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Article

Affiliate Stigma and Social Support as Correlates of Quality of Life of Parents Raising Children with Autism

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Abstract: There is a paucity of studies that explore how quality of life is correlated with affiliate stigma and social support. The objective of this study was to explore the association of affiliate stigma, social support, and quality of life among parents raising children with autism. Using a cross-sectional quantitative design, 118 parents were purposively sampled from the Non-Governmental Organisation in Gauteng province, South Africa. Data was collected using self-report measures of affiliate stigma, social support, and quality of life. The collected data were analysed using Pearson's correlation coefficients. The study results indicated that affiliate stigma was negatively correlated with quality of life r (118) = -.367 p, <.001. The study's findings indicate a statistically significant positive correlation between social support r (118) = .422, p <.001, and quality of life. This study's results indicate social support plays a significant positive role in the quality of life of parents raising children with autism. Stigma does negatively impact the quality of life of parents raising children with autism. This study suggests that more social support services and awareness campaigns can improve the quality of life of parents raising children with autism. The study results suggest that screening for the quality of life of parents of children diagnosed with ASD by healthcare professionals should be part of the child's routine medical checkups.

Keywords: Affiliate stigma; social support; quality of life; parents; children; autism.

Introduction

Autism Spectrum Disorder is a psychiatric condition that falls in the category of neurodevelopmental disorders. This condition is characterised by impairments in social and communication skills together with restricted repetitive behavioural patterns (American Psychiatric Association, 2013). Statistics of autism in South Africa are estimated to be 270,000 (Van Biljon et al., 2015) with newly diagnosed cases increasing. This condition is lifelong and is mainly diagnosed in childhood. Due to the impairments in functioning such as challenges in managing daily activities, and poor communication and social skills (Gorlin et al., 2016), children diagnosed with ASD often need constant close supervision and care. Parents continue taking over all caregiver responsibilities, finding the appropriate school for the child, and worrying about the child's future (Sukmak & Sangsuk, 2018). This continues even in their adult lives (Howlin et al., 2004) resulting in a continuous emotionally draining experience.

Parents raising children diagnosed with autism face multiple challenges Masaba et al., (2021). The challenges include caregiver burden (Mak & Cheung, 2012; Pandey & Sharma, 2018), family stigma and community stigma (Altiere & Von Kulge, 2009), inadequate social support, and insufficient resources for the child with special needs (Sukmak & Sangsuk, 2018). Other challenges range from accepting the child's diagnosis to social isolation which negatively impacts their mental health (Smith et al., 2024). Some parents do experience mental health problems such as depression (Lai et al., 2015; Pondé et al., 2023). Parental mental health challenges such as depression are of serious concern due to their potential negative impact on caregiving responsibilities. This might lead to parents unintentionally neglecting their dependent children who are living with autism compromising proper care, rehabilitation, and poor stimulation within the home environment. The deterioration of the child's functional abilities will in turn perpetuate the parent's psychological difficulties (Musetti, 2024), creating a vicious cycle. Raising a child with autism often results in parenting stress associated with the family's quality of life (Wang et al., 2020).

Most autism studies conducted in South Africa focus on caregiver burden or experiences (Lentoor et al., 2023; van Niekerk et al., 2023). Furthermore, Melamu et al. (2024) and Manono et al (2023) focused on knowledge and understanding of ASD. Monnapula-Mazabane and Petersen (2023) focused on the fear of stigma associated with the illness. On the other hand, Mazibuko et al. (2020) focused on stigma as it is associated with a lack of family support. None of these studies explored parental quality of life. Dardas and Ahmad (2015) explored coping strategies as a mediator or a moderator of the quality of life of fathers raising children with ASD. Turnage and Conner (2022) highlighted the need to explore the father's quality of life. Both studies failed to recommend the inclusion of mothers when assessing parental quality of life further widening the knowledge gap. A recent study by Salami and Alhalah (2024) explored affiliate stigma, perceived social support, and family functioning as predictors of quality of life among parents raising children with autism. Since this study was conducted in Saudi Arabia, there remains much to be explored in the South African context.

