

**PSYCHOLOGICAL DISTRESS AMONG SIBLINGS OF CHILDREN WITH AUTISM
SPECTRUM DISORDER IN RIVERS STATE NIGERIA**

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DECLARATION

I hereby declare that this research project is my original work and that it has not been submitted elsewhere for diploma, fellowship or degree.

Where other sources of information have been used, they have been duly acknowledged

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TABLE OF CONTENTS

TITLE PAGE	
DECLARATION	i
SUPERVISOR’S SIGNATURE	ii
TABLE OF CONTENTS.....	iii
LIST OF FIGURES	vii
LIST OF TABLES	ix
LIST OF APPENDICES.....	x
LIST OF ABBREVIATIONS AND THEIR MEANINGS	xi
ABSTRACT.....	xii
CHAPTER ONE.....	1
INTRODUCTION	Error! Bookmark not defined. 1
1.1 BACKGROUND OF THE STUDY	Error! Bookmark not defined. 1
1.2 JUSTIFICATION AND RELEVANCE OF THE STUDY IN NIGERIA.....	Error! Bookmark not defined. 6
1.3 AIM OF THE STUDY	7
1.4 SPECIFIC OBJECTIVES	7
1.5 NULL HYPOTHESES.....	8
1.6 ALTERNATIVE HYPOTHESIS.....	8

CHAPTER 2	9
LITERATURE REVIEW	9
2.1 AUTISM SPECTRUM DISORDERS	9
2.1.1 Definitions and classification of ASDs	9
2.1.2 Evolution of ASDs through the years	10
2.1.3 Prevalence of ASD	12
2.2 IMPACT OF DISORDERS ON THE FAMILY	13
2.2.1 Physical Disorders and the family.....	13
2.2.2 Mental Disorders and the family.....	14
2.3 IMPACT OF AUTISM ON THE FAMILY.....	14
2.3.1 Impact on the caregivers	14
2.3.2 Impact on other healthy children in the family	14
2.3.2.a Negative outcomes	14
2.3.2.b Positive Outcomes.....	17
2.4 PSYCHOLOGICAL DISTRESS	18
2.4.1 Definition of Psychological Distress.....	18
2.4.2 Causes, Forms and Assessment of Psychological distress.....	19
2.4.4 Symptoms of Psychological distress	20
2.4.5 Effects of Psychological Distress.....	21

2.4.6 Prevalence of Psychological distress among people with medical conditions (mental and physical)	21
2.4.6 Relevance of Psychological distress	22
2.5 AUTISM AND PSYCHOLOGICAL DISTRESS	22
CHAPTER 3	24
METHODOLOGY	24
3.1 STUDY LOCATION	24
3.2 STUDY POPULATION	24
3.3 INCLUSION CRITERIA	24
3.4 EXCLUSION CRITERIA.....	24
3.5 STUDY DESIGN.....	25
3.6 SAMPLING TECHNIQUE	25
3.7 SAMPLE SIZE CALCULATION	25
3.8 STUDY INSTRUMENTS	26
3.9 STUDY PROCEDURE.....	29
3.10 ETHICAL CONSIDERATION	29
3.11 DATA MANAGEMENT.....	30
CHAPTER 4	32
RESULTS	32
4.1 Socio-demographic characteristics of the study participants	32

4.2 Age of respondents.....	35
4.3 Parents Educational Attainment.....	36
4.5 Socio-economic status.....	38
4.5a Occupation of parents.....	38
4.5b Wealth index rating.....	40
4.6 Aggression in siblings.....	42
4.7 Influence of religion on respondents.....	44
4.9 Relationship between psychological distress and respondents group (case & control).....	46
CHAPTER 5.....	47
DISCUSSION, CONCLUSION AND RECOMMENDATIONS.....	47
5.1 Discussion.....	47
Socio-demographics.....	47
Wealth index.....	49
Perceived aggression.....	49
Psychological distress.....	49
5.2 Limitations of the study.....	53
5.3 Conclusion.....	55
REFERENCES.....	56
APPENDI Error!	
defined.	62
Bookmark	not

INFORMED CONSENT FORM.....	62
APPENDIX 2A.....	64
SOCIO-DEMOGRAPHIC QUESTIONNAIRE.....	64
APPENDIX 2B.....	69
STRENGTHS AND DIFFICULTIES QUESTIONNAIRE.....	69
APPENDIX 2C.....	71
SHORT MOODS AND FEELINGS QUESTIONNAIRE.....	71
APPENDIX 2D.....	72
CHILDREN’S HOPE SCALE.....	72
APPENDIX 2E.....	73
Beck Anxiety Inventory.....	73

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LIST OF FIGURES

Figure	Title	Page
4.1	Age of respondents	34

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LIST OF TABLES

Table	Title	Page
2.1	Number and percent of recent research articles on individuals versus families, by disability type	5
2.2	Distribution of types of family interventions across disability groups	5
4.1	Socio-demographic details of respondents	33
4.2	Parents educational attainment	36
4.3	Occupation of parents	38
4.4	Wealth index of respondents	40
4.5	Aggression in siblings of respondents	42
4.6	Influence of religion on respondents	44
4.7	Independent t-test to compare mean scores of SDQ, SMFQ, CHS and BAI	45

LIST OF APPENDICES

APPENDIX No	Title	Page
Appendix 1	Informed Consent Form	62
Appendix 2a	Socio-demographic Questionnaire	64
Appendix 2b	Strength and Difficulties Questionnaire	69
Appendix 2c	Short Moods and Feelings Questionnaire	71
Appendix 2d	Children's Hope Scale	72
Appendix 2e	Beck Anxiety Inventory	73`

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LIST OF ABBREVIATIONS AND THEIR MEANINGS

Abbreviations	Meanings
AICAPAP Professions	International Association for Child and Adolescent Psychiatry and Allied Professions
ASD	Autism Spectrum Disorder
CDC	Center for Disease Control and Prevention
DSM-5	Diagnostic and Statistical Manual-5
HIC	High Income Countries
ICD-10	international classification of diseases 10 th edition
LMICs	Low and Middle Income Countries
LSD	Lysergic Acid Diethylamide
NDD	Neuro-Developmental Disorders
NIMH	National Institute for Mental Health
NINDS	National Institute of Neurological Disorders And Stroke
NIH	National Institute of Health
PDD-NOS	Pervasive Developmental Disorders Not Otherwise Specified
SDQ	Strengths and Difficulties Questionnaire
SPSS 22	Statistical Package for Social Sciences version 22.0 software
USA	United States of America
WHO	World Health Organization

ABSTRACT

Background:

Autism Spectrum Disorders (ASDs) refer to a range of conditions characterized by some degree of impaired social behavior, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out repetitively. Most mental health research on ASD have focused solely on children affected by autism and their parents to the neglect of the other children within the family whose well-being may be affected by difficulties related to their sibling affected by autism. Similarly, the main focus of interventions for families with children with autism tend to be on the affected child and parents. The interventions do not extend to other healthy children within the family who, although not primary caregivers live with and bear some of the burden (psychological if not physical) associated with living with a child affected by autism. This study was carried out with the aim of assessing if having a sibling with autism spectrum disorder predisposes a child to psychological distress compared with not having a sibling with autism. The study was carried out in Port Harcourt, Rivers State Nigeria.

Methodology:

The study was a cross sectional case control study that involved 48 participants in Port Harcourt, Rivers State Nigeria. Cases were 16 siblings of children with autism and controls were 32 siblings of children without autism (i.e 1:2 case control design). The two groups were closely matched for age and gender. In addition to a socio-demographic questionnaire, participants completed the Strengths and Difficulties Questionnaire (a measure of psychological distress), Children's Hope Scale, Short Moods and Feelings Questionnaire (a measure of depressive symptoms) Beck Anxiety Inventory.

Results:

Respondents mean age was 11.56 years (SD = 2.9). There were 16 male respondents of which; 7 of the 16 (43.7%) were siblings of children with autism and 9 out of 32 (28.1%) were siblings of regular children without autism, Of the 32 female respondents, 9 out of the 16 (56.3%) were siblings of children with autism and 23 of 32 (71.9%) were siblings of regular children without autism. Majority of the mothers and fathers in both groups were married, had university education and worked in professional jobs. Siblings of children with autism (cases) and siblings of children without autism (controls) did not differ significantly on Wealth rating (an index of socio-economic status) or on any other outcome measures (Strength and Difficulties, Children's Hope Scale, Short Moods and Feelings and Beck Anxiety Inventory)..

Conclusion:

The study's findings suggest that siblings of children with autism are no more likely to be psychologically distressed when compared with siblings of children without autism. This may indicate a level of resilience among the siblings of children with autism. The resilience factors may include the fact that most of the children came from intact families with well educated parents who work professional jobs. It is recommended that this study be replicated with a larger sample size that is more typical of the average Nigerian family to determine generalizability of the findings.

Key Words: Autism Spectrum Disorder, Siblings, Psychological Distress

CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND OF THE STUDY

The movie “my sister’s keeper” tells the story of Anna Fitzgerald, an 11 year old girl who was conceived by in vitro fertilization as a ‘savior sister’ for her elder sister Kate who suffers from acute promyelocytic leukemia. All her life, Anna (having been engineered to be a genetic match to Kate) has been made to donate blood, tissue and organs. However when her sister goes into renal failure, she realizes that she is going to be forced by their mother to donate a kidney this leads to her suing her parents for medical emancipation. Although fictional, this movie is a great illustration of the magnitude of distress and ‘disruption’ the diagnosis of a disorder can create within the family system.

