

**HELP-SEEKING BEHAVIOUR OF PARENTS OF
CHILDREN WITH AUTISM SPECTRUM
DISORDER IN ACCRA, GHANA.**

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**THIS DISSERTATION IS SUBMITTED TO THE UNIVERSITY
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DECLARATION

I, **GETRUDE ABBEY**, do hereby declare that this dissertation which is being submitted in fulfillment of the requirements for the Master of Science degree in speech and language therapy is the result of my own research performed under supervision, and that except where otherwise other sources are acknowledged and duly referenced, this work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

I hereby give permission for the Department of Audiology Speech and Language Therapy to seek dissemination/publication of the dissertation in any appropriate format. Authorship in such circumstances to be jointly held between me as the first author and the research supervisors as subsequent authors.

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DEDICATION

This work is dedicated to the Almighty God. The dedication is also extended to my husband, Mr. Samuel Essel Otabil; my mother, Ms. Emelia Quaye; my children, Samuel and Emmanuel; my family; and all families with children with Autism Spectrum Disorder in Ghana.

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LIST OF ABBREVIATIONS

APA:	American Psychiatry Association
ASD:	Autism Spectrum Disorder
ASOG:	Autism Society of Ghana
DIET:	District Inclusive Education Team
GHS:	Ghana Health Service
GAPH:	Global Autism Public Health
HSB:	Help-Seeking Behaviour
IE:	Inclusive Education
LMIC:	Low and Middle-Income Countries
NGO:	Non-Governmental Organization
QOL:	Quality of Life
SLT:	Speech and Language Therapy
SLTs:	Speech and Language Therapists
SS:	Special Schools
UK:	United Kingdom
USA:	United States of America
WHO:	World Health Organization

ABSTRACT

Background: An understanding of where families affected by Autism Spectrum Disorder (ASD) seek help is important in the development of services in a country like Ghana where speech and language therapy is a relatively new concept. It appears there is very limited literature related to the help-seeking behaviour (HSB) of parents of children with ASD in Ghana. It is important to respect where parents seek help from in order to build on the existing practices in the provision of services.

Aim: The aim of the study is to explore the help-seeking behaviour of parents of children with ASD in the city of Accra, Ghana.

Method: The study employed a qualitative design specifically, phenomenological approach. A convenience sampling technique was employed to select 10 parents of children with ASD. A semi-structured interview guide was used to collect the data. Participants were requested to report on their own experiences of seeking help for their children with ASD. Interviews were audio recorded, transcribed and analyzed with qualitative content analysis.

Results: Ten respondents participated in the study. The results indicated that the places parents seek help from are the educational, health and religious sectors. Parents also seek help from health personnel and religious leaders. The help parents receive from the sources include information, counseling, support, assessment and speech therapy. The major challenge parents face is financial challenge. The most useful source of help identified was the special need school and the least useful help was from the church.

Conclusion: This information is useful in the structure of services for parents of children with ASD.

CHAPTER ONE

INTRODUCTION

1.1 Background

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by a deficit in social interaction, communication and repetitive restricted behaviour that is noticed before the age of 3 years (American Psychiatry Association, 2013). It starts in childhood and tends to continue into adulthood. Some individuals are able to live independent lives but others need support throughout their lives (WHO, 2017).

Continuing research has not been able to identify a clear cause (Yates & Couteur, 2016) but there is evidence that it is caused by some genetic and environmental factors (Deth, Muratore, Benzecry, Power-Charnitsky, & Waly, 2008). The cultural belief of the cause of a disease and societal norms affect how people respond and seek help for that condition (Wegner & Rhoda, 2015). According to the Western World, ASD is believed to be caused by genetic and environmental factors (WHO, 2017) whiles in many parts of Africa, it is believed to be caused by evil spirits and witchcraft (Bakare, 2009).

Studies in Africa, though limited, have shown that cases presented for orthodox clinical practice are characterized by late presentation/diagnosis, normally above the age of 8 years and in turn, late intervention. This has been attributed to low levels of knowledge and awareness about ASD in Africa, the problem with help-seeking behaviour and lack of mental health care facilities and trained personnel (Bakare & Munir, 2011).

There is significant and widespread stigma attached to ASD (Kinnear, Link, Ballan, & Fischbach, 2016) as well as the emotional and economic burden on both the individuals and their families (WHO, 2017). The future of children diagnosed with ASD is uncertain (Mackintosh, Myers, & Goin-kochel, 2005). Parents go through lots of stress and confusion

as they try to understand their children's difficulties (Chao, Chang, Chin, Li, & Chen, 2017). People with disabilities (which includes ASD) generally have poor health, low educational achievement, fewer economic opportunities and a higher rate of poverty (WHO, 2011). A study conducted by Das, Das, Nath, Dutta, Bora & Hadarika (2017) in East India with a marginalized population indicated that the impact of ASD affects not only parents but also grandparents and siblings. The process of parenting has been a challenge for many. Some parents have had to discontinue their jobs to dedicate more time to caring for their children.

Children with ASD in Africa have less access to appropriate developmental services (Ruparelia et al., 2016). In Ghana, a child with a disability of school-going age should be enrolled in a school ("Persons With Disability Act, 2006 Act 715," 2006). Children with disability are really underrepresented in the Ghanaian education system and the special education needs of those who are enrolled are not really met (Anthony, 2010). There are also limited recognized rehabilitation services in Ghana (Wylie et al., 2017).

There is no known medication that directly treats the core symptoms of ASD (Yu & King, 2016; WHO, 2011). There is however, evidence that early intervention is crucial and the earlier intervention is started, the better the effect on the child's development (Koegel, Koegel, Ashbaugh, & Bradshaw, 2014). The core symptoms of ASD: the lack of joint attention and reciprocal communication can be managed with early social-communication based intervention (Yates & Couteur, 2016; NINDS, 2015).

Though there is very limited data on ASD in Ghana, a study conducted by Manu (2012), on the topic, 'belief and attitude concerning autism in Ghana', indicated that parents' help-seeking behaviour is affected by what they believe to be the cause of ASD. Parents who attributed the cause of ASD to unknown factors as well as those who attributed it to biological factors sought for biological (behaviour training) and religious intervention for

their children (Manu, 2012). People are also likely to seek help from a variety of sectors for communication disorders in Ghana (Wylie et al., 2017).

Careful examination is needed as efforts are being made to develop the profession of speech and language therapy in Sub-Saharan Africa to assist with the rehabilitation process of people with communication disorders. The traditional models of intervention are respected and therefore should not be abandoned completely. Speech and language therapy originated from the Western countries and therefore the practice is based on their culture (Pillay & Kathard, 2018). Geiger (2015) has however expressed the importance and need for building on culturally relevant approaches and practices to be adopted in the management of communication disability in Africa. The traditional models of intervention are respected and therefore should not be abandoned completely.

According to the above literature, lack of knowledge about ASD is one of the reasons that cause parents to look for treatment at various places and therefore end up reporting late for diagnosis and subsequent intervention which in turn affect the child's functional abilities. Which places do parents take their children to seek help and which people do they consult that cause a delay in diagnosing and subsequent intervention? Another reason is the lack of trained personnel. Speech and language therapy is a relatively new concept in Ghana. As such there are very few speech and language therapists in Ghana. Ghana is in the process of training the first batch of speech and language therapists who will assist with the rehabilitation process for people with communication disabilities of which ASD is part. Which places have parents gone to seek help from for their children and what kind of help have they been given over the years? This study seeks to bridge this knowledge gap. This background gives a reason to conduct a study of the lived experiences of parents with children with ASD in Ghana.

1.2 Problem Statement

Autism Spectrum Disorders is noted to be diagnosed late among children in Africa (Bakare & Munir, 2011). This has been attributed to a lack of knowledge about ASD, negative cultural beliefs, and practices, inadequate number of trained personnel and inadequate rehabilitation centers (Bakare, 2009). According to the World Health Organization (2017), there is a global increase in the prevalence of ASD. The following figures given by the Centers for Disease Control, USA (2012) show the increasing trend: from approximately 1 in 110 in 2006, it rose to 1 in 88 in 2008 and 1 in 68 in 2010. Although this trend has been attributed to a number of factors including increased awareness, expansion of diagnostic criteria, better diagnostic tools and improved reporting (WHO fact sheet, 2017), the increase in prevalence makes intervention programmes very crucial (Koegel et al., 2014). According to Shumway and Wetherby (2009), the second year of life is very crucial to examine the early development and emerging symptoms of ASD. There is also an awareness that early intervention can significantly preempt the symptoms. Due to this knowledge, it is crucial to not only identify the disorder early but also to begin intervention programmes as early as possible. Experts working with children who have been diagnosed with ASD agree that early intervention is critical (Corsello, 2005). Early intervention improves communication skills, interpersonal skills, motor skills and play skills. It also reduces autism symptoms and behavioural problems (Burnette, Biswell, & Trott, 2016). However, factors such as parents' educational status, the extent of knowledge about ASD, income status, and the geographical location affect the choice and initiation of service (Alnemary, Aldhalaan, Simon-Cereijido, & Alnemary, 2017). This leads to delay in diagnosis and subsequent treatment, which leads to lower educational and functional outcome (Antezana, Scarpa, Valdespino, Albright, & Richey, 2017).

Autism Spectrum Disorder is a relatively new disability in Ghana. There are just a few schools in Accra to serve children in this population, the majority of which are private schools. Some of these schools are not easily accessible to the population due to the high level of fees charged. A lot of progress has been made over the past years through the work of parents' advocacy and awareness creation. However, very little is understood about the experiences of parents as they seek help for their children.

It appears there is no literature in Ghana to know how, or if people with communication disability help themselves or seek help (Wylie et al., 2017). There is no published document with respect to the situation in Ghana. Currently, no study has been conducted to investigate the help-seeking behaviour of families with children with ASD from the ages of three (3) years to eighteen (18) years. In light of the above consideration, it is therefore imperative that a study is carried out to investigate the help-seeking behaviour of parents of children with ASD. There is much to be gained from studying the lived experiences of parents in order to better inform about efforts towards the improvement of the situation of parents and children diagnosed with ASD.

1.3 Aim of the study

The aim of the research is to understand the help-seeking behaviour of parents of children with ASD in the city of Accra, Ghana.

