

SCHOOL OF NURSING
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA, LEGON

**EXPERIENCES OF MOTHERS WITH INTELLECTUALLY CHALLENGED
CHILDREN IN TAMALE METROPOLIS**

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Declaration

I, Millicent Aarah-Bapuah, certify that this thesis is the result of a research undertaken towards the award of the Master of Philosophy in Nursing Degree in the School of Nursing, University of Ghana, Legon. This research has been undertaken with the guidance and supervision of Dr. Florence Naab, School of Nursing University of Ghana, Legon and Dr. Michael Wombeogo, School of Allied Health Sciences University for Development Studies, Tamale. The undersigned supervisors certify that they have read the thesis and have recommended it to the School of Nursing for acceptance.

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Abstract

Studies have shown that caring for a child who is intellectually challenged can be very stressful to all members of the family. Currently, care of children with intellectual disabilities is primarily undertaken by mothers who are considered the primary care givers based on the traditional roles they assume which often predispose them to a lot of physical, mental, psychological and economic stress. However, literature about intellectual disability in Ghana is scanty. This study therefore explored the experiences of mothers with intellectually challenged children in Tamale Metropolis using Hill's ABCX Family stress model as a guiding framework to understand the experiences of these mothers. A qualitative exploratory descriptive approach was adopted for the study. Data was collected through in-depth interviews of twelve (12) purposively selected mothers with intellectually challenged children attending Yumba Special School in Tamale. Interviews were audio taped and later transcribed verbatim and analysed using thematic content analysis. Five (5) themes were identified and described as follows: caring for a child with intellectual challenge, crises-meeting resources, meaning mothers make of the event, outcome (crises) and factors that predispose mothers to stress. In conclusion the study found that mothers with intellectually challenged children experience physical, emotional, social, financial and work challenges but have limited resources to deal with these challenges. Characteristics of the child and mother's own characteristics such as educational and income status as well as access to social support services predispose mothers to physical and mental health outcomes. However healthcare workers do not provide mothers with the requisite information to help them understand and better cope with their situation. Therefore, educational curricular adjustment for health trainees to include intellectual disability issues as well as implementation of social intervention policies to support these mothers will assist them in their care giving role.

Dedication

This thesis is dedicated to my family without whom I could not have succeeded especially, my husband and children for their support, understanding, sacrifice and love throughout the period of my course. I also dedicate this work to my mother-in-law who took care of my children throughout the entire period.



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List of Abbreviations

ADD	Action on Disability and Development
AAIDD	American Association of Intellectual and Developmental Disabilities
ID	Intellectual Disability
IDN	Intellectual Disability Nursing
IQ	Intelligence Quotient
IRB	Institutional Review Board
JSS	Junior High School
MoH	Ministry of Health
MoE	Ministry of Education
MoGCSP	Ministry of Gender, Children & Social Protection
NGO	Non-Governmental Organisation
PACID	Parent Association of Children with Intellectual Disability
PTA	Parent Teacher Association
QOL	Quality Of Life
TaMA	Tamale Metropolitan Assembly
TCA	Thematic Content Analysis
WHO	World Health Organisation

CHAPTER ONE

INTRODUCTION

This chapter consists of the background information, problem statement, purpose and objectives of the study, significance of the study and operational definition of key terms.

1.1 Background of the Study

Every parents' desire is to watch their children grow up to be independent and responsible but the birth of a child with a disability increases the possibility of provoking feelings of loss, helplessness and failure (Olsson & Hwang, 2008). Caring for a child who is intellectually challenged is usually long-term and can be very stressful to all members of the family. Many studies have reported higher level of stress in parents of children with intellectual challenges compared to parents of normally developing children (Gupta & Kaur, 2010; Olsson & Hwang, 2008). It has also been established that mothers who basically are the primary care givers in the family go through more stress compared to fathers (Gerstein et al., 2009; John, 2012; Norizan & Shamsuddin, 2010; Olsson & Hwang, 2008). The stress affects all aspects of their lives including physical, mental, psychological, spiritual, and economical (Davies & Honeyman, 2013; Gupta & Kaur, 2010). Studies indicate that mothers experience more mental stress than physical stress (Bourke-Taylor, Howie, & Law, 2010; Gupta & Kaur, 2010).

Mothers of intellectually challenged children spend more energy and time attending to the special needs of their children who depend on them for feeding, personal hygiene, among others (Nurullah, 2013). Furthermore, child behaviour characteristic and parental stress have been reported to have an important association (Norizan & Shamsuddin, 2010). It has also been reported that, children who have a higher dependent degree of daily living activity cause a higher

level of strain and that, the longer the intellectually challenged child is cared for, the greater the level of strain felt by the mother (Tsai & Wang, 2009).

The World Health Organization (WHO) in a revolution on the conceptualization of intellectual disability (ID) proposed that it should no longer be regarded as a disease or even the simple consequence of disease but rather as a problem of the functioning of the whole person (WHO, 2010). The new classification improves on the previous one by adding the factor of environmental context. In other words, disabilities arise when bodily impairments and functional limitations, including mental ones, interact with negative social and physical environmental effects (WHO, 2010). In accordance with this new approach to disability, such terms as mental retardation, mental sub-normality and mental handicap, which are considered pejorative, are gradually being replaced by intellectual or learning disability (WHO, 2010). Accordingly, the WHO (2010) referred to “children with intellectual disabilities” as children with significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) and to cope independently (impaired social functioning), which started before adulthood and has a lasting effect on development. This definition encompasses children with a broad range of disabilities. Many children with intellectual disabilities also have physical and/or sensory impairments (WHO, 2010). The definition covers children with autism who also have intellectual disabilities but not those with higher-level autistic spectrum disorders, who may be of average or above average intelligence (WHO, 2010). The American Association of Intellectual and Developmental Disability (AAIDD) also defines Intellectual disability as a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills which originates before the age of 18 (AAIDD, 2008). In other words, the individual has difficulty in reasoning, planning, solving

problems, thinking abstractly, comprehending complex ideas, learning quickly, and learning from experience (AAIDD, 2008). They also may not appropriately perform adaptive behaviour skills such as conceptual (receptive and expressive language, money concept), social (interpersonal, responsibility, gullibility, self-esteem, obey rules) and practical skills involving personal activities of daily living such as eating, dressing, mobility and toileting and instrumental activities of daily living such as preparing meals, taking medication, using the telephone, managing money, using transportation, and doing housekeeping activities (AAIDD, 2008). Significant limitations in adaptive behaviour impact a person's daily life and affect the ability to respond to a particular situation or to the environment (AAIDD, 2008). Some children and adolescents with intellectual disabilities display challenging behaviour, characterized by being aggressive, destructive, attention-seeking, self-injurious, stereotypy, and other kinds of disruptive and socially inappropriate behaviour (Gavidia-Payne & Hudson, 2002).

According to the WHO, children with intellectual disability have greater health needs but also experience greater barriers in accessing appropriate health care. Key barriers include poor knowledge and training of health professionals on disability issues, communication difficulties (poor patterns of communication with the child), negative attitudes, poor intersectoral collaboration and the lack of reliable health monitoring data for this population (WHO, 2010). Children with intellectual disabilities are subjected more to common health risk factors related to diet, weight and physical inactivity as well as impaired vision and hearing, respiratory diseases and dental problems (Michael, 2008). Up to one third have an associated physical disability, most often cerebral palsy, which puts them at risk of postural deformities, pulmonary infections, gastrointestinal problems and urinary incontinence (Michael, 2008). They are 20 times more

likely to have epilepsy and are at the highest risk of sudden unexpected death in epilepsy (Michael, 2008).

Meanwhile, health care has undergone considerable change and development over the last decade, and parents are being actively encouraged not only to be involved in their children's care but also to take some control of it (Peate & Whiting, 2006). When discussing the importance of working closely with families, the term 'family-centred care' is frequently used. Family-centred care is a concept that is widely respected; many healthcare professionals working with children and their families reflect its importance in their philosophies (Peate & Whiting, 2006). Besides, there is a growing research based evidence that institutionalization is an active source of harm and that institutions simply do not provide a suitable environment for any child to grow up, as they foster inhumane, dehumanizing, coercive and abusive forms of experience that systematically harm physical and mental health and can result in reduced life expectancy, or in the worst cases, in early death (WHO, 2010).

Globally there is a general lack of easily available statistical information on children with intellectual disability (ID) and the services available to them. It has been estimated based on the Intelligence quotient (IQ) <70 criterion, that about 1% to 3% of the general population has intellectual disability (WHO, 2010). The incidence of severe intellectual disability (IQ<50) is estimated at around 0.4%. The prevalence of intellectual disability is expected to rise by about 1% per year during the next 10years as prenatal, neonatal and general health care improves the survival rate and life expectancy of children and adults with more complex need (Michael, 2008). The WHO estimates the disability rate of Ghana to be between 7 and 10 per cent (The Danish Council of Organizations of Disabled People, 2007). In Ghana, no accurate national survey has been carried out to determine the disability rate. The 2010 general census did not also

provide concrete data on disability in the country hence statistic on intellectual disability in Ghana are scattered. People with disabilities in Ghana are estimated to comprise of 10 to 15 per cent of the total population and about four (4) to five (5) out of 1000 births suffer from Cerebral palsy in Ghana (Ghana News Agency, 2011).

In spite of the increased levels of stress shown in parents of children with intellectual disabilities, many parents and families of such children are well-adapted and appear resilient in the face of challenges (Gerstein, Crnic, Blacher, & Baker, 2009). In other words, the experience of stress varies for individuals and families and may be seen as subjective feeling. An ecological systems analysis indicates that ‘micro- (parenting practices, parent-child relations), meso-systems (caregivers' marital relations, religious social support), and macro-systems (cultural variations, racial and ethnic disparities, health care delivery system)’ are factors that influence parenting success (Algood, Harris, & Hong, 2013). Other studies have shown similar findings that mothers with greater levels of social support experience lower levels of parenting stress (Hill & Rose, 2009; Tsai & Wang, 2009). Another study in south-west of Sweden found partner support to be very important in easing the burden on the mother as single mothers were found to be more vulnerable to stress (Olsson & Hwang, 2008). However because the birth of a disabled child is often viewed negatively especially in Africa, some husbands deny paternity to the child and therefore abandon or divorce their wives leaving them to bear this burden in isolation (Aldersey, 2012).

In a study of parents with children with developmental disability in Canada, all parents mentioned that they were subjected to stereotypes and social stigma because their child had a disability (Nurullah, 2013). Stigma and discrimination was seen in many other studies across the world (Njenga, 2009; Nurullah, 2013). In Africa, many cultures appear to have negative beliefs

about intellectual disability. For instance in Tanzania, a study revealed that the birth of a disabled child was seen as a ‘bad omen’ and wealthier families were accused of sacrificing their child’s intellectual capacity for wealth (Aldersey, 2012). Another study in Kenya showed care givers being either associated with ‘evils spirits (jinnis), punishment from God, or witchcraft’ (Gona, Mungala-Odera, & Hartly, 2011). Such negative beliefs serve as basis for discrimination, stigmatization and isolation of disabled children and their families by society. To avoid being stigmatized some parents hide their disabled child and do not openly seek help which leads to higher stress (Norizan & Shamsuddin, 2010). Some parents also view their child’s disability as a burden and this is a predictor of higher level of stress (Nurullah, 2013).

In Ghana, children with disabilities face a lot of discrimination at all levels of their lives whether in the family, school or workplace. It has been noted that individuals with intellectual disability are not only more likely to be poor but are subject to prejudice, social isolation and discrimination. Also, some families discriminate against children with intellectual disability because they would finance the education of a child without disability than the one with disability (Ghana News Agency, 2011).

As a means of coping, parents lean on their religious beliefs to help them make sense of their child’s disability. Some parents perceive the child’s disability as a gift from God and a test of faith (Gona et al., 2011). Others also try to dwell on the benefit of the care experience. They say that the experience help them to become more patient and resilient in the face of challenges. Such positive perceptions promote adaptation and reduce stress (Nurullah, 2013). Another form of coping adopted by parents is by sharing experiences through self-help groups. For instance in Taiwan, mothers with intellectually disabled children meet together sporadically and irregularly to share experiences and engage in related activities. Since professionals are rarely involved in

these self-help groups, mothers are only able to share their experiences with each other (Tsai & Wang, 2009). There is a need for investigations into beliefs and perceptions of Ghanaians about intellectual disability and the coping strategies they employ.

The Parents association of children with intellectual disability (PACID) Ghana is a Non-Governmental Organization (NGO) established in 2001 as a result of a desperate cry for help by parents of children with ID. It was therefore set up to lend support to children having ID in Ghana (Ghana News Agency, 2011). PACID works to improve life and conditions for children with intellectual disabilities in Ghana through awareness creation activities at local, regional and national levels (The Danish Council of Organizations of Disabled People, 2007). Autism Ghana, a foundation set up by a parent of an autistic child has also been creating awareness about autism and also provides institutional care and therapies aim at improving their skills in personal care, language, motor abilities (The Danish Council of Organizations of Disabled People, 2007). This is a clear indication that people with intellectual challenges are not well taken care of by the country leaving the burden on only the parents of these children. The Yumba special school is a government assisted school for children with intellectual challenges in Tamale with a total enrolment of about 108 children. However, anecdotal report indicates that the school is faced with many logistic and financial challenges as government grant is not frequent and woefully inadequate.

Meanwhile, Ghana passed the Disability Bill in 2006 seeking to protect the fundamental human rights of the disabled and also provide for their health, education and employment needs among others. The bill places on the state an onus to provide for free general and specialist medical care, rehabilitative operation treatment and appropriate assistive devices for persons

with total disability. It also states inclusion of the study of disability and disability related issues in the curricula of training institutions for health professionals. This is aimed at developing appropriate human resources to provide rehabilitation services and periodic screening of children for early detection and management (Persons with Disability Act, 2006). All the above sections of the bill relate to health and if implemented will benefit the disabled and their care givers immensely. Unfortunately most of the provisions of the bill have not been implemented till date.

A review of existing literature shows that many studies have revealed caregiver stress and the many factors that influence it (Gerstein et al., 2009; Gona et al., 2011; Gupta & Kaur, 2010; Hill & Rose, 2009; John, 2012). Some studies have revealed some positive experience and how successful and resilient some families have been amidst the stress (Algood et al., 2013; Davies & Honeyman, 2013; Norizan & Shamsuddin, 2010). However, most of these studies were conducted in the western world and the findings might not be applicable to the Ghanaian situation. Although, few studies have been carried out in some African countries like Tanzania, Kenya, and South Africa, the findings have indicated little success and resilience in families of children with intellectual challenges (Aldersey, 2012; Gona et al., 2011). In Ghana only one study was cited describing the experiences of mothers with children with disability. Participants for that study had children with other disabilities other than intellectual disabilities; therefore the findings may not be entirely applicable. Also the setting for that study is in the southern part of the country and may serve for comparing differences between the north and the south. Therefore, there appear to be limited literature about the care giving experience of mothers with intellectually disabled children in Ghana. This study explored the Ghanaian perspective of the experience of mothers with intellectually challenged children using the ABC-X model of family stress as a guiding framework.

1.2 Problem Statement

In most societies, mothers are considered the primary care givers based on the traditional roles they assume which often predispose them to a lot of physical, mental, psychological and economic stress (Davies & Honeyman, 2013). “Living with and caring for a child with intellectual disabilities can have clearly adverse effect on the health and well-being of parents, siblings and extended family members. For parents, having a disabled child may affect all aspects of family life, including decisions about work, education, family finances and social relations” (WHO, 2010 p.7). Coming to terms with the reality of the disability initially causes emotional turmoil on mothers. This experience may also create a sense of guilt, shame, denial, anger and other negative emotions which results in difficulty accepting the child with ID (Nurullah, 2013).

Moreover, studies have reported instances where some mothers are blamed by their husbands and/or family members for the birth of a child with a disability (Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010; Nurullah, 2013). Under such circumstances, mothers are obliged to take on total responsibility of caring for the child and are deprived of social life (Edwardraj et al., 2010). Due to the challenging behaviour displayed by most children with ID mothers hardly get spare time for themselves as all their time is spent caring for the child. Their personal interests are subordinated for their children (Brown, Geider, Primrose, & Jokinen, 2011) leaving them stressed out most often.

Social isolation and discrimination is a key issue that confronts many mothers with intellectually challenged children. Mothers described being left out from many invitation lists to social functions for fear that they may bring along their child with ID who might create embarrassing scenes (Bourke-Taylor et al., 2010). Some mothers are being abandoned by their

spouses and sometimes the whole family just because they have given birth to a child with an intellectual disability (Aldersey, 2012).

The care - giving experience can be positive and adapting when the right environment is created. However, most mothers with intellectually disabled children are faced with numerous challenges preventing them from adapting and providing the care needed for the disabled child. Children with intellectual challenges require some form of assistive care at some point.

However, healthcare systems and social welfare services in Ghana like many African countries have not provided centres for rehabilitation therapies for enhancing the abilities of these children even though by the disability act, are supposed to be provided for all districts. Where available they may be improperly managed and therefore may be non-functional or expensive to be accessed by the poor (The Danish Council of Organizations of Disabled people, 2007). As a result there is prolonged dependence on care givers (mothers) for self-care needs and a resultant high level of stress experience (Tsai & Wang, 2009).

Despite the stress involved in caring for children with intellectual challenges, there seems to be little evidence of collaboration and partnership with services and professionals. As a result, accessing services is usually labelled as cumbersome with many bureaucratic processes (Griffith & Hastings, 2013a). Also, mothers get little or no support from family, community or professionals and therefore cope alone (Griffith & Hastings, 2013a). Due to high level of care-giving demand coupled with lack of rehabilitation services in the community, mothers are compelled to learn new skills to cope with child's disability at home (Gona et al 2011). Mothers even have to improvise materials for exercises at their homes in order to maintain continuity of therapy.

Yet the vital information mothers require from health professionals to help them better care for the intellectually challenged at home is usually not provided (Davies & Honeyman, 2013). Parents are usually not informed early about the diagnosis of their child. Following confirmation of the diagnosis, parents are again not taken through counselling and education regarding what to expect, what to do, what services are available to them and where to get help, leaving them to explore the solutions by themselves. This trajectory culminates in stress especially involving the mother (Griffith & Hastings, 2013a; Tsai & Wang, 2009).

Moreover, caring for children with disability may grind down the limited resources of families in terms of cost to access services and further increase parenting stress (Norizan & Shamsuddin, 2010). Although mothers require more money to take care of treatment, training or therapies of the child, they also have reduced opportunity to work to earn income because they are preoccupied with meeting the needs of the child (Bourke-Taylor et al., 2010). This could result in frustration in mothers to the extent that they may wish the child was dead (Edwardraj et al., 2010). In some western countries like Sweden, there are free services available to the vulnerable groups and most parents also received a monthly financial grant to compensate for expenses and reduced income caused by care-taking demands. This may significantly reduce extreme stress and financial strain in families from the lowest socio-economic group (Olsson & Hwang, 2008). However such opportunities seem not to be available in Africa where most people are poor.

Meanwhile chronic stressors can wear down the body, particularly the cardiovascular, immune, and gastrointestinal systems (Miodrag & Hodapp, 2010a). Parents (especially mothers) of children with ID most often encounter severe, chronic stressors, particularly those involving child behaviour problems and extreme care giving need.

Currently, care of children with intellectual disabilities is primarily undertaken by mothers (Tsai & Wang, 2009). However ID and mothers experience have not been given the needed attention in Ghana especially in the Northern region. This is evidenced by the apparent scarcity of published information on intellectual disability. Therefore, there was the need to explore the experiences of mothers with intellectually disabled children in Tamale. This study explored the challenges of mothers, their resources, their perceptions and health outcomes of the care giving role on mothers as well as the factors which predisposed mothers to stress. The ABCX model of family stress was used as an organising framework.

1.3 Purpose of the Study

The purpose of this study was to explore the experiences of mothers with intellectually challenged children in the Tamale metropolis.

1.3.1 Objectives of the Study

The objectives of this study were to;

1. Describe the challenges of mothers with intellectually challenged children in Tamale
2. Identify the resources and coping strategies of mothers with intellectually challenged children
3. Explore the perceptions of mothers about the disability of their children.
4. Describe the impact of the child's disability on the health of mothers.
5. Identify the factors that predispose mothers of intellectually challenged children to stress.

1.3.2 Research Questions

1. What are the challenges of mothers of intellectually challenged children?

2. What are the resources and coping strategies used by mothers with intellectually challenged children
3. What are the perceptions of mothers about their children who have intellectual disability?
4. What is the impact of children's disabilities on the health of their mothers?
5. What factors predispose mothers with intellectually challenged children to stress?

1.4 Significance of the Study

The findings of the study may inform health care professionals especially nurses about the challenges faced by mothers caring for intellectually challenged children at home and the need to provide timely and appropriate information and support to family care-givers.

The department of social welfare and other organisations may also be informed by the findings of this study about the need to roll out specific interventions targeted at assisting mothers caring for intellectually challenged children to help reduce the burden.

International organisations and benevolent societies may see the need to provide or donate funds to provide and equip centres of rehabilitation for children with intellectual disabilities.

The general public may also be informed of their role in supporting families with intellectually challenged children rather than stigmatizing them.

The findings of this study hope to add to the literature on intellectual disability and family care issues in Tamale (Ghana) and also serve as a foundation for further studies.

1.5 Operational Definition of Terms

Intellectually challenged child - any person below 18 years who has deficit in learning, understanding or performing basic life skills or activities

Mother - a woman who has either given birth to, adopted or playing the motherly role to an intellectually challenged child and is directly or indirectly involved in caring for the child

Challenging behaviour/ Behaviour characteristics – actions peculiar to intellectually disabled persons e.g. being aggressive, destructive, attention-seeking, self-injurious, sexually inappropriate, noisy and hyperactive behaviours or other kinds of disruptive and socially inappropriate behaviour

Stress – a feeling of being physically, mentally, socially or economically weighed down or burdened as a result of having or caring for a child with intellectual disability

Experience – a subjective impression/ feeling of mothers with intellectually challenged children resulting from having or caring for a child with intellectual challenge.

CHAPTER TWO

THEORETICAL FRAMEWORK OF THE STUDY/ LITERATURE REVIEW

This chapter describes the theoretical framework used to guide the study and relevant literature reviewed. The ABCX model of family stress was applied to put the research findings into context. The chapter highlights some important findings in existing literature focusing on the challenges that mothers with intellectually challenged children face in the care process. The factors that predispose mothers to stress or protect them from experiencing stress; coping strategies and the perceptions of mothers about their child with intellectual disability (ID) are also discussed. Literature on the impact of the child's disability on the health of the mother has also been highlighted. The chapter concludes with a summary and identification of gaps in the literature indicating areas addressed by this study.

