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TITLE: COMMUNITY CULTURAL BELIEFS & PRACTICES ABOUT AUTISM IN SELECTED AREAS IN WA MUNICIPALITY.

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DECLARATION

I hereby declare that this submission is my own research work towards the award of Master Degree in Speech and Language Therapy and that to the best of my knowledge, it contains neither previously published material by any other person nor presented for the award of any other degree in this university or elsewhere except where references are made to other authors for their contributions.

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DEDICATION

To the Almighty Allah, my lovely family and my supervisors.

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I wish to express my sincerest gratitude to my supervisors especially Dr. Patricia M. Amos, for her patience and outstanding supervision throughout the course of the research work. My profound gratitude also goes to my family especially my husband Mr. Mohammad M Sangari for the support given me throughout the entire course of my study. Thanks to the people of the Wa Municipality whose enormous contributions have made this research a successful one.

ABSTRACT

It is imperative to establish that autism spectrum disorder is considered one of the most widely recognized developmental disorders that has gained much prominence on a global scale at the turn of the century which is susceptible to varied interpretations in cross-cultural context. It is highly characterized by cognitive, social, communication deficits and neurodevelopmental delay and in effect exerts greater socio-economic burden on families and caregivers with increasing cause for concern going forward.

The overarching purpose of the study was to explore community cultural beliefs and practices about autism spectrum disorder in three selected communities in the Wa Municipality of the Upper West Region. Study employed phenomenological research design with a qualitative method of approach. Both purposive and snowball sampling techniques were employed with a sample size of 30. The study made use of only primary sources of data elicited with the aid of semi-structured interviews and focus group discussions. Data analysis was mainly statistically descriptive with phenomenological interpretive analysis. Data analyzed from the findings arrived at the conclusion that culture play a cardinal and inextricable role in shaping participants knowledge, attitudes, beliefs and interpretations ascribed to autism spectrum disorder which consequently shape participants health-seeking behaviours and interventions.

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INTRODUCTION

1.1 Background to the Study

The rising prevalence of Autism Spectrum Disorder (ASD) has gained much prominence on a global scale at the turn of the century as one of the pervasive developmental disorders posing a grave health threat and socio-economic burdens on major stakeholders. It is highly characterized by developmental, social, communication and behavioral deficits yet has attracted little attention in resource constrained economies over the past few decades notably in Sub-Sahara Africa (Cardon & Marshall, 2017).

Presently, ASD constitutes one of the global neurodevelopmental disorders previously classified under a class of certain developmental disorders separately described as autistic disorder, pervasive developmental disorder and asperser's syndrome with symptoms ranging from mild to severe relative to time (Cogzell, 2018).

However, grounded on the belief that disability is a social construct, cross-cultural studies revealed that culture play an inextricable role in shaping families knowledge, attitude and perception. Again, beliefs ascribed to developmental disorders as well as interpretations and intervention choices that consequently shape their health seeking behaviors (Mandell et al., 2018).

Autism Spectrum Disorder is noted by the World Health Organisation (WHO) as a mental disorder closely related to persons with autism, aspersers syndrome or a developmental disorder not closely specified. Common symptoms and risks factors include; social and communication deficits, stereotyped character with limited interest in socialization which is quite prevalent in many developing parts of the world with high socio-economic inequalities (Durkin et al., 2015).

Devoid of well- established universal causes and threshold for diagnoses of ASD has equally subjected the disorder to varied methods of treatment. Some of these include psychiatric, cognitive, behavioral, therapeutic, pharmacological and other sensory and relational mechanisms respectively while the decision for treatment also vary substantially based on the conceptualization and interpretations ascribed to the disorder (Cloete & Obaigwa, 2019).

The absence of unified and harmonized criteria of diagnosing ASD constitutes one of the binding constraints that exacerbates the increasing prevalence and limited interventions of the disorder in many developing parts of the world notably Africa (Washinton-Nortey & Serpell, 2021).

This consequently contributes to some of the factors that hamper efforts towards combating the phenomenon in many transition and resource constrained economies accompanied with marginal increase in stigmatization, marginalization and social exclusion with poor life trajectory (Serpell et al., 2021).

The approaches to healthcare and health seeking behavior of people with Autism vary disproportionately across individual, groups and communities. These are informed by various determinants, including; economic, social, environmental, political, relationships and network structures. Other determinants include; demographic characteristics, healthcare system of that community, education, costs, proximity, access and perceived quality of the approach (Siddiqui, 2011).

ASD is prevalent and endemic in Sub-Sahara Africa with the poor and marginalized at the greatest of risks. Prevalence of this challenge is attributed to resource constraints and socio-economic disparities, cultural variations, low education and awareness, lack of campaign and sensitization (Wang & Casillas, 2012).

Other causes due to fragmented knowledge, poor monitoring and surveillance, inadequate reporting of cases, low political will and commitment and absence of integrated and collaborative efforts with inclusive policies which collectively contribute to limited interventions towards managing the disorder among victims (Wang & Casillas, 2012).

Moreover, the lack of broad-based national healthcare policies and strategies coupled with absence of public education and sensitization programs accompanied with fragmented investment and resource allocation utterly remained key barriers and challenges to addressing the disorder among victims in many communities (Tromans, et al., 2021).

1.2 Statement of the problem

The health and socio-economic consequences of ASD are more severe in developing economies rather than developed ones relative to resource constraints, high costs with limited access to professional treatment. This stimulates the need for concerted efforts with inclusive policies to building momentum towards early diagnoses and treatment intervention (Durkin et al., 2015).

However, efforts to accurately establish global prevalence of ASD have been hampered relative to fragmented knowledge and absence of quality healthcare infrastructure coupled with inadequate professionally trained healthcare providers for early diagnosis and treatment interventions. This accounts for the recent reports of increasing global prevalence which is estimated to be 1% of the global population (Shilubane & Mazibuko, 2020).

Moreover, it is empirically estimated that 62 out of 10,000 proportion of the global population are affected with ASD and presently considered as one of the most common developmental disorders among children (Thomas PD et al., 2015).

In furtherance, according to epidemiological data published by the World Health Organization in 2013 cited by (Eugenia, 2019) revealed that, estimated global prevalence of ASD is one person in 160 representing 7.6million disability adjusted life-style with 0.3% of global burden.

In the context of Africa, the maiden research on ASD prevalence is traced back in 1987 in some selected African countries including Ghana, South Africa, Zimbabwe, Nigeria, Zambia and Kenya with 1,321 participants. Results from the findings reported a prevalence of 0.7% of persons with ASD. Prevalence in other African countries such as Tunisia stood at 33%; 11.5% of Egypt and 11.4% in the South-East Corridors of Nigeria (Thomas PD et al., 2015).

Comparatively in the context of Sub-Saharan Africa, the precise prevalence of ASD is unknown as opposed to the advanced world because the concept is less explored with only a few arsenal of studies conducted accompanied with fragmented knowledge and literature deficit (Shilubane & Mazibuko, 2020).

More specifically in the context of Ghana, recent studies conducted by (Thomas PD et al., 2015) on family perspectives of ASD in the urban setting of Ghana reported a prevalence of 38.7% of children under age fourteen with ASD. However, the limitation or gap of this study is that it focused only on the urban areas of the country so results from their findings and conclusion cannot be generalized and inferred to the entire regions of the country.

This challenge was corroborated and re-echoed by that of (Mckay et al., 2015) relative to their studies on ‘meeting the needs of children and families with Communication and other developmental difficulties’ in the Greater Accra Region. On the exact prevalence, they noted that Communication and other Developmental Difficulties in the context of developing economies where Ghana is not exempted are difficult to establish occasioned by inadequate diagnostic services and inconsistent records keeping.

Results from their findings also suggest that families of persons with such developmental difficulties are in search for innovative avenues to addressing the needs of persons with developmental deficits. Deductively, the limitation and gap of this findings is that, it focused only on the Awaawaa2 community located in Haatso in the Greater Region.

The study focused specifically on Communication Difficulties with just a sample size of nine which accounts for why results from their findings and conclusion can neither be generalized nor inferred to other communities in Ghana. However, central to this challenge is the absence of well-established consensus scholarly and professional view relative to the precise causes of ASD coupled with substantial variations in global epidemiological, geographical and cultural differences which precipitate diverse perceptions and interpretations about ASD (Shilubane & Mazibuko, 2020).

In a more recent research conducted with respect to parents experience in raising a child with Autism Spectrum Disorder in the Ghanaian context, using a qualitative case study with interpretive technique, and sample of eight constituting five parents and three institutional heads. The outcome of results from the findings revealed that, children with ASD are highly stressed and stigmatized accompanied with inability to access Basic Education in Ghana (Eugenia, 2019).

The outcome of results from the findings reported further that parents religious and cultural affiliations constitute the primary drivers that shape their Knowledge and perception about the causes of ASD which ultimately influences their health seeking interventions with most families resorting to spiritual means for treatment (Eugenia, 2019).

Generally, it is empirically established that the few available research in the context of Africa have not comprehensively established the precise prevalence of ASD. Moreover, the literature reported further that the few available literature in the context of Africa and Ghana in particular are based on clinical characteristics of persons with ASD which reveals similarities between that of Africa and the Western World (Eugenia, 2019).

Deducing from the empirical evidence, suffice to establish that in many developing economies and emerging markets globally, Autism Spectrum Disorder and other developmental disorders have not received adequate attention from major stakeholders making the concept less explored accompanied with fragmented knowledge with relatively low amount of scholarly literature to that effect.

More importantly, it is worth to note that the few available research conducted on developmental disorders in Ghana are only limited to the urban areas of the country while other parts of the country especially the rural areas have not had adequate representation in national research with limited interventions. This further widens the paucity of gap between expectations of ASD caregivers, and level of stakeholders' intervention relative to aid and research.

Moreover, it was also identified that the few available scholarly literature on ASD has over-reported and represented only families of high income and educational status. Ultimately, few empirical literature on ASD in the context of Ghana are largely qualitative with relatively lower sample size with low statistical power and also focused largely on urban areas. Grappled with these challenges stimulated the need to fill this gap by exploring community cultural beliefs and practices about ASD with focus on selected communities in the Upper West Region of Ghana where the concept is less explored due to little attention and lack of research around the area.

1.3 Aim of the Study

The general objective of the study is to explore community cultural beliefs and practices about Autism Spectrum Disorder in selected communities of the Wa Municipality in the Upper West Region of Ghana.

1.4 The specific objectives of the study are to;

1. Explore the nature of autism among people in the Wa Municipality
2. Identify the mode of diagnoses of ASD among victims in the Municipality
3. Identify how culture influence the healthcare seeking behaviors of families of persons with of ASD in the Municipality

4. Identify the barriers and challenges contributing to limited interventions in managing ASD in the Wa Municipality

1.5 Justification of the Study

The study will have both theoretical and socio-economic relevance; the study contributed enormously to the public as a repository of key information to researchers, policy makers and stakeholders. Moreover, the research also contributed tremendously to policy makers and government of developing states on the need for inclusive and collaborative National Health Approach for sustainable policy interventions to address the socio-economic and health burden exerted on caregivers and families of persons with ASD and other stakeholders in the society.

Ultimately, the study will contribute to identifying the barriers, challenges and complexities contributing to the low amount of knowledge and education while advocating for broad-base and inclusive national healthcare policies and strategies geared towards collaborative efforts to increasing campaigns and sensitization programmes, increasing community outreach, monitoring and surveillance as well as adequate reporting of ASD cases and general public cooperation to help address the socio-economic and health impact of ASD in the Ghanaian Society.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction: This chapter deals mainly with the review of relevant and related literature relative to ASD. It comprises with the conceptual as well as theoretical and empirical reviews of scholarly literature on Autism Spectrum Disorder, the perceived causes, mode of diagnosis and common etiologies, and how cultural values and norms shape the knowledge, attitudes and perceptions about ASD and treatment interventions.

2.2 Conceptual Review

Autism Spectrum Disorder (ASD) is considered as a cognitive and neurodevelopmental challenge within the global scale. A global phenomenon affecting many children accompanied with a predisposition of several impairments. It is quite pervasive and stressful for both victims and caregivers susceptible to cultural beliefs in many parts of the world (Shilubane & Mazibuko, 2020).

Global prevalence of ASD is reportedly on the surge over the past few years and has been considered as one of the most common developmental disorders. Empirically, ASD prevalence is estimated to be 1% of the global population. It is also estimated that 62 out of 10,000 proportion of the global population are affected with ASD while other reports estimates that one person in every 150 children has ASD (Budiyanto, Kieron, Rufaida, & Khofidotur, 2020).

In effect, the World Health Organization (WHO) therefore urged member states to treat ASD a public health concern with concerted and collaborative efforts to adapt inclusive and broad-based policies and sustainable strategies to promote knowledge sharing and other interventions to ameliorating the grave socio-economic burden it exerts on persons with ASD, their families and caregivers respectively (Mandell et al., 2018).

It is unanimously established by scholar and professionals that literature about ASD is woefully scanty with increasing lack of knowledge that consequently lead to late diagnosis of the disorder among persons with ASD (Durkin et al., 2015).

In the context of Africa, prevalence of ASD is still unknown that makes it quite trivial to establish the precise prevalence of ASD in both low and middle income countries. For instance, it is empirically evidenced that research on ASD in Sub-Sahara Africa is fragmented relative to its exact causes which accounts for the limited intervention by stakeholders (Cloete & Obaigwa, 2019).

