# EFFECTS OF PSYCHOEDUCATION ON PSYCHOLOGICAL DISTRESS AND BURDEN OF CARE AMONG CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS IN UCH, IBADAN

**BY**

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# DEDICATION

This research work is dedicated firstly to the Sovereign of the Universe whose name is JEHOVAH and then secondly to my ever supportive and caring husband Paul and lovely children – Henry, Priscilla and Josiah.

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# KEYS TO ABBREVIATIONS

| | |
|---|---|
| **ASD -** | Autism Spectrum Disorder |
| **APA -** | American Psychiatric Association |
| **CDC -** | Centre for Disease prevention and Control |
| **LMICs -** | Low and Middle Income Countries |
| **WHO -** | World Health Organization |
| **UCH -** | University College Hospital |
| **U.I -** | University of Ibadan |
| **PECS -** | Picture Exchange Communication System |

Operational Definition of Terms

**Caregiver:** A caregiver in this study refer to the parent of a child with Autism Spectrum Disorder

# ABSTRACT

**Background:** The role of caregivers of Children with ASD comes with an enormous burden that may impact negatively on their psychological, psychosocial and economic wellbeing. This study therefore seeks to assess the effects of psychoeducation on psychological distress and burden of care among caregivers of children with autism spectrum disorders in a tertiary healthcare facility in Ibadan, Nigeria.

**Methodology**: A total of 16 caregivers of children with ASD were recruited for this study from the Child and Adolescent Mental Health Clinic, University College Hospital, Ibadan and thereafter underwent a three weeks of psychoeducation based on a structured treatment module. The outcome measures; psychological distress (measured with the General Health Questionnaire – GHQ), Burden (measured with Zarit Burden Instrument), and Knowledge of management of challenging behaviour), were administered at baseline, immediately after the last intervention session and 3 weeks after the last intervention. A client satisfaction questionnaire was administered separately immediately after the last intervention session.

**Results**: The mean age of 42.53 ± 8.53 years and majority of the children were males (81.8%), presently enrolled in primary school (69.2%). Repeated measure ANOVA analysis showed that the training intervention resulted in a statistically significant increase in the mean Knowledge on Challenging Behaviour Management score from baseline to immediate post intervention and a further improvement by 3 weeks post intervention. There was a significant reduction in the mean burden scores from baseline to immediate post intervention but this was not sustained by 3 weeks post intervention. A surprising increase in GHQ scores was observed from baseline to immediate post-intervention which was still elevated at the time of the second post intervention assessment.

**Conclusions:** The result showed that a brief 3 session psychoeducation intervention can significantly improve caregivers' knowledge of management of challenging behaviours in children with autism. However, the beneficial effect on burden was transient. However, there appeared to have been an apparent increase the caregivers' psychological distress. Further larger and longer studies with control groups are required to further evaluate the findings of the current study.

(Word count  333)

# CHAPTER ONE

# INTRODUCTION

## 1.1 Background

Autism Spectrum Disorders (ASDs), which include autism, Asperger's Syndrome  and other pervasive neurodevelopmental disorders, are a spectrum of behaviorally defined disorders, characterized by impaired socialization, impaired verbal and nonverbal communication, and repetitive, restricted patterns of behavior (Clarke et al., 2005). In Nigeria, the prevalence of ASD has been reported to be as high as 11.4% (Bakare et al., 2012) among children with intellectual disability living in an institution. Although once considered a rare occurrence in developing countries, recent hospital based studies indicate that ASD is on the rise especially due to an increased awareness, improved detection/recognition of symptoms and broadening definition of ASD since parents and caregivers of children with ASD now readily report these cases to health facilities (Yeargin - Allsop et al, 2003; APA, 2013).  Despite increased awareness about the condition in these settings, there is still paucity of research from Nigeria exploring the prevalence of ASD among the general populace.

There is an enormous amount of burden associated with caring for children with ASD. This can be due to ASD itself or other morbid conditions and manifestations associated with the illness. Studies have shown that children with ASD will in their early years; experience a number of abnormalities including seizures, behavioural changes and autistic regression (Tuchman, 2003). According to Bakare et al (2012), although most children with ASD will show normal development in their early years, about 33% of them will experience verbal impairment, and at least one seizure episode by adolescence, followed by behavioral changes, autistic regression between 18 months and 2 years old and regression in cognitive function between their third and tenth birthday. Additionally, children with ASD will require specialist care with regular visits to the mental health clinic to access medications and other supportive care.

In most low and middle income settings like Nigeria, the responsibility of caring for children with neurodevelopmental disorders including ASD is the exclusive reserve of their caregivers who typically include their parents, and other close relatives who may act as guardian. However the role of caregivers comes with an enormous burden that may impact negatively on the psychological, psychosocial and economic wellbeing of these caregivers. In most instances, these caregivers may also lack adequate knowledge of the disorder, and may easily be frustrated when the child does not show much improvement after considerable time and resources have been invested in treatment and medication fees (Rhoades et al., 2007). Carers may incur additional burden from spending enormous time and financial resources in the pursuit of miraculous cures based on unproven claims of efficacy. Investments in these types of treatments are often driven by a combination of desperation and lack of knowledge of ASD and the interventions that are backed by good evidence. This study therefore seeks to explore the effect of psychoeducation on the psychological distress and burden of care of caregivers of children with Autism Spectrum Disorders in UCH, a tertiary level health facility in Ibadan, South Western Nigeria.

## 1.2. Justification

In most African countries and especially in Nigeria, there is a dearth of experts in the field of autism research, despite a relative increase in the number of reported cases from 0.4 per 1000, to 20 per 1000 prevalence rate (Yeargin- Allsop et al., 2003; CDC, 2007; CDC, 2012). This is partly due to the fact that parents and caregivers of children with ASD are often unprepared for the enormous burden associated with caring for these children and as such do not readily present their children for care at health centers to receive the care they need for them to live healthier lives. Several studies drawn from different Nigerian authors showed that most children with ASD make their first visits to a health facility at ages ranging from 13 to 17 years (Onuora, 1992, Bakare et al, 2008; Bello-Mojeed et al, 2010). According to Bakare & Munir (2011), late age of presentation to orthodox clinical practice are common observations among caregivers bringing their children to the health facility. Some possible reasons for this trend may stem from a low level of knowledge and awareness about ASDs, a complicated help-seeking pathway; unavailability of early educational and behavioural interventions. In addition, inadequate mental healthcare facilities and trained personnel relative to the number of children also contributes to late presentation.

Furthermore, studies have shown that caregivers of children with ASD often suffer discrimination and stigmatization by other members of the community as a result of caring for these children (Bakare et al, 2009). Additionally, caregivers of children with ASD may also experience psychological distress, and other mental health challenges (Bello- Mojeed 2013).

Early identification and adequate management of children with ASD have been shown to improve both treatment and health outcome (Clarke et al, 2005); and caregivers play a critical role in ensuring that these children get the requisite care required to live healthy lives and  to access care critical to their continuous wellbeing. Hence, these caregivers need to be psychologically, emotionally and physically resilient enough to carry out this crucial task. Moreover, some authors are advocating a multidisciplinary approach in addressing management of childhood autism and other developmental disorders (Bakare & Munir, 2011). This multidisciplinary approach may include involving the children and their parents, as well as incorporating behavioral therapy, special education, communication and social skill training and management of disruptive behavior with psychotropic medications when indicated (Shinnar et al., 2001). However, while a multidisciplinary effort is helpful, most health centres in LMICs often lack the requisite professionals and tools to deliver a multidisciplinary intervention to address management of children with ASD (Bakare et al., 2009). Furthermore, there is paucity of studies implementing interventions with a multidisciplinary approach in the management of children with developmental disorders.

This study therefore seeks to assess the effects of psychoeducation on psychological distress and burden of care among caregivers of children with autism spectrum disorders in a tertiary healthcare facility in Ibadan, Nigeria. The psychoeducation approach will involve training caregivers in understanding ASD, and the different aspects of caring for their children and helping them live better and healthier lives. It is hoped that findings from this study will be valuable in helping to forge strong multidisciplinary teams of health workers in providing care to children with ASD as well as other neurodevelopmental disorders in Nigeria and other LMICs.

## AIMS AND OBJECTIVES

Broad objective:

To assess effects of Psychoeducation on Psychological Distress and Burden of Care among Caregivers of Children with Autism Spectrum Disorders in UCH, Ibadan.

Specific Objectives

1. To assess the psychological distress of caregivers of children with Autism Spectrum Disorder.
2. To assess the burden of care of caregivers of children with Autism Spectrum Disorder
3. To assess the knowledge of the caregivers on challenging behaviour management pre and post intervention.
4. To determine the effect of psychoeducation on psychological distress on caregivers of children with Autism Spectrum Disorder.
5. To determine the effect of psychoeducation on burden of care among caregivers of children with Autism Spectrum Disorder.

### 1.4. Research Questions

1. What is the level of psychological distress among caregivers of children with Autism Spectrum Disorder?
2. What is the level of burden of care among caregivers of children with Autism Spectrum Disorder?
3. What is the effect of Psychoeducation on psychological distress on caregivers of children with Autism Spectrum Disorder?

4. What is the effect of Psychoeducation on burden of care among caregivers of children with Autism Spectrum Disorder?

## 1.5. Hypotheses

Hypothesis 1:

Null hypothesis ($H_0$): There will be no significant effect of psychoeducation on psychological distress among caregivers of children with autism spectrum disorder.

Alternate hypothesis ($H_1$): There will be significant effect of psychoeducation on psychological distress among caregivers of children with autism spectrum disorder.

Hypothesis 2:

Null hypothesis ($H_0$): There will be no significant effect of psychoeducation on burden of care among caregivers of children with autism spectrum disorder

Alternate hypothesis ($H_1$): There will be significant effect of psychoeducation on burden of care among caregivers of children with autism spectrum disorder.

(Total words 1333)

# CHAPTER TWO

# LITERATURE REVIEW

## 2.1 CONCEPT OF AUTISM SPECTRUM DISORDERS

Autism spectrum disorder (ASD) refers to a group of complex neurodevelopment disorders characterized by repetitive and characteristic patterns of behaviour and difficulties with social communication and interaction. Regarded as one of the leading mental health illnesses, Autism usually emerges during the first 3 years of life with the severity of presentation depending on age, intelligence and language ability of the child (APA, 2013 and Bavin et al., 2014)

ASD can be diagnosed by clinical interview, observation, direct assessments, and/or behavioural ratings. The spectrum of symptoms in ASD ranges from mild to severe and are often always associated with sensory and cognitive abnormalities. Other symptoms such as abnormal self-absorption characterized by lack of response to other persons, limited ability or disinclination to communicate and socialize may also ensue from which the term autism is derived.

The three main areas affected by the disorder are speech or communication, social skills, and behaviour, and these symptoms are usually present from early childhood and affect daily functioning (APA, 2013, Woodman 2016)

Individuals with autism do not necessarily look obviously different from others, but may be impaired in their speech, behaviour, learning, and the way they perceive the world around them. Consequently, the impact on the child is usually lifelong, and the caregivers are not exempted. (APA, 2013 and Hobson 2016).

## 2.2 PREVALENCE OF ASD

Globally, ASD occurs in all racial, ethnic, and socioeconomic groups with one in every 160 persons is estimated to live with ASD, contributing to 7.6 million disability life adjusted years (WHO, 2013). Studies from other developed countries like Sweden and England have also reported prevalence rate of about 5.3 per 1000 and 6.2 per 1000 respectively among preschool children (Gillberg et al., 1999; Chakrabarti & Fombonne, 2001). In the United States, the CDC has estimated that autism spectrum disorder occurs in about 1 in 68 children, occurring about 4.5 times more among boys (CDC, 2006).

In Africa, studies have shown that the prevalence of ASD range between 11.5% and 33.6% among African children with developmental disorders (Seif Eldin et al., 2008). Other studies conducted among children in Sub-Saharan Africa have also reported high occurrence of ASD (Ametepee, et al., 2009). Similarly, studies on ASD document a large burden of nonverbal ASD cases (50−71%) and over 60% comorbid intellectual disability among African children with ASD (Belhadj, et al., 2006). These traits of ASD in Africa, has also been associated with potential infectious aetiology, late diagnosis, and poor management (Newton et al., 2013).

