

Decoding the Support Needs of Parents of Children with Autism in Kenya

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<https://doi.org/10.51867/ajernet.6.1.46>

ABSTRACT

Online social forums have been used by parents of children with disabilities as a support system where they freely share information, experiences, and their worries. The objective of this study was to examine the kinds of social support sought or received by parents of children with autism in Kenya, in order to understand their care and support needs. Data in the form of chat messages was collected from a parents WhatsApp forum by downloading it through the group administrators. Drawing on the social support theory, the study utilized the content analysis method to analyze the chat messages posted by parents. A deductive approach was employed to code the data into various themes using the Social Support Behavior Code. The study findings revealed that most parents of children with autism sought and received emotional support, followed by informational support. In addition, the study established that the needs of parents of children with autism revolved around finding solutions related to their children with autism, mainly focusing on behavior management, access to education and addressing delays in developmental milestones. Further, parents' conversations revealed a need to know how to deal with the high burden of care associated with nurturing a child with autism. The study concludes that parenting and caring for a child with autism is associated with a high burden of care and imparts on the wellbeing of the parent. The study thus recommends the design, testing, and implementation of parental support programs to meet the emotional and informational support needs of parents. The study also recommends concerted efforts by stakeholders to develop a behavior management toolkit to support the parent in nurturing care, and establishment of respite centers for parents to relieve the high burden of care.

Keywords: Autism Spectrum Disorder (ASD), Behavior Management, Caregiver, Parents of Children with Autism, Social Support

I. INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social and communication behavior, restricted activities and interests, repetitive patterns of behavior, as well as sensory abnormalities (Faja & Dawson, 2017; Hirota & King, 2023; American Psychiatric Association [APA], 2013). These impairments are identifiable beginning early in life (American Psychiatric Association, 2013; Lord et al., 2020). Globally, the reported prevalence of autism ranges between 1% and 2% (Maenner et al., 2023; Zablotsky & Black, 2020), with higher estimates observed in high-income countries. For instance, the Centers for Disease Control and Prevention reports that ASD affects one in every 36 children. Children and adolescents with ASD typically require support and interventions that address behavioral, educational, health, leisure, and family needs (Hyman et al., 2020; Demir & Arslankaya, 2024).

While robust prevalence data exists in many parts of the world, there is limited specific data on ASD in sub-Saharan Africa. Nevertheless, it is essential to note that autism affects people from all racial, ethnic, and socioeconomic backgrounds (Shaw et al., 2021). In the African context, the challenges of diagnosis, limited resources, and varied cultural perceptions underscore the need for tailored interventions and support systems for families affected by ASD.

In Kenya, as in many African nations, the challenges associated with raising a child with ASD are compounded by factors such as limited access to specialized services, educational barriers, and socio-economic constraints. Nurturing children with ASD is associated with greater parenting stress compared to parenting typically developing children or

those with other developmental disabilities (Hayes & Watson, 2013). Parents and caregivers often face a high burden of care, which may result in heightened stress, depression, social isolation, anxiety, and even financial challenges (Khusaifan & El Keshky, 2021; Shattnawi et al., 2021; Hermaszewska & Sin, 2021; Scheerer et al., 2024; Burrell et al., 2017; Tathgur & Kang, 2021). This burden may also lead to reduced participation in social and leisure activities, further aggravating psychosocial difficulties (Walton, 2019).

Autism can be likened to a spectrum of colors produced when white light passes through a prism – violet, indigo, blue, green, yellow, orange, and red. Each child on the autism spectrum represents a unique color, thereby necessitating individualized approaches to care and intervention (Milton et al., 2021). Despite the myriad challenges, the negative effects of these stressors can be mitigated by effective social support (Shepherd et al., 2020; Ault et al., 2021). Research suggests that addressing the social support needs of parents should be prioritized to promote both their physical and mental well-being (Robinson & Weiss, 2021; Melrose et al., 201).

Given the full-time responsibility of caring for a child with ASD, many parents in Kenya experience severe strain, which affects not only their well-being but also their ability to secure necessary interventions for their children. Families remain the primary source of support, and thus understanding the social support needs of these parents is imperative for both research and practical intervention (Lord et al., 2020; Hyman et al., 2020).

1.1 Statement of the Problem

Caring for a child with autism has been associated with a high burden of care. This may in turn have a detrimental effect on the psychosocial wellbeing of the parents who are the overall caregiver and spend most of the time with the child (Tathgur and Kang, 2021). In Kenya, parents of children with autism often encounter stigma, financial and caregiving burden when nurturing their child with autism (Masaba et al., 2021). This may be aggravated by lack of formal knowledge on what to expect, what to do, where and when to seek help.

Parents of children with autism in Kenya are the primary caregiver for their children and therefore continue to bear the burden associated with raising a child with autism (Osoro, 2019). This situation puts parents at risk of stress, depression and related mental health challenges. It is therefore imperative to explore evidence-based social support mechanisms that would help alleviate this burden on the parent, while leveraging on the technological advancements.

The growth in online social platforms and the internet has increased the demand for online social services (Sahoo & Gupta, 2019). Organized social groups and virtual communities have entered the quickly expanding online space (Symon & Walker, 2023). However, the use of online social space by persons with disabilities or by caregivers and parents of children with disabilities in Kenya is still an area with limited research evidence.