It is a fact that having a major illness can have a major psychological impact on the individual. This has been shown over time by a wide range of research. A 2012 study reported 17.1% prevalence rates for psychological distress among outpatients in Pretoria(Peltzer *et al.*, 2012). Another study reported 81% prevalence of psychological distress among tuberculosis patients in South Africa (Peltzer *et al.*, 2012). In a study on children with congenital heart disease, it was discovered that they are more likely to experience distress than their healthy counterparts(Johnson and Francis, retrieved 2017). A Nigerian study by Bakare et al (2008) found a 3-fold increase in emotional disorders among children with sickle cell disease. In recent times though, focus is gradually growing to encompass the families of the individual with the illness and not just the ill person.

Since the early 1900s when the word of autism was first used, there has been a continuous upspring of research into the field. According to the World Health Organization (WHO), ASDs refers to a range of conditions characterized by some degree of impaired social behavior, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out repetitively (WHO _ *Autism spectrum disorders*, 2017). Different professional bodies have given different definitions over time but they all still revolve around the basic criteria given in the definition by the WHO. Autism (sometimes called “classical autism”) is the most common condition in a group of developmental disorders known as the autism spectrum disorders (ASDs) and is characterized by impaired social interaction, problems with verbal and nonverbal communication, and unusual, repetitive, or severely limited activities and interests (NINDS, NIH, 2009). Other ASDs include Asperger Syndrome, Rett Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder not otherwise specified, usually referred to as PDD-NOS (Canha, 2010) although the DSM now recommends the term ‘Autism Spectrum Disorder’.

ASDs are quite common in present times although, we can clearly see that the reported prevalence rates vary across international organizations. Current global prevalence rate for ASD as reported by a review of existing literature is set at 62/10000 (Mayada *et al.*, 2012). Globally however the World Health Organization (WHO) reports that 1 in 160 children have ASDs worldwide (WHO _ *Autism spectrum disorders*, 2017).

As at the year 2014, the Center for Disease Control and prevention (CDC) reported that about 1 percent of the world population has autism. This is in agreement with the prevalence reported by the DSM-5 at 1% across U.S and non U.S countries. Currently however, the CDC reports an

estimated 1 out of every 68 children in the US (CDC, 2014) and in the United Kingdom, 1 out of every 100 children (NAS, 2014) has been identified with autism spectrum disorder (ASD).

Within the African context, there is no official public figure for prevalence rates. This is said to be as a result of the fact that prevalence data are not centralized and collated properly. This doesn't mean that there have not been research on prevalence of autism in the African society, it just means that we cannot comfortably state that statistics are still as large as that of High Income Countries or not. Bakare(2011) attempts to review literature and highlight prevalence rates across various countries in Africa. This was done in a bid to counter the notion propounded by (Sanua, 1984)who opined that ASD may largely be a disorder of children living in Western Industrialized Countries with high technological development as a result, may be uncommon among African Children. Bakare reported a prevalence of 0.7% in Africa in general (Lotter, 1978), 11.5% in Tunisia and 33.6% in Egypt among children with intellectual disability (Seif Elden et al, 2008). Interestingly, the estimated prevalence rate for ASD in Nigeria was found to be 0.08% (Bakare et al, 2011) – This was said to most likely have been influenced by low help seeking behavior for Childhood Neurodevelopment Disorders (NDD) (Bakare & Munir, 1984)

Psychological distress on the other hand is said to be a term used to describe unpleasant feelings and emotions that are capable of influencing functioning. This is a phenomenon that has been identified as being strongly influential on the wellbeing of persons with both physical and mental disorders. Different studies have reported varying degrees of psychological distress among persons with various physical ailments.

A 2012 study reported 17.1% prevalence rates for psychological distress among outpatients in Pretoria and 81% prevalence among tuberculosis patients in South Africa (Peltzer *et al.*, 2012).

In a study on children with congenital heart disease, it was discovered that they are more likely

to experience distress that their healthy counterparts (Johnson & Francis, retrieved 2017). In like manner, psychological distress has been identified among caregivers of persons with mental disorders (Ong *et al.*, 2016a).

There is an increasing interest at understanding family resilience and how families cope with adversities such as the presence of a child with a chronic illness. Despite this growing interest, there are few studies among families with children who have disabilities (Bayat, 2007). Large-scale studies on the consequences of children disability on families can be found in the literature since at least the early 1970s, when it was finally recognized that “a family with a child who has a disability is a family with disability” (Giulio *et al.*, 2014; Glidden, 1993). In reviewing the research works on disorders and their impact on the family, it is observed that more emphasis was placed on physical disorders than on mental. However with the growing mental health field and knowledge about the burden of mental health conditions, this trend is changing. International health organizations are paying attention and creating plans and programs like the World Health Organization (WHO) Mental Health Action Plan (2013-2020), that incorporate mental health into medical care. Although there is still a lot of stigma attached to mental health, there has been a significant increase in the diagnosis and knowledge about mental health conditions. This increase in the number of children being diagnosed with chronic illnesses which could be attributed to improved diagnostic tools or an increase in public awareness about disorders in general has motivated a lot of research into the effect of specific diagnosis on families. This increase in diagnosis is a major achievement for the mental health field and although these achievements are celebrated, they are accompanied by increased care giving burden to all members of a household with a child with disability (Havercamp *et al.*, 2013).

Despite the increase in diagnosis and research, it has been observed that most researchers focus on the impact of the diagnosis on the individual rather than the family in general. A review by(Dykens, 2015), compared the number of studies done among individuals with the disorders versus those done for the families. The summary of those findings is shown in table 1 below

	Estimated Prevalence%	Articles on affected individuals	Articles on family life	% of family to individual studies	% of all family articles
Autism Spectrum Disorders (2)	1 %	3 1 1 4	1 1 0	3 %	6 4 %
Intellectual Disabilities (3)	1 %	1 1 1	1 9	1 7 %	1 1 %
Developmental Disabilities (4)	6 %	1 0 2	2 2 2 2	2 %	1 3 %
Genetic IDD symptoms(5)	. 0 5 %	4 1 6	1 1	2 %	6 %
Child Psychiatric disorders (6)	1 9 %	2 3 0 4	1 1	< 1 %	6 %
T o t a l		6 0 4 7	1 7 3	3 %	1 0 0 %

Table 2.1: Number and percent of recent research articles on individuals versus families, by disability type(Dykens, 2015)

The study went on to look at the kind of interventions done for the families and this shows an even greater gap. This is shown in table 2 below

Types of family intervention	Autism Spectrum Disorders	Intellectual/Developmental Disabilities	Psychiatric Disorders	T o t a l
Psycho-educational, support	5	5	1	1 1
Marriage or family therapy	3	0	0	3

Respite care, short breaks	2	1	0	3	
Mindfulness-based stress reduction	1	2	0	3	
Theory, models, recommendations	3	0	1	4	
T o t a l	1	4	8	2	4

Table 2.2: Distribution of types of family interventions across disability groups (Dykens, 2015)

It can be seen from the table above that there all of the interventions are channeled towards reducing care burden for the caregivers who in most cases are the parents or legal guardian. These interventions do not extend to other healthy children within the family who, although not primary caregivers have to live with and bear some of the burden (psychological if not physical) of the presence of the disabled child. The sibling bond is the marathon runner of human relationships; it is the longest lasting relationship, enduring from the birth of the youngest sibling to the death of the first to go (Green, 2013). This sibling bond has been shown to be susceptible to .It has long been recognized that well siblings of children with chronic illness are potentially the most overlooked and unhappy family member (Gettings et al., 2015). This is very true and observable for siblings of children with chronic physical disorders, howbeit those with mental illnesses.

Of recent though, researchers have observed this gap and are attempting to meet up. This has led to the discovery that it is not that parents overlook their other children who are typically developing, they simply worry that they can't provide enough for all their children. The typically developing offspring fare relatively well compared with the child with special health care needs, and parents instinctively give more time and energy to the child most in need.

1.2 JUSTIFICATION AND RELEVANCE OF THE STUDY IN NIGERIA

It is well known that the diagnosis of a childhood chronic illness whether physical or mental affects both the child and his or her family (Palmer et al., 2017). There have been many studies to identify the effects on the caregivers but few on the siblings. As such the mental and emotional health of siblings are being overlooked

Most research into mental health field has been focused solely on children with mental disorders and their parents to the neglect of the other children within the family who have to live with the affected children. A lot of time, except for screening purposes mental health workers hardly pay attention to the siblings. It's as though they are forgotten and relegated to the background by both the caregivers and medical personnel. It is as though there is this unconscious tendency to forget that these siblings at one level or the other are also caregivers and might need to be supported. It is beneficial to the health of these siblings for health care professionals to understand that they are also caregivers and as such might be more predisposed to psychological distress. Such recognition of siblings' daily coping responses is a first step in the promotion of positive adaptation and health (Cox *et al.*, 2003). This will enable all parties concerned to make effort in interventions that will promote psychological wellbeing and reduce distress among siblings by improving siblings' knowledge, coping with caring and overall psychological wellbeing. In this way, they will invariably be more equipped to provide improved care services for the disabled child.

1.3 AIM OF THE STUDY

The aim of this study is to compare the level of psychological distress amongst siblings of children with ASD as compared with healthy controls who have no siblings with ASD or other disabilities.

1.4 SPECIFIC OBJECTIVES

To compare the level of psychological distress among siblings of children with ASD as compared with healthy controls who have no siblings with ASD or other disabilities

To determine the correlates of psychological distress among siblings of children with ASD and healthy controls who have no siblings with ASD or other disabilities

1.5 NULL HYPOTHESES

There will be no significant difference in the level of psychological distress among siblings of children with ASD and healthy controls who have no siblings with ASD or other disabilities.

