

UNDERSTANDING THE RELATIONSHIP BETWEEN PARENTAL STIGMA AND COPING BEHAVIORS IN FAMILIES WITH AUTISTIC CHILDREN AT KATALEMWA CHESHIRE HOME IN KAWEMPE DIVISION, KAMPALA

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ABSTRACT

This study sought to understand the interplay of Parental stigma and coping Behaviors in Families with autistic Children at Katalemwa Cheshire home in Kawempe Division Kampala. Both Self-administered questionnaires and Interview guides were used in data collection. Quantitatively data was analyzed using Data was analyzed using Pearson Correlation product moment. The findings indicated that there was low inverse insignificant relationship between stigma and coping ($r = -.002$, $p = .993 > 0.05$) this implies that when Stigma is high the tendency for coping will be low, and when Stigma is low the possibility of coping is high. This aligns with Hayes (2020) who showed that accepting difficult emotions and staying present improves problem-solving. This highlights the flexible nature of human responses, where individuals can react to situations in both helpful and unhelpful ways. While Qualitative data analysis revealed some parents raising children with autism cannot accept to live with the condition of their children and this affects their daily lives, Parents need to be given psychosocial support, Parents need to accept to live with the mental disability of their children. This finding aligns with a study by Postula & Bieleninik's (2023), which emphasizes autism spectrum disorder as a lifelong condition. Their findings underscore the importance of supporting parents in understanding and accepting their children's experiences throughout life.

Keywords: *Stress, Stigma, Parents, Autism.*

INTRODUCTION

Khanh et al. (2023) asserts that early diagnosis and intervention for autistic children are crucial, and parental perceptions regarding stigma can significantly impact this process. Furthermore, parents actively contribute to their children's social integration, but effectively managing their children's healthcare demands substantial time, dedication, and emotional resilience from the parents themselves.

According to Yasutake & Lombardo (2020), Stigma refers to negative attitudes and beliefs held by society towards a group of people. In the context of autism, stigma can manifest as prejudice, discrimination, and social isolation experienced by families raising children with autism spectrum disorder. While stigma is widely perceived as a significant challenge faced by these families, large-scale, systematic studies on this topic have been limited.

Raising a child with autism spectrum disorder presents unique challenges for families. A study by Singh & Banerjee (2022) explored the specific behaviors associated with social rejection and how they impact family dynamics. Their findings highlight a concerning correlation between autistic behaviors and social stigma.

Stanton et al. (2021), suggests that coping is not a one-size-fits-all solution, but rather a dynamic process. People adapt their coping methods over time and across different situations to meet the ever-changing demands of stressors. This means that using positive coping strategies, such as seeking social support or engaging in problem-solving, is associated with better mental health outcomes.

In the context of families with autistic children, this adaptability is particularly important. Parents may need to employ different coping mechanisms to manage the various challenges they face, such as social stigma, behavioral difficulties, and emotional strain.

MAIN BODY

Al-Oran & Khaun (2021), asserts that core challenges of autism spectrum disorder (ASD) include difficulties with behavior management, communication, and social interaction. These difficulties extend to interactions with parents and other caregivers. This is because social and communication deficits are defining characteristics of ASD as outlined by the American Psychiatric Association.

A study by NIMH (2023) revealed that raising a child with autism spectrum disorder presents unique challenges that extend beyond the adjustments families naturally experience with a new child. Parents of children with autism spectrum disorder must grapple with the ongoing development and specific characteristics of the disability. This unique parenting journey can be a significant source of stress and may contribute to feelings of stigma

RELATED LITERATURE:

A study by Santon et al. (2021) Individuals employ various strategies, termed coping mechanisms, to navigate demanding situation. This involves adapting cognitive processes and behaviors to effectively manage challenges and stressors. Coping often entails modifying one's approach to situations perceived as exceeding their current capabilities. These strategies serve to support emotional well-being during periods of difficulty.

Research by Ng et al. (2020), revealed that social stigma surrounding autism spectrum disorder often manifests through labelling, stereotyping, exclusion, and societal discrimination against affected individuals and their families. This is particularly concerning as individuals with ASD may not exhibit outward signs of disability but may display challenging behaviors like tantrums, self-injury, and aggression. Mis-attributing these behaviors to poor parenting solely amplifies the stigma experienced by families. This study further suggests that parents of children diagnosed with Autistic Spectrum disorder often experience an initial phase of shock and grief .

A comprehensive examination of the correlation between parental stigma and coping mechanisms within households raising children with autism is essential for understanding the intricate dynamics at play in such families (Weiner et al., 2020).

Weiner et al. (2020), suggests that families caring for children with Autism Spectrum Disorder often navigate a demanding path, frequently experiencing a decline in their overall well-being. These families commonly face an array of health issues and emotional struggles.

These challenges can lead to the development of negative thought patterns, feelings of isolation, and even clinical depression in some family members (Singh et al., 2022).

Caring for individuals with autism spectrum disorder presents intricate difficulties, often leading to substantial stress and potential social stigma for the families involved.

As cited in Smythe (2021), the early years resemble a crucial construction phase for the brain, overflowing with immense potential yet demanding scrupulous care. This period of rapid development witnesses' language, cognitive abilities, motor skills, and social interactions functioning as building blocks, collectively laying the foundation for a child's increasing independence as they acquire knowledge and mature.

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In another study by Crocker et al. (2021) revealed that these social difficulties can persist into adolescence, with autistic individuals forming even fewer friendships compared to those with other special needs.

Shattuck et al. (2022) confirms that educational and employment opportunities can also be limited for autistic individuals due to these challenges. Furthermore, social integration can be difficult, potentially leading to feelings of isolation and exclusion (Birenbaum et al., 2019).

