ENSIGN GLOBAL COLLEGE, KPONG, EASTERN REGION GHANA

AN ASSESSMENT OF THE QUALITY OF LIFE OF CAREGIVERS OF CHILDREN LIVING WITH AUTISM IN THE GREATER ACCRA REGION OF GHANA

BY

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DECLARATION

I, Bio Jody Yeboaa hereby declare that "An Assessment of the Quality of Life of Caregivers of the Children Living with Autism in the Greater Accra Region, Ghana" is my work as a student of the School of Public Health, Ensign Global College. All sources and information used have been acknowledged.

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DEDICATION

I would like to express my heartfelt dedication with gratitude and sincere recognition to the Almighty God, 'the one whose cattle is upon the thousand hills'. This work is dedicated to my mother Esther Agyeman, my sister Fredrica Yaa Abrefi Antwi, and Mercy Demaris Quarm whose resilience, charisma, abundant prayers, and encouragement led me throughout my study. No amount of words can express how valuable you are to me. I am very much grateful for your support and sacrifices towards my academic development.

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DEFINITION OF TERMS

Autism or Autism Spectrum Disorder: Autism is a developmental disability which is as a result of a neurological disorder that affects functioning of the brain and typically appears during the first three years of life.

Adaptive Behavior: The ability to adjust to new situations and to apply familiar or new skills to those situations.

Advocate: An individual who represents or speaks out on behalf of another person's interests.

Communication: The developmental area that involves skills which enable people to understand (receptive language) and share (expressive language) thoughts and feelings.

Developmental Disability: Any physical or mental condition (such as mental retardation, cerebral palsy, epilepsy, autism or a neurological disorder) that has the following characteristics: (1) begins before the age of 22 years, (2) causes the child to acquire skills at a slower rate than peers, (3) is expected to continue indefinitely and (4) impairs the child's ability to function normally in society.

Diagnostic and Statistical Manual of Mental Disorders: The fifth edition of the reference manual published by the American Psychiatric Association. The DSM-V appears to be the most widely used manual of diagnostic criteria for autism spectrum disorders in the United States.

Primary Caregiver: A primary caregiver of autistic children is an individual who takes on the primary responsibility for the care, support, and well-being of a child with autism spectrum disorder (ASD).

ABBREVIATIONS/ ACRONYMS

| QOL | Quality of Life |
|----------|--|
| CDC | Centre for Disease Control |
| WHO | World Health Organization |
| SEM | Socio-Ecological Model |
| НОА | Home Owners Association |
| ASD | Autism Spectrum Disorder |
| DSM-5 | Diagnostic and Statistical Manual of Mental Disorder |
| APA | American Psychiatric Association |
| DALY | Disability-Adjusted Life Years |
| AAG | Autism Ambassadors of Ghana |
| GHS | Ghana Health Service |
| COVID-19 | Coronavirus Disease of 2019 |

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ABSTRACT

Introduction: The study explores the quality of life (QoL) experienced by caregivers of children living with autism in the Greater Accra Region of Ghana. Caregivers of children with autism often face unique challenges that can impact their overall well-being. Understanding the factors influencing their quality of life is essential for developing targeted interventions and support systems.

Methods: A descriptive cross-sectional research design using a quantitative approach was used to collect relevant data from caregivers who visited any of the four institutions during the study period.

Results: The quantitative analysis revealed significant patterns in caregivers' quality of Life, with educational levels, employment types and sources of knowledge. In this study, however, socio economic status, impact of caregiving, health literacy and religiosity had no significant association with the quality of life of caregivers (p= 0.078, 0.060, 0.563, 0.450 respectively). Also, it was noted from this study that, caregivers with higher monthly family income were 6 times more likely to have a high quality of life. Again, caregivers with lower levels of education have a lower quality of life.

Conclusion: The research underscores the multifaceted nature of caregivers' experiences in the context of autism caregiving. The study reveals the need for comprehensive interventions, including improved access to specialized services, workplace flexibility, and enhanced support networks. By addressing the challenges caregivers face, policymakers, healthcare providers, and support organizations can contribute to enhancing the QoL of caregivers of children living with autism in the Greater Accra Region.

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background of Study

Autism is a developmental disorder that impacts the lives of individuals across the lifespan. The disorder manifests various anomalies within a wide range of behaviors of people living with the disorder including repetitive behaviors, social skills, speech difficulties and non-verbal communications. People living with autistic disorders may also be reserved and self-restricted from society (Abolkheirian et al., 2022). The disorder has received attention following its trend of epidemiology and identifying a rise in the number of people who develop the neuro-anomaly. According to the Africa Centers for Disease Control and Prevention (CDC) Autism and developmental disability monitoring network, 1 in 44 children have autism (CDC, 2022).

Autism management demands constant monitoring and a lot of time. Caregivers of autistic individuals are therefore trapped in constant attention, as well as physical and emotional exhaustion due to unusual reactions to sensations, and challenges of transiting from one activity to the other among autistic individuals (World Health Organization [WHO], 2021). For such conditions, caregivers are faced with myriads of barriers which affect their quality of life as well as that of autistic patients. Caregivers lose out on economic activities, face societal neglect as well as isolation. The situation is worse for single-parent caregivers who may have little or no support in caring for children with Autism (Mavropoulou & Sideridis, 2014).

A thorough measure of attributes such as anxiety, depression, emotional and psychological stress which affect the well-being and contributes to the quality of life of caregivers raising autistic individuals must be acknowledged (Vohra et al., 2014). As a condition related to mental health,

caregivers must have strong value for themselves, have a meaning in life, and high sense of positivity, in the context of cultural and social values which relates to their goals, achievements and expectation as this is a measure of QOL which affect the quality of care autistic individuals receive (Alhazmi et al., 2018).

In caring for autistic individuals, healthcare providers have heavily relied on family centered care, which significantly recognize children's caregivers as focal to positive outcomes in autism management, emphasizing the need to understand the QOL of caregivers in managing autism (Gentles et al., 2020). The WHO for instance has designed a training schedule purposely for care givers of people living with autism in the light of caregivers playing a focal role in the betterment of autistic people (WHO, 2022). However, caregivers have been identified with several situations which weakens their quality of life.

The lack of understanding of caregivers QOL and their needs in giving care to autistic individuals has been documented globally. In India, parents of people living with autism are said to have unmet needs in several domains of measures of quality of life. Caregivers physical, environmental and psychological quality of life have been found to be mediated by the condition of their children, especially among caregivers from a nuclear family (Jain et al., 2019). In the United States, caregivers for autistic individuals have reported limited access to care for their children's condition. Caregivers as a result have poor physical and mental health responses to their children's condition feeling helpless, anxious and depressed (Vohra et al., 2014). However, caregivers in such developed countries like USA and Canada are able to build resilience, perceive and achieve their goals in all aspects of their lives including education and finances, and heightens their QOL. The role of available social support and available professional help improved the conditions of caregivers and in some instances brought couples together the more (Ruiz-Robledillo et al., 2014).

In the Sub-Saharan African Region, caring for autistic individuals has been described a big burden as a results of challenges caregivers are faced with. Social isolation and Stigmatization take burden caregivers with a lot of emotional stress, and depression (Cloete & Obaigwa, 2019). Cultural and religious believes imbibed in tradition influence caregivers' perspective of the autism. This has contributed to a poor understanding and treatment approach towards managing their autistic individuals and most importantly perceiving the aspects of the condition which affect their mental and emotional health (Madlala, 2012). Evidence from countries like Kenya and South Africa shows that limited attention is paid to the condition of people who care for autistic patients. Interventions are mainly focused on the management of their children and how to make a meaningful life out their conditions, whiles the pathways surrounding the disability which affects the QOL of caregivers is not given the needed or no attention (Cloete & Obaigwa, 2019; Fewster et al., 2020; Madlala, 2012).

In Ghana, there is a huge deficit in care for mental and developmental disabilities within the health care system. The needs of patients with disabilities are not being adequately met. Caregivers are therefore not served any better (WHO, 2022a). Families find autistic conditions mysterious and therefore attend to their children's condition with religious believes and tradition from cultural connotations which contribute to poor emotional responses, anxiety, depression and societal neglect. The QOL of caregivers invariably become poor (Allotey, 2019). This study therefore seeks to investigate the quality of life of caregivers of children living with autism in Ghana.

1.2 Problem Statement

The quality of life of caregivers of children living with autism children influence the management outcomes of children condition, yet the needed efforts such as social support, professional support as well as medical support which will contribute to a good quality of life is limited in Ghana (WHO, 2022).

According to a thorough assessment of the prevalence of autism among children and adolescents, 14.3% of children in sub-Saharan Africa have symptoms associated with autism (Mabrouk et al., 2022).

Institutions such as religion, culture and the extended family stigmatize and neglect caregivers who are already faced with health system challenges, financial difficulties and limited time to engage in activities which contribute to their economic gains (Allotey, 2019). In Ghana, there are scanty records on the QOL of caregivers in caring for children and adolescents with autism. Nonetheless, research has shown that providing long-term care may have an impact on the caregivers' overall well-being, financial situation, and physical, social, and mental health (Okoye et al., 2019). Because psychological and emotional strain among caregivers affects the quality of care provided, it is imperative that the strain receives the proper attention and support for the child's benefit (Rocha & A rcinas, 2020). Previous studies have shown that caregivers' physical and mental health may be negatively impacted by taking on too much duty (Gbiri et al., 2015). Gugala, (2021) claim that caregivers' responsibilities may negatively impact their social, cultural, and professional lives, hence lowering their quality of life. The high financial demands of caring for an autistic child may negatively affect financial resources, which in turn may increase the stress levels of the caregivers.

Research has shown that low financial resources, everyday experiences of caring for children with autism, and superstitious beliefs related to autism may all contribute to a lack of social support among carers and perhaps lower quality of life (Bunning et al., 2020).

4

Cultural preconceptions and misconceptions regarding autism impact attitudes toward patients as well as caregivers. Due to pervasive false public perceptions and beliefs, children with autism and their families are even subjected to social discrimination (Salleh et al., 2020). This incident consequently emphasizes how critical it is to increase our understanding of autism in order to provide patients with better care. In Ghana, because of the myths surrounding the etiology of autism, autistic children and their caregivers do not receive the support required to enhance the caregivers' quality of life, which invariably affects the autistic patient as well (Oti-Boadi, Dankyi & Kwakye-Nuako, 2020). The quality of life of those who care for children with autism has been the subject of numerous studies in other nations, but in Ghana's jurisdiction, very little research has been done (Oti-Boadi, Dankyi & Kwakye-Nuako, 2020). The present study assesses the QoL of caregivers of children with autism in the Greater Accra Region.

1.3 Rationale of the Study

The sustainable development goal three (SDG 3.0) of "leaving no one behind" supports the need for this study by stating that "understanding the needs of all those engaged with a particular health condition is vital to achieve" (United Nations [UN], 2015). This study will contribute to a better understanding of the situation of parents of autistic children, which will inform the design of interventions and policies addressing concerns related to the management of autism. The study will also elucidate elements that affect the quality of life for carers of children living with autism as well as existing literature. The results of this study will advance our understanding of caregivers' QOL and act as a guide for subsequent research. The health care system will also be informed on designing systems to positively influence the caregivers' QOL.

1.4 Conceptual Framework

This study reviews a model that is related to the study topic and relevant in shaping the understanding of caregivers' quality of life. The study, therefore, adopts the social-ecological model (SEM). The enabling and inhibitory elements connected to human activities are shown via a SEM. The model in this study served as a reference for evaluating the quality of life of caregivers for autistic children. According to Schlebusch et al. (2017), the model was also utilized to help uncover variables related to the quality of life for kids with autism. Four levels make up the model: society, relationship, community, and individual. Factors at the individual level are related to a person's knowledge, attitudes, and beliefs. Relationship-level factors are people in their social network, such family and friends, who have the power to influence decisions about house renovations. The different environments in which individuals live and work (such as Homeowners' Associations (HOAs), which may have an impact on their capacity to carry out house renovations) are examples of community-level issues. Lastly, national, state, and local regulations that affect a person's behavior are the focus of policy-level considerations (e.g., zoning restrictions that may determine how soon a refurbishment can occur). As a result, the social-ecological model might highlight elements that the literature hasn't previously discussed in relation to the quality of life experienced by those who look after autistic children.

The framework outlines the process via which caregivers of autistic children can improve their quality of life. The model identifies the primary antecedents of the caregivers' sociodemographic traits (age, sex, education, occupation, residence, and income) as well as their quality of life, which is the study's key outcome variable. When evaluating the quality of life of caregivers, factors such as their place of residence, sex, and level of education are significant. There is a strong correlation in the literature between these traits and life satisfaction. Caregiving has been shown to have a

noticeable effect on the caregivers' sleep, social life, money, and energy levels, among other things. This impact also acts as a mediator between the caregiver's sociodemographic status and quality of life. Therefore, the impact of caring can moderate this link to either harm or improve quality of life, even though it is often reported that female caregivers have worse quality of life measurements.



Figure 1: Conceptual Framework- Quality of Life of caregivers

Sources: Schlebusch, Dada and Samuels, (2017).

1.5 Research Questions

- 1. What is the socio-demographic characteristics and socio-economic status of caregivers of children living with autism in the Greater Accra Region?
- 2. What is the status of the quality of life of caregivers of children living with Autism in the Greater Accra Region?
- 3. What are the factors associated with caregivers' quality of life?

1.6 Main Objectives.

1.6.1 General Objective.

To assess the quality of life of caregivers of children living with autism in the Greater Accra Region.

1.6.2 Specific Objectives

Specifically, this study seeks to

- 1. Assess the socio-demographic characteristics and socio-economic status of caregivers of children living with autism in the Greater Accra Region
- Examine the quality of life of caregivers of children living with Autism in the Greater Accra Region
- 3. To evaluate the factors associated with the quality of life of children living with Autism

1.7 Profile of the study

Greater-Accra is where the study was carried out. Within the country, the Region is surrounded by the Eastern Region to the north, the Volta Region to the east, the Gulf of Guinea to the south, and the Central Region to the west. It is one of the sixteen regions that make up the country. 29 districts make up the region.

The population of Greater Accra Region according to recent census figures is about 5,455,692 (Ghana Statistical Services, 2021). 51.9 percent of the population is female, and 48.1 percent is male. Most people in the area live in cities. Its youthful population (those under 15 years old) (42.6%) and sex ratio of 93 show a broad base demographic pyramid that tapers down with a tiny amount of elderly people (those 60 and more) making up 5.9 percent.