This study sought to examine the different kinds of social support sought or received by parents of children with autism through their online WhatsApp group, to provide a good understanding of their social support needs, and to inform policy and practice in the field of social support for parents and families of children with disabilities.

1.2 Research Objective

To examine the kinds of social support sought or received by parents of children with autism through an online WhatsApp platform.

II. LITERATURE REVIEW

2.1 Theoretical Review

2.1.1 Social Support Behavior Theory

The social support behavior framework guided the study. The social support behavior code (SSBC) was originally developed by Cutrona and Suhr in 1992 and later modified for online use by Coulson and Greenwood (2012). This study adopted the modified version of the SSBC code for online content.

The SSBC consists of five main social support categories that are divided into twenty-three subcategories. The five main social support categories are: informational support, emotional support, esteem support, network support and tangible aid. According to the code, informational support entails receiving help related to advice, referral or situational appraisal. Emotional support is help related to encouragement, sympathy, empathy and affection. On the other hand, esteem support relates to giving compliments, validation and relief of blame. Network support is about linking with new people, presence during difficult times, and companionship. Finally, tangible aid is about the help received including monetary and in-kind either directly or indirectly (Coulson & Greenwood, 2012). Table I shows the 23 sub-categories and their descriptions.

The SSBC suits this study since it lays out social support categories that relate to study participants experiencing a high burden of care, such as parents and caregivers of children with ASD. The SSBC informed the analysis process by guiding the coding and analysis of the data collected from the parents' WhatsApp group into the various categories and subcategories defined in the code.

Table 1
Social Support Behavior Code

Support type	Definition
Informational support	Definition
Advice	Provides ideas or suggestions for action
Referral	Refers the recipient to other sources of information or help
Situation appraisal	Helps reassess or redefine the situation being faced by the recipient
Teaching	Offers detailed information, facts or news
Emotional support	Definition
Relationship	Conveys the importance of closeness
Physical affection	Offers physical contact, such as hugs and kisses
Confidentiality	Keeps the recipient's problem in confidence
Sympathy	Sorrow or regret for the situation faced by the recipient
Understanding/Empathy	Expression of understanding of the situation or discloses similar experiences in a way that conveys understanding.
Encouragement	Provides the recipient with hope and confidence
Prayer	Offers prayer for the recipient
Esteem support	Definition
Complement	Saying positive things about the recipient
Validation	Provides agreement with the views of the recipient
Relief of blame	Alleviates any feeling of guilt the recipient has about the situation
Network Support	Definition
Access	Provides the recipient with access to new people
Presence	Offers to be there
Companions	Reminds the recipient that others share similar experiences and are available
Tangible aid	Definition
Loan	Lend money to the recipient
Direct task	Offers to do a direct task
Indirect task	Offers to take over a task from the recipient while they are stressed
Active participation	Offers to join the recipient in an activity
Willingness	Offers or expressions of desire to help

2.2 Empirical Review

Social support appears to buffer the detrimental effect of symptom severity associated with raising a child with ASD. It should be considered when delivering care and support interventions to parents and caregivers of these children (Feng et al., 2022). Formal and informal social support have been studied, and their effects have been documented. In a study by Shepherd et al. (2020), informal social support and social media were perceived as more helpful than formal support. Drogomyretska et al. (2020) investigated the relationship between perceived social support and parental stress. Their results indicated that perceived social support from friends was the most important factor in protecting against stress.

Khusaifan and El Keshky (2021) studied the impact of social support as a moderator between parental stress and life satisfaction among parents of children with ASD. Their research established that social support moderates the relationship between family stress and life satisfaction. They recommended that social support, including the use of social media groups, be considered in supporting parents of children with ASD facing stress. Robinson and Weiss (2021) examined the stress-buffering effects of perceived and received support and established that both types of support were significantly associated with less reported stress.

With technological advancements, increased internet use, and the growing accessibility of online social platforms, there has been an increased demand for online services, expanded social networks, and the creation of online forums. Online settings provide new ways of supporting people seeking online services such as health care, information, and social support.

Online forums consist of a group of individuals with a common interest or a shared purpose, whose interactions are governed by policies in the form of rules; who have ongoing and persistent interactions; who use electronic communication as the primary form of interaction to support and mediate social interaction and facilitate a sense of togetherness (Bronstein, 2017). Online forums provide a dynamic environment where individuals share valuable informal information, discuss social, mental, and health-related topics, offer and receive emotional support, learn how

other people have dealt with problems through experience sharing, and receive informational support (Smedley & Coulson, 2017; Bronstein, 2017).

Participants of online forums are both the producers of social support content and the consumers (Smedley & Coulson, 2017). For instance, through online social forums, parents and caregivers of children with ASD can learn from each other, interact with professionals, and possibly get social support (Bi et al., 2022). This is why these online social support forums are created for participants to interact with each other by posting messages and reading replies (Smedley & Coulson, 2017; Smedley et al. 2015).

A qualitative study by Reinke and Solheim (2015) provides insights into the online social support experiences of mothers of children with ASD. The researchers highlight the importance of the internet and associated online activities as vital sources of emotional and informational support for this population. Given that an ASD diagnosis does not explicitly describe the level of autism gradation or symptom severity, mothers often face uncertainty and a heightened need for information and support. The study underscores the emergence of an understanding about the significance of online social support networks, which enable mothers to access valuable information as well as emotional validation and connection when navigating the challenges of caring for a child with ASD.

