The Impact of Psychological Well-being on the Quality of Life of Caregivers of Children with Autism Spectrum Disorder in Special Schools in Luanda Sub-county, Vihiga County

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Abstract

Caregivers of children living with autism spectrum disorder are confronted with many obstacles that have an impact on their psychological health and, in turn, their quality of life. This study explores the influence of psychological well-being on quality of life of caregivers of children with Autism Spectrum Disorder (ASD) attending special schools in Luanda Sub-County, Vihiga County. This study adopted the Social-Ecological System Theory to explain how the caregivers of ASD children interact with different contexts as they execute their caregiving responsibilities. The research employed a phenomenal approach and purposive sampling method to select the respondents from special schools in Luanda Sub-County. The tools employed for the study were interview guide and focus group discussions. Data was gathered via videotape recordings and field notes and then transcribed word for word. The objective of the study was to explore how the psychological well-being encompassing aspects such as autonomy, personal growth, and self-acceptance of the caregivers' of children with

ASD affects their overall quality of life. The study found out that numerous challenges faced by the caregivers revolve around lack of information and awareness regarding ASD which delayed the diagnosis of ASD. These affected their self- acceptance, autonomy, and personal growth, which in turn influenced their Quality of Life (QOL). The study recommends raising public awareness about ASD, providing caregivers with skills to manage socially unacceptable behaviors, make therapies accessible and affordable for the caregivers, and provide them with support to help them improve their psychosocial well-being and QOL.

Keywords: Autism spectrum disorder, quality of life, caregivers, psychological well-being, self-acceptance, autonomy, personal growth.

Introduction

Autism is a neurodevelopmental disorder that is mostly detected in children and is marked by recurrent behaviors, verbal abnormalities, and trouble interacting with others (Frazier et al., 2018). It is a chronic condition that impairs general development and is frequently associated with various health and developmental conditions such as mental disorders, digestive disorders, and intellectual disabilities (Karpur et al., 2019). Sadly, there is yet no known cause of ASD or treatment (Kanja et al., 2022). This reveals that the caregivers will take years caring their children with ASD.

In most cases, parents or guardians are the caregivers or children with ASD. Nurturing them is demanding both psychologically and physically (Napitupulu & Kurniawan, 2024). A child diagnosed with autism needs specialized attention and care in a variety of areas, including treatment, education, and self-help. Nonetheless, it has frequently been discovered that caregivers of ASD children have mental health issues and poor psychological well-being (PWB) (Andrez et al., 2020). The focus of this study was to explore how the caregivers attain their self-acceptance, personal growth and autonomy.

The prevalence of ASD is an issue that is currently gaining a lot of attention. Data suggest that the prevalence of ASD has increased exponentially over the past ten years (Zhao & Fu, 2022). According to the World Health Organization (2023), autism affects about 1 in 100 children. All throughout the caregiver's life, raising a child with developmental disabilities is a complex and challenging condition (Papadopoulos, 2021). In the USA, caregiving of children with ASD disrupts the caregiver's ordinary routine (Li et al., 2024). Similarly, in the UK, the caregivers of children lacked the information about ASD which affected their comprehension of behavioral difficulties among those children (Legg & Tickle, 2019). In Turkey, all the caregivers' energy is directed toward their ASD children which hinders them from making decisions that could sustain themselves (Kalac, 2020). When the caregivers of children with ASD are not able to make independent decisions, it can impact their psychological well-being which can affect their QOL In Africa, the prevalence of ASD is not well known. However, several studies have reported the challenges that the caregivers undergo. For instance, in Nigeria, it was reported that the caregivers of children with disabilities faced challenges including money, health-related issues, strained social relationships, worries about their children's future, and a need for social support. This brought a lot of psychological distress to the caregivers (Adedeji, 2018). Studies carried out in Kenya reveal that caregivers of children with ASD undergo a lot of challenges which bring psychological distress in their lives. For instance, a study conducted by Kamau (2017) reported that many caregivers are ignorant about the diagnosis and the rehabilitation services that are accessible. This includes healthcare professionals who are also not very knowledgeable about ASD, which results in subpar treatment. Another study conducted by Cloete & Obaigwa (2019) revealed that the caregivers of children with ASD had limited knowledge about the disorder. As a direct consequence, the lack of information about ASD, prolonged the caregivers' agony and acceptance that their children were affected. All these studies reveal the challenges the caregivers undergo which deter them from attaining their psycholofgical well-being. However none of these studies explored the psychological well-being on QOL of caregivers of children living with ASD. That is why the study explored the psychological well-being on QOL of caregivers of children living with ASD.