However, a few empirical studies established that only 2% of the population is affected by ASD with 5000 new cases predicted per annual. In other African countries, healthcare professionals, caregivers and the community at large have minimal knowledge and awareness due to lack of standardized screening and diagnostic criteria (Shilubane & Mazibuko, 2020).

The maiden research on ASD prevalence in the context of Africa was 1987 by Victor Lotter consisting of Ghana, South Africa, Zimbabwe, Nigeria, Zambia and Kenya where he examined a sample of 1,321 participants. However, his findings revealed a prevalence of 0.7% of ASD. Presently in Ghana, recent empirical findings reported that 38.7% of children under age fourteen are affected with ASD. However, despite this empirical findings, the exact prevalence of ASD in Ghana is still unknown while prevalence in other African countries including; Tunisia 33.6%, Egypt 11.5% and 11.4% in South-East corridors of Nigeria respectively (Thomas et al., 2015).

Moreover, there is little knowledge about ASD due to lack of awareness and community sensitization leading to incidence of under-reporting of cases because most people still believe that some of these developmental disorders are caused by supernatural forces including witchcraft and other spiritual forces (Sritharan & Koola, 2019). The increasing prevalence is also attributed to lack of quality healthcare facilities and insufficient trained healthcare professionals to provide early diagnosis and treatment.

However, the culture and belief system of parents, caregivers and the entire community also influence their intervention choices, attitudes and health seeking behaviors respectively. Family's beliefs and cultural practices shape the explanations and interpretations given to the disorder, the time taken to seek medical intervention, and the help preference as well (Sritharan & Koola, 2019).

ASD exerts greater socio-economic and public health burden on major stakeholders including parents, caregivers and health professionals including; financial burden, stress, stigma, isolation from social activities, tension and frustration, lack of support and limited access to support services and interventions accompanied with poor life trajectories despite coping strategies may vary disproportionately based on age and gender differences (Washinton-Nortey & Serpell, 2021).

However, in recondition of widespread reports of increasing prevalence of persons with ASD at the turn of the century therefore elucidates the need for more research, in order to unearth effective strategic interventions aimed at reducing the burden on families, caregivers and other major stakeholders in the society.

2.2.1 Perceived Causes of ASD

The absence of unified established etiologies and prognosis of ASD has made it susceptible to varied means of diagnoses and treatment generally classified under environmental, medical, behavioural/physiological as well as genetic/biological and socio-cultural.

There have substantial and varied factors influencing individuals, group and community beliefs perceptions as well as social attitudes towards the relative causes of ASD which as a consequence shape their perceptions, health-seeking behaviour and intervention choices. For instance, empirical research evidenced that some families of persons with ASD attribute causes of the disorder to supernatural forces while others associate it to genetic factors (Kim et al., 2018).

In the cultural context of Asia, some Asian families beliefs in relation to the causes of ASD are traced to religious factors where families believed that persons with neurodevelopmental disorders such ASD are gifts from origin (Mello et al., 2018). In the African perspective, perceived causes of ASD is commonly attributed to spiritual forces based on cultural interpretations. For instance, some of the empirical findings revealed causes of ASD to be generally attributed to curses of the lesser gods as a form of punishment to the victim for a crime committed while others attribute it to witchcraft, reincarnation and other cultural attributes (Serpell et al., 2021).

Moreover, other causes of ASD based on a study by (Zakirova-Engstrand, Hirvikoski, Allodi, & Roll-Pettersson, 2020) have been identified to include genetic or medical conditions, environmental factors as well as supernatural and religious factors respectively. Devoid of common established etiologies, other scholars attribute the causes of ASD to the interplay of both biological and environmental factors respectively (Roll-Pttersson et al., 2020).

Furtherance of this, other studies empirically evidenced that African families beliefs relative to the causes of ASD are based on physiological factors including; diet and medications during pregnancy. For instance, a study in Kenya in relation to families' beliefs about the causes of ASD reported that some families believed ASD is caused by sorcery and evil spirits (Mello et al., 2018). Deducing from the substantial variations relative to the causes of ASD suffice to establish that perceived etiologies of ASD varies disproportionately in diverse cultural contexts which in effect informs the diagnostic approach and interventions choices respectively (Mello et al., 2018).

For instance, caregivers and families conceptualization and interpretations about the relative causes of ASD informs their health preference and treatment decisions as well as intervention choices respectively. This absence of universal and internationally agreed causes of ASD contributes to factors impeding global efforts towards establishing the precise prevalence of ASD as well as its relative to causes (Mello et al., 2018).

2.2.2 Common Symptoms of ASD

Studies evidenced that onset of common signs and symptom of ASD initiates within the first year or between 1-5 years period of early childhood development where communication and language development constitutes a fundamental attribute for effective social interaction

(Roll-Pttersson et al., 2020). Generally, symptoms of ASD are in continuum ranging from mild to severe respectively.

The extant or degree of symptom severity vary disproportionately relative to age and gender disparities. For instance, research empirically reported that neurodevelopmental disorders such as ASD among male individuals is more severe and excruciating as opposed to females comparatively. Further, females are also reported to have better coping strategies than males (Washinton-Nortey & Serpell, 2021).

However, regardless of gender, age and other socio-demographic and cultural affiliations, common signs and symptoms of ASD have been identified to include; predisposition of developmental delays, communication and social deficits, aggressiveness and hyperactivity, repetitiveness of behaviour, eating and sleeping difficulties as well as general cognitive and physiological impairments (Thomas et al., 2015). Moreover, ASD is also highly characterized by neurodevelopmental delays accompanied with cognitive and mental retardation, predisposition of social deficits as well as tension and frustration with limited intervention and support services by stakeholders (Washinton-Nortey & Serpell, 2021).

Ultimately, persons with ASD are also characterized by unusual and repetitive behaviours with general disinterest in socialization due to delayed social skills, high temperament and throwing of tantrums accompanied with inability of knowing their names within the first twelve months. Moreover, it is also exhibit symptoms including delayed in language, speech and communication skills (Thomas PD et al., 2015).

2.2.3 Challenges faced by caregivers & Families of Persons with ASD

It is common knowledge from research that globally, persons with ASD face myriad challenges some of which have been identified to include; stigmatization and marginalization, oppression and social exclusion and general negative attitude and social distancing from families of persons with ASD (Park, Lee, & Kim, 2018). Moreover, both caregivers and families of persons with ASD experience many challenges among which include; stress and trauma mist especially when condition become chronic accompanied with limited interventions (Soares et al., 2020).

In addition, taking care of persons with ASD also placed a huge socio-economic and financial burden on families and caregivers in search for the appropriate approach or combination of approaches to managing or ameliorating the disorder coupled with lack of stakeholder intervention and support services to families of persons with ASD (Manning, Billian, Allen, & Soares, 2020).

2.2.4 Mode of Diagnosis and Treatment Interventions

There is a consensus scholarly view in relation to the absence of unified established criteria or threshold for diagnosing ASD notably in many parts of the developing world relative to lack of well-trained healthcare professionals and the appropriate diagnostic equipment's due to resource constraints and cultural beliefs (Thomas et al., 2015).

As a consequence, it has made ASD susceptible to varied interpretations and prognosis based on cultural contexts. However, common prognosis of ASD have been identified to include; *behavioral criteria and psychiatric thus, medically related approaches.* Moreover, there is equally lack of a specified method of cure to ASD but common types of therapies to improve coping behaviors include; Cognitive Behavioral Therapy (CBT), Psychodynamic Therapy & Exposure Based Therapy, Speech & Language Therapy (S&LT) (Agency for Healthcare Research and Quality, 2017).

Moreover, Interpersonal Therapy (IPT), Group Therapy (GT), Cognitive Processing Therapy (CPT), Psychotherapy & Brainwave Neurofeedback, Prolong Exposure Therapy (PET) and Narrative Exposure Therapy (NET), Sensory Integration (INT) and Occupational Therapy

(OT) collectively constitute some of the common interventions and coping strategies developed to manage symptoms severity as well as improve coping behaviors of persons with ASD

(Agency for Healthcare Research and Quality, 2017).

2.2.5 Cultural Influence on Health Seeking Behaviours of Families' of Persons with ASD.

Studies in a cross-cultural context revealed that, culture play an inextricable role of shaping individuals, group and ethnic extant of knowledge, attitude, perceptions, beliefs and general way of life if the people including their healthcare systems and health-seeking behaviours which in effect influences their intervention choices (Millau, Rivard, & Mello, 2018).

However, the approaches to health-seeking behaviours of families and caregivers of persons with ASD vary disproportionately in diverse cultural contexts and geographical settings. This is further informed by certain determinants or variables including socio-cultural beliefs and practices, socio-economic, environmental and political institutional structures, demographic factors, social ties and networks and the available healthcare system of the community. (Siddiqui, 2011).

Moreover, other factors that influence the health-seeking behaviour and intervention mechanisms of families of persons with ASD include family educational background, socio-economic status and costs of accessing quality healthcare services, proximity in terms of easy accessibility and the perceived quality of the health approach. These constitute some of the factors that influence the health preference and health-seeking behaviours as well as intervention choices of families of persons with ASD (Siddiqui, 2011).

Deducing from these factors suffice to establish that cultural diversity and ethnicity shapes families and caregivers knowledge, perception as well as understanding and interpretation of symptoms' of ASD based on differences in normative behaviours exhibited by persons with ASD. These factors further determine the intervention approach and time of intervention respectively.

However, it is also important to note that symptoms of ASD may not vary significantly among persons from different cultural and ethnic backgrounds but the knowledge, attitude, perception as well as understanding and interpretations given to the symptoms may vary disproportionately. This informs the intervention choices as well as the time of intervention. In effect, it is safe to establish that parents understanding and interpretation of the causes as well as signs and symptoms of ASD irrespective of ethnicity or cultural background will help develop and tailor the appropriate interventions for effective treatment or management of ASD.

2.5 Theoretical Review.

The theoretical underpinning of this research work was reinforced by the Klienman's explanatory of illness and chronic condition. The theory is embedded on five underlying components of explanatory of illness including; (a) etiologies of the condition, (b) the time and mode of onset of symptoms, (c) pathophysiology, (d) the cause of the illness and extant of symptoms severity and (e) treatment mechanisms (Roll-Pttersson et al., 2020).

The theory argue further that culture has a significant influence in shaping individuals knowledge, attitude, perceptions and explanations ascribed to social or human problem. The explanatory models ascribed to the condition is based on the culture and belief systems, religious, educational and professional backgrounds, social class as well as the knowledge and individual past experience with the condition and their approach to various healthcare systems (Roll-Pttersson et al., 2020).

Moreover, Klienman noted further that the explanations given to a sickness may vary disproportionately among healthcare professionals and patients or the patients' family members and caregivers which constitute either a barrier to administer treatment or combination alternative approaches to healthcare (Roll-Pttersson et al., 2020).

As a consequence, it is imperative for professional healthcare providers to investigate thoroughly relative to the nature and causes of the disorder, the onset of symptoms and the degree of symptom severity and treatment mechanisms (Roll-Pttersson et al., 2020).

The rationale and justification for the choice of this is based on the fact that it is embedded on anthropological and cross-cultural studies and it is employed to explain the knowledge, attitude and perceptions ascribed to the live experience of persons in relation to a chronic condition or disorder.

Moreover, the rationale and justification underpinning the choice of this theory was further reinforced by the fact that it is considered the most appropriate theoretical model that provide better understanding and interpretations of the knowledge, attitude and perceptions as well as explanations and interpretations ascribed to the live experience of persons with a developmental disorder within a particular cultural context.

To the best of my knowledge, this study constitutes the first ever research in the Wa Municipality that employ this theoretical construct in attempt to explore families knowledge, attitude and perception as well as cultural beliefs and interpretations ascribed to ASD and their health-seeking behaviours and interventions choices.

2.6 Empirical Literature

The empirical review of this study analyzes scholarly literature in relation to the influence of culture based on families' beliefs and perceptions about the causes of ASD and their healthcare-seeking behaviours and intervention choices.

For instance, based on a study by (Mello et al., 2018) on families' perception about the causes and treatment of ASD using a sample size of 45 with semi-structured interviews with qualitative method and thematic analysis reported that causes of ASD were traced to environmental factors including diet and vaccines respectively.

Moreover, a study by (Kim et al., 2018) on Korean adults' belief about social distance towards attention deficit hyperactivity disorder Tourette syndrome and Autism Spectrum Disorder using questionnaire and panel online survey method with sample size of 673 to ascertain perceived causes of each disorder. However, causes of ASD reported to be environmental, dietary/physiological and biological factors respectively.

Deducing from the findings of (Mello et al., 2018) and (Kim et al., 2018) on the causes of ASD portray or revealed the same similarities identified to include environmental and dietary factors being the underlying causes of ASD despite not taking into consideration the cultural context as well as socio-economic and demographic factors respectively.

However, their findings are also in line with (Boom et al., 2020) on the belief of adults in relation to the causes of autism and vaccine hesitancy among parents of children with ASD using online survey questionnaire with sample size of 225 which revealed that vaccine hesitant families of persons with ASD attribute causes of the disorder to accident, injury, dietary, emotional, environmental and vaccines being the underlying causes of ASD.