Through the analysis of content generated through online interactions, researchers can study different topical issues discussed, experiences shared, and the different coping strategies employed by the participants in addressing social issues facing them (Smedley & Coulson, 2017). The current study examines the kinds of social support sought or received by parents of children with ASD as expressed in an online forum.

2.3 Conceptual Framework

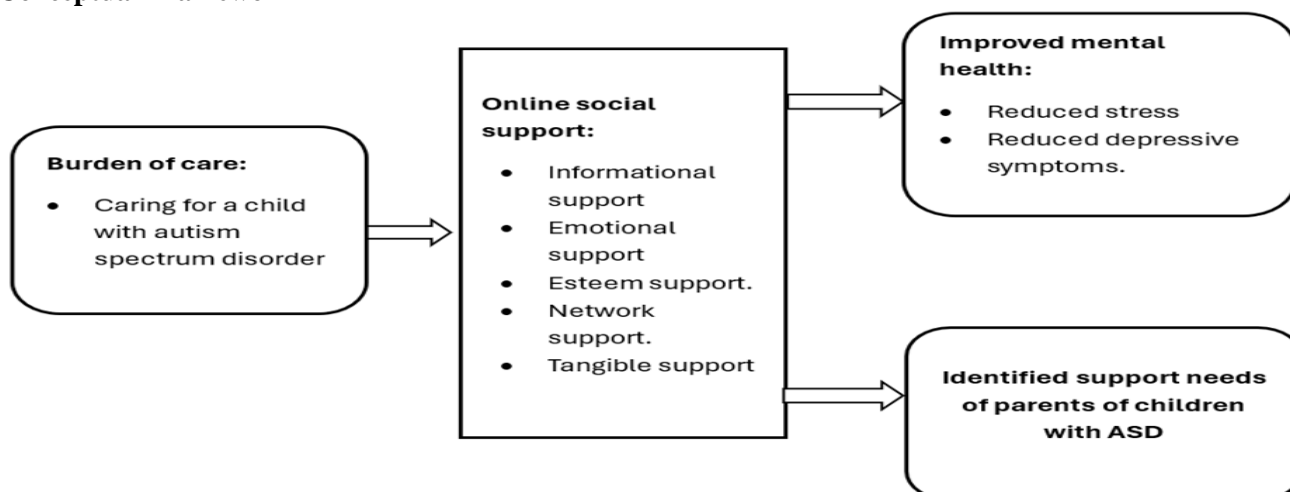


Figure 1

Conceptual Framework

Source: Authors (2024)

This study argues that in the context of a perceived stressful event such as raising a child with autism spectrum disorder, online social support acts as the mediating factor. Improved mental health and identified care and support needs of the parents become the perceived outcome. It is important to understand the support needs of parents of children with ASD, particularly in SSA, where evidence of such needs remains scarce. Understanding the support needs could lead to more targeted interventions for these parents. Online forums can offer a good opportunity to understand the support needs of parents of children with ASD. For instance, they give a safe space for parents to express themselves more freely. We relied on the WhatsApp online forum for parents with children with ASD to investigate their support needs.

III. METHODOLOGY

3.1 Research Design

The study utilized quantitative and qualitative content analysis methods to analyze online messages posted by parents of children with ASD. Content analysis was chosen since it provides a systematic and objective means of describing and quantifying phenomena (Elo & Kyngäs, 2008). In addition, content analysis was used for this study to make valid inferences from online parents' data, to provide knowledge, new insights, a representation of facts and a practical action guide.

3.2 Target Population

The target population consisted of Kenyan parents of children with autism spectrum disorder belonging to an online social forum. The WhatsApp forum from which this data was collected was started in 2019 by Jacqueline Mathaga as an initiative of Arthur's Dream Autism Trust (ADAT). The forum aimed to connect parents and caregivers of children with disabilities across Kenya, providing a supportive community for shared learning, self-advocacy, and access to essential resources. The creation of this forum was informed by the need to bridge gaps in knowledge, facilitate peer support, and advocate for the rights and well-being of children and adults with disabilities. At the time of conducting this study, the online parents' forum (community) consisted of four WhatsApp groups of parents of children with different types of disabilities, with an average of 300 parents per group.

3.3 Sample Size and Sampling Procedures

Parents of children with autism, belonging to group 3 of the WhatsApp community were purposely selected for this study. This group was considered since it had consistent postings relating to autism spectrum disorder.

3.4 Data Collection Procedures

Data in the form of online chat messages was collected from an online forum (WhatsApp) consisting of Kenyan parents of children with disabilities. Specifically, data was collected from group 3 of the parent's community. The data collection process involved exporting the data from the WhatsApp group by the group administrator and sharing with the principal investigator via email. The data was then saved in a word processor and was cleaned following a set of inclusion criteria.

Inclusion criteria

For content to qualify for this study and proceed into the analysis stage, it had to meet the following inclusion criteria: messages posted between May 2023 and April 2024 so as to give a round-the-calendar picture of parents' social support needs; messages about autism; messages on social support and messages in English or Kiswahili because these were the most used languages in the group as well as the official national languages in Kenya.

3.5 Data Analysis

Content analysis was used to examine the kinds of social support sought by parents of children with autism. It was possible to distill and code textual data into categories through content analysis. Simple statistics were used to summarize the data by counting the number of occurrences in each category (Krippendorff, 2018; Smedley & Coulson, 2017). A deductive approach was employed to code the data into various themes using the Social Support Behavior Code (SSBC).

