

DECLARATION

I, **Naomi Manu**, do hereby declare that except for references to other people’s work, which have been duly acknowledged, this work was conducted by me under the supervision of **Prof. Birthe Loa Knizez** at the Institute of Psychology, Norwegian University of Science and Technology (NTNU), Trondheim-Norway, during the 2011/2012 academic year. In accordance with NTNU’s regulations, this work has neither been submitted in whole nor in part for any degree in this university or elsewhere.

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Date

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This work has been submitted for examination with my approval.

Signed:

Prof. Birthe Loa Knizez

Date

(Supervisor)

DEDICATION

Your joy is to see your children attain heights you never reached; to my parents, Joseph Kwasi Manu and Debora Oforiwaa, I dedicate this work to you.

To you, my friend and husband Kwame, this piece is for you as well. Although we were separated by thousands of miles, you gave me your usual unfailing encouragement and support. I only hope that the final product goes well in justifying my absence.

Finally, this work is dedicated to every child with autism in Ghana; you have helped me develop both as a professional and as a human being.

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ABSTRACT

Autism is a life-long invisible impairment with an unknown etiology. Current literature shows an increase in the diagnosis of autism worldwide. This qualitative study explores the attitudes and beliefs which surround childhood autism in Ghana. In-depth interviews were conducted with four (4) parents whose children have autism and three (3) key informants; a Religious Leader, a Health Worker and an Administrator of a Special school in Accra, Ghana. A semi-structured interview guide was used for the interviews and the Interpretative Phenomenological Analysis (IPA) used for the data analysis. Results show that parents whose children have autism attribute the cause of autism to biological, environmental and to unknown factors. Parents and their children with autism relied on institutions for children with autism, family members and other non-relatives for support. It was indicated that the characteristics of autism, the cultural expectations from parents and their children as well as conflicting beliefs with regards to the appropriate intervention for the child with autism were major challenges. Parents employed behavior training and religious interventions to manage their children's autism. Despite these approaches, parents are uncertain about the future of their children.

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LIST OF ABBREVIATIONS

ASD- Autism Spectrum Disorder

ADHD- Attention Deficit Hyperactivity Disorder

CDC- Center for Disease Control and Prevention

CHRI- Commonwealth Human Rights Initiative

DSM- Diagnostic and Statistical Manual of Mental Disorders

FCUBE- Free Compulsory Universal Basic Education

GDP- Gross Domestic Product

GES- Ghana Education Service

GSS- Ghana Statistic Service

ICD- International Statistical Classification of Diseases and Related Health Problems

IPA- Interpretative Phenomenological Approach

NCPD - National Council of Persons with Disability

WHO-World Health Organization

Chapter One

INTRODUCTION

1.1.0. Background to the Study

Autism Spectrum Disorder (ASD) is a complex developmental disorder considered as the most severe childhood psychiatric disorder by some (Shyu & Tsai, 2010). Childhood autism is described in the International Statistical Classification of Diseases and Related Health Problems (ICD)-10 as a

type of pervasive developmental disorder defined by (a) the presence of abnormal or impaired development that is manifest before the age of three years, and (b) the characteristic type of abnormal functioning in all the three areas of psychopathology: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behavior. (F84.0)

Aside these diagnostic features, some children may show phobias, temper tantrums, eating problems and sleeping disturbance (ibid).

The diagnosis of autism was mentioned first time when Leo Kanner in 1943 published a paper about his observation of 11 children from 1938 to 1943. Kanner (1943) indicated that the condition of these children differed markedly and uniquely from anything that had been reported previously. He borrowed the term “autism” from Eugen Bleuler (1857-1939) who was a Swiss psychiatrist to describe these children (Irwin, MacSween & Kerns, 2011). The word autism is made up from the Greek words *autos* meaning “self” and *ismos* that is a suffix of “state or action” (ibid).

Autism is a spectrum disorder. The term “autism spectrum” was pioneered by Wing to show a range of disorders varying in symptoms, severity and prognosis (as cited by Farrugia,

2009). ASD encompasses a variety of behavioral defined conditions; it thereby affects each individual differently (Center for Disease Control and Prevention -CDC, 2009). For instance, while some individuals with autism may experience sleep disturbances, others may not. Some can be very mild and others can have a severe impact. Some individuals with autism who have mild symptoms can perform “normal” activities just as anyone else around them. In severe instances, they are completely unable to take part in normal society (CDC, 2009). The onset of symptoms and exact nature of the symptoms differ from person to person. However, persons with autism have in common symptoms, such as problems with social interaction and communication which qualify them to fall into the axis.

Unlike some developmental disabilities like mental retardation which have some biological markers, autism has no clear biological marker (Gupta & Singhal, 2005). It is an invisible impairment; thus there is nothing showing on persons with autism that they are disabled or impaired. Autism is only observed through the behavior of children. Unfortunately, there is also no medical test like a blood test used to diagnose autism (Autism and Developmental Disabilities Monitoring Network, 2006; CDC, 2009). Diagnosis of autism is based on evaluations such as, clinical observation, parent’s interview, developmental histories, speech and language assessment and the use of one or more psychological tests (ibid). There are speculations that autism might be caused by a strong gene which combines with an environmental factor to impair a child’s early social experiences (Boutot & Tincani, 2009). In spite of these assumptions, the exact cause is still unknown.

According to Campbell, Davarya, Elsabbagh, Madden and Fombonne (2011) it is essential to examine and determine the prevalence of autism over time. This is to ensure training of ASD diagnosticians and to understand causal mechanisms of autism. Nevertheless, autism is behaviorally defined therefore determining its prevalence is more difficult than for a disorder which has visible biological markers (ibid). Very often, instead of

parents and professional seeking early intervention for affected children, there is the “wait and see attitude” in diagnosing autism and finding a remedy (Denkyirah & Agbeke, 2010).

According to Rutter (2005) although it is impossible to know the incidence of autism because of the uncertainty in defining the syndrome, it is likely that 30 to 60 in every 10,000 assumed cases of autism have autism. A report by CDC (2009) showed that in the United States, one child in every hundred and ten children has autism. The prevalence rate for ASD in Norway is 51 per 10,000 children (Isaksen, Diseth, Schjøberg & Skjeldal, 2012). Autism is more common in males as compared to females with the ratio being four males to one female (Lord & Bishop, 2010; CDC, 2009) and it is found in all parts of the world, Ghana inclusive (Bakare & Munir, 2011; Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004). It has no respect for race, nationality, ethnicity or social boundaries and it occurs equitably across all demographical groups (ibid).

1.2.0. Statement of the Problem

Ghana passed the Persons with Disability Act (ACT 715) in August 2006. It has been six (6) years down the line, and the country has put into place various measures to address the needs of persons with disabilities. In spite of these efforts, persons with disability still face inequalities in economic, social and political arena.

Tradition has made some people believe that disabled people should have little or no rights in the society (Kassah, 1998). A large number of Ghanaians also believe that disabilities are contagious and caused by spiritual forces (Reynolds, 2010). Disability is seen as shameful considering the way disabled people are treated in Ghana. Kassah (1998) states clearly how disabled people on the streets of Accra were carried out of the city and hidden prior to the International Conference of Non-Alliance Countries held in Ghana in 1991. This

exercise was executed against the will of the disabled people yet city dwellers saw the presence of persons with disabilities as shameful to the country.

The complexities about autism are much known in western societies due to the awareness creation through the use of various media (Lord & Bishop, 2010). In converse, the knowledge about autism in Africa is low (Igwe, Bakare, Agomoh, Onyeame & Okonkwo, 2010). Bakare *et al.* (2009a) are of the view that, in sub Sahara Africa, child mental health has received inadequate attention from policy makers. In Ghana there is only one pediatrician who diagnoses autism; Dr. Emmanuel V. Badoe who is the director of the Neurology Development Clinic at the Korle Bu Teaching Hospital in Accra (Anthony, 2009).

In 2006 when Ghana passed its ACT 715 for disabled people, the National Council of Persons with Disability (NCPD) did not consider autism to be a disability (AllAfrica, 06/04/2009). With invisible impairments like autism with unknown etiology from the scientific community, beliefs become more severe and varied. Moreover, children with autism and their families are stigmatized because of the disruptive nature of autistic symptoms, the normal physical appearance of the children and the lack of public knowledge and understanding with regards to the nature of autism (Gray, 2002).

Children with autism have low social interaction and communication skills so growing up in collectivist societies is burdensome for family. In Ghana, it is usually expected that children interact and play amongst themselves. According to Salm and Falola (2002), in both urban and rural Ghana, leisure and entertainment time involve social relations like sharing stories and spending time with others. Families who are raising children with autism in collectivist societies may have a challenge because of the withdrawal of their children with autism from other people and their lack of social interaction.

Several researches on disability have shown that with the coming of the missionaries to Africa in the 19th century and the introduction of Christianity, beliefs about disability have become more ambiguous. Kassah (1998) indicates that although many Ghanaians are Christians, most combine traditional religion with Christianity. As a result, the notion about disability being a curse from the gods or caused by witch craft still prevails.

Contrary to the notion above, Christianity seems not to have brought a different view about disability. The Christian scriptures portray disability negatively (Mackelprang & Salsgiver, 2009). There are so many scriptures in the bible which link disability to sin and evil (ibid). Unfortunately, many disabled people go through brutish rituals in church places for religious healing. There seem to be no difference between the African traditional causal attribution of disability which results in brutalization and the Christian causal attribution. Reynolds (2010) found in a research that disability in Ghana is characterized by neglect, cruelty and degradation meted out to this population.

Apart from these cultural surges in Africa specifically Ghana, the relatively early onset of autism, the unknown etiology, its invisibility and triad of behavior excesses and deficits places a heavy burden on families who have a child with autism. Autism is a life-long impairment therefore it requires a joint effort between individuals, family members, professionals, and members of the community to meet the needs of the child with autism. Raising a child with autism is a challenge to caregivers because these children require much resource compared to other children (Schall, 2000).

Research on disability and specifically autism is not a new phenomenon in Ghana; studies done include the access to education for children with autism (Anthony, 2010); ways children with autism can transition effectively from one level to the other in schools (Denkyirah & Abeke, 2010) and views on disability from the perspectives of community

leaders (Reynolds, 2010). This study on disability in Ghana tackled the beliefs and the attitudes which besiege childhood autism in Accra, Ghana.

1.3.0. Aims and Objectives

The goal of the study was to investigate the beliefs and the attitudes which surround childhood autism in Ghana by investigating into the causal attribution of autism among parents who have children with autism. A marked variation is observed in how various cultures interpret disabilities (Groce, 1999). Therefore, the study sought to investigate and develop an understanding of autism based on parental perspectives and the community. The study also sought to find the experiences of these families by examining the challenges in their day to day interactions in the Ghanaian society. Emphasis was also placed on the institutional arrangements for the children with autism and the available governmental support. Finally, the way culture and religious beliefs influence parents help-seeking behavior for their children with autism was also explored.

1.4.0. Research Questions

1. How do parents whose children have autism perceive autism?
2. Does parents' knowledge of autism influence the help they seek for their children with autism?
3. How do parents who have children with autism perceive the social support they receive?

1.5.0 Significance of the study

According to Mackelprang and Salsgiver (2009) it is crucial to explore the ways societies and cultures view disability because this knowledge helps in drawing intervention approaches. As a result, to implement an intervention program for children with autism and their families in Ghana, it is important to understand the underpinning factors that influence the attitude towards children with autism, the support families who have a child with autism receive and the way these families manage the challenges associated with children's autism.

The study may also serve as a call out to governmental and policy makers in Ghana about the plight of families raising children with autism. This could serve as a guide to stakeholders in putting in place the necessary frameworks and legislature to address the needs of children with autism in all aspect of their life. The study can provide Non-governmental organizations and other charitable organizations in and outside Ghana first hand information about issues concerning autism in Ghana. Organizations that provide human services need to know the culture and beliefs concerning autism in Ghana to aid them in dealing with clients they come across.

1.6.0 Operational Definition

Autism: The term will be used as shorthand for Childhood Autism as defined in the ICD-10 and in the Diagnostic and Statistical Manual of Mental Disorders-Text Revised.

Chapter Two

THEORIES, CONCEPTS AND REVIEW OF LITERATURE

2.1.0. Theoretical Background

Considering the aims and objectives for the study and the research questions I intended to answer, I decided to explore the Attribution Theory, Symbolic Interaction Theory, Medical Systems and the concepts, Stigma and Social Support.

2.2.0. Attribution Theory

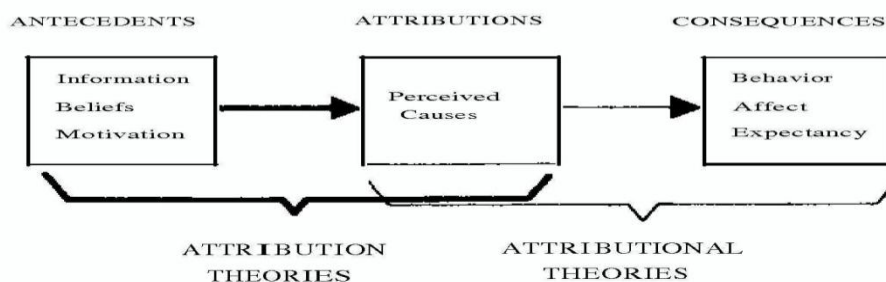
The attribution theory provides a good structure for understanding the reasons that underline the meanings most parents associate to the challenges faced by their children with autism. Generally, attribution theory explains the various processes that inform peoples attempt to make inferences and justify behavioral tendencies. This is done to develop a meaningful outlook of the world they live (Tetlock & Levi, 1982). The basis of most attribution theory is the fact that human beings process information intuitively with the aim of explaining behavior to help them secure control over their environment (Heider, 1958; Kelley, 1967).

The theory also deals with the study of perceived causation, attribution- referring to the perception or inference of a cause (Kelley & Michela, 1980) and the attempt to make causal explanations to questions beginning with “why” (Kelley, 1973). It highlights the fact that inferences and conclusions drawn are from mere assumptions and not from concrete scientific basis. This assertion has been further explained by Hewstone (1996). He is of the view that, attribution is about common sense approach to explanations as studied in social psychological framework. The attribution theory guides a person’s interaction in the world because it deals with a person’s understanding of the causal structure of the world (Kelley & Michela, 1980).

In the course of making attributions, various cognitive biases such as intergroup attribution come to play. In intergroup attribution, the attributes which are given to a person's behavior does not relate basically to individual's characteristics, but to characteristics associated with the entire group to which a person is a member of (Hewstone, 1996). It also explains the manner in which members of one social group interpret the outcomes and consequences of behavior of members of their own group and that of other social groups (ibid).

The general model of attribution field (in figure 1.0 below) as outlined by Kelley and Michela (1980) consists of *antecedents* (preceding occurrences), *attributions* and *consequences* (result of previous occurrences). On the antecedent side, certain information about behavior and circumstances of its occurrences are used by a person or the perceiver to infer causation. Weiner (1992) refers to casual antecedents as “the information used or the processes or structures activated that enable one to reach a casual ascription, and thus to attain “deeper” knowledge” (P. 232). That is, information processing operates jointly with preexisting assumption and expectations. For instance, a person's beliefs about a situation will influence the way the situation will be perceived. Attributions are in the middle of the field and it is the ascriptions people make about causes. The consequences side of the attribution field deals with a perceiver's reaction or evaluation of the behavior.

