EFFECTS OF PSYCHO-EDUCATION ON PSYCHOLOGICAL DISTRESS AND BURDEN OF CARE ON CAREGIVERS OF CHILDREN AND ADOLESCENTS WITH EPILEPTIC SEIZURES IN THE FEDERAL NEURO-PSYCHIATRIC HOSPITAL, BENIN

BY

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MATRIC NO:201265

A PROJECT SUBMITTED TO THE CENTRE FOR CHILD AND ADOLESCENT MENTAL HEALTH (CCAMH), IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE IN CHILD AND ADOLESCENT MENTAL HEALTH (MSC.CAMH) OF THE UNIVERSITY OF IBADAN

MAY, 2018

Supervisors' attestation

This is to attest that this project was supervised by us:

………………………….

Dr Cornelius Ani

Imperial College London, London

………………………….

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DECLARATION

I hereby declare that the project entitled “THE EFFECTS OF PSYCHO-EDUCATION ON PSYCHOLOGICAL DISTRESS AND BURDEN OF CARE ON CAREGIVERS OF CHILDREN AND ADOLESCENT WITH EPILEPTIC SEIZURES IN BENIN CITY”, in partial fulfilment of the requirement for the award of the degree of Master of Science in Child and Adolescent Mental Health (MSc. CAMH) of the University of Ibadan .is a record of bonafide project work carried out by me under the guidance and supervision of Drs’ Cornelius Ani and Haleem Abdurahman. I further declare that the work reported in this project has not been submitted and will not be submitted either in part or in full for the award of any other degree or diploma in this institution or any other institution or University.

Yours Signature of Candidate

Nkechi Agnes IGBINIGIE

Date 12th October, 2018

DEDICATION

This work is dedicated to all caregivers of children and adolescent with epilepsy all over the world especially those who gave consent to partake in this research, for their continuous love and care for their children despite the huge burden and stress associated with this onerous task

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LIST OF ACRONYMS

Acronyms	**Meanings**
APA	American Psychiatric Association
AED	Anti-epileptic Drug
ASD	Autism Spectrum Disorder
ANOVA	Analysis of Variance
BF	Blood film
BMP	Behaviour Management Plan
CRA	Carers Rights Association
CAMH	Child and Adolescent Mental Health
EEG	Electroencephalogram
ESD	Epileptic Seizure Disorder
FBA	Functional Behaviour Analysis
GHQ12	General Health Questionnaire12
HADs	Hospital Anxiety and Depression scale
ILAE	International League Against Epilepsy
ID	Identification
KOEQ	Knowledge of Epilepsy Questionnaire
LAMIC	Low and Middle Income Countries
MP	Malaria Parasite
PWE	People with Epilepsy
SOF	Statement of Function
SDQ	Socio-Demographic Questionnaire
WHO	World Health Organisation
ZBI	Zarit Burden Scale.

ABSTRACT

Background: Epilepsy is one condition widely reported as capable of causing psychological difficulties and distress to caregivers. Evidence has shown that social, psychological and behavioural aspects of epilepsy are among the least understood and most neglected in research in Low and Middle Income Countries (Ani et al 2011). This study investigated the effect of a psycho educational intervention that includes behavioural training intervention for caregivers to use functional behaviour analysis (FBA) to manage aggressiveness in children with epilepsy.

Methodology: The study used a pre and post design involving 40 caregivers of children and adolescent clinically diagnosed with epileptic seizure disorder. The sampling level of stress and anxiety were determined at baseline and repeated at immediate post-intervention and repeated at 2 weeks post intervention using the Hospital Anxiety Depression Scale, (HADS), and the Zarit Burden Interview (ZBI). The General Health Questionnaire (GHQ-12) and Knowledge of Epilepsy Questionnaire (KOE) were also administered at baseline and repeated at immediate post and 2 weeks post intervention. The intervention used comprised of (3) sessions. Each session consisted interactive lecture, group discussion and problem solving. While data analysis for the pre and post was performed using Statistical Package for the Social Sciences (SPSS version 20) software to achieve Summary and inferential statistics were used. Socio-demographic details of caregivers and their children were presented using numbers and proportions for categorical variables, percentages for continuous variables and Mean and Standard Deviation for continuous measures. Comparison of the effect of the intervention was carried out using Repeated Measures ANOVA of the outcome variables at three time points (baseline, immediate post and second post intervention). At a level of significance of (0.005)

Results: The social demographic characteristics of the respondents showed that 28 (70%) of them attained secondary education, 34(85%) were currently employed and 31(77%) lived in a monogamous family setting and about one third of the respondents 27(67%) were currently married. The predominant occupation among the respondents was trading / business 20(58%) while the characteristics of the respondents' spouses showed that 36(90%) were currently employed. There was a significant reduction in mean HADS scores from baseline to two weeks post intervention (Mean diff: 7.786, P = <0.001) and from immediate post intervention to two weeks post intervention (Mean diff: 4.536, P = 0.025). ZBI also showed a significant reduction in mean Burden of care scores from baseline to immediate post intervention, and baseline to two weeks post intervention time point (Mean diff: 14.143, P = 0.004) and (Mean diff: 20.643, P = <0.001) respectively. These findings indicate significant reductions in anxiety and depression, and burden from baseline that were sustained through to the second post intervention assessment. The study also found a significant decline in the proportion of caregivers meeting the cut-off for psychological distress on the GHQ between the immediate post intervention time point 33(91.7%) and two weeks post intervention 19(67.9%) which was statistically significantly (p<0.001). However, there was no significant change in Knowledge.

Conclusion: Findings from this study show that training that includes behavioural intervention for managing aggression can be associated with reduced anxiety and depression, as well as burden for caregivers of children and adolescents with epileptic seizures. Therefore, supporting caregivers of children with epilepsy with such training could go a long way in reducing the burden of care on the family.

Key words: caregivers, epileptic seizure, children and adolescent, behaviour training intervention, burden, psychological distress.

Word count: 563

CHAPTER ONE

INTRODUCTION

1.1 Background of the study

Epilepsy can cause psychological difficulties and distress to caregivers of patients suffering from the condition. There has been acknowledgement that the social, psychological and behavioural aspects of epilepsy are among the least understood and most neglected in epilepsy research (Hermann and Jacoby, 2009).

Epilepsy has been described as a condition that is characterized by an 'emotionally straining experience' (Ryan and Raisanen, 2012), and can cause severe burden for People with Epilepsy (PWE) and their Carers (Canuet et.al. 2009 Schechter, 2006; Wang et.al.2009). There is also misconception among some people that the disease is caused by evil spirits, witches or that the child is demon-possessed or that it was contagious and could be passed on to others through the evil breath of the person suffering from the illness (ILAE, 2003).

Studies have shown that caregiving can have negative consequences on the health of family caregivers. These include fatigue, sleep problems, depression, anxiety, and burnout (Hudson et.al, 2010). Studies also indicate that epilepsy may cause high levels of psychosocial difficulties for all family members, including stigmatization, stress, psychiatric morbidity, marital problems, poor self-esteem and restriction of social activities (Neil et al, 2000)

1.2 Statement of the problem /justification

Emotional distress among caregivers has been defined as mood disturbances like anxiety, depression, feeling of loneliness, isolation, fearfulness and being easily bothered – all arising from providing care for a sick relative (Medalie, 1994). A study done by Y O Oshodi et al (2011) showed that of the fifty three caregivers relatives in the study, half of them had psychological distress (43.8%) and (63%) had more burden. The mean score among the caregivers was 41(±18.6SD) with scores ranging from 0.00-89.00 and 45.3% of relations experiencing more than average burden of care. This shows there is a significant level of burden and psychological distress experienced by caregivers in this study location.

Across more than 20 studies published in the past decade, there was consistent evidence that caregiving placed family members at risk of depression (Deimling et al, 2001). In fact caregivers had higher rates of depression than the general population (Jackson and Cleary, 1995).

Multiple studies have shown that the incidence of depression in caregivers is high ranging from 18 to 47%, and caregivers who are depressed experience higher degrees of burden (Lawton et al, 1991)

Despite being the fourth most common neurological condition, caregiver burden in epilepsy has attracted disproportionally less attention than in less prevalent neurological conditions such as Alzheimer's disease, multiple sclerosis, Parkinson's disease and amyotrophic lateral sclerosis. (Karakis *et al* 2014).

The diagnosis of epilepsy in their children can lead to stress in parents, resulting in higher divorcee rate (Michael et al., 2007). Focus by parents on the child with epilepsy can result in poor relationships between the child with epilepsy and siblings and psychological difficulties among siblings. Such focus can also affect family cohesion and relations between the family and their community. It can result in people with epilepsy growing up to make poor parent themselves (Buchanan N, 2002)

Studies have identified that carers' wellbeing is associated with their caregiving capacity; that is, poorer wellbeing affects propensity to provide adequate support, which in turn is believed to be influential in shaping patients' prognosis and relapse rates (Smith et al, 2014). Therefore based on the stress-appraisal-coping theory as applied in family caregiving (Szmukler et al, 1996), it has been long hypothesised that, psychoeducation, with education as its core features and prime aim, works directly in improving carers' knowledge about epilepsy and related caregiving issues.

1.3 Aim

This study aimed to assess the effect of psychoeducation on caregivers of children and adolescent with epileptic seizures attending the Federal Neuropsychiatric Hospital Benin

1.4 Specific Objectives

1. To determine baseline psychological distress of caregivers of children and adolescents with epileptic seizures.
2. To determine baseline burden of care of caregivers of children and adolescents with epileptic seizures
3. To evaluate the effect of psychoeducation on psychological distress experienced by caregivers of children and adolescents with epileptic seizures.
4. To evaluate the effects of psychoeducation on burden of care experienced by caregivers of children and adolescents with epileptic seizures

1.5 Null hypotheses

There would be no significant difference in the measures of psychological distress of the caregiver's of children and adolescent with epilepsy pre and post intervention.

CHAPTER TWO

LITERATURE REVIEW

2.1 Definition and description of epileptic seizures

A seizure is a brief change in normal electrical brain activity, resulting in alterations in awareness, perception, behaviour or movement (Fischer *et al.*, 2014). Seizure affects persons of all ages but are particularly common in children

A seizure is also defined as an uncontrolled electrical activity in the brain which may produce a physical convulsion, minor physical signs, thought disturbances, or a combination of symptoms, seizures can be caused by head injuries, brain tumours, lead poisoning, and maldevelopment of the brain, genetic and infectious illness and fevers (Khair 2015). Another definition of seizure is a sudden attack (as of disease) especially the physical manifestations (as convulsions, sensory disturbances, or loss of consciousness) resulting from abnormal electrical discharges in the brain (as in epilepsy).

Epilepsy on the other hand is any of various disorders marked by abnormal electrical discharges in the brain and typically manifested by sudden brief episodes of altered or diminished consciousness, involuntary movements, or convulsions (Khair 2015).

However epilepsy was defined conceptually in 2005 as a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures. (Fisher *et al* 2014) This definition is usually practically applied as having two unprovoked seizures less than 24 hours apart. The International League Against Epilepsy (Fisher et *al* 2014) further recommended through a task force to alter the definition for the special circumstances that do not meet the two unprovoked seizures criteria

. Therefore the task force proposed that epilepsy to be considered a disease of the brain defined by having any of the following conditions (1) At least two unprovoked (or reflex) seizures, occurring less than 24 hours apart; (2) one unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years or (3) diagnosis of an epilepsy syndrome.

According to WHO (Megiddo *et al*, 2016) Epilepsy is defined as a chronic disorder of the brain that affects people worldwide. It is characterised by recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body (partial) or the entire body (generalized), and are sometimes accompanied by loss of consciousness and control of bladder function

2.2 History of epilepsy

The history of epilepsy is intermingled with the history of human existence. The first reports on epilepsy can be traced back to the Assyrian texts; almost 2,000 B.C. At the beginning of the 18th century, the view that epilepsy was an idiopathic disease deriving from brain and other inner organs prevailed (Magiorkinis, et *al* 2014).

Epilepsy is the most common non-infectious neurologic disease in developing African countries, including Nigeria and it remains a major medical and social problem. Historically, epilepsy was believed to be a sacred disease that is the result of the invasion of the body by a god. It was thought that only a god could deprive a healthy man of his senses, throw him to the ground convulse him and then rapidly restore him to his former self again.(Reynolds,1988).