The association of affiliate stigma and social support among parents raising children in Gauteng, South Africa is yet to be determined. In South Africa, social support and stigma play important in managing illnesses, and this should be contextualised. African cultural diversity should be considered when studying Autism (Sefotho & Onyishi, 2021; Aderinto, 2023). In some instances, ASD is regarded as a punishment for parents. In South Africa, cultural beliefs associated with the aetiology of ASD contribute to delayed help-seeking behaviour leading to a delay in diagnosis (Melamu, et al., 2024). Manono, et al. (2023) further support this reporting that cultural and religious beliefs influence the entire diagnostic process. This is also linked to long waiting periods. Further delay in the child's diagnosis negatively impacts parental quality of life.

There is clear evidence of socioeconomic disparities rooted in South Africa's apartheid legacy. Parents of children with ASD reported financial burden associated with the children's needs (Mazibuko et al 2020). Limited access to healthcare services is also a challenge. Most people rely on government healthcare systems with long waiting times to access treatment. For those in private healthcare, funds are often insufficient to cover all treatment-related costs. Furthermore, the lack of adequate schools' results in parents outsourcing private education for their children. In government schools, many teachers lack adequate training to work with children with ASD (Mpangane, et al., 2024) further straining parents.

There is also limited access and low parental involvement when children are placed in school (Janse van Rensburg & Johnson, 2023). Some parents struggle with the severity of their child's diagnosis (Turnage & Conner, 2022). Caregivers of children diagnosed with ASD do not disclose the child's diagnosis due to fear of stigma (Monnapula-Mazabane & Petersen, 2023). Stigma is associated with poor family support (Mazibuko, et al., 2020) and poor family function and social function (Turnage & Conner, 2022). Furthermore, negative societal stereotypes about ASD lead to poor social support (Sefotho & Onyishi, 2021). All these negatively contribute to parents' quality of life. Broad socio-cultural differences in South Africa make direct comparisons between the quality of life of parents of children with ASD and those in developed countries such as America and Europe (Pillay, et at., 2021) challenging. This suggests that contextually relevant local studies are relevant

Therefore, this study aims to close this gap. This current study investigates the relationship between affiliate stigma, social support, and quality of life among parents raising children with Autism. The study hypothesised that affiliate stigma negatively correlates with the quality of life, while social support has a positive correlation with the quality of life.

Literature Review

The quality of life is the degree to which an individual is satisfied with their life experiences and physical and psychological requirements (Rice, 1984). The World Health Organization Quality of Life (WHOQOL) group defines QOL as “individuals' perceptions of their position in life in the context of the culture and value systems in which they live and about their goals, expectations, standards, and concerns." (WHOQOL Group, 1998). Parents raising children with mental illness generally report a poorer quality of life than parents raising children without mental illness (Dey et al., 2019). Parents raising children living with autism experience poor quality of life (Pondé et al., 2023). Mannion and Leader (2023) argued that this decline was linked to the child’s sleep problems. For some parents, quality of life is negatively affected by the child’s behavioural and emotional challenges such as struggling to deal with changes or crying for no reason (Musetti, 2024). The child's behavioural and emotional difficulties are also associated with parental stress (Robinson & Weiss, 2020), which in turn is related to poor quality of life (Wang et al., 2020).

In addition to poor quality of life, parents raising children with autism reported experiencing stigma (Aishaiga et al., 2020) regardless of culture (Liao, 2019). Stigma is understood as biased prejudicial attitudes that are discriminatory by a majority group towards a minority group (Corrigan, 2000). Mak and Chueng (2008) introduced the concept of affiliate stigma, which occurs when family members of a stigmatised person internalise negative societal attitudes. Caregivers of children with intellectual disability and autism reported a high level of affiliate stigma compared to those caring for children with intellectual disability only. This affiliate stigma contributes to the caregiving burden (Mak & Cheung, 2012) as they experience stigma from their family members and church members to the extent that they stop attending church (Altiere & Von Kulge, 2009). This isolation often stems from misunderstandings about ADS behaviours, which are perceived as disruptive or socially inappropriate.