In Nigeria, the prevalence of ASD has been estimated to be as high as 11.4% in a study conducted by Bakare et al., (2012) among children with intellectual disability. Though there is increase in prevalence of ASD reported in America and Europe, there is very few data on the community prevalence of ASD in developing countries like Nigeria (Bakare and Munir, 2011; Bello- Mojeed et al., 2013b). Like in many developing countries, the burden of ASD is highly underestimated since prevalence of ASD in the African region and other low or middle income regions is still unclear. Furthermore, there is a high rate of underreporting of cases of ASD due to late presentation of cases at both orthodox and formal health facilities across the country. For example several studies conducted in Nigeria have shown that the common age range of presentation of cases of ASD at both orthodox and formal health facilities range from 13 to 17 years (Onuora, 1992, Bakare et al, 2008; Bello-Mojeed et al, 2010) which further buttresses the significance of underreporting of these cases.

## 2.3 Impairments in Autism Spectrum Disorder

Impairment of autism include unresponsiveness, lack of interest, avoidance of contact, loneliness, trouble understanding other people feelings, delayed speech and language skills, repeatability of words or phrase over and over (echolalia), get upset easily by minor changes, display of obsessive interest, flapping of hands, rocking of body, unusual reaction to sounds, taste, look or feelings etc. (Mundy and Neal, 2001).

Furthermore, children with ASD may also display anti-social behaviour, disinterestedness in other people around them and may preoccupy themselves with stereotypic and repetitive activities of interest such as finger snapping, to and fro movements including arranging objects in meaningless patterns or irregular rotation of objects as well as flapping of hands. In some extreme cases, they may engage in other detrimental activities like biting the wrists, and banging the head which may further worsen their health condition (Campbell et al and Soke 2017).

Another major impairment associated with ASD is the inherent poor social communication skill; since children with ASD usually have difficulty in acquiring and developing languages. Evidence shows that one third or half of the victims of autism are unable to develop sufficient speech needed for effective day to day communication (Bryson, 1996; Lord and Paul, 1997 Thurm 2015). As a result of this, the affected children are faced with the challenge of either not being able to develop speech or do that sparingly. Thus these children find it stressful or uneasy to start and maintain good communication flow; and generally lack the required creativity to interpret words or sentences and rely solely on syntax to decrypt sentences. In some instances, they may also result in strange prosody, verbatim repetition of words or phrase otherwise called echolalia, as well as pronoun reversal (Paul et al., 1988 and APA 2013)

Certain known genetic disorders are associated with an increased risk for autism, including Fragile X syndrome (which causes intellectual disability) and tuberous sclerosis (which causes benign tumours to grow in the brain and other vital organs) each of which results from a mutation in a single, but different, gene. Recently, researchers have discovered other genetic mutations in children diagnosed with autism, including some that have not yet been designated as named syndromes (Yrigollen 2016 and Benvenuto 2017).

## 2.4 AETIOLOGY OF AUTISM SPECTRUM DISORDERS

Autism Spectrum Disorder is typically diagnosed on the basis of behavioural symptoms without reference to aetiology. There is no single cause identifiably associated with ASD but available data suggest that autism results from different sets of causal factors or risks factors which can be genetic, neurobiological and environmental. Genetic risk factors associated with the x-chromosome, discovered that almost 20% of infants with older biological siblings with ASD also develops ASD (Ozonoff et al, 2011). Studies have also shown that if one of a monozygotic twins is diagnosed with ASD then there is a 76% chance that the other one will develop ASD, while the percentage in fraternal twins is 34% for same sex twins and 18% for boy – girl pairs (Frazier et al, 2014).

Neurobiological Factors have also been implicated for example, abnormalities in the genetic code may result in abnormal mechanism for brain development that can result in structural and functional brain abnormalities along with symptomatic behaviours (Williams, 2010). Neurobiological differences associated with a diagnosis of ASD includes problems with genetic code development (Abraham and Geschwind,2010),structural and functional abnormalities of the brain which includes increased gray matter in the frontal and temporal lobes (Carper and Courchesne, 2005; Hazlett et al 2006;), increased white matter compared with gray matter in adolescence (Volkmar, Lord, Bailey, Shultz and Klin,2004), and differences in the brain response to the environment (Jones, Carr and Klin,2008). A number of environmental exposures have been identified as risk factors such as lead (Landrigan et al, 2012), polychlorinated biphenyl and insecticides (Shelton et al, 2012).

## 2.5 MANAGEMENT OPTIONS

Therapists often use behavior therapy as a means of treatment for ASD (Lubestky et al., 1994). The right behavior therapy for each child and adolescent with autism may include one or more of the following techniques.

### Applied Behavioural Analysis (ABA)

**ABA** (Cooper et al., 2007) is used to help the child with autism reach positive goals and extinguish negative behaviours. Here, the child would be observed and goals will be set as regards the targeted behavior. Then the therapist would reward the behaviours expected to be achieved while ignoring the undesired ones. If a caregiver learns ABA, then less time will be spent with the therapist and so the child can be engaged in other social activities (Virués-Ortega 2010).

Functional Behavioural Analysis (FBA):

It is used to resolve challenging behaviours which can be distressing to the care giver and can limit a person's access to the community facilities (Lubestky et al., 1994 and Hanley et al., 2010).

**FBA** is a process of determining the purpose or reason for certain behaviours shown by the child. It is based on gathering and analyzing information from ABC Charts whereby **A** = Antecedents (What happened before the challenging behavior), **B** = Behaviour (The exhibited challenging behavior by the child) and **C=** Consequences (Caregiver's intervention known/ unknown to caregiver that resolved the challenging behavior). If a caregiver is properly educated on FBA and practices this in the care of a child with autism, then the rate of having a challenging behavior will reduce and the psychological distress and burden of care of the caregiver will reduce too.

Relationship Development Interventions (RDI)

This type of behavior therapy focuses on achieving positive social behaviours in a child with autism (Gutstein et al., 2007). In this form of intervention, a caregiver is more involved than a therapist in that after the initial assessment and setting of goals by the therapist, the caregiver either attends an intensive workshop or watches a video which teaches them how to carry out the therapy. The caregiver submits video of themselves with the child in other to get feedback from the therapist who in turn will give advice on further treatment. This **RDI**, works best in young children, but can still work well for older children.

Sensory Integration Therapy (SIT)

**SIT** (Lang et al., 2012) works to help improve an autistic child's sensitivities to sensory stimuli such as loud noises, bright lights and touches which can be overwhelming. Here the therapist exposes the child to increasing level of stimuli being worked on .Though the therapist needs to push the child's limit but this must not be forced.

Communication Interventions (CI)

Due to lack of effective communication, the child with autism can exhibit challenging behaviour out of frustration and misunderstanding of the situation (Goldstein et al., 2002). So, by teaching effective communication skills whether verbal or non- verbal such as the Picture Exchange Communication System (**PECS**) (Bondy and Frost 1994) a child can express his/her desires. Social Learning can happen through modelling, peer tutoring, games and many others.

Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH).

This model is used to achieve positive results in social and maladaptive behaviours in children with ASD. Here, a well structure and organized environment is used at all times to create activities which are predictably sequenced and visually organized to create positive outcomes for the child (Schopler and Van Bourgondien 1991). If caregivers are taught to use a similar method at home then this will help in reducing the burden of caring for children with ASD.

Family Therapy (FT)

Here, the caregiver and other members of the family are educated on how to play and interact meaningfully with the child, provide for and support the child and primary caregiver so as to reduce the psychological distress and burden of caring for the child with autism (Pinsof and Wynne 1995).

## 2.6 CAREGIVERS ROLE IN MANAGEMENT OF ASD

Childhood autism is a developmental disorder that could have better prognosis with early intervention, which is often achieved through early recognition and diagnosis (AAP, 2001). Caregivers of children with ASD who often happen to be either their parents, close relatives or in some cases employed caretakers, play a pivotal role in the recognition and early diagnosis of ASD needed to forestall further deterioration of their health. Unfortunately, there is usually paucity of quality information regarding ASD needed to influence positive help-seeking behavior and early intervention in a formal healthcare facility (Bakare et al., 2009). On detection of ASD among children, caregivers are faced with the enormous task of bringing these children to access care at the mental health clinic, hence they constantly have to endure long waiting time at these facilities or in some cases engage in regular movement from one facility to another (Maes et al., 2003). Given that the developmental and psychiatric problems of children with ASD are so specific and demanding, mental health care for these persons must usually be taken seriously with all medication and hospital appointments adhered to; hence some countries have developed and implemented outreach services, crisis intervention teams, diagnostic and counselling facilities to support caregivers and their children in their natural living and working environment.

Caregivers are highly indispensable accompaniment to children suffering from ASD. Occasionally, some of the caregivers have mental health challenges and the very first task they have to address is coming to terms with the child’s diagnosis. It then stands to reason that for the establishment of an effective, healthy attachment and sensitive caregiving, there is utmost need for the caregivers to come to a resolution with the diagnosis of the child.  Therefore, resolution failure will amount to maternal/caregivers’ distress, poor social support as well as high caregiver burden (Kearney et al 2011).

## 2.7 PSYCHOLOGICAL DISTRESS OF CAREGIVERS OF CHILDREN WITH AUTSIM SPECTRUM DISORDERS.

Caregiving for children with any form of neurodevelopmental disorder is associated with a lot of psychological problems as reported among mothers of children with developmental disorders (Magana and Smith, 2006). Caring for children with special needs do not only impact the lives of the caregivers alone, but also on all the members of the family. Studies have shown consistently that caring for a child with ASD at home can be associated with a higher level of family burden (Baker *et al.* 1997; Guralnick 1997 and Mcstay 2014). Parents may experience one or more aspects of their situation as stressful and think that they do not possess effective strategies or resources to cope with the situation. While other factors such as the child's features, family characteristics as well as other contextual factors may intensify or moderate parenting stress or successful adaptation, the stressful conditions nonetheless still persist as long as the child remains in the home and caregivers may still find it difficult caring for their child especially in the face of offensive, socially disturbing and provocative or stereotypically behaviours (Baker *et al.* 1997).

The impact of stress due to the behavioural pattern of children with ASD are observed to be profound not only on the affected child but also more especially on the caregiver who actually experience psychological distress that is associated with such caregiving (Mojeed – Bello et al, 2010; Mojeed – Bello., et al 2013a). According to Laxman et al (2014), father's literacy and responsive involvement in caregiving reduces the level of psychological distress of mothers of children with ASD. The study further showed that appropriate psychoeducation can help reduce caregiver's psychological distress. This study aims as assessing the effects of psychoeducation as an intervention for reducing psychological distress of caregivers of children with ASD.

## 2.8 PSYCHOEDUCATION INTERVENTION FOR MANAGEMENT OF PSYCHOLOGICAL DISTRESS

As previously reported in the literature, caregivers/parents of children with autism spectrum disorder (ASD) experience a lot of stress and face numerous challenges, while caring for their children. The reported stress may however not be unrelated to the challenging behavior displayed by these children, but also the low awareness about the disorder, inadequate provisions for services, and difficulty in accessing them (Divan et al., 2012).

Caring for children also has a negative impact on the overall health of the caregivers and other relatives. Therefore, the role of interventions targeting these stressful conditions especially for the caregivers of these children cannot be overemphasized, as such interventions has the potential of improving the lives of both the children and their families.

Psychoeducation is a form of education offered to mentally ill patients, their caregivers and families to assist them in better managing their condition (Aghkwu and Takai 2015). According to social work dictionary, psychoeducation is a process of educating individual with mental disorder, their caregivers and family members about the nature of the illness, including its aetiology, progression, consequences, prognosis, treatment and alternatives (Barker 2003). The aim of psychoeducation is to enable the parents as well as the relatives of the affected child to have a better insight of the situation in order to foster effective management system for quick recovery and the total wellbeing of the patient. (Barker 2003)

Donker in his article titled "Psychotherapy and re-education" was the first to use the term "psycho-education", and after several decades after introduction of the term, Tomlinson incorporated it into medical literature (Donker et al 2009). The term was also better established and popularised and had found use in improving the health care for sufferers of AIDS, cancer, diabetes, hypertension, schizophrenia and other mental health illnesses (Baumi et al 2006).

