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SCHOOL OF NURSING

COLLEGE OF HEALTH SCIENCES

UNIVERSITY OF GHANA LEGON

# ADAPTATION EXPERIENCES OF FAMILY CAREGIVERS OF CHILDREN WITH CONGENITAL BIRTH DEFECTS IN THE ACCRA METROPOLIS.

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

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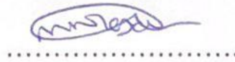
# DECLARATION

I, Daniel Yao Ahiable, certify that, this thesis is the result of a research undertaken, towards the award of Master of Philosophy in Nursing Degree in the School of Nursing and Midwifery, University of Ghana, Legon. This research has been undertaken under the guidance and supervision of Dr. Mary Ani-Amponsah, School of Nursing and Midwifery, University of Ghana, Legon and Mr. Armin Jibril Muhammad, also of School of Nursing and Midwifery University of Ghana Legon. The undersigned supervisors certify that they have read the thesis and have recommended it to the School of Nursing and Midwifery for acceptance.

DANIEL AHIABLE YAO ....20/09/2021....

(STUDENT) Signature Date

DR. MARY ANI-AMPONSAH  ........................ ....20/9/2021....

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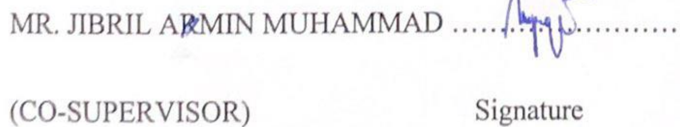

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# DEDICATION

I dedicate this thesis to my family, without whom I could not have succeeded in my academic endeavour. My wife and daughter deserve special mention for their support, love, understanding and sacrifice throughout the period. This work is also dedicated to the Director of Medical Services and the authorities of the 37 Military Hospital, for giving me study leave to pursue the course.

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# LIST OF ABBREVIATIONS

| | |
|---|---|
| CINAHL | Cumulated Index to Nursing and Allied Health Literature |
| DALYS | Disability Adjusted Life Years |
| MOH | Ministry of Health |
| NCD | National Council on Disability |
| UNICEF | Unite Nations Children's Fund |
| WHO | World Health Organisation. |
| YLL | Years of Life Lost |

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# ABSTRACT

Literature evidence indicate that, taking care of children with congenital birth defects can be a difficult task to the caregivers, who most of the time are mothers, fathers or dedicated family relations of the children. The caregiver role is seen to be associated with a lot of hassles, which may predispose the prospective caregivers to psychological as well as physical ill-health situations. However, only few works have been done on the experiences of caregivers of children with condition-specific defects in Ghana. This work therefore explored the adaptation experiences of family caregivers of children with congenital birth defects in the Accra Metropolis, using the transactional stress model by Lazarus (1991), as the guiding framework and adopting five objectives suggested by its constructs. The study adopted a qualitative descriptive approach. Data was collected through in-depth face to face interview sessions with thirteen (13) purposively selected participants, using the Dzorwulu special school as the setting. The interviews were audio-taped, transcribed verbatim and analysed using thematic content analysis. In all, seven themes were identified as follows; Life events of family caregivers, appraisals of these events, resources and support available to them, health consequences they face, their coping strategies, adaptation measures and their religiosity. In conclusion the study found out that; family caregivers consider having a child with congenital birth defects as a major life event, face a lot of challenges in caring for them with less resources and support. But the effect on their health was minimal as they adopted a number of coping and adaptation strategies. Meanwhile, religiosity appeared to have given them respite on issues that went beyond their imagination. Specific policies are therefore required to support caregivers of children with congenital defects to enhance their role.

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# CHARPTER ONE: INTRODUCTION

In this chapter, the background information, problem statement, purpose and objectives of the study, significance of the study and the operational definition of key terms are presented.

## 1.1 Background of the Study

Children are perceived as gifts from God, and as such, caring for them brings God's blessing to the caregiver and vice versa (Aarah-Bapuah, 2015; Corcoran, Berry, & Hill, 2015; Darkwah, Daniel, & Asumeng, 2016). Parents will therefore like to see their children happy, maximize their full potentials, and not be limited by any disability (Besnoy et al., 2015; Finke et al., 2019). Even before a child is born, the first thing most parents want to know about, is whether the baby is healthy (Nykänen, Vehviläinen-Julkunen, & Klemetti, 2017; Øyen & Aune, 2016). When parents learn about a baby's birth defect in the prenatal period, they are often devastated (Carlsson, Starke, & Mattsson, 2017; Zeytinoğlu, Davey, Crerand, Fisher, & Akyil, 2017). They may become so preoccupied with their baby's medical condition and medical visits that, they cannot enjoy their pregnancy (Carlsson et al., 2017). After birth, if a child is diagnosed with a birth defect, parents often go through stages of grief, similar to those they would have, if they had lost the child (Bonsu et al., 2018; Hlongwa & Rispel, 2018). While that may seem odd to many, the parents actually did lose a child, the "normal," healthy child that they were expecting (Nahal, Wigert, Imam, & Axelsson, 2017).

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Birth defects are also known as congenital anomalies, congenital disorders or congenital malformations. Congenital anomalies can be defined as; structural or functional anomalies (e.g. metabolic disorders) that occur during intrauterine life and can be identified prenatally, at birth or later in life (WHO, 2016 ). There are over seven thousand (7000) types of known birth defects (Sarmah, Muralidharan, & Marrs, 2016), the severest and commonest of which include; congenital heart defects, neural tube defects and down syndrome (WHO, 2016 ). Although approximately 50% of all congenital anomalies cannot be linked to a specific cause, there are some known causes or risk factors (WHO, 2016 ). Risk factors for congenital disorders include genetic, environmental and wider societal factors (Moorthie, Blencowe, Darlison, Lawn, Mastroiacovo, et al., 2018). The occurrence and severity of specific congenital disorders are differentially influenced by these risk factors, with some disorders influenced more by genes (e.g. single gene disorders) and others by environmental agents (e.g. those caused by infections) (Moorthie, Blencowe, Darlison, Lawn, Mastroiacovo, et al., 2018). A positive family history (having a similarly affected first degree relative) was documented to have links with the incident of having a child with congenital defects (Feldkamp, Carey, Byrne, Krikov, & Botto, 2017).

Maternal infectious diseases such as Syphilis and Rubella are a significant cause of birth defects in low-and middle-income countries (WHO, 2019). Maternal illnesses like diabetes mellitus, conditions such as iodine and folic acid deficiency, and exposure to medicines and recreational drugs, including alcohol and tobacco, certain environmental chemicals, and high doses of radiation are other factors that can cause birth defects (WHO, 2019). On the 1st of February 2016 the World Health Organization (WHO) declared the strongly suspected causal link between Zika virus infection in pregnant women and

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microcephaly in newborns a Public Health Emergency of International Concern (WHO, 2016 ).

Raising a healthy child put parents in need to have ongoing changes in their lifestyle and arrangements to face constant changes with child growth, this need would therefore be doubled for parents of children with disabilities (Bawalsah, 2016). Children with congenital malformations have an enormous direct impact on their parents and family, beginning from the prenatal period, spanning through the entire life of the child in some cases (Emordi & Osifo, 2018). An estimated 70% of congenital disorders are preventable or their effect can be substantially mitigated and quality of life improved (Darmstadt et al., 2016). Yet, an 'incurable' anomaly may endanger the whole family's wellbeing, as key resources must be allocated to care for the afflicted child (Sitkin, Ozgediz, Donkor, & Farmer, 2015).

Birth defects affect us all, but particularly families with children who have any or multiplicity of them (Feldkamp et al., 2017). Globally, an estimated 303, 000 newborns die within 4 weeks of birth every year, due to congenital anomalies (WHO, 2019). Since deaths as a result of congenital defects tend to occur so early in life (Liu et al., 2012), the burden in years of life lost (YLL) is higher (Boyle et al., 2018). In terms of disability adjusted life years (DALYS), these defects account for 25.3-38.8 million globally (Murray et al., 2012). According to a Global, regional, and national causes of under-5 mortality in 2000–15, compiled as an updated systematic analysis with implications for the Sustainable Development Goals, 54 countries described as; low mortality stratum for neonatal and infant mortality, have congenital abnormalities, as their leading cause of death (Liu et al., 2016). In the United States and China, congenital abnormalities are the leading cause of

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under-five mortality (Liu et al., 2016). It is estimated that, about 94% of severe congenital anomalies occur in low- and middle-income countries (WHO, 2019). Even though not the leading cause of under-five mortality, the number of death related to congenital defects in low and middle income countries are higher, compared to areas where it is the leading cause of infant death (Liu et al., 2016). The most frequent types of birth defects in the sub-Sahara African region include, musculoskeletal defects, followed by neural tube defects, cardiovascular defects, gastrointestinal defects, orofacial clefts and other unspecified defects form the minority (Adane, Afework, Seyoum, & Gebrie, 2020). Meanwhile, disability at age 5 due to congenital disorders also continue to rise in the Eastern Mediterranean, African and South-East Asian regions (Moorthie, Blencowe, Darlison, Lawn, Mastroiacovo, et al., 2018). Literature on incidence or prevalence rate of congenital defects in lower and middle income countries is scarce. (Toobaie et al., 2019). This appears to be the case of most Sub Saharan African countries.

In Ghana, a 2015 UNICEF report, placed congenital anomalies as the fourth leading cause of neonatal death, contributing to about 10.3% of all cases (UNICEF, 2016). Another study conducted on; the predictors of infant mortality in the Ashanti region, reported a finding of 9.3% of infant mortality being caused by congenital anomalies (Annan & Asiedu, 2018). Even though, caregivers face a lot of challenges in caring for children with congenital defects, studies have shown that, some care givers show so much resiliency and are able to adapt to the situation better (Aarah-Bapuah, 2015; Amae, Kamiyama, & Ueno, 2017). Parents of children with disabilities tend to use various strategies to cope with stress (Amae et al., 2017; Findler, Jacoby, & Gabis, 2016). Contrary to this, in some jurisdictions, children with congenital defects are met with hostility. Studies have shown that, some are

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locked up in rooms because, they consider them to be a disgrace to the entire family (Bonsu et al., 2018; Hlongwa & Rispel, 2018).

Through literature review, it is evident that, many research works revealed stress associated with caring for children with congenital defects and the various factors responsible for the situation (Aarah-Bapuah, 2015; Bonsu et al., 2018; Edwin, Edwin, & McGee, 2015; Hlongwa & Rispel, 2018; Zeytinoğlu et al., 2017). Other studies reported favourable outcomes resulting from how resilient the affected families or caregivers were and the kind of support they had (Albert, 2018; Nahal et al., 2017; Onyedibe, Ugwu, Mefoh, & Onuiri, 2018; Shilling, Bailey, Logan, & Morris, 2015). However, most of these studies were unidimensional. Thus they are condition specific works and do not give the readers the choice of listening to variety of experiences in one work. Other studies discovered during the process which focused on all the defects, were mainly quantitative and reported on the incidence rate of congenital defects on the global as well as regional scales (Moorthie, Blencowe, Darlison, Lawn, Morris, et al., 2018; WHO, 2016 ). The trend appears to be the same in Africa. Just few studies were observed to have explained the experiences of caregivers of children with congenital defects in general, qualitatively. In Ghana, apart from most of the studies being condition specific, only one study was identified to have explored caregivers' experiences using the transactional stress theory. This study will explore the adaptation experiences of family caregivers of children with congenital defects, using the Transactional Stress Model by Lazarus (1991), as the guiding framework.

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### 1.2 Problem Statement

In Ghana, giving birth to a child is every parents' expectation and this experience is met with much delight. But what happens if this expectation is met but the reality is that, the child has some form of abnormality or abnormalities? (Richter, 2019). Statistics from the national population and housing census 2010, shows that 737,743 people live with some form of disabilities representing 3% of the population of Ghana (Ghana Statistical Service, 2012). Out of this, 132,881 are children within the age of 1to 14 years (Ghana Statistical Service, 2012). However, it appears, no literature exists on the number of these disabilities, that are as a result of congenital defects. A study conducted in Tamale teaching Hospital, on some of these anomalies diagnosed at birth between the years 2011 to 2015, reported; Spina bifida as the most common visible congenital anomaly, followed by Exomphalus, orofacial cleft, Hydrocephalus, imperforated anus, talipes equinovarus, meningocele, Down syndrome, Gastroschisis, Anencephaly, meningoencephalocele, achondroplasia, imperforate urethra, siamin twins, encephalocele and other unspecified defects in that succession (Nuertey et al., 2017).

Studies in Ghana revealed that, giving birth to a child with defects is received with shock (Bonsu et al., 2018; Oti-Boadi, 2017; Zuurmond et al., 2019). It was even reported that some mothers did all the required scanning tests while the baby was in utero, but the defect was not noticed till birth (Bonsu et al., 2018). While some attach superstitious connotation to the event, others blame it on sins purported to be committed by themselves, families or their community (Antwi-Kusi et al., 2015). Some fathers were also reported to have abandoned their spouses out of disappointment, leaving the care burden on the mothers (Bonsu et al., 2018).

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Caring for children with congenital defects can be a challenging task for caregivers (Richter, 2019). Many caregivers reported varying levels of stress, affecting all aspects of family life, including decisions about work, education, family finances and social relations (Aarah-Bapuah, 2015; Bonsu et al., 2018; Oti-Boadi, 2017; Zuurmond et al., 2019) Perceived and actual stigma seem to have dominated findings reported by most of the studies encountered. Caregivers especially mothers were reported to be discriminated against (Bonsu et al., 2018). Some were even thrown out of their family houses for being cursed by the gods, resulting in giving birth to a child with congenital defect (Bonsu et al., 2018). Others reported not just family exclusion, but also hatred from family and relations, making them to avoid all social relations and live in solitude (Zuurmond et al., 2019). Furthermore, most studies reported good communication and caring relationship with health care workers, but others reported instances where; due to lack of proper diagnosis and understanding of the condition, caregivers have to hop from one traditional healer to the other (Zuurmond et al., 2019).

Corrective surgical interventions and on few occasions medical management can improve the conditions of these children and facilitate the caring relationship (Edwin et al., 2015; Sitkin et al., 2015). However, most caregivers of children with congenital defects, are faced with several challenges, preventing them from adapting and providing the care needed for these children (Oti-Boadi, 2017). Poverty was identified as one of the devastating challenges faced by family caregivers that prevented them from adjusting to the care burden (Edwin et al., 2015; Zuurmond et al., 2019). This is because, even though caregivers need money to take care of the surgeries and general upkeep of these children, some of them have to sacrifice their job and source of livelihood just to care for them

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(Edwin et al., 2015). Social support has been found as one of the coping mechanism for caregivers of children with congenital defects, but these systems are generally weak in Ghana (Richter, 2019). Hence, apart from spousal support, peer support and that of the health or rehabilitative team, most studies reported virtually the non-existence of other forms of support that persons from other jurisdiction in High Income Countries may have (Antwi-Kusi et al., 2015; Edwin et al., 2015). This further makes the caregiving burden unbearable and may result in infanticide where superstition is attached to the severe forms of these defects. For instance in 2011, a documentary featured by the Ghana news agency indicated that, children with congenital defects are being killed in the Yendi municipality located in the northern region of Ghana (Oppong-Ansah, 2012). These may also leave other caregivers with the option of expressing suicidal tendencies as captured in the hotline documentary dubbed “Born Special”. Here a care giver of a child born with cerebral palsy revealed that, at times she feels like killing the child and committing suicide (Richter, 2019).

Chronic stress, if not well managed may not only lead to the activation of stress-responsive organs, but also is commonly associated with risky life-style modifications, and systemic diseases especially cardiovascular diseases (Golbidi, Frisbee, & Laher, 2015). Adaptation is therefore the surest way to go if caregiving experiences will be better expressed and family harmony restored (Bawalsah, 2016). Evidence from scarcity of literature in this area indicate that, caregiver adaptation experiences in caring for children with congenital defects has not been given much attention even in the Greater Accra region of Ghana, where the main referral hospital for such defects is located. It is therefore important to delve into this area, explore and describe these experiences from the

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participants' point of view. The transactional stress model by Lazarus (1991) was used as the guiding framework.

### 1.3 Purpose of the Study

The purpose of this study was to explore the experiences of family caregivers of children with congenital birth defects.

#### 1.3.1 Objectives of the Study

The specific objectives of the study include: To

1. describe the life events of family caregivers of children with congenital birth defects.
2. examine the challenges threat and harm or loss (appraisal) of family caregivers of children with congenital defects.
3. determine resources and support (social, personal and material) available to caregivers of children with congenital birth defects.
4. explain the health consequences of family caregivers of children with congenital birth defects.
5. describe the coping strategies of family caregivers of children with congenital birth defects.

#### 1.3.2 Research Questions

The questions formulated for the study were:

1. What are the life events of family caregivers of children with congenital birth defects?

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2. What challenges, threats and harm or loss (appraisal) do family caregivers of children with congenital birth defects face?
3. What resources and support (social, personal, material) are available to caregivers of children with congenital birth defects?
4. What health consequences do family caregivers of children with congenital birth defects have?
5. What coping strategies do family caregivers of children with congenital birth defects adopt?

## 1.4 Significance of the Study

The findings from this study are expected to serve the following purposes:

To highlight the care needs of family caregivers with children having varying degrees of congenital defects. So that, health care workers can develop tailored programs for such persons regardless of their social and cultural orientations.

It will also help bodies responsible for protecting the vulnerable in our society such as; the social welfare and the National Council on Disability to make informed modifications in plans, programmes and policies for future development, regarding specific interventions aimed at supporting persons caring for children with congenital defects.

Government organizations such as the Ministry of Health and non-governmental organizations, benevolent societies and philanthropists might also find the information emanating from this study useful. As it may re-emphasize the need for them to commit funds or logistics needed to support caregivers of children with congenital defects in hospitals, special rehabilitation centres and homes.

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The general public may be informed by this work, on the roles individuals can play to prevent or minimize stigmatization of caregivers of children with congenital defects to enhance outcomes.

The findings of this work also hope to add to literature on caring for children with congenital defects in the Accra Metropolis of Ghana and serve as a source of reference for other researchers.

### 1.5 Operational Definition

**Adaptation-**the ability of a caregiver to change and or adjust to fit the care giving role of a child with congenital defect barring all perceived and or actual burdens.

**Child with congenital defect-** any person below the age of 18years, who has a structural or functional anomaly/ anomalies known to have occurred during intrauterine life and was identified prenatally, at birth or later in life.

**Experience-**a subjective feeling or impression of a caregiver of a child/ children with congenital defect(s) emanating from the caregiving role.

**Family caregiver**-any person related to or otherwise, performing the role of caring for a child with congenital defect(s) solely or supporting others to do so for no monetary gains.

**Stress-**a feeling of becoming physically, psychologically, emotionally, socially and economically worn out or incapacitated as a result of caring for a child with congenital defect(s).

### 1.6 Organization of the Thesis

The first chapter of this work, consists of; introduction, background of the study, problem statement, purpose of the study, objectives, research questions, significance of the study

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and the operational definitions. Chapter Two offers the review of relevant literature, done in line with the theoretical framework guiding the study. Chapter Three explains the various research processes which constitute the methodology. These include; the research design, setting, target population, inclusion and exclusion criteria, sampling size and technique, data collection tool and procedure, data management, analysis and methodological rigour. In chapter Four, the findings of the study are presented. In chapter Five the findings of the study are presented. These were all done in relation to the guiding theoretical framework. The sixth and final chapter contains the summary of the entire work, implications, limitations and conclusions. It further offered some recommendations for improvements.

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# CHAPTER TWO: LITERATURE REVIEW

## THEORETICAL FRAMEWORK OF THE STUDY/ LITERATURE REVIEW

This chapter contain a description of the theoretical framework employed in guiding this work and a review of related literature found to be relevant to the subject. The transactional stress model by Lazarus in 1991 which was based on the Transactional Stress and Coping Theory by Lazarus in 1966, was used to assist in giving the research direction and putting the findings into context. Before settling on this theoretical framework, the researcher reviewed the family stress resiliency and coping theory by MacCubbin and MacCubin in 1996, but the constructs and prepositions were so many that, the researcher could not have explored it to the fullest considering the time limit within which the study was to be conducted. The researcher also reviewed the ABCX model of family stress by Reubin Hill in 1958, but the X talks about crisis situation to the extent that, the family can no longer remain intact. However, the researcher wanted an outcome that will inspire others to adapt hence settling on the on The Transactional Stress Theory. Chapter also brings to light, some of the salient findings in literature by researchers on issues relating to; the reception caregivers give to the news of having to take care of a child with congenital defect(s), the factors that predispose family caregivers to stress, the availability or otherwise of resources and how these influenced the level of stress experienced by care givers and the coping strategies that enabled the care givers to adjust to the situation. The concluding part of the chapter will showcase a summary and gaps identified in literature on the areas of focus, suggested by the guiding framework.

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## 2.1 Theoretical Framework of the Transactional Stress Theory/ Model.

Dr. Richard Lazarus first wrote about his Transactional Theory of Stress and Coping in 1966 (Lazarus & Folkman, 1984). His model evaluates how major life events and daily hassles can influence emotions with the emphasis on cognitive appraisal and coping with stress (Folkman & Lazarus, 1988). Historically, research on the health consequences of stressful life events, started with clinical records of individual reaction to war (Schwarzer, 2013 ). Over the years, the popularity of research related to stress has dwindled, however, the occurrence of major events like wars, technological advancements, globalization coupled with attempts to theoretically explain the transactional stress process, have ensured that, the link between individual experiences, health adaptation and performance remain viable as a subject for research (O'Driscoll, Brough, & Kalliath, 2009).

According to Lazarus, stress is a relationship between the person and the environment that is appraised by the person as being demanding or exceeding his/ her resources and endangering his/ her wellbeing (Lazarus, 1966; Lazarus & Lazarus, 1991). This suggests that, the level of stress experienced by the individual depends on how much of a value the person places on the outcome of the event; if it is of no relevance to the person and no threat, there will be no stress, but if their expectation is high, and it fails, the encounter will pose a threat or challenge sparking a stress reaction (Lazarus & Folkman, 1984). Meanwhile it is believed that, stress is a major factor which has an impact on the physical and mental health of victims (Lupien, McEwen, Gunnar, & Heim, 2009).