A meta-synthesis of qualitative studies of parents raising children with autism showed that parents experienced different types of stigmas such as felt stigma, enacted stigma, and variations which are related to affiliate stigma (Salleh et al., 2020). This was further supported by Ye et al., (2024) and Zhang et al., (2018) who reported that affiliate stigma negatively predicted the quality of life among parents of children with autism. This literature suggests that parents raising children with autism experience affiliate stigma which negatively affects their quality of life rendering them vulnerable to other challenges. This is evident in the work of Wang et al., (2024) who argued that this perceived stigma is correlated with social anxiety among parents of ASD children. Fathers raising children with ASD reported experiencing stigma and blame from their communities (Alareeki et al., 2022) while mothers reported experiencing self and enacted stigma (Aishaigi et al., 2020).

Social support plays a crucial role in mitigating these challenges. Social support is defined by Wills (1991) as an individual’s perception or experience of feeling loved, cared for, and valued by other people and belonging to a social network that assists. However, parents of children with autism often lack social support due to the stigma around ASD (Alshaigi et al., 2020). Among a sample of parents raising children with autism, Salami and Alhalal (2024) found that affiliate stigma, perceived social support, and family functioning had significantly predicted quality of life. Social support has a direct impact on parents’ well-being, with inadequate support increasing parental stress (Ban et al., 2021). Mothers, in particular, report experiencing rejection and isolation from their communities and insufficient emotional support from their spouses. However, they found solace in their support groups (Lamba et al., 2022). A recent systematic review by Ault et al., (2021) indicated that social support, regardless of whether it is formal or informal, helped in decreasing stress and improving the mental health of caregivers of children with autism. When there is isolation, there is a lack of caregiver support on the individual and family levels. Social support is a predictor of quality of life with family support predicting physical quality of life and friend support predicting mental quality of life (Ji et al., 2014). The authors argued that family members help with household responsibilities while friends provide emotional support. This is because social support serves as a protective factor for this population of parents raising children with autism (Khusaifan, et al., 2021). Thus, making social support the most important factor for parents of children with autism (Robinson & Weiss, 2020). Drogomyretska and colleagues (2020) further argue that social support, especially from friends, was a protective factor against parental stress in parents of children with autism.

Autism remains a stigmatised condition in Africa (Sangare et al., 2019). A lack of knowledge about ASD continues to contribute to stigma and discrimination (Oduyemi et al., 2021; Adams, 2024). This knowledge gap is not limited to parents, families, and communities but extends to future healthcare professionals. A recent South African study by De Jongh and Mapiso (2024) found that university students training in health sciences lacked sufficient knowledge about ASD. This is concerning, as these professionals are expected to conduct assessments, make diagnoses, and develop intervention plans for children with ASD. Adams (2024) further highlights the issue by reporting that parents often lack adequate professional support.

The reviewed literature indicates that similar trends exist across Africa, with research primarily focusing on knowledge and understanding of ASD, as well as challenges related to caregiver burden and stigma. However, there is a noticeable lack of quantitative studies examining parental quality of life. This contrasts with research in Asia, Europe, and America, where quantitative studies frequently explore the parental quality of life of ASD caregiver burden.

Methodology

A cross-sectional quantitative design was used. The dependent variable was quality of life, and the independent variable was affiliate stigma and social support. This cross-sectional study was carried out electronically where participants had to complete an online survey. Table 1 below presents the demographic details of the sample.