In furtherance of this, (Roll-Pttersson et al., 2020) analyzed the explanatory models of families of persons with autism spectrum disorder in different cultural context with the application of semi-structured interview and qualitative method of content analysis to ascertain families conceptualization and interpretation ascribed to ASD.

Results from the findings revealed that perceived causes of ASD is attributed to environmental factors, genetic as well as religious and supernatural causes. However, drawing from the perspective of the findings, environmental and genetic factors have been identified as the most common causes of ASD despite contextual variations of the various studies. Moreover**,** (Cardon & Marshall, 2017) analyzes parents experience in raising a child with ASD in a cross-cultural context citing the case of the United States and Senegal respectively.

The study employed semi-structured interviews with inductive phenomenological approach of data analysis. However, results from the findings revealed variations in relation to community and social support services, while numerous treatment options accompanied with easy access treatment and quality healthcare available for American families as opposed to Senegal in the West African context.

Finally on a study by (Riccio, 2011) in attempt to address the knowledge, social attitude and perceptions as well as stakeholder interventions and support services to persons with ASD in Kenya using structured interview. Results from the findings showed a general negative perception about persons with ASD. The findings further revealed that there is general lack of knowledge and awareness creation about ASD which in effect contributes to stigmatization and marginalization of children with ASD.

From the analysis, much of the empirical findings identified common causes of ASD to include both environmental and genetic factors respectively. Conversely, the flaw of these findings include their lack of recognition for cultural diversity, socio-economic and geographical disparities, income distribution and inequalities among families as well as families educational background which ultimately influence their knowledge, attitude, perception and interpretations ascribed to causes of ASD.

Moreover, the findings is also flawed on the basis of the fact that there exist lack of a universal criteria and internationally recognized and acceptable threshold for diagnosing and treatment of ASD grounded on the fact resource constrained economies suffer the greatest of risks of ASD as opposed to the developed ones owing to lack of professional systems for effective diagnoses and treatment.

CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction: This chapter involves the study methodology employed to collect and analyze the relevant and related data required to achieve the overarching purpose of the research work. This consist mainly of the research design, study approach, research population, sample technique & sample size, instrumentation, method of data collection and analysis as well as ethical consideration, expected outcome of the study and trustworthiness of the research work.

3.1 Study Setting

The WA Municipal constitute one of the eleven Districts and Municipalities in the Upper West Region with a population 200,672. Males constitute 98,493 representing 49.0 % while females constitute 102,179 representing 51.0% with a sex ratio of 97.7 respectively. The Municipality has a youthful population with 35% below 15 years (GSS, 2020).

Total age dependency of the Municipality is 65.1. Total fertility ratio of the Municipality is 3.3 as opposed to 3.5 of total regional fertility. The general fertility rate constitute 82.6 births per 1000 women aged 15-49 years. The total crude birth rate for the Municipality include 22.7 per 1000 population while crude dearth rate is 5.0 deaths per 1000 (GSS, 2020).

About 45.4% of the population representing 12 years and above are married while 48.2% are not married, widows constitute respectively 4% and divorce 1.1% respectively. 65.2% of the population representing 11 years and above are literates while 34.8% are not educated. Male literates constitutes 74.1% as opposed to 56.7% of females. Moreover, 54.8% of the population of the Municipality aged 15 years and above are economically active while 45.2% are not economically active (GSS, 2020).

The Wa Municipal constitutes the researcher's own community and the rationale for the choice of this community is informed by the lack of adequate representation on both national and international research scale with virtually no research conducted on how cultural beliefs and practices influences their knowledge, attitude and perceptions about ASD within the community which as a consequence informs the purpose of this study and choice of the community.

3.2 Study Approach

The approach to a research work constitutes the plan and set of procedures that spells-out the specific steps taken to collect and analyze data to ascertain the overarching purpose of the study. This study employed a qualitative method of research approach which according to (Creswell & Creswell, 2018) is based on the process of exploring the conceptualizations and interpretations ascribed to a human and social phenomenon. This method of approach deals with a qualitative and inductive method of orientation embedded on the process of collecting text-based data from respondents setting while building from a more specific to general themes.

The rationale and justification for the choice of this approach was reinforced by the fact that it enables the researcher to gain much insight as well as holistic and comprehensive understanding of participants lived experience and how they ascribe meanings and interpretations to their own experience.

The underlying advantages of this method of orientation as proposed by (Creswell & Creswell, 2018) include the following; the researcher constitutes an important instrument in the data collection process by creating an interactive relationship with respondents in order to ensure adequate exploration of information.

Moreover, the qualitative method of orientation is also common feature of phenomenological and interpretive designs where data is elicited from multiple sources and enables the researcher to explore details of participants lived experience. More importantly, the qualitative method of orientation is based on an inductive process of collecting data from a relatively small sample of participants, analyzing the data and making generalization of statements (Cogzell, 2018).

Finally, as the knowledge, attitudes, perceptions as well as understanding and interpretations of ASD in the Wa Municipality is less explored, qualitative method of approach to this research was considered most appropriate to achieving the overarching purpose of the study.

3.3 Research Design

This study employed a phenomenological method of research design based on an inquiry that stemmed from both philosophy and psychology where the researcher narrates or describes the lived experience of individuals or group relative to a particular phenomenon as described by other participants (Creswell & Creswell, 2018).

Moreover, the phenomenological research design focus primarily on what participants share in common as they pass through similar live experience of a particular phenomenon where grief is universally experienced. In this design, the researcher collects data from participants who have experience in the phenomenon that enable the researcher describe precisely what the participants go through or experience and they experience it (Creswell & Creswell, 2018).

The phenomenological interpretive research design goes beyond a simple description of the phenomenon but also takes into consideration of the subjective meanings ascribed to the phenomenon relative to participants' unique and individual experience (Cogzell, 2018).

More importantly, the rationale and justification for the choice of the phenomenological study design was reinforced by the nature of the research problem and the intended objectives to achieve thereof.

3.4 Study Population

The population of the study is the Wa Municipality with total population of 200,672 with males constituting 98,493 representing 49% while females constitute 102,179 representing 51% respectively. However, the target population for the study include caregivers and families of persons with ASD, professional healthcare providers and teachers in the Sombo, Biihe and the Kpongu communities.

The eligibility of these groups of people that are participant must be 18 years and above, ability to communicate and provide information on behalf the autistic person. The exclusion criteria are autistic persons with behavioural and communication impairments. In phenomenological studies however, it is very crucial for the researcher to select respondents with the requisite expertise and experience with respect to the topic under investigation (Cogzell, 2018).

3.5 Sample Size

The study employed a sample size of thirty (30) and comprises mainly of (10) people from families of persons with ASD, (10) caregivers, (5) teachers and (5) professional healthcare providers. The rationale and justification for the sample size of thirty (30) was reinforced by the impracticability to involve all participants in the research area. Grounded on this basis, the sample was therefore employed to represent the general population of the study area.

For instance, (Cohen et al., 2007) noted that for a qualitative study, a sample size of 30 is more than adequate in representing the population of the general population of the study area. The researcher also took into consideration of the time and financial constraints in involved conducting the research work.

3.6 Sampling Method

The study employed snowball and purposive sampling techniques in selecting the participants for the study. The purposive sampling technique is an attribute of a qualitative research approach. With this sampling technique, the researcher can easily identify and select based on his/her judgment the principal participants with the required experience and information regarding the research problem under inquiry (Cohen, 2007).

The rationale and justification for the choice of the purposive sampling technique was to help identify and select teachers, community chiefs and elders and professional healthcare providers in the research setting who have the requisite knowledge in the subject matter relative to culture of the community and how it shapes the conceptualization and interpretations ascribed to Autism Spectrum Disorder.

The snowball sampling technique on the other hand was employed to help identify the principal respondents with the requisite knowledge and experience with respect to ASD and these include families and caregivers of persons with ASD. With the snowball sampling technique, identification of one participant will further lead to the identification of more target respondents with the relevant knowledge and experience with respect to ASD.

3.7 Data Collection Instruments

The overarching purpose of the study was to assess community cultural beliefs and practices and how it shapes the understanding and interpretations ascribed to the lived experience of persons with ASD in the Sombo, Biihe and Kpangu communities in the Wa Municipality of the Upper West Region.

A qualitative research with a phenomenological design was employed to collect data from multiple sources to explore adequate information for deeper understating of the phenomenon under study and simultaneously provide credibility and rigour to the research work (Cogzell, 2018).

The interview was designed purposely to collect primary data from teachers, community chiefs and elders and professional healthcare providers relative to participants' knowledge understanding, and interpretations ascribed to ASD as well as its etiological causes, mode of screening/prognosis, intervention choices and health-seeking behaviours. Data was elicited with the aid of semi-structured interview guide containing a catalogue of sixteen open-ended type questions that were designed with the aid of the research questions developed to address the problem.

Interview questions to be discussed were designed in a sequential and flexible form in order to create a free interaction among participants that enabled the researcher to explore more information and sub-themes about the cultural beliefs and practices and interpretations ascribed to the lived experience of persons with ASD in the Wa Municipality.

More importantly, the advantage of the open-ended type of interview questions is that it provided adequate room and freedom for participants to express their views freely by narrating their experience about the phenomenon and simultaneously allowed the researcher to probe further questions in order to explore detailed and accurate information on the phenomenon (Cogzell, 2018).

Participants were given prior notice about the interview, the schedule and the venue during which participants consent form was served. Teachers and professional healthcare providers were interviewed in their respective work settings based on schedule. Sixteen questions were asked during the interview some of which include the following, do you know any developmental disorder called autism and what are the characteristics of persons with autism? Do you know anyone with such developmental delay? If yes, then explain some of the signs shown by autistic persons. Do you know the causes of ASD? If yes, then explain in your opinion the causes of ASD. Are there professional healthcare facilities for screening/diagnosing ASD? What are the factors influencing intervention choices and health seeking behavious of families of persons with ASD?

How do cultural beliefs and practices shape the health seeking behaviours and intervention choices of families of persons with ASD? In your opinion, state the barriers and challenges contributing to limited interventions by major stakeholders towards effective treatment or management of ASD in the Wa Municipality.

3.8 Data Collection Procedure

Prior to initiation of data collection process, respondents' consent was sought before granting interviews and discussing of relevant issues with key respondents with respect to their expertise and lived experience in relation to ASD. Interviews and focus group discussion with participants were conducted by the researcher in person and face-to-face. This data collection procedure allowed the researcher to probe follow-up questions during the survey in order to explore sufficient and accurate information in relation to the understanding and interpretations ascribed to participants lived experience with Autism Spectrum Disorder.

Both interviews and focus discussions were done with the aid of a guide containing a catalogue of sixteen questions which constituted the basis of the research questions. The researcher also conducted (2) focus group discussions with families and caregivers of persons with ASD in order to explore detailed and accurate information about participants lived experience and interpretations given to the phenomenon.

The focus group discussion constituted ten (10) participants of caregivers and families of persons with ASD in the selected communities. Each focus group contained (5) participants all of whom were mothers and caregivers of persons with ASD. Discussion was held in a convening point in the respective communities where members often gather in the evening after all day work. Accessibility was granted based on trust and ties between the researcher and members of the community.

Discussions with participants were cordial, interactive and guided by a catalogue of sixteen questions designed in an open-ended form. This enabled the researcher to elicited detailed information from participants relative to their understanding and interpretations ascribed to the lived experience of persons with ASD in the three selected communities.

Prior to initiation of group discussions, participants were pre-informed and served with a consent form where the main purpose of the research was discussed taking into consideration the risks and benefits involved and as well acknowledged their right to participate, decline or withdraw at any stage of the proceedings.

The consent form was also read and content was interpreted to participants in the (*Walli*) local dialect and they were given the opportunity to decide participate or withdraw. Moreover, participants were also informed that audio recording and photos maybe taken during the process and they reserved the right to accept or decline.

Moreover, participants were also informed that the purpose of the research was to fulfil academic requirement and outcome of the findings were to be presented to the University of Ghana School of Biomedical and Allied Health Sciences (SBAHS) and it may be electronically published by the University's library or any other journal as an article.

In general, both the interviews and focus group discussions lasted between twenty (20) to thirty five minutes (35). The entire data collection process was very cordial and successful and took only seven (7) days to complete the process without any challenge except a case where a few participants were skeptical and therefore declined to participate in the focus group discussion.

3.9 Ethical Consideration of the Research Work

Before commencement of collection of field data, participants consent was sought through a consent letter in which the purpose of the study as well as the benefits and risks were discussed and acknowledged their right to decline or withdraw at any stage of the proceedings. More importantly, an ethical approval was also sought and granted by the Ethics and Protocol Review Committee of the University of Ghana's School of Biomedical and Allied Health Sciences (SBAHS), to ensure that data collection process does not subject participants to any form of risks or harm.

As a consequence, the aim of the research work is to fulfil an academic requirement for that matter, information provided by participants was treated with utmost confidentiality and anonymity and shall not be disclosed to the general public except where permission was granted by participants.

3.10 Trustworthiness

The trustworthiness of a qualitative research work is embedded in its *credibility, transferability, dependability and confirmability.* The underlying essence of ensuring trustworthiness of a research work is to ensure accuracy and consistency of results from the research findings in relation to other researchers and different research projects using multiple procedures (Creswell & Creswell, 2018).