Figure 1.0. General model of the attribution field by Kelley and Michela (1980)



2.2.1. Attributional Theory of Motivation and Emotion

Bernard Weiner focused his attribution theory on motivation and emotion (Weiner, 1986). This theory is important in understanding the causal attributions which parents whose children have autism make to their children's condition because the theory provides an understanding on what motivates a parent to make a particular inference and not the other and its consequences on the parent. According to Weiner (1986), attributional analyses start when there is an outcome such as success or failure in an achievement-related task; or when there is social acceptance or rejection. When this happens, a person investigates the factors that accounted for such an outcome. The way a person makes causal attributions about outcomes have been classified along three causal dimensions (ibid). These are Locus of Causality, Stability and Controllability.

The locus of causality refers to the internality or externality of an attribution (Weiner, 1986). Rotter (1990) refers internal locus of control to the degree to which a person supposes that an outcome of a behavior is dependent on his or her own behavior. In other words, a person believes that he or she is responsible for what happens in his or her life. There is believes that decisions and effort on his or her part definitely make a difference in the outcome. In converse, a person who scores at the external end imagines that the outcome of his or her behavior is as a result of other people's decisions or some external force such as chance, luck or fate, or the outcome is merely unpredictable (ibid).

According to Weiner (1986) the internal versus external dimensions allow a person to take into consideration where causes are perceived and a person's emotional reaction depends on these dimensions. When a person makes an internal attribution for an unwanted event, he or she faces self-focused negative emotions such as guilt and shame whereas a person who

makes an external attribution for unwanted event faces anger and resentment which is externally focused (Weiner, 1986).

The second causal dimension identified by Weiner (1986) is stability. This deals with the temporal nature of the cause. This varies from stable to unstable or whether the causes change over time or not. If causal conditions are perceived as likely to change, then the present outcome may not be expected to repeat in the future or there may be uncertainty about subsequent outcomes (Weiner, 1986). The stability nature of an event has implications for future occurrences (ibid).

Controllability is the third dimension identified by Weiner (1986). It deals with the level of volitional control that a person has over a cause. Volitional or optional control includes traits such as industriousness and laziness. These traits can be willed to change by a person.

2.2.2. Attribution Theory in Psychology of Religion

Attribution theory in Psychology of Religion takes into consideration the effects of contextual factors, characteristics of both event and attributor in making inferences. The theory therefore provides a good framework to understand the explanations parents whose children have autism give to the disorder in Ghana. According to Spilka, Shaver and Kirkpatrick (1985) people have the option to choose between religious or non-religious explanations to every phenomenon. A person's decision to choose between the two is premeditated by certain factors. The theory aims to explain when and why a person chooses one kind of attribution and not the other (ibid). In many cases, more than one cause may be considered as operating with respect to a given phenomenon (Spilka, Shaver & Kirkpatrick,

1985). In respect to this, Spilka, Shaver and Kirkpatrick (1985) have outlined four factors which determine attribution. They indicate that the interaction of these factors determines whether a person will make a religious or a naturalistic attribution to a phenomenon. The factors include characteristics of the attributor, the context of the attributor, characteristics of the event and the context of the event. These factors have been delineated below.

Characteristics of the Attributor

This deals with a person's predispositions towards the use or against the use of religion in explaining events. According to Spilka, Shaver and Kirkpatrick (1985), individuals differ remarkably from the way they use religious or naturalistic explanations. The belief which directs a person's behavior could be as a result of the person's social interaction, education and upbringing. As has been stated by Mackelprang and Salsgiver (2009) "Our internalized values and beliefs come from a variety of sources, including the aggregate culture, various subcultures, family teaching, life journeys, and educational experiences" (P. 1). The features of a person to choose either religious explanation or naturalistic explanation determine the level of one's *religiosity* (Spilka, Shaver & Kirkpatrick, 1985).

The efficacy of religious and naturalistic mechanisms for controlling and predicting outcomes in the world may be other characteristics of the attributor which has implication for attribution (Spilka, Shaver & Kirkpatrick, 1985). Moreover, a person's decision to choose either a religious or non-religious explanation is based on the importance in determining and maintaining the individual's positive self-concept.

Context of the Attributor

A person's explanation to an event is largely influenced by some contextual factors. Spilka, Shaver and Kirkpatrick (1985) postulate that the context where the attributor finds him or

herself can either bring about or hinder some kind of cognitive processes. In a context where religious explanations are more prominent and available to the attributor, then the attributor may be influenced to go by a religious interpretation (ibid). Other contextual factor which may affect the attributor is the presence and the opinions of other people. The attribution that a person will make depends on the rate at which people in the setting either directly or indirectly encourage or discourage the application of religious attributions (Spilka, Shaver & Kirkpatrick, 1985). Social coercion is another contextual factor which may affect the attributor. That is, if an attributor believes that other people will like them more if a particular attribution is made, then the attributor will be more likely to adopt that attribution strategy.

Characteristic of the Event

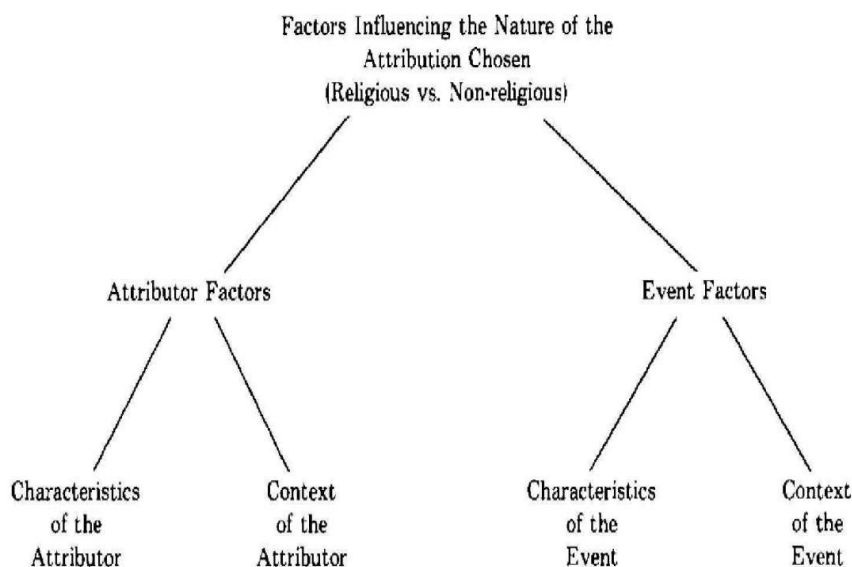
According to Spilka, Shaver and Kirkpatrick (1985), every individual has an existing cognitive structure in which new information is assimilated into. Thompson and Janigian (1988) have proposed that “individuals have *life* schemes that provide a sense of order and purpose in one’s life” (P. 260). The choice of a religious or a naturalistic attribution is influenced by the degree to which the event to be explained is in line with the attributor’s meaning-belief system (Spilka, Shaver & Kirkpatrick, 1985). Events similar to previous ones are prearranged attributions as the previous one. Other influential characteristics of the events include the efficacy of religious or naturalistic mechanisms controlling similar events (ibid).

In the view of Spilka, Shaver and Kirkpatrick (1985) people who have both religious and naturalistic meaning-belief system have two sets of beliefs into which they have to assimilate information.

Context of the Event

This refers to the place in which an event occurred. According to Spilka, Shaver and Kirkpatrick (1985) the environment (religious or non-religious) within which the “to-be-explained event” occurs has an impact on the attribution process. For instance, if an event occurred in a highly religious setting, the likelihood of the attributor associating a religious meaning-belief is higher. Spilka, Shaver and Kirkpatrick (1985) have delineated these factors in a diagram below;

Figure 2.0. Classification Hierarchy of Factors influencing the use of Religious versus Non-Religious Attribution (Spilka, Shaver & Kirkpatrick, 1985)



2.3.0. Symbolic Interaction Theory

The underlining principle of the symbolic interaction theory is meaning derivation (Aksan, Kisac, Aydin & Demirbuken, 2009). Parents whose children have autism attempt to construct meanings to their children's condition and this theory provides a framework through which individual's derive meanings for events. Thus, the theory takes into accounts how parents form meanings for their children's condition out of their interactions with people. In trying to understand families and other social worlds of people, the Symbolic Interaction Theory offers a good theoretical perspective (LaRossa & Reites, 1993). The theory operates on the premises that, people act towards things based on the meaning they have for them. These meanings on which people act are derived from their social interactions with other members of the community (Okello & Neema, 2007). Events get their meanings through human interpretations and these meanings which are given to objects, events and situations are not inherent in them. Rather, they are products of human responses to them. Derived meanings are not stable; they are constantly modified through the process of human interpretation (Okello & Neema, 2007; Stryker & Vryan, 2003).

Thompson and Janigian (1988) define a search for meaning as “a search for meaningfulness, for understanding how the event fits into a larger context” (P. 263). Stryker and Vryan (2003) are of the view that, every individual's has a cognitive structure where information is processed internally yet meaning derivation is shaped by social processes. People compare the information they process with preexisting norms and beliefs for appropriateness (ibid). In defining situations, people use whatever cues which may be available, preferring relevant cues but using less or even irrelevant cues when necessary and drawing on experiences (Skyker, 1987).

2.4.0. Externalizing and Internalizing Medical Belief Systems

Medical beliefs exist as part of the larger cultural systems. According to Young (1976) the explanations which are associated to sickness determine the reliable therapeutic strategies to adopt. These explanations involve the organization of facts about the onset and course of sickness (Young, 1976). The various ways of organizing these facts include etiological and physiological explanations. It is based on these explanations that medical beliefs systems are established (ibid). Young (1976) believes that, the medical beliefs system can be conceptualized according to the level at which they are dominated by either form of explanations. Two types of medical belief systems have been distinguished by Young (1976); the externalizing system and internalizing system.

2.4.1. Externalizing System

This form of belief system makes use of etiological explanations of sickness. Etiological explanations involve the use of narratives in which significant medical events occurred (Young, 1976). In this form of belief system, explanations of sickness involve the time before the sickness commenced and other subsequent events. These explanations about the onset and course of sickness are linked together through cause and effects. According to Young (1976) connection between cause and effect is usually in a manner in which the sick person had no control over the occurrence.

In the externalizing system, sickness is seen to be purposely caused by a man or an anthropomorphic spirit (Young, 1976). He states that “sickness is itself a symptom of disrupted relations, not between organs, but between people or between people and anthropomorphized spirits who mirror or invert the moral order of society” (p. 149). Sickness as viewed from the perspective of the externalizing belief system shows a causal relationship between witches or an ancestral spirits and man.

Diagnostic in this system concerns an attempt to know what brought the sick person into the attention of the pathogenic agency which may be witches or an ancestral spirits (Young, 1976). This kind of explanation is usually seen to be supernatural and non-empirical.

2.4.2. Internalizing System

Internalizing system of medical belief makes use of physiological explanations. Physiological explanations deal with narratives about a malfunction of a bodily organ (Young, 1976).

Internalizing belief system focuses on the functions of different parts of the body. This belief system shows that sickness results from a disturbed body part or body system. Diagnoses involve a link between physiological and etiological events to the sequence of biophysical signs which mark the course of disease episodes (ibid). In spite of the importance of etiological explanations in diagnoses, Young (1976) emphasizes that diagnosis in the internalizing belief system completely rests on the efforts of the healer to interpret events in physiological terms.

The internalizing system constitutes the biomedical model (Garro, 2000) which is the explanation of disease in terms of biochemical or neurophysiological processes (Engel, 1977). Biomedicine is known to be commonly used in the organization of information in western societies (Ritenbaugh, 1982; Engel, 1977) and it is based on reality and the outside world which is scientifically termed as objectivity and realism (Fabrega, 2000). According to Young (1976), the physiological explanations in the internalizing system are usually rationalized on a theory or a set of theories.

2.5.0. Related Concepts

2.5.1. Stigma

Goffman's (1963) classic study of the concept of stigma has been applied to a variety of conditions and various forms of illnesses like mental illness, HIV/AIDS, epilepsy and cancer (as cited in MacRae, 1999). According to Burke and Parker (2006) "Stigma is the associative condition that predisposes people towards set attitudes, which, rather than being biologically driven, reflect the continuation of socializing(or perhaps un-socializing) experiences and then feature as a form of discrimination against certain groups of people" (p. 16). Kurzban and Leary (2001) also indicate that "stigmatization occurs when an individual is negatively evaluated, be it conceptualized in terms of discrediting negative attributions; perceived illegitimacy; or a devalued social identity" (p. 188).

Goffman (1963) identified three types of stigma. These are abnormalities of the body or a person's physical deformities, blemishes left as a result of a person's experiences such as unnatural patterns or mental disorders and stigma which results from ones race, nationality or religion. Marks depicting stigma can be visible or invisible on a person and can be controlled or uncontrolled by a person (Major & O'Brien, 2005). Attributes which depict stigma create attention for people because they are not desired (Goffman 1963). When a person possesses stigmatizing attributes, it turns other people away which make it difficult for the stigmatized individual to function normally in the social intercourse (ibid).

Parker and Aggleton (2003) argue that Goffman's emphasis on stigma as a "discrediting attribute" has led to a focus on stigma as if it were a kind of thing (in particular, a cultural or even individual value) or a relatively static characteristic or feature. They indicate that stigma is at some level culturally constructed. A model of health-related stigma as a social process has been proposed by Deacon (2006). The model postulates that

blaming certain groups of people for having an illness provides people who stigmatize an opportunity to distance themselves and their in-groups from risk of infection. This represents the main cause for producing stigma in the society (Deacon 2006). Ignorance of transmission methods, poverty or gender inequality create social contexts in which stigma is formulated and enacted. Stigma always results in blaming, shaming and status loss for the stigmatized person or group but it does not always have to result in discrimination to have a negative effect. Negative effects of stigma include status loss, discrimination, and failure to take advantage of social, economic and healthcare opportunities because of expected stigma and discrimination (ibid).

According to Major and O'Brien (2005) stigma is relational and context specific and "does not reside in the person but in the social context" (p. 39). Parker and Aggleton (2003) have emphasized the importance to recognize that stigma arises and stigmatization takes shape in specific contexts of culture and power. Stigma always has a history which influences when it appears and the form it takes (ibid).

2.5.2 Social Support

One of the many definitions of Social support is the definition by Shumaker and Brownell (1984) which indicates Social support to be the exchange of resources between a provider and a recipient which is perceived by both individuals to be intended to enhance the wellbeing of the recipient. Two approaches to understanding social support include the structural and the functional approaches (Uchino, 2004). The structural approach to social support has to do with the existence and interconnection among social ties (ibid). It also consists of the number of people in one's social network and their range. Functional approach deals with the specific purpose that such relationship may serve (ibid). Three forms of support have been categorized under the functional approach to social support (Jou as cited in Jou & Fukada,

2001). These are; *needed support* which is the support a person requires, *perceived support*- a person's perception of availability of support and *actual support*- support that has been received in the past.

Some models link social support and health; most of these models are variants of what are termed stress-related and direct effect model (Uchino, 2004). The buffering model is among the most popular stress-related model and it postulates social support as fundamentally healthy as it reduces the harmful effects of stress in a person's life (ibid). The main effect model proposes social support to be beneficial irrespective of whether persons are under stress or not (Cohen & Wills, 1985).