The history of epilepsy can also be traced back to the Holy Bible in the book according to Saint Mark, (Saint Mark’s Gospel, Chapter 9, and verses 17-27) which described it as a foul spirit that was cast out of a young man with fits. The ‘Dictator Perpetuus’ of the Roman Empire, the great

Julius Caesar likely had Epilepsy on the basis of documented four attacks that were probably complex partial seizures. Also it is possible that he had absence attacks as a child and a teenager. It is also alleged that his son and other relatives also had seizures. The aetiology of epilepsy in this Julio-Claudia family is probably linked to inheritance (Hughes, 2004). This historical legacy has continued to influence public attitude to epilepsy making it a dreaded disease. These beliefs have resulted in patients with epilepsy (PWE) being ostracized, stigmatized and misunderstood (Hughes, 2004).

2.3 Patterns / types of epilepsy

Seizures are categorised into simple and complex seizures, this categorization is important for determining treatment and prognosis. Seizures are associated with varying degrees of stigma and discrimination due to their obvious manifestation. For example, Partial seizures are less stigmatizing as they are often concealable while Focal and Generalized are obvious and associated with more burden.

When a seizure is associated with a specific cerebral location, that is, concentrates in a region of discharging epileptogenic foci (a discrete area of the brain wherein the electrical discharges that give rise to a seizure originate), it is called partial seizure and these are further sub classified into simple and complex seizures. There is also partial seizure with secondary generalization. Generalized seizures (which are all complex) include absence seizures or petit mal, tonic –clonic or grand mal seizures. There are also myoclonic seizures, and atonic seizures (ILAE 2010). The 2017 classification of epilepsy (ILAE 2017) shows that there are now 3 major groups of seizures which are;

The Generalized Onset Seizures**:** **-** these seizures affect both sides of the brain or groups of cells on both sides of the brain at the same time. The term was used before and still includes seizures like tonic-clonic, absence, or atonic. In this type of seizure there is impaired awareness. The second group of seizure is the Focal Onset Seizures: **-** this term focal is used instead of partial to be more accurate when talking about where seizures begin. Focal seizures can start in one area or group of cells in one side of the brain. This focal onset is subdivided into two (a) Focal Onset Aware Seizures; this is when a person is awake and aware during a seizure, which is called a focal aware seizure. This used to be called a simple partial seizure. (b) Focal Onset Impaired Awareness; when a person is confused or their awareness is affected in some way during a focal seizure, which is called a focal impaired awareness seizure. This used to be called complex partial seizure. The third group of seizure according to the new classification of seizure type basic version is the;

Unknown Onset Seizures: when the beginning of a seizure is not known, it is now called an unknown onset seizure. A seizure could also be called an unknown onset if it is not witnessed or seen by anyone, for example when seizures happen at night or in a person who lives alone.

As more information is learned, an unknown onset may later be diagnosed as a focal or generalised seizure.

This new classification simply separates the different symptoms that occur during a seizure into groups that involve movement.

For generalized onset seizures**:**

Motor symptoms may include sustained rhythmical jerking movements (clonic), muscles becoming weak or limp (atonic), muscles becoming tense or rigid (tonic), brief muscle twitching (myoclonus), or epileptic spasms (body flexes and extends repeatedly).

Non- motor symptoms are usually called absence seizures. These can be typical or atypical absence seizures (staring spells). Absence seizures can also have brief twitches (myoclonus) that can affect a specific part of the body or just the eyelids

For focal onset seizures**:**

Motor symptoms may also include jerking (clonic), muscles becoming limp or weak (atonic), tense or rigid muscles (tonic), brief muscle twitching (myoclonus), or epileptic spasms. There may also be automatisms or repeated automatic movements, like clapping or rubbing of hands, lipsmacking or chewing, or running.

Non-motor symptoms**:** Examples of symptoms that do not affect movement could be changes in sensation, emotions, thinking or cognition, autonomic functions (such as gastrointestinal sensations waves of heat or cold, Goosebumps, heart racing etc.), or lack of movement (called behaviour arrest.).

For unknown onset seizures Motor seizures are described as either tonic- clonic or epileptic spasms.

Non- motor seizures usually include a behaviour arrest. This means that when movement stops the person may just stare and not make any other movements (ILAE, 2017)

2.4 Prevalence of epilepsy

Epilepsy is a non-communicable disorder that affects people of all ages, and the most common non-infectious neurological disease in developing countries, including Nigeria (WHO 2000; Pandolfo, 2011). However, it has been noted that epilepsy is more common among older adults (Wyllie, 2011). In 2013 alone, for instance, about 22 million people world-wide were diagnosed with a new case of epilepsy (Global Burden of Disease Study, 2015). Nearly 80% of epileptic cases occur in developing nations (Murray, 2014). In 2013, it resulted in 116,000 deaths up from 112,000 deaths in 1990 (Bernke, 2011). People with epilepsy respond to treatment approximately 70% of the time. In Nigeria, people with epilepsy and their families suffer from stigma and discrimination (WHO, 2016).

An accurate estimate of all “seizures” in childhood is not available but it has been estimated that the life time risk of a seizure of any kind is about 8% (Hauser *et al*, 1993; Hauser, 1994). The lifetime risk of epilepsy is about 1%, an additional 1% will have a single unprovoked seizure that does not recur but it is unclear how much of the remaining 2% lifetime risk of a seizure is encountered in childhood. Provoked seizures seem to have little or no risk of recurrence once the provoking factor has resolved, with the exception of febrile seizures. The sequence of a provoked seizure followed later by epilepsy is uncommon.

Despite being a common neurological disorder, epilepsy seems to be the least understood and most feared disorder in most parts of the world, which is further complicated in developing counties by its attribution to demonic possession, and the perception that it is transmissible by contact (Ani *et al*, 2011).

The prevalence of epilepsy in childhood is approximately 0.5%. In industrialised countries, an average of about 50 per 100,000 children newly develop epilepsy each year. Children account for 25% of all new cases of epilepsy (Camfield and Camfield 2014). In developed nations, the onset occurs most frequently at infancy and old age (Wyllie, 2011), whereas in developing nations a new onset occurs more in older children and young adults. This disparity does not in any way suggest that different types of epilepsy exist between people in developed nations and those in developing nations. It means, however that the underlying differences are environmental factors rather than biological factor(s) (Newton, 2012).

Furthermore, research findings show that about 5-10% of people in the world will have an unprovoked seizure by the age of 80 (Wilden & Cohen-Gadol, 2012), and the chances of experiencing a second seizure are between 40%-50% (Berg, 2008). In developed nations, legal safety restrictions are placed on those with epilepsy, ranging from driving to swimming alone in a pool until they are free of seizures for a specific length of time (Delvin et al., 2012). Disability Acts that prohibit undue restriction and discrimination against people with disabilities protect people with epilepsy and make effective interventions available. These privileges are not available for people with epilepsy in Nigeria yet reliable evidence shows that nearly 80% of the people with epilepsy in the world live in developing countries like Nigeria (Devlin *et al,* 2012). Most cases of epilepsy are found in rural and sub-urban areas (WHO, 2002).

From the small number of community based studies available the point prevalence of epilepsy varies from 5.3 to 37 per 1000 in Nigeria (Osuntokun et al, 1987). A study done in a rural community in Udo, Edo state using a door –to-door survey, found a point prevalence of epilepsy of 6.2 per 1000 (Dada, 1989).

2.5 Effects of epilepsy on family

After a child has had several seizures and a diagnosis of epilepsy is made, parents/ caregivers often experience feelings of fear or worry, which is normal and understandable. Most people are afraid of the unknown. There may be overwhelming feelings of sadness or depression, as parents grieve for what they perceive as the loss of their "normal" healthy child. They grieve for the life changes that will come with having epilepsy. These feelings often precede a parent coming to terms with epilepsy and accepting it as just part of their child's life. Some parents feel it is somehow their fault or feel resentful about the new challenges and demands they will be facing, and then experience guilt for feeling this way (Sahu et al., 2014).

Although the negative effect of epilepsy on patient's psychological well-being has been increasingly documented in the last decade, the influence of the condition on the family has attracted much less interest (Ellis *et al*, 2000). This study examined the effects of psychoeducation on the psychological distress and burden of care among caregivers of children and adolescent with epilepsy, other studies have indicated that epilepsy can cause high levels of psychosocial difficulties for all family members including stigmatization, stress, psychiatric morbidity, marital problems, poor self-esteem and restriction of social activities. The attitude and perception of family members may be an important factor in the adjustment of the family (Ellis *et al*, 2000). Anxiety is common and parents or caregivers may have a number of overwhelming worries: will my child die? Will he be brain damaged or experience problems with development? Can I let my child play by himself? Can he go to camp or play football? What will my family and friends say? What do I do with my child? Along with all these concerns, parents also struggle with the unpredictability of seizures and often feel they have no control over what will happen. They worry about whether their child is safe while away from home. They worry that teachers or other adults will mishandle seizures or will make the situation worse by overreacting. Parents also worry about the potential side effects of their child's medications or the impact of missing school due to seizures and medical appointments (Sahu et al., 2014)

The effects of epilepsy extends beyond those with the diagnosis and impacts families , communities and society, the negative effects can be further magnified by individual coping styles and resources available to families of those with epilepsy (Sahu et al., 2014). Siblings of children with epilepsy are not left out of these negative effects of epilepsy on the family. Studies have shown that epilepsy has a severe impact not only in the patient's life, or immediate carers but in the lives of their siblings as well, (Tsuchie, *et al* 2006). This study found that 55% of the siblings of children with epilepsy were scared and 60.5% were sad after the diagnosis of epilepsy.

2.6 Stigma and discrimination associated with seizure disorders

The etymological origins of the word "stigma" takes us to ancient Greece, where the term denoted the branding or tattooing practiced on slaves, criminals and those deemed "outside" citizenship and disgraced. Over time, the word has evolved and acquired varying connotations (Thomas and Nair, 2011).

The sociologist Erving Goffman, defined stigma as an attribute that has the potential to discredit an individual, and the possession of which results in the "tainting" of social identity (Goffman, 1963). Those who bear a stigmatizing trait become targets for stereotypes built around that trait, prejudicial attitudes and discriminatory behaviour such as shunning, exclusion and punishment. For instance, irrespective of the type of epilepsy, this condition continues to have wide-ranging impacts on multiple domains of an individual's life. For example, a seizure that lasts only a few seconds can result in the complete loss of driving privileges, as Indian law still refuses licences to people with epilepsy (Thomas and Nair, 2011). A study done in the Eastern part of Nigeria showed that patients suffering from epilepsy are usually stigmatized in the Nigerian context. This stigmatization is borne by the various beliefs about the cause of epilepsy, and its attribution to witchcraft thereby dissuading them from seeking treatment in dedicated clinics (Nnanwuba *et al*, 2016).

Stigmatization of people with seizure disorders is a worldwide problem; the disorder is even more stigmatized than for instance –Parkinson's disease, multiple sclerosis or cancer (Daher, 2012). It carries a stigma that dates back to ancient civilizations. Many patients, doctors, and families say the stigma hampers public recognition and ability to raise money for research. While many public figures with cancer (or cancer in the family) are forthcoming about the illness, the same does not go for epilepsy or seizures (Daher, 2012).

The multiple levels along which stigma can be experienced contribute to the "burden" of epilepsy in ways that cannot necessarily be quantified using traditional measures such as mortality and morbidity measures (Morrell 2002). At the individual level, stigma can manifest itself in the form of diminished self-confidence, withdrawal, self-imposed isolation, financial loses and tendencies to internalize shame as well as negative perceptions of the self and of the disorder, all of which have numerous trickle-down effects on practically all aspects of an individual's life. At the level of larger social units, stigma is manifested in multiple ways. For instance, epilepsy-related stigma has the potential to influence social variables such as social integration with social networks and peer group activities (Deirdre *et al*., 2007). A young child with seizure disorder or epilepsy maybe refused continued access to education because social attitudes in educational institutions are prejudicial and discriminatory. Marriages may be halted by families if discovered that either of the partners has seizure. Employers may refuse employment to potential employees with epilepsy, or refuse advancement to existing employees with epilepsy /seizure. Nowhere is epilepsy associated stigma more disabling than in sub Saharan Africa where epilepsy rate far exceeds those in developed countries (Deirdre *et al*., 2007).

