



## EFFICACY OF MINDFULNESS THERAPY IN MITIGATING PSYCHOLOGICAL DISTRESS AMONG INFORMAL CAREGIVERS OF CHILDREN WITH AUTISM: AN ANALYSIS OF PREDICTIVE FACTORS

Okoro D. J.<sup>1</sup>, Inyang U. E.<sup>2</sup>, Akpan W. E.<sup>3</sup> and Umoh U. I.<sup>4</sup>

<sup>1</sup>Department of Psychology, University of Uyo, Uyo, Nigeria.

Email: [dorothyokorojohn@gmail.com](mailto:dorothyokorojohn@gmail.com)

<sup>2</sup>Department of Psychology, University of Uyo, Uyo, Nigeria.

Email: [usenessieninyang@gmail.com](mailto:usenessieninyang@gmail.com)

<sup>3</sup>Department of Psychology, University of Uyo, Uyo, Nigeria.

<sup>4</sup>Department of Community Health, WOCLIF College of Health Technology, Etinan, Nigeria.

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**ABSTRACT:** *The mental health of informal caregivers, especially those caring for children with autism spectrum disorder (ASD), is a growing concern, particularly in resource-limited settings. This multi-phase study investigated the roles of health literacy and perceived stigmatisation on psychological distress among informal caregivers of children with ASD in Akwa Ibom State, Nigeria. Phase One involved instrument adaptation and validation through a pilot study. Phase Two utilized a cross-sectional design to collect survey data from 195 caregivers, identifying those experiencing psychological distress. Phase Three employed a pre-test, post-test control group experimental design to evaluate the effectiveness of Mindfulness Therapy in reducing psychological distress. Findings from Phase Two revealed that health literacy significantly and negatively predicted psychological distress ( $\beta = -0.04$ ;  $p < 0.05$ ), while perceived stigmatisation had a significant positive effect ( $\beta = 0.05$ ;  $p < 0.05$ ). The regression model explained 5% of the variance in psychological distress, with both variables collectively contributing to caregivers' distress levels ( $F(3, 191) = 4.53$ ,  $p = 0.004$ ). In Phase Three, results showed that Mindfulness Therapy significantly reduced psychological distress compared to the control group ( $t = 4.50$ ,  $p < 0.05$ ). Paired samples  $t$ -tests confirmed a significant reduction in distress levels among the Mindfulness Therapy group ( $t = 4.91$ ,  $p < 0.05$ ), with a mean difference of 13.50 between pre- and post-intervention scores. The study revealed the need for accessible mental health interventions for caregivers of children with ASD. It recommends training mental health professionals in evidence-based therapies like Mindfulness Therapy.*

**KEYWORDS:** Caregivers, Autism spectrum disorder, Psychological distress, Mindfulness Therapy, Health literacy.



## INTRODUCTION

The psychological distress experienced by informal caregivers of children with autism spectrum disorder (ASD) manifests in various ways, significantly impacting their well-being. Research highlights how the unpredictable and challenging behaviours characteristic of ASD can evoke feelings of frustration, helplessness, and emotional exhaustion among caregivers. Autism Spectrum Disorder (ASD) constitutes a pressing global health concern, with a staggering prevalence of approximately 1 in 160 children worldwide, as reported by the World Health Organization (WHO, 2022). The global ASD prevalence has been trending upward, with an estimated 52 million individuals affected worldwide since 2010, according to Elsabbagh *et al.* (2012) and Baxter *et al.* (2015). In the United States, the prevalence of ASD is reportedly 1 in 68 children, as documented by Baxter *et al.* (2015). In the sub-Saharan African region, the prevalence of ASD among children with intellectual disability is estimated to be around 0.8% (Hayes and Watson, 2018). Country-specific epidemiological data reveal disparate prevalence rates, including a reported 1 in 190 children with autism disorder in Nigeria (Okorie, 2018). Cross-national studies have shown higher prevalence rates among children with developmental disorders, such as 11.4% for autism in a cohort of Nigerian children with intellectual disability (Bakare *et al.*, 2012, 33.6% for ASD among children with developmental disorders in Egypt, and 11.5% in Tunisia (Seif Eldin *et al.*, 2008).

The condition represents a wide continuum of associated cognitive and neuro-behavioural disorders, characterized by three core defining symptoms (American Psychiatric Association [APA], 2013). These symptoms include deficits in socialization, deficits in verbal and nonverbal communication, and restricted and repetitive patterns of behaviour (APA, 2013). Autism Spectrum Disorder is a neurodevelopmental condition characterized by challenges in social interaction, communication difficulties, and repetitive behaviours. The term "spectrum" underscores the vast variation in the manifestation of symptoms, ranging from mild to severe (APA, 2013). The prevalence of ASD has been on the rise, with global estimates indicating its widespread impact on individuals and their families (Centers for Disease Control, 2021). Children with ASD often encounter difficulties in establishing and maintaining social relationships. The complex nature of their communication challenges can manifest in delayed language development or atypical use of gestures and expressions. Additionally, the presence of repetitive behaviours or intense focus on specific interests contributes to the unique profile of individuals with ASD. The impact of autism extends beyond the affected child, shaping the dynamics of the entire family unit (Lord and Bishop, 2010). Furthermore, the daily routines of families with a child with ASD are often marked by a need for structure and predictability. Any deviation from established routines can be distressing for the child, amplifying the stress experienced by caregivers. The challenges in maintaining a balance between the needs of the child with ASD and those of other family members add a layer of complexity (Karst and Van Hecke, 2012).

