

# Understanding and Addressing the Impact of Parental Stress and Stigma in Raising Children with Autism Spectrum Disorder (ASD) in Low-Resource Settings

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## ABSTRACT

The burden on parents raising children with Autism Spectrum Disorder (ASD) is escalating globally, particularly in middle and low-income countries, where access to resources and support is limited. This study aimed to investigate the levels of stress, stigma, and coping strategies among parents of children with ASD in Kawempe Division, Kampala, Uganda. Through a sample of 28 parents drawn from Katalemwa Cheshire Home, data was collected using self-administered questionnaires and analyzed using descriptive statistics. The results revealed very high levels of stress and stigma among parents, as evidenced by a grand mean of 3.71 (SD = 0.79) for stress and 3.57 (SD = 0.55) for stigma. These stressors encompassed various domains, including financial difficulties, marital conflicts, and psychological strain resulting from societal discrimination. Parents reported experiencing feelings of shame, embarrassment, and hopelessness, exacerbated by societal misconceptions and the lack of support systems. Notably, the prevalence of anxiety symptoms among parents (45.9%) surpassed previous estimates, indicating a significant mental health burden within this population. Furthermore, the coping mechanisms employed by parents were found to be inadequate, with a grand mean of 1.78 (SD = 0.77) for coping strategies. Positive coping strategies, such as seeking new job opportunities for their children, were limited, while negative coping mechanisms, including substance abuse and rudeness, were more prevalent. These findings underscore the urgent need for tailored interventions to equip parents with effective coping strategies and stress management techniques. The study highlights the challenges faced by parents raising children with ASD in low-resource settings, shedding light on the psychological, social, and economic burdens they endure. Addressing these challenges requires comprehensive support systems, including training programs, workshops, and access to resources aimed at empowering parents and enhancing their well-being. By understanding and addressing the specific stressors and coping mechanisms within this population, interventions can be developed to alleviate the burdens faced by parents, ultimately improving their quality of life and promoting the holistic development of children with ASD.

**Keywords:** Stress, Stigma, Coping Strategies, Autism Spectrum Disorder, Raising children.

## INTRODUCTION

The parental burden of raising children with autism spectrum disorder (ASD) is increasing globally, with great effect in the mental health of several parents. Most of the parental-victims live middle-income and low-income countries, where they are stressed and stigmatized [1]. Though all parents experience stress of raising children and one is not unaware of the distinct responsibilities associated being parents, parenting stress and stigma for parents raising children with ASD has been reported to be incredibly challenging; its impacts are further exacerbated by socioeconomic status. Low socioeconomic standing of families militates against proper information and understanding about their children's condition and experience uncertainty and

disappointment about their children's future and developmental restrictions. Moreover, parents may feel overwhelmed and burdened and even find it challenging to follow treatment and rehabilitation plans recommended for their children [2].

ASD is a complex neurological disorder that has created a global health concern [3]. It is characterized communication and social interaction impairment [4]. More so, children that are suffering ASD are always known to be exhibiting maladaptive behavior and having difficulty in developing appropriate relationships. Over the years, enormous number of children affected by ASD has dramatically risen [5]. One out of every 160 children globally is estimated to have ASD [6]. While previous studies

suggest families adjust to the challenges of raising a child with autistic spectrum disorder over time [7], the specific levels of stress, stigma, and coping strategies employed by parents in Kawempe Division, Kampala, Uganda, remain under-investigated. This study addressed this gap by evaluating the levels of stress, stigma, and coping strategies employed by parents raising children with ASD at Katalemwa Cheshire Home in Kawempe

Division, Kampala, Uganda. However, the present study aimed to explore exclusively parents raising children with ASD at Katalemwa Cheshire Home in Kawempe Division, Kampala Capital City Authority, Uganda, to necessitate proper understanding of the stressful and stigma burdens parents experience while raising children with ASD, and discover efficacious interventions that can promote mental health of parents that are raising children with ASD.

## METHODOLOGY

### Targeted population and sample size

A total of 30 participants-comprising only parents raising children with ASD formed the target population. From this targeted population, a sample of 28 participants was drawn using Krejcie and Morgan [8] recommendation on sample size generation.

### Sampling technique and procedure

The researchers employed a simple random sampling technique to select 28 participants (both male and female participants). Self-administered questionnaires were used in data collection. The data were analyzed using frequencies, percentages, mean, and standard deviation.