Analysis Process

Data processing started with cleaning the harvested content to remove content that was not related to autism. Two researchers read the messages and deleted the content that was not related to autism. This was followed by anonymizing the content, removing any personal identifiers such as the names of the parent or of the child.

After this, textual content was classified into various social support themes and sub-themes as per the social support behavior code. This process involved two researchers thoroughly reading and re-reading the text before placing it under the agreed theme or sub-themes, clearly labeled column-wise in a spreadsheet. Whenever there was a disagreement on where to place a text, a third researcher was involved to ensure the text was placed in the best-fit theme. Descriptions for each theme and sub-themes, as defined by Coulson and Greenwood (2012) were followed closely throughout the coding process.

A total of 325 text messages that met the inclusion criteria were distilled and coded into categories. The number of occurrences in each category were then counted to produce simple statistics consisting of frequencies and percentages for the five themes and 23 sub-themes (see appendix I).

3.6 Ethical Considerations

The study was conducted in accordance with the Declaration of Helsinki revised in 2013 and the study protocol was approved by the African Medical and Research Foundation's Ethics and Scientific Review Committee (AMREF-ESRC:P1767/2024). In addition, full disclosure was made to the parents through their WhatsApp group about the purpose of the study, and informed consent was obtained from the parents, caregivers and administrators of the online WhatsApp forum. Further, the anonymity of the online forum and that of the participants was observed through removing potentially identifiable information such as names. The researchers accessed the data in its raw form and then anonymized it by removing personal identifiers before analysis and reporting. For instance, the quotes were reported anonymously without identifying the participant's name. In addition, participants were assigned pseudonyms to conceal their real identity. Confidentiality was duly followed in managing private information collected from the online social forum. For instance, the researchers signed a binding data confidentiality agreement before handling any data.

IV. FINDINGS & DISCUSSION

4.1 Response Rate

The study sought to establish the kinds of social support sought or received by parents of children with autism through an analysis of messages posted in an online social forum. The findings revealed that parents of children with autism sought/received different kinds of social support, such as informational, emotional, esteem, network, and tangible aid. Findings further indicate that the majority of the parents of children with autism mainly receive emotional support, followed by informational support. On the other hand, tangible aid and network support were the least sought social support (see Figure 2). It can therefore be deduced that the social support needs of parents of children with autism are majorly the need for emotional support and need for informational support.

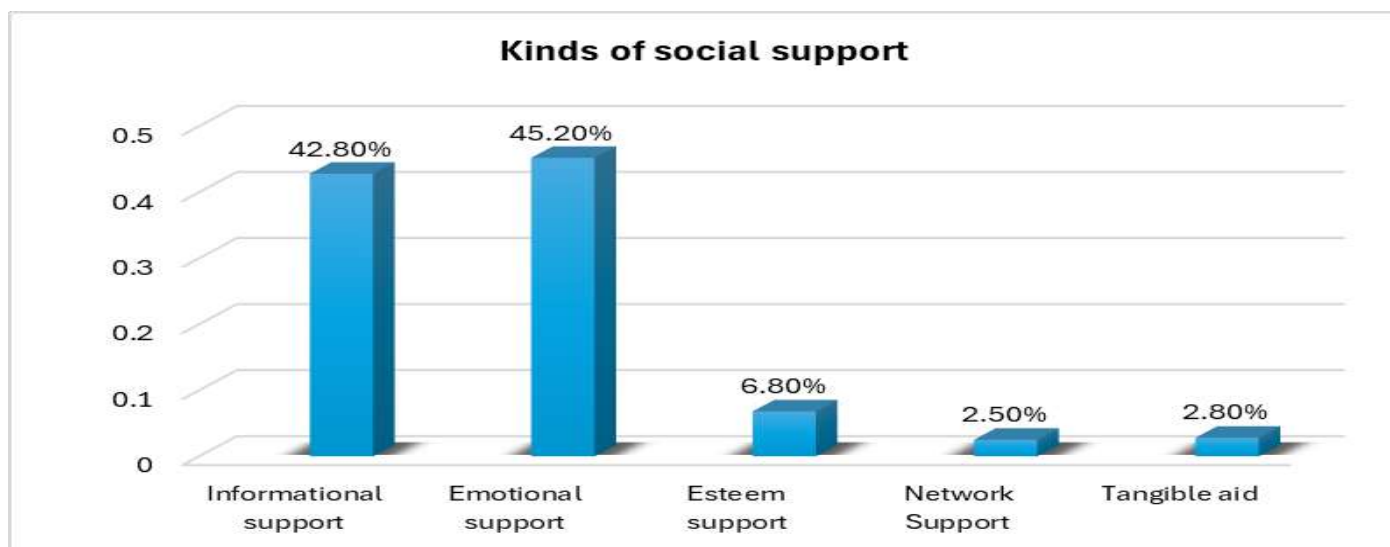
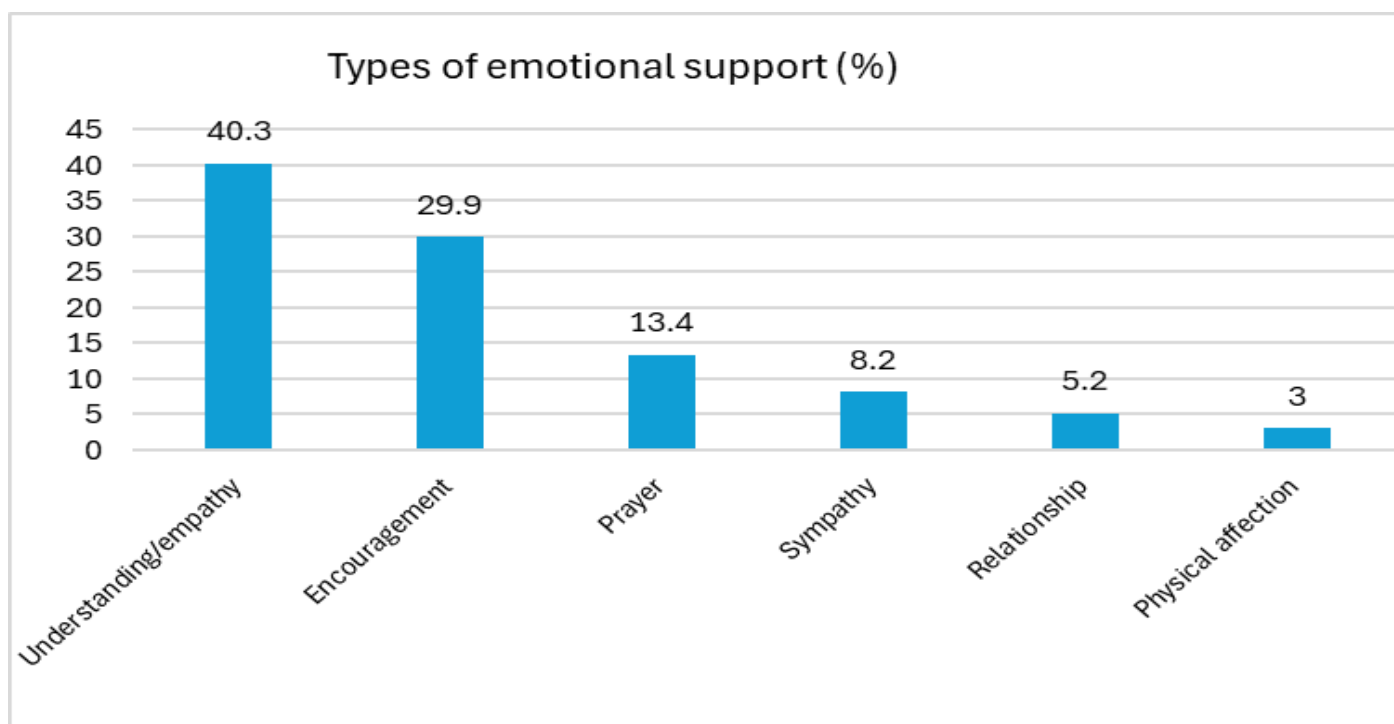