1.6 ALTERNATIVE HYPOTHESIS

There will be a statistically significant difference in the level of psychological distress among siblings of children with ASD and healthy controls who have no siblings with ASD or other disabilities.

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CHAPTER 2

LITERATURE REVIEW

2.1 AUTISM SPECTRUM DISORDERS

2.1.1 Definitions and classification of ASDs

Over the years ASDs have been given a variety of definitions that have been influenced by the amount of information available at that given time about the disorders. In the early 1900s the word '*Autism*' was first used in describing a subset of schizophrenia which presented with withdrawal and self-absorption. This description and definition lasted over two decades and was re-emphasized by prominent Psychiatrists and researchers like Leo Kanner (who coined the terminology 'early infantile autism' in reference to children who followed a strict routine persistently and showed heightened preference to aloneness) and Hans Asperger (who was the first to discover the milder form of autism where children were highly intelligent but had social interaction problems and specific obsessive interests now known as Asperger's syndrome).

As these definitions continuously evolved there were more researchers getting interest in the field. This led to a rise in studies into ASDs, an increase in frequency of diagnosis and broader classifications based on symptom. Previously, ASDs had been divided into 5 types

1. Autism
2. Asperger Syndrome
3. Rett Syndrome
4. Childhood Disintegrative Disorder

Currently however, the DSM 5 uses only 1 category for all of them as Autism Spectrum Disorder. Current definition by the WHO is that ASDs refers to a range of conditions characterized by some degree of impaired social behavior, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out repetitively

2.1.2 Evolution of ASDs through the years

The symptomatic descriptions of ASDs have constantly changes form when the term was first used. The earliest recorded occurrence of the term Autism was between 1908 and 1911 when Eugene Bleuler used it to describe certain schizophrenic symptoms. This lasted almost a decade until the 1920s when the belief that autism symptoms were caused by diet, this led to the use of biochemical treatments and diet restrictions for children who were diagnosed with autism. The 1930s saw the introduction of Electroconvulsive therapy/Electroshock therapy to treat self-destructive and antisocial symptoms.

The 1940s is believed to be the hallmark year as it saw for the first time a clear cut definition of autism by child psychiatrist Leo Kanner. He defined autism as “lack of affective contact, fascination with objects, desire for sameness and non-communicative language before 30 months of age.” This triggered more research into the disorders and led to the detection of a condition that was similar to autism by German scientist Hans Asperger, this condition we now know today as Asperger’s syndrome

The 1950s is considered as almost a regression in the upsurge of groundbreaking research into autism. This decade saw the spread of the ‘refrigerator mothers’ theory by Psychologist Bruno Bettelheim. This theory propounded that autism was caused by cold and unloving mothers. This narrowed down research work to focusing more on impact of life experiences than on genetic

factors. This resulted in the use of ‘parentectomy’ which is basically institutionalization for long periods of time. This era also saw the classification of autism under schizophrenia in the *International Statistical Classification of Diseases and Related Health Problems*. This classification has long since been debunked. This regression can be said to have still continued into the 1960s when pain and punishment were inflicted on autistic children to try to correct the antisocial behaviors. This decade also saw a rise in the use of Lysergic Acid Diethylamide (LSD) a psychedelic medication in the treatment of autism symptoms. It was believed that altering the patient’s state of perception could alleviate symptoms. The only positive thing (according to present definitions of positives) from this era was the establishment of the “Autism Society of America”; this is the first recorded advocacy group for autism.

1970s saw a shift from the ‘impact of life experiences’ viewpoint to the ‘genetics’ view. Twin studies were done and it was determined that autism was more genetics and biological differences in brain development than environment. This was the major turning point in autism research.

1980s brought the inclusion of autism in the DSM for the first time as ‘infantile autism’. This condition was officially separated from childhood schizophrenia. By the next DSM publication in 1987, ‘infantile autism’ was replaced with ‘autism disorder’ and it was broadened to include diagnostic criteria checklist. This year also saw the first study by UCLA Psychologist Ivar Lovaas on the effect of intensive behavioral therapy on autism. This was a breakthrough because it offered hope to parents that their children could actually be assisted to have normal lives. The year 1988 saw the release of the movie *Rain Man* which was about an autistic savant with photographic memory. It helped to raise public awareness about autism.

1990s saw the inclusion of special education services for autistic children in public schools, it also saw the inclusion of Asperger's syndrome to the DSM thus expanding the autism spectrum to include milder cases in which individuals are more highly functioning. This decade also saw the use of 'holding therapy', a form of treatment in which children are restrained and forced to perform various social functions like maintaining eye contact.

Previously, Asperger's syndrome and Autistic Disorder were separate disorders. They were listed as subcategories within the diagnosis of "Pervasive Developmental Disorders." However, this separation has changed. The latest edition of the manual from the American Psychiatric Association, the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, does not highlight subcategories of a larger disorder. The manual includes the range of characteristics and severity within one category. People whose symptoms were previously diagnosed as Asperger's syndrome or Autistic Disorder is now included as part of the category called Autism Spectrum Disorder (ASD). Autism research has come a long way and due to a more thorough understanding of the disorder and more effective symptom treatments, more children are being diagnosed and getting the necessary help they need to live more fulfilling lives (Costello et al., 2005)

2.1.3 Prevalence of ASD

As at the year 2014, the Center for Disease Control and prevention (CDC) reported that about 1 percent of the world population has autism. This is in agreement with the prevalence reported by the DSM-5 at 1% across U.S and non U.S countries. Currently however, the CDC reports an estimated 1 out of every 68 children in the US (CDC, 2014) and in the United Kingdom, 1 out of every 100 children (NAS, 2014) has been identified with autism spectrum disorder (ASD).

There is no official public figure for prevalence rates in Africa as a whole; rather, we see different countries reporting different prevalence rates each. This does not mean that there have not been research on prevalence of autism in the African society, it just means that we cannot comfortably state that statistics are still as large as that of High Income Countries or not. Bakare (2011) reviewed existing literature and highlighted the prevalence rates across various countries in Africa. He reported a prevalence of 0.7% in Africa in general (Lotter, 1978), 11.5% in Tunisia and 33.6% in Egypt among children with intellectual disability (Seif et al., 2008). Interestingly, the estimated prevalence rate for ASD in Nigeria was found to be 0.08% (Bakare et al, 2011). This was said to most likely have been influenced by low help seeking behavior for Childhood Neurodevelopment Disorders (NDD)(Bakare & Munir, 1984)

2.2 IMPACT OF DISORDERS ON THE FAMILY

2.2.1 Physical Disorders and the family

Disability or chronic illness in a child has been observed to create stressors and new demands for all family members. Most research has focused on the parental perspective. There are little data from children themselves regarding daily coping responses related to living with a brother or sister with disabilities(Cox *et al.*, 2003). This may be as a result of the fact that most children who have siblings with disabilities/disorders are forced to learn independence early and as such learn to care for themselves early and not expect much attention from their parents/caregivers. In recent times though, the scope of research is broadening and beginning to incorporate other healthy in the family.

A 2013 study done among siblings of children with disabilities, found that siblings of children with disabilities were more likely than siblings residing with typically developing children to have problems with interpersonal relationships, psychopathological functioning, functioning at school, and use of leisure time(Goudie *et al.*, 2013).

2.2.2 Mental Disorders and the family

Ensuring that an individual with ASD lives in an environment that caters for their complex needs requires a large commitment from the family (Green, 2013). With the shift from institutionalization of persons with mental illness, family members have taken on an increased role of full time care giving for patients. This increased burden has been shown to result in some form of psychological distress (Ong & Ibrahim, 2016). In the research referenced above the researchers were able to record 31.5% of caregivers of persons with schizophrenia scoring high on the Kessler Psychological Distress scale.

2.3 IMPACT OF AUTISM ON THE FAMILY

2.3.1 Impact on the caregivers

Past research has been focused on the correlation between stigma and coping with psychological distress among caregivers of different countries and their populations (Ong *et al.*, 2016b). A review of 40 studies conducted between 1970 and 1995 indicated that 60% of parents with children with developmental disabilities reported manifestations of increased risk or negative effects on the well siblings(Green, 2013)

2.3.2 Impact on other healthy children in the family

2.3.2.a Negative outcomes

Children with ASD and their families are saddled with diverse and varying forms of challenges (Bello-Mojeed *et al.*, 2016). Research into siblings of children with autism have varied over time, some studies report increased risk while others report increased positive outcomes. This serves to constantly reflect that no two families are identical and as such, several factors influence whether what the outcomes will be for these siblings.

Existing literature has shown mixed results relating to the impact upon children of having a sibling with a disability. Although a large percentage of research has shown that siblings of children with autism may be more at risk than siblings of children with other disabilities, all existing research studies all agree that there is a higher risk when compared with siblings of healthy controls. Siblings of children with autism have been shown to do more poorly on a number of outcome measures in comparison to siblings of other developmental disabilities and those with only typically developing siblings (Green, 2013).

In a 2003 study by Hastings *et al.*, it was found that these siblings when rated by their mothers have more behavior problems and fewer pro-social behaviors than a sample of siblings of normal children. It also went further to show that boys with siblings who have autism, and also those younger than their sibling with autism, engaged in fewer pro-social behaviors (Hastings, 2003).