Children with ASD often require specialised interventions tailored to their unique needs, such as speech therapy, occupational therapy, and behavioural support. However, accessing these services can be particularly challenging in resource-limited regions such as Nigeria or during periods of disruption, such as the COVID-19 pandemic (Matson *et al.*, 2012).

The diagnosis of ASD is based on criteria outlined in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), which include persistent deficits in social communication and interaction alongside restricted, repetitive behaviours, interests, or activities (APA, 2013).



Symptoms typically manifest in early childhood and can vary in severity. Common challenges include difficulties in reciprocal social interactions, such as understanding and responding to social cues, and impairments in nonverbal communication, such as limited eye contact or gestures. Additionally, repetitive behaviours, an insistence on sameness, and intense focus on specific interests are often characteristic of the disorder (Lord & Bishop, 2010).

Caring for a child with ASD significantly impacts the psychological well-being of informal caregivers. Various factors contribute to elevated levels of psychological distress among these caregivers, including difficulties in accessing essential services, such as education and therapy, which can evoke feelings of frustration and helplessness (Matson et al., 2012). The unique needs of children with ASD often demand substantial time and energy, leading to disrupted family routines centred around the child's requirements. These relentless caregiving demands leave little room for respite or self-care, frequently resulting in psychological distress (Karst & Van Hecke, 2012).

Psychological distress is a complex and multifaceted concept that encompasses a range of emotional, cognitive, and behavioural symptoms indicating mental suffering or discomfort. Various definitions and perspectives exist within the literature, reflecting the diverse nature of this phenomenon. One definition, proposed by Kessler *et al.* (2002), characterizes psychological distress as a state of emotional suffering that involves symptoms such as depression and anxiety. According to this perspective, distress is viewed as a continuum, ranging from mild symptoms to severe psychiatric disorders. This conceptualization highlights the interconnectedness of various mental health issues and emphasizes the importance of understanding distress within a broader spectrum. Another perspective on psychological distress is offered by Lazarus and Folkman (1984), who define it as the emotional response to a perceived imbalance between the demands placed on an individual and the resources available to cope with those demands. This stress-based view suggests that distress arises when individuals perceive their environmental stressors as exceeding their ability to effectively cope.

The cognitive aspects of psychological distress are evident in the form of intrusive thoughts, worry, and rumination about the child's future and well-being (Hayes and Watson, 2018). The ongoing demands of caregiving may lead to cognitive overload, affecting the caregiver's ability to concentrate, make decisions, and solve problems effectively. Behaviourally, psychological distress may result in changes in the caregiver's coping strategies, potentially leading to maladaptive behaviours such as avoidance or social withdrawal (Smith *et al.*, 2010). The strain on social relationships, including marital and familial bonds, is a common consequence, further exacerbating the caregiver's distress (Gray, 2006). The quality of care provided by family caregivers is intricately linked to their psychological well-being. Research indicates that caregivers experiencing higher levels of psychological distress may struggle to engage effectively with their child, implement therapeutic interventions, and maintain consistency in caregiving practices (Benson, 2014). This, in turn, can impact the child's development and well-being.

Mindfulness Therapy has emerged as a promising intervention for addressing psychological distress among informal caregivers of children with Autism Spectrum Disorder (ASD). Mindfulness practices, which involve maintaining present-moment awareness with acceptance, have been adapted to diverse populations due to their effectiveness in managing stress, emotional dysregulation, and psychological distress. Their application to caregivers of children



with developmental disabilities like autism is particularly relevant, as these individuals often face unique and persistent challenges.

Mindfulness Therapy combines acceptance, self-regulation, and stress-reducing strategies with awareness-based treatments. It provides individuals with tools to manage strong emotions, strengthen interpersonal relationships, and enhance their overall quality of life. For caregivers of children with autism, Mindfulness Therapy offers a structured approach to managing the stress and emotional exhaustion commonly associated with their responsibilities. Central to its approach are techniques for emotional awareness, distress tolerance, and compassionate communication. Emotional awareness techniques enable caregivers to identify and regulate the intense emotions arising from their children's Behavioural and communication challenges. Distress tolerance strategies offer methods for remaining present and resilient in high-stress situations, while compassionate communication fosters healthier relationships and conflict resolution with family members, healthcare providers, and others involved in the child's care.

Recent studies confirm the success of Mindfulness Therapy in reducing emotional stress among caregivers. For instance, a meta-analysis by Liu et al. (2017) demonstrated that mindfulness-based interventions significantly improved depression, perceived stress, and mental health-related quality of life in family caregivers of individuals with dementia. Similarly, a Cochrane review by Liu et al. (2018) found that mindfulness-based stress reduction (MBSR) may reduce depressive symptoms and anxiety in family caregivers of people with dementia. These findings highlight the therapeutic potential of Mindfulness Therapy in enhancing emotional well-being and reducing psychological distress among caregivers.