Moreover, to enhance trustworthiness of the research work, the researcher conducted multiple examination and independent cross-checking of data transcripts in order to avoid possible mistakes during the process of data transcription. In furtherance, the researcher also ensured continuous comparison of data codes and writing of memos about the codes and the relative meanings assigned to the codes in order to avoid any form of drift in the definition of codes.

The credibility of results from a research findings is embedded on the coherent justification of themes, the confidence and precision and authenticity of the research work and its ability to represent the true reflection of participants' views and experience based on the standpoint of the researcher, participants of the survey and readers of the report (Creswell & Creswell, 2018).

To enhance credibility of the research findings, *pro-longed time spent in the field survey by the researcher* which enabled the researcher to explore detailed information in order to gain deeper understanding and interpretation of participants lived experience. Moreover, data elicited from multiple sources were converged and triangulated which enabled the researcher to eliminate any form of bias and incongruence of results from the findings.

Transferability of results from the research findings is based on the quality of a research work to be generalized and inferred to different research settings and different people or samples to demonstrate its accuracy and consistency of results across different researchers and different projects (Creswell & Creswell, 2018).

To ensure transferability of results from the findings, information elicited from the field was given a *rich thick description* including the study setting and major themes discovered from the findings. This make results from the findings richer and realistic and in effect give readers a shared experience in the study setting.

Dependability of the findings is based on the process of establishing stability of results from the findings by presentation of parts of the final report of the research to participants of the survey for member checking or evaluation to ascertain the accuracy of data presentation, analysis and interpretation of results from the findings (Creswell & Creswell, 2018).

To ensure dependability of results from the research findings, *member checking* was done through a follow-up interview involving participants of the survey in order to solicit for comments to ascertain whether data captured, analyzed and interpreted in the report are a true reflection and representation of their views or otherwise.

Finally on conformability of the research findings, the confirmability of results from a research findings is based on the extent to which results from the findings can be confirmed by other research scholars in order to ensure that data analysis and interpretations were not based on the figment of the researcher's own imagination but rather derived from data elicited from the field (Korstjens & Moser, 2018).

In this study, confirmability of results from the findings was based on audit trial which described all the necessary steps and procedure employed to conduct the research work including analysis of data, presentation of results as well as report from the findings.

3.11 Data Management & Analysis

Data analysis was mainly statistically descriptive and case reporting following, data convergence, sorting, preliminary reading and transcription in order to ensure comprehensive analysis and interpretation of participants lived experience ascribed to ASD.

Further coding was done on coding sheet in order to avoid drifts and to as well ensure adequate protection of participants' integrity, confidentiality and anonymity.

Preliminary review was conducted on data solicited from the field for identification and categorization of information into themes and sub-themes, merging of information into descriptive codes that aided comprehensive analysis and interpretation of data to facilitate preparation and presentation of report.

3.12 Expected Outcome

The outcome of this study will contribute to the limited pool of knowledge and literature with respect to ASD. Moreover, the outcome of the study will further contribute to providing insight into identifying the barriers and challenges contributing to late diagnosis of ASD in the Wa Municipality as well as the factors contributing to the limited interventions to addressing the socio-economic and health burden on major stakeholders.

The purpose of the research is to partially fulfil an academic requirement for the award of master's degree. However, it is hoped that proposed recommendations after the study would complement existing policy initiatives to influence efforts towards increasing awareness, education and knowledge sharing on the prevalence and impact of ASD in the Ghanaian context notably in the Wa Municipality of the Upper West Region.

CHAPTER FOUR

ANALYSIS AND DISCUSSION OF FINDINGS

4.0 Introduction

This section of the study deals with the presentation and analysis of data from the research findings. The study employed statistically descriptive as well as Phenomenological Interpretive Analysis to present summaries of the findings following verbatim transcription of data obtained from the survey based on participants lived experience relative to ASD.

Data elicited from the survey was first sorted, followed by first reading and categorization of information obtained from the field then subsequently transcribed where significant statements were noted and then finally coded to avoid potential drift and to ensure anonymity for adequate protection of participants' integrity and confidentiality.

Results from the research findings were presented in comprehensive and summarized format following the use of statistical tools such as, frequencies, percentages, graphs and charts. The analysis and interpretation of results from the findings were embedded in exploring community cultural beliefs and practices and how it shapes individual understanding and interpretations ascribed to the lived experience of persons with Autism Spectrum Disorder in the Sombo, Biihe and Kpongu communities of the Wa Municipality of the Upper West Region.

4.1 Socio-Demographic Characteristics of Participants in the Survey.

The socio-demographic features captured for analysis constituted participants gender, age, level of education and marital status. The socio-demographic characteristics have so much significance on the purpose of the research work relative to participants' knowledge, understanding and interpretation of ASD, its causal factors, mode of diagnosis and healthcare approaches and health-seeking behaviours of families and caregivers of persons with ASD in the community.

The overarching purpose of the analysis is to establish a link between results from the findings and scholarly literature in order to generate valuable information that help contribute to efforts geared towards establishing ASD prevalence both in regional, national and international research.

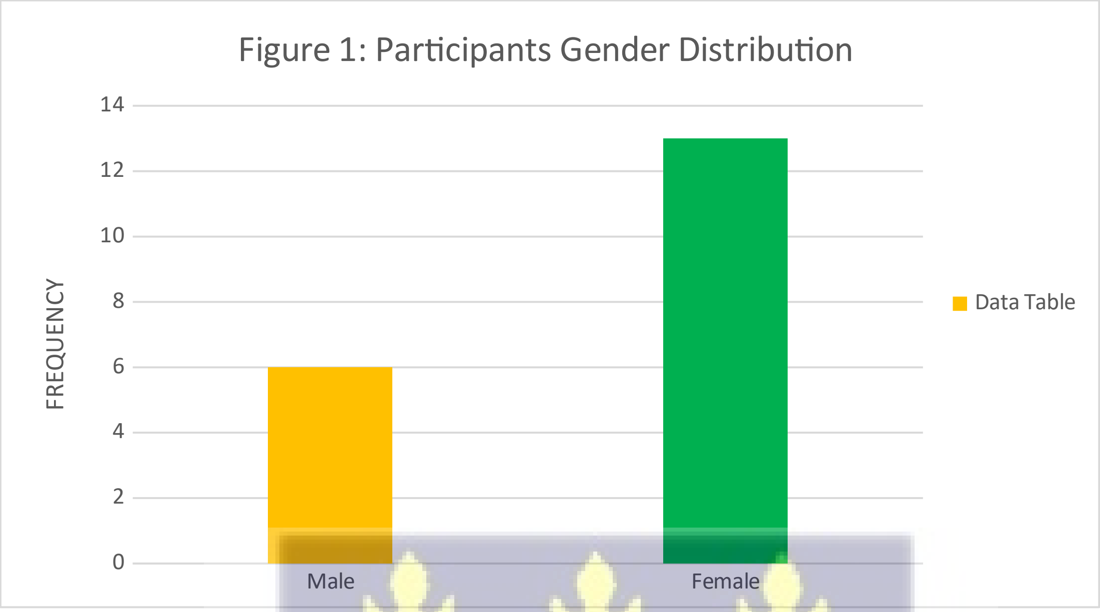
Table 1: Sample Distribution.

Parameter	Frequency	Percent %
Professional Healthcare providers	4	21%
Teachers	2	10%
Families & Caregivers	10	53%
Community Elders	3	16%
Total	**19**	**100**

Source: Field Survey, 2022.

In all, data was obtained from nineteen (19) participants representing 63% of total sample of (30). Reason being that a few participants were skeptical and therefore declined to participate in the focus group discussion and interviews which accounts for the reduction in target sample size.

Figure 1: Participants Gender Distribution

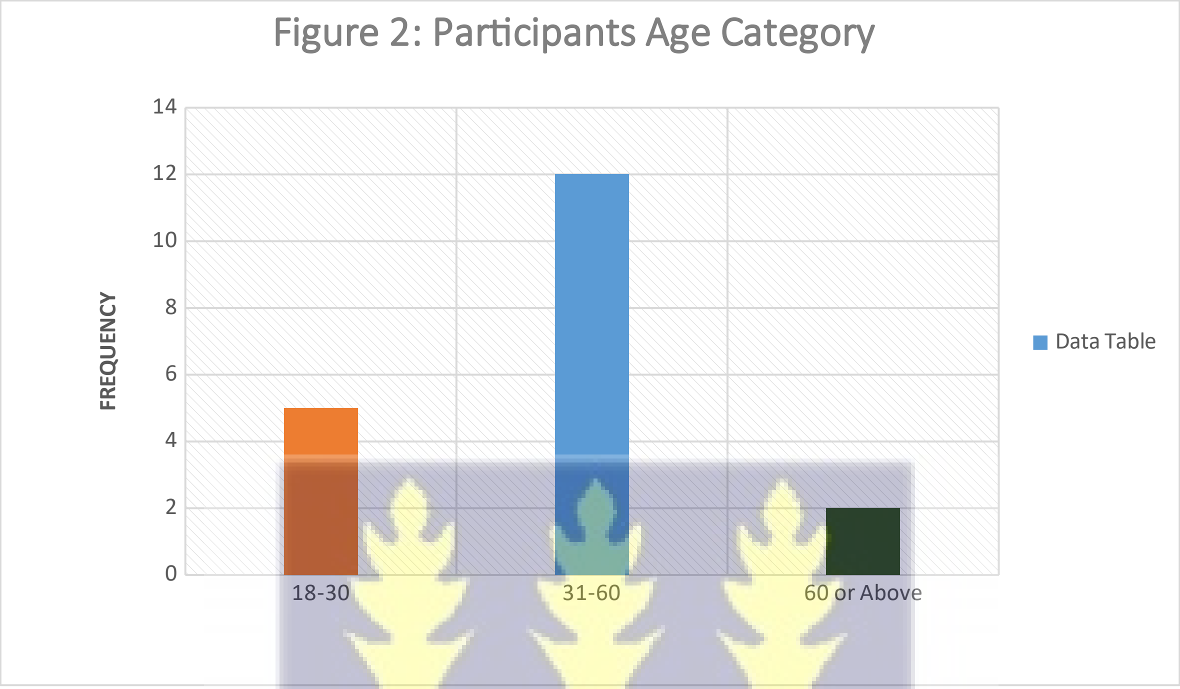


Source: Research Findings December, 2022.

As depicted in **figure1**; the researcher sought to ascertain the set of gender distribution of participants of the survey based on their genetically determined traits of being a male, female or otherwise. Data obtained from the survey revealed that out of the total sample drawn, (n=6) participants representing 32% constituted males while (n=13) representing 68% constituted females respectively. In general, data obtained from participants revealed that both set of gender constituted participants of the study and in effect seeks to demonstrate that data obtained from the findings as well as the analysis of results from the findings did not suffer any form of bias.

The significance of gender differences further explains their inextricable roles in socio-economic and household decision making including the intervention choices and approach to healthcare as well as the time taken to seek medical help. However, the skewed results in favour of female participants was generally attributed to the female dominated area or role in child care as opposed to males in the community in which sample was taken.

Figure 2: Participants Age Distribution

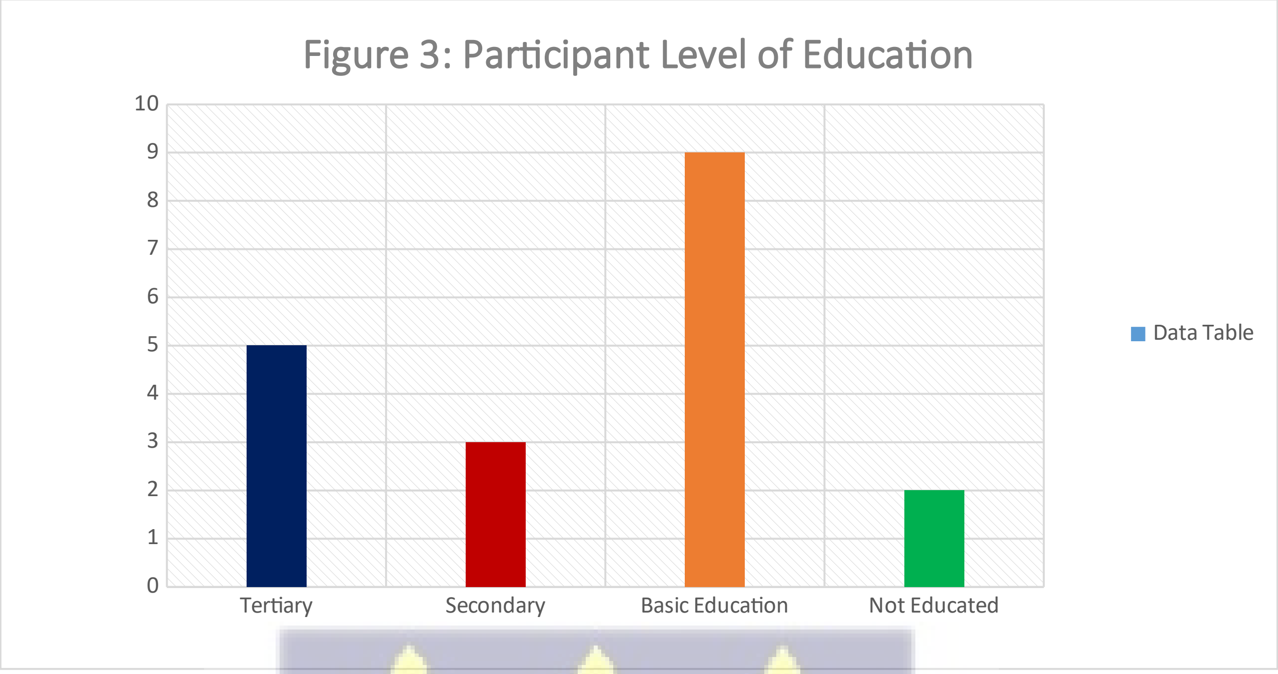


Source: Research Findings December, 2022.