Figure 2
Kinds of social support

4.1.1 Emotional Support

Different kinds of emotional support were examined to understand the emotional needs of parents and caregivers of children with autism. A total of 147 text messages were analyzed under this theme, and categorization was done for each sub-theme. The findings indicate that the majority of parents with children with autism received empathy in their journey of caring for their children. This was followed by the need for encouragement (See Figure 3).

**Figure 3**

Types of Emotional Support received by Parents

The findings show that empathy or understanding was the type of emotional support received by most parents. This was revealed by the high number of messages shared online by most parents. Parents exchanged messages that expressed an understanding of the situation one of them was going through or disclosed similar experiences in a way that conveyed understanding. One of the needs identified through their conversations was the need for support on how to address the behavioral challenges of children with ASD. For instance, parents expressed frustrations about dealing with new behavioral habits that children with autism develop, such as refusal to wear clothes or hysterical laughter, among others. In response, other parents showed understanding and empathy by sharing their own experiences and what they did to manage the situation:

Parent A1:

“We had a naked phase too. He lived walking around naked. For a while and as long as it was hot, I let him be but kids grow up and visitors come so it needed to end. So what I did was I started creating trips like going to the shop and I would tell him people who go to shops wear clothes. Then I started telling him people who go outside the house wear clothes. And finally people who come out of their rooms wear clothes. As long as he is outside his room then clothes must be worn. In his bedroom akae (let him stay) how he wants. Kwani (Are) we are always dressed in our rooms. 🙏🙏 So begin with a general rule and then narrow it.”

Parent A2:

“Woi i feel you mum...mine used to eat them 🤢...ata pupu yake (even the excrement) but i thank God she stopped by herself...she used even to chew her clothes tearing any clothes she comes across with... removing all the clothes...she just wanted to stay naked 🤢. God is faithful she stopped after exposing her”

Parent A3:

“Right now am dealing with hysterical laughs sounds funny but can be annoying alienda holiday ocha (went for holiday in the rural home) he came with a habit of laughing literally hysterically about anything and everything like ile ya madharau (with arrogance)...akifanya kitu umchape (if he does something and you beat him) he will hysterically laugh ukiachana na yeye (once you let him go)...he laughs every second aki kwa bara bara kwa nyumba (on the road, in the house)... anywhere.”

Parent A4:

“Last few months habit is people's feet...he will crawl to touch.”

Parent A5:

"Mine is a mwiko (cooking stick) 🍷🍷🍷 which she'll cling onto until she retires to bed and immediately she wakes up that's the first thing to look for o'wise (otherwise) if not found expect a huge meltdown."