The kid reliance ratio is greater (42.6%) than the old age dependency ratio (48.5%). The overall age dependency ratio is 48.5 percent. The area has an equatorial climate that is dry. There are two wet seasons there. While the second season starts in mid-August and runs through October, the first one starts in May and concludes in mid-July.

The Accra Metropolitan Area is divided into three main vegetation zones: shrub land, grassland, and coastal land. In the area of health service, there are one (1) Regional Hospital, eleven (11) District Hospital, facilities, one hundred and eighty (180) Hospital within the Region. Thirty-three public health Centre, twenty-one (21); Poly Clinic, four hundred and thirteen (413) Private facility, Two-hundred and ninety-eight (298) clinic Six hundred and ninety-six (696) within the region (Greater-Accra region Health Directorate, 2019).



Figure 2: Map of Greater Accra Region Source: (Report, 2016)

1.8 Scope of the Study

The study is limited to Ghana, specifically the Greater Accra region. The rationale for choosing the Region is that it is the researcher's residence and her occupational site. This would help the

researcher get quicker clarification of issues from the respondents. This study focused on the QoL of caregivers with children living with Autism in the Greater Accra region. This included caregivers who seek care for their children in the various selected hospitals. The period under study was January 2023 to September 2023. Resource constraints also compelled the researcher to limit the study to Ghana. The study population was limited to caregivers seeking care at the selected hospitals in the Greater Accra Region of Ghana. The researcher administered questionnaires to Caregivers at each selected Hospital. The researcher gathered data to assessed the quality of life of caregivers of children living with autism in the Greater Accra Region

1.9 Organization of the study

Six major chapters comprise this study. Chapter one begins with an introduction that covers the following topics: background, problem description, study objectives, research questions, scope and limitations, study significance, and study organization. The second chapter is made of important literatures which were thoroughly reviewed in line with socio- economic factors of caregivers, burden and religiosity related factors associated with caregivers' quality of life. The third chapter gives the geography of study area and research methodology; the study area, s The study's design, population under investigation, sampling strategy, sample size, data sources, data gathering mode, data analysis, and ethical considerations. The analysis of the obtained data for the study was done in the fourth chapter. Descriptive statistics was used to give an analytical view of the data gathered. This is in the form of frequencies and percentages presented in tables, graphs and charts. Discussion of the study was done in chapter five whereas chapter six was focused on the overall summary of findings resulting in conclusion, appropriate recommendations and suggestion for further research were presented.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Introduction

In this section of our research, authors' perspectives on the investigation at hand were comprehensively examine differently. The study focused on the socio-economic factors of caregivers, their burden of care, health literacy levels, and the impact of religiosity on their quality of life (QoL). Furthermore, theoretical underpinnings of this study were expounded. The discussion delved into socio-economic and religiosity-related factors before culminating with empirical studies and a conceptual framework that illuminates the correlation between caregivers' factors and their QoL.

2.2 Conceptual review

2.2.1 Autism spectrum disorder (ASD)

The symptoms of Autism Spectrum Disorder (ASD) include difficulties with social interaction, communication, and behaviour. A growing number of children are being diagnosed with this neurodevelopmental disorder, which often manifests in infancy or toddlerhood (La Roche et al., 2018). Over time, the diagnostic criteria for ASD have undergone a significant evolution, leading to a better understanding of the condition.

Current diagnostic criteria for ASD group the illness into a spectrum, which encompasses a variety of problems that may manifest in various ways and to variable degrees for different people. Persistent difficulties with social communication and interaction, as well as restricted, repetitive patterns of behaviour, interests, or activities, are hallmarks of autism spectrum disorder (DSM-5) (Green et al., 2016). Some people have milder forms of these symptoms than others, and this is not always the case.

According to Baird and Norbury (2016), autism spectrum disorder (ASD) is a neurodevelopmental disorder marked by limited, repetitive patterns of behavior, interests, or activities, as well as chronic deficiencies in social communication and social interaction. The way that a person is able to operate in other aspects of life, such as at work and in school, can be greatly impacted by these symptoms. Apart from restricted interests and repetitive activities, people with ASD frequently struggle with communication and social engagement (Stratis & Lecavalier, 2013). ASD diagnosis criteria are found in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), an American Psychiatric Association (APA) manual used by medical professionals to make mental health diagnoses.

It is unclear what causes ASD, although studies have shown that a mix of genetic and environmental variables is probably to blame (Heys et al., 2017). Children with ASD have a better chance of thriving with the help of early intervention, according to research (Heys et al., 2017). Although the exact causes of ASD are unknown to researchers, studies indicate that a combination of an individual's genetic makeup and environmental factors can contribute to the development of ASD.(Geschwind, 2015). There is currently no cure for ASD, but early diagnosis and intervention can improve outcomes. Treatment for ASD is typically individualized and may involve a combination of behavioral, educational, and pharmacological interventions. Social skills training, speech therapy, and occupational therapy can also be helpful in improving communication, social interaction, and adaptive behaviors. In addition, support from family members, caregivers, and community resources can also be beneficial (Bhome et al., 2021). In sum, ASD is intricate and multifaceted, and our knowledge of the illness grows as more is learned about it. The diagnosis of ASD may have far-reaching effects on a person's life, including their social and emotional well-being, their ability to learn and succeed in the workplace, and their health care requirements. ASD is a complex and multifaceted disorder that affects individuals in a variety of ways. While there is still much to be learned about the causes and effective treatments for ASD, ongoing research and clinical efforts continue to improve our understanding and ability to support individuals with this disorder, continued research, advocacy, and support can help to improve outcomes and quality of life for individuals with ASD and their families.

2.2.2 The Global Burden of Autism Spectrum Disorder (ASD)

A preliminary finding indicating the number of cases of autism may be lower than those seen in the UK was made in the 1970s in a paper detailing autism among children with mental disabilities who were known to authorities in six central and southern African countries (Elsabbagh et al., 2012). Researchers have recently done a number of studies on the worldwide burden of ASD in an effort to comprehend the condition's prevalence and effects on individuals, families, and society at large. ASD was found to be one of the major causes of disability among children and young people, accounting for close to 1.5 million disability-adjusted life years (DALYs) lost globally, according to Rynkiewicz et al., (2016), who used data from the Global Burden of Disease survey to estimate the global burden of ASD in the year 2000. The majority of the burden was attributable to lost years of life owing to premature mortality, emphasizing the significance of early identification and care for people with ASD. A review by Chiarotti & Venerosi, (2020) examined the latest prevalence estimates of ASD from studies conducted since 2014. The authors found that the prevalence of ASD varies widely across different regions and countries, ranging from 0.2% to 4.3% depending on the study population and diagnostic criteria used. The authors also noted that the prevalence of ASD appears to be increasing over time, although this may be due in part to improved diagnostic practices and increased awareness of the condition. A recent study by the Li et al., (2022) presented an in-depth examination of the global impact of ASD from 1990 to 2019. The frequency of ASD climbed by 142% throughout this time span, and the illness accounted for 33.8 million DALYs globally in 2019. The authors also found a number of risk variables that contribute to the prevalence of ASD, such as air pollution, maternal smoking, and poor nutrition during pregnancy (Li et al., 2022).

To conclude, as the prevalence of ASD rises, it is increasingly being seen as a serious public health issue throughout the world (Robertson et al., 2020). When comparing industrialized and developing nations, the prevalence of ASD is greater in the former (Maenner et al., 2021). However, an accurate estimation of the global burden of ASD is hindered by the lack of reliable prevalence data in many developing countries.

2.2.3 Quality of life of primary caregiver of ASD

The effects of autism spectrum disorder (ASD) extend beyond the person who has been diagnosed with the disease to include the people who provide them daily care and assistance. Researchers are concerned about the quality of life of main carers of children with ASD since they confront so many difficulties in dealing with the disease. In this review of the literature, we look at what we know currently about how ASD affects the quality of life of primary carers.

Caretakers of children with ASD have been demonstrated to have a worse quality of life compared to those of children with other developmental disorders or generally functioning children. Quality of life for carers is negatively impacted by the disorder's related caregiving load, stress, and anxiety (Rayan & Ahmad, 2016). Caretakers of children with ASD reported inferior physical, emotional, and social functioning quality of life compared to those of generally developing children, as shown in research by Kousha et al., (2016).

When compared to other developmental disorders, the cost of caring for a child with ASD is much higher due to the complexity and intensity of the care they need. Providers of care must also attend to the psychological and Behavioural needs of their patients. Carers of children with ASD have been shown to have increased stress and worry, which may have negative effects on their mental and physical health (Rayan & Ahmad, 2016). Their standard of living may suffer as a result, and they may need extra help with the caregiving responsibilities.

Psychoeducation, counselling, and social support are only some of the therapies made available to parents of children with autism spectrum disorder. The goal of these programs is to help carers have a better quality of life by giving them the tools they need to deal with the disease (Rayan & Ahmad, 2016). Carers' stress may be mitigated and their quality of life enhanced by receiving respite care, according to research by Nankervis et al., (2011). A study conducted by Larson, (2022) investigated the experiences of primary caregivers of children with autism spectrum disorder (ASD). The results showed that the majority of caregivers reported problems in the dimension of 'relational problems with the care recipient' (84%). This may be attributed to the communication difficulties experienced by individuals with ASD, which can make it challenging to form and maintain relationships.

In addition, approximately half of the caregivers reported problems in the dimensions of 'combining the care with daily activities' (51%), 'physical health problems' (51%), and 'mental health problems' (46%). These results highlight the significant burden that caregivers of children with ASD face, as they have to balance caregiving responsibilities with their own daily activities and maintain their own physical and mental well-being.

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Furthermore, financial problems were reported by 20% of the caregivers, which can be attributed to the high costs associated with caring for a child with ASD, such as therapy and medical expenses. Despite these challenges, nearly all primary caregivers reported deriving some level of fulfillment from caring for their children (96%, of whom 65% 'a lot') and experiencing support in providing their care (88%, of whom 36% 'a lot').

The mean utility score of primary caregivers was 77.33, indicating that they value caregiving for their children with ASD. The average happiness score was 7.6 on the CarerQol-VAS, suggesting that despite the challenges, primary caregivers experience some level of happiness in their role. Interestingly, the mean utility and happiness scores did not differ between primary caregivers with and without secondary caregivers, indicating that the presence of a secondary caregiver does not significantly impact the caregivers' quality of life.

Overall, the study highlights the challenges faced by caregivers of children with ASD, including relational, physical, mental, and financial difficulties. Despite these challenges, the majority of caregiver's report deriving fulfillment from their role and experiencing support in providing care for their children. The findings emphasize the importance of providing adequate support and resources to caregivers of children with ASD, to alleviate the burden they face and improve their quality of life.

In conclusion, main carers may experience a considerable decline in quality of life as a result of caring for a kid with ASD. The disorder's accompanying caregiving burden, stress, and worry may have negative effects on a person's mental and physical health, lowering their quality of life. It is possible to improve carers' quality of life via interventions including psychoeducation, counselling, social support, and respite care.

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2.2.4 Challenges and Barriers to ASD Intervention projects

Professional treatments and services are crucial for children with ASD, but overcoming a number of obstacles has proven difficult. The difficulties encountered by intervention efforts for children with ASD are discussed here, along with their consequences for success.

A Systematic Review of Quality of Life for Family Members of Children with Autism Spectrum Disorder in Asia by Vincent et al., (2019) found that ASD intervention programs in low- and middle-income countries encounter considerable hurdles due to a lack of funding, a lack of educated experts, a lack of understanding and acceptance of ASD, and cultural views. These findings were consistent to the study conducted by Rabbani et al., (2021) in Bangladesh who reported that ASD intervention efforts in India struggled due to a lack of skilled specialists, poor resources, limited awareness, and stigma.

This was in line with the findings from the study carried out by Suliman-Lavie et al., (2020) that came to the conclusion that Arabic language difficulties, a lack of standardized screening and diagnosis, and a lack of educated experts were all major obstacles to ASD intervention programs in Arab nations.

The necessity for telehealth services, the availability of technology, and the capacity of families to engage in virtual therapies were all underlined in research by Kumm et al., (2021), which also highlighted the difficulties of delivering ASD interventions during the COVID-19 pandemic.

Challenges and obstacles found in ASD intervention initiatives have major repercussions for providing quality care to children with ASD. The creation and execution of measures to combat cultural attitudes and stigmas, as well as to raise public and professional knowledge of ASD, increase financing, and improve professional training, are all necessary. Furthermore, the COVID-

19 pandemic has brought to light the necessity of adaptability in the delivery of ASD interventions and the significance of tele-health services.

Significant consequences for the efficient delivery of treatments and services to children with ASD are at stake due to the difficulties encountered by ASD intervention initiatives in Ghana and other low- and middle-income countries. However, Spence et al., (2011), specified that improving the lives of children with ASD and their families means tackling these obstacles and finding ways to overcome them discovered that rural families had restricted access to ASD intervention services, resulting in delays in diagnosis and treatment. Similarly, Ruiz Calzada et al., (2012) in their study which aimed to explore High-functioning Autism and Asperger's disorder, discovered that minority populations had limited access to ASD intervention services, resulting in inequities in diagnosis and treatment. A study by Wang, (2022) in the United State found that funding was a significant barrier to implementing evidence-based ASD intervention programs. Limited funding and resources can limit the availability of trained professionals and access to specialized equipment, resulting in lower-quality interventions. A study by Ospina et al., (2008) found that many healthcare professionals lacked the necessary training and education to effectively diagnose and treat individuals with ASD. Similarly, a study by O'Toole et al., (2021) found that many school-based intervention providers lacked the necessary training and education to implement evidence-based ASD intervention programs.

According to a study conducted by Kovács et al., (2022) cultural competence among healthcare personnel was critical to the success of ASD intervention programs among Latino families. Similarly, Guan et al., (2019) discovered that cultural competence was critical to the success of school-based ASD intervention programs for Native American families. Parental involvement is essential to the success of ASD intervention programs. According to (Rojas-Torres et al., 2020)

parental involvement in ASD intervention programs was linked to better results for children with ASD. However, parental engagement limitations, such as a lack of time and resources, can restrict the success of ASD intervention programs.

2.3 Empirical Review

2.3.1 The prevalence of Autism spectrum disorder (ASD)

Estimates of the prevalence of ASD have increased during the last several years, however these numbers may be misleading since they rely on the study population and approach.

The CDC performed one of the most extensive investigations to date on the incidence of ASD in the United States. One in every 54 children in the study had ASD, with males being diagnosed four times more often than girls (Maenner et al., 2021).