2.6.0. Review of Related Studies

2.6.1. Disease Classifications

Several researches have been done to show the various ways in which disease are classified in Ghana. A research was done by Fosu (1981) to identify the beliefs and behavior about disease in Ghana. The findings revealed how people interpret phenomena based on causes. He highlighted "cause" as the most important part of disease diagnosis and grouped diseases along three broad categories. These categories are: diseases believed to be naturally caused, those believed to be supernaturally caused and diseases assumed to be caused by both natural and supernatural agents. Naturally caused disease was viewed to be in the domain of scientific medicine and these are caused by natural agents such as worms, insects, improper health regimen and malfunctioning of body organs.

According to Fosu (1981) diseases with supernatural origins are in the domain of the traditional healers. He grouped these kinds of diseases into two: those which originate from

the good agent and those which originate from the bad agent. The good agents include *Onyame*¹ and the *ancestral gods*.² The good agents inflict disease on people who break important laws of the community. For instance, people who abandon orphans and widows who have been left in their care or people who breached taboos faced the wrath of the good agents. Basically, it was believed that the good agents do this to ensure that people lead acceptable lives in the community. Diseases which are afflicted by the bad agents are considered as a punishment for a person's misbehavior. The bad agents mentioned were witches, sorcerers and demons. Disease caused by these bad agents aims at disrupting a person's progress and bringing reproach to the person. Mental illness, sterility and leprosy were disease classified under this category. The use of traditional or scientific health care services depends on whether a disease is considered to be of natural origin or of supernatural origin (Fosu, 1981).

Care givers in Ghana adopt a number of approaches to manage or treat mental disorders. Services include biomedical approach which has its source from colonial period (Read, Adiibokah & Nyame, 2009; Twumasi, 1981). In spite of this, religious healing is central in all.³ Autism like other mental disorders is treated in the churches by pastors or in the shrines by fetish priests. A report from the Commonwealth Human Rights Initiative (CHRI) has shown that Ghana lacks adequate mental health care and this has contributed to the growth of prayer camps for religious healing. The report showed that patients at these centers are not on any medical care rather, patients are chained, starved and abused of other human rights

¹ Onyame- one of the variant names of God, commonly used among the Akans of Ghana.

² Ancestral gods- spirits of deceased relatives; they are believed to have the power to influence the fortune of the living. Also known as 'deity'.

³ Cure through spiritual means. The three dominant religions in Ghana - Christianity, Islam and Traditional Religion practice religious healing.

(http://humanrightsinitiative.org/index.php?option=com_content&view=article&id=769&Itemid=573). The reports from the 2010 Country Reports on Human Rights Practices pointed out that in Ghana:

Human rights activists expressed concerns about "prayer camps" in which individuals believed to be possessed by evil spirits were chained for weeks, physically assaulted, and denied food and water. The camps targeted persons with mental illnesses. Camp supervisors diagnosed mental illness as a "demonic affliction" and prevented patients from consuming food or water, often for seven consecutive days, to cleanse victims of their evil spirits. Some victims were estimated to be as young as six years old.

Families sent these victims to be exorcised of evil spirits or cured of their physical or mental illnesses. Victims were held at the camps until they were considered healed.... No regulations were implemented by year's end. (8/04/ 2011, pp. 25- 26).

Despite the chaining and beating of people with mental disorders, the approach remains the most patronized (Read, Adiibokah & Nyame, 2009). Nana Oye Lithur, the Ashanti Regional Co-ordinator of CHRI pointed out that prayer camps are patronized because they are cheaper compared to the psychiatric hospitals. Again, family members sent mentally ill relatives to the prayer camps because they want to keep them out of the home (Modern Ghana, 1/05/2009).

In the view of de Graft Aikins (2005) the choice of health seeking in Ghana draws on but transcends culture. The need for an effective and less expensive pharmacological treatment and relief from the physical and psychosocial burdens shape medical care. According to de Graft Aikins (2005) spiritual causal theories still exists within the Ghanaian public sphere, but their structure and function is complex. Findings from her research indicated that a minority of rural participants attribute diabetes to two main causes; witchcraft

(people who possess mystical powers) and to sorcery (malevolent actions caused by ordinary people through the use of spells and rituals). She indicates further that spiritual causal theories do not shape illness practices as predictably as is reported in most studies. Most people who utilize traditional religious healing abandon this for biomedical treatment when there was no improvement in their physical health. According to de Graft Aikins (2005) some people attribute disease to spiritual causes but do not seek spiritual treatment.

2.6.2. Explanatory Models

Shyu and Tsai (2010) have used an explanatory model to explain the ways parents who have children with autism explain and choose therapies for their children in Taiwan. The parental explanatory model was seen to affect the type of therapy parents whose children have autism adopt for their children. Results from the study indicated that parents hold both biological and supernatural beliefs about the cause of their children's autism. These beliefs by parents co-exist without any inconsistencies. Consequently, parents select multiple treatment strategies.

Results of this study were similar to a study by Wilcox, Washburn and Patel (2007) on the explanatory models of parents who have children diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) in India. Parents in the study by Wilcox, Washburn and Patel (2007) also attribute the cause of their children's ADHD to a myriad of causes. Some women whose children had autism investigated the cause of their children's problem by visiting the doctors who delivered these children to find whether there was an injury at the time of birth (Gray, 1993). Despite mothers being told that circumstances surrounding the delivery of the child could not be linked to their children's autism, mothers still believe that something might have happened to their children during delivery.

One difference between the study by Shyu and Tsai (2010) in autism and that by Wilcox, Washburn and Patel (2007) in ADHD is that in the later study parents sent their children to the Child Development Center which uses a biomedical model but parents refused to treat their children's problems with medicine. They relied on religious approaches and other behavioral interventions. According to Jenson, Green, Singh, Best and Ellis (1998) parents who have children with ADHD attribute their children's worst behavior to poor medications. Children's good behavior was a result of parents own effort.

Bakare *et al.* (2009b) have indicated that in the sub Sahara Africa, the information provided by health care workers to parents whose children have autism are sometimes inadequate, misguided and misleading. Information is influenced by the beliefs of health care workers. Bakare *et al.* (2009b) have it that;

In the context of sub-Saharan Africa, where healthcare workers living among the general population in the community often play a pivotal role in offering medical advice and providing information on healthcare related issues to people in their immediate community, healthcare workers' cultural perspectives and their opinions or beliefs on etiology of developmental disorders such as ASD would greatly influence the help-seeking behavior of parents of children with ASD living around them in the immediate community. (p. 2)

Knowledge provided by health care workers to parents about the cause of their children's autism has a great impact on help seeking. According to Bakare *et al.* (2009b), majority of health care workers subscribe the etiology of autism to a biological cause. Some believe that ASD is caused by maternal infections and there are health workers who are of the view that ASD is caused by supernatural agents. In their study, majority of the health care

workers considered autism to be preventable. Prevention was achieved through being forgiven of sins and ending up relationships from cursed ancestral spirits.

2.6.3. Social Experience of Stigma.

An Attributional Analysis of Reaction to Stigma by Weiner, Perry and Magnusson (1988) examined the perceived cause of stigma and reactions to the stigmatized person. Stigma was examined based on its controllability (the stigmatized bears personal responsibility of the cause of stigma) and its stability (reversibility of the behavior causing stigma). Stigmas whose onsets were controllable were linked with no pity, anger and less desire to help. Controllable stigmas were seen as reversible. On the other hand, stigmas which were uncontrollable were associated with pity, no anger and affective reactions. These stigmas were seen as stable and irreversible. According to Weiner (1992) causal beliefs either encourage anger or sympathy to stigmatized individuals.

Children with autism are not the only people who experience stigma instead stigma transcend to their close relatives (Gray, 2002). According to Mak and Kwok (2010) “Stigma not only impacts the discredited individuals themselves; it can affect individuals who are closely associated with these stigmatized individuals (i.e., family members, caregivers, friends, or service providers)” (P. 2045). Gray (1993) investigated the extent to which parents whose children have been diagnosed of autism experience stigma. Parents perception of stigma, the nature of the stigma and the factors associated with the parents’ perception were observed. Results from the study showed that not all parents perceive that they are stigmatized because of their child’s autism. They admitted that it is highly difficult to manage their children especially in public places. Families were stigmatized as a result of the poor

social interaction of children. Moreover, the normal appearance of the children with autism but their disordered behavior made it very challenging for parents in public.

Parent's perception of stigma was also influenced by sex characteristics. Mothers in the study felt they were more stigmatized than the fathers did. Mothers may have perceived themselves as stigmatized because of the tendency for mothers to take greater representation of the family in public (Gray, 1993). The mothers in the study took more active role in caring for their children with autism in contrast to the men. They were basically involved in getting treatments for their children and dealt with other practical issues with regards to the children's disorder.

Another challenge parents whose children have autism face is the unpredictable nature of the behavior of children in public places (Ryan, 2010). Children with autism sometimes disgraced their parents in public by putting up unaccepted behavior (ibid). Some parents felt ashamed at the behavior of their children. In addition, parents were afraid of what their children could do in public. Most of these parents therefore refused to go to public places with them. Other parents reduced the rate at which they went out with their children with autism. According to some parents, they learnt ways of handling their children's behavior in public places yet these strategies prove futile.

Aside the unpredictable nature of the behavior of children with autism in public places, the response of other people to the children's misbehavior was also problematic to some parents (Ryan, 2010). Parents felt ashamed of what other parents would think about them when their children with autism behaved in an unacceptable manner. According to Ryan (2010) many parents who sent their children with autism to public places reported of strange looks, stare and glare from strangers when their children behaved differently.

Barke, Nyarko and Klecha (2011) assert that mentally ill people in Ghana are viewed to be dangerous because they become aggressive and fight on minor provocation. People are thereby entreated to keep a safe distance from them. According to Barke, Nyarko and Klecha (2011) mentally ill patients constantly report of rejection and discrimination in their day to day activities.

Chapter Three

METHODOLOGY

3.1.0. Introduction

As an Exploratory study, I choose to use the Qualitative Research Approach. This research approach focuses on exploration, examination and the description of the phenomenon of interest thereby giving the researcher a deeper understanding of the subjects under study (Brinkmann & Kvale, 2005). It offers the opportunity to know how people view and adjust to the world, how they experience events and “what it is like” to experience a specific condition (Willig, 2008).

3.2.0. Ghana: The research setting

Data for the study was gathered in Accra in the Greater Accra region of Ghana. Ghana is located in the west coast of Africa bounded to the north by Burkina Faso, to the east by the Republic of Togo and to the west by La Côte d'Ivoire. At the southern part of the country is the Gulf of Guinea. The total land area of the country is 238,535 square kilometers. Data from the 2010 census estimated that there are 24,233,431 persons living in Ghana (Ghana Statistical Service-GSS, 2011).

Like all other African countries, religion is a central part in the lives of most Ghanaians. Freedom of religion is a constitutional right and the most common religions in Ghana are Christianity, Islam and Traditional religions. In addition, there are minor groups of Hindus, Buddhists and atheists. About 60% of Ghanaians are Christians and they are mostly found in the southern part of the country whereas Muslims dominate the Northern sector (Briggs, 2008). According to Kassah (1998) most Christians in Ghana combine Christianity

with traditional religion so it is not surprising to uncover that Christians visit their home town to perform traditional religious rites.

Geographically, Ghana is partitioned into ten (10) regions with the Northern region occupying the largest land area (see Map 1. for the Map of Ghana). Greater Accra region is the smallest of the ten regions yet the second most populous (GSS, 2011). The 2010 census estimated the population of the region to be 3,909,764. This constituted 1,884,127 males and 2,025,637 females (GSS, 2011). Accra is the capital of the Greater Accra region and also the capital of Ghana. It is the administrative and the economic hub of Ghana, with the seat of the Government and also the main gateway to the country.

The World Bank estimated in 2008 that, Accra's economy constituted about 10% of the total Gross Domestic Product (GDP) of Ghana (Farvacque-Vitkovic, Raghunath, Eghoff & Boakye, 2008). Due to the high economic activities in Accra, many people from other parts of the country and beyond have migrated to the city. Gradually, Accra is becoming cosmopolitan. Most of the country's well known health institutions are located in Accra as well as most Special Schools (schools for disabled).

Having considered the above factors, I found it appropriate and conducive to gather my research data from this setting. Collecting data from this setting gave me the opportunity to get my targeted sample from diverse background. Specifically, I got my participants through a center for children with autism which is located in Accra. As at the time of data collection, there were thirty-two (32) children with autism at the center.



Figure 3: Map OF Ghana. (GSS, 2011)

3.3.0. Getting the Information I Needed

According to Kvale and Brinkmann (2009) the knowledge produced by any interview research rests on the social relationship of the interviewer and the interviewees; this is enhanced by the interviewer’s ability to create a conducive environment and platform necessary for talks involving private events. Doing disability research involves several

challenges and dilemmas; the challenges faced by non-disabled researchers doing disability research have been outlined by some researchers. For instance by Singal (2010).

As a non-disabled researcher, I envisaged it would be difficult for my participants to feel free and disclose their lived experiences. Also, I foresaw the tendency that participants might view the research as an exploitation thus “interested in extracting data and then disappearing” (Stanfield, 1999 p. 419). Although the interviewers were not disabled themselves, they were parents whose children’s were living with a disability. The above reasons seemed as a blockade between the information I needed and me. To break the barrier to the information, I volunteered at the autism center where I recruited my participants. At the center, I served as a class facilitator and assisted in some administrative work. This role lasted for a period of one month. Most interviews were conducted during this period.

3.4.0. The Sample

Seven (7) participants were interviewed in the research. Out of the seven (7) participants, four (4) were parents who had children with autism. They included two (2) male and two (2) female parents. These parents provided the main data for the research. The decision to interview four (4) parents was influenced by Smith and Osborn (2008) recommendation that five or six participants are good sample size when students want to use the Interpretative Phenomenological Analysis (IPA) in analyzing data. They go further to recommend that for students who have no experience of IPA, it is extremely advisable to use a lesser sample than has been indicated. The sample size was influenced by this premise. The remaining three (3) participants were one (1) male health worker; one (1) female administrator of a special school and one (1) male religious leader. They served as key informants to the study.

3.4.1. Sampling Technique

The purposive sampling technique was used in recruiting the participants. Specifically, I wanted parents who were living with their children with autism⁴. I also wanted parents whose children with autism were less than ten (10) years old. I presumed that, the experiences and coping strategies of parents could be influenced by how long they have lived with their children.

Information letters and stamped envelopes addressed to myself were given to the administrator of the center I was working. These were to be given to parents who were in my criterion. Parents who wanted to participate in the study were to indicate their willingness by returning their addresses to me in the envelopes I provided. Parents who were willing to participate also had the option of informing the administrator of the school who would in turn inform me.

After weeks of this action, there was no response from any of the parents. As the time for fieldwork was getting limited, the administrator pointed out that it would be difficult to get participants with the approach I was using. She suggested the approach usually used in recruiting participants at the center, which was the administrator verbally seeking the consent of the parents to participate in the study.

This approach proved to be very beneficial to the research. The administrator gave me the contacts of parents she had spoken to and who have agreed to participate in the study. I then contacted these parents to arrange a time and venue for the interviews. Three out of the four parents whose children have autism preferred being interviewed at the center; therefore in each instance, a confined place at the center was arranged.

⁴ Although some of the children I saw at the center seemed not to meet all the diagnostic features of ASD, I found out all the children were in the continuum.