The application of psychoeducation in the management of ASD cannot be over-emphasized especially among people with ASD, their care givers as well as their family members (Aghukwa and Takai 2015). Because of the unquantified and enumerable efficacy of psycho-education, it has experienced a paradigm shift from the traditional medical model of management of pathology and dysfunction to a holistic approach with health and patients empowerment at the core of the model (Dixon, 1999 and Lima 2017). Psychoeducation has a lot of components which will further help in reducing psychological distress in caregivers of children with ASD and very few studies have explored this hence this study has been designed to explore the effectiveness of psychoeducation in relieving psychological distress on caregivers of children with ASD .

### 2.8.1 The merits of Psychoeducational interventions

The intervention is not time consuming. As such, the patients do not get bored and there is low attrition rates among participants (Aghukwa et al 2005). Furthermore, a better understanding of the patient is promoted, they can rationally counsel themselves. As a result of the instructive nature of the education, patient's confidence and wellbeing is highly improved. Thirdly, the effective structuring of the session enables so much therapeutic achievement. The tendency of the session becoming "chat or gist sessions" is highly reduced because of the well-structured format. Fourthly, it is very advantageous in the sense that it is an evidenced based intervention. The intervention is directed toward client's goals and not attempting the therapist's goals on the client (Semple at al 2005).

### 2.8.2 Effectiveness of Psychoeducation on psychological distress

In 2009, Donker *et al.*, was the first to publish a meta-analysis on psycho-education and its effectiveness in coping  with psychological distress among adult population. Over 9010 abstracts were identified by their study and five papers were specifically targeted at curbing psychological distress through psycho-education. The pooled standard effect size for reduced symptoms of depression and psychological distress intervention was $d = 0.01 – 0.40$, $Z = 2.04$, $P= 0.05$, the number needed to treat = 9). It was concluded by Donker and his team that psycho-education is an effective tool in the management of psychological distress.

An author in his recent descriptive study in Nigeria randomly enrolled 336 patients and their relatives in a tertiary hospital, investigating their views and perspective on psycho-education. At the end of the research, it was discovered that majority of the patients on their visitation days to the clinic did not receive enough psychoeducational intervention despite its affordability, simplicity and effectiveness (Aghukwa and Takai 2015). In addition, it was suggested by the author that patients experiencing other forms of psychological distress can have their cases ameliorated by participating in a brief inexpensive psycho - educational interventions during clinic visitation.

### 2.9 Relevance of this study to the practice of CAMH

The burden resulting from care of children with Autism spectrum Disorder is demonstrably high, and this causes significant distress to the family members and careers.  This distress directly affects the caregivers' motivation and willingness to continue caregiving when overwhelmed. Addressing the burden and the distress resulting from this, by proper and effective psycho-education can greatly help such caregivers withstand this responsibility. This indirectly improves the care the children with autism will get and their eventual outcomes will be improved. Also, the intervention will reduce the use of clinical services by the caregivers who will be better able to cope with these stressors.

(Total words = 3372)

# CHAPTER THREE

# STUDY METHODOLOGY

## 3.1.Study Location

The study was conducted in the Child and Adolescent Mental Health (CAMH) Clinic, University College Hospital, Ibadan.

The University College Hospital was established by an act of parliament on November 1952 in response to the need for the training of medical and other health personnel for the country and the West Africa sub- region (UCH, 2011). It is strategically located in Ibadan North local Government Area along Queen Elizabeth Road. It was formally commissioned on 20th November 1957 (UCH, 2011). It presently has 929 bed spaces, over 60 departments (clinical and non- clinical), runs 96 consultative outpatient clinics of which the Child and Adolescents Clinic is one and has community based outreach centres at Abedo, Sepeteri, Igbo-Ora, Okuku, Jago and Elesu.

The CAMH Clinic was officially opened on the 16th November 2012. It has three consultants, three resident doctors, two nurses and medical record officers. Children who need services such as speech and language therapy and hearing tests are usually referred to have such outside the centre. CAMH clinic caters for the mental health of children and adolescents aged between 2 – 19 years. The clinic holds on Mondays and on Thursdays and caters for all mental health issues including Autism Spectrum Disorders and other Neurodevelopmental Disorders, Seizure Disorders and Psychotic Disorders. The average clinic attendance of children with ASD is about 4 – 6 monthly. The children are often accompanied by their caregivers and /or other relatives.

### 3.2. Study design

A one group pre and post study design was used for this research project. Study participants were randomly selected using a table of random numbers.

### 3.3. Study Population

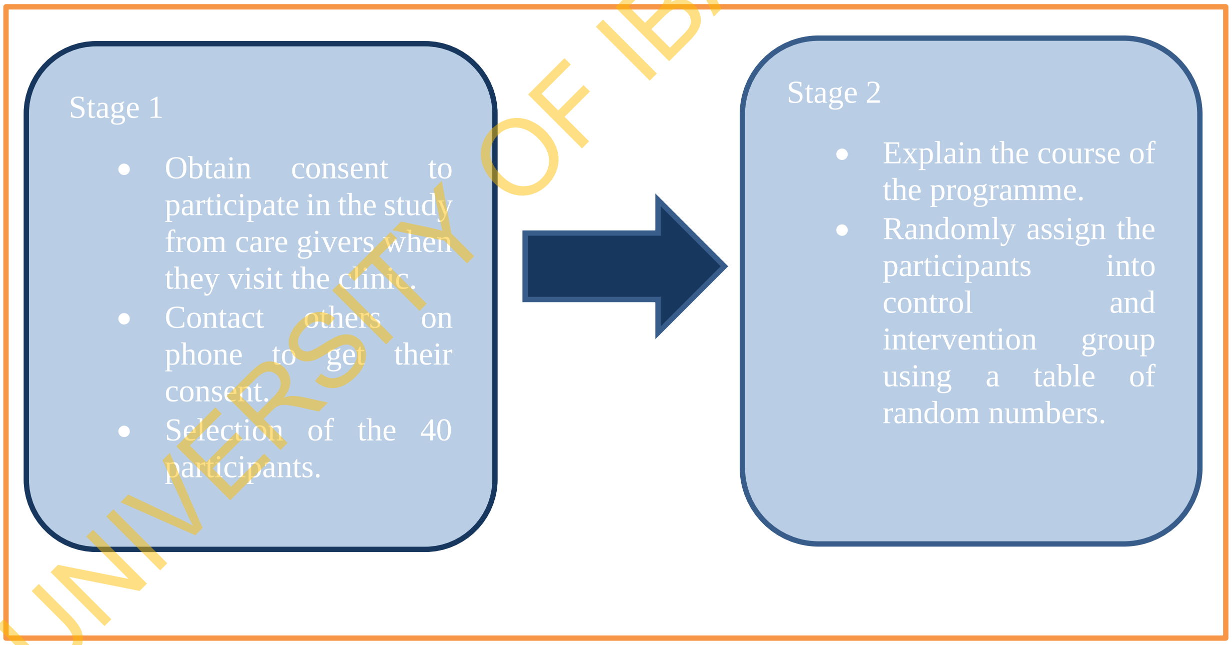
Study participants were caregivers of children with ASD who attend the Child and Adolescent Mental Health Clinic at the University College Hospital, Ibadan.

Study inclusion criteria:

**a.** Caregivers willing to give consent.

**b.** Caregivers aged 18 years and above

**c.** Caregivers of children with primary diagnosis of ASD.



Stage 1

- Obtain consent to participate in the study from care givers when they visit the clinic.
- Contact others on phone to get their consent.
- Selection of the 40 participants.

Stage 2

- Explain the course of the programme.
- Randomly assign the participants into control and intervention group using a table of random numbers.

**Figure 1: Study Flow Chart Diagram**

Study exclusion criteria:

(1) Caregivers who are below 18 years of age.

(2) Caregivers of children with primary diagnosis of seizure disorder, or intellectual disability.

(3) Caregivers who are currently unwell with a medical or severe psychiatric disorder.

### 3.4.Sample Size Determination

The sample size was based on the formulae:

$n = 2F (\sigma/d)^2$ (Wade 1999)

Where:

$\sigma$ = represents the standard deviation for the outcme measure:

F = 7.85, assuming 80% power and 0.05 level of significance ( Wade, 1999);

d = expected difference expected between baseline and post intervention.

Assuming the intervention will produce a reduction of one standard deviation in the outcome measure (for example, psyhological distress) between the baseline and post intervention assessment, then the sample size would be :

$2x\ 7.85 (1/1)^2 = 16$

This was increased to 20 in order to account for possible attrition in the course of the study.

## 3.5.Sampling Technique

From the CAMH clinic records, a total number of 53 patients have been diagnosed with ASD between 2013 and 2017. These patients are also currently receiving treatment at the CAMH clinic in UCH. Recruitment of participants was done in 2 stages:

Stage 1

Eligible caregivers of children with confirmed ASD were approached as they attended their clinic appointment and their consent sought as to participating in the proposed study while others whose appointment date is later were contacted through the telephone to discuss the purpose of the study and seek their consent in participating in the study. This involved the use of random numbers in selecting the first 20 caregivers from the sampling frame of 53 potential respondents to be contacted.

Stage 2

Caregivers who agreed to participate were given explanation as to the course of the programme and what they stand to benefit from participating in the study were recruited into the study

### Data collection instruments

Quantitative data was collected using an interviewer administered questionnaire. The interviewer was blinded to study group assignment.

Five key data sets were collected using different instruments. These included:

1. Socio-Demographic characteristics
2. Zarit Burden Instrument for assessment of burden of care
3. Knowledge on Challenging Behaviour Management Questionnaire

4. General Health Questionnaire for assessment of psychological distress
5. A Client Satisfaction questionnaire.

**a.** **The Socio-Demographic Questionnaire (SDQ)** This consists of questions relating to socio demographic characteristics adapted from a questionnaire used in a previous study on adolescents in rural and urban Ibadan (Omigbodun et al., 2008).

**b.** The Zarit Burden Interview (Zarit et al., 1985) is a 22-item questionnaire with a five-item response set ranging from ''never'' to ''nearly always''. The tool examines the caregiver's report of their challenges including physical and psychological health, finances, social life, and the relationship with the patient. It has been validated for use in Nigeria and utilized by various investigators across Nigeria (Olagunju et al, 2017, Adeosun, 2013,Nuhu et al.,2010, ).

**c.** **Knowledge on Challenging Behaviour Management Questionnaire (KCBM)** is a 12-item questionnaire with a three – item response set of "true", "false" and "don't know" is used to assess caregivers knowledge of what constitutes a challenging behavior and how to deal with it. This questionnaire which has been used among carers of children with Autism in Nigeria (Bello-Mojeed et al 2016) was adapted for this study.

**d.** General Health Questionnaire (GHQ-12) (Goldberg et al., 1997) - This is a 12 item short screening self-reported instrument that assesses distress as well as psychiatric morbidity noticed by the individual over the past four weeks (Goldberg &Williams, 1988). Each question has 4 responses which were scored 0, 0, and 1, 1. For example, if an individual ticked response 1 or 2 on any item, such an individual is scored zero (0) for that item, whereas, if the same individual ticked response 3 or 4 on another item, he/she is scored 1. The summed score for any individual ranges from zero (0) twelve (12). A cut-off score of

2 or more has been used in previous studies in Nigeria (Gureje and Obikoya, 1990; Adeyemi et al.,1996; Omigbodun et al., 2006; Yunusa and Obembe, 2013; Ani et al, 2011b).

e. **Client Satisfaction Questionnaire:** This consists of eight questions modified from the Client satisfaction questionnaire (Atkinson and Greenfield, 2004). Each question is scored on a scale of 1 to 4 giving a total score of between 8- 32. Five open ended questions will be added to capture what participants liked about the programme, what they didn't like, their best and least liked topics, and how the programme could be improved in the future.

### 3.6.Study Procedure

The study was conducted in three stages: pre-intervention, immediate post-intervention and post-intervention assessment of participants' psychological distress and burden of care associated with caring for children with ASD.