Psychological well-being is very essential to the life of caregivers of children with ASD. According to Kanja et al.(2022), Psychological well-being of caregivers not only enables providing children with autism a high-quality care but also allows caregivers to reach their full potential as human beings thus improving their QOL. If caregivers are sick or have low PWB, they cannot perform the responsibility properly and therefore their QOL will be affected.

Psychological well-being may be measured in six dimensions: autonomy, self-acceptance, environmental mastery, purpose in life, personal progress, and positive connections with others (Napitupulu & Kurniawan, 2024). In order to attain optimal psychological well-being, an individual must score well on all six dimensions. Research on psychological well-being is crucial since parents of autistic children will need to care for their children for many years to come.

Statement of the Problem

According to the World Health Organization (2023), the global prevalence of ASD is 1 in every 100 children while in Kenya it is 1 in every 25 children (Masaba, et al., 2021). As a result of the increasing prevalence of Autism Spectrum Disorder globally, caregivers of children with ASD are confronted with multiple challenges which affect their psychological well-being thus affecting their QOL.

However, most of the existing research primarily focused on the children living with ASD and other aspects that influence the well-being of caregivers. In consequence, the existing research neglected the critical role of PWB on QOL of caregivers. For instance, a study conducted by Ireri et al. (2019) focused on treating anxiety and social deficits in children with ASD, a study conducted by Kanja et al. (2022) focused on the effects of caregiving to ASD children on the caregiver's PWB.

Despite the numerous studies conducted on autism disorders, there is no study carried out in Luanda Sub-county that explored the PWB on QOL of caregivers in special schools. Thus this study attempted to fill the knowledge gap by exploring the PWB on the quality of life of caregivers of children with autism spectrum disorder in special schools in Luanda Sub-county, Vihiga County.

Objective of the Study

To explore the effect of psychological well-being of the caregivers of children with ASD on quality of life in special schools in Luanda Sub-County, Vihiga County.

Research Question

How does psychological well-being of caregivers of children with ASD influence their quality of life in special schools in Luanda Sub-County, Vihiga County?

Theoretical Framework

The study was guided by two theories: Social Ecological Systems Theory (SEST) and Cognitive Behavioral Theory (CBT). SEST is aided in the investigation of how the PWB of caregivers of children with ASD is supported or deranged by various ecological systems. While CBT directed the study in identifying the coping strategies used by the caregivers and their efficacy. Furthermore, this theory supported research aimed at identifying the illogical beliefs that preoccupy caregivers of children with ASD.

Social-Ecological System Theory

This study employed the above theory by Urie Bronfenbrenner to explain how the caregivers of ASD children interact with different contexts as they execute their caregiving responsibilities. Bronfenbrenner points out five systems of surroundings that affect the growth of an individual which entails the microsystem, mesosystem, ecosystem, macro system and chronosystem (Rizk et al ., 2023). However, this study employed only three systems which are relevant to the study. These entail microsystem, mesosystem, and macro system.

This study employed the SEST because it points out particular environmental systems (micro-, meso-, exo-, and macro-systems) that support the psychological wellbeing of caregivers in light of autonomy, self–acceptance, and personal growth. It is through the interaction within the various systems in the environment that the well-being of the individual can be maintained or destroyed which affects their QOL.

The SEST examined how the interaction of the caregivers within the microsystem affects their psychological wellbeing which in turn influences their QOL. When immediate surroundings (spouse, siblings, neighbors, friends, and grandparents) offer assistance to caregivers, it makes them attain PWB(autonomy, self-acceptance, personal growth) which improves their QOL. However, when the main caregivers are left to handle the difficulties of parenting alone and when their connections with close friends and family are unsupportive, it may affect their capacity to attain autonomy, self-acceptance, personal growth, which may affect their QOL (Rizk et al., 2023).