1.4 Specific objectives of the study

- To determine the places and people parents of children with ASD report having sought help from to address the needs of their children.
- To explore the help parents of children with ASD report they received from the sources they found.
- To identify the challenges of parents of children with ASD when seeking help.

- To identify the type of help parents report as most and least useful.

1.5 Significance of the study

This research will provide information on the experiences of parents of children as they raise their children with ASD. This will give an insight into the journey of these parents. This research will also make a number of contributions to the country and the world at large on the issue of ASD.

There is a body of literature on raising children with ASD across the globe but there is limited literature in Ghana which describes the experiences of parents in Ghana. This research conducted by this author will be shared with other researchers and therefore it is hoped that it will inform the need for services and support for families raising children in this population in Accra.

Again, this research will encourage other researchers to further explore the experiences of parents with children with ASD to better understand how to approach service delivery. Further research in this area will help a better understanding of the parents' priority and expectations for their children's development which is essential for treatment planning. The study will provide results on the help-seeking behaviour of parents of children with ASD in Accra. The practice of the people will be understood and therefore could be incorporated into service planning.

This research will also help direct the kind of information to be given to the general public in terms of where to seek help and the need to seek help as early as possible in order to improve quality of life and function. The results of the research may guide policy makers to assess the need to allocate funds to set up rehabilitation centers and whether there is a justification to train more speech and language therapists to help with the rehabilitation process.

1.6 Organization of the work

This dissertation is divided into six main chapters organized as follows:

- Chapter One discusses the nature and background of the research problem, identifies the research objectives and significance of the study.
- Chapter Two covers relevant literature related to Autism Spectrum Disorder and help-seeking behaviour.
- Chapter Three deals with methods and techniques used for data collection.
- Chapter Four discusses the results and findings of the data collected.
- Chapter Five deals with the discussion of the results enumerated in Chapter Four.
- Chapter Six deals with the conclusion drawn from the study and makes appropriate recommendations to the Regional Health Directorate and the Ministry of Health as well as other professionals involved in the provision of services to persons with ASD and their families.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter reviews relevant literature and covers Autism Spectrum Disorder, the impact of ASD on families and the individual, importance of early intervention, rehabilitation services, beliefs and perceptions about ASD. It also covers the effect of ASD on the individual and the family, the Ghanaian culture and ASD, importance of early intervention for ASD, beliefs and perceptions about ASD, role of education in ASD, help-seeking behaviour, help-seeking behaviour in ASD, factors that influence the choice of help, rehabilitation services for ASD and then the research gap.

2.1 Autism Spectrum Disorder

Autism Spectrum Disorder is a neurodevelopmental disorder that is characterized by social communication deficit, challenges in social interaction and restricted interest and repetitive behaviour (American Psychiatry Association, 2013). It was first discovered by Leo Kanner in 1943 where he described eleven children he had studied as having autism. He noticed that these children just wanted to be by themselves and away from others. The children had a combination of severe social and variable language dysfunction as well as repetitive restricted behaviour (Kanner, 1943). Autism Spectrum Disorder as the name implies, is a spectrum disorder. The term "spectrum" refers to the wide range of symptoms and the levels of impairments that people with ASD can have. The diagnosis of autism in children who have fewer support needs may have a presentation similar to other developmental disorders. Also, those with significant support need are also likely to have symptoms that overlap with other developmental disorders such as language delay and non-verbal social disorder (Autism Speaks, 2018; Koegel, Koegel, Ashbaugh, & Bradshaw, 2014).

According to the World Health Organization, the global average prevalence of ASD has been estimated to be 1 in 160 as of 2013 which is accounting for 0.3% of the global burden of disease. Although well-controlled studies have reported higher values, the prevalence in many low and middle-income countries including Ghana is yet unknown (World Health Organization, 2013). The number of diagnosis of ASD has increased over the years (Koegel et al., 2014). The Autism and Developmental Disability Monitoring Network has been tracking the prevalence of ASD. This was done for the Centers for Disease Control and Prevention (CDC). The prevalence of ASD was stated to be approximately 1 in 110 in 2006, 1 in 88 in 2008 and 1 in 68 in 2010 (Centers for Disease and Control, 2012). Studies have shown that autism is four times more common in boys than in girls (Yu & King, 2016). Another study also revealed that boys are 4.5 times more likely to be identified with ASD than girls (National Center on Birth Defects and Developmental Disabilities, 2016).

The manifestation of symptoms of ASD ranges from mild to very severe. Some of the signs and symptoms of ASD includes the following: avoidance or inconsistent eye contact, keeps to self, delayed speech and language, gives unrelated answers to questions, gets upset with little changes in routines, repetition of words or phrases (echolalia) and difficulty with topic maintenance during conversations (National Institute of Mental Health, 2015). Individuals with ASD may also have co-morbid conditions which include seizure disorder, depression, anxiety and attention deficit hyperactivity disorder (ADHD) (Centers for Disease and Control, 2012).

Diagnosing ASD can sometimes be challenging since there is no medical test that can be done to diagnose the disorder (Centers for Disease Control and Prevention (CDC), 2018). There are also individual variations in the degree of severity, language and intellectual abilities which make diagnosing challenging (Yates & Couteur, 2016). Autism Spectrum Disorder can be detected as early as 18 months or younger but can be diagnosed between 2 to

3 years (CDC, 2018). The diagnostic and statistical manual for mental health, fifth edition (DSM-5) gives a guideline for diagnosing ASD (American Psychiatry Association, 2013).

According to the National Institute of Neurologic Disorders and Stroke (2015), there is no known cure for ASD. Therapies and behavioural interventions are designed to remedy specific symptoms and can substantially improve symptoms. The ideal treatment plan coordinates therapies and interventions that meet the specific needs of the individual. Most health care professionals agree that the earlier the intervention, the better.

Until some few years ago, ASD was thought to occur in developed countries with advanced technology (Bakare & Munir, 2011). A literature search conducted on case series and case reports of ASD in Africa identified that apart from the core symptoms of ASD which are, impairment in social interaction, communication and restricted, repetitive repertoire of behavior, the majority of the cases that presented to the orthodox clinical practice was non-verbal. A common co-morbid disorder that was also noticed was intellectual disability (Barnevik-Olsson, Gillberg, & Fernell, 2008) and epilepsy (Belhadj, Mrad & Halayem, 2006).

Another observation that was made is late presentation/diagnosis which eventually leads to late intervention. Majority of the cases presented for the first time were above the age of 8 years. The attempted explanation given to this observation included a low level of knowledge and awareness about ASD in Africa, the problem with HSB, the lack of trained personnel and mental health care facilities (Bakare & Munir, 2011). Findings from Africa indicate late identification and poor level of awareness despite the constant demonstration by research that ASD can be identified as early as during infancy (Bello-Mojeed, Bakare, & Munir, 2014).

2.2.1 Impact of ASD on the Individual and the Family

The family provides the major source of support for children with disabilities. Most caregivers are mothers and fathers. Grandparents are also available to provide custodial care (Neely-Barnes & Dia, 2008). Studies have shown that life proves to be difficult and frustrating for parents of children with ASD than other long-term disabilities (Koegel et al., 2014). Mothers of children with ASD express more anxiety, stress, and depression (Hodgetts, McConnell, Zwaigenbaum, & Nicholas, 2016). Reducing parental stress and improving quality of life (QOL) is a continuous concern for families of children with ASD. Reducing parental stress could improve the QOL for these families and vice versa (Hsiao, Higgins, Pierce, Schaefer, & Tandy, 2017).

A recent report by the World Health Organization (2017) stated that ASD often imposes significant emotional and economic burden on people with the disorder and their families. Some major challenges also include social stigma, isolation, and discrimination. A study conducted by Das, Das, Nath, Dutta, Bora & Hadarika (2017) in East India with a marginalized population indicated that the impact of ASD affects not only parents but also grandparents and siblings. The process of parenting has been a challenge for many. Some parents have to discontinue their jobs in order to dedicate more time to caring for their children. There is a significant and widespread stigma attached to ASD (Kinnear et al., 2016) as well as the emotional and economic burden on both the individuals and their families (WHO, 2017).

2.2.2 Stigma

Stigma is defined by Goffman (1963), as “an attribute that is deeply discrediting and that reduces a person from a whole and unusual person to a tainted and discounted one”. It therefore, infers that stigma represents something disgraceful about the individual. Goffman further pointed out that these attributes are socially defined and therefore separating what is

accepted as normal from what is not. It therefore means that stigma is not a feature of physical characteristics but rather develops as a result of social reactions to such characteristics. According to Goffman, there are three types of stigma: physical deformities, behavioural attribute and attribute related to belonging to a particular group or race.

According to Agbenyega (2003), stigma is the negative and prejudiced ways people with disability are labelled. Superstition, lack of knowledge/ignorance, old belief systems and a possibility to exclude people who are perceived as different are some of the causes of stigma (Avoke, 2002).

Public attitude towards people with disability in Africa is often based on fear and misunderstanding leading to stereotype which exposes them to prejudice, discrimination and ultimately denial of rights and resources that are offered to all citizens (Baffoe, 2013).

A study conducted in South Korea by Grinker (2007) indicated that cultural stigma was intense in the urban areas and therefore forcing families to have a change in lifestyle. Many families found it easier to raise their children with ASD in the rural setting rather than in the urban setting. They therefore either give up their jobs and move to the village or send the child to parents or grandparents in the village. It is also reported that families in the village had less discomfort with talking about children with ASD while families in the cities refused to talk about the children for fear of further shaming the children and their families.

A study conducted by Baffoe (2013), on persons with disability in Ghana revealed the first major concern of persons with disability as stigma. He further stated that “stigma is the single most difficult barrier to living a “normal” and productive life by persons with disability”.

Stigma results in fear, stereotyping, anger, low self-esteem, avoidant behaviours, self-blame among others (Dhar, 2009 cited in Baffoe, 2013). Stigma can also prevent people from

seeking help; it can also lead to a state of despair when in fact persons with disability can function when societal barriers are removed. It can also prevent individuals from advocating for services that may eventually have an impact on social policies and laws (Baffoe, 2013).

2.3 The Ghanaian Society and ASD

In the Ghanaian society, pregnancy and birth are perceived as a blessing and therefore associated with high expectations. Children are seen as assets and therefore measures are put in place to protect the child from being born with a disability. Pregnant women are subjected to the compliance of various taboos and rituals especially in the rural communities to ensure the child is not born with any disability (Agbenyega, 2015).