Parent A6:

"Mine has an 'obsession' with motorbikes that one of the sofas arm is his bike he has keys (that we don't use) and when riding lazima avae kofia (must put on a cap) and does exactly how the boda guyz (motorbike riders) do from starting the bike to bending on corners...aaah! Can't wait to see whats next Mine sleeps with his imaginary bike keys and kofia (cap) during school days his school bag sleeps besides him"

Encouragement was the second type of emotional support that was given by most parents. Encouragement gives the recipient hope and confidence (Coulson & Greenwood, 2012). Parents within the online social support network encouraged each other. In their conversations, the needs on how to address behavioral challenges, how to address delays in developmental milestones, and access to education for children with autism were revealed. Some of the efforts made by parents in response to these needs were sharing and learning from experiences of each other, encouraging each other, patience, therapy, and spirituality. For instance, one parent shared this with the others:

Parent A7:

"My fellow parents these are the best gifts that God has given us. It's our great responsibility to take care of them despite the challenges. Let's not tire training them again and again. Training is hard and costly. God is faithful and will reward the work of our hands. Let prayer be the key. Blessed Sunday."

In another conversation, one of the parents was worried by the fact that the child with autism had not achieved any milestone in communication despite the efforts made. After posting his/her frustrations to the parents' online social network, he/she received many messages of encouragement. For instance, one of the parents said:

Parent A8:

"Am encouraging you pray for your child and take him to school as advised. Not forgetting that I visited so many schools and they were unwilling to admit him, but I prayed that he shall find favour in eyes of men as he has found favour in eyes of God. I pray that soon he will talk. We also continue with therapy twice per week, which we do every Wednesday and Saturday, so on Wednesday he doesn't go to school."

Another parent extended encouragement by sharing this:

Parent A9:

"Yes, school helps and so does therapy, do them simultaneously. Mine was nonverbal until 5 years but started speaking when I took him to school coupled with therapy he improved alot."

Parent A10: *"Glory to God for your son. The much I know is that autism varies from one child to the other just like development milestone to any other kid. Give your child time and relax in God you will see things happening"*

Another discouraged parent received this as an encouragement to keep going:

Parent A11:

Hugs mama keep strong may God continue to be your pillar of strength, hope and keep refilling you with his grace and peace 🙏🌿

Another parent sought encouragement on the non-verbal situation of a child with ASD:

Parent A12

"Good morning Do we have parents with testimonies of their Autistic children who move from nonverbal to verbal? Please encourage us"

As the parents encouraged each other, they also appreciated that taking care of a child with autism is not an easy journey. One parent shared this:

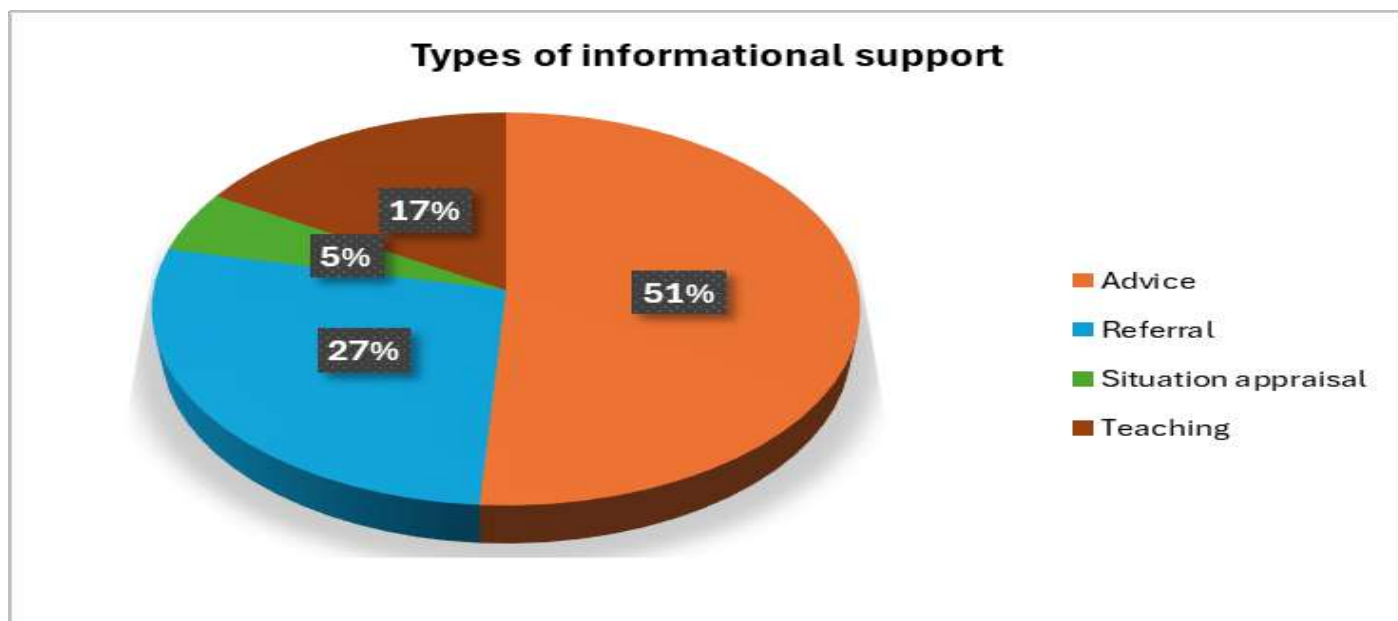
Parent A13:

"True, being a parent of a special child is so hard, you bleed inside and pretend everything is okay, not to hurt your child"

Generally, parents shared words of encouragement depending on the type of situation shared by any of them through the online forum. The discussions majorly revolved around, the ability of their children to communicate or achieve other developmental milestones, finding school for the child, dealing with new habits and behaviors portrayed by the children with autism among others.