### 3.7.Questionnaire Administration

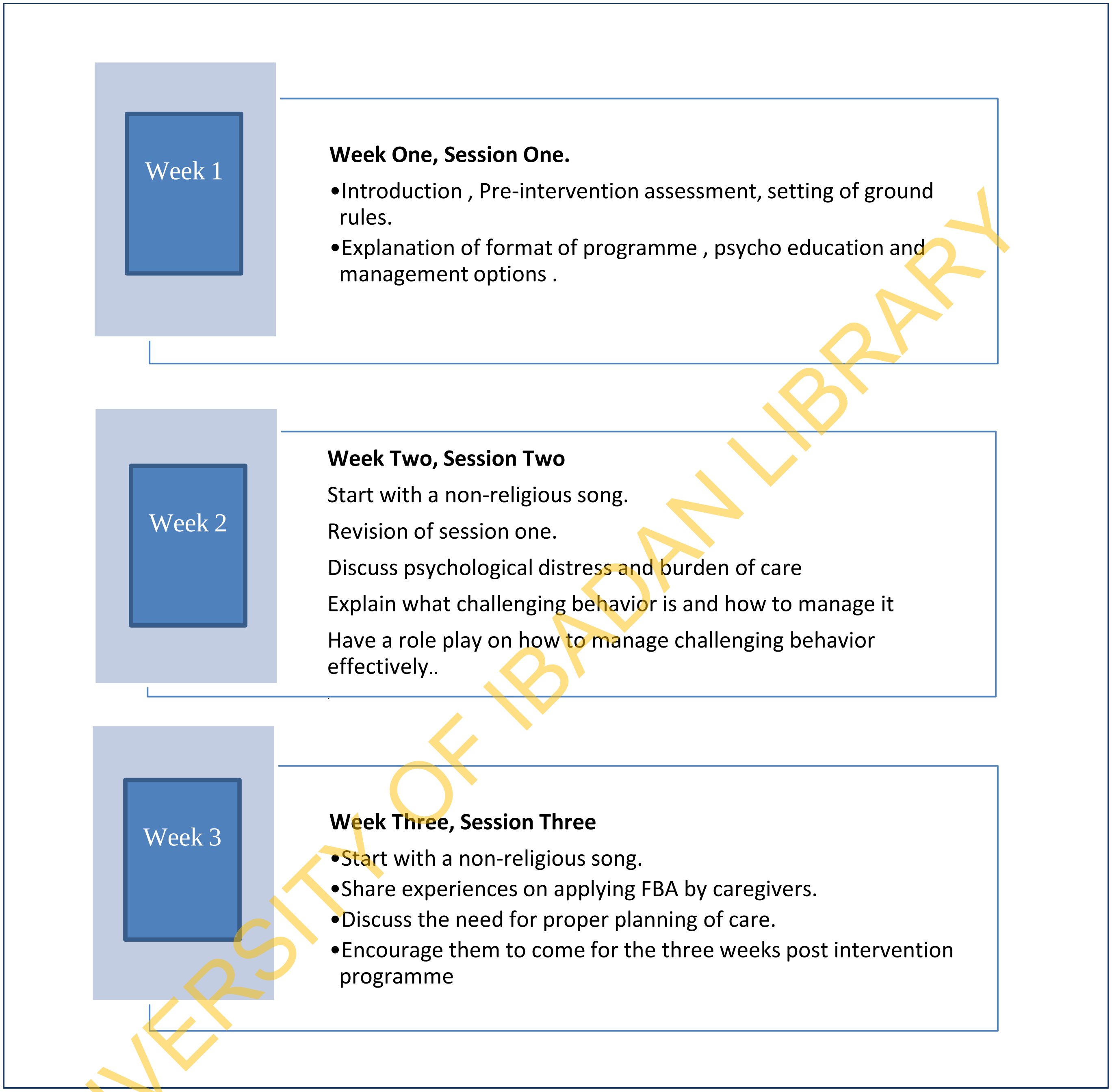
***Pre- intervention:*** The Socio- Demographic Questionnaire, the General Health Questionnaire and Zarit Burden Index were administered to all the caregivers of the children with ASD by a trained interviewer who was blinded to the study hypothesis to avoid bias. The interviewer was trained using a group of caregivers who were not in the study. These same caregivers were involved in piloting to test for reliability of the instruments. Those who have difficulty in communicating in English language were interviewed in Yoruba language.

Training intervention

Participants selected into the intervention group were offered one session of psychological intervention per week for 3 weeks. The intervention was adapted from a Behavioural Intervention Manual which is a group- based intervention for caregivers of children with autism and aggressive behaviour in Nigeria (Ani, 2014). Finally, caregivers were helped to understand basic strategies for preventing or managing challenging behaviours.

Post intervention

Three weeks after the last intervention session, a second assessment of participants' questionnaires was administered to the study participants to assess the effect of the intervention on the caregivers. A client satisfaction questionnaire was also administered at the end to assess their level of satisfaction with the training programme.



**Week One, Session One.**

- Introduction , Pre-intervention assessment, setting of ground rules.
- Explanation of format of programme , psycho education and management options .

**Week Two, Session Two**

Start with a non-religious song.

Revision of session one.

Discuss psychological distress and burden of care

Explain what challenging behavior is and how to manage it

Have a role play on how to manage challenging behavior effectively..

**Week Three, Session Three**

- Start with a non-religious song.
- Share experiences on applying FBA by caregivers.
- Discuss the need for proper planning of care.
- Encourage them to come for the three weeks post intervention programme

**Figure Two: Weekly schedule of training intervention.**

### 3.8. Data Management and Analysis

The variables collected and analyzed both at baseline and post intervention included demographics such as age, psychological distress and burden of care. Continuous univariate data such as age and scores on rating scales were described as means and standard deviations while categorical variables were described as proportions and frequencies.

Treatment effect was determined using repeated measures ANOVA with sphericity assumption for the outcome measures taking into account the different times points of assessment. The assessment of the three dependent outcomes including caregivers' knowledge, burden of care and psychological distress was carried out to evaluate the effect of the training intervention among only the intervention group. All results was interpreted as statistically significant at 5% level.

### 3.9.Ethical Considerations

Ethical approval for study implementation was obtained from the UI/UCH Ethical Review Committee, University of Ibadan. Permission for study was also obtained from the Head of Department, Child and Adolescents Mental Health, University College Hospital Ibadan.

**Informed consent:** Written informed consent was obtained from all participants.

**Confidentiality of data:** Confidentiality of participants' information was ensured by adopting a de-identified approach to data handling, with the use of unique identifiers for study participants.

**Beneficence to participants:** All participants received free health counselling as well as other incentives for participating in the study.

**Non-maleficence to participants:** The risk of harm to study participants was estimated as low. Password protected computerized systems was used for data management.

**Voluntariness:** Participation in this research was entirely voluntary and eligible individuals was assured of their choice to participate in the study or not.

(Total words = 1634)

# CHAPTER FOUR

# RESULTS

## 4.1. Baseline socio demographic characteristics of respondents.

A total of 16 respondents were recruited for this study. Table 4.1, shows the socio-demographic characteristics of the caregivers. Results showed that the mean age of the caregivers was 42.53 ± 8.53 years, and majority of the caregivers had attained tertiary education (87.50%), earned above NGN 20,000 (31.25%) and practiced Christianity (62.50%). The family settings for the caregivers were mostly monogamous (68.75%), predominantly of Yoruba ethnicity (87.5%), and had mostly between 1 to 3 children (69.7%). The Median monthly Income for the caregivers was 45,000 naira (IQR: 20,000 – 75,000).

Table 1: Socio-demographic characteristics of study participants at baseline.

| Description | N (or Mean ±SD) | Percent (%) |
|---|---|---|
| **Age (in years)** | 42.53 ± 8.53 | |
| **Gender** | | |
| Male | 5 | 31.25 |
| Female | 11 | 68.75 |
| **Marital status** | | |
| Currently unmarried | 5 | 31.25 |
| Currently married | 11 | 68.75 |
| **Educational level** | | |
| Primary | 0 | 0 |
| Secondary | 2 | 12.5 |
| Tertiary | 14 | 87.50 |
| **Employment status** | | |
| Employed | 9 | 56.25 |
| Unemployed | 6 | 37.50 |
| **Occupation** | | |
| Trader | 5 | 31.25 |
| Professional | 5 | 31.25 |
| Teacher | 2 | 12.50 |
| **Average monthly income** | | |
| < 20,000 | 4 | 25.00 |
| > 20,000 | 5 | 31.25 |
| **Religion** | | |
| Christianity | 10 | 62.50 |
| Islam | 6 | 37.50 |
| **Ethnicity** | | |
| Yoruba | 14 | 87.50 |
| Others | 2 | 12.50 |
| **Family type** | | |
| Monogamous | 11 | 68.75 |
| Polygamous | 3 | 18.75 |
| **Number of children** | 2.73 ± 1.16 | |

### 4.2. Baseline characteristics of children with ASD

Table 4.2 shows the characteristics of the ASD children. Results showed that the mean ages of the children was 8.50 ± 4.44 years. Majority of the children were males (75.00%), they were presently enrolled in school (81.25%) and mainly in primary school (62.5%). Similarly, majority of the children were also shown to engage in playful activities with their friends/siblings (97.0%). The most common reasons for non-enrolment in school was due to child's health condition (87.50%), followed by receiving of treatment (12.5%).

Table 2: Baseline characteristics of children

| Description | N | Percent (%) |
|---|---|---|
| Age (in years) | 8.50 + 4.44 | |
| Gender | | |
| Male | 12 | 75.00 |
| Female | 3 | 18.75 |
| Child is enrolled in school | | |
| Yes | 13 | 81.25 |
| No | 3 | 18.75 |
| **If no why (N =7)** | | |
| Can’t cope | 0 | 0.00 |
| Due to child’s health condition | 1 | 6.25 |
| Treatment | 2 | 12.50 |
| **School enrolled** | | |
| Primary | 10 | 62.50 |
| Secondary | 2 | 12.50 |
| Tertiary | 1 | 6.25 |
| **Number of times child has been absent from school due to illness** | | |
| Once | 0 | 0 |
| Twice | 1 | 6.25 |
| 3 times and above | 0 | 0 |
| Does child play with friends/siblings | | |
| Yes | 14 | 87.50 |
| No | 1 | 6.25 |

## 4.3. Summary of burden of care among caregivers of children with ASD

Table 4.3a shows the burden of care (assessed by the Zarit burden of care questionnaire) among caregivers of children with ASD. Results showed that the mean burden of care score at baseline was significantly higher (57.87 ± 13.08) than at post intervention 1 (47.81 ± 10.55) and post intervention 2 (54.87 ± 14.63).

A repeated measures ANOVA with Sphericity assumption determined that mean Zarit burden scores differed significantly between the different intervention points (F: 2, 30) = 4.723, P = 0.016). Table 4.3b shows the pairwise comparison of burden of care between the baseline and other two post-intervention time points. Post hoc tests using the Bonferroni correction revealed that the training intervention exercise resulted in a statistically significant reduction in mean burden of care scores from baseline to Post intervention-1 assessment (Mean diff: 10.063; P value = 0.025). Conversely, there was no significant change in mean burden of care scores between baseline and post intervention point 2, nor between intervention points1 and 2 (P>0.05). This suggests that the intervention resulted in a transient reduction in burden for the intervention group but this was not sustained during the second post intervention assessment.

Table 4.3a: Comparison of Burden of care scores among caregivers of children with ASD at baseline and at post intervention.

| Description | Intervention group Mean (SD) | F (2, 30) | Eta Squared | P Value |
|---|---|---|---|---|
| Baseline Score | 57.87 (13.08) | 4.728 | 0.240 | 0.016 |
| Post intervention 1 | 47.81 (10.53) | | | |
| Post intervention 2 | 54.87 (14.63) | | | |

*n = 16

Table 4.3b: Pairwise comparison of burden of care scores among the intervention group

| Intervention group | Intervention group | Mean Difference | P value |
|---|---|---|---|
| Baseline | Post intervention 1 | 10.063* | **0.025** |
| | Post intervention 2 | 3.000 | 1.000 |
| Post intervention 1 | Baseline | -10.063* | 0.025 |
| | Post intervention 2 | -7.063 | 0.125 |
| Post intervention 2 | Baseline | -3.000 | 1.000 |
| | Post intervention 1 | 7.063 | 0.125 |

* = significant at $p < 0.05$

## 4.4. Summary of Psychological distress among caregivers

Table 4.4 shows the psychological distress (assessed by the GHQ questionnaire) among caregivers of children with ASD. A repeated measures ANOVA with Sphericity assumption was used to determine the difference in mean GHQ scores between the different intervention points (F: 2, 30) = 7.853). Results showed that the mean GHQ scores significantly increased from 6.60 ± 2.72 at baseline to 9.73 ± 2.18 at post intervention 1 as well as to 9.87 ± 3.35 at post intervention 2 (P = 0.016).