The convenient sampling approach was used in recruiting the key informants. Information letters were as well sent to individuals whom I knew constituted the target key informants for approval. A date and venue were fixed for the interviews.

3.5.0. Data Collection

Technically, the data collection was in two folds; data from parents who have children with autism and data from the key informants. In both categories, interviews were conducted with the help of interview guides designed for both groups (see appendix). The interviews with the parents whose children have autism sought to understand their experiences from own their own perspectives. Interviews aim to obtain descriptions of the interviewee's lived world with respect to interpretation of the meaning of the described phenomenon (Kvale and Brinkmann, 2009). The interviews provided me the opportunity to step into the life world of the parents (McCracken, 1988).

All interviews were semi-structured. The semi-structured interview was used because it gave the chance to participants to talk about a particular aspect of their life and experience. The use of a semi-structured interview guide shapes the conversation between the interviewer and the interviewee by touching on all themes which are of interest to the interviewer.

3.5.1. Procedure for the Interviews

Prior to each of the interviews, I had been in contact with my participants either in person or on the phone. I allowed the participants to choose a venue and time they deemed convenient to be interviewed during my initial contact with them. In instances where we could not make an arrangement for the first time, parents sent text message as to where and were we could meet.

All participants had previously received the information letters which contained the aims and purpose of the research yet I gave them extra copies to read before the start of every interview. Once they had finished reading, I asked them if there was something which was not clear to them. In all the interviews, I was asked to explain the purpose of the study. In a case of a participant who was unable to read, I went through all the points in a local language.

When participants have finished with every question they had, I asked them if they were still willing to participate in the study which would be audio taped. Once they had affirmed, I issued the informed consent form to them to sign. Not following the semi-structured interview guides in an orderly manner, I made sure I covered all the themes that were in the interview guides by highlighting topics which were already covered.

3.5.2. Informal Conversation and Observation

Although the data collection method for the study was only interviews with parents and selected key informants, I had the opportunity to have informal interactions with some other sets of people in and outside the center. These included caregivers of the children, teachers at the center and some other volunteers I met at the center. These conversations help me to properly understand the issues about autism in Ghana.

I also had the opportunity to observe the classroom setting for the children, the available resources, the way they were treated at the center, the time children were brought to school and picked back home and a lot more activities with regards to the children. This background knowledge helped me to understand some terms (as used by parents and in the center) parents used in the interviews. Moreover, my observations prepared me to ask some questions during the interviews

3.5.3. Language for the Interviews

Participant had the option of speaking in English, which is the official language of Ghana or in Twi⁵. Five (5) out of the seven (7) interviews I conducted were in English. Some participants intermittently interlaced it with Twi. Two (2) of the interviews were conducted in Twi.

3.5.4. Technical Support

A digital voice recorder was used to record all the interviews. I also made use of semi-structured interview guides during the interviews.

3.6.0. Transcription

According to Kvale and Brinkmann (2009), “a transcript is a translation from one narrative mode-oral discourse-into another narrative mode-written discourse” and it serves as “the solid rock-bottom empirical data of an interview project” (P. 178). I used the semantic level transcription for transcribing all the interviews I conducted. Smith and Osborn (2008) have indicated that this technique enables researchers to get a complete representation of the verbally collected data and it maintains the originality of the data. With the interviews I conducted in Twi, I translated everything into English and transcribed them as well.

3.6.1. Analysis of Data

Although data analysis is not the same as data reduction, it is valid to say that paring down and condensing the chunk of data collected from fieldwork is a major preoccupation of all analysts (Hardy & Bryman, 2004). With the vast data I got from the field, I trimmed it down

⁵ Twi is the first language of over 50% of the entire populace of Ghana and it is spoken by about 70% of the entire people in Ghana (Briggs 2008).

by excluding the parts that were not in line with my research questions. Initially, I wrote down all the themes emerging from the data. I found out that some themes were more prominent than others due to their occurrences in the interviews.

I analyzed interviews I conducted with parents whose children have autism with the Interpretative Phenomenological Analysis (IPA). I decided to use this approach because IPA explores into detail how participants make sense of their experiences and events (Smith & Osborn, 2008). IPA also explores an individual personal perception or account of an event. With the interviews I had with the key informants, I used the thematic analysis because of its flexibility and usefulness in providing a rich and detailed account of data (Braun & Clarke, 2006).

3.7.0. Validity and Reliability

It is of great importance for Qualitative researchers to demonstrate the credibility of their researches. Validity in Qualitative research deals with the accuracy of participants account to their real social phenomena and is to them (Schwandt as cited in Creswell & Miller, 2000). Reliability on the other hand deals with the consistency and the trustworthiness of the research data; it has to do with whether research participants will give the same or different answers if they are being interviewed by another interviewer (Kvale & Brinkmann, 2009). My prolonged engagement on the field for data collection and constant reflexivity strengthened the validity and reliability of the study. In addition, the use of a semi-structured interview guide to avoid rewording of interview questions was very beneficial.

3.7.1. Prolonged Engagement in the Field

According to Creswell and Miller (2000) one of the effective procedures for qualitative researchers to maintain validity is to spend a long period of time on the research site. It is

known that when researchers work for an extended period of time with their participants during data collection, research validity and vitality is strengthened (Fetterman as cited in Creswell & Miller, 2000). Also, Merten (2003) claims it is important for researchers to spend time with their participants or their population of interest. By doing this, researchers are able to do away with several biases, specifically “(a) building trust, (b) using appropriate theoretical framework, (c) developing balanced questions, and (d) developing questions that might lead to transformative answers” (P. 144).

As I have indicated elsewhere in this paper, I worked with the children of the parents I interviewed for a period of one month. As a tradition at the center, facilitators welcome children each morning and picked their lunch packs from people who brought the children to school. Being a facilitator, I played this role. This gave me the opportunity to meet some of the parents prior to them becoming my research participants. *Inter views* with the parents later on were more or less, an opportunity for the parents (interviewee) and me (interviewer) to exchange ideas about the child we cared for (Kvale & Brinkmann, 2009).

I occasionally had informal chats with some of the parent in our subsequent meetings. Parents asked me about the progress of the research and most times, it set a stage for them to talk about their experience. Most of the subsequent informal conversations were in line with the information they gave me during the interviews.

3.7.2. Reflexivity during Fieldwork

Pyett (2003) has indicated the importance of constant reflexivity and self-scrutiny in Qualitative Research. The behavior of researchers always has the potential of affecting our research participants (Finlay 2002). Issues relating to gender, dominance, sexuality, race, age and class all have the potential of affecting Qualitative research. “Reflexivity—where

researchers engage in explicit, self-aware analysis of their own role-offers one tool for such evaluation” (Finlay 2002, p.1).

To ensure that my data was free from any researcher characteristics, I had to constantly do an introspection to see whether I was influencing the information the subjects were giving me. I did this by monitoring the way I spoke to the participants and the way I posed questions especially the questions which were not part of the interview guide.

3.8.0. Ethical Issues

Ethical issues are predominant in every interview research and these issues must be well treated. If a researcher is ethical, then it means the researcher is opening up to others, acting for the good of participants, trying to see others exactly the way they are rather than the researcher imposing his or her ideas and biases on the subjects (Brinkmann & Kvale, 2005). Ethical principles outlining professional guidelines for the conduct of research were strictly adhered to in this research. Ethical clearance for the research was approved in both Norway and Ghana before starting the interviews.

3.8.1. Informed Consent

The aims and objectives of the research were thoroughly explained to all the participants before every interview. Prior to this, an information letter which contained a summary of the project description had been given to all the participants. This was done to give a clearer description of the study they would be taking part. Participants were alerted of the anticipated advantages and the disadvantages for participation in the research. I told the participants the expected time duration for the interview. Moreover, I each sought participants consent before recording the interviews.

All these were done or explained in a language that they understood. Finally, I gave Informed Consent forms (see appendix) to be signed by all participants to indicate their willingness to take part in the study.

3.8.2. Anonymity

Participation in the study was strictly anonymous. Participants in the study provided neither their names nor their addresses. Any other information that could help trace the participants was not taken in the research. All the participants in the study were given code numbers for easy identification. For instance, “M” represented “male” and “F” represented “female”. A.D., H.W. and R.L. were used for the Administrator of the school, Health Worker and Religious Leader respectively.

In situations where participants mistakenly mentioned their names or that of their children, the names were replaced with a pseudonym. The name of the autism center and its location has deliberately been omitted from the research.

3.8.3. Confidentiality

It is a responsibility as a researcher to protect any information that my informants provided me and treat it with the highest level of confidentiality. All the interviews I conducted were one-on-one. Thus, there was no other person present at the time of the interview so information given remains between the interviewee and me. Recorded interviews were transferred to my personal computer for transcription. The interviews are accessible to me alone and the transcripts accessible to my supervisor. Information stored will remain with me and will be used for the purposes of the research alone. Once the research is over, all the recording and any other data on field will be deleted or destroyed.

3.8.4. Free withdrawal

As part of the information I gave to the research participants, I made it known that they had every right to fully withdraw from the study without any consequences. Participants signing the informed consent did not bind them to finish the interviews. They could withdraw from the study at any point in time. It was also not mandatory for participants to answer every question I asked.

Chapter Four

4.0. RESULTS AND DISCUSSION

The analysis of the data was done using the Interpretative Phenomenological Analysis. The data revealed six themes with each having sub-themes. Emerged themes include Knowledge and Perception about Autism, Parental Causal Attribution, Available Help, Perceived Challenge, Parental Help Seeking and Vision for the Future.

4.2.0. Knowledge and Perception about Autism.

The theme relates to the doctrines, beliefs and information which people have about autism in Ghana. These doctrines, beliefs and information serve as antecedent factors in the attribution process (Kelley & Michela, 1980). According to Jovchelovitch (2007) people in different contexts and at different times produce different views, symbols and narratives about what is true. The interviews showed that different people in different fields and social classes have distinct knowledge and perceptions about autism. Data from the research indicated that prior to the diagnosing of children's autism, their parents had no knowledge about the disorder. The term autism was new to parents; its diagnosis and prognosis were as well unknown to them. As a parent puts it, *"No, as of the time, we had no knowledge of what autism was"* (M1).

According to Okello and Neema (2007) meanings are given to objects and phenomenon through human interpretation and results from interactions with others. Societal norms, values and belief systems serve as guidelines and filter the information parents receive from others. A parent indicated that *"I have some formal education so I started listening to health programs on TV and radio when we realized there was something wrong. I sometimes called on phone-in programs to tell them about her situation"* (F2). In this statement the

parent relies on the public to understand her child's differentness. Societal beliefs and knowledge about autism manifest through the explanations people give to parents.

Three sub-themes were obtained from the data from the various interpretations people place on behaviors exhibited by children with autism and these are Information about Autism, Autism as a contagious disease and Autism as a possession. The sub-themes present the worldview of autism through the experiences of parents with the society.

4.2.1. Misinformation about Autism

This subtheme presents the amount of information people have about autism. This is analyzed through parents' interactions with other people. The dialogue with parents showed that some people consider autism to be an illness. From the interviews with parents, the actions of their children were first interpreted by others to fall in the domain of natural cause. As a parent bluntly puts it *"My sister then told me that she thinks she has a problem so I should take her to the hospital and so I took her to a nearby clinic and they gave her treatment"* (F2). It can be gathered from this excerpt that, F2 adhered to the beliefs and further recommendation which was made by her sister. The behavior change in the child was interpreted to occur as a result of a malfunctioning bodily organ; therefore the child was taken to the hospital.

According to de Graft Aikns (2005), many people in Ghana seek health from physicians upon identifying that they are unwell. Biomedical beliefs about illness in Ghana is traced to the colonial era when a campaign of enlightenment was used to persuade people that traditional healers were insincere and ignorant (Twumasi, 1981). In spite of this, most people have poor habits with regards to regular hospital check-ups (de Graft Aikns, 2005). Although traditional medicine is losing its popularity, people in the rural areas of Ghana still patronized the system. Most people living in the urban centers and educated people patronize the formal health care compared to the traditional medicine (ibid). In the view of Salm and Falola (2002)

urbanization and the intrusion of external cultures in Ghana have transformed the physico-spiritual components of the average Ghanaian worldview.

The data also revealed that for some reasons, the physicians who the parents made initial contact with about their children's condition had inadequate knowledge about autism. A parent indicated that "*We consulted our family doctor who was a General Practitioner. He told us that because boys sometimes have a delayed speech, we should wait for some time. So we had to wait*" (M1). From M1's statements, the initial contact with the physician caused a delayed diagnosis. This could be as a result of lack of diagnostic tool in setting diagnosis for autism. Consequently, the physician's beliefs about the cause of the child's behavior change retarded the parent's further actions.

I gathered that amnesic information on the part of parents play a decisive role here. Physicians pick cues from the narrations made by parents with regards to the child's sudden behavior change. These narrations include parents' observation of their child prior to the visit to the hospital and the situational factors surrounding the behavior change. Loss of memory about these events and a distortion in narration influences diagnosis which results in late diagnoses and late intervention for the child.

Another factor which could account for a delay in diagnosis may be a result of wrong diagnosis by physicians. This happens when parents give an accurate representation of their children's change in behavior to the physicians but then physicians fail to associate the narratives to autism. For instance, the behavioral change in children may be associated to another childhood illness. In addition, not all physicians are good listeners; some might fail to pick up the important cues from narratives. Stressing this point is the fact that parents and physician consider the developmental milestone of children with autism to occur later compare to the normal episode.

In addition, the diagnosis made by Ghanaian physicians may be influenced by their personal beliefs. Thus, there is an impact of socio-cultural beliefs on the practices of Ghanaian physicians. Consequently, physicians fail to give appropriate advice to parents when they visit the hospitals. I gathered from the interviews that physicians do not refer behavioral conditions of the children to the appropriate specialists for early assessment. Rather, physicians try to give medication to children's behavioral problems. For instance in the excerpt by F2, she indicated her child was given treatment when she took her to the clinic. Igwe, Bakare, Agomoh, Onyeame & Okonkwo (2011) have indicated that in spite of pediatric and psychiatric nurses being members of multidisciplinary teams who care for children with childhood autism and provide adequate counseling to the families of these children, pediatric and psychiatric nurses in Africa do not have enough knowledge about childhood autism.

The data showed that though parents make a good approach by first seeking biomedical intervention, unrewarded efforts might diminish in the long run. One parent indicated that *"we were going every week; we went for some time but there was no difference and it was costly"* (F2). This suggests that prolonged engagement with the formal health care without any improvement might cause a relapse. When general practitioners are unable to make a proper diagnose of autism or make the required referral, the parent might seek help from elsewhere within the communities.

Inferring from the attribution theory by Spilka, Shaver and Kirkpatrick (1985) the attribution which is made about children's sudden behavior change is guided by personal characteristics like level of education of the attributor. A parent stated that,

And then in fall of 2004 we did the conference call with a pediatrician and an ENT specialist and they said we should get him tested for hearing because it is possible that he is hearing impaired..... My mum didn't take him to the hearing thing because

she said the boy reacts to sound; my mother is a retired nurse and she said the boy react to sound so she doesn't think he was deaf⁶ (F2).

From this excerpt, the level of education and information the child's grandmother possessed had an impact on the help which was to be sought for the child.