In seeking to explore the relative age distribution of participants who participated in the survey as depicted in **figure2;** data elicited from the survey turned out that (n=5) representing 26% were between 18-30 years; (n=12) representing 63% were 31-60 years while (n=2) representing 11% were 60 years or above.

However, drawing from the perspective of the findings, majority of the participants from whom sample was taken constituted (n=12) with the age range of 31-60 years. However, age play an inextricable role in determining participants long experience and expertise in narrating and interpretation of cultures of the community and how it shapes the life of both individuals and groups respectively.

Figure 3: Respondents Level of Education

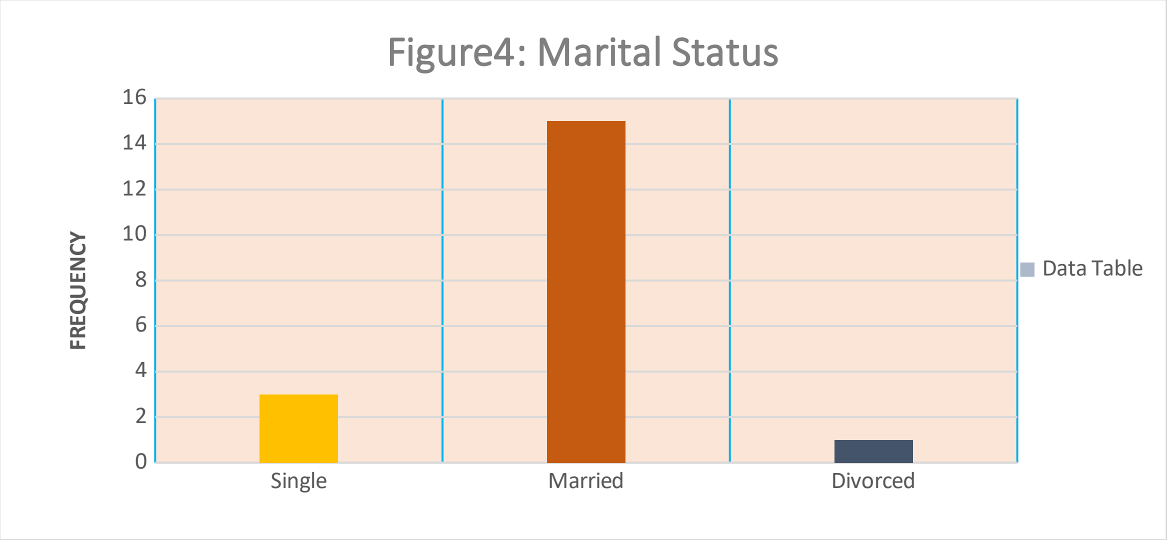


Source: Research Findings December, 2022.

Moreover, on the socio-demographic data; the researcher sought to explore participants level of education as depicted in figure 4 and based on data obtained from the survey, (n=5) representing 26% had tertiary education; (n=3) representing 16% had secondary education; (n=9) representing 47% had basic education while (n=2) representing 11% did not have formal education.

Drawing from the findings, a significant proportion of respondents who participated in the survey had some form of formal education. However, results obtained from the findings revealed that family's educational background play an inextricable role in shaping family's knowledge, attitude, perception as well as interpretations given to ASD relative to the causes which in effect informs the health preference and health seeking-behaviors of families and caregivers relative to the approach and time of intervention. More specifically, educated families and caregivers of persons with ASD have better appreciation and understanding of the causes and interpretation of ASD as opposed to uneducated families.

Figure 4: Participants Marital Status



Source: Research Findings December, 2022.

Finally on the socio-demographic data; the researcher sought to ascertain the marital status of participants in the survey. However, data obtained turned out that (n=3) representing 16% were unmarried; (n=15) representing 79% were married while (n=1) representing 5% of divorced participants.

Taking care of persons with ASD is extremely trivial and stressful and as well places a huge socio-economic and financial burden on both parents of families of persons with ASD. Grounded on this basis, both parents through concerted efforts can best manage the disorder in search for best approach or combination of approaches and intervention mechanisms for treatment as opposed to the case of single parent.

4.2 Participants Knowledge about ASD in the three Communities:

In this objective of the study, the researcher sought to explore participant's knowledge and interpretation ascribe to persons with ASD in the three selected communities of the Wa Municipality. To achieve this objective, the researcher posed the following question during interview with professional healthcare providers. *What do you know about Autism Spectrum*

Disorder and what are the common symptoms? Subtheme: Understanding & interpretations ascribed to Autism Spectrum Disorder.

However, data elicited and analyzed revealed results from the findings as follows;

> …*"I know autism to be a neurodevelopmental disorder with predisposition of mental retardation accompanied with communication & social deficits"… Psychiatrist F1.*

In general, results from the findings relative to interview with F1 being psychiatrist suggest that, participant has a fair knowledge about the concept of ASD based on participants explanations and interpretations ascribe to persons with ASD. This is corroborated with report from previous findings where ASD is described as a condition characterized with neurodevelopmental delay accompanied with cognitive and mental retardation with a predisposition of social deficits as well as tension and frustration experienced by families and caregivers of persons with the disorder.

In furtherance, interview with *F2, a psychiatric nurse* on participant's knowledge and interpretations about ASD recounted that:

> …*"I know ASD to be a developmental challenge among children with common developmental delays. They have a repetitive lifestyle, sometimes throw tantrums and cannot mention their names at the early stage of growth"…*

Deducing from results from the findings based on interpretations ascribed to persons with ASD by F2 seeks to suggest that participant has a fair knowledge in relation to the nature of ASD and some of its common signs and symptoms predisposed by persons with ASD such as their unusual and repetitive behaviours with delay in language and communication skills with inability of knowing their names at the early stage of growth and childhood development.

Moreover, interview with F3, a Registered General Nurse narrated that;

> …*"The few clinical signs that I know about autistic persons is that they are anti-social, communication difficulties, sometimes aggressive and hyper reactive and also throw tantrums"…*

Deductively, the findings based on interview with F3 on participant's understanding and interpretation ascribed to ASD revealed that the participant who is also a Registered General Nurse has an appreciable knowledge and understanding of persons with ASD based on few clinical examination and reports. This findings is consistent with report of F2 where children with ASD are described as highly characterized by social and communication deficits and often times throw tantrums.

Also, it emerged from the findings based on interview with participant F4, a class teacher who recounted that:

> …"*We had one in our school here and what I observed is that she could not speak nor play with the other colleagues. She was also sometimes aggressive, restless and sometimes uneasy to control. Due to the communication difficulties, she was withdrawn by the parents"…*

Participant F4 is a class teacher who previously had an autistic person in his class. Based on narration from his experience, the child was anti-social, sometimes, hyper or aggressive and uneasy to control. The findings revealed further that the child also had communication difficulties for which reason she was withdrawn by the parents due to the communication difficulties.

Generally, results from the findings seeks to suggest that participants have a fair knowledge relative to the concept of ASD based on participants understanding and interpretations ascribed to the disorder.

4.2.1 Participants Perception about Etiological Causes of ASD:

Sub-theme**:** *participants' beliefs, attitudes and perceptions in relation to the etiological causes of ASD.* To achieve this objective, participants were required to explain their opinions and perceptions about the causes of ASD. However, data elicited from the survey revealed the following results from the findings. Data elicited from the survey emerged as follows;

> *…"There are no universally established threshold or criteria to diagnose the causes of ASD but certainly, I know it is a genetic disorder"… Psychiatrist F1.*

However, results from the findings revealed that participants F1, being a psychiatrists and professional healthcare provider has attributed the etiological causes of ASD to biological and genetic factors. This obviously constitutes one of the common perception and viewpoint shared by most practitioners and research scholars of the subject matter.

Moreover, it was echoed by F2, a psychiatric nurse based on his view that:

> ..*"ASD in the best of my knowledge is a medically related condition and can only be managed through therapeutic interventions to improve coping strategies"*...

However, data elicited and analyzed revealed that unlike F1, F2 attributed the etiological causes of ASD as a medically related condition that can be managed by various therapeutic strategies. Generally, suffice to establish that participants' views and opinions in relation to the etiological causes of ASD varies substantially and disproportionately which in effect shape their intervention choices.

4.2.2 The Socio-economic Burden of Raising a Child with ASD:

Subtheme: *Parents challenge in raising a child with Autism Spectrum Disorder*. The purpose of this object was to explore information in relation to the socio-economic burden imposed on families and caregivers of persons with ASD. Data elicited from the findings revealed the following results as narrated by:

> …"*Based on experience, I know raising a child with ASD is very strenuous because people with such conditions require much love, attention & care. Notwithstanding the stress, stigma & financial burden on parents in seeking medical interventions"... Teacher F5.*

Participant F5 who is a teacher narrated based on his experience that raising children with ASD is quite stressful and strenuous including stigmatization and financial burden faced by families and caregivers of persons with ASD in the community.

4.3 Mode of prognosis of ASD in the three selected communities:

Subtheme: Access to diagnostic services in the three communities.

To achieve the second objective on the mode of prognosis of ASD in the three selected communities, the following specific questions were asked during the interview. Are there adequate medical equipment for diagnosis of persons with ASD in the communities?

However, based on data elicited from the findings, participant F6, a Medical Assistant asserted that:

> …"*To the best of my knowledge, there has not been any medical equipment for diagnosis of persons with ASD. There is no internationally recognized thresholds or universal criteria for diagnosing ASD besides, we do not have the appropriate equipment & facilities to carry out such exercise. But from professional experience, prognosis is usually done through behavioural criteria based on predisposition of common signs & symptoms"…*

Based on submissions by the Medical Assistant, there are no adequate and quality medical equipment and facilities for prognosis of persons with ASD in the three selected communities. However, he narrated further that based on professional practice, prognosis is usually done through behavioural criteria based on predisposition of common signs and symptoms.

4.4 Factors influencing intervention Choices & Health-seeking Behaviour

Subtheme: *determinants of caregivers and family intervention choices.* Based on data elicited from the survey, results from the findings in relation to the factors influencing intervention choices and health-seeking behaviours of families and caregivers of persons with ASD based on professional experience was recounted by participants as follows;

Participant F6, a medical assistant recounted that:

> *…"Well, from professional experience and research, the most common factors influencing the intervention choices and health-seeking behaviours of families include; family income status, family's culture & religious affiliations, family education & social status and family's perception of quality with respect to the type of healthcare system." In other occasions, proximity and cost of access also play a cardinal role on family's health seeking behaviours & intervention choices"…*

Results from the findings seeks to suggest that a plethora of factors influence the health-seeking behaviour and intervention choices by families and caregivers of persons with ASD in the three selected communities among which have been identified to include families income and level of education which play an inextricable role in shaping parents understanding and interpretations ascribed to ASD.

4.5 Gender Influence on Coping Strategies:

Subtheme*: understanding gender disparity and its influence on coping strategies.* The underlying purpose of this objective was to ascertain gender differences and its influence on coping strategies among persons with ASD in the three selected communities. To achieve this objective, the following question posed during interview with a medical assistant. Does gender disparity influence symptoms severity and coping strategies of persons with ASD?

However, data elicited from the survey based on interview with participant F6, a medical assistant emerged as follows:

> *…"From professional experience, I am not certain but studies has it that, females have a better coping strategies than males"…*

However, results from the findings revealed that there is no medically or clinically proven that any specific gender has better coping strategy as opposed to the other. Conversely, the findings revealed further an opposing view that research female persons with ASD have a better coping strategies as opposed to males based on scholarly view expressed in research.

Generally, results from the findings presented opposing perspectives relative to the influence of gender disparity on coping strategies of persons with ASD.

4.6 Cultural influence on Families health seeking-Behaviour

Subtheme: *the role of culture on families' health-seeking behaviour.* Culture arguably play a cardinal role in shaping individuals knowledge, attitude and perception as well as general way of life including their approaches to health-seeking behaviours and intervention choices. To achieve this objective, the researcher posed the following question during interview with community elders. Does your cultural beliefs influence your health-seeking behaviour?

Data elicited from the survey was discounted by community elders as follows:

> *…"Yes culture does because, my father & grandfather taught me a lot of herbs with which I can heal or cure many sickness". "Moreover, some of the sicknesses require spiritual healing and not medical treatment as most people do in this modern generation"… Participant F7, Community chief.*

However, results from the findings turned out that indeed, community cultural beliefs play an inextricable role in shaping the health-seeking behaviour and intervention choices as noted by chief of the community.