Table 1. Participants demographic (N=118)

		N	%
Gender	Male	8	6.8
	Female	110	93.2
Race	Black	91	77.1
	White	24	20.3
	Coloured	2	1.7
	Indian	1	.0
Relationship status	Married	59	50.0
	Dating	9	7.6
	Divorced	12	10.2
	Single	38	32.2
Level of education	Below matric	2	1.7
	Matric	14	11.9
	Diploma	8	6.8
	Degree	63	53.4
	Post-graduate	31	26.6
Employment status	Employed	67	56.8
	Unemployed	41	34.7
	Self-Employed	10	8.5

The participants in this study were mainly female (93.2%) with very few males (6.8%). The age ranged from 24 to 68 years with a mean age of 40.28 (SD- 8.11). They were predominantly black (77.1%) followed by Caucasian (20.3%), coloured (1.7%), and Indian (.8%). Half of the sample indicated that they were married (50.0%), followed by those who were single (32.2%), divorced (10.2%) and dating (7.6%). Just more than half of the participants indicated that they were employed (56%) followed by those who were unemployed (34.7%) and self-employed (8.5%). A good number of the sample had a university degree (53.4%), followed by those with a post-graduate degree (26.6%), matric (11.9%), and diploma (6.8%). Very few did not complete high school education (1.7%).

1. Study Setting

This study was conducted in Gauteng Province, South Africa. The participants were recruited from a Non-Governmental Organisation. This organization has a strong network with hospitals in Gauteng province. The researchers approached Autism South Africa because they are one registered organisation that caters to children and adults living with autism and has different intervention programmes for children, parents, and families. A formula for unknown population size was used to calculate this study's sample size. Following the principles of this formula, sample size = $(1.96^2) \times 0.5 \times (1- 0.5) / 0.05^2$ 384 was estimated for this study. However, due to the nature of the sample population, only 118 participants could participate.

The 118 participants were purposively selected as they had characteristics that the researchers were interested in. The use of small sample sizes in these populations is not relatively new. For example, Alhazmi, et al (2023) used a sample of 54 parents when exploring the quality of life of parents of children diagnosed with ASD in Saudi Arabia. The total number of participants was deemed sufficient to continue with data analysis due to the characteristic's nature of the sample. The characteristics were such that for participants to be included in the study, they had to be biological parents or legal guardians of children living with autism. The participant should have been staying with the child in the same household. Their child should have been 18 years or below. A registered healthcare professional should have confirmed the child's diagnosis. The participants' relationship or marital status was not a determining factor for participation. A total number of 118 participants was deemed sufficient to continue with the analysis. This is because of the purposive nature of the study that required parents to be participants

2. Measures

World Health Organisation Quality of Life

The World Health Organization Quality of Life Scale (WHOQoL- Brief) is a 26-item measure of quality of life (Lu et al 2015). This scale has four subscales that assess physical health, psychological health, social relationships, and personal environment of quality of life. Items are scored on a Likert scale of 1-5 with higher scores indicating good quality of life. Mashola and Mothabeng (2019) reported a Cronbach's alpha of .83.

Affiliate Stigma Scale

Affiliate stigma was measured with an affiliate stigma scale which is a 22-item with 4 subscales that measure emotions, cognitive abilities, behaviour, and self-esteem. Some examples of the items on the scale include "I feel that I am inferior to others" The measure is a 4-point Likert scale with responses ranging from 1 to 4, with higher scores suggesting higher levels of affiliate stigma (Mak & Cheung, 2008). Ye et al., (2024) reported a Cronbach's alpha of .90 among parents raising children with autism.

Multidimensional Perceived Stigma Scale

Participants' social support was measured using a multidimensional scale of perceived social support which covers three subscales of social support (family, friends, and significant other) (Zimet 1988) This is a 12-item scale with questions such as "there is a special person who is around when I am in need" and it is measured on a Likert scale of 7 points with responses ranging from 1 (strongly disagree) to 7 (strongly agree). A Cronbach's alpha of .92 was reported by Wang (2024) among parents raising children with autism.