Table 4.4b shows the post hoc pairwise comparison of mean GHQ scores between the baseline and other two post-intervention time points using the Bonferroni correction. Results revealed that the training intervention exercise was associated with in a significant increase in the mean GHQ scores only from baseline to Post intervention-1 assessment (Mean diff: 3.133; *P* = 0.008) and from baseline to post intervention-2 assessment (Mean diff: 10.063; P value = 0.025). The difference between the GHQ scores between post intervention 1 assessment and post intervention-2 assessment time points was however not statistically significant (P>0.05)

Table 4.4a: Comparison of Psychological distress scores in the intervention group at the three time points

| Description | Intervention group Mean (SD) | F (2, 30) | Eta Squared | P Value |
|---|---|---|---|---|
| Baseline Score | 6.60 (2.72) | 7.853 | 0.359 | 0.002 |
| Post intervention 1 | 9.73 (2.18) | | | |
| Post intervention 2 | 9.87 (3.35) | | | |

Table 4.4b: Pairwise comparison of Psychological distress scores among the intervention group at baseline and at post intervention.

| **Intervention group** | **Intervention group** | **Mean Difference** | **P value** |
|---|---|---|---|
| Baseline | Post intervention 1 | $-3.133^{*}$ | 0.008 |
| | Post intervention 2 | $-3.267^{*}$ | 0.015 |
| Post intervention 1 | Baseline | $3.133^{*}$ | 0.008 |
| | Post intervention 2 | -0.133 | 1.000 |
| Post intervention 2 | Baseline | $3.267^{*}$ | 0.015 |
| | Post intervention 1 | 0.133 | 1.000 |

* = significant at $p < 0.05$

### 4.5. Knowledge of Challenging Behaviour Management among caregivers

Table 4.5a shows the Knowledge on Challenging Behaviour Management among caregivers of children with ASD. A repeated measures ANOVA with Sphericity assumption was used to determine the difference in mean Knowledge on Challenging Behaviour Management scores at baseline and the other intervention points (*F:* 2, 30) = 14.752). Results showed that there was a significant increase in mean Knowledge on Challenging Behaviour Management score from baseline (13.87 ± 0.88) to both post intervention 1 (14.94 ± 1.65) and post intervention 2 (17.06 ± 1.84) time points ($P < 0.001$).

Table 4.5b shows the Post hoc pairwise comparison of Knowledge on Challenging Behaviour Management score between control and intervention group using the Bonferroni correction. Results showed that the intervention resulted in a statistically significant increase in mean Knowledge of Challenging Behaviour Management scores for the Intervention Group from baseline to Post intervention –2 (Mean diff: 3.188; $P < 0.001$) and from Post intervention –1 to Post intervention – 2 (Mean diff: 2.125; $P = 0.023$). This suggests that the intervention improved the knowledge of the intervention group but this only became statistically significant by the second post intervention measure.

Table 4.5a: Comparison of Knowledge on Challenging Behaviour Management scores in the intervention group at the three time points

| Description | Intervention group*<br>Mean (SD) | F (2, 30) | Eta Squared | P Value |
|---|---|---|---|---|
| Baseline Score | 13.88 (0.88) | 14.752 | 0.496 | <0.001 |
| Post intervention 1 | 14.93 (1.65) | | | |
| Post intervention 2 | 17.06 (1.84) | | | |

*N= 16

Table 4.5b: Pairwise comparison of Knowledge on Challenging Behaviour Management scores among the intervention group.

| Intervention group | Intervention group | Mean Difference | P value |
|---|---|---|---|
| Baseline | Post intervention 1 | -1.063 | 0.127 |
|  | Post intervention 2 | $-3.188^*$ | <0.001 |
| Post intervention 1 | Baseline | 1.063 | 0.127 |
|  | Post intervention 2 | $-2.125^*$ | 0.023 |
| Post intervention 2 | Baseline | $3.188^*$ | <0.001 |
|  | Post intervention 1 | $2.125^*$ | 0.023 |

## 4.6. Satisfaction of training intervention among caregivers (n = 16)

Table 4.6 shows the satisfaction experience of the training intervention among caregivers of children with ASD who underwent training intervention.  Results showed that majority of the participants (62.5%) rated the training program as excellent, said they got the kind of help they wanted (75.0%) and that the training mostly met their need (62.5%). About 81% also reported that the training helped them to cope better with caring for their child. Similarly, majority (68.8%) reported that they would definitely recommend the training program to a friend if s/he had stress problems, while 75% said they would definitely come back if they were to needed help again. Majority (87.5%) also said that they were very satisfied with the help they received through the training, while overall, 81.3% of the participants said they were very satisfied with the training program.

Participants in the training intervention shared some of their experiences regarding the training intervention, and also made some recommendations towards improving the training program. Figure 4.2 showed that the presentations/lectures was the most liked (43.75%). Followed by the interactions/experience sharing (31.25%), and the warmth/supportive ambience (12.5%). Majority of the participants also reported that the topic they liked best was on managing challenging behaviours using functional behavioural analysis (87.5%), followed by communicating with ASD children using pictures and sensory stimulation (12.5%) each.

Figure 4.4 shows the suggestions expressed regarding improving the training intervention. Results showed that  "making the program more frequent and continuous" was the most expressed by participants (43.75%), followed by "expanding the program to include other caregivers" (31.25%), while "involving more consultants in the program", as well as "providing information & educational (IEC) material for reference purposes" (12.50%) were least expressed.

Table 4.6: Satisfaction of training intervention among caregivers of children with ASD.

| **Description** | **N** | **Percent (%)** |
|---|---|---|
| **How do you rate the training** | | |
| Good | 6 | 37.5 |
| Excellent | 10 | 62.5 |
| **Did you get the kind of help you wanted** | | |
| Yes | 12 | 75.0 |
| Somehow | 4 | 25.0 |
| **To what extent did the training program met your need** | | |
| Few | 1 | 6.3 |
| Most | 10 | 62.5 |
| Almost | 5 | 31.3 |
| **If a friend had stress problem would you recommend the training program to him/her** | | |
| Yes probably | 5 | 31.3 |
| Yes definitely | 11 | 68.8 |
| **How satisfied are you with the help you received** | | |
| Mostly | 2 | 12.5 |
| Very satisfied | 14 | 87.5 |
| **Has the training helped you to cope better with caring for your child** | | |
| A little | 3 | 18.8 |
| Yes | 13 | 81.3 |
| **Overall, how satisfied are you with the program** | | |
| Mostly | 3 | 18.8 |
| Very satisfied | 13 | 81.3 |
| **If you were to need help again would you come back** | | |
| Yes probably | 4 | 25.0 |
| Yes definitely | 12 | 75.0 |

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Figure 4.2: What I liked best in this program

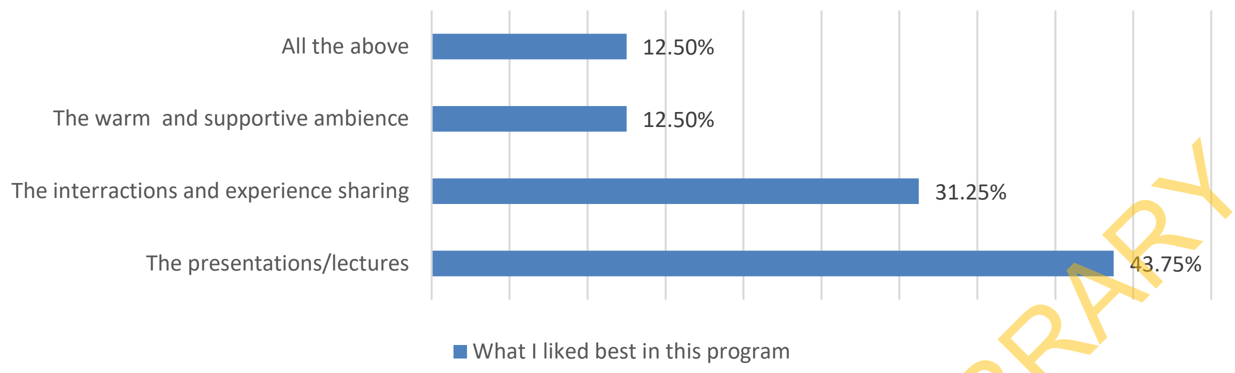


Figure 4.3: The topic I liked best

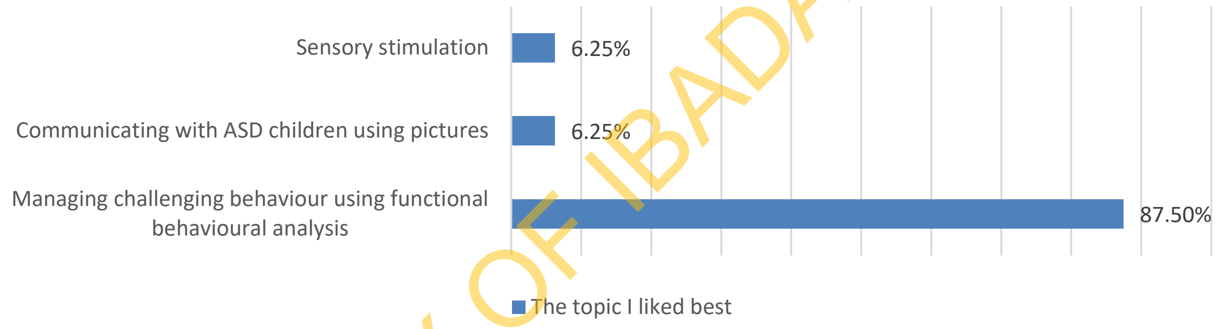
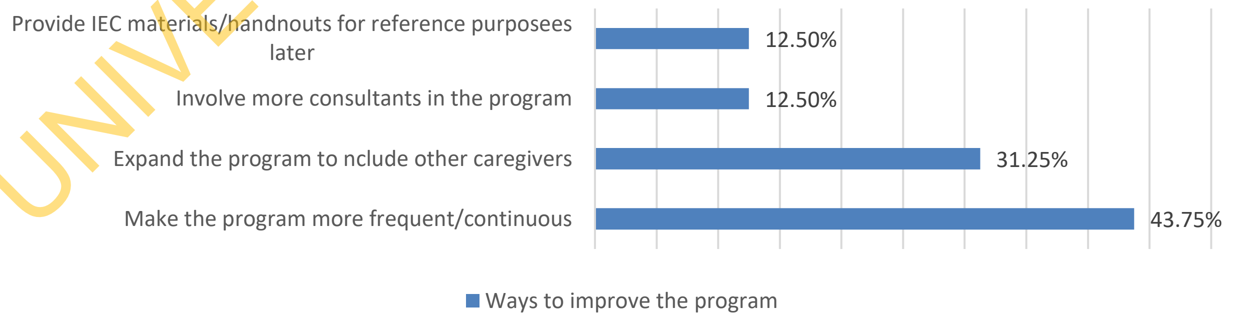


Figure 4.4: Ways to improve the program



# CHAPTER FIVE

# DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS

## 5.1 DISCUSSIONS

The role of caregivers of children with Autism Spectrum Disorders (ASDs) comes with a huge burden that negatively affects the psychological, psychosocial and economic wellbeing of these caregivers (Bello-Mojeed et al, 2010) and these may be due to the children's impaired socialization, impaired verbal and non- verbal communication and restrictive, repetitive patterns of behaviour which may be challenging ( Bello- Mojeed et al., 2010).In many cases, the caregivers lack adequate knowledge about the disorder and become easily frustrated in the course of caring for their children with ASDs (Rhoades et al, 2007, Bello- Mojeed et al,2010). Challenging behaviours has been shown to be a feature of some children with ASD and this in turn has disabling consequences on these children and their caregivers (Bello – Mojeed et. al, 2013a; Farmer, 2011; Bello – Mojeed, 2009).