2.1. Theoretical Framework: The ABCX Model of Family Stress

Reuben Hill (the father of family stress theories) in 1949 developed the family stress theory to explain the crisis-proneness and freedom from crisis among families (Weber, 2010). Current family researchers continue to refine the family stress model and expand its application to a variety of family situations (Pat-Horenczyk, Brom, & Vogel, 2013). Although Hill referred to the components of the ABCX Formula in his 1949 work, he did not label the components as A, B, C, and X until 1958. The formula describes a family crises (X) as resulting from the interaction of a major stressor (A) with a family's crises-meeting resources (B) and the meaning the family makes of the event (C). The 'A' event is an external event which the family is not adequately prepared for. The hardship caused by this event is likely to differ from family to family, but are conceptualized as part of the stressor. An important aspect of the model is that the family or

individual's interpretation of the stressor and evaluation of their resources to cope with it will determine whether they will be besieged and experience a crisis (Pat-Horenczyk et al., 2013).

Weber (2010) while discussing individual and family stress described the constructs of the ABCX formula in her book as follows:

Conceptual frame work of the ABCX formula

A B . C —————> X

A. The Crisis-Precipitating Event/Stressor

Hill, (1949) used the term crisis precipitating event and stressor to mean a situation for which the family has had little or no prior precipitation and must therefore be viewed as problematic. He asserted that crises-precipitating events affect families differently based on hardships that accompany them. Hill defined hardships as complications of a stressor that demand competencies (resources) from the family. Whether or not a stressor led to hardship (and to what extent) determined whether a family defined a stressor positively or negatively. According to the ABCX formula the crisis – precipitating event or stressor interacted with the family's crisis – meeting resources.

B. The Family Crisis – Meeting Resources

Hill defined family crisis – meeting resources as factors in the family organization that, by their presence, protected the family from crisis or, by their absence, predisposed a family to crisis. In other words the resources determined the adequacy (crisis-proofness) or inadequacy (crisis-proneness) of the family. Hill accordingly, summarized the family's crisis – meeting resources from a previous study, as family integration and family adaptability (Weber, 2010).

According to the formula the crisis- precipitating event and the family's resources interacted with the family's definition of the event.

C. The definition the Family makes of the Event

According to the ABCX formula, the subjective definition the family made of the event equalled the meaning or interpretation of the event and its accompanying hardships for the family. Hill (1949) indicated that the tendency to perceive the stressor event and the accompanying hardships of the stressor as crisis- producing/-provoking versus challenging made the family more crisis-prone. The crisis-precipitating event, the individual or family's resources, and the family's perception of the event interacted to result in crisis.

X. The Crisis

In the ABCX model, a family in crisis would experience changes in role patterns and shifting expectations, resulting in reduced affectional and emotion-satisfying performance. For instance a family in crisis might experience sharp changes in the sexual area, such as in the frequency and pattern of sexual relations especially when the stressor is a loss of a child. The outcome of the interaction of the stressor, resources and perceptions can be positive and/or negative.

The model has been used for many studies involving individuals and families experiencing various stressors. Even though the ABCX model has been widely used to study family stress, it has also been used by researchers to study individual stress (Ellingsen, Baker, Blacher, & Crnic, 2013; Norizan & Shamsuddin, 2010). The model is found suitable for this study because mothers with intellectually challenged children are prone to crises. Having a child with intellectual disability is a stressor which mothers are often not adequately prepared for, which may present hardships to mothers and interact with the coping resources as well as their perception

(dispositional optimism) about the situation. This could precipitate crises with its attendant problems in mothers.

Thus, in the present study, the ‘A’ event refers to the child with intellectual disability and the associated difficulties it presents to the mother. The ‘B’ refers to the mothers’ resources and coping strategies. The ‘C’ component refers to the mother’s dispositional optimism or perception about the event of having a child with an intellectual challenge. Lastly, the ‘X’ component refers to the outcome of the interaction of the all the components above on the mother’s health and her parenting role.

2.2. LITERATURE REVIEW

This section of the chapter reviewed relevant literature on experiences of mothers of children with various forms of intellectual and developmental disabilities. A wide range of sources was consulted including books, published papers, journals, and the internet. The following databases were accessed: PUBMED, HINARI, Sage, Science Direct, Medline, and Google Scholar. Key words and phrases used in the search were mothers, children with intellectual disability, challenges, coping strategies, maternal health, factors, resources, and perception of mothers. The literature is organised according to the objectives of the study.

2.2.1. The Challenges of Mothers with Intellectually Challenged Children

Over the years, many researchers have described the experiences of parenting a child with intellectual disability (ID) as stressful and challenging especially for mothers who are the primary caregivers of children in the family (Gona et al., 2011; Hill & Rose, 2009; Norizan & Shamsuddin, 2010).

Several studies across the globe have reported that anxiety, depression and stress are major challenges confronting mothers with intellectually challenged children in many settings (Edwardraj et al., 2010; Gona et al., 2011; Olsson & Hwang, 2008). It has been reported that the stress of mothering a child with intellectual disability affects all aspects of mothers' life including mentally, physically, emotionally, socially and economically (Davies & Honeyman, 2013; Gupta & Kaur, 2010). Typically, mothers go through a lot of anxiety, depression (clinically diagnosed in some cases) and stress. In Australia, a qualitative study involving eight mothers described the first five years of the diagnosis as the most challenging period often characterized by days of excessive emotional distress described as 'dark days' or 'self pity days' (Bourke-Taylor et al., 2010, p. 131). That study further observed that care giving meant constant involvement in direct or indirect care involving advocating, organizing and planning for the needs of the child and future. In a similar study involving four mothers in Alberta, Canada, the initial period of the diagnosis was described by most mothers as characterized by shock because they never expected that their most dreamed of child would turn out to be intellectually disabled. It was further noted that taking responsibility for the child with ID may create a sense of burden and cause emotional confusion on mothers (Nurullah, 2013). The experience may create a sense of guilt, shame, denial, anger and other negative emotions which results in difficulty of accepting the child with ID (Nurullah, 2013). In Africa, a study in Kenya, reports that carers often felt that their dreams and expectations regarding the prospects of the child had been crushed by the disability as most parents invest in their children with the hope that they will help them in their old age (Gona et al., 2011).

Available literature suggests that caring for children with disability and people who are severely dependent for whatever reason is time-consuming and exhausting (Bourke-Taylor et al.,

2010; Hubert, 2011; Nurullah, 2013; Tsai & Wang, 2009). Mothers require extra energy and time to care for the special needs of an intellectually challenged child which often cause them a lot of physical stress (Tsai & Wang, 2009). For instance, all the participants in a study referred to the relentless and intense nature of taking care of the child's needs. They described it as a 'mind boggling, fulltime job 24/7' which mothers have to deal with for a long time as people with disabilities now live longer (Bourke-Taylor et al., 2010, p. 132). In addition to being responsible for meeting the needs of the child and preparing an appropriate environment for the child's healthy growth and development, parents with ID children are burdened with additional responsibility of giving medications, teaching the child skills (for performing activities of daily living) and doing physiotherapy (Nurullah, 2013). Also a child with a challenging behaviour with physical impairments may require a timetable for standing, toileting, feeding (could be gastrostomy feeding) or changing position to prevent pressure sores. Others may be hyperactive, destructive, and injurious, requiring close supervision at all times. These activities require that mothers' daily activities and homes be highly structured and organized to meet the child's needs. Consequently, mothers' freedom to pursue other interests and run other errands may be curtailed (Bourke-Taylor et al., 2010). A qualitative study in England, on perspectives of mothers of young people (15-22years) with severe intellectual disabilities and challenging behaviour revealed that most children with ID needed continuous care and attention, not only by day but also at night. In that study, this responsibility was taken by the mothers, who seemed to 'listen' in their sleep and attended to seizures, wet beds and general wakefulness. Many mothers slept at least part of the night in the same room as disabled child, some every night (Hubert, 2011, p. 218).

Stigma of the disability and social isolation are reported to be the biggest challenge among mothers (Gona et al., 2011; McNally et al., 2013). This is usually portrayed in the form of gestures such as pointing, laughing and staring, or by people avoiding the child (McNally et al., 2013). Courtesy or affiliate stigma may also affect those who are closely associated, such as members of the family, friends and even professionals that work with the person (Ali, Hassiotis, Strydom, & King, 2012). Mothers may be abandoned by their husbands due to courtesy stigma while wealthy parents may be accused of sacrificing the child's intellectual capacity for wealth (Aldersey, 2012).

In studying caregivers of seriously disabled children and their relationship with the labour market, Borst (2010) noted that mothers of intellectually challenged children encounter financial problems in relation to the care giving process. It was observed that mothers require extra money to take care of treatment, training or therapies of the child with intellectual disability, however, they also have limited opportunity to work because of the needs of the child (Borst, 2010). In similar studies, mothers indicated that the demands of care giving may require that they leave their paid jobs in order to care for the child's needs (John, 2012; McNally et al., 2013). Where the mother has no paid job, her chances of being employed are reduced because employers tend to weigh the number of working hours that will be sacrificed for care giving (Borst, 2010). As a result, mothers are faced with isolation from the job market and this may affect their quality of life, self-esteem and self actualization (Borst, 2010). At the extreme, a study reported situations in which financial difficulties have led mothers to wish for the death of the intellectually challenged child as they find the cost of treatment to be expensive (Edwardraj et al., 2010). This shows the extent of frustration and burden imposed on mothers with intellectually challenged children by economic constraints. Furthermore, most parents invest on their children for future

benefits and wellbeing (Gona et al., 2011). Parents of disabled children have to clothe, feed and meet all their daily needs without any anticipatory future gains which create in parents a sense of loss. On the contrary Norizan and Shamsuddin (2010) noted that having to care for children with disability may erode the limited resources of families in terms of cost to access services and will further increase parenting stress. However that study did not show any relationship between family financial resources and parental stress. This relationship was only speculated to be negative. Similarly, a quantitative study of families of children with intellectual disability in Sweden did not find any association between economic level and stress among mothers (Olsson & Hwang, 2008). This lack of association was attributed to availability of free services and monthly financial grant for families from low socioeconomic group (Olsson & Hwang, 2008). As a result it appears that, caring for a child with ID poses financial challenge to mothers. However the extent of the hardship varies depending on government financial support.

Furthermore, studies have indicated that having a disabled child places a strain on marital relationships. The birth of a disabled child may create tension between spouses as they tend to blame each other with mothers being the victims of blame in most cases as reported by Anum, (2011) in a study of four families with disabled children in the Dangme West District of Accra, Ghana. Divorce and separation may result when couples are unable to adjust to the pressure. In most cases fathers abandon their wives and family because of the birth of a child with a disability (Aldersey, 2012; Nurullah, 2013). Mothers in qualitative studies in India and Southern England reported being obsessed about raising the child with ID. As a result, the bond between mothers and their children with intellectual challenge is often so great that mothers tend to neglect or care less about their husbands. This may put marital relationships at risk and contribute to breakdown of relationships of family and friends resulting in social isolation (Divan, Vajaratkar, Desai,

Strik-Lievers, & Patel, 2012; Hubert, 2011). In some cases, the diagnosis may change the couple's dream of a large family either for fear that the next child might also have a disability or as a result of lack of support and stress involved in caring for the child with intellectual challenge (John, 2012).

On the contrary, however, the birth of a child with an ID can bring couples closer together as they lean on each other for support. For instance, in a qualitative study, a mother in retrospect gave account of how her husband was transformed from a quarrelsome, unreligious social drinker to a tender, God-fearing man as they sought religious sustenance following the birth of the child with intellectual challenge (Divan et al., 2012).

Accordingly, for families with other children, mothers experience anxiety and guilt about how their other children (without disability) cope since they tend to give more attention to the child with disability to the disadvantage of the normally developing children. Qualitative studies have indicated that siblings (especially female siblings) sometimes assumed responsibility of protecting and caring for their sibling with ID (Dyson, 2010; John, 2012). On the contrary, some sibling may be unreceptive of the behaviours of their disabled sibling. This can be overwhelming and distressful to mothers as they may face difficulty dealing with uncooperative siblings (Dyson, 2010).

As shown in some quantitative studies, mothers with greater level of social support experience less amount of stress (Hill & Rose, 2009; Olsson & Hwang, 2008). However studies have shown varied reactions from extended families with only few mothers getting extended family support (Anum, 2011; Edwardraj et al., 2010; John, 2012). Such support usually comes

from the mother's own family, while reactions from the husband's family (in-laws) are basically rejection of the child and the mother or ambivalence (John, 2012).

2.2.2 Resources and Coping Strategies of Mothers with Intellectually Challenged Children

The ABCX formula described the 'B' component as crises meeting resources which by their availability or otherwise protect the individual from stress or predispose them to stress. This section takes a review of literature which highlights sources of support and coping strategies employed by mothers with intellectually challenged children.

Many mothers and family caregivers in general, rely on the availability of support systems as valuable resources to help them perform their role effectively. In studying the relationship between caregiver's strain and social support among mothers of children with ID in Taiwan, Tsai & Wang, (2009) noted that the sources of social support can be formal or informal. Where formal sources of social support include healthcare professionals, social workers, teachers, social organisations, support groups and other professional organisations; and informal sources of social support include spouse, friends, relatives, neighbours and colleagues. That study further established a negative correlation between strain and social support indicating that the higher the social support the lower the level strain felt by mothers. They also found that emotional support received the highest score and informational support received the lowest score. This implies that informal sources of support which basically provide emotional support were most easily accessed by mothers in that study as compared to formal sources which provide informational and material support. Hence the spouse, family members, friends and neighbours are the commonest resources available to mothers.

The salience of the extended family system can serve as a vital source of support for mothers caring for intellectually challenged children (Aldersey, 2012). However, when the family portray lack of acceptance of the child and tend to compare the intellectually challenged child to cousins of normal development, and to either decide against having a second child or delay having a second child, they impinge on the mother's experience negatively (John, 2012). A study of perspectives of mothers of young people with severe intellectual disability and challenging behaviour in southern England reported that, in such situations (involving severe ID), kinship rights and obligations are likely to collapse. In that study, grandparents in fact disowned their grand child with disability, many parents felt that their own extended families, and people who had been their friends, instead of helping to integrate them into the community, or into their own social worlds, tended to treat them as though they were separate islands, adrift from the known wider world (Hubert, 2011). Other studies have reported a lack of support from family, friends and neighbours. Conversely, out of 10 Japanese mothers with multiple children with intellectual disabilities, 6 mothers received support from their parents, husbands, and husband's parents (Kimura & Yamazaki, 2013). This indicates that there may be variations in kinship social support across countries and ethnicities based on perceptions about intellectual disability. People relate differently to children with intellectual disabilities as well as their mothers based on their cultural perceptions. Some negative cultures characterize people with intellectual disability as bad omen labelling them with derogatory terms. However, some cultures are very receptive and mothers find their neighbours to be very supportive (Aldersey, 2012).

Studies have reported that mothers with intellectually challenged children use various strategies to deal with the challenges they encounter in the trajectory. Most of these studies have categorized the coping strategies using Lazarus and Folkman's theoretical framework on coping

mainly into problem-focused coping and emotion-focused coping styles (Gona et al., 2011; Mirsaleh, Rezai, Khabaz, Afkhami Ardekani, & Abdi, 2011; Peer & Hillman, 2012). Problem-focused coping strategies include cognitive and behavioural efforts based on problem-solving that help to change or to manage the stressful situation. On the other hand, emotion-focused coping strategies include cognitive and behavioural efforts that help the individual reduce the level of stress experienced but do not directly focus on solving the problem (Mirsaleh et al., 2011). Emotion focused or palliative (Bingham, Correa, & Huber, 2012a) coping strategies include avoidance, questioning “why,” minimizing, denial, self-blame, and wishful thinking, while problem-focused coping strategies include seeking social support, reframing, seeking spiritual support, and seeking professional support (Bingham et al., 2012a).

Findings from a quantitative study suggest that parents who used more problem-focused coping strategies experienced significantly less stress related to parenting in comparison to parents who utilized a larger proportion of emotion-focused coping strategies (Peer & Hillman, 2012a). However, another study by Mirsaleh et al., (2011) found that mothers of children with ID used the emotion- focused coping strategies more than those without ID. This was only speculated to be due to lack of training of mothers by competent health professionals. It therefore appears that preferences of mothers regarding coping strategies are varied.

Furthermore some studies indicate that many mothers of children with ID employ religious support systems to cope with their stressor (child’s disability) (Divan et al., 2012; Edwardraj et al., 2010; John, 2012; Mirsaleh et al., 2011). Mothers often turned to their respective personal faiths as a source of comfort and hope (Edwardraj et al., 2010). In other words they cast their burden onto God. However John, (2012) notes that in India, when religion is used to positively reframe the child’s disability (for example as a blessing), it may be adaptive, but when it

contributes to fatalistic or self-destructive beliefs (for example karma/destiny or as punishment for past sins), it perhaps becomes maladaptive. This area however requires further investigation as suggested.

Findings indicate that, some mothers try to dwell on the benefit of the care experience mostly through reframing as a problem-solving coping strategy (Benson, 2010; Bingham et al., 2012a). Reframing occurs as an individual responds to a situation by emphasizing its positive aspects over the negative ones (Benson, 2010). Accordingly, such positive perceptions promote adaption and reduce stress (Nurullah, 2013). In addition to reframing, all six mothers in a qualitative study are reported to have sought professional support by asking questions and demanding explanations so that they could either be reassured or instructed on how to help their children. They also aggressively researched to be informed about the specific diagnoses, possible therapies, and general disability information regarding their children both at the initial stages and as ongoing activity (Bingham et al., 2012a).

In Kenya, Gona et al (2011) report that due to the demanding nature of care giving and the lack of rehabilitation services in the community, mothers had to learn new skills to cope with child's disability. They even improvised materials for exercises at their homes in order to maintain continuity of therapy. It is however consoling to know that in that study, some mothers were able to get external support in the form of materials from Non-governmental Organizations (NGOs), charitable organizations and sometimes individuals who support caregivers by providing wheelchairs and food. They also sometimes assist in paying treatment bills for children (Gona et al., 2011).

Some mothers with intellectually challenged children find sharing experiences through self-help groups or mother-to-mother support groups or peer group as beneficial as they realize that they are not alone. These groups may be organized by professional as part of early intervention measures or without any professional input (Bingham et al., 2012a; Tsai & Wang, 2009).

2.2.3. Perceptions of Mothers about Their Intellectually Challenged children

Although perception or how one defined a stressor has been identified by Hill, (1958) to influence the person's ability to deal with it in order to prevent crises, there appears to be limited literature on mothers' perception about their children with disability.

Dispositional optimism which refers to an individual's general positive expectation about the future was found to be significantly related to positive parenting of mothers in a study. Mothers with high optimism engaged in more positive parenting, showing more affection and love to the child (Ellingsen et al., 2013). In a quantitative study in South-eastern Michigan involving 127 parents or primary caregivers (96 females), a regression analysis established a significant relationship between optimism and stress which suggests that having an optimistic personal disposition is very important for parents to avoid the stress associated with providing care to their child. The authors speculated that having a positive outlook on life allows caregivers to see the benefit and joy of having a child and to avoid dwelling on the potential negative aspects of parenting an individual with an intellectual disability (Peer & Hillman, 2012a). Similarly, Scharer et al.,(2009) who studied mothers of children under 12 years with various mental and developmental disorders interacting with web-based or Telephone-based support nurses reported that mothers found positive and affirming characteristics in their child despite the difficulties and regardless of the emotional strains felt, the joys they felt with their children apparent.

On the contrary, Griffith & Hastings, (2013a) reported in a meta-synthesis of 17 studies reviewed that, carers expressed great fear and anxiety about care of their family member in future when they (carers) are no longer there. They further reported that carers feared that their family member may become a target for sexual assault, not loved as an individual or heavily drugged to control their challenging behaviour. Though they had low expectations, they had high hopes for their family member's future care.

While mothers of children with ID in Sweden describe negative emotions in relation to the child and the disability, they also describe positive emotions that seemed to balance the negative experiences (Boström, Broberg, & Hwang, 2009). Viewing the child as a blessing and blaming one's own or child's destiny had religious connotations and may constitute adaptive or maladaptive belief depending on which side one belongs (John, 2012). Similarly, Nurullah, (2013), reported that some mothers perceive the intellectually challenged child as a burden and may even question why God has burdened them with a child who is intellectually challenged. Ironically, with time parents tend to appreciate their children for who they are. That study also found that parents were generally not very positive about expectations of their children, developing as responsible adults in the future with regards to career, independence (Nurullah, 2013). In a similar study, all participants appear to have accepted the child with the disability and had stopped seeking for cure. A mother categorically stated that “..... acceptance comes by knowing”(Aldersey, 2012, p. 5). She expressed further that health professionals around at birth (doctors, midwives) are not trained to counsel mothers when a child is born with a disability. Mothers in that study advocated that early adequate counselling would provide parents with knowledge about the disability thereby fostering their ready acceptance of the children and their disability (Aldersey, 2012).

Mothers perception about causes and nature of intellectual disability may influence their experience in caring for these children (Edwardraj et al., 2010). In India, mothers attribute medical causes for the intellectual disability to three primary factors: (1) medications taken during pregnancy; (2) fever, illness and seizures; and (3) poor antenatal care (Edwardraj et al., 2010). In the same study, consanguineous marriage (marriage between people related by blood or of same ancestral origin) was also perceived as a cause by many of the participants, while others felt that inadequate medical supervision during delivery might have caused the problem. In addition to these, psychological, environmental and genetic causes were also considered. Blame and guilt are often associated with these perceptions. On the nature of the problem, mothers had mixed opinions. Those undergoing parent training however, were able to report clearly, the fact that, treatment would bring about improvement, whereas others who were not undergoing any training felt that the child would be completely alright when he grows up (Edwardraj et al., 2010).

However, in Kenya, Gona et al., (2011) report that disability is associated with cultural beliefs and superstition such as evil spirits, punishment from God or witchcraft. They speculated this could possibly explain the aspect of people spreading rumours about parent with ID children. Some mothers who may be ignorant of the nature of the problem aggressively search for cure and in doing so those who are educated may explore scientific and Western cures while those not educated use traditional beliefs, witchcraft, and religion as reported in Tanzania (Aldersey, 2012). Mothers are found visiting prayer camps and attending healing crusade or moving from one traditional healer to another in the bid to find cure for their child's disability. However, mothers later accept the children when they fail to find a solution (Aldersey, 2012; Gona et al., 2011).

