

VOLUME 6 ISSUE 3, 2021

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Journal of Social Sciences

Published by
Faculty of the Social Sciences
Enugu State University of Science & Technology
www.esutjss.com

STIGMATIZATION, COPING STRATEGIES AND DEPRESSION AMONG PARENTS OF AUTISTIC CHILDREN

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Abstract

This study investigated stigmatization and coping strategies as predictors of depression among parents of children with autism spectrum disorder (ASD) in South-East Nigeria. Using the purposive sampling technique, a total of 138 parents with autistic children comprising 69 females and 69 males were drawn from institutions of learning for autistic children across the five states of South-East, Nigeria. Stigmatization Impact Scale (SIS) (Okafor, 2019), Health and Daily Living Form: Adult Form B(HDL-AFB)(Moos, Cronkite and Finney (1990), and Radloff's epidemiological studies depression scale (CES-D) Radloff (1977), were used to collect the data. The design was cross-sectional design while descriptive statistics correlation and hierarchical multiple regression were used for analysis. The results revealed that stigmatization predicted depression among parents of children with ASD ($\beta = .50, t = 8.37, p < .05$). Also, parenting an autistic child predicted depression ($\beta = .17, t = 2.20, p < .05$) and coping strategy (avoidance coping) positively predicted depression ($\beta = .50, t = 4.9, p < .05$) among parents with autistic children in South-East Nigeria. The results were discussed with relevant literature and it was recommended that stigmatization and avoidance coping should be avoided to forestall depression among parents with autistic children. Limitations and suggestions for further studies were highlighted

Keywords: *Autism spectrum disorders, Coping strategy, Depression, Parents, Stigmatization.*

Introduction

Parenthood can bring unspeakable joy to the family but this joy can turn to sorrow if a couple gives birth to a child with autism spectrum disorder (ASD) (Palmer, 2012). Autism spectrum disorder is a developmental disability characterized by social and communication impairment and restricted interest and repetitive behaviour (APA 2002) It involves delays in the development of imaginative, social and communicative skills (DSM-5, 2013). Davidson, Blankstein, Flett and Neale (2010) observed that ASD is found in all socio-economic classes, ethnic and racial groups; and some parents whose children are diagnosed with ASD find it difficult to cope with challenges involved in raising them. Such parents seem to present symptoms of depression such as anxiety, low mood, great sadness and feelings of worthlessness, disappointment, hopelessness, guilt and shame. (Diagnostic and Statistical Manual of Mental Disorders – DSM-5, 2013). Many theories have been

proposed to explain depression and among them is the cognitive theory (Becks, 1967). Becks posited that depression can occur based on how individuals process their life experiences. The cognitive theory of depression tries to explain human behaviour by understanding the thought processes of an individual. Cognitive theorists believe that people's interpretations of events or their experiences may be distorted, inaccurate or unhelpful, which eventually affect their behaviour especially when there is a psychopathological symptom (Conner, 2010; Beck & Fleming, 2021; Beck, 1967). Wolpert (2001) observed that depression is a serious illness that can make the individual feel ashamed or stigmatized.

Stigma refers to negative attitudes, prejudice and negative behaviour (discrimination) toward people living with developmental global delay and other forms of mental illness. This is consistent with the views of Christ, Holt, White and Green (2007) that due to the impairment in executive abilities like cognitive powers, autistic children may be inhibited to conform to social expectations, hence may be viewed as social problems because of their behaviours. This can limit the interaction of their parents with other people. Corrigan (2014) identified two types of stigmas, namely self-stigma and public stigma. Self-stigma is a negative belief about oneself, expressed in character weakness and competence, feeling of low esteem and low self-efficiency. And public stigma is the negative reaction or prejudice that the general population has against people that are mentally challenged. Hornby (2006) explained that stigmatization relates to treating people in a way that makes them feel that they are very bad or unimportant. Various kinds of literature reveal that many characteristics associated with autistic children were significant contributing factors to the stigmatization and depression that their parents go through (Benson, 2006; Carroll, 2013; Christ, et al, 2007). Stigmatization of victims of ASD and mental illness, in general, are not limited to uniformed members of the public but among even well-trained professionals from most mental health disciplines (Keane, 1990). Capital District Health Authority (2013) observed that one of the greatest obstacles to improved mental health is the stigma surrounding mental illness. According to Oguama, Uka, Chukwu and Nwaoha (2020), the experience of stigma on mentally challenged persons in assessing medical services in the developing world like Nigeria is better imagined than experienced. Family members may try to hide a mental illness like ASD and may not get help because of fear of how the individual will be treated by relatives, friends and the community. However, depending on the coping strategies adopted by the parents of ASD, children may experience bouts of depressive symptoms which could hurt their health and quality of life.