Lazarus (1991) therefore conceives stress as “an active, unfolding process that is composed of causal antecedents, mediating processes, and effects”. Antecedents are person’s variables, such as commitments or beliefs, and environmental variables like

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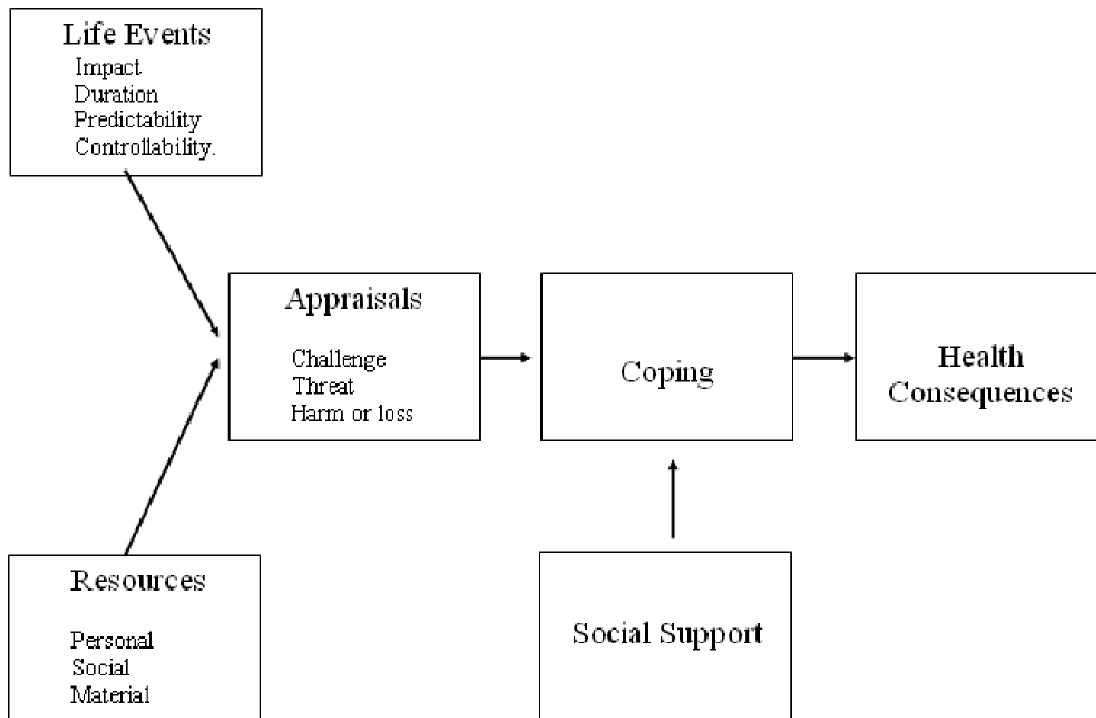
demands or situational constraints. Mediating processes refer to coping and appraisals of demands and resources (Schwarzer, 2013 ). Below is the conceptual framework and the description of the various constructs constituting it.

**Fig 2.1 The Conceptual the Model of the Transactional Stress Theory**




**Life events**

According to Lazarus and Folkman, stress can emanate from two main types of stimuli, namely; major life events and hassles (Lazarus & Folkman, 1984). Major life events can also be categorized into two domains. These are both outside the control of the individual, however, the difference between the two is that, whilst the first affect a large number of people, the second type affects just few people. The first, also termed environmental (natural), refers to events that are unforeseen and unpredictable and outside a person's imagination and control, for instance; cataclysmic phenomena like earthquakes,

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floods or bush-fires that affect a large number of people. Other examples include human induced disasters such as war, airplane disasters, ship wrecks, and tragedies such as terrorist attacks. The second type of major life events include; the death of a loved one, divorce, disability or a life-threatening illness. These are events that involve few victims even though their impact cannot be underestimated (Lazarus & Folkman, 1984). Their assertion further suggests that, every event leads to an individual experience, however, these are based on; the history, stage of life, circumstances and the significance of the event to the individual.

Daily hassles on the other hand are those events considered unimportant compared to major life events. They include repeated occurrences such as; arguments, money issues and family worries. They are events that most people may overlook, but they can lead to annoyance, irritation, distress and feeling of overwhelmed by responsibilities. They consequently predispose the individual to psychological and physical symptoms and invariably are responsible for inducing stress at the expense of the major events which were reported to have no impact at all (Lazarus & Folkman, 1987).

Duration has been found to be very important in determining the impact of life event. For instance a sudden death by a relative in a vehicular accident may have a different impact compared to someone who has passed on after a protracted period of chronic illness (Lazarus & Folkman, 1984). Consequently, the degree to which the individual has control over the event and can determine its occurrence or otherwise, determines the magnitude of its impact.

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### Appraisal

Cognitive appraisal is perceived as a personal evaluative process which categorizes a situation and focus on the implication, meaning or significance of the changing relationship between the person and the environment (Lazarus & Folkman, 1984), mostly producing an emotional feedback. Cognitive appraisals are classified into two, namely primary (demand) and secondary (resource) appraisals while the outcomes are divided into challenge, threat and harm/loss categories (Schwarzer, 2013 ).

### Primary Appraisal

According to Schwazer (2013), demand appraisal refers to the stakes a person has in a stressful encounter. A situation is appraised as challenging when it mobilizes physical and mental activity and involvement. In the evaluation of a challenge, a person may see an opportunity to prove herself or himself, anticipating gain, mastery, or personal growth from the venture. The situation is experienced as pleasant, exciting, and interesting, and the person feels ardent and confident in being able to meet the demands. Threat occurs when the individual perceives danger, expecting physical injuries or blows to one's self-esteem. In the experience of harm/loss, damage has already occurred. This can be the injury or loss of valued persons, important objects, self-worth, or social standing.

### Secondary Appraisal

Secondary appraisal is the evaluative judgement of the situation in terms of the significance of the event for their well-being and what can be done to alleviate and manage the situation (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). Here, the individual evaluates his or her competence, social support, and material or other resources that can help to readapt to the circumstances and to re-establish equilibrium between person and

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environment (Schwarzer, 2013 ). Hobfoll theorized that, the conservation of resources is the main human motive in the struggle with stressful encounters. These resources according to him includes; objects (e.g., property, car), conditions (e.g., close friendship, marriage, job security), personal characteristics (e.g., self-esteem, mastery), or energies (e.g., money, knowledge). Change in these resources may either be a gain or loss, meanwhile a loss appears to be particularly stressful, whereas the mere lack of resources or their availability seems to be less influential (Hobfoll, 1988).

It is important to note that, primary and secondary appraisal cannot be considered as separate processes, but are interdependent and influence each other. Meanwhile, another form of appraisal is reappraisal, which, on the basis of new information, can sometimes mediate the evaluation of the situation (Lazarus & Folkman, 1984), resulting in the outcome being modified to be less, or more, threatening.

**Coping**

Coping results from appraisal that suggests that, the requirement to satisfy a demand of an event is beyond personal resources, making the individual to elicit an emotional feedback indicating harm and threat (Lazarus & Folkman, 1987). The functions of this appraisal is to change the relationship between the person and the environment and to influence the threshold of emotional distress (Lazarus, 1991). Coping is made up of both cognitive and behavioural drives needed to manage the internal and or external environment when there is some level of disparity between a person's perception of his/ her ability and resources to handle the psychological stress (Lazarus & Folkman, 1984). Hence coping can be defined by the relationship that exist between the person and the environment (Lazarus & Folkman, 1984). It also relies on subjective view of situation in life such as; well-being, social

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functioning, and somatic health and the premium placed on them by the individual within a period of time (Bandura, 1998).

**Social Support**

Social support is described as the interpersonal engagement that comprises both emotional and instrumental dimensions (Wandersman, Wandersman, & Kahn, 1980). It is reported as the main resource that enable persons cope with stress (Friborg, Hjemdal, Rosenvinge, & Martinussen, 2003). The social environment is perceived by Lazarus as a factor that can offer both stress and support to an individual (Lazarus & Folkman, 1984). People who feel geographically isolated or don't have close relationships are more likely to have lower coping strategies and negative emotional responses, whilst a strong social network can provide emotional support, direct aid and services, information and advice (Lazarus & Folkman, 1984). All of these can assist an individual to cope with both major life events and daily hassles. However, the inadequacy or lack of social support in stressful encounters, may increase vulnerability tendencies leading to psychological distress, emotional problems, functional problems and somatic illnesses (Barth, Schneider, & Von Känel, 2010).

**Health Consequences**.

Based on the perception of the individual, isolated experiences of daily hassles and major life events may be seen as mundane situations, which may not be stressful or important, however, a pile up of these experiences over extended period of time, may have devastating health effects (Schwarzer, 2013 ). Also, extreme stressors can create both acute and prolonged psychological distress and bodily ailments (Lagraauw, Kuiper, & Bot, 2015). Research findings continue to be inconsistent in terms of whether it is the nature of the

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event or its aftermath reactions, that are responsible for the difficulty in adjusting to the situation (Schwarzer, 2013 ). Stress is perceived to operate in three dimensions, namely; alarm, resistance and exhaustion. Meanwhile when the organism's resistance breaks down, the long period which may follow this may itself result in illness (Selye, 1956). According to Schwarzer (2013), there are three major pathways that link stressful life events to ill health. These include; physiological changes as a mediator between origin and outcome, (in particular changes of immune parameters, and endocrine and cardiovascular reactivity), the tendency to resort to health-compromising behaviors, and negative affect often associated with experiencing stress, which are health compromising in the long run.

The model has been used to study stress inducing situations affecting people on a large scale and as individuals (Folkman & Lazarus, 1984). Other works have also used the model to study parenting related stress in varied situations (Craig et al., 2016; Woodman, Mawdsley, & Hauser-Cram, 2015). The model is found suitable for this study because, having a child with congenital birth defects is described by parents as a major event associated with a lot of hassles making it difficult to get rid of from memory. This is in line with the second classification of major life events which normally involve just few people or an individual, even though their impact cannot be underestimated.

The birth of the child with congenital birth defect is the major life event, that impacted negatively on the family caregivers, because the event was sudden, unpredictable and uncontrollable. Their assessment of the situations as a challenge, threat harm or loss was because their resources and support were not adequate to come to terms with the situation. They therefore coped with the situation with the little social support they

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received. The last construct described the outcome of all these situations on the psychological as well as the physical health trajectories of the family caregivers.

## 2.2 Literature Review

This aspect of the chapter presents the review of relevant literature on the adaptation experiences of family care givers of children with congenital birth defects. Myriad of sources were consulted for information on the subject. These include; books, published journals, papers, periodicals, news items, and the internet. The data bases accessed were, Science direct, CINAHL, PUBMED, Scopus and Google Scholar. Key words and phrases used for the search were; family care givers, adaptation experiences, coping strategies, adjustment, children with congenital defects/ anomalies/ abnormalities, life events, resources, social support, appraisal, and health consequences / effects. The review is done in line with the objectives of the study and carefully crafted around the constructs of the conceptual model guiding the study.

### 2.2.1 Life Events of Family Caregivers of Children with Congenital Birth Defects

The major life event of caregivers of children with congenital defects is the abnormality or the defect itself as posited by Lazarus as the second classification of major life events which affect just few people (Lazarus & Folkman, 1984). Evidence from existing literature indicates that, having to live with a child with a congenital anomaly can be demanding and full of stress to mothers who most of the time are the primary caregivers of children in the family system (Cohen, 2018; Deater-Deckard & Panneton, 2017; Dogbe, Kyeremateng, Opoku, Nketsia, & Hammond, 2019; Walerius, Fogleman, & Rosen, 2016). Even though most research works reported that caregiving stress begins from infancy, it actually exists before the birth of the child (Deater-Deckard & Panneton, 2017) as the prenatal diagnosis

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of a congenital birth defect is met with high level of anxiety by will be caregivers (McKechnie, Pridham, & Tluczek, 2016). A study conducted in Sydney Australia on Parents' perceptions of counselling following prenatal diagnosis of congenital anomalies of the kidney and urinary tract reported that, parents expressed feelings of shock, fear and uncertainty after the news of the diagnosis was communicated to them (Marokakis, Kasparian, & Kennedy, 2017). Another study conducted at Sweden on the emotional process from diagnosis to birth following a prenatal diagnosis of a foetal anomaly reported parents having three phases of shock, existential crisis, and life remodeling (Carlsson et al., 2017).

After birth, the nature, severity and care demands of the condition is a major source of stress for the caregivers, as some of these conditions may demand life-long management or care (Golfenshtein, Srulovici, & Medoff-Cooper, 2016). According to a study conducted on caregivers' perceptions of healthcare provision and support for children born with cleft lip and palate in South Africa, it was reported that the defect itself induced feelings of shock, anxiety, distress, worry, sadness, and misery among parents and caregivers (Hlongwa & Rispel, 2018).

Research findings indicate that; the birth of a disabled child may result in heated arguments between spouses as they tend to blame themselves or each other for being the possible cause of the child's predicament (Carlsson et al., 2017; Nahal et al., 2017; Zeytinoğlu et al., 2017). For instance a study reported that, mothers expressed much guilt feeling over considering themselves as the potential cause of their child's anomaly through their use of medications and other lifestyle considerations (Carlsson et al., 2017). Reports from another study on Palestinian mothers' experiences of having a child with spina bifida

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revealed that, relatives are a major source of blame for caregivers of children with congenital defects as mothers on most of the occasions, are blamed for giving birth to abnormal child leading to guilt feeling and abandonment (Nahal et al., 2017). The blame seems to go beyond mortals as invisible beings are also blamed on most occasions for punishing people with hassles connected to taking care of a child with congenital defects. This is evident in a study in which, will be caregivers of a child with anomaly blamed God for being unfair to them (Carlsson et al., 2017). Meanwhile, others felt their faith was challenged hence, they became withdrawn and depressed (Masulani- Mwale, Mathanga, Silungwe, Kauye, & Gladstone, 2016). In the African context, these arguments and blames may put strains on marital as well as family ties (Emordi & Osifo, 2018).

Furthermore, children with congenital defects, may experience frequent medical interventions, prolonged hospitalizations, or special care at home, and these expose their families to enormous financial burden (Edwin et al., 2015; Seltzer, Henderson, & Boss, 2016). It was observed that caregivers engage in trying to meet all the needs of the affected child at the expense of the healthy siblings and this require extra financial commitments (Mooney-Doyle, dos Santos, Szylit, & Deatrick, 2017). This study further reported that, caregivers may experience increased risk of stress, related to hassles linked to demands that constitute daily living such as; food, vouchers, money, job security, flexible work arrangements and transportation. In a study on financial and social hardships in 167 families with children having medical complexities in Cincinati children's hospital, it was reported that, 44% of the families revealed out of pocket settlement of bills for the medical care of their children and half of the study sample reported financial problems related to the medical care of their affected children (Thomson et al., 2016). Meanwhile, studies have

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reported that most of these caregivers sacrifice their jobs from which they earn a living, in order to have enough time to cater for the needs of the affected child (Pelentsov, Fielder, & Esterman, 2016). For example, Thomson et al (2016) reported that 60% of caregivers of children with medical complexities stopped working whilst 66% percent of the 167 families revealed; a family member have to reduce the number of working hours in order to care for the child. In Ghana where parents may not earn much to pay for the surgical interventions for some of these children vis a vis their perceived poor prognosis, these children may be neglected or wished dead (Edwin et al., 2015) increasing caregiver stress.

### 2.2.2 Resources Available to Caregivers of Children with Congenital Birth Defects

According to Lazarus resource availability or otherwise determines the secondary form of appraisal the individual makes when faced with a stressful life situation (Lazarus & Folkman, 1984), as objects, personal characteristics and energies serve as personal, social or material shields in times of adversity (Schwarzer, 2013 ). In support of this assertion many study findings have reported that, the personal characteristics of the caregivers such as age, gender, educational as well as employment status determines the level of the caregiver's resilience in coping with the stress associated with caring for a child with congenital defects (Golfenshtein et al., 2016; Sharda, Sutherby, Cavanaugh, Hughes, & Woodward, 2019).

Mothers who are of the feminine gender were seen to be more equipped with the natural instinct of caring, which represent a personal resource with which to appraise the life event of having to care for a child with congenital defects (Brock, 2017). It is therefore not surprising that most studies reported higher involvement of mothers in the caregiver role to children with congenital defects (Anderson, 2018; Razera, Trettene, Tabaquim, &

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Niquerito, 2017; Zeytinoğlu et al., 2017). In a study conducted on the perceived quality of life among caregivers of children with a childhood-onset of dystrophinopathy in the United States, it was reported that out 191 caregivers, 92% were women who are also the biological mothers of this children (Frishman et al., 2017). Similar to this finding, is a qualitative study conducted in Ghana on support programmes for care givers of children with disabilities, which reported that among the 17 caregivers who participated in the study, 14 were biological mothers, three were grandmothers and just one male who is a cousin to the child with disability participated in the study (Zuurmond et al., 2019). These also explain why mothers are often reported to experience high level of stress related to caring for children with congenital defects than fathers (Cohen et al., 2016; Golfenshtein et al., 2016).

Findings from studies on household income and socioeconomic status seem to be divided, on how these influence the appraisal of having to care for a child with congenital defects. Some studies reported that taking care of children with congenital defects places so much economic burden on the family, hence, socio economic status of the caregivers can significantly aid them in positive appraisal of the event of caring for a child with disabilities (Lawson, Papadakis, & Grayson, 2018; Mooney-Doyle et al., 2017; Ooi, Ong, Jacob, & Khan, 2016). In studying the economic burden of pre-surgical treatment of congenital heart diseases in Nigeria, it was reported that, the participants reported how expensive it is to take care of a child with the condition, as most caregivers have to do out of pocket payments of bills, having in mind that most of their care cost is not covered by health insurance (Duru et al., 2020). The study further added that, most of these caregivers, spend more than 10% of their income threshold on these children, a situation which may

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lead them to assess loan facilities in order to pay for their care demands. This implies that, persons with higher socio economic status have good adjustment in caring for children with congenital defects than caregivers with lower socio economic status (Lawson, Papadakis, & Grayson, 2018). Contrary to this finding, a study conducted by Stover (2017) reported no significant difference between the overall household income, and the daily hassles experienced by care givers of children with disability in. This study further reported same findings for educational level as well as employment status.

Social resources have been found to be the major resources that influence the kind of appraisal care givers of children with congenital defects give to the event (Golfenshtein et al., 2016; Halstead, Griffith, & Hastings, 2018; Hlongwa & Rispel, 2018; Shilling et al., 2015). The most common social resources available to care givers of children with congenital defects is support from their families, friends and others in similar circumstances (Zeytinoğlu et al., 2017). This seem to explain why most studies reviewed reported that, high care giver stress is mainly reported in single parenting as well as caregivers who are divorced or separated (Hlongwa & Rispel, 2018; John, Bower, & McCullough, 2016). In line with this, a study reported that, the presence of an adult partner in the house play a role in reducing daily hassles among care givers of children with disability (Zeytinoğlu et al., 2017). This assertion was made based on the finding that, caregivers of children with cleft lip or palate who are married experienced lower levels of daily hassles compared those who confirmed their status as divorced, separated or never married. This also confirms the finding that, during stressful times, caregivers working in teams and supporting each other are able to handle challenges better than individuals (Zeytinoğlu et al., 2017). Other social resources available to caregivers, are their families

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both nuclear and extended (Nahal et al., 2017). This is also evident in a case study on coping pattern in the mother of a child with multiple anomaly by Amae et al (2016), who reported good perception of extended family support and its subsequent aid it offered the caregiver to cope with stigma and care demands of the child with multiple congenital anomalies.

According to Nahal et al (2017), when a child suffering from spina bifida survives and grow, there exist the need for other support groups such as the health care team, whose activities give the care givers hope. Support groups that may serve as social resources for care givers of children with congenital defects include persons with similar care responsibilities, religious bodies, insurance companies, Government, non-governmental institutions (NGOs), Philanthropists and benevolent institutions (Marshall, Tanner, Kozyr, & Kirby, 2015). However most of the caregivers of these children wished to have such support but are ignorant or have difficulty assessing the services of these groups (Kayhan & Özaydin, 2018), contributing to the care giver stress.

### 2.2.3 Appraisal Ascribed to the Event by Family Caregivers of Children with Congenital Defects

Based on the assertion of Schwarzer (2013), the appraisal of a situation as a threat, harm or loss depend on the relevance of the event to the one involved. This is because, threats depict the individuals' expectation of a noxious stimulant while harm or loss are the aftermath of the experience. Care givers of children with congenital defects express several fears with regards to the child's condition which can best be described as seeing the situation as a threat. As revealed by a study finding, even before the birth of a child with congenital defects, expectant care givers express divergent views with regards to their

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emotional and cognitive preparedness, to meet the care needs of the child (McKechnie, Pridham, & Tluczek, 2015). This appears to portray the child's defect as a threat to the emotional, psychological, physical and social wellbeing of the family. This assertion has been further established by Zeytinoglu et al (2017) who reported that parents described the prenatal diagnosis of children with cleft lip as threatening their emotions to the extent that it was difficult keeping their emotions "in check".

After birth, care givers may express varying levels of anxiety toward the condition which most of the time may be rare. For instance, Amae et al (2017) in their case study on coping patterns in a mother of a child with multiple congenital anomalies reported a care giver, who apart from not knowing the condition, was surprised to hear from the medical practitioners that, the daughter is the fourth child ever in the world to have been born with Biliary Atresia with anorectal agenesis without a fistula and urogenital malformation. Other care givers do their uttermost best to meet the needs of the child but continue to be haunted constantly by the threat of unknown prognosis of the child's condition and the stressor that the child may die (Amae et al., 2017; Carlsson et al., 2017). Findings from studies indicate that, the difficulty involved in the care of the child also threatens the family cohesion in most situations (Nahal et al., 2017; Zuurmond et al., 2019).

According to a study report, the mother of a child with multiple anomalies have to abort a subsequent pregnancy and resign from her work in order to have time to take care of the affected child. In addition, other parents expressed feelings of guilt and were remorseful for neglecting other siblings due to their care roles (Pelentsov et al., 2016). Also, as reported by a study finding, couples taking care of a child with cleft lip described how they sometimes visit their frustrations on each other, with regards to the difficulties

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experienced in managing the division of labour in caring for the child, the guilt feeling and the financial burden placed on them (Zeytinoğlu et al., 2017). This work further reported that, in cases where the care givers are also the biological parents of the child with congenital anomalies, they continue to be threatened by the fear that any other sibling afterwards may be born with same or even complex defects.

Furthermore, the actual loss of a perfect child to death or defects continue to surround the roles of caregivers (Bonsu et al., 2018; Giúdici, Bokser, Maricic, Golombek, & Ferrario, 2016). Findings from studies reported that, mothers of children born with cleft lip in Ghana, expected healthy and beautiful babies; hence the birth of the deformed baby was not considered an ideal gift from God (Bonsu et al., 2018). Similar to this finding, Zeytinoglu (2017) reported that, parents of children diagnosed prenatally of cleft lip, described the situation as taking the pure joy away from having a baby, as the diagnosis only gave them the opportunity to grieve over the loss of a perfect child before birth.

Congenital defects have also been described as a major cause of death in children (Liu et al., 2016), hence it appears children born with the complex form of some of these defects may not survive progressively into healthy adults. In a study conducted on Babies born with gastroschisis and followed up to the age of six years in Argentina, it was observed that they are faced with long-term morbidity and impairments (Giúdici et al., 2016).

Even though some studies reported that parents or caregivers of children with congenital defects perceive the event with a positive lens (Nahal et al., 2017; Salkas, Magaña, Marques, & Mirza, 2016) most of these participants, in these studies were observed to have employed a lot of coping mechanism for good effect. On the average,

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literature on the appraisal of the event of taking care of a child with congenital defect(s), describes the encounter as a challenge to the caregivers.