Beyond the direct benefits of mindfulness-based interventions, understanding the predictive factors contributing to psychological distress is crucial. This study also examined two important variables—health literacy and perceived stigmatisation—and their roles in shaping the psychological experiences of caregivers.

Effective caregiving depends on health literacy, which is the ability to obtain, understand, and apply health information. Health literacy is divided by Nutbeam (2000) into functional, interactive, and critical levels, each requiring particular knowledge to negotiate healthcare systems and make wise decisions. Limited health literacy can affect understanding of medical instructions, inhibit advocacy efforts, and aggravate emotions of anger and powerlessness for carers of children with autism spectrum disorder (ASD). Inappropriate health literacy is linked to worse health outcomes and higher healthcare use (Sørensen et al. 2012). This suggests that an inability to combine caring duties with coping resources heightens stress levels. Lazarus and Folkman's (1984) stress-coping model offers a theoretical framework relating low health literacy to psychological distress. According to the model, stress results from an imbalance between the demands placed on an individual and their perceived resources to cope with those demands. In this context, low health literacy can exacerbate psychological distress by limiting a caregiver's ability to comprehend health information, navigate healthcare systems, and effectively manage caregiving responsibilities. This limitation can lead to feelings of inadequacy and heightened stress, as caregivers may struggle to make informed decisions and advocate effectively for their children. Consequently, enhancing health literacy is crucial for empowering caregivers, enabling them to better understand medical information, access appropriate services, and implement effective coping strategies, thereby reducing psychological distress and improving overall well-being. Empirical studies, including those by Osborne and Osborne (2013), Jones et al. (2015), and Wolf et al. (2018,) have confirmed these



links by showing that low health literacy carers have more stress, misinterpret treatment plans, and run across communication problems with doctors.

Another variable considered in the study was perceived stigmatisation (PS). PS Originate from society's misunderstandings regarding autism, stigmatisation causes carers to feel social discredit and estrangement. Desmond (2019) underlines how discrimination, social isolation, and low self-esteem result from societal expectations and preconceptions that sometimes place caregivers as deviant or ineffective. Empirical research consistently demonstrates a positive correlation between perceived stigmatisation and psychological distress. For instance, a systematic review by Mitter et al. (2019) highlighted that family caregivers of individuals with intellectual disabilities and autism frequently encounter stigma, resulting in various negative outcomes. These adverse effects can persist over time, underscoring the enduring impact of perceived stigmatisation on caregivers' mental health.

Studies on components like caregiving responsibilities, stigmatisation, and financial stress have mostly focused on formal carers, therefore excluding the special experiences of informal carers who often provide main support in family settings. The research mostly ignores the particular difficulties informal caregivers experience, including fewer support systems and more emotional tiredness. Furthermore, complicating a thorough knowledge of carers' experiences are differences in approaches, sample demographics, and cultural settings; especially in society and cultural settings like Nigeria. Although there is increasing evidence of distress in Nigeria within this demographic, no previous research has looked at the efficacy of psychological interventions, therefore leaving a major void in practical approaches for mental health care. This study examined Mindfulness Therapy's efficacy as a focused intervention meant to lower psychological stress for caregivers of children with autism. It also investigated how caregivers' distress may be predicted by health literacy and perceived stigmatisation. Mindfulness Therapy was thus expected to be useful in lowering psychological stress among Akwa Ibom State's informal carers of children with ASD; perceived stigmatisation would positively predict psychological distress, and health literacy would negatively predict psychological distress. It was hypothesized that health literacy would negatively predict psychological distress among family caregivers of children with ASD. It was also perceived stigmatisation would positively predict psychological distress among family caregivers of children with ASD. Furthermore, it was proposed that mindfulness therapy would be effective in reducing psychological distress among informal caregivers of children with ASD.





## METHOD

The study employed a combination of research designs across three phases. Phase One focused on instrument adaptation and validation through a pilot study. Phase Two involved survey data collection using an ex-post facto design. Participants experiencing psychological distress were identified during this phase. Phase Three constituted the intervention stage, employing a pre-posttest control group experimental design. This design facilitated the comparison of participant groups and measured the extent of change resulting from the intervention. The intervention consisted of two groups: an experimental group undergoing Mindfulness Therapy and a control group receiving health talks.

### PHASE ONE

#### Research Design

The phase employed an ex-post-facto design to pilot-test the instruments used for data analysis.

#### Research Setting

The pilot study took place at the Ani Special Care Facility located on Nwaniba Road, Uyo. Established in 2007, this facility offers assistance and support to children with special needs, as well as to educate and train their caregivers in managing the associated challenges.

#### Sample and Sampling Procedures

A total of 30 participants were purposively selected from the Ani Care Centre, which was not part of the main study.

#### Measures

The primary data collection tool used in this study was a questionnaire divided into four sections. The questionnaire comprised various sections to gather pertinent information. Section A focused on demographic details of the participants, including age, gender, relationship with the child, educational qualifications, and marital status. Section B was the Kessler Psychological Distress Scale developed by Kessler et al (2002). Section C was the Perceived Stigmatisation Scale developed by King *et al* (2007). Section D was the Health Literacy Scale for Adults, developed by Tavousi *et al.* (2020).