3. Procedure

Data collection commenced after ethical approval from the Sefako Makgatho Health Sciences University Research Ethics Committee (SMUREC) (SMUREC/M/159/2020:PG) was received. Furthermore, the Gauteng regional development officer for Autism South Africa permitted the researchers to use their database and platform to recruit participants. For participants to participate in the study, they had to complete an online survey shared on the Autism South Africa database. The survey was created on Google Docs (Docs Editors, 2016) on a password-protected computer. The online survey was constructed with strict ethical guidelines. When participants clicked on the survey link, the first section they could access was detailed information about the study, followed by a detailed consent form. Participants could not proceed to the survey questions if they did not complete the consent form. The information on the consent form highlighted ethical principles of maintaining confidentiality and anonymity, privacy, the right to withdraw from the survey at any time, and information regarding counselling services. Participants were not required to use their identifying details when completing the survey. Participants were linked to a non-governmental organisation. This might have had potential response bias. However, this was minimised by allowing the participants to complete the survey without using their identified information ensuring anonymity throughout the process.

4. Statistical methods

Data were analysed using the Statistical Package of Social Science (SPSS) software programme version 28. Descriptive statistics were used to describe the study sample profile. Pearson correlation was used to test the hypothesis which stated that affiliate stigma will have a negative correlation with quality of life while social support will have a positive correlation with quality of life. The statistical significance was set at $p < .05$.

The Findings

The study hypothesised that affiliate stigma has a negative correlation with the quality of life while social support has a positive correlation with the quality of life. The results are presented in Table 2 Below.

Table 2 Affiliate stigma, social support and quality of life

Variables	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**
Special person	1													
Family support	,542**	1												
Friend support	,551**	,438**	1											
Total social support	,843**	,809**	,811**	1										
Emotion	-,161	-,146	-,060	-,149										
Cognitive	-,129	-,087	-,148	-,148	,669**	1								
Behaviour	-,143	-,079	-,167	-,158	,350**	,451**	1							
Self-esteem	-,092	-,081	-,039	-,085	,498**	,500**	,436**	1						
Affiliate stigma	-,161	-,123	-,125	-,165	,823**	,884**	,619**	,775**	1					
Physical	,322**	,171	,179	,271**	-,138	-,213*	-,157	-,213*	-,232*	1				
Psychological	,369**	,251**	,186*	,325**	-,354**	-,286**	-,156	-,161	-,313**	,511**	1			
Social	,505**	,418**	,435**	,551**	-,411**	-,361**	-,300**	-,341**	-,448**	,468**	,514**	1		
Environmental	,292**	,199*	,251**	,300**	-,150	-,352**	-,107	-,130	-,261**	,592**	,492**	,449**	1	
Quality of life total	,430**	,309**	,305**	,422**	-,293**	-,379**	-,189*	-,242**	-,367**	,805**	,749**	,692**	,876**	1

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

1. Affiliate Stigma

The study findings showed that affiliate stigma (r(118) = -.367, p <.001), emotion (r(118) = -.239, p <.001), cognitive (r(118) = -.397, p <.001), behaviour (r(118) = -.189, p <.04) and self-esteem (r(118) = -.242, p <.008) negatively correlated with quality of life parents raising children living with autism. Affiliate stigma further showed a negative correlation with physical subtype (r(118) = -.232, p <.011), psychological (r(118) = -.313, p <.001), social (r (118) = -.448, p <.001) and environmental (r(118) = -.268, p <.004) quality of life of parents of children living with autism. These results suggest that parents experiencing stigma in one form, or another will report poor quality of life in different forms.

2. Social Support

The results revealed that total social support and the 3 subscales of social support (r(118) = .422, p <.001), special person (r(118) = .430, p <.001), family support (r(118) = .309, p <.001), and friend support (r(118) = .305, p <.001) were positively correlated with quality of life of parents raising children living with autism.