### 2.2.4 Coping Strategies of Family Caregivers of Children with Congenital Birth Defects

By seeing the role of caring for a child with congenital anomaly as a challenge with limited resources, caregivers try to make major changes in all aspects of their lives to accept and have some form of control over the situation (Amae et al., 2017; Cuzzocrea, Murdaca, Costa, Filippello, & Larcan, 2016) Majority of works on caring for children with congenital defects pointed out that, coping and positive perceptions have a positive impact on care givers' well-being, regardless of the level of their child's behavioral problems, be it intellectual or developmental disability (Amae et al., 2017; Halstead et al., 2018)

Meanwhile it appears some researchers believe that, even though coping strategies are of essence to care givers' distress, some may end up increasing parental distress and lower the self-esteem of affected children, based on the nature and severity of the child's condition (Cuzzocrea et al., 2016; Franzblau et al., 2015). The ensuing paragraphs describe some of the common coping strategies reported by literature as useful for care givers of children with congenital defects.

Denial or avoidance has been reported as one of the major coping mechanisms employed by caregivers of children with congenital defects (Cuzzocrea et al., 2016; Nahal et al., 2017). Denial is described as; refusing to acknowledge that something is wrong (Mayo Clinic Staff, 2017). According to these same writers, denial, is a way of coping with emotional conflict, stress, painful thoughts, threatening information and anxiety. The individual can be in denial about anything that makes him or any other related person feel;

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vulnerable or threatened, about the possibility of losing self-control in situations such as; illness, addiction, eating disorder, personal violence, financial problems or relationship conflict. This is confirmed by a systematic review and meta-analysis, conducted on coping in parents of children with congenital heart disease which revealed that; in the early stages of receiving information on the heart defects of their children, many caregivers reported trying to forget about or deny the prevailing problem until they receive reminders from the health care practitioners on visits (Lumsden, Smith, & Wittkowski, 2019).

Literature search also revealed that, some caregivers cope with the situation by reconstructing it to have positive connotations. For instance, these care givers try to gain normality of the situation by not perceiving the child's condition as a reason to give them preference in their care endeavour. Rather, they raise them as normal children who have equal survival possibility and ability (Lumsden et al., 2019). Another study titled, "A Multifaceted Model of Changes and Adaptation among Korean Mothers of Children with Disabilities" reported similar findings, when it uncovered that, mothers in the study learned to reconstruct positive meaning to their children condition regardless of whether there have been improvement or not (Park & Chung, 2015). However, those caring for children with mild defects found it difficult disengaging their minds of the hope that their children will get completely cured, they added.

Furthermore, care givers of children with congenital anomalies tend to look for support from spouse, family, friends and groups formed by persons in similar situation as a means to cope with the care burden (Marshall et al., 2015; Zeytinoğlu et al., 2017). Shared experiences resulting from the context of social isolation for care givers, tend to be a mobilizing force that bring them together to charter a meaningful collaboration that

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enhances coping (Park & Chung, 2015). This was exactly what the findings of Zeytinoglu et al (2017) reported, when they revealed that in studying experiences of couples caring for a child born with cleft lip and/or palate, couples supported each other in varied ways by; having open conversations about the condition, going to medical appointments together, trying to share childcare, being affectionate toward each other, and giving each other respite, as needed. All these, give credence to a study report indicating that, coping is enhanced by the level of support available to the caregiver.

Also important, spirituality has been found as a major coping mechanism for caregivers of children with congenital defects, as care givers see these children either as a blessing or curse from God (Abu-Ras, Saleh, & Birani, 2018; Holt, 2016; Nahal et al., 2017). For instance, in a qualitative study, majority (47) of caregivers reported that, they saw the child with disability as a positive sign from God as against just one mother, who indicated that, the child with disability could be a punishment from God (Salkas et al., 2016). Meanwhile those with the assertion that the child is a blessing based their conviction on three main beliefs, namely; the child is a blessing, the child is part of God's plan and special children are given to special parent. In a quantitative study on Parental stress, coping strategies and social support in families of children with a disability, it was reported that, turning to religion was used more by care givers of children with autism spectrum disease than social support (Cuzzocrea et al., 2016). In Africa where spirituality seems to dominate scientific proof, a qualitative study conducted on Experiences of Mothers of Children with Intellectual Disability in Ghana reported that, all the eleven mothers who participated in the study perceived their situation as the will of God rather than a curse (Oti-Boadi, 2017). This idea of giving things that are beyond the imagination of the

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individual to a supreme being reduces care giver's psychological stress and enhance adaptability (Franzblau et al., 2015)

On the contrary, some studies have reported certain coping mechanism that are quite interesting and may not improve self-esteem of affected children but rather increase care giver stress (Franzblau et al., 2015; Tilahun et al., 2016). For example, parents or care givers of children with congenital defects may make fun of the situation, hide the affected child or body part, ignore responding to questions about their condition or even refuse to disclose their predicament (Franzblau et al., 2015). Stigma appears to be the most reason why care givers tend to hide these children. Tilahun et al (2016) reported this in a cross sectional facility based survey on Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country, when it was revealed that out of 102 participants, 43.1 % indicated they get worried sometimes, often or a lot about being treated differently. Similarly, 45.1 % felt ashamed or embarrassed about their child's condition, 26.4 % felt a need to hide the problem from people in the community, whilst 26.7 % made an effort to keep their child's condition a secret. Others include; 26.7 % were worried that people would be reluctant to marry into their family and 39.3 % worried about taking their child out of the house. According to the same study, few of the participants also reported negative coping strategies such as; chewing Catha edulis (khat), drinking alcohol and smoking cigarettes.

### 2.2.5 Social Support Available to Family Caregivers of Children with Congenital Birth Defects

Social support, largely regarded as an important aspect of strong relationship, is described as the psychological and material resources provided by a social network to help

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individual's cope with stress (Cherry, 2018). These social network most of the time comprise family and friends that the individual turns to, when facing a personal crisis or when having the desire to spend time with people who are affectionate towards you (Cherry, 2018). Findings from studies indicate that, lack or inadequacy of social support is predictive of high stress levels whereas a strong social support system has enormous positive impact in reliving care giver stress (Findler et al., 2016; Golfenshtein, Deatrick, Lisanti, & Medoff-Cooper, 2017). In caring for children with congenital defects, studies have reported that, care givers identify themselves, friends, family members, health care professionals and church as their main source of social support (Oti-Boadi, 2017; Zeytinoğlu et al., 2017).

#### 2.2.5.1 Personal Support

In the first place, caregivers whether as individuals, couples or a group are described as a leading source of social support (Mokhtari & Abootorabi, 2019; Zeytinoğlu et al., 2017). This is because, apart from relying on others, the individual also serve as a form of support for many people in life (Cherry, 2018). As posited by Shilling et al (2015), as individuals, parents of disabled children have a wealth of shared experience that they can always draw on to give support to others in the same situation. As couples, the sharing of the care giver responsibility appears to be of immense benefit in reducing stress. For instance, a study conducted on; partner parenting stress as a predictor of family cohesion in parents of adolescents with developmental disabilities, it was reported that the greater the partner stress, the weaker the family cohesion and vice versa. (Mitchell, Szczerepa, & Hauser-Cram, 2016). Thus divorce or separation may expose a single caregiver to numerous hassles and increased stress (Stover, 2017).

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### 2.2.5.2 Social Support

In addition, family and friends have been reported to play a significant role, when it comes to supporting persons faced with a stressful situation (Cuzzocrea et al., 2016). According to a study on experiences of couples caring for a child born with cleft lip and/or palate in the United States, Zeytinoglu et al (2017) reported that, some family members did not just take up the care giving role of these children when their parents are at work, but also learned how to feed them. Others cared for older siblings when couples are required to send the affected child for health care and also provided the affected couple with emotional support. The care givers appreciated every bit of the support they received from these social networks as they described friends visiting and embracing their children, being sympathetic towards them and bringing overs meals at the time they don't have time to prepare one as reassuring. Similar findings were reported by Halstead et al (2018) in a quantitative study on Social support, coping, and positive perceptions as potential protective factors for the well-being of mothers of children with intellectual and developmental disabilities. As a regression analysis revealed a classic protective factor pattern in all the three models of life satisfaction, depression and positive affect.

Being a member of a group by virtue of employment, religion, assessing health care service at a facility with supportive health care team, and being in a group with persons having same care giving responsibilities have also been found to be major sources of social support (Oti-Boadi, 2017). However, physically being a member of a group was not seen as a necessary activity to prevent isolation by care givers. Instead, the knowledge and reassurances shared by the members of such groups is what actually create that sense of a virtual community (Shilling et al., 2015). According to a study conducted in the United

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states, participants who were couples caring for children with cleft lip and palate reported enjoying immense support from coworkers and neighbours, in the form of words of encouragement and prayer cards (Zeytinoğlu et al., 2017).

Support from health care providers cannot be reemphasized in caring for children with congenital defects (Hlongwa & Rispel, 2018; Tilahun et al., 2016). While some seek health care from traditional institutions, others do so at biomedical health institutions. For example, in a study conducted on Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country, it was revealed that, more than half of the caregivers indicated they first sought help from traditional places, while just under half of the participants first approached a biomedical institution (Tilahun et al., 2016). Generally, support from health care providers have been described by the various studies as having good impact on reducing care giver stress, however, where deficiencies such as; lack of adequate information on the child's condition and hostile attitude from health team members occur, it further contributes to care giver stress (Bonsu et al., 2018; Hlongwa & Rispel, 2018)

Even though many studies reviewed, stressed on the importance of social support in protecting families of children with congenital defects, it seems there are variations in the impact of these social support systems and the defect of the child being cared for. According to the report of a quantitative study on parental stress, coping strategies and social support in families of children with a disability in Messina Italy, all the 50 couples who participated in the study agreed that support from others was lower than support from the family (Cuzzocrea et al., 2016). This according to them was as a result of the kind of

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defect. As some defects, don't have much support in the social context. For example, families of children with low functioning conditions with specific reference to autism.

### 2.2.6 Health Consequences of Family Caregivers of Children with Congenital Birth Defects

According to the World Health Organization, health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO, 1948). Even though, health is influenced by; physical, psychological and social factors and is a relative state, that vary from person to person (Munro et al., 2016), generally, caring for a chronically ill and disabled child at home is reported to be associated with poorer or worst health related quality of life for the care givers (Miodrag, Burke, Tanner- Smith, & Hodapp, 2015; Pinquart, 2018; Vonneilich, Lüdecke, & Kofahl, 2016). This results due to the level of stress these care givers are exposed to Evidence from available literature suggest that, prolong exposure to stress can lead to emotional and physical ill-health consequences (Adamsson & Bernhardsson, 2018; Golbidi et al., 2015). As reported by a retrospective review on Symptoms that may be stress-related and lead to exhaustion disorder in Swedish primary care, out of the 115 patients that were reviewed, 53% of the patients, had another present or prior mental diagnosis, for instance general anxiety disorder or depression. Physical illness found accompanying the exhaustion disorder was present in 61% and included primarily hypothyroidism, hypertension, diabetes, and cardiovascular disease (Adamsson & Bernhardsson, 2018). Meanwhile other stress related complaints reported by the same study include; pain, fatigue, gastrointestinal symptoms, and sleep disturbance.

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As reported by Vonneilich et al (2016), the severity of the stress associated with caring for a child with a disability, could be such that, even coping mechanisms can only deal with the psychological aspect of it, but cannot alter the long term association between care level and physical health. The extent of the impact can even be worse as reported by a study which revealed that, mothers of infants born with major congenital anomalies were more likely to die from all natural causes with specific reference to cardiovascular diseases and respiratory diseases, than those of presumably healthy infant (Cohen et al., 2016).

The most common health related problems reported by studies in this domain may be put into psychological and physical health concerns. These poor health concerns of the care givers mainly emanate from fatigue associated with the daily hassles involved in taking care of the children, the psychological stress of the anomaly, stigma and on some occasions trying to achieve family cohesion (Adamsson & Bernhardsson, 2018; Golfenshtein et al., 2016; Kvarme et al., 2016). Also worth noting, findings from some studies reported how, taking care of children with congenital defects can deprive the care givers of majority of their sleeping time leading to negative impact on their coping ability (Chambers & Chambers, 2015; Macedo, Silva, Paiva, & Ramos, 2015; Orta et al., 2016)

Physically, care givers or parents of children with congenital defects, reported various degrees of somatic health complains such as; being extremely tired (Caicedo, 2015), pains in the hand, back (Kvarme et al., 2016), migraine, stomach and intestinal ulcers, asthma and rheumatic problems increasing their physician visits and medication intake compared to those caring for children without such conditions (Brehaut et al., 2019). For instance, according to a study on the experiences of parents who are caring for adolescents with cerebral palsy during transition to adulthood, it was reported that, all the

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eight mothers and seven fathers who participated in the study, revealed that, their own wellbeing was dependent on the wellbeing of the affected adolescents, as the hassles associated with coordinating work and social life, with the needs of their child, negatively affected their health (Björquist, Nordmark, & Hallström, 2016).

Psychologically, care givers expressed a lot of emotional stress right from the disclosure of the diagnosis to the long preceding period of care (Amae et al., 2017; Antwi-Kusi et al., 2015). Caregivers are reported to have felt sorrow when they thought about; what life would have been like for their child, had he or she not had a disability (Björquist et al., 2016). MaKechnie et al (2016) reported a similar finding in a qualitative research; when three out of twelve parents diagnosed prenatally of congenital heart defect, reported clinical symptoms of anxiety and depression. When this is not handled well, some of these caregivers may end up having psychological concerns of mental health magnitude (Woolf- King, Arnold, Weiss, & Teitel, 2018).

According to a study conducted on immigrant parents from Pakistan, Poland and Vietnam, who are care givers of children with complex health needs, in Norway, a mother described the care giving role as "being on duty all the time", while other care givers described how children with complex health needs, can stay awake up to 0400hours and tell stories that happened two years back, with some others making noise all night. In situations such as theirs, where you have no other choice than to sleep in the same room with all your children, everyone is faced with sleep interruptions and associated stress (Kvarme et al., 2016).

In summary, findings from the various studies reviewed, revealed that, caregivers of children with congenital defects, generally perceive the situation as a challenge, threat

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harm or loss to them. This is based on the premise that, the event is considered as sudden and uncontrollable with both immediate and long term impacts (Carlsson et al., 2017; Golfenshtein et al., 2016). Findings from other studies also reported how the availability of personal resources, both inherent qualities and assistance from others, material belongings such as money and property can influence the level at which these caregivers' stress is experienced (Lawson, Papadakis, & Grayson, 2018; Mooney-Doyle et al., 2017). Consequently, the situation is normally perceived as being beyond the resource capability of the care giver in question, hence numerous coping or adaptation mechanisms are employed to at least obtain some balance and strive towards attaining normality (Amae et al., 2017; Cuzzocrea et al., 2016) The quest for equilibrium, balance or normality in the family life results in individuals looking for support from their social networks which most studies have reported to be relative (Cherry, 2018; Findler et al., 2016). Some get such support even though with some initial resistance (Zeytinoğlu et al., 2017) but others, are faced with rejection, and stigma leading to isolation and on some occasions, depression (Tilahun et al., 2016).

Nevertheless it has been reported that, the stress emanating from caring for children with congenital defects can negatively affect the health of the caregivers in both physical and psychological dimensions (Björquist et al., 2016; Woolf- King et al., 2018). Deductions from the review suggests that, caring for children with congenital defects comes with a lot of negative experiences everywhere. But qualitative study reports on the subject seem to be dominated by condition specific studies, while the quantitative studies were more of prevalence and comparative studies. Moreover, majority of the studies that have been reviewed were done abroad with few studies cited from the African context.

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In Ghana, studies in the area are few. Meanwhile, none of these studies explained the adaptation experiences of care givers of children with different congenital defects in one work. It is therefore obvious that, caregiver experiences with children having congenital defects, has been less explored in Ghana. In addition, only one study by Anderson, (2018) on "Experiences of Caregivers of Children with Cleft Lip and/or Palate Receiving Treatment at the Reconstructive Plastic Surgery and Burns Center of the Korle-Bu Teaching Hospital" used the stress appraisal and coping theory as a back-up to the adult personal resiliency theory by Robert Taormina, (2015). As a result, the current study used qualitative approach to explore the experiences of care givers of children with congenital defects in the Accra metropolis.

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# CHAPTER THREE: METHODOLOGY

This chapter contains explanation to the research design and the method that was employed to conduct the study. It also showcased a vivid description of the study setting, the various techniques that were used to select the sample, collect and analyze the data. The strategies employed to adhere to the tenets of rigour and obtain ethical clearance were also specified.

## 3.1 Research Design

This study employed the exploratory-descriptive design. Qualitative research works seek to understand the experiences of a group of participants, with regards to their encounter with a situation or phenomenon (Denzin & Lincoln, 2005). Its methods aim at answering questions about the what, how and or why of a given situation rather than measuring and quantifying the effects of the phenomenon (Flick, 2018). Researchers, explore situations, that they seem to have less or no scientific knowledge about (Stebbins, 2001). With regards, the choice of this approach was based on an observation made during literature review, as it appears the topic has not been extensively studied especially in Ghana, making it look relatively new and emerging. This approach therefore offered the researcher, the avenue to obtain in-depth description of the subjective adaptation experiences of family care givers of children with congenital defects and highlighted the phenomenon from their point of view.

## 3.2 Research Setting

The study was conducted in the Accra Metropolis, which is one of the two main metropolitan districts of the Greater Accra Region of Ghana. It is the largest Metropolis in Ghana which also houses the seat of Government. Administratively, the Accra metropolis

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is divided into eleven sub districts, namely; Ablekuma south, Ablekuma Central, Ashiedu Keteke, Osu Klotey, La, Ayawaso East, Ayawaso Central, Okai Koi South, Ablekuma North, Okai Koi North and Ayawaso West Wuogon (Ghana Statistical Service, 2012).

It has a population of 1,848,614, with a total female population of 960,941 and male population of 887,673 (Ghana Statistical Service, 2012). It has a total land surface area of about 173 km2 and lies within the geographical grid coordinates of 5°32'59.99" North and 0°12'60.00" E (Open Street Map contributors, 2019). The local dialect spoken in the area is Ga, however, due to regional diversification, cultural and ethnic heterogeneity, other local languages are spoken. Apart from the official English language, other popular languages that are spoken by the general populace include; Twi and Fante.

In term of health infrastructure, the area holds about 20 state-owned health facilities including two tertiary hospitals and over 800 private health facilities. One of these tertiary hospitals, is the Korle bu teaching Hospital which is the main referral point for children born with congenital defects. However, Dzorwulu Special school; a notable public special school, that admits from a wide range of children with congenital birth defects was used as a point of contact to have access to participants for the study. The Accra metropolis was chosen because, it has a number of institutions designated for the care of children with congenital birth defects. This presented the researcher with enough potential participants to obtain rich data. The school was also chosen because of its convenience in terms of accessibility by the researcher and the fact that the researcher can get a number of these caregivers of children with the characteristics required for the study in aggregation. Below is diagram showing the map of the Accra Metropolis.

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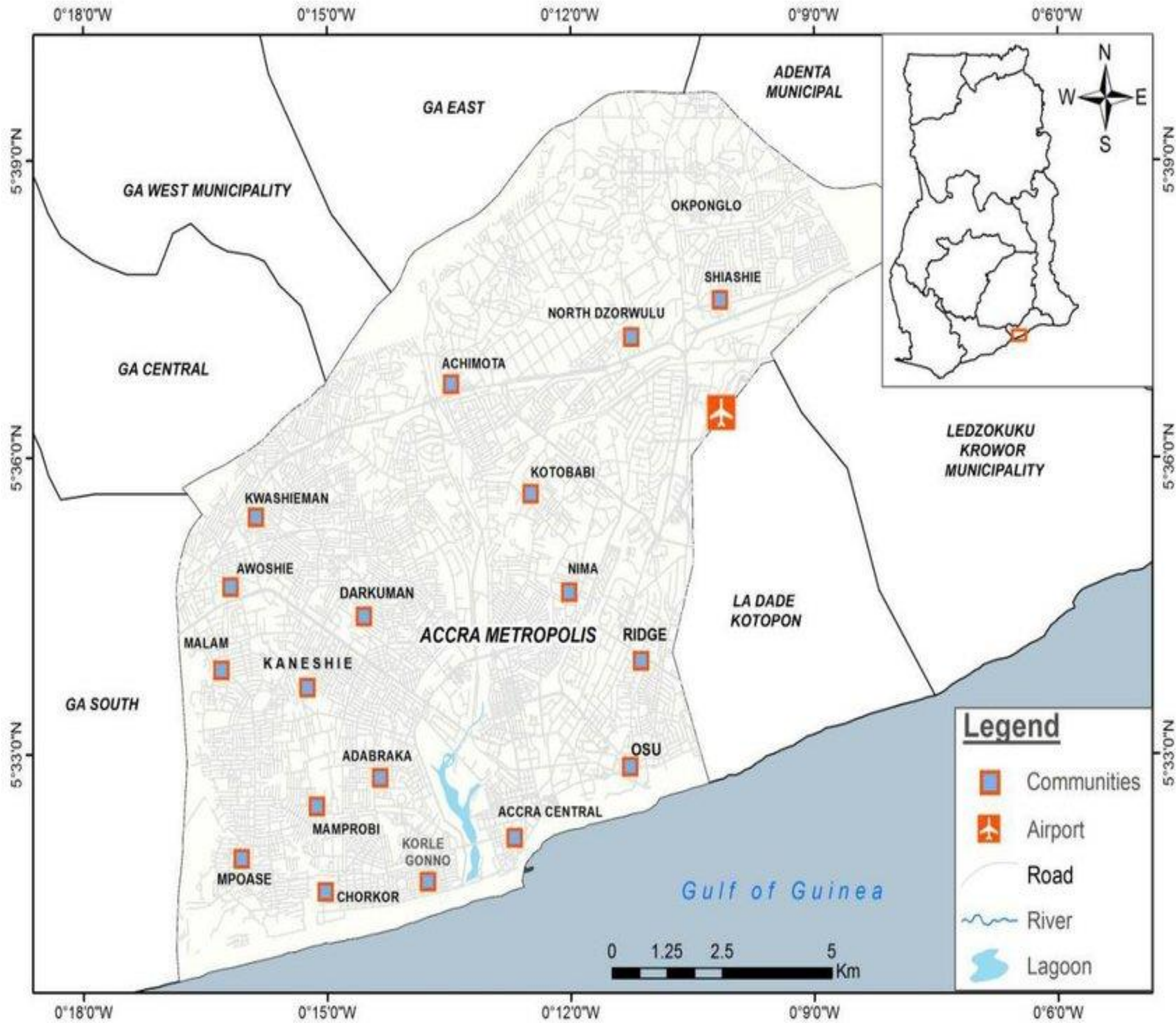
**Fig 3.1 Map of the Accra Metropolis**




Source; (Accra Metropolitan Assembly, 2017)

### 3.3 Target Population

The target population is all persons taking care of children with any congenital anomaly in a health facility or home, within the Accra Metropolis out of the 1,727 children with disability in the greater Accra region, according to the 2010 population and housing census of Ghana.

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### 3.3.1 Inclusion Criteria

The study included; parents, family members or other persons who have taken up the care giver role of children with congenital defects in the Accra metropolis. Only those who could communicate with at least English Language or Twi and consented to be participants in the study were included.