2.2.4. Impact of the Child's Disability on the Health of the Mother

The World Health Organization defines health as a state of complete physical, mental and social well-being and not merely the absence of a disease or infirmity (WHO, 1946). Today, we continue to strive for this utopian state regardless of all impediments. Reaching a state of healthy wellbeing may prove extremely hard when parenting a child with special needs. The characteristics of the child, of one's own feelings and expectations and varying support system (both formal and informal) all contribute to the state of wellbeing.

It is empirically known (Miodrag & Hodapp, 2010a) that chronic stressors can wear down the body, particularly the cardiovascular, immune, and gastrointestinal systems. Furthermore parents (especially mothers) of children with intellectual or developmental disabilities more often encounter severe, chronic stressors, particularly those involving child behaviour problems and extreme caregiving needs. Chronic stress has the ability to permeate various body systems and create a susceptibility to disease, illness, and poor health. Moreover, there seems to be a ripple effect, whereby, chronic stress disturbs multiple systems causing more damage to overall health. Also, frequent activation of the stress response adversely affects physical and mental health (Miodrag & Hodapp, 2010b).

Studies have reported mental and physical health problems in mothers with intellectually challenged children. Poor physical health of mothers has been attributed to exhaustion surrounding the daily hassles in meeting the needs of their children in addition to other family roles (Davis et al., 2010; Mackey & Goddard, 2006). In addition to this, mothers also experience sleep pattern disturbances due to waking up frequently to attend to the needs of the child (Kerri & Gemma, 2013).

A study in England found that mothers of children with developmental disabilities had higher systolic blood pressure over the day compared to control mothers indicating poor cardiovascular functioning and increased risk for cardiovascular diseases (Gallagher & Whiteley, 2012). That study also found poor immune and neuroendocrine function among mothers of children with developmental disability relative to control mothers as supported by other studies (Lovell, Moss, & Wetherell, 2012). It was therefore inferred that mothers may be at increased risk of future health problems through physiological vulnerability (Gallagher & Whiteley, 2012). Similarly, in America, the prevalence of arthritis, high blood pressure, obesity, and activity limitation was significantly higher for aging female family caregivers than for their counterparts in the general population (Yamaki, Hsieh, & Heller, 2009). In addition, middle aged female caregivers reported higher prevalence of diabetes and high blood cholesterol level than women of same age group in the general population (Yamaki et al., 2009).

On the other hand, factors affecting the mental health of mothers with intellectually challenged children have been identified as mainly stress, anxiety, and depression (Gupta & Kaur, 2010; Olsson & Hwang, 2008). Studies have indicated that mental stress is significantly higher than physical stress among mothers with intellectually challenged children (Gupta & Kaur, 2010). For instance in a study mothers described experiencing clinically diagnosed depression and suicidal tendencies and had to be put on psychiatric medications for several months (Bourke-Taylor et al., 2010).

A qualitative study aimed to explore the quality of life (QOL) of parents of children with cerebral palsy reported that some parents rated their QOL to be good which they attributed to their personality, the amount of support they receive, and their attitudes. On the other hand, other parents reported poor QOL as all their time is spent on caregiving with little or no support (Davis

et al., 2010). Some quantitative studies have found strong association between maternal depression and the child's characteristics, maternal coping resources and availability of support.

Apart from physical and mental health problems, mothers of intellectually challenged children also experience changes in their social relations with their spouses, family and friends. This mostly results in social isolation (Davis et al., 2010).

2.2.5. Factors that Predispose Mothers of Intellectually Disabled Children to Stress

Many factors have been identified by different studies that predispose mothers with intellectually disabled children to stress. Of particular interest is the broad categorization by Algood, Harris, and Hong, (2013) in their ecological systems analysis. They classified factors that influence parenting success into “micro- (parenting practices, parent-child relations), meso- (caregivers' marital relations, religious social support), and macro-systems (cultural variations, racial and ethnic disparities, health care delivery system)” (Algood et al., 2013, p. 128). In partial support of the micro system factors, Nurullah, (2013) using interpretive description of qualitative data, reports that some parents change their style of parenting from traditional to a unique style to accommodate the needs of their child with a the disability. That study emphasized that stress may result if the parenting style adopted is inappropriate in containing the child's behaviour characteristics (Nurullah 2013). Similarly, some quantitative studies have identified significant evidence of association between each of maternal adaptive or coping behaviour and child behaviour difficulties and the stress experienced by the mother (Hill & Rose, 2009; Norizan & Shamsuddin, 2010). For instance, mothers with higher levels of parenting satisfaction, [which was measured by the Parenting Sense of Competence Scale (PSOC-S)] had lower levels of parenting stress in Hill and Rose's study while maternal depression and lack of acceptance were significant predictors of parenting stress rather than child's behavioural problem in the

study by Norizan and Shamsuddin. Additionally, the characteristics of the child also influence parent's perception and description of the child as some children especially those with Down syndrome are generally known to be sociable and fun to be with (Grein & Glidden, 2014).

Ellingsen et al., (2013) in studying resilience parenting of preschool children at developmental risk found that low family income as well as child developmental delay and high child behaviour problems were risk factors related to less positive parenting. They also found that mother's education and optimism were personal resources which served as protective factors to parental functioning and that mothers with more education engaged in more positive parenting at higher levels of risk than mothers with less education. These finding suggests that education and high family income are important variables in reducing the burden of caring for a child with ID whilst increasing resilience. Apart from that, it has been established that education empowers women to be able to defend their rights or stand up against any unfair treatment from their husbands or society in general (Mendel-Anonuevo, 1995).

In line with the meso-system factors as mentioned above, Hill and Rose, (2009) referred to the social support as environmental characteristics and identified an association between social support and parenting stress in their study. Mothers with greater levels of social support experienced lower levels of parenting stress as a result of informal kinship and social organisations (Hill & Rose, 2009). Similarly, studies have reported higher parenting stress among single mothers than mothers living with a partner (Norizan & Shamsuddin, 2010; Olsson & Hwang, 2008). Therefore it appears that social support is a very important influential factor of maternal stress.

As a macro-system factor, studies have reported the important role health care delivery system and its collaborators have to play in alleviating maternal stress in mothers with intellectually challenged children (Davies & Honeyman, 2013; Gona et al., 2011). For instance studies have emphasised mothers' need for information, training and practical support to fulfil their caring role effectively while maintaining the wellbeing of the family unit (Gona et al., 2011; Davies & Honeyman 2013). Unfortunately most services are reported to be difficult to access and retain, and variable in quality. Mothers highlighted that getting access to services required a huge effort owing to little or no collaboration and coordination of services for children with intellectual disability (Griffith & Hastings, 2013a). Participants interviewed in a study indicated that carers visit health facilities with their disabled child, but the reception accorded them in these facilities are not to their expectations. Furthermore, carers experience frustration as they are detained in hospital wards without any medical attention or advice. In addition, carers sometimes left the hospital without proper discharge procedures. This attitude from the hospital staff was speculated to result in most carers patronizing traditional healers rather than a hospital clinician (Gona et al., 2011, p 183).

Apart from the health system, the structure of the educational system may also not adequately meet the needs of the children and their parents as reported by a study in Canada by Dyson (2010) where parents had a negative relationship with the school system as a result of unsatisfactory encounters which included incompetent initial assessment, uncoordinated service delivery, labelling, and rejection of the child. Such conditions rather add to the stress of parents instead of relieving them as expected.

Gona et al, 2011 again observed that because of poverty mothers become handicapped in providing optimal care to the children. All the external resources available to facilitate good

caring practices are reduced by poverty. The data reveal a lot of difficulties among carers in meeting basic needs like food, clothing, fees and money for drugs.

However, there appear to be limited literature on the relationship between racial or ethnic disparities as a macro system factor and predisposition to stress among mothers with intellectually challenged children

In summary, studies reviewed so far have shown that mothers with intellectually challenged children encounter numerous physical, emotional, economic and social hardships from the trajectory of caring for the child (Edwardraj et al., 2010; Nurullah, 2013). Several studies have identified factors ranging from child factors, maternal factors, family, sociocultural and religious support factors as having important influence on the positive and negative experience of this trajectory (Algood et al., 2013; Bourke-Taylor et al., 2010; Edwardraj et al., 2010; Gona et al., 2011; John, 2012; Olsson & Hwang, 2008). It has also been reported that the health of mothers with intellectually challenged children could be affected in many ways as they suffer depression, anxiety, physical conditions and emotional stress (Davies & Honeyman, 2013; Miodrag & Hodapp, 2010a; Nurullah, 2013). However, literature in this area is limited in scope. Most mothers hold different perceptions about their intellectually challenged child. While some mothers view the child as a burden, a punishment from God, others see them as God's gift, and dwell in their abilities hence promoting acceptance. Also the coping strategies often employed by mothers with intellectually challenged children have been identified to include emotion focused coping strategies (avoidance, questioning "why," minimizing, denial, self-blame, and wishful thinking) and problem-solving coping strategies (seeking social support, reframing, seeking spiritual support, and seeking professional support) (Bingham et al., 2012a). There is a need for

investigations into beliefs and perceptions of Ghanaians about intellectual disability and the coping strategies they employ.

It is obvious that the literature portray a negative experience among mothers with few reports of positive experiences. Literature regarding the impact of having a child with ID on the health of mothers with intellectually challenged children is limited in scope with emphasis on mental health and little on physical and social health of mothers.

Moreover, all the studies that have been reviewed were conducted in countries abroad particularly in the western world with a few studies in Africa. Only one study was cited from Ghana (Anum, 2011), which is a qualitative study conducted in southern Ghana.

It is therefore apparent that mothers' experiences with children with intellectual disability have not been well investigated in Ghana. Also, though few of the studies reviewed applied the ABC-X family stress model, they employed quantitative approach in answering their research questions. Therefore, the present study employed a qualitative approach to explore the experiences of mothers with intellectually challenged children in the Tamale metropolis of northern Ghana.

CHAPTER THREE

METHODOLOGY

In this chapter, the research design and methods used to conduct the study are explained. The setting where the study was conducted is described as well as the various techniques used to select the sample, collect and analyse the data. The chapter also presents strategies employed for methodological rigour and ethical clearance.

3.1. Research Design

This study employed qualitative exploratory- descriptive design in answering the research question “what are the experiences of mothers with intellectually challenged children?” The general aim of qualitative studies is to understand the experiences and attitudes of a particular group of respondents. These methods usually aim to answer questions about the ‘what’, ‘how’ or ‘why’ of a phenomenon rather than ‘how many’ or ‘how much’, which are answered by quantitative methods (Bricki, 2007). This approach was chosen based on the nature of the of the research question. Also, the topic is a relatively new phenomenon which has not been extensively studied especially in Ghana. Therefore, using this approach afforded the researcher an opportunity to elicit thick descriptions of the subjective experiences of mothers with intellectually challenged children and also gave insight into the phenomenon.

3.2. Research Setting

The study was conducted within the Tamale metropolis in the northern region of Ghana. It is one of the six Metropolitan Assemblies in the country and the only Metropolis in the Northern part of Ghana. Tamale Metropolitan Assembly (TaMA) has 3 sub metros comprising Tamale Central, North and South. The TaMA is one of the 26 districts and is located in the centre of the

Northern Region sharing boundaries with Savelugu- Nanton to the north, Yendi Municipal Assembly to the east, Tolon-Kumbungu to the west, Central Gonja to the south west and East Gonja to the south. The Metropolis has a total population of 371,351 with a projected 2.9% regional growth rate from the 2010 census. The Northern Region has the largest land mass in Ghana. The Metropolis has a total estimated land size of 750 km sq which is about 13% of the total land area of the Northern Region.

Tamale metropolis is the administrative capital for the Northern Region of Ghana. The predominant ethnic group is Mole-Dagbon with Dagbaane as the main language. However, urban Tamale has a high number of settlers from other regions. The indigenes are predominantly Muslims (84%). Christians constitute 13.6% (with Catholics forming 43.7%), traditional worshippers constitute 1.6%, and others form less than 1%. Agriculture, hunting and forestry are the main economic activities. 83% of the economically active group are in private informal sector, 11.5% in private formal sector whilst 4.3% are in public sector. Polygamy is a common practice of the people with functional extended family systems. The health needs of the people are provided for by a Teaching hospital, two Regional hospitals, Christian health facilities and private hospitals and clinics. There are two drop-in facilities for psychiatric patients; Tsi-sampaa run by 'basic needs', a Non-Governmental Organisation (NGO) and Shekina, run by a private practitioner. These also serve as referral points for treatment of psychiatric conditions associated with children with intellectual disabilities. Apart from these drop - in facilities, the health conditions of children with intellectual disability are handled by the mainstream health facilities.

The metropolis also has a total of 598 public basic schools including 1 special school ('Yumba' special school) with a total enrolment of about 102 children with various forms of intellectual disabilities. The school was established in 2003 by Mrs. Georgina Nuagah, an

educationist, who is currently the head-teacher of the school. The school which started from a garage at the resource centre for people with disabilities with 8 children with intellectual disabilities has evolved to its current status through the benevolence and hard work of the founder and her associates. The school is the only one of its kind in the metropolis. It is currently a government assisted school with 11 trained teachers and 3 untrained teachers, as well as 13 non-teaching staff including an accountant, an administrative secretary, a storekeeper, a labourer, 2 cooks, 1 pantry, 2 cleaners, 2 drivers, and 2 watchmen for day and night.

The children are taught daily life skills, communication skills and vocational skills like weaving of doormat, tie and dye, sewing, car wash, and cooking, to enable them live as independently as possible within their families and society. The school is located at the south-eastern part of Tamale along the Tamale-Yendi road. It is a day school running from Monday to Friday with only five classrooms and an office which are poorly furnished and not enclosed by a fence. The school has a kitchen which is a partly enclosed structure erected from mud and wood and roofed with zinc from where the children are given breakfast and lunch each day. The school has two mini- buses which convey children at designated locations in the metropolis to and from school each day.

Anecdotal evidence indicated that mothers of children with intellectual disability in Tamale, do not openly associate with their children with the disability and this posed a challenge to recruitment of participant for this study. Therefore the Yumba Special School which is the only Special School for children with intellectual disability in the Northern region served as a source of contact with participants.

3.3. Target Population

The target population was all mothers with intellectually challenged children whose children attend Yumba Special School in Tamale.

3.3.1. Inclusion Criteria

The study included biological and foster mothers of intellectually challenged children of Yumba Special School who consented to participate in the study. The study also included only mothers who could speak at least Dagbaani, Mampruli, Dagare or English.

3.3.2. Exclusion Criteria

Mothers with intellectual disability or poor mental health were excluded from the study.

3.4. Sample Size and Sampling Technique

The sample size for the study was determined by data saturation. Saturation according to Polit & Hungler, (1999) is when the researcher perceives an end because no new information is elicited. Data was considered to be at the point of saturation when the researcher noticed repetition in the responses with no emerging new information or responses. On this basis, the sample for the study consisted of twelve (12) mothers. The study used purposive or judgemental sampling method to select participants for the study. In purposive sampling (which is symbolic with qualitative studies) the researcher decides what purpose he or she wants informants to serve, and then goes out to find some (Russell, 2006). This method enabled the researcher to intentionally recruit mothers with intellectually challenged children who gave in-depth information that elicited their lived experiences.

3.5. Data Collection Tool

In collecting the data, in-depth face- to- face interviews were conducted using a semi-structured interview guide. The interview guide contained open-ended questions which were developed based on the objectives of the study, literature review and the constructs of the model being adopted as the guiding framework for the study. The interview guide was divided into two sections. The first section mainly collected demographic data while the second section consisted of main questions and probes.

The interview guide was pretested with two mothers with intellectually challenged children attending Yumba Special School in Tamale, one in English and one in Dagbaane. This was to ensure clarity of the guiding questions. The results also helped the researcher to fine tune the questions. The pilot interview also offered the researcher an opportunity to practice and improve her interviewing skills and that of the translator who was trained to conduct some of the interviews. The data collected during the pre-test was later added to the study since there were no significant amendments to the tool after the pre-test. Also, it became difficult to find participants prior to data saturation.

3.6. Procedure for Data Collection

Ethical approval was sought from the Institutional Review Board of Noguchi memorial institute for medical research. Following this, a formal permission was sought from the Yumba Special School with an introductory letter from the School of Nursing, University of Ghana, stating the purpose of the study as well as a copy of an ethical approval. When permission was granted, the headmistress of the school selected two teachers who helped to cross-check records of some pupils for their addresses and contact numbers of their parents. A pre- interview meeting was held with the teachers to brief them on the purpose of the study. They were also provided

with a sheet which spelt out the purpose of the study. Following this, the teachers provided the researcher with a list of contact numbers of mothers of some children and also opted to pre-inform some mothers especially the educated ones before I could contact them. This was to avoid the possibility of mothers having the impression that the school was disclosing their personal information without their permission. The researcher contacted the first mother on phone, explained the purpose of the study to her and sought her verbal consent and a meeting scheduled. All other respondents were recruited through the same process. The researcher met and interacted with suitable participants to create rapport and to further explain the purpose of the study. The participants were also informed that participation in the study was strictly voluntary, and they had the right to opt out of the study at any point without suffering any form of penalty or mistreatment of the child at school. Participants were also informed that the period of interaction would last for about 2 to 3 months as they could be contacted after the interview for further clarification or verification of their responses in the course of the study. When participants agreed to participate, interviews were scheduled. The venue, date and time for each interview was determined by the participants but agreed by both researcher and participant. Participants were made to sign or thumbprint on two consent forms prior to commencement of the interview. The participants kept one consent form while the researcher kept the second one for future eventualities and as part of an audit trail. The interviews were conducted in the language that both the participant and researcher or translator could speak fluently. In all, three languages were used, English, Dagbaani and Dagaare. The researcher trained a translator to conduct the interviews in Dagbaani since she is not fluent in speaking most of the northern languages but can understand a few. The translator also transcribed these interviews into the English language verbatim. However the researcher listened to the tapes and crosschecked with

the transcripts to ensure accuracy in the transcription since she could understand Dagbaani but could not speak fluently. The interviews lasted between 30 to 60 minutes per session. The interviews were audio-taped with permission from participants. Responses were probed or redirected when necessary to maintain focus. The researcher also kept detailed field notes of the environment, nonverbal cues, interruptions, personal reflexions about observations made during the interviews among other things. Data collection started on 15th October, 2014 and ended on 16th February, 2015.

3.7. Data Management and Analysis

In qualitative studies, data analysis begins even before data collection and is a continuous process (Russell, 2006). In this study, data was analysed concurrently with data collection. The volumes of data that were generated from the study were manually coded and analysed by the researcher. The interviews were audio taped, played back repeatedly and transcribed verbatim after each interview. This enabled the researcher to determine areas which needed to be probed in subsequent interviews. Interviews conducted in the local languages were transcribed in English language by the researcher (if in Dagaare) or the translator (for those in Dagbaani). This was to avoid distortion of the data. Audio tapes were later played back for amendment of the transcripts where necessary before analysis begun. The field notes containing date, time, and venue of entry of all observations, interruptions recorded during the interviews were integrated during the transcription. A separate file is being kept for each participant. All names of participants and their children were replaced with pseudonyms. Each of the transcribed interviews was coded according to the order in which interviews were conducted, labelled and saved in a folder on a personal computer with a password known only to the researcher and on an external hard drive as back up. Consent forms and materials containing identifiable information

have been separated from the transcribed data and saved separately. These and all other documents (hard copies of transcripts, external hard drive and audio tapes) have been safely kept in a locked cabinet and will be kept for at least five years accessible to only the researcher and her supervisors.

The researcher employed thematic content analysis as a methodological tool to analyze the data. Thematic Content Analysis (TCA) is a descriptive presentation of qualitative data (Anderson, 2007). This method involves looking across all the data to identify the main themes that summarize all the views you have collected (Anderson, 2007). In applying this process, the researcher first read and re-read the transcripts in order to familiarize with the data. The researcher then identified and grouped the data units or statements under the predetermined themes which are based on the constructs of the model guiding the study. This was done for all interview transcripts. All other data which could not be categorized under any of the themes was content analysed into new themes or categories. The researcher discussed the analyses of the first two interview transcripts with her supervisor before subsequent interviews and analysis. Discussion with supervisor continued until all the data had been analysed. This was to ensure that data had been exhaustively and exclusively placed under the right themes or categories.

3.8. Methodological Rigour (Trustworthiness)

Rigour in qualitative research refers to the extent to which the researcher is able to justify that the study's findings and interpretations truly reflect participants experience and are reliable. Krefting, (1991) describes Lincoln & Guba's (1985) concepts of trustworthiness (credibility, transferability, dependability, and confirmability) and suggested strategies that researchers could use to enhance the worth of their study.

3.8.1 Credibility

Credibility or the truth value in qualitative research is obtained from the discovery of human experiences as they are lived and perceived by the informant. It estimates how confident the researcher is with the truth of the findings based on the study design, informant and context (Krefting, 1991). To achieve credibility in this study, the researcher engaged in prolonged engagement by spending 3 months in the field collecting data. Twelve participants were interviewed and by the twelfth participant, data had saturated. Also each of participants was engaged in about 30-60 minutes period of interview and observation and data from both interviews and observations integrated during analysis for the purpose of triangulation. The researcher employed 'reflexivity' which is the influence of the investigators own background, perception and interest on the quality of the research process (Krefting, 1991 p. 218). The researcher was conscious of her own perceptions and prejudice about disability and how these could influence the study. These included the fact that the researcher is a nurse and a mother who has lived in the research setting for over fourteen years and has witnessed some negative attitudes of colleagues and community members towards children with intellectual disability and their mothers. However, through reflexivity these preconceptions were made bare and never influenced the research process. The researcher's supervisors also provided concurrent audit of the study using audit trails that were provided by the researcher.

3.8.2 Transferability

Transferability is the criterion against which the applicability of qualitative data can be assessed (Krefting, 1991). Transferability refers to the ability of the research findings to fit into similar contexts outside the study situation. To ensure transferability, the researcher has provided adequate background information about the respondents, the research context and setting to

allow others to assess how transferable the findings are (Krefting, 1991). The researcher has also kept an audit trail of all the events and procedures in the study. However, the particular group that has been studied may not exactly relate to other mothers with intellectually challenged children in similar context and hence findings and conclusions may not be applicable in all cases.

3.8.3 Dependability

Dependability concerns the degree to which the results of the study are consistent or replicable with the same subjects or in similar context. To ensure that the findings and conclusions are dependable, the researcher closely worked with her supervisor throughout the study and also kept audit trail of all the events and procedures followed in the study. The researcher used the code and recode procedure in analyzing the data. This procedure requires that, after coding a segment of data, the researcher should wait at least 2 weeks and then return and recode the same data and compare the results. The researcher has also provided detailed description of the research design, procedures used in collecting and analyzing the data, and background information on respondents.