The expectation from the family after birth is for the child to be able to sit, crawl, walk as well as other activities within an expected timeframe. Any diversion from this expectation is considered a breach from that traditional belief system (Avoke 2010). The birth of a disabled child could lead to negative reactions from the family.

Some ethnic groups in the Ghanaian society have a belief that children born with any kind of disability are outcasts who will not be able to be integrated into the society. They are also seen as not having the capacity to achieve anything beneficial in life (Slikker, 2009). Persons with disability and their families are treated differently from all other persons in many countries including Ghana. They are seen as a punishment from God (Avoke, 2002). Even though disabled children are targets of abuse, such issues remain mostly undocumented open secrets in many countries including Ghana (Kassa, 2012).

According to WHO (2017), the level of intellectual functioning of an individual with ASD varies from profound impairment to superior level. They are also often subject to stigma, discrimination, and human rights violation.

In Ghana, individuals with intellectual disability are given demeaning names in the various local dialects within the different ethnic groups (Agbenyega, 2005). Agbenyega further stated that these names signify insults such as idiots, fools, and feeble-mindedness. The “Gas” call them “buuluu” which means reduced mental ability. Again, the Ewes in the Volta Region refer to them as “asotowo” meaning a fool or an idiot. These names are influenced by the belief systems of the Ghanaian society which affect the individual negatively.

Sadly enough, the individual is not the only person affected by the impact of the disability. It extends to significant others such as the family members and other individuals who have some form of relationship with the individual (Anum, 2011). Studies done on the family and disability have concluded that stigma is experienced from the general public even though the family members do not necessarily have the disability (Anum, 2011; Slikker, 2009).

2.4 Importance of Early Intervention for ASD

There is evidence that early intervention is crucial and the earlier intervention started the better the effect on the child’s development will be (Koegel et al., 2014). Early intervention also reduces the cost of intervention (Jacobson, Mulick & Green, 1998; Jacobson & Mulick, 2000; Chasson, Harris & Neely, (2007). The increased prevalence of ASD has led to the payment of attention on assessment and intervention issues. Findings from Camarata (2014) indicated ASD as being a lifelong disability. Other case examples have children who have been able to eliminate their symptoms to a level where they are able to fit into the society (Koegel & LaZebnik, 2004; Lovaas, 1987). More than half of these children have been able to function eventually without the need for any special support. This is however unlikely without early intervention. There is an increased likelihood of improved healthcare outcome with early intervention (Koegel et al., 2014). The core symptoms of ASD, lack of joint attention and reciprocal communication can be managed with early social-communication

based intervention (Yates & Couteur, 2016; NINDS, 2015). Early intervention enhances the potential for independence in adulthood (Chua & Wong, 2017).

2.5 Beliefs and Perceptions about ASD

The perception of new events is influenced by one's family and cultural values. The cultural values of people shape their thoughts and feelings about themselves and the world around them, as well as how they treat people with ASD. The family is the basic unit of socialization and is important in defining the roles and rules of conduct (Pitten, 2008). There are a number of beliefs and perceptions about ASD. According to WHO (2017), ASD is believed to be caused by genetic and environmental factors. In many parts of Africa, it is believed to be caused by evil spirits and witchcraft (Bakare, 2009). In the South Korean and Chinese cultures, autism is believed to be caused by the sins of parents and ancestors. In the Pakistani, Bangladeshi Muslim and Ultraorthodox Jewish communities, it is believed to be caused by their god's will. In Western medicine, autism is believed to be genetic, incurable and the individual will be limited in many aspects of their daily lives (Ecker, 2010).

A research conducted by Gona et al. (2015), among parents and professionals in Kenyan Coast revealed the belief in preternatural causes of ASD as evil spirits, witchcraft and curses. They also believe there are biomedical causes which include: infections, drug abuse, malnutrition, birth complication and genetically related problems. The treatment of ASD was also perceived to vary from traditional and spiritual healing to modern treatment in health facilities. It also included consultation with traditional healers, offering prayers to God and visit the hospital (Gona et al., 2015).

2.6 Role of Education in ASD

The Ghana Education system has not been able to effectively address the needs of pupils with learning disability in the mainstream schools. The fundamental reason has been attributed to

the lack of competence by teachers to handle children with special needs (Alhassan & Abosi, 2014). Inclusion in education is based on the fact that every child will be able to achieve his/her maximum level if given the right support and educational opportunity (Agbenyega, 2008).

A research conducted by Anthony (2010), on access to education for students with ASD in Ghana identified a number of challenges including Institutional challenges. There are a number of different agencies responsible for the provision of special education in Ghana. These agencies are the Ghana Education Service, Ministry of Education, Social Welfare and Assessment centres. Unfortunately, the sharing of responsibilities between these agencies has often resulted in confusion, bureaucracy, responsibility shifting and lack of collaboration. The referral system for students who are already in school can be confusing due to lack of specialists, shortage of equipment and absence of screening procedure. Another revelation was that children with ASD were seen as useless and therefore there was no need to invest in their education. Again current policies in Ghana are neither effective nor enforced to be able to change the beliefs about disability. It is therefore causing a major barrier to the implementation of inclusive education and education for all (Anthony, 2010).

Financial and support of educational services for persons with special needs is a primary concern for all countries regardless of available resources (Peters, 2003).

According to the Ministry of Education on the revised edition of the inclusive education policy of Ghana (2015), mainstream schools are to provide education for all children regardless of their physical, intellectual, social, emotional, linguistic or other conditions. However, special schools also have an important role to play in the implementation of inclusive education. Special schools are to work hand in hand with the regular schools to accommodate children with special needs in the regular schools. Every special needs school

has to be connected to an assessment centre with well trained personnel and equipment to foster periodic screening, assessment and diagnosis. Again, personnel from the special schools are to be included in the District Inclusive Education Team (DIET) to enhance monitoring and evaluation of school reforms to achieve inclusion (Government of Ghana, 2015).

2.7 Help-Seeking Behaviour

Help-Seeking Behaviour (HSB) is the concept that is used for exploring and understanding patients' delay and prompt action across a variety of health conditions. The term is used interchangeably with health-seeking behaviour. It is the act of searching for a relief or cure for a health need (Cornally Nicola and Geraldine McCarthy, 2011). According to Nadler (1991), help-seeking interactions involve three entities; the person in need of help, the helper and the need. According to McCarthy & Nicola (2011), researchers of HSB agree that problem recognition and definition of the problem must occur before help-seeking behaviour can be executed. Help seeking behavior is a representation of a deliberate action to solve a problem that challenges personal abilities. It is a complex decision-making process that begins with the identification and definition of a problem, leading to a decision for an action. Once the intention to act is formed, selection of the source of help is made. Contact and disclosure of the problem are made in exchange for help (Nicola & McCarthy, 2011).

Help-seeking behaviour is connected with a specific problem. There cannot be help-seeking if there is no problem or difficulty from which to provide relief. Help-seeking behaviour generally involves more than one person. In the process of seeking help, a person looks for another to provide assistance or relief. Help seekers play an active role in the help-seeking process. In that, they have to search their environment to find individuals who have solutions to their problem and initial interaction with these potential helpers. In other words, help

seekers play a major role in determining whether they get the help they need or not (Lee, 1997).

2.8 Help-Seeking Behaviour for ASD

There is limited research investigating communication disability responses in the region (Wylie et al 2007). According to literature, parents seek help from more than one source. Some parents reported having sought information from an average of five (5) to six (6) different sources (Mackintosh, Myers, & Goin-kochel, 2005).

There is a similar study in communication disability conducted by Hopf et al. (2017), in Fuji on the topic, communication disability in Fuji: community self-help and help-seeking behaviour. It was a thematic analysis of 144 questionnaires about actions to support a fictional child and adult with a communication disability. Responses were in 2 categories: what they will do themselves (self-help) and where they will seek help from (help-seeking). Help-seeking behaviours included seeking help from community members, professionals, spiritual leaders or western medicine practitioners.

A study conducted in the Philippines by Quilendrin et al. (2015) revealed the majority (78%) of children's symptoms were recognized by family members/relatives. After recognition of symptoms, 34% of parents initially sought help from a general or developmental paediatrician; 7% from relatives, 7% from the internet; 5% from teachers, 5% from neurologist, 5% from friends; and 2% from religious leaders. The diagnosis was confirmed by a developmental paediatrician in the majority (83%) of the cases at a mean age of 39.39 months which is 14.98 months after initial recognition of symptoms.

Another research conducted by Mire et al. (2015) indicated that school-based services are among the most frequently used by parents. Parents rely on the school to provide intervention for their children.

Among the native population within the West African culture, especially those less affected by Western Culture, traditional and faith healers play a very important role in counseling the community on various health-related conditions (Semela, 2001). In many parts of Africa, many less severe cases of autism are likely to seek help from prayer houses, spiritual and traditional healers while more severe non-verbal with intellectual disability are more likely to present to the orthodox medical practice for help. This is largely because of intolerable symptoms to the parents (Bakare, 2016).

Another study in Ghana by Wylie et al (2017) on the topic, self-help and help-seeking behaviour for communication disorder indicated a likelihood for people to seek help from a variety of sectors. These include: Western healthcare sector (Doctor, Hospital, Medical Specialist, Nurse, SLT/ speech specialist, Midwife, Speech and hearing center, health center and psychiatry hospital); religious sector (pastor, priest, imam, God, Prayer camps, church); traditional belief sector (herbalist, spiritualist, fetish priest, traditional doctor, native doctor, shrine, witch camp, witch doctor); community sector (community members, elderly persons, orphanage); education sector (school for the deaf, mainstream school, special school, teacher); others (parliamentarian, non-governmental organization, gym, government, asylum).

The family is also another means of support for people with communication disability. Without the primary support from the family person with disabilities will not be able to break social barriers due to their inability to access education and other developmentally useful services (Opoku et al., 2017).

2.9 Factors that Influence the Choice of Help for ASD

A number of factors influence the choice of treatment. These include both parental and child factors. Child factors include child's age, cognitive function and ASD symptoms. Parental

factors include family income, parent's level of education, parents perception of ASD, cultural background (Mire, Gealy, Kubiszyn, Burrige, & Goin-Kochel, 2015) and the geographical location (Alnemary, Aldhalaan, Simon-Cereijido, & Alnemary, 2017). Help-seeking behaviour is also influenced mainly by sociocognitive factors (Cornally Nicola and Geraldine McCarthy, 2011). The cultural belief of the cause of the disease and societal norms affect how people respond and seek help for that condition (Wegner & Rhoda, 2015).

