

**SCHOOL OF NURSING AND MIDWIFERY
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA**



**PARENTS' PERSPECTIVES ON THE QUALITY OF LIFE
OF ADOLESCENTS LIVING WITH AUTISM SPECTRUM
DISORDER: A STUDY IN THE ACCRA METROPOLIS**

BY

**KHADIJA ATCHULO
10754084**

**THIS THESIS IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON IN
PARTIAL FULFILLMENT OF THE REQUIREMENT
FOR THE AWARD OF MASTER OF PHILOSOPHY
DEGREE IN NURSING.**

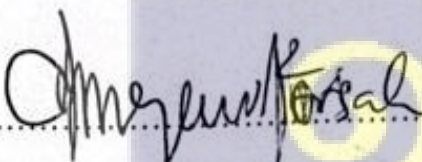
MARCH, 2022

DECLARATION


I, Khadija Atchulo hereby declare that this thesis is the product of my original work, except for cited articles which were duly referenced. This study was undertaken under the direction and tutelage of Dr. Kwadwo Ameyaw Korsah and Madam Patricia Avadu, both at the School of Nursing and Midwifery, University of Ghana. This work has never been submitted to any other institution by anyone for any award.

Signature:  Date: 24/01/2023

Khadija Atchulo
(10754084)

Signature:  Date: 24-01-23

Dr. Kwadwo Ameyaw Korsah
(Principal Supervisor)

Signature:  Date: 24-01-23

Madam Patricia Avadu
(Co Supervisor)



DEDICATION

I dedicate this work to God Almighty for guiding me through this journey and to my late mother Madam Amamata Mahama



ACKNOWLEDGEMENT

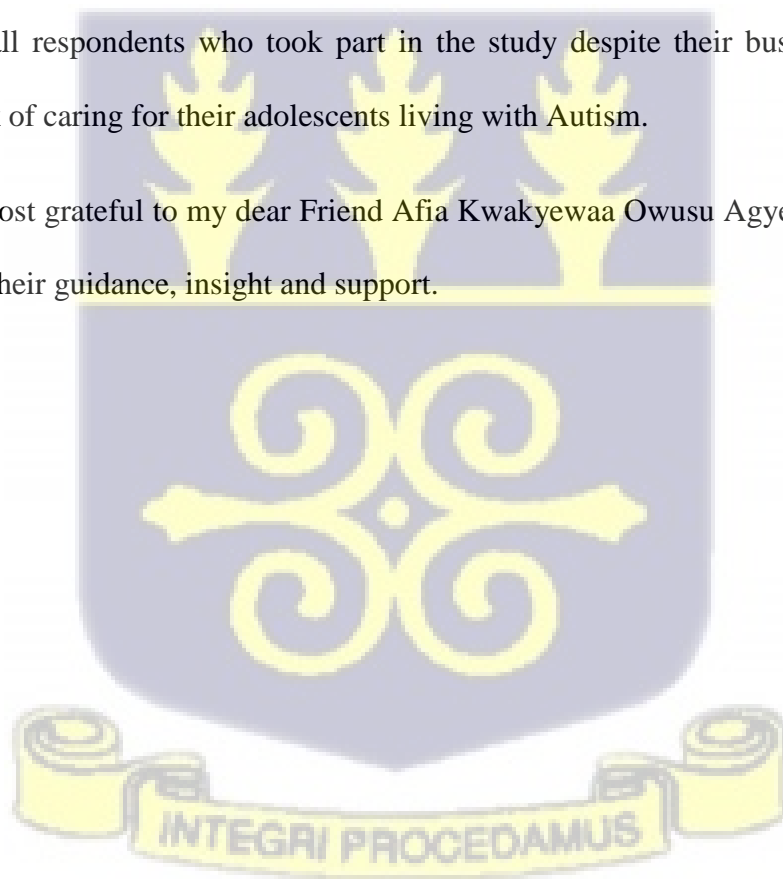
My deepest appreciation to my principal supervisor Dr. Kwadwo Ameyaw Korsah, without his tutelage this thesis would not be possible. Thanks to Madam Patricia Avadu for her dedication and commitment as an outstanding co-supervisor. My Profound gratitude to Mr Atchulo Abdulai my father and Iddi Emelia for their financial support and encouragement.

My sincerest gratitude to my dear Husband Mr. Abdul Wahab Atchulo, My children Tasneem, Ziyad and Kaysan for their unflinching support.

I would like to express my gratitude to all lecturers of school of Nursing and Midwifery, University of Ghana for this opportunity

Also, I thank all respondents who took part in the study despite their busy schedules and demanding task of caring for their adolescents living with Autism.

Finally, I am most grateful to my dear Friend Afia Kwakyewaa Owusu Agyemang and to my colleagues for their guidance, insight and support.



ABSTRACT

Autism Spectrum Disorder remains one of the growing public health conditions that have devastating effects on the wellbeing and quality of life of adolescents. Using the quality of life model by Betty Ferrel propounded in 1996 as an organizing framework, this study investigates the parents' perspectives on the quality of life of adolescents living with autism. The objectives which are based on the constructs of the model were investigated including the physical wellbeing, social wellbeing, psychological wellbeing and spiritual wellbeing. The study was an exploratory descriptive study involving 13 participants in the Accra metropolis. With the consent of the participants, data was collected using a semi structured interview guide. The responses were recorded, transcribed, coded and subsequently into subthemes and themes. A thematic content analysis revealed (5) themes and (17) subthemes. According to this study findings, adolescents with autism were found to have low quality of physical wellbeing. They were not physically independent, suffered other conditions as result of autism and could not perform basic life functions without assistance. They had a good social wellbeing evident by their cordial relationship with their peers and relatives at the same time they had poor oral communication. Adolescents with autism were found to have reduced psychological wellbeing. They are moody, irritated, isolated at times, interactive and sometimes aggressive. Furthermore, adolescents with autism had improved spiritual wellbeing and could engage in religious activities. Also, there were no support systems thus recreational centers, job opportunities and educational support. Muslim respondents were not available for this study due to their cultural beliefs, children with Autism in the Muslim community were taken to the villages and left there. This gap should be researched in the future. In conclusion, the public should be sensitized and educated on Autism spectrum disorder and government as well as non- governmental organizations should provide training and educational support for autistic adolescents.

TABLE OF CONTENTS

DECLARATION	i
DEDICATION	ii
ACKNOWLEDGEMENT	iii
ABSTRACT	iv
TABLE OF CONTENT	v
LIST OF TABLES	viii
LIST OF FIGURES	ix
CHAPTER ONE	1
INTRODUCTION	1
1.1 Background to the Study	1
1.2 Problem Statement	5
1.3 Purpose of the Study	6
1.4 Research Objectives	7
1.5 Research Questions	7
1.6 Significance of the Study	7
1.7 Operational Definitions	8
CHAPTER TWO	10
LITERATURE REVIEW	10
2.0 Introduction	10
2.1 Intellectual Disability	10
2.2 Autism Spectrum Disorder	13
2.3 Challenges of Children and Adolescents with ASD	15
2.4 Assessing Quality of Life in Adolescents with ASD	16
2.5 Justification of Model Used	18
2.5.1 Description of the Theoretical Model Employed for this Study	19
2.5.2 Physical well-being	20
2.5.3 Psychological well-being	20
2.5.4 Social well-being	21
2.5.5 Spiritual well-being	21
2.6 Related Empirical Evidence	22

2.6.1 The Physical Well-Being of Adolescents With Autism	22
2.6.2 Psychological Wellbeing of Adolescents with Autism.....	23
2.6.3 Social Wellbeing of Adolescents with Autism	24
2.6.4 Spiritual Wellbeing of Adolescents with Autism	27
CHAPTER THREE	30
METHODS	30
3.0 Introduction.....	30
3.1 Philosophical Underpinning of the Study	30
3.1.1 Ontology	30
3.1.2 Epistemology	30
3.1.3 Axiology	31
3.2 Research Design.....	31
3.3 Study Setting.....	31
3.4 Target Population.....	31
3.5 Inclusion Criteria	32
3.6 Exclusion Criteria	32
3.7 Sample Size and Sampling Technique.....	32
3.8 Data Gathering Tool and Procedure	33
3.9 Piloting of Study	33
3.10 Data Analysis	34
3.11 Rigour	34
3.12 Ethical Consideration.....	35
CHAPTER FOUR.....	36
PRESENTATION OF FINDINGS.....	36
4.0 Introduction.....	36
4.1 Demographic Characteristics of Participants.....	36
4.2 Quality of Life of Adolescents Living with Autism	37
4.3 Physical Wellbeing of the Adolescent with Autism	38
4.3.1 Physical Independence.....	39
4.3.2 Physical Deformity	40
4.3.3 Medical Fitness	40

4.4 Social Wellbeing of the Adolescent with Autism.....	41
4.4.1 Socialization/Loneliness	41
4.4.2 Change in Lifestyle	42
4.4.3 Impaired Communication	43
4.5 Psychological Wellbeing of the Adolescent with Autism	44
4.5.1 Depression.....	44
4.5.2 Financial Burden.....	45
4.5.3 Sleep Patterns.....	46
4.6 Spiritual Wellbeing of the Adolescent with Autism.....	47
4.6.1 Religious Engagement	47
4.6.2 Undertaking Spiritual Activities	48
4.7 Support Systems Available to the Adolescents with Autism.....	49
4.7.1 Job Opportunities.....	49
4.7.2 Medical Interventions	50
4.7.3 Community Engagement and Information.....	50
CHAPTER FIVE	54
DISCUSSION OF FINDINGS	54
5.0 Introduction.....	54
5.1 Evaluation of the Model Used for this Study.....	62
CHAPTER SIX.....	65
SUMMARY, CONCLUSION, IMPLICATIONS, LIMITATIONS AND RECOMMENDATIONS	65
6.0 Introduction.....	65
6.1 Summary	65
6.2 Conclusion	66
6.3 Implications of the study.....	67
6.4 Limitations	68
6.5 Recommendations based on the findings.....	69
REFERENCES	70
INTERVIEW GUIDE.....	87

LIST OF TABLES

Table 4.1: Demographic Characteristics of Participants.....38
Table 4.2: Themes and Sub-themes from Transcribed Data.....37



LIST OF FIGURES

Figure 1: The Quality of Life Model 19



CHAPTER ONE

INTRODUCTION

1.1 Background to the Study

Adolescence with autism spectrum disorder (ASD) are faced with challenges that affects their social communication and interaction (Oti-Boadi et al., 2020). Autism spectrum disorder remains one of the growing public health conditions that have devastating effects on the wellbeing and quality of life of adolescents. This condition has no cure, and the child is expected to live with it all their life. The autism spectrum disorder, according to the Diagnostic and Statistical Manual of Mental Disorders -5 (DSM-5), which is one of the most commonly used tools for psychiatric diagnosis is “persistent deficits in social communication and social interaction across multiple contexts” (American Psychiatric Association, 2013). It is classified as a ‘spectrum disorder’ due to the different combinations and severity of symptoms exhibited among such individuals. The autism spectrum disorders include impairments in social interaction and communication and behaviours, interest, and activities that are repetitive and restrictive. Dodd and Harrison (2009) intimate that children or adolescents with autism often have challenges with comprehension, hence would not be able to easily understand some simple issues and adhere to instructions. They also may have challenges in respect of adjusting to societal changes, prone to self-isolation and confinement as a result of an inability to interact within their social environment. The child with autism spectrum disorder cannot play with their peers, they are not able to follow age-appropriate instructions and they also suffer a delay in growth milestones. Aside from having communication impairments, Mazurek, Kanne and Wodka (2013) indicate autistic individuals exhibit aggressive behaviours with others mostly behaving in a very reckless manner. Twi-Yeboah (2019) also notes unresolved influences and acting in unmannered or unacceptable ways as behavioural traits of individuals living with autism. Common

behavioural traits of ASD in Africa include extremely delayed speech, intellectual disability and late identification (Ruparelia et al., 2016).

The cause of the disorder has been a subject of an investigation by researchers. However, scientific evidence suggests that environmental and genetic factors could predispose a child to the condition. The disorder is mostly diagnosed in the first five (5) years of the child's life because of the signs and symptoms exhibited such as delay of speech, uneven cognitive abilities, inability to play with peers, and often detached from the world.

Globally, autism spectrum disorder has become a growing public health concern that affects the quality of life of affected children and adolescents. The autism spectrum disorder occurs in almost all regions, races and ethnicities across the world (WHO, 2013). It is estimated from epidemiological data that the global prevalence of autism spectrum disorder is one person in 160, accounting for more than 7.6 million disability-adjusted life years and 0.3% of the global burden of disease (WHO, 2013). A recent study further estimates that for every 59 live births, one is diagnosed with autism worldwide, with the prevalence of autism being on a constant rise over the last decade, from 2- 5/10,000 to 1:59 children; 1 in 37 boys and 1 in 151 girls (Vetri & Roccella, 2020). Also, research suggests that the prevalence rate of ASD in the United States of America with data from 11 sites is 1:54 in 8-year-old children. The global prevalence of autism is clearly gaining attention in the literature. Though the WHO has indicated the disorder occurs in all regions across the world, irrespective of race and ethnicity, prevalence data on the prevalence rate of the disease in Africa continue to be missing (Twi-Yeboah (2019). The Center for Disease Control and Prevention (CDC), as cited in Abubakar, Ssewanyana and Newton (2016) for instance is concerned about the paucity of empirical evidence on ASD in Ghana, as well as other sub-Saharan African countries. That notwithstanding, there have been a number of reports to corroborate the assertion of the WHO that ASD is gaining predominance in Africa (Denkyirah&Agbeke,

2010; Ruparelia et al., 2016; Abubakar et al., 2016). These reports have not only enumerated the behaviour traits of ASD but pointed out the quality of life for these individuals.

Quality of life has been viewed from different perspectives within the literature. It may be viewed as the influence of a disability or disease on individual functioning (de Maeyer et al., 2011), and how the family system is affected by diseases (Balcells-Balcella et al., 2019), or the absence of pathology (Cummins et al., 2004). However, the concept is mostly viewed as multidimensional which explores the 'state of personal wellbeing...with universal characteristics and others that are culture-dependent (Suarez, 2020; p. 5). The domains of quality of life are generally understood to be emotional well-being, material well-being, physical well-being, social inclusion and rights, self-determination, personal development and interpersonal relationships (Schalock, Verdugo & Gomez, 2011). Ferrell et al. (1996) earlier identified four main domains of quality of life: which are physical wellbeing, psychological well-being social well-being and spiritual well-being. In the study of intellectual disability specifically, the evaluation of the quality of life remains paramount. The model is essential for social change and developing a paradigm of service provision and assessment in the healthcare environment (Schalock et al., 2016; Schalock & Keith, 2016; Suárez, 2020).

The physical wellbeing of every adolescent plays a significant role in their proper growth and development. However, the evidence available indicates that autistic children have a poor quality of physical life as parents fear that children could be hurt during physical activity and therefore restrict and overprotect them to ensure their safety (Merriman et al., 2020). The impact of ASD on the physical wellbeing of children and adolescents with the disorder has also been in relation to their health status. Individuals with ASD have been reported to have suffered from epilepsy, a mental disorder (Dillenburger et al., 2016). Most of

the psychiatric health conditions with ASD include anxiety, depression, attention deficit, hyperactivity, and disruptive, among others (American Psychiatric Association, 2013).

In addition, studies over the period indicate several social challenges adolescents with autism face every day in their lives. In some of these instances, the adolescents living with autism stay indoors for fear of people knowing of their condition and distancing themselves from them and their families. Even sometimes parents of such affected individuals deliberately put them away from their friends for fear they may not be able to communicate effectively with their colleagues which affects their social life (van Ewijk et al., 2020).

In Africa, studies report that there is a major gap in information and knowledge about autism spectrum disorder in the medical fraternity and the general population. It further indicates that there is a paucity of data on the prevalence of the disease condition and the quality of life of the affected children in the African region (Bakare, Ebigbo & Ubochi, 2012; Pamela, Badoe & Owusu, 2015). There is therefore a need for more studies in Africa to determine the magnitude of the problem of ASD and the quality of life of children affected by ASD in the region to help in policy planning on issues of childhood developmental disorders (Abubakar, Ssewanyana & Newton, 2016).

Moreover, it is reported that in some parts of the African region, children with autism spectrum disorder and their parents are discriminated against and stigmatized against. These have been attributed to cultural and spiritual beliefs around developmental disabilities and the belief that Autism is not a medical condition. It is often perceived as a punishment from the gods to the parents or a curse for a wrongful act leading to the poor psychological and spiritual well-being of autistic children (Manu, 2012; Ruparelia et al., 2016).

In Ghana, studies show that data on autism spectrum disorder (ASD) and the quality of life of affected children is limited. However, the available data estimates that 38.7% of

children under the age of 14 years live with the disorder (Ruparelia et al., 2016). Furthermore, in Ghana, primary caregivers of autistic children who are usually the parents are shunned and ostracized by society and the children who have the condition are stigmatized. These affect negatively the social and psychological well-being and the quality of life of autistic children and their families (Oti-Boadi, Dankyi, Kwakye-Nuako, & Disorders, 2020). This leads to children with ASD feeling rejected and being of less worth to society. For their parents and relatives, the ostracization by society makes it impossible for them to be fully integrated into society and have normal interaction in their community. As shared by (Ruparelia et al., 2016) and Twi-Yeboah (2019), there is a general perception in most African communities in terms of ASD having spiritual connotations. Most people would hence not want to associate themselves through interaction, with children or adolescents with ASD and their families.

Again, a study in Ghana on challenges parents with autistic children face from the perspectives of parents, found the struggle to have meaningful conversations with their children and living with the pain of experiencing financial challenges in their daily activities with their autistic children as some of the challenges (Agyekum, 2018). The parents and their autistic children also face stigmatization from the general public especially when the autistic children are sent to public gatherings leading to a poor-quality life of the children socially and psychologically (Agyekum, 2018). The Ghanaian community does not openly embrace nor welcome autistic children and adolescents. Their relatives are also shunned and not welcomed into the midst of others.

1.2 Problem Statement

Adolescence comes with changes that bring about challenges and special needs. These challenges are much different and severe for adolescents with autism. It is a very difficult period in the lives of autistic adolescents as well as their parents. Adolescents with ASD

usually experience difficulties in establishing or maintaining peer relationships, participating in social and recreational activities, and often report having few friendships (Ruparelia et al., 2016; Oti-Boadi et al., 2020; van Ewijk et al., 2020).

Also, there are limited social facilities and training centres for adolescents with autism in Ghana to assist them deal with the developmental challenges associated with adolescence. The few Training Centres in existence are struggling to survive due to a lack of support from government and non-governmental organizations. Well-established training centres are also expensive with parents being unable to afford their tuition fees. This situation has serious implications on the quality of life of adolescents with autism in Ghana.

Despite the challenges of adolescents with an autism spectrum disorder in Ghana, coupled with limited support for their daily lives, few studies have been conducted on the phenomenon. These studies have largely focused on childhood autism, speech and language therapy and modification of learning environments for children with an autism spectrum disorder. This approach has led to a dearth of data on the quality of life of adolescents with an autism spectrum disorder in Ghana (Agyekum, 2018; Twi-Yeboah, 2019).