4.1.2 Informational Support

The overall findings showed that informational support was ranked the 2nd most sought or received social support by most parents online out of the five kinds of social support under study, at 42.8%. A total of 139 text messages under this theme were analyzed further, and categorization was done for each sub-theme. After examining the different categories of informational support, most of the parents of children with autism were seeking or received advice, followed by referral. On the other hand, situational appraisal was the least shared type of informational support. See Figure 4.

**Figure 4**

Types of Informational Support sought by Parents Online

These findings can be translated to the different types of informational needs by parents of children with autism, with most parents in need of advice-related information. Parents sought or received advice mainly on care, diet, and security for the child with autism. The burden of care also came out through the parents' messages. For instance, one parent needed advice on delegated caregiving for a boy with autism while the parent went to work.

Parent B1:

"Moms with older children on the spectrum especially boys...what did you do when your child wouldn't be left with a house help anymore? Because of their ages? And you have to go to work?"

Safety needs also came up as parents were sharing advice on the precautions to take in case a child with autism gets lost for ease of identification since the child may not express themselves.

Parent B2:

"Meanwhile can we speak about what to do when your child with a disability elopes or gets lost? What is your strategy for finding them or keeping them safe?"

In response to this, one of the parents gave some information on an observed practice that would help.

Parent B3:

"I see people use bracelets with their details. I would love to see samples that would work for my children."

This study also identified nutritional needs as parents sought advice related to the diet for their children with autism.

For instance, one parent posted this:

Parent B4:

"Good afternoon, any mum here who cook pancakes for their autistic kid? What flour do you use that is gluten-free? A picture of the flour will be of help"

Referral was the second type of information support sought by most parents after advice. Most parents were seeking referrals for therapy services, schools, caregivers, and where to get specific items to support developmental aspects of the child with autism. For instance, one parent asked for referral information on where to get a specific item:

Parent B5:

"Hi ...Where can we get pocket pouches? I looked in the supermarket didn't get"

Parents also sought or received information that would build on their knowledge to care for their child with autism. One parent posted an image and tagged a message seeking for further information:

Parent B6:

"Hey. What are these and their use?"

In response to the question, another parent responded with more information (teaching) about the item:

Parent B7:

"They are noise canceling. Our Autism champs (children) sometimes noise disturb them ...like in public places like buses or church. So they put them on and they minimise the noise"

Parents also learned from each other how to use affirmative language, such as ‘champions’ and ‘talented differently’, when referring to children with autism. In addition, a need to address developmental delays in children with ASD was identified as parents learned from one another and shared ideas.

Parent B8:

“Autistic kids are talented differently it's up to us caregivers to accept them as they are and help them be even better in areas that they are good at, some may develop speech while others maybe non-verbal forever, some may learn to use phones others may not, others may be learn to write others may not so it's our responsibilities as we train these kids help recognize their areas of strength and let the kids be in their natural environments the way they are wako tu sawa (they are just ok) don't force exotic environments on them only support them to be better at the end of the day who has correct definition of a human being to say our kids are different.”

The parents also learned from each other that autism was not an illness and that they needed to understand when and why to seek medication.

Parent B9:

Autism isn't an illness so it doesn't require medicine. The comobidities (comorbidities) or other things that happen with autism may be medical issues that need medicine. So what is the medicine for? As a parent you have to be able to know what your child is being treated for. Sorry I am using this as a teaching moment. 🙏 Kuna mtu alisema hizo dawa hudamage Brain (Somebody said the medicines damage the brain), and am coming to realize oh oh help me God”

Generally, parents needed deeper knowledge on subjects like understanding autism, how to take care of children with ASD, how to address developmental delays, types of therapy and when to go for them, use of drugs and when to seek medication, among others.

4.1.3 Esteem Support

The overall frequency of esteem support was 6.8% out of the five kinds of social support under study. Even though esteem was not a frequently shared kind of social support, parents received more ‘complement’ related support, followed by ‘validation’ while ‘relief of blame’ came in last. On ‘complement support,’ parents appreciated each other for their efforts in taking care of the children with autism. For instance, some parents had this to say:

Parent C1:

“You are a very strong mum. May the Lord keep you strong for many years. May you never lack. God's child' 🙏”

Parent C2:

“Good job on creating awareness on Autism on a national stage.”

Another parent appreciated the collective efforts of parents and the community in promoting the inclusion of persons with neurodevelopmental disabilities:

Parent C2:

“This recognition is a testament to the collective efforts of our amazing community and the impactful initiatives we've undertaken to promote inclusivity for persons with neurodevelopmental disabilities & your support means the world to us 🙏🙏🙏!”

4.1.4 Network Support

Network support was the least sought for social support by parents of children with autism at 2.46%). Parents who sought network support focused mostly on access to new people, such as therapists, shadow teachers, and caregivers. For instance:

Parent D1:

“Kindly post for me in your group. Am looking for a special education teacher who can work full-time with a 3yr old autistic boy”

In addition to the network support, the theme of education-related needs came up as the parent seeking support was considering the option of homeschooling.