3.8.4 Confirmability

In order to establish confirmability the researcher has kept an audit trail of audiotapes, field notes, transcripts, interview questions, consent forms and all other relevant information and documents regarding the study. These will be made available for any future auditing of the study for confirmatory purposes. The researcher also worked closely with her supervisor who has provided concurrent audit throughout the entire research process.

3.9 Ethical Consideration

This study commenced after ethical approval was given by the Institution Review Board (IRB) of Noguchi Memorial Institute for Medical Research. Permission was also sought from the Yumba Special School with an introductory letter from the School of Nursing, University of Ghana and a copy of the ethical approval from Noguchi. Principles such as consent procedures, ensuring confidentiality, privacy, risk and benefit were followed. The researcher explained the purpose, objectives and potential benefits and risk to participants in their preferred language and gave them ample time to decide on their participation. They were also made aware that interviews will be recorded in tapes. Participants who agreed and met the inclusion criteria for the study were asked to give their consent by signing or thumb-printing two consent forms. Respondents were made aware of their rights to opt out of the study even after signing the consent form without any consequences. The participants were also informed that the data will be used only for the purpose for which it is collected and will be accessible to only the researcher, her supervisor and a translator.

Anonymity was ensured by assigning pseudonyms to each participant during recruitment which was subsequently used on all notes and transcripts. Pseudonyms were also used to replace names that were mentioned during the interview and later in quoting verbatim expressions from participants. Participants were assured that they would not be linked to the information they provide without their permission. The researcher was cautious in asking emotion laden questions. Participants were comfortable with the questions asked and so none was referred to the counselor who was engaged for any eventualities. Participants were made aware that the data, consent forms, audiotapes, transcripts and all other documents will be kept safely for at least five years after the study. They were informed that ethical clearance will be sought if the data is to be used

for any other purpose in future. The participants were assured of anonymity during publications of any aspects of the study. The researcher intends to share findings with participants through debriefing in order to get all participants together to form a self help group. Participants were provided with a snack as a compensation or honorarium for their time and efforts.

CHAPTER FOUR

RESULTS/FINDINGS

This chapter mainly presents the findings of the study. Five (5) major themes emerged based on the constructs of the ABCX family stress model and contextual analysis of the data. These major themes include: Caring for an intellectually challenged child, crises-meeting resources, the meaning mothers make out of having a child with intellectual challenge, the outcomes and predisposing factors to stress. These themes are described with supporting quotes from the interviews. The demographic characteristics of participants are presented first, followed by the themes.

4.1 Demographic Characteristics of Study Participants

In all, twelfth (12) mothers participated in the study comprising eleven (11) biological mothers and one (1) foster mother. All mothers had one child who is intellectually challenged except one mother who had two children with intellectual disability. The ages of the mothers ranged from 38 to 61 years with six (6) being 50 and above, and six being below 50 years. The mothers had different educational backgrounds. Most (6) of the mothers had tertiary education with a few (3) JSS leavers and the rest (3) with no formal education. Also, majority (4) of the mothers interviewed were teachers, three (3) in active service with one is retired, an agric worker, a midwife and a few (4) working as cleaners in schools, hospital or city cleaners. Apart from these, some of the mothers also engaged in private businesses and menial jobs or petty trading to support their main work. Their income levels ranged between a minimum of fifteen Ghana cedi (GH¢15) to one thousand five hundred Ghana cedi (GH¢ 1,500) with majority (7)

earning below five hundred Ghana cedi (GH¢ 500) and a few (3) earning above one thousand Ghana cedi (GH¢ 1,000). The rest (3) earned between GH¢500- GH¢1000

All the mothers understood and spoke Dagbani. Majority (7) were fluent in English language with a few (3) who could neither speak nor understand English. Two (2) mothers could understand but not speak English. In addition, all participants live within the Tamale metropolis and are Ghanaians by nationality. Religions professed by participants were mainly Christianity (7) and Islam (5).

Most (7) of the mothers were married and living with their husbands, a few (3) widowed and a few (2) divorced or separated from their husbands. They also had between 1 and 8 children with most (8) mothers having 5 and below. The rest (4) of the mothers had 6 children though some had more than 6 children but lost either one or two to death. The children were aged between 8 and 28 years with majority (9) between 18 and 28 and a few (4) below 18.

4.2. Organization of themes

The findings have been categorized according to the constructs of the ABCX model of family stress and presented in line with the objectives of the study. Four main themes emerged based on the model with eleven sub-themes. The sub-themes were identified from participants' subjective descriptions of their experiences. One other major finding; predisposing factors to stress, emerged contextually from the data with four sub-themes. However, it is also in line with the objectives of the study. In all, the findings have been categorized into five (5) themes with fifteen (15) subthemes. Details of the themes and sub-themes are presented in table 4.1 below.

Table 4.1: Themes and Sub-themes from Transcribed Data

THEMES	SUBTHEMES
1. Caring for a child with intellectual challenge	<ul style="list-style-type: none"> ▪ Physical challenges ▪ Financial challenges ▪ Work challenges ▪ Emotional challenges ▪ Social challenges
2. Crises meeting resources	<ul style="list-style-type: none"> ▪ Support systems ▪ Coping strategies
3. Meaning mothers make of the event	<ul style="list-style-type: none"> ▪ Optimism/positive emotions ▪ Negative emotions ▪ Perceptions about the causes
4. Outcome (Crises)	<ul style="list-style-type: none"> ▪ Maternal health outcomes
5. Factors that predispose mothers to stress	<ul style="list-style-type: none"> ▪ Child characteristics ▪ Maternal characteristics ▪ Access to social support ▪ Unmet Expectations

4.3 Caring for a Child with Intellectual Challenge

Having and caring for a child with intellectual disability is a stressor which brought along many hardships or challenges to mothers of such children. The mothers experienced challenges in five forms or areas: physical, financial, work, emotional and social challenges or difficulties.

4.3.1 Physical challenges

Physical challenges of mothers were experienced in various forms. The commonest of which was the difficulty in training the child to be able to independently carry out self care activities or activities of daily living ranging from feeding, to bathing and toileting appropriately. Most mothers shared that the children were very slow in learning and also not willing to learn in some cases, so they had to persuade them or allow them to learn when they are ready. Joyce recounts that:

“.....even though we are teaching him it’s not easy, for them if they are not ready to learn anything you just leave them and come another time and they will do it . So he is slow”. **(Joyce)**

Angela also shares her story:

“But whilst he was growing, I was training him to wash his own things because he will wee-wee and poopoh there. Because of that I brought the other children too so that they will be helping me. He didn’t want to learn anything because of the brain issue. When you ask him to wash he will just be at one spot. Even to wash his face it was a problem he couldn’t wash.”
(Angela)

This difficulty was partly due to lack of knowledge and information about the nature of the condition of the child and its management as most mothers confessed that they were not told anything about the child’s condition before being discharged from the hospital. Some said they were only advised to send the child for herbal treatment.

“... the nurses when they speak their English you can't understand and the convulsion they didn't explain what happened or tell us anything.” (Mpaga)

“No no, nobody mentioned anything, even though I knew that she was sick, but how long was it to be with her, how soon was it to finish so that was my only worry for the first time but later on when it stopped like that, I took it in good faith.” (Charity)

“No they didn't tell me anything. They discharged us and only told us to go and look for herbal treatment.” (Mary)

Apart from that, most mothers expressed that they had to deal with the excessive care-giving demands of their children often comparing them to normal children of their age regarding the level of dependence the children had on them. They mentioned that even at their ages (most of whom above eighteen years) they (mothers) did almost everything for them because the children could not do anything for themselves. They had to feed them, bath them, dress them, brush their teeth, wash their cloths, cook several times in a day because they eat too much and many more. The following narratives by three mothers depict the level of care - giving burden experienced:

“And she can't do anything for herself, I do everything for her. I bath her, I feed her because sometimes she refuses to feed by herself so and you want her to eat so what will you do, you have to feed her, even when she agrees to feed by herself, I have to place something like a napkin around her neck if not she will mess up her dress”. (Ewurama)

“..... I get pepsodent on a brush, put him on my labs and brush his teeth, bath him, and fetch koko for him to take.” (Mary)

“As for the difficulties, they eat a lot, they eat a lot, because of the drugs, we have to make sure we cook morning, afternoon, and evening; even if there is no food we have to put something down for him.... Even upon all that he will still go somewhere and be looking for food to eat.” (Angela)

These notwithstanding, a few mothers voiced their difficulty in dealing with the challenging behaviours that their children exhibited. They described the children as being temperamental and could be violent and destructive when angry. In such situations the mothers are sometimes

physically harmed by the child. Hence mothers have to ensure that they rearrange their homes so as to keep valuables and dangerous objects out of reach of the child. Apoka shares her story:

“She used to have a very bad temperament. She could scatter all these things in the room when she gets angry, so because of her that we had to even pack (pointing around the virtually empty sitting room). One day she just pulled down my dinner set and glasses, and could just throw anything at anybody, but now those traits are gone. ...when she used to be hostile and I used to be angry, because one day she even bit my breast in anger.” (Apoka)

Mothers also had to protect their children from physical harm and abuse because they felt that the children were vulnerable and could not protect themselves from any harm. Mary and Charity had this to say:

“I cannot go anywhere and leave him because he cannot be on his own. If a bicycle or car is coming he doesn't know that he should step aside or give way all these I am guiding him on that.” (Mary)

“We can't just leave her here anywhere, because I know she cannot take care of herself to some extent. You know some people they see her and think she is just free like that or she is free to do other things. Because She can't remember certain things, you do something wrong to her, she can only complain but she cannot tell you exactly. It's because of that (abuse) I'm afraid.” (Charity)

The mothers also expressed that they found it difficult getting treatment or cure for their children's condition. Also, when the children are ill, they faced difficulties accessing health care. Some mothers therefore resorted to self- prescription and over the counter drugs to treat their children. Also, the fact that they have to visit the hospital every month to collect drugs for the children as most of them were on daily or routine medications for epilepsy was also considered a challenge. Below are statements showing mothers' challenges in getting treatment for their children.

“Treating him is my main challenge as for feeding and other welfare issues God is taking care of us. However getting him treated is the problem.” (Selma).

“It’s always difficult to see the doctor for treatment, so me I don’t often send her to the hospital. You know everybody struggles at the hospital, In terms of the long queues, we all join the same queue.” (Alice)

Another mother who had to go to the clinic every month for drugs without seeing any improvement in the child’s condition expressed her frustrations:

“But I don’t know why up to now.... they said when they take the drug for a longtime sometime it changes, but he has taken the drugs for long yet we are not seeing any changes.” (Angela)

Apart from difficulty accessing health care, part of the challenge had to do with the child’s attitude when ill. The mothers said the children were difficult to handle when ill because they could not stand the sight of the health personnel. Ayi narrates her difficulty and how she deals with it by self- prescribing medication for her daughter:

“Ae! she doesn’t go to the hospital, even how to send her to see the doctor, she won’t enter, when she is sick is only God that am praying. So if she is even sick how to send her to the hospital is a problem for me. So I will just buy drugs and mix and give to her. Handling her is too difficult when she is sick.” (Ayi)

Joyce also narrates her challenge which is similar to that of Ayi but she has a different approach in dealing with it.

“.... because that boy you can’t send him to a public hospital. He won’t even stand and because of injections, when there are two or three people around him he gets suspicious that you want to hold him for injection or something. So at a public hospital I don’t think..... So we’ve taken it upon ourselves to get a private doctor if not for all of us just for him.” (Joyce)

4.3.2 Financial challenges

Financial challenges of mothers boarded around lack of financial support from spouse and family especially for mothers with low income status. They experienced difficulties in meeting basic needs of the child including feeding, clothing, and accommodation. They also spend money on medication and payment of school expenses such as Parent Teacher Association (PTA) levy for fuelling the school bus. These were coupled with the fact that they had no knowledge of any available formal source of financial assistance for this group of children and this increased their burden. For instance, Selma shared her story on lack of financial support:

“For all these years nobody has even offered a pesewa to say take this and look for medicine even till I went to Adabraka and came nobody asked me how much did you spend.” (Selma)

Ayi who is widowed shared her difficulty meeting the basic needs of her daughter:

“The difficulty is because the father is not there and am alone, now how to get her uniform, her things, pad even to buy for her is difficult for me, her clothing in the house, how to feed them if not for this school like it will be difficult for me.” (Ayi)

For some mothers they spent more on clothing because the children do not know how to take care of their cloths. Either they cannot operate the zipper or buttons and therefore end up destroying the clothes or they misplace their sandals when they go to school or to play requiring constant replacement, hence extra cost on cloths. Mpage had this to say:

“..... only sometimes she might forget her sandals at the school bus or somewhere. When she comes and you ask her she will just keep quiet then you too you just have to ignore her and go and buy new ones for her.” (Mpage)

Mothers also spent money on drugs which were in most cases supposed to be free but were not available at the mental health clinic and had to be purchased from a pharmacy store. Mary narrates the difficulty she goes through to get money for her child's treatment as follows:

“No if it happens and I have money for transport I will send him to the hospital but if there is no money I will give the para while I sell water to gather money for transport. Honestly when we go they don’t charge any fee, my only problem is money for transport. If the medicine is there they give if it’s not there he will write for me to go and buy. So I will come home and sell water get the money and buy the medicine for him.” (Mary)

Angela, a teacher considers the medicines to be expensive. She says:

“They are expensive. The other time they asked me to buy for 2 months. It was eeh 36+36 that’s how much, 72 cedis, I bought so if it’s one month, 36 cedis.” (Angela)

Mary who was chased out of her husband’s house with her children and was staying in somebody’s house needed money to put up or rent an accommodation for herself and her children. She said:

“Our main problem is coming to this school; because we don’t have accommodation ehee because where we are staying currently the owner is at the farm if he comes we don’t know where we will go ehee”. (Mary)

The mothers also had some expenses to meet at the school the children attended which included buying school uniform and paying levy to support fuelling of the school bus. Akolpoka shared her view and the position of most parents about PTA levy for fuelling of the school bus in the following narrative:

“there are challenges, because most parents, the issue of the bus, they said PTA will always levy parents to contribute to buy fuel for the bus, but the assembly too is supporting to fuel the bus, so you know these our children already the money is not there, to pay how much, 50 cedi per term for a child to just go and eat and play and come home so it has been a challenge as I am saying.” (Akolpoka)

On the contrary, mothers with high socio-economic background did not express much financial challenges.

4.3.3 Work challenges

Work challenges experienced by mothers had to do with where to leave the child during working hours especially when the children were younger because there was no special school at that time. Apart from that, some working mothers said they had to wake up extra early to prepare the child for school and also get ready for work in order not to be late. Others resorted to keeping maid servants to assist them. Ewurama had this to say:

“Abena can be very difficult sometimes so usually I wake up by 4 am and have my bath.Because one cannot tell how the day will be, I have to wake up extra early, because I don't want to be late for work.” (Ewurama)

Angela also describes her challenge:

“Sometimes I will come to school, break time I will rush back to see how he is fairing, how he is lying in the room then I will come back to work and close before I will go back. So you see, cost”. (Angela)

Charity also described how she managed with her maid to enable her meet her work demands.

“That time was lucky I had a maid who was helping me. She nursed her backing her and then we used to go together to school until I delivered the second one, the maid used to sit with her at home and I will send the junior one to school and come back.” (Charity)

4.3.4 Emotional challenges

Emotional challenges that confronted mothers were quiet intense and varied. Most of the mothers went through worry and frustration about their child's overdependence on them considering their age. They felt that if it were not for the condition, the children would have been at higher levels with their education or even be self-reliant and that was course for great worry

for all the mothers. Apart from that they also went through periods of sadness which made some of them breakdown and cry. They also experienced anger, disappointment, heartbreak, shame, blame, fear and lamentation. Some of the mothers also experience pressure from their husbands and relatives to “shie’ (a ritual way of doing away with the child) the child. These were evident by the following narratives:

“Sometimes when I sit down and I look at the junior ones the way they are going and what they are doing and I look at her, at least it becomes a bit worrying.”

(Akolpoka)

“My only worry is that the one he is following, today he is SSS 3, by now wouldn't he have been somewhere near him ? ehee. So that's my major worry.”

(Selma)

Joyce describes her frustration:

“It's difficult because, there are things that we expect him at 23 to be doing which he cannot do so it's frustrating. Because he is so much dependent on us, you find people becoming fed up, but as for the mother, she can never be fed up.So when it comes like that it is so emotional and I breakdown but is not all the time.”. (Joyce)

Another mother whose two children were both intellectually challenged expressed her disappointment and heartbreak over her children's condition saying:

“If they were healthy they would have been helpful but looking at how they are it makes me think a lot and sometimes I feel disappointed and heartbroken.”

(Hwabu)

A few mothers suffered blame from their husbands for the child's condition. For instance, Akolpoka's husband blamed her for always sleeping outside in the night for fresh air during her pregnancy. Meanwhile sleeping outside is a common practice in the north especially during the warm season. She had this to say:

“Even it came to a time my husband said me I fear heat too much when I sleep outside and he ask me to go inside I don’t want to do that and in fact it really became a problem. Blame was the number one because of other reasons people were giving, bathing late in the night, these were all some reasons that people were giving.”(Akolpoka)

Alice, who took the child for an operation with full support of her father -in -law whilst the husband was away in school was also blamed by her husband for her action. She says:

“Eeh as for the blame, he said if we didn’t do the operation may be it would have resolved. We wanted it and went for the operation. But I know what happened.”
(Alice)

For some mothers, the child’s behaviours coupled with lack of support, initiates sudden outbursts of anger and frustrations. Angela confessed that:

“so they have just left this boy for me, he is my property, you see the problem, so sometimes it comes with frustration and anger when you think of all these things. because there are certain things that they will do and before you realize what you don’t even want to say, you are saying, you just come out with some anger because of the way uhuu.” (Angela)

4.3.5 Social challenges

Most of the mothers experienced challenges in their social relationships either with their husbands, family, friends or neighbours in their communities. These challenges included marital strain, divorce/ separation and subsequent neglect by husband and family members, stigmatization or social isolation and subordination of their personal interest. To add to this, the mothers also had to deal with people’s perceptions about the way they cared for their children.

A few of the mothers who still lived with their husbands had some strain on their marriages because of issues concerning the child with intellectual disability. However, siblings of the child were generally supportive and did not pose a strain on mothers.

“Sometimes certain things will happen and you know the men, the way the father will talk, (pathed) it’s not pleasant at all,..... ..., and sometimes honestly even in the house she does certain things and the way he treats her am not happy, he shouts at her, why should she be like that, But any time he’s just... though I don’t feel happy but I just try to talk to him,” (Akolpoka)

On the contrary, some husbands were very caring and supportive.

Some mothers got separated from their husbands and families for giving birth to a child with intellectual disability and for refusing to yield to pressure to have the child killed through ritual sacrifice. As a result they have also been neglected by their husbands and families and described coping alone.

“Then he told me one day that this is not a child we should let him go meaning we should kill him. He insisted even with his family members, they threatened to sack me to go with my child if I don’t let him go. Then he also started bringing herbs for me to boil for him to drink and bath. So I thought he was helping me to treat him. And I didn’t know and was also boiling them for him, helping my husband to kill my son. And since we left he (referring to husband) has not even asked to know where we are or whether the child is alive or dead. I have been on my own till date.Uoi as for family nobody will help you take care of him, that’s why I said if you have this kind of child then you are cut-off from family.” (Selma)

Mary also narrates how she got separated from her husband and family:

“He told me that the child, I should look for where to stay with him because the child is not his child. I was sitting there with this sick one and he said if I don’t send the child away he will kill me and kill the child. This was how come I went to Kparesi to beg for a room to stay with them while coming here to help out. He has left me.” (Mary)

Some mothers also experienced some forms of stigmatization or discrimination of their children and themselves by relatives and neighbours. They saw how their children were despised or disregarded by people. Joyce narrates that:

“Like he happens to soil himselfnobody is willing to touch, even just bring it out and the mother will wash..... So I start talking and before I realise I am crying. I say ah! I didn't go to buy it, so we shouldn't despise him like that.” (Joyce)

Selma also complains of how other parents react unjustly to her son. She says:

“what he says he doesn't like, maybe he doesn't like noise, they will make noise for him and when he beats them up their parents come to complain that he is beating up their children, as for what their children did to him, they would not mention that.” (Selma)

One mother was stigmatized and discriminated against by her neighbours in the same compound to an extent that they would not buy anything from her and as a result, she stopped selling her provisions. She shares her story:

“Ohh this compound matter uhmm we can't even talk about it, it's even now that its better otherwise when we came (shaking her head). Even now the way they behave, I can't sell anything in this compound; if you sell they don't want it. Because when we came there was no toilet room, if she says she is going to toilet which is a public toilet a distance away, before she gets there, she has already soiled herself. So when they saw that everybody knew that as for us we are “feces people”. (Alice)

A few mothers also thought that their relatives and friends were pretending to have accepted them and their children with intellectual disability or to be comfortable with the situation as depicted by Joyce's conviction as follows:

“Sometimes I can see pretence. When you go in the way they are playing with him is like superficial because you are there but if you are not there it may not be like that.” (Joyce)

Similarly, Ewurama had some doubts about people's love for her daughter. She adds that:

“Oh everybody likes her, she is fun to be with so people don't have problem with her, unless they are pretending in front of me.” (Ewurama)

However, some mothers acknowledged that the level of stigma has gradually reduced owing to the amount of public education that has been done and people have become more receptive towards them. Only a few ignorant people and children still stigmatize the intellectually challenged children.

“You know the way the sickness is some feel that it is contagious, you know that, and some feel that it is a spirit or something creating it, so they won’t like to come near, but now the education is going that it is not contagious, it is not any spiritual thing, people are getting to understand it better, sometimes when he falls and am holding her some people come to help but it’s not everybody you will get to do that.”

(Angela)

The perpetrators of stigmatization or discrimination were mostly children, but adults were generally friendlier as Ewurama and Mary explained:

“You know these Dagomba children sometimes they throw her stones, but most people especially the adults like her.” **(Ewurama)**

“Sometimes some children will say hey run and leave this boy he is a dirty boy or some will throw stones at him. When they are doing that and elders are there they will come out and shout at them or if their parents are there they will come out and cane them. As for that they are helping me on that.” **(Mary)**

Additionally, most mothers felt restricted by their children’s condition in pursuing their personal interests. They could not freely go to functions or travel and leave the children and they could not also send the children along because they were difficult to handle.