Cognitive Behavioral Theory

Cognitive Behavioral Therapy (CBT) is a model that integrates both behavioral and cognitive aspects. It is primarily attributed to Albert Ellis and Aaron Beck (Chand et al., 2024; Corey, 2014). According to Aaron, all psychiatric disorders share disordered thinking, which affects a client's mood and behavior. People report feeling less depressed and engaging in maladaptive behavior when they learn to assess their thoughts more realistically and adaptively (Beck, 2021; Nakao et al., 2021). It functions by teaching people different ways of thinking and acting, which in turn revitalizes them.

Behaviorism and cognitive therapy are two different schools of psychology that led to cognitive behavioral therapy (CBT), which examines the connection between emotions, thoughts, and behaviors. These two methods can be identified as the origin of CBT (Morrow, 2022). Rational Emotional Theory (REBT) which was established by Albert Ellis in 1979 has found its basis in CBT. It seeks to assist individuals in challenging unproductive thinking to prevent unpleasant feelings or behaviors. According to the ABC model, an individual's perception, belief, or assessment of an event or problem determines their emotions and behavior rather than the situation, occurrence, or consequences. While it is impossible to control an occurrence, one can control thoughts to achieve the desired result (Corey, 2014; Kanja et al., 2022).

The model suited the study because caregivers are occupied with negative thoughts about themselves and their children with ASD which affect their PWB and their QOL. For instance, the caregivers of children with ASD blamed themselves for the condition of their children which affected their comprehension of behavioral difficulties among children with ASD (Legg & Tickle, 2019). These can affect their ability to cope positively with their challenges of taking caking care of their children living with ASD. The CBT model helped to identify and change the negative thoughts and beliefs occupied by the caregivers with ASD which hinders them from developing adaptive coping strategies to help them cope with their children with ASD.

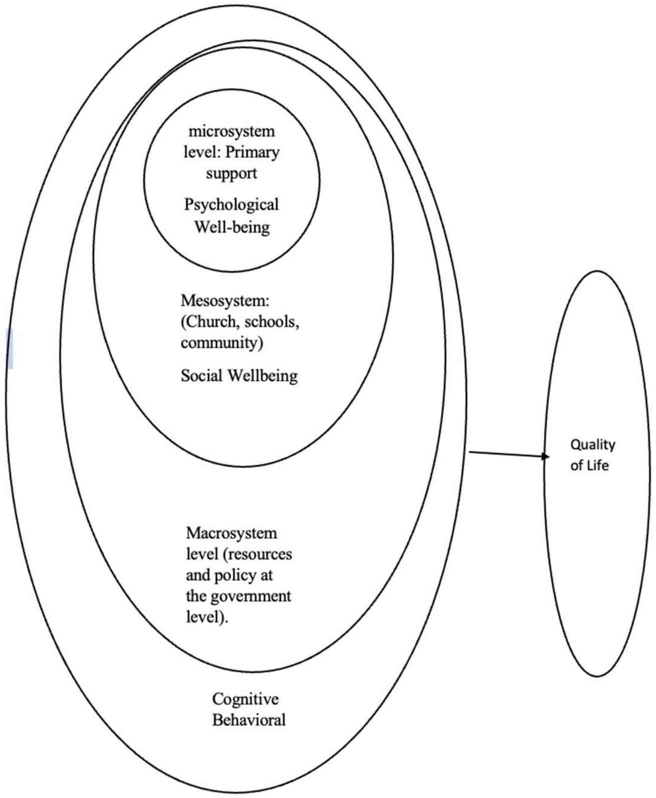

Figure 1: Theoretical Framework

Source: Researcher, 2025

Empirical Literature Review

Quality of life is an essential pointer to health. It embodies the overall well-being and happiness of an individual (Florentina, 2018). Caregivers of children with ASD need to have a good QOL to function and operate well. Nevertheless, most of the caregivers of children with ASD have reported to have low QOL compared to caregivers of children with normal development (Farah, 2019). This is because of the many challenges involved (Marsack-Topolewski, 2020). There is dearth of information on how PWB of caregivers affects their

QOL. Therefore, this study endeavored to fill this gap by specifically offering an in-depth discussion exploring the PWB on QOL of caregivers of children living with ASD.

