. They want to hear their children communicating verbally almost instantly. They lack patience and they don't value any alternative means of communication other than verbal."

The themes that emerged from these interviews highlight the importance of caregiver involvement and support in both OT and SLP settings. Key themes include the need for training and coaching, skills transfer, observation of therapy sessions, and education on tools and resources for communication support. Furthermore, the interviews shed light on challenges such as limited access, lack of awareness, cost, and various barriers, including time constraints and competing needs.

In conclusion, there is a clear need to address these themes and challenges to better support caregivers and their children in achieving speech and language goals. Increased awareness, improved availability and accessibility of speech and language pathology services, cost-effectiveness, and recognition of alternative means of communication and social skills development are crucial for empowering caregivers and promoting effective

communication support at home as stated in various studies (Gona et al., 2016, Kang et al., 2021., Poter et al., 2020, Cloete et al., 2019, Khoza Shangaze et al., 2021). It is essential for stakeholders, including speech and language pathologists, policymakers, and the government, to collaborate and take proactive measures to address these needs to enhance the overall development and well-being of children with communication difficulties.

6. Summary, Conclusions and Recommendations

The study aimed to establish the extent of caregivers' involvement in SLP services to enhance the communication abilities of children with autism spectrum disorder. The research assumed caregivers being aware of their roles and actively being involved in SLP services help to mitigate the communication deficits of their children with ASD.

6.1 Summary of the study findings

According to the research findings more than half of the caregivers had knowledge of SLP services and sought speech and language therapy services while slightly less than half were not aware of speech and language therapy services. On the other hand, the majority of the caregivers indicated a high level of involvement in the intervention process. The research results further showed a majority of the caregivers recognized the benefits of SLP services in improving the communication abilities of their children. These include speech development, alternative forms of communication, social skills, and functional communication. However, some parents expressed dissatisfaction highlighting individual differences in therapy progress, and also the therapists expressed a lack of cooperation by some caregivers during therapy sessions. They expected instant outcomes. Barriers to accessing SLP services included financial constraints, limited availability, long distances to therapy centers, lack of awareness, and dissatisfaction with therapy effectiveness.

6.2 Conclusions

The research findings reveal that the majority of the caregivers are aware of speech and language therapy services and are involved in seeking therapy services to enhance communication abilities in children with ASD. Caregiver involvement and support are found to be crucial, including training, coaching, observation of therapy sessions, and training on tools and resources for communication support. Addressing these themes and challenges is essential to empower caregivers and promote effective communication support at home.

6.3 Recommendations

There is a need for government and non-governmental organization to collaborate in promoting awareness, training more speech therapists and funding therapy sessions

through free insurance. Many caregivers cannot afford to consistently pay for therapy. There is also a need for both local and county governments to work in collaboration to support parents and caregivers of individuals with ASD including making appropriate policies. More funding is necessary to enhance research on socio-communication challenges and culturally responsive intervention strategies.

Conflict of Interest Statement

The authors hereby declare no conflict of interest. Neither of them works for the institution of research and none of them is affiliated with it in any way. No financial or any other form of benefit was accrued from the institution or any other source for the purpose of the research.

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