2.7 Emotional and psychological outcomes of seizure disorder

Fears and anxieties are common in virtually every one’s life, but for those who have epilepsy, fears and anxieties are usually much deeper than those of the average person (Vazquez and Devinsky, 2003). Epilepsy has many non-medical effects on the people with epilepsy, their family and community. Although epilepsy is a medical condition, the person with epilepsy also has to cope with its psychological and social consequences. The diagnosis of epilepsy on its own can result in severe psychological difficulties for the person with epilepsy (Beyenburg, *.et al.*, 2005). Grief at the realization of being disabled goes through stages of shock, anxiety, bargaining and denial, mourning and depression, internalized anger, externalized anger, acknowledgment and finally acceptance and adjustment. Such grief can occur either at onset or on realization of difference (Jacoby *et al*., 2004).

Other emotional states which may recur include anxiety at not knowing when the next seizure will occur and feelings of helplessness and lack of control. Guilt can result in affective disorder. Anxiety combined with guilt can grow to become depression. Lowered energy and vitality may result in disrupted sleep patterns, while defencelessness can lead to need to want to conceal, anger and bitterness (Beyenburg, *.et al.*, 2005).

The fact remains that epilepsy is a” hidden” or “invisible” disability without symptoms except during a seizure and it often has no apparent cause, which results in a fear of the unknown. This makes it easy to deny, leading to poor drug compliance and a refusal to alter life style. Being "hidden" denotes difficulty for other people to interact, and concealment makes it difficult to find other people with epilepsy for support (Hills 2007).

The emotional and psychological impact of a child's diagnosis of epilepsy for the family is an overwhelming experience which leads to stress for parents, resulting in higher divorce rate. Focus by parents on the child with epilepsy can result in poor relationship between the child with epilepsy and siblings. Such focus can also affect family cohesion and relations between family and their community. It can result in the people with epilepsy growing up to make a poor parent themselves (Austin *et al*., 1996).

A higher prevalence of learning disabilities and memory problems is found in people with epilepsy, often caused by co-morbidities such as brain damage. Attention deficits occur during seizures, especially during absence seizures in school children. Antiepileptic drug side effects of drowsiness and short attention span can affect educational achievement, and commonly exacerbated by polytherapy (Loring 2004). Studies showed that patients with epilepsy live with significantly higher levels of psychological distress, Sixty-seven percent of the people with epilepsy reported living with high levels of psychological distress and similarly, comorbidity of epilepsy with other psychological complications is very common (Khalid and Aslam 2011).

2.8 Caregiver burden resulting from patient's seizure disorder

Carers have been identified as persons closely involved with rendering care to a physically or mentally ill person who is too ill, or frail to be self-supportive (CRA 2012). Epilepsy is a chronic, unpredictable and frequently disabling neurologic disorder that poses numerous challenges and consequences at multiple levels. It imposes a significant toll to the patient in terms of personal suffering, to the family for daily assistance and to the society as a whole with regards to the morbidity and its socioeconomic repercussions (Karachis, *et al*., 2014).

Performance of care-giving role can adversely impact the health of Carers themselves with resultant physical, psychological, and emotional symptoms which may be severe enough to impair social and occupational functioning. Such adverse health impact arising from the caring role has been recognized in the psychiatric literature as "caregiver burden" and has been defined as a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual (Burns *et al.*, 2011).

Caregivers, unlike healthcare providers such as physicians and nurses, typically provide daily care for people with epilepsy. These caregivers' usually family members, friends, are responsible for making treatment decisions, providing support, and managing daily activities. Epilepsy has been found to be associated with caregivers and family member's quality of life, lifestyle, psychological health, social well- being and time away from their work. Also, limited knowledge on providing care has been associated with greater caregiver burden (Gupta *et al.*, 2012).

Burden of care is a multi-factorial construct which includes emotional, psychological, physical and economic impact as well as related distressing feelings such as shame, embarrassment, anger, feeling of guilt and self-blame (Awad et al., 2008). It is customary to describe burden as objective or subjective. Objective burden refers to changes in household routine, family or social relations, work, leisure, and physical health; while subjective burden consists of subjective distress among relatives, including impact on mental health (Awad et al., 2008). Family Carers have been described as forgotten patients and it was suggested that caregiver's symptoms such as mood swing, fatigue, headaches, joint pains and muscle pains, marital and family conflicts, and financial problems may be a reflection of caregiver stress in looking after a sick relative (Canning *et al*., 1996).

2.9 Definition of psychoeducation

Psychoeducation can be defined as the "process of teaching clients with mental illness and their family members about the nature of the illness, including its aetiology, progression, consequences, prognosis, treatment and alternatives" (Barker 2003 as cited by Srivastava et al 2016).

Psychoeducation has also been defined as "the education of a person with a psychiatric disorder in subject areas that serve the goals of treatment and rehabilitation". According to the American Psychiatric Association (APA 2006), psychoeducation includes cognitive, behavioural, and supportive therapeutic elements. According to WHO " psychoeducation refers to the process of providing education and information to those seeking or receiving mental health services, such as people diagnosed with mental health conditions (or life- threatening /terminal illness) and their family members" (WHO, 2016)

2.10 History of psychoeducation

The concept of psychoeducation was first noted in the medical literature, in an article by John E. Donley "Psychotherapy and re-education" in the Journal of *Abnormal Psychology*, published in 1911. The first use of the word psychoeducation appeared in the medical literature 30years later in the title of the book the *psychoeducation clinic* by Brian E. Tomlinson. New York. This book was published in 1941.

The popularization and development of the term psychoeducation into its current form is widely attributed to the American researcher C.M. Anderson in 1980 in the context of Schizophrenia. Her research concentrated on educating relations concerning the symptoms and the process of schizophrenia (Anderson et al, 1980). Similarly, the study is concerned with the psychological distress and burden of the carers, therefore, the need to educate the caregivers/family members of children with epilepsy on the symptoms, types, and emergency management of epilepsy and challenging behaviours associated with this condition. Also, her research focused on the stabilization of social authority and on the improvement in handling of the family members among themselves. Finally, C.M Anderson's research on behaviour therapy has its origin in the patient's relearning of emotional and social skills. In last few years systemic group programs have been developed, in order to make the knowledge more understanding to patients and their families.

Psychoeducation is an educative method based on clinical findings for providing information and training to families with psychiatrically ill persons to work together with mental health professionals as part of an overall plan for their ill family members. Imminent goals of psychoeducation are to prevent patients with severe mental illnesses from having frequent relapsing episodes of illness, ensuring medicine as well as treatment adherence, and to promote their re-entry into their home communities, with particular regards to their social and occupational functioning, to achieve these goals, psychoeducation programmes seek to provide families with the information they need about mental illness and the coping skills that will help them deal with their loved ones' psychiatric disorder. Therefore the goal of psychoeducation is to offer education and therapeutic strategies to improve the quality of life for the family while decreasing the possibility of relapse for the patient (Solomon, 1996). It has also been described as a "systemic didactic" psychotherapeutic intervention, designed to inform patients and their relatives about the disorder and to promote coping "(Lincoln *et al*, 2007). By strengthening the coping skills communication and problem solving abilities of the family, the well-being and adaptability of the individual and family members are expected to improve (Srivastava, 2016).

2.11 Theories supporting psychoeducation

The increasing emphasis on education for those with mental health problems is partially due to the consumer movement with its advocacy for an individual's rights and empowerment (Kane 1998). Psychoeducation covers a fundamental right of the individual to be informed about his or her illness (Colom & Lam 2005). These authors described psychoeducation as a therapeutic approach that does not focus on abnormality diagnosis, prescription, therapy, or cure, but on goal setting, skill teaching, satisfaction and goal achievement. Furthermore, Colom and Lam stated that psychoeducation focuses on compliance enhancement, early identification of prodromal signs, and the importance of life- style regularity, exploring individuals' health beliefs and illness-awareness, and enabling the individual to understand the complex relationship between symptoms, personality, interpersonal environment, and medication side-effects (Colom &Lam 2005). Psychoeducation is employed in many countries throughout the world, for example, the UK, Denmark, USA, France, Poland, Australia, South Africa, and Norway.

Morse (2004) explained that the theory behind psychoeducation is based upon individual psychology; a holistic approach to understanding what it means to be human. There are three strands embodied in individual psychology. Firstly, dynamic psychology, which is the study of emotional aspects, for example: motivation, purpose, fears, hopes, goals, and perceptions of self. Secondly, how to learn and acquire new knowledge and skills. Thirdly, developmental psychology, which incorporates biological substrata, organic factors, and individually unique maturational process. In addition to these three strands, Morse stated that participant's social interactions are considered to be crucial in the delivery of psychoeducation. Furthermore, Wood and colleagues described the importance of cognitive psychology in psychoeducation, as it involves challenging maladaptive thinking processes and suggesting alternative adaptive patterns of thinking (Wood et al 1999). These authors described the theoretical perspective of psychoeducation as integrated, holistic, multicultural, multimodal, functional, systemic, and comprehensive. This inclusive adaptive and flexible theoretical perspective underpins many different psychological educational interventions and has been applied in a variety of forms and situations, and to a variety of different mental disorders (Griffiths .2006).

Additional support for psycho-education also comes from an Iranian based randomized-control trial (Khoshknab *et al*, 2013). In this study 71 caregivers of patients with schizophrenia took part in a group psychoeducation therapy to reduce family burden on caregivers of Iranian patients with schizophrenia. The results showed that a 4-week group psychoeducation programme was significant in reducing family burden by more than one third.

2.12 Review on studies that have used psychoeducation

Studies have shown that psychoeducation programme for families /caregivers who care for relative with schizophrenia or other severe mental illness have been commonly used and found effective in research among western and Chinese populations (Chien 2008) when describing the successful psychoeducation programme used in their study, highlighted the importance of a family needs assessment, the encouragement of peer support between participants and adequate staff training as well as on-going supervision. Gidron *et al*, (2008) indicated that educational and supportive group participation of families who are caring for a relative with severe mental illness enhances the knowledge of the illness, its treatment and mental health services needed, and encourages the utilization of the social resources available and the employment of more frequently active help-seeking coping strategies. A randomized controlled trial conducted with a sample of 68 Chinese families of people suffering from schizophrenia in Hong Kong, who were randomly assigned to either a family psychoeducation or support group showed that both groups reported greater improvements in family and patient functioning and shorter lengths of patient hospitalizations at the two post-tests (one month and one year after completion of the intervention) (Chien 2008)

CHAPTER THREE

METHODOLOGY

3.1 Study Location

The study was carried out at the Out Patient clinic of the Federal Neuro Psychiatric Hospital Uselu Benin City Edo state, Nigeria, between January 2018 and March 2018. It is a stand-alone psychiatric hospital which offers inpatient, outpatient and community mental health services to ambulant and referred cases from Edo state and its neighbouring states. The Child and Adolescent unit of the hospital was donated by Rotary Club of Uselu and Commissioned 27th June, 1998. Services commenced almost immediately with in-patient care for adolescents while the out-patient services and all new cases were seen at the emergency clinic by a resident doctor who takes history and reviews with a consultant psychiatrist. Adolescents who present in emergency with active seizure disorder//epilepsy are placed on 24 hours observation and commenced on intramuscular diazepam along with anti-epileptic drug specifically sodium valproate.

Thereafter series of investigations Electroencephalogram (EEG), Liver function test (LFT), Blood film for malaria parasite test (BF/MP), Urinalysis for, microscopy, culture and sensitivity (m/c/s) are carried out. After the emergency care, if patient does not require in-patient care he/she will be booked to be seen by the Child and Adolescent Mental Health team (CAMH) on the next available clinic date. Any child with neurological complication is referred to University of Benin Teaching Hospital (UBTH) for the neurologist to see and continue management The child and adolescent unit runs clinic twice a week, where an average of 25 follow up and 5 new cases are attended to by the professionals in the clinic including, residents, consultants, nurses, Psychologist., the occupational therapist, and the social welfare officers.

The unit also has a system of making reminder calls to patients and their caregivers at least a day before the next scheduled visit, this has been effective as 85% of patients and Carers called respond and turn up for their various appointments.

3.2 Study design

The study was a one-group pre-post intervention study without a control group.

3.3 Study population

The study population are caregivers of children and adolescents attending the child and adolescent clinic of Federal Neuro Psychiatric Hospital. Uselu Benin City

3.3.1 Inclusion criteria

- Caregivers of children and adolescent between the ages of 6 years and 18 years
- Caregivers of children and adolescents who have been attending the clinic for up to 6months and consent to participate
- Caregivers of children and adolescents who have been on AED for 3 months or longer

3.3.2 Exclusion criteria

- Caregivers of children who have not been attending clinic for up to 6 months or defaulted for more than 6 months
- Caregivers with history of epilepsy or any psychiatric condition.