Psychological well-being refers to a state where individuals can perform their duties with efficiency, are more emotionally stable, reach their maximum potential, show necessary maturity, and exhibit mental health that is in good shape (Alsa et al., 2021). PWB encompasses self-acceptance, autonomy, and environmental mastery (Celestine, 2021). This study will explore how self-acceptance, autonomy and personal growth affect the QOL of the caregivers of children with ASD in special schools.

Self-Acceptance

Self-acceptance refers to the ability to face reality instead of succumbing to hopelessness (Mansur et al., 2022). Self-acceptance is very essential for individuals to attain their well-being (Medvedor & Lindhuis, 2019).A study conduccted in the USA by Hartmann (2020) revealed that the caregivers felt relieved after they have been given an answer concerning the symptoms of their children with ASD. This means they accepted the condition of their children which gave them relief. Nevertheless, a study conducted in Canada by Gentles et al. (2020) revealed that caregivers often struggle with a lack of knowledge regarding autism spectrum disorder (ASD) before, during, and after diagnosis.

In the UK, the caregivers blamed themselves for the condition of their children because of lack of information which affected their comprehension of behavioral difficulties among children with ASD (Legg & Tickle, 2019). Additionally, lack of awareness also led to the hesitation of the caregivers to seek early intervention for their children with ASD (Yaacob et al., 2021, Mushtaq et al., 2024). Additionally, a study conducted in the Philippines by Chepngetich et al. (2022) revealed that the ability for the caregivers to develop self-acceptance was affected because of their initial hope for their children to be healthy, successful, and similar to or better than themselves. When they realized their child had ASD they were in total shock, denial, and distress which affected their QOL. Abdullah et al. (2021) add by stating that the caregivers first struggled to accept the reality that their children had ASD. They went through stages of denial since it was difficult to face the harsh reality that their children had a disability.

Again, another study conducted in Indonesia by Napitupulu and Kurniawan (2022) revealed that caregivers lack of self-acceptance is attributed to their negative mindset. This is demonstrated by conduct blame and regretting why they have children with ASD. The caregivers of children with ASD occupy their mind with negative thoughts about the cause of the condition which include blaming themsleves for poor upbringing of their children and for not spending enough time with their children which they fear had impacted their children's growth and conduct.

Likewise, in a study conducted in South Africa by Shilubane & Mazibuko (2023) revealed that cultural beliefs among the caregivers hindered them from accepting the condition of their child and seeking earlier diagnosis. Instead they turned to traditional healers who performed magic on their children. This is supported by a study carried out in Malaysia by Yaacobet al. (2022), which discovered that cultural beliefs of the caregivers influenced their ability to aquire the right information about the condition of their children. Though the studies were to reveal how self–acceptance is intergral in PWB, they did not point out how social acceptance affected the psychological well-being on QOL of caregivers.

Autonomy

Autonomy refers to the ability to make decisions for oneself, to be independent, and to control one's conduct without the help of outside factors (Claudia & Weles, 2022). People with high levels of autonomy are free to follow their objectives and passions, which might enhance their PWB thus affecting their QOL. Caregivers who have high levels of autonomy are able to manage everyday chores because their minds are not distracted by unnecessary tasks (Napitupulu & Kurniawan, 2024).

Nonetheless, caregivers encounter many challenges while taking care of their ASD children which can limit their capacity to be autonomous. A study conducted in the USA by Dieleman et al. (2019) revealed that caregivers face challenges such as inadequate free time and financial constraints which can limit them from satisfying their urge for autonomy. Similarly, a study carried out in Australia revealed that caregivers frequently felt limited autonomy with everyday tasks arranged around their children's demands and therapies (Davy et al., 2022). When the caregivers are not able to make independent decision it impacts their PWB which affects their QOL.

Additionally, a study conducted by Marsack et al. (2021) pointed out that parental stress is increased when children with ASD have limited autonomy with things like clothing and toileting, while caregiver's stress is reduced when autonomy skills are increased. This is supported by a study by Jonge et al. (2024), who noted that caregivers in remote areas face greater difficulties when their children lacked autonomy. Though the studies focused on children's autonomy, it can still affect the caregivers' autonomy because children with ASD cannot carry out their own things independendly. It forces the caregivers to spend most of their time supporting children living with ASD, which limits their independence to take care of themselves and the rest of the family members.