Furthermore, social support is positively associated with physical subtype (r(118) = .271, p <.003), psychological subtype (r (118) = .325, p <.001), social subtype (r(118) = .551, p <.001) and environmental subtype (r(118) = .300, p <.001) of quality of life of parents raising children living with autism. These results inform that parents who receive adequate social support from friends, family members, and special persons will report a good quality of life. These results accept the study hypothesis.

Discussion

The study hypothesised that affiliate stigma would negatively correlate with the quality of life, while social support would have a positive correlation with the quality of life of parents raising children with autism. The results confirmed that affiliate stigma is negatively associated with parental quality of life. These findings align with previous studies by Ye et al. (2024) and Zhang et al. (2018), which reported that affiliate stigma is a significant negative predictor of quality of life among parents of children with autism.

This form of stigma, which encompasses emotional, cognitive, behavioral, and self-esteem-related aspects, contributes to the observed negative correlation. Similarly, Salleh et al. (2020) highlighted that parents experience various types of stigmas, including felt stigma, enacted stigma, and other variations related to affiliate stigma. These results suggest that parents who experience stigma in any form are more likely to report a lower quality of life in multiple dimensions. What we are learning from this study is that stigma, regardless of form, is a negative factor of quality of life. This is a significant challenge as stigma can arise from strangers, community members including other family members. When surrounded by a stigmatising community, parents raising children with autism are rendered socially vulnerable as autism is regarded as a stigmatised condition (Alshaigi et al., 2020) They are likely to be isolated, hindering them from the needed social connectedness. This is because where there is stigma, there is limited social support (Lamba et al., 2022). This social isolation negatively impacts their mental health (Smith et al., 2024) creating a vicious cycle of vulnerability.

The results of this study are influenced by the level of stigma reported in ASD studies. Parental quality of life is closely linked to the stigma associated with autism (Alhazmi et al., 2023). South African caregivers experience ASD-related stigma (Monnapula-Mazabane and Petersen, 2022) which is associated with a lack of knowledge about ASD (Melamu, et al. 2024). In Asia, studies have shown that parents often struggle with a lack of knowledge about ASD, which, along with stigma, poses significant challenges (Smith et al., 2024; Wang et al., 2024). The same trend was reported among Malaysian parents who reported limited understanding of autism (Arunasalam, et al. 2024). Similar trends have been observed in Africa (Oduyemi et al., 2021; Sangare et al., 2019). In Nigeria, Adams (2024) notes that this lack of knowledge is compounded by inadequate professional support, further hindering the well-being of parents raising children with autism.

Continuous community ignorance about mental illness contributes to the perpetuation of stigma and limits social support. Mdluli et al. (2022) highlighted that a lack of understanding about autism remains a significant challenge. When community members are uninformed about autism, they struggle to recognise its presentation, often misinterpreting the child's behavior and stigmatising the parent as a result. This creates a dual burden for parents, as they must manage their child's behavior while also coping with public judgment and discrimination. Cultural beliefs further shape how autism-related stigma manifests, particularly in South Africa, where traditional belief systems strongly influence perceptions of illness and treatment. Mthombeni and Nwoye (2018) found that some mothers in KwaZulu-Natal associate autism with supernatural causes, attributing it to spirits, God, or ancestors. Salkas (2016) and Mthombeni and Nwoye (2018) noted that autism is sometimes viewed as divine or ancestral punishment for a family's transgression of socio-cultural norms. Additionally, some communities link autism to witchcraft (Mdluli et al., 2022). These beliefs contribute to social exclusion, as families of children with autism may be avoided or stigmatized due to fears surrounding these perceived supernatural causes. In Kenya (Greer et al., 2022) and Nigeria (Adams, 2024), cultural beliefs play a significant role in shaping perceptions of autism, often influencing how its causes are understood. In these contexts, autism is sometimes attributed to supernatural or spiritual causes, which can contribute to stigma and misconceptions. Such cultural explanations may affect how families seek support, access interventions, and cope with the challenges of raising a child with autism.

