UNIVERSITY OF EDUCATION, WINNEBA

EXPERIENCES OF PARENTS OF CHILDREN WITH AUTISM IN ABOOM UNIT FOR CHILDREN WITH INTELLECTUAL DISABILITIES IN CAPE COAST, GHANA

LETICIA DELINSKY OTABIL

MASTER OF PHILOSOPHY

2021

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LETICIA DELINSKY OTABIL
(8180150014)

A thesis in the Department of Special Education,
Faculty of Educational Studies, submitted to the School of
Graduate Studies in partial fulfillment
Of the requirements for the award of the degree of
Master of Philosophy
(Special Education)
In the University of Education, Winneba

MAY, 2021

DECLARATION

Student's Declaration

I, Leticia Delinsky Otabil, hereby declare that this dissertation is my own effort with the exception of quotations and references contained in published works, which have all been identified and duly acknowledged, is entirely my own original work, and it has not been submitted, either in part or whole, for another degree in this University or elsewhere.

Signature: ……………………………..…………

Date: ………………………………………….……

Supervisor's Declaration

I hereby declare that the preparation and presentation of this thesis/project work was supervised in accordance with the guidelines for the supervision of long essays laid down by the University of Education, Winneba.

Name of Supervisor: Prof. Grace Yawo Gadagbui

Signature: ……………………………..………..

Date: ………………………………………….…….

DEDICATION

I would like to dedicate this research to my dear Dad, Mr. Alfred Otabil, who taught me that in life, the most valuable asset you can give your child is education and for his words of encouragement throughout the master's journey.

ACKNOWLEDGEMENTS

I would first like to thank the Almighty God for his mercies, guidance, wisdom, and blessing to me throughout my life. I extend my gratitude to my supervisor, Professor Grace Yawo Gadagbui who took the pain and vetted the work chapter by chapter, making suggestions and corrections where necessary. I would like to also extend my gratitude to Professor Samuel K. Hayford for assisting me in making the necessary corrections to the final work. Thank you to all mothers and fathers of children with autism who took the time out of their busy schedules to share their experiences with me and participated in this study. I am very grateful to all the lecturers in the Department of Special Education, University of Education, Winneba who in diverse ways rendered invaluable services in the course of the compilation of materials for the work. My appreciation also goes to my colleagues masters students at the department of special education for their invaluable assistance and words of encouragement.

Furthermore, I would like to thank my family for their endless support and guidance. I am grateful to Mr. Ebenezer Donkoh, thank you for assisting me in my research, corrections and your words of encouragement. Crosby, I do not know how I would have functioned without your enormous and continued support throughout my master’s degree programme. Thank you for being there. I am grateful.

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ABSTRACT

This qualitative phenomenological study described experiences of parents of children with autism in Cape Coast in the Central Region of Ghana. Ten parents participated in the study. Data were collected and analysed using interpretative phenomenological analysis. Semi-structured interview and observation were used to generate detailed descriptions of the phenomena. Data analysis from the narrative dialogues brought out four main themes (a) emotional impact (b) financial challenges (c) support services, and (d) coping strategies. The results revealed that, parents experience greater stress and sadness in caring for a child with autism. Their increased responsibility in caring for their children resulted in their spouses and other family members blaming them for the cause of the child's disability. Increased time in caring for a child with autism made spouses feel neglected, thus causing marital conflicts and of other siblings in the family. Parents of children with autism were faced with superstitious beliefs, and stigmatization for associating themselves with a child with autism. Other significant findings include financial demands on parents and a connection between disability and poverty, especially mothers, as well as difficulty accessing education for their children. The study recommended that the government, non-governmental organizations, and the social welfare department should ensure continuous in-depth public education and sensitization on disability to help tackle stigma. Future research should investigate experiences of siblings and extended family members of children with autism.

CHAPTER ONE

INTRODUCTION

1.1 Background to the Study

Autism is defined as a 'neurodevelopmental disorder, persisting deficits in social interaction across multiple context, alongside restricted, repetitive patterns, interests, or activities as manifested by at least two prototypically inflexible behaviours (Bolte, 2014). Autism is also defined as a pervasive neurodevelopmental disorder that is characterized by impairments in social communication and restricted repetitive patterns of behaviour, interests or activities (American Psychiatric Association, 2013).

Autism is a disorder that manifests differently in terms of severity, from mild to profound. This means that those with mild autism may show delays in non-communicative language skills and social interaction skills, whereas others may have little or no speech (Gadagbui, 2017). There are four main disorders that fall under autism spectrum, and they are Autistic Disorder, Childhood Disintegrative Disorder, Rett Syndrome and Pervasive Development Disorder Not Otherwise Specified (PDD-NOS) (Ryan et al., 2011).

According to DeGrace (2004), children with autism spectrum disorder exhibit the following characteristics: preference for sameness, a need for routine or ritualistic behaviours, difficulty in communication, abnormal sleeping patterns, unusual eating habits, temper tantrums, and aggression to self (self-injury) and to others. These characteristics overwhelm parents who then shop for answers for their child's exceptional behaviour and a typical development, such as changes towards inflexibility in routines, pervasive anxiety, and hyper-sensory sensitiveness. Parenting is a highly stressful job and becoming a parent of a child with autism is one of the most stressful events that can occur and requires a constant supports from family members and the society (Rose, 1964; Thompson, 2000). And these families require constant positive coping mechanisms to sail through in caring for their children successfully.

The family and the society at large become excited when a baby is born, a great joy it gives and brings in ushering to parenthood. The family life changes due to the dawn of a new baby. With the expectations surrounding child birth, when a mother gives birth to a child with a disability, her life or thoughts are permeated by feelings of sadness, disappointment, anger, shock, and many more. From the moment that parents begin to suspect that there is something ‘different ’about their child, their journey of family life begins with challenges.

The initial reaction to the birth of a child with autism maybe numbness and is likely to be negative and similar to those related to loss of a loved one (Blachar & Baker, 2007; Hill & Rose, 2009). It is a traumatic experience for the whole family but the family starts an adaptation battle to recover their balance.

Families that have children with disabilities including autism live a unique experience of despair, fear and exhaustion (Barnbill, 2000). In addition to adaptations that a family makes to accommodate the birth of a child with a disability, many families tend to face serious crises in the lives for several years. Turnbull and Turnbull (1986, cited in Gadagbui, 2003) pointed out some of these crises. For example, Turnbull and Turnbull pointed out that a child’s disability attacks the fabric of a marriage in four ways. Firstly, the birth of a child with a disability excites powerful emotions in both parents, parents’ emotions become an effective state of consciousness in which joy, sorrow and hate is experienced (Gadagbui, 2003). In this context, parents experience a level of sorrow and anger because the child is not the ideal child that they anticipated. The anger makes parents unconsciously consider the child to be responsible for crushing their ambitions.

Secondly, a child with a disability in the family acts as a dispiriting symbol of shared failure. In some cases, parents see the child with a disability as a totem of their own personal failure. The feelings of a damaged self-esteem give rise to intensive feelings of inferiority and shame. Parents tend to feel that the child with a disability destructs the ambitions and wishes for a happy family life. Parents find themselves in a state of constant ambivalence. On one hand, they feel they have to love and protect the child, but on the other hand, social values cause them to feel discomfort, feelings of failure and inability to accept the child as a 'beloved' one (Gadagbui, 2003).

Thirdly, the birth of a child with a disability in the family reshapes the organization of the family. The burden of a child care is not divided equally between parents, in the Ghanaian context mostly mothers stay home and care for the child, while fathers go to work. In some cases, devotion of the mother to care for the child may make the father feel neglected, which sometimes results in violence, and hence, reshapes the organization of the family (Gadagbui, 2003).

Fourthly, the birth of a child with a disability in the family creates fertile ground for conflicts. A practical example is the shift of devotion of the mother to care for the child may make the father feel neglected, which sometimes can result in violence. Sometimes, the core conflict stems from the fact that each parent conceives the situation in a different way and since the financial expenses change drastically compared to their previous situation or that of other families, this could create a fertile ground for conflict (Kandel & Merrick, 2003).

Shyu et al. (2010) conducted a study in Taiwan which he interviewed 13 parents of young children with autism about the impact of having a child diagnosed on the spectrum. The parents reported that their children's disability caused financial strains and make them feel stressed, depressed, tired, and exhausted, and always kept them worrying about what the future would hold for their children. Their parent-child relationships were negatively impacted, in that, they felt they had lost total confidence in parenting styles and their ability to parent their child.

In Ghana, Anthony (2010) found that many mothers were blamed in some way for causing their child's autism, resulting in significant stress and isolation. Additionally, Ghanaian culture places an emphasis on every child's social life and how appropriate it is and believed that something contrary to that (anti-social) is wickedness. Rites of passages are held in the highest esteem and typically require a demonstration of social savvy in some form. Looking at the social impairment that comes with autism, the expected rites of passages would be difficult for most children of autism to perform. Their difficulties relating socially often result in stigmatization and increased isolation from society. Finally, Anthony (2010) was of the view that, because children with autism have difficulties in relation to the societal norms, they are often viewed as "useless" and unable to acquire knowledge or give back to society. In addition to the isolation, families report feeling isolated and stigmatized, unable to attend community events, church services, and other social events or celebrations.

1.2 Statement of the Problem

Over the years, individuals, families, NGOs, institutions and government bodies have increasingly shown interest in disability-related issues. Policies have been enacted and Special schools have been set up by some NGOs and individuals to cater for the educational needs of children with autism. As a result, government established the District Assembly Common Fund to support parents having children with disabilities. However, it appears parents' raising a child with autism is expensive due to medical expenses, therapy services and the cost of educating their children with autism. This financial cost of raising a child with autism may create emotional trauma in parents. It seems that awareness creation of autism is not widespread in Ghana, as well as standardized diagnostic centers and service providers nationwide seem to be inadequate. It therefore stems from the fact that parents have inadequate information about how to care for their children with autism. These could result to negative experiences in parents due to the inability of government to provide adequate assistance in the provision of resources (Anthony, 2010). Although considerable research has been conducted in Ghana on experiences of parents who have children with autism, Oti-Boadi (2017) confirmed that there has not been enough progress in the provision of resources or services to support parents who are affected by the emotional problems associated with raising a child with autism. In fact, Wireku-Gyebi and Ashiagbor (2018) mentioned that information about autism in Africa is not comprehensive enough. This is therefore the gap that this study has taken on to explore.

1.3 Purpose of the Study

The purpose of the study was to examine experiences of parents of children with autism in Aboom unit for children with intellectual disabilities in Cape Coast, Ghana.

1.4 Objectives of the Study

The following objectives were developed for the study:

1. Describe the emotional problems on parents of children with autism.
2. Explore the financial challenges of parents of children with autism.
3. Examine support services on parents of children with autism.
4. Describe coping strategies of parents of children with autism.

1.5 Research Questions

1. What emotional problems do parents of children with autism experience?
2. What financial challenges do parents of children with autism face?
3. How do support services influence the overall well-being of parents of children with autism?
4. What coping strategies do parents of children with autism use?

1.6 Significance of the Study

The study on experiences of parents of children with autism in Aboom unit for children with intellectual disabilities in Cape Coast, Ghana was significant because the results would help reveal the emotional impacts of parents of children with autism and this will enable relevant authorities to develop appropriate parents support programmes to help such families cope with parenting their child.

Additionally, the results of this study would reveal the financial challenges of parents of children with autism and the need for stakeholders to form parents support networks to help such parents to cope with the children’s condition.

Furthermore, this study would reveal the support services available for parents of children with autism and the need to provide adequate practical support to persons with autism and their families.

Also, the study would reveal coping strategies of parents of children with autism and the findings would provide information to other parents of children with autism on coping strategies they can also use in caring for their children.

Lastly, the results of the study would add to the body of literature available in Ghana and generate new understanding that might be useful for future researchers.

1.7 Limitation

There were several limitations. First, the researcher involved a sample of 10 participants, that is likely not be the representative of the general population of parents of children with autism. However, the purpose of the study was to to examine the context of an experience so that new knowledge could be added to a related context.

Also, a much smaller number of fathers participated in the study. Mothers made more than half the participants. So, the females outnumbered the males, making it unequal gender representation.

1.8 Operational Definition of Terms

Experience: A lived event of something.

Parent: For the purpose of this study, a parent is defined as the primary care taker of the child and who lives with them.

Autism: It is a disorder that is characterized by difficulty in communicating, repetitive behaviour and poor social interaction.

Autism Spectrum Disorder: It is an umbrella of developmental disabilities that includes Autistic Disorder, Childhood Disintegrative Disorder, Rett Syndrome and Pervasive Development Disorder Not Otherwise Specified (PDD-NOS)

Coping strategy: It is a way one use to get over a tragedy.

1.9 Delimitation of the Study

The study was delimited to 10 parents of children with autism in Cape Coast in the Central Region of Ghana. The study explored four variables: (1) emotional problems on parents of children with autism, (2) financial challenges of parents of children with autism, (3) support services on parents of children with autism, and (4) coping strategies of parents of children with autism.

1.10 Organization of the Study

The study consists of five chapters. Chapter One introduces the significant issues addressed in the thesis including, background to the study, the research problems, purpose of the study, research objectives, and research questions. Chapter Two is the review of related literature of earlier studies conducted on the topic, and theoretical. Chapter Three discusses the methodology and procedures, which were employed in executing the study such as the population and sample, the research approach, instrumentation, and data analysis method. Chapter Four presents the findings of the study, and analysis and discussion of the findings; and Chapter Five discusses the summary of the findings, conclusions, recommendations, and suggestions for further studies.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

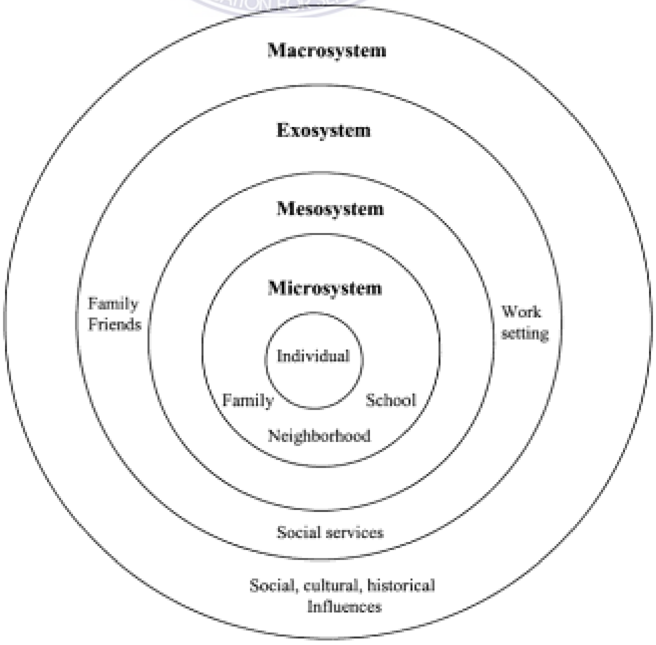
This chapter reviews related literature on experiences of parents of children with autism. The chapter has been organised under the following sub-headings:

a) Theoretical framework- the ecological systems theory
b) Emotional problems on parents of children with autism
c) Financial challenges of parents of children with Autism.
d) Support services for parents of children with autism.
e) Coping strategies of parents to the birth of a child with autism.
f) Summary of the literature.

2.2 Theoretical Framework

Figure 1

Brofenbrenner's (1979) Ecological Systems Theory



This study adopted the Brofenbrenner's (1979) ecological systems theory. The ecological systems focal point is by recognizing the individual and families in their living setting as the organism whose environmental interrelationships are under evaluation. Brofenbrenner (1979) considered the world as an ecological system in which human development occurs. For Brofenbrenner, every individual is seen as an active human being who interacts with its environments and not only gets affected by it, but reforms it. Therefore, the relation that lies between the individual and the environment is said to be "reciprocity" (Brofenbrenner, 1979). Brofenbrenner set out four important environment systems but later proposed another system called chronosystem in 1986 (Gadagbui, 2012) that influences an individual's development.

The researcher intended to explore parents' experiences of raising a child with autism and how it affected their quality of life. Brofenbrenner's theory (1979) is relevant because the development of a child and that of the family do not grow in isolation (Goelman et al., 2001), and the types of systems fit closely or inside each other and affect one another. Inside each other ecological systems are the entirety of the organism and the environments that communicate, interdependently. Brofenbrenner embedded the various systems of our ecological environment, and they are the microsystem, mesosystem, exosystem, macrosystem, and chronosystem.

The microsystem is the first system that the child has direct contact with. It is between the child and its immediate setting including the home, school, peers, neighbours and all activities or interpersonal relationship that exist in the child's immediate setting (Gadagbui, 2012). In this system, parents' beliefs and behaviour affect the child and that of the child's own behavior and beliefs of the parents (Gadagbui, 2012).

According to Gadagbui (2012), Brofenbrenner saw mesosystem as a set of relations between the microsystem. The mesosystem is the interaction between two systems that make up the microsystem. In this system, developmentalists used a number of settings such as home, school and church to assess the significance of the mesosystem (Gadagbui, 2012). The interaction between the school and the home is a vital tool understood to be important as it will impact on the child's ability to read (Brofenbrenner, 1979).

The third system is the exosystem. This is the large system in which children have no direct role but it influences their lives. For example, if a parent of a child with a disability quit work to take care of the child or was laid off work, it affects the parents' financial needs. If the parents' finances are not going well, they affect the provision for the child's needs. This will include parents' workplace, media, finances and government agencies (Brofenbrenner, 1979).

The fourth system is the macrosystem. The macrosystem deals with the attitudes, cultural beliefs- customs and laws (Berk, 2000, as cited in Gadagbui, 2012). In this system, when the child becomes an adult and decides to marry he/she is allowed to marry from any religious background of his/her choice but not from the one he/she was raised from (Gadagbui, 2012). For example the current government COVID-19 restrictions on social gatherings reduce the services to families with children with disabilities.

In 1986, Brofenbrenner added chronosystem to the ecological system. The chronosystem encompasses all changes and experiences overtime in his/her life, across all layers of the ecological system (Brofenbrenner, 1994). It involves the change individual experience throughout his/her life as he/she grows, how he/she perceive things around him/her changed due to the experiences he/she has gathered over the years and the impact of the experience on his way of life (Brofenbrenner, 1979). It is important to recall that families grow within complicated and interconnected systems (Seligman & Darling, 1997). This framework thought about the experiences of the individual from these numbers of view points and research based in this framework contemplate these ecological systems when interpreting the phenomena.

2.3 Emotional Problems on Parents of Children with Autism

The life of a family changes significantly and each member of the family must adjust and adapt to the new dawn of the birth of a new child. Families of children with disabilities are likely to experience a change of routines in their daily activities, roles and in addition experience a high level of stress to the regular stress of parenting (Karst & Vanhecke, 2012). Parents of children with disabilities have been questioned about their child's disability, as well as managing stigmatization and discrimination by the society. Parents with children with disabilities are at a higher risk of experiencing stress than that of parents without children with disabilities (Karst & Vanhecke, 2012). A number of factors influence the level of stress parents face in raising a child with a disability. These are: organization of the family, the child's characteristics, family resources, marital relationships, support services and coping (Gona et al., 2011). Under the emotional impact of having a child with autism, parents become stressed up raising their children. Stress and the causes of stress is discussed below.