*The Kessler Psychological Distress Scale (K10):* This is a validated tool used to measure psychological distress. Its psychometric properties include reliability and validity, making it a valuable instrument in clinical and research settings. It is a 10-item scale employing a Likert-type format with five response options for each item, ranging from "None of the time" to "All of the time," corresponding to scores of 1 to 5, respectively. The K10 has demonstrated good internal consistency (.79), indicating that the items in the scale are reliably measuring the same underlying construct of psychological distress. Test-retest reliability (.84) has also been established, suggesting that the scores obtained from the scale are stable over time. The K10 has been shown to have good concurrent validity, meaning that it correlates well with other established measures of psychological distress.

Additionally, the scale has demonstrated good discriminant validity, as it can distinguish between individuals with different levels of psychological distress. The interpretation of K10



scores provides valuable information about an individual's level of psychological distress: Scores ranging from 10 to 19 suggest that the individual is likely to be well, with minimal psychological distress. Scores between 20 and 24 indicate a likelihood of a mild disorder, suggesting some level of psychological distress that may warrant attention. Scores falling within the range of 25 to 29 are indicative of a moderate disorder, suggesting a more significant level of psychological distress that may require intervention. Scores between 30 and 50 signal a likelihood of a severe disorder, indicating high levels of psychological distress that may necessitate immediate intervention and support. The instrument had a robust Cronbach Alpha of .74 and a split-half reliability of .69 after the pilot study. Item total analysis revealed coefficients ranging from 0.43 to 0.58

*The Perceived Stigmatisation Scale:* This is a 21-item scale designed to assess the negative evaluation of a person as tainted or discredited based on caring for children with a developmental disability. The scale is rated on a 5-point Likert format of 1-5. (5= Strongly Agree, 4 = Agree, 3 = Neither agree or disagree, 2= Disagree, 1= Strongly Disagree). All items on the scale are directly scored. This implies that a score of 5 to awarded to 'Strongly Agree', 4 to 'Agree', 3 to 'Neither agree or disagree', 2 to 'Disagree', and 1 to 'Strongly Disagree'. The lowest possible score is 21, while the highest possible score is 105. The norm of the instrument is 62. This infers that scores from 62 and above indicate high perceived stigmatisation while lower than 21-61 is indicative of low perception of stigmatisation. The authors reported a Cronbach alpha of .87 which is indicative of good reliability. Results of the pilot study revealed a Cronbach alpha of .87 and Split-half of .79 was obtained for the scale. Item total analysis revealed coefficients ranging from 0.31 to 0.71.

The Health Literacy Instrument for Adults (HELIA) is a 33-item psychometrically evaluated instrument developed to measure health literacy among adults. It is designed in a 5-Likert point response format of Never, Rarely, Sometimes, Usually, and Always. The HELIA assesses various dimensions of health literacy, including access to information, reading, understanding, appraisal (4 items), and decision-making/behavioural intention through a comprehensive questionnaire. The instrument underwent rigorous psychometric evaluation, including content validity assessment by experts in public health, exploratory factor analysis, confirmatory factor analysis, and assessment of internal consistency and stability. The results of these analyses demonstrated satisfactory psychometric properties of the HELIA. The instrument showed good internal consistency, with Cronbach's alpha coefficients ranging from 0.72 to 0.89 for the five factors.

Additionally, the test-retest analysis indicated acceptable stability, with an inter-item correlation ranging from 0.34 -.67. The mean score for health literacy as measured by the HELIA in the study sample was 76.3 (SD = 15.1) out of 100, indicating a relatively high level of health literacy among the participants. Results of the pilot study revealed a Cronbach alpha of .66, and a Split-half of .65 was obtained for the scale. Item total analysis revealed coefficients ranging from 0.39 to 0.65.



## **Research Procedure**

Ethical approval was obtained from the Akwa Ibom State Health Research Ethics and was presented to the selected care facility, seeking their consent and assistance. With their assistance, caregivers were reached during session days. Caregivers who agreed to participate were required to give informed consent before completing the questionnaire. Data were collected through the administration of a questionnaire, with a total of 30 copies of the questionnaire distributed in the facility.

## **Method of Data Analysis**

The data gathered from participants underwent data analysis utilizing Item analysis, and evaluations of Cronbach's alpha and split-half reliability were conducted.

## **PHASE TWO**

### **Research Design**

A cross-sectional research design was employed for this phase of the study.

### **Research Area**

The study was carried out across various care facilities in Akwa Ibom State, Nigeria. A total of six care facilities were selected, with two facilities from each senatorial district in the state. The selected facilities were: Women and Community Livelihood Foundation (WOCLIF) and Brainy Hives Special School in Uyo Senatorial District; African Children Centre and Shalom Children Care Centre in Eket Senatorial District; and First Love and Peace Foundation (FLPF) and St Joseph Rehabilitation Centre in Ikot Ekpene Senatorial District. These facilities specialise in providing comprehensive care and support services for children with special needs, including autism. They serve as coordinating centres for diagnosis, therapy, and intervention and offer training and guidance for parents and caregivers on how to optimise care for their children with autism. The facilities provide a range of services, including linkage services to healthcare facilities for assessment, treatment, and rehabilitation, to enhance the overall well-being and quality of life of children with autism and their families. The facilities were recommended by the Ministry of Women and Social Welfare as the only known care centres for children with autism in the state.