There is very limited data on ASD and help seeking in Ghana. A study conducted in Ghana by Manu (2012), on the topic, belief and attitude concerning autism in Ghana, indicated that parents' HSB is affected by what they believe to be the cause of ASD. Parents who attributed the cause of ASD to unknown factors sought for biological (behaviour training) and religious intervention. Parents who also attributed the cause to biological factors also sought for both biological and religious intervention for their children (Manu, 2012).

2.10 Parents Preferred Source of Help

Mackintosh, Myers and Goin-Kochel (2006), conducted a survey of parents of children with ASD to examine their sources of information. It was revealed that the most common source was the opinion of other parents of children with ASD. It was then followed by books and websites rather than other professionals. Another study by Osborne and Reed (2008) on communication between health professionals and parents of children with ASD using focused group discussion revealed that parents had difficulty with obtaining information from professionals. They therefore went out to seek information on their own which led to increased anxiety and worry. Based on their experience, the parents suggested the need for health professionals to be trained on interpersonal skills to know how to give information and also know the kind of information to give to parents.

A study by Hand (2006) also revealed that professionals are barriers to information seeking. According to Hand, the manner in which some professionals asked questions and explained information did not invite parents to ask questions.

There are three major religions practiced in Ghana. Christianity is predominantly practiced in the south, Islam in the northern part and followers of traditional African religion is spread throughout the country. Ghana is known to employ both spiritual healing and orthodox medicine for the treatment of diseases (Adu-gyamfi, 2015). Treatment for disability is often sought by means of prayers, visit to the prayer camps or spiritual leaders. Sometimes traditional doctors are consulted for treatment (Slikker, 2009).

2.11 Rehabilitation Services

According to the World Health Organization (2011), it is estimated that one billion people worldwide experience some form of disability and need health and rehabilitation services. A study conducted from data for assessing supply and the need for rehabilitative personnel was extracted and analyzed from the statistical database of the WHO and other national and international health information sources. Findings from the study paint a global picture of the need for human resources for rehabilitation, but sadly and not surprisingly, there is an inadequate supply of rehabilitation health professionals among the low and middle-income countries. Many of these countries are located in sub-Saharan Africa. This region also happens to be the region where the disease burden related to causes requiring rehabilitation professional skills tends to be greatest (Gupta, Castillo-laborde, & Landry, 2011). Rehabilitation service development is therefore very necessary. In North East India, there are very limited centers available to provide equipped formal training techniques (Das, Das, Nath, Dutta, & Bora, 2017). There is often poor access to appropriate support and services in low

resource context. Globally, access to services and support for people with ASD is inadequate (WHO, 2016).

The Global Autism Public Health (GAPH) Initiative which was launched in 2008 in collaboration with partners from more than twenty (20) countries across six (6) continents have models which involve several components. One of the components was about the process for developing an effective ASD awareness campaign. It suggested that coordination of awareness activities with research and service development is critical for success, as increased awareness is likely to increase demand for the service (Wallace et al., 2012).

A research conducted in seven (7) West African Countries including Benin, Burkina Faso, Mali, Niger, Senegal, Sierra Leone and Togo in 2011 by Handicap International/ DECISIPH Project on the topic “Access to Services for people with disability” revealed a lack of accessibility to rehabilitation services (Bruce, 2011). Other studies have also stated the lack of rehabilitation services in low and middle-income countries (Jesus, Landry, Dussault, & Fronteira, 2017) Despite greater need, low and middle-income Countries have less trained personnel skilled in rehabilitation services. Rehabilitation is largely a human endeavor and therefore there is a need to have the right number of trained personnel (Gupta, Castillo-Laborde, & Landry, 2011). There is an exceedingly small number of speech and language therapists in the ‘Majority World’ Countries. Most global activities about communication disability are held between SLTs in high-income countries, rather than including recently established groups in the low-income countries. There is a need for more links between SLTs in the Minority and Majority Worlds with the aim of promoting the rights of people with communication disorders (PWCD) (Wickenden, 2013).

Ghana has a population of 29.6 million and is one of the leading countries in Africa with freedom of speech and press freedom (World Bank, 2018). It is also a signatory to the

Convention on the Rights of Persons with Disabilities. There is limited Recognition of rehabilitation services for communication disability in Ghana (Wylie et al., 2017) and for that matter ASD. There are increasing trends of shifting towards inclusion but the practice of institutionalization seems unlikely to change (Avoke 2001). Speech and language therapists are part of the team involved in the rehabilitation process of children with ASD. There are approximately 5 Speech and Language therapists practicing in Ghana. Although there are limited services for communication disability in Ghana, the development of information with respect to help-seeking activities families are likely to engage in will give the new profession of SLT an opportunity to build on what families are already doing in Ghana (Wylie et al., 2017).

2.12 Barriers to access of services

There are several factors that influence access to ASD services. These include geographical and financial barriers. Limited services availability is also a dominant barrier (Dababnah & Bulson, 2015). According to Antezana et al. (2017), rural communities face significant challenges regarding the adequate availability of services for ASD. This leads to risk for delayed ASD screening and diagnosis, yielding lower educational and functional outcomes due to late implementation of the intervention. A qualitative study conducted in Toronto, Canada with immigrant mothers of children with ASD from diverse ethnocultural background revealed that there are inequalities in the current access pathways for ASD. There is, therefore, the need for focused attention to address it (Khanlou et al., 2017).

A research qualitative study conducted by Dababnah & Bulson (2015), in a landlocked area in the Middle East bounded by Israel and Jordan called the West Bank on the topic, access to autism-related services revealed that there was a difficulty with finding trained professionals to provide the needed services. There was also the financial cost of the services provided which was a persistent problem for the majority of the participants. Another barrier was

geographic barrier which was also a major problem for the majority of the participants. It was again revealed that a lack of local health, educational and supportive services for children with ASD in the West Bank. It, therefore, means that parents who were not able to travel with their children outside the West Bank for the necessary services had to keep their children at home without any treatment.

A research conducted in the northern part of Ghana (Tamale) among people with disability outlined a number of barriers that prevent access to services. These include among others: attitudinal barriers (labeling/stigma, discrimination, negative imagery of persons with disability); institutional barriers (rehabilitation centres, non-performing laws) and informational barriers (Naami, 2014).

2.13 Research Gap

Few studies on ASD have been reported in Ghana and very few have been reported on help-seeking behavior with respect to ASD. Currently, no research study is available on the help-seeking behavior of parents of children aged between 3 years and 18 years with ASD in Ghana. There is, therefore, a gap in the literature. No research has also been conducted to determine the kind of help parents received from the places they sought help from to address the needs of their children with respect to the same age range. Again, no research has been conducted on the challenges parents face in the process of seeking help for their children. Finally, no research has been conducted on the usefulness of the help they received at the places they went to seek help. On these bases, this research study was conducted to address some of the research gaps by establishing the help-seeking behavior of parents of children with ASD in Accra.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

This chapter discusses the research methodology that was used to explore the help-seeking behavior of parents of children with ASD. The chapter includes research design, study site, study population, inclusion criteria, exclusion criteria, sampling technique, data collection procedure, data management, data analysis procedure, ethical consideration and dissemination of results.

3.1 Study Design

A qualitative research design, specifically phenomenology was employed. This research design was chosen because the study intended to explore the lived experiences of parents whose children have been diagnosed with ASD with respect to the places and people they have sought help from, the kind of help they were given, which ones they reported were most useful and least useful and the barriers they faced when seeking help for their children. According to Kvale (2006), interviews allow people to freely present their lived experiences in their own words. It also helps the researcher and the respondent to have a close personal interaction.

3.2 Study Site

Data for the study was collected from Greater Accra, the capital city of Ghana. Ghana is located in West Africa. Its North, South, East and West borders are delineated by Burkina Faso, Gulf of Guinea, Togo and Ivory Coast respectively. The current population of Ghana is 29.6 million (World Bank, 2018). There are 10 regions in Ghana. Greater Accra is the smallest but most populous and most urban city in Ghana. It is made up of people from different religious background and ethnic groups with the major ones being Ga-Dangbe,

Akan and Ewe (“Accra Population,” 2018). Most special needs schools are found in this region. For this reason, the researcher chose to conduct the study in Greater Accra.

Within the Greater Accra Metropolitan Area, Autism Awareness Care and Training (AACT) Centre is one of the special schools that focuses exclusively on children with ASD. The children are also from different ethnic groups, socioeconomic and religious backgrounds.

Autism Awareness Care and Training (AACT) Centre was established in 1998 by Mrs. Serwah Quaynor. Her son was diagnosed with Autism at the age of 2 years in the United States of America. She returned to Ghana with her son in 1998 when he was 16 years old. All efforts to find services proved difficult. She was therefore motivated to form autism family support group and then this led to the establishment of AACT. The vision of the Centre is to see a society that is more inclusive and sensitive to the needs of persons with ASD. Their mission is to work to support individuals and families affected by ASD (Autism Awareness Care and Training, 2018).

3.3 Study Population

The population is the group of individuals who the finding and the implication of the study are generalized (Sampson, 2012). The population for the study is made up of parents who have children with ASD.

3.3.1 Sample Size

According to Gall et al. (1996), a sample is a selection from the population that the researcher wants to study. The total sample size for this study consisted of 10 respondents.

3.3.2 Sampling

Sampling is the method used to select a given number of people or things from a population (Mertens, 1998). Gall et al. (2003) also added that a sampling procedure could be used only

when a target population is identified. The sampling technique used for the selection of the participants was a convenient sampling technique. According to Babbie (2005), this sampling method implies that the individual must be available and willing to participate in the study. This technique was the best from the researcher's perspective because the majority of the parents were not willing to participate. The whole population (30) was targeted for the study. After several visits to the school's premises personally with three (3) outright rejections, several phone calls and text messages, the researcher got access to twenty-three (23) parents who were targeted for the study. One (1) parent went on admission (labour). Five (5) of the parents who gave out their telephone numbers did not respond to neither calls nor text messages. Three (3) of them said they would get back to the researcher but failed to do so. When called, they did not respond to the calls. Two (2) parents said they have been respondents in other studies and have not seen any benefit. Two (2) agreed to take part in the study but on the appointment date, they were out of reach. Several attempts to reach them proved futile. The researcher was therefore left with no choice than to sample by convenience.