### 3.3.2 Exclusion Criteria

Caregivers living in the Accra Metropolis, who are caring for children with disabilities that have varying etiologies other than congenital.

### 3.4 Sample Size and Sampling Technique

The principle of data saturation was used as the standard to determine the sample size. According to authorities in this area, saturation is attained when the researchers, consider to end their quest for further data because, no new information is elicited (Polit & Beck, 2004). In this regard, data was considered to have reached saturation when the researcher noticed that, the new data is just a repetition of the previous ones with no new information emerging (Polit & Beck, 2004). It is based on this assertion, thirteen (13) family caregivers constituted the sample size for the study. The study also used purposive sampling technique in selecting the participants. With this technique, the researcher selects those cases that are easiest to access under given conditions (Patton, 2002). Apart from it being symbolic to qualitative methods, this technique also gives the researchers the flexibility to decide what purpose they want the participants to serve even before going to search for them (Bryman, 2016). Its use enabled the researcher to deliberately recruit care givers of children with congenital defects who gave valuable information depicting their experiences.

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### 3.5 Data Collection Tool

Data were collected through in-depth face to face interviews guided by a semi structured interview guide (Appendix E). Items on the interview guide, comprised open ended questions that were formulated based on the constructs of the theory guiding the study, through to the objectives of the study and the literature review segment. The interview guide had two main section, namely; the first section that was designed purposely to elicit demographic responses, while the second section was composed of the main questions addressing the various constructs and the subsequent probing questions based on the main ones.

### 3.6 Pretesting

The interview guide was pre-tested on two care givers of children with congenital birth defects at the 37 military Hospital. The relevance of this endeavour was to offer the researcher the opportunity to assess the clarity of the questions, rephrase them when required, and sharpen his interview skills for the actual study. Data collected were not included in the analysis of the main study.

### 3.7 Procedure for Data Collection

Ethical approval was obtained from the Institutional Review Board of the Noguchi Memorial Institute for Medical Research (Appendix A). Permission was also obtained from the headmaster of the Dzorwulu special school through an introductory letter from the School of Nursing and Midwifery, University of Ghana (Appendix B), since this facility served as the main centre for contacting caregivers. The letter indicated the purpose for the study and served as a supporting document for the ethical clearance that was obtained for the same purpose.

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The researcher went to the school to establish rapport with the headmaster and teachers prior to the submission of the introductory letter and the ethical clearance details. When the ethical clearance was approved, the Covid-19 pandemic came in with partial lockdown and closure of schools. Hence, the researcher contacted the headmaster of the Dzorwulu special school who further gave him the contact number of a teacher to assist in contacting prospective caregivers for the study. The teacher then gave the contact number of those who showed interest of being participants for the study to the researcher. This offered him the opportunity to introduce himself to the participants, made his intentions known to them and sought their permission for the study. Based on mutual acceptance between the participants and the researcher, a venue and convenient time were scheduled for the individual interviews. The first participant was recruited after she agreed on phone to be part of the study. She agreed to meet the researcher at home, so the researcher went over to her house to conduct the interview. In all seven (7) participants were interviewed at home and four (4) at the health facility where the researcher works after they agreed on phone to be part of the study. However, the remaining two (2) participants were recruited through snowballing as they were contacted with assistance from some of the participants who were interviewed earlier and recruited after consenting to be part of the study. Interviews were transcribed right after each sassion, hence the researcher reached saturation after the tenth ($10^{th}$) participant. However, due to the varied nature of the defects, three more interviews were conducted to reaffirm saturation.

The researcher established rapport with each participant and sought their permission prior to the interview. The Covid-19 protocols such as; washing of hands with soap under running water, the use of hand sanitizers, wearing of face masks were observed

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while the interview venue was open and well ventilated. The sitting arrangement was such that, even though it was face to face, the over two metres (2m) distancing was observed between the researcher and the individual participants. They were also informed that, participating in the study was strictly voluntary as they have the right to withdraw from the study at any time they wish to do so. In addition, they were informed that the period for the study will last for three months hence they have the liberty to choose any convenient time within the time frame. Meanwhile they were also informed that within the same time frame they could be called upon for further verification or clarification when required. Participants were made to sign or append their initials to the consent forms prior to the start of the interviews. This consent forms were further stamped and signed by the headmaster of the school as a witness and this forms part of the audit trail for the study. In all, seven (7) interviews were conducted in English language and six (6) in Twi and transcribed verbatim. The interviews lasted between 25minutes to 50minutes per session. They were audiotaped based on the permission of the participant. Probing questions were asked based on the responses from the participants and this helped in keeping the participant in line with the research objectives. The data collection procedure started on the 2$^{nd}$ of July, 2020 and ended on the 30$^{th}$ of September, 2020

### 3.8 Data Management

Peculiar to qualitative studies, after all interviews were transcribed and rechecked, coding ensued (Sutton & Austin, 2015). The data that was generated, was therefore manually coded before analysis. The audiotaped interviews were also well stored by saving them in folders protected by complex passwords which was not disclosed to anyone. Separate files were created for different participants while all names of participants and the respective

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children they care for, were replaced by pseudonyms. Transcribed interviews and consent forms that may bear any identity of the participants have been securely protected at the School of Nursing and Midwifery University of Ghana, for safe keeping. All these were to ensure that, no one else gets access to the data except the researcher and his supervisor.

### 3.9 Data analysis

In terms of analysis, thematic content analysis procedure was employed. This was to ensure that, the researcher familiarized himself with the data. Thematic content analysis has been defined as "a method for identifying, analyzing and reporting patterns (themes) within data"(Braun & Clarke, 2006). Theming involves aggregating codes from one or more transcripts to present findings of a study in a meaningful way (Sutton & Austin, 2015). This may not be associated with any pre-existing theoretical framework and can be used across a wide range of qualitative studies (Braun & Clarke, 2006). However, the themes in this study were suggested by the constructs of the model guiding the research work as postulated by other authorities (Ryan & Bernard, 2003). The researcher did extensive reading of the transcribed interviews in order to group data under the thematic areas for enhanced analysis. Meanwhile, other related information relevant to the study, that did not fall under any of the constructs created room for the researcher to formulate emerging themes that were not necessarily part of the predetermined ones. This therefore means that, the researcher played a vital role in analyzing the data, as asserted by Braun & Clark (2006).

The six main steps of conducting thematic content analysis suggested by Braun and Clark (2006) were followed. These include; familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report. In the current study, the researcher transcribed all the audio-taped interviews

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verbatim and read through all the transcripts. Since the interview guide was based on the constructs of the theoretical framework, five themes were already determined. Two others emerged from the interviews. Secondly the researcher generated codes based on unique but similar expressions shared by participants. These codes were assigned to these similar expressions by highlighting them and placing the codes as comments on the right margin of the transcribed interviews on the computer. Similar codes were put together as subthemes under the five pre-determined ones. Meanwhile the other subthemes were grouped together to obtain the two emerging ones. The themes were checked to ensure they conform to the subthemes and the codes. They were thus defined as the fifth step required. The study findings were therefore reported based on these arrangements.

### 3.10 Methodological Rigour (Trustworthiness)

In qualitative research, the extent to which the researcher is able to prove, that the findings of the study actually portray the real experiences of the participants is termed rigour. Various authorities have their views as to what should constitute rigour. Notably, Guba & Lincoln in 1985 came up with the concept of trustworthiness in research, as the product of credibility, transferability, dependability and confirmability (Krefting, 1991). In 1994 they added authenticity (Cope, 2014). This work therefore dwelled mainly on these principles. Meanwhile, other less stringent ones proposed by other authorities such as; explicitness, vividness, creativity, thoroughness, congruence and specificity were ensured, though not explicitly.

#### 3.10.1 Credibility

This describes how confident the researcher is with regards to the truth in the findings, taking into consideration, the study design, the participants and the context (Krefting,

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1991). To ensure this work is credible, the researcher engaged the participants for relatively a long period of time. Data collection lasted for three months. This gave the researcher ample time to engage the participants. The engagement took the form of a conversation, observation and noting down important non-verbal cues lasting for at least 25 minutes to 50 minutes per participant. Again, 13 participants were interviewed and by the 13th, data saturation was reached. This number of participants, alongside the varying nature of the defects included in the study enabled the researcher to obtain varying experiences on the same subject. A process described as triangulation (Krefting, 1991).

The researcher used reflexivity in order to be mindful of the influence his personal experience can have on the study (Krefting, 1991) and prevent that. This is because, the researcher is a nurse who has stayed in the research setting for over 12 years and privileged to see how some of the caregivers beg for alms along major streets to care for these children, likewise the negative attitude exhibited by some health care providers towards these caregivers. Then the supervisor's audit was paramount in ensuring the researcher's discovered truth reflected the real experience of the participants.

### 3.10.2 Transferability

According to Krefting (1991), transferability is the principle against which the applicability of qualitative data can be examined. This implies that, the ability of a research finding to fit into similar contexts outside that of the study situation denote how transferable it is. To ensure transferability, the researcher ensured that, the background information of the participants was clearly presented, as well as the context and the setting. This was to enable others to determine how transferable the findings were (Krefting, 1991).

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The researcher also kept audit trails of all events, procedures and engagements, so that by following these, others can assess the transferability or otherwise of the study.

### 3.10.3 Dependability

This describes the level at which the findings of the study are consistent or easy to replicate with the same participants or in similar contexts over a period of time. To ensure this, the researcher worked closely with his supervisor throughout the study whilst the detailed background information of the participants and the audit trails that were kept served the same purpose.

### 3.10.4 Confirmability

Confirmability refers to the researcher's ability to prove that, the data is the actual representation of the participants' responses and not the researcher's biases or viewpoints (Polit & Beck, 2008). The researcher can demonstrate confirmability by describing how conclusions and interpretations were established, and proving that, the findings were derived directly from the data (Cope, 2014). In order to ensure confirmability, the researcher reported the findings by providing verbatim quotes from the participants that vividly described each emerging theme, audit trails were also kept as evidences for any future confirmatory reasons. The researcher also worked closely with his supervisor, noting all the concurrent audit guidelines she provided.

### 3.10.5 Authenticity

Authenticity bothers on the researcher's integrity. Hence it describes the ability and extent to which the researcher expresses the feelings and emotions of the participant's experiences

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in a faithful manner (Polit & Beck, 2008). By reporting this way, readers grasp the essence of the experience through the participant quotes (Cope, 2014). This was ensured by the researcher through picturesque descriptions of the experiences from the participants' point of view using field notes, through expert, supervisors as well as peer review of audit trails and findings.

### 3.11 Ethical Consideration

Before the start of this study, ethical approval was obtained from the Institutional Review Board (IRB) of the Noguchi Memorial Institute of Medical Research (Appendix A). Formal permission was also sought from the headmaster of the Dzorwulu special school, using an introductory letter from the School of Nursing and Midwifery, University of Ghana (Appendix B).

In addition, the researcher adhered to ethical principles related to anonymity, consent, confidentiality, risk, privacy and beneficence. The participants were given prior information on the purpose, objectives, possible benefits, risks, the preferred language and the intention to audio-tape the interviews for the study. This was followed by a period of personal deliberation, within which the participant decided whether to participate or not. Participants, who agreed on these terms, were considered for the study.

Participants were informed of their right to withdraw from the study at any point they felt to do so, even if they had signed the consent form. They were informed of their liberty to voice out any concerns without consequences, whilst the security of the information they offered was reassured to them. They were assured that, the only persons that had access to the data up to date is the researcher and the supervisors.

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In terms of anonymity, pseudonyms were used to present the verbatim quotes from the participants, hence their identity was never disclosed or linked to any expression. The researcher was also cautious in asking trigger questions even though arrangements was made with a clinical psychologist (Dr. Samuel Adjorlolo with mobile number 0204197158), who was readily available at the time of the interview, to deal with such situations at no cost to the participants. No participant was referred to the psychologist, as they were all comfortable with the questions asked during the interview sessions. The data in the form of consent forms, audio recordings, field notes, transcripts and all related documents, have been kept safely and will remain the same for at least five years after the study.

To show appreciation to participants, the researcher provided them with a snack in honour of their time and valuable contribution to the study.

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# CHAPTER FOUR: RESULTS/FINDINGS

This chapter presents the main findings of the study, after analyzing the data in relation to the theoretical framework guiding the study. Five main themes were identified based on the constructs of the Transactional Stress Model by Lazarus (1991). These include; the life events, challenges, available resources or otherwise, health consequences and coping or adaptation strategies employed by family caregivers with children having varying forms and degrees of congenital defects in the Accra metropolis. Embodied in this chapter is a description of these themes and their respective sub-themes supported by verbatim quotes from the interviews conducted.

## 4.1 Demographic Characteristics of Study Participants

A total of thirteen (13) caregivers participated in the study. These comprise, ten (10) female participants who are all biological mothers caring for their own children with congenital birth defects and three (3) men, two of whom are biological fathers of their respective children and one (1) who is an elder brother to the child. The ages of the participants ranged between 30 to 77 years with eight (8) being below the age of 50 and five (5) being above the age of 50 years respectively. In all, two (2) participants had tertiary education with one actually being a graduate. Three (3) had Secondary school education. However, whilst one completed the then sixth form, the other ended at form five whilst the third completed the current Senior Secondary School system. One (1) attended a vocational school, and five (5) others had some basic education. They include; two (2) who completed the then Middle school system, two (2) others completed the current Junior Senior Secondary School system, whilst one ended at Junior Secondary School form one (1). One of the two (2)

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remaining participants stopped schooling at primary three whilst the other had no formal education.

In terms of economic activities, five (5) of the participants interviewed engage in the following trading activities; two of them sell groceries, one sells used clothing, and the remaining two trade in foodstuffs. Three have retired from active services; one as a broadcast journalist, another as a teacher and the third as a member of a private security firm. Out of the remaining five (5) participants; four can be described based on their economic activities as; a clerk, a pupil teacher, a seamstress (itinerant) and a cobbler while one did not have any source of livelihood. Their monthly income earnings ranged between one hundred Ghana Cedis (GH¢ 100.00) to two thousand Ghana Cedis (GH¢ 2,000.00), while majority of them (8) earned thousand cedis and above, three earned below one thousand Ghana cedis and two had no established income.

All the participants understand and could speak the Twi language. Six (6) could speak English fluently, four (4) could understand but couldn't speak the English language whilst three (3) could neither speak nor understand the English language. Furthermore, all the participants live within the Accra Metropolis with majority (11) being Christians and the remaining two (2) being Muslims.

In addition, six (6) of the participants were married and living with their spouses, five (5) have separated from their spouses, but described their status as being single whilst two (2) were divorced. They also had between one (1) to eight (8) children with most participant (12) having five and below number of children. Thus the only person to have gotten above 5, had eight (8). Some variations existed between the number of children they cared for compared to their biological children, this is because, some have adopted children

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in addition to what they had whilst others indicated that, their elderly children have left home and are on their own. The children the study focused on were between the ages of 8 to 27 years. The defects encountered include; six (6) cases of down syndrome, three (3) cases of congenital microcephaly, three (3) children had cerebral palsy and one (1) case of spina bifida. Tables showing the demographic characteristics of the participants have been displayed as Appendix G.

### 4.2 Organization of Themes

The findings of the study have been presented based on the constructs of the Transactional Stress Model by Lazarus (1991), supported by the objectives of the study. Two other themes; adaptation and religiosity, as a way of justifying the unthinkable emerged. The seven (7) themes and nineteen (19) sub-themes have been presented in table 4.2 below.

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**Table 4.1 Themes and sub-themes from transcribed data**

| MAIN THEMES | SUB-THEMES |
|---|---|
| 1. Life events of family caregivers of children with congenital birth defects | i. Impact.<br>ii. Duration.<br>iii. Predictability. |
| 2. Appraisals assigned to the event by family care givers of children with congenital defects | i. Challenges<br>ii. Threat<br>iii. Harm/Loss. |
| 3. Resources and support (social, personal and material) available to caregivers of children with congenital birth defects | i. Personal support<br>ii. Social support. |
| 4. Health consequences of family caregivers of children with congenital birth defects. | i. Stress<br>ii. Physical injury. |
| 5. Coping strategies of family care givers of children with congenital birth defects | i. Knowledge<br>ii. Characteristics of child.<br>iii. Faith in minor improvements. |
| **EMERGING THEMES** | |
| 6. Adaptation measures by family caregivers. | i. Time<br>ii. Determination.<br>iii. Resiliency. |
| 7. Religiosity as a way of justifying the unthinkable. | i. Take things as they are.<br>ii. Test of faith.<br>iii. Blessing in disguise. |

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### 4.3 Life Events of Family Caregivers of Children with Congenital Birth Defects

The event of having a child with a congenital birth defects seem to be an event that cannot be forgotten by the care caregivers. The reasons for the memorability of this event has been expressed by the caregivers in three main domains. These include; the impact of the event itself, the expanse of time you will have to continue your care duties, and how unpredictable the event could be.

#### 4.3.1 The Impact of the Event of Giving Birth to a Child with Congenital Birth Defect

Participants expressed the impact associated with the event of having to care for a child with congenital birth defects, as a reason why the event is considered a major life event. Common expressions made suggests that it is characterized by a lot of hassles and uneasiness. These stem from the breaking of the news, to number of times medical care has to be sought for the child. Maame expressed this as:

> *... when I, gave birth to my son and there were so much problems at the hospital, he was sick the next day, another sickness will come in, before when he grew up around like four years we got to know that he was a special child, this thing I will always remember that time.* **(Maame)**

According to Akos, the event being important is based on the difficulty associated with it. She recounts:

> *That important thing I always remember is giving birth to my son, I didn't find it easy, very difficult.* **(Akos)**

It was also revealed that, other associated events which otherwise could have been associated with the birth of any normal child, like caesarian sections added to the uniqueness of the caregiving thereby making the event stick to memory:

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*... what I will not forget in my life is that, my last born the way I suffered because of her. Anytime I give birth, God helps me, but when it got to her, they performed operation for me because of that, most of the time I remember because when I gave birth to all her brothers and sisters, they've never done operation for me but when it got to her they performed operation on me.* (**Ayerkie**).

To some, the strange nature of the defect is what makes it more of a major life event that cannot be erased from memory:

*Oh! the most serious thing that happened to me, is experiencing the life of my son, when I realized he is a special child. At the beginning, I didn't know anything about a special child, so it was very difficult to handle it.* (**Atswei**)

**4.3.2 Duration as a Reason for Classifying Life Events**

Family care givers expressed the sudden nature the event takes, as a reason why they consider it an event of much significance. This, according to them, induced unpleasant feelings of hopelessness and worry especially, thinking about when they perceive to see some improvements. Naa recounts:

*...It's my child that I always think about, that, I have carried pregnancy for nine months, and you are going to give birth and you get this….* **(Naa)**

The expanse of time one have to contend with the situation is equally enough to highlight its significance:

*... ask me, how long am I going to live with this special child? If you are not a special child, you are ok, you are lucky, you are blessed.* **(Esi)**

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Meanwhile, when hope for improvement is shattered and change seem not to be forthcoming, then the event become familiar and relevant. This is illustrated in the following expressions:

> *…. as for his age, I don't consider it, so his everything I place him as someone who is under five, that is how I see him.* **(Efua)**

> *He is just like this, I have not seen any change in him, what he does is to eat, then I will bath him, that's all, so that's how I see it.* **(Anima)**

### 4.3.3 Predictability as a Reason for Classifying Life Events

Family caregivers described the event of giving birth to or finding out about the status of a child with congenital birth defects as shrouded in a lot of uncertainty. This makes it even more frightening as it is perceived that no one can be insulated against the event no matter your personality or status in society. This was portrayed by Akos as:

> *….my son, he grew up as a healthy child and as he was growing, two, three years the only word that he can say is 'maa' so you will not see anything that this child will be a handicapped child but as soon as he is growing the talking is not coming so we checked out from Korle Bu and they finally told me he is handicapped child and nothing shows from the beginning that he is handicapped till the time he grown up before I knew that it's a handicap.* **(Akos)**

But as to who it may affect, it was evident from their responses that, it may happen to anyone:

> *Whatever happen in this world, once it has befallen someone, it can equally befall you.* **(Atswei)**

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Including expert who we believe could have done something different to mitigate the situation:

> *...it can happen to anyone. I know a girl, who is also like this. The father is a doctor the mother is a doctor, retired doctors.* **(Esi)**

### 4.4 Appraisals Assigned to the Event

Caring for a child with congenital birth defects has been described as a difficulty by all the family caregivers. It was described by most of them as a challenging situation because, it is associated with a lot of stress inducing hassles, that the individual need to gather a lot of physical and psychological effort to handle. It was also seen as a threat to their self-esteem and on other occasions as a harm or loss to them as individuals or their family unit. They therefore felt neglected and most of the time became withdrawn.

#### 4.4.1 Challenges experienced by family caregivers

Family caregivers unanimously described the situation as challenging based on the numerous forms of hardships they go through. These include; physical challenges, financial issues and employment or economic activity issues. The most reported physical challenge was in the area of self-care, as most of the children are not able to bath, brush their teeth, eat or wash their clothes unless they are either assisted or everything is done for them:

> *...In the morning like this, I normally wash his things then I will bath him, feed him and after that I have to be monitoring him because he can't do anything* **(Efua)**

> *...I will bath him, I will brush his teeth, I will wash for him, I do one or two stuffs for him, he can't do anything.* **(Maame)**

> *.... whatever he is supposed to do, he is not able unless you do for him.*

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> *You have to help him in everything, so it's difficult. Even if you are at home, may be his dress is dirty, or he has spilt water on the floor and everything, you are the one going to do all. So the problems are really many and serious* **(Kobby)**

Perhaps what is more disappointing is when you expect them to do certain things for themselves based on their age and they are not able. To Efua, no matter the age they are like children below the age of five years that must be holistically cared for:

> *... you see, his behavior, if you have a child less than five years, how he does his things, if he wants to urinate he needs assistance, if he wants to eat he needs assistance, if he will wear his dress, you have to brush his teeth, everything that he will do, unless you assist him, so as for me, that's how I see him, so I see him to be under five years.* **(Efua)**

Even those who repose confidence in them and give them the opportunity to do things for themselves, expressed their frustration as to how they will end up giving you more work:

> *...and whatever he will have to do, unless am there to monitor him. Don't do this, am there to monitor him. Don't do this, don't do that, because, when I leave him what he will do will be worse. If there is an iron and he feels like plugging it then he will go and do so, unless I pack everything into the bedroom and lock the door.* **(Anima)**

Another challenge most family caregivers expressed was in the area of finance. According to them, most of these children impose financial burdens on them. This they expressed, is as a result of their healthcare demands:

> *...I've gone through problems, because even it gets to some time that if I even send him to the hospital, the money I will use to pay for the services I don't have, have you seen it? It gets to sometimes, I can send him to the hospital, I will sit there for a very long time, they will*

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*say buy medication but the money I have to use to buy it is not available, have you seen it? They will say do this, but I can't.* **(Abiba)**

Kpakpo shared a similar sentiment as he recounts:

*... you know, you have to once a while, take him to the hospital, to treat him and then, common things like malaria here and there, you have to buy, some supportive vitamins and proteins yeah, to support, you know, so that makes you think, you see how to do everything for him, so sometimes, money matter.* **(Kpakpo)**

Meanwhile, as they strive hard to find solution to their financial crisis, the time they need to focus on the care giving burden, serves as an impediment to the various economic activities they engage in to make ends meet. Most of the family caregivers revealed, how they have to spend days, months and even years at home, taking care of these children at the expense of their work and how this further worsened their plight. Maame, Anima and Kobby had these to say:

*...I was working, I have to stop for seven years to take care of him, for him to do something otherwise you can't leave him for anybody, no one will have that time.* **(Maame)**

*... for about 9 years now, am not able to engage in any activity called work, because, I can't leave him and go and work.* **(Anima)**

*... as for caring for him, it's a real problem, it's not every day that you will be able to go to work. Right now, in case he is sick or he is not feeling well right now, your everything is spoilt. Because he can't take care of himself so that you can say, even if he is sick I can leave him and go, no! and let's say he is sick in addition, then it's even more difficult. Even if it's one month, you will have to stay at home and take care of him until he is fine.* **(Kobby)**

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**4.4.2 Threat Experiences**

In analyzing the issues raised by the family caregivers, it is evident that some of their challenges have to do with issues that they perceived as dangers, or blows to their self-esteem. This therefore represent the various perceived as well as actual emotional challenges faced by them, as these threaten their psychological wellbeing. Even though in varied expressions, majority of the family caregivers disclosed experiencing sad moments upon reflecting on the event, blamed themselves as well as others for the occurrence, felt the presence of the child may lead to other difficulties, and had doubts or thoughts of future uncertainties.