This research, therefore, seeks to fill this evidence gap by exploring the physical, psychological, social and spiritual wellbeing of adolescents with autism, and the support systems available to them to live productive lives.

1.3 Purpose of the Study

The purpose of this study was to assess the quality of life of adolescents living with autism in Greater Accra Metropolis.

1.4 Research Objectives

The research objectives are to:

1. Explore the physical wellbeing of the adolescent with autism
2. Investigate the social wellbeing of the adolescent with autism
3. Identify the psychological wellbeing of the adolescent with autism
4. Examine the spiritual wellbeing of the adolescent with autism
5. Explore the support systems available to adolescents with autism?

1.5 Research Questions

1. What is the physical wellbeing of adolescents with autism?
2. What is the social wellbeing of adolescents with autism?
3. What is the psychological well-being of adolescents with autism?
4. What is the spiritual well-being of adolescents with autism?
5. What support systems are available to adolescents with autism?

1.6 Significance of the Study

The findings of the study would inform government, non-governmental organizations, and the general public on the importance of establishing affordable but comfortable training centres for adolescence with autism to improve the quality of their lives as well as that of their parents. The result of the study would highlight the need for government to take practical steps and institute appropriate measures which would support adolescents with ASD and their families live a better life.

The findings of this study would increase knowledge on adolescent autism, and give an insight into their quality of life. It would also enhance the education of parents of adolescents with autism to give better care to their children and serve as a resource material for health specialists dealing with adolescents with autism. Public health practitioners would rely on the findings of this study to identify effective strategies, various support systems and educational content to improve the total integration of autistic individuals into the Ghanaian society. As a resource material, this study would inform health managers and practitioners in designing appropriate frameworks to support the development and growth of individuals with ASD. Documenting the quality of life of adolescents with ASD would generally improve healthcare practice.

This study would also serve as useful material and literature for future researchers interested in studying autism disease and other developmental disorders in children and adolescents in Ghana. The recommendations made in the study would provide a clear direction for future researches to increase knowledge on developmental disorders and the quality of life among adolescents and children with ASD. More so, this study would become a reference material for academicians in the field of health and medical care.

1.7 Operational Definitions

Autism: A developmental disorder that impairs the ability to communicate and interact.

Parents/participants: Primary caregivers of adolescents with autism.

Adolescents: children between the ages of 10 and 19 living with Autism Spectrum Disorder

Wellbeing: The physical, social, spiritual, and psychological health status of the adolescent with autism

Spiritual wellbeing: The ability to worship and perform one's religious obligations normally

Physical wellbeing: The ability to function well physically

Psychological wellbeing: The ability to function well emotionally.

Social wellbeing: The ability to interact with peers, parents, and society as a whole.

Quality of life: The standard of health, comfort, and happiness of adolescents with autism



CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter centers on relevant literature in support of the phenomenon being studied. It offers a succinct and clear argument in support of the rationale stated for the study. The review equally brings to light evidence and knowledge available in the aspect of developmental disorders. Information pertaining to ASD and the quality of life of adolescents with ASD have been carefully synthesized in this chapter. To ensure a coherent presentation of information, the chapter is divided into two parts. The first part focuses on the concepts relating to the study. In addition, justification of the model employed for this study is presented. This includes the physical wellbeing, social wellbeing, psychological wellbeing and spiritual wellbeing. The search for information was done using the following databases: PubMed, CINAHL, African Index Medicus (AIM), Google Scholar, HINARI and Medline. The review was done by querying these databases using the MeSH headings: "autism among adolescents "Autism spectrum disorder", "Autism", "Autism and adolescents", "intellectual disability". The review focused largely on theoretical models to guide the study and studies that have been done about autism in line with the objectives of the study.

2.1 Intellectual Disability

The concept of intellectual disability has been defined as limitations exhibited in the functioning of an individual's intellectual capacity (Schalock, 2017; Schalock et al. 2019). Furthermore, Schalock et al. (2019) include in the definition of intellectual disability the limitations in adapting to behaviours which are expressed cognitively and to develop the ability to engage in practical and social skills prior to the age of eight. The term is also defined by the Department of Health (United Kingdom) (2001) as "a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence),

with; A reduced ability to cope independently (impaired social functioning); which started before adulthood with a lasting effect on development” (p. 14). The various definitions and attempts to describe intellectual disability do not differ on any significant terms. The definitions underscore the fact that the state of functioning characterized by reduced ability to undertake an activity or skill based largely on cognition could best be described as intellectual disability. Though the definition for the concept have considerably changed over the decades, Shree and Shukla (2016) intimate that the widely accepted definition for the concept remains that of the American Association on Intellectual Developmental Disabilities (AAIDD). The association defines the concept as “significantly sub average general intellectual functioning existing concurrently with deficit in adaptive behaviour and manifested during the developmental period that adversely affects a child’s educational performance. The AAIDD cautions that the term intellectual disability should not be used synonymously with mental retardation, as some authors may do. This caution is given on the premise that the use of the term intellectual disability, as opposed to mental retardation is not only less offensive and consistent with terminology used globally, but reflects the significant change of the construct of disability within the framework of the WHO and AAIDD (Shree & Shukla, 2016).

The application of the concept is applied based on a proposed five assumptions suggested by Luckasson et al. (2002). First of the assumption is that there must be consideration given to the limitations in the cognitive function of the individual based on their context of environment. The context of their community must be typical of their age, culture and peers. Secondly, the assessment or application of the term must also take into careful consideration the linguistic and cultural diversity of the individual. The differences that may be present in the functioning of an individual must consider the variations in sensory and motor abilities, communication differences and other behavioural factors (Shree &

Shukla, 2016). The strengths of an individual which may present limitations in motor and cognitive functioning is another assumption which also needs to be considered in the application of the concept. Luckasson et al. (2002) further assumes that the application of the concept of intellectual disability must also see the description of the limitations as a means to profile a support system. The concept must in other words be applied as a measure to develop effective support systems as the limitations are being described (Shree & Shukla, 2016). Lastly, the application of the concept of intellectual disability is to be applied within the framework of developing a supportive mechanism which could generally enhance or improve the life functioning of the individual identified to have reduced functionality.

Individuals with intellectual disability are presented with some characteristics which however differ from person to person. Literature has however outlined some general characteristics or manifestations of people with intellectual disability. Happé & Frith (2020) posits that though people with intellectual disability differ significantly, they generally have delayed cognitive development. Such individuals exhibit delayed or slowed learning pace. The general cognition and ability to learn or obtain information is generally considered to be slow among individuals with intellectual disability, than their counterparts without intellectual disability (Happé & Frith, 2020).

There is also significant below average rate in the rate of learning and memory capacity for individuals with intellectual disability. Thurm et al., (2019) claim that individuals with intellectual disability mostly develop their set of learning rather at a slow rate and cannot relate nor apply information to novel situations. Such individuals exhibit challenges with information retention and would not be able to select appropriate learning sets and strategies. More so, they cannot appropriately use memory strategies in learning situations (Happé & Frith, 2020). This also results in challenges with maintaining focus on

stimuli and may often attend to wrong things in real life or in a learning situation (Thurm et al., 2019).

Attention deficit is another manifestation or characteristic of intellectual disability. (Buchnat et al. (2020) claims that the inability of individuals with intellectual disability to focus on a stimulus results in their inability to attend to a task for a specific time. They cannot control external influences which are distractions. They cannot hence decipher between relevant issues and situations both in their learning environment and social situations. In the learning environment for instance, the adolescent with intellectual disability would not be able to pay attention to a lesson nor be able to filter information and determine salient learning points (Buchnat et al., 2020).

Other significant characteristics or manifestations of intellectual disability include difficulty in the application of adaptive skills (Happé & Frith, 2020), poor self-regulation or organisational ability (Beck et al., 2020), delayed speech and poor language comprehension (Wynn et al., 2018), low self- motivation, poor academic achievement (Buchnat et al., 2020) and impaired physical abilities in using their visual senses, auditory, motor and orthopaedic abilities (Shree & Shukla, 2016).

2.2 Autism Spectrum Disorder

Autism spectrum disorder have been categorized or classified as an intellectual disability or a mental health disorder. Prior to the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) by the American Psychiatric Association (APA) in 1980, autism was only considered as a form of schizophrenia, because it was addressed as a psychosis (APA, 2000). Others also referred to it as pervasive developmental disorder (Wing & Gould, 1979). However, the APA (2013) broadly categorized all the subtypes of pervasive developmental disorder into what it called autism spectrum disorder. However, Balmana and

Calvo (2014) indicate that the APA excludes Rett's syndrome in its classification of autism spectrum disorder because, Rett's syndrome is genetically-based hence, not included in the clinical category of autism spectrum disorder. In describing autism spectrum disorder, the new classification reduces the disease to a dyad, which is characterised by deficiency in communication and interaction with one's social environment and repetitive or restrictive interests and behaviours (WHO, 2018; APA, 2013). Adopting this new classification, Eapen et al. (2014) describe autism spectrum disorder as “ a life- long neurodevelopmental mental disorder characterised by impairments in social interaction, verbal and nonverbal communication, and a restricted repertoire of activities and interests” (p.1). The classification further includes sensorial disturbances including hypo-reactivity and hyper-reactivity such as being hypersensitive to pain and hyperacusis (APA, 2013). Dunn et al. (2019) counter popular belief that individual with autism spectrum disorder show intellectual disability. They make the assertion that some individuals with autism spectrum disorder may not necessarily present with intellectual disability. The ICD-11 clearly captures individuals without disorder of intellectual development in its classification of autism spectrum disorder (WHO, 2018).

To further describe autism spectrum disorder, the WHO (2018) intimate that the disorder is usually characterized with persistent deficits which are obviously excessive, or atypical for a person's environment and age. This is to say that a person may exhibit certain deficit in a particular behaviour which is obviously excessive, unusual and irregular considering the sociocultural and age of the individual. The persistence of the deficits could be present in the inability of the individual to maintain reciprocal interaction with the social environment through communication, repetitive and restricted patterns in behaviours, activities and interest (Arias et al., 2018). Though the disorder may occur during the developmental period, its symptoms usually manifest later in the life of the individual. The deficits which manifest in symptoms are only realised when social demands begin to exceed

the individual's capacity. It is only when the individual is not able to meet their social demands due to their limited capacities and abilities that the existence of the disorder is observed. The severity of the deficit impairs functioning in respect of occupational, social, educational, family and other critical aspect of an individual's life where they are required to fill an expected function (Chou et al., 2017).

2.3 Challenges of Children and Adolescents with ASD

The presence of autism spectrum disorder distorts the normal cognitive functioning of adolescents and children. Classified as an intellectual disability, autism spectrum disorder presents various malfunctions in children or adolescents diagnosed with the disease (See, 2012). Literature carried out around the world and among different individuals show evidence of challenges faced by people with the disease. It is however not surprising that such individuals have been reported to have faced a number of challenges in their daily lives. These challenges, according to Green et al. (2004) are as a result of the negative impact of the disease on the basic functional ability of individuals with the disease. Though the challenges vary from children to children, their general performance in basic life functions remain abysmal and poor. In Green et al's (2004) estimation for instance, children with autism have poor academic achievements compared to their counterparts without the disease. This challenge observed among such category of children could for instance be as a result of how underdeveloped their cognition ability is. Children with autism mostly have challenges maintaining their focus and attention on tasks. They also have challenges with memory retention. These challenges become a barrier to their successful performance in respect of academic activities. Such children hence become under achievers in respect of academic work. In relation to academic challenges, Liu et al. (2016) laments the nature of education and formal training most children with autism are offered. They indicate that most countries around the world do not integrate children with autism into mainstream schools. This makes

such children feel segregated, further proving their low worth in the society. There remains lack of national policies and educational programmes to fully integrate children with autism into mainstream education, or to even offer them some form of quality education and training to support them function fully.

In another breadth, Tonkin et al. (2014) report that children with autism spectrum disorder have challenges making friends. These friends have been reported to have found it challenging easily socialising in their environment by interacting with their peers. These children normally have fewer friends and the only friends they mostly have are those with similar condition. Lai et al. (2011) had reported in their study that children with autism spectrum disorder have either no friends or just a handful of playing mates. Children or other adolescents were found not to be willing nor in the position to keep social contact or interaction with individuals with autism spectrum disorder. Shamsudin and Rahman (2014) intimate that autism, like any other mental disorder is often stigmatized. Autistic children are mostly considered strange and slow due to their condition. Such perception held among people influences their attitude and behaviour towards autistic children (Arif et al., 2013), explaining the inability of autistic children to make friends or have play mates. Papadopulous (2016) also explains that children with autism spectrum disorder are not able to make friends for the fear of being bullied. These children see themselves being helpless. They see themselves as not being fit and hence, have low self-image (Buchnat et al., 2020). They are marginalized within their society. In schools, these children become victims of abuse and episodes of bully, which makes them not opening up to engage with other peers.

2.4 Assessing Quality of Life in Adolescents with ASD

WHO (1995) explains quality of life as “a measure of ‘an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (p.1405). The concept has been

widely defined to mean a multidimensional concept which reflects how individuals perceive themselves in respect of their living conditions, health, wellbeing, social life, education, play and leisure (UNICEF, 1989; Felce & Perry, 1995). As a multidimensional concept, the framework encompasses both non-health and health related domains of functioning. The quality of life model proposes eight core domains: emotional wellbeing, personal development, material wellbeing, self-determination, social inclusion, interpersonal relations, rights and physical wellbeing (Schalock et al., 2008). The model offers a potential tool and a useful index to fully comprehend and understand the difficulties and challenges faced with individuals with some kind of diseases or complications. Among children with autism spectrum disorder, the quality of life model is a useful index in understanding fully the behaviour of such children and also become a component used to adjust to the needs and challenges of these individuals (Burgess & Gutstein, 2007; Gerber et al., 2008; Cappe et al., 2011).

There is expanding and growing inquiry into measuring the quality of life of children and adolescents with autism. Several scales and models have particularly been used to measure the quality of life of children and adolescents with autism. The WHOQoL-BREF scale have been widely applied to studies of quality of life of autistic children, as evident in the literature (Hong et al., 2016; Bishop-Fitzpatrick et al., 2017; Lin, 2014; Moss et al., 2017). Though this scale has been proven to produce comparable results across countries, it cannot be self-administered among those with intellectual disability. Other scales applied in studies of QoL include INICO-FEAPS scale (Gomez et al., 2015; Schalock & Verdugo, 2002), Quality of Life Questionnaire (QoLQ) (Gal et al., 2015; Katz et al., 2015; Garcia-Villamizar et al., 2013), Quality of Life Inventory (QoLI) (Hesselmark et al., 2014), Comparative Quality of Life Questionnaire (ComQoL) (Saldana et al., 2009), SF-36 (RAND-36) (Geurts, 2015), Medical Outcomes Study Short-Form health Survey Version 2 (SF-12 v.2)

(Khanna et al., 2014), Novel Quality of Life Measures (QoL1, QoL2) (Billstedt et al., 2011) and Quality Improvement Model and the Quality of Life Model (Ferrell et al., 1996).

2.5 Justification of Model Used

In reviewing the literature on a theoretical model for this study, several models, including Perry's Theory of Stress (Perry, 1988), the Quality Improvement Model and the Quality of Life Model (Ferrell et al., 1996) were chanced upon. The Quality of Life Model was chosen because it takes into account the various important variables including the physical wellbeing, social, psychological, spiritual wellbeing and the total quality of life of autistic adolescents. The theory for this study is the Quality of Life Model. The Quality of Life Model was initially developed to measure the domains of quality of life in long term cancer survivors to appreciate their specific concerns. This model has four main domains which are physical wellbeing, psychological wellbeing, social wellbeing and spiritual wellbeing.

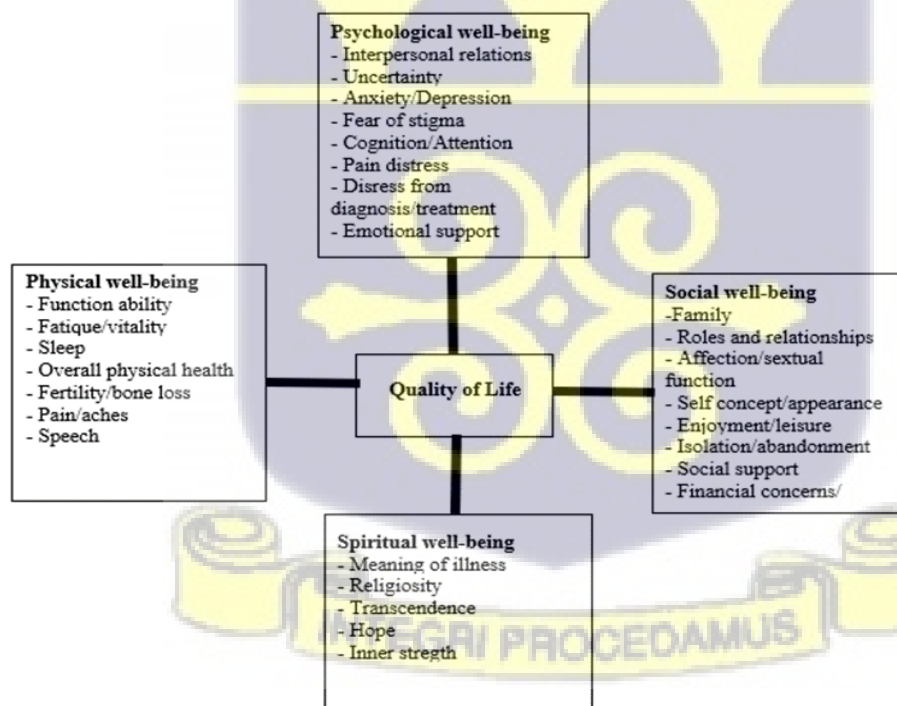


Figure 1: The Quality of Life Model

2.5.1 Description of the Theoretical Model Employed for this Study

The World Health Organization defines the quality of life as an individual's perception of their position in life in the context of their culture and value systems in which they live and about their goals, expectations, standards and concern. In the view of Suárez (2020), the concept has not been unifiably defined due to the various perspectives from which it has been taken. He however defines it as “a state of personal wellbeing that is multidimensional, has some universal characteristics and others that are culture-dependent, has objective and subjective components and is influenced by individual and environmental factors” (Suárez, 2020; p. 15). Ashing-Giwa et al. (2004) describes it as a multidimensional concept that assesses physical, functional, psychological/emotional, and social wellbeing in relation to health. Therefore, for the patient to have a complete quality of life, all variables must be positive and balanced. On the other hand, negative effect of any of the independent variable thus affects negatively the quality of life of the patient.

Prior to its usage in multidisciplinary areas, the concept only emerged in discussions related to ‘happiness’ and ‘wellbeing’ (Schalock et al., 2007). It was not until recent times that the concept has had subjective notions with notions to include individual and subjective characteristics (Gomez et al., 2010). The emergence of the term was applied to emphasize the quality in an outcome or a product. This was in relation to the quality and wellbeing of individuals regard to be at risk of social exclusion. As a tool for social change, the concept quality of life is multidimensional. In the view of Schalock and Keith (2016), the concept determines the domains for measuring quality outcomes. In recent practice, the concept has not only offered a philosophical perspective of a social construct such as developmental and intellectual disorders, but has offered a paradigm development for assessment and service provision (Claes et al., 2010; Schalock et al., 2018).