This agrees with another study by (Bagenholm *et al.*, 1991) which compared 60 children and young adults between 5 and 20 years of age, 20 of whom had siblings with autism, 20 of whom had siblings with mental retardation, and 20 of whom had siblings who were free of handicap. The study found out that siblings of handicapped children and especially siblings of children

with autism were more concerned about the future. They also felt lonely more often and many of them had peer problems. They often regarded their handicapped siblings as a burden. They tended to have only one sibling. Siblings often did not know why their handicapped brother or sister was different from other children. There were more behavior disturbances in the siblings of handicapped children(BÅGENHOLM and GILLBERG, 1991).

The data analysis of the siblings' perceptions yielded 6 themes: (a) difficulties and negative impact of their brother's condition on themselves and their family, (b) how others' reactions to their brother negatively affected them as siblings, (c) how their histories with their brothers contextualized their present circumstances, (d) the varying degrees of acceptance and tolerance towards their brothers, (e) positive perceptions and experiences with their brothers, and (f) their thoughts and worries about the future . Aspect(2013) reports that some factors that may account for increased risk in siblings of children with ASDs include

1. The severity of ASD in the affected child
2. Availability of social support
3. Socio-economic status
4. Degree of family cohesion
5. Parental well-being and
6. Individual character traits.

These factors are all likely to play a role in determining outcomes for the neuro-typical children of families affected by ASD(O'Brien et al., 2009Havercamp et al., 2013).

Petalas et al, 2009 also identified factors that could increase the risk for siblings of children with ASD to develop negative psychosocial traits. These factors include

1. Loneliness
2. concern about the future
3. behavioral disturbances
4. poor relationships with peers
5. anger towards the sibling with ASD (particularly if that sibling is aggressive)
6. Vulnerability to stress and depression. (Petalas *et al.*, 2009).

Siblings of children with chronic illness or ASD have also been reported to be at an increased risk for negative psychological adjustment and negative psychological effects; in particular for internalizing behaviors such as anxiety and depression. Negative manifestations include anger, resentment, frustration, loneliness, sadness, worry, fear, over-identification, feeling envious or jealous, confusion, secluding themselves and regression. These could result from less parental attention, excessive demands placed upon siblings and a perception of unequal treatment. The nature and degree of need their affected brother/sister has should be taken into account when considering the impact on siblings. The greater the care-giving demands and hence parental attention the child with a chronic illness needs, the more the siblings are negatively affected (Gettings *et al.*, 2015).

Results reveal that siblings of autistic children have more internalizing and externalizing behavior problems than siblings of developmentally normal children; however, the three groups did not differ significantly on measures of perceived self-competence or parents' report of social competence. Examination of demographic variables indicate that age of sibling and parents' marital satisfaction were associated with siblings' psychological functioning (Minton *et al.*, 1982)

2.3.2.b Positive Outcomes

In a very interesting twist, a study by Aspect, 2013 found out that children who have siblings with ASD can have positive outcomes, especially when they have good levels of family and community support (Aspect, 2013). This is in line with the records that other researchers have found no difference in levels of adjustment between siblings of individuals with ASD and those with only typically developing siblings (Dewey, 2002) or those with siblings with other developmental diagnoses (Pilowsky et al., 2007).

Even more promising, the positive impacts of growing up with a sibling with ASD are becoming known. Siblings of individuals with autism have been reported to have less conflict in the sibling relationship (Dewey, 2002), family resilience (Bayat, 2007), and increased self-perceived competence (Rodrigue et al., 1993, Verte et al., 2003, Macks & Reeve, 2007). They have also been shown to have a more positive opinion of the sibling relationship (Stoneman, 2003), positive psychosocial and emotional development conditional upon limited demographic risk factors (Macks & Reeve, 2007), feelings of empathy for their sibling (Sivberg, 2007), and increased maturity (Green, 2013).

Another study by Hosseinkhanzadeh et al, 2014 reports that the difference in the quality of sibling relationship and antisocial behaviors of siblings of 'mentally retarded' children and healthy children was not significant ($F= 2.022$, $P < 0.138$) (Hosseinkhanzadeh *et al.*, 2014).

2.4 PSYCHOLOGICAL DISTRESS

2.4.1 Definition of Psychological Distress

Psychological distress otherwise known as mental distress according to the Psychology online dictionary, can be defined as symptoms of anxiety and depression in persons who do not fit an

established criteria of psychological disorder. Decker (1997) and Burnette and Mui (1997), conceptualized psychological distress as lack of enthusiasm, problems with sleep (trouble falling asleep or staying asleep), feeling downhearted or blue, feeling hopeless about the future, feeling emotionally bored (for example, crying easily or feeling like crying) or losing interest in things and thoughts of suicide (Weaver, 1995). Lerutla (2000) defined psychological distress as the emotional condition that one feels when it is necessary to cope with upsetting, frustrating or harmful situations. (Berlin, no date)add that psychological distress is the unpleasant subjective state of depression and anxiety (being tense, restless, worried irritable and afraid), which has both emotional and psychological manifestations.

Psychological distress has been said to be a result of seemingly normal fluctuations in the mood of normal individuals. However, this condition is usually an alert of a looming depressive event for those who are susceptible to such events. Psychological distress is a general term used to describe unpleasant feelings or emotions that impact your level of functioning. In other words, it is psychological discomfort that interferes with your activities of daily living. Psychological distress can result in negative views of the environment, others, and the self. Sadness, anxiety, distraction, and symptoms of mental illness are manifestations of psychological distress.

2.4.2 Causes, Forms and Assessment of Psychological distress

Traumatic experiences, such as the death of a loved one, are causes of psychological distress. Psychological distress can be thought of as a maladaptive response to a stressful situation. Psychological distress occurs when external events or stressors place demands upon us that we are unable to cope with. For example, we may struggle to accept that a loved one is no longer with us. As a result, we become sad and have trouble getting out of bed, we are unable to focus at work, and we lose interest in social activities.

Major life transitions, i.e. moving to a new state or graduating from college, can be a source of psychological stress if you are unable to cope with the demands that these transitions place on you or are having difficulty adjusting to the new situation. Sudden unexpected events, such as a loved one's death of a heart attack or being fired from a job, can also cause psychological distress.

Even everyday stressors, such as traffic, have the potential to cause psychological distress. Some other sources of psychological distress include:

1. Cancer and other medical illness
2. Divorce
3. Starting a new job
4. Being a victim of bullying
5. Adverse school experiences
6. Adverse work experiences
7. Infertility
8. Mental illness (Drapeau et al., 2007)

2.4.4 Symptoms of Psychological distress

As we previously stated, psychological distress is a subjective experience. Just as no two people experience events in the same way, no two people manifest psychological distress in exactly same way. For example, suppose that you and your mother were in a car accident and both experienced psychological distress as a result. Yet while you experience sleep disturbances, fatigue, and sadness, your mother experiences anxiety related to driving and memory problems and avoids social activities.

1. Other symptoms of psychological distress include:
2. Weight gain
3. Anger management problems
4. Obsessive thoughts or compulsions
5. Physical symptoms not explained by a medical condition
6. Decreased pleasure in sexual activities
7. Hallucinations
8. Delusions
9. Reckless acts, i.e. excessive shopping sprees
10. Belief that others can hear your thoughts
11. Belief that your thoughts are not your own
12. Strange or unusual behaviors, i.e. wearing your clothing backwards

2.4.5 Effects of Psychological Distress

Psychological distress has been found to be very common in palliative care patients and their families, and anger as a form of psychological distress is a complex emotion experienced by many patients at the end of life.

2.4.6 Prevalence of Psychological distress among people with medical conditions (mental and physical)

It is a fact that having a major illness can have a major psychological impact on the individual. This has been shown over time by a wide range of research. A 2012 study reported 17.1% prevalence rates for psychological distress among outpatients in Pretoria (Peltzer *et al.*, 2012). Another study reported 81% prevalence of psychological distress among tuberculosis patients in

South Africa (Peltzer *et al.*, 2012). In a study on children with congenital heart disease, it was discovered that they are more likely to experience distress than their healthy counterparts (Johnson & Francis, retrieved 2017). A Nigerian study by Bakare *et al* (2008) found a 3-fold increase in emotional disorders among children with sickle cell disease

2.4.6 Relevance of Psychological distress

Psychological distress is not just a negative symptom. It has been found that a certain level such as anger is expected and considered normal in terminally ill patients as it serves as a form of tension release as well as a coping mechanism for the patient as a way to disguise fear and anxiety (O'Brien *et al.*, 2009). Patients owing to their situation, such responses may also be dysfunctional. This paper aims to highlight the challenges and complexities of adequately assessing and supporting palliative care patients who are presenting with psychological distress in the form of anger, in order to relieve their suffering and assist them in resolving their issues and improving their quality of life. Anger can be difficult to treat, and for some patients can be more distressing than some physical symptoms. Hence this paper also aims to offer anger management guidance to palliative care practitioners. Just as mental illness can influence all aspects of your life, psychological distress can also impact your functioning. Psychological distress can interfere with your work performance. For example, you may find it harder to concentrate and may find yourself easily distracted while working. Students who experience psychological distress may find it hard to focus on their schoolwork or in class, especially if they are experiencing hallucinations or delusions.