Coping strategy refers to self-protective measures used by the individual concerned to remain healthy and functional even in the face of conflict (Omeje, 2000). It involves engaging in a set of responses that reduce the external stimuli, psychological reaction, anxiety, stressful negative events and depressive symptoms (McCrea, 1984; Folkman, Lazarus, Gruen, & Delongis, 1986). Some researchers have shown that parents with autistic children or mentally challenged children experience physical, psychological and emotional stress more than average parents without ASD (Davidson et al. 2010; Notbohm, 2005; Zimbardo, 2009; Bailey & Smith, 2003). A person's

susceptibility to psychological stress is mostly influenced by his or her temperament, coping skills and available social support. Two coping strategies that can be adopted are problem-focused and emotion-focused (Mgbenkemi, Omeje, & Eze, 2017).

A problem-Focused Strategy is an effort aimed at resolving or managing a stressful event or a problem that causes distress. It involves an attempt to understand and define the problem and devising an effective coping skill to deal with the situation. On the other hand, the Emotion-Focused Strategy is aimed at managing or reducing the emotional distress that is or might be elicited by the stressor (Folkman & Lazarus, 1985). Not much effort is made to address the root cause of the problem. This could be considered as avoidance in nature or inward-focused which could lead to depression. In other words, drawing from the tenets of cognitive theory of depression, it could be deduced that negative perception of ASD and the associated stigmatization predispose the parents to depression.

Statement of the problem

In Nigeria, especially in Igboland or the South-East, comprising the States of Abia, Anambra, Ebonyi, Enugu and Imo, there is a perceived prejudice and stigma against parents of children with autism spectrum disorder (ASD) and other mental health challenges. The prejudice and stigma seem to be based on misconceptions and lack of understanding about the aetiology of autism and mental health problems in general (Lesi, Adeyemi, Aina, Oshodi, Umeh, Olagunju, & Oyibo, 2014). This has a negative impact on the parents of autistic children as well as the children themselves (Oshodi, Campbell, & Lesi, 2019). Some scholars have claimed that stigmatization and coping strategies can predict depression among parents raising children with ASD (England & Sim, 2009; Aaron, Elliott and Benz, 2012; Cauda-Laufer, 2017). But most of the previous studies on this subject were carried out outside the Nigerian environment (Aaron, Timothy, Elliott and Michael, 2012; Cauda-Laufer, 2017). These studies offered valuable insights but were limited in scope as the concept of “Stigma” was missing. Also, related studies carried out in Nigeria by Mgbenkemi (2014) did not address the problem of stigma which is prevalent in Nigeria, especially in the South Eastern region.

A similar study by Bakare, Taiwo, Bello-Mojeed & Munir (2019) failed to deal with stigma and depression experienced by parents of autistic children. Although Cantwell, Muldoon and Gallagher (2015) discussed stigma, there was no focus on coping strategies employed by parents of autistic children. Therefore, the purpose of this study was specifically to investigate whether stigmatization of and coping strategies adopted by parents of autistic children will predict depression among parents with autistic children in South-East Nigeria. It was hypothesized that stigmatization and coping strategies will predict depression among parents of children with ASD in South-East Nigeria.

Method

Participants

A total of 138 parents of autistic children participated in the study. The participants were drawn from the South-East of Nigeria comprising the states of Abia, Anambra, Ebonyi, Enugu and Imo. All the children whose parents participated in the study are in special institutions for children with ASD, which include: Abia State Special Education Center for Deaf and Mentally Challenged, Aba and Umuahia (40 participants), Peace therapeutic Special International School, Mkpok Anambra State (21 participants), Ebonyi State Special School, Abakaliki (15 participants), Therapeutic Day Care Center Abakpa Enugu State (42 participants), and Don Guanella Centre, Nnebukwu Imo State (20 participants). The purposive sampling technique was used to draw the participants with particular characteristics that meet the purpose of the study (Mook, 1983; Cresswell & Plano-Clark, 2011).

Instruments

Three sets of instruments were used for this study, namely, Stigmatization Impact Scale (Okafor, 2019), The Health and Daily Living Form: Adult Form B (Moos, Cronkite and Finney (1990) validated by Omeje (2000) and Okafor, (2021), and Center for Epidemiological Studies Depression Scale (CES-D) Radloff (1977) validated by Omeje (2000) and Okafor (2021).