According to the Quality of Life model, the quality of life of an individual can be explained with four domains or parameters (Ferrel et al., 1996): physical wellbeing, psychological wellbeing, social wellbeing and spiritual wellbeing. The domains are considered as perceptions and conditions, as well as behaviours that indicate an individual's wellbeing (Schalock & Verdugo, 2002). Each domain or parameter has indicators. Gomez et al. (2016b) point out the indicators are essential for improving results. However, they caution that organizational, professional, culture and individual factors may vary and affect the usefulness of these indicators.

2.5.2 Physical well-being

This refers to the control or relief of symptoms and the ability to have physical independence and be capable of doing all the basic functions of life as a person. It is related to the general feeling of having good health, being in great shape and having good eating habits (Gomez et al. (2012b). This is reflected in having good sleep, good and constant eating patterns, improved physical health and general health status. The physical wellbeing of individuals is affected by challenges including functional ability, fatigue or vitality, sleep, overall physical health, fertility or bone loss, pain or aches, swellings of any part of the body and weight loss.

2.5.3 Psychological well-being

This is related to the ability to sustain a sense of control in the face of life against illness characterized by altered life priorities, emotional distress, and fear of the unknown as well as a positive life change. Described as emotional wellbeing, Gomez et al. (2012b) define it as the feeling of calmness, being safe, not nervous and the general feeling of being relaxed. This is reflected by one's satisfaction with life, having good self-image, being stable and exhibiting positive mental health. The psychological challenges are made up of the elements such as interpersonal factors, uncertainty, anxiety or depression, fear of reoccurrence,

cognition or attention, pain distress, distress from diagnosis treatment and emotional support. These are the individual elements that define psychological wellbeing of individuals.

2.5.4 Social well-being

Social wellbeing refers to adjusted life by the impact of illness on individuals, their roles and relationships and how good they can deal with those factors. In terms of social inclusion, Gomez et al. (2012b) points as social wellbeing as having the ability or opportunity to go to places and participate in community activities. This provides a sense of feeling integrated and having the total support of others. Relatedly, social wellbeing may include the sense of being considered equal to others and hence, receiving equal treatment and respect for one's opinions and desires. Relation with others, being able to have and keep friends and appropriately get along with others also reflects social wellbeing (Suárez, 2020). ASD and its management alter social roles and limit social activities of patients. The social wellbeing challenges consist of family, role relationships, affection and sexual function, self-concept and appearance, enjoyment or leisure, isolation or abandonment, social support and financial concerns or employment.

2.5.5 Spiritual well-being

Spiritual wellbeing depends on how good or well an individual is able to control uncertainty that is created by the hope and derive from illness experience. According to Liu (2016), spirituality is a person's inner resource used to cope with stressors. Involvement in spiritual or religious activities enhances ability to overcome fears. Spiritual well-being are faith-base and existential coping component including cultivating meaning of illness, religiosity, transcendence, hope and inner strength. Spirituality is a valuable management resource.

2.6 Related Empirical Evidence

Under this section thus the empirical review is simply talking about the various researches done by other researchers concerning my topic or peoples research works that are similar to my research work. In this section works done by other researchers in line with the topic will be reviewed.

2.6.1 The Physical Well-Being of Adolescents with Autism

Empirical studies conducted in the area of autism among adolescents have identified physical factors which affect their wellbeing. The most-reported factors affecting physical wellbeing included time spent engaging in sedentary activities at home (i.e., playing video games, watching television), feeling tired, feeling bored with physical activity. Therefore, social support in these areas may be a critical aspect to consider in promoting their physical wellbeing. (Garrido et al., 2020).

Adolescents with ASD have been reported to have lower health-related scores. Such adolescents have had poor physical and health status (Kuhlthau et al., 2013). These adolescents have been reported to have sleep disorders as well as gastrointestinal imbalances (Mazurek&Petroski, 2015). Due to their developmental challenges and underdevelopment of their cognitive abilities, these adolescents have higher incidence of sleep disorders. Their curtailed eating patterns have also resulted in gastrointestinal disorders. More so, adolescents with ASD have had lower health since they are not able to verbalize their conditions and health concerns. Their communicative deficiencies remain a barrier in accessing healthcare services (Broder-Fingert et al., 2016; Demer, 2018). Havercam et al. (2016) also indicate the lack of training for healthcare professionals to support autistic adolescents is a barrier to the physical wellbeing of adolescents with ASD.

In a systematic review carried out by Merriman et al. (2020) to assess how parents consider the physical wellbeing of their children with autism, the findings showed that

parents feared that children could be hurt during physical activity and so had to overprotect them to ensure their safety. Sometimes parents of such affected individuals deliberately put them away from their friends for fear they may not be able to communicate effectively with their colleagues which also affects their quality of life (van Ewijk et al., 2020).

A similar study on the quality of life of autistic children in China reported that the overall quality of life of the children was lower than normal children, particularly in areas such as physical functioning, social and mental health (Zhen-Huan, Qiao-Ling, Zhang-Yong, Xiao-Zhen, 2016).

2.6.2 Psychological Wellbeing of Adolescents with Autism

The risks to psychological well-being for children with autism spectrum disorders are well-documented. Children with autism often have elevated levels of depression. The daily mood of children with autism also is more negative than children without disabilities (Sonido et al., 2020). Social support has long been recognized as an important component in the stress process and a predictor of the psychological well-being of the individuals and the quality of life of these individuals (Tricia, Owusu, Tyrone, & McKay, 2015).

Depression in adolescents with autism can include isolation and interpersonal struggles, which may be present in adolescents with autism, and there is always a concern about suicidality in adolescents with depression (Bent et al., 2020). Individuals with autism and depression may experience an increase in obsessions and rituals or, by contrast, a complete loss of interest in former preoccupations. Agitation, stereotypical behaviours, and self-injury may increase with depression among adolescents with autism (Merriman et al., 2020).

From observation, this is the leading cost for parents especially those engaged in taking and caring for adolescents with autism. Sometimes, psychologically, parents resort to spiritual interventions contemplating the amount they would have to pay for medical bills.

Sometimes, social workers advocate for the policy to be fully implemented in the country to help safe parents take care of adolescents with autism. Another item that expands the psychological well-being of parents and even adolescents with autism is the issue of financial burden. Parents shared that they have to always take “dropping” to prevent them from having to face people who were not ready to accept their children or make any contact with them. For example, a father described an experience he had on public transport, which led to him resorting to dropping: when going somewhere with him, you always have to take dropping (Leader et al., 2020).

There is a lot of stigmas attached to disability in Ghana, and autism is not a led out. Stigma arises from the perception people have about a particular thing. In Ghana, perceptions about disability are not a good one which has led to disablism in all aspects of society. The stigma that society showed towards autistic children put a strain on their parents. Parents receive discouraging and insulting comments when they go out with their autistic children, which causes younger parents, especially mothers to keep their children from the public. This is coupled with little or no mental and psychological support from the Ghanaian health system (Formentos, Ae-Ngibise, Nyame & Asante, 2021).

2.6.3 Social Wellbeing of Adolescents with Autism

Studies have revealed autistic adolescents are often lonelier than non-autistic adolescents. Loneliness for both autistic and non-autistic adults relate to social skills and dissatisfaction with social support even among their immediate parents and family members. These affect the quality of life of these persons with the issue of loneliness which is often very difficult for people to manage at certain times (Lawson et al., 2020). Similarly, studies have revealed that autistic adolescents have many barriers to socializing, for example, noisy environments or a culture of drinking alcohol is often difficult for such people. It has been revealed that socializing with non-autistic adults can be exhausting, challenging, or anxiety-

provoking (Bent et al., 2020). Some were bullied which gave them a negative impression of socializing. Some autistic adults said that a quiet setting, sport, or recreation activities can support them to socialize more (Sonido et al., 2020).

Also, social challenges found among adolescents living with autism such as changes in lifestyle appear as a consequence of adaptation to new routines and time schedules imposed by the treatment and hospital visits. In addition, adolescents with autism adapt to a reduced functional level and lower capacity to perform usual tasks. The disease may entail changes in married life and sexual relationships. Social wellbeing may be so pervasive that, the affected individual even lose control of themselves (Garrido et al., 2020).

High-functioning autistic adults report a pervasive sense of loneliness about their dissimilarity and lack of belonging to the surrounding world (Garrido et al., 2020). This feeling may be compared to cultural loneliness. Seemingly, the incapability to communicate with others with the use of a language is also a type of loneliness (Anixt et al., 2020). Sometimes, adolescents with autism may be more aware of the social communication deficits that come with the diagnosis, and it is theorized that higher functioning adolescents may experience this more acutely. While this may be true, the lack of reliable rating and diagnostic scales for depression in individuals with autism makes it difficult to accurately measure rates of depression among individuals with more severe verbal deficits (Garrido et al., 2020).

Participation in social activities for adolescents with ASD has been limited and challenging. Such adolescents have difficulty getting involved and being included or integrated into their society (Ghanouni et al., 2019; Taheri et al., 2016). For such adolescents, their social inclusion and involvement does not go beyond their immediate family. Askari et al. (2015) recount that adolescents with ASD are only able to participate in social activities

and events among their immediate family members. Such adolescents are reported to be at higher risk of being bullied and rejected, though they could be better participants in social activities than children with other forms of disabilities (Shattuck et al., 2011; Cappadocia et al., 2012). The fear of being bullied and rejected by others makes it challenging for such adolescents to actively engage in social activities. This situation could negatively impact social development and could have negative consequences on the emotional wellbeing of adolescents with ASD (Feuerbacher et al., 2017; Dovgan & Mazurek, 2019).

Adolescents with ASD do not only have challenges with social inclusion but hindered interpersonal relationship (Schiavone et al., 2018). It has been established the inability of autistic adolescents to be fully integrated in their society and engage in community activities hinders interpersonal relationship. Adolescents would be able to form and maintain their relationship with other people only when they engage with people within their community (Kasari et al., 2011). Most adolescents have less friendship as compared to adolescents with other types of disabilities (Rowley et al., 2012). They are not able to form a larger circle of friendship, especially with adolescents without disabilities. This results in the feelings of loneliness (Petrina et al., 2014). Roda and Estes (2018) indicate most adolescents with autism end up drawing closer to adults and other autistic children. Jaswal and Akhtar (2019) however recommend that adolescents with autism have higher desire for interaction and bonding. Hence, appropriate support systems if granted could increase social participation and interpersonal relationship among them.

Related to social wellbeing is economic dependence. Cheak-Zamora et al. (2017) discuss this as material wellbeing. They draw attention to the fact that adolescents with ASD are highly dependent on their parents and other family members. They are unable to engage in any meaningful economic activity to have control over material possessions. Autistic

adolescents have low or no employments and remain a burden on their family members (Anderson et al., 2014; Cheak-Zamora et al., 2017).

2.6.4 Spiritual Wellbeing of Adolescents with Autism

Scripture says that God-shaped all of creation and “saw all that God had made, and behold, it was very good” (Gen.1:31). Each person is shaped into God’s good image. John writes, “God so loved the world that he gave his only son so that everyone who believes in him may not perish but have eternal life” (John 3:16). God is invested in creation; he shaped it, including humanity God continues to love every individual still, without exception (Kunz, 2011). Pope John Paul II asserts, “It must be affirmed that the disabled person is one of us, a sharer in the same humanity”. In some cases, this uniqueness creates barriers to full participation in the life of the church because the church is reluctant to embrace people with disabilities (Walsh et al., 2011).

Spirituality seems to represent a relevant domain in the person-centred care planning and outcome assessment for persons with autism and low-functioning autism spectrum disorder (Walsh et al., 2011). While churches may be willing to welcome them and their families, there are often barriers that prevent children with autism from participating in worship (Kunz, 2011). Sometimes, it’s as simple as a set of stairs at the front door that serves as a barrier to a child in a wheelchair. Other times, a church’s programs might not have room for kids with special needs. Or well-meaning congregation members may think going to church is a waste of time for children who have autism (Walsh et al., 2011). Kunz (2011) observed that everyone is needed; all parts are required for the body to be complete and fulfil its purpose. Within the life of a congregational community, faith is formed, shared, and strengthened; relationships are forged and deepened, and gifts are discovered, developed, and dispensed. Unfortunately, too many people with autism do not experience the same opportunities as others to grow spiritually, enjoy community and experience relationships.

Musical instruments, choirs, bands, bells, as well as those speaking over an amplified system contribute to the sensory input for any worship gathering. According to Collins and Ault (2020), people with autism often notice sounds too faint for others to hear, are overly startled by unexpected sounds and often find sounds of a particular pitch unbearable. Touching hands, an embrace during the passing of the peace, the stiffness of a pew, or the texture of a seat cushion can provide more sensory input than a person with autism can process. Bright lights, particular colours, image patterns, or unexpected movements can also distract and provide more sensory input with which a person with autism is prepared to cope (Walsh et al., 2011).

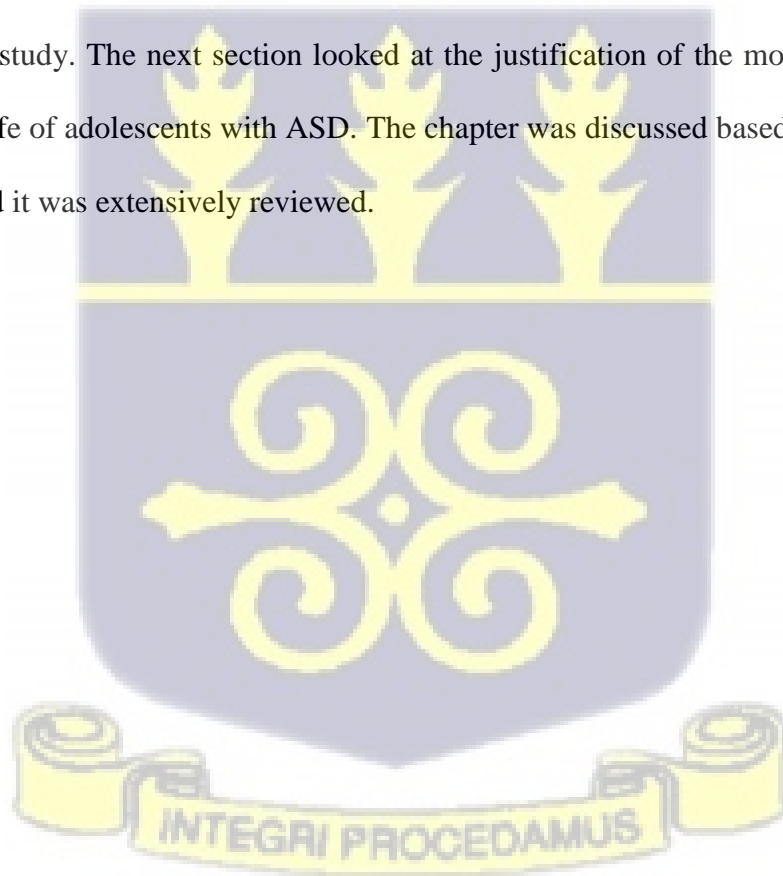
Also, structure and the predictability it provides is a very common need for someone with autism. Knowing what comes next provides a sense of peace that a fluid agenda will not provide. Many of the contemporary worship services gather without a bulletin or a printed schedule for the worship service (Scahill & Karen, 2010). While non-bulletined worship services seem to provide a relaxed worship experience for many neurotypicals, not knowing what will next or when the current experience will end creates a great deal of anxiety for someone with autism (Walsh et al., 2011). Parents of adolescents with Autism Spectrum Disorder are faced with the great challenges of having meaningful conversations with the adolescents, financial challenges in their daily activities and life, the cost of educating them as there are no government schools for these adolescents as well as the cost of transporting them.

Parents of autistic children additionally face stigmatization from their families and the culminating high levels of stress among parents and adolescents as well. These challenges have been reported to influence the perception and perspective understanding and exploration of parents' perspectives on the quality of life of their adolescents of parents of adolescents with an autism spectrum disorder. Several studies were identified in this literature search but

many of which focused on children with autism. Therefore, theoretical understanding and exploration of the quality of life of adolescents with autism include their physical wellbeing, psychological wellbeing, social and spiritual well-being (Tricia et al., 2015).

4.7 Summary of the Literature Review

This chapter centers on relevant literature in support of the phenomenon being studied. It offered a succinct and clear argument in support of the rationale stated for the study. The review equally brought to light evidence and knowledge available in the aspect of developmental disorders. Information pertaining to ASD and the quality of life of adolescents with ASD have been carefully synthesized in this chapter. To ensure a coherent presentation of information, the chapter was divided into two parts. The first part focused on the concepts relating to this study. The next section looked at the justification of the model employed on the quality of life of adolescents with ASD. The chapter was discussed based on the objective of the study and it was extensively reviewed.



CHAPTER THREE

METHODS

3.0 Introduction

This chapter focused on details of the research methods employed for this study in order to answer the research questions. The chapter outlines the research design, the research setting, target population and sample size. It also explains the data gathering tool, data gathering procedure, data management, inclusion and exclusion criteria as well as how the data was analysed.

3.1 Philosophical Underpinning of the Study

This study was underpinned by interpretivism. From this philosophical standpoint, reality depends largely on the sense and meaning-making of individuals of situations or phenomena. This philosophical orientation allowed thick descriptions of participants' experiences on the quality of autistic adolescents from multiple perspectives for better understanding.

3.1.1 Ontology

Interpretivist researchers view the truth or reality as socially constructed, multiple and subjective. This study was done with this ontological position to explore the quality of life of autistic adolescents from parents' perspectives.

3.1.2 Epistemology

The interpretive epistemological approach sees its research participants as actors who play a major role in the construction of reality. This philosophical position suggests that knowledge is better explored using naturalistic approaches. From this perspective, data collection for the study was through face-to-face in-depth interviews with the participants which put them at the centre of knowledge construction. The findings of the study were supported with verbatim quotes from the participants, which gave them a role in generating knowledge.

3.1.3 Axiology

This aspect of the philosophical underpinning relates to the role values, ethics and morality play in social research. From this stance, ethical clearance and approval were obtained for the study. Informed consent of participants was obtained and anonymity and confidentiality were maintained.

3.2 Research Design

An exploratory descriptive design to qualitative research was used in describing the parents' perspective of the quality of life of their adolescents living with autism. Exploratory studies are taken when little is known about the area studied (Polit et al., 2001). This design was chosen because it allowed for extensive exploration of the personal experiences of the respondents on the quality of life of autistic adolescents. The key benefits of using the exploratory research design is to increase understanding and also to improve the researcher's knowledge and understanding of the phenomenon. It also serves as literature for future studies about the phenomenon.

3.3 Study Setting

The study was conducted in the Accra metropolis in the Greater Accra region, the capital of Ghana. The district was established by the local Government Act of 1993 (Act 462) and legislative instrument. It covers an area of 225.67km square with an estimated population of 2.27million as of 2012. Today, the Accra Metropolitan District is one of the 10 districts which make up the Accra Metropolitan area. It is organized into 12 government districts, 11 municipal districts and the Accra Metropolitan District which is the only district within the capital to be granted city status.