2.3.1 Definition and causes of stress

Everyone will experience stress depending on the person’s level and ability to manage crises and is based on their appraisal of whether an event exceeds their ability to adaptively manage their situation and is normal part of life (Butcher et al., 2010). Stress refers to "both the adjective demands placed on an individual and to the individual’s internal biological and psychological responses to such demands" (Butcher, Mineka, Hooley, Taylor & Anthony, 2010, p. 150). Stress is difficult to explain because it is based on an individual's understanding of an event or situation. Stress is caused by changes in a person's interaction with the environment, people, changes in a person's lifestyle, job pressures, financial challenges, family problems, personal loss, or negative emotions can also be caused by our day to day activities (Nealy et al., 2012).

According to the American Psychological Association (2015), there are three types of stress: acute, episodic and chronic stress. Acute stress is often short term and can be very sudden and intense and is the most common. It is the demands that come from our daily activities (e.g. riding a roller coaster), can be fun but in larger doses (e.g. meeting an important, rushed deadline at work) can be exhausting and can result in psychological problems. Episodic acute stress is a type of stress which affects individuals who experience frequent acute stress. Chronic stress involves "one or more forms of stress on-going for several months" (Butcher et al., 2010, p. 245) and is much longer in duration than the other two forms of stress. Chronic stress is the most dangerous because it comes with high levels of stress for unlimited period of time which the human body is unable to bear. Parenting is a highly stressful job, and becoming a parent of a child with autism is one of the most stressful events that can occur due to the complexity of the symptoms that characterize autism (Griffithet al., 2011). Families require constant positive coping mechanisms in caring for their children successfully. Several studies have been done on the emotional experiences of parents of children with autism.

Meirsschant et al. (2010) conducted a mixed method study involving 17 mothers who had children with autism. Using open-ended questions, the mothers were asked about the impact of having a child with autism on their family and personal life. Mothers revealed that having a child with autism affected their quality of life. Aspects reported as stressful included inaccessible care giving system; worries about the child's future; impact on the other siblings, and myth and misconception of autism that had consequences on their family life. Meirsschant et al. found that mothers showed a high level of commitment and determination to do everything they could for their child with autism, and thereby developed numerous coping strategies.

Similarly, Allik et al. (2006) in Sweden to examine the emotional impact of having a child with autism. The study involved 61 parents of children with autism (31 mothers and 30 fathers). Asperger syndrome, high-Functioning autism (HFA), or other children of average (AS), were surveyed regarding their health and quality of life. The results were compared to the results of the survey when administered to 59 parents (30 mothers and 29 fathers) of age– and gender-matched children with typical development. The findings of the study revealed that mothers of children with autism tended to show poorer physical health when compared to that of fathers of children with autism. Additionally, the results suggested that the better teacher- and parent-rated prosocial behaviours of the child, the better the reported physical health of the mother. However, no differences were noted in reported mental well-being amongst the groups. The authors concluded that it is mother’s health and quality of life that is most impacted by having a child diagnosed with autism, and that this impact is both unique and strong, especially when their child exhibits higher levels of behaviour problems but not necessarily an overall greater degree of impairment related to autism.

Farrugia (2009) in Australia explored the stigmatization experienced by families of children with autism as well as their level of awareness surrounding issues related to autism, and how it affected them emotionally. The study involved 16 parents (11 mothers, 5 fathers) and was done through a support group to participate. Semi-structured interview was used and this was done in their home. According to the researcher, all of the parents told researchers that they knew that 'something was wrong' even prior to their child getting their diagnosis and most parents believed their child's symptoms were as a result of biological factors. Family life changed significantly as a result of their child's condition and the families also spoke of structuring their lives to meet the child's needs. Parents also reported experiencing an anti-social world when they got to find out of their child's condition. Overall, the researcher concluded that knowing and believing that their child's condition as a medical condition helps the family to have control over stigma and even the shame and guilt as experienced by others in cultures where etiology is much less understood. Another recent research team from Australia examined the self-efficacy, well-being and fatigue of mothers of children with autism (Giallo et al., 2011).

Although parents in the Farrugia study reported having fairly positive cognitions surrounding their experience raising a child on the spectrum, the findings from the study suggested that there might still be great difficulties for these families. More specifically, after surveying 59 parents of children with autism on their level of fatigue, depression, anxiety, stress, and sense of competence and comparing them to a community sample, mothers typically reported moderate levels of fatigue significantly greater fatigue than parents of typically developing children. It follows that mothers who reported being fatigued also reported greater levels of depression, anxiety, and stress. Fatigue appeared to be the result of a combination of a number of factors including quality of maternal sleep, perceived need for social support, more problematic child behaviour, poorer quality diet, with little exercise, as well as lower educational attainment, which when combined accounted for approximately 63% of the variance. The qualities of physical activity, perceived need for social support, quality of sleep are the strongest predictors of fatigue. These findings show case the need for greater support of many forms for mothers of children with autism.

A study was conducted in Turkey by Bilgin and Kucuk (2010), in which they interviewed parents of children with autism about their emotional experiences related to the children's disability and the influence it had on them. Mothers representing 30% reported experiencing difficulty accepting their children in the community. When asked about stress, 47% of mothers reported that they had difficulties related to a lack of knowledge about what caused autism in their children or how to care for them as well as 49% of mothers said they had issues of financial difficulties. Mothers were also asked to share how they coped with the difficulties they face, 23% reported solidarity within their family and having mutual support with their husbands, 19% also reported being able to talk out their worries with family and 9% also reported being able to talk out with friends, or resignation 12%. Participants also reported strategies they used to cope with their situation, strategies in coping included brisk walking 9%, crying 7%, and smoking or using alcohol or coffee 7%.

Similarly, parents in Kenya, especially mothers, are consistently blamed for the cause of their child's condition (Riccio, 2011). Not surprisingly, these mothers report emotional stress, guilt, financial hardships, and disrupted family relationships. As a result of this stigmatization, many fathers abandon the family in an effort to save themselves and their future children from the curse. As a reason of that, Riccio stated that many mothers are tasked with raising the child alone, many hide their children away or choose to painfully dump them to get to free themselves (Riccio, 2011).

Finally, Anthony (2009) interviewed parents regarding their experiences of raising a child with autism. The researcher found that many mothers are blamed in some way for causing their child's autism resulting in significant stress and isolation. Additionally, Ghanaian culture places an emphasis on every child's social life and how appropriate it is and believed that something contrary to that (anti-social) is wickedness. Rites of passages are held in the highest esteem and typically require a demonstration of social savvy in some form. Looking at the social impairment it comes with autism, the expected rites of passages would be difficult for most children of autism to perform. Their difficulties relating socially often result in stigmatization, increased isolating them from society. Finally, Anthony (2009) was of the view that, because children with autism have difficulties in relation to the societal norms, they are often viewed as "useless" and unable to acquire knowledge or give back to society. In addition to the isolation, families report feeling isolated and stigmatized, unable to attend community events, church service and other social event or celebrations because of their child's behaviours and the way Ghanaian society perceive these normal characteristics of autism.

2.3.2 Stigma

Studies conducted by Kinnear et al. (2015) reported that in the United States and Canada, parents who had children with autism were often excluded from events and activities by others because of their child's disability. Similarly Gona et al. (2016) emphasized that, in Kenya, parents who have children with autism often experienced stereotyping and negative public reactions. Likewise, in Ghana parents and children with autism are ignored from society and labelled with names such as "fools", and "idiots" (Amponteng et al., 2018; Avoke, 2002). In Taiwan the challenge of stigma from the society is evident from the husband's family where the mother is expected to bear the blame of not being able to provide a healthy child to carry on the family name, especially where the child is a boy (Hsu et al., 2015). Societal attitudes and superstitious beliefs on disability in Africa are often based on fear and misunderstanding and therefore stereotype people with disabilities and families exposing them to prejudice, stigma and discrimination (Avoke, 2002). In Ghana, stigmatization and discrimination still remain a challenge in helping include persons with disabilities and families into the society. People with disabilities are labeled as "children from the forest and rivers" and were in the past returned to the forest or river under the pretense of helping them return to where they came from (Avoke, 2002; Bolts & Owusu, 2013). Stigma in the Ghanaian society is more intense due to the existence of strong cultured beliefs that throw negative light on disability (Yekple, 2014). Mothers of children with autism may also internalize the stigma they experience from family and the society and blame themselves for being responsible for their child's condition, not being a good parent and this further come to a climax into the experiences of guilt, shame, inferiority complex, and psychological distress (Mark & Kwok, 2010).

2.4 Financial Challenges

Caring for children with autism is very expensive and requires additional services from families and community at large. According to Resch et al. (2010), financial cost of raising a child with disability is estimated approximately three times greater than the cost incurred raising a child without disability.

As stated earlier in the background, Shyu et al. (2010) reported that parents felt that their child’s condition caused financial strain and made them feel depressed, tired, exhausted, and frequently worried about their child’s future. Their parent-child relationship was impacted in that they felt they had lost confidence in their ability to parent their child. The researcher revealed that parents shopping for solutions for their child tend to drain them financially.

Similarly, parents in Kenya especially mothers, are consistently blamed for the cause of their child's condition (Riccio, 2011). Not surprisingly, these mothers report emotional stress, guilt, financial hardships, and disrupted family relationships. As a result of this, many fathers abandon the family in an effort to save themselves and leave parenting of the child on the mother alone. As a result, many mothers are tasked with raising the child alone, many hide their children away or choose to painfully dump them to get to free themselves of how caring for autism financially needs.

Agyekum (2018) assessed 33 parents of children with autism about the impact that their child’s disability had on their finances. The study revealed that parents had various ways in caring for their children with autism and manged to cover extra expenses they incurred in caring for a child with autism. The study also revealed that the increased financial challenges were due to medical expenses, transportation and the cost of educating their children with autism.

Medical care for routine check-ups is expensive and the most challenging for parents. Sharp and Baker (2007) stated that the likelihood of financial challenges is related with the use of medical interventions, having unreimbursed medical or therapy expenses, and having relatively lower income. Medical treatment in Ghana is expensive, and medical treatment of autism is not included in the National Health

Insurance scheme. Additionally, because of the expensiveness of the medical treatment, parents rely on spiritual intervention.

2.5 Support Services for Parents of Children with Autism

Parents need support in coping with raising a child with autism. In a study by Mansell and Morris (2004) in Britain on the experiences of parents related to accessing supports and services for their children. In that study, 100 parents completed a questionnaire about their experiences in accessing supports and services for their children Mansell and Morris looked at the treatments methods and schools that were useful. They found that 87% of the parents considered the most helpful treatment method to be speech and language therapy, and about 69% of the parents reported that the most useful schools were special schools or units. Occupational therapy and behaviour management were rated as being moderately useful. Parents noted the lack of resources and long waiting lists for behaviour therapy as being problematic.

Following this study, another group of researchers conducted interviews with 68 mothers of children with autism to better understand their social support, mental health status, and their satisfaction with services (Bromley et al., 2004). In this study, about 40% of mothers reported feeling that their current housing situation was unsuitable for raising their child, and less than 50% of the mothers reported support from family or friends. Parents did report having support from coworkers 70%, parents' groups 85%, social groups/clubs 99%, religious organizations 78%, and early intervention programs 85%. Only six percent of parents reported finding their child's school as a source of support. While almost all parents reported being aware of the various services surveyed and asked about, very few parents were able to obtain those services. About 75% of the parents said that they were able to access speech therapy, 47% could access a pediatrician or doctor, and about 31% said that they could access a social worker. Less than 20% of parents surveyed said that they could access a psychiatrist, clinical psychologist, disabled child's team, alternative therapy, respite, support workers, or educational psychologists. About 96% of children were attending schools, but only 74% of parents said it was their preferred school. The most commonly reported unmet needs included help with care during the holidays 93%, to do things parents enjoy 91%, advice on the best way to help their child 87%, someone to talk to 85%, help with making plans for the child's future 81%, and managing the child's behaviour 80%. The parents mentioned a number of other unmet needs including advice on services, meeting other parents, and respite care.

In a study by McCabe (2007) in China, in which mixed approach method was used to collect data with an open-ended questionnaire and semi-structured interviews to better understand the experiences of families of children diagnosed with autism in accessing services and supports for their child. One of the themes that emerged was lack of schooling opportunities and rejection. McCabe found that parents expressed strong desire to have their children educated in school, but they were unduly required to prepare their children with a variety of basic learning skills and daily living skills (e.g., being able to sit for instruction, being able to understand the teacher's verbal commands, being potty trained, etc.) or they could be rejected from general education schools. It was also noted that special schools in most areas were limited. The researcher observed that parents who had strong connections in the communities with limited educational opportunities for children with autism, were the only ones whose children could go to school.

McCabe (2008b) also researched the impact of parent-to-parent support in China and found that support from other families of children with autism was of a very significant importance to other parents of children with autism. Parents expressed the benefits of parent-to-parent support provided to them through training programs they attended: sharing and learning from one another and support and accepting each other.

According to McCabe (2008b), with regards to sharing and learning from one another, some mothers even remarked that, after completing the program, they would still make time to contact one another. Parents noted that during their time at the centre, they also benefited by learning from other parents mistakes in teaching their children that they would like to avoid in the future. Parents also noted that they felt bonded to the other parents in the program and that the emotional support and encouragement of the other parents were essential. McCabe (2008b) concluded that, because of the overwhelming benefits discussed by parents who participated in the study, parent-to-parent support groups should be considered for inclusion in all interventions programs for children with autism and their parents.

In a Turkish study by Bilgin and Kucuk (2010), involving 43 mothers of children with autism aged 6-13 years; the researchers interviewed the mothers about their experiences concerning access to services and supports. In terms of the perceived resources for support in raising their child, the mothers reported budgeting 33%, receiving financial aid from family 23%, as well as relying on the cohesiveness of their family for support 14%. Only a small number 9% reported being supported by close relatives, and approximately 21% reported having no financial or emotional support. Mothers were asked to describe what they expected for their children to receive when attending school and many of them 72% reported wanting their child to learn to be independent, and 47% of them wanted their child to be able to communicate their needs to others. Of the number, 14% of them wanted their child to be able to speak fluently; 7% wanted their child to improve their maladaptive behaviours; and 7% wanted their child to be able to develop at least a little speech. About 14% expected their child to have good opportunities for the best education or to be literate 9%. In terms of what they saw in the future for their children, 50 % of the parents mentioned that they wanted their child to have made major improvement in their ability to self-care, and 15% believed that their future would always involve caring for their child with autism.

About 14% of mothers wanted their child to be able to speak fluently or to improve their maladaptive behaviours 7%, with around 7% wanting for their child to be able to develop at least a little speech. Few 14% expected their child to have good opportunities for the best education or 9% to be literate. In terms of what they saw in the future for their children, many parents 59% again mentioned wanting their child to have made major improvement in their ability to self-care, with many 47% believing their future would always involve caring for their child with autism. About 14% of mothers stated they hoped for their child to be able to speak, or to be social 7%, or 7% were concerned for the future of their child.

Finally, the research done in Ghana by Anthony (2009) revealed that stigmatization and isolation for having a child with autism was pervasive within most communities. In relation to how the stigma influenced treatment, many families report difficulty with accessing inclusive education for their child despite a right to enjoy such services. Interestingly, despite how difficult it is to raise a child with autism in Ghana because of stigmatization, lack of support services, emotional challenges and discrimination, many participants who had their child diagnosed abroad returned to Ghana. When probed further, it appears that some find it easier to retire in Ghana to care for their child or return to have the support of relatives. Parents interviewed in Kenya report very similar experiences in that, although inclusive education is currently being advocated in the country, many still report they find it difficult to get access to educational services for children with autism and also mentioned having limited available resources in accessing treatment (Riccio, 2011).

2.5.1 Access to education

Education is a right and must be enjoyed by all. The United Nations Universal Declaration Of Human Rights: article 26 states that everyone shall have the right to education and the Convention on the Right of Persons with Disabilities reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental human rights. In accordance with these, the 1992 constitution of the republic of Ghana article 24(1) stipulates that all persons shall have the rights to equal opportunities and facilities and with the view of achieving the full realization of that right, basic education shall be free, compulsory and available to all. Access to basic education is a fundamental human right. However, Lias et al. (2016) and Johansson (2015) argued that parents who have children with autism struggle to ensure their child's admission and continuity in school. According to Webster et al. (2016), in Malaysia, India, Australia, and the United States, parents get access to education for their children but is not enough. According to Webster et al. (2016), parents in Malaysia, India, Australia, and the United States are involved in the education for their children, but they still need more access and involvement. For instance, they want to be part of decision making process and discuss appropriate intervention strategies for their children.

Bolts and Owusu (2013) reported that 35% of their sample answered that it was very difficult to get good quality education for children with autism and children with intellectual disability, and 46% of the same respondents that getting education for children with autism and children with intellectual disability is difficult. This indicates that the parents encountered difficulty in seeking education for people with autism and disabilities in general.

In the year 2000, the United Nations established a set of goals in the field of education known as the "Education For All (EFA)" goals with the aim of sustaining development (United Nations Resources for Speakers on Global Issues - Education for All (EFA)". 2016). EFA established six goals and out of the six, the first goal state to “expand early childhood care and education" while the 6th goal is to improve the quality of education" (United Nations Resources for Speakers on Global Issues - Education for All (EFA)", 2016).

In accordance with the achievement of the EFA goals, Anthony (2009) concluded that children with disabilities are still underrepresented in the Ghanaian educational system. The reason being that special education is expensive and is for the minority and as such, is not given priority funding by the government. Also, the general attitude of some parents is that special education for children with autism is a waste of resources that are already limited because no returns will come from educating these children.

2.6 Coping Strategies of Parents of Children with Autism

The coping process involves virtually every level of human functioning: cognitive, behavioural, affective, and physiological. Coping strategies refer to the specific efforts, involving the levels of human functioning, that people use to control, endure, and minimize stressful events. Coping refers to the ways people react or respond to stressful situations both cognitively and behaviourally (Benson, 2014).

Parents and families make considerable adjustments when parenting a child with autism in their quality of life, and coping strategies have been found to be one tool by which individuals use to respond to situations, function adequately, and to regain control and coherence (Benson, 2014). Building adaptive coping skills manages the frustration, stress, and ‘ceaseless uncertainties and feelings of anxiety’ that can result from parenting a child with autism. Becoming a parent of a child with a disability can bring about stress and change (Dabrowska & Pisula, 2010). From the moment that parents begin to suspect that there is something 'different' about their child, family life changes and some level of disruption occur and require a new level of balance or may have the possibility to change in the family functioning (Hall & Graff, 2012). How well a family copes with the child's disability will depend on a number of factors, including parental support, the parents’ evaluation of the situation, their ability to function, and any additional stress they are experiencing (Gona et al., 2011). The ability of families to adapt can positively influence maternal depression and challenging behaviour of the child. Coping involves a multifaceted approach that weighs the effectiveness of possible coping options and their potential to mediate stress. The success of coping is influenced by the context in which it is used and can signal the changes of the person within that environment (Compas, 1998). Coping of parents of a child with autism can include improved family cohesion; positive reappraisal or reframing of their stressful situations; creating and establishing a ‘new normal’; making sense and finding benefit; and promoting strengths.