“You see a small journey like this I can’t go. People are in the house but how she is they can’t handle her. And if I mean to take her she is too big for me to take her and be roaming about. So when am going to some place like this it’s difficult for me.” **(Ayi)**

“... handling them is difficult, if you send them somewhere they will disturb you.” **(Hawabu)**

“This girl the way she can disturb, I can’t go with her to church. She will disturb, so I don’t go with her.” **(Ewurama)**

Apart from the difficulty in handling them, Alice had a different reason for not attending functions with her daughter, which was to avoid shame because her daughter had incontinence of faeces and could soil herself at any time which would be a shameful experience for her. She had this to say:

“Even now I can’t take her to the midst of people let alone travel with her, how you will manage and she will not go to toilet about three times it will be difficult. So my suffering with her has to do with the toilet. If you will go then you will also suffer some shame. Sometimes I used to leave her with my mother otherwise when I send her, I will suffer.” (Alice)

The mothers also had to deal with public perceptions about the way they handled the children. For instance, according to a mother, people thought that she could not buy clothes for her child and this perception was stressful to her. She reports that:

“Sometimes some people will just call him around there and pack their old things, a bag full and he will bring and then I will complain, this boy cannot wash his things, he cannot even wear them, I am having my thing and I know the problem, then you feel that he is not having things, and you will go and pack old things, full bag and give it to him and he will come and pack them. So it’s not easy. So these are the stressful things we go through.” (Angela)

4.4 Crises – Meeting Resources

Crises – meeting resources refers to factors in the family organization that, by their presence, protected the mother from crisis or, by their absence, predisposed a mother to crisis. In other words, the resources determined the adequacy (crisis-proofness) or inadequacy (crisis-proneness) of the mother. The narrations of mothers in the study revealed their resources which helped them deal with their situation. Two sub-themes that emerged were support systems available to mothers and coping strategies employed to deal with hardships.

4.4.1 Support Systems Available to Mothers

Support systems refer to various sources and forms of support that is available to mothers with intellectually challenged children. The mothers relied on four main sources of support which were social support, informational support, traditional healers and their sources of income. Most of the mothers enjoyed social support from their spouses, extended family members/relatives of self or husband, siblings of the child, friends and neighbours and significant others, in the form of physical work of care-giving and emotional support. Below are statements of their narrations:

“Luckily as I said, we have other relatives in the house so they are so helpful.” (Joyce)

“He (husband) was ok, he has been caring, and he likes her like all the other children.” (Ewurama)

“So the grand parents also liked her. They even sponsored the operation, if not for them, the father didn’t contribute much until the operation was over.” (Alice)

For some mothers, family support was unilateral since it came from only the mother’s side and none from the husband’s side as indicated in Ayi and Hawabu’s statements:

“As for their uncles that is my brothers and their wives and my sisters, because now am not in my husband’s house, am in my father’s house, and how we are its good I don’t have any problem with them.” (Ayi)

“My own family, they are helping me to take care of them. As for my husband’s people, they don’t care about them. Since my husband died, I have been taking care of them alone and with the help of people who support for God’s sake.”

Hawabu

The siblings of the child with intellectual disability were also another source of support for most mothers especially, female siblings who helped the mothers with the physical

work of care giving. The understanding shown by other siblings gave mothers some relief. Ewurama states that:

“They are fine with her, the second one is a girl, and she is grown so she helps me with bathing her or feeding. But the boy, he I don’t allow him to bath, or feed her.” (Ewurama)

Apoka also had this to say about the relationship among her children:

“My senior daughter when she went to UK, she had to do a short course on this because of her, they are all doing well, the second one too is a doctor so she also appreciate her. The one who even comes after her when she is even sick and she is vomiting, even when she was small she could collect the vomitus in her hand (demonstrating). It is she and even the doctor who occasionally quarrel, because she is full of nonsense ooooh.” (Apoka)

Mpaga had emotional support from her husband as indicated in her narration.

“They (family members) are all understanding, they believe it is the will of God even sometimes she will do something, I will not know where my tears come from, then the father will say, you don’t know what God wills for you so don’t worry, then I will be consoled and stop crying.” (Mpaga)

A few of the mothers had physical support from community members in the form of food stuff and clothing. Apart from that, adult community members or neighbours helped protect the child from being beaten or harmed by other children. Hawabu received food stuff from her community members as reported in her narration:

“As for support, the community (Muslim) members really support me. I will be ungrateful if I say they are not helpful. As I mentioned, they give us food and clothing. Every fasting season they give me a bag of corn and it can last us the year.” (Hawabu)

A few mothers also got informational support from health personnel, from reading about child’s condition and from attending meetings involving parents of children with disability. However, most of the mothers said the health personnel did not tell them anything about the condition of

the child, its cause, course or treatment choices and outcomes. Thus these sources of information were not readily available to all mothers. It took personal efforts of mothers to acquire the needed information to help them better understand and care for their children. Hence informational support was used only by mothers who were well educated.

“..... we confronted them with the situation and they invited us to the hospital and so we went and it was at that point that they explained certain things about the condition, they gave a lot of advices, they also tried to counsel us not to blame one another, because initially when it happened people were giving all sort of reasons for that, ahaa. So until we finally got to the hospital and then the doctors started explaining these things then through that we learnt, for me, me for one I, I started learning a lot.” (Akolpoka)

“It’s now that because of her I am reading a lot of things and trying to know more about her condition.” (Apoka)

Most of the mothers also sought local medicine in addition to orthodox medicine to treat or cure their children. Among those who sought local medicine, some believed it had positive impact on the child’s condition while others did not see any benefits. A few mothers relied solely on orthodox medicine while others relied solely on local medicine. The following statements reveal the use of orthodox and /or local medicine:

“We tried local but it was not changing, so many people we changed, it was not doing.” (Angela)

“But when we were discharged from the hospital and came home, someone took us to a local drugs person, that they call it “asrat”. Well I don’t know if it was coincidence or because we just came from the hospital and I didn’t know the difference, it just ended there.” (Charity)

“They say what the Dagombas call it ‘doggu’. And the English people call it what convulsion. So that made her sits for up to four years without crawling. And God led me to one man and he helped to cure her, she didn’t even crawl before she even walked when she just sat at once she just started walking. The man was a herbalist from Wenchi but now he is dead.” (Ayi)

“We basically relied on the hospital spending about one month during one of the admissions.” (Mpaga)

Additionally, the mothers had various sources of income for financial support. A few mothers on salary said it was enough to take care of the needs of the child and family. Mothers who were not on salary depended on menial jobs to earn a livelihood for the family but would like to be supported to better care for their children. A few mothers on salary still had some businesses running to support it.

“My salary is there, I run a bar and a guest house. As for the resources, even though the business is not as vibrant as it is. But I always say that when God gives you a load he finds a way to lighten the burden. I have never slept and gotten up and have no pesewa on me.” (Apoka)

“Oh my salary is there, it’s ok for me.” (Ewurama)

Contrarily, Selma described her source of income or financial support which was woefully inadequate to meet her needs:

“Honestly. Only the soap money from this school is my only source of livelihood. Apart from that I don’t have any help anywhere. And as school is in session like this we come and we all get something to eat. When there is no school I use ‘gongon’ to fetch water and sell, by then the other siblings are all at home to take care of him.” (Mary)

Also, some family members served as sources of financial support to some mothers:

“As for the family the elder sisters and the father are those who help me, the elder sisters give her money to go to school. The food I cook and sell, the profit is what I use to buy food for us to eat and also buy clothes. The profit is ok for the basic needs but there is nothing to save.” (Mpaga)

Although most mothers had heard about social welfare services, none of them had ever received any support from there, though some tried to get help from there. However, a few mothers were

not aware of the existence of social welfare or did not know that they could get some help from them.

The presence of the special school also served as a source of support for some mothers. They felt that it was a safe place to leave the child while they went about their daily duties. They also acknowledged that it had helped to improve the condition of the child especially their speech development. The following narratives depict these assertions:

“You know as for the school, we just sent her there so that if am at work; I know that she is somewhere safe but I don’t expect her to learn anything. Not that the school is not helping, she is the problem, she just can’t learn anything. At least when she started her speech was very bad but now there is improvement.” (Ewurama)

“So when he is well and he is at school I am at peace. I know that he’s at school, closing we all meet in the house.” (Angela)

4.4.2 Coping Strategies

Coping strategies refer to the ways and means employed by mothers to help them deal with the hardships that came with having a child with intellectual challenge. The descriptions of mothers depicted the strategies they used to cope with their challenges. Most of the mothers used emotion - focused coping strategies. These strategies only temporarily relieved the mothers of their emotional difficulties but did not offer concrete solutions to the problem. These strategies included: studying or observing the likes and dislikes of the child; ignoring the child’s challenging behaviours; accepting the situation as it is; Satisfaction from seeing improvement in the child from the training given; Self encouragement and self control; or engaging in work. For instance, Apoka studied her daughter and devised a strategy of ignoring her to get her conform. She says:

“We have studied her, when she misbehaves, we just ignore her, she doesn’t want to be snubbed, that is one of the ways we can get her to conform, you come you go to your room, you don’t mind her, do your independent work, but to sit down and joke, she can even come and say mama am sorry.” (Apoka)

Ewurama’s approach was similar to that of Apoka

“I just keep quiet, when am annoyed I won’t talk, that’s how I am.” (Ewurama)

On the other hand, Joyce uses her work and self control to divert her attention from her emotions. She narrates that:

“..... Like am saying you become emotional for some time, it may carry you to work side but within sometime when you engage in the work it goes. Because it doesn’t linger for long when it comes I try to control it.” (Joyce)

Apart from that a few mothers were consoled when they compared their children to others and that helped them cope. Below are Joyce and Akolpoka’s quotes:

“.... but I went to the school and saw some children I just knelt down and thanked God. I don’t think I would have been able to cope. But if those people are coping why am I worrying myself. I just say that and am consoled.” (Joyce)

For Akolpoka, comparing the child with others gave her some encouragement and satisfaction. It meant that the training she gave was yielding positive results.

“Looking at her and if I look at others own and see her I just become encouraged for the little that I have been able to train her she’s coping. I just encourage myself and I tell myself that whether you like it or not she is like that so you have to adjust.”(Akolpoka)

Additionally, some mothers coped by accepting the situation and giving it to God in prayer.

“You just give all to God. Because if not God there is nothing I can do.” (Selma)

“And when I perform ablution and pray for us, then I feel better” (Mary)

Angela used her determination to move on thereby apportioning time for her activities

“I don’t let that one put me down, I am there, whatever I am supposed to do, I apportion my time and do it.” (Angela)

In addition to the above, a few of the mothers also employed problem-focused coping strategies that aimed at addressing their problems or challenges. Some of these strategies included seeking information by reading more. This helped them understand the child’s condition and what could be done to assist them. Only a few educated mothers reported reading more about the child’s condition. A few mothers also sought professional support by engaging health professionals to source for information and direction. The following quotes depict this:

“It’s now that because of her I am reading a lot of things and trying to know more about her condition.” (Apoka)

“And because of that we were going frequently to the hospital for advice and other things. So it really encouraged me and I got to know that this is just a normal human being, the only thing is that growth is not as it should be, growth is slow and there are certain things that she will take a longer time before she could develop them.” (Akolpoka)

A few mothers also joined a self help group comprising parents of children with disabilities, a group formed by a Non- Governmental Organization (NGO) called Action for Disability and Development (ADD). However most of those who joined the association were not regular or had dropped out for some reasons. One mother stopped because she felt she had a lot of other association meetings to attend at her church. Another mother was not regular because she felt the association should have been for only mothers since the men usually dominated the meeting. One mother, Akolpoka who was an executive member of the organization shared the benefits she received in her narrative stating that:

“In fact from day one when we joined the association Action for Disability and Development (ADD) that I learnt about special schools, where to find them

they invite us for meetings we have learnt a lot, capacity building workshops, educate us on issues of disability, our children. It is on that level that has helped me to understand and learn more about disabled people. It has also helped me to better assist my child with intellectual disability.” (Akolpoka)

Some mothers used Reframing, by seeing the negatives as positive,

“...but apart from that we have integrated her, she is just a God’s gift, we try to even see the negatives as positives, because we cannot have a 100%.” (Apoka)

To meet the health needs of their children a few of mothers resorted to self - prescription as a means to cope with the difficulties they faced in accessing health care when the children are ill, others also sought local medicines as reported above.

“I have made myself a doctor, I told him, because of that I have made myself a doctor. when it(epileptic attack) is so rampant, I suspect malaria then I will go and buy malaria drugs for him to take.” (Angela)

“..... if it’s just the diarrhoea or its now the headache I just buy flagyl for her.” (Alice)

The mothers also used the special school as a coping resource. They felt that sending the child to the school gave them space and time to work and do other activities. Apart from that the school also helped to improve some abilities of the child.

4.5 Meaning Mothers Make of the Event

The meaning the individual makes of the event is one of the constructs of the ABCX family stress model and a major theme that emerged from the data. According to the ABCX formula, the subjective definition a person makes of the event (stressor) equalled the meaning or interpretation of the event and its accompanying hardships for the individual/ family.

Mothers in this study had varied perceptions and interpretations of their child’s disability. Although most of them were not very optimistic, a few mothers had a high sense of hope about

the future of their children and also gave positive descriptions of them. In addition, mothers shared their perceptions about the cause of their children's condition. They mostly attributed medical causes to the child's condition but mentioned certain cultural reasons which other people gave as possible causes of the condition. They did not believe in superstition or that someone was to blame for it. Hence the meaning mothers made of the child's condition was seen in three forms: optimistic /positive emotion, negative emotion, and perception of causes.

4.5.1 Optimism /positive emotions

Optimism in mothers was expressed with regard to general independence, career or work and married life of their children. A few mothers expressed a high sense of optimism that their child's condition will improve and they would be able to live as independently as possible, be able to do some work and possibly marry in future. This firm conviction was linked with faith in God. This was evident in such expressions as:

“Well! I know that he will pick up one day, he may get some hand work to be doing, I don't know about his marriage life, whether it will happen if it happens fine but at least he should be able to do...., if he becomes independent, that is even my hope, my prayer, he should become independent first, if he is independent any other thing can...”. (Joyce)

And the following statement by Selma

“My hope is that if God is on his side he will get better. I am not thinking that he will not get well unless God does not grant it.” (Selma).

The level of optimism to some extent had an influence on the care given to the child. For some mothers, the tendency is to give maximum attention or affection to the child. The likely result is that the child is accepted and well catered for and the level stress in the mother therefore becomes minimal. A mother shares her opinion on giving affection to her child:

“So among all my children they say all my attention is on this one, I said yes, my attention will be on him, all of you know your left and right, but he doesn’t know. If I don’t give him that attention and leave him where will he pass? He will become useless.” (Selma)

Similarly another mother recounts how her child is lucky because she enjoys the affection of all family members;

“No no, they felt she needed it(attention), that is why I said even the last born could even put her hand, even when she was five years could hold her hands like this, collect her vomitus, throw away and clean her even when I am not there. So they all see her as a special child and they all want to give her that attention, so she’s been lucky”(Apoka)

In addition, most of the mothers enjoy some good moments with their children. Getting such good times for most mothers however depends on the behaviour characteristics and personality type of the child and when the children are in their good mood. Mothers whose children are easy going with humorous character enjoyed more good moments than those with antisocial and overly aggressive type. The mothers also gave positive descriptions of their children in ways that expresses positive emotions. For instance, Ewurama and Apoka expressed that:

“As I said she is fun to be with, she likes it when you sit by her and just be talking, say anything, whether you make sense or not she is excited hearing you talking with her. And she can also sing for me in her own way or words and we have fun so we are very fine”. (Ewurama).

“they are special gifts from God, and that there is joy in taking care of them. There is joy in taking care of those beautiful children”. (Apoka)

Apoka also recalled that:

“Oh! when she is in her good moods. Most at times the good moments are more because she is, I told you she is amiable, she is sociable she has funny expressions about everybody, father, mother, our friends...”(Apoka)

4.5.2 Negative Emotions

Negative emotions depict pessimism, having a gloomy outlook of the situation. Contrary to having high sense of hope for the future of their children, majority of the mothers in this study expressed negative emotions and thought that there was no future for the child regarding career, independence and marriage while others had feelings of uncertainty about what the future holds for their children. For instance one mother had this to say about the future of her daughter:

“Hooo future! (Exclaim with disbelieve). There is no future for her. Somebody who cannot do anything for herself at this age. You cannot train her at anything.” (Ewurama)

Similarly, Alice thinks that her child has no future. She reports that:

“Does this one also have a future? She is stuck with me for life. Am just keeping her by my side.” (Alice)

Most mothers were quiet uncertain about the future of their children but relied on the will of God for it. For some, their uncertainty was based on the condition that if they are able to train them to a certain level, or get better interventions that would maximize the potential in the child, then they would be able predict how the future would be. They felt that the children were not getting the right interventions. These were evident in the following statements:

“So what is her future, is she just going to be like that, as for these things I always say it is God who has the answer, because he alone knows what is best and what the future holds.” (Akolpoka)

“In terms of marriage, unless, that part am thinking of it now, until she knows how to cook then I will, I will have the hope that if she gets married she will be able to do something. Apart from that, that path, am not putting that one into her mind and she too as she knows, she is not ready to be married”(Charity)

Another mother expressed her desire to see her daughter manage independently in future. She says:

“Yeah, we would have wished we could actually get a place where we could utilize her brains effectively, for her to be able to get something independent on her own.” (Apoka)

4.5.3 Perceptions about the causes

This involves the subjective thoughts of mothers as to why their children were intellectually challenged. The mother’s narrations gave their views and interpretations of reasons for their children’s disability. These perceptions of mothers are: medical causes, the will of God, cultural beliefs.

Most of the mothers attributed medical causes to the reason for their children’s disability even though in some cases they could not explain or justify their opinion. Their views had some basis in the conditions surrounding the birth of the child, onset of the condition and their experience with medical or health services.

A mother whose child was born with *imperforate ano* and had a surgery done to create an anus for her and later suffered convulsive attack had this to say about the cause of her child’s condition:

“Okey, me I think it’s the operation that was not properly done and while she was a neonate considering the time she was born the weather was cold, around September, may be the cold affected her and in addition to the convulsion. I don’t know what really happened”. (Alice)

Another mother who suffered a prolonged labour shared her view but could not justify her claim. She said:

“About her condition, well as I said I don’t know, whether it was the prolonged labour.... Or is genetic or the measles, or, I cannot tell”.

(Charity)

Apoka who had taken a step further to read more about her child’s condition and reflected on some instances surrounding the pregnancy, birth, and care of the child after birth, also gave her opinion about the cause of her child’s condition. She reports that:

“They (doctors) said it was a crack in the brain. But they asked me some questions. It’s now that because of her I am reading a lot of things and trying to know more about her condition. Then I got to know that before I delivered her I had mumps, severe mumps. Then when I was in labour that was in Bawku hospital, when I said the baby was coming they didn’t even think I was serious, then when she was about three-four months she fell from a height, a table taller than this (pointing to a dining table). But I didn’t take it serious, so may be all those put together could have brought about her condition.” (Apoka)

Although in their opinion, most mothers thought that the child’s condition was medical, a few mothers also narrated some cultural beliefs which other people, neighbours, relatives or friends, attributed to the child’s condition. In some instances the mothers are blamed for breaking such cultural norms. One mother narrated that:

“For instance it came to sometime they said that a pregnant woman doesn’t sleep outside when there is moonlight and so maybe that might have caused that, or you go somewhere in the night late and you’re coming you may meet something, all sought of reasons. Blame was the number one because of other reasons people were giving, bathing late in the night, these were all some reasons that people were giving.” (Akolpoka)

Similarly another mother who nearly missed the opportunity of giving birth again or having more children because of people’s reasons for her child’s condition narrated her story. That:

“She is my first child, I nearly didn’t give birth again after having her because one old lady told me that the problem is from my womb and that all my children will be like that so I was afraid to have more children, but the

contraceptive I was using failed me. And fortunately that one, she was different so that encouraged me to have the third.” (Ewurama)

A few of the mothers indicated that their children’s condition was the will of God. They saw it as a task which God has given them which they had to accomplish. Below are their statements:

“That’s why I said when God gives you such a child, just know he has given you work and he want to see how you will carry it out. And judgment day he will ask you questions.” (Selma)

“I believe it is God’s work and when God give you work you don’t have to complain. It is God’s work.” (Mpaga)

4.6 Outcome

Outcome describes the effect of the interaction of having a child with intellectual challenge and its accompanying hardships with mother’s resources and coping mechanism and the meaning they make of their situation on the mother’s health and functioning. Mothers gave some description of the effects of the trajectory on their health basically in two areas: mental and physical. However most of the health effects or impacts were seen in the mental area than in the physical aspect even though most of the mothers considered themselves to be generally healthy. Those who had more serious health physical problems like hypertension, arthritis, osteoarthritis headaches and waste pains, did not clearly attribute it to the effects of the care giving. The commonest physical health problems that mothers recalled, boarded around sleeplessness, waking up tired and sleepy, and weight loss. Three mothers described their physical health situation by the following narratives:

“As for health wise whether he is there or not when you are aging there are other things that you face. Like this BP and the rest, they say too much talking can cause BP and sometime you don’t even talk but you still get BP isn’t it, ahaa. So maybe it is a contributory factor. I’m getting all those things now. I got up one day and I had sharp pain here, in my chest here, it was terrible, I couldn’t turn, I can’t swallow anything.” (Angela)

“He doesn’t sleep in the night. Sometimes the time he’s suppose to sleep he will be lying down he can’t sleep. And if he can’t sleep, I too cannot sleep, because if you leave him he can destroy things ahaa so you end up getting up tired in the morning, tired and sleepy. Those are the only days.” (Joyce)

“For five years I never put my head down to sleep, I can’t sleep, daytime has its problems, and night time has its problem how will you sleep. You can even take food to eat and it will start you just push it aside. Those days I was just like one (pointing out a finger), very slim.”(Selma)

On the other hand, mental health problems recalled by most mothers boarded around too much thinking and worrying and being emotional about the child’s condition and their future.

The following narratives depict this:

“That is what I said you just be thinking and worrying, you look at her quietly and a lot of things go through your mind. What will become of her in future?”(Mpaga)

“The way they are worries me. If they were healthy they would have been helpful but looking at how they are it makes me think a lot and sometimes I feel disappointed and heartbroken, but I haven’t developed high blood pressure or anything.” (Hawabu)

For Angela, she developed a kind of phobia for or a conditioned response (a particular behaviour which is elicited any time a particular stimulus is present) to certain sounds.