Procedure

The researchers then obtained a letter from the Department of Psychology ESUT and Departmental research ethics committee introducing them to the school management and participants. All the seven therapeutic institutions in the South-East participated in the study. The researchers solicited their permission to use a sample of the parents of children with an autism spectrum disorder in their respective institutions as participants for the study. With this letter, the researchers obtained permission from the management of the selected schools in each state with easy access to only parents of Autistic Spectrum Disorders (ASD). The researchers thereafter recruited and trained state secretaries (i.e., the contact teacher as provided by the management of the institution) as research assistants to administer and collect copies of the questionnaire in all of the selected schools. With the help of the state secretaries, a list of all the parents who have autistic children was made available and copies of the questionnaire were administered. The participants who consented to be a part of the study were advised to take the questionnaire home, study the items carefully, complete and return to their state secretaries within one week. All participants were informed that participation is voluntary and their data would remain confidential. The researchers explained the nature of the research to the management. Out of 200 copies of questionnaires distributed, 138 were properly completed and returned. 32 copies were not returned while 30 copies were not properly filled and discarded. Hence, the 138 copies that were properly filled and returned were used for analysis and testing of the hypotheses.

Design and Statistics

A cross-sectional survey design was used to collect the data while hierarchical multiple regression was used for analyses.

Results

Table 1: Descriptive statistics and correlations of study variables.

Variables	M	SD	1	2	3	4	5	6	7	8	9
AGEB4M			1	.38**	.11	.10	-.18**	-.01	.19**	.03	-.01
LOM	13.47	7.11		1	.15	.19	.26**	.39**	.18	.39**	.23*
EL					1	.09	.09	-.03	.30**	-.09	-.02
PAC						1	.13*	.12	.16*	.20**	.29**
Stigmatization	21.82	8.64						1	-.24**	.35**	.63**
Approach coping	23.10	6.11							1	.13*	.03
Avoidance coping	10.61	3.32								1	.49**
Depression	37.12	7.31									1

*Note: *p < .05, ** p < .01; AGEB4M=Age before Marriage; EL= Educational Level [1=Never attended school; 2=primary school completed with certificate; 3=junior secondary school completed with certificate; 4=senior secondary school completed with certificate; 5=teacher training, OND, NCE; 6= Graduate (B.Sc, B.A., B.Ed., HND)]; LOM= Length of Marriage; PAC=Parenting an Autistic Child (coded '0' for no, '1' for yes)*

Table 1 presents the descriptive statistics and correlations for the study variables. Length of marriage was positively correlated with depression ($r = .23, p < 0.05$). Parenting an Autistic child correlated with depression ($r = .29, p < 0.01$). Stigmatization was positively correlated with depression ($r = .63, p < 0.01$), meaning that the higher the stigmatization experienced the more likely would they be depressed. Coping strategy (avoidance coping) positively correlated with depression ($r = .49, p < 0.01$). While age before marriage, educational level and coping strategy (approach coping) does not have a significant relationship with depression.

Table 2: Summary of Hierarchical Multiple Regression Analysis for Variables Predicting Depression among parents with autistic children

Variables	Step 1			Step 2			Step 3			β	SE	t
	B	SE	t	B	SE	T	B	SE	t			
AGE_BM	-.11	.59	-1.43									
EDU	-.05	.43	-.80									
PAC	.17	.51	2.20*									
Stigmatization							.50	.05	8.37*			
Approach coping										-.13	.06	-2.50*
Avoidance coping										.25	.11	4.94**
R	.138			.518			.653			.711		
R ²	.019			.269			.427			.505		
ΔR^2	.019			.249			.158			.079		
F	1.661			23.402**			37.804**			36.752**		

Note: * $p > .05$, ** $p > .01$; AGE_{B4M}=Age before Marriage; EL= Educational Level [1=Never attended school; 2=primary school completed with certificate; 3=junior secondary school completed with certificate; 4=senior secondary school completed with certificate; 5=teacher training, OND, NCE; 6= Graduate (B.Sc, B.A., B.Ed., HND)]; LOM= Length of Marriage; PAC=Parenting an Autistic Child)

Results of the hierarchical multiple regression for the test of depression as shown in Table 2. The variables were entered in stepwise models. The demographic variables (age before marriage, educational level, parents with an autistic child) in Step 1 of the regression analysis and only parents with an autistic child were a significant positive predictor of depression ($\beta = .17, t = 2.20, p < .05$). The demographic variables accounted for 1.9% of the variance in depression among parents with autistic children. In step 2, stigmatization was a significant positive predictor of depression ($\beta = .50, t = 8.37, p < .05$) stigmatization accounted for 43% of variance in depression among parents with autistic children. Finally, in step 3, coping strategy (approach coping strategy) approach was a significant negative predictor of depression ($\beta = -.13, t = -2.50, p < .05$), while and avoidance coping was also a significant positive predictor of depression ($\beta = .25, t = 4.94, p < .01$). Coping strategy (approach and avoidance) accounted for 7.9% of the variance in depression among parents with autistic children