## RESULTS

**Table 1: Levels of Stigma, Stress and Coping among Parents Raising Children with Autism.**

Items	Mean	SD	Interpretation
<b>Psychological stress</b>			
I have financial problems	4.32	1.06	Very high
My marriage has conflicts	4.11	.99	High
The death of my boss has affected my well being	3.96	.99	High
I want to fight any person	3.43	1.19	High
I want to kick anything	3.54	1.14	High
I feel angry at my friends	3.50	1.04	High
I hate illiterate people	3.61	1.23	High
I feel jealousy for my husband	4.36	.49	Very high
<b>Aggregate mean and SD</b>	<b>3.85</b>	<b>1.02</b>	<b>High</b>
<b>Self-stigma</b>			
I am ashamed of my family	3.50	.51	Very high
People like humiliating me in public	3.68	.48	Very high
I prefer staying alone	3.57	.50	Very high
I have lost hope in my child	3.25	.84	High
People isolate me by the society	3.64	.49	Very high
I feel discriminated by the society	3.79	.49	Very high
<b>Aggregate mean and SD</b>	<b>3.57</b>	<b>0.55</b>	<b>Very high</b>
<b>Grand mean and SD</b>	<b>3.71</b>	<b>0.79</b>	<b>Very high</b>
<b>Positive coping</b>			
I got a new job for my son	1.32	.55	Very low
I accept to live with my sickness	1.57	.69	Very low
I relax to release my attention	2.04	.69	Low
<b>Aggregate mean and SD</b>	<b>1.64</b>	<b>0.64</b>	<b>Very low</b>
<b>Negative coping</b>			
I don't live in denial	1.93	.81	Low
I abuse drugs when am annoyed	1.86	.93	Low
I become rude when not happy	1.96	.96	low
<b>Aggregate mean and SD</b>	<b>1.92</b>	<b>0.9</b>	<b>low</b>
<b>Grand mean and SD</b>	<b>1.78</b>	<b>0.77</b>	<b>low</b>

N=28

## DISCUSSION

The results of the study show that parents of autistic children generally had very high levels of stress and stigma (Grand mean = 3.71, Sd = 0.79), and low levels of coping (Grand mean = 1.78, Sd = 0.77). Although our results for anxiety (45.9%) are comparable to those of the [9], their prevalence estimate of stress symptoms (46%) differs slightly from ours. A study done in the United States with the Beck Anxiety Inventory revealed that 12% of parents reported having anxiety symptoms. In addition, our study sample has a greater prevalence of anxiety than the 33% reported in a meta-analysis of publications using self-reported measures [10, 11].

The study demonstrated that a variety of stressors that were substantial sources of psychological load were encountered by parents raising children with ASD. The psychological load that women in this study faced was influenced by feelings of anxiety, frustration, hopelessness, and overload related to the practice of raising a child with ASD. The results of this study, which are in line with previous researches, indicated that mothers had emotional issues, particularly depression [12, 13]. Social status and the primary symptoms of the children with autism are correlated with emotional issues in mothers of autistic children. Parents of children with ASD in the US reported far greater levels of parenting stress and depression than parents of children without ASD, according to research by [14].

In this study, as in previous qualitative research in Sub-Saharan Africa [15, 16, 17, 18, 19], parents reported a significant societal hardship. The parents' social burdens were particularly noticeable when they discussed how their ASD affected their social lives and how they were affected by internalised and affiliate stigma. According to the current research, parents frequently internalised external criticism associated with stigma, which led to feelings of guilt, shame, embarrassment, and helplessness. They also believed that they had little to no control over the discrimination and social prejudices that accompanied their children's condition. In Addis Ababa, Ethiopia, Cobert [20] carried out research with 102 carers of children with ASD and intellectual disabilities that showed how widespread stigma is. According to the study, more than 40% of

Parents who are not provided with adequate physical support to care for their impaired children experience physical exhaustion and social humiliation. The majority of the parents who participated in our study said that taking care of their impaired children prevents them from having much time for themselves and their social lives. Child minders are hard to come by, and special

parents were concerned about receiving different treatment; 46 out of 102 felt guilty or embarrassed about their child's condition; roughly 27% felt that they had to keep their child's condition a secret from others; and nearly 50% felt that they were to blame for the child's condition. Furthermore, the parents in this study reported social stigma experiences, which is in line with research from low- and middle-income countries [21] as well as high-income nations [22]. According to earlier qualitative research Pohl, Crockford, Blakemore, Allison and Baron-Cohen and [23], the parents in this study faced stigma because their kids were wrongly labelled as "crazy," "naughty Zuurmond, Seeley and Nyant," or "demon-possessed." They also faced criticism for not having the parenting skills necessary to discipline or control their kids when they acted in a way that was socially inappropriate in public. Therefore, in order to avoid social criticism and reduce anxiety about their child's possible behavioural outburst in public, parents in this study frequently shunned socially engaging activities. This avoided conduct led to (self) isolation and loneliness, which has been validated by prior research [24]. Mothers' health and well-being are negatively impacted by social isolation and loneliness, according a recent scoping review [24]. Loneliness and isolation have been linked in studies to depression, elevated stress levels, and burnout in parents [25]. The results corroborate the research by [23], which demonstrated that parents of ASD children are often left out or marginalised in the community and may feel especially alone when others do not accept their child.

Parents of children with ASD who are marginalised may experience increased parenting stress and poor mental health as a result of not being able to seek social assistance in their communities. This study adds to the body of research demonstrating that mothers take responsibility for their children's stigmatised conditions and suffer stigma by affiliation with them. These overall results are consistent with previous researches which found that people experience discomfort when they believe they are powerless to control or manage changes brought about by everyday activities [24, 25]. Distress is now more widely acknowledged as a component that can lower most people's quality of life.

## CONCLUSION

education schools are practically nonexistent in our community. Parents who care for their impaired children may also experience sadness due to feelings of guilt about the child's condition. The majority of parents hold themselves responsible for the state of their kids. This sense of shame and the blame game/argument may be the result of parents not

receiving enough information and education about the issues affecting their children.

### Recommendations

The study suggests that parents should be offered training programs and workshops that focused on equipping them with effective coping strategies and

stress management techniques and also provide tools and resources to help parents better navigate the challenges associated with raising a child with ASD which will significantly improve their well-being and quality of life.

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