“Hah huum, now that am used to it, before, when he shouts, I will shake. Up to now when I hear somebody make a by heart noise some where my body will shiver, I will just shake as if he is the one falling. Any shout anywhere, I will get that shock?” (Angela)

4.7. Factors which Predispose Mothers to Stress

This theme emerged from the data. It concerns factors that have been identified to contribute to the stress of mothers of children with intellectual challenge. These factors are related to the characteristics of the child and mother; mother’s access to social support and certain expectations of mothers which are unmet.

4.7.1 Child characteristics

Child characteristics refer to the features in the child which influence their level of dependability on their mothers as well as the behaviours they portray, which include aggression, disruptive, attention seeking or calm, friendly and humorous. A few mothers recalled that their children were not really a problem for them because these children could perform some activities of daily living independently or to some extent. They also described the children as calm or not aggressive.

“looking at him now he doesn’t resemble someone who has a problem, I will call him to come and you see, he can eat, walk, talk, bath, he doesn’t have incontinence like others he can do everything by himself. That is the training I have given him. However if you are not patient you cannot handle him.”

(Selma)

“And in the midst of her colleagues you realize that she is a bit different, people see her and always come to me and say oo,... one woman told me if her child was like mine, like ooo she wouldn’t have any headache at all, that it’s not easy on her with her child, because they can’t leave her alone at home and go elsewhere, or they can’t leave her to go to hear and come when she puts her head, she’s just going, if nobody stops her, then she’s just gone like that they go and search for her again..... her speech is not very fluent and she speaks slow, but she’s not the (path) those who are very hard, harsh, she’s the calm type, apart from being in the house she doesn’t go to the houses around at all.” **(Akolpoka)**

“She cleans, she weeps, she can wash bowls, almost everything she can do apart from cooking, am now still teaching her the cooking part, but as I said she can bath herself, she washes her things.” **(Charity)**

However, others felt that their children were so much dependent on them. For instance

Ewurama describes her situation:

“And she can’t do anything for herself, I do everything for her. I bath her, I feed her because sometimes she refuses to feed by herself so and you want her to eat so what will you do, you have to feed her.” **(Ewurama)**

Angela recalls that her son roams a lot picking up things. She says:

“.....and this thing makes him to just roam anyhow. When he gets up because he has nothing doing, he will just be roaming like a mad boy, picking things, before you hear, he has fallen here and they will come and call you that he is lying over there. But when he was small we could carry him but now he is big.” (Angela).

4.7.2 Maternal characteristics

The mothers' narratives indicated that their individual characteristics were a contributory factor to their stress experience with their children. These characteristics included the educational background and socioeconomic status of the mothers. Mothers who had higher educational background reported less stressful experience than mothers with lower or no formal education. This was because they had more knowledge and understanding of the child's condition and better ways of dealing with it.

“my education is a bit higher than that of my husband and I realized that there are some of the things when they explained still he wouldn't understand. But I really understood where he was coming from. I have learnt a lot, I can say out of 100 I will say about 70% or even 80% of the issues I understand and I've adjusted to it, but the father will not still understand.” (Akolpoka)

“Education is not just the book knowledge; there are other things we should be enlightened with. Ehee. So I know that it is a medical problem, I don't think of any superstition.”

Most of the mothers with higher education also had good income and could afford better care and interventions for dealing with their situation. For instance a mother was ready to pay any amount to get better interventions for her child's future. She stated this as we concluded our chat:

“When you explore and there is any possibility, we will not mind the cost. We will not mind the cost. We want to try and see if we can get a future for her.” (Apoka)

Another mother mentioned the initiative she took with her husband to get a private doctor to handle the child's case at their own cost.

“But even at his older age my husband has a doctor, a family dr. who attends to him at home; in fact he has been handling this boy’s case, because that boy you can’t send him to a public hospital... So we’ve taken it upon ourselves to get a private doctor if not for all of us just for him.” (Joyce)

4.7.3 Mothers’ Access to social support

The mothers’ narrations described the types of social support that was available to them. While some mothers had very good and varied sources of social support, other mothers had little or no social support. Family social support was the most accessible by most mothers. Mothers who were still living with their husbands thought that the husbands were very supportive. Mothers who were widowed or separated from their husbands described coping alone. These mothers also felt that they were not getting any or adequate support from their husband’s family.

4.7.4 Unmet expectations

The mothers gave narrations that suggested that they had some expectations from the society especially health personnel, education service and the media which have not been met. They identified some gaps in these areas and also suggested ways to fill those gaps.

For instance regarding health care system, Angela identified that services for children with intellectual disability was scattered or not as comprehensive as expected. She expected that personnel who attended to these children at the mental health clinic would be equipped to do comprehensive assessment of the children at each visit and treat appropriately instead of just issuing routine drugs to them. For her, this would reduce their stress of having to send the child to general hospital to queue again for treatment after queuing at the mental health clinic for routine drugs. Apart from that, she also noted that there was only one specialist who was also not permanent but comes occasionally. Below is her narration:

“We have also registered with this eer, you know there is a special doctor for them at eer at west hospital or so, once a while we go there and they put him on some drugs..... Then I asked the doctor, now when they come you people the way you check us and give us drugs when we are sick, when we bring these special children you don't check their BP, you don't check their temperature then you just give them those drugs for us to go away. Then they said we can send them to the normal doctors for them to check them. Why not just combine and check them because you are trained for that ehee, they said we should send them to the normal doctors, so how can I bring him here you will only give me drugs then I will go and make another line for that one. So I said when he is sick, I suspect malaria, I treat malaria. And you know they are scarce, only one, he comes not very often, once a while that you will meet him in the hospital but there are other people to assist him. At least check the boy's temperature, check the ehee so that if there is something else you will know, right now only the drugs, does it mean that other sickness does not attack them?” (Angela)

Similarly, Joyce had a special concern about the unequalled attention that children or people with intellectual disability received compared to people with other disabilities especially those with physical disability. She was of the opinion that the formation of a mother support group could send a signal to the people concerned that children with intellectual disability also need their attention. Below is her narration:

“My concern is that, when they talk of the disabled, persons with intellectual disability are not mentioned I don't know why it is like that because usually the emphasis is on the physically challenged, physically challenged, they don't think about these other people they are always the disabled, the disabled, they bring them, only the physically challenged, sometimes you won't even see the deaf and dumb. They are just one way, physically challenged; they are the only disabled people.One of us was emphasising that, coming together we could even be the mouthpiece for our children because they cannot talk. So I don't know whether with the formation of such a group whether the signal can be sent to the people concerned that there are also people like this who need their attention.” (Joyce)

Additionally, some mothers' expectations regarding their children's education were also not met by the special school and the educational policies regarding special education. For instance, Apoka felt that the school adopted by the region for reintegrating the children to mainstream

education did not have the right person to head it. She also lamented over the kind of training given her daughter at the special school as indicated by the following narrative:

“we would have wished we could actually get a place where we could utilize her brains effectively. For her to be able to get something independent on her own.You see, she should have gone into the main streaming, she shouldn't have been with these people, but where they are, they are using Dabokpa, just here as their mainstreaming school, but even that school it was not a special education teacher who was the head and therefore did not even understand how to integrate (incorporate) them. But now I hear they have pulled one of the teachers to that place to head. So I said I will discuss with him, because honestly, she is wasting over there, she is wasting there and I think she has even deteriorated her more than ...we find some improvement for her. As for new horizon, she was good.”

(Apoka)

Alice was also not happy that the school asked parents of grown children to withdraw their wards and enrol them into apprentice in various vocational training programmes. She felt that the teachers in that school having undergone special training in how to handle such children would be the best people to train the children in any skill. She also thought that it would be difficult combining the intellectually challenged with normal apprentices for training.

“I thought the school they are attending, I mean the special school, I thought they will teach them handwork, such people they can't mix with intelligent people to teach them. Like this their school they are alone, I thought they would teach them handwork or catering cooking, because those teachers can teach them better than us. For instance she fears the teachers, she herself comes to describe that they stir TZ, banku and prepare soup, but when she gets home she will lust be sleeping if you want to wake her up trouble ehee so I thought the school they will teach them something only for them to call for one PTA meeting last year me I don't even attend their meetings because I don't have means. I heard they said we should come and take them, those who are grown and go and put them on apprentice for 2yrs then they will return for the school to pass them out. So I said what work can you put such a person and with who..... If she will go and add to normal apprentice to learn, she will only be running errands, pick this for me, pick that for me. She needs attention. I see it to be a waste of time. So I want to see if they know they can't I will just let her come and sit at home....” **(Alice)**

In summary, the findings of this study revealed the diverse experiences of mothers with intellectually challenged children in Tamale metropolis. Though the study explored these experiences using the ABCX family stress model, some of the themes and subthemes emerged from the subjective perspectives of the mothers about their experiences. The demographic characteristics revealed that all the mothers were caring for their biological children except one mother with an adopted child. All the mothers had one child who is intellectually challenged except one mother with two children who were intellectually challenged. The mothers had different educational backgrounds including tertiary with few being illiterates. Narrations of the mothers revealed their challenges, their resources and coping strategies, their perceptions about the child's disability, the factors that predisposed them to stress and their health outcomes as a result of the trajectory.

The mothers gave varied descriptions of their experiences in these major areas. These experiences include physical, financial, work, emotional, and social challenges. The findings revealed that mothers had various support systems and coping strategies which served as resources used to deal with the hardships they encountered. Family social support was considered a very important resource for mothers. While some mothers received full support of their husbands and family, others felt neglected by them. The mothers were optimistic, pessimistic or uncertain about the future of the child but generally perceived medical causes to the child's condition. Characteristics of the child and mother, and mother's access to social support coupled with certain gaps in health and educational services and the media were some factors that predisposed mothers to stress. In conclusion, the trajectory had some physical and mental health outcomes on the health of mothers.

CHAPTER FIVE

DISCUSSION OF FINDINGS/RESULTS

In this chapter, the discussion of the findings of the study is presented. The findings are discussed with reference to existing literature based on the constructs of the organising framework of the study. The discussion begins with the demographic characteristics of the participants followed by the major themes.

5.1 Demographic Characteristics

The study comprised mothers of intellectually challenged children, most of whom were literates and semi-literates and a few illiterates. This variation in educational levels is an indication that giving birth to a child with disability has no regard for status. Anybody can give birth to a child with a defect. Most of the mothers were also married and still living with their husbands while the rest were single parents either divorced or widowed. All the mothers who were divorced were forced to leave their husbands' houses for the single reason that they had given birth to a child who has an intellectual disability. One important observation about the mothers who were divorced was the fact that they were all illiterates. None of the well educated mothers in this study was divorced. One can therefore assert that, these uneducated mothers could not fight for their rights or defend themselves because it has been established that education empowers women to be able to defend their rights or stand up against any unfair treatment from their husbands or society in general (Mendel-Anonuevo, 1995). Besides, the educated mothers were also able to search for information about the child's condition and how to get better interventions for them which was not the case among illiterate mothers. These mothers were not just divorced, but were also neglected with their children and had to take care of the

children alone without the emotional, physical and financial support of their husbands or their relatives. This finding is consistent with a study in south-west of Sweden which reported that single mothers with intellectually challenged children are more vulnerable to stress than mothers who had partner support (Olsson & Hwang, 2008). The married mothers on the other hand enjoyed the support of their husbands.

Most of the mothers had their children above eighteen years which means that these children were young adults who under normal circumstances within the Ghanaian society are expected to be independent. Yet they were still dependent on their mothers, which explain the frustration and worry that the mothers experienced. This finding is in accordance with the findings of a study which indicated that the longer the intellectually challenged child is being cared for, the more the stress experienced (Tsai and Wang, 2009).

5.2 Challenges of caring for a child with intellectual challenge

Having and caring for a child with intellectual disability has been described as stressful and challenging especially for mothers who are the primary care givers of children in the family. In the present study, mothers were the primary care givers, bearing most of the burden of care giving associated with caring for intellectually challenged children. The mothers experienced physical, emotional, financial, work, and social challenges. This implies that the burden of having and caring for a child with intellectual disability affects every aspect of the mother's life. This finding of the study is in accordance with studies which reported that the stress of caring for children with intellectual disability affects all aspects of the mothers lives including, physical, mental, psychological, spiritual and economical (Davies & Honeyman, 2013; Gupta & Kaur, 2010). Mothers in this study experienced physical difficulties in training the child to be able to perform basic daily life skills independently and dealing with excessive demands of care giving

which included bathing, feeding, brushing, dressing, constant washing of soiled clothes, cooking several times in a day, giving medication among other things. These activities were done by the mothers for their children from birth till their present ages and still on-going and would most likely continue for as long as the children live. This finding is consistent with a study by Nurullah (2013) in Alberta, Canada, who reported that parents with intellectually challenged children have an additional responsibility of giving medications, teaching the child skills and doing physiotherapy, even though mothers in this study did not report taking their children through physiotherapy. These difficulties were attributed to the slow nature or low IQ of the child which affects their ability to learn or master basic skills and this determined the level of dependence of the child. The study also found that the mothers had challenges dealing with the challenging behaviours that the children exhibited. Some of these behaviours were, being temperamental, violent, destructive, angry and uncooperative. There were instances where a child could angrily pull down and break dinner set, or throw objects at whoever is around. Mothers in this study reported rearranging their homes and keeping valuables out of child's reach as a means of dealing with the child's challenging behaviour. This finding shows similarity with that of a study by Bourke-Taylor, Howie, & Law, (2010) where mothers had to rearrange or modify their homes so as to contain the behaviours of their children. The mothers probably experienced these difficulties because they lacked the requisite training, skill or education on how to train such children and to deal with such behaviours. This would have prepared them psychologically for the task ahead. However, the findings of this study also revealed that the mothers were not given any information about the nature of the child's condition by the health personnel and so did not know what to expect as the children grew or what to do for them at each stage. This finding is in accordance with studies by Griffith & Hastings (2013a) and Tsai &

Wang, (2009) who reported that following the diagnosis, parents are not taken through counselling and education regarding what to expect, what to do, what services are available to them and where to get help, leaving them to explore the solutions by themselves culminating into stress. This is probably so because most of the health personnel themselves are not adequately trained on how to communicate with or handle children with intellectual disabilities. This assertion confirms that of WHO (2010) that poor knowledge and training of health professionals on disability issues, poor patterns of communicating with the child, negative attitudes, poor inter-sectoral collaboration and lack of reliable health monitoring data for this population are key barriers to accessing health care. Similarly, this study also found that mothers experienced difficulty accessing health care owing to the long queues because there were no separate consulting rooms for special children. Part of this difficulty was due to the disjointed nature of services available to mothers whereby mothers go to one facility for routine drugs and to another for assessment, diagnosis and treatment of other ailments. Apart from these system challenges, part of the problem reported by some mothers was related to the child's uncooperative attitude when ill, which makes them difficult to handle. Most of the children were afraid of the hospital environment and the staff and would not cooperate when taken to the hospital. This made most mothers resort to self-prescribing drugs for the child during ill-health. The children probably were not cooperating because of previous negative experiences they had with health personnel who are inadequately trained to communicate effectively with such children.

Mothers in this study experienced difficulties in meeting basic needs of the child including feeding, clothing, and accommodation as a result of financial challenges. They were also required to spend money on medication, transportation to and from the hospital and payment of school expenses such as Parent Teacher Association (PTA) levy for fuelling the school bus. This

difficulty was particularly experienced by mothers with low income status. McNally et al., (2013) also reported financial challenges among parents and care givers of children with disabilities in the Moshi region of Tanzania in meeting necessities like food, clothes, nappies/diapers and shelter and high hospital and transport fees.

Although Northern region is considered among the poorest regions in the country, signs of severe poverty were particularly observed among unemployed and divorced mothers as some of them seemed to expect some assistance from the researcher. One might say that everybody in Ghana today is faced with economic hardships whether they have a child with intellectual disability (ID) or not. The difference in the experience of economic hardship between mothers with intellectually challenged children and mothers with normally developing children could be seen in the fact that there are extra requirements in meeting the basic needs of children with intellectual disability compared to normally developing children. For instance, children with ID eat more as compared to normal children partly because of the drugs they take; they cannot maintain their clothes and sandals therefore requiring constant replacement and most of them are on medications which are not always available with health insurance cover and have to be purchased out of pocket. The unavailability of drugs at health facilities requires mothers to purchase them at pharmacies at a higher cost.

The study also revealed that the mothers did not know of any available formal sources of financial support. The question is, are there any formal sources of financial support for this group of people in Ghana? And how accessible are they? Until recently, the only outfit which offered some support for people with disability generally was the social welfare services. Meanwhile, some mothers in this study were not aware of the existence of social welfare or did not know that they could get some help from them. The few mothers, who were aware of social welfare and

actually sought assistance from them, never received any support from them. They attributed it to the bureaucratic processes involved and the fact that the service is operated on the basis of 'who you know'. This finding is contrary to the findings of a study by Olsson and Hwang (2008) in Sweden which indicated that in that country, there are free services available to the vulnerable groups and in addition, most parents received a monthly grant to compensate for expenses and reduced income caused by care giving demands. This reduced the financial strain on families from the lowest socio-economic group. Recently in Ghana, there have been some interventions by the Ministry of Gender and Social Protection to get some livelihood empowerment funds to people with disability and the aged but how accessible are these funds to mothers with intellectually challenged children?

The findings of this study also showed that working mothers experienced some challenges basically regarding where to leave the child during working hours especially when the children were much younger and not yet enrolled into the special school. The mothers also had to wake up extra early to prepare the child for school and also get ready for work in order not to be late for work. The reason being that the children do not often cooperate and mothers have to spend several minutes to hours persuading them to have their bath, eat and dress up for school. Significantly, a mother confessed having to go back home severally to check on her child on days when he has had epileptic attacks and cannot go to school. This act could greatly affect a mother's productivity at work and result in demotion or sack or reduced income for the mother especially in an establishment where one is paid according to the number of hours you work in a day. In contrast to mothers working difficulties, some mothers in Australia and Tanzania are reported to have reduced opportunity to work because they are preoccupied with meeting the needs of the child or stopped working in order to take care of the child (Bourke-Taylor et al.,

2010; McNally et al., 2013). In this study, none of the mothers was forced to quit a job in order to take care of the child as reported in other studies

The emotional challenges experienced by mothers in this study were quite intense and varied. Some of these included worry, frustration, anger, disappointment, heartbreak, shame, blame, fear, periods of sadness which made some of them breakdown and cry. This finding is consistent with a study by Nurullah (2013) that the experience of coming to terms with the reality of the disability initially may create a sense of guilt, shame, denial, anger, and other negative emotions. Worry and frustration were experienced by all the mothers in this study. The mothers were worried about the future of their children and frustrated over the child's continuous dependence despite their efforts over the years in training them to be independent. These emotions were triggered by the fact that mothers kept comparing the intellectually challenged child to younger siblings or other children of normal development. By doing so they probably saw the weaknesses in the child and this increased their worry, disappointments, and frustration. This tendency to compare the child with a typically developing child was also common among parents interviewed in Canada (Nurullah 2013).

This present study also found that mothers were being blamed for the child's condition though it was in a few cases. The blame came from their husbands who probably did not understand the cause of the problem or had some beliefs which they attributed to the child's condition. For instance, a mother was blamed by her husband for sleeping outside for fresh air as a pregnant woman during the warm season. This finding is consistent with findings of similar studies that mothers are being blamed by their husbands and /or family members and others for the birth of a child with disability (Anum, 2011, Edwardraj et al, 2010, Nurullah 2013). Those who blame mothers for giving birth to children with disability are probably ignorant about the

causes or predisposing factors to giving birth to a child with intellectual disability.

Notwithstanding, some mothers could actually be guilty if their life style or activities during pregnancy or after delivery predisposed the foetus or baby to such defects. For instance, habits such as drinking alcohol, smoking, or abuse of drugs and poor diet during pregnancy, poor antenatal attendance and traumatic brain injuries are reported to increase the risk of intellectual disability (Tammy, Zupanick, & Dombeck, 2014). Contrary to the findings of Nurullah (2013) who also reported self –blame among mothers, mothers in the present study did not blame themselves for the child’s condition. Apart from that, some mothers went through pressure from their husbands and family members to ‘shie’ (a ritual killing of a spirit child) the child. In some Ghanaian cultures, children with ID are considered as spirit children and such cultures have prescribed ways of getting rid of them (Anum, 2011). However, this practice is gradually fading away in recent times owing to education and advocacy on human rights. Husbands or families who still hold such beliefs pressurize mothers to give out their children to be gotten rid off. Mothers’ constant refusal in most cases result in divorce. Anum (2011) attributes this behaviour to the fact that these husbands or relatives want to avoid courtesy stigma which is the stigma experienced as a result of an association with a person with a stigmatizing condition.

Social challenges experienced by mothers in the present study included marital strain, divorce/ separation and subsequent neglect by husband and family members, stigmatization, social isolation, and subordination of their personal interest. Some mothers in this study suffered separation from their husbands and families and were left to fend for themselves and their children alone. They got divorced after the children developed intellectual disability. In most of such cases, mothers were given an option to either have the child killed or leave with the child and when they refused to yield to such pressures, they were thrown out of their matrimonial

homes. The families of the husbands and sometimes of the mothers themselves supported such ideas and so equally did not want to have anything to do with the child. These actions were based on the cultural belief that children with intellectual disabilities were spirit children and should be sent to their rightful places. This finding is consistent with studies in Tanzania and Kenya where indigenes are asserted to have a negative cultural outlook on people with disability which characterizes such people as bad omen and parents are associated with evil spirits, punishment from God, or witchcraft (Aldersey, 2012; Gona et al., 2011). For mothers who were fortunate to remain married after having a child with intellectual disability, they felt that their husbands were very understanding and supportive.

However, a few of them experienced some strain in their marriages as a result of issues/conflicts surrounding the child. For instance, a mother was unhappy about how her husband sometimes shouts at her daughter and in such situations she has to intervene by talking with the husband. Marital strain was also reported in a study by Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, (2012) where lack of understanding of the reason for the condition occasionally brought conflict between partners in the form of ‘blame game’ (p. 195). It appears the husbands’ educational status and religiosity influenced how supportive they were of their wives and the child with intellectual disability. This is because most of the husbands who supported their wives were educated except one who was not educated but was a religious leader. Those who divorced their wives were all not educated. Siblings of the children with intellectual disability in this study also understood and helped their mothers with physical work of care giving or watching over the child whilst mothers were absent or engaged in other activities. Though mothers gave special attention to the child with disability than the other children with normal development, the siblings thought it was necessary and therefore did not pose a bother. This

finding supports that of Dyson (2010) and John (2012) who found that siblings (especially females) sometimes assumed responsibility of protecting and caring for their sibling with ID. However, on the contrary, Dyson also found that some siblings were unreceptive of the behaviours of their disabled sibling and mothers felt anxious and guilty about how their other children coped when they gave more attention to the child with disability.