Another study conducted in Kenya revealed that the high expense of treatments limits the caregivers' ability to choose preferred health institutions for their children. The only preferred place to take their children with ASD for treatment was in Kenyatta National and Referral Hospital (Kanja et al., 2022). The inability to be autonomous hinders the caregivers from attaining PWB and to provide quality care to their children. However, a study conducted in coastal part of Kenya by Gona et al. (2024) discovered that that caregivers saw school enrollment as a tool to help them have the independence of performing other obligations. Additionally, a study carried out in Nairobi by Kanja et al. (2022) established that caregivers who had enough assistance from relatives were able to perform family obligations in addition to caring for their children with ASD. This is supported by a study carried out by Hoopen, et al., (2020) which discovered that caregivers in families with supportive parental subsystems were well-complemented and supported in their roles.

Personal Growth

Personal growth refers to the process of continuing to reach one's own potential. It entails growing personally as well as embracing emerging challenges in life (Maurer et al., 2023). Every individual has to undergo personal growth in life to enjoy good QOL. Nevertheless Personal development of caregivers is bound to be delayed because of the increasing psychological challenges that arise as a result of taking care of children living with ASD.

In the USA, caregivers frequently have to rearrange their schedules to accommodate the unique needs of their children. This may involve cutting back on job hours or even leaving the workforce entirely to take on full-time caring responsibilities (Li et al., 2024). The reduction of working hours can lower down the caregivers' chances of promotion which can hinder them from attaining the psychological need for personal growth. Additionally, caregivers frequently report reduced self-care, relaxation, and work involvement as a result of increased hours devoted to caregiving-related tasks (Bhopti et al., 2020). This implies that caregivers may struggle to maintain a career balance alongside caregiving responsibilities. This can be problematic as involvement in regular professions is considered an important feature of a person's growth (Davy et al., 2022).

Similarly, a study conducted in Saudi Arabia by Hemdi & Daley (2017) revealed that the caregivers took the major responsibilities of caring for both the children and the entire family because of lack of support from the members of the family. This is in agreement with a study conducted by Yaacob et al. (2022) which pointed out that most of the caregivers report a lack of support from family members who were unaware of their child's condition and did not provide necessary assistance. When the caregivers lack support from significant others, it means that they carry the burden of caregiving alone, which hinders them from the ability to achieve personal growth.

Nevertheless, other studies have revealed that caregivers of ASD children may still attain their personal growth despite their challenges of caregiving. For instance, a study conducted in Malaysia by Singh et al. (2023) discovered that, after a period of interaction between the caregivers and their ASD children, the caregivers experienced personal growth. This is because the caregivers were able to have understanding about children with impairment and come to terms with the condition of their ASD children. Additionally, they were able to accept both the children's talents and shortcomings and avoiding being in denial. Similarly, a study carried out by Manyara & Mwarari (2020) revealed that caregivers rely on the intervention of God for the condition of their children. The caregivers’ optimistic spirit about the future of their children reduced their worries and increased their growth and QOL. However the studies did not reveal how personal growth can affect the PWB on QOL of caregivers. This study explored how personal growth affect the PWB on QOL of caregivers of children with ASD in special schools in Luanda Sub-County, Vihiga County.

Research Methodology

The researcher employed a qualitative design, and phenomenological approach with the aim of identifying commonalities among participants (Makunika, 2020). The phenomenological approach helped the researcher to gain a better understanding of the encounters experienced by the caregivers, and also to aid in getting the chance to monitor the non-verbal cues in addition to the verbal communication from the interview that were conducted (Ha, 2018).

Locale of Study

The study was conducted in special schools located in Luanda Sub-County, Vihiga County. Luanda Sub-County was chosen because there was scanty information about PWB on QOL of caregivers of children with ASD and that is why this study is conducted (County Annual Development Plan (2022/2024).