The majority of the caregivers who participated in this study were 45 years and below and this is similar to a recent study conducted in a clinical setting in which majority of caregivers were 45 years and below (Olagunju et al., 2017). This observation is a reflection of the age bracket of active child rearing and parents in this age bracket are likely to have children who are still at the active age of development.

The current study adopted a pre and post study design aimed at determining the effects of psychoeducation on psychological distress and burden of care among caregivers of children with ASD. This study compared the pre and post intervention effect of psychoeducation which included

Picture Exchange Communication System (PECS) and management of challenging behaviour using Functional Behavioural Analysis (FBA) on the intervention group.

### 5.1.1 Socio- Demographic Characteristics of the Caregivers

Most of the caregivers in this study were females with a mean age of 43.42_+7.88, similar to the gender distribution and mean age that were found in a similar study conducted in Lagos (Olagunju et al.2017) where majority of the participants were females aged 45 and above. Majority of the caregivers were married with some form of formal education and own their businesses with an average income of #45,000 monthly. Participants were mostly Christians, married in a monogamous setting, from the Yoruba tribe and having minimum of 2 to 3 children. This parameter fits a study conducted in Lagos by Bello- Mojeed, (2013a) where most of the caregivers were females, in a monogamous marriage, from the Yoruba tribe, having a form of formal education and a minimum of 2 to 3 children.

### 5.1.2 Socio- Demographic Characteristics of the children

Majority of the children with ASD whose caregivers were participated in this study were males and between 8 and 9years of age. This observation is a reflection of the age at diagnosis of ASD pre- adolescent period. It was observed that few of the children were not in school mainly due to the disabilities from ASD. In a study carried out in Ibadan, it was found out that 27.6% of the children were out of school due to non- availability of suitable schools to meet the specific educational needs of these children (Omigbodun, 2004). This has been similarly reported in studies in other parts of Nigeria (Aderinto et al., 2000).

### 5.1.3 Psychological Distress and Burden of Care among the Caregivers

A study conducted in Lagos identified some of the commonest challenging behaviours expressed by children with ASD to include aggressive behaviours towards a person or property, destructiveness, hitting, spitting, pulling, throwing objects, head banging and biting; which may be a source of distress and burden among their caregivers (Bello- Mojeed, 2013b). This type of finding is the basis for our hypothesis that sycho-educational training carers that include advice on managing challenging behaviours would significantly reduce the caregivers' psychological distress and burden of care.

However, and contrary to the above hypothesis, the findings from this study showed that the GHQ scores significantly increased with the training intervention from the baseline point. This was a surprising finding, which could be that the training sensitised the caregivers to greater awareness of the difficulties associated with ASD thereby unexpectedly increasing their psychological distress.

The training resulted in a reduction of burden scores at immediate post intervention compared with baseline but this was not sustained by the second post intervention measure. This observation may be connected to the fact that although the intervention provided some initial hope and relief, the caregivers could not sustain the gains because it takes time to apply the learning from the intervention before reduction in challenging behaviours can be observed in their children. It might be that a longer follow up would have shown another subsequent reduction in burden once the caregivers have been able to apply the strategies and observe reductions in their children's challenging behaviour. A similar reduction in psychological distress may also have been observed with a longer follow up. However the short time needed to complete the M.Sc. research work did not allow for a longer follow-up.

### 5.1.4 Effectiveness of FBA and PECS intervention

The current study included training the caregivers on Functional Behavioural Analysis and use of Picture Exchange to improve communication – all of which were designed to help reduce challenging behaviour in children with ASD. This is based on evidence from previous interventional studies that have reported that functional behavioural analysis can significantly reduce the challenging behaviours of children with ASD when applied consistently. For example, Bello- Mojeed (2013a) in a study conducted in a clinic in a tertiary health institution in Lagos, taught 20 mothers in a 5-week training intervention period, on the use of Functional Behavioural Analysis (FBA) to understand and manage challenging behaviours in children with ASD. This study which was based on a treatment module developed by Ani (2014) found reduced rates of challenging behaviours in the children post intervention. Also Frea et al (2001) in his study reported an immediate reduction of aggression in children with ASD and Intellectual Disability through the use of Picture Exchange Communication System (PECS).

Many studies carried out on behavioural interventions for challenging behaviours documented significant reduction in such behaviours thereby resulting in reduction in psychological distress and burden of care among caregivers of children with ASD (Bello- Mojeed et al., 2009; Bello-Mojeed et al., 2011; Bello- Mojeed et al., 2013b).

### 5.1.5 Knowledge of Caregivers on Management of Challenging Behaviour

Findings from this study showed that the knowledge of management challenging behaviour among the intervention group significantly increased at post – intervention from baseline scores. This showed that the training intervention resulted in a progressive gain in the caregivers’ knowledge of the strategies taught to manage challenging behaviours. The knowledge increase was however observed to be highest in the knowledge of items that has to do with erroneous positive reinforcers which may be due to the fact that there could be pre-existing low level of knowledge of ASD in the cohort as has been found in other studies in Nigeria (Bello- Mojeed et al., 2013b; Bakare and Munir, 2011).

Ingersoll and Dvortesak (2006) in a study for parents of children with ASD, conducted six sessions of training over a period of 9 weeks and observed an increase in knowledge from 26% to 75%. The current study shows that it is feasible to increase the knowledge of caregivers on aspects of ASD such as behaviour management within as short as 3 sessions.

### 5.1.6 Satisfaction with the Intervention Programme

All the caregivers expressed strong satisfaction for the training programme. This report is similar to the finding in studies by Ingersoll et al, (2006) and Bello- Mojeed (2013b) that reported excellent parental satisfaction following a parental educational training for mothers of children with ASD in a school and clinical setting respectively. This finding is also reported in other studies where respondents expressed satisfaction about intervention programmes targeted at reducing challenging behaviours in schools (Machalicek et al., 2007).

Additionally, the satisfaction for the training intervention program also reflected in their suggestions to continue the training intervention and also expand the training to beyond caregivers accessing care at the child adolescent and mental health clinic in our settings.

### 5.1.7 Strengths and Limitations

**Strengths:-**

1. During the intervention programme, FBA and PECS were taught to the caregivers which is an improvement over a study conducted in Lagos by Bello- Mojeed (2013b) where only FBA was used.

2. The outcome measures were assessed by a blinded interviewer who was unaware of the study hypothesis which provided some masking.

**Limitations**

1. The lack of a control group means that other factors unrelated to the intervention may explain any differences found. Such factors include practice effect.
2. The small sample size makes it difficult to generalize findings to the general population of caregivers of children with ASD.
3. The duration of the study was also short which made long term outcome evaluation difficult. This is due to the duration of the M.Sc. programme.
4. The post intervention assessment was only 3 weeks after the end of the programme which was not enough to determine sustainability of the intervention and may not have allowed for proper internalizing of the training acquired.
5. The intervention was associated with an apparent increase in the carer’s psychological distress, which was a possible unexpected side effect.

## 5.2 Conclusions

Caregivers of children with ASD experience a high level of psychological distress and burden of care as a result of caring for their children especially those with challenging behaviour. So interventions which are directed at reducing these challenging behaviours can be an important instrument for improving the physical and psychological health of these caregivers.

This study gives credence to the saying that ‘Knowledge is Power”. Giving Psychoeducation to the caregivers can empower them by making aware of several aspects of ASD such as different options for management of challenging behaviour.

Teaching of Functional Behavioural Analysis (FBA) delivered by a non- specialist over a shorter period of 3 sessions instead of 5 sessions used in a previous study (Bello-Mojeed,2013b) was shown to be effective in improving the care givers’ knowledge on managing challenging behaviour in children with ASD. This suggest that antecedent- based behavioural interventions such as FBA when combined with Picture Exchange Communication System (PECS) can be effective in improving carers’ knowledge in a Low and Middle Income Country like Nigeria.

## 5.3 Recommendations

In view of the findings in this study, the following recommendations are made:-

1. Further studies with larger sample sizes and a control groups are required to further evaluate the intervention used in this study.
2. Longer time for post assessment should be allowed for proper internalizing of skills learnt by the caregivers.
3. In view of the psychological distress and burden of care among these caregivers, they need a forum whereby they can interact frequently with each other and share experiences. Hence a support group should be set up facilitated by all health professionals working in such Settings.
4. Psychoeducation should be given to all caregivers of children with ASD as routine in clinical setting as this will help reduce their sense of isolation and potentially reduce the burden of care by reassuring them that they are not "ALONE" in this world having a child with ASD.
5. Training caregivers in a naturalistic environment should be an integral part of behavioural intervention programmes.

(Word count 1867)

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## Appendix A: CONSENT FORM FOR STUDY PARTICIPATION

IRB approval number: __________

This research study entitled *"Effects of psychoeducation on psychological distress and burden of care among caregivers of children with Autism Spectrum Disorders in UCH, Ibadan"* is being conducted by Mrs. Ukpe of the University College Hospital, Ibadan. The purpose of the research is to find out whether a psychoeducational intervention will be helpful in improving the psychological distress and burden of care among caregivers of ASD in this environment.

Statement of person obtaining informed consent:

I have fully explained this research to ______________________________________

and have given sufficient information, including about risks and benefits, to make an informed decision.

DATE: ______________________________________

NAME: __________________________________ SIGNATURE: ____________________

**Statement of person giving consent:**

I have read the description of the research and have it translated into language I understand. I have also discussed with the researcher to my satisfaction. I understand that my participation is voluntary. I know enough about the purpose, methods, risks and benefits of the study to judge that I want to take part in it. I understand that I may freely stop being part of the study at any time. I received a copy of this consent form and additional information sheet to keep for myself.

DATE: ______________________________________

NAME: ___________________________________ SIGNATURE: ____________

## Appendix B: Proposed Questionnaire

SOCIODEMOGRAPHIC DETAILS

1. What is your gender? (1). Female ☐ (2). Male ☐
2. How old are you? (in years) ____________________
3. What is your highest Level of education? (1). Nil ☐ (2). Primary school ☐ (3). Junior Secondary School ☐ (4). Senior Secondary School ☐ (5). Tertiary ☐ (6). Postgraduate ☐
4. Are you currently employed? (1) Yes ☐ (2) No ☐
5. If yes, what is your current occupation in past 6 months? _________________________
6. What is your current average monthly income in Naira? _______________________
7. What is your current marital status? (1). Single ☐ (2). Married ☐ (3). Divorced ☐ (4). Separated ☐ (5). Widowed ☐
8. What type of Family is yours? (1) Monogamous ☐ (2) Polygamous ☐
9. How many children do you have? __________________
10. What Religion do you practice? (1). Christian ☐ (2). Islam ☐ (3). Traditional ☐
11. What tribe are you? (1) Yoruba ☐ (2) Igbo ☐ (3). Hausa ☐ (4). Others specify____________
12. What is the Sex of the child that is being treated in this clinic/Ward? (1). Female ☐ (2). Male ☐
13. What is his or her age in years? _________________
14. Is your child currently enrolled in a school? (1) Yes ☐ (2) No ☐
15. If Yes, which school is patient attending currently? (1). Primary school ☐ (2). Junior Secondary School ☐ (3). Senior Secondary School ☐ (4). Tertiary ☐
16. If No, why? ___________________________________
17. In the last 3 months, how many times has child being absent from school as a result of his/her illness?
18. When was the last time your child went to school (in months) _______________________
19. Does your child still play with his or her siblings and friends? (1) Yes ☐ (2) No ☐
20. If No, to the above Question, kindly state why? ______________________________
21. How much do you pay for treatment every month? (in Naira) ___________________

| SECTION B: ZARIT BURDEN INTERVIEW | Never | Rarely | Sometime | Quite Frequently | Nearly Always |
|---|---|---|---|---|---|
| Please circle the response the best describes how you feel. | | | | | |
| 1. Do you feel that your child asks for more help than he/she needs? | | | | | |
| 2. Do you feel that because of the time you spend with your child that you don’t have enough time for yourself? | | | | | |
| 3. Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work? | | | | | |
| 4. Do you feel embarrassed over your child’s behavior? | | | | | |
| 5. Do you feel angry when you are around your child? | | | | | |
| 6. Do you feel that your child currently affects your relationships with other family members or friends in a negative way? | | | | | |
| 7. Are you afraid what the future holds for your child? | | | | | |
| 8. Do you feel your child is dependent on you? | | | | | |
| 9. Do you feel strained when you are around your child? | | | | | |
| 10. Do you feel your health has suffered because of your involvement with your child? | | | | | |
| 11. Do you feel that you don’t have as much privacy as you would like because of your child? | | | | | |
| 12. Do you feel that your social life has suffered because you are caring for your child? | | | | | |
| 13. Do you feel uncomfortable about having your friends visit because of your child? | | | | | |
| 14. Do you feel that your child seems to expect you to take care of him/her as if you were the only one he/she could depend on? | | | | | |
| 15. Do you feel that you don’t have enough money to take care of your child in addition to the rest of your expenses? | | | | | |
| 16. Do you feel that you will be unable to take care of your child much longer? | | | | | |
| 17. Do you feel you have lost control of your life since your child’s illness? | | | | | |
| 18. Do you wish you could leave the care of your child to someone else? | | | | | |
| 19. Do you feel uncertain about what to do about your child? | | | | | |
| 20. Do you feel you should be doing more for your child? | | | | | |
| 21. Do you feel you could do a better job in caring for your child? | | | | | |
| 22. Overall, how burdened do you feel in caring for your child? | | | | | |