The incidence of autism spectrum disorder (ASD) varies greatly throughout European nations. The prevalence of ASD varied from 1.16 per 1,000 children in Romania to 15.68 per 1,000 children in Denmark, according to a systematic review and meta-analysis done by Maenner et al., (2021).

The prevalence of ASD appears to vary by geographic region and demographic factors. A study conducted in the United States reported a prevalence of 1.7% among 8-year-old children (Baio et al., 2018). The prevalence was higher among boys (4.0%) than girls (1.0%). Other studies have reported higher prevalence rates in some regions of the world, such as South Korea, where a prevalence of 2.64% was reported among 7 to 12-year-old children (Kim et al., 2011).

In general, research reveal vastly different rates of ASD prevalence among areas and nations. More research is needed to determine the causes of these differences. Even within Asia, there is a broad range in ASD prevalence. Prevalence rates ranged from 0.2% in Laos to 7.3% in South Korea, according to a meta-analysis of Asian studies undertaken by Xu and colleagues (2018), yielding an overall prevalence estimate of 1.7%. Although research on the prevalence of autism spectrum disorder (ASD) in South America is limited, available data show rates anywhere from 0.4% in Chile to 2.4% in Brazil (Molina et al., 2020). A study conducted in rural areas of Bangladesh found that the prevalence of autism in children aged 18-36 months was 0.75/1000. In comparison, the prevalence of cerebral palsy and developmental delays was much higher. This study highlighted the lack of age-specific early diagnosis of autism in rural communities. A national study conducted in a rural community of Bangladesh in 2013, which included 7280 children aged 0-9 years, reported an overall prevalence of ASD of 1.55/1000 (Akhter et al., 2018). The study also revealed that the prevalence of ASD in the rural community studied was 0.68/1000 (Akhter et al., 2018). Another estimate suggested that about 300,000 children in Bangladesh were affected by autism, with one case in every 94 boys and one in every 150 girls suffering from ASD (Akhter et al., 2018).

Studies have reported varying estimates of the prevalence of ASD. A meta-analysis of 27 studies, which included data from 14 countries, reported a global prevalence of ASD of 62 cases per 10,000 individuals (Elsabbagh et al., 2012) . A more recent systematic review of 57 studies, which included data from 29 countries, reported a median prevalence of ASD of 0.62% (1 in 161) (Elsabbagh et al., 2012).

However, these results contradict the findings of Bakare et al. (2018), who found that the frequency of ASD is lower in Africa, according to studies, compared to other locations. Their findings revealed that a pooled prevalence estimate of 0.16%, with rates ranging from 0.04% in Egypt to 0.78% in South Africa.

2.3.2 The Current State of Autism spectrum disorder (ASD) in Ghana

The prevalence of ASD has been rising worldwide, and this trend can also be seen in Ghana.

The incidence of ASD in Ghana is estimated to be about 0.7%, with a male-to-female ratio of 2:1, according to recent research by Essien, (2016). Delays in diagnosis and treatment may result from a lack of knowledge of ASD among both medical professionals and the general population in Ghana, according to the research.

Enoch et al., (2017) conducted research on the lives of Ghanaian parents who have children with autism spectrum disorder. The research showed that parents had a hard time getting their kids the help they needed in school and with health issues. In addition, educators' limited knowledge of autism spectrum disorder (ASD) hampered their ability to meet the unique needs of students with ASD in the classroom.

Lim et al., (2023)conducted research to better understand how medical professionals in Ghana see and treat children with autism spectrum disorder. According to the results of the research, there are considerable knowledge and training gaps among healthcare workers when it comes to autism spectrum disorder (ASD). The report also stressed the need of educating medical practitioners in Ghana about autism spectrum disorder.

Furthermore, there is a serious problem in Ghana due to a lack of resources, such as trained healthcare professionals and inadequate funding for research on ASD. The World Health Organization (WHO) reports that psychiatrists and clinical psychologists, both of whom are crucial in the diagnosis and treatment of ASD, are in limited supply in Ghana.

As a result, the diagnosis, treatment, and management of ASD in Ghana need require more public attention, educational opportunities, and financial backing. The quality of life for people with ASD and their families in Ghana may be enhanced by focusing on these areas. There is limited research on the prevalence of ASD in Ghana, it is thought to be on the rise, with an estimated 20,000

individuals affected (Hagan et al., 2018). Despite its increasing incidence, there is a lack of awareness and understanding of ASD in Ghana, as well as restricted access to appropriate healthcare services and resources. According to Amu, Dickson, and Mensah (2019), many families with children with ASD in Ghana experience major barriers to getting diagnostic and treatment services, such as long wait periods, expensive fees, and a scarcity of competent healthcare experts. In addition, many families endure stigma and discrimination connected to their child's condition, which can further limit access to school and community support. Efforts are underway to address these challenges and improve outcomes for individuals with ASD in Ghana. The Autism Ambassadors of Ghana (AAG), a non-profit organization founded in 2011, is working to increase awareness and understanding of ASD, as well as advocate for improved access to healthcare services and resources (Hagan et al., 2018). In addition, the Ghana Health Service (GHS) is working to develop and implement a national autism policy, which aims to improve access to diagnosis, treatment, and support services for individuals with ASD and their families (Ghana Health Service, 2019).

While there is still much work to be done, these efforts represent important steps towards improving the current state of ASD in Ghana. Increased awareness and understanding of ASD, as well as improved access to healthcare services and resources, can help to improve outcomes and quality of life for individuals with ASD and their families in Ghana. In Ghana, autism spectrum disorder (ASD) is a developing public health concern, with low awareness, understanding, and access to appropriate healthcare services and resources. Ongoing initiatives to raise awareness, lobby for better access to care, and develop national laws and guidelines are critical steps toward improving the current situation of ASD in Ghana. To address the issues and improve outcomes for
people with ASD and their families in Ghana and beyond, more research and collaboration are needed.

2.3.3 Caregivers' Response to Autism spectrum disorder (ASD)

Many caregivers of children with ASD report feeling overwhelmed by the demands of caregiving. To create successful support programs for carers and persons with ASD, we must first understand their responses to ASD. The literature on caregiver's responses to autism spectrum disorder is discussed here.

Kheirollahzadeh et al., (2021) performed research in Iran and showed that parents caring for children with autism spectrum disorder (ASD) had considerably greater levels of stress and worse quality of life than parents caring for children without ASD. The stress, anxiety, and depression levels of carers of children with ASD were shown to be significantly greater than those of carers of normally developing children in research conducted by Sivaraman & Antony, (2018) in India. These results indicate an elevated risk of mental health issues for carers of children with ASD.

Carers of children with ASD in the United States reported having to alter their daily routines and schedules often to meet their child's demands, according to qualitative research conducted by Alresheed et al., (2018), they also said that, because of their child's behaviour problems, they felt lonely and had trouble interacting with other parents. Carers of children with ASD in the United States had to negotiate complicated healthcare systems and fight for their children's needs, according to qualitative research conducted by Kibria & Becerra, (2021).

Akintunde, (2023) conducted research in Nigeria and showed that carers of children with ASD had less awareness of the disorder than those caring for children without ASD. This points to the potential importance of raising awareness and educating carers in underdeveloped nations about ASD. Carers of children with ASD reported positive improvements in their perspective on life, such as improved empathy, patience, and acceptance, according to research conducted by Vilanova et al., (2022) in India. They also felt like they had more people rooting for them socially.

The evidence concludes that caring for a kid with ASD may be very stressful and demanding for the primary carer. Parents may have to rearrange their schedules, learn to use unfamiliar healthcare systems, and fight for their child's rights. Carers in underdeveloped nations may have less information about ASD, but they may also have more opportunities for personal growth. To create successful support programs for carers and persons with ASD, we must first understand their reactions to ASD. The COVID-19 pandemic has had a profound impact on individuals with ASD and their families, with many experiencing high levels of stress and disruption to their lives. A recent study by Robertson et al., (2020) found that during the COVID-19 crisis, individuals with ASD and their families reported significant stress related to isolation, illness, and finances. Caregivers of people with ASD experience a variety of challenges in managing their loved ones' symptoms, such as communication difficulties, sensory sensitivities, and behavioral issues (Nicolaidis et al., 2015). Caregivers of people with ASD have high levels of stress and mental health issues, with many experiencing feelings of despair, anxiety, and burnout (Keefer et al., 2018). One study by Schieve et al., (2012) examined the prevalence of caregiver-reported health problems among parents of children with ASD. The researchers found that parents of children with ASD were more likely to report poorer mental and physical health than parents of children without ASD. The authors noted that these health disparities may be due in part to the increased caregiving demands placed on parents of children with ASD, as well as the social isolation and stress associated with caring for a child with a chronic condition. Another study by Hamm, (2020) explored the experiences of fathers of children with ASD. The authors found that fathers often feel

excluded from the caregiving process, as the majority of interventions and support services for ASD are targeted towards mothers. Fathers also reported experiencing stigma and discrimination related to their child's diagnosis, which can lead to feelings of isolation and decreased social support. A study by Lebert-Charron et al., (2022) examined the relationship between parental stress and the use of coping strategies among parents of children with ASD. The authors found that parents who reported higher levels of stress were more likely to use avoidant coping strategies, such as denial and distraction, than parents who reported lower levels of stress. The authors suggested that interventions aimed at reducing parental stress and promoting positive coping strategies may help to improve the well-being of parents of children with ASD.

In conclusion, the literature on caregivers' response to ASD highlights the unique challenges faced by caregivers and the impact of caregiving on their well-being. Caregivers of individuals with ASD may experience increased stress, social isolation, and poorer health outcomes compared to caregivers of children without ASD.

2.3.4 Socio-economic factors of caregivers of children living with autism

It is estimated that one child in every 54 has autistic spectrum disorder (Maenner et al., 2021). In the treatment and care of children with autism spectrum condition, caregivers are essential. Treatment success for autism spectrum disorder (ASD) depends on caregivers' comprehension of the condition. The purpose of this analysis is to determine whether there is a connection between carers' socioeconomic status and their degree of autism spectrum disorder (ASD) education.

Studies were examined. The review suggests that caregivers' understanding of autism spectrum disorder was shown to be correlated with socioeconomic characteristics (Trew, 2022), including education, employment, and monthly family income. Carer understanding of ASD was not

significantly related to marital status or religious affiliation (Alim et al., 2016; Tesfaye et al., 2020). Alim et al. (2016) and Tesfaye et al. (2020) reported contradictory findings when controlling for age and country of residence. Some studies found a significant correlation between carer sex and ASD knowledge, while others did not (Rinaldi et al., 2022).

This review's results imply that socioeconomic status has a significant effect in the degree to which carers are aware of ASD. Knowledge of autism spectrum disorders was strongly correlated with educational attainment, work status, and household income. These results emphasize the need to educate and assist carers from lower socioeconomic backgrounds in order to increase their awareness of and comfort with autism spectrum disorder.

In sum, the amount of education, occupation, and income of carers are all significant indicators of their familiarity with ASD. This analysis highlights the need of designing treatments specifically for low-income carers to increase their awareness and comprehension of autism spectrum disorder.

Samadi & Samadi, (2020) have investigated the relationship between socio-economic factors and caregiving for individuals with ASD. A systematic review of 40 studies reported that caregivers from lower socio-economic backgrounds experienced greater caregiving burden, stress, and reduced quality of life compared to those from higher socio-economic backgrounds (Keefer et al., 2018). Factors such as lower income, lower education level, and unemployment were associated with greater caregiver burden and stress.

Poverty and a lack of resources were found to be significant barriers to getting appropriate treatment and assistance for children with ASD in an Indian study (Valagussa et al., 2018). Caregivers from lower socioeconomic backgrounds reported having restricted access to ASD information and resources, as well as healthcare and educational services.

Another study conducted in the United States reported that lower income was associated with delayed diagnosis of ASD and reduced access to early intervention services (Schieve et al., 2012). Caregivers from lower income backgrounds were also more likely to report unmet service needs for their child with ASD.

It is crucial to emphasize that the impact of socioeconomic issues on ASD caregiving can be complex and multifaceted. Other elements that may have a role include cultural views, familial relationships, and social support. Nonetheless, knowing the association between socioeconomic characteristics and caregiving for people with ASD can help develop targeted interventions and policies to support caregivers and enhance outcomes for people with ASD and their families.

2.3.5 Child-related factors

The impact of children's ASD symptoms on their carers was investigated in 2012 research by de Schipper et al., (2016). Carer stress was shown to be positively correlated with the severity of autism spectrum disorder symptoms. Chanie et al., (2021) conducted research to see whether carer load increased with increasing age upon diagnosis. The research indicated that the burden on carers increased for those whose children received an ASD diagnosis later in life.

Caines, (2019) conducted research on how co-occurring mental health conditions affect carer burden. Comorbid mental diseases were related with higher levels of carer burden in this research of children with ASD.

Atun-Einy et al., (2022) looked at how behavioral issues in children with ASD affected carer load. Aggression, self-injury, and hyperactivity are only some of the behavioral issues linked to greater load on carers.

Carer stress as a result of sleep issues in children with ASD was also studied by Mutluer et al., (2020). Carer load was substantially correlated with poor sleep quality, according to the research.

Overall, the studies reveal that the degree of carer burden among parents of children with ASD might be significantly impacted by child-related characteristics such as the severity of ASD symptoms, the age at diagnosis, the presence of comorbid mental illnesses, behavioural issues, and sleep problems.

Gender is a well-known child-related component in autism spectrum disorder. Boys are three to four times more likely than girls to be diagnosed with ASD (Frazier et al., 2014). The causes of this gender bias are unknown, but it is considered to be due to differences in brain development and function. Another child-related aspect explored in ASD is age at diagnosis. Early detection and intervention are crucial for improving outcomes for people with ASD, and multiple studies have found that earlier detection is related with improved results (Ruttle et al., 2013). However, diagnosing ASD can be difficult, especially in younger children who have not yet completely acquired social and communication skills.

Several studies have also investigated the relationship between cognitive functioning and ASD. Individuals with ASD can have a range of cognitive abilities, from intellectual disability to aboveaverage intelligence. A study by Postorino et al., (2016) found that individuals with ASD and intellectual disability had more severe impairments in adaptive functioning, language, and socialization compared to those with average or above-average intelligence.

Sensory processing is another child-related factor that has been studied in ASD. Individuals with ASD may experience sensory processing difficulties, such as over or under sensitivity to sensory stimuli (Robertson & Simmons, 2013). Sensory processing difficulties can impact daily functioning, socialization, and behavior, and may be an important target for intervention in individuals with ASD.