Population of the Study

The study entailed informal and formal caregivers of children with ASD from special schools in Luanda Sub-County, Vihiga- County. The informal caregivers consisted of mothers, fathers, grandmothers and an aunt. The formal caregivers were comprised of special school teachers, matrons and cooks. In Luanda Sub-county there are only three special schools namely: Ebusiratsi, Wandeche, and Musitinyi with a total population of 28 caregivers of children with ASD (Educational Assessment And Resource Center Vihiga County, 2024). As demonstrated in Table 1. below.

Table 1: Population of the study

Name of the special school	No. of informal caregivers	No. of formal caregivers	Total population
Ebusiratsi Special School	10	3	13
Wandeche Special School	5	3	8
Musitinyi Special School	4	3	8

Total	19	9	28

Source: Educational assessment and resource center Vihiga County, 2024.

Sampling Size and Sampling Procedure

According to Creswell (2017), a sample is a representative population of individuals chosen from the entire population who share comparable features and allow the researcher to conclude the entire population. The study employed purposive sampling for both formal and informal caregivers. According to Staller (2021), purposive sampling is a sampling method in which the researcher uses judgment to determine which person would offer the greatest perspective on the phenomena of interest, then deliberately welcomes those particular perspectives into the study.

The study purposively sampled 19 informal caregivers and 9 formal caregivers as respondents of the study from the special schools in Luanda Sub-County in Vihiga County. 8 respondents were exposed to an in-depth interview; 11 respondents were exposed to two Focus Group Discussions (FGDs) while 9 formal caregivers (teachers, matrons, cooks) were exposed to in-depth interview alone. The study employed purposive sampling to allow the researcher in selecting participants who were available to provide the required data and meet the study objective. The study's inclusion/exclusion criteria required that respondents be caregivers of children with ASD who are enrolled in special schools in Luanda Sub-County in Vihiga County. All the face to face interviews took place at the researcher’s compound, while the FGD were held at special schools in Luanda Sub-County. The in-depth interviews with formal caregivers were done over the phone. The sample size criteria relied on data saturation (Cresswell, 2017). The 28 caregivers of the study provided adequate information, resulting in data saturation.

Data Collection Instruments

Interviews were preferred to other techniques of data collection because of their capacity to gather comprehensive and in-depth data about a research topic from the source and provide insights from participants' emotions and viewpoints.

The Study Findings

The study collected data from 28 respondents which entailed 19 informal caregivers and 9 formal caregivers. Their response rate was 59.38 % for informal caregivers and 28.13% for the formal caregivers. According to Fincham (2008), most researchers should aim at having a response rate of approximate 60% from this view the studies response rate of 87.5% was successful. The response rate result is displayed in the Table 2 below.

Table 2: Response rate distribution

Caregivers	Number of respondents	Response rate
Informal	19 out of 20	59.38 %
Formal	9 out of 12	28.13 %
Total	28 out of 32	87.5%

Source: Field data 2024

The research question that the study endeavored to answer was, how does psychological well-being influence quality of life of caregivers of children with ASD in special schools in Luanda Sub-County? To realize the objective, the study interrogated the caregivers on how they knew their children had ASD, their reactions after it was confirmed their children had ASD and the beliefs they have about ASD. Moreover, they were also interviewed on how caring for children with ASD affect their decision making, how they manage their daily activities. Finally, they were interviewed about their support systems and their future plans for their children with ASD. Their responses provided information on how their PWB affected their QOL. Their feedback was portrayed by a summary of themes and sub-themes that were picked up in the in-depth interview as pointers of psychological well-being in table 10.

Table 3: Themes and sub-themes pointers of psychological well-being on QOL

Themes	Sub-themes
Self- Acceptance	Knowing a child has ASD (no information), Reaction (denial, shock, frustrated, sadness anxiety, depression, self-blame). Beliefs about ASD (witchcraft).
Autonomy	Decision making, Reduced travelling managing daily activities,
Personal growth	Support system, Future for the child,

Source: Field data 2024

Self-Acceptance

The study explored how taking care of children with ASD affected the self-acceptance of caregivers thus influencing their QOL. The themes that emerged include no information about ASD, denial, shock, frustration, or witchcraft.

No information about ASD

A significant 15 (79%) of the caregivers did not have any information about Autism Spectrum Disorder (ASD). Their personal views were captured in the following statements:

Respondent KA1001 who was a health record and information officer, a mother of 11-year-old boy with ASD had this to say:

"*Before the diagnosis was made I had no information about ASD because I had never witnessed a person with such condition. It was really hard for me to accept that my child was autistic until I started looking for material through the internet to help me understand the condition*".