SECTION C: General Health Questionnaire

| GHQ 12:<br>We want to know how your health has been in general over the last few weeks. Please read the questions below and each of the four possible answers. Circle the response that best applies to you. | More so than usual | Same as usual | Less so than usual | Much less than usual |
|---|---|---|---|---|
| 1. Have you recently Been able to concentrate on what you're doing? | | | | |
| 2. Have you recently Lost much sleep over worry? | | | | |
| 3. Have you recently Felt that you are playing a useful part in things? | | | | |
| 4. Have you recently Felt capable of making decisions about things? | | | | |
| 5. Have you recently Felt constantly under strain? | | | | |
| 6. Have you recently Felt you couldn't overcome your difficulties? | | | | |
| 7. Have you recently Been able to enjoy your normal day to day activities? | | | | |
| 8. Have you recently Been able to face up to your problems? | | | | |
| 9. Have you recently Been feeling unhappy or depressed? | | | | |
| 10. Have you recently Been losing confidence in yourself? | | | | |
| 11. Have you recently Been thinking of yourself as a worthless person? | | | | |
| 12. Have you recently Been feeling reasonably happy, all things considered? | | | | |

SECTION D: Knowledge on Challenging Behaviour Management Questionnaire (KCBM)

| SN | QUESTION | TRUE | FALSE | DON'T KNOW |
|---|---|---|---|---|
| 1 | Children with difficult behaviours can also positive attributes or strengths | | | |
| 2 | Once a child has difficult behavior, it is not possible to make it better | | | |
| 3 | Behaviors usually have a purpose or reason | | | |
| 4 | The frequency of a child's difficult behaviors can reduce by giving the child reward when he/she behave well | | | |
| 5 | For a child who is unable to explain thing, the purpose of a challenging behavior can be identified by examine what he/she was doing before the behavior. | | | |
| 6 | A child's favorite activities or toy can be used to encourage them to behave more positively. | | | |
| 7 | Understanding how a challenging behavior end can help to identify how to prevent it in future. | | | |
| 8 | Non physical punishment such as removing something a child likes if they behave badly can be used to reduces his/her challenging behavior. | | | |
| 9 | Beating or slapping a child with difficult behavior is a positives way to reduce the child behavior | | | |
| 10 | It is possible for a child's problem behavior to occur only at certain time, places or toward certain person | | | |
| 11 | Parent of children with difficult behavior may feel better if they can say positive thing about the child | | | |
| 12 | Praising a child for doing well can be a good way to encourage the child to behave better. | | | |

SECTION E: Training intervention satisfaction questionnaire

1. How would you rate the training program

   (1) Poor Fair ☐ (2). Good Excellent ☐

2. Did you get the kind of help you wanted?

   (1) Not at all ☐ (2) not really ☐ (3) Yes, someho☐ (4) Y☐

3. To what extent did the training program met your needs?

(1) Met none of my needs (2☐et only a few (☐Met most of my needs (4)☐t

almost all my needs ☐

4. If a friend had stress problem, would you recommend the raining program to him/her?

2 Definitely not ☐No, probably not ☐Yes probably ☐

(4) Yes Definitely ☐

5. How satisfied are you with the help you received?

   1. Very dissatisfied ☐(2) Quite dissatisfied ☐(3) mostly satisfied ☐

4) Very satisfied ☐

6. Has the training program helped you to cope better with caring for your child/ward?

   (1) Not at all ☐ (2) No it didn’t really help really ☐ (3) Yes, a litt☐

   (4) Yes a lot ☐

7. Overall, how satisfied are you with the program

   (1) Very dissatisfied ☐ (2) Quite dissatisfied☐ (3) mostly satisfie☐

(4) Very satisfied ☐

8. If you were to need help again, would you come back to

(1) Definitely not ☐ (2) No, probably not ☐ (3) Yes probably ☐

(4) Yes Definitely ☐

9. What I like best about the program

________________________________________________

________________________________________________

10. The topics/aspects I like best

________________________________________________

________________________________________________

11. The topics/aspects I didn’t really like are

________________________________________________

________________________________________________

12. My suggestions to improve the training program are:

________________________________________________

________________________________________________

# APPENDIX C

## BEHAVIOURAL INTERVENTION MANUAL FOR AGGRESSION IN ASD

Brief group - based intervention for caregivers of children with autism and aggressive behaviours in Nigeria.

### Treatment Protocol

By

Dr. Cornelius Ani

This protocol for caregivers of children of autism was delivered for 3 weeks. The protocol is based on previous works including Durand and Cummins (1998) and Iwata and Dozier (2008).

The main aim of this intervention is to reduce challenging behaviour. This intervention protocol, was subjected to various changes in order to adapt it for use with caregivers in Nigeria. The changes below were made:

1. Group format was used as this is more accessible to young people in developing countries
2. The number of sessions was reduced to 3 as more sessions are not feasible presently in a Low income country such as Nigeria.
3. The language and examples used were simplified, adapted and translated to meet the needs of the participants.
4. Religious themes were incorporated as appropriate due to prevalence of high religious coping in Nigeria.

## BACKGROUND

Caregivers of children with autism spectrum disorders has been reported to experience a lot of stress and face numerous challenges while caring for their children which may however not be unrelated to the challenging behaviours displayed by these children (Divan et al, 2012).

Hence Functional Behaviour Assessment (FBA) is a reliable technique in understanding a behavior and those factors that influence it. It is based on the fact that human behaviours serve a "function" so understanding and identifying the functions of such challenging behaviours, can provide opportunities to modify the triggers or maintaining factors of such behaviours. FBA has been shown to be effective in the management of challenging behavior in children with autism spectrum disorders thereby reducing the psychological distress and burden of care of caregivers. Due to the reduced resources and socio- cultural differences in a developing country like Nigeria, it is not certain if some standard strategies on FBA would be feasible. The concept of how FBA translates into local language, the optimum number of sessions to produce efficacy in a low income settings and the minimum level of therapist's expertise are all areas that need to be explored.

The process involves:

1. The behaviour would be specified in a precise and reliable way.

2. Identifying possible triggers of the behaviours which may include (1) Positive events which can be objects or sensory stimuli, (ii). Negative events (e.g. tasks) that when removed immediately after a challenging behavior can increase the index behavior.

3. During the process of functional analysis, the information gathered allows identification of triggers of problem behavior and help reduce the likelihood of recurrence of the index behavior.

In this program's intervention the sessions are divided into three, each session per week. The first session deals with the general concept of Autism Spectrum Disorders which includes what autism is, its prevalence rate, how to recognize early signs of autism, myths about autism and the different management options.

The second session focuses on the what psychological distress and burden of care involves, explaining the causes. In this session also, what constitutes challenging behaviour, possible triggers of such behaviour and how to manage challenging behaviour using Functional Behavioural Analysis (FBA) will be discussed and practicalized by having a role play showing how to effectively manage challenging behaviour using FBA.

The third session will be used to review and reinforce important messages/ lessons learnt in the first two sessions and caregivers will be encouraged to apply all lessons learnt, adhere to medication advice and always keep follow – up appointments.

## RATIONALE FOR CHOICE OF SESSION CONTENTS

This programme aims at using psychoeducation and a Functional Behavioural Analysis brief group – based intervention which will be both effective and feasible in a developing country like Nigeria. So this programme has been package in a way that it will be easily delivered by a professional with a non – specialist expertise in FBA.

The first session focusses on Psychoeducation of caregivers on the general concept of ASD because proper understanding of ASD by these caregivers will help de – mystify ASD and give them ray of hope that there is possibility of improvement in their children's condition.

The second session stresses on how caring for these children can led to psychological distress and burden of care in caregivers. It also focusses on FBA, its principles of operation and goes on to help parents identify potential triggers and maintaining factors for challenging behaviours in their children. There will be group interview with caregivers based on group interview pointers adapted from Iwata and Dozier (2008).

The essence of the interview is to identify unique antecedents and consequences in child's environment that are linked to challenging behaviours. The group interview will include questions such as:-

1. What event was occurring before the challenging behaviour seem to predict its occurrence of the behaviour?
2. What event occurred just before the challenging behaviour that seem to predict non-occurrence of behaviour?
3. What are the consequences that seem to be the maintaining factors for the behaviour?

4. What appropriate behaviour might produce the same consequences as the index behaviour?

The role play include in this session, will further show how effective applying FBA in a LMIC setting is. After the role play, caregivers assisted by the therapist are expected to be able to identify triggers and maintaining factors of challenging behaviours and this would help in the reduction of psychological distress and burden of care of these caregivers.

Session three focusses on helping the caregivers see the practicality of the FBA and the applicability of psychoeducation in reduction of psychological distress and burden of care. The importance of keeping medication advice and follow – up appointment will also be further stressed.

INSTRUCTIONS FOR THERAPIST

Please use this manual as a guide. Key areas are to be focused on and principles that serve as guides for the analyzing the challenging behaviours are provided in the manual

So encourage each caregiver to work on specific difficulties relating to their own child and bring these to the sessions.

Each session spans between 1 – 2 hours. The manual at times suggest specific time intervals for each activity, Try to adhere to these timings to avoid the sessions running overtime as this may discourage the caregivers from future participation or missing out some steps in sessions. The caregivers are encouraged to practice what they have learnt in the sessions at home and any difficulties discussed during the next session.

Materials Required:-

- A memo pad for each caregiver to jot down things learned during the sessions, those who cannot write will be assisted by the research assistants.
- A flip chart
- Marker Pens
- Soft drinks, Water and Snacks
- A private, spacious and quiet room to accommodate 40 caregivers.

## (A) INTRODUCTION AND GROUND RULES

Start the first session with an introduction of yourself, each member of the group and set the ground rules for the sessions.

### INTRODUCTION:

Introduce yourself and ask each member of the group to do same using their first name only. Ensure the introduction is non- threatening by asking them to avoid saying things about themselves which may be embarrassing to themselves. It may be sufficient for them to simply say their names only.

To reduce caregivers anxiety, inhibition and help them relax, sing a well-rehearsed welcome song which is popular, local, soul-lifting that is acceptable to all in the group irrespective of their religious affiliation. Start the song and encourage the caregivers to join in singing. After the song, appreciate them all for singing so melodiously.

Time: 5 mins.

## GROUND RULES FOR EACH SESSION

Time: 5 mins

1. Please be punctual for all sessions by arriving g on time.
2. Proper attendance in all the three weeks of programme as each week, will build on previous week activities.
3. Respect each other by not interrupting or shouting other people down when they have the floor to share their experience.
4. Avoid side talks during sessions.
5. Be honest and ready to share experience as regards caring for children with autism.
6. Be **CONFIDENTIAL** only share what you have learned with other people if you so desire but DO NOT mention names of other caregivers.
7. Do NOT share what you have learned with other caregivers until after the end of the programme. (Intervention group only).
8. Do all practice exercises as this will enhance learning
9. There will be regular breaks and refreshments.