3.4 Target Population

The target population is the number of individuals that meet the designated set of criteria for the study (Lo Biondo-wood & Haber, 2010). The population of this study were parents with autistic children who are adolescents in the Greater Accra Region. They are the

population because they have in-depth knowledge and understanding of the quality of life of adolescents living with Autism.

3.5 Inclusion Criteria

Polit, Beck and Hungler (2006) explain inclusion criteria as the characteristics that individuals must possess to be eligible for a study. The inclusion criteria for this study included:

1. Parents of autistic adolescents (10-19 years) who could speak the English Language, Twi, Hausa or Gonja. This is because the researcher is fluent in the above languages and will help appreciate and interpret the views of the respondents better
2. Parents of autistic adolescents who had lived with their children all their lives.

3.6 Exclusion Criteria

Exclusion criteria are attributes of individuals that are irrelevant to the study (Polit & Beck, 2008). In this study, parents who did not consent were excluded. The exclusion criteria for this study included:

1. Parents with autistic children who did not fall within the age bracket 10-19 years.
2. Parents of autistic adolescents who have not lived with the children.
3. Parents of autistic adolescents who do not speak the English Language, Twi, Hausa or Gonja.

3.7 Sample Size and Sampling Technique

A non-probability purposive sampling technique, as well as snowballing, were used to select participants taking into consideration the inclusion and exclusion criteria. Since parents of children with autism were specifically needed, they were purposively sampled. This sampling technique was adopted by identifying specifically parents who have adolescents with autism. The snowballing technique was further used to identify other parents. Parents directed researcher to other parents who also had children with autism. This technique

enabled participants to help recruit others for the study since there is no data on the location of such parents within the municipality.

The selection criteria were explained to participants and only those who gave their consent were contacted. The purpose of the study including the significance as well as the fact that the study is for academic purposes was explained to the participants. The selection and recruitment of participants continued until data saturation occurred (a point where no new information was coming from additional interviews).

3.8 Data Gathering Tool and Procedure

Before data collection started, a letter of introduction from the School of Nursing and Midwifery, University of Ghana and a copy of the ethical clearance were obtained. The study was explained including inclusion and exclusion criteria. The data collection for this study was done through face to face in-depth interviews using a semi-structured interview guide developed based on the objectives of the study. The objectives were derived from the constructs of the model employed for this study. The guide contained open-ended questions which helped the researcher to collect in-depth information about the phenomena. The open-ended questions also allowed the researcher to follow up on emerging themes during the interviews and the participants to express themselves. Individual interviews were conducted at different times and places depending on the participants' schedules and convenience. The Interviews were recorded using an audiotape recorder with the consent of the participants. An assurance of confidentiality of the participants' information and their anonymity were given. The necessary COVID-19 protocols were adhered to during the face-to-face interviews including maintaining at least a distance of one metre and wearing face masks.

3.9 Piloting of Study

A piloting of the study was done using two participants. Audios of the two interviews that were recorded were transcribed verbatim, coded and analysed. This allowed for

inconsistencies and unclear wording of questions to be identified which were corrected before the actual data collection started.

3.10 Data Analysis

The data collection and analysis were done concurrently and continued throughout the study process as is the case in qualitative studies using the thematic content analysis approach (Miles & Huberman, 1994). The interviews were transcribed verbatim and the transcripts and the field notes were read carefully and severally for familiarization of the data. The researcher generated initial codes to reduce the data into segments, revised the codes and searched for initial themes (relevant recurring ideas). A refinement of the themes was done through defining and naming themes to determine the meaning and relevance of each theme, determine subthemes and their consistency with the main themes. The final themes and subthemes were formed and the last stage of the data analysis which is the report writing was done.

3.11 Rigour

Lincoln and Guba (1985), proposed four (4) criteria for evaluating the rigour of qualitative research. These criteria include the following: credibility, dependability, transferability and confirmability. For the credibility of the research, the researcher consulted the participants after data collection to ensure completeness and accuracy of data, and its interpretation and analysis (member-checking). This ensured that the data from the participants were complete, accurate, well contextualized, and interpreted.

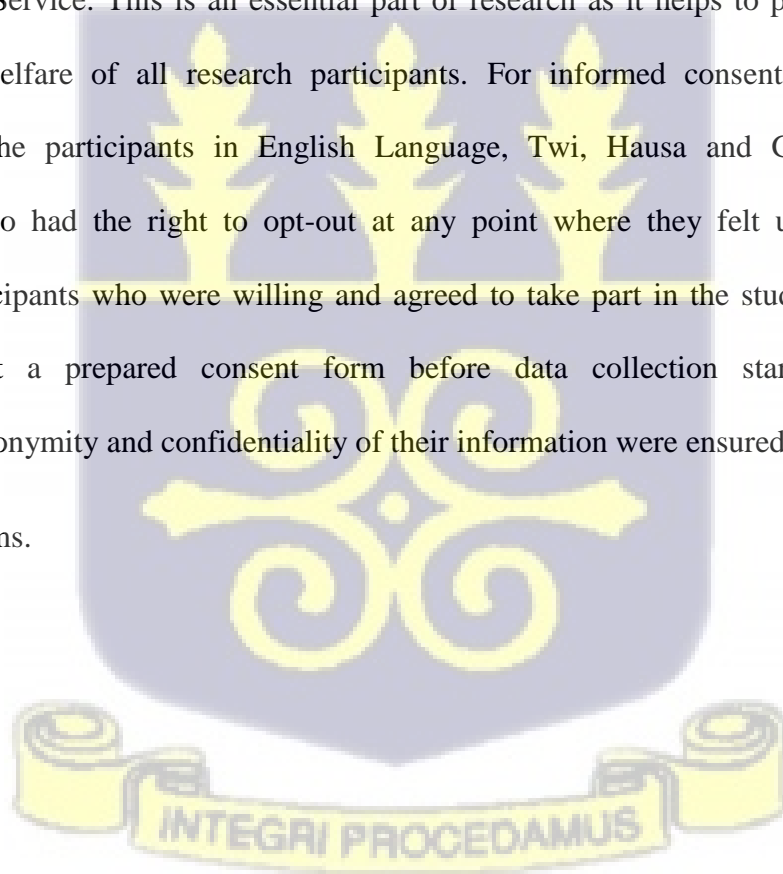
Additionally, an in-depth description of the methodology used for the research was maintained to ensure the study's dependability by providing in detail, the methodology, design, data collection and analysis of the study.

Also, a detailed description of the study and the context in which it was carried out was done. The researcher further maintained participants' accounts in presenting the findings which ensured transferability.

Moreover, an audit trail; a detailed collection of documentation regarding all the aspects of the research process was maintained which ensured confirmability of the study process. This evidence trail included documentation on data collection, design, the researcher's experience and data analysis.

3.12 Ethical Consideration

Ethical clearance and approval were sought from the Ethical Review Board of The Ghana Health Service. This is an essential part of research as it helps to protect the rights, privacy and welfare of all research participants. For informed consent, the study was explained to the participants in English Language, Twi, Hausa and Gonja (Ghanaian languages), who had the right to opt-out at any point where they felt uncomfortable to continue. Participants who were willing and agreed to take part in the study were made to sign/thumbprint a prepared consent form before data collection started. The study participants' anonymity and confidentiality of their information were ensured by identifying with pseudonyms.



CHAPTER FOUR

PRESENTATION OF FINDINGS

4.0 Introduction

The study assessed the quality of life of adolescents living with autism spectrum disorder in Ghana. To address the challenges faced by such adolescents and fill the dearth of knowledge and literature available on the subject, thirteen (13) parents of adolescents with autism were sampled from the Accra metropolis in the Greater Accra Region. Qualitative data was collected using a self-developed interview guide. After engaging respondents in face-to-face interviews, the data was transcribed for onward analysis. This chapter provides the analysis of the qualitative data obtained from the respondents. Analysis is done using the thematic content analysis approach. The findings made have been presented under themes and subthemes.

4.1 Demographic Characteristics of Participants

Thirteen participants were enrolled and interviewed in this study. Eight (8) participants constituted females and five (5) participants constituted males. They were all Christians and of Ghanaian nationality. The age range of the participants was between thirty-two (32) and fifty-two (52) with child's age ranging from ten to seventeen. Out of those who participated in the study, five (5) were between the ages of 30-39, seven (7) between 40-49 and one (1) above 50 years. With regard to their educational level, four (4) had no formal education, two (2) had secondary education and seven (7) had tertiary education. Most of the participants were fluent in English. The table below details the sociodemographic characteristics of participants (Table 4.1).

Table 4.1 Demographical Characteristics of Participants

PARTICIPANTS	GENDER	AGE	CHILD'S AGE	RELIGION	EDUCATION	OCCUPATION
R01	Female	32	12	Christian	No formal education	Trader
R02	Female	47	15	Christian	No formal education	Trader
R03	Female	43	13	Christian	No formal education	House wife
R04	Female	40	15	Christian	Tertiary	Civil Servant
R05	Male	45	14	Christian	Tertiary	Engineer
R06	Male	47	17	Christian	Tertiary	Entrepreneur
R07	Male	38	11	Christian	Tertiary	Teacher
R08	Female	36	10	Christian	No Formal education	Trader
R09	Male	41	12	Christian	Secondary	Business
R10	Female	42	11	Christian	Tertiary	Teacher
R11	Male	52	16	Christian	Tertiary	Banker
R12	Female	32	11	Christian	Secondary	Shop Keeper
R13	Female	38	12	Christian	Tertiary	Teacher

4.2 Quality of Life of Adolescents Living with Autism

The aim of the study was to assess the quality of life of adolescents living with autism spectrum disorder in Ghana. Various domains of the adolescent with the disease was assessed using the Quality of Life Model (Ferrell et al., 1996). Five (5) themes and seventeen (17) sub-themes were obtained from the analysis. A tabular representation of the themes and sub-themes has been presented in Table 4.2.



Table 4.2: Themes and Sub-themes from Transcribed Data

THEME	SUB-THEMES
Physical wellbeing of the Adolescent with Autism	<ol style="list-style-type: none"> 1. Physical independence 2. Physical deformity 3. Medical fitness 4. Abuse
Social wellbeing of the Adolescent with Autism	<ol style="list-style-type: none"> 1. Socialization/Loneliness 2. Changes in lifestyle 3. Impaired communication
Psychological wellbeing of the Adolescent with Autism	<ol style="list-style-type: none"> 1. Depression 2. Financial burden 3. Level of understanding and comprehension 4. Sleep patterns
Spiritual wellbeing of the Adolescent with Autism	<ol style="list-style-type: none"> 1. Engagement at religious gatherings 2. Undertaking spiritual activities
Support systems of the Adolescent with Autism	<ol style="list-style-type: none"> 1. Job opportunities 2. Medical interventions 3. Community engagement with information

4.3 Physical Wellbeing of the Adolescent with Autism

Parents of adolescents with autism spectrum disorder pointed out the physical wellbeing and health of their children. In the engagement, they shared how the disease has impacted the physical health of their children. The sub-themes relating to the physical wellbeing of adolescents with autism spectrum disorder, as shared by respondents were in reference to control of symptoms to attain physical independence in performing basic life functions, physical deformity and medical fitness.

4.3.1 Physical Independence

Adolescents with autism are affected physically by the disease. They were reported to basically not have independence. Due to their condition, they required some level of external support in events such as eating, and doing basic household chores. They were also able to gain education, though most of them had delayed schooling. Most of the adolescents with autism were found not to have fully gained independence and control or relief of symptoms to function within the society. They were able to perform some basic life functions with some level of external help. Some of the parents made remarks as follows:

“I will say that the sickness has delayed a lot of things in his life, firstly, his education, he is 13 years now, he should have been in class 6 or Junior High School (JHS) 1, but he is now in kg2” – [R07]

“Things like his education. Like the way he will progress in his education and social habit which he is left behind. Some of the things kids at that age could do he’s not able to do” [R10]

Another parent had this to say:

“With bathing, I still bath him myself because he cannot bath himself well, so I bath him.” – [R01]

“He’s able to do it by himself but you’d have to guide him especially with the bathing and brushing. Unless you guide him to do it.” [R06]

“Previously, he was not able to put food in his mouth, I used to feed him, but for now, he can feed himself.” [R05]

From the narration, the education of persons with autism is delayed due their condition. They are unable to perform certain activities of daily living without assistance. This suggest that adolescent with autism may not be fully independent in carrying out activities of daily living.

4.3.2 Physical Deformity

Autism spectrum disorder had affected children by deforming some part of their body. Respondents shared that the disease has contributed to some sort of deformity in their children. Not many of the parents had reported incidences of physical deformity in their children. The comment was:

“So his, his feet...he doesn’t place it on the ground like we do so its curved. It’s a bit deformed. I’m sure because he doesn’t feel balanced” [R05]

“It was not easy but its just his neck...its turned one side as you can see.” [R09]

This highlights the physical complications adolescent with autism experience thus could negatively affect their self-image.

4.3.3 Medical Fitness

Apart from having autism, parents who pointed out that their children had other forms of medical-related challenges mentioned seizures. Children who were unfit medically had showed some episodes of seizure, which their parents indicated had been in relation to their autistic condition. Others indicated the low level of energy such children had to carry out activities. Comments made in relation to this are:

“He had seizures when he was a child. That be, that is gradual seizures and he’s on medication.” [R01]

“For his physical health, you know, but it’s like he’s having seizures” [R03]

“Yes, he gets tired sometimes and he will stop what he is doing” [R09]

“When he is doing some work or when you tell him to work, he will do it and then he will stop. You will see that he is tired” [R05]

This implies that parents associate the emergence of medical complications such as seizures to the presence of autism in their wards.

4.3.4 Abuse

Parents also talked about the abuse of their adolescents living with autism spectrum disorder by their teachers and facilitators. This has caused some parents to withdraw their children from school whilst others changed school. A parent explained how she always found her son soiled with faecal matter and therefore had to change his school

“My child cannot talk so he cannot use the toilet, when I go to pick him he is always soiled with toilet. The teachers don’t care to help him, I therefore had to change school” [R12]

Furthermore, another parent explained she had to stop her child from schooling altogether because he was physically abused by his teachers.

“We found a school here for him which was also a special school but errm I don’t know the word to use but they were abusing the children for my son they abused him physically so he’s home. I can’t watch my son suffer” [R11]

4.4 Social Wellbeing of the Adolescent with Autism

Another aspect of adolescents’ quality of life in respect of autism spectrum was their social wellbeing. Respondents shared how the disease has impacted or affected the social composition of adolescents. The sub-themes connecting to the social wellbeing of adolescents with autism are socialization and loneliness, change in lifestyle and impaired communication.

4.4.1 Socialization/Loneliness

Autism may impact the social wellbeing of adolescents and children with the disease. It makes them unable to fully integrate into their society as a lot of people are unwilling to embrace these individuals. Respondents indicated however that the condition has not entirely impacted the social wellbeing of their children negatively. They are able to establish cordial relationship with their peers and relatives and some were reported to have friends both at school and home. Remarks made include:

“As for him, he plays with anyone he becomes friends with, and I buy things for them. And he is not harsh, so he gets a lot of friends. All those in the school are very free with him, even the teachers there.” [R09]

“Whenever he gets in the midst of people, they all like him, even with those who see him for the first time because he will call you or come closer to you whether he knows you or not” [R01]

“He is very sociable and leaves his name wherever he goes. Even with the church we stopped going to, a lot of them do not know my name, they call me by his name” [R05]

“If you engage him to play and he is comfortable with the kind of play, why not. If not, I mean he loses interest and they also get bored and so he doesn't really stay for long but if it's something he likes, he will play and be laughing” [R13]

Some participants however pointed out their children were not able to fully integrate into their society. They are not able to make friends for themselves and are not embraced or welcomed by other people in the society. Though the number of respondents who made this admission is in the minority group, it is significant to point it out. Their remarks were:

“He doesn't have friends. Because he has autism. He's within himself. I don't think he understands the concept of friendship. He doesn't really, he's not into that he is not able to like initiate and continue with that friendship” [R010]

“People have tried to be friends with him but then, this is Ghana. People are not too comfortable around others with special needs.” [R08]

“Mostly he is in the house. He doesn't really have friends... sometimes they see him to be someone who is not mentally sound especially with how he behave” [R06]

“There are some people who will look at your face and not even sit by you in a trotro” [R04]

The narration suggests the society is not receptive to adolescents with autism thus negatively affecting their social interactions. This might lead to self-isolation for persons with special needs.

4.4.2 Change in Lifestyle

Another important issue related to the social wellbeing of adolescents with autism is their change in lifestyle. Through the engagement had with respondents, they made it known that autism has changed the lifestyle of their children in terms of their becoming restless and

noisy; and inability to secure any form of a decent work. The comments shared by respondents were:

“You will be walking with him and he suddenly becomes aggressive and He will be scratching you, biting you and sometimes people will approach me and ask why he is behaving in that manner.” [R09]

“Sometimes too he touches things and scatters them around and he also destroys them. And the way he behaves. If he wants something and we are not able to provide the way he reacts. He destroys things, has made him slow in catching up with certain things in life.” [R07]

“There are times that he becomes very very hyper. If he wants something and he does not get it or if he needs something and you are delaying. He will start banging the wall. He will start hitting the wall hand or foot.” [R13]

A participant had this to say in relation to finding it difficult to get work for an autistic adolescent:

“We are rather looking for work for him I decided to find something for him to do like a skilled work rather than he being idle at home so that if we die, he will not suffer, but its not been easy” [R08]

4.4.3 Impaired Communication

Remarks given by respondents pointed to the fact that autism has resulted in children’s impaired communication ability. Due to their condition, they are unable to communicate effectively which also affects their social interaction. Some remarks are shared below:

“It’s difficult because he’s non-verbal. I’ll say he’s pre verbal not non-verbal because he has words, when he wants to, he says it. Occasionally, you’ll find him crying that you wouldn’t know.” [R04]

“He wouldn’t come in straight conversation and I mean say words and in terms of request, laughing is an alternative to saying something.” [R09]

“Yes, he doesn’t talk well. You can’t hear him well. It is not clear.” [R01]

Two other respondents had this to say:

“They cannot communicate properly apart from that they are normal human beings.” [R12]

“They are non-verbal there are certain things they cannot say and if you are not close to them you wouldn’t know.” [R05]

Another respondent opined that their inability to express themselves makes it difficult to solve their needs. Below is how it was expressed:

“When he needs something, he is not able to say it. So you will not know what he needs and it is very difficult.” [R07]

This appears to highlight the communication challenges adolescent with autism has thereby impeding effective interaction with their caregivers and the society.

4.5 Psychological Wellbeing of the Adolescent with Autism

Psychological wellbeing, a construct of the quality of life model was explored among adolescents with autism spectrum disorder. Respondents were guided in identifying the impact of the disease on the psychological and cognitive domains of the adolescent. The following sub-themes came up from the face-to-face engagement: depression, financial burden, level of comprehension and sleep patterns.