In furtherance, data obtained from the survey further revealed by participant F8, chief linguists of the community reechoed that:

> *…"We believe that our traditional healthcare system is more effective than the orthodox system." Our traditional system of healing is not also expensive compared to the orthodox mode of treatment"…*

In addition, data elicited from the findings further revealed by participant F9, the chief's right hand asserted that:

> *…"My grandfather was a traditional healer, a seer/soothsayer so I grow up and inherited the traditional healing from him". "I have been able to cure many sicknesses and the patience got healed without any side effect." The first thing I do is to consult my ancestors and our lesser-gods to ascertain the cause before I can commence treatment"…*

However, data elicited from interview with professional healthcare providers, teachers and community chiefs and elders revealed that participants understanding and interpretations ascribed to ASD varies substantially and disproportionately despite the fact virtually all participants have a fair knowledge relative to the nature and characteristics of persons with ASD.

Moreover, data obtained from interview revealed further that participants understanding and interpretations attributed to the etiological causes of ASD also vary substantially and disproportionately broadly classified under genetic/biological, socio-cultural and medical.

Ultimately, results from the findings also demonstrated that factors such as family's educational status, size of income as well as family's culture and religion constituted some of the factors that influences intervention choices and health-seeking behaviours.

4.7 Results from Focus Group Discussion

Two focus group discussions were conducted with key participants constituting only families & caregivers of persons with ASD in the three selected communities. Each focus group contained five participants each. The data solicited from this source were consolidated and further coded as F10, F11….F19. This was to ensure comprehensive analysis in order to protect the integrity, anonymity and confidentiality of respondents since they did not want their names to be categorically mentioned. The purpose of the focus group discussion was to unearth participants lived experience and factors that influence their health seeking behaviour & intervention choice.

4.7.1 Families & Caregivers knowledge & Interpretation of the lived experience of persons with ASD.

Photograph 1: First Focus Group Discussion with (6) Participants

Source: Research Findings December, 2022.

To make the discussion more interactive for better understanding, the discussion was done in the Waale local dialect in order to ensure that participants have full understating of the topic of discussion and to be able to contribute meaningful information to achieve the purpose of the discussion. The research objective was guided by the following questions during the discussion; do you know any developmental disorder called Autism? If yes, then explain the characteristics of persons with ASD.

However, data obtained from the findings emerged that virtually all the ten participants have a fair knowledge about ASD which is dialectically known as *"chogii"* in the Waale local language in relation to "*children with special needs".* These are children with physiological, psychological, cognitive and social needs due to their associated disabilities.

F10 is mother of a child with ASD and explaining the lived experience of her daughter, she said:

> *…"I got to know much about ASD (chogii) after I had my second daughter when she was two and half years because she could not talk like my other two children. My husband met with his family and he was advised to consult a seer/soothsayer to ascertain the cause of the problem. Two days later, my husband told me that the seer/soothsayer said the problem with my daughter is due to 'sorcery' caused by demons and principalities"…*

F10 being a mother of two and half year daughter with ASD, she started spotting these signs of developmental deficits on her daughter based on behavioural changes relative to communication difficulties noticed at the early stage of growth. Upon spiritual consultations by the husband, it was reported that the disorder is based on "*sorcery*" caused by demons and principalities. In this case, parents understanding and interpretations of the lived experience of their daughter is based on the spiritual interpretations ascribed to persons with developmental deficits.

In furtherance, it emerged from the findings that F11, a mother of eighteen months baby with developmental difficulties narrated that:

> *…"I have been married since 1992 and I have five children three of whom are males and two are females. I discovered in the first eighteen months that my third child physical outlooks were different from the other siblings and I was really terrified because I did not know exactly what was happening. The problem keep getting worst as his growing so my husband and I decided to resort to different approaches in search for cure for my son and these included malams, herbalists and native doctors. After consultation of these people, we did not get any better results till now. At one time, I suggested to my husband we take him to the hospital but due to financial challenges, we could not take him to the hospital for proper cure"…*

Participant F11, a mother of person with ASD started noticing certain developmental delays in her son after eighteen months of birth which appeared both strange and terrifying to both parents in the first time. Signs and symptoms appeared in a continuum and grows from mild to severe from different stages of growth based on parents' narration. Out of desperation, both parents decided to resort to different approaches in search for cure and these included both traditional and spiritual. However, the family was financially strained for which reason they could not seek for medical treatment.

In this case, parents understanding and interpretation of the lived experience of their son was not clear because they both did not know neither the problem nor its etiological causes. However, what informed parents health seeking behavior and intervention choice was based on family's income and economic status which constituted a barrier to accessing appropriate medical help for their daughter.

It was also revealed from the findings that, participant F12 had three children among which were two females and one male. Among these three, two were autistic thus, the first and the third.

Following include what she narrated:

> *…"I started noticing strange signs in my first son after he was three years and few months old. I realized he could not talk and often have this strange habit of isolation and not wanting to play with her other brother and sister in the house and due to this reason, he cannot go to school F12 (Mother of autistic person). The same also happened to my third child after several weeks of observations, I noticed a delay in their language and communication skills. Due to this reason, my husband and I have divorced for over six years now. Since then, it has become stressful and extremely difficult to raise the children alone"…*

Consistent with participant F11, F12 cannot not seek for any medical intervention due to the stress and trauma she goes through coupled with the socio-economic and financial burden imposed on her in raising the children as a single parent. In this case, socio-economic and financial constraints constituted the barriers to families in seeking medical interventions.

As narrated by the next participant F13 on the lived experience of her daughter, she said:

> *…"My daughter is one, year nine months now but she still cannot speak and does not also know her name. I consulted a few friends who were also in labour in the same month I was put bed and the case of their children is different from mine. I consulted a neighbor who is also a nurse in our community and she said my daughter may be a late talker but for now we should monitoring keep till gets two years. I am indeed devastated because that is my first time of having such experience yet my husband is out of the country for two years now"…*

As evidenced in the case of participant F13, a mother of twenty one months old baby getting devastated after she noticed a delay in speech, language and communication by her daughter after twenty one months. Upon consultation of a professional nurse, she was told her child might be a late talker but she has to keep monitoring until her daughter gets two years then they can draw conclusion on her child's situation or better still, consult a speech and language therapist for assistance.

Photograph 2: Second Focus Group Discussion with families & caregivers

Source: Research Findings October, 2022.

4.7.2 Families & Caregivers Understanding & Interpretations Ascribed to Persons with ASD

It also emerged from the findings by participant F14, a caregiver narrated as follows:

> …"*My nephew seven years old now at the early stage of three years was physically observed and certain developmental deficits were noticed. Some of the characteristics noticed were communication difficulties, sometimes very calm in isolation and other times too very aggressive, hyper and anti-socialization. Upon several medical consultations, he was reported to have neurodevelopmental delays which is causing mental retardation and other developmental difficulties. It however recommended for us resort to some therapeutic measure that can help reduce symptom severity and chronicity of the disorder*"…

In view of participant F14 narrative, after several professional consultations, her nephew was reported to have neurodevelopmental delays which is a feature of ASD despite recommendations for therapeutic interventions to help reduce symptoms severity.

Ultimately, data obtained from the discussion revealed that participant F15 is an aunt of a 14 year old girl who is autistic. From the discussion, she narrated that:

> …"*She was two years old when my brother brought her for me to look after her in his stead. I enrolled her in school and few months after, the teachers and myself coincidently noticed strange features of communication and socialization challenges. We did several medical consultations and a doctor told us the problem is caused by developmental delays so he asked us to see a neurologist or speech and language therapist for help but due to financial challenges we could afford the costs to access proper medical as recommended. Because of her condition, about three different schools denied us admission for enrolment so we decided to resort to the community day school*"…

Consistent with the previous findings, participants are ever ready and willing to seek medical interventions but proximity, socio-economic and financial challenges have often constituted major constraints that hamper families' efforts towards seeking proper medical care.

4.5 Discussion

4.5.1 Participants Knowledge about ASD.

Data obtained from the findings emerged that virtually all the participants have a fair knowledge about ASD. Families and caregivers of the three selected communities referred to persons with developmental deficits as "Chogii" in the local (Waale) dialect also known as "*children with special needs*" which describes persons with developmental deficits accompanied with predisposition of behavioural, social and communication deformities that make them socially unfit into the community and are therefore stigmatized and socially excluded from all social events and gatherings. This is consistent with report from the findings of (Serpell et al., 2021) where ASD is described as a developmental disorder characterized by social and communication deficits accompanied with marginalization, stigmatization and social exclusion which is highly common in resource constrained economies in many developing parts of the world.

Precise prevalence was identified to include six families with seven (7) persons with developmental delays in the three selected communities. Three of whom were males while four were females while four (4) constituted males with age range 1-14 yeas respectively.

4.5.2 *Prognosis of ASD in the three selected communities*

However, in order to establish common etiologies causes of ASD in the three selected communities, the researcher probed follow-up questions in order to explore the mode of diagnosis or prognosis of persons with ASD in the communities. Data obtained to this effect revealed that predisposition of developmental delays and behavioural deficits were noticed by families of persons with ASD at the early stages of child growth where language and communication constitute essential factor and fundamental variable for effective social interaction. On set of common signs and symptoms were noticed at the early stages of child growth based on behavioural assessment and evaluation system. However, this result is corroborated with report from the findings of

4.5.3 Common Signs & Symptoms

Symptoms of ASD are in a continuum and in effect vary disproportionately from mild to severe from stages of child growth and development. Common signs and symptoms were identified to include; developmental delays, communication deficits, anti-socialization, hyperactivity, aggressive and restlessness and general physiological and psychological impairments. However, in line with the findings of (Roll-Pttersson et al., 2020), common signs and symptoms of ASD are noticed between year 1-to-5 of the early stage of child growth where language development and communication constitute an essential attribute for effective social interaction.

4.5.4 Perceived Etiological Causes of ASD

Data obtained and analyzed from the findings revealed that different individuals and groups attribute different causes to ASD. For instance, professional healthcare providers attributed the etiological causes of ASD to genetic/ biological factors and medically related condition which is consist with previous findings of (Roll-Pttersson et al., 2020).

Conversely, families and caregivers of persons with ASD on the other hand attributed the etiological causes of ASD to spiritual factors including *sorcery, demons and principalities* which is consistent with report from the findings of (Mello et al., 2018) where common etiological causes of ASD are attributed to evil spirits.

However, drawing from the perspective of the findings, causes of ASD vary substantially and disproportionately relative to individual knowledge, attitude as well as perception and interpretations ascribed to the disorder.

4.5.5 Community Cultural Beliefs & Its Influence on Intervention Choices

Data elicited and analyzed from the findings revealed that culture play an inextricable role in shaping the knowledge, attitude and perception of individuals and group and the interpretations ascribed to a particular social phenomenon. From the survey, interview with community chief and elders revealed that the culture of the community is passed from generations unknown up to present day and these customs and belief systems contributed to shaping the general way of life of people in the community including their intervention choices, healthcare system and health-seeking behaviours. Results from this finding is consistent and reechoed by (Mandell et al., 2018) where it is clearly established that families beliefs and interpretations ascribed to developmental disorders consequently shape their intervention choices and health-seeking behaviours.

However, results from the findings revealed that families and caregivers who attribute the etiological causes of ASD to spiritual and supernatural forces resorted to primary healthcare providers including herbalists, malams and native doctors for spiritual healing and deliverance while those whose beliefs are based on genetic/medical causes also resorted to professional healthcare interventions for treatment or management of the condition. Moreover, other families and caregivers sought multiple approaches and intervention choices in order to improve coping strategies.

4.5.6 Factors influencing health seeking behaviours & intervention choices

In seeking to explore the factors influencing health seeking behaviours and intervention choices for treatment of persons with ASD, the findings revealed the following factors including; socio-economic factors such as family's income, family educational background, costs of seeking medical healthcare, proximity and accessibility to professional healthcare, perceived quality of the approach. Moreover, family's culture & religious affiliations which is consistent with report from the findings of (Siddiqui, 2011) where it is emphasized that social, economic, demographic, political, demographic, social tiles and network and the available healthcare system of the community constitute some of the variables that influence intervention choices and health-seeking behaviours of families and caregivers of persons with ASD.

4.5.7 Challenges faced by families in raising children with ASD in the communities

Data elicited from the findings revealed that families and caregivers of persons with ASD in the three selected communities are faced with many challenges some of which were discovered to include stigmatization, marginalization and social exclusion, negative attitude and social distancing from autistic persons, stress, frustrations and financial difficulties. This result is consistent with report from previous findings evidenced in (Park, Lee, & Kim, 2018), where they clearly opined that families of persons with ASD undergo through many challenges including oppression, stigmatization, general negative attitude and social distancing from families of persons with ASD.

4.5.8 Barriers/Challenges impeding stakeholder intervention

Despite the substantial difficulties, there is also lack of stakeholder intervention to support families of persons with ASD in the Wa Municipality. Among these include lack of political will and commitment, lack of inclusive and broad-base national healthcare policies, lack of public health education, fragmented knowledge due to lack of research and knowledge sharing, lack of medical equipment's and facilities. These constituted some of the barriers identified to hamper stakeholder inventions in support of families' efforts towards raising children with ASD in the Wa Municipality of the Upper West Region.

This in effect requires the need to reinforce calls from government, Civil Society Organisations, Non-Governmental Organisations and other corporate and philanthropic bodies to support families and caregivers of persons with ASD in the selected communities of the Wa Municipality.

CHAPTER FIVE

SUMMARY OF FINDINGS, CONCLUSION AND RECOMMENDATIONS

5.0 Introduction

This chapter constitutes a summary and synthesis of key findings. It presents a summary of results from the findings in accordance with the research objectives and questions and closely followed by the conclusion and recommendations for future research.