In addition to the above, the study found some forms of discrimination and stigmatization of mothers and their children by relatives and neighbours. These were in the form of people despising the child, disregard by other parents who unjustly accuse the ID child of beating up their children, children throwing stones at the ID child and calling the ID children names such as 'dirty boy'. Notably, the perpetrators of such discriminatory acts were mostly children whilst most adult neighbours were protective and friendlier towards the child and mother. However, some mothers acknowledged that the level of stigma has gradually reduced owing to the amount of public education that has gone round and people have become more receptive towards them. Many studies have identified stigma, discrimination and social isolation as huge challenges that mothers have to deal with (Aldersey, 2012; Anum, 2011; Gona et al., 2011; McNally et al., 2013). This is usually portrayed in the form of pointing, laughing and staring or by people avoiding the child.

These behaviours have cultural bases since they are more obvious in cultures where people with intellectual disability are characterized as bad omen and given derogatory names and wealthy parents are accused of using their disabled children for rituals (Aldersey, 2012). In this study, a mother and her family were tagged as 'faeces people' by neighbours in the same compound who refused to buy anything from her. As a result, she stopped selling her provisions and this obviously impacted negatively on her economic situation. Similarly, Ali, Hassiotis,

Strydom, and King (2012) in a systematic review of literature examining self stigma and courtesy or affiliate stigma reported that courtesy or affiliate stigma may affect those who are closely associated, such as family members, friends, and even professionals who work with the person. These authors further noticed that both individuals with intellectual disability and their families experienced stigma which impacts negatively on their psychological wellbeing. In the present study, only a few mothers described instances of affiliate stigma. The study also found that some people (relatives, friends and neighbours) pretend to love and accept the child with intellectual disability when the mothers are present, but in their absence, they tend to maltreat the child.

The mothers reported being restricted by the children's condition from pursuing their personal interests. This often results in social isolation of mothers which has the tendency to affect the mother's wellbeing. They could not freely attend functions or travel without the children and neither could they also send them along because they were difficult to handle. The mothers were also afraid of being embarrassed by behaviours that the children might put up. This finding supports the assertion by Bourke-Taylor et al., (2010) that mothers' freedom to pursue other interest may be curtailed because some children have behaviours that require close supervision at all times. In addition to this, mothers in that study reported not being invited to social functions for fear that they would bring along their child with ID who might create embarrassing scenes. The present study also revealed that mothers had to deal with public perceptions about the way they cared for their children. Some people who probably did not understand the children's condition felt that mothers were not performing their mothering role effectively. This made mothers to feel that their integrity as a mother was being questioned. This most likely demoralizes and thwarts the efforts of the mother.

5.3 Crises-meeting resources

Availability of resources determine the adequacy or inadequacy of an individual or family to deal with a crises provoking or stressful event. In this study, mothers relied on various support systems and employed various coping strategies to deal with their challenges. They mainly used support systems categorized as social support, informational support, traditional healers and their sources of income to deal with their practical and emotional challenges. The sources of social support were their husbands, extended family members, siblings of the child, friends and neighbours who provided material support mostly in the form of helping with physical work of care giving, assistance with money or clothes and food. They also supported mothers emotionally by their understanding and acceptance of the child and directly consoling mothers in their moments of distress. Hence informal sources of support were the most common sources of support available to mothers however, formal sources of support were not readily accessible to most mothers. These findings support that of Tsai and Wang, (2009) who found spousal support as the most common source of social support with only a few formal resources available.

That study also found that social support generally played a key role in reducing the strain experienced by mothers of intellectually challenged children. For mothers who were living with their husbands, the husbands provided physical and emotional support to them. These mothers appeared to be very comfortable or well adjusted with their situation as compared to mothers who were widowed or divorced and neglected. This finding conforms to that of Olsson and Hwang (2008) who analysed quantitative data and found that single mothers had more highly elevated depression scores than mothers living with partners. In this study extended family support was unilateral for some mothers as they received the support from only their own

family and none from their husband's side. The salience of the extended family system can serve a vital source of support for mothers as their lack of acceptance and support causes stress for mothers (Aldersey, 2012; John, 2012). However, it is observed that currently in the Ghanaian society the strong extended family bonds that used to exist have been weakened by migration and westernization. Siblings (especially females) of the child with ID also served as valuable sources of support for mothers in this study, often helping to care for the child especially while mothers were away. Neighbours or community members provided material support in the form of food and clothing and also protected the child from being beaten or harmed by other children. These gestures were done on grounds of charity or sympathy. In one community for instance, the Muslim group provided a widow who had two intellectually challenged children with a bag of corn every fasting season and this was enough to last them a year. However this was a rare gesture in most communities within the metropolis. Some individuals in some communities provided clothes for children with ID which reduced the mothers spending on clothes.

The findings also indicate that some mothers also sought information from health care providers, and by reading written literature to help them understand and better assist their children. In most cases the mothers were not given adequate information by health providers and had to resort to reading on their own to get the information they needed. This fact was also reported by Tsai & Wang's (2009) study which further suggested that health professionals could design a manual on caring for children with physical and intellectual disability which could provide information on proper method of care and rehabilitation as well as available social and welfare services. A few mothers had informational support from joining an association of parents of children with disability, a group formed by a Non-governmental Organisation (NGO) called Action on Disability and Development (ADD). The information received helped mothers

to better understand the child's condition and provide the necessary assistance that the child requires. Currently the group appears to be nonexistent. This is because although most mothers were aware of such an association, they were not active members because it was a group for all parents (mothers and fathers) of children with various disabilities and so mothers probably could not identify with it. They would have preferred a more specific group for only mothers with intellectually challenged children rather than disability in general. This is because children with intellectual disability are uniquely different from children with other disabilities. It was observed that only educated mothers were able to access formal support. This finding is confirmed by a study in India by Kumar, (2008) who found that most mothers who are educated seek professional help, provide appropriate and timely interventions for the child, are aware of the need for seminars and workshops and are generally more exposed to the prevailing facilities that will improve their child's condition and also have frequent contacts with the experts and professionals.

Another finding of this study is that most mothers sought local medicine in addition to orthodox medicine to cure the child or to treat ailments associated with the disability. Probably, they sought local treatment because they believed in its potency or because they were advised by their significant others including health professionals to seek them. Gona et al. (2011) speculated that negative attitude of health staff towards mothers and their children at health facilities could account for most carers patronizing traditional healers rather than hospital clinicians.

The study found that mothers relied on their salaries, businesses or menial jobs as sources of income and financial support. While some mothers on salaries still had some businesses running, others did menial jobs such as fetching water for people for a fee, milling people's corn, and seasonal selling of bush berries among others. No formal sources of financial support were

available for mothers. Even though some sought assistance from social welfare services, they never got any. Their sources of income depended on their educational and employment status.

Another key finding is that the special school served as a source of support for mothers. It provided a safe place to leave the child while mothers went about their daily duties. The mothers also acknowledged that the school had helped to improve the condition of the child especially speech development as reported by Brown, Geider, Primrose, and Jokinen, (2011). However, mothers seemed to expect more from the special school in improving the independence of the children.

Apart from the resources mentioned above, the findings indicate that the mothers used both emotion-focused coping and problem - focused coping strategies to deal with their situations as found in other studies (Bingham, Correa, & Huber, 2012b; Mirsaleh et al., 2011; Peer & Hillman, 2012b). In the present study, mothers used emotion - focused coping strategies identified as studying or observing the likes and dislikes of the child; ignoring the child's challenging behaviours; Satisfaction from seeing improvement in the child from the training given; Self encouragement and self control; or engaging in work. These strategies only temporarily relieved the mothers of their emotional difficulties but did not offer concrete solutions to the problem. Some mothers also employed problem-focused coping strategies that aimed at addressing their problems or challenges. Some of these strategies included seeking information by reading more, engaging health professionals to source for information and direction, joining a peer group, reframing (seeing the negatives as positives), accepting the situation as it is by giving all to God in prayers; enrolling the child in the special school and self – prescribing drugs when the child is ill to avoid the stress of taking the child to a health facility. In contrast with Mirsaleh et al.'s, (2011) quantitative study in Iran, the mothers in this study

apparently used more problem-focused coping strategies than emotion – focused as most of them had accepted the situation by giving all to God. This difference may be due to difference in study approach, because, this study did not use any scale to measure coping style of mothers and therefore might not accurately determine which style was significantly used. However, most of the mothers had accepted and adjusted to the situation and were looking for support in training the child in vocational skills to secure their independence in future and therefore appeared to be under less stress. Meanwhile, Peer and Hillman (2012b) suggest that the use of more problem-focused coping results in less stress experience. However, another reason for the apparent minimal stress seen could also be that time has healed their wounds and they no longer see the child as a problem as most of the children were above 18 years.

5.4 The Meaning Mothers Makes of the Event

Mothers in the study assigned varied interpretations to their child's condition viewing it either with optimism, pessimism or uncertainty. They also attributed medical causes to it. A few mothers expressed a high sense of hope about the future of their children. They were optimistic that the child would one day be able to live independently, engage in a job and possibly marry. This strong conviction was however faith based as they combined hope with prayers and depended on the will of God to be done. Their optimism to some extent increased their level of attention or affection for the child leading to acceptance and reduced stress perception. This finding corroborates the findings of studies in America by Ellingsen, Baker, Blacher, and Crnic, (2013) which reported that mothers with high optimism engaged in more positive parenting, and Peer & Hillman, (2012b) who concluded that having an optimistic personal disposition helps parents to avoid associated care giving stress by dwelling on benefit and joy of having a child. In line with the latter, mothers in the present study occasionally had good moments with the child

and gave positive descriptions of the child in ways that expressed positive emotions. Such moments only came when the child was in a good mood. Similarly, Scharer et al., (2009) who studied mothers of children under 12 years with various mental and developmental disorders reported that mothers found positive and affirming characteristics in their child despite the difficulties and regardless of the emotional strains mothers felt, the joys they felt with their children were apparent. However, the characteristics of the child also influenced the parent's perception and description as some children especially those with Down syndrome are generally known to be sociable and fun to be with (Grein & Glidden, 2014).

On the contrary, some mothers also expressed pessimism about future employment, marriage and general independence of the child often expressing negative emotions which depict such perceptions. They felt that there was no future for the child. Other mothers were uncertain and could not predict what the future held for their children. These findings support findings of studies by (Griffith & Hastings, 2013b; Nurullah, 2013) where mothers were generally not very positive about future expectations of their children but hoped for the best. The mothers probably did not see any positive sign of progress in the child's development to give them any hope. Also, (Griffith & Hastings, 2013b) reported in a meta-synthesis of published literature reviewed that carers expressed great fear and anxiety about care of their family member in future when they (care givers) are no longer there. They further reported that care givers feared that their family member may become a target for sexual assault, not loved as an individual or heavily drugged to control their challenging behaviour. The mothers in this study were of the view that unless they were able to get better interventions to train the child to acquire certain skills and maximize the potential in them, the future remained bleak for them. The mothers felt that the children were not getting the right interventions. This is because in Tamale and Ghana for that matter, there are

no centres for rehabilitation therapies for this group of people even though per the disability Act such centres are supposed to be made available. Where available they are non-functional or difficult to access (The Danish Council of Organizations of Disabled people, 2007). The mothers' pessimism and uncertainty could also be related to the severity of the child's disability because some of the children are totally dependent and with very low IQ which makes them unable to learn any skill. Contrary to studies (John, 2012; Nurullah, 2013) which reported mothers viewing the child as a burden or curse and blaming God for giving them such burden, mothers in this study accepted the child as God's gift and a test of faith amidst their uncertainties as similarly reported by (Raman et al., 2010). Besides, Saloviita, Itälina, and Leinonen's (2003) study found that negatively defining of the situation as a burden or catastrophic was a strong predictor of parental stress.

Mothers in this study generally attributed medical causes to the child's condition. According to the mothers, convulsion was the commonest cause of ID. Other perceived medical causes were prolonged labour, prenatal infections such as mumps, trauma to the head during infancy, genetic and congenital defects. These perceptions were identified based on the conditions surrounding the birth of the child, onset of the condition and mothers experience with medical or health services. These findings show similarity with that of a study (Edwardraj, et al, 2010) in India where mothers attributed medical causes of ID to three primary factors: (1) medications taken during pregnancy; (2) fever, illness and seizures; and (3) poor antenatal care. Consanguineous marriage was also perceived as a cause by many of the participants, while others felt that inadequate medical supervision during delivery was the cause. In addition to these, psychological, environmental and genetic causes were also considered in that study. Apart from these medically related causes, the mothers in the present study also saw the child's

disability as a God-given task which must be accomplished. Mothers gave cultural beliefs which other people, neighbours, relatives or friends, ascribed to the child's condition as mentioned in other studies (Gona et al., 2011) which sometimes serve as basis for blaming the mother for the child's condition. The mothers in the study did not personally ascribe to such beliefs.

5.5 Outcomes

Outcome in this study was explored in relation to maternal health. Mothers in the study were generally in good health; however the effect of caring for the child affected mothers physically and mentally. Most of the health effects were seen in the mental area than in the physical aspect as majority of the mothers reported thinking, worrying about the child's future and being emotional. These findings support findings of several studies (Bourke-Taylor et al., 2010; Gupta & Kaur, 2010; Olsson & Hwang, 2008) who reported stress, anxiety and depression as the main mental health challenges of mothers. Contrary to Bourke-Taylor et al.'s study in 2010, none of the mothers in the present study experienced clinically diagnosed depression or anxiety disorder. Additionally, a mother developed a conditioned response or phobia to a type sound made by her son as aura to his seizure attacks causing her to shiver whenever she heard similar sounds even when the son is far away. Mothers who reported more serious physical health problems like hypertension, arthritis, osteoarthritis, headaches and waste pains, did not directly attribute them to the effects of the care giving. Rather, they felt these were normal with aging as most mothers were above 40 years. However a study in America has established that these health effects could result from the trajectory of caring for children with disability (Yamaki et al., 2009). In that study the prevalence of arthritis, high blood pressure, obesity, and activity limitation was significantly higher for aging female family caregivers than for their counterparts in the general population. The commonest physical health problems reported by mothers in

relation to the care-giving in this study, boarded around sleeplessness, waking up tired and sleepy, waist pains and weight loss. Sleeplessness was reported in several other studies (Davies & Honeyman, 2013; Davis et al., 2010; Mackey & Goddard, 2006).

5.6 Factors which Predispose Mothers to Stress

From the mothers narrations certain factors were identified to predispose them to stress. These were related to characteristics of the child and mother; mother' access to social support and certain expectations of mothers which are unmet. Stress in this study is defined as a feeling of being physically, mentally, socially or economically weighed down or burdened as a result of having or caring for a child with intellectual disability

Child characteristics such as degree of dependence and display of challenging behaviour predisposed the mother to stress. While mothers whose children could perform activities of daily living or self care activities to some extent appeared to be less affected by the child's condition, mothers whose children had very low IQ and could not perform any self care for themselves but totally depended on the mothers for such care were more stressed out. For instance, some children could bath, wash their cloths, feed by themselves and even engage in house hold chores like cleaning the house, washing dishes and running errands while others could not do any of these. The child's ability to do these things depends on the diagnosis of the condition; however it was difficult to determine the diagnosis of some of the children in the study because such diagnosis had not been medically established. Meanwhile, child characteristics have been found to be an influential factor in predicting/determining maternal stress by several studies (Hill & Rose, 2009; Norizan & Shamsuddin, 2010).

Maternal characteristics such as educational and socioeconomic status were found to influence maternal stress experience. Mothers who had higher educational background reported less stressful experience than mothers with lower or no formal education. This was because they had more knowledge and understanding of the child's condition and better ways of dealing with it. Mothers with higher education also had good employment and good income and therefore could afford better care and interventions for the child. For instance, a mother was ready to pay any amount to get better interventions for her child's future. On the contrary, the less educated and uneducated who were also unemployed relied on menial jobs to meet basic needs and were therefore overwhelmed by the extra financial responsibilities that come with taking care of a child with intellectual challenge. These findings conform with findings of Ellingsen et al., (2013) which found that low family income (as well as child developmental delay and high child behaviour problems) were risk factors related to less positive parenting and that mothers with more education engaged in more positive parenting at higher levels of risk than mothers with less education. This finding suggests that education and high family income are important variables in reducing the burden of caring for a child with ID whilst increasing resilience.

Access to social support varied for mothers in this study. While some mothers had very good and varied sources of social support, other mothers had little or no social support. Informal sources of social support such as spouse, friends, relatives, neighbours were the most accessible. Family social support was the commonest source of support for all mothers. This was particularly from spouse and siblings of the child. Some mothers also got material support from friends and community members in the form of food and clothes. However; there was very little support from social organizations or Non-Governmental Organisations which appeared non-existent. Accordingly, mothers with greater levels of social support experience lower levels of

parenting stress as a result of informal kinship and social organisations (Hill & Rose, 2009). Formal sources of social support which include healthcare professionals, social workers, teachers, social organisations, support groups and other professional organizations (Tsai & Wang, 2009) were not readily accessible to mothers in the present study. These sources of support often provide informational and material support. The mothers in the present study indicated that health professionals did not give them any information about the child. Similarly, Tsai & Wang (2009) whose study established a negative correlation between strain and social support indicating that the higher the social support the lower the level strain also found that emotional support received the highest score and informational support received the lowest score. As in the present study, mothers could only get emotional and physical support from family members but not informational support which can be accessed from formal sources which were not readily available to mothers. Mothers therefore had to figure out by themselves what was wrong with the child and what to do to help them which contribute to their stress. Besides mothers need information, training and practical support to perform their caring role effectively while maintaining the wellbeing of the family (Griffith & Hastings, 2013b)

Apart from that, healthcare services were not organized into a comprehensive package for this group of people as most mothers expected. There was also just one specialist to attend to the children and also this specialist is not permanent or resident in the metropolis but comes occasionally. As a result mothers go through a lot of stress to access health care for their children. Similar findings were reported in a study where mothers highlighted that getting access to services required a huge effort owing to little or no collaboration and coordination of services for children with intellectual disability (Griffith & Hastings, 2013a).

Unequal media reportage and attention of policy makers to issues concerning children or people with intellectual disability as compared to other types of disability was a great concern to some mothers in the study. They felt that most of the social interventions available for people with disability only benefit those with physical disabilities and not people with intellectual disability. They suggested the formation of a mother support group as the first step to addressing this issue with the hope that mothers would serve as the mouth piece and advocates for their children with intellectual disability because the children cannot talk for themselves.

Additionally, some mothers' expectations regarding their children's education were not met by the special school and the educational policies regarding special education. For instance, a mother felt that the school adopted by the region for reintegrating the children to mainstream education did not have the right person to head it. She also lamented over the kind of training given her daughter at the special school adding that she had rather deteriorated. Others were also disappointed at the school's decision for parents to withdraw their grown children and enrol them into apprentice in various vocational training programmes. They felt that the teachers in that school having undergone special training on how to handle such children would be the best people to train the children in any skill. They also thought that it would be difficult combining the intellectually challenged with normal apprentices for training. This increased their worry about the future of the children. These findings are consistent with a study in Canada by Dyson (2010) which reported parents having negative relationship with the school system as a result of unsatisfactory encounters which included incompetent initial assessment, uncoordinated service delivery, labelling, and rejection of the child. However issues of labelling and rejection of the child at school were not found in the present study.

In summary, the findings of the study were consistent with the constructs of the ABCX model of family stress. In line with 'A' (event and its hardships), the study has established that mothers caring for a child with intellectual challenge go through hardships including physical, emotional, social, financial, and work difficulties. Physically, they are burdened with excessive care giving demands like assisting the child in performing activities of daily living and training the child towards independence. Dealing with challenging behaviours that children display, getting treatment for the child and protecting the child from harm also physically affect the mother. These difficulties result from lack of knowledge and information from healthcare providers on the nature of the child's condition and its management. Mothers are also emotionally laden with worry and frustration, anger, disappointment, shame, blame and fear. Worry and frustrations about the child growing up to be independent was experienced by all the mothers in the study. Divorce, separation from family, neglect, family pressure to 'shie' the child, stigma and discrimination, pretence, social isolation, and negative public judgment of mothers mothering role were the social challenges encountered by mothers in this study. Some of the mothers could not meet basic needs of the child, or easily afford medications and transportation of the child to hospital or/ and school as a result of poverty or low income status. Working mothers initially faced difficulties regarding where to leave the child during working hours prior to when the special school was established. Apart from that, they also had to wake up extra early to prepare the children who in most cases are not cooperative, in order not to be late for work. They may also be forced to leave work to go and check on the child at home and return to work on days that the child is not able to go to school. Marital, educational, employment and income status greatly determined the levels of difficulties experienced by the mothers.

The mothers relied on social support of their spouses, siblings of the child, relatives, friends and neighbours as crises-meeting resources ('B') to deal with their challenges. Some mothers sought informational support by contacting health professionals, reading, or actively joining an association of parents with disability. This means that informational support could only be accessed by educated mothers. The special school also served as a source of support for mothers. However, mothers could not get support from social welfare service due to the bureaucratic procedures involved. Apart from these resources, mothers also used emotion - focused coping strategies which temporarily served to relieve their emotional stress and problem-focused coping strategies which sought to practically address the challenges they faced. Some of the emotion-focused strategies were, observing, ignoring, self encouragement, and self control while reframing, seeking information, acceptance, enrolling the child in special school were some problem focused coping strategies employed by the mothers.

In defining their situation or making meaning of the event ('C'), the mothers were optimistic about future independence, work and marriage of their children. They also gave positive descriptions of the child as lovely, sociable, and fun to be with. Others were also pessimistic or uncertain about the child's future. They thought that the children were so much dependent on them and very slow at learning any skill because of their low IQ and so would not be able to work or marry in future. They however hoped that they could get better interventions that could help the children improve. The mothers generally attributed medical causes such as convulsion, prolonged labour, prenatal infections and genetic causes to their children's condition. They did not believe in superstitious causes even though people around them attributed some cultural beliefs such as staying out late in the night whilst pregnant, to be possible causes of the child's condition. Although mothers in the study were generally healthy, the care giving

trajectory had physical and mental health outcomes ('X') for the mothers. Physically, they had sleepless nights often waking up tired, waist pains, and weight loss. Mentally, they were constantly thinking, worrying and often emotional about the child's condition but not clinically depressed.

Other findings that were not clearly consistent with the constructs of ABCX model of family stress were maternal characteristics, access to social support and unmet expectations of mothers regarding health, education, social services and the media. These were factors identified that predisposed the mothers to stress.