Genetic factors are also thought to play a role in the development of ASD. While the causes of ASD are not fully understood, studies have reported a high degree of heritability, with estimates ranging from 50-90% (Xie et al., 2020). Several genes have been implicated in the development of ASD, and ongoing research is aimed at better understanding the genetic basis of the disorder. Language development is a critical child-related factor in ASD. Children with ASD may have delayed language development or exhibit atypical language development patterns, such as echolalia or idiosyncratic speech (Bacon et al., 2019). Language difficulties can impact socialization, academic achievement, and daily functioning, and are a key target for intervention in children with ASD.

Behavioral difficulties are another child-related factor that is commonly observed in children with ASD. These may include repetitive behaviors, self-injurious behaviors, and aggressive behaviors (Lecavalier, 2016). Behavioral difficulties can have a significant impact on daily functioning and may be a key target for intervention in children with ASD.

2.3.6 Burden related factors associated with caregivers' QoL

Carers of children with Autism spectrum disorder (ASD) have a number of challenges that may negatively impact their quality of life (QoL). The severity of the child's symptoms, the caregiver's educational background, and the caregiver's work situation are all relevant variables.

Carers' quality of life (QoL) is severely affected by the intensity of the child's symptoms, according to research (Kózka & Basista, 2016). It has been discovered that the quality of life (QoL) of carers whose charges have more severe symptoms is lower.

Carer burden and quality of life are also affected by the caregiver's degree of education. Carer stress and quality of life (QoL) decline with decreasing education (Kózka & Basista, 2016) It's

possible that parents are overwhelmed because they lack the information and tools necessary to appropriately manage their child's symptoms.

Carer stress and quality of life may also be affected by a person's employment situation. Studies have shown that working carers have a greater burden and a worse quality of life than their unemployed counterparts (Kózka & Basista, 2016). This might be owing to the difficulty of juggling work and caregiving duties or a lack of workplace assistance.

The research also identifies the child's age, gender, and concomitant diseases as contributors to burden (Kózka & Basista, 2016). Despite some consistency, these characteristics have been proven to affect carer burden and quality of life.

The overall quality of life of carers of children with ASD may be affected by a number of burdenrelated aspects, as shown by empirical research. If healthcare providers and policymakers have a better grasp of these determinants, they will be better equipped to provide treatments and support services tailored to carers' unique needs and enhance their quality of life. Studies have reported that caregivers of individuals with more severe ASD symptoms tend to have lower QoL (Ng et al., 2016). This may be due to the increased demands of caregiving for individuals with more severe symptoms, which can impact caregivers' physical and emotional well-being.

Caregivers' own mental health and well-being has also been found to be associated with their QoL in ASD. Studies have reported that caregivers with higher levels of anxiety, depression, and stress tend to have lower QoL (Ng et al., 2016). This highlights the importance of addressing caregivers' mental health needs and providing them with appropriate support.

The level of social functioning of an individual with ASD has also been linked to carers' QoL Tsvetkova et al., (2021) discovered that caregivers of people with worse social functioning had lower QoL. Individuals with lower social functioning may require more social support and may be more isolated, which might have an impact on caregivers' own social support networks.

Gender has also been linked to carers' quality of life in ASD. According to certain studies, female caregivers have lower QoL than male caregivers (Ng et al., 2016). This could be related to differences in coping mechanisms between men and women, or to the additional duties that women may have in caring positions. A study by Kapp et al., (2019) found that caregivers of younger children with ASD reported lower QoL than caregivers of older children with ASD. This may be due to the increased demands of caring for younger children, who may require more intensive care and supervision.

2.3.7 Religiosity related factors associated with caregivers' QoL

Few studies have looked at the relationship between religious beliefs and QoL among carers of children with autism spectrum disorder (ASD). However, there is evidence that religiosity can help parents caring for children with autism spectrum disorder reduce stress and improve quality of life. Papadopoulos et al. (2019) found a correlation between the quality of life and religion of parents of autistic children in Lebanon. Higher religiosity caregivers had reduced levels of stress, hopelessness, and anxiety, according to research. In their 2020 study, Bertelli et al. examined the connection between Jordanian caregivers of autistic children's quality of life and their religion. According to their research, caregivers with higher degrees of religiosity had better quality of life and experienced less stress and depression.

This contradict the findings of the study by Wang, (2022) who discovered that religiosity did not predict QoL among Pakistani carers of autistic children. As potential reasons for the study's results, cultural and religious diversity within the sample population were presented.

Studies in general have shown that higher levels of religiosity are associated with better QoL and lower levels of stress and unhappiness among carers of children with ASD; however, research on this issue is limited.

Caregivers of people with ASD may find that religion and religiosity are significant aspects of their lives. Research has looked into the connection between caregivers' quality of life and religiosity, with varying degrees of success. Higher levels of religiosity have been linked in certain studies to improved quality of life (QoL) in caregivers of people with ASD (Koumarianou et al., 2021). According to a 2013 study by Heo and Koeske, carers with higher QoL also reported higher levels of religious coping. Studies on carers of people with ASD, however, have not found a connection between religiosity and quality of life. Ayesha et al.'s study from 2022 revealed no connection at all between religious coping strategies and caregivers' quality of life for children with ASD.

One explanation for the contradictory findings is that religiosity may have distinct meanings and purposes for different people and civilizations. Religion and spirituality may provide a source of comfort, support, and meaning in the lives of some carers, which may help them cope with the stress and difficulty of caring for individuals with ASD. Religion may not be a substantial source of support for others, and may potentially add to their stress and strain.

The type of religiosity may also influence the link between religiosity and QoL in carers of people with ASD. Various aspects of religiosity have been studied, including religious affiliation, religious attendance, and religious coping. Also, Nematollahi et al., (2021) discovered that carers who reported higher levels of religious coping had lower levels of anxiety but no significant differences in QoL compared to caregivers who reported lower levels of religious coping.

The relationship between religiosity and QoL in caregivers of individuals with ASD is complex and may depend on individual and cultural factors. More research is needed to better understand the role of religiosity and spirituality in the lives of caregivers of individuals with ASD, and to develop interventions and support that are sensitive to the cultural and religious diversity of caregivers.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Introduction

This chapter presents the methods, research techniques and procedures employed for the study. All research methods and designs used by this study are explained and demonstrated in the light of the principal and specific objectives.

3.2 Research Methods and Designs

Research methods and design provide an operational framework within which data is gathered, evaluated, and processed via different analysis processes and techniques in order to evaluate meaningful research output. It lays out the sequence of events that must occur in order for the research project to be completed effectively. This research employed a cross-sectional descriptive study approach to investigate the quality of life of caregivers of children living with autism in the Greater Accra Region.

3.3 Study Settings

The Greater Accra area's chosen amenities served as the study's site. These establishments, which serve the total projected population of twenty-five million, include the Accra Psychiatric Hospitals, Korle-Bu Teaching Hospital, Tema General Hospital, and Missions Paediatric Hospital. These four locations served as the study's locations.

Situated in Tema Metropolis, inside the Greater Accra Region of Ghana, is Tema General Hospital, a metropolitan hospital. The building was constructed between 1954 and 1957 to provide healthcare for port personnel. There are ten wards and 280 beds in the hospital overall. In all of the main clinical specialties, such as internal medicine, general surgery, pediatrics, obstetrics and gynecology, dentistry, and ophthalmology, it provides both general and specialist care services. There are roughly 680 people working there overall, comprising 340 nurses, 40 additional medical doctors, and 10 specialists. Tema General hospital is a very busy Hospital with a daily average OutPatient Department attendance of 650 and an average bed occupancy rate of 80%. Mission Paediatric Hospital is a specialist pediatric clinic that emphasis on pediatric neurodevelopment. The hospital is located at Olympics Road Kokomlemle in the Greater Accra Region. The hospital offers specialist pediatric services to children under eighteen years. The Mission Paediatric Hospital has a comprehensive and modern laboratory attached to the clinic that offer dental surgery services and ophthalmology services amongst others. The hospital provides developmental assessments for preschool intakes and also specialize in Neurodevelopmental Assessments. Moreover, the Mission hospital provides diagnostic assessments for Autism spectrum disorders, Attention Deficit Hyperactivity Disorder, Intellectual Disability amongst others.

Additionally, the Accra Psychiatric Hospital is located in Ghana's Greater Accra Region on Asylum Down, Castle Road. It was founded in 1975 and can accommodate 500 beds. In addition to a small number of cases from nearby nations, the hospital sees mental health patients from all around Ghana. Located in Accra, Ghana's Ablekuma South Metropolitan District, is the public Korle-Bu Teaching Hospital. At present, the Korle Bu Teaching Hospital boasts 21 clinical and diagnostic departments, three Centers of Excellence, 2,000 beds, and ranks third in size among referral centers in Africa. Additionally, it has 1,500 outpatient visits on average and 250 inpatient stays.

3.4 Study population

With the assistance of the on-duty nurses, caregivers who visited any of the four hospitals throughout the study period were identified and contacted in order to gather pertinent data for the research.

3.5 Inclusion and exclusion criteria

3.5.1 Inclusion criteria

Principal caregivers (<60 years old) of children and adolescents diagnosed with autism spectrum disorder between the ages of 2 and 18 who did not have any behavioral issues or medical comorbidities requiring priority management were included in the study. Those who had been caring for the patients for at least six months before the study period and who were willing to take part in the research were also included in the study. The study also included community health nurses, and community health nurses.

3.5.2 Exclusion criteria

The study did not include caregivers who suffered from mental health issues. Those who were a first-time attendant in the facility or whose children had other neurological issues were also not allowed to attend. Excluded from the study were students on attachment, national service or rotation nurses, and community health professionals with less than a year of experience.

3.6 Sampling and Sample size determination

This section comprises how the sample size was determined, the sampling technique used, data collection techniques, and tools that were used in the study. The prevalence of childhood autism in Sub-Sahara Africa is 14.3% (Melissa et. al, 2016). Adopting Mendhall's formula. This is used if a sample size has a finite proportion (Mendahall, 1971). A finite population correction will be

applied if the population size is not large. At 95% confidence interval, with a design effect of 1 and a precision of 5% will be used.

Sample size $n = \frac{\text{DEFF*Np}(1-p)}{d2/Z21-\alpha/2*(N-1)+p*(1-p)}$ (Open Epi version 3 Source calculator)

Where;

Deff is the design effect =1

N is the finite population = 515 [Estimated population]

p is the proportion of mental disorders among children in Sub-Sahara Africa =14.3% (Melissa et.

d is the precision =0.05 z is the z-value at the 95% confidence level = 1.96

Therefore,

$$n = \frac{1*515*0.143+(1-14.3)}{(0.05)2/(1.96)^{2*(515-1)+0.143*(1-14.3)}} = 139$$

Adding 10% non-response $(139 \times 0.10 = 13.9 \approx 14)$ gives 139 +14= 153. A total sample size of **153 caregivers** will be recruited for the study.

In this investigation, a non-random (purposive) sampling strategy was applied. According to each chosen hospital's size, a computed sample size was assigned (Table 1.1). Using ICD-10 criteria, study sites identified the folders containing children diagnosed with autism for a minimum of the last six months. Additionally, the study sites identified the carers who accompany the patients to the facilities. The caregivers who were identified had additional questioning to confirm if they truly serve as the primary caregivers or if they merely act in that capacity. The trial continued until

at least 153 samples were obtained at each of the four study locations, with those who were determined to be the real carers taking part.

Calculating sample size for each Hospital using the population sample size (153).

Sample size per hospital =

Number of caregivers per hospitalTotal number of caregivers per in select district× Population sample size

| Name of Hospital | Estimated population | Sample size | | |
|-----------------------------|----------------------|-------------|--|--|
| | N= 515 | n = 153 | | |
| Tema General Hospital | 120 | 36 | | |
| Mission Paediatric Hospital | 100 | 30 | | |
| Accra Psychiatric Hospitals | 35 | 10 | | |
| Korle-Bu Teaching Hospital | 260 | 77 | | |

Table 1: Sample size based on Hospital caregivers' population proportionate to size (PPS)

3.7 Data collection techniques and tools

For this research, a structured questionnaire was used to gather data from respondents. The data was collected over the span of a month (June and July 2023) with the assistance of three (3)

research assistants at each facility. Interviews were conducted via phone, at the hospital or home based on the respondent's preference. Follow-ups and discussions were held to address any issues that arose during the data collection process. Each questionnaire took around 20-25 minutes to interview each respondent. There are many parts to the questionnaire. Section A of the questionnaire collected information on the carers' socio-demographic traits and socioeconomic level. The B section also focused on the quality of life of carers of children with autism. Section D captured questions on impact of impact Caregiving using WHO impact Caregiving Scale. Respondents Health Literacy questions were captured in section E of the questionnaire.

The WHOQOL-100 and WHOQOL-BREF abridged instruments (EUROHIS-QOL) with an 8item index was used to measure the caregiver's quality of life of children with mental illnesses. The EUROHIS-QOL (WHO-8) is a simple and quick way to assess carers' overall quality of life. Two items per QOL domain (social, psychological, physical, and environmental) was scored on a 5-point Likert scale ranging from 1 (not at all/very dissatisfied) to 5 (completely/very satisfied), with a lower score indicating poor QOL and a higher score indicating better QOL (Da Rocha et al., 2012). The carers' burden and religiosity scales were also used in the research.

3.8 Study variables

3.8.1 Dependent Variable

In this study, the quality of life of carers of children with autism was the dependent variable. The quality of health indicator used in this study was the WHO EUROHIS-QOL quality of life index.

3.8.2 Independent variables

The socioeconomic position of the individual, their sociodemographic traits, the care load, their religiosity, and their health literacy in relation to the quality of life of carers for children with autism are the independent factors that were employed in this study.

3.9 Pretesting

In order to identify potential problems with clarity, sequencing, and difficulty, the questionnaire was pre-tested utilizing convenient sample on twenty (20) caregivers at the Appolonia Sub Municipal in the Kpone Katamanso. This was done in order to gauge how long it would take to complete the questionnaire. The study's conclusions did not contain data from the pre-tested questionnaires, but a detailed discussion of the comments helped shape the final instruments.

3.10 Data Quality and Management

Data collected from the field was organized, stored, preserved, and only shared and used for the research project. Data was kept confidential and private. Hard copies were securely kept in a locked filing cabinet while soft copies were also stored on a USB flash drive that is securely password protected. Only the principal investigator and data collectors have access to the collected data.