3.4 Procedure for Data Collection

A semi-structured interview guide was prepared. The researcher contacted the parents personally at the school premises and informed them individually about the research. The telephone numbers of those interested were taken and contacted individually by the researcher. Participation information sheet was given and explained to them. Appointments were scheduled for those who met the inclusion criteria and agreed to be part of the research. Convenient venues, times and dates were decided on by the participants. They also signed a consent form after the contents were read to them. Those who preferred to be interviewed on the telephone were also sent soft copies of the participation form. Opportunities were given for them to ask any question that needed to be answered before the interview started. The

participants were then interviewed to unearth their help-seeking behaviour and challenges. Eight interviews were conducted in English and two in a local dialect (Twi). Responses were audio recorded.

3.5 Inclusion and Exclusion Criteria

3.5.1 Inclusion Criteria

Participants who were included in the research were parents who have a child or children with diagnosis of ASD. Participants are also 18 years and above. Participants' children are between 3 years and 18 years. All the participants live in Accra with their families.

3.5.2 Exclusion Criteria

Participants who were excluded included parents whose children were older than 18 years. And those whose children did not attend AACT centre.

3.6 Research Tools

The methodological tool used for gathering the information for this study was interview. The respondents were interviewed with a semi-structured interview guide. The interview guide allowed the researcher to ask follow up questions. Avoke (2005) asserted that interviews are important aspects of qualitative studies that allow verbal interaction with the respondents when conducting research. Interviews were also described as a form of a conversation between two people. They could be fully structured, semi-structured or unstructured. He continued that strategies for interviewing could involve the use of telephone, face to face or one-on-one or focus groups.

For this study, one-on-one interview method was employed. Questions were structured based on the literature review and the objectives of the research. There were seven closed-ended questions that were answered for the demographic section of both child and parent. They included: age of child, age of parent, gender of child, gender of parent, relationship, religion,

educational status of parent. Some of these questions help to determine the inclusion and exclusion criteria. The semi-structured questions were also ten in number.

The whole interview was audio recorded. The researcher asked questions and responses were also documented one at a time. This allowed the respondent enough time and also enabled a comfortable environment to share ideas. The interview took approximately thirty (30) minutes. According to Bell (1993), a semi-structured interview allows the respondents the freedom to talk about the topic and share their views in their own time.

Piloting of the questions was undertaken with five parents. Two of whom have children with special needs. The other three have children without special needs. Their views on the structure and the understanding of the questions were requested. Subsequent review was made based on their feedback.

Documentation was also another instrument used in the data collection. Creswell (2005) noted that documents are records obtained by the qualitative researcher about a site or participants in a study. They could be private or public and include newspaper, journals, school records, folders, letters, archived records, correspondence or official government records and official government papers.

With respect to this study, documents such as the admission reports and assessment documents were examined. Their diagnoses were noted as well as some of the schools and facilities the child attended before coming to AACT.

Field notes were also used when the need arises.

3.7 Reliability and Validation

According to Yin (1994), the main objective of reliability is for another investigator to achieve the same findings and conclusion when the same procedure described by the earlier investigator is followed to conduct the same study again. Data was collected from different

sources to ensure reliability. In addition to the interviews, documents from the research setting, field notes and informal observations were also used.

3.8 Data Analysis

The interviews were audio recorded after participants' consent was sought. The recordings in "Twi" were translated to English and transcribed. The recordings were then transcribed in Microsoft Word and saved. The researcher listened to the audiotapes and also read and re-read the transcriptions. This was done to get an idea of the whole data. Ideas were written down as they emerged. One transcript was taken at a time and the underlining meaning were sought and typed according to the objectives of the study. Each objective was taken at a time and similar themes that emerged were put together as one. Qualitative content analysis was used to analyze the data. Qualitative content analysis is an approach that aims at analyzing communicating material in a systematic way (Mayring, 2007). With this approach, data was analyzed and systematically explored to generate meanings and existing data were recorded. In reporting the findings, examples from the respondents' verbatim statement were included to engage the reader in a consensual validation of the text.

3.9 Ethics

The ethical issues considered in this study were permission, informed consent, confidentiality and anonymity. With permission, ethical approval was given by the Ethics and Protocol Review Committee (EPRC) of the School of Biomedical and Allied Health Sciences (SBAHS), University of Ghana. An introductory letter was also given by the Department of Audiology, Speech and Language Therapy introducing the researcher to the Head of the school. On arrival, the school was used in getting in touch with the parents. Respondents were also informed about the nature and purpose of the study, and informed consent was sought before interviewing them. Confidentiality and anonymity included disguising the

names of the members in the field notes and keeping the information confidential from others. There was also the use of pseudonyms to protect the anonymity of the respondents in all transcripts and reports. The respondents were also assured that the information gathered was for a purely academic purpose.

3.10 Dissemination of Results

The research findings have been submitted as a Master of Science Degree in Speech and Language Therapy to the University of Ghana, College of Health Sciences, and the Department of Audiology, Speech and Language Therapy, School of Biomedical and Allied Health Sciences. Parts of the work which are of scientific value will be published in local and international peer-reviewed journals.

CHAPTER FOUR

DATA ANALYSIS AND RESULTS

4.0 Introduction

This chapter presents the results of data obtained from the study and discusses them in line with the literature review. Data were obtained from 10 parents who have children with ASD. The data were analyzed according to the objectives of the study. Main issues covered included background characteristics of the respondents, places and people parents of children with ASD report having sought help from to address the needs of their children, help parents of children with ASD report they received from the sources, challenges of parents of children with ASD when seeking help and the type of help parents report as most and least useful.

4.1 Background Characteristics

Table 4.1: Distribution: gender, age, age ASD signs noticed and age at diagnosis

Child	Gender	Age	Age signs noticed (years)	Age at diagnosis (years)	Age intervention started (years)
C1	Male	16	2	3.8	3.8
C2	Female	13	2	3	4
C3	Male	16	3	5	7
C4	Male	15	2	4	6
C5	Male	15	2.5	3.6	4
C6	Female	11	1	6	7
C7	Male	13	3	7	11
C8	Male	11	2	5	8
C9	Male	13	2	4	5
C10	Female	14	3	6	7

Source: Field data, 2018

Majority of the children 70% (n=7) were males and 30% (n=3) were females. The ages of the children were from 11 years to 16 years. Majority of the children 30% (n=3) were 13 years,

20% (n=2) were 16 years, 20% (n=2) were 15 years, 10% (n=1) was 14 years and then finally 20% (n=2) were 11 years.

4.1.1 Age signs noticed

Parents noticed some changes in the developmental milestones of their children when they were between the ages of 1 to 3 years. Majority of the children 50% (n=5) were noticed to be having signs of likelihood of special needs at the age of 2 years; 10% (n=1) was noticed at the age of 1 year; 10% (n=1) was also noticed at the age of 2.5 years; 30% (n=3) were noticed at the age of 3 years.

4.1.2 Age at diagnosis

Children were diagnosed between the ages of 3 years and 7 years. Majority of the children 70% (n=7) were diagnosed between the ages of 3-5 years and 30% (3) were diagnosed between 5-7 years.

4.1.3 Age intervention started

The lowest age the children started intervention services was 3.8 years and the highest age was 11 years.

Table 4.2: Demographics of Parents (Respondents)

Parent	Age	Gender	Relation	Edu. Status	Occupation	Religion
R1	50-59	Female	Mother	Tertiary	Librarian	Christianity
R2	40-49	Female	Mother	Post Sec.	Seamstress	Christianity
R3	40-49	Female	Mother	Tertiary	Teacher	Christianity
R4	40-49	Male	Father	Tertiary	Accountant	Christianity
R5	40-49	Female	Mother	Tertiary	Banker	Christianity
R6	30-39	Female	Mother	Tertiary	Teacher	Christianity
R7	40-49	Female	Mother	Tertiary	Manager	Christianity
R8	40-49	Male	Father	Secondary	Driver	Christianity
R9	40-49	Female	Mother	Secondary	Trader	Christianity
R10	40-49	Female	Mother	Tertiary	Business woman	Christianity

Source: Field data, 2018

All the respondents 100% (n=10) were biological parents of the children with majority 80% (n=8) of them being the mothers and 20% (2) of them being the fathers. Majority of the respondents representing 80% (n=8) were females and 20% (2) were males. Again, the ages of majority 80% (n=8) of the respondents were between 40-49 years; 10% (n=1) was between 30-39 years; 10% (n=1) was between 50-59 years. The educational status of the respondents were; majority 80% (n=8) of the respondents have had tertiary education; 20% (n=2) have had secondary education and 1% (n=1) have had postsecondary education. All the respondents 100% (n=10) are working parents. Again all the respondents 100% (n=10) are Christians.

4.2 Sources of Help

The first objective of the study focused on the places and people parents of children with ASD report having sought help. In line with this, the results and discussion looked at both the places and people parents of children with ASD report having sought help. The places that emerged were the internet, special schools, hospitals, mainstream schools, churches, hearing centres, prayer camps and the psychiatry hospitals.

4.2.1 Internet as a Place of Help

With advancement in technology, internet has been considered one of the most important sources of information. In line with this, the respondents mentioned internet as one of the places they sought help for their children with ASD. In confirming how she got help from the internet, a 51-year old mother said the following:

We started having concern when he was getting to three (3) years and he wasn't talking. So, we first went online to find out what the possible problem was, and we discussed it with an ENT Specialist and by then my son was in Ghana and we were in UK. So, we discussed it with a doctor friend and he referred us to his friend who is an ENT Specialist. So, he said my child should be tested for hearing. Then, I said, I told the doctor that I don't think he has a problem with his hearing because he didn't like the noise of a blender. I mean from when he was a baby and he still doesn't like it, so at least if he can hear the blender in use, he shouldn't have a problem with his hearing. So, the problem is not likely loss of hearing. Then, we went on and we saw something called Autism. A lot of the things described were things we recognized in our son.

Another participant said:

You see for some of those outside Ghana, it wasn't a new thing. We had some few friends who will google and you know...Then there is this speech site that Auntie S directed us to.