The quests for a clearer understanding by the parents regarding their children's condition make them consider every meaning people ascribe. According to Kelly and Michela (1980) attribution is only a perceived causation and this goes to attest that, in the absence of professional diagnose or advice, the available interpretation would be taken as the ideal. Another parent's experience was in another form. The parent indicated that "*the other tenants said she was too abrasive but she will stop when she grows up*" (F2). The same participant said that, "*people said she was a very strong girl who did not cry even when she fell down*" (F2). In this context also, the parent took the explanations which were given to her by the people she lived and interacted with. Inappropriate education about autism militates against early diagnosis which in turn prevents parents from seeking early and appropriate interventions for their children with autism. As a result the critical period for children with autism is mostly missed.

Even when there is early diagnosis, parents and family members intransigent behavior prevent intervention. Another parent noted that "*we told my mother and my mum too said "oh my grandson doesn't have autism. He is my only grandson and he doesn't have autism". So we said wait*" (F1). This means that there is inaction regarding children's condition at the onset of autism. There seem to be a denial of diagnosis on the part of family members. This affirms what Denkyirah and Agbeke (2010) call the "wait and see attitude" which results in a loss of critical years of intensive intervention in the lives of children with autism. According

⁶The autistic child was staying with the grandmother by then.

to Igwe *et al.* (2011) early recognition, diagnosis and interventions in the lives of children with autism are known to improve prognosis yet in a context where knowledge about autism is low, there is the luck of this intervention to yield a result.

4.1.2. Contagious

This theme deals with people's perception and beliefs about the acquisition of autism.

Analyses of the available data indicate that autism is sometimes seen as contagious. This theme can be viewed from two perspectives. Autism is seen as a transmissible disease or illness and can be transmitted from an infected child to another. Secondly, children with autism are regarded as being possessed by evil spirits or ancestors.

Illness

There is an existing structure in the Ghanaian society about the causes of various medical conditions (Fosu, 1981). From the interviews, some people the parents interacted with believed that autism is a naturally caused condition which is contagious and can be transmitted from the infected child to another person just like most conventional viral and bacterial caused disease. Classification of autism this way falls under the internalizing medical belief system as proposed by Young (1976). According to Fosu (1981) naturally caused disease fall under the domain of scientific medicine and restoration of health was at the hospitals and clinics. As a result, people in this category of belief resort to conventional medical care upon the discovery of changes in normal behavior of their children. The modes of transmission are thought to be through physical contact or getting closer to an infected child. This belief is deeply rooted in the society and can be seen in an extract from one interview *"of course there are some people who say "don't touch him, don't go near him, or don't sit beside him"* (M2). This shows the societal believe that any bodily contact with the child with autism can result into autism. I gleaned from the on-going discussion that despite the view on the mode of transmission of autism, children with autism are not viewed to be

infected with autism from others. Rather, they are perceived as the primary causal agents of autism.

The above excerpt further suggests that children with autism face rejection and isolation from the public before and after their diagnosing. According to Deacon's (2006) model of health-related stigma as a social process, people who stigmatize ill people do that because they are afraid of going close to the sick person. The fear of contracting the infection drives their actions. The model further points out how ignorance feeds into stigmatization. Stigma faced by parents whose children have autism is not directly linked to the personal characteristics of parents rather this stigma is relational due to their association with their children with autism. For instance a parent felt stigmatized in this excerpt "*I had to stop going to church because it feels as if people don't want to come close. Nobody would sit close to us and those who do, move to other seats after a while. We will be the only people sitting on the entire roll*" (F2).

In the above excerpt, people refuse to come close to F2 because of her child's condition which has been related to her. I gathered that when people identify any behavior difference from what is considered as normal, they turn to have other notions about the person. Some people are afraid that going close to the person may render them into the same condition which is viewed to be undesirable. In effect, this shapes their social relations and may accede to parent's perception of themselves as different from other parents. It was also found that these parents also showed some care in their social relations. A parent disclosed that "*For me, I'm very curious about spreading the news; I haven't told a lot of people, there are a few friends I trust that I have told them*" (F1). This excerpt by F1 shows that she does not want people to know that her child has autism. I gathered that she is afraid of how people will react to the child's condition and the various attributions people may ascribe. I also gleaned that F1 does this to protect her self-image.

Contrary to the opinions above, the personal hygiene of children with autism revealed to cause rejection. Several researches have expressed the difficulties children with autism face in maintaining personal hygiene. For instance Wrobel (2003) indicates that children with autism have difficulties understanding most verbal information and modeling behavior which make it difficult for them to practice personal hygiene. An interview with a key informant showed that people do not go close to children with autism because some of them are unkempt and exhibit weird behaviors. For instance it was indicated that *“you see, some of them have watering mouths so it’s a little difficult for people, especially children to associate with them, it is not like a discrimination but their behavior drives others away”* (R. L.). R.L. suggests that attitudes towards children with autism are not meant to isolate them as “sick” persons instead people are not comfortable with the behavior and actions that these children put forth. I gleaned that the repetitive behavioral signs of children with autism and their tantrums may be interpreted as aggressions. This may drive people away from the child with the intention of maintaining safety.

Spiritual Possession

This theme encompasses the beliefs that autism is a spiritual possession and can be transferred or transmitted to others. Parents’ interaction with the society showed that autism is viewed as a demon which resides within the child with autism. Behaviors exhibited by the children with autism are perceived as manifestations of the spirits residing within them and these spirits may move from the affected child to another through physical contact. In line with Fosu’s (1981) classification of disease, autism falls under the group of diseases which are believed to be caused by supernatural agents. It also falls under the externalizing medical belief system (Young, 1976). One parent indicated that *“for them, they don’t know what autism is. They don’t understand it, all they think is she is under the control of some demon”* (F2). From this excerpt, the parent indicates the perception people have about her child’s

condition. She portrays how people perceive her child's condition to be as a result of a spiritual being which dwells within her child. Autism is believed to manifest in the child with autism through the actions of a demon.

According to Nukunya (2003) witches are believed to account for unexpected or underserved misfortune where it is not recognized that such a misfortune can happen by chance or by natural causes. I perceived that the normal appearance and behavior of the child from the early life stages and the sudden behavior change may account for this belief. It is believed that children are not born with the disorder; they are inflicted with autism after birth by an agent. The bodies of children with autism have therefore become the abode for spirits.

The causative agents of this category of illness are either the good agent or the bad agent (Fosu, 1981). The good agents include the deities and "Onyame"; they punish people who go against societal norms (ibid). Gyekye (2003) also states that,

Misfortunes and disasters that befall individuals, clans, or communities are very often interpreted as the consequences of, or perhaps, as punishment sent by the supernatural powers for bad conduct or failure to fulfill certain moral obligation to kinsfolk or community. (Pp. 17-18)

In the African cultural values, it is believed that individuals always account or bear responsibility for their deeds (ibid). It is therefore perceived that retribution has befallen parents whose children have autism. People under ancestral curse may as well be inflicted with autism.

The bad agents also include evil doers who it is assumed operate against the success of the child (Fosu, 1981). This could be intended to avoid the parents from having a peaceful mind. It is believed then that there is a human who operates secretly against the child. This could be as a result of mere jealousy on the part of the person. Another parent said that "*some people think this kid is bewitched, there are a thousand beliefs about the witches. It is all over*

the place” (M2). These statements by M2 affirm the societal beliefs about autism. I gathered that children who are spiritually possessed do not have answers to their conditions. Thus, the behavior change is manipulated by an external agent whom the child cannot control.

An interview with the religious leader indicated that *“some of the children have good spirits; their souls do not like the spirits which are transferred to them so they behave abnormally”*. From this excerpt by the religious leader, he portrays autism as a spirit in itself. He shows that a child who has a good spirit would retort to bad spirits transferred to them. Thus, the extract depicts the belief held by some people on how and why children with autism behave abnormally. I gathered that as these spiritual beings are believed to reside in the bodies of children with autism, they dictate the behavior of the children. These spirits can also change their dwelling into the bodies of other people and can thereby be cast out of the child’s body.

The administrator of the special school also had this to say; *“you see, some of them react to excessive noise and to new environment so when they are taken to the church, that is when their atypical behavior manifests”*. I gleaned that the atypical behaviors which children with autism show are interpreted to be a manifestation of the spirit residing in the child. I also perceive that because children with autism sometimes behave normally and at other times in an abnormal manner, their behavior is seen to be manipulated by an agent. The manifestation of atypical behavior in children with autism at the church may be interpreted as manifestations of the spirits residing in the child.

4.1.3 Possession (Transfiguration)

This theme portrays the belief that children with autism are spirits who have changed their appearance into human forms. It also covers the idea that children with autism are spirits who

come to cause havoc to their parents. According to Denham, Adongo, Freyberg and Hodgson (2010) deformed children and children who exhibit unusual behavior are normally considered as spirit children. Spirit children are considered as non-human beings or animals, which live in the bush. It is believed these beings can transform themselves into human forms to torment parents and cause family breakdown (ibid).

From the interviews with the parents, I found that children whose behaviors differ from other children are believed to be non-humans. A participant pointed out that *“later when they said she was not normal, they were thinking I had done something which they were not aware of. My mother then said my daughter is not a normal child, but “nsuo ba⁷”* (F2). This extract by F2 shows the knowledge held about children with autism as spirits who have altered their outward appearance to human forms.

Interviews with the religious leader also affirmed this belief. He indicated that, *“children sought from the gods cannot be healed no matter how you pray for them; the parents made that choice and they have to live with it”*. I also picked from the above excerpt that children who have a life-long behavioral problem may be considered as transformed beings and they cannot be healed as such. I gathered that there is the tendency to blame parents for seeking these children from a gods or goddess. A parent who first experiences infertility and later gives birth to a child with autism may be tagged to have sought the child from a lesser god. I picked up that people who are of this belief may perceive children as having answers to their behavior difference.

⁷Nsuo ba- literally means “water/river child”. Rivers are seen as living things therefore they are designated gender and names. It is believed the rivers have children and parents who face infertility may seek a child from a river. These spirit children transform themselves into human forms and then they are born by people who request for them.

4. 2. Parental Causal Attribution

The theme is about parent's notion of the cause of their children's autism. Attributions made by parents for their children's condition are influenced by their beliefs. These beliefs are shaped by the society and have a reflection on the type of help they seek for the children's condition. Three subthemes underscore the predictions given to autism by parents. These are unknown etiology, biological etiology and environmental etiology. The analyses showed that some parent believed the cause of their children's autism was a combination of two or more factors.

4.2.1. Unknown

This subtheme entails the views about autism as a disorder with an unknown cause. Researchers across the globe have not found any convincing etiological factor for autism (CDC, 2009). No environmental or biological factor has been attributed to the disorder until date. The discourses of the informants suggested that the actual cause of their children's autism is not known to them. *"For now I don't know what caused his autism, I have done plenty reading and research to inform myself about my boy"* (M2). From this extract, the parent reports that he has no idea of what could have caused his child's disorder. He shows that after reading about autism and trying to construct a meaning for his son's condition, he has no knowledge as to what could have been the possible cause.

I picked up that M2 makes this type of ascription because he relies on researches on autism to construct a meaning to his child's disorder. No research has confirmed the actual cause of autism, though there are some papers which only put up assumptions. For instance, Boutot and Tincani (2009) have predicted that a strong environmental factor combines with a biological factor to cause autism. But as to what these environmental factors are, it is not yet known. In this type of ascription, the parent remains in a dilemma.

Another parent stated that,

“ my son was going through all kinds of developments, he sat at the right time, walked around the same time as the previous children, by eight months, he was getting up and taking steps so you are not expecting anything than the usual. And so he even started mimicking adverts on TV⁸. My wife and I failed to recognize any change in his behavior. But at a point in time we realized for unknown reasons he was no more talking and it was shocking”. (M1)

As M1 stated, he missed the actual onset of the disorder. In this case, he is unable to get a proper account of his child's sudden behavior change. He is unable to link any situational factor to the onset of his son's autism. There is no meaning derivation for a parent who falls under this category of attribution. Autism as viewed from this point by a parent is seen to be a very complex disorder. There is lack of prognostication which may threaten parents about the repetition of the phenomenon.

4.2.2. Biological/ It was meant to be

The current sub-theme portrays the views of parents regarding autism as a biologically caused disorder. Biological includes the structure, formation and growth of the child's bodily organs. It deals with how the body is put together, the genetic lineage or hereditary.

Discourse with parents about the biological cause of autism revealed that some parents believe their children's disorder is a result of a hormonal or a chemical disturbance. For instance, a parent was of this opinion. *Well I know he is supposed to be born with it, then it manifests at a certain time. I know it has to do with some hormones and chemicals which are supposed to be in excess or deficiency. I have forgotten the name now”* (M2).

⁸ TV-Television

I collected from the above extract that autism is viewed by M2 to be a disorder which his child was destined to have and not necessarily from anything that happened to the child. He relates the cause of his son's disorder to some internal mechanisms which trigger autism in the child. Another parent puts it in a different way; *"It is something that has to do with the child's biological make-up; it's neither the food nor drink you take in"* (F1).

According to Weiner's (1986) Attributional Theory of Motivation and Emotion, parents who make this ascription make an external locus of causality. Although this attribution relates to internal or inherent trait of parents or is specific to the child, the choice to children's autism is not determined by the parents. Rather, this decision is determined by a powerful other. Parents do not have volition over the cause; thus it's occurrence is uncontrollable by parents. I deduced that because parents make an external locus of causality, it appears it reduces their sense of guilt. Parents think they are not responsible for the disorder and they could not control the incidence in any way. For instance M2 indicated that, *"I don't have a problem talking about my son; after all, it's not something I caused. Why should I be bothered?"* This excerpt by M2 shows his opinion that he did not contribute to his son's disorder. He views his son's disorder as something which was meant to happen in his son's life.

Stressing the point will mean that parents who attribute the cause of autism to biological factors believe that their children disorder is a result of the children's fate. According to Norenzayan and Lee (2010) fatalism is known to be related to negative consequences. The issue of autism having a biological cause but determine by fate shifts the cause from internal locus of causality to the external.

More so, the discourse with M2 and F1 above appear to me that parents may shift blames among themselves. Since autism results from the biological make-up of the child

which is hereditary, parents may consider themselves or their partners as the ones who transferred the disorder to the child.

4.2.3. Environmental

This sub-theme covers the perceived environmental factors that parents who have children with autism link to their children's autism. Parents who have children with autism believe that something specific caused or contributed to their children's autism (Harrington, Patrick, Edwards & Brand, 2006). As parents search for the cause of their children's autism, they consider some of the environmental factors which could have resulted into their children's autism. For instance a parent expressed that,

One of the parents I met here strongly believes it has to do with where the child was born. I don't know but she so strongly believes in it. I use to chat her up when we met here to pick up our kids. You see, she has two children, the first one was born in Ghana and is ok, and the second one was born in the UK, and has autism. They made me believe that the midwife might have done something to him at the initial stage of delivery. (M2)

I gathered from this excerpt that when environmental attribution is made, parents do not consider their own actions rather, they consider the actions of other people. The excerpt appears to mean that children's autism was intentionally inflicted on them by a third party. The attribution which is made here falls under the external locus of causality by Bernard Weiner (1986). This means that the cause of autism in children was under the control of a powerful other.

The extract appears that parent's perceive some environmental factors causing autism to be preventable. Although the cause of autism is attributed to an external event, parents perceive the situational factors as a result of choices they made. F2 expressed that *"I didn't*

intentionally take any medicine during pregnancy that might have caused it. If for anything, it was meant for her good" (F2). This extract from F2 points to the idea that her child's condition could have been caused by some of the prenatal medications she received. Although she does not point to a particular act, she believes her child's condition could be caused by medications intended for another purpose.