3.11 Data analysis

After being gathered, the questionnaire was cross-checked for accuracy and consistency, coded, and added to the Epi Data version 4.1 statistical tool. After data cleansing, it was exported to STATA Windows 17.0 for examination. Every variable was described using descriptive statistics. Proportions were calculated for each category variable using the frequency distribution method. To find the degree to which the individual data values deviate from the mean, the mean age and its standard deviation were calculated. The sociodemographic variables, socioeconomic status, and environmental factors linked to carers of children with autism and their quality of life (QOL) were ascertained through the application of logistic regression analysis. In order to accomplish this, a chi-square test analysis between the independent factors and the result variable was first conducted. The final logistic regression models were fitted with socio-demographic factors that

had p-values ≤ 0.05 in the chi-square analysis. This allowed us to examine the Adjusted Odds Ratio (AOR) with a 95% confidence interval (CI) to determine the degree of relationship.

3.12 Ethical issues

The Ensign Global College ethical committee was consulted in order to obtain ethical clearance. We got approval from the facilities to carry out the study. Before every interview, the participant was given a thorough explanation of the method and an informed consent form. Prior to the questionnaires being distributed, each respondent was given the choice to choose not to answer any of the questions. In addition, the participants were informed that they might discontinue the study at any moment. Both the secrecy of the responses and the safety of the respondents were guaranteed.

3.13 Limitations

Despite the important information this study provides, it has some limitations. This study adopted a quantitative approach to data collection without qualitative in-depth interpretation of the respondents' views. A mixed method would have been appropriate but due to time constraints, it was not used. Small number of respondents were achieved relative to the intended sample size. This was due to the study's boundary like the unavailability of the study population. A small sample size might not fully capture the diversity and complexity of caregivers' experiences in the Greater Accra Region. Researchers should transparently acknowledge the limitations of the small sample size in the study's discussion section.

CHAPTER FOUR

4.0 RESULTS

4.1 Introduction

This chapter presents the quantitative analysis of the data collected from the survey. It focuses on the key findings and emerging issues in an assessment of the quality of life of caregivers of children living with autism in the Greater Accra region, Ghana. The chapter is structured in accordance with the research objective which seeks to assess the quality of life of caregivers of children living with Autism in the Greater Accra Region. The analysis of quantitative data reveals significant patterns in caregivers' Quality of Life. The findings of the study are presented in tables and figures. These are categorized into the socio-demographic characteristics data, socio-economic status, and contextual factors associated with caregivers of children living with autism and the quality-of-life (QOL) of caregivers

4.2 Socio-demographic and Socio-economic Information of Caregivers

Overall, the study response rate was 73.2% (112 out of 153). Table 1 below presents an overview of the socio-demographic characteristics and Socio-economic Information of Caregivers. A total of 112 caregivers of children living with Autism were enrolled in the study from the selected facilities in the Greater Accra Region. A higher proportion of the caregivers, 57 (50.9%) were from Korle-Bu Teaching Hospital with 34 (30.3%) from Tema General Hospital, 14 (12.5%) from Accra Psychiatric Hospital and 7 (6.3%) from Mission Hospital. Specifically, the mean age of the caregivers was 38.5 [Standard Deviation (SD) 8.7] years. Of the caregivers, 39 (34.8%) were aged between 30 - 35 years. A higher proportion of the caregivers were female and a few were males (82.1% and 17.9% respectively). More than half (67.9%) of caregivers were Christians.

With regards to the level of education, approximately half of the caregivers (45.5%) had tertiary education, one-third (31.3%) had secondary education, 20.5% also had Junior level education and 2.7% had no education. 75.9 percent of the caregivers were employed. Approximately half of the caregivers (54.5%) had a formal employment type. Of the respondents, 56.3% earned between GH @ 1000 - GH5000. A summary of the selected characteristics of the participants is presented in Table 2 below.

| Variables | Frequency (N=112) | Percentage (%) | | |
|-------------------------------------|----------------------------------|----------------|--|--|
| Name of Hospital | | | | |
| Accra Psychiatric Hospital | 14 | 12.5 | | |
| Tema General Hospital | 34 | 30.3 | | |
| Korle-Bu Teaching Hospital | 57 | 50.9 | | |
| Mission Paediatric Hospital | 7 | 6.3 | | |
| Mean age of Caregivers (years ± SD) | $\textbf{38.5} \pm \textbf{8.7}$ | | | |
| Age in years | | | | |
| 30 - 35 | 39 | 34.8 | | |
| 36-40 | 34 | 30.4 | | |
| 41 - 45 | 24 | 21.4 | | |
| 46+ | 15 | 13.4 | | |
| Sex | | | | |
| Female | 92 | 82.1 | | |
| Male | 20 | 17.9 | | |
| Marital Status | | | | |
| Divorced | 19 | 16.9 | | |

Table 2: Socio-demographic and Socio-economic Information of Caregivers

| Married | 76 | 67.9 |
|---|-----|------|
| Never Married | 14 | 12.5 |
| Widow/ Widower | 3 | 2.7 |
| Place of Residence | | |
| Rural | 21 | 18.7 |
| Urban | 91 | 81.3 |
| Religion | | |
| Muslim | 9 | 8.0 |
| Christian | 101 | 90.2 |
| Traditionalist | 2 | 1.8 |
| Educational Level | | |
| No education | 3 | 2.7 |
| Junior Level | 23 | 20.5 |
| Secondary | 35 | 31.3 |
| Tertiary | 51 | 45.5 |
| Employment Status | | |
| Employed | 85 | 75.9 |
| Unemployed | 27 | 24.1 |
| Employment Type | | |
| Formal | 61 | 54.5 |
| Informal | 51 | 45.5 |
| Socio-Economic Status | | |
| Monthly Family Income | | |
| <gh₡500< td=""><td>8</td><td>7.1</td></gh₡500<> | 8 | 7.1 |
| GH¢500-GH1000 | 31 | 27.7 |

| GH₡1000 -GH5000 | 63 | 56.3 | | |
|---|-----------|------|--|--|
| GH5000 Above | 10 | 8.9 | | |
| Mean age of care-recipient (years ± SD) | 6.9 ± 4.9 | | | |
| Care Recipients' Age in years | | | | |
| 2-5 | 56 | 50.0 | | |
| 6 – 12 | 45 | 40.2 | | |
| 13+ | 11 | 9.8 | | |
| Sex of the Care Recipients | | | | |
| Female | 39 | 34.8 | | |
| Male | 73 | 65.2 | | |
| Are you the Primary Caregiver? | | | | |
| No | 10 | 8.9 | | |
| Yes | 102 | 91.1 | | |
| Are you related to this child? | | | | |
| No | 7 | 6.3 | | |
| Yes | 105 | 93.7 | | |
| If yes, what is your relationship with the child? | | | | |
| Grandchild | 6 | 5.4 | | |
| Child | 94 | 83.9 | | |
| Siblings | 5 | 4.5 | | |
| Others | 7 | 6.2 | | |

4.3 Care and Knowledge about Autism

Table 3 below presents an overview of the care and knowledge about autism. Of the respondents, 92.9% had knowledge about autism. Approximately, 45.5% reported their source of knowledge from the hospitals. Also, 64.9% reported they knew the mild kind of autism. More than half (64.9%) reported that their children had the mild form/ level of autism. A higher proportion (89.3%) of caregivers assisted their care recipient to perform on a regular basis. Similarly, a higher proportion of caregivers assisted their care recipient in taking their bath and managing their medications (86.9% and 89.7% respectively). Also, 69.6% of caregivers have been caregivers for less than 6 years. A summary of the selected characteristics of the participants is presented in Table 3 below.

| Variables | Frequency (N=112) | Percentage (%) |
|-------------------------------------|-------------------|----------------|
| Do you have knowledge about Autism? | | |
| No | 8 | 7.1 |
| Yes | 104 | 92.9 |
| Sources of Knowledge | | |
| Family/ Friend | 10 | 8.9 |
| Hospital | 51 | 45.5 |
| Internet | 34 | 30.4 |
| Radio/ Television | 8 | 7.1 |
| Other | 9 | 8.1 |
| What kind of autism do you know? | | |
| Mild | 78 | 69.6 |
| Moderate | 19 | 16.9 |
| Severe | 15 | 13.5 |

Table 3: Caregivers' Care and Knowledge about Autism

| What level of autism of the child? | | |
|---|-----|------|
| Mild | 81 | 72.3 |
| Moderate | 16 | 14.3 |
| Severe | 15 | 13.4 |
| Do you assist your care recipient to perform on a regular basis? | | |
| No | 12 | 10.7 |
| Yes | 100 | 89.3 |
| If yes, please what do you do for the child? | | |
| Dressing | 82 | 82.8 |
| Taking a bath | 86 | 86.9 |
| Toilet | 57 | 57.6 |
| Walking inside the house | 23 | 23.2 |
| Sitting up | 23 | 23.2 |
| Do you assist your care recipient on a regular basis with any of the following? | | |
| No | 10 | 8.9 |
| Yes | 102 | 91.1 |
| If yes what do you do to assist your care recipient on a regular basis? | | |
| Transportation | 39 | 40.2 |
| Meal preparation | 59 | 60.8 |
| Managing finances | 10 | 10.3 |
| Shopping | 14 | 14.4 |
| Housework | 21 | 21.6 |
| Medication management | 87 | 89.7 |

| Arranging for outside services to help him or her | 15 | 15.5 |
|---|----|------|
| How long have you been a caregiver? | | |
| < 6 years | 78 | 69.6 |
| >= 6 years | 34 | 30.4 |
| Does someone support in caring for the child? | | |
| No | 21 | 18.7 |
| Yes | 91 | 81.3 |
| If yes, what is your relationship? | | |
| Mother | 35 | 31.3 |
| Aunty | 12 | 10.7 |
| Father | 20 | 17.8 |
| Others | 45 | 40.2 |
| Do you pay for this extra support? | | |
| No | 67 | 59.8 |
| Yes | 45 | 40.2 |
| | | |

4.4 Quality of Life of Primary Caregivers.

Of the caregivers who responded, 56 (50.0%) rated their quality of life as neutral. Forty-five (45; 40.2%) moderately had enough energy for everyday life. Also, 38 (33.9%) had a little enough money to meet their needs. Fifty-one (51; 45.5%) were neutrally satisfied with their health. Forty-five (45; 46.15%) were neutrally satisfied with their ability to perform their daily living activities. Forty-nine (49; 43.8%) were neutrally satisfied with themselves. Forty-three (43; 38.4%) were neutrally satisfied with their personal relationship. A summary of the selected characteristics of the participants is presented in Table 4 below.

| Responses | Very | Poor | Po | oor | Ne | utral | G | ood | Very | v Good | Total |
|--|-------|---------|-------|--------------|-----|---------|----|--------|----------------|---------|-------------|
| | Ν | % | Ν | % | Ν | % | Ν | % | Ν | % | N (%) |
| How would you rate your quality of life? | 6 | 5.4 | 25 | 22.3 | 56 | 50.0 | 16 | 14.3 | 9 | 8.0 | 112 (100.0) |
| | Not | at all | Al | ittle | Mod | erately | M | Mostly | | pletely | |
| | N | % | Ν | % | N | % | Ν | % | Ν | % | |
| Do you have enough energy for everyday life? | 8 | 7.1 | 26 | 23.2 | 45 | 40.2 | 19 | 16.9 | 14 | 12.6 | 112 (100.0) |
| Have you enough money to meet your needs? | 11 | 9.8 | 38 | 33.9 | 37 | 33.0 | 16 | 14.4 | 10 | 8.9 | 112 (100.0) |
| | Stro | ongly | Dissa | Dissatisfied | | Neutral | | isfied | Very Satisfied | | |
| | Dissa | tisfied | | | | | | | | | |
| | Ν | % | Ν | % | Ν | % | Ν | % | Ν | % | |
| How satisfied are you with your health? | 7 | 6.3 | 19 | 16.9 | 51 | 45.5 | 19 | 16.9 | 16 | 14.4 | 112 (100.0) |
| How satisfied are you with your ability to perform your daily living activities? | 4 | 3.6 | 26 | 23.2 | 45 | 40.2 | 25 | 22.3 | 12 | 10.7 | 112 (100.0) |
| How satisfied are you with yourself? | 5 | 4.5 | 26 | 23.2 | 49 | 43.8 | 20 | 17.9 | 12 | 10.1 | 112 (100.0) |
| How satisfied are you with your personal relationships? | 11 | 9.8 | 30 | 26.8 | 43 | 38.4 | 14 | 12.5 | 14 | 12.5 | 112 (100.0) |
| How satisfied are you with the conditions of your living place? | 8 | 7.1 | 21 | 18.8 | 43 | 38.4 | 18 | 16.1 | 22 | 19.6 | 112 (100.0) |

 Table 4: Proportion of participants with responses to questions on the Quality of life of the primary caregiver

4.4.1 Proportions of the Quality of Life of Caregivers

With respect to the quality of life of caregivers, this study observed no significant difference (56; 50.00%) of the quality of life among caregivers. This was measured by adding all responses and determining the mean score between responses given per the quality of life of caregivers' assessment (High Quality of Life is scored as \geq 21.640, Low perception is a score of <21.640). Figure 3 below represents the levels of quality of life among respondents.



Figure 3: The levels of Quality of Life among respondents.

4.5 The Centrality of Religiosity of Caregivers

With regards to the centrality of religiosity of caregivers, 67 (59.8%), more than once a week, do take part in religious services. One-hundred and two (102; 91.1%) less often do pray. Seventy-eight (78; 69.7%) more than once a week do meditate. Sixty-four (64; 57.1%) very often do believe that God or something divine exists. A summary of the selected characteristics of the participants is presented in Table 5 below.

| Responses | Ne | ever | Less oftenA few times a yearOne or threeMore than once a weekN%N%N | Total | | | | | | | |
|---|-------|------|--|--------|--------------|--------------|-------|-------|------|---------|-------------|
| | Ν | % | Ν | % | Ν | % | Ν | % | Ν | % | N (%) |
| How often do you take part in religious services? | - | - | 3 | 2.7 | 10 | 8.9 | 32 | 28.6 | 67 | 59.8 | 112 (100.0) |
| How often do you pray? | - | - | 102 | 91.1 | 4 | 3.6 | - | - | 6 | 5.4 | 112 (100.0) |
| How often do you meditate? | 5 | 4.5 | 6 | 5.4 | 5 | 4.5 | 18 | 16.1 | 78 | 69.7 | 112(100.0) |
| | Never | ever | Rarely | | Occasionally | | Often | | Very | v often | |
| | Ν | % | Ν | % | Ν | % | Ν | % | Ν | % | |
| To what extent do you believe that God or something divine exists? | - | - | 3 | 2.7 | 8 | 7.1 | 37 | 33.0 | 64 | 57.1 | 112 (100.0) |
| | Ne | ever | Ra | Rarely | | Occasionally | | Often | | v often | |
| | Ν | % | Ν | % | Ν | % | Ν | % | N | % | |
| How often do you think about religious issues? | - | - | 3 | 2.7 | 11 | 9.8 | 54 | 48.2 | 44 | 39.3 | 112 (100.0) |
| How often do you experience situations in which you have the feeling that God or something divine intervenes in your life? | - | • | - | - | 15 | 13.4 | 56 | 50.0 | 41 | 36.6 | 112 (100.0) |

Table 5: Proportion of participants with responses to questions on the Centrality of Religiosity of caregivers.