2.5 AUTISM AND PSYCHOLOGICAL DISTRESS

Most research into autism effects on siblings have looked at (a) autism and behavioral problems (Hastings, 2003; Rodrigue *et al.*, 1993), (b) autism and psychosocial problems (BÅGENHOLM

and GILLBERG, 1991), (c) emotional problems (Macks & Reeve, 2007; Petalas *et al.*, 2009). In a review of research on emotional problems associated with siblings of children with autism (Green, 2013), it is seen that most research identify

1. Emotional intelligence (E. Gray, 1998)
2. Loneliness (Dewey, 2002)
3. Stress and depression (L. McIntyre, 2010)
4. Internalizing problems and aggression (Cuskelly, 2006)
5. Depression and anxiety (Seltzer, 2007)
6. Fear, anxiety and social isolation (Sivberg, 2014)
7. Guilt (S. Opperman, 2003)

These areas studied are essential to the development of these siblings. Psychological distress is something that has been reported to occur in families with children who have chronic medical conditions; therefore it is necessary to check for this among families of children with mental disorders. (Sin J, 2015) report that “Many people with severe mental illness (SMI) have siblings and that despite a wealth of research being done on, in reducing relapse and promoting compliance with treatment, siblings remain relatively invisible in clinical service settings as well as in research studies. Knowing this and knowing the factors that could contribute to negative outcomes and knowing that the relationship between people with disabilities and their siblings is an important issue because of the important implications that it has in child development (Hosseinkhanzadeh *et al.*, 2014), it is essential to identify the presence of psychological distress experienced by siblings of autistic children in typical Nigerian families. This is hoped, to propel the mental health field a step further and enable mental health workers to create interventions that could address these challenges.

CHAPTER 3

METHODOLOGY

3.1 STUDY LOCATION

This study was carried out in Port-Harcourt, Nigeria. Port Harcourt is the capital and largest city in Rivers State, Nigeria. It lies along the Bonny River and is located in the Niger Delta. As of 2016, the Port Harcourt urban area has an estimated population of 1,865,000 inhabitants, making it one of the largest metropolitan areas in Nigeria. The area that became Port Harcourt in 1912 was said to have been part of the farmlands of the Diobu village group of the Ikwerre. The colonial administration of Nigeria created the port to export coal from the collieries of Enugu located 243 kilometers (151 mi) north of Port Harcourt, to which it was linked by a railway called the Eastern Line. The Niger Delta is well known for a crude oil and is the National base of major oil companies like Royal Dutch Shell and Chevron. Port Harcourt spans eight local government areas that include Port Harcourt, Okrika, Obio-Akpor, Ikwerre, Oyigbo, Ogu-Bolo, Etche and Eleme. Port Harcourt, which is the current capital of Rivers State, is highly congested as it is the only major city of the state.

3.2 STUDY POPULATION

School age children and adolescents (7-15 year old) siblings of children with ASD and age and gender matched healthy controls who have no siblings with ASD or other disabilities.

3.3 INCLUSION CRITERIA

All assenting children for who consent has been given by their parents participated in the study.

3.4 EXCLUSION CRITERIA

1. Siblings who are too young (below 7 years) or too old (above 18 years).
2. Children who were physically ill
3. Children who had some form of mental disorder including intellectual disability.

3.5 STUDY DESIGN

This was a case-control study where siblings of children with autism were the cases and healthy children with siblings without ASD or other disabilities were the controls.

3.6 SAMPLING TECHNIQUE

Participants were selected using convenience sampling. Each child selected who had a sibling with ASD was matched by age and gender to a selected child who had no sibling with ASD or other disabilities.

3.7 SAMPLE SIZE CALCULATION

This was a case control study of two groups. The minimum sample size to identify the difference in mean scores in the outcome measure (e.g. total difficulties score on the SDQ) between the siblings of children with ASD and the healthy controls with no siblings with ASD or other disabilities was earlier calculated as given by the formula below

$$n \geq \frac{2F\sigma^2}{d^2}$$

(Wade 1999)

where

n = size of each of the two groups (total sample = 2xn)

σ = standard deviation of the outcome measure

d = smallest difference that is expected between the groups

With respect to depressive symptoms which was measured by the Short Mood and Feeling Questionnaire (Short MFQ). $\sigma = 4.0$.

Assuming

d = is half a standard deviation difference between the two groups in the outcome measures such as SDQ

$F = 7.85$ (a constant based on 80% power and 5% level of significance) (Wade 1999)

The minimum sample size required to identify 0.5 (half) standard deviation difference the outcome measure with 80% power and 5% level of significance is:

$$n \geq \frac{2 \times 7.85 \times 1^2}{0.5^2}$$

$n = 62$ per group

Sample size is $62 \times 2 = 124$ in total

However, due to difficulties encountered in recruiting these participants, the sample size was reduced (with the consent of supervisors) to 16 in the experimental group and 32 in the control group using the ratio 1:2.

3.8 STUDY INSTRUMENTS

1. **Socio-demographic Questionnaire** (Appendix 3A): This questionnaire measures variables relating to age, gender, religion, family background, size and structure of the family, level of education and occupation of parents questionnaire. It was used to collect demographic information. It is modeled after that used in a previous study carried out among adolescents in Southwest Nigeria (Omigbodun O, 2008). The Yoruba part of the

scale was replaced with a pidgin English translation and the school report section was removed as it was not relevant to the study.

A measure of family wealth was included as an index of socio-economic status since parent's occupation alone is an unreliable index in Nigeria partly because children may be unsure of their parent's precise occupations. For example, a respondent could say the parent works in the civil service. Except specified, it is almost impossible to determine what level of the civil service that parent is on thus making it difficult to predict earnings and consequently socio-economic status (SES) of the family. Thus wealth ratings have been used by other studies in Nigeria as a more accurate reflection of the SES. For purposes of the wealth rating, 1 mark each was assigned to household ownership of a mobile phone, gas cooker, fridge/freezer, satellite dish, flat screen TV, computer/laptop and air conditioning. 2 points were given for owning a generator set, 3 points for owning a Car and 4 points for owning a house. The maximum score on the wealth index was 16 points.

Two additional questions were added to measure aggressive behavior in the siblings, these two questions were rated on a 3-likert scale consisting of 'Not true' (with a score of 0), somewhat true (with a score of 1) and 'Certainly True'(with a score of 2).

2. **Strengths and Difficulties Questionnaire (SDQ)** (Appendix 3B): This is a self report inventory for adolescents and children age 11-17. This tool was developed by child Psychiatrist Robert N. Goodman. It measures emotional, conduct, hyperactivity and peer problems. The SDQ has been used in many studies and translated into a variety of languages. The SDQ is of three versions: the short form, the long form and a follow-up form to be used after interventions. The short form SDQ has been estimated to take about

3-5 minutes to complete. The SDQ is very easy to use and score. It can be used by parents, teachers, and researchers and as a self-report scale. The SDQ is a 25 item scale measuring 5 attributes emotional symptoms (5 items), conduct problems (5 items), hyperactivity/inattention (5 items), peer relationship problems (5 items), pro-social behavior (5 items). These items are rated on a 3-likert scale consisting of 'Not true' (with a score of 0), somewhat true (with a score of 1) and 'Certainly True' (with a score of 2). The SDQ has been used in Nigeria (Bakare and Munir, 1984; Oluremi, 2013).

3. **Short Mood and Feelings Questionnaire (SMFQ)** (Appendix 3C): This is a 13-item self rated screening questionnaire for depression in children between the ages of 7-18 (Angold et al., 1995). It has been used in several developing countries (Walker, 2007, Thabet, 2004) including among Nigerian adolescents (Bella-Awusah et al., 2016). Statements are rated on a three point scale ranging from "true", "sometimes" and "not true" scored as 0, 1 and 2. Sum total scores ≥ 12 indicate more depressive symptoms (Messer *et al.*, 1995).
4. **Children's Hope Scale (CHS)** (Appendix 3D): This is a six question instrument designed to measure children's hope. It has a 6 point Likert scale response format ranging from "none of the time" (score of 1) to "all of the time" (score of 6) (Snyder, 1997). The sum total of each respondent is divided by the number of items on the scale to obtain the mean score for each individual. Mean scores of ≥ 4 indicate positive goal oriented thinking while scores of \leq indicate low hope (Bickman et al., 2007).
5. **Beck Anxiety Inventory** (Appendix 3E): the Beck anxiety inventory is a 21-item measure of anxiety symptoms experienced over the past one week (Beck et al., 1988) and takes about 5 to 10 minutes to complete. It can be used on adolescents. Items are rated on a 3-Likert scale with values ranging from 0 (not at all) to 3 (severely). Scores of 0-9

indicates normal to minimal anxiety, 10 – 18 indicate severe anxiety (Beck et al., 1988).

It has been used in Ghana (Addom, 2015).

3.9 STUDY PROCEDURE

Potential participants for the study were identified and recruited based on inclusion and exclusion criteria. The directors of 2 special needs schools (The Child Special School and Otana Hearing and Edu –Health Services) and 1 Autism center (OLG Health Foundation and Autism Center) served as intermediaries through whom the researcher was able to access families and the children. In the special needs schools, the researcher met the parents individually and spoke to them concerning the research work. The parents who gave their consent then brought their children to the school while coming to do school run and the questionnaires were administered. With the Autism center however, parents were reluctant to meet with the researcher directly, therefore a 1-day training was done for a member of staff on how to administer the instruments. This member of staff then went to the homes of the children and administered the questionnaires. For the control group, participants were recruited from one Private school (Tessy International Nursery, Primary and Secondary School). Participants were selected from the Primary and Secondary levels of the school and were selected based on age and gender match with each participant in the experimental group.

3.10 ETHICAL CONSIDERATION

Ethical approval was obtained from the Rivers State Ministry of Health Ethical committee. All children/adolescents recruited for the study were required to sign an assent form (Appendix A1) after their caregivers have signed consent forms (appendix A2). However, many of the parents brought their children to participate in the research but refused to sign consent forms, their

reason being that they don't want their names recorded anywhere. Those who signed only did so after the nature, purpose and scope of the study had been fully explained. For the control group, the researcher spoke with the parents during a PTA (Parents Teachers Association) meeting and explained the research to them. After reviewing the questionnaire, some parents however decided not to sign individual consent forms. The principal was instructed to just sign one consent form covering all the students who got to participate in the research.