A research by Thompson, Levitt and Stanwood (2009) indicate that some drugs which are exposed to women at prenatal have a damaging effect on the developing fetus.

Another excerpt from the interviews points to a postnatal factor that could have caused the child's autism. M1 pointed out that, *"We had a nanny for him. We talked to the nanny at length and she said that there was no accident."* This excerpt points to the idea that the sudden behavior change of the child could be due to an accident which the child was involved. M1 further indicated that *"at a point in time we were thinking he might have fallen and suffered a head injury"*.

I gathered from the above excerpts that though parents were told at the time of diagnosis of the children's autism that the condition have no known cause, parents still attribute the cause to one or more factors.

4.2.4. Bridging the Gap: Parental Casual Attribution

Parental causal attributions as seen from the various sub-themes suggest that the ascriptions which parents make towards their children's autism are partly influenced by antecedent factors. Antecedent factors (as identified in the previous theme) are the Knowledge and Perceptions which people have about autism. These include the beliefs that are held by people about autism. The symbolic interaction theory postulates that meaning derivations takes place from people's interactions in the communities (Skyker, 1987; Stryker & Vryan, 2003; Okello & Neema, 2007) thus the information which parents receive from the people they interact with about their children's autism may have an impact on parental attribution.

The identified Knowledge and Perceptions about autism include Misinformation about Autism, the belief that autism is contagious and autism as a possession. Despite these antecedent factors which are expected to influence parents' ascription to autism, they ascribed their children's autism to Environmental, Biological and to Unknown factors.

These ascriptions made by parents further suggest that there are other factors that influence parents' *attribution*- an attempt to derive a meaning. Although the society has an influence on the meaning derivation process, the Symbolic Interaction Theory further states that each individual has an active cognitive structure, and therefore constantly compares the meanings they get from their interactions with people to their preexisting knowledge for appropriateness (Stryker & Vryan, 2003). Potential factors may include the personal characteristics of parents which have an impact on the attribution process (Kelley & Michela, 1980). Parents' educational level and the amount of information they possess may account for the attribution they make.

Moreover, the autism center where children had been enrolled may have influenced the attributions that these parents make. The symbolic interaction theory indicates that meaning derivation is an ongoing process (Stryker & Vryan, 2003). As a result, parents may constantly redefine the meaning they have about the cause of their children's autism depending on its laudability to them. Constant redefinition for the cause of autism may be enhanced by the fact that the cause of autism is still unknown.

4.3.0 Available Help

This theme analyses the response to questions relating to the support parents whose children have autism receive. It includes the *needed support*, the *perceived support* and the *actual support* for children with autism and their parents. The relatively early onset of autism with

an unknown etiology and “triad of behavior excesses and deficits” (Quitero & McIntyre, 2010) necessitate a joint effort between individuals, family members, professionals and the community to meet the needs of children with autism. The response from the interviews revealed three major bodies which provide assistance to children with autism and their family in Ghana. These bodies and the help they provide have been delineated below.

4.3.1 Institutional Arrangements

This section under available help parents receive reveals the governmental and non-governmental bodies which are set in place to provide assistance to children with autism and their families in Ghana. The participants indicated that special schools for children served as the primary resource for their children. *“he started coming here when he was age two and half; you see, I had to redraw him from the school he was attending because the complaints were becoming too much. It was obvious they no longer want him there. So I brought him here”* (M2).

This part of the interview portrays the rejection faced by children with autism who attend mainstream schools. Children with autism are expelled because of their behavior difference and tantrums. The excerpt shows that the child was not assessed or referred to a special education officer. According to Anthony (2009) the system in Ghana requires teachers who have a concern about a student to report the situation to the head of the school; in turn the head of the school has to refer the child to a special education officer. The excerpt shows that the actions of the teachers were not guided by this principle and information about children to their parents was mostly in the form of criticism.

There is lack of inclusive education in Ghana and according to Mitchell (2005) schools should adopt practices that would enable children with special educational needs to actively participate in the mainstream education. Through this, social exclusion is eliminated

(Vitello & Mithang as cited in Ainscow & Miles, 2008). The government of Ghana has put in place structures to ensure inclusive education in Ghana. For instance, the Persons with Disability (2006) indicates that

A person responsible for admission into a school or other institution of learning shall not refuse to give admission to a person with disability on account of the disability unless the person with disability has been assessed by the Ministry responsible for Education in collaboration with the Ministries responsible for Health and Social Welfare to be a person who clearly requires to be in a special school for children or persons with disability. (Act 715, article 20)

With this as the basis, all schools in Ghana are demanded to enroll every child unless otherwise has been stated. In spite of this, the Ghana Education Service (GES) (as cited in Anthony, 2009) report that, assessment of students identified to have problems is hindered due to lack of specialists, shortage of equipment and the absence of screening procedures. Thus there is no assessment of such identified students and the school authorities resort to dismissal or call on parents to redraw their wards. M2 further indicates that there are few institutions for children with autism in Ghana. He stated that

Like this center, if there were a lot, if there was one closer to me; I live in Tema⁹ and I have to drive him here every morning before I go to work and pick him up every evening. If there was one which is a boarding institution, I mean if I had options. It will all make life easier for me and better for him. (M2)

Inadequate infrastructure for children with autism poses stress to the parent and the child since the few available ones are barely accessible to parents. In addition, since these institutions for children with autism are few, parents lack the choice for the right places equipped with resources for the child's special needs. According to the law on Person with

⁹ Tema is a city in the Greater Accra Region of Ghana. It is approximately 25 kilometers from Accra where the autism center is located.

Disability, the government of Ghana is supposed to establish and rehabilitate existing centers in every district of the country. This to date has not been fully complied with and the few existing centers lack the needed resources required to cater for children with autism.

M1 also expressed concern about the lack of support for children with autism in Ghana. He stated bluntly that,

“Right now, there is no governmental support. So everything is the few philanthropists and what the parents can do. We do not have any financial support. Meanwhile if my child were attending the schools the so called normal children are attending, like the government schools, there would have been government support. I do not even have the least that my ordinary son would have had, despite the taxes I pay.

I gathered that while children in the mainstream schools enjoy Free Compulsory Universal Basic Education (FCUBE) and the Nutrition and School Feeding program, their fellow children with autism are not given any of these benefits although the disability law (article 18) enjoins the government to provide free education to persons with disability. Six years after the passage of the law, children with autism in Ghana do not have access to the free education policy. An interview with the administrator of the special school affirmed the above allegations. She asserted that *“we receive no governmental support. Mrs. Kyeremeh¹⁰ has been fighting for this for years but they don’t mind her”*. Although the center is the only center specifically designed for children with autism in Ghana, children at the center do not benefit from any governmental support.

¹⁰Name is pseudonym, refers to the founder of the center

4.3.2 Family Support

This section analyses the support parents receive from their families in the up-bringing of their children with autism. According to Lloyd and Blanc (1996) parenting is a shared responsibility in Africa, and children grow up with more than one “mother” or more than one “father”. The interviews revealed that other family members like the grandmothers and aunties of the child with autism play an integral part in upbringing of the child. The help provided by these relatives include the day to day assistance of the child with autism. For example, a parent indicated that *“I live with my mother in-law so we sort of run our schedule... my mother in-law helps when I’m not around. My husband and I also run our schedule around our children”* (F1). I gathered that parents who have children with autism need the assistance of an extra person to effectively cater for the child due to the difficulties associated in catering for the needs of such children. The old aged women in the families therefore act as unpaid caregivers to the child with autism whereas the parents embarked on their daily routine to keep the family going.

Family support goes beyond the day to day assistance of the child. I found in the data that some parents get financial assistance from other members of the extended family to support the children since they are known to require extra resources compared to normal children. As indicated by a parent *“Right now, I receive sponsorship for her training, and my sister also gives me money for other things. From next month, I will start working and I will employ a carer¹¹ and I will use the money my sister gives me to pay her carer”* (F2). The above extracts also confirms that, parents who have children with autism might need a second

¹¹Carer- refers to an assistant to an autistic child at the autism center. Parents hire these individuals to assist their children at the center. These assistants are paid by the parents, which is separate from the “school” fees.

*The interviewer served as the own assistant to the child at the center.

party to either provide direct assistance to the child or provide financial assistance to the family. It appears impossible for parents to take up both roles.

Child upbringing in Ghana goes beyond the parents; this is clear in sayings like “*it takes the whole community to raise a child*”. According to Gyekye (2003), caring for others and interdependence are core communal values in African societies. He indicates that communal values are “those values that underpin and guide the type of social relations, attitudes, and behavior that ought to exist between individuals who live together in a community, sharing a social life and having a sense of common good” (p. 35). It is the responsibility of the entire family members to give training and advice to the child. Members of the family have a shared responsibility in the upbringing of the young ones in the family.

Despite all parents expressing that they receive support in one way or the other, I picked up that there are variations regarding the help parents get. While some parents said that the support they receive are adequate, others complained about inadequacy. For instance, although F2 receives financial support from her sister and sponsorship from a non-relative for her child’s education, she indicated that “*When I am going on an errand and I ask them to look after her for me till I return, they tell me they will also be going out soon and can’t do it. If I know I will not keep long, then I lock her up in the room until I am back. But by the time I return, they will all be in the house*”¹² (F2).

I gleaned that the economic status of the parents has a direct impact on the support parents receive from the family members. For instance I gathered that, while F2 receives financial assistance from a relative, she indicates that there are relatives that refuse to assist her with the child when she wants to go on errands.

¹² Interviewee lived in a family house with other relatives and non-relative.

Gyekye (2003) indicates that despite the communal system in African societies, individualistic values still prevail and people are supposed to bear the consequences for their actions. I gathered from the above excerpts that the perception held by family members about autism may influence their help to the child and the parents. A parent whose child has autism and is perceived as paying retribution for sins may not receive adequate support from members of the community.

Danquah (1982) has it that Ghana is undergoing rapid social change in that there is a breakdown of the extended family which in the past has provided personal and social security. Parents who have a child with autism and whose extended family structure is weak may get less help from other family members in the upbringing of the child with autism.

4.3.3 Non-Family Support

This section of the analysis presents the support which parents and their children with autism receive from people who are not their family members. This group includes colleagues, friends, healthcare providers and other individuals who the parent and the child with autism come across in their day to day activities. The parents indicated that people express the willingness to help the child with autism when the child's condition is made known to them. M1 shared this experience below;

"I took my son to a health facility for a yellow fever injection because we had to make a trip. We were waiting in the queue to be attended to and my son was disturbing. You can't get an autistic child sitting down for a long hours without him getting up. So he got up and was shouting and then the nurse came out and asked who that was. And whose child is making the noise. And I told her he is my son. And I told her immediately that my child is autistic. Do you know what autism is? So somebody else

heard and she stepped in so they isolated us immediately and gave us a good service”.

M1’s experience points to the fact that when people are made to understand the cause of misbehavior among children with autism, people may offer more support to the child and the family. It also points to the fact that people’s negative attitude towards the child with autism and the family stems from ignorance.

M2 also stated that *“There are times my friends tell me they want to go on a ride with him. I tell them to manage him for an hour or two and see how it is like”*. From this excerpt by M1, his friends try to understand the behavior of the child with autism. In another way, they want to spend time with the child by acting as a care giver. I picked from the above excerpts that when people understand the cause of children’s behavior, they show positive attitudes to the parent and the child with autism.

I also found in the interviews that there are some non-relatives who give financial support to parents. The supports usually go into educating or training the children with autism. These non-family members may include charity organizations and other non-governmental organizations spearheaded campaigns about autism in Ghana.

4.4.0 Perceived Challenge

This theme talks about the challenges parents whose children have autism indicate they face in the society. Three sub-themes emerged under this theme and they are: The “normal” Child in Context, Socio-cultural Norms in Ghana and Conflicting Beliefs.

4.4.1 The Child in Context

This sub-theme presents the challenges parents perceive they faced because of the behavior of their children with autism. Children with autism appear to be normal but their behavior is sometimes abnormal. The analyses of informants' response to questions about the challenges they face in the society revealed that, the most prominent challenge parents' encounter is children's hyperactivity and tantrums in the public. Nukunya (2003) has it that "When children are brought into the world they must be trained in the accepted modes of behavior in the society [and] This is the responsibility of the parents" (p. 51). Children's hyperactivity and the tantrums they exhibit in public are considered unacceptable in the society. A parent indicated that, "*Sometimes he is very unconventional so getting him into a typical Ghanaian society where everybody sees a well brought up kid as one who is well behaved and conforming, I must say is very difficult*" (M1).

There are norms which govern every aspect of behavior in every society therefore children who are of age are expected to abide by these societal norms. Children learn these norms consciously and unconsciously through the process of socialization. According to Elkin (1960) socialization is the process through which a person learns the way of living of a particular society or social group in order to function appropriately within it; and the family acts as a primary socializing agency to the child (Nukunya, 2003). When children with autism are unable to follow laid down societal rules, the perception is that the parents have failed to instill in the children the rules governing behavior in the society. This comes as an embarrassment to parents. The behavior of children with autism, thus their inability to conform to societal rules makes parents feel insecure in public. I gathered from a parent that, his child with autism's unresponsive and unpredictable behavior in public make him attracts unwanted attention. He indicated that,

“When he starts his things in public, people are like can’t you shut the child up, can’t you speak to him? I’m like no, that boy does his things differently. They will be like, “what is that, what kind of misbehavior is that”. When people persist for some time, I ask them, “am I well behaved?” and if they answer yes, I tell them then if the son of a well behaved man is misbehaving, you should know that there is something wrong” (M2). I picked up from the excerpt that people around the child with autism expect the child to behave like any other child.

In addition to the above, parents may be perceived as irresponsible parents. Children with autism are seen as “spoilt” children because they do not follow the societal norms. Parents who may be concerned about societal attitude may decide not to send these children to public places. They may hide children from people to avoid their judgments. Other parents may also avoid getting themselves involved into social events like parties and churches.

Another problem faced by parents is inability of their children with autism to form social relationships with people. M2 said that *“he is mostly to himself; sometimes you will find him at the corner of his room. Even when he wakes up in the middle of the night, you will find him lining up things. It is like he is sufficient with himself, he doesn’t need anybody”*. In this statement by M2, he feels bothered that his son is not able to reach out to him and other people as a member of a dyad. Kanner (1943) indicates that children with autism express an extreme aloneness and do not act in response to anything from the environment. Thus the social world of children with autism differs from that of other children. Gyekye (2003) shows the African perspective that, “Social life is natural to the human being because every human being is born into an existing human society”. (p. 36). He points out that, naturally every individual is from the onset of life, a social being and cannot isolate him or herself from other members of the community. The behavior of children with autism to isolate themselves from others become a challenge to the parents.

4.4.2 Socio-cultural norms in Ghana

This sub-theme under perceived challenge talks about the challenges parents who give birth to children with autism encounter as a result of societal expectations and rules that guide behavior. Analyses of the data revealed that socio-cultural norms regarding child bearing in Ghana was challenging to parents whose children have autism. Gyekye (2003) indicates that “In the African view the whole or ultimate purpose of marriage is procreation- to produce children who will continue with the heritage and name of the family, so that the family does not diminish or disappear” (P. 83). Interviews revealed that parents had high expectations bringing forth and this expectation was shared with other family members as well. F1 indicated that *“the boy was like an answer to prayer and we pampered him”*. *“So my living room was full of toys for this only child of Christy and Jack¹³. I mean my husband and I got married in 1995 and we had our first child in 2002.”* The enthusiasm and the expectations in child bearing pose a challenge to parents whose children get autism. Nukunya (2003) has indicated that, women in the Ghanaian society receive high social positions based on the number of children they have and the achievement of these children. It is therefore a serious challenge to have a child with a life-long impairment due to the value placed on the roles children play in the lives of the parents.