4.5.1 Depression

Engagement with respondents showed that children or adolescents with autism do not react negatively when they are depressed or have feelings of anxiety. Respondents admitted their children had mood swings. They sometimes became irritated, moody, quiet, drawn from other people and at times also became open and interactive. Comments made include:

“Oh, if you observe him, he relates very well and plays with everyone. But when a lot of people are around, I make him sit at where I sit because of the way he was harsh, I was afraid he would find something and hit people with it” [R07]

“Sometimes you will see him being quiet and those times when you can see that when nothing is wrong with him, he’s always calm, you’ll see him smiling, not that moody.” [R01]

“There are times that he is err, irritated if I should say. Like at odd times, you will see he is irritated and just by himself.” [R013]

Other respondents had these to say:

“If he is in a car and maybe we are going somewhere and he want something and he does not get ahh suddenly then he gets angry. When the car stops sometimes he fall to the ground and be rolling” [R03]

“When he wants to sleep. Like he’s feeling sleepy, that is when you will see that he will sit there calmly. Or when he is not feeling well. Aside that, he doesn’t sit at one place at all” [R08]

“Sometimes you can see that he is moody other times too you cannot really figure out what is happening to him. Sometimes it looks like he is angry, he is angry sometimes he looks like he is not angry” [R06]

It appears the mood and reactions of adolescents with autism changes quite often and parents sometimes are unable to figure out the reason why.

4.5.2 Financial Burden

The financial burden associated with caring for the adolescent with autism was also explored during the interview. Respondents majorly indicated it was costly having an adolescent with autism. Medication, treatment procedure, feeding, schooling and general upkeep of the adolescent with autism was described as a financially demanding situation.

Remarks made were:

“The drugs I have bought during his childhood is not a joke. His father was jobless at that time. I was responsible for everything. I cannot remember how much but it is a lot.” [R03]

“It has and I don’t think he is the only person. Every mother or every parent raising a special child will tell you that it costs the family financially.” [R01]

“Yes. Her medications are expensive. Where she is now her therapies are expensive. You know. Everything about it is expensive so off course it will affect me.” [R13]

Furthermore, participants opined that it was financially demanding to cater for their educational needs. They opined as follows:

“The school now is expensive. And his medical checkup and all things...every main stream school I took him to, he was charged more...than a, you know, typical I mean, student or people...It’s always expensive” [R10]

“Its cost involving you know this kind of school. Its cost involving. I mean sometimes you have to get a teacher that will be taking him through some lessons at home and the materials that that they use to learn and the school fees too it’s not easy.” [R02]

Though majority of the respondents had described the burden of having an adolescent with autism as financially demanding, a number of them did not think so. These respondents did not attribute the psychological wellbeing of the adolescent to financial burden. They remarked:

“Oh financially, Aunty, I would be telling lies if I say that his sickness has affected us financially. I mean, errr, he has brought us luck... I wouldn’t say that his sickness has affected our finances but God through him has brought us luck.” [R09]

“NO NO.. I believe whatever, I mean I always keep telling people that if you are asked to do errm if there was a cure for it, I would have cured my son a long time” [R05]

This finding gives credence to the argument that it is financially burdensome to cater for an autistic child in our part of the world where there are no support schemes to support persons with autism.

4.5.3 Sleep Patterns

Respondents generally indicated adolescent with autism have not been affected in respect of their sleep patterns. Their pattern of sleep has not been negatively impacted nor been distorted by the disease. They were generally reported to have no problems or difficulties with their sleep. Comments given by respondents were:

“As for him, he can sleep very well...He does not joke with his sleep. Whenever is he sleepy, he will go and sleep...When he sees a nice picture behind a book which he likes, he will hold it and sleep with it.” [R07]

“He has been getting a good sleep” [R01]

“He hasn’t got any sleeping problems.” [R09]

“Generally, no. it just sometimes that he finds difficulty in sleeping...either he will be singing or humming throughout the night because he is not feeling sleepy, but it doesn’t happen often. Many a time, he’s tired, he wants to go to bed.” [R05]

Though some used to have sleeping difficulties, the respondents claim it was intermittent and was not serious. They expressed as follows:

“He has no problem with sleeping, he used to have challenges with sleep. He will wake up and scream all night” [R02]

“Please he is able to sleep at night. Most at times he up during the day but during the evening he sleeps it’s just once in a blue moon when he doesn’t sleep early.” [R04]

4.6 Spiritual Wellbeing of the Adolescent with Autism

The last construct of the model in assessing the quality of life among adolescents with autism spectrum disorder is spiritual wellbeing. This construct looks at the spiritual engagement and impact of the disease on the adolescent with autism. Two (2) sub-themes, religious engagement and undertaking spiritual activities came up after the thematic content analysis of the data.

4.6.1 Religious Engagement

It came to light that adolescents with autism spectrum disorder are not negatively impacted in respect of their religious activities and engagement. It was reported that adolescents were able to fully engage with their religious community irrespective of their medical condition. All respondents who were Christians of different denominations admitted adolescents were fully embraced in their church community. They regularly participated in church activities and their presence at church premises was always regular. Remarks made were:

“He wants to go so I have decided to talk to him to sit quietly when I take him to church next year but he makes noise and talks when the priest is also talking.” [R10]

“He goes to church. He dances. He’s always in the queues for offering and so forth.” [R02]

“Sunday he is in a hurry to go to church. Yes he likes God so we go to church. On Sunday if he doesn’t go to church I mean you see him that he is not happy. He wants to go to church.” [R07]

Others had these to add:

“She is first class, she’s the leader at Presby, with that one, she’s first class, she irons her clothes on Saturday, she goes to church every Sunday” [R09]

“We attend church with him, Sometimes if the church is singing praises and he is sitting down he normally stands up and starts clapping.” [R08]

It seems though most parents and children are able to attend church, a few number of participants are not able to. This is due to the fact that, the children disrupt proceedings by talking and making other forms of noise.

4.6.2 Undertaking Spiritual Activities

Adolescents were reported to have undertaken various religious activities. Their medical condition did not prevent them from doing some spiritual activities such as praying, singing, dancing at church, and clapping. They expressed their faith by undertaking these activities. Some comments made by respondents were:

“When she wakes us and does this [bows her head], I do not know what she says. Every morning when she wakes up, she puts her head down but I do not know what she says.” [R13]

“He is nonverbal. He wouldn’t be praying or you won’t see him praying but when its prayer time and then let’s say people are erm praying...opening your arms and all those ones, You will see him doing that and that one he sees people doing that so he imitates.” [R01]

“Normally the only thing you’ll see is that he’s dancing...” [R05]

“He will take part as in not really singing or dancing but he’s there. He doesn’t speak so I mean when he’s tired, you will find him laughing or acting out and then he will be given a break.” [R09]

“When we want to pray we need to engage him and say the Lord’s Prayer. And he knows the whole thing” [R07]

“The only thing he did was that he likes drumming, so he will always be with the instrumentalists. He will always sit beside them. When they see that they are playing, we will also be making his own beats. When he puts the stick down, he will also go and sit behind the drums and also be playing.” [R11]

“ He will just sit; he will just sit beside us and we will pray” [R10]

From the narration, it appears that some of the adolescents are able to attend church and have adopted other ways of participating in the religious activities carried out through observation.

4.7 Support Systems Available to the Adolescents with Autism

Adolescents with autism require support systems and mechanisms which would help them become functional in their society. These systems could be both personal and external systems which aim at improving the quality of life of the adolescent with autism. They could include spiritual interventions, recreational activities, job opportunities, medical interventions and community engagement and informational support. Unfortunately, there were not support systems available to the adolescent with autism.

Respondents however pointed out what support systems could be put in place to help the adolescent with autism function well in their society. These include job opportunities, medical intervention and awareness creation and education.

4.7.1 Job Opportunities

Respondents believed that the adolescent with autism required job opportunities. Such an opportunity would help them engage in an economic activity which would help them become functionally independently. Comments made include:

“I want them to find work for him, I do not want anything. Something that he can do and get something to buy food” [R07]

“Maybe he can get some to do which can help him to get a place to work. There are a lot of sick people at workplaces” [R10]

“Yes, he should get the job, get money, and see that work before we eat, whatever that he can do to get money is what I want.” [R01]

“We would all want the government to come in with centers that will help them, you know, probably achieve something for themselves. Because they are growing so if you don't want them to be a liability on the nation or their parents and all of that. And they are something they can actually do. Just that we haven't really trained them” [R12]

This highlights the lack of skill, available resources and therefore unemployment of adolescents living autism. It appears the parents are worried they might not be independent in the near future.

4.7.2 Medical Interventions

Another support system that respondents pointed out include medical intervention. They indicate they require medical intervention to support manage the health of the adolescent. They requested health facilities to support adolescents with medicines which would improve their health. Some comments made include:

“Oh, as for me, support like drugs that will make him calm and sit quietly and study is what I want” [R04]

“Drugs that will make him calm and make him stay quietly among his siblings without hurting anyone and study is all that I seek for.” [R02]

The parents are of the view that drugs should be made available to reduce aggression in adolescents living with autism so they can socially interact better.

4.7.3 Community Engagement and Information

Community engagement and information dissemination was another support system indicated by respondents. They opined that community engagement and information dissemination could enable adolescents with autism fully integrate into the community. It would as well help people have better understanding of autism and relate well with adolescents with the disease. Remarks made are:

“Society as a whole. Normally, people don’t understand what autism is. So it’s difficult for people to accept them.” [R07]

“The awareness creation has not gone far for people to understand which is a bit okay but when you move to the rural areas it becomes difficult for people to understand them.” [R11]

“We need to do a lot of education. Because my sister I was driving one day and somebody fell down and people were running away.” [R05]

“The advocacy for people to err, to know about disability as a challenge like autism and what they go through, you know they need to understand them and accept them and when it comes to schooling” [R02]

“They need to understand that people like that look alright but they have a disability” [R13]

From the narration, parents are of the view that the public has no knowledge about Autism hence the neglect and lack of acceptance. They will want the government to create awareness on the condition and the need to support children living with autism.

4.8 Researcher’s Reflections of the Findings of this Study

The researcher is able to draw conclusions based on evidence and information given by the respondents in data collection, taking into consideration the conditions under which their views were expressed. The respondents were contacted mostly through snowballing. The purpose of the study was explained and some respondents willingly agreed to be a part of the study and be interviewed. Others were initially skeptical because they didn’t want to be stigmatized by society until they were shown introductory letters from school of nursing, University of Ghana, clearance from Ghana Health Service, an informed consent and assured of privacy and confidentiality. The researcher also being a professional nurse helped convince respondents to fully participate without fear. Some interviews were carried out on phone but majority of the respondents agreed to be interviewed in their homes. The researcher established rapport with the respondents to allay their anxiety and make them comfortable enough to express their experiences and perspectives on the quality of life their adolescent children living with autism. This was done by discussing with them their sociodemographic characteristics as well as my profession as a nurse and my encounter with special needs children. The challenge the researcher encountered was recruitment as some parents do not want to be identified as parents with special needs children. The researcher had to volunteer in an autism center to meet some of the respondents, this also helped to elicit the

right information from parents thereby enriching data. All respondents were relaxed during the interview and seem happy to share their perspectives. They also saw it as an avenue and opportunity to speak out their grievances and share their pain. The researcher during data collection did not come across Muslims with adolescents living with autism. The chief executive officer of Autism awareness center explained that due to cultural believes by Muslims, children with autism are taken to the village and left behind. All respondents were ready to give further information any time the need arises.

4.9 Summary of the Findings

Most Parents of adolescents with autism explained that their children are not independent but rely on their assistance to perform some basic life activities like bathing, eating and grooming themselves. They also bemoaned that their education is delayed since they are unable to keep up with their peers in school. In some instances, adolescents with autism have had to be withdrawn from school due to poor performance and abuse by teachers. Seizures have been reported in some adolescents with autism which are attributed to the disease condition. Some depend on medication to resolve seizures while others simply outgrow the seizures.

Though some parents are secluded from society due to the condition of their wards, a good number indicated that the condition has not impacted the social wellbeing of their children negatively. They were however quick to add that effective communication is a challenge which affects their social interaction. Adolescents with autism suffer mood swings, they can be happy and interactive as well as become moody and drawn. Furthermore, it came to light that it was financially demanding to care for their wards. Schools demanded for exorbitant fees, medical bills and the general upkeep of adolescents with autism was expensive. Some parents mentioned that their children had sleep issues at night but generally most adolescents slept soundly all through the night. It was reported that most adolescents

with autism loved to take part in religious activities and were welcomed in most churches though they sometimes interrupted proceedings by talking or clapping. Parents indicated that they require medical intervention to help support in the care of their wards, they will also want the general public to be educated and engaged in autism for better understanding and acceptance.



CHAPTER FIVE

DISCUSSION OF FINDINGS

5.0 Introduction

The study explored the quality of life of the adolescent with autism in Ghana from the experiences of their parents. Previous chapter has provided the findings made after interviews had been conducted with parents of adolescents with autism spectrum disorder. This chapter focuses on the discussion on the findings presented in previous chapter. Thorough deductions and meanings are assigned to each of the observations made from the interview engagement. Discussion of each theme has been ably done under separate headings, referring to literature evidence. The relationship of the findings in terms of similarities and distinctions with empirical evidence has been done in this chapter.

Theme 1: Physical Wellbeing of the Adolescent with Autism

Adolescents with autism were found to have not gained physical independence. Their condition has rendered them being dependent. Though they were reported to have the ability to perform some basic life functions, they do require an amount of external support from their caretakers and other relatives. In terms of bathing, feeding, and doing some household chores adolescents with autism were given support. Though a few of them were reported to have the ability to feed on their own, most of the sampled parents indicated their children required support to feed. Bathing was also done under the supervision of parents. It was also realized that cleaning, washing of clothes and dishes and other complex household chores were mostly not one by adolescents. Parents indicated they exempted their children from undertaking these activities. Their medical condition and inability to have full coordination did not allow them to perform household chores. Thus, other activities that they could perform was done under intense supervision. It could be therefore inferred that adolescents with autism do not have physical independence, an indication that their physical wellbeing

has been negatively affected. Gomez et al. (2012b) opine that physical wellbeing refers to the overall physical health and functional ability of a person. One's inability to have full functional ability, independent of external support would amount to physical wellbeing. Per this assertion, adolescents with autism could be described not to have good physical wellbeing. The observation made in this study affirms earlier empirical report in China by Zhen-Huan et al. (2016) and van Ewijk et al. (2020) who found out that the physical wellbeing of adolescents with autism is affected by their physical functioning and social inactivity. In their study, they similarly reported that adolescent with autism required support to perform basic life functions including feeding and bathing.

Aside not having physical independence, some of the adolescents with autism were reported to have seizures. Respondents did indicate that adolescents have experienced some episodes of seizures, which is attributed to their medical condition. Similar report was made by Dillenburger et al. (2016) who indicate that ASD impact the physical wellbeing of adolescents, since they have suffered epilepsy and seizures. The American Psychiatric Association (2013) also affirms that among the psychiatric conditions reported among adolescents and children with ASD is epilepsy. Aside this, some adolescents had physical deformity. Their deformity was majorly in respect of their having deformed feet and neck. Some mothers lamented how their children had been deformed as a result of having autism. It could be deduced therefore that autism makes adolescents medically unfit, which negatively impacts their physical wellbeing. It comes clear from the interview engagement that adolescents with autism have poor physical health. They are reported to have been medically unfit. Due to this, adolescent with ASD are not able to have independence. They are always under the supervision of an older person, presumably considered "normal". It is based on their poor quality of physical life that Merriman et al. (2020) intimate that most parents do not allow their children or adolescents with ASD to entirely engage in physical activity. They

are always kept under surveillance, of which same was reported in the current study. Some of the adolescents were also physically and psychologically abused by teachers and had to either be taken to other schools or stopped schooling entirely. This leads to poor quality of life especially for adolescents who stopped schooling.

Theme 2: Social Wellbeing of the Adolescent with Autism

It was interestingly observed that adolescents with ASD are able to establish cordial relationship with their peers and relatives as some had friends both at school and home. This refutes earlier observations made by Sonido et al. (2020), Lawson et al. (2020) and Garrido et al. (2020). They had indicated that adolescents with ASD are often lonelier than non-autistic adolescents. It however affirms report made by Jaswal and Akhtar (2019). From the engagement had with parents of adolescents with ASD, it was observed that these adolescents had not been rendered unsociable or lonely. Though they are medically unfit and physically dependent, they are able to relate cordially with people within their immediate community. Those who had the opportunity to be placed in schools were found to have made friends for themselves. In their homes, adolescents related well with their siblings and other relatives. Others also involved in religious activities such as attending religious gathering. They moved along with their peers at home and engaged in some playful activities with them. Parents happily indicated that their children have not been drawn from their society due to their medical condition. Recounting various instances where adolescents with ASD mostly found themselves, they were found to relate open with those that they knew and those that they did not. The friendly attitude of adolescents, as reported by their mothers, made them loved and fond of most people in their community. It can therefore be concluded that adolescents with ASD are not challenged in terms of socializing with their peers and other people in their community. Their social wellbeing cannot be said to have been affected nor have they been rendered incapable to interact with people within their community.

This observation does not however negate some observations made in the literature (Lawson et al., 2020; Bent et al., 2020; Sonido et al., 2020; Garrido et al., 2020; Shattuck et al., 2011; Cppadocia et al., 2012), in respect of ASD rendering adolescents incapable of socializing and interacting with people in their community. Few of the parents sampled for the study indicated their children were not able to make friends. These respondents, though in the minority affirmed assertions made in the literature that adolescents with ASD are mostly lonely and unsociable (Sonido et al., 2020; Lawson et al., 2020; Bent et al., 2020). The variation in observation could possibly be attributed to some demographic and environmental factors such as training and parental background of the adolescents. The community in which these adolescents find themselves and the training they had could determine their ability to socialize. More so, the severity of their condition could account for the variation in observation made.

In respect of communication, most of the adolescents were reported to have poor speech ability. Respondents did indicate that their children were not able to effectively engage in speech activities. Their condition has affected their speech ability. Their verbal capacity has been rendered ineffective, resulting in their inability to fully engage in oral conversation with other people in their community. Hence, parents described their children as being non-verbal. Those who try to communicate orally have challenges making clear and audible utterances. This affects their social wellbeing as they are unable to interact socially. More so, they are unable to make timely request should they need some assistance. Parents therefore indicated how challenging this was in catering for the adolescent with ASD. Since they have impaired speech, one is required to keep constant eye on them to determine their needs. Similar observations had been made by Anixt et al. (2020), Ruparelia et al. (2016) and Garrido et al. (2020) who in their respective empirical study realized adolescents with ASD had impaired communication ability.

One other issue in relation to the social wellbeing of adolescents with ASD is change in their lifestyle. Garrido et al. (2020) agree with Ghanouni et al. (2019) and Taheri et al. (2016) that adolescents with ASD have new routines and time schedules, which brought about changes in their lifestyles. From the current investigation, respondents affirmed the delay in educational and training pursuit for the autistic adolescent. Due to their medical condition, autistic adolescents were not able to attain the same feet of educational and training level as other non-autistic adolescents. They could not enter school early nor able to have a family of their own. Their condition hence amounted to a change in their lifestyle.

It was reported that adolescents with ASD are restless, hyper and noisy. They are often not calm as they were mostly seen engaged in hyper activities. They were reported being aggressive, unstable and destructive. Parents indicated that their children have been rendered restless and destructive by the disease. With their age, they are expected to be measured in their behaviour, calm and orderly. However, the disease has changed their lifestyle.