3.4 Sample size calculation

The sample size is based on the formulae:

$$n = \frac{\sigma_d{}^2 (Z_\beta + Z_{\alpha/2})^2}{\text{difference}^2}$$

where :

n = sample size

σ = standard deviation of the within - pair difference

diffference = clinically meaningful difference

Z_β = corresponds to power (.84 = 80% power)

$Z_{\alpha/2}$ = corresponds to two - tailed significance level (1.96 for $\alpha = .05$)

At a 1 standard deviation within pair difference and clinically significant difference in GHQ scores of 1 point, minimum sample size was calculated to be 40.

3.5 Sampling Technique

Consecutive sampling was used to recruit study participants from the list of children and adolescent with epileptic seizure disorder which was retrieved from the hospital medical records. Caregivers of children and adolescents with epileptic seizures who met the inclusion criteria and gave informed consent, were recruited consecutively, until the sample size of 40 was reached.

3.6 Study instruments

3.6.1 Socio- Demographic characteristics Questionnaire.

This is the first instrument used for data collection (Appendices 1&11). The socio-demographic questionnaire comprised questions used to collect information to measure variables such as age, gender, marital status, educational level, occupation and employment status. It is modelled after that used in previous study carried out among adolescents in Southwest Nigeria (Omigbodun, 2008). It has a Yoruba and an English version, but the English version was used for this study and the school report section was removed since it was not relevant to the study

3.6.2 The Knowledge of Epilepsy Questionnaire (KOEQ)

This is a standardised questionnaire comprised of three sections demographic questions, knowledge of epilepsy and attitude towards epilepsy. After reviewing several survey instruments the researcher then modified a 22-item questionnaire from a study on knowledge and Attitudes in Canadian college students by Young, et al,(2002) into a 9-item questionnaire which tested for knowledge from (questions 1-5) while (questions 6-9) only tested for attitude/perception. This questionnaire was used to assess the knowledge of the participants at baseline, and at pre and post intervention respectively. The instrument was however not translated because participants spoke English

3.6.3 Zarit Burden Interview (ZBI)

This instrument is a self-administered 22- item questionnaire (Zarit et al, 1980) which assesses how a person feels when taking care of another person. It is an instrument used for measuring the caregiver's perceived burden of providing family care. The 22 items are assessed on a 5-point Likert scale ranging from o='never to 4='nearly always. Maximum obtainable point is a point between 21-40 points. '. The rating of sum of points gives the severity of the burden experienced by the caregiver. A point of between 0-20 mean "little burden", 21-40 points "mild to moderate burden",41-60 points "moderate to severe", and 61-88 "severe burden". The questions focus on major areas such as caregiver's health, psychological well-being finances, social life and the relationship between the caregiver and the patient. The instrument has been used and found to be adequate for Nigerian subjects (Bello-Mojeed, 2009- Bello-Mojeed et al, 2013a). It was used in this study to assess for burden on the caregivers, pre and post intervention

3.6.4 General Health Questionnare-12(GHQ)

The General Health Questionnaire-12 (Appendix 1V) was used in this study to assess for psychological distress/mental health of the mothers pre and post intervention. The GHQ12 (Goldberg, 1972) contains 12 questions with answer options as follows: “Better than usual”, “Same as usual”, “Worse than usual”, and “Much worse than usual “. The scoring of the GHQ-12 used in this study is the 0-0-1-1, (0= “Better than usual,” 0= “Same as usual”, 1= “Less than usual”, and 1= “Much less than”). The cut off point for psychological distress used in this study was at a score of 3 points as suggested by Gureje and Obikoya (1990). Caregivers with a GHQ 12 score of 3 and above were deemed to have psychological distress. This instrument has been validated for use with report of good psychometric properties in Nigeria (Gureje and Obikoya, 1990). It has been translated into Yoruba and used in the country (Gureje and Obikoya, 1990). The English version was however used in this study as the subjects spoke English and not Yoruba.

3.6.5 Hospital Anxiety Depression Scale (HADS)

The Hospital Anxiety and Depression Scale was developed by Zigmond and Snaith in 1983 to identify caseness (possible & probable) for anxiety disorders and depression among patients in non-psychiatric hospital clinic. It is divided into an Anxiety Subscale (HADS=A) and Depression Subscale (HADS-D) both containing seven items. The instrument has been validated in many countries including Nigeria (Abiodun, 1994). The instrument consists of 7 items each for depression and anxiety.

Scales are rated from to 0=3 to (maximum obtainable). A cut off point of 8 and above in either anxiety or depression subscale indicates depression or anxiety

. The scoring on this instrument reads:

Total score – Depression (D) -Anxiety – (A)

0-7 =normal,

8-10 =Borderline (abnormal) (borderline case)

11-21 = Abnormal (case)

3.7 Study procedure

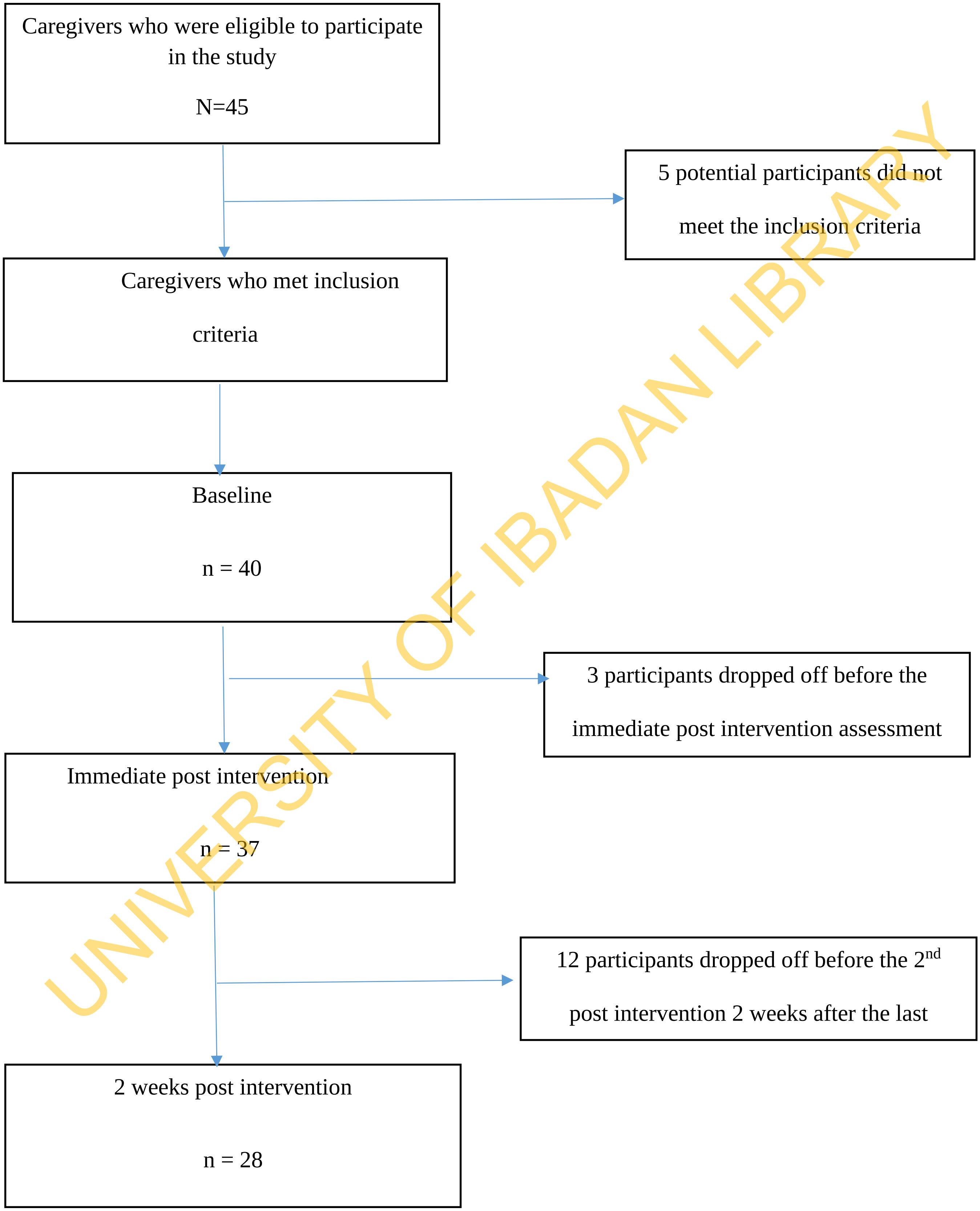
A list of children and adolescents who had a diagnosis of epileptic seizures made by a consultant and have been attending clinic for 6 months were retrieved from the hospitals' Medical Records Unit until required number of participants was attained . Phone calls were made with the assistance of the Social Welfare Officer to those who were eligible to participate in the study, asking for their willingness to participate while some who could not be reached on phone were recruited while on clinic appointment with their children.

At baseline the socio- demographic questionnaire was used to collect demographic information of both the child and caregiver. The General Health Questionnaire measured the psychological distress and general mental health status of the respondents at the baseline and compared with after intervention. The Zarit Burden interview and the knowledge of epilepsy questionnaire were also administered at baseline and post intervention. The questionnaires were all interviewer-administered using the services of a trained research assistant who was blinded to the study hypotheses. The research assistant also used Pidgin English for those who do not have a good understanding of English language during her interview sessions. Pidgin English is an English -based language spoken as lingua franca across Nigeria.

The clinic reception was neatly arranged with chairs by the researcher and her assistant, with the kind approval of the hospitals' management for all the intervention sessions since all the sessions were held on Saturdays. The interventions designed by the researcher and the supervisor took place once a week (every Saturday) for three weeks as against the four weeks session designed by the manual drawn from Bello-Mojeed, (2013). This was as a result of concerns raised by the participants who are mostly traders, farmers and business persons about losing income. Each session lasted for 1 hour to 1 hour 20 minutes. In between sessions, caregivers were communicated with via telephone calls to assist with any difficult situation and remind them of the next intervention session. At the end of session 3 which was a build-up on session 2, each participant was helped to advance their statement of function (SOF) to a Behaviour management plan for their child. Thereafter the same instruments used for the baseline assessments except the socio-demographic questionnaire (SDQ) were re- administered at immediate- post and 2 weeks post-intervention. Two sessions of the intervention selected randomly were audio recorded and assessed by an experienced clinician to determine if the intervention was administered consistently according to the manual. Completed attendance was judged as attending 2 or 3 of the intervention sessions.

The caregivers were encouraged to practice the strategies in the Behaviour management plan every day and to free-call the researcher if they are having trouble putting the strategies into practice at home.

Flow chart showing participants recruitment for the study



2.8 Intervention

Behavioural Intervention Manual for caregivers of children and adolescents with epileptic seizure disorder draws on previous work and manuals of the effectiveness of parent-mediated behavioural intervention for aggressive behaviour in children with ASD by (Bello-Mojeed, et al 2013). It was delivered by the researcher. The intervention was delivered on a group basis as this is more cost-effective in a Low and Middle Income Country (LMIC) such as Nigeria.

The intervention used comprised of (3) sessions (Appendix VI). Each session consisted interactive lecture, group discussion and problem solving. The first session involved introduction on the concepts such as Epilepsy, seizure types, myths and beliefs associated with the condition, and associated impairments and aggression in Epilepsy. Second session was designed to explain the basic principles of Functional Behaviour Analysis (FBA) for aggression identified in epileptic seizure disorder and identification of triggers for aggression. . The third and the last session was a further extension / reinforcement of the issues covered in the first and second sessions. This helped to embed the concepts and address the practical issues arising from the caregivers' use of the strategies with their children.

2.9 Data Analysis

All analyses for the pre and post intervention was performed using Statistical Package for the Social Sciences (SPSS version 20) software to achieve summary and inferential statistics. Socio-demographic details of the caregivers and their children was presented using numbers and percentages for categorical variables and Mean and Standard Deviation for continuous measures. Comparison of the effect of the intervention was carried out using Repeated Measures ANOVA of the outcome variables at three time points (baseline, and immediate post intervention and second post intervention).. The level of significance was at p= 0.005

2.10 Ethical Considerations

Ethical approval to carry out this study was from the Ethical Review Committee of Federal Neuro-Psychiatric Hospital Uselu, Benin City (Appendix vii). All data collected from the participants were kept confidential. After compiling a list of consenting and eligible caregivers from the medical records, those who agreed to participate in the study were assigned an ID number. A list of subject names and ID numbers were kept in a locked cabinet and only the researcher had access to this cabinet. After the data entry was complete, the master list of names and ID numbers were destroyed. The caregivers who participated were informed of their right to withdraw from the intervention prior to or during the study. They were also informed that withdrawal from the study would not affect the ongoing treatment of their child. The intervention did not cause any risk of harm. However, there were inconveniences involved in the time of administering the questionnaires and the intervention sessions considering the role of most of these participants in family affairs. This was minimized by giving some incentives which included providing them money for transportation and giving them light refreshments.