CONFIDENTIALITY OF DATA: strict confidentiality was maintained with respect to handling of data. Information provided was made available only to the researcher and the assistant (from OLG). All participants were assigned serial numbers which was the only identifying feature on the questionnaire.

TRANSLATION OF PROTOCOL INTO LOCAL LANGUAGE: All study instruments were translated into pidgin English for those who found that easier. However during the course of the research, this was not necessary as all the participants clearly understood English Language. Those who had minor issues were assisted by the researcher and the assistants.

BENEFICENCE: Directors of the organizations only consented to inform their parents about the research under the condition that the findings from the research would be duly communicated to them so they can take appropriate care measures for those requiring therapy and counseling.

NON-MALEFICIENCE: No risks were involved in the conduct of this study. The questionnaires that were used do not contain sensitive and invasive questions.

3.11 DATA MANAGEMENT

The data collected was checked for completeness and inconsistencies at the end of each data collection day. Any inconsistencies were corrected. Questionnaires with major errors were

discarded. At the end of data collection, the data was entered into SPSS version 22 software where it was cleaned and analyzed. Means and standard deviation of continuous variables were computed while categorical variables were displayed as frequencies.

The psychological distress scores were computed for each participant and means and standard deviation obtained for each group were categorized by age and other socio-demographic variables. The differences in the mean values obtained was examined for significance. Age of respondents was summarized using mean and standard deviation.

Frequencies and cross tabulation of variables was generated to check for data entry errors and missing values. The socio-demographic characteristics of the study participants were analyzed using descriptive statistics. Inferential statistical methods such as Chi-square test of significance was carried out to explore the relationship between having a sibling with autism spectrum disorder and psychological distress. The student's T-test of significance was performed to determine differences in mean scores for the 4 instruments used.

CHAPTER 4

RESULTS

4.1 Socio-demographic characteristics of the study participants

A total of 48 students (16 siblings of children with autism and 32 siblings of regular children without autism) participated in the study in a 1:2 case-control design. 50 questionnaires were issued of which 48 were valid for analysis yielding a 96% response rate. Table 4.1 presents the socio-demographic characteristics of the study participants.

The mean age of respondents was 12.29 with the minimum and maximum age being 7 and 15 respectively. In addition, the study comprised of 16 male respondents of which; 7 of 16 (43.7%) siblings of children with autism and 9 of 32 (28.1%) siblings of regular children without autism were males, Of the 32 female respondents, 9 of 16 (56.3%) siblings of children with autism were female and 23 of 32 (71.9%) siblings of regular children without autism were females. Also 1 (6.2%) siblings of children with autism belonged to the Islamic religion and 15 (97.8) respondents were Christians, while for the siblings of regular children without autism, 1 (3.1%) belonged to the Islamic religion and 31(96.9%) were Christian. The table also shows that a larger percentage of the participants 25 (9 (52.3%) who were siblings of children with autism and 16 (50%) siblings of regular children) were from monogamous homes,. In addition, 14 (87.5%) siblings of children with autism and 19 (59.4%) siblings of regular children without autism were from a family where their parents were married and lived together, (6.25%) of the siblings of children with autism and 13 (40.6%) siblings of regular children without autism were from a separated/divorced parent and 1 (6.25%) respondent with sibling with autism reported that the father was dead.

Table 4.1: Socio-demographics details of participants

Characteristics	Cases		Controls		χ^2	df	P
	n	%	n	%			
Gender							
Male	7	43.7	9	28.1	1.172	1	0.339
Female	9	56.3	23	71.9			
Religion							
Islam	1	6.3	1	3.1	0.261	1	1.000
Orthodox Christian	15	93.7	31	96.9			
Family Type							
Monogamous	9	56.3	16	50	0.167	1	0.765
Polygamous	7	42.7	16	50			
Marital status of parents							
Married					7.549	1	0.23
Separated/divorced	14	87.5	19	59.4			
Father is dead	1	6.25	13	40.6			
	1	6.25	0	00			
Number of Mother's Children							
1-4					0.000	1	1.000
> 4	10	62.5	20	62.5			
	6	37.5	12	37.5			
Number of Father's children							
1-4							

> 4	8	50	10	31.2	1.600	1	0.206
	8	50	22	68.8			
Who brought you up							
Both parents	13	81.8	27	84.4			
One parent/grandparents/other relatives	3	37.5	5	15.6	<i>1.000</i>	1	0.784
Who do you live with presently							
Both parents	13	81.3	28	87.5			
One parent/grandparents/other relatives	3	18.8	4	12.5	<i>0.672</i>	1	0.563

*: value significant at P <0.05 (same applies to all tables below)

Italics represent fisher's exact test result

4.2 Age of respondents

The bar chart below (Fig 4.1) indicates the mean age of respondents was

Fig 4.1



Mean = 11.56
SD = 2.88

4.3 Parents Educational Attainment

Table 4.2 shows a cross tabulation of respondent's parental educational attainment. The results shows that majority {12 (75%)} of the fathers of siblings of children with autism had attained a university education as compared to 24 (75%) of siblings of regular children without autism. Also, 12 (75%) of the mothers of siblings of children with autism had attained a university education as compared with 23 (71.9%) of siblings of regular children without autism.

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Table 4.2 Parents Educational Attainment

Characteristics	Cases		Controls	
	n	%	n	%
Father				
Primary/Koranic School and Secondary School	3	18.8	1	3.1
Post secondary(Non-University) and University	13	81.3	25	78.1
Mother				
Secondary and Post secondary(Non-University)	3	12	12	9.40
University Degree and above	3	75	23	71.9

Father's educational attainment $\chi^2= 6.138$, df = 2, p = 0.046*

*6(12.5%) of the respondents indicated that they did not know their father's level of education

Mother's educational attainment $\chi^2= 1.907$, df = 2, p = 0.385

*7(14.6%) of the respondents indicated that they did not know their mother's level of education

4.5 Socio-economic status

The socio-economic status of respondents was measured in 2 ways

4.5a Occupation of parents

The occupation of respondent's parents was merged into 3 broad groups for easier analysis. The grouping was

1. Unknown/Unemployed
2. Traders/Business
3. Professionals/Civil Servants.

Table 4.3 shows that 9 (43.7%) siblings of children with autism and 17 (53.1%) of the controls had mothers working in professional jobs. This pattern is similar with father's occupation 7 (43.7%) and 20 (62.5) respectively worked in professional jobs.

Table 4.3: Occupation of parents

Characteristics	Cases		Control	
	n	%	n	%
Father				
Unknown/Unemployed	3	18.8	6	18.8
Traders/Business	6	37.5	6	18.7
Professionals/Civil Servants	7	43.7	20	62.5
Mother				
Unknown/Unemployed	2	12.5	8	25
Traders/Business	5	31.3	7	21.9
Professionals/Civil Servants	9	56.2	17	53.1
Father's occupation $\chi^2=2.167$, df = 2, p = 0.338				
Mother's occupation $\chi^2=1.194$, df = 2, p = 0.550				

4.5b Wealth index rating

This was necessary because in the Nigerian context, occupation of parents is not a reliable way of checking socio-economic status (as explained in chapter 3.8).

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Table 4.4: Wealth index of respondents

Characteristics	Cases	Controls	t	df	P
	Mean (SD)	Mean (SD)			
	14.19 (6.93)	13.90 (3.48)	0.188	46	.188

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4.6 Aggression in siblings

This aims to look at whether there is a significant difference in the level of aggression children with a sibling with autism experience as compared to the controls.

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Table 4.5: Aggression in siblings of respondents

Characteristics	Cases	Controls	t	df	P
	Mean (SD)	Mean (SD)			
	0.94 (1.18)	2.22 (3.52)	- 1.411	46	.165

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4.7 Influence of religion on respondents

This aspect looked at the religious status of respondents and the impact of religion on individual and family lives.

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Table 4.6 Influence of religion on respondents

Characteristics	Cases		Control	
	n	%	n	%
Religious Status				
Yes	16	100	31	96.9
No	0	0	1	3.1
Impact of religion on individual life				
Very much	14	87.5	20	62.5
Much	2	12.5	10	31.3
Just a little	0	0	2	6.3
Impact of religion on family life				
Very much	14	87.5	21	87.5
Much	2	12.5	10	31.3
Just a little	0	0	1	3.1

Religious status $\chi^2= 0.511$, df = 1, p = 0.475

Influence of religion on individual life $\chi^2= 3.441$, df = 2, p = 0.179

Influence of religion on family life $\chi^2= 2.700$, df = 2, p = 0.259

4.9 Relationship between psychological distress and respondents group (case & control)

Table 4.7 presents the mean scores of psychological distress among the case and controls on the three instruments used (SDQ, SMFQ, CHS and BAI). As seen from this table, there is no statistically significant relationship found between psychological distress and having a sibling with or without autism.

Table 4.7: Independent t-test to compare mean scores of SDQ, SMFQ, CHS and BAI

	Cases	Controls	t	df	P
	Mean (SD)	Mean (SD)			
SDQ	8.81(6.79)	9.22 (4.17)	-.256	46	.799
SMFQ	3.81 (4.65)	3.09 (3.16)	.633	46	.530
CHS	24.94 (6.89)	23.50 (4.79)	.403	46	.403
BAI	23.50 (51.50)	4.34 (10.07)	.333	46	.333

Key:

SDQ = Strengths and Difficulties Questionnaire (total maximum score = 40)
SMFQ = Short Moods and Feelings Questionnaire (total maximum score = 26)
CHS = Children's Hope Scale (total maximum score = 36)
BAI = Beck Anxiety Inventory (total maximum score = 63)

CHAPTER 5

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Discussion

This chapter would discuss the findings from this study that was aimed at comparing levels of Psychological distress among siblings of children with autism as compared with siblings of children without autism. Compared with siblings of children without autism, this study found no significant difference in scores of the siblings of children with autism on the Strengths and Difficulties Questionnaire, Short Mood and Feelings Questionnaire, the Hope Scale or the Beck Anxiety Inventory. The findings from this research would be discussed in 3 stages.