According to Benson (2014) coping strategies have often been conceptualized as either problem-focused coping or emotion-focused coping. Problem-focused coping uses a set of plans that work to change the situation. Emotion-focused coping uses set of plans that work to reduce emotional reactions to the situations. It is revealed that resources and coping strategies have being used interchangeably, because they are mistaken to mean the same. The families' coping resources are the individual and collectives strengths or assets the family has available to it, whereas coping strategies are what family members actually do, think, and feel with these resources (Boss, 1987). Family members may use existing coping behaviours that have worked in the past, or develop new behaviours. The aim of coping strategies is to strengthen or maintain family resources, protect the family from the demands of stressful encounters (Judge, 1998), reduce the sources of stress or negative emotions (McCubbin, 1979), and achieve a balance in family functioning.

Benson (2014) identified four coping strategies used by parents of children with autism which was a factor analysis. These include engagement (problem-focused coping), disengagement (withdrawing from the stressor), distraction (thinking about things other than the stressor), and cognitive reframing (thinking of the stressor more positively, acceptance and religious coping. Samadi et al. (2013) in comparing parents of children with autism to parents of typically developing children, found that parents of children, aged three to 17 years with autism, tended to rely more on emotion-focused coping strategy, which are usually associated with more positive results. Problem-focused coping may be seen as less effective by parents of children with autism because autism is considered as a life-long disability. Parents of children with autism may also use problem-focused coping strategies less often because it is sometimes uncertain on how to best approach a problem that their children may be facing. Parents of children with autism may depend more on emotion-focused coping strategies such as withdrawal due to their emotional distress, which may have additional negative effects on their own well-being (Samadi, et al., 2013).

Research has shown that every coping strategy used by parents has its own effects on their health. Distraction and engagement coping strategies are generally associated with poorer outcomes. These types of coping strategies are connected to higher levels of anger, stress, depression and lower well-being and parenting success in a study of mothers of children with autism (Benson, 2010). Furthermore, the use of active avoidance coping was associated with more stress and mental health problems for parents of children with autism. In general, problem-focused coping and positive-reframing are the best results for parents of children with disabilities (McStay et al., 2015). Mothers who used these coping strategies had less stress and higher parenting success and well-being over a seven-year period (Benson, 2014). Cognitive reframing was associated with better well-being and reduced the negative effects of child challenging behaviour for mothers of children with autism (Benson, 2010, 2014). Positive coping strategies have seen to have positive result even on a biological level.

Religious coping and family outcomes has been associated with having positive or negative results for parents of children with disabilities and the relation between them is less clear (Kamei, 2015) Some studies have found that coping through spiritual support has been related to lower parental distress among parents of children with autism (Manning et al., 2011). According to Paynter et al. (2013) parents who used religious or denial coping had higher levels of stress/depression. Manning et al. (2011) included a racially diverse sample from throughout the United States; whereas the participants from other studies were from the United Kingdom. Hastings (2002) and Australia Paynter et al. (2013) in addition, black and Hispanic parents in the United States who participated in a qualitative study, highlighted the significance of spiritual support (Hall et al., 2017), whereas this theme was less prevalent in other qualitative studies that included predominantly white samples (Ludlow et al., 2012). According to Pozo et al. (2014), the researcher found that for fathers of children with autism, active avoidance strategies (e.g., distraction, disengagement, denial) were associated with higher family quality of life, whereas for mothers of children with autism, positive coping strategies (e.g., problem-focused coping) were associated to higher family quality of life.

A mixed method research by Kenny and McGilloway (2007) who surveyed 32 parents on how they coped with their parenting role of having a child with autism; these researchers identified numerous factors that influenced the participants' ability to cope. One such factor was the quantity and quality of information given to parents at the time of their child's diagnosis, with only 13% stating that they were given information at the time of diagnosis, and only 3 of them felt satisfied with the information. Of the 32 parents, 19 expressed that they felt they had received insufficient information about their child's diagnosis as they were growing older. The findings were similar in a qualitative study by Towers and Swift (2006), who interviewed 21 fathers of children with autism in an area of Wales and found that fathers had found it difficult to receive the news of and come to terms with their child's diagnosis. Kiernan and Qureshi (1993) identified similar findings and suggested that professionals should take care not to discredit and devalue parents approaches to coping.

2.6.1 Spiritual belief

According to Gona et al. (2016), parents of children with autism in Kenya sought spiritual belief as a means of coping with their children's condition. Anthony (2011) revealed that Ghana is no different. He pointed out that spiritual and religious belief systems influenced the perceptions of and treatment towards individuals with disability in the Ghanaian society. Spiritual belief help as a means for parents to cope with the situation. Seeking for spiritual help offers them the hope that their situation will become better and less stressful. In Ghana, Oti-Boadi (2017) revealed that, despite difficulty caring for a child with a disability, parents possessed strategies such as spiritual beliefs, hope, family and community support, personal and family resources, and acceptance, adaptability and normalization (McCubbin & Patterson, 1982) were recounted by parents as providing meaning and purpose for their lives, and helped them to adjust and cope to their new life. Oti-Boadi (2017) revealed that about 95% of the mothers of children with a disability emphasized the role of their spiritual belief in coping with their children's autism. Their belief was that God knows best and knew the reason for given them such children. On the contrary, 5% of the mothers felt frustrated by their own spirituality because they felt that had not been treated fairly by God who had given them such a child.

2.6.2 Social support

Social support is defined as the network of family, friends, neighbours and community members that offer financial, emotional, psychological and physical assistance in times of need. According to Rodriguez (2011) social support is one of the major coping mechanisms that is found to be helpful in bringing down parents stress and daily negative mood. In supporting this, Ekas, Lickenbrock and Whitman (2010) admittedly described the significant of social support in reducing family stress and resulted in family coherence.

Parents of children with autism need support to assist them emotionally and physically by being provided the needed resources (Hall & Graff, 2012). While the primary social support includes spouses, neighbours, family and friends who offer emotional and mental assistance, informal support on the other hand involves other parents of children with autism and local organizations that give instruction, guidance, respite care, and social needs (Ekas, Lickenbrock & Whitman, 2010).

Obeid and Daou (2014) in Lebanon reported that social support services had a positive impact on parents and help to receive relevant information on the spectrum, and reduced their level of stress. The study also revealed that other parents relied on other parents with children with autism for support, thus leading to friendship.

According to Paynter et al. (2018), mothers of children with autism have been found to use positive appraisal (become stronger out of a situation) as a coping strategy in dealing with stress additional pressure it comes with raising a child with autism. In Kirsten's (2008), phenomenological study which explored what meaning does raising a child with autism have for parents? Participants made reference to a number of positive changes in their situation such as a re-evaluation of their general outlook on life such that they had become mentally stronger, more resilient in the face of stress; and more appreciative of life and the small things that can make them happy.

2.6.3 Acceptance, adaptability and normalization

Acceptance is the willingness to tolerate a difficult situation. The initial reaction to the birth of a child with autism spectrum disorder is likely to be negative and if the family thrives in rising to the complex demands and enduring to the demands it reaches the stage of parents accepting the child. Accepting the child is when parents make logical search for possible professional solutions and does not seek for 'magical' solutions. In the acceptance process, families learn to understand the reason of the pain and the limits within which the child may develop towards independence. Families learn to appreciate their inner strength to deal with the pain and consider different solutions. Adaptability is the process of adjusting to new situations and normalization is becoming aware of the normal rhythm of life cycle and to conform to or reduce to a norm or standard. Ekas et al. (2010) found that, the initial reaction of learning of the child's diagnosis, parents experience a sense of shock, frustration, sense of loss, grief. However, they were able to go through these challenges or experiences by first accepting the situation and think of the way forward.

Research has proven that families who have moderate levels of cohesion and adaptability have higher levels of coping through positively (Altiere & von Kluge, 2009). Again, Shah et al. (2010), stated that a positive attitude and acceptance of the child's diagnosis were a very important aspects of getting through the situation. This enabled them to get adequate and appropriate interventions for their children and parents themselves.

Finally, Sweden by Sivberg (2002), states that a strong sense of cohesion and acceptance had a strong stress reducing effect regardless of a life's situation as a parent of a child with autism. These parents reported that they developed their adaptability skills as they educated themselves and learned new strategies and skills to create a more cohesive family unit.

2.6.4 Personal and family resources

Parents of children with autism need variety range of coping strategies that are relevant for the challenges they face (Hall et al., 2011). The individuals own resources are the wider range of support available to each family member. The persons own resources available to them will impact a person's ability to cope effectively in stressful moment. When there are adequate personal resources available to the family members, stressful event is viewed differently and has less impact (Ungar et al., 2013).

Kwai-sang Yau and Li-Tsang (1999) outlined four basic components of personal resources: financial, educational, health, and psychological resources. Education is the key to success. Educational resources help a person's ability to solve problem. Financial resources is defined as how affluent the family is financially, psychological resources include personality characteristics and self-esteem and family members physical health all have consequence on coping. Self-esteem and sense of mastery over the situation are more successful than real coping behaviours when facing tensions over which an individual has little or no control (Pearlin & Schooler, 1978). However, when it comes to interpersonal relationships, specific coping behaviors are often made more successful than psychological resources (Pearlin & Schooler, 1982). One can conclude that every situation will require different coping strategies or resources.

The family's resources are the sociological, economical, psychological, emotional and physical assets that family members can draw upon in response to a stressful event. The level of commitment at the beginning or prior to the crises event influences the family's ability to cope and the response outcome (McCubbin & Patterson, 1983). Family's resources can also include the number of parents in a household. Family support is seen to have positive role in families coping and adapting the challenges caused by the child's autism. According to Ungar et al. (2013), family is viewed as one unit; therefore families who are connected to each other more closely as a functioning style use positive coping mechanisms. Several studies conducted by (Abbott & Meredith, 1986; Friedrichet al. 1985; Schillinget al., 1984) have documented the significance of having a firm parental alliance. These researchers found that marital satisfaction was the single best predictor of parental adjustment and minimize the amount of stress connected with caring for a child with a disability. The outcome of the results reveals that the level of strength in a marriage is censorious in predicting adaptation to a stressful event (Abbott & Meredith, 1986). Researchers have found out that single parents who have children with disabilities are at a greater risk of increased stress due to the complex demands of a two-parent household (Beckman, 1983; Vadasy, 1986).

McCubbin and Patterson (1982) involving 217 families who have children with cerebral palsy found that the involvement and togetherness of the family system as a unit, helped to maintain stability and cooperation, which were significant for both parents who had children with cerebral palsy. According to McCubbin et al. (1979) also revealed that mothers coping were aimed at maintaining family cohesiveness and the support and concerns from the fathers were able to successfully manage taking care of a child with a disability. According to Burr, et al. (1994), family cohesion is seen to be effective when it is well maintained and mostly used in stress management.

Communication is a great tool for every healthy relationship. The family's ability to communicate and express their feelings and thoughts is significant in maintaining a healthy family relationship (Amato, 2010). Having an open and candid communication involves paying attention to every little detail and being sensitive to gestures and signs-non-verbal communication (Burr et al., 1994). Although certain families may have additional means and resources of coping to the situation, not all families have to be from two-parent households, financially stable, well-educated to overcome a situation. Healthy families recognize crises as a means to focus on family strengths and resources while becoming stronger in the process (Amato, 2010). Families who have children with disabilities overcome the complex demands it comes with raising a child with a disability by working together to find solution to the situation, share roles and responsibilities, ideas, communicate their thoughts and feelings with one another (Amato, 2010).

2.7 Summary of the Literature and Gap

Chapter two provided an outline of the theory underpinning the study and the literature review. Brofenbrenners ecological systems theory was viewed as a suitable theoretical basis for the current study. The theory which indicated that the development of a child and that of the family do not grow in isolation and the types of systems namely microsystem, mesosystem, exosystem, macrosystem and chronosystem fit closely or inside each other and affect one another. Relevant related literature on the research topic highlighted on the financial cost of raising a child with autism, the support services parents receive, emotional challenges and the coping strategies parents employ in caring for their children with autism.

The empirical studies reviewed in this study on experiences of parents of children with autism were all conducted across the World and in Africa. Findings from the empirical studies indicate that parenting a child with autism is a highly stressful event. They may find it difficult to get access to appropriate education for their children and to receive the necessary support services to help raise their children. Some studies indicate that the birth of a child with a disability, in addition to the regular adaptation, serious crises interprets family life and the fabric of a marriage is attacked. From the literature materials reviewed, it was observed that there exists limited research in the Ghanaian society with regards to experiences of parents of children with autism compared to the western world. Also, the few studies done are mostly quantitative based. Here, quantitative based studies reported results based on large data thus they could not highlight in-depth and more detailed contextual experiences of raising a child with autism. Therefore, this study intends to fill this gap by using phenomenology as a qualitative research method to add new perspectives to the discourse surrounding parental experiences in Ghana.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

The following areas were covered under the methodology: Research approach, research design, population, sample size, sampling techniques, instrumentation, procedure for data collection, and data analysis.

3.2 Research Approach

The study adopted a qualitative approach because it provides an in-depth understanding of a very rich description of the experiences of participants (Creswell, 2007). In qualitative approaches, the researcher is interested in understanding the context in which the participants are and how it influences their lives (Maxwell, 2005). Adopting qualitative method for collection of data allows an in-depth investigation of research questions and phenomena, enabling them to be understood through discovering, exploring, developing and testing various assumptions about social reality (Miles & Huberman, 1994). The qualitative approach is more in-depth understanding of people’s experiences and opinions regarding family life.

The use of qualitative approach allows respondents to share their stories, as they themselves understand their own individual experience, which is impossible to use a quantitative approach. Also, qualitative allows researchers to conduct and collect data in the participants own unique setting and focuses on how participants interpret and make meaning of their experience (Creswell, 2007).

3.3 Research Design

Phenomenology is an approach that looks for to consider the lived human experience encounters and the way things are seen and show up to the awareness (Smith et al., 2009). The research design for this study was a phenomenological approach which ensures a detailed description of the phenomenon under study (Smith & Osborn, 2003). This approach was chosen because it could enable the researcher seek reality from the participants' narratives of their experiences, and to produce in-depth description of the phenomenon.

3.4 Population

Population refers to any collection of specified groups of human beings or non-human entities (Creswell, 2007). Twenty participants were involved in the study. This comprised of 20 parents who had children with autism attending school at Aboom Unit for children with intellectual disabilities at Cape Coast. Target population for the study were 20 parents in Central Region and accessible population were 20 parents of children with autism attending school at Aboom Unit for children with intellectual disabilities at Cape Coast.

3.5 Sample Size

It is not possible to use all members of the population due to its large number of people involved, a sample was therefore needed. Ten parents were involved in the study. The researcher came about the sample size through the data base of Aboom Unit for children with intellectual disabilities at Cape Coast. According to Creswell (2007), sampling is said to be statistical in practice and an important aspect of data collection. It is the selection of an unbiased subset of respondents from the population of individuals with a keen interest to yield some knowledge about the population of concern.

3.6 Sampling Technique

The procedure for the selection of the sample size was purposive and snowballing sampling technique because the researcher wanted to select participants who would meet the exact criteria for the study (Teddlie & Yu, 2007), and who could provide the data the researcher wanted (Curtis et al, 2000). Eights participants were purposively selected from Aboom Unit for children with intellectual disabilities at Cape Coast and two were selected through snowballing technique. According to Creswell (2003), a researcher's choice of a sample is dependent on how adequate it is in answering the research questions. A snowballing method is a method of sampling that asks other participants or community members to identify more individuals that could also give out information for the purpose of the study (Creswell, 2007).

3.7 Instrumentation

Within qualitative approach there are quite a number of methods for data collection including in-depth interviews, often tape recording, observation and focus group discussion (Ulin, Robinson & Tolley, 2012). For the purpose of this study, the researcher used semi-structured interview (in-depth) which is the most used and common method in phenomenological studies (DiCicco-Bloom & Crabtree, 2006). The purpose of the researcher using this method was to probe deeply and analyse intensively the life cycle of parents who have children with autism.

3.7.1 Semi-structured interview

Semi-structured interview (face to face) was used to elicit information. Semi-structured is a common and powerful method utilized in order to attempt to understand other people (Baumbusch & Clark, 2010; Fontana & Frey, 2000). An open-ended question was asked to allow the participants to respond freely without fear, panic and constraints (Gill, Stewart, Treasure & Chadwick, 2008). The questions were generated from the literature related studies that inquired into the experiences of parents of children with autism and were created on the basis of professional discussions with the researcher's supervisor.

The use of interviews provides more meaning on the topic being reviewed (Gill et al., 2008). The use of diary was also to be considered in the research as this contributed to the fullest possible record of what happened and become an integral component, alongside the audio recording. Diary was also as a means to document comments after interviews that are pertinent to the study.

Cohen, Manion, and Morison (2000) regards an interview as an exchange of views between two people on a topic of mutual interest and emphasizes the social context of research data. It is a research instrument and involves the collection of data through verbal and non -verbal interaction between the interviewer and the interviewee. Gall, Gall and Borg (2007) stated that the advantage of interview is its adaptability; skilled interviewers make an effort to build trust and rapport with respondents thus making it possible to obtain necessary information that the individual probably would not reveal by any other data collection method and also can follow up a respondent's answers to obtain more information and clarify vague situations.

3.7.2 Interview procedure

Semi-structured interview guide was used to gather the qualitative data for the study. The interviews were scheduled at a time and location convenient for the participants. Participants were given the chance to ask any questions and concerns regarding the study. Interviews lasted 50-60 minutes. Some interviews were done in the evening and others in the afternoon. Participants were called by phone to remind them of the scheduled time a week beforehand to avoid any unwanted surprises on the interview day. All interviews were held at the participant’s home, as this was the most convenient place.

3.8 Ethical Consideration

Participants were assured that their privacy wouldn't be taken for granted. The researcher made them aware, they can pull out of the study, anytime they wanted. Permission was obtained from them to tape record and take notes of the responses before conducting the interview. Names of all participants are pseudonyms to protect confidentiality.

3.8.1 Trustworthiness

Trust is important in studies were participants share delicate personal information. I needed to assure the participants to develop some trusting relationship. Developing trusting relationship was important to enable participants speak freely on personal issues. Each participant was allowed to respond freely without fear and panic. Every aspect of the study was made known to them verbally before and during the interview process.

3.9 Procedure for Data Collection

To begin with my search, having already come into contact with a participant of a child with autism through a colleague, that participant recommended a parent and an educational institution for the special needs in Cape Coast. I visited the school, and I met the head of the school. The school authorities directed the researcher to the residence of parents who agreed to participate in the study. The head of the school first made contact with the other parents of children with autism to explain to them the reason for contacting them. After getting to know their contact information's, the researcher called and scheduled a meeting to finally meet them. After meeting the participants of children with autism, I explained what the research was about. The researcher visited the participants for the study for the second time to familiarize myself with them before the actual interview day.