### **Sample and Sampling Techniques**

A sample size of 195 caregivers participated in the study. The caregivers were selected using purposive sampling techniques from the population of caregivers supporting children with autism spectrum disorder (ASD) across the six selected care facilities in Akwa Ibom State, Nigeria.

#### ***The inclusion criteria for caregivers in this study were:***

- i. They were primary caregivers of children who had been clinically diagnosed with ASD by a qualified healthcare professional
- ii. They were involved in the daily care and management of their child's condition





- iii. They had been providing care for their child with ASD for at least one year. This was to ensure that the caregivers had an adequate level of experience in caregiving for children with autism to make meaningful contributions to the study.
- iv. They were willing to participate in the study and provide informed consent

***The exclusion criteria for caregivers in this study were:***

- a) They were not primary caregivers of children with ASD
- b) Their child had not been clinically diagnosed with ASD by a qualified healthcare professional
- c) They had less than one year of experience in caring for a child with ASD
- d) They were not willing to participate in the study or provide informed consent

The caregivers were chosen based on their involvement in providing care for children with autism disorder across the selected care facilities for at least one year. This ensured that the caregivers had sufficient experience and knowledge of caring for children with ASD and were, therefore, able to provide valuable insights and information for the study.

**Method of Data Collection**

The data collection process was done in two stages, first was the training of research assistants and the administration of the research questionnaire.

Ethical approval for this study was sought and obtained from the Akwa Ibom State Health Research Committee and was presented to the selected care facilities, outlining the purpose and procedures of the study.

Prior to data collection, each facility manager was met, and the purpose of the study was explained to them in detail. They were provided with a textbook to record the code assigned to each participant, along with their names. This ensured that the researcher did not have access to any participant's name but could request the code if necessary. This procedure was implemented to facilitate a high level of confidentiality throughout the research. The selected care facilities assisted in facilitating access to participants by coordinating with caregivers during their regular visit days. The facility managers then gave the date when they usually have group activities for the researcher to visit and explain the research purpose to potential participants. The caregivers who visited on the date were met, and the purpose of the study was explained to them. Caregivers who expressed willingness to participate were approached during their scheduled visit days at the care facilities. Before data collection, they were provided with detailed information about the study objectives and procedures. Informed consent was obtained from each participant before they completed the questionnaire.

**Measures**

The instruments revalidated in phase one were used for data collection in this phase.



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## Method of Data Analysis

The data obtained were subjected to statistical analysis. Presentations of such data were carefully and systematically done using statistical tables. The simple percentage method was used to analyze the background information of respondents. Pearson Product Moment Correlation was used to analyse the relationship between the study's variables. Subsequently, multiple regression was used to test the hypotheses formulated for this phase of the study.

## Ethical Issues

Participants were required to complete an approved informed consent form before participating in the study. They were provided with comprehensive information regarding the study's objectives, time commitments, and the assurance of anonymity for their responses. Participation was entirely voluntary, and participants were not subjected to coercion, pressure, deception, or manipulation to induce their participation. The researchers provided transparent explanations of the study's nature, affiliations, professional standing, and intended use of findings. Participants were afforded the right to refuse to answer any questions they deemed objectionable and could withdraw from the study at any time without prejudice. Confidentiality was strictly maintained, with the questionnaire designed to prevent disclosure of personal or children's identities. Furthermore, participants were not required to provide their names or assigned numbers, thereby ensuring the confidentiality of their responses.

## PHASE THREE

This phase focused on the experiment conducted to test the efficacy of Mindfulness Therapy in reducing psychological distress among caregivers.

## Research Design

Phase three of the research employed a pre-test, post-test control experimental design. This design was chosen to assess the effectiveness of Mindfulness Therapy in reducing psychological distress among those who experienced high psychological distress in phase two of the study. Participants were divided into two groups: the Mindfulness Therapy group, which received the treatment, and the control group, which benefited from health talk.

## Research Participants

All participants were selected from those who participated in the second phase of the study and met the criteria for inclusion based on high elevations on the psychological distress scale. Sixty-three (63) participants reported severe psychological distress from the survey in the second phase of the research. The codes of participants who reported severe psychological distress were given to the centres from where they were selected for them to be contacted and invited participants to participate in the third phase of the study. Initially, 51 participants indicated interest in the intervention across the three senatorial districts. Of the 51, a total of 46 participated on the first day of the experiment; subsequently, 8 withdrew from the experiment before it ended. 38 participants, made up of 30 females and 8 males, participated till the end of the experiment. Therefore, the number of participants was determined by the number of those who were willing to participate in this phase.



## **Sampling Procedure**

In the third phase of the study, a purposive sampling method was employed to select participants, adhering to the stringent criteria established during phase two. This approach ensured that the participants selected were individuals who had experienced severe psychological distress in the survey phase of the research.