In the first place, majority of the caregivers who are also biological mothers of the children express their disappointment at the event, by revealing they felt bitter, sad and cried. This is evident in the following narratives:

> *... because he is a special child at times I feel pain and I feel hurt.*
> *Because every parent has a purpose of giving birth so by all means,*
> *as a parent at times, I feel very bitter in my heart.* **(Akos)**

> *…if am there, I will just be crying and be asking myself, why did it*
> *happen that way.* **(Anima)**

While experiencing the most intense forms of these emotions, most of the family caregivers try to blame either their actions or inactions or those of others as the cause of their predicament. While Anima blamed herself and wanted to medically find out whether the problem is from her or elsewhere in this narrative:

> *... if it's from my family or that of the man I can't tell, but personally,*
> *I see it like if I had enough money I would go and check the body for*
> *the doctor to see any problem, that I have so he can let me know.* **(Anima)**

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Atswei placed hers' squarely on the negligence of some health care providers:

> *.... when I was laboring for this boy, you go to the hospital they tell you it is not your time, go back home, I was laboring, discharging, whatever, for one good week, all the water came out and then it was becoming black and blood was coming then I said aah! it looks as if am going to die and it was one nurse who just sympathized with me, so it was just as the head came then I just delivered but throughout, they didn't tell me anything.* **(Atwei)**

Superstitious beliefs were not left out of the blame game, as some blamed their situation on them.:

> *... I said it and people also said same because, the reason why that thing came into my mind is that, the first wife ... couldn't give birth and I gave birth to a boy for him. So the second time she will notice it, I was carrying this boy's pregnancy so what happened was, the woman started traveling at short intervals, and whenever am there, I feel like I've gotten miscarriage then they will rush me to polyclinic, and my mum too was going round praying for me and the likes, it was through these series of prayers, that I gave birth to the child. So my entire mind tells me it's the woman who "took me somewhere.* **(Sika)**

The presence of this children also pose threats of insecurity as they may get missing or hurt by unsuspecting people and add to the numerous hassles the family caregivers face. Hence they prefer keeping them indoor where they can monitor them. Akos shared her sentiments:

> *...at times he gets missing, three days, four days, it has affected me three days four days, you are looking for your child, I mean you are a parent you will feel it, you will waste money, at times I will go on*

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*radio and those things ahaa! When he goes out, maybe he will get missing, so he doesn't go out and he is always with me even when am going somewhere, he is always with me.* **(Akos)**

To Kobby, aside the missing you also have to protect him from any harm. He recounts:

*.... he is always around you, at times if you leave to do something and come all of a sudden by the time you come back then he has vanished from the house, so every day you have to keep your eyes on him, so that, no one will hurt him or he will not go and do anything.* **(Kobby)**

Aside all these, when it comes to the issue that raises the most emotional concern among the care givers, they all described the uncertainties surrounding their own future and that of the children as their main fear inducing concern. Most of them were satisfied and content with the sort of care they give to the children, but what happens if they are no more and what will become of these children, remains a questions that keep troubling their minds. This is evident in the following narratives:

*… my worry is that the way he is, I may say if I die and leave him very young, he will suffer, so always my prayer is that, I should live longer and take care of him to a certain extent.* **(Salifu)**

Efua expressed her worry in a similar way:

*Ooh! the only thing I see about it is that, this one, when will he be able to do something for you? and again as humans, you can't live forever, if one day you are no more, what can he do on his own to help himself? So these are my only worries about him.* **(Efua)**

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In the case of Atswei who is 63years old, the fear is not only about what will happen if she is no more, but currently she is aging and may not have all the strength needed to continue her caregiving activities:

> *… my problem is, now am growing old, I don't know how to handle him when am a little weaker, than as I am, for that one I even told him that I don't know what will happen.* **(Atswei)**

**4.4.3 Harms or Losses**

As a harm or loss, a damage might have already resulted in the form of a physical injury or loss of a valued person, important object, self-worth or social standing. The study result revealed that, all the care givers wished their children were normal. Furthermore, most caregivers had expectations as to the kind of child they were expecting and the role they wanted him or her to play but unfortunately, these expectations were not met hence they felt they have lost that perfect person they were expecting. Also, most of them felt stigmatized and rejected by spouses, family and friends including social groupings they belonged to. Kpakpo shared his story:

> *…so as if he has become a little bit sort of small burden but well, this is because, when your child is young, you will take special care of him, but when he grows, he can do certain things for himself, but here we are, you will still treat him as a baby.* **(Kpakpo)**

Others had specific expectations from these children based on their unique situations. The fact that these were not met, means they have lost that ideal child, hence indicating a challenge. This is portrayed in this narrative by Akos:

> *… Oooh! you know am somebody that, am the only child of my father so though my age was a bit this thing to give birth, I was happy when*

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*I wanted to give birth too because, I know that finally I have a brother or sister. So I was happy to share ideas with, talk to, ahaa! you see so when I gave birth and later I know the child was special, I felt sad. I was like aah! my dreams did not come true, so at times I feel sad.* **(Akos)**

Salifu on the other hand feels he would have done better if he were normal compared to the other siblings:

*... it pains me that it was so because am seeing that, he is somebody who if he is in his normal state, he will have done well, he will do better as I compare to his senior brothers and he is someone who is eager to do something* **(Salifu)**

Even where the person is a sibling to the child, these unmet expectation is seen as a loss. Kobby expressed his disappointment:

*...I've observed that, my elderly sibling always walks in two's so the one following me that I hope to go through life with, oh let's go here, oh 'charlie' let's pass here, let's go and do this or that, the person I have to share ideas with, it did not happen that way, you see, so anytime, his entire burdens have added to yours because he is not able to do what you expect of him you are the one going to take over all the suffering, so at times if am there, even when I came you can see that am not of myself...* **(Kobby)**

Socially, perceived and actual stigma was experienced by majority of the family caregivers. This stigma stemmed from the behaviour of individuals, bodies or community members towards them. They disclosed this by observing how people stared at them in public, tagging them with names and making derogatory remarks about them. Abiba recounts:

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*... it disturbs me because, when you are even walking with him and people see you, they can stare at you, have you seen it, they can stare at you.* (**Abiba)**

Akos shared her bitter encounter with her family and how she responded:

*... for my family matter, I don't want to talk about it because, I remember somebody came to me and asked me, we don't have this one in the family, how did you get it and I just kept quiet and entered my room, so you know I've told you that, people don't understand.* **(Akos)**

Anima shared her frustration on how people did not only stared at her but points at the child, ask questions and laugh at her:

*They will be pointing at him, so when he reaches there then they will say eeei! which human being is this? have you seen it? So when I go out, they laugh at me.* **(Anima)**

To Naa, the stigma is the main impediment to seeking for assistance in caring for the child. This is because, she has been introduced to groups that assist caregivers of handicapped children but she declined to go for such an assistant for the fear of being featured in a television documentary:

*... even the other time I was walking at Pokuase when a certain sister said I should take him, wherever, and they will help me, and I said as for me, I don't like a situation where I will appear on television. Or do you understand what am saying? You will appear on TV and someone will say eeeei! she has sent the child, she is bringing the child o!, have you seen it, so there are a lot of things that people say.* **(Naa)**

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Tagging has also been revealed as a source of major challenge. For instance, some of these caregivers are seen as evil and punished with the child's predicament. Akos share her story:

> *... when you give birth to those children, they think, what word will I use at all? you are the most sinful person in the world it's not like this time the education is around the whole place so people understand it but 14years though, it exists, but the education is not much so when you have a child in that family it's like you brought all calamity to the family.* **(Akos)**

Esi recounted a similar story:

> *They say oh, this is "Nsuoba" (water baby) this one the parents are wicked that's why God punished them with this.* **(Esi)**

The import of these stigma and tagging, has also been revealed as the main strains on family cohesion. As some of the caregivers were either divorced or separated from their spouses. Most of the men disserted their wives because of the child's predicament and even those who are still together expressed how this difficulty, sometimes generate squabbles at home. But per the narratives, siblings were generally described as being helpful. To these, Abiba had this to say:

> *... do you think if he were to be normal like the sisters, the father would leave the house? We will have stayed together fine, because, when we gave birth to two and they were correct, we were together, but with this, he has cared for him, to the extent that, he is now tired, so when he wants to wait for the child or something he is wasting his time. Because of the child he even feels, he might not be able to make property for himself* **(Abiba)**

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The issue does not only affect marriages, as relationships and getting a prospective spouse becomes difficult and frustrating. For instance, Maame described her situation:

> *... and in relationship too, everybody thinks I wish, I want you but I don't want your son, you see? Because he thinks when we get together we will give birth to the same, you understand? So that's so much difficulty on my relationship, because of him.* **(Maame)**

Naa is married and thankful to the husband for his continuous support, but indicated that, things are not always smooth:

> *...As for that one I will say even the man, when it gets to sometimes he becomes annoyed, it happens o! the man at times, he gets tired and become fed up, if you disturb him with your child's issues too much, he at times say am tired.* **(Naa)**

**4.5 Resources and Support Available to Caregivers**

In times of difficulty, resources and social support are crucial, even though both cannot be the absolute solutions to all the hassles of life. The data generated seem to portray this assertion, as all the caregivers agreed that, getting assistance is very helpful when in such a situation. However, the support most of them obtained in the form of resources were personal and social, even though these were woefully inadequate.

Personally, majority of the caregivers engaged in some form of trading activities, others are employed, or enjoying paid pensions. This therefore serve as their source of livelihood. Through these they were able to provide some of the care needs of the children. Narratives to these effect includes:

> *... the factor that help me is work, if you are not working, you can't help, so am able to organize myself and work.* **(Ayerkie)**

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Atswei a civil servant, currently enjoying her pension had this to say:

> *Ooooh! once I was a worker, I don't have a problem of taking care of him, what he will wear, what he will eat, his hospital, I could bear everything am still enjoying my pension and am being paid, he doesn't have a problem, I don't have problem caring for him.* **(Atswei)**

The narratives of personal support, go beyond their economic activities, because they believed personal endowments such as being a female as well as possessing the attributes of patience and love are personal resources that enhance the caregiver role. For instance; to Abiba and other biological mothers, their gender and motherly qualities, are the main factors that motivated them in providing care when obviously their male partners flee:

> *... but because, he is my child I have given birth to, and because I am a woman, I can't run away and leave him, so that's why I am holding on with his care.* **(Abiba)**

The findings also revealed that, all the caregivers receive some social support no matter how negligible, but from varying sources. The common sources include, health care providers, friends, siblings and very few mentioned their family and or spouses. These supports were mainly in the form of money, clothes, food and encouragements. For instance, Anima recounted her encounter with the health team:

> *...I remember, the time he drank the parazone like this, when I got to the hospital, you know am also somebody, when something happens to my child then I become alarmed. So when I got there I shouted eeeei! my child has drunk parazone ooo! because of that, they did not even ask for my card, so when I was shouting, then the doctor came out and*

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*he called the nurses, then they rushed, things, so whenever I send him for weighing, when I get there, the moment the doctor. sees me, even if we are in a queue, the moment the doctor. sees me, then he will say, let me take care of my small boy before, as for the doctors, they really like the child.* **(Anima)**

Sika shared the immense help she gets from friends:

*... my friends, were the ones that helped me a lot, they helped me a lot. God said we should speak the truth, some, when he is going to school, may be take this money for what? to buy things for him, some too if they come and visit, they will say take this money and use it to prepare food for him, ehee!* **(Sika)**

Naa also expressed gratitude to the husband in the following words:

*… it's my husband that I will thank. That, still, he is holding on to us and taking care of us small small, when my Dad was alive, he helped us a little bit, but because he is no more, all the burdens are now on my husband ehee! we don't have anyone to help to care for him.* **(Naa).**

Kpakpo on the other hand, had an understanding family, hence the care duties are not just his, but shared with the entire family:

*... the problem is not only mine, it's for the family, so we all share.* **(Kpakpo)**

**4.6 Health Consequences Faced by Family Caregivers**

Even though they all reported numerous hassles associated with their care giving endeavour, majority confirmed being in good health and had no health issues emanating from their care duties. Few family caregivers who had health implications, reported mild

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form of stress due to excessive thinking and musculoskeletal pains resulting from the extended period they have to carry these children at their back and sometimes home accidents that occur in their quest to provide care. For instance, Akos shared her story, as to how the stress can predispose you to other illnesses:

> *... mostly, because, I've told you that at times he will be missing for a while, walking, going here and there, it's not easy, by all means, it will affect your health. When you are stressed any sickness can come, malaria can come it could be anything, anytime at all.* **(Akos)**

Kobby also described how the extra thinking you engage in, has the tendency of slowing you down and making you feel you are not well and need medical care:

> *...There are times you will feel that you are not feeling fine, as said by a friend of mine, he said "am not sick but am not well" ehee! So at times you will go and check your BP and check other things and see the Doctor, then you will realize oh, it's not any sickness that is troubling you but maybe it's the thinking that is making you slow ahaa!* **(Kobby)**

In terms of physical injuries, Naa who has to carry her son for six (6) years recounted:

> *I had waist pains. You know he was always at my back, so the Doctor said, if I continue carrying him at my back, I will feel pains in my backbone. Even up to today, if am there, sometimes I feel it.* **(Naa)**

On the same issue, Esi recounted how she fell, got injured and had to go through medical as well as physiotherapy treatments, in her bid to bath the child:

> *As for my health, I am not fine, I fell down. When I was going to bath her one day, I slipped and fell down in the bathroom. So now I have spinal problem. I attend clinic and I go to physio as well.* **(Esi)**

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Meanwhile apart from Esi, other family caregivers who reported having health consequences handled the situation at home. Ayerkie recounts:

> *...so if there is any ointment or I go and buy some medication, smear it and sleep* **(Ayerkie)**

**4.7 Coping Strategies**

Findings from the study revealed that, no matter the resources available to the caregiver, they were not enough to completely deal with the challenges associated with the caregiving burden. Hence to at least obtain some level of equilibrium, these caregivers adopt strategies most of which look like defense mechanisms, to cope with the situation as there seem to be no permanent solution to the issue. Time however is of essence, because, the duration these coping mechanisms last, determines whether they can be termed as adaptation or not. Some of the common coping strategies unveiled by the family caregivers include; having knowledge about the child's condition, positive behavioural characteristics of the child, having the feeling that theirs is better compared to others and having faith in observing minor changes in the child's condition. Atswei shared the relief her educational experience had on her situation:

> *...I had a chance to study at University of Winneba, a special child's course, then I realized the way to treat him and observe him and then, that pain went over; I just took it as part of my duties.* **(Atswei)**

Akos did not just studied the child's likes and dislikes but went ahead to consult specialist, attended workshops and conducted personal searches using the internet for information. These she said enhanced her situation:

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*... At first I have this difficulty but as soon as I understand the condition, the advantages the disadvantages and those things, now I can cope. I've been following them, I once went to, they organized a programme at "awa awaa atuu" Haatso, I went there. I learnt a lot. I make research on my phone, food that is good for them I ask doctors and those things. I now understand, so whether somebody will do something, or not I understand the thing so it doesn't worry me.* **(Akos)**

Another very recurring coping mechanism shared by the caregivers is, appreciating the positive side of the behavior put up by the children they cared for. According to them all these children have special abilities that when they exhibit amuse you the caregiver and gives you relief:

*...you see because he does certain things which the normal couldn't and that even amuses you.* **(Kpakpo)**

According to Kobby this even lingers in memory in the absence of the child:

*... if am with him, certain things he will say to make me laugh, if I remember such things, then I will say aah! Kwadwo paa, he is funny oo! he has some terms may be if you call him that, Kwodwo come or stop what you are doing, he will say 'clear off me', so that clear off that he will say, the way he will say it will make you laugh, have you seen it ehee! Because, what you are telling him doesn't require that response, but he has said that so when it happens that way then it makes you happy and laugh. So even if he is not around you and you remember him, you will realize such issues occupy your mind and make you laugh ehee! It makes you happy that aah, that's Kwodwo talking* **(Kobby)**

Furthermore, majority of the family caregivers take consolation in finding out that, the kind of defect their child is having is mild compared to others. This according to them

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is not based on just their assessment but also listening to predicaments shared by others and praises they receive for taking good care of theirs. For instance, Anima recounts:

> *…excuse me to say, some their child is lying inside their rooms and they can't even get up. So such a person, when she sees mine, then she will become happy, whilst am feeling so much sorrow about my child, when she rather sees mine, then she is happy, and say, if I were to get it like this, I will have liked it. Two persons, anytime they see my child, even, me who say it is not good for me, but they are envious of my child; as for you, your child can do almost everything o! yes for your child he is adorable o! even mine, I did not get it like that o! When they say that, I also feel happy within, then I will say eei God, not knowing am also better than someone o! so am grateful.* **(Anima)**

Efua shared a similar story:

> *… even some have more conditions. Some, one person cannot walk, the same cannot hear anything, cannot see and a whole lot, so at times I feel mine is even better.* **(Efua)**

Kobby thinks, if the situation should be scored, his brother might even obtain a perfect score compared to others:

> *…Oh that one I take it that, he is not the only person ehee! there are people whose own are worse than mine, because, there are some people, they can't even walk, but mine he is able to walk, you can go out to places with him. So that aspect doesn't worry me at all ahaa! So, when I remember that, then I become free. Even when you observed well, if you look at others carefully how some of them are seriously, and you compare to yours. Oh, you will realize that if we are finding average, like you will even be scored hundred percent ahaa! That is how it is.* **(Kobby)**

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To Ayerkie the comparison goes beyond just those who have ever given birth, because there are several others who just wanted to be called a mother, but were not privileged to even have the one she is taking care of:

> *... there are people who, excuse me to say, they even wanted to give birth to a child, so they can call her mother but she did not get.* **(Ayerkie)**

Nevertheless, majority of the family caregivers anticipated future changes based on improvements they observe in the child's condition now, and that served as a major coping strategy. Narratives on this include;

To Maame, the changes she has started seeing gives her hope:

> *...I know one day, things will go well, yeah, gradually he is beginning to have changes not like first.* **(Maame)**

Akos shared same experience:

> *... I believe one day one day things will turn. As soon as he understands, he hears he do actions one day will be his turn.* **(Akos)**

To Salifu, his concern for impaired speech is defeated by the little speech attempt made by the child and it's just about a matter of time and things will improve:

> *... he is changing, he is changing, as for now, he can think a little so I know with the passage of time, the talking will come, all I need is for him to speak.* **(Salifu)**

### 4.8 Adaptation Measures

One of the two emerging themes identified from the data has to do with the long term adjustments these family caregivers adopted, to become better suited to their care-giving

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duties barring all the challenges. Most of the caregivers in the study revealed strategies that kept them going, to have come in three main forms. These include; time, determination and resiliency. Majority of the responses seem to confirm the saying that, 'time heals'. This is because, the lengthy period the care giving role takes makes the caregivers become sort of used to the routines associated with it and also appear to become so much bonded to these children even more than the others who are normal. To Esi the passage of time was the turning point in adjusting to the situation:

*But, as time goes on and just going on and then am able to care for her.* **(Esi)**

Kobby on the same issues, has become familiar with what it entails and does it unconditionally:

*... so in my case it's like I've done it to the extent that am used to it, so whenever I see them, I draw all of them closer to me just exactly as I am,I don't discriminate ahaa! It's so.* **(Kobby)**

To Abiba, the hassles she has gone through to provide care for the child, has created a stronger bond which may cause severe emotional response when severed:

*...I like him so much, because I suffered because of him, so personally, among all my children, my entire heart is on him, I like him so much serious. So if, right now, my child should die, it will disturb me, it can make something happen to me eheeh! because, I really suffered because of this child so if something happens to him it will worry me...* **(Abiba)**

Other participants also shared how their determination to see good in adverse situation, enhanced their dedication to adjust to the situation. According to them, they are determined to do anything for them to also feel they are human beings, who they really are

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because, they would have done the same thing if they were to be normal children. Abiba recounts:

> *... you will not say he is a special child so he is not a human being, or you will go and throw him away or that you won't care for him. He is also a human being.* **(Abiba)**

Akos decided to adjust by focusing on her son to see what his future will turn out to be:

> *...I didn't end it there, because there is a word saying that, disability is not inability so, we don't ask why? but ask what next? so I put myself together and I want to focus on him, to see what he can do in his future. That's my focus now.* **(Akos)**

Kpakpo described the situation as not being a big deal to him because, people are born that way whilst others are born normal. However, even the normal ones can become helpless through accident. So it isn't an issue:

> *... you see some people here will be born handicapped, some people in the course of their life, will get accident and become handicapped. So what is the big deal? (He laughed) yeah.* **(Kpakpo)**

The third adaptation strategy identified was the resiliency exhibited through the strong desire that, they will provide care no matter the level of discouragement. They also indicated that, they would have done the same, for themselves or if the child were to be a normal one. Hence they don't see why they should hesitate when it comes to the one with congenital defect. This was portrayed in the narratives below by Ayerkie and Akos:

> *...Somebody even told me I am wasting money, but I said as for human being you will waste money on human, but may be because of God, in the future, she will be better than the elderly ones, so am not bothered about the money I am wasting.* **(Ayerkie)**

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Meanwhile it is not what others will say that will perturb Akos:

> *I don't care what they will say because, somebody will say am above it.* **(Akos)**

Finally, it was disclosed by some of the caregivers that, providing for children with congenital birth defects is not much different from doing so for one's own self or the normal children. So once you can adjust to the care for self and the normal child, you should be able to do same for those they are caring for. Kobby and Esi disclosed the rationale behind their motivation:

> *...Oh with that one, personally, I have been doing it for myself, so if he needs something, why can't I do it for him?* **(Kobby)**

> *... but what I ask myself is, if she were to be normal, am I not going to do the same thing?* **(Esi)**

Naa painted the same picture by saying:

> *...like these normal ones go to schools, if they are hungry, can you go and tell someone that my children are hungry? you can't say that, because they are your children, how you will manage to get them food, you will get them food mmm! so that's the issue.* **(Naa)**

**4.9 Religiosity as a Way of Justifying the Unthinkable**

One important theme that also emerged from the data and run through it right from the beginning to the end is the attribution of situations that seem to be beyond the imagination of the caregivers to a supreme being (God). All the family caregivers believed in and venerates God no matter the religion. They mentioned the name of God severally even though with different attributions. They indicated praying to God on several subjects, ranging from making requests for changes in the child's situation to giving thanks for

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improvements observed. Based on the findings, majority of the attributes can be categorized in three areas. These include; what God gives cannot be changed, hence it has to be taken like that, God tests the faith of his servants and God gives blessings in disguise.