Socio-demographics

This study found that a larger portion of the respondents were below 12 years. This might account to an extent for the lack of psychological distress identified. This could be attributed to the findings of (Ferraioli and Harris, 2009) who states that at this age the sibling's level of understanding of the disorder is not that much as they do not really comprehend the constellation of deficits associated with autism. They went further to state that at this stage the siblings are building social relationship which most times revolve round the family members. As the children grow into teenagers, they become more self-conscious and this affects their sibling relationship. Also at this age, they do not carry a large portion of the care burden and as such might not really understand the concept of being responsible for their sibling with autism. For most children, at

this stage of life, they can assist in basic house chores while their needs are all provided for them. As they grow older, and then gradually incorporate into taking care of the needs of the sibling with autism, there is a possibility that their distress levels could rise.

The study also found that more participants in both the case and control groups were female. This is consistent with previous studies such as (Shivers et al., 2017) which found that female children are more involved in the care of siblings and as such develop a closer bond. This could also be said to be a reason why psychological distress was not significant. The female siblings may see the child with autism as their personal 'baby' so they are more favorably disposed towards the behavioral challenges of the child. This may account for their not being distressed. Another study also reports that female siblings with autism showed more positive aspect in their sibling relation regardless of the gender of the sibling with autism, whereas male siblings reported a lower score on positive aspects of sibling relationship with a female sibling with autism than with a male siblings (Orsmond et al., 2009).

This study found that more parents of the children with autism were still married 87.5% compared with parents of children without autism (59.4%). A lot of research has been done to check the relationship between having a child with autism and increased risk of divorce and the results are not consistent. Many researchers report that having a child with autism increases marital dissatisfaction and stress thus resulting in an increased risk of divorce (Hartley *et al.*, 2011; Santamaria *et al.*, 2012). Some other researchers also found that the risk for divorce comes up when the child with autism grows into adolescence (Hartley *et al.*, 2010). Yet some other research has found that there is no increased risk for divorce than with families of children without autism (Freedman *et al.*, 2012; Shivers et al., 2017). The low divorce rates between the two groups in the current study could be partly because of the low divorce rate in Africa

compared to other continents (Shelley and Sarah, 2015). Within the Nigerian context, (Bello-Mojeed *et al.*, 2016) reported a high percentage (85%) of respondents still being married despite having a child with autism.

The current study found that a high proportion of mothers of children with autism had a higher level of education, which is consistent with a previous Nigerian study (Bello-Mojeed *et al.*, 2016) which reported that 60% of mothers of autistic children in their sample attained Tertiary education.

Wealth index

Wealth index rating was also not significantly different between the families of children with autism and those without. This suggests that there was no marked difference between the socio-economic status of the two groups of families. This finding goes against existing literature that found increased financial stress on families of children with autism compared with families of children without autism (Simelane, 2015). Low socio-economic status has also been linked with co-morbid problems in children with autism and their siblings (Rosa *et al.*, 2016).

Perceived aggression

This study found that the level of the respondent's perceived aggression from their sibling does not differ across the case and control groups. This suggests that among the respondent's with siblings with autism, the level of aggression displayed by their sibling with autism was not significantly high. Due to the small sample size, this result cannot be generalized. However it is important to note that this goes to buttress the point that not all autistic children display aggressive behavior (Autism Speaks, 2012).

Psychological distress

In contrast to the study hypothesis, having a sibling with autism did not generate more psychological distress than having a sibling without autism. This finding is in contrast to research that showed increased emotional problems among siblings of children with autism (Shivers et al., 2017). The latter does not invalidate the findings of the current study and instead may show that within the African society, there could possibly be some factors that protect siblings of children with autism from Psychological Distress. Some of the factors identified here are:

1. Extended family support system:

In comparing child rearing practices in Africa with that in European countries and the Americas, it has been discovered that there are major differences. Within the African culture, it has been reported that a lot of persons both family (nuclear and extended) and non family members are involved in raising a child (Timyan, 1988). This may partly account for the lack of significant Psychological distress experienced by siblings of children with autism in that there is reduced care burden on the nuclear family due to the support of the extended family. When there is another family member or friend willing to assist in the care of the child with autism, there is reduced marital dissatisfaction and invariably higher levels of self esteem in the siblings as suggested by (Rodrigue et al., 1993).

2. Religious coping:

Religious coping has been identified as a protective factor for emotional distress among people going through different traumatic situations within the African context. (Breland-Noble *et al.*, 2015) identified religious coping as being important for improving treatment-seeking behaviours

and reducing racial mental health disparities among African-American youths with Depression. In another study in Ghana, results showed that a positive relationship existed between positive religious coping and reduced somatization and anxiety among women suffering from infertility. This goes to suggest that religion may help to reduce psychological distress which is in line with the findings of the current study that 87.5% of respondents in both groups reported that their religious beliefs strongly affected their family life and 87.5% of the siblings of children with autism reported that their religious beliefs affected their individual lives.

3. Resilience:

This could also be said to be a major contributing factor to the result of the study. Within the African context, children have been found to have developed stronger resilience than their western counterparts (American Psychological Association Task Force on Resilience and Strength in Black Children and Adolescents, 2008). This could be said to be as a result of the various more challenging life situations they are exposed to on a daily basis. It is possible that there are more pressing life issues (such as the current economic situation in the country which could affect parent's ability to pay school fees and meet basic needs like food and shelter) bothering the respondents that overshadowed their perception of Psychological distress brought about as a result of having an autistic sibling. There have also been studies that show that having a child with autism helps the family to build stronger resilience as compared with regular families who do not have any major challenge to cope with (M. Bayat, 2007). This could account for the lack of disparity found in the level of psychological distress across the cases and controls.

4. Educational level of the parents

From the current study, it can be seen that a large percentage of both parents across the two samples had a University degree and above. This could account for the lack of significance in levels of psychological distress. In quite a number of family studies, increased education level and consequently greater socio-economic status has been found to significantly reduce emotional stress levels within the family (Lundström *et al.*, 2014).

5. Socio-economic status of parents

From the results of the study, it can be seen that a large percent of the families in both the case and control group had parents working in professional jobs. This could have been a contributing factor to the results obtained. It has been shown by various researchers that socio-economic status is significantly related to stress levels among families with children with disorders in general (Ambikile and Outwater, 2012). Thus, if siblings of children with autism come from families with well educated and professionally employed parents, they are less likely to be psychologically distressed.

6. Time frame

During the course of the research it was observed that parents only gave consent for their children to participate under the condition that they are able to fill it quickly during the brief time parents spent for picking the child with autism from school. This could have been a factor that contributed to the results obtained. If the parents had been a little bit more patient and allowed the respondents take their time in filling the questionnaire, there is a possibility that a different result would have been observed.

5.2 Limitations of the study

1. A major limitation of the study was the small sample size. This was as a result of reluctance on the part of parents and proprietors of schools to allow the researcher access to participants. Thus, the ability of the result to be generalized was affected.
2. Secondly, this study is limited to just families with autistic children in schools. This was because the schools served as a more organized avenue to get access to the families. However, the schools were special schools and as such charge much higher fees than regular schools. Therefore it is a possibility that only families of a higher income than average could afford to place their children in those schools. Thus the results could be said to not be a good representation of the families with Autistic children in Port-Harcourt or other parts of Nigeria.
3. Rivers state is an oil producing state and as such may have families with a higher income than some non oil producing states in Nigeria. Thus the study may not generalize to the average Nigerian family.
4. Respondents filled the instruments in a hurry, this was as a result of the fact that parents consented only on the condition that it doesn't take more than 10/15 minutes for the questionnaires to be filled.
5. The questionnaire was considered as too bulky by some parents and they therefore refused to consent to their children participating in the research. Some of the respondents also complained about the questionnaire being too bulky.
6. Instruments used: During the course of the research it was discovered that some of the instruments used (e.g Beck Anxiety Inventory) had some items that the respondents could not relate with and struggled to understand. The researcher had to explain some of the

anxiety symptoms such as ‘numbness or tingling’ using local ‘lingo’. This could be said to have contributed to the results obtained.

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5.3 Conclusion

This study was done with the aim of identifying if siblings of children with autism spectrum disorder within Nigeria experience more psychological distress than siblings of children without autism spectrum disorder.

The results show that siblings of children with autism were not more psychologically distressed than siblings of children without autism. This suggests that the results of similar studies in Europe and America does not hold within Nigeria as was hypothesized. Due to the lack of studies in this field currently within the African context, it is impossible for the researcher to say if this situation is specific to Port Harcourt or Nigeria or if it would still hold within other African countries. Therefore there is a need for this study to be replicated in other parts of Nigeria and other African countries.

If it is determined that African children as a whole are not as pre-disposed as their western counterparts to experiencing psychological distress, the findings can inform programs and interventions to build on the various coping mechanisms identified.

If on the other hand, it is determined that African children who are siblings of children with autism are as predisposed to experiencing psychological distress as children in the western world, then interventions would need to be developed to support the siblings of affected children.