To mitigate the influence of unknown variables on the study results, participants were randomly assigned to either the treatment or control group using a simple random technique. Specifically, the folded paper method was applied to facilitate the random assignment process. Participants were required to pick a folded paper, and those who picked folded number 1 were assigned to the experimental group, while those who picked folded number 2 were assigned to the control group. This randomization process ensured that any extraneous variables were evenly distributed across both groups, thereby enhancing the internal validity of the study.

## **Experimental Procedure**

Upon arrival, participants were warmly welcomed and briefed on the purpose of the study. They were informed that the study aimed to investigate the effectiveness of Mindfulness Therapy in reducing psychological distress among caregivers of children with autism. Participants were assured of the confidentiality and anonymity of their responses. The control group received a health talk for 4 weeks, while the experimental group received the Mindfulness intervention for 4 weeks. The Mindfulness intervention consisted of four sessions, each lasting approximately 1:30 hour, and was facilitated by a licensed clinical psychologist. The sessions were conducted at three care centres which acted as intervention centres for each senatorial district of Akwa Ibom State: Women and Community Livelihood Foundation for participants drawn from Uyo Senatorial district, First Love Foundation for Ikot Ekpene Senatorial district, and Shalom Care Centre for Eket Senatorial district.

The Mindfulness intervention focused on teaching participants skills and techniques to manage their emotions and reduce psychological distress. Participants were encouraged to practice these skills outside of the sessions and to apply them to their daily lives. A pre-test on the Psychological Distress Scale was administered to both groups on the first day of the study, while post-test measures were administered on the last day of the study. The experiment took place on Tuesdays, Wednesdays, and Fridays of the week, from 10:00 am to 11:30 am, over 4 weeks. To prevent favouritism and ensure equitable treatment, all participants received an equal token economy. Specifically, a flat amount was provided to cover their transportation costs for each day of the research. This welfare package was designed to demonstrate appreciation for participants' time and effort while also ensuring that no individual or group received preferential treatment.

## **Instrument for Data Collection**

A 2-section Questionnaire was used for data collection in this phase. Section A focused on the demographic details of the participants, including age, gender, relationship with the child, educational qualifications, and marital status. Section B was the Kessler Psychological Distress Scale developed by Kessler et al. (2002).



## Data Analysis

To test the stated hypotheses in this phase, both paired and unpaired sample t-tests were employed. The selection of these statistical techniques was justified due to their suitability for comparing the means of two related groups, such as the experimental and control groups in this study and the pre and post-test of the experimental group.

## Ethical Issue

Throughout this phase, the researcher rigorously observed and upheld the highest ethical standards contained in the ethical approval protocol given by the Akwa Ibom State Health Research Ethics Committee to ensure the protection of participants' rights and dignity. The core of these ethical considerations is presented below. Informed written consent was obtained from all participants before their involvement in the study. This was achieved by providing detailed explanations regarding the study's purpose, significance, and potential risks and benefits. Participants were assured that their participation would not result in any negative consequences and that they would be free from any harm or discomfort.

Participants were assured of confidentiality, with all information collected treated with utmost privacy and discretion. The researcher ensured that all data collected were stored securely and that only authorized personnel had access to the data. Participants retained the right to withhold or withdraw consent at any stage of the study without facing any repercussions or penalties. This ensured that participants were free to make informed decisions about their involvement in the study and that they were not coerced or pressured into participating. No forms of deception were utilized to gather information, maintaining transparency and integrity throughout the research process. The researcher ensured that all information provided to participants was accurate, truthful, and free from any misleading or false claims.

## RESULTS

The table below presents demographic information of the study's respondents

**Table 1: Respondents' Demographic Variables**

Variable	Category	Frequency	Percentage (%)
<b>Sex</b>	Male	50	25.6
	Female	145	74.4
<b>Age</b>	< 40 years	88	45.1
	40 years and above	107	54.9
<b>Marital Status</b>	Single	54	27.7
	Married	126	64.6
	Separated	7	3.6
	Widow/Widower	7	3.6
<b>Duration of Care</b>	< 10 years	167	85.6
	10 years and above	28	14.4



Relationship to Child				
	Biological Parents	111	56.9	
	Grand Parents	18	9.2	
	Sibling	31	15.9	
	Family Member	25	12.8	
	Friend	9	4.6	
	Others	1	0.5	
		<b>195</b>	<b>100.0</b>	

**Table 2: Zero Order Correlation Matrix Showing Relationship among Demographic Variables**

	1	2	3	4	5	Mean	SD
11						1.74	0.44
22	0.09					41.21	11.78
33	0.14*	0.51**				1.83	0.66
44	-0.10	0.47**	0.36**			5.26	3.56
55	0.02	-0.32**	-0.37**	-0.25**		2.00	1.31

Note: \*p < 0.05, \*\*p < 0.01, \*\*\*p < 0.001

Key: 1 = Sex, 2 = Age, 3 = Marital Status, 4 = Duration of Care, 5 = Relationship with child,