A formal introductory letter was taken from the department of special education to seek the permission of the participants to avail themselves for the interview. This was followed by a telephone call to finally confirm from the participants their consent and assistance prior to the interview and inform participants of the purpose of the research. If the participants agree, the researcher together with the participants agreed on the time and venue for the interview.

A voice recorder was used to record participant's responses (Jacob & Furgerson, 2012). Probing technique was also be used when responses lacks adequate detail and clarity.

3.10 Data Analysis

After conducting the interview, the recordings were transcribed immediately. All tape-recorded interviews were transcribed using the Microsoft Word's word processing program. The researcher asked the help of some PhD students good and experienced in qualitative research to assist in transcribing the tapes. The transcribed data was also be reviewed by the researcher to ensure that all the details of the interview were captured accurately. Analysis was done using the principles of Interpretative Phenomenological Analysis (IPA) which basically deals with examining how people make sense of their experiences (Smith & Osborn, 2003). IPA analysis involves a comprehensive exploration of the interview text to determine how the participants construct their meaning of a phenomenon under study. It emphasises on a detailed in-depth exploration of each individuals experience and a commitment to doing justice to each participant's account (Smith & Eatough, 2006). This study is phenomenological because it seeks to gain a deeper understanding of the experiences of parents of children with autism. The following four steps involved in IPA are followed:

a. familiarization with the data
b. generating initial codes and searching for themes
c. reviewing themes
d. defining and naming themes.

First, each transcript was read and reread to get familiar with it and to identify important quotes and phrases within each transcript. The researcher proceeded to make notes from the transcripts documenting similar quotes and phrases. These notes represented a description of the participants' experiences and the researchers' interpretation of the transcripts. Second, codes and themes were generated by examining the transcripts for identifiable themes in the parent's narrative. Third, themes were reviewed by comparing the themes across the number of transcripts, identifying connections between preliminary themes and editing the themes. At the fourth and final stage of the analysis, the themes were named and a thematic network was developed to summarize all the main themes and their sub themes.

CHAPTER FOUR

RESULTS AND DISCUSSIONS

4.1 Introduction

This chapter presents the data analysis and discussion for the study which aimed at investigating the experiences of parents having children with autism. In this chapter, the researcher presents the data gathered qualitatively. The demographic characteristics of respondents were discussed followed by the thematic analysis of the qualitative data. Data was gathered for the purpose of answering these research questions:

a. What emotional problems do parents of children with autism experiemce?
b. What financial challenges do parents of children with autism face?
c. How do support services influence the overall well-being of parents of children with autism?
d. What coping strategies do parents of children with autism use?

In answering these research questions, interpretative phenomenological analysis (IPA) analysis of the qualitative data which produced four themes that best expressed the emotional, financial, support services and coping strategies of having a child with autism. Ten parents, fathers and mothers of children with autism were interviewed. Six participants were interviewed in Fante language and four were interviewed in English Language. The Fante responses from the six participants were translated in English language. Verbatim expressions of the participants were also used when necessary. The findings were presented here in the form of main themes and sub themes in line with the research questions. Names of all participants in the submissions are pseudonyms.

4.2 Demographic Characteristics of Parents (Names of all participants are pseudonyms)

Table 1

Demographic Characteristics of the Respondents

Name	Sex	Age	No. Children	Level of education	Religion	Employment status	Marital Status	Relationship with child
Florence	F	45	3	Secondary	Christian	Trader	Married	Mother
Diana	F	36	2	Primary	Christian	Unemployed	Separated	Mother
Mary	F	38	1	Primary	Christian	Trader	Married	Mother
Theresa	F	41	4	Secondary	Christian	Trader	Separated	Mother
Love	F	25	2	Primary	Christian	Unemployed	Single	Mother
Joseph	M	33	2	GCSE	Christian	Civil servant	Married	Father
Benedicta	F	37	2	Diploma	Christian	Teacher	Married	Mother
David	M	50	4	Secondary	Christian	Welder	Married	Father
Grace	F	23	1	Primary	Christian	Unemployed	Single	Mother
Felicia	F	47	5	Diploma	Christian	Civil servant	Married	Mother

A total of ten (10) parents comprising of 8 females and 2 males were recruited for this study. The participants aged from 23-50 years. There was a vast difference of participants educational level. Four of the participants had only primary education, three secondary, one GCSE and two had a university diploma. Three participants were not employed, two were civil servants, one was a teacher, one was a welder and three engaged in petty trading (small scale business). All 10 participants were Christians. Eight of the participants were the biological mothers of the children and two biological fathers. Six of the participants indicated that they were married, but just 2 of the participants among the married participants spoke of the involvement of their spouse in providing care and supports to the child with autism. Two indicated that they were married but not living with their spouse but separated. Two of the participants indicated that they were single because the father of the children had not shown interest in marrying them.

The themes in figure 3 below show the main themes and sub themes associated with the parental experiences of having a child with autism. However, it is principal to note that the themes are not solely independent, but are connected to one another in explaining parents experiences. The main themes and sub themes addressing the four research questions is presented below.

Table 2

Main themes and Sub themes from the Four Research Questions

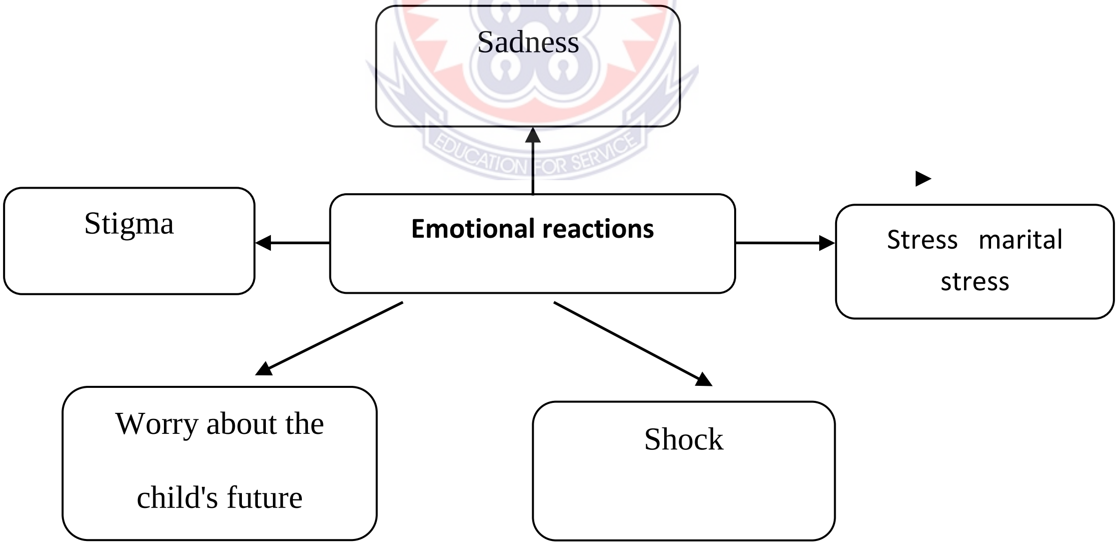
Main theme	
Emotional Problems	**Sub themes**
	• Stigma • Stress-marital stress • Sadness • Shock • Worry about child's future
Financial Challenges	**Sub themes**
	• Issues of earning a living • Medical expenses • Travelling expenses • Education cost
Support services	**Sub themes**
	• Access to education • Involvement of parents in their children's education • Support from family, friends and neighbours. • Support and advice • Parent to parent support • Parent support groups • Support and advice by specialists
Coping strategies	**Sub themes**
	• Religious and spiritual beliefs • Hope • Support from family and friends

4.3 Emotional Problems of Parents of Children with Autism

The main theme on emotional reactions which is situated at the centre of the figure 3 describes the problems of parents who have children with autism. Emotions are the expressions of one's inner feelings. Emotion is a mental and physiological state associated with a wide variety of feelings, thoughts and behaviours. Examples of emotions are happiness, fear, anger, sadness, surprise and disgust (Ekman & Heider, 1988). Parents of children with autism reported of emotional problems in the form of sadness, stress, worry and shock. Under this main theme, five (5) sub-themes were identified: sadness, stigma, and worry about the child's future, shock and stress which were the experiences of the parents.

Figure 2

Theme One: Emotional Problems of Parents of Children with Autism



The following responses were obtained through the interview process.

4.3.1 Sadness

Sadness is a feeling that is linked with the loss of someone or something important or worthy (Garg & Lerner, 2013). Individual's feeling sad express their emotion by verbal and non-verbal means (Gross, 1998a). Verbal expressions are communicated in words including writing and orally talking about it. Non-verbal expressions are communicated in changes of facial reactions, vocal expressions and body gestures/movement. Participants expressed their sadness by vocal expression, watery eyes and stingy in the throat. Their voice became lower in pitch and softer in volume or higher in pitch and louder in volume, for example crying. Participants shared their experiences of sadness as a result of having a child with autism. They cried their heart out in expressing misery for the child's "out of the norm" behaviour. Four participants shared their experience in Fante language. The Fante responses from the participants were translated in English language. Participants shared their experience as follows:

A participant has this to say in Fante:

> *"Musuii mber a mohu dɛ me ba no nsonsonee wɔ no ho. Menyiwa angye osiandɛ nna menyiwa ndado. Nokwar, me nyinsan abofra no, me nya enyidado dɛ mɔ wo ba a ɔwɔ ahomka nanso amba no dɛm. Ntsi merɛhoow ara yie na me sui ndanyina"*
>
> "I cried the day I found out that my child was different. I wasn't excited at all because I never expected it. In fact when pregnant, my expectation was to give birth to healthy baby little did I know my child will deviate from norm. So that made me sad which made me cry all day long" (Grace)

Another participant intimated in Fante that:

> *"Musuii ara yie. Me yɛɛ ma'adwen dɛ merenwo biom osan abofra no nsonsonee wɔ no ho ntsi. Ɔyɛ yaw ara yie. Eyi yɛ ɔyaw kɛse a mafamu wɔ wiase yi mu dɛ mɔ wo ba a ɔyɛ yarfo".*
>
> "I cried my heart out. I even decided not to give birth again because of the child's condition. It was a painful situation. This is the most painful thing I have ever experienced in my life, that is to give birth to a child with a disability. (Diana).

The view of another participant in Fante here:

> *"Yaw a efamu dze wo dɛm abofra no nnda fa mu. Ɔyɛ tse dɛ wiase nyinaa robɔbɔ wo do sɛ ewo ba onntum nnka nnkɔ nyimpa mu. Musuii bebree ma mefɔnee yɛ ketseketse. Nna minntum ndzidzi yie mpo dɛ mereka nda papa"*

> "The pain you experience of giving birth to such a child is not easy. It felt like the whole world is crushing down on you when you give birth to a child with autism. I cried so much that I grew lean in the process (loss weight). I couldn't eat well not to even talk of a good sleep" (Florence)

A participant also has this to say in Fante:

> *"Ahyɛse no manngye anntomu dɛ me ba no yɛ yarfo. Megyee dzii dɛ biribi bɔn biara runntum nyɛ me ba no osiandɛ midzii edziban a ahoɔdzen wɔ mu na midzii datsernyi ne afotu aber a nna m'enyinsen no. Musuii ara yie. Manngye dɛm nhwehwɛmu no anntomu"*

> “I initially denied my child had that disability. I believed that nothing bad can happen to my baby because I ate healthy food and followed the entire doctor's advice during my pregnancy. I cried so hard. I couldn't accept that diagnosis"(Mary)

From the above it is obvious that parents who have children with disabilities experience sadness and they expressed that by crying their heart out.

This finding is in line with Frijda (2005), Lazarus (1991), and Lench, Sarah, and Shane (2011), who asserted that sadness is an emotion that brings out a sense of being unhappy in response to grief. Also, this sense of misfortune can relate to any resources that influence ones well-being or general well-being, such as the passing of a cherished one, having a child with a disability, an experience with a weakening affliction, or a breakup with someone you love or cared for (Keller & Nesse, 2006; Nesse, 2006; Raghunathan & Pham, 1999).

The findings are in line with Kubler-Ross's (1969, cited in Gadagbui, 2012) five stages of grief. They are denial, anger, bargaining, depression and acceptance (DABDA).

Denial: It is when individuals grieving over the loss of a loved one or the birth of a child with a disability refuse to accept or admit the diagnosis given to them by a specialist or doctor, consciously or unconsciously (Gadagbui, 2012). For example denying could be in the form of feeling reluctant to accept and admit the child has a disability, and also the child would need a special and differential treatment in the child's education. E.g. breakup or divorce: “They are just upset. This will soon be over"

Anger: This stage is when parents show an intense emotional state of a strong response to a hurt or unexpected event or tragedy. Parents begin to ask questions about themselves. “Why should this happen to me?" Some parents knowingly and unknowingly direct the anger to the specialist or doctor from given such news (Gadagbui, 2012).

Bargaining: In this stage, parents negotiate with the specialist or doctor on ways to improve the child's situation. For example buying a wheelchair for a cerebral palsy child for mobility, buying a hearing aid for the hearing impaired to hear better, referring the child to a physiotherapist for massage, exercise and physical therapy (Gadagbui, 2012).

Depression: In this stage, parents get angry of themselves. They feel sad, regret and not sure of uncertainties later in life. They feel lonely in this stage during which you reflect and process on what's going on around you.

Acceptance: This depicts that parents have come to understand the need to accept the situation and now seek for advice and lobby for interventions to improve on the child's condition. Example of the acceptance stage: breakup: "I made a good choice of letting him/her go", illness: he can hear again with the help of a hearing aid (Gadagbui, 2012).

4.3.2 Worry about the child's future

"Worry is a chain of thoughts and images, negatively affect-laden and relatively uncontrollable. “It represents an attempt to engage in mental problem-solving on an issue whose outcome is uncertain but contains the possibility of one or more negative outcomes" (Borkovec et al., 1983, p.9-16). Again, worry is a way of thinking about the uncertainties of the future in a way that leaves you anxious. Participants unanimously expressed worry over their child's present and future situation. The Fante responses from the participants were translated in English language. Two participants shared their experience in Fante language. The Fante responses from the participants were translated in English language. Participants shared their experience as follows:

A participant asserted in Fante that:

> *"Ɔyɛ a ne daakye ho haw me paa. Seseiara dze oriyin.Woedzi mfe du-ebien naaso ndzɛmba bi wɔ hɔ a ɔwɔ dɛ otum yɛ ma no ho naaso onntum na ɔhaw me wɔdza abrabɔ dze wɔ ma no daakye. Ɔyɛ a ɔhaw me daadaa na ɔto me adwendwen. Mewerɛfir dza daakye bɛ yɛ ama no"*
>
> “I worry so much about his future. He is growing older now. He is 12 years old but there are things he should be able to do for himself but he can't and I worry about what the future holds for him. I am plagued by constant worries and anxious thoughts. I forget about what I have to do for him now and think of how the future is going to be like for him" (Mary)

The view of another participant in Fante here:

> *"Mibisa meho ebɛnadze na obotum ayɛ ama no ho na woana na ɔbɔhwɛ no. Onntum nnyɛ hwee mma no ho. Woedzi mfe du. Ne daakye ho haw me. Ne daakye na ɔhaw me kɛse. Ebɛn kwan na ɔbɛfa do abɔ ne bra daakye aber a minnyi hɔ. Hmmmm- musuro mpo"*
>
> “I ask myself what can she do for herself and who would take care of her. She can't do anything for herself. She is 10years now. I worry about her future. Her future is what I worry about the most. How is she going to survive the future without me around? Hmmmmm...I'm even scared" (Florence).

The findings from the above revealed that participants expressed worry over their child's future. Parents were concerned with the future of the child with autism. They shared that they weren't preparing the child for the future and weren't putting together the right services that would prepare the child for the future. Participants were concerned about their child's inability to be independent, communicate with others, care for themselves, and interact with others without relying frequently on others for assistance. This was evident when Mary revealed that she worries over her child's inability to do anything for himself and worry over what the future holds for him. This finding is consistent with studies that have shown that parents worry over their child's future. For instance, (Heiman, 2002) conducted a study on parents' concerns of the future of their children with a disability. The research revealed that many parents expressed concerns in their child's financial future, physical independence, education of the child and future employment.

Also, this finding is in line with Waggoner and Wilgosh (1990) who asserted that parents show concern about the child's future and the ability to function in a friendly environment or less sheltered settings.

4.3.3 Stress

Stress refers to the tending demands placed on a person's internal biological and physiological reactions to such request (Butcher, et al., 2010). How people interpret their stress is based on their evaluation of whether an event surpasses their ability to cope and manage their situation (Lazarus & Folkman, 1984). Stress is an unavoidable part of life. When stress happen or continue for a long time can lead to a number of short and long term negative health effects. Stress can lead to depression, anxiety, angry, drug or alcohol misuse, restlessness, lack of motivation or focus. The findings from the data gathered revealed that parents who have children with autism while caring for their children experience stress emotionally, financially and in their marriage life.

Participants revealed that caring for a child with autism is demanding and they experience a high level of stress. Participants were asked what they go through in taking care of their children, most participants with a change in their tone of voice, revealed being emotionally and financially stressed because they felt they were on their own and since there was no social support systems in place, they felt they were stuck and left to deal with everything on their own. Two participants shared their experiences in English language and four participants shared their experiences in Fante language. The Fante responses from the participants were translated in English language. These were evident when parents reported their experiences as follows:

A participant expressed that in Fante:

> *"Wɔ ne nhwehwɛmu m'adwen yɛ basaa a nna munnhu dza nna haw no yɛ. Medze me ba no kɔɔ ayarsabea ahorrow a nna morohwehwɛ ne haw no nsɔwano.Seseira me ba basia no ne tsebea no boor mo do nye mbrɛ a nna m'abrabɔ rotwa noho. Mekae dɛ nanka morotɔ ewudur anom"*
>
> "Prior to her diagnosis, I was confused by not knowing exactly what the problem was. I moved my child from one hospital to the other trying to find solution to the problem" now I am overwhelmed by my daughter's condition and the way my life was turning around. I remember I nearly bought poison to drink" (Florence).

At this point, we had to stop the interview because she was very emotional and started crying. The researcher consoled her until she was calm and ready to continue the interview.

Another participant indicated that:

> “I am always crying in the night. I get up in the night to think and I get so emotional when I think of the task ahead of me. There is no hope for me. At times I just ask myself what I did wrong to deserve this"(Benedicta).