The believe that, God cannot be challenged, so whenever He gives something, He has a reason for doing so, hence mortals must take it just as it is delivered unto them, was expressed by all the participant. Below are some of their statements to that effect:

> *...what I normally say is God, it is God who gave him to me, so what can you do? ehee! it's not that you gave birth to a child who is like this. So you don't know why it happened that way, so I have given all my issues to God.* **(Sika)**

To Abiba even though it's God who gave you the child, you don't have to throw your hands in despair but take good care of that gift:

> *... it's God who gave him to you so you can't do anything about it o! eheee! you have to work hard and take care of him until you see what God will do.* **(Abiba)**

Efua also shared her thought as to why issues of this nature defies science, go beyond comprehension and only a super force could be responsible:

> *...Ooooh if you watch carefully, it is God who does His things because I am now 40 years so by then I was 30years and my husband was 36, I don't think our age is an issue. Personally I did not make any attempt to abort the child and did not take any herbal medicine too. So you see? It is God.* **(Efua)**

The second believe that emerged was that, God uses adverse situations to test the faith of his servants. By this, the caregivers see the child as an entity being monitored by a

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supreme creator and every act of injustice against the child will not go unpunished. As a result, for the caregivers to please that supreme being, they must do their utmost best.

Kpakpo expressed this by saying:

> *…. this thing is a normal thing which happens everywhere so, we take things as they come, may be this thing is your test. As for God you know, so accept everything as your responsibility and then you do it; you are doing it for him, but you are doing it for God, because God created everybody you see now ehee!* **(Kpkpo)**

Akos belives this test is to reveal the glory of God:

> *…Oooh! God's words, because it happened in the Bible, when the disciples were called, is it, the mother who have committed a sin or is it a curse? He said, so that people will see my glory. So may be God want people to see His glory, that encouraged me a bit and when He (God) speaks too nobody speaks, when He says yes its yes and when He says no its no, so God knows.* **(Akos)**

Finally, having such children to care for has been portrayed as a blessing in disguise to the caregiver. To them the child is likened to a rose which always come with thorns. So, once the individual successfully go through the test, the situation can become a blessing. These blessing can be seen in the caregiver's health, daily living and prosperity. Anima revealed how God blessed her with good health:

> *…In terms of caring for the child, by the grace of God, I continue to do health insurance, but I will never send it to any health facility. If it expires, I will renew it but I will never send it. In terms of sickness by the grace of God, he has taken such burdens away from me.* **(Anima)**

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Esi shares her source of prosperity as:

> *…I am a single parent, but I have cared for three University Students, my own child and two others are my sibling's children and then what I get from my shop is less than thousand Ghana Cedis a month. So if you take care, good care from your heart and you care for these children it's blessings from God that will be upon you all the time.* **(Esi)**

Meanwhile, to Kpakpo, these blessings go beyond the physical world, as eternal life may be yours if you take good care of these children:

> *…and when you do, God will repay you, if not now, then, some time to come because we said we have eternal life. So in everything we do, we should, think about God first* **(Kpakpo)**

All the above expressions portray that; the participants believed in God. This believe is what has given them the sense of hope to face the realities of life, whenever they felt overwhelmed by the child's predicament or the hassles associated with it the caregiver role.

### 4.10 Summary of Findings

In summary, the findings obtained from the study, revealed the various subjective experiences of family caregivers of children with congenital birth defects in the Accra metropolis. The transactional stress model by Lazarus (1991), was used to explore the experiences of these caregivers. However, some other themes emerged from the data and were explored as such. The demographic characteristics revealed that, all the caregivers had family relationship with the children. Ten were biological mothers, two were biological fathers and one was an elder sibling (elder brother) to the child. They also had different levels of education ranging from tertiary to just one person who did not get any form of

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formal education. The various narratives obtained showcased, their significant life events, the kind of appraisals assigned to these life events, resources and support available to them, health consequences they face, their coping strategies, how they adapt to the situation and the part played by religiosity in explaining situations that look unimaginable.

The family caregivers disclosed several experiences that fell under the following categories; major or memorable life events, challenges, threats, harm or loss posed by these events, resources (personal social as well as material) available to them, the health issues they face, coping methods, adaptation strategies and religious sentiments expressed by them. The hassles associated with the caregiving role, were considered to be the main source of stress which may lead to psychological or physical ill-health unless adequate social support enhances coping. They all expressed the tiring nature of the hassles associated with their caregiving role. Some had some level of resources and social support but others had just little. Most of them indicated the myriads of coping strategies they have adopted in the short term as well as the adaptation mechanisms they employed as medium and long term management tools. But their subjective narratives also suggested that, the situation does not have a lasting solution, hence religion became the terminal point in trying to come to terms with the situation. In conclusion, all the aforementioned mechanisms, led to just few caregivers reporting health consequences.

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# CHAPTER 5: DISCUSSION OF FINDINGS/RESULTS

This chapter contains the discussions of the findings of the study. Here, existing literature in line with the constructs of the theoretical framework guiding the study, served as a reference to which the findings of this work were compared and contrasted. Just like the findings, it begins with the demographic characteristics of the participants ensued by the major themes of the theory.

## 5.1 Demographic characteristics

The participants of the study were made up ten biological mothers, two biological fathers and one male sibling (elder brother) of the respective children. Even though they all have family relations with the children, their gender suggests that any family member can take up the care giving role. However, the mothers of these children happen to be in the majority. Supporting the argument that mothers most often than not, form the larger group of caregivers to children with congenital birth defects (Dapaah, Addo, & Effe, 2020; Dogbe et al., 2019; Masefield et al., 2020)

Their educational level varies greatly, because while some had completed tertiary education others had little education or dropped out of school and one reported not having any form of formal education. Thus level of education, even though generally low in this study, did not in any way prevent an individual from taking up the caregiving roles of a child with congenital birth defect. One salient issue that was observed is that, all the men in the study who are caring for these children are married and enjoying the support of their wives, while majority of the women were either divorced or separated from their spouses and hence preferred to be described as single. The reasons for these have been largely due to the predicament of the children. This finding is in line with other studies that posited

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that, having a child with congenital defects result in disturbances in marriages (Aarah-Bapuah, 2015; Emordi & Osifo, 2018). One can therefore deduce that, women are vulnerable and hence many unwarranted accusations are easily labelled against them and little or virtually no protection seem to be available to them (Khan, 2020). All the participants except one, had some form of income generating activity, but petty trading dominates and income levels were generally low.

It was also observed that, few of the children being cared for were above the age of 18 years. This qualifies them as young adults. The fact that, they cannot lead independent life and have to be cared for explains the duration within which caregiving lasts. The least number of years a child is cared for in this work is 8 years but there appears to be no limit to the care duties as majority of them will have to be assisted or wholly cared for, for life. This supports the assertion of another study which reported that, children with special needs usually need care and assistance over a long period of time within which the healthy ones become gradually more independent (Hauge et al., 2015).

### 5.2 Life events of family caregivers of children with congenital birth defects

Having or caring for a child with congenital birth defects have been described as a major life event that keeps lingering in the minds of the caregivers. In the current study, the family caregivers disclosed that, the event impacted negatively on them, left them with a lot of life changing hassles, which they probably have to continue for the rest of their lives and how helpless they felt when they realized that, the event was sudden and they couldn't do anything about it. This suggests that, the event of having or caring for a child with congenital birth defects, impose long-lasting impressions on all aspects of the family caregivers' life. This finding is in accordance with findings from other works, which

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established that; getting the diagnosis of a chronic disability is clearly a life-changing event which exposes the caregivers of such children to various forms of stress (Chambers & Chambers, 2015; Zamani, Zamani, Habibi, & Abedini, 2017).

The impact of the event in this study, was mainly portrayed in negative terms. This is because the family caregivers described the difficulties associated with the hassles which constituted the life changing experiences they had by finding out how different their child's condition is and the struggles imbibed in the efforts made to come to terms with the situation. They mentioned that, they had difficulty understanding the child's condition. Because they did not know what it was and how to handle their care needs. This finding is similar to that of other studies which reported that, parents of children with disability, did not only expressed shock at the turn of events, but have to contend with new health conditions with strange medical terms (Carlsson et al., 2017; Chambers & Chambers, 2015). Also, the children were born with difficulties such as prolonged labour and through first time caesarian sections. Even those that were born through normal delivery came with health complications like recurring convulsions, jaundice, and strange appearance, hence they have to be admitted for long. After discharge, they still have to keep going for medical care and assistance and this placed a lot of burden on family caregivers. This finding is consistent with another study which reported that, primary caregivers of children with cerebral palsy had to endure long and difficult encounters with multiple health care providers (Kyeremateng et al., 2019).

One other reason why the event is remarkable to the family caregivers, has to do with time. They described the event to be sudden, because all along, they never thought a pregnancy lasting for nine months can result in a child with defects. Even after finding out

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the child's condition, they reported the event as worth remembering considering that, they cared for these children for long but saw little or no improvement. Hence to them, even with their age the caregivers need to do everything for them as their care needs are just like those of children under five years of age. These support findings in other studies that, reported life-long caregiving encounter with children with special needs (Nazzal & Al-Rawajfah, 2018; Pinquart, 2018). These therefore explain why they feel their life revolves round the event.

Nonetheless, the study revealed responses of unpredictability of the event, as why it is considered the most thought about. They believed their experience was unexpected and it is something that can happen to anyone regardless of economic or social status. This suggests why these caregivers were ill-prepared for the numerous life changing situations they faced. Hence qualifying the event as a major and memorable one. A similar finding was reported by Bonsu et al (2018) where the event of giving birth to a child with hare lip or palate was so much unexpected, after a lot of efforts were made to detect the possibility of abnormality or otherwise, even before birth.

### 5.3 Appraisals Assigned to the Birth Defects

Caring for a child with congenital birth defects has been described as a daunting task associated with numerous challenges, threats and harm or loss to the respective family caregivers. In the current study, the family caregivers who were all biologically related to their respective children as mothers, fathers or sibling reported several difficulties they have to endure. They experienced physical, financial and employment or economic activity challenges. They experienced threats in the areas of self-blame or shifting blame to others, perceived the presence of the child may lead to other difficulties, and also had doubts

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especially as to how the future will turn out to be. They expressed their harm or loss situations, as unmet expectations of a normal child, stigma they faced and actually losing spouses, family, friends and other social group memberships. These reflect the extent to which the caregiving burden affects all aspects of life of the caregivers. This finding is consistent with that of other studies that reported that caring for a child with special needs affects all the domains of life of the caregiver (Badu, 2016; Emordi & Osifo, 2018; Kotzky et al., 2019; Nazzal & Al-Rawajfah, 2018).

Physically the family caregivers experienced difficulties with the care burden they have to face in the form of assisting or entirely bathing these children, brushing their teeth, feeding them, washing their clothes and monitoring them. This is because, no matter the age of these children, they cannot be left to live independent lives. They therefore have to endure the demands of a life-long care burden. This study corroborates with another study; which described the physical challenges associated with caring for a child with cerebral palsy in a rural setting in Ghana such as bathing, changing diapers and linen as the most difficult and tiring (Nyante & Carpenter, 2019). These according to the study were made worse by the medical conditions like; neurological as well as musculoskeletal deficits associated with these defects. This study also revealed that, caregivers even fear to allow some of these children practice self-care activities for the fear that they may end up giving them more work to do. This is based on the back-drop that, most of these children have bahavioural deficits and may get hurt with broken glasses, spilled water or other fluids, drink unsuspecting harmful fluids and make the caregiving situation worse. The caregivers therefore prefer to do everything for them. Similar findings were obtained by another descriptive study in the United States of America and Canada, on ‘care giver inputs to

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optimize the design of paediatric care planning guide for rehabilitation'. Here caregivers described the inability of children with special needs to live independent lives as challenging, however, they try to rearrange their materials for easy reach and this improved the situation (Khetani, Lim, & Corden, 2017). This is missing in the present study because, caregivers probably do not have enough knowledge on the conditions of these children and how minor environmental modifications can enhance outcomes. In relation to this, the present study reported some of the family caregivers did not obtain information from healthcare professionals on the conditions of these children and their educational backgrounds were generally low hence, they based their source of information on hearsay. Misinformation from this sources in the African context, becomes a barrier to caring for these children. This finding conforms with another study conducted in Western Cape; South Africa where most of these information on the perceived cause of the condition of cerebral palsy from others were inaccurate and demeaning to the caregivers (Pretorius & Steadman, 2018).

Family caregivers in the study experienced difficulty in providing adequate healthcare services to their respective children. This is as a result of the cost of healthcare services, medications and transportation. Others complained of how difficult things can become in an attempt to feed the children and provide them with their basic needs like clothes and toiletries on daily basis, especially those that have to contend with taking care of other siblings of the affected child in addition, mostly without spousal support. These together, place a huge financial burden on them. This finding is congruent to that of another study by Dogbe et al (2019), where all caregivers of special children in their study on familiar

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and sibling relationship following the diagnosis of cerebral palsy in a child in Ghana reported financial burden as having a huge toll on them.

Even though the Accra metropolis is the commercial hub of the country and most of the caregivers disclosed being involved in one economic activity or the other, family caregivers express how difficult it is, to come by money to support the care needs self, let alone dependents. To the extent that, even those who were satisfied with their financial positions confessed, they will be glad if they could get some financial support from somewhere because even as big as the sea may look, other water bodies still drain into it. This describes the extent to which the extra care burdens incurred by family caregivers of children with congenital birth defects require massive financial support compared to caregivers of relatively healthy children. For instance, children with congenital defects frequently visits health facilities for care and follow-up services, are placed on special medications as well as food supplements, they are not able to keep their clothes well and therefore need frequent replacement, wastes toiletries when given the opportunity to practice their self-care activities, waste utilities such as pipe born water and electricity among others if not monitored. All these activities come with cost and thus worsen the financial situation of the caregiver. This support the assertion that caring for children with special needs consume a huge part of the family’s resources (Nazzal & Al-Rawajfah, 2018).

Despite the huge financial burden imposed on the family caregivers by the care needs of these children, the time needed to concentrate on the caregiving endeavour limits the ability of the caregivers to fully engage in any economic activity to make ends meet. They reported being unable to leave the children with other people in order to pursue other

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ventures because, they lack social support and feel others will not understand the child's situation. This led to most especially the biological mothers having to stay home for days and even years without any form of income generating work. They also described how they have to waste time in persuading them until they are convinced before they avail themselves for care activities. All these prevented most formal working engagements. Meanwhile, even as they try to do other non-formal works, this situation affected their time greatly and further reduced their income. Other studies reported similar findings where caregivers had to abandon their work just to meet the care needs of these children with special needs (Badu, 2016; Dogbe et al., 2019; Pretorius & Steadman, 2018).

In addition to the challenges expressed, the study also found some threatening difficulties experienced by the family caregivers. They raised emotional concerns of sadness, feeling bitter at heart, blamed themselves and others, envisaged the event may bring other difficulties and had doubts about the future. Some family caregivers in the study, experience extreme sadness, felt God or nature had not been fair to them, felt downhearted and cried all the time as the event continues to linger in their memory. Whilst crying they continue to ask themselves why? A question that seem not to be have any answer. As painful as the situation is to them, they are either not prepared to share or felt others are not ready to listen to their story. Hence they keep issues to themselves and once in a while get emotional outbursts. This finding is consistent with other studies that caregivers of children with congenital birth defects who are mostly mothers described the situation as very hurting; and characterized by unstable emotions as if the world is crushing up on them (Collins & Coughlan, 2016; Kyeremateng et al., 2019)

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They also blamed themselves as well as the negligence of others mostly health care workers and unsupportive spouses covertly for the event. The study found family caregivers having conflicting thoughts as to what the cause of the incident might be. Whilst some blamed themselves for giving birth at a tender age, others felt they gave birth at comparatively older age. Due to cultural believes, some felt the situation came as a punishment for sins committed by them, their spouse or family relations. Similar to this finding, is a study conducted on stigma and forgiveness in Ghanaian mothers of children with autism spectrum disorder; where some of the mothers blamed themselves for being responsible for the child's condition (Oti-Boadi, Dankyi, & Kwakye-Nuako, 2020). However, whilst some of the mothers in the study indicated that they had some warning signs, spiritually, the family caregivers in the presents study did not have that opportunity, else some would have done something else to mitigate the situation. Meanwhile, the blame for others goes beyond the family relations. As some blamed delay of care activities by health workers and superstitious hostilities from rivals as the result of the situation they find themselves in. A caregiver who is a biological mother, expressed her frustration as to how her rival who couldn't give birth took steps perceived as a consultation with spiritual entities, to ruin her marriage with the husband through the child's situation. This finding is congruent to that of a study conducted by Pretorius & Steadman (2018). In their study, several caregivers of children with cerebral palsy reported the prevailing believe that, disability is the result of practices relating to witchcraft.

Furthermore, the study revealed that, family caregivers live in constant fear and insecurity, due to the perceived challenges that the child's condition may pose. Most of them expressed the high possibility of the child getting missing and be hurt by

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unscrupulous persons within their immediate environment and beyond. This is because, they have mental defects and some cannot talk hence cannot give information to trace caregivers. This therefore partly accounts for the reason why most of the family caregivers prefer to be indoor with their respective children leading to social isolation. Contrary to this finding, a study conducted in Zambia on the challenges experienced by mothers caring for children with cerebral palsy, reported that the source of social isolation was mainly due to lack of social support and partly due to the fear of rejection and blame from other people (Singogo, Mweshi, & Rhoda, 2015)

Nonetheless and perhaps the most reported issue of threat is the anxiety that surrounds the future of the children. Family caregivers painted gloomy impressions about what will become of these children when they are aged, weak, incapacitated or dead. As they felt they are the only source of patience, love and comfort for this children. Hence their frail status when old or their passing into eternity will unleash so much suffering on these children as they can't live independent lives. This finding is consistent with that of a study conducted in Jordan; where mothers caring for children with disability felt that beside them, no other person in this world would ever give the same level of care to these children. These the writers described as a blend of deep love and deep fear being portrayed concurrently (Nazzal & Al-Rawajfah, 2018).

Harm or loss situations experienced by family care givers were expressed as; wishing they had normal children, having unmet expectations from the children and actually losing family and group membership feeling. Here the harm or loss did not particularly refer to physical injury but rather, the loss of a valued person, self-worth and social standing. All the family caregivers in the study wished they had normal children. Their reasons for this

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were based on constant comparisons made between the capabilities of the normal child as compared to the child with anomaly. They expected that at a certain age the normal child should be able to meet a certain developmental milestone or lead an independent life as much as possible. Thus they should be able to bath, brush their teeth, wash their own clothing and even feed by themselves. However, comparing their age and the fact that they still have to give them total care like toddlers, is seen as a loss of the normal child. Similar findings of caregivers wishing to have normal children were obtained by other studies in Ghana and other parts of the world (Aarah-Bapuah, 2015; Fernández-Alcántara et al., 2015).

Also on issues of loss, most of the family caregivers have specific and unique expectations from their children. One caregiver expressed her disappointment at how she expected the child to fill a sibling gap she had, because, she is the only child of the parents, but to her, this will continue to remain as a dream. Others also used their personal life trajectory as a yardstick to measure that of the children they cared for. To them they wished these children also grow without any limiting disability of any sort. One caregiver who is also a mother just wanted to see the child walk and have the thinking capability just as her. The fact that these expectations were not met makes them feel they have lost that perfect child they were expecting, just as portrayed in a study on the experiences of Palestinian mother caring for their children with spina bifida (Nahal et al., 2017).

The comparison again leads caregivers to feel that, these children with would have done better if they were normal. They believed that, looking at their predicament and what they are still able to do, they felt if they were to be normal, they would have been very intelligent, obedient, respectful and responsible than their normal counterparts. This

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supports the reason why some caregivers go the extra mile to defend their children by stating what they could do when they realize that, others want to underestimate their abilities (Lee, Park, & Recchia, 2015).

The issues of perceived and actual stigma were reported by all the family caregivers in the current study. They reported situations where others stared at them sarcastically, pointed hands at them, laughed at them and made demeaning statements about them just because of their association with the children. These feelings probably stemmed from societal definition of what normality is. Members of some families and their various communities, based their view of normalcy on the appearance of the children as well as their behaviour and attitude. According to them these children have different appearance compared to the normal child which attract wide view from people once they go out there. Others cannot tolerate crowd, hence make noise prompting people to focus on them. One mother recounted her bitter encounter; when she was sacked from a church of all places, because the ushers told her the noise her child is making is disturbing others. As reported by other studies, these and other negative attitudes against caregivers, give them the feeling that all is not well (Pretorius & Steadman, 2018; Singogo et al., 2015).

Caregivers were also tagged with names that had damning effects on their self-worth. Some were judged as being paid for their evil deeds in the form of their child's condition. Others called these children with names like 'water baby or snake' which was so challenging to their confidence in public as reported by other studies (Mokhtari & Abootorabi, 2019; Su, Cuskelly, Gilmore, & Sullivan, 2018). Whilst some have decided to isolate themselves from social activities as revealed by the following studies (Faw & Leustek, 2015; Marquis, Hayes, & McGrail, 2019; Singogo et al., 2015), majority of the

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caregivers in the present study disclosed that, they went almost everywhere with the children, as their main fear is; when they are leave them at home, they may worry other people who may intend hurt them. This finding is also based on the fact that, majority of the family caregivers were staying in rented compound houses, where their immediate neighbours neither had such children nor were family relations hence they fear the child may be hurt by others or vice versa (Nazzal & Al-Rawajfah, 2018).

The challenge posed by stigma is so devastating that, one mother referred to it as the reason why she declined to avail herself for assistance from a Non- Governmental institution (NGO). She described her fear for what others will say, if she is featured in a television documentary as a result of the assistance that will be offered her and the child. This finding is consistent with another study which posited that, being looked down upon, is the reason why family caregivers of special children feel reluctant to seek help (Su et al., 2018).