Our study sample primarily consists of females, specifically mothers of children with autism. This indirectly highlights that mothers are disproportionately affected by affiliate stigma. A previous study by Aishaigi et al. (2020) found that mothers experience both self-stigma and enacted stigma. As primary caregivers, mothers are traditionally responsible for their children's well-being (Johnson et al., 2011) and caring for a child with autism further predisposes them to a lower quality of life. Research has also pointed to gender disparities in the quality of life of parents of children with autism (Vasilopoulou & Nisbet, 2016), with mothers reporting lower quality of life compared to fathers (Hsiao, 2018). This suggests that when designing stigma-reduction and quality-of-life interventions for parents, a more personalized approach tailored to the unique challenges faced by mothers is essential.

This study’s results revealed that social support from friends, family, and special persons has a positive correlation with quality of life. The findings of our study are supported by Kuru and Piyal 2018 who found a positive correlation between social support and quality of life among parents raising children with autism. In our current study, we found that social support from a special person had a higher correlation with quality of life. This study indicated that social support from family members and friends also showed a positive correlation. This is because social support serves as a protective factor for this population of parents raising children with autism (Khusaifan, et al., 2021). Previous studies indicated that family support predicts physical quality of life and friend support predicts mental quality of life (Ji et al 2014). When one has social support, the support structures play different roles ranging from assisting with caregiving responsibilities or providing care to the caregiver. For those parents who struggle to participate in social activities, when they receive support through someone who takes care of the child for the day, that can be seen as a timeout allowing an opportunity to connect with other people outside the family life. Caregivers of children with autism with good social support reported less caregiver negative impact (Christopher et al., 2023). Drogomyretska and colleagues (2020) further argue that social support, especially from friends, was a protective factor against parental stress in parents of children with autism.

Further results show that social support positively correlated with different subtypes of quality of life, i.e., physical, psychological, social, and environmental. This was a contradiction with the work of Lamba et al., (2022) which mentioned that mothers raising children with ASD experienced rejection and isolation from their communities. They further experienced inadequate emotional support from their spouses but found solace in their support groups. This social support can even be in informal contexts (Searing et al., 2015). Informal social support has been correlated with quality of life among caregivers of children with autism (Marsack & Samuel, 2017). These support networks help with information sharing and sharing of personal experiences. This translates to parents feeling heard and validated by other parents sharing the same experiences. Additionally, with shared information, parents can be informed about resources available to them and their child living with autism leading to a better quality of life. Social support does help individuals feel socially connected (Reinke & Solheim, 2015) leading to better parental coping resources (Weinberg, 2021) impairing the quality of life.

The results of the study could be silently influenced by coping mechanisms employed by parents. It is argued that problem-focused coping mechanisms positively correlate with well-being (Lin, 2015). Problem-focused coping mechanisms have been argued by Lazarus and Folkman (1984) who indicated that an individual is actively taking action to find solutions related to their stressor. Parents employing problem-focused coping mechanisms are likely to reach out for help from different sources including support networks when they do not get support from their primary support structures. Those individuals who can reach out feel socially connected (Reinke & Solheim, 2015) leading to better parental coping resources (Weinberg, 2021). In the South African context, where sociodemographic challenges related to autism persist (Pillay et al., 2021), parental coping mechanisms remain under strain. Raju et al. (2023) further emphasize that quality of life is also correlated with socioeconomic status, highlighting the broader impact of financial and social disparities. These economic challenges impact parents' caregiving responsibilities for children with special needs (Manamela, et al. 2024). Socioeconomic disparities continue to play a significant role, limiting access to essential resources and support systems.

Poor access to adequate healthcare services for children with autism further exacerbates parental stress, as caregivers struggle to secure necessary interventions. Additionally, stigma within family systems and communities remains a persistent issue, further isolating parents and compounding their challenges.