5.1 Summary of key Findings

5.1.1 Objective 1: Nature of Autism among people in the Wa Municipality

The research findings in line with the first research objective was guided by the following research questions; do you know any disorder called autism? If yes, then explain the nature of how persons with autism behave. Do you know anyone with such developmental disorder? If yes, then explain the signs and symptoms shown by persons with such disorder. Do you know what causes such developmental disorder? If yes, then explain in your opinion the causes of such developmental disorder. Explain your knowledge, attitude and perception about persons with such developmental disorder. Does such developmental disorder pose any socio-economic burden on the family? If yes, then explain.

The research findings in line with respondents' knowledge about ASD revealed that significant proportion of partisans in the Kpongu, Biihe and Sombo communities have fair knowledge about ASD as they locally referred to it as "Chogii" in the Waale language in relation to persons with developmental deficits.

Moreover, in line with the number of persons with developmental deficits in the three selected communities, it was found that precise prevalence of ASD in the three selected communities was seven constituting three males and four females.

In furtherance, the research findings in line with the *signs and symptoms* exhibited by persons with ASD were recounted to be anti-socialization, predisposition of developmental delays, communication deficits, mentally retarded cognitive and psychological developmental challenges and hyperactivity.

In addition, with the research findings in line with the *causes of ASD,* two opposing perspectives were found. Families and caregivers attributed the causes of ASD to culture and spirituality based on the belief that persons with ASD are from divine origin or evil spirit caused by demons and principalities. The other perspective is based on genetic and environmental factors by healthcare practitioners. These two opposing perspectives therefore shape families or individual health seeking behaviours and intervention choices.

Ultimately, results from the findings in line with the socio-economic burden of ASD, participants recounted that raising a child with ASD require enough income and effort in seeking appropriate health interventions for management of the condition before it develops into the chronic stage.

Families with high income and economic status were able to access appropriate health interventions to help manage the symptom severity and improve the coping strategies while families with low income economic on the other hand could not access proper health care due to financial constraints.

5.1.2 Objective 2: Mode of Diagnosis of ASD in the three selected communities

To achieve the second objective on the mode of prognosis of ASD in the three selected communities, the following specific questions were asked in order to illicit more information relative to the diagnostic criteria of ASD in the Wa Municipality. Following are the questions; are there quality and adequate medical facilities to diagnose persons with ASD in the community? What method is used in diagnosing ASD in the community?

What influence the health seeking behaviours and intervention choices of families of persons with ASD? Are there coping strategies for persons with ASD? Do gender differences influence the symptoms severity and coping behaviours of persons with ASD? Are there interventions put in place for management or treatment of persons with ASD?

However, results from the research findings on the availability of quality and adequate medical facilities for diagnosing ASD in the communities revealed lack of medical facilities to diagnose persons with ASD in the three selected communities despite families' willingness to seek medical intervention. Moreover, relative to the findings on the mode of prognosis of persons with ASD by families revealed that the most common criteria for diagnosing ASD is *behavioural* based on the onset of symptoms predisposition.

In furtherance, on what influences the health seeking behaviour and intervention choices of families of persons with ASD, the findings revealed that family income and socio-economic status, proximity relative to accessibility, family norms, religious and cultural belief systems, perceived quality of the approach and the costs associated with accessibility.

On gender differences and its influence on coping behaviours of persons with ASD, results from the findings showed no clear evidence due to fragmented knowledge to that effect. As a consequence, the findings also revealed the absence of appropriate mechanisms put in place to reduce symptoms severity and improve coping strategies of persons with ASD in the selected communities.

5.1.3 Objective 3: Influence of Culture on Health-seeking Behaviour of Families of persons with ASD.

To achieve this objective, the following specific questions asked; do cultural beliefs and practices have any influence on health seeking behaviours and interventions of families of persons with ASD? Are there other factors influencing the intervention choices and health seeking behaviours of families of persons with ASD?

Responses gathered from the findings revealed that both family's *religious and cultural beliefs and practices* have a significant influence in shaping families' beliefs and perceptions as well as interventions and health seeking behaviours as participants' recounted occasions where they consulted seers or sooth Sayers in order to know the cause of the predicament.

Moreover, other factors identified to influence or shape family's intervention choices and health seeking behaviours were recounted to include; family's income and socio-economic status, proximity and accessibility to health facilities, family cultural beliefs and religious affiliations', family's perceptions of quality about the healthcare system and the costs associated with accessibility.

5.1.4 Objective 4: Barriers and Challenges Affecting Interventions of Stakeholders in Managing ASD.

To achieve this objective, the researcher posed the following questions; are there adequate interventions by major stakeholders in managing the ASD in the community? In your opinion, state the barriers and challenges contributing to limited interventions by major stakeholders towards effective treatment or management of ASD in the Wa Municipal.

However, results from the findings showed lack of interventions mechanisms in managing cases of ASD in the community. Additionally, the study also revealed many factors that strained stakeholder interventions in managing ASD which were identified to include; lack of political will and commitment, fragmented knowledge on common etiologies and threshold for diagnosis, lack of education, community outreach and sensitization programmes, lack of inclusive policies and collaborative efforts and lack of broad-base and national healthcare programmes taking into consideration of ASD.

5.2 Implications

The concept of ASD in the study setting is less explored with woefully scanty amount of scholarly literature. The study will be more impactful as a repository of key information to researchers, policy makers, academia and the general public as a reference tool for future studies.

There is lack of collaborative efforts and inclusive policy interventions towards addressing the socio-economic impact of ASD in the Ghanaian context. The study will be of tremendous impact advocating for need for sustainable in and inclusive education and healthcare policies towards addressing the needs of persons with ASD.

More importantly, there is fragmented knowledge and research on the concept of ASD in the Upper West Region and how culture and religious affiliations shape individual knowledge, attitude, perceptions and interpretations attributed to ASD. However, the study will be more impactful as an educational tool to the people of the Upper West Region of Ghana.

Presently, there is lack of public health education about ASD in the Upper West Region. It is therefore recommended that educational and public health policy makers should provide community outreach programs and public health campaign in order to increase sensitization and awareness about ASD and its prevalence in the Wa Municipality.

Ultimately, there is lack of effective surveillance, monitoring and incomprehensive records keeping that hamper efforts towards establishing the precise prevalence of ASD both in the Upper West Region and Ghana as a whole. The study will be more impactful on efforts towards effective surveillance, monitoring and proper records keeping relative to the prevalence of ASD in the Wa Municipality and Ghana as a country.

5.3 Conclusion: It is imperative to state that culture paly an inextricable role in shaping the knowledge, attitude and perception as well as the interpretations and beliefs ascribed to ascribed to social phenomena.

The main purpose of the study was to explore community cultural beliefs and practices about Autism Spectrum Disorder. The research employed only primary sources of data to elicit more detailed information about participants lived experience in the Wa Municipality.

Data analysis was aided by Microsoft Excel and drawing from the perspective of the findings, suffice to establish that cultural beliefs and practices play a crucial role in shaping the knowledge, attitude, perceptions and interpretations ascribed to the concept of ASD as well as their intervention choices and health seeking behaviours.

However, despite the findings, the study will be closely followed by the following recommendations for future research on the subject matter.

5.4 Recommendations Based on the Research Findings.

1. The recommendations based on the findings of the research work based on the need for inclusive policies and collaborative efforts from government, Civil Society Organizations and Non-Governmental Organizations to address the needs of persons with developmental deficits including Autism Spectrum Disorder in the Wa Municipality and the Ghanaian society in general.

2. Moreover, it is recommended that government and professional healthcare service providers and must enhance public health campaign, educational programmes, knowledge sharing and public awareness on developmental deficits including autism spectrum disorder

for purpose of sensitization and improving public knowledge on the risk factors and its debilitating effects on the well-being of children.

3. More importantly, there is the need for public-private partnership with concerted efforts towards increasing access to diagnostic services for early intervention in order to address the needs of children with developmental deficits.

4. In furtherance, government together with other major stakeholders must improve, professional education, training and research towards establishing accurate prevalence of autism spectrum disorder, its impact on national socio-economic development with remedial measures to address the needs children with developmental deficits.

5. Finally, there is the need for concerted efforts towards improving surveillance, accurate and timely reporting and efficient records keeping on cases relating to developmental deficits in order to contribute to global efforts towards establishing prevalence of ASD.

5.5 Recommendations for future research

The main purpose of the study is to explore community cultural beliefs and practices about Autism Spectrum Disorder in three selected communities of the Wa Municipality of the Upper West Region. However, it is recommended that future researchers focus efforts on how cultural and religious affiliations shape the Knowledge, Attitude and Perception on the interpretation of ASD. Moreover, it is recommended that future researchers should focus efforts on the socio-economic burden of raising a child with ASD. Also, future researchers should direct conscious efforts on the prevalence of ASD in the Ghanaian context.

5.6 Limitations of the Research work

The limitations of the study based on the research findings are based on the fact that the magnitude of the research work was broad and therefore covered only a few population and sample of the study setting. For that matter, results from the findings cannot be generalized and inferred to the entire Municipality of the region. Moreover, there is literature deficit in relation to the subject matter which contributed to narrowing the scope and range of the research work. Also, during data collection process, some participants were very skeptical and in effect declined to participate in the survey. Finally, entire cost involved in conducting the study was inefficient for that matter, the researcher was both time and financially constrained taking into consideration cost of transportation and other overheads involved through data collection process.

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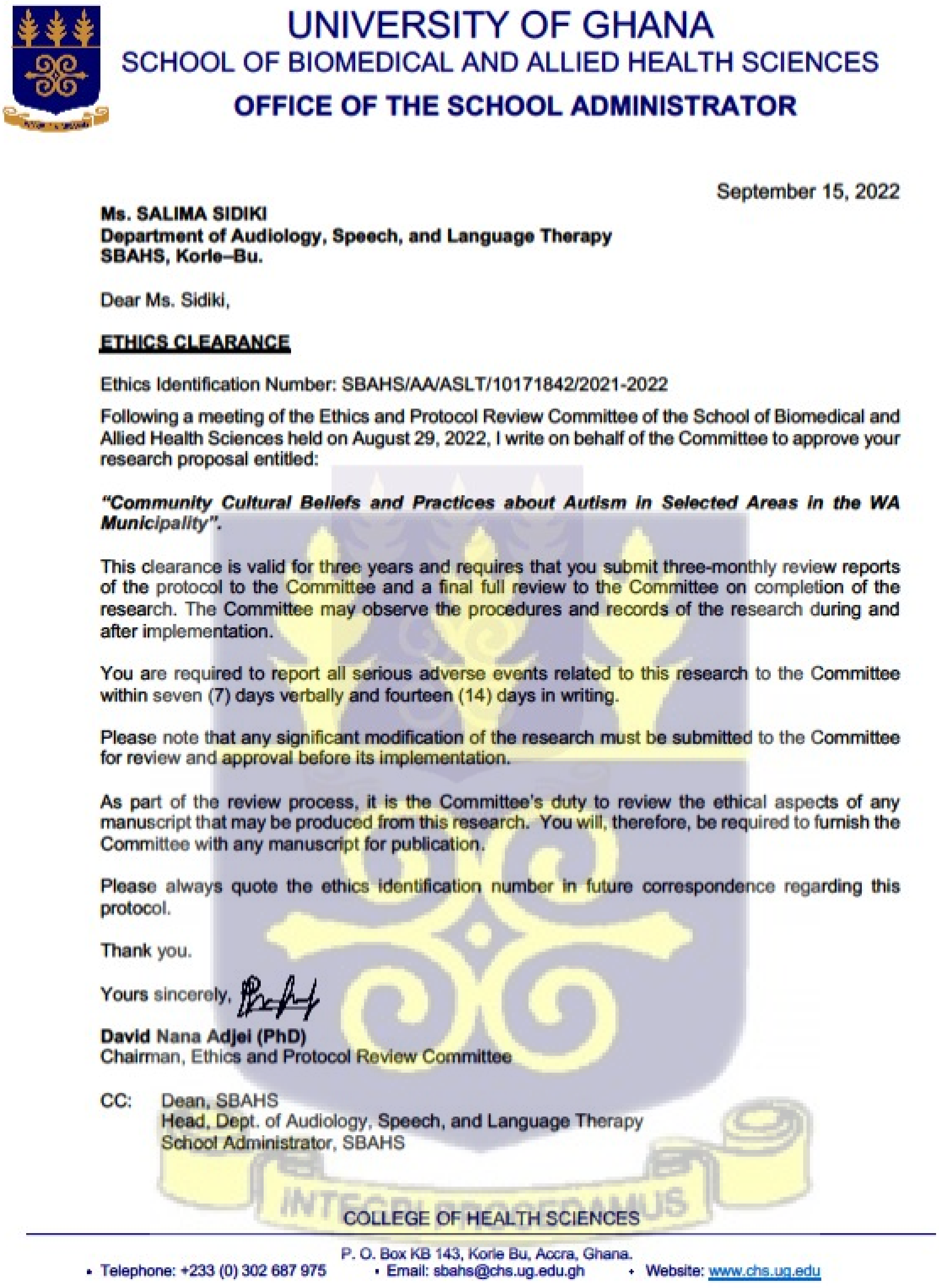

UNIVERSITY OF GHANA
SCHOOL OF BIOMEDICAL AND ALLIED HEALTH SCIENCES
OFFICE OF THE SCHOOL ADMINISTRATOR

September 15, 2022

Ms. SALIMA SIDIKI
Department of Audiology, Speech, and Language Therapy
SBAHS, Korle–Bu.