Based on the observations made, it can be deduced that adolescents with ASD have good quality of social wellbeing. Social wellbeing has been described to include the ability or opportunity to go to places and participate in community activities, relation with others, being able to have and keep friends and appropriately get along with others (Suárez, 2020; Gomez et al., 2012b). Based on this assertion, adolescents with ASD sampled for the current study could be said to good quality of social wellbeing. They were mostly able to keep friends, though their communication ability however remains impaired. They were able to engage in community activities such as playing with friends and even attending religious functions.

Theme 3: Psychological Wellbeing of the Adolescent with Autism

Adolescents with ASD were reported to have been moody. They were said to have changed their moods often based on the situation they found themselves. They were at times irritated, moody, quiet, isolated and at times also open and interactive. It comes clear from the observation that autistic adolescents did not balance of emotions. They were not able to control their emotions. Some of them were reported to easily change in mood and become angry or irritated at the least provocation. It is obvious that autism has negative impact on the psyche of adolescents as it made them have little control over their emotions. Similar to reports of Sonido et al. (2020), Tricia et al. (2015) and Bent et al. (2020), autistic adolescents change mood often and are not predictable. The observations made in these reports have hence been affirmed by the findings made in the current study.

Interestingly, it was reported that autistic adolescents do not have sleep problems. This contradicts observations made by Mazurek and Petroski (2015), Broder-Finger et al. (2016) and Demet (2018). Respondents refuted the claim that adolescents with autism have sleep disorders. They made the assertion their children do not have challenges with sleep. They were able to sleep as non-autistic individuals will do. Though they are autistic and have cognitive malfunctions, it would have been expected that their sleep pattern is likewise affected. These individuals were however different. They did not report any challenge nor difficulty in their patterns of sleep. It could therefore be inferred that autistic adolescents have not been negatively affected psychologically in terms of their sleep patterns.

Another key observation made was in respect of the financial burden associated with autism. Respondents generally indicated the disease is financially burdening. They admitted to the fact that taking care of an adolescent with autism is financially draining. This was attributed to the high cost of medication associated with the disease and the lack of support from society and the government. This equally adds to psychological burden. As reported by

Leader et al. (2020), the issue of financial burden expands the psychological wellbeing of parents and even adolescents with autism. Their report hence has received affirmation in this current study.

According to Gomez et al. (2012b) psychological wellbeing reflects in one's stability, control and balance of emotions, cognition balance and attention. Leader et al. (2020) also consider financial burden as a factor which lowers the psychological wellbeing of adolescents with autism. Based on the observations made, it could be seen that adolescents with autism have reduced psychological wellbeing. They have less control over their emotions, hence become moody. The issue of financial burden was also pointed out.

Theme 4: Spiritual Wellbeing of the Adolescent with Autism

Observations made indicated that autistic adolescents have high spiritual wellbeing. Liu (2016) intimate that spiritual wellbeing includes fait-base and religiosity aspects of the autistic adolescents which improves their functionality. Gomez et al. (2012b) consider spiritual wellbeing as a valuable management resource for the adolescent with autism. Respondents pointed out that adolescents with ASD are able to fully engage in religious activities. These adolescents engaged in congregational services and participated fully in these activities. Singing, drumming and dancing were some religious activities which adolescents with ASD were engaged in. This refutes assertions made by Walsh et al. (2011), Kunz (2011) and Collins and Ault (2020) that the uniqueness of autistic adolescents creates barriers to full participation in life of the church. Their engagement in these activities helped them to fully socialize and integrate into their community. In the view of Gomez (2012b), engagement in religious events and activities are measures available to the adolescent with autism to manage stress related to the disease. It could be inferred based on this assertion that autistic adolescents are able to manage their condition since they engaged in religious activities. It could also be seen that autistic adolescents have high spiritual wellbeing.

Theme 5: Support Systems Available to the Adolescents with Autism

vanEwijk et al. (2020) intimate that autistic adolescents require various support systems to enhance their functionality. Their normal functioning and social integration would be achieved if they are adequately supported. It was unfortunately uncovered that no support systems existed for the autistic adolescent. Respondents did not point out the existence of any support system for the adolescent with ASD. There were no recreational facilities, job avenues and direct government support for the adolescent with autism. It is clear therefore that the autistic adolescent has no support systems to improve their functionality. This observation affirms what was found by Boadi et al. (2020) and Agyekum (2018) that no support systems exists for the autistic adolescent in Ghana and those in some major parts of Africa.

Respondents further requested some support systems for the autistic adolescent. They mentioned job opportunities, medical intervention and community engagement. Respondents believed job opportunities and skill training could help autistic adolescents ad make independent and socially acceptable and functional in the community. More so, medical support was identified by respondents. Due to the financial burden of the disease on the adolescent and their family, as well as the effect of the disease on their health, respondents believed medical support was appropriate to help the adolescent with ASD. They requested for treatment support to improve the wellbeing of the adolescent. To reduce the stigma associated with ASD, respondents requested community engagement and information dissemination. Manu (2012), Ruparelia et al. (2016), Agyekum (2018) and Oti-Boadi et al. (2020) noted that there is a lot of stigma attached to autistic adolescents and children in Africa. The negative perception and stigma faced by autistic individuals account for their inability to gain improved wellbeing and health. They shared that information on the disease

should be extensive to improve the perception held about adolescents with ASD. Similar assertions and suggestions were made by respondent in the current study.

5.1 Evaluation of the Model Used for this Study

The Quality of Life model by Betty Ferrel served as the organizing framework for this research. The objectives were developed based on the constructs of the model which include physical wellbeing, psychological wellbeing, social wellbeing and spiritual wellbeing were used to develop the objectives of the study as well as review literature. Most of the findings of the study were consistent with the constructs of the Quality of Life model.

Based on the Quality of Life model, the findings of this study revealed the physical, social, psychological and spiritual wellbeing of adolescents with autism. However, findings of this study revealed some factors which were not captured by the model. This was abuse of adolescents living with autism, the findings revealed that some adolescents living with autism were being abused both physically and psychologically. An additional theme that emerged from the data was inconsistent with the constructs of the theoretical framework. The study identified support systems as a theme and therefore suggest the theory should be modified in the future to make room for support systems as major construct.

5.2 Research Reflexivity

Before the Research

The researcher first heard of autism spectrum disorder when her daughter was very hyperactive and had delayed speech at two years. A paediatrician said she could be autistic and therefore was monitored for years but eventually wasn't diagnosed. The researcher is a practicing nurse and worked at the ears, nose and throat department of Okomfo Anokye teaching hospital, Kumasi where children with autism were referred for audiology. These children came in very aggressive sometimes and was difficult assessing their hearing. Mothers could be seen embarrassed by the actions of the children under the prying eyes of

people. This ignited my interest in Autism spectrum disorder for years until I got the opportunity to study the phenomenon. I wondered what it felt like to care for a child with autism and also the challenges they faced aside what I witnessed as a nurse. Over the years, I realized it wasn't so uncommon to meet children with autism but the adolescents seem not to exist hence my decision to research into the quality of life of adolescents with autism. Before the research, I was of the view that they attended mainstream school and quite independent in terms of their physical needs as adolescents. I also felt that parents had knowledge about the disease condition. As a nurse, parents were open to me about their wards condition and were ready to give information freely. The researcher also thought that there was no disparity in the fees charged in autism schools and that of the mainstream schools.

After Research

The main research came with a lot of challenges. The researcher decided to volunteer in an autism center to get acquainted with parents and their wards as well as to appreciate the care given in the center. Though I learnt a lot in my readings, the feeling was different experiencing so many adolescents with autism under one roof. I learnt that autism as a spectrum affected everyone differently and they faced different challenges and disabilities. Each child had a facilitator to themselves due to the level of care needed hence the high cost of tuition fee. Each child had specific goals designed by both parents and facilitators. Some facilitators showed me scares from injuries caused by the children during their episodes of aggression. Was able to acquaint myself with a few parents and they subsequently led me to other parents. During interviews some parents expressed how they were devastated with the condition of their wards and were praying for a miracle. Some felt having the interview was an opportunity to express their emotions. I spoke to more mothers than fathers and some explained that the fathers were out of their lives as a result of the condition of their wards. The few fathers I spoke to were very much invested in the lives of their children. A male

respondent told me how much he loves his son and goes everywhere with him. He even built a personal pool for him at home when he discovered his son's love for playing in water. Another male respondent I interviewed lived in fear of what might happen to his son should he pass someday.

As a nurse I have learnt to be more tolerant and understanding when caring for clients with autism as well as their parents. If possible, they should be given preferential treatment when seeking health care. As nurse educator, every health care giver should be given training and well informed about autism. The general public should also be sensitized about autism and the need to show empathy and care to affected families.



CHAPTER SIX

SUMMARY, CONCLUSION, IMPLICATIONS, LIMITATIONS AND RECOMMENDATIONS

6.0 Introduction

The study was set off to explore the quality of life of adolescents living with autism in Ghana. The previous chapter has provided a thorough discussion of the findings made from the interview engagements. This chapter offers a summary of the intentions and processes used in the study. It also draws out the conclusions arrived at by the investigator, the implications of the study in nursing and Limitations. Recommendations for future studies, policy and education.

6.1 Summary

This study explored the quality of life of adolescents living with autism in Ghana. Though quality of life of autistic individuals have been explored in the literature, the quality of life of the Ghanaian autistic adolescent has been under studied. The study therefore was an attempt to fill this evidence gap by exploring the physical, psychological, social and spiritual wellbeing of adolescents with autism, and the support systems available to them to live productive lives. Ferrel et al.'s (1996) quality improvement model and the quality of life model was chosen for this study. It was an exploratory qualitative study that collected data using an interview guide. The guide was developed by the investigator based on literature evidence. A sample of thirteen (13) parents of autistic adolescents in the Greater Accra region were sampled, Sampling was done using the purposive and snowballing techniques. Data was analyzed using thematic content analysis.

6.2 Conclusion

Adolescents with ASD were found to have low quality of physical wellbeing. They were found to have been affected negatively by the disease. They were not physically independent, had some physical deformations and medical illness. Their condition rendered them incapable of performing basic life functions unless under the assistance and supervision of their parents. Seizures, deformed feet and neck were also reported among autistic adolescents. These affected the physical wellbeing of adolescents, making them to have lower quality of life.

Contrary to literature, autistic adolescents had good social rapport. Irrespective of their medical condition and physically inabilities, they were reported to have had cordial relationship with their peers, relatives and other people in their community. They however had poor oral communication abilities. This affected their ability to maintain communication with people. Adolescents were also hyper and restless. In conclusion, autistic adolescents had good social wellbeing, as they were able to establish good and cordial relationship with people within their community.

Autistic adolescents were found to have reduced psychological wellbeing. They were reported to be moody, irritated, isolated at times, open and interactive. They were unable to maintain balanced behaviour. They were seen reacting differently at every point in time. Financial burden accounting to reduced psychological wellbeing was also reported. Adolescents with ASD however did not face distorted sleep patterns.

Finally, autistic adolescents had improved spiritual wellbeing. Parents indicated autistic adolescents could fully engage in religious activities and other spiritual events. They could pray, attend church, danced and sang at church. This was seen as a resource for which autistic adolescents received support to improve their functionality.

There were no support systems for the autistic adolescent. Recreational centers, job opportunities and educational support were not available for the autistic adolescents. Hence, parents pleaded for job and training opportunities, medical intervention and community engagement. These measures were to support autistic adolescents to function properly in their community.

6.3 Implications of the study

The findings of this study have implications for nursing practice, nursing research, caregiving, nursing education and policy formulation

6.3.1 Nursing Practice

The findings of this study showed that more adolescents living with autism in the Accra metropolis had a low quality of life due to their condition. Nurses in practice can help improve their quality of life by educating both parents and adolescents on how to cope and live with the condition. The parents should be involved and supported because of the stress that comes with caring for children with autism. They could also be taken through counselling and therapy to

assist them live with the condition. The general public should also be educated to be more understanding, tolerant and accommodating of adolescents living with autism as well as their parents. Health care should be readily and easily accessible to these parents and their children. Hospital management should put measures in place to enable parents and children feel comfortable at the various health facilities.

6.3.2 Nursing Research and Education

There is the need to conduct further studies on adolescent autism spectrum disorder especially in other metropolis to assess the quality of life of adolescents living with autism. This will enable the researcher to ascertain if there are similarities or disparities in the quality

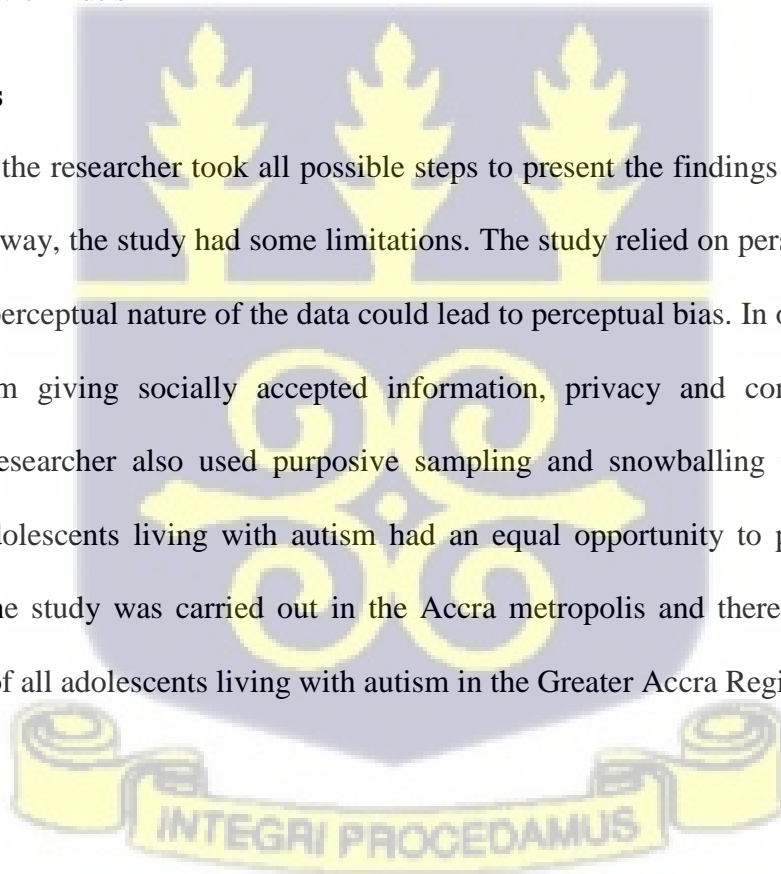
of life of adolescents living with autism. It took this research to learn about very significant issues pertaining to autism, though I have practiced as a nurse for 8 years. It's therefore prudent that autism as a disease condition should be studied in our various health institutions. The general public should also be given the needed education

6.3.3 Policy Making

The findings of the study showed that health professionals and some care givers had limited knowledge on autism. Policy makers should therefore enact a policy that to ensure training and sensitization of health workers and care givers of children with Autism. The government should also provide infrastructure and avenues for teaching and learning for children living with Autism

6.4 Limitations

Though the researcher took all possible steps to present the findings of the study in a comprehensive way, the study had some limitations. The study relied on personal perspective and due to the perceptual nature of the data could lead to perceptual bias. In other to avoid the respondent from giving socially accepted information, privacy and confidentiality was ensured. The researcher also used purposive sampling and snowballing therefore not all parents with adolescents living with autism had an equal opportunity to participate in the study. Lastly the study was carried out in the Accra metropolis and therefore cannot be a representation of all adolescents living with autism in the Greater Accra Region.



6.5 Recommendations based on the findings

1. Government should provide recreational and social centers to support the normal growth and functioning of autistic adolescents as most of the adolescents with autism are normally left to the fate of the family to help provide some form of recreation for their own.
2. Government and other non-governmental organizations should provide training and educational support for autistic adolescents. For instance, some corporate organizations as part of the corporate social responsibilities can embark on training to give these autistic children some form of trade.
3. Health educators should enhance public education on autism among Ghanaian populace to reduce stigma surrounding the autism spectrum disorder.
4. The quality of life of autistic adolescents in other parts of Ghana should also be explored.
5. There is also the need for strict policies by the Ministry of education for preschools to incorporate early childhood education and special-needs education in to the training for all preschool teachers which will help them to integrate the children into the school curriculum.
6. Much awareness needs to be created by the autistic center especially in the month of autism through educational seminars and the media aimed at educating the public on autism spectrum disorder.

REFERENCES

- Abubakar, A., Ssewanyana, M., & Newton, C. R. (2016). A systematic review of research on autism spectrum disorders in sub-Saharan Africa. *Behavioural Neurology*, 2016.
- Agyekum, H. A. (2018). Challenges of parents with autistic children in Ghana. *Brain DisordTher* 7, 248. DOI: 10.4172/2168-975X.1000248
- American Association on Intellectual and Developmental Disabilities. (2010). *Definition of intellectual disability*. Retrieved from: <http://aaidd.org/intellectual-disability/definition#.V3T8YDVa8ZM>
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed. Rev.). Washington, DC: American Psychiatric Association.
- American Psychiatry Association (2013). *Diagnostic and statistical manual of mental disorders 5. American Journal of Psychiatry* (5th ed.). Wahington, DC: American Psychiatric Publishing.
- Anderson, K. A., Shattuck, P. T., Cooper, B. P., Roux, A. M., & Wagner, M. (2014). Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism*, 18, 5, 562-570. doi:10.1177/1362361313481860
- Anixt, J. S., Murray, D. S., Coury, D. L., Kuhlthau, K. A., Eskra, D., Seide, J., & Fedele, A. (2020). Improving behaviour challenges and quality of life in the autism learning health network. *Pediatrics*, 145(Supplement 1), S20-S29.
- Arias, V. B., Gómez, L. E., Morán, M. L., Alcedo, M. A., Monsalve, A. Y & Fontanil, M. Y. (2018). Does quality of life differ for children with autism spectrum disorder and intellectual disability compared to peers without autism? *Journal of Autism and Developmental Disorders*, 48, 123-136. doi: 10.1007/s10803-017-3289-8.

- Arif, M. M., Niazy, A., Hassan, B., & Ahmed, F. (2013). *Awareness of autism in primary school Teachers*. Hindawi Publishing Corporation, 10.
- Askari, S., Anaby, D., Bergthorson, M., Majnemer, A., Elsabbagh, M., & Zwaigenbaum, L. (2015). Participation of children and youth with autism spectrum disorder: a scoping review. *Journal of Autism and Developmental Disorders*, 2, 103–114. doi:10.1007/s40489-014-0040-7
- Bakare, M. O., Ebigbo, P. O., & Ubochi, V. N. (2012). Prevalence of autism spectrum disorder among Nigerian children with intellectual disability. *A Stopgap Assessment*. 23, 2, 513-518.
- Bakare, M., O., & Munir, K., M. (2011). Autism spectrum disorders (ASD) in Africa: a perspective. *Afr J Psychiatry*, 14, 3, 208-10. DOI: 10.4314/ajpsy.v14i3.3.
- Balcells-Balcells, A., Giné, C., Guàrdia-Olmos, J., Summers, J. A., & Mas, J. M. (2019). Impact of supports and partnership on family quality of life. *Research in Developmental Disabilities*, 85, 50-60. doi:10.1016/j.ridd.2018.10.006
- Balmaña, N., & Calvo, R. (2014). Trastornos del espectroautista. In L. Ezpeleta, and Y J. Toro (Eds.), *Psicopatología del desarrollo* (pp. 191-210). Madrid, Spain: Pirámide
- Bent, S., Wahlberg, J., Chen, Y., Widjaja, F., McDonald, M. G., & Hendren, R. L. (2020). Quality of life among school-age children with autism: the Oak Hill school outcomes study: quality of life in autism. In *Seminars in Pediatric Neurology* (p. 100808). WB Saunders.
- Beck, K., Greco, C., Terhorst, L., Mindfulness, E. S. (2020). Mindfulness-based stress reduction for adults with autism spectrum disorder: feasibility and estimated effects. *Springer*. Retrieved October 27, 2022, from

<https://link.springer.com/article/10.1007/s12671-020-01345-2>

Billstedt, E., Gillberg, I. C. & Gillberg, C. (2011). Aspects of quality of life in adults diagnosed with autism in childhood: A population-based study. *Autism, 15*, 7-20.