CHAPTER FOUR

RESULTS

4.1a Socio demographic characteristics of respondents

A total of 40 respondents were recruited for this study and all respondents underwent training intervention with assessments conducted immediately after the training and two weeks after the training. Table 4.1a, shows the socio-demographic characteristics of the caregivers sampled. Results showed that majority of the respondents attained secondary education (70.0%), were currently employed (85.0%) and lived in a monogamous family setting (75.0%). About one third of the respondents (67.5%) were currently married and practiced Christianity – Pentecostalism.

The predominant occupation among the respondents was trading/business (55.0%), while 17.5% were either artisans or professionals. The characteristics of respondents' spouses showed that 90% were currently employed, with trading/business being the most common occupation (42.5%)

The socio-demographic results also showed that the mean age of the caregivers was 46.55± 8.53years. The caregivers had a mean 4.00±2.002 number of children with mean number of years married as 21.03±6.11 years. The income of both the caregivers and their spouses were N20, 000 ranging from 15000-35000 and N20000-N40000 respectively.

The socio-demographic results showed that the respondents were predominantly female 39(97.5%) with only one male parent 1(2.5%) and separated from spouse.

Table 4.1a: Socio-demographic characteristics of respondents N=

Variables	Frequency(n)	Percentage (%)
Gender		
Female	39	97.5
Male	1	2.5
Marital status		
Currently married	27	67.5
Previously married	13	32.5
Educational level		
Primary	3	7.5
Secondary	28	70.0
Tertiary	9	22.5
Employment status		
Employed	34	85.0
Unemployed	6	15.0
Occupation		
Artisan	7	20.6
Trader/business	20	58.8
Professionals	7	20.6
Husbands educational level		
Primary	7	17.5
Secondary	16	40.0
Tertiary	11	27.5
Husbands employment status		
Employed	36	90.0
Unknown	4	10.0
Husband's Occupation		
Professionals	9	25.0
Artisan	10	27.8
Trader /business	17	47.2
Practice any religion		
Yes	37	92.5
No	3	7.5
Religion		
Islam	1	2.5
Christianity (Orthodox)	12	30.0
Christian (Pentecostal)	27	67.5
Family type		
Monogamous	31	77.5
Polygamous	9	22.5

4.2. Characteristics of children with Epilepsy

Table 4.2a shows the characteristics of the children with Epilepsy. Majority of the children were males (77.5%), were all presently enrolled in school (100%) with 37.5% in primary school followed by(32.5%) in senior secondary and(30.0%) in junior secondary.

Table 4.2b shows the summary of quantitative characteristics of the children. Results showed that the mean age of the children were 13.20 ± 3.47 years, the mean age of first diagnosis and first contact with the clinic was 9.4 ± 3.8 years and 9.1 ± 3.8 years respectively.

Table 4.2a: Characteristics of children with Epilepsy N=

Description		Percentage (%)
Gender		
Male	31	77.5
Female	9	22.5
Educational level		
Primary	15	37.5
Junior Secondary	12	30.0
Senior Secondary	13	32.53.

Table 4.2.b: Characteristics of variables

Description	Mean ± SD
Age of child	13.20 ± 3.47
Age at first contact with clinic	9.08 ± 3.79
Age at first diagnosis	9.38 ± 3.79

4.3. Knowledge of Epilepsy among caregivers of children with Epilepsy

Table 4.3 shows the Knowledge of epilepsy among caregivers of children with Epilepsy. Results showed that there was no significant difference in Mean Knowledge of Epilepsy scores between baseline (5.57 ± 1.77) and immediate post intervention (5.64 ± 1.25) or two weeks post intervention (5.43 ± 1.59) scores ($p>0.05$).

Table 4.3: Comparison of Knowledge of epilepsy among caregivers of children with Epilepsy at baseline and post intervention.

Description	Mean (SD)	F (2, 54)	Eta Squared	P Value
Baseline Score	5.57±1.77	0.250	0.010	>0.05
Post intervention 1	5.64±1.25			
Post intervention 2	5.43±1.59			

4.4. Burden of care among caregivers of children with Epilepsy

Table 4.4a shows the difference in mean burden of care among caregivers of children with Epilepsy using a repeated measures ANOVA with a Greenhouse-Geisser correction. Results showed that there was a significant reduction (*F:* 2,49.57) = 18.265, *P*<0.001) in the mean total burden of care score from 33.11 ± 14.68 (at baseline) to 18.96 ± 13.31 (at immediate post intervention) and 12.46 ± 9.29 (at two weeks post intervention).

The pairwise comparison of burden of care between the baseline and the post intervention time points is shown in Table 4.4b. Post hoc tests using the Bonferroni correction showed that the training intervention exercise resulted in a significant reduction in mean burden of care scores from baseline to immediate post intervention, and baseline to two weeks post intervention time points (Mean diff: 14.143, P = 0.004) and (Mean diff: 20.643, P = <0.001) respectively. Conversely, there was no significant difference in the mean burden of care scores between immediate post intervention and two weeks post intervention burden of care mean scores among the caregivers (Mean diff: 6.500, P > 0.05).

Further analysis of the Burden of Care using a categorical approach in which the Burden of Care scores are split into Mild-Moderate vs Severe (Table 4c) showed a statistically significant reduction in proportion of participants in the "Severe" category at baseline compared with the two post-intervention measurement points.

Table 4.4a: Comparison of Burden of care scores at baseline and post intervention.

Description	Zarit Burden Scores Mean (SD)	F (2, 49.57)	Eta Squared	P Value
Baseline Score	33.11 (14.68)	18.265	0.404	<0.001
Post intervention 1	18.96 (13.32)			
Post intervention 2	12.46 (9.29)			

Table 4.4b: Pairwise comparison of burden of care scores among the caregivers

Intervention group (I)	**Intervention group (J)**	**Mean Difference (I-J)**	**p value**
Baseline	Post intervention 1	14.143*	**0.004**
	Post intervention 2	20.643*	**<0.001**
Post intervention 1	Baseline	-14.143*	**0.004**
	Post intervention 2	6.500	0.148
Post intervention 2	Baseline	-20.643*	**<0.001**
	Post intervention 1	-6.500	0.148

Table 4.4c: Comparison of Burden of care scores at baseline and post intervention.

Burden of care	**Group**			**X^2**	**P value**
	Baseline **n (%)**	**Post intervention 1** **n (%)**	**Post intervention 2** **n (%)**		
Mild to Moderate	24 (60.0)	34 (91.9)	27 (96.4)	18.609	<0.001
Severe Burden	16 (40.0)	3 (8.1)	1 (3.6)		
Total	40 (100%)	37 (100%)	28 (100%)		

4.5. Psychological distress among caregivers of children with Epilepsy

Table 4.5a shows the psychological distress (Assessed by the GHQ questionnaire) among caregivers of children with Epilepsy. Table 4.5a, showed that the prevalence of participants meeting the cut-off for psychological distress declined from 37 (92.5%) at baseline to 33 (91.7%) at post intervention 1 and 19 (67.9%) at post intervention 2 ($p = 0.008$)

Further analysis of the GHQ scores as a continuous measure (Table 4.5b) also showed that there was a significant decline in psychological distress (GHQ) scores at post intervention 1 and post intervention 2 from the baseline ($P < 0.05$). The pairwise comparison of GHQ scores (psychological distress) between the baseline and the post intervention time points is shown in Table 4.5c. Post hoc tests showed that the training intervention exercise resulted in a significant decline in the mean GHQ scores from baseline to immediate post intervention, and baseline to two weeks post intervention time points (Mean diff: 2.679, $p < 0.001$) and (Mean diff: 1.857, $P = 0.004$) respectively. There was no significant difference in the mean GHQ scores between baseline and immediate post intervention ($P = 0.484$).

Table 4.5a: changes in proportion of participants meeting cut-off for psychological distress on GHQ12 from baseline to two post-intervention time points

Changes in psychological distress among caregivers	**Group**			**X^2**	**P value**
	Baseline	**Post 1**	**Post 2**		
GHQ score < 3	3 (7.5)	3 (8.3)	9 (32.1)	9.758	**0.008****
GHQ score ≥ 3	37 (92.5)	33 (91.7)	19 (67.9)		

** indicates significance

Table 4.5b: Comparison of means GHQ scores at baseline and two post intervention time points.

Description	Total Mean (SD)	F (2, 54)	Eta Squared	P Value
Baseline Score	5.28 (2.16)	14.245	0.345	<0.001
Post intervention 1	4.46 (2.23)			
Post intervention 2	2.61 (1.49)			

Table 4.5c: Pairwise comparison of psychological distress among the intervention group.

Intervention group (I)	**Intervention group (J)**	**Mean Difference (I-J)**	**P value**
Baseline	Post intervention 1	0.821	0.484
	Post intervention 2	2.679	**<0.001**
Post intervention 1	Baseline	-0.821	0.484
	Post intervention 2	1.857*	**0.004****
Post intervention 2	Baseline	-2.679	**<0.001**
	Post intervention 1	-1.857	**0.004****

** indicates significance

4.6. Hospital Anxiety and Depression status among caregivers of children with Epilepsy

The Hospital Anxiety and Depression Scale questionnaire scores were analysed separate for depression and anxiety, and also categorically and as a continuous measure. Categorical analysis of depression scores (Table 4.6a) showed no significant decline in the proportion of participants scoring above the cut-off from baseline to the two post-intervention time points. However, a similar categorical analysis for Anxiety Scores (Table 4.6b) showed a statistically significant decline in those meeting cut-off for Anxiety from baseline to the two post-intervention measures.

Table 4.6c shows the analysis of HADS as a continuous measure using repeated measures ANOVA. Results showed that there was a significant reduction (F: 2, 49.05 = 16.105, $P<0.001$) in the mean total hospital anxiety & depression score from 20.36 ± 3.55 (at baseline) to 17.10 ± 5.90 (at immediate post intervention) and 12.57 ± 4.49 (at two weeks post intervention).

The pairwise comparison of anxiety and depression between the baseline and the post intervention time points is shown in Table 4.6d. Post hoc analysis showed that the training intervention exercise resulted in a significant reduction in mean Hospital anxiety & depression scores from baseline to two weeks post intervention time points (Mean diff: 7.786, P = <0.001) and from immediate post intervention to two weeks post intervention (Mean diff: 4.536, P = 0.025) respectively. Conversely, there was no significant difference in the Mean Hospital anxiety & depression scores between baseline time point and immediate post intervention among the caregivers (Mean diff: 3.250, P = 0.089).

Table 4.6a: Comparison of HADs (Depression) categories across the different intervention time points

	Group			Total	X^2	P value
	Baseline	**Post 1**	**Post 2**			
HADs Depression						
Depression absent	6 (15.0)	9 (24.3)	10 (35.7)	25 (23.8)	3.904	0.142
Depression present	34 (85.0)	28 (75.7)	18 (64.3)	80 (76.2)		

Table 4.6b: Comparison of HADs (Anxiety) categories across the different intervention time points

	Group			Total	X^2	P value
	Baseline	Post 1	Post 2			
HADs Anxiety						
Anxiety absent	15 (37.5)	18 (48.6)	25 (89.3)	58 (55.2)	18.867	**<0.001**
Anxiety present	25 (62.5)	19 (51.4)	3 (10.7)	47 (44.8)		

Table 4.6c: Comparison of Hospital Anxiety and Depression Scale questionnaire scores from baseline to the two post-intervention points using Repeated Measures ANOVA.