CHAPTER SIX

SUMMARY, IMPLICATIONS, LIMITATIONS, CONCLUSION AND RECOMMENDATIONS

This chapter presents the summary of the entire study, implications, limitations, conclusions and recommendations.

6.1 Summary of the Study

The study explored the experiences of mothers with intellectually challenged children using the ABCX model of family stress as a guiding framework. Prior to commencement of data collection, ethical approval was sought from Institutional Review Board of Noguchi and permission from Yumba special school. Data collection started on 15th October, 2014 and ended on 16th February, 2015. Participants gave their consent by signing or thumb printing consent forms before interviews were conducted. Each interview was audio taped and transcribed verbatim and data analysed using thematic content analysis.

The key findings of the study indicate that mothers encounter physical, emotional, financial, work and social challenges as a result of having and caring for a child with intellectual disability. They experience difficulties in training the child, dealing with excessive care giving demands and challenging behaviours displayed by the child. They are emotionally laden with worry, frustration, disappointment, anger, and blame and may suffer divorce, separation from family, neglect, social isolation and discrimination. Some mothers also experience financial difficulties in meeting basic needs of the child and paying for medications and transportation to and from hospital and school.

Child characteristics such as degree of dependence and maternal characteristics such as level of education and income level were factors which predisposed mothers to stress. Apart from that, mother's access to social support also plays a key role in determining if the mother will be overwhelmed. Moreover, the mothers expected to be given adequate information about the child's condition and its management by health care providers and that health care services for children with intellectual disability would be organized into a more comprehensive package which was not the case. This would have enabled them to better care for their children and also reduced the stress that mothers experienced. The mothers were also concerned about the apparent lack of attention of media and relevant bodies on issues related to people with intellectual disabilities. A few mothers felt that the special school should have helped to train their children in vocational skills instead of asking parents to enrol the children in apprenticeship outside the school. These unmet expectations predisposed mothers to stress by increasing their worries and frustrations.

However, the mothers used various sources of support and coping strategies to deal with their situations. Informal sources of support were mainly their spouses and siblings of the child and in some cases, relatives, friends and neighbours. These sources provided mainly emotional and physical support to mothers. However, getting formal support from health care providers, social organizations and support groups required a huge effort from mothers as they were not readily available. The mothers used both emotion-focused and problem-focused coping strategies to help them adjust and adapt with their situation. Emotion-focused coping strategies employed by the mothers include, observing, ignoring, satisfaction from seeing improvement in the child, comparing the child with other children with intellectual disabilities, self-encouragement and self-control. Positive reframing, seeking information from health workers and by reading,

acceptance, prayers, were the problem-focused coping strategies employed by the mothers in this study.

While some mothers were optimistic about future independence, work and marriage of their children, others were either pessimistic or uncertain about the future. The mothers also gave positive descriptions of their children and did not see the child as a burden or a curse. They generally attributed the cause of their children's condition to medical reasons such as convulsions, prenatal infections, and prolonged labour and genetic conditions. However, according to the mothers, the people around them related the child's condition to certain cultural beliefs and superstitions.

Lastly, the mothers identified physical health outcomes such as sleeplessness, tiredness, waist pains and loss of weight and mental health outcomes such as thinking, worrying and frustrations as related to caring for their children with intellectual disability.

6.2 Implications

The findings of the study have some implications in relation to nursing practice, nursing education, nursing research and policy formulation.

6.2.1 For Nursing Practice

The findings of the study indicate that mothers expectation of health workers especially nurses to assist them understand their children's condition and how they can better assist them was not met. The mothers indicated that they were not told anything about the child's disability before being discharged from the hospital. It therefore supposes that nurses have an important role to play in supporting mothers who bring their children with intellectual disability to health facilities. Nurses are expected to give mothers the needed information and practical assistance to

help them train the child and also manage the maladaptive behaviours that the children display. Nurses, especially those at the neonatal and/or paediatric units should also be able to detect early signs of intellectual disability and refer for further assessment for the diagnosis to be established. They should also counsel mothers from the early stages of the diagnosis and let them know what to expect as the child develops and how they can assist the child at each stage. This will help mothers adjust and adapt quickly to their situation thereby reducing their stress.

6.2.2 For Nursing Education

There is information gap between nurses and mothers of children with intellectual disabilities. To bridge this gap, there is the need for inclusion of intellectual disability issues into the curricular for training of nurses both theoretically and practically. The curriculum should address the knowledge gap of nurses and improve their ability to effectively communication with children with intellectual challenges. This will enable nurses offer mothers or parents appropriate information regarding the various intellectual disabilities, their causes, characteristic features, behaviours to expect, possible interventions for these behaviours and where to find them.

In Ghana currently, there is no room for specialization in intellectual disability nursing as in other countries. Institutions of nursing training such as universities and nurses training colleges could develop curricular for Intellectual Disability Nursing (IDN) and introduce this as a specialty nursing programme in the discipline either as an undergraduate or post graduate course. This would help prepare nurses with the resources to address the unique health needs of the growing population of people with intellectual disabilities and their families across lifespan in all settings.

6.2.3 For Nursing Research

This study revealed the need for further research on experiences of mothers with intellectually challenged children to provide better understanding of the phenomenon. The present study explored the experiences of mothers through a qualitative application of the ABCX model of family stress. Future studies could measure key variables in the ABCX model quantitatively to assess the magnitude of burden, resources, and outcome on mothers. Tamale metropolis, the setting of this study, is an urban city; future studies could explore experiences of rural mothers. Other areas of interest may be to explore the experiences of fathers or the whole family as a unit or the perspectives of health workers and teachers in the special school in order to get a broader understanding of the challenges and successes in caring for a child with intellectual challenge.

6.2.4 For Policy Formulation

The findings revealed that mothers had difficulties getting treatment for their children because of the disorganized nature of the services and because of frequent shortage of certain drugs at the health facilities. Mothers also identified lack of specialist to attend to the children. It therefore beholds on the policy making body of the Ministry of Health to formulate policies that ensure that health facilities are intellectual disability friendly, and that specialist are trained to meet the needs of such special people.

6.3 Limitations

The researcher acknowledges limitations of the study. The relatively small sample size and the specific context of the study was aimed at acquiring rich descriptive data. As a result, the sample may not be representative of the general population and, therefore, generalization of the findings should be considered with caution. However, the findings are consistent with other

studies in Ghana and other countries and therefore transferability is possible when there is similarity of context.

Translation of some data may pose a threat to trustworthiness as the exact meaning of some expressions may be lost, however extreme efforts were made to use words and expressions which are closest to the translated words.

6.4 Conclusions

Most of the findings of the study were consistent with the constructs of the ABCX model of family stress. These include, challenges of caring for a child with intellectual challenge, child characteristics, crises-meeting resources, meaning mothers make of the event and outcome on mother's health. Other findings that were not clearly consistent with the constructs of ABCX model of family stress were maternal characteristics, access to social support and unmet expectations of mothers regarding health, education, social services and the media. The findings reveal that the mothers encounter many challenges while caring for a child with intellectual challenge which tends to physically and mentally affect their health. Various sources of social support and coping strategies are employed by the mothers help them deal with their situations. The mothers' perceptions about the child were varied. They were optimistic, pessimistic or uncertain about the future of the child but generally attributed medical causes to the child's condition. However they believed that with the right interventions and by faith, their children will have better future. In conclusion, the study found that mothers, who were educated, had good income, were able to access formal support, and had better understanding of the child's condition and its management and coped better. However, there is the need for early detection, counselling and education of mothers about the child's condition. This will help in the adaptation of mothers and result in improved health outcomes of both mother and child. Therefore,

curriculum for training of health professionals should be developed or adapted to include intellectual disability issues in order to prepare them adequately to meet the health needs of children with intellectual disability and their families in Ghana.

6.5 Recommendations

The following recommendations have been made based on the findings of the study to the following bodies and institutions.

6.5.1 To Ministry of Health (MoH)

The ministry should;

- Carry out screening exercises to identify children with ID for early intervention.
- Intensify education of the public through the media on the causes of ID to eradicate stigma and discrimination and also solicit public support for them.
- Ensure that all health professional have adequate knowledge about ID and train specialists in ID care.
- Give priority to children with ID at all Out Patient Departments (OPDs) of health facilities.
- Ensure constant supply of required medicines.
- Collaborate with relevant agencies and stakeholder to establish rehabilitation centres for therapies and training and design interventions to support mothers.

6.5.2 To Ministry of Education (MoE)

The ministry should;

- Critically appraise the existing special schools and ensure that they are adequately resourced to benefit the children and in effect, their mothers as well.
- Set up more special schools or provide selected mainstream schools with qualified staff and resources so that the children with ID can benefit from education.
- Establish vocational training institutions or equip the special schools with trained personnel and resources to teach the children various vocational skills to help them be self employed in future.

6.5.3 To the Department of Social welfare

The department of social welfare should;

- Collaborate with the National Council on Disability, the Ministry of Gender, Children and Social Protection (MGCSP), and NGOs to put up support systems specifically for families of children with ID
- Set up and resource rehabilitation centres to train children with ID.
- Ensure that the systems operate impartially and with minimal bureaucracy.

6.5.4 To the General Public

The public should;

- Avoid discrimination or stigmatization of people with ID or their families
- Support people with ID to live normal lives.

6.5.5 To mothers

- Mothers should come together to form mother-to mother-support groups to encourage and support each other and also advocate for their children.

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APPENDICES

**Appendix A: Ethical Clearance (Noguchi Memorial Institute for Medical Research-
Institutional Review Board)**

<p>NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH <i>Established 1979</i> <i>A Constituent of the College of Health Sciences</i> University of Ghana</p>		
<p>Phone: +233-302-916438 (Direct) +233-289-522574 Fax: +233-302-502182/513202 E-mail: nirb@noguchi.ug.edu.gh Telex No: 2556 UGL GH</p>	<p>INSTITUTIONAL REVIEW BOARD</p> 	<p>Post Office Box LG 581 Legon, Accra Ghana</p>
<p>My Ref. No: DF.22 Your Ref. No:</p>		<p>3rd September, 2014</p>
<p>ETHICAL CLEARANCE</p>		
<p>FEDERALWIDE ASSURANCE FWA 00001824</p>		<p>IRB 00001276</p>
<p>NMIMR-IRB CPN 008/14-15</p>		<p>IORG 0000908</p>
<p>On 3rd September 2014, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting reviewed and approved your protocol titled:</p>		
<p>TITLE OF PROTOCOL</p>	<p>: Experiences of mothers with intellectually challenged children in Tamale Metropolis</p>	
<p>PRINCIPAL INVESTIGATOR</p>	<p>: Millicent Aarah-Bapuah, MPhil Cand.</p>	
<p>Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.</p>		
<p>Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.</p>		
<p>Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.</p>		
<p>This certificate is valid 2nd September, 2015. You are to submit annual reports for continuing review.</p>		
<p>Signature of Chair:</p>		
 <p>Mrs. Chris Dadzie (NMIMR – IRB, Chair)</p>		
<p>cc: Professor Kwadwo Koram Director, Noguchi Memorial Institute for Medical Research, University of Ghana, Legon</p>		

Appendix B: Introductory Letter

**SCHOOL OF NURSING
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA
LEGON**

Telephone: 0302-513255 (Dean)
Ext. 6206
0302-513250 } Secretary
028 9531213 }

Fax: 513255
E-mail: nursing@ug.edu.gh



P. O. Box LG 43
LEGON, GHANA

Our Ref: SON/F.11
Your Ref:

August 14, 2014

The Headmistress
Yumba Special School
Tamale
N/R

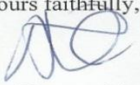
Dear Sir/Madam,

INTRODUCTORY LETTER

I write to introduce to you Millicent Aarah-Bapuah, an MPhil student of the School of Nursing, University of Ghana, Legon. She is conducting a research project on “**Experiences of Mothers with Intellectually Challenged Children in Tamale**”.

I should be most grateful if you could kindly assist her with the information that she may require.

Thank you.

Yours faithfully,


Dr. Florence Naab
SUPERVISOR

Appendix C: Information Sheet

INFORMATION SHEET

Title of Research: Experiences of Mothers with Intellectually Challenged Children in Tamale Metropolis

Purpose of Study: This study is been carried out for academic purposes and is intended to explore the experiences of mothers with intellectually challenged children in Tamale Metropolis.

Objectives of the Study

The objectives of this study are to;

1. Describe the challenges of mothers with intellectually challenged children in Tamale
2. Identify the factors that predispose mothers of intellectually challenged children to stress.
3. Identify the coping strategies of mothers with intellectually challenged children
4. Explore the perceptions of mothers about the disability of their children.
5. Describe the impact of the child's disability on the health of mothers.

Study Participants

Inclusion Criteria: The study will include biological and foster mothers of intellectually challenged children of Yumba Special School who consent to participate in the study. The study will also include only mothers who can speak at least Dagbani, Mampruli, Dagaare or English.

Exclusion Criteria: Mothers with intellectual disability or poor mental health will be excluded from the study.

Ethical Considerations

This study has received ethical approval from Institution Review Board (IRB) of Noguchi Memorial Institute for Medical Research. Principles such as consent procedures, ensuring confidentiality, privacy, risk and benefit will be followed. The researcher will explain the purpose, objectives and potential benefits and risk to participants in their preferred language and give them ample time to decide on their participation.

Possible Risk and Discomfort

You are not exposed to any risk by your participation in this study. However, some questions may make you uncomfortable during the interview. You have the right to refuse to answer any questions that may make you feel uncomfortable. Besides, in case you are disturbed, the services of a counsellor will be made available at no cost to you (counsellor's contact details: Mrs Genevieve Jimpetey; 0208976621).

Possible Benefits

There are no direct benefits to you as a participant. However the potential benefit of your participation is that you have the opportunity to share your experiences which may be used to help other mothers in similar situations. Also, your participation will provide health workers and the general public an insight into the challenges and successes involved in caring for a child with intellectual disability.

Confidentiality

The interview will be audio-tape recorded with your permission. However, your name, address or any information that may link you to the information you provide will not be recorded. If you

mistakenly mention names during the interview, such names will be replaced with false names instead. The information you provide will be kept under lock and key and will be accessible only to my supervisor and me.

Compensation

You will not be given any money but a snack will be provided to replenish your energy after the interview.

Voluntary Participation and Right to Leave the Research

Your participation to this study is voluntary and you have the right to withdraw from the study at any point in time. Your withdrawal from the study will not affect any services your child receives from the school.

Contacts for Additional Information

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Phone number: +233 (0) 242388584/261115892

Email: mwombeogo@yahoo.com

Appendix D: Consent Form

Title: Experiences of mothers with intellectually challenged children in Tamale Metropolis

Principal Investigator: Aarah-Bapuah Millicent

Address: School of Nursing, College of Health Sciences, University of Ghana, Legon-Accra.

General Information about the Research

Caring for children with intellectual disability could be very challenging for all members of the family. The reason for this research is to understand what is involved in being a mother with an intellectually challenged child or children. If you agree to be part of this study, i would like you to share with me your challenges, your resources, how you cope or deal with your situation and also your opinion about your child and any effect that caring for your child may have on your own health. You will be invited for an interview in which you and i will have a chat for about thirty minutes to one hour. However, you may be contacted after the interview or chat for any clarifications or confirmation on the information you give within three months after the chat. We will use English, Dagbaani, Mampruli or Dagaare depending on which one you can speak well. You are free to share with me information that you have regarding the care of your child. You will be required to sign or thumbprint a consent form to show your agreement to participate before we begin the chat. With your permission the chat will be recorded with an audio tape and written out later.

Possible Risk and Discomfort

You are not exposed to any risk by your participation in this study. However, some questions may make you uncomfortable during the interview. You have the right to refuse to answer any

questions that may make you feel uncomfortable. Besides, in case you are disturbed, the services of a counsellor will be made available at no cost to you (counsellor's contact details: Mrs Genevieve Jimpetey; 0208976621).

Possible Benefits

There are no direct benefits to you as a participant. However the potential benefit of your participation is that you have the opportunity to share your experiences which may be used to help other mothers in similar situations. Also, your participation will provide health workers and the general public an insight into the challenges and successes involved in caring for a child with intellectual disability.

Confidentiality

The interview will be audio-tape recorded with your permission. However, your name, address or any information that may link you to the information you provide will not be recorded. If you mistakenly mention names during the interview, such names will be replaced with false names instead. The information you provide will be kept under lock and key and will be accessible only to my supervisor and me.

Compensation

You will not be given any money but a snack will be provided to replenish your energy after the interview.

Voluntary Participation and Right to Leave the Research

Your participation to this study is voluntary and you have the right to withdraw from the study at any point in time. Your withdrawal from the study will not affect any services your child receives from the school.

Contacts for Additional Information**Millicent Aarah-Bapuah**

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Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your right as a research participant you can contact the IRB office between the hours of 8am-5pm through the landline 0302916438 or email address: nirb@noguchi.mimcom.org

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title
“Experiences of mothers with intellectually challenged children in Tamale Metropolis” has
 been read and explained to me. I have been given an opportunity to have any questions about the
 research answered to my satisfaction. I agree to participate as a volunteer.

Date

Name and signature or mark of volunteer

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risk and procedures were read to the volunteer. All questions
 were answered and the volunteer has agreed to take part in the research.

Date

Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with
 participating in this research have been explained to the above individual.

Date

Name and signature of Person who Obtained Consent

Appendix E: Interview Guide

Section A: Demographic Information

1. What is your name?
2. How old are you?
3. What is your level of educational?
4. What work do you do?
5. How much do you earn in a week or a month?
6. What language (s) do you speak?
7. Where do you live?
8. Are you a Ghanaian?
9. Which Religious faith do you belong?
10. Are you married?
11. How many children do you have?
12. Is your child with disability your first child
13. How old is your child with disability

Section B: Guiding Question

A: Having a child with intellectual disability and the difficulties it presents to the mother

- Please begin by telling me about your child who is disabled
- What is your typical day like?
- Tell me about the difficulties you face
- How has caring for your child altered your choice of activities you participate?

B: Crises-meeting resources: Resources used by mothers to deal with the event (having a child with ID)

- Describe all the factors that affect how you are able to look after your child to your satisfaction
- Do you go into the community with your child?
- How are you and your child treated in the community?
- How are you and your child treated in your family?
- Tell me about a time when things have gone well in your family
- How do you manage practical and emotional demands?
- Tell me about your interaction with health care or social service
- How do you mobilize resources?
- Tell me about how you deal with the difficulties you face?

C: Meaning the Individual makes of the Stressor Event; the meaning mothers make of having a child with an intellectual disability

- What do you think about your child's disability?
- What do you think is the reason for his/her disability?

- What are your strongest feelings and emotions about your child's disability?
- How do you see your child in the future?

X: Outcome

- How do you relate with your child with disability?
- How has having the child with disability affected your role as a mother?
- How would you describe your own health?
- How has having the child with disability affected your health?
- What advice would you give another woman in your situation who is just beginning a similar journey?

Appendix F: Thematic Codes and Descriptions**Table 8.1: Description of Themes and Subthemes**

Themes and subthemes	Codes	Description
1.Challenges in caring for intellectually challenged child	CHA	The difficulties and hardships associated with caring for a child with intellectual disability
i. Physical challenges	Phy	Difficulties related to physical work of care giving
ii. Financial challenges	fin	Monetary difficulties face by mothers
iii. Work challenges	wrk	Difficulties mothers experienced with their employment or work
iv. Emotional challenges	emo	Provoking feelings that the mothers experienced such as disappointment and heartbreak.
v. Social challenges	soc	Difficulties mothers experienced regarding their interaction with family, friends, neighbours and society in general
2.Crises meeting resources	RES	Assets that are at the disposal of mothers of children with ID which help them manage with their difficulties
i. Sources of support	Sop	People and institutions which assisted mothers and their children and family
ii. Coping Strategies	cop	Ways and means employed by mothers in dealing with their situation
3.Meaning mothers make of event	MMM	The definitions mothers gave to their situation.
i. Optimism/positive emotions	opt	The perception that the child is a beautiful gift of God who will be independent in future
iii. Negative emotions	neg	The perception that the child has no

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future

iv.	Perception of mothers about causes	per	The subjective reasons the mothers gave for the child's disability
4.	Outcome	OUT	Outcome describes the effects of the interaction of having a child with intellectual challenge and its accompanying hardships with mother's resources and coping mechanism and the meaning they make of their situation on the mother's health and functioning.
	Maternal Health Outcome	mah	The effects of having and caring for a child with ID on the health of the mother
5.	Factors which predisposes mothers to stress	FPS	Issues which by their absence are presence increased mothers' burden.
i.	Child characteristics	cch	This refers to features of the child that made the child more dependent or otherwise on the mother
ii.	Maternal characteristics	mch	This refers to qualities of the mother that made her more or less resistant to stress
iii.	Access to social support	Ass	This involves the availability or otherwise of social support to mothers
iv.	Unmet expectations	une	This refers to hopes that mothers had on the educational, health and social systems which were not met.

Appendix G: Summary of Demographic characteristics of Study Participants**Table 8.2: Demographic Characteristics of Study Participants**

PSEUDONYM	ANGELA	CHARITY	MARY	APOKA	AYI	HAWABU	MPAGA	SELMA	AKOLPOKA
AGE	50	61	38*	54	38	40	56*	40	48
LEVEL OF EDUCATION	Tertiary	Tertiary	No	Tertiary	JSS	No	No	JSS	Tertiary
TYPE OF WORK	Teacher	teacher	cleaner (not on roll)	Teacher	Cook	Cleaner (ZL)	Food (yoroyoro) seller	Cleaner	Teacher
MONTHLY INCOME (Ghc)	909	Retired	15	1500	350	-	No savings	250	850
LANGUAGE USED	English	English	Dagbani	English	English	Dagbani	Dagbani	Dagbani	English
WHERE LIVE	Sakasaka	T. poly	Kparesi	Russian bungalows	Wamale	Changli	Dohinayili	Wamale	Jisonayile
NATIONALITY	Ghanaian	"	"	"	"	"	"	"	"
RELIGION	Christian	Christian	Muslim	Christian	muslim	Muslim	Muslim	Muslim	Christian
MARITAL STATUS	Married	Married	Divorced	Married	Widowed	Widowed	Married	Divorced	Married
NO. OF CHILDREN	1biologic (dead) 3adopted	2	8, 2D;6A	4	7, 1D;6A	3, 1D;2A	5	8, 2D;6A	5
POSITION OF CHILD WITH ID	-	1 st	2 nd	3 rd	5 th	1 st & 2 nd	5 th	8 th	1 st
AGE OF CHILD/SEX	24yrs/M	20yrs/F	8yrs/M	28yrs/F	18yrs/F	15 & 10 M	20yrs /F	16yrs/M	26yrs/F