Meanwhile, the loss of that important person does not refer only to the child, but the product of the stigma associated with the event is responsible for the conflicts in marital relationships, leading to divorce or separations in most of the marriages and difficulty in getting a prospective spouse in ensuing relationships. Two family caregivers who were divorced in the study, and others who were separated but preferred to refer to their status as being single, blamed their situation on their association with the child. They recounted how they were disserted by their husbands, who denied the children or became tired with the situation and therefore decided to flee as reported by some studies (Aarah-Bapuah, 2015; Singogo et al., 2015). This is however contrary to another study conducted among couples caring for children with cleft lip or palate at Delaware in the United States of

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America, where all the couples disclosed that their care-giving duties rather strengthened their marital relationships (Zeytinoğlu et al., 2017). Differences in culture might therefore be at play in this situation. Also related to this, one person reported, that she still receives assistance from the child's father, but her marital bond has been severed and prospective husbands always get a change of mind whenever they find out about the child's condition and this has affected her quest to remarry.

Finally, one would have thought that, the three (3) male participating in this study and the few women who are still married and received support from their spouses will be immune to these challenges, but their narratives prove otherwise. They reported how the situation frequently generates misunderstandings at home, requiring sacrifices from one or both partners. Issues such as caring for the child at the expense of one's schedules, financing the medical bills of these children, making environmental changes to suit them and tolerating their behavior sometimes bring conflicts at home. This finding shows similarity with another study conducted on the experiences and expectation of parents with in-school children with intellectual disability. In this study the participants reported having marital issues because their spouses actually failed to cater for the needs of the children (Opoku et al., 2020).

### 5.4 Resources and Support

Personal innate endowments, and overt physical and material resources as well as those, obtained from others in the form of support are the main yardsticks, that determine whether the individual will be able to cope with the hassles associated with an adverse situation or be overwhelmed and be stressed up. Family caregivers in this study, mentioned various resources they had or others provided them as the main factors that helped them to come

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to terms with the situation both in the short, medium and long terms. Their income generating activity or work has been mentioned by majority of them as their main source of assistance. This is in contrast to other findings that suggests spouses and family as the main sources of support for children with special needs (Su et al., 2018; Zeytinoğlu et al., 2017). This may probably be due to the fact that, majority of the participants in the current study were single handedly caring for the respective children, which may predispose them to high risk of stress as found by an integrative review on the life of mothers caring for children and adolescents with chronic illnesses (Macedo et al., 2015) This support is further strengthened by their personal endowments such as; being a female and for that matter a mother, being patient as well as loving.

Other sources of resources, were mainly, supports obtained from others such as; the health care team, friends, siblings of the child and very few instances where their spouses served as a source of support for them. The actual kind of support obtained from these sources include; money, clothing, food and encouragements. This support findings from other studies (Pelentsov et al., 2016; Zeytinoğlu et al., 2017), even though the kind and magnitude of support may vary.

One important finding is that, all the participant believed that, getting assistance in situations such as this, is of immense help to the caregiver, as the hassles may be shared in such instances reducing their impact on the caregiver. This is consistent with the results of other quantitative studies which posited that, social support have a moderating effect or reduces the impact of the caregiver burden for children with special needs (Klutse & Naab, 2017; Lawson, Papadakis, & Holmbeck, 2018). Social support therefore has the tendency

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of reducing the effects of the challenges that the family caregiver is exposed to and also improve his or her quality of life.

In this study family caregivers relied heavily on their work as a source of livelihood for themselves and their children. Majority engaged in some form of buying and selling of items including fruits and vegetables, groceries, cooked food, shoe mending, itinerant tailoring not forgetting personal pension earnings, which generate income for them. They therefore use the money they earn to take care of all the needs of the child. No matter how inadequate this may be, most of them indicated that things are difficult for everyone so, it is not always you have to approach others for help. Hence when they have the resources, they are able to do their best and when the tables turn, unless it gets to the extreme or else they try to handle things by themselves. This finding is consistent with that of another study which reported that, mothers of children with intellectual disability in the Tamale Metropolis, stated their; salaries, businesses or menial jobs, as their source of financial (Aarah-Bapuah, 2015).

Findings also revealed that, all except one caregiver received commendable support from the health care team members. They described the psychological assistance provided them by the health team as enormous. Healthcare providers were described as very caring, to these children. They exhibited these by; providing them with information on the care needs of the child, allowing them to jumps queues to receive care, encouraging them to care for the children, acknowledging and praising their efforts, giving them free health care and payment of transportation fares for some, on certain occasions. This is consistent with another finding by Mooney-Doyle et al (2017); where parents of children with life threatening illnesses in the United states of America disclosed receiving immense support

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from the healthcare team in the form of guidance or hospital friendly policies, enabling them to maintain family relations and enhanced child care. The only contrary case was when a mother was mocked by a healthcare provider that, there is nothing that can be done for a child like this, so she should take him away, a bitter experience she will always recount. This kind of rude attitude towards such caregivers may make their situation more distressing. This finding conforms with that of a study in south Africa by Hlongwa & Rispel, (2018), which reported such situations as deficiencies in the health care system.

Following the healthcare providers, the next common source of social support in this study was from friends. To most of them, friends played a significant role in supporting them. They recounted situations whereby their friends' commendation to them for taking good care of their children, gave them some form of relief. Friends also provided them with money, food, fruits, and clothes to care for the children. These gifts were given to them as a way of sympathizing with them or upon request when they are hard-up. Some strangers coming into contact with these children for the first time feel sad for their situation and react by presenting them with some gifts while some do so, based on the special abilities of the child. For instance, some of the children can dance, very well at gatherings prompting people to give them money. This finding is contrary to another finding which reported that, children with severe intellectual disability in Limpopo; South Africa were described as bad luck, hidden by their parents and received no support from community members (Khanyi, 2018). This variation in the severity of stigma may be as a result of cultural differences.

In terms of the family unit, older siblings were generally commended for assisting in the care of their younger sibling with anomaly. They were portrayed to have shown love towards their sibling by supporting the caregiver with money and other resources, willingly

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to cater for the care needs of the child. Since most of them are old and staying on their own, they show their love by visiting frequently and making phone calls to find out about their sibling's needs so they can support. Similar to this finding is a study, that reported that, adult siblings of children with disability performed roles such as; care giver, friend, advocate, sibling, legal representative, leisure planner and informal service coordinator (G.S.S, 2012). However, the same study reported that, some of these roles were directly assigned to these siblings by their parents. However, in the present study the siblings took up these responsibilities on their own accord. This has also been found by Dogbe et al (2019) who reported that, siblings of children with cerebral palsy in Ghana showed love, respect and general acceptance towards their afflicted sibling even though they exhibited initial unhappiness. Few caregivers were grateful for receiving support in the form of physical and material assistance from their families as well as their spouses.

The only participant to have received some form of support from a Non-Governmental institution, couldn't mention the name of the NGO. According to her, she was introduced to the organization by a friend, and she was supported with a refrigerator, which she currently uses to prepare ice blocks for sale, to support the child. This raises questions as to the reason why no formal assistance seems to be available to these family caregivers. This may possibly be due to their declination to seek assistance from these institutions due to stigma as a participant recounted or lack of awareness of the existence of formal assistance available to them. Contrary to this finding, a study conducted on mothers of children with orofacial clefts in this same country, reported that all the participant received support from an NGO named Smile Ghana (Dapaah et al., 2020). The variations in the kind as well as severity of the child's defect, may probably be the factor

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that determine the kind and source of support caregivers may likely obtain. Currently in Ghana, it appears no tangible governmental support is available to caregivers of children with congenital birth defects as reported in other jurisdictions such as South Africa; where the state provided the caregivers with care grants (Pretorius & Steadman, 2018) or in China, where the government gives subsidies to such persons or families with difficulty and even fund the rehabilitation programs for children living with disabilities (Su et al., 2018).

### 5.5 Health Consequences Faced by Family Caregivers

Even though many studies reported serious health consequences as the outcome of limited resources and support in taking care of children with special needs, as the case seem to portray here (Björquist et al., 2016; Miodrag et al., 2015; Woolf- King et al., 2018), majority of the family caregivers in this study indicated that, they are in good health. Others reported having health conditions, which were not the result of their care duties. Some attributed the situation to the aging process as they are currently above 60 years. However, one male caregiver who is a biological father suffering from stroke, attributed his condition to a spiritual blow he experienced at his waist, which led to his retirement from work.

Few caregivers reported experiencing mild psychological stress and backache. One caregiver described the stress she went through in search for the child, when he got missing. To her, being stressed up can predispose an individual to malaria or any other sickness. In addition, one caregiver described the excessive thinking associated with the event as; having a dulling effect on all aspects of the caregiver's life. The backache reported by few family caregivers, occurred as a result of the extended duration they have to carry these children at their back, in spite of the fact that, they have grown and gained weight. The severe form of the backache was the once experienced by one mother who accidentally,

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slipped and fell while trying to bath her child. These portray how vulnerable these family caregivers may be, to serious psychological as well as physical health consequences. Thus, even though they may not be showing signs or symptoms, they are more likely to develop ill health compared to those caring for normal children (Pilapil, Coletti, Rabey, & DeLaet, 2017). Meanwhile they, managed these conditions at home using over the counter medications, and soothing ointments among others, or went for medical check-up. The only person who sought some medical care and still goes for physiotherapy care was the one who slipped and fell.

**5.6 Coping Strategies of Family Caregivers**

Judging from the low level of stress and health consequences reported by this study, it suggests that, family caregivers employed coping mechanisms extensively in their bid to attain some level of balance between the caregiver demands and the limited resources and support situation they find themselves in. This support the assertion that, caregivers who employ more active coping measures, experience relatively, lower caregiver stress (Zaidman-Zait et al., 2017). These measures, mainly constitute strategies employed by family caregivers in the interim, to come to terms with the situation, knowing that there is no permanent solution to it. To achieve this, the study found that, the family caregivers used the following; knowing about the child's condition, the severity or otherwise of the child's condition, positive behavioural characteristics of the child and having faith in minor improvements.

In the present study, family caregivers confirmed that, their knowledge on how to treat their children, observe them, feed them, care for them, their strengths as well as their fallibilities, came as a huge relief to them. This relief, made them to accept the situation as

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part of their duties and strengthened them against the issues of stigma. Pelentsov et al (2016) reported a similar finding in a qualitative study conducted on "the supportive care needs of parents with a child with a rare disease". Their study reported that, parents described their knowledge of the child's condition as not only equipping them to better care for the child, but also, facilitate open discussion with health care professionals, regarding vital information on the child's condition and care decisions. Most of them mentioned the health care personnel as their main source of information on the child's condition, while the few educated ones, had information from their study encounter or personal efforts in conducting online search or through participation in workshops to support that of the health team. This finding concur with other findings which reported that caregivers of children with varying types of congenital birth defects, obtain information from the health care team, teachers of special schools and through personal effort (Aarah-Bapuah, 2015; Oti-Boadi, 2015).

Another way participants express their coping instincts, is to enjoy the funny part of their special abilities. According to them, these children say things, dance or make gestures that the normal child may not be able to do. Sometimes too, what they do are incongruent with their age or the typical response required by the situation at hand. This leaves the caregivers no other option than to laugh or smile. This amusement does not only give them relief in the short term, but lingers in memory and induces same effect even when the child is not around. This finding is congruent with that of another study conducted by Broady, Stoyle & Morse (2017) in Australia, where caregivers of children with disability disclosed that, despite the frustrating attitude of these children, they are also extremely amusing and makes them laugh.

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The findings also indicate that, family caregivers described how they feel, happy, consider their situation as better or perfect and give thanks to God, upon hearing, seeing or finding out that, other people have children with severe or multiple defects compared to theirs. Palestinian mothers of children with disability shared similar sentiments by saying they feel fortunate and blessed considering the difficulties other families encounter (Abu-Ras et al., 2018). This is also, consistent with several other quantitative studies that reported that the level of stress of the caregivers of children with special needs is directly related to the severity of the child's defect (Dias et al., 2019; Fernández-Alcántara et al., 2015; Pinquart, 2018). Thus the more severe the defect, the more worrying the situation is to the caregiver and vice versa. For some caregivers who are biological mothers, the joy stemmed from just having a child to call theirs. Because, there are several people out there who are desperate to give birth so they could assume the status of a mother, but were not fortunate to even get the type they are taking care of. This is what gladdens their hearts and make them grateful. As many African cultures portray, not having a child comes with so many devastating consequences. For instance, a study in Mali, reported that, women who don't have a child are considered to be inferior to all fertile women. They therefore feel so useless to the extent of saying; they wished they never came to this world, if God knew he will not give them a child of their own (Hess, Ross, & Gililland Jr, 2018). This appear to justify why mothers in these study see the situation as a fortune.

Nonetheless the family caregivers also expressed a lot of optimism in improvements in their child's condition as they are beginning to see changes now. Minor changes such as the child being able to walk, speak, hear, move body parts or reason gives them hope that, the child may be able to take decision, perform self-care activities and

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relatively lead independent life. This finding go to strengthen the assertion that, taking care of children with congenital anomalies is not always associated with negative experiences. It also come with positive ones no matter how small they may be, hence by appreciating this little changes, caregivers are able to face the future with hope. The caregivers appreciate their little accomplishments which make them happy (Park & Chung, 2015).

**5.7 Adaptation Measures Adopted by Family Caregivers**

Aside the repeated use of these coping mechanisms, family caregivers have expressed their satisfaction in fulfilling the care needs of the children. This helped them to adapt to the situation at least in the medium or long term, because they are aware of the fact that, no perfect solution is available. By adaptation, they have accepted that, caring for these children is their responsibility and by doing so, they are safeguarding the lives of the children, who after all, deserve care just like any other child (Henry, Sheffield Morris, & Harrist, 2015). To adapt to their various situations, the participants relied on time, determination and resiliency to attain some form of mastery over the obviously challenging situation.

Most of these family caregivers have performed their care duties for a minimum of 9 to 27 years and still counting. They described the related features of their long years of care such as; the passage of time, becoming used to the routines of care and reflections on the persistent difficult times spent together with these children, as their turning points towards adaptation. These made them to become used to their care demands, accept them as they are, and strengthened the bond between them and their children with congenital birth defects. Thus the magnitude of the challenges seem to vary over time, as posited in a book on family caregiving (Bailey & Harrist, 2018). Some mothers recounted how the

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situation made them to love these children more than their other siblings who are normal, to the extent that, the death of that child may have devastating consequences on them. This finding is consistent with that of other studies that reported strains in parental care to the normal siblings of children with special health needs due to the long periods of devotion to the care needs of the afflicted child (Corcoran et al., 2015; Dogbe et al., 2019).

This study also found that, the family caregivers had a determination that is driven by the desire to ensure that, the defect does not become an impediment to the ability of the children to maintain their identity and fit into future roles, as the realities surrounding the dynamics of life, must be faced head-on. They disclosed that, they are also human beings as we are, deserve to be cared for and not thrown away. They also described not seeing their disability as inability, hence keeping focus to see better outcomes. Meanwhile, accidents in life may change the life trajectory of otherwise normal children. So, it is not a big deal. This seems to explain why another study reported that, caregivers recognized and stood by the capabilities of these children no matter the severity of their disability (Lee et al., 2015). In consonance with the world view that disability is not inability.

In addition to all the above, some family caregivers, resolved to be resolute and not be bothered by whatever others do or say. They described how they decided not to be bothered by comments such as, you are wasting money on them, they are evil so go and see them off, or they are punishments or curses. One caregiver recounted her resilience over stigma, when she was correcting a speech made by another child, only for someone to rebuke her that if she were to get that of her son like that wouldn't she be happy? To her, she is above such situations and will correct any child whenever his or her speech is inappropriate. This is in consonance with another study which caregivers reported having

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a strong will to see thing through, as a driving motive in caring for children with special needs (Abu-Ras et al., 2018)

Finally, on adaptation, the participants in the study try to justify the hassles they go through, as situations that are not so much different from what they would have experienced if the children were to be normal. According to them, they would have faced situations such as, proving them with food, toiletries, clothing, school fees and other expenses as they do to themselves or other normal children. Hence why should their situation be different? Even when things become difficult, they are motivated to manage the situation just like they will be doing in the absence of the child's condition. Contrary to using this as an adaptive mechanism, Bailey and Harrist (2018); described taking the situation as mundane and not recognizing the added responsibilities, as an impediment to the family's quest to achieve balance or accept the 'new normal'. But with this situation the family caregivers may probably be using this as a medium term measure, having in mind that they may not get any finality to the issue. These factors strengthened them to adjust and move on with their caregiving duties.

### 5.8 Religiosity as a Way of Justifying the Unthinkable

Throughout the study, one issue that kept recurring was the believe in a supernatural entity (God). This is expected because all the participants indicated they belong to a religious group. Eleven (11) of them were Christians and two (2) were Muslims. In Ghana the 2010 Population and Housing Census reported that about 71.1% of the population of country are Christians as against 17.1% who are Muslims. This might be the reason why majority of the participants were Christians. But their repeated expression of faith in God seem to portray how deep they value their faith. This is in line with findings from another study

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that reported that, caregivers who demonstrate filial piety are likely to take on the caregiver role of family relations willingly (Nguyen & Levkoff, 2020). Their belief and faith mainly helped them to either cope or adapt to the situation; as one's level of religiosity is directly related to one's ability to withstand adversity (Dey, Amponsah, & Wiafe-Akenteng, 2019). They portrayed their religiosity by starting and ending majority of their statements with God. Even though some of their statements suggested that, God could be behind the cause of the child's condition, they blamed their sins and those of others as the reason why God do such things to offset bigger calamities. God is therefore just and sacrosanct as portrayed by other studies (Dias et al., 2019; Masulani- Mwale et al., 2016; Oti-Boadi, 2015). They described how they directly sought spiritual assistance through prayers, visiting churches and prayer camps or how others interceded on their behalf through same acts of worship. Their belief in God, may be put in the following categories: Firstly, gifts from God must be taken like that. Secondly, some untoward situations are tests from God and finally, the blessings of God come disguised.

God in this study has been described by the participants as the supreme giver of children. Because He is all knowing, He knows the reason why He gives such children to their families. He also does things that are beyond our thinking capability, hence no mitigating efforts can influence His decision. As a mortal, all you can do is to take the situation as it is, thank Him for it, do your possible best to improve the situation and leave the rest to Him. These ideas were expressed by all the family caregivers irrespective of their gender, or educational background supporting the assertion that, the issue of religiosity goes beyond gender orientation or educational and scientific enlightenment (Reader et al., 2020)

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Other attributes of God that culminated into the second category indicates that, the hassles associated with the care role of these children, are tests from God. They believe once you declare yourself as a servant of God, you will be tested with adversity like the child's condition. They again believe that, one may fail this test by killing the child, throwing the child away, abandoning the child or maltreating the child. However, to pass this test, means one must take good care of the child because, whatever is done to the child is assumed as being done directly to God. Nyantey & Carpenter (2019) reported a similar finding in their study when the caregivers of children with cerebral palsy in Ghana described their assessed level of care as a way of serving God in anticipation of his blessings. Others also see the testing situation as a way for God to prove His worth and showcase His glory. With regards, they believe every little improvement they see in the child's condition is part of a God's grand plan to heal the child so that others can use the situation to proclaim His glory. These, accounted for their extra devotion to religion and fostered their relationship with God just as reported by Nazzal & Al-Rawajfah (2018) in their study on the lived experiences of Jordanian mothers caring for a child with disability.

The third and final category of findings relating to religiosity in this study, portrayed the situation as a blessing in disguise from God. Their narratives suggested that, by giving proper care to these children, God rewards the caregivers with good health and prosperity. One caregiver shared the instances the situation has taken the burden of sickness away from her to the extent that, she continues to renew her health insurance but never falls sick, let alone use it to seek healthcare. In addition to good health, the family caregivers believe by dedicating and whole heartedly taking care of these children, God's everlasting blessing saw them care for other children through university education, regardless of their

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meagre income. For few others, the reward goes beyond this world, because, when you don't receive your reward now, it will be some time to come in the form of eternal life. This finding is in accordance with the findings of a study in which some of the Palestinian mothers of children with disability expressed the desire that, they wish all their caregiving hassles will be rewarded by Allah in heaven (Abu-Ras et al., 2018).

In summary, the findings of the study were presented in relation to the constructs of the transactions stress theory by Lazarus (1991). Consistent with life events, the study found that family caregivers considered having a child with congenital birth defects, as a major life event, because it impacted negatively on them bringing a lot of difficulties, hassles and recurring psycho-social thoughts. The event was also sudden and unexpected but left them with a life-long journey of care provision with little or sometimes no result for their efforts among others. Meanwhile, the unpredictable nature of the event left them in awe and these accounted for the indelibility of the event to them and qualifies it as a significant life event.

Under demand appraisal, the family caregivers revealed their assessment of the situation by ascribing it as a challenge, threat harm or loss. As a challenge, the family caregivers reported facing a lot of physical difficulties in assisting these children or completely performing all their personal care activities for them no matter their level of development. They also faced a lot of financial problems as a result of the number of times they have to assess medical care for them and the complexity surrounding their condition demanding travelling in order to obtain specialized care from experts. Notwithstanding all these, the care demands also leave them with minimal time to concentrate on any economic activity, rendering most of them out job and losing their source of regular income. In

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addition to the challenges, they also faced threatening situations. These included the emotional concerns of sadness, bitter feelings, self blames and apportioning blames to others for their perceived contributions to the situation, having forecast of negative situations that the event is likely to bring and finally casting doubts as to what will happen if they should surrender their care-giving duties, due to old age or in the worst circumstance of their passing. Talking about harm or lost, their main concern was not a physical injury, but rather the loss of personal worth, unmet expectations and love relationships through stigma tagging and insecurity. The manifestations of these include, the emotional feelings of sadness, crying, keeping to self, facing forced separation and divorce situations among others.

In the midst of all these difficulties, family caregivers disclosed resource constraints, as they have to heavily depend on their personal income in the form of salaries, pension pays and proceeds from menial jobs they do. Though they all had some form of social support, these were mainly from informal and inconsistent sources, such as gifts from friends, assistance from siblings of the afflicted child and on very few occasions, their spouses, family relations and the community. These gifts were as a result of request, given out of sympathy or based on the child's exhibition of his or her special abilities.

Despite all these, family caregivers generally reported having good health. Some participants complained of having poor health situations not linked to their caregiving duties and few of them complained of mild psychological stress and back ache emanating from excessive thinking, prolong period of carrying these children at their back and one accidental bathroom fall in an attempt to bath the child.

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The only possible reason for their health trajectories described in this study, is their immense use of coping strategies. To come to terms with the situation in the short term and have some relief, the family caregivers used the knowledge gained concerning the child's condition, finding out that others are caring for children with multiples or worse conditions, enjoying the funny side of their behaviour and observing minor improvements in the condition of these children over time. These strengthened them and gave them hope that, things may turn around.

In the medium and long term, they adapt to the situation and become better suited for their roles, having in mind that there may not be any lasting resolution to their current situation. They adapted by; gaining mastery over the routines associated with the caregiver role over relatively long periods of time, being determined to see good in adversity, becoming resilient to external negative influences and trying to see the event as a mundane situation. Thus they were of the view that, what they were doing wouldn't have been much different is the children were to be normal.

As with any human endeavour, some questions seemed to go beyond human imagination and remained unanswered. But religiosity came in strongly to serve as the last resort to their quest for lasting resolution. Religiosity therefore helped them both to cope and adapt to the situation. Through the religious lense, they viewed their situation as; a gift from God that is beyond human understanding and must be accepted as it is, a test to their individual faith with varying reasons and a rose that comes with thorns or a blessing in disguise. All these except adaptation and religiosity have been clearly outlined by the transactional stress model. However, literature on the subject encompasses all.

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# CHAPTER SIX: SUMMARY, IMPLICATIONS, LIMITATIONS, CONCLUSION AND RECOMMENDATIONS

Contained in this chapter, is the precis of the whole study, the implications, limitations and recommendations.

## 6.1 Summary of the Study

The adaptation experiences of family caregivers of children with congenital birth defects were explored in this study, using the transactional stress model by Lazarus (1991) as the guiding conceptual framework. After obtaining approval and supervisory support from the Maternal and Child Health department of Nursing; University of Ghana Legon, ethical approval was sought from Noguchi Memorial Institute for Medical Research. A written permission was also obtained from the Dzorwulu special school. Data collection commenced on the 2nd of July, 2020 and ended on the 30$^{th}$ of September, 2020. Consent was obtained from the participants in the form of their signatures or initials, while all the protocols for covid-19 prevention and control were observed, prior to their individual interview sessions. These interviews were transcribed verbatim and analyzed using thematic content analysis.

Major findings of the study revealed that, family caregivers of children with congenital birth defects consider the event as a major life event, because, its impact brought difficulties. The event is also sudden and unpredictable, but leaves a long lasting impression in their minds. Moreover, it came along with challenges, threats and harm or loss. They faced challenges of excessive care demands, inadequate finance, and being unable to work. The event threatened their emotions as they felt sad, blamed themselves and others, cried, felt unsecured that, the child may get missing or be hurt by others and

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have to live with anxiety over who to take up the care duties in their absence. They also counted the loss of a perfect child, deficits in the expected capability of the child, stigma, forced separations and divorce as their harm or loss situations.

Most family caregivers reported having less personal resources especially money; owing to their less paying employment situations, pension status, petty trading or menial jobs they engage in. But this is what they heavily relied on, as their social support was informal, less and inconsistent. They had these social supports; in the form of gifts of money, food and clothing from the elderly siblings of the afflicted child, friends and on few occasions, their spouses, families and the members of their various communities. Formal supports from government and NGOs were however missing as just one participant was given a deep freezer by an NGO, as a way of supporting her, to care for the child. Notwithstanding all these, family caregivers described their health status as generally good or their present ill-health situations were not a product of their care duties. The very few participants who disclosed having any health consequences such as; stress and backache, described them as mild and did not require hospitalization or medical attention.

Further findings suggested that, family care givers used a lot of coping mechanism to handle the situation in the short term. They employed strategies such as; knowing about the child's condition from the medical team, through further education or online search as a way of getting some form of relief. Knowing the child's defect is better compared to others who have to care for children with multiple or severe defects was gratifying to them. Meanwhile, laughing when amused by the behaviour of these children and getting excited by the minor improvement like talking, hearing, making gestures and the likes, make them feel happy even though momentarily.

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In addition to coping, the long periods of their continuous care provision made them familiar with the situation. Determination to make the best of the prevailing situation motivated them to become more suited for their roles. Their resiliency to negative posturing from significant others, emerged from knowing that, they have to accept them as part of the family unit and treat them as any other member. These, in addition to considering the situation as normal, were their responses that proved that, they had adapted to the situation.

Finally, knowing that there is no permanent resolution to the numerous challenges they faced, left them with a lot of mind boggling questions which most of the time go unanswered. But religiosity appeared to be the termination point for such issues. These were portrayed in the following beliefs; children with congenital birth defects were gifts from God. As the event was planned by God they have to accept them like that. It was also seen as a test to a believers' faith and lastly it may be a hidden blessing pending the caregiver's efforts to uncover.

## 6.2 Implications

Findings of this study have implications for; nursing practice, nursing education, nursing research and policy.

### 6.2.1 Nursing Practice

Findings of the study revealed that, the main source of information for family caregivers on the conditions of their children with congenital birth defects; is from the healthcare professionals. This, coupled with the increased number of times medical care is sought for these children, suggest that, nurses will have several encounters with them. Just as the knowledge they obtained strengthened them, the same way any negative attitude will affect these caregivers. Hence nurses have a major role to play in giving assistance to such

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caregivers. In providing exemplary care to these caregivers, nurses must prepare them psychologically to receive the news of the diagnosis through counselling, teach them life style modifications they need at home to help the situation, demonstrate feeding techniques on certain occasions, and show acceptance by giving same or even better coordinated care to such children just as they do to the normal ones.

While counselling them, they should also include their spouses, inform them of possible future expectations and link them to NGOs where feasible, to enable them, obtain some assistance and reduce the hassles they have to face as well as promote family cohesion.

### 6.2.2 Nursing Education

Even though the study found that healthcare workers were the main source of information for family caregivers, this information were scanty and disjointed. There is no structured program in the curriculum for training nurses to obtain knowledge and skills on how to provide tailored care for person in these circumstances, through collaboration with other health care team members. This work therefore exposed that missing link. It is imperative then, for curriculum planners to include courses that will enhance the knowledge and skills of nurses in the area of collaborative practice. This will enable nurses to coordinate information from all other professionals that may be linked to the care and rehabilitation of these children to effectively communicate with family caregivers.

Currently in Ghana, there is no structured program on collaborative practice in the curriculum for training healthcare providers at any level, and there is no specialized training program for nurses who will like to take up a career in the area of congenital birth defects or disability nursing in general. Institutions for training nurses can take this up and

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introduce specialties in this area which will produce professionals instilled with the ideals of collaborative practice to bring enhanced outcomes.

### 6.2.3 For Research

This study suggests the need for further research on the adaptation experiences of family caregivers of children with congenital birth defects in other to unveil other dimensions to the issue and provide enhanced understanding of the phenomenon. The study qualitatively explored the adaptation experiences of family caregivers of children with congenital birth defects using transactional stress model by Lazarus (1991). Further studies could explore other conceptual models or quantitatively measure the variables in this model, to obtain scores that will reflect the level to which the event is considered a major life event, the impact the various appraisal domains have on the caregiver, the moderating effect of social support, health consequences and the level to which coping and adaptation strategies worked.

The Greater Accra region is an urban centre, hence the study can also be replicated in a similar urban setting to obtain diverse perspectives surrounding the phenomenon. Other areas may include the perspectives of institutional caregivers like nurses, teachers of special schools, orphanages and rehabilitation centres.

### 6.2.4 Policy Formulation

The present study found that most family caregivers could not follow through the health seeking interventions of these children to the later, because the services were either not available or were too expensive. The onus then lies with the ministry of health to include the treatment and rehabilitation of these children in the national health insurance scheme. Another area of policy interest is to ensure that health care facilities are equipped

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with specialized units manned by experts who will collaboratively, provide tailored care to such children. This will reduce transportation cost and caregiver burden.

### 6.3 Limitations

As a limitation to the study, the researcher acknowledged that, even though the findings were consistent with other studies in Ghana and other parts of the world, transferability is only possible where the contexts are similar. Meanwhile translations done from Twi to the English language may pose a threat to trustworthiness. But efforts were made to present the findings using words and phrases that are nearest in meaning to the spoken ones from the participants. The Covid-19 pandemic came along with restrictions on movement and person to person contact making it difficult to get assess to participants for the study. The researcher however used the snowballing technique to recruit participants and observed all the safety protocols to ensure that the family caregivers were safe throughout the interview session.

### 6.4 Conclusions

Generally, the findings of the study were in consonance with the constructs of the transactional stress model by Lazarus (1991). For instance, family care givers considered having a child with congenital birth defect as a major life event because, the phenomenon unleashed negative hassles on them, as it was sudden and unpredicted but left them with long life-long struggles difficult to get over. In assessing the situation, they described the difficulties they faced in the form of challenges, threats and harm or loss. Meanwhile, they have to rely on their personal resources as they had less social support from family relations and society. However, the health toll of these consequences on them, was mild due to their reliance on coping strategies. With time, determination and resilience, most of them

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became used to their care activities and described them as normal situations. Meanwhile, the situation seems to have no final resolution. They therefore rested their frustrations and fears on religiosity and this gave them strength to move on with their caregiver roles.

In conclusion, the study establishes that, family caregivers consider; being educated or having knowledge on the condition of their respective children, having consistent income generating ventures, spousal as well as family support and possessing strong religious ideals as virtues that promote coping and better adapt adaptability to their caregiver roles. However, no matter the mode of adaptation, the fact still remains that, help to persons taking care of children with congenital birth defects is insatiable. Hence healthcare providers must liaise with governmental and non-governmental institutions as well as the general public to assist them in ways, that will enhance their plight; for instance, tactful breaking of news of adversity to them, fostering family cohesion and providing resource assistance where possible, considering the impact of the event and further stigma and societal ridicule they face. Moreover, despite the report of less health consequences, there is the need to coordinate the activities of all caregivers, to provide a holistic care and foster adaptation. This therefore calls for the inculcation of collaborative practice, in the various curricular of health training institutions to prepare professionals adequately to meet the healthcare needs of children with congenital birth defects and their caregivers in Ghana.

## 6.5 Recommendations

Based on the findings of this study, the researcher made the following recommendations to the following bodies and institutions.

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### 6.5.1 The Ministry of Health (MOH)

The ministry should;

1. Ensure that, healthcare professionals working in maternal and child health units have adequate knowledge and skills in screening and early detection of congenital birth defects.
2. Train healthcare providers on counselling, required to break news of adversity to caregivers of children having varied types and severity of disabilities.
3. Intensify efforts to include the care and rehabilitations services of children with congenital birth defects in the national health insurance scheme.
4. Liaise with the government to include caregivers of children with congenital birth defects in the Lively Empowerment Against Poverty (LEAP) program, so they can get some stipends, to cushion them economically.
5. Recognize and prioritize the work of the Chaplain, Imam and other religious leaders, in the health care team to provide religious support to caregivers of children with congenital birth defects.

### 6.5.2 The Department of Social Welfare

The department of social welfare should;

1. Cooperate with other institutions such as; the National Council on Disability (NCD), the ministry of Gender and Social Protection and NGOs to establish and strengthen existing support systems for children with congenital birth defects and their caregivers.
2. Provide assistance to existing health facilities, so they can render rehabilitative services to children with different congenital birth defects across the country.

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3. Remove impediments to assessing services by children with congenital birth defects and their caregivers such as; bureaucracy, favouritism and discrimination.

### 6.5.3 The General Public

The general public should be trained and sensitized to:

1. Avoid tagging and stigmatizing children with congenital birth defects and their caregivers.
2. Accept and create conducive environment for children with congenital birth defects and their caregivers to attain the best possible quality of life.
3. Understand and play their roles in the collaborative process involved in the treatment and rehabilitation of children with congenital birth defects.

### 6.5.4 Family Social Support Networks

Persons related or unrelated to children with congenital birth defects, who have assumed their caregiving role should;

1. Come together, to form a community, not only to share ideas and experiences, but also to provide support for one another.

### 6.5.5 Religious Groups

Religious groups intensify effort in:

1. Using sermons and other programs to educate their members against stigma and inspire hope in caregivers.
2. Recognize the roles religiosity play in the lives of persons going through adversity and support such persons emotionally through prayers and counselling.
3. Liaise with government and other NGOs to solicit help for children with disabilities and their caregivers.

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# APPENDICES

## Appendix A: Ethical clearance.

NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH
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1st July, 2020

ETHICAL CLEARANCE

**FEDERALWIDE ASSURANCE FWA 00001824** **IRB 00001276**

**NMIMR-IRB CPN 043/19-20** **IORG 0000908**

On 1st July 2020, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting reviewed and approved your revised protocol titled:

**TITLE OF PROTOCOL** : **Adaptation experiences of family caregivers of children with congenital birth defects in the Accra Metropolis**

**PRINCIPAL INVESTIGATOR** : **Daniel Ahiable Yao, MPhil Cand.**

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.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 31st May, 2021. You are to submit annual reports for continuing review.

Signature of Chair: ............................................
Mrs. Chris Dadzie
(NMIMR – IRB CHAIR)

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**Appendix B: Introductory letter.**

UNIVERSITY OF GHANA
DEPARTMENT OF MATERNAL AND CHILD HEALTH
SCHOOL OF NURSING

Ref. No.: ID: 10702781 February 6, 2020

The Headmaster
Dzorwulu Special School
Dzorwulu – Accra

Dear Sir,

LETTER OF INTRODUCTION

I write to introduce to you Daniel Yao Ahiable, an MPhil second year student of the School of Nursing and Midwifery of the College of Health Sciences, University of Ghana.

The Scientific Review Committee of the School has approved the thesis topic: **"Adaptation Experiences of Family Care Givers of Children with Congenital Birth Defects in the Accra Metropolis".**

Your facility has been identified by the student as the site for his data collection. I am therefore requesting permission for the student to collect data in your facility.

It would be appreciated if he is given the necessary assistance

Yours faithfully,

Dr. Florence Naab
**Head, Dept. of Maternal and Child Health**

COLLEGE OF HEALTH SCIENCES

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## Appendix C: Information sheet

INFORMATION SHEET

**Title of the research:** Adaptation experiences of family caregivers of children with congenital birth defects in the Accra metropolis.

**Purpose of the study:** The purpose of this study is to explore the experiences of family caregivers of children with congenital birth defects.

**Objectives of the study:**

The specific objectives of the study include: To

1. describe the life events of family caregivers of children with congenital birth defects
2. examine the challenges threat and harm or loss (appraisal) of family caregivers of children with congenital defects
3. determine resources and support (social, personal and material) available to caregivers of children with congenital birth defects
4. explain the health consequences of family caregivers of children with congenital birth defects.
5. describe the coping strategies of family caregivers of children with congenital birth defects

**Study participants**

**Inclusion Criteria**

The study included; parents, family members or other persons who have taken up the care giver role of children with congenital defects in the Accra metropolis. Only those who

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could communicate with at least English Language or Twi and consented to be participants in the study were included.

**Exclusion criteria**

Caregivers living in the Accra Metropolis, who are caring for children with disabilities that have varying etiologies other than congenital.

**Ethical considerations**

This study obtained ethical approval from the Institutional Review Board (IRB) of the Noguchi Memorial Institute of Medical Research (NMIMR). The procedures involved in ensuring principles such as consent, confidentiality, risk and benefit will be followed. The researcher will explain the purpose, objectives benefits and potential risks to the participants, who will also be given ample time to make decision on their participation before recruitment.

**Possible Risks and Discomforts**

You will not be exposed to any risk by virtue of your participation in this study. However, during the interview, you may feel uncomfortable with some of the questions. You have the right to refuse to answer any question you are not comfortable with. Aside that, in case you feel so disturbed, the services of a clinical psychologist (Dr. Samuel Adjorlolo with mobile number 0204197158) will be made available at no cost to you.

**Possible Benefits**

You are not assured of any direct benefit by being a participant of this study. However, the possible benefits of your participation include; the experiences you have the opportunity to share, may be used to help other care givers who may find themselves in similar situations. In addition, your participation will offer health care workers, policy makers and

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the general public valuable information about how challenging or successful it is to care for a child with congenital defect(s).

**Confidentiality**

Your permission will be sought in every situation including your agreement to participate and before audio-taping the interview. Any information that may link you to any information you will provide such as your name or address will be anonymised. If you mention names during the interview session, such names will be replaced with pseudonyms. Meanwhile, the security of the information you provide, will be ensured by keeping it under lock and key, only to be accessed by my supervisor and me.

**Compensation**

You will not be given any financial compensation, but a snack (canned malt and meat pie) will be offered you at the end of the interview to replenish your energy.

**Voluntary Participation and Right to Leave the Research**

Your participation in this study is voluntary, hence you have the right to withdraw from the study at any point in time even if you have signed the consent form. Your withdrawal from the study will not affect any support you receive in caring for the child.

**Contacts for Additional Information**

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## Appendix D: Consent form

Title: Adaptation experiences of family caregivers of children with congenital birth defects in the Accra metropolis.

Principal Investigator: Daniel Yao Ahiable

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

**General Information about Research**

Generally, caring for children with varying degrees and severity of congenital defects can be stressful. In that, the event itself may be unexpected and shocking, threaten the ability of the family's resources, become so challenging that, coping appears to become difficult. These, alongside weak social support systems may predispose care givers to some negative health consequences. However, certain caregivers are able to adjust better to their roles than others. The reason for this study is to determine what it takes for a care giver to adapt to his or her role of caring for a child with congenital birth defects.

**Possible Risks and Discomforts**

There are no foreseeable risks, however, during the interview, you may feel uncomfortable with some of the questions. You have the right to refuse to answer any question you are not comfortable with. Aside that, in case you feel so disturbed, the services of a clinical psychologist (Dr. Samuel Adjorlolo with mobile number 0204197158) will be made available at no cost to you during the interview.

**Possible Benefits**

You are not assured of any direct benefit by being a participant of this study. However, the possible benefits of your participation include: The experiences you have the opportunity

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to share may be used to help other care givers who may find themselves in similar situations. In addition, your participation will offer health care workers, policy makers and the general public valuable information about how challenging or successful it is to care for a child with congenital defect(s).

**Confidentiality**

Your permission will be sought in every situation including your agreement to participate and before audio-taping the interview. Any information that may link you to any information you will provide such as your name or address will be anonymised. If you mention names during the interview session, such names will be replaced with pseudonyms. Meanwhile, the security of the information you provide, will be ensured by keeping it under lock and key, only to be accessed by my supervisor and me.

**Compensation**

You will not be given any compensation, but a snack (canned malt and meat pie) will be offered you to replenish your energy.

**Voluntary Participation and Right to Leave the Research**

Your participation in this study is voluntary, hence you have the right to withdraw from the study at any point in time even if you have signed the consent form. Your withdrawal from the study will not affect any support you receive in caring for the child.

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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 rights as a research participant, you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.ug.edu.gh

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VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title ***(Adaptation experiences of family care givers of children with congenital birth defects in the Accra 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 also understand that, there will be no adverse effect or medical care or other benefits. 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, risks 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

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I agree to my interview being audio-recorded.

______________________ ______________________________________________

Date Name and signature or mark of volunteer

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## Appendix E: Interview Guide

**Section A: Demographic Information**

Date of interview…………… Pseudonym………… Duration of interview…….............

1. Age?.......................................................................................................................

2. What is your level of education?.........................................................................

3. What work do you do?.........................................................................................

4. How much do you earn; in a week……………….,in a month.....................................

5. What language (s) do you speak?........................................................................

6. Where do you live?...............................................................................................

7. Nationality?...........................................................................................

8. If your answer to question 8 is no, which country are you a national of? ………………

9. Which Religious faith do you belong?..................................................................

10. Are you married?.................................................................................................

11. How many children do you have?.......................................................................

12. How many children do you care for?..................................................................

13. How are you related to the child with special need?..................................................

14. How old is the child with special need?...............................................................

15. How long have you been caring for the child with special need?.................................

**Section B: Guiding Questions: Life events of family care givers of children with congenital birth defects**

1. Please tell me about things that happened in your life
2. Please tell me about the child with special need

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3. How is your typical day like?

4. Tell me about the difficulties you face

5. How has caring for the child influenced the activities you engage in?

**Section C: Challenges threat and harm or loss (appraisal) family care givers ascribe to the event of caring for children with congenital defect**

1. What do you think about the child's special need?

2. What do you think is the reason for the child's becoming special?

3. Tell me about your deepest feelings and emotions about the child's special need

4. What do you feel when you see other children without special need?

5. How do you see the future of the child?

**Section D: Resources and support (social, personal and material) available to care givers of children with congenital birth defects.**

**Resources**

1. Kindly describe all the factors that influence your ability to care for the child with special need

2. How do other family members treat you and the child?

3. Which community events do you attend with the child?

4. How do community members treat you and the child?

5. Tell me about the times you felt satisfied for meeting all the child's needs

6. Tell me more about how you are able to mobilize resources

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**Social support**

1. Tell me about those you will like to show gratitude to and why?
2. Tell me about your interaction with health care or social service?
3. Do you know of other people who are also caring for children with similar special needs?
4. How will you describe the roles others play to assist you care for the child?

**Section E: Health consequences of family care givers of children with congenital birth defects**

1. How will you describe your current health status?
2. How has caring for the child with special need affected your health?
3. Do you have to visit the hospital, due to the stress you experience?
4. How do you manage your health situation at home?
5. What will you tell other people caring for children with similar special needs?

**Section F: Coping strategies of family care givers of children with congenital birth defects**

1. Tell me about how you deal with the difficulties you face
2. Describe the factors that keep you going
3. What are the activities that take your mind off the difficulties you face?
4. How do you manage emotional issues relating to the child’s special need?

**Appendix F: Summary of Demographic characteristics of Study Participants.**

**DEMOGRAPHIC CHARACTERISTICS OF STUDY PARTICIPANTS**

| pseudonym | Akos | Sika | Maame | Abiba | Salifu | Kobby | Ayerkie | Atswei | Kpakpo | Anima | Naa | efua | esi |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| age | 30 | 46 | 35 | 40 | 59 | 43 | 62 | 63 | 77 | 42 | 45 | 40 | 59 |
| level of education | Voc. Sch. | middle school | graduate | nill | form 5 | jss | primary 3 | tertiary | sixth form | jss | jss1 | sss | middle school |
| type of work | trader | Nill | clerk at gprtu | trader | retired | cobbler | seamstress (itinerant) | retired | retired | trader | trader | pupil teacher | shop attendant |
| level of monthly income (ghc) | 1500 | Nill | 1000 | 300 | Nill | 1000 | 100 | 1,500 | 2,000 | 1000 | 500 | 1000 | 1000 |
| language used | Eng | Twi | english | twi | english | twi | twi | english | english | twi | twi | twi | english |
| nationality | Ghana | ghanaian | ghanaian | ghanaian | Ghanaian | ghanaian | ghanaian | ghananian | ghanaian | ghanaian | ghanaian | ghanaian | ghanaian |
| religion | Christ. | christian | christian | moslem | moslem | christian | christian | christian | christian | christian | christian | chistian | christian |
| marital status | single | Single | single | divorced | married | married | married | married | married | single | married | single | divorced |
| number of biological children | 1 | 4 | 1 | 3 | 3 | 5 | 8 | 4 | 4 | 1 | 3 | 3 | 2 |
| number of children cared for | 1 | 4 | 3 | 4 | 4 | 7 | 3 | 1 | 6 | 4 | 5 | 3 | 2 |
| relation to child | mo | Mother | mother | mother | father | elder brother | mother | mother | father | mother | mother | mother | mother |
| defect of child | down syndrome | congenital microcephaly | down syndrome | cerebral palsy | down syndrome | down syndrome | congenital microcephaly | down syndrome | congenital microcephaly | cerebral palsy | cerebral palsy | spina bifida | down syndrome |
| age of child | 14 | 11 | 9 | 8 | 9 | 24 | 15 | 27 | 20 | 13 | 15 | 10 | 12 |
| years caring for child with defect | 14 | 11 | 9 | 8 | 9 | 18 | 15 | 27 | 20 | 13 | 15 | 10 | 12 |