Description	HADs Scores Mean (SD)	F (2, 49.05)	Eta Squared	P Value
Baseline Score	20.36 (3.55)	16.105	0.374	<0.001
Post intervention 1	17.10 (5.90)			
Post intervention 2	12.57 (4.49)			

Table 4.6d: Pairwise comparison of Hospital Anxiety and Depression scale questionnaire scores from baseline to the two post-intervention points

Intervention group (I)	**Intervention group (J)**	**Mean Difference (I-J)**	**p value**
Baseline	Post intervention 1	3.250	0.089
	Post intervention 2	7.786*	**0.000**
Post intervention 1	Baseline	-3.250	0.089
	Post intervention 2	4.536*	**0.025**
Post intervention 2	Baseline	-7.786*	**0.000**
	Post intervention 1	-4.536*	**0.025**

CHAPTER FIVE

DISCUSSION, CONCLUSION, AND RECOMMENDATIONS

5.1 Discussion

Epilepsy is an important neurological problem in developing countries and has been associated with significant psychosocial maladjustment in both the affected children and their families (Lagunju *et al*, 2009). In Austria, Freilinger and colleagues reported behavioural and emotional problems in 22% of children with epilepsy (Freilinger *et al* 2006). However research evidence from developed countries, has shown that effective behavioural intervention exists and can be delivered by caregivers of children with challenging behaviours such as aggressiveness (Athens and Vollmer 2010)

The current study is a quasi-experimental pre-post trial of the effectiveness of Psychoeducation on the psychological distress and burden of care of caregivers of children and adolescents with epilepsy. This study showed that psychoeducation training programme for Caregivers on knowledge of epilepsy and behaviour management intervention for aggressiveness seen in children with epilepsy significantly reduced the level of stress and burden of the caregivers.

Majority of the caregivers in this study were females (97.5 %). Most were either farmers, traders or businesswomen (55.0%) while 17.5% were either artisans or professionals and only 10% were unemployed. This figure accounts for the fact that women from this area are very industrious, hardworking and independent but can also be saddled with the care of the child and other family issues, which can make them become overwhelmed and helpless. Some of the caregivers were separated or divorced. A past study showed stress of the child's condition may lead to separation or divorce (Austin *et al*, 1996). However, this report of divorce or separation is similar to a report among caregivers of patients with schizophrenia in Nigeria (Yusuf *et al*., 2009). The women in most sub-Saharan African communities are the traditional caregivers for patients with chronic illnesses.

Fears have been reported as a difficult experience for patients with epilepsy and their Carers (Saegsuwan *et al*, 2013) and that fear can also increase caregiver stress and anxiety (Cushner-Weinstein *et al*, 2008). This emphasizes the importance of psychoeducational interventions such as in this study which showed a significant reduction in the anxiety level of caregivers (HADS) in the immediate post intervention and a further reduction two weeks post intervention.

5.1.1 Socio- Demographic characteristics of Respondents

A total of 40 caregivers who were all family members mostly mothers and only one male who is also a parent took part in the intervention. The Social demographic characteristics showed that 27(67.5%) of the caregivers were married while 13(32.5%) were previously married. This proportion of marital breakdown of 32.5% is very high compared to the average of less than 1% in Nigeria (National Bureau of Statistics 2016). The high divorce rate could be attributable to some of the emotional, psychological, and socio-economic stresses associated with having a child with epilepsy (Austin et al, 1996). The majority of the caregivers (70.0%) attained secondary education, (22.5%) had tertiary education, and (85.0%) were employed mostly trading and business (55.0%). The caregivers were mostly Christians and Pentecostal (67.5%). It was also notable that most of the caregivers had a monogamous family type (75.5%) as compared to another study done in a different part of Nigeria, (Nuhu *et al* 2010) which reported that majority of the caregivers in that study of caregivers of patients with epilepsy had polygamous family type. This difference may be due to religious and cultural differences as most of the caregivers in the current study practice

Christianity (which does not allow polygamy) whereas the study by (Nuhu *et al* 2010) was in a part of Nigeria where Islam is a common religion (which allows polygamy).

5.1.2 Characteristics of Children with Epileptic Seizures.

Majority of the children were males (77.5%) and their mean age was 13.20± 3.47 years all presently enrolled in school (100%) mainly in primary school (37.5%). The high rate of school enrolment is very encouraging as it suggests that the caregivers are ensuring that their children are given the same opportunities for development as other children who do not have epilepsy. The mean age at first diagnosis and first contact with clinic was 9.38± 3.79 years and 9.08± 3.79 years respectively, this indicates that the children fall within the age range of early onset of epilepsy in children (Neubauer *et al*., 2008).

5.1.3 Knowledge of Epilepsy among Caregivers of Children with Epileptic Seizures.

There was no significant difference in the mean knowledge of epilepsy scores between baseline (5.57±1.77) and immediate post intervention (5.64±1.25) or two weeks post intervention (5.43± 1.59) (P>0.05). This non-significant difference may have resulted from the fact that the 3 sessions of training over 3 weeks was too short to change some of the deeply held and culturally dominant beliefs about epilepsy. Another factor could be that some of the caregivers missed the first session of the training programme which was the main psycho-education session. Despite this negative finding, it is still advocated that Structured psychoeducational programs that teach coping skills relevant to the tasks and demands of caregiving can be useful to caregivers (Toseland *et al*; 2001). It has been suggested that distressed caregivers may more likely benefit from such approaches than other caregivers (Toseland *et al*., 2001).

5.1.4 Burden of Care among Caregivers of children with Epilepsy

The training intervention resulted in a significant reduction in the burden of care as assessed by the Zarit burden Interview (ZBI) from baseline to immediate post intervention which was sustained two weeks post intervention. Reviews indicate that psychoeducational programs can be effective in lowering distress and burden, and increasing wellbeing and satisfaction (Toseland *et al*, 2001). This was evident in the current study which showed a significant reduction of caregivers burden from baseline 16 (40.05%) to immediate post intervention 3(8.1%) and a further reduction at 2weeks post intervention 1(3.6%) which was statistical significant with p value of <0.001. Apart from psychological impact of epilepsy, burden may also result from not being employed and having to stay at home to look after the child with epilepsy. A study conducted in Nigeria   has reported a significant impact of epilepsy on some parents caring for their children with epilepsy and a significant proportion of these parents had to stop working in order to have enough time to look after the children (Lagunju *et al*, 2009). The report of burden of care in this study using the Zarit Burden Scale, revealed that 16(40.0%) of the caregivers had severe burden, this is higher than another Nigerian study which found that a 15.5% of parents (caregivers) reported a significant burden in their caregiving role (Lagunju, *et al* 2012).

5.1.5 Hospital Anxiety and Depression status of Caregivers of children with Epilepsy.

Education and training programs strive to help caregivers by educating them about resources and by teaching specific problem solving and coping techniques (Toseland et al., 2001). However, studies assessing the effectiveness of skills training have produced equivocal and at times, contradicting result, but training on specific skills that are clearly operational, practiced, and used to resolve real life problems have been found to produce significant changes in outcome measures directly related to those skills (Bourgeois, *et al* 1996). This current study on psychoeducation for caregivers, that include behaviour management and aggressiveness of children with epilepsy revealed a significant reduction in caregiver level of anxiety and depression using the. The results showed that at baseline out of 40 caregivers 25(62.5%) presented with anxiety, which dropped to 19 (51.4%) at the immediate post intervention with a further significant drop to 3(10.7%) at two weeks post intervention time point, which is statistically significant (p=0.001). The total HADS scores also showed a significant reduction from baseline to two weeks post intervention.

Problem solving and behaviour management interventions have been found to demonstrate effectiveness among carers of people with epilepsy (Pusey & Richards, 2001). This is consistent with the current study which found that a 3week programme that included teaching caregivers' skills to manage aggressive behaviours associated with epilepsy and how to implement emergency measures at time of seizures resulted in a decrease in anxiety among caregivers . Although we did not measure if the training led to actual reductions in aggressive behaviour and or whether the carers were able to implement the emergency measures, it is possible that knowing what to do in such circumstances was enough to help the carers to become less anxious. This finding could have clinical implications in supporting caregivers of children with epilepsy because the mental health needs of children with epilepsy cannot be met adequately in absence of optimal attention given to that of the caregivers.

5.1.6 Psychological Distress among Caregivers of children with Epilepsy.

As shown in Table 4.5a. In this study 37 (92.5%) caregivers (parents) reported a significant level of psychological distress. This is much higher than in another Nigerian study which found psychological distress among 39.6% of caregivers of children with neurodevelopmental disorders (Lagunju, *et al*, 2012). The resultant outcome of the psychoeducational training intervention programme revealed that the psychological distress of the caregivers was significantly reduced between the immediate post intervention time point 33 (91.7%) and two weeks post intervention 19 (67.9%).

5.2 Limitations

The limitations of this study include:

This was a quasi-experimental pre –post trial without a control group. This means that alternative explanations for the improvements in outcome measures cannot be ruled out. Such alternative explanations include socially desirable responding, practice effect, and regression to the mean.

The sample size was small and makes it difficult to generalize findings to the general population of caregivers with epileptic seizures. This might also explain why one of the outcome measures was not statistically significantly different (i.e. Knowledge of Epilepsy) – a possible Type II Error.

The knowledge scale measured both knowledge and stigma. The fact that stigma takes longer to change may explain why the whole scale was not different across the two post intervention assessments.

The duration of the intervention was short, lasting for only three sessions over three weeks. This may explain the lack of difference in one of the outcome measures such as knowledge of epilepsy. Also, there was no time to follow up the caregivers beyond 2 weeks. These time limitations were necessitated by the duration of the MSc. Programme.

Another limitation of this study was that there was no proof of the use of the training by caregivers like the use of checklists to ascertain if and how the caregivers applied the training.

5.3 Conclusions

Caregivers of Nigerian children and adolescent with epileptic seizures experience a high level of psychological distress which is also associated with enormous burden. Behavioural interventions aimed at reducing aggressive behaviours could have a reciprocal effect on mental health of caregivers of children and adolescent with epileptic seizures. Hence strategies aimed at reducing challenging behaviours such as aggression in seizure can be used as an important tool for improving mental health of family caregivers especially mothers of affected children and adolescents. Targeting caregivers of children with epilepsy will go a long way in scaling up services for children with epilepsy and reducing the burden of care on the family

Caring for patients with epilepsy can be challenging and associated with enormous burden. Therefore, any intervention to reduce burden of care is encouraged. This study showed that an intervention that included psycho-education and specific intervention on reducing aggressive behaviour using principles of functional behaviour analysis (FBA) delivered by non-behavioural specialist over a relatively short period (3 sessions) was helpful in reducing burden and anxiety among the caregivers.

Findings from this study show that parents of children with epilepsy could be trained to deliver effective behavioural intervention for their affected children, indicating that caregivers can learn skills necessary to manage some of the comorbid problems in epilepsy such as aggressive behaviour. This is important in scaling up services and has implication for improving access to care and optimizing outcome for children and adolescent with epileptic seizures and their caregivers.

5.4 Recommendations

Caregivers especially mothers of children with epilepsy should be screened for psychological distress.

Psycho-education programme should be incorporated into the management of children with epileptic seizure disorder

Functional behaviour analysis to identify modifiable triggers and maintaining factors for aggressive behaviour should be incorporated into the education programmes for carers of children with epileptic seizure disorder and aggression

Caregiver educational intervention programmes to reduce the burden of care in epileptic seizure disorder should be implemented early

The findings from this study should be replicated with a larger sample size with a control group

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APPENDIX 1

INFORMED CONSENT FORM FOR THE PARTICIPANTS (CAREGIVERS)

Title of Research: Effects of Psycho-education on Psychological Distress and Burden of Care of Caregivers of Children and Adolescent in the Federal Neuropsychiatric Hospital, Benin-City.

The study is conducted by Nkechi .A. Igbinigie, a Masters student of the Centre for Child and Adolescent Mental Health, University of Ibadan Nigeria. The purpose of the research is to assess the effects of Psycho-education on Psychological Distress and Burden of Care of caregivers of children and adolescent with epileptic seizures attending the Child and Adolescent Clinic of the Federal Neuropsychiatric Hospital Uselu, Benin (FNPH)

The study would be carried out in two stages, the first stage you will be asked to fill some questionnaires. The questionnaires would ask questions about your knowledge of epilepsy and management. While the other questionnaires would ask basically about your general health, the burden of care of your child and its effects on your psychosocial wellbeing. The stage two would involve an intervention, where you would be taught everything about epilepsy the types and presentations including the management. You will also be taught how to manage any challenging behaviours that may be associated with epilepsy and ways of relieving the burden of care of your child to enable you focus on yourself and other family matters. You do not have to answer any question if you feel the questions invades on your privacy or make you uncomfortable. The goals of this study would be to improve the caregiver's psychosocial wellbeing, their knowledge, perception and management of epilepsy as well as dispel some of the myths and misconception, In addition it would also improve adherence to their children's treatment and follow up and improve their hope, knowing that they are not alone. We hope the intervention would achieve the above, although we are not certain.

All information collected in this study, will be coded using numbers and no name would be recorded so it cannot be linked to you. Furthermore your name would not be used in any publications or reported.