4.5.1 The Centrality of Religiosity among Caregivers

With respect to the centrality of religiosity among caregivers, this study observed no significant difference in the religiosity ranks among caregivers [Low Centrality of Religiosity (50.0%); High Centrality of Religiosity (50.0%)]. This was measured by determining the mean score between responses given per the centrality of religiosity of caregivers' assessment (High Centrality of Religiosity is scored as ≥ 16.37 , Low Centrality of Religiosity is a score of <16.37). Figure 4 below represents the overall centrality of religiosity among caregivers.



Figure 4: The overall Centrality of Religiosity among caregivers

4.6 Impact of Caregiving on Caregivers

With regards to the impact of caregiving on caregivers, 34 (30.4%) moderately find difficulty getting enough sleep. Also, 57 (50.9%) do not (None) face problems getting enough food to eat. Thirty-one (27.7%) moderately do not have enough energy for extra work. Thirty-six (32.1%) moderately cannot take care of health, ailment/chronic condition. A summary of the selected characteristics of the participants is presented in Table 6 below.

| Responses | N | one | Ν | lild | Mo | derate | Se | vere | Ext | reme | Total |
|--|----|------|----|------|----|--------|----|------|-----|------|-------------|
| | Ν | % | Ν | % | Ν | % | Ν | % | Ν | % | N (%) |
| Difficulty getting enough sleep | 18 | 16.1 | 30 | 26.8 | 34 | 30.3 | 18 | 16.1 | 12 | 10.7 | 112 (100.0) |
| Problem getting enough food to eat | 57 | 50.9 | 19 | 16.9 | 21 | 18.8 | 8 | 7.1 | 7 | 6.3 | 112 (100.0) |
| Not enough energy for extra work | 28 | 25.0 | 31 | 27.7 | 31 | 27.7 | 12 | 10.7 | 10 | 8.9 | 112 (100.0) |
| Cannot take care of health, ailment/chronic condition | 28 | 25.0 | 30 | 26.8 | 36 | 32.1 | 10 | 8.9 | 8 | 7.2 | 112 (100.0) |
| Unable to pay for medication/treatment for ailment/chronic condition alone | 41 | 36.6 | 24 | 21.4 | 29 | 25.9 | 13 | 11.6 | 5 | 4.5 | 112 (100.0) |
| Cannot visit friends and relatives as much as before | 29 | 25.9 | 20 | 17.9 | 22 | 19.6 | 27 | 24.1 | 14 | 12.5 | 112 (100.0) |
| Cannot share feelings about caregiving responsibility with others | 37 | 33.0 | 27 | 24.1 | 34 | 30.4 | 5 | 4.5 | 9 | 8.0 | 112 (100.0) |
| Experienced financial problems due to loss of income | 45 | 40.2 | 20 | 17.9 | 24 | 21.4 | 16 | 14.2 | 7 | 6.3 | 112 (100.0) |
| Do not know the correct care to provide for health problems of care recipients | 28 | 25.0 | 23 | 20.5 | 47 | 41.9 | 7 | 6.3 | 7 | 6.3 | 112 (100.0) |

Table 6: Proportion of participants with responses to questions on the Centrality of Religiosity

| Experienced stigma or problems | 44 | 39.3 | 17 | 15.2 | 20 | 17.9 | 11 | 9.7 | 20 | 17.9 | 112 (100.0) |
|-------------------------------------|----|------|----|------|----|------|----|-----|----|------|-------------|
| as a result of the care recipient's | | | | | | | | | | | |
| liness or death | | | | | | | | | | | |

4.6.1 Proportions on the Impact of Caregiving on Caregivers

With respect to the impact of caregiving on caregivers, this study observed a low (58, 51.8%) impact of caregiving on caregivers and a high (54, 48.2%) impact of caregiving on caregivers. This was measured by determining the mean score between responses given per the impact of caregiving of caregivers' assessment (High impact of caregiving is scored as \geq 24.42, Low impact of caregiving is a score of <24.42). Figure 5 below represents the overall centrality of religiosity among caregivers



Figure 5: The level of Impact of Caregiving

4.7 The Health Literacy of Caregivers.

Table 7 shows the health literacy of caregivers. Of the caregivers, 70 (62.5%) easily find out where to get professional help when they are ill. Also, 72 (64.3%) easily understand information about what to do in a medical emergency. Sixty-nine (69; 61.6%) easily judge the advantages and disadvantages of different treatment options. Sixty-five (65; 58.0%) easily act on advice from your doctor or pharmacist. A summary of the selected characteristics of the participants is presented in Table 7 below.

| Responses | Very | y Easy | Easy | | Dif | ficult | Very I | Difficult | Ref | usal | Total |
|---|------|--------|------|------|-----|--------|--------|-----------|-----|------|-------------|
| | N | % | Ν | % | N | % | Ν | % | Ν | % | N (%) |
| To find out where to get professional help when you are ill? | 32 | 28.6 | 70 | 62.4 | 6 | 5.4 | 1 | 0.9 | 3 | 2.7 | 112 (100.0) |
| To understand information about what to do in a medical emergency? | 25 | 22.3 | 72 | 64.3 | 11 | 9.8 | 4 | 3.6 | - | - | 112 (100.0) |
| To judge the advantages and disadvantages of different treatment options? | 26 | 23.2 | 69 | 61.6 | 12 | 10.7 | 5 | 4.5 | - | - | 112 (100.0) |
| To act on advice from your doctor or pharmacist? | 34 | 30.4 | 65 | 58.0 | 11 | 9.8 | 2 | 1.8 | - | - | 112 (100.0) |
| To find information on how to handle mental health problems? | 17 | 15.2 | 65 | 58.0 | 23 | 20.5 | 7 | 6.3 | - | - | 112 (100.0) |
| To understand information about recommended health screening or examinations? | 18 | 16.1 | 74 | 66.1 | 16 | 14.3 | 4 | 3.5 | - | - | 112 (100.0) |
| To judge if information on healthy habits, such as smoking, low physical activity | 26 | 23.2 | 78 | 69.6 | 8 | 7.2 | - | - | - | - | 112 (100.0) |

 Table 7: Proportion of participants with responses to questions on the Health Literacy
| or drinking too much alcohol are reliable? | | | | | | | | | | | |
|---|----|------|----|------|----|------|---|-----|---|---|-------------|
| To decide how you can protect yourself form illness using information form illness mass media? | 29 | 25.9 | 72 | 64.3 | 11 | 9.8 | - | - | - | - | 112 (100.0) |
| To find information on healthy lifestyle such as physical exercise, healthy food or nutrition? | 27 | 24.1 | 77 | 68.8 | 8 | 7.1 | - | - | - | - | 112 (100.0) |
| To understand advice concerning your health from family or friends? | 26 | 23.2 | 75 | 66.9 | 11 | 9.9 | - | - | - | - | 112 (100.0) |
| To judge how your housing conditions may affect your health and well-being? | 28 | 25.0 | 77 | 68.8 | 5 | 4.5 | 2 | 1.7 | - | - | 112 (100.0) |
| To make decision to improve your health and well-being? | 50 | 44.6 | 50 | 44.6 | 12 | 10.7 | - | - | - | - | 112 (100.0) |

4.7.1 Proportions of the Levels of Health Literacy of Caregivers.

With regards to the levels of health literacy of caregivers, this study observed a high (59.82%) level of health literacy of caregivers and a low (40.18%) level of health literacy of caregivers. This was measured by determining the mean score between responses given per the impact of caregiving of caregivers' assessment (High level of Health Literacy is scored as \geq 22.71, Low level of Health Literacy is a score of <22.71). Figure 6 below represents the overall levels of Health Literacy of caregivers.



Figure 6: The levels of Health of Literacy of caregivers.

4.8 Association of factors influencing the Quality of life of caregivers.

4.8.1 Socio-demographics and socio- economic factors influencing the Quality of Life caregivers

Table 8 below represents the chi-square test of association between socio-demographic characteristics, socioeconomic status, contextual factors, and the Quality of Life of caregivers with children living with Autism. The study revealed that associations between Employment type (p=0.003), educational level (p=0.010), and being a primary caregiver (p=0.047) were statistically significant to the Quality of life of caregivers.

| Variables | | Quality | y of Life | | χ^2 (p-Value)/Fisher's exact |
|--------------------------------|--------|---------|-----------|------|-----------------------------------|
| - | Low | | High | | - |
| - | Ν | % | Ν | % | _ |
| Name of Hospital | | | | | 1.84 (0.606) |
| Accra Psychiatric Hospital | 7 | 50.0 | 7 | 50.0 | |
| Tema General Hospital | 16 | 47.1 | 18 | 52.9 | |
| Korle-Bu Teaching Hospital | 31 | 54.4 | 26 | 45.6 | |
| Mission Paediatric Hospital | 2 | 28.6 | 5 | 71.4 | |
| Socio-demographic and Socio-ec | onomic | status | | | |
| Age | | | | | 6.35 (0.097) |
| 30 - 35 | 21 | 53.8 | 18 | 46.2 | |
| 36 - 40 | 21 | 61.8 | 13 | 38.2 | |
| 41 – 45 | 7 | 29.2 | 17 | 70.8 | |
| 46+ | 7 | 46.7 | 8 | 53.3 | |
| Sex of Caregivers | | | | | 0.97 (0.324) |

Table 8: Bivariate analysis of factors influencing the Quality of life of caregivers

| Female | 48 | 52.2 | 44 | 47.8 | |
|------------------------|----|------|----|-------|---------------|
| Male | 8 | 40.0 | 12 | 60.0 | |
| Care Recipients' Age | | | | | 0.11 (0.945) |
| 2-5 | 28 | 50.0 | 28 | 50.0 | |
| 6 – 12 | 23 | 51.1 | 22 | 48.9 | |
| 13+ | 5 | 45.5 | 6 | 54.5 | |
| Sex of Care Recipients | | | | | 0.35 (0.552) |
| Female | 21 | 53.8 | 18 | 46.2 | |
| Male | 35 | 47.9 | 38 | 52.1 | |
| Marital Status | | | | | 7.27 (0.064) |
| Divorced | 11 | 57.9 | 8 | 42.1 | |
| Married | 32 | 42.1 | 44 | 57.9 | |
| Never Married | 11 | 78.6 | 3 | 21.4 | |
| Widow/ Widower | 2 | 66.7 | 1 | 33.3 | |
| Place of Residence | | | | | 1.47 (0.226) |
| Rural | 13 | 61.9 | 8 | 38.1 | |
| Urban | 43 | 47.3 | 48 | 52.7 | |
| Religion | | | | | 1.09 (0.580) |
| Muslim | 3 | 33.3 | 6 | 66.7 | |
| Christianity | 52 | 51.5 | 49 | 48.5 | |
| Traditionalist | 1 | 50.0 | 1 | 50.0 | |
| Educational Level | | | | | 10.89 (0.010) |
| No education | 0 | 00.0 | 3 | 100.0 | |
| Junior level | 17 | 73.9 | 6 | 26.1 | |
| Secondary | 19 | 54.3 | 16 | 45.7 | |
| | | | | | |

| Tertiory | 20 | 30.2 | 31 | 60.0 | |
|---|------------------------------|--|------------------------------|--|------------------------------|
| Tertiary | 20 | 39.2 | 51 | 00.9 | |
| Employment Status | | | | | 0.05 (0.825) |
| Employed | 42 | 49.4 | 43 | 50.6 | |
| Unemployed | 14 | 51.8 | 13 | 48.2 | |
| Employment Type | | | | | 6.08 (0.022) |
| Formal | 26 | 39.3 | 37 | 60.7 | |
| Informal | 32 | 62.7 | 19 | 37.3 | |
| Monthly Family Income | | | | | 4.92 (0.189) |
| <gh¢500< td=""><td>5</td><td>62.5</td><td>3</td><td>37.5</td><td></td></gh¢500<> | 5 | 62.5 | 3 | 37.5 | |
| GH₡500-GH1000 | 18 | 58.1 | 13 | 41.9 | |
| GH₡1000 -GH5000 | 31 | 49.2 | 32 | 50.8 | |
| GH5000 Above | 2 | 200.0 | 8 | 80.0 | |
| Are you the primary caregiver? | | | | | 3.95 (0.047) |
| No | 2 | 20.0 | 8 | 80.0 | |
| Yes | 54 | 52.9 | 48 | 47.1 | |
| Are you related to this child? | | | | | 0.15(0.000) |
| | | | | | 0.15 (0.696) |
| No | 3 | 42.9 | 4 | 57.1 | 0.13 (0.696) |
| No Yes | 3 53 | 42.9 50.5 | 4 52 | 57.1 49.5 | 0.13 (0.696) |
| No Yes If yes, what is your relationship with the child? | 3 53 | 42.9 50.5 | 4 52 | 57.1 49.5 | 1.05 (0.789) |
| No Yes If yes, what is your relationship with the child? Grandchild | 3 53 4 | 42.9 50.5 66.7 | 4 52 2 | 57.1 49.5 33.3 | 0.13 (0.696) 1.05 (0.789) |
| No Yes If yes, what is your relationship with the child? Grandchild Child | 3 53 4 46 | 42.9 50.5 66.7 48.9 | 4 52 2 48 | 57.149.533.351.1 | 0.13 (0.696) 1.05 (0.789) |
| No Yes If yes, what is your relationship with the child? Grandchild Child Sibling | 3 53 4 46 3 | 42.9 50.5 66.7 48.9 60.0 | 4 52 2 48 2 | 57.1 49.5 33.3 51.1 40.0 | 0.13 (0.696) |
| No Yes If yes, what is your relationship with the child? Grandchild Child Sibling Others | 3 53 4 46 3 3 | 42.9 50.5 66.7 48.9 60.0 42.9 | 4 52 2 48 2 4 | 57.1 49.5 33.3 51.1 40.0 57.1 | 0.13 (0.696) |