Results presented in Table 2 indicate that marital status showed a significant positive correlation with age ( $r = 0.51^{**}$ ,  $p < 0.001$ ) and duration of care ( $r = 0.36^{**}$ ,  $p < 0.001$ ), while demonstrating a significant negative correlation with relationship to the child ( $r = -0.37^{**}$ ,  $p < 0.001$ ). Duration of care was significantly positively correlated with age ( $r = 0.47^{**}$ ,  $p < 0.001$ ) and marital status ( $r = 0.36^{**}$ ,  $p < 0.001$ ), but negatively correlated with relationship to the child ( $r = -0.25^{**}$ ,  $p < 0.001$ ). Relationship to the child exhibited a significant negative correlation with age ( $r = -0.32^{**}$ ,  $p < 0.001$ ), marital status ( $r = -0.37^{**}$ ,  $p < 0.001$ ), and duration of care ( $r = -0.25^{**}$ ,  $p < 0.001$ ).

**Table 3: Summary of Multiple Regression Analysis Showing the Predictive Role of Health Literacy and Perceived Stigmatisation on Psychological Distress among Informal Caregivers of Children with Autism**

Variables	$\beta$	t-value	Sig.	R	R Square	Std. Error	df	F	Sig.
Health Literacy	-0.04	-2.24	0.03	0.23	0.05	8.06	3	4.53	<.05
Perceived Stigmatisation	0.05	1.98	0.05						

**Dependent Variable: Psychological Distress**

The results presented in Table 3 provide findings on the roles of health literacy and perceived stigmatisation in predicting psychological distress among 195 informal caregivers of children with autism. The regression model shows an R-value of 0.23 and an R Square of 0.05, indicating that approximately 5% of the variance in psychological distress is explained by the combined effects of health literacy and perceived stigmatisation. The standard error of the





estimate is 8.06, reflecting the average deviation of the observed psychological distress values from the predicted values.

Health literacy significantly and negatively predicted psychological distress ( $\beta = -0.04$ ;  $t = -2.24$ ;  $p < 0.05$ ), indicating that higher health literacy is associated with lower psychological distress among informal caregivers. This confirms the hypothesis that health literacy negatively predicts psychological distress. Perceived stigmatisation had a significant positive effect on psychological distress ( $\beta = 0.05$ ;  $t = 1.98$ ;  $p < 0.05$ ), suggesting that higher perceived stigmatisation is linked to higher psychological distress among informal caregivers. This supports the hypothesis that perceived stigmatisation positively predicts psychological distress.

The overall regression model was statistically significant ( $F(3, 191) = 4.53$ ,  $p = 0.004$ ), indicating that health literacy and perceived stigmatisation collectively contribute to psychological distress among informal caregivers of children with autism.

**Table 4: Independent-Sample T-test Comparing Psychological Distress Levels Between the Study's Control and Experimental Groups**

Group	Mean	SD	SE	t-value	df	P
Post-Control	22.10	10.20	2.34			
Post-Intervention	18.00	4.00	0.92	4.50	36	<.05

Results in Table 4 indicate a significant effect of DBT intervention on psychological distress among informal caregivers of children with autism ( $t = 4.50$ ,  $p < .05$ ). The mean psychological distress score for the control group ( $M = 22.10$ ,  $SD = 10.20$ ) was significantly higher than that of the DBT intervention group ( $M = 18.00$ ,  $SD = 4.00$ ). This suggests that mindfulness intervention effectively reduces psychological distress in caregivers.

**Table 5: Paired Samples t-test Comparing Pre- and Post-Intervention Psychological Distress Scores in the Experimental Group**

Pair	N	Pre- Intervention Mean	Post- Intervention Mean	Mean Difference	Std. Deviation	Std. Error Mean	t- value	df	P
Pre- vs Post- Intervention	19	31.50	18.00	13.50	12.00	2.75	4.91	18	<.05

Table 5 presents a paired samples t-test, showing a significant decrease in psychological distress in the DBT intervention group after treatment ( $t = 4.91$ ,  $p < .05$ ). The mean distress



score was higher before the intervention ( $M = 31.50$ ,  $SD = 12.00$ ) and significantly lower after ( $M = 18.00$ ,  $SD = 4.00$ ). The mean difference of 13.50 suggests that mindfulness intervention was effective in reducing psychological distress levels among caregivers. Hence, the hypothesis earlier stated in this regard was confirmed.

## DISCUSSION OF FINDINGS

The findings of the study support the first hypothesis that health literacy will significantly predict psychological distress among informal caregivers of children with autism. Higher levels of health literacy were associated with lower levels of psychological distress, aligning with several studies in the literature. Osborne and Osborne (2013) found a significant negative correlation between health literacy levels and psychological distress, suggesting that adequate health literacy skills serve as a protective factor against psychological distress. Similarly, Jones *et al.* (2015) demonstrated that higher health literacy was consistently associated with lower levels of psychological distress over time. Health literacy empowers caregivers by providing them with the knowledge and skills needed to understand and manage their child's condition effectively. Caregivers with higher health literacy are better equipped to navigate the complexities of the healthcare system, access relevant information, and make informed decisions about their child's care. This empowerment reduces feelings of uncertainty and anxiety, leading to lower levels of psychological distress. Moreover, health literacy may enable caregivers to communicate more effectively with healthcare professionals, ensuring that they receive appropriate support and guidance. Caregivers with higher health literacy are more likely to ask questions, seek clarification, and advocate for their child's needs, resulting in better healthcare experiences and outcomes. This positive interaction with healthcare providers can alleviate caregivers' stress and contribute to their overall well-being.