Some of the sessions would be audio recorded but this would be used strictly for the purpose of the study. Your participation is voluntary. If you are having a second thought and do not want to participate, it will have no effect on your child's treatment in this hospital nor your family.

There would be light refreshments provided during each session and when you fill the questionnaires. In addition your transport fare to and from will be augmented considering the present hike in transport fares by the commercial drivers. The intervention would take place in 3 weeks with one session of about 1 ½ hours per week. In the last stage, after intervention you would fill another questionnaire.

Consent statement

If you have fully understood the study, and would be willing to participate in the study, please kindly sign in the space provide.

Sign /thumbprint……………………………..Date…………………

Name………………………………………………….

APPENDIX 2

SOCIO-DEMOGRAPHIC QUESTIONNAIRE FOR THE CHILD

1. Age of the child (in years) [ ]
2. Date of birth of the child (in years)________
3. Gender _________ Male [ ] Female [ ]
4. Educational level______________
5. What is the position of the child among his /her siblings children [ ]
6. Age of child at first contact with the Clinic (years)
7. Age when first diagnosed epilepsy (years)

APPENDX 11: SOCIO-DEMOGRAPHIC QUESTIONNAIRE FOR THE CAREGIVERS

1. how old are you [ ]
2. What is your date of birth (Day/Month/Year)?
3. Where do you live (Address of present abode) -_______________
4. Do you practice any religion? No [ ], Yes [ ]
5. Please write down the exact place you attend for worship_____________

(a)Islam (b) Orthodox Christian (c) Pentecostal Christian (d) Traditional religion (e) other.

6. Marital Status__ Single [ ], Married [ ], Separated [ ], Divorced [ ], Widowed [ ],

7. If married, what is your age (in years) at marriage [ ]

8. Type of family____________ Monogamous [ ], Polygamous [ ].

9. Educational level, please specify

7. Your Employment status Unemployed [ ], Employed [ ]

10. Your Occupation -----------------

11. Your Monthly income ------------------

12. If employed. What is the effect of caring for this child on your work, please?

Specify__________

13. Educational level of husband/wife, please specify___________

14. Employment status of your husband/wife Unemployed [ ], Employed [ ]

15. Occupation of your husband/ wife ----------------

16. Monthly income of your husband /wife ----------------

17. No. of your children -------------------- [please specify]

APPENDIX 3

KNOWLEDGE OF EPILEPSY QUESTIONNAIRE

For the following questions, choose the best answer:

1. Do you know or have you ever known anyone with epilepsy?

   [ ] yes [ ] no

2. Have you ever seen anyone having an epileptic seizure?

   [ ] yes [ ] no

3. What do you think causes epilepsy?

   [ ] accidents

   [ ] inherited disease

   [ ] insanity or mental illnesses

   [ ] brain tumours

   [ ] birth defects

   [ ] stroke

   [ ] all of the above can cause epilepsy

   [ ] don't know

4. What do you think an epileptic attack is? (Pick any that you think apply.)

   [ ] a convulsion or shaking

   [ ] a loss of consciousness

   [ ] an episode of behavioural change

   [ ] a period of memory disturbance

   [ ] any of the above

   [ ] don't know

5. What do you do if your child starts having an epileptic seizure at home?

   [ ] put something in the child's mouth to prevent him /her from choking with his / her tongue.

   [ ] hold the child tight so that he / she stops shaking

   [ ] lie the child on his / her back

   [ ] call for help from neighbors

   [ ] move the child to an area where he / she cannot hurt him / herself while having seizure

6. Would you object to having any of your (eventual) or children associate with person's who had sometimes epileptic seizures in school or in a playground?

   [ ] yes [ ] no

7. Would you object to a person with epilepsy marrying a close relative of yours (brothers, sister or child)

   [ ] yes [ ] no

8. Do you think persons with epilepsy should have children?

   [ ] yes [ ] no

9. Do you think that in general, persons with epilepsy should be employed at the same jobs as other people?

   [ ] yes [ ] no

Thank you for your contribution to this project. We appreciate the time you have taken to answer our questions. If you have additional comments, please list them below.

APPENDIX 4

THE ZARIT BURDEN INTERVIEW

Please circle the response the best describes how you feel.	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	Score
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4	
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4	
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4	
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4	
5. Do you feel angry when you are around your relative?	0	1	2	3	4	
6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4	
7. Are you afraid what the future holds for your relative?	0	1	2	3	4	
8. Do you feel your relative is dependent on you?	0	1	2	3	4	
9. Do you feel strained when you are around your relative?	0	1	2	3	4	
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4	
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4	
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4	
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4	
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4	

15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4	
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4	
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4	
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4	
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4	
20. Do you feel you should be doing more for your relative?	0	1	2	3	4	
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4	
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4	

APPENDIX 5

GENERAL HEALTH QUESTIONNAIRE (GHQ-12)

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. Thank you for answering all the questions.

Have you recently	0 better than usual	1 same as usual	2 less than usual	3 much less than usual
1. Been able to concentrate on what you're doing?				
2. Lost much sleep over worry?				
3. Felt that you are playing a useful part in things?				
4. Felt capable of making decisions about things?				
5. Felt constantly under strain?				
6. Felt you couldn't overcome your difficulties?				
7. Been able to enjoy your normal day to day activities?				
8. Been able to face up to your problems?				
9. Been feeling unhappy or depressed?				
10. Been losing confidence in yourself?				

11. Been thinking of yourself as a worthless person?

12. Been feeling reasonably happy, all things considered?

APPENDIX 6

Hospital Anxiety and Depression Scale (HADS)

They should give an immediate response and be dissuaded from thinking too long about their answers.

		Not at all	**From time to time, occasionally**	**A lot of the time**	**Most of the time**
S/n		0	1	2	3
1	**I feel tense or 'wound up'**				
2	**I still enjoy the things I used to enjoy**				
3	**I get a sort of frightened feeling as if something awful is about to happen**				
4	**I can laugh and see the funny side of things**				
5	**Worrying thoughts go through my mind**				
6	**I feel cheerful**				
7	**I can sit at ease and feel relaxed**				
8	**I feel as if I am slowed down**				
9	**I get a sort of frightened feeling like 'butterflies' in the stomach**				
10	**I have lost interest in my appearance**				
11	**I feel restless as I have to be on the move**				
12	**I look forward with enjoyment to things**				
13	**I get sudden feelings of panic**				
14	**I can enjoy a good book or radio or TV program**				

APPENDIX 7

BEHAVIOURAL INTERVENTION MANUAL FOR CAREGIVERS OF CHILDREN AND ADOLESCENT WITH EPILEPTIC SEIZURES.

Drawn from Bello- Mojeed, 2013.

SESSION 1

Introduction and ground rules.

Introduce yourself and ask each group member to introduce themselves using their first names only. Make the introduction non-threatening by avoiding people having to say things they may be embarrassed about. It may be sufficient enough for them to just say their first name.

To reduce caregivers 'inhibition and help them relax, tell them you are going to sing a welcome song and you would like them to clap along or join in the song. After the song, applaud the parents and say how well they sang.

Time = 5mins

GROUND RULES FOR SESSIONS

Time =5mins

1 Please be punctual

2. Come every week. Each session builds on the previous week. It is therefore necessary for every session to be attended in order to benefit fully from the programme.

3. It is essential for every session to be attended by every participant in order to gain the full benefit of the programme.

4. Do the "practice". By practicing what you have learnt in this session at home, you will find the sessions more helpful.

5. Confidentiality is very paramount in group sessions, so it should be stressed continually throughout the sessions. However if you want to share what you have learnt with other people it's alright, but do not mention the names of other participants, their children or anything they said during the sessions.

.6. Try to express yourself as honestly as possible about who you are and just how you are coping with the huge challenge and burden of caring for your child.

.7. There will be regular breaks and refreshments.

Ask the caregivers to add more rules if they wish.

(b) Psycho education, building strength and hope.

It is a fact that Carers have been told the reason for inviting them to the programme, but it is also possible for them to have forgotten or not too sure what the programme is all about. Therefore, it is an opportunity to help them understand and remind them of what and how the programme runs.

The caregivers may have had seizures or epilepsy explained to them on their first visit or during clerking / assessment, but no longer remember some of the details. They may not be aware that seizure disorders are common and have not also met other caregivers whose children have similar condition, and they may be completely ignorant of the cause of these seizures, and comorbidities associated with the condition which causes challenging behaviours seen in children with epilepsy. They may also have lost hope and unaware that it is possible for their child's seizures to reduce or abate completely and they may not fully understand their role in the child's improvement. Parents may develop a better sense of relief and hope if we provide explanation to help them to have a more realistic understanding of these issues and by sharing experience with other caregivers.

During this session caregivers were made to see the similarities in the seizure types of children of other members in the programme, and learnt that epilepsy is not contagious and it is curable. They were also thought how to encourage themselves through "Positive self-talk".

PURPOSE OF SESSION 1

1. See similarities between the seizure types of children of parents in the programme
2. Learn that seizure disorders are neither contagious nor incurable
3. Learn to encourage themselves through positive self-talk

Time: 35 minutes

Say:

You were invited to take part in this program because you have a child who has a condition called epileptic seizure disorder and they can also sometimes behave in a way that can make you worry that they may injure someone or themselves

This part of the meeting is intended to help us understand more about epilepsy and the strength and challenges that our children may have.

Although we are here to discuss challenges, it is important for us to also look for and acknowledge the other strength that our children may have.

Say:

Think of your child without concentrating on the difficulties they present (we are also going to talk about this later) But for now, try and identify one or more things that are good about them. It does not matter how big or small the things may be, try and identify at least one good thing

Acknowledge that it may not be easy for some parents to think of something positive about their child who has epilepsy, more so because of the myths and beliefs associated with the condition, but encourage every caregiver to try hard with exercise and identify at least one thing that is positive.

This should be written on the flip chart against the child's name. If a caregiver is unable to identify a specific strength or positive attributes held by other persons in relation to the child (e.g. if the child is loved by parents or siblings or by Supreme Being

At the end of this exercise, transfer the identified qualities from the flip chart into each caregiver's book and write it in a way to be used as positive self-talk ('Although Efosa has epilepsy and can be so overwhelming for me , he is a lovely boy')

Say;

Positive talks and our utterances about us have a powerful effect on us and our children. For instance, if we think only of all the challenges our children have, and its effect on us, we may start making negative comments about ourselves such as “I am not a good mother “ “everything my child is going through is my fault “ or about our child “ my child’s epilepsy is a course so there is no cure for it “

The more often we say negative things about ourselves, the more we may start believing them and start behaving in a way to make the negative statement come true (self-fulfilling prophesy). Fortunately, the opposite is also true of positive statements about us and our child. We can make ourselves feel more positive and help our child’s condition and behaviour become more positive.

Now go on to discuss some of the burden associated with care and management of a child with epilepsy. Explain that the group will now look at some of the burden associated with epilepsy work out strategies on how the program can be used to help solve some of the problems

Ask group members to identify some of the signs and types of seizures their child have that are different from other children they know who have epilepsy (e.g. Siblings cousins). Then discuss the similarities and use the signs and seizure type to explain epileptic seizures.

These would help group members realize that their children’s symptoms are similar and not unique to them. It is also better to explain epilepsy in this experiential way rather than theoretically.

Note that most if not all of the Carers would mention forgetfulness, jerking movements, convulsion, poor academic performance ,aggression , when they discuss their child's condition (because they were selected due to having a child with epilepsy.

Say: Epilepsy affects 50 per 100,000 children, so the group members are not the only persons with a child with epilepsy. The condition is associated with loss of consciousness, odd behaviour; distorted perceptions such as identified by the group, loss of consciousness could be after a seizure, and odd behavior such as conduct disorder and delinquencies. These behaviors can be very difficult and unpleasant for the Carers, but a lot can be done to make it better. This programme is specially designed to give psychosocial support to prevent burnout and better able to manage the child's condition.

Say that no matter how bad the child's condition may be, it is possible for it to get better.

Remind the caregivers on how important what we say to ourselves can be. Say that however difficult their child's condition may be, you would like them to make another "positive confession "about their situation. Explain that no matter how difficult things are, if we look closely in ALL other aspects of our life, they may find something to encourage themselves with (even if it is the fact they are alive, or have other healthy children).

Encourage them to choose a positive comment from their own experience or take one from a proverb or Quran or Bible e.g. “ it is well with my child”, “when God says Yes nobody can say no”,” once there is life there is hope’

Add the positive comment to their book to make a total of two or more positive self-talk (one from earlier in the session).