According to Dyer (2007) “children confer social status and rights of property and inheritance, assist with labour, satisfy emotional needs, offer social security in old age, and provide continuity through re-incarnation and maintaining the family name”(p. 75). Nukunya (2003) is of the same opinion; children serve as insurance to their parents at old age. This further implies that parents want to have children who can be better off themselves. Parents thereby do their best to give the children the best of life. *“What me and my husband can do to make him a productive adult, we will do”* (F1). Children have the responsibility to cater for

¹³ Names are pseudonyms

their aged parents and as such, they are expected to be independent to start up family roles at a stage in their lives. This responsibility of children is summarized in one popular adage by the Akans in Ghana, “If someone looks after you to grow your teeth, you must also look after him [or her] to lose his [or her] teeth” (Nukunya, 2003; p.89).

In the view of Hoffman and Hoffman (as cited in Dyer 2007) children’s value lies in the roles they serve and the needs they fulfill for their parents and the society. Children with autism cannot play the roles of a child to the parents; instead the child becomes a perpetual liability.

This also has some repercussion on the marital lives of the couple. It was picked from the interviews that, male parent do not give adequate assistance to their partners in caring for the child with autism and all help seeking efforts for the child are embarked on by the woman. F2 indicated that “*I also want to say this; the men don’t help when there is a problem like this. I have to do everything and it makes me feel I am the cause of the problem*”. This could be due to the fact that traditionally the women are responsible for the upbringing of the child.

4.4.3. Conflicting Beliefs

The subtheme discusses the difficulties parents whose children have autism encounter with people with regards to the type of help they need to seek for the child. Although procreation is the sole responsibility of the parents, the training and the welfare of the child rest on other members of the community (Nukunya, 2003). The findings points to important roles played by some people in the lives of parents in the help seeking process. Decision to seek for a particular help for children with autism does not rest entirely on the beliefs of parents but also

the beliefs of friends, relatives and other people in the community. Analyses of the data under the parents perceived challenges brought up that parent receive pressure from people to seek other interventions for their child with autism. For instance M1 said that,

“You see, it feels like I do it sometimes just to help people and not because of myself or for my son. People think that you need to seek religious intervention. And you need to be careful, if you say no, it might mean that you don’t care for your child and Ghana we are quit pious, we are believers so sometimes you have to know things and manage people. But most of the time, the few things I have been saying, we have been to some places because some people put pressure, pressure, pressure, you have to go, you have to go.”

In this excerpt, M2 points to the involvement of other people in help seeking for the child with autism. According to a Mande adage, “a child is not “for” one person.” (Bledsoe, 1990, P. 75) The adage signifies the role and the influence community members have in the upbringing of the child. This influence appears to override the interest of the parents sometimes. This could be for the reason that, parents consider themselves as part of the community and must conform to the prevailing values. I gathered that the involvement of other people complicate the meaning giving to autism. When community members persuade parents to seek other forms of help for their children with autism, then there may be a difference in the causal ascriptions between parents and the people who put pressure on parents. In other words, parents’ perceptions about autism may be different from what community members perceive of the condition.

From the excerpt above, I gleaned that even when parents do not believe in the suggested intervention, they have to conform to let people know that they do respect their

opinions. The involvement of others people in the life of the child and the disagreements on the help seeking process complicates matters for the parents and the child.

4.5.0 Help Seeking

This section of the findings presents the help parents whose children have autism seek for their children. The decision to adopt a particular help does not solely depend on parent's conceptualization of autism. As has been indicated earlier, the influences of other people play an important role here. Although participants understood and stressed that autism was incurable, many hoped for a cure. A key informant noted that "*Sometimes parents feel we should have a magic to let their children speak and behave normally*" (A.D.). The finding points out that even after the acceptance of diagnoses by parents, they continue to define their children's behavior, evaluate and reevaluate the condition.

The analysis revealed two major help seeking approaches parents adopt for their children with autism. These approaches are (1) Behavior Training; and (2) Religious Healing. It was also evident that parents adopt multi-approach to ensure that their children get well.

4.5.1 Behavior Training

Despite autism being incurable, researches indicate that early intervention in the lives of children with autism results in a significant improvement in the majority of them. Research by Weiss (1999) supports the use of early, intensive, behavioral intervention for children with autism. Interventions are known to reduce the disruptive behaviors whereas educating the child with autism helps them to learn self-help skills. For most children with autism, these allow them to be independent (ibid).

The interviews conducted revealed that parents adopt different behavior changing approaches to correct or shape the behavior excesses of their children with autism. These include the service of professional trainers and home based training. Children receive professional help in the centers they have been enrolled. A parent said that, *“we have been coming here for six months now. There has been some improvement in her life. She is able to sit for some time at church and she dances to the music”* (F2). I picked up that this parent gets productive results from the behavior training of her child. In other words, the training children with autism receive at the center help reform children’s behavior excesses and reduce parental stress. F1 indicated that, *“But for now, its therapy”* (F1). The WHO (2011) report on disability has it that, therapy is concerned with the restoration and compensation for the loss of functioning in every area of a person’s life. Therapeutic workers include occupational therapists, orthotists, physiotherapists, prosthetists, psychologists, social workers and speech and language therapists (ibid). Parents therefore rely on these individuals to help shape the behavior of children.

Aside the center where children had been enrolled, parents also took up some on the training roles in the homes. Home training includes the services of the parents, siblings, grandparents and nannies. For instance F1 indicated further that,

“He was potty trained in 2006, not the bowel movement, for urinating. So he was dry from late 2006 to 2007. That’s like a five year old. That is when he was dry, like when he needs to go and urinate he would go and do it. But the bowel movement, it was in 2009 that he got it. And occasionally he regrets it. He will go to the “loo” and not clean his bottom or not clean it properly. With time consistently, he realized that we will not accept dirty underwear. I have taught him how to wash. He still knows that even when the underwear is dirty, I disapprove. So we have tried” (F1).

This excerpt also shows how the parents personally involve themselves to the training of their child and how this training has refined the life of the child. M1 also said that *“I’m trying to train him to be independent so that he can function well”*. A research by Sheinkopf and Siegel (1998) shows that intensive home-based behavioral therapy is a very effective approach to treating autism.

4.5.2 Religious Healing

This section of the analyses under Help Seeking explores the religious interventions parents adopt for their children with autism. There appears to be no bearing from the way parents conceptualize autism, and this mode of help seeking for their children with autism. Salm and Falola (2002) are of the view that *“Religion is inseparable from virtually every aspect of Ghanaian life”* (p. 33). Thus even when parents whose children have autism do not believe in spiritual causal attributions of autism, the application of religious concepts play an integral role in their help seeking behavior. One of the parents interviewed indicated that, *“I pray for my child and I know that God is able to do everything. Maybe one day she will talk”* (F2). This extract portrays the parent’s believe in God as all powerful and able to restore the health of her child with autism.

According to Tarakeshwar and Pargament (2001) religion can mean different things to different people; some people look to religion for a meaning of a phenomenon, some for comfort, and some in search for a self whereas others search for physical, psychological and emotional well-being. I gleaned from the excerpt that, believe in religious healing serve as a coping strategy for the parents. Thus believe in God by parents gives an assurance for the future of the child.

“I am a very religious person, a practical Christian myself, and every day I pray for him. Even this morning I prayed for him before coming. I pray to god to touch him and order things around. There are times I visit my pastor, we talk about his condition

and we pray. My brothers and sisters also come around to pray for him. I see it as a normal thing” (M2)

The application of religious principles by parents indicates that, parents are also members of the Ghanaian society therefore the belief system play a role in their behavior. Gyekye (2003) states clearly that “To be born into the African society is to be born into a culture that is intensely and pervasively religious” (p. 4). In another way, parent may have adopted this form of help seeking due to the pressure they receive from other people in the community. Consequently, parents practice religious interventions alongside behavior training for their children with autism.

Interviews with key informants also confirmed the belief in religious healing. When the administrator of the special school was questioned about the application of religious techniques in restoring health for the children with autism, she commented that,

“It depends, I think that alongside the training, parents should pray. The religious leader needs to understand that this is a neurological disorder; I believe in prayer, I believe in God’s healing but the children are not possessed and should not be subjected to beatings. It should be a prayer for healing and not deliverance” (A.D.).

The health worker also had this to say about religious healing, *“I believe in God, and I know miracles happen. Parents can pray and fast, but they should not stop training the child” (R.L.).*

The above voices portray religious healing as an intrinsic part of the Ghanaian. Thus, irrespective of the causal attribution made about autism, the belief that God is all powerful to heal children with autism dominates.

4.5.3 Bridging the Gap: Help Seeking

Researches on help seeking behavior show that the type of help seeking people adopt for illness is directed by the causal attributions which is made to that illness. (For example,

Wrigley, Jackson, Judd & Komiti, 2005; Narikiyo & Kameoka, 1992). In the current study, the help which is sought by parents whose children have autism is not only influenced by the ascriptions parents make. Parents indicated the etiology of autism to be biological, environmental and to unknown factors, and the help they sought for their children were both behavior training and religious intervention. Young's (1976) medical belief system and Fosu's (1981) disease classification suggest that, people apply religious interventions when they ascribe illnesses to fall within the domain of supernatural causation. The application of religious intervention for children as seen in the data does not stem from the attributions that are made. It is perceived that parents' religious beliefs and their experiences in the Ghanaian society may have allowed this.

Salm and Falola (2002) indicate that religion is an essential part in the life of every Ghanaian. Consequently, the belief that God is a Supreme Being, who is able to cure both naturally and supernaturally caused sickness may have accounted for parents' application of religious intervention. It is also projected that the minimal improvement parents observe in their children after receiving behavior training would result in seeking other forms of help. Spilka, Shaver and Kirkpatrick (1985) indicate the efficacy of religious and naturalistic mechanisms for controlling and predicting outcomes in the attribution process. This is particularly important when results from this study are compared to the findings of de Graft Aikins (2005). She indicates that spiritual causal theories do not shape illness practices as reported in most studies in Ghana. In her study, most people who utilized traditional religious healing abandoned this for biomedical treatment when there was no improvement in their physical health. According to de Graft Aikins (2005) some people attribute disease to spiritual causes but do not seek spiritual treatment. Parents in the current study make biomedical attribution yet they combine biomedical treatment with religious interventions because of their religious beliefs.

4.6 Vision for the Future

The theme examines parent's views about the future of their children with autism. It deals with parents forecast about the future of their children with autism. It appears the ambiguity about the cause of autism and the type of help which is considered appropriate for the children creates uncertainties to parents. Causal attribution helps to foretell the future and control future occurrences (Kelley, 1967). Thus, where there are uncertainties about the cause of a phenomenon, there is lack of control over it in the future. This theme has been categorized under; Anticipation towards the Future of the Child with Autism and Integration of the Child with Autism into the Ghanaian Society.

4.6.1 Anticipation towards the Future of the Child with Autism

This subtheme reveals parents expectations about the future of their children with autism. It concerns how the children with autism can become independent adults. Parents expressed concerns about their children getting the adequate interventions which can make them independent adults. In spite of the various interventions adopted by parents, data revealed that the future of the children with autism is blurring with no assurance to their parents. When F1 was asked about her short and long term expectations about her child, she stated that *"I don't know, I don't know what the future holds. I take one day at a time....I will cross the bridge when I get to it"* (F1).

From the above extract, it seems F1 does not have any knowledge on how her child will proceed in life. She makes these statements because she is not certain about the circumstances surrounding the future of her son with autism. She continues by indicating that she lives a day at a time suggesting no dream towards the future with regards to her child with autism. This could be because F1 only holds assumptions about the cause of her son's

autism; the actual cause is still unknown to her. Autism as a life-long impairment may reduce the assurance she has about her child future.

Parent M1 also expressed that, *“If there was a school where he can be taken through a purposeful training to give him a professional skill, maybe to get them ready for engagement by other people”* (M1). In this statement also, the parent seems to be uncertain about the future of his son. M1 perceives the interventions his child receives as inadequate to make him independent and self reliant in the future. In the absence of institutions which can functionally train the child with autism, M1 has no aspirations towards the future of his child with autism.

Despite all the efforts parents seem to put into children’s future, it appears they are still worried about what the future holds for the children. This worry stems from the disorder being a life-long impairment, the characteristics of the disorder and inadequate resources for children with autism.

4.6.2 Acceptance of Children with Autism into the Ghanaian Society

Children with autism are known to have poor social interactions and problems in their social relationships with other individuals. This characteristic was a central part of Leo Kanner (1943)’s classic work on *Autism Disturbances of Affective Contact*. Throughout the years, the quality of social interactions has been a common feature of all diagnostic classification systems; for example in the ICD-10 and in the (DSM) IV-TR. Poor quality social interactions for children with autism who are growing up in collectivist societies would be problematic to parents who are upbringing these children and the children as well.

From the interviews, I found that parents were doubtful about the acceptance of their children with autism in the Ghanaian society. M2 brought up that, *“Right now you are*

researching into it, if you come back [to Ghana] and bring a thousand ideas; I wonder how many the society is ready to take and use them.” In this excerpt, M2 worries about the beliefs which people have about autism in Ghana. He believes that, not many people would accept new information about autism. I also gleaned from the above extract that, parents perceive the prevailing beliefs and attitudes surrounding autism in Ghana to hinder the progress of the children. According to Reynolds (2010), people with disability in Ghana are neglected due to the prevailing beliefs. In the words of the health worker, it is important that individual with autism are integrated into the daily activities of the society. He stated that, *“We need to integrate them into the society; we need to break what we call the sound barrier of these kids”*. This statement by the health worker seems to be a call-out to people on the need to integrate children with autism into the society.

Parent F2 indicated that, *“What is important for me is that he grows up in an atmosphere of love. And fortunately, his father and I love him. He lives with us. Until the good Lord takes us home¹⁴, he will live with his parents. And for me, I take one day at a time and hope for the best.... He is made in God’s image and likeness, just like any other child”* (F1). These statements by F2 points to the fact that not everyone is willing to accept the child with autism. She believes that it is only when her son lives with the parents where he can get adequate love and care. She limits the love and care her child with autism is supposed to receive from the community to herself and to the father of the child. This suggests that her child may face rejection from other members of her community. Moreover, her statement about her child being in the likeness of God points out that there are people who have different opinion about her child with autism. I gleaned from this statement that F1 perceives that some people consider her son to be inferior compared to other children without autism.

¹⁴Life after death.

4.7.0 Determinants of Help Seeking for Children with Autism in Ghana.

Figure (4) below which is labeled *Determinants of Help Seeking for Children with Autism in Ghana* presents a framework for understanding autism in Ghana. It summarizes the research findings, thus Knowledge and Perception about autism, the Casual Attributions and Help Seeking made by parents for their children’s autism, the Available Help to parents and their children with autism, and parents’ projections towards their children’s future.