4.8.2 Care and Knowledge of Autism factors influencing Quality of Life of caregivers.

Table 8 below represents the chi-square test of association between Care and Knowledge of Autism and the Quality of Life of caregivers with children living with Autism. The study revealed no significant association between care and knowledge of Autism to the Quality of Life of caregivers.

| | Quality | of Life | | | |
|--|---------|---------|------|------|-----------------------------------|
| Variables | Low | | High | | χ^2 (p-Value)/Fisher's exact |
| | Ν | % | N | % | |
| Knowledge about autism | | | | | |
| Do you have Knowledge about autism? | | | | | 0.54 (0.463) |
| No | 5 | 62.5 | 3 | 37.5 | |
| Yes | 51 | 49.0 | 53 | 50.9 | |
| Sources of Knowledge | | | | | 7.75 (0.101) |
| Family/ Friend | 7 | 70.0 | 3 | 30.0 | |
| Hospital | 24 | 47.1 | 27 | 52.9 | |
| Internet | 15 | 44.1 | 19 | 55.9 | |
| Radio/ Television | 7 | 87.5 | 1 | 12.5 | |
| Other | 3 | 33.3 | 6 | 66.7 | |
| What kind of autism do you know? | | | | | 1.64 (0.440) |
| Mild | 31 | 49.2 | 32 | 50.8 | |
| Moderate | 9 | 47.4 | 10 | 52.6 | |
| Severe | 10 | 66.7 | 5 | 33.3 | |

 Table 8: Bivariate analysis of factors influencing the Quality of life of caregivers (continued...)

| What is the level of autism of the child? | | | | | 1.73 (0.422) |
|--|----|------|----|------|--------------|
| Mild | 33 | 48.5 | 35 | 51.5 | |
| Moderate | 9 | 56.2 | 7 | 43.8 | |
| Severe | 10 | 66.7 | 5 | 33.3 | |
| Do you assist your care recipient to perform on a regular basis? | | | | | 0.37 (0.761) |
| No | 5 | 41.7 | 7 | 58.3 | |
| Yes | 51 | 51.0 | 49 | 9.0 | |
| How long have you been a caregiver to this person? | | | | | 0.17 (0.837) |
| < 6 years | 38 | 48.7 | 40 | 51.3 | |
| >= 6 years | 18 | 52.9 | 16 | 47.1 | |
| Does someone support in caring for the child? | | | | | 0.63 (0.429) |
| No | 11 | 52.4 | 10 | 47.6 | |
| Yes | 45 | 49.5 | 46 | 50.5 | |
| If yes, what is your relationship? | | | | | 2.93 (0.408) |
| Mother | 13 | 37.1 | 22 | 62.9 | |
| Aunty | 7 | 58.3 | 5 | 41.7 | |
| Father | 11 | 55.0 | 9 | 45.0 | |
| Others | 12 | 54.5 | 10 | 45.5 | |
| Do you pay for this extra support? | | | | | 0.85 (0.400) |
| No | 30 | 44.8 | 37 | 55.2 | |

| Yes | 18 | 54.5 | 15 | 45.5 | |
|--------------------------------|----|------|----|------|--------------|
| Contextual Factors | | | | | |
| Centrality of Religiosity | | | | | 0.57 (0.571) |
| Low Centrality of Religiosity | 26 | 46.4 | 30 | 53.6 | |
| High Centrality of Religiosity | 30 | 53.6 | 26 | 46.4 | |
| Impact of Caregiving | | | | | 3.58 (0.059) |
| Low impact of caregiving | 24 | 41.4 | 34 | 58.6 | |
| High impact of caregiving | 32 | 59.3 | 22 | 40.7 | |
| Level of Health Literacy | | | | | 0.33 (0.700) |
| Low Level of Health literacy | 21 | 46.7 | 24 | 53.3 | |
| High level of Health literacy | 35 | 52.2 | 32 | 47.8 | |
| | | | | | |

4.9 Factors influencing the Quality of life of caregivers based on the selected facilities.

Table 9 below presents sociodemographic characteristics, socioeconomic status, and contextual factors influencing the quality of life of caregivers with children living with Autism in Selected Facilities in the Greater Accra Region. These estimates are presented in two models: Crude Odds Ratio (COR) and Adjusted Odds Ratio (AOR). Employment type, educational level and source of knowledge were the main factors influencing the quality of life of caregivers with children living with Autism among caregivers.

Caregivers with an informal type of employment were 61% less likely to have a high quality of life (COR=0.39; 95% CI: 0.17 – 0.92). Also, caregivers who had a junior level of education were 78% less likely to have a high quality of life (COR=0.22; 95% CI: 0.08 – 0.68). Similarly, caregivers who had knowledge from the internet were 13 times more likely to have a high quality of life (AOR=13.88; 95% CI: 1.05 – 182.99).

| Variables | COR (95% CI) p-value | AOR (95% CI) p-value |
|-----------------------------|---------------------------|-----------------------------|
| Name of Hospital | | |
| Accra Psychiatric Hospital | Ref | Ref |
| Tema General Hospital | 0.90 (0.15 - 5.35) 0.912 | 0.90 (0.15 - 5.36) 0.912 |
| Korle-Bu Teaching Hospital | 0.69 (0.11 - 4.09) 0.678 | 0.68 (0.11 - 4.09) 0.678 |
| Mission Paediatric Hospital | 0.89 (0.05 - 16.66) 0.941 | 0.89 (0.05 - 16.66) 0.941 |
| Sex of Caregivers | | |
| Female | Ref | Ref |
| Male | 1.64 (6.12 – 4.38) 0.326 | 0.55 (0.09 - 3.09) 0.495 |
| Care Recipients' Age | | |
| 2-5 | Ref | Ref |
| 6 – 12 | 0.96 (0.44 - 2.09) 0.912 | 1.19 (0.32 - 4.47) 0.790 |
| 13+ | 1.2 (0.33 – 4.39) 0.783 | 0.99 (0.12 - 8.38) 1.000 |
| Sex of Care Recipients | | |
| Female | Ref | Ref |
| Male | 1.27 (0.58 - 2.76) 0.552 | 1.25 (0.42 - 3.68) 0.685 |
| Sources of Knowledge | | |
| Family/ Friend | Ref | Ref |
| Hospital | 2.63 (0.61 - 11.30) 0.195 | 8.27 (0.73 – 93.29) 0.088 |
| Internet | 2.96 (0.65 - 13.41) 0.160 | 13.88 (1.05 – 182.99) 0.046 |
| Radio/ Television | 0.33 (0.03 – 4.04) 0.388 | - |
| Educational level | | |
| No Education | Ref | Ref |
| Junior Level | 0.22 (0.08 - 0.68) 0.008 | 0.36 (0.07 - 1.91) 0.232 |

Table 9: Multivariate analysis of factors influencing the Quality of life of caregivers

| Secondary | 0.54 (0.23 – 1.29) 0.170 | 0.83 (0.21 – 3.32) 0.798 |
|---|---------------------------|---------------------------|
| Tertiary | Ref | - |
| Employment Type | | |
| Formal | Ref | Ref |
| Informal | 0.39 (0.18 - 0.83) 0.015 | 0.58 (0.05 - 1.172) 0.085 |
| Monthly Family Income | | |
| <gh¢500< td=""><td>Ref</td><td>Ref</td></gh¢500<> | Ref | Ref |
| GH₡500-GH1000 | 6.67 (0.89 - 54.96) 0.078 | 0.58 (0.05 - 6.50) 0.656 |
| GH₡1000 -GH5000 | 1.72 (0.38 - 7.82) 0.482 | 0.66 (0.06 - 6.83) 0.727 |
| GH5000 Above | 1.20 (0.24 – 5.96) 0.820 | 1.35 (0.06 - 31.39) 0.848 |
| Are you the primary caregiver? | | |
| No | Ref | Ref |
| Yes | 0.22 (0.04 - 1.09) 0.065 | 0.24 (0.05 - 1.33) 0.104 |
| Do you assist your care recipient on a regular basis? | | |
| No | Ref | Ref |
| Yes | 0.68 (0.20 - 2.31) 0.543 | 0.38 (0.05 - 2.88) 0.351 |
| Centrality of Religiosity | | |
| Low Centrality of Religiosity | Ref | Ref |
| High Centrality of Religiosity | 0.75 (0.36 - 1.58) 0.450 | 0.79 (0.37 – 1.69) 0.550 |
| Impact of Caregiving | | |
| Low impact of caregiving | Ref | Ref |
| High impact of caregiving | 0.48 (0.23 - 1.03) 0.060 | 0.49 (0.23 - 1.06) 0.072 |
| Health Literacy | | |
| | | |

| Low health literacy | Ref | Ref |
|----------------------|--------------------------|--------------------------|
| High health literacy | 0.80 (0.38 - 1.71) 0.563 | 0.79 (0.37 – 1.73) 0.567 |

CHAPTER FIVE

5.0 DISCUSSION

5.1 Introduction

The goal of the current study was to investigate the quality of life in the Greater Accra Region for those who provide care for children with autism. According to this study, carers' quality of life with children who have autism is influenced by health literacy, caregiving impact, monthly family income, and religiosity. No indication of a statistically significant difference was found. However, the study discovered that the primary determinants impacting the quality of life of caregivers of children with autism were educational level, kind of occupation, and information source among caregivers, among other controlled variables. The study brings new evidence to the decades of research on assessing the quality of life of caregivers of children living with autism in the Greater Accra Region.

5.2 The socio-demographic characteristics and socio-economic status of caregivers of children living with autism.

In relation to the effect of monthly family income on caregivers of children with autism, the results of this study suggested that individuals with higher monthly incomes had a higher quality of life than those with lower monthly incomes, albeit this relationship was not statistically significant. Previous research provided extensive support for these findings about the connection between participants' quality of life and monthly income (Joung, 2022; Lone et al., 2022; Alhazmi et al., 2018; Marsack-Topolewski & Church, 2019; Alenazi et al., 2020; Calonge-Torres et al., 2017; Keefer et al., 2018). This suggests that a family's financial situation has a big impact on a lot of different areas of the wellbeing of parents of autistic children. Therefore, the more money a caregiver has, the more able they are to support and care for their clients. (Alhazmi et al., 2018).

Previous findings suggested that low income badly affects self-esteem, blocked aspirations, increased frustration, reduced efficacy, fatalism, and lower mastery and personal control (Lone et al., 2022).

The nature (type) of employment is a pivotal factor influencing caregivers' quality of life. This study found that caregivers with an informal type of employment were 61% less likely to have a high quality of life. The ability to work flexible hours or take time off to care for their children's needs may be difficult for caregivers in these employment kinds. They might experience increased stress and decreased well-being as a result. Informal employment arrangements may result in financial strain, restricted access to healthcare, and a lack of social support, all of which could lower the quality of life for carers as a whole.

In relation to education level, the results of this study indicated that caregivers who had a junior level of education were 78% less likely to have a high quality of life. This finding is in confirmation of a study by Karker, (2018) which reported, in a population-based studies of caregivers, demographic variables such as low education levels were identified as determinants of low Quality of Life among caregivers. Possible explanations for this finding are caregivers with lower levels of education perceive more challenges when managing their emotional well-being and fulfilling their caregiving roles (Sulaimani et al., 2023). Also, caregivers with lower levels of education may have limited access to information, resources, and support systems that can help them effectively cope with emotional challenges. This outcome is, however, contrary to that of Kandeger et al., (2018) who found educational status not significantly affecting the quality of life of caregivers.

Lastly, caregivers who had knowledge from the internet were 13 times more likely to have a high quality of life. The result is in line with those of previous studies. The source of knowledge about

autism greatly influences caregivers' ability to provide appropriate care and support. The role of the internet as a source of knowledge presents a paradoxical influence on caregivers' quality of life. Caregivers who access accurate and reliable information from reputable sources, such as the internet, tend to have a better grasp of the condition's nuances. This knowledge equips them with effective strategies for managing challenges and maximizing the potential of children with autism. As a result, caregivers who are well-informed through other credible sources often experience higher quality of life due to increased confidence and reduced feelings of helplessness. While the internet provides vast information about autism and caregiving strategies, its quality and accuracy vary widely. Caregivers relying solely on internet sources might encounter conflicting information that can lead to confusion and stress. This observation points to the need for proper guidance and support to help caregivers discern reliable sources from misinformation. When used discerningly, the internet can empower caregivers with information that positively affects their quality of life.

5.3 The factors associated with the quality of life of children living with Autism.

Very little was found in the literature on the question of religiosity influencing the quality of life of caregivers. On the question of religiosity, this study found no significant association with the caregiver's quality of life when the quality of life and the centrality of religiosity variables were considered. This finding is similar to findings by other studies (Kheir et al., 2012; Schertz et al., 2016; Wang, 2022; Ayesha et al., 2022). In contrast, a study in Lebanon by Papadopoulos et al., (2019) reported there was a relationship between religion and quality of life among carers of autistic children. This finding could be ascribed to the fact that religiosity may have distinct meanings and purposes for different people and civilizations.

While the findings on the impact of caregiving may not show statistical significance, the impact of caregiving cannot be overlooked. The results of this study showed that caregivers who had a high impact of caregiving were 52% less likely to have a high quality of life. Conflicting evidence was found regarding the types of burden that affected caregivers. Nonetheless, this result has previously been described by Marsack-Topolewski & Church, (2019) who found that caregivers who reported higher levels of developmental burden tended to have lower quality of life. A possible explanation for this might be that the overwhelming nature of constant attention, emotional strain, and adaptation to the unpredictable nature of autism caregiving could take a toll on caregivers' lives.

Health literacy encompasses caregivers' ability to understand, process, and utilize health-related information to make informed decisions. The current study found that caregivers with high levels of health literacy were 20% less likely to have a high quality of life despite lacking statistical significance. This finding is consistent with that of Lindly et al., (2022) whose findings demonstrated how parent's health literacy affects services use. This result may be explained by the fact that higher health literacy enables caregivers to navigate medical systems, service use, therapies, and interventions more effectively, enhancing their quality of life indirectly.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

In conclusion, this study highlights the importance of assessing the Quality of Life of caregivers of children with autism in the Greater Accra Region. The Quality of Life of caregivers of children living with autism is influenced by a complex interplay of factors. Based on the findings of this study, educational level, employment type, and source of knowledge were the three critical factors that impact caregivers' quality of life in the Greater Accra Region. By unraveling the intricate dynamics that shape caregivers' experiences, the research contributes to the broader understanding of autism care in urban contexts. As our understanding of these influences deepen, policymakers and healthcare providers can design more targeted holistic support systems and effective interventions that acknowledge and address the challenges faced by caregivers, ultimately enhancing their quality of life and the overall well-being of families affected by autism.