ENDING SESSION 1

KEY MESSAGES FROM SESSION 1

1. Read the key messages aloud and check every group members understands them
2. Ask the group if they have any questions or comments
3. Check that every group member has two or more suggested self-talk for them

Key messages

1. They are not alone
2. They and their child have strength despite the burden of care of the child.
3. What we say to ourselves can affect how we feel about ourselves and our child. So they were encouraged to repeat the two or more positive self-talk about their child and about themselves written in their book.
4. This programme can help to make their child’s condition manageable

PRACTICE

SAY; I would like to talk about the importance of practicing the skills you learn in the group. Some of you may be thinking “what do you mean by practice? “. Practice means doing brief activities on your own outside of the group.

You can think of the skills you learn here as tools to use in your everyday life to improve or manage the care of your child. By trying out your new skills at home while you are still coming here, you can report back to the group and let us know what worked for you and what did not work. Then we can figure out other ways to make them work better.

This treatment will be successful for you if you learn skills for managing your child’s condition and feel confident using the skills regularly at home. You will need to practice because if you do not practice the skills, you will not learn them

Each session’s practice consist of one or more things that everybody in the group will do before next meeting.

Practice for session 1

Repeat your two or more positive statement about your child and yourself every day. Try and add new positive statements before the next meeting

Remember to bring your memo pad to the next meeting

SESSION TWO

Understanding how to identify problems that can arise from caregiving

This session helps participants understand how caregiving can result in distress. It describes the situation and helps the caregiver express their feelings clearly without any bitterness or quilt feelings about the child's symptoms and presentations

PURPOSE OF SESSION 2

1. To understand the principle that specific problems arising from each care giving circumstance must be addressed at a practical level.
2. To facilitate increased empathy toward and tolerance of care recipient's emotional and behavioral problems
3. To identify the causes of epilepsy relapse and complications due to lack of control of these factors.
4. To become more aware of the problem and the process of problem solving in terms of how to implement emergency measures at the time of seizures.

Instruction to the therapist:

Start by finding out how caregivers found the practice task after session 1 and trouble shoot any problem identified.

Start session 2 by ensuring each caregiver have their memo pad with their child's name on it

Show caregivers who can write how to enter the answers to the questions below the paper

Get an assistant to help the caregivers who do not know how to write.

Ask the questions below and for each caregiver who is able to identify the response that best describes how the caregivers feels

The typical care giving stressors and demands, you will also explore the possible negative affect including guilt, sadness, dread, worry and ambivalence about care, witnessing the suffering of their child during seizure attacks.

Say

In the first session, we explained that a child with epilepsy may have challenging behaviours which may constitute significant stressors for the caregiver. Informing the caregivers that there are ways of identifying the reasons why a child with epilepsy may have challenging behaviors and use this information to make the behavior better.

Say:

Human behaviour serve a purpose for the person. In people with epilepsy or any co morbidity like learning difficulty it may be difficult for them to tell us what the purpose of the behaviour is. However, there is a special way that can help us work the reason for this behaviour. This information can help us find ways to make the behaviours' less likely to occur.

Say:

The techniques starts by finding out as much information as possible about things going on before the seizure occurs that could lead to the challenging behaviour. It is called Antecedent. The next step is to find out how the behaviour usually ends. This is called consequences, we can help to identify the reasons why the behaviour starts and what keeps it going we call this technique ABC. (Using the first letter in the names).

Say;

We are now going to put this in action for each caregiver .this involves asking everyone together a number of questions. Please answer as it applies to your child. Please think carefully and ask questions if this is not clear. This part of the session is like the foundation. So we need to make sure we do it properly in order for the next stage to be successful.

Describe the situation in which the child manifest this behaviour or when seizures occurs

Days / times ____

Duration (if seizure)-____

Parts of the body affected (if seizure)

Location /places____--

Persons present at the time ___________________________________

Activity the child is doing   ____________________________

What happened before the challenging behaviour occurs ___________________________

Describe the situations in which the behaviour is less likely to occur.

Day /time ____________________________________

Location /places__________________________________

Persons present _______________________________

Activity the child is doing _____________________________

Explain possible triggers

Ask

The following questions and check every caregiver has taken time to think about it and provide an answer. If the initial answer is "YES" ask the caregiver to provide details to clarify the full circumstance. For example if the caregiver answers "yes" to whether the behaviour results in the child feeling better or getting what he wants, get more details of the thing that made the child feel better. This is deliberate to help caregivers who may not understand the question when asked in one pattern.

Could the behaviour be as a result of a form of discomfort (e.g., fear, stress, embarrassment)?

Could the behaviour be the result of any medical condition? (E.g. seizures)

Could the behaviour be the side effect of medication?

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

Does it occur at certain times?

Does the behaviour occur only with certain people?

Could the behaviour be related to wanting to do things but he cannot?

Is the behaviour as a result of the embarrassment of having epilepsy?

Is the behaviour a response to certain upsetting situation (e.g. being stigmatized, too many people in the room, too much lightening / darkness)?

Possible consequences

Does the behaviour allow the child to gain something? (Does he express feeling better,)

Does the behaviour allow the child to avoid or escape from an embarrassing situation (e.g. social interaction)?

Are there alternative behaviours that can be strengthened as a replacement for the child's challenging behaviours? If so, please suggest below

1. ______________________________-
2. ______________________________
3. ______________________________
4. _____________________________

Things the child prefers or likes to do

List things that appears 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. Activity they like (toys, games ,tv)_____________________________
3. Food, snacks & drinks they like _______________________________

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

1. The challenging BEHAVIOUR (e.g. aggression, non-engagement,)
2. SETTING / PLACE (e.g. time , location) where it happens most
3. ATECEDENT (e.g. fear , stress, hunger)
4. CONSEQUENCES (e.g at the end of activity he gets what he wants)

5. FUNCTION (e.g gain something 2 avoid something /escape, 3. Increase / decrease stimulation.)

The caregivers will be assisted to write a STATEMENT OF FUNCTION (SOF) this communicates the function of the behaviour and provides information relevant to making effective intervention decision THE SOF should include

(a) The target behaviour concern (b) the identified antecedent (s.), any person or anything identified from the analysis who or that appears to be influencing the behaviour positively & negatively , (d.) the function (s) of the behaviour , (e.), preferences that could be used as rein forcers / rewards, and (g.),any other additional information that may help understanding the statement .

ENDING SESSION 2

1. Say; having discussed how to analyse your child's behaviour to identify the possible reasons that make it occur and keep them going. We have summarized the results for your child (see statement of function). The next step is to use this information to find a way to start helping you to reduce the challenging behaviour he shows so that you will have some respite.
2. Read the key messages aloud
3. Ask group members if they have any questions or comments.

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 it 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 daily.

Remember to keep trying to add more positive comments

Remember to bring your memo pad to the next meeting.

Say: we encourage you to do these home practices. They are part of the programme. You are here in the meeting for only a short time, and eventually you would have completed the entire programme. Once you have completed the programme, these strategies will help you continue to help your child. Therefore, it is really important that you continue to do each Practice task before the next meeting.

SESSION 3

Putting into practice strategies to reduce aggressive behaviours.

PURPOSE OF SESSION 3

Use the Functional behaviour plan produced in session 2 to create a simple behaviour management plan.

Instruction to the therapist:

Start by checking how caregiver found tasks after session 2 and trouble shoot any problem identified. Check if they feel that the Functional behaviour Plan shows a good match with their experience of their child's aggressive behaviour. Clarify any problems

Start session 3 by ensuring each caregiver has their own memo pad with their child's name on it, which has the functional behaviour plan developed in the last session.

BEHAVIOUR REDUCTION METHODS

Procedures are selected based on the assessment of the controlling variables. Treatment includes manipulation of antecedents as well as consequences.

Three Goals to Reduce Challenging Behaviours Are

1. Eliminate the Behaviour's establishing operation through removing the triggers
2. Eliminate the Behaviour's rein forcing contingency by modifying the consequence.
3. Replace the Behaviour with an alternative Response

The above goals can be achieved using the recommendations below.

If the problem behaviour is a function of

ATTENTION OR THINGS

1. Give lots of extraction or the desired thing (if appropriate) to prevent the behaviour
2. Teach /encourage the child to ask for attention or the desired thing and give attention or the object when he asks (i.e. when he uses the replacement behaviour).
3. If the problem is a function of ESCAPE or AVOIDING DEMANDS

   Reduce the motivation to escape by reducing demand and give attention or the object when he asks (i.e. when he uses the replacement behaviour).

The problem behaviour is a function of ESCAPE 0r AVOIDING DEMANDS

Reduce the motivation to escape by reducing demands and by giving choices

TEACH the child a communication behaviour of asking for a break or choice to replace the problem behaviour. Give a break and or choice whenever the child asks at first (i.e. reinforce)

INTERVENTION BASED UPON FUNCTION OF THE BEHAVIOUR

Interventions for Behaviours Maintained by SOCIAL POSITIVE REINFORCEMENT.

Differential reinforcement of more positive behaviours e.g give a positive reinforcer (i.e. a reward) if challenging behaviour has not occurred for a period of time. Choose a reward from the list of activities the child enjoys as previously documented in Session 2

Differential reinforcement of alternative behaviour e.g teach the child to get your attention or other positive things through a more appropriate behaviour. This frequently takes the form of teaching the child to ask or request attention or activities without misbehaving to get it. Reward the child any time they use the more positive behaviour.

Interventions for Behaviours Maintained by NEGATIVE REINFORCEMENT ESCAPE / AVOIDANCE)

Distinction through Prevention of Escape; this is the most effective technique to decrease escape / avoidance motivated behaviour because it removes the reinforcer, which is to avoid a task. It is also the most difficult to implement because it sometimes requires physically stopping the child from leaving or avoiding the task.

Development of Appropriate Escape Behaviour. This is a technique designed to teach a child to request his reinforcer (e.g politely refuse a demand) more appropriately instead of becoming aggressive.

Interventions for Behaviours Maintained by AUTOMATIC POSITIVE REINFORCEMENT

Reinforcement of Alternative Self-Stimulating Responses: this procedure requires that a child whose aggression is maintained by lack of opportunity for self-stimulatory activity may be allowed to engage in self-stimulation e.g walking around, shouting, running, but only at certain times when it is safer and less disruptive at home.

Sensory Extinction: Removal or attenuation of the sensory reinforcer maintaining the behaviour (e.g stop giving him games that make him more aggressive)

At the end of Session 3, all the caregivers should have been helped to advance their Statement of Function to a Behaviour management plan (BMP).

The BMP for each child should state specific strategies to (a) modify the identified antecedent(s), (b), alter the function(s) of the behaviour, (c), rewards for displaying less aggressive behaviour and rewards for more cooperative behaviour,(d), non-physical consequences for aggressive behaviour.

ENDING SESSION 3.

Read the key messages aloud

Say: *Congratulations*! You have completed 3 sessions. You are working hard to learn how to reduce your child's challenging behaviour. We have two more sessions to go.

KEY MESSAGES

Challenging behaviours can be reduced by reducing / modifying the situations that make the behaviours more likely or things the child is trying to achieve with the behaviour, and by rewarding the child for being less aggressive and using more cooperative behaviour

PRACTICE

Practice the strategies in your BMP every day. "Flash-call" the therapist if you are having trouble putting the strategies into practice at home. The therapist will call back and discuss how to resolve the problem.

Remind yourself that you are not alone and you are doing this for the benefit of your child and yourself.

SESSION 4

Feedback on initial application of Behaviour Management Plan and troubleshooting of difficulties encountered.

PURPOSE

For each caregiver to share with the group their experiences of applying the functional behaviour plan developed in session 3 and to address difficulties encountered in doing so

Introduction to session 4

Explain to the caregivers that starting a new intervention at home is not easy. It involves doing things differently for both the caregiver, the child and other members of the family. Therefore, it is quite normal to encounter some problems initially and this should not be a discouragement.

Say to them that one of the most famous scientist in the World ever (Albert Einstein) said “the only person who has never made a mistake is someone who has not tried anything new”. So it is ok if they found the initial practice difficult and if they made mistakes. The purpose of the session is to provide opportunity to discuss what has worked well and help resolve the situations that have not gone as well as hoped.

But privately as the caregivers arrive how they found the start of the programme at the start the feedback with caregivers who have achieved some success with the plan. This will encourage other caregivers who may have it harder to see that success is achievable

Move onto the caregivers who found it difficult and discuss what the problem was and resolve it. Encourage caregivers who were more successful to share and support those who were less successful.