Likewise, Respondent KA10017, a business lady and mother of a 12 year old boy explained:

"To say the truth, I don't understand this condition. I have only heard of it but there is no one who has given me enough details about the condition to help me understand".

Similarly, Respondent KA10012, a mother of a 7-year-old boy with ASD said:

"*Ever since I was born many years ago I have never seen or heard a child with such a condition like my son, ... now that I did not understand what the condition was and I'm also poor, I decided to stay with him at home…. when my pastor visited me she advised me to take him to Vihiga Assessment center to be assessed…. "*.

Furthermore, Respondent KA1005, a father of 15 year old boy with ASD had this to say, "*Truly speaking I didn't understand what the condition is all about because I have never come across such in my life. Initially I thought my child had epileptic because of the convulsion but after the diagnosis it was revealed that she had ASD"*

The caregivers had limited awareness about ASD despite their children being diagnosed with ASD. This is similar to the previous studies conducted in Kenya by Cloete & Obaigwa, (2019), which revealed that the caregivers had limited knowledge about ASD which affected their ability to accept the condition of their ASD children, nor realize the early symptoms of ASD their children manifest or comprehend the behavioral difficulties and delayed milestones among their ASD children. This was captured from their verbatim expressions below:

Respondent KA10017, a mother of a 12 year old boy with ASD narrated:

"*Now it reached a time he was supposed to be sitting but he never sat, he delayed… He was very slow even in walking. God helped him to sit but it took 9 years to walk just by the grace of God. I did not understand the reason for the delay*.

Likewise, Respondent KA1009, a widow with a 17 year old boy with ASD added: *"my son did not develop like other children….. Imagine he walked when he was two years…. By the age of 3 years he could not talk but he could scream like crazy… I knew something was wrong".*

Similarly, Respondent KA1002 a mother of a 9 year old boy with ASD had this to say:

"*He also developed a funny character. For instance, he was very aggressive and he really loved beating others without a reason. He also used to bite his hands until blood oozes. He was very hyperactive. He could not settle in one place. He used to jump from one corner to another. Additionally, my child used to eat too much when he doesn't have something to eat at night you will find him eating the blanket. Such character really stressed me so much because you could not stop him and he listen. In fact, when you stop him that's when he will throw tantrum and scream like crazy. This brought a lot of anxiety to me because I did not understand what condition my child was suffering from".*

The caregivers were aware that their children had a problem because of their problematic behaviors, however they lacked understanding of the major symptoms of ASD which prevented them from seeking early interventions. This is similar to the early findings conducted by Legg and & Tickle, (2019) which discovered that lack of information deterred the caregivers of children with ASD to realize the unusual behavior their child was manifesting. Likewise, (Yaacob et al., 2022; Mushtaq et al., 2024) established that lack of information lead to the hesitation of the caregivers of children with ASD to seek early intervention for their child with ASD.

Some parents ignored the severity of the condition and declined to accept their child's need for medical assistance. For instance Respondent KA 10019, a single mother of a 13 year old boy with ASD explained: "*my child looked normal yet behaved abnormally. I did not know where to start*." Similarly, Respondent KA10013, a grandmother of a 9 year old boy with ASD added: "*I didn't seek medical attention for my child because my sister told me that some boys behave like mine … and that he will outgrow his bad behaviors*" .

This study confirmed that the lack of information affected the ability of the caregivers of children with ASD to develop self-acceptance which led in the delayed diagnosis. The delayed diagnosis increased their level of stress and anxiety which affected their QOL. This is similar to the findings of Salomone et al., (2018), which indicated that stress and anxiety among caregivers affected their QOL

Denial, shock, frustrated, sadness, anxiety, self-blame, depression, acceptance

A significant number (17 persons, or 89.47%) of caregivers experienced a range of negative feelings, including denial, shock, frustrated, sadness, anxiety depression, and distress. Some respondents questioned God why he allowed such condition to their children. Some cried and blamed themselves about the condition of their children. However, others accepted the condition of their children after searching for information from the internet . Below are their verbatim statements:

Respondent KA10018 a mother of an 11 year old boy with ASD had this to say:

"*When I received the information that my child was suffering from ASD, I was very shocked and in total denial. I hoped that the doctor had made a wrong diagnosis and that my son was suffering from something else. Though he explained to me what ASD was and that my son was manifesting the symptoms I didn't want to belief him. I was really scared and the information was unbearable to me".*

Likewise, Respondent KA10011, a mother of an 11 year old girl had this to say:

"*When my girl was diagnosed with this condition I was very sad and in disbelief. I blamed myself and thought maybe it was because I over bled when I was carrying her pregnancy which might have affected her development in the womb. Or maybe it was the abuse I used to be abused by my husband which had affected her and caused her develop such condition".*

Also, Respondent KA1003 recounted her experiences:

"When I realized the normal behavior of a normal child was no more, I was very sad, I cried, cried and cried. I thought if I cry and cry things will be fine. I blamed God why has he allowed such thing to happen to my child? I decide to seek help through prayers so I took my child to "Nabii" (prophets) to be prayed for hoping my child will normalize but it didn't work".

Respondent KA10016, further narrated her experiences:

"*When I realized that my child had autism I was in deep distressed. I got the information in the evening when I was preparing to go to class. I was so stressed even though I didn't attend the class nor eat any food. That was the worst information I had ever received. I asked myself so many questions without an answer. I wondered what would have been the cause of the condition. I pleaded with God that if it was because of our sins, he pardon us and restore our child to normal. It has not been easy to accept the condition of my child but right now I'm trying*".

The reaction of the caregivers after the diagnosis reveals that they did not accept immediately the news about the condition of their children. When they realized their children had ASD they were in total shock, denial, and distress which affected their QOL. Abdullah et al. (2021) confirmed by stating that the caregivers first struggled to accept the reality that their child has ASD.

However, 2 (10.53%) of the caregivers of children with ASD reported that they felt relieved after the diagnosis. Respondent KA1004 reported that she was relieved upon realizing her child was autistic. The following are her narration: "*When my child was diagnosed with SD, I felt relieved because I had suffered with my child for long but now I was relieved because I could take her to school as I rest and do other things*":

Similarly, Respondent KA10017 a mother of a 12 year old boy with ASD added: *"I felt relieved because I had suffered with the child for long. Therefore, I accepted and took it the way it was. However, understanding that their children has ASD did not take away the challenges that arise as a result of caregiving".*

These findings are in agreement with a previous study carried out by Hartmann, (2020), which revealed that the caregivers of children with ASD felt relieved after they have been given an answer concerning the symptoms of their children with ASD. However, understanding that their children have ASD does not lessen the stress that is associated with the burden of taking care of their children with ASD which affects their PWB thus affecting their QOL.

Conclusion

The study established that the caregiver's individual experiences of taking care of children with ASD affected their Psychological Well-Being. Majority15 (79%) of the caregivers narrated that they had no information and knowledge about ASD until their children were diagnosed with ASD. As a direct consequence, the lack of information affected the caregiver's comprehension of behavioral difficulties among children with ASD. It also affected their abilities to develop self- acceptance which led in the delayed diagnosis. The delayed diagnosis increased their level of stress and anxiety which affected their QOL.

Moreover, the study found that majority of caregivers experienced a range of negative feelings However, other caregivers accepted the condition of their children after searching for information from the internet. Though, understanding that their children had ASD did not lower the stress that was associated with the burden of taking care of their children with ASD which affected their PWB and QOL. Additionally, caregivers believed ASD was attached to witchcraft, for they observed their successful growth of their children drastically change within a period of time to worse situation.

Recommendation

The study recommends that healthcare institutions, government agencies, and NGOs prioritize awareness campaigns and educational programs to provide caregivers with accessible and accurate information about Autism Spectrum Disorder (ASD). Early intervention programs should be enhanced to ensure timely diagnosis, reducing stress and anxiety among caregivers. Additionally, psychosocial support services, including counseling and peer support groups, should be established to help caregivers navigate the emotional and psychological challenges of raising children with ASD. Addressing cultural misconceptions and stigma through community engagement initiatives can also improve understanding and acceptance of ASD.

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