4.2.2 School as a place of help

With the existence of special needs schools and mainstream schools for children with ASD, all the respondents mentioned as part of their places of help, these two places. For the respondents, such places of help were either recommended by friends or family members who had knowledge about such places. Others also knew of such places prior to the diagnosis of their children. A respondent described how the child started at the mainstream school and ended up at the special needs school by saying:

I sent her to the mainstream school. I always had complains anytime I went for her. Sometimes the teachers will tell me that she run to the street, she is too aggressive, she cannot sit at one place even for a short time. Finally, the teachers told me not to bring her to the school again so we stopped. One medical NGO, told me about autism center and I sent her there. We have been on and off. She started when she was 4 years old. But sometimes we stop and stay at home for about 6 months to 1 year because of financial problem and then, we start again (Female, 40 years old).

Another participant also indicated the following:

Yes! He was in the mainstream school before I took him to the recommended place, I just took him there just to see whether he was going to adjust but he just threw himself on the ground, he was in tantrum, in fact, they could not help him out. So I took him out and sent him back to where he was going to school After some time in the

mainstream I realized that he really needed a special aid. So I needed to find him a special school. That was when I decided to bring him to the autism centre.

(Female, 42 years old).

4.2.3 Health Facilities as Place of Help

Health facilities were also mentioned by the study participants as places they sought help for their children with ASD. In relation to this, some of the respondents mentioned hospitals as the places they sought help while others spoke about psychiatry hospital and hearing centre. In narrating the movement from one health facility to another, a respondent described how help was sought from one health facility to another. In describing this, she said the following:

I think the only place I have been to was when we travelled to the UK. I have seen the GP. That is the only place I've been. When we came back to Ghana, we went to Korle-Bu once and we were asked to see a speech therapist. We've been going for some time and we stopped because I really don't see what was going on. So we stopped and we came to AACT (Female, 40 years).

Another participant said:

We sent him to Korle-Bu. There is one doctor there called doctor ×. And we went to a hearing center. The one at Achimota. We did the assessment at Korle-Bu (Male, 40-49 years).

4.2.4 Religious Centres

Religious centres also emerged as places participants sought help for their children with ASD. Specifically, Church and prayer camp appeared as the main religious centres respondents sought help for their children with ASD. The decision to seek help from such places was influenced by respondents' beliefs and faith. In line with this, a participant said:

I have also been to several churches. About 5 different churches. Some of the pastors just pray and tell me to trust God. Others pray and give me oil to smear on the child after bathing her. Some of my family members and friends told me about some churches that I could send the child to. So I sent him to the churches but I did not really see any improvement (Female, 40 years).

A male respondent also said that in seeking help for the child with ASD, he has been to a lot of prayer camps. With this, he indicated the following:

Yes, a lot of prayer camps and we still pray for him (Male, 40-49 years).

Closely related to the places of help, some of the parents of children with ASD report having sought help from were health professionals (ENT specialist, doctor, Neuropaediatrician, speech and language therapist, paediatricians), pastors and support groups.

4.2.5 Health Professionals

In seeking help from health facilities, the participants mentioned specifically the people they sought help from. Such people include ENT specialist, doctor, Neuropaediatrician, speech specialist, paediatricians. The participants said the following when asked about the people they sought help from:

I don't know of her specialty, but I think she is a Pediatrician. In the UK there is something called a community-based something. She knows much about autism (Female, 51 years).

Another respondent also mentioned a neurologist as the person he sought help from. With this he said:

We sent him to Korle-Bu. There is one Doctor there called Dr.Y. He is a neuropeadiatrician. We did the assessment at Korle-Bu. And we also went to a hearing center, the one at Achimota. (Male, 40-49 years).

4.2.6 Pastors

As heads of religious centres, it was obvious to find out that respondents sought help from pastors for the children who were suffering from ASD. These pastors were considered as having the power and authority to provide cure to their children. In affirmation, a respondent said:

One Sunday the proprietor of the school came to our house to discuss my child's condition with me. I was quite disturbed. So I went to discuss the issue with my pastor. He prayed for me and advised me to keep trusting God (Male, 50 years).

Another respondent said:

I have also been to several pastors. About 5 different pastors. Some of the pastors just prayed and told me to trust God. Others prayed and gave me oil to smear on the child after bathing her (Female, 40 years).

4.2.7 Support Groups

Another significant group of people that provided help to parents of children with ASD were support groups. Such groups were either family members of the respondents, friends or community-based parent support groups. The parent support group is made up of parents of children with ASD; professionals like paediatricians, neuropeadiatricians, SLTs; founders of special schools; special needs teachers and representation from the government. Such groups share experiences and ideas and provide help to parents when the need arises. Overall, the

respondents indicated that such support groups have been instrumental in their life. The participants said the following about support groups as sources of help:

Now you know there is ASOG and there are professionals, parents, founders of schools who are all on the platform. There are some who are not in any of these categories but are friends. For example there is a lady who was in the previous government who help with awareness creation. There are various platforms. There are various training sessions organized for parents (Female, 40-49 years).

Similarly, another respondent also added:

There is a platform called autism society of Ghana (ASOG) and all the parents..., some parents, those who are interested are members. So we take solace when we get to the platform. So anytime you are down you run quickly to the platform. If you have also done something that has helped your child you say it and others also learn from it. The platform is very helpful (Female, 30-39 years).

The family was also identified as another means of support for the respondents. The respondent said the following:

My family has been very supportive in terms of taking care of her when I am out. My mother especially. Now she is aging. She can't walk properly too and I am a single parent. So that is my problem now (Female, 30-39 years).

4.3 Kind of Help Received by Parents of Children with ASD

Help-seeking behaviour is a representation of a deliberate action to solve a problem that challenges personal abilities. It is a complex decision-making process that begins with the identification and definition of a problem, leading to a decision for an action. Once the intention to act is formed, selection of the source of help is made. Contact and disclosure of

the problem are made in exchange for help (Nicola & McCarthy, 2011). In line with this, respondents expressed their views on the kind of help they received from the sources they sought help from. Basically, respondents indicated that they received help in the form of information, counselling, speech therapy, assessment and prayers.

4.3.1 Information

Due to the unique role of information in autism, respondents were of the view that the sources of help provided them information about ASD. Such information, for the respondents, is essential in their bid to find solutions to their problems. Describing how information was obtained, a 51 year old mother said:

Like, I said, we went online to search to find out exactly what we could be dealing with. So, even, before my son had come to UK we had had some information online ourselves and we knew that there was a chance that the boy could have autism.

4.3.2 Counselling

Counselling is another help that parents of children with ASD received from the sources of help. The nature and manner in which counselling was provided differed based on the source of help. For some of the respondents, counselling was given by health professionals, while others also received counselling from pastors. Affirming counselling as a type of help, a respondent said:

Well it was an assessment, and then we were given counselling and what we need to do and what we need to avoid, I don't remember we were given any medication (Male, 40-49 years).

4.3.3 Speech therapy

Speech therapy also emerged as a type of help participants obtained for their children. A respondent said the following in describing the processes involved in speech therapy:

Normally the speech therapy, when you go they will tell you what you have to do. Umm, in the long while another person will come. They will all tell you that all the effort depends on us the parents and that, we have to encourage them. Most of these speech therapists...,if there were schools where we have speech therapists who come there consistently to help or where the children are kept in a boarding facility where all these people are going to be, that will be very different. You understand! But these speech therapists where you see them once a while, they will tell you a whole lot of “this depends on you and that depends on you”. It gets to a point you realize you are not making any headway you will rather get one speech therapist who will be teaching your child (Male, 40-49 years).

4.3.4 Assessment

Assessing children with autism was considered an important help for parents of children with ASD. This is because the result of the assessment indicates the nature and the extent of the condition. As a type of help, respondents shared their views on how they receive help in the form of assessment. In line with this, one of the respondents said:

I took him to another mainstream school and they recommended another assessment centre at Achimota. I took him there for assessment so they did psychiatry test and other tests and they said he should still go back to the mainstream and that he needed one on one, so I should look for a special teacher in the government school. He also had behavioural problems too in the school. It was a psychiatrist who recommended that I bring him to the autism centre because they train people and he doesn't think

the mainstream will help him. So after consideration, then I brought him to the center
(Female, 40-49 years).

4.3.5 Prayers

On the basis that respondents sought help from prayer camps and Churches, it was obvious that prayer emerged as a type of help obtained by parents of children with ASD. With this, it was realized that some of the pastors just pray and tell respondents to trust God. Others pray and give me oil to smear on the child after bathing. A forty-year-old female respondent had this to say on prayer as a type of help:

I have also been to several churches. About 5 different churches. Some of the pastors just pray and tell me to trust God. Others pray and give me oil to smear on the child after bathing her. Some of my family members and friends told me about some churches that I could send the child to. So I sent him to the churches but I did not really see any improvement (Female, 40 years).

4.4 Challenges Associated with Help-Seeking

Help-seeking behaviour is also influenced mainly by sociocognitive factors (Cornally Nicola and Geraldine McCarthy, 2011). In line with this, results from the study identified financial problems and behaviour of children as the challenges they face when seeking help. These challenges either made it difficult for them to get the help they want or lead to a total denial of help.

4.4.1 Financial problems

Financial problems emanated as a challenge associated with help-seeking among parents of children with ASD. These problems occurred in the form of the inability to pay school fees, transportation, long distances to the autism centre or provide support at home. A respondent said the following when asked about the challenges with help-seeking:

The challenges I faced and still face is with finance. Her school fees is so expensive. There was an NGO that was helping with the fees but they have stopped operating because of financial constraint. The other thing is with transportation. The school is not very far from here but as I said earlier, we have to walk from the house to the junction and that is quite a distance.. (Female, 40 years).

Another respondent also said this in relation to financial challenges:

The financial stress is a challenge because even now I have to find someone to take care of him at home but it means I have to put somebody on income because it's one on one. Because I am using the center's personnel and am paying a little higher than the others. But I have to always come to pick him when they close and I have to leave work and come and pick him because I can't get anyone to pick him up for me. One point I had to ask the help of drivers and he also came and it did not help. That is a lot of money. It is not easy at all because it is a condition that you need a one on one. Someone should attend to him throughout the day. Combining this with work is not easy. Meanwhile, it's the work that will generate income for you to do that (Female, 40-49 years).