It is worth noting that social support can take place in many forms such as friends, family, church, support groups, and professionals. It could be that due to various forms of social support, these parents did have access to one or more forms of social support. For other parents, professional support is deemed relevant. This professional support is characterised by organisational support, autism support groups, professional mental health services, and therapeutic services (Marsack-Topolewski, 2020). Healthcare care professionals should not focus on the child, and screening of parents' possible psychological difficulties but serve as support structures as well. Goedeke (2019) reported that professional support for parents raising children with autism helps decrease care-related stress.

Our sample indicates that the majority of participants were married. Given the challenges associated with poor quality of life, it is important to recognize that marital relationships may also be affected, potentially leading to further isolation when partners are unable to support each other. Lamba et al. (2022) previously highlighted that mothers of children with autism often experience inadequate emotional support from their spouses. This lack of support may be linked to the marital dissatisfaction frequently reported among parents of children with autism (Gau et al., 2012), preventing these couples from benefiting from the traditional emotional and social support that intimate partnerships typically provide. The findings of this study suggest that the quality of life for parents raising children with autism is negatively impacted by affiliate stigma, which manifests through emotional, cognitive, behavioral, and self-esteem-related factors. Women, in particular, appear to be more vulnerable to poor quality of life due to their primary caregiving responsibilities and the lack of spousal support. As a result, many mothers rely on informal social support structures to help them manage the demands of caregiving.

From this study's findings, it is evident that there needs to be tailor-made intervention strategies for parents of children with autism. These should also include strengthening their social networks to limit the isolation they are experiencing due to raising a child with autism. The support networks can be for mothers and fathers separately and in turn can provide each other with spousal support. There is a need for more structured government-provided support services. It is recommended that for every parent whose child is newly diagnosed with autism, it be standard practice that they are referred to appropriate care support services instead of a wait-and-see approach. More awareness campaigns aimed at reducing the stigma associated with autism and enhancing social support are needed. Research studies aimed at stigma reduction interventions are of paramount importance.

Conclusion

This study concludes that there is a negative correlation between affiliate stigma and quality of life. Furthermore, there is a positive correlation between social support and quality of life. This implies that those participants who reported higher levels of affiliate stigma and lower levels of social support reported poor quality of life. This was also observed in different domains of affiliate stigma, i.e., emotional abilities, cognitive abilities, behaviour, and self-esteem which all negatively correlated with quality of life.

The cross-sectional nature of this study is a limitation, cause and effect could not be established. There was no collateral information to augment the self-reported quality of life. Parents might have over-reported or under-reported their levels of quality of life. This study was quantitative, there was no opportunity to explore these parents' reports qualitatively. Future studies should consider mixed-method approaches. Due to the small sample size, and that the study was limited to parents who had contact with Autism in South Africa, these results cannot be generalised to the population of parents in Gauteng Province and other settings.

Lack of data on the children's severity of the autism presentation or comorbid conditions denies the opportunity to assess if the child's presentation could also influence the quality of life. There was no control group of children diagnosed with other developmental disabilities to determine their parents' quality of life. This should be investigated. Future studies should consider longitudinal design to evaluate if the quality of life decreases or increases when the child living with autism grows older. As much as parents in this study had to be staying with the child, time spent directly caring for the child was not explored. It cannot be determined that this poor quality of life could be attributed to extended periods of caring for a child with autism. Future studies should control for confounding variables such as socio-demographic factors, including parental education level, household economic status, child's age, and severity of diagnosis, as these may significantly impact quality of life. Additionally, research should focus on larger sample sizes, particularly among parents in rural areas.

The study findings suggest that healthcare professionals should incorporate quality-of-life screenings for parents of children diagnosed with ASD as part of routine medical checkups. Government policies should be revised to recognize parents as service users, ensuring they receive their own tailored intervention plans. Furthermore, awareness campaigns should extend beyond the child's condition to address the challenges faced by parents. Stigma eradication efforts and community-based interventions aimed at empowering parents are essential. Strengthening social support programs with sustained government funding is also necessary. Lastly, the Departments of Health, Social Development, and Basic Education must collaborate rather than operate in isolation when addressing ASD-related issues.

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