Ask caregivers to add more to the ground rules if they so desire.

**B. PSYCHOEDUCATION** on general concept of autism, giving hope and strength.

The caregivers will be reminded of the purpose of inviting them to the programme since they might have forgotten or not sure what the programme is all about or what they stand to benefit from the programme or the course the programme will follow. They will be given an overview of the general concept of autism which includes the prevalence rate as this will help the caregivers develop a better sense of relief and hope as they will now know that they are not alone with their children.

Knowledge about the management options, will give the caregivers further relief that their children's behaviour will improve and they will see also what they can do to help such improvement.

PURPOSE OF SESSION ONE: Help caregivers to:

1. Understand what ASD is.

2. Understand some treatment options.

3. Encourage themselves with positive self-talk.

Time: 35 mins

Say,

You were invited to take part in this programme because you have a child who has a condition called autism and their behaviour makes you worry so much that it causes psychological distress and burden to you. This session of the programme is intended to help you understand more about autism, the strength and challenge that these children may have.

Say,

Think of your child without focusing on their present challenge. Try to identify one or more good things about your child. It does not matter how big or small, just try and identify at least one good thing your child possess.

Acknowledge that it may not be easy for some caregivers to think of something positive about their child with autism exhibiting challenging behaviour (which has contributed immensely to their psychological distress and burden of care) but encourage each caregiver to try hard and identify at least one good thing about their child.

As each caregiver identifies an attribute of their children, write it on the flip board against child's name. If identifying a good attribute is difficult for a caregiver, expand the search for such to include positive attributes held by other people about the child (for example the child is beautiful, handsome, loved by family members).

At the end of this exercise, ask each caregiver to write the identified attribute of their child on the flip board to the memo pads given to each of them as this will be used as positive self-talk for example, “Although Funmi has autism and the burden of caring for her is enormous, she is loveable and beautiful” (those who cannot write, will be assisted to do so by the research assistants).

Say,

What we say to or about ourselves and our children has powerful effect on us and our children. If we think only of the challenges our children has and start making bad comments about ourselves, this will weigh us down and we will feel upset which will lead to more psychological distress and burden of care of our children. But if we say positive things about ourselves and our children, we can make ourselves feel more positive and help us see our children’s behaviour in a positive light which in turn will help reduce the psychological distress we experience and the burden of care of our children.

Say,

Since we have seen how important it is for you (Caregivers), to have positive view of yourselves, it is now time to learn about autism spectrum disorders.

Please pay rapt attention to this brief lecture that discusses what autism spectrum disorder is, the risk factors, prevalence rate, myths, early detection of autism and the management options. At the end of the discussion, if you have any question or need any clarification, please feel very free to ask and I will be very happy to answer your questions or give you clarification.

After answering all the questions raised and giving needed clarification, Read the key messages aloud and ensure all the caregivers understand them. Check that every caregiver has two or more suggested

Positive self- talk. Then ask caregivers simple and non-technical questions to assess their understanding of the lecture.

Key Messages

1. 1: 100 child has autism hence they are not alone.

2. They and their children have strengths despite the challenging behaviour of their children

3. What we say about ourselves and our children has either positive or negative effects on the psychological wellbeing and care of these children.

4. Challenging behaviours can improve with effective management options.

PRACTICE

Say,

The importance of practicing the skills you learn in this group cannot be overemphasized. You have to carry out the brief activities demonstrated during this sessions on your own at home. You can think of the skills you learned in this programme as tools to use in your everyday life to improve your child’s behaviour. By trying out your new acquired skills at home, while you are still coming to this programme and making reports on your progress, we will know what works for you and what does not and then we can come up with ways to make them work better.

Each session consists of one or more things to practice at home.

PRACTICE FOR SESSION ONE

- Repeat your two or more positive attributes about your child and yourself every day. Try and add more before next session.

- The challenging behaviour of your child will improve.

Appreciate all caregivers for their patience and then give light refreshments.

## SESSION TWO

Understanding what contributes to psychological distress and burden of care among caregivers - Challenging Behaviour, How to identify triggers of challenging behavior using Functional Behavioural Analysis (FBA).

This session helps caregivers to understand the main contributor of psychological distress and burden of care among caregivers which is challenging behaviour. It will help understanding the principles of FBA by explaining the idea that human behavior have a "Function" and that the "Function" of challenging Behaviour can be identified in a systematic way that can help in the reduction of the behaviour.

During this session, the caregivers will be assisted in analyzing their child's challenging behaviour, identifying the purpose of the behaviour and how these analysis can help reduce the challenging behaviour.

### PURPOSE OF SESSION TWO

1. Understand the major contributor of psychological distress and burden of care among the caregivers.
2. To identify the principles that challenging behaviour have a function.
3. To identify the function and maintaining factors of challenging behaviour by exploring the antecedents and consequences of the behaviour.

4. To devise a simple behaviour management plan based on the above analyses.

Instructions to therapist:

Check how the caregivers found the practice task after session one and trouble shoot any problems identified.

Introduce session two, by explaining the purpose of the session to the understanding of all the caregivers. The aim is for all the caregivers to be able to identify one trigger and / or maintaining factor for the child's aggressive behaviour that could be used to formulate a functional behaviour management plan. The triggers / antecedents explored includes locations, Times, Persons present, Physiological (e.g. Pain), Demands, Attention, Tangible gains or an Avoidance of tangible consequences.

Say,

In the first session, we explained that there are techniques for identifying the reasons why a child with autism may have challenging behaviour so use this information to make the behavior better.

Say,

Human behaviours serve a purpose or function for the person. In persons with autism and learning difficulty, it may be difficult for them to tell us what the purpose of the behaviour is. However, there is a special technique that can help us work out the reasons for the behaviour. This information can help us find ways to make the behaviour less likely to occur.

Say,

The techniques starts by finding out as much information as possible about the things going on before the challenging behaviour starts and we call this "Antecedents". The next step is to find out how the behaviour usually ends this we call "Consequence". So by exploring the "**A**ntecedents", the actual "**B**ehaviour" and the "**C**onsequences", we can help to identify the reasons why the behaviour starts and what keeps it going. We can call this technique **ABC** (using the first letter in the name).

Say

We are now going to put this in action for each parent. This involves asking the caregivers together a number of questions. Please answer as it applies to your child. Please think carefully and ask questions if this is not clear.

Describe the situations in which the challenging behaviour is **most** likely to occur in terms of:

Days/Times ___________________________________________

Location/ places _________________________________________

Persons Present at the time _____________________________________

Activity the child is doing _______________________________________

What happens just before the challenging behaviour occurs ___________________

Describe the situations in which the behavior is **least** likely to occur:

Days/Times ______________________________________________________________

Location/Places __________________________________________________________

Persons Present___________________________________________________________

Activity the child is doing _________________________________________________

Explore possible triggers in more details

Ask,

The following questions and check that every caregiver has taken time to think about it and provide an answer. If the initial answer is "YES", ask the caregiver to provide more details to clarify the full circumstance. For example, if the caregiver answers "Yes" to

whether the behaviour results in the child getting more of what he/she wants, get more details of the thing the child gets that he/ she wants. Some of the questions are asked twice in different ways. This is deliberate to help caregivers who may not understand the question when asked in one style.

Could the behaviour be the result of any form of discomfort (e.g. response to pain)?

Could the behaviour be a sign of lack of a basic need (e.g. Thirst, hunger, lack of rest)?

Could the behaviour be a side effect of medication?

Could the behaviour be the result of a medical condition (e.g. Seizures)?

Are there any circumstances in which the behaviour is more likely to occur?

Are there any circumstances in which the behaviour is less likely to occur?

Does the behavior occur whenever you stop attending to the child?

Does the child seem to do this behaviour to upset anyone or annoy you when you are not paying attention to him / her (e.g. sitting in a separate room, interacting with another child) as if he seem to do this behaviour to get you to spend more time with him or her?

Does this behaviour ever occur to get a toy, food, or drink?

Does this behaviour occur when you take away a favorite toy or food or drink?

Does this behaviour stop occurring shortly after you give the child a toy or food or drink?

Does this behaviour seem to occur when the child has been told that they can't do something they wanted to do?

Does it occur at certain times of the day?

Does the behaviour occur only with certain people?

Does this behaviour occur following request to him/ her to perform a difficult task?

Does the behaviour occur when request is made for him/her to do something?

Could the behaviour be related to any problem with your child not being able to communicate his/her needs?

Is the behaviour related to any particular activities?

Is the behaviour in response to upsetting situations (e.g. being ignored, being asked to do something , too much noise, too many people in the room, too much darkness/lighting, change in routine, moving from one activity to another, being given food he/she does not like, being made to wear clothes he/she dislikes etc.)?

Possible Consequences

Does the behaviour allow the child to gain something (e.g. Does he/she get to do what he/she prefers/ wants)?

Does the behaviour allow the child to avoid, or escape from an upsetting situation (e.g. what he/she does not want to do, social interaction, pain etc.)?

Does the behaviour provide self- stimulation (e.g. does it happen more when he/she is bored)?

Does the behaviour occur as a result of his/her favourite activity being stopped?

Are there some alternative behaviours that could be strengthened as a replacements for the child's challenging behaviours? If so, please suggest them below.

Possible replacement behaviour

1. ____________________________________________

2. ____________________________________________

3. ____________________________________________________________

4. _____________________________________________________________

Things the child prefers or likes to do

List things that appear to be your child's preferences that might be used therefore as rewards to encourage more appropriate behaviour.

1. People they like to spend time with ________________________________
2. Activities they like (Toys, Games, T.V) ________________________________
3. Food, snacks and drinks they like _____________________________________

At the end of the above discussions, help each caregiver to complete the following

1. The Challenging BEHAVIOUR (e.g. tantrums, aggression, non- engagement, non-compliance):
2. SETTING/PLACE (e.g. time, location, transition) where it happens most:
3. ANTECEDENTS (e.g. hunger, pain, demands made on him/her to do something or stop an activity):
4. CONSEQUENCES (e.g. end of activity, he gets attention):
5. FUNCTION (e.g. 1.Gain something: 2. Avoid something/ escape: 3. Increase/decrease stimulation):

Now help the caregivers to write a **Statement of Function (SOF)**, which communicates the function of the behaviour and provides information relevant to making effective intervention decisions. The SOF should include (a) The target behaviour of concern, (b) the identified antecedent(s), any person identified from the analysis who appear to be influencing the behaviour positively or negatively, (d) the function(s) of the behaviour, (e) preferences that could be used as reinforcers/rewards, and(e) any other additional information that may help understanding the statement.

To make the lessons learnt more effective and drive home all points learned, Use the research assistants to demonstrate effective behavioural management plan through role play.

ENDING SESSION TWO

Say,

1. Today we have discussed how to analyse your child's behaviour to identify the possible reasons that make it to occur and keep them going. We summarized the results for your child (see Statement of Function). We have also shown you through this well-rehearsed role play how to go about the management plan. The next step is to use this information to find a way to start helping you to reduce the challenging behaviour your child shows as this will help reduce the psychological distress and burden of care you experience as a result of caring for your child.

2. Read the key messages aloud.

3. Ask the caregivers if they have any questions or comments or need clarifications.

Key Message

Behaviour can be analysed to identify the reasons behind it by looking at the Antecedents (what happens before the challenging behaviour starts) and the Consequences (how the behaviour ended).

PRACTICE

Read the Statement of Function arrived at for your child every day and check if it feels accurate for your child or if something important has been missed out.

Continue to make positive comments about your child and yourself at least once a day.

Remember to keep trying to add more positive comments.

Remember to bring your memo pad to the next session.

SESSION THREE

Conclusion of the Training Programme

Say,

I welcome you all to this last session of the educational programme. I thank you all finding time to attend despite the fact that you all are very busy people. I'll sing to you a song of appreciation.

Sing a local well known song that is acceptable to all the caregivers irrespective of their religious inclination, ask them to clap for themselves for being excellent caregivers who wants the best for their children.

Then review the key messages from each session and check that every caregiver, has positive self-talk.

Do a formal ending, obtain the first post intervention measures and allow the caregivers to say their good byes.