The following recommendations are made:

- 1) For further studies, a larger sample should be utilized. This will help in making sure that the results are a good representation of the general population.

- 2) For further research, siblings of autistic children who are not enrolled in private schools/centers should be recruited for research. This would give for a wider range of family types and therefore more findings among siblings regarding their autistic sibling.
- 3) For further studies, including siblings of autistic children who have clinically diagnosed aggressive and self injurious behavior would help in making the data richer.
- 4) A combination of both quantitative and qualitative methods of data collection should be used in future research; this I believe would make for more empirical findings.
- 5) For further studies, it is important that the instruments should be shorter and fully adapted for the Nigerian child; this would make responding to them easier and would help for a wider sample. If this could not be done, then it may be better to use just one instrument like the Kessler Psychological distress scale 6 (this scale has only 6 items and respondents would be able to fill it with ease). However for this to be done, this instrument would need to be validated in Nigeria.

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WHO _ Autism spectrum disorders (no date).

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APPENDIX 1

INFORMED CONSENT FORM

PSYCHOLOGICAL DISTRESS AMONG SIBLINGS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN RIVERS STATE NIGERIA

This study is being conducted by Ibeh Ugochi Ifeoluwa of the Center for Child and Adolescent Mental Health, University of Ibadan. The purpose of this study is to find out about how you view yourself.

In the course of this study, you will be asked some questions regarding your personal information, your family, and your relationships with people as well as symptoms that may suggest mental health problems. These questions will be asked in form of questionnaires and as such you would not need to dialogue with the researcher. Your participation would not cost you anything.

All information collected in the course of this research will be given code numbers and as such no names will be used when recording. This is to ensure that you remain anonymous and that the responses cannot be traced back to you should the work be published.

Your participation in this study is voluntary and if you decide not to participate, it will not affect your interactions with the researcher. It is also important to state that you are free to withdraw from this research at any given time should you feel uncomfortable.

I -----hereby state that I have fully explained this research to ----- and have given sufficient information including risks and benefits to make an informed decision.

Date-----

Signature-----

I -----having been fully briefed on the purpose, method, risks and benefits of the research and having clearly understood that my participation is voluntary hereby consent to participate in this study.

Date-----

Signature-----

Name-----

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APPENDIX 2A

SOCIO-DEMOGRAPHIC QUESTIONNAIRE

Serial Number: _____

Today's Date: ____/____/____

SCHOOL HEALTH QUESTIONNAIRE IN ENGLISH & PIDGIN

Please write the answers to the questions or draw a circle where it applies to you. This is not an examination it is only to find out about you and your health.

SECTION I

Personal Information

1. Name of School:

2. Class:

3. Where do you live? (Address of Present Abode):

4. What is your date of birth? Date of Birth: _____

Day Month Year

5. How old are you? _____

6. Are you a boy or a girl? (a) Boy (b) girl

7. Do you practice any religion? No Yes

8. Please write down the exact place you attend for worship

- (a) Islam (b) Orthodox Christian (c) Pentecostal Christian (d) Traditional religion
(e) Other

9. How much does the teaching of your religion guide your behavior?

- (a) Very much (b) much (c) Just a little (d) Not at all

10. How much does the teaching of your religion guide your family life?

- (a) Very much (b) much (c) Just a little (d) Not at all

Family Information

11. Family Type: (a) Monogamous (b) Polygamous

12. Marital Status of Parents:

- (a) Married (b) Separated/Divorced (c) Father is dead (d) Mother is dead (e) Mother & Father are dead

13. Number of Mother's Children:

14. Number of Father's Children:

15. What is your position among your father's children? _____

16. What is your position among your mother's children? _____

17. How many husbands has your mother had? _____

18. Who do you live with presently?

- (a) Parents (b) Mother (c) Father (d) Grandparents (e) Grandmother
(f) Grandfather (g) other [please specify] _____

19. Who brought you up from your childhood?

- (a) Parents (b) Mother (c) Father (d) Grandparents (e) Grandmother
(f) Grandfather (g) other [please specify] _____

20. How many different people have you left your parents to live with from your childhood?

21. If more than one person, list the people, time spent and whether experience was good or bad?

Person lived with	from which age to which age	Experience (good or bad)
-------------------	-----------------------------	--------------------------

22. Do you do any kind of work to earn money before or after school? Yes No

23. If yes, please describe what you do _____

24. Level of Father's Education

- (a) No Formal Education (b) Koranic School (c) Primary School (d) Secondary School
(e) Post Secondary (Non-University) (f) University Degree and above (g) I do not know

25. Occupation of Father: [Write the exact occupation] _____ / I do not know

26. Level of Mother's Education

- (a) No Formal Education (b) Koranic School (c) Primary School (d) Secondary School
(e) Post Secondary (Non-University) (f) University Degree and above (g) I do not know

27. Occupation of Mother: [Write in the exact occupation] _____ / I do not know

28. Please indicate if your father or mother or the person you live with owns any of the following

Material	Yes	No
House		
Motor Car		
Flat Screen Television		
Satellite dish		

Computer/Laptop		
Fridge		
Air conditioning		
Generator set		
Gas cooker		

29. Do you like your family? Yes No

30a. If Yes, Why? _____

30b. If No, Why? _____

		N o t t r u e	Somewhat true	Certainly true
31	My sibling has hit me before such that it resulted in an injury			
32	My siblings have prevented me from siblings at night			

APPENDIX 2B

STRENGTHS AND DIFFICULTIES QUESTIONNAIRE

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best as you can even if you are not absolutely certain. Please give your answers on the basis of how things have been for you over the last six months.

S/N		Not True	Somewhat True	Certainly True
1	I try to be nice to other people. I care about their feelings			
2	I am restless, I cannot stay still for long			
3	I get a lot of headaches, stomach-aches, or sickness			
4	I usually share with others (food, games, pens etc)			
5	I get very angry and often lose my temper			
6	I am usually on my own. I generally play alone or keep to myself.			
7	I usually do as I am told			
8	I worry a lot			
9	I am helpful if someone is hurt, upset or feeling ill			

10	I am constantly fidgeting or squirming			
11	I have one good friend or more			
12	I fight a lot. I can make other people do what I want			
13	I am often unhappy, down-hearted or tearful			
14	Other people my age generally like me			
15	I am easily distracted, I find it difficult to concentrate			
16	I am nervous in new situations. I easily lose confidence			
17	I am kind to younger children			
18	I am often accused of lying or cheating			
19	Other children or young people pick on me or bully me			
20	I often volunteer to help others (parents, teachers, children)			
21	I think before I do things			
22	I take things that are not mine from home, school or elsewhere			
23	I get on better with adults than with people my own age			
24	I have many fears, I am easily scared			
25	I finish the work I'm doing. My attention is good			

Name:

Sex: Male Female

Date of Birth: -----

Signature----- Date -----

THANK YOU VERY MUCH FOR YOUR HELP

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APPENDIX 2C

SHORT MOODS AND FEELINGS QUESTIONNAIRE

This form is about how you might have been feeling or acting recently.

For each question, please check () how you have been feeling or acting in the past two weeks.

If a sentence was not true about you, check NOT TRUE. If a sentence was only sometimes true, check SOMETIMES. If a sentence was true about you most of the time, check TRUE.

s/n		NOT TRUE	SOMEWHAT TRUE	CERTAINLY TRUE
1	I felt miserable or unhappy			
2	I didn't enjoy anything at all			
3	I felt so tired I just sat around and did nothing			
4	I was very restless			
5	I felt I was no good anymore			
6	I cried a lot			
7	I found it hard to think properly or concentrate			
8	I hated myself			

9	I was a bad person			
10	I felt lonely I thought			
11	I thought nobody really loved me			
12	I could never be as good as other kids			
13	I did everything wrong			

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APPENDIX 2D

CHILDREN'S HOPE SCALE

The six sentences below describe how you think of yourself and how you do things in general. For each sentence, please think about how you are in most situations, and tick the one that best describes you.

s/n		None of the time 0	A little of the time 1	Some of the time 2	A lot of the time 3	Most of the time 4	All of the time 5
1	I think I am doing pretty well						
2	I can think of many ways to get the things in life that are most important to me						
3	I am doing just as well as other kids my age						
4	When I have a problem, I can come up with a lot of ways to solve it						
5	I think the things I have done in the past will help me in the future						
6	Even when others want to quit, I know that I can find ways to solve the problem.						

APPENDIX 2E

Beck Anxiety Inventory

Below is a list of common symptoms of anxiety. Please read each item carefully. Indicate how much you were bothered by each symptom in the last one month including today, marking an X in the degree of disturbance in the column of cells on the right.

No.	S y m p t o m s	H o w m u c h y o u w e r e b o t h e r e d			
		Not at all 0 It did not bothe	M i l d 1 It bothered a lit	M o d e r a t e 2 It bothered a lo	S e v e r e 3 I could almost
1 .	Numbness or tingling				
2 .	F e e l i n g h o t				
3 .	Weakness in legs				
4 .	Not able to relax				

5 .	Fear of the worst happening				
6 .	D i z z y				
7 .	Heart beating fast or heart racing				
8 .	R e s t l e s s				
9 .	Afraid or terrified				
10.	Worried or tense				
11.	Feeling of choking				
12.	Shaky or trembling hands				
13.	T r e m b l i n g				
14.	Fear of losing control				
15.	Difficulty in breathing				
16.	F e a r o f d y i n g				
17.	Fearful or frightened				
18.	Discomfort in the stomach or indigestion				
19.	F a i n t o r w e a k				
20.	Feeling hot in the face				
21.	Sweat (not due to heat)				

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