Still confirming financial problems as challenges parents of ASD children face, another respondent said:

Yes, generally you know because of their condition, they will not join commercial vehicles. Umm, you have to get a special vehicle for them with a driver. The driver must also understand their condition. The driver has to be dedicated. In their crisis, the driver must know how to help them. All these ones are added on expenses (Male, 40-49 years).

4.4.2 Behaviour of Children

The behaviour of children with ASD also served as a key challenge for parents. This was because parents felt that the condition makes their children very aggressive and uncontrollable. As a result, parents feel reluctant to take them out to seek help. In line with this, a respondent said:

My main challenge was the behaviour. Sometimes he behaves strangely. He will be claiming things and go and sit on top of the wardrobe and things. So the problem was with the child and not the people I was going to seek help from. Because when we went to the UK we did not pay anything. It was free. My sister was outside, London. So we did not even pay one pound. He was even registered on their insurance and I still have the number (Female, 40-49 years).

Similarly, another respondent said the following:

Another challenge is managing him at home because am told he is kept under control at school but at home, he misbehaves a lot so I have to find a way around it. At home, when we had visitors he disgraces himself so it's really a challenge (Female, 40-49 years).

4.5 Most and Least Useful Sources of Help

The last objective of the study explored the most useful and the least useful sources of help. The idea was to find out from respondents which of the sources of help they have found most beneficial and less beneficial. It emerged that the most useful source of help is special needs school and the least useful source of help is the church.

In affirming special needs school as the most useful source of help, a respondent said the following:

I think the most useful is the special needs school. They understand the children and they teach them to be able to do some basic things for themselves. They are taught to be able to brush their teeth, and take care of themselves (Female, 40 years).

Similarly, another respondent also said the following in support of special needs school as the most useful source of help:

I will choose the special needs school because of the training they give them (Male, 40-49 years).

On the contrary, one of the respondents who mentioned the Church as the least useful source of help also said:

The church! They will give you oil and other things to apply on her but it does not work. They give you direction (awankyere). Sometimes it is fasting. You will wake up and pray at a particular time for her. But all these things did not work (Female, 40 years).

4.6 Summary

All the respondents were biological parents of the children with ASD. Parents' account on the places they received help were recorded verbatim. The places included the internet, schools health facilities and religious centres. The people also included health professional, pastors support groups which included the family. The help received included information, counseling, assessment, prayers and speech therapy. The result revealed that parents had challenge with finances and the behavior of their children.

CHAPTER FIVE

DISCUSSION

5.0 Introduction

In this chapter, the results obtained from the study are discussed and related to the information from the literature. There is limited documented research in relation to the HSB of parents of children with ASD in Ghana.

The aim of the research was to understand the HSB of parents of children with ASD. The specific objectives of the study focused on the following: to determine the places and people parents of children with ASD report having sought help from to address the needs of their children; to explore the help parents report they received from the sources they found; to determine the challenges of parents of children with ASD when seeking help; to identify the type of help parents report as most and least useful.

5.1 Demographics

The participants in the current study had children aged between eleven (11) and sixteen (16) years. In light of this, it is important to note that parents were reflecting on a time when services may have been relatively new or not yet developed. There is a likelihood of little awareness and knowledge about ASD at that time. This is consistent with Bakare and Munir (2011) who attempted to explain the late diagnosis of ASD in Africa. According to Bakare and Munir, the attempted explanation given to this observation included a low level of knowledge and awareness about ASD in Africa, the problem with help seeking behaviour, the lack of trained personnel as well as mental healthcare facilities. This was evident with what a participant said, *‘Sometimes when they are not feeling well and we send them to the hospital, we end up educating the Doctor about the condition because they do not know. We the parents now become the quasi doctor, explaining to the main Doctor about the condition.*

Majority of the children 70% (n=7) were males and 30% (n=3) were females. This result is consistent WHO, (2016); Yu & King (2016); National Center on Birth Defects and Developmental Disabilities, (2016). All these studies stated a higher prevalence ASD in boys than in girls.

All the respondents except two (2) reported they noticed signs of delayed milestone of their children before the age of three (3) years. This finding is consistent with American Psychiatry Association (2013) which reported that ASD is a neurodevelopmental disorder characterized by a deficit in social interaction, communication and repetitive restricted behaviour that is noticed before the age of three (3) years.

5.2 Sources of help

The first objective is about sources of help. The results revealed that parents sought help from a variety of sources which included the following places: internet, schools (mainstream and special needs), health facilities and religious centres, support groups and the family. This is consistent with the findings of Wylie et al. (2016), who found that people were likely to seek help from the above mentioned places as the sources of help for communication disorders. In addition, Wylie et al. found out people also sought help from places such as witch camps, shrines, school for the deaf and orphanage which is contrary to the current study finding. This is likely due to the fact tha Wylie et al. looked broadly at communication disabilities whiles the currents studies focused on ASD Again, Wylie et al. used hypothetical questions whiles the current study focused on the life experiences of the respondents.

The finding of the current study is also consistent with Adu-Gyamfi, (2015) who stated that Ghana is known to employ both spiritual healing and orthodox medicine for the treatment of diseases. In the current study, all the respondents visited the hospital and in addition to that, sought help from the religious sector. Slikker, (2009), found out that treatment for disability

is sought from the prayer camps or spiritual leaders. Hopf et al. (2017) also mentioned HSB included seeking help from community members, professionals, spiritual leaders or western medicine practitioners which is consistent with the current study.

Wylie et al. (2017), also stated that people were likely to seek information from a variety of sources which is consistent with the current finding. The movement from one source to the other could also be attributed to the lack of knowledge about ASD and the cultural belief as reported by Bakare & Munir, (2011).

Parents report they sought help from the following people in this study: ENT specialists, doctors, SLTs, pastors, neuropeadiatricians and peadiatricians. The finding is consistent with Wylie et al, (2017) who also reported ENT specialists, doctors, SLTs, pastors, neuropeadiatricians and peadiatricians in their study. Wylie et al. also mentioned in addition to the above, nurses, midwives and politicians which was contrary to the current study.

The other group of people parents reported they sought help from was the family. This finding is consistent with Opoku el al. (2017) who reported that the family is also another means of support for people with communication disability. Without the primary support from the family person with disabilities will not be able to break social barriers due to their inability to access education and other developmentally useful services.

5.3 The Help Received

The second objective was the help parents reported they received. Participants in this study reported they received information, counseling, assessment, prayers and speech therapy from the various places they sought help from. This is in line with Hand (2006) who identified that professionals give information to parents who have children with ASD. Gona et al (2015) also identified prayers as one of the treatments for ASD whiles Slikker, (2009) identified prayers as one of the treatments for disability in Ghana.

5.4 Challenges

The third objective was the challenges parents face in seeking help. The main challenge identified in this study is the financial burden. This finding is in line with Dababnah & Bulson, (2015) who stated financial challenge as one of the barriers to accessing services for people with ASD. This challenge is in the aspect of the money to pay for school fees, transportation as well as cost of employing a caregiver to take care of the child especially if both parents are working. The aspect of stigma did not really seem to be a major challenge for the respondents. Although there is a lot in the literature about stigmatization of both the individual and the family (Kinnear et al., 2016; Grinker, 2007), especially in the low and middle income countries, respondents in this study did not report it as a challenge. A study conducted by Baffoe (2013), on persons with disability in Ghana revealed the first major concern of persons with disability as stigma. He further stated that “stigma is the single most difficult barrier to living a “normal” and productive life by persons with disability”.

5.5 Most and Least Useful Source of Help

In this study, the most preferred source of help was the special schools. It is consistent with the literature (Mire et al., 2015) which talked about school-based services being the most frequently used by parents of children with ASD. Results from this study are also consistent with a study by Mackintosh, Myers and Goin-Kochel, (2006) which talked about parents’ preference for information from other parents with children with ASD. The reason for special school being the most useful source of help to my respondents could be explained by the fact that the founder of the special needs school has a child with ASD and therefore understood other parents with similar situations.

The least preferred source of help in the current study was the church. It is contrary to the literature by Osborne and Reed (2008), which identified other health professionals as the least preferred source. This could be as a result of cultural differences. The reason given by the

respondents in Osborne and Reed was the manner in which the health professionals delivered information. The reason is consistent with what some parents also said during the interview. Some of the respondents had issues with the way some professionals especially the doctors delivered information to the parents. According to the parents, the doctors did not spend enough time with the parents are not supportive enough. They do not give the kind of support parents expect from them.

5.6 Summary

In summary, majority of the respondents identified signs of delayed milestone before the age of three (3) years. Respondents sought help from different places and people. Some of which were consistent with the literature. There were some places and people that were not revealed in the current study although they were mentioned in the literature. The help received included information, counseling, assessment, prayers and speech therapy. The challenge parents had with help seeking was financial challenge. Literature mentioned stigma which did not seem to be an issue for the respondents. The most and least useful source of help was from the special school and church respectively.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.0 Introduction

In this chapter, the summary of the research findings, conclusion and recommendations are presented.

6.1 Conclusion

The study explored the HSB of parents of children with ASD in Accra, Ghana. The study looked at the sources of help parents seek to solve the needs of their children. It was revealed that parents sought help from a variety of sources including educational, medical and religious sectors. The places parents sought help from included: internet; schools (special and mainstream schools); health facilities (hospital, ENT centre, psychiatry hospital,) and religious centres (prayer camps and churches).

The people parents sought help from included: health professionals (ENT specialists, doctors, neuropaediatrician, SLTs, paediatricians); pastors and support groups. The help parents received also varied from counseling, information, support, assessment, prayers and speech therapy services. The main challenge faced by the respondents of the study was a financial challenge. Finally, the most useful source of help identified in his study was from the special school and the church was the least source of help reported by the respondents.

In conclusion, the study revealed that 80% of the respondents noticed delayed milestone of their children before the age of 3 years, diagnosis was received between the ages of 3.8 years to 7 years. Diagnosing ASD is the first step to planning and implementing intervention. Early intervention is very important for the quality of life as well as the developmental outcome of the children. Parents seek help from different sources to meet the needs of their children.

Parents are therefore likely to seek help from the right sources as early as possible with education and the availability of facilities and trained personnel.