Furthermore, the study also supports the second hypothesis, which proposed that perceived stigmatisation will significantly predict psychological distress among informal caregivers of children with autism. Caregivers who perceived higher levels of stigmatisation reported higher levels of psychological distress, which is consistent with findings from previous research. Mitter *et al.* (2019) and Desmond (2019) both reported that higher perceived stigmatisation was associated with greater psychological distress among caregivers.

These findings suggest that any intervention aimed at reducing psychological distress must address both health literacy and perceived stigmatisation. Improving health literacy alone may not be sufficient if caregivers continue to face stigmatisation. Therefore, a dual approach that enhances caregivers' health literacy while also working to reduce societal stigma will provide a more comprehensive solution to the mental health challenges faced by caregivers. Creating supportive communities, fostering positive healthcare experiences, and promoting awareness can lead to significant reductions in caregiver distress, ultimately improving both their psychological health and the well-being of the children under their care.

The study also revealed that mindfulness therapy is effective in reducing the experience of psychological distress among informal caregivers of children with autism, thereby supporting the third hypothesis. While the study's findings on mindfulness therapy are novel, they suggest promising avenues for improving caregiver well-being. The practical skills taught in mindfulness therapy—mindfulness, distress tolerance, emotion regulation, and interpersonal effectiveness—are highly relevant for caregivers of children with autism. Integrating



mindfulness therapy into caregiver support programs could enhance their ability to manage stress and emotional challenges, ultimately reducing psychological distress and improving their overall quality of life. Further research is needed to explore the long-term benefits of mindfulness therapy for this population and to refine these interventions to maximize their effectiveness.

## CONCLUSION

Based on the findings of the study, the following conclusions were drawn

- i. Higher levels of health literacy were associated with lower levels of psychological distress among informal caregivers of children with autism as health literacy negatively predicted psychological distress among the population.
- ii. Perceived stigmatisation is a significant positive predictor of psychological distress among informal caregivers of children with autism.
- iii. Mindfulness Therapy is effective in reducing psychological distress among informal caregivers of children with autism caregivers.

## RECOMMENDATIONS

The following recommendations are made based on the findings of the study;

- i. Government health departments, non-governmental organisations (NGOs), and autism advocacy groups should lead public education campaigns to reduce the stigmatisation associated with autism and mental health issues. By fostering a more inclusive and supportive community, these campaigns will help caregivers experience less stigmatisation and increase social support. Additionally, the broader community will benefit from a better understanding of autism and mental health issues, promoting more empathetic and supportive attitudes.
- ii. Health service providers, local government agencies, and non-profit organisations should collaborate to improve the accessibility and quality of support services for caregivers. This effort will ensure caregivers have access to high-quality, tailored support services that meet their specific needs. By reducing barriers to these services, caregivers will experience a decrease in psychological distress and an improvement in their overall well-being.
- iii. It is also recommended that policies integrating awareness of developmental disorders into postnatal care be developed and implemented. Such policies should ensure that new parents receive comprehensive information about developmental disorders, including early signs, available resources, and support options, as part of routine postnatal care. This approach would facilitate early detection and intervention for developmental disorders, empowering parents with the knowledge they need to seek timely support. By embedding this awareness into postnatal care, healthcare systems can promote early identification, reduce stigmatisation, and improve outcomes for children and their



families. Implementing these policies will not only enhance caregiver readiness and understanding but also contribute to more effective management and support strategies from the outset.

- iv. Healthcare organisations, educational institutions, and autism support organisations should develop and implement comprehensive health literacy programs. These programs should cover autism, effective caregiving strategies, and healthcare navigation. Enhanced health literacy will empower caregivers with the knowledge and skills needed to manage their child's condition effectively, thereby reducing their own psychological distress.
- v. Mental health professionals, caregiver support organisations, and healthcare providers should incorporate Mindfulness Therapy into caregiver support programs. Integrating MT will provide caregivers with practical skills for managing stress, regulating emotions, and improving interpersonal effectiveness. This will directly benefit caregivers by reducing psychological distress and enhancing their mental health outcomes.
- vi. Community organisations, local support groups, and advocacy networks should establish and reinforce community-based support networks for caregivers. These networks should offer emotional and practical support, helping to alleviate feelings of isolation and distress. By providing a robust support system, caregivers' quality of life and emotional well-being will improve.
- vii. Policymakers, government agencies, and advocacy groups should advocate for and implement policy changes that provide better support for caregivers. This includes integrating awareness of developmental disorders into postnatal care programs. Policies should include increased financial support, improved access to services, and specific provisions for addressing the unique needs of caregivers. Enhanced awareness and support structures will reduce barriers and improve overall caregiver support, leading to more effective management of caregiving responsibilities and reduced distress.

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