Bishop-Fitzpatrick, L., Mazefsky, C. A., & Eack, S. M. (2017). The combined impact of social support and perceived stress on quality of life in adults with autism spectrum disorder and without intellectual disability. *Autism: The International Journal of Research and Practice*. <https://doi.org/10.1177/1362361317703090>
[1362361317703090](https://doi.org/10.1177/1362361317703090)

Broder-Fingert, S., Shui, A., Ferrone, C., Iannuzzi, D., Cheng, E. R., Giaque, A., Kuhlthau, K. (2016). A pilot study of autism-specific care plans during hospital admission. *Pediatrics, 137*, 2, 196-204. doi:10.1542/peds.2015-2851R

Buchnat, M., Specjalnej, A. W.-K. P. (2020). Online education of students with mild intellectual disability and autism spectrum disorder during the COVID-19 pandemic. *Sciendocom*. <https://doi.org/10.14746/ikps.2020.29.07>

Buntinx, W. H., & Schalock, R. L. (2010). Models of disability, quality of life, and individualized supports: implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities, 7*(4), 283-294. doi:10.1111/j.1741-1130.2010.00278.x

Burgess, F. & Gutstein, S. E. (2007). Quality of life for people with autism: raising the standard for evaluating successful outcomes. *Child and Adolescent Mental Health, 12*(2), 80-86.

- Cappadocia, M. C., Weiss, J. A., & Pepler, D. (2012). Bullying experiences among children and youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42, 2, 266-277. doi:10.1007/s10803-011-1241-x
- Cappe, E., Wolff, M., Bobet, R., & Adrien, J. L. (2011). Quality of life: a key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes. *Quality of Life Research*, 20(8), 1279–1294.
- Cheak-Zamora, N. C., Teti, M., Peters, C., & Maurer-Batjer, A. (2017). Financial capabilities among youth with autism spectrum disorder. *Journal of Child and Family Studies*, 26, 5, 1310-1317. doi:10.1007/s10826-017-0669-9
- Chou, Y. C., Wehmeyer, M. L., Shogren, K. A., Palmer, S. B. Y. & Lee, J. H. (2017). Autism and self-determination: factor analysis of two measures of self-determination. *Focus on Autism and Other Developmental Disabilities*, 32(3), 163-175. doi: 10.1177/1088357615611391.
- Claes, C., van Hove, G., van Loon, J., Vandeveld, S., & Schalock, R. L. (2010). Quality of life measurement in the field of intellectual disabilities: eight principles for assessing quality of life-related personal outcomes. *Social Indicators Research*, 98, 1, 61-72. doi: 10.1007/s11205-009-9517-7
- Collins, B., & Ault, M. (2020). Including persons with disabilities in the religious community: program models implemented by two churches. *Journal of Religion, Disability & Health*, 14, 2, 113-131.
- Cummins, R. A., Lau, A. L. D., & Stokes, M. (2004). HRQOL and subjective well-being: Noncomplementary forms of outcome measurement. *Expert Review of*

Pharmacoeconomics & Outcomes Research, 4, 4, 413-420.

doi:10.1586/14737167.4.4.413

deMaeyer, J., Vanderplasschen, W., Lammertyn, J., van Nieuwenhuizen, C., Sabbe, B., & Broekaert, E. (2011). Current quality of life and its determinants among opiate-dependent individuals five years after starting methadone treatment. *Quality of Life Research*, 20, 1, 139-150. doi:10.1007/s11136-010-9732—3

deVries, M., Cader, S., Colleer, L., Batteux, E., Yasdiman, M. B., Tan, Y. J., Disorders, D. (2020). University students' notion of autism spectrum conditions: a cross-cultural study, 1-14.

Demer, L. L. (2018). The autism spectrum: human rights perspectives. *Pediatrics*, 141, 4, 369-372. doi:10.1542/peds.2016-43000

Denkyirah, A. M., & Agbeke, W. K. (2010). Strategies for transitioning preschoolers with autism spectrum disorders to kindergarten. *Early Childhood Education Journal*, 38, 4, 265–270. <https://doi.org/10.1007/s10643-010-0407-z>

Department of Health (United Kingdom) (2001). *Valuing people: A new strategy for learning disability for the 21st century: A white paper*. Retrieved from <http://www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf>.

Dillenburger, K., Jordan, J. A., McKerr, L., Lloyd, K., & Schubotz, D. (2017). Autism awareness in children and young people: surveys of two populations. *Journal of Intellectual Disability Research*, 61, 8, 766–777. <https://doi.org/10.1111/jir.12389>

Dodd Inglese, M., & Harrison Elder, J. (2009). Caring for children with autism spectrum disorder. Part I: Prevalence, etiology, and core features. *Journal of Pediatric Nursing*, 24, 1, 41–48. <https://doi.org/10.1016/j.pedn.2007.12.006>

- Dovgan, K. N., & Mazurek, M. O. (2019). Relations among activity participation, friendship, and internalizing problems in children with autism spectrum disorder. *Autism, 23*, 3, 750-758. doi:10.1177/1362361318775541
- Dunn, K., Rydzewska, E., MacIntyre, C., Rintoul, J., & Cooper, S. A. (2019). The prevalence and general health status of people with intellectual disabilities and autism co-occurring together: a total population study. *Journal of Intellectual Disability Research, 63*(4), 277-285. doi:10.1111/jir.12573
- Felce, D., & Perry, J. (1995). Quality of life: its definition and measurement. *Research in Developmental Disabilities, 16*. 54-74.
- Ferrell, B. R., Grant, M., Funk, B., Garcia, N., Otis-Green, S., & Schaffner, M. L. (1996). Quality of life in breast cancer. *Cancer Practice, 4*, 331-340.
- Feuerbacher, S., Moore, M., & Gill, H. (2017). Bullying and social vulnerability of students with autism spectrum disorder. In C. Little (Ed.), *Supporting social inclusion for students with autism spectrum disorders: Insights from research and practice* (pp. 33-45). New York, NY: Taylor & Francis.
- Formentos, A., Ae-Ngibise, N., K., Nyame, S. & Asante, K.,P. (2021). Situational analysis of service provision for adolescents with mental and neurological disorders in in two districts of Ghana. *International Journal of Mental Health Systems, 15*, 35. <https://doi.org/10.1186/s13033-021-00457-z>
- Gal, E., Selanikyo, E., Erez, A. B. H. & Katz, N. (2015). Integration in the vocational World: How does it affect quality of life and Subjective well-being of young adults with ASD. *International Journal Of Environmental Research and Public Health, 12*, 10820-10832.

- Garcia-Villamizar, D. & Matson, S. (2013). Quality of life as a mediator between behavioral challenges and autistic traits for adults with intellectual disabilities. *Research in Autism Spectrum Disorders*, 7, 624-629.
- Garrido, D., Carballo, G., & Garcia-Retamero, R. (2020). Siblings of children with autism spectrum disorders: social support and family quality of life. *Quality of Life Research*, 1-10.
- Gerber, F., Baud, M. A., Giroud, M., & Galli G. C. (2008). Quality of life of adults with pervasive developmental disorders and intellectual disabilities. *Journal of Autism and Developmental Disorders*, 38(9), 1654–1665.
- Ghanouni, P., Jarus, T., Zwicker, J. G., Lucyshyn, J., Chauhan, S., & Moir, C. (2019). Perceived barriers and existing challenges in participation of children with autism spectrum disorders: “He did not understand and no one else seemed to understand him”. *Journal of Autism and Developmental Disorders*, 49, 8, 3136-3145. doi:10.1007/s10803-019-04036-7
- Gómez, L. E., Alcedo, M. A., Verdugo, M. A., Arias, B., Fontanil, Y., Arias, V. B., & Morán, L. (2016). *EscalaKidsLife: evaluación de la calidad de vida de niños y adolescentes con discapacidad intelectual*. [Kids life scale: evaluation of the quality of life of children and adolescents with intellectual disabilities]. Salamanca, Spain: Instituto Universitario de Integración en la Comunidad. Retrieved from https://sid.usal.es/docs/F8/FDO27258/Herramientas_10_2016.pdf
- Gómez, L. E., Arias, B., Verdugo, M. A., & Navas, P. (2012). An outcomes-based assessment of quality of life in social services. *Social Indicators Research*, 106, 1, 81-93. doi:10.1007/s11205-011-9794-9

- Gómez, L. E., Verdugo, M. A., & Arias, B. (2010). Calidad de vida individual: avances en su conceptualización y retos emergentes en el ámbito de la discapacidad. [Candid individual life: advances in its conceptualization and emerging challenges in the field of disability] *Behavioral Psychology/Psicología Conductual*, 18, 3, 453-472.
- Gomez, L. E., Verdugo, M. A., & Arias, B. (2015). Validity and reliability of the INICO-FEAPS scale: An assessment of quality of life for people with intellectual and developmental disabilities. *Research in Developmental Disabilities*, 36, 600–610
- Green, H., McGinnity, A., Meltzer, H., Ford, T., & Goodman, R. (2004). Mental health of children and young people in Great Britain, 2004. In *National statistics*. <https://doi.org/10.1037/e557702010-001>
- Happé, F., & Frith, U. (2020). Annual Research Review: Looking back to look forward – changes in the concept of autism and implications for future research. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 61(3), 218–232. <https://doi.org/10.1111/JCPP.13176>
- Havercamp, S. M., Ratliff-Schaub, K., Navas, P., Johnson, C. N., Bush, K. L., & Souders, H. T. (2016). Preparing tomorrow's doctors to care for patients with autism spectrum disorder. *Intellectual and Developmental Disabilities*, 54, 3, 202-216. doi:10.1352/1934-9556-54.3.202
- Hesselmark, E., Plenty, S. & Bejerot, S. (2014). Group cognitive behavioural therapy and group recreational activity for adults with autism spectrum disorders: A preliminary randomized controlled trial. *Autism*, 18, 672-683.
- Hong, J., Bishop-Fitzpatrick, L., Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2016). Factors associated with subjective quality of life of adults with autism spectrum

- disorder: Self-report versus maternal reports. *Journal of Autism and Developmental Disorders*, 46(4), 1368–1378.
- Hourcade, J. (2002). *Mental retardation: Update 2002*. Arlington, VA: ERIC.
- Jaswal, V. K., & Akhtar, N. (2019). Being versus appearing socially uninterested: challenging assumptions about social motivation in autism. *Behavioral and Brain Sciences*, 42, e82. doi: 10.1017/S0140525X18001826
- Kaiser, A. P. (2000). Teaching functional communication skills. In M. E. Snell & F. Brown (Eds.), *Instruction of persons with severe disabilities* (5th ed., p. 453-492). Columbus, OH: Merrill.
- Kasari, C., Locke, J., Gulsrud, A., & Rotheram-Fuller, E. (2011). Social networks and friendships at school: comparing children with and without ASD. *Journal of Autism and Developmental Disorders*, 41, 5, 533-544. doi:10.1007/s10803-010-1076-x
- Katz, N., Dejak, I. & Gal, E. (2015). Work performance evaluation and QoL of adults with High Functioning Autism Spectrum Disorders (HFASD). *Work*, 51, 887-892.
- Khanna, R., Jariwala-Parikh, K., West-Strum, D. & Mahabaleshwarkar, R. (2014). Health-related quality of life and its determinants among adults with autism. *Research in Autism Spectrum Disorders*, 8, 157-167
- Kuhlthau, K., Kovacs, E., Hall, T., Clemmons, T., Orlich F., Delahaye, J., Sikora, D. (2013). Health-related quality of life for children with ASD: associations with behavioral characteristics. *Research in Autism Spectrum Disorders*, 7, 1035–1042. doi:10.1016/j.rasd.2013.04.006
- Kunz, R. (2011). You have not forgotten us: towards a disability-accessible church and society. *Journal of Religion, Disability & Health*, 15, 1, 20-33.

- Lai, M.-C., Lombardo, M. V, Pasco, G., Ruigrok, A. N. V, Wheelwright, S. J., Sadek, S. A., & Baron-Cohen, S. (2011). A behavioral comparison of male and female adults with high functioning autism spectrum conditions. *PloS One*, 6(6), e20835. <https://doi.org/10.1371/journal.pone.0020835>
- Lawson, L. P., Richdale, A. L., Haschek, A., Flower, R. L., Vartuli, J., Arnold, S. R., & Trollor, J. N. (2020). Cross-sectional and longitudinal predictors of quality of life in autistic individuals from adolescence to adulthood: The role of mental health and sleep quality. *Autism*, 24, 4, 954-967.
- Leader, G., O'Reilly, M., Gilroy, S. P., Chen, J. L., Ferrari, C., & Mannion, A. (2020). Comorbid feeding and gastrointestinal symptoms, challenging behavior, sensory issues, adaptive functioning and quality of life in children and adolescents with autism spectrum disorder. *Developmental Neurorehabilitation*, 1-10.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. sage.
- Lin, L. Y. (2014). Quality of life of Taiwanese adults with autism spectrum disorder. *PloS One*, 9(10) e109567-e109567.
- Liu, Y., Li, J., Zheng, Q., Zaroff, C. M., Hall, B. J., Li, X., & Hao, Y. (2016). Knowledge, attitudes, and perceptions of autism spectrum disorder in a stratified sampling of preschool teachers in China. *BMC Psychiatry*, 16(1), 1–12. <https://doi.org/10.1186/s12888-016-0845->
- Lo-Biondo-Wood G, Haber J. (2010). *Nursing Research Methods and Critical Appraisal for Evidence-Based Practice*. 7 edn. Missouri: Mosby Elsevier.
- Luckasson, R., Borthwick-Duffy, S., Butinx, W., Coulter, D., Craig, E., Reeve, A., Schalock, R., Snell, M., Spitalnick, D., Spreat, S., & Tasse, M. (2002). *Mental retardation:*

Definition, support and systems (10thed.). Washington, DC: American Association on Mental Retardation.

Manu, N. (2012). *Beliefs and attitude towards autism*. Norwegian University of Science and Technology.

Mazurek, M. O., & Petroski, G. F. (2015). Sleep problems in children with autism spectrum disorder: examining the contributions of sensory over-responsivity and anxiety. *Sleep Medicine, 16*, 2, 270-279. doi:10.1016/j.sleep.2014.11.006

Mazurek, M. O., Kanne, S. M., & Wodka, E. L. (2013). Physical aggression in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders, 7*, 3, 455–465. <https://doi.org/10.1016/j.rasd.2012.11.004>

Merriman, K., Burke, T., & O'Reilly, G. (2020). A systematic review of the effectiveness and efficacy of clinician-led psychological interventions for parents of children with ASD. *Research in Autism Spectrum Disorders, 76*, 101584.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*. sage.

Moss, P., Mandy, W., & Howlin, P. (2017). Child and adult factors related to quality of life in adults with autism. *Journal of Autism and Developmental Disorders, 47*(6), 1830–1837.

Oti-Boadi, M., Dankyi, E., & Kwakye-Nuako, D. (2020). *Stigma and forgiveness in Ghanaian mothers of children with autism spectrum disorders (ASD)*. 1-10.

Pamela, D. T., Badoe, E.V., & Owusu, N. A. (2015). Family perspectives of autism spectrum disorder in urban Ghana. *Journal of the International Child Neurology Association*.

- Papadopoulos, C. (2016). Autism stigma and the role of ethnicity and culture. *Autism Research*, (November). Retrieved from <https://network.autism.org.uk/sites/default/files/ckfinder/files/Autism-stigma-role-of-ethnicity-PDF-version.pdf>
- Petrina, N., Carter, M., & Stephenson, J. (2014). The nature of friendship in children with autism spectrum disorders: a systematic review. *Research in Autism Spectrum Disorders*, 8, 2, 111-126. doi:10.1016/j.rasd.2013.10.016
- Polit, D. F., Beck, C. T. & Hungler, B. P. (2001). *Essentials of nursing research: Methods, appraisal and utilization*. (5th ed.). Lippincott-Raven, Philadelphia.
- Polit, D.F., Beck, C.T., 2008. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*, 8th ed. Lippincott Williams & Wilkins, Philadelphia, PA.
- Polit, D., & Hungler, B. (1999). *Nursing research: Principles and methods*. New York: J B Lippincott.
- Polit, D. F., Beck, C. T., & Hungler, B. P. (2006). *Essentials of nursing research: Methods, appraisal, and utilization* (6th ed.). New York, NY: Lippincott.
- Rodda, A., & Estes, A. (2018). Beyond social skills: supporting peer relationships and friendships for school-aged children with autism spectrum disorder. *Seminars in Speech and Language*, 39, 2, 178-194. doi:10.1055/s-0038-1628369
- Rowley, E., Chandler, S., Baird, G., Simonoff, E., Pickles, A., Loucas, T., & Charman, T. (2012). The experience of friendship, victimization and bullying in children with an autism spectrum disorder: associations with child characteristics and school placement. *Research in Autism Spectrum Disorders*, 6, 1126–1134. doi:10.1016/j.rasd.2012.03.004

- Ruparelia, K., Abubakar, A., Badoe, E., Bakare, M., Visser, K., Chugani, D. C., & Shih, A. J. (2016). *Autism spectrum disorders in Africa: Current challenges in identification, assessment, and treatment: A report on the International child neurology association meeting on ASD in Africa, Ghana, April 3-5, 2014*. 31, 8, 1018-1026.
- Saldaña, D., Álvarez, R. M., Lobatón, S., Lopez, A. M., Moreno, M. & Rojano, M. (2009). Objective and subjective quality of life in adults with autism spectrum disorders in southern Spain. *Autism*, 13, 303-316.
- Scahill, L. & Karen, B. (2010). The rise in autism and the mercury myth. *Journal of Child & Adolescent Psychiatric Nursing*, 22, 1 (2009), 51-53. Academic Search Premier. Web. 12.
- Schalock, R. L. (2017). Introduction to the special issue on disability policy in a time of change. *Intellectual and Developmental Disabilities*, 55, 215-222. doi:10.1352/1934-9556-55.4.215
- Schalock, R. L., & Keith, K. D. (2016). The evolution of the quality-of-life concept. In R. L. Schalock & K. D. Keith (Eds.), *Cross-cultural quality of life: enhancing the lives of people with intellectual disability* (pp. 3-12). Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Schalock, R. L., & Verdugo, M. A. (2002). *Handbook on quality of life for human service practitioners*. Washington, DC: American Association on Mental Retardation.
- Schalock, R. L., & Verdugo, M. A. (2002). *Quality of life for human service practitioners*. Washington, DC: American Association on Mental Retardation
- Schalock, R. L., & Verdugo, M. A. (2007). El concepto de calidad de vida en los servicios y apoyos para personas con discapacidad intelectual. [The concept of quality of life in services an support for people with intellectual disabilities] *Siglo Cero*, 38, 4, 21-36.