6.2 Recommendations

The following recommendations will be beneficial if adopted

- Promote Health Literacy and Education Programs: Given the significance of health literacy in caregivers' ability to navigate autism-related information and services, the Ministry of Health should foster collaboration with the Ministry of Information to implement health literacy and education programs targeted to help dispel misconceptions about autism and reduce the stigma associated with among caregivers with a lower level of education.
- 2. Virtual Counseling Services: Health facilities should Integrate virtual counseling services where caregivers can seek professional guidance and emotional support. This can be

particularly valuable for addressing the unique challenges associated with caregiving for individuals with autism.

3. Establish initiatives to recognize and appreciate the contributions of caregivers with an informal type of employment. This can include community awards, public acknowledgments, or appreciation events to highlight the importance of their role. Caregivers with an informal type of employment should have policies that will cover them living with autism.

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APPENDIX A: QUESTIONNAIRE ENSIGN GLOBAL COLLEGE

PROJECT WORK QUESTIONNAIRE

Dear Respondent, the researcher is an MPH student at the Ensign Global College, researching "The Quality of Life of Caregivers of Children Living with Autism in the Greater Accra Region". It would be much appreciated if you could complete this questionnaire which would take about 15 minutes. You are kindly requested to answer all the questions as honestly as possible without any compulsion. Your time and willingness to participate in this study are very much appreciated. Thank you.

Name of Facility.....

Unique ID for Respondent |___|

Date of interview (dd/mm/yyyy): |____|

Interviewer Name:

| 1. | Sex | 1. Female |
|----|---|---|
| | | 2. Male |
| 2 | What is your age in years? | |
| 3 | Marital status | Married Never married Divorced Widow/widower |
| 4 | Place of residence (District/ Municipality) | |
| 5 | Religion | Christian Muslim Traditionalist Others (specify) |

Section A: Socio-demographic and Socio-economic Information of Caregivers

| 6 | What is your current level of education? | No education Primary level Junior level Secondary Tertiary |
|----------|---|---|
| 7 | Employment status | Unemployed Employed |
| 8 | If employed, what is the type of employment | Formal Informal |
| 9 | Monthly family income | <ghø500< li=""> GHØ500-GH1000 GHØ1000 -GH5000 GH5000 Above </ghø500<> |
| 10 11 | Do you have any knowledge about autism? Sources of knowledge | 1. YES 2. NO |
| 12. | What kind of autism do you know | 1. Mild 2. Moderate |
| 13. | What are some of the characteristics of ques.12. | 5. 560616 |

Child-related information

| 14 | How old is the care recipient? | |
|----|---|--|
| 15 | What is the Sex of the care recipient? | 1. Female 2. Male |
| 16 | Are you the primary caregiver? | 1. Yes 2. No |
| 17 | Are you related to this child? | 1. Yes 2. No |
| 18 | If yes, what is your relationship with the child? | Child Sibling Grandchild Others (Specify) |

| 19 | Do you assist your care recipient to perform on a regular basis? | 1. Yes 2. No Please, tick the one applicable. Taking a bath() Toilet () Walking inside the house () Dressing () Sitting up () |
|----|---|--|
| 29 | Do you assist your care recipient on a regular basis with any of the following – transportation, meal preparation, managing finances, shopping, housework, medication management, or arranging for outside services to help him or her? | 1. Yes2. NoPlease, tick the oneapplicable.Transportation ()Meal preparation ()Managing finances ()Shopping ()Housework ()Medication management ()Arranging for outsideservices to help him or her () |
| 21 | How long have you been a caregiver to this person? | |
| 22 | Does someone support in caring for the child? | 1. Yes 2. No |
| 23 | If yes, what is your relationship? | 1.Father 2. Mother 3.Aunty 4. Uncle |
| 24 | Do you pay for this extra support? | 1. Yes 2. No |

Section B: Quality of life of primary caregiver (WHO EUROHIS - QOL INDEX) Please answer the questions below by circling the appropriate response which best describes how you feel.

| Very Poor | Poor | Neutral | Good | Very Good |
|-----------|------|---------|------|-----------|
|-----------|------|---------|------|-----------|

| 25 | How would you rate your quality of life? | 1 | 2 | 3 | 4 | 5 |
|----|--|--------------------------|--------------|------------|-----------|-------------------|
| | | Not at all | A little | Moderately | Mostly | Completely |
| 26 | Do you have enough energy for everyday life? | 1 | 2 | 3 | 4 | 5 |
| | | Strongly Dissatisfied | Dissatisfied | Neutral | Satisfied | Very Satisfied |
| 27 | Have you enough money to meet your needs? | 1 | 2 | 3 | 4 | 5 |
| 28 | How satisfied are you with your health? | 1 | 2 | 3 | 4 | 5 |
| 29 | How satisfied are you with your ability to perform your daily living activities? | 1 | 2 | 3 | 4 | 5 |
| 30 | How satisfied are you with yourself? | 1 | 2 | 3 | 4 | 5 |
| 31 | How satisfied are you with your personal relationships? | 1 | 2 | 3 | 4 | 5 |
| 32 | How satisfied are you with the conditions of your living place? | 1 | 2 | 3 | 4 | 5 |

Section C: Centrality of Religiosity (CRS-5 Scale) Please answer the questions below by circling the appropriate response which best describes what you do.

| | Scale items | Never (1) | Less often (2) | A few times a year (3) | Oneorthreetimestimesamonth(4) | More than once a week (5) |
|----|---|----------------|----------------------|------------------------------|-------------------------------|------------------------------------|
| 33 | How often do you take part in religious services? | 1 | 2 | 3 | 4 | 5 |
| 34 | How often do you pray? | 1 | 2 | 3 | 4 | 5 |
| 35 | How often do you meditate? | 1 | 2 | 3 | 4 | 5 |
| | | Not at all (1) | Not very much (2) | Moderately (3) | Quite a bit (4) | Very much so (5) |

| 36 | To what extent do you believe | 1 | 2 | 3 | 4 | 5 |
|----|---|-------|--------|--------------|-------|------------|
| | that God or something divine | | | | | |
| | exists? | | | | | |
| | | Never | Rarely | Occasionally | Often | Very often |
| | | (1) | (2) | (3) | (4) | (5) |
| 37 | How often do you think about religious issues? | 1 | 2 | 3 | 4 | 5 |
| 38 | How often do you experience situations in which you have the feeling that God or something divine intervenes in your life? | 1 | 2 | 3 | 4 | 5 |

Section D: WHO Impact of Caregiving Scale

Please answer the questions below by circling the appropriate response which best describes your situation.

| | Scale items | None | Mild | Moderate | Severe | Extreme |
|----|--|------|------|----------|--------|---------|
| | | (1) | (2) | (3) | (4) | (5) |
| 26 | Difficulty getting enough sleep | 1 | 2 | 3 | 4 | 5 |
| 27 | Problem getting enough food to eat | 1 | 2 | 3 | 4 | 5 |
| 28 | Not enough energy for extra work | 1 | 2 | 3 | 4 | 5 |
| 29 | Cannot take care of health, ailment/chronic condition | 1 | 2 | 3 | 4 | 5 |
| 30 | Unabletopayformedication/treatmentforailment/chronic condition alone | 1 | 2 | 3 | 4 | 5 |
| 31 | Cannot visit friends and relatives as much as before | 1 | 2 | 3 | 4 | 5 |
| 32 | Cannot share feelings about caregiving responsibility with others | 1 | 2 | 3 | 4 | 5 |

| 32 | Experienced financial problems due to loss of income | 1 | 2 | 3 | 4 | 5 |
|----|---|---|---|---|---|---|
| 33 | Do not know the correct care to provide for health problems of care recipients | 1 | 2 | 3 | 4 | 5 |
| 34 | Experienced stigma or problems as a result of the care recipient's illness or death | 1 | 2 | 3 | 4 | 5 |

Section E: Health Literacy question. Please circle the appropriate answer.

| | | Very easy | Easy | Difficult | Very difficult | Refusal |
|----|---|-----------|------|-----------|----------------|---------|
| 35 | To find out where to get professional help when you are ill? | 1 | 2 | 3 | 4 | 5 |
| 36 | To understand information about what to do in a medical emergency? | 1 | 2 | 3 | 4 | 5 |
| 37 | Tojudgetheadvantagesanddisadvantagesofdifferenttreatmentoptions? | 1 | 2 | 3 | 4 | 5 |
| 38 | To act on advice from your doctor or pharmacist? | 1 | 2 | 3 | 4 | 5 |
| 39 | To find information on how to handle mental health problems? | 1 | 2 | 3 | 4 | 5 |
| 40 | Tounderstandinformationaboutrecommendedhealth | 1 | 2 | 3 | 4 | 5 |

| | screening or examinations? | | | | | |
|----|---|---|---|---|---|---|
| 41 | Tojudgeifinformationonhealthy habits, such assmoking, low physicalactivityordrinkingtoomuch alcoholarereliable? | 1 | 2 | 3 | 4 | 5 |
| 42 | To decide how you can protect yourself form illness using information form illness mass media? | 1 | 2 | 3 | 4 | 5 |
| 43 | To find information on healthy lifestyle such as physical exercise, healthy food or nutrition? | 1 | 2 | 3 | 4 | 5 |
| 44 | To understand advice concerning your health from family or friends? | 1 | 2 | 3 | 4 | 5 |
| 45 | To judge how your housing conditions may affect your health and well-being? | 1 | 2 | 3 | 4 | 5 |
| 46 | To make decision to improve your health and well-being? | 1 | 2 | 3 | 4 | 5 |

OUR CORE VALUES:

- Dedication and Excellence
 Partnership
- Professionalism
- Teamwork

My Ref. No. MHA/APH/G-109 Your Ref. No:

MS. JODY YEBOAH BIO ENSIGN GLOBAL COLLEGE KPONG- GHANA

Dear Ms. Jody Yeboah Bio,

APPROVAL OF RESEARCH PROPOSAL

We wish to inform you that, the Research and Ethical Review Committee of this facility has recommended approval of your proposed topic: "AN ASSESSMENT OF THE QUALITY OF LIFE OF CAREGIVERS OF THE CHILDREN LIVING WITH AUTISM IN THE GREATER ACCRA REGION, GHANA."

You are therefore entreated to:

- i. Liaise with the Hospital's Research and Ethical Review Committee in recruiting the required participants for the study.
- ii. Observe strict anonymity of volunteering study participants and the data/information obtained must be held in utmost confidentiality.
- iii. Submit a copy of the final report of the study to the Hospital.

We wish you the best of luck in your endeavour.

We look forward to working with you.

Congratulations!

Mr. Julius B. Kuusaalesuo Deputy Director (Administration) For: Hospital Director

Cc: The Chairperson, Research and Ethical Review Committee, APH



ACCRA PSYCHIATRIC HOSPITAL P. O. BOX 1305, ACCRA. GHANA. 0577690772/1 admin@accrapsychiatrichospital.org Digital Address: GA 051-5235

12th July, 2023.


KORLE BU TEACHING HOSPITAL P. G. BOX KB 77, KORLE BU, ACCRA.

Tel: +233 302 6671596673034-6 Fas: +233 302 667159 Email: Info@kbfth.gov.gb pr@kbfth.gov.gb Website: www.kbfth.gov.gb

21" July, 2023

JODY BIO YEBOAA ENSIGN GLOBAL COLLEGE ACCRA

INSTITUTIONAL APPROVAL: KORLE BU TEACHING HOSPITAL-SCIENTIFIC AND TECHNICAL COMMITTEE/INSTITUTIONAL REVIEW BOARD (KBTH-STC/IRB/000124/2023

Following approval of your study entitled "An Assessment of the Quality of Life of Caregivers of the Children Living with Autism in Selected Facilities in the Greater Accra Region, Ghana" by the Korle Bu Teaching Hospital-Scientific and Technical Committee/Institutional Review Board.

I am pleased to inform you that institutional approval has been granted for the conduct of your study in Korle Bu Teaching Hospital.

Please contact the Heads of Departments to discuss the commencement date of the study.

Please note that, this institutional approval is rendered invalid if the terms of the Institutional Reviewed Board/Scientific and Technical Committee approval are violated.

Sincere regards,

Dr. Harry Akoto Ag. Director of Medical Affairs For: Chief Executive

JODY YEBOAA BIO

Email: jodybio2@gmail.com/ yeboaabio@gmail.com Tel: 024 485 7660

PERSONAL DATA

| Gender: | Female |
|-----------------|------------------------------|
| Date of Birth: | 26 th July, 1985. |
| Place of Birth: | Tema, Greater Accra Region |
| Nationality: | Ghanaian |
| Marital status: | Single |

LANGUAGES SPOKEN/ UNDERSTOOD

Local: Twi Foreign: English

CAREER OBJECTIVE

To acquire a challenging position to meet my competencies, capabilities, skills, education and experience while creating more rooms for learning and contributing to the growth of the organization.

EDUCATIONAL BACKGROUND AND QUALIFICATION

- 1. University of Health and Allied Sciences, Ho (Bsc. Public Health (Mental Health) 2019 2022
- 2. College of Health, Kintampo (Diploma in Community Mental Health) 2013 2014
- 3. Central University College, Accra (Bsc. Administration (Accounting) 2008 2012
- 4. University of Ghana, Legon (Diploma in Statistics) 2008 2012
- 5. Community Health Nursing Training School, Oda (Certificate)
- 6. Ghana Secondary School, Koforidua (Visual Arts, SSSCE) 2000 2003

KEY COMPETENCIES, SKILLS AND ABILITIES

- Ability to deliver service before deadline
- Punctual and self-motivated
- Able to adapt to change easily
- Ability to follow instructions
- Good interpersonal and formal communication skills

WORK EXPERIENCE

| 1. | TEMA POLYCLINIC (Community Health Nurse) - | 2007 - 2008 |
|----|---|----------------|
| 2. | TEMA EAST U-Compound CHPS (Community Health Officer) - | Jan – Oct 2008 |
| 3. | APPOLONIA HEALTH CENTER (Community Mental Health Officer) - | 2008 - 2018 |
| 4. | ZENU HEALTH CENTER (Public Health Officer) - | 2019 – Date |

INTEREST AND HOBBIES

• Cooking

REFEREES

Dr. Lamptey Medical Doctor Zenu Health Center (0506741210) **Mrs. Gifty Ofori Ansah** District Health Director Ningo Prampram District (0244256707) Mrs. Veronica Ampabeng-Kyereme Deputy Director of Nursing Services Kpone Katamanso (0244510173)

2004 - 2006