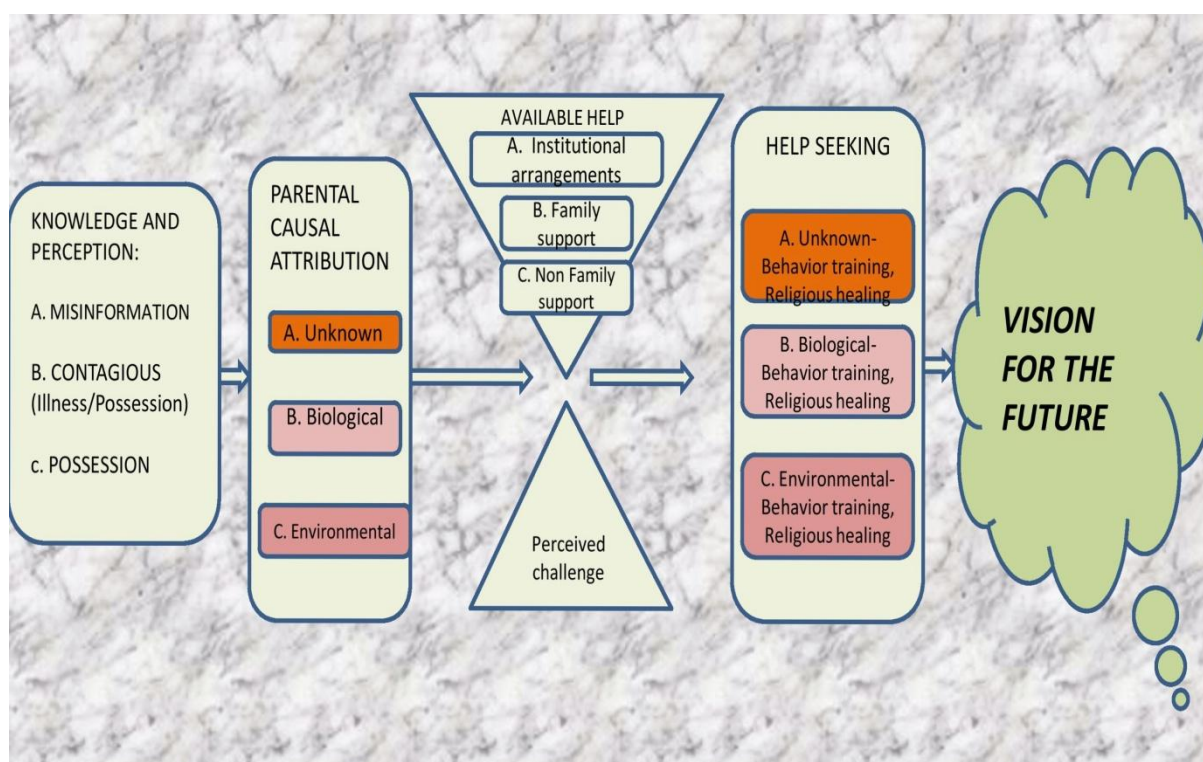


Figure (4): Determinants of Help Seeking for Children with Autism in Ghana

From the above framework, Knowledge and Perceptions represent the beliefs which are held about autism by some people in Ghana. This knowledge is misinformed beliefs about autism and it includes the view that children with autism are abrasive children who would learn to behavior properly with time. Perceptions about autism being contagious and the view that it is a spiritual possession are apparent among some people.

Parental causal attribution and help seeking show that, parents who attributed the cause of autism to unknown factors sought for both biomedical (behavior training) and religious intervention for their children. It can also be seen that, when biological attribution is made to autism, parents sought for biomedical intervention as well as religious intervention. There was no difference in the intervention approaches which was sought by parents making environmental attribution to their children's autism.

The available resources that were identified in parents' narratives included institutional arrangement which refers to the autism center where children had been enrolled for behavior training. Other support groups were family members who mostly acted as unpaid caregivers to the child and lastly, support provided by non family members to the child and family. Despite the support received by parents and children, parents reported of having problems with societal expectations with regards to the "normal" appearance of children. Another challenge was the ideological difference between parents and community members as to the appropriate intervention to seek for children's autism. As seen in the figure, parental perceive support and their perceived challenge affect their help seeking behavior. The future of the children still appeared to be vague and full of uncertainties to the parents of these children.

Chapter Five

GENERAL DISCUSSION AND CONCLUSION

5.1.0 Overview of Findings.

The study aimed at investigating the causal attributions which are made by parents whose children have autism and its impact on their help seeking behavior. It also aimed at delving into the challenges faced by these parents and their experiences with the society. The last objective of the study was to investigate the support parents and their children with autism receive from both the community and the government. The findings from the study showed that the help which parents seek for their children with autism is not only mediated by their perception of the cause of autism. Parents believe that their children's autism was caused either by environmental factors, biological factors, unknown factors or a combination of two of the factors mentioned. In seeking interventions for children, parents relied on behavior training and religious interventions.

5.2.0. Limitations of the Study

There are a few setbacks to the study which need to be addressed. One of the reasons for choosing the research setting was to get participants who were from diverse background. Yet, due to the research topic and difficulty in recruiting participants, all parents who were interviewed had their children in the autism center. This may have influenced their responses. Again, the scope of the study did not cover participant's backgrounds particularly their levels of education, their economic standing and their religious beliefs. Most people who are willing to talk about disabilities related to them are usually the elite with good economic standing; their opinions might not usually be the voices or represent the needs of those with low economic standing (Ingtad, 1999).

5.3.0 Methodological Issues

The sampling technique and interview setting were setbacks encountered on field. In my project description, sampling was to be done by contacting parents who responded to information letters given to them by the administrator of the school. Unfortunately, this approach failed as parents who received these letters did not respond to them. This caused a delayed in the data collection process.

Instead of interviewing the head of the special school as stated in my project description, I ended up interviewing the administrator of the autism center. While working there, I found that the head of the center barely stayed at the center and it was the administrator who ran all the affairs at the center. Moreover, the head of the center is the founder and a mother of a child with autism therefore I doubted the kind of information she was going to give me, whether it would be as a mother to a child with autism or as a head of an autism center. Upon considering my semi structured interview guide, my respondent had much flexibility to touch on topics beyond the scope of the guide. Therefore, I realized it was not appropriate to interview her. Interviewing the administrator was the best fit for the information I needed.

According to Murray (2003), interviewers need to give their interviewees the priority to choose the interview setting. The most important thing for qualitative researchers is to make their participants feel comfortable and safer to disclose information. In this regard, many of the parents I interviewed preferred to be interviewed at the autism center. Despite arranging a quiet room for the interviews, in all instances either the children of the interviewees or other children destructed the interviews.

5.4.0 Strengths of the Study.

As an exploratory study, the study provides a thorough representation of the beliefs and the attitudes besieging children with autism and their families. The study presents the accounts from the “emic” perspective, which is the “native’s point of view” (Morse & Field, 1995). Researches involving the health of people are best understood when investigated from the ‘emic’ perspective (ibid). Thus this study which interviewed parents whose children have autism and living with these children presents a fair account of the phenomenon.

5.5.0 Directions for Future Research

The subject matter can also be studied in the same context to investigate how parental social class and level of education influence their attributions and help seeking behavior. As an exploratory study, these variables were not controlled. A Quantitative enquiry would help to identify the relationship among these variables (Creswell, 2009). In addition, participants could be recruited from different settings for diversity.

5.6.0. Recommendations

The Ghanaian society seems to be potentially high on communal support and seemingly high on governmental intentions but considering the support which children with autism and their families receive and their experiences, it appears that there is misinformation between parents who have children with autism, and some community members. The knowledge and perceptions which some people have about autism seem to hinder the help which children with autism and their families should receive. It is high time governmental, non-governmental and other charitable organizations educate people about the nature of autism

and what children with autism need from the people around them. This could be done through the use of the various media. In addition, school going children need to be sensitized about disabilities. Unless people are made to understand this, the child with autism can never receive the adequate support needed to live like any other child.

Unfortunately, there are no governmental bodies which children with autism can depend on in the Ghanaian society therefore these children rely solely on the family and the community for support. Governmental bodies like The Ministry of Women and Children's Affairs, Ghana Education Service and the Department of Social Welfare need to address the plight of children with autism in Ghana by providing the children and their families with the adequate resources. These resources need to address the functional as well as the affective needs of children with autism and their families.

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APPENDICES

Appendix I

Interview Guide (semi-structured)

Interview Guide “A”

This is an interview guide designed for parents who have children diagnosed with autism.

The researcher will not go accordingly to the order of the questions but at the end of the interview session, the researcher should cover all the questions. It is however not mandatory for participants to answer all the questions.

Can you tell me about, how and when you learned that your child had special problems?

Can you tell me how and when your child got the diagnosis of autism?

Did you know anything about autism before your child diagnosed?

What do you think causes autism?

How do people (family and friends) meet your child?

Do you get any support from them? What kind of support?

Is the support you receive from them enough?

Do you have any day to day challenges that you face having this child? If so, can you please tell me about them?

What help do you seek for your child?

What do you think can be done to improve the lives of autistic children and their families?

Is there anything that I did not ask you that you consider important for this topic?

BELIEFS AND ATTITUDES SURROUNDING AUTISM

How do you feel being interviewed on this topic?

Thank you for allowing me to interview you!

Interview Guide “B”

This is an interview guide designed for health workers, religious leaders and heads of schools to know about their perception of childhood autism.

What do you know about autism?

What do you think causes autism?

Have you had any experience with families with an autistic child?

What are some of the challenges you perceive autistic children and their families face?

What kind of help should families seek for these children?

Is it fit for such children to be part of the society?

Do you think they receive enough support in the community?

What do you think can be done to improve the lives of autistic children?

Is there anything that I did not ask you that you consider important for this topic?

Thank you for allowing me to interview you!

Appendix II

Information Letter

Request for participation in a research project

Perception of childhood autism in Ghana

Background and purpose

This is a request for you to participate in a research study that intends to find out how autism is perceived. The research aims at reflecting upon the causal attribution of autism among parents who have autistic children. It also seeks to find the experiences of families who have an autistic child and lastly, the way culture; specifically religion and spirituality influence the help being sought for autistic children. The researcher would also want to know about the perceived social support these families and their autistic children receive. Parents of autistic children, a religious leader, a head of school as well as a health worker will be interviewed because of their regular exposure to these children. This research can help policy makers in drawing an intervention program for autistic children and their families. This research is a partial fulfilment of an award of a Master's degree at the Norwegian University of Science and Technology for the researcher.

What does the study entail?

There is going to be a one on one interview with the researcher. The interviewees have the right of choosing an interview venue which is convenient to them and the interview will be done in a language that both the interviewer and the interviewee have a good command of. The whole interview process will be recorded with an audio recorder. Participation in the

study is voluntary, and so there is no effect if you decide not to participate. Participants have the right to opt out of the interview at any point in time. It is also not a must to answer every question that is asked by the interviewer.

Potential advantages

This study will serve as a tool to identifying the challenges of families who have an autistic child. It will also help in knowing the needs of autistic children and their families and finally, the research can help policy makers in drawing an intervention program for autistic children and their families.

Potential Disadvantages

The researcher would want the parents of autistic children to reflect back on some of their experiences. When questions about their challenges of having an autistic child are asked, it might happen that these reflections might cause emotional breakdown. It is also anticipated that, parents might feel uncomfortable regarding some of the topics which will be raised in the interview.

What will happen to the information about you?

Any information which is given out will be treated as confidential. The information will be saved in a highly secured medium which can be accessed by the researcher and the supervisor only. The data that are registered about you will only be used in accordance with the purpose of the study as described above. All the data will be processed without name, ID number or other directly recognisable type of information. A code number links you to your data and samples through a list of names. It will not be possible to identify you in the results of the study when these are published.

Voluntary participation

Participation in the study is voluntary. You can withdraw your consent to participate in the study at any time and without stating any particular reason. This will not have any consequences for you. If you wish to participate, sign the declaration of consent on the final page. If you agree to participate at this time, you may later on withdraw your consent without being affected in any way. If you later on wish to withdraw your consent or have questions concerning the study, you may contact the researcher on phone number 00233208217948 or send an email to manunaomi75@yahoo.com. An email can also be sent to Prof. Birthe Loa Knizek, my supervisor for this study on: birthe.loa.knizek@svt.ntnu.no

Further information on the study can be found in Chapter A – *Further elaboration of what the study entails*

The declaration of consent follows Chapter B.

Chapter A – Further elaboration of what the study entails

Criteria for participation

Participants must fulfil the criteria of having an autistic child or being a health worker, a religious leader or a head of a special school. Stamped envelopes which are addressed to the researcher will be given to the heads of the special schools in the community, expected to be given to the parents who have autistic children. These stamped envelopes would contain information about the study. Parents have to indicate their willingness to participate in the study by sending the given envelopes back to the researcher or by contacting the head of the special school, who will inform the researcher.

Background information about the study

Autism is a complex developmental disability which appears in the first three years of life and affects a person's ability to communicate and interact with other people. Researches indicate that, autism is found in all cultures and it has no social boundaries. A child in every hundred children is autistic in U.S. but in Africa specifically Ghana, the prevalence rate of autism is unknown. One of the factors for this is assumed to be the fact that most of autistic children are not taken to the health institution to be diagnosed of it. Attitudes surrounding disability in Ghana are complex, varied and dynamic. The research seeks to explore the ways in which local knowledge, attitudes and beliefs surrounding disability influence the socially constructed experience of autism in Ghana. The study seeks to address how the perception of autism influences the type of help caretakers of these children seek for the children and their perceived social support.

Alternative procedures received if he or she chooses not to participate in the study

There will not be any effects if you do not wish to take part in the study. Participants, who give their consent to take part in the study, have the right to withdraw from the session at any point in time. When participants opt out because of any discomfort from the study, first treatment will be given by the researcher, who is also a prospective psychologist. A referral to a counsellor or a social worker will be made if needed.

Schedule – what happens and when does it happen?

Participants have the right to choose a venue and time for the interview. This is to allow the participant choose a time which is appropriate and a venue which is convenient and comfortable for the participant. If it becomes difficult for a participant to arrange a venue for the interview, the researcher will have to book a place where the participants feel comfortable to be interviewed.

Potential advantages

This study will serve as a tool to identifying the challenges of families who have an autistic child by examining their day to day experiences in the community. It will also help in knowing the needs of autistic children and their families, the type of social support these families perceive to receive in the community and the type of help parents with an autistic child seek for their autistic children. The research can help policy makers in drawing an intervention program for autistic children and their families.

Potential discomforts or disadvantages

The researcher would want the parents of autistic children to reflect back on some of their experiences. When questions about their challenges of having an autistic child are asked, it might happen that these reflections might cause emotional breakdown. It is also anticipated

that, parents might feel uncomfortable regarding some of the topics which will be raised in the interview. The study will have to be stopped if any of these discomforts show up in participants.

Participant's responsibility

Participants do not have any responsibility to bear. In case of booking a place for the interview and if due to emotional breakdown participants need to see a counsellor, all the cost will be taken care of by the researcher,

Compensation

There will be no compensation for participation however, all participants will be given a symbolic gift serving as a token of gratitude for volunteering as a participant.

Appendix III

Informed Consent Form

Consent for participation in the study

I am willing to participate in the study.

(Signed by the project participant, date)

Proxy consent when this is warranted, either in addition to or in place of the participant's consent.

(Signed by representative, date)

I confirm that I have given information about the study.

(Signed, role in the study, date)