4.1.5 Tangible Aid

Generally, tangible aid was rarely sought by parents (2.77%) compared to informational (42.77%) and emotional support (45.2%). However, on the occasions when this type of social support was sought, three sub-themes came out - direct task, willingness to help, and financial support. In addition, the need for spiritual support and financial support also came up. The research team added financial support as a new sub-theme since it was not featured within

the social support behavior code used in this study. One parent appreciated the other parents for the prayers and financial support received:

Parent E1:

“Dear champions I am so blessed by being part of you, some 5 months ago, I came here and asked for prayers because of my daughter who was in ICU... thank you for the money you sent to me towards the bill, thank you!”

4.2 Discussions

Online Support Groups (OSGs) have emerged as dynamic platforms where individuals with shared health concerns can exchange not only information but also diverse forms of psychosocial support (Pan et al., 2019). This study examined the types of support messages exchanged among parents of children with ASD, revealing two primary themes: emotional and informational support. Emotional support messages accounted for 45.23% of interactions, while informational support messages made up 42.77%.

These findings are consistent with previous research, such as Wang et al. (2021), which demonstrates that emotional support in digital environments can significantly enhance well-being and happiness. Similarly, Roffeei et al. (2015) found that Facebook groups for parents of children with autism predominantly facilitated informational (30.7%) and emotional support (27.8%). However, our study diverged from Roffeei et al. (2015) in terms of esteem and network support. In our data, these categories were notably lower (ranging from 2.46% to 6.77%) compared to their reported figures (20.2–20.9%). This discrepancy may be attributable to contextual differences, such as the platform’s design, user demographics, or temporal factors influencing online communication trends.

Beyond the primary dimensions of support, the broader literature suggests that OSGs also have the potential to facilitate other important functions such as identity validation, empowerment, and even advocacy (Bi et al., 2022). For example, while our study observed low levels of tangible support and modest esteem and network support, other research indicates that such dimensions may become more pronounced in settings where users engage in extended interactions or when platforms integrate structured support interventions (Barak et al., 2008). This suggests that the role of digital support is multifaceted and may evolve over time with increased user engagement and technological enhancements.

Moreover, participation in OSGs appears to mitigate isolation and stress often reported by parents of children with ASD. As highlighted by Bakar and Bakar (2019), these virtual spaces not only provide a venue for information exchange but also offer emotional validation and empathy - factors that are crucial for alleviating the psychosocial burdens associated with caregiving. The perceived anonymity and reduced social risk inherent in online interactions may further promote candid disclosures and the development of supportive relationships, thereby contributing to improved mental health outcomes (Barak et al., 2008).

The implications of these findings extend beyond mere categorization of support types. They suggest that OSGs can serve as an important adjunct to traditional support services, especially in contexts where access to in-person support is limited. This has particular relevance for parents of children with ASD, who often navigate high caregiving burdens and social isolation. Future research could explore the integration of digital support with community-based services to develop comprehensive intervention strategies that address both the emotional and practical needs of these families.

V. CONCLUSIONS & RECOMMENDATIONS

5.1 Conclusions

The study concludes that caring for a child with autism is associated with a high burden of care and imparts the well-being of parents. Emotional support and informational support comprise the most desired social support by parents of children with ASD. This, therefore, translates to the parents' need for interventions that can address their emotional and informational support to reduce the burden of care in raising children with ASD.

5.2 Recommendations

The study recommends the design, testing, and implementation of parental support programs mainly targeting the emotional well-being of parents and offering informational support on how to address challenges experienced when raising children with ASD, such as how to address behavioral challenges and delays in achievement of developmental milestones, among others. The study also recommends relooking at the education system and structures to enhance access to education, retention, and transition of learners with Autism. Further the study recommends development of an evidence-based toolkit on behavior management of children with autism, for use by the parent. Finally, the study recommends concerted efforts by stakeholders within the social support and well-being sector to establish centers for parents that would help relieve the high burden of caring for a child with autism and boost the parents' well-being.

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Appendix I

Frequency of social support categories and sub-categories sought/received by parents of children with ASD

Kinds of social support	Frequency	Percentage
Informational support		
Advice	71	21.85%
Referral	38	11.69%
Situation appraisal	7	2.15%
Teaching	23	7.08%
Sub-total (Informational support)	139	42.77%
Emotional support		
Relationship	7	2.15%
Physical affection	4	1.23%
Confidentiality	0	0.00%
Sympathy	11	3.38%
Understanding/empathy	54	16.62%
Encouragement	40	12.31%
Prayer	18	5.54%
Sub-total (emotional support)	147	45.23%
Esteem support		
Complement	13	4.00%
Validation	6	1.85%
Relief of blame	3	0.92%
Sub-total (esteem support)	22	6.77%
Network Support		
Access	7	2.15%
Presence	0	0.00%
Companions	1	0.31%
Sub-total (Network support)	8	2.46%
Tangible aid		
Loan	0	0.00%
Direct task	3	0.92%
Indirect task	0	0.00%
Active participation	0	0.00%
Willingness	3	0.92%
Financial support (Additional code)	3	0.92%
Sub-total (Tangible support)	9	2.77%
Total social support messages analyzed	325	100%