Grace also has this to say in Fante:

> *"Sɛ medze no puei na ɔhyɛ ase reyɛ dza ɔmmfata a, nna nkorɔfo hwɛ hɛn ma me yɛ basaa. Ɔtɔdabi a menye nkorɔfo ko sɛ wɔdze dzin ahorow dze frɛ no a, tse dɛ "bɔdamfo, nsuba". Musu na mibisa me ho dɛ, ebenadze na ɔyɛ emi?*
>
> “When I take her out and he begins his tantrums, people look at us and I become so embarrassed. I sometimes fight with people for calling him names, like "bodamfo (mentally ill)", nsuba (river child)". I weep and ask myself, why me? (Grace)

Meanwhile some participants were emotionally disturbed by their children's inability to communicate and move around especially when they can't speak out for something they want. Stating it makes it difficult to understand their child and care for them adequately. Also, they were emotionally stressed by their children's unusual behaviour at home and in public places. Some mentioned that their children spit on others without any provocation, bang their heads against a wall with no reason, harm themselves or their siblings during play and ran towards moving vehicles when they get the least opportunity. In their own words, parents shared:

A participant asserted that:

> “Everyone abandons you when you give birth to a child with a disability. It is difficult not knowing when he is in pain or need something. Moving on in life is a dream. At least he should talk so I will know how he feels and what is exactly wrong with him to enable me to know the kind of help he needs. It is hard to see your child hurting himself without any obvious reason.... I get stressed out when I think about it" (Joseph)

A participant intimated that in Fante:

> *"Nna morokɔ pɛ biribi wɔ guamu nna okɔdo gyinagyina kwan no mu. Nna minnyim dza ɔhaw no. Ahyɛse no nna medwen dɛ ɔrebɛyɛ dza ɔhaw no. Ahyɛse no nna medwen dɛ ɔrebɛyɛ dza ɔmmfata.*

> *Ekyir yi mebohun dɛ onntum nnantsew yie. Migyinaa kakra nna mohwɛɛ ne mpaboa no mu na mohun dɛ nsɔɛ wo ne mpaboa no mu. Me were howee na musui kakra"*
>
> "I was going to get something at the market and she kept stopping. I didn't know what was wrong with her. I initially thought she was going to have tantrums. I later realized she wasn't walking properly, I stopped for a moment and checked her shoes only to find thorns in her shoes. I was sad and cried for a moment" (Love)

The view of another participant in Fante:

> *"Nkorɔfo frɛ no dɛ no ho nnyɛ no yie na ɔma mewerɛhow. Me nyaayianka obotum ayɛ komm na ɔnyɛ pitsirpitsir. Sɛ me mba nkaa no dze mbirika ba me nkyɛn osiandɛ ɔkaa hɔn aber a hɔn redzi agor nna minya atinka dɛ m'edzi nkogu dɛ Egya dɛ mepɛ bea a oye na ɔhyɛ nkuran ama hɔn"*
>
> "People call him abnormal and it makes me sad. I wish he could be calm and not hyperactive. When my other children come running to me because he bite them during play time, I feel I have failed as a father in providing a better, safe and conducive environment for them" (David)

When participants were asked about how they perceived raising their children with autism, all participants shared that, it was tough and stressful. They clarified why it is stressful by citing occasions that enlightened their impression. From the above analysis, it is clear that caring for a child with autism is demanding and they experience a high level of stress. The findings from the data gathered revealed that parents are emotionally stressed as a result of their children's condition. For example Florence report of almost drinking poison to end it all (commit suicide) because of the stress and difficulties she faced in her community because of the child's "out of the norm behaviour" and how challenging it was raising a child with autism.

The findings from the data gathered revealed that stress involved many different aspects but concentrated around four issues: cost of care, child behaviours, safety of the child and less communication. Parents described continuing or constant behaviours' associated with autism, such as crying, difficulty sleeping, flapping hands and inappropriate social interaction, which influenced stress in parents who have children with autism. Parents also related their stress to constantly on call to meet the child's needs that they couldn't take breaks or rest in order to get enough strength to do other activities for the day. Parents also shared that their stress was related to the child's safety and the safety of other siblings.

Stressful behaviours like constant crying, inability to sleep, hyperactivity and self-injurious as stress irritating. Parents shared that they experience stress in providing care to the child. This included the time it took them to make the children ready for an event. For example, dressing up and feeding them. Stress was related to the child's lack of communication. Parents find it difficult to know the needs of the child, due to the child's inability to communicate it to them. Stress was also related to the financial strain of caring for a child with autism especially the cost of special services like physical therapy, speech and language therapy and medications. Parents also shared that they had difficulty in working to earn a living because of the time needed to care for their children at home.

The findings agree with Marks,et al. 2016) and Webster, et al., 2016), who noted that parents experience stress following the diagnosis of their children and their effort to try and acquire knowledge about the condition and what it means for their child.

Also, from the above, it is clear that the findings on stress is in line with the research by An, Chan and Kaukenova (2018) which indicates that parents or caregiver stress was related with inadequate and incomplete social supports, stigma, and isolation from social events. Also, coping and adapting to societal negative attitudes, financial burden and striving for support services, and always having to communicate and construct relationship with health specialists and education contribute extremely to this feeling of stress.

In a like manner, Love also reported that she frequently sobs at night since of the torment and pity she feels by her daughters' condition. Additionally, Grace's rage at offensive names like "nsuba, bodamfo" used on her daughter when she stepped out in public places eventually leading to her fighting with individuals who name her child as such. These instances evidently show how parents who have children with autism face in their daily lives and the discouraging results of society's unacceptance of individuals with autism.

The findings is also in conformity with Fletcher, Markoulakis and Bryden (2012) who opine that parenting is a highly stressful job, and becoming a parent of a child with autism is one of the most stressful events that can occur and requires constant supports from family members and the society. Parents of a child with autism go through physical and mental health issues like depression, anxiety, and increase in weight due to their child's condition.

4.3.3.1 Marital stress

Stress refers to the tending demands placed on a person's internal biological and physiological reactions to request (Butcher, et al., 2010). How people interpret their stress is based on their evaluation of whether an event surpasses their ability to cope and manage their situation (Lazarus & Folkman, 1984).

Some participants expressed intensive stress on their marriage life as a result of their children's condition. Out of the 10 parents who were interviewed, six were married and out of the six married only two of them spoke of the involvement of their spouse in providing care and supports to the child. Two reported that they were married but not living with their spouse but separated. Two of the participants indicated that they were single because the father of the children had not shown interest in marrying them. In all six marriages, participants reported that challenges on the marriage were partially because their spouse believed that either they, or their relatives did not care for the child when needed or they were spiritually responsible for the child's condition. Two participants shared their experience in Fante language and one participant shared his experience in English language. The Fante responses from the participants were translated in English language. Participants shared their feelings as the following:

A participant asserted that:

> “My wife wasn't taking good care of our son and this disturbed me and other kids. She didn't make our home happy. At some point she made it impossible to stay at home because I constantly prompted her of how she wasn't taking proper care of the family so she got offended." (Joseph)

Another participant intimidated in Fante that:

> *"Me yer kyerɛɛ dɛ, emi na m'agyegye hɛn ba no do ma ayɛ no dzen dɛ onyi afofor benya nkitahozdi na mantsetse no yie ntsi onntum nnyɛ dza ɔsɛ fata no no. Bi tse dɛ obotwutwow n'ara ne kyɛnse a woedzidzi mu na mbom ɔdze n'adwen kɔ mbofraba nkaa no do sen abofra no a onntum nnye afofor innya nkitahodze. Biribiara ɔfa abofra no ne nkitahodze wɔ nkorɔfo afofor mu no nnhia no"*

> "My wife blamed me of pampering our child with autism and not train him properly that is why he is unable to do things expected of him. Like washing the dish on his own after eating therefore she focused on the other kids than the child with autism. Everything about the child with autism is of no interest to her" (David)

The view of another participant in Fante:

> *"Me kun dze asɛm tow me maame do dɛ ɔno na ɔdze bayie reyɛ hɔn ba. Me maame ne honhom bɔn na ama hɛn ba yi ɔwɔ dɛm tsebea yi mu. Iyi hyɛɛ ase aber a me maame bɛtsena hɛn nkyɛn abosoom ebiasa dɛ ɔroboa ahwɛ me ba no abera mewoo me ba no"*

> “My husband blamed my mother of bewitching our child. My mother's evil spirit has caused our child's condition. This started when my

> mother stayed with us for 3months to help take care of the baby when I delivered" (Florence)

The findings from the above indicate that participants face challenges in their marital life due to the birth of a child with autism in the family. Participants responses were in line with a research conducted by Turnbull and Turnbull (1986, cited in Gadagbui, 2003) that a child's disability attacks the fabric of a marriage in four ways, these are: it excites powerful emotions in both parents, acts as a dispiriting symbol of shared failure, reshapes the organization of the family and create fertile ground for conflicts.

The birth of a child with a disability excites powerful emotions in both parents. Their emotions become an effective state of consciousness in which joy, sorrow and hate is experienced. The anger makes parents unconsciously consider the child to be responsible for crushing their ambitions. Again, the birth of a child with a disability in the family act as a dispiriting symbol of shared failure. In some cases parents see the child with a disability as a totem of their own personal failure. Also, the birth of a child with a disability in the family reshapes the organization of the family. The burden of childcare is not divided equally between parents which become a burden. It's mostly seen that mothers stay home and care for the child, while fathers go to work. In some case, devotion of the mother to care for the child may make the father feel neglected, which sometimes result in violence and hence reshapes the organization of the family and further create fertile ground for conflicts.

Lastly, the birth of a child with a disability in the family creates fertile ground for conflicts. A practical example is the shift of devotion of the mother to care for the child may make the father feel neglected, which sometimes can result in violence. The study revealed that, parents who have children with autism experience marital stress as a result of their partners attributing their children's condition as spiritual and blaming them for it, inadequate care for their children with autism. The birth of a child with a disability in the family affects not only parent’s emotions, resources but also siblings and the extended family who are blamed and labelled as witches.

For instance Joseph and David accused their wife's of not taking proper care of their children with autism. It is also evident when Diana shared that her husband accused her mother of bewitching their child.

These show serious pressure on parents perseverance in their marriage by merit of their child with autism. Additionally, parents raised concerns of misinterpretation about the cause of autism spectrum disorder within the Ghanaian society due to superstitious devout and cultural beliefs.

Again, from the above analysis it is clear that the findings of marital stress is in line with the study by (Harper, et al., 2013) who reported that parents find difficulty in family and the quality of their marital life like adaptability, fondness expression and marital contentment when caring for a child with autism.

4.3.4 Shock

Shock is when oxygen and nutrient supply become accurately insufficient to converge the metabolic request of the body's organ systems (Delia & Rafael, 2014). For the sake of this study, shock is defined as the unexpected event. Participants shared of their shock when they discovered their child had a disability and how it took a long time to believe it. Participants shared their experience in Fante language. The Fante responses from the participants were translated in English language.

Participants shared their experience as follows:

A participant asserted in Fante that:

> *"Ɔtɔɔ mo do. Ma'ndwen ho da dɛ menya abofra a no ho atɔ kyima, osiandɛ tsitsir nna ɔyɛ m'abakan"*
>
> "It came as a shock to me. I never anticipated for a child with a disability, in particular because he was my first child" (Mary)

Another participant intimidated that:

> *"Mbom dze, ɔtɔɔ mo do a nna munntum nkasa dɛ menya m'abakan a no honamdua atɔ kyima. Ɔnnda famu kraa. Naaso Nyame nam ne tum do mam ba a ɔtɔɔ do ebien a nna ɔwɔ ahoɔdzen na ne beebia ntɔɔ kyima"*
>
> "In fact, I was shocked and speechless to have my first child born with a disability. It's not going to be easy at all. But God in his capacity gave us a second child who was healthy and had no disability" (David)

From the above, the father clearly showed his reaction of shock when he was told he would be having a child with autism. In order to alleviate this shock, he carefully thought of having a second child as compensation and reassured himself of a brighter tomorrow. And also, parents feel that a child born with a disability in the family act as a dispiriting symbol of shared failure. So in order to restore their confidence in themselves and in the community, a second child was or became an option to consider.

The above revelation is in line with Hill and Rose (2009) who opined that the loss of a loved one or uncertainties of life can effect a change on family life system and create the need for the family to adjust and reorganize to the new change. It can be hard to accept what happened and may numb, have trouble believing that you had a child with a disability.

Lastly, the initial reaction to the birth of a child with autism spectrum disorder maybe numbness and is likely to be negative and similar to those related to loss of a loved one (Blachar & Baker, 2007; Hill & Rose, 2009).

4.3.6 Stigma

"Stigma is a deeply discrediting attribute that makes an individual different from others by reducing him from a whole and usual person to a tainted discounted one" it is an illuminating excursion into the situation of persons who are unable to conform to standards that society calls normal" (Goffman, 1963, p. 6). Their image of themselves must daily confront and be affronted by the image which others reflect back to them. Link and Phelan (2001) defined stigma as the labelling of a person or group as aberrant or departing from usual or unaccepted standards and basically unlike oneself. Stigma was in the form of labelling, name calling and pointing fingers at them.

Pryor and Reeder (2011) segmented a conceptual framework model that seeks to bring greater clarity to the present but various literature on stigma. The model represents four types of stigma. They are public stigma, self-stigma, stigma by association and structural stigma. Public stigma is the process by which individuals in the community accept the stereotypes of a condition and then act in a discriminatory way. The second type of stigma is self-stigma. Self-stigma is when people make part of one's nature that is not based on reason or actual experience and discriminate against themselves as it were. For example, blame themselves for being responsible for their child's condition. The third type of stigma in Pryor and Reeders model is stigma by association. Stigma by association is similar to Goffman's (1963) courtesy stigma and involves social and psychological response to people connected with a stigmatized person, for example, family and friends as well as peoples response to being associated with a stigmatized person. Finally, the fourth type of stigma is structural stigma. Structural stigma is defined as the "legitimization and perpetuation of a stigmatized status by society's institutions and ideological systems (Pryor & Reeder, 2011).

Participants revealed that people stopped associating with them when they realized they had or were in contact with a child with a disability. It emerged that parents while raising their children with autism are stigmatized because of superstitious beliefs, religious beliefs that they are the cause of their children's condition. Parents reported people believed in the beliefs of the ancient days. They believed that children with a disability came about as a result of sins committed by the parents or used their children for money rituals, hence to discourage others from doing same act. Parents of such children were labelled as being wicked and selfish people. Participants therefore believed that it was because of the ancient beliefs that people in the society ignore them, point accusing fingers at them and call them names like "bosomba (child of the gods)", "sikadur (blood money)". In addition, the participants reported that other people see them to be the cause of the child's condition because they did partake an unprescribed drug during their pregnancy period. Four participants shared their experience in Fante and one shared her experience in English language. The Fante responses from the participants were translated in English language. Participants shared their experience as follows:

A participant asserted that:

> *"Metsee dɛ obi reka dɛ, hwɛ abofra banyin ba ne papa dze no agye sika dur. Dɛm ntsi na ne papa wɔ hyɛn. Ne papa nyaa ne sika no nyinaa fii amandze a ɔdze ne ba no yɛɛ. Sikadur nkotsee na wonyim naaso wɔmmpɛ dɛ wɔbɛyɛ edwuma dzen enya sika"*

> “I heard someone say" look at this boy his father has used him for sikadur (blood money). That is why his dad has a car. His dad got all his money from the rituals he used on his son. Sikadur (blood money) is all that they know but they don't want to work hard for money"(Mary)

She explained that because the child’s father is well to do (wealthy), people assumed he has used his son for money rituals (sikadur)". They whisper to themselves and call us names like "sikadur fie"," nsuba maame" each time they see us"

The view of another participant in Fante here:

> *"Me kun egyae dɛ odzi m'edziban osiandɛ ɔdze too mo do dɛ medze bayie ayɛ me ba basia no. Ebusua kɛse no mu mba no dwen dɛ medze me ba no ayɛ juju". Me bisa hɔn dɛ sɛ ɔyɛ dɛm a ebɛnadze nsti na minnyi sika yi? Biribiara mu no, ɔgye dzi dɛ obi a ɔwɔ sunsum bɔn na ɔdze biribi ayɛ me ba basiaba fɛfɛɛfɛw no"*

> “My husband has stopped eating my food because he blamed me of bewitching our daughter. Some of the extended families think I have used my child for "juju" I asked them so assuming I've indeed used my daughter for "juju". Why am I not wealthy? However, she believed someone else with evil intentions had possessed her pretty daughter” (Diana)

Another participant intimidated in Fante that:

> *"Me mpena a ɔdze tow m'enyim dɛ ɔbɔwar me no gyaa me osiandɛ me woo abofra a ɔnnka nnkɔ nyimpa mu. Ɔdze tow m'enyim dɛ menye me ba basia no ntsew adze mu nna m'angye annto mu. Mekaa kyerɛɛ no dɛ, onntum ndɔ me ba basia no a, nna menso minntum entoa nkitahodze no do ntsi ogyaa me"*

> "My boyfriend who had proposed to marry me broke up with me because I gave birth to a child with autism. He asked me to cut ties with my daughter and I refused to pay heed to his request. I told him if he can't love my daughter too then I can't also continue the relationship so he broke up with me" (Grace)

Love also has this to say in Fante:

> *"Hɔn a wonyim me ba no ne tsebea no ammpen dɛ wɔbɛbɛn no wɔ baguam nna hɔn a wɔtsetsebɛn hɛn no mma hɔn mba no kwan ma wɔnnye me babasia no nndzi agor osiandɛ sɛ wɔnye no dzi agor a, mbofra afofor nnye hɔn nndzi agor"*

> “People who knew about my daughters condition refused to be closer to her in public places and some of my neighbours do not allow their children to play with my daughter because when they do play with her, other children refuse to play with them" (Love)

Theresa also added some of the neighbours have stopped her daughter from playing with their children.

She remembered one neighbour said:

> “I didn't ask you to invite curse upon you when you became pregnant. I didn't ask you to take any drug when you were pregnant". That was when she realized that other than the assumptions that she had been cursed, people also assumed that, she caused her daughters condition by taking some sort of drug. (Theresa)

When participants were asked about how society treats them for having a child with autism, most of the participants revealed been stigmatized. Africans take priority in religion in anything they do hence religion gives meaning and importance to their lives. In Africa, religion is life and life is religion (Opoku, 1969, cited in Addai, Opoku-Agyeman & Ghartey, 2011, p. 993-997). As a matter of fact Ghana is noted for its religiousity with the three overwhelming religions namely, Christianity, Islam and African traditional religion (Golo & Yaro, 2013). Therefore, the results of the responses from the participants are not surprising that spirituality and cultural factors was attributed or linked to the cause of autism in Ghana. This was evident when participants shared that people labelled or called children with autism as Nsuba (a child from the river), Juju (ritual), and Bodamfo" (mentally ill).

Ironically, it can be observed that some parents worry over what people accuse them of being spiritually responsible for their child's condition, also same parents believe that their children's condition is caused by someone with supernatural powers. Hence they also responsible for the blame game by accusing others of being spiritually responsible for their children's condition. This was evident when Florence narrated that, she believes that someone else who has spiritual powers has possessed the child in order to make her grief in pain.

These confirms to the fact that the Ghanaian society still attribute the cause of a child with a disability as spiritual and also have the belief that someone's supernatural powers result in their child's condition. Superstitious beliefs still exist in the Ghanaian society. Theresa also reported that people attributed the cause of her child's condition to some drugs she took during pregnancy.