- Schalock, R. L., Bonham, G. S., & Verdugo, M. A. (2008). The conceptualization and measurement of quality of life: implications for program planning and evaluation in the field of intellectual disabilities. *Evaluation and Program Planning*, 31(2), 181–190.
- Schalock, R. L., Luckasson, R., & Tassé, M. J. (2019). The contemporary view of intellectual and developmental disabilities: implications for psychologists. *Psicothema*, 31(3), 223–228. doi:10.7334/psicothema2019.119
- Schalock, R. L., Luckasson, R., Tassé, M. J., & Verdugo, M. A. (2018). A holistic theoretical approach to intellectual disability: going beyond the four current perspectives. *Intellectual and Developmental Disabilities*, 56, 2, 79–89. doi:10.1352/1934-9556-56.2.79.
- Schalock, R. L., Verdugo, M. A., & Gómez, L. E. (2011). Evidence-based practices in the field of intellectual and developmental disabilities. *Evaluation and Program Planning*, 34, 273–282. doi:10.1016/j.evalprogplan.2010.10.004
- Schalock, R. L., Verdugo, M. A., Gómez, L. E., & Reinders, H. (2016). Moving us toward a theory of individual quality of life. *American Journal on Intellectual and Developmental Disabilities*, 121, 1, 1–12. doi:10.1352/1944-7558-121.1.1
- Schiavone, N., Szczepanik, D., Koutras, J., Pfeiffer, B., & Slugg, L. (2018). Caregiver strategies to enhance participation in children with autism spectrum disorder. *OTJR: Occupation, Participation and Health*, 38, 4, 235–244. doi:10.1177/1539449218786713
- See, C. M. (2012). The use of music and movement therapy to modify behaviour of children with autism. *Pertanika Journal of Social Science and Humanities*, 20(4), 1103–1116.

- Shamsudin, S. B., & Rahman, A. S. S. (2014). A preliminary study : awareness , knowledge and attitude of people towards children with autism. *Proceeding of the Social Sciences Research ICSSR, 2014*(June), 322–332
- Shattuck, P. T., Orsmond, G. I., Wagner, M., & Cooper, B. P. (2011). Participation in social activities among adolescents with an autism spectrum disorder. *PloS One, 6*, 11, e27176. doi:10.1371/journal.pone.0027176
- Shree, A. & Shukla, P. C. (2016). Intellectual disability: definition, classification, causes and characteristics. *Learning Community, 7*(1), 9-20
- Sonido, M. T., Hwang, Y. I. J., Trollor, J. N., & Arnold, S. R. (2020). The mental well-being of informal carers of adults on the autism spectrum: a systematic review. *Review Journal of Autism and Developmental Disorders, 7*, 1, 63-77.
- Suarez, M, L, M. (2020). *Quality of life in children and youth with autism spectrum disorder and intellectual disability*. [Doctoral dissertation] Universidad de Oviedo
- Taheri, A., Perry, A., & Minnes, P. (2016). Examining the social participation of children and adolescents with intellectual disabilities and autism spectrum disorder in relation to peers. *Journal of Intellectual Disability Research, 60*, 5, 435-443. doi:10.1111/jir.12289
- Thurm, A., Farmer, C., Salzman, E., Lord, C., & Bishop, S. (2019). State of the field: Differentiating intellectual disability from autism spectrum disorder. *Frontiers in Psychiatry, 10*, 526. <https://doi.org/10.3389/FPSYT.2019.00526/BIBTEX>
- Tonkin, B. L., Ogilvie, B. D., Greenwood, S. A., Law, M. C., & Anaby, D. R. (2014). The participation of children and youth with disabilities in activities outside of school: A

scoping review. *Canadian Journal of Occupational Therapy*, 81(4), 226–236.

<https://doi.org/10.1177/0008417414550998>

Tricia, S., Owusu, A., Tyrone, P. & McKay, M (2015). Meeting the needs of children and families with communication and other developmental difficulties in Accra, Ghana—An assessment of the AwaaWaa2 Community-based Program. *Global Social Welfare*, 2, 111–118. DOI 10.1007/s40609-015-0033-1

Twi-Yeboah, A. (2019). *Perception of child autism among preschool teachers in the Ledzokuku-Krowor municipal assembly*. [Master's dissertation] University of Ghana.

UNICEF. (1989). *The convention on the rights of the Child*. Available at: <http://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf>

vanEwijk, H., Wansink-Lokerman, M., Lamerz, A., & van den Broek, S. (2020). Positive effects of surfing on psychological wellbeing for children with developmental difficulties. *Global Journal of Community Psychology Practice*, 11, 2.

Vetri, L., & Roccella, M. (2020). On the playing field to improve: A goal for autism. *Medicina*, 56(11), 585.

Walsh, M. B., Alice, W. & William, C. G. (2011). *Autism and faith: a journey into community*. New Brunswick: Elizabeth M. Boggs Center on Developmental Disabilities.

Wehman, P. (1997). *Exceptional individuals in school, community, and work*. Austin, TX: PRO-ED.

WHO (2018). CIE-11. *International classification of diseases* (11thed.). Retrieved from <https://icd.who.int/browse11/l-m/es>

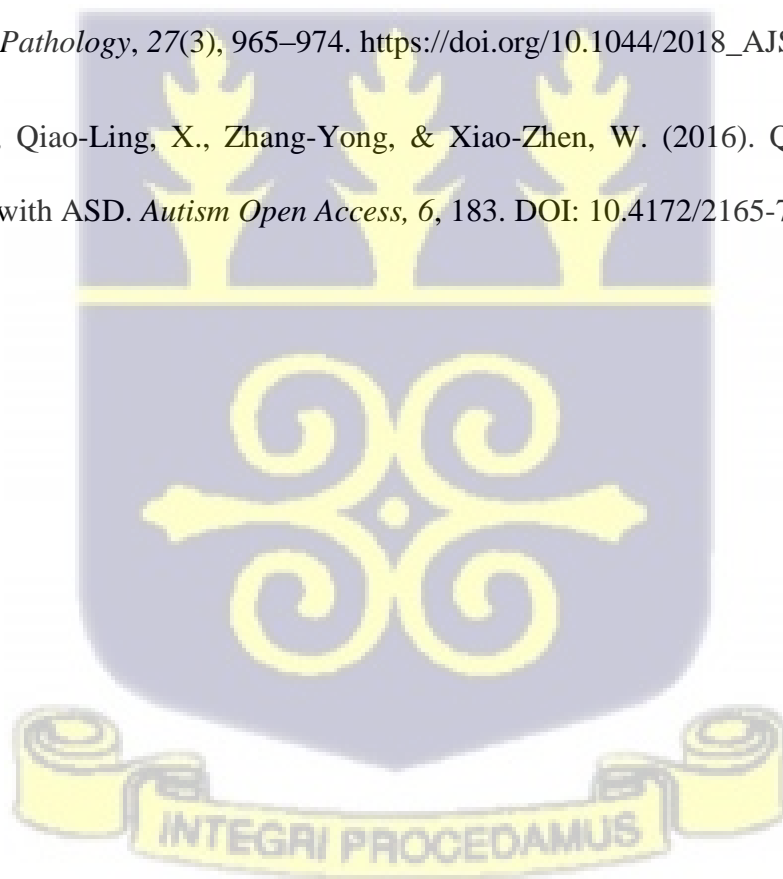
Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9, 11–29.

World Health Organization. (1995). *The world health organization quality of life assessment (WHOQOL)*:

World Health Organization. (2013). International statistical classification of diseases and related health problems (10th revision). Geneva: WHO. [Google Scholar]

Wynn, C. J., Borrie, S. A., & Sellers, T. P. (2018). Speech Rate Entrainment in Children and Adults With and Without Autism Spectrum Disorder. *American Journal of Speech-Language Pathology*, 27(3), 965–974. https://doi.org/10.1044/2018_AJSLP-17-0134

Zhen-Huan, L., Qiao-Ling, X., Zhang-Yong, & Xiao-Zhen, W. (2016). Quality of life of children with ASD. *Autism Open Access*, 6, 183. DOI: 10.4172/2165-7890.1000183



INTERVIEW GUIDE

SECTION A

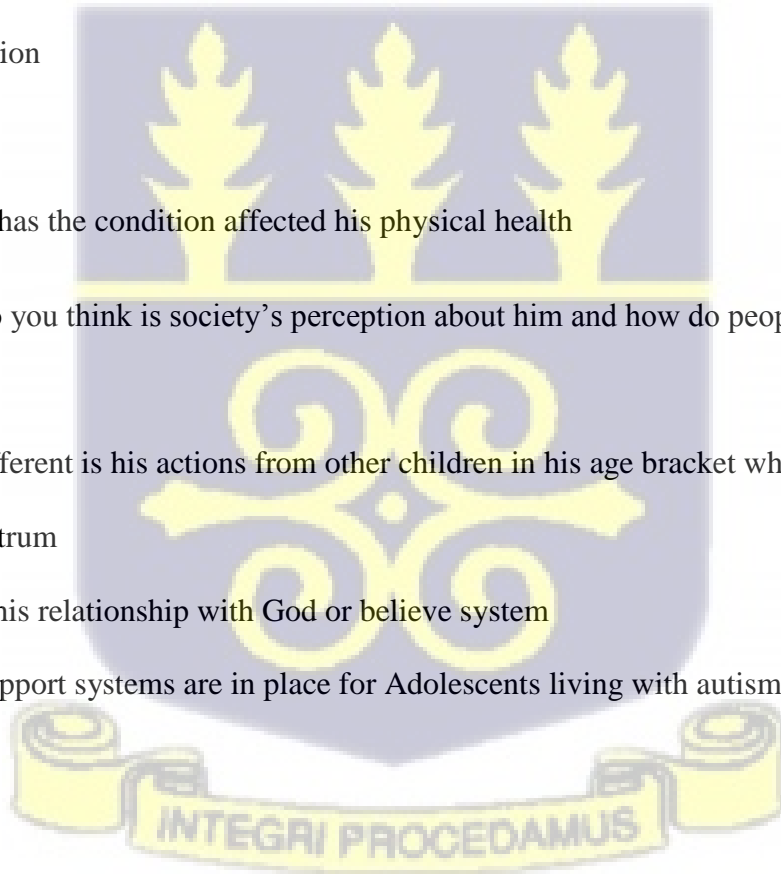
PERSONAL INFORMATION

1. What is your child's age?.....
2. Sex: male[] female
3. Religion: Muslim[] Christian[] Traditionalist[]
4. Ethnicity: Gonja[] Ashant[] Hausa[] Others(specify).....
5. Educational Status: Primary school[] Junior high[] Senior high[] Tertiary[] No education[]
6. Marital Status: Married[] Divorced[] Single[]
7. Occupation

SECTION B

To what extent has the condition affected his physical health

1. What do you think is society's perception about him and how do people relate with him
2. How different is his actions from other children in his age bracket who are not under the spectrum
3. How is his relationship with God or believe system
4. What support systems are in place for Adolescents living with autism



GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

In case of reply the number and date of this Letter should be quoted.



Research & Development Division
Ghana Health Service
P. O. Box MB 190
Accra
Digital Address: GA-050-3303
Mob: +233-50-3539896
Tel: +233-302-681109
Fax + 233-302-685424
Email: ethics.research@ghsmail.org
19th July, 2021

My Ref. GHS/RDD/ERC/Admin/App 121/283
Your Ref. No.

Khadija Atchulo
University of Ghana,
School of Nursing and Midwifery
P. O. Box LG 43 Legon, Accra

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol.

GHS-ERC Number	GHS-ERC 049/05/21
Project Title	Parents' Perspectives on Quality of Life of Adolescents Living with Autism Spectrum Disorder: A Study in the Accra Metropolis.
Approval Date	19 th July, 2021
Expiry Date	18 th July, 2022
GHS-ERC Decision	Approved

This approval requires the following from the Principal Investigator

- Submission of yearly progress report of the study to the Ethics Review Committee (ERC)
- Renewal of ethical approval if the study lasts for more than 12 months,
- Reporting of all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.
- Submission of a final report after completion of the study
- Informing ERC if study cannot be implemented or is discontinued and reasons why
- Informing the ERC and your sponsor (where applicable) before any publication of the research findings.
- Please note that any modification of the study without ERC approval of the amendment is invalid.

The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Kindly quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED.....
Dr. James Akazili
(Head, Ethics & Research Management Department)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra



UNIVERSITY OF GHANA
SCHOOL OF NURSING AND MIDWIFERY

Ref. No.:

ID: 10754084

18th May, 2021

**The Chairperson,
Ethics Review Committee
Ghana Health Service
Accra.**

Dear Sir/Madam,

LETTER OF INTRODUCTION – ETHICAL CLEARANCE

I write to introduce to you **Khadija Atchulo**, an MPhil Nursing student at the School of Nursing and Midwifery, University of Ghana, Legon.

The Scientific Review Committee of the School has approved the thesis topic: **“Parents’ Perspectives on Quality of Life of Adolescents Living with Autism Spectrum Disorder: A Study in the Accra Metropolis.”**

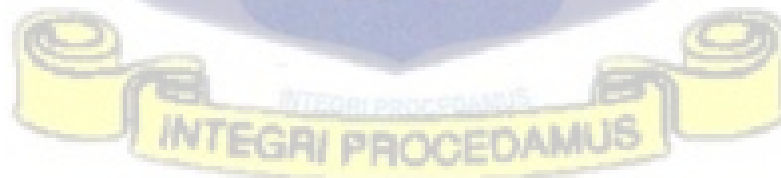
As part of the School’s requirement, the student is required to obtain ethical clearance before embarking on data collection.

I hope that the Committee will consider the proposal and grant her ethical clearance to enable her to undertake the study.

Thank you.

Yours faithfully,

**Charles A. Klutse
School Administrator**



COLLEGE OF HEALTH SCIENCES



UNIVERSITY OF GHANA
DEPARTMENT OF ADULT HEALTH
SCHOOL OF NURSING

Ref. No.: ID: T0754084

18th May, 2021

**The Chairperson.
Ethics Review Committee
Ghana Health Service
Accra.**

Dear Sir/Madam,

LETTER OF SUPPORT – ETHICAL CLEARANCE

This letter is to support the application for ethical clearance of **Khadija Atchulo**, an MPhil. Nursing student in the Department of Adult Health at the School of Nursing and Midwifery, University of Ghana, Legon.

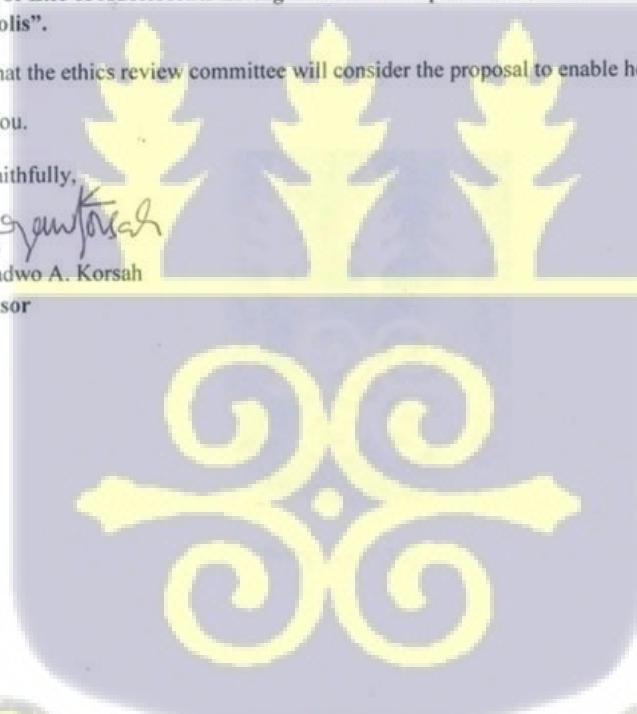
As part of the programme, she is to undertake a research on the topic: **“Parents’ Perspectives on Quality of Life of Adolescents Living with Autism Spectrum Disorder: A Study in the Accra Metropolis”**.

I hope that the ethics review committee will consider the proposal to enable her collect data.

Thank you.

Yours faithfully,

Dr. Kwadwo A. Korsah
Supervisor



COLLEGE OF HEALTH SCIENCES

• P. O. Box LG 43, Legon, Accra, Ghana. • Telephone: +233 (0) 302 513 250 / 0289 531 213
• Email: adulthealth.son@chs.ug.edu.gh • Website: www.nursing.chs.ug.edu.gh

INTEGRI PROCEDAMUS



UNIVERSITY OF GHANA
DEPARTMENT OF ADULT HEALTH
SCHOOL OF NURSING

Ref. No.:

ID: 10754084

18th May, 2021

The Chairperson.
Ethics Review Committee
Ghana Health Service
Accra.

Dear Sir/Madam,

LETTER OF SUPPORT – ETHICAL CLEARANCE

This letter is to support the application for ethical clearance of **Khadija Atchulo**, an MPhil. Nursing student in the Department of Adult Health at the School of Nursing and Midwifery, University of Ghana, Legon.

As part of the programme, she is to undertake a research on the topic: **“Parents’ Perspectives on Quality of Life of Adolescents Living with Autism Spectrum Disorder: A Study in the Accra Metropolis.”**

I hope that the ethics review committee will consider the proposal to enable her collect data.

Thank you.

Yours faithfully,

Ms. Patricia Avadu
Supervisor



COLLEGE OF HEALTH SCIENCES

• P. O. Box LG 43, Legon, Accra, Ghana. • Telephone: +233 (0) 302 513 250 / 0289 531 213
• Email: adulthealth.son@chs.ug.edu.gh • Website: www.nursing.chs.ug.edu.gh

CONSENT FORM

PARENTS' PERSPECTIVES ON QUALITY OF LIFE OF ADOLESCENTS LIVING WITH
AUTISM SPECTRUM DISORDER: A STUDY IN THE ACCRA METROPOLIS

PARTICIPANTS' STATEMENT

I acknowledge that I have read or have had the purpose and contents of the Participants' Information Sheet read and all questions satisfactorily explained to me in a language I understand (English). I fully understand the contents and any potential implications as well as my right to change my mind (i.e. withdraw from the research) even after I have signed this form.

I voluntarily agree to be part of this research.

Name of Participant.....

Participants' SignatureOR Thumb

Print.....

Date:.....



INVESTIGATOR'S STATEMENT

I certify that the participant has been given ample time to read and learn about the study. All questions and clarifications raised by the participant have been addressed.

Investigator's name.....

Signature.....

Date.....

Should you wish to contact me at any stage regarding consent you can contact me at

Tel:+233 266002666, 0200231222

Email:atchulokhadija1@gmail.com