A study by Whitney & Smith (2020) affirms that these social and developmental hurdles can contribute to a higher prevalence of bullying experienced by autistic individuals. The challenges faced by these children can undoubtedly be a source of stress and stigma for parents raising children with autism spectrum disorder.

This risk is further amplified when the child exhibits challenging behaviors or the family faces additional burdens like financial strain or limited social support (Seltzer et al., 2022).

Baxy et al. (2020) suggests that several factors may contribute to these mental health challenges, including heightened parental anxiety, feelings of inadequacy in their parenting role, and a decline in marital satisfaction.

A study by Paccaud et al. (2021), suggests that active participation by parents and guardians is essential for maximizing the effectiveness of interventions and educational programs designed to support children with autism, encouraging early social interaction is paramount. This can involve facilitating activities like talking, playing, or even engaging in shared activities like prayer with their peers by fostering early social inclusion, children develop positive social skills, build stronger relationships with others, and cultivate a sense of belonging.

According to General, (2021) parental stigma can significantly affect coping behaviors within these families. Some parents may adopt avoidant coping strategies, such as denial or withdrawal, to shield themselves from the negative effects of stigma. Others may engage in seeking social support, education, and advocacy to empower themselves and their children. Understanding the dynamics between parental stigma and coping behaviors is crucial for developing targeted interventions and support systems that promote resilience and well-being in families with autistic children. Further research in this area is essential to enhance our understanding and address the complex interplay between stigma, coping mechanisms, and family dynamics in the context of autism.

Research by Pyscher et.al. (n.d) revealed that while poverty undeniably presents challenges for children's well-being, strong family bonds can foster resilience. This concept extends to families with autistic children. Despite potential stigma associated with autism, a supportive family environment can equip parents with better coping mechanisms to navigate these challenges.

METHODOLOGY

The research focused solely on parents who are raising children diagnosed with autism. It involved a total of 30 participants, comprising both men and women. Following the

recommendations of Morgan and Krejcie (1970), the aim was to recruit 28 participants from this specific demographic. A simple random sampling method was utilized to ensure the inclusion of both genders. Data collection methods included self-administered questionnaires and face-to-face interviews. Furthermore, qualitative data were obtained from three key informants—a psychiatric nurse, a counselor, and an occupational therapist—selected through purposive sampling from the staff at Katalemwa Cheshire Home. The gathered data were analyzed using frequencies, percentages, mean, and standard deviation.

LIMITATIONS OF THE STUDY

Although input from key informants like psychiatric nurses, counselors, and occupational therapists was sought to offer qualitative insights, it's important to note that their viewpoints might not comprehensively depict the experiences of parents raising children with autism spectrum disorder. Including perspectives from other pertinent stakeholders such as educators, social workers, or community leaders could enhance the richness of the study's findings.

FINDINGS

This study investigated the relationship between Parental Stigma and Coping Behaviors in Families with Autistic Children at Katalemwa Cheshire Home in Kawempe Division, Kampala District. The initial goal was to examine these factors through the application of descriptive statistics, focusing particularly on mean values and standard deviations. Mean values offer insights into the average score across the dataset, providing a central reference point for understanding the overall performance or tendency of the variables under consideration. On the other hand, standard deviations serve to measure the extent of variation or dispersion among individual data points in relation to the mean. A larger standard deviation indicates a greater degree of diversity or deviation from the average, while a smaller deviation implies more consistency or proximity to the mean. By incorporating both mean values and standard deviations in the analysis, researchers can gain a comprehensive understanding of the distribution and characteristics of the data. This approach facilitates the identification of overarching patterns, trends, and discrepancies within the dataset, thereby enabling a more nuanced interpretation of the factors being assessed. Ultimately, leveraging descriptive statistics helps researchers to elucidate the underlying dynamics and complexities inherent in the phenomena under investigation, enhancing the depth and reliability of their findings.

Table showing the relationship between stigma and coping.

Description (stigma)	Measure Value (coping)
Pearson Correlation (r)	- .002
P-value	.993
N=	28

DISCUSSIONS

The outcomes indicate a feeble negative correlation, lacking statistical significance, between stigma and coping ($r = -.002$, $p = .993 > 0.05$). This implies that higher levels of stigma are associated with reduced coping tendencies, while lower stigma levels correspond to heightened coping likelihood. These findings align with Forum's (2023) research, which underscores that behaviors resulting from developmental disorders, trauma, and akin origins can be effectively addressed but not remedied through disciplinary measures

RECOMMENDATIONS

1. Design workshops or training sessions specifically aimed at equipping parents with effective coping mechanisms to manage stress, anxiety, and emotional challenges associated with raising a child with autism.
2. Emphasize the importance of techniques like relaxation exercises, mindfulness practices, and cognitive-behavioral therapy (CBT) for managing stress and improving emotional well-being
3. Initiate educational campaigns to dispel myths and misconceptions surrounding autism spectrum disorder (ASD)
4. Facilitate the creation of support groups where parents can connect, share experiences, and learn coping strategies from each other.
5. Develop initiatives that foster inclusivity and acceptance of individuals with ASD within the community.
6. Conduct in-depth interviews with parents to gain a deeper understanding of their lived experiences, coping strategies, and specific challenges related to stigma.
7. Organize workshops and training programs for professionals like educators, healthcare providers, and social workers to improve their understanding and interaction with families affected by Autism Spectrum Disorder.
8. While the current study suggests a weak correlation between stigma and coping, investigate other potential factors that might influence parental coping mechanisms. This could include social support systems, access to resources, and individual personality traits.

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