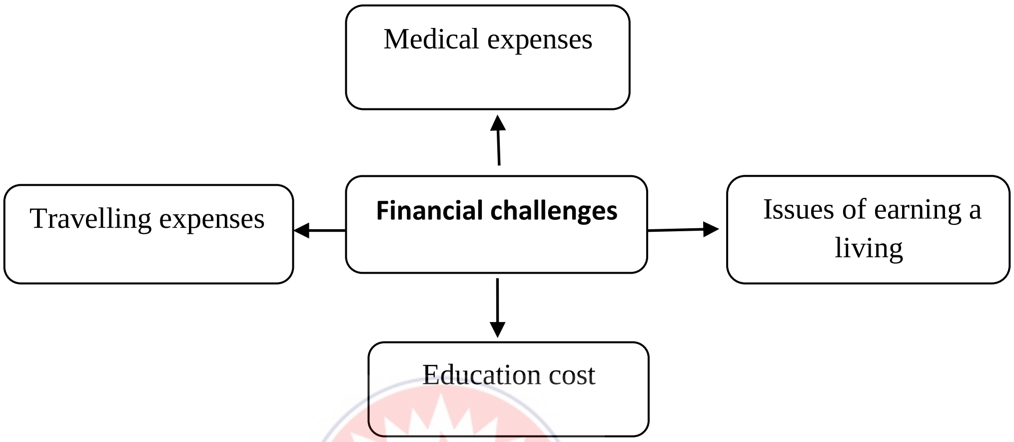
The research confirmed that parents of children with autism are avoided in the society and are not involved in activities or events (Amponteng, et al., 2018; Avoke, 2002; Kinnear, et al., 2015; Gona et al., 2016). Parents of children with autism are stigmatized and discriminated against because of their involvement with autistic children. However, when you look at the rest of the world, the Ghanaian society plays more emphasis on spiritual and superstitious beliefs. For example, Grace reported that her boyfriend who had proposed marriage to her broke off the relationship because he realized the child she is caring for had autism. In Diana's words, she confirmed that people who know her refuse to associate with them when they meet in public places and some neighbours prevented their children from playing with the child with autism. With the reason that other children refused to play with their children because of the children having autism. These experiences evidently show how parents with children with autism go through in the society and also how supernatural and superstitious beliefs have taken over the system even when modernization and education are taking over the world, but still same members of Ghanaian community rely on religious and spiritual beliefs.

4.4 Financial Challenges Parents of Children with Autism Face

The main theme on financial challenges which is situated at the centre of the Figure 3 describes the financial challenges of having a child with autism.

Figure 3

Theme Two: Financial Challenges Parents of Children with Autism Face



Under this main theme, four (4) sub-themes were identified: medical expenses, travelling expenses, education cost and issues of earning a living which were the experiences of the parents. All participants shared their sentiments that caring for a child with autism was draining their pocket and it's not something that is going to stop. It is lifelong financial strain. They were all of the view that raising a child with or without a disability is expensive. However, caring for a child with autism significantly added to their financial challenges. The following responses were obtained through the interview process.

4.4.1 Medical expenses

The participants were of the view that they spent most of their financial resources on drugs and intervention that they anticipate that situations would improve their children's condition or be healed completely. Participants shared that they have used large sums of money on spiritual interventions, herbal medicines, and drugs prescribed by health professionals. They added that upon all efforts made did not improve the child's condition or quality of life. Two participants shared their experience in English and two shared their experience in Fante language. The Fante responses from the participants were translated in English language.

A participant has this to say:

> “I’ve spent a lot on medications. I have to buy drugs to treat certain symptoms associated with autism. It is financially draining. I have bought a lot of drugs but none has been effective. How can I be spending so much on medications that I don't see the expected positive result" (Theresa)

Another participant indicated in Fante that:

> “Hmmm, I don't know what to say about this anymore, my child's condition has taken away all the money I've saved for uncertainties in the future. I've spent so much that I can't even calculate the money I've spent so far" (Felicia)

Participant shared her experience in Fante here:

> *"Me maame nkumaa kyerɛɛ me nhaban edur. Meenyi gyee ho na mehyɛɛ ase dɛ morotɔ na mereyɛ bi ama me ba no. Meyɛɛ no mber kakra naaso mennhu mpontu biara. Ebenadze ntsi na mɔbɔkaw wɔ adze a ɔmmfa nsusuando papa biara remmba! Meewie! Memmpɛ ebibidur biara biom"*

> “I was introduced to herbal medicines by my aunties. I got interested in it and started buying and preparing some for the child. I used it for sometime but did not see any improvement. How can I be spending so much on things that yield no positive result? I'm done!! No more herbal medicines" (Love)

Another participant shared her experience in Fante:

> *"Mehwee nkratow wɔ tv do a nna ɔreka sunsum mu mboa ma hɔn a wohia mboa no. M'enyi gyee dɛ metsee dɛm asɛm no ntsi mefaa hɔn number nna menye hɔn nyaa nkitahodze ekyir yi. Me pɛɛ mber a menye hɔn behyia. Mekɔseraa hɔn wɔ bea a wodzi dwuma mpɛn pii a nna morodwen dɛ menya beebi a bɔhyɛ wɔm. Hom maa metɔ ndzɛmba bebree bi tse dɛ nkyirefuwa, apɔnkye, tam fitaa. Ɔyɛɛ afrafra edur dze maa me dɛ memfa mma abofra no. Meyɛɛ dza wɔkaa no nyinara naaso sika a metua no wɔ me ba no ne tsebea no mu no annkosi hwee"*

> “I watched an advert on tv talking about spiritual help for persons with special needs. I was excited to hear that so I took their contact information and got in touched with them later. I booked an appointment with them. I visited the place on several occasions thinking I've found something promising. They made me buy a lot of things like eggs, goat and white cloth. Prepared some concoctions for me to be given to the child. I did all that they asked me but all the money I paid for my child's condition to improve proved futile"(Mary)

The study conducted revealed that parents had challenges with their finances when caring for a child with autism. The above revelation is in line with Depape and Lindsay (2014) who opined that just as parents around the world face financial challenges with regards to medical, travelling and accessing quality education for their children, they still have to be responsible for the well-being of their children. So are parents in Ghana are financially stressed up in caring for their children. Again, it was revealed that not only education and medical expenses that are draining them financially but seeking spiritual help also added up to their financial burden. Some participants risk seeking for spiritual help for their children because of the belief they have in spirituality and religion although their children's condition has been explained to them medically. This explains why even after diagnosis, parents still resort to spending so much on seeking spiritual intervention to improve their children's condition.

Again, the findings is in conformity with Sharp and Baker (2007) who stated that medical care for routine check-ups is expensive and the most challenging for parents the likelihood of financial challenges is related with the use of medical interventions, having unreimbursed medical or therapy expenses, and having relatively lower income.

Participants responses were in line with a statement said by Dobson, Middleton and Beardworth (2001) were they stated that having a child with special needs digs deeper into the pockets of parents.

4.4.2 Travelling expenses

Participants also shared the extra money they had to use for transportation. Making appointments with health professionals, spiritualist and herbalist required them to transport the children and themselves to the appointments. Participants added that they sometimes hire a car to transport them to their destination due to negative reactions from people in a public transport towards the child. One participant shared her experience in English and one shared her experience in Fante language. The Fante response from the participant was translated in English language.

A participant shared:

> “The money I spend on transportation alone is too much for me. I'm really tired. I have to hire a car to transport us to the place because when I take public transport, people look us in a way that I find uncomfortable and feel offended. I sometimes quarrel with some passengers to defend my child" (Theresa)

One participant shared her experience in Fante:

> *"Sika a medze yɛɛ car akatua nkotsee botum ayɛ adze a mfaso hɔ ho. Ɔtɔ dabi a ɔwɔ dɛ me dze me yafun to hɔ a mirinndzidzi dɛ ma ɔbɛyɛ a motum dze me ba no afa car dze no akɔ bea a wɔakyerɛ me no. Ɔnnyɛ akwantu a ɔda famu naaso ɔwɔdɛ medze me enyigye bɔ afɔr ma me ba no"*
>
> “The money I use on transportation alone can be used for something profitable. Sometimes I have to go hungry in order to transport my child to the appointments. It's not an easy journey but I have to sacrifice my happiness for that of my child" (Grace)

When participants were asked about their financial challenges, participants revealed that the cost of transportation added additional cost on their financial budget.

4.4.3 Give up work to care for the child (issues of earning a living)

Based on the demographic characteristics of the participants, 3 were unemployed but all expressed the desire to work and have an income for themselves. What they used to earn was nothing to write home about. However, it was better than nothing. The participants gave up on the search for jobs due to their child's condition. The decision to also combine the responsibilities of making a living and caring for their children were not an easy task. Participants shared their experience in Fante language. The Fante responses from the participants were translated in English language.

A participant has this to say in Fante:

> *"Nna menso meyɛ adzepan nyi naaso minnyi mu bio.Ɔnam me ba no ne tsebea no ntsi. Ne nhwɛe gye me mber nyinara ntsi minnya mber nnyɛ edwuma. Ɔyɛ brɛ.*
>
> "I was a seamstress but I am no longer in the business due to my child's condition. Caring for her takes away all the time so I don't get the time to work. It's very tiring" (Diana)

Another participant intimidated in Fante that:

> *"Dɛ mohwɛ abofra no do egyae me dɛ mepɛ sika dze ahwɛ mo ho. Nna motɔn dɔkon wɔ kwan ho. Menntum minngyae me ba no nkotsee wɔ fie ntsi ɔwɔ dɛ migyae adze tɔn na mohwɛ me ba no. Menntum memmfa no nhyɛ m'ekyir ɔnam m'edwuma no su ntsi, ɔwɔ dɛ metu enguan dze car ekyir tɔn adze. Ne mo yɛ dur"*
>
> "Caring for this child has stopped me from earning a living for myself. I used to sell kenkey at the road side. I can't leave my child alone at home so I had to stop selling and look after my child. I can't carry her at my back too due to the nature of the work, I have to run after cars to sell. She is heavy"(Love)

The view of another participant in Fante here:

> *"Nna motɔn nduadzewa wɔ aban eskuul. Migyaee adze tɔn ber a nna me ba ne nhwɛɛ no ho hia. M'ammpɛ adzetɔfo no binom nso suban. Ebinom gyae dɛ wɔrotɔ adze wɔ me nkyɛn aber a wohuu dɛ mewɔ ba a no ho atɔ kyima. Odurr mber bi no me nduadzewa sɛe osiandɛ nna wɔnntɔ. Aber biara mebɔ kaw"*

> “I used to sell fruits at one of the public schools. I stopped selling when caring for my child was demanding. I didn't also like the attitudes of some of the buyers. Some stopped buying from me when they noticed I had a child with special needs. At some point my fruits got rotten because they weren't buying. I was always making losses"(Grace)

The data presented and analyzed in this section indicates that the participants gave up on the search for jobs due to their child's condition in order to give proper care to their children at home. This finding is in conformity with Paterson (2011) who highlighted that most parents give up work to care for their children with a disability.

4.4.4 Education cost

Given the absent of sufficient and appropriate free education, many parents have turned to in enrolling their children in private schools. As a result of this, the cost of private education is costly as shared by some of the participants. Participants whose children attend government schools or charity schools expressed concern about the high cost of educating their children in a private school has become a barrier in accessing education in the private schools. Two participants shared their experience in English and one participant shared her experience in Fante language. The Fante response from the participant was translated in English language.

A participant shared:

> “Do you know how much I pay for the child's fees? It is outrageous. But I have no other option than to enrol him in the private school. The cost of my child's education alone is draining me financially “(Joseph)

The view of another participant in Fante here:

> *"Minyim ebusua bebree a wɔpɛ dɛ wɔdze hɔn mba kɔ ankorankor skuul naaso ɔnam ne bo no ntsi, hɔn mba no tse fie. M'abɔ mbɔdzen dɛ m'ama me ba no da ho ara kɔ ankorankor skuul. Ɔnnda famu"*

> "I know a lot of families who want to enrol their children in a private school but due to the high cost of tuition fees, their children are staying home" I have tried my best to still allow my child to enrol in a private school. It is not easy" (Florence)

Another participant intimidated that:

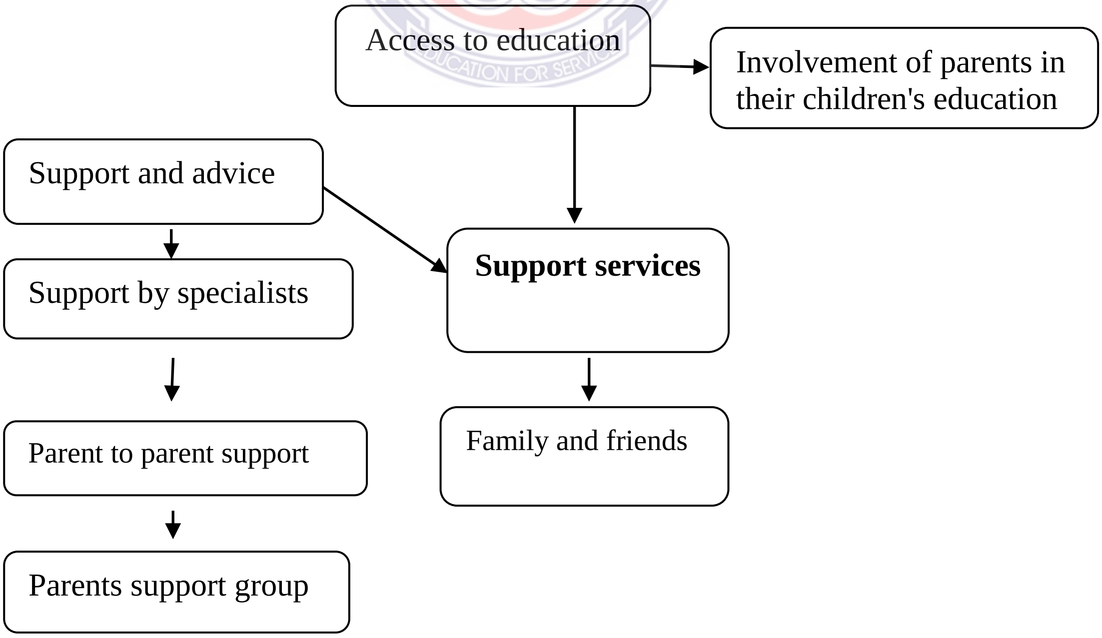
> “Why is the education of persons with special needs more expensive than that of persons without special needs? I don't understand why that should be!! I pay a lot for my child's education because I want the best of education for my child." (Felicia)

4.5 Support Services influenced the Overall well-being of Parents of Children with Autism

The main theme on support services which is situated at the centre of the Figure 4 describes the services parents who have children with autism receive.

Figure 4

Theme Three: Support Services influenced the Overall well-being of Parents of Children with Autism



Parents of children with autism reported of support services in the form of, support and advice from specialist, parents to parents support and parents support group. Under this main theme, five sub-themes were identified: support and advice from specialist, parent to parent support, access to education, family and friends and parents support group which were the experiences of the parents. The following responses were obtained through the interview process.

4.5.1 Access to education

Participants shared their experiences on accessing basic education for their children with autism. It was revealed that accessing basic education for their children was a challenge. It was deduced that accessing education for their children was easy when symptoms of autism weren't shown. However, everything changed when they showed signs of autism. It became difficult to keep them in schools, especially in the governments schools. Parents observed that, the private schools accepted them because of the school fees they pay while governments schools, where they paid little or no fees, recommended that they withdraw their children and sende them to special needs school. Furthermore, some participants reported that, there existed limited government special needs schools for autism in Aboom, Cape Coast. Also, there were few private schools for children with autism; where gaining admission for the wards was not a difficult task; however, the schools fees they had to pay discouraged them, because the fees were extremely expensive. Two participants shared their experience in Fante and one shared her experience in English language. The Fante responses from the participants were translated in English language. Participants shared their experience as follows:

A participant has this to say in Fante:

> "*Medze me ba banyinba no kɔɔr daadaa ankorankor skuul naaso mehuu no dɛ nna onntu mpɔn. Wɔdze no too skuul no mu ɔnam skuul fees. Minyaa atinka bi dɛ nna sika no a yetua no na wɔpɛ. Mehyɛɛ ase hwehwɛɛ ankorankor skuul a hɔn dwumadzi fa dɛm nkorɔfo no ho dɛ medze rema no. Minyaa bi naaso nna skuul fees no bo yɛ dzen. Awofo binom a nna wonntum ntua no yii hɔn mba no fri skuul no mu.*"
>
> "I sent my son to a regular private school but I realized he wasn't improving. They just kept him in the school because of the fees. I felt they were only interested in the money we were paying. I started searching for a private special school for him. I found one but it was so expensive. Some parents who couldn't afford the fees withdrew their children from the school" (Mary)

Another participant indicated in Fante that:

> "*Aber a me ba basia ne nhwehwɛɛmu kyerɛɛ dɛ ɔyɛ yarfo no, me bɔɔ mbɔdzen dɛ menya skuul mu kwan ama no. Na meyɛɛ no, nna ɔwɔ dɛ yɛtsena car mu donhwer eduanan ansaana yeedu skuul no mu. Ɔtɔ dabi a, minnya kaar nnkɔ skuul no mu. Mesɛe ndɔnhwer bebree wɔ kwando wɔ no nwomasua ho. Eyi nna ano yɛ dzen ntsi nna ɔwɔ dɛ mema ɔtsena fie mber kakra dɛ okosii dɛ onyaa skuul no bi wɔ beebia ɔbɛn hɛn.*"
>
> "When my daughter was diagnosed with autism, I struggled to gain admission for her and when I did, we had to be in a car for 40minutes to get to the school. Sometimes I don't get car to the school. I spend so many hours on the road for her education. This became unbearable so I had to make her stay at home for a while until she gained admission to a school closer by "(Florence)

The story was no different from Theresa, who revealed to have struggled to gain admission for her daughter.

> "I paid three times the fees I pay for my other children. It's not easy to pay the fees of one child and to talk of the fees of a special child. I pay so much on my child's education." (Theresa)

One mother also revealed that the government special schools weren't in good shape in terms of resources. She shared her experience in Fante:

> *"Mekɔɔ kɔseraa skuul no bi a nna wɔhwɛ hɔn a hɔn ho atɔ kyima, na me ho bɔw me. Mehuu ankorankor ahorowa nna wohia nhwɛdo soronko wɔ skuul dankor mu. M'enyiwa anngye ho. Ɔsor obiara dza otum yɛ na n'ahoɔdzen ntsi ebɛnadze ntsi na wɔwɔ skuul dankor mu. Ana worokɔ sua adze kor? "minntum nye me ba no nkɔ dɛm skuul no."*

> “I went to visit some special schools, I was surprised. I saw different types of persons with special needs in one class. I didn't like it. They have different abilities and strengths so why are they all in one class. Are they going to learn the same thing? I cannot enrol my child in that school" (Florence)

Eventually she didn't send her child to that school and therefore had no knowledge of what special school is and that the school in question is like in practice. She further complained that*:*

> "*Skuul no nnyi ntsetsee papa, ebɛnadze ntsi na wɔ skuul dan kor mu hɔn nyinara na hɔn sintɔ nko. Dɛm na me ba no ɔrokosua adze*"
>
> "The schools did not have a proper care system, how come they mix the children in one class? They have different disabilities. Is this how my child is going to learn" (Florence)

When participants for the study were asked to share their experience on accessing basic education for their children with autism, most of them reported that they found it difficult to access education for their children. Majority of them shared that they could neither get admission in the government special schools nor government mainstream schools. Participants revealed that the criteria these government institutions looked for in admitting their children with autism were unrealistic. Some participants whose children got the opportunity to enroll in the government intuitions also complained about the distance which they had to travel to get their children to school, and this became stressful for them, The situation eventually compelled them to give up on their children's education.