Dear Ms. Sidiki,

ETHICS CLEARANCE

Ethics Identification Number: SBAHS/AA/ASLT/10171842/2021-2022

Following a meeting of the Ethics and Protocol Review Committee of the School of Biomedical and Allied Health Sciences held on August 29, 2022, I write on behalf of the Committee to approve your research proposal entitled:

"Community Cultural Beliefs and Practices about Autism in Selected Areas in the WA Municipality".

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

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

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

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

Please always quote the ethics identification number in future correspondence regarding this protocol.

Thank you.

Yours sincerely,

David Nana Adjei (PhD)
Chairman, Ethics and Protocol Review Committee

CC: Dean, SBAHS
Head, Dept. of Audiology, Speech, and Language Therapy
School Administrator, SBAHS

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PARTICIPANT INFORMATION SHEET FOR FAMILY AND CAREGIVERS OF INDIVIDUALS WITH AUTISM IN THE WA MUNICIPAL.

My name is Salima Sidiki, a post graduate student of the University Ghana, Legon. I am considering if family members and caregivers of persons with Autism can participate in a research aimed at exploring community cultural beliefs and practices about Autism. Participation in this research is voluntary and so respondents reserve the right to decline, participate or withdraw at any time for personal discretion. If you are participating, then you will be required to take part in an interview and you will be asked questions to provide information to the best of your knowledge about people with autism and how cultural beliefs and practices of the community shape your knowledge, attitude and perception about autism, mode of intervention and health-seeking behaviors of families and caregivers.

Details of the study are as follows;

The research is divided into three main sections. The first section involves an interview with you about persons with autism and the interview is anticipated to last not more than an hour. The second section involves both open-ended and close-ended type questions on the mode of screening or diagnosing autism in the community, treatment interventions as well as the barriers and challenges contributing to limited interventions in managing the disorder.

The third section involves focus group discussion of key issues in respect of your experience and knowledge about the causes of autism, signs and symptoms and the influence of cultural beliefs in healthcare seeking-behaviors. Information provided will be confidential and anonymous and use for only the intended purpose. Information provided will be consolidated for analysis and will not be disclosed to any third-party.

I therefore agree to participate in the study and hereby certify that I am 18 years or above.

Name of interviewee……………. Sign/Thumbprint……………… Date……………

Name of interviewer …………… Sign/Thumbprint……………… Date…………….

CONSENT ASSENT FORM FOR FAMILY MEMBERS AND CAREGOVERS OF INDIVIDUALS WITH AUTISM.

The nature and purpose of this research “exploring community cultural beliefs and practices about Autism” has comprehensively been explained to me and I clearly understand I will be interviewed and that the information provided can be recorded or documented.

I understand the purpose of the research is to fulfil an academic requirement and therefore, information provided will be treated with utmost confidentiality and anonymity. I understand I have the right to participate, refusal to participate and can discontinue at any stage of the process. The risks and benefits involved have been explained to me and my concerns regarding the process have been adequately addressed and I agree to participate in the research study.

Participant ………………. Sign/thumbprint…………… Date……………..

I Salima Sidiki have explained the purpose and nature of the research work to the participant including the risks and benefits involved and I believed the participant is well informed and understands the consequences of participating in the exercise.

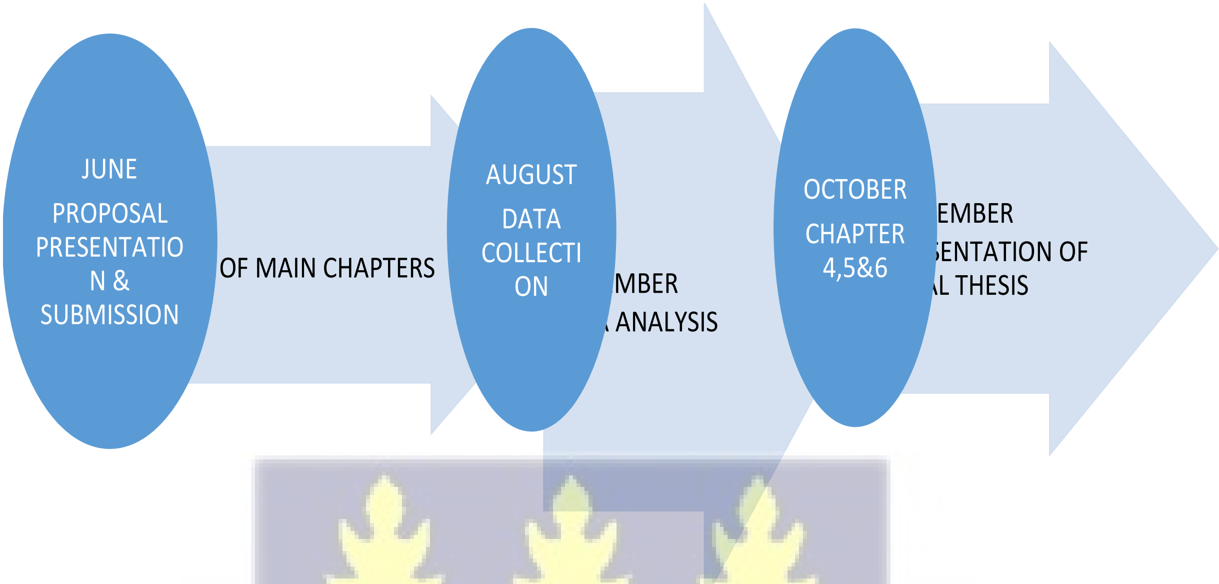
Investigator…………….. Sign/thumbprint…………… Date……………

STATEMENT OF WITNESS

I was present while the benefits, risks and procedures were read to the participant. All questions and concerns were addressed and the participant agreed to participate voluntarily in the research study.

Witness name……………… Sign/thumbprint …………………… Date…………………

WORK SCHEDULE



BUDGET STATEMENT

ITEM	COST (GHC)
Transportation	1,500
Printing	500
Instrumentation	300
Volunteers	700
Miscellaneous	1,000
TOTAL	**GHC 4,000**

APPENDIXES

INTERVIEW GUIDE

Dear respondents,

I am a student of the University of Ghana, School of Biometrical and Allied Health Sciences, department of speech and language therapy, conducting a research on community cultural beliefs and practices about Autism in some selected areas in the Wa Municipal in the Upper West Region. I would be much grateful if could provide responses to the following questions to the best of your knowledge. The information provided is for only academic purpose and therefore the confidentiality and anonymity of the respondent are guaranteed.

Your participation will be much appreciated.

Please tick **(√)** *one where multiple response choice is provided.*

APPENDIX A: Socio-Demographic Data of Respondent

1. Gender Male [ ] Female [ ]
2. Age-group 18-30 [ ] 31-60 [ ] 60+ [ ]
3. Level of education Diploma [ ] Professional [ ] Bachelor degree [ ] Master's degree [ ] Other (Specify) [ ]

APPENDIX B: Nature of Autism among individuals in the Wa Municiapl

1. Do you know any disorder called Autism? if yes, then explain the nature of how persons with autism behave.

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2. Do you know anyone with such developmental delay? If yes, then explain the signs and symptoms showed by individuals with such disorder.

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3. Do you know what causes such disorder? If yes, then explain in your opinion the causes of such developmental disorder.

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4. Explain your knowledge, attitude and perception about individuals with such developmental disorder

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5. Does such disorder poses any socio-economic or health burden on the family? If yes, then explain how.

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APPENDIX C: Mode of Screening/diagnosing ASD in the Wa Municipal

6. Are there quality and adequate professional healthcare facilities for screening/diagnosing ASD in the Municipality? If yes, then explain

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7. What method is applied in diagnosing ASD in the Wa Municipal?

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8. Explain what influences intervention choices and health-seeking behaviours of families and ASD caregivers……………………………………………...

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9. Are there coping strategies for individuals with developmental delays? If yes, then mention some of the coping strategies…………………………………

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10. Do gender differences influence symptoms severity and coping behaviours? If yes, then explain…………………………………………………………………...

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11. Are there interventions put in place for treatment or managing conditions of ASD? If yes, then mention some of these mechanisms…………………......

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APPENDIX D: Influence of Culture on Health-seeking Behavior of Families of victims with ASD.

12. Does the culture and beliefs of Wa municipal influence healthcare choices and health-seeking behaviours of families and caregivers of ASD victims? If yes, then explain how cultural norms and beliefs influence intervention choices and health-seeking behaviours.

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13. Are there other factors and forces influencing intervention choices and health-seeking behaviours of families and caregivers of victims with ASD in the Wa community? If yes, then state some of these factors.

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APPENDIX E: Barriers and Challenges Affecting Interventions of Stakeholders in Managing ASD.

14. Are there adequate interventions by major stakeholders in managing ASD in the Wa Municipal? Explain

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15. In your opinion, state the barriers and challenges contributing to limited interventions by major stakeholders towards effective treatment or management of ASD in the Wa Municipal.

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16. Based on the barriers and challenges identified, propose recommendations to help improve effective treatment or management of ASD conditions in the Wa Municipal.

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End of interview.

Table 1: Results from Semi-structured Interviews

Research Objective	Themes	Quotes from interviews
Participants’ knowledge about ASD:		
Explain the nature of Persons with ASD:		Psychiatrist F1: “I know autism to be a neurodevelopmental disorder with predisposition of mental retardation accompanied with communication & social deficits.”
		Psychiatric nurse F2: “I know ASD to be a developmental challenge among children with common developmental delays”.
Signs & Symptoms shown by Persons with ASD:		Registered General Nurse F3: “The few clinical signs that I know about autistic patience is that they are anti-social, communication difficulties, sometimes aggressive and hyper reactive and also throw tantrums.”
		Teacher F4: “We had one in our school here and what I observed I that she could not speak nor play with the other colleagues. She was also sometimes aggressive and restless”

Explain your knowledge, attitude & Perception about persons with ASD.	Psychiatrist F1: “There are no universally established threshold to diagnose the causes of ASD but certainly, I know it is a genetic disorder”.
	F2: Psychiatric nurse: ASD in the best of my knowledge is a medically related condition and can only be managed through therapeutic interventions to improve coping strategies.
Describe the socio-economic burden associated with ASD if any.	Teacher F5: I know raising a child with ASD is very strenuous because people with such conditions require much love, attention & care. Notwithstanding the stress, stigma & financial burden on parents in seeking medical interventions.
Mode of prognosis of ASD in the community:	
Are there adequate medical Equipment’s for ASD diagnosis?	Medical Assistant F6: To the best of my knowledge, there has not been any.
Describe how you diagnose	

Persons with ASD.	MAF6: There no internationally recognized thresholds or universal criteria for diagnosing ASD besides, we do not have the appropriate equipment & facilities to carry out such exercise. But from professional experience, prognosis is usually done through behavioural criteria based on predisposition of common signs & symptoms.
State the factors that influence- Intervention choices & health Health seeking behaviours of Families of persons with ASD.	MA F6: "Well, from professional experience and research, the most common factors include; family income status, family's culture & religious affiliations, level of education & social status and family's perception of quality with respect to the type of healthcare system." In other occasions, proximity and cost of access also play an influential

	role on family’s health seeking behaviours & intervention choices.
Does gender disparity influence Symptoms severity & coping- Behaviuor of persons with ASD?	MA F6: “From professional experience, I am not certain but studies has it that, females have a better coping strategies than males”.
Are there interventions put into treat or manage ASD?	MAF6: “In our facility, no.” But same cannot be said about other facilities.
Cultural influence on Families health seeking- Behaviours.	
Does your culture influence- Your health seeking behavior And how?	Community chief F7: “Yes it does because, my father & grandfather taught me a lot of herbs with which I can heal or cure many sickness”. Moreover, some of the sicknesses require

	spiritual healing and not medical treatment as most people do in this modern generation.
	Chief linguist F7: “we believe that our traditional healthcare system is more effective than the orthodox system.” Our traditional system of healing is not also expensive compared to the orthodox mode of treatment.
	Chief’s right hand f8: “My grandfather was a traditional healer so I grow up and inherited the traditional healing from him”. “I have been able to cure many sicknesses and the patience got healed without any side effect.”
Are there other factors- Influencing your health Interventions & healthcare Seeking behaviour?	Sub-chief F9: “Yes”. “My father was a “seer/soothsayer” and it is passed down to me so whenever I am consulted with some strange sicknesses, the first thing I do is to consult my ancestors and our lesser-gods to

	ascertain the cause before I can commence treatment”.
Barriers & Challenges Affecting Stakeholder Interventions in- Managing ASD in the Wa Municipality.	
Are there adequate Interventions put in place by stakeholders to managing ASD in the community?	Psychiatrist F1: “No”. “There is no any stakeholder intervention much as ASD & our community is concerned”.
In your opinion, State some of the Barriers & challenges Impeding stakeholders Intervention in managing ASD.	Psychiatrist F1: Some of the challenges include lack of political will & commitment, lack of inclusive & broad-base national healthcare policies, & lack of public health education.

MA F6: “In my opinion, some of these challenges include fragmented knowledge in relation to ASD, lack of adequate medical equipment’s & health facilities.