Summary of findings

1. Parenting an autistic child was a significant predictor of depression
2. Stigmatization was a significant positive predictor of depression

3. Coping strategy (approach coping) was a significant negative predictor of depression
4. Coping strategy (avoidance coping) was a significant positive predictor of depression

Discussion

In this study, it was hypothesized that stigmatization will predict depression among parents of autistic children in South east-Nigeria. The hypothesis was confirmed and accepted as true. This is consistent with Anyanwu, Onuigbo, Obiyo, Eze, et al., (2019) who support that the stigma and stress experienced in raising an autistic child in modern-day Nigeria are enormous. Such stress could harm parents; evoke anger, anxiety, and sadness, thereby leading to depression. The experience of shame and stigma can lead to the feeling of humiliation, social exclusion and isolation (Baba, 2014) with the consequent depressive symptoms.

The second hypothesis which predicted that coping strategy will significantly predict depression in parents of autistic children in South East of Nigeria was also confirmed. While Problem-focused coping strategy exerted significant positive prediction on depression Emotion-focused coping strategy exerted a significant negative prediction on depression. This finding suggests that the intensity of depression depends on the type of coping skills used. This is consistent with the study of Miranda, Mira, Bereguer, Rosello and Baixauli (2019) which indicates that lack of appropriate coping strategy could lead to depression among parents with autistic children. Rodriguez-Hernandez et al., (2012) also confirmed that parents who had difficulties with coping when raising autistic children could experience depression. Similarly, the study of Bailey and Smith (2003) revealed that problem-focused coping strategies are more effective than emotion-focused strategies in decreasing the stimulus that causes depression. This was supported by the findings of Ebata and Moos (1994) and Cherry (2012). Although problem-focused is more effective, some parents of autistic children gravitate towards emotion-focused strategies because they find it easier for adapting to circumstances that would not change (Mgbenkendi, 2014). The participants in this study who chose emotion-focused coping strategies engaged in some positive thinking attitudes to modulate the impact of the challenges they experience in parenting autistic children. Some engaged in self-isolation, avoidance and invoking of their religious beliefs as a way of dealing with the problem. The parents of autistic children who employed problem-focused reached out for support, established healthy boundaries in their relationships, devised ways of doing their tasks in such a way that they can function effectively despite the challenges they face with raising an autistic child.

Limitations

Although this study has made a significant contribution in establishing scientifically that stigmatization and coping strategies predict depression, thereby providing a valuable tool for therapists and those who work with parents of autistic children, it has some limitations that limit its generalization:

- 1) This research was restricted to parents of autistic children who are enrolled on special schools for autistic children. It was also restricted to parents who are educated. This was due to a lack of

funds to extend the research to uneducated parents and parents in suburbs who could not afford to send their autistic children to special centres in South-East Nigeria.

2) Since this area of investigation is not common in South-East Nigeria, there was non-availability of relevant materials such as books, journals and audio-visuals to facilitate the research.

Suggestions for Further Studies

Since this study was limited to parents of autistic children who are in institutions and educated parents, there is a need for comparative research extended to parents of autistic children who are in the communities and who are not educated to know whether stigmatization and coping strategies will predict depression in those parents too.

To the best knowledge of the researcher, there doesn't seem to be any empirical study on the role of age, occupation, religion and income in predicting marital conflict, stigmatization, coping strategies on depression among parents of autistic children in South East, Nigeria. Therefore, it would be important to do a comparative investigation with such parents to determine the correlation between the variables and depression in their lives. If the result comes out in the affirmative, it will make the theory generalizable.

Conclusion and Recommendations

This study confirms stigmatization and coping strategies as predictors of depression among parents of autistic children in South-East Nigeria. It helps parents of autistic children understand that with healthy coping strategies they can deal with the factors that trigger depressive symptoms in their lives. Engaging such parents through psycho-education enables them to acquire auto-esteem and self-confidence to overcome the negative impact of stigmatization which will help them to maintain not only their good health but also that of their children. Participants in this study discovered that they are not alone in this struggle; they were able to interact with other parents, share experiences and support one another. This helped to reduce the stigmatization impact, feeling of isolation and loneliness which made life unpleasant for them. Finally, this study heralds further study on parents raising autistic children in South-East Nigeria and other parts of Africa to correct the misconceptions people have about ASD and thus help ameliorate the suffering and pain of parents with autistic children, and consequently reduce their level of anxiety, worry and depressive symptoms that could even lead to premature death. It is recommended that parents of autistic children in South East Nigeria form a support group in their communities where they can be educated about the condition of their children and receive support for themselves. Government and policymakers should create inclusive educational resources for educators, therapists, parents of autistic children; and people dealing with mental health problems, in general, to help eliminate the stigma associated with mental health.

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