Again, parents also reported that access to private schools and special needs schools was easy but was very expensive, therefore money became a barrier in accessing private basic education for their children. It further created a massive financial burden on family finances which were stressful for them.

Education is a right and must be enjoyed by all. The United Nations Universal Declaration of Human Rights: article 26 states that everyone shall have the right to education and the convention on the right of persons with disabilities reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental human rights. In accordance with these, the 1992 constitution of the republic of Ghana article 24(1) stipulates that all persons shall have the rights to equal opportunities and facilities and with the view of achieving the full realization of that right, basic education shall be free, compulsory and available to all (Anthony, 2010). This study revealed that parents in Ghana find it difficult to gain access to basic education for their children with autism.

Although there are laws and policies enacted to make accessibility of education easy for persons with disability, parents of children with autism still struggle to gain admission for their children.

4.5.2 Involvement of parents in their children's education

There was a significant difference in terms of parents' interest in their children's education. Whenever the learning difficulty of the child is greater, the parents showed or expressed low interest in educating their child and equivalently higher interest when learning was easier for the child. One participant shared her experience in English and one participant shared his experience in Fante language. The Fante response from the participant was translated in English language.

A participant has this to say in Fante:

> "*Mepɛdɛ ɔbɔ ne bra dɛ mbrɛ a ɔbɔboa no. Memmpɛ dɛ me ba no bosua adze wɔ aber a onntum innya ntseasee ntsɛntsɛm. Mɛtsetsee me ba no sɛ me ma osua adze a. Dɛm no ye sen dɛ ɔbɛhaw n'adwen*"

> "I want him to live his life as much as possible. I do not want my child to learn since he can't grasp concepts easily. I will be disturbing my child if I allow him to learn. He's better this way than stressing his brain"(Diana)

Nevertheless, parents prioritize education and are keen for integration in mainstream schools if their child has no or minor learning difficulty.

A participant shared his sentiment:

> “My keen interest is for my son’s school to evolve him so that he can be like the normal people. He has to take advantage of the school, in every aspect and not behaviour training alone. He doesn't only need the behaviour training but be able to grasp concept and make meaning out of them"(Joseph)

The data presented and analyzed in this section indicates that parent showed less interest in their children's education and equivalently higher interest when learning was easier for the child.

4.5.3 Support and advice

Participants also shared they receive support and advice from specialist, parents-to parents support, and by parents support groups. All participants stated that each of these three strategies or ways of support services and advice is yielding a positive result and showing some positive significance in their lives.

4.5.4 Support and advice by specialists

Most of the participants mentioned the importance of the support and advice by specialists. They shared their feelings on doubtful things that many of their questions were not answered and they were still waiting for a response. Also, many participants, especially mothers, showed the desire to receive supports in the areas of emotional, psychological support from the specialist, unlike the fathers who showed less interest in the importance of these kinds of support. However, all fathers attested to the fact that mothers needed emotional and psychological support because of their sensitive nature. Five participants shared their experiences in Fante and three participants shared their experience in English. The Fante responses from the participants were translated into English. Participants shared their experience as follows:

A participant shared his experience in Fante:

> "*Menndwen dɛ mihia adwen mu mboa biaa. Me da Nyame ase dɛ meyɛ banyin. Dɛm mboa yi bɔboa mbasiafo osiandɛ wo yɛ mberɛw na afei wonnyi ahoɔdzen bebree a wɔdze begyina nsɔhwɛ mu. Menndwen nsɛmnsɛm bi ho dɛm na mbom medwen dɛ maamefo na wohia no kɛse*"
>
> "I don't think I need psychological help. Thank God I am a man. This kind of support will help the women because they are very fragile and are not strong enough to stand tragedies. I am not that sensitive to issues but I think mothers need it the most" (David)

Another participant laughed out loud and indicated that:

> “Hell no!! I am strong so this is not for me but I think is a laudable suggestion for my wife since she has been affected by our child's condition the most" (Joseph)

It was not that fathers did not buy into the idea or declined the idea of getting emotional and psychological support, because it was not important or beneficial to them; rather turning down the idea might be attributed to the stereotype that men are stronger creatures and, therefore, the rest of their families depend on.

Some participants stated that the advice they got from specialists sometimes made them feel relaxed. They felt that they had met someone who could understand them and knew exactly what they were going through.

A participant had this to say:

> “I feel at home whenever I visit the doctor at the hospital. I feel he knows and understands my pain. Not all doctors are friendly so I really appreciate his effort"(Benedicta)

A participant shared her experience in Fante:

> "*Onyi me kasa dɛ ma onyim mfe pii. M'enyi gye kwan a ɔma minya atinka no. Ɔtɔ dabi na mekɔsera no a memmpɛ dɛ mesan aba fie. Ɔhyɛ me nkuran dɛ mma memmpa aba. Ɔma me enyigye dɛ mehu dɛ obi rekyerɛ n'enyigye wɔ m'asɛm no ho*"
>
> "She talks to me as if she has known me for years. I like how she makes me feel. At times when I visit, I don't want to come back home. She inspires me to never give-up. It gives me joy to see someone show interest in my case" (Florence)

In some cases, culture played a role in the choice of specialist. They preferred specialists of their gender. Some participants, especially the mothers, explained that their partners would want to go with them to the appointment to see the specialist.

A participant asserted that:

> "I prefer to go with my wife to see the specialist. They do not know how to keep conversations short. She can spend the whole day at the hospital. She has to take care of other matters too"(Joseph)

Some mothers also talked about working with a female specialist because they believe that they will understand them better than the male specialists:

A participant shared her experience in Fante:

> *"Mepɛ basia ɔhwɛ nkorɔfo osiandɛ obenya mber ama me. Obetsie me akyɛn mbanyin a wɔ hwɛ nkorɔfo dɛm no motum maaka biribiara akyerɛ no*"
>
> "I prefer a female specialist because she will have time for me. She will listen to me more than the male specialist. I can open up to her"(Diana)

Another participant intimated that:

> “If I want to talk about things concerning me and my child then I need a woman. A woman will understand me better than a man. Women are sensitive to issues so if I get sensitive she will bear with me“(Theresa)

Some participants also stated that they would not mind if the specialist was a man or a *woman, although majority preferred a specialist of the same gender.*

Felicia has this to say:

> “It does not matter and having a woman or man specialist won't make any significant difference. What is important is he /she knows the work well that he can help with my child's condition. Understands my situation and that of my child is the most important thing" (Felicia)

Another participant asserted her experience in Fante:

> "*Menyi ɔhaw biara dɛ ɔyɛ banyin anaa basia. Ma ohia ara nye dɛ nyimpa no wɔ ntsetsee wɔ edwuma no ho dɛ nyimdzenyi, dɛ banyin anaa basia obotum ayɛ*"
> “I don't have a problem with having a man or woman. All that matters is the persons experience in the work as a specialist, whether he or she can deliver" (Grace)

The view of another participant in Fante here:

> "*Dɛm ber yi nnyɛ bera ɔwɔ dɛ mekyerɛ dɛ mepɛ banyin anaa basia. Mepɛ dɛ me ba no ne tsebea no yɛ yiɛ ntsi ɔmmfa meho. Dza mehia ara nye obi a ɔyɛ nyimdzenyi papa*"
>
> “This is not the time for me to be choosing over a man or a woman. I want my child's condition to improve so I don't really care about it. All I want is a good specialist" (Mary)

4.5.5 Parent support groups

During the interview, participants also talked about the importance of parent support groups. They involved themselves in these groups because they shared experiences of having a child with autism and general information about disability. . However, the motive of fathers joining these kinds of support groups is that they hoped that conditions of children with disability would improve. One participant shared his experience in English and one participant shared his experience in Fante. The Fante response from the participant was translated into English . Participants shared their experience as follows:

A participant shared his experience in Fante:

> "*Menndwen ho dɛ motum menye awofo binom edzi ehyia aber wɔafrɛ nhyiam. Minnyi dɛm mber no. Ɔwɔ dɛ medze me mber yɛ adze fofor. Sɛ minyim dɛ ɔyɛ adze a me ba no benya ho mfaso dza mɔkɔ naaso monkɔ nkɔtsena hɔ mbɔ nkɔmbɔ.*"
>
> “I don’t think I can meet with other parents anytime meeting is called. I don't have the time. I need to do other things with my time. If it's about something that I know my child would benefit then I would go but won't go and sit there for only chatting"(David)

Another participant intimidated that:

> “There should be orderliness in the meeting. Most meetings I attend are not properly arranged. They make us spend all our time in one meeting. It should be well organized" (Joseph)

It was evident that fathers placed more emphasis on organization and respect for time. Moreover, many of the mothers stated that they would prefer someone to track time and progress during the meeting. And mothers expressed great zeal and interest in support groups. Participants shared their experience in Fante as follows:

A participant asserted that:

> "*Minyim dɛ ɔyɛ adzesua kɛse dɛ mohu awofo binom wɔwɔ mbofra a hɔn ho atɔkyima. Obotum kwan kor ana ibi aboa esi wo nkitahodze wɔ afofor ho pi*"
>
> “I know is a great experience for me to meet other parents who have children with autism. It can one way or the other build your interpersonal relationship" (Mary)

Another participant intimated that:

> "*Dɛ mihyia maamefo a wɔwɔ mbofra a hɔn ho atɔkyima no aboa me pii. Wɔ dɛm nhiamu yi mu bi, mihyiaa maame a ɔyɛ nankotsee tse dɛ mara. Yɛbɔɔ mu dwendwen kwan a yebotum dze hɛn mba papa nom afa do*"
>
> “Meeting other mothers who have children with autism has helped me a lot. Through this meeting, I met a single mother like myself. We came together to deliberate on how we can deal with our child's fathers"(laughs)" (Grace)

The view of another participant:

> "*Ɔnam dɛm nhyiamu yi, metum egyina obiara a ɔtsetseem' ɔnam me ba no ne tsebea no ntsi. Minyaa akokodur wɔ dɛm mboa kuw yi mu. Mboa kuw maa me tum dze gyinaa obiara a ɔka nsɛm hunu fa meho nye me ba no ho*"
>
> "Through the meeting, I was able to face anyone who harasses me because of my child's condition. I became confident through this support group. The support group gave me the zeal to face anybody who talks trash about me and my child." (Florence)

It was also revealed that mothers had most interest in this kind of support than the fathers. One participant shared his experience in English and three participants shared their experience in Fante language. The Fante responses from the participants were translated in English language.

Participants shared their experience as follows:

A participant has this to say:

> "I don't think this is a good idea. How can a grownup like me be going about asking my fellow men for assistance? I can't ask my fellow man about the welfare of his child. It is someway" (Joseph)

The view of another participant in Fante:

> "Hɛn nyinara wɔ haw. Ebɛnadze ntsina na ɔwɔ dɛ mekyerɛ anaa *mekasa fa me haw no kyerɛ no na ɔnonso yɛ dɛmara. Nyansa biara nnyi mu mma me*"
>
> "We all have our problems. Why should I share or complain about my problems to him and he does the same? It does not make any sense to me" (David)

Perhaps, this could be as a result of the stereotype that men are strong; they don't show their weakness and do not need the help of a fellow man or father like him. This was evident in Joseph's narrative:

> "My pride and dignity did not allow me to seek help from my fellow man or father. I didn't think I would need the support but now I feel it is very important to have that kind of father-father support" (Joseph)

All fathers believed that mother-to-mother support would be good for their wives, but there was no need for fathers to meet with other fathers. Participants shared their experience in Fante as follows:

A participant has this to say:

> "*Me yer hia mboa fri ne nyɛnko basia hɔ osiandɛ mbaa ankasa tse hɔn hɔ ase yie. Menndwen dɛ mboa ofi egya nna egya ho hia. Maamefo hɔn gyinae wɔ etuhoakyɛ ma hɔn mba no so kyɛn hɔn papa*"

> "My wife needs the support from a fellow woman because women in general understand each other very well. I don't think support from father-father is important. Mothers level of commitment to the child is greater than that of the fathers" (David)

Participants also liked the idea of parent-parents support. A participant asserted that:

> "*Dɛm mboa yi ye ma awofo. Ɔboa hɛn ma yɛkyɛ hɛn adwen nna nsɛm wɔ hɛn ba hɔn tsebea mu. Ɔyɛ me enyigye dɛ megyee dɛm mboa yi tuu mu.*"

> "This kind of support is good for parents. It helped us share ideas and information on our child's condition. I'm happy I signed up for this kind of help" (Love)

The view of another participant in Fante:

> "*Minyim kwan a dɛm awofo nna awofo mboa yi aboa me. Aboa me ma m'atse me ba no ne tsebea ase yie. Minya atinka dɛ yɛ wɔ hɛnho hɛnho beebia a yebehyia. Iyi nye adze a yebotum ayɛ ama hɛnho hɛnho dze ahyɛ hɛnho hɛnho dzen ama yeetum egyina hɛn nsɔhwɛ ano*"

> "I know how this parent-parent support has helped me. It has helped me to understand my child's condition very well. I feel we have each other wherever we meet. This is the least thing we can do to strengthen each other to overcome our challenges"(Grace).

4.5.6 Support from family, friends and neighbours

Participants expressed mixed reactions about support they got from family, friends, and neighbours, and this contributed significantly to their psychological functioning. Participants reported of the limited they got from family, friends and neighbours. One participant shared her experience in English and three participants shared their experience in Fante language. The Fante responses from the participants were translated in English language. Participants shared their experience as follows:

A participant asserted in Fante that:

> "*Ebusua no mboa koraa. Sɛ wɔba bɛsera yɛn a, dza wɔka ara nye dɛ yenyim wɔ tsebea naaso hmmmm. Hɛn nso yɛ wɔ hɛn mba a ɔwɔ dɛ yɛhwɛ hɔn.*"
>
> "The family is not helping at all. When they come and visit all they say is they know my situation but hmmm...we also have our own children to take care of "(Grace)

Another participant intimated in Fante that:

> "*Minnya mboa wɔ obiara hɔ osiandɛ obiara dwen dɛ abrabɔ yɛ dzen wɔ beebiara ntsi obiara na ne dze Nyame yɛ hɛn nyinaa hɛn dze. Metwer Onyankopɔn kɛse nna me mba.*"
>
> "I don't get support from anyone because everybody thinks that, there's hardship everywhere so each one for himself God for us all. I rely on the Almighty God and my children" (David)

The view of another participant here:

> "My family thinks that I brought that upon myself so I should deal with it on my own. I wanted a child like that so I should find a way to deal with the challenges am facing"(Benedicta)

Although several participants shared they received very little support from family and friends, others were of grateful heart of the support they received even though they were little. This was evident in the statements below:

> "I married a good helping mate. My husband helps a lot in taking care of the child. He takes her to school, when he sees I feel tired or unwell. He plays with her. He is very supportive. My family and that of my husband's support me a lot. They have been helpful" (Benedicta)

Another participant intimated in Fante that:

> "*Minya mboa fi hɔn a yɛ nye hɔn tsetse no nso hɔ. Sɛ ɔwɔ dɛ mopuei kɔpɛ edziban ho ndzɛmba wɔ guamu a, hɔn a yɛ nye hɔn tse no fi hɔn*

> *pɛmu bisa me dɛ, wobotum aboa me. Wɔ hwɛ no dɛ kɔpem dɛ mefi guamu aba*."
>
> “I get some support from my neighbours too. When I have to step out to get some food stuff from the market, some neighbours voluntarily ask me if they could be of help. They look after her till I get back from the market" (Grace)

The view of another participant here:

> "*Me nyɛnko wɔ kotokoraba a ɔyɛ a mpɛn pii mefrɛ no sɛ m'abrɛ a.Wɔ asɔr nso, kyerɛkyerɛnyi a ɔkyerɛ mbofra adze no boa hɛn, boa me ba banyin no ma ɔhyɛ beebia ɔkyerɛ adze wɔ asɔr hɔ no na ɔbɔ no ho ban fi mbofra nkaa no ho a wobotum ayɛ no basabasa. Wɔ m'ebusuafo no dze ɔyɛ a wɔba nserahwɛ. Ɔtɔ dabi a, ɔwɔ dɛ mokɔ abowano a wɔbɔboa me*."
>
> “I have a friend in kotokroba whom I usually call when am stressed. At church too, the Sunday school teacher supports us, help my son to fit into her class at church and protects her from other children who might try to be rude to him. With my family it’s once in a while, in terms of visitation. Sometimes if I have to go out they come in to help" (Mary)

When participants were asked about the support they got from specialists, family, friends and neighbours, parents support groups, parent-parent support and from the community, most of the participants indicated that they got support from the list mentioned above. However some indicated that the supports they got were not enough. Many of the participants explained that the extended family system was being replaced by the nuclear family system where members are just concerned about their immediate family (Apt, 2012). In today's African family, the support from extended family is debilitating and it appears that the saying that "each for himself God for us all" is the order of the day; rather than the belief that “everybody is the brother's keeper.

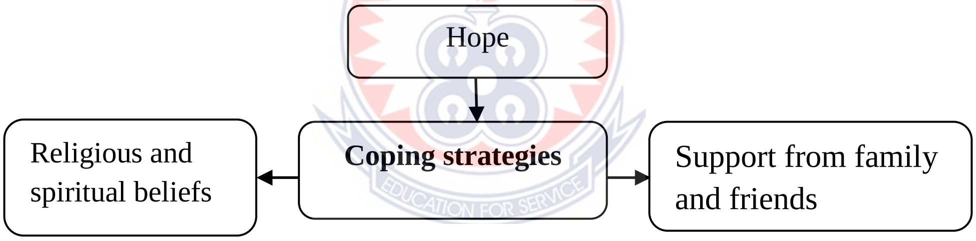
This finding is in line with Glazzard and Overall (2012); Thomas et al. (2015); Paynter et al. (2018); Stewart et al. (2017) who asserted that parents of children with disability in Ghana depend on their friends and family members for financial assistance because most of them could not afford the high cost of medical, education, professional and spiritual intervention that came with caring for their children with autism.

4.6 Coping strategies of Parents of Children with Autism use

The main theme on coping strategies, which is situated at the centre of Figure 5 describes the coping strategies of parents of children with autism.