6.2 Limitation

The major problem the researcher faced was the reluctance of parents to participate in the study. Some of them complained they did not get any positive outcome from previous research studies they have participated in. Others did not respond at all. There is therefore a potential for selection bias to skew results towards people who are motivated to participate in this study.

The study was conducted in only one special school and therefore a small sample size was used.

There was another limitation with the face-to-face interview technique. This resulted in some form of “social desirability bias” where respondents are likely to give answers based on what they felt was acceptable to society.

Further challenge was data translation from one language to the other. Data translation is likely to pose some threat on trustworthiness since there is a likelihood of losing the exact meaning of some expressions in the local language. Twi was used by some of the respondents and had to be translated into English. There were certain words in Twi that did not have the equivalents in English. Nonetheless, efforts were made to get equivalent translation.

Some of the children might not have been clinically diagnosed by a neuropeadiatrician. When a child is suspected of having ASD, the child is referred to the neuropeadiatrician for clinical diagnosis. To the best of the researcher’s knowledge there are only two (2) neuropeadiatricians in Ghana. The researcher was also not able to request for a report of diagnosis before recruiting parents to be part of the research because majority of the parents

were not willing to participate in the first place. Since the school is ASD-specific and according to the administration only children with ASD were admitted, the researcher decided to forgo the request of the diagnostic report.

6.3 Recommendation

Based on the study findings, the following recommendations were made:

1. The Ministry of Health should train more persons involved in the provision of services for persons with ASD such as SLTs, neuropsychiatrists, etc. to assist with the diagnosis and rehabilitation process. Parents seek help from different sources to meet the needs of their children. The right professionals should therefore be available to be accessed whenever needed in order to start intervention early.
2. Other persons such as the teachers, religious leaders, other health worker and persons who come into contact with parents and children with ASD should be given education on ASD to be able to assist whenever they are consulted. Parents and children with ASD come into contact with the teachers at school, health workers at the health facilities and religious leaders at the religious centres. Education of all these people will put them in a better position to give the right information to parents when they are approached.
3. The government should put measures in place to establish more ASD-specific special schools to help with the rehabilitation of children with ASD. There is limited ASD-specific special school in the whole of the Accra Metropolitan Area which is inadequate for children with ASD.
4. It is very important for parents to go to the right sources when they notice any delay in the milestones of their children. The general public should be educated on ASD in order to be equipped with information on where to seek help as well as what to do when delayed milestones are noticed.

5. The Government should provide financial support to families in the care of children with ASD to help reduce the financial burden of caring for them. The challenge of parents according to this study is financial burden. The government should therefore come to their aid with some financial support.
6. This study should be replicated on a larger scale involving parents whose children do not attend special schools, different educational background, different socioeconomic background and different religious background to be able to have a broader idea of what the situation is like.
7. Further study is needed to find out the expectation of parents of children with ASD from health professionals in order to promote effective collaboration.
8. Philanthropists, non-governmental organizations and individuals are also encouraged to take interest in children with ASD and support them in any way possible.

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APPENDIX I

Participant Information Sheet

My name is Getrude Abbey, a 2nd year MSc. Speech and Language Therapy student in the Department of Audiology, Speech and Language Therapy of the University of Ghana. You are kindly invited to participate in a research study on the topic “HELP SEEKING BEHAVIOUR OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN ACCRA, GHANA”.

Background information to the study

Autism Spectrum Disorder is a complex developmental disorder noticed within the early years of a child’s development. Communication disability in Ghana is poorly recognized and rehabilitation services are also limited, just as other low and middle-income countries. Speech and language therapy is relatively new in Ghana and originates from the ‘Western’ world. It is therefore very important to get documented information on where parents seek help and the challenges they face in their search for help and support for their children. There is extremely little information on ASD and help-seeking behaviour. There is therefore, a need to conduct a study in this area.

You will be required to answer a questionnaire which would last about 10 minutes. All information will be kept strictly anonymous and confidential. Participation is voluntary.

Potential Advantages of the study

Information provided will be incorporated into service planning and education. Policy makers will also see the need to allocate funds to set up rehabilitation centers and to train more speech and language therapists to help with the rehabilitation process. Policy makers will also know what know what parents expect from them. This research is also in partial fulfillment of an award of a Master’s Degree in Speech and Language Therapy at the University of Ghana.

Potential disadvantage of the study

Some of the questions that will be asked may need a reflection on a past experience you might have wanted to have forgotten. This may bring some emotional breakdown.

Additional information

The study has received ethical clearance from the University of Ghana. I am most grateful for your consideration. This form is for you to keep. If you have any concerns please contact me on this number (0243645667).

I am most grateful for accepting to participate. Kindly sign the consent form and fill the questionnaire. The consent form will require only your signature and date.

APPENDIX II

INFORMED CONSENT

INFORMED CONSENT FORM

DEPARTMENT OF AUDIOLOGY, SPEECH AND LANGUAGE THERAPY

SCHOOL OF BIOMEDICAL AND ALLIED HEALTH SCIENCES

COLLEGE OF HEALTH SCIENCES, UNIVERSITY OF GHANA

The document describing the benefits and the procedure for the research: Help-seeking behaviour of parents of children with Autism Spectrum Disorder in Accra, Ghana, has been read and/or explained to me. I have been given an opportunity to participant.

I confirm that:

1. The nature and potential benefits associated with participating in this research have been explained to me.
2. I understand I can withdraw at any time without giving reasons and that I will not be penalized for withdrawing nor will I be questioned.
3. I have been given the opportunity to ask questions about the project and my participation.
4. The procedure regarding confidentiality has been clearly explained (pseudonyms, anonymity of data, etc.) to me.
5. The use of data in research, publication, sharing and archiving has been explained to me.

Signature of Participant

Date

Signature of Researcher

Date

APPENDIX III

INTERVIEW GUIDE

INTERVIEW GUIDE

PROJECT TITLE: HELP SEEKING BEHAVIOUR OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN ACCRA, GHANA.

Demographics

1. Age of child
2. Gender
3. Age of parent
4. Gender
5. Relation
6. Religion
7. Educational status
 - a. Primary
 - b. Secondary
 - c. Post-secondary
 - d. Tertiary
 - e. other.....

Objective 1- sources of help

1. Tell me about how you got to know about your child's diagnosis?
2. Tell me about the places you have been to for advice or help for your child.
3. Tell me about the people you consulted for advice or help for your child (community members, professionals, family members).

Objective 2- kind of help

4. What did the people you consulted do or say to you?

Objective 3 - Challenges

5. Did you face any challenges in your search for support and information for your child? If yes, please tell me about it.
6. How did you cope with these challenges?

Objective 4- most and least useful

7. Which help/support in your opinion was most useful? Why?

8. Which help/support in your opinion was least useful? Why?

Additional information

9. What do you think can be done for children with ASD and their families?

10. Is there anything else you would like to tell me?

APPENDIX IV

PERMISSION TO CARRY OUT RESEARCH AT THE STUDY SITE



UNIVERSITY OF GHANA
DEPARTMENT OF AUDIOLOGY, SPEECH
AND LANGUAGE THERAPY
SCHOOL OF BIOMEDICAL AND ALLIED HEALTH SCIENCES

Ref. No.:

April 19, 2018

The Head
Autism Awareness Care and Training Centre
P.O. Box 053043
Osu

Dear Madam


PERMISSION TO CARRY OUT POSTGRADUATE RESEARCH STUDY AT
AUTISM AWARENESS CARE AND TRAINING CENTRE

The Department of Audiology, Speech and Language Therapy of the University of Ghana School of Biomedical and Allied Health Sciences (SBAHS) presents its compliments to the Autism Awareness Care and Training Centre.

Mrs. Gertrude Abbey (10632922) is a 2nd year MSc Speech and Language Therapy student in the Department of Audiology, Speech and Language Therapy of the University of Ghana. She is conducting a research study on "*Help Seeking Behaviour of Parents of Children with Autism Spectrum Disorder in Accra*" under the supervision of Dr. Akanlig-Pare (Linguistics lecturer) and Ms. Nana Akua Owusu (Speech and Language Therapist). The Autism Awareness Care and Training Centre has been chosen as the study site and the SBAHS Ethics and Protocol Review Committee has reviewed and passed her research proposal as satisfying ethical requirements.

In this regard, the Department humbly requests your kind consideration to grant permission to Mrs. Gertrude Abbey to carry out her research study at your Centre during the period 2nd -16th May 2018 for the common good of the hospital and the University. Thank you.

Yours faithfully,


DR. S. ANIM-SAMPONG
(Ag. Head of Department)

cc: Dean SBAHS
Dr. Akanlig-Pare
Ms. N.A. Owusu

APPENDIX V

ETHICAL CLEARANCE



UNIVERSITY OF GHANA
SCHOOL OF BIOMEDICAL AND ALLIED HEALTH SCIENCES

30th January, 2018.

Ref. No.:

Ms. Getrude Abbey
Dept. of Audiology, Speech and Language Therapy
SBAHS,
Korle-Bu.

Dear Ms. Getrude Abbey,

ETHICS CLEARANCE

Ethics Identification Number: SBAHS – ASLT/10632922/SA/2017-2018.

Following a meeting of the Ethics and Protocol Review Committee of the School of Biomedical and Allied Health Sciences held on Tuesday 30th January, 2018. I write on behalf of the Committee to approve your research proposal as follows:

TITLE OF RESEARCH PROPOSAL: HELP SEEKING BEHAVIOUR OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN ACCRA, GHANA.

This approval requires that you submit three-monthly review reports of the protocol to the Committee and a final full review to the Committee on completion of the research. The Committee may observe the procedures and records of the research during and after implementation.

Please note that any significant modification of the research must be submitted to the Committee for review and approval before its implementation.

You are required to report all serious adverse events related to this research to the Committee within seven (7) days verbally and fourteen (14) days in writing.


As part of the review process, it is the Committee's duty to review the ethical aspects of any manuscript that may be produced from this research. You will therefore, be required to furnish the Committee with any manuscript for publication.

This reviewed report is valid till 31st August, 2018.

Please always quote the ethical identification number in all future correspondence in relation to this protocol.

Thank you.

Yours sincerely,


Dr. S. D. Amanquah
(Chairman, Ethics and Protocol Review Committee)

Cc: Dean
Head, Dept. of Audiology, Speech and Language Therapy
School Officer

COLLEGE OF HEALTH SCIENCES

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