Figure 5

Theme Four: Coping strategies of Parents of Children with Autism use



Under this main theme, three sub-themes were identified: namely, religious and spiritual beliefs, support from family and friends, and hope which were the experiences of the parents. Parents constantly reported of coping strategies in the form of religious beliefs, hope, and support from family and friends to overcome the challenges of raising a child with autism. Despite the numerous challenges parents who have children with autism face, they also reported a variety of coping strategies to deal with their problems. It became evident during the interview that parents had devised their own coping strategies. The following responses were obtained through the interview process.

4.6.1 Hope

Participants were hopeful of the future of the children and interestingly their hope hinged on their spirituality that God has a purpose for the child in their lives. Though participants in this study were very conscious of the limitations of their children, they also expressed hope in the midst of despair. One participant shared her experience in Fante and one shared her experience in English language. The Fante response from the participant was translated in English language. Participants shared their experience as follows:

A participant has this to say:

> "I know there is hope for the future for my child because since she started school she has really improved and am so thankful to God that we did not abandon her. My child is my responsibility regardless of the difficulties I face. She is my first child so I have to give her the best of everything so that she can be who I want her to be in future. She is my first love. I love her so much because she gives me hope to go on in life" (Benedicta)

A participant shared her experience in Fante:

> "*Mehyɛ awofo a wɔ wɔ dɛm tsebea dɛ mara yi mu nso dɛ mma wɔ mmpa aba wɔ hɔn mba no ho osiandɛ wonnyim dza hɔn mba no bɛyɛ daakye. Enyidado wɔ hɔ ma obiara*"
>
> “I encourage parents in a similar situation to never give up on their children because they do not know what will become of their children in future. There is hope for everyone" (Mary)

The findings from the study revealed that even though parents go through some challenges in caring for their children with autism, hope was identified as a coping strategy to overcome challenges. Although they expressed worry and sadness for their children condition, they were hopeful for a brighter future for themselves and that of their children. And parents expressed and explained their situations to a higher degree in terms of their spirituality.

4.6.2 Support from family and friends

Participants expressed mixed reactions about support they get from family, friends, community professionals and this contributed significantly to their psychological functioning. Some participants reported of the limited support they got from family and friends. Three participants shared their experience in Fante and one shared her experience into English. The Fante responses from the participants were translated into English. Participants shared their experience as follows:

A participant asserted in Fante that:

> "*Ebusua no mboa koraa. Sɛ wɔba bɛsera yɛn a, dza wɔka ara nye dɛ yenyim wɔ tsebea naaso, hmmmm. Hɛn nso yɛwɔ hɛn mba a ɔwɔ dɛ yɛ hwɛ hɔn*."
>
> "The family is not helping at all. When they come and visit all they say is they know my situation but hmmm...we also have our own children to take care of "(Grace)

Another participant intimated that:

> "*Minnya mboa wɔ obiara hɔ osiandɛ obiara dwen dɛ abrabɔ yɛ dzen wɔ beebiara ntsi obiara na ne dze Nyame yɛ hɛn nyinaa hɛn dze. Metwer Onyankopɔn kɛse nna me mba*."
>
> “I don't get support from anyone because everybody thinks that, there's hardship everywhere so each one for himself God for us all. I rely on the Almighty God and my children" (David)

The view of another participant worthwhile here:

> “My family thinks that I brought that upon myself so I should deal with it on my own. I wanted a child like that so I should find a way to deal with the challenges am facing"(Benedicta)

Although several participants shared they received very little support from family and friends, others were of grateful heart of the support they received even though they were little. This was evident in the statements below:

> “I married a good helping mate. My husband helps a lot in taking care of the child. He takes her to school, when he sees I feel tired or unwell. He plays with her. He is very supportive. My family and that of my husband's support me a lot. They have been helpful" (Benedicta)

Another participant intimated in Fante that:

> "*Minya mboa fi hɔn a yɛ nye hɔn tsetse no nso hɔ. Sɛ ɔwɔ dɛ mopuei kɔpɛ edziban ho ndzɛmba wɔ guamu a, hɔn a yɛ nye hɔn tse no fi hɔ pɛ mu bisa me dɛ, wobotum aboa me. Wɔ hwɛ no do kɔpem dɛ mefi guamu aba.*"
>
> “I get some support from my neighbours too. When I have to step out to get some food stuff from the market, some neighbours voluntarily ask me if they could be of help. They look after her till I get back from the market" (Grace)

The view of another participant in Fante:

> "*Me nyɛnko wɔ Kotokoraba a ɔyɛ a mpɛn pii mefrɛ no sɛ m'abrɛ a.Wɔ asɔr nso, kyerɛkyerɛnyi a ɔkyerɛ mboframba adze no boa hɛn, boa me ba banyin no ma ɔhyɛ beebia ɔkyerɛ adze wɔ asɔr hɔ no na ɔbɔ no ho ban fi mbofra nkaa no ho a wobotum ayɛ no basabasa. Wɔ m'ebusuafo no dze ɔyɛ a wɔba nserahwɛ. Ɔtɔ dabi a, ɔwɔ dɛ mokɔ abowano a wɔ bɔboa me.*"
>
> “I have a friend in Kotokroba whom I usually call when am stressed. At church too, the Sunday school teacher supports us, help my son to fit into her class at church and protects her from other children who might try to be rude to him. With my family it’s once in a while, in terms of visitation. Sometimes if I have to go out they come in to help" (Mary)

The findings from the study discovered that due to the limited support services parents of children with autism get, parents then depend on family and friends to help cope with the challenges they face in caring for a child with autism. Most of the participants relied on friends and family members for financial assistance because of the high financial demand in relation to education cost, medical, travelling expenses and spiritual intervention in caring for their children with autism. This finding is in line with Glazzard and Overall, 2012; Thomas et al., 2015; Paynter et al., 2018;

Stewart et al., 2017) who asserted that parents of children with disability in Ghana depend on their friends and family members for financial assistance because most of them could not afford the high cost of medical, education, professional and spiritual intervention that came with caring for their children with autism. This was evident when some participants shared. Joseph revealed that he spends so much on his child's school fees in the private school. Mary also added that searching for spiritual help for the child has drained her pocket.

4.6.3 Religious and spiritual beliefs

Participants described their conscious effort to apply the principles of their religion to solve their personal problems and minimize or accept the burden of caring for their child with autism. According to the participants, one way they could also think of coping with the situation was to stop thinking about it. Letting it be. In the real sense, this can be seen as a form of denial. A number of the participants personalized the burden of caring. For instance, five of the participants shared their experiences in Fante and two shared their experiences in English. The Fante responses from the participants were translated in English language. Participants shared their experience as follows:

A participant has this to say in Fante:

> "*Merefa abrabɔ dzendzen mu naaso osiandɛ meyɛ kristonyi memmpɛ dɛ mebrɛ mo ho dze me ho ahyehyɛ ndzɛmba bɔn a ɔrototo me sesiara. Ɔwɔ dɛ mekom mitsir mu na mefam'osiandɛ migye dzi dɛ akodzen nye saafee. Ɔwɔ dɛ me dwen kwan a motum ahwɛ me ba no.*"
>
> “I am going through a lot of hardships but because am a Christian, I don't want to stress myself in the bad things happening to me at the moment. I have to endure because I believe endurance is the key. I just have to let things go and concentrate on how I can care for her."(Love)

Another participant intimated in Fante that:

> "*Ɔyɛ a musu na mibisa Nyame siantsir dɛm ro to me. Mekakyerɛ Nyankopɔn dɛ ɔnkyerɛ mi kwan. Mobuei Kyirɛwsɛm na me kan. Mo werɛ fir me haw nyin*aa."
>
> "I do cry and ask God why this is happening to me. I tell God to show me a way. I open the bible and read. I forgot about them" (Florence)

The view of another participant worthwhile here:

> "*Ɔyɛɛ me dɛ mennom ewudur na memfa ne nyinara mbra ewiei. Naaso sesiara a me ho agye biribiara ɔfa me ba basia no ho, minnya atinka dɛ mbrɛ a nna ɔtse no bio. Mehuu Nyankopɔn no a ɔdze ma na ɔno nye ayarsa panyin nso. Memma nkorɔfo hɔn adwenkyerɛ nhaw me. Aber biara ɔwɔ me tsir mu dɛ Ewuradze bɛsa no yar. Nna ɔhaw me naaso ɔnnye dɛm bio.*"
>
> "I felt like drinking poison to end it all. But now that I am used to everything about my daughter, I do not feel like the way I used to again. I have realized that it is God who gives and he is the master healer as well. I do not let people's opinion bother me. I always have it at the back of my mind that the lord will heal her. I used to worry a lot but not anymore." (Diana)

Another participant has this to say in Fante:

> "Mekan kyirewsɛm dze hyɛ me gyedze mu dzen wɔ Ewurdze mu. Miggye dzi dɛ sɛ idzi mbuada na ebɔ'mpaedu a ɔbɛyɛ no ntsɛm ara"
>
> "I read the bible to strengthen my faith in the lord. I believe if you fast and pray he will answer you quickly" (Mary)

Some participants also used their past experience as a coping strategy to overcome the challenges they face.

A participant asserted that:

> "I feel bad but I am someone who does not get discouraged easily. I tell myself Gods plan is the best and he makes everything beautiful in his time. I believe in his time"(Theresa)

Another participant has this to say in Fante:

> "*Nyame ayɛ nokwarfo ama me na mebusaufo na megye dzi dɛ ɔbɛsan ayɛ no bio. Ɔbɛba wɔ dɛm tsebea yi mu nso.*"

> “God has been so faithful to me and my family so I believe that he will make it happen again. He will intervene in this situation too."(Grace)

The view of another participant worthwhile here:

> “I leave things in the hands of the Almighty God. He is my pillar of strength. It is written in Philippians 4:6; Becareful for nothing: but in everything by prayer and supplication with thanksgiving let your requests be made known unto God."(Benedicta)

Another participant shared her experience in Fante:

> "*Ɔwɔ botae ma hɛn abrabɔ, wɔaye bi da. Minyim dɛ Nyame onyim dza oye. Wɔ Nyame mu no, biribiara ye. Biribiara nyi wɔ a Nyankopɔn nntum nnyɛ mma ne mba. Ɔdɔ hɛn na ɔmma yɛmmbrɛ.*"

> “He has a purpose for our lives, he has done it before. I know God knows best. With God everything is possible. There's nothing God cannot do for his children. He loves us and he won't let us suffer."(Love)

During this study, it was revealed that parents who have children with autism devised means or ways to cope with their children's condition just like parents in the rest of the world who have children with autism. Therefore, they generated different strategies to cope and manage their children's condition. These include seeking religious and spiritual help, family and friends and hope for a brighter future.

In Kenya, parents of children with autism sought for spiritual and religious help as a coping strategy on their children's condition (Gona, et al., 2016). Given that religious and spiritual belief systems play a role in the treatments of children with autism in the Ghanaian society (Anthony, 2011). It was believed that parents coped using religious and spiritual systems. It was deduced from the study that, in the Ghanaian society, illness has both physical and spiritual forms (Okyerefo & Fiaveh, 2017). This type of coping strategy gave the main idea of the cause of their children's condition and gave them hope that the future will be brighter for their children. Some participants shared that God gave them a child with autism for a reason.

CHAPTER FIVE

SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter deals with the summary, conclusions and recommendations for further studies based on the findings from the study.

5.2 Summary

The study explored the lived experiences of parents of children with autism in Cape Coast in the Central Region of Ghana. Based on this, the study specifically sought to find out: the emotional problems on parents of children with autism, explore the financial challenges of parents of children with autism, examine the support services on parents of children with autism and find out the extent to which parents cope with the birth of a child with autism. The research conducted adopted a qualitative approach that employed phenomenological as a design in order to find answers to the research questions. The population of interest was parents of children with autism. Data were collected using semi-structured interview guide from a sample of ten (10) parents. Interviews were conducted in individuals' homes. The data was analysed thematically using the principles of interpretive phenomenological analysis (IPA) which basically deals with examining how people make sense of their experiences (Smith & Osborn, 2003). The main themes and sub-themes were identified and discussed and the findings were observed:

5.2.1 Emotional problems

The findings of the study revealed that parents of children with autism experience stigma, sadness, marital stress, and financial difficulties in caring for their children. Additionally, parents experience stigma because of the belief that spirituality is the cause of their children's condition and are stigmatized due to their association to children with autism. Religion and spiritual belief played a role in the lives of parents who have autism because participants believed that the cause of their child's condition was a test of their faith in God.

5.2.2 Financial challenges

The study was evident that parents of children with autism experience financial challenges, thus resorted to family and friends for support. However, the support they get from family and friends were not enough. The study revealed that despite the financial drain of raising a child with autism brings about, parents showed interest in continuing to look for solutions to their child's condition even when they have resorted to some which were not effective. It was also revealed that parents will continue to look for appropriate schooling options regardless of the cost of tuition for their children. These show how concerned the participants are of their children.

5.2.3 Support services

Also, the findings of the study was evident that despite the existence of numerous policies and laws like the Convention on the Right of Persons with Disabilities, the United Nations Universal Declaration of Human Rights just to mention a few, accessibility of basic education to all regardless of type of disability, parents reported finding it difficult to access basic education for their children. Even when getting access to private institutions was easy, money became a barrier to access good education for their children. More so, the study revealed that parents had support from specialist, parent-parents support, and parent support groups. The study revealed that parents relied on friends and family members for advice and financial assistance because of the high financial demands in relation to education cost, medical, travelling expenses and spiritual intervention in caring for their children with autism.

5.2.4 Coping strategies

Additionally, it was revealed that despite the challenges of parents of children with autism face, parents invented methods to cope with the challenges they face. Such coping methods or strategies are by seeking support from family and friends, seeking religious and spiritual support, and the hope that things will get better in future.

5.3 Conclusion

Based on the findings, the study concluded on that parents experience greater stress and sadness in caring for a child with autism. Their increased responsibility in caring for their children resulted in their spouses and other family members blaming them for the cause of the child's disability.

Increased time in caring for a child with autism made spouses fell neglected and this caused marital conflicts because of the little or less time they spend with their partners at the same time , this negatively affect parenting for other siblings in the family.

Parents of children with autism were faced with superstitious beliefs and stigmatized for associating themselves with a child with autism.

Caring for a child with autism increases financial demands and this study saw a connection between disability and poverty, especially mothers are unable to go out and earn a living because they have to stay home and care for them. The expense of medical care, travelling (appointment to see a specialist) and cost of education deepened the financial burden on parents.

Parents face challenges in accessing education for their children. Mainstream schools are unwilling to accommodate them because of their highly concentrated demands in educating children with autism. Private schools who are willing to accommodate them charge huge sums of money for tuition which adds to their existing financial burden.

The researcher wishes to conclude that government and non-governmental organizations should try as much as possible to maintain the support groups like parent-parents support, parent support groups in order to share with each other vital information on issues relating to their children's condition and to be an avenue to rely on each other for help and assistance.

5.4 Recommendations

The following recommendations are made based on the findings of the study:

a. The Government should recognize the need to ensure emotional support for parents by creating support networks and linking parents to counselling and psychological therapies and increase social intervention programmes.
b. Government funding must be available and sufficient to parents in order to cover the expenses associated with the provision of medical treatment and day to day activities of raising their children.
c. The Social Welfare Department and other disability organizations should create parents support groups across the country and at the local levels to help parents engage better and learn from each other. Also, create more awareness on the need to form support groups on autism although this has been started but on a small scale.
d. Continuous in-depth public education, and sensitization of societies knowledge on disability to help tackle stigma. Currently, stigma preventions

are cantered on western information systems, and fall flat to address innate understanding of autism.

e. Educational policy makers and implementation of educational policies should periodically have a circular table talk on the policies and its implementations to find out how best to bridge the gap between the policies enacted and its implementation process. Action is required after policies are been enacted.

f. Parents who have children with autism should encourage other parents who have children with disabilities on their coping strategies they employed in getting over their challenges.and increase social intervention.

5.5 Suggestion for Future Research

Experiences of having a child with autism should be extended to siblings and extended families.

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APPENDICES

APPENDIX A

Letter of Introduction

UNIVERSITY OF EDUCATION, WINNEBA
FACULTY OF EDUCATIONAL STUDIES
DEPARTMENT OF SPECIAL EDUCATION
✉ P.O. Box 25, Winneba, Ghana
sped@uew.edu.gh
☎ +233 (020) 2041069

17th December, 2020

TO WHOM IT MAY CONCERN

Dear Sir,

LETTER OF INTRODUCTION: MS. LETICIA DELINSKY OTABIL

I write to introduce to you, **Ms. Leticia Delinsky Otabil** an M.Phil. student of the Department of Special Education with index number 8180150014.

She is currently working on his thesis on the topic: "**Experiences of Parents who have Children with Autism in some selected Homes in Cape Coast, Central Region of Ghana**". She needs to interview parents.

I would be grateful if you could give her the needed assistance to enable her collect the data.

Thank you for the consideration and assistance.

Yours faithfully,

UNIVERSITY OF EDUCATION, WINNEBA
DEPARTMENT OF SPECIAL EDUCATION
UEW

MRS. JOYCE O. M. TSATSU
for: (Ag. Head of Department)

www.uew.edu.gh

APPENDIX B

Semi-Structured Interview Guide

UNIVERSITY OF EDUCATION, WINNEBA
FACULTY OF EDUCATIONAL STUDIES
DEPARTMENT OF SPECIAL EDUCATION

Semi-structured interview guide for parents of children with autism in Aboom in Cape Coast, Central Region of Ghana.

Research question 1: What emotional problems do parents of children with autism experience?

1. What are the most prevalent feelings you have experienced raising your child?

   Probes: grief, stress, sadness, stigma, disappointment and anxiety

2. How would you describe a child with autism and what feelings come to your mind when autism is mentioned?
3. Do you think about your child's future? What are your major concerns? Are you hopeful about a bright future for your child?

Research question 2: What financial challenges do parents of children with autism face?

1. Are you working? If no, how do you care for your child?

Probes: Medical expenses, cost of education, specialist appointment and travelling expenses

Research question 3: How do support services influence the overall well-being of parents of children with autism?

1. How do you feel about resources and supports available to parents?

Probes: community support, family and friends and health professionals.

2. Is your child currently schooling?

Probes: If no why? If yes, is the school mainstream or special need? Private or government?

3. Tell me about your experiences when seeking education for your child.

Is the school nearby or far from your home?

4. Has there been any significant changes in your child since he or she started schooling?

Probe: if yes, what are they?

5. What kind of services are available to your child and your family?

Research Question 4: What coping strategies do parents of children with autism use?

1. How do you cope with your child's condition? Are the strategies you use been helpful?

Additional questions

1. Who first mentioned autism to you?
2. Does having a child with autism affect you as a parent?
3. Has the disorder influenced your attitude towards raising the child?
4. How has raising a child with autism influenced your personal growth?
5. What are some of the challenges you've faced?
6. Describe your day to day activities at home after your child was diagnosed

with autism. Are there any significant differences from how it was before the diagnosis?

7. What are your experiences about the social perceptions of your child with autism?
8. Was your first impulse to seek for medical or spiritual help?

The participants were asked if they want to share